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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 will complete follow-up surveys annually until they reach the age of 18 years or decline to participate

Results

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

Table 1. Baseline Demographics and Disease Characteristics

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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Disclosures: W Macfadden and EB Leary are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. F Gwadry-Sridhar is the founder and CEO of Pulse Inframe, Inc., which was hired by Jazz Pharmaceuticals to build the CATNAP real-world data registry. J Owens has received consultancy fees from Jazz Pharmaceuticals, Harmony Biosciences, Idorsia, Citrine, Clair Labs, and Sleep Number, and receives royalties from WebMD, Wolters Kluwer, and Taylor & Francis.

Figure 1. Common Symptoms^a at Diagnosis

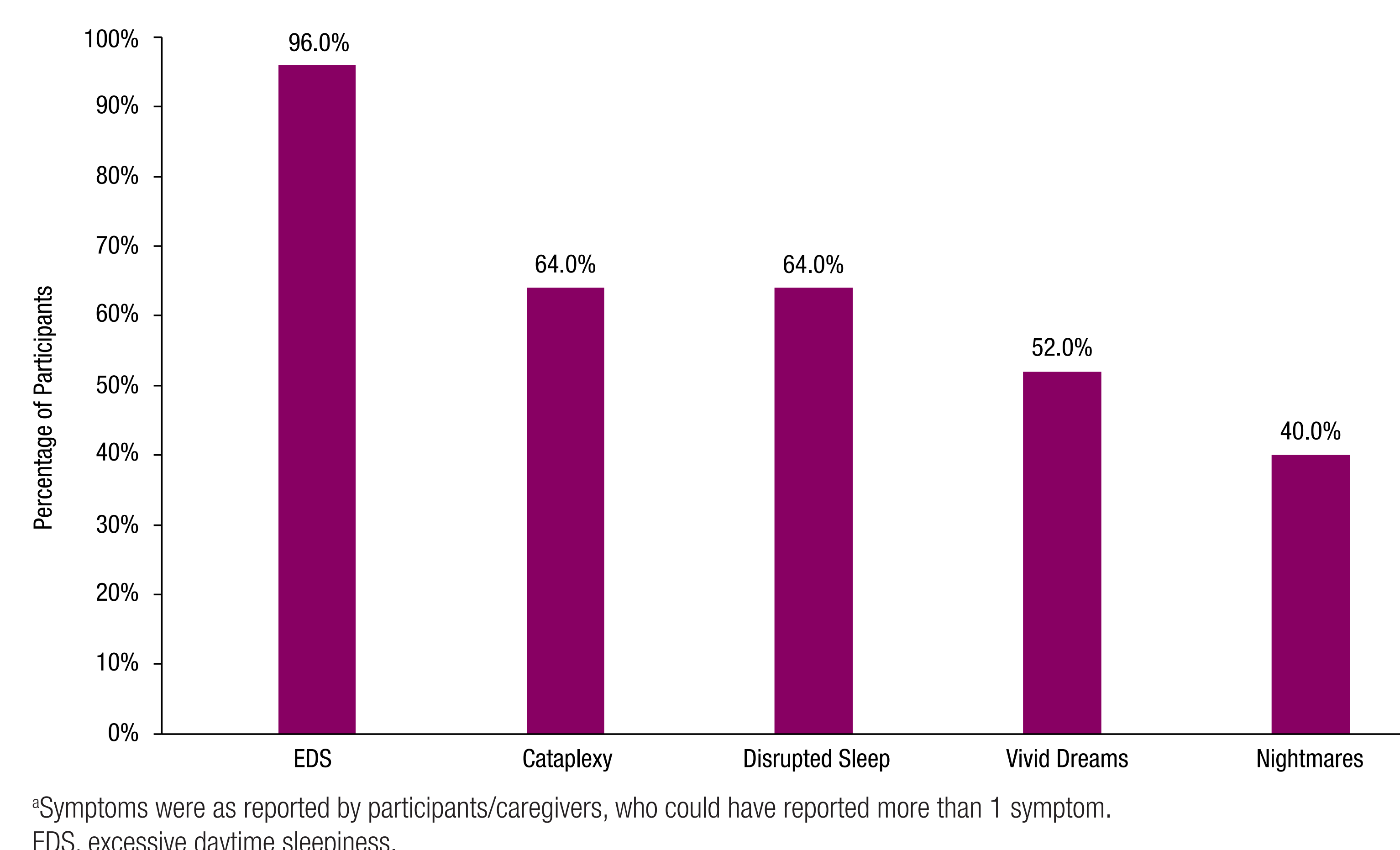


