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Sleep in Teens With Type 1 Diabetes Perspectives From Adolescents and Their Caregivers

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Abstract

Purpose—The purpose of this study is to identify barriers, facilitators, and consequences of obtaining sufficient sleep in adolescents with type 1 diabetes.

Methods—Semistructured interviews were conducted with 25 adolescents (52% female, mean age = 15.6 years) and 25 caregivers. Interviews were transcribed and coded using Atlas.ti. A thematic analytic approach was used to identify and organize significant patterns of meaning (themes) and interpret themes across the data.

Results—Several barriers were identified, with the most common being the use of electronics before bed and sleep disturbances related to diabetes management. Caregivers described strategies for helping adolescents achieve sufficient sleep, such as enforcing bedtimes and limiting distractions, but many adolescents could not identify facilitators of sleep. Weekday/weekend discrepancies in sleep timing were commonly disclosed.

Conclusions—This study is the first to examine the perceptions of barriers and facilitators to obtaining sufficient sleep in adolescents with T1D and their caregivers. Results have the potential to inform providers' recommendations regarding sleep, including possible interventions to promote sleep in this high-risk population.

It is well-established that adolescents with type 1 diabetes (T1D) are at increased risk for problems with adherence and deteriorating glycemic control, and sleep has recently been identified as a risk factor for poor diabetes-related outcomes.^{1,2} Sleep disturbances, including insufficient sleep, may negatively affect glycemic control directly through increased insulin resistance³ and indirectly through poor diabetes management, such as poor food choices and reduced motivation for self-care.⁴ In pediatric T1D, sleep disturbances are common given the intermittent need for overnight glucose monitoring and occasional nocturnal hypoglycemia. Adolescents with T1D have been observed to have more frequent and longer overnight awakenings and shorter sleep duration than their peers without diabetes.^{5–8} Further, variability in sleep timing (ie, delayed weekend bedtime) has been associated with poorer glycemic control in people with T1D.^{9,10}

The American Academy of Pediatrics recommends that adolescents sleep 8 to 10 hours per night¹¹; however, national survey data indicate that up to 87% of adolescents in the general population get fewer than 8 hours of sleep per night,^{12,13} with similar rates reported for adolescents with T1D.^{14,15} While sleep disturbances have biological, circadian, and neurodevelopmental causes, they are also influenced by environmental and psychosocial factors, which are modifiable.¹⁶ Sleep disturbances and circadian rhythm change throughout the course of development, and during adolescence, the biological shift in sleep/wake times associated with a delay in melatonin secretion, in combination with early school times, often contributes to shorter sleep duration.¹⁶ In addition, academic demands, work, extracurricular activities, increased electronic media use, and social interaction (eg, text messaging, social media) are associated with later bedtimes and difficulty falling asleep among adolescents.^{17,18} Caffeine consumption, which increases in adolescence, is also strongly associated with sleep disturbances.¹⁹ Fortunately, enforced bedtimes are shown to improve sleep in adolescents,²⁰ and removing television and internet-connected electronic devices from adolescents' bedrooms is associated with better sleep.²¹ It is not known, however, whether these same barriers and facilitators to obtaining sufficient sleep apply for adolescents with T1D.

Sleep may be an important risk or protective factor for diabetes-related outcomes in adolescents with T1D. However, standards of care for youth with T1D fail to routinely address sleep characteristics, such as total sleep time, sleep/wake times, or sleep quality,^{22,23} and the role of sleep in self-management and adherence is still not well understood. Moreover, most research on sleep habits in adolescents has relied on survey measures, and no qualitative studies have been conducted to understand sleep in adolescents with T1D. The goal of this research was to identify and explore topics related to sleep habits in adolescents with T1D from both the adolescents' and caregivers' perspectives. Working from a biopsychosocial and contextual model of sleep,^{24,25} which highlights the need to consider the social environment and psychosocial factors, interviews were conducted with adolescents with T1D and their caregivers to identify barriers, facilitators, and consequences of insufficient sleep to inform providers' recommendations and to identify targets for intervention.

