

LETTERS TO THE EDITOR

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

Umair Akram, PhD

Department of Psychology, Sociology, and Politics, Sheffield Hallam University, Sheffield, United Kingdom

Hypersomnias of central origin involve a distinct deficit in the maintenance of diurnal wakefulness, quantified by the pathological experience of excessive daytime sleepiness.<sup>1,2</sup> Like narcolepsy, idiopathic hypersomnia (IH) is an equally debilitating condition that commonly presents alongside additional ailments that include long and unrefreshing naps, longer nocturnal sleep, difficulties in awakening, excessive sleep inertia, and impaired neuropsychological function.<sup>3,4</sup> For example, patients with IH frequently self-report sleep inertia, unrefreshing nocturnal sleep and naps, and multiple alarm use.<sup>3,4</sup> Despite this, inclusion of patients with IH in studies examining psychosocial and occupational consequences of hypersomnia of central origin remains sparse. Generally, the outcomes of narcolepsy studies in this context are largely extrapolated to the IH population. Therefore, as a remote worker with an 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 colleagues<sup>5</sup> with great interest.

Sampling outpatients with a confirmed diagnosis of narcolepsy type 1, narcolepsy type 2, or IH, the authors examined possible alterations in sleep and psychological well-being following coronavirus disease 2019 (COVID-19)–related lockdown measures in France. Here, several perceived improvements in sleep-associated symptoms were reported by many patients with a hypersomnia of central origin. In particular, teleworkers reported a significantly reduced daytime sleepiness and an increase in nocturnal sleep duration, whereas those with IH exhibited a phase-delayed circadian rhythm. While a 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 was related to greater psychological well-being. 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 IH.

Decomposing the outcomes of patients with IH, the data presented by Nigam and colleagues<sup>5</sup> indicate that approximately one-third of those with IH 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 characterized by an evening chronotype preference,<sup>6</sup> and typically presents alongside several key features of circadian rhythm disruption and delayed sleep-phase syndrome<sup>7</sup> including excessive daytime sleepiness, 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 IH,<sup>8–10</sup> with some studies evidencing prolonged period lengths when observing melatonin profiles.<sup>9</sup>

The perhaps most prominent observation includes the reduction in pharmacological stimulant medication use in 43% of patients with IH. While pharmacological stimulants serve to temporarily reduce the experience of excessive daytime sleepiness, several prominent side effects limit the favorability of this approach. For example, in patients with narcolepsy, traditional amphetamine drugs (ie, methylphenidate, Adderall) are associated with appetite suppression, aggression, abnormal motor movements, hypertension, nausea, and irritability, and in some cases, psychotic experiences.<sup>11,12</sup> Behavioral treatments help patients cope with the debilitating nature of their symptoms while facilitating the maintenance of a regular schedule of nocturnal sleep and daytime napping.<sup>13</sup> Here, the extra and self-managed time consequential of the lockdown experience likely accentuated the deployment of behavioral strategies, particularly napping, to self-manage symptoms while minimizing the adverse effects of pharmacological stimulant use.

Given the nature of IH, the pursuit of a normal work–life balance comes with great difficulty for several reasons. Employers do not often understand the nature of IH and, like myself, many patients struggle to articulately verbalize the symptom experience to others.<sup>14</sup> Indeed, it would be fair to assume that members of general population are largely unfamiliar with the term “idiopathic hypersomnia.”<sup>15</sup> Typically, I must explain, “it’s like narcolepsy,” before one realizes 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 behavioral adjustments, including scheduled napping, at least in locations where IH is considered a disability, thereby making behavioral accommodations a legal requirement. Where support is absent, many employees sacrifice their own lunch and break times to nap.<sup>16</sup> The latter may be less effective given the substantial interindividual variability in

the optimal frequency, duration, and timing of scheduled daytime naps among individuals with a hypersomnia of central origin.<sup>16,17</sup> Next, workplace stigma appears to be commonly reported among individuals with narcolepsy, where napping and reports of sleepiness are misattributed to being lazy, which may limit career progression.<sup>18,19</sup> Poor quality of life and psychological distress commonly co-occur with IH,<sup>20</sup> and workplace stigma in this population is evidenced to be associated with reduced functioning and symptoms of depression.<sup>19</sup>

Theoretically, several cognitive and behavioral factors may interact with poor workplace management of IH, 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 (eg, “I have so much to do,” “What if I’m fired”) and rumination (eg, “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 colleagues<sup>5</sup> highlights the benefits of teleworking during the lockdown period of the COVID-19 pandemic for patients with narcolepsy and IH. As a remote worker and long-sleeping individual with IH, 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 individuals with IH, 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 well-being should also be explored.

To summarize, I would like to thank Nigam and colleagues<sup>5</sup> for their work and inclusion of patients with IH. I hope, with additional research, employers may offer a degree of respite for those with IH, 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.

## CITATION

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Address correspondence to: Umair Akram, PhD, Department of Psychology, Sociology and Politics, Sheffield Hallam University, Collegiate Crescent, Sheffield, South Yorkshire, S10 2BP, UK; Email: u.akram@shu.ac.uk

## DISCLOSURE STATEMENT

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