

SLEEP 2022, the 36th Annual Meeting of the Associated Professional Sleep Societies (APSS) June 4-8, 2022 • Charlotte, NC

Introduction

- Limited information is available on the natural history, presentation, and management of pediatric narcolepsy
- Children, Adolescents, and Their providers: the Narcolepsy Assessment Partnership* (CATNAP®) is a retrospective and prospective, longitudinal, multicenter, web-based pediatric registry (ClinicalTrials.gov identifier: NCT04899947)
- CATNAP is a next-generation registry that collects relevant real-world clinical information from patients, caregivers, and clinicians

Objective

- The primary objectives of CATNAP are to improve understanding of the natural history of pediatric narcolepsy, characterize symptom presentation and diagnosis, and understand treatment practices and outcomes

Methods

- Eligible children/adolescents (<18 years) had a physician-confirmed diagnosis of narcolepsy, were willing and able to participate in this English-based registry, and provided informed consent
- Using web-based portals, patients, caregivers, and clinicians completed an initial survey on sociodemographic characteristics; diagnostic, medical, and treatment history; comorbidities; and disease progression
- Participants completed follow-up surveys annually until they reached the age of 18 years or declined to participate

Results

- Patient/caregiver-reported interim baseline data are included for 25 participants

Characteristic	Participants (N=25)
Age at diagnosis, years, mean (SD)	11.0 (4.0)
Age 1 to <5 years, n (%)	1 (4.0)
Age 5 to <10 years, n (%)	8 (32.0)
Age ≥10 years, n (%)	16 (64.0)
Age at first consultation for symptoms, years	
Age 1 to <5 years, n (%)	4 (16.0)
Age 5 to <10 years, n (%)	9 (36.0)
Age ≥10 years, n (%)	12 (48.0)
Age at study recruitment, years, mean (SD)	15.6 (2.9)
Sex, n (%)	
Female	13 (52.0)
Race, n (%)	
White	15 (60.0)
Black or African American	10 (40.0)
Ethnicity, n (%)	
Hispanic or Latino	2 (8.0)
Not Hispanic or Latino	23 (92.0)
Narcolepsy type, n (%)	
Type 1 (with cataplexy)	16 (64.0)
Type 2 (without cataplexy)	7 (28.0)
Unsure	2 (8.0)

SD, standard deviation.

