302

A Conceptual Disease Model of the Symptoms and Impacts of Narcolepsy Type 1 From the Patient Perspective

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Objective

- This qualitative study explored patients' perspectives on the most bothersome and meaningful symptoms and impacts of narcolepsy type 1 (NT1), resulting in a comprehensive conceptual disease model

Conclusions

- Qualitative interviews revealed that patients with NT1 experience highly bothersome symptoms across multiple symptom domains, including daytime sleepiness, impaired wakefulness cognition, nighttime sleep problems, and fatigue
  - Notably, while the NT1 symptoms of cataplexy, hypnagogic/hypnopompic hallucinations, and sleep paralysis were frequently reported, the average bothersomeness score associated with these symptoms was below the prespecified saliency threshold of 5 out of 10
  - These findings underscore the importance of symptoms beyond the classic symptom pentad for NT1 (cataplexy, excessive daytime sleepiness [EDS], disrupted nighttime sleep, hypnagogic/hypnopompic hallucinations, and sleep paralysis),[1,2] including sleep inertia, cognitive symptoms, and brain fog
- Salient impacts affected domains across participants' lives, including activities of daily living, behavioral/emotional, school/work, and social domains
- Findings are based on self-reported experiences, which may be influenced by recall or participants' ability to describe symptoms and impacts
- A conceptual disease model was developed to systematically capture the lived experiences of patients with NT1, providing a critical framework for understanding patient perspectives and guiding future research and interventions

References: 1. American Academy of Sleep Medicine. *International Classification of Sleep Disorders – Third Edition*, Text Revision. Darien, IL: American Academy of Sleep Medicine; 2023. **2.** Morse AM, et al. *CNS Drugs*. 2025;39(Suppl 1):9-22. **3.** Bassetti CLA, et al. *Nat Rev Neurol*. 2019;15(9):519-539.

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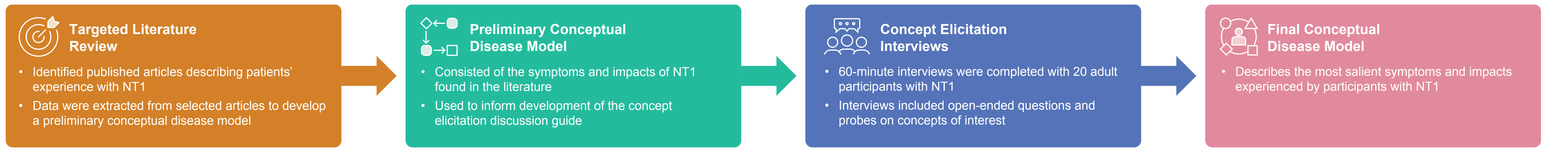
Introduction

- Narcolepsy is a central disorder of hypersomnolence comprised of 2 main subtypes: narcolepsy type 1 (NT1) and narcolepsy type 2 (NT2)[1]
- The classic symptom pentad for NT1 includes cataplexy, excessive daytime sleepiness (EDS), disrupted nighttime sleep, hypnagogic/hypnopompic hallucinations, and sleep paralysis[1,2]
- In addition to this pentad, a broader spectrum of symptoms may impact patients' daily functioning and quality of life[2,3]

Methods

- A targeted literature review was conducted to develop a preliminary conceptual disease model of the symptoms and impacts of NT1
- This preliminary conceptual model informed the development of the interview guide used in concept elicitation interviews with 20 adults with NT1

Figure 1. Study Design

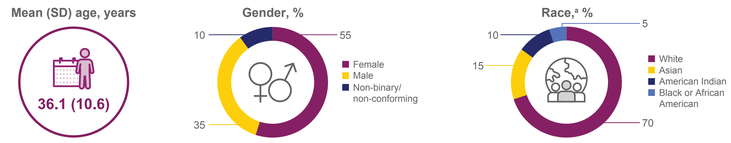


NT1, narcolepsy type 1.

