Plan Overview

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Title: The Night-time Experiences and Sleep of Children and Young People Living with Type 1 Diabetes and their Siblings: A Qualitative Study.

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Project abstract:

Qualitative evidence on the sleep and nighttime experiences of children and young people with T1D is relatively sparce and mostly focused on CYP and caregivers' accounts, rather than CYP-only approaches. Across existing studies, a pattern can be observed: disrupted sleep is reported, in the majority, due to diabetes-related factors. This includes overnight T1D management, glucose monitoring, fear of hypoglycemia, device alarms, and adolescents' increasing responsibility for nighttime diabetes self-management (e.g., Bowen et al., 2024; Macaulay et al., 2019; Bergner et al., 2018). The role of diabetes technology is mixed. Families often see assistive technology as a facilitator of sleep, but they also describe it as a source of disturbance (e.g., Hart et al., 2022; Kimbell et al., 2022; Macaulay et al., 2019).

The present study will employ Reflexive Thematic Analysis (RTA, Braun & Clarke, 2023) to explore the sleep and nightime experiences of CYP with T1D and those of their siblings without the condition.

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Copyright information:

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The Night-time Experiences and Sleep of Children and Young People Living with Type 1 Diabetes and their Siblings: A Qualitative Study.

Administrative Data

Please define an ID for your DMP.

S3BV

Which funder are you applying to?

N/a

What is the title of your project?

The Night-time Experiences & Sleep of Children and Young People Living with Type 1 Diabetes and their Siblings: A Qualitative Study.

Briefly describe your project.

Families caring for a child or young person (CYP) living with Type 1 Diabetes (T1D) often face nighttime demands related to the condition (e.g., glucose monitoring, alarms, fear of hypoglycaemia, etc.), all of which may disrupt sleep across the household. However, few studies have examined this relationship across the wider family system – and particularly with regards to siblings.

Furthermore, qualitative evidence on the sleep and nighttime experiences of children and young people with T1D is relatively sparce and mostly focused on caregivers' accounts, rather than CYP themselves. Across existing studies, a pattern can be observed: disrupted sleep is reported, in the majority, due to diabetes-related factors. This includes overnight T1D management, glucose monitoring, fear of hypoglycemia, device alarms, and adolescents' increasing responsibility for nighttime diabetes self-management (e.g., Bowen et al., 2024; Macaulay et al., 2019; Bergner et al., 2018). The role of diabetes technology in this sleep disruption is mixed. Families often see assistive technology as a facilitator of sleep, but they also describe it as a source of disturbance (e.g., Hart et al., 2022; Kimbell et al., 2022; Macaulay et al., 2019).

Although this body of research has provided valuable insights into the nighttime experiences of families living with T1D, much of this evidence is derived from parents' and caregivers' perspectives. Even when CYP are included as participants, their own accounts feature less prominently in the reported findings than those of their parents or caregivers. Consequently, the voices of children and young people themselves remain comparatively overlooked.

The sleep of siblings of children with T1D has not been investigated to date. However, existing evidence suggests that siblings can have diabetes-related responsibilities, experience emotional burden, and may receive less parental attention due to the demands of T1D management (Cao et al., 2021). These findings indicate that siblings could potentially be vulnerable to sleep disruption and altered nighttime experiences, yet this possibility remains entirely unexplored.

Taken together, these gaps limit our understanding of how T1D shapes nighttime experiences and sleep across the family. Understanding such experiences is important as, even outside the context of T1D, sleep of poor quality has been associated with higher symptoms of anxiety, depression, internalising difficulties (e.g., Marino et al, 2021; Orchard et al., 2020; Gregory & Sadeh, 2016), and externalising behavioural problems (Tussey & Wong, 2023). This association goes beyond psychopathology, with large studies reporting a link between sleep disturbances and worse later physical health-related quality of life (Williamson et al., 2020; Ferreira et al., 2025). Identifying the barriers, facilitators, and support needs experienced by families may help inform future interventions, clinical practice, and family-centred care.

To address these gaps, this preregistration describes a study exploring the sleep and nighttime experiences of CYP living with T1D and those of their siblings without T1D. The following sections outline the projects' aims, research questions, methodology, participant characteristics, recruitment strategy, data collection procedures, and analysis plan.

Who is the primary investigator on the project? Please also name any co-investigators on the project.

Beatriz Venancio (lead researcher), Alice M. Gregory &; Jakke Tamminen (Senior Researchers)

Who is the project data contact?

Beatriz.Venancio.2025@live.rhul.ac.uk

Data Collection

What types of data/ files will be created?

We will generate original data, collected specifically for this study. Data will consist of audio-recorded semi-structured interviews and verbatim transcripts. Reflexive notes will also be recorded when appropriate. Demographic information will be collected as screening for eligibility and to contextualise the participants accounts (via Microsoft Forms). The final transcripts and questionnaire data will be pseudoanonymised and will not contain any identifiable information.

What is the estimated total volume of data, number of items / files and largest individual file / items size?

5-10 GB

How will the data be collected or created?

Data will be collected directly from participants.

- Prior to the interview, participants, or their parent/caregiver where appropriate, will complete a short online questionnaire using Microsoft Forms to assess eligibility and collect demographic information.
- Qualitative data will be generated through online individual semi-structured interviews with CYP with T1D and their siblings without T1D. I
- The recordings will be transcribed verbatim, with transcription assisted by Microsoft Copilot through the Royal Holloway institutional account.
- Each transcript will subsequently be checked against the original audio recording by the lead researcher to ensure accuracy and identifying information will be removed prior to analysis. Reflexive notes and analytic memos may also be created during data collection and analysis.