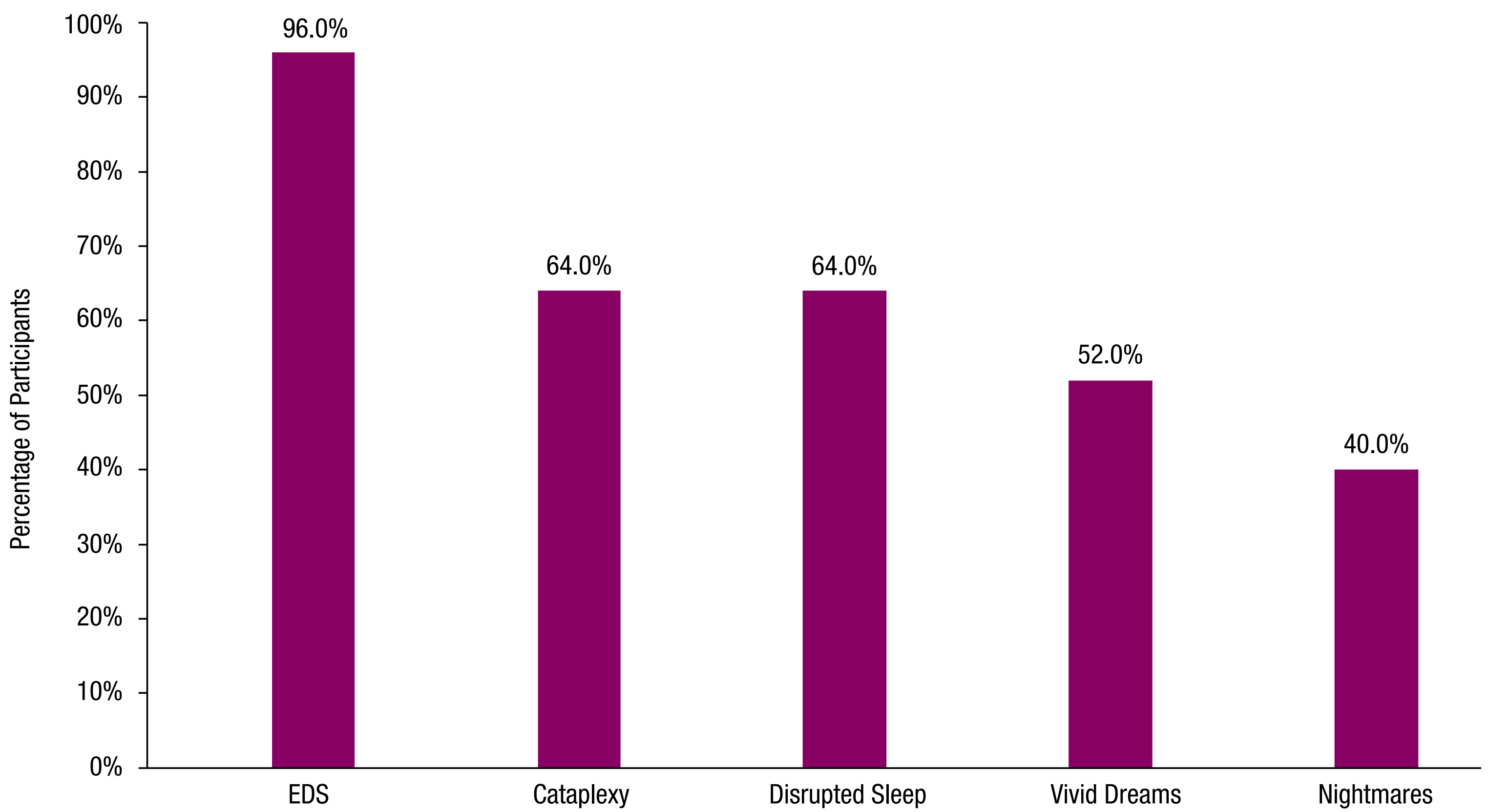
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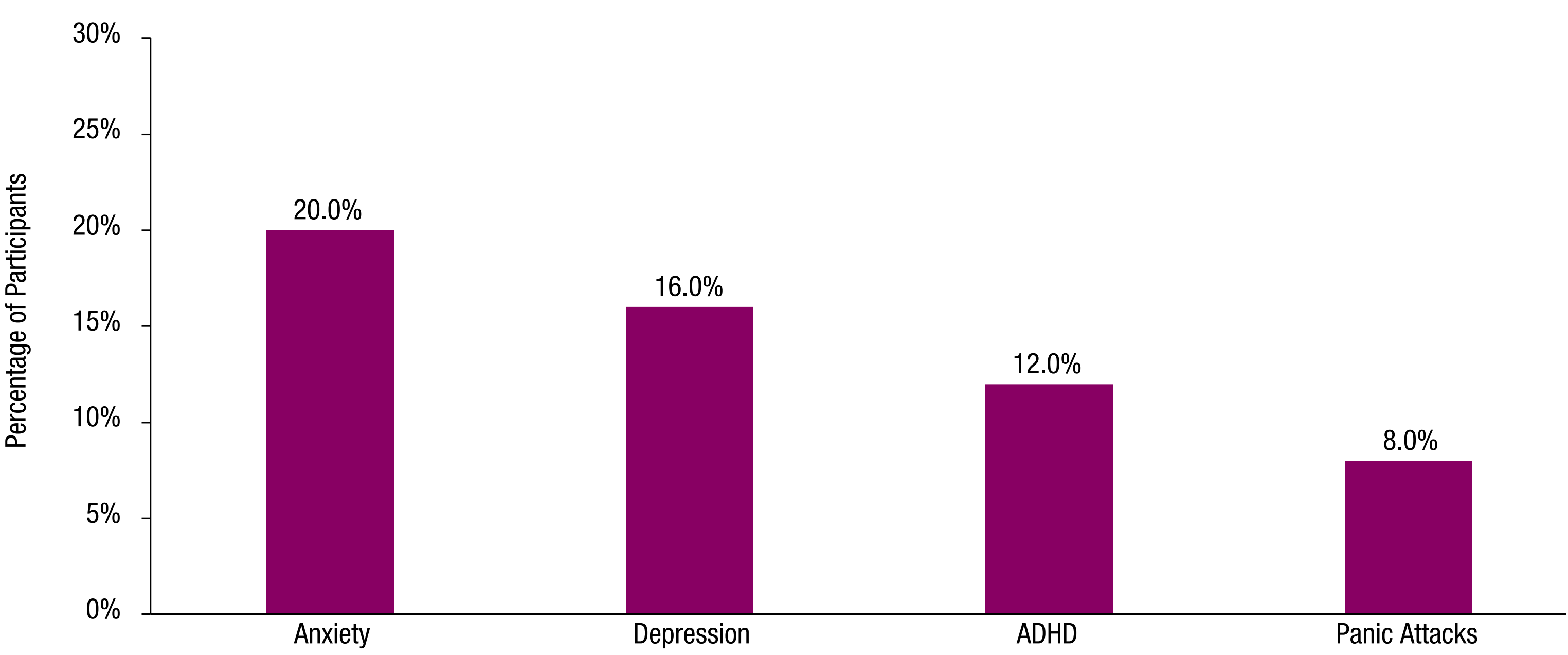
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Figure 1. Common Symptoms^a at Diagnosis



