

“Sleeping My Life Away”: Experiences of Living with Idiopathic Hypersomnia

Kristoffer Bothelius, Nadjela Salimi, Rebecca E. M. Lehtilä, Tomas Furmark & Christina Nehlin Gordh

To cite this article: Kristoffer Bothelius, Nadjela Salimi, Rebecca E. M. Lehtilä, Tomas Furmark & Christina Nehlin Gordh (2025) “Sleeping My Life Away”: Experiences of Living with Idiopathic Hypersomnia, Behavioral Sleep Medicine, 23:3, 360-368, DOI: [10.1080/15402002.2025.2475913](https://doi.org/10.1080/15402002.2025.2475913)

To link to this article: <https://doi.org/10.1080/15402002.2025.2475913>



© 2025 The Author(s). Published with license by Taylor & Francis Group, LLC.



[View supplementary material](#)



Published online: 07 Mar 2025.



[Submit your article to this journal](#)



Article views: 494



[View related articles](#)



[View Crossmark data](#)

“Sleeping My Life Away”: Experiences of Living with Idiopathic Hypersomnia

Kristoffer Bothelius^a, Nadjela Salimi^b, Rebecca E. M. Lehtilä^b, Tomas Furmark^b, and Christina Nehlin Gordh^c

^aDepartment of Surgical Sciences, Uppsala University, Uppsala, Sweden; ^bDepartment of Psychology, Uppsala University, Uppsala, Sweden; ^cDepartment of Medical Sciences, Uppsala University, Uppsala, Sweden

ABSTRACT

Objectives: Individuals with idiopathic hypersomnia (IH) report several subjective emotional and cognitive symptoms, as well as impairments in daily functioning. Coping strategies are frequently used, but their effectiveness is perceived to be minimal. The aim of the present study was to delve into the patient perspective on navigating life with IH, emphasizing patients’ personal narratives.

Method: Utilizing a purposeful sample method, twelve participants diagnosed with IH underwent telephone interviews guided by a semi-structured protocol. The interviews were subjected to thematic analysis to extract relevant themes.


Results: Analysis unveiled three primary themes along with subthemes: 1) Being confined, characterized by excessive daytime sleepiness, negative emotional processes and cognitive disturbances, 2) Missing out on life, involving loss of time and adverse social consequences, and 3) Trying to cope, encompassing strategies like napping, adapting, activating oneself and mentally fighting sleepiness, while also embracing acceptance and self-compassion.

Conclusions: The identified themes reflected numerous aspects previously reported to be associated with living with IH. Notably, the study brought novel subthemes to light, such as the existential dilemma of “sleeping one’s life away” and feelings of guilt and shame. Furthermore, the study underscored the significance of acceptance and self-compassion as coping strategies.

Introduction

Idiopathic hypersomnia (IH) is a rare central hypersomnolence disorder characterized by excessive daytime somnolence and frequently notable sleep inertia, despite sufficient or prolonged sleep duration, typically spanning 12 to 14 hours (Trotti & Arnulf, 2021). In the revised third edition of the International Classification of Sleep Disorders (ICSD-3 TR), the diagnostic criteria include daily periods of irrepressible need to sleep, or daytime lapses into sleep occurring for at least three months, no cataplexy, multiple sleep latency tests with mean sleep latency <8 minutes or total sleep time >660 minutes, without evidence of insufficient sleep syndrome or findings consistent with a diagnosis of narcolepsy type 1 or 2, and not better explained by another disorder or use of drugs or medications (American Academy of Sleep Medicine, 2023). The prevalence of IH is not precisely known, but considered to be approximately 10% of that of narcolepsy (Billiard & Dauvilliers, 2001), and most IH

CONTACT Kristoffer Bothelius  kristoffer.bothelius@uu.se  Department of Surgical Sciences, Uppsala University, Uppsala University Hospital, Uppsala 751 85, Sweden

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/15402002.2025.2475913>

© 2025 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

studies are small, comprising 10 to 77 participants (Vernet et al., 2010). However, recent data suggest that the condition may be more common than previously presumed, with an estimated prevalence of 1.5% within the working population (Plante et al., 2024).

