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Sleep and Night-time Caregiving in Parents of Children and Adolescents with Type 1 Diabetes Mellitus – A Qualitative Study

Grace C. Macaulay ^a, Sara E. Boucher ^a, Ahrabie Yogarajah^a, Barbara C. Galland ^a, and Benjamin J. Wheeler ^{a,b}

^aDepartment of Women's and Children's Health, University of Otago, Dunedin, New Zealand; ^bPaediatric Endocrinology, Southern District Health Board, Dunedin, New Zealand

ABSTRACT

Background: Type 1 diabetes mellitus (T1DM) is a common chronic illness of childhood, with parents assuming considerable responsibility for night-time diabetes caregiving. This qualitative study explored diabetes-related factors affecting, and solutions proposed to improve, parental sleep.

Participants: 10 mothers and 10 fathers of children ≤18 years of age with T1DM in Otago, New Zealand.

Methods: Semi-structured individual interviews were audio-recorded, transcribed, and systematically coded for themes. Parents completed the Pittsburgh Sleep Quality Index (PSQI) and habitual sleep of parents and children were assessed via 7-day actigraphy.


Results: Parents ($n = 20$) and their children with T1DM ($n = 16$) were aged between 32 and 54 years, and 1 and 17 years, respectively. PSQI revealed poor quality sleep in 13/20 parents. A range of diabetes-related factors, including glucose monitoring and fear of hypoglycemia, contributed to parental sleep disturbance, including awakenings and the perception of "sleeping lightly". Two distinct time periods resulted in greater sleep disturbance, notably, following T1DM diagnosis and when transitioning to using a new diabetes technology. Factors influencing maternal and paternal sleep were similar, but, generally, mothers described greater night-time care burden and sleep disturbance. While the use of diabetes technologies was generally advocated to improve parental sleep and the provision of nocturnal T1DM care, they were also perceived to potentially contribute to parental sleep disturbance.

Conclusions: Pediatric diabetes care teams should be aware of diabetes-related factors potentially affecting parental sleep, the mixed impacts of diabetes technologies, and consider tailored parental support and education to reduce the burden of nocturnal care.

Background

Type 1 diabetes mellitus (T1DM) is one of the most common chronic illnesses of childhood and requires ongoing intensive management. Parents of children with T1DM assume the majority of responsibility for medical care (Monaghan, Herbert, Cogen, & Streisand, 2012; Monaghan, Hilliard, Cogen, & Streisand, 2009; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002), with parents of young children understandably carrying a greater burden of care (Patton, Dolan, Henry, & Powers, 2007; Sullivan-Bolyai et al., 2002; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). Such aspects of care include frequent blood glucose monitoring, insulin administration and dietary modification to maintain

CONTACT Sara E. Boucher  sara.boucher@otago.ac.nz  Department of Women's and Children's Health, University of Otago, PO Box 56, Dunedin 9054, New Zealand

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optimal glycaemic control and prevent both hypo- and hyperglycemia (Danne et al., 2018; DiMeglio et al., 2018; Smart et al., 2018). Similar to experiences of parents of children with other chronic illness (Meltzer & Moore, 2008), the often complex “around the clock” care and vigilance required to manage T1DM can contribute to parental sleep disturbance and chronic sleep deprivation (Barnard, James, et al., 2016; Herbert, Monaghan, Cogen, & Streisand, 2015; Jaser et al., 2017; Landau et al., 2014; Monaghan et al., 2009, 2012; Sullivan-Bolyai et al., 2003) with subsequent negative impacts on psychosocial functioning (Barnard, James, et al., 2016).

Parents of children with T1DM frequently report poor quality sleep largely attributed to nocturnal blood glucose monitoring (NBGM) (Barnard, James, et al., 2016; Herbert et al., 2015; Monaghan et al., 2012) and fear of hypoglycaemia (Barnard, James, et al., 2016; Herbert et al., 2015; Jaser et al., 2017; Rankin et al., 2016; Sullivan-Bolyai et al., 2003). In a large descriptive study of sleep among over 500 parents of children with T1DM (Jaser et al., 2017), 51% of the parents reported sleep duration less than the 7–9 hours recommended for optimal health (Hirshkowitz et al., 2015). Further, 53% of these parents met criteria for poor quality sleep based upon the Pittsburgh Sleep Quality Index (PSQI) (Jaser et al., 2017). However, these findings are predominantly from cross-sectional survey-based studies and there is currently a paucity of qualitative research exploring the in-depth experiences of parental night-time caregiving behaviors and sleep disturbance. In particular, few studies have explored the breadth and interplay of diabetes-related factors contributing to sleep disturbance among parents of children of varying ages, nor the means by which these factors impact the varying dimensions of sleep. While previous studies have primarily focused on parents of young children with T1DM (Herbert et al., 2015; Jaser et al., 2017; Monaghan et al., 2009, 2012), two recent studies found caregivers of adolescents with T1DM reported similar experiences to caregivers of younger children – with NBGM, diabetes devices and fear of hypoglycemia contributing to poor sleep and low mood (Bergner et al., 2018; Feeley et al., 2019). Further in-depth examination of how the age and developmental stage of children (including adolescents) and how the duration of their T1DM diagnosis affects parental experiences is required. Gaps in knowledge also exist in understanding how experiences and parental roles may differ between mothers and fathers, given previous studies have primarily included only mothers (Barnard, James, et al., 2016; Herbert et al., 2015; Landau et al., 2014; Monaghan et al., 2009, 2012; Sullivan-Bolyai et al., 2002, 2003).