Figure 2. Common Psychiatric Comorbidities^a

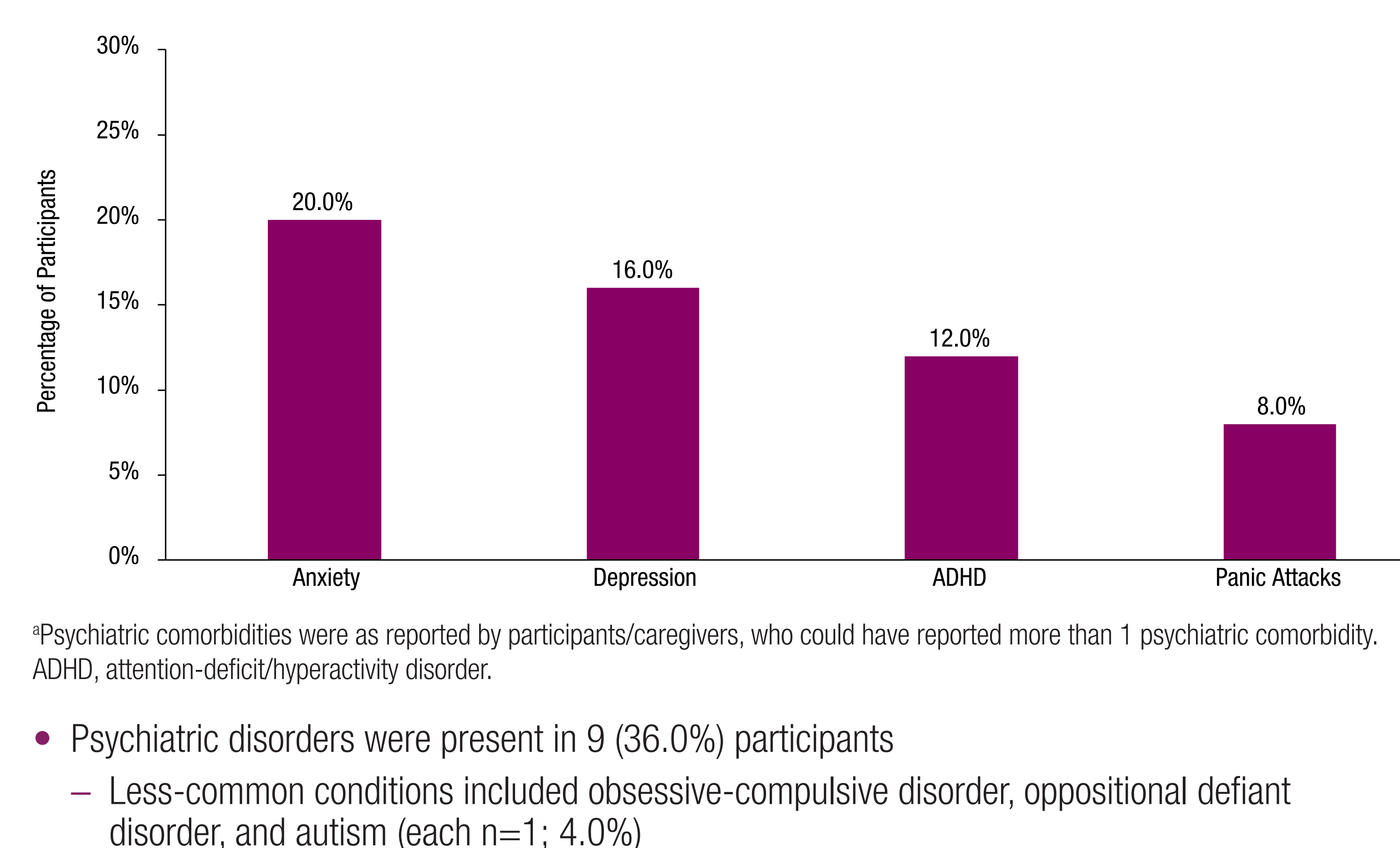


Figure 3. Frequency of Misdiagnosis^a

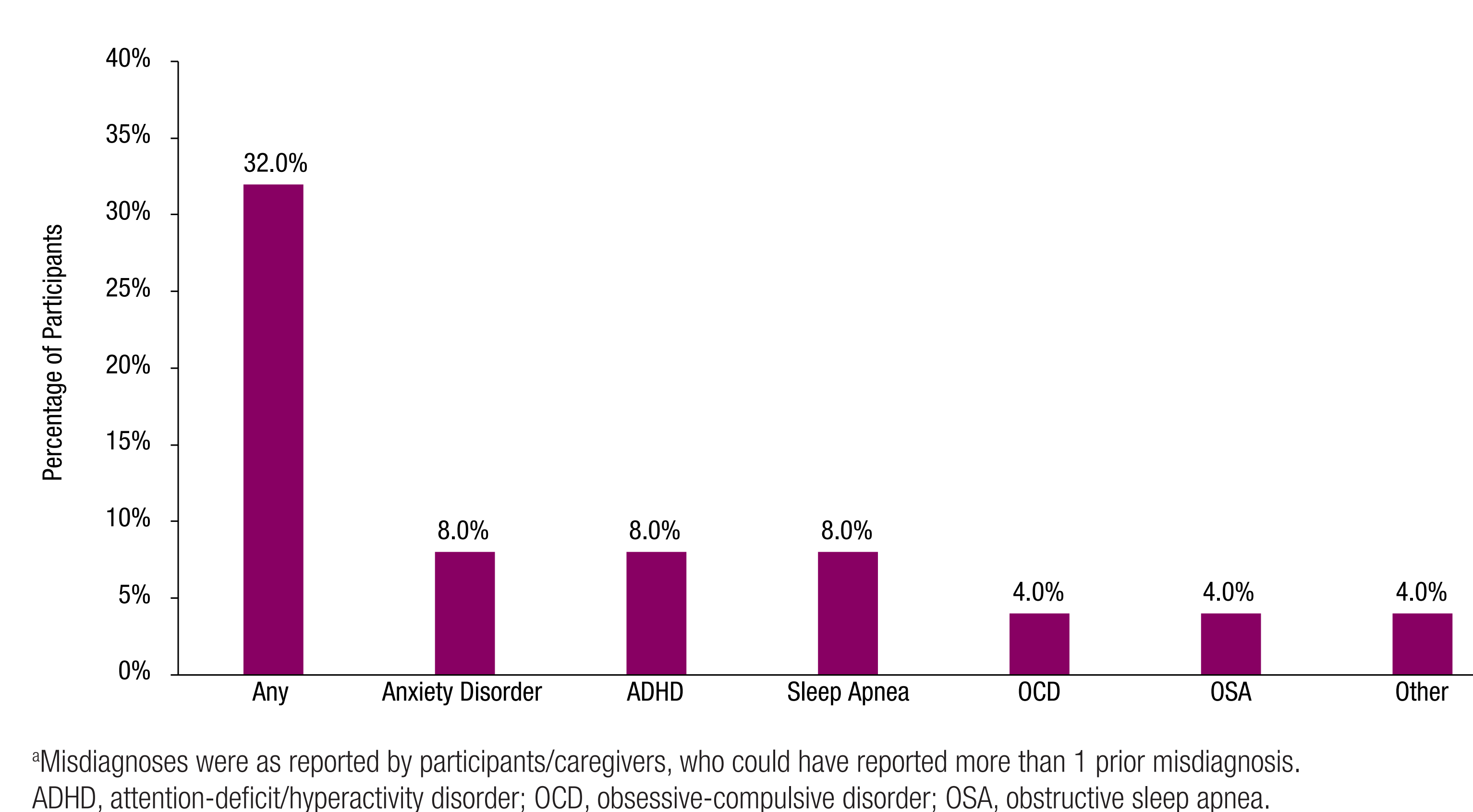


Figure 4. Most Common Medications^a Being Taken for Narcolepsy

