Finding out your child has Type 1 Diabetes: understanding the experiences of parents when their child is diagnosed with type 1 diabetes.

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University College London

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: 

Name: Molly Sharp

Date: 6th July 2023

Overview

In 2019, Diabetes UK released a report recommending more research be conducted to explore the impact of the delivery of a diagnosis of type 1 diabetes (T1D) on the wellbeing of people living with the condition. The following thesis aims to add to this evidence base by exploring the diagnosis experiences of parents of children and adolescents living with T1D. This is achieved by firstly synthesising existing literature addressing this topic, and by qualitatively exploring parents' accounts of the diagnosis experience to contribute further to the evidence base.

Part One comprises a systematic literature review of existing literature focusing on the diagnosis experiences of parents of children and adolescents with T1D. Of the publications retrieved, 21 are included and analysed using thematic synthesis. Themes include: 'Realising something was wrong', 'Hearing the diagnosis', 'An overwhelming initiation to T1D', 'Stepping out into a new reality', and 'The transformational impact of diagnosis'. Findings highlight the long-term emotional impact of finding out one's child has T1D, factors that help and harm parents during this process, and the need for further exploration of the experiences of parents throughout the entirety of the diagnosis journey.

Part Two comprises an Interpretive Phenomenonlogical Analysis (IPA) study exploring parents' experiences of their children being diagnosed with T1D in the UK, including exploration of the healthcare recieved. Ten parents participated in semi-structured interviews. Identified themes included 'Responding to a crisis', 'A sudden state of uncertainty', 'A threat to parental role', 'Developing a new parental role', and 'T1D diagnosis holds a distressing legacy'. Parents described the array of emotions they experienced at different times during the diagnosis journey and how some of these endured,

how interactions with healthcare professionals (HCPs) promoted and undermined their sense of safety during the diagnosis, and the impact of the diagnosis on their parental identity.

Part Three brings together the primary researcher's reflections on issues and dilemmas that came up during the research process. Reflexivity and the role of self in the research are discussed, as well as a discussion on issues of power.

Impact Statement

The Paediatric Psychological Preventative Health Model (PPPHM; Kazak et al., 2006) is a framework that aims to identify psychosocial need and reduce psychosocial harm for children with chronic illnesses and their families. The current research project falls within the PPPMH, by providing insights about the impact on parents of their child being diagnosed with T1D. This includes developing an understanding of diagnosis factors that contributed to parents' psychological distress and adjustment difficulties, and their emotonal and informational support needs at the time of diagnosis and during the immediate aftermath.

The research project attempts to respond to a call by Diabetes UK (Wylie et al., 2019) for more research to be conducted focusing on the impact of a delivery of T1D diagnosis on people living with the condition, in order to prevent the onset mental health difficulties at the time of diagnosis and improve the long-term wellbeing of people living with T1D. Part One, to the author's knowledge, represents the first systematic review to specifically examine existing qualitative research evidence on parents' experiences of their children being diagnosed with T1D. Parents represent an important group of stakeholders, and it is hoped that the findings could be used to inform future research, such as in the development of interventions designed to improve the process of diagnosis and to reduce its negative consequences, and especially to improve the equity of care provision for families at diagnosis across world regions.

Part Two adds to the existing literature base, specifically contributing a current understanding of parents' experiences of T1D diagnosis in the UK, across the duration of the diagnosis journey. It provides in-depth understanding into the impact of diagnosis of T1D on parents, including their emotional experiences, the helpful and harmful practices of HCPs,

and parents' support needs. It is hoped that these findings form a basis for advancing research on what may help minimise distress across a more diverse sample. The findings are also of significant clinical value, emphasising the importance of clear and empathic communication and reassurance at diagnosis, and the need to improve knowledge gaps in non-specialist HCPs. Parents also highlighted the value of specialist practical support in the aftermath of diagnosis, and a need for better access to specialist emotional support during and following the diagnosis. It is hoped that these findings will support healthcare services and policy makers across the UK to develop these areas in order to better serve the needs of parents during their child's diagnosis of T1D.

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On Children

And a woman who held a babe against her bosom said, "Speak to us of Children".
And he said:
Your children are not your children.
They are the sons and daughters of Life's longing for itself.
They come through you but not from you,
And though they are with you yet they belong not to you.
You may give them your love but not your thoughts,
For they have their own thoughts.
You may house their bodies but not their souls,
For their souls dwell in the house of tomorrow, which you cannot visit, not even in your dreams.
You may strive to be like them, but seek not to make them like you.
For life goes not backward nor tarries with yesterday.
You are the bows from which your children as living arrows are sent forth.
The archer sees the mark upon the path of the infinite, and He bends you with His might that His arrows may go swift and far.
Let your bending in the archer's hand be for gladness;
For even as He loves the arrow that flies, so He loves also the bow that is stable.

Gibran, K. (1923). On children. *From The Prophet*.

Part One: Systematic Literature Review

A systematic review of qualitative studies exploring the experiences of parents when their child is diagnosed with Type 1 Diabetes.

Abstract

Evidence suggests that how the diagnosis of type 1 diabetes (T1D) is delivered may have a lasting impact on the mental well-being of people living with the condition and their families. Whilst there is increased literature focusing on the psychosocial impact of diagnosis of T1D, a consolidation of literature pertaining to parents' experiences of having a child diagnosed with T1D has not been attempted. **Aim**. The current review seeks to synthesise parents' accounts of their child being diagnosed with T1D, with hopes this could inform healthcare practices on diagnosis delivery. **Method**. Twenty one studies were retrieved using a systematic search strategy across three databases, all of which used qualitative methodology. Thematic synthesis was used to analyse the data. **Results**. Five overarching analytical themes were generated, titled 'Realising something was wrong', 'Hearing the diagnosis', 'An overwhelming initiation to T1D', 'Stepping out into a new reality', and 'The transformational impact of diagnosis'. **Conclusions**. A child's diagnosis of T1D has a lasting emotional impact on parents. Various factors may lessen the burden of diagnosis on parents and promote their adjustment to life with T1D, and healthcare practices could be modified to reduce the stress and trauma of T1D diagnosis for parents and families.

Introduction

Type 1 diabetes (T1D) is an auto-immune condition affecting upward of 8.4 million people worldwide (Gregory et al., 2022), including 1.5 million people aged under 20. T1D is the most prevalent long-term metabolic disorder affecting children and adolescents (Rankin et al., 2014), with incidence continuing to increase rapidly in these age cohorts (Rahmati et al., 2022; Ogle et al., 2022). Whilst there are significant gaps in the data available, findings suggest that the highest incidences of T1D in children and adolescents continue to predominate Northern European countries (particularly Finland, Norway & Sweden). However, the most pronounced increases in incidence in recent years have been in African, Middle Eastern and North African regions (Ogle et al., 2022).

Type 1 Diabetes

Insulin is a hormone vital for converting glucose for the body to be able to use as energy. Without insulin, high amounts of glucose will be left in the blood, which has dangerous consequences. These include long-term complications such as blindness and nerve damage (Atkinson et al., 2014) and acute illness, such as diabetic ketoacidosis (DKA), which may be life threatening (Dhatariya et al., 2020). T1D is believed to be precipitated by the destruction of insulin-producing pancreatic cells, meaning that the pancreas creates little to no insulin (Atkinson et al., 2014).

People living with T1D require insulin to be subcutaneously injected or infused into the bloodstream to maintain optimal metabolic control. T1D therefore involves continuous daily management, including blood glucose monitoring (BGM) and food intake monitoring to establish how much insulin to take. Additional factors, such as exercise, stress, menstruation, and dehydration, also affect blood glucose levels and must therefore be accounted for in T1D

management (American Diabetes Association, 2018). For children and adolescents diagnosed with T1D, caregivers are frequently required to assist with T1D management (Anderson et al., 2017), often taking primary responsibility for T1D care (Whittemore et al., 2012). This involves undertaking frequent monitoring of blood glucose levels, determining, and administering insulin doses, and counting carbohydrates to maintain blood glucose levels within a recommended range (Rankin et al., 2016).

Diagnosis of T1D

T1D is diagnosed when blood glucose concentration is equal to or above 11.1 mmol/l alongside presence of clinical symptoms including excessive urination, excessive thirst, and unexplained weight loss (World Health Organisation, 2006).

Clinical guidelines developed by the International Society of Pediatric and Adolescent Diabetes (IPSAD) stipulate the importance of T1D education, from the point of diagnosis, as a cost-effective intervention to empower children and families in the management of the condition (Phelan et al., 2018). The guidelines posit that a structured education should be provided, where possible by trained healthcare professionals (HCPs), at the time of diagnosis, and revised and reviewed regularly as determined by regular individual assessment of need. T1D education should include a simple explanation of how the diagnosis has been made, the cause of symptoms, and need for lifelong insulin replacement therapy. It should also include explanations of the relationships between food, blood glucose and insulin and provide various "survival skills" (p.79), including education on continuous glucose monitoring, ketone monitoring, insulin techniques and information on storage, as well as carbohydrate counting guidance. The guidelines state that initial learning should be reinforced by written, diagrammatic or other visual materials. Importantly, they also specify that HCPs should

"reassure [families] that with insulin replacement the child will regain health and energy quickly" (p.79), and that education should involve exploring feelings of guilt and blame, and normalising reactions of grief to diagnosis. Evidence shows that psychoeducational interventions of this kind benefit glycaemic control for children and adolescents and psychological outcomes for families (Couch et al., 2008; Peyrot & Rubin, 2007). IPSAD guidelines also indicate that general and diabetes-related family functioning should be assessed at diagnosis and that preventative interventions should be offered after diagnosis (Delamatar et al., 2018), given evidence that several family factors may have implications for children and adolescents' psychosocial wellbeing and glycaemic control. These factors include parents' psychological adjustment (Whittemore et al., 2012) and stress (Moreira et al., 2014; Helgeson et al., 2012), and levels of diabetes-related family conflict (Hilliard et al., 2013).

As well as these best practice clinical care guidelines, IPSAD also published an appendix outlining "recommended care" levels (Codner et al., 2018a, p.326). This is in acknowledgement that significant wealth disparities across world regions mean that many developing countries may not have the health infrastructure, personnel or procedures to deliver all the best practice standards. The recommended care guidelines, intended for use in resource-limited settings, specify that all children and adolescents with T1D and their caregivers should have access to a basic education and practical skills training as soon as possible following diagnosis (Codner et al., 2018b). They also suggest that T1D care should include the recognition of the potentially serious impact of T1D on psychosocial functioning for the child/adolescent and family, that professionals should be prepared to discuss psychological difficulties associated with T1D, and that adolescents and their families may need individualised, culturally sensitive support.

The impact of T1D diagnosis on children and families

Research suggests that across world regions, the journey to T1D diagnosis is often stressful for families. Children may be misdiagnosed (Usher-Smith et al., 2012; Mavinkurve et al., 2021), and often they are very unwell when they receive a diagnosis. Several studies report that rates of life-threatening DKA at diagnosis have remained stable in multiple countries over the past 20 years (Schober et al., 2010; Jefferies et al., 2015; Rewers et al., 2015; Usher-Smith et al., 2012; RCPHC, 2022). Literature has highlighted traumatic responses amongst parents following their child's diagnosis of T1D (Whittemore et al., 2012; Rechenberg et al., 2017; Schiaffini et al., 2019). Further evidence emphasises the grief reactions parents experience when coming to terms with their child's diagnosis of a chronic health condition (Coffey, 2006; Kepreotes et al., 2010) and the need for life-long treatment (Whittemore et al., 2012). Research has also suggested that parents' psychological distress at diagnosis predicts later distress and negatively impacts on child psychological adjustment (Whittemore et al., 2012). This may have a knock-on effect on childrens' ongoing adjustment (Delamater et al., 2018; Luyckx, 2010), which is especially important given evidence that the mental health distress of children with T1D is predictive of their glycaemic control (Hood et al., 2011; Jaser et al., 2017).

In light of these findings, a report published by Diabetes UK (Wylie et al., 2019) identifying key gaps in the research evidence base of people living with T1D, stipulates "a need to understand the impact of the delivery of a diagnosis" (p.1535). The authors suggest that identifying factors which contribute to a positive diagnosis experience, and understanding how to diagnose T1D whilst minimising shock and trauma, may reduce the risk of the diagnosis experience having a negative effect on the future mental wellbeing of people living with T1D.

The report specifically recommends that researchers "systematically review the current research evidence in this area" (p.1536). Evidence of the significant emotional impact on parents of their child being diagnosed with T1D (Whittemore et al., 2012; Rechenberg et al., 2017; Schiaffini et al., 2019) suggests that parent perspectives may inform these research gaps. Furthemore, since parents play a vital role in T1D management, and parental psychological distress at diagnosis is believed to have a significant influence on children with T1D's well-being and diabetes-related outcomes, they are vital stakeholders and informants on this issue. Whilst research to date has synthesised parents' experiences of generally caring for a child with T1D (such as Whittemore et al., 2012), there is currently no synthesis which specifically focuses on parents' experiences of their child's T1D diagnosis.

Aims

The primary aim of the current systematic review is to synthesise parents' accounts of the delivery of their child's diagnosis of T1D. The secondary aim is that the review findings can inform healthcare practices focused on the diagnosis of T1D in children and adolescents, by shedding light on the ways the delivery of diagnosis can help or harm.

Method

A systematic review was conducted, informed by PRISMA guidelines (Page et al., 2021), between November 2022 and May 2023 (PROSPERO Registration Number: CRD42022387084).

Search strategy

After several scoping searches, three bibliographic databases (MEDLINE, PsycINFO and CINAHL) were searched for relevant literature from 2000 until December 2022. An outline of the search syntax used for each database is presented in Appendix A. Search terms consisted of synonyms for each key concept pertaining to the research question, including 'parents', 'Type 1 Diabetes', 'childhood and adolescence', and 'diagnosis'. The search terms were then combined. The terms were intentionally broad and inclusive to promote the sensitivity of the search and capture all potentially relevant papers. The searches were informed by the support of an information specialist (the Head of Library Skills at UCL) and tailored for each of the bibliographic databases chosen. For example, each database uses unique Medical Subject Headings (MeSH) to index articles, therefore these were identified for each separate database. Further, PsycINFO does not have MeSH pertaining to one key search concept, 'childhood and adolescence', unlike the other databases. Therefore, the PsycINFO strategy utilised a textword search for the concept 'child' as well as searching the database using additional 'child' and 'adolescent' limits, to ensure all relevant articles were found. First, titles of articles were screened for relevance, after which abstracts were reviewed to determine which studies would be accessed in full. If the outcome of the abstract review remained unclear, the study was retrieved in full. Full texts were assessed for relevance using the criteria outlined below. Studies that did not meet the criteria were excluded; their bibliographic details and reasons for exclusion are listed in Table 1. A subset of abstracts (10%) and full texts (30%) were randomly selected and screened by a second independent reviewer (KT) for inclusion in the review, resulting in inter-rater agreement of 100% and 70% agreement, respectively (Landris & Koch, 1977). All discrepancies were resolved by discussion. Supplementary to electronic searches, reference lists of all the included studies were hand-screened for further papers.

Inclusion and exclusion criteria

Studies were included if they (a) reported on experiences of parents and carers of young people aged 0-18 at the time of research; (b) focused on the delivery of the diagnosis of the child or young person's T1D. Studies involving a wider focus (such as the experience of parenting a child with diabetes), which reported separately on the diagnosis delivery, were included; (c) reported on primary data; and (d) were published after 1999. At the point of the search being carried out, the inclusion criteria did not specify any particular methodological approach. However, the study's particular focus on the subjective experiences of parents and carers was anticipated to align more closely with qualitative research designs.

Studies were excluded if they (a) did not report specifically on the diagnosis experience, instead focusing on the experience of T1D more generally; (b) focused on parents'/carers' accounts of their adult children's diagnosis of T1D; (c) provided children's accounts of their diagnosis of T1D only; and (d) focused on medical accounts of T1D diagnosis only.

Quality assessment

Qualitative research is varied, underpinned by a vast array of philosophical and epistemological positions and utilising many diverse approaches to data collection and analysis. There has been a great deal of debate within the qualitative research community regarding whether it is appropriate to critically appraise qualitative research, and whether it is possible to do so in a meaningful way (Dixon-Woods et al., 2007; Carroll & Booth, 2015). However, in recent years including a critical appraisal has become the dominant approach for researchers publishing qualitative evidence syntheses (Hannes & Mcaitis, 2012), and attention has turned to what criteria researchers should use to inform critical appraisal (Carroll & Booth, 2015). In this study, the research team assessed the quality of included studies using the

qualitative Critical Appraisal Skills Programme Qualitative Checklist (CASP-QC, 2018; see Appendix B). The CASP-QC, a widely adopted tool, can be applied flexibly to guide the assessment process and is applicable to various epistemological stances. Each quality domain was assessed in each study and rated as 'no features present' (0), 'some features present' (1), 'most features present' (2), or 'not relevant', following which total scores were divided by the number of relevant domains (see Table 2 for a breakdown of scores).

Data extraction

The data extracted from included studies consisted of author(s), year of publication, study aims, methodology and type of analysis, number of participants, country of study, relationship of participant to child (e.g. mothers, fathers), age of child at time of study, time since diagnosis of T1D, and study exclusion crtieria (see Table 1.) All data were recorded in an Excel spreadsheet.

Analysis

There are several possible methods of qualitative evidence synthesis (Barnett-Page & Thomas, 2009), including thematic synthesis (Thomas & Harden, 2008), framework synthesis (Oliver et al., 2008) and meta- ethnography (Noblit & Hare, 1988). The appropriateness of each approach is informed by the question, aims, and theoretical position of the research (Boland et al., 2017). A thematic synthesis approach was chosen for the present literature review due to its appropriateness when considering these aspects (Boland et al., 2017). The thematic synthesis methodology was developed for systematic reviews addressing the perspectives and experiences of participants, with the clear objective of using the findings to inform policy and practice (Thomas & Harden, 2008). It is both an integrative and interpretative method (Boland et al., 2017), seeking to summarise the data and generate

new concepts (Barnett-Page & Thomas, 2009). This aligns with the present study's attempt to synthesise literature on parents' experiences of their child's T1D diagnosis, with the hopes that this may generate ideas on how services might manage and support this process. Thematic synthesis shares the critical realist stance adopted by the author and that informs the research question and approach (Thoms & Harden, 2008). Critical realism adopts a realist ontology (acknowledging the existence of an independent reality) and a relativistic epistemology (what we observe is mediated through our beliefs and perception; Fryer, 2022).

Articles were reviewed using the data analysis stages outlined by Thomas & Harden (2008). Line-by-line coding was performed on any text pertaining to parents' experiences of their child's diagnosis under sections labelled 'findings' or 'results' of the included papers, including quotations from participants. The results were entered into a Word document and each sentence was coded according to meaning and content. A screenshot of a section of a worked example is included in Appendix C. Next, all codes from stage 1 were imported into an Excel file, where concepts pulled from the initial 259 codes were 'translated' across studies, and grouped into a colour-coded framework of descriptive themes (see Appendices D & E). This led to the development of higher-order analytic themes, where the reviewer endeavours to 'go beyond' what was reported in primary studies by reflectively examining the data using their own insights and understanding. Themes were generated by the author and subsequently reviewed and finalised with the research team (VM, KT).

Author's background and preconceptions

The analysis presented should be contextualised within the author's own experiences and assumptions, which, adopting a critical realist stance, will affect the process of deriving meaning from the data (Fryer, 2022). As a trainee clinical psychologist, the author is drawn to

understanding experiences through a psychological lens, with an emphasis on people's meaning-making process. The author was supervised by clinical psychologists in the field of paediatric health settings (KS) and diabetes (VM), but the author themselves had no prior experience working in these areas. The author has experienced an intimate family member receiving a diagnosis of a serious health condition, which they perceived as abrupt and frightening. The author also grew up with a parent diagnosed with T1D. Although the author attended to their own experiences and assumptions around family experiences of T1D and diagnosis of serious health conditions, and of their bias towards psychological ways of thinking and understanding, these will likely be reflected in the themes generated.

Results

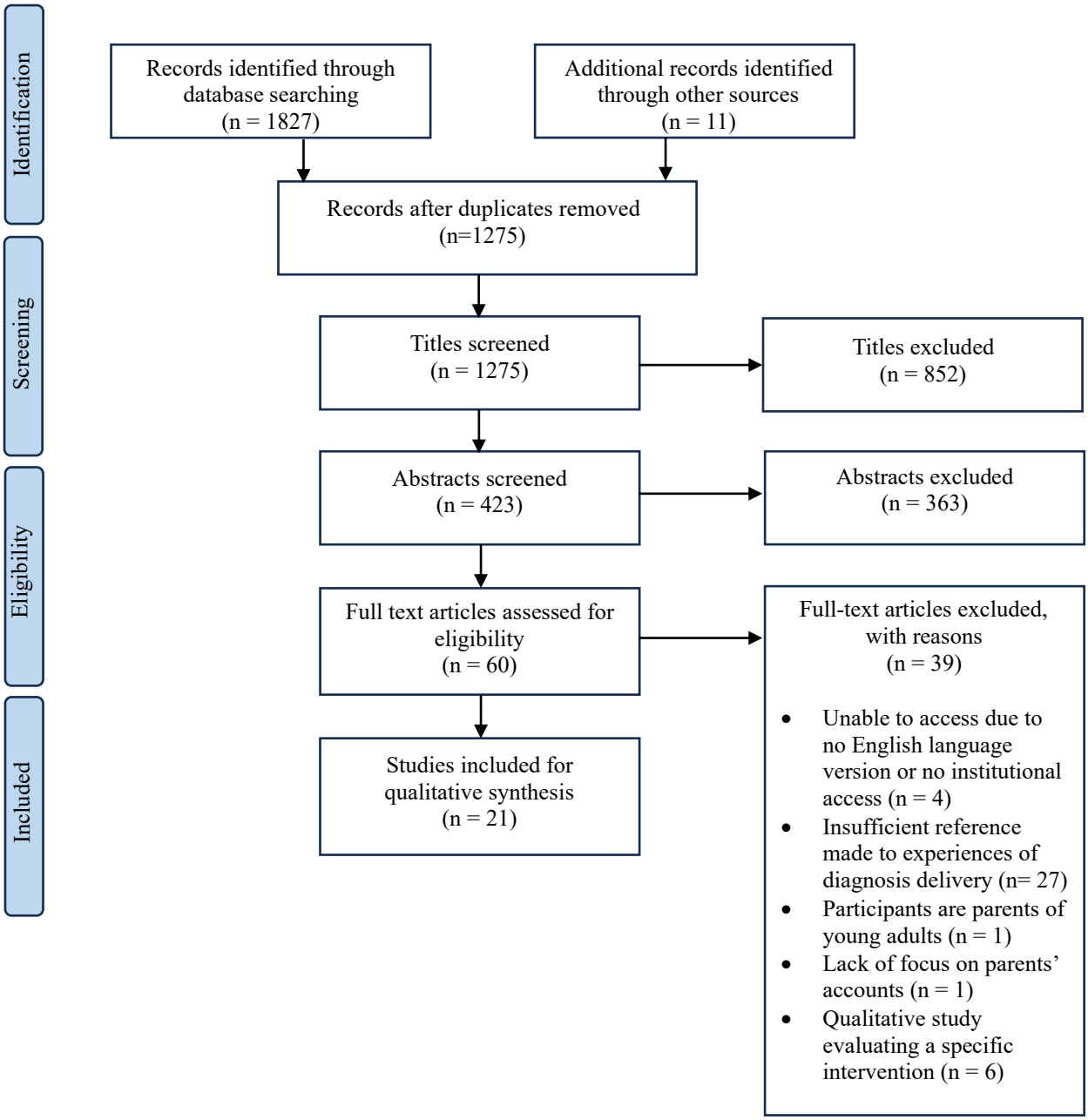
Overview of results

The search retrieved 1827 articles. After deduplication, 1275 titles were read and reviewed against the inclusion/exclusion criteria, yielding 423 titles eligible for further review. Abstracts were then reviewed against the same criteria, and 363 papers at this stage were excluded due to reporting on medical literature or due to lack of reporting on experiences of delivery of T1D diagnosis. The full-texts of the 60 remaining papers were intended to be reviewed. However, four full-texts where not available, due to being unable to access an English language translation, or lack of instintutional access to retrieve the article. Where possible, efforts were made to reach out to the authors via ResearchGate, however the author did not receive any responses. After the available 56 articles were read in full, 35 were excluded. Reasons for exclusion included: insufficient reference made to the experiences of diagnosis delivery, participants being parents to young adults rather than children and young people, a lack of focus on parents' own accounts of the experience, or the article representing findings from a qualitative evaluation study of a specific intervention. The final review

included 21 articles, including one that was identified from hand-searching the reference lists of eligible articles. In the case of articles by two authors, the same data were found to be represented in two separate studies (Lowes et al., 2004 & 2005; and Rankin et al., 2014 & 2016). For the purposes of simplicity, the findings from each set of studies were combined and will be represented as one study, respectively (Lowes et al., 2005 & Rankin et al., 2016). One study (Haugvik et al., 2017) included parents of children up to the age of 23. The research team deliberated, and it was agreed the study should be included due to the relevance of content and inclusion of parents of children ranging from 3-18 as well as over-18s. All papers in the final review used a qualitative methodology.

Figure 1

Flow diagram depicting an overview of the selection process for eligible studies



Description of reviewed studies

Twenty-one articles (representing 19 studies), reporting on the experiences of approximately 375 parents of children diagnosed with T1D, were included in the review. Seven of these studies further reported on experiences of families (including young people

diagnosed with T1D and siblings) alongside parents, with one study also consulting General Practioners (GPs) on their perspectives. Eleven studies directly explored parents' perspectives on experiencing their child being diagnosed with T1D, whereas all other studies featured the diagnosis of T1D within broader conversations about living with T1D. Within those 11 studies, two studies specifically focused on experiences of education about T1D during diagnosis, whilst two studies specifically explored parents' experiences of the pathway to their child receiving the diagnosis.

The studies included parents from ten countries, including those in North America (n = 4), South America (n = 1), Central Asia (n = 1), the Middle East (n = 4), Europe (n = 6) and east Africa (n = 1). Whilst experiences of mothers predominated, studies included the experiences of at least 93 fathers and one uncle (two studies did not report on the relationship of parent to child). Ages of children diagnosed with T1D at the time of the study ranged from 2 – 23 years, and time elapsed since diagnosis ranged from 10 days to 12 years. Two studies did not report time elapsed since diagnosis. All included studies reported qualitative findings. Across studies, chosen methodologies included individual interviews (n = 19), focus groups (n = 2) and written accounts (n = 1), analysed using an array of frameworks. Key characteristics and details of the included studies can be found in Table 1.

Table 1

Key characteristics of articles included in the review

First Author	Code	Year	Study Aims	Data collection & analysis	N	Country	Relationship of participant to child	Age of child at time of study	Time since diagnosis	Exclusion criteria
Abolhassani	Ab	2013	To explore Iranian mothers' experience of children with diabetes	Semi-structured interviews; content analysis	11	Iran	All mothers	4-16 years	< 1 year	Over 1 year since diagnosis; no major role in care of child
Assad	As	2022	To explore the experiences of Saudi mothers whose children have T1D & deepen understanding of coping strategies/needs at diagnosis	Semi-structured interviews; descriptive phenomenological analysis	11	Saudi Arabia	All mothers	5-18 years	6 months - 2 years	Under 6 months since diagnosis; other coexisting long-term conditions
Chan Sun	Ch	2021	(1) to explore the lived experience of mothers having a child with T1DM in Mauritius; and (2) to grasp the psychosocial aspect of parenting a child with T1D	Semi-structured interviews; phenomenological analysis	11	Mauritius	All mothers	3 – 11 years	2 - 4 years	Aged under 18; non-Mauritian background; a cognitive impairment or disability that would impact ability to participate
da Silva	da	2017	To understand the perception of parents of children and adolescents in relation to the diagnosis of T1D	Semi-structured interviews; content analysis	11	Brazil	9 mothers; 2 fathers	5 - 17 years	1 - 11 years	Aged under 18
Haugvik	Ha	2017	To explore and describe perceptions and experiences of living with T1D among children/youths in Tajikistan	Semi-structured interviews; systematic text condensation	19	Tajikistan	15 mothers; 4 fathers	3 – 23 years	2 - 12 years	Non-Tajik background
Khandan	Kh	2018	To explore mothers' experiences in the pathway to diagnosis of T1D in their children	Semi-structured interview; content analysis	15	Iran	All mothers	7 – 14 years	1 - 7 years	Under 1 year since diagnosis
Kingod	Kin	2020	To thoroughly describe the phenomenon of the challenges and obstacles faced by parents of young children with T1D	Focus group, online study of Facebook group, semi-structured interviews; phenomenological analysis	Exact number not available; at least 9 focus group participants and 3 interview participants	Denmark	Exact breakdown not available; 3 interview participants mothers	3 - 6 years	Not available	Not available
Klee	Kle	2020	To explore east African families' perceptions of the T1D training they received and their ability to transfer the learning to the home	Semi-structured interviews; thematic analysis	7	USA	5 mothers, 1 father, 1 uncle	3 - 16 years	≥ 2 years	No role in managing child's T1D, child aged above 16; non-native to East African country; over 2 years since diagnosis
Lowes	Lo	2004 / 2005	To explore parents' experience of having a child diagnosed with T1D, managed at home, and their first year following diagnosis	Semi-structured interviews; thematic analysis	38	Wales, UK	Not available	2 – 15 years	10 days - 12 months	Parents of children clinically unwell at diagnosis who required further hospitalisation
Perez	Pe	2019	To understand: 1) What types of uncertainty do parents of a child with T1D report experiencing; & 2) How do parents manage this uncertainty?	Semi-structured interviews; thematic analysis	29	USA	26 mothers, 3 fathers	2-17 years	1 month - 10 years	Not available
Rankin	Ra	2014 / 2016	To explore from parents' perspectives the circumstances and events which led to their child being diagnosed with T1D	Semi-structured interviews; thematic analysis	54	Scotland, UK	38 mothers; 16 fathers	2 – 12 years	1 - 11 years	Under 6 months since diagnosis
Rossiter	Ros	2019	To elicit in-depth understanding of UAE mothers' perspectives and	Semi-structured interviews; Yin's	4	UAE	All mothers	3 - 8 years	≤ 1 year	Over 1 year since diagnosis; mothers not of Arabic descent or Muslim faith

			experiences of having a child diagnosed with T1D	(2010) 5 phases of analysis						
Sand	San	2018	To explore the process of family dynamics when a child has been diagnosed with T1D	Focus groups, individual interviews (5); grounded theory	29	Sweden	17 mothers; 12 fathers	3 - 17 years	8 - 29 months	Non-fluent in Swedish
Smaldone	Sm	2011	To identify parents' perceptions of psychosocial adaptations in parenting young children with T1D from diagnosis through childhood	Semi-structured interviews; content analysis	14	USA	7 mothers; 7 fathers	7.6 - 14.6 years	4.3 - 11.7 years	Parents of children above age 5 at diagnosis
Spencer	Spe	2013	To qualitatively explore the lived experiences of adolescents with T1D and their parents	Semi-structured interviews; interpretive phenomenological analysis	27	England, UK	20 mothers; 7 fathers	13 - 16 years	Unavailable	Parents of adolescence receiving treatment for psychiatric or additional chronic conditions
Sullivan-Bolyai	Sul	2006	To describe fathers' experiences in parenting and managing the care of their young children with T1D	Semi-structured interviews; fundamental qualitative description	14	USA	All fathers	2 - 8 years	2 weeks - 3 years	Not available
Thoft	Th	2022	To explore children's and parents' experiences of the child being diagnosed with T1D and receiving diabetes education during hospitalisation	Semi-structured interviews; thematic analysis	20	Denmark	14 mothers; 6 fathers	6 - 13 years	5 - 9 months	Children outside of 6-13 age range; non-fluent in Danish; sibling with T1D, social or health-related issues that could compromise study participation
Usher-Smith	Ush	2013	To explore the pathway to diagnosis of T1D in children from the perspective of the child, family, and general practitioner (GP)	Semi-structured interviews; thematic analysis	26	England, UK	16 mothers; 10 fathers	2 - 14 years	$\leq$ 3 months	If clinical team advised that participation could adversely affect child's care; non-fluent in English
Wennick	We	2006	To elucidate the whole family's lived experience when a child in the family is diagnosed as having T1D	Semi-structured interviews; hermeneutic phenomenological analysis	23	Sweden	12 mothers; 11 fathers	7 - 14 years	1 - 3 months	Parents of children under age 7

Note. Table showing key information extracted from each of the included studies. USA: United States of America. UK: United Kingdom of Great Britain. UAE: United Arab Emirates.