Individuals with IH frequently report subjective experiences of mental fatigability, memory problems, attention deficits, not feeling revitalized after a usual night's sleep or a nap (Vernet et al., 2010), depressive symptoms, and impairments in daily functioning (Stevens et al., 2023). These challenges contribute to an overall reduction in health-related quality of life (Ozaki et al., 2012; Wasling et al., 2020). The US Food and Drug Administration has approved sodium oxybate for the treatment of adults with IH (Trotti, 2022). A Cochrane review has shown that modafinil is effective against self-reported sleepiness, improves the ability to remain awake, and significantly decreases disease gravity (Trotti et al., 2021). The optimal role of various pharmacological treatments in future paradigms remains unclear. Due to the heterogeneity of IH, treatments should be tailored to the clinical presentation, comorbidities, lifestyle, and potential adverse effects (Arnulf et al., 2023). However, symptoms frequently persist despite pharmacological treatment (Trotti et al., 2020), necessitating the use of nonpharmacological strategies. Although daytime napping is unrefreshing for more than half of the IH population (Mombelli et al., 2023), it remains the most frequently used strategy for managing IH. This is followed by planned nocturnal sleep, using caffeine, and exercising, although the perceived effect of these strategies is low (Neikrug et al., 2017). However, a novel cognitive behavioral therapy for hypersomnia (CBT-H) shows potential in reducing depressive symptoms and improving self-efficacy (Ong et al., 2020).

Notwithstanding the existing body of research on IH, there is a scarcity of qualitative interview studies, which offers participants the opportunity to express their personal thoughts, emotions, and lived experiences of managing IH. A deepened understanding could contribute to the enhancement of therapeutic interventions and the direction of future research endeavors. Thus, the aim of the present study was to explore the participants' perspectives on living and coping with IH.

Methods

Setting and participants

Participants were selected among individuals diagnosed with IH at the Sleep Unit at Uppsala University Hospital, Sweden, using polysomnography and multiple sleep latency tests. Between 1 January 2010 and 31 December 2019, there were 216 potential participants, of whom 193 met the inclusion criteria for the study: fulfilling diagnostic criteria for IH and age between 18 and 70 years at the time of data collection. Written information about the study and a consent form were sent by post to all potential participants. Informed consent was obtained from 93 individuals. From this group, a purposeful sample of twelve individuals was selected to mirror the overall age distribution and maintain the 3:2 ratio of women to men present in the entire eligible sample. This sampling method was utilized to ensure that the final sample accurately represented the age and sex distribution of the initial group. The study was approved by the Swedish Ethical Review Authority (Dnr 2021-03458).

Procedure

The research team developed a semi-structured interview guide, drawing on clinical expertise and existing knowledge of idiopathic hypersomnia's impact on daily life (Vernet et al., 2010) and its management strategies (Neikrug et al., 2017). The questions pertained to the participants' experiences of living with IH. After the first four interviews, the interview guide was assessed and revised to better encapsulate the research question through the addition of questions on wakefulness and moving the focus from sleep only. All interviews, including the first four, were included in the analysis. The revised interview guide is enclosed in the Supplemental material, see Supplemental Table 1.

Interviews were held in Swedish by authors NS and RL, who were senior psychology students at the time. The interviewers periodically summarized the participants' answers to ensure they were correctly understood, and probing was used when there was a need for clarification. None of the interviewed persons was previously acquainted with the interviewers. After thorough discussions within the research group, we deemed it unlikely that our pre-understandings affected the interview process or the interpretation of the results in any manner that could introduce bias. Data were collected through voice calls and recorded with an audio recorder. The interviews, conducted in Swedish, were transcribed verbatim by the interviewers.