Methods

Research Design

To obtain adolescents' and caregivers' perspectives on sleep habits and the impact T1D may have on sleep, a qualitative phenomenological approach was chosen to explore the meanings and perspectives of research participants. The goal of a phenomenological approach is to develop a composite description of "how" people experience a phenomenon in the context of their daily lives.²⁶

Participants

Adolescents and their caregivers were recruited from a large pediatric diabetes clinic at an academic medical center in the Southeast. Eligible participants were between the ages of 13 and 17 years who had a diagnosis of T1D for at least 1 year. Patients with developmental

delays or neurologic disorders were excluded. Efforts were made to obtain a diverse sample using a maximum variation sampling method²⁷ with respect to age, gender, diabetes devices used, and race/ethnicity, commensurate with the demographics of the clinic. Trained research assistants (RAs) approached eligible patients in the waiting room or in an examination room at their regularly scheduled clinic visits. If families expressed interest in the study, the RA met with them in a private space to obtain informed consent/assent, with participation in the protocol approved by the university's Institutional Review Board.

Data Collection

Data collection occurred from December 2016 to February 2017. Adolescents' point-of-care A1C values and blood glucose monitoring data (via glucometer download) were obtained as part of the regular clinic visit. Demographic information was provided by caregivers. RAs trained in the study protocol, as well as principles of qualitative interviewing and type 1 diabetes management, conducted semistructured interviews with adolescents (n = 25) and their caregivers (n = 25). Adolescent and caregiver interviews were conducted separately (a total of 50 interviews) in private rooms and were audio recorded. Caregivers and adolescents received a \$20 gift card each for their time. Interview questions were developed with input from a team of experts, which included a sleep medicine physician, a pediatric endocrinologist, a nurse practitioner diabetes educator, a pediatric psychologist, and an expert in qualitative research. Questions explored adolescents' general sleep habits, bedtime activities, and nighttime diabetes treatment regimen. Sample questions included, "In what ways does lack of sleep affect your diabetes management?" and "In what ways do diabetes-related technology or devices impact your sleep?" On average, caregiver interviews lasted 18 minutes (range = 11–37 minutes). Teen interviews tended to be shorter, lasting, on average, 15 minutes (range = 9–21 minutes). Interviews were transcribed by trained research staff, checked for accuracy, and uploaded to ATLAS.ti 8 for analysis.²⁸

Qualitative Analysis

Thematic analytic methods were used to identify and organize significant patterns of meaning (themes) and interpret themes across the data.²⁹ While some codes were predetermined based on a review of the literature and input from experts (eg, what constituted sufficient hours of sleep), most codes emerged from data. All 4 coders first reviewed 2 transcripts to generate initial codes (open coding) that identified adolescents' sleep habits. These codes were reviewed by the team, and any discrepancies in the definitions and application of codes were discussed until consensus was reached, which resulted in an interrater reliability rate of 82%. The remaining transcripts were then divided among the team for coding. All codes were verified by 2 or more members of the research team upon initial coding and after collapsing based on similarities in groups of codes, resulting in key themes. Furthermore, any discrepancies among the coders were discussed until consensus was reached.

Results

Table 1 presents sample characteristics of 25 adolescent-caregiver dyads. Approximately half of adolescents used insulin pumps, 20% used continuous glucose monitors (CGMs),

52% were female, and the mean A1C was 8.9% (74 mmol/mol), which was representative of the clinic population. The following themes emerged from the data.

