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Sleep in Caregivers of Children with Type 1 Diabetes

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Abstract

Purpose: The purpose of this study was to explore caregiver's description of their experience of nighttime sleep.

Design and Methods: Caregivers (N=22) of children 10–18 years of age with T1D were recruited for this descriptive study. Anonymous questionnaires contained demographic information and both open and close-ended questions that focused on caregiving as it related to sleep. Open-ended questions were reviewed to help understand the effect of nocturnal caregiving activities on parental sleep.

Results: The sample of caregivers were all female, had a mean age 43 years; 96% graduated high school; 68% married or partnered, 100% Caucasian. Children had been diagnosed with T1D for a mean of 5 years, with a mean age of 12.2 years. Caregivers reported short sleep duration (mean 5.8 hours). Over half of participants reported they required ≥ 7 hours of sleep to feel their best, 64% reporting trouble sleeping at night, and 86% reported that caregiving interfered with their night time sleep, while 54% responded that sleep was "very important." Content analysis of the open ended questions revealed two themes 1) Anxiety about child's blood glucose levels, 2) Nighttime disruptions

Conclusions: Caregivers are frequently sleep deprived and worry about their child's nighttime glucose. Caregiving duties, anxiety, and sleep fragmentation may contribute to their poor sleep.

Type 1 diabetes (T1D) is one of the major chronic illnesses in youth, with nearly 15,000 new cases diagnosed in children each year in the United States ¹. With a diagnosis of T1D comes a laundry list of lifestyle changes and care needs, as everything from healthy eating and activity to insulin administration must now be carefully monitored and managed. For many children, their parents or an adult caregiver take on much of the responsibility of managing a disease that requires 24-hour vigilance ^{2–4}. For many parents, caregiving and monitoring

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does not end during the night, and especially for diabetes, where nighttime hypoglycemia is a constant concern ⁵.

Nocturnal hypoglycemia, a blood glucose that falls and stays below the safe range at night while the child is asleep, is a major stressor for parents of children with T1D. Children with T1D are especially susceptible for a sustained, below normal blood glucose that could potentially lead to permanent neurological damage, seizures, or possibly even death ^{6,7}. Therefore, getting an adequate amount of sleep may be a challenge for caregivers for various reasons including checking blood glucose during the nighttime hours, and treating and monitoring their child after a hypoglycemic event ⁵. Although caregivers of children with T1D are known to be at increased risk for poor sleep, little has been done to characterize sleep in this population.

Sleep has important implications for every aspect of a caregiver's life, although it often received little attention ⁸. Previous research has linked poor sleep or disrupted sleep in healthy adults with elevated blood pressure, poor cardiovascular outcomes, impaired memory, and increased reports of stroke, cancer, fatigue, and higher risk of obesity ⁹⁻¹¹. While there are few studies examining sleep in caregivers of children with chronic illness, and even less in caregivers of children with T1D, researchers have found that poor sleep is a concern. Poor sleep or disrupted sleep in caregivers of children with a chronic illness has led to decreased overall quality of life, elevated feelings of stress, depressive symptoms, and poorer health outcomes, as well as increased feelings of fatigue ¹²⁻¹⁵. Of the few studies done in caregivers of children with T1D, most have focused on the child's sleep ¹⁶.

Sleep has been a reported problem for children with T1D ¹⁷. When compared to age matched controls, children with T1D reported less sleep, had more bedtime resistance, and co-slept with their parents more frequently ^{18,19}. The child's poor sleep may have implications for the parent, however, little is known about the sleep in the caregiver of a child with T1D or caregiver and child dyad ²⁰. This represents a critical gap in the literature regarding caregivers of children with T1D. Therefore, the purpose of this study was to explore caregiver's description of their experience of nighttime sleep while maintaining care of young children with T1D

Methods

Design

This non-experimental, descriptive study examined sleep and caregiving information in a sample of caregivers of young children with T1D who were recruited from a T1D overnight camp. The camp is a resident camp with both staff and camper cabins, and includes activities such as wall climbing, hikes, arts and crafts, as well as ball fields. On site are pediatric physicians, certified diabetes nurse educators, dietitians, and counselors who carefully monitor the camper's diabetes management, diet, and activity. Campers are also provided education on managing nutrition, exercise, and medications. Free response data were analyzed from three open-ended questions, while quantitative data were collected through a brief questionnaire on sleep. The study received IRB approval before recruitment began.