Diabetes technology is rapidly advancing and its uptake is increasing, especially in the use of continuous glucose monitoring (CGM) devices (Foster et al., 2019). CGM technology uses a subcutaneous sensor to continuously measure interstitial glucose levels (as opposed to blood), and has the ability to display retrospective glucose data and alarm at pre-specified out-of-target glucose levels. CGM has been hypothesized to improve night-time caregiving experiences and parental sleep (Landau et al., 2014). However, evidence on the impacts of CGM use in this regard are limited and emergent findings have been conflicting (Barnard, Crabtree, et al., 2016; Jaser et al., 2017; Landau et al., 2014; Lawton et al., 2018; Pickup, Ford Holloway, & Samsi, 2015). In particular, a large descriptive study showed no association between CGM use and parental sleep quality (Jaser et al., 2017) and a small study using actigraphy data indicated increased parental awakening episodes when CGM was used (Landau et al., 2014). Further, another glucose monitoring device often referred to as intermittent CGM (iCGM) or flash glucose monitoring (FGM) is now increasing in use and has been shown to reduce hypoglycemia in adults (Oskarsson et al., 2018). However, it may be less effective for reducing time spent in hypoglycemia in those with impaired hypoglycaemic awareness (Reddy et al., 2018). This device provides similar glucose data to traditional CGM but only when the sensor is scanned with a handheld reader and does not have pre-specified glucose level alarms. The impact of this device upon parental sleep remains unknown.

Finally, gaining an understanding of parental insights and perceptions regarding potential solutions to improve nocturnal diabetes caregiving and parental sleep is important in order to develop acceptable and effective interventions. To our knowledge, there are no established recommendations on night-time diabetes management nor studies exploring interventions to improve sleep in this population of parents. Previous research has suggested young children with T1DM should have their

early-morning (2 a.m.) glucose levels regularly monitored (Porter, Keating, Byrne, & Jones, 1997) and, regardless of age, children with T1DM should have their glucose levels checked during the night in response to changes in their insulin therapy, patterns of consistently high fasting glucose levels (Gan, Albanese-O'Neill, & Haller, 2012) and to detect exercise-induced nocturnal hypoglycemia (The Diabetes Research in Children Network Study Group, 2008). However, night-time care recommendations are intentionally vague to accommodate individual patient differences.

Therefore, the objectives of this study were to explore and describe: the range and interplay of diabetes-specific factors affecting parental sleep; the nature of such sleep disturbance; the respective nocturnal experiences and share of care between mothers and fathers; the impacts of night-time caregiving on daytime functioning that arise due to sleep disturbance; and proposed solutions to decrease the burden of night-time diabetes caregiving and improve parental sleep. Additionally, objective sleep measures from actigraphy and subjective reporting of sleep quality were used to supplement and authenticate the qualitative component.

Methods

Study design

A generic qualitative study design (not guided by an explicit or established set of philosophic assumptions) (Caelli, Ray, & Mill, 2003) was used to explore and describe parents' experiences related to night-time diabetes caregiving and sleep, with the aim of translating new knowledge into clinical practice.

Study setting and participants

The study was conducted in the Otago/Southland region of New Zealand from November 2017 to July 2018, with interviews among mothers taking place in the first half of the study period and interviews with fathers in the second half of the study period. Participants were parents of children with T1DM recruited through the Southern District Health Board pediatric diabetes outpatient clinics (total pediatric diabetes population approximately 170 individuals). The study was described to potential participants as an exploration of parents' experiences of how childhood diabetes may or may not have affected their sleep at any point since their child's diagnosis. Potential participants were informed that they would be asked to complete a demographic and sleep questionnaire, wear an activity monitor for one week and take part in an interview lasting up to 60 minutes. Inclusion criteria were having at least one child with T1DM ≤ 18 years of age and being able to make sufficient time to participate in the interview. Purposive sampling (Etikan, Musa, & Alkassim, 2016) was used to maximize the variation in the study sample. Participant characteristics intentionally spanned sociodemographic and diabetes specific factors selected a priori and informed by the existing literature and investigator expertise in diabetes and sleep. These characteristics included: single- and two-parent households; varying approaches to glucose monitoring and insulin administration; a wide age span across parents' children with T1DM and children's duration of diabetes; and varying levels of current or historical glycaemic control (as measured by glycated haemoglobin; HbA1c), including those ranging from optimal ($\text{HbA1c} \leq 53$ mmol/mol; 7.0%) to significantly suboptimal ($\text{HbA1c} > 100$ mmol/mol; $>11\%$) control. Recruitment continued until each characteristic was broadly represented in the study sample.

Data collection

Interviews

After written consent and demographic data were obtained, interviews were conducted face-to-face in the home of participants, in a clinic research room, or via a videoconference application (Zoom®) by one of two investigators (AY and GM) who were not involved in the usual clinical care of these families. Both

interviewers received the same training, followed semi-structured interview guides informed by the literature and expertise in pediatric diabetes (BW) and pediatric sleep (BG) (see Supplementary Table 2), and were observed (by SB) during two interviews each to ensure consistency in interviewing practices. Mothers and fathers from the same household were always interviewed separately. Interviews were audio-recorded and subsequently transcribed verbatim, de-identified and checked for accuracy. All participants were offered the opportunity to review their transcripts. Each participant received a NZ \$20 grocery voucher as a token of appreciation.

Demographics, sleep, and physical activity

Parents provided basic demographic data on themselves, and their child/children with T1DM, and completed the PSQI questionnaire – a validated 19-item self-report instrument that assesses perceived sleep quality in adults (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989; Carpenter & Andrykowski, 1998). The PSQI has good reliability with high internal consistency (Cronbach's $\alpha = 0.83$) (Buysse et al., 1989). PSQI scores range from 0 to 21, with a score greater than five indicating poor sleep quality (Buysse et al., 1989). PSQI data were not seen prior to qualitative data collection by interviewers, but has been subsequently used to describe sleep experiences of participants more fully. To gather an objective measure of habitual sleep, wakefulness and periods of disturbance, both participants and their children with T1DM were asked to wear an Actigraph® (ActiGraph® wGT3X-BT, Pensacola, USA) accelerometer (activity monitor worn on the non-dominant wrist) for 7 days and nights around the time of their interviews.

