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**Depression, Anxiety, General Parenting Stress, and Diabetes-Specific Parenting Stress in
Parents of Children with Type 1 Diabetes: An Updated Review;
and The Experiences of Young People with Type 1 Diabetes who Access Transition Services**

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Doctorate in Clinical Psychology

The University of Edinburgh

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Personal Acknowledgements

I would like to thank my family and friends for their support during this Doctorate. I would particularly like to acknowledge my Gran, and my Aunts, for always being there for me, even when there have been bumps in other areas of life during this Doctorate.

In addition, I would like to acknowledge D, for being a little ray of sunshine even on grey days. You have helped me to keep perspective and to keep going, even when it is hard, by showing me what really matters and is important. I have learnt so much from you, and my life is all the richer for having you in it. I dedicate this thesis to you.

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Abstract of Thesis

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Systematic Review:

A previous review looked at the psychological experience of parents caring for a child with Type 1 Diabetes (T1D), however, there were some limitations of their review. This updated review used a more comprehensive search strategy to synthesise and quality review what is known about depression, anxiety, general parenting stress, and diabetes-specific parenting stress in parents who care for a child with T1D.

Studies on parents caring for children with T1D included at least one measure of parental adjustment, stress, anxiety, or depression were included in this review. The following online databases were searched: CINAHL, Embase, Medline, PsycINFO, Prospero, and The Cochrane Database of Systematic Reviews.

A total of 16 studies met criteria for this review. Evidence indicated prevalence of depression in parents of a child with T1D was 13%-49%. Parents of a child with Type 1 diabetes (T1D) had higher prevalence rates of depression and anxiety. The majority of studies in this review found no evidence that parents of children with Type 1 diabetes had higher rates of depression. Evidence indicated parents may be at a slightly increased risk of anxiety, with limited evidence that anxiety and depression were higher in mothers than fathers. Evidence and data for general and diabetes-related parenting stress was very limited, with parenting stress tending to be

higher in parents of children with Type 1 diabetes compared to parents of healthy children. Additionally, they also experience specific diabetes-related parenting stress specific to their child's diabetes. This indicates that these parents may have a slightly increased likelihood/vulnerability to poorer mental health. There was also some evidence of parental mental health being associated with diabetes outcomes, and that ethnicity and family income are associated with poorer outcomes.

This review found an increased risk of these parents having poorer mental health. Evidence was limited and of variable quality, with issues regarding measures used, and completeness of the data collected and reported. Larger-scale and more diverse and representative samples are required in future research. Clinicians and health services need to be aware of the potential psychological impact for parents, and consider assessment/screening where appropriate. There is a need for evidence-based effective psychological interventions for parents, as there is growing evidence that poor parental mental health has a detrimental impact not just on parents but also on child mental health, and diabetes management and outcomes.

Empirical Paper:

There is a lack of qualitative research on young people with Type 1 diabetes (T1D) during transition from adolescence into adulthood. The aim of this project was to explore this, in the context of the specific developmental challenges and processes that occur during adolescence. A qualitative approach was used, with individual semi-structured interviews carried out with young people (N=8). Interviews were audio-recorded and transcribed, before being analysed using Thematic Analysis.

Qualitative analysis identified the following 2 master themes: (1) My internal experience of transition, as someone with T1D, and (2) External factors and supports: what helps or hinders transition. Subthemes for (1) turning point to taking on ownership of my diabetes, loneliness/feeling different, daily hassles and consequences of managing blood glucose levels, and relationship between T1D and mental health. Subthemes for (2) were shift of support from family to peers, use of healthcare services, the role of technology, and supports at school/work. Some of the subthemes support existing research, whilst the subthemes regarding the relationship between T1D and mental health, and the role of technology were new findings having not previously been found in research on this topic with this specific age group. Themes

reflected on developmental tasks of adolescence including identity, autonomy, and abstract thinking and decision-making.

The findings are discussed in relation to the specific challenges of adolescence. Implications for clinical practice and research are also discussed, with suggestions made for future research and practice to try to address.



Lay Summary of Thesis

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Depression, Anxiety, General Parenting Stress, and Diabetes-Specific Parenting Stress in Parents of Children with Type 1 Diabetes: An Updated Review:

This updated review looked at depression, anxiety, general parenting stress, and diabetes-specific parenting stress in parents who care for a child with Type 1 Diabetes (T1D).

A total of 16 studies met criteria for this review. Evidence indicated prevalence of depression in parents of a child with T1D was 13%-49%. Parents of a child with Type 1 diabetes (T1D) had higher prevalence rates of depression and anxiety. Most studies in this review found no evidence that parents of children with Type 1 diabetes had higher rates of depression. Evidence indicated parents may be at a slightly increased risk of anxiety, with limited evidence that anxiety and depression were higher in mothers than fathers. Evidence and data for general and diabetes-related parenting stress was very limited, with parenting stress tending to be higher in parents of children with Type 1 diabetes compared to parents of healthy children. Additionally, they also experience specific diabetes-related parenting stress specific to their child's diabetes. This indicates that these parents may have a slightly increased likelihood/vulnerability to poorer mental health. There was also some evidence of parental mental health being associated with diabetes outcomes, and that ethnicity and family income are associated with poorer outcomes. This review found an increased risk of these parents having poorer mental health. Evidence was limited and of variable quality, with issues regarding measures used, and completeness of the

data collected and reported. Issues for future research to address are discussed, as well as clinical implications for staff working with parents of children and adolescents with T1D.

The Experiences of Young People with Type 1 Diabetes who Access Transition Services:

There is a lack of research on young people with Type 1 diabetes (T1D) during transition from adolescence into adulthood. The aim of this project was to explore this. A total of 8 young people with T1D were interviewed about their experiences of transition services for diabetes. Interviews were analysed using Thematic Analysis.

From the analysis, there were 2 master themes: (1) My internal experience of transition, as someone with T1D, and (2) External factors and supports: what helps or hinders transition. Subthemes for (1) turning point to taking on ownership of my diabetes, loneliness/feeling different, daily hassles and consequences of managing blood glucose levels, and relationship between T1D and mental health. Subthemes for (2) were shift of support from family to peers, use of healthcare services, the role of technology, and supports at school/work. Some of the subthemes support existing research, whilst the subthemes regarding the relationship between T1D and mental health, and the role of technology were new findings having not previously been found in research on this topic with this specific age group.

The findings are discussed in relation to the specific challenges of adolescence. Implications for clinical practice and research are also discussed, with suggestions made for future research and practice to try to address.

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Title Page – Systematic Review

Full Title: Depression, Anxiety, General Parenting Stress, and Diabetes-Specific Parenting Stress in Parents of Children with Type 1 Diabetes: An Updated Review

Running Title: Experience of Parents of Children with Type 1 Diabetes

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Keywords: Parents; Psychology; Type 1 Diabetes; Children

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This review has been written in a style suitable for publication in the British Journal of Health Psychology. A copy of the author guidance for this journal is included in Appendix 1

ABSTRACT

Purpose: A previous review looked at the psychological experience of parents caring for a child with Type 1 Diabetes (T1D), however, there were some limitations of their review. This updated review used a more comprehensive search strategy to synthesise and quality review what is known about depression, anxiety, general parenting stress, and diabetes-specific parenting stress in for parents who care for a child with T1D.

Methods: Studies on parents caring for children with T1D that included at least one measure of parental adjustment, stress, anxiety, or depression were included in this review. The following online databases were searched: CINAHL, Embase, Medline, PsycINFO, Prospero, and The Cochrane Database of Systematic Reviews. Included studies were also quality assessed.

Results: A total of 16 studies met criteria for this review. Evidence indicated prevalence of depression in parents of a child with T1D was 13%-49%. Parents of a child with Type 1 diabetes (T1D) had higher prevalence rates of depression and anxiety. The majority of studies in this review found no evidence that parents of children with Type 1 diabetes had higher rates of depression. Evidence indicated parents may be at a slightly increased risk of anxiety, with limited evidence that anxiety and depression were higher in mothers than fathers. Evidence and data for general and diabetes-related parenting stress was very limited, with parenting stress tending to be higher in parents of children with Type 1 diabetes compared to parents of healthy children. Additionally, they also experience specific diabetes-related parenting stress specific to their child's diabetes. This indicates that these parents may have a slightly increased likelihood/vulnerability to poorer mental health. There was also some evidence of parental mental health being associated with diabetes outcomes, and that ethnicity and family income are associated with poorer outcomes.

Conclusion: This review found an increased risk of these parents having poorer mental health. Evidence was limited and of variable quality, with issues regarding measures used, and completeness of the data collected and reported. Larger-scale and more diverse and representative samples are required in future research. Clinicians and health services need to be aware of the potential psychological impact for parents and consider assessment/screening where appropriate. There is a need for evidence-based effective

psychological interventions for parents, as there is growing evidence that poor parental mental health has a detrimental impact not just on parents but also on child mental health, and diabetes management and outcomes.

INTRODUCTION

Impact of parenting a child with a chronic illness

There are additional challenges for parents raising a child with a chronic illness. There is strong and consistent evidence that parenting a child with a chronic illness has an impact on parental mental health. A recent review and meta-analysis comparing parents of children with a chronic illness to parents of healthy children found that parents of children with chronic illness had significantly higher levels of depression (35% meeting clinical cut-off score vs 19% of control group) and anxiety (57% meeting clinical cut-off vs. 38%) and concluded that parents of children with a chronic illness experience poorer mental health (Cohn, Pechlivanoglou, Lee, Mahant, et al., in press).

Similar results have been found for parenting stress. Cousino & Hazen (2013) found in their review that parenting stress was significantly higher in parents of children with a chronic illness, and that it was associated with poorer psychological adjustment both in parents and children.

However, there are many types of chronic illness and symptoms, prognosis, and treatments can vary widely between different illnesses/conditions. For example, some chronic illnesses are potentially life-limiting such as cystic fibrosis, whilst others, whilst challenging, such as eczema, are not. One study found parents of children with cancer reported significantly higher levels of stress than parents of children with other chronic illnesses (Masa'Deh, 2015). Therefore, it is acknowledged that parents' experiences of caring for a child with a chronic illness may vary depending on the nature of the chronic illness their child has, and the particular challenges this brings.

This review looks at Depression, Anxiety, General Parenting Stress, and Diabetes-Specific Parenting Stress in parents of children with Type 1 Diabetes (T1D), the first since Whittemore et al.'s (2012) previous review on this topic.

Impact of parenting a child with Type 1 diabetes

Type 1 diabetes (T1D) is an autoimmune condition and develops when insulin-producing cells in the pancreas are damaged, and it is not clear what exactly causes the body to attack

these cells (JRDF, 2017). It is often diagnosed in childhood, and is a chronic condition requiring lifelong daily management, as there are serious, disabling consequences if it is not well-managed. Consequences of poorly managed diabetes include diabetic retinopathy (loss of vision), neuropathy, hypoglycaemia (low blood sugar), and hyperglycaemia (high blood sugar). Hypoglycaemia can lead to seizures and loss of consciousness, whilst hyperglycaemia can cause diabetic ketoacidosis (DKA) which can lead to diabetic coma and can be fatal. Sometimes admission to hospital due to DKA leads to T1D being diagnosed. Prevalence rates of type 1 diabetes are increasing each year, with higher rates in Scotland compared to other parts of the UK (Diabetes UK, 2016a). Scotland has the third highest incidence of type 1 diabetes in children under 14 in the world (Diabetes UK, 2013). In Scotland, the mortality rate for patients with Type 1 diabetes is 2.6 times higher than the general population (Diabetes UK, 2013).

There are a number of daily challenges for parents caring for a young child with Type 1 diabetes, in addition to the risks and complications mentioned above. These include physiological challenges, issues around mealtimes and dietary intake, managing physical activity, as well as psycho-social challenges e.g. play, sleep (see Streisand & Monaghan, 2014, for an overview of these). Additionally, as children grow and develop, the roles that parents take on in terms of diabetes-related care will likely change as their child reaches adolescence, which can bring its own new challenges. Caring for a child with T1D puts a lot of responsibility on parents to ultimately keep their child alive, and requires *intensive daily* management.

A systematic review by Whittemore et al. (2012) looking at the psychological experience of parents, caring for a child with T1D, found the prevalence of psychological distress ranged from 10% to 74%, although in the majority of studies it ranged from 20% - 30%. Looking at specific areas of mental health, they found prevalence rates for anxiety ranged from 21% - 59%, depressive symptoms from 10%-74%, psychological distress from 29% - 33%, and symptoms of Post-Traumatic Stress Disorder (PTSD) from 19% - 24%. Overall, they found that parents of a child with T1D experience greater distress than parents of healthy children. They also found evidence for some differences in psychological outcomes between mothers and fathers. There was also evidence that mental health was associated with a number of other factors including child and diabetes management outcomes. However, the literature

search strategy employed by Whitemore et al. (2012) used limited search terms, for example they only used the term “parent” and did not include other variants such as “mother” and “father”. Similarly, for diabetes terms, they only used “type 1 diabetes”. In addition, they did not use truncation to capture variants of search terms. This means that potentially relevant research may have been inadvertently missed due to limitations in their search strategy. As a result, this may have had an impact in terms of reducing the quality and quantity of the studies identified, and thus included in their review.

There is some evidence that some mothers may experience the diagnosis of their child having T1D as traumatic, with a review finding that some mothers were experiencing significant post-traumatic stress symptoms, and that whilst this was most severe at disease onset, their symptoms often persisted for 1 to 5 years after diagnosis (Rechenberg, Grey, & Sadler, 2017). This same review found evidence that mothers post-traumatic stress symptoms adversely affected children’s health. This suggests the impact for mothers of their child being diagnosed with T1D, as well as all the responsibility for daily, intensive treatment to manage T1D, can have a significant impact on mothers’ mental health.

The research literature on parents has focused predominately on mothers. Research has shown that mothers can experience a need for constant vigilance and worry over their child with T1D, and difficulties accessing supports can lead to mental health difficulties (Sullivan-Bolyai et al., 2003), whilst the same author also compared mothers to a control group and found their experiences differed, with mothers of children with T1D experiencing anxiety around hypoglycaemia, and accessing services capable of looking after their child and their diabetes (Sullivan-Bolyai et al., 2002).

There has been some recent research that has focussed predominately on fathers. A recent study found fathers of children with T1D experienced significantly more general parenting stress than fathers of healthy children (Limbers & Teasdale, 2018). Another study found that fathers parenting stress was positively associated with state anxiety and mother-reported difficult child behaviour (Mitchell, Hilliard, Mednick, Henderson, et al., 2009). In the Mitchell et al. (2009) study fathers completed less than 20% of daily instances of glucose monitoring and administering insulin, though this may be due to the study being on parents of very young children aged 2-6 years, and mothers tending to take on more care-giving responsibilities, especially when children are very young.

Aim of review

The aim of the current review is to look at the literature since Whitemore et al.'s (2012) original review was published, focusing on quantitative research only. As far as we are aware this is the first updated review since Whitemore et al. (2012) original review was published in 2012. From searching databases, it was noted there has been a fair amount of research published since, justifying an updated review on this topic. In addition, this updated review sought to overcome some of the limitations of Whitemore et al.'s (2012) review, such as improving upon the search strategy by including additional search terms- (e.g. both "diabetes mellitus type 1" and "type 1 diabetes" were used to search for type 1 diabetes research), using truncation (e.g. "child*" to include variations of "child" such as "children"), and employing a more robust and comprehensive strategy through the use of Boolean operators. In addition, in the current review, the inclusion criteria were tightened (for example excluding studies where children had comorbid health conditions) meaning the potential for some confounding factors was reduced.

The current review will specifically look at depression, anxiety, general parenting stress, and diabetes-specific parenting stress in parents of children with Type 1 diabetes.

This review will seek to answer this by looking at the prevalence rates of the specified psychological outcomes, as well as whether there are any differences between mothers and fathers, and control groups. Finally, this review will also look at whether depression, anxiety, general parenting stress, and diabetes-specific parenting stress are associated with other relevant outcomes, namely child-reported outcomes, and diabetes management.

METHODOLOGY

A systematic review was conducted to identify all findings of current quantitative research on depression, anxiety, general parenting stress, and diabetes-specific parenting stress in parents of children with Type 1 diabetes, since Whittmore et al's (2012) review. This review followed the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (Moher, Liberati, Tetzlaff, Altman et al., 2009), commonly referred to as PRISMA guidance (see Appendix 2). Prior to conducting the review, the protocol was registered with PROSPERO, the prospective systematic review database (registration number: CRD42019159924).

Inclusion/Exclusion Criteria

In order to be included in this review, a study had to contain all the following features, (a) be a peer-reviewed cross-sectional or longitudinal study published in the English language (b) have a parental perspective and/or parental standardised psychological outcome measure including at least one of stress, anxiety, depression or adjustment (c) be quantitative research only [mixed methods were included if quantitative results had been reported separately to qualitative] (d) the population investigated were parents of children under 18 with type 1 diabetes, and (e) were published between 2011 and 2020, and had not previously been included in Whittmore et al.'s (2012) review.

Studies were excluded if they were conference papers (as unable to get full text), research protocols, intervention studies or case studies. Studies that included parents of children with other medical conditions were excluded if it was not possible to separate out data specifically for parents of children with type 1 diabetes. Studies that included children with type 1 diabetes who had other comorbid physical or mental health conditions were also excluded. Studies that focused on a specific topic such as driving or needle anxiety were excluded, as well as studies that focused on child or family adjustment and did not include parental psychological outcomes or the parental perspective.

Search Strategy

The following databases were searched as part of this updated review; CINAHL, Embase, MEDLINE and PsycINFO. Some of the databases searched in this review included those originally searched by the Whittemore et al. (2012) review. The databases chosen for this updated search were done following consultation and advice from an information officer experienced in advising on systematic reviews.

The Cochrane Library and PROSPERO were also searched to ensure that there were no current or previous systematic reviews that had been carried out on this topic since the Whittemore et al. (2012) review.

Search Terms

As part of this updated review, additional search terms were added to Whittemore et al.'s (2012) original search strategy. This was done to try to ensure the search for relevant studies was more comprehensive.

The search terms were divided into four different categories by breaking down the review question. The first parent terms included *parent-child relations*, *mother-child relations*, *father-child relations*, *single parent*, *family relations*, and *parenting*. The child/young person terms included the terms *child*, *adolescen**, and *young adult*. The type 1 diabetes terms included *diabetes mellitus type 1* and *type 1 diabetes*. The final fourth category contained psychological terms including *emotional adjustment*, *psychological adjustment*, *psychological stress*, *anxiety disorders*, *anxiety*, *depression*, and *depressive symptoms*. Within categories, search terms were combined using the Boolean OR, before all 4 categories were combined using the Boolean AND. It should be noted that search terms were used consistently across all 4 databases, however, slight tweaks were made to the wording of terms as MeSH terms varied slightly across all 4 databases.

Study Selection/Analysis

Following initial database searches, all results were transferred to an online reference

manager for systematic reviews (www.covidence.org). An initial screening of article titles and abstracts were carried out to eliminate studies which did not contain the desired population or variables. The reference manager automatically removed identical duplicates. Non-identical versions of papers which were clearly duplicates were removed by the reviewer during the initial screening process. A full text review was then carried out for the remaining articles and literature which did not meet criteria was removed. Data from the remaining studies was extracted and is summarised in Tables 1 and 2, which includes the following information; author, number of participants, study design, description of relevant measures, and summary of relevant findings.

A quality assessment was then carried out on all studies. The Newcastle-Ottawa Quality Assessment Scale (NOS) was used for cohort and case-control studies, whilst the Agency for Healthcare Research and Quality (AHRQ) tool was used for cross-sectional studies, with both tools being recommended in Zeng et al.'s (2015) review of quality assessment tools.

The quality review was carried out by two independent reviewers for half of the studies (8 studies out of 16), with the remaining studies being rated by one independent reviewer. Inter-rated concordance ranged from 38% to 83%, with the average inter-rater agreement being 64%. Any discrepancy in quality rating was discussed and a final rating was mutually agreed upon. Following this, the findings of the review were summarised and discussed.

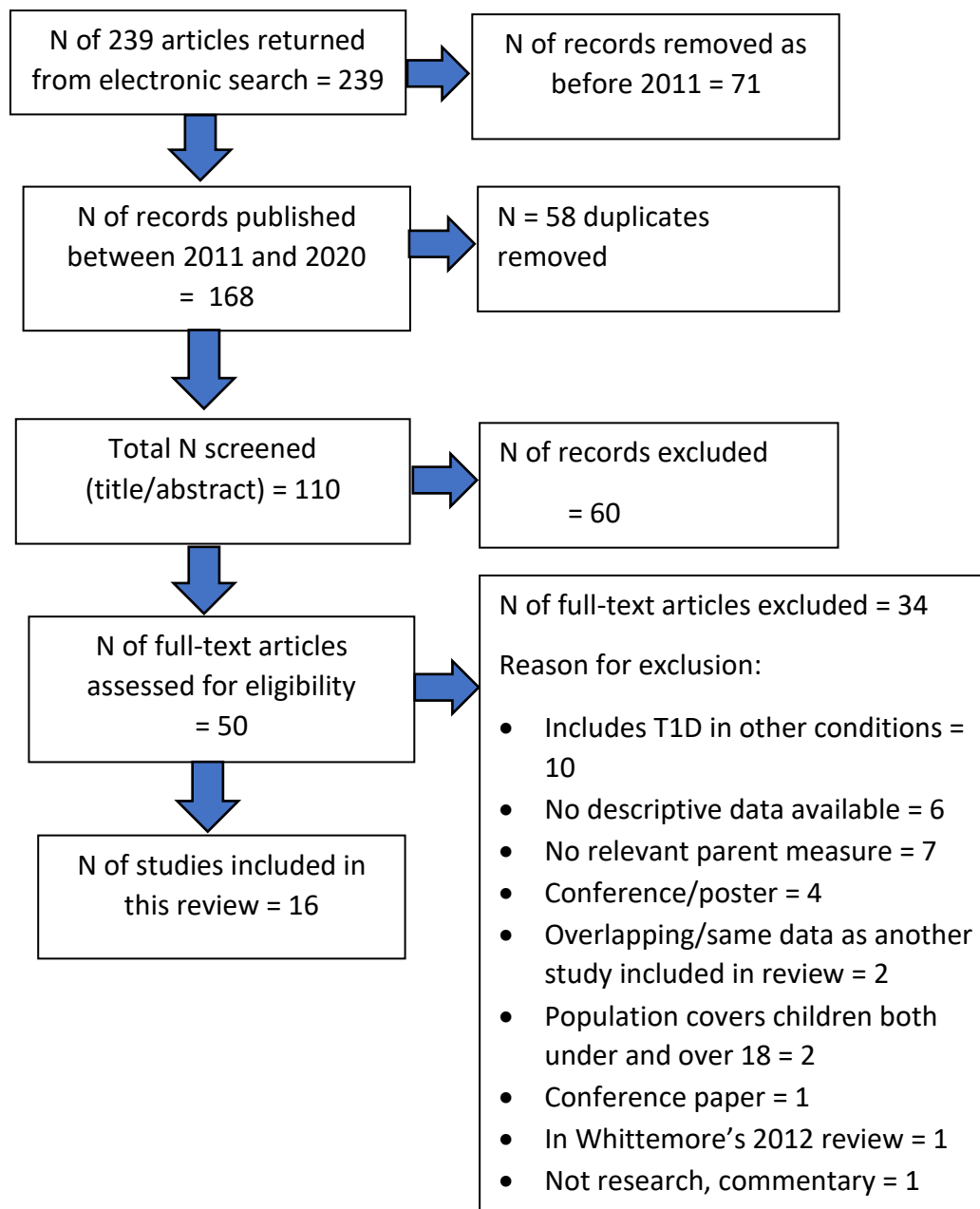
RESULTS

Included Studies

Following literature searches there ended up being two deviations from the original registered protocol. Firstly, no studies that met inclusion criteria and looked specifically at measures of adjustment were found. As a result, it was not possible for this review to look at adjustment. Secondly, included studies that had a measure of stress, included separate measures of general parenting stress and diabetes-specific parenting stress. Therefore, it was felt appropriate to distinguish between these two types of parenting stress, and as a result they were looked at and reported separately.

