

COMMENTARY

Improving the Comprehensive Care of Patients With Hypersomnia Disorders: A Commentary on “Behavioral Sleep Medicine Services for Hypersomnia Disorders: A Survey Study”

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“The goal [of treatment] should be to produce the fullest possible return of normal function for patients at work, at school, at home, and socially” (Morgenthaler et al., 2007, p. 1707).

Hypersomnia disorders (HD) can have a pervasive and detrimental impact on patient quality of life. Advances in the pharmacological treatment of HD have resulted in increased hope for patients that their symptoms, including daytime sleepiness, cataplexy, hypnagogic hallucinations, and sleep paralysis, can be managed (Billiard et al, 2006; Morgenthaler et al., 2007). However, there are known limitations of currently available medication options. Patients report poor efficacy, difficulty coping with treatment side effects, drug tolerance, and issues with medication adherence (Wozniak & Quinnell, 2015). Beyond these challenges, it is important to recognize that the comprehensive treatment of any sleep disorder cannot focus only on symptom reduction, but must also strive to find ways to empower patients to learn how to effectively cope with their disorder.

Neikrug, Crawford, and Ong have made a significant contribution to our knowledge of the experiences of patients with HD and their interest in both pharmacological and nonpharmacological treatments for their sleep disorder (Neikrug, Crawford, & Ong, 2016). Their Internet-based survey of 371 patients who self-identified with HD was unique as it was conducted in collaboration with a patient-run organization (Wake Up Narcolepsy). Findings suggest that there is a sizeable proportion of patients whose needs are not being fully met with medications alone. Twenty-three percent of patients reported that side effects made it difficult to consistently adhere

to their medication, and the mean effectiveness rating for medication was 6.0 (0 = not at all effective, 10 = most effective).

More than 90% of patients in their sample endorsed the use of nonpharmacological strategies to cope with HD. It is worth noting that the value of individual therapeutic approaches was limited: effectiveness ratings for the 10 strategies queried ranged from 1.9 to 4.3 (0–10 scale). These findings are not surprising, as the vast majority of these approaches were learned from nonprofessional sources (e.g., Internet), and were likely to be implemented without significant prior planning or consistent outcomes monitoring. This presents an excellent opportunity for further research examining the development of a more regimented and rigorous nonpharmacological approach in the clinical management of HD symptoms (Neikrug & Ong, 2016). As the majority of the sample indicated a preference for a clinician with a background in *both* mental health and sleep medicine, behavioral sleep medicine providers could play a key role in such treatments. Although the accuracy of the HD diagnosis could not be confirmed in this anonymous study, and nonstandardized survey measures were used, these novel findings stimulate further discussion about the potential value of, and patient desire for, a complement to pharmacotherapy in the treatment of HD. Given the considerable psychosocial consequences of HD, it is important that this innovative paper help to spur future research that helps patients successfully live with an incurable sleep disorder.

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