

## Impact of Chronic Sleep Disturbance For People Living With T1 Diabetes

Running Title: Chronic Sleep Disturbance and T1D

Katharine Barnard PhD<sup>1</sup>, Janet James PhD<sup>1</sup>, David Kerr MD<sup>2</sup>, Peter Adolffson MD<sup>3</sup>, Asher Runion<sup>4</sup> and George Serbedzija<sup>4</sup>

1. Faculty of Health & Social Science, Bournemouth University, Bournemouth, UK
2. William Sansum Diabetes Center, Santa Barbara, California, USA
3. Institute of Clinical Sciences, Sahlgrenska Academy at University of Gothenburg. The Hospital of Halland, Kungälv, Sweden
4. Unitio Inc and T1 Diabetes Exchange, Boston, USA

### Corresponding author:

Katharine Barnard CPsychol AFBPsS  
Faculty of Health and Social Science  
Bournemouth University  
Royal London House  
Christchurch Road  
Bournemouth

E: [kbarnard@bournemouth.ac.uk](mailto:kbarnard@bournemouth.ac.uk)

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Novelty Statement:

- Chronic sleep disturbance is prevalent amongst adults with T1D and parents/carers of children with T1D. Chronic sleep disturbance is associated with worry, anxiety, sadness, depression, decreased stress tolerance, reduced cognitive level, impotence, increased risk of seizures, hypertension, cardiovascular disease and impaired immune function
- Adults and parents report considerable negative impact of chronic sleep disturbance on diabetes self-management behaviors and decision-making ability
- People living with T1D need to be better supported to reduce the burden of chronic sleep disturbance

## Impact of Chronic Sleep ~~Disturbance~~ Interruption for People Living With T1 Diabetes

### Abstract

**Aim:** To explore personal experiences and to determine the impact of impaired sleep on well-being and diabetes-related activities/decision-making among a cohort of people living with T1D.

**Method:** Adults with T1D over the age of 18 and parents/carers of children with T1D were invited to complete an online questionnaire about their quality and quantity of sleep. Questions included impact of sleep on diabetes-related decision-making, on effective calculation of bolus doses, on important aspects of psychosocial functioning and frequency of waking. Diasend download data ~~was~~ were used to objectively determine frequency of nocturnal blood glucose testing in children.

**Results:** Two hundred and fifty-eight parent/carer participants ( $n=221$  female (85.6%)) and 192 adults with T1D ( $n=145$ , female (75.5%), age range 19 to 89 years) took part. Two hundred and thirty-nine parents/carers and 160 adults believed waking in the night has an impact on their usual daily functioning. Of these, 236 parents/carers and 151 (64%) adults reported the impact as negative. Chronic sleep ~~disturbance~~ interruption was associated with detrimental impact on mood, work, family relationships, ability to exercise regularly, ability to eat healthily and happiness.

**Conclusion:** Chronic sleep ~~disturbance~~ interruption is highly prevalent in adults with T1D and parents/carers of children with T1D with negative effects on daily functioning and well-being. Appropriate interventions are required to alleviate this burden of T1D, address modifiable risk factors for nocturnal ~~hypoglycaemia~~ hypoglycemia and reduce the (perceived) need for nocturnal waking.

## Impact of Chronic Sleep Disturbance For People Living With T1 Diabetes

### Introduction

Many individuals living with type 1 diabetes (T1D), and parents of children with the condition routinely undertake nocturnal blood glucose testing to check for [hypoglycaemia/hypoglycemia](#), setting alarms to wake in the early hours of the morning, thus causing a regular [disturbance/interruption](#) of their sleep. Fear of nocturnal [hypoglycaemia/hypoglycemia](#) is especially prevalent amongst adults with T1D as well as parents of children with diabetes, representing a major challenge and potential barrier to achieving optimal [glycaemic/glycemic](#) control [1]. This is not surprising given that [hypoglycaemic/hypoglycemic](#) events occurring at night are a common complication of insulin treatment [2]. Moreover, nocturnal [hypoglycaemia/hypoglycemia](#) is associated to another cornerstone in the management of diabetes: exercise. Nocturnal [hypoglycaemia/hypoglycemia](#) is common after afternoon exercise [3].

