



## Research article

# Caregiver burden among parents of children with type 1 diabetes: A qualitative scoping review

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## ARTICLE INFO

## Keywords:

Diabetes mellitus type one  
Parents  
Caregiver burden  
Caregiver stress  
Child  
Qualitative methods

## ABSTRACT

**Objectives:** Type one diabetes (T1D) in children places substantial responsibility on parents as caregivers. This study investigated caregiver burden in parents of children with T1D by exploring the financial, physical, social, spiritual, and emotional or psychological problems they experienced.

**Methods:** We conducted a qualitative scoping review of the databases PsycINFO, PROSPERO, OVID Medline, OVID EMBASE, Cochrane Library (CDSR and Central), EBSCO CINAHL, ProQuest Dissertations and Theses Global, and SCOPUS. Of 119 full text articles assessed for eligibility, 18 peer-reviewed qualitative studies were included. Studies were considered relevant if they focused on diabetes management and parental burden or the experience of caregiving for a child with T1D.

**Results:** Using thematic analysis, six interrelated themes were identified: (a) experiencing chronic sorrow, (b) assuming responsibility for glucose highs and lows, (c) managing T1D and nighttime sleep disturbances, (d) making career sacrifices and choices to optimize T1D care, (e) navigating social experiences postdiagnosis, and (f) discovering new sources of support through online platforms.

**Conclusions:** This synthesis highlights an all-encompassing experience involved in caretaking for a child with T1D. Caregiving duties lead to a constant sense of vigilance, especially due to fear of hypoglycemic incidents. Parents commonly experience challenges with balancing work demands with T1D management, which lead to career and financial sacrifices. Their burden of care is exacerbated by a lack of reliable respite care but helped somewhat by online peer support. Future research is needed on the care burden differences between mothers and fathers and how socio-demographic factors affect how caregiver burden is experienced.

## 1. Background

Type 1 diabetes (T1D), formally known as insulin dependent, juvenile, or childhood-onset diabetes, is the most common incurable endocrine disorder among children and is on the rise globally [1]. T1D is estimated to account for 10% of all diabetes cases, with incidence rates increasing 3%–4% yearly [2–4]. The interplay among several environmental and genetic factors and exposure trajectories have been linked to the onset of T1D, with no conclusive explanation for its cause [3]. In T1D, the pancreas produces little or

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<https://doi.org/10.1016/j.heliyon.2024.e27539>

Received 19 August 2023; Received in revised form 5 February 2024; Accepted 1 March 2024

Available online 12 March 2024

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no insulin, a glucose-regulating hormone, due to the destruction of insulin-producing B cells [3]. The associated health complications and long-term health risks can be severe, including kidney failure, cardiovascular disease, retinopathy, hypoglycemia (glucose that falls and stays below a safe range), limb amputations, and neuropathy [5].

Given that T1D is diagnosed at a young age, children are significantly dependent on their parents for the management and care of their diabetes [6]. In addition to the normative tasks of supporting the cognitive, physical, and emotional growth of their children, parents of children with T1D are required to consistently monitor and regulate diet and exercise, utilize technologies such as a glucometer or insulin pump, or administer daily insulin injections, and prevent hypoglycemia episodes [7,8]. The responsibilities involved in managing T1D in children can be taxing for a caregiver [9]. Any error in daily management can lead to an acute event, so constant daily treatment, vigilance, and management are required to reduce the risk of complications [10]. As a result, the imbalance of time and demand between caretaking and other required responsibilities and roles can result in caregiver burden [11]. Caregiver burden refers to the financial, physical, social, spiritual, and emotional or psychological problems experienced by family members caring for a chronically ill loved one [12,13].

Although some reviews of quantitative evidence have aimed to understand the psychological impacts of caregiving for a child with a chronic condition, including T1D [14], no qualitative review has specifically explored the multifaceted dimensions of the caregiver burden among parents of children with T1D. One recent qualitative systematic review [15] aimed to fill this knowledge gap; however, they confined their review to the experiences of parents of children with T1D under the age of 8, limited their search to studies published in 2002 and onwards, and did not specifically aim to explore the concept of caregiver burden.

Therefore, we conducted a qualitative scoping review to describe the breadth of experiences and perspectives of caregiver burden, as defined by Chou [12], among parents. That is, we used the dimensions of financial, physical, social, spiritual, and emotional or psychological stressors as a guiding framework to explore the underlying attributes and consequences of caregiver burden in parents of children with T1D. This review is also unique in that it was not confined to reviewing experiences of parents of children of a particular age group. We aimed to capture what is known about caregiver burden among parents of children of any age with T1D. Understanding the caregiver burden experience of parents of children with T1D may provide direction on how best to alleviate some of the burden of care. Research has indicated that enhanced support for caregivers also translates to better caregiving, diabetes management, and health outcomes in their affected children [10,16].

## 2. Methods

Scoping reviews are commonly conducted to explore the nature and scope of research on a topic [17]. By systematically “mapping” the literature, scoping reviews provide readers with an overview of existing literature to identify areas where further research may be required [17]. As such, this qualitative scoping review aimed to (a) describe and understand the published evidence base on parental caregiver burden for children with T1D and (b) identify gaps in the existing literature and highlight implications for future research. We conducted the review process using the five stages of Arksey and O’Malley’s [17] methodological framework: (a) identifying the research question; (b) searching for relevant studies; (c) selecting relevant studies; (d) collecting, charting, analyzing, and summarizing the data; and (e) summarizing the results.