Data analysis

All transcripts were independently coded by two investigators (GM and SB). Initial transcripts were manually coded and then all transcripts were re-coded in qualitative data analysis software (NVivo 11 Plus, QSR International Pty Ltd, VIC, Australia) using a framework of pre-determined and inductively generated codes. Inter-coder agreement was assessed by GM and SB who compared codes in order to reach a consensus that all key experiences had been captured. Thematic analysis, as described by Daniel and Harland (Daniel & Harland, 2017, pp. 98–110), followed, with coded segments of data compared for emerging themes through an iterative process of discussion between the research team, until a consensus on categories and themes was reached. Response rates for each theme and subtheme were quantified to aid determination of thematic saturation, as well as to enhance the clarity of the common experiences among parents. The final sample size was determined by relative data saturation, in that, across all interviews and within interviews with mothers and fathers, respectively, no new themes emerged in the final 3–4 interviews within each group of parents. A conceptual model was developed to capture the complexity and interrelations of diabetes-related factors affecting night-time caregiving and parental sleep (Supplemental Figure 3).

Actigraphy data were analyzed in 15 second epochs using a count-scaled algorithm (Galland, Kennedy, Mitchell, & Taylor, 2012) written in MatLabTM (MathWorks, Natick, MA, USA). Sleep onset was scored as the start of the first 15 continuous minutes of sleep preceded by 5 minutes of awake, and sleep offset as the last of 15 continuous minutes of sleep followed by 5 minutes of awake. The scoring definition for wake events was at least 5 consecutive minutes scored as awake preceded by 15 minutes of sleep. Relevant sleep variables included those related to: sleep timing (sleep onset and sleep offset); sleep quantity (Sleep Period Time [SPT] defined as the elapsed time between sleep onset and sleep offset; Total Sleep Time [TST] defined as the time between sleep onset and sleep offset, minus awakenings); sleep quality (Percent Sleep defined as the percent of time asleep between sleep onset and offset $[(TST/SPT) \times 100]$); wake events defined in terms of both frequency (the number occurring across the SPT) and the total duration of minutes spent awake following sleep onset presented as wake after sleep onset (WASO).

Results

Eighteen mothers and 14 fathers were invited to participate in the study. Ten mothers and 10 fathers were interviewed (55.5% and 71.4% recruitment rates, respectively). Of these 20 participants, four sets of parents were from the same household and one mother and father of the same child were separated. Between participants, 16 children with T1DM were involved in the study. Participants ranged in age from 33 to 54 years (mothers' mean age 44.5 ± 7.2 years; fathers' mean age 43.3 ± 6.8 years), were predominantly NZ European/European and married/partnered. Most (9/10) fathers were employed full time whereas 4/10 mothers were employed full time. Participants' children were aged 1 to 17 years (mothers' children's mean age 8.4 ± 4.6 years; fathers' children's mean age 9.0 ± 4.3); diabetes duration ranged from 0.5 to 11.4 years (mothers' children's mean diabetes duration 2.4 ± 2.3 years; fathers' children's mean diabetes duration 3.8 ± 3.5 years). Basic demographic information is displayed in Table 1. Duration of interviews varied from 35 to 61 minutes, with a median of 45 minutes.

PSQI and actigraphy

Nine out of 10 mothers and 4/10 fathers reported poor quality sleep based upon PSQI scores > 5 (Table 1). Actigraphy data were collected for 16/20 parents (mean valid nights 6.2 ± 1.4) and 14/16 children with T1DM (mean valid nights 5.8 ± 1.4). Actigraphy data were missing for the remaining participants due to non-wear and technical issues. Actigraphy sleep parameters for both parents and their children with T1DM are displayed in Supplemental Table 1 using means weighted to reflect differences in the relative contributions of the number of week days vs weekend days. Parental actigraphy data showed that 3/16 parents had an average sleep duration (based on Sleep Period Time/SPT) of < 7 hours. Child sleep duration results demonstrated that 7/14 of children did not have SPTs within two standard deviations of age appropriate normal mean values derived from meta-analytic data (Galland et al., 2018). Actigraphy analysis also indicated those meeting or not meeting appropriate sleep quality recommendations (Ohayon et al., 2017), including: 3/16 parents and 8/14 children having an average wake after sleep onset (WASO) ≥ 41 minutes indicative of poor sleep quality for all age groups in this study; no participant had on average four or more awakenings per

Table 1. Baseline characteristics of participants (and their children with T1DM) and Pittsburgh Sleep Quality Index (PSQI) scores.

Characteristics	Mothers ($n = 10$) ^a	Fathers ($n = 10$)
Age (yrs): mean (SD), range	44.6 (7.2), 33–54	43.3 (6.8), 32–50
Ethnicity: NZ European/European; n (%)	10 (100)	9 (90) ^b
Marital status: Married/Partner; n (%)	8 (80)	9 (90)
Employment: Full-time; n (%)	4 (40)	9 (90)
Household income: $< \$50,000/50\text{--}100,000/>100,000$; n (%)	3 (30)/6 (60)/1 (10)	3 (30)/4 (40)/3 (30)
NZDep2013 ^c Index: median (range)	3 (2–9)	2.5 (1–7)
Age of child with T1DM (yrs): mean (SD), range	8.4 (4.6), 1–17	9.0 (4.3), 3–14
Age of child at T1DM diagnosis (yrs): mean (SD), range	6 (4.4), 0.5–16.1	5.2 (2.9), 0.5–10.0
Time since child's T1DM diagnosis (yrs): mean (SD), range	2.4 (2.3), 0.5–6.5	3.8 (3.5), 0.6–11.4
Child's insulin regimen: CSII ^d /MDI; n (%)	7 (64)/4 (36)	5 (50%)/5 (50%)
Child's glucose monitoring: SMBG/CGM/FGM; n (%)	4 (36)/5 (45)/2 (18)	4 (40)/2 (20)/4 (40)
Pittsburgh Sleep Quality Index (PSQI)	Mothers ($n = 10$)	Fathers ($n = 10$)
Global score: mean (SD), range	8.7 (3.3), 3–15	5.7 (2.8), 3–12
Poor quality sleep (score > 5): n (%)	9 (90)	4 (40)

^aMothers had 11 children with T1DM (as one Mother had two children with T1DM).

