Residual Symptom Burden in Patients With Narcolepsy Satisfied With Treatment: Subgroup Analysis From the CRESCENDO Survey



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Key Objective

 To describe the treatment experience and unmet need in patients with narcolepsy type 1 who express satisfaction with their current pharmacotherapy

Introduction

- People living with narcolepsy type 1 (narcolepsy with cataplexy [NT1]) often experience breakthrough symptoms, including excessive daytime sleepiness (EDS), cataplexy, and cognitive difficulties, even when taking multiple medications^{1,2}
- The CRESCENDO survey examined the patient experience in patients with NT1, providing a detailed characterization of symptom burden²
 - To see a previous presentation of results in the overall population, scan the QR code below:

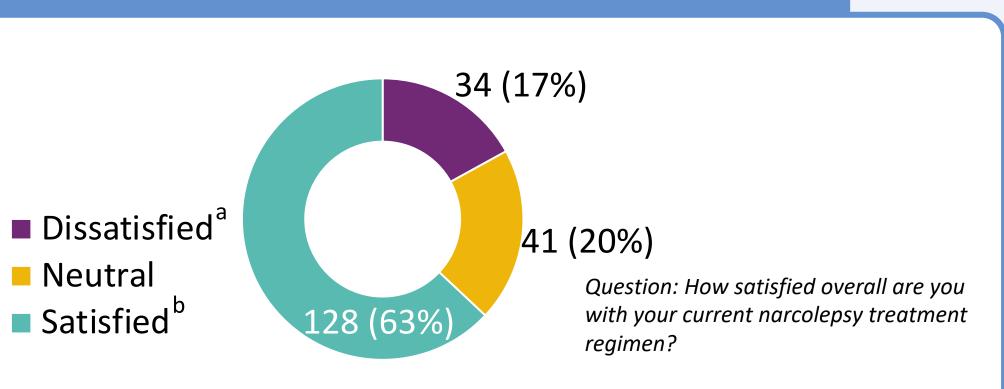
 Here we report a subgroup analysis of respondents reporting overall satisfaction with their current pharmacologic treatment to quantify residual symptoms in this population and understand which factors differentiate these patients from those who were not satisfied

Methods

- The CRESCENDO survey was conducted from October–December 2023 in adults diagnosed with NT1 who were currently taking an FDA-approved medication for narcolepsy and included assessments of symptom burden and impact on quality of life
- CRESCENDO was developed and executed in partnership with the patient advocacy organization Narcolepsy Network; a third-party research firm conducted the survey and ensured respondent privacy
- Of 203 total respondents recruited, this subgroup analysis included 128 respondents who were satisfied and 75 who were not satisfied with their current narcolepsy treatment based on a 5-point categorical scale (1=very satisfied, 5=very dissatisfied)

Results

Figure 1. Treatment Satisfaction



 Common reasons for satisfaction included symptom improvement (70%) and ability to complete more activities (37%)

