# An Assessment of the Educational Needs of Pulmonologists and Other Healthcare Providers in the United States on the Management of Patients With Narcolepsy

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### Background

- Narcolepsy is a chronic, rare central disorder of hypersomnolence, with two phenotypes: narcolepsy type 1 (NT1) and narcolepsy type 2 (NT2)<sup>1</sup>; patients with NT1 experience a loss of orexin-producing neurons leading to low levels of orexin and dysregulation of the sleep-wake cycle<sup>2</sup>
- Symptoms of narcolepsy include excessive daytime sleepiness, disrupted nighttime sleep, hypnagogic/hypnopompic hallucinations, and sleep paralysis. NT1 is differentiated by the presence of cataplexy, sudden loss of muscle tone triggered by strong emotions<sup>2</sup>
- Cognitive symptoms of NT1 are common and disruptive, often persisting despite standard treatments, and negatively impact daily functioning, work, education, and social interactions, thereby diminishing overall quality of
- Effective management of NT1 may involve a combination of medication, lifestyle changes, and supportive therapies, with the choice of medication being largely based on individual patient needs, symptoms, and medical history<sup>3,4</sup>

## Purpose

- We conducted a survey to assess clinician practice patterns, attitudes, knowledge about orexin, and information-seeking behaviors related to NT1 management
- The aim of this survey was to determine the educational gaps and continuing educational needs of clinicians related to the management of patients with NT1 in an effort to gain insights leading to improved disease management and QOL

### Methods

#### Survey Methodology

- 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
- The survey 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

