

# Understanding the Debilitating Nature of Narcolepsy in Patients' Own Words: A Social Listening Analysis

Anne Marie Morse, DO<sup>1</sup>; Maggie Lavender, MSN, RN, FNP-C<sup>2</sup>; Matthew Horsnell, BS<sup>3</sup>; Lois Krahn, MD<sup>4</sup>; Luis E. Ortiz, MD<sup>5</sup>; Dianna Cronin, BS<sup>6</sup>; Beth Schneider, BA<sup>6</sup>; Jennifer Gudeman, PharmD<sup>7</sup>

<sup>1</sup>Geisinger Commonwealth School of Medicine, Geisinger Medical Center, Janet Weis Children's Hospital, Danville, PA, USA; <sup>2</sup>Comprehensive Sleep Medicine Associates, Houston, TX, USA; <sup>3</sup>Patient Author, Erin, TN, USA; <sup>4</sup>Mayo Clinic, Phoenix, AZ, USA;

<sup>5</sup>Johns Hopkins Medical Institutions, Johns Hopkins All Children's Hospital, St. Petersburg, FL, USA; <sup>6</sup>MyHealthTeam, San Francisco, CA, USA; <sup>7</sup>Avadel Pharmaceuticals, Chesterfield, MO, USA

## Background

- Narcolepsy is a rare, chronic hypersomnolence disorder characterized by debilitating symptoms, including excessive daytime sleepiness (EDS), cataplexy, and disrupted nighttime sleep<sup>1</sup>
- Symptoms most typically appear during adolescence<sup>2</sup>; however, previous reports suggest that diagnosis can be complicated by lack of symptom recognition or misdiagnoses and may be delayed by >10 years<sup>2,3</sup>
- Real-world information and experiences from people with narcolepsy (PWN) may be better captured within a closed patient community

## Objective

- To further characterize the many struggles and unmet needs of PWN, passive social listening was used to explore how PWN describe the condition using their own words

## Methods

### Study Design

- MyNarcolepsyTeam is a social network where >10,000 members can organically share their experiences living with narcolepsy with one another
- A 27-question online survey was fielded from February 17, 2022, to March 15, 2022
  - 3959 individuals from the MyNarcolepsyTeam community were invited to participate
  - Participants were not compensated for their time
- After the survey, organic posts, comments, questions, and answers posted from January 2022 to October 2023 were analyzed to add more dimension to how PWN experience narcolepsy
- All personally identifiable information was removed
- All data were analyzed descriptively

## Results

- 110 individuals based in the US responded to the survey (Table 1)

**Table 1. Demographic Characteristics of Survey Respondents**

Characteristic (%)	Percentage of Respondents (N=110)
Age range	
<40 years	23
40–49 years	24
50–59 years	23
≥60 years	30
Female	84
Narcolepsy type	
NT1	48
NT2	32
Unsure of type	20

