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Sleep Disorders

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AN ASSESSMENT OF THE EDUCATIONAL NEEDS OF PULMONOLOGISTS AND OTHER HEALTH CARE PROVIDERS IN THE UNITED STATES ON THE MANAGEMENT OF PATIENTS WITH NARCOLEPSY

CYNTHIA KOZIC SATISH RAO MD, MS ANNE ROC GREG SALINAS BRANDON COLEMAN AND MORGAN LEAFE

PURPOSE: Narcolepsy type 1 (NT1) is associated with excessive daytime sleepiness, cataplexy, and other sleep-wake disturbances due to loss of orexin neurons. We conducted a survey to assess clinician practice patterns, attitudes, knowledge, and information-seeking behaviors related to narcolepsy management.

METHODS: A survey on clinical experiences of managing sleep disorders was distributed to pulmonologists, neurologists, psychiatrists, and primary care sleep specialists, who were screened to ensure they managed patients with sleep disorders (80%–92% worked at sleep centers, except the psychiatrists, who encountered ≥40 patients/week with sleep-related concerns). The survey included a simulated case scenario designed to understand clinicians' approaches to diagnosis and treatment of a patient who reported difficulty staying awake during the day and difficulty sleeping at night. Subsequent questions included an assessment of clinicians' understanding of emerging treatments for narcolepsy and orexin biology. The topic of narcolepsy was initially masked from survey respondents; as the case progressed, a diagnosis of NT1 was established. Descriptive statistics were used to summarize results.

RESULTS: In total, 242 clinicians responded, including pulmonologists (n=77), neurologists (n=55), psychiatrists (n=60), and primary care sleep specialists (n=50). Among pulmonologist respondents, mean time in clinical practice was 18 years, and mean number of patients presenting with sleep-related concerns was 55 per week. Of pulmonologist respondents, 74% included narcolepsy in their top 3 differential diagnoses for the case scenario, compared with 40%–76% of other clinicians. DSM-5 or ICSD criteria were used in the patient's initial assessment by 52% of pulmonologists and 45%–85% of other clinicians; while 97% of pulmonologists would order polysomnography, only 84% would order a multiple sleep latency test. Only 26%–27% of all clinicians recognized that facial twitching could be a cataplectic event. Clinicians' initial medication recommendations for a diagnosis of NT1 varied; most would start with a nonamphetamine stimulant (47% of pulmonologists and 55%–70% of other clinicians), and few pulmonologists recommended sodium oxybate or pitolisant (46% combined). Comorbid anxiety or depression and substance use disorders would change the treatment approach by 40% and 66% of pulmonologists, respectively. Few clinicians (≤34%) would change their treatment approach between NT2 and NT1. Clinicians reported only moderate satisfaction with currently available treatment options for patients with narcolepsy, and they had limited familiarity with emerging treatment options, such as the orexin receptor 2–selective agonist TAK-861. Most clinicians were aware that orexin deficiency leads to the inability to maintain wakefulness (82% of pulmonologists and 72%–85% of other clinicians), although many clinicians were unaware of the role of orexin in energy homeostasis (57% of pulmonologists and 38%–50% of other clinicians), glucose metabolism (81% of pulmonologists and 76%–82% of other clinicians), and pain perception (88% of pulmonologists and 78%–90% of other clinicians).

CONCLUSIONS: This survey provides evidence that clinicians who manage patients with sleep disorders, including pulmonologists, have educational needs in narcolepsy and orexin sleep science.

CLINICAL IMPLICATIONS: Specific educational topics relevant to clinicians who manage patients with sleep disorders include the diagnostic approach and treatment of narcolepsy, emerging treatments for narcolepsy, and orexin biology.

DISCLOSURES:

No relevant relationships by Brandon Coleman

Employee relationship with Takeda Pharmaceuticals U.S.A., Inc. Please note: 07/2014-current Added 02/20/2025 by Cynthia Kozic, source=Web Response, value=Salary