The consequences of chronic sleep [disturbance-interruption](#) are often underappreciated in T1D care [4]. Whilst it is established that sleep problems can impact negatively on an individual's physical and mental well-being [4,5] the impact for parents of children with T1D can be similarly negative. Decreased sleep duration and/or impaired sleep quality directly influence glucose regulation – even a single night of partial sleep restriction in adults reduces insulin sensitivity by 14–21%, suggesting that exposure to chronic sleep restriction might contribute to insulin resistance in patients with T1D [6]. This is very relevant for T1D management as insulin resistance is known to be associated with an increased risk for microvascular and macrovascular complications in type 1 diabetes [7]. Thus, if T1D indeed causes disruption of sleep patterns, this may in turn impair glucose regulation, creating a vicious circle.

Irrespective of the impact of waking up to test blood glucose levels during the night, normal sleep architecture may also be disturbed in T1D after many years of living with the condition, with increased risk of next day depression and reduced quality of life. Daily functioning is also negatively impacted by chronic sleep [disturbance/interruption](#), leading to poor work and school performance and increasing the possibility of [behavioural/behavioral](#) problems, impaired learning and suboptimal emotional regulation [8]. Yet several risk factors associated with nocturnal [hypoglycaemia/hypoglycemia](#) are modifiable.

The aim of this mixed-methods study was to ~~objectively~~ quantify the extent of chronic sleep ~~disturbance-interruption~~ and to subjectively explore personal experiences of the impact of impaired sleep on well-being and diabetes-related activities/decision-making among a cohort of people living with T1D and their parent/carers.

### **Methods and Participants**

Adults with T1D over the age of 18 and parents/carers of children with T1D were invited to complete an online ~~questionnaire~~questionnaire about their quality and quantity of sleep. The survey was hosted on the secure University of Southampton isurvey site for one month following approval granted by local ethical review board. Each participant provided informed consent prior to study start. The questions were developed by the multi-disciplinary research team including people with T1D, prior to piloting with potential participants. Minor revisions were made in line with feedback prior to 'going live' in May 2015. In order to establish the extent of nocturnal blood glucose monitoring amongst a large clinic population, Diasend (medical information software) download data ~~was were scrutinized-analysed~~ for >200 days of glucose meter data for 5040 children.

Advertising occurred via social media sites Twitter, Facebook, Glu and DiabetesMine; patient advocacy groups including INPUT, Diabetes UK and Diabetes Research and Wellness Foundation charities; and investigators' healthcare professional networks. All eligible participants had access to a link to the online survey. A copy of the questions is attached.

The study was conducted in accordance with the Declaration of Helsinki.

Quantitative responses were ~~analysed~~analyzed using SPSS statistical software v.21 and free text responses were ~~analysed~~analyzed using thematic coding and content analysis. Free text data were analyzed using constant comparison methodology with two researchers independently analyzing and coding the text, before consensus was reached on key themes and findings.

## Results

According to Diasend data, Ninety-nine percent of families ( $n=4,990$ ) performed blood glucose testing during the night (defined as between midnight up to 6am), with 24% ( $n=1,210$ ) of families measuring 3-6 nights per week and 15% ( $n=756$ ) measuring at least 50% of nights. Two hundred and fifty-eight parent/carer participants ( $n=221$  female (85.6%)) and 192 adults with T1D ( $n=145$ , female (75.5%), age range 19 to 89 years) took part. See tables 1-79 below for detailed results. More than half of participants had experienced CGM use with only 42% of children and 21% of adults having never used a CGM. Of those that had used CGM, 37% of children ( $n=95$ ) and 59% of adults ( $n=114$ ) were current users.

Table One: Insulin Delivery Method Currently Used

	<b>Children <i>n</i> (%)</b>	<b>Adults <i>n</i> (%)</b>
Insulin pump	167 (64.7)	139 (72.4)
Injections using an insulin pen	80 (31.0)	32 (16.7)
Injections using a syringe	4 (1.6)	1 (0.5)
Inhaled insulin	1 (0.4)	0

Table Two: Continuous Glucose Monitor (CGM) use

	<b>Children <i>n</i> (%)</b>	<b>Adults <i>n</i> (%)</b>
<u>Current CGM user</u>	<u>95 (36.8)</u>	<u>114 (59.4)</u>
<u>Former CGM user</u>	<u>21 (8.1)</u>	<u>18 (9.4)</u>
<u>Have never used a CGM</u>	<u>109 (42.2)</u>	<u>41 (21.4)</u>

Table ~~Three~~Two: Frequency of waking during the night on average:

	<b>Parents/Carers <i>n</i> (%)</b>	<b>Adults <i>n</i> (%)</b>
Once a week	14 (5.4)	29 (15.1)
2-3 times a week	47 (18.2)	44 (22.9)
4-5 times a week	37 (14.3)	49 (15.5)

Every night	86 (33.3)	34 (17.7)
More than once a night	69 (26.7)	27 (14.1)

251 (97.3%) parents/carers and 181 (94.3%) adults

Two hundred and thirty-nine parents/carers and 160 adults believed waking in the night impacted their usual daily functioning. Of these, 236 parents/carers and 151 adults reported the impact as negative.