A total of 239 articles were identified from searches of electronic databases. After limiting articles to those published between 2011 and 2012, 168 articles remained. After applying the inclusion/exclusion criteria and removing duplicates, a total of 16 articles remained and were included in this review. A brief description of the process and reasons for exclusion are included in Figure 1 below.

Fig. 1. PRISMA Diagram



Study Characteristics

The 16 studies included in this review were published between 2011 and 2020 (see Table 1 for details on study characteristics). In terms of study design, 12 were cross-sectional, 2 were cross-sectional control, and 2 were prospective longitudinal, with follow up periods of 12 months and 16 months respectively.

Most studies were conducted in the USA (n=10). Of the six studies remaining, 1 was from Australia, with the other 5 all from Europe, specifically Belgium (n=1), UK (n=1), Slovenia (n=1), The Netherlands (n=1) and Portugal (n=1). Nearly all studies recruited through outpatient health settings (n=14), with the number of sites (where reported) ranging from 1 to 9, though majority recruited through one site (n=6) or two sites (n=4). Of the 2 remaining studies, one recruited both through outpatient settings and diabetes summer camps, and one study recruited exclusively through diabetes summer camps.

Sample sizes of parents in the studies ranged from 24 to 906 (mean=193). The majority of studies (n=9) included both mothers and fathers, however, of these, in 6 studies mothers made up between 82-94% of parents included. There were 5 studies that focused solely on mothers (n=5), and 2 studies included parents but did not specify number or proportion of which were mothers or fathers.

In terms of children's ages, the majority of studies included parents of children with T1D who were aged 8-18 years. Only 3 studies included very young children, and in terms of mean age of children, only 2 studies had children's mean age as under 8 years old.

Therefore, most of the studies in this review were of parents of children either entering or in adolescence. The minimum time the child had been diagnosed with T1D in most studies was between 6 and 12 months as outlined in each study's inclusion criteria. Across studies, there was an approximately equal representation of gender in the children, with the majority of studies having between 45-55% of children in their sample being female (n=9). In addition, studies varied in terms of how the child's diabetes was treated, with some children having insulin pumps, some on conventional regimes, basal bolus regimes, continuous glucose monitoring, or on multiple daily injections.

Table 1 – Study/Sample Characteristics

Author	Location	Sample Characteristics	Study Data	Inclusion/Exclusion Criteria
Burckhardt et al. (2018)	Australia – outpatient single site	<i>N</i> = 49 parents (% mothers/fathers not specified). Children (mean age 9.5yrs, SD 1.9), diabetes duration (mean = 3.9yrs, SD=2.5). 63% female. 64% used insulin pump.	Cross-sectional	<i>Inclusion:</i> parents of children with T1D for more than a year, aged 2-12 years. Parents had to have not used Continuous Glucose Monitoring (CGM) for preceding 6 months.
Clayton et al. (2013)	USA – outpatient setting, single site	<i>N</i> = 230 mothers at baseline (77% Caucasian, 68% married). Most mothers aged between 31 and 50, and were married. Mean age of adolescents was 13.8 yrs (SD = 1.8). Mean time since diagnosis was 4.26 yrs (SD=3.48) <i>N</i> = 132 mothers at 12 month follow-up.	Prospective longitudinal	<i>Inclusion:</i> English-speaking mothers of adolescents with Type 1 diabetes aged 11-18 years. <i>Exclusion:</i> Adolescents having co-existing primary medical disease
Drew et al. (2011)	USA – outpatient setting, 2 sites	<i>N</i> = 252 mothers (mean age 39.64 yrs, SD = 6.34). 88% married. <i>N</i> = 188 fathers (mean age 42.08 yrs, SD = 6.32). Adolescents (mean age 12.49 yrs, SD=1.53). Mean duration of T1D = 4.13 yrs, (SD=3) 94% Caucasian, <i>N</i> = 250 English-speaking (<i>N</i> =2 Spanish speaking), 53.6% female, predominately middle class, 50.8% on insulin pumps, with rest on multiple daily injections.	Cross-sectional	<i>Inclusion:</i> Mothers had to be living with adolescent aged 10-14 years with Type 1 diabetes for more than a year, and able to speak Spanish or English.

Jaser et al. (2014)	USA – outpatient setting, single site	N= 118 mothers (mean age 44.2 yrs, SD=5.8) 75% married/partnered, 78% white. Adolescents (mean age=12.8yrs, SD= 2). Mean duration of T1D=4.9yrs, (SD=3.6). 46% female. 82% on injections, 18% on insulin pump	Cross-sectional	<i>Inclusion:</i> mothers had to be currently living with adolescent and able to speak and read English. Adolescents' age 10-16 years had to have a diagnosis of T1D for at least 6 months, no other major health problems, and be able to speak and read English.
Law et al. (2013)	England, UK – outpatient setting, 8 sites	N= 203 parents (data only available for N=129, of which 106 or 82% were mothers) Adolescents (mean age=14.5yrs, SD= 1.83), mean duration of T1D = 5.8yrs (SD=3.7). 46% male. 61% reported using 2 injections a day, 3% reported using 3 injections a day, whilst 30% reported using 4 injections a day. 6% were on an insulin pump.	Cross-sectional	<i>Inclusion:</i> primary caregiver of a child aged 12-18yrs diagnosed with T1D for at least a year. Child to have no known co-morbid medical conditions and be fluent English speakers.
Maas-van Schaijk et al. (2013)	The Netherlands – outpatient setting, nine hospital sites. Control group recruited through 5 schools.	N=126 mothers and N=103 fathers of children with T1D. N= 151 children with T1D. Children (mean age= 14.89yrs, SD=1.71), mean duration of T1D=5.74yrs, (SD=3.92). 57% female. 53% on pump, 47% on multiple daily injections. All children were Caucasian, 13% had single parents, 87% had parents married/together. N= 106 mothers and N= 55 fathers of healthy children recruited from 5 secondary schools in same geographic	Cross-sectional control	<i>Criteria for parents of T1D children:</i> child aged between 12-18 yrs, attending secondary school, have had T1D for at least 6 months, and no comorbid medical or psychiatric conditions. <i>Criteria for parents of control children:</i> matched to T1D group by age, gender, and education level. Children not to have T1D or any other medical or psychiatric condition.

		region as those with T1D. No significant differences between T1D group and control group on child age, gender, education level, or family constellation.		
Monaghan et al. (2012)	USA – outpatient setting, inner city clinic and regional outpatient centres	<p><i>N</i>= 24 parents (mean age 34.8 yrs, <i>SD</i>=6.16). 88% female (<i>N</i>=21 were mothers, <i>N</i>=3 fathers), 92% married. 79% had a higher education degree, 75% reported annual income of at least \$50,000.</p> <p>Children (mean age 4.1yrs, <i>SD</i>=0.8), mean duration of T1D=2.06yrs (<i>SD</i>=0.57). 75% Caucasian. 50% male. 46% were on conventional regimen of 2-3 injections per day, 54% on multiple daily injections (MDI). No children had insulin pumps or CGM.</p>	Cross-sectional	<p><i>Inclusion</i>: parents had to be primary caregivers of children between 2 and 5 years old who had T1D for at least 6 months.</p> <p><i>Exclusion</i>: Parents who were not fluent in English, parents whose children had been diagnosed with an additional chronic illness.</p>
Moreira et al. (2013)	Portugal – outpatient setting, two sites. Control group recruited through a single school	<p><i>N</i>= 104 parents of children with T1D. Parent (mean age=41.98yrs, <i>SD</i>=6.01), 94% mothers, 91% married, 24% had college or graduate degree, and 75% were employed. Children (mean age=12.33yrs, <i>SD</i>=3.66), mean duration of T1D=5.63yrs (<i>SD</i>=3.86). 55.8% female. 85.6% on 4 or more injections per day, 5.8% on insulin pump, 1% on 2-3 injections, 7.7% missing information. When children split into groups by age, <i>N</i>= 49</p>	Cross-sectional control	<p><i>Criteria for parents of T1D children</i>: primary caregiver of child with T1D, child to be between 8-18 yrs, and have been diagnosed with T1D for at least 6 months, child to have no serious comorbid medical or mental conditions.</p> <p><i>Criteria for parents of control children</i>: child to have no diagnosis of a chronic health condition, child aged 8-18 yrs. Child not to have any significant developmental delays or severe psychiatric disorders.</p>

		<p>children age 8-12yrs, and $N=55$ children aged 13-18yrs.</p> <p>$N= 142$ parents of healthy children. Control group did not differ significantly to T1D parent group on parent age, parent gender, marital status, education, family income, or professional status. Also, no significant difference on child age, age groups, or gender.</p>		
Pate et al. (2019)	Slovenia – outpatient setting, single site	<p>$N=125$ families ($N=120$ mothers, $N=79$ fathers). For 74 children both parents participated (59%), for 46 children mother only(37%), and for 5 children father only (4%)</p> <p>Mothers (mean age=41.7yrs, $SD=5.7$). Fathers (mean age=44.9yrs, $SD=6.7$). Children (mean age=12.4yrs, $SD=3$). Mean duration of T1D=4.9yrs ($SD=2.8$). 53% female. 20% injections, 80% on insulin pump (of which 8.8% also using CGMS too).</p>	Cross-sectional	<i>Inclusion:</i> parent of child aged 7 to 17 years old with T1D, and had to have had T1D for at least a year.
Patton et al. (2011)	USA – outpatient setting, two sites	<p>$N= 39$ parents (mean age = 35.1yrs, $SD=6.4$)</p> <p>$N= 32$ mothers, $N= 6$ fathers, and $N=1$ custodial grandparent. 74% married, 54% reported annual income of at least \$50,000.</p>	Cross-sectional	<i>Inclusion:</i> child less than 7 yrs old, T1D diagnosis for at least a year, and child on intensive insulin treatment (e.g. insulin pump or multiple daily injections), and English spoken at home. Parents had a primary role in child’s daily diabetes self-care.

		Children (mean age=5.1yrs, SD=1.1), 51% male. 62% on insulin pump, 82% Caucasian.		
Robinson et al. (2016)	USA- outpatient setting, two sites	<i>N</i> =257 parents. 91% mothers. 77% married. Children (mean age=12.8yrs, SD=1.2). Mean duration of T1D=5.1yrs (SD=3.1). 51% male, 69% Caucasian, 81% of families' middle-class socio-economic status. 44% on insulin pump, 20% on basal bolus.	Cross-sectional	<i>Inclusion:</i> parent of child aged 11-14yrs with diagnosis of T1D for at least 1 year, no significant medical comorbidities, and fluent in reading English.
Rumburg et al. (2017)	USA – outpatient setting, single site	<i>N</i> =81 mothers Children (mean age= 13.3yrs, SD=1.96)	Cross-sectional	<i>Inclusion:</i> mothers of children aged 10-16yrs with a diagnosis of T1D for at least 1 year. To be able to speak and read English.
Sweenie et al. (2014)	USA – outpatient setting, several sites	<i>N</i> = 86 parents. 93% were mothers (<i>N</i> =80), 74% married, 77.5% reported annual income of at least \$50,000. Children (mean age=10.8yrs, SD=0.75). Duration of T1D (mean=4.2yrs, SD=2.64). 56% on conventional regime of 2-3 injections a day, 44% on insulin pump or multiple daily injections. 73% Caucasian.	Cross-sectional	<i>Inclusion:</i> child aged 9-11 yrs old, ability to speak and read English. Being free of developmental disabilities, psychotic disorders, or other serious medical conditions, and females not having reached puberty. Parents to be primary caregiver.
Van Gampelaere et al. (2018)	Belgium – outpatient setting, single site	<i>N</i> = 43 mothers (mean age=41yrs, SD=4.98). 76.7% married/cohabiting.	Cross-sectional	<i>Inclusion:</i> child had to have diagnosis of T1D, aged 8-15 yrs, and not have any other physical or pervasive developmental disorder. Both parent and child had to be Dutch-speaking.

		Children (mean age=12yrs, SD=2.07). Duration of T1D (mean=4.67yrs, SD=3.32), 57% female		
Vesco et al. (2018)	USA – from 44 diabetes camps	N=906 parents (89.8% mothers, 9% fathers, 1.2% other). Nearly normal distribution of annual family income. Children (mean age= 14.40yrs, SD=1.49). Mean duration of T1D = 7.18yrs, (SD=2.74). 57.6% female, 90.5% Caucasian. 74.5% used insulin pump, 12.9% used continuous glucose monitoring.	Cross-sectional	<i>Inclusion:</i> primary caregiver willing to consent and participate. Child had to be between 12-18 yrs old with T1D. Families had to be fluent in English.
Wiebe et al. (2011)	USA – 3 sites, outpatient setting, mailing clinic patients, and registration for summer diabetes camps	N=82 mothers. 99% European-American and 90% married. Children at baseline (mean age=12.79 yrs, SD=1.70) and follow-up (mean age=14.16yrs, SD=1.69). Duration of T1D (mean=5.4yrs). 52% male. Majority on multiple daily injections (percentage not specified).	Prospective longitudinal (baseline and 16 month follow-up)	<i>Inclusion:</i> child aged 10-15yrs, have been diagnosed with T1D for at least 1 year. Mothers had to be living with their child with T1D.

Study findings (see Table 2)

Depression

Of the 16 studies, 11 studies used a validated measure of depression, 9 of which were cross-sectional and 2 were longitudinal. Six measures were used across studies including the Center for Epidemiological Studies Depression Scale (CES-D, n=5), Beck Depression Inventory-Second Edition (BDI-II, n=2), Patient Health Questionnaire (PHQ9, n=1), Depression subscale of the Hospital Anxiety and Depression Scale (HADS, n=1), negative affect schedule of the Positive and Negative Affect Schedule (PANAS, n=1), and the Depression subscale of the Depression Anxiety Stress Scale (DASS, n=1).

The general global prevalence rate for depression is 4.4%, with the rate for females being 5.1% whilst the rate for males is 3.6% (World Health Organisation, 2017). Six studies reported prevalence of a probable mood disorder, and this ranged from 13% to 49% in studies which featured only mothers or that were predominately made up of mothers. The prevalence rates of these 6 studies that reported prevalence rates were all higher than the global prevalence rates. The only study to report the prevalence in fathers separately found the rate to be 17.8% (Drew et al., 2011). This was however based on a sample of only 188 fathers, all recruited from 2 sites in the USA, that were largely Caucasian, middle-class and English-speaking, and so should be interpreted with caution. In terms of depression over time, only 1 study reported prevalence over time (Wiebe et al., 2011), and it was found that prevalence remained at 28% at baseline and 16 month follow-up, though it was noted that within their sample some mothers who were depressed at baseline were not at follow-up and vice versa. However, Wiebe et al. (2011) only had 82 mothers in their study, and nearly all were European-American, so this should be interpreted with caution. Another study (Clayton et al., 2013) using a different measure found that mothers mean depression scores were above the clinical cut-off for mild depression at both baseline and 12 month follow-up, but that there had been a slight decrease over time in mean score at follow-up.

Studies that did not report prevalence, did provide descriptive statistics (means and standard deviations), and a few studies did report both (e.g. Drew et al., 2011). Of the 5 studies that used the CES-D, the clinical cut-off for interpreting likely depression is a score of

16 or more (Radloff, 1977). Of the 5 studies using the CES-D, only 1 had mean scores above 16 (Wiebe et al., 2011), with the other 4 studies not reporting an elevated mean on depression scores. However, from the standard deviations reported, it was clear that all 5 studies had at least some parents scoring 16 or more.

Of the 2 studies that used the BDI-II (clinical cut-off is 14 or more) mean scores were in the sub-clinical range, with no elevated mean anxiety scores reported. However, again standard deviations indicated that at least some parents were scoring in the clinical range.

The study that used the PHQ9 (Rumberg et al., 2017) reported a mean score for depression being in the mild range (mean=6.49, mild range 5-9), with 49% being above the clinical cut-off for mild depressive symptoms, and 25% above the cut-off for moderate depressive symptoms.

The study that used the HADS depression subscale reported mean scores for depression being in the sub-clinical range. They also included a control group of parents of “healthy” children (Moreira et al., 2013), found that there was no significant difference in depressive symptoms between parents of children with T1D and parents of healthy children.

Only one study compared mothers and fathers separately on depression (Pate et al., 2019, using the PANAS) and found mothers reported significantly more negative emotions (i.e. depressive symptoms) than fathers. This mirrors gender differences seen in the general population regarding depression. They found no difference between mothers and fathers on measures of positive emotions.

The study that used the depression subscale of the DASS (Burckhardt et al., 2018) reported mean depression scores that were in the sub-clinical range, indicating no elevated rates of depression in their sample.

Whilst these results fall within the broad range of 10 to 74% of parents reporting depressive symptoms that Whittemore et al.’s (2012) original review found, the results differ somewhat in that the studies reported lower prevalence in the current review with prevalence of probable depression ranging from 13-49%.

Table 2 – Summary of Study Findings

Author	Measures Used	Relevant Findings
Burckhardt et al. (2018)	<i>Depression:</i> Depression Anxiety Stress Scale (DASS) <i>Anxiety:</i> STAI and Hypoglycaemia Fear Survey (HFS-P)	<u>DASS</u> results – Depression (mean = 6.1, SD = 8.4), Anxiety (mean = 5.9, SD = 8.3), Stress (mean = 12.4, SD = 9.0). <u>STAI</u> results – State (mean = 38.1, SD = 11.7), Trait (mean = 41.1, SD = 9.9). <u>HFS</u> results – Behaviour (mean=24.3, SD=5), Worry (mean=30.6, SD=12.4). Total (mean = 54.9, SD = 14.7) Found that that parental stress and anxiety improved following intervention (CGM with remote monitoring to alert parent if child’s blood glucose went too high or low).
Clayton et al. (2013)	<i>Depression:</i> CES-D	CES-D at baseline (N=220) mean=21.91 (SD=8.55, range=9-51). At 12 month follow-up (N=118) mean=17.20 (SD=5.46, range=8-34). Maternal depressive symptoms were higher the more recent their child’s diabetes diagnosis. Maternal depressive symptoms did not differ by ethnicity or socioeconomic status. Maternal depressive symptoms at baseline were correlated with and predicted healthcare use and charges (i.e. cost) at 12 and 24 month follow-up (using multivariate longitudinal analyses). Adolescents of mothers with high depressive symptoms were twice as likely to have an emergency room visit and three times as likely to have a hospitalisation in the subsequent 2 years, compared to adolescents of mothers with low depressive symptoms.
Drew et al. (2011)	<i>Depression:</i> CES-D (score ≥ 16 classified as clinically depressed)	Prevalence of clinical depression was 28.2% of mothers (mean = 12.42, SD = 10.04), and 17.8% of fathers (mean = 9.01, SD = 7.93). Higher mother and father depressive symptoms were correlated with lower family income (p<.01). Higher maternal depressive symptoms were correlated with lower levels of mother and father acceptance. Paternal depressive symptoms did not correlate with paternal acceptance.
Jaser et al. (2014)	<i>Depression:</i> CES-D <i>Anxiety:</i> state subscale of STAI	<u>Prevalence of depression</u> – 18% scored above clinical cut-off for depression (mean = 10.2, SD = 8.3)

	<i>Diabetes-related parenting stress: Responses to Stress Questionnaire</i>	<p><u>Diabetes related parenting stress</u> - all mothers reported some on the RSQ (mean = 12.4, SD=3.4, range= 5-22).</p> <p><u>Anxiety</u> – 13% reported high current state anxiety (mean = 32.4, SD = 9.3) (not anxiety disorder).</p> <p><u>Maternal diabetes-related stress</u> was significantly positively correlated with anxiety and depression. Found depressive symptoms and state anxiety correlated significantly with maternal coping styles. Found maternal depressive symptoms correlated with poorer adolescent quality of life. Found maternal coping styles mediated relationship between diabetes-related parenting stress and state anxiety and depression.</p>
Law et al. (2013)	<i>Parental Diabetes-related stress: Problem Areas in Diabetes (PAID)</i>	<p>PAID results – mean=2.6, SD=0.9</p> <p>Correlation found diabetes-related parenting stress was significantly positively correlated with adolescent diabetes-related distress ($p<.001$) and disagreements about responsibility for diabetes management between parent and adolescent when both assume responsibility ($p<.01$). It was significantly negatively correlated with adolescent self-efficacy, parental perceptions of adolescent self-efficacy, and increased agreement of responsibility between parent and adolescent for diabetes self-care activities.</p> <p>Hierarchical regression analyses indicated that 22% of parental diabetes-related stress was predicted by higher HbA1c (measures of glycaemic control), adolescent self-efficacy, parents perceptions of adolescent self-efficacy, and disagreements in family diabetes responsibility.</p>
Maas-van Schaijk et al. (2013)	<i>Parenting Stress: Parenting Stress Index (PSI- short form)</i>	<p><u>Parenting Stress:</u></p> <p>Fathers of adolescents with T1D reported significantly more parenting stress (mean=49.64, SD=26.34) than fathers in control group (mean=40.65, SD=14.87) ($p<.05$).</p> <p>There was no significant difference between mothers of adolescents with T1D (mean=44.87, SD=20.68) and mothers in control group (mean=40.17, SD=18.69).</p> <p>There were no significant differences between T1D mothers and fathers (mothers mean=45.04, SD=20.93 vs. fathers mean=46.65, SD=22.66).</p>

		<p><u>Impact of T1D adolescents risk for depression on parenting stress</u> - fathers of T1D adolescents at high risk of depression reported significantly more parenting stress (mean=75.20, SD=29.94 vs. fathers of adolescents not at risk of depression mean=46.63, SD=24.5). This was also found to be significant in mothers of T1D adolescents (high risk of adolescent depression parenting stress in mothers mean=60.43, SD=28.28 vs. no risk mean=42.57, SD=18.12).</p> <p><u>Parenting stress of T1D mothers differed when compared diabetes control of adolescents</u> (based on HbA1c) - mothers of adolescents with poorly controlled diabetes reporting significantly more parenting stress than mothers of adolescents with sub-optimally controlled, and optimally controlled diabetes. No significant differences were found in fathers when comparing adolescents' level of diabetic control. No significant effect of adolescent age on parental stress in either mothers or fathers.</p> <p><u>Correlation</u> found mothers and fathers parenting stress were strongly positively correlated. In mothers of T1D adolescents, parenting stress was significantly correlated with HbA1C (p<.01).</p> <p>Regression models found fathers parenting stress explained 18% and mothers 19% of the variance in HbA1c. Whilst for adolescent-reported depressive symptoms, regression found fathers parenting stress explained 24.8% and mothers 21.6% of the variance.</p>
Monaghan et al. (2012)	<p><i>Depression: CES-D</i> <i>Anxiety: state subscale of STAI</i> <i>Diabetes-related parenting stress: PIP</i></p>	<p><u>Depression</u> results (CES-D mean=14.75. SD=10.54, range =0-45). <u>STAI</u> state subscale (mean= 38.29, SD=10.25, range = 20-57). <u>Diabetes-related parenting stress</u> frequency (mean = 102.17, SD=29.64, range=49-162) and difficulty (mean=94.71, SD=31.69, range=42-153). All above measures were significantly positively correlated with each other (all ps<.05). Increased child behavioural insomnia was significantly correlated with greater difficulty with diabetes-related parenting stress and depression (p<.05). Greater behavioural sleep resistance in children was positively correlated with more</p>