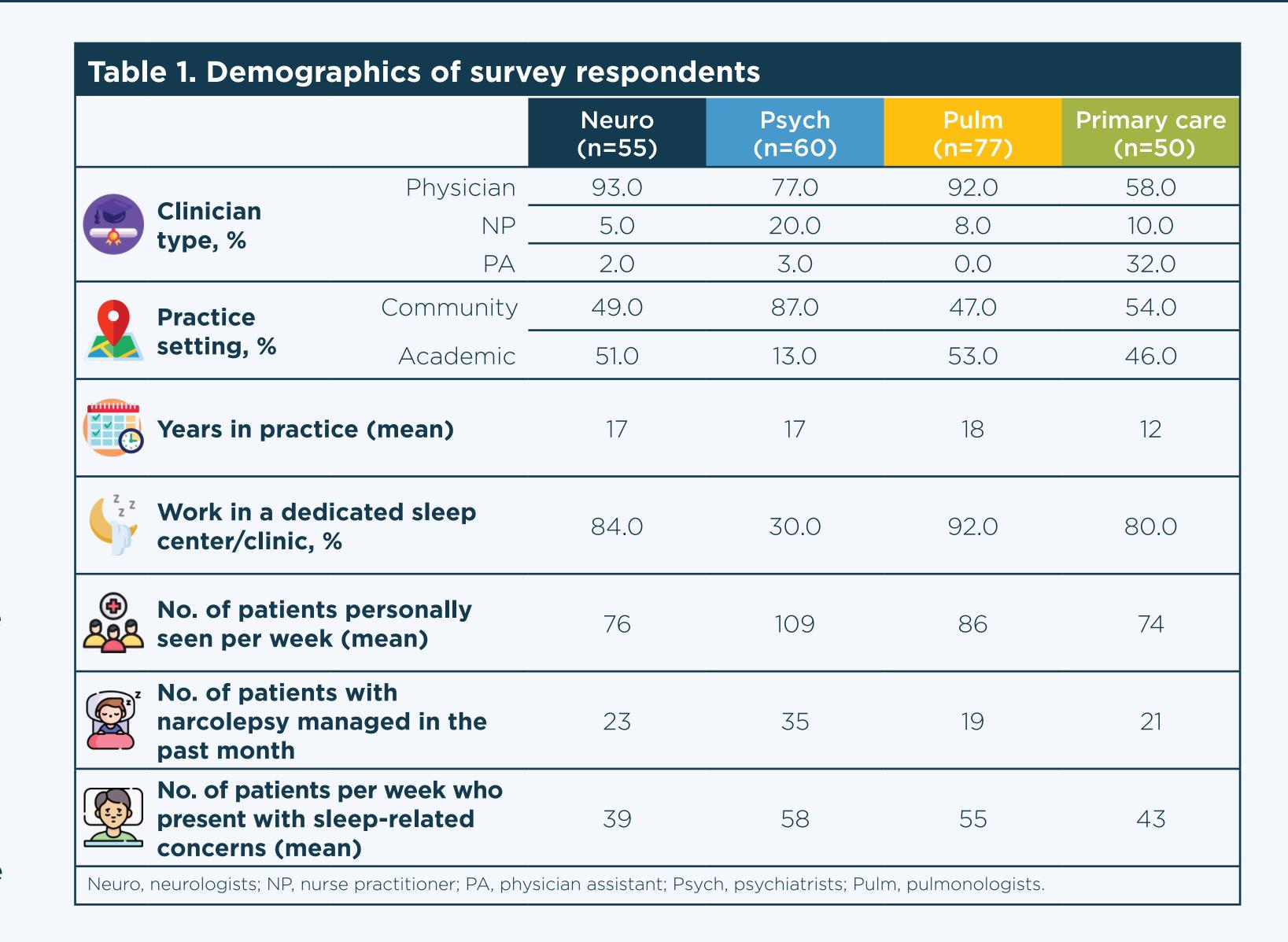
#### Analysis

- Descriptive statistics were used to summarize results
- Subanalyses were conducted to evaluate differences by key subgroups, which included clinician type, patient load, and years in practice