Data analysis

The interview data were analyzed using applied thematic analysis (Guest et al., 2012), a method that integrates elements from various theoretical and methodological perspectives. The primary objective of applied thematic analysis is to present participants' thoughts and experiences as accurately and comprehensively as possible. The analysis was performed by NS, RL, and CNG, a senior researcher with extensive experience in qualitative research methods. The analysis began with thorough familiarization with the data, followed by the identification and coding of patterns into themes and sub-themes. This was a dynamic, iterative process involving repeated reading and revising of the themes, rather than a linear progression. Instead of utilizing software, codes and themes were collaboratively developed and refined during regular joint meetings. Themes were identified and analyzed inductively, meaning they emerged directly from the data rather than from predetermined hypotheses. The analysis continued until the authors reached consensus that the themes were clearly defined and accurately reflected the data.

Results

Upon completion of twelve interviews, information from the last ones did not yield any changes to the previously identified themes. Thus, we deemed that saturation was achieved (Guest et al., 2020; Malterud et al., 2016). The participants ($n = 12$) were eight women and four men. Their mean age was 38 years ($SD \pm 11.5$, range = 24–62). The interviews lasted between 17 and 47 minutes ($M = 28$, $SD \pm 8.5$). In the analysis of the interviews, three major themes were identified: 1) Being confined, 2) Missing out on life, and 3) Trying to cope. The themes and subthemes are presented below, with verbatim quotes translated into English, to illustrate the findings.

Theme 1: being confined

Negative emotional processes

Participants in this study reported experiencing negative emotions associated with their IH. They expressed feelings of sadness, hopelessness, and a lack of motivation:

If I'm very tired, everything is annoying and I feel really depressed, and then I just want to sleep. (...) I feel so bad that I, when I felt really bad, when I was working, before I went on sick leave, I got really depressed, and didn't care if I lived. Everything irritates me, the only thing I can think about is sleeping. It's like the only thing that exists then. (#6)

The overwhelming fatigue and constant sleepiness contributed to emotional distress:

When you don't have the energy and can't do what you want, then you feel limited. And then you get sad and low, unfortunately. (#4)

Anxious thoughts were prevalent, with participants expressing worries about the future and whether their sleeping problems would improve:

Will this ever get better? Will it get worse? That's something no one knows. (#6)

Participants also mentioned fear of starting a family due to their IH and its impact on childcare capacity, and fear about their future ability to support themselves:

What worries me the most is that I will not be able to support myself. (#6)

Feelings of guilt and shame were also common; guilt for not being able to fulfill responsibilities or meet societal expectations due to their excessive need for sleep, and shame and self-blame for an inability to function like people without IH:

There is this feeling of guilt that I'm not doing enough, that I'm letting people down. (#1)

Excessive daytime sleepiness

All participants described a significant need for sleep, feelings of constant sleepiness, bodily heaviness, and occasional nausea. Periods of idleness, for instance during school lectures or work meetings, led to difficulties staying awake, with a sudden, intense urge to sleep:

I can't say that it is paralyzing fatigue, because it's not. But it's a very sudden, heavy sleepiness. It's difficult to describe. Sometimes, it feels as if the body is not getting sufficient oxygen. You yawn and breathe. I do get enough oxygen though. It's mainly that I feel a huge drowsiness . . . And it can come suddenly. . . . I don't notice when I fall asleep. (#5)

They described an overwhelming preoccupation with sleep during these periods and not being able to think of anything but sleep. However, none of the participants characterized the urge as uncontrollable, i.e., they were able to stay awake if necessary:

No, it's not that I can't handle it, but rather that I feel extremely, extremely tired, and I really struggle not to fall asleep if I lie down and relax. In those moments, I need to interrupt what I'm doing and get up to do something else, just to combat that overwhelming fatigue. It's like, you would do anything to be able to sleep [at that moment], even just a little while. But it's not that I involuntarily fall asleep, it's more about feeling this extreme fatigue and almost getting angry because all you want is to be left alone to sleep for a while. (#10)

Participants said that sleep came easily, regardless of previous daytime naps, season, and activity level, though there was a variation, with some participants also recounting difficulties falling asleep due to stress and fear of parasomnias, such as sleep paralysis and nighttime hallucinations:

I get sleep paralysis and some nights I can't sleep at all. So, it's very varied. (#12)

Cognitive disturbances

Participants described having mental fatigue on many occasions. This was distinct from bodily tiredness, as it involved slow thinking and an inability to maintain focus:

I'm very . . . brain tired or whatever I should call it, during the day. Very slow in the head, sort of. I am not so sharp in my thinking. (#8)

Participants reported having depleted energy reserves, and that all their energy was consumed by their day jobs.