^bEthnicity of remaining participant was Māori (indigenous population of New Zealand).

^cNZDep2013 Deprivation Index: a measure of socioeconomic status, 1 less deprived and 10 most deprived (Atkinson, Salmond, & Crampton, 2014).

^dTotal number of children on SAP therapy: $n = 7$ ($n = 5$ and $n = 2$, children of mothers and fathers, respectively); total number of children on FAP therapy: $n = 3$ ($n = 1$ and $n = 2$, children of mothers and fathers, respectively).

Abbreviations: CGM: Continuous glucose monitoring, CSII: Continuous subcutaneous insulin infusion (via an insulin pump), FAP: Flash-augmented pump, FGM: Flash glucose monitoring, MDI: Multiple daily injections, SAP: Sensor-augmented pump; SMBG Self-monitoring blood glucose by way of capillary blood fingerstick test.

night (inappropriate indicator of good sleep quality), and 7/16 parents and 4/14 children had one or fewer awakenings per night (indicating good sleep quality). Two out of 16 parents and 1/14 children had an average percent sleep <85%. In sleep quality recommendations, sleep efficiencies < 85% are considered poor sleep quality (Ohayon et al., 2017) across all ages. Our proxy measure for sleep efficiency (sleep percent), did not include sleep latency in the equation, hence we cannot compare our data with sleep efficiency recommendations with full accuracy. Scatter plots of sleep timing (onset/offset) and sleep duration parameters from individual participants as a function of age are illustrated in Supplemental Figures 1 and 2.

Themes

Themes and sub-themes were identified and grouped into the following four overarching categories: perceived nature of parental sleep disturbance; diabetes-factors affecting parental sleep; impacts of sleep disturbance; and solutions proposed to improve nocturnal T1DM care and parental sleep. The interplay of emergent diabetes-specific factors affecting varying aspects of sleep and the perceived impacts are modeled in Supplemental Figure 3. Additionally, participants' perceptions regarding the respective nocturnal experiences and share of care between mothers and fathers are discussed.

Perceived sleep disturbance related to their child's T1DM illness and care

All participants' sleep had been disturbed at some stage due to an aspect of their child's illness or care requirements. The nature, extent, and duration of sleep disturbance varied both between participants, and temporally for an individual. The dimensions of sleep affected at any point in time included: awakenings (n = 20); difficulty initiating sleep onset (n = 3) or falling back asleep following an awakening (n = 9); delayed bedtimes (n = 7); and the perception of "sleeping lightly" (n = 9). These culminated in perceived reduced sleep quantity and quality, the latter supported by the PSQI data in mothers at least, where almost all (9/10) reached a global score indicative of poor sleep quality (Table 1). Perceived severity and impact of sleep disturbance varied from participants who described few awakenings to others who described repeated and frequent nightly awakenings and the perception of limited restorative sleep. See Table 2 for further details.

Aspects of diabetes care affecting parental sleep

Representative quotes from themes and respective sub-themes within this category are displayed in Table 2. All participants described that nocturnal blood glucose monitoring (NBGM) affected their sleep, by either delaying bedtimes or contributing to awakenings (quote 1). All other identified factors were seen to affect sleep either, via the need to increase the frequency or necessity of NBGM, or independently of NBGM. The four major drivers of NBGM were: fear of immediate harm due to low glucose levels at night (nocturnal hypoglycaemia) (quotes 2, 3); concerns regarding both immediate and long-term harm from elevated glucose levels at night (nocturnal hyperglycaemia and long-term health impacts) (quote 5); variability in their child's daytime diet and exercise (quote 6); and generalized worry for their child's wellbeing (quote 7). These factors also led to repetitive thoughts and worry at night (i.e. nocturnal rumination) for some – affecting sleep directly through difficulties falling asleep and perceived poor sleep quality. A lack of nocturnal hypoglycemia awareness in children, previous experiences of hypoglycemia, and instances of significant fluctuation in their child's blood glucose levels all exacerbated their fear of nocturnal hypoglycaemia. In addition, the frequency or necessity of NBGM also increased due to: variability and unpredictability in their child's blood glucose levels (quote 8); changes in their child's growth or development (quote 9, 10); their child being acutely unwell (quote 11); changes in their child's management regimen or routine; and their own desire for optimal nocturnal blood glucose levels.

Table 2. Diabetes-related factors affecting parental sleep theme: representative quotes.

