

Table S1: Logistic Regression Analysis of Predictors of Delayed Narcolepsy Diagnosis (≥1 year) from Symptom Onset

Predictor	B	SE	OR	95% CI	P-Value
Pediatric Onset of Symptoms	0.88	0.17	2.41	1.75-3.33	<0.0005
Cataplexy	0.58	0.2	1.79	1.22-2.62	0.003
Current Age	-1.06	0.17	0.35	0.25-0.49	<0.0005

Pediatric Onset of Symptoms =Onset of symptoms <18 years of age vs. ≥18 years of age (reference); Cataplexy=no cataplexy symptoms vs. presence of cataplexy symptoms (reference); Current Age=<35 years vs. ≥35 years (reference) at time of survey

Table S2: Logistic Regression Analysis of Predictors of Depressive Symptoms Among Participants with Narcolepsy

Predictor	B	SE	OR	95% CI	P-Value
Pediatric Onset of Symptoms	-0.13	0.19	0.88	0.61-1.27	0.49
Cataplexy	0.002	0.2	1	0.68-1.47	0.99
Current Age	0.19	0.18	1.2	0.85-1.73	0.28
Diagnostic Delay	-0.24	0.19	0.79	0.55-1.12	0.18

The term “Depressive symptoms” refers to frequency of participants reporting “depression” when asked about other conditions they currently manage. Pediatric Onset of Symptoms =Onset of symptoms <18 years of age vs. ≥18 years of age (reference); Cataplexy=no cataplexy symptoms vs. presence of cataplexy symptoms (reference); Current Age=<35 years vs. ≥35 years (reference) at time of survey; Diagnostic Delay= diagnosis made >5 years from symptom onset vs. ≤ 5 years (reference)

Disease Burden Database Questions

Question 1: Which of the following best describes your (primary) relationship to narcolepsy?

1. I have been diagnosed with narcolepsy by a healthcare professional
2. I have been diagnosed with a hypersomnia syndrome by a healthcare professional
3. I have a condition that has the symptoms of narcolepsy but I have not been diagnosed by a healthcare professional
4. I am a parent, spouse and/or a primary caregiver for someone who has narcolepsy (Note: Please think about the person who has narcolepsy as you answer this survey)
5. I am a healthcare professional who cares for people with narcolepsy
6. I am a family member or close friend of someone who has narcolepsy, but I am not the primary caregiver
7. None of the above

Question 2: Please indicate whether you (or the person close to you) experience cataplexy (striking and sudden episodes of muscle weakness often triggered by emotions) as part of your narcolepsy

1. Yes, cataplexy is something I have experienced
2. No, cataplexy is not something I have experienced
3. I don't know what cataplexy is
4. I know what cataplexy is, but I'm not sure if I experience it or not

Question 3: Are the episodes of cataplexy you experience triggered by any of the following activities? (Check all that apply.)

1. I don't experience cataplexy or I don't know if I do
2. Laughing excitedly
3. Laughing
4. Chuckling
5. Making a sharp-minded remark
6. Being tickled
7. Tickling someone
8. Telling a joke
9. Before reaching the punchline of a joke
10. Hearing a joke
11. Being startled
12. Being angry
13. In pain
14. While eating
15. Being the center of attention
16. Spontaneously or no apparent reason

Question 4a: How would you describe the severity of your condition without treatment?

1. Mild
2. Moderate
3. Severe
4. No Response-patient
5. No Response-other

Question 4b: How would you describe the severity of your condition with treatment?

1. Mild
2. Moderate
3. Severe
4. No Response-patient
5. No Response-other

Question 5: What changes have you had to make in your life because of narcolepsy? (If you're answering from the point of view of a family member or caregiver, please include changes in your own life.)

Open-Ended Response

Question 6: Are there other diagnoses you have to manage? Categorical responses and open text

0. No; narcolepsy is the only condition that has been diagnosed (or is suspected)
1. There is **one** other co-existing condition that requires active management
2. There are **two** other co-existing conditions that require active management
3. There are **three or more** co-existing conditions that require active management

Question 7: Do any of these other conditions interfere with treatment you might consider using for narcolepsy?

