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Around-the-clock: Caregiving at night for juveniles living with type 1 diabetes – a systematic review

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ABSTRACT

Caring for children with type 1 diabetes (T1D) can require around-the-clock attention but there is little acknowledgment of the impact that nocturnal caregiving can have on caregivers in clinical care provision. This systematic review aimed to (1) explicate nocturnal caregiving practice (NCP) by identifying and synthesising peer-reviewed research to establish the prevalence and nature of NCP, (2) explore the impacts of NCP for caregivers, (3) evaluate the perceived value of technology for supporting NCP, and (4) examine potential solutions for mitigating NCP burden. In January, 2022, the databases CINAHL, MEDLINE, Web of Science, PsycINFO, Scopus and EMBASE were searched to identify peer-reviewed studies, published in English since 1997, which addressed NCP for juveniles with T1D. Quantitative, qualitative and mixed-methods studies were included. Risk of bias analysis was carried out using the quality assessment with diverse studies tool. Where possible, quantitative data were aggregated. Qualitative data was subjected to a narrative synthesis, using thematic analysis. Thirty-one studies met inclusion criteria, comprising 3,547 caregivers. 88% of caregivers engaged in NCP, though frequency was variable. Over 50% of participants (19–80%) failed to get adequate sleep and 54% reported poor sleep quality. Qualitative testimony detailed adverse impacts of NCP; exhaustion, difficulty making illness-management decisions, negative impacts on mood and physical health. Benefits from technology were equivocal. Evidence regarding predictors and associations for NCP, such as patient age, was contradictory. 83% of authors recommended that sleep be routinely addressed in clinic, which is not current practice. This review provides clear evidence that NCP in T1D is pervasive with significant negative impacts on caregivers. These secondary impacts of juvenile T1D need to be acknowledged so that care guidelines can be modified and psychosocial supports can be developed for use in clinical treatment environments.

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Background

Type 1 diabetes (T1D) prevalence rates are increasing, particularly among children under 5 (Patterson et al., 2019). Currently, one in 400–600 children globally will receive this diagnosis (Mobasseri et al., 2020). Juvenile T1D puts an enormous strain on families (Jaser et al., 2009) with management in children more difficult than in adults (Herbert et al., 2015; O'Hara et al., 2016). The difficulties of maintaining stable blood glucose and the consequences of not achieving this control are well documented (Diabetes Control and Complications Trial Research Group, 1993; Fullerton et al., 2014; Kahanovitz et al., 2017).

Successful illness management and better health outcomes for juveniles can be dependent on quality of caregiving (Schunk et al., 2015), which is a 24-h responsibility (Streisand & Monaghan, 2014). In delivering round-the-clock care, parent caregivers can experience multiple night-time wakings, while illness-related stress may also contribute to sleep disturbance (American Diabetes Association, 2018). Current international clinical care guidelines do not address night-time caregiving or illness monitoring specifically (Silverstein et al., 2005). For example, the updated Clinical Practice Consensus Guidelines from the International Society for Paediatric and Adolescent Diabetes (ISPAD.org, 2018) acknowledges distress in parent caregivers, emphasising the need to provide support to promote better diabetes management, though no reference is made to potential impacts of nocturnal caregiving. This is not surprising, as nocturnal caregiving has received very little attention in the research literature to date (Ji et al., 2021).

Use of diabetes illness-management technology has significantly changed the treatment landscape for T1D in recent years, with clear benefits for overall illness management (Naranjo et al., 2016). However, while continuous glucose monitors (CGM) and closed-loop technologies are promoted to reduce nocturnal care burden, the degree to which technologies in their present form moderate or mitigate nocturnal caregiving challenges is uncertain (Cobry et al., 2022). In addition, significant variance in technology uptake has been observed; this appears to be due to cost and availability as well as personal choice (Naranjo et al., 2016).

Objectives

This review aimed to identify and synthesise research on nocturnal caregiving for juveniles with T1D in the home setting, with five research questions:

(1) What is the prevalence of nocturnal caregiving practice (NCP) among parent caregivers?
(2) What is the lived experience of NCP among parent caregivers?
(3) What are the impacts of NCP on parent caregivers and on diabetes-related health outcomes for juveniles?
(4) What is the efficacy, impact and perceived value of technological innovations for reducing the burden of nocturnal caregiving?
(5) What are the potential solutions for supporting caregivers in managing this burden?

Methods

The review protocol was registered with PROSPERO in January 2022 (CRD42022298562). Reporting follows PRISMA 2020 (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Page et al., 2021; see supplementary materials Table S1 for PRISMA checklist).

Eligibility criteria

Inclusion and exclusion criteria were developed using the SPIDER framework (Cooke et al., 2012): The sample of concern was parent caregivers for juvenile patients diagnosed with T1D (0–18 years), excluding parents of children with comorbid conditions or samples with undifferentiated type 2 populations. The phenomenon of interest was nocturnal illness management activities, classified as any action that would not occur without the existence of a diagnosis of T1D, taking place after the juvenile has gone to bed and before both parties (caregiver/patient) would normally rise in the morning. There were no restrictions placed on research design. Research evaluation of any caregiver physical or mental health outcomes or any patient diabetes-related physical health outcomes were considered, but not specialist endocrinologic or other biomedical endpoints. Quantitative, qualitative and mixed-methods research, published in the English language, in peer reviewed journals, since 1997 was considered. See supplementary materials (Table S2) for further detail on inclusion and exclusion criteria.

Information sources and search strategy

The following databases were searched in January 2022: MEDLINE (Ovid), Web of Science (Clarivate), CINAHL and PsycINFO (EBSCOhost), Scopus and EMBASE. Reference lists of key publications were reviewed to confirm that all relevant data was captured. The search strategy was developed in collaboration with a specialist subject librarian using related terms harvested from literature published in the area (specifically, terms relating to type 1 diabetes AND paediatric OR juvenile AND caregiver OR parent AND nocturnal OR sleep). A sample database search is included in the supplementary materials (Table S3).