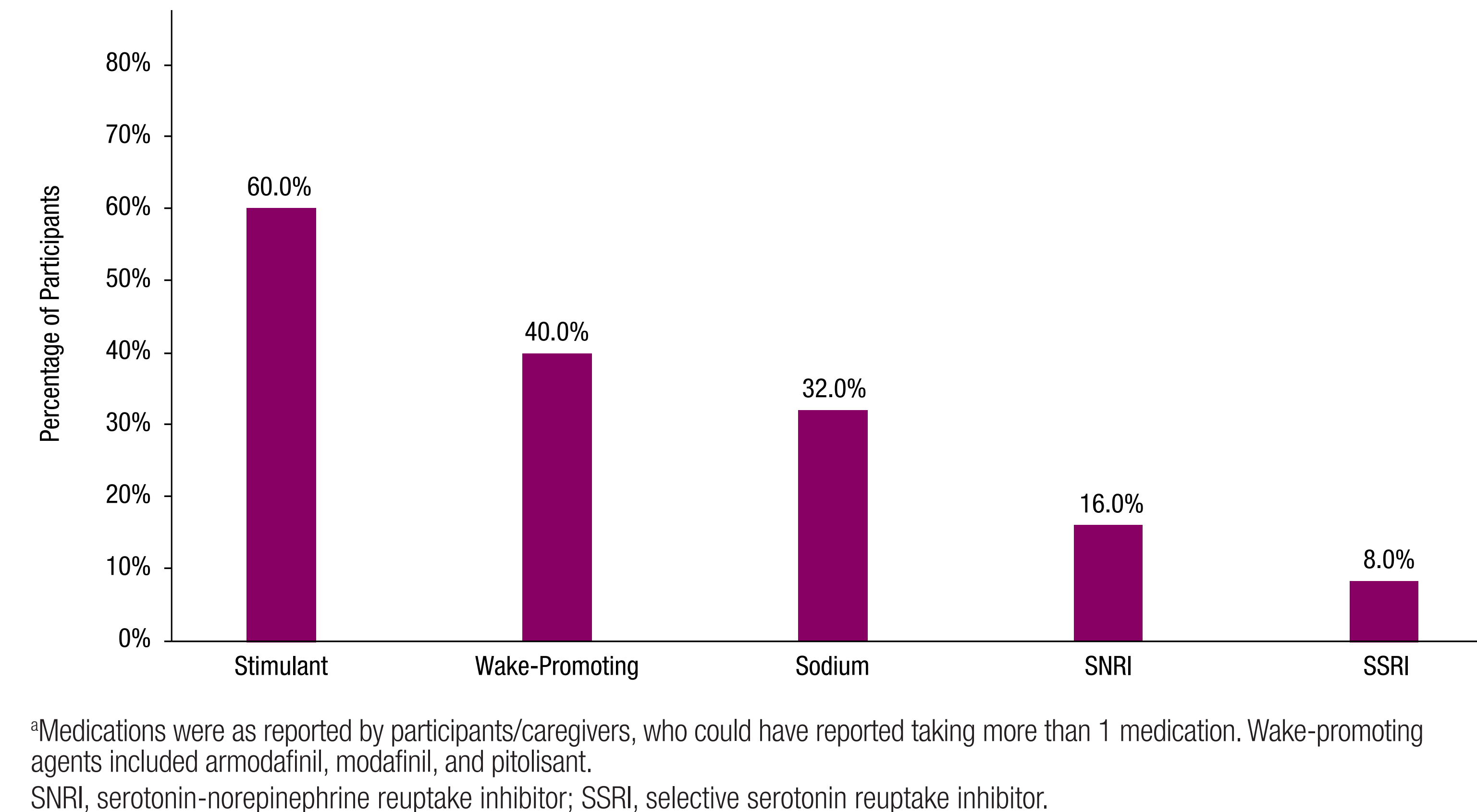


Figure 5. Diagnosing Physician

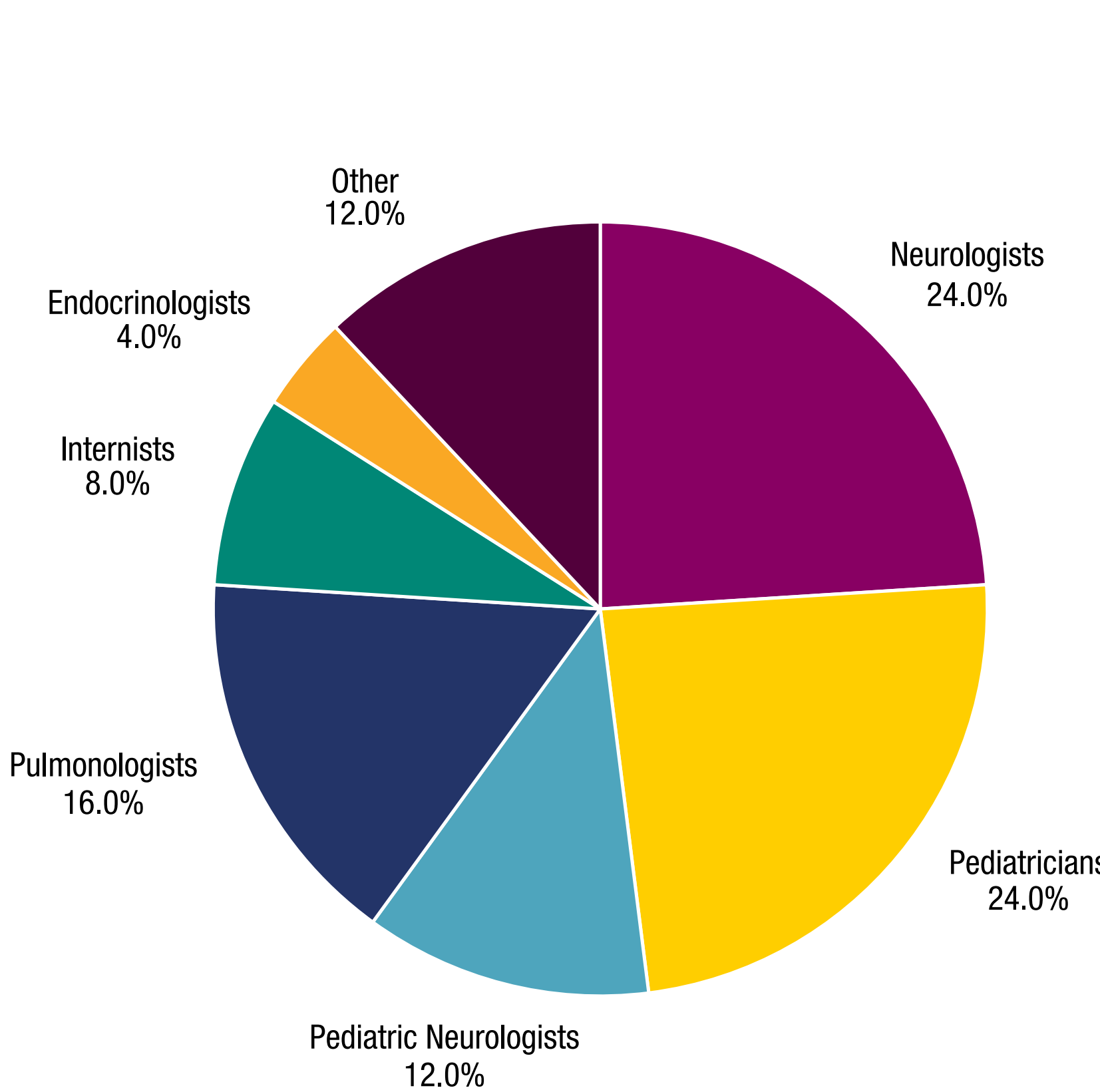


Figure 6. Number of Cataplexy Episodes per Day at Time of Diagnosis^a

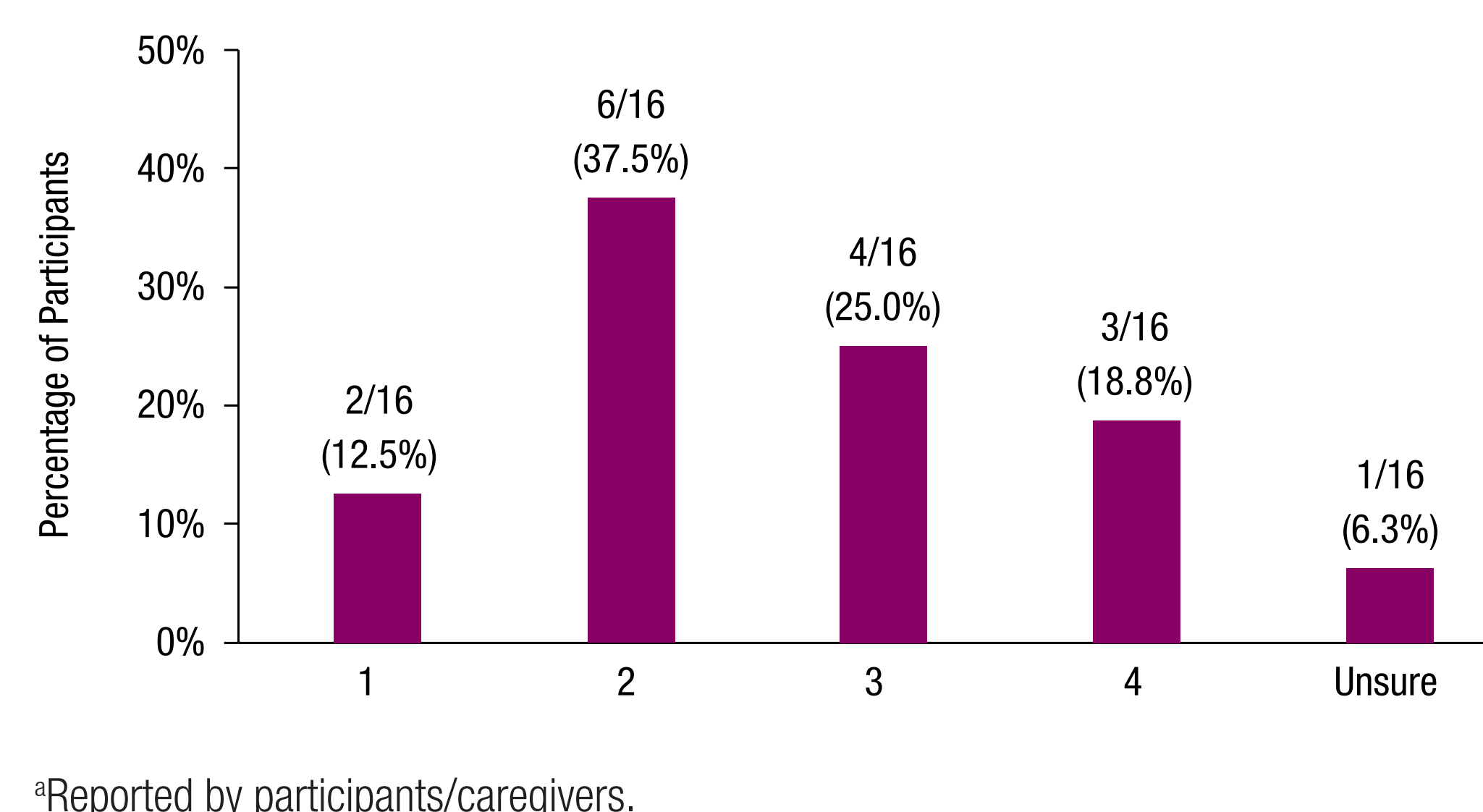
