Title: A patient first perspective of sleep disturbance across therapeutic areas: A systematic literature review of qualitative studies

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Abstract

Background: Sleep, a vital pillar of health, impacts daily functioning and overall quality of life. Despite extensive research on sleep disturbances within specific therapeutic areas (TAs), there's limited understanding of how these disturbances affect patients across multiple TAs. This systematic literature review adopts a patient-centered approach to explore the meaningful aspects of health and concepts of interest relating to sleep and sleep disturbances across a variety of TAs, utilizing qualitative research to bridge the gap between patient experiences and clinical measures.

Methods: A systematic search was conducted in Embase and PubMed for qualitative studies on sleep within selected TAs, using a pre-registered strategy. Initial screenings based on titles and abstracts were followed by full-text reviews and quality appraisal using the CASP checklist.

Results: From 3856 unique publications, 51 full-text articles were analyzed across 11 TAs. Thematic analysis highlighted issues within the sleep window, and proximal and distal impacts of sleep disturbances. Using thematic analysis a conceptual model was developed, illustrating a multitude of sleep disturbances' from a patient-first perspective, which emphasized sleep quality's role in daily functionality.

Discussion: This review emphasizes the importance of incorporating patient perspectives into sleep research and clinical practice. By presenting a holistic conceptual model, it provides a foundation for developing outcome measures that reflect meaningful aspects of patients' sleep experiences. This patient-centered approach highlights the need for novel methodologies in sleep research, beyond traditional clinical outcome assessments, to capture the full spectrum of sleep disturbances' impacts on patients' lives across various TAs.

Keywords: Sleep, Patient perspective, qualitative sleep review, broad sleep quality issues

Introduction & Background

Sleep is an essential pillar of health and is vital for day-to-day functioning and life. According to the Center for Disease Control and Prevention, 1 in 3 adults in the general public report not getting enough sleep. A single night of inadequate sleep can cause measurable cognitive and general functioning deficits [1,2]. Furthermore, chronic insufficient sleep is linked to a broad range of diseases and disorders [3-5]. Many recent studies have begun to investigate the connection between sleep disruption presentation and disease.

Polysomnography (PSG) is the primary diagnostic tool for various sleep conditions and diseases [6,7]. Analysis of PSG has characterized how aspects of sleep, such as rapid eye movement (REM) and non-REM (NREM) sleep, are affected by diseases and disorders. However, PSG has many limitations, such as, limited recording duration, costly, typically clinic-based, and may impact sleep quality. Recently, many digital tools have emerged that enable measurements of sleep in the home environment [8,9]. However, there is a disconnect between the data acquired by digital health technologies for sleep and what is meaningful to patients. To promote research and care delivery to patients that better address *their* concerns with sleep, it is important to examine patient perspectives and experiences.

In this systematic literature review we summarize first-person accounts of patients' sleep and sleep disturbance concerns and perceptions across 11 TAs: Circadian Rhythm Disorders, Hypersomnolence, Parasomnias, Insomnia, Sleep related breathing disorders, Heart failure, Arrhythmia, Stroke, Depression, Menopause, and Parkinson's Disease. We chose these TAs because they cover a varied group of diseases and disorders and because they are associated with poor sleep. Though there has been research on how sleep disturbance affects these TAs individually, it is not known how sleep disturbance manifests and affects patients across all these TAs. The goal of this review is to identify key patient-relevant sleep and sleep disturbance issues across the TAs using literature-based quotes that describe how these sleep issues affect patients in the short and long term. We use this evidence to generate a conceptual model of sleep and sleep disturbances across the TAs. Future use of this conceptual model could guide the development of novel patient centric DHTs for clinical use and delivery of care for a broad range of diseases and disorders.

Methods

Search Strategy

We conducted a systematic search of *qualitative* original peer-reviewed articles containing "sleep" MESH terms in the title or abstract in each of the chosen therapeutic areas in Embase and PubMed using a pre-registered search strategy (PROSPERO ID=432662). The search was conducted in July 2023 and included articles published between 2003 and 2023 in any language.

Screening

The titles and abstracts were initially screened by four members of the author group (SG, KR, SL, PF) using the PICOS framework (Table 1) [10,11]. All records were screened initially by two reviewers. Upon disagreement for inclusion, a third reviewer was asked to review the record, this occurred approximately 8 times. All records with agreement from two reviewers proceeded to a full text screening.

During the full text portion of the screening, reviewers assessed the articles for continued relevance. If relevant, the Critical Appraisal Skills Program (CASP) checklist for qualitative research was applied [12]. The CASP is a checklist that allows for researchers to use a structured approach for interrogating the quality of the study. If the study was rejected, the reason for the rejection was made in a tracking document (Supplementary material 1)

Table 1. The PICOS Framework used in the systematic review

Participants	1. Exclude papers that do not report data from human participants. 2. Exclude papers that do not report one or both of: a. Participants representing the relevant condition of interest.[a] b. Participants representing the caregiver of a person living with the condition of interest.[a]
Intervention	N/A
Comparator	N/A
Outcome/s	3. Exclude papers that do not report on qualitative data regarding one or more aspects of sleep and/or sleep disturbance.
Study design	4. Exclude papers based on studies that do not report prospectively-collected data.

a. Parkinson's disease, menopause, depression, atrial fibrillation, heart failure, stroke, or any primary sleep disorder.

Thematic analysis

Articles selected from screening were coded by four reviewers (SG, KR, SL, PF) using a thematic analysis approach [13]. This process included familiarization with the data through an initial reading of the publications, generating initial codes, collating the codes and developing themes and concepts, reviewing the themes and concepts, defining and naming themes and concepts and creating a conceptual model. The primary focus was on coding participant quotes, while relevant sections of authors' result interpretations were also included.

To ensure consistency, eight articles were initially reviewed and coded by all reviewers. Results were discussed for alignment. Then, the primary author (SG) harmonized all codes with input from other reviewers.

To define the themes, codes were extracted into an online workspace [14] and quotes were extracted to a searchable database (Supplementary material 2). The author team reviewed the extracted codes, associated quotes and original articles to group codes into themes. This was led by two authors (PG, SG) with substantial input from the remaining authors. Themes were identified and assigned names. Concepts were derived from the associated code groups, with reference to the original text and quote database. A conceptual model was developed and underwent two rounds of expert review from the author team and experts from the DiMe Core Digital Measures of Sleep team.

Results

The search resulted in 3856 unique publications. The initial title screen reduced the total number of publications to 171. The DiMe Core Digital Measures of Sleep team completed an abstract screen, further reducing the total to 74 publications. These 74 publications were subject to a full text review and assessed using the CASP appraisal system. After the full text review and quality appraisal, 51 remained (Figure 1, Table 2). The 51 full text articles were coded with Atlas.ti (Table 3). A total of 469 codes were created.

Fig. 1 Prisma Diagram of screened publications
A PRISMA of how the papers were screened and processed, irespective of therapeutic areas.

