A systematic review of parents' experiences of raising a child with type 1 diabetes

SAFFRON SIMPSON, PAUL HANNA, CHRISTINA J JONES

Abstract

Background: **There are currently 1.1 million young people estimated to have type 1 diabetes (T1D) across the world. A diagnosis of T1D impacts not only the children's lives but also those of the parents.**

Aim: **To understand the experiences of parents raising a child with T1D.**

Methods: **For inclusion, studies had to report qualitative data on parents' experiences of raising a child with a diagnosis of T1D. Parents included mothers, fathers or any other primary caregivers. Eleven databases were systematically searched for relevant articles. Studies were quality assessed and study characteristics extracted. The data were thematically synthesised.**

Results: **Thirty-two studies met the inclusion criteria. Thematic synthesis yielded two analytical themes: 'adjusting to a new reality' and 'navigating appropriate T1D support'. The five descriptive themes that contributed to these were 'distressing diagnostic experience', 'change of life routine', 'enablers and barriers to support from others', 'reconstruction of family dynamics' and 'psychological impact over time'.**

Conclusions: **Difficulties parents encounter in support received from school and healthcare professionals are highlighted. Parents' mental health needs should be attended to throughout T1D clinic appointments. Future research should explore fathers' experiences, as well as characteristics (such as employment status, education, relationship status and underlying mental health issues) which may affect parental experience, given the paucity of existing evidence.**

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Key words: type 1 diabetes, parents, children, systematic review, diabetes mellitus, qualitative research, experiences, carers

Introduction

A diagnosis of type 1 diabetes (T1D) impacts not only the life of the child but also the parents. There has been a wealth of research conducted into the experiences of parents raising a child with T1D. The existing literature reports an impact on, but not limited to, psychological well-being,[1] finances,[2] diet,[3] family life[4] and social life.[5] Whilst a mixed methods systematic review on psychological experiences of parents of children with T1D provided important information on the prevalence of psychological distress,[6] the authors excluded studies that did not include parental psychological outcomes and studies that focused solely on family adjustment or functioning. Consequently, there may be important research pertaining to parents' experiences that were excluded. The aim of this current systematic review is to update and extend on the previous review by collating and synthesising the qualitative evidence on the broader range of parental experiences of raising a child with T1D. Therefore, this review offers a contribution to clinical practice by informing healthcare professionals about parental experience to enhance delivery of care to families and support T1D management.

School of Psychology, University of Surrey, Guildford, UK

Address for correspondence: Miss Saffron Simpson
Room 12b AC 04, School of Psychology, University of Surrey, Guildford, GU2 7XH, UK
E-mail: saffron.simpson@surrey.ac.uk

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Methods

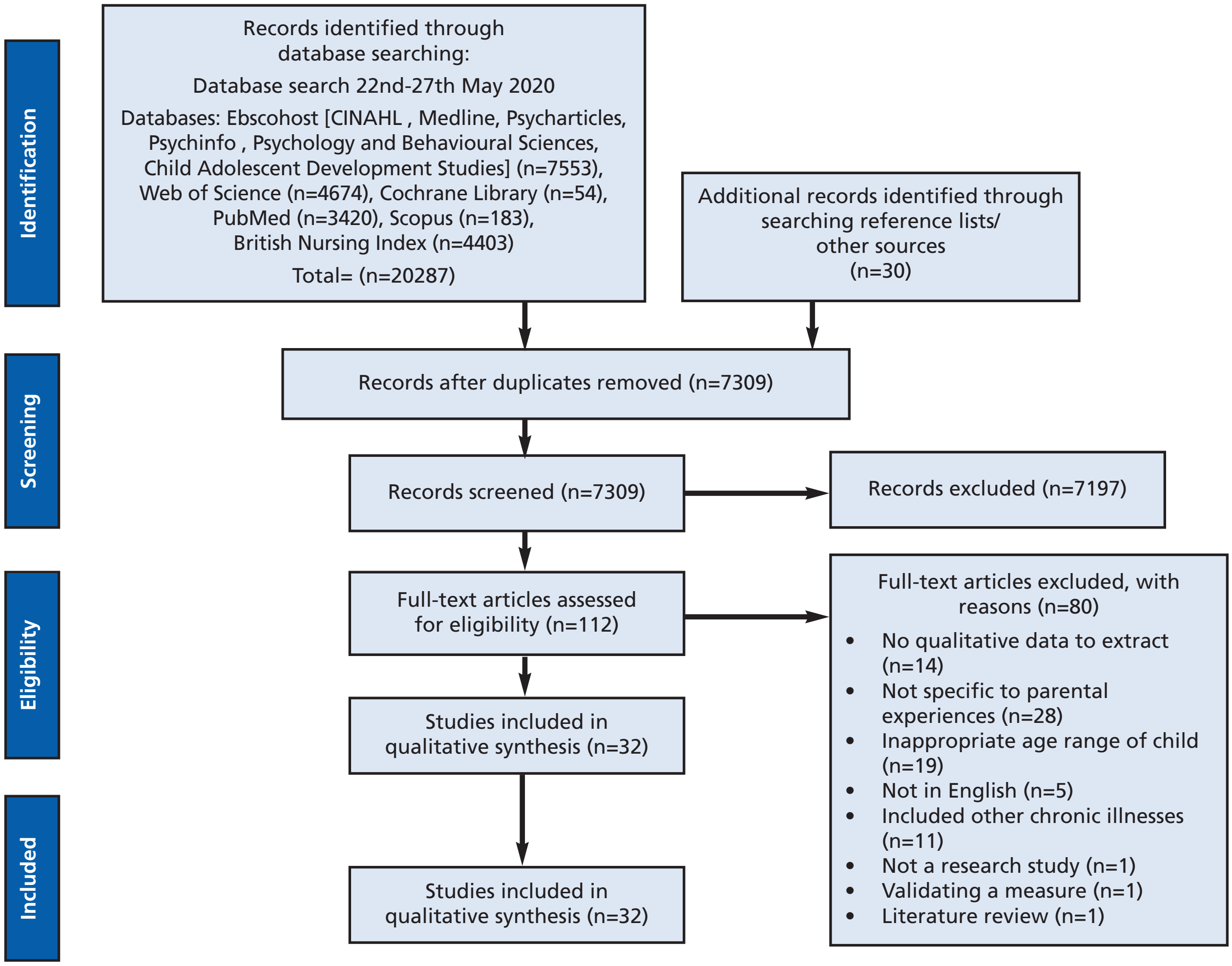
This systematic review follows the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines[7] (Appendix 1 available at www.bjd-abcd.com) and was prospectively registered on Prospero (CRD42020173872). Studies were eligible for inclusion if they were (1) qualitative or mixed methods in design where qualitative data could be extracted and (2) report parental (age >18 years including mothers, fathers or primary caregivers) experiences of raising a child (aged 0–17 years) with a diagnosis of T1D. Studies were excluded if the child had a diagnosis of type 2 diabetes or had another comorbid long-term condition. Only studies in English were included and there was no restriction on publication date.