- During their interviews, participants were asked to provide severity ratings (0–10) for all NT1 symptoms and bothersomeness ratings (0–10) for all current NT1 symptoms and impacts; participants also reported their 3 worst and 3 most bothersome symptoms and impacts
- Concept frequencies and bothersomeness ratings were used to evaluate salience (reported by ≥50% of participants; average bothersomeness rating ≥5) and finalize the conceptual disease model
- Scan the QR code for more information on patient recruitment, inclusion/exclusion criteria, and additional details on the interview/coding process

Results

Figure 2. Participant-Reported Demographics (N=20)



[a]Participant may select >1 option.
SD, standard deviation.

Table 1. Frequency, Severity, and Bothersomeness of Salient Symptoms[a]

Symptoms	Participants with NT1, N=20, n (%)	Spontaneous, n	Probed, n	Severity rating, mean (SD)[b,c]	Bothersomeness rating, mean (SD)[b,d]
Chronic daytime sleepiness	20 (100.0)	18	2	8.8 (1.7)	7.4 (1.9)
Unintentionally falling asleep during the day	20 (100.0)	12	8	8.5 (1.7)	7.2 (2.0)
Memory problems	19 (95.0)	12	7	7.0 (1.2)	7.8 (2.2)
Brain fog	17 (85.0)	9	8	7.8 (1.3)	7.9 (1.5)
Napping/excessive napping	17 (85.0)	17	0	10.0 (0.0)	6.6 (1.9)
Difficulty concentrating/focusing	14 (70.0)	9	5	7.5 (1.8)	7.8 (2.1)
Automatic behaviors	14 (70.0)	6	8	7.4 (2.2)	5.7 (3.1)
Sleep inertia	13 (65.0)	11	2	6.6 (2.4)	7.0 (2.7)
Difficulty communicating thoughts	12 (60.0)	8	4	6.8 (1.8)	7.2 (3.2)
Difficulty staying asleep	12 (60.0)	5	7	6.8 (2.6)	5.6 (2.5)
Fatigue	11 (55.0)	4	7	7.9 (2.2)	6.5 (2.4)
Difficulty falling asleep	11 (55.0)	8	3	7.7 (1.2)	5.1 (1.6)

[a]Salient symptoms are those reported by ≥50% of participants with an average bothersome rating ≥5. [b]Severity and bothersomeness ratings were based only on participants who provided a rating. [c]Severity ratings were assessed on a 0–10 scale, where 0 = not severe at all and 10 = extremely severe. [d]Bothersomeness ratings were assessed on a 0–10 scale, where 0 = not bothersome at all and 10 = extremely bothersome.
NT1, narcolepsy type 1; SD, standard deviation.

- The most frequently reported salient symptoms (≥65%) were chronic daytime sleepiness, unintentionally falling asleep during the day, memory problems, brain fog, napping/excessive napping, difficulty concentrating/focusing, automatic behaviors, and sleep inertia
- When at their worst, the most severe salient symptoms (mean severity rating ≥8) included napping/excessive napping, chronic daytime sleepiness, and unintentionally falling asleep during the day
- The most bothersome salient symptoms (mean bothersomeness rating ≥7.5) were brain fog, memory problems, and difficulty concentrating/focusing

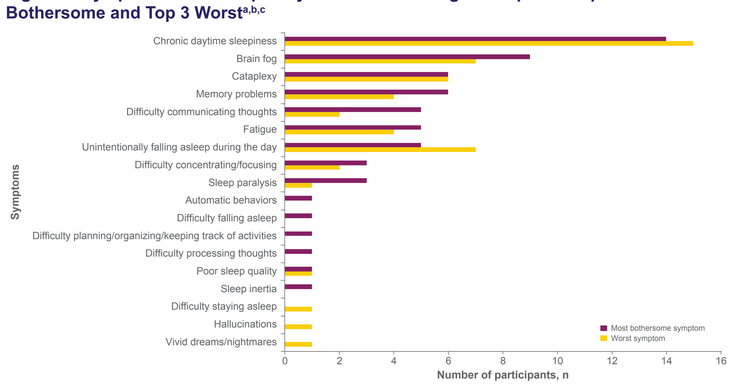
Table 2. Frequency and Bothersomeness of Salient Impacts[a]