Sleep Characteristics

In terms of sleep characteristics, nearly three-fourths (72%) of adolescents stated that they believed they needed to get more sleep, and almost two-thirds (60%) reported getting less than the recommended 8 hours per night. However, only 1 adolescent reported a diagnosed sleep disorder. While most teens reported sleeping alone in their beds every night, there was variation in the levels of light exposure experienced by teens during the night; 30.8% (n = 8) of teens slept with some form of light on. Most teens (92%) described differences between sleep on school days and weekend days or holidays, especially staying up and sleeping in much later on the weekends. “On a weekend, if I don’t have work then I’m going to bed whenever I want, waking up whenever I want” (teen 105, F, age 17). Notably, 32% of teens in the current sample reported getting 10 or more hours of sleep on week-end nights, in contrast to only 1 teen (teen 125, F, age 14) who reported getting 10 or more hours of sleep on week-nights. Sleep habits were more consistent during the school week compared with the weekends. Only 1 participant reported sleeping at different households throughout the school week, whereas the weekends were more variable for all participants, including sleepovers with peers and family visitation arrangements.

Most (80%) caregivers acknowledged that their teen received less than the recommended 8 hours of sleep per night. On average, teen sleep duration on weeknights was reported by caregivers as 7.6 hours; however, on weekend nights, caregivers reported their teens slept 9.1 hours on average. Despite this increase in sleep duration, caregiver-reported bedtimes were on average 2.3 hours later on weekend nights than on weeknights, indicating a large shift in sleep timing.

Barriers to Obtaining Sufficient Sleep

Teens described a variety of barriers to obtaining sufficient sleep. Most (92%) adolescents reported using electronics such as cell phones, laptop computers, and/or television before bed. When asked how this interfered with obtaining sufficient sleep, one teen (teen 105, F, age 17) said, “I play games and I can’t stop or I just watch videos on YouTube a lot,” leading to delayed bedtimes during the school week as well as on the weekends/holidays. “When I get home after sports, I’ll eat dinner and then I’ll have my phone or my computer for a while, and it usually delays how long it’ll take for me to do my homework” (teen 111, M, age 15). Teens also reported that factors such as homework or school-related activities, sports, and other external factors (eg, siblings, pets, outside noise) delayed and disrupted their sleep.

I have a lot of homework and I don’t usually finish my homework until 10:00, 10:30. I get a shower and it’s already 11:00 and then you get in bed and you’re not gonna fall asleep right when you get in bed. Say you’re asleep by midnight. Then you have to get up by 6 to get to school on time. (Teen 126, F, age 17)

Younger adolescents (13–15 years) reported barriers pertaining to phone and electronics usage and other external factors more frequently, whereas older adolescents (16–17 years) reported homework or school-related activities more frequently.

More than half (56%) of teens reported that their mood affects their quality of sleep; however, the effects of mood that teens described were variable. One teen reported, “When I go to sleep happy, I’m just like, I can just sleep for the rest of the night. But when I go to sleep grumpy, I just constantly wake up” (teen 120, M, age 13). Another reported, “If I’m happy, I won’t go to bed when I’m supposed to, but if I’m like, tired I’ll obviously go to bed normally” (teen 105, F, age 17).

Like the teens, some caregivers reported phone and electronic use, homework, and other external factors (eg, neighborhood noise) as barriers to teens’ sleep. However, caregivers reported that the most significant disruptions to adolescents’ sleep were diabetes related. Many (72%) caregivers, particularly caregivers of teens using pumps, reported that their child woke up throughout the night because of symptoms of hypo- or hyperglycemia. Several reported that their adolescent would wake due to thirst or frequent urination. One caregiver commented that “thirst and needing to use the bathroom wake [her teen] out of a dead sleep” (caregiver 120, F, age 49). Another reported that her teen “usually sleeps fine, unless his blood sugar’s high. Then he’s up every couple hours” (caregiver 123, F, age 49). Although most caregivers reported that the symptoms of abnormal blood glucose levels wake their teens, diabetes management posed another barrier to sleep. Treating low blood glucose levels at bedtime was indicated as a specific obstacle to obtaining adequate sleep duration.