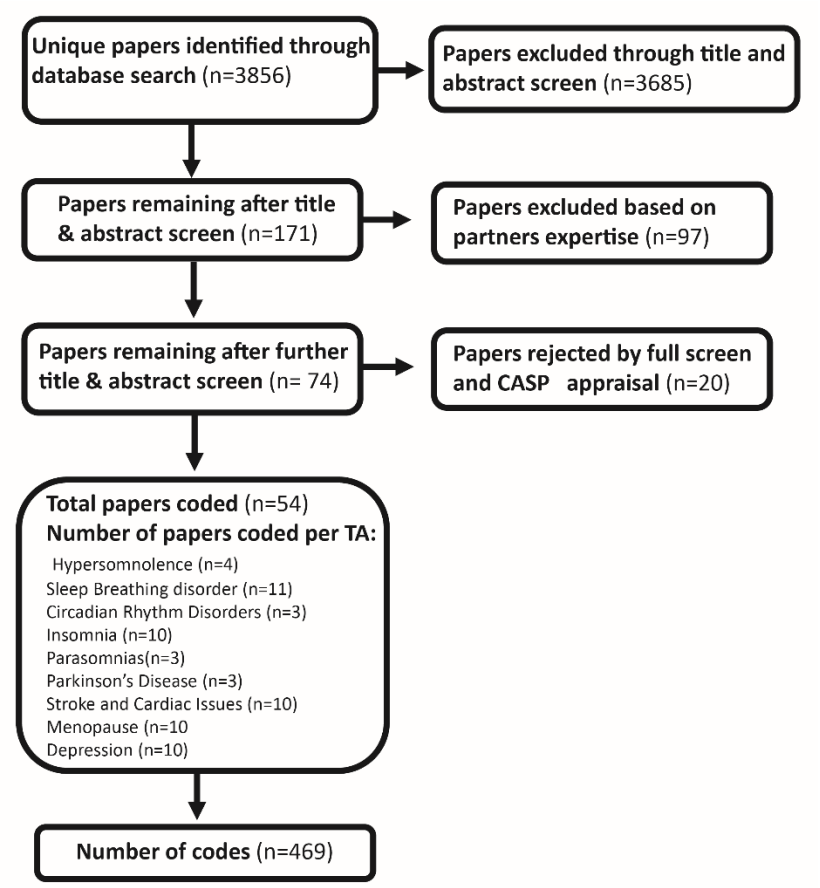


Table 2. A breakdown of the retrieved and screened publications for each TA

Therapeutic area	Initial paper total (no duplicates)	Initial total after title and abstract screen	Reduced total after expert title and abstract screen	Number of papers included
Circadian Rhythm Disorders	113	12	3	3
Hypersomnolence	314	13	4	4
Parasomnias	462	9	5	3
Insomnia	646	34	14	11[a]
Sleep breathing related disorders	735	24	13	11[a]
Heart failure	37	11	8	6
Arrhythmia	16	2	1	0
Stroke	107	16	5	3
Depression	1053	18	8	6
Menopause	112	11	5	2
Parkinson’s Disease	261	21	7	3
All TAs combined	3856	171	74	51[a]

a.(ong, 2017) is both an insomnia and sleep breathing related disorders publication, therefore it is counted for both but only counted once in the total.

Table 3. Summary of full text articles extracted for information

Therapeutic area	Author & year	Number	Title	Qualitative Sample Size	Sample Characteristics	Study type	Geographic region
Sleep Breathing Related Disorders	Haighton, 2022	1	Perspectives on paediatric sleep-disordered breathing in the UK: a qualitative study	11	Parents of children aged 2-9 with symptoms of sleep disordered breathing referred to a regional ENT clinic	semi structured face to face or telephone interviews	UK
	Ye, 2018	2	Couples' experiences with continuous positive airway pressure treatment: a dyadic perspective	20	Patients with obstructive sleep apnea and their partners; newly diagnosed with OSA, CPAP eligible, cohabiting or married 1 yr	face-to-face semi-structured in-depth open-ended interviews	USA
	Ahonen, 2022	3	The terrible dryness woke me up, I had some trouble breathing-Critical situations related to oral health as described by CPAP-treated persons with obstructive sleep apnea	18	adults with long-term experience of continuous Positive airway pressure-treatment	semi-structured interview	Sweden

	Ong, 2017	4	Management of Obstructive Sleep Apnea and Comorbid Insomnia: A Mixed-Methods Evaluation	29	Adults with comorbid insomnia and SDB	mixed methods	USA
	Rudolph, 2018	5	The patient's perioperative perspective during the treatment of obstructive sleep apnea: a pilot study. Sleep Breath	17	Patients who failed continuous positive airway pressure (CPAP) treatment of obstructive sleep apnea and underwent airway surgery	semi structured interview	USA
	Chou,2021	6	Treatment burden experienced by patients with obstructive sleep apnoea using continuous positive airway pressure therapy.	19	Adult OSA patients using CPAP	1:1 interviews	Australia
	Luyster, 2016	7	Patient and Partner Experiences With Obstructive Sleep Apnea and CPAP Treatment: A Qualitative Analysis.	27	Adults with OSA using CPAP and their partners	focus groups, both in person and telephone	USA
	Hu,2014	8	Life experiences among obstructive sleep apnoea patients receiving continuous positive airway pressure therapy.	22	OSA patients undergoing CPAP therapy	1:1 interviews	Taiwan
	Henry, 2012	9	“Listening for his breath:” The significance of gender and partner reporting on the diagnosis,	24	Patients with OSA diagnosed and partners	1:1 interviews	USA

			management, and treatment of obstructive sleep apnea				
	Bronstrom, 2007	10	Obstructive sleep apnoea syndrome–patients' perceptions of their sleep and its effects on their life situation	20	Patients with untreated OSA	1:1 interviews	Sweden
	Davies, 2019	11	Parental Experience of Sleep Disordered Breathing in Infants With Cleft Palate Comparing Parental and Clinical Priorities.	23	Parents whose kids have sleep disordered breathing	telephone and face to face interviews	UK
Stroke	Young, 2015	12	Poststroke Fatigue: The Patient Perspective	10	Patients who previously had suffered a stroke and reported symptoms of fatigue	1:1 interviews	UK
	Cronfalk, 2020	13	A qualitative study-Patient experience of tactile massage after stroke.	8	Adults 65+ with first time stroke admitted to rehab, fluent in Swedish	1:1 interviews	Sweden
	Widar, 2004	14	Coping with long-term pain after a stroke.	43	15 with central post-stroke pain (CPSP), 18 with nociceptive pain, and 10 with tension-type headache	1:1 interviews	Sweden

Parkinson's Disease	van Gilst, 2016	15	A grounded theory study on the influence of sleep on Parkinson's symptoms.	14	Adult (age 55-75); 5-30 yrs with parkinson	1:1 interviews	Netherlands
	Wade, 2020	16	Factors related to sleep disturbances for individuals with Parkinson's disease: A regional perspective.	49	Patients with PD ages 53-87	mixed methods study with an interview component	Australia
	Hogland, 2022	17	"Like a Wave" in Its Variable Shape, Breadth, and Depth: A Qualitative Interview Study of Experiences of Daytime Sleepiness in People with Parkinson's Disease	12	Five women and seven men (42-82 years) with PD for 1.5 to 21 years and excessive daytime sleepiness (i.e., a score of >10 on the Epworth Sleepiness Scale)	1:1 interviews	Sweden
Menopause	2012, Vigeta	18	Sleep in postmenopausal women.	22	Postmenopausal women	1:1 interviews	Brazil
	Hsu, 2009	19	Sleep disturbance experiences among perimenopausal women in Taiwan.	21	Perimenopausal women	1:1 interviews	Taiwan
Insomnia	Carey, 2010	20	Focusing on the Experience of Insomnia	16	Patients with Chronic insomnia (5 related to MDD)	focus Groups	USA
	Cheung, 2017	21	Mapping the illness trajectories of insomnia: A biographical disruption?	51	22 patients from sleep and psychology clinics who have insomnia diagnosed or self-report insomnia	1:1 interviews	Australia

					symptoms; 29 from general community		
	Akram, 2018	22	Qualitative Examination of Daytime Monitoring and Selective Attention in Insomnia	11	Insomnia patients	1:1 interviews	UK
	Yung, 2015	23	The Experience of Chronic Insomnia in Chinese Adults: A Study Using Focus Groups and Insomnia Experience Diaries	43	Insomnia patients	sleep diaries and focus groups	China
	Lin, 2022	24	Experiences of Middle Aged and Older Taiwanese Adults With Chronic Insomnia: A Descriptive Qualitative Study	17	Middle to elder adults with insomnia	1:1 interviews	Taiwan
	Hiller, 2013	25	Trying to fall asleep while catastrophising what sleep-disordered adolescents think and feel.	40	Adolescents diagnosed with delayed sleep phase disorder	catastrophizing interviews	Australia
	Berkley, 2020	26	The effects of insomnia on older adults' quality of life and daily functioning A mixed-methods study	18	Aged adults with insomnia	1:1 interviews	USA
	Kleinman, 2013	27	Patient Reported Outcomes in Insomnia: Development of a Conceptual Framework and Endpoint Model	28	USA adults	focus groups	USA