Eleven databases were systematically searched from their inception to May 2020 (Appendix 2 available at www.bjd-abcd.com). Articles were screened for relevance against the eligibility criteria at the title and abstract stage. The reasons for exclusion can be found in the PRISMA flow chart (Figure 1). Reference lists of the relevant studies were also searched for any additional research that may not have been captured by the original search.

To appraise the quality of the relevant studies, the Critical Appraisal Skills Programme (CASP) qualitative checklist was used.[8] This was initially undertaken by the first author, with a subset of papers checked by the last author. No articles were excluded based on study quality.

Thematic synthesis[9] was used to analyse and integrate the qualitative data, involving line-by-line inductive coding of the entire results section for each study. Codes were then collated and reviewed to examine for differences, patterns and similarities. This

Figure 1. PRISMA flow diagram



allowed the codes to be organised into groups for descriptive themes to be constructed. In order to address the research question and go beyond the content of the primary studies, analytical themes were then derived. The descriptive themes with illustrative quotations are detailed in Table 1.

Results

Study characteristics and quality

The systematic search yielded 7,309 results after duplicates were removed, with 32 studies published between 1995 and 2020 included (Figure 1). There were 1,417 participants across the 32 studies; 25 studies provided parents' gender, 526 of which were mothers (72%) and 149 fathers (28%). The ages of parents ranged from 22 to 58 years and the age of the child ranged from 2 to 17 years. Only seven studies reported on ethnicity, of which six reported that participants were either entirely or majority white. Studies were predominantly conducted in Europe (n=16). The data collection methods varied but the predominant approach was interviews (n=27) (Table 2).

The 'relationship between researcher and participants being adequately considered' received the highest amount of 'unclear' scoring across the studies. All 32 studies were assessed as having a clear statement of the aims of the research (Q1) and qualitative methodology being appropriate (Q2). Overall, 26 of the 32 studies were judged as adequately reporting at least seven of the 10 CASP checklist items (Table 3).

Thematic synthesis findings

Adjusting to a new reality

This analytical theme reflects the new reality parents face whilst raising a child with T1D, beginning at diagnosis and involving changes to daily routines, dietary habits and learning new caregiving skills. This new reality influenced their decision-making about celebrations, family outings and future children. Parents were affected financially and emotionally, with the emotional impact starting at diagnosis. With time, parents became used to this new reality and it became part of daily life. This analytical theme is explored further below through the descriptive themes it was derived from: 'distressing diagnostic experience', 'change of life routine' and 'reconstruction of family dynamics'.

Table 1 Qualitative synthesis: analytical themes, descriptive themes, example codes and illustrative quotations

Analytical themes	Descriptive themes	Example codes	Illustrative quotations
Adjusting to a new reality	Distressing diagnostic experience	Interpretation of pre-diagnostic/initial symptoms	"I was determined it was a urine infection. I thought, no. It just won't be diabetes. It's bound to be a urine infection".[32]
		Misdiagnosis/lack of diagnosis by professionals	"Often the young child had been misdiagnosed as having meningitis, leukaemia or another devastating illness".[30]
		Blame game for cause of diagnosis	"I honestly went through what I might have done wrong … You somehow just imagine that you have caused the sickness, because you have made some mistakes in the care of the child".[17]
		Emotional diagnostic reaction	"I was shocked. I felt the world was finished for me. I could not bear the conditions and I did not understand the things that they were telling me".[10]
		Hospitalisation	"We were at the hospital crying. My wife also thought it was horrific, she was as shocked as I was. It makes me want to cry. It was overwhelming, and a disaster telling my parents and my daughter. I was bawling. It is a serious disease".[23]
	Change of life routine after diagnosis	Learning behavioural cues	"He was acting goofy, and I thought he was just kidding around, and then I tested him and he was 35! I had to experience it [the link between behavior and blood glucose level] to really get it".[27]
		Importance of routine/careful planning	"You can't just walk out the door like you used to be able to; you have to plan things all the time. Basically the whole day revolves around it, absolutely everything!"[4]
		Difficulties with insulin administration	"Applying insulin is a horror, it's a needle in our hearts when we apply it. (Dedication) was a way to make me feel better too".[3]
		Managing unpredictable blood glucose readings	"The child's level of blood glucose is a challenge to predict. Her level of blood glucose has always been unpredictable—for instance, it is high on a Monday morning, and then on Tuesday and Wednesday, it is suddenly low, even though she eats the same".[13]
	Reconstruction of family dynamics	Main topic of conversation	"We have a lot of conversations about diabetes. It's the type of disease that just takes over our discussions".[23]
		Impact on parents' relationship	"We do communicate, should I say it, even better [now] ... We probably take more of a share in some ways".[4]
		Responsibility distribution/ spousal support	"So the (diabetes) nurse came and spoke properly to my husband and told him he has to be a part of this because I can't do it by myself … he listened to what she was saying … Yes, I'm glad that he realises that he has to participate/we have decided that I'm going to have some days off. When I have time off I really want to feel like I have time off … So we decided to have, one weekend is daddy's weekend; one is mine and then a weekend when we are all together. When he (the son) is sitting and eating he shows me the pen and I say "Yes, but now daddy is sitting with you" "Yes, but you must look." So I do take the largest part. And that is fine by me; I do like to be in control of the situation".[34]
		Impact on siblings	"The other one rebels against the sick child, feels jealous and even anger and I still have to split them to avoid fighting. My other daughter is jealous and keeps complaining that I don't like her, but it is not like this, it is because the sick one deserves more care. The other children even pretended to be sick to call my attention".[15]