### Results

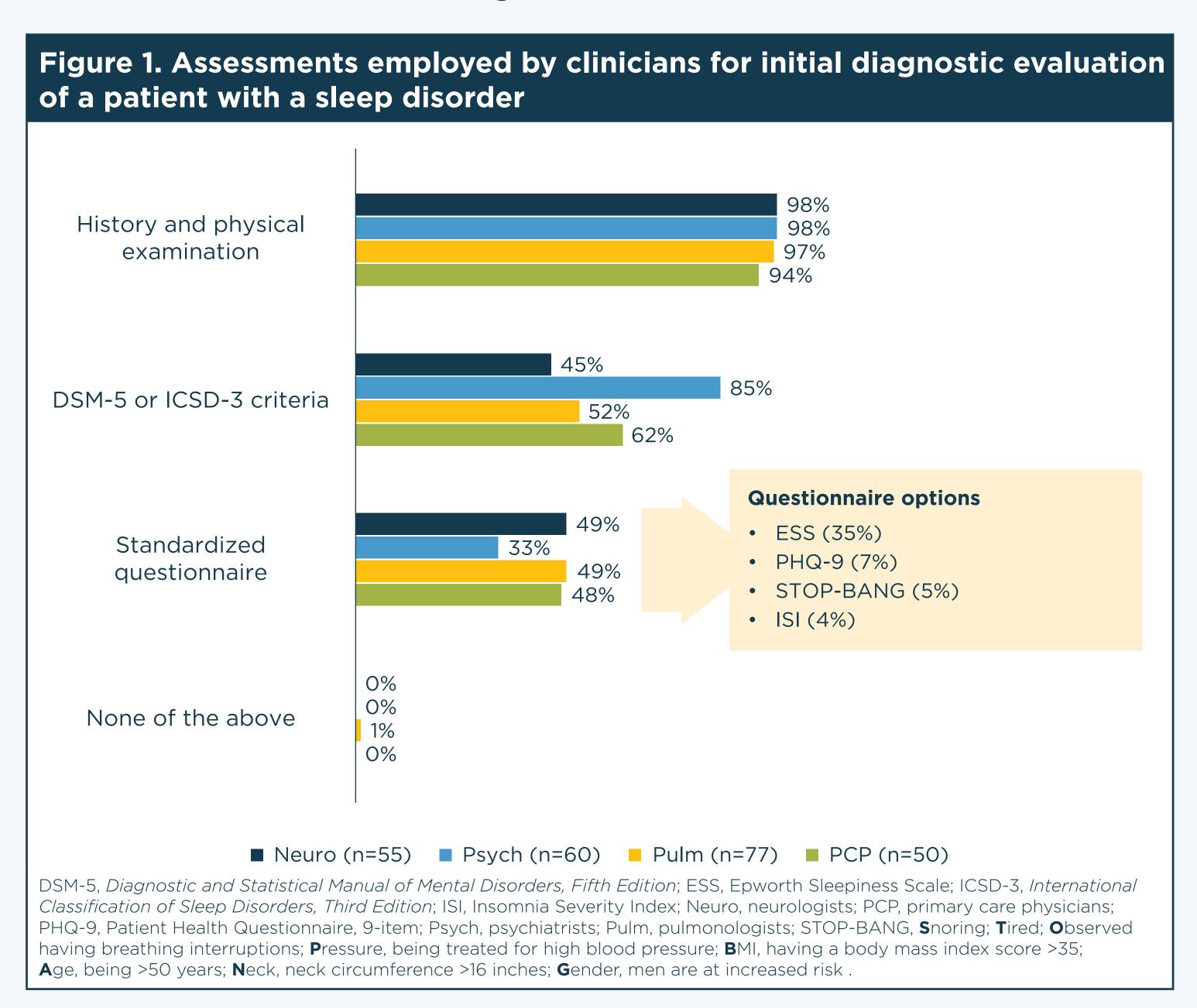
#### Respondent Demographics

- In total, 242 clinicians responded, including pulmonologists (n=77), psychiatrists (n=60), neurologists (n=55), and primary care sleep specialists (n=50; **Table 1**)
- Among pulmonologist respondents, the mean time in clinical practice was 18 years, and mean number of patients currently presenting with sleep-related concerns was 55 per week (**Table 1**)
- 74% of pulmonologists included NT1 in their top 3 differential diagnoses for the case scenario, compared with 40%-76% of other clinicians