### 2.1. Stage 1: identifying the research question

The research question that guided this review was: What is the experience of caregiver burden among parents of children with T1D?

### 2.2. Stage 2: identifying relevant studies

The scoping review search strategy aimed to find articles describing the experiences of social, physical, emotional, or psychological and spiritual burden among parents caring for children with T1D. To identify relevant studies, a list of search terms was first developed in consultation with an expert health sciences librarian and by reading through the literature. Keyword sets were established through an iterative process of testing and refining words and search concepts. The librarian then executed a search using controlled vocabulary (e.g., MeSH, Emtree) and keywords representing the concepts “caregivers,” “burden,” “type 1 diabetes,” and “qualitative studies” on the following databases: PsycINFO, PROSPERO, OVID Medline, OVID EMBASE, Cochrane Library (CDSR and Central), EBSCO CINAHL, ProQuest Dissertations and Theses Global, and SCOPUS. To ensure comprehensiveness, databases were searched from inception to December 2022, and we did not limit our search to published reports only. We also searched the grey literature using the search string “T1D” AND “caregiving burden” AND “parents” on Google (in January 2023). The first 25 results were screened and reviewed; however, no data from these search results was found relevant or included in our study. The full search strategy for each database and inclusion PRISMA-S checklist can be found in the supplementary materials.

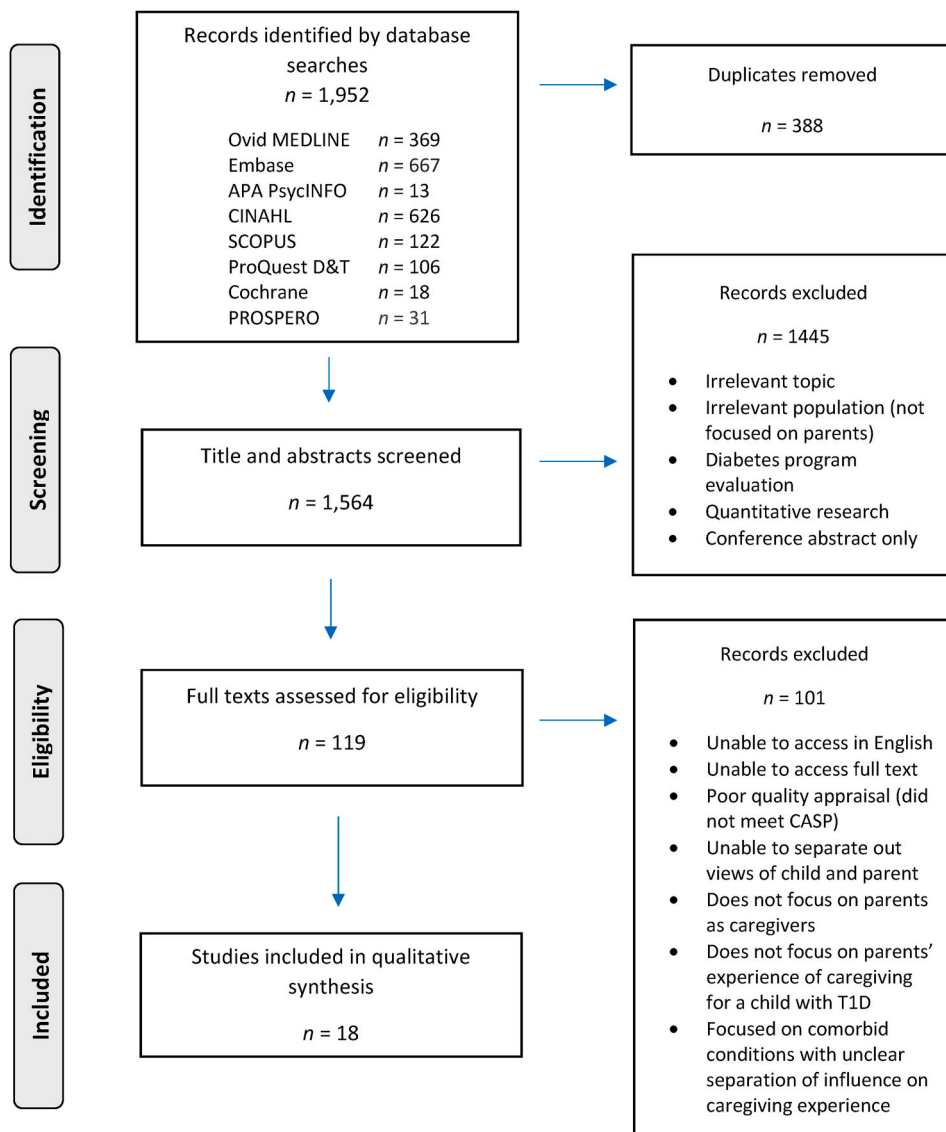
Adult-only and quantitative studies were excluded. No other limits were applied. A total of 1952 citations were exported to Covidence, a review management software. Duplicates (388) were removed, leaving 1564 search results to review for inclusion and exclusion, and 119 full-text articles to review for analysis. Of the 119 full-text articles that were selected for review, 18 were included in this scoping review (see [Appendix](#) for a summary of the data).