		<p>frequent and greater difficulty with diabetes-related parenting stress, higher anxiety, and more depressive symptoms ($p < .05$).</p> <p>Parents of children on multiple daily injections reported significantly more frequent stress in the hour leading up to bed than parents of children on conventional regimens. No other significant difference on parental depression, anxiety or diabetes-related stress were found when parents of children that were on multiple daily injections were compared to those on conventional regimen.</p>
<p>Moreira et al. (2013)</p>	<p><i>Depression:</i> Depression subscale of HADS <i>Anxiety:</i> Anxiety subscale of HADS <i>Parental Stress:</i> Parental Distress subscale of the Parenting Stress Index-Short Form (PSI-SF)</p>	<p><u>Depressive</u> symptoms: in T1D group 66.3% in normal range, 23.1% in mild, 8.7% in moderate, and 1.9% in severe. Only 10.6% of T1D parents scored above 11, indicating the probable presence of a mood disorder. In control group 77.5% normal range, 15.5% mild, 6.3% moderate, and 0.7% severe. Mean HADS depression score in T1D child group (mean=6.10, SD=3.75) and T1D adolescent group (mean=5.63, SD=3.77). There was no significant difference in depressive symptoms between the T1D and control group.</p> <p><u>Anxiety</u> symptoms: in T1D parent group 38.5% in normal range, 31.7% in mild range, 17.3% in moderate range, and 12.5% in severe range. 29.8% of T1D parents scored above 11, indicating the probable presence of an anxiety disorder. In control group 57.7% normal range, 21.8% mild, 19% moderate, and 1.4% severe. Mean HADS anxiety score in T1D children group (mean=8.94, SD=4.14) and T1D adolescent group (mean=8.75, SD=4.22). Parents of children with T1D were significantly more anxious than parents in the control group ($p < .01$).</p> <p><u>Parental stress:</u> T1D child group (mean=26.23, SD=8.82) and T1D adolescent group (mean=29.00, SD=9.13) compared to control child group (mean=24.71, SD=6.54) and control adolescent group (mean=27.34, SD=8.11). Parents of adolescents (regardless of whether had T1D or control) had significantly higher levels of parental stress than parents of children, but there was no significant effect of group or interaction ($p < .05$).</p> <p><u>Correlation:</u> in both T1D and control groups family cohesion correlated negatively with anxiety, depression, and parental stress. In T1D parents, higher levels of</p>

		<p>negative impact of T1D correlated with higher levels of depression, anxiety, and parental stress (all $p < .01$).</p> <p>Mediation analysis: it was found that higher levels of family cohesion were associated with lower negative impact of T1D which in turn was associated with better quality of life and lower levels of parental stress, and anxiety and depressive symptoms.</p>
Pate et al. (2019)	<p><i>Depression:</i> Positive and Negative Affect Schedule (PANAS)/</p> <p><i>Anxiety:</i> trait subscale of STAI, and Hypoglycaemia Fear Survey-Parent Version (HFS-P).</p>	<p>Comparing mother-father dyads ($n=72-74$):</p> <p><u>Depression</u>: no significant difference between mothers (mean=35.2, SD=5.6) and fathers (mean=34.4, SD=6.1) on positive emotions. Mothers (mean=24.2, SD=6.8) reported significantly more negative emotions than fathers (mean=22, SD=6.1), ($p < .05$).</p> <p><u>Anxiety</u>: mothers (mean = 40.6, SD=8.8) reported significantly more trait anxiety than fathers (mean=36.4, SD=8.4) on STAI ($p < .01$).</p> <p><u>HFS-P</u> – mothers reported significantly higher fear of hypoglycaemia (mean=67.3, SD=16.5) than fathers (mean=62.8, SD=13.6), ($p < .05$). Additionally, mothers reported significantly more preventative behaviours (mean=30.4, SD=7.4) compared to fathers (mean=28.2, SD=6.6), ($p < .05$). The difference between mothers (mean=36.7, SD=11.3) and fathers (mean=34.4, SD=9.8) on worry subscale was not significant but was approaching significant ($p = .06$).</p> <p>Mothers whose children had experienced at least one episode of hypoglycaemia used significantly more preventative behaviours to avoid hypoglycaemia ($p < .05$). In both mothers and fathers, more anxiety symptoms were associated with worse subjective well-being. In fathers, only anxiety significantly correlated with lower satisfaction with glycaemic control and lower self-perceived knowledge about child's T1D.</p>
Patton et al. (2011)	<p><i>Depression:</i> BDI-II</p> <p><i>Anxiety:</i> Hypoglycaemia Fear Survey- Parents of Young Children (HFS-PYC)</p>	<p><u>Depression</u>: 13% of parents had a total score in the mild to moderate range of depressive symptoms on the BDI-II (mean=9.1, SD=10.1).</p> <p><u>HFS-PYC</u> results - (mean= 78.6, SD=18.4).</p> <p><u>Diabetes-related parenting stress</u> – frequency (mean=107.3, SD=32.6), difficulty (mean=92.7, SD=33).</p>

	<i>Diabetes-related parenting stress: PIP</i>	<p>Correlational analysis found that more frequent diabetes-related parenting stress and more difficult diabetes-related parenting stress were both significantly associated with increased fear of hypoglycaemia and higher depressive symptoms (all $ps < .05$).</p> <p>Linear regression found that 58% of diabetes-related parenting stress frequency was predicted by parental depressive symptoms, whilst 68% of diabetes-related parenting stress difficulty was predicted by parental depressive symptoms and fear of hypoglycaemia.</p>
Robinson et al. (2016)	<p><i>Depression: BDI-II</i> <i>Anxiety: Worry subscale of Hypoglycaemia Fear Survey-Parent (HFS-P)</i> <i>Diabetes-related parenting stress: PIP</i></p>	<p><u>Depression</u> results - (mean score=7.9, SD=7.7, range 0-44) <u>Anxiety</u> – (mean score=18.4, SD=8.9, range=0-50). <u>Diabetes-related Parenting Stress</u> – frequency (mean=90.5, SD=24.6, range=43-189), difficulty (mean=83.7, SD=26.6, range =42-161).</p> <p>Structural Equation Modelling (SEM) indicated that less parental distress (comprised of depression, parenting stress, and anxiety) was significantly related to higher parental self-efficacy for diabetes management and to more authoritative parenting.</p>
Rumburg et al. (2017)	<p><i>Depression: Patient Health Questionnaire (PHQ-9)</i> <i>Parental diabetes-related distress: Parent Diabetes Distress Scale (P-DDS)</i></p>	<p><u>Depression</u>: (mean=6.49, SD=6.61). 49% were above clinical cut-off for mild depressive symptoms, and 25% above cut-off for moderate depressive symptoms. In addition, 37% of mothers reported a psychological disorder (most common diagnosis was depression) at time of study. (NOTED in study that glycaemic control in adolescents was very poor in this study).</p> <p>Correlation found that maternal depressive symptoms were significantly positively correlated with glycaemic control for mothers of 10-12 yr olds but not mothers of 13-16 yr olds. Higher levels of maternal depressive symptoms significantly correlated with poorer glycaemic control for mothers of girls, but not boys. Multivariate analyses found maternal depressive symptoms significantly predicted glycaemic control.</p> <p><u>Parental diabetes-related distress</u>: (mean=1.44, SD=0.83). 26% above clinical cut-off for diabetes distress. Found that within P-DDS subscales that distress about</p>

		<p>self, teen, and relationship with teen, were all significantly positively correlated with maternal depressive symptoms ($p < .001$). For mothers of 10-12yr olds, relationship with teen distress was significantly correlated with glycaemic control, but not for mothers of 13-16yr olds.</p> <p>Multivariate analyses found parental diabetes-related distress did not significantly predict glycaemic control.</p>
Sweenie et al. (2014)	<i>Diabetes-related parenting stress: difficulty subscale of PIP</i>	<p>Diabetes-related parenting stress: PIP difficulty score results (mean=79.9, SD=25.4, range=42-158).</p> <p>Greater diabetes-related parenting stress was negatively correlated with annual household income ($p < .01$). Diabetes-related parenting stress was significantly positively correlated with child-reported critical parenting behaviours ($p < .01$) and parent-reported problematic child behaviours ($p < .05$).</p> <p>Diabetes-related parenting stress accounted for 55% of the association between child problem behaviours and critical parenting behaviours.</p>
Van Gampelaere et al. (2018)	<i>Diabetes-related parenting stress: PIP</i>	<p><u>Diabetes-related parenting stress</u>: PIP score results (mean=95.56, SD=27.22).</p> <p>Both general distress and diabetes-related parenting stress were significantly positively correlated with child-reported depressive symptoms ($p < .05$) but not child-reported anxiety symptoms.</p> <p>Regression found diabetes-related parenting stress was a significant predictor of child anxiety and depressive symptoms, but that parental general distress was not a significant predictor of these.</p>
Vesco et al. (2018)	<i>Parental diabetes-related distress: Problem Areas in Diabetes for Parents of Teens (P-PAID-T)</i>	<p>Parental diabetes-related distress: P-PAID-T results (mean= 78.84, SD= 24.76).</p> <p>Higher parental diabetes-related distress was associated with child racial minority status ($p = .028$) and lower family income ($p < .001$). Lower distress was associated with pump use ($p = .002$). Glycaemic control (parent-reported HbA1C) was positively associated with parent diabetes-related distress. When parent-adolescent dyads both reported concordant lower distress, HbA1c was lower compared to concordantly higher distress dyads. Parents who were more distressed than their child reported higher parent-reported HbA1c than parents whose distress was lower than their child's. In parent-adolescent dyads that</p>

		concordantly reported low distress, adolescents reported diabetes-related strengths than concordantly high distress dyad as well as discordant dyads.
Wiebe et al. (2011)	<i>Depression: CESD</i>	<p>CESD: 28% (23 mothers) were above clinical cut-off (score of 16 or more) at each time points, while 9 were above this cut-off at both time points.</p> <p>Correlation: baseline maternal depressive symptoms were significantly positively correlated with higher maternal involvement in diabetes tasks at baseline and follow-up ($p < .05$). Baseline maternal depressive symptoms were significantly negatively correlated with lower (i.e. better) metabolic control as measured by HbA1c ($p < .05$).</p> <p>Regression analyses: maternal depressive symptoms were associated with higher levels of mother-reported maternal involvement in diabetes tasks, and slower declines in involvement across time. When mothers experienced higher symptoms of depression, maternal involvement was associated with fewer emotional and physical benefits for the adolescent. Children of mothers with fewer depressive symptoms, who had lower involvement at baseline and larger declines in involvement across time, had poorer subsequent adherence. Maternal depressive symptoms had no effect on adolescent depression or metabolic control (HbA1c) at follow-up.</p>

Anxiety

Seven studies included a validated anxiety measure, including the State Trait Anxiety Inventory (STAI, n=4), the Hypoglycaemia Fear Survey-Parent Version (HFS-P, n=4), the Anxiety subscale of the HADS (n=1), and the Anxiety subscale of the DASS (n=1). It was noted that of the studies using the STAI, only one study used both the trait and state subscales (Burckhardt et al., 2018), with 2 studies only using the state subscale, and one using only the trait subscale. This means for studies that only used a subscale as opposed to the full measure, it is not possible to comment on anxiety *disorder*, but only that specific subscale of anxiety. All seven studies that included an anxiety measure were cross-sectional. The global prevalence rate for anxiety is 3.6%, with this being higher in females than males (4.6% in females vs. 2.6% in males), (World Health Organisation, 2017). The two studies that reported prevalence data, both had higher rates than this, with 13% of their sample scoring above the clinical cut-off for state anxiety (Jaser et al., 2014), whilst in Moreira et al. (2013) study they reported prevalence rates (for HADS anxiety scale) of 31.7% of parents being in the mild range, 17.3% in the moderate, and 12.5% in the severe range, with 29.8% scoring above 11 indicating the probable presence of an anxiety disorder. These prevalence rates are lower than the 21 – 59% suggested by Whittemore et al. (2012).

On the STAI, higher scores indicate higher anxiety, and although there are no rigid cut-offs, it has been suggested that a cut-off score of 39-40 indicates clinically significant symptoms of anxiety (Julian, 2011). On the STAI state subscale (n=3), mean scores were 32.4, 38.1, and 38.29, all of which are just below the clinical cut-off anxiety. For the trait subscale (n=2), mean scores were 40.6 and 41.1 for mothers, and 36.4 for fathers, indicating clinical levels of anxiety (albeit at the milder end of the clinical range) in mothers but not fathers. The one study (Pate et al., 2019) that compared mothers and father separately used the trait subscale of the STAI and found mothers reported significantly more anxiety than fathers, which mirrors the gender differences in anxiety rates seen in the general population.

The study that used the anxiety subscale of the HADS (Moreira et al., 2013) found parents of children 8-12 years old with T1D had a mean anxiety score of 8.94, whilst parents of children with T1D aged 13-18 years had a mean anxiety score of 8.75, both of which are in the mild clinical range (scores of 8-10 fall in this range). This

study also had a control group of parents as a comparator and found that parents of children with T1D were significantly more anxious than parents in the control group.

The study that used the anxiety subscale of the DASS (Burckhardt et al., 2018) found the reported mean anxiety scores were at the milder end of the clinical range (mean = 5.9).

The HFS-P consists of 2 subscales, a behaviour, and a worry subscale, with higher scores indicating higher fear of hypoglycaemia, though it is noted there are no defined cut-off scores for this measure. Of the 4 studies that used the HFS-P, 2 studies reported both subscales separately, one reported a total score combining the two subscales, and one only used the worry subscale. For the worry subscale, mean scores (n=3) ranged from 18.4 to 67.3 indicating a very broad range. For the behaviour subscale, the mean scores (n=2) ranged from 24.3 to 30.4. The remaining study that reported the total of both subscales added together had a mean score of 78.6. Only one study compared mothers and fathers (Pate et al., 2019) and found that mothers reported significantly more preventative behaviours than fathers on the behaviour subscale (mean =67.3 vs. 62.8), with the difference on the worry scale approaching significance (mean=36.7 for mothers vs. 34.4 for fathers, $p=0.06$).

General Parenting Stress

Only 2 studies included a measure of general parenting stress, using the Parenting Stress Index-Short Form (PSI-SF). One study used only the parental distress subscale (Moreira et al., 2013), whilst the other only reported a total parenting stress score (Maas-van Schaaijk et al., 2013). Both these studies were cross-sectional and had a control group of parents of children with no health conditions. In the study (Maas-van Schaaijk et al., 2013) that reported mothers and fathers scores separately it was found that there was no significant difference between mothers and fathers of children with T1D on total parenting stress. Fathers of children with T1D reported significantly more parenting stress than fathers in the control group, but there was no significant difference between mothers in the T1D and control group. In the other study (Moreira et al., 2013) that used the parental distress subscale only, it was found that parents of children aged 13-18yrs had significantly higher parenting

stress than parents of children aged 8-12 yrs, regardless of whether their child had T1D or were in control group. They also found regardless of age, there were no significant differences in general parenting stress between parents of children with T1D and those without.

Diabetes-related parenting stress

Nine studies included some form of diabetes-related parenting stress and all were cross-sectional in design. Measures used included the Paediatric Inventory for Parents (PIP, n=5), the Problem Areas in Diabetes-Parent version (PAID-P, n=2), Parent Diabetes Distress Scale (P-DDS, n=1), and the Responses to Stress Questionnaire (RSQ, n=1). The PAID-P, P-DDS and RSQ are diabetes specific measures, whilst the PIP is a measure of non-specific illness-related parenting stress.

The PIP is comprised of a difficulty and frequency subscale with potential scores ranging on each subscale from a minimum of 42 to a maximum of 210. Higher scores indicate greater stress, however, there are no defined cut-off scores, or categories. For studies that reported frequency (n=3) the mean scores ranged from 90.5 to 107.3. For difficulty (n=4) the mean scores ranged from 79.9 to 94.71. The remaining study (Van Gampeleare et al., 2018) reported a composite total PIP score which had a mean of 95.56.

The PAID-P was used in 2 studies, with higher scores indicating greater stress. However, the version of the PAID-P used differed slightly with the PAID-P in Law et al. (2013) having 20 items, whilst the one used in Vesco et al. (2018) had 26 items as it was developed a number of years after the Law study was published and specifically adapted for parents of teenagers (although it was noted that both studies recruited parents of children aged between 12-18 years). In the Law study the mean PAID-P score was 2.6, whilst in the Vesco et al. (2018) study the mean score was 78.84. The impact of using the “same” but ultimately non-identical measure, as well as differences in reporting scores, make comparison across these 2 studies difficult.

Whilst only one study used the P-DDS (Rumburg et al. 2017), they did report both descriptive data and prevalence. The mean score was 1.44, which falls in the ‘little to no distress’ range (Hessler et al., 2016). However, it was noted that 26% of

parents were above the clinical cut-off for diabetes-related parenting stress (defined as a mean score of 2 or more).

On the single study that used the RSQ (Jaser et al., 2014), the mean score was 12.4, however all mothers in the study reported some diabetes-related parenting stress.

Factors Associated with Anxiety, Depression, General Parenting Stress, and Diabetes-Specific Parenting Stress

A number of studies used correlation analyses. Associations found in these studies that were relevant and pertinent to the review outcome variables are reported here.

There was evidence across a number of studies of the 4 outcome variables of interest correlating significantly with each other. For example, it was found that diabetes-related parenting stress was significantly positively correlated with anxiety and depression in several studies (Jaser et al., 2014; Monaghan et al., 2012; Patton et al., 2011), all of which were quality assessed in this review, and scored relatively highly. Though it must be noted that this finding was found either in mothers only studies or studies that were predominately made up of mothers. Whilst 3 of the subscales of a diabetes-related parenting stress measure all significantly positively correlated with maternal depressive symptoms (Rumburg et al., 2017), although in that study very little data is available on the characteristics of the mothers in their sample (only N was reported), meaning it is hard to generalise the findings to the population. It was also found that mothers and fathers parenting stress strongly positively correlated (Maas-van Schaaijk et al., 2013).

There was some weak evidence that characteristics relating to timing of T1D diagnosis were associated with depression. Maternal depressive symptoms were higher the more recent their child's diabetes diagnosis (Clayton et al., 2013). This finding may not have been found in other studies as most studies had inclusion criteria stating a minimum of 6 to 12 months of having been diagnosed with T1D. Interestingly Vesco et al. (2018) found that lower diabetes-related parenting stress was correlated with pump use. It was noted that whilst studies did represent a range of therapeutic treatments that children use to manage T1D, insulin pumps are a relatively new technology and therefore, this may be why this was the only study

to report this. Pate et al. (2019) also found that mothers whose child had experienced hypoglycaemia previously, used significantly more preventative behaviours to avoid hypoglycaemia.

There was also some evidence in a number of studies indicating that parental mental health has an impact on child and adolescent outcomes. Jaser et al. (2014) found that maternal depressive symptoms significantly correlated with poorer adolescent quality of life, which in turn was significantly correlated with adolescent depressive symptoms. Jaser et al. (2014) did try to control for factors that could impact on adolescent quality of life, as they found duration of diabetes, glycaemic control, and maternal coping styles, were not significantly associated with adolescent quality of life. However, the finding that glycaemic control was not a factor may be partly due to the sample of adolescents in their study having relatively good control, so should be interpreted with caution. Law et al. (2013) found diabetes-related parenting stress was significantly positively correlated with adolescent diabetes-related distress. General distress and diabetes-related parenting stress were both positively correlated with child-reported depressive symptoms (Van Gampelaere et al., 2018). Maas-van Schaaijk et al. (2013) found maternal stress was significantly correlated with glycaemic control of adolescents as measured using HbA1c levels. Rumburg et al. (2017) found that maternal depressive symptoms were significantly positively correlated with glycaemic control for mothers of 10-12 year olds, but not mothers of 13-16 year olds. They also found that maternal depressive symptoms correlated significantly with poorer glycaemic control for mothers of girls but not boys. Vesco et al. (2018) found parental diabetes-related distress was positively associated with increased HbA1c (i.e. poorer glycaemic control). The opposite result was found in Wiebe et al. (2011) where maternal depressive symptoms were negatively correlated with glycaemic control, and that maternal depressive symptoms were significantly positively correlated with higher maternal involvement in diabetes tasks at baseline and 16 month follow-up. As this was the only study in this review to find this, it must be interpreted with caution, as the sample was relatively small (N=82) and it was only one of two studies in this review that recruited from diabetes camps in the USA (the rest of the studies recruited solely through outpatient settings), although on the quality assessment, this study was found to be of relatively good quality.

In terms of the potential impact of demographic characteristics, not all studies reported demographic data, and the quality of data reported varied. Family income and ethnicity were suggested to play a role in parental mental health and diabetes outcomes. Family income was found to be significantly correlated with increased mother and father depressive symptoms, lower levels of parental acceptance, and worse glycaemic control as measured by HbA1c (Drew et al., 2011), whilst in Sweenie et al.'s (2014) study, household income significantly correlated with all outcome measures including diabetes-related parenting stress. In Vesco et al. (2018) family income and child ethnicity both significantly correlated with higher levels of diabetes-related parenting stress, and worse glycaemic control as measured by HbA1c. However, other studies results did not support this, for example, Clayton et al. (2013) found no significant effect of socioeconomic status on maternal depression, although this study lacked power to be able to make any assertions regarding ethnicity.

Other factors out with the scope of this review were also found. Moreira et al. (2013) found in both parents of T1D children and control group parents that family cohesion correlated negatively with anxiety, depression, and parental stress. In parents of T1D children, higher levels of the perceived negative impact of T1D correlated significantly with higher levels of depression, anxiety, and parental stress. Whilst Pate et al. (2019) found higher parental anxiety correlated with poorer parental subjective well-being. Sweenie et al. (2014) found diabetes-related parenting stress was significantly positively correlated with child-reported critical parenting behaviours and parent-reported problematic child behaviours.

Quality Assessment

All studies were formally rated for quality. The tools chosen for quality assessment were done so having been recommended in Zeng et al.'s (2015) broad review of quality assessment tools. The quality review was carried out by two independent reviewers, with one reviewer assessing all studies, and the second reviewer assessing 50% of studies (n=8). Any discrepancy in quality rating was discussed and a final rating was mutually agreed upon.

For cross-sectional studies (n=14) the Agency for Healthcare Research and Quality (AHRQ) tool was used but modified to create a better fitting assessment for the multiple domains the review question was looking to answer. This included the removal of two questions regarding follow-up as this did not apply to cross-sectional studies. The AHRQ is answered on a 3 point scale, with 2 being 'Yes', 1 being 'Partially Yes', and 0 being 'No', with the option to score questions that are not applicable as 'N/A'. The maximum possible score on the AHRQ ranged from 12 to 18 (refer to Appendix 3 for a copy of the adapted AHRQ tool)

For cohort studies (n=2), the Newcastle-Ottawa Quality Assessment Scale (NOS) was used. This was tailored for the review, with two questions being removed, one on the control group and the other on the outcome of interest not being present at the start of the study as both these questions were not applicable to the studies being rated. From the modified NOS there were 6 questions, each question scores a maximum of 1 star, except the comparability question for which a maximum of 2 stars can be given. The maximum total score on the NOS was 7 (refer to Appendix 4 for a copy of the adapted NOS tool).

To allow comparison between studies rated on the AHRQ and the NOS, the scores on both were calculated as a percentage. It is acknowledged that there are potential issues regarding making numerical points ratings using quality tools. For example, it assumes that all items are equally weighted in their contribution to a total score, and that a total score is the most valuable number. However, despite these issues and possible limitations, using a numerical quality assessment tool, can help when trying to evaluate quality across studies in a systematic way. Please refer to Table 3 for AHRQ ratings and Table 4 for NOS ratings of studies.

The quality scores of the studies in the review ranged from 42.86% to 83.33%. The mean percentage score across all studies was 66.81%.

Results of the quality assessment indicated that all studies had used at least one validated measure of the outcome variables that the review was focused on. It was noted that of the 4 specific outcome variables of interest that this review focused on, no single study included measures for all 4 of these outcomes. In addition, it was noted that in some studies only part of a measure had been administered (e.g. in

Jaser et al., 2014, only the state subscale of the STAI had been used), which did result in a lower quality rating than studies that had used all subscales of a measure. This has the knock-on impact of making it harder to compare results of the same measures if only partial data on that measure is available.