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Table 1 Qualitative synthesis: analytical themes, descriptive themes, example codes and illustrative quotations continued

Analytical themes	Descriptive themes	Example codes	Illustrative quotations
		Sharing decision making	"We would ask the other what would you give her and then we would compare answers and if we were off a bit we kind of averaged them. So, we had to come up with our own little thing to make sure we were doing it right. God forbid you felt you made a mistake and the kid went low that day ...".[25]
		Issues of independence	"The main difference has been ... he's just the last year or so been at the age where you're letting go ... they can make decisions ... go into town and things. And suddenly, you're having to come back in again as the vigilant parent. It sort of collides with the emerging independence. And working out how to manage that and allow him to carry on becoming more and more independent is quite a juggling act".[32]
	Psychological impact	Emotional impact	"I went into a total depression Even [my husband] couldn't understand how I felt. It was frightening; I actually had suicidal thoughts. I was driving across the bridge. [My toddler with diabetes] was with me and I suddenly thought I can't go on with all this. I had this desire to drive into the oncoming traffic and end it all. The feeling came back several times so I went for help. It was frightening".[30]
		Night-time anxiety	"… I still have nightly anxiety as I cannot truly rely on the levels as I could before, as puberty has started and the remission is all gone; thus, I have to adjust the dosages considerably more exactly and monitor the blood sugar more often ….".[36]
		Fear of hypoglycaemia	"Every time that she does get near a hypo, when her figures are low, I do find myself, maybe I don't show it as much, but deep down I do have a bit of a panic attack thinking this could lead into something else. Is she going to collapse?"[33]
		Worries about the future	'I am always thinking about his future. I wonder what will happen to his body. Can he be successful in his life? I do not know; the future is unclear".[31]
		Grief/sense of loss	"You go through a grieving process, and you know you grieve for near death ... but you still have to grieve for the loss of your healthy child".[4]
Navigating appropriate T1D support	Enablers and barriers to support from others	Lack of understanding from others	"I think the biggest frustration was when we [were] first diagnosed. You know people just don't realise the constantness of it, that's what I find tiring".[4]
		Others' inappropriate diabetes management	"We had an incident last Friday where he was the student of the month. He got to go to this party with all these kids, and he was told that he couldn't have a snack, basically because he's diabetic. That happens all the time to him, and it's really hard to explain to a seven-year-old [...] Why couldn't they just call me and say, "Hey, can he have a snack?" That's one of the harder things, because people don't understand how it makes him feel".[12]
		Reduced social contact	"Slowly, people visiting became less and sympathies became by telephone. As everyone was busy with their own lives".[10]
		Difficult clinic experiences	"I often feel stressed up to about a week before I go to clinic. I worry about what my son's HbA_{1c} results will be. I start to feel like I have not done enough to make sure his blood sugars have been stable. I sometimes feel under confident in my ability to treat and care for my son. I feel a poor blood test at clinic reflects on my care and ability".[22]
		Importance of diabetes community	"Being involved in the diabetes community led to forming new friendships and deriving meaning from advocacy efforts".[1]

T1D, type 1 diabetes mellitus

Table 2 Study characteristics

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Khandan *et al* (2018)[17] Iran	To explore mothers' experiences in the maze path to the diagnosis of children's disease	15 mothers with children (aged ≤14 years) who suffered from T1D and at least one year had passed since diabetes was detected in their children	Semi-structured interviews	Content analysis	Themes: Entanglement in the maze path of the disease diagnosis Facing the reality of the child's disease To grin and bear with new conditions
Albolhassani *et al* (2013)[18] Iran	Explore mothers' experience of children with diabetes	11 mothers 28–42 years. Children aged 4–16. All participants married	Interviews	Content analysis	Themes: Reaction at time of diagnosis: denial, shock, presentiment, concern, anger, anxiety, impatience and crying, lack of info, lack of attention to their needs, lack of enough opportunities to accept the disease Disease consequences for mothers: living with uncertainty and concern, trust in God and spiritual connection, false hope.
Anderson *et al* (2018)[2] Jamaica	Determine the challenges, coping strategies and needs of urban and rural Jamaican caregivers of adolescents with diabetes, and suggest ways to assist coping	19 caregivers of adolescents with diabetes. Adolescents aged 12–17	Focus groups	Thematic analysis	Main challenges caregivers faced were keeping their children healthy, managing conflict with their children, and financial concerns. They met these challenges with problem-focused and emotion-focused coping strategies
Commissariat *et al* (2019)[19] USA	Explore parent perceptions of the burdens of caring for very young children with T1D	79 parents with a child <8 years with T1D	Semi-structured qualitative interviews	Thematic analysis	(1) Emotional burden of diabetes on themselves and their children. (2) Burden of finding, training and trusting effective secondary caregivers to manage the child's diabetes. (3) Suggestions for how more comprehensive, personalised diabetes education from healthcare providers for parents and secondary caregivers could help reduce parent burden and worry
Sullivan-Bolyai *et al* (2003)[5] UK	Describe the day-to-day experiences of mothers raising young children <4 years with T1D	Sample of 28 English-speaking mothers of children <4 years of age diagnosed with T1D for at least 3 months	Descriptive, naturalistic inquiry interview	Descriptive, naturalistic inquiry principles	Constant vigilance: 3 aspects of constant vigilance: day-to-day concerns, day-to-day management, and supportive resources. Burden of Constant Vigilance on Mothers' Physical and Emotional Health
Pimentel *et al* (2017)[3] Brazil	To understand the perception of parents of children and adolescents in relation to the diagnosis of T1D	11 parents of children and adolescents with T1D	Semi-structured questionnaire	Content analysis	Experiencing the diagnosis and being transformed by the disease of the child

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Table 2 Study characteristics continued