Table ~~Four~~ Three: Reported Causes of waking during the night:

Cause	Parents/Carers <i>n</i> (%)	Adults <i>n</i> (%)
To do a blood glucose test	90 (34.9)	16 (8.3)
Continuous glucose monitor alarm	56 (21.7)	72 (37.5)
Fear of <u>hypoglycaemia</u> <u>hypoglycemia</u>	43 (16.7)	18 (9.4)
Experiencing/child experiencing <u>hypoglycaemia</u> <u>hypoglycemia</u>	39 (15.1)	35 (18.2)
Fear of <u>hyperglycaemia</u> <u>hyperglycemia</u>	1 (0.4)	0
Experiencing/child experiencing <u>hyperglycaemia</u> <u>hyperglycemia</u>	4 (1.6)	2 (1.0)
Recommended by healthcare professional	6 (2.3)	0
Recommended by someone else	1 (0.4)	0
Insulin pump alarm	3 (1.2)	2 (1.0)
Other	19 (7.4)	40 (20.8)

'Other' : 'all of above (*n*=25), combined fear of hypo/hyper (*n*14), alarms not specified (*n*=11), to urinate (*n*=12)

Table Five~~Four~~: If the CGM alarms, how often does a 'false' alarm wake you in the night?

Frequency of False Alarm	Parents/Carers <i>n</i> (%)	Adults <i>n</i> (%)
Rarely	67 (26.0)	75 (38.5)

1-2 times a month	18 (7.0)	22 (11.5)
Once a week	14 (5.4)	22 (11.5)
More than once a week	19 (7.4)	15 (7.8)

'false alarm' is defined as an alarm that, on closer examination was not appropriate, e.g. an incorrect bg reading on CGM causing an alarm

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Only nineteen percent of parents/carers and twelve percent of adults reported that Table Six: Impact of waking during the night on ... night impacted on their ability to effectively calculate a bolus dose. Furthermore, thirty-five percent of parents/carers and thirty-three percent of adults said it affected their ability to make diabetes-related decisions. This is inconsistent however with the responses to questions that delved more deeply into such impact as detailed in Tables Five and Six below.

	<b>Parents/Carers</b> <i>n (%)</i>		<b>Adults</b> <i>n (%)</i>	
	<b>Yes</b>	<b>No</b>	<b>Yes</b>	<b>No</b>
<u>Effectively calculating a bolus dose</u>	<u>49 (19)</u>	<u>197 (76)</u>	<u>23 (12)</u>	<u>162 (84)</u>
<u>Ability to make diabetes related decisions</u>	<u>90 (35)</u>	<u>160 (62)</u>	<u>64 (33)</u>	<u>121 (63)</u>

Table SevenFive: Parents/carers: Impact of waking during the night on ...

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>N/A</b>
Your mood	2	28	74	95	44	2
Your work	8	41	83	62	32	17
Your family relationships	9	36	79	82	37	3
Your ability to exercise regularly	24	40	49	66	61	5
Your ability to eat healthily	30	61	42	69	37	3
Your happiness	9	37	79	60	54	5

1 (no problem) – 5 (severely affected)

Table [EightSix](#): Adults with T1D: Impact of waking during the night on ...

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>N/A</b>
Your mood	14	28	66	54	19	1
Your work	22	41	54	47	11	7
Your family relationships	35	52	39	40	9	6
Your ability to exercise regularly	41	31	46	40	18	5
Your ability to eat healthily	47	39	41	38	10	3
Your happiness	20	28	55	50	29	1

1 (no problem) – 5 (severely affected)

#### Positive Impact of Waking During the Night

A small number of adults reported positive aspects of nocturnal waking to be the ability to quickly make blood glucose corrections ( $n=11$ ) and therefore feel healthier or less unwell the next day. Parents/carers reported positives in more dramatic terms e.g. ‘diabetic child is living ...’, ‘I go back to sleep knowing my kids are alive ...’ and ‘I’d rather be tired than my son going into a coma because blood dropped too low ...’. Parents also reported the reassurance of their child being in a ‘safe’ range of blood glucose level ( $n=5$ ).