In terms of risk of bias, there were 6 studies that only recruited through a single site. Several studies did not report sufficient basic descriptive demographic data on parents and their children. In addition, only 1 study (Jaser et al., 2014) provided explicit power or sample size calculations.

Table 3 – Quality Assessment for Agency for Healthcare Research and Quality (AHRQ) studies

	Burckhardt et al. (2018)	Drew et al. (2011)	Jaser et al. (2014)	Law et al. (2013)	Maas-van Schaaijk et al. (2013)	Monaghan et al. (2012)	Moreira et al. (2013)
1. Unbiased selection?	1	2	1	2	2	2	1
2. Selection minimizes baseline differences?	N/A	N/A	N/A	N/A	2	N/A	1
3. Sample size/Power calculated?	0	0	2	0	0	0	0
4. Adequate cohort description?	1	2	2	1	1	2	2
5. Validated depression measure?	2	2	2	N/A	N/A	2	2
6. Validated anxiety measure?	2	N/A	1	N/A	N/A	1	2
7. Validated general parenting stress measure?	N/A	N/A	N/A	N/A	2	N/A	1
8. Validated diabetes-related parenting stress measure?	N/A	N/A	1	2	N/A	2	N/A
9. Analysis controls for confounding?	0	2	2	2	1	2	2
10. Analytic methods appropriate?	2	2	2	2	2	1	2
Total Score =	8/14	10/12	13/16	9/12	10/14	12/16	13/18
Percentage Score (%)	57.14	83.33	81.25	75.00	71.43	75.00	72.22

Key for ratings: 2 being 'Yes', 1 being 'Partially Yes', and 0 being 'No', and not applicable as 'N/A'.

Table 3 – Quality Assessment for Agency for Healthcare Research and Quality (AHRQ) studies

(continued)

	Pate et al. (2019)	Patton et al. (2011)	Robinson et al. (2016)	Rumburg et al. (2017)	Sweenie et al. (2014)	Van Gampelaere et al.	Vesco et al. (2018)
1. Unbiased selection?	1	2	2	1	2	1	1
2. Selection minimizes baseline differences?	1	N/A	N/A	N/A	N/A	N/A	N/A
3. Sample size/Power calculated?	0	0	0	0	0	0	0
4. Adequate cohort description?	1	2	1	0	1	1	1
5. Validated depression measure?	2	2	2	2	N/A	N/A	N/A
6. Validated anxiety measure?	1	2	1	N/A	N/A	N/A	N/A
7. Validated general parenting stress measure?	N/A	N/A	N/A	N/A	N/A	1	N/A
8. Validated diabetes-related parenting stress measure?	N/A	2	2	2	1	1	2
9. Analysis controls for confounding?	1	1	0	1	1	1	2
10. Analytic methods appropriate?	2	2	2	2	2	1	2
Total Score =	9/16	13/16	10/16	8/14	7/12	6/14	8/12
Percentage Score (%)	56.25	81.25	62.50	57.14	58.33	42.86	66.66

Table 4 – Quality Assessment for Newcastle Ottawa Scale (NOS) studies

	Clayton et al. (2013)	Wiebe et al. (2011)
1. Representativeness of cohort?	1	1
2. Ascertainment of T1D?	1	1
3. Comparability	0	1
4. Assessment of outcome	0	0
5. Sufficient follow-up?	1	1
6. Adequacy of follow-up?	1	1
Total Score =	4/7	5/7
Percentage Score (%)	57.14	71.43

DISCUSSION

The aim of the current review was to look at the quantitative research since Whittemore et al.'s (2012) review, focusing on depression, anxiety, general parenting stress, and diabetes-specific parenting stress in parents of children with Type 1 diabetes. This review found evidence that parents of a child with Type 1 diabetes (T1D) had higher prevalence rates of depression and anxiety. Regarding depression, the majority of studies in this review found no evidence that parents of children with Type 1 diabetes had higher rates of depression. There was some limited evidence that these parents may be at a slightly increased risk of anxiety, though evidence indicated that for most this was in the mild end of the clinical range. There was some limited evidence that anxiety and depression were higher in mothers than fathers. Evidence regarding parenting stress was limited, with parenting stress tending to be higher in parents of children with Type 1 diabetes compared to parents of healthy children. Additionally, they also experience specific diabetes-related parenting stress specific to their child's diabetes. This indicates that these parents may have a slightly increased likelihood/vulnerability to poorer mental health.

Comparing with previous research and reviews

This review found prevalence of depression in parents of children with T1D ranged from 13% to 49%. This range is somewhat larger than the prevalence Whittemore et al.'s (2012) found of 10% to 74%, (however, they reported one study that included parents whose child had just been diagnosed had significantly higher prevalence and once this was removed, the prevalence of depression from most studies was 20% to 30%). The current review found no difference in depressive symptoms when compared to parents of healthy children, however only one study actually measured this. This result differs to a recent review and meta-analysis which found parents of children with a chronic illness had higher depression than parents of healthy children (Cohn, Pechlivanoglou, Lee, Mahant, et al., in press). A possible likely reason for the current review finding no effect is that only 1 study in the current review had a control group and looked at depression allowing a direct comparison to be made.

In terms of anxiety, the two studies that assessed prevalence of anxiety found rates of 13 and 61.5% respectively. From other studies it was clear that some parents were scoring in the clinical range for anxiety. Again, this range is similar to Whittemore et al.'s (2012) finding of prevalence from 21% to 59%. There was some evidence that mothers are more anxious than fathers, and parents of a child with T1D experience more anxiety than parents of children without T1D. This finding is consistent with findings in chronic ill health in children generally (Cohn, Pechlivanoglou, Lee, Mahant, et al., in press).

Regarding parenting stress, prevalence data was not available, however, it was found that there was no difference between mothers and fathers, and fathers had significantly more parenting stress than fathers in a control group, with no difference found between mothers, though this may be due to the small number of studies in the review that included parenting stress as an outcome variable. This somewhat supports a previous review and meta-analysis that have found parenting stress is higher in parents of children with chronic illnesses than parents of healthy children (Cousino & Hazen, 2013; Pinquart, 2018).

For diabetes-related parenting stress, only one study reported prevalence data with 26% of parents above the clinical cut-off. This was just slightly less than Whittemore et al.'s (2012) review, which found prevalence of diabetes specific psychological distress of around 30%. The results regarding general and diabetes-related parenting stress are important as previous research in this specific population has found general and diabetes-specific parenting stress are associated with poorer parental mental health, and these having an effect on child outcomes (Helgeson, Becker, Escobar, & Siminerio, 2012).

In Whittemore et al.'s (2012) review they also reported the prevalence of symptoms of PTSD (although this was not one of their explicit search terms), however, no studies in the current review included PTSD symptoms as an outcome variable.

There was also some evidence that the time since their child had been diagnosed with T1D affected the psychological experience of parents. For example, Clayton et al.'s (2013) study found maternal depressive symptoms were higher the more recent their child's diabetes diagnosis. This finding may not have been found in other

studies as most studies had inclusion criteria stating a minimum of 6 to 12 months of having been diagnosed with T1D. This suggests there may be a developmental process of adjustment in parents coming to terms/adjusting psychologically to the initial impact of diagnosis, when potential mood disturbance may be at its most acute.

Similarly, to Whittemore et al. (2012), the current review found some evidence that depression, anxiety, and diabetes-related parenting stress correlate significantly with each other. This was also the case for evidence that parental depressive symptoms were associated with poorer child self-report quality of life. Further, the current review found general distress and diabetes-related distress being associated with child-reported depressive symptoms and adolescent-reported diabetes-related distress.

There was limited evidence of the impact of demographics, with most studies reporting some level of this, though it did vary (e.g. Moreira et al., 2017 reported marital status, employment, and education level but not ethnicity). In this review 2 studies reported no demographic information (Burckhard et al., 2018; Rumburg et al., 2017). The majority of studies reported demographic information as descriptive data, some did analyse this (usually using correlation to check whether it associated with outcome variables). From this, only certain demographics were found to associate with parental mental health, and/or diabetes-related outcomes, and these were family income and ethnicity.

There were numerous issues regarding the quality of the included studies. Firstly, there was a lack of completeness of data e.g. studies reported type of therapy that children were on but often it did not add up to 100% (e.g. Vesco et al., 2018). Secondly, some studies did not report basic descriptive data (e.g. mean, SD, range, or prevalence using percentage above or below a specified clinical cut-off). This was the case not just for data on participant characteristics (e.g. Burckhardt et al., 2018), but also for outcome measures in a number of studies. The impact of these various limitations is that it limits the applicability and generalisability of the results of these studies as the data lacks context about the specific sample it is from.

Some studies only used parts of a measure or scale (e.g. both Jaser et al. [2014] and Monaghan et al. [2012] only used the state subscale of the STAI). Other studies used the same measure, but upon closer examination, these were found to be different versions of a measure, differed on the number of items, and how the score on this measure was calculated and reported (e.g. Law et al. [2013] and Vesco et al., [2018] both used different versions of the PAID). Whilst there was evidence of the validity and psychometric properties of the measures reported, this is limited if only a part of the measure or scale is administered, or different versions are used. This can make it more difficult to compare results across studies. This is compounded if some studies also only report a total score for a scale, as opposed to reporting scores for each subscale. A further issue is that some measures have clinical cut-offs and categories (e.g. mild, moderate, severe) such as the CES-D, whilst other measures such as the HFS-P, do not have any. This can make it difficult to interpret/compare within and across studies, particularly when trying to establish if any change in score is clinically meaningful or not.

In addition, evidence indicated all 4 psychological factors were found to correlate to some extent. Diabetes-related parenting stress was significantly positively correlated with anxiety and depression in several studies (Jaser et al., 2014; Monaghan et al., 2012; Patton et al., 2011). However, this finding was found either in mothers only studies or studies that were predominately made up of mothers. It has to be acknowledged that there may be other factors contributing to this. For example, women have greater prevalence of anxiety and depression than men (WHO, 1997). Women also tend to take on more caregiving duties and responsibilities in their role as mothers to their child with T1D. It has been found that mothers report significantly higher burden related to medical treatment than fathers (Haugstvedt, Wentzel-Larson, Rokne, & Graue, 2011).

Unfortunately, since Whitemore et al.'s (2012) review, there continues to be a lack of high quality studies on fathers. Very few studies included fathers in sufficient numbers to allow comparisons between mothers and fathers on the outcome variables of interest. A number of studies did include fathers but these were still the minority. Other types of primary caregiver (e.g. grandparents, same sex families,

foster carers) were also not included in sufficient numbers to enable any meaningful conclusions to be drawn.

In Whitemore et al. (2012) original review, they recommended a number of specific tools for assessing parental stress, anxiety, and depression in parents of children with T1D, including the PIP, STAI, BDI and CES-D, and it was positive and encouraging to see that the majority of studies in the updated review used at least one of these measures.

Strengths

As far as we are aware this is the first updated review since Whitemore et al. (2012) original review was published in 2012. From searching databases it was noted there has been a fair amount of research published since, justifying an updated review on this topic. In addition, as there was sufficient research published since, the inclusion criteria for this review were able to be tightened (for example excluding studies where children had comorbid health conditions) meaning the potential for some confounding factors was reduced.

In addition, this review tried to improve upon Whitemore et al. (2012) search strategy by including additional search terms and employing a more robust and comprehensive search strategy through the use of Boolean operators. In addition, steps were taken to try to maximise the scientific rigour of this review process, including pre-registering the planned review with Prospero, and having a second independent rater to assist with quality assessment of the included studies.

This review did also try to include studies that looked at fathers as well as mothers, as well as some studies that included other primary caregivers, e.g. grandparents, though numbers were very small, meaning no meaningful analysis could be carried out.

Limitations

The exclusion of studies of children who had co-morbid physical or mental health conditions, must also be acknowledged as a limitation. The decision to exclude co-

morbidities was taken on the basis of improving the specific focus of the review. However, it is acknowledged that excluding co-morbidities has an impact on the application and ecological validity of the results of the review to this population. Children with T1D have an increased risk of certain conditions including thyroid disorders, non-infectious enteritis and colitis, cardiovascular disease, mental disorders, epilepsy, and (obstructive) pulmonary disease (Farsani et al., 2015).

The majority of studies included in this review were carried out in the USA. It has to be acknowledged that different models of healthcare may affect the usefulness of the review findings and may have had an impact on the outcome variables the review was looking at. It is also noted that the majority of participants in studies were Caucasian. In addition (as part of the inclusion criteria) the majority of studies included English-speakers. This potentially limits applicability of the findings to a wider range of cultures and countries where English is not the main language. Additionally, diabetes prevalence varies by country, with higher prevalence in the Middle East (e.g. Kuwait and Libya) (Tuomehlito, 2013). These countries often have different family structures compared to western countries, and this can have implications for the applicability of these findings from a global health perspective.

Unlike Whitemore et al. (2012) study, this updated review focused purely on quantitative studies. Including qualitative studies was considered beyond the scope and resources of the current review. Whilst some studies had large numbers of participants, a number had small sample sizes, and this limits the applicability of their findings. It is also noted that very few studies had a control or comparator group. Finally, this review did not include grey literature or dissertations, focusing only on peer-reviewed published studies.

Implications of review for research

There is a need for research studies to include more diverse samples in research so the findings can be applied to a broader and/or overlooked populations of parents of children with T1D. This is pertinent in terms of potential high-risk families, for example single parents where very little research has looked at their experiences (see Brown, Weiner, Kupst, Brennan, et al., 2008), as well as parents with disabilities,

from ethnic minorities, low socioeconomic backgrounds, and people living in low and middle income countries. Without representing these samples, it is very difficult to generalise research findings to these populations or identify risk factors.

Research also needs to ensure adequate basic descriptive data on the characteristics of participants are collected and reported. Whilst this review did not include intervention studies, it did include studies where sufficient baseline data were reported and met inclusion criteria. It is suggested that in terms of widening the evidence base, and improving the quality of the available studies, all future studies should include reporting at a minimum basic descriptive characteristics of the sample, as a number of potentially relevant studies were excluded from this review because no descriptive data was available.

Additionally, there was a lack of longitudinal research, with the majority being cross-sectional. This limited what could be concluded about the psychological experience over time. It would be helpful to establish how the experience changes as there may be particular times when psychological distress is particularly acute e.g. in first year after diagnosis, but not much is known about the experience 5 or 10 years down the line.

Further, particularly during the period of quality assessment, it became apparent that research has tended to focus on one or two of the 4 psychological factors (anxiety, depression, parenting stress, and diabetes-related parenting stress) this review looked at. Bearing in mind that there was some evidence of correlation between some of these factors, it would be helpful for future research to look at including more than one of these factors, as this would clarify potential relationships between them, as well as contribute to the evidence base as the number of studies that had included measures of parenting stress and/or diabetes-related parenting stress were particularly limited.

Implications of review for clinical practice

Clinically, it is clear from this review that parenting a child with T1D can have an impact on mental health, and care providers and clinicians need to be aware of this, not just in terms of the impact on the parent, but also that there is some evidence of this having a detrimental impact on child outcomes. Further, the evidence in this review suggested that parental mental health may be most significantly impacted at the time of their child being diagnosed with T1D, suggesting a possible developmental process of adjustment for parents following their child's diagnosis. Longitudinal research would help establish if this is the case or not.

It is recommended that screening and assessing of parents may be appropriate. Whittemore et al. (2012) suggested this in their review, that screening should happen at the time of child's diagnosis, then annually and/or during child's developmental transitions. They also suggested certain groups of parents should be screened more frequently due to increased risk of mental health, including single parents, those from ethnic minorities, and those lacking any social support. However, this would require some planning in terms of what measures to use, and creating pathways to treatment and support. It is likely that the presentation of mental health difficulties that parents experience will vary, and so a stepped care model would likely be most appropriate, as this would be most responsive to the level of distress parents are experiencing. In addition, a stepped care model would allow parents to be stepped up to more intensive/specialist support should their mental health worsen. However, the creation of pathways, and having tiered levels of support would require staff resources in terms of time allocated to this, training to upskill existing staff, as well as commitment nationally to ensure equity of service and support. Potentially, there could be a role for third sector services to take on the lower level, mild to moderate type work e.g. Diabetes UK. However, as this currently does not exist in the UK, there would be a need to potentially pilot or evaluate this in some way, to measure demand and efficacy (likely through outcome measures).

Whittemore et al (2012) recommended psychological interventions for parents, noting that most interventions have focused on improving physical diabetes indicators, as opposed to parental psychological distress. However, a recent

Cochrane review, looking at psychological interventions for parents of children and adolescents with chronic illness, found that for parents of children with T1D they may improve parenting behaviour, but there was no evidence that they improved parental mental health (Law, Fisher, Eccleston, & Palermo, 2019). A key issue in the Cochrane review regarding T1D studies was that they were assessed as being of very low quality. They did however look at therapy type across chronic illness and concluded that Cognitive Behavioural Therapy (CBT) and Problem-Solving Therapy (PST) may help with parenting behaviour, but only PST was found to help with parental mental health. Whilst they did also include other forms of therapy including family therapy and multisystemic therapy, the data on these was insufficient to allow evaluation. CBT and PST both had the largest number of studies and participants, and it may be that this influenced the fact that they were found to be effective, in terms of the only good quality evidence being for them. Thus, it is clear there is a need for further high quality research on psychological interventions for parents, that are family-based, and systemic in approach to establish whether these are effective in improving parental mental health of children with T1D (as well as other chronic illnesses).

Conclusion

This review found evidence that parenting a child with Type 1 diabetes (T1D) can be difficult with higher prevalence rates of anxiety and depression. However, the majority of studies in this review found no evidence that parents of children with Type 1 diabetes had higher rates of depression. There was some evidence that these parents may be at a slightly increased risk of anxiety, though for most this was in the mild end of the clinical range. There was limited evidence that anxiety and depression were higher in mothers than fathers. Evidence regarding parenting stress was limited, with parenting stress tending to be higher in parents of children with Type 1 diabetes compared to parents of healthy children. Additionally, they also experience specific diabetes-related parenting stress specific to their child's diabetes. This indicates that these parents are potentially more vulnerable to experiencing poorer mental health.

However, a key issue remains around the quality of studies significantly affecting the usability and generalisability of the data from studies to the population of parents of

children with T1D. There is a need for research to be more representativeness in terms of family composition, race, disability, and culture. It is recommended that clinicians and health services are aware of the potential psychological impact of parenting a child with T1D, and consider assessment/screening where appropriate. There is also a need for evidence-based effective psychological interventions for parents caring for a child with T1D. It is also recommended that parents are signposted and offered a range of supports as there is growing evidence indicating that poor parental mental health has a detrimental impact not just on parents but also on child mental health, and diabetes management and outcomes.

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APPENDICES

Appendix 1: British Journal of Health Psychology Author Guidelines

Sections

Submission

Aims and Scope

Manuscript Categories and Requirements

Preparing the Submission

Editorial Policies and Ethical Considerations

Author Licensing

Publication Process After Acceptance

Post Publication

Editorial Office Contact Details

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <http://www.editorialmanager.com/bjhp>

Click here for more details on how to use [Editorial Manager](#).

All papers published in the *British Journal of Health Psychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

experimental and clinical research on aetiology

management of acute and chronic illness

responses to ill-health

screening and medical procedures

psychosocial mediators of health-related behaviours

influence of emotion on health and health-related behaviours

psychosocial processes relevant to disease outcomes

psychological interventions in health and disease

emotional and behavioural responses to ill health, screening and medical procedures

psychological aspects of prevention

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

The types of paper invited are:

papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations; theoretical papers which report analyses on established theories in health psychology;

we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with

qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

All systematic reviews must be pre-registered. The pre-registered details should be given in the methods section but blinded for peer review (i.e., 'the review was preregistered at [BLINDED]'); the details can be added at proof stage. Registration documents should be uploaded as title page files when possible, so that they are available to the Editor but not to reviewers.

Please refer to the separate guidelines for [Registered Reports](#).

4. PREPARING THE SUBMISSION

Contributions must be typed in double spacing. All sheets must be numbered.

Cover Letters

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; statement of contribution; main text file; figures/tables; supporting information.

Title Page

You may like to use [this template](#) for your title page. The title page should contain:

A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));

A short running title of less than 40 characters;

The full names of the authors;

The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Abstract;

Keywords;

Acknowledgments.

Authorship

Please refer to the journal's Authorship policy in the Editorial Policies and Ethical Considerations section for details on author listing eligibility. When entering the author names into Editorial Manager, the corresponding author will be asked to

provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.

Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).

Keywords

Please provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Statement of Contribution

All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

Main Text File

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

Title

Main text

References

Tables and figures (each complete with title and footnotes)

Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.

The journal uses British spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

References should be prepared according to the *Publication Manual of the American Psychological Association* (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page 1, and a DOI should be provided for all references where available.

For more information about APA referencing style, please refer to the [APA FAQ](#).

Reference examples follow:

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486. doi:[10.1176/appi.ajp.159.3.483](https://doi.org/10.1176/appi.ajp.159.3.483)

Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from <http://www.youtube.com/watch?v=Vja83KLQXZs>

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Colour figures. Figures submitted in colour may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

[Click here](#) for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association. The following points provide general advice on formatting and style.

Language: Authors must avoid the use of sexist or any other discriminatory language.

Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Units of measurement: Measurements should be given in SI or SI-derived units. Visit the [Bureau International des Poids et Mesures \(BIPM\) website](#) for more information about SI units.

Effect size: In normal circumstances, effect size should be incorporated.

Numbers: numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Appendix 2: PRISMA Checklist (from Moher et al., 2009)

<i>Table 1. Checklist of Items to Include When Reporting a Systematic Review or Meta-Analysis</i>			
Section/Topic	Item #	Checklist Item	Reported on Page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., <i>I</i> ²) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome-level assessment (see Item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group and (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., health care providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

Appendix 3: Example of blank adapted AHRQ tool

Name of Study: _____

Agency for Healthcare Research and Quality (AHRQ) tool – Proforma

Item Number	Items on AHRQ	Score 2=Yes Score 1 = Partially Yes Score 0 = No Can't tell or N/A
1	Unbiased selection of the cohort?	
2	Selection minimizes baseline differences in prognostic factors?	
3	Sample size calculated/ 5% difference?	
4	Adequate description of the cohort?	
5	Validated depression measure?	
6	Validated anxiety measure?	
7	Validated general parenting stress measure?	
8	Validated diabetes-related parenting stress measure?	
9	Outcome assessment blind to exposure?	
10	Adequate follow-up period?	
11	Completeness of follow-up?	
12	Analysis controls for confounding?	
13	Analytic methods appropriate?	
	Total Score	
	Percentage Score	

Appendix 4: Adapted blank NOS tool

	Name of paper
1. Representativeness of cohort?	
2. Ascertainment of T1D?	
3. Comparability	
4. Assessment of outcome	
5. Sufficient follow-up?	
6. Adequacy of follow-up?	
Total Score =	
Percentage Score (%)	

Title Page – Empirical Paper

Full Title: The Experiences of Young People with Type 1 Diabetes who Access
Transition Services

Running Title: Experiences of Transition for Young People with Type 1 Diabetes

Authors: Gillian Thompson (Trainee Clinical Psychologist, NHS Grampian)

Dr David Gillanders (Head of Clinical and Health Psychology)

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Dr David Gillanders (University of Edinburgh)

Acknowledgments: No Grant Support/Funding was provided for this Study

This review has been written in a style suitable for publication in the Journal of Clinical Psychology. A copy of the author guidance for this journal is included in Appendix 1.

ABSTRACT

Objectives: There is a lack of qualitative research on young people with Type 1 diabetes (T1D) during transition from adolescence into adulthood. The aim of this project was to explore this, in the context of the specific developmental challenges and processes that occur during adolescence.