Selection process, data collection process and data items

Retrieved records were uploaded to Endnote (version 20). The literature was screened digitally in Endnote for duplicates and checked by the primary researcher, deletions were made where appropriate. All screening of remaining titles, abstracts and texts was carried out by two researchers working independently. Initially, titles and abstracts were screened to establish whether the publications met eligibility requirements. Some deletions were made. Following this, the full texts of remaining publications were screened for eligibility. Where opinions did not align, researchers discussed discrepancies until they were resolved. Thirty-one studies were deemed eligible to be included in the review.

A data extraction form was developed and piloted on a randomly selected subset of eligible publications. Data was then extracted from all eligible

publications in duplicate, ensuring that all data points were captured. Data extraction categories included: Demographic and illness-related variables (patient – age/haemoglobin A1c [biochemical marker for blood glucose control]/duration of diagnosis; participant – gender/SES/relation to patient); illness management regimen (use of technology, multiple daily injections); methods and methodologies (quantitative, qualitative, mixed methods, data collection tools); any reported findings relating to nocturnal caregiving activities (sleep quantity and quality, impacts, drivers and characteristics of the behaviours); researchers' conclusions and recommendations.

Study risk of bias and reporting bias assessment

The quality assessment with diverse studies (QuADS) tool was selected to assess study quality because it facilitates quality assessments across mixed study reviews and places equal emphasis on methodology and reporting domains (Harrison et al., 2021). Inter-rater reliability was established as substantial ($k = 0.67–0.91$), as was face and content validity in health research contexts (Harrison et al., 2021). The tool rates each paper across 13 criteria with each scored between 0 and 3, the range of potential total scores is 0–39. The tool does not provide indicative score categories and scores are interpreted in relation to the overall body of scores (studies). The review was carried out by two reviewers, working independently.

Synthesis methods

This research utilised a narrative synthesis methodology, following guidance by Popay et al. (2006). Due to the complex nature of the phenomenon being explored by a heterogeneous group of studies, individual research questions were addressed by utilising a variety of analytic techniques associated with the narrative synthesis methodology and which were deemed appropriate for achieving the research objectives. Techniques included; aggregating descriptive statistics and scores for similar measured variables across studies (e.g. actigraphy studies), clustering studies by theme to aggregate findings, interpreting data using narrative text, calculating weighted frequencies (vote-counting) and weighted means where possible, tabulating heterogeneous data by theme (e.g. sleep disruption) for comparative analysis. Qualitative data was synthesised using thematic analysis, whereby data was aggregated to create higher-order categories of overarching themes. Data were tabulated and presented with illustrative quotes. Subgroup analyses (e.g. technology use; moderating variables) used aggregated descriptive statistics and narrative syntheses where relevant to the review aims. Due to the heterogeneous nature of the subject field, a variety of measurement modalities were employed, these were included or excluded from the synthesis as appropriate. Outlying or ill-fitting data was summarised and placed within the context of the field of knowledge. A more detailed outline of six phases involved in the narrative synthesis process is provided below.

Outline of narrative synthesising process

Phase 1. The five research questions outlined in the introduction were developed based on a review of the background literature and in consultation with a panel of experts by lived experience (i.e. caregivers of juveniles with T1D), who were purposively recruited using convenience sampling ($n = 4$). Due to the broad, heterogeneous nature of the enquiry and data captured by the search, researchers selected a 'narrative synthesis' approach as the best-fitting option for keeping the data synthesis focused and for facilitating a predominantly textual approach to interpreting the data.

Phase 2. Articles resulting from the database search and screening process were read multiple times so that researchers could familiarize themselves with the key concepts, constructs and approaches employed for data gathering/interpretation.

Phase 3. A preliminary map of the evidence, as it pertained to each of the research questions, was developed. Potential lines of evidence-based argument were explored.

Phase 4. Researchers considered the relationships between findings (contradictory or complementary) and studies were clustered to address the individual research objectives. A plan for syntheses that were deemed appropriate for pooled quantitative and qualitative data was devised iteratively (details above).

Phase 5. A framework was developed to guide the process of reporting the narrative synthesis, this comprised a series of themes, linking data to research questions, bridging quantitative and qualitative findings and driving interpretations.

Phase 6. Robustness of the synthesis was supported by consultation with a panel of experts by lived experience ($n = 4$).

Results

Study selection

A total of 878 studies were found following the database search. Following duplicate removal, the titles and abstracts of 480 records were screened. Of these, the full-texts of 93 articles were assessed. This led to 31 studies being included in the review (see Figure 1).

Summary of selected studies

Studies comprised a total of 3,547 caregivers. Twenty-one studies were quantitative in design, 7 qualitative and 3 mixed-methods. Six studies utilised actigraphy technology to gather objective data on sleep. Six reported purposively recruiting primary caregivers and one study recruited maternal caregivers only. Female gender was reported by 77–100% of caregiver participants. A summary of study characteristics is available in the supplementary materials (Table S4).