Will any existing research data be used? If yes, describe any actions that will need to be taken in order to gain access to this data.

N/a

Are there any special tools and/or software needed to work with or view the data? If yes, describe any actions that will need be taken to access these tools or software.

Yes, Microsoft forms and Copilot via institutional account. No further actions are necessary to access the software.

Documentation and Metadata

What documentation and metadata will accompany the data?

The data will be accompanied by the study protocol/preregistration, interview schedules, participant information and consent/assent documentation, demographic information, and relevant analytic notes. Unique participant codes will be used to link associated data files while maintaining pseudonymisation.

Ethics and Legal Compliance

Have you completed the University Ethics review process?
A DMP must be created and attached to the research ethics application. This process is only required after a project has been awarded or the research activity has been approved.

No yet. This file will be attached to the ethics application and updated after approval.

How will any ethical aspects related to RDM and / or highlighted in the Ethics process be managed?

Ethical approval will be obtained from Royal Holloway before data collection. Informed consent/assent will be obtained as appropriate, and participants will be informed about how their data will be collected, stored and used. Identifiable data will be kept confidential and stored securely, with interview transcripts pseudonymised prior to analysis. Data management will comply with UK GDPR, the Data Protection Act 2018, and Royal Holloway's research data management requirements.

How will any personal identifying data be kept separately to responses?

Personal identifying information will be stored separately from participants' research data. Participants will be assigned unique identification codes, which will be used on interview recordings, transcripts and other research data. The file linking participant identities to these codes will be encrypted, stored separately in secure Royal Holloway storage, and accessible only to authorised members of the research team. Transcripts will be pseudonymised, with identifying information removed prior to analysis.

Who will own the copyright of the research data?

Copyright for the research output and documentation generated in this project will rest with all authors, Royal Holloway, and collaborating institutions. Any publications resulting from the project may be subject to publisher copyright transfer agreements.

Are there any specific copyright / IP aspects that need to be considered?

Question not answered.

Storage and backup during the research

How will the data be stored and backed up during the research?

Research data will be stored in three locations: secure Royal Holloway institutional cloud storage, an encrypted password-

protected computer, and an encrypted portable drive. Access will be restricted to authorised members of the research team. Maintaining copies across these locations will provide backup and reduce the risk of data loss.

How will you manage access and security during the research?

Access to research data will be restricted to authorised members of the research team and it wont be shared via unsecured platforms.

Will the data be shared and accessed by other collaborators, colleagues etc during the research? If yes, how will this be managed?

No.

Evaluation and retention

Which data needs to be retained after the research ends?

Pseudonymised interview transcripts and relevant supporting documentation. Participants' contact details will be retained separately until 2029, in a encrypted device.

Where will this retained data be stored?

Encrypted portable drive and secure, encrypted Royal Holloway institutional cloud storage.

How long will the data be kept for?

Question not answered.

Does any data need to be destroyed / deleted? If yes, how will this be managed and by who and when?

Identifiable data will be deleted by 2029.

Data Sharing after research ends

Which data will need to be shared?

Data necessary to support research publications may be shared, where appropriate. This may include de-identified interview extracts, supporting documentation and, where ethically and legally permissible, de-identified transcripts. Full transcripts will not be made openly available where there is a risk of participant identification. Any data sharing will be consistent with participant consent, ethical approval and data protection requirements.

Where will this data be stored?

Encrypted portable drive and secure, encrypted Royal Holloway institutional cloud storage.

How will the data be shared eg considerations around Open Access, terms of reuse and licencing?

De-identified data may be made available upon reasonable request, subject to participant consent, ethical approval, and data protection and confidentiality requirements. Requests will be assessed by the research team before access is granted. Due to the potentially identifiable nature of qualitative interview data, full transcripts will not be made openly accessible.

Where will the location of the data be recorded?

Question not answered.

Has consent been acquired /agreed from participants to share the data?

Consent for appropriate data sharing and future research use will be obtained through the Participant Information Sheet and consent/assent forms. Participants will be informed about what data may be shared and how confidentiality will be protected. Participants will also be asked separately whether they consent to their name and email address being securely retained so that they may be contacted about future research studies.

Are any restrictions on data sharing required?

Question not answered.

Responsibilities and Resources

Who will be responsible for research data management?

Beatriz Venancio.

What resources will you require to deliver your plan?

All needed resources are already available.

State any identified costs and sources of funding for resources.

Question not answered.

Please outline the actions that you will take to manage the research data when the project ends / before leaving the University

- Delete participant names/email addresses and the participant identification key by 2029.
- Delete original interview audio recordings once they are no longer required for transcription/checking and any applicable withdrawal period has passed.
- Retain pseudonymised interview transcripts and relevant research documentation securely for research integrity, publication and potential future reuse.
- Ensure retained data contain no unnecessary identifying information.
- Transfer responsibility/access for retained research data to the PI or appropriate secure Royal Holloway storage before leaving the University.
- Document the final storage location and any access restrictions for retained data.

Who will manage the research data after project end / after the PI leaves the University to continue to meet any requirements?

Responsibility for managing the retained research data will be reviewed at the end of the project and/or before the lead researcher leaves the University.