



# “I’ve Had an Alarm Set for 3:00 a.m. for Decades”: The Impact of Type 1 Diabetes on Sleep

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There is a dearth of research characterizing the impact on a caregiver’s sleep when caring for a minor with type 1 diabetes. This study used focus groups of people with type 1 diabetes and caregivers of minors with type 1 diabetes to explore the experience of how diabetes affects sleep. The occurrence of both unanticipated and planned sleep disruptions led to the majority of participants reporting that their sleep was considerably affected by diabetes. Despite the improvement in blood glucose management that diabetes technology devices can provide, people with type 1 diabetes and their caregivers still report sleep disruption and sleep loss resulting from overnight diabetes management.

The daily self-management behaviors involved in living with type 1 diabetes can be more difficult overnight for people with type 1 diabetes, caregivers, and other household members and can lead to sleep disruptions and emotional experiences such as worrying about severe hypoglycemia occurring during sleep. On average, people with type 1 diabetes experience nocturnal hypoglycemia 25% of the time (1). Emotional experiences can also include fear of hypoglycemia, which refers to extreme worry and anxiety-like symptoms experienced by people living with type 1 diabetes and their caregivers regarding hypoglycemia. Such feelings can result in negative diabetes management behaviors and negatively affect quality of life (2,3). Disturbances caused by diabetes device alarms and fear of hypoglycemia are common barriers to sleep for people with diabetes (4). Research suggests that interventions should be developed to target overnight glycemic management and fear of hypoglycemia to improve sleep quality (5).

## Sleep and Type 1 Diabetes

Poor sleep quality, including inadequate amount of sleep and sleep disruptions, has negative health consequences

and is a frequent complaint among adults with type 1 diabetes. Greater variability in day-to-day sleep schedules affects blood glucose and is associated with greater insulin needs (6). People with type 1 diabetes experience higher rates of sleep disturbance, which can be attributed to diabetes device alerts (e.g., low and high glucose alarms on continuous glucose monitoring [CGM] systems) and maintenance notifications, as well as symptoms related to glycemic excursions (7). Research suggests that there are disparities related to sleep in people with type 1 diabetes compared with those without type 1 diabetes (8).

In addition to sleep disturbance, adults with type 1 diabetes have self-reported poorer sleep quality than adults without type 1 diabetes, and children with type 1 diabetes have been found to have shorter measured sleep duration than children without type 1 diabetes (9). Furthermore, people with type 1 diabetes and poor sleep quality (sleeping  $\leq 6$  hours per night) were found to have poorer glycemic management (9). A review of sleep-related disorders further detailed the relationship between sleep and glycemic outcomes in people with type 1 diabetes (10). However, caregivers’ experience, diabetes-specific management behaviors, and the role of diabetes devices were not thoroughly explored.

## Caregiver Sleep Experience

Caregivers of minors with type 1 diabetes often maintain primary responsibility for diabetes management throughout the day, with unique challenges arising at night and during sleep (11). Research suggests that there is an association between caregivers’ sleep quality, well-being, and fear of hypoglycemia and their children’s sleep quality (12). Much like adults with type 1 diabetes, hypervigilant monitoring behaviors and fear of hypoglycemia can keep parents of children with type 1 diabetes awake at night or lead them to wake up frequently to check

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on their child (13). However, a gap exists in the literature elucidating caregivers' sleep experiences.

In studies investigating parental burdens of diabetes and its impact on family life, more than half of parents of children with type 1 diabetes self-reported a negative impact on the amount or quality of their sleep (14,15). Despite improvements in diabetes technologies, many aspects of sleep continue to be impaired because of diabetes maintenance needs. When comparing parental sleep before and during regular use of CGM, quality of sleep remained relatively unchanged; however, the number of times parents woke up and total time awake were greater after initiating CGM use (16).

Because of diabetes-related disturbances, management requirements, and worry, sleep is one of many aspects of daily life that can be significantly affected by type 1 diabetes. Both people with type 1 diabetes and caregivers of minors with type 1 diabetes may experience sleep loss or disruption from overnight diabetes management. However, there is a lack of research examining the nature of these experiences from the perspectives of both people with diabetes and caregivers. The primary objective of this study was to understand the impact of type 1 diabetes on sleep, as well as on the daily lives of people with type 1 diabetes and caregivers of minors with type 1 diabetes via qualitative data collected during focus groups.