Design: Qualitative approach with young people with T1D accessing NHS diabetes transition service.

Methods: Individual semi-structured interviews were carried out with young people (N=8). Interviews were audio-recorded and transcribed, before being analysed using Thematic Analysis.

Results: Qualitative analysis identified the following 2 master themes: (1) My internal experience of transition, as someone with T1D, and (2) External factors and supports: what helps or hinders transition. Subthemes for (1) turning point to taking on ownership of my diabetes, loneliness/feeling different, daily hassles and consequences of managing blood glucose levels, and relationship between T1D and mental health. Subthemes for (2) were shift of support from family to peers, use of healthcare services, the role of technology, and supports at school/work. Some of the subthemes support existing research, whilst the subthemes regarding the relationship between T1D and mental health, and the role of technology were new findings having not previously been found in research on this topic with this specific age group. Themes reflected on developmental tasks of adolescence including identity, autonomy, and abstract thinking and decision-making.

Conclusions: The findings are discussed in relation to the specific challenges of adolescence. Implications for clinical practice and research are also discussed, with suggestions made for future research and practice to try to address.

1. INTRODUCTION

1.1 Diabetes – type, prevalence, and cost

In Scotland alone, the NHS spends over £1bn on diabetes, 80 per cent of this is spent on managing avoidable complications, and inpatient care accounts for 30 per cent of the cost of treating diabetes (Diabetes UK, 2013). There are 2 types of diabetes, with approximately 10% of people having type 1 diabetes (T1D) (Diabetes UK, 2016a).

Type 1 diabetes (T1D) is an autoimmune condition and develops when insulin-producing cells in the pancreas are damaged, and it is not clear what exactly causes the body to attack these cells, though genetics are thought to partly play a role (JDRF, 2020a). It is often diagnosed in childhood, and is a chronic condition requiring lifelong management.

Worldwide, prevalence rates of type 1 diabetes are increasing each year, though rates vary by country (Patterson et al., 2012). Epidemiologically, research indicates T1D has increased worldwide at a relative increase rate of 3-4% each year (Tuomilehto, 2013). There is some evidence that rates may be higher for those from ethnic minority backgrounds (Mayer-Davis, et al., 2017). It is not fully understood why the incidence of T1D is increasing at such a high rate.

In the UK, there are over 29,000 children living with T1D, with the incidence increasing by 4% each year (JDRF, 2020b). For children aged under 5, the UK incidence rate has increased 5% each year in this age group for the past 20 years (JDRF, 2020b). Prevalence rates are higher in Scotland compared to other parts of the UK (Diabetes UK, 2016a). Incidence rates for diagnosis of T1D in Scotland are highest in those aged 10-14 years (64 per 100,000 population per year) (Scottish Diabetes Survey 2018).

However, there is also the impact of having T1D for the individual to consider. Indeed, there has been an acknowledgement that there needs to be a cultural shift

in attitude to empower people with diabetes to self-manage, with healthcare staff supporting and working with them (Diabetes UK, 2009).

1.2 Type 1 diabetes – complications and management

The mortality rate for people with T1D is 2.6 times higher than the general population (Diabetes UK, 2013). Average life expectancy is more than 10 years shorter for those with T1D compared to those without (Livingstone et al., 2015).

Insulin is essential in regulating levels of glucose in the blood, and in T1D the body cannot produce insulin naturally. Blood glucose levels vary depending on a variety of factors including food intake and exercise. Effectively self-managing T1D requires significant daily and lifelong management to keep blood glucose levels within a specified range to prevent hypoglycaemia (low blood sugar) and hyperglycaemia (high blood sugar). Regular monitoring of blood glucose (HbA1c) levels throughout the day is essential, and insulin is injected or pumped in numerous times a day. For a person with T1D, during their lifetime they will have roughly 65,000 injections, and will measure their blood glucose levels more than 80,000 times (JDRF, 2020b). Specialist NHS diabetes services include reviews of blood sugar levels, as well as annual foot and vision check-ups.

Without insulin, blood glucose levels increase, causing damage to nerves and blood vessels, including the eyes and feet, as well as the kidneys (JDRF, 2020a) resulting in diabetic retinopathy and neuropathy as well as kidney damage. Potentially fatal complications include diabetic coma and diabetic ketoacidosis (DKA). There is some evidence that high levels of deprivation and low socio-economic status increase the risk of DKA (Gibb, Teoh, Graham, & Lockman, 2016; Lindner, Rathmann, & Rosenbauer, 2018). Recurrent DKA increases the risk of death (Gibb et al., 2016).

There have been recent developments in technology that have changed ways of managing diabetes. These include continuous glucose monitoring (CGM) instead of finger prick blood tests, and insulin pumps instead of multiple daily injections. The proportion of children and adults with an insulin pump increased from 2013 to 2018

(Scottish Diabetes Survey, 2018). However, most young people remain on multiple daily injections. Research in young people comparing the benefits of insulin pumps over multiple daily injections is somewhat mixed (Blair et al., 2019; Jakisch et al., 2007).

1.3 The Developmental Psychology Perspective of Adolescence

Adolescence brings with it numerous unique developmental challenges. These can broadly be categorised as physical, cognitive, emotional, social, and behavioural (APA, 2002). It is important to note that all these developmental challenges and experiences take place over the course of adolescence and are gradual in nature, there is also some overlap between these, as these developments do not occur in a vacuum. Additionally, the age and rate at which individual adolescents will master these varies due to individual differences.

In terms of physical development, puberty brings with it many body changes, as the adolescent reaches sexual maturation. Puberty tends to occur earlier in girls than boys, and the process of reaching sexual maturation takes several years.

Additionally, the physical changes in the body that adolescents experience can lead to increased awareness and focus on their appearance in terms of wanting to fit in with peers, as well as becoming more conscious of wanting to appear attractive to others.

Cognitively, brain changes occur during adolescence. This results in the adolescent being able to start thinking abstractly, and to weigh up pros and cons or different options to a problem. They also start to develop a sense of values and increased awareness of morals, as they become more aware of alternative perspectives to their own.

Emotionally, the adolescent becomes more fully aware of their sense of self, and begins to experiment with their own identity as differentiated from that of their parents or caregivers. Potential issues this brings is the risk of low self-esteem if there is a discrepancy between how they see themselves, and how they want to be

(APA, 2002). Emotional development tasks include recognising and managing their emotions and developing a greater sense of empathy. Being Lesbian, Gay, Bisexual or Transgender (LGBT), having a disability, or chronic illness can add to this challenge in terms of building self-esteem (APA, 2002).

In terms of social development, peer relationships become more important during adolescence as they move from family to peer group as a major source of influence, particularly in developing their sense of self and identity. Additionally, new types of social role can occur, such as romantic/sexual relationships, as well as starting employment. This brings new responsibilities for adolescents to navigate.

Lastly, behaviourally, adolescents can engage in risk-taking behaviours, such as substance misuse and sex, as they experiment with identity. It is felt that it is normal for adolescents to experiment, but it does challenge their ability to make wise decisions and can be influenced by impulsivity and wishing to fit in with peers. This can sometimes lead to poor decisions being made, as this is a learning experience for them (APA, 2002). During this, adolescents are experimenting with increasing autonomy, resisting authority, and developing their sense of self and agency.

As young people journey through adolescence, they will encounter these challenges, and will typically experience certain developmental tasks as part of adolescence. An overview of developmental tasks of adolescence is shown in Table 1.

There are a range of different developmental theories, to try to explain and understand the psychological underpinnings of these challenges young people face during adolescence. Developmentally, from a basic level and early age, conditioning and reinforcement can impact behaviour in terms of making it more or less likely depending on the use of reward or punishment. Bandura's (1971) social learning theory would suggest adolescent behaviour comes from observing and imitating the behaviour of others such as peers, however, criticism of these theories is that they are somewhat simplistic explanations for what are complex developmental processes.

Stage of Adolescence	Biological (i.e. Puberty)	Psychological	Social
Early ↓	Girls – breast buds and pubic hair develop. Growth spurt starts. Boys – enlargement of testicles; genital growth starts	Concrete thinking; progression of sexual identity development (e.g. sexual orientation); reassess body image; possible same-sex peer interest.	Start to emotionally separate from parents; strong peer identification begins; early exploratory risk-taking behaviours e.g. smoking.
Mid ↓	Girls – menstruation begins; female body shape develops with fat deposition e.g. hips. Boys – semenarche; voice deepens; growth spurt begins	Abstract thinking but see self as “bullet-proof”, verbal abilities increase; identify law with morality; fervent ideology begins (e.g. religious).	Emotional separation from parents grows; identify strongly with peers; increased health risk behaviours (e.g. alcohol); heterosexual interest in peers; vocational plans begin.
Late	Boys – increase in muscle and body hair	Complex abstract thinking; able to identify difference between law and morality; impulse control increases; personal identity further develops; further development or rejection of ideology (e.g. political, religious).	Social autonomy develops; intimate relationships; develop financial independence and vocational abilities.

Table 1: Developmental tasks of adolescence (adapted from McIntosh, Helms, Smyth, Eds, *Forfar and Arneil's textbook of paediatrics*, 6th Ed, Edinburgh: Churchill Livingstone, 2003: 1757-1768; cited in Christie & Viner, 2005).

Piaget's (1964) theory of cognitive development in children posits that there are 4 stages children go through, starting with sensori-motor from birth to roughly 18 months where the infant grasps the concept of object permanence, then pre-operational, followed by concrete operational. The fourth stage, formal operational, occurs during adolescence, and is characterised by the adolescent developing higher level abstract and reasoning skills, for example being able to reason and consider hypothetical situations including more sophisticated and long-term perspective taking around the consequences of their own behaviour.

Attachment theory (Bowlby, 1977) posits that as helpless babies we look to a caregiver (usually mother) to meet all our needs for warmth, food, and love. Where this caregiver is consistent and responsive, we learn that our needs are important,

other people care about us, and from this secure base, the growing child feels able to learn and explore. Attachment theory argues that these early attachments are crucial in terms of forming a blueprint about what we learn about ourselves, and our relationships with others. From a developmental perspective, attachment partly shapes the relationships that a child and adolescent make, both platonic, as well as romantic and sexual relationships.

In terms of emotion regulation, potentially both attachment theory and social learning theory could apply in terms of explaining how children and adolescents can learn to regulate their emotions. However, a criticism of specific developmental theories is that they often focus on one specific part, and do not account for the adolescent being in a system, with multiple internal and external demands (Christie & Viner, 2005).

1.4 Difficulties with transition for young people with T1D

When children are young, often their diabetes is managed by their parents. During adolescence and early adulthood, management shifts to the individual themselves managing their own diabetes. At the same time as having to take on this responsibility for their diabetes, they are becoming more independent and autonomous. There are important transitions in life they will face, along with T1D, including education, such as leaving school, going on to further education or starting employment; dating and relationships; as well as milestones around being old enough to learn to drive and drink alcohol. Adolescence is a time of experimentation, and potential rebellion, and with all these challenges that an adolescent has to negotiate, it could be argued that it is unreasonable to expect them to get these things “right” first time, or to always be able to self-manage T1D successfully.

During this period of transition, adherence can be particularly poor due to a number of challenges and barriers, both internal and external (Borus & Laffel, 2010). For example, cognitive challenges include the ability to perspective take on the long-term consequences of their own healthcare actions, as this is an emergent and not

fully developed skill. Qualitative research with 16-25 year olds found themes relating to the impact of T1D upon perceptions of self once diagnosed, the impact of this on relationships with peers and family, as well as having to cope with their own personal mortality and the long-term consequences of diabetes (Dovey-Pearce, Doherty, & May, 2007).

In terms of diabetes management, glycaemic control has been found to be particularly poor in mid to late teens (Acharya et al., 2008). Although, other research has found that during and following transition to a specialist T1D service, glycaemic control improved over time but blood pressure and weight significantly increased (Melvin, Redahan, Hatunic, & McQuaid, 2019). In terms of engaging with diabetes services, clinic attendance at diabetes clinic has been found to be more likely to worsen during transition (Scottish Diabetes Survey, 2018; Sheehan, While, & Coyne, 2015).

In summary, the literature suggests that transition can be a time of increased burden, complications of self-management, increased distress, and reduced service use for adolescents with Type 1 Diabetes. Based on the theoretical understanding of the developmental challenges of adolescence, and how these could clash with the daily management of diabetes, it can be hypothesised that transition is hard for adolescents with T1D. A small number of qualitative studies have focused on transition for young people with T1D.

1.5 Qualitative Research in Type 1 diabetes in young people transitioning from child to adult services

There is some existing qualitative research that has looked at experiences of diabetes healthcare in young people with T1D. Hynes, Byrne, Casey, Dineen, & O'Hara (2015) explored clinic attendance amongst young adults aged 16-28 and found that their perceptions of the value in attending the clinic was influenced by the relationship they had with healthcare staff. This finding was also supported in a study of young people aged 17-18 years old who transitioned from paediatric to adult diabetes services. It was found that the relationship with healthcare staff was

very important, with young people either preferring a personal or professional relationship, and feeling more involved when staff took a genuine interest in their life (Hansen & Jensen, 2017). However, there are some strengths and limitations, as whilst Hansen & Jansen (2017) focused on transition in diabetes services, the age range they included was very narrow, whilst Hynes et al. (2015) had a much larger age range, but their focus was narrowed to clinic attendance specifically. The developmental psychology perspective indicates adolescent development is a process that takes more than two years but should be complete a number of years before the age of 28 (the upper age limit in Hynes et al., 2015).

In a UK study of 16-25 year olds exploring their experiences of diabetes services, it was found that a number of factors shaped this; including continuity of staff contact, the quality and type of interaction with healthcare staff, style of interaction changing as young people became older, and environment and access such as waiting times and making appointments (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005). In that study, young people gave suggestions for service development including: evening and weekend clinics; improving consultations by staff being sensitive and interested in the young person's life and not just their diabetes; improving information available to young people so it is relevant to their needs; and possible extra services such as being able to have question and answer sessions with staff, and a diabetes counsellor (Dovey-Pearce et al., 2005). However, it should be noted that participants in Dovey-Pearce et al. (2005) included Type 1 and Type 2 diabetes, and participants were recruited from a mix of adult and paediatric services. Whilst the age range in Dovey-Pearce et al. (2005) ensured the transition period was well-covered, the inclusion of both Type 1 and 2 diabetes is a limitation, as the treatment regimes do differ, as well as known lifestyle factors (e.g. diet, weight) increasing the likelihood of Type 2 but not Type 1 diabetes. The other limitation is that whilst they focused on transition, this was specifically only their experiences of diabetes services, and did not include other areas of their life.

Overall, there is limited research that has explored young people's experiences with specialist diabetes transition services in the NHS. Several studies have only looked at adult services, or have looked at transition but in a service different to the UK model

and system of healthcare. The focus specifically on young people's experiences with diabetes services, has meant that research has neglected the wider lived experiences of young people with Type 1 diabetes as they transition from adolescence into adulthood, and the developmental challenges and tasks that they face during this period of their life.

1.6 Need for transition-specific care from NHS services

Given that developmental psychology theory suggests very specific needs of teens during this period, it is no surprise that many health organisations have developed 'transition services' to bridge between paediatric and adult diabetes services. The UK and the NHS in Scotland is no exception and national policy has been to develop transition services. For example, the National Diabetes Transition Audit, 2011-2017 (2019) in England and Wales. The equivalent in Scotland is the Diabetes Action Plan (2010 and 2014). More recently Diabetes UK have published information on transition aimed at young people with T1D around what to expect as they move from child to adult diabetes care (Diabetes UK, 2016b).

1.7 Aims and Objectives of this Research Study

There has been little research looking at young peoples' experiences of transition in Scotland, since the Diabetes Action Plan was published in 2010. This project aims to address this gap in the research literature. The project focused on the experiences of young people with type 1 diabetes aged 16 – 22 years of age who access a specialist NHS diabetes transition service. The transition during adolescence into adulthood is a particularly difficult time for young people with diabetes. Therefore this project aims to shed light on how developmental processes for young people interface with diabetes self-management, their relationships with specialist diabetes health services, and how this is managed and negotiated in terms of the young person's developmental journey and developing sense of self.

The primary objective of this research study was to explore the experiences of young people with type 1 diabetes who access transition services. The secondary

objectives were to explore what it was like to be a young person with type 1 diabetes transitioning from childhood into adulthood. What was it like for the young person moving from child services to the young person's service? What helped and what hindered engagement with the diabetes service? What could the diabetes service do differently to make it easier to engage?

2. METHODOLOGY

2.1 Study Design

A qualitative methodology, using semi-structured interviews was used. This gave some structure to the interview, whilst still allowing some flexibility for young people to share their experiences.

2.2 Participant Recruitment

Participants were recruited from the young people's service which run clinics twice a month at Aberdeen Royal Infirmary. Recruitment ran from August 2018 to October 2018, then resumed in October 2019 until February 2020. When young people arrived for their appointment, they were given written information about the study (from the consultant and diabetes specialist nurse in the service) and a copy of the participant information sheet (see Appendix 5) by reception staff. Once they had time to read the information, they were then approached by the first author who asked them if they had any questions and whether they wished to take part or not.

2.3 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria outlined below were used in the study.

Inclusion Criteria:

- Diagnosis of type 1 diabetes
- Age 16 to 22 years old
- Able to give signed informed consent
- Able to understand and converse in spoken English
- Have accessed the diabetes transition service in NHS Grampian

Exclusion Criteria:

- Diagnosis of type 2 diabetes
- Being under the age of 16 years old
- Experiencing severe and enduring mental health difficulties
- Having ongoing risk issues (e.g. in terms of suicidality, self-harm, or substance misuse), or social work involvement

2.4 Data Collection

Young people who met inclusion criteria and provided written informed consent to take part in the study were interviewed by the first author. In line with qualitative principles, one-on-one, in depth semi-structured interviews were conducted. A semi-structured interview schedule (refer to Table 2) was developed in line with the research objectives, and consisted of 7 broad questions looking at how they managed their diabetes; whether and how their role in self-managing had changed during adolescence; the impact of having diabetes; perceptions of the young people's diabetes service including the experience of transition; perceptions of other healthcare services; supports/systems; and suggested improvements to diabetes services. The interview schedule was used flexibly to provide participants with space to share their experiences to maximise the collection of valid in-depth data and to allow for any unexpected issues to be discussed and explored.

1. How do you self-manage your diabetes?
e.g. tell me about your routine for managing diabetes, how do you feel about the routine? What do you do in a typical day to manage your diabetes?
2. How has your role for self-managing changed as a young adult compared to a child?
e.g. have you had to do more as you have got older? Did you choose to do this or have to do this? How do you feel about these changes?
3. Impact of having diabetes
e.g. what are your beliefs about having diabetes? What are your feelings about diabetes? What impact does it have on your sense of self? On your plans/hopes for the future? Mental health/wellbeing? Activities? Impact on social life?

4. Perceptions of young peoples' diabetes service
e.g. transition (move from paediatric to young peoples' service). What helps/works well? What does not work so well?
 5. Perceptions of other healthcare services such as GP and primary care
e.g. Are other healthcare professionals/services involved? How involved are they? Is it easy to get support? What do they do well? What could they do better?
 6. Supports – health services, family, social, school/uni/work
e.g. health services? Family such as parents or siblings? Social such as friends/peers? Is school/uni/work understanding? What do they do that helps? Or does not help? How does this affect self-management during transition? Does it make it easier or harder?
 7. Suggested improvements to diabetes services
e.g. what could they do better? What could be different?
- Anything else you would like to add?

Table 2: Semi-structured interview schedule, including prompts that were used if needed.

Self-reported background information was also collected during the interview from participants. This included:

- the participant's age and gender
- years since diagnosed with T1D, and whether they were on basal bolus or insulin pump therapy
- any comorbid health conditions
- Whether they were at school, in further education or employment.
- How long they had attended the young peoples' service.

Participants were given the choice of being interviewed face to face, by videocall, or telephone. All participants chose to be interviewed either face to face or by telephone. Interviews were audio-recorded and then transcribed verbatim by the first author afterwards.

2.5 Ethical Approval

As this research study recruited NHS patients, the study received ethical approval from the NHS Health Research Authority, with it being reviewed by the London – South East Research Ethics Committee (REC reference 18/LO/1654). The study also received approval from the local Research and Development Team in NHS Grampian.

2.6 Participant Characteristics

A total of 8 participants were recruited, of which 5 were female and 3 were male, with ages ranging from 17 to 22, with a mean age of 19 years. Age at diagnosis of type 1 diabetes ranged from 2 to 13 years, with a mean average of 9 years. Time since diagnosis ranged from 6 to 16 years with a mean of approximately 10 years. In terms of treatment regimen for diabetes, 2 were using insulin pumps, whilst 6 were using basal bolus injections. For glucose monitoring, 2 were using blood glucose monitoring (commonly referred to as the finger prick test), 3 were using continuous glucose monitoring (a sensor with a small needle is attached to the skin), and 1 was using a combination of both.

In terms of sample homogeneity, incidence rates for diagnosis of T1D in Scotland are highest in those aged 10-14 years (Scottish Diabetes Survey 2018), and this was reflected in the current study's sample, with 5 of the 8 participants being diagnosed with T1D between the age of 10 to 14 years. In addition, the majority of participants were on multiple daily injections, which is generally representative of the population of young people with T1D. On a positive note there was some heterogeneity of treatment regimens, including 2 participants being on insulin pumps, and some using CGMs (continuous glucose monitoring) instead of finger prick tests. This represents the recent impact of technology in terms of providing a range of possible treatment regimens for managing T1D.

2.7 Analysis

Several different qualitative analysis methods were initially considered, before deciding on Thematic Analysis. These included Discourse Analysis, which looks at

how people use language to create and enact identities (Starks & Trinidad, 2007), however, this was not felt to be a suitable approach. Grounded theory is commonly used to explain a process or action through a theory (Padgett, 2016), but it was felt this method would not have been appropriate to answer the research questions in this project. Drawbacks of grounded theory include potential for methodological errors and limited generalisability (Hussein, Hirst, Salyers, & Osuji, 2014). A Phenomenological approach was utilised as it was felt this would best answer the research questions in terms of focusing on the *experience* of young people with T1D (Starks & Trinidad, 2007). Within Phenomenological approaches, both Thematic Analysis, and Interpretative Phenomenological Analysis (IPA) were considered. IPA was felt to not be an appropriate research method as it is focused on understanding the unique experience of each participant (Smith, Flowers, & Larkin, 2009; Starks & Trinidad, 2007). Thematic analysis was chosen as it allows rich data to be gathered, whilst also allowing some generalizability and flexibility of applying the findings to the wider population of people with T1D.

The thematic analysis was carried out by the first author in line with the 6 phases suggested by Braun & Clarke (2006). These are as follows:

1. Getting familiar with the data by reading and re-reading transcripts and noting down initial ideas.
2. Generating initial codes systematically across the entire data set, and collating data relevant to each code.
3. Searching for themes by collating the data into possible themes.
4. Reviewing themes, checking that they fit in relation to phases 1 and 2. Making a 'map' of the thematic analysis.
5. Defining and naming themes using ongoing analysis to refine themes, and generating clear names and definitions for all themes.
6. Producing the report by selecting appropriate examples from the transcripts that vividly illustrate the themes, relating these to the research questions and literature.

2.8 Rigour and Reflexivity

Rigour concerns the integrity of a study of how a study is conducted, with a view to minimising bias. Noble & Smith (2015) compiled a list of 9 strategies for qualitative researchers to adopt that can help enhance rigour, and several of these strategies were included in the present study, such as the use of rich verbatim descriptions of participants' accounts to support findings; semi-structured interviews that had been audio recorded to allow for revisiting of the data to check as themes emerged and that these remained true to participants experiences; and keeping a reflective journal with decisions documented for the duration of this project. In addition, the researcher had regular supervision to help them be aware of biases and assumptions.