#### Negative Impact of Waking During the Night

One hundred and forty-seven adults and two hundred and forty-three parents/carers provided free text responses about the negative impact of chronic sleep disturbance.

Table [NineSeven](#): Key negative themes:

<b>Theme</b>	<b>Adults <i>n</i> (%)</b>	<b>Parents/Carers <i>n</i> (%)</b>
Exhaustion / tiredness	95 (49)	154 (60)
Poor concentration / lack of focus	32 (17)	72 (28)
Poor quality sleep	30 (16)	19 (7)



Bad mood, impatient, grumpy, short tempered	18 (9)	45 (17)
Poorer performance next day	12 (6)	58 (22)
Impaired blood glucose control	9 (5)	0
Emotional difficulties / anxiety / depression	4 (2)	40 (16)
Feeling unsafe	1	0
Trouble losing weight	1	1
Difficulties exercising	0	3 (1)
Poorer communication / family time / social life	0	15(6)
Poor personal health	0	29 (11)

Free text comments from adult comments include:

- “Tired, irritable groggy, easily distracted at work, less patience, less energy”
- “It is difficult to function properly”
- “I never feel rested when I wake up”
- “More prone to being grumpy, short tempered, hard to concentrate and more likely to feel depressed”

Parent/Carer comments include:

- “Exhaustion. It is torture”
- “Feel unmotivated and tired most days while pushing on to do the daily things that need accomplished”
- “Feel tired often ... affects relationship with family and friends as not enough energy. One of my friends said ‘it has lost a part of me’
- “I am never truly rested since my daughter’s diagnosis 3 years ago”

#### Impact of sleep disturbance on bolus calculations

Twelve adults and thirty-five parents/carers reported difficulties in concentration when making calculations i.e.:

Adults:

- “feels like your brain isn’t working properly”
- “makes it harder to think about mathematical equations”
- “not fully conscious so not thinking 100% clearly”.

Parents/carers:

- “it’s hard to make good decisions when you are exhausted”
- “brain does not function, even though you want it ~~to~~”
- “the other day I gave the wrong dose”
- “I have bolused her for a correction and food in the middle of the night out of habit ... she should only be getting a correction”

#### Impact of sleep disturbance on diabetes-related decisions

Forty-one parents/carers and eighteen adults reported poor concentration and diabetes-related decisions to be more difficult, with mistakes or ‘wrong’ decisions being a consequence i.e.:

Parents/carers:

- “I’ll be more likely to over-correct a low, then she’ll jack up too high”
- “I choose to have my daughters at a higher BG than I would typically want them to be”
- “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”
- “sometimes I’m so confused and fuzzy, I have a hard time concentrating”

Adults:

- “Because of being tired ... I feel that I might not be making the best diabetes choices during the night”
- “Exhaustion impedes all decisions”
- “More likely to rage bolus”
- “Taking too little or too much insulin or over-writing a low”
- “Once I injected extra insulin and it was too much”

#### **Discussion**

The data shows that waking during the night as a direct consequence of living with T1D is highly prevalent. 99% of parents/carers wake to some extent with over half, and a third of adults,

waking at least once every night or more than once a night. This is consistent with previous literature and highlights a major burden of T1D on the ability to have a normal sleep pattern [4]. Furthermore, increased time in deep sleep is associated with less risk of hypoglycemia at night as well as improved HbA1c levels [9]. Here also, the majority of participants believed this had a negative impact on their usual daily functioning.

Whilst most participants were using insulin pump therapy, use of continuous glucose monitoring was low amongst children compared with adult participants. Rates of CGM use are still higher amongst participants than in the general T1D population where reported usage is around 7% [10]. Therefore, even with access to modern technology, sleep ~~disturbance-interruption~~ remains common and may even be augmented by the devices themselves [11]. Interestingly, there were no specific difference between CGM users and non-CGM users in terms of frequency of waking during the night nor reported impact on psychosocial functioning.