### 2.3. Stage 3: selecting relevant studies

Once duplicates were removed, each result was independently screened and reviewed first by title and abstract and then by full-text

review by the research lead and a research assistant. As an additional review measure, reference lists of included studies were also manually reviewed to ensure no relevant articles had been missed. No additional relevant articles were identified through this search. Non-peer-reviewed sources that were exported to Covidence from our search strategy were screened but not selected for full-text review as these search results did not address our research question. The research lead and research assistant independently conducted the quality appraisal using the Critical Appraisal Skills Programme for qualitative research (CASP; see <https://casp-uk.net/>) for studies in full-text review. Any conflicts over inclusion of studies during any stage of the screening and review process were carefully considered, discussed, and resolved. A third individual provided input and guidance when a decision could not be made.

Peer-reviewed qualitative studies were considered relevant if they specifically focused on diabetes management and burden among parents or the day-to-day experience of caregiving for a child with T1D. More specifically, articles were included if they had a discussion of psychological, emotional, social, financial, physical, and or spiritual experiences of parents of children with T1D. Studies that focused on diabetes technology, diabetes program evaluation, or the experiences of those who were not parental caregivers, such as medical professionals or school staff, were excluded. Research articles or studies involving interviews of parent–child dyads that did not clearly differentiate between the parent’s and child’s experiences in the findings were omitted. Finally, we did not include studies that were not translated into or accessible in English. This process left 18 papers for inclusion in data extraction (see Fig. 1).



Note. D&T = Dissertations and Theses.

Fig. 1. Prisma diagram, search results, and article Selection.

Note. D&T = dissertations and theses.

## 2.4. Stage 4: charting and synthesizing the data

Scoping reviews involve a practice of charting the existing literature or evidence base [17]. We created a comprehensive charting table in Microsoft Excel to extract data from the literature selected for this review synthesis to answer the research question. The extraction table was developed by the research lead and reviewed by the research assistant to ensure breadth. Data were first extracted to summarize study characteristics such as study descriptors, study aims, methods, and geographical location where the study was conducted. Then, we charted the goal of each paper, the main findings, included themes and subthemes, the gendered experience of caregiving, study implications, and noteworthy quotes and findings related to financial, spiritual, physical, social, emotional, and psychological stressors for each study.

The research lead and research assistant independently extracted data for each full-text article and compared and combined those data. A pilot of the extraction was first conducted to ensure each person was recording similar data. During the data extraction process, additional charting sections were added to the table if deemed essential or initially overlooked. All changes to the process and charting table were documented. To confirm that no information was missed, all articles were re-read and extracted from once again if a new section of inquiry was added to the table.

Following Maxwell's [18] and Miles and Huberman's [19] qualitative techniques, we analyzed the extracted and charted data using thematic analysis. The data were open coded and reviewed for patterns, similarities, and differences. This was done within and across the charted domains of social, financial, physical, emotional, or psychological and spiritual experience to identify emerging themes. Disagreements in data analysis were resolved through discussion and data review until both researchers reached a consensus.

## 3. Results

This scoping review explored the existing literature on the experiences of caregiver burden among parents caring for children with T1D. Of the 18 studies included in this review, two studies recruited only mothers as participants whereas the remainder recruited both fathers and mothers as participants. Mothers represented a larger percentage of the participants compared to fathers in these studies.

Six interrelated themes were identified and are described in detail below: (a) experiencing chronic sorrow, (b) assuming responsibility for glucose highs and lows, (c) managing T1D and nighttime sleep disturbances, (d) making career sacrifices and choices to optimize T1D care, (e) navigating social experiences postdiagnosis, and (f) discovering new sources of support through online platforms.

### 3.1. Theme 1: experiencing chronic sorrow

Across all studies, parents described the initial sense of shock, anxiety, guilt, and despair they experienced when their child was first diagnosed with T1D. Parents expressed feeling overwhelmed and filled with sadness and self-doubt as they adjusted to diabetes care [8]. One parent explained: "I felt like my old kid was taken away and now I had this new kid that I didn't know how to take care of. I didn't even know how to go about it" [8], [p. 90]. However, although this normative initial state of shock and anxiety lessened over time, we found that a sense of grief and loss lingered; some parents described that it even intensified at times. Parents expressed concern over the complex life their children would have to endure and described a sense of loss [20]. They discussed grieving for their child's inability to indulge in food without repercussions, the loss of spontaneity and freedom for them and their children, a life of monitoring glucose numbers and fearing health outcomes, and, commonly, the loss of a previously healthy child [9,21].

Findings from the studies we reviewed indicated that feelings of grief and loss were common irrespective of the amount of time that had passed since diagnosis [21–23]. One mother in a study by Abdoli et al. [22], [p. 4], for instance, shared: "I think it's a never-ending process with grief. You cry for a life that you never had or a life that you missed. You cry for a good night's sleep. ... I miss having a life of my own." Even if parents' feelings of despair were not as intense as the initial period postdiagnosis, such feelings could easily resurface [22]. One parent explained: "As time goes by, there is not the same drama about the whole thing, but I still feel the despair and the loneliness when I let it come to me" [24], [p. 4]. In fact, when assessing long-term experiences in parents specifically, Bowes et al. [23] found that although parents adapted to the needs of T1D management, their experience of resurgent grief was common even 7–10 years after diagnosis.

### 3.2. Theme 2: assuming responsibility for glucose highs and lows

A major psychological and emotional burden experienced by parents caring for children with T1D is anxiety related to maintaining glucose levels within ideal or clinically recommended ranges. Parents have emphasized the importance, responsibility, and pressure of sustaining near-normal glycemic control to optimize their child's quality of life and health outcomes [21,22,25]. Higher glucose levels are unequivocally and exponentially linked to the risk of diabetes-related complications [26]. As such, many parents have identified a sense of powerlessness, failure, fear, and guilt associated with the inability to maintain their children's glucose within the recommended or ideal range. In a qualitative descriptive study Abdoli et al. [22], [p. 4] conducted, one parent shared:

It's kind of a guessing game. I know it's based on math, but diabetes doesn't always listen to math. No matter how hard we try, diabetes is gonna sometimes just throw us a curve ball. I am trying to do my best for his [my son's] diabetes, but I can't. I can't keep it on track, which is very frustrating. It is scary to think "I'm causing serious damage to my son's body."