Quality Assessment

Quality ratings ranged from 1.1 to 1.9 out of 2, representing moderate-high quality across studies. An overview of the quality assessment can be found in Table 2. The eligible studies represented a range of countries and experiences, however there were some gaps in reporting of useful information. One study did not provide adequate information on the number of total participants (Kingod & Grabowski, 2020), two studies did not provide a breakdown of the participants' relationship to the child with T1D (Kingod & Grabowski, 2020; Lowes et al., 2005), and three did not provide information on study exclusion criteria (Kingod & Grabowski, 2020; Perez et al., 2019; Sullivan-Bolyai et al., 2006).

Reflexivity about the role of subjectivity in the research process is considered an important aspect of qualitative research. Reflexivity is considered both a concept and a process in qualitative research (Dowling, 2006), and involves making "the relationship between and the influence of the researcher and the participants explicit" (Jootun et al., 2009, p.45). This includes reflection and transparency about the researcher's actions, feelings, and perceptions, imperative given the researcher acts as the main instrument of data collection (Florczak, 2021). Despite its importance, only five studies explicitly stated or acknowledged their positioning and how this might impact their research, with nine studies not providing any reflexive commentary. Exploring inter-subjective meanings through researcher triangulation is also commonly used to improve the completeness and rigour of qualitative research (Palaganas et al., 2017). All but five studies reported that the analyses was conducted by more than one researcher, either in part or in full.

There is debate within the qualitative research field about how and whether to use quality appraisals in the next stages of data synthesis (Long et al., 2020; Malterud, 2018; Caroll &

Booth, 2015). For example, some authors choose to omit studies with low quality appraisal ratings, or to weight the analysis based on quality appraisal ratings. Whilst the studies contained in the present review include a variety of strengths and limitations according to the CASP criteria, for several reasons it was decided to include all studies in the analysis, weighted equally. Firstly, all the included studies achieved a moderate to high quality rating, ranging from 1.1 – 1.9, suggesting they each provide sufficiently rigorous and valuable findings for synthsis. Secondly, the included studies represent participants from a wide range of countries of origin. The research team believed that, given concerns about the lack of diverse ethnic and georgraphical representation in diabetes research (Chan et al., 2022) and inequitable diabetes outcomes to do with geography and race (Agarwal et al., 2023), it was important to give equal weight to the included studies and the voices of participants within.

Table 2

Quality assessment of eligible studies

	Ab	As	Ch	da	Ha	Kh	Kin	Kle	Lo	Pe	Ra	Ros	San	Sm	Spe	Sul	Th	Ush	We
Aim	2	2	2	2	2	1	1	2	2	2	2	2	2	2	2	2	2	2	2
Qualitative methodology	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Design	1	2	1	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
Recruitment	2	1	1	1	1	1	1	1	2	1	1	1	2	1	2	2	1	1	2
Data collection	2	2	2	1	2	1	1	1	1	1	2	1	2	2	1	2	1	2	1
Relationship	1	2	2	0	1	0	0	0	2	0	0	1	0	0	2	2	1	0	1
Ethical issues	2	2	1	1	2	1	2	1	1	1	1	2	2	1	2	1	2	1	2
Analysis	2	2	2	1	1	2	1	2	2	2	2	2	2	2	2	2	2	2	2
Findings	1	1	2	1	1	1	1	1	2	1	1	1	1	1	2	2	2	1	2
Value/Implications	1	2	1	1	2	1	1	1	2	2	2	2	1	2	2	1	2	2	1
Total	**1.6**	**1.8**	**1.6**	**1.1**	**1.6**	**1.1**	**1.2**	**1.2**	**1.8**	**1.3**	**1.5**	**1.5**	**1.6**	**1.4**	**1.9**	**1.7**	**1.7**	**1.4**	**1.6**

Note. Table showing quality assessment of included studies using the CASP-QC.
Key: 0 = no features present/unknown; 1 = some features present; 2 = most features present, n/a = not applicable

Thematic synthesis

A thematic synthesis of the eligible studies gives five overarching analytical themes, each with a subset of descriptive themes. A summary can be found in Table 3 which includes analytical themes, descriptive themes, and patterns occurrence. A diamond symbol signifies the supporting quotes which have been chosen from primary studies to elucidate the themes. They are presented in italics throughout the synthesis. Superfluous material within quotation marks has been replaced with an ellipsis.

Table 3

Overarching themes and patterns of occurrence

Overarching Analytical Theme	Descriptive Theme	Ab	As	Ch	da	Ha	Kh	Kin	Kle	Lo*	Pe	Ra*	Ros	San	Sm	Spe	Sul	Th	Ush	We
Realising something was wrong	Noticing the signs						♦			♦		♦							♦	
	Deciding to seek medical care											♦							♦	
	Initial responses of HCPs					♦	♦			♦					♦					
Hearing the diagnosis	Emotional reactions to diagnosis	♦	♦	♦								♦		♦			♦			
	Wanting to find the cause		♦	♦		♦	♦									♦				
An overwhelming initiation to T1D	Experiences of T1D education							♦	♦		♦				♦		♦	♦		
	Distress about insulin injections		♦			♦											♦			
	Developing new fears	♦									♦									♦
	The powerful role of HCPs				♦							♦	♦		♦		♦	♦		♦
Stepping out into a new reality	A state of constant vigilance			♦				♦		♦		♦					♦			♦
	The responses of outsiders				♦						♦	♦	♦	♦	♦	♦				
	The impact of HCP support					♦		♦				♦	♦			♦	♦	♦		
The transformational impact of diagnosis	Diagnosis as a watershed moment in the lives of parents				♦					♦	♦		♦							♦
	Developing acceptance	♦	♦				♦			♦			♦		♦		♦			♦

1. Realising something was wrong

Participants in 12 papers reflected on the period leading up to their child's diagnosis and the process of initially seeking medical help. Three descriptive themes are presented under this analytic theme: Noticing the signs, Deciding to seek medical care, and Initial responses of HCPs.

1.1 Noticing the signs. Many participants spoke about the period before the diagnosis and noticing something was wrong with their child. Parents described symptoms including excessive thirst, frequent urination, tiredness, weight loss and weakness. Many parents initially attributed the symptoms to other causes, such as puberty, "*a phase*" *(Usher-Smith et al., 2013 p.6, England),* hot weather, other infections or illnesses, difficulties at school, and changes to their child's routine. Parents frequently reported lack of familiarity with T1D, or the subtlety of their child's symptoms, as reasons for not suspecting T1D:

> *Most mothers stated that due to lack of familiarity with T1DM and its symptoms, they thought that their children had one of the most common childhood diseases, such as urinary infection and parasitic diseases. "My daughter drank too much water and had enuresis. I thought that she might have a urinary problem". (Khandan et al., 2018, p.638, Iran).*

> *"I think it [diabetes] was just somewhere in my mind but, you know, she wasn't poorly so I kind of thought 'well she seems like a well child that drinks a lot really'. You expect to see a sort of poorly child don't you, or some other sort of symptoms that were more obvious." (Usher-Smith et al., 2013, p.9, England).*

However, participants in seven studies spoke about suspecting that T1D might be the cause of their children's symptoms:

> *Around one third of parents described having known and recognized, or having received prompts from others, that symptoms such as excessive thirst and urination were indicative of T1D and how…they had made rapid appointments with doctors to discuss their concerns. This typically included parents who had T1D themselves, mothers who had had gestational diabetes, those working in health care professions…and those whose family members, friends, or colleagues had the disease: "my friend's husband was recently diagnosed, so I was aware of the symptoms". (Rankin et al., 2016, p.594, Scotland).*

Around one third participants in *Rankin et al.'s (2016)* study reported acting quickly on their concerns about possible T1D. However, participants in other studies expressed their own or a co-parent's feelings of ambivalence and denial about acting on these suspicions:

> *"I thought, 'No. It just won't be diabetes. It's bound to be a urine infection'…I suppose I was trying to convince myself on the way to the hospital. That, no, nothing like that could happen to me or mine. (Lowes et al., 2005, p.258, Wales).*

Participants expressed several explanations for denying their suspicions, including fears of making T1D real by acknowledging it, familiarity with T1D through loved ones or professional careers and not wanting this to be true, and not being able to conceive that T1D could happen to their child. Some participants also made sense of their feelings of denial by reflecting on a lack of family history of T1D.

1.2 Deciding to seek medical care. Many participants spoke about factors that impacted on them seeking medical help for their children. For lots of parents, escalation of their children's' symptoms acted as "*tipping points*" *(Rankin et al., 2016, p.595, Scotland)* that led them to consult a medic:

> *"Then it came to a crux, he was in the bath and he turned round on all fours and was drinking the bath water. He actually had his head in the water, drinking it. He was just so desperate. When I took him out of the bath night, he was quite shut down, peripherally, actually, purple lips, hands, feet." (Rankin et al., 2016, 595, Scotland).*

Several other reasons were cited by participants for deciding to seek medical care, including children presenting with symptoms uncharacteristic of them, other people starting to notice changes in the child, and searching on the internet either raising or confirming concerns about T1D.

Usher-Smith et al.'s (2013) study reported various factors that delayed parents seeking medical support for their children. Factors named by the 26 participants in England included concerns about wasting GP time, fear of T1D diagnosis, and adopting a 'watch and wait' approach to their children's symptoms. *Usher-Smith et al. (2013)* and *Khandan et al. (2018)* both quoted participants' lack of awareness about the seriousness of their children's condition as a cause of delays in seeking medical input. Participants in a few studies spoke about asking for the advice of loved ones and the validating or dismissive power of the responses:

> *"… I said to her we'd noticed that, you know, talking like you do to your Mum, did she think there was anything, and Mum's answer, as always is, "If you're not*

happy, go to the doctor's and get it checked out". If you think there's something wrong, don't waste any time, so we didn't…Not that I, we needed her to say, "You should take her," but, you know, it makes you feel a bit better about going." (Usher-Smith et al., 2013, p.8, England).

1.3 Initial responses of HCPs. Numerous participants recalled experiences with HCPs when they sought out medical advice for their children. In several studies, participants recalled receiving quick confirmation of their child's diagnosis. For some parents, HCP's responses highlighted the urgency of the situation they faced:

"When I told the doctor my child's symptoms, he did a diabetes test and his glucose level is 600. He told us to hospitalize our child immediately." (Khandan et al., 2018, p.638, Iran).

The urgency of HCP responses was perceived differently by participants. Some experienced this as appropriate, timely service and were pleased. For others, the urgency conveyed felt frightening and overwhelming:

Ten (53%) parents viewed it as cause for concern, four of whom likened the experience to 'roller coasting', 'railroading'or 'steam-rollering': "I couldn't believe the urgency … I couldn't understand why the prognosis (sic) was so rushed, and why she had to become an insulin diabetic that night. Why couldn't it wait a week? Why couldn't we see how she went? I felt I was losing control, I suppose. I felt like saying, now wait. Let's all calm down now…but it all seemed to be railroaded on so fast." (Lowes et al., 2005, p.533, Wales).

In several studies, participants felt they had received ineffective responses after initially approaching medical staff. Participants in four studies reported undermining and invalidating reactions by HCPs:

> *Prior to diagnosis, the majority of parents…left office encounters feeling that they had not been taken seriously and/or blamed for their lack of parental experience or parenting behaviors…: "I remember taking her to her pediatrician, because one of the things is she just never slept she would just wake up screaming and crying. So we had taken her to the doctor, we'd just tell him that there's something the matter and I remember him telling us that it was just us. We were just new parents and that the kid was being manipulative and he said "No, it's just you", and he kind of just put the blame back on us." (Smaldone & Ritholtz, 2011, p.89, USA).*

In five studies participants spoke about challenges they faced due to HCPs misattributing symptoms of T1D to other causes, and misdiagnosis:

> *Five of 18 families experienced life threatening complications as a consequence of late diagnosis. One father described the helplessness and despair when their daughter was transferred from one clinic to another, receiving treatment for various diseases including measles, food allergy, intestinal worms, typhoid fever and malaria: "Wherever we had been, the hospital, the diagnostic center and other places, nobody found out what was going on…When we went to this other hospital they said they needed to "wash and clean" her stomach and she got glucose infusion. After that she went into a coma." (Haugvik et al., 2017, p.133, Tajikistan).*

2. Hearing the diagnosis

In all but three studies, participants discussed the impact of hearing their child's diagnosis for the first time. Two descriptive themes are contained within this analytical theme: Emotional reactions to diagnosis, and Wanting to find the cause.

2.1 Emotional reactions to diagnosis. Sixteen studies reported on participants' emotional reactions to receiving their children's' diagnosis. Reactions of shock and disbelief were commonly reported: *"I felt like I'd hit, you know, I'd hit a brick wall, felt like I'd been in a car crash, actually" (Rankin et al., 2016, p.596, Scotland).* For some parents, disbelief was amplified into denial and mistrust of the diagnosis: "*Something in me tells me that your child will be ok. This disease does not remain. She will have a complete cure within 3 to 4 months" (Abolhassani et al., 2013, p.307, Iran).* Indeed, many studies explicitly referred to parents experiencing grief reactions, where shock, disbelief, denial, anger and despair were common:

> *"It is too hard for me. I am asking why my kid? I have never thought that my child have diabetes. I did not think that my 4-year-old kid gets diabetes. I had heard that diabetes can be for adolescence, or had seen it on posters, but I never thought that a 4-year-old child can have diabetes. From last night, my world is dark, and I do not know what to do." (Abolhassani et al., 2013, p.306, Iran).*

Three studies reported that parents experienced guilt at the diagnosis, particularly about not having sought medical intervention earlier*: "was I not a caring enough parent?...I don't think we picked it up early enough, she was very, very, very ill when we took her in. It haunts me" (Rankin et al.,2016, p.596, Scotland)*. Across studies, some parents experienced

ongoing emotional distress when reflecting on their child's diagnosis, and some expressed continuing feels of guilt. The emotional weight of diagnosis was also signified by participants reporting ongoing traumatic memories about hearing the diagnosis and of their children's hospitalisation: *"This experience will haunt me for life. It feels as if it had happened yesterday. I still remember all the emotions I've felt that day…" (Chan Sun et al., 2021, p.106, Mauritius).*

Some studies elucidated the impact of familiarity with T1D on parents' emotional reactions. Some parents with prior knowledge of T1D described feeling as though their child's T1D diagnosis represented a "*threat" (Sand et al., 2017, p.103, Sweden)* and "*the realization of one of their worst fears*" *(Sullivan-Bolyai et al., 2006, p.27, USA).* For other parents, a lack of knowledge of T1D affected their response, including not understanding the implications of the diagnosis straight away and a delayed emotional reaction, as well as fear of the unknown: "*I thought if they gave her insulin and her blood sugar went back down…she would be fine, that was it. I had no idea that this was a lifelong disease" (Asaad et al., 2022, p.5, Saudi Arabia).*

2.2 Wanting to find the cause. Participants in several studies reacted to their child's diagnosis by feeling a deep need to find the causes of their child's condition. Some participants in *Asaad et al., (2022)* and *Haugvik et al., (2017)* attributed T1D to "*evil eye*" (*Asaad et al., 2022, p.5, Saudi Arabia)*. As *Haugvik et al., (2017)* explained:

> *The concept of a malevolent evil eye is a religious/spiritual belief…During the interviews, it was explained that someone could cast the evil eye on another person through an ill wishing look, if he/she felt envious of the attributes or good fortune of the other person. A mother explained: "Some people say, because she is a very smart*

and beautiful girl, diabetes is given by the evil eye…Whatever is beautiful or pretty, people give more attention to…my daughter started speaking when she was three years old; she could speak very well; maybe that is why she got the evil eye…" (Haugvik et al., 2017, p.132, Tajikistan).

Participants in *Haugvik et al., (2017)* and *Spencer et al., (2012)* also attributed the cause of T1D to their children experiencing some kind of emotional stress, particularly becoming afraid. Across several studies, participants reported believing that they were to blame for their children's T1D, for example due to shouting at or in front of their children, *"improper management of the child's food" (Khandan et al., 2018, p.639, Iran),* "*genetics and viruses*" *(Spencer et al., 2012, p.e20, England),* mothers' breastfeeding habits or diet during pregnancy. Many participants articulated a strong sense of guilt and responsibility regarding their child's diagnosis:

Most mothers expressed that they felt responsible for their child's suffering despite being told otherwise. They think that their past actions might have led to their child's condition: "I feel guilty that I may have done something wrong that has resulted in my child's diabetes as I'm the one who feeds him and takes care of him." (Chan Sun et al., 2021, p.106, Mauritius).

3. An overwhelming initiation to T1D

Participants in all but three studies reflected on the period immediately after their child's diagnosis, where they began to develop more of an understanding of T1D and what their child's diagnosis would mean. This analytic theme is conveyed through four descriptive

themes: Experiences of T1D education, Distress about insulin injections, Developing new fears, and The powerful role of HCPs.

3.1 Experiences of T1D Education. Participants in twelve studies discussed their experiences of receiving T1D education soon after their child received a diagnosis of T1D. Several parents reflected positively on this experience, and some described not receiving sufficient information during the education process. However, the majority conveyed this as a challenging time, describing being overloaded by information. One parent described this period as feeling like a "*baptism by fire" (Smaldone & Ritholtz, 2011, p.90, USA),* and several participants in *Kingod and Grabowski's (2020)* study in Denmark referred to being "*bombarded*" with information *(p.1478).* Many participants spoke of feeling overwhelmed and confused:

> *"It was a lot to take in, and now I would say as someone who has a slightly better than the layperson comprehension…from my work environment. So, to me, they weren't completely speaking a different language, but I remember many times thinking, if you had no clue about this, this completely hits you out of nowhere. If you were a completely non-medical person, this would absolutely be overwhelming, because it was such a volume of information in such a short amount of time." (Perez et al., 2018, p.951, USA).*

Many parents also specifically discussed the challenges of learning about T1D management whilst still coming to terms with their child's diagnosis. Some parents felt that their intense emotional reactions at diagnosis meant it was hard to take on the education so soon afterwards:

"I did not feel like I was there at the time; I was confused. My sister and husband listened a lot. They told me a lot. It was too much for me. I was scared. I have to get used to it (the diabetes diagnosis), then I will be able to understand." (Klee et al., 2020, p.148, USA study focusing on experiences of East African migrant families).

"I think there was so much information that in the beginning, I didn't feel that I had space, head space, to even want to go look for more information. There was just so much there that I was trying to process." (Perez et al., 2018, p. 954, USA).

Participants in several studies described how, despite feeling overwhelmed by T1D education, they recognised a need to "*suck it up and…step up to the plate*" *(Sullivan-Bolyai et al., 2006, p.28, USA)*; to learn about T1D to support their children and be able to keep them safe:

"You are in a kind of bubble of both sorrow of what has happened but also, we just need to learn so much before we can go home…" Dad agreed. This illustrates that the parents needed to manage emotionally and learn about T1D simultaneously." (Thoft et al., 2022, p.26, Denmark).

Other perspectives on T1D education were also provided by a few participants. Participants in *Rossiter et al.'s (2018)* study based in the UAE expressed considerable gratitude for the T1D education received, and some in *Wennick and Hallström's (2006) Sweden-based* study felt they were given a helpful amount of responsibility which empowered them and supported their learning. *Klee et al.'s (2020)* study participants

highlighted the challenges of trying to apply T1D education about food to different cultural eating practices:

"They do not understand how we eat…they would not be able to understand because they are doctors, so they understood what they are teaching us but not how we live" (Klee et al., 2020, p.149, USA study focusing on experiences of East African migrant families).

Participants in *Klee et al.'s (2020)* study also commented on the benefits of challenges of using interpreters during T1D education. This included the value of having a nurse who could speak participants' native language to improve the quality of T1D education, and the challenges when interpreters do not understand the matters being communicated. Participants in *Perez et al.'s (2018)* study based in the USA stated that not enough attention was given to discussing the financial implications of T1D and how to plan for a lifetime of medication during their T1D education.

3.2 Distress about insulin injections. Participants in 11 studies described their distress about coming to terms with needing to give their children insulin injections following the diagnosis. For many participants, this was described as the most difficult aspect of the diagnosis experience: "*Honestly, training on giving the injections, it was heart-breaking, devastating. It was the most difficult thing" (Asaad et al., 2022, p.6, Saudi Arabia).*

Some parents described learning about insulin injections being the moment their child's diagnosis sunk in. Others described their distress at having to inflict pain on their child, their fears about getting something wrong: "*You make a mistake and you can kill your child!" (Sullivan-Bolyai et al., 2006, p.27, USA),* and having to overcome their own needle

phobia to give the injections. Participants in *Kingod and Grabowski (2020), Rankin et al. (2016),* and *Smaldone and Ritholtz (2011)* described dreading the injections, with some fearing they would not be able to give them or trying to resist them. In *Haugvik et al. (2017),* this resistance was particularly emphasised, with some parents not giving their children injections following their diagnosis:

> *Most families knew insulin was essential nevertheless, both parents and children/youths reported injections were skipped regularly…Many parents used the Tajik expression "dilam mesuzad", meaning "my heart burns", when explaining why they did not want to force their child to take insulin: "My daughter cried when I gave her injections. She cried "Don't do that! Don't do that!" Because my heart burned, I could not do the insulin injections" (M-01)… "For almost one month he did not get insulin injections, because we just didn't want to hurt him anymore, but then he got very, very sick. Then, we started to do injections again"(M-18). (Haugvik et al., 2017, p.133, Tajikistan).*

3.3. Developing new fears. The majority of participants discussed how, as they became more familiar with what their child's diagnosis meant, they developed a great deal of new fear. Many participants were fearful about how T1D might impact their child's future, including their schooling, independence, ability to have children, and marriage prospects. Numerous parents spoke of developing fears about the long-term implications of T1D on their child's health, including fears of medical complications and reduced life expectancy:

> *Parents were worried about disease-related complications and death caused by the illness, knowledge that weighed heavily on their shoulders and filled them with*

sorrow and despair, even though they hardly ever verbalized their thoughts to anyone else. (Wennick & Hallström, 2006, p.377, Sweden).

Participants across studies also articulated new fears about what their child's diagnosis would mean for themselves as parents. Eight studies outlined parents' reported fears about being responsible for managing their child's T1D. These fears related to the possibility of doing something wrong and inadvertently harming the child, to feeling oddly unfamiliar with their child following the diagnosis, and feeling underconfident that they would be able to cope at home:

"…I do not want her blood sugar to increase or decrease…she experience a coma, it is very hard, I scared. I fear when I take home her blood sugar will increase or decrease. I do not know what I should do. When I am here, I am sure that I can rely on hospital. However, I do not know what will happen when I get home." (Abolhassani et al.,2013, p.307, Iran).

Furthermore, participants in three studies articulated fears about the permanency of T1D and what this would mean for themselves. This included fears about the impact on their careers, and about the possibility that they might have to play an ongoing role in their children's' T1D management into their adulthoods:

"My first thought was, "What's going to happen?" Knowing that my husband and I both work full-time jobs and that neither of us were in a position to be able to quit our jobs and become a fulltime pancreas…Then, how am I not going to kill this kid? I think that was probably my biggest issue. We don't have medical

backgrounds…How can I possibly do what they're telling me to do at the hospital and know that I'm going to have to probably do this forever?" (Perez et al., 2019, p.951, USA)

3.4. The powerful role of HCPs. Participants' accounts alluded to the power held by HCPs in influencing their experiences of their children's' diagnosis and period of initial hospitalisation. Several parents discussed ways that HCPs' actions increased their sense of overwhelm during the early stages of their children's' diagnosis. This included HCPs demonstrating a lack of empathy and emotional support:

"The nurses themselves said: "You have to adapt and it's going to be like this forever!" The doctor also terrified me a lot, she said that I had to prepare for the worst, that destroyed me, I thought: 'Ok, he is dying!'" (da Silva et al., 2017, p.1121, Brazil).

"Then the doctor came in and he said "okay". He's a very abrupt man. He came and he pinched (child's) skin and it stood up. He said, "Yes, he's very dehydrated." Then I just said, "What is wrong with him?"...So he came back in and he said, "There's sugar in his urine. You're going to need to go (to the hospital) now. He's diabetic" and then he walked out of the room. He just left me there with this baby, and I just started to cry." (Smaldone & Ritholtz, 2011, p.89, USA).

Some participants felt there was an over-focus on practical aspects of T1D education without attending to parents' more basic needs, including a brief explanation of T1D and the medical interventions being done to their children, reassurance that they and their children would be okay, and acknowledgement of parents' emotional turmoil:

"…it was so much practical information, you know, "this is how you keep him alive, this is about carbohydrate". It was like, but actually I wanted to know, is he going to die?...I really know that it is serious but I think, for a parent, it would have been good to have a little bit of the comforting, like "you're going to be okay". (Rankin et al., 2016, p.584, Scotland).

Others commented on the need for HCPs to incorporate a broader sense of how T1D would affect the lives of families: "*you want to see how this is really going to impact your life" (Rankin et al., 2016, p.585, Scotland)*; and for them to avoid inconsistencies: "*One nurse would come in and say do it this way, another would come in and show us a different way" (Sullivan-Bolyai et al., 2006, p.28, USA).*

Several participants highlighted positive qualities of their HCPs, demonstrating their power to reduce feelings of overwhelm and provide *"a safety net" (Thoft et al., 2022, p.27, Denmark)* or *"bubble" (Wennick & Hallström, 2006, p.378, Sweden)* during these early stages following diagnosis. Participants emphasised the value of HCPs who were comforting and gentle, who provided messages of reassurance and hope, and who were consistent and available:

"I got full support from the ER, the pediatric physician comforted me a lot and made me feel that I'm strong and brave enough to face the new situation." (Rossiter et al., 2018, p.5, UAE).

Some participants in *Thoft et al.'s (2022)* study emphasised the value of personalised, flexible care and use of child-friendly educational resources. Some also described how reassurance from HCPs had the power to reduce feelings of guilt and fear at diagnosis:

> *Being told that you have not done anything wrong was important to both children and parents, as it relieved their worries. This is an example of how healthcare professionals supported and comforted the families based on their individual needs. (Thoft et al., 2022, p.27, Denmark)*

4. Stepping out into a new reality

Participants in all but three studies discussed the days following their child's diagnosis, where they began to adopt T1D management themselves and faced the new reality of parenting a child with T1D. This analytical theme is outlined through three descriptive themes: A state of constant vigilance, The responses of outsiders, and The impact of HCP support.

4.1 A state of constant vigilance. Most participants described their state of mind in the early days after their child's diagnosis as being all-consumed by T1D: *"even if you are not thinking about it [the illness], you are" (Sullivan-Bolyai et al., 2006, p.28, USA).* Participants in *Lowes et al.'s (2005)* study based in Wales likened this state to being in *"auto pilot" (p.256),* and, for some, a state of *"pure fear" (p.257).* Participants described a constant daily battle to maintain control and keep blood glucose within range due to concerns about the short-term and long-term consequences of high and low levels:

One parent described it as walking along a very narrow road with a wide ditch for high and low blood glucose levels on each side of the road, yet lacking experience of how to remain on the road. The families fought a hard battle in their effort to maintain even blood glucose levels, and parents often expressed a feeling of being a total failure if the levels were high or low. (Wennick & Hallström, 2006, p.381, Sweden).