Theme (n) ^a	Quote (participant number)
Diabetes-related factors affecting parental sleep	
Nocturnal glucose monitoring (NBGM) (20/20)	1) "For the first probably three or four months, it wouldn't be uncommon for me to get up at three a.m. and check her, maybe get up again if I had to, or sometimes I'll just stay up till one or two [AM] to check her and that did impact my sleep quite badly." (14)
Fear of low glucose at night (nocturnal hypoglycaemia) (19/20)	2) "I don't want to wake up in the morning and go to wake her up and she's dead, basically." (10) 3) "I'd hate that she went into a coma, a diabetic coma when she's asleep and I'm asleep in the next room ... you get a bit paranoid about that sort of thing." (15)
Treating high or low glucose (18/20)	4) "I don't want to admit this to you but I never like giving him the full [insulin] dose. I can't get him that low at night. So (partner) works out 6 [units] and I go 'oh don't give him that' so you're thinking about this late at night, it could be quarter to one [AM] ... you really have to wake up at night and think about this sort of thing and what you're going to do." (4)
Concerns for elevated glucose at night (nocturnal hyperglycaemia) (16/20)	5) So we would check her at twelve [AM] and then if that wasn't happy we would check her at two [AM] and then check her at four [AM] ... it's probably because we are pedantic about the whole thing, we just try to minimise damage from sugars overnight." (1)
Variability in daytime diet & exercise (15/20)	6) "It's difficult because if we've had a day camping then we don't eat our normal diet and then her blood sugars are very volatile and those nights are much harder usually because there'll be a huge rise and then a huge drop if she's been exercising, it's just a bit more chaotic." (1)
Generalised worry for child's wellbeing (15/20)	7) "You sleep with that anxiety when he's had a bad night, so I don't always sleep terribly well. I don't go into a deep sleep on those nights unless I'm extremely exhausted, and it's always the apprehension of waking up the next morning and walking in and giving him a shake to wake him up. You know, is he going to ... so it's not pleasant." (2)
Variable/Unpredictable BGLs (15/20)	8) "(Child) was quite sick and he was unstable so his levels would fluctuate quite quickly so we were checking him every night every hour, because his levels would fluctuate so much. We were doing [checks] every two hours when we got [home] from the hospital but he was still having really bad lows and so we were going [to check him] every hour." (7)
Changes in child's growth/development (13/20)	9) "Obviously when his diabetes kicks in and his honeymooning finishes I'll be a bit more vigilant and check every night because it's something that worries you, yeah what's happening during the night." (9) 10) "Yeah when he's having growth spurts that's difficult, that's when we're up a lot [in the night] because obviously we've got no idea whether he's going high, low or indifferent yeah." (18)
Child acutely unwell (13/20)	11) "When she gets unwell it's probably worse because you're up more often checking." (3)
Child or partner waking for care (13/20)	12) "We have noticed that when he is high or when he is low he does tend to wake himself up." (11) 13) "I think I sort of wake when (partner)'s getting up or something's happening or you know yeah, not fully awake but just interrupted sleep." (12)
Diabetes technology (12/20) CGM/iCGM systems & alarms (12/20)	14) "We have the CGM, which is a mixed blessing. In the old days before we had it we would check her before we went to bed and then get up at midnight to check her again to make sure she had no insulin on board, and then we would be quite comfortable to leave her until the morning, but since we've had the CGM it's opened your eyes a bit more to what happens in between when you think she's okay. Sometimes they [BGLs] do a bit of a roller-coaster during the night." (1)
Insulin pump failures/alarms (3/20)	15) "The site failure is always in the back of your mind at night-time because that's when things generally turn to custard with the insulin pump, and that's why I always have a high alarm set." (1)

^an numbers of participants describing each theme/subtheme

Abbreviations: BGL, Blood glucose level; CGM, Continuous glucose monitoring; FGM, Flash glucose monitoring

On occasion, NBGM led to subsequent nocturnal management, including insulin administration. Such decisions were perceived to require an increased level of alertness, contributing to prolonged awakenings or difficulty falling asleep in some cases (quote 4). Compounding this, rumination on the appropriateness of decisions, nocturnal light stimulus, and distress related to upsetting their child by performing NBGM or insulin injections exacerbated difficulties falling back asleep.

Participants stressed the importance of minimizing their child's sleep disturbance in their approach to nocturnal management. Thus, NBGM was almost entirely performed by parents, even for adolescents potentially capable of self-managing overnight. Further, parental sleep was disrupted by their child's awakenings, especially if their child awoke feeling unwell due to hypo- or hyperglycemia (quote 12).

While nocturnal caregiving experiences varied, two distinct periods were associated with an increased burden of care and greater sleep disturbance. The first was immediately after their child's T1DM diagnosis, when parents faced the challenge of learning to manage a chronic illness. Perceived limited support, children who were young at diagnosis, early episodes of hypoglycemia, and significantly fluctuating blood glucose levels all exacerbated nocturnal concerns and sleep disturbance in this period (quote 8). The second period encompassed that of transitioning to, and, using a new diabetes technology. For some participants, the increased ease of access to a substantial amount of glucose information by using newer glucose monitoring technology increased the frequency of NBGM. This was in part due to increased insights into their child's nocturnal trends and subsequent worry from hypoglycemia or hyperglycemia identified while their child was asleep (quote 14). Participants highlighted that it took time before they felt confident using such a device, with this varying from weeks to months. Further, pre-set alarms for out of target glucose levels on glucose monitoring devices and insulin pump technical problems contributed to awakenings (quote 15).

While more participants faced greater sleep disturbance earlier on in their child's illness, particularly when their child was young, not all shared this experience. Others felt that their burden of nocturnal care and sleep disturbance had not improved as their child grew older or had worsened over time due to their child's changing stage of life. For example, one participant worried at night about the safety of their teenage son given his late night socializing and alcohol consumption, while another felt that frequency of their NBGM would increase as their child transitioned out of an initial "honeymoon" phase (i.e., partial remission) of T1DM (quote 9).

Perceived impacts of sleep disturbance

Representative quotes from themes and respective sub-themes within this category are displayed in [Table 3](#). Sleep disturbance affected cognitive functioning, emotional wellbeing and physical health to varying degrees. The majority of participants described fatigue and low energy from nocturnal caregiving and sleep disturbance at some stage in their child's illness (quote 16). For a few participants, this was perceived to have negative physical health impacts, including headaches, poorer dietary choices and reduced exercise (quote 20). In addition, sleep disturbance along with tiredness, affected work performance for half of the participants (quote 18) and resulted in perceived poorer T1DM management decision-making for a few (quote 22). Participants also described negative impacts upon their emotional wellbeing and mood, with tiredness and stress contributing to short tempers, decreased patience and irritability, with associated impacts upon relationships (quote 21).

Proposed solutions to improve nocturnal T1DM care and sleep

A range of potential solutions (or aspects of care) which had made, or were perceived could make, a difference was mentioned. Representative quotes from themes and sub-themes in this category are displayed in [Table 4](#). Importantly, participants highlighted that an improvement in nocturnal T1DM caregiving burden may not necessarily improve their sleep and vice versa.

Table 3. Impacts of sleep disturbance theme: representative quotes.