1. Yes (please feel free to comment more below)
2. No
3. I don't know
4. Not applicable
5. Prefer not to answer

Question 8: How many years since narcolepsy first affected your life?

1. Within the past 12 months
2. 1-2 years
3. 3-5 years
4. 6-10 years
5. 11-20 years
6. More than 20 years

Question 9: How long did it take for you to get diagnosed with narcolepsy (or with a hypersomnia syndrome)?

1. Within 1 month of onset
2. 1-3 months of onset
3. 4-6 months of onset
4. 7-12 months of onset
5. 1-2 years of onset
6. 3-5 years of onset
7. 6-10 years of onset
8. More than 10 years

Question 10a: What is your age (or the age of the person with narcolepsy with whom you are close)?

1. 10 or younger
2. 11 to 17
3. 18 to 24
4. 25 to 34
5. 35 to 44
6. 45 to 54
7. 55 to 64
8. 65 to 74
9. 75 or older

Question 10b: What was your age when narcolepsy symptoms began?

1. 10 or younger
2. 11 to 17
3. 18 to 24
4. 25 to 34
5. 35 to 44
6. 45 to 54
7. 55 to 64
8. 65 to 74
9. 75 or older

Question 11: Of all the symptoms that you experience because of your condition, which one to three symptoms have the MOST SIGNIFICANT impact on your life?

1. Excessive daytime sleepiness
2. Distinct sleep attacks
3. Cataplexy (striking, sudden episodes of muscle weakness, often triggered by emotions)
4. Disrupted nighttime sleep
5. Sleep paralysis
6. Vivid hallucinations upon waking or falling asleep (called "hypnagogic and hypnopompic hallucinations")
7. Waking unrefreshed in the morning
8. General fatigue/never feel rested
9. Automatic behaviors -- actions that occur as you're falling asleep or waking up that you don't remember
10. Difficulty thinking, remembering, concentrating or paying attention
11. Mental fog/fogginess
12. Irritability, mood instability and/or less positive mood
13. Feelings of "hyperactivity" and a need to speed up actions
14. Excessive weight gain
15. Periodic limb movements during sleep (sometimes referred to as "restless legs")

Question 12a: How often EACH DAY do you experience the major narcolepsy feature of excessive daytime sleepiness without treatment? (This might include distinct sleep attacks, general fatigue and/or never feeling rested.)

0. 0
1. 1 to 2
2. 3 to 5
3. 6 or more

Question 12b: How often EACH DAY do you experience the major narcolepsy feature of excessive daytime sleepiness with treatment? (This might include distinct sleep attacks, general fatigue and/or never feeling rested.)

0. 0
1. 1 to 2
2. 3 to 5
3. 6 or more

Question 13a: How often EACH DAY do you experience cataplexy (striking or sudden episodes of muscle weakness often triggered by emotions) without treatment?

0. 0
1. 1 to 2
2. 3 to 5
3. 6 or more

Question 13b: How often EACH DAY do you experience cataplexy (striking or sudden episodes of muscle weakness often triggered by emotions) with treatment?

0. 0
1. 1 to 2
2. 3 to 5
3. 6 or more

Question 14: Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition? (Please check all that apply.)

1. Sleep through the night
2. Perform as I'd like to at work or at school
3. Express emotions freely without fearing an attack of cataplexy
4. Get through the day without falling asleep
5. Exercise or play sports
6. Perform self-care the way I'd like to
7. Perform household duties like cooking, cleaning, caring for family
8. Socializing/interacting with family and friends
9. Drive a car or other vehicle (without limitations)
10. Start a Family

Question 15: How has your condition changed over time? (Choose the answer that best represents your experience and feel free to comment more in the text box below.)