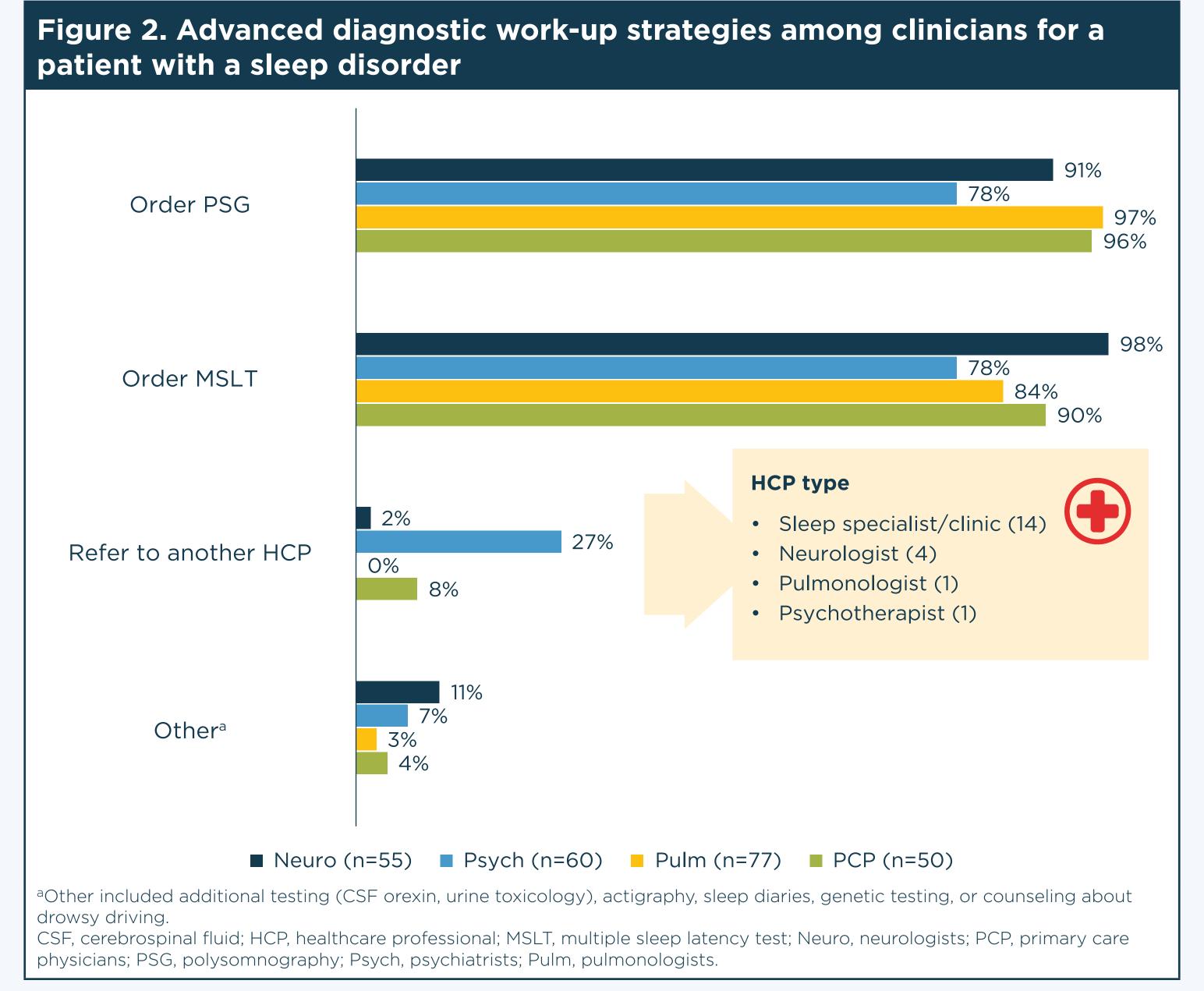


#### Assessment Tools Used for Diagnostic Work-up

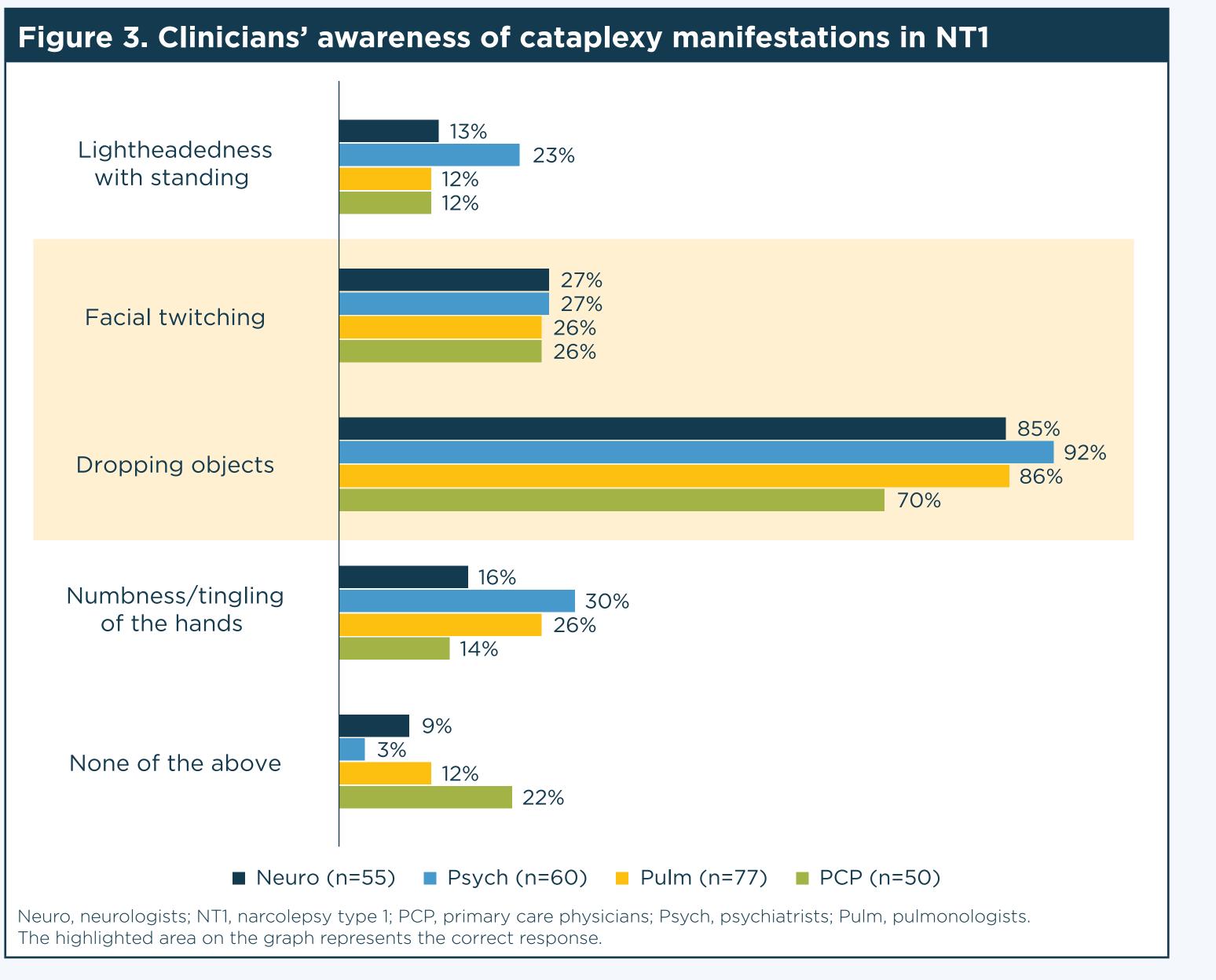
- The majority of clinicians (94%–98%), including 97% of pulmonologists, indicated that they would conduct a comprehensive history and physical examination as part of the initial diagnostic evaluation of this patient (Figure 1)
- Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) or International Classification of Sleep Disorders criteria, Third Edition (ICSD-3) would be used in the patient's initial assessment by 52% of pulmonologists and 45%-85% of other clinicians (**Figure 1**)