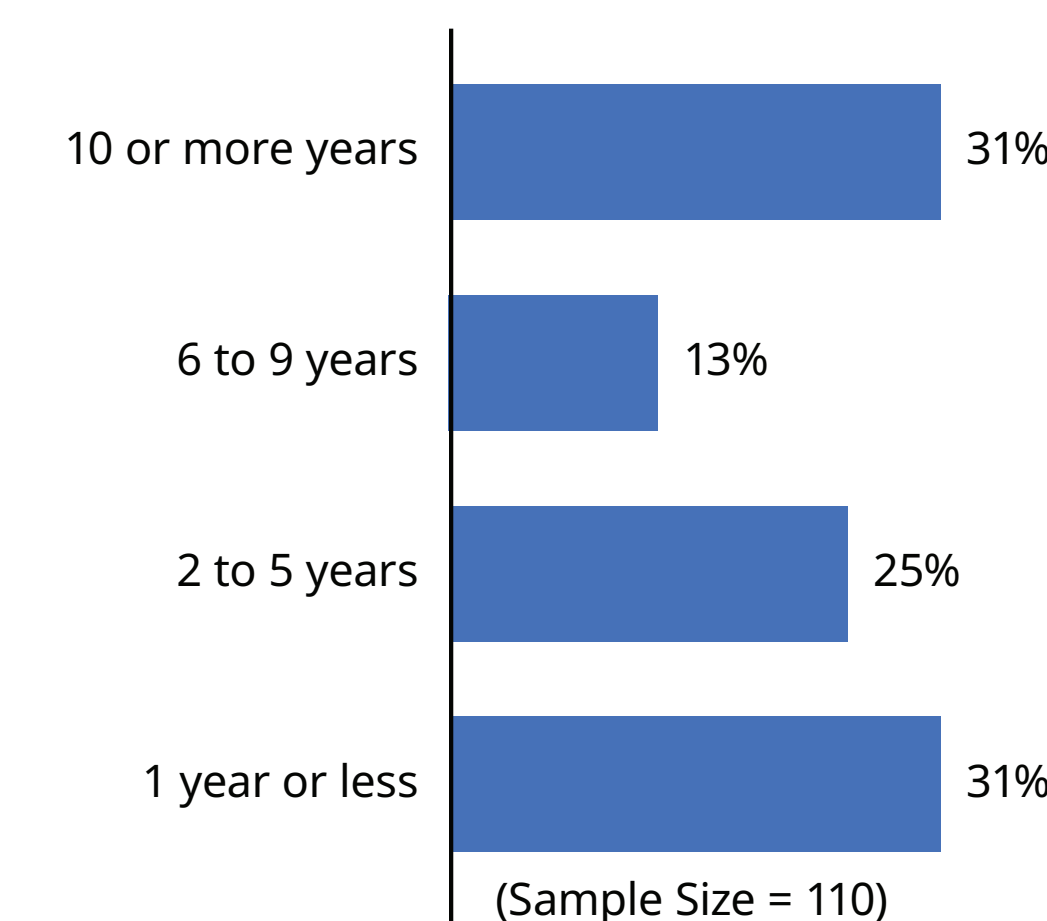
NT1, narcolepsy type 1; NT2, narcolepsy type 2.

### Long Path to Narcolepsy Diagnosis

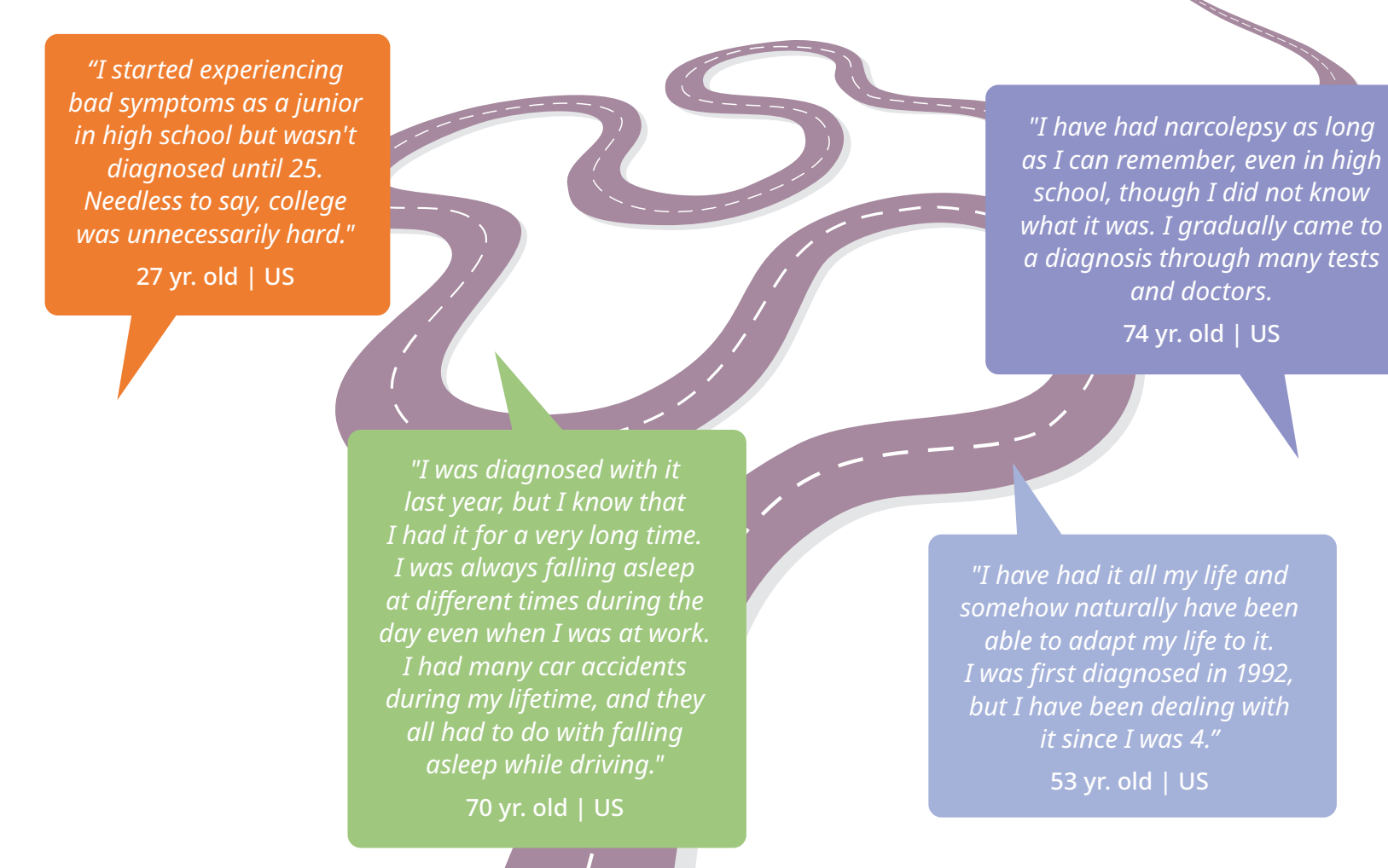
- 31% of respondents reported that the time from symptom onset to diagnosis was ≥10 years (Figure 1)
  - Social listening highlighted both misdiagnoses (eg, depression) and "missed" diagnoses (eg, sleep apnea but not narcolepsy)

