


# “I Live in Constant Fear of Highs,” the Daily Impact of Type I Diabetes

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## Abstract

Limited research exists regarding the burdens associated with type I diabetes (T1D). The study's objective was to understand the impact of T1D from people with T1D and caregivers of minors with T1D. Six focus groups were conducted, with a total of 31 participants. Participants included people with T1D, ages 23 to 72 ( $n = 17$ ) and caregivers ages 34 to 55 ( $n = 14$ ). Participants were recruited from T1D Exchange Glu. People with T1D reported time spent managing diabetes had greatest impact, while caregivers reported financial and employment sacrifices as most impactful. Our findings provide insight into the real-world daily impact of diabetes.

## Keywords

type I diabetes, cost, hypoglycemia, mental health

## Introduction

People with type 1 diabetes (T1D) and caregivers of minors with T1D experience significant impact to many aspects of daily life because of the disease. Essentially, every area of life is affected by T1D, an autoimmune disease that affects the insulin-producing  $\beta$  cells in the pancreas. Treatment for T1D includes balancing food consumption, physical activity, stress, and insulin (by multiple daily injections or continuous subcutaneous insulin infusion via insulin pump). Insulin is adjusted according to the aforementioned elements and blood glucose levels, which requires constant carbohydrate counting and self-monitoring glucose multiple times per day or wearing a continuous glucose monitor (CGM) (1).

Although the economic cost has been well-documented (2), the psychosocial “cost” remains undetermined. This includes, but is not limited to, the psychosocial impact of physical complications associated with the disease, changes in lifestyle required by therapy, and fear of both short- and long-term health consequences (1). These factors often lead to increased rates of depression and anxiety, diabetes distress, and other treatment burden-related issues (3,4). Depression is related to a decrease in diabetes management behaviors, higher hemoglobin A<sub>1c</sub> (A<sub>1c</sub>) and lower quality of life (5,6), while higher anxiety predicted higher A<sub>1c</sub> in adolescents with T1D (5). In addition, elevated family conflict

and less parental monitoring are risk factors for poorer glycemic management (7).

Daily T1D management may impact many individuals including the person with T1D, their spouses, siblings, and parents. Specifically, parents of minors with T1D experience a variety of psychosocial burdens and lifestyle changes associated with diabetes as they are often responsible for most of their child's diabetes management. Worry about hypoglycemia, potential complications in the future, and blood glucose excursions have been reported by parents of children with T1D (8).

## Methods

The primary objective of this study was to identify aspects of life that are impacted by T1D in people with diabetes and caregivers living in the United States. Six focus groups were conducted based on previously identified themes from existing literature and interviews with persons with T1D,

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caregivers, and health care providers regarding disruptions and impact in daily activities. Five focus groups were conducted online, and one was conducted in-person totaling 31 participants. Following institutional review board approval, all participants were recruited from T1D Exchange Glu (www.myglu.org), an online community for individuals living with T1D. Participants provided written consent before participating. Focus groups were audio-recorded and transcribed.

### Demographics

Focus groups consisted of adults with T1D, caregivers of minors with T1D, or a mix of both. A summary of participant demographics is provided in Table 1.

### Qualitative Analysis

Data from focus groups were thematically analyzed with a qualitative data analysis framework that is flexible and aims to improve precision and contextual fit (9). Coders identified all possible patterns and themes found among the participant quotes. Themes were then defined, reviewed, and finalized.

### Results

Participants described the impact on their daily life. Daily disruptions were largely due to managing hypoglycemia, hyperglycemia, and various diabetes technology all at the same time.

#### Missed Opportunities

Sacrifices related to employment, travel, finances, education, and recreational activities were described by participants. "It's definitely affected me career wise. I'm not able, until my son gets old enough to self-care after school, I'm not able to work in the field, but I have experience which is a hindrance." Others discussed not being able to pursue their preferred career because of diabetes. One person with T1D said: "don't know if I would be at this job if it wasn't for the situation I'm in and the health insurance I have access to. I work for the government so obviously nobody's getting rich here, but like I said, my job for my situation is worth a lot more money than what my salary is."

#### Blood Glucose Management

Blood glucose management was described as impactful on a daily basis. Participants stated that hypoglycemia impacts daily routine, serves as a barrier to exercise and travel, creates negative school and work experience, occurs overnight, includes fear of hypoglycemia, and experiencing hypoglycemia unawareness. Participants stated that they were fearful of traveling: "I'm afraid to go places because if I have a low, or if I were to pass out or something, and I was in a different country or a different place." Participants reported the impact of attitudes changing during hyperglycemia, having

**Table 1.** Participant Demographics.<sup>a</sup>

CGM use, n (%)	22 (70.9%)
Private insurance, n (%)	29 (93.9%)
People with T1D	N = 17
Age, mean (SD)	44.29 (14.7)
Duration of diabetes, mean (SD)	25.7 (16.5)
Self-reported HbA <sub>1c</sub> , %, mean (SD)	6.9% (0.9)
Female, n (%)	13 (76.5%)
CSII use, n	16 (94.1%)
MDI, n	1 (4.9%)
Caregivers	N = 14
Age, years, mean (SD)	45.36 (5.4)
Male, n (%)	13 (92.6%)
Child age, mean (SD)	11.36 (3.5)
Child duration of diabetes, mean (SD)	5.57 (2.8)
Child's HbA <sub>1c</sub> , %, mean (SD)	7.2% (0.5)
CSII use, n	13 (92.9%)
MDI, n	1 (6.1%)

Abbreviations: CGM, continuous glucose monitor; CSII, continuous subcutaneous insulin infusion; HbA<sub>1c</sub>, hemoglobin A<sub>1c</sub>; SD, standard deviation; T1D, type 1 diabetes.