Reflexivity in qualitative research is also important to consider, as it can be affected by the researcher's characteristics and experiences in terms of whether they share these with study participants or whether the researcher has no familiarity or experience with what is being studied (Berger, 2015). There are advantages and disadvantages of both. The researcher had experience of working in NHS mental health services with adults with learning disabilities, some of whom had co-morbid chronic health conditions, including a few that had T1D. In addition, the researcher has a family member with Type 2 diabetes. In terms of being mindful and aware of potential biases, and transparency, prior to this research study, the researcher's knowledge of T1D was limited, with them having never worked in a T1D service. One advantage of this is that the researcher did not take on an 'expert' role, and due to their lack of familiarity with this particular area, may be more likely to explore this with a fresh and different viewpoint; however, disadvantages of this are that a researcher who has no experience in the area of study may have difficulties conceptualising research questions(s) that are relevant to participants' experiences (Berger, 2015). To help address the latter concern and ensure research questions were appropriate, prior to conducting this research the researcher observed appointments in the Young Persons T1D clinic (with the consent of the young people, and none of those observed were participants in this study) and met with the medical consultant in the service. In addition, the researcher was not based within

the T1D service, meaning there was reduced bias in terms of asking about experiences of the T1D service. For example, if the researcher had been based in the service, participants may have been reluctant to reveal critical opinions about their experiences of the service.

3. RESULTS

3.1 Sample and Participant Characteristics

Pseudonyms	Gender	Age when diagnosed	Current age	Treatment Regime	In school, Further education or employment
Robert	M	10	22	Insulin Pump	Further education
Rose	F	10	17	CGM ¹ and multiple daily injections	Further education
Nathan	M	10	18	Finger prick tests and multiple daily injections	Employment
Eilidh	F	9	17	CGM and multiple daily injections	School
Paul	M	11	20	Insulin Pump	Employment
Lily	F	8	20	CGM and multiple daily injections	Further education
Hannah	F	2	18	Mix of finger prick tests and CGM, and multiple daily injections	Further education
Marianne	F	13	19	Finger prick tests and multiple daily injections	Further education

Table 3: Participant Characteristics regarding diabetes and treatment regime.

3.2 Overview of Results from Thematic Analysis

The thematic analysis of the data from the transcripts found 2 master themes, the first was ‘My internal experience of transition, as someone with Type 1 Diabetes’, while the second was ‘External factors and supports: what helps or hinders

¹ CGM (Continuous Glucose Monitoring)

transition’. When participants described their experiences of transition with T1D, they spoke of internal experiences in terms of emotions and how they practically manage, whilst also mentioning a variety of other people, as well as technology as external supports to help manage T1D and their transition into adulthood. Within each master theme there were several subthemes. For the second master theme, regarding factors and supports during transition, there were overarching themes across subthemes of what is helpful and supportive, and what is not, and these are both detailed as both sides of the same coin within each subtheme. For an overview of master and subthemes please refer to Table 4 below.

Master Theme	Subthemes
My internal experience of transition, as someone with Type 1 Diabetes	Turning point to taking on ownership of my diabetes
	Feeling lonely and different to others due to having T1D
	Daily hassles and consequences of managing blood glucose levels
	Relationship between Mental Health/Wellbeing and T1D
External factors and supports: what helps or hinders transition	Shift of support from family to peers
	Formal supports/use of healthcare services
	The role of Technology
	Supports at school/further education/work

Table 4: Overview of master and subthemes

3.3 ‘My Internal Experience of Transition, as Someone with Type 1 Diabetes’

Within this master theme, there were 4 subthemes:

3.3.1 Turning point to taking on ownership of my diabetes

All participants spoke of there being a key shift/turning point where they decided to take on more responsibility and autonomy for managing their T1D, often this was not so much an increase in actually carrying out day to day T1D tasks, but a shift in attitude and view of themselves as being solely responsible for managing their T1D. These turning points were often significant periods of transition and change in their lives, for example, moving away to university or living on their own.

Robert: But it was when I moved out pretty much it was all in my own hands, moved to [city in central belt]

I: so would that have been 17/18?

Robert: eh 18

I: 18 okay, so was that when you took over?

Robert: yeah, I was pretty much in complete self control then, well I was always in self-control but I didn't have my mum like giving me advice all the time.

Rose: With college I've had to sort of just step up my game and be more independent

Nathan: It was partly like a mindset change and a situational change because things did change (referring to T1D tasks and managing these) after I went into DKA² and my parents started finding out about all this stuff, there was other stuff going on too...

There was also a sense of evolving processes as they moved into adulthood, for example, in terms of increasing acceptance of their T1D, and this forming part of their identity of self. This led on to them being more open with others about their T1D.

Paul: when I was initially diagnosed with it, all the doctors would say, oh, it's not going to make a difference at all, but I felt like, even in like the back of my head I was isolating myself when I probably shouldn't have been, but generally over the years I've been doing that less and just going along with it.... I mean, I've certainly opened up to my friends around me a bit more about it (T1D), because before I was in school and it felt really awkward to bring up because as a kid it was a bit awkward to bring anything like that up.

This was echoed in both an acknowledgement among participants that their knowledge of T1D had increased over time, along with their independence of managing their diabetes, and there was a sense that they had mastered some autonomy and control of T1D. Young people had found ways of coping with having a chronic condition, for example a number of participants spoke of the importance and benefits of having a routine.

Lily: I'd say it's (T1D control and management) better now than it was

² DKA (Diabetic Ketoacidosis)

when I was younger, 'cause I didn't care as much. Or didn't, like, really understand the importance of, like, keeping it in...on track (referring to keeping blood sugar levels in specified range).

Marianne: I just had to change like little things, like my long acting insulin I'd have to increase and then increase it to what I was eating, but it was a bit stressful cos it was very up and down. Like I wasn't really sure and that's been for a few years, it goes, like it'll be fine, I'll have a good few months and then I don't know, my routine will change and then it all goes to pot, like I don't know what I'm doing with it. Erm, so I think that's a really big thing, is having a routine is really important because you know what you're doing and if the routine... Like, it's obviously fine to have a break and like going on holiday, for example, that's totally changing it. You just have to make sure that you are...or knowing like what you're going to do to change it cos it's not going to be the same as your daily routine, if you know what I mean.

What was also clear is that young people's feelings about and towards diabetes are not static, but dynamic and vary at times depending on health status, mood and hassles they are experiencing.

Eilidh: It kind of depends which day I'm having. Like, if I'm having a good day then it (T1D) doesn't really affect me, it's kind of just I know that I've got it and I just have to deal with it, like it's a part of me. But then there's other days where I'm just like, I wish I didn't have it and stuff.

3.3.2 Feeling lonely and different to others due to having T1D

There was a strong sense of feeling different to others, and that only other people with T1D truly understand and “get” what it is like to manage and deal with all that diabetes entails. Several young people spoke of either being the only one at school who had diabetes, or of themselves and/or others hiding their diabetes by doing diabetes care tasks discreetly or away from others.

Hannah: (friends) don't really understand why I don't take care of it, but I don't understand in myself, so it's hard to explain. Cos they're like, 'oh if you just do your injection, you wouldn't end up in hospital'. Like, pretty easy and simple. But it's not so easy and simple to me.

Eilidh: It's a bit difficult cos you don't really know where to find other people. Unless they go to your school or your college or uni, or whatever, you don't really know where to... It is quite hard to like know that...like you do know that there are other people with diabetes your age out there but you just feel alone cos you don't know any personally.

A lack of peer support with others with T1D of the same or similar age was apparent, with several voicing a view that there is a need for opportunities to meet peers, and that they would value this.

Nathan: I think for diabetes then having a group thing would definitely be useful, like I said earlier, just being able to get out and meet other people with diabetes,... so that's one thing you have in common, and then if they're also having problems with their mental health that's another thing you have in common, so it's just another support group, really, you know what I mean?

There was also a sense of wanting to be “normal” and not different from other children and young people, and this is particularly strong during adolescence and early adulthood. This may reflect coming to terms with the chronic nature of having T1D as they have gotten older. There was also evidence of some tension between avoidance and acceptance of T1D, as expressed by Marianne.

Marianne: I mean, just like normal things really that young people do, like wanting to go to festivals and stuff. For me, like all I really think about is the impact that's going to have on my diabetes. But then I just remember that I can't let it rule my life, like I have to get on with my life. But it is a bit of a battle in my head like to try and still... you know...

Overall, it is acknowledged within this subtheme that all the elements described above are inter-related, for example, the lack of peer support was compounded by feeling that some children and young people feel they have to hide their T1D.

3.3.3 Daily hassles and consequences of managing blood glucose levels

A common theme within this subtheme was of the challenge around keeping blood sugar levels within range and being vigilant for warning signs of high and low blood sugar levels (hypos and hypers respectively). There was also mention from several participants (who used finger prick tests and multiple daily injections) of unwelcome side effects from their treatment regime such as numbness in their fingers, and lumps in their skin from injecting.

Eilidh: Yeah. Like, the days that I do have good days, I'll send a picture of my levels to my best friend and like she'll get excited with me. But then days that they're not doing as well, I still send a picture to her and

she'll ask me questions, like if I'm not doing this, or stuff. So, she'll try and help me as well

*Robert: if you're high you'll be more agitated and grumpy, and if you're low you just can't focus and like you've, like missed a couple of meals and you know feel a bit off, it's kind of like **that** [emphasis given by Robert] but just more intense*

The challenge of managing blood sugar levels also related to concerns around serious complications from difficulties managing blood sugar levels, such as diabetic ketoacidosis (DKA) which is a medical emergency and requires urgent medical attention as untreated it can be fatal. A number of participants had reported being life-threateningly ill with DKA and had required hospital admission(s) to treat this.

Rose: I had DKA at one point..., I was in resus...It was scary stuff.

As well as medical consequences, there were also psychosocial consequences. Related to the challenge of managing blood sugar levels, there was a sense of emotional cost, particularly when control of blood sugar levels was poor, even when young people were trying hard to manage this. Participants described feelings of shame, guilt, and embarrassment regarding the impact of poor control and not managing to keep blood sugar levels in desired range.

Nathan: Erm, yeah, like sometimes I miss appointments intentionally because I feel guilty, I don't want to have to go because I feel like I have to explain myself, if you get what I mean, for bad control, erm...yeah...:I feel like I'll be judged, but I know that's not true, you know. Sort of like, I kind of feel guilty too...I don't know why, just...

There were also elements of negotiating new challenges as they got older, for example, alcohol, as young people reached the age of being legally able to drink. Several spoke of limiting their alcohol intake, and/or avoiding certain types of alcoholic drinks that were particularly high in sugar such as cider or cocktails. Participants spoke of weighing up the risks and benefits of this, and the impact it can have on their blood sugar levels. This weighing up of pros and cons, could reflect their developing abstract thinking skills, which could be mediating or buffering the desire to rebel or engage in risk-taking behaviour.

Robert: drinking has an effect on diabetes just in general, so not to do the

pump, but just need to be aware of, alcohol makes you go lower in the night which is dangerous, but there's a lot of carbohydrates in alcohol so it's a bit of a balancing act as well

For some participants, having T1D had affected how they saw themselves, in social situations, and their hopes for the future, whilst others spoke of it having no impact.

[In response to being asked if T1D had an impact on plans and hopes for the future]

Nathan: Yeah, I'd say so. Erm...sometimes it makes it gloomier because it's like if I don't look after myself then, like I said earlier, by the time I'm in my twenties I could go blind, but then again that also could be a motivator for the future because I really don't want to go blind...Erm, it could be or it could not be, you know?

Robert: no, a lot of my friends won't even notice that I do my blood test, like cos it's just very discreet and it's not a big deal socially at all really.

3.3.4 Relationship between Mental Health/Wellbeing and T1D

There was a strong sense of T1D having some impact on mental health and wellbeing for participants. For participants the nature of the relationship between mental health and T1D varied, and was not always clear cut, with some explicitly stating that T1D had contributed to mental health difficulties, whilst for some the direction of the relationship between T1D and mental health was not so clear, and they were more closely entangled.

Nathan: I think it was my diabetes that really triggered my mental health problems, because I was a really happy kid before, before diagnosed, erm but then the other thing is when I got diagnosed, it wasn't like I just was, [Nathan clicked fingers] oh, I'm depressed now, it was all very subconscious because when I got that, I didn't take it in. Like I was told I was diabetic, I was told all these things

Rose: I struggled really, really, really severely with anxiety at school. And yeah, the diabetes and anxiety was intertwined.

There was a sense of ambivalence and at times resentment towards having T1D, in terms of the additional demands T1D can bring. For some these feelings had been particularly present during their younger years in early adolescence, and they were able to reflect that these feelings had changed somewhat as they had aged and journeyed into young adulthood. There was a sense that as participants had become

older their mental health had improved, or at least they had found some ways of managing this and feeling more in control.

Rose: Mmm, yeah. I was very resentful towards it (referring to T1D) at a younger age, and it's sort of just become part of me now.... Erm, but there was a time where I just hated it so much, I hated it.

Nathan: erm when I was 17 right that was when it was probably at the worst, I went into DKA..., I didn't take my insulin for about three months.... Cos I didn't care, I didn't really care what was happening. (referring to ambivalent feelings about having T1D).

Related to the sense of ambivalence, was variable motivation, which several participants spoke of, and the impact this has on feeling able and wanting to carry out associated T1D tasks.

Hannah: Cos if I'm doing something (referring to T1D tasks), I'm actually trying really, really hard, and if I'm not doing something, I'm just not doing it. So it's either not doing it or doing it a hundred per cent.

Within this subtheme, a number of participants spoke specifically about anxiety. This was in two areas, firstly anxiety about managing blood sugar levels, for example, anxiety about hypoglycaemic attacks. Secondly, several participants also spoke of different types of anxiety having an impact on health-related activities. For some this was about specific things such as going into hospital for certain hospital procedures (such as cannula insertion to help treat DKA), whilst for others it was more general anxiety, such as anxiety around speaking on the telephone, which had an impact for some in terms of feeling able to contact or respond to healthcare staff for advice/support.

Eilidh: It's like...I suffer from anxiety, so it's kind of like diabetes on top of dealing with anxiety as well.

Nathan: There is, there's a call line (for diabetes service) that you can get in touch with, or a text line, but that's not really that useful when you have phone call anxiety

3.4 'External Factors and Supports: What Helps or Hinders Transition'

3.4.1 Shift of support from family to peers

Across participants, the biggest and most common informal support was parents. Wider family members did not really feature in participants experiences, with a few exceptions to this. The common theme within this, was of parents being key in terms of managing T1D, particularly at diagnosis, and with more involvement when the young person was younger (e.g. pre-school/primary school age).

Paul: I mean, a lot of my control before came from my parents being there and like helping me with it, but as I've gotten older, I've learned how my body works

Hannah: she (mum) would do my diabetes stuff for me (when I was younger) so I wouldn't really feel like I have it (T1D)

However, participants described a shift in the type of support they received from their parents, particularly as they moved towards important periods of transition such as moving to secondary school or entering adolescence. At these times, participants described themselves taking on more responsibility of doing tasks, whilst their parents were encouraging them to do this, and took on a more supervisory role. Within parents, there was for some a sense of mothers being more involved in T1D tasks, knowledge, and responsibilities, compared to fathers. This suggests that adolescents attachment to their parents is still significant, but that the nature of this has changed, and been re-negotiated in some ways.

Eilidh: Well like my parents would encourage me to like help them do it all. Like, they would help...encourage me to carb count but with them supervising me, and they'd encourage me to test my own levels and stuff. So, they would help me. So, it was, yeah, gradual..

Marianne: At the start (after diagnosis), for the first couple of years she (mum) did help me, and the first couple of months like she'd be waking me up in the night to do my sugar test and stuff. But erm I don't know really, I think it's something you have to learn to be independent with really.

For those young people who were managing their T1D independently, for example, those living away from home whilst at university, there was still a sense of parents being a source of support, but that the type and form had changed. Young people spoke of parents as often being there for emotional support or looking to them as trusted sources of T1D knowledge.

Paul: It's just sort of that I feel like either I would know myself or my parents would know (referring to if needed support who would go to)

I: and can I ask; with your mum is that predominantly emotional support or is it practical, kind of, support?

Marianne: It's everything really yeah... if I've got struggles and I don't know what to do, if my sugars have been high for a while or low for a while, she'll tell me what to do really and what to adjust so...

The main other key source of support was friends. There was a range of what participants found was helpful in terms of support from friends. For some it was being able to discuss things related to their T1D and feel supported and accepted by a specific friend, who they felt understood and “got” them. This may reflect young people’s relationships with peers becoming more important as they move from family to peer group as a major source of influence.

Eilidh: Like, after opening up to my best friend and her understanding as well, like now I realise that if I do open up, then people will understand.

With this shift from family to peers, there were certain things that participants valued from their peers. For most participants, there was a sense that what made support from friends helpful, was participants having control over who, what, and when they shared information about their T1D with. Some described their friends showing interest in learning about their T1D, whilst others appreciated friends not asking them personal questions about this, but instead leaving it up to them what they wanted to share. There was a strong sense of it being important to feel accepted by friends, and this likely reflects the shift in friendships with peers becoming more important, and possibly a need to identify with a peer group.

Paul: the people around me just accept me for who I am without really questioning it. You know, sometimes they are curious when I'm doing a blood test or anything like that, but I don't feel like it's had a negative impact.

3.4.2 Formal supports/use of healthcare services

In terms of healthcare services, all participants were accessing the Young Persons T1D service. They were also asked about other healthcare services in the NHS that they used such as GPs, however, most were predominately only using the Young Persons T1D service. In terms of the actual transition from the Children’s T1D

service to the Young Persons service, most participants described this in positive terms, with it being remembered as quite a quick transition, with a key shift being a change in the role of the young person, with them taking a more independent and responsive role in discussions with healthcare staff, in marked contrast to their role when seen at the children's service, where it was described that discussion happened between staff and parents predominately. In terms of possible areas for improvement with transition, some participants felt communication around the changes and what to expect could have been better.

In terms of what participants appreciated about healthcare services there were several components within this subtheme. One of the key things was staff, in terms of them being approachable, non-judgemental, warm, and having knowledge/expertise of T1D. This helped participants feel safe and welcome.

Robert: I kind of the doctors and nurses here are all very good and they are all very knowledgeable and they, it's quite clear they'll actually take care of the patients. Like you probably saw a nurse come through giving spare pens cos she was 'oh your pens probably out of date', and things. So they're very thoughtful and that's the main reason I've stayed with this clinic (referring to staying despite attending university in another part of the country).

Lily: Er, I think all the staff are quite good. They're all quite friendly and approachable.

Related to the above was the importance of the relationship/bond that young people had with staff, and a sense of familiarity. This was more likely where it was possible to have continuity and consistency in the healthcare staff they saw, which was especially important to a number of participants, who valued staff knowing their story and about them as individuals. For other participants, they had experienced lack of continuity of staff, however, they reported that they had not found this detrimental where staff had taken the time to read up on their notes and find out about them. Participants reported feeling more able to be open and honest with staff when they had built up a relationship with them and felt more able to discuss and explore any difficulties. The qualities young people described as being important in staff mirror those to an extent in attachment theory in terms of qualities of a consistent caregiver.

[In response to being asked how it feels when it's a new or different doctor they see at clinic].

Robert: it feels like you're more, just like, numbers on a sheet. Like they look at your blood readings and it's, it's either talking about all this, or they're doctor know-how and they don't like know you, so it feels like they're kind of just dealing with you know just like your numbers and not. When it's a doctor that knows you better and they know you before it just feels, although it'd probably been the same thing it just feels like it's better care

Hannah: I'm more attached to her (regular T1D doctor) at this point, so I'm more willing to tell her things I wouldn't say to a new person every single time.

Rose: it was like I'd talked to her before, even though I'd never talked to this consultant before, she was absolutely lovely, they all just...I, it's almost like talking to a friend, rather than... some extremely high up person that's going to give you in trouble.

...I: so when you're going in, it's somebody you've not met, like a doctor or nurse, do you find you're having to start right back at the beginning, or do you find that they have a sense of...?

Rose: They always seem to have...some idea of what's going on. I've never had to really explain anything.

It was also important for participants that there was time/opportunities to bring up any concerns or ask questions they had (e.g. about upcoming age-related events such as driving, drinking alcohol, which reflect the increase in potential risk-taking and rebellion associated with adolescence), and to feel heard and listened to as an individual. At appointments young people are given a form to tick boxes of various topics they want to discuss, or to write down questions prior to their appointment with the doctor, and most participants reported finding this useful.

Rose: Mmm, as long as I'm safe, that's all they're really concerned about, safe and as stable as possible.

I: When you say safe, is that in terms of your diabetes, or is that in terms of you just generally?

Rose: A bit of both actually. In terms of the numbers, they're not looking for perfection, they're looking for not in DKA, not with ketones, not anything that's going to affect my long-term health.

Marianne: I never feel rushed or anything,... do you know what I mean, like I don't feel rushed to have to talk about things, like, the appointments are, like, long and that's a good thing.

Another key thing regarding staff was the importance of communication, particularly around how information was communicated and the experience of this for young people, for example, there was a sense that what was helpful was staff working *with* the young person around particular issues/difficulties, using a collaborative approach. This reflects a change in the young person becoming more active and developing a sense of agency.

Eilidh: She (T1D doctor) kind of just reassured me that I was trying my hardest and that she knew that things just didn't go right all the time. So, it felt like she had diabetes, but she didn't. So, it felt like she had it and she knew exactly what happened even though she didn't.

Additionally, for nearly all participants the Young Persons T1D service was their main and only formal source of support for their T1D. All participants knew they could contact the service in between appointments if needed for advice/support, and a number found contact from diabetic nurses (usually by text) to be helpful in terms of checking how they were.

Robert: if I had a problem with diabetes I would be phoning up here first (referring to diabetes YP clinic) anyway

Conversely, what participants found unhelpful was feeling blamed, being told what to do, and when appointments focused only on numbers (in terms of blood sugar levels and T1D control).

Eilidh: Like...because I went in once and they didn't...I didn't have good control and stuff, and they were sitting there writing down, this is what you're going to do, this is what you're going to do, this is what you're going to do. And I just came out feeling like, you've not told me that I'm doing well, you're just telling me that I've got so much to improve on....It was overwhelming. Like, I came out and I turned to my mum, I was like, I don't know what I'm doing, like what am I doing wrong and stuff?

Rose: They weren't talking to me, they were talking to the figures. It wasn't my life, it was the diabetes.

In terms of the structure and format of healthcare services and appointments, generally participants preferred the service's integrated appointment. (The integrated appointment was a service initiative in which patients could attend lab result, nursing, and medical consultations sequentially at the same visit). They

described not having to wait long during their appointment to be seen by the different members of the Young Persons T1D service, and it being easy to re-arrange and book appointments. On the flipside, elements that were viewed as unhelpful were inconsistent contact in between appointments from staff, lack of choice around which doctor they see, and limited flexibility/choice when booking appointments.

Lily: It's quite a bit quicker. You're definitely waiting around less.

Robert: mmm it's not flexible is why because it's only two days a week on the third week of every month....yeah, so it's pretty limiting.

Some participants had accessed mental health support in the NHS. This ranged from their GP prescribing anti-depressants; accessing generic mental health services; or being referred on to specialist diabetic mental health input, namely clinical psychology specifically attached to the Young Persons T1D service. Experiences with these were generally limited, one participant reported a positive experience with their GP, whilst another reported a negative experience with generic mental health services. In terms of clinical psychology in the Young Persons T1D service, several participants had been referred on to this by the service, with some choosing to engage and some not; those who had engaged described this input as helpful.

Rose: I just went back to the doctor (GP), it was obvious I needed something to help. So, the doctor was like, 'okay we're going to put you on this anti-depressant', and he's just, he's kept in contact with me, making sure that the dosage is correct, and I see him every month.

Rose: I've been seeing a clinical psychologist for a year, a year and a half, she's been amazing...she's been great, helped me talk over everything... Sort of think about...solutions, or ways of, not really solutions, ways of dealing with the situation at hand, ...rather than just kind of getting on with it.