Impact	Participants with NT1, N=20, n (%)	Spontaneous, n	Probed, n	Bothersomeness rating, mean (SD)[b,c]
Difficulty driving/unable to drive	20 (100.0)	15	5	6.6 (3.3)
Difficulty planning for/attending social activities	18 (90.0)	12	6	7.0 (2.8)
Difficulty with work	15 (75.0)	11	4	8.5 (1.5)
Difficulty with iADLs (eg, cooking, daily routine/chores)	14 (70.0)	8	6	6.9 (2.3)
Feeling anxious	12 (60.0)	5	7	7.6 (2.1)
Stress	12 (60.0)	7	5	7.3 (2.3)
Annoyance/frustration	12 (60.0)	11	1	6.0 (2.2)
Difficulty with school	11 (55.0)	11	0	8.0 (1.7)
Cataplexy-related falls/accidents	11 (55.0)	9	2	6.2 (3.1)
Negative impacts on relationships	10 (50.0)	5	5	7.4 (2.7)

[a]Salient impacts are those reported by ≥50% of participants with an average bothersome rating ≥5. [b]Bothersomeness ratings were based only on participants who provided a rating. [c]Bothersomeness ratings were assessed on a 0–10 scale, where 0 = not bothersome at all and 10 = extremely bothersome.
iADL, instrumental activity of daily living; NT1, narcolepsy type 1; SD, standard deviation.

- The most frequently reported salient impacts (≥70%) included difficulty driving/unable to drive, difficulty planning for/attending social activities, difficulty with work, and difficulty with instrumental activities of daily living
- The most bothersome impacts (mean bothersomeness rating ≥8) included difficulty with work and difficulty with school

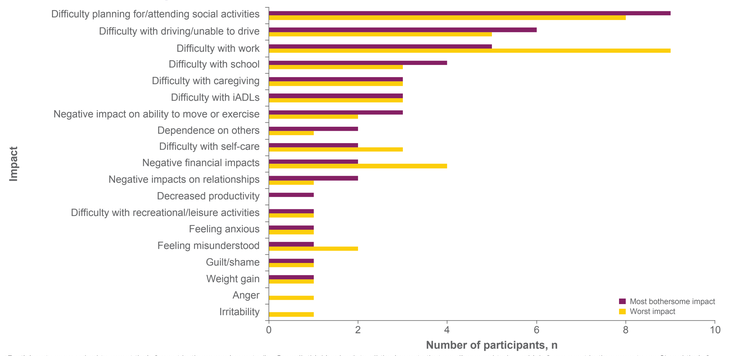
Figure 3. Symptoms Most Frequently Mentioned Among Participants' Top 3 Most Bothersome and Top 3 Worst[a,b,c]



[a]Participants were asked to report their 3 most bothersome symptoms (ie, Overall, thinking back to all the symptoms that we discussed today, which 3 are most bothersome to you?) and their 3 worst symptoms (ie, Out of all the symptoms you experience, which 3 would you call your worst symptoms?). [b]n=19 participants (95.0%) reported their worst symptoms and all participants (N=20, 100.0%) reported their most bothersome symptoms. Not all participants reported their 3 worst and most bothersome symptoms because 1) the moderator did not ask due to time constraints or 2) the participant reported fewer than 3 worst or most bothersome symptoms. [c]Results are presented from most to least commonly reported bothersome symptoms.

- Chronic daytime sleepiness, brain fog, cataplexy, and memory problems were the most frequently mentioned among the 3 most bothersome symptoms
- The most frequently mentioned worst symptoms also included chronic daytime sleepiness and brain fog, as well as unintentionally falling asleep during the day

Figure 4. Impacts Most Frequently Mentioned Among Participants' Top 3 Most Bothersome and Top 3 Worst[a,b,c]

