

## A SECONDARY ANALYSIS OF A SYSTEMATIC LITERATURE REVIEW ON NOCTURNAL CAREGIVING FOR JUVENILES WITH TYPE 1 DIABETES - FROM THE PERSPECTIVE OF THE LIVED EXPERIENCE

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### Abstract

The nocturnal caregiving burden for parents of juveniles with Type 1 Diabetes (T1D) is significant but underexplored in research to date. To address this, a systematic literature review (SLR) was carried out to capture and aggregate relevant data. This paper describes a secondary, mixed-methods analysis of the 31 publications identified in this SLR, utilising an ‘engaged research’ approach, whereby a patient-researcher carried out the analysis in collaborations with a panel of patient experts. The aim was to respond to the research, interpret the findings and identify issues, through the lens of lived experience. Using thematic analysis, five high-level themes were identified: 1. Distributed knowledge; 2. Maternal burden; 3. Are these conclusions relevant for me?; 4. What about the confounders?; and 5. Outstanding questions. Findings could be helpful for directing future research designs in juvenile T1D and facilitating study outcomes that more accurately reflect the concerns and interests of parent caregivers and their children. This research has demonstrated the value of patient participation in every stage of the health research process.

**Keywords:** *Paediatric Type 1 Diabetes, nocturnal caregiving, engaged research, PPI.*

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### 1. Background

Type 1 Diabetes (T1D) is a chronic autoimmune disease, typically diagnosed in childhood. Prevalence rates vary globally, but approximately 1 in 400–600 will receive a diagnosis (Mobasserri et al., 2020). Caring for children with T1D requires around-the-clock care, but little attention has been given to the impact that nocturnal caregiving practice (NCP) has on families. In 2022, a systematic literature review (SLR) was carried out by the authors to explicate nocturnal parental caregiving for juveniles with T1D. This review also aimed to establish the prevalence of NCP, explore associations and predictors, impacts and the role of technology (Howard, Maguire & Corrigan, 2023). The current paper is a commentary on high-level themes and issues that were identified across the body of included literature from the perspective of a researcher with close personal experience of the condition, in collaboration with a PPI (patient and public involvement) expert panel.

### 2. Methods

Thirty-one peer-reviewed papers were included in the SLR (21 quantitative, 7 qualitative, 3 mixed-methods; n = 3,547 parent caregiver participants). A secondary analysis of these publications and the SLR findings was carried out, taking a constructivist standpoint and utilising a thematic analysis methodology. The analytic process was multi-staged and iterative. Stage 1: The patient-researcher carried out an incipient analysis. Stage 2. Initial findings were presented to an expert panel of caregivers for juveniles with T1D (n=4) for discussion and feedback. Stage 3: A Delphi method process (iterative questioning, summarising, questioning) refined diverse opinions to reach a consensus understanding (Linstone & Turoff, 1979). Stage 4: A second focus group facilitated discussion on a high-level rationale for interpreting the analysis, leading to the development of five themes.

### 3. Findings

#### 3.1. Theme 1: Distributed knowledge

Given the collaborative nature of T1D care (patient/caregiver with HCP), as well as the active role required of the patient/caregiver, it was surprising that only two studies referenced stakeholder input in the methodology. Quality assessment found only 10% of the studies were deemed to be of moderately-high quality or above for the item that identifies; ‘evidence that stakeholders have been considered in the design or conduct’. One study developed a questionnaire with a multi-disciplinary team including individuals with T1D, while another developed research materials with a team of experts, but no patients (Barnard et al., 2016; Bergner et al., 2018, cited in Howard et al., 2023).

#### 3.2. Theme 2: Maternal burden in nocturnal caregiving

Across studies reporting caregiver participant gender, 77-100% were female. Interestingly, samples including more fathers appeared to capture a different profile of caregiving behaviour. In Haugstvedt et al., (2011, cited in Howard et al., 2023), utilising a sample that was 48.5% male, only 27% of all the participants engaged in NCP  $\geq 1$  per week - the lowest rate found in the studies reviewed. Given that few caregivers report sharing night-time duties and that more equal division of burden with greater appreciation of a partner’s efforts decreased maternal emotional distress (Feeley et al., 2019; Haugstvedt et al., 2011, cited in Howard et al., 2023), highlighting issues related to gender and caregiving roles is necessary to identify and prioritise targets for intervention and discern requirements for support.