Parents commonly discussed various unexpected and unanticipated factors that influenced their child's fluctuating blood glucose

levels. And, because of the unpredictable nature of T1D and the importance of maintaining healthy glucose levels, diabetes care was greatly associated with a perpetual state of vigilance, food intake monitoring, and parents having to take precautions [6,20–22,24,27]. Parents interviewed across several studies echoed one another's sentiments, with comments such as "I worry about his blood sugar number all the time" [6], [p. 82], and "You must be focused at all times. You must be focused on what you do; you must be able to plan. Therefore, you must always be ahead of the game and continuously plan" [20], [p. 152]. In fact, parents anticipated not ever being unconcerned about their child's glucose levels. As father of a 10-year-old girl expressed, "I see it as a lifelong role, myself. Even when she's married, I'll be phoning up saying, 'What's your BM [blood sugar level]?' I really believe that's what I'll be like" [28], [p. 256].

Caregivers have also emphasized an associated sense of self-doubt and anxiety with managing glucose levels as they have had to make daily and emergency decisions related to glucose adjustments. This type of anxiety was mainly described by mothers, as compared to fathers, given that mothers were represented as being the primary caregiver or decision-maker in the majority of the studies included in this scoping review. For instance, one mother shared: "The first time I wanted to inject insulin, my hands were shaking. I was so upset and scared that I could not do it, so I asked my brother to inject the insulin" [29, p. 80].

Self-doubt about one's ability to manage glucose highs and lows was especially a concern during the early days postdiagnosis and often improved over time [24,29]. Even so, stress with management of appropriate glucose levels and overall fear of deadly consequences remained a constant in the lives of caregivers [6,24,29,30]. Fears were intensified among parents of younger children with T1D because younger children are less capable of identifying and communicating their physical symptoms to their parents [24,25]. Findings from several studies emphasize the importance of health care providers offering more direction and reassurance after diagnosis. Knowledge and mastery of skills required to manage T1D, especially soon after diagnosis, can improve parents' ability to cope, raise their sense of empowerment, reduce their perception of stress, and thus mitigate caregiver burden [7,31]. In fact, clear home management directions and consistent follow-ups have been shown to enable parents to effectively integrate diabetes management into a family's lifestyle and improve control over glucose highs and lows [25].

### 3.3. Theme 3: managing T1D and nighttime sleep disturbances

Findings from the literature consistently indicate that sleep deprivation due to nighttime caregiving is a common burden among parents of children with T1D. This is often due to being woken by alarms from diabetes management devices and doing multiple glucose checks throughout the night [6,20,22,24,32]. Hypoglycemia or severely low blood sugar is the greatest feared outcome among parents during nighttime diabetes care, resulting in repeated nocturnal glucose monitoring [6,24,25,32]. Parents commonly report that this fear leads to a lack of sleep, stress, exhaustion, and anxious or interrupted sleeping patterns. For example, in a qualitative study of caregiver blogs that Oser et al. [30], [p. 4] conducted, one mother shared:

How do I explain to you that some nights the exhaustion holds me like a straight jacket, ... that the nights are all encompassing, and I will hold my tears to fall back into my body rather than intentionally give in to the fear and exhaustion?

Other parents shared similar sentiments: "I just don't get a full night's sleep, ever. I just feel like I'm constantly tired" [32], [p. 630]; "I test her [my daughter's] blood sugar every 2 h between 10 p.m. and 6 a.m. in an attempt to catch any fluctuations that might require an intervention" [20], [p. 5]; and "I am the mother of a 12-year-old diabetic child. I don't know what it's like to go to sleep at night and know for certain [my] child will wake up in the morning" [22], [p. 4].

Challenged with balancing adequate sleep and their need for wanting to know frequently what their child's blood glucose levels were during the night, parental caregiver participants in many studies described the negative impacts sleep deprivation had on their emotional and physical well-being [6,9,32]. A mother of a six-year-old boy explained:

I feel unhappy when I think about not sleeping, feeling anxious and feeling tired and moody all the time. So, it's rather contradictory because I am obviously satisfied that things are well and that [my child] feels fine. ... At the same time, I may not feel satisfied because I do not feel well, really. [20, p. 154]

Fatigue and sleep disturbance were noted to result in short tempers, reduced ability to exercise and make decisions, delayed work performance, poor dietary choices, decreased patience, and irritability. Some study participants expressed that sleep deprivation also led to reduced relationship satisfaction and worsened their home environment [6,32]. For instance, one participant explained:

I'm finding, you know, particularly when there's a marked difference between when we've had quite a bit of sleep and when we haven't had any sleep, in the way that we all interact with each other and the happiness that flows around the house. [32, p. 630]

Findings from various studies indicate that caregiver sleep disruption continues irrespective of the child's age and development [9, 32].

