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A Conceptual Disease Model of the Symptoms and Impacts of Narcolepsy Type 2 From the Patient Perspective

Cristina Casstevens, PhD[1]; Kiran Maski, MD, MPH[2]; Nancy Foldvary-Schaefer, DO, MS[3]; Luis E. Ortiz, MD[4]; Meagan Farrell, PhD[5]; Christina A. Graham, BS, BA[6]; Claire Mobley, MPH[5]; Emily Kim, MPH[5]; Mia Wraight, BS[1]; Jed Black, MD[1,7]; Joshua R. Steinerman, MD[8]; David T. Plante, MD, PhD[9]

[1]Jazz Pharmaceuticals, Palo Alto, CA, USA; [2]Department of Neurology, Boston Children's Hospital, Boston, MA, USA; [3]Sleep Disorders Center, Neurological Institute, Cleveland Clinic, Cleveland, OH, USA; [4]Johns Hopkins All Children's Hospital, St. Petersburg, FL, USA; [5]IQVIA, New York, NY, USA; [6]IQVIA, Boston, MA, USA; [7]Center for Sleep Sciences and Medicine, Stanford University School of Medicine, Palo Alto, CA, USA; [8]Jazz Pharmaceuticals, Philadelphia, PA, USA; [9]University of Wisconsin School of Medicine and Public Health, Madison, WI, USA

Objective

- This qualitative study explored patients' perspectives on the most relevant and important symptoms and impacts of narcolepsy type 2 (NT2), resulting in a comprehensive conceptual disease model

Conclusions

- Qualitative interviews revealed that patients with NT2 experience relevant and important symptoms in addition to excessive daytime sleepiness, including brain fog, sleep inertia, and cognitive difficulties
  - Salient symptoms are reported to affect activities of daily living, and have occupational, social, and emotional impacts
- 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 NT2, 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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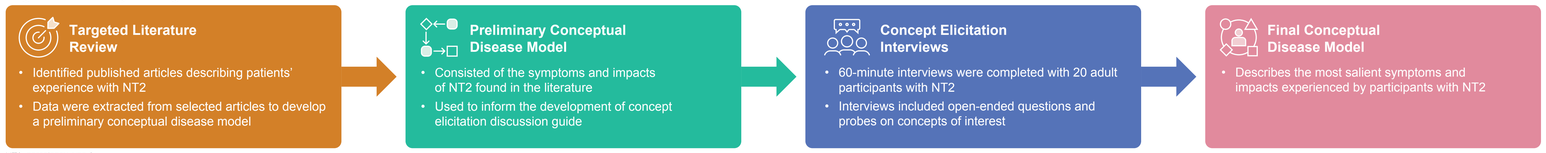
Introduction

- Narcolepsy is a central disorder of hypersomnolence comprised of 2 main subtypes: narcolepsy type 1 (NT1) and narcolepsy type 2 (NT2)[1]
  - NT2 is characterized by excessive daytime sleepiness (EDS) as well as other diagnostically relevant symptoms, including disrupted nighttime sleep, sleep paralysis, and hypnagogic/hypnopompic hallucinations that collectively interfere with everyday functioning and quality of life[1-3]
- There is limited first-hand data describing the lived patient experience with NT2
- Symptoms of NT2 are complex and heterogeneous and often overlap with symptoms of other conditions, so it is important to collect data directly from individuals with NT2 to holistically understand patients' experiences[1]

Methods

- A targeted literature review was conducted to develop a preliminary conceptual disease model of the symptoms and impacts of NT2
- This preliminary conceptual model informed the development of the interview guide used in concept elicitation interviews with 20 adults with NT2

Figure 1. Study Design

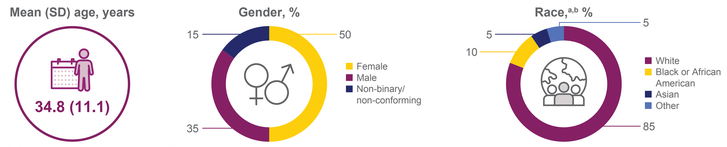


NT2, narcolepsy type 2.