Theme 2: missing out on life

Lost time

The consequences of IH were highly disruptive and participants emphasized the substantial amount of time they lost due to their excessive need for sleep:

It's like this, I can go to bed and sleep for several hours, whether it's during the day or in the morning. It feels like a significant amount of time is being wasted. And it's not . . . It's not depressing . . . It's disappointing, because there are so many other things I would have liked to do instead. That's it. Yes, that's it. It's the feeling that a lot of time is slipping away, that I could have done something else with. (#5)

This lost time led to frustration and a sense of missing out on life's experiences:

So much time just disappears. Feels like I'm sleeping my life away. (. . .) Yes, I don't have time for much else, I don't have the energy for much more than work. All my strength goes into that. Other than that, when I'm finally home, I can't do much. I only do what absolutely needs to be done, like taking the dogs out or buying groceries. Not much else gets accomplished. My friends have grown tired of me a long time ago. I couldn't join them going out, whether it's for a meal or to have fun. It mostly ends with me staying at home. So, it's tough. (#4)

Participants expressed feelings of sadness when seeing friends and family progressing in their lives while they felt stagnant, unable to achieve normative milestones such as securing a job, completing their education, or starting a family.

And it was really difficult to see my friends move on with their lives while I could barely get out the door. (#6)

Social consequences

The exaggerated need for sleep was felt to have a negative impact on family life:

My partner thinks we don't have much time together because I often sleep. I can't remember the last time I finished watching a movie. I think I've hardly ever seen a whole movie because as soon as I sit or lie down to watch TV, I fall asleep. (. . .) I can go to bed around the same time as my children, around 8, 9, at the latest 10, and sleep through the night. But even when I wake up in the morning, I can go back to bed and continue sleeping. So, a lot of time goes into sleep, but I have still found a balance that allows me to have a functioning work life, at least, and it's more my family that gets affected by this fatigue. (#10)

Participants also described negative reactions and prejudice from others about their sleepiness, with perceptions that they were being lazy:

That's actually the most difficult part, that people can get annoyed because I don't have the energy to join in on things or socialize in the same way . . . Like my friends might do. (#12)

This was often described as a feeling of being misunderstood. They felt that their diagnosis was not recognized and support was not provided readily:

Not many people understand what it means to be mentally fatigued. It sounds almost like it's made up, but I do have this diagnosis. (#4)

However, others recounted having supportive friends and family members who they felt both understood their problems and helped them in everyday life, e.g., by helping them go shopping.

Theme 3: trying to cope

Napping

Taking a nap was the primary coping strategy reported:

I usually . . . at work for example, you can go to a recovery room for a while and just lie down and close your eyes. Just for 20 minutes, it can help. I've sort of tried to find my own ways of managing everyday life anyhow. (#3)

However, naps had mixed results; some participants described them as helpful to make it through the day, while others did not feel that this was the case:

It doesn't matter if I got a full night's sleep or if I took a nap. Regardless of if it's a short nap or a long nap, I never feel like I'm awake. (#2)

Adapting

Participants described the importance of adjusting their daily routines to accommodate their IH symptoms, emphasizing the need to prioritize tasks during periods of higher energy and to plan their activities. Through effective daily structuring, participants sought to optimize their functioning and conserve energy for essential tasks:

I try to maintain my routines as best as I can and not break them, so I exercise at regular hours, eat at regular hours, and go to sleep at regular hours. So, that's what I felt has actually made a difference. (#12)