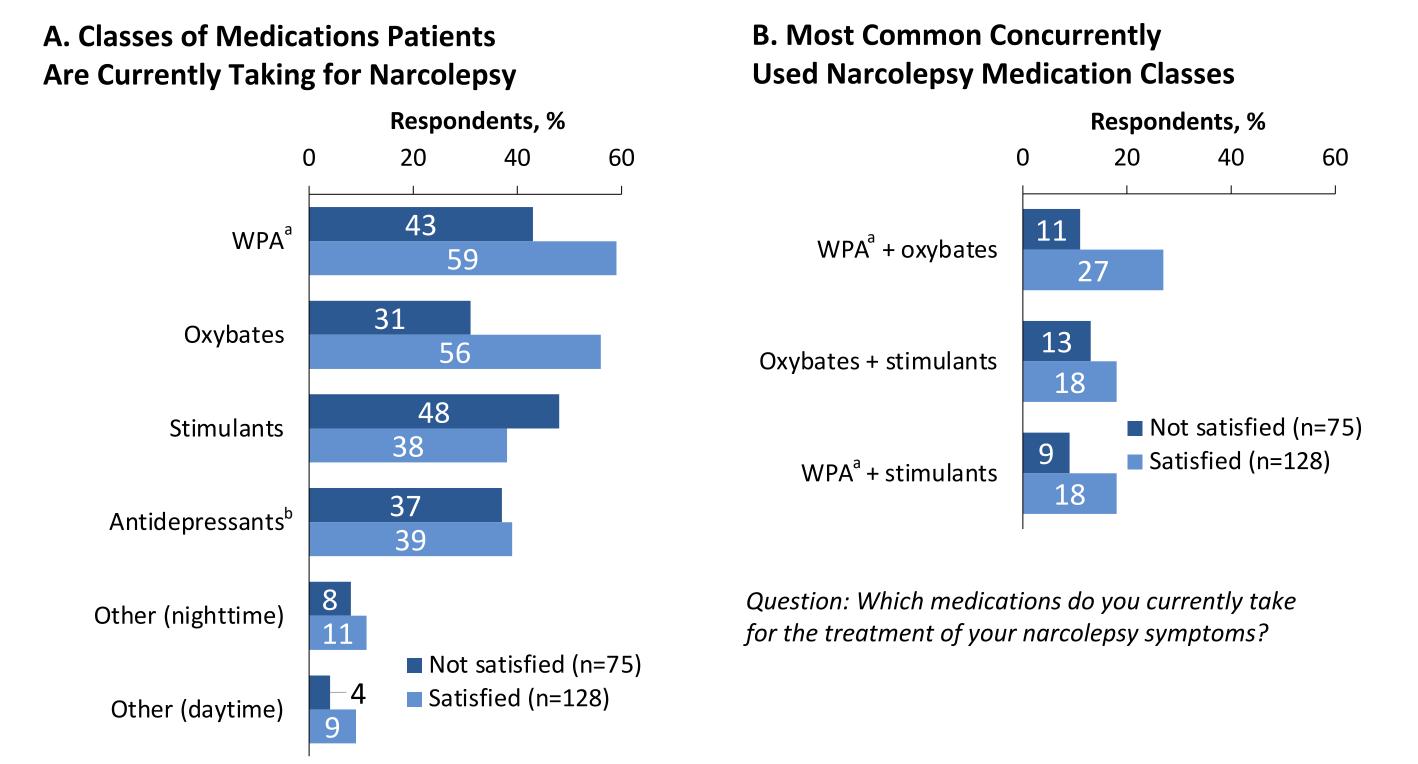
Includes "satisfied" and "very satisfied" categories.

Neutral

Table 1. Baseline Demographic and Clinical Characteristics	Not satisfied ^a (n=75)	Satisfied ^b (n=128)
Age, mean (range)	43 (18–82)	41 (18–78)
Age at symptom onset, mean (range)	18 (5–51)	18 (1–63)
Age at diagnosis, mean (range)	30 (10–67)	27 (8–64)
Gender, n (%)		
Female	49 (65)	81 (63)
Decline to answer	9 (12)	22 (17)
Hispanic/Latino, n (%)		
No	61 (81)	98 (77)
Decline to answer	10 (13)	24 (19)
Race, n (%)		
White	56 (75)	87 (68)
White alncludes "neutral," "dissatisfied," and "very dissatisfied" categories.	56 (75)	87 (68)