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Haslund-Thomsen *et al* (2020)[20] Denmark	To explore parents' experience of having a child aged 4–9 years with T1D using continuous glucose monitoring (CGM)	Danish-speaking parents of children with T1D aged 4–9 years who receive care and treatment at the diabetes units	Semi-structured interviews	Thematic analysis	(1) Living in the context of the unpredictability of diabetes. (2) Establishing a sense of control and security with CGM. (3) Learning to use and trust CGM and educating other caregivers
Povlsen *et al* (2009)[21] Denmark and Egypt	To explore variations in how parents living as immigrants in Denmark and in their native country had perceived learning to live with a child with diabetes	Arabic-speaking parents, who had immigrated to Denmark, where their child had been diagnosed with diabetes, were matched with Arabic-speaking parents living in their native country (Egypt). The children were 7–16 years old and all had T1D	Semi-structured interviews	Phenomeno-graphic approach	Disease's influence on the family situation: Shock and disaster Change in parental roles Change in social relations Learning about diabetes management: Professional education and support Search for additional knowledge Future prospects for the child: Anxiety Faith and hope
Martins *et al* (2014)[22] Brazil	To understand the experience of mothers in the care of the child with T1D in a unit of Tertiary Reference in Diabetes	12 mothers of children with T1D participated	Semi-structured interview	Content analysis	Multiple feeling generated in the impact of the diagnosis; mother facing the competitiveness of affection among the children, experience of the mother in the expansion of the locus daily care
Kratzer (2012)[23] Ghana	To explore the structural barriers faced by families coping with T1D in Ghana and to provide insight for policy development	9 parents	Semi-structured individual interviews	Thematic analysis	Global themes: Access to health, social relationships and roles of the lay carer Five key barriers to families coping with T1D in Ghana: primary care facilities, schools, financial burden, lack of formal support and access the information
Seppänen *et al* (1999)[24] Finland	Describe and understand the parental coping and social support received by the parents of diabetic children	Two sets of parents of two girls (3 and 4 years old) admitted into hospital because of diagnosed diabetes. Parents aged 35–40 years	Interview and observation	Time series and content analysis	Six phases of parental coping were identified: disbelief, lack of information and guilt, learning to care, normalisation, uncertainty and reorganisation. In the different phases of parental coping, the parents' experience of stress, coping strategies and sense of control varied
Lawton *et al* (2014)[25] UK	To explore the difficulties parents encounter in trying to achieve clinically recommended blood glucose levels and how they could be better supported to optimise their child's glycaemic control	54 parents of children with T1D (≤12 years)	Interviews	Thematic analysis	Fear of hypoglycaemia, monitoring and supervision, school/nursery and other settings outside the home, cocooning versus accommodating a 'normal' childhood, 'home' and 'away' targets, experiences of consultations and support needs

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Table 2 Study characteristics continued

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Wennick *et al* (2007)[26] Sweden	Elucidate families' lived experience of diabetes 1 year after a child was diagnosed with T1D	11 Swedish-speaking family members with children aged 9–14 years	Interviews	Phenomeno-logical analysis	Identified as living an ordinary yet different life: feeling acceptance yet frustration, being healthy yet invisibly ill, feeling independent yet supervised, feeling confident yet insecure
Wennick *et al* (2006)[27] Sweden	Elucidate the whole family's lived experience when a child in the family is diagnosed with T1D	23 parents (12 mothers and 11 fathers)	Interviews 1–3 months after the child was diagnosed	Hermeneutic phenomenology	Ongoing learning process including learning about the inevitable and learning about the extent. The learning process was experienced as a recurrent phenomenon when the family was exposed to new situations or contexts
Barone *et al* (2019)[28] Italy	Exploring the meaning-making processes related to the maternal elaboration of their child's diagnosis of chronic illness	21 mothers of young patients with T1D aged 6–17 years	Individual interviews	Grounded theory	Emotional regulation, collaboration in the therapeutic management, presentation of the disease and social sharing of the disease. The mediation function can act on two different levels: an intra-personal level, by fostering maternal elaboration of the disease; and an inter-personal level, by promoting the child's meaning making process and the actions to manage their disease
Lowes *et al* (2015)[29] UK	Explore the experiences of children and adolescents with T1D and those of their carers concerning living with and managing diabetes and attending paediatric diabetes services in the UK	Children and adolescents aged 7–15 years with T1D of at least 1 year duration and one of their carers	Questionnaires contained free-text boxes	Qualitative descriptive analysis	'Attending clinic', 'communication skills', 'emotional responses to T1D' and 'emotional support in clinic'
Sand *et al* (2018)[30] Sweden	To explore the process of family dynamics when a child has been diagnosed with T1D	29 parents (17 mothers, 12 fathers) and 7 siblings of 20 children with T1D aged 5–17 years participated	Focus groups and individual interviews	Grounded theory	The child's sudden loss of health, and in three related categories: preconceptions, psychological reactions, and impact on family relationships
Nurmi *et al* (2012)[31] Canada	To explore a parent's sense of meaning in relation to the parenting of a child with T1D	13 parents. Children aged 7–17 all diagnosed with diabetes at least 1 year prior to the interviews. The length of time the participants' children had lived with diabetes ranged from 1–13 years	Interviews	Content analysis.	Being like everyone else and protecting the children

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Table 2 Study characteristics