Theme (n) ^a	Quote (participant number)
Perceived impacts of sleep disturbance	
Fatigue/low energy (17/20)	16) "I just don't get a full night's sleep, ever. I just feel like I'm constantly tired." (5)
Impacts on mood/stress (10/20)	17) "As I said moods probably, stress levels go up when you're tired too because you have less of an ability to handle something." (4)
Impacts on work performance (8/20)	18) "For instance (partner) will ask how work was and I say 'I don't know, I'm just so tired, I can't even function and focus on what I need to be doing at work'. That's how bad it is. I guess for me, I describe it like being in a constant haze sometimes, there's no clarity." (6)
Cognitive impacts (8/20)	19) "With diabetes you have to be so well managed and if you don't have a good night's sleep you can't focus and get work done. I've noticed my memory has lapsed quite a bit, and sometimes I wake up and think if I've organized things. Your head feels like it's spinning especially if it's been a trying night." (9)
Reduced exercise (6/20)	20) "It's just nice to get out and do some exercise but when you're feeling really tired you're oh yeah you know I might give it a miss, but if you had a good night's sleep the night before you'd probably be like oh let's do it." (14)
Impacts on relationships (5/20)	21) "I'm finding you know, particularly when there's a marked difference between when we've had quite a bit of sleep and when we haven't had any sleep, in the way that we all interact with each other and the happiness that flows around the house." (11)
Impacts on diabetes management (4/20)	22) "It might be pertinent to say, if the brain's not working all that well then at night you might not make the most logical decisions, not in a negligent way but just not choosing an easier way. Like the next morning I'll wake up and wonder why I did that ... things like forgetting to bolus after a milo or turning off a basal for two hours instead of one and she wakes up high." (1)

^an numbers of participants describing each theme/subtheme

The use of newer glucose monitoring technology (i.e., CGM and FGM) was described by the majority of participants as offering the greatest benefit. Having access to substantial glucose data and trends were perceived to improve decision-making throughout the night (quote 26). Additionally, being able to view glucose data on receivers or remotely on devices, including smartphones, minimized sleep disruption by enabling participants to check levels while still in bed (quote 27). Further, CGM device alarms gave some participants "peace of mind" that they would be alerted in advance to a potentially serious medical event and therefore improved their perception of overall sleep quality (quote 23, 24). While some participants seemed unaware that this alarm technology existed, others had specifically chosen CGM technology as their preferred monitoring approach for this feature. Importantly, half of participants mentioned that receiving additional funding would improve access to such technology (quote 25). Finally, the use of this technology allowed parents to monitor their child's glucose levels without disturbing their child's sleep, but not necessarily improving their own sleep.

In regards to other technology, half of the participants mentioned that the use of an insulin pump at night had improved nocturnal care. Of these, a number also felt their sleep had improved by being able to achieve tighter control of blood glucose levels overnight (quote 28). Additionally, a couple of participants noted that accessing closed-loop (artificial pancreas) technology would be of substantial benefit to their child's T1DM night-time care and their sleep by potentially eliminating any need for NBGM.

On reflection, participants shared different experiences and opinions regarding the role of night-time management advice from their wider health-care team. Around half of parents suggested clearer guidance around nocturnal care practices, particularly early on after T1DM diagnosis, may have been helpful (quote 29). Others, however, suggested that experience over time was the biggest asset to providing optimal nocturnal care. Further, a number of participants highlighted the importance of sharing nocturnal care between couples (quote 32), and a few parents suggested extra child-care support from family, friends, or a professional carer would be of benefit.

Table 4. Proposed solutions to improve nocturnal T1DM caregiving and parental sleep theme: representative quotes.

Theme (n) ^a	Quote (participant number)
Proposed solutions to improve nocturnal caregiving and parental sleep	
Use of CGM or iCGM systems (18/20) Alarms (12/20)	23) "Yeah, so that's really helpful because it [CGM] alarms if he goes low and high, so that means I do get a lot more sleep just knowing that the machine will wake me if he goes low." (5) 24) "That [CGM] just changed our life completely, because we have the alarms, and the alarms and all go to the phone so yeah, so [I'm] now probably getting up three times a night, not anything like I was, and the only time I'd be getting up is if an alarm has gone off, so they're either low or high and so you actually have a reason to get up rather than just guessing and checking. If we didn't have those, then we would still be doing [checks] two or three hourly, yeah. That [CGM] was definitely a life changer." (7)
Providing funding (10/20)	25) "Oh, it was really reassuring [using the CGM], because then you know what's constantly going on, because when he had that, I wouldn't have to wake him in the night, I could just be checking it myself and it would be fabulous, but it's just the cost at the moment." (2)
Access to increased glucose information and trends (9/20)	26) "It [FGM] monitors through the night so it collects data so if you can track him through the night you can come to some conclusions like he's doing alright, which I would find reassuring and it tells you if he's arrowing up or down so if it's going the right way then yeah, don't have to worry about it so there'd be a bit of comfort in that." (4)
Accessing data on devices (7/20)	27) "I do wake and I do check her receiver which is beside my bed but unless she's high or the alarm goes off for her being low, if she's sitting ok I just roll over and go back to sleep. And it's pretty automatic now. Half the time I don't even know I've done it." (8)
Use of an insulin pump (9/20)	28) "Yeah, certainly the use of the pump has helped because we can alter the background basal to make things a bit more level, a bit more flowing and then yeah, got that control pretty well. It's good especially at night. Night is the one that you know takes its toll on us I suppose." (12)
Nocturnal T1DM management education and support (8/20)	29) "... probably there should be more guidelines from the doctor about how often to test during the night yeah. They might just give a wee bit more peace of mind yeah." (16)
Time and experience (8/20)	30) "It is really hard at the beginning, but it will come right, and you will be able to manage it. It just doesn't seem like that at the beginning and yes you will be getting up and you know, and you will not be getting enough sleep at the beginning which won't help you and it will make you feel like it's harder, but you will get through it. Yep at three months [after diagnosis] you'll look back and you'll be going yeah, starting to manage this now, actually it's not too bad." (14)
Family, friend or carer support (8/20)	31) "I suppose trying to get family on board as soon as you can because if they can go through your learning, well that's going to help you." (2)
Shared nocturnal care (6/20)	32) "It's trying to work out ways to get your sleep and you've got to share it [night-time care]. You can't just leave it to one person to do. Even the child can't do it by themselves either." (18)
Nocturnal glucose monitoring (5/20)	33) "Like if someone told me I couldn't test anymore and I shouldn't it wouldn't change what I need to do to be comfortable; I wouldn't sleep if I didn't test. I need that to be able to sleep, so I think you really have to do what fits for your family and what fits for you." (4)