	Simon, 2010	28	Not Just a Minor Thing It Is Something Major Which Stops You From Functioning Daily: Quality of Life and Daytime Functioning in Insomnia	11	Insomnia patients	focus groups	Scotland
	Harvey, 2008	29	The subjective meaning of sleep quality: A comparison of individuals with and without insomnia	53	Individuals with insomnia (n = 25) and normal sleepers (n = 28)	a “Speak Freely” procedure, a “Sleep Quality Interview”and a sleep quality diary	USA
Heart Failure	Andrews, 2013	30	“I'd eat a bucket of nails if you told me it would help me sleep:” Perceptions of insomnia and its treatment in patients with stable heart failure	11	Adults with NYHA II-IV	focus groups	USA
	Inyoum, 2022	31	Lived experiences of patients implanted with left ventricular assist devices.	21	Patients with Heart Ware or Heart Mate implant device for heart failure	1:1 interviews	Germany
	Gullvag, 2019	32	Sleepless nights and sleepy days: a qualitative study exploring the experiences of patients with chronic heart failure and newly verified sleep-disordered breathing	17	14 men, 3 women diagnosed with chronic heart failure & verified sleep-disordered breathing (9 obstructive, 7 central, 1 mixed)	1:1 interviews	Norway
	Brostrom , 2003	33	Congestive heart failure, spouses' support and the couple's sleep situation: a critical incident technique analysis	25	Spouses of Heart Failure Patients	semi structured interview	Sweden

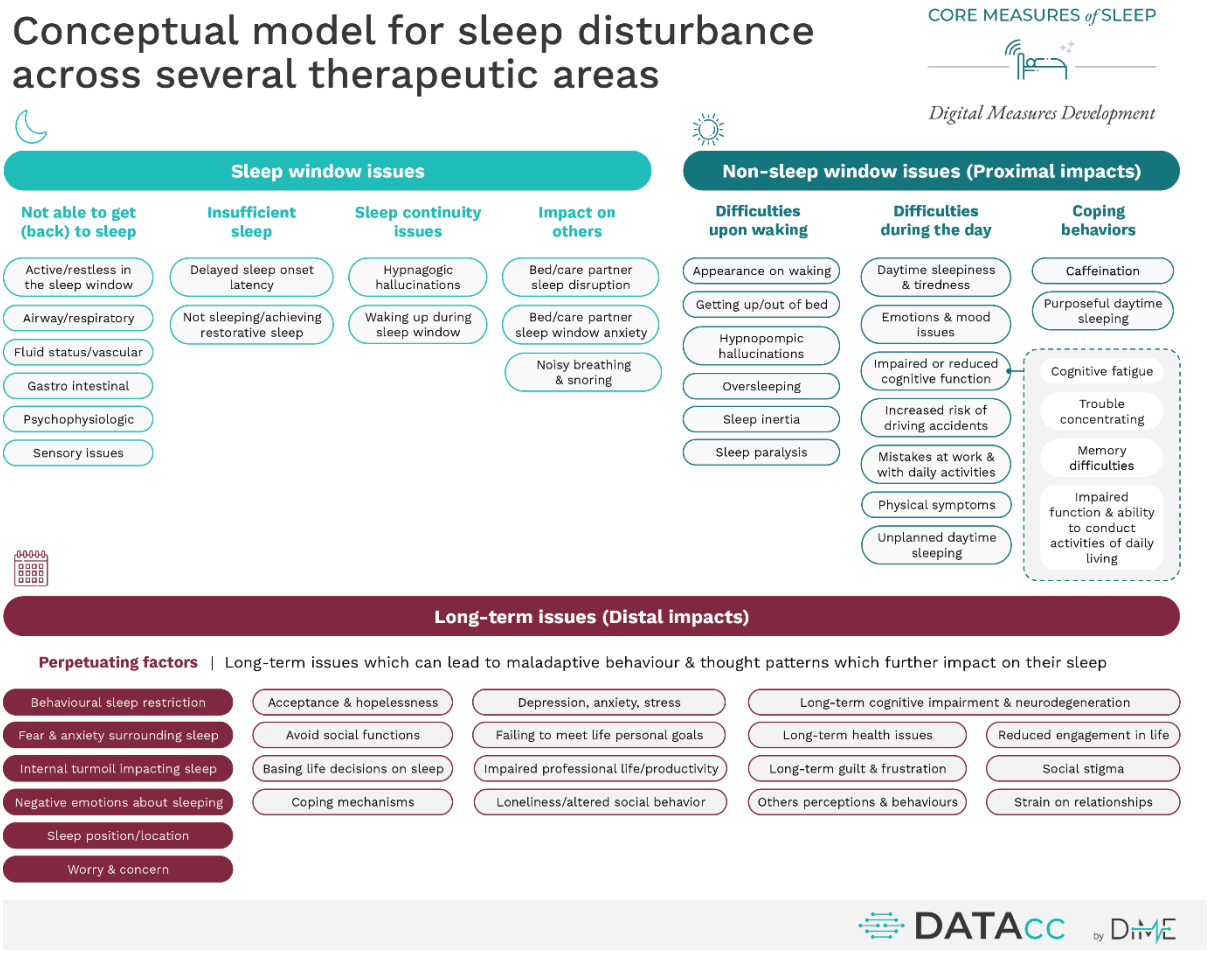
	DiFusco, 2019	34	Maternal experiences of caring for a child with a ventricular assist device	6	Mothers of children with VAD	interview over phone, 1:1 interviews	USA
	Barnes, 2006	35	Prevalence of symptoms in a community-based sample of heart failure patients.	17	Heart failure patients, mostly male	mixed methods	UK
Depression	Conroy, 2015	36	A Pilot Study on Adolescents With Depression and Insomnia: Qualitative Findings From Focus Groups	13	Adolescents with insomnia and depression	focus groups	USA
	Bitew, 2020	37	Stakeholder perspectives on antenatal depression and the potential for psychological intervention in rural Ethiopia: a qualitative study.	14	Antenatal women with depression and their healthcare workers	1:1 interviews	Ethiopia
	Jernslett, 2021	38	The experience of sleep problems for adolescents with depression in short-term psychological therapy.	23	Adolescents with sleep disturbances and have diagnosed of MDD	1:1 interviews	UK
	Pereira, 2007	39	The explanatory models of depression in low income countries: listening to women in India.	12	Women who were ever-married and who had been found to be suffering from a depressive disorder on the basis of a structured diagnostic interview	1:1 interviews	India