- During their interviews, participants were asked to provide severity ratings (0–10) for all NT2 symptoms at their worst, as well as bothersomeness ratings (0–10) for all current NT2 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 participant recruitment, inclusion/exclusion criteria, and additional details on the interview/coding process

Results

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



[a]Participants may select more than 1 option. [b]Participant who selected "Other" reported their race as "Hispanic or Latino/a" or "mixed race Latinx."
SD, standard deviation.

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

Symptoms	Participants with NT2, 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	8.5 (1.7)	8.6 (1.6)
Brain fog	19 (95.0)	8	11	7.3 (1.6)	8.3 (1.5)
Fatigue	18 (90.0)	14	4	8.1 (1.4)	8.2 (1.7)
Memory problems	18 (90.0)	9	9	6.3 (1.7)	7.5 (1.6)
Unintentionally falling asleep during the day	17 (85.0)	12	5	8.1 (2.2)	8.5 (2.1)
Napping/excessive napping	17 (85.0)	16	1	7.3 (2.8)	6.3 (2.8)
Difficulty concentrating/focusing	16 (80.0)	10	6	7.6 (1.4)	8.2 (1.5)
Sleep inertia	16 (80.0)	7	9	6.9 (2.3)	7.8 (1.8)
Difficulty processing/understanding thoughts	15 (75.0)	7	8	6.3 (2.4)	7.0 (2.5)
Difficulty communicating thoughts	15 (75.0)	4	11	5.8 (2.7)	6.8 (2.3)
Difficulty staying asleep	15 (75.0)	8	7	6.3 (2.2)	6.1 (2.5)
Difficulty planning/organizing	14 (70.0)	0	14	5.9 (2.5)	5.6 (3.0)
Lack of energy	13 (65.0)	7	6	7.4 (1.5)	9.0 (1.1)
Automatic behaviors	13 (65.0)	4	9	5.2 (1.2)	6.1 (1.4)
Difficulty falling asleep	11 (55.0)	3	8	7.2 (2.3)	7.3 (1.5)
Sleep paralysis	11 (55.0)	4	7	4.4 (2.4)	5.3 (2.4)
Hallucinations	10 (50.0)	5	5	4.3 (2.1)	5.1 (2.1)

[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.
NT2, narcolepsy type 2; SD, standard deviation.

- The most frequently reported salient symptoms (≥80%) included chronic daytime sleepiness, brain fog, fatigue, memory problems, unintentionally falling asleep during the day, napping/excessive napping, difficulty concentrating/focusing, and sleep inertia
- At their worst, the most severe salient symptoms (mean severity rating ≥8) included chronic daytime sleepiness, fatigue, and unintentionally falling asleep during the day
- The most bothersome salient symptoms (mean bothersomeness rating ≥8) were lack of energy, chronic daytime sleepiness, unintentionally falling asleep during the day, brain fog, fatigue, and difficulty concentrating/focusing

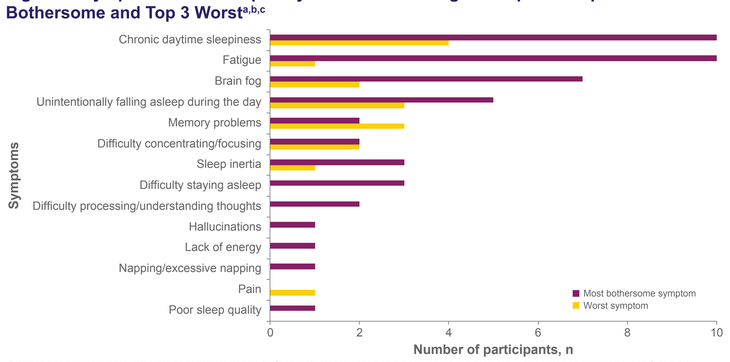
Table 2. Frequency and Bothersomeness of Salient Impacts[a]