Participants felt a responsibility to monitor their children closely to keep them safe, including being constantly alert when their children were playing, exercising, attending school, and particularly during the night. This was largely due to significant fears about their child experiencing severe hypoglycaemia: *"parent's worst nightmare" (Kingod & Grabowski, 2020, p.1479, Denmark),* which could threaten their child's life:

"I have become an insomniac. I don't sleep at night as every 2-3 hours I have to check on him…I sleep only 2-3 hours. It's my son's diabetes that has made me like that." (Chan Sun et al., 2021, p.106, Mauritius).

"I would test her, I would go through the motions at night, really, to be there…and sometimes I would go through in the morning, try and wake her and if she was in quite a deep sleep, 'cause she can be in a deep sleep, I was, my, your heart pounded, you know, and your stomach…" (Rankin et al., 2016, p.585, Scotland).

4.2 The responses of outsiders. Participants across studies described how the reception of their child's diagnosis by members of their communities had a significant impact on their adjustment to their new reality. Participants in eight studies spoke about experiencing

social stigma following the diagnosis. Some parents felt judged due to others' lack of understanding of T1D, for example, people believing that parents had caused the T1D through their parenting practices, or criticising parents for allowing their children to eat chocolate after the diagnosis: "*The general public is uneducated [about T1D]" (Perez et al., 2018, p.952, USA)*. Many participants spoke about their children facing rejection and alienation from peers following the diagnosis. This was often due to misinformation, such as fear that T1D is contagious, and was sometimes exacerbated by othering behaviour of school staff:

> *"After the onset of T1DM, the preschool teacher thought it would be better for him to eat a piece of fruit in the mornings. But the other children didn't. He had it around 10 a.m. and then he just sat there. All the other children hung around watching him when he ate the fruit. That was difficult." (Sand et al., 2017, p.108, Sweden).*

For some families this had a significantly detrimental impact, including children stopping school due to discrimination or struggling to navigate peer relationships:

> *"He doesn't see any of his friends out of school, he doesn't do anything over the weekend he doesn't do anything of a night…the summer before he was diagnosed I couldn't keep him in he was out all the time…he's not ready to do that yet." (Spencer et al., 2012, p. e20, England).*

Participants often found this upsetting and sometimes struggled to help their children navigate this harsh new reality. Some parents felt isolated themselves as they attempted to

support their children with their feelings of isolation, educate others about T1D and advocate for them at school:

> *"What I feel is that we parents make this effort, he also makes an effort, to be a normal child, the whole family does, but the community itself does not make an effort to receive it as a normal child." (da Silva et al. 2017, p.1121, Brazil).*

However, participants in several studies also spoke about how the support offered by their communities helped to make adjusting to their new reality more manageable. Some described reassuring responses from their childrens' schools and friends and feeling less isolated due to the support of friends and family:

> *"Our relations[hips] with our friends in general were so good, and some of them became closer and friendlier to us." (Rossiter et al., 2018, p.5, UAE).*

> *"My mom had made the decision early on that she wanted to take an active role in caring for her. 'You show me what to do, you go out, you do what you gotta do'. I think even though it was only temporary, a couple hours or overnight. She understood because she was doing it with me." (Smaldone & Ritholtz, 2011, p.90, USA).*

Participants also highlighted the value of connecting with others with experience of T1D to help them adjust to their new reality. Some parents were connected to other families with a child with T1D through third sector organisations (Chan Sun et al., 2021, Mauritius; Perez et al., 2018, USA) as well as through online support groups and social media (Asaad et al., 2022, Saudi Arabia; Smaldone & Ritholtz, 2011, USA; Perez et al., 2018, USA; Rankin et

al., 2016, Scotland) . This benefitted families by reducing uncertainty about their child's future and answering their "*real-world questions" (Perez et al., 2018, p.953, USA).* Parents also felt this support *"lessened feelings of aloneness" (Smaldone & Ritholtz, 2011, p.91, USA)*. A minority of participants described wishing they had had more access to peer support with families with lived experience of T1D at the time of diagnosis to gain practical and emotional support. An even smaller number spoke about avoiding opportunities for peer support: *"the thought of going to talk about it might have even been a bit much" (Rankin et al., 2016, p.588, Scotland);* or of having negative experiences: "*It's all the people that are struggling the most that seem to post in some of those forums." (Perez et al., 2018, p.954, USA).*

4.3 The impact of HCP support. Participants elucidated how the quality of support from HCPs significantly impacted their families as they stepped out into a new reality with T1D. Participants in *Rankin et al.'s (2016)* study based in Scotland described a dearth of emotional support in the weeks following their childrens' diagnosis: *"there was nobody to speak to you about how you were actually feeling" (p.586),* and some felt reluctant to ask due to fear of judgement by HCPs.

Many participants outlined the negative impacts of a lack of adequate practical support following their child's diagnosis. For some, the support offered felt generic and they desired more individualised, hands-on support that dealt with the day-to-day issues facing them, such as how to cook for a child diagnosed with T1D and how to give their child insulin injections whilst minimising distress. Some participants spoke of having access to a 24-hour support hotline but this being insufficient to meet their needs, whilst participants in *Asaad et al.'s (2022)* study based in Saudi Arabia wished this kind of resource would have been

available to them. One participant in *Rossiter et al.'s (2018)* UAE-based study described "*Phoning the clinic and nobody answers" (p.6)*. Participants in *Kingod & Grabowski's (2020)* study described how the minimal training offered to children's' schools left parents acting as a hotline themselves when issues arose with their children's' T1D management:

> *"When you leave the hospital, you must train daycare workers, who are very scared. And when you're scared it's difficult to listen. We were also beginners and therefore our training was not structured, and when we became more routinized, we had to change our explanations." (Kingod & Grabowski, 2020, p.1480, Denmark).*

In *Haugvik et al.'s (2017)* study based in Tajikistan, described as one of the 20 poorest nations in the world and one having a low incidence of T1D, support and supplies for families were notably scarce:

> *Ultimately, the many questions families dwelt on in isolation remained unanswered, adding to the emotional burden. A mother said: "My daughter is often very sad about her situation. Sometimes she says that she would rather die". (Haugvik et al., 2017, p.135, Tajikistan).*

Numerous participants also spoke about positive experiences of support from specialist HCPs during this period. Participants reflected positively on being given reading materials, and those who did receive a more hands-on, practical education, such as *"making concrete meals" (Thoft et al., 2022, p.27, Denmark),* found this valuable. Participants praised specialist HCPs for helping with problem-solving and gradually promoting parents' confidence: "*Gradually the doctor would say, 'What do you think we should do?' to give you*

more control…" (Sullivan-Bolyai et al., 2006, p.28, USA), and providing availability and reassurance:

> *"They'll make time, if they haven't got time then they'll say, well there's a diary, let's sit down and work out when we can see you, but usually they can see me then." (Spencer et al., 2012, p.e20, England).*

5. The transformational impact of diagnosis

This analytic theme encapsulates participants' reflections on how their children's' diagnoses transformed their lives, and their process of adjustment. This analytic theme was addressed in 15 papers. Two descriptive themes are contained within this analytical theme: Diagnosis as a watershed moment in the lives of parents and Developing acceptance.

5.1 Diagnosis of T1D as a watershed moment in the lives of parents. Many participants spoke to the ways that their child's diagnosis of T1D represented a *"watershed" (da Silva et al., 2017, p.1120)* moment in their lives:

> *…the father…would remember the healthy moments and would compare them with the triggering of the illness that brought the suffering of his daughter: "He (father) divided by photos, because he sees photos and says: "Ah!! Here she was not sick yet, and in that one, she was already sick"" (da Silva et al., 2017, p.1120, Brazil).*

"So things have changed slightly and, as they change after someone's died, there's a change in routine, a change in the way you do things…it's made me think of the life that used to be and the life that is now." (Lowes et al., 2005, p.533, Wales).

Participants described how their child's diagnosis led to *"radical change" (da Silva et al., 2017, p.1121, Brazil),* including adapting family routines and changing the eating habits of the *"entire house" (Rossiter et al., 2018, p.6, UAE*). Their lives now required excessive planning; the need to *"live life by the clock" (Wennick & Hallström, 2006, p.379, Sweden)* and a loss of spontaneity. Participants also described how their child's diagnosis impacted on their own professional, domestic, social, and emotional lives:

"My profession and my husband's changed a lot. I quit work, I closed the shop, today I do not work anymore, I spend more time at home because it's something that cannot be left to someone else, a paid worker, to apply the insulin, to decide what the kid is going to eat, that's for the father and the mother to do, thus, the family matter changed completely." (da Silva et al., 2017, p.1123, Brazil).

Participants in three studies also expressed how their child's diagnosis of T1D had a transformational impact on the family's finances:

"I think that honestly some of the most stressful stuff in the last year has just been trying to deal with insurance, pharmacies, and the financial side of it. A lot of time on the phone trying to figure out what things were covered…and just feeling so overwhelmed with that…and in the beginning, too, making sure you have enough supplies. Like we only got 200 test strips or something for the first month, and, you

know, of course we didn't have a CGM [Continuous Glucose Monitor] or anything, and you're just testing all the time because you have a kid who doesn't really know what a high or low [blood glucose] feels like, and you're freaked out all the time." (Perez et al., 2018, p.952, USA).

5.2 Developing acceptance. Many parents experienced emotional turmoil in the period following their child's diagnosis of T1D, with some fearing they would never recover from the ordeal:

"In the first month, I did not allow anyone into my house. I had concerned, I became gloomy and I did not want to go anywhere." (Khandan et al., 2018, p.639, Iran).

They felt as if things would never be alright again and that they would not get over the fact that their child had been diagnosed as having diabetes. (Wennick & Hallström, 2006, p.377, Sweden).

However, many parents articulated the ways they began to gain acceptance and learn to cope with the transformational impact of their child's diagnosis. Some participants spoke to co-parenting with another parent, and how supporting each other and working as team helped them to cope:

"I was completely overwhelmed, but my husband, we were a team, so that was huge. We did everything together. We did the checking her together and we were figuring it out together so that really helped a lot because we didn't feel like we were completely alone." (Smaldone & Ritholtz, 2011, p.90, USA).

A few participants coped by attempting to *"put things into perspective" (Lowes et al., 2005, p.258, Wales)* by trying to find positives in their situation:

> *"I look at him running around now, and I think, well, OK, it's an injection, it's blood sugars, it's making sure he's eating a healthy diet…so really, what sacrifice is that? He's healthy now, and it's very little really, if you think about it in those terms…We could dwell on all the negatives, and let's ruin our lives. Or we could look at the positives, and let's get on with it, and let's look forward to a life that's different to how it used to be." (Lowes et al., 2005, p.258, Wales).*

Participants in six studies spoke about the role of faith and spirituality in coping with and developing acceptance of their child's diagnosis. Some participants described their closeness to a higher power giving them emotional strength, and the courage to take on T1D management. Several articulated how their faith provided comfort that their child would be safe. Participants in some studies suggested that faith had helped them accept their child's diagnosis, viewing it as part of their destiny or a *"divine test" (Abolhassani et al., 2013, p.307, Iran):*

> *"I did not want to see my child in this condition, I gradually got used to it. What can I do, these are all a divine exam." (Khandan et al., 2018, p.640, Iran).*

> *"I have a strong faith in Allah, and we as Muslims should surrender to Allah's destiny." (Rossiter et al., 2018, p.5, UAE).*

A small number of participants described continuing to struggle with accepting their child's diagnosis: "*Still, I cannot accept this because when I see my son suffering, I suffer more than him" (Khandan et al., 201, p.640, Iran)*, whilst a few reported that familiarity with the condition facilitated quicker acceptance. Several participants named continuing to hope that someday there would be a cure for T1D, which helped them to carry on:

> *"…whenever I have a downside…my first thought is they wouldn't be talking of cures unless there was some possibility…in the future…you think, well, he's only 12." (Lowes et al., 2005, p.258, Wales).*

However, for many participants, the *"transformational potential"* of time *(Asaad et al., 2022, p.7, Saudi Arabia)* was a key element in a journey towards acceptance. Participants articulated how *"gradually over time" (Rossiter et al., 2018, p.6, UAE),* gaining knowledge and familiarity with T1D and its management helped build their confidence and improve their emotional state: "*…like anything, the more you do it [diabetes care], the better you are at it" (Sullivan-Bolyai et al., 2006, p.28, USA).* In time, their children's' T1D became a part of normal life:

> *The strength of participants' experiences and their gradual recovery was eloquently summarized by one mother: "And there was never a case of a child diagnosed with T1DM where the parents were normal. They were all devastated, were emotionally destroyed and they all adapted and adjusted and became normal. Life doesn't come to an end." (Asaad et al., 2022, p.7, Saudi Arabia).*

Discussion

The current systematic literature review of 21 articles primarily aimed to synthesise parents' accounts of the experiences of their child's diagnosis of T1D. A secondary aim was to inform healthcare practices of the ways that delivery of diagnosis may help or harm families (Wylie et al., 2019). The synthesis resulted in five overarching analytical themes, including 'Realising something was wrong', 'Hearing the diagnosis', 'An overwhelming initiation to T1D', 'Stepping out into a new reality', and 'The transofmational impact of diagnosis'.

Overview of findings

Across studies, many parents spoke about their process of realising their child was not well. For some, a lack of familiarity with T1D led them to delay seeking medical attention. Even with parents who suspected T1D, many delayed seeking medical care due to not understanding T1D's seriousness or fear of facing this reality. These insights may contribute to our understanding of the continually high rates of DKA at diagnosis across countries (Schober et al., 2010; Jefferies et al., 2015; Rewers et al., 2015; Usher-Smith et al., 2012), despite awareness-raising efforts (Deylami et al., 2018). Some parents received swift medical intervention when presenting their child to HCPs. Perspectives on this differed, with some finding the urgent responsiveness timely and supportive, whilst for others, the sense of urgency brought gravity to their situation. Some parents feared for their child, reporting confusion and a felt loss of control. This is consistent with broader literature on parents' experiences of their children's' admissions to hospital (Board & Ryan-Wenger, 2003; Simeone et al., 2018). Importantly, parents across studies also reported receiving inadequate responses to their child's condition at their first medical contact, including invalidating and dismissive responses, and misdiagnosis, consistent with other accounts (Usher-Smith et al.,

2012; Mavinkurve et al., 2021). For many families, this resulted in life-threatening complications (Haugvik et al., 2017) and unnecessary additional trauma at diagnosis.

Parents across studies outlined the intense emotional impact of hearing their child's diagnosis. Commonly reported reactions included shock and disbelief, denial and mistrust, and grief. This is consistent with broader literature exploring the emotional impact on parents of a child's diagnosis of a chronic health condition (Coffey, 2006; Kepreotes et al., 2010). Importantly, parents across studies reported strong feelings of guilt and blame for not seeking earlier medical support. Many parents also described ongoing traumatic memories even years after the experience of diagnosis, adding to existing knowledge of the traumatic responses often experienced by parents following their child's T1D diagnosis (Whittemore et al., 2012; Rechenberg et al., 2017; Schiaffini et al., 2019). Another prevalent reaction of parents across studies was of needing to understand the causes of T1D. This is understandable given the causes of T1D are complex and not fully understood (Rewers et al., 2018). This reaction can also be understood through considering literature on trauma and loss, which suggests that such experiences involve "the shattering of assumptive worlds" (Janoff-Bulman, 1992) and that individuals often subsequently engage in a process of sense-making, developing explanations for a seemingly incomprehensible event within existing 'assumptive schemas' or world views (Janoff-Bulman, 1992). In the current synthesis, attributions of cause to an 'evil eye' were common in some cultural contexts, and across studies parents frequently reported locating blame in themselves for their child's diagnosis. The latter finding is consistent with those of other studies exploring parents' reactions to a child's diagnosis of a chronic health condition (Diaz-Caneja et al, 2005; Kirk et al., 2015).

Parents gave several perspectives on their experiences of T1D education, with some finding it a positive experience overall and feeling grateful, in line with evidence of the benefits of such psychoeducational interventions (Couch et al., 2008; Peyrot & Rubin, 2007). Many described feeling overwhelmed by so much novel information, especially whilst still processing their child's diagnosis, and feeling pressure in knowing that learning was necessary so they would be able to keep their child safe. Lots of parents spoke in detail about the distress of learning about insulin injections, including some parents who struggled so much they avoided injections altogether, leading to their children becoming critically ill (Haugvik et al., 2017). Parents highlighted the importance of considering the individual needs of families, in line with existing recommendations (Phelan et al., 2018). This included the need in some contexts for education about the financial implications of T1D, and the need to provide culturally sensitive or adapted education depending on cultural eating practices, and acknowledgement that it may take some families more time and effort to adopt guidance. Parents are required to learn a lot soon after their child's diagnosis of T1D. Many parents articulated how learning more about T1D brought about novel fears about their children's' long-term health and wellbeing, and the significant implications of T1D for the lives of the whole family. Findings from the broader literature on parents of children with chronic health conditions identify that parents often begin to worry about the future during their child's first hospitalisation (Kepreotes et al., 2010). Furthermore, parents provided insights about the powerful impact of both helpful and harmful interactions with HCPs during the diagnosis. Factors which parents perceived as helpful during interactions with HCPs at diagnosis included empathy, messages of hope, reassurance, consistency and availability, and efforts to reduce feelings of guilt and blame. Inversely, factors that parents identified as contributing to their sense of overwhelm during early stages after the diagnosis included unempathetic communication by HCPs, lack of explanation given about T1D and medical interventions,

lack of acknowledgement of the emotional impact of the diagnosis, and lack of reassurance about the future and their child's safety. These findings are supported by other studies which higlight the importance that parents attribtute to HCPs' empathy and clarity when seeking medical input for their children (Gemmiti et al., 2017; Diaz-Caneja et al, 2005; Board & Ryan-Wenger, 2003). They are also in alignement with IPSAD guidelines (Phelan et al., 2018) on the important qualities of T1D education.

Parents in many studies spoke to the profound impact of T1D on their lives in the aftermath of the diagnosis. Many parents described complete changes to their daily routines following the diagnosis. They described being in a state of constant vigilance about their children's' safety due to the consistent demands of T1D management. Parents spoke of feeling compelled to stay close to their children to keep them safe and outlined the detrimental impact of this vigilance on parents' own wellbeing (such as high levels of worry and lack of sleep). Parents also provided insights about factors which may contribute to or provide protection from adjustment difficulties following diagnosis. A lot of parents outlined how the reactions of others affected their adjustment to their new reality with T1D. Some parents spoke about lack of understanding and stigma about T1D leading to judgement, alienation, and loneliness. This is consistent with other findings that T1D continues to be a stigmatised condition around the globe (Hirsch, 2022; Jaacks et al., 2015; Crespo-Ramos et al., 2018). Others spoke about the importance of supportive extended networks, including family, friends, and the child's school and how this facilitated adjustment, in line with studies showing that perceived social support is predictive of parental stress and adjustement in similar populations (von Weiss et al., 2002). Furthermore, parents who had the opportunity to speak to other parents with experience of parenting a child with T1D predominantly found this to be helpful and reduce feelings of loneliness, and those who didn't have this resource

mostly desired it. This is in line with similar studies (Rearick et al., 2011; Monaghan et al., 2011). Participants emphasised the important influence of HCPs during this initial period of adjustment. Participants who had access to hands-on practical support from specialist HCPs valued this, and specifically named availability, problem solving support and confidence building as key factors promoting adjustment. This is consistent with IPSAD recommendations that children and adolescents should have access to a multidisciplinary diabetes healthcare team from the time of diagnosis (Phelan et al., 2018). Conversely, some parents described how the support they were offered was not sufficiently helpful due to not being hands-on enough, not involving liaison with the child's broader network (such as school), and not sufficiently addressing the emotional ramifications of the diagnosis. Some parents had very little access to HCP support following the diagnosis, and their questions and concerns during the period of adjustment remained unanswered. Many parents also shed light on personal and psychological factors that helped support their adjustment to their child's diagnosis of T1D, including the value of teamwork with a co-parent, religion and faith, preserving hopefulness about a future cure, and the transformational impact of time.

Clinical implications and future research

The current synthesis highlights valuable contributions in the context of Diabetes UK's (Wylie et al., 2019) call for a need to increase understanding of factors that mark a positive diagnosis experience, and what might help to reduce the stress and trauma of diagnosis to promote the long-term adjustment and wellbeing of families.

Study findings of parents' lack of awareness of T1D symptoms, dismissive responses from HCPs and misdiagnosis may shed some light on the ongoing challenge of high rates of life-threatening DKA at diagnosis (Schober et al., 2010; Jefferies et al., 2015; Rewers et al.,

2015; Usher-Smith et al., 2012; RCPHC, 2022). Studies highlight the particularly intense emotional impact of receiving a diagnosis when one's child is in a critical condition. Awareness raising campaigns to familiarise members of the public, as well as HCPs, about the signs of T1D have been shown to have some effectiveness in improving timely diagnosis (Deylami et al., 2018; Holder & Ehehalt, 2020), and their use may help to reduce delays in diagnosis, therefore reducing the trauma families experience when a child is diagnosed with T1D.

Findings from the current synthesis elucidate some of the key psychological reactions which parents describe following a child's diagnosis of T1D, as well as their perspectives on T1D education. Their accounts reinforce many aspects of IPSAD guidance on the important tenets of T1D education at diagnosis (Phelan et al., 2018). These include the value of educators providing a basic explanation of T1D, an explanation about the causes of T1D, and including discussions about reactions of guilt and grief at the time of diagnosis. The accounts also endorse the need for repetition of T1D education after the initial shock of diagnosis has subsided, when parents may feel more able to take in novel information. The review highlights that specific sensitivity and reassurance may be needed when educating parents about insulin injections, given its heavy emotional impact and the fact that inability to adopt injections may have life-threatening consequences. From synthesising these studies, it is clear many of the IPSAD principles on T1D education during diagnosis are not being consistently applied. Where possible, health systems should endeavour to heed this guidance to improve families' experiences of diagnosis in the hopes of reducing trauma and stress and empowering them with desired knowledge at the beginning of their journey.

The present review also illuminated important issues which may contribute to adjustment difficulties in the aftermath of diagnosis. These included uninformed and stigmatising responses from others, as well as lacking availability and quality of HCP support in the period following diagnosis. Awareness campaigns may be helpful to efforts to reduce stigma and increase understanding of T1D (Diabetes UK, 2014; Lloyd et al., 2018). Where possible, health services should endeavour to include people from children's extended networks in some aspects of T1D education, to improve their awareness and reduce parents' feelings of isolation. The synthesis highlights significant disparities in the care available to families following a child's diagnosis of T1D, as previously found (Codner et al., 2018b). Where possible, families and HCPs responding to T1D diagnosis in under-resourced regions and systems should be guided towards the International Diabetes Federation's "Life For a Child" and "Changing Diabetes in Children" programmes, which may be able to help with access to resources and psychoeducational materials (Codner et al., 2018b). Codner et al (2018a) also state that governments and health authorities could help improve the safety and wellbeing of children with T1D and their families around the world by "waiving export/ import taxes and by clearing administrative obstacles so that these resources can reach patients as quickly and efficiently as possible" (p.327). HCPs responding to T1D diagnosis in well-resourced, multi-cultural settings should adopt a curious and flexible approach to T1D education, taking time to enquire about cultural food practices within families and make necessary adjustments. Use of interpreters when working with families with a different first language should be considered to improve experience of T1D education. Furthermore, the present review highlighted personal and psychological factors which parents identified as supporting their adjustment to T1D. Many participants, especially based in Muslim-majority countries, reported on the role of religion and faith in helping them come to terms with their child's diagnosis. Clinicians should strive to be curious and encouraging about the myriad of

possible coping resources and support systems families may draw upon as they adjust to a child's T1D diagnosis. The transformational power of time was also a highly reported supportive factor. HCPs involved in supporting families through a diagnosis of T1D should consider how they might be able to sensitively promote this message. For example, offering to connect families of a newly diagnosed child with a family who are further along in their adjustment to T1D may provide an opportunity for reassurance about the transformational power of time. Evidence supports the use of structured social support interventions for parents of children with T1D (Rearick et al., 2011; Monaghan et al., 2011). Rearick et al.'s (2011) sudy found that a structured peer social support intervention resulted in parents reporting reduced feelings of isolation and mental health symptoms, and increased knowledge of strategies that helped with their sense of adjustement.

Given the findings of the present review and in line with Wylie et al.'s (2019) recommendations, valuable future research endeavours would include reviewing the current literature focusing on the use of language in healthcare settings at diagnosis on the mental wellbeing of children and families. Furthermore, interventions harnessing the findings from the present review could be developed and investigated, in an effort to improve the process of diagnosis.

Limitations of review

The review was limited by several factors. Firstly, the restrictions due to not being able to access some articles in the English language or due to institutional access issues may have meant that some relevant studies were not included in the review and may contribute to an overly anglicised interpretation of available studies. Furthermore, the absence of grey literature searching may have further limited the scope of the synthesis. Three bibliographic

databases were searched to improve the reach of the review, but it remains possible that searching more widely may have resulted in more eligible articles. Whilst the review did include articles that considered the perspectives of fathers, the voices of mothers were most strongly represented, and the scope of the review meant that the perspectives of diagnosis of other caregivers and siblings were not represented.

One challenge of synthesising qualitative research is that it requires the findings of individual studies to be decontextualised from their unique empirical and socio-cultural settings, which is challenging given that a core tenet of qualitative research is to explicate these unique aspects of experience (Yardley, 2000; Thomas & Harden, 2008). The current synthesis attempted to synthesise findings across countries, time frames, and health structures. This had the potential to be evermore challenging, given that our understanding of the causes of T1D, and approaches to diagnosis and management have undergone substantial change in recent decades and are constantly evolving (NICE, 2018; Richardson & Pugliese, 2021). However, there were no major differences in contributions to theme according to country of study or date of publication, perhaps adding strength and value to such attempts to synthesise a diverse array of articles. For practitioners and policy makers who work within specific cultural contexts and health structures, the review findings may lack a level of specificity in their practical utility, due to the inclusion of studies from such a variety of countries, each with unique cultures and health structures. However, for clinicians working in multi-cultural settings, where they may diagnose T1D in children from families with diverse cultural heritages, the review findings may have added value. For example, the synthesis highlights the importance of considering cultural food practices when providing T1D education, and the value faith may have for some religious families when coming to terms

with their child's diagnosis. These important findings would not have been elucidated if not for the inclusion of a diverse array of studies.

As mentioned, another challenge of the sytnehsis was the need to decontextualise individual studies from their own empirical contexts, including their unique study aims. The aim of the present review was to synthesise existing literature on parents' experiences of their child being diagnosed with T1D, and particularly the delivery of the diagnosis, in the hopes that this could help to inform healthcare practices. The review, by necessity, incorporated all relevant literature pertaining to these aims. However, this literature included studies with a variety of unique focal points. For example, some studies were focused on parents' experiences of the pathway to receiving diagnosis (such as Usher-Smith et al., 2013 and Khandan et al., 2018). Some studies focused on the process of adjustment after diagnosis (such as Kingod & Grabowski, 2020). Other studies focused on parents' experiences of T1D education (such as Klee et al., 2020). Whilst for some, diagnosis was merely part of a broader study interested in parents' experiences of raising a child with T1D (such as Abolhassani et al., 2013 and Spencer et al., 2012). This means that the participants represented have not been able to report on their experiences pertaining to all aspects of the diagnosis experience, from their child becoming unwell, to diagnosis delivery, T1D education, and adjusting to life with T1D. This may reduce the practical utility of some of the findings for practioners and policy makers working in specific contexts and health structures. It also highlights the potential value of further research to be conducted within specific cultural settings and health systems that focuses on the entire experience of diagnosis.

Conclusion

The current review has synthesised existing research on parents' experiences of their child's diagnosis of T1D. Findings highlight the impact of stressful routes to diagnosis on parents, parents' emotional reactions to the delivery of diagnosis and factors they identified as influencing this impact, as well as issues affecting parents' early adjustment to life with T1D. It provides reinforcement for existing guidelines on delivering a diagnosis and demonstrates a need for these guidelines to be attended to. It also provides additional insights that could help to inform healthcare practices in the diagnosis of T1D. Future research including reviewing the existing literature on the impact of language used in healthcare settings at diagnosis, conducting more research focused on the entire diagnosis experience, and developing interventions based on the key findings of this review, would be of value.

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Part Two: Empirical Paper

"The scars are still very raw."

Finding out your child has Type 1 Diabetes: a qualitative study into the experiences of parents.

Abstract

Literature on the mental health of young people living with type 1 diabetes (T1D) and their families has considerably evolved over the last decade. However, there is a need for more research exploring how the delivery of diagnosis of T1D is experienced by children and families in the UK, including experiences of healthcare received. **Aim**. This study aimed to explore the diagnosis experiences of parents of children living with T1D, including their views on the healthcare received. **Method**. Semi-structured interviews were carried out with 10 parents 35-62 months after their children were diagnosed with T1D. Children were aged 11-16 at the time of diagnosis. Nine of the parents identified as White British, and one opted not to disclose their ethnicity. An Interpretive Phenomenological Analysis (IPA) framework was used to analyse the interviews. **Results.** Five superordinate themes were generated: 'Responding to a crisis', 'A sudden state of uncertainty', 'A threat to parental role', 'Developing a new parental role', and 'T1D diagnosis holds a distressing legacy'. **Conclusions**. Parents reflected on the emotional impact of their children being diagnosed with T1D, and the ways interactions with HCPs during and following diagnosis promoted and undermined their adjustment. It would be valuable to provide training to non-specialist HCPs about diagnosing T1D, to emphasise the need for clear and empathic communication at diagnosis, and to support parents to process trauma and grief responses to diagnosis.

Introduction

Type 1 Diabetes (T1D) is a chronic autoimmune condition affecting more than 30,000 children and young people in the UK (Royal College of Paediatrics and Child Health, 2022). One in 500 children under 15 in the UK have T1D, and the incidence in this age cohort increased significantly, by 20.7%, between 2019/20 and 2020/21 (RCPHC, 2022).