Sample

A convenience sample of self-identified caregivers (N=22) of children greater than 10 years of age with T1D were recruited for this descriptive study. Inclusion criteria for participants were age 18 years or older, have child with T1D who lives primarily in their home, able to read, write, and speak English, and not be diagnosed with a primary sleep disorder (e.g. insomnia, obstructive sleep apnea, or restless leg syndrome). The child had to be 10 years of age or older and have the diagnosis of T1D for at least 2 years. Recruitment occurred while caregivers were checking their child in for a 1 week overnight diabetes summer camp. Fliers were distributed, and a table was set up so that after checking in their child for camp, caregivers could approach and receive more information on the study. Camp was chosen as a place for recruitment as it affords a forum for parents to circulate during camp check-in so that they may gather information at various tables and booths and network with staff and other family members.

Measures

Since there are no questionnaires specifically designed for sleep in children or caregivers with T1D, and given that the main purpose of this study was to explore caregiver's experience with sleep, two questionnaires were developed. Caregiver's were asked to fill out two investigator designed questionnaires specifically focused on diabetes care and sleep without identifiers. These questionnaires were reviewed by diabetes clinicians (i.e. physician, nurse practitioner, and certified diabetes educator) for face validity. The first was a demographic questionnaire asking basic questions about the caregiver and their child's diabetes routine.

The second questionnaire focused on sleep and caregiving, and had open and closed ended questions for them to answer. The questionnaire asked several questions, including if the caregiver shared duties during the day or at night, and if so, with whom, and if the child used an insulin pump, how many times the child's blood glucose was checked, if the child had nighttime glucose checks. Sleep questions were focused on asking the caregiver how important sleep was to them, asking them to estimate how many hours of sleep they got at night, how many hours they felt they needed to be at their best, if they had trouble sleeping at night and why, and if caregiving activities interfered with their ability to get enough sleep at night and how or why.

Data Analysis

Questionnaires were completed on site and returned to the investigator. Quantitative data were described with descriptive statistics. Open-ended questions were transcribed and reviewed to help understand the effect of nocturnal caregiving activities on the caregiver's sleep through content analysis. Two separate reviewers read the open-ended questions and highlighted important phrases or words. Highlighted phrases and words were then clustered into codes, then condensed into themes. The two reviewers met to compare themes and responses for agreement. Themes were developed for each of the questions until saturation was achieved. Each sentence was considered a response and placed with similar answers until data could no longer be collapsed. Two members of the research team coded all

responses, with a third resolving any conflicts. Inter-coder reliability was assessed by 3 members of the research team coding a random sample of responses.

Results

Description of the Sample

The mean age of caregivers (N=22) was 43 years (range 34 to 55 years), with almost all (n=20) self-identifying as the biological parent and the other 2 as grandparents. Most of the sample were mothers (n=19) or grandmothers (n=2). The majority (n=20) reported they were married, 1 divorced, and 1 never married. All of the caregivers self-identified as Caucasian and as high school graduates. All caregivers reported getting up at night to check their child's glucose, and 18 caregivers (81%) reported their child used an insulin pump. None of the caregivers reported that their child used a continuous blood glucose monitor. The child had been diagnosed with T1D for a mean of 5.36 years (range of 2–16 years), mean age of the child was 12.2 years (range 10–18 years)

Qualitative Responses

Respondent's answers to the open-ended questions can be grouped into two themes: that their (caregiver) sleep was negatively affected by anxiety about hypoglycemia and that their sleep was fragmented and inadequate because of difficulty in initiating sleep or after waking at night to check the child's blood glucose.

Anxiety about child's blood glucose levels—Caregivers voiced a fear about their child's maintaining a safe blood glucose level and reported that this fear was a constant part of their lives, regardless of time of day. Some of their responses were “I am worried about my daughter's numbers during the day and night,” and “I worry about his blood sugar number all the time,” and “I worry about my son's blood sugar constantly.” Many participants felt that the fear of hypoglycemic events affected their lives on an ongoing basis.

One participant wrote, “If my daughter is low, I test every 10 minutes until she is 80 and safe,” while another participant wrote “I worry if my daughter is low and worry if my daughter is going to wake up okay in the morning.” Finally, one caregiver summarized their experience as, “If he is low, I have to treat and check his blood sugar 2 hours later. I am sometimes up every 2 hours to correct the highs and lows. Sometimes I have trouble waking him when low and it is stressful!”