### Figure 1. Long Path to a Narcolepsy Diagnosis

Q. Thinking about when you first went to a doctor to discuss your symptoms, approximately how many years did it take before you were diagnosed with narcolepsy?



#### Road to a Correct Diagnosis Can Take Many Years



### Comorbidities

- Almost half (43%) of respondents reported pain as a comorbidity (Figure 2)
  - Social listening revealed the burden of painful comorbidities (eg, fibromyalgia, migraines, neuropathy), which often lead to additional medications and further sleep disruption

### Figure 2. Pain-Based Comorbidities in Patients' Own Words

**In total, 43% suffer with some type of pain as a comorbidity:**

"I suffer daily pain. It seems it's not enough to suffer with not being able to go to sleep and not being able to stay awake and then pain is added to the mix."

"I'm in a little pain due to fibromyalgia."

"I have sleep apnea and narcolepsy. Plus, I have chronic fatigue syndrome and fibromyalgia and lots of other things wrong with me."

"It has become debilitating having so many sleep disorders and how they have impacted my chronic migraines."

"I have been doing a lot of reading and it's saying that narcolepsy can create migraines. Between the narcolepsy medication and the migraine medication I am starting to feel over medicated."

"I have neuropathy in all of my extremities. I have pain in my legs most days and nights."