### 3.4. Theme 4: making career sacrifices and choices to optimize T1D care

Contemplating alternative career choices is a common part of T1D care for many parents. Due to the constant need to monitor and manage their children's health needs, most parents of children with T1D have reported experiencing some form of impact on their careers postdiagnosis. For many parents, the burden of care results in decisions to adjust work hours, not pursue higher career ambitions due to the potential work demands involved, and avoid desired job opportunities without adequate diabetes health benefit packages [29,33,34]. For instance, describing her career ambitions postdiagnosis, one mother in Tong et al.'s [34], [p. 5] study

involving parental caregivers of children with T1D in China shared:

Now I rarely focus my energy on the company [I work for]; I just get off work as soon as possible. I used to leave early and return late to make money. Now I quit my job and found a new one that can make a living while taking care of my child.

In our review, we also found career-related decisions to be influenced by the economic burden that T1D imposes on families. For example, parents expressed financial stresses, such as “The test strip and the insulin needle are too expensive. We did not have such costs earlier; we have to save by cutting down on family expenses for the sake of our child” [29], [p. 82]. To alleviate the financial burden involved in T1D care and to meet the high costs of treatment, some parents have contemplated how to work longer hours and sought to find higher-paying jobs, especially if they did not have extended health benefits [29,35].

Balancing new health costs with the demanding care involved in managing T1D has led to various employment decisions and stressors among parents. However, given that women take responsibility for most of a child’s caregiving needs, including for children with T1D [36,37], sacrificing and modifying career commitments were more commonly discussed among mothers than fathers in the literature we reviewed.

### 3.5. Theme 5: navigating social experiences postdiagnosis

Learning to navigate social experiences was another situation parents of children with T1D commonly found themselves in postdiagnosis. Many parents struggled with attending social gatherings due to the disruptiveness and seriousness of their child’s disease. They found it difficult to be present and not concentrated on monitoring their child’s potential glucose fluctuations or dietary restrictions. For instance, one parent explained:

It is inevitable that [when living with a child with T1D] you can’t be the same as other families. We have to consider our child’s physical strength and whether [he] can eat regularly. Especially when faced with a table full of good food, it is uncomfortable for the child to see others eating. [34, p. 5]

Other parents shared that postdiagnosis, they avoided taking vacations and attending outings and social events altogether. One said, “There’s just so much to do for our infant. The management consumes our lives. There is no time to socialize, no time even for each other” [36], [p. 574]. Another stated, “Since my child had a ketosis coma, I have never dared to relax again. I have lost myself. Every day in the year, there are no more visits to relatives or friends” [34], [p. 5].

Even when parents longed for social connection with others, or alone time for self-care practices, and they strived to plan date nights, events, and getaways without their children present, they experienced challenges with finding reliable formal and informal supports for respite care. Once parents had overcome the hurdle of needing to trust others to manage their child’s complex health needs, they then found that caretakers and family members were reluctant to care for the child in the parents’ absence [8,9,29]. Extended family members, friends, and formal supports either refused to babysit, were not skilled in diabetes management, or were unwilling to learn how to care for a child with T1D. A mother of a 3-year-old boy explained: “No [secondary] caregivers felt comfortable. ... None of the babysitters that we were interviewing felt comfortable giving an insulin shot with a syringe” [25], [p. 380]. Another mother from a different study similarly said, “Nobody is willing to accept him for a day. They say they are afraid. If his blood sugar goes up or down, they cannot calculate his insulin unit” [29], [p. 80].

Parents also expressed that there was a lack of knowledgeable formal respite supports available to them, such as caregivers and care aids who knew how to manage T1D. A lack of social supports and thus reduced opportunities to socialize have been found to negatively impact parent caregivers’ mental health and well-being. Parents have shared feeling more depressed, stressed, and isolated because of the restrictions they have on socializing, joining recreational activities, and spontaneously attending events since their child’s T1D diagnosis [36], [79].

### 3.6. Theme 6: discovering new sources of support through online platforms

Parents of children with T1D have commonly expressed feeling stigmatized and misunderstood by their extended family members and by parents whose children do not have T1D. The responsibility of care involved with T1D is often unrecognized and underestimated, leaving them feeling unsupported and lonely [21]. For instance, in a phenomenological study of parents’ caregiving experience by Rifshana et al. [27], [p. 3233], one participant stated:

I don’t think people truly understand how hard it is on us on a physical, daily, everyday thing. People don’t get it. And I think because we are coping and we’re fine, people just think oh it must be fine. But it’s really hard, and they don’t get that. They don’t get that, um, whereas if your child had cancer, people’d drop off meals and people would be running round after you, thinking oh you poor things it’s terrible, but they’re like oh no it’s fine.

Although medical staff and diabetes teams were considered important sources of support, parents felt that they too did not fully understand the struggle of caring for a child with T1D and were not always available to immediately answer questions or discuss concerns that arose unexpectedly [35]. As a result of this sensed lack of understanding, many caregivers highlighted the importance of finding new supports, friendships, and comfort in connecting with other parents of children with T1D, also referred to as peer support. Peer support “involves learning and information exchange in interaction with people in similar situations” [38], [p. 1176]. In the T1D community, peer support was often found through online networks such as blogs, Facebook groups, and online forums.

The quality and availability of support and understanding from other parents of children with T1D alleviated stress and loneliness

among caregivers and created an opportunity to ask questions and discuss how to navigate diabetes care. Parents of children with T1D expressed the benefits peer support had in their lives as caregivers through sentiments such as, “The only time you don’t feel lonely is when you have that bond with others in the type 1 community” [35], [p. 6], and “I found the [parenting children with T1D] blog early in our journey and it gave me so much more than you will ever know” [30], [p. 5]. Another parent noted, “We’ve shared everything right from the beginning. ... It’s nice to have someone else to bounce this off of. I’m like, he’s been high here, here, here, and here. What do you think? And we figured it out” [8], [p. 90].