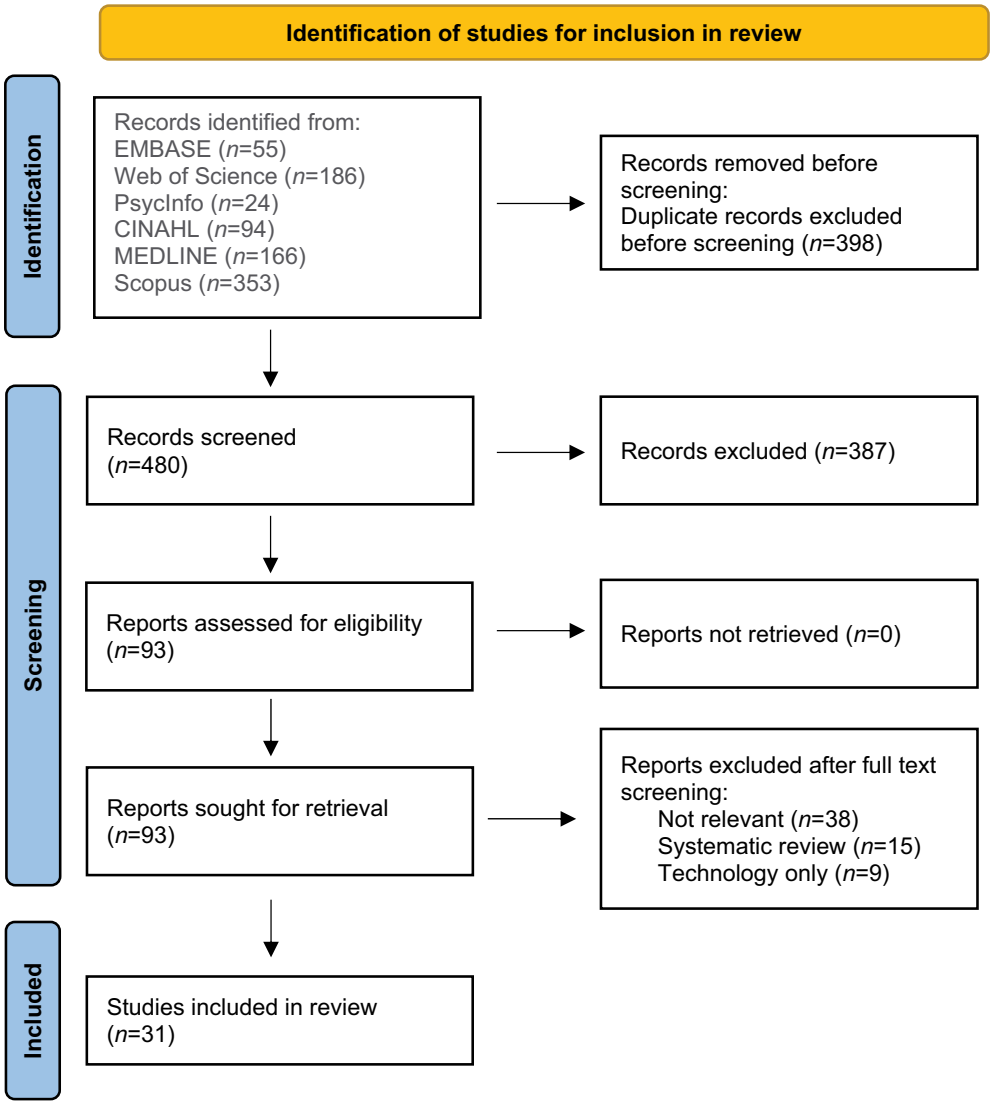

Figure 1. PRISMA 2020 flow chart.

Quality assessment: study risk of bias and reporting bias

QuADS scores ranged between 24 and 37 (mean 30.7), adhering to a normal distribution with no strong outliers (see Table S5 in supplementary materials). None of the studies were assigned a zero mark for any criteria. Studies performed well when considered in relation to the high-level research design criteria, e.g. 'clarity around key concepts', and also in relation to higher-level reporting, e.g. 'sufficient detail in statement of aims'. Scores were more variable for detailed criteria in methodological domains such as; 'provision of recruitment data'. In some instances, reporting on criteria, e.g. 'rationale for choice of data collection tool/s', tended toward the descriptive rather than provision of a rationale. In the

context of this analysis, it is notable that the poorest ratings were given for criteria 12; 'evidence that research stakeholders have been considered in research design or conduct', with only 10% of studies scoring 2 or above. Though none of the studies was ranked at a level that would cause concern and require the exclusion of data, a moderate risk of selection bias cannot be discounted and broader generalizability of some findings are potentially equivocal.

Data synthesis

Prevalence of NCP

To establish a foundation for understanding the importance of this research topic the review's primary aim was to explore the prevalence to which NCP was a feature of caregiving for juveniles with T1D. Fourteen studies, comprising 1,635 participants, as well as 5,000 downloads of data from a diabetes blood glucose monitoring databank, provided information on this (see Table S6 in supplementary materials for a detailed report). Eleven studies reported the percentage of parents engaged in NCP, with a weighted aggregate percentage mean of 88.3% (n = 1,301). However, there was notable variation in frequency of practice. Significant numbers of participants engaged in NCP nightly, with a number documenting multiple daily NCP events. For example, Barnard et al. (2016) in study 1, found that 33% of participants engaged in NCP every night, with 27% doing so more than once per night. Moderate levels of NCP were reported in some studies; utilising a very large sample of downloaded data (n = 4990) in study 2, Barnard et al. (2016) found that 24% of participants were engaging in NCP 3–6 nights a week, while Sinisterra et al. (2020) found that 63% of participants engaged in NCP 3+ times per week. Other studies reported significantly lower frequencies; in Haugstvedt et al. (2011), only 27% engaged in NCP ≥ 1 per week, though in this sample cohort, mothers and fathers were equally represented and the primary caregiver was not identified.

Understanding the lived experience of NCP

Synthesis of data from 16 studies that investigated some aspect of the lived experience of NCP led to the identification of three themes; characteristics of NCP, drivers of NCP, predictors of NCP (see Table 1).

Theme 1. Characteristics of NCP. At a high-level, NCP is understood as; 'caregivers monitoring and/or responding to overnight blood-glucose excursions'. Seven studies provided detail on the practice; postponing caregiver bedtime in response to low or high blood glucose readings (Bergner et al., 2018), waking early to facilitate a pre-bolus of insulin to cover their child's breakfast (Carreon et al., 2021), setting alarms to carry out NCP tasks and/or responding to prompts or alarms from technology (Bergner et al., 2018; Feeley et al., 2019). Nonetheless, there was a paucity of data overall on the granular detail of NCP. A single study, Barnard et al. (2016), surveyed NCP prompts (n = 251 approx.), finding that 35% woke to monitor blood glucose; 22% woke in response to an alarm; 15% in response to a hypoglycaemic event; and 2% in response to a hyperglycaemic event. In each scenario, illness management was required (children woken to consume fast-acting carbohydrates or administration of insulin, follow up monitoring).