The most commonly reported cause of waking for parents/carers was to conduct SMBG, whereas for adults it was to respond to a CGM. Rates of 'false' alarms were reported to be relatively low, however 19.8% of parents/carers and 30.8% of adults experienced waking due to a false alarm at least once a month. Experience, or fear of, ~~hypoglycaemia~~~~hypoglycemia~~ were common, reported by 32% of parents and 28% of adults. This is again consistent with previous studies where fear of ~~hypoglycaemia~~~~hypoglycemia~~ particularly is pervasive [12]. Furthermore, ~~hypoglycaemia~~~~hypoglycemia~~ unawareness affects around 25% of people with T1D and contributes to both fear and associated ~~behaviours~~~~behaviors~~, often resulting in reliance on family members to detect and treat severe hypo episodes [13] suggesting an urgent and extensive need for information and support for family members.

de Zoysa et al (2013) DAFNE HART [14] pilot study data shows an intervention based on motivational interviewing and cognitive behavior techniques was effective, however participant numbers were small and data ~~is-somewhat~~ lacking on the sustainability of any improvement. Several risk factors to reduce the risk of nocturnal ~~hypoglycaemia~~~~hypoglycemia~~ are modifiable, including awareness of the impact of HbA1c level, exercise, bedtime blood glucose level and prior daytime ~~hypoglycaemic~~~~hypoglycemic~~ events [15]. It may be that greater awareness of these risk factors may help patients and providers decrease the risk of ~~hypoglycaemia~~~~hypoglycemia~~ at

night. Other nocturnal hypoglycemia avoidance strategies include the use of insulin pumps with low glucose suspend features [16], considering different insulin formulations, use of insulin bolus calculators [17] and in the near future use of overnight automated closed-loop systems [18]. For others using medications to help with diabetes related complications, choice of prescription medicine can impact sleep quality and architecture [19].

~~A minority of participants reported aspects Positive aspects of of nocturnal testing were reported by a minority of participants to be positive~~ for example adults reported the ability to quickly make blood glucose corrections whilst parents/carers reported reassurance as a key positive. Dramatically parents also described that testing during the night enabled them to know their child was alive and in a 'safe' range. It could be argued that this reassurance is somewhat false, however, resulting from a pervasive and maladaptive fear. Perception and understanding of risk, in a culturally risk averse population, requires greater clarification in terms of how risk is perceived and the implications for parents in terms of potential societal judgment and disapproval. [20].

Interestingly, the majority of participants said that waking during the night did not impact on their ability to effectively calculate an insulin bolus dose or make diabetes-related decisions the next day. This is inconsistent with the free text responses where the majority of participants reported exhaustion/tiredness as a negative impact of chronic sleep ~~disturbance-interruption~~ and poor concentration/lack of focus. Chronic sleep disturbance is associated with poorer cognitive function, reduced ability for rational thought, poorer well-being, psychological stress, poor physical health and heightened sensitivity [21,22]. Improved sleep, by comparison, is associated with child and family functioning.

~~Both parents/carers and adult participants commonly reported the negative~~Negative impact on important aspects of psychosocial functioning ~~were commonly reported by both parents/carers and adult participants~~. These included mood, work, family relationships, exercise, healthy eating and happiness. Free text responses similarly reported bad mood, impatience and short temper, emotional difficulties, increased anxiety and depression. Each of these is associated with poorer health (of carers) and suboptimal ~~glycaemie~~glycemic control.

Limitations of the current study include the online study design of the survey and the self-select nature of participation; thus survey participants may not be representative of the wider T1D population. As data was obtained from two different datasets, it was not possible to draw direct comparisons across them. Furthermore, the self-report data, whilst providing valuable information on the impact of chronic sleep interruption, may lead to a rather crude estimate of the sleep characteristics per se which require further investigation. -Strengths however include the online study design as it enabled us to reach a wide range of participants from the UK and USA and larger numbers of participants than would have been possible with local paper survey. Additional strengths include the mixed methods approach, enabling participants to provide greater detail about the impact of chronic sleep disturbance on a range of aspects of their daily lives and functioning.

### **Conclusions**

Chronic sleep disturbance-interruption is highly prevalent in adults with T1D and parents/carers of children with T1D with negative effects on daily functioning and well-being. Further research on sleep characteristics and development of appropriate interventions are required. Modifiable risk factors -to alleviate this burden of T1D, address modifiable risk factors for nocturnal hypoglycaemia~~hypoglycemia~~ should also be targeted ~~and to~~ reduce the (perceived) need for nocturnal waking.

## List of Abbreviations

T1D	-	Type 1 diabetes
CGM	-	Continuous glucose monitoring
<i>n</i>	-	number (of participants)
SMBG	-	Self-monitoring of blood glucose
DAFNE	-	Dose Adjustment For Normal Eating
UK	-	United Kingdom
USA	-	United States of America

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