	Gebara, 2022	40	Illness narratives and preferences for treatment among older veterans living with treatment resistant depression and insomnia.	35	Veterans age 60+ w/LLTRD & insomnia receiving psych treatment thru VA	1:1 interviews	USA
	Littlewood, 2016	41	Understanding the role of sleep in suicide risk: qualitative interview study.	11	18 people with experience of a major depressive episode, and suicidal thoughts and behaviours	1:1 interviews	UK
Circadian Rhythm	Montie 2019	42	The impact of delayed sleep phase disorder on adolescents and their family	12	6 adolescents with circadian rhythm disorder type DSPD. Four boys, ages 13, 15, 15, 16. Two girls, ages 12, 17. 1 parent of each adolescent also interviewed.	1:1 interview	Netherlands
	Bastille-Denis, 2020	43	Are cognitive variables that maintain insomnia also involved in shift work disorder?	47	25 SWD and 22 good sleepers	catastrophizing interview	Canada
	Ose, 2019	44	One-year trial of 12-hour shifts in a non-intensive care unit and an intensive care unit in a public hospital: a qualitative study of 24 nurses' experiences	24	Female nurses working 12-hour shifts, 16 in the Medical unit and 8 in the ICU for 1-year; no further demo. data	1:1 interviews	Norway

Hypersomnolence	Francesc hini, 2020	45	Giving a voice to cataplectic experience recollections from patients with narcolepsy type 1	22	12 male, 10 female patients	1:1 interviews	Italy
	Chen, 2022	46	Living with narcolepsy during adolescence A qualitative study	18	18 male patients aged 10-17	in depth interview	Canada
	Ong, 2021	47	How Does Narcolepsy Impact Health-Related Quality of Life?: A Mixed-Methods Study	29	Narcolepsy adult patients	mixed methods	USA
	Wehrle, 2011	48	Growing up with narcolepsy: consequences for adolescents and young adults.	9	4 female and 5 male patients aged 15-29 yrs,	1:1 interviews	Australia
Parasomnias	Dantas, 2008	49	Restless legs syndrome in institutionalized elderly	32	Over 65, no dementia	face to face interviews	Brazil
	Piccietti, 2011	50	Pediatric restless legs syndrome: analysis of symptom descriptions and drawings.	33	Children with RLS	1:1 interviews	USA
	Jacobson , 2009	51	The nightmares of Puerto Ricans an embodied altered states of consciousness perspective	60	Inner-city Puerto Rican community, 22 psychiatric outpatients	open-ended interviews	Puerto Rico

In order to create a conceptual model, the codes were grouped into themes and concepts. Concepts were attributed to three broad groups based on their proximity to the sleep window, defined as the period when an individual attempts to sleep. These included concepts relating directly to the sleep window, and two different types of impacts: 1) proximal impacts were immediately due to sleep disruption the night before and 2) distal impacts were due to accumulated effects of continued sleep disruption. Some distal impacts are thought to further impact sleep or cause sleep disruption. In line with the 3P model of insomnia that ascribes sleep disturbance to predisposing, precipitating, and perpetuating factors (Spielman, Caruso & Glovinsky, 1987), this latter subgroup of distal impacts were highlighted as perpetuating factors (Figure 2.) In the following sections we describe each of the three broad groups created. Findings are displayed across TAs unless specified otherwise.

Fig. 2 A conceptual model of patient perspectives on sleep disruption and associated impacts across therapeutic areas. Patient quotes were grouped into three categories. First, sleep window issues (teal) included issues patients had while trying to sleep. Second were Non-sleep window issues (proximal impact, teal) that occurred outside the standard sleep period and indicated poor sleep quality. Third were long term issues (distal impacts, maroon) which dealt with the issues that occurred following chronic poor sleep quality.



Sleep window issues

The literature review provided insight into issues that patients across TAs report as important in the sleep window. This includes both issues that prevent sleep and those that disrupt sleep once it is achieved. The concepts presented in the sleep window issues section of the conceptual model represent two broad categories: sleep issues experienced by the patient, and the impact of the patient's sleep issues on the bed partner or care partner.

Sleep quality

Sleep quality, as defined here, is not a single measurement of efficiency as it is used elsewhere. Rather, we focus on subjective sleep quality defined as the patient's reported feeling of being refreshed or restored by sleep. Many different aspects of sleep can impact subjective sleep quality, including sleep behaviors such as the time it takes to get to sleep, waking up in the night, sensory issues disturbing sleep and restless sleep. Despite no single aspect of sleep being a sole determinant of subjective sleep quality, the overarching concept of subjective sleep quality was found in this work to be important to patients across all therapeutic areas, even if it was not directly referred to as “sleep quality”.

- *“I felt that I could not inhale air, then I awoke, and* ***my sleep was interrupted, impacting my sleep quality****”* - Patient, Sleep related breathing disorder, Hu et al., 2014
- *“…****and it wasn't quality sleep, so, it's like you're not sleeping every night****”* - Patient, Sleep related breathing disorder, Luyster et al., 2016
- *“lousy terrible sleeper”* - Patient, Heart failure, Andrews et al., 2013
- *“****Sleep was poor or didn’t come at all****”* - Patient, Insomnia, Yung et al., 2015
- *“****After you wake up you feel really lethargic, really tired! This is because you didn’t really sleep.****”* - Patient, Menopause, Hsu et al., 2009

Several specific meaningful aspects of health were found to lead to the described sleep quality issues. The first of these were symptoms, feelings, or general restlessness that prevented the individual from getting to sleep or returning to sleep if they woke up. These were typically either symptoms related to a sleep condition or a comorbid condition that led to sleep disturbance, or the individual being active in the sleep window *because* of the symptoms or simply because they couldn’t get back to sleep (leading to a vicious cycle).

- *“Just like a little—like bugs are crawling up, sometimes.”* Child patient, Parasomnia, Piccietti et al., 2011
- *“****You toss and turn, unable to sleep*** *and you end up like this.* ***Sometimes I get up as soon as I lie down****”* Patient, Menopause, (Hsu et al, 2009)
- *“Because that was a truly frightening experience.* ***It was as if it was your last breath of air*** *when you came up like that.”* Patient, Heart failure(Gullvag at al, 2019)
- *“****I put my clothes on; I take them off, and it really keeps me up.*** *My sleep is chopped into pieces.”* Patient, Menopause (2012, Vigeta)

Insufficient sleep

Another, related aspect impacting subjective sleep quality was insufficient sleep. This was either caused by a difficulty in achieving sleep (sleep onset latency) or feeling like sleep

wasn't long enough to be restorative or, in rare cases, the perception that sleep was never achieved.

- *"You figure every half an hour I wasn't sleeping, because I was stopping breathing. So, **instead of getting eight hours of sleep I was really getting four hours sleep**"* - Patient, Sleep related breathing disorder, Luyster et al., 2016
- *"...just four straight hours of sleep, then I think I would feel pretty good. Now I have to force myself out of bed."* Patient Heart failure(Andrews,2013)
- *"I feel exhausted, even after sleep ... feel raving tired"* Patient, Stroke (Young, 2015)
- *"when you wake up the next morning and **you don't even think about whether you slept or didn't sleep**, you just carried on"* Patient, Insomnia (Klienman, 2013)

Sleep continuity issues

Many patients attributed insufficient sleep to sleep continuity issues. Patient quotes depicted a disruption to continuous sleep, which interrupts the cyclic nature of sleep. The cause of these disruptions have different, condition-related etiologies. Some relate to comorbid conditions that wake the individual up, and some relate to sleep disorder symptoms like hypnagogic hallucinations, but have the same impact - breaking up the time spent sleeping across the sleep period.