Table 1. Characteristics and drivers of NCP with illustrative quotes.

Theme 1: Characteristics of NCP	
Quotes	'If she's low before she goes to bed . . . 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' (Bergner et al., 2018) 'Morning time, I have to get him up earlier just to make sure he's got medicine in him and snack before we leave' (Carreon et al., 2021) 'I am sometimes up every 2 hours to correct the highs and lows' (Feeley et al., 2019) ' . . . try to stay awake because if I fall asleep I might not hear my alarm to test again' (Feeley et al., 2019) 'Higher numbers for my boys to ensure sleep for myself is sometimes a necessary trade off, but never a comfortable one' (Oser et al., 2017) 'Normal alarm settings for years now include two-night checks then @ 6.30am, normal life still begins' (Walker et al., 2016) 'Waking up to check lows requires waiting to make sure the BS are coming up. I have a hard time falling back to sleep' (Feeley et al., 2019) 'I'll probably stay up a couple of hours to make sure he moves [glucose rise/fall] . . . .I would say per week I probably lose about 7 hours, maybe more' (Bispham et al., 2021)
Theme 2: Drivers for NCP	
Sub-themes	Quotes
Anxiety	'Well, I feel worried every time she goes to sleep' (Carreon et al., 2021). 'I don't want to wake up in the morning and go to wake her up and she's dead, basically' (Macaulay et al., 2020) 'I have this image of a ship going through a very narrow strait with very high sharp rocks on either side . . . at night-time you never really know what is going to hit' (Sullivan Bolyai et al., 2003)
Hypoglycaemia mitigation	'I'd rather be tired than my son going into a coma because blood dropped too low' (Barnard et al., 2016) 'Sometimes I have trouble waking him when [he's] low and it is stressful'(Feeley et al., 2019) 'My sleep is broken into 2 to 3 hours at a time to check him if he's low' (Feeley et al., 2019)
Hyperglycaemia mitigation	' . . . we just try to minimise damage from [high] sugars overnight' (Macaulay et al., 2020)
Variable mediating factors	' . . . if she's sick I set my alarm to make sure I'm up every 4 hours to check her sugar around the clock' (Bergner et al., 2018). ' . . . we don't eat our normal diet and then her blood sugars are very volatile' (Macaulay et al., 2020) ' . . . there'll be a huge rise and then a huge drop if she's been exercising, it's just a bit more chaotic'(Macaulay et al., 2020) ' . . . how much insulin he has on board is important, and . . . how recently he ate matters too' (Bispham et al., 2021)
Theme 3: Predictors and associations for NCP	
Sub-themes	Findings
Duration of Illness	Conflicted (Feeley et al., 2019; Lindström et al., 2011; Macaulay et al., 2020; M. C. Monaghan et al., 2009)
Patient's age	No relationship found (Feeley et al., 2021; Harrington et al., 2017; Macaulay et al., 2020)
Fear of hypoglycaemia	Higher FoH was associated with poorer sleep (Abitbol & Palmert, 2021; Herbert et al., 2015; Jaser et al., 2017)

Theme 2. Drivers of NCP. Among data on 'drivers for practice of NCP' found in seven studies, the most prevalent theme was 'hypoglycaemia mitigation'; participants were aware of the significant harms that could result when blood glucose levels drop below target levels; some participants feared seizures at night and even death, while others had previous experiences that drove their concerns or had children who they felt were hypo-unaware (didn't wake when glucose level dropped precipitously). The second sub-theme expands on the first and speaks to participants' experience of 'anxiety', which encompasses fear of hypoglycaemia, as well as generalized worry and nocturnal rumination. Some participants felt that worries were experienced most strongly after diagnosis or when transitioning to a new treatment regimen, while for others the worry changed in nature but was nevertheless persistent through the duration of caregiving experience. In

the third sub-theme 'hyperglycaemia mitigation', participants were driven to engage in NCP in order to administer insulin as mitigation against long-term impacts of high blood glucose. The desire to 'optimise' blood glucose control by engaging with it 24 h a day emerged as a driver also, though this was not a prominent concern, as illustrated in Barnard et al. (2016); where researchers found 17% of participants were driven by fear of hypoglycaemia and only 0.5% reported concerns related to hyperglycaemia. In the final sub-theme 'variable mediating factors', participants identified variable personal factors, recognised to impact on stability of patient blood glucose levels, which drove NCP for some. Examples included; day-to-day variations in diet and exercise and impacts of hormonal changes associated with developmental stage.

Theme 3. Predictors and Associations for NCP. Limited, sometimes contradictory, findings on predictors or associations for NCP were found:

Duration of illness. Macaulay et al. (2020) found that sleep disruption reduced with duration of diagnosis, other findings indicated that sleep duration actually increased with longer duration of diagnoses (Feeley et al., 2019; Monaghan et al., 2009). Feeley et al. (2021) found no significant relationship between the two and relatedly, Lindström et al. (2011), found no association between caregiver burnout and duration of illness.

Patient's age. Studies explored the association between child age and caregiver sleep (or NCP), with concordant findings. In Feeley et al. (2021) no significant relationship between age and parent sleep was found and in Harrington et al. (2017), age was not a predictor of perceived burden (including sleep interference) in three patient age cohorts. In Macaulay et al. (2020) authors stated that though NCP evolves over time, it endures irrespective of age.

Fear of hypoglycaemia (FoH). FoH was associated with sleep in a number of studies; in Herbert et al. (2015), parents experiencing greater hypoglycaemia worry reported greater sleep disruption through NCP, while in Jaser et al. (2017), greater FoH was linked to higher NCP and sleep deficits, although NCP frequency was not associated with parent sleep quality. Similarly, associations between higher FoH and more frequent overnight checks as well as diminished sleep quality and daytime fatigue were found in Abitbol and Palmert (2021).