Facilitators of Obtaining Sufficient Sleep

Adolescents employed multiple strategies in an effort to improve their sleep. While each participant provided responses unique to their situations, several similar strategies were used. For example, multiple adolescents perceived that use of electronics was a strategy to fall asleep more quickly. For example, one teen reported, “I watch Netflix cause it’ll help me fall asleep” (teen 126, F, age 17). In addition to the use of electronics, the sleep aid melatonin was a popular strategy. Other more unique examples included the use of “lavender spray” to help fall asleep (teen 105, F, age 17), while another teen stated, “I just spin around in a circle just to make myself dizzy and then I just go to sleep” (teen 103, M, age 13). It is notable that almost 50% of adolescents ($n = 12$) said “none” or “I don’t know” when asked about facilitators to obtaining sufficient sleep. Males were more likely than females to have not tried any strategies.

Caregivers reported using several strategies to help adolescents increase the duration and quality of their sleep. The most common strategy was enforcing early bedtimes, but less than half of caregivers (48%) reported consistently setting bedtimes to ensure their teen was getting enough sleep. In addition, several caregivers reported using soothing sounds including playing music, nature sounds, or ambient noise to help their teen relax and fall asleep. Some caregivers ($n = 8$) also reported trying to limit distractions around bedtime to aid their teen in falling asleep. They described removing electronic devices from their teen’s bedroom and trying other techniques such as using sleep masks and mindful scheduling to

reduce distractions and activity before bedtime. A few caregivers also reported using sleep aids such as melatonin or allergy medicine to induce sleepiness in their teens before bed. One caregiver (caregiver 122, F, age 42) reported reducing caffeine intake to help her teen sleep.

Diabetes-Related Sleep Disruptions

Adolescents frequently described how T1D affected their sleep, including delaying bedtime due to diabetes management (32%) and frequent awakenings during the night (72%), often to use the restroom (48%). One teen noted that his sleep was affected by T1D saying, “it affects it a little because like sometimes I have to wake up either to pee maybe because my blood sugar’s high or I wake up feeling low and need to get something to eat” (teen 122, M, age 15). “You have to wake up more, because you have to check your sugar in the middle of the night if you need to” (teen 103, F, age 14). Teens reported waking at night due to high blood glucose levels (48%), low blood glucose levels (44%), or both (32%).

Participants also reported being woken by alarms from their sensors/pumps or from the pain associated with “rolling over” on their devices. “My CGM will wake me up sometimes whenever I’m high or low but sometimes I sleep through it” (teen 116, F, age 17). Another teen noted, “My insulin pump sometimes, it gets snagged in between my sheets or sometimes it’ll just beep for no reason and so I have to get up and check make sure everything’s good” (teen 125, F, age 14). Caregivers also reported that alarms from insulin pumps and CGMs have interrupted their teens’ sleep (n = 9; 44% were current CGM users). One caregiver indicated that her teen’s CGM was “kind of a curse” initially, because of its many alarms (caregiver 118, F, age 42).

Caregivers were also aware of the ways in which their child’s T1D affected their own sleep. Some caregivers postponed their own bedtime or set personal alarms to monitor their child’s blood glucose. Others were woken and alerted to diabetes-related concerns by their teen or their teen’s CGM alarms. Nocturnal caregiving behaviors were reported by 76% of caregivers, of which 47% reported that they regularly checked their child’s blood glucose at least once during the night. Caregivers described feelings of anxiety related to their child’s diabetes management, reporting a heightened sense of worry and increased overnight monitoring when their child had low blood glucose before bed, was sick, or after a change to their teen’s insulin regimen.

If she’s low right before she goes to bed . . . then of course we have to eat, drink, do something in order to get her sugar back up and I have to keep her awake and I have to stay awake in order to recheck it. I’m the one who gets up during the night then afterwards in the middle of the night to check it. . . . If she’s low around bedtime I have to get up during the night to check it or if she’s sick I set my alarm to make sure I’m up every 4 hours to check her sugar around the clock. (Caregiver 125, F, age 46)

Interestingly, nocturnal caregiving practices were described by caregivers whose teens used CGM as well as caregivers of teens who did not. Three of the 5 caregivers whose teen used CGM reported that they still checked their teen’s blood glucose at night. Caregivers described their own delayed or disrupted sleep and its impact on mood. Caregivers reported

difficulty falling asleep, interrupted sleep, and feeling tired and cranky the following day. “I’m up all the time. I mean, I feel like there is a reason 40-year-olds don’t have newborns because every 2 hours waking up is hard. I mean, it makes me really cranky the next day” (caregiver 118, F, age 42).