Study (author, year, country)	**Aim**	**Participants**	**Data collection method**	**Data analysis**	**Key findings**
Symons *et al* (2015)[4] New Zealand	To improve health professionals' understanding of the impact on families of living with a child diagnosed with T1D. The study gives voice to parents of children diagnosed with T1D, providing an opportunity for them to speak of their experiences and convey the realities, challenges and struggles of everyday life caring for a child with this condition	Nine parents/caregivers of a child, aged 4–14 years who had been diagnosed with T1D at least 12 months previously	Semi-structured interviews	Thematic analysis	Disruption to family life; impact on family relationships; psychosocial effects of living with T1D; and adaptation to a 'new normal'
Pierce *et al* (2017)[1] USA	Parenting young children with type 1 diabetes (YC-T1D) entails pervasive challenges; parental coping may influence child and parent outcomes. This study used a qualitative descriptive design to describe these challenges	153 active Parent Crowd participants. The parents were predominantly non-Hispanic Caucasian (90.2%). Diversity Focus Group participants were 13 parents of 8 children with T1D aged 7 years (M=4.75, SD=1.39) diagnosed with T1D before age 6 (range 1–5 years; M=2.63, SD=1.30), Hispanic (n=3) or African American (n=5)	Crowdsourcing free-text questionnaires and focus groups	Content analysis	Similar domains and themes emerged from responses of crowdsourcing and focus group participants. In each domain, parenting YC-T1D was challenging, but there was also substantial evidence of positive coping strategies and adaptability
Smaldone *et al* (2011) USA	To explore perceptions of psychosocial adaptations in parenting young children with T1D from diagnosis through childhood	14 parents (3 mothers, 3 fathers and 4 couples) of 11 children (diagnosed at age 3.2 (1.7) years; 36% in DKA; diabetes duration 8.0 (3.7) years; current age 11.1 (3.5) years)	Interview	Content analysis	Three pertinent themes were identified: diagnostic experiences: frustrations, fears, and doubts; adapting to diabetes; and negotiating developmental transitions
Rifshana *et al* (2017)[33] New Zealand	To add to the literature on embodiment within care-giving by exploring the lived experience of parents of children with T1D	17 parents (14 mothers and 3 fathers) of children aged 4–12 years who had been diagnosed with T1D for a minimum of 6 months	Semi-structured interviews	IPA	Prominent theme: Looking after a child with diabetes: 'Issues of embodiment'. Two specific aspects of this main theme: 'Constant vigilance and careful management' and 'Comparing diabetes with other condition'

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Table 2 Study characteristics continued

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Sullivan-Bolyai *et al* (2006)[34] USA	To describe fathers' experiences in parenting and managing the care of their young children with T1D	14 fathers of 15 children with T1D. Of the 15 children (2 were siblings), 9 were male and 6 female. Their mean age was 5±2 years (range 2–8 years) and mean duration of illness was 1.4±0.8 months (range 2 weeks to 3 years)	Interviews	Naturalistic inquiry and content analysis	"From sadness to action" with 6 categories emerging: (1) "shock and awe" (after diagnosis); (2) quick response to the diagnosis and learning diabetes care: "suck it up and do it"; (3) "staying in the loop" (practising the skills, tasks and responsibilities of diabetes management); (4) "partnerships in care" (tag teaming or co-parenting); (5) active participation (being actively involved in their children's day-to-day care and benefiting from participating in this care); and (6) mantra for living with diabetes: child first, diabetes second
Lowes *et al* (2005)[35] UK)	To explore parents' experiences of having a child diagnosed T1D and their adjustment and adaptation over the first year	38 parents, including two single-parent families. Median age 39 years (range 23–49). Median age of their newly diagnosed children (11 boys and 9 girls) was 9 years (range 2–15). Three parents had T1D. Four parents had another family member with T1D or T2DM	Interviews	Unclear/Framework of the Theory of Psychosocial Transition	Before diagnosis, most parents associated their child's symptoms with normal childhood illnesses. The unexpectedness and speed of the diagnosis left all parents ill-prepared to deal with the situation. Their world suddenly changed, leaving them insecure and uncertain about the future. Diabetes intruded emotionally and practically upon all of their lives. Parents successfully adjusted and adapted their lives and rebuilt a new model of the world to accommodate their child's diabetes. However, this dynamic process has no guaranteed endpoint for parents
Spencer *et al* (2012)[36] UK	To explore adolescents' and parents' experiences of living with T1D from an interpretive phenomenological perspective	20 adolescents (9 male, 11 female) with T1D and 27 parents (7 male, 20 female); all were white British	Interviews	IPA	Stage 1: adapting to the diagnosis Stage 2: learning to live with diabetes Stage 3: gaining independence
Hatton *et al* (1995)[37] Canada	To gain knowledge and understanding of the parents' experiences	8 two-parent families with an infant or toddler with diabetes, who had been managing the child's diabetes for a minimum of 2 months. The children with diabetes ranged in age from 5 weeks to 31 months at time of diagnosis, with an average age of 18 months	Interviews	Phenomenological analytical procedures	Diagnosis and child's hospitalisation, adjusting to care at home, and long-term adaptation. Within these phases, parents described inordinate amounts of stress exacerbated by the child's young age and the complex intrusive nature of diabetes management

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Table 2 Study characteristics continued

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Khandan *et al* (2018)[38] Iran	To explore the experiences of diabetic children's mothers from the transfer of caring role	11 Iranian mothers of children aged ≤14 years with T1D	Semi-structured interviews	Phenomenological method	'Facing the care management challenges,' 'care in the shadow of concern', and 'hard life in the impasse of diabetes'
Lowes *et al* (2004)[39] UK	To explore parents' experience of having a child diagnosed with T1D managed at home and their first year following diagnosis	38 parents. All parents were white English-speaking. Their median age was 39 (range 23–49) years and the median age of their newly diagnosed children (11 boys, 9 girls) was 9 (range 2–15) years	Interviews	Unclear/thematic	Many parents were alarmed by the speed of diagnosis following the gradual progress of their child's symptoms. The provision of timely adequate information was important to all parents. Although five parents had initial concerns about going home, all parents were subsequently pleased their children had not been hospitalised. Home management enabled parents to integrate diabetes management into the family's normal lifestyle from diagnosis. Professional support, particularly accessible telephone advice, was valued by and reassured parents. Parents experienced a loss of spontaneity, a continuing fear of hypoglycaemia and did not want their child to feel different to other children. Acutely aware of the seriousness of diabetes, they did their utmost to achieve optimal glycaemic control but felt that diabetes could not 'dominate' if they were to lead a 'normal' life
Marshall *et al* (2009)[40] UK	To explore and describe the experiences of children and their parents living with T1D from diagnosis onwards	10 children (aged 4–17, time since diagnosis 10 months–8 years) and 11 parents (10 mothers, 1 father) were interviewed (1 couple was interviewed together)	Interviews	Thematic analysis	Four themes: transition, attachment, loss and meaning were common to the children's and parents' data with 'normal' being the central unifying theme
Sparud-Lundin *et al* (2013)[41] Sweden	To explore parents' process of changes and challenges in their patterns of daily activities after the onset of diabetes in a child	36 parents involved and their children, 21 mothers and 15 fathers of 23 children with T1D 8–10 months after onset	Interviews	Qualitative comparative analysis	The core category depicts how the illness forced parents to reconstruct their family project with respect to patterns of daily activities and gender structures. The emerging subcategories of reinforced mothering and adjusted fathering illustrate the parents' effort to handle contemporary and contradictory demands