- *"I went to bed at 12:30, I was up at 1:30, **then up again at three am and then four**. I said the hell with it and I put the TV on."* Patient, Heart failure (Andrews, 2013)
- *"I go to bed at eleven and **then probably sleep for a couple of hours before it starts**. I usually wake up because I have to go to the bathroom"* Patient, Sleep related breathing disorders (Bronstrom, 2007)
- *"I dreamt that one of my caseworkers, they were looking for her to kill her, and it was such a terrible dream... **and then I woke up crying**"* Patient, Parasomnia (Jacobson, 2009)

Impacts on others

Finally, individuals who experienced sleep window issues negatively affected the sleep of their bed partner or care partner. These sleep disruptions primarily occurred in the sleep breathing disorders and heart failure TAs and had two causes: 1) bed or care partner sleep was directly disrupted through noisy breathing or snoring, or 2) indirect sleep disruption caused by stress or concern over a behavior or symptom of their sick partner.

- *"He coughs a lot at night and has to sit up and complains that he cannot breathe. **Of course then I wake up too**"* Partner, Heart failure (Bronstrom, 2003)
- *"It wasn't good for us. We were still newlyweds and **we weren't even able to sleep in the same room together**. I couldn't take it—I was staying up all night, **I had insomnia because I was listening to him**."* Partner, Sleep breathing related disorders (Luyster, 2016)
- *"For me it seems like **this has affected her almost more than it has affected me**. Because **she has been lying awake** and has heard me breathe in, and then it has stopped."* Patient talking about bed partner, Heart failure (Gullvag, 2019)

Non sleep window issues (proximal impacts)

The proximal impacts of poor quality sleep on the next day's functioning fell into three broad categories: difficulties upon waking, difficulties during the day, and coping behaviors to deal with the impacts of sleep disruption.

Difficulties upon waking

Difficulties upon waking included sleep inertia (the feeling tired upon waking) which was experienced broadly across therapeutic areas:

- *"**After you wake up you feel really lethargic**, really tired! "* Patient, Menopause (Hsu, 2009)
- *"**the worse part I think is getting up in a morning.** It takes me ages. I think it's the tiredness that affects me most. "* Patient, Heart Disease (Barnes, 2006)

Oversleeping because of a poor night's sleep and concerns about physical appearance upon waking were not reported often. Oversleeping was restricted to depression and also included the feeling of not wanting to wake up, and appearance issues had different etiologies - some were related to not sleeping enough (insomnia), and some were related to wearing a CPAP mask (sleep breathing disorders)

- *"I used to cancel everything...**I just wanted to sleep all the time** because I knew that if I stayed awake I'd just feel sad, and I didn't want to feel sad, so"* Patient, depression (Jernslett, 2021)

There was some mention of hypnopompic hallucinations and sleep paralysis causing the individual to feel stuck in between wake and sleep, but this was restricted to the hypersomnolence therapeutic area

- *"You're mentally awake. **Your brain's telling your body to move and you just can't**"* Patient, Hypersomnolence (Wehrle, 2011)
- *"you're paralyzed for 20 minutes **and you can't move** and sometimes it feels like you can't breathe."* Patient, Hypersomnolence (Chen, 2022)

Difficulties during the day

Difficulties during the day related to diverse impacts, but were found to relate most often to the effects of sleep disturbances on cognition, emotion and ability to function in the waking hours.

Impaired cognitive function was hallmarked by reports from the literature of a general inability or reduced capacity to process information or learn new information, specifically driven by difficulty concentrating, memory difficulties and cognitive fatigue. These impacts manifested as further issues such as less engagement with activities of daily living.

- *"I'm tired when I'm at work, **I can't concentrate**, I become sloppy which is bad. After I get home I don't want to cook, nor do I want to do chores. **My whole life rhythm is messed up**."* Patient, Menopause (Hsu, 2009)
- *"I was really tired, **couldn't cope, couldn't study late at night, couldn't concentrate**"* Patient, Hypersomnolence (Wehrle, 2011)
- *"One participant indicated that it negatively affected his decision making, whereas another reported that his **"short-term memory is shot."** One participant also reported, **"I just can't seem to concentrate right and I make stupid mistakes"*** Researcher summary, Insomnia (Kleinman, 2013)

There was an emphasis from the patient self-report that concentration, fatigue and memory difficulties were particularly pronounced at work and while driving due to the increased risk of mistakes and accidents.

- *"Having **trouble in focusing** and doing the work."* Patient, Circadian Rhythm Disorder (Bastille-Denis, 2020)
- *"impacts your workday, you're frustrated...I'm in charge of people, and I go and **snap out on them at work because I'm tired**"* Patient, Sleep related breathing disorders (Luyster, 2016)
- *"**I had three car accidents in six weeks**. They were ALL my fault. Two of them **I didn't even know I was involved in until afterwards.**"* Patient, Sleep related breathing disorders (Henry, 2012)

As noted above in the patient quotes, the immediate impacts of sleep disturbance also include an emotional component. A lack of sleep was reported to increase frustration, reduce patience and lower mood. Patients reported reacting negatively towards others they worked with or whom they were normally cordial, such as family and friends. They also noted that this was completely out of character and driven by the effects of sleep disturbance.

- *"**Feeling guilty, irritable or frustrated. Lacking patience, motivation or interest**"* Researcher summary, Circadian Rhythm (Bastille-Denis, 2020)
- *"Because when you do not sleep **you get moody, for no reason**. Even to my best friend, my parents...it would do like that (snaps fingers)"* Patient, Sleep breathing related disorder (Rudolph, 2018)
- *"**I'll just be in that really cranky mood**, and I don't want to say something I'm going to regret"* Patient, Hypersomnolence (Chen, 2022)

Finally, there were reports of unplanned napping from being overly tired in the day.

- *"You don't know what's happening with this situation. You don't know what you said. ... **Certain times you'll be dozing off** and you'll be saying some crazy stuff. When you wake up, people are mad at you."* Patient, Hypersomnolence (Chen, 2022)
- *"**patients reported that they fell asleep despite their best effort not to do so**"* Researcher summary, Stroke (Young, 2015)

However, not all napping was incidental. Coping mechanisms were mentioned substantially across TAs, though some unsuccessful, and mainly involved intentional napping and caffeine consumption.

- *"**Take a nap to refresh** and restart my body and brain"* Patient, Parkinson's Disease (Hogland, 2022)
- *"Two participants without cataplexy **consumed up to 15 cups of coffee per day**"* Researcher summary, Hypersomnolence (Wehrle, 2011)

Long term (distal) issues of sleep problems

Chronic sleep disruptions can have a long lasting impact on an individual's life and health. In the conceptual model, this has been defined in two broad categories: long-term health and life problems and long term problems that lead to more sleep problems, referred to here as perpetuating factors.

Long term health and life problems

Overall, the long term health and life problems are encapsulated by the following quote, showing in the patient's own words the wide impact sleep disruption has

- *"Because it's [insomnia] built up over a week or so many years or whatever, it kind of grinds you down, it does affect every single part of your day: : : and it's not just a minor thing, it is something major which just, you know,* ***it stops you from functioning daily.****"* Patient, Insomnia (Simon, 2010)

Patients reported that their mental health was impacted through issues such as depression, loneliness, and hopelessness. Social stigma, and an overall reduction in social life, a lack of support from peers and guilt from the long-term impact of sleep disruption on others was found to arise from chronic issues with sleep. This leads to patients feeling like they were not understood by others around them and to subsequently withdraw from life.