Insufficient Sleep and Diabetes Management

In addition, quality of sleep seemed to have an impact on diabetes management; several teens described becoming more “forgetful” or “lazy” about diabetes management if their quality of sleep was poor the night before. For example, one teen said that, without enough sleep, “I seem more lazy and it’s where I don’t want to test and I don’t want to get up to eat, and if I do eat I don’t test and I forget to take my insulin” (teen 104, F, 16). Teens also reported making unhealthy food choices after a poor night’s sleep. One participant explained, “It probably makes [food choice] poor because whenever I get up I’m hungry and I just eat the first thing I see pretty much” (teen 123, M, age 13). Skipping meals because of insufficient/excess sleep was also commonly reported by teens ($n = 9$).

Generally if I don’t get enough sleep I don’t really eat that day. If I do [eat] it’s not very much. It’s like maybe half a sandwich. . . . I’m not really on top of anything . . . I’m not my usual self. I don’t like do things, I just kinda sit. (Teen 126, F, age 17)

Teens were less likely to report excess sleep having any impact on their diabetes management.

Similarly, most caregivers also believed that insufficient sleep in their teens has a negative impact on diabetes management. Most caregivers (92%) reported that teens were less motivated to adhere to their treatment regimens after a night of poor sleep. One caregiver noted that “the lack of sleep would probably cause [her teen] to not be able to keep track of his blood sugars or test when he needs—it probably causes him to be a little lazy about it” (caregiver 119, F, age 38). One father indicated that “if [his teen] doesn’t get enough sleep and she’s in a rush, then it causes her to sometimes forget her glucose monitor” (caregiver 116, M, age 50). Other caregivers noted that a lack of sleep makes their teen more forgetful, causing them to overlook aspects of their diabetes care.

Discussion

Sleep habits represent an unappreciated factor with the potential to improve diabetes outcomes, as accumulating evidence indicates that sleep disturbances are a risk factor for problems with glycemic control and diabetes management.² However, more information was needed regarding the factors most salient for adolescents with T1D. The current study gives providers a place to start—asking about barriers to achieving sufficient sleep, strategies the family has tried to promote sleep, and discrepancies between weekday/weekend sleep habits. These findings suggest opportunities to educate families on healthy sleep habits, such as supporting and reinforcing caregivers’ attempts to limit electronics and set bedtimes. In addition, providers can talk with caregivers about nocturnal caregiving and the possibility of diabetes technology to reduce sleep disturbances related to diabetes.

First, consistent with previous studies,³⁰ the over-whelming majority of teens in the current sample described using electronics before bed. Cain and Gradisar¹⁷ have suggested a theoretical model in which increased media use results in increased sleep problems via several mechanisms. Media use displaces sleep or sleep hygiene–related activities, and the use of electronics before bed may also cause physical, mental, and emotional arousal, which prevents good-quality sleep. Lastly, electronics typically emit blue light, which has been linked to suppression of melatonin secretion and delayed circadian rhythms.³¹ In keeping with this model, smartphone ownership has been linked to later bedtimes, and electronic media use was related to shorter sleep duration and greater sleep difficulties.³² Based on findings from the current study, in conjunction with those from the sleep literature, it is recommended that parents set a “media curfew,” such that teens put away all electronics at least 1 hour before bed or at a time that allows for sufficient sleep. In addition, removing electronics such as televisions, game consoles, computers, and phones from teens’ bedrooms overnight is recommended. In addition, many teens reported leaving lights, such as lamps or nightlights, on while they slept. Previous studies have indicated that light exposure can negatively affect sleep, as light inhibits the production of melatonin, a hormone that aids in circadian rhythms.³³ Sleeping in an environment with an artificial light source may impede teens’ sleep quantity and quality.