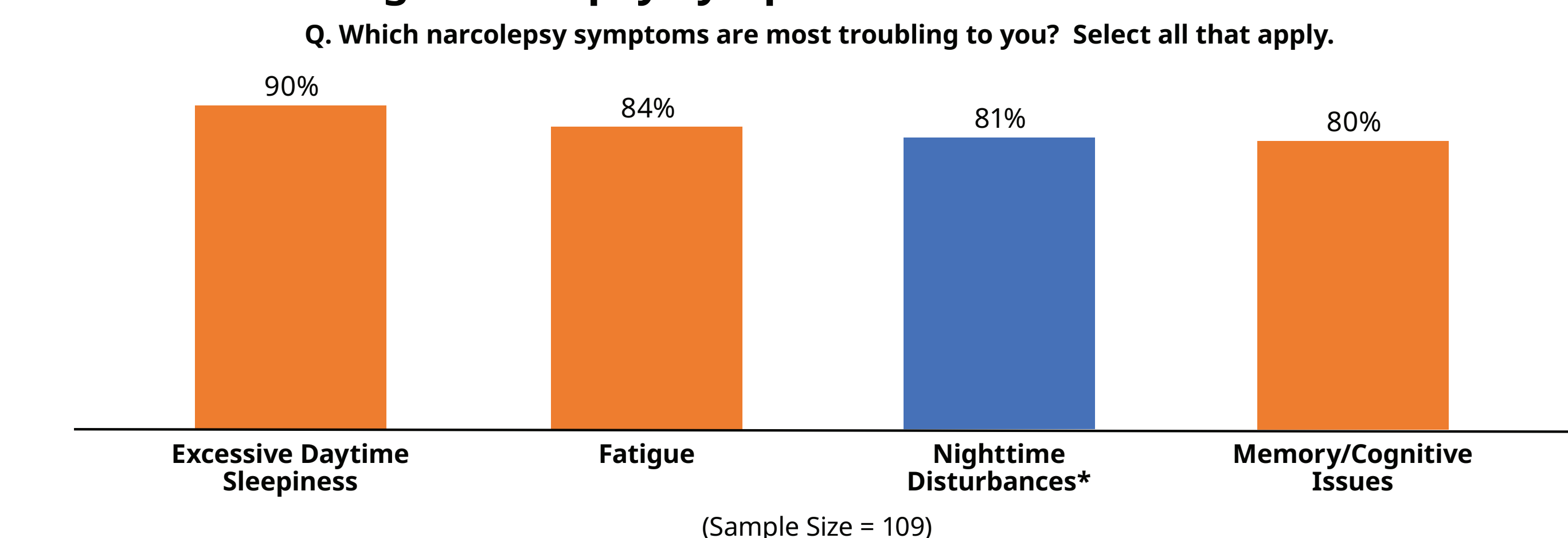
"I had Lyrica added to my lineup and it helped the restless leg and neuropathy."

### Most Troubling Narcolepsy Symptoms

- EDS and nighttime disturbances were reported as most troubling by 90% and 81% of respondents, respectively (Figure 3A)
- Nighttime disruptions experienced by PWN included poor sleep quality, vivid dreams, frequent awakenings, sleep paralysis, and abnormal rapid eye movement cycles (Figure 3B)
  - Structured routines helped improve sleep for some PWN