## Research Design and Methods

Advertising material containing study information was posted on T1D Exchange Glu ([www.myglu.org](http://www.myglu.org)), an online community for individuals living with type 1 diabetes. The advertisements contained a link to a brief screener for eligibility, and demographic information (race/ethnicity, estimated household income, and participant-reported A1C) was also collected to generate a randomly selected, representative sample of qualified participants to invite to participate and to describe the study sample. Participants were eligible for the study if they were >18 years of age, English speaking, and either an adult with type 1 diabetes or a caregiver of a minor (age <18 years) with type 1 diabetes who had not participated in a clinical trial in the past 12 months.

Eligible prospective participants who were interested provided their contact information with best times to be reached, and a T1D Exchange research team member reached out via e-mail with a link to the electronic informed consent form, research team contact information for questions, and available timeslots to schedule the focus group.

This study was approved by the Quorum Review institutional review board, and all participants provided electronic informed consent before participating. The research team consisted of a research assistant and two research scientists (J.A.B. and A.S.H.).

Six focus groups were conducted based on themes regarding sleep, finances, missed opportunities, and disruptions in daily activities that were previously identified from interviews with people with type 1 diabetes, caregivers, and health care providers (HCPs). The focus groups consisted of people with type 1 diabetes, caregivers of minors with type 1 diabetes, or a mixed group of both (Table 1). Each focus group was moderated by a research scientist with experience in type 1 diabetes (J.A.B. or A.S.H.) and was conducted in a conversational style flowing through topics listed in a focus group guide. The guide was developed based on existing literature and previously conducted one-on-one interviews with patients and HCPs and included broad questions and prompts that invited the participants to share their input (e.g., "Can you tell us about how diabetes has impacted your sleep?," "How often do you wake during the night to manage your/your child's diabetes?," and "How many hours of sleep do you lose due to diabetes per week?"). When appropriate, moderators probed further for more detailed responses. Focus groups were audio-recorded and transcribed.

## Qualitative Analysis

Data from focus groups were deductively and inductively derived using thematic analysis, a type of data analysis in which coders sort themes that appear repeatedly in text, interviews, and other types of qualitative data (17). The two coders were the same for each step of the analysis and used a qualitative data analysis framework appropriate for analyzing focus group data (18). Authors J.A.B. and A.S.H. served as coders and coded the data by first reviewing the full dataset and making initial comments, including identifying potential themes and categories. They then identified all possible patterns and themes found among the categorized codes. The coders reviewed the themes and further refined them to improve precision and contextual fit. The coders met to resolve conflicts and achieve consensus.

## Results

Five focus groups were conducted online, and one was conducted in person in San Diego, CA, with a total of 31 participants. Each focus group included adults with type 1 diabetes, caregivers of minors with type 1 diabetes, or

**TABLE 1** Focus Group Breakdown

Focus Group	People With Type 1 Diabetes	Caregivers	Impact Rating*
FG #1 (online, people with diabetes only)	6	0	9
FG #2 (online, people with diabetes and caregivers)	3	3	9.16
FG #3 (online, caregivers only)	0	3	4.5
FG #4 (in person, people with diabetes only)	8	0	9
FG #5 (online, caregivers only)	0	3	8.5
FG #6 (online, caregivers only)	0	5	10

\*Focus group average in response to “On a scale of 0–10, with 0 being no impact at all, how would you rate the disruption that diabetes has had on your sleep?”

both. Seventeen people with type 1 diabetes participated, ranging in age from 23 to 72 years (mean 44.29, SD 14.7), with a duration of type 1 diabetes ranging from 2 to 53 years (mean 25.7, SD 16.5). Participants provided their most recent A1C levels, which ranged from 5.1 to 9.0% (mean 6.9, SD 0.9). Of the people with diabetes, 16 used an insulin pump and one was on a multiple daily injection (MDI) insulin regimen. Fourteen caregivers of minors with diabetes participated, ranging in age from 34 to 55 years (mean 45.36, SD 5.4). Their children with type 1 diabetes ranged in age from 7 to 15 years (mean 11.36, SD 3.5), and the children’s most recent A1C ranged from 6.4 to 8.1% (mean 7.2, SD 0.5). Thirteen children were pump users, and 1 was on an MDI regimen (Table 2).