Impacts of NCP on parent caregivers and diabetes-related health outcomes for patients

Impacts on caregiver sleep. Thirteen studies measured sleep quantity achieved by caregivers. Studies used a variety of approaches, including self-report sleep duration, objective sleep-duration data collected using actigraphy technology, and the percentage of participants who reported sleep disruptions linked to NCP (see Table S7 in supplementary materials for tabulated results).

Self-report and objective data on sleep quantity. High variability in self-reported sleep quantity was found, with percentages of participants falling below the threshold for

adequate sleep ranging between 19% and 80%. Moreover, aggregated self-report data on total nightly sleep duration found a mean sleep duration of 6.42 h, which falls short of the recommended 7–9 h. Data from actigraphy studies (presented in supplementary materials, Table S8) was aggregated to show a mean total sleep sime of 6.85 h ($n = 106$). In adults, sleep efficiency (SE) of 95% is indicative of a good night's sleep. For the aggregate group, SE was 87.49%, which indicates a moderately poor night's sleep. The wake after sleep onset (WASO) score for the aggregate group ($n = 66$) was 37.26 m (9.1%). Normal adult scores are below 10% or 42 min of a 7-h sleep. Finally, in the vast majority of self-report data (98%), 51.3% of participants were not reaching recommended sleep duration. Notably, aggregated actigraphy data on sleep duration returned a similar weighted mean of 50.21% sleeping <7 h.

Sleep quality. Eleven studies deployed the Pittsburgh Sleep Quality Index to explore caregiver sleep quality (see Table S9 in supplementary materials). With a global score range of 0–21, a score of >5 is considered to be an indicator of a clinically significant level of poor sleep (Buysse et al., 1989). Fifty-four per cent of 663 parent caregivers returned scores >5, while the mean global score was 7.06 ($n = 404$), Macaulay et al. (2020) found a notable difference between maternal and paternal scores (8.7 and 5.7, respectively). Five studies reported on the percentage of caregivers ($n = 790$) who agreed that NCP disrupted their sleep, with a mean of 59.9% (range 58–79%). In addition, Burckhardt et al. (2019) asked 60 participants to rate the impact of NCP on sleep on a 7-point scale (0=never; 7=always); the median recorded score was 5, suggesting significant impact. In Lindström et al. (2011), of participants scoring over a threshold for clinical burnout, 64% of mothers and 38% of fathers reported NCP driven sleep disruption. Finally, a study of maternal caregivers ($n = 75$) found 49.3% slept less than the required 7 h, in comparison to 26.5% of controls ($n = 49$) (Bahadur et al., 2022).

Other impacts for caregivers from NCP. Barnard et al. (2016) documented other reported impacts of NCP; exhaustion (60%), poor concentration and lack of focus (28%), next day poorer performance (22%), bad mood and impatience (17%), anxiety and depression (16%). Similarly, Macaulay et al. (2020), found that sleep disturbance affected cognitive, emotional and physical health to varying degrees; fatigue (85%), mood and stress (50%), work performance (40%), cognitive function (40%), exercise (30%), relationships (25%), and lastly, impacting on diabetes management (20%).

Six studies contained relevant qualitative data, several made reference to the experience of 'sleep problems' resulting from NCP; reduced ability to fall asleep (Bergner et al., 2018) or to return to sleep after NCP (Feeley et al., 2019). Analysis of qualitative data identified three novel themes; 'Physical Impacts', 'Social and Emotional Impacts' and 'Impacts on illness management' (see Table 2). Physical consequences from sleep disruption were extensive and included; exhaustion, poor concentration, poor performance at work, daytime dysfunction, cognitive deficits, stress, weight gain, poor lifestyle choices, migraines, difficulties driving, low energy and health problems. Social and emotional impacts included; poor mood, anxiety, depression, feeling isolated, emotional distress, worry, reduced wellbeing, low patience, irritability and negative impacts on relationships. In addition, across studies, some participants spoke about the effects of sleep disturbance on T1D illness management.

Table 2. Impacts from NCP: themes and quotes.

Themes	Quotes
Physical and cognitive impacts	'Exhaustion. It is torture' (Barnard et al., 2016) ' . . . some nights the exhaustion holds me like a straight-jacket . . . ' (Oser et al., 2017) 'Well, it definitely makes me tired. During the day I feel like you're back in the stage where you have a new-born and you're up all the time' (Carreon et al., 2021) 'I can't even function and focus on what I need to be doing at work' (Macaulay et al., 2020)
Emotional and social impacts	' . . . affects relationships with family and friends as not enough energy. One of my friends said 'it has lost a part of me'' (Barnard et al., 2016) ' . . . every 2 hours waking up is hard. I mean, it makes me really cranky the next day' (Bergner et al., 2018) ' . . . moods probably, stress levels go up when you're tired too because you've less of an ability to handle something' (Macaulay et al., 2020) ' . . . 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' (Macaulay et al., 2020)
Impacts on illness management	' . . . it's hard to make good decisions when you are exhausted' (Barnard et al., 2016) 'I have bolused her . . . in the middle of the night out of habit . . . she should only be getting a correction' (Barnard et al., 2016) 'When I reach the point of utter exhaustion, I will let high numbers go uncorrected if it means I get a few more minutes of sleep' (Barnard et al., 2016) ' . . . if the brain's not working all that well then at night you might not make the most logical decisions . . . ' (Macaulay et al., 2020) ' . . . I'll wake up and wonder why I did that . . . things like forgetting to bolus . . . or turning off basal for two hours instead of one and she wakes up high' (Macaulay et al., 2020)

Impact on Health-Related Outcomes for Patients. In Monaghan et al. (2012), researchers looked to establish whether frequency of NCP could have a positive impact on illness outcomes, utilising A1c as a proxy for illness management, no relationship was found. Similarly, in De Beaufort et al. (2021), researchers found no association between parental sleepiness and A1c and in Monaghan et al. (2009), no differences were found in A1c between those who engaged in NCP rarely/never, sometimes or often/always. Furthermore, findings from other studies suggest that parents of children with higher A1c scores (suggesting poorer blood glucose management) had worse sleep (Feeley et al., 2021; Herbert et al., 2015; Morrow et al., 2022).

