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## “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

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### Abstract

**Background:** Across all age groups, management of type 1 diabetes (T1D) places substantial responsibility and emotional burden upon families. This study explored parent perceptions of the burdens of caring for very young children with T1D.

**Methods:** Semi-structured qualitative interviews were conducted with parents (85% mothers) of 79 children with T1D, aged 1 to <8 years old, from four diverse pediatric diabetes clinical centers. Interviews were transcribed, coded, and analyzed using hybrid thematic analysis to derive central themes.

**Results:** Youth (77% White) had T1D for 6 months: age (M ± SD) 5.2 ± 1.5 years, diabetes duration 2.4 ± 1.3 years, and A1c 63 ± 10 mmol/mol (7.9 ± 0.9%); 66% used an insulin pump and 61% used CGM. Three major themes emerged related to diabetes burdens: (a) the emotional burden of diabetes on themselves and their children, (b) the burden of finding, training, and trusting effective secondary caregivers to manage the child’s diabetes, and (c) suggestions for how more comprehensive, personalized diabetes education from healthcare providers for parents and secondary caregivers could help reduce parent burden and worry.

**Conclusions:** In families with very young children with T1D, parental perceptions of the burden of managing diabetes are common and could be mitigated by tailored education programs that increase parent knowledge, bolster parents’ confidence in themselves, and increase trust in their

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CONFLICT OF INTEREST

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secondary caregivers to manage diabetes. Reduced parental burden and increased caregiver knowledge may positively impact child's glycemic control, as well as improve parent and child quality of life.

### Keywords

adolescent; blood glucose; caregivers; child; glycated hemoglobin A; parents; quality of life; type 1 diabetes mellitus

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## 1 | INTRODUCTION

Very young children with type 1 diabetes (T1D) and their families face many unique challenges in both the medical and emotional management of diabetes. Managing glucose levels can be particularly difficult alongside the typical challenges associated with this developmental period, such as “picky eating” and unpredictable frequency of physical activity.<sup>1</sup> In addition, parents of young children with T1D also experience the emotional burdens of diabetes, including worries about hypoglycemia, future complications, and impact on the child's quality of life.<sup>2</sup> As such, research has shown that many parents of young children with T1D endorse symptoms of anxiety, depression, stress, and distress.<sup>1,3-5</sup> The complexities of management, combined with the worry that many young children with T1D may not be able to vocalize their treatment needs or symptoms of hypoglycemia or hyperglycemia, may lead many parents to be hesitant to leave their child in the care of others. A study of mothers of young children with T1D reported that hypervigilance necessary to accomplish required daily management included repeated evaluations of others' abilities to care for their child.<sup>6</sup> In a recent study of 134 parents of young children with T1D, 44% of parents reported that T1D affected their decision to enroll their child in school/daycare, and 12% removed their child from a school/daycare because of difficulty managing T1D in those settings. These parents also reported lower quality of life associated with poorer school/daycare functioning and greater fear of hypoglycemia.<sup>7</sup>

As parents maintain the primary responsibility in diabetes management in young children, whose management plans frequently change, it is important to understand not only parent perspectives on where the greatest burdens lie but also how parents believe those burdens can be reduced, particularly in an era of rapidly advancing diabetes technologies. Qualitative research is an ideal approach to understand the unique challenges of vulnerable groups,<sup>8</sup> and has previously been employed to understand the experience of parents of young children with T1D.<sup>6,9</sup> Mixedmethods approaches have also been used to study specific issues (such as barriers to healthy eating in young children with T1D), as well as aid in the design and refinement of behavioral interventions.<sup>10,11</sup> In this study, interviews were conducted as part of the planning phase of a clinical trial to enhance CGM use and improve both glycemic control in young children and quality of life in their parents. We used qualitative methodology to explore parents' perspectives related to the burdens of managing their child's T1D as well as parent-reported opportunities to relieve these burdens in order to inform the intervention components.

## 2 | METHODS

Semi-structured interviews were conducted from December 2015 to April 2016 with 79 parents/guardians across four major diabetes centers in the United States (Indiana University, Joslin Diabetes Center, Texas Children's Hospital, and Yale School of Medicine [Appendix]). In this preliminary study, we used clinical data collected from the medical record, demographic data from parent-completed surveys, and qualitative data generated from semi-structured interviews regarding parent opinions on the impact of T1D on the family. This manuscript explores themes uncovered in the qualitative data, which were used to inform the design of the family-focused behavioral intervention tested in the subsequent CGM trial.