<sup>a</sup>N = 31.

hyperglycemia at school, family struggles, fatigue, anxiety about complications, glucose variability, and not having symptoms of hyperglycemia. One caregiver said: "I live in constant fear of highs [ . . . ] my son he is less responsive to insulin when he is high. It takes longer to get him down than it does when he's low to get him up."

#### Family Life

Participants reported experiencing issues with their siblings after diagnosis and varying amounts of social support from their family members. An additional participant was concerned that they are not a good parent due to T1D. "For me, I feel badly, just 'cause I feel like I'm maybe not as good of a parent, just 'cause I'm super impatient due to the highs and lows and stuff like that." Participants reported experiencing tension with their family members surrounding diabetes: "My husband and I fight about management, who did a good job, who did a bad job," "What did you feed him? What did you tell the nurses? Why did you do that?" [ . . . ] It impacts our alone time, it impacts how we manage our child, it impacts our relationship with our other child. Huge impact."

#### Work and School Disruptions

Work and school disruptions were discussed at length, including both positive and negative work experiences, school experiences, and unanticipated schedule adjustments. Participants stated that when they should be working, they were taking care of T1D-related needs instead. "My boss had to drive me to the hospital because I was throwing up from such high blood sugar." Participants reported a variety of work truancy, "I have times like right now, where my pump completely runs out of insulin, and my back up insulin in my purse is missing. I have to leave early or, I have a high blood

sugar and so I feel really awful, and so I go home a little early, or I come in a little late.” Multiple participants reported that their income was impacted by their need to be flexible for T1D. For example, “It definitely affected our income. It went from full time working in payroll and accounting to third shift at a gas station so it was definitely a cut in both hours and pay. But working an office job, they’re not flexible as far as coming in late or having to leave to run to the school or just stay home with a sick child. That just wasn’t feasible for me to stay there.”

### Time Management

Time management was a distinct barrier, with an emphasis on planning for diabetes. Participants were always thinking about diabetes, time dedicated to health care and insurance issues, dealing with constant alarms, and time spent at pharmacies, communicating about treatment decisions and correcting out of range blood sugars. For example, “I think it’s constant, like she said I’m always thinking about it, even if I’m doing something else but, when was the last time I checked my blood sugar? When did I change my pump last?” Participants described constantly managing T1D for their children, “Pretty much constantly managing it. I weigh her food. I have a carb scale that tells the carbs. So for every meal I’m weighing things, telling her how much insulin to give and on her CGM [ . . . ] So I’m constantly looking at my phone to see what her blood sugar is.”

### Discussion

People with T1D and caregivers of minors with T1D are heavily influenced by the demands of managing a chronic illness that requires multiple complex tasks be performed everyday. The focus groups provided insights to better understand the impact of T1D on everyday life, on relationships, and identified missed opportunities due to T1D.

Participants consistently described the disruptions of diabetes as having a significant impact on their lives. The extra time that they dedicate to T1D management was also frequently mentioned. The impact described here can result in diabetes-related distress which can occur independently of depression and general anxiety. Understanding the real burden that people with diabetes and caregivers face while managing T1D can help health care providers and vested stakeholders to make informed decisions to improve disease management.

### Implications

Living with diabetes appears to have a significant impact beyond day-to-day management, potentially altering decisions, impacting relationships with family members, and changing career paths. Many people reported that it is an all day, everyday, mental demand that becomes second nature,

thus it is difficult to accurately identify how disruptive and time-consuming it can be.

### Limitations

This study has limitations that may have impacted the findings: the small sample included more people with T1D than caregivers. The average A<sub>1c</sub> of participants was not representative of the general T1D population. Overall, focus group attendees were college educated and privately insured and most of them were using insulin pumps and CGMs to manage diabetes.


### Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: A.S.H. and J.B. are employees of T1D Exchange. A.H.M.-F. is a former employee of T1D Exchange. L.F. and M.N.-P. are employees of Eli Lilly and own stock in the company.

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### References

1. American Diabetes Association. 7. Diabetes technology: standards of medical care in diabetes—2019. *Diabetes Care*. 2019; 42:S71-S80.
2. American Diabetes Association. Economic costs of diabetes in the US in 2017. *Diabetes Care*. 2018;41:917-28.
3. Hyman DY, De Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M. Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. *Diabetes Care*. 2016;39:2126-40.
4. Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. The prevalence of comorbid depression in adults with diabetes. *Diabetes Care*. 2001;24:1069-78.
5. Hilliard ME, Herzer M, Dolan LM, Hood KK. Psychological screening in adolescents with type 1 diabetes predicts outcomes one year later. *Diabetes Res Clin Pract*. 2011;94:39-44.
6. McGrady ME, Hood KK. Depressive symptoms in adolescents with type 1 diabetes: associations with longitudinal outcomes. *Diabetes Res Clin Pract*. 2010;88:e35-7.
7. Hilliard ME, Holmes CS, Chen R, Maher K, Robinson E, Streisand R. Disentangling the roles of parental monitoring and family conflict in adolescents’ management of type 1 diabetes. *Health Psychol*. 2013;32:388-96.
8. Harrington KR, Boyle CT, Miller KM, Hilliard ME, Anderson BJ, Van Name M, et al. Management and family burdens endorsed by parents of youth <7 years old with type 1 diabetes. *J Diabetes Sci Technol*. 2017;11:980-7.
9. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77-101.

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**Alicia H McAuliffe-Fogarty**, PhD, CPsychol, completed her fellowships at the Yale University School of Medicine and is a clinical health psychologist specializing in diabetes.