Results

Figure 2. Medication Usage Patterns

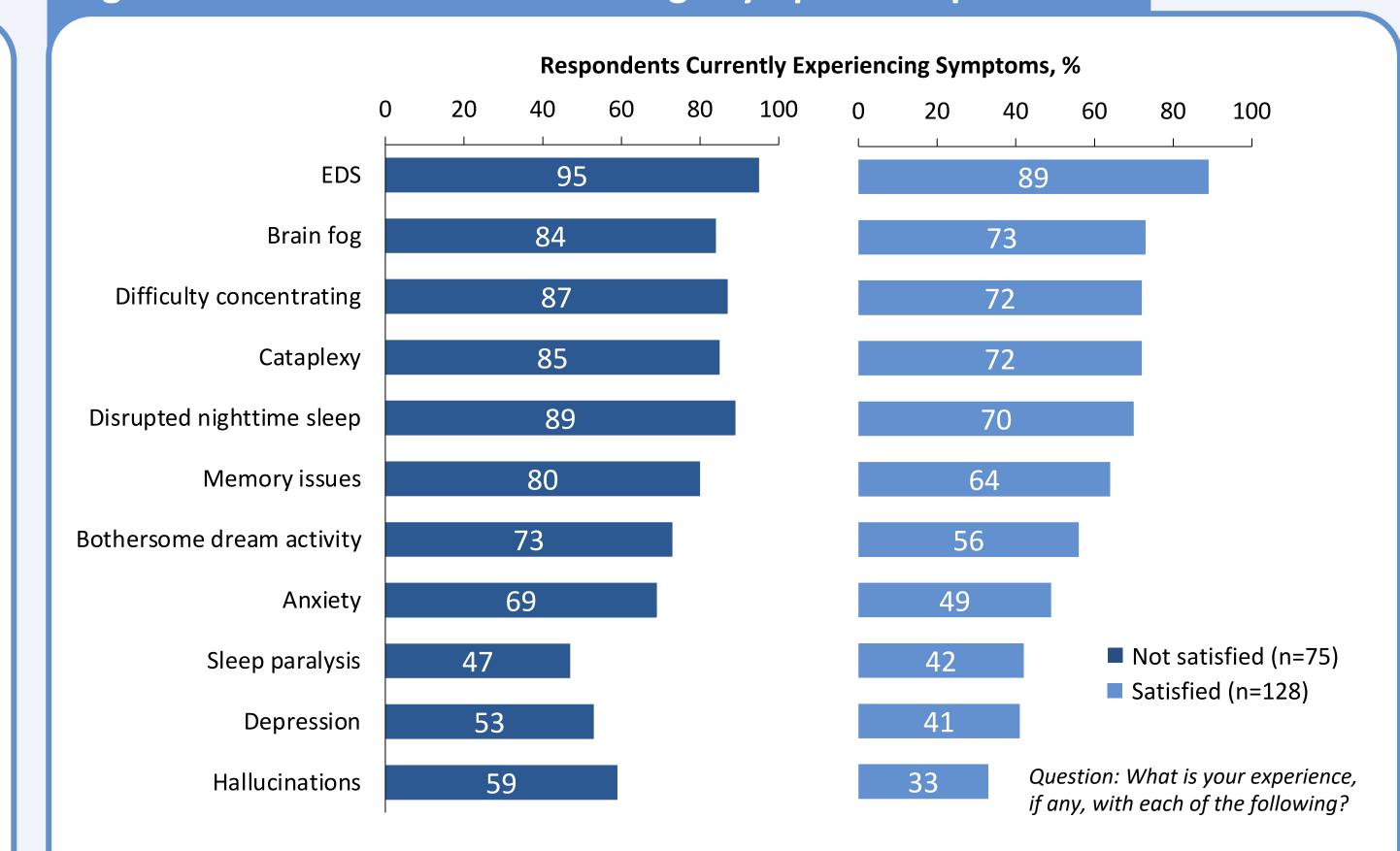


- A greater proportion of respondents who were satisfied with their current treatment were receiving wakepromoting agents (WPA) and oxybates than those who were not satisfied with treatment (Figure 2A)
- Polypharmacy was more common in respondents who were satisfied with treatment vs not satisfied (Figure) **2B**); 65.6% of satisfied respondents reported taking medications from 2 or more classes vs 52.0% of not satisfied respondents

WPAs included armodafinil, modafinil, pitolisant, and solriamfetol

WPA, wake-promoting agent.