1. It is more stable and manageable now than when it first started
2. It is worse and more unpredictable now than when it first started
3. It is generally about the same as when I first became ill
4. I am better informed and prepared to manage my condition but the symptoms and severity are about the same
5. I feel more overwhelmed and less prepared to manage my condition compared to when it first started
6. None of the above

Question 16: Do your symptoms come and go? (Check all that apply.)

1. My symptoms are present on a daily basis
2. My symptoms vary from day-to-day or week-to-week
3. I go through periods when I'm not bothered by the symptoms and other periods when they impact my life
4. The level of symptoms varies according to how well my treatments are working
5. The level of symptoms varies according to other factors in my life
6. None of the above

Question 17: Is there anything you've found that makes your symptoms better?

Open-Ended Response

Question 18: Is there anything you know makes your symptoms worse?

Open-Ended Response

Question 19: Which of the following do you use to help treat your condition or its symptoms? (Check option that applies): 19a) Prescription Meds approved for Narcolepsy, cataplexy or excessive daytime sleepiness; 19b) Other prescription medications; 19c) Over-the-counter products; 19d) Other therapies (like lifestyle modification, vitamins, nutritional supplements, yoga, acupuncture, taking naps and dietary changes); 19e) None of the above).

1. Current
2. Past
3. Never
4. I don't know
5. Prefer not to answer
6. Current and Past

Question 20: Being more specific, do you take or have you taken in the past any of the 4 prescription medicines specifically approved for narcolepsy? Check option that applies: 20a) Armodafinil, 20b) Dextroamphetamine/amphetamine, 20c) Modafinil, 20d) Sodium Oxybate).

1. Current
2. Past
3. Never
4. I don't know
5. Prefer not to answer
6. Current and Past

Question 21: Have you used any other prescription medicines to help treat your condition or its symptoms? Check option that applies: 21a) stimulants, 21b) anti-cataplectics, 21c) hypnotics/sedatives

1. Current
2. Past
3. Never
4. I don't know
5. Prefer not to answer
6. Current and Past

Question 22: What specific symptoms do your therapies address? (Mark all that apply) for each 1 = yes, 2 = no

1. Excessive daytime sleepiness
2. Distinct sleep attacks
3. Cataplexy (striking, sudden episodes of muscle weakness, often triggered by emotions)
4. Disrupted nighttime sleep
5. Sleep paralysis
6. Vivid hallucinations upon waking or falling asleep (called "hypnagogic and hypnopompic hallucinations")
7. Waking unrefreshed in the morning
8. General fatigue/never feel rested
9. Automatic behaviors -- actions that occur as you're falling asleep or waking up that you don't remember
10. Difficulty thinking, remembering, concentrating or paying attention
11. Problems with organization or planning
12. Mental fog/fogginess
13. Irritability
14. Mood instability and/or less positive mood
15. Feelings of "hyperactivity" and a need to speed up actions
16. Excessive weight gain
17. Periodic limb movements during sleep (sometimes referred to as "restless legs")

Question 23: Think about how your treatment regimen changed over time. Compared to a year ago, how do you use each of these treatment approaches to help manage your condition? Check response that applies: 23a) Prescription Medications, 23b) over-the-counter products, 23c) other therapies (lifestyle modification, vitamins, nutritional supplements, yoga, acupuncture, taking naps and dietary changes)

1. More actively now
2. Less actively now
3. About the Same
4. Haven't ever used
5. Prefer not to answer

Question 24: How well do these therapies improve your ability to do specific activities that are important in your daily life? Check response that applies: 24a) Prescription Medications, 24b) over-the-counter products, 24c) other therapies (lifestyle modification, vitamins, nutritional supplements, yoga, acupuncture, taking naps and dietary changes)

1. Substantial improvement
2. Some improvement
3. Neither helps nor hurts
4. Some harm
5. Substantial harm
6. I don't know
7. Prefer not to answer or doesn't apply

Question 25: What are the most substantial downsides to your current therapies and how do they affect your daily life?

Open-Ended Question

Question 26: Assuming there is no complete cure for your condition, what specific things would you look for in an ideal therapy for your condition?

Open-Ended Question