• For advanced diagnostic work-up, while 97% of pulmonologists indicated they would order polysomnography, only 84% reported they would request a multiple sleep latency test (Figure 2)

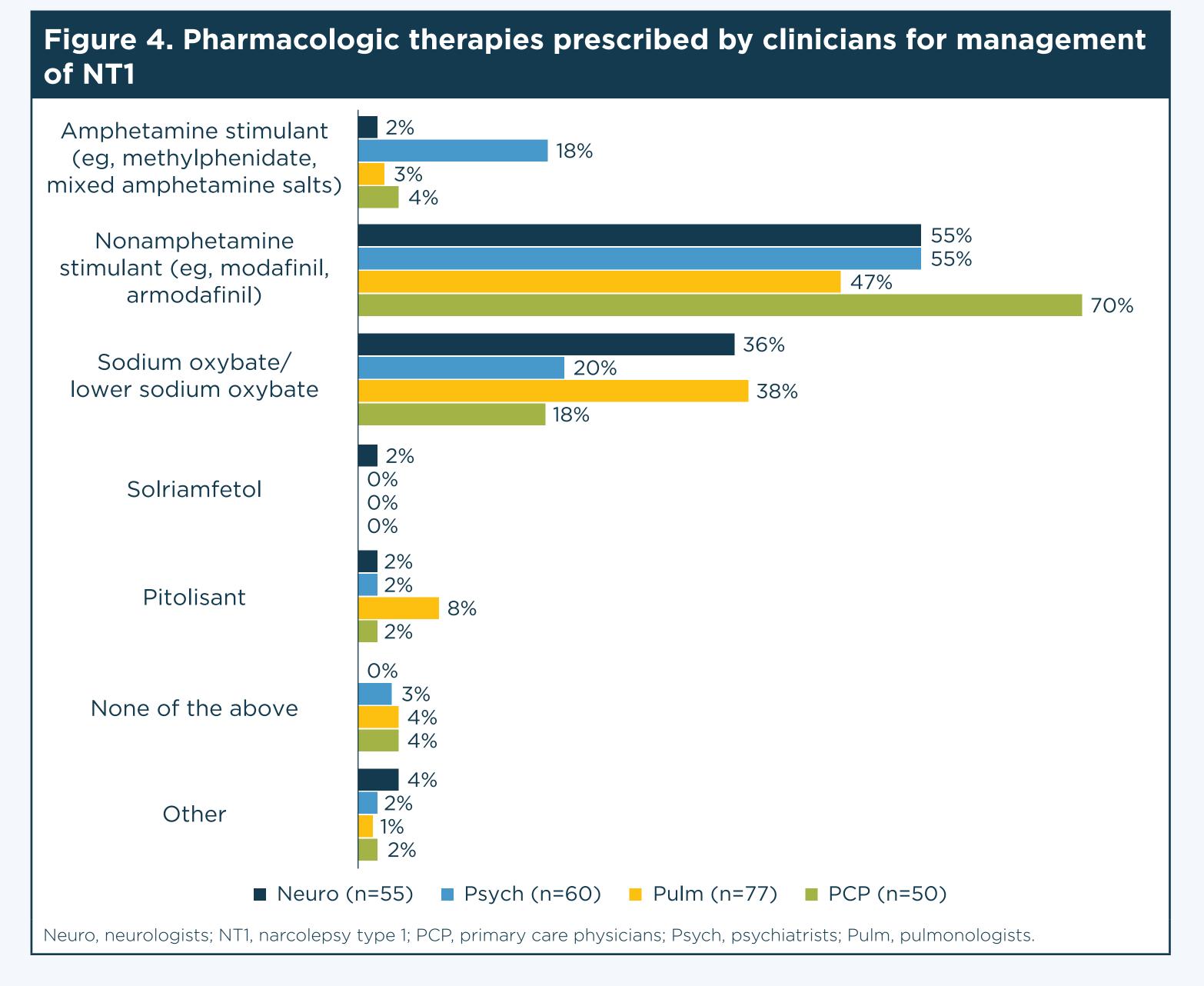


The association between object dropping and cataplexy was widely recognized by clinicians (70%-92%), including 86% of pulmonologists, while only 26%-27% of all clinicians (26% of pulmonologists) recognized that facial twitching could be a cataplectic event (**Figure 3**)