Nighttime disruptions—The second theme that was almost universal to the caregivers was that their sleep was chronically disrupted in order to monitor blood glucose levels. In response to having a child with nocturnal hypoglycemia, a caregiver explained that “If I have to correct his sugar, I stay up at night and check constantly to make sure it is coming up.” Another caregiver described that “My sleep is broken into 2–3 hours at a time to check him if he's low. I rarely sleep through the night, waking every 1–2 hours.” Another caregiver wrote about staying up late in order to monitor blood glucose and then sometimes needing to remain awake throughout the night to monitor levels, “Sometimes I just stay up to do the

midnight checks. If it is a night of great needs, then I don't get much sleep because of checking every 10 minutes.”

This theme was further elucidated by another caregiver who described difficulty in returning to sleep after waking to monitor blood sugars, “Waking up to check lows requires waiting to make sure the BS are coming up. I have a hard time falling back to sleep.” Other caregivers echoed how their sleep was disturbed by saying, “I either can't get to sleep or wake up multiple times during the night,” and another caregiver stated, “I wake up multiple times every night to check my son's blood sugar.” Finally, a caregiver plaintively characterized her experience as the life of a caregiver of a child with T1D “Up testing, up worrying, try to stay awake because if I fall asleep I might not hear my alarm to test again.”

Quantitative Responses on Sleep

Table 1 depicts responses by the caregivers concerning their sleep. While most of the sample responded that they recognized that sleep was either “very important” or “important”, only one of the respondents reported an average sleep duration of 8 or more hours a night. Three out of four respondents reported an average sleep duration of 6 hours or less, an hour less than the recommended duration of seven hour a night ²¹. While the average “amount of sleep required to feel their best” was over 8 hours a night, over half the respondents reported that they usually obtained 1 to 3 hours less than what they felt they required.

The negative effect of nighttime caregiving on sleep was reflected on the caregiving responses to a series of questions. While over half of the respondents (n=14; 64%) reported that they “shared daytime caregiving duties,” the majority responded that “nighttime caregiving duties” were not shared (n=15; 68%) and almost all the caregivers responded that caregiving interfered with their nighttime sleep (n=19; 86%). Caregivers with a child who had been diagnosed with diabetes for five or more years had significantly shorter sleep duration compared to caregivers with a child who had been diagnosed with T1D for four or less years (respectively, (5.27 hours ± 1.0 vs. 6.36 hours ± 1.28; $p=.039$). There was no statistically significant ($p>.05$) difference in sleep duration between caregivers who had trouble sleeping at night with those who denied difficulty or between persons who responded they did or did not share nighttime caregiving duties. However, persons who responded they did not have trouble sleeping at night or that they shared caregiving duties averaged approximately 30 minutes longer sleep. Inadequate sleep duration was accepted as part of caregiving a child with T1D, only one out of three caregivers responded affirmatively that they thought it was possible to overcome the challenges they personally had to obtain adequate sleep.

Discussion of Findings

The purpose of this study was to explore caregiver's description of their experience of nighttime sleep while maintaining care of young children with type 1 diabetes. There is a gap in the literature in examining how diabetes management may influence caregivers at night ¹⁷. In this study, caregivers reported obtaining less sleep than recommendations and the majority also reported not getting enough sleep to “feel their best,” and that caregiving duties may have negatively influenced their sleep. Also, very few caregivers reported sharing

nighttime caregiving duties. Caregivers also spoke about anxiety due to nighttime hypoglycemia and nighttime disruptions due to diabetes care for their child.

In both their qualitative and quantitative responses, caregivers described a continuous pattern of obtaining inadequate sleep that was driven by both the demands of maintaining safety for their child and the anxiety they had of possibly not being awake and able to respond. While this study focused specifically on sleep, the findings are supportive of previous literature in mothers of children with T1D in general, which found that many mothers reported sleep deprivation and feelings of isolation as they adjusted to their child's routine²². In a recent survey study of 597 children and parents, parents overwhelmingly (74%) reported worrying about their child having a low blood glucose (regardless of time), and also reported diminished amount or quality of sleep for family members as one of the most important family burden factors²³. Likewise, in a sample of 258 parent/child participants, chronic sleep interruption was identified as a stressor and was significantly associated with detrimental impact on mood, work, family relationships, ability to exercise regularly, eat healthily, and overall happiness²⁴. These findings support the importance of sleep and the implications it may have for overall quality of life.

Fear of hypoglycemia and nighttime disruption may be a common concern for parents and children with T1D. Monaghan and colleagues⁵ quantitatively examined nighttime caregiving behaviors of parents of preschool aged children. They found that nighttime blood glucose checks were performed regularly and were associated with child's insulin regimen and with duration of child's illness (longer duration was associated with more frequent nighttime checks)⁵. However, in a study of parents of children with T1D where researchers examined parent's sleep, hypoglycemia worry, and diabetes self-efficacy, it was found that the most important predictor of nighttime blood glucose checks was parent's worry and anxiety over their child, not duration of disease⁷. Conversely, in Sullivan-Bolyai, et al.'s²² qualitative work, parents indicated that time was a factor in acclimating to their child's disease and becoming less anxious about diabetes management, suggesting self-efficacy in disease management was highly important.