In terms of possible areas of improvement, several themes arose. These included consistency of staff, choice of which staff they see was also a common theme, as some participants described some staff as being more understanding and had a preference over who they wanted to see. It was also felt by a number of participants that communication could be better particularly around diabetes-related workshops and groups, as most participants were unaware/unsure what was on offer and what

they could access. In terms of young people who had been admitted to general hospital wards, there was a sense that general ward staff knowledge of T1D was patchy and variable at times.

Robert: Er they do a lot of workshops up here, which I would be interested in.

Eilidh: Well I've never been told about them. There could be but...[when asked if aware if service run any groups/workshops].

Rose: the nurses [referring to non-diabetes specialists] didn't know how to carb count, so they were telling me different information about how much insulin I should be taking

3.4.3 The role of Technology

In terms of this subtheme, 'technology' refers to electronic aids for helping to manage T1D, such as continuous glucose monitors (CGM) and insulin pumps, as well as carb counting apps.

For participants CGM and/or insulin pumps had been very helpful, and in some cases, almost transformative in the benefit to the young person in terms of the impact this had for them. For example, with the CGM, participants described being able to use their mobile phone to easily scan the CGM sensor to get a reading of their blood sugar levels as well as not having to get out the required equipment and experience the pain of a finger prick blood test. Across participants, there was near unanimous positive feedback regarding the benefit of CGMs, particularly around helping young people easily and regularly check their levels.

*Rose: It's awesome, it's actually been **life-changing** [emphasis given by Rose].*

Hannah: it's easier. It's way faster. I can just, you know, grab it and check it (referring to using phone to scan CGM sensor to get blood sugar level reading).

For participants who had insulin pumps, they described numerous advantages of the pump, in terms of the amount and way insulin was delivered, and the ease of inputting the relevant information, with the pump calculating the amount of insulin required.

Paul: Generally I find it's easier to manage in a way that I feel like I have more

freedom when it comes to meals, it means that rather than having to take out a pen, put on needle and then inject myself figuring all the information out either in my head or on a calculator, having this (pump) just means that I input information there and then I can like eat. So generally I feel like it gives me more freedom compared to a pen.

However, there was also a flipside that emerged from participants, that whilst there are benefits of CGM and pumps, they also described drawbacks and limits of these. For both CGMs and pumps, whilst participants reported the NHS now funds these, in order to access this through the NHS (i.e. at no cost), participants reported having to demonstrate “good” control of their T1D, and go through a process of meeting certain conditions before being able to access a CGM and/or pump.

Marianne: So that put me off (trying to get CGM) and I sort of felt like oh I don't really need it that much and I didn't have the time to be doing all that stuff....But now I feel like it will help so it might be worth it to just give it a try.

Several participants were going through the required process of either trying to get a CGM or pump or considering this. A number spoke of being previously offered either a CGM or pump, but at the time feeling the required conditions to meet felt overwhelming. For one participant, the requirement of demonstrating “good” control was a barrier to her trying to improve her control, and there was a clear sense of frustration.

Hannah: it's, kind of, pointless because (CGM) helps me with checking my sugars cos I tend to check way more when I have a (CGM). So it helps me to manage my diabetes. But in order to get it, I have to manage my diabetes first, which is, kind of... feels a bit...pointless.

Additionally, whilst there was a sense of the advantages of pumps and CGM as mentioned above, participants described that they still held responsibility for managing their T1D, for example, changing sensors for CGM at regular specified times, inputting various bits of information into the pump, as well as adjusting pump settings. There was very much a sense that this technology can be useful and helpful, however, there is still a need for the young person to check and monitor this.

Robert: the pump just gives you insulin, you need to know your blood sugar,

you have to get up and do your blood tests, well I have to with a blood test meter.

The majority of participants carb counted (though a few did not) to help know how much insulin to take if they were injecting, or to input the figures into the pump so the pump could accurately calculate this. Several had previously attended a workshop on carb counting to learn about this, and used books, though reflected that now there were apps, though the use was limited for participants who had been carb counting regularly as they spoke of just *knowing* the carb count for certain foods.

Rose: Yeah, I went to a dietician, I think...but I kind of just learned it (carb counting) myself more or less, because you get to know how much is in everything. Having it so long, you automatically figure it out.

Eilidh: I don't use it as much now because I understand carb counting a lot more, but it's, yeah, easier and quicker, yeah (referring to carb counting app versus book).

3.4.4 Supports at school/further education/work

There was a mix in terms of experiences of support in schools, further education such as college and university, and for those in employment. For schools, participants described mixed experiences. Some reported school as being accommodating, with teachers seeking out/learning about T1D, as well as being able to leave class early to carry out T1D tasks. For others, they described school as being an unsupportive environment, for example, some teachers not being understanding or lacking knowledge about how T1D is managed and this having a knock-on impact on teachers' expectations of the young person.

Eilidh: When I first started (at secondary school), we just met up with my pastoral care teacher and just said to her and explained everything and what I'd have to do. And they just said, "Do you want to get out of class ten minutes early, you can so that you can go get your lunch and deal with everything before everyone else comes out in a rush when lunch comes?"

For participants in further education, there was a clear sense of a shift in the difference of the school environment versus that of college/university. This was particularly apparent in the sense of not having to ask or explain if they needed to

leave the room, with the environment being more laidback and the young person feeling less “different” to the rest of their peers.

Marianne: college is quite laid back, really, if I need to leave the room I just get up and leave

Additionally, those in further education generally described being able to easily access appropriate supports, for example, extra time in exams if needed to do T1D tasks or experienced a hypo. Although some were offered support, there was generally an expectation that they were required to seek out and ask for support if they needed this.

Lily: Yeah, I've been offered, like, extra time for exams and things like that if I need it, because of the diabetes.

Robert: Oh school was very accommodating yeah. Uni you more have to look for the, look for the accommodation kind of, if that makes sense. you need to like go yourself and say look I have diabetes. I won't like go around looking for people to accommodate.

A possible explanation for mixed experiences in school could be that young people are transitioning into adulthood but not yet technically adults and thus not treated as such, whilst at further education, the majority of their peers will be adults, and they will thus be treated as such, reducing the power imbalance that is present in school settings.

Encouragingly for those participants who were either currently or previously employed, they spoke of employers being understanding and accommodating around their T1D, in terms of if the young person had to do any T1D tasks. There was a strong sense of young people having taken ownership and responsibility of communicating this openly and clearly with their colleagues and employers, with several referring to a need for those they work with to be aware that they have T1D, in case they become suddenly seriously unwell. This shift demonstrates the development of abstract thinking as young people weigh up the pros and cons of informing versus not informing employer of their T1D, as well as possibly reflecting that T1D has become an accepted part of their identity.

Lily: (employer's) been, like, understanding with it and just let me do what I need to do.

Nathan: Em, whenever I'm looking a bit pale or whatever, they're always, are you okay? You need to test your bloods? You know, just making sure I'm good. Erm, they all know about it (that I have T1D)... I had to tell them.

3.5 Impact of Rigour and Reflexivity Processes

Strategies implemented in this study to enhance rigour included the use of rich verbatim descriptions of participants' accounts to support findings, which can be seen in the quotes from participants to illustrate themes earlier on in the current chapter. Additionally, all semi-structured interviews were audio recorded to allow the researcher to revisit the data to check as themes emerged and that these remained true to participants experiences.

The researcher also kept a reflective journal with decisions documented for the duration of this project. As a result of using the reflective journal, the researcher was able to identify early on that several participants had spoken about mental health (interviews 2 -3), and as a result, for subsequent interviews, this was something that the researcher did explicitly ask future participants about (see Appendix 6 for entry in reflective journal following these particular interviews and the impact of this on subsequent participant interviews). In addition, the researcher made use of supervision to reflect on their assumptions and biases during the process of data collection and analysis.

4. DISCUSSION

4.1 Summary of Results and How They Relate to Existing Literature

There has been a dearth of research looking at young peoples' experiences of transition in Scotland, since the Diabetes Action Plan was published in 2010. The purpose of the current research study was to try to address this gap in the research literature. The current study found 2 broad key themes relating to young peoples' experiences of transition. Firstly, the internal experience of transition with T1D, and secondly, external factors/sources of support and what is and is not helpful during transition. There were also 2 new findings from the current study that emerged relating to 2 subthemes, namely the relationship between Type 1 diabetes and mental health, and the role of technology in diabetes care and management.

The existing research on T1D is partly limited by the age range of the children, adolescents, and young people/adults varying across studies. As the present study's age range for participants was 16-22, this means findings from existing research with children (i.e. under 18 years of age) are potentially relevant, as is research on young adults (i.e. those aged 18-25 years). In addition, the present study found 2 themes, however, existing research indicates no single study has looked at this topic and found the same themes, although, a number of studies have results relating to at least one subtheme, or part of a master theme. This may be due to the current study having quite a broad focus on transition, whilst other studies have tended to only look at a specific part of transition.

In terms of new findings, the current study's subtheme of the relationship between mental health and T1D was a new finding, as previous qualitative research (Dovey-Pearce et al., 2007; Freeborn et al, 2013) had not identified this as an important theme or subtheme. The majority of research that has looked at mental health in young people with T1D has used a quantitative approach, often asking the question 'do young people with T1D have higher prevalence of mental health difficulties than those without'. The research on mental health in young people with T1D is somewhat mixed. Some research has found that young people with T1D were 2-3

times more likely to meet diagnostic criteria for a psychiatric disorder (Northam, Matthews, Anderson, Cameron, & Werther, 2004), and that they are at an increased risk of psychiatric disorder compared to those without (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009). Longitudinal research found that over 11-13 years, the prevalence in the sample that had psychiatric disorders increased from 16% to 28%, though this was not statistically significant, but they did find that baseline psychiatric scores predicted follow-up scores (Bryden, Dunger, Mayou, Peveler, & Neil, 2003). However, more recent research has suggested this is not clear cut, as several studies found that children and young people with T1D do not have an increased risk of mental health difficulties compared to those without T1D (Munkacsi, Papp, Felszhegy, Ezster-Kovacs, & Nagy, 2018; Sivertson, Petrie, Wilhelmsen-Langeland, & Hysing, 2014). The current study indicates that mental health difficulties are an issue for some young people with T1D during transition, and that there is ambivalence towards T1D at times, which then impacts on the young person's sense of self and identity. It can also lead to risk-taking behaviour, in terms of poorer self-management, such as missing insulin, and blood sugar readings.

The second new finding in the present study was that technology was perceived by young people as helping support them manage their T1D, using CGMs and/or insulin pumps. This was a new finding when compared to previous studies on the experiences of young people with T1D (see Dovey-Pearce et al, 2005; 2007; Freeborn et al., 2013; Hansen & Jansen, 2017; Hynes et al., 2015). It is not definitely known why this is, but it may be due to the technology not being widely used when some of the earlier studies were conducted and/or the wider focus of the current study allowing this subtheme to become apparent.

In terms of the first key theme on the personal internal experience of young people, the present study found subthemes including the turning point to taking on ownership of my diabetes, feeling lonely and different to peers, and the daily hassles and consequences of managing blood glucose levels. Regarding the increasing influence of peers, this may reflect social changes during adolescence including an increased desire to fit in, and to hide their T1D. Wanting to fit in with peers could

support social learning theory (Bandura, 1971). Dovey-Pearce et al. (2007), in their study of 16-25 year olds, found similar themes of feeling different to peers, and impact of being diagnosed with diabetes, and integrating this into their concept of self, for example, the demands of diabetes and the nature that these are life-long. However their study included those with Type 2 diabetes as well as T1D. Freeborn et al. (2013) also found similar results in challenges of having T1D being managing low blood sugars, T1D tasks including checking blood sugar levels and administering insulin, and feeling different and/or alone, although the children in their study were aged 7-16 years. Additionally, Marshall, Carter, Rose, & Brotherton's (2009) study on children aged 4-17 years found the overarching theme for children (and their parents) was around trying to feel normal and minimising the differences that having T1D made. Although they had younger children than the present study, it did support the current study's subtheme of wanting to feel normal and not be different to peers. This suggests that in adolescence, and even pre-adolescence, children are acutely aware of their T1D, and that this can mark them as different to their peers. To try to overcome this, during adolescence young people try to seek out contact with peers with T1D, as this can aid in negotiating their sense of self in social situations as they move from family to peer group as a major source of influence. This also suggests there is potentially ongoing ambivalence towards T1D for a large proportion of childhood, which could have a detrimental impact on the young person's developing sense of self. The potential impact of ambivalence, such as poorer self-management, could reflect the process of cognitive maturation during adolescence, as perspective taking only emerges in adolescence, and is not fully developed so decisions can be prone to impulsivity and short-term bias.

For the second key theme on the external supports and what helps, the present study found subthemes including the shift of support from family to peers, formal healthcare services, and supports at school, further education, and work. Young people tended to still look to parents for support, though this had evolved from practical to emotional support. From an attachment theory perspective, young people explored and returned to the secure base of their parents. Very young children do this, and this could be seen as re-enacting this in relation to diabetes management in their teens. With regard to accessing healthcare services, it was

apparent that the quality of the relationship that young people have with healthcare staff is a strong influence on their experience, and this echoes previous research findings (Hansen & Jensen, 2017; Hynes et al., 2017). Additionally, the other key finding that young people would like services to have more flexibility around appointments and improve communication, is also supported by previous research (Dovey-Pearce et al., 2005).

In terms of the developmental challenges of adolescence (APA, 2002), participants did not really talk about the physical in terms of puberty and sexual maturation. It is not clear why this is. Possible explanations may be that participants did not feel comfortable bringing this up in a one-off interview, or possibly the interviewer did not go into enough depth with participants to elicit this.

It was worth noting that when comparing the study results to existing research literature, often what qualitative research has been done in diabetes, has either focused specifically on the experience of having T1D, or the experience of accessing T1D services. The current study's broad focus allowed both of these areas to be explored and reported in the one study (Dovey-Pearce et al., 2005 and 2007 studies appear to have used the same participants, but reported and published their findings on these 2 areas separately).

In terms of the results of the themes from the young people in transition in the current study, there were some differences and similarities when compared to younger and older samples of people with T1D. In terms of feeling different to peers and the demands of managing T1D, similar findings have been found in studies of 11-14 year olds (Chao et al., 2016) and 23-30 year olds (Balfe et al., 2013). In terms of the benefit of technology, similar findings indicating the benefits of CGMs specifically, have been found in older adults aged 65 and over with T1D (Litchman & Allen 2017).

However, in the study of 11-14 year olds a difference was that school was a major stressor for that age group (Chao et al., 2016), whilst for those aged 23-30 years, key issues were significant concerns about the future such as amputations due to complications of diabetes, and concerns about pregnancy for females with T1D (Balfe et al., 2013).

4.2 Clinical Implications

Broadly speaking there are several clinical implications arising from the results of this study. Firstly, that it is important to young people with T1D that they feel understood, and for others to appreciate and have awareness of the potential challenges young people with T1D can face and cope with. Additionally, it can be very lonely and isolating for young people with T1D, with the feeling of being different particularly an issue during adolescence and early adulthood. This indicates difficulties for young people in negotiating their sense of self in social situations as they move from family to peer group as a major source of influence. To support young people with this, there is a clear need for opportunities for peer support with other people with T1D at a similar age. It was not clear from the participants whether the issue is a lack of opportunities for peer support and/or if these opportunities already exist but are poorly advertised/communicated to young people.

The relationship between mental health and T1D, suggests there is a need for young people to be able to access appropriate psychological support to help them manage mental health difficulties that may be related to or impacting their T1D. This could possibly be when they are diagnosed in the form of basic psychoeducation and strategies around managing anxiety and depression, or as they enter adolescence or early adulthood. In addition, there should be clear pathways and communication around how young people can access suitable and timely mental health support including psychological input. This is particularly pertinent as there is some evidence that mental health difficulties can increase over time (Bryden, Dunger, Mayou, Peveler, & Neil, 2003).

In terms of the results for T1D healthcare services, specifically for transition, young people valued the shift in their role allowing them more autonomy, and the opportunity to work collaboratively with staff on any issues. This reflects young people's growing sense of self and independence as they renegotiate their relationships with adults, where they are more active and have a greater sense of

agency. More generally, in terms of staff factors, there is a need for healthcare staff to try to build warm, supportive, and relationships with young people, as this will help facilitate engagement. Ways of doing this include getting to know the young person, giving space to talk about things other than just their diabetes and meter readings, and staff being understanding and compassionate, particularly if young people are having difficulties managing their T1D. In terms of the structure/format of these services, from this study young people spoke about wanting more flexibility in terms of times/dates of appointments, and the choice to be able to see the same staff. In terms of ways of contact, a number of young people very clearly expressed a preference for face to face contact with healthcare staff, but spoke positively of text being used in terms of text reminders for appointments, and being able to send/receive texts with diabetes staff (mainly nurses) in between appointments.

4.3 Strengths and Limitations

A key strength of this study is that it helped address a gap in the current research literature on this topic. The advantage of recruiting through the NHS young person's diabetes service, as opposed to for example, social media, is that it independently verified that all participants in this study had T1D. Additionally, the use of a qualitative approach allowed rich data to be gathered, whilst the semi-structured interview schedule, helped keep the focus on experiences, but also enabled some flexibility and broadness in what could be covered in the interview. Additionally, the participants in this study broadly represented the different treatment regimes that young people with T1D can be on (e.g. pump, CGM, multiple daily injections, finger prick tests), as well as included young people from a range of settings including school, further education and work. Although the sample is small, it is felt to represent a good range of the experiences of young people with T1D, and therefore this increases the reliability and validity of the findings to this population.

It had been hoped to ideally recruit between 10-15 young people for this research study, however, recruitment was challenging at times, and the uptake from the monthly clinics was variable. There were several reasons that may explain the difficulties regarding recruitment. Firstly, it became apparent that the do not attend

(DNA) rate for the young persons' clinic was about 50%, meaning that this study is prone to sampling bias. It is also acknowledged that the age range of young people that this study sought to recruit from coincides with a time in young people's lives where there are potentially a number of significant life events and milestones going on for them (e.g. exams, applying to university, preparing to move out the family home), that likely may have meant that they may have felt they did not have the time or motivation to take part in this study.

It is also acknowledged that due to the recruitment strategy, only young people who were engaging with the diabetes service, were invited to take part, though it is noted that engagement with services can be of varying degrees. The views and experiences of young people who do not engage with services are important too, but there are numerous difficulties engaging them in research, hence, for this project, the decision was made to recruit solely through the diabetes service. Therefore, the findings of this study may have limited applicability to young people not engaging with services. Further limitations are that participants were recruited from a single city hospital clinic site in a single health board, and diversity was also limited as all participants were Caucasian.

Another limitation is that rigour could have been improved, employing more of the strategies suggested by Noble & Smith (2015). For example, having more than one person carry out the thematic analysis as this can facilitate different perspectives as well as minimise bias. Another option would also have been to have multiple interviews with participants to allow them to share their experiences more in depth. However, in the current study, neither of these options were feasible, in terms of resources for a second person, nor in terms of placing additional demands on participants, as well as the impact of time restrictions for the researcher.

4.4 Further Research

The current study adds to the existing limited research literature on the experiences of young people with T1D as they transition from adolescence into adulthood,

however, there were some limitations with this research. It is important that future research tries to address these, and suggestions for this are given below.

The current research on mental health in young people with T1D is somewhat mixed, with most research being quantitative in nature and comparing young people with T1D to those without. What is clear is that for a significant proportion of young people with T1D, some will experience mental health difficulties, and the existing qualitative research looking at this area appears very limited, meaning not much is really known about how this affects young people, and if there are certain specific types of mental health difficulties that are especially prevalent in young people with T1D. Longitudinal research with mixed methods could help illuminate this.

The finding about the impact of technology in terms of CGM and insulin pumps is a potential avenue of further research. Due to this technology being relatively new, research on the experience of this is limited. In this study, participants generally spoke very positively about the benefits of CGMs and insulin pumps. Future research should explore whether CGM and/or pump use is associated with reduced distress; or whether it increases acceptance of T1D in young people.

Future research should try to include more representative and diverse samples e.g. ethnicity, those living in rural areas (in addition to those living in city and suburban areas), as this will help increase the generalisability of research findings, particularly for groups that are under-represented in research. Further, ideally, recruitment should be from a range of sites (e.g. multiple health boards) or sources (e.g. third sector) to help ensure a representative sample. This is particularly important in trying to access and include those who do not engage with mainstream health services. Possible ways of engaging with harder to reach populations in future could include online recruitment, use of snowballing method, and recruiting through third sector organisations. It would be interesting to see if further studies that are more representative of this population elicit similar results to the current study. Finally, research into psychological interventions to support good wellbeing, management, and good mental health, that integrate findings from developmental psychology, behaviour psychology and family systems theories would be helpful. This could then

further inform and strengthen the evidence base for making any research-led changes to clinical services in healthcare, as well as approaches for the different parts of the system (e.g. family, friends) around young people.

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6. APPENDICES

Appendix 1: Journal of Clinical Psychology Author Guidelines

1. SUBMISSION AND PEER REVIEW PROCESS

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <https://mc.manuscriptcentral.com/jclp>. Please note: In Session articles are published by invitation only. Authors will receive an invitation with a custom link to ScholarOne.

For help with submissions, please contact: Swathi Kumaran at JCLPjournal@wiley.com.

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Open Access

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This journal expects data sharing. Please review Wiley's policy [here](#), where you will be able to see and select the availability statement that is right for your submission.

Data Citation

Please review Wiley's data citation policy [here](#).

Funding

Authors should list all funding sources in the Acknowledgements section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: <https://www.crossref.org/services/funder-registry/>

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Please see [here](#) and scroll down for a description of authorship criteria.

ORCID

This journal requires ORCID. Please see Wiley's resources on ORCID [here](#).

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The corresponding author is responsible for obtaining written permission to reproduce the material "in print and other media" from the publisher of the original source, and for supplying Wiley with that permission upon submission.

Title Page

The title page should contain:

A brief informative title containing the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));

A short running title of less than 40 characters;

The full names of the authors;

The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Acknowledgments.

Main Text File

For journals operating a double-blind peer review process, please ensure that all identifying information such as author names and affiliations, acknowledgements or explicit mentions of author institution in the text are on a separate page.

The main text file should be in word or PDF format and include:

A short informative title containing the major key words. The title should not contain abbreviations

The full names of the authors with institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Acknowledgments;

Abstract structured (objective(s)/methods/results/conclusion)

Up to six keywords;

Main body:

regular section formatted as introduction, materials & methods, results, discussion, conclusion

In Session (invitation only) formatted as introduction, Case Illustration (including separate sections on Presenting Problem & Client Description, Case Formulation, Course of

Treatment, Outcome and Prognosis), Clinical Practices and Summary, and Selected References & Recommended Readings

References (for In Session, please provide no more than 20 references);

Tables (each table complete with title and footnotes);

Figures: Figure legends must be added beneath each individual image during upload AND as a complete list in the text.

Reference Style

This journal uses APA reference style. Find more information on reference style guidelines [here](#).

Figures and Supporting Information

Figures, supporting information and appendices should be supplied as separate files. [Click here](#) for the basic figure requirements for figures submitted with manuscripts for peer review, as well as the more detailed post-acceptance figure requirements. [Click here](#) for Wiley’s FAQs on supporting information.

2. ARTICLE TYPES

Article Type	Description	Abstract / Structure	Other Requirements
Original Papers	reports of new research findings or conceptual analyses that make a significant contribution to knowledge	Yes, Structured	Data Availability Statement
Comprehensive Reviews	critical reviews of the literature, including systematic reviews and meta-analyses	Yes, unstructured	
Training and Professional Issues	Original research and training methods related to the education and training of professional psychologists	Yes, structured	Data Availability Statement
Case Reports (In Session – by invitation only)	original articles illustrated through case reports	Yes, structured	Data Availability Statement
Peer Review			

This journal operates under a double-blind peer review model. You can read more about peer review model [here](#). Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements.