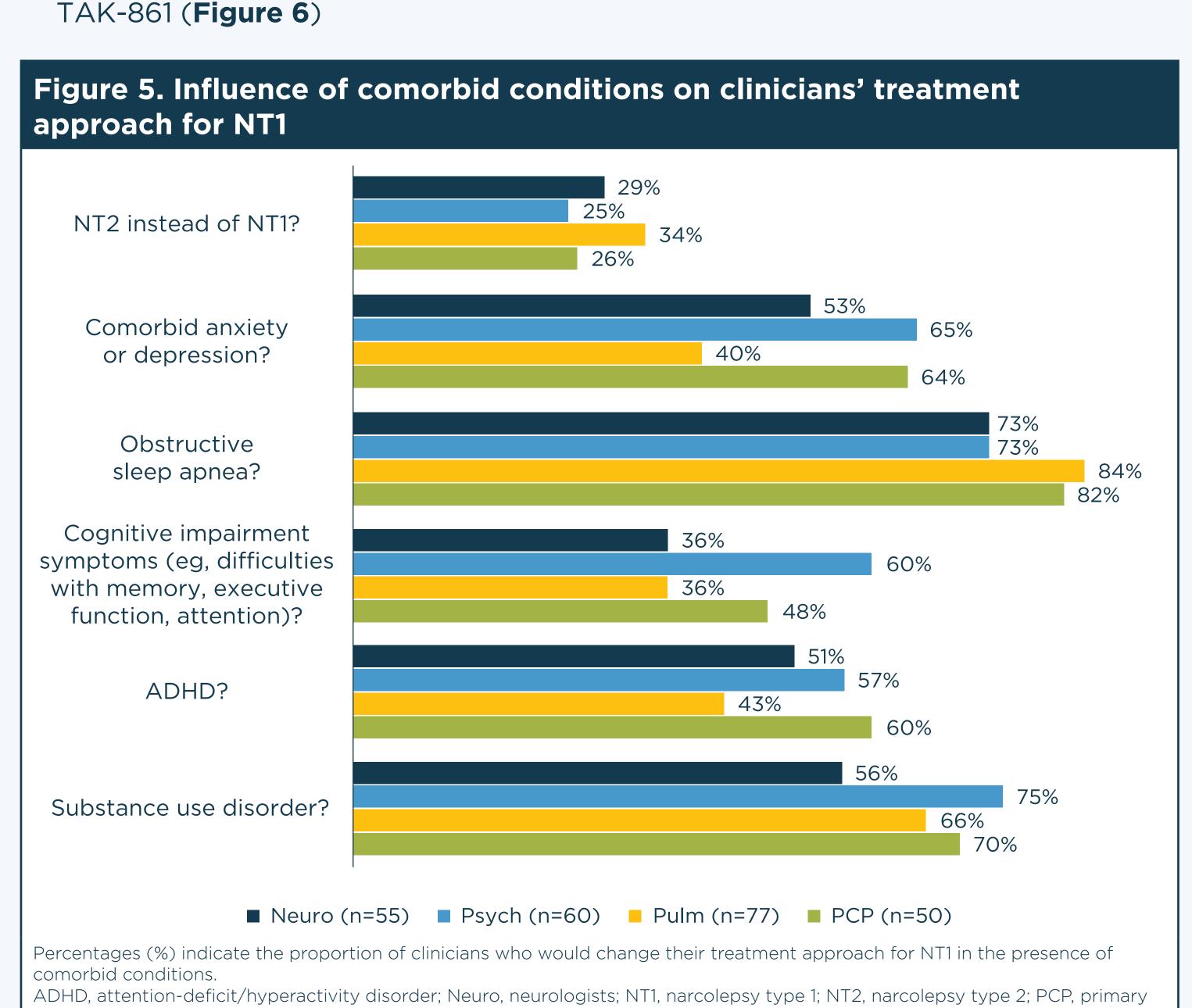


#### Management of Narcolepsy

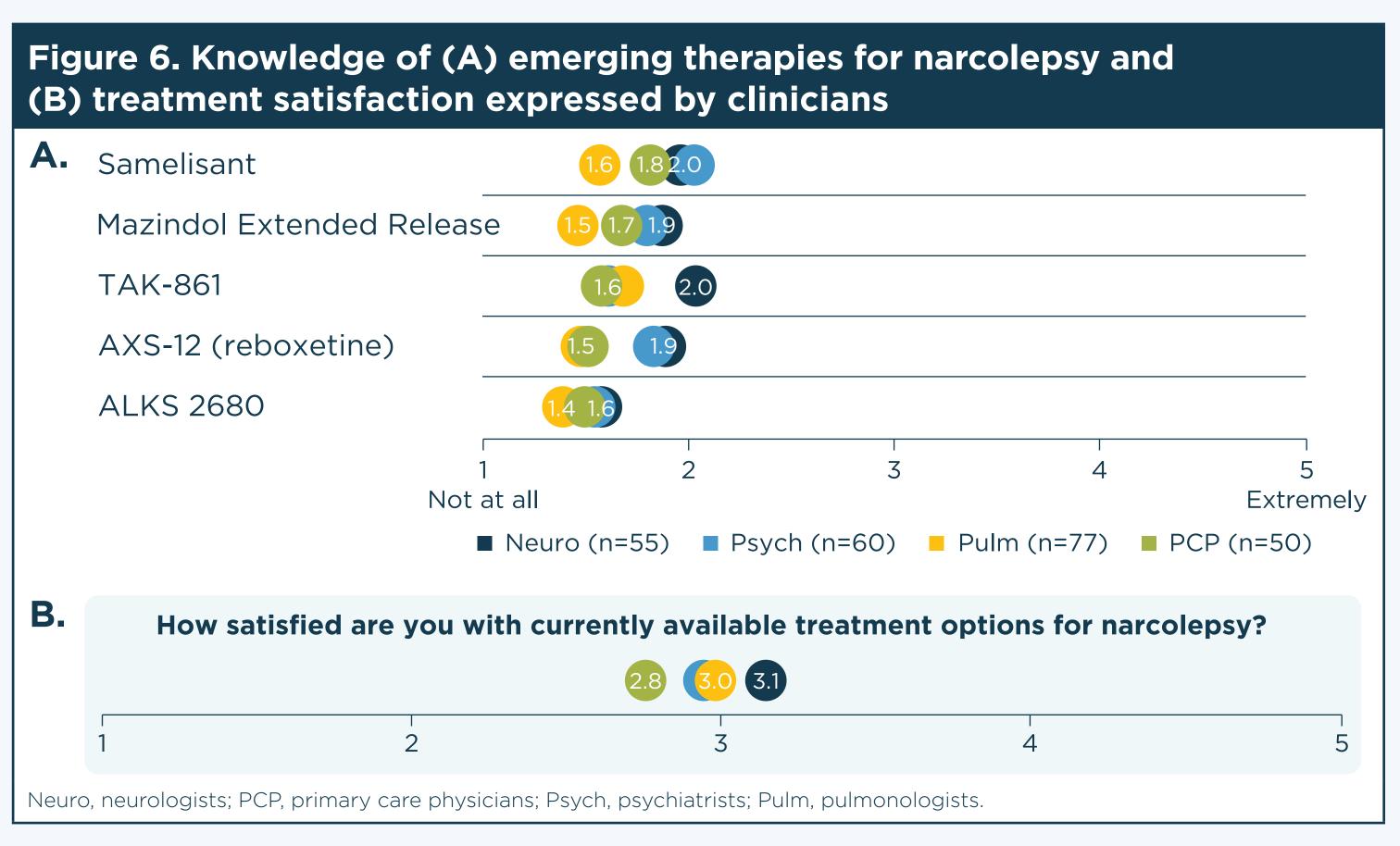
 Clinicians' initial medication recommendations for a diagnosis of NT1 varied; most reported they would start with a nonamphetamine stimulant (47% of pulmonologists; 55%-70% of other clinicians), and few pulmonologists recommended sodium oxybate or pitolisant (46% combined) (Figure 4)



- Comorbid anxiety or depression and substance use disorder would change the treatment approach by 40% and 66% of pulmonologists, respectively (Figure 5)
- About a third of clinicians (≤34%) indicated they would change their treatment approach between NT2 and NT1 (Figure 5)
- 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 (**Figure 6**)