### Figure 3. Narcolepsy Symptoms

#### A. Most Troubling Narcolepsy Symptoms



#### B. Troubling Nighttime Disturbances in Patients' Own Words

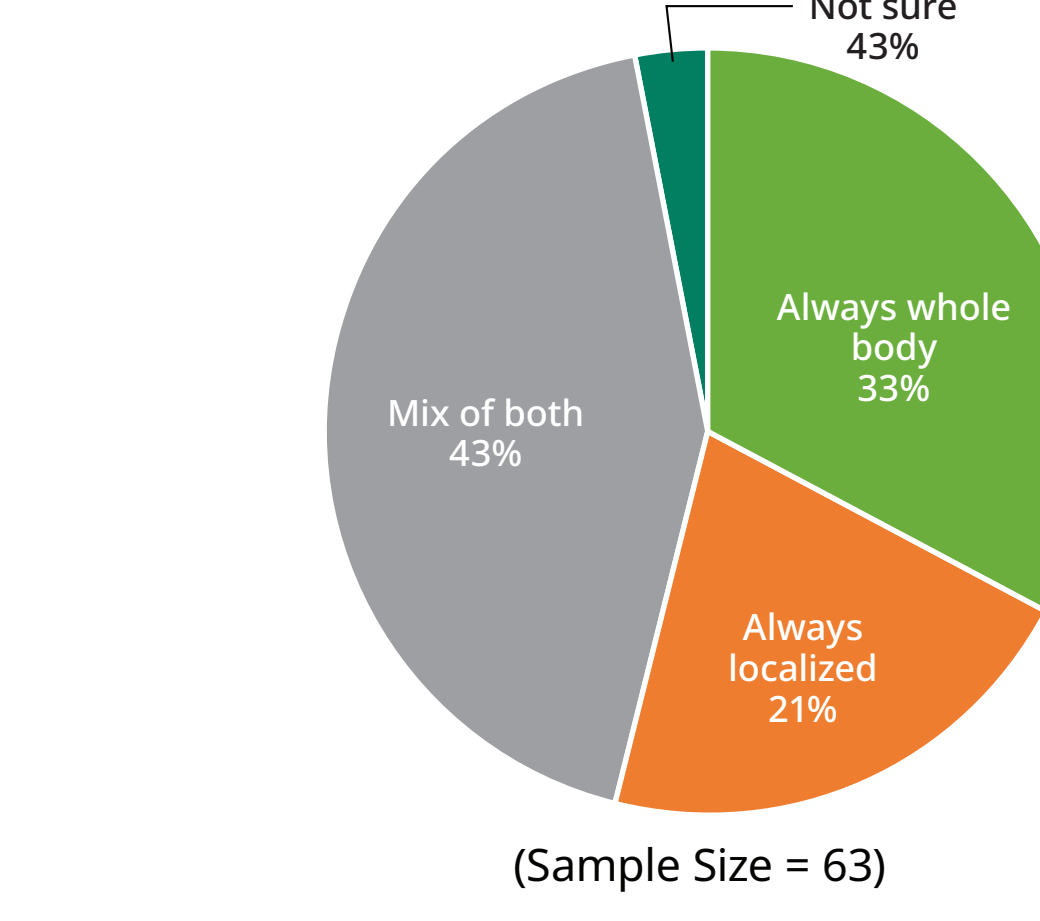
\*Nighttime disturbances include anyone mentioning poor quality sleep, disrupted/fragmented sleep, insomnia, or frequent awakenings.  
REM, rapid eye movement.

### Cataplexy

- Cataplexy experience differed among survey respondents (Figure 4)
  - Social listening highlighted the dangers of cataplexy, including risk of falls and/or fractures

### Figure 4. How Cataplexy is Experienced

Q. Have you generally experienced cataplexy in your whole body or in more localized areas? (Asked of those indicating they have Type 1 narcolepsy or who have experienced cataplexy)