Value of technology for reducing nocturnal burden

Three studies utilised actigraphy to measure the effect that use of illness-management technology (CGM; closed loop) had on caregiver sleep quantity (Bisio et al., 2021; Cobry et al., 2020; Landau et al., 2014). Participant testimony enhanced these findings with qualitative data.

Quantifying the impact of technology on caregiver sleep. Aggregated findings from the technology group showed a total sleep time of 6.51 h, SE of 88.3% and WASO of 37.5 min (see Table S10 in supplementary materials). Two studies reported pre- and post-technology intervention actigraphy data; with aggregate total sleep times of 6.43 h and 6.27 h, respectively, indicating that no benefits for sleep were found for these cohorts (Table S11 in supplementary materials).

Caregiver experience of technology and sleep. Eight studies gathered qualitative data on nocturnal caregiving while exploring the effectiveness of technology-based interventions for illness management (total $n = 194$; see Table 3). Themes have been

Table 3. Themes and sub-themes for perceived value of technology for reducing burden of NCP.

Sub-theme (%)	Caregiver quotes
Theme 1: Benefits of technology	
Improved sleep (100%)	'I started to feel human again, rejuvenated, could tackle the world, I was getting sleep' (Feeley et al., 2019). 'I sleep better, I am calmer' (Monaghan et al., 2009) 'First time we as parents were able to sleep the night straight since diagnosis' (Lindström et al., 2011)
Reduced anxiety (88%)	'We were sleeping better because we had that safety and more comfort' (Haugstvedt et al., 2011) 'I can go to sleep as it will go off if she has a low' (Feeley et al., 2019)
Positive impact on NCP (50%)	'Not sort of either having to check on her every 2h' (Feeley et al., 2019) 'I can just roll over have a quick look and go back to sleep. So you're getting up less, possibly waking more' (Haugstvedt et al., 2011) ' . . . not having to drag yourself out of bed testing at 2 or 3 o'clock in the morning . . . ' (Abitbol & Palmert, 2021)
Reduced nocturnal hypos (38%)	' . . . less hypoglycaemia because at night time we would have that alarm to stop it from happening . . . ' (Haugstvedt et al., 2011)
Better control (38%)	'The whole next day her blood sugar would be great' (Barnard et al., 2016) 'Numbers were perfect'/'Didn't want to give it back' (Abitbol & Palmert, 2021)
Sharing of burden (38%)	' . . . it made him [partner] more present and more able to have a role in the care' (Feeley et al., 2019)
Theme 2: Costs & barriers	
Technology issues (63%)	'Sometimes we just find it's disconnected, and we don't really know why' (Haugstvedt et al., 2011) 'Sometimes in the middle of the night the signal is lost . . . the CGM won't beep' (Herbert et al., 2015)
Trust and accuracy (38%)	' . . . I check the blood . . . those differences scare us' (Jaser et al., 2016)
Alarms as mixed blessing (38%)	' . . . it wasn't giving accurate readings and it was alerting the whole house a thousand times' (Herbert et al., 2015) ' . . . we had a problem . . . it was alarming all the time' (Abitbol & Palmert, 2021) 'Somewhere, a CGM alarmed and into the story enters Diabetes as a main antagonist' (Oser et al., 2017)
Constant flow of data (25%)	' . . . too much information'/'It fed into the fact that I was so anxious about it. It kinda wasn't worth it for me' (Herbert et al., 2015)
Physical discomfort (25%)	'The insertion system I think is horrific. It's a big needle. It's gonna hurt' (Herbert et al., 2015) ' . . . she'd to wear this great big sensor, the pumps and then this great big computer' (Barnard et al., 2016)

given representative frequencies (x/8), presented as percentages. Two overarching themes were identified; 'Benefits' and 'Costs & Barriers', with a number of sub-themes in each.

The strongest finding, present as a theme in all eight studies, was that sleep improved through use of technology. In the main, participants found that requirements to engage with NCP were reduced or made more manageable, for instance, in Elbalshy et al. (2020) participants reported that easy access to blood glucose levels and information on trends, as well as alarms, reduced disease burden and improved sleep quality. However, significant numbers of participants found that technology increased their nocturnal burden of care by prompting increased night-time vigilance through availability of data and alarms (where research alarm settings were reported there was wide variation (Burckhardt et al., 2018)). Lastly, in Cobry et al. (2020), 17% of participants left the study as they experienced the technology as disruptive.

Solutions and recommendations

Data across all the studies in the review was analysed in order to generate recommendations for potential interventions and approaches to mitigate or moderate nocturnal caregiver burden. This was achieved by examining both the participant caregiver perspective and the conclusions drawn by the studies' authors.

Solutions from the caregivers' perspective. With the exception of McCaulay et al. (2020), generating qualitative data on potential solutions or approaches to address NCP burden was not a stated aim of any of the studies. Nonetheless, considerable data was identified to address this. Analysis revealed two dominant sub-themes. Firstly, a desire among participants for 'access to technology'; 'He has a glucose monitor that will alarm of [sic] he goes too low or too high so there have been nights that I've slept all the way through' (Carreon et al., 2021). Indeed, 50% of participants in McCaulay et al. (2020) were optimistic about the potential for technologically supported, blood-glucose measuring and remote monitoring to relieve nocturnal burden, although authors' note that 'some [participants] were unaware that this technology existed'. In addition, there is some evidence that parents with greater 'fear of hypoglycaemia' utilised more technology, the direction of this relationship is uncertain (Van Name et al., 2018). The second sub-theme was 'support', which was also seen as key to burden relief, for example, caregiver advocacy blogs and online peer support were experienced as helpful; '[Peer support] knowing there are others out there going through the same things helps other people so much' (Oser et al., 2017). Overall, shared responsibility for primary caregiving as well as respite opportunities were considered to be the most helpful options. Furthermore, participants felt that clearer guidance from the diabetes clinic would be beneficial. In Sullivan Bolyai et al. (2003), some caregivers felt that this aspect of caregiving was not recognised in clinical care settings, and it was found that mothers with the least support resources (internal and external) experienced more anger and overwhelm.