#### 4. Discussion

This qualitative scoping review aimed to synthesize and describe caregiver burden, which we defined as financial, physical, social, spiritual, and emotional or psychological stressors among parents of children with T1D [12,13]. This synthesis highlights, through the identification of six interrelated themes, constant and all-encompassing experiences involved in caretaking for a child living with T1D. We first discuss these themes and their interrelationships. We then revisit the gaps in the research and suggest ideas for future inquiries before sharing our conclusions.

Parents experience an initial period of sadness, shock, and overwhelm after their child is diagnosed with T1D, but they must quickly adapt to a new normal. New routines are established to accommodate care needs, and all life decisions are made with prioritizing T1D management in mind. For instance, we found career choices to be a common factor that parents had to reassess. Hours spent at work were either reduced to accommodate demanding and routine-based management needs or increased to accommodate the high costs associated with care [29,33,34]. Diabetes-related costs were particularly concerning when parents did not have health insurance or adequate coverage for diabetes supplies. In the studies we reviewed, female participants interviewed were more expressive about needing to reconsider, restrict, or modify their employment situations compared to their male counterparts.

As part of their new normal, parents partake in constant monitoring of glucose highs and lows to achieve healthy and ideal glucose levels for their child. Numbers outside of an ideal glucose range are often accompanied with a strong sense of guilt, shame, anxiety, and concern for negative future health outcomes. These emotions lead to a constant sense of vigilance and calculated planning during T1D care, creating a more restrictive lifestyle for parents, thereby limiting time for self-care, reducing opportunities for social activities, and worsening experiences of poor mental health [20–22,24,27,34]. These negative emotions and their repercussions are exacerbated by lingering feeling of sadness and grief that persist even years after the initial diagnosis. Parents lament the loss of the typical life experiences their healthy child would have had and grieve for the difficult life their child will undergo.

Although daytime T1D glucose management has its own challenges, we found concern over unstable glucose numbers, especially fear of hypoglycemic incidents, to be exceptionally worrisome during nighttime diabetes monitoring. This finding also appeared in Kimbell et al.’s [15] systematic review. This fear and the related need to complete frequent nighttime checks often results in unrestful and reduced sleep leading to disruptions in mood for both parent and child, conflict between married couples, and even physical implications such as headaches. Given that mothers reported being mostly responsible for nighttime caregiving duties, they relatedly also expressed more sleep deprivation compared to fathers [6,9,24,25,32].

Our findings suggest that the burden of care experienced by parents of children with T1D is influenced not only by the unique requirements of T1D management, but also by the parents’ perception of social support received. Family and friends’ lack of understanding and willingness to learn about T1D was a common complaint for parents. This dearth of support results in parents having reduced access to respite care from extended family members and concerns with entrusting others to capably manage their child’s diabetes. In addition to a lack of respite care from informal supports, parents stated that paid formal supports such as babysitters skilled with T1D training were equally difficult to find [1,8,9,29].

A lack of available and reliable respite care made it challenging for parents to partake in the types of activities they enjoyed prior to their child’s T1D diagnosis: travelling, investing in longer hours at work, having date nights, participating in social activities, or generally having time away from T1D care duties. For many parents, this was not simply a new normal they needed to accept, but rather an aspect of their lives they missed and associated with a sense of loss [7,9,36]. Lacking respite care also resulted in attending social settings with new challenges that parents had to navigate and manage. Parents expressed that they were unable to escape their sense of vigilance and their obligations to monitor their children during outings, disrupting their enjoyment [34]. These findings emphasize the importance of access to respite care and the need to train and equip professionals or extended family members with the skills to offer safe and reliable respite relief to parents. Such assistance may improve the mental health of parents and support their ongoing ability to care for their children’s T1D needs.

Our findings demonstrate that parents of children with T1D undeniably face many novel experiences and challenges. They must consider alternative ways of navigating through work–life balance, social activities, and daily and nighttime routines in order to provide optimal care for their children. However, we also found that parents were resourceful and sought assistance elsewhere when they felt unsupported by their family members or health care professionals [27]. More specifically, they found comfort, relief, and practical support in connecting with other parents of children with T1D. Online diabetes communities have emerged that use forums, Facebook group pages, and blogs as popular platforms for peer support. Through these interactions, parents receive benefits such as finding social connection and emotional support, having opportunities to discuss technology and device use, learning about and sharing medical information, and sharing personal stories, successes, and challenges. This online peer support has been an important support system that parents of children with T1D have used to offset any absence of support they have felt by others [8,30,35].

Our six common themes exemplify the financial, physical, social, and emotional or psychological stressors in the definition of caregiver burden we chose (see the next section for a discussion of the spiritual dimension). Although some of our themes may align more with one stress domain compared to another, it is important to recognize that these stressors overlap. For instance, even though

the theme of making career sacrifices and choices to optimize T1D care falls more within the realm of financial stressors, career sacrifices and changes can arguably have emotional and psychological impacts and thus also be considered an emotional stressor. This line of thought suggests that improving or alleviating stress from one area of a parent's life could have positive outcomes on one or more other areas. In fact, some research has even identified the positive impact that reduced burden of care on parents may have on the health of the child with T1D, such as more stable glucose numbers [10,16]. Stable glucose numbers may then have a domino effect, whereby that improved health outcome reduces the parents' anxiety and fear.