- *"[People say:]* ***I don't think you have narcolepsy. I think you're just tired****."* Patient, Hypersomnolence (Ong, 2021)
- *"****My friends don't understand,*** *they tell me to just go to bed early and get a good night of sleep...****It's frustrating because it's not my fault"*** Patient, Circadian Rhythm disorder (Montie, 2019)
- *"****We had a lot of good friends before****, several families that we spent time together with. He doesn't want to do that now... He's often tired and sleeps more."* Partner, Heart failure (Bronstrom, 2003)
- *"****They were able to "deal with it" by minimizing interactions*** *with their clients and co-workers, using such tactics as not picking up the telephone, using caller ID to screen calls, or staying in their offices"* Researcher summary, Insomnia (Kleinman, 2013)

Within the patients' own lives, there was a severe reduction in their ability to achieve goals or be engaged. A chronic disruption to sleep prevented patients from achieving their life goals, leading to guilt and regrets about the direction their life had taken

- *"I cannot keep up with developments and changes that are experienced by my friends or classmates ... When I return to school,* ***I seem to have missed out on everything****"* Patient, Circadian Rhythm disorder (Montie, 2019)
- *"I certainly have lots of regrets about my life and things that I haven't done and haven't achieved ...* ***if I could establish a sleep pattern again, I would take on a lot of challenges*** *in my life, ... I would definitely change a lot"* Patient, Insomnia (Simon, 2010)

<u>Perpetuating factors</u>

Some long-term impacts of disrupted sleep led to perpetuating factors that continued to reinforce the sleep disruption. Key concepts included patients' thoughts and feelings surrounding falling asleep, such as thoughts of anxiety, fear, worry and concern about their inability to fall asleep. This ultimately prevented the patients from achieving sleep. These patients found ways of changing their routine to help aid sleep, although these methods were not always representative of good sleep hygiene

- *"I've always thought I wished it was light all the time... I wished it didn't stop at night* ***you know because when the world stops, my heads still going and my worlds still going and, there's nobody there****."* Patient, Depression (Littlewood, 2016)
- *worrying, I wake up and can't go back to sleep"* Patient, Stroke (Cronfalk, 2020)
- *"****I wait until I'm dead tired****. I'm afraid of going to bed and I think this is a good way to cope with my situation" Patient,* Sleep Breathing Disorder (Bronstrom, 2007)

Discussion

This systematic literature review presents a significant advancement in understanding patient-centric accounts of sleep and sleep disturbances across TAs. Our results are summarized in a holistic conceptual model of sleep and sleep disturbances. This work begins to bridge the gap between subjective patient experiences and existing objective clinical measures. These results set the foundation for selecting sleep-related outcomes for evaluation across many TAs.

The conceptual model of sleep emphasizes patient perspectives, providing a robust framework for understanding sleep and its disturbances. Critically, this patient-centered approach enables researchers and clinicians to identify meaningful aspects of sleep experience that significantly impact patients' quality of life, going beyond the traditional Clinical Outcome Assessments (COAs). The model facilitates the integration of objective sleep measures in clinical research and practice. Although PSG is one available methodology for objective assessment of sleep, digital health technologies could be implemented alongside questionnaires for a more comprehensive sleep quality measurement. For example, the distal impacts in the model may be most appropriately measured using traditional COAs, whereas the sleep window issues could benefit from repeated assessment using digital health technologies.

The comparison between patients' views on sleep across the TAs underscores a critical insight: patients often perceive sleep quality not just in terms of quantity and consistency, but in how it affects their ability to engage in daily activities, emotional well-being, and overall health. This can be noted with patients concerned with their performance at work or with family and loved ones. Such concerns as this merit a push for novel outlooks on how to quantify sleep quality, outside the gold standard PSG, to fully capture the implications of sleep disruption in a naturalistic environment.

The results here, though broad, only examine 11 TAs, many of which are sleep disorders. Additionally, the review focuses on systematic sleep disturbance issues across therapeutic areas, as opposed to focusing on individual differences between TAs. It is clear that some aspects are more pertinent to a given TA than others. Although these TAs were selected to offer an omni-therapeutic insight to sleep disturbance, adopters of this model may want to supplement this work through further assessment of the literature in their specific therapeutic area of focus to ensure the concepts are appropriate and prioritized for their own work.

To fully realize the potential that digital measurement can offer to sleep measurement, a consistent approach, specifying a set of digitally mature, core sleep measures is needed. One way of accomplishing this is to build on existing recommendations, such as those arising from the National Sleep Foundation (American National Standards Institute/Consumer Technology Association/National Sleep Foundation;2022). The work presented here contributes to that goal through identifying patient relevant concepts arising consistently across multiple TAs. A future direction using this work to inform core measures of sleep that are meaningful and can be assessed in a patient's home environment will help to standardize the field sleep and allow greater comparability between results.

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References

(1) Tononi, G., & Cirelli, C. (2014). Sleep and the price of plasticity: from synaptic and cellular homeostasis to memory consolidation and integration. *Neuron*, *81*(1), 12–34. https://doi.org/10.1016/j.neuron.2013.12.025

(2) Diekelmann, S., & Born, J. (2010). The memory function of sleep. *Nature reviews. Neuroscience*, *11*(2), 114–126. https://doi.org/10.1038/nrn2762

(3) Thorpy M. J. (2012). Classification of sleep disorders. *Neurotherapeutics : the journal of the American Society for Experimental NeuroTherapeutics*, *9*(4), 687–701. https://doi.org/10.1007/s13311-012-0145-6

(4) Kwok, C. S., Kontopantelis, E., Kuligowski, G., Gray, M., Muhyaldeen, A., Gale, C. P., Peat, G. M., Cleator, J., Chew-Graham, C., Loke, Y. K., & Mamas, M. A. (2018). Self-Reported Sleep Duration and Quality and Cardiovascular Disease and Mortality: A Dose-Response Meta-Analysis. *Journal of the American Heart Association*, *7*(15), e008552. https://doi.org/10.1161/JAHA.118.008552

(5) Barone, I., Hawks-Mayer, H. & Lipton, J. O. Mechanisms of sleep and circadian ontogeny through the lens of neurodevelopmental disorders. *Neurobiol Learn Mem* 160, 160-172 (2019). https://doi.org:10.1016/j.nlm.2019.01.011

(6) Markun, L. C., & Sampat, A. (2020). Clinician-Focused Overview and Developments in Polysomnography. *Current sleep medicine reports*, *6*(4), 309–321. https://doi.org/10.1007/s40675-020-00197-5

(7) Rundo, J. V., & Downey, R., 3rd (2019). Polysomnography. *Handbook of clinical neurology*, *160*, 381–392. https://doi.org/10.1016/B978-0-444-64032-1.00025-4

(8) Arnardottir, E. S., Islind, A. S., & Óskarsdóttir, M. (2021). The Future of Sleep Measurements: A Review and Perspective. *Sleep medicine clinics*, *16*(3), 447–464. https://doi.org/10.1016/j.jsmc.2021.05.004

(9) Perez-Pozuelo, I., Zhai, B., Palotti, J., Mall, R., Aupetit, M., Garcia-Gomez, J. M., Taheri, S., Guan, Y., & Fernandez-Luque, L. (2020). The future of sleep health: a data-driven revolution in sleep science and medicine. *NPJ digital medicine*, *3*, 42. https://doi.org/10.1038/s41746-020-0244-4

(10) Amir-Behghadami, M., & Janati, A. (2020). Population, Intervention, Comparison, Outcomes and Study (PICOS) design as a framework to formulate eligibility criteria in systematic reviews. *Emergency Medicine Journal*.

(11) Higgins JP, Green S. Cochrane handbook for systematic reviews of interventions. Vol 4: John Wiley & Sons, 2011.

(12) Critical Appraisal Skills Programme (2023). CASP Qualitative Studies Checklist. [online] Available at: https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf. Accessed: July 2023.

