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LETTERS TO THE EDITOR

Moving the dial on behavioral interventions for idiopathic hypersomnia

Response to Akram U. Teleworking during a pandemic: perspective of an idiopathic hypersomnia patient. *J Clin Sleep Med*. 2022;18(5):1471–1472. doi: 10.5664/jcsm.9902

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We warmly thank Dr. Akram for the astute commentary provided on our recent paper "Sleeping through a pandemic: impact of COVID-19–related restrictions on narcolepsy and idiopathic hypersomnia,"[1] and for sharing a unique personal experience as both a sleep researcher and a person living with idiopathic hypersomnia (IH).[2] Dr. Akram touches on several important points related to the unique psychosocial, occupational, and behavioral aspects of IH compared with narcolepsy.

We agree with Dr. Akram that IH has been understudied compared with narcolepsy, and clinicians have relied on extrapolated data from the narcolepsy literature. Considering the protean clinical and etiological distinctions between narcolepsy and IH, this is not a desirable approach going forward. The inclusion of large cohorts of participants with IH in hypersomnia studies and the development of clinical trials assessing IH specifically are important remedial steps in this regard. There is cause for optimism, though, as the landscape has been changing rapidly. We recently contributed to the first large randomized clinical trial of low sodium oxybate in IH,[3] a significant step forward for the IH community that may help bolster future research initiatives in this population. We are glad that Dr. Akram feels that our study, which included a plurality of IH participants, has also contributed meaningfully to the IH literature.

The importance of behavioral interventions has long been acknowledged by clinicians caring for patients with central hypersomnias, but there has been little formal study of their efficacy or their optimal use. In the case of narcolepsy, scheduled naps are recommended, as they are refreshing and typically short enough to fit into a quick break from work or school. Most people with IH, however, do not experience the same benefit from napping (although some short sleepers with IH may) and on the contrary avoid them. As Dr. Akram correctly points out, suboptimal cognitive functioning in the morning hours may force people with IH to carryover work until later in the workday or in evenings. Indeed, in our clinical practice, patients with IH typically report that morning hours are by far the most difficult of the day, and often report acceptable (if not perfect) cognition in the afternoon. Therefore, more appropriate behavioral recommendations to improve daytime functioning in IH may include prolonging sleep time and shifting their work time later in the day. Plus, time spent commuting adds to the fatigue of these patients. A quiet place (not always possible at a workplace) improves focusing. These interventions are difficult to integrate in a typical workday, which highlights the potential benefits of teleworking or adjusted work scheduling (later start times, for example). Our findings of improvement in sleepiness, sleep duration, and circadian realignment (particularly in participants with IH) during the lockdown and remote working support this approach.

Thus, we hope that our findings will help empower clinicians to begin advocating more strongly for robust workplace adaptations for our patients with central hypersomnias, and we look forward to future studies confirming these findings prospectively.

CITATION

Nigam M, Leu-Semenescu S, Arnulf I. Moving the dial on behavioral interventions for idiopathic hypersomnia. *J Clin Sleep Med*. 2022;18(5):1473–1474.

REFERENCES

1. Nigam M, Hippolyte A, Dodet P, et al. Sleeping through a pandemic: impact of COVID-19–related restrictions on narcolepsy and idiopathic hypersomnia. *J Clin Sleep Med*. 2022;18(1):255–263.
2. Akram U. Teleworking during a pandemic: perspective of an idiopathic hypersomnia patient. *J Clin Sleep Med*. 2022;18(5):1471–1472.
3. Dauvilliers Y, Arnulf I, Foldvary-Schaefer N, et al. Safety and efficacy of lower-sodium oxybate in adults with idiopathic hypersomnia: a phase 3, placebo-controlled, double-blind, randomised withdrawal study. *Lancet Neurol*. 2022;21(1):53–65.

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