Solutions from the researchers' perspective. Across 23 relevant papers within the review, conclusion sections and recommendations were analysed thematically to explore the proposed changes that authors felt could potentially reduce NCP burden or increase benefits for this caregiving cohort (see Table 4).

The first theme; 'Addressing Nocturnal Caregiving Routinely in Clinic' was prevalent in 70% of studies. Among the sub-themes, 'ask about it' had strongest representation. Offering non-specified support or intervention in clinic was also strongly represented as a sub-theme, while more specified intervention suggestions included; sleep education, improved guidelines for nocturnal care, promoting shared care duties and a more nuanced approach to education on the benefits of technology. A second theme 'Research and Innovation' had two dominant sub-themes; 'predictors and associations for NCP', where research to explore modifiable characteristics was envisaged, and; 'value of technology', where further and more detailed exploration of the potential for technology to ease the burden was proposed. Lastly, it was proposed that future research would benefit from the inclusion of objective data collection on sleep using actigraphy technology.

Table 4. Author conclusions and recommendations.

Sub-themes	Quotes
Theme 1: Address nocturnal caregiving routinely in clinic (83%)*	
Ask about it (70%)	'Given how common sleep disturbances are in this population, diabetes care providers should ask about sleep as part of routine clinical practice . . . ' (Morrow et al., 2022) 'Partnership with the family is key to providing parents with the support and recognition that they deserve, considering the care they are providing' (Sullivan Bolyai et al., 2003)
Offer support or behavioural interventions (44%)	' . . . intervention for sleep and mental health can increase the quality of life of both the children with T1DM and their parents' (Bahadur et al., 2022) ' . . . family-based interventions, aimed to support parents in managing their child's diabetes have had positive effects on glycaemic control as well as parent-child relationships' (De Beaufort et al., 2021)
Promote realistic view of technology (22%)	' . . . families should be aware of the potential for such [tech] devices to also contribute to sleep disruption' (Macaulay et al., 2020). ' . . . mixed blessing of frequent information about BF levels and increased opportunities for fine-tuning management' (M. C. Monaghan et al., 2009)
Sleep education (26%) and caregiving guidelines (17%)	'Health-care providers are in a unique and important position to reinforce the importance of sleep' (Feeley et al., 2021) 'Parents would likely benefit from guidelines regarding night-time T1D management' (Herbert et al., 2015)
Encourage sharing of burden (9%)	'Paediatric diabetes teams . . . encourage shared nocturnal care between caregivers/parents' (Macaulay et al., 2020)
Theme 2: Research and innovation (57%)	
Predictors and associations for NCP (44%)	' . . . analyse associations between . . . [A1c] and treatment-related variables' (Haugstvedt et al., 2011) '[explore] factors causing sleep disruption' (Bispham et al., 2021) ' . . . understand how poor sleep affects the health outcomes of parents' (Bispham et al., 2021)
Value of technology to ease nocturnal burden (26%)	' . . . fully investigate the effect of new diabetes devices such as CGM and insulin pump on sleep and behaviour' (Bahadur et al., 2022) ' . . . impact of these devices on parental sleep warrants further evaluation . . . ' (Cobry et al., 2021)
Actigraphy (22%)	'It is recommended that objective measures of sleep, such as actigraphy, be incorporated in study designs . . . ' (Herbert et al., 2015)

*Themes and sub-themes are given representative frequencies (x/22) to deepen interpretation, these are presented as percentages.

Discussion

This review has firmly established NCP as a common feature of caregiving for juveniles with T1D among a large sample of caregivers ($n = 3{,}547$), echoing the concerns voiced by researchers working with smaller sample populations that T1D is 'a disease that requires 24-hr vigilance' (Feeley et al., 2019; $n = 22$). It has shown that NCP generates a sustained and significant burden for caregivers that has real-life impacts, which are in line with those experienced by caregivers for children with other chronic diseases; 'depression and anxiety . . . elevated rates of negative daytime functioning' (Meltzer & Moore, 2008). This is particularly unwelcome, when considered, in light of the knowledge that poor caregiver wellbeing can also impact negatively on children's physical and mental health outcomes (Pierce et al., 2017; Pena-Shaff et al., 2023) and that poor parental sleep quality has been associated with lower self-efficacy for diabetes management (Herbert et al., 2015).

The review found significant levels of variability in NCP among the studies (Abitbol & Palmert, 2021; Barnard et al., 2016; Monaghan et al., 2012). Establishing the aggregated mean across this large sample group was valuable. For international care guidelines to acknowledge this aspect of the caregiver experience, a clear picture of behaviour patterns is required. A reasonable summary of this evidence proposes that approximately a third of caregivers engage in NCP infrequently or never (Monaghan et al., 2012), a third with moderate frequency (Burckhardt et al., 2019) and a third frequently (always or multiple-times nightly) (Herbert et al., 2015). This was the case despite the inclusion of secondary caregivers in some larger study cohorts (Haugstvedt et al., 2011; Lindström et al., 2011). This aligns with the limited studies in the area, which do 'consistently demonstrate that parents of children with T1D experience poor sleep quality' (Perez et al., 2018). Nevertheless, the scale of the issue is striking, particularly when considered in the context of the findings on impacts for caregivers that are reflected in the qualitative evidence, e.g. 'It's 24/7. There's never a break. There's never a vacation' (Carreon et al., 2021).

