SLEEP² Narcolepsy Survey Results

CODY HAVENS, MPH
Overview of Narcolepsy Survey Development

Created by Rebecca Fuoco & Julie Flygare of Project Sleep

16-item online survey

Responses were collected over a 4 month period between 4/3/2017-8/3/2017

Disseminated through Project Sleep’s social media pages and listserve

Total of 1239 responses (approximately 90% were patients)
Number of respondents

- Provider
- Caregiver
- Researcher
- IH
- N + C
- N w/o C
- Undiagnosed
- Other

N = 1170
Country of Respondents

- USA
- UK
- Canada
- Australia
Gender of Respondents

- Missing
- Female
- Male
- Other

Percentages:
- Female: 80%
- Missing: 20%
- Male: 0%
- Other: 0%
ANOVA; P value <0.0001

Compared to undiagnosed cases

P < 0.10

** P < 0.05

Compared to caregivers

$ Compared to caregivers

Age of respondents

95% CI What is your age (or the age of the person with narcolepsy you care for)?

Subject

Caregiver

Idiopathic Hypersomnia

Narcolepsy with Cataplexy

Narcolepsy w/o Cataplexy

Undiagnosed Narcolepsy

ANOVA; P value <0.0001
Time to Diagnosis (Self-reported)

ANOVA; $P < 0.0001$

Compared to undiagnosed cases

Compared to caregivers

95% CI How long (in) did you experience symptoms of narcolepsy before you received a diagnosis?

Subject

Caregiver, Idiopathic Hypersomnia, Narcolepsy with Cataplexy, Narcolepsy w/o Cataplexy, Undiagnosed Narcolepsy

ANOVA; $P value < 0.0001$
Before starting treatment, which 1-3 narcolepsy symptoms had the most significant impact on your life?

1. Episodes of excessive daytime sleepiness that come and go
2. General fatigue throughout the day
3. Cataplexy (muscle weakness generally accompanied by emotions)
4. Sleep paralysis (feeling unable to move upon waking up or falling asleep)
5. Hypnagogic and/or hypnopompic hallucinations (vivid hallucinations upon waking up or falling asleep)
6. Disrupted nighttime sleep
7. Brain fog (difficulty thinking, concentrating, or paying attention; trouble remembering things)
8. “Automatic behaviors”—actions that occur as you’re falling asleep or waking up that you don’t remember
9. Waking unrefreshed in the morning
10. General fatigue/never feel rested
11. Irritability or mood instability
12. Excessive weight gain
13. Other
Before starting treatment, which 1-3 narcolepsy symptoms had the most significant impact on your life?

- Excessive daytime sleepiness
- General fatigue
- Cataplexy
- Sleep paralysis
- Hypnagogic and/or hypnopompic hallucinations
- Disrupted nighttime sleep
- Brain fog
- "Automatic behaviors"
- Unrefreshing Sleep
- Irritability or mood instability
- Excessive weight gain
- Other

Brain Fog = difficulty thinking, concentrating, or paying attention; trouble remembering things

Number of respondents
After starting treatment, which 1-3 narcolepsy symptoms had the most significant impact on your life?

Brain Fog = difficulty thinking, concentrating, or paying attention; trouble remembering things
On a scale of 1 to 5 (1 being “not at all effective” and 5 being “extremely effective”), how effective is your current treatment regimen in reducing your most significant symptoms?
What are you currently using to treat your symptoms (all that apply)?

- Stimulants
- Sedatives
- Cataplexy
- Medications
- Naps
- Sleep
- Hygiene
- Other
What are the **most significant downsides** to your current treatment regimen? (rank up to three, with "1" being the most significant)
When evaluating the effectiveness of therapies for narcolepsy, what are the most important factors to you?
Aside from effectiveness, what are the most important factors you would consider when evaluating therapies for narcolepsy? (rank up to three, with "1" being the most significant)

Expense
Care for myself?
Functioning in school/work
Overall health/risks?

What areas of narcolepsy research would you most like to see prioritized by scientists? (rank up to three, with "1" being the most significant)

- Developing therapies that directly impact the underlying disease process
- Developing precision medicine approaches (customizing treatment and care based on individual needs)
- Improving therapies that address symptoms more effectively and/or with less side effects
- Understanding the biology of narcolepsy (e.g., possible autoimmune basis; genetics)
- Understanding the impact of narcolepsy on cognitive functioning (e.g., explaining how sleep impairments affect learning)
- Improving the diagnosis process (e.g., reducing time-to-diagnosis, more accurate tests)
- Utilizing a comprehensive approach to treating narcolepsy (e.g., involving mental health professionals)
- Preventing and treating co-existing conditions or complications (e.g., digestive issues, mental health problems)
- Developing educational or behavioral strategies to improve sleep hygiene or management skills
- Understanding and addressing the psychological, social, and/or emotional impact of narcolepsy
- Other (please specify)