^an numbers of participants describing each theme/subtheme

Abbreviations: CGM, Continuous glucose monitoring; FGM, Flash glucose monitoring; T1DM, type 1 diabetes mellitus

Other ways of improving sleep unrelated to T1DM care included: catching up on sleep at other times (n = 7), practicing good sleep habits and hygiene (n = 7), increasing exercise (n = 6), relaxation or a pre-bedtime routine (n = 5), and using medicines or supplements (n = 3).

Finally, despite potential solutions, many perceived that some degree of sleep disturbance was unavoidable if they were to provide necessary nocturnal care for their child's health. This was regardless of advice or advances in technology, and seen as integral to caring for a child with T1DM.

While NBGM caused awakenings, some participants reflected that foregoing such checks would significantly reduce their overall sleep quality (quote 33).

Experiences of mothers and fathers

In general, the aspects of diabetes-care influencing maternal and paternal sleep were similar. However, participants more frequently described mothers as having difficulties falling asleep and attaining restful sleep pertaining to worry about their child's wellbeing and care. Such experiences were in part attributed to: mothers providing more of the daytime care of their children; a mother's "natural instincts"; and perceptions that fathers were more easily able to "switch off" or fall back asleep following a management decision at night than mothers.

While many participants shared night-time caregiving between couples, on the whole respondents indicated that mothers carried the greater responsibility for care at night. The reasons for this included: wanting fathers to attain adequate sleep given their work responsibilities (including using heavy machinery); the opinion that mothers were more conscientious with T1DM care; the child's preference for their mother; and the fact that many mothers felt that they slept "lightly" and would be awoken easily anyway. However, a number of fathers – particularly in cases where a child's parents were separated and the father was the primary caregiver at times, or when their partner was away – described similar sleep disturbance and night-time caregiving responsibility. Accordingly, those participants (mothers and fathers, alike) with greater burden of night-time care understandably described more frequent negative impacts from disturbed sleep.

Discussion

To our knowledge, this is the first qualitative study to provide an in-depth examination of the aspects of childhood and adolescent diabetes care affecting parental sleep, to explore the respective night-time caregiving experiences of both mothers and fathers, and to consider parental perspectives on solutions to improve both their sleep and night-time care. Overall, our findings highlight the varying impacts childhood diabetes can have upon parental sleep. These impacts are multidimensional, and while issues contributing to parental sleep disruption may evolve over time and with changing developmental phase (e.g. infant vs teenager), aspects of parental sleep disruption appear to continue irrespective of child age and development.

Reflecting previous research (Feeley et al., 2019; Herbert et al., 2015; Jaser et al., 2017; Landau et al., 2014; Monaghan et al., 2009, 2012; Sullivan-Bolyai et al., 2003), participants' narratives and PSQI scores suggested considerable sleep disturbance, leading to detrimental effects on daytime functioning for some parents. Additionally, although this study was not designed to statistically compare actigraphy data with normative values, or sleep recommendations, it is noteworthy that mean actigraphy values recorded from parents (and their children) for the number of overnight awakenings >5 minutes reached National Sleep Foundation recommendations of "uncertainty" as an indicator of poor sleep quality (Ohayon et al., 2017). This finding perhaps warrants inclusion of actigraphy in future studies of caregivers' and childrens' sleep as a complement to self-reported sleep characteristics.

As demonstrated in our model, we highlight the myriad and interplay of aspects of childhood T1DM perceived to be affecting parental sleep. The level of detail and nuances provided would not have been captured with survey-based research. Of the themes that emerged, NBGM (Barnard, James, et al., 2016; Herbert et al., 2015; Monaghan et al., 2012), fear of nocturnal hypoglycaemia (Barnard, James, et al., 2016; Herbert et al., 2015; Jaser et al., 2017; Rankin et al., 2016; Sullivan-Bolyai et al., 2003), and use of diabetes technology (Barnard, Crabtree, et al., 2016; Barnard, James, et al., 2016; Landau et al., 2014; Lawton et al., 2018; Pickup et al., 2015) have previously been associated with parental sleep disturbance. However, a number of emergent themes - including variability and unpredictability in blood glucose levels, variability in children's exercise and diet, and changes in children's growth and development - to our knowledge, have not previously been described in existing literature specifically related to parental

sleep. While Barnard et al. (Barnard, James, et al., 2016) found that parental awakenings were infrequently attributed to hyperglycemia fear, our study suggests that concerns for both hyperglycemia and hypoglycemia are major drivers of NBGM. Thus, means by which blood glucose level variability and excursions can be reduced, including through the use of emerging diabetes technology (Elleri et al., 2010), may offer the potential for significant parental sleep improvement, but clearly requires further investigation.

Our study illuminates both the way in which parental sleep is affected, as well as the dimensions of sleep impacted. The understanding and distinction that parental sleep was seen to be impacted in two ways – through the need to perform or increase the frequency of NBGM and independently of it – is noteworthy. Such observations may be helpful and relevant when considering the development of interventions to improve sleep in this population. For example, potential behavioral interventions suggested to reduce parental fear of nocturnal hypoglycemia (Monzon, McDonough, Meltzer, & Patton, 2018), may have dual benefit – by reducing perceived poor sleep quality attributed to hypoglycemia worry, as well as reducing the perceived necessity or frequency of NBGM and subsequent awakenings.