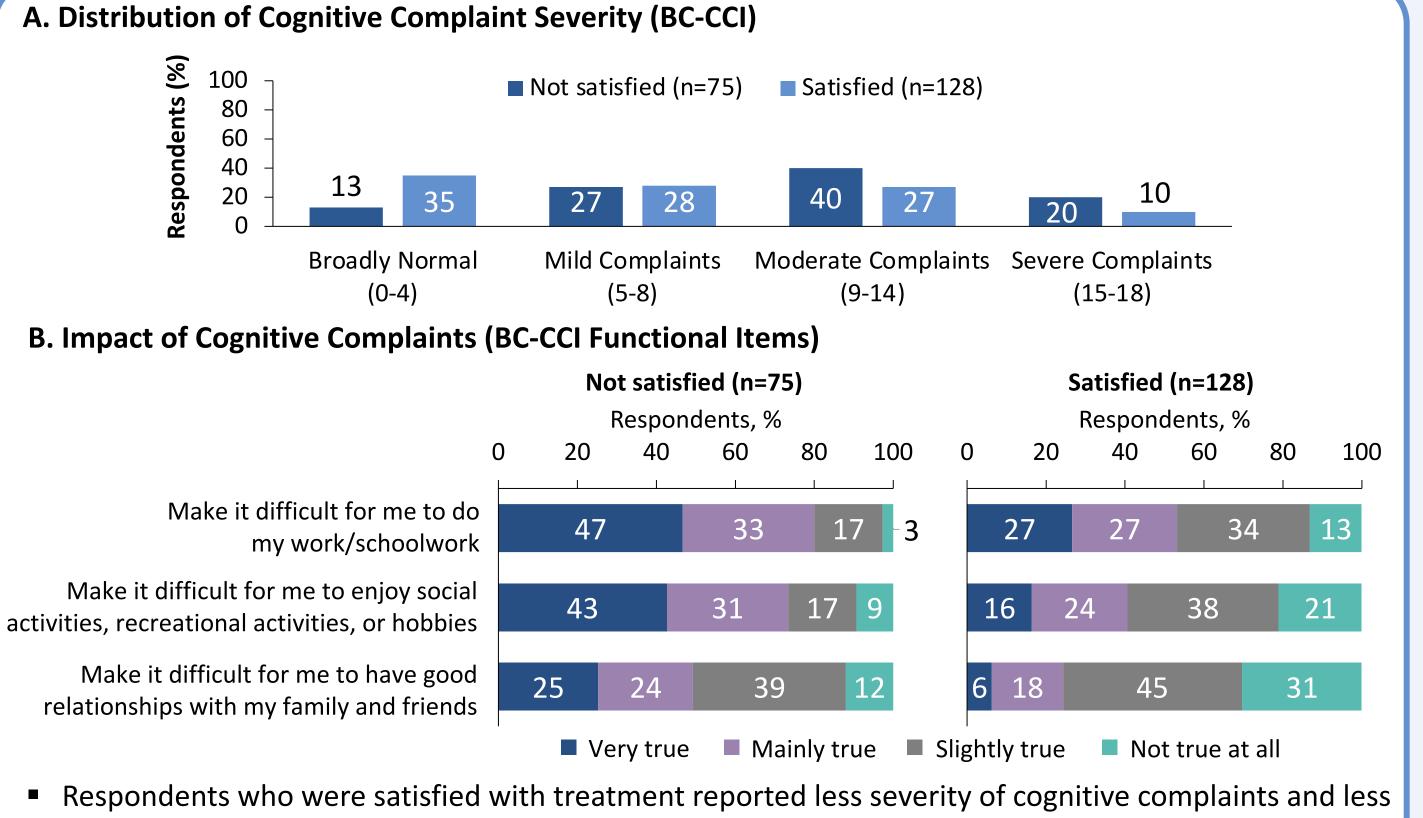
Figure 3. Prevalence of Breakthrough Symptoms Experienced



- Although breakthrough symptoms were less common in respondents who were satisfied with treatment vs not satisfied, the prevalence of breakthrough symptoms remained high
- Almost all participants reported breakthrough EDS regardless of their satisfaction; however, a greater proportion of those in the not satisfied group (80%) had Epworth Sleepiness Scale scores >10 compared with those who expressed satisfaction (54%)

EDS. excessive daytime sleepiness

Figure 4. Cognitive Complaints and Impact on Quality of Life

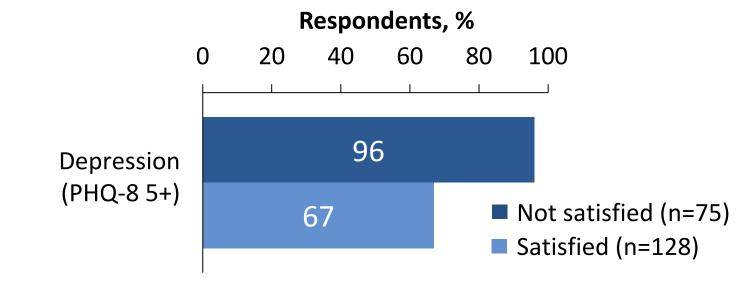


- of an impact on quality of life vs those who were not satisfied
- Most respondents who were satisfied with treatment still indicated at least some difficulty with work or social life due to their cognitive symptoms, indicating residual functional burden