Activating oneself

Participants reported using specific activities to promote wakefulness and combat sleepiness. These included engaging in mentally stimulating tasks such as handcraft, going for walks, and using a mobile phone for entertainment. By engaging in such activities, they sought to sustain alertness and counteract the pervasive drowsiness associated with IH. However, the effectiveness of these strategies varied between individuals:

Other strategies are to just keep going, finding things that catch my interest. It doesn't make me less tired, but I become a little more alert . . . if there are things that are very, very interesting. (#9)

Fighting mentally

Participants described pushing through the sleepiness when they had no other option, but reported that this would come at a later "cost": low mood, irritability, and a need to catch up on sleep:

I think the most challenging thing about living with my diagnosis is that I have to ignore a clear signal. I have to ignore that signal and force myself to do things even though there's a loud scream telling me that I need to sleep. And that leads to . . . well, it's not always good to ignore this signal. (#9)

Acceptance

Participants emphasized the importance of acceptance and self-compassion in coping with their IH. They recognized the need to be kind to themselves and acknowledge their limitations:

You must be kind to yourself. Yes, I think that the first step is to accept it. That's really the only thing you can do. (#1)

By accepting their situation and making accommodations, some participants aimed to reduce self-blame and cultivate a more positive mind-set:

It's something that I've had to learn to live with. To try and encourage myself and believe that I'm worthy even if I don't perform up to par. Yeah, to simply exist. And I don't have the same abilities I did before, but this is where I am, and I'm doing what I can, and that has to be enough. (#6)

Discussion

In this study, three distinct themes were identified. The first theme, being confined, comprised the diagnostic criterion of excessive daytime sleepiness, as well as cognitive disturbances and negative emotional processes in the form of depression and anxiety. This theme aligns with published questionnaire data in which more than half of the respondents reported moderate to severe depressive symptoms and cognitive complaints, such as brain fog (Stevens et al., 2023; Vernet et al., 2010). Although it has been hard to quantify objective differences compared with controls with regard to cognitive functions, impairments in certain aspects of attention, as measured by neuropsychological tests, have been reported (Filardi et al., 2021). IH-related guilt and shame have not been studied specifically, but guilt has been reported in relation to other chronic diseases (Cerna et al., 2022). Inconsistency in findings regarding guilt in chronic conditions identified by Cerna et al. (2022) highlights the need for further research in this area. However, patient – provider interactions have been shown to be constrained by patient self-blame and guilt (Franklin et al., 2018). The feeling of guilt

might impact adherence or compliance to treatment plans, but research suggests that acceptance of the disease plays a more crucial role. Higher acceptance levels are associated with better adherence (Bonikowska et al., 2021).

The second theme, missing out on life, with the subthemes lost time and social consequences, reflected more existential aspects of quality of life. These aspects may not be easily transferred to questionnaire items or objective testing, but subjective impairments in social functioning and perceived prejudice have been described (Stevens et al., 2023), as well as impaired general health-related quality of life (Ozaki et al., 2012; Wasling et al., 2020). However, the distinct sense that life is passing by and that others are maturing and developing, while you are sleeping away your time, has not been reported before in connection with IH.

The third theme, trying to cope, includes apparent and previously reported strategies such as napping, adapting, and activating oneself (Neikrug et al., 2017). The perceived limited effectiveness of these approaches was in line with previous results (Vernet et al., 2010). Less visible and more rarely reported approaches, such as fighting mentally and “pushing through” the sleepiness, were also found in the present study. The participants emphasized the significance of acceptance and self-compassion as crucial components in navigating life with IH. These concepts have been recognized as potentially important in both management and treatment of other long-term diseases (Ambrosio et al., 2015; Kilic et al., 2021). Acceptance can be seen as the opposite of fighting, which is suggested to be a possible avoidance pattern in insomnia (Bothelius et al., 2015), and self-compassion has been described as the opposite of shame (Gilbert, 2017). Acceptance and mindfulness-based therapies have demonstrated efficacy in treating anxiety and depression (Johannsen et al., 2022). However, while approaches based on acceptance and self-compassion have not been described specifically in relation to IH, interventions targeting these concepts have been included in treatment packages for hypersomnia (Ong et al., 2020).