Reflecting previous research, the period following a child's T1DM diagnosis understandably brings many new challenges for parents, not least sleep disturbance due to concerns for a child's wellbeing overnight and T1DM management requirements (Rankin et al., 2016). However, the finding that sleep disturbances may also exacerbate around the time their child starts using a new diabetes technology – prior to gaining confidence and familiarity with using such a device overnight – may offer helpful new insights, as well as explanations for previously conflicting evidence (Landau et al., 2014). Given some participants advocated for increased nocturnal T1DM management education, guidelines and support, pediatric diabetes care teams could consider targeting families during these two specific time periods.

While glucose monitoring technology, and to a lesser degree insulin pumps, were advocated to improve participants' sleep and the provision of nocturnal care, the potential for these devices to contribute to sleep problems should be discussed with families. Similar to previous research (Lawton et al., 2018; Pickup et al., 2015), CGM system features were perceived in our study to improve the quality of parental sleep. However, like others (Barnard, Crabtree, et al., 2016; Lawton et al., 2018; Pickup et al., 2015), we found that alarms on devices also contributed to awakenings. Additionally, as postulated by Monaghan et al. (Monaghan et al., 2009), increased access to substantial glucose information overwhelmed some parents, particularly early on in device use, leading to an increase in NBGM and associated sleep disturbance.

As reflected in a recent study of caregivers of adolescents with T1DM (Bergner et al., 2018), our study found that parental sleep disturbance was not only limited to those with young children, but influenced by factors across all age groups including growth spurts and changing developmental stages. Finally, in accordance with findings of greater maternal stress and burden related to T1DM caregiving (Hansen, Weissbrod, Schwartz, & Taylor, 2012; Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011), our study illuminated differences in the share and impact of night-time caregiving – with maternal sleep more often affected (due to an often greater role in primary caregiving). As such, increasing the share of nocturnal care between parents/caregivers where possible was suggested by participants and could be encouraged by pediatric diabetes care teams.

This study had a number of strengths, including a rigorous in-depth exploration of maternal and paternal sleep and night-time caregiving experiences amongst a sample that is broadly representative of mothers and fathers from diverse households, and supplementation with actigraphy. However, it is not without limitations. As with qualitative studies, the interpretation of results is limited to the study sample and we cannot claim that the results of this study include all possible themes and subthemes regarding parental sleep and night-time experiences. The sample may be biased towards families who regularly attend diabetes clinic visits and perceive diabetes caregiving at night as being particularly detrimental to themselves or their spouse/partner in regards to sleep quality and the impacts of poor sleep. However, the inclusion of both mothers and fathers with a range of different household structures

and care arrangements, and diversity in their children's age and diabetes characteristics, helps to provide and clarify a range of parental experiences – reinforcing and supplementing existing literature. While four sets of parents interviewed were from the same household, this is unlikely to impact the validity of our findings as themes were explored across the entire data set. Given the potentially sensitive nature of mental, physical and spiritual health, we may have missed how some of these aspects of health interplay with night-time experiences and the impacts of sleep disturbance. If anything, potential omissions, may underestimate the severity of the impacts of sleep disturbance. Given parents reflected on changes to their sleep since their child's diagnosis – rather than sharing their experiences over repeated interviews – it is likely their recall may not have been entirely accurate. However, experiences shared by parents of older children when their children were younger mirrored those experiences of current parents of younger children with T1DM. Further, within actigraphy data, we did not account for daytime napping (in parents nor children) and thus sleep duration parameters could have been underestimated. Finally, while we did not exclude participants based upon pre-existing health conditions which have the potential to exacerbate or compound sleep problems, potential co-morbidities do not negate the narratives provided and provide rich real-world experiences.

Future directions for research could include corroboration of this data with longitudinal survey designs, complemented by actigraphy collection. Such research could include larger parent–child samples to investigate within-person changes to sleep over time, including the impacts of a child's age and developmental stage and child's diabetes-specific changes, as well as further quantitative work investigating the impact of hypoglycemia and newer diabetes therapies on sleep. These studies could include validated questionnaires for hypoglycemia as well using both actigraphy and polysomnography.

Conclusion

Pediatric diabetes teams should be aware of diabetes-related factors potentially affecting parental sleep, encourage shared nocturnal care between caregivers/parents, and consider tailoring nocturnal T1DM management education and support to reduce the burden of night-time care for such families. This study provides an understanding of the specific time periods in which additional education and support may be most beneficial, namely, the period immediately after their child's T1DM diagnosis and when transitioning to using a new diabetes technology. Newer diabetes technology has significant potential to improve both parental sleep and nocturnal T1DM care, however, families should be aware of the potential for such devices to also contribute to sleep disruption. Future research should use longitudinal observational study designs among representative study samples to elucidate within-parent/caregiver changes to sleep over time.

Abbreviations

CGM, Continuous glucose monitoring; CSII, Continuous subcutaneous insulin infusion (via an insulin pump); FAP, Flash-augmented pump; FGM, Flash glucose monitoring; iCGM, Intermittent continuous glucose monitoring; MDI, Multiple daily injections; NBGM, Nocturnal blood glucose monitoring; NZDep2013, New Zealand Deprivation Index 2013; PSQI, Pittsburgh Sleep Quality Index; SAP, Sensor-augmented pump; SMBG, Self-monitoring blood glucose; SPT, Sleep Period Time; T1DM, Type 1 diabetes mellitus, WASO, Wake After Sleep Onset.

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No potential conflict of interest was reported by the authors.

Ethics approval

The study was approved by the University of Otago Health and Disability Ethics Committee (Ethics ref: H17/129)

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ORCID

Grace C. Macaulay  <http://orcid.org/0000-0003-2641-3359>

Sara E. Boucher  <http://orcid.org/0000-0002-8358-881X>

Barbara C. Galland  <http://orcid.org/0000-0002-2376-3575>

Benjamin J. Wheeler  <http://orcid.org/0000-0003-3348-5238>

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