T1D is diagnosed when blood glucose concentration is equal to or above 11.1 mmol/l alongside the presence of clinical symptoms including excessive urination, excessive thirst, and unexplained weight loss (World Health Organisation, 2006). Managing T1D requires a complex regimen of insulin treatment with continual management throughout the day. Parents are therefore required to assist with T1D management, often taking primary responsibility for management in pre-adolescent children (Rankin et al., 2016). This involves undertaking frequent monitoring of blood glucose levels, determining, and administering insulin doses, and counting carbohydrates to promote recommended blood glucose levels (Rankin et al., 2016).

NICE (2018) stipulates national recommendations about the care that families in the UK should receive at diagnosis of T1D. This includes immediate referral to a specialist paediatric T1D team, who should provide a tailored education programme about T1D management, information about support groups and organisations, information about insulin therapy, and dietary and exercise advice. NICE (2018) also specifies that children and young people, as well as their families and caregivers, should be offered tailored emotional support after diagnosis, and timely ongoing access to specialist mental health professionals where needed. This is due to research literature demonstrating the negative impact of emotional and behavioural issues on T1D management. For example, studies have shown that adjustment

issues following diagnosis are associated with ongoing adjustment issues (Delamater, 2009; Luyckx et al., 2010) and that depression in children and young people with T1D negatively predicts glycemic control (Hood et al., 2011; Jaser et al., 2017; Hilliard et al., 2016). Findings show that parental psychological distress at diagnosis predict their later distress, and negatively impacts child psychological adjustment (Whittemore et al., 2012). Parenting stress has also been indicated as a risk factor of depression in children with T1D in several studies (Whittemore et al., 2012; Mullins et al., 2004; Maas-van Schaaijk et al., 2013). Furthermore, evidence suggests that T1D diagnosis can impact the quality of life of the whole family, including siblings. A recent review found that siblings often feel overwhelmed and powerless at diagnosis, and may be more likely to develop emotional and behavioural problems than their peers (Chan & Shorey, 2022). Furthermore, Jackson et al. (2008) found that factors associated with poorer sibling adjustment included higher levels of parenting stress and poorer adjustment of the child with T1D.

In 2019, Diabetes UK reported recommendations for research priorities linked to mental health and T1D (Wylie et al., 2019), including a call for more research focusing on the "primary prevention of mental health issues at the time of diagnosis of diabetes" (p1535). Wylie et al. (2019) assert that there is a need to understand the impact of the delivery of diagnosis, the hallmarks of a positive diagnosis experience, and to find factors that could reduce the stress and trauma associated with diagnosis of T1D. The authors explicitly recommend a systematic review of existing literature, "before exploring the features of diagnosis that may help or harm subsequent mental wellbeing through qualitative research" (p.1536). To address these research needs, it is important to speak directly to those with experience of T1D diagnosis and of living with T1D. Given that parents often play a central role in T1D management, and that their psychological distress may impact on the

psychological and diabetes-related wellbeing of their children, they represent valuable and informative stakeholders in the quest to answer questions about the impact of T1D diagnosis.

Existing literature from UK settings exploring parents' accounts of their children's' T1D diagnosis has elucidated several important findings. Several studies (Lowes et al., 2004; Spencer et al., 2012; Rankin et al., 2014) have highlighted parents' experiences leading up to diagnosis, including how parents often attributed alternative explanations to their child's symptoms, or in some cases denied the possibility of T1D. This lack of awareness of the seriousness of T1D delayed parents from seeking medical care, sometimes resulting in their children being in a state of critical illness at diagnosis (Lowes et al., 2004; Spencer et al., 2012; Rankin et al., 2014). Misdiagnosis and dismissive responses by GPs were also cited by parents as contributing to delays in diagnosis (Spencer et al., 2012; Usher-Smith et al., 2013; Rankin et al., 2014), with some feeling they had to put pressure on GPs for their child to have the necessary tests performed (Usher-Smith et al., 2013). Parents reflected on their emotional reactions when their child did receive the diagnosis, which included feelings of powerlessness, shock and disbelief, loss, and guilt and blame (Lowes et al., 2004; Lowes et al, 2005; Spencer et al., 2013; Rankin et al., 2014).

Some studies also commented on parents' experiences of T1D education. The majority of parents identified T1D education as overwhelming, with lots of information to absorb as they were still coming to terms with their child's diagnosis (Lowes et al., 2004; Spencer et al., 2012; Rankin et al., 2016). Participants in Spencer et al.'s (2012) study emphasised the value of HCPs taking a sensitive approach to T1D education. During T1D education and the early stages of learning to manage T1D, parents described particular fears about insulin injections (Lowes et al., 2005; Rankin et al., 2016) and severe hypoglycemia

(Lowes et al., 2004; Rankin et al., 2016). Some studies reported on parents' positive experiences of support from specialist HCPs following their child's diagnosis (Lowes et al., 2004; Spencer et al., 2012). However, participants in Rankin et al.'s (2016) study highlighted a lack of emotional support and reassurance during and following diagnosis, and insufficient practical day-to-day advice, gaps which some believed would have ideally been filled through peer support.

These findings highlight important aspects of parents' experiences of diagnosis, contributing to our understanding of the factors which may help or harm parents of children diagnosed with T1D. The studies have tended to focus on the pathway leading to diagnosis, perhaps due to a desire to understand potential reasons for the prevalence of children presenting with life-threatening DKA at diagnosis (Usher-Smith et al., 2012; RCPHC, 2022). Only Rankin et al.'s (2016) study specifically focused on parents' experiences of information and support received at diagnosis. No studies explicitly focused on the experiences of the delivery of diagnosis by HCPs. Further research would be valuable to reinforce and augment existing findings, particularly given the rising prevalence of T1D in children and adolescents in the UK (RCPHC, 2022). Research encompassing the entire period from a child becoming unwell, to delivery of diagnosis, to a family beginning to adjust to life with T1D is lacking, and may help provide deeper insights into factors that impact parents during and following their child's diagnosis of T1D and how healthcare practices could be improved.

Aims

The primary aim of this study was to provide further understanding of the experiences of parents when their child is diagnosed with T1D in the UK. Additional aims are that the study findings will further elucidate features of T1D diagnosis that may help or harm families

(Wylie et al., 2019), and provide insights to inform healthcare practices around the diagnosis of T1D.

Method

Interpretive Phenomenological Analysis (IPA)

IPA is a qualitative research method interested in how people make sense of experiences that take on a significance in their life (Smith et al., 2022). It is an idiographic approach that values the unique aspects of individuals' sense-making process. IPA has been used extensively in health research and has frequently been used to understand how people give meaning to bodily experiences, and experiences of accessing healthcare (Brocki & Wearden, 2006).

IPA is phenomenological, concerned with individuals' subjective accounts (Brocki & Wearden, 2006), and posits that meanings are only accessible through an interpretive process, which is dependent on, and affected by, the researcher's own conceptions (Smith, Jarman, & Osborn, 1999). Its ideographic underpinnings emphasise the value of each participant's individual contributions as well as the similarities and dissimilarities between facets of each participant's experience (Smith et al., 2022).

This project followed the IPA framework suggested by Smith et al. (2022). Data were collected using semi-structured interviews, considered a highly appropriate method, inviting participants to present a rich, specific personal account of their experiences (Smith et al., 2002).

Participants and recruitment

A purposive and homogeneous sample was recruited in line with IPA principles, which, for the purpose of this study, was defined as: parents who had experienced their children being diagnosed with T1D. Further details of inclusion criteria and recruitment processes are outlined below.

Inclusion criteria

Participants had to meet the following inclusion criteria:

1. To have a child currently aged between 11-17, who was diagnosed with T1D in the UK between July 2017 and February 2020.
2. To have been present for some part of their child's diagnosis of T1D (such as escorted the child to the GP or met the child at the hospital).
3. To be able to speak English sufficiently well to engage in an interview without an interpreter present.
4. For the child of interest not to have any additional primary chronic physical health conditions that require consistent self-management.

Addressing point (1), the earliest diagnosis date limit of July 2017 was set due to the research team's hypothesis that interviewing parents with children diagnosed further in the past might lead to greater difficulties recalling the early phase of diagnosis and heighten risk of entangling more recent experiences with those from this early phase. The latest diagnosis date limit of February 2020 was to ensure that participants' children were not diagnosed during the COVID-19 pandemic, which was hypothesised to alter the diagnostic experience (Unsworth et al., 2020). This limit also helped avoid the "honeymoon period" associated with T1D diagnosis, which may have impacted parents' reflections on the diagnosis experience itself. The honeymoon period associated with T1D

is believed to last approximately 7 - 8 months post-diagnosis, where individuals still produce some insulin and T1D may be more easily managed (Abdul-Rasoul et al., 2006). The age limit was set due to the hypothesis that parents of younger children might have a significantly different experience of diagnosis. These decisions helped to increase sample homogeneity, in line with guidelines around IPA (Smith et al., 2022). For point (3), it was unfortunately not possible to use interpreters due to funding limitations. Finally, point (4) was to control for pre-existing health conditions that may have significantly altered the experience of parents having a child diagnosed with T1D.

Recruitment procedures

A previous study was conducted in 2020/21 by a member of the research team (KT), which explored children's experiences of receiving a T1D diagnosis. The participants were recruited through two national UK diabetes charities: Diabetes UK and the Juvenile Diabetes Research Foundation (JDRF). Due to the study involving children under 16, parental consent was required and parents were required to organise their children's' involvement in the study. Five of these parents consented to being recontacted about the present study and expressed ongoing interest when recontacted. Three of them expressed interest on behalf of themselves and a co-parent. In each case, the lead researcher contacted the co-parent by email following the same process. Two parents reached out to KT regarding her study after her recruitment phase had already been completed. She shared details with them about the present parent study and they both expressed interest. All ten interested participants were emailed by the lead researcher with information sheets (see Appendix F) and encouraged to discuss any clarifying questions. If still interested, the lead researcher sent a link and a personalised code generated through Research Electronic Data Capture (REDCap), a secure web application hosted by UCL, where they could complete the consent form (see Appendix G) and

questionnaires. All participants were offered reimbursement for their participation with a £10 Love2Shop voucher.

Ethical Considerations

Ethical approval was obtained from the University College London (UCL) research ethics committee (see Appendix H), project identification number 19685/001; data protection registration number Z6364106/2022/05/25.

An ethical issue requiring consideration was the potential for participants to experience distress whilst recounting their experiences of their child's T1D diagnosis. Participants were reminded by the researcher to only share as much information as they felt comfortable with and that they could terminate the interview at any point. Following the interview, the researcher debriefed participants and checked whether they were left with any distress or questions.

Another ethical consideration was the possibility that participant disclosures during interviews could present cause for concern about the safety of a child with T1D (due to T1D management or safeguarding concerns). All participants were asked to provide details of their GP during the consenting process and informed that these details would be used in the rare event that an interview raised concerns about significant risk posed to a child. It was communicated that any concerns would be discussed with the research team (including specialist Clinical Psychologists who collectively hold extensive knowledge of paediatric health and risk management, and T1D management).

To preserve the confidentiality of participants, several procedures were followed. Questionnaires and written consent were collected on a secure platform (REDCap) hosted by UCL within their Data Safe Haven, used for handling confidential data. Interviews were digitally recorded, and participants were assigned a unique identification number (ID). Audio recordings were also stored on UCL's Data Safe Haven. Any personally identifiable information, such as real names and addresses, were removed from the transcripts and quotations to ensure anonymity. Transcript files were password protected using a password only known by the researcher.

Data collection

Data were collected by semi-structured interview. Questionnaires were completed before the interviews to gather contextual information about the participants, and participants were encouraged to reach out to the lead researcher with any questions or concerns. Due to convenience and participants being spread throughout the UK, all interviews were held via video call. Written consent was collected via REDCap prior to interview, including consent to be contacted afterwards as part of data analytic process.

Questionnaires

Details of the participant's demographic information, relationship to their child, and management of their child's T1D were collected to contextualise the sample.

Diabetes Information Questionnaire (see Appendix I)

The diabetes information questionnaire was designed by the research team. It captures demographic data (including gender and ethnicity of parent and child, and child's age) and information on diabetes care and management. This data includes date of diagnosis, current

blood glucose monitoring method and insulin delivery method, and who is primarily in charge of management (participant, child, both or other), and a subjective rating how well management of their child's T1D is going currently. This information was intended to provide an overall impression of the sample demographics, T1D management and level of independence and interdependence within the family system, to contextualise the sample and establish any differences across participants.

Semi-structured interview

Interviews were conducted over Microsoft Teams. The research team discussed the presence of co-parenting couples and how best to approach these interviews. It was decided that it would be optimal to interview participants individually due to several reasons. Firstly, given the research aim to understand the individual experiences of parents. Secondly, given the critical realist stance adopted, recognising the individual reality of a person within the context of a family reality (Holstein & Gubrium, 1997). Finally, given the use of IPA methodology, which emphasises the importance of unique aspects of individual experience (Smith et al., 2009). The main researcher asked participants for their preference, and all participants agreed to undertake individual interviews. Interview length ranged between 57 and 113 minutes (M = 83.7) and were audio recorded and transcribed verbatim for analysis. Following the interview, participants were appropriately debriefed.

A semi-structured interview guide (see Appendix J) was developed with the research team. The research team comprised of two trainee clinical psychologists and two qualified clinical psychologists, one with experience of working with children with complex health conditions and their families, and one with experience working with the T1D population. The interview schedule was developed to attempt to explore the entirety of parents' diagnosis

experience including: their child becoming unwell, receiving their child's diagnosis of T1D, adjusting to living with T1D, experience of healthcare, and of friends and family.

Data analysis

The analysis followed Smith et al.'s stages of IPA analysis (2022). All interviews were initially transcribed verbatim by the lead researcher, then identifying details were removed to maintain participant anonymity and recordings were deleted. Each transcript was analysed separately following the below steps before connections were explored across transcripts.

Each transcript was read and re-read, allowing immersion in the data. The researcher reflected on notes they made immediately before and following each interview. Following this stage, the semantic content and language use were examined, and exploratory notes made. Initial notes were then consolidated into experiential statements and then clustered into experiential themes. Individual tables were created to represent the experiential themes for each participant before turning to the next transcript. Finally, patterns of similarity and difference were explored across cases to develop a set of Group Experiential Themes and a table was developed to represent these. The research team met regularly throughout data analysis to discuss emerging concepts.

Validity and quality

There is a diverse array of approaches to reflecting on the quality and validity of qualitative research (Elliot et al., 1999; Yardley, 2000). Some of the aspects relevant to the current research, including its epistemological and methodological assumptions, are explored below.

Sensitivity to context

Sensitivity to context within qualitative research, as outlined by Yardley (2000) pertains to the empirical and socio-cultural contexts of the research, as well as the power dynamics between researcher and participant. The researcher utilised relevant empirical work and theory to inform the development of the research aims, interview and analysis. The researcher used the expertise of the research team, consisting of two qualified clinical psychologists, one working with children and young people living with long-term health conditions and extensive experience supervising qualitative research, and one working with adults with T1D and experience conducting qualitative research, and one fellow trainee clinical psychologist with lived experience of T1D. The information sheets, consent forms and interview guide for the present study were adapted from versions used for a previous 2020/2021 study conducted by a research team member (KT) exploring children's experience of receiving a T1D diagnosis. In the development of the initial materials the researcher (KT) contacted Diabetes UK's young adults panel, and four adults aged 22-30 diagnosed with T1D as children were consulted and their feedback integrated. The appropriateness of member checking has been critiqued by qualitative researchers who have expressed concerns about its epistemological fit and ability to meaningfully impact power dynamics (Motulsky, 2021).

Rigour

Rigour refers to the completeness of analysis. The researcher engaged in several levels of analysis in line with Smith's (2022) analytic guidelines, which emphasise the importance of going beyond superficial interpretations. The analysis was further supported by frequent discussions with supervisors (KS, VM), who helped the researcher deepen their exploration (Yardley, 2000).

Transparency & Reflexivity

Transparency refers to the presentation of analysis as well as reflexivity regarding the researcher's own assumptions and experiences. The author has presented excerpts of data so that readers can perceive patterns identified by the analysis (see Appendix K) and included quotations throughout the 'Results' to illustrate the themes. The researcher conducted a bracketing interview before commencing the interviews to explore their preconceptions. The researcher also kept a reflective journal throughout all stages of the research to reflect on their thoughts, feelings, and biases. Some of the aspects that arose are outlined in the statement below.

The lead researcher is a White, middle-class, able-bodied woman and this informs their worldview and perspective. The author has experienced a close family member receiving a diagnosis of a serious health condition, which they perceived as abrupt, frightening, and confusing. They experienced the healthcare received at the time of diagnosis and subsequently as inadequate and lacking compassion. The author also grew up with a parent diagnosed with T1D and perceived the condition to be manageable but also constant, and sometimes demanding and frightening. Within clinical practice, the author has been drawn to working with children and families, preferring therapeutic approaches that emphasise unique lived experience, the role of emotions, attachment, and familial and socio-cultural systems. The author has not previously worked or engaged with children in paediatric settings. Although the author attended to their own experiences and assumptions around family experiences of T1D and diagnosis of serious health conditions, and of their bias towards psychological ways of thinking and understanding, these will likely be reflected in the themes generated.

Results

Ten participants took part in the study (see Table 1 for participant demographics and children's T1D information). Seventy percent of participants identified as women, and 90% identified themselves as White British, with one participant opting for the 'prefer not to say' option. Participant's children at the time of interviews ranged from 11 to 16, and time elapsed since their children's diagnosis ranged from 35 months to 62 months. All participants subjectively rated their child's current T1D management as going'well' or 'very well'. Where appropriate, quotes have been edited for readability. Pseudonyms have been chosen to protect the anonymity of participants and names have not been matched to participant characteristics to ensure confidentiality. Participants included three sets of co-habiting couples, who shall not be explicitly named or linked to ensure confidentiality. The remaining four participants were unconnected from each other. One participant's child was diagnosed in another country whilst on holiday, however they immediately returned to the UK on receiving the T1D diagnosis. The research team agreed that this account met the inclusion criteria, because whilst the diagnosis delivery took place abroad, most of the diagnosis experience pertained to the UK context and was not sufficiently different from other accounts. For this participant, the specific details of diagnosis delivery were excluded from analysis, and the rest of the account was accepted.

Table 1

Participant detail

Participant number	Gender	Ethnicity	Tools used to manage T1D	Primary manager of T1D	Subjective rating of T1D management
1	Female	White British	rt-CGM[a] & CSII[b]	Child	Well
2	Female	White British	rt-CGM & CSII	Parent & child	Very well
3	Male	White British	rt-CGM & CSII	Child	Well
4	Female	White British	rt-CGM & MDII[c]	Parent & child	Very well
5	Female	White British	CGM[d] & CSII	Parent & child	Well
6	Female	White British	CGM & CSII	Parent & child	Well
7	Female	White British	rt-CGM & CSII	Parent & child	Well
8	Male	Prefer not to say	rt-CGM & CSII	Parent & child	Well
9	Male	White British	rt-CGM & CSII	Parent & child	Very well
10	Female	White British	rt-CGM & CSII	Parent & child	Well

Note. Table showing participant demographic information and T1D management information.

[a] rtCGM - real-time continuous glucose monitoring; [b] CSII - Continuous subcutaneous insulin infusion; [c] MDII – multiple daily insulin injections; [d] CGM - intermittently scanned continuous glucose monitoring.

Five superordinate themes were generated from the data: ‘Responding to a crisis’; ‘A sudden state of uncertainty’; ‘A threat to parental role’; ‘Developing a new parental role’; and ‘T1D diagnosis holds a distressing legacy’. Table 2 displays the themes and patterns of occurrence across participants. A diamond symbol indicates which participants’ quotations have been used to elucidate each theme.

Table 2

Superordinate, sub-themes, patterns of occurrence and use of quotations

Superordinate Themes	Subthemes	Kate	Denise	Mark	Sofia	Penny	Emma	Jude	Lily	Nazir	Ethan	Frequency
Responding to a crisis	Entering action mode	♦	♦		♦			♦				10
	Holding the burden of worry		♦			♦		♦				5
	Overwhelming feelings of guilt		♦	♦								6
A sudden state of uncertainty	Relying on unreliable messengers		♦		♦	♦			♦		♦	9
	Being in the hands of a vulnerable system	♦				♦					♦	9
	Looking towards an uncertain future	♦		♦	♦		♦					8
A threat to parental role	T1D threatening to undermine parents' expertise	♦					♦	♦		♦		10
	Being unable to protect child from T1D		♦							♦		6
	The diabetes nurse assuming a parental role						♦		♦			9
Developing a new parental role	Striving not to let T1D take control					♦			♦		♦	10
	The importance of returning to normal life							♦			♦	8
	Advocating in a hostile & ignorant world			♦						♦		8
	Never switching off worry		♦									9
T1D diagnosis holds a distressing legacy	Memories of T1D carry great significance									♦		5
	Emotions connected to diagnosis are still painful					♦				♦	♦	10

Notations were used within quotes as follows:

Omission of intervening material […]

Explanatory information (the GP)

Non-verbal communication [pause]

Speech emphasis <u>underlined</u>

Please note that all names used in the analysis (including names of parents, children, and HCPs) have been pseudonymised to protect the confidentiality of participants.

Responding to a crisis

"…you don't think about… yourself in that situation, you just think about everything that has happened to them." (Kate, p.20)

All participants spoke to this superordinate theme during their interviews. It captures the experience of parents realising and responding to their child's escalating illness, and how participants reflect on their experience of these moments. This is elaborated in the following sub-themes: Entering action mode; Holding the burden of worry; and Being overcome with feelings of guilt.

Entering action mode. All participants alluded to entering action mode to get their child to safety. Kate, Denise, Sofia, Lily, and Nazir spoke to the perceived role of maternal intuition in getting medical attention at the particular time they did. Denise and Sofia spoke about following their maternal instincts in the face of dismissive responses by healthcare professionals (HCPs). Kate and others described their maternal instincts about something being wrong as a driver to seek medical input:

> Kate: I don't even know that I knew what…level of care she needed at that stage. I just knew that there was something wrong and…my husband said to me, "you're a mum…you need to follow your gut." I knew there was something not right with her. (p.9)

Kate suggests that, whilst lacking specific knowledge of her daughter's medical condition, she possesses a special kind of parental knowledge of her daughter that told her something was "not right". Recall of her husband's reply "you're a mum" conveys her perception of something inherently maternal about this knowledge, or perhaps a sense that the identity of a mother is intimately bound with having this special knowledge.

The sense of urgency expressed by Kate, Denise, Sofia, and Jude when describing the moments leading up to diagnosis also spoke to the need for action mode:

> Sofia: It was the longest taxi ride ever [small laugh]. I even thought that…he went out of the city to go back into the city. It felt like a very long time. (p.5)

Sofia's emphasis on her perception of time slowing down during their journey to hospital speaks to her anxiety and internal sense of urgency to get her child to safety. For others, the speed of response to their child's illness indicated that the situation was urgent:

> Jude: …they did whisk us in pretty quickly…there were lots of people, obviously, it was a hot, sunny day, lots of kids with broken bits. But we did get whisked to the front of the queue, which again makes you think, *oh okay*. (p.7)

> Denise: It just seemed a lot of people standing around, waiting for us to get there. They probably weren't waiting for us, but it just felt at that time as if we had got this entourage of people…It was just that image of getting there and thinking, *my goodness, this must be something really serious because why would they do all this*? (p.14)

Jude's repeated use of "whisk" reflects the quick and sudden way in which her child was moved through the hospital system. Denise's strong visual memory of an "entourage" of HCPs waiting for her and her child to arrive evokes the seriousness of the situation they had found themselves in. Both parents allude to their experience of an anxious internal voice attempting to make sense of their urgent hospital reception.

Kate, Mark, Jude, Lily and Ethan spoke about entering a practical mindset to prioritise their child's safety:

> Kate: …it's almost like you're in a different body for a time… you're in a state of shock, but also, *I've got to get on with this*. You know, *we've got to go to the hospital, I've got to get her to the hospital safely*…So you just almost go into that whole, like, robot mode… (p.13)

Kate's use of "robot mode" encapsulates lots of aspects of the practical mind-set that participants described, including a feeling of disconnect from body and emotions, and an intense focus on the tasks of getting their child to hospital and taking on board as much information as possible about their child's health. The feeling of disconnect from emotions was highly reported by participants, with many participants commenting on scant memories of emotions during this phase of their experience. Sofia went further by suggesting that emotions are antithetical to responding to this sort of crisis:

> Sofia: you can't think clear when you get too emotional, so…we were just trying to get through the next hour. (p.11)

Holding the burden of worry. Kate, Denise, Sofia, Penny, and Jude spoke to the idea that as parents, they felt responsible for holding and carrying all the worries presented when responding to the crisis of their children's' escalating illness. This was expressed in parent's descriptions of minimising their own emotions about unfolding events, in favour of dedicating all their energy to ensuring their child's wellbeing:

> Denise: I wasn't really thinking more than *let's just get him some help now and try not to get him upset and be a mum really and do what you've got to do*….I think when I got there and I just saw everybody lined up [sighs] that just felt awful…I think it was at that point I just thought, I felt like I was going to get upset but you've just got to hold it together, haven't you? (p.9)

Denise interweaving the phrase "be a mum" demonstrates how she views her parental role as intimately connected with an ability to hold her own feelings together and prioritise her child's physical and emotional safety. This sentiment was shared by several participants who believed their children would look to them for cues on the safety of the situation, and described a parental instinct to want to protect them from worry:

> Jude: I think I was trying to not panic and not worry just because obviously I didn't want Nichola to realise that I was worried, and I wanted to keep her calm and, you know, happy and not worry about it beforehand. (p.8)

Jude describes working hard to manage her feelings of worry due to a concern about her daughter noticing, and this leading her to carry anticipatory worry of her own. Jude communicates a sense of responsibility to manage her own feelings to avoid this outcome.

Overwhelming feels of guilt. Six participants spoke about the intense feelings of guilt and responsibility they felt in the aftermath of responding to the diagnosis. Kate, Denise, Mark, Emma expressed guilt for not having recognised their child's symptoms and acting sooner.

> Mark: But the whole feeling of having let them down by not spotting it sooner. That was the overriding thing at the beginning, *what should we have done? Are we bad parents?* (p.5)

Mark recollects how guilty feelings permeated his early moments of the diagnosis. He recalls believing that not recognising his daughter's T1D symptoms represented a failure to protect his child. As well as perhaps asking HCPs for reassurance, Mark seems to have been ruminating inwardly over the question: "*are we bad parents?*".

Denise, Mark, Penny and Nazir recounted an intense sense of responsibility and blame for causing T1D in the immediate aftermath of the crisis:

> Denise: I kept thinking *have I fed him something?* [cries]. *Have I done it?* [cries]. And that was a really big thing for me because I am a bit of a crazy parent, I just think *how is it my fault?* I just want him to have the best life he can have; I just adore him. I kept thinking, *have I done this to him?* (p.32)

Denise's powerful emotions and movement between past and present tense in this passage speak to the strength and pervasiveness of her self-accusatory questions about the ongoing mystery of what caused her child to develop T1D.

A sudden state of uncertainty

"I felt absolutely helpless because I didn't know what was going on" (Nazir, p.13)

All participants addressed this superordinate theme during their interviews. It captures the ways that aspects of the diagnosis lurched parents into a state of uncertainty, with sub-themes including: Relying on unreliable messengers; Being in the hands of a vulnerable system; and Looking towards an uncertain future.

Relying on unreliable messengers. Nine participants highlighted ways in which the quality of communication by HCPs had a considerable impact on their sense of uncertainty during diagnosis. For Sofia, Jude, Penny, Nazir and Ethan, what they experienced as evasive communication at the first point of seeking medical help resulted in a heightened sense of uncertainty. Penny and Ethan described how the temperate response and subdued assertion by primary care HCPs that they should head to A&E meant they were not emotionally or practically prepared for what was to come:

> Ethan: …we managed to get her to the hospital…Still at this point, we hadn't been told anything. So at [walk-in hospital] they said, "The bloods are a little bit high." They weren't a little bit high; they were absolutely- It was obvious to the doctor that she had T1D…But she didn't then choose to tell us, she just said, "Go to A&E." (p.3)

Ethan's frustration rose whilst recalling this aspect of his experience, particularly when commenting on his daughter's "absolutely" high blood glucose levels. This perhaps highlights a more knowledgeable present self, looking back with a frustrated protectiveness at

how uninformed and vulnerable he and his child were then. His anger is further illustrated when he characterises the doctor's muted communication as an intentional choice.

For Sofia, an emotional reaction by a primary care HCP to her child's blood glucose test in the absence of any other information unhelpfully exacerbated her sense of danger:

> Sofia: She showed me the meter, and it was, I think, 25.7 and um…[pause] she looked at me and she was tearful [small laugh], which I found quite strange…and I'm going to say unprofessional…because in that moment I, uh… I didn't know what it meant…I knew it was high, because otherwise, why would she show me that with that very sad look on her face? (p.6)

Later, Sofia reflects on a subsequent interaction with a HCP:

> Sofia: …they were quite calm, …and I think delivered, at that point, the right amount of information that we could cope with regarding what was happening.
>
> INT: And compared to how you felt with the first nurse, how did her interaction with you make you feel in that moment?
>
> Sofia: A bit more safe?…you know, I think seeing people calm around you and not, not crying [small laugh], gave us a sense of feeling a bit more safe (p.9).

Sofia expresses clearly how a calm, thoughtful HCP promoted her sense of safety. In their interviews, Denise, Mark, Penny, Emma, Jude and Ethan also articulated the power that

a moment of reassurance communicated by a professional had in reducing their sense of uncertainty.

Penny, Lily, Nazir and Ethan described the impact of an unempathetic delivery of the T1D diagnosis and how this contributed to a sense of vulnerability:

> Penny: …when it's your little eight-year-old sitting there all vulnerable and she finds out by someone saying, "Oh, she's got it," "it", what is it? It makes it sound like even more scary and other worldly…it, she's got it. They didn't say, "Oh, sorry, she has got type 1." (p. 24)

Penny highlights how the words used to convey her child's diagnosis held a great deal of weight. Her increasing agitation and repetition of "it" add emphasis to her description of how the language used made T1D take on an intimidating, other-worldly entity in her mind.