While previous studies on IH have primarily relied on standardized measures, this study’s qualitative approach allowed participants to express their thoughts in their own words, providing a more nuanced and comprehensive understanding of their experiences. From a scientific standpoint, the qualitative findings from this study can lead to the development of new hypotheses regarding the nature of IH and its treatment. Qualitative studies, such as the current one, are valuable as they enable individuals to share their personal experiences and thoughts, offering caregivers valuable insights into the lived experiences of patients with IH. Understanding patients’ perspectives is essential, as successful treatment often relies on patients feeling understood by their caregiver (Cooley & Lajoy, 1980). This understanding can enhance the caregiver-patient relationship and improve treatment effectiveness. Given the absence of an established treatment algorithm or standardized protocols for IH, a highly individualized approach is necessary, combining both pharmacologic and nonpharmacologic strategies (Arnulf et al., 2023). However, treatment accessibility is further complicated by the lack of robust evidence for nonpharmacological interventions and the limited availability of specialists, particularly in cognitive-behavioral therapy (Thorpy et al., 2024).

In the present study, participants reflected many previously reported aspects of living with IH, such as excessive daytime sleepiness, cognitive disturbances, and emotional distress, while also revealing novel insights, including the existential experience of “sleeping life away,” along with profound feelings of guilt and shame. Additionally, acceptance and self-compassion emerged as important coping strategies for this patient group. These findings indicate that future research should investigate how these concepts can be applied in understanding and managing individuals with IH. Integrating these approaches into IH treatment could provide more tailored and effective strategies, addressing a significant gap in current treatment modalities.

Strengths and limitations

A notable strength is that the study was conducted in a clinical setting, involving individuals who had been referred to and subsequently diagnosed at a specialist sleep clinic. Another strength was the use of a semi-structured interview guide that allowed the participants to use their own words to describe their

experiences, and that the guide was revised early on, to better capture the unique aspects of the participants' stories. This study, consistent with many qualitative research designs, utilized a small sample size. However, this should not be viewed as a limitation. Qualitative research prioritizes generating new insights over generalizability, particularly in contexts like this study, where the focus is on life with a rare, complex, and potentially highly disabling condition that remains relatively unknown.

Acknowledgments

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors utilized ChatGPT-4 for language editing in order to enhance clarity and expression. After using this tool, the authors reviewed and edited the content as needed and takes full responsibility for the content of the published article.

Author contributions

CRedit: **Kristoffer Bothelius**: Project leader, Study design, Planning, Preparations, Interpretation, Writing and revising manuscript; **Nadjela Salimi**: Data collection, Analyses, Interpretation, Writing and Revising manuscript; **Rebecca E. M. Lehtilä**: Data collection, Analyses, Interpretation, Writing and Revising manuscript; **Tomas Furmark**: Supervision, Analyses, Interpretation and Revising manuscript; **Christina Nehlin Gordh**: Development of procedures, Planning, Preparations, Training of interviewers, Supervision, Analyses, Interpretation, Preparing, Writing and Revising manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Kristoffer Bothelius  <http://orcid.org/0000-0002-3075-4861>