## 5. Research gaps and implications for future research

Kimbell et al. [15] conducted a recent systematic review that aimed to fill a similar research gap as this review paper. Their study parameters were different, but they echoed similar findings. This overlap in findings, we argue, strengthens the results of both studies. Overall, they highlighted the impacts of psychological, physical, and financial stressors on parents caring for children with T1D. First, they noted the stress related to the perpetual state of hypervigilance needed to manage glucose levels, especially during the night. Second, they found that parents had difficulty with finding reliable respite care and entrusting others with their child. They termed these experiences as 'monopolization of life'. As our study inclusion criteria was not limited to caregiving for children under a particular age group, our findings add to the literature and exemplify that caregiver burden remains continuous in the lives of parents.

These intersecting findings notwithstanding, large gaps remain in the literature on T1D and parental caregiver burden. For instance, in our review we found no data on the role or impact of spirituality, nor was it included in any of the research questions of any studies. Additionally, even though social and financial stressors were documented across study findings and resulted in common themes for this synthesis, we did not find any articles that specifically explored these domains of life in depth. Given the financial and social burdens a T1D diagnosis creates, specific research dedicated to these aspects is warranted.

Likewise, we found minimal discussion on the specific care burden differences between fathers and mothers. This gap is noteworthy given that mothers were consistently identified as primary caregivers and noted to take on more care management tasks compared to fathers. Understanding how mothers and fathers uniquely experience their caregiver roles and caregiver burden would allow health professionals to identify how to alleviate stressors and provide support that is more tailored. One reason for the limited discussion on this topic may be because fathers represented a smaller percentage of the participants in the research studies compared to mothers, thereby stipulating less gender-based information.

Furthermore, whereas we discovered consistency of findings across the studies, the majority were conducted in the United States or Europe and recruited predominantly White participants. Only two of the studies we extracted data from were conducted elsewhere: one in China and one in Iran. A limitation of this synthesis was that we included only articles published in English. We may have missed important information published in different languages. Additionally, the majority of the participants in the studies we reviewed were married, cohabitating with their partner, and employed. As such, the experiences presented in this synthesis may not be reflective of parents who are unemployed, single, or from a different racial or cultural background. Future research would benefit from considering the impacts of different socioeconomic and demographic backgrounds as they relate to caregiver burden. More nuanced findings and details about participant data may help health professionals and policy decision-makers offer more customized supports and solutions to aid parents of children with T1D.

## 6. Conclusions

This qualitative scoping review is the first to explore the concept of caregiver burden among parents of children with T1D. The current literature emphasizes themes of persistent financial, physical, social, and emotional or psychological stress that stems from caring for a child diagnosed with T1D. The importance of respite care and social support in alleviating these stressors and aiding parents in their role as caregiver are also discussed. Future research would benefit from exploring if and how mothers and fathers experience caregiver burden differently and the role of sociodemographic factors in how caregiver burden is experienced. Studies dedicated to explicitly exploring the domains of financial, physical, social, spiritual, and emotional or psychological stress would also be useful. Such research findings may instigate the development and provision of nuanced and tailored supports.

### Data availability

Data associated with this study have been deposited into the ERA (Education and Research Archive), the University of Alberta's institutional repository <https://library.ualberta.ca/research-support/era>.

### CRedit authorship contribution statement

**Tara Azimi:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Formal analysis, Conceptualization. **Jeff Johnson:** Writing – review & editing, Supervision. **Sandra M. Campbell:** Investigation. **Stephanie Montesanti:** Writing – review & editing, Supervision, Conceptualization.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to

influence the work reported in this paper.

## Acknowledgements

We thank research assistant Sharon Tahir for her support with screening articles, extracting data, and appraising studies in full-text review using the CASP, and librarian Sandra M. Campbell for her assistance in conducting the search strategy. We also acknowledge funding received from the Women and Children's Health Research Institute (WCHRI) and the University of Alberta (The Alberta Graduate Excellence Scholarship). Tara Azimi led the review, and her PhD is supported through these awards.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2024.e27539>.

## Appendix. Summary of Data From Included Studies

Author and year	Title	Setting	Data collection sources	Sample	Study findings
Abdoli et al., 2020	I Don't Have the Choice to Burnout: Experiences of Parents of Children With Type 1 Diabetes	Eight videos produced in the United States, six in the United Kingdom, one in Canada, and six in unknown countries	Video blogs	21 parents	Parental burnout is related to exhaustion resulting from the daily demands of diabetes care (e. g., self-care behaviors, insurance, and pharmacy), feeling powerless to attain diabetes care goals consistently, and loss of a previous way of life.
Commissariat et al., 2020	"I'm Essentially His Pancreas": Parent Perceptions of Diabetes Burden and Opportunities to Reduce Burden in the Care of Children <8 Years Old With Type 1 Diabetes	United States	Semi-structured interviews	79 parents or legal guardians	Parents struggled with the (a) emotional burden of diabetes on themselves and their children; (b) burden of finding, training, and trusting effective secondary caregivers; and (c) need for more comprehensive diabetes education from healthcare providers that could help reduce their burden.
Bowes et al., 2009	Chronic Sorrow: Periodic Resurgence of Grief in Parents of Children With Type 1 Diabetes Seven to Ten Years After Diagnosis	United Kingdom	Semi-structured interviews	17 parents	Parents, especially mothers, experienced grief and despair even 7–10 years after their child's diagnosis.
Eshtehardi et al., 2021	On the Money: Parental Perspectives About Finances and Type 1 Diabetes in Youth	United States	Semi-structured interviews	20 parents	Parents of youth with T1D described experiencing financial hardships and making sacrifices in their spending or employment decisions to afford the costs of diabetes care.
Feely et al., 2019	Sleep in Caregivers of Children With Type 1 Diabetes	United States	Open-ended question-naire	22 parents	Caregivers are frequently sleep-deprived and experience anxiety about their child's nighttime glucose levels. Caregiving duties, anxiety, and sleep fragmentation contribute to the poor sleep in parents.
Hatton et al., 1995	Parents' Perceptions of Caring for an Infant or Toddler With Diabetes	Canada	Minimally structured interviews	Eight two-parent families	Stresses were experienced through three distinct phases: the child's diagnosis and hospitalization, adjusting to care at home, and long-term adaptation. Parents experienced recurring sadness, anger, anxiety, fear, and perceived loss of control throughout these phases.
Iversen et al., 2018	Being Mothers and Fathers of a Child With Type 1 Diabetes Aged 1–7 Years: A Phenomen-ological Study of Parents' Experiences	Norway	Semi-structured interviews	15 parents	Parents found the management of T1D to be life-changing, requiring constant care resulting in the establishment of new routines. They reported difficulty with constant worry and