### Frequency of Interrupted Sleep

Living with and managing type 1 diabetes can affect sleep as a result of overnight symptoms and worry about blood glucose levels and diligent management behaviors. As one person with type 1 diabetes stated, “I wake up every 2–3 hours, or even less,” highlighting how frequently sleep can be interrupted. A caregiver reported constant vigilance monitoring the child’s blood glucose, saying, “We pretty much look at it every 2 hours, 24 hours a day. So overnight, occasionally I’ll turn it off and let [a CGM] alarm wake me, but usually we set the alarm every 2 hours and glance and go back to bed.”

Sleep duration was limited for many people. As one person with diabetes reported, “I don’t think I’ve slept more than 4–5 hours straight since I was diagnosed.” Frequent waking during the night varied, with one person noting that, “. . . on a good night, I don’t wake up at all, but my [insulin] pump wakes me up sometimes up to 12 times at night.” Most participants reported sleep interruptions resulting from glucose and device management. Regarding waking up to alarms, one person with diabetes

said, “I would say at least one or two times a night.” A caregiver reported a similar frequency of sleep disruption: “I’d say I would average twice a night,” but one participant emphasized that there was variability between nights, saying, “Some nights it’s zero, and some nights it’s literally 12.”

### Types of Sleep Disruptions

Both unanticipated (waking up because of hypoglycemia or hyperglycemia symptoms or device alarms) and planned (setting alarms during the night to check or manage blood glucose) sleep disruptions were reported by both people with type 1 diabetes and caregivers.

### Unanticipated Sleep Disruptions

Unplanned sleep disruptions were reported to affect both people with type 1 diabetes and their families.

Some participants reported that CGM usage has changed their life, including their decision-making around diabetes. For example, one caregiver stated that, “We’ll let her go to sleep at 95 [mg/dL] or something, but I will stay up for a little while to make sure it’s not going down. If she didn’t have the CGM, I’d probably feel safer [at] like 120 [mg/dL], but because of the CGM and the fact that her pump will suspend if she’s going low, I feel okay at 95 . . .” However, many participants also described CGM alarms waking them up multiple times during the night.

A caregiver mentioned the psychosocial factors associated with sleep and overnight management for herself and her child, saying, “The other issue I have with sleep, it’s not just me, I think there’s a lot of sleep anxiety from my son. And we do not talk about it, but I know that he must hear it or see it because he has just a lot of the anxiety about mak[ing] sure he’s in range.” She continued, “I feel more for him than I do for me because I can definitely see

**TABLE 2** Participant Demographics (*N* = 31)

<i>People with type 1 diabetes (n = 17)</i>	
Age, years	44.29 ± 14.7
Duration of diabetes, years	25.7 ± 16.5
Self-reported A1C, %	6.9 ± 0.9
Female sex	13 (76.5)
Insulin pump use	16 (94.1)
MDI insulin regimen	1 (4.9)
CGM use	13 (76.5)
Private insurance	15 (88.2)
<i>Caregivers (n = 14)</i>	
Age, years	45.36 ± 5.4
Female sex	13 (92.6)
Child's age, years	11.36 ± 3.5
Child's duration of diabetes, years	5.57 ± 2.8
Child's A1C, %	7.2 ± 0.5
Insulin pump use	13 (92.9)
MDI insulin regimen	1 (6.1)
CGM use	9 (64.3)
Private insurance	14 (100)

Data are mean ± SD or *n* (%).

how it affects him. He is definitely scared of something happening at night and making sure I'm close by to check that alarm."

Unanticipated disruptions can also affect spouses and other people within the household. As one participant said, "[T]he CGM does do the alarming at night. It not only wakes me up, but it wakes my husband up, too, so it's kind of an inconvenience to him as well." Similarly, another participant said, "[M]y husband, luckily this is his nature, but I really think part of the reason why he gets up so early in the morning at 4:00 a.m. is because that was my danger time back in the day. That's around when he started doing that." Another person with diabetes reported that overnight diabetes care becomes the responsibility of his spouse because he may not wake up. "It's been a big impact for my wife because there's a lot of times I won't wake up, especially if I fall asleep quickly," he said. "So, she has to take care of me. So, she doesn't sleep nearly as well as she used to."

### Planned Sleep Disruptions

In addition to unanticipated sleep disruptions that are associated with diabetes management, participants also

reported avoiding sleep because of blood glucose checks and setting alarms to wake up throughout the night for diabetes-related management or "peace of mind" (i.e., checking CGM, administering correction doses, or adjusting pump settings).