#### 3.3. Theme 3: Is this about me: To what extent are the findings generalisable?

The review included 23 studies that reported mean sample HbA1cs (n=2,889). Only one study, Jaser (2017, cited in Howard et al., 2023), used a sample from a clinic and reported both the sample mean A1c and the full, clinic-wide mean A1c (7.8% and 8.4% respectively). The clinic mean serves as a good reference for comparison across the other studies; two studies reported sample means of 8.4%, two reported means above 8.4% and most (n=19) reported mean A1cs below 8.4% (lowest = 7.2%). These are not insignificant variations, as shown by the EDIC (epidemiology of diabetes interventions and complications) observational study where a 1% HbA1c increase was shown to be equivalent to an increased risk of T1D complications, which was equivalent to 5.6 - 18 additional years of living with T1D (Bebu et al., 2020).

#### 3.4. Theme 4: What about the confounders?

Analysis of studies, revealed a number of issues or confounding factors, challenging the credibility of some findings for patient-researchers. Lived-experience suggests that the variables identified below would have almost certainly influenced study outcomes if they were not controlled for.

**Treatment regimens.** Many caregivers have experience of a variety of treatment regimens; syringes, insulin pens or pumps for dosing, finger stick blood glucose testing, flash or continuous glucose monitors. Each scenario brings different burdens and challenges. These data were undifferentiated in the majority of studies, making it difficult to find the resulting conclusions convincing.

**Alarm settings and target ranges.** Few studies reported these. For example, Buckhardt et al., (2018, cited in Howard et al., 2023) found that among 49 participants; “most chose a low alert setting between 3.1 and 5.3, and high alert between 8.0 and 20.0”. Where programmed settings on illness-management tools are not explicitly referenced or vary to this degree, it’s difficult to draw meaning from some of the research outcomes.

**Honeymoon period.** The ‘honeymoon period’ is the time it takes for the diseased pancreas to stop producing insulin entirely. During this time illness management can be significantly easier as indigenous insulin is still being produced. It is commonly regarded that a honeymoon period can last up to one year (Sokołowska, Chobot, & Jarosz-Chobot, 2016). While most of the studies referenced a minimum required length of time since diagnosis in their recruitment criteria, these varied significantly (3–12 months), weakening the evidence as the inclusion of ‘honeymooning’ data may obscure and/or dilute findings.

#### 3.5. Theme 5: Outstanding questions of significant interest to caregivers

**Effectiveness of NCP.** Important questions for parents are whether NCP benefits their child’s health and, if it does, what the optimum levels are for balancing burdens with benefits. Only two authors addressed the first question (Monaghan, 2012, 2009; De Beaufort et al., 2021, cited in Howard et al., 2023), with none addressing the second question. No relationship between caregiver sleep and better patient health outcomes was found, however this does not align with lived experience or with evidence across the studies as a whole, where high levels of NCP were found (88% across participants) and, as detailed above, the patient group reported significantly better health outcomes (as measured by A1c) than clinic means.

**Hyperglycaemia.** *Hyperglycaemia* management and mitigation is almost never mentioned in the NCP literature. Feeley et al., (2019, cited in Howard et al., 2023), uses the labels ‘anxiety about blood glucose levels’ and ‘anxiety about hypoglycaemia’ interchangeably, despite the fact that these are not in effect the same thing because ‘blood glucose levels’ could be low (hypoglycaemic) or high (hyperglycaemic). For some parents, the benefits of tight management of hyperglycaemia during the night means that day-time management can afford to be slightly less restrictive. Not all parents can engage at this level. It would be helpful to have the benefits of this facet of NCP justified and validated by the research.

**Myth of overnight blood glucose stability.** Throughout the literature reviewed, there was a marked absence of discussion on overnight blood glucose stability. Evidence is growing, through use of new glucose monitoring technologies that supports what many caregivers have known from their own experience, which is that much greater nocturnal fluctuations in blood glucose occur overnight than previously thought (Gardner et al., 2023). Research is required that responds to these findings.

**Secondary harms for caregivers.** Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane & Grey et al. (2003) noted that caregiving mothers reporting health problems that they attributed to the impact from caregiving burden. Only three of the other studies identified by the review, from the following 20 years of research, acknowledged this issue and the majority of data referenced was only captured when caregivers incidentally reported impacts from NCP.

#### 4. Discussion and conclusion

This novel approach to engaged research found that the body of literature on nocturnal caregiving for juveniles with T1D contains unintentional biases and confounders that somewhat limit its generalizability and utility. These findings suggest that health-related research would benefit from designing study protocols that incorporate the highest level of patient involvement (driving and directing the work), which will then be more acutely attuned to the specifics of the lived experience, thereby building a more robust evidence base, leading to interventions that have greater acceptability and effectiveness for the target population.

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