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Table 2 Study characteristics continued

Study (author, year, country)	Aim	Participants	Data collection method	Data analysis	Key findings
Smith *et al* (2010)[42] USA	Examined child and parent perceptions of the child and parent roles in diabetes management as well as the child's attitude toward his or her diabetes	49 mothers, 6 fathers and 4 guardians of children with T1D. 60 children (22 boys and 36 girls). Children ranged in age from 8 years 6 months to 15 years 8 months (M=12 years 2 months; SD=2 years 1 month)	Interviews	Grounded Theory Approach	Themes: daily activities, Forgetting, having difficulty, being on the pump
Wennick *et al* (2009)[43] Sweden	To illuminate family members' everyday experiences 3 years after a child had been diagnosed with T1D	9 fathers aged 33–54 years (median 45 years) and 11 mothers aged 33–48 years (median 43 years)	Individual interviews	Content analysis	Eight categories were identified to describe the families' every-day experience: (a) knowledge and tried experience give skills; (b) capricious blood sugar level; (c) ambivalent parenthood; (d) stressful daily planning; (e) physical activity as pleasure and annoyance; (f) fear of losing control; (g) a private and public concern; and (h) needed and not needed medical service

T1D, type 1 diabetes mellitus

Distressing diagnostic experience

This theme was present in 20 of the 32 primary studies which represents 63% of the studies (Table 4). Parents reported a distressing diagnostic experience that brought up a range of unsettling emotions such as shock, disbelief, anger, stress, anxiety, grief and sadness. Some parents were overwhelmed and tearful at diagnosis, describing it as extremely painful and traumatic. Some of the shock at diagnosis was explained as being due to the lack of understanding of T1D, incorrectly assuming this was not a condition which affected children. Parents experienced guilt at not noticing symptoms and often blamed themselves for T1D; trying to pinpoint the cause through examining their care of the child. The route to diagnosis was not always straightforward; reasons included misdiagnosis by doctors, parents not recognising T1D symptoms or attributing symptoms to other common conditions, which sometimes resulted in delaying seeking medical support. In some situations this delay in receiving an accurate and timely diagnosis led to the child's health deteriorating to the point of hospitalisation, which was distressing for parents. Parents had difficulty initially accepting the diagnosis although most came to terms with the diagnosis with time.

Change of life routine after diagnosis

This theme was present in 27 of the 32 primary studies which represents 84% of the studies (Table 4). Parents described a change of life routine after receiving the diagnosis that involved complex T1D management. Parents expressed concerns about their ability to be able to care and cope with the complex regimens. Parents learnt multiple new T1D-related caregiving skills such as administering insulin and understanding behavioural cues that may indicate hyperglycemia or hypoglycemia, which could change as the child developed. For example, one parent described that their child would be argumentative when their bloods were high and go very pale when their bloods were low. Parents struggled with the unpredictability of T1D, specifically around blood glucose levels. This unpredictability resulted in parents closely monitoring their children and blood glucose levels. Parents described the incessant nature of managing the disease and the time-consuming day-to-day responsibilities. Parents experienced a loss of spontaneity and flexibility in their daily routine as planning was always required, especially with food and play or activities. There were financial implications of raising a child with T1D, whether this was from a dietary perspective of buying sugar free/low sugar food, or through T1D care such as insulin and diabetes-related supplies. The cost of T1D care was a particular concern for those parents who did not have adequate funding for this through their country's healthcare/insurance. This was prevalent in seven studies which were undertaken in Jamaica, Brazil, Egypt, Ghana, Iran and USA.

Parents' employment was also impacted, with some parents taking on more work to cover the cost of T1D treatment and others having to give up work or change to part-time because of managing T1D care, such as frequent doctors' appointments. Dietary requirements were described as complicating celebrations such as birthday parties or family meals out. After time, parents reported the change in life routine being a new normal and part of daily life.

Table 3 Critical Appraisal Skills Programme Qualitative Checklist

First author and year	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	'Y' total for each study
Khandan *et al* (2018)[17]	Y	Y	Y	Y	Y	C	C	Y	Y	Y	8/10
Albolhassani *et al* (2013)[18]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Anderson *et al* (2018)	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8/10
Commissariat *et al* (2020)[19]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9/10
Sullivan-Bolyai *et al* (2003)[5]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Pimentel *et al* (2017)[3]	Y	Y	Y	Y	Y	C	Y	Y	C	Y	8/10
Haslund-Thomsen *et al* (2020)[20]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Povlsen *et al* (2009)[21]	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8/10
Martins *et al* (2014)[22]	Y	Y	Y	C	Y	C	Y	C	C	C	5/10
Kratzer (2012)[23]	Y	Y	C	Y	Y	C	Y	C	Y	Y	7/10
Seppänen *et al* (1999)[24]	Y	Y	Y	C	Y	C	C	Y	Y	C	7/10
Lawton *et al* (2015)[25]	Y	Y	Y	Y	Y	C	C	Y	Y	Y	8/10
Wennick *et al* (2007)[26]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Wennick *et al* (2006)[27]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Barone *et al* (2019)[28]	Y	Y	Y	C	C	C	Y	Y	C	C	5/10
Lowes *et al* (2014)[29]	Y	Y	C	Y	C	C	C	Y	Y	C	5/10
Sand *et al* (2017)[30]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9/10
Nurmi *et al* (2012)[31]	Y	Y	Y	C	C	C	C	Y	Y	Y	6/10
Symons *et al* (2015)[4]	Y	Y	Y	C	Y	C	C	C	Y	Y	6/10
Pierce *et al* (2017)[1]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9/10
Smaldone *et al* (2011)[32]	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8/10
Rifshana *et al* (2017)[33]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Sullivan-Bolyai *et al* (2006)[34]	Y	Y	Y	C	Y	C	Y	Y	Y	Y	8/10
Lowes *et al* (2005)[35]	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	9/10
Spencer *et al* (2012)[36]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Hatton *et al* (1995)[37]	Y	Y	Y	Y	Y	C	C	C	Y	Y	7/10
Khandan *et al* (2018)[38]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Lowes *et al* (2004)[39]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Marshall *et al* (2009)[40]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9/10
Sparud-Lundin *et al* (2013)[41]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	8/10
Smith *et al* (2010)[42]	Y	Y	C	C	C	C	C	C	Y	Y	4/10
Wennick *et al* (2009)[43]	Y	Y	C	Y	Y	C	Y	Y	Y	Y	8/10
'Y' total for each question	32/32	32/32	26/32	25/32	28/32	10/32	26/32	27/32	29/32	28/32	