Adults with type 1 diabetes reported avoiding sleep for a variety of reasons related to blood glucose management and diabetes devices, including but not limited to being out of their overnight blood glucose range and monitoring blood glucose levels. Many participants reported using their diabetes devices for overnight decision-making and choosing to put off going to sleep, including one person with diabetes, who reported, "Sometimes, I have to; my CGM indicates that I got to fix something, so I put off going to sleep an hour or two. Not every night, though. And, thanks again to my husband, I sleep through a lot of times now because the alarms wake him up; it won't wake me up."

Caregivers reported similar experiences with avoiding sleep. "Arrows are important, and how much insulin he has on board is important, and . . . how recently he ate matters, too," said one caregiver. "But if he's about 100 [mg/dL] and steady, I'll let him go [to sleep]. I won't go to sleep because I'll keep an eye on him to make sure he's not going anywhere." Another caregiver was not as reliant on alarms, reporting that she would put off sleep to check on her child. "If I know he's been tracking really low or high, I'll probably stay up a couple hours to make sure he moves," she said. "And sometimes, it takes a couple hours for him to move. So, yeah, I would say per week I probably lose about 7 hours, maybe more, a week."

Although setting overnight alarms to check blood glucose was not a behavior that everyone engaged in, it was primarily reported by caregivers of minors with type 1 diabetes. Several caregivers set multiple alarms to make sure their child's blood glucose was in range, despite having a CGM system. One said, "I set my alarm . . . I have two alarms—just an alarm clock that I set at night—at 2:30 and 3:00 a.m., and in case I sleep through those, I also set a couple of alarms on my phone just because I want to wake up just to look at . . . usually, I'll just look at the CGM if it's been reliable." One caregiver reported only setting alarms through the night when starting new technology, saying, "If he should happen to realize at 9:00 at night that, oh, he needs to start a new CGM [sensor], then I'm setting my alarm to get up throughout the night to double check his sugars. And so, as long as the technology is working, you sleep far better than if you don't have the technology." Another participant agreed that CGM and pump features make her more comfortable with her child's



overnight diabetes management, but said she still sets alarms to check. “I do set my alarm every night, every night, at three in the morning. I always have to make sure. Either way.”

Only one person with type 1 diabetes reported setting intentional alarms to wake up through the night, saying, “I’ve had an alarm set for 3:00 a.m. for decades. I test at 3:00 in the morning and wherever my number is, even if the [CGM system] says it’s 80 [mg/dL], I’m still testing.” However, another person with type 1 diabetes reported not setting alarms, but rather waking up intermittently. “I wake up every 2–3 hours, or even less. I wake up, check it, go to the bathroom, [and] go back to sleep.”

### *Rating the Impact of Diabetes on Sleep*

Although one caregiver reported that diabetes had no impact on sleep, participants overall reported that diabetes had a great impact on their sleep (Table 1). In addition to rating the impact of diabetes on sleep on a scale of 0 (no impact) to 10, a participant identified the impact on her spouse, saying, “If you ask my husband that question about diabetes messing with his sleep [laughs], he would be saying 8 or 9 now, and he would have said, 3 years ago, he probably would have said 1 or 2.” She said she believes the increase in impact is associated with her current use of CGM and particularly, “The CGM alarms. He’s much more aware of it. It’s in his face more.” However, one caregiver had a different experience with her child’s CGM use. “If I wake up for any reason, I’ll check it. Obviously, if it goes off, I check it. He’s been on a CGM now since [age] 3, so however many years that is, 6 years, it has allowed me to get more sleep.”

Participants reported waking up multiple times during the night for CGM alarms. They also reported being very cautious about correction boluses overnight. “I would say we’re more aggressive in treating highs during the day than what we do at night. And it could be . . . because, at night, you’re struggling with deciding whether or not, how much you need your sleep. Because, sometimes, he’ll come down faster at night, or you’re not paying attention to it because you’re sleeping. There’s more of a concern, for me at least, in doing corrections. During the day, we might do a correction if he’s, like, 200 [mg/dL], where at night, I’d be not as likely to do a correction because he’ll probably come down, and if I do a correction, he might come down too much, and then I’m not gonna sleep.”