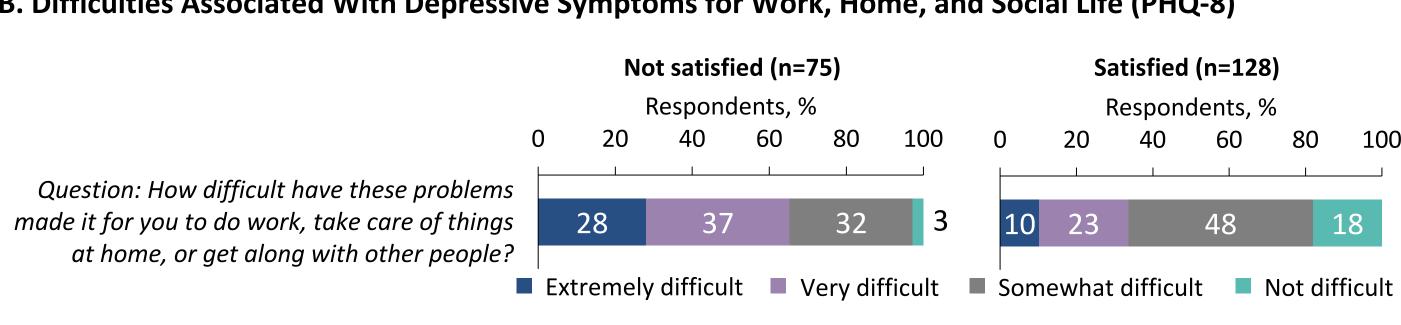
BC-CCI, British Columbia Cognitive Complaints Inventory

Figure 5. Depressive Symptoms and Impact on Quality of Life

A. Proportion of Respondents With Depression as measured by the Patient Health Questionnaire-8 (PHQ-8)



B. Difficulties Associated With Depressive Symptoms for Work, Home, and Social Life (PHQ-8)



- The proportion of patients with depression was higher as assessed by the PHQ-8 (Figure 5A) vs a self-report (Figure 3)
- Rates of depression were lower in respondents who were satisfied with treatment vs not satisfied, although over half of respondents who were satisfied with their treatment still reported depression
- Most respondents who were satisfied with treatment indicated at least some difficulty with work, home or social life due to depressive symptoms (Figure 5B)

Numbers may not add up to 100% due to rounding.

Figure 6. Breakthrough Cataplexy

B. Impact of Cataplexy on Quality of Life A. Frequency of Cataplexy Attacks in Respondents **Experiencing Breakthrough Cataplexy** Respondents Who Agree/Extremely Agree, a % A few times per year or less Suffering from slurred speech 63 embarrasses me Once per month 69 Falling down embarrasses me Cataplexy burdens my ■ A few times per month professional life 53 Cataplexy burdens my social ■ Multiple times per week ■ Not satisfied (n=55) Satisfied (n=75) Cataplexy is a burden on my day-to-day life Once per day or more Question: Thinking of your cataplexy on a typical

- Respondents who were satisfied with treatment experienced attacks less often and reported less of a burden than those who were not
- Half or more of patients who were satisfied still report that cataplexy embarrasses them and burdens their work or social lives (Figure 6B)

Percentages based on the population experiencing breakthrough cataplexy with non-missing data.

Satisfied

(n=92)

Not satisfied

(n=64)

Conclusions

- Respondents who reported overall satisfaction with their current NT1 treatment regime experienced a lower frequency and severity of symptoms vs those who were not satisfied
- However, respondents who reported overall satisfaction with their current treatment continued to experience substantial and diverse symptoms
- These findings reveal a disconnect between patientreported treatment satisfaction and the degree of symptom resolution, which may reflect limitations of current therapies, underreporting of ongoing symptoms, or diminished patient expectations
- Overall, the results of this study suggest the need for enhanced assessment of residual symptoms and novel approaches to treating narcolepsy

References

1. Swick TJ. *Nat Sci Sleep.* 2015;7:159-69.

bIncludes "satisfied" and "very satisfied" categories.

2. Thorpy MJ, et al. Presented at: American Academy of Neurology (AAN) 77th Annual Meeting; April 5–9, 2025; Copenhagen, Denmark.

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day, please indicate how much you agree or

disagree with each of the following statements?

Disclosures

M.J. Thorpy serves as a consultant to Axsome Therapeutics A. Kant and K. Harper are affiliated with Narcolepsy Network **E.B. Leary** is a former employee of Axsome Therapeutics **G.M.L. Eglit, S. Floam, and H. Tabuteau** are current employees of Axsome Therapeutics