Table 4 Themes present in included studies

First author and year	Distressing diagnostic experience	Change of life routine	Reconstruction of family dynamics	Psychological impact over time	Enablers and barriers to support from others
Khandan *et al* (2018)[17]	X	X	X	X	X
Albolhassani *et al* (2013)[18]	X	X		X	X
Anderson *et al* (2018)[2]	X	X	X		X
Commissariat *et al* (2020)[19]		X	X	X	X
Sullivan-Bolyai *et al* (2003)[5]		X		X	X
Pimentel *et al* (2017)	X	X	X	X	X
Haslund-Thomsen *et al* (2020)[20]	X	X	X	X	
Povlsen *et al* (2009)[21]	X	X		X	X
Martins *et al* (2013)[22]	X	X	X	X	X
Kratzer (2012)[23]	X	X		X	X
Seppänen *et al* (1999)[24]	X	X		X	X
Lawton *et al* (2014)[25]		X	X	X	X
Wennick *et al* (2007)[26]		X	X	X	X
Wennick *et al* (2006)[27]	X			X	X
Barone *et al* (2019)[28]			X	X	
Lowes *et al* (2015)[29]		X		X	X
Sand *et al* (2017)[30]	X		X	X	X
Nurmi *et al* (2012)[31]		X	X		X
Crawford *et al* (2015)		X	X	X	X
Pierce *et al* (2017)[1]	X			X	X
Smaldone *et al* (2011)[32]	X	X	X	X	X
Rifshana *et al* (2017)[33]		X	X		
Sullivan-Bolyai *et al* (2006)[34]	X	X	X	X	X
Lowes *et al* (2005)[35]	X	X	X	X	
Spencer *et al* (2012)[36]	X	X	X	X	X
Hatton *et al* (1995)[37]	X	X		X	X
Khandan *et al* (2018)[38]	X	X	X	X	X
Lowes *et al* (2004)[39]	X	X	X	X	X
Marshall *et al* (2009)[40]	X	X	X	X	
Sparud-Lundin *et al* (2013)[41]		X	X	X	
Smith *et al* (2010)[42]		X			
Wennick *et al* (2009)[43]				X	X

Reconstruction of family dynamics

This theme was present in 21 of the 32 primary studies which represents 66% of the studies (Table 4). Family life was experienced as being disrupted for everyone involved as they all had to adapt to a new routine. Some parents reported a positive impact on the parental relationship and family structure, such as better communication with their partner, better family cohesion and healthier lifestyles. Other parents reported negative impacts, such as deterioration in emotional and physical intimacy and spending time together due to sharing care equally. Parents described T1D as being the main topic discussed, and for some this was seen as a positive part of the relationship; however, other parents felt their whole life was now taken up with T1D-related tasks. Parents described their parental role changing to more of a supervisory and controlling role. In parental relationships where there were unequal divisions of T1D care or lack of spousal support, this often led to resentment, tension or, in some cases, ending of their relationship. Parents reported conflict between siblings as a result of the child with T1D getting more attention from the parents although, in some families, siblings were described as being caring towards their sibling with T1D. As a result of raising a child with T1D, parents expressed concerns about having future children in case they too received a diagnosis of T1D.

Navigating appropriate T1D support

This analytical theme illustrates that the emotional impact of raising a child with T1D persists past diagnosis due to the demands of T1D management and ongoing concerns about their child. The systems surrounding parents played a key role in how supported they felt whilst raising a child with T1D. Parents had difficulties finding and trusting caregivers to provide appropriate support to their child. They had concerns about nursery and school management of T1D and spent time advocating for their child to ensure they received appropriate care. T1D care teams were identified as a key source of support, although parents had mixed experiences of their encounters with them. Parents experienced a lack of understanding from others of the reality of living with T1D, both from their social support network and professionals. Parents longed for more emotional support to be offered by professionals. This analytical theme is explored further below through the descriptive themes from which it was derived: ‘psychological impact over time’ and ‘enablers and barriers to support from others’.

Psychological impact over time

This theme was present in 28 of the 32 primary studies which represents 88% of the studies (Table 4). Parents reported feeling overwhelmed, stressed, depressed, guilty, irritable and exhausted from the demands of T1D management. Parents reported a fear of hypoglycemia, which intensified at night-time. Parents struggled with sleep deprivation, which was often linked to night-time fears of finding their child unconscious or dead, leading to them getting up at night to check on their child. In the most severe cases, some parents had considered ending their life in the early weeks following diagnosis while others had been hospitalised. Parents experienced numerous concerns about their T1D child's future including: the child's current and future independent T1D management, long-term health complications including death, and the psychological impact on their child. When parents experienced a crisis or traumatic event such as severe hypoglycemia, their confidence fell and their anxiety increased. Some parents had fears and difficulty with giving injections. Parents had worries about how care providers such as nursery or school would manage their child’s T1D care. There were some parents who tried to remain positive by looking at positive aspects of the situation and hoping for a cure for T1D. Some parents also reported feeling like they were coping most of the time.