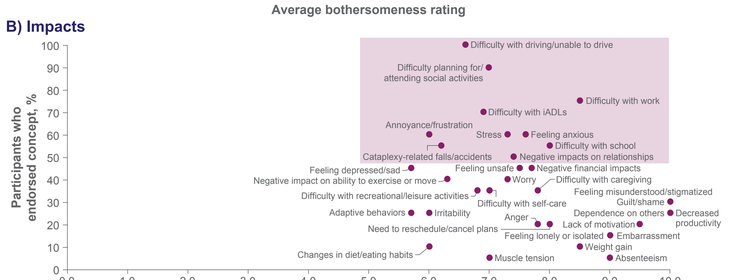


[a]Participants were asked to report their 3 most bothersome impacts (ie, Overall, thinking back to all the impacts that we discussed today, which 3 are most bothersome to you?) and their 3 worst impacts (ie, Out of all the impacts you experience, which 3 would you call your worst impacts?). [b]n=17 participants (85.0%) reported their worst impacts and n=18 participants (90.0%) reported their most bothersome impacts. Not all participants reported their 3 worst and most bothersome impacts because 1) the moderator did not ask due to time constraints or 2) the participant reported fewer than 3 worst or most bothersome impacts. [c]Results are presented from most to least commonly reported bothersome impact.
iADL, instrumental activity of daily living.

- Difficulty planning for/attending social activities, difficulty driving/unable to drive, and difficulty with work were the most frequently mentioned among the top 3 most bothersome and top 3 worst impacts

Figure 5. Most Prevalent and Highly Bothersome Symptoms and Impacts in NT1[a]

A) Symptoms

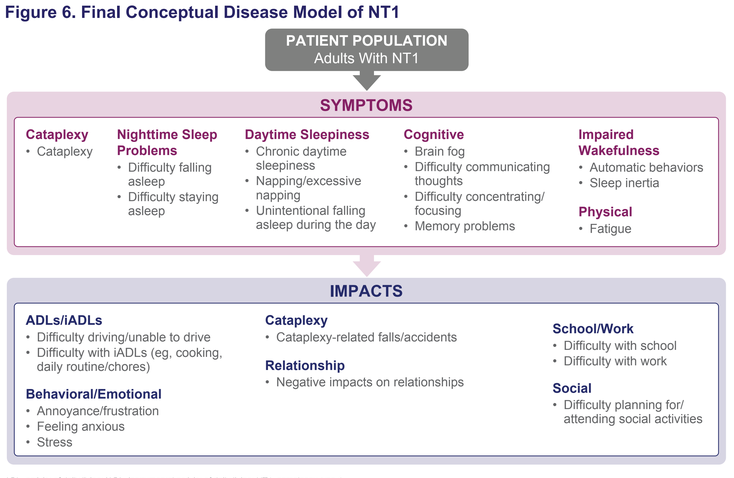


B) Impacts

[a]Salient symptoms and impacts reported by ≥50.0% of participants with an average bothersome rating ≥5.0 are displayed in the upper right quadrant. Only those concepts reported by ≥50.0% of participants and/or with an average bothersome rating ≥5.0 are displayed in the figure.
iADL, instrumental activity of daily living; NT1, narcolepsy type 1.

- Participants reported 30 symptoms and 38 impacts; 12 symptoms and 10 impacts met the saliency threshold and were included in the final conceptual disease model
- Salient symptoms fell across several domains, including daytime sleepiness, impaired wakefulness, cognition, nighttime sleep problems, and fatigue
- Salient impacts fell across several domains, including difficulties with activities of daily life, school or work, and planning/attending social events

Figure 6. Final Conceptual Disease Model of NT1



ADL, activity of daily living; iADL, instrumental activity of daily living; NT1, narcolepsy type 1.

302

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Supplemental Methods

Participant recruitment

- Adults with NT1 were recruited through a third-party recruitment vendor, patient advocacy groups, and a patient disease conference

Inclusion criteria

- 18 to 64 years of age at the time of screening
- Diagnosis of NT1 as confirmed through medical records that clearly indicate diagnosis or completion of a Confirmation of Diagnosis Form by the participant's clinician
- Currently experiencing excessive daytime sleepiness
  - If receiving treatment for NT1, must have excessive daytime sleepiness that persists despite treatment
- Cataplexy
- Current experience with cataplexy attacks
  - Based on the response to the question, "On average, how many cataplexy attacks do you have during a typical 2-week period?"
- Able to communicate, read, and write fluently in English
- Able to participate in a one-on-one 60-minute interview in English using an internet enabled computer or other device with screensharing/screen-viewing capabilities
- Resides in the US
- Consents to participate in this study
- Willing to provide permission for interview to be audio-recorded