References

- Ambrosio, L., Senosiain Garcia, J. M., Riverol Fernandez, M., Anaut Bravo, S., Diaz De Cerio Ayesa, S., Ursua Sesma, M. E., Caparros, N., & Portillo, M. C. (2015). Living with chronic illness in adults: A concept analysis. *Journal of Clinical Nursing*, 24(17–18), 2357–2367. <https://doi.org/10.1111/jocn.12827>
- Arnulf, I., Thomas, R., Roy, A., & Dauvilliers, Y. (2023). Update on the treatment of idiopathic hypersomnia: Progress, challenges, and expert opinion. *Sleep Medicine Reviews*, 69, 101766. <https://doi.org/10.1016/j.smr.2023.101766>
- Billiard, M., & Dauvilliers, Y. (2001). Idiopathic hypersomnia. *Sleep Medicine Reviews*, 5(5), 349–358. <https://doi.org/10.1053/smr.2001.0168>
- Bonikowska, I., Szwamel, K., & Uchmanowicz, I. (2021). Analysis of the impact of disease acceptance, demographic, and clinical variables on adherence to treatment recommendations in elderly type 2 diabetes mellitus patients. *International Journal of Environmental Research and Public Health*, 18(16), 8658. <https://doi.org/10.3390/ijerph18168658>
- Bothelius, K., Jernelov, S., Fredrikson, M., McCracken, L. M., & Kaldo, V. (2015). Measuring acceptance of sleep difficulties: The development of the sleep problem acceptance questionnaire. *Sleep*, 38(11), 1815–1822. <https://doi.org/10.5665/sleep.5170>
- Cerna, A., Malinakova, K., Van Dijk, J. P., Zidkova, R., & Tavel, P. (2022). Guilt, shame and their associations with chronic diseases in Czech adults. *Psychology, Health and Medicine*, 27(2), 503–512. <https://doi.org/10.1080/13548506.2021.1903058>
- Cooley, E. J., & Lajoy, R. (1980). Therapeutic relationship and improvement as perceived by clients and therapists. *Journal of Clinical Psychology*, 36(2), 562–570. <https://doi.org/10.1002/jclp.6120360230>