The finding that nocturnal caregiving described by the caregivers in the current sample is similar to what has been reported in previous studies of caregivers of younger children with T1D was somewhat surprising.^{34,35} Nighttime blood glucose monitoring, sleep disturbances due to diabetes devices, and fear of hypoglycemia around bedtime were prevalent, similar to parents of younger children with T1D. This suggests that caregivers continue to experience disruptions to their own sleep related to caring for a child with T1D, even when that child reaches adolescence. Furthermore, the stress of caring for a child with T1D is compounded with increased stress due to poor sleep. As indicated in prior studies,³⁶ the quality of a child’s sleep can predict the quality of sleep experienced by their caretaker. This in turn predicts the caretaker’s mood, stress levels, and fatigue, such that poorer sleep quality results in greater stress and worse moods.³⁵ Diabetes-related sleep disturbances act to interfere with sleep quality and duration in both teens with T1D and their caregivers, resulting in increased caregiver stress. Although many families have embraced new technology and devices (eg, continuous glucose monitoring) as a way to increase information on blood glucose levels and reduce the risk for hypoglycemia, findings from the current study revealed that many caregivers continue to check on their adolescent children at night, even when using CGM. Further, diabetes devices frequently disrupt adolescent and caregiver sleep with alarms. Thus, it is recommended that providers talk with families about the potential for better outcomes with recent advancements (eg, more accurate sensors and hybrid closed-loop insulin delivery systems), while being realistic about the limitations of diabetes technology.

Finally, both adolescents and their caregivers described great variability in sleep timing and sleep habits between weeknight and weekend nights, with later bedtimes, greater use of electronics, and more variation in sleep environment on the weekends as compared with weekdays. Given recent findings from studies showing that variability in sleep timing is negatively associated with glycemic control,² this may be another area for providers to target.

It is well-documented that insufficient sleep is a risk factor for a variety of physical and psychosocial problems in adolescence.¹⁶ Researchers are also increasingly recognizing the importance of sleep for the behavioral and emotional health of adolescents. Increasing evidence^{37–39} supports the relationship between inadequate sleep and depression or depressive symptoms. Insufficient sleep in adolescence is also linked to risk behavior,^{40–43} including a higher incidence of alcohol and drug use.^{38,43} All of these psychosocial consequences of insufficient sleep are likely to impair adolescents' ability to manage diabetes effectively.

Developmental changes in sleep patterns during adolescence are well-characterized, and existing evidence^{25,44,45} has demonstrated that bioregulatory systems controlling sleep, as well as environmental and psychosocial factors, are involved in these observed changes. While healthy sleep habits are important for all adolescents, the consequences of insufficient sleep are even more deleterious for teens with T1D, as sleep disturbances are linked to poorer glycemic control and greater problems with adherence. Findings from the current study point to some of the potentially modifiable environmental and psychosocial factors. Keeping a regular sleep schedule across the school week and during week-ends and avoiding late bedtimes may minimize risks to adolescent daytime functioning. Furthermore, adolescents can maintain good sleep quality by engaging in good sleep hygiene practices,⁴⁶ such as avoiding caffeine, strenuous physical exercise, bright light, and electronics prior to bedtime. These components can be incorporated in the development of sleep-promoting interventions, and future research should evaluate the extent to which they can be adapted to address diabetes-specific challenges.

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Table 1

Participant Characteristics (n = 25 Adolescent-Caregiver Dyads)

Factor	M ± SD or n (%)
Adolescent age, y	15.56 ± 1.48
Adolescent race/ethnicity	
White, non-Hispanic	20 (80)
African American	3 (12)
Hispanic/Latino	1 (4)
Asian	1 (4)
Adolescent duration of diabetes, y	6.15 ± 4.04
Adolescent A1C, %	8.93 ± 1.95
Adolescent gender (female)	13 (52)
Treatment type	
Insulin pump	14 (56)
Injection	11 (44)
Continuous glucose monitor usage	5 (20)
Caregiver type (parent)	23 (92)
Caregiver gender (female)	22 (88)
Insurance (public)	6 (24)