Overall, findings indicated that NCP was rarely addressed by healthcare professionals (HCPs) in clinical care provision (Feeley et al., 2021; Macaulay et al., 2020; Sullivan Bolyai et al., 2003) and that the consequences for caregivers are often underappreciated by HCPs (Barnard et al., 2016). A number of authors in the studies reviewed speculated on the cause; Feeley et al. (2019) felt that clinicians had a large amount of information to impart and therefor NCP may be overlooked, Macaulay et al. (2020) felt that recommendations for NCP were deliberately vague to accommodate individual differences, while Haugstvedt et al. (2011) argued that it was challenging for HCPs to find a balance between delivering realistic information regarding risk without potentially stimulating fear and anxiety in parent caregivers. It is likely that all the arguments provide valid explanations of contributory factors. Furthermore, several authors in the review agreed with Silverstein et al. (2005), noting that globally, clinical care guidelines do not address nocturnal caregiving or provide recommendations (Bergner et al., 2018; Carreon et al., 2021; Herbert et al., 2015; Jaser et al., 2017; M. Monaghan et al., 2012), in addition, 29% of the articles made explicit reference to the lack of supporting literature, describing NCP as 'overlooked' and 'understudied' (Abitbol & Palmert, 2021; Bispham et al., 2021; Carreon et al., 2021; Feeley et al., 2019; Macaulay et al., 2020).

Enquiry into variables that may moderate or predict the behaviours did not appear to identify any substantially influential factors, with studies reporting contradictory findings. For example; the lowest proportions of participant caregivers engaging in NCP (68%) utilised one of the youngest sample patient cohorts in the review (mean 4.5 year) (Monaghan et al., 2009), but in Jaser et al. (2016), with a patient sample of similar age profile (mean 4.1 year), 100% of the caregivers reported engaging in NCP. These findings are indicative of the complexity of the issues at play. We know that a deep understanding of behavioural determinants is key for the development of behavioural and psycho-social interventions in the health domain (Bauman et al., 2002), this review clearly indicates that more, high-quality research is needed to explore the causal relationships.

Arguably, the most important body of data to emerge from this review relates to the impacts from NCP. Unsurprisingly, the most direct impact from NCP is on caregiver

sleep. Interestingly, in Carreon et al. (2021), no questions on sleep were posed but nevertheless, 68% of parent-caregiver participants mentioned it in their responses. At a higher-level, it is notable that in the review sample overall, more than half of participants were not achieving the recommended sleep duration of 7–9 h. To appreciate the significance of this finding it is important to recognise that 7 hours is the *minimum* requirement for sleep (Hirshkowitz et al., 2015). This research provides a cross-sectional analysis of what is, in actuality, an ongoing experience that may potentially endure for years (Sousa et al., 2023). In Feeley et al. (2019), participants reported that they required 8.5 h sleep per night to feel their best.

As far back as 2003, authors Sullivan-Bolyai et al., stated that a particularly important finding from their study was the health problems that caregiving mothers attributed to the burden of providing around-the-clock care to their child. Although Feeley et al. (2019) noted that 'meaningful questions' need to be asked about the health of sleep-deprived caregivers and Macaulay et al. (2020) reported some physical health impacts from sleep disturbance, surprisingly little data was gathered in the intervening years on caregiver personal physical health and its association with chronic sleep disturbance.

Prevalence levels of NCP appear to remain consistent whether technology (CGM. CSII) is utilised or not, which aligns with emerging literature (Aouchiche et al., 2024; Macaulay et al., 2020). Furthermore, this time aligning with evidence on the value of technology for beneficial non-medical outcomes in T1D (Bahadur et al., 2022; Jaser et al., 2017; Perez et al., 2018), the review found contradictory evidence on the impact of technology on caregiver sleep, which interestingly, did not appear to translate into a negative user experience. Indeed, Landau et al. (2014) reported that although nocturnal awakenings increased with use of CGM, self-perception of sleep quality remained unchanged. Qualitative data on the perceived value of technology was also conflicted (Abitbol & Palmert, 2021; Haugstvedt et al., 2011) but it suggested that a powerful mechanism for improved caregiver sleep (and tolerance for physical burden associated with technologies) may be located in the psychological benefits of reduced anxiety found with automated blood glucose monitoring, bolusing and alarms (Abitbol & Palmert, 2021; Feeley et al., 2019; Haugstvedt et al., 2011). Indeed, across the studies, the majority of participants were willing to sustain some increased burdens (sleep or other) in order to achieve reduced anxiety or illness benefits for the patient (Carreon et al., 2021; Landau et al., 2014). This is an important insight, given the significant levels of associated burden documented here, and in the literature (Tanenbaum et al., 2023). Finally, growing evidence on the closed-loop system (combining the technologies) strongly suggests that it is 'a promising device' for addressing the NCP burden and improving caregiver sleep (Perez et al., 2018). While more positive developments are anticipated, it is important to remember that a digital divide exists here as elsewhere. Research must be cognisant that significant numbers of caregivers/patient dyads will not have access and that not all children will choose or will tolerate the technologies (K. Gajewska, 2022; K. A. Gajewska et al., 2021).

Limitations

Due to the heterogeneous nature of data collection methods among included studies, it was not possible to carry out overarching meta-analyses. Also, variations in eligibility

criteria across studies may have impacted on the data. The quality assessment highlighted a lack of stakeholder involvement in the research (only 10% of studies scoring 2 or above). With caregiver lived experience the focus of many enquiries, it is likely that patient experts could have offered useful insights to drive research design. In addition, few of the studies reported purposive recruitment of primary caregivers, hence findings may to some degree represent the amalgamated experience of primary and secondary caregivers. Lastly, mean HbA1cs of patient samples, in many studies, were not representative of the general population of juveniles with T1D.

Conclusion

It is clear that these findings provide powerful evidence that issues related to NCP are pervasive and significant negative impacts are endured. Nineteen studies (83%) proposed that addressing NCP routinely in clinical care was key to supporting this community of caregivers. Information to direct stakeholders on approaches to alleviating this burden are contained in this group of studies, further work is needed that responds to this evidence.

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Author contribution statement

SC, RM and VH conceived, designed and planned the study. VH carried out the data search, data analysis and drafted the manuscript. EDB, JDK and ND carried out independent secondary screening reviews of literature returned by the search. SC and RM helped shape the research by providing critical feedback to support the iterative process of developing a final manuscript.

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