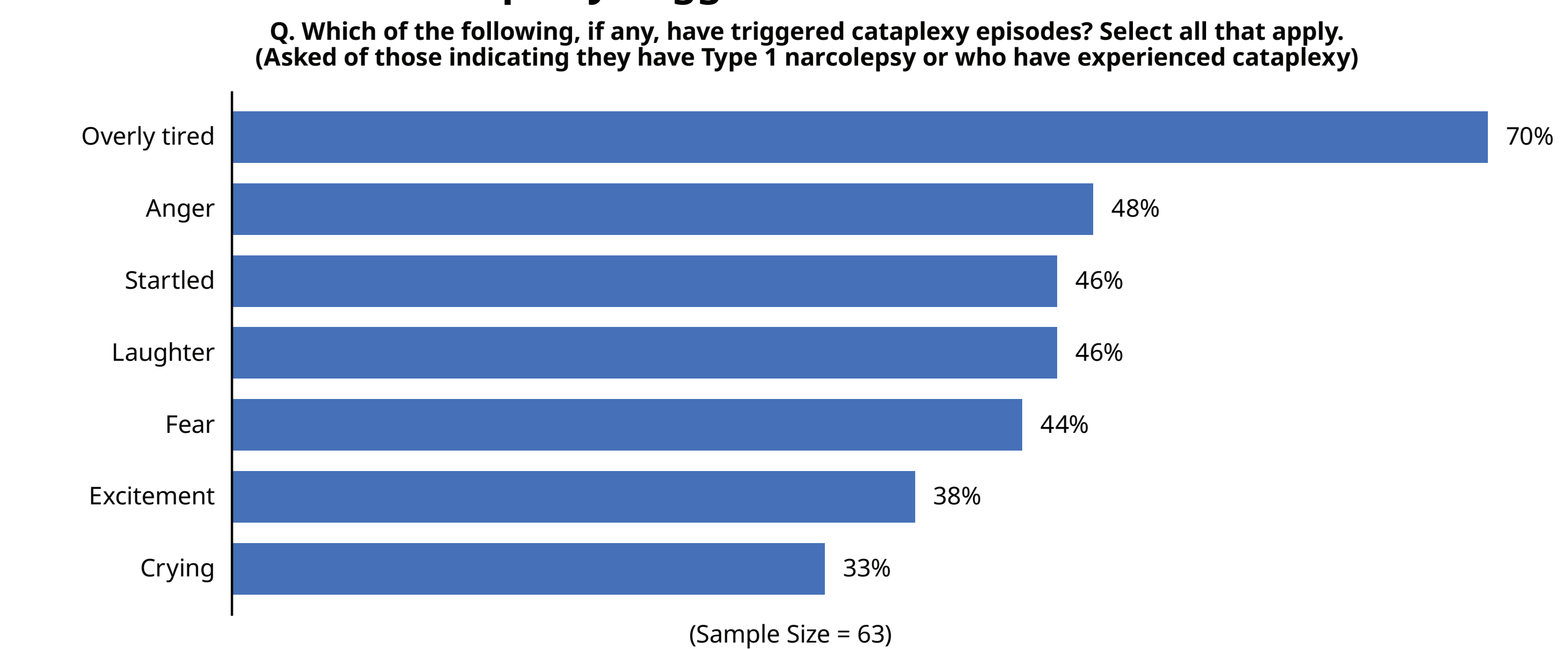


EMT, emergency medical technician.

- The most commonly reported cataplexy trigger was being overly tired (Figure 5A)
  - Organic conversations revealed the full range of emotions that can trigger a cataplexy episode (eg, laughter, being startled, feeling stressed; Figure 5B)

### Figure 5. Cataplexy Triggers

#### A. Most Common Cataplexy Triggers



#### B. Cataplexy Triggers in Patients' Own Words

### Treatment Rituals

- 65% of respondents were taking ≥2 medications to treat daytime and/or nighttime narcolepsy symptoms
  - Organic conversations highlighted the challenges PWN experience while managing complex treatment regimens

## Conclusions

- PWN often experience diagnostic delays, burdensome symptoms and comorbidities, and difficulties managing complex medication regimens
- Insight into the narcolepsy experience in PWN's own words may help sleep specialists better understand the challenges and needs of PWN, which may lead to faster diagnosis and more effective, individualized treatment

**References** 1. Bassetti CLA, et al. *Nat Rev Neurol*. 2019;15(9):519-539. 2. Golden EC and Liptford MC. *Cleve Clin J Med*. 2018;85(12):959-969. 3. Thorpy M and Morse AM. *Sleep Med Clin*. 2017;12(1):61-71.

**Acknowledgments** Editorial support was provided by The Curry Rockefeller Group, LLC, a Citrus Health Group, Inc., company (Chicago, IL), and was funded by Avadel Pharmaceuticals, Chesterfield, MO.

**Funding** This study was funded by Avadel Pharmaceuticals (Chesterfield, MO, USA).

**Disclosures** AMM has served as a consultant, speaker, and/or on advisory boards for Avadel Pharmaceuticals, Eisai, Harmony Biosciences, Jazz Pharmaceuticals, NLS Pharmaceuticals, Alkermes, and Takeda Pharmaceutical Co; has received grant funding from National Institutes of Health, UCB Pharmaceuticals, Jazz Pharmaceuticals, ResMed Foundation, Coverts Foundation, and Geisinger Health Plan; is the CEO of DAMM Good Sleep, LLC; and has served as an advisor for Neura Health. ML is a speaker or has received consulting fees for participation on advisory boards for Avadel Pharmaceuticals and Harmony Biosciences. MH is a consultant to Avadel Pharmaceuticals; has received compensation or honoraria from Alkermes, Axsome Therapeutics, Centessa Pharmaceuticals, and Harmony Biosciences; and is a member of the Sleep Consortium Advisory Board. LK is a consultant for and/or has served on advisory boards for Avadel Pharmaceuticals, Harmony Biosciences, and Takeda. LEO has served on advisory boards for Avadel Pharmaceuticals and Jazz Pharmaceuticals. DC and BS are employees of MyHealthTeam, which received funding to conduct the research. JG is an employee of Avadel Pharmaceuticals.