Impact	Participants with NT2, N=20, n (%)	Spontaneous, n	Probed, n	Bothersomeness rating, mean (SD)[b,c]
Difficulty with iADLs (eg, cooking, daily routine/chores)	20 (100.0)	13	7	6.7 (2.7)
Difficulty with work	18 (90.0)	16	2	8.2 (2.1)
Difficulty planning for/attending social activities	17 (85.0)	10	7	6.7 (1.9)
Negative impacts on relationships	16 (80.0)	3	13	6.5 (2.4)
Difficulty driving/unable to drive	15 (75.0)	10	5	7.2 (2.4)
Stress	14 (70.0)	7	7	6.2 (1.7)
Feeling depressed/sad	14 (70.0)	6	8	6.0 (3.1)
Feeling anxious	13 (65.0)	6	7	7.5 (1.8)
Difficulty with recreational/leisure activities	13 (65.0)	5	8	6.4 (1.9)
Annoyance/frustration	11 (55.0)	10	1	7.3 (1.4)
Difficulty with school	10 (50.0)	10	0	9.0 (1.7)
Negative impact on ability to exercise or move	10 (50.0)	6	4	6.5 (1.5)
Difficulty with self-care	10 (50.0)	0	10	5.6 (2.5)

[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; NT2, narcolepsy type 2; SD, standard deviation.

- The most frequently reported salient impacts (≥80%) were difficulty with iADLs, difficulty with work, difficulty with planning for/attending social activities, and negative impacts on relationships
- The most bothersome salient impacts (mean bothersomeness rating ≥8) were difficulty with school and difficulty with work

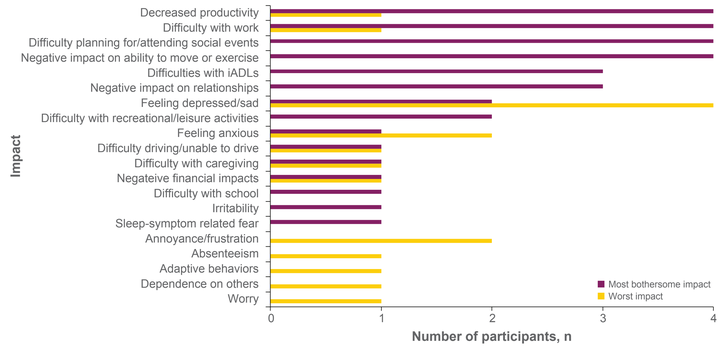
Figure 3. Symptoms Most Frequently Mentioned Among Participants' Top 3 Most Bothersome and Top 3 Worst[a,b,c]



[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=11 participants (55.0%) reported their worst symptoms and n=16 participants (80.0%) 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, fatigue, and brain fog were frequently reported among the top 3 most bothersome symptoms
- Chronic daytime sleepiness, unintentionally falling asleep during the day, and memory problems were frequently reported among the top 3 worst symptoms

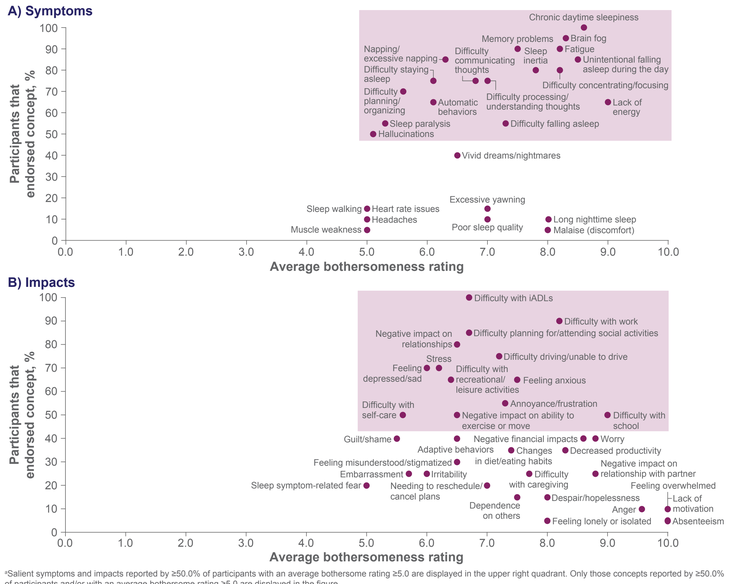
Figure 4. Impacts Most Frequently Mentioned Among Participants' Top 3 Most Bothersome and Top 3 Worst[a,b,c]



[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=9 participants (45.0%) reported their worst impacts and n=14 participants (70.0%) 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.