In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is [available here](#).

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Please review Wiley's policies surrounding human studies, animal studies, clinical trial registration, biosecurity, and research reporting guidelines [here](#).

This journal follows the core practices of the [Committee on Publication Ethics \(COPE\)](#) and handles cases of research and publication misconduct accordingly (<https://publicationethics.org/core-practices>).

This journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors [here](#). Wiley's Publication Ethics Guidelines can be found [here](#).



THE UNIVERSITY
of EDINBURGH

Non-CTIMP Study Protocol

Experiences of young people with Type 1 diabetes who access transition services

	The University of Edinburgh
Protocol authors	Gillian Thompson
Principal Investigator	Gillian Thompson, Trainee Clinical Psychologist
Sponsor number	CAHSS1807/02
REC Number	Insert REC number before finalisation
Version Number and Date	Version 1 at 08.08.2018

INTRODUCTION

BACKGROUND

Diabetes – type, prevalence, and cost

In Scotland alone, the NHS spends over £1bn on diabetes, 80 per cent of this is spent on managing avoidable complications, and inpatient care accounts for 30 per cent of treating diabetes (Diabetes UK, 2013). There are 2 types of diabetes, with approximately 10% of people have type 1 diabetes (T1D) (Diabetes UK, 2016a). This project will be looking specifically at T1D only.

Type 1 diabetes (T1D) is an autoimmune condition and develops when insulin-producing cells in the pancreas are damaged, and it is not clear what exactly causes the body to attack these cells (JRDF, 2017). It is often diagnosed in childhood, and is a chronic condition requires lifelong management.

Prevalence rates of type 1 diabetes are increasing each year, with higher rates in Scotland compared to other parts of the UK (Diabetes UK, 2016a). Scotland has the third highest incidence of type 1 diabetes in children under 14 in the world (Diabetes UK, 2013).

Diabetes is a serious illness, affecting a significant proportion of people, and uses a significant amount of NHS resources. However, there is also the impact of having T1D for the individual to consider. Indeed, there has been an acknowledgement that there needs to be a cultural shift in attitude to empower people with diabetes to self-manage, with healthcare staff supporting and working with them (Diabetes UK, 2009).

Type 1 diabetes – complications and management

Insulin is essential in regulating levels of glucose in the blood, and in T1D the body cannot produce insulin naturally. Without insulin, blood glucose levels increase, which can cause damage to nerves and blood vessels, including the eyes and feet, as well as the kidneys (JRDF, 2017). The mortality rate for patients with Type 1 diabetes is 2.6 times higher than the general population (Diabetes UK, 2013).

Effectively self-managing T1D requires significant daily and lifelong management by the person with T1D. Regular monitoring of blood glucose (HbA1c) levels throughout the day is essential, and insulin is injected or pumped in numerous times a day. Blood glucose levels vary depending on what is eaten, as well as level of exercise, and the individual has to try to monitor all of these factors, and keep their levels within a specified range to prevent hypoglycaemia (when there is too much insulin in the blood) and hyperglycaemia (when there is too little insulin in the blood) (JRDF, 2017) which can lead to diabetic coma and possible death. Other serious health complications from T1D include diabetic retinopathy (loss of vision) and neuropathy (for example damaging nerves in the feet increasing risk of ulcer and potential amputation of foot). For people with T1D there are specialist NHS diabetes services, including review of blood sugar levels, as well as annual foot and vision check-ups.

Difficulties around the transition from childhood to adulthood for young people with Type 1 diabetes

When children are young, often their diabetes is managed by their parents. During adolescence and early adulthood the management shifts to the individual themselves managing their own diabetes. At the same time as having to take on this responsibility for their diabetes, there are important transitions in life they will face including education, such as leaving school, going on to further

education or starting employment; dating and relationships; as well as milestones around being old enough to learn to drive and drink alcohol.

During this period of transition, adherence can be particularly poor due to a number of challenges and barriers, both internal and external (Borus & Laffel, 2010). Qualitative research in a UK sample of 16-25 year olds explored the impact of diabetes on adolescent and young adult development and found themes relating to the impact of diabetes upon perceptions of self once diagnosed with type 1 diabetes, and the impact of this on relationships with peers and family, as well as having to cope with their own personal mortality and the long-term consequences of diabetes (Dovey-Pearce, Doherty, & May, 2007).

In a Scottish cross-sectional study of 15-25 year olds it was found that those in their early 20s had better glycaemic control than those in their mid to late teens (Acharya, Philip, Viswanath, Boroujerdi, Waugh, & Pearson, 2008).

A systematic review exploring the impact and experiences of transition from child to adult healthcare services for diabetes found that clinic attendance was worse after transition, with increased difficulties in accessing and maintaining healthcare, with some young people not being properly prepared to self-manage their diabetes, although it was acknowledged in this review that there was a lack of high quality research studies (Sheehan, While, & Coyne, 2015).

Qualitative Research in Type 1 diabetes in young people transitioning from child to adult services

There is some existing qualitative research that has looked at experiences of diabetes healthcare in young people with T1D. An Irish study explored clinic attendance amongst young adults aged 16-28 and found that their perceptions of the value in attending the clinic was influenced by relationship they had with healthcare staff (Hynes, Byrne, Casey, Dineen, & O'Hara, 2015). This finding was also supported in a Danish study of young people aged 17-18 years old who transitioned from paediatric to adult diabetes services. It was found that the relationship with the healthcare staff was very important, with young people either preferring a personal or professional relationship, and feeling more involved when staff took a genuine interest in their life (Hansen & Jensen, 2017).

In a UK study of 16-25 year olds exploring their experiences of diabetes services, it was found that a number of factors shaped this; including continuity of staff contact, the quality and type of interaction with healthcare staff, style of interaction changing as young people became older, and environment and access such as waiting times and making appointments (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005). In this study young people gave suggestions for service development including: Improving the organisation of the clinic such as evening and weekend clinics; improving consultations by staff being sensitive and interested in the young person's life and not just their diabetes; improving information available to young people so it is relevant to their needs; and possible extra services such as being able to have question and answer sessions with staff, and a diabetes counsellor (Dovey-Pearce et al., 2005). However, it should be noted that participants in Dovey-Pearce et al. (2005) included Type 1 and Type 2 diabetes, and participants were recruited from a mix of adult and paediatric services.

Overall, there is limited research that has explored young people's experiences with specialist diabetes transition services in the NHS. Several studies have only looked at adult services, or have looked at transition but in a service different to the UK model and system of healthcare.

Drivers for transition-specific care from NHS services

There have been a number of national policies that have driven services to develop specific transition services for young people with T1D. This includes the Diabetes Action Plan (2010) which stated that the organization of paediatric care at local and national levels would be reviewed, with each health board having to develop and show evidence of a transitional care plan for young people with T1D by June 2011.

This led to a working group being set up (Type 1 Diabetes Short Life Working Group, 2009) which reviewed existing services as well as made some initial recommendations re: transition-specific care. A Childhood and Adolescent subgroup for Scotland being set up in 2011, with a specific project looking at implementing a programme to improve the transition process for young people with T1D (Diabetes Action Plan, 2014).

More recently Diabetes UK have published information on transition aimed at young people with T1D around what to expect as they move from child to adult diabetes care (Diabetes UK, 2016b).

RATIONALE FOR STUDY

There has been little research looking at transition and young peoples' experiences of this in Scotland, since the Diabetes Action Plan was published in 2010. The proposed project will aim to address this gap. The project will focus on the experiences of young people with type 1 diabetes aged 16 – 22 years of age who access a specialist NHS diabetes transition service. The transition during adolescence into adulthood is a particularly difficult time for young people with diabetes. Therefore this project will also help shed light on how developmental processes for young people interface with diabetes self-management, their relationships with specialist diabetes health services, and how this is managed and negotiated in terms of the young person's developmental journey and developing sense of self.

A qualitative methodology, using semi-structured interviews will be used. This will give some structure to the interview, but still allow flexibility for young people to share their experiences.

As it is anticipated that the focus of the project will be on young people's experiences of accessing the diabetes transition service, and the findings will be used broadly at a service level, it is felt that Thematic Analysis is best suited to answer the research aims of the project.

This project will help shed light on the different factors and their impact on promoting or hindering engagement. The results of this project will help inform the delivery of the diabetes transition service in NHS Grampian but potentially in other transition services in other health boards in Scotland and the rest of the UK. The results could also help services nationally and internationally consider the way they deliver and engage with young people with diabetes, and potentially other chronic health conditions.

Increasing engagement in diabetes transition services would also have a potential impact on improving outcomes and managing risk in young people, at the level of the young person, as well as at a wider service level.

STUDY OBJECTIVES

OBJECTIVES

Primary Objective

To explore the experiences of young people with type 1 diabetes who access transition services

Secondary Objectives

What is it like to be a young person with type 1 diabetes transitioning from childhood into adulthood? Exploring the interface between diabetes, self-management, relationships with health services, specialist transitions models of health service, and the identity and developmental tasks of adolescence.

What is it like for the young person moving from child services to young person's service?

What helps and what hinders engagement with the diabetes service currently? What could the diabetes service do differently to make it easier to engage?

STUDY DESIGN

Detail: type of and length of study, consider a schematic diagram of the study design, duration of participant involvement, study setting

The recruitment period for the project will be from August 2018 until September 2020. It is hoped that sufficient participants will be recruited by December 2019.

NUMBER OF PARTICIPANTS

Qualitative research sample sizes are smaller than those used in quantitative research. A sample size of 8 to 12 people is proposed, however up to a total of 15 participants could be recruited to allow for potential attrition (or in case additional interviews are required to ensure data of sufficient quality is collected).

Currently 261 young people are known to the service in NHS Grampian, which covers Aberdeen, Aberdeenshire, and Moray. Of these, approximately 200 are invited to attend the Aberdeen Royal Infirmary Clinic, from where participants will be recruited. It is felt feasible to recruit a sample size of up to 15 young people for this project from a population of 200.

INCLUSION CRITERIA

Diagnosis of type 1 diabetes

Age 16 to 22 years old

Able to give signed informed consent

Able to understand and converse in spoken English

Have accessed the diabetes transition service in NHS Grampian

EXCLUSION CRITERIA

Diagnosis of type 2 diabetes

Being under the age of 16 years old

Experiencing severe and enduring mental health difficulties

Having ongoing risk issues or social work involvement

PARTICIPANT SELECTION AND ENROLMENT

IDENTIFYING PARTICIPANTS

The diabetes transition clinic staff will identify potential participants for the study.

Participants will be sent a study information sheet with their appointment letter to the clinic. As the service is planning to eventually switch from letters to text reminders in the near future, when this occurs, the text will contain a weblink to the study wikilink, giving more information about the study to potential participants

Prior to each clinic, the researcher will meet with the staff in the diabetes service who will advise if there are any potential participants who the team feel should not be approached or informed about the project (for example those who cannot consent, have ongoing risk issues or social work involvement such as child/adult protection concerns, or those with severe and enduring mental health difficulties for whom participating in an interview may cause significant additional distress).

During the transition clinics for young people, the researcher will be present in the waiting area, where they will approach potential participants to let them know about the project and to see whether they wish to take part or not, and answer any questions they have regarding the project. The trainee plans to use an NHS mobile phone from the paediatric department that will be used solely for this research project. The phone number will be given out in the study information sheet so potential participants are able to contact the researcher directly should they have any questions about the project, or to arrange a convenient time to carry out the interview. This mobile phone can also be used to text a reminder of any interviews the day before to participants.

CONSENTING PARTICIPANTS

An information sheet will be given to potential participants and they will have the opportunity to ask questions. If participants wish to take part then informed written consent will be obtained from participants by the researcher.

Withdrawal of Study Participants

Participants are free to withdraw from the study at any point or a participant can be withdrawn by the Investigator. If withdrawal occurs, the primary reason for withdrawal will be documented in the participant's case report form, if possible. However, participants have the right to withdraw at any point without having to give a reason for this.

DATA COLLECTION

A one-off interview lasting about an hour will be how data will be collected. The interview will be audio-recorded for transcription to enable thematic analysis.

Self-reported background information will be collected during the interview from participants. This will include:

the participant's age and gender

years since diagnosed with T1D, whether they are on basal bolus or insulin pump therapy

any comorbid health conditions

Whether they are at school, further education or employment.

How long they have attended young peoples' service.

Interviews

In line with qualitative principles, one-on-one, in depth semi-structured interviews will be conducted. A semi-structured interview schedule will be developed in line with the research

objectives and using key literature within this area. The schedule will consist of 4 – 8 broad questions. Interviews will take place in a room on NHS Grampian’s premises or at the participant’s home, depending on each participant’s preferences.

Topics covered in the interview will reflect the research aims of this project. The interview schedule will be used flexibly to provide participants with space to share their experiences to maximise the collection of valid in-depth data and for any unexpected issues to be discussed and explored.

Source Data Documentation

After interview, the audio-recording will be transcribed by the researcher, with personal and identifiable details removed to protect participants’ confidentiality.

STATISTICS AND DATA ANALYSIS

SAMPLE SIZE CALCULATION

Approximately 200 young people are invited to attend the Aberdeen Royal Infirmary Clinic, from where participants will be recruited. It is felt feasible to recruit a sample size of up to 15 young people for this project from a population of 200. The recruitment period is felt to be adequate to recruit participants from monthly clinics.

PROPOSED ANALYSES

A number of different qualitative analysis methods were explored, before it was decided that the data will be analysed using Thematic Analysis. This method has been chosen as it allows rich data to be gathered, whilst also allowing some generalizability and flexibility of applying the findings to the wider population of people with T1D.

The thematic analysis will be carried out by the trainee in line with the 6 phases suggested by Braun & Clarke (2006). These are as follows:

1. Getting familiar with the data by reading and re-reading transcripts and noting down initial ideas.
2. Generating initial codes systematically across the entire data set, and collating data relevant to each code.
3. Searching for themes by collating the data into possible themes.
4. Reviewing themes, checking that they fit in relation to phases 1 and 2. Making a ‘map’ of the thematic analysis.
5. Defining and naming themes using ongoing analysis to refine themes, and generating clear names and definitions for all themes.
6. Producing the report by selecting appropriate examples from the transcripts that vividly illustrate the themes, relating these to the research questions and literature.

Appendix 3: Copy of REC Approval Letter for Study



Health Research Authority

London - South East Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8002

18 September 2018

Dr David Gillanders
Doctoral Programme in Clinical Psychology, University of Edinburgh
School of Health in Social Science, Teviot Place
Edinburgh
EH8 9AG

Dear Dr Gillanders

Study title:	Experiences of young people with type 1 diabetes who access transition services.
REC reference:	18/LO/1654
Protocol number:	CAHSS1807/02
IRAS project ID:	249168

The Proportionate Review Sub-committee of the London - South East Research Ethics Committee reviewed the above application via correspondence.

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 hra.studyregistration@nhs.net outlining the reasons for your request. 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.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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 and HCRW Approval (England and Wales)/ 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").

Extract of the meeting minutes

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The PRS Sub-Committee sought further clarification as to what the researchers would do in the event that some clinical malfeasance was alleged during the interview.

Ms Gillian Thompson replied that in the event some clinical malfeasance was alleged during the interview regarding the service, then the plan of action would be as follows. Firstly she would take the allegation to both her field and academic supervisors (Drs Allan and Gillanders) to discuss and get advice. She said that it was likely that there would be 2 options following this, which one she would do, would depend on the advice of her supervisors. These 2 options would be either to encourage or support the interviewee to make a complaint following NHS Grampian's complaints procedure, or to raise it with the consultant in the service.

The PRS Sub-Committee noted that the interview could take an hour and agreed that this may be quite burdensome on the interviewee. The PRS Sub-Committee sought clarification as to whether it would be possible for the interviewee to have a break during the interview.

Ms Thompson confirmed that it would be possible for interviewees to have a break during the interview, should they wish.

The PRS Sub-Committee was happy with the responses.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Copies of advertisement materials for research participants [Information for Study Wiki Page]	Version 1	08 August 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Insurance Certificate for Sponsor]	Version 1	31 July 2018
Interview schedules or topic guides for participants [Semi-structured Interview Schedule]	Version 1	08 August 2018
IRAS Application Form [IRAS_Form_03092018]		03 September 2018
Letters of invitation to participant [Letter from Service to Young People's Clinic Attendees]	1	24 August 2018
Participant consent form [Consent Form]	Version 1	08 August 2018
Participant information sheet (PIS) [Participant Information Sheet]	Version 1	08 August 2018
Research protocol or project proposal [Protocol]	Version 1	08 August 2018
Summary CV for Chief Investigator (CI) [CV for CI David Gillanders]	Version 1	08 August 2018
Summary CV for student [Gillian Thompson CV]	Version 1	31 July 2018
Summary CV for supervisor (student research) [Dr Ashley Allan CV]	Version 1	31 July 2018
Summary CV for supervisor (student research) [Dr David Gillanders CV]	Version 1	31 July 2018
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Clinical Trial Liability]	Version 1	31 July 2018
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Liability Insurance]	Version 1	01 August 2018
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Sponsor Insurance]	Version 1	24 July 2018

Membership of the Proportionate Review Sub-Committee

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

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 reviewReporting 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.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received 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/>

HRA Training

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

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

18/LO/1654

Please quote this number on all correspondence
--

Yours sincerely

On behalf of
Ms Stephanie Cooper
Chair

Email: nrescommittee.london-southeast@nhs.net

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"



Health Research Authority

Copy to: Ms Charlotte Smith
Dr Susan Ridge,
Grampian Health Board

London - South East Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting

Committee Members:

Name	Profession	Present	Notes
Professor Anthony Fox in the Chair	Pharmaceutical Medicine	Yes	
Mr Guy Gardener	Retired Assistant Chief Constable	Yes	
Professor Eleni Palazidou	Consultant Psychiatrist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Ewa Grzegorska	REC Assistant

Appendix 4: Copy of permission letter for project from local R&D

Research and Development Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB



Ms Gillian Thompson
NHS Grampian
Dept of Paediatric Psychology
RACH
Aberdeen

Date 18/09/2018
Project No 2018PC010
Enquiries to Lynn / Louise
Extension 53846
Direct Line 01224 553846
Email grampian.randdpermissions@nhs.net

Dear Ms Thompson

Management Permission for Non-Commercial Research

STUDY TITLE: Experiences of young people with type 1 diabetes who access transition services
PROTOCOL NO: V1: 08.08.18
REC REF: 18/LO/1854
R&D REF: 2018PC010

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2008, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

- 1) The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:
 - Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).
 - A change of Principal Investigator in Grampian or Chief Investigator.
 - Any change to funding or any additional funding
- 2) The R&D Office will be notified when the study ends.
- 3) The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

Susan Ridge
Non-Commercial Manager

cc: CI – Dr David Gillanders
Research Monitor

Sponsor: University of Edinburgh

Appendix 5: Copy of Participant Information Sheet



THE UNIVERSITY
of EDINBURGH

Patient Information Sheet Guide

Study title: Experiences of young people with type 1 diabetes who access transition services.

Principal Investigator: Gillian Thompson (Trainee Clinical Psychologist, NHS Grampian/University of Edinburgh)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others, such as your GP and relatives, if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

What is the purpose of the study?

Little is known about the experiences of young people with type 1 diabetes as they move from adolescence into adulthood, and access the young people's clinic. The aim of this study is to find out about young peoples' experience of this. The study will involve a one-off interview with each young person. Interviews will be on a 1:1 basis with the researcher, and will last up to 60 minutes.

Why have I been invited to take part?

You have been invited as you are a young person aged 16 – 22 years old who has Type 1 diabetes and attend the young people's clinic at Aberdeen Royal Infirmary. A total of 10 – 15 young people will be interviewed for this study.

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 will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive.

What will happen to me if I take part?

Feel free to think it over before deciding whether to take part. If you have any questions please ask the researcher, who will be happy to answer these. If you decide to take part, then you will be asked to give consent by the researcher. This involves you signing a consent form stating that you are choosing to participate in the study and have had the opportunity to ask questions. You can contact the researcher so that a time can be arranged for you to be interviewed about your experiences of having Type 1 diabetes and accessing the young people's clinic. A one-off interview will take place either face to face at Aberdeen

Royal Infirmary or at your home, or by telephone or by video call using Attend Anywhere. Where the interview is carried out will depend on what you would prefer. This interview will last up to an hour.

During the interview if there is anything you do not wish to answer it is perfectly okay to let the researcher know this, and they will respect your wishes. The interview will be audio-recorded and typed up afterwards by the researcher. All personal and identifiable details about you will be removed so no-one outside the study group will know who has taken part.

What are the possible benefits of taking part?

There is no intended personal benefit to taking part. However, the information we get from this study will help us better understand the needs of young people with Type 1 diabetes, which can be useful for the young people's clinic. As a thank you for participating, all participants in the study will be entered into a prize draw for a chance to win a £30 Amazon voucher or equivalent value store of your choice.

What are the possible disadvantages and risks of taking part?

There are no known disadvantages, though by taking part in an interview, you would be giving your time and sharing your experiences with the researcher. There are no anticipated risks to taking part. In the unlikely event that you do feel upset by any of the questions asked you can either speak to the researcher or your care team. If you change your mind you are free to withdraw at any point.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any identifiable data will be kept and stored securely within the NHS on NHS Grampian's secure server, which only the principal investigator will have access to.

Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

You can find out more about how we use your information and our legal basis for doing so in our Privacy Notice at: <https://www.ed.ac.uk/records-management/privacy-notice-research>

What will happen to the results of the research study?

The results will be written up formally as part of the researcher's doctoral thesis project. The study will be written up for publication in a peer-reviewed journal.

It is also planned that a brief summary of the findings from the study will be published online on the study information page, which anyone with an interest in the study can access to find out about the results of the study.

You will not be identified in any report or publication, as all personal details will be removed to protect your confidentiality.

When you agree to take part in a research study, the anonymised information collected may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and social care research. Your information will only be used by researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for

the purpose of health and social care research and cannot be used to contact you or affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Who is organising and funding the research?

This research has been organised by Gillian Thompson (Trainee Clinical Psychologist) as part of their Clinical Psychology Doctorate. This research is being supervised by Dr Ashley Allan (NHS Grampian) and Dr David Gillanders (University of Edinburgh). The study is funded by the University of Edinburgh and NHS Grampian.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. A favourable ethical opinion has been obtained from London – South East Ethics Committee. The study proposal has been reviewed by the researcher’s educational supervisor and by independent academic staff within the School of Health in Social Science at the University of Edinburgh.

Contact Information

If you have any further questions about the study please contact Gillian Thompson (Trainee Clinical Psychologist) on: XXXXXX or email: XXXXXX

If you would like to discuss this study with someone independent of the study team please contact XXXXX: XXXXXX or email: XXXXXX

If you wish to make a complaint about the study please contact NHS Grampian:

NHS Grampian Feedback Service
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Tel: 0345 337 6338

Email: nhsgrampian.feedback@nhs.net

Data Protection Officer contact information:

University of Edinburgh
Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL
Tel: 0131 651 4114
Email: dpo@ed.ac.uk

Appendix 6: Extract of Reflective Journal Entry

“ last clinic in (month) were much better. Did 2 interviews today. Really interesting interviews today, mental health came up in both. Very grateful both young people were willing to talk about their personal experiences and share them even though they have had difficult times, lot of respect for them and the resilience they show”.

As a result of the above, in subsequent interviews, the researcher specifically asked about mental health if it was not brought up by the participant. Two examples of this and the different responses are illustrated below:

“Int: Has...any impact on, kind of, wellbeing, mental health?”

Lily: Not particularly”

“Int: Okay, and has diabetes...has it ever had an impact on your sense of wellbeing or mental health or anything?”

Marianne: Erm, yeah, I think so, to a certain extent. I mean, I do worry about getting unwell because that’s just a nightmare with diabetes when you’re ill”