Exclusion criteria

- Diagnosis of a medical condition (other than NT1) or drug use that is associated with excessive daytime sleepiness
- Untreated or inadequately treated sleep-disordered breathing (ie, obstructive sleep apnea, central sleep apnea) or periodic limb movement disorder resulting in daytime sleepiness
- Average total sleep time <6 hours of sleep per night over the last 6 months
- Occupation requiring nighttime or variable shift work

Interview and coding details

- Interviews were conducted in 4 waves (n=5 for each wave) to assess saturation, defined as the point at which no new concepts were reported
- Interview transcripts were coded using qualitative analysis software (MAXQDA) with a focus on identifying reported symptoms and impacts; coding was guided by a prespecified coding framework and codebook, which were informed by the preliminary conceptual disease model, discussion guide, and research objectives, and was overseen by the coding lead
- The primary goals of transcript coding were to assess 1) the number of participants reporting each concept (ie, symptoms, impacts), 2) whether concepts were reported spontaneously or after probing, 3) characteristics of concepts (eg, frequency, duration, severity), and 4) average severity and bothersome ratings for symptoms and average bothersome ratings for impacts
  - Concepts identified through the targeted literature review, such as excessive daytime sleepiness, brain fog, cognitive complaints, and fatigue, were further explored through probing to generate in-depth qualitative insights and to assess whether, and how, participants differentiate among these conceptually related symptoms

Supplemental Results

Supplemental Table S1. Participant-Reported Demographic and Health Information

Characteristic	Participants with NT1 (N=20)
Age (years)	
Mean (SD)	36.1 (10.6)
Median	37
Range	18–52
Gender, n (%)	
Female	11 (55.0)
Male	7 (35.0)
Non-binary/non-conforming	2 (10.0)
Race,[a] n (%)	
American Indian or Alaska Native	2 (10.0)
Asian	3 (15.0)
Black or African American	1 (5.0)
White	14 (70.0)
Other[b]	2 (10.0)
Ethnicity, n (%)	
Hispanic or Latino/a	4 (20.0)
Not Hispanic or Latino/a	16 (80.0)
Work status,[a] n (%)	
Working full-time	7 (35.0)
Working part-time	4 (20.0)
Seeking work opportunities	1 (5.0)
Student	6 (30.0)
Unable to work	4 (20.0)
Homemaker	1 (5.0)
Highest level of education achieved, n (%)	
High school graduate or GED equivalent	2 (10.0)
Some college	5 (25.0)
Associate degree	2 (10.0)
Bachelor's degree	8 (40.0)
Master's degree	2 (20.0)
Doctorate degree	1 (5.0)
Diagnosed with comorbid sleep disorder, n (%)	
Sleep apnea[c]	5 (25.0)
Restless leg syndrome[c]	5 (25.0)
None	12 (60.0)
Average hours of sleep per night over the past 6 months[d]	
Mean (SD)	6.7 (0.7)
Median	7
Range	6–8
Currently taking prescription medication for narcolepsy, n (%)	
Yes	10 (50.0)
No	9 (45.0)
Did not provide a response	1 (5.0)
Currently taking over-the-counter medication or product, n (%)	
Yes	12 (60.0)
No	7 (35.0)
Did not provide a response	1 (5.0)
Average number of cataplexy attacks in a typical 2-week period	
Mean (SD)	15.6 (15.9)
Median	10
Range	1–56

[a]Participant may select >1 option. [b]Participants who selected "Other" reported their race as "Hispanic or Latino/a" or "mixed-race Latinx" or did not specify. [c]Eligibility criteria allowed for the enrollment of participants with adequately treated sleep-disordered breathing (eg, obstructive sleep apnea, central sleep apnea) or periodic limb movement disorder. [d]Eligibility criteria required that enrolled participants had an average total sleep time of ≥6 hours of sleep per night independent of time in bed over the past 6 months.
GED, general educational development; NT1, narcolepsy type 1; SD, standard deviation.