- Decreased productivity, difficulty with work, difficulty planning for/attending social activities, and negative impact on ability to move or exercise were frequently reported as the top 3 most bothersome impacts
- Feeling depressed/sad was commonly reported as a top 3 worst impact

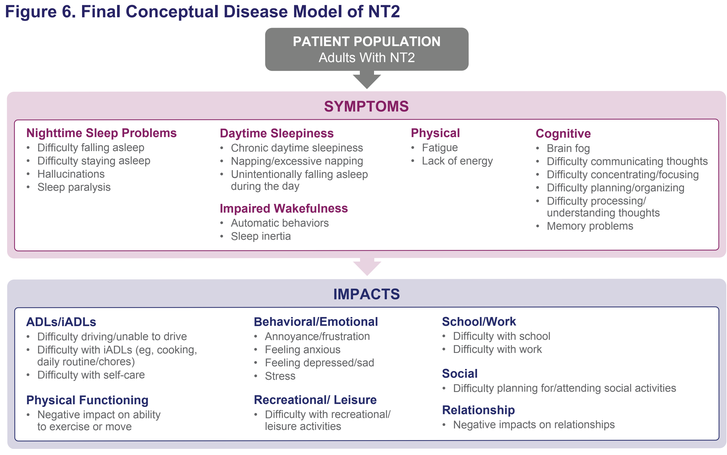
Figure 5. Most Prevalent and Highly Bothersome Symptoms and Impacts in NT2[a]



[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 activities of daily living; NT2, narcolepsy type 2.

- Participants identified 30 symptoms and 38 impacts of NT2; 17 symptoms and 13 impacts were deemed salient and informed the final conceptual model
- Salient symptoms spanned several domains, including daytime sleepiness, impaired cognition, physical symptoms, impaired wakefulness, and nighttime sleep problems
- Salient impacts spanned several domains, including difficulties with activities of daily life, school or work, planning/attending social events

Figure 6. Final Conceptual Disease Model of NT2



ADL, activity of daily living; iADL, instrumental activity of daily living; NT2, narcolepsy type 2.

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Supplemental Methods

Participant recruitment

- Adults with NT2 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 NT2 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 NT2, must have excessive daytime sleepiness that persists despite treatment
- 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 NT2) 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 of 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 NT2 (N=20)
Age (years)	
Mean (SD)	34.8 (11.1)
Median	33.0
Range	21–57
Gender, n (%)	
Female	10 (50.0)
Male	7 (35.0)
Non-binary/non-conforming	3 (15.0)
Race (participant may select more than 1 option), n (%)	
Asian	1 (5.0)
Black or African American	2 (10.0)
White	17 (85.0)
Other[a]	1 (5.0)
Ethnicity, n (%)	
Hispanic or Latino/a	2 (10.0)
Not Hispanic or Latino/a	18 (90.0)
Work status[b], n (%)	
Working full-time	11 (55.0)
Working part-time	2 (10.0)
Seeking work opportunities	2 (10.0)
Student	3 (15.0)
Retired	1 (5.0)
Unable to work	2 (10.0)
Highest level of education achieved, n (%)	
High school graduate or GED equivalent	4 (20)
Some college	3 (15.0)
Associate degree	1 (5.0)
Bachelor's degree	5 (25.0)
Master's degree	6 (30.0)
Doctorate degree	1 (5.0)
Diagnosed with comorbid sleep disorder, n (%)	
Sleep apnea[c]	4 (20.0)
Average hours of sleep per night over the past 6 months[d]	
Mean (SD)	7.4 (1.3)
Median	7
Range	6–10
Currently taking prescription medication for narcolepsy, n (%)	
Yes	10 (50.0)
No	8 (40.0)
Did not provide a response	2 (10.0)
Currently taking over-the-counter medication or product for narcolepsy, n (%)	
Yes	7 (35.0)
No	11 (55.0)
Did not provide a response	2 (10.0)

[a]Participants who selected Other reported their race as "Hispanic or Latino/a" or "mixed race Latinx." [b]Participant may select more than 1 option. [c]Eligibility criteria allowed for the enrollment of participants with adequately treated sleep-disordered breathing (ie, obstructive sleep apnea, central sleep apnea) or periodic limb movement disorder. [d]Eligibility criteria required that enrolled participants with narcolepsy had an average total sleep time of ≥6 hours of sleep per night independent of time in bed over the last 6 months.
GED, general educational development; NT2, narcolepsy type 2; SD, standard deviation.