^aSymptoms were as reported by participants/caregivers, who could have reported more than 1 symptom. EDS, excessive daytime sleepiness.

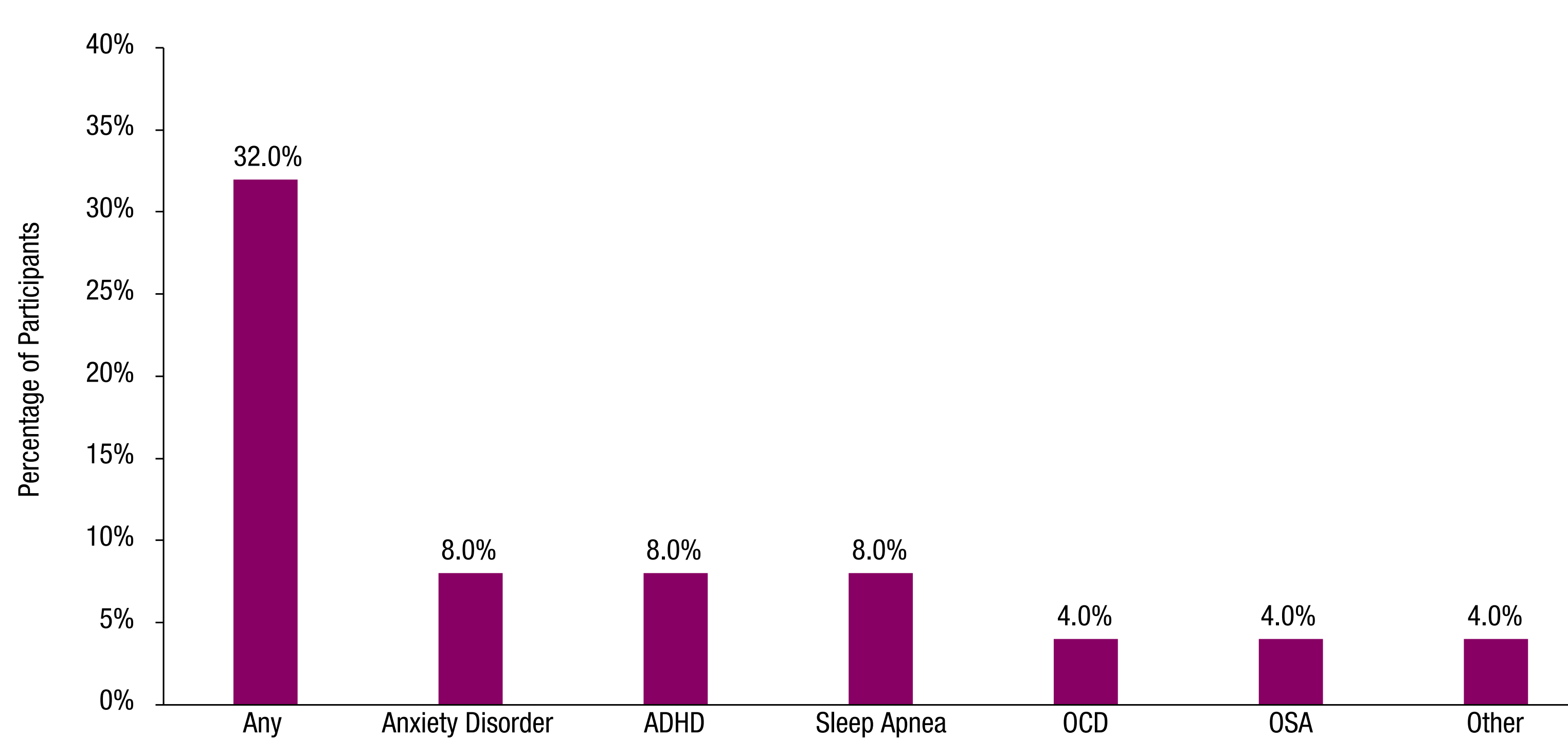
Figure 2. Common Psychiatric Comorbidities^a



