Bedtime Story - nocturnal caregiving for juveniles with Type 1 Diabetes

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Background

- Type 1 Diabetes (T1D) is an autoimmune disease typically diagnosed in childhood
- One in 4-600 juveniles diagnosed annually, Ireland is at the higher end of diagnoses¹
- Diagnoses have been increasing at an alarming rate,
 particularly among the under 5s²
- Nocturnal illness management plays a crucial role in health outcomes for juveniles with T1D³
- Nocturnal caregiving practice (NCP) receives minimal attention in research and treatment guidelines⁴
- Consequently, very little is on offer to support this highly burdened population

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Establish the

prevalence of NCP

among parent

caregivers of T1D

Detail the characteristics of NCP

Explore impacts on caregiver sleep and understand the real-life consequences

Establish an understanding of caregiver requirements for support

Methods

Study 1 Systematic Review of literature exploring NCP in T1D (completed)

Study 2

A multi-phased, mixed-methods study, driven by public and patient involvement (PPI)

Phase 1

Online Survey - exploring findings from the systematic review in the Irish context

Phase 2

Individual semi-structured interviews and focus groups investigating potential solutions for support

Systematic Review - Findings

31 Studies met inclusion criteria

Population 3,547 caregivers

88% engaged in NCP

Significant variability in NCP

1/3 NCP Rarely or Never

1/3 Moderate NCP 3+ per week

1/3 Frequent NCP
≥ 1 nightly



Impacts on sleep

- Over 50% of caregivers (19-80%) below threshold for adequate sleep
- 54% scored for poor sleep quality on the PSQI⁵
- 60% reported significantly disrupted sleep

Caregivers say...

"Some nights the exhaustion holds me like a straight jacket... "...every 2 hours waking up is hard. I mean, it makes me really cranky the next day"

"...it's hard to make good
[illness management] decisions
when you are exhausted

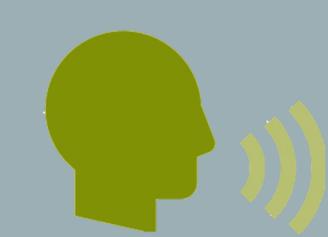
"One of my friends said 'it has lost a part of me



"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

"I can't even function and focus on what I need to be doing at work

Researchers say...



"diabetes care providers should ask about sleep as part of routine clinical practice...

> 82% of Authors Agree

Discussion



- Supporting the development of care guidelines to include protocols for acknowledging NCP within clinical settings
- Later studies will use co-design principles to explore a potential support solutions and explore their feasibility with stakeholder input
- Findings from this study will have applications for other cohorts burdened by nocturnal caregiving responsibilities, such as those caring for individuals living with dementia, physical disability or ASD.