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Author and year	Title	Setting	Data collection sources	Sample	Study findings
Khandan et al., 2018	Lived Experiences of Mothers With Diabetic Children From the Transfer of Caring Role	Iran	Semi-structured and open-ended interviews	11 mothers	monitoring. Mothers expressed struggling more emotionally than fathers. Mothers felt constantly responsible for their child's glucose levels. They experienced financial and social challenges as a result of their child's care needs.
Lindström et al., 2017	"Mission Impossible": The Mothering of a Child With Type 1 Diabetes—From the Perspective of Mothers Experiencing Burnout	Sweden	Semi-structured interviews	21 mothers	Mothering a child with T1D involves an all-encompassing sense of responsibility and constant evaluation of mothering skills.
Lowes et al., 2005	Newly Diagnosed Childhood Diabetes: A Psychosocial Transition for Parents?	United Kingdom	Semi-structured interviews at 10 days, 4 months, and 12 months post- diagnosis	19 parents	Parents aim to adapt to a new lifestyle to meet the needs of their children with T1D. However, a T1D diagnosis continues to feel unpredictable, requiring constant revision and adaptation.
Macaulay et al., 2020	Sleep and Night-Time Caregiving in Parents of Children and Adolescents With Type 1 Diabetes Mellitus: A Qualitative Study	New Zealand	Semi-structured interviews	20 parents	Two periods are associated with an increased burden of care and greater sleep disturbance: immediately after their child's T1D diagnosis and the period of transitioning to using a new diabetes technology.
Oser et al., 2017	A Novel Approach to Identifying Barriers and Facilitators in Raising a Child With Type 1 Diabetes: Qualitative Analysis of Caregiver Blogs	United States	Blog posts	Three online blogs of 140 blog posts and 663 comments	Parents assume significant emotional and physical burdens in caring for their children with T1D. They face persistent fear and worry, especially surrounding hypoglycemia at nighttime. Consistent with previous findings, parents also expressed a sense of chronic sorrow with their child's condition. Parents find support through blog post discussions and connecting with other parents online.
Perez et al., 2019	Communicatively Exploring Uncertainty Management of Parents of Children With Type 1 Diabetes	United States	Interviews	29 parents	Three main forms of uncertainty surrounding their child's T1D diagnosis were reported: medical, social, and financial. Parents struggled with a lack of respite care and support from family and medical professionals; fears, frustrations, and doubts while adapting to diabetes care; and financial stress due to the cost of diabetes care.
Rifshana et al., 2017	The Parental Experience of Caring for a Child With Type 1 Diabetes	New Zealand	Semi-structured interviews	17 parents	The demands of TD1 are ever-present, requiring ongoing conscious effort, active engagement, and attention, leading to a high degree of parental involvement and a lack of respite for the parents.
Smaldone & Ritholz, 2011	Perceptions of Parenting Children With Type 1 Diabetes Diagnosed in Early Childhood	United States	Open-ended interviews	14 parents	Experiencing inadequate direction and communication from health staff, feeling isolated and unsupported by others, and feeling overwhelmed with navigating diabetes care were major challenges for parents. Learning how to manage child developmental transitions with

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Author and year	Title	Setting	Data collection sources	Sample	Study findings
Sullivan-Bolyai et al., 2003	Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes	United States	Semi-structured interviews	28 mothers	T1D was also a source of distress for parents. "Constant vigilance" was the primary behavior strategy mothers used for day-to-day management. The ongoing responsibility was compounded by the insecurity over whether one was providing adequate and vigilant care.
Symons et al., 2015	"The Whole Day Revolves Around It": Families' Experiences of Living With a Child With Type 1 Diabetes—A Descriptive Study	New Zealand	Semi-structured interviews	9 parents	Parents need to reappraise their lifestyle and adjust routines to accommodate dietary restrictions. Numerous T1D care management tasks need to be considered when day-to-day activities and social outings are being planned. Spontaneity disappears and families may become socially isolated if parents are uncomfortable leaving their child with T1D with others.
Tong et al., 2022	Characterising Common Challenges Faced by Parental Caregivers of Children With Type 1 Diabetes Mellitus in Mainland China: A Qualitative Study	China	Semi-structured interviews	20 parents	Parents experienced persistent psychological stress, changes to family function, challenges with daily management of glucose levels, changes in financial stability and career opportunities, and a lack of support from others.

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