Denise, Lily, Jude, Penny, Sofia, Nazir, and Ethan spoke to a lack of explanation of T1D at the point of diagnosis. This had significant implications on parents' sense of uncertainty, with some parents left fearing the worst:

> Denise: when they first confirmed it, afterwards when Ben wasn't there…I remember saying to the nurse, "Is he going to die?" That's what I thought [cries]... That was my first question. "Is he going to die? (p.17)

Denise's tearful recollection demonstrates the intense sense of fear parents were left with when their child was given a diagnosis of T1D in the absence of any other explanatory information or reassurance.

Furthermore, Penny, Jude, Lily and Nazir detailed the sense of uncertainty and helplessness at their children undergoing invasive medical procedures with little explanation provided by HCPs:

> Lily: That was the worst bit, is that no one really…explained what was going on, so I was just trying to listen to their conversations, almost, and piece together what the heck they were talking about…I mean, they definitely got his blood sugars down, and they definitely were putting the right thing in the drip, now, thinking back. But they just didn't really explain what they were doing…so I was really just trying to figure out what on earth was going on. (p.10)

Similarly to Ethan, the frustration conveyed in Lily's account by exclaiming "what the heck" and "what on earth", might reflect the horror of knowledgeable 'present Lily' "now, thinking back" on what the more vulnerable 'past Lily' had to go through. The sense of helplessness and confusion Lily conveys was mirrored by several other participants. Penny and Jude used language such as "poking", "prodding", and "sticking" to describe early medical interventions, conveying a disempowering sense of their child being 'done to'.

Being in the hands of a vulnerable system. Nine participants outlined the uncertainty brought about by not feeling sufficiently contained by the systems and structures in place during the process of their child receiving a diagnosis of T1D. Eight described how

the significant knowledge and training gaps of non-specialist HCPs contributed to a sense of uncertainty. For Kate, Sofia, Emma and Jude, these knowledge gaps were clear at first point of accessing medical help:

> Kate: I really felt like the doctor was kind of in that unknown ground for her…I can still see her fumbling with the technology, doing the prick test and then not understanding the reading. She got the book out to look at the reading, and I remember Jenna and I…looking over her shoulder like, *why is it taking you so long to understand this?!*...So I think our experience…of the doctor was more positive than other people's I've heard about, but also it still concerns me. (p.15)

Kate's use of language such as "unknown ground" and "fumbling" paint a picture of a HCP facing an unfamiliar, perhaps novel situation. The exclamation in Kate's unuttered question accentuates a sense of bafflement at the HCP's slowness and unfamiliarity. Kate's movement from past to present tense highlights how she was and remains concerned about the lack of familiarity with T1D in primary healthcare settings.

For Denise, Penny, Jude, Lily, Nazir, and Ethan, knowledge gaps became painfully and frustratingly clear at A&E when the parents were forced to wait for the diabetes team before being given any information or education about T1D:

> Ethan: …we just had this wilderness of Friday because the entire diabetic department were off, and then the Saturday and then the Sunday where they weren't working anyway. That-that was difficult. (p.27).

Ethan's use of "wilderness" evokes an image of being abandoned in an inhospitable place due to the absence of the diabetes team. Adding richness to this narrative, other participants spoke of waiting, being left, and being dumped when the diagnosis occurred during a weekend or bank holiday (when diabetes teams typically do not work), or when the diabetes team were all simultaneously taking leave from work, due to the absence of other knowledgeable staff.

Furthermore, Penny, Ethan, and Nazir discussed the impact of what they perceived to be an overwhelmed healthcare system on their containment and sense of safety during the process of diagnosis. They outlined several ways the overwhelmed system heightened uncertainty during their children's diagnosis, including their sense of being cared for by overworked staff, and of understaffing and underfunding issues affecting the availability of equipment and quality of care received in A&E:

> Penny: The way they did the finger pricks was so uncaring…for a kid that's been newly diagnosed with this horrible thing, those stapler ones?...I tried it, they really hurt. Little eight-year-old fingers…they just go, "Right, finger." They don't take any care…they're just sort of treated like a pin cushion…I mean can you spring [sic] for some better? I know, I get it, it's underfunded…But for little children, can you please give a more gentle way of doing a finger prick?...one time…it wouldn't stop bleeding…they had to do a lot of finger pricks with those horrible staplers. I mean, I know they're trying to save money, but just for the kids ward at least, you know?

Penny's frustrated, too-late pleas for A&E to purchase child-friendly blood testing equipment sit painfully alongside her acknowledgement that underfunding might have been responsible for the "uncaring" service her daughter received. The stirring image of her child's "little eight-year-old fingers…bleeding" and being treated like a "pin cushion" evokes a powerful sense of fragility and danger.

Looking towards an uncertain future. Eight participants painted a picture of being thrown into a sudden state of uncertainty about the future when their children were diagnosed with T1D:

> Kate: …having to go back to the hospital the next day and being given more and more information, um, and then coming away from that and knowing that that is going to be the rest of your life going, going forward- or obviously her life going forward. (p.31).

Kate originally names the impact of the diagnosis on the rest of her own life, before quickly adjusting to speak about the impact on her child's future. Interestingly, Mark and Sofia shared similar ways of speaking:

> Mark: …there was the whole sort of shock of that you've now got a chronic illness that you're going to have to deal with for the rest of your life. (p.7).

This may represent the strong sense of responsibility parents felt regarding the future management of their children's T1D. The language perhaps also alludes to parents reckoning

with how the diagnosis meant a sudden deviation from what they had expected at this juncture of parenthood, to something less clear. Some participants spoke more directly to this:

> Sofia: …I would have had to acknowledge what it means for me. And I tried to focus on what this means for him. And you do feel sorry for yourself [small laugh].
>
> INT: …could you say more about that? What was it you were avoiding about what it meant for you?
>
> Sofia: Um…[small pause] maybe in terms of what we would have had to, to do for him for a long time. (p.28)

After asking Sofia to elaborate on her comment, there still felt to be some avoidance in her communication, perhaps reflecting an ongoing avoidance of looking ahead to an uncertain future. The avoidance may also have spoken to a discomfort or sense of inappropriateness felt in acknowledging her own sadness about the impact that her child's diagnosis may have on her forthcoming experience of parenthood.

Denise, Sofia, Penny, Emma and Nazir spoke about how diagnosis of T1D brought up feelings of uncertainty and grief about the limitations T1D might pose for their child's future:

> Emma: we of course knew immediately that this thing was going to be with him and there were some things that he was just not going to be able to do as normal. (p.12).

Emma's use of "immediately" speaks to an abrupt and unforeseen shift she experienced on hearing their child's diagnosis, and an ambiguity about how it might hinder him in the future.

A threat to the parental role

"She was completely just looking to me…and I knew that I wasn't in control…God, it was so hard." (Ethan, p.17).

All participants spoke to this superordinate theme during their interviews. It addresses the ways in which their child's diagnosis of T1D jeopardised their parental authority, elucidated through three sub-themes: T1D threatening to undermine parents' expertise; Being unable to protect your child from T1D; and The diabetes nurse assuming a parental role.

T1D threatening to undermine parents' expertise. All participants spoke to the ways the T1D diagnosis threatened to undermine their parental expertise. Nine participants spoke about their lack of prior knowledge of T1D and receiving an onslaught of new information at diagnosis:

> Jude: You are bombarded with a lot of information, there's a lot to take onboard. (p.16).

Jude and Mark spoke about feeling "bombarded" with information, with other participants referring to feeling as if their "head might explode", and of receiving too much to "take in". These illustrative phrases paint a picture of parents under attack, or about to burst due to the amount of novel information presented during diagnosis.

Kate and Sofia compellingly alluded to the threat T1D posed to their expertise, when describing harsh realisations about no longer feeling like an omniscient figure for their children:

> Kate: …[turns away from camera, becoming tearful] still makes me feel emotional…[more tearful, pitch rising] she's saying "Why did this happen to me?" And we were saying, "I don't know". When Jenna is questioning "why?", what can I say to her? I have no rhyme or reason. And still, medically, we don't really understand how she got it…there was definitely that whole "Why me?" And then all of us just crying, and of course, not being able to answer that. And still to this day, not being able to answer that, so. (p.14)

The intensity of emotion Kate presents whilst describing not being able to answer her child's existential questions about T1D may point to the pain of her perceived loss of expertise. This starkly contrasts to Kate's earlier description of possessing a special kind of parental knowledge about her daughter before her diagnosis. Kate's continual questioning and moving between past and present tenses suggest that this role conflict is an ongoing source of anguish.

Denise, Sofia, Lily and Nazir spoke about their fears of bringing their child home and challenges of early T1D management. Sofia and Nazir made explicit comparison to the feeling they had of bringing their child home as a new-born:

> Nazir: You become an overzealous parent. You think you've got a new-born again. You're up every two hours finger pricking, checking that they're alive, that they're breathing. (p.21).

This analogy conjures a sense of franticness, of renewed fears about his child's safety, and of feeling incompetent in meeting his child's needs. Contrastingly, Emma and Ethan alluded to how some prior familiarity with T1D contributed to a partial preservation of parental expertise:

> Emma: …it meant that actually when we came home and Dan was asking questions, we could answer…we could draw him diagrams and tell him exactly what was wrong...So I think from that perspective that helped because it wasn't something ethereal that we were in the same state as he was and we…had to all muck in to find an explanation…I guess that probably gave us a bit more feeling of control perhaps. (p.20).

Emma's comment about her prior knowledge meaning she was not "in the same state" of not knowing as her son suggests she was able to maintain a more comfortable continuation of the established family hierarchy. She explicitly reflects on how her prior knowledge gave her a feeling of control and implies that this invoked a privilege compared to parents with less familiarity with T1D.

Being unable to protect your child from T1D. Kate, Denise, Sofia, Mark, Penny and Nazir discussed how the diagnosis of T1D came with a loss of feeling able to protect their child, something which threatened their parental identity. Kate, Denise, and Sofia

described how early experiences of injecting their children with insulin challenged their parental instinct to protect:

> Denise:…this whole thing of injecting your child, knowing you've got to, knowing it hurts, but you are saving their life, aren't you? There's all those feelings, thinking *he's crying, he doesn't want me to do it to him, but I've got to do it otherwise he's going to die.* That's kind of like [cries], kind of the facts of the matter, you know? (p.22).

Denise outlines the juxtaposition of having to do a procedure that causes her child harm but that also keeps him safe from harm. The description of her internal thought process, rife with conflict, and the painful emotions still raised when discussing it highlight the ways that insulin injections presented a threat to her parental identity.

Kate, Denise, Sofia, Mark, Penny and Nazir all alluded to a sense of powerlessness that they could not protect their child from the burden of T1D:

> Nazir: …you feel like, as a parent…the instinct to take bad things away from your children very much. There isn't a day that goes by that I don't wish that it was me rather than him, not a day. (p.29).

Nazir describes how the diagnosis of T1D clashed with his "instinct" to protect his child from harm. He laments in present tense about wishing he could have T1D instead of his son, with repetition of "not a day" giving additional weight to his conviction of his impossible desire. Kate, Denise, Sofia, Mark, Penny and Nazir all explicitly stated wanting to

remove or fix their child's T1D, and wishing they could have T1D instead of their child, alluding to their sense of a warped parental role.

The diabetes nurse assuming a parental role. Nine participants spoke to the ways the diabetes team, particularly the diabetes nurses, fulfilled a parental function for parents when families were first coming to terms with T1D diagnosis and integrating T1D management into their lives. For Lily, the parallels between her family's nurse, Hazel, and a mother were unambiguous:

> Lily: She's the one that just knows what to do. It's almost like when you're little and your mum just knows what to do, right?…you know when she's around, it's all fine because she just knows what to do. (p.26)

Lily's words highlight how Hazel felt like a knowledgeable and containing presence. Jude and Nazir also named their diabetes nurse's knowledge and experience being helpful and containing during the early phases following diagnosis. Lily's comment that "when she's around, it's all fine" echoes the effect a secure attachment figure has on their baby.

All nine participants spoke about the usefulness of having the diabetes team on-call, and of being heavily reliant on them in early days and weeks for practical and emotional support. Diabetes nurses were frequently praised for being reliably available at all hours, and for going above and beyond to support their families, much like a mother does for her new-born infant:

> Emma: they were at the end of the phone if we needed to ask a question. Really, really good at reassuring us that actually we were doing the right thing and that it sounded like we knew what we were doing. It was okay. (p.14)

Emma speaks about the stable availability and reassurance her diabetes team offered in the early days after diagnosis. The detached final line "It was okay" adds emphasis, conveying the power of the sense of safety the team were able to provide.

Lily also alluded to her family's diabetes nurse progressively supporting her independence in managing her child's T1D, much like a 'good enough' parent supports child's gradual development (Winnicott, 1971):

> Lily: She doesn't make you feel like she knows everything, and you know nothing. She always tries to involve you in decisions, and…I mean, obviously her objective is to get you independent. (p.30).

In these ways, diabetes teams were able to provide a 'holding' function that allowed parents to adapt to their new parental identity.

Developing a new parental role

"I think my whole reason for being for Ben is that things are just normal. You've got type 1, but that's not going to affect anything we do." (Denise, p.26)

All participants spoke to this superordinate theme during their interviews. It paints a picture of how participants developed new ways to fulfil and bolster their parental role in the

wake of their child's diagnosis of T1D. This is captured through four sub-themes: Striving not to let T1D take control; The importance of returning to normal life; Advocating in a hostile and ignorant world; and Never switching off worry.

Striving not to let T1D take control. All the participants spoke about the threat of T1D taking dominance in their children's lives, and their efforts to protect their children from this possibility in the aftermath of diagnosis. Mark, Sofia, Penny, Emma, Nazir and Ethan elucidated a growing awareness of the ways T1D had the capacity to take control. Here Penny recalls an upsetting memory from a few days after her child's diagnosis:

> Penny: …she got some new dolls for her birthday, and she said…"Oh, you've got diabetes now," to one of her dolls. That's quite sad…just seeing her playing it out, I suppose, her sadness in her games is upsetting as a parent…*poor dolly, you were happy carefree dolly and now you're not a happy carefree dolly now. Now you've got diabetes like me. I'm not a happy, carefree person anymore.* (p. 19)

Penny recalls a sense of sadness at witnessing her daughter making sense of her T1D diagnosis through play, interpreting that her daughter was playing out a loss of the carefree joy of childhood due to the new burden she had to carry.

Denise, Mark, Lily, Nazir and Ethan spoke to striving against this, describing how they felt compelled to use their parental authority to convey early messages to their children that their lives would not be defined or controlled by T1D:

Ethan: …one of the things she said is "Does this mean I can't be a surgeon anymore?"…One of the first questions that came into her mind…And I just wanted to be able to say to her, "It absolutely doesn't mean that you can't do anything. You just- Keep those dreams, keep those ambitions. That's part of who you are, and I don't want that part of you to change. (p.21)

Ethan's plea for his daughter to "keep those ambitions" speaks to a fear of losing her to T1D. His statement "I don't want that part…to change" signifies ways in which T1D has already changed aspects of his daughter, and his wanting to limit the scope of T1D's control. Sofia, Penny, Emma, Jude, Lily and Nazir described how seeking out contact with other families with children with T1D helped bolster their own hope, and gave them confidence in the messages they felt compelled to provide to their children:

Penny: …hearing it from a first-hand person with a child that has it, it does make you feel a bit better. You think, *Okay, well yes, it is shit, but they've coped and she's fine...*(p.43)

Kate, Denise, Mark, Lily and Nazir talked about striving against T1D taking control by supporting their child's speedy mastery of T1D management:

Lily: …it has been important to us that he was independent because we didn't ever want him to feel, *oh, I can't do that because of diabetes.* Because that's when I think they start to resent, and we just don't want that. (p.38)

Lily links the importance she ascribes to her child's independence with T1D to not wanting him to feel restricted by his diagnosis. She and others spoke to fears of their child becoming fatigued or resentful towards T1D, and a belief that their child developing an early sense of control over T1D might help to contain risk of diabetes burnout (Abdoli et al., 2020).

The importance of returning to normal life. Eight participants discussed the value of re-establishing a sense of normality following diagnosis and their roles as parents in promoting this. Mark, Sofia, Emma, Jude, Lily and Ethan ascribed considerable value to their children returning to normal life quickly following diagnosis:

> Jude: …it was just like, let's just get back to school, we could sit at home feeling sorry for ourselves, but you've got to get back in, let's just do it. (p.17)

Many parents shared Jude's sentiment about the benefits of not spending too much time "wallowing" or "dwelling" on the diagnosis, and instead getting stuck back into normal life. Some parents did not see value in dwelling on T1D when it could not be changed, whilst for others it was felt that dwelling on the burdensome aspects of T1D would make it harder for their child to integrate their T1D into their identity and heighten the risk of T1D fatigue and resentment.

Seven participants discussed their role in helping with T1D management to ensure their child would not have to feel different or miss out on formative childhood experiences. Ethan outlined a time soon after diagnosis when his child's T1D equipment broke, putting her sporting competition in jeopardy:

Ethan: Carys is…actually competing, and I've had to go outside into the car park, which was freezing, and try to, on the phone, work out how to be able to fix this thing...I just thought, you know, no one was going to stop me because I had to get this done…

…

INT: …I can see it's made you emotional. What is it…that makes you feel emotional, telling that story?

Ethan: I came so close to failing…I was able to, by the skin of my teeth, sort it out so that it would work… (p.14)

In this passage, Ethan communicates a strong sense of duty to find a solution to his child's equipment breakdown to ensure she would not miss out. This is most strongly conveyed in his statement "I came so close to failing", suggesting that had he not been able to fix the equipment, this would have represented a failure to fulfill his parental duties.

Advocating in a hostile and ignorant world. Eight participants spoke to the difficulties of reintegrating into normal life due to the ignorance and hostility of those unfamiliar with T1D, and forging a role in facilitating an easier journey for their child. Seven participants expressed intense upset at the ignorance and hostility of others about T1D and the ways this made it more difficult for their family to reintegrate following diagnosis:

Nazir: …letting friends and family know, particularly family who have no idea what this stuff means…they immediately think of the worst. That doesn't help either because in some way, shape or form, all you want to do is to go into a shell and

protect your child and protect your family and isolate yourself from everyone, but you know you can't. You've got to let people know, plan for what's going to come next… (p.24)

Nazir shares a powerful metaphor of wishing he and his family could go "into a shell" for protection immediately after the diagnosis, much like a crab uses its shell as refuge against dangerous predators. In this case, the dangerous predators Nazir alludes to are friends and family with little understanding of T1D.

Mark, Kate, Emma and Lily spoke to their role in advocating for their children in the face of ignorant and hostile others:

Mark: I think it was just us being a bit evangelical about it and trying to get people to understand and go from zero to some understanding… (p.24)

Mark's use of "evangelical" suggests he strongly believed in the importance of educating others and bringing them along on the journey of learning about T1D. It also suggests that he spent a lot of time trying to encourage understanding in others, as a means of supporting his daughter's reintegration following diagnosis.

Never switching off worry. Another aspect of participants developing a new parental role in the face of T1D was conveyed through descriptions of a novel, unrelenting sense of worry. For Kate, Denise, Mark, Penny, Jude and Ethan, this sense of worry was communicated through descriptions of T1D management as constant and unyielding:

> Denise: I mean I didn't sleep for eighteen months because I was literally up every couple of hours testing blood, doing insulin, and trying to keep him as level as possible…I was just exhausted really, and just that level of adrenaline keeping you going. (p. 30)

Denise speaks about the lengths she took to keep her child's blood glucose levels stable following diagnosis. Kate, Penny, Lily and Nazir also spoke about their loss of sleep following diagnosis, due to worries about their child's levels at night-time and a sense of responsibility to oversee night-time T1D management. Denise's reference to adrenaline sustaining her further points to a perpetual state of stress and fear that assisted her in fulfilling her new parental duties.

T1D diagnosis holds a distressing legacy

> *"[Through tears] oh dear, it brings it all back doesn't it."* (Jude; p.2)

All participants brought light to this superordinate theme during the interviews. It surmises how participants' ways of speaking about their experiences of their children's T1D diagnosis illustrate a legacy of distress they continue to carry. This is outlined through two sub-themes: Memories of T1D diagnosis carry great significance; and Emotions connected to diagnosis are still painful.

Memories of T1D diagnosis carry great significance. Five participants spoke to the significance that their memories of their child's T1D diagnosis held. Kate, Nazir and Sofia specifically described the diagnosis experience as unforgettable. Kate, Penny, Lily and Nazir also conveyed a sense that their memories of diagnosis sit amongst other traumatic memories,

often by making connections between the experience of T1D diagnosis and other traumatic experiences of illness and healthcare:

> Nazir: I vividly recollect…I mentioned [name of wife] had pre-eclampsia with Oliver. It was worse second time round with Annie. Annie was born early. [Name of wife] developed a blood infection, and I didn't know…we were in the hospital, I didn't know. The doctor came in and said, "Can you sign this because we need to get her to surgery?" I said, "So when are you going to be doing this?" She said, "Within the next 10 minutes." They just wheeled her away and you're just trusting people that they're going to do the right thing. You have no idea… (p.13)

Nazir uses a previous traumatic memory of his wife being critically unwell to illuminate his experience of his son's T1D diagnosis. Nazir repeats "I didn't know", perhaps to indicate the vulnerable position not knowing left him in. He describes how medics "just wheeled her away", alluding to a suddenness and lack of empathy akin to his experience of his son's T1D diagnosis. Furthermore, the final line conveys Nazir's sense of helplessness in the hands of health professionals, who he had no choice but to trust, again mirroring his experience of his child's T1D diagnosis.

Emotions connected to diagnosis are still painful. All participants spoke directly and indirectly to how, years later, speaking about memories of their child's T1D diagnosis brought up intensely painful emotions:

> Nazir: The scars are still relatively raw I would say. I can't watch any programme on TV that has anything to do with hospitals, I can't do it,

particularly…anything to do with children, I can't do it. I don't have the ability or the tools to be able to manage or handle that. The scars are still very raw even though…Oliver was diagnosed almost three years ago. What's the date today? It will be three years on Thursday. You never forget. (p.14)

Nazir's repeated powerful metaphor of "raw scars" highlights the diagnosis as a wound that continues to be painful and sensitive. Repetition of "I can't" when talking about TV shows involving hospitals strengthens his message that he does not feel emotionally equipped to face material that might activate traumatic memories of the diagnosis experience.

Penny, Lily and Ethan shared reflections that if they had been offered more emotional support during and following the diagnosis, it may have helped to process and cope with the psychological impact. Penny and Lily spoke about wanting to be signposted to more resources focused on the emotional impact of T1D, to give them a sense of what to expect on their journey and to validate their emotions about the diagnosis. All three participants discussed wishing there had been more opportunities to speak with a trained mental health professional, a resource that was not offered:

Penny: She made a sort of off-hand comment like, "Oh, we couldn't speak to the parents, but it's more for the children because they're the ones going through it," and the way she said it made me feel like *oh, so if I ask to speak to you, you're going to treat me like I'm a…big baby*. (p.33)

Penny recalls asking for emotional support and this resulting in her feeling invalidated and shamed. Penny, Lily and Ethan described how having this sort of space could have provided an opportunity to process their feelings about the diagnosis, to receive empathy and validation about their emotional experiences, reassurance about feelings of guilt and blame, and to provide containment that may have made them better containers for their children. Instead, these parents received limited options regarding psychological support:

> Ethan: It's difficult to be able to go off and speak to somebody…The best thing that you can do is go back to your GP and say, "I now feel like I'm suffering from depression," and then they will put you onto a psychologist, who you can then say, "Actually, I'm pretty much just absolutely still feeling like I've been hit by a bowling ball because of the diabetes." (p.36).

Ethan suggests that generic pathways of mental health support might not adequately meet the needs of parents following their child's T1D diagnosis, and that parents should be supported to address its lasting and weighty "bowling ball" impact.

Discussion

This study aimed to explore parents' experiences of their children being diagnosed with T1D. Findings suggest that the experience of T1D diagnosis led parents to undergo a vast array of emotions, including panic and fear, guilt, helplessness, and pride. Participants described how different interactions with HCPs promoted and undermined their sense of safety during the diagnosis. Participants reflected about the impact diagnosis had on their parental role, causing a loss of confidence as parents grappled with the diagnosis. They

outlined journeys of finding their feet and incorporating T1D into an augmented parental identity. Their stories elucidated enduring distressing memories of the diagnosis experience.

On the edge of a precipice

Participants described carrying a great emotional load early in their children's T1D diagnoses, due to stress from the pre-diagnosis period, feeling a need to conceal their level of concern to protect their children, and intense feelings of guilt and blame immediately after diagnosis. Extant literature involving parents of children with T1D (Bowes et al., 2009; Rankin et al., 2014; Rankin et al., 2016) and of children with other medical conditions (Diaz-Caneja et al, 2005; Kirk et al., 2015) has highlighted feelings of guilt and blame during first hospital admission. The findings of this study bring to light the nuances of parents' emotional experience before even reaching hospital and add richness to understandings of the emotional load parents bear with diagnosis. Parents were required to quickly grapple with what diagnosis meant for theirs and their children's lives going forward, leaving them with a strong sense of uncertainty and responsibility about the future. Literature has previously highlighted parents' intense sense of responsibility about their children's T1D management (Rankin et al., 2016; Coffey et al., 2006). The present study contributes to our understanding of how early these fears develop during the diagnosis of T1D, a valuable finding given evidence that early parenting stress may impact on parents' engagement with T1D education and sense of self-efficacy with T1D management (Streisand et al., 2005).

Participants depicted being lurched into a state of psychological uncertainty during their children's hospital admissions, exacerbating their already heavy emotional load. Several studies have reported on a sense of role loss parents experience during their child's hospital admission (Board & Ryan-Wenger, 2003; Simeone et al., 2018), described by Foster et al.

(2013) as changing from "the protective parent to…the helpless onlooker" (p.446). This is consistent with current participants identifying strong feelings of helplessness and loss of parental authority during their child's hospital admission. Participants detailed how evasive and unempathetic communication by HCPs exacerbated their feelings of helplessness during diagnosis. Participants also expressed their distress at their children having invasive medical procedures without sufficient communication about what and why this was being done. These findings are congruous with literature highlighting the significance of quality communication from HCPs to parents during hospital admissions of their children, specifying the importance of empathy and clarity (Gemmiti et al., 2017; Diaz-Caneja et al, 2005; Board & Ryan-Wenger, 2003; Kee et al., 2018). These qualities are believed to help emotionally reassure parents, meaning they are more able to take on T1D education (Rankin et al., 2016), and lessening the longer-term impact of diagnosis on parents' wellbeing (Board & Ryan-Wenger, 2003). Clear and empathic communication during diagnosis may also help redress the imbalance of power felt between parents and HCPs (Board & Ryan-Wenger, 2003; Neill & Coyn, 2018), which perhaps contributed to parents' sense of helplessness at diagnosis described in the present study. Participants commented on the significance that reassuring and comforting moments with knowledgeable HCPs held in promoting their sense of safety.

Participants portrayed the harmful impact of a perceived lack of knowledge, awareness, and confidence by non-specialist HCPs in responding to T1D throughout their diagnosis journeys. This is supported by existing calls in the UK to enhance training so that all medical professionals have the skills and knowledge to notice the symptoms of T1D (Diabetes UK, 2014) and attend to the needs of inpatients with complex conditions (Royal College of Physicians, 2015; George et al., 2011; Rajendran et al., 2015), including T1D (Edge et al., 2012). The accounts of participants in the present study suggest that gaps

remain. Current clinical guidelines (NICE, 2018) recommend the immediate referral of children with suspected T1D to specialist multi-disciplinary paediatric diabetes teams. This is noteworthy given recent findings that only 52% of paediatric diabetes services across the UK meet the Royal College of Nurse's recommended nurse-to-patient ratio (Charalampopoulos et al., 2018). The present study highlights specific challenges of this approach for families being diagnosed during the weekend and bank holidays. Given the rising prevalence of T1D and increasing complexity of insulin treatments started following diagnosis, staffing issues in specialist teams and knowledge gaps in non-specialist medical professionals must be carefully considered to ensure the wellbeing of families. Several participants spoke about resource and staffing issues currently facing health services and how this negatively affected their diagnosis experience. Similar accounts have been shared in other recent qualitative research with young people and their parents attending A&E (Owens et al., 2016; Mitrofan et al., 2019) and with NHS staff (Egan et al., 2019; Kerasidou & Kingori, 2019).

Losing and rebuilding parental identity

Participants outlined ways that T1D diagnosis posed a threat to their existing conceptualisation of their parental role. Their expertise was threatened by having to learn a great deal of novel information during T1D education, and parents felt deskilled in the early phases of T1D management, comparing the experience to bringing home a new-born baby. These findings add to research evidence of a sense of overwhelm caused by early T1D education and management (Rankin et al., 2016; Kovacs et al., 1990), and of the ways T1D diagnosis can create fear for parents regarding their ability to support their children (Streisand et al., 2008). Parents reported intense distress about having to give insulin injections, corroborating existing research (Lowes et al., 2005; Rankin et al., 2016), and alluded to a sense of failure due to not being able to protect their child from T1D. Parents recounted

overwhelmingly positive care from their diabetes teams during the early stages post-diagnosis, specifically highlighting the benefits of reassurance, availability, and confidence-building.