- Filardi, M., D'Anselmo, A., Agnoli, S., Rubaltelli, E., Mastria, S., Mangiaruga, A., Franceschini, C., Pizza, F., Corazza, G. E., & Plazzi, G. (2021). Cognitive dysfunction in central disorders of hypersomnolence: A systematic review. *Sleep Medicine Reviews*, 59, 101510. <https://doi.org/10.1016/j.smrv.2021.101510>
- Franklin, M., Lewis, S., Willis, K., Bourke-Taylor, H., & Smith, L. (2018). Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness*, 14(2), 79–103. <https://doi.org/10.1177/1742395317710082>
- Gilbert, P. (2017). Shame and the vulnerable self in medical contexts: The compassionate solution. *Medical Humanities*, 43(4), 211–217. <https://doi.org/10.1136/medhum-2016-011159>
- Guest, G., MacQueen, K., & Namey, E. (2012). *Applied thematic analysis*. <https://methods.sagepub.com/book/applied-thematic-analysis>
- Guest, G., Namey, E., Chen, M., & Soundy, A. (2020). A simple method to assess and report thematic saturation in qualitative research. *PLOS ONE*, 15(5), e0232076. <https://doi.org/10.1371/journal.pone.0232076>
- American Academy of Sleep Medicine. (2023). *International classification of sleep disorders* (3rd ed. text rev.) Darien, IL: Author.
- Johannsen, M., Nissen, E. R., Lunderoff, M., & O'Toole, M. S. (2022). Mediators of acceptance and mindfulness-based therapies for anxiety and depression: A systematic review and meta-analysis. *Clinical Psychology Review*, 94, 102156. <https://doi.org/10.1016/j.cpr.2022.102156>
- Kilic, A., Hudson, J., McCracken, L. M., Ruparelia, R., Fawson, S., & Hughes, L. D. (2021). A systematic review of the effectiveness of self-compassion-related interventions for individuals with chronic physical health conditions. *Behavior Therapy*, 52(3), 607–625. <https://doi.org/10.1016/j.beth.2020.08.001>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *The Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Mombelli, S., Deshaies-Rugama, A. S., Blais, H., Sekerovic, Z., Thompson, C., Desautels, A., Montplaisir, J., Nigam, M., Carrier, J., & Gosselin, N. (2023). Are unrefreshing naps associated with nocturnal sleep architecture specificities in idiopathic hypersomnia? *Sleep*, 46(11). <https://doi.org/10.1093/sleep/zsad175>
- Neikrug, A. B., Crawford, M. R., & Ong, J. C. (2017). Behavioral sleep medicine services for hypersomnia disorders: A survey study. *Behavioral Sleep Medicine*, 15(2), 158–171. <https://doi.org/10.1080/15402002.2015.1120201>
- Ong, J. C., Dawson, S. C., Mundt, J. M., & Moore, C. (2020). Developing a cognitive behavioral therapy for hypersomnia using telehealth: A feasibility study. *Journal of Clinical Sleep Medicine*, 16(12), 2047–2062. <https://doi.org/10.5664/jcsm.8750>
- Ozaki, A., Inoue, Y., Hayashida, K., Nakajima, T., Honda, M., Usui, A., Komada, Y., Kobayashi, M., & Takahashi, K. (2012). Quality of life in patients with narcolepsy with cataplexy, narcolepsy without cataplexy, and idiopathic hypersomnia without long sleep time: Comparison between patients on psychostimulants, drug-naïve patients and the general Japanese population. *Sleep Medicine*, 13(2), 200–206. <https://doi.org/10.1016/j.sleep.2011.07.014>
- Plante, D. T., Hagen, E. W., Barnett, J. H., Mignot, E., & Peppard, P. E. (2024). Prevalence and course of idiopathic hypersomnia in the Wisconsin sleep cohort study. *Neurology*, 102(2), e207994. <https://doi.org/10.1212/WNL.000000000000207994>
- Stevens, J., Schneider, L. D., Husain, A. M., Ito, D., Fuller, D. S., Zee, P. C., & Macfadden, W. (2023). Impairment in functioning and quality of life in patients with idiopathic hypersomnia: The real world idiopathic hypersomnia outcomes study (ARISE). *Nature and Science of Sleep*, 15, 593–606. <https://doi.org/10.2147/NSS.S396641>
- Thorpy, M. J., Krahn, L., Ruoff, C., & Foldvary-Schaefer, N. (2024). Clinical considerations in the treatment of idiopathic hypersomnia. *Sleep Medicine*, 119, 488–498. <https://doi.org/10.1016/j.sleep.2024.05.013>
- Trotti, L. M. (2022). Idiopathic hypersomnia: Does first to approval mean first-line treatment? *Lancet Neurology*, 21(1), 25–26. [https://doi.org/10.1016/S1474-4422\(21\)00419-1](https://doi.org/10.1016/S1474-4422(21)00419-1)
- Trotti, L. M., & Arnulf, I. (2021). Idiopathic hypersomnia and other hypersomnia syndromes. *Neurotherapeutics*, 18(1), 20–31. <https://doi.org/10.1007/s13311-020-00919-1>
- Trotti, L. M., Becker, L. A., Friederich Murray, C., & Hoque, R. (2021). Medications for daytime sleepiness in individuals with idiopathic hypersomnia. *Cochrane Database Systematic Reviews*, 5(5), CD012714. <https://doi.org/10.1002/14651858.CD012714.pub2>
- Trotti, L. M., Ong, J. C., Plante, D. T., Friederich Murray, C., King, R., & Bliwise, D. L. (2020). Disease symptomatology and response to treatment in people with idiopathic hypersomnia: Initial data from the hypersomnia foundation registry. *Sleep Medicine*, 75, 343–349. <https://doi.org/10.1016/j.sleep.2020.08.034>
- Vernet, C., Leu-Semenescu, S., Buzare, M. A., & Arnulf, I. (2010). Subjective symptoms in idiopathic hypersomnia: Beyond excessive sleepiness. *Journal of Sleep Research*, 19(4), 525–534. <https://doi.org/10.1111/j.1365-2869.2010.00824.x>
- Wasling, H. B., Bornstein, A., & Wasling, P. (2020). Quality of life and procrastination in post-H1N1 narcolepsy, sporadic narcolepsy and idiopathic hypersomnia, a Swedish cross-sectional study. *Sleep Medicine*, 76, 104–112. <https://doi.org/10.1016/j.sleep.2020.10.014>