### 2.1 | Participants

Participants were parents or guardians of children under the age of 8 with T1D. Eligible parents were required to have a child between the ages of 1 to <8 with T1D duration of at least 6 months and an A1c <91 mmol/mol (<10.5%). Parents of children with profound developmental disabilities were excluded from the study. While possible for two parents to be present at the interview, only one was designated as the primary diabetes caretaker.

### 2.2 | Recruitment

Eligible participants were identified and recruited through providers at each site as well as using the T1D Exchange clinic registry from the Jaeb Center for Health Research. Parents at some sites were initially sent letters about study participation, and follow-up was conducted by phone or in-person if a parent expressed interest. At other sites, parents were approached at the time of their child's clinic visit. Parents who were not already enrolled in the clinic registry were invited to join the study and the clinic registry at the same time. Prior to participation in any study procedures, parents met with study staff to learn about the study, ask questions, and provide written informed consent. The protocol was approved by the Institutional Review Boards at each of the four sites, as well as at the Jaeb Center for Health Research, the coordinating center for the study. Total time for survey completion and interviews ranged from 60 to 90 minutes.

### 2.3 | Qualitative data collection

Content questions for the semi-structured interviews were consensus-derived from experienced clinicians and psychologists at the participating sites. Interview questions were tailored to each family based on their current and previous (if applicable) diabetes technology use (MDI, pump, and CGM). Questions broadly explored the challenges of diabetes management, how/why families chose their current diabetes care regimen, if/how diabetes technology has benefitted the family, how technology use has affected daily life and management, parent desires for change in management regimens, and parents' feelings about diabetes care when their children are in the care of other adults. Each study site aimed to recruit 20 families (number of patients per site ranged from 16 to 24) for semistructured interviews or focus groups; recruitment was stratified by age (parents of children with T1D ages <5 and 5-7) and A1c (<58 and 58 mmol/mol [ $<7.5\%$  and  $7.5\%$ ]) to ensure equal distribution in the study population. Two psychologists on the study team trained research

staff at each site in qualitative interviewing techniques to ensure consistent methods across sites. Interviews were audio recorded and transcribed by a HIPAA-compliant transcription service (Landmark Associates Inc.) prior to analysis, and coded using NVivo software version 11.2.<sup>12</sup>

## 2.4 | Data analysis

Three coders (one psychology fellow and two research assistants) analyzed the transcripts using a hybrid approach to thematic analysis. Hybrid thematic analysis has previously been used to combine both deductive and inductive methods,<sup>13</sup> drawing on the advantages of both methods in order to enhance rigor and ensure a thorough patient-driven and theory-driven understanding of the data. An initial list of codes was created based upon topics of the interview questions (eg, challenges to pump use and benefits of pump use), an organizational approach known as “template” style.<sup>14</sup> This deductive approach was based on pre-existing knowledge and recognition of the potential burdens faced by parents of young children with T1D, and meant to highlight specific technology-related burdens that could be addressed by the behavioral intervention. The full group of investigators further refined the initial template, created a preliminary codebook, and applied the codes to all transcripts. Next, new ideas were derived from the data through an inductive approach to thematic analysis. Braun and Clarke’s guidelines for thematic analysis were used to identify patterns and overarching themes within the data: familiarization with the data, generating a list of initial codes, searching for themes among codes, reviewing themes among coders, defining and accurately naming themes, and producing a final report.<sup>15</sup> New codes were generated through open-coding each transcript; open-coding is an exploratory process in which the coders analyze transcripts line by line to highlight as many broad categories and ideas that naturally emerge from the data as possible.<sup>16</sup> Coders compared their respective codes and idea units to formulate a comprehensive list of ideas discussed within the text and further refined the codebook. This inductive approach took a participant-driven approach in exploring new ideas for other burdens (eg, emotional) and how parents thought these burdens could be relieved. Once saturation of themes was reached, coders discontinued generating new codes. All transcripts were then double coded by a second coder using the most up-to-date codebook to ensure interrater reliability and agreement. Raters discussed coding discrepancies and made adjustments until a unanimous consensus was reached. The coding team analyzed final codes, and grouped them into larger idea units and overarching themes. A multidisciplinary team of investigators (pediatric endocrinologists, psychologists, and a social worker) reviewed the findings. This process, known as analyst triangulation, reduces potential bias in interpretation of the results and further validates the findings.<sup>17</sup>

## 3 | RESULTS

Parents of 79 children with T1D under the age of 8 years old participated in the study, with one parent interviewed as the primary diabetes caretaker per family. Approximately 86% of participants were mothers. Children of participating parents were predominantly non-Hispanic white (77%), with a mean age of  $5.2 \pm 1.5$  years and mean diabetes duration of  $2.4 \pm 1.3$  years. Approximately 66% used an insulin pump, 61% used CGM, and youth had a mean A1c of  $63 \pm 10$  mmol/mol ( $7.9 \pm 0.9\%$ ) (Table 1).

