

Teleworking during a pandemic: perspective of an idiopathic hypersomnia patient

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Title: Teleworking during a pandemic: perspective of an idiopathic hypersomnia patient

Commentary on Nigam et al. 2021. Sleeping through a pandemic: impact of COVID-19 related restrictions on narcolepsy and idiopathic hypersomnia.

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Hypersomnias of central origin involve a distinct deficit in the maintenance of diurnal wakefulness, quantified by the pathological experience of excessive daytime sleepiness (EDS).¹⁻² Like narcolepsy, idiopathic hypersomnia is an equally debilitating condition that commonly presents alongside additional ailments which include: long and unrefreshing naps, longer nocturnal sleep, difficulties in awakening, excessive sleep inertia, and impaired neuropsychological function.³⁻⁴ For example, IH patients frequently self-report: sleep inertia, unrefreshing nocturnal sleep and naps, and multiple alarm use.³⁻⁴ Despite this, inclusion of idiopathic hypersomnia patients in studies examining psychosocial and occupational consequences of hypersomnia of central origin remain sparse. Generally, the outcomes of narcolepsy studies in this context are largely extrapolated to the IH population. Therefore, as a remote worker with an idiopathic hypersomnia (IH) diagnosis, I read the recent work 'Sleeping through a pandemic: impact of COVID-19–related restrictions on narcolepsy and idiopathic hypersomnia' by Nigam and colleagues⁵ with great interest.

Sampling outpatients with a confirmed diagnosis of narcolepsy type-1, narcolepsy type-2 or idiopathic hypersomnia, the authors examined possible alterations in sleep and psychological wellbeing following COVID-19 related lockdown measures in France. Here, several perceived improvements in sleep associated symptoms were reported by many patients suffering from a hypersomnia of central origin. In particular, teleworkers reported a significantly reduced daytime sleepiness and an increase in nocturnal sleep duration, whereas those with idiopathic hypersomnia exhibited a phase delayed circadian rhythm. While few disliked the lockdown, a substantial proportion perceived the experience in a more positive manner. Here, inductive thematic analysis attributed observed sleep improvements to increased flexibility in nap scheduling, circadian realignment, and reduced commute time. Finally, extra time for self-care, hobbies and social activities were related to greater psychological wellbeing. Given the debilitating nature of hypersomnolence disorders, these outcomes provide significant clinical and occupational implications for a subset of this population. Indeed, if the benefits observed in this study are replicated and longitudinally sustained, employers should provide teleworking as a reasonable workplace adjustment for individuals with narcolepsy and idiopathic hypersomnia.

Decomposing the outcomes of IH patients, the data presented by Nigam and colleagues⁵ indicates that approximately a third of those with idiopathic hypersomnia reported reduced fatigue and improved concentration. This may be explained by the emergence of a more natural alignment of the circadian rhythm and the additional sleep obtained. Indeed, IH is often characterised by an evening chronotype preference⁶, and typically presents alongside several key features of circadian rhythm disruption and delayed sleep phase syndrome⁷ including EDS, profound sleep inertia, and cognitive dysfunction. Clinical observations of melatonin and cortisol profiles across the night also indicate a circadian phase delay as a key feature of IH⁸⁻¹⁰, with some studies evidencing prolonged period lengths when observing melatonin profiles.⁹

The perhaps most prominent observation includes the reduction of pharmacological stimulant medication use in 43% of IH patients. Whilst pharmacological stimulants serve to temporarily reduce the experience of EDS, several prominent side effects limit the favourability of this approach. For example, in narcoleptic patients, traditional amphetamine drugs (i.e., methylphenidate, adderal) are associated with appetite suppression, aggression, abnormal motor movements, hypertension, nausea and irritability, and in some cases; psychotic experiences.¹¹⁻¹² Behavioural treatments help patients cope with the debilitating nature of their symptoms whilst facilitating the maintenance of a regular schedule of nocturnal sleep and daytime napping.¹³ Here, the extra and self-managed time consequential of the lockdown experience likely accentuated the deployment of

behavioural strategies, particularly napping, to self-manage symptoms whilst minimizing the adverse effects of pharmacological stimulant use.

Given the nature of idiopathic hypersomnia, the pursuit of a normal work-life balance comes with great difficulty for several reasons. Employers don't often understand the nature of idiopathic hypersomnia and like myself, many patients struggle to articulately verbalise the symptom experience to others.¹⁴ Indeed, it would be fair to assume that members of general population are largely unfamiliar with the term idiopathic hypersomnia.¹⁵ Typically, I must explain "it's like narcolepsy" before one realises that IH is a sleep disorder. I found the most concise way to describe the experience using the Japanese proverb, '*Inemuri*', which means *being present while asleep*. Nevertheless, an understanding employer may support the recommended behavioural adjustments including scheduled napping, at least in locations where IH is considered a disability thereby making behavioural accommodations a legal requirement. Where support is absent, many employees sacrifice their own lunch and break times to nap.¹⁶ The latter may be less effective given the substantial interindividual variability in the optimal frequency, duration and timing of scheduled daytime naps amongst individuals with a hypersomnia of central origin.¹⁶⁻¹⁷ Next, workplace stigma appears to be commonly reported amongst individuals with narcolepsy, where napping and reports of sleepiness are misattributed to being lazy which may limit career progression.¹⁸⁻¹⁹ Poor quality of life and psychiatric distress commonly co-occur with IH²⁰, and workplace stigma in this population is evidenced to be associated with reduced functioning and symptoms of depression.¹⁹

Theoretically, several cognitive and behavioural factors may interact with poor workplace management of idiopathic hypersomnia, precipitating a negative cycle of adverse psychosocial consequences. Difficulties including fatigue and impaired concentration may result in a later working pattern and working outside of contracted hours to complete tasks and compensate for time lost during the day. Consequently, reducing time for personal activities, particularly in long sleeping individuals with IH. The long-term experience of playing catch up may serve to perpetuate the onset of, or pre-existing, worry (e.g., "I have so much to do", "What if I'm fired") and rumination (e.g., "how did I perform?", "I could have performed better") about work performance which ultimately may facilitate overworking and possible burn-out in those with IH. Together, these factors possibly contribute to the experience of anxiety, depression, and loneliness in this population.

The important work by Nigam and colleagues⁵ highlights the benefits of teleworking during the lockdown period of the COVID-19 pandemic for patients with narcolepsy and idiopathic hypersomnia. As a remote worker and long-sleeping individual with idiopathic hypersomnia, I concur with this notion. Moving forward, research should further explore the mechanisms underlying the benefits of teleworking in those with IH. Indeed, several candidate factors may play a crucial role in determining *for whom* and *under which* conditions teleworking should be considered a reasonable workplace adjustment. More specifically, the possible moderating effects of: long vs. short sleeping IH subjects; chronotype preference; timing of objective phase markers in the context of circadian realignment; living situation; nature of work; and work-related anxiety. Furthermore, work-related consequences on psychosocial wellbeing should also be explored.

To summarize, I would like to thank Nigam and colleagues⁵ for their work and inclusion of IH patients. Hopefully, with additional research, employers may offer a degree of respite for those suffering from idiopathic hypersomnia. Specifically, by allowing such individuals to adhere to their natural circadian rhythm, utilize an individually tailored work schedule, seeking to reduce workplace stigma, and by providing the option of teleworking.

Abbreviations

EDS, Excessive daytime sleepiness

IH, Idiopathic Hypersomnia

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