Participants painted a picture of rebuilding a parental identity in the face of their child's T1D diagnosis. Parents described a strong desire to prevent T1D from taking control over their children, using their parental authority to promote hopeful messages about the future and supporting children's increasing mastery over T1D management. Parents also identified a role in helping their children regain a sense of normality, by encouraging them to return to normal activities and supporting with T1D management in the background. Participants spoke about ignorance and hostility their children faced after diagnosis, supported by findings that T1D is still not well-understood (Simmons et al., 2017), and advocating for their children to help them reintegrate into normal life. The juxtaposition of parents highlighting parental authority, supporting T1D management, and advocacy alongside promoting children's mastery and independence might speak to the fact that the children in the study were diagnosed during adolescence. Adolescence is understood to involve social role transition in families, as young people strive for greater independence and autonomy (Laursen & Collins, 2009). Adolescence is defined by influential peer relationships (Crone & Dahl, 2012), known to impact on adolescent health behaviours (Cattelino et al., 2014). Parents appeared to forge a nuanced role, encompassing taking on management and advocacy, as well as promoting autonomy, demonstrating their efforts to support their children to navigate an adolescence with T1D.

Parents also described how their new role encompassed a constant state of worry. Similar perspectives have been identified in other qualitative studies (Rankin et al.2016;

Sullivan-Bolyai et al. 2003; Lowes et al., 2005). Worry appeared to permeate day-to-day experiences of parenting an adolescent newly diagnosed with T1D. Parents also described projected worries about the future, when their children would have to look after themselves, consistent with findings from a meta-synthesis focusing on the experiences of parents of children with chronic health conditions (Kepreotes et al., 2010) and other studies about parents of children with T1D (Spencer et al., 2013).

Grief & trauma: lost opportunities for processing

Participants expressed the lasting impression of their diagnosis experiences, including the unforgettable quality of memories, and the painful emotions which endure. Their accounts are consistent with literature characterising the chronic grief associated with parents' experiences of chronic illness diagnosis in their children (Kepreotes et al., 2010), as well as literature demonstrating parents' traumatic responses following a child's diagnosis of T1D (Whittemore et al., 2012; Rechenberg et al., 2017; Schiaffini et al., 2019).

Several participants outlined a lack of support in processing their emotions about their child's diagnosis, and insufficient resources to help them emotionally prepare for navigating newly diagnosed T1D. Since 2004, NICE have recommended that young people and their families/carers in the UK should receive access to emotional support following diagnosis, and access to timely support from mental health professionals with T1D experience if there is evidence of psychological difficulties. Despite improvements in the provision of specialist psychological services in paediatric diabetes teams in recent years (Charalampopoulos et al., 2018), findings from the present study suggest that parents' access to specialist psychological support following diagnosis remains an ongoing issue in some instances.

Clinical Implications

These findings provide meaningful insights relating to the research priorities outlined by Wylie et al., (2019), including "to understand the impact of the delivery of a diagnosis, identify the hallmarks of a positive diagnosis experience" and "find factors which could reduce the stress or trauma of diagnosis" (p.1535). Parent perspectives are imperative to understanding factors which might contribute to positive versus stressful and traumatic experiences of diagnosis. Parents play a vital role in T1D management and parental psychological distress at diagnosis has been found to predict later distress, and to negatively impact child psychological adjustment (Whittemore et al., 2012). Research evidence shows that children with psychological adjustment issues following diagnosis are more likely to experience continued adjustment difficulties (Delamater, 2018; Luyckx et al., 2010). Furthermore, evidence demonstrates that children's mental health distress predicts diabetes metabolic control (Hood et al., 2011; Jaser et al., 2017; Hilliard et al., 2016).

The findings suggest that feelings of guilt and blame are very live for parents at diagnosis, and HCPs providing reassurance may help to contain these feelings. Empathic, clear communication by HCPs was considered highly valuable and may help reduce feelings of helplessness experienced by parents during diagnosis. Empathic communication might include providing reassurance that their child is going to be OK, that the parents are not to blame for T1D and that they did the right thing by seeking medical help when they did. Clear communication might involve providing a brief, simple explanation of T1D early during hospitalisation, and where possible explaining the what and why of medical interventions being carried out. HCPs using considerate language to avoid eliciting greater fear is supported by recent guidelines (NICE, 2018; Lloyd et al., 2018). Participants highlighted the incredible value of dedicated, available, knowledgeable, specialist paediatric diabetes staff

who provided reassurance and built parent's confidence as they learned to parent in the context of T1D. However, non-specialist HCPs and policy makers should not assume that rapid referral to a specialist paediatric team will adequately fulfill parents' pressing information and education needs at diagnosis, for reasons previously outlined (Charalampopoulos et al., 2018). The traumatic impact of experiences of insufficient information sharing and communication at diagnosis had a long-lasting impact on participants and influenced families' early experiences of living with T1D. The findings support evidence of a need to fill the training gaps of non-specialist medics regarding T1D (Royal College of Physicians, 2015; George et al., 2011; Rajendran et al., 2015), so they can provide basic information and reassurance about T1D at point of diagnosis in cases where paediatric specialist diabetes teams are not available. This may become an increasingly pressing issue given staffing difficulties (Charalampopoulos et al., 2018) and increasing incidence of T1D. Participants specifically wished they had received reassurance that whilst T1D is a chronic health condition requiring close management, their children would be able to live fulfilling lives.

Findings that diagnosis was associated with a loss of parental role brings awareness to these intense emotional experiences. Greater awareness may allow HCPs working with parents at T1D diagnosis to offer them anticipatory guidance about what they might expect and normalise and validate these emotional experiences. This awareness could also offer insights about contributory issues for families struggling to integrate T1D care afterwards. Participants expressed ongoing grief and trauma responses related to their children's diagnosis, and some suggested that greater access to emotional support and resources at diagnosis might have been helpful. This is consistent with NICE (2018) guidelines

recommending that family/carers should receive access to emotional support following diagnosis, and timely access support to mental health professionals if indicated.

Limitations and future Research

The present study used IPA methodology, where a researcher attempts to make meaning out of the accounts of a small group of participants about their experience of a phenomenon (Smith et al., 2022). All participants were recruited indirectly through a large, well-known diabetes charity, implying an existing awareness of, and involvement with, community support. Participants all appeared to have positive relationships with their healthcare teams and reported positively on their children's current T1D management (all rated T1D management as going 'well' or 'very well'). In addition, participants self-selected to participate, suggesting a level of comfort in discussing their experiences. The present study therefore does not capture the experience of parents who are less engaged with the T1D community or their children's healthcare teams, or who are struggling significantly with their children's T1D management. The study had limited ethnic and cultural diversity of participants, which is unfortunate given evidence of the additional barriers non-English speaking parents of children with chronic conditions experience in terms of communication and support issues when seeking medical care in the UK (Atkin & Ahmad, 2000), and insufficient qualitative accounts of the experiences of Global Majority families (Kepreotes et al., 2010). The sampling strategy may have had an impact (recruiting through Diabetes UK, a national diabetes charity) given evidence that people with diabetes from minoritised backgrounds often do not receive equitable access to healthcare and support services (Zeh et al., 2014). Future research would be valuable to address some of the limitations of the present study, namely understanding the perspectives of a more diverse array of families, perhaps with a specific focus on the experiences of families less engaged with their diabetes teams, or

of those parents known to face institutional racism when seeking medical care (Atkin & Ahmad, 2000). Furthermore, the participants were not asked to provide demographic information including SES, parent age and level of education. Is is therefore possible that participants came from a small demographic pool and that their experiences may not be representative of other UK families. However, recruiting through a national diabetes charity meant participants represented a reasonable variety of locations across the UK, and therefore a variety of NHS hospitals and GPs, and the similarity in their experiences is of note. Future research should endeavour to record more demographic details to promote transparency and help to contextualise the sample.

Another possible limitation of the study is in the decision to interview parents of children and adolescents aged between 11 and 16, many of whom were diagnosed on the cusp of adolescence. Adolescence represents a unique period of development involving social role transition in families, as young people seek independence and autonomy (Laursen & Collins, 2009). It is therefore possible that some pertinent aspects of parens' experiences were connected to this methodological choice, particularly themes around losing and rebuilding parental identity. These findings may therefore not be representative of the experiences of parents of younger children receiving diagnosis of T1D. The majority of existing UK based studies include parents of children with a wide age range, from 2-15. Perhaps the specific of focus of the present study on the experiences of parents of adolescence could also be considered a strength, in terms of IPA's tenet that greater sample homogeneity can result in deeper analysis (Smith et al., 2022). Future research focusing on parents of this age group may help to further unpack the impact of adolescence on parents' sense-making and adjustment to T1D diagnosis.

Furthemore, a limitation of the study may be that parents were interviewed 35 months to 62 months following their child's diagnosis. The diagnostic window for inclusion was set in an attempt to find balance between avoiding the "honeymoon period" in T1D, avoiding interviewing participants whose children were diagnosed during the COVID-19 pandemic, (Unsworth et al., 2020), whilst also wanting parents to have sufficient memory of the diagnosis. However, it is possible that having such a significant gap between diagnosis and recall may have meant parents had time to process, normalise and speak about their experiences, which may have therefore impacted on what they shared during the interviews.

Conclusion

Parents articulated the emotional impact of their children being diagnosed with T1D. They spoke to the ways interactions with HCPs during and following diagnosis promoted and undermined their sense of safety. Their experiences point to a need to scaffold parents during diagnosis to reduce helplessness and uncertainty, to communicate clearly and empathically, and to provide spaces and resources to help parents process trauma and grief responses in the wake of their children's diagnosis.

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Part Three: Critical Appraisal

Critical Appraisal

In Part Three of the thesis, I, the researcher will reflect upon the experience of conducting this research. The first section focuses on reflexivity, including discussion of my own experiences and how I attempted to maintain awareness and reflection of the impact of these throughout the different stages of research. Secondly, it focuses on issues of power that arose during the process of conducting the research. Quotes from a bracketing interview conducted before the data collection phase of the research, and the reflective log completed throughout the research process, are presented in italics to elucidate the issues discussed, and in the interests of transparency (Florczak, 2021).

Reflexivity and exploring my position throughout the research

Reflexivity is considered to play a role of significant importance when conducting qualitative research (Dowling, 2006; Jootun et al., 2009). Dowling (2006) outlines how reflexivity involves the researcher(s) being aware in the moment of what is influencing one's own "internal and external responses" (p.8), as well as holding awareness of one's relationship to the research topic and the participants. Parahoo (2006) defines reflexivity as "the continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence" (Jootun et al., 2009, p. 42). Within IPA, it is recognised that attempts to make sense of research data will include some influence of projection on the part of the researcher (Smith et al., 2022), and that "putting aside" (Jootun et al., 2009, p.42) one's preconceptions and beliefs is not entirely possible. It is therefore probable that a different researcher with different life experiences, values and beliefs may have developed different, yet equally valid interpretations of the data. Steps were taken to try and maintain reflexivity during the research process, such as completing a bracketing interview with a fellow trainee clinical psychologist in advance of conducting interviews and keeping a reflective journal

throughout the research process to increase awareness of my own perceptions and reactions. I also regularly consulted with members of my research team throughout all stages of the research, to further enhance reflexivity (Dowling, 2006) and help me to maintain harmony between endeavoring to take analysis "deeper" through my own interpretations and trying to "stay close" to participants' own accounts (Smith et al., 2022). Here, I discuss some of the dominant thoughts and reflections that emerged along the way.

In reflecting on the factors that motivated me to choose this research topic, the bracketing interview elucidated personal experiences that held resonance, as well some of my professional experiences. Firstly, I grew up with a father with T1D, which led me to have a particular relationship with and interest in T1D that others without a familial connection may not share. Furthermore, in my early 20s my mother was diagnosed with and died from cancer, which was a very significant experience in my life. During my bracketing interview, I reflected about how the research topic was advertised to students by stating that the study hoped to inform healthcare practices around the diagnosis of T1D, and how this may have resonated with me:

> *"Yeah, so I guess that aspect of there being an implicit nod to the harms that health systems can do, which is connected to a different experience, which is my mum's healthcare experience and the position of being a family uh…at the whim of a healthcare system and how disempowering that can feel." (Bracketing interview, 10/08/2022)*

My motivation to conduct this study was also connected to my professional experiences. Before clinical training, I worked as a research assistant for several years.

Whilst this experience helped me to develop an appreciation for the importance of both quantitative and qualitative methodologies, it allowed me to develop awareness of my personal investment in qualitative research. Particularly, the paradigm's interest in the lived reality of individuals and personal meaning-making, and its attempts to capture and convey this through dialogue with a researcher, were consistent with my values. This research topic was therefore appealing to me, because I strongly wished to pursue a project with a qualitative focus for my doctoral thesis.

My bracketing interview also allowed me to explore preconceptions I might have about the research topic before beginning to conduct interviews, based on both my personal experiences and my prior investigations of the research literature. The narratives I have around my father's T1D diagnosis, which occurred before I was born, included that the period preceding the diagnosis was stressful and confusing, that the diagnosis was a seminal moment in his life, and that a conversation with a straightforward and compassionate diabetes consultant held great significance to him. Perhaps the more loaded of my preconceptions were connected to my experiences of my mother's care during and after her cancer diagnosis:

> *"…the experiences of information sharing, diagnosis sharing, understanding what was going to happen next all feeling really difficult, and confusing, and unclear quite a lot of the time. So I definitely come with a laden assumption that healthcare systems don't always deal really gently with big bits of news and information." (Bracketing interview, 10/08/2022)*

Reflecting on my preconceptions allowed me to consider how my existing knowledge and experiences might lead me to assume understanding of participants without adequate exploration, and think about how to mitigate this:

> *"I think with the interviews I'll have to be mindful of being led down certain paths, maybe particularly around difficult experiences of receiving diagnosis, the mum stuff, that sort of stuff. And getting really hooked into something and overidentifying with it or being overfamiliar. And really being careful to make people be explicit about exactly what that experience was for them, rather than assuming any shared experience there." (Bracketing interview, 10/08/2022)*

Using a reflective journal throughout the research process was extremely valuable in helping me maintain a curious stance about my own emotional responses during data collection and analysis. During the interview process, I noticed sometimes feeling sensitive to accounts of unempathetic treatment by HCPs, feelings of disempowerment, and comments about overstretched services and staff, which strongly connected to my own experiences of my mother's cancer diagnosis. Keeping the journal helped me reflect on these reactions and resist a tendency to lean into my own views, helping to 'bracket' my experiences so as not to 'contaminate' participants own unique accounts with my own biases:

> *"I was aware of myself feeling a bit upset and detached when the participant was reflecting upon her own medical traumas and she was feeling angry about it (because of my own shared experiences). I wanted to give this topic (quite novel in the interviews) enough space but didn't want to over-privilege it because it aligns with my perspective." (Reflective journal, 28/11/2022)*

Furthermore, during some interviews, I noticed an internal reaction when participants seemed to promote a stance which I considered dismissive of emotions, that promoted wanting to keep going and not dwell on emotions. In my reflective log, I tried to reflect on the reasons for my reaction as well as the impact it might be having on interviews:

> *"Do I assume presentation of things going well is emotionally dishonest/oversimplified? I find myself a bit internally resistant to "keep calm and carry on" ideas or the notion that we "shouldn't let it change us". Where does that come from me? Why do I resist those ideas?" (Reflective log, 07/10/2022)*

I reflected that some of my reactions were due to my clinical work and interests, where I tend to lean into approaches that promote emotion as healthy expression and suggest that attempting to exert lots of control over emotional expression can have negative consequences (Harris, 2022). I reflected that accounts of positive experience of diagnosis sometimes jarred with me, perhaps on one level because these did not align with what I expected to find, and because they raised anxiety about the relevance of my research. This highlights a challenge of needing to validate and rationalise a study within the context of broader research, whilst also needing to stay close and honestly portray the specific experiences of my participants. I also reflected on how painful emotions and upsetting situations were dealt with when I was a child:

> *"I noticed a small internal flinch at the idea that "we can't just snuggle up on sofa"...can't we? That's one of the things I was encouraged to do when I was little and things were feeling challenging." (Reflective log, 07/10/2022)*

This leads onto another challenge that I considered in the reflexivity process, pertaining to embodying a dual identity of a researcher and a clinician in training. In my clinical work, I endeavour to be an empathic clinician and attempt to co-construct a shared understanding with a client about what they might be discussing. This may sometimes involve accepting and validating their expression (such as "I felt angry") without always asking them to explore this more deeply. I was aware that the approach of IPA would require me to explore participants' statements deeply and not to assume shared meaning (Smith et al., 2022). Before starting the interviews, I worried that this might sometimes be awkward or jarring for participants, which felt at odds with my intentions in my work as a clinician. This worry was only realised a handful of times during interviews:

> *"Tricky bit where I asked what I thought was an IPA question…Tried to preface with 'I know it's a weird question, but for the sake of the interview, why did x bring up those emotions in you?'. I wondered if the participant seemed…to find the question a bit invalidating? But we were able to move on. She said at the end it had 'felt therapeutic to talk about it' which I took as a good sign. I hope I didn't add too many of my own thoughts or insights, but maybe felt a bit pulled into validating this participant." (Research log, 28/11/2022)*

As alluded to in the above reflection, another dilemma that arose from this dual role included trying to refrain from making too many interpretations, additions or reframes as one might be more likely to in a therapeutic context. Furthermore, I perceived a dilemma about the extent to which is ethical to ask clarifying questions, to gain more analytic depth, when parents were becoming distressed by speaking about their experiences of diagnosis.

Reflecting on this in my log and with my research team, I endeavoured to strike a balance between gently exploring participants' assertions, respectfully moving on when this was signalled by them, and regularly reminding participants that they could pause the interview or choose to move on from a question at any point.

Furthermore, my reflexivity process allowed me to consider my own assumptions about how participants might interpret me. In my bracketing interview, I wondered whether because of my appearance, participants might read me as a young woman and assume (correctly) that I am not a parent myself. I wondered if this might lead participants to feel less trusting of my capabilities to understand and 'hold' their emotional experiences, and therefore limit what they decided to share. I also became aware of my identity as an HCP and the different ways this might impact what participants decided to share:

*"…we're asking really specifically about the experience of diagnosis, and depending on the family's relationship to help, relationship to mental health input, relationship to health professionals more generally, might inform the way they think about me. I like to think that people often…they like the opportunity to share their experiences. And that they value the opportunity to be asked about their experiences…But at the same time it is important to be mindful that I'm working within the organisation that I'm asking them to reflect on. And that may lead to some projection onto me about their experiences, it might lead to some minimising of the things they've experienced because I'm part of that system. Or it could be like an opportunity to talk about all the things that they feel upset about with their child's experience***."** *(Bracketing interview, 10/08/2022)*

Ultimately this issue did not feel extremely pertinent during my interviews, however I think it was important to hold it in my mind and reflect on. One way in which arguably it may have influenced the interviews was in the significant commentary by participants about lack of emotional support at diagnosis, with some participants speaking explicitly about the lack of emotional support, mental health support or clinical psychology provision during and after their child's diagnosis. Perhaps these aspects of participants' experiences were more apparent to them in the context of speaking with me, a trainee clinical psychologist, or perhaps there may have been some social desirability bias at play (Grimm, 2010). It remains possible that parents may not have spoken to these issues as much had someone else been interviewing them. However, these comments remain extremely relevant and important to understanding parents' experiences of their child's T1D diagnosis and reiterate the findings of other literature in the field (Rankin et al., 2016).

In my bracketing interview, I also wondered whether or not to disclose my personal relationship to T1D:

"Obviously I don't have T1D, I'm speaking to parents who may or may not have diabetes and I also don't have it. So I think that's an interesting thing. I haven't really thought yet about how to present myself, or disclosure of having a family member with diabetes, and how/when that might be appropriate. I can imagine that without making it clear, parents might assume I have no connection to diabetes beyond an academic interest. I don't know what that would mean, whether that would make them more careful about what they share…'this girl doesn't have diabetes and she also doesn't have children, so why is she interested? How is she really going to be able to get this or hold it?'." (Bracketing interview, 10/08/2022)

This reflection helped me begin to consider this dilemma with the research team. I decided not to disclose my connection to T1D ahead of the interviews, due to wondering whether it might distract participants from the topic at hand, lead them to assume shared knowledge, and perhaps lead to unhelpful comparisons. However, I did tell participants about my relationship to T1D after each interview during our debrief. This felt very natural as almost all parents asked me explicitly about my interest in the research area, whilst protecting the data from contamination.

Issues of power during the research process

Issues of power are very relevant to research practices, and in some ways especially pertain to qualitative research. Whilst quantitative research adopts a positivist position that scientific investigation can produce objective data, which can be quantified, qualitative research operates by "letting the investigated object speak" (Kvale, 1996, p.1) The present study adopted a constructivist epistemological stance, where the construction of knowledge is seen as involving an active process by the researcher rather than "a capture of social reality" (Anyan, 2013, p.2). This process of knowledge construction is vulnerable to power dynamics at all stages of the research process. Some issues that felt particularly pertinent to the present research study are outlined below.

One issue relating to power arose when applying for ethical approval for the present study. The research team considered the possibility that interviews with parents about their experiences of diagnosis might also elucidate present day safeguarding issues, pertaining to their general emotional wellbeing, or specifically relating to their T1D management. The research team decided that it might be valuable to ask participants to provide their GP details

and be explicit that these would only be used if issues relating to child safeguarding were disclosed. I discussed the ethics committee's response during my bracketing interview:

> *"we actually got push back from the ethics committee, who sort of said how are you going to determine what is good or reasonable management, when actually the experience of management is extremely difficult and complex? So how are you going to be sure that you're not just going to pathologise families who are doing their best? Which I thought was really interesting and not expected."*

The research team discussed this and responded to the committee by naming our collective experiences with assessing and managing risk and the complexities of T1D management. We also named our recognition that difficulties with diabetes management are often part of learning and adjusting to the condition, and that our intention would not be to further stigmatise families. Luckily, this issue did not arise during the process of conducting interviews.

During the data collection process, I sometimes felt unsure of how best to strike a balance between engaging with the material the participant was bringing (Smith et al., 2022) versus being concerned with the content of the interview schedule: This connects to a form of power described by Anyan (2013) as "agenda-setting power" (p.3):

> *"I felt she sometimes veered into present issues, or talked about things that, from my perspective, were less relevant to diagnosis. I tried my best to sit with it and see if she brought it back round herself. But sometimes (especially towards the end of interview and I was aware of time dwindling), I might have been more directive. I hope this did not overly impact the interview." (Reflective log, 25/10/22)*

The researcher is often positioned as the person who directs the interview by asking questions and moderating the interview, as alluded to in this passage. From journaling and discussions with the research team, I believe I was able to find ways to manage this dilemma, namely by letting participants speak freely and seeing what came up, and if necessary, asking them explicitly about how this linked to their experience of diagnosis. I am glad I was able to resist my urge to quickly return to the topic of diagnosis, because allowing participants to share their own narratives elucidated interesting and relevant content addressing the research question. For example, multiple parents made comparisons between diagnosis and other traumatic medical experiences, which became something that I wrote about in my analysis.

Another issue of power pertains to the data analysis stage. At times, it felt difficult to know how to organise the data and I experienced an ethical dilemma about what to feature in the analysis. Due to this being a doctoral piece of research, and in line with Smith et al.'s (2022) guidelines, I interviewed 10 participants about their experiences. This was somewhat challenging in the context of IPA, which intends to privilege the meaning-making of individuals' narratives (Smith et al., 2022). Some parents were more expressive than others, and, as mentioned, some spoke about matters that I perceived to be less relevant to the research question. I was forced to exclude some valuable and highly sensitive contributions of participants from the final narrative because of my perception that this material was less relevant to my research question. This speaks to the powerful role of the research in deciding which, why and how narratives are represented (Pillow, 2003). I tried to redress these power dynamics in a few ways. Firstly, the research team was consulted at various stages of analysis to discuss and question my organisation of the data. Secondly, despite the transcripts varying substantially in length, I attempted to give each participant a similar amount of space within

the analysis, in line with the ideographic tenets of IPA (Smith et al., 2022). The research team also discussed the possibility of conducting member checking, "the process of soliciting feedback from one's participants about one's data or interpretations" (Motulsky, 2013, p.389). However, the team eventually agreed not to engage in this, due to several issues with the practice. Firstly, whilst member checking has been touted as a means of ensuring the trustworthiness and validity of a study's findings, this is at odds with the constructionist epistemological stance of the authors, and with the methodological tenets of IPA (Smith et al., 2022). We would argue that rather than the research process being an attempt to accurately capture participants' "objective" social reality, it is a process of joint knowledge construction, an active process by the researcher and the participant, where the researcher's preconceptions cannot be entirely set aside (Anyan, 2013; Smith et al., 2022). Secondly, whilst member checking may have "transformational validity" (Motulsky, 2013, p.394) when used in a timely, thoughtful and genuinely empowering way, the research team did not feel that the timescale of the current project would allow for participants to be consulted in sufficient depth. The consequences of "transactional" member-checking (Motulsky, 2013, p.394) include risking participant distress from reviewing transcripts and interpretations, and difficulties with how best to consolidate disagreements and challenges between research and participants, and also within participants. Issues of power-sharing and member-checking will be returned to in the event that the authors attempt to publish the present research and will be given sufficient time and consideration.

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Appendices

Appendix A. Full list of search terms

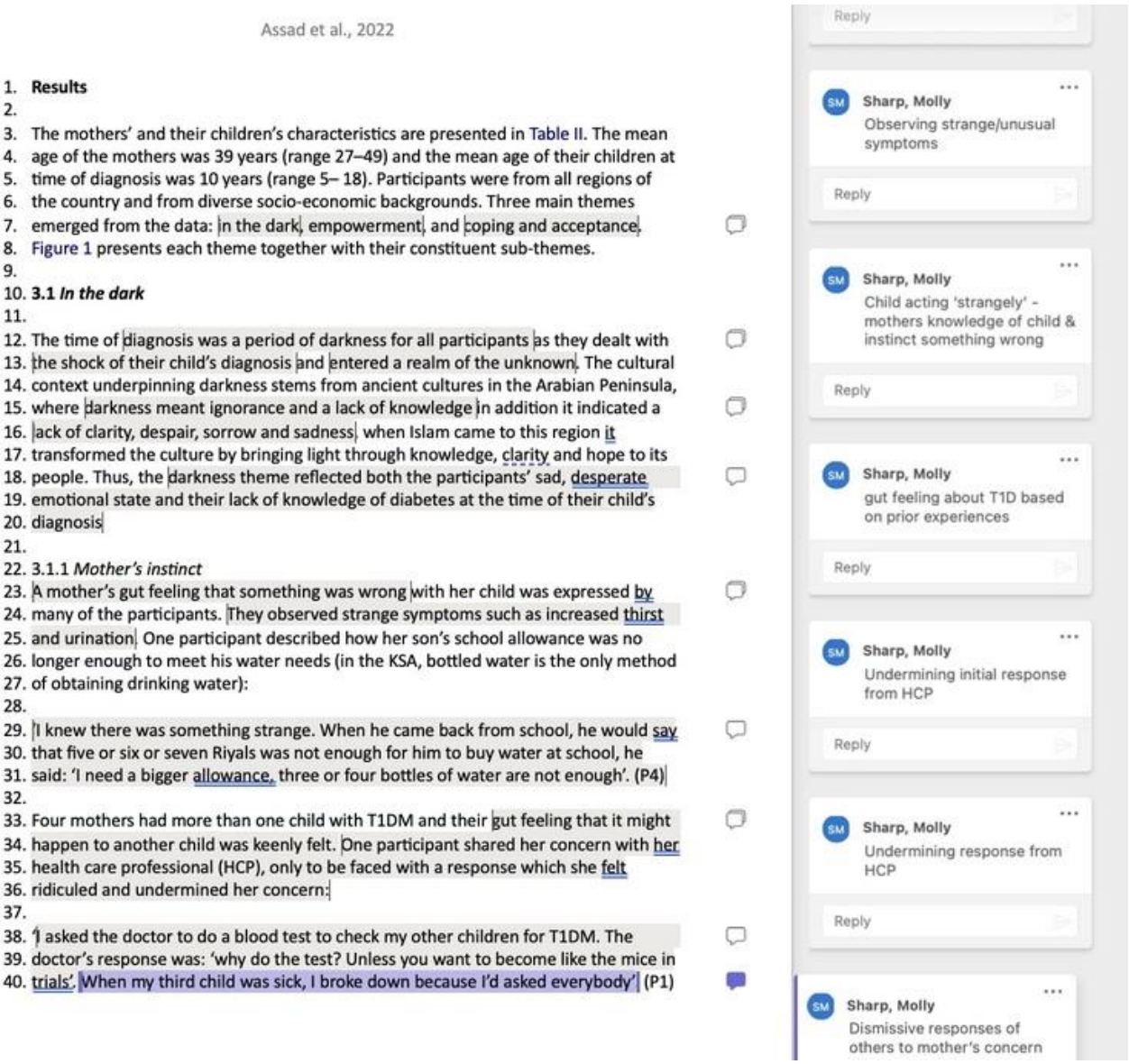
1st Stem Group: Type of Population: Parents		
MEDLINE	**PSYCInfo**	**CINAHL**
1. exp Parents/ 2. (parent* or caregiv* or caretak* or carer* or guardian*).tw,kf. 3. (mother* or mum* or mom*).tw,kf. 4. (father* or dad*).tw,kf. 5. 1 or 2 or 3 or 4	1. exp Parents/ 2. (parent* or caregiv* or caretak* or carer* or guardian*).tw,id. 3. (mother* or mum* or mom*).tw,id. 4. (father* or dad*).tw,id. 5. 1 or 2 or 3 or 4	1. (MH "Parents+") 2. TI ((parent* or caregiv* or caretak* or carer* or guardian*)) OR AB ((parent* or caregiv* or caretak* or carer* or guardian*)) 3. TI ((mother* or mum* or mom*)) OR AB ((mother* or mum* or mom*)) 4. TI ((father* or dad*)) OR AB ((father* or dad*)) 5. 1 or 2 or 3 or 4
2nd Stem group: Diabetes		
MEDLINE	**PsycINFO**	**CINAHL**
6. exp Diabetes Mellitus, Type 1/ 7. (IDDM or T1DM or T1D).tw,kf. 8. (insulin* adj2 diabet*).tw,kf. 9. (p?ediatric* diabet* or childhood* diabet* or adolescen* diabet*).tw,kf. 10. (typ? 1 diabet* or typ? I diabet* or typ?1 diabet* or typ?I diabet* or typ? one diabet* or typ?one diabet*).tw,kf. 11. 6 or 7 or 8 or 9 or 10	6. (IDDM or T1DM or T1D).tw,id. 8. (insulin* adj2 diabet*).tw,id. 9. (p?ediatric* diabet* or childhood* diabet* or adolescen* diabet*).tw,id. 10. 6 or 7 or 8 or 9	6. (MH "Diabetes Mellitus, Type 1+") 7. TI ((IDDM or T1DM or T1D)) OR AB ((IDDM or T1DM or T1D)) 8. TI (insulin* N2 diabet*) OR AB (insulin* N2 diabet*) 9. TI ((p#ediatric* diabet* or childhood* diabet* or adolescen* diabet*)) OR AB ((p#ediatric* diabet* or childhood* diabet* or adolescen* diabet*)) 10. TI ((typ# 1 diabet* or typ# I diabet* or typ#1 diabet* or typ#I diabet* or typ# one diabet* or typ#one diabet*)) OR AB ((typ# 1 diabet* or typ# I diabet* or typ#1 diabet* or typ#I diabet* or typ# one diabet* or typ#one diabet*)) 11. 6 or 7 or 8 or 9 or 10
3rd Stem Group: Diagnosis experience		
MEDLINE	**PSYCInfo**	**CINAHL**
12. exp diagnosis/ed, px [Education, Psychology] 13. diagnos*.tw,kf. 14. 12 or 13	11. exp diagnosis/ 12. diagnos*.tw,id. 13. 11 or 12	12. (MH "Diagnosis+/ED/PF") 13. TI (diagnos*) OR AB (diagnos*) 14. 12 or 13
4th Stem Group : Children & adolescents		
MEDLINE	**PSYCInfo**	**CINAHL**
15. (child* or stepchild* or step-child* or kid or kids or girl or girls or boy or boys or teen* or youth* or youngster* or adolescent* or adolescence or preschool* or pre-school* or kindergarten* or school* or juvenile* or minors or p?ediatric* or PICU).ti,ab. or exp child/	14. (child* or stepchild* or step-child* or kid or kids or girl or girls or boy or boys or teen* or youth* or youngster* or adolescent* or adolescence or preschool* or pre-school* or kindergarten* or school* or juvenile* or minors or p?ediatric* or PICU).ti,ab.	15. TI (MH "Child+") OR (MH "Adolescence+") 16. TI ((child* or stepchild* or step-child* or kid or kids or girl or girls or boy or boys or teen* or youth* or youngster* or adolescent* or adolescence or preschool* or pre-school* or kindergarten* or school* or

		juvenile* or minors or p?ediatric* or PICU)) OR AB ((child* or stepchild* or step-child* or kid or kids or girl or girls or boy or boys or teen* or youth* or youngster* or adolescent* or adolescence or preschool* or pre-school* or kindergarten* or school* or juvenile* or minors or p?ediatric* or PICU 17. 15 or 16
Final search lines		
16. 5 and 11 and 14 and 15	15. 5 and 10 and 13 and 14 16. 5 and 10 and 13 17. limit 16 to (100 childhood <birth to age 12 yrs> or 200 adolescence <age 13 to 17 yrs>) 18. 15 or 17	18. 5 and ss and 14 and 17