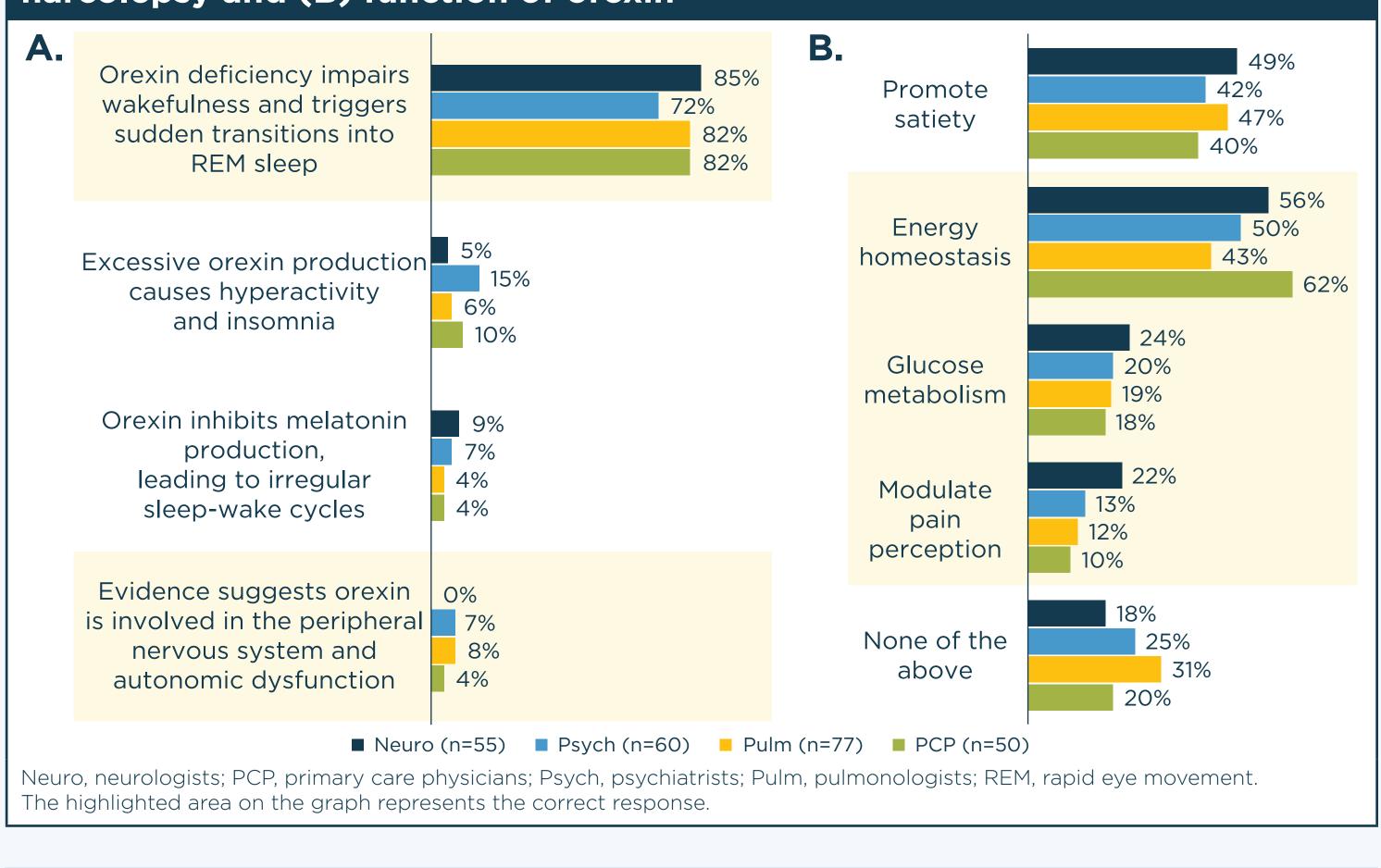


care physicians; Psych, psychiatrists; Pulm, pulmonologists



 Most clinicians were aware that orexin deficiency leads to the inability to maintain wakefulness (82% of pulmonologists; 72%-85% of other clinicians), although many clinicians were unaware of the role of orexin in energy homeostasis (57% of pulmonologists; 38%-50% of other clinicians), glucose metabolism (81% of pulmonologists; 76%-82% of other clinicians), and pain perception (88% of pulmonologists; 78%-90% of other clinicians; **Figure 7**)

#### Figure 7. Clinicians' awareness of (A) the mechanisms and role of orexin in narcolepsy and (B) function of orexin



### Conclusions

- This survey provides evidence that clinicians who manage patients with sleep disorders, including pulmonologists, have educational needs in narcolepsy and orexin sleep science
- Pulmonologists and other clinicians who manage patients with sleep disorders are only moderately satisfied with currently available treatments for those with narcolepsy, and have limited familiarity with emerging treatment options

### 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