Disease duration and parent's worry over nighttime hypoglycemia may be associated. The longer a child has had T1D, and therefore the longer the parent and child have been managing T1D, the more chances there are to experience and go through overnight complications, prompting higher vigilance to avoid them. Likewise, the longer a caregiver has been managing their child's T1D, the more likely they are to anticipate certain events and adjust their diabetes management accordingly (for example, more nighttime blood glucose checks when their child has had a "bad" day)^{18,25}. However, this relationship deserves more research attention, especially in examining the impact of parent and child sleep, and how new technology, such as continuous glucose monitoring, may impact nighttime routines and parent's anxiety²⁶.

The finding that few primary caregivers share nighttime care is reflected in previous literature of caregiving for a child with a chronic illness^{14,27}. In many cases, there is a primary caregiver who takes on most of the responsibility for the child's management, including nighttime care. This can be due to a number of reasons, including work scheduling

and shifts, other children, single parent or caregiver families, or lack of resources, among others^{6,28}. It does, however, raise meaningful questions about caregiver outcomes and health, especially for chronically sleep deprived parents. Chronic sleep deprivation may place a caregiver at greater risk for depression, heightened anxiety, weight gain, and other health issues, as well as having an impact on their overall daily functioning^{24,29,30}. Future studies should include longitudinal measures of caregiver outcomes in order to better understand the impact of chronic sleep deprivation.

Limitations

The results of this study are limited by the small sample size that lacked diversity and the cross-sectional design that precluded causality. In addition, sleep duration was measured by only a single question and no objective measure such as an actigraph was used to determine objective sleep duration, sleep fragmentation, or other sleep metrics such as sleep latency, sleep efficiency, or time awake after sleep onset. Stress and anxiety were not measured using a quantitative questionnaire, but did emerge as themes from qualitative data. For future studies, this may be necessary to expand upon.

Implications and/or recommendations for clinical use

These findings suggest that caregivers of children with T1D are frequently sleep deprived and may have chronic anxiety about getting adequate nighttime sleep that may endanger their child. With all of the information and skills training that needs to be addressed during diabetes self-management education, caregiver sleep habits may be overlooked. Diabetes educators who are sensitive to the psychosocial and family stressors that accompany care of children and adolescents with diabetes should consider assessing sleep behaviors given its potential influence on the daily rigors of diabetes tasks that they are required to provide³¹. Health care providers should consider assessing the parent and child's sleep schedule during clinic visits, in order to identify sleep issues that may be arising. Diabetes educators should include support for parent and child on nighttime diabetes care and management, and need to consider the importance of sleep and healthy sleep patterns. For example, recommending options, like diabetes camp or overnights with trained family members, offer a chance for caregiver respite in care. Finally, there is a need for additional research to explore ways that technology can be used to maintain nighttime safety and improve sleep for both children and their caregivers.

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Table 1:

Respondents Sleep Characteristics

Question	Mean ± SD(range) or Frequency(%)
Sleep Duration	5.8 hours (3 hours-9 hours)
Required Sleep Duration to “feel best”	8.5 hours (5 hours-9 hours)
“Trouble” sleeping at night	“Yes”: 14 (64%) mean sleep duration 5.6 hours ± 1.2 “No”: 8 (36%) mean sleep duration 6.1 hours ± 1.5
Caregiving activities interfere with sleep	“Yes”: 19 (86%) “No”: 3 (14%)
“Share” nighttime caregiving duties?	“Yes”=7; mean sleep duration 6.3 hours ± 1.1 “No”= 15; mean sleep duration 5.6 hours ± 1.3

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Table 2.

Sleep and Caregiving Questions

Sleep Questions
How important is sleep to you?
About how many hours of sleep do you get at night on a typical night?
How many hours of sleep do you need to feel your best?
Describe your nighttime sleep routine.
Do you have trouble sleeping at night? Why?
Does caregiving influence how you sleep at night? How?
Caregiving Questions
How long has your child had diabetes?
How old is your child?
Does your child use an insulin pump? (yes/no) or Continuous glucose monitoring (yes/no)
Does your child have nighttime blood glucose checks?
Do you share caregiving responsibilities? (yes/no)
Do you share nighttime caregiving responsibilities? (yes/no) If yes, with whom?

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