Appendix B. CASP-QC checklist

Domain	Features	Comments & Score
1. Was there a clear aim of the research?	• There is a clear statement of the aims of the research	**Score:**
2. Is the qualitative methodology appropriate?	• Qualitative methodology is appropriate • Actions and/or subjective experiences of participants are sough to be interpreted	**Score:**
3. Was the research design appropriate to address the aims of the research?	• The research design has been justified • The decision regarding use of methodology has been discussed • The decision regarding the use of analysis has been described	**Score:**
4. Was the recruitment strategy appropriate to the aims of the research?	• Selection of participants has been discussed • Recruitment issues (e.g. biases) have been discussed • Exclusion discussed?	**Score:**
5. Was the data collected in a way that addressed the research issue?	• The setting for data collection has been justified • The approach to data collection has been outlined clearly (e.g. semi-structured interview, focus group etc.) • Methods of data collection are detailed and explicit (e.g. use of interview schedules, topics etc.) • Data recording has been outlined (e.g. audio recordings etc.) • Saturation of data has been discussed	**Score:**
6. Has the relationship between the researcher and participants been adequately considered?	• The role of the researchers has been critically examined incl. preconceptions, potential biases during various stages of the study	**Score:**
7. Have ethical issues been taken into consideration?	• Explanation of research to participants clearly outlined and consistent with appropriate ethical standards • Ethical issues raised by the study have been discussed (e.g. informed consent, confidentiality etc.) • Approval from an ethics committee has been sought	**Score:**
8. Was the data analysis sufficiently rigorous?	• Analysis processes are described in depth e.g. how categories / themes were derived from the data • Data analysis completed by multiple reviewers	**Score:**
9. Is there a clear statement of findings?	• Findings have been explicitly stated • Sufficient data are presented supporting the findings • Data presentation has been justified • Contradictory data have been presented and taken into account • Credibility of findings have been explored (e.g. respondent validation, peer review) • Subjectivity of findings have been discussed (e.g. contextualization, consideration of co-creation of findings, analysis of researcher-participant relationship) • Limitations of findings have been acknowledged	**Score:**
10. How valuable is the research?	• The researcher discusses the contribution of the research to existing knowledge and understanding (e.g. practice, policy, existing research literature)	**Score:**

Appendix C. A worked example of line-by-line coding of eligible texts



Assad et al., 2022

1. **Results**
2.
3. The mothers' and their children's characteristics are presented in Table II. The mean
4. age of the mothers was 39 years (range 27–49) and the mean age of their children at
5. time of diagnosis was 10 years (range 5– 18). Participants were from all regions of
6. the country and from diverse socio-economic backgrounds. Three main themes
7. emerged from the data: in the dark, empowerment, and coping and acceptance.
8. Figure 1 presents each theme together with their constituent sub-themes.
9.
10. **3.1 *In the dark***
11.
12. The time of diagnosis was a period of darkness for all participants as they dealt with
13. the shock of their child's diagnosis and entered a realm of the unknown. The cultural
14. context underpinning darkness stems from ancient cultures in the Arabian Peninsula,
15. where darkness meant ignorance and a lack of knowledge in addition it indicated a
16. lack of clarity, despair, sorrow and sadness, when Islam came to this region it
17. transformed the culture by bringing light through knowledge, clarity and hope to its
18. people. Thus, the darkness theme reflected both the participants' sad, desperate
19. emotional state and their lack of knowledge of diabetes at the time of their child's
20. diagnosis
21.
22. 3.1.1 *Mother's instinct*
23. A mother's gut feeling that something was wrong with her child was expressed by
24. many of the participants. They observed strange symptoms such as increased thirst
25. and urination. One participant described how her son's school allowance was no
26. longer enough to meet his water needs (in the KSA, bottled water is the only method
27. of obtaining drinking water):
28.
29. 'I knew there was something strange. When he came back from school, he would say
30. that five or six or seven Riyals was not enough for him to buy water at school, he
31. said: 'I need a bigger allowance, three or four bottles of water are not enough'. (P4)
32.
33. Four mothers had more than one child with T1DM and their gut feeling that it might
34. happen to another child was keenly felt. One participant shared her concern with her
35. health care professional (HCP), only to be faced with a response which she felt
36. ridiculed and undermined her concern:
37.
38. 'I asked the doctor to do a blood test to check my other children for T1DM. The
39. doctor's response was: 'why do the test? Unless you want to become like the mice in
40. trials'. When my third child was sick, I broke down because I'd asked everybody' (P1)

Reply

Sharp, Molly
Observing strange/unusual symptoms

Reply

Sharp, Molly
Child acting 'strangely' - mothers knowledge of child & instinct something wrong

Reply

Sharp, Molly
gut feeling about T1D based on prior experiences

Reply

Sharp, Molly
Undermining initial response from HCP

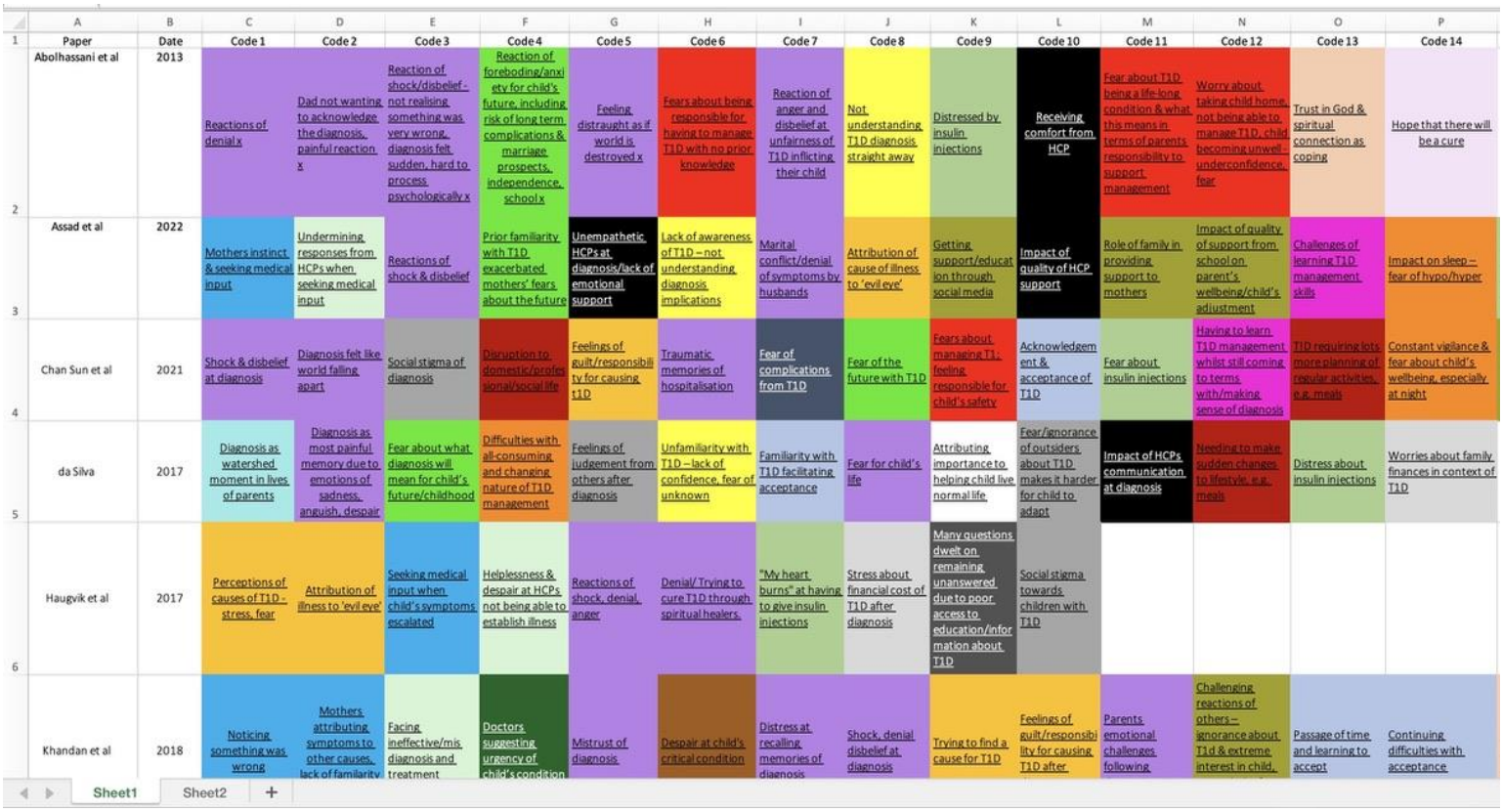
Reply

Sharp, Molly
Undermining response from HCP

Reply

Sharp, Molly
Dismissive responses of others to mother's concern

Appendix D. Colour-coded framework based on initial codes (full framework not shown)



Paper	Date	Code 1	Code 2	Code 3	Code 4	Code 5	Code 6	Code 7	Code 8	Code 9	Code 10	Code 11	Code 12	Code 13	Code 14
Abolhassani et al	2013	Reactions of denial x	Dad not wanting to acknowledge the diagnosis, painful reaction x	Reaction of shock/disbelief - not realising something was very wrong, diagnosis felt sudden, hard to process psychologically x	Reaction of foreboding/anxiety for child's future, including risk of long term complications & marriage prospects, independence, school x	Feeling distraught as if world is destroyed x	Fears about being responsible for having to manage T1D with no prior knowledge	Reaction of anger and disbelief at unfairness of T1D inflicting their child	Not understanding T1D diagnosis straight away	Distressed by insulin injections	Receiving comfort from HCP	Fear about T1D being a life-long condition & what this means in terms of parents responsibility to support management	Worry about taking child home, not being able to manage T1D, child becoming unwell - underconfidence, fear	Trust in God & spiritual connection as coping	Hope that there will be a cure
Assad et al	2022	Mothers instinct & seeking medical input	Undermining responses from HCPs when seeking medical input	Reactions of shock & disbelief	Prior familiarity with T1D exacerbated mothers' fears about the future	Unempathetic HCPs at diagnosis/lack of emotional support	Lack of awareness of T1D – not understanding diagnosis implications	Marital conflict/denial of symptoms by husbands	Attribution of cause of illness to 'evil eye'	Getting support/education through social media	Impact of quality of HCP support	Role of family in providing support to mothers	Impact of quality of support from school on parent's wellbeing/child's adjustment	Challenges of learning T1D management skills	Impact on sleep – fear of hypo/hyper
Chan Sun et al	2021	Shock & disbelief at diagnosis	Diagnosis felt like world falling apart	Social stigma of diagnosis	Disruption to domestic/professional/social life	Feelings of guilt/responsibility for causing t1D	Traumatic memories of hospitalisation	Fear of complications from T1D	Fear of the future with T1D	Fears about managing T1: feeling responsible for child's safety	Acknowledgement & acceptance of T1D	Fear about insulin injections	Having to learn T1D management whilst still coming to terms with/making sense of diagnosis	T1D requiring lots more planning of regular activities, e.g. meals	Constant vigilance & fear about child's wellbeing, especially at night
da Silva	2017	Diagnosis as watershed moment in lives of parents	Diagnosis as most painful memory due to emotions of sadness, anguish, despair	Fear about what diagnosis will mean for child's future/childhood	Difficulties with all-consuming and changing nature of T1D management	Feelings of judgement from others after diagnosis	Unfamiliarity with T1D – lack of confidence, fear of unknown	Familiarity with T1D facilitating acceptance	Fear for child's life	Attributing importance to helping child live normal life	Fear/ignorance of outsiders about T1D makes it harder for child to adapt	Impact of HCPs communication at diagnosis	Needing to make sudden changes to lifestyle, e.g. meals	Distress about insulin injections	Worries about family finances in context of T1D
Haugvik et al	2017	Perceptions of causes of T1D - stress, fear	Attribution of illness to 'evil eye'	Seeking medical input when child's symptoms escalated	Helplessness & despair at HCPs not being able to establish illness	Reactions of shock, denial, anger	Denial/ Trying to cure T1D through spiritual healers.	"My heart burns" at having to give insulin injections	Stress about financial cost of T1D after diagnosis	Many questions dwelt on remaining unanswered due to poor access to education/information about T1D	Social stigma towards children with T1D				
Khandan et al	2018	Noticing something was wrong	Mothers attributing symptoms to other causes, lack of familarity	Facing ineffective/mis diagnosis and treatment	Doctors suggesting urgency of child's condition	Mistrust of diagnosis	Despair at child's critical condition	Distress at recalling memories of diagnosis	Shock, denial disbelief at diagnosis	Trying to find a cause for T1D	Feelings of guilt/responsibility for causing T1D after	Parents emotional challenges following	Challenging reactions of others – ignorance about T1d & extreme interest in child,	Passage of time and learning to accept	Continuing difficulties with acceptance

Appendix E. Colour-coded framework of descriptive themes (full framework not shown)

Emotional reactions to diagnosis	Fear for child's future	Fear of sudden responsibility - in the immediate & distant future	Impact of lack of prior knowledge at diagnosis	Distress about having to give insulin injections	Ways of coping with diagnosis	Noticing something was wrong & approaches to seeking medical input
Reactions of denial (AB)	Reaction of foreboding/anxiety for child's future, including risk of long term complications & marriage prospects, independence, school (Ab)	Fears about being responsible for having to manage T1D with no prior knowledge (Ab)	Not understanding T1D diagnosis straight away (Ab)	Distressed by insulin injections (Ab)	Trust in God & spiritual connection as coping (AB)	Mothers instinct & seeking medical input (As)
Reactions of shock, denial, anger (Ha)	Worries about impact on child's normal activities (Lo)	Worry about taking child home, not being able to manage T1D, child becoming unwell - underconfidence, fear (Ab)	Lack of awareness of T1D – not understanding diagnosis implications (As)	Emotional pain about giving insulin injections (As)	Viewing T1D as a divine test (Ab)	Noticing something was wrong (Kh)
Mistrust of diagnosis (Kha)	Prior familiarity with T1D exacerbated mothers' fears about the future (As)	Fears about managing T1; feeling responsible for child's safety (Ch)	Unfamiliarity with T1D left some parents unprepared for what to expect (Ra)	Fear about insulin injections (Ch)	Faith & prayer as ways of coping (As)	Mothers attributing symptoms to other causes, lack of familarity T1D (Kh)
Denial/ Trying to cure T1D through spiritual healers (Ha)	Fear of the future with T1D (Ch)	Fears about doing something wrong and harming child (Ki)	Lack of knowledge of T1D meant some parents did not understand long-term implications of T1D (Sa)	Distress about insulin injections (da)	Coping through faith (Ch)	Suspecting T1D (Ra)
Reactions of denial (Sa)	Fear about what diagnosis will mean for child's future/childhood (da)	Fear about leaving hospital & being responsible for T1D management (Ki)	Unfamiliarity with T1D – lack of confidence, fear of unknown (da)	"My heart burns" at having to give insulin injections (Ha)	Viewing diabetes as a divine test (Kh)	Attributing symptoms to other things; not thinking symptoms were serious cause for concern (Ra)
Denial about T1D (Ra)	Sense of foreboding about what was to come (Lo)	Fear and confusion initially at having to manage T1D - under-confident (KL)		Insulin injections as daunting (Ki)	Coping strategies - taking 1 day at a time, finding routine, planning ahead, talking to others with experience, looking at the positives (Lo)	Misattribution of symptoms by parents before diagnosis (Spe)
Dad not wanting to acknowledge the diagnosis, painful reaction (AB)	Fear about what diagnosis means for child's future (Pe)	Feeling reluctant to leave hospital - fear of managing T1D alone (Sma)		Insulin injections devastating & made reality sink in (Lo)	Coping through faith (Ro)	Suspecting T1D/infection (Th)
Shock, denial disbelief at diagnosis (Kh)	Worry & fear about child's future with T1D (Ro)	Overwhelmed and filled with self-doubt about managing T1D (Sma)		Trauma & distress of navigating early insulin injections (Ra)	Focusing on practical aspects of diagnosis (Lo)	Subtlety of symptoms & difficulties recognising (Ush)
Reaction of shock/disbelief - not realising something was very wrong, diagnosis felt sudden, hard to process psychologically (Ab)	Anxiety about children's future and having to be responsible for their own management (Spe)	Having to go home when not ready - feeling a lack of safety (Th)		Fear & lack of confidence with insulin injections (Sma)	Hope that there will be a cure (Ab)	Alternative explanations attributed to symptoms (Ush)
Reactions of shock & disbelief (As)	Worries about impact of T1D on children's future (Sul)	Fear on leaving hospital and feeling responsible to care for child with t1D - fear of unintentionally hurting them (we)		Coming to terms with insulin injections - having to cause pain, fear of getting it wrong (Sul)	Devastated by permanence but optimistic about cure (Lo)	Noticing symtpoms - hoping it was T1D & hoping it wasn't (We)
Shock & disbelief at diagnosis (Ch)	Fear of complications from T1D (Cha)	Feeling insecure and underconfident in T1D management when returning home from hospital (we)		Pressure and worry about learning how to give insulin injections (Th)	Hope of cure as coping (Lo)	Marital conflict/denial of symptoms by husbands before diagnosis (As)
Shock, fear, disbelief, and confusion at diagnosis (KL)	Fear of long-term implications of poor control over T1D (Lo)	Losing sense of being person child could rely on, leading them to feel insecure (wen)				State of denial before diagnosis (Pe)
Shock and awe at diagosis - traumatic (Sul)	Those with familiarity with T1D felt fear about long-term implications (Th)	Feeling newly deskilled/ unfamiliar with child following diagnosis (Sma)				Worry and denial of possible T1D (Lo)
Shock and disbelief at diagnosis (Ro)	Fears about long-term complictions (We)	Worries about coping with T1D at home (Lo)				Role of others in deciding to seek medical input – denial? (Ab)
Shock & disbelief at diagnosis (we)	Fear of complications from T1D (Cha)					

Appendix F. Participant information sheet

LONDON'S GLOBAL UNIVERSITY
RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

UCL

Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: 19685/001

Title of Study:

Finding out your child has Type 1 Diabetes: a qualitative study into the experiences of parents and carers of children living with Type 1 Diabetes

Department:

Clinical Education and Health Psychology

Name and Contact Details of the Researcher(s):

Molly Sharp
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Katie Trigg
Email Address: Kathryn.Trigg.19@ucl.ac.uk
Dr Vicky McKechnie (Clinical Psychologist)
Email Address: v.mckechnie@ucl.ac.uk

Name and Contact Details of the Principal Researcher:

Kristina Soon
Email address: k.soon@ucl.ac.uk

We are researchers, clinical psychologists and trainee clinical psychologists at University College London (UCL). We would like to invite you to take part in a research study. This study is being carried out by a trainee clinical psychologist undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL.

Please read this information sheet if you are interested in taking part. It is completely up to you if you would like to take part in this study. Take some time to read the following information carefully. You may also discuss it with others if you would like to. If you are happy to join in, we will ask you to complete a consent form before any information is collected. Please do ask us if you have any questions, or if you would like more information.

Why are you doing this study?

In 2019, Diabetes UK released some topics about Diabetes and mental health that needed to be researched more. One of those topics is: the primary prevention of mental health difficulties at the time of diagnosis. In this study we would like to hear from, and listen to, parents and carers about their experiences of their child being diagnosed with Type 1 Diabetes. There has not been much research into this so it is unclear how the diagnosis experience may impact on parents and carers. This includes: what happened before their child was diagnosed with Type 1 Diabetes, how they found the healthcare they experienced, how they were told their child has Type 1 Diabetes and how they have found living with Type 1 Diabetes since their child has been diagnosed.

We are hoping that this research will be a starting point in understanding how parents and carers experience their child being diagnosed with Type 1 Diabetes, and how we can improve mental health outcomes for parents and children at the time of diagnosis

Can I take part?

You can take part in this study if your child is aged between 11 - 17, they received a diagnosis of Type 1 Diabetes in the UK between January 2018 and February 2020, and you were present during the process of receiving a diagnosis. If two or more co-parents would like to be involved in the study, they are warmly encouraged – please speak to the researcher for more details.

We will be recruiting other participants through the Diabetes UK advert. We may also advertise the study through JDRF (a Type 1 Diabetes charity) if we need to.

Do I have to take part?

No, it is up to you to decide. If you take part in the study, it will not affect the healthcare your child receives, or your ongoing relationship with Diabetes UK. If you do decide that you are happy to take part, we will also ask you to sign a consent form. You will be given a copy of this which you can keep for your own records.

You are free to stop taking part in this study at any time within a month of the interview. You do not have to give a reason for no longer wanting to take part and just need to let us know by emailing molly.sharp.13@ucl.ac.uk. If you do decide that you no longer want to take part in the study, then any personal data that you have provided up to that point will be deleted unless you agree otherwise.

What will I be asked to do?

We will ask you to complete a consent form to make sure you understand the study and what participation involves. You will be asked to complete two online questionnaires and a contact details form, which we will email to you, and take part in a one-to-one interview either over a video call on Microsoft Teams or by telephone (whichever you would prefer). The interview will be with the student researcher (Molly Sharp). We may ask to speak to you again if we have any ideas that we would like to follow up or information we would like them to confirm. When the study has been written up, we will send you a summary of the findings.

The contact details form and questionnaires should take no longer than 15 minutes to complete. If you would prefer the researcher can complete the questionnaires with you over Microsoft Teams or a telephone call. The questionnaires include: a 'Diabetes Information Questionnaire' which asks questions about the details and management of your child's Diabetes, and the 'Perceived Stress Scale' which asks questions about your wellbeing.

The interview may last up to 90 minutes. We may also ask to re-interview you if we think it may be useful to hear more of your views on the topic. You will be offered a £10 Love2Shop voucher to thank you for your time and effort spent taking part in the study.

Will I be recorded and how will the recorded media be used?

Yes. We need to audio record the interviews to be able to analyse them. As soon as the student researcher has completed the interview with you the recording will be immediately transferred to the

UCL secure server for security purposes. The original recording will then be deleted. Only the student researchers (Katie Trigg & Molly Sharp) will have access to the recordings. All recordings will then be transcribed by the student researcher (Molly Sharp) so that we have a script of the interview. At this point, all information relating to your identity (for example, your name) will be removed. All audio recordings will be destroyed following full transcription.

What are the benefits of participating in this study?

We hope that this research will give you the opportunity to talk about and reflect on your experience of your child's diagnosis of Type 1 Diabetes. It will also offer you the opportunity to voice your opinions on the healthcare your child received and whether you feel that this experience had an impact on yours and your child's emotional wellbeing. We are hoping that the findings from this study will be a starting point to understanding how we can improve the diagnosis experience of Type 1 Diabetes for young people and to improve future mental health outcomes.

What are the risks of participating in this study?

Whilst we are confident that taking part in this study will not harm you, we do acknowledge that discussing the experience of your child being diagnosed with Type 1 Diabetes may be distressing for some parents and carers. If you appear distressed during the interview you will be asked if they wish to continue. The interview can be stopped and terminated at any time. If you become upset after the interview has finished you can contact the researcher by emailing molly.sharp.13@ucl.ac.uk, or the Principal Investigator, Dr Kristina Soon, by emailing k.soon@ucl.ac.uk. The research team is experienced in assessing and managing psychological concerns. We can also direct you to the appropriate healthcare service if we think that further support is needed. In addition, following participation in the study, we will provide you with details of services and resources to access if you or your child wish to do so.

What if there is a problem?

UCL complaints systems are available to you if you have any concerns about any part of the study, or any way that you have been approached or treated by the research team. If you would like to make a complaint, please email the Principal Researcher, Dr Kristina Soon, on k.soon@ucl.ac.uk. Should you feel that your complaint has not been handled well enough, you can contact that Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

Will my confidentiality be protected?

We respect your privacy and are committed to protecting both your and your child's personal data. All of the information that we collect about you and your child during the course of the study will be kept strictly confidential. Audio recordings from the interview will be securely destroyed as soon as the interview transcription is complete. Participants will be identified by a code number only and all interview transcripts and will be kept on UCL secure servers for the duration of the study. The findings of this study will be written up as part of the student researcher's research project for the UCL Doctorate in Clinical Psychology training programme. Your and your child's personal details (e.g., name) will not be identifiable in this or any future publications. The results are likely to be published in order to inform healthcare professionals and help other researchers who want to improve the diagnosis experience for young people

living with Type 1 Diabetes. The results may include quotes from your comments during the interview, however, we will make sure that it does not contain anything that would identify you.

The only exception to confidentiality is if we hear anything which causes us to be concerned that someone might be in danger of harm (whether that is you, your child, or someone else). If this happens, we may need to seek other help and inform other relevant agencies to keep you, your child and anyone else safe. For these reasons, if you decide to participate in the study, we will ask you to provide the contact details of your family's general practitioner. Your GP will only be contacted if the researchers believe that someone could be at risk of imminent harm.

What will happen to the results of the research project?

Once the study has been completed the results will be published in a report as part of the student researcher's thesis project. The results will also be submitted to scientific journals and conferences. You will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a one-page summary of the study findings. As mentioned above, confidentiality will be maintained. It will not be possible to identify you from any publications.

We are very keen to expand this research to improve our ability to develop healthcare services for young people with type 1 diabetes and their families. As such, further studies may be conducted that are linked to this one and data collected in this study may be used in combination with future studies. Any data used in this way will be pseudonymised, meaning that it will not contain any information that would identify you.

Sources of Additional Support

If you are concerned about yours or your child's well-being and would like additional support for their mental health, then please do consider contacting the following services:

- The Diabetes UK website and helpline (https://www.diabetes.org.uk)
- Your registered GP
- Your child's Diabetes healthcare team

Local Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk. They make sure that information is handled securely and safely. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice, click here. The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The categories of personal data used will be as follows: your name and contact details will be used so that we can contact you about the study. The lawful basis that would be used to process your personal data (such as, name or date of birth) will be performance of a task in the public interest. Your personal data will be processed so long as it is required for the research project and then it will be securely deleted. If we are able to anonymise or

pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible. Your anonymised data will be stored securely, under password protected files. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Who is organising and funding the research?

This study is funded by UCL's department of Clinical, Educational and Health Psychology.

You will be given a copy of this information sheet and one for your child to keep for your own records. If you consent to your child participating in the study, you will be asked to complete a consent form which you will also be given a copy of for your own records.

Thank you for reading this information sheet and for considering taking part in this research study.