Three major themes emerged from the data centered around parent-reported burden: (a) the emotional burden of diabetes on themselves and their children, (b) the burden of finding, training, and trusting effective secondary caregivers, and (c) the need for more comprehensive diabetes education from healthcare providers that could help reduce parent burden.

### 3.1 | The emotional burden of diabetes

Parents noted the emotional burden of diabetes was not restricted to the child with T1D, and that the parents themselves felt emotionally impacted by the management demands of diabetes in daily life. Specifically, parents felt burdened by the responsibility of having to explain diabetes and teach diabetes management to other adults in the child's life. In some cases, parents reported frustration because, despite teaching other adults about diabetes, they were required to maintain full responsibility for management because other caregivers would frequently reach out with questions.

“The hard part was any time her numbers would be slightly off, they [the school] would just call us all the time or really just want us to come and take her, dismiss her for the day, or come and give her shot.” (Father of a 6-year-old girl)

Beyond the intricacies of management, parents also needed to convey to other adult care providers the need to avoid imposing unnecessary restrictions or shame on the child with diabetes or on the parent.

“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.” (Mother of a 7-year-old boy)

Parents were also burdened by the need to frequently re-explain diabetes care to their children. They reported struggling to explain to their young child why s/he has to engage in T1D care tasks unlike their peers. Many parents also reported personally struggling to come to terms with the idea that their child is different from other children, despite efforts to help the child feel like everyone else.

“I feel bad for her, then it starts wearing on me emotionally, and then I'm thinking, 'Why [did this happen]?' I just had to explain to her, 'Unfortunately, this is what it is. This is what we have to do. Let's do this and move onto what we have to do next.'” (Mother of a 5-year-old girl)

In regard to emotional burden on the child, parents reported believing that the most difficult aspect of diabetes for their children was the inconvenient and isolating nature of living with diabetes, which could result in child rebellion against T1D management.

“She's tired of having diabetes. 'I'm tired of this, Mom. I don't want to do this anymore. I'm tired of being poked. I don't want this anymore.'” (Mother of a 5-year-old girl)

“We’ve had some other problems with him behavior-wise and not wanting to have it [diabetes] anymore and going through a stage of rebellion with it. That’s been difficult.[...] He was sneaking food and trying to eat without taking his medicine.”  
(Mother of a 6-year-old boy)

Many parents reported attempting to reduce the emotional impact of T1D by avoiding restrictions on their child (eg, permitting treats) and normalizing T1D care by openly engaging in management around others.

“We just do everything in public. I don’t want him to feel like he needs to run and hide to do any of his insulin. We try to make that as open as possible and not hide from it.” (Mother of 7-year-old boy)

### 3.2 | Parental burden associated with secondary caregivers

Parents reported multiple burdens related to other adults (eg, family members, babysitters, and teachers/daycare providers) who care for the child with diabetes (referred to in this paper as secondary caregivers). While most parents reported that secondary caregivers had the potential to alleviate parental burdens, the majority of parents reported struggling to find people who were willing and able to learn enough about diabetes and its management to care for the child. For example, parents reported finding few secondary caregivers who would be willing to dose insulin, particularly for children on injections.

“No [secondary] caregivers felt comfortable. [...] We didn’t have any family nearby. None of the babysitters that we were interviewing felt comfortable giving an insulin shot with a syringe.” (Mother of a 3-year-old boy)

Parents also noted difficulties trusting secondary caregivers with their child’s care. Many parents cited the relentless burden of vigilance over their child’s care, even when the child was with another adult caregiver: parents believed they needed to be constantly watching, and even managing the child’s diabetes from afar, due to concerns about widely fluctuating glucose levels and risk for emergency situations. Many reported a lack of confidence in the secondary caregivers’ general T1D knowledge, and worried about secondary caregivers’ abilities to identify and treat varying glucose levels, particularly related to hypoglycemia.

“It’s this constant worry about whether the babysitter or the people at school are going to adequately take care of him [...] You never know. Some days, he drops to 50[mg/dl, 2.8 mmol/L] at school. I can see it on my phone, but I’m eight miles away or ten miles away. I have to depend upon the people at the school to take care of him. That’s a challenge.” (Father of a 4-year-old boy)

Lastly, many parents reported intentionally raising the child’s target glucose level when in the care of secondary caregivers, as a way of coping with their own fears that an secondary caregiver would be unable to identify and treat hypoglycemia in a timely manner.