(13) Miro (2022). Miro online whiteboard (no version provided). RealTimeBoard, Inc. www.miro.com

(14) Haighton, C., Watson, R. M., Wilson, J. A., & Powell, S. (2022). Perspectives on paediatric sleep-disordered breathing in the UK: a qualitative study. *The Journal of Laryngology & Otology*, 136(6), 520-526.

(15) Ye, L., Antonelli, M. T., Willis, D. G., Kayser, K., Malhotra, A., & Patel, S. R. (2017). Couples' experiences with continuous positive airway pressure treatment: a dyadic perspective. *Sleep Health*, 3(5), 362-367.

(16) Ahonen H, Broström A, Fransson EI, Neher M, Lindmark U. The terrible dryness woke me up, I had some trouble breathing-Critical situations related to oral health as

described by CPAP-treated persons with obstructive sleep apnea. *J Sleep Res*. 2022 Dec;31(6):e1

(17) Ong, J. C., Crawford, M. R., Kong, A., Park, M., Cvengros, J. A., Crisostomo, M. I., Alexander, E. I., & Wyatt, J. K. (2017). Management of Obstructive Sleep Apnea and Comorbid Insomnia: A Mixed-Methods Evaluation. *Behavioral sleep medicine*, 15(3), 180–197.

(18) Rudolph MA, Rotsides JM, Zapanta PE. The patient's perioperative perspective during the treatment of obstructive sleep apnea: a pilot study. *Sleep Breath*. 2018 Dec;22(4):997-1003. doi: 10.1007/s11325-018-1638-2. Epub 2018 Feb 8. PMID: 29423766.

(19) Chou, M. S. H., Ting, N. C. H., El-Turk, N., Harrington, Z., & Dobler, C. C. (2021). Treatment burden experienced by patients with obstructive sleep apnoea using continuous positive airway pressure therapy. *PloS one*, 16(6), e0252915. https://doi.org/10.1371/

(20) Luyster, F. S., Dunbar-Jacob, J., Aloia, M. S., Martire, L. M., Buysse, D. J., & Strollo, P. J. (2016). Patient and Partner Experiences With Obstructive Sleep Apnea and CPAP Treatment: A Qualitative Analysis. *Behavioral sleep medicine*, 14(1), 67–84. https://

(21) Hu, S. T., Yu, C. C., Lee, P. S., & Tsao, L. I. (2014). Life experiences among obstructive sleep apnoea patients receiving continuous positive airway pressure therapy. Journal of clinical nursing, 23(1-2), 268-278.

(22) Henry, D., & Rosenthal, L. (2013). “Listening for his breath:” The significance of gender and partner reporting on the diagnosis, management, and treatment of obstructive sleep apnea. *Social science & medicine*, 79, 48-56.

(23) Broström, A., Johansson, P., Strömberg, A., Albers, J., Mårtensson, J., & Svanborg, E. (2007). Obstructive sleep apnoea syndrome–patients' perceptions of their sleep and its effects on their life situation. *Journal of Advanced Nursing*, 57(3), 318-327.

(24) Davies, K., Lin, Y. L., Glenny, A. M., Callery, P., & Bruce, I. A. (2019). Parental Experience of Sleep-Disordered Breathing in Infants With Cleft Palate: Comparing Parental and Clinical Priorities. *The Cleft palate-craniofacial journal*: official publicatio

(25) Young, C. A., Mills, R. J., Gibbons, C., & Thornton, E. W. (2013). Poststroke fatigue: the patient perspective. *Topics in stroke rehabilitation*, 20(6), 478-484.

(26) Seiger Cronfalk, B., Åkesson, E., Nygren, J., Nyström, A., Strandell, A. M., Ruas, J., & von Euler, M. (2020). A qualitative study—Patient experience of tactile massage after stroke. *Nursing open*, 7(5), 1446-1452.

(27) Widar M, Ek AC, Ahlström G. Coping with long-term pain after a stroke. *J Pain Symptom Manage*. 2004 Mar;27(3):215-25. doi: 10.1016/j.jpainsymman.2003.07.006. PMID: 15010100.

(28) van Gilst MM, Cramer IC, Bloem BR, Overeem S, Faber MJ. A grounded theory study on the influence of sleep on Parkinson's symptoms. *BMC Res Notes*. 2016 Jun 10;9:299. doi: 10.1186/s13104-016-2114-3. PMID: 27283443; PMCID: PMC4901477.

(29) Wade, R., Pachana, N. A., Mellick, G., & Dissanayaka, N. (2020). Factors related to sleep disturbances for individuals with Parkinson’s disease: A regional perspective. *International Psychogeriatrics*, 32(7), 827-838.

(30) Höglund, A., Hagell, P., Östlund, U., Fredrikson, S., & Sandlund, C. (2022). Like a Wave in Its Variable Shape, Breadth, and Depth: A Qualitative Interview Study of Experiences of Daytime Sleepiness in People with Parkinson's Disease. *Parkinson's disease*, 2022, 9980177. https://doi.org/10.1155/2022/9980177

(31) Vigeta, S. M. G., Hachul, H., Tufik, S., & de Oliveira, E. M. (2012). Sleep in postmenopausal women. *Qualitative Health Research*, 22(4), 466-475.

(32) Hsu, H. C., Chen, N. H., Jou, H. J., An, C., & Tsao, L. I. (2009). Sleep disturbance experiences among perimenopausal women in Taiwan. *Journal of Clinical Nursing*, 18(15), 2116-2124.
(33) Carey, T. J., Moul, D. E., Pilkonis, P., Germain, A., & Buysse, D. J. (2005). Focusing on the experience of insomnia. *Behavioral sleep medicine*, 3(2), 73-86.
(34) Cheung, J. M., Saini, B., Bartlett, D. J., Laba, T. L., & Mason, P. H. (2017). Mapping the illness trajectories of insomnia: a biographical disruption?. *Sociology of Health & Illness*, 39(5), 659-679.
(35) Akram, U., Kay, S. & Fonquerine, Z. Qualitative Examination of Daytime Monitoring and Selective Attention in Insomnia. *Sleep Vigilance* 2, 149–155 (2018). https://doi.org/10.1007/s41782-018-0049-6
(36) Yung KP, Chung KF, Ho FY, Yeung WF, Ng TH. The Experience of Chronic Insomnia in Chinese Adults: A Study Using Focus Groups and Insomnia Experience Diaries. *Behav Sleep Med*. 2016 Jul-Aug;14(4):406-28. doi: 10.1080/15402002.2015.1017097. Epub 2015 Sep 22. PMI
(37) Lin, C. L., Lin, C. P., & Sun, J. C. (2022). Experiences of Middle-Aged and Older Taiwanese Adults With Chronic Insomnia: A Descriptive Qualitative Study. *Journal of gerontological nursing*, 48(11), 21–28. https://doi.org/10.3928/00989134-20221003-06
(38) Hiller, R. M., Lovato, N., Gradisar, M., Oliver, M., & Slater, A. (2014). Trying to fall asleep while catastrophising: what sleep-disordered adolescents think and feel. *Sleep Medicine*, 15(1), 96-103.
(39) Berkley, A. S., Carter, P. A., Yoder, L. H., Acton, G., & Holahan, C. K. (2020). The effects of insomnia on older adults' quality of life and daily functioning: A mixed-methods study. *Geriatric nursing* (New York, N.Y.), 41(6), 832–838. https://doi.org/10.101
(40) Kleinman L, Buysse DJ, Harding G, Lichstein K, Kalsekar A, Roth T. Patient-reported outcomes in insomnia: development of a conceptual framework and endpoint model. *Behav Sleep Med*. 201311(1):23-36. doi: 10.1080/15402002.2011.607199. PMID: 23347114.
(41) Kyle SD, Espie CA, Morgan K. ...Not just a minor thing, it is something major, which stops you from functioning daily: quality of life and daytime functioning in insomnia. *Behav Sleep Med*. 20108(3):123-40. doi: 10.1080/15402002.2010.487450. PMID: 20582756.
(42) Harvey, A. G., Stinson, K., Whitaker, K. L., Moskovitz, D., & Virk, H. (2008). The subjective meaning of sleep quality: a comparison of individuals with and without insomnia. *Sleep*, 31(3), 383–393. https://doi.org/10.1093/sleep/31.3.383
(43) Andrews, L. K., Coviello, J., Hurley, E., Rose, L., & Redeker, N. S. (2013). “I'd eat a bucket of nails if you told me it would help me sleep:” Perceptions of insomnia and its treatment in patients with stable heart failure. *Heart & lung*, 42(5), 339-345.
(44) Inyom, C., Haese, T., Schoenrath, F., Potapov, E., & Knierim, J. (2022). Lived experiences of patients implanted with left ventricular assist devices. *Heart & Lung*, 55, 155-161.
(45) Gullvåg, M., Gjeilo, K. H., Fålun, N., Norekvål, T. M., Mo, R., & Broström, A. (2019). Sleepless nights and sleepy days: a qualitative study exploring the experiences of patients with chronic heart failure and newly verified sleep-disordered breathing. *Scandinavian journal of caring sciences*, 33(3), 750–759. https://doi.org/10.1111/scs.12672
(46) Broström A, Strömberg A, Dahlström U, Fridlund B. Congestive heart failure, spouses' support and the couple's sleep situation: a critical incident technique analysis. *J Clin Nurs*. 2003 Mar;12(2):223-33, 34. doi: 10.1046/j.1365-2702.2003.00692.x. PMID: 126035
(47) DiFusco, L. A., Saylor, J. L., & Schell, K. A. (2020). Maternal experiences of caring for a child with a ventricular assist device. *Pediatric transplantation*, 24(1), e13620.