If you have any questions about this study, please contact: Molly Sharp at molly.sharp.13@ucl.ac.uk

Appendix G. Participant consent form

Participant Information Sheet For Parent/Carer participants

UCL Research Ethics Committee Approval ID Number: 19685/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study:

Finding out your child has Type 1 Diabetes: a qualitative study into the experiences of parents and carers of children living with Type 1 Diabetes

Department:

Clinical Education and Health Psychology

Name and Contact Details of the Researcher(s):

Molly Sharp

Email Address: molly.sharp.13@ucl.ac.uk

Katie Trigg

Email Address: Kathryn.Trigg.19@ucl.ac.uk

Dr Vicky McKechnie (Clinical Psychologist)

Email Address: v.mckechnie@ucl.ac.uk

Name and Contact Details of the Principal Researcher:

Kristina Soon

Email address: k.soon@ucl.ac.uk

We are researchers, clinical psychologists and trainee clinical psychologists at University College London (UCL). We would like to invite you to take part in a research study. This study is being carried out by a trainee clinical psychologist undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL.

Please read this information sheet if you are interested in taking part. It is completely up to you if you would like to take part in this study. Take some time to read the following information carefully. You may also discuss it with others if you would like to. If you are happy to join in, we will ask you to complete a consent form before any information is collected. Please do ask us if you have any questions, or if you would like more information.

Why are we doing this study?

In 2019, Diabetes UK released some topics about Diabetes and mental health that needed to be researched more. One of those topics is: the primary prevention of mental health

difficulties at the time of diagnosis. In this study we would like to hear from, and listen to, parents and carers about their experiences of their child being diagnosed with Type 1

Diabetes. There has not been much research into this so it is unclear how the diagnosis experience may impact on parents and carers. This includes: what happened before their child was diagnosed with Type 1 Diabetes, how they found the healthcare they experienced, how they were told their child has Type 1 Diabetes and how they have found living with Type 1 Diabetes since their child has been diagnosed.

We are hoping that this research will be a starting point in understanding how parents and carers experience their child being diagnosed with Type 1 Diabetes, and how we can improve mental health outcomes for parents and children at the time of diagnosis.

Can I take part?
You can take part in this study if your child has received a diagnosis of Type 1 Diabetes in the UK in 2019 and is aged 8-17 and you were present during the process of receiving a diagnosis.

We will be recruiting other participants through the Diabetes UK advert. We may also advertise the study through JDRF (a Type 1 Diabetes charity) if we need to.

Do I have to take part?
No, it is up to you to decide. If you take part in the study it will not affect the healthcare your child receives, or your ongoing relationship with Diabetes UK. If you do decide that you are happy to take part we will also ask you to sign a consent form. You will be given a copy of this which you can keep for your own records.

You are free to stop taking part in this study at any time within a month of the interview. You do not have to give a reason for no longer wanting to take part and just need to let us know by emailing molly.sharp.13@ucl.ac.uk. If you do decide that you no longer want to take part in the study then any personal data that you have provided up to that point will be deleted unless you agree otherwise.

What will I be asked to do?
We will ask you to complete a consent form to make sure you understand the study and what participation involves. You will be asked to complete two online questionnaires, which we will email to you, and take part in a one-to-one interview either over a video call on Microsoft Teams or by telephone (whichever you would prefer). The interview will be with the student researcher (Molly Sharp). We may ask to speak to you again if we have any ideas that we would like to follow up or information we would like them to confirm. When the study has been written up we will send you a summary of the findings.

The questionnaires should take no longer than 15 minutes to complete. If you would prefer the researcher can complete the questionnaires with you over Microsoft Teams or a

telephone call. The questionnaires include: a 'Diabetes Information Questionnaire' which asks questions about the details and management of your child's Diabetes, and the 'Perceived Stress Scale' which asks questions about your wellbeing.

The interview may last up to 90 minutes. We may also ask to re-interview you if we think it may be useful to hear more of your views on the topic. You will be offered a £10 love to shop voucher to thank you for your time and effort spent taking part in the study.

Will I be recorded and how will the recorded media be used?
Yes. We need to audio record the interviews to be able to analyse them. As soon as the student researcher has completed the interview with you the recording will be immediately transferred to the UCL secure server for security purposes. The original recording will then be deleted. Only the student researchers (Katie Trigg & Molly Sharp) will have access to the recordings. All recordings will then be transcribed by the student researcher (Molly Sharp) so that we have a script of the interview. At this point, all information relating to your identity (for example, your name) will be removed. All audio recordings will be destroyed following full transcription.

What are the benefits of participating in this study?
We hope that this research will give you the opportunity to talk about and reflect on your experience of your child's diagnosis of Type 1 Diabetes. It will also offer you the opportunity to voice your opinions on the healthcare your child received and whether you feel that this experience had an impact on yours and your child's emotional wellbeing. We are hoping that the findings from this study will be a starting point to understanding how we can improve the diagnosis experience of Type 1 Diabetes for young people and to improve future mental health outcomes.

What are the risks of participating in this study?
Whilst we are confident that taking part in this study will not harm you, we do acknowledge that discussing the experience of your child being diagnosed with Type 1 Diabetes may be distressing for some parents and carers. If you appear distressed during the interview you will be asked if they wish to continue. The interview can be stopped and terminated at any time. If you become upset after the interview has finished you can contact the researcher by emailing molly.sharp.13@ucl.ac.uk, or the Principal Investigator, Dr Kristina Soon, by emailing k.soon@ucl.ac.uk. The research team is experienced in assessing and managing psychological concerns. We can also direct you to the appropriate healthcare service if we think that further support is needed. In addition, following participation in the study, we will provide you with details of services and resources to access if you or your child wish to do so.

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Will my confidentiality be protected?
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The only exception to confidentiality is if we hear anything which causes us to be concerned that someone might be in danger of harm (whether that is you, your child, or someone else). If this happens, we may need to seek other help and inform other relevant agencies to keep you, your child and anyone else safe. For these reasons, if you decide to participate in the study, we will ask you to provide the contact details of your family's general practitioner. Your GP will only be contacted if the researchers believe that someone could be at risk of imminent harm.

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We are very keen to expand this research to improve our ability to develop healthcare services for young people with type 1 diabetes and their families. As such, further studies may be conducted that are linked to this one and data collected in this study may be used in combination with future studies. Any data used in this way will be pseudonymised, meaning that it will not contain any information that would identify you.

Sources of Additional Support
If you are concerned about yours or your child's well-being and would like additional support for their mental health then please do consider contacting the following services:

- The Diabetes UK website and helpline (https://www.diabetes.org.uk)
- Your registered GP
- Your child's Diabetes healthcare team

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Notice:

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Who is organising and funding the research?
This study is funded by UCL's department of Clinical, Educational and Health Psychology.

You will be given a copy of this information sheet and one for your child to keep for your own records. If you consent to your child participating in the study, you will be asked to complete a consent form which you will also be given a copy of for your own records.

Thank you for reading this information sheet and for considering taking part in this research study.

If you have any questions about this study please contact: Molly Sharp at molly.sharp.13@ucl.ac.uk

Appendix H. Ethical Approval

APPROVED: Ethical Amendment Request: Study ID 19685/001

VPRO.Ethics <ethics@ucl.ac.uk>

Tuesday, 3 May 2022 at 13:36

To: Sharp, Molly

High-Risk-Applicatio... 7.1 MB | Amendment_Approv... 298 KB

Download All · Preview All

Dear Molly

I am pleased to confirm that your attached amendment request has now been approved. Please take this email as confirmation of that approval.

IMPORTANT: For projects collecting personal data only
You should inform the Data Protection (DP) Team – data-protection@ucl.ac.uk of your proposed amendments, including requests to extend ethics approval for an additional period. Please ensure that you quote your DP registration number when you correspond with the Team.

Best wishes, Helen

Helen Dougal
UCL Research Ethics Co-ordinator
Office of the Vice-Provost (Research, Innovation and Global Engagement)
University College London
2 Taviton Street, London, WC1H 0BT
Email: ethics@ucl.ac.uk

Appendix I. Diabetes Information Questionnaire

Diabetes Information Questionnaire (parent participant)

This questionnaire will ask you some questions about you and your child with Type 1 Diabetes.

Please do take your time to complete the questionnaire and try to provide as much detail as possible. The information you share in this questionnaire will be kept anonymous. If you have any questions or concerns about this questionnaire. When you meet with the researcher (Molly Sharp) for your interview, they will check that the questionnaires have been completed. You can ask them for help with any questions you do not understand. Alternatively, you can email: molly.sharp.13@ucl.ac.uk for help.

How would you describe your gender?

Prefer not to say

What is your ethnic group? Please select the option that best describes your background.

Asian or Asian Brtish
- Bangladeshi
- Chinese
- Indian
- Pakistani
- Another Asian Background

Black, African, Black British or Caribbean (includes any Black background)
- African
- Caribbean
- Another Black background

Mixed or multiple ethic groups (includes any Mixed background)
- Asian and White
- Black African and While
- Black Caribben and White
- Another Mixed background

White (includes any White background)
- British, English, Nothern Irish, Scottish of Welsh
- Irish
- Irish Traveller or Gypsy
- Another White background

Another ethnic group
- Arab
- Another ethnic background

Prefer not to say

How old is your child?

Prefer not to say

How would you describe your child's gender?

Prefer not to say

What is your child's ethnic group? Please select the option that best describes your child's background.

Asian or Asian British
- Bangladeshi
- Chinese
- Indian
- Pakistani
- Another Asian Background

Black, African, Black British or Caribbean (includes any Black background)
- African
- Caribbean
- Another Black background

Mixed or multiple ethic groups (includes any Mixed background)
- Asian and White
- Black African and While
- Black Caribben and White
- Another Mixed background

White (includes any White background)

British, English, Nothern Irish, Scottish of Welsh
- Irish
- Irish Traveller or Gypsy
- Another White background

Another ethnic group
- Arab
- Another ethnic background

Prefer not to say

Who is your child's primary caregiver?

Me

Other (Please indicate:)

Prefer not to say

What month and year was your child diagnosed with Type 1 Diabetes?

Month……. Year……

Prefer not to say

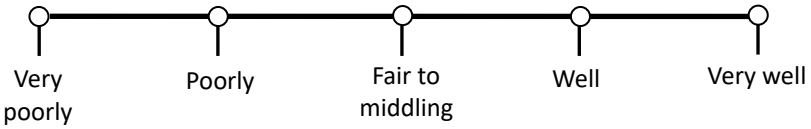
In the past month, how has your child been administering insulin (please choose one option that you use most of the time)?
Insulin Pump
Multiple Daily Injections
Prefer not to say

Who is in charge of giving your child's insulin?
My child
Myself
Both myself and my child
Other (please indicate:)
Prefer not to say

How is your child's blood sugar levels monitored most of the time (please choose one option used most of the time)?
Self-monitoring of blood glucose (fingerprick testing)
Real time continuous glucose monitoring (e.g. Dexcom G6)
Flash glucose monitoring (e.g. FreeStyle Libre)
Prefer not to say

Who is in charge of monitoring your child's blood glucose levels?
My child
Myself
Both myself and my child
Other (please indicate:)
Prefer not to say

How do you feel management of your child's diabetes is going?



Appendix J. Interview topic guide

Finding out your child has Type 1 Diabetes: a qualitative study into the experiences of parents and carers of children living with Type 1 Diabetes.

Interview Topic Guide

Initial Open-Ended Questions
As I have explained, I am interested in your experience of finding out your child has Type 1 Diabetes.

1. Can you tell me what was happening in the weeks before you were told your child had type 1 diabetes?
   Follow up questions If needed:
   a. Could you describe what happened that led to you being told your child had type 1 diabetes?
2. Can you tell me about how you were told your child has type 1 diabetes?
   Follow up questions If needed:
   a. Did you know anything about type 1 diabetes before being told your child had it?
   b. What types of people/healthcare professionals did you meet when you found out your child had type 1 diabetes? What did they do? Can you tell me about what that was like?
   c. Was there anyone or anything that was particularly helpful to you during this time?
   d. Can you describe what you were told about your child having type 1 diabetes and what that was like?

3. Can you describe what happened in the few weeks after you were told your child has type 1 diabetes?
   Follow up questions If needed:
   a. Can you describe what it was like going home after the diagnosis?
   b. Where there any new healthcare professionals involved? How were they involved?
   c. Did you have support from anyone else?
   d. Was there anyone or anything that was particularly helpful to you during this time?

Intermediate Questions

4. Can you tell me what having a child with type 1 diabetes has been like since finding out your child has this condition?

Follow up questions If needed:

a. Has your experience of parenting changed since finding out that your child has this condition?
b. If it has changed, how has it changed?
c. Have you learned anything about yourself since finding out that your child has type 1 diabetes?

5. Can you tell me about how your family/closest network have been since you found out that you have Type 1 Diabetes?

   Follow up questions If needed:

   a. What were the relationships in your family like before finding out your child had type 1 diabetes and what are they like now?
   b. (If there are any changes) Why do you think this has changed?

Ending Questions

6. After having these experiences, what advice would you give to someone else who has just found out that their child has type 1 diabetes?

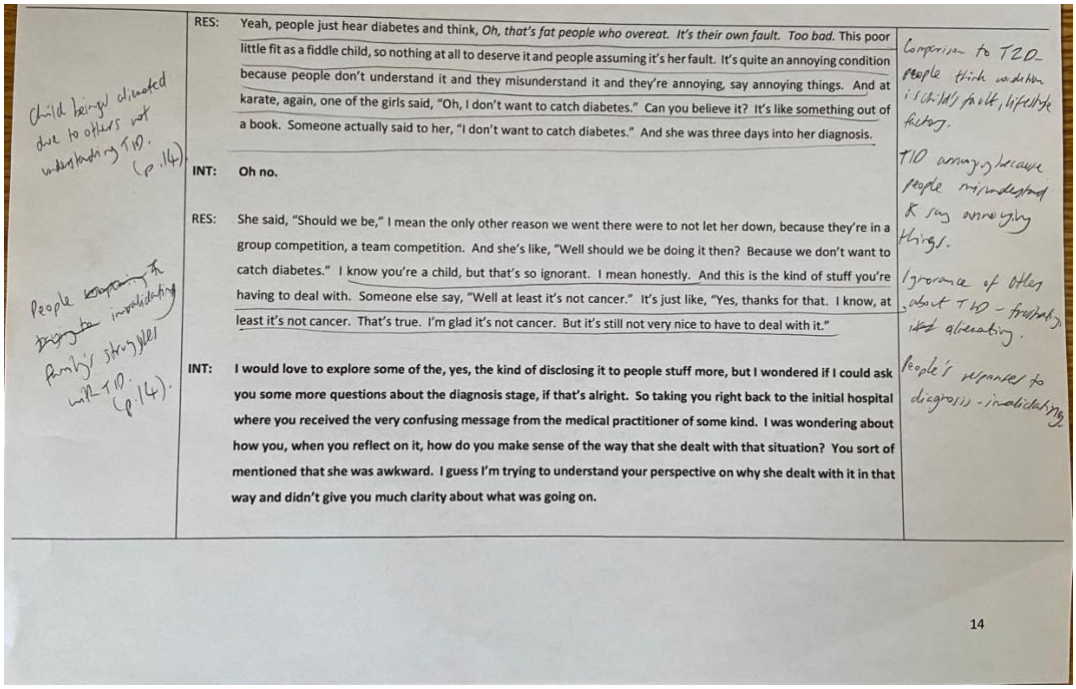
7. And what advice would you give to the people who try to help/healthcare professionals when diagnosing young people with Type 1 Diabetes?

8. Is there something else you think I should know?

9. Do you have any questions for me?

Appendix K. Excerpts from data analysis

Original transcript with explanatory comments (right-hand side) and experiental statements (left-hand side) - Penny



RES: Yeah, people just hear diabetes and think, *Oh, that's fat people who overeat. It's their own fault. Too bad.* This poor little fit as a fiddle child, so nothing at all to deserve it and people assuming it's her fault. It's quite an annoying condition because people don't understand it and they misunderstand it and they're annoying, say annoying things. And at karate, again, one of the girls said, "Oh, I don't want to catch diabetes." Can you believe it? It's like something out of a book. Someone actually said to her, "I don't want to catch diabetes." And she was three days into her diagnosis.

INT: **Oh no.**

RES: She said, "Should we be," I mean the only other reason we went there were to not let her down, because they're in a group competition, a team competition. And she's like, "Well should we be doing it then? Because we don't want to catch diabetes." I know you're a child, but that's so ignorant. I mean honestly. And this is the kind of stuff you're having to deal with. Someone else say, "Well at least it's not cancer." It's just like, "Yes, thanks for that. I know, at least it's not cancer. That's true. I'm glad it's not cancer. But it's still not very nice to have to deal with it."

INT: **I would love to explore some of the, yes, the kind of disclosing it to people stuff more, but I wondered if I could ask you some more questions about the diagnosis stage, if that's alright. So taking you right back to the initial hospital where you received the very confusing message from the medical practitioner of some kind. I was wondering about how you, when you reflect on it, how do you make sense of the way that she dealt with that situation? You sort of mentioned that she was awkward. I guess I'm trying to understand your perspective on why she dealt with it in that way and didn't give you much clarity about what was going on.**

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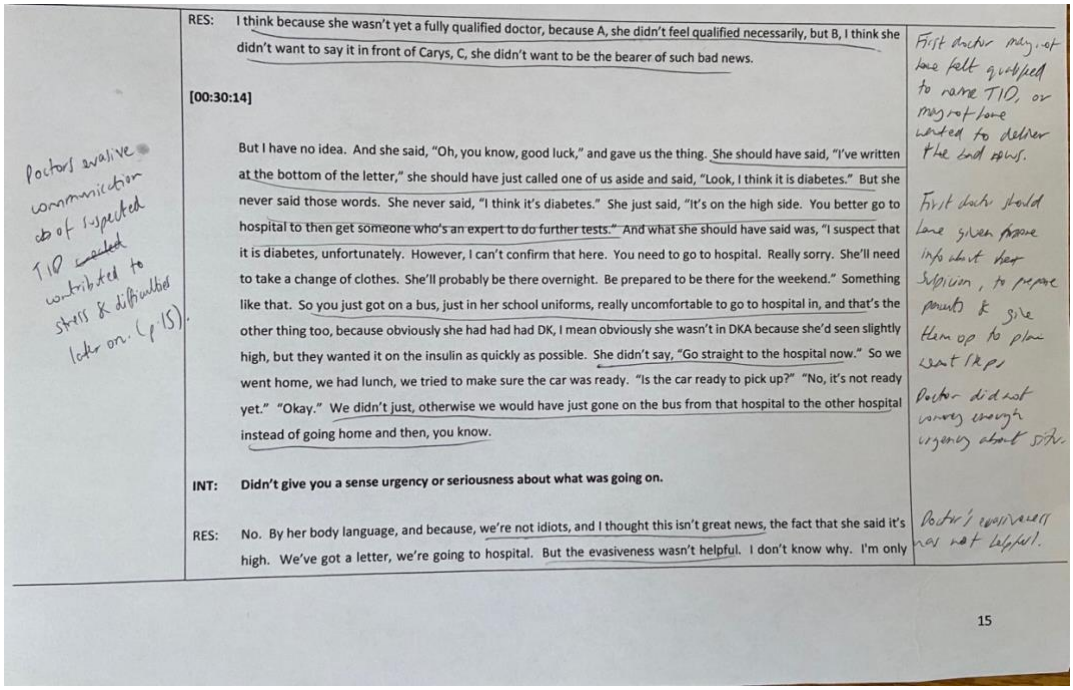

RES: I think because she wasn't yet a fully qualified doctor, because A, she didn't feel qualified necessarily, but B, I think she didn't want to say it in front of Carys, C, she didn't want to be the bearer of such bad news.

[00:30:14]

But I have no idea. And she said, "Oh, you know, good luck," and gave us the thing. She should have said, "I've written at the bottom of the letter," she should have just called one of us aside and said, "Look, I think it is diabetes." But she never said those words. She never said, "I think it's diabetes." She just said, "It's on the high side. You better go to hospital to then get someone who's an expert to do further tests." And what she should have said was, "I suspect that it is diabetes, unfortunately. However, I can't confirm that here. You need to go to hospital. Really sorry. She'll need to take a change of clothes. She'll probably be there overnight. Be prepared to be there for the weekend." Something like that. So you just got on a bus, just in her school uniforms, really uncomfortable to go to hospital in, and that's the other thing too, because obviously she had had had DK, I mean obviously she wasn't in DKA because she'd seen slightly high, but they wanted it on the insulin as quickly as possible. She didn't say, "Go straight to the hospital now." So we went home, we had lunch, we tried to make sure the car was ready. "Is the car ready to pick up?" "No, it's not ready yet." "Okay." We didn't just, otherwise we would have just gone on the bus from that hospital to the other hospital instead of going home and then, you know.

INT: **Didn't give you a sense urgency or seriousness about what was going on.**

RES: No. By her body language, and because, we're not idiots, and I thought this isn't great news, the fact that she said it's high. We've got a letter, we're going to hospital. But the evasiveness wasn't helpful. I don't know why. I'm only

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Table of Penny's Personal Experiential Themes (PETs)

Getting the diagnosis – poor communication, inadequate care & feeing abandoned	Penny	
Walk-in doctor's evasive communication led to parents not being prepared for what was to come	• Evasive communication did not prepare parents for what was to come - "…she never said those words, she never said, "I think it's diabetes." She just said, "It's on the high side. You better go to hospital to then get someone who's an expert to do further tests." And what she should have said was, "I suspect that it is diabetes, unfortunately. However, I can't confirm that here. You need to go to hospital. Really sorry. She'll need to take a change of clothes. She'll probably be there overnight. Be prepared to be there for the weekend." Something like that. ~~So~~ you just got on a bus, just in her school uniforms, really uncomfortable to go to hospital in… She didn't say, "Go straight to the hospital ~~now"otherwise~~ we would have just gone on the bus from that hospital to the other hospital instead of going home… the evasiveness wasn't helpful."/ "[Child] would have been more comfortable, because I felt really bad, she was sitting there in a school uniform, being poked and prodded, not very comfortable. She should have been in ~~pyjamas~~ or a nightie or something a lot more comfortable. I would have known sooner to ~~make arrangements~~ for my son… I don't know if the whole thing with the, "Oh, that's great news," if she'd known it's probably diabetes, whether that would have been…"/ "…perhaps if she had handled it differently, the practitioner, it wouldn't perhaps have gone quite so badly, because we would have known, *okay, she's got type 1*." (~~also~~ 9 & 12 but have not included) • Parent sensed walk-in doctor did not want to be bearer of bad news of suspected T1D - "I think because she wasn't yet a fully qualified doctor, because A, she didn't feel qualified necessarily, but B, I think she didn't want to say it in front of [child] C, she didn't want to be the bearer of such bad news… We're already ready to hear the bad news, so just take one of us aside and just say it."	15/16/24 15
A&E doctor's blunt delivery made diagnosis more painful & intimidating	• "Think before you speak" – blunt delivery unempathetic - "And when I said, "Oh, thank God," he was acting surprised, "Oh no, she's got it," it was just, think before you speak type of ~~thing."~~ • Way diagnosis was delivered gave "unnecessary relief" then the blunt reality - "And this is the bit that makes me ~~really angry~~… He said, erm, "Good news," or something, ~~or~~ "Great, that's great news," or something. I can't believe I can't remember what those words were, and I said, "Oh, thank God!" Because I thought that means that she doesn't have diabetes. It was something like wow that's great news, or that's so good, or that's such a good result, or something along ~~those kind of lines~~. And I went, "Oh, thank God!" And he went, "Oh no, she's got it." And that is how all three of us found out about this life term condition, long term, ~~life long~~ condition is, "Oh no, she's got it."/ "…so it just caused all this unnecessary moment of relief and then angst…" • Diagnosis delivery made T1D seem scary and otherworldly – "it" - "…when it's your little eight-year-old sitting there all vulnerable and she finds out by someone saying, "Oh, she's got it," "it", what is it? It makes it sound like even more scary and other worldly and it, she's got it. They didn't say, "Oh, sorry, she has got type 1.""	23 6/7 24
Medical interventions without explanation led to extra confusion	• "Poking & prodding" without explanation - "So the doctor is in poking and prodding at her. He did, what I now know is a ketones test, but I didn't know what it was then. I thought he was testing her blood." • If HCPs had explained their interventions, pain of false hope at diagnosis could have been avoided - "But what they should have said was, "So what we're first going to do though is check ketone levels."	6 7

Reintegrating into the world- invalidating reactions & the value of connecting with other T1D families	Penny	
The reactions of others in the outside world made adjusting to T1D more difficult	• The outside world was not always accommodating to T1D – made adjustment harder - "…the school caterers weren't helpful…They wouldn't, they basically don't know what carbs there are, and…so she couldn't get school dinners anymore... And so yeah, all these extra stressors and strains that you didn't have to think about in the morning when you're trying to get them off to school, now having to pack a lunch." • Child being alienated after diagnosis due to others not understanding T1D - "…one of the girls said, "Oh, I don't want to catch diabetes."	20 14 13/14 20

Penny's PET table

	Can you believe it? It's like something out of a book. Someone actually said to her, "I don't want to catch diabetes." And she was three days into her diagnosis."36 • People's comments invalidating family's struggles with T1D - He said "Oh, well I would expect someone with epilepsy maybe to pass out in my class, but not someone with diabetes." It's just like, it's just people don't know. They just think it's nothing. And someone else said, "Oh, but you can cure it, can't you?" And I said, "No." I said, "Type 2 can be reversed, but that's type 2." Why they called them both diabetes, they should definitely just give them both a different name. It's just too confusing for people… It's quite an annoying condition because people don't understand it and they misunderstand it and they're annoying, say annoying things." / "And this is the kind of stuff you're having to deal with. Someone else say, "Well at least it's not cancer." It's just like, "Yes, thanks for that. I know, at least it's not cancer. That's true. I'm glad it's not cancer. But it's still not very nice to have to deal with it."" • COVID-19 lockdown felt like a relief – it gave time to get to groups with management away from the outside world – "We were almost glad when Covid happened because when we had the lockdown it gave us time to kind of get to grips with it all without having the pressure of trying to get to and from school…it was so stressful that we just thought at least with lockdown we can just focus on getting to grips with the diabetes without having to worry about all the other noise that um, you know, that comes with it"	
Connecting with other families with T1D experience provided much needed empathy & reassurance	• Empathy & reassurance first hand from those with experience of T1D – powerful - "…hearing it from a first-hand person with a child that has it, it does make you feel a bit better. You think, *Okay, well yes, it is shit, but they've coped and she's fine,* and all this kind of stuff." • Connecting with others with understanding of T1D – helpful - "…what I found really helpful was a nice lady at school heard through the school nurse about the diagnosis, because her daughter had type 1 as well, and she just wrote me a really nice letter…"	43 42

Table of Group Experiential Themes (GETs) – Penny's relevant material

A sudden state of uncertainty		
Sub-theme		**Transcript (page number)**
Reliant on unreliable messengers	*Evasive communication increasing uncertainty*	• Evasive communication did not prepare parents for what was to come- "…she never said those words, she never said, "I think it's diabetes." She just said, "It's on the high side. You better go to hospital to then get someone who's an expert to do further tests." And what she should have said was, "I suspect that it is diabetes, unfortunately. However, I can't confirm that here. You need to go to hospital. Really sorry. She'll need to take a change of clothes. She'll probably be there overnight. Be prepared to be there for the weekend." Something like that. So you just got on a bus, just in her school uniforms, really uncomfortable to go to hospital in… She didn't say, "Go straight to the hospital now"otherwise we would have just gone on the bus from that hospital to the other hospital instead of going home… the evasiveness wasn't helpful." (15) • "[Child] would have been more comfortable, because I felt really bad, she was sitting there in a school uniform, being poked and prodded, not very comfortable. She should have been in pyjamas or a nightie or something a lot more comfortable. I would have known sooner to make arrangements for my son… I don't know if the whole thing with the, "Oh, that's great news," if she'd known it's probably diabetes, whether that would have been…"(16) • "…perhaps if she had handled it differently, the practitioner, it wouldn't perhaps have gone quite so badly, because we would have known, *okay, she's got type 1*." (also 9 & 12 but have not included) (24) • Parent sensed walk-in doctor did not want to be bearer of bad news of suspected T1D- "I think because she wasn't yet a fully qualified doctor, because A, she didn't feel qualified necessarily, but B, I think she didn't want to say it in front of [child], C, she didn't want to be the bearer of such bad news… We're already ready to hear the bad news, so just take one of us aside and just say it." (15)
	Unempathetic delivery at diagnosis	• "Think before you speak" – blunt delivery unempathetic- "And when I said, "Oh, thank God," he was acting surprised, "Oh no, she's got it," it was just, think before you speak type of thing." (23) • Way diagnosis was delivered gave "unnecessary relief" then the blunt reality- "And this is the bit that makes me really angry... He said, erm, "Good news," or something, or, "Great, that's great news," or something. I can't believe I can't remember what those words were, and I said, "Oh, thank God!" Because I thought that means that she doesn't have diabetes. It was something like wow that's great news, or that's so good, or that's such a good result, or something along those kind of lines. And I went, "Oh, thank God!" And he went, "Oh no, she's got it." And that is how all three of us found out about this life term condition, long term, life long condition is, "Oh no, she's got it." (6) • "…so it just caused all this unnecessary moment of relief and then angst…" (7) • Diagnosis delivery made T1D seem scary and otherworldly – "it"- "…when it's your little eight-year-old sitting there all vulnerable and she finds out by someone saying, "Oh, she's got it," "it", what is it? It makes it sound like even more scary and other worldly and it, she's got it. They didn't say, "Oh, sorry, she has got type 1."" (24)
	Child undergoing invasive medical procedures	• Poking & prodding" without explanation- "So the doctor is in poking and prodding at her. He did, what I now know is a ketones test, but I didn't know what it was then. I thought he was testing her blood." (6) • If HCPs had explained their interventions, pain of false hope at diagnosis could have been avoided- "But what they should have said was, "So what we're first going to do though is check ketone levels." Or they could have said, "I've already checked, yes, she's type 1. Now we're checking how serious, if she's in DKA." …But they didn't. They just, "You know why you're here?" "Yes." Started testing. "Oh, that's great news," and I just thought, *Oh my God! She*

		doesn't have it! Oh my God! And to then get told, “Oh no, she's got it,” you know, it, you know, not “I'm really sorry.” (7)