^aPsychiatric comorbidities were as reported by participants/caregivers, who could have reported more than 1 psychiatric comorbidity. ADHD, attention-deficit/hyperactivity disorder.

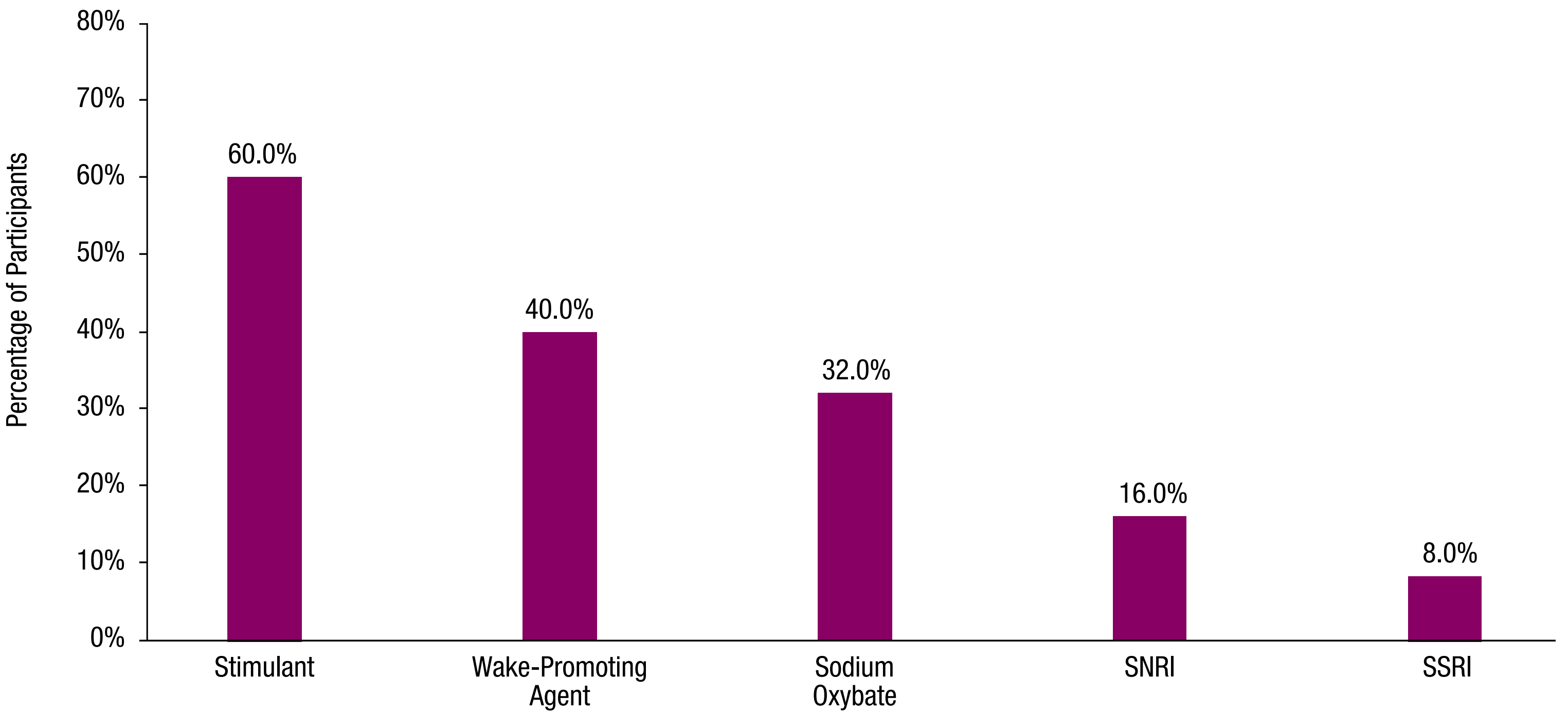
- Psychiatric disorders were present in 9 (36.0%) participants
 - Less-common conditions included obsessive-compulsive disorder, oppositional defiant disorder, and autism (each n=1; 4.0%)

Figure 3. Frequency of Misdiagnosis^a



^aMisdiagnoses were as reported by participants/caregivers, who could have reported more than 1 prior misdiagnosis. ADHD, attention-deficit/hyperactivity disorder; OCD, obsessive-compulsive disorder; OSA, obstructive sleep apnea.