“When we leave her with somebody, we say it’s better for her to be high than to be low, because we can always correct that. We know that’s not good long-term, but it’s safer to be high than for her to be low and have low blood sugar and pass out.”  
(Mother of a 5-year-old girl)

### 3.3 | Parental expectations for additional support and education to alleviate burden

Parents of young children with T1D sought ways to alleviate the overwhelming burdens of their child's diabetes management, including concerns over the child's short- and long-term health and the responsibility of identifying, educating, and remotely supervising other adults involved in the child's care. To reduce these burdens, parents wanted more comprehensive, formal education in order to increase their confidence in their own knowledge regarding management of diabetes. They believed that receiving increased knowledge information about both acute and chronic complications of T1D would serve to reduce worry by providing the tools to avoid the "worst case scenario".

"I think there's this desire to not talk about the really unpleasant, the absolute worst things that can happen. I think that's the thing that parents are obviously going to worry about the most, and so to just not talk about it doesn't work. You have to address it. To say 'Yep, this is a possibility [...] There are some good ways to prevent that.'" (Father of a 4-year-old girl)

Parents also wanted to receive education and support directly from their healthcare providers rather than via a website or diabetes device company in order to receive a more personalized approach. They specified a need for education to be geared specifically towards managing diabetes in their young children.

"They [HCP] gave us a website that we could look at for a particular monitor. They didn't show it to us, which was a little bit disappointing [...] I think it would've been great if we could've actually seen one and had more information about how it actually works listening to our caregiver [HCP], as opposed to going online and trying to fumble through it ourselves." (Mother of a 5-year-old girl)

"[My child with T1D] has mentioned, 'I don't want something stuck to me.' I need to understand more about what we're going to really gain from it [device] before we encourage her to do it. Right now, I think I don't have enough information about how it's really going to help us." (Mother of a 5-year-old girl)

Finally, parents expressed a desire for separate, structured educational courses that would teach secondary caregivers about T1D care, including insulin administration and symptom recognition of hypo- and hyperglycemia. Notably, nearly all parents endorsed a need for help in educating secondary caregivers in schools or daycare settings.

"I wish we did have access where we live to more classes that were available for caregivers, formal classes. It's one thing for us to talk them through it and go through it. The first time we had to train his teachers when he was first diagnosed—our nurse practitioner actually came out and trained everyone." (Mother of a 5-year-old boy)

## 4 | DISCUSSION

The burdens of T1D on families with young children are common and multifactorial. These burdens warrant attention in order to help parents and children navigate the rigors of daily diabetes management and to arm families with the strategies needed to positively cope with

the unremitting and lifelong nature of the disease. Recognizing and addressing burden in parents of young children with T1D may not only impact quality of life in parents but also provide them with the support and tools needed to better care for their children and model more positive attitudes to guide their children's adaptation to diabetes now and in the future, which may ultimately result in improved glycemic control.

Parents in our study reported substantial emotional burden in caring for their child, centered around the need to repeatedly explain the details and necessity of T1D care to their child as well as other adults involved in the child's life. It is possible that actively educating the child and other adults can act as a means of normalizing the illness for the family and for those around them; however, trying to normalize diabetes may be especially difficult if parents fear their child's life will be forever negatively impacted by having diabetes. Parents even reported that the responsibility of teaching other caregivers about T1D was especially onerous given that many were still struggling with personally coming to terms with the impact of diabetes on their own daily lives and how it may affect their child's future. This finding is notable, as previous research has shown that mothers who find it more upsetting to manage their child's diabetes are at higher risk of anxiety and depressive symptoms,<sup>4</sup> indicating a need to help parents find a way to better cope with the emotional burden of T1D.

Similarly, parents' emotions also seem affected by how they perceived their child's adjustment to diabetes. Many parents reported feeling personally distressed when they perceived their child felt different from others. Previous research has shown that parents report stress over their child being perceived as different around peers because of certain aspects of their treatment regimen, such as diet.<sup>10</sup> Understandably, disruptions to typical child activities, such as taking insulin for food at a party or stopping physical activity to check blood glucose levels, may negatively affect a child's perception of diabetes. Parents may subsequently feel particularly distressed if they are unable to relieve or explain away their young child's struggles in a manner the child can understand. Some parents reported their child refusing to engage in diabetes care when the child expressed feeling different from others. A perceived lack of normalcy may be associated with this reduced willingness to engage in management in order to reduce stigma and burden, while normalization of T1D may suggest that management is more routine and integrated in daily life.<sup>18</sup> Refusal to comply with diabetes care in this young age group places added burden on parents to complete the diabetes care tasks while managing the child's emotional and behavioral difficulties. This can complicate parents' efforts to best support their child's physical and emotional health.