(48) Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S., & Small, N. (2006). Prevalence of symptoms in a community-based sample of heart failure patients. *Journal of pain and symptom management*, 32(3), 208–216. https://doi.org/10.1016/j.jpain

(49) Conroy, D. A., Czopp, A. M., Dore-Stites, D., Dopp, R. R., Armitage, R., Hoban, T. F., & Arnedt, J. T. (2017). A pilot study on adolescents with depression and insomnia: qualitative findings from focus groups. *Behavioral sleep medicine*, 15(1), 22-38.

(50) Bitew, T., Keynejad, R., Honikman, S., Sorsdahl, K., Myers, B., Fekadu, A., & Hanlon, C. (2020). Stakeholder perspectives on antenatal depression and the potential for psychological intervention in rural Ethiopia: a qualitative study. *BMC pregnancy and child*

(51) Jernslett, M., Thackeray, L., Orchard, F., & Midgley, N. (2021). The experience of sleep problems for adolescents with depression in short-term psychological therapy. *Clinical child psychology and psychiatry*, 26(4), 938-953.

(52) Pereira B, Andrew G, Pednekar S, Pai R, Pelto P, Patel V. The explanatory models of depression in low income countries: listening to women in India. *J Affect Disord*. 2007 Sep;102(1-3):209-18. doi: 10.1016/j.jad.2006.09.025. Epub 2006 Oct 30. PMID: 17074394.

(53) Gebara, M. A., DiNapoli, E., Hamm, M. E., Rodriguez, K. L., Kasckow, J. W., Lederer, L. G., Bramoweth, A. D., & Karp, J. F. (2020). Illness narratives and preferences for treatment among older veterans living with treatment-resistant depression and insomnia. *Annals of clinical psychiatry : official journal of the American Academy of Clinical Psychiatrists*, 32(2), 81–89.Littlewood, D. L., Gooding, P., Kyle, S. D., Pratt, D., & Peters, S. (2016). Understanding the role of sleep in suicide risk: qualitative interview study. *BMJ open*, 6(8), e012113. https://doi.org/10.1136/bmjopen-2016-012113

(54) Montie, K., Quaedackers, L., Perlitius, V., van der Horst, E., Vandenbussche, N., Overeem, S., & Pillen, S. (2019). The impact of delayed sleep phase disorder on adolescents and their family. *Sleep Medicine*, 64, 15-22.

(55) Bastille-Denis E, Lemyre A, Pappathomas A, Roy M, Vallières A. Are cognitive variables that maintain insomnia also involved in shift work disorder? *Sleep Health*. 2020 Jun;6(3):399-406. doi: 10.1016/j.sleh.2020.02.015. Epub 2020 Apr 9. PMID: 32280017.

(56) Ose, S. O., Tjønnås, M. S., Kaspersen, S. L., & Færevik, H. (2019). One-year trial of 12-hour shifts in a non-intensive care unit and an intensive care unit in a public hospital: a qualitative study of 24 nurses' experiences. *BMJ open*, 9(7), e024292.

(57) Franceschini, C., Fante, C., Folli, M. C., Filosa, M., Pizza, F., Antelmi, E., ... & Plazzi, G. (2020). Giving a voice to cataplectic experience: recollections from patients with narcolepsy type 1. *Journal of Clinical Sleep Medicine*, 16(4), 597-603.

(58) Chen, A., Parmar, A., Naik, T., Hutchinson, C., Frankel, L., Zweerink, A., ... & Narang, I. (2022). Living with narcolepsy during adolescence: A qualitative study. Canadian Journal of Respiratory, Critical Care, and Sleep Medicine, 6(3), 161-168.

(59) Ong, J. C., Fox, R. S., Brower, R. F., Mazurek, S., & Moore, C. (2021). How Does Narcolepsy Impact Health-Related Quality of Life? A Mixed-Methods Study. Behavioral sleep medicine, 19(2), 145–158. https://doi.org/10.1080/15402002.2020.1715411

(60) Wehrle, R., & Bruck, D. (2011). Growing up with narcolepsy: consequences for adolescents and young adults. *Somnologie-Schlafforschung und Schlafmedizin*, 15(1), 32-38.

(61) Dantas FG, Medeiros JL, Farias KS, Ribeiro CD. Restless legs syndrome in institutionalized elderly. *Arq Neuropsiquiatr*. 2008 Jun;66(2B):328-30. doi: 10.1590/s0004-282x2008000300008. PMID: 18641865.

(62) Picchietti, D. L., Arbuckle, R. A., Abetz, L., Durmer, J. S., Ivanenko, A., Owens, J. A., Croenlein, J., Allen, R. P., & Walters, A. S. (2011). Pediatric restless legs syndrome: analysis of symptom descriptions and drawings. *Journal of child neurology*, 26(11
(63) Jacobson CJ Jr. The nightmares of Puerto Ricans: an embodied 'altered states of consciousness' perspective. *Cult Med Psychiatry*. 2009 Jun;33(2):266-89. doi: 10.1007/s11013-009-9135-5. PMID: 19326194.
(64) American National Standards Institute/Consumer Technology Association/National Sleep Foundation (2022). Definitions and Characteristics for Wearable Sleep Monitors. ANSI/CTA/NSF-2052.1-A. https://www.thensf.org/wp-content/uploads/2022/10/ANSI-CTA-NSF-2052.1-A-FINAL.pdf

Figure legends:

Supplemental Material:

Supplemental material 1. The analysis CASP analysis performed.
Supplemental material 2. Quotes coded from patients.

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