## **Discussion**

The focus groups in this study provided insights to better understand the impact of type 1 diabetes on sleep,

common management and monitoring behaviors, and concerns that influence nocturnal diabetes management. Many participants reported disruptions in their sleep. With sleep quality being associated with self-management behaviors (19) and sleep variability being associated with insulin needs (6) and A1C (9), it is crucial to identify diabetes-related factors disrupting sleep to improve sleep duration, quality, and diabetes outcomes.

Although there has been an increase in literature regarding the relationship between sleep and type 1 diabetes, more research is needed to understand not only the physiological implications of poor-quality and limited sleep, but also the factors causing sleep disruptions. Moreover, parents of children with type 1 diabetes report similar levels of impact on their sleep as adults with type 1 diabetes, which may affect their decision-making in caring for their child; however, little research has explored these outcomes. People with type 1 diabetes, as well as caregivers of minors with type 1 diabetes, experience a variety of diabetes-related sleep disruptions, but there is no existing diabetes-specific measure to capture disease-specific nuances in sleep disturbances.

Consistent with existing literature, participants in this study reported waking up because of CGM alerts and notifications (16). Participants reported waking frequently to check their CGM, including several caregivers who said they set alarms to make sure that their child’s blood glucose was in range, despite having a CGM system. It is not clear how many times caregivers wake up per night for “peace of mind” versus for device alerts or intervention, nor is the duration of such wake times known. What is clear, however, is that sleep is significantly affected overall.

Type 1 diabetes frequently disrupts daily living, including causing the loss of several hours of sleep per week related to hypoglycemia, hyperglycemia, and worry about diabetes management. Consistent with existing literature, the majority of caregivers in this study reported disrupting their own sleep to monitor their child’s blood glucose levels (20). Participants stated that, when they should be doing daily activities such as working or sleeping, they were instead taking care of diabetes-related needs. Understanding the real burden that people with type 1 diabetes and caregivers face while managing type 1 diabetes help HCPs and stakeholders make informed decisions to better manage this disease.

### *Implications*

The findings of this study suggest that people with type 1 diabetes and caregivers may lose several hours of sleep

per week because of diabetes management-related issues or worry. Much like people with diabetes, caregivers reported waking up several times per week because of CGM and other device alarms throughout the night. In addition to responding to alarms and alerts resulting from blood glucose excursions, many parents reported setting additional alarms to wake up during the night to check their child's blood glucose and make sure it is in the normal range. Further investigation is necessary to understand how poor sleep affects the health outcomes of parents and their diabetes-related decision-making for their child with type 1 diabetes. These findings also indicate that overnight disturbances can extend beyond sleep-related comorbidities and should be considered by HCPs and diabetes care teams.

### Limitations

This study has limitations that may have affected the findings. The focus groups varied by size, and the sample included more people with type 1 diabetes than caregivers. Additionally, participants were recruited using T1D Exchange Glu, which means participants are engaged enough to seek out a diabetes website. Of note, the majority of people with diabetes are not active in these types of communities. The average A1C of participants was near the American Diabetes Association's recommended target, which is not representative of the general population with type 1 diabetes. Overall, focus group attendees were educated and insured, and most of them were using insulin pumps and CGM systems to manage diabetes. Finally, due to the nature of diabetes, it was difficult for many people to quantify the number of times they wake up per week from diabetes-related occurrences and for peace of mind.

### Research Needs

Future research should quantify the loss of sleep caused by diabetes-related factors in the broader population of people with diabetes and caregivers, as well as the impact of poorer sleep on daily life. Developing a validated measure to identify the average amount of sleep lost because of diabetes-related issues and worry would aid in decision making and may influence HCP recommendations about care and diabetes device use. Quantifying these variables may also help researchers examine the impact of sleep loss on daily activities in both people with diabetes and caregivers and may help diabetes device developers improve devices to reduce the overnight burden of diabetes care.

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### DUALITY OF INTEREST

J.A.B. and A.S.H. are employees and A.H.M.-F. is a former employee of T1D Exchange. L.F. and M.P.-N. are employees of and stock shareholders in Eli Lilly and Company. No other potential conflicts of interest related to this article were reported.

### AUTHOR CONTRIBUTIONS

J.A.B. interpreted data and wrote the manuscript. A.S.H. analyzed and interpreted data and critically revised the manuscript. L.F., M.P.-N., and A.H.M.-F. reviewed/edited the manuscript. J.A.B. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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