Enablers and barriers to support from others

This theme was present in 25 of the 32 primary studies which represents 78% of the studies (Table 4). Parents felt there was a lack of understanding from others about how T1D is caused or managed – for example, parents felt that others did not understand the constant nature of T1D care. Parents reported difficulty finding caregivers who were able to engage with T1D management; this was partly due to some caregivers not feeling comfortable giving insulin injections. Parents also had difficulty trusting others with providing appropriate care to their child, as they wondered whether they would be able to attend to T1D emergencies – for example, being able to identify and treat hypoglycemia. However, for some parents they did not have a choice but to trust other caregivers due to work commitments. Some parents received support from family and described them as playing an important role in caring for their child, but for other parents there was a lack of support from family who were reluctant to get involved in care. Parents reported a negative impact on their social life as a result of T1D care and management. Parents were concerned by the lack of support from school in adhering to T1D management – for example, not attending to the child’s dietary needs or inappropriate care by putting unnecessary restrictions on the child (ie, refusal of snacks or calling an ambulance rather than giving an injection). Parents also experienced school staff as generally lacking sufficient knowledge about T1D which caused concern. However, there were some parents who reported receiving good support from school – for example, some schools had extra staff to support their child with T1D care and provided regular communication with parents.

The T1D healthcare team was viewed as a helpful, valuable resource whose availability and support after discharge was important. Although some parents felt they received a lack of professional support and that the T1D team lacked up-to-date information in developments, giving conflicting advice from within the team. Parents felt that T1D clinic staff did not understand the reality of living with and managing T1D, and had unrealistic expectations of what can be achieved. This resulted in some parents feeling anxious going into clinic appointments as they felt they were going to be reprimanded or judged despite their best efforts. Some parents described positive experiences of the clinic as they felt reassured that they were doing a good job and received good support from T1D professionals. There were some parents who felt there was a lack of emotional support offered and wanted better access to mental health services. Parents advocated for their children to protect them from being mistreated when others may not understand or accommodate their needs. Parents viewed participating in T1D fundraising events and interacting with other families living with T1D as helpful and important, and also reduced feelings of isolation, gave a sense of belonging and instilled hope.

Discussion

In this review, 32 studies on parents' experiences of raising a child with T1D from 13 countries were thematically synthesised. The findings revealed that, when a child is diagnosed with T1D, the parents enter a new reality of living with T1D to which they have to adapt. Highly prevalent from the studies was the psychological impact over time, with parents reporting feeling overwhelmed, stressed and depressed, which was likely as a result of the change of life routine.

These findings support the systematic review by Whittemore *et al*,[6] with parents describing diagnosis as an emotionally distressing experience, family life being disrupted by T1D and the psychological impact of raising a child with T1D. Similarly, a review that examined parenting stress among caregivers of children with chronic illness[10] found parents experienced significantly greater general parenting stress than caregivers of healthy children, and this stress is also associated with poorer psychological adjustment. This would suggest that this current review sheds further light on the fact that, despite the recommendations made in these reviews and probable subsequent developments in clinical practice or management of T1D, parents still experience difficulties in these areas.

This qualitative synthesis provides an important original contribution to knowledge by highlighting the specific difficulties some parents experience in receiving appropriate support from school and in T1D clinic appointments, with some parents feeling that clinic staff do not understand the reality of living with and managing T1D, which has the potential to impact on their psychological well-being.

In line with National Institute for Health and Care Excellence (NICE) guidelines for T1D management,[11] school staff supporting children with T1D should have regular liaison with diabetes teams with adequate information provision and parents should be offered signposting to diabetes support groups and organisations. There also needs to be regular screening for parental mental health difficulties, which has been recommended to occur from the point of diagnosis,[12] especially for suicidal thoughts in the immediate post-diagnosis period. If a need is indicated, parents should be provided with access or appropriate referrals to mental health professionals.[11,13] Psychological interventions and parenting interventions can help to reduce parental ditstress.[14,15]

Healthcare professionals should be aware of the impact of raising a child with T1D on the parents' relationship; they should enquire and assess for family conflict, negotiating a plan for resolution or referring to appropriate mental health support where appropriate.[13] NICE recommends that parents who are experiencing diabetes-related family conflict should be offered specific family-based behavioural interventions, such as behavioural family systems therapy.[11] This aligns with existing research that has found behavioural family systems therapy, focused on communication styles, results in reduced diabetes-specific conflict.[16] Intervening early could have positive outcomes and potentially keep families together, therefore maintaining support for the whole family.

Key messages

- Parents' lives are impacted when their child is diagnosed with T1D
- They have to adjust to a new reality and navigate the world of T1D to access appropriate support, encountering barriers that can occur along the way
- Parents’ mental health needs should be reviewed throughout T1D clinic appointments, and they should be assisted to access psychological intervention if a need is highlighted

Healthcare professionals should be aware of the anxiety parents may feel about clinic appointments and the impact this can have on their mental health if they feel they are not able to live up to staff expectations. Healthcare professionals should ensure they are realistic with their expectations, empathic, praise and acknowledge parents' effort when they are trying their best, whilst avoiding judgement to help reduce any feelings of anxiety and blame. Additionally, where possible they should ensure that conflicting advice isn't given to parents from different clinic staff.

The strengths of this review include the extensive amount of data over 25 years across multiple countries and the comprehensive analytical approach to searches and data analysis, as well as including a critical appraisal of all studies and attempting to contact authors where information was unclear. Additionally, it was prospectively registered on Prospero to reduce the potential for bias and enhance transparency in outcome reporting. A limitation of this review is that language restrictions were in place which meant that relevant data may have been missed. Moreover, there was limited diversity in the sample of participants in relation to reported ethnicity and gender, which has the ability to impact on parental experiences. There was a notable difference in mother and father participants, with the perspectives of fathers being infrequent. Other areas which can influence the parental experience include characteristics such as employment status, education, relationship status and underlying mental health issues/anxieties. Future research should investigate these areas and have a broader diverse participant pool that is reflective of the population, which should include more fathers and participants from more culturally diverse backgrounds to ascertain their experience and enhance their voice within the literature.

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Appendix 1. PRISMA 2009 Checklist

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

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For more information, visit: **www.prisma-statement.org**.

Appendix 2. Search Strategy

Eleven databases (Ebscohost [CINAHL, Medline, Psycharticles, Psychinfo, Psychology and Behavioural Sciences, Child Adolescent Development Studies], Web of Science, Cochrane Library, PubMed, Scopus and British Nursing Index) were systematically searched from their inception to May 2020. The search terms used were: (1) parents or caregivers or mother or mum or mom or father or dad or parent or guardian, (2) diabetes, (3) Challenge* or attit* or experience* or view* or perce* or cop* or behav* or diffic* or belief* or rais*.