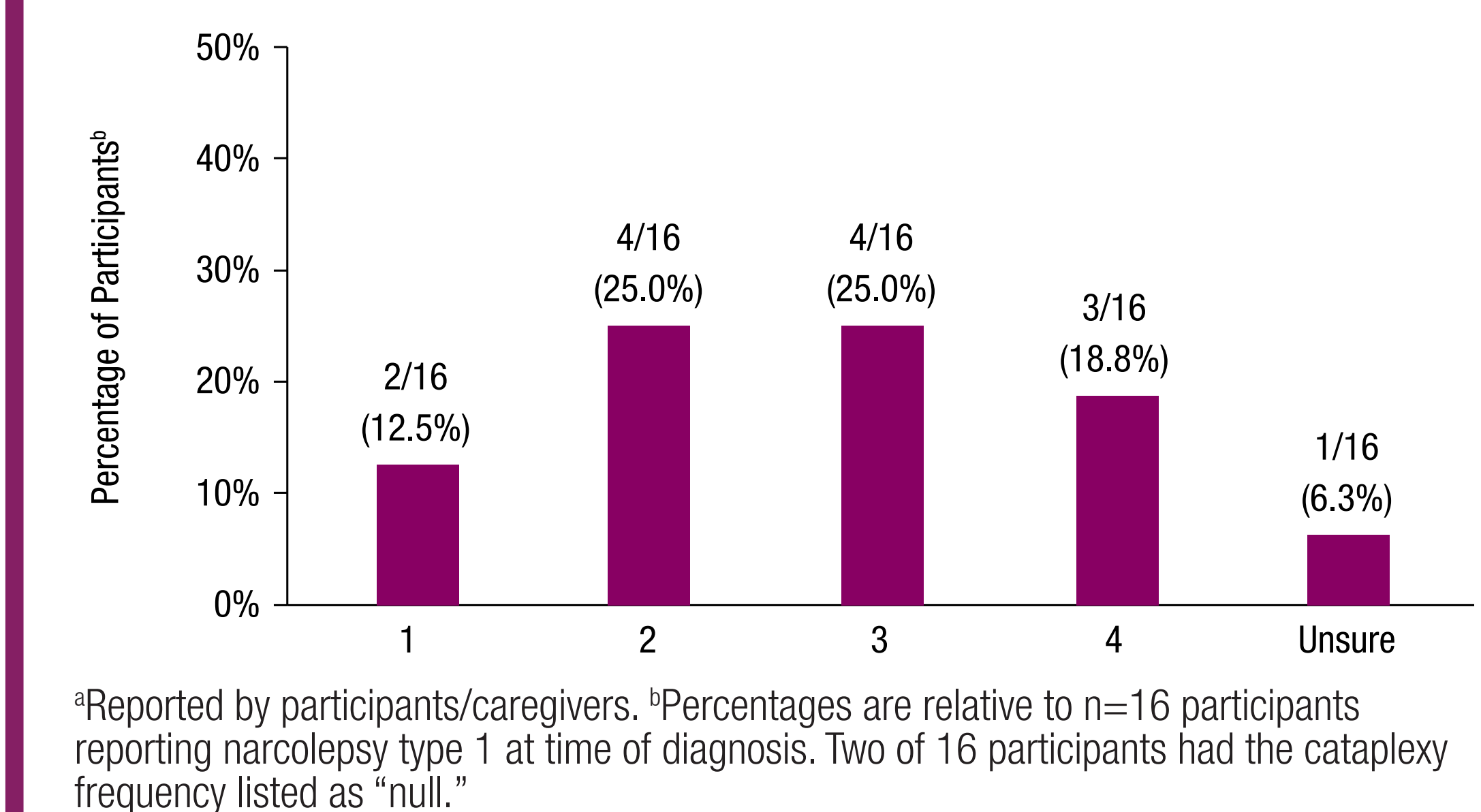


Figure 7. Number of Days With Cataplexy Attacks per Week During Past 6 Months^a



- 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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