Given the overwhelming responsibility for their child's diabetes care, parents sought help from secondary caregivers. However, the majority of parents reported difficulty finding and trusting willing secondary caregivers with their child's diabetes care. Parents have reported that fewer than half of Pre-K to Kindergarten students have a nurse available at school, and 21% reported having no one other than a school nurse available to help with diabetes management tasks at school.<sup>19</sup> Additionally, secondary caregivers unfamiliar with diabetes care may be reluctant to take on responsibility for a young child's health, particularly those on injections, given the need for detailed vigilance and the child's possible inability to



articulate his/her needs. In turn, parents feared that secondary care providers would be unable to identify and manage hypo- and hyperglycemia. Some parents even endorsed increasing their child's target glucose levels in order to ensure safety when the child was under the supervision of others. Previous research has similarly found parents may purposefully engage in behaviors that raise their child's blood glucose levels (eg, overfeeding, reducing basal or bolus insulin doses) in order to combat a fear of hypoglycemia.<sup>20,21</sup>

Despite these challenges, parents were vocal about opportunities to reduce their burdens through comprehensive, repeated diabetes education. Parents voiced interests in learning about various topics, including overall management of diabetes in young children, technology use, future complications, and education specific for secondary caregivers. Notably, parents emphasized that they wanted education directly from their healthcare providers rather than websites or technology companies. Though all centers in the current study provide comprehensive education, particularly at diagnosis, parents emphasized the need for repeated, individualized education from their HCPs specific to their child/family, and included new treatment options. Individualized education from a provider who understands the nuances of diabetes in young children and the background of the family likely eases some stress on parents, helps them feel supported when new questions arise, and allows them to develop a more open and trusting relationship with their diabetes care team. Parents reported that more diabetes management knowledge would have the potential to reduce their worry while increasing confidence in their own management ability as well as in their ability to teach secondary caregivers necessary management skills. Additionally, parents requested structured, yet individualized, diabetes education and hands-on training of secondary caregivers from the healthcare team, including the use of technologies (eg, pumps and continuous glucose monitors) and injection-based treatment. A recent position statement from the American Diabetes Association echos parents' desire for formal education, noting that for young children, all childcare staff responsible for the child should have a basic knowledge of diabetes and its management, and know who to contact for help if necessary; the authors also suggest that staff more involved in the child's care may require advanced education, such as insulin administration, carbohydrate counting, and more.<sup>22</sup> Detailed education and communication with the child's diabetes team may serve to increase the willingness and confidence of the secondary caregivers to share responsibility in the child's diabetes management. Further education may also help to optimize parents' and children's quality of life as well as the child's glycemic control by reducing parental fear of hypoglycemia, and thus reduce the need for parents to aim for higher target glucose levels in order to avoid hypoglycemia.

Some limitations exist to our study. First, interviews reflect the perceptions mainly of mothers, likely the primary diabetes caregivers for their children, who received care at tertiary care diabetes clinics. Future research should aim to include perceptions of fathers and other caregivers. However, our sample included a diverse sample (23% racial/ethnic minorities) of parents across four pediatric US diabetes centers, a notable strength.

Educational and psychosocial interventions that address common parent-reported burdens may help parents to better manage their stresses and model positive attitudes towards

diabetes for their children.<sup>23–26</sup> For example, our results suggest that an effective intervention should equip parents with realistic expectations about glucose variability in young children, provide comprehensive continuous education in new technologies and overall diabetes care, and train parents in how to explain diabetes treatment to other caregivers and adults in their child's life. By modeling positive attitudes and reducing emotional burdens early in life, parents can positively impact their children's current and future views of diabetes management, treatment adherence, glycemic control, and quality of life.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**TABLE 1**

## Participant characteristics (N = 79)

<b>Youth characteristics</b>	<b>M ± SD or %</b>
Age (years)	5.2 ± 1.5
T1D duration (years)	2.4 ± 1.3
Race (% non-Hispanic white)	77
Insulin pump users (%)	66
CGM users (%)	61
HbA1c (%)	7.9 ± 0.9
(mmol/mol)	63 ± 9.8
<b>Parent characteristics</b>	
Parent participant (% mothers)	86
Education (% bachelor's degree or higher)	61
Annual household income (% >75 000)	55

Abbreviations: A1c, hemoglobin A1c; CGM, continuous glucose monitor; M, mean; T1D, type 1 diabetes.