Figure 4. Most Common Medications^a Being Taken for Narcolepsy



^aMedications were as reported by participants/caregivers, who could have reported taking more than 1 medication. Wake-promoting agents included armodafinil, modafinil, and pitolisant. SNRI, serotonin-norepinephrine reuptake inhibitor; SSRI, selective serotonin reuptake inhibitor.

Figure 5. Diagnosing Physician

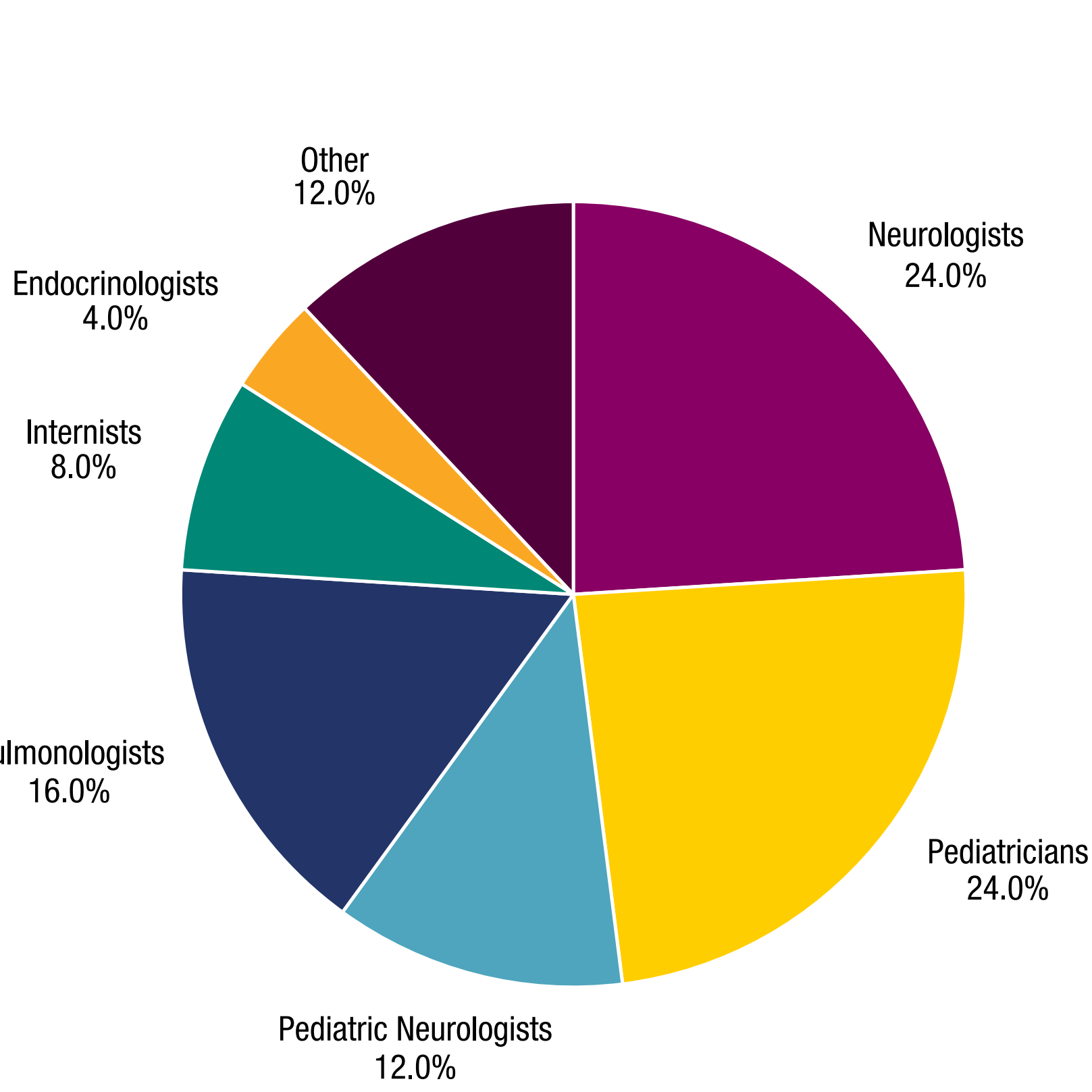
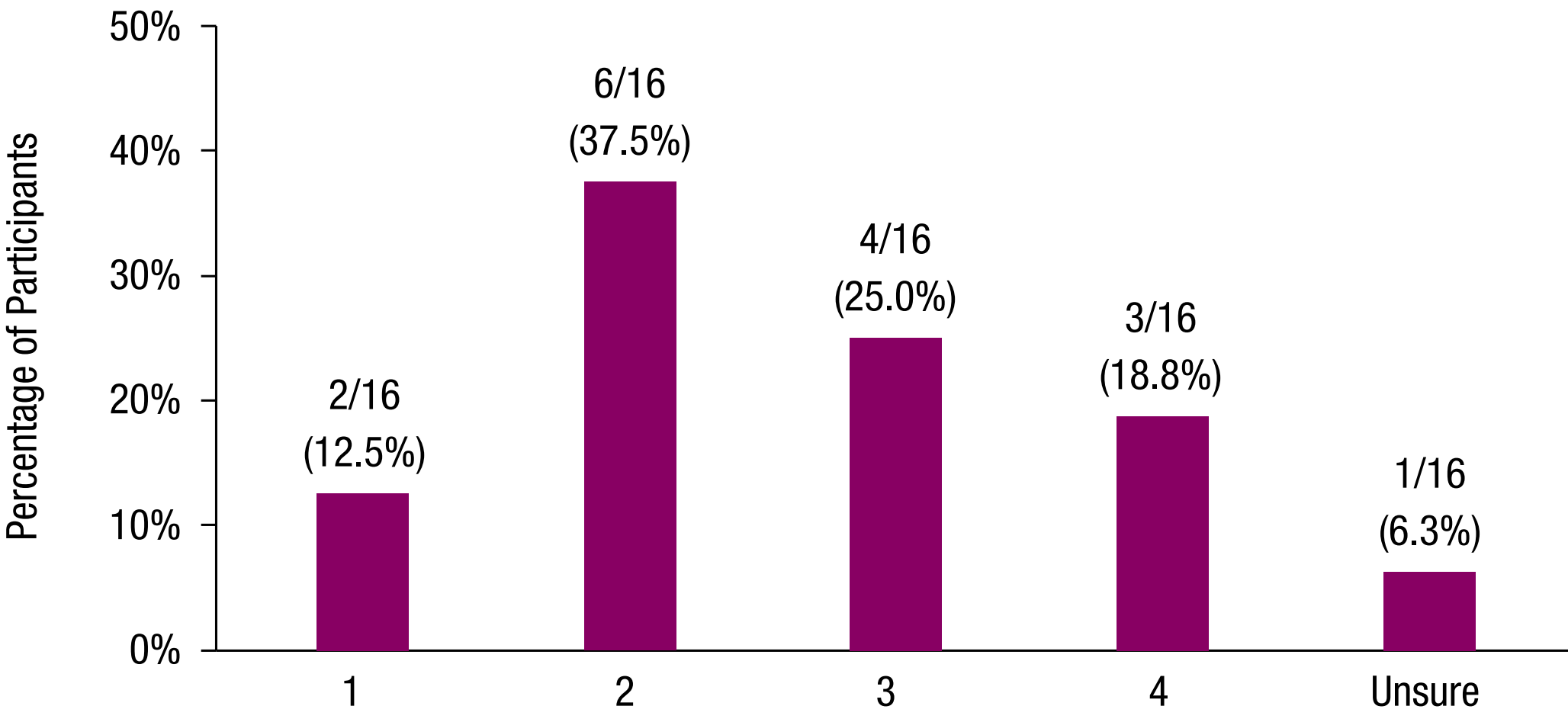
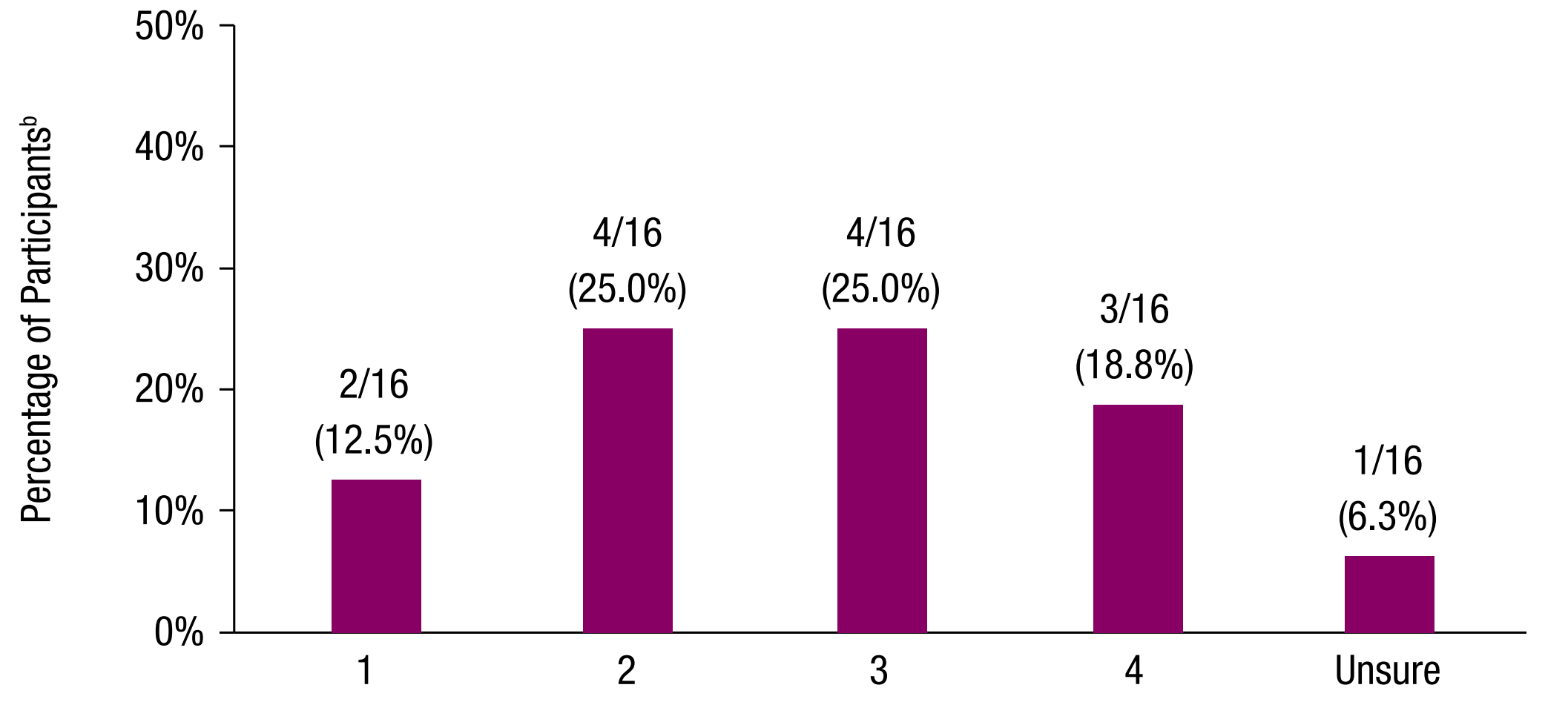


Figure 6. Number of Cataplexy Episodes per Day at Time of Diagnosis^a



^aReported by participants/caregivers.

Figure 7. Number of Days With Cataplexy Attacks per Week During Past 6 Months^a



^aReported by participants/caregivers. ^bPercentages are relative to n=16 participants reporting narcolepsy type 1 at time of diagnosis. Two of 16 participants had the cataplexy frequency listed as “null.”

- In participants with narcolepsy type 1 (n=16), warning symptoms for cataplexy were reported by 7 participants (43.8%)
 - These included a sense that cataplexy was imminent without physical symptoms, a sense that time had somewhat suspended, fear/fright, and a feeling of warmth (each n=1; 6.3%)

Conclusions

- Interim baseline data from CATNAP provide valuable information on the experience and management of pediatric narcolepsy
- These data will facilitate the education of patients and caregivers, inform clinical decision-making, and potentially improve timing to diagnose narcolepsy



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