

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



Michael J. Thorpy,<sup>1</sup> Amy Kant,<sup>2</sup> Keith Harper,<sup>2</sup> Eileen B. Leary,<sup>3</sup> Graham M. L. Eglit,<sup>4</sup> Samantha Floam,<sup>4</sup> Herriot Tabuteau<sup>4</sup>

<sup>1</sup>Montefiore Medical Center, Sleep-Wake Disorders Center, Bronx, NY, United States, <sup>2</sup>Narcolepsy Network, Camas, WA, United States, <sup>3</sup>Formerly of Axsome Therapeutics, Inc., New York, NY, United States, <sup>4</sup>Axsome Therapeutics, Inc., New York, NY, United States

## 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<sup>1,2</sup>
- The CRESCENDO survey examined the patient experience in patients with NT1, providing a detailed characterization of symptom burden<sup>2</sup>
  - To see a previous presentation of results in the overall population, scan the QR code:
- 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)

## References

- Swick TJ. *Am J Sleep*. 2015;7:159-169.
- Thorpy MJ, et al. Presented at: American Academy of Neurology (AAN) 77th Annual Meeting; April 5–9, 2025; Copenhagen, Denmark.

**Acknowledgments**  
The authors would like to thank the patients, study investigator, and study staff for their contributions to this research. This study was sponsored by Axsome Therapeutics, Inc. Under the direction of the authors, Rebecca Lane, PhD, of Peloton Advantage, LLC, an OPEN Health company, provided medical writing and editorial support, which was funded by Axsome Therapeutics.

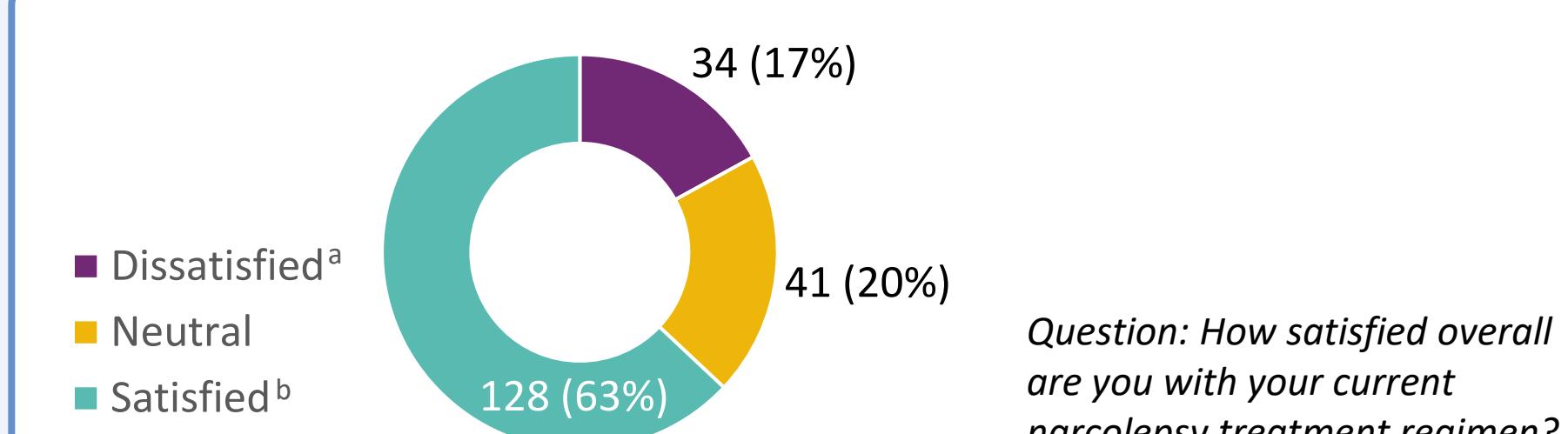
**QR Code**  
Scan the QR code at the top of this poster or access <https://www.crescendo-sleep.com/symptom-breakthroughs.html> to view or download a PDF of this poster or access additional information.

**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.



## Results

Figure 1. Treatment Satisfaction



Question: How satisfied overall are you with your current narcolepsy treatment regimen?

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

<sup>a</sup>Includes "neutral," "dissatisfied," and "very dissatisfied" categories.

<sup>b</sup>Includes "satisfied" and "very satisfied" categories.

Table 1. Baseline Demographic and Clinical Characteristics

	Not satisfied <sup>a</sup> (n=75)	Satisfied <sup>b</sup> (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)

<sup>a</sup>Includes "neutral," "dissatisfied," and "very dissatisfied" categories.

<sup>b</sup>Includes "satisfied" and "very satisfied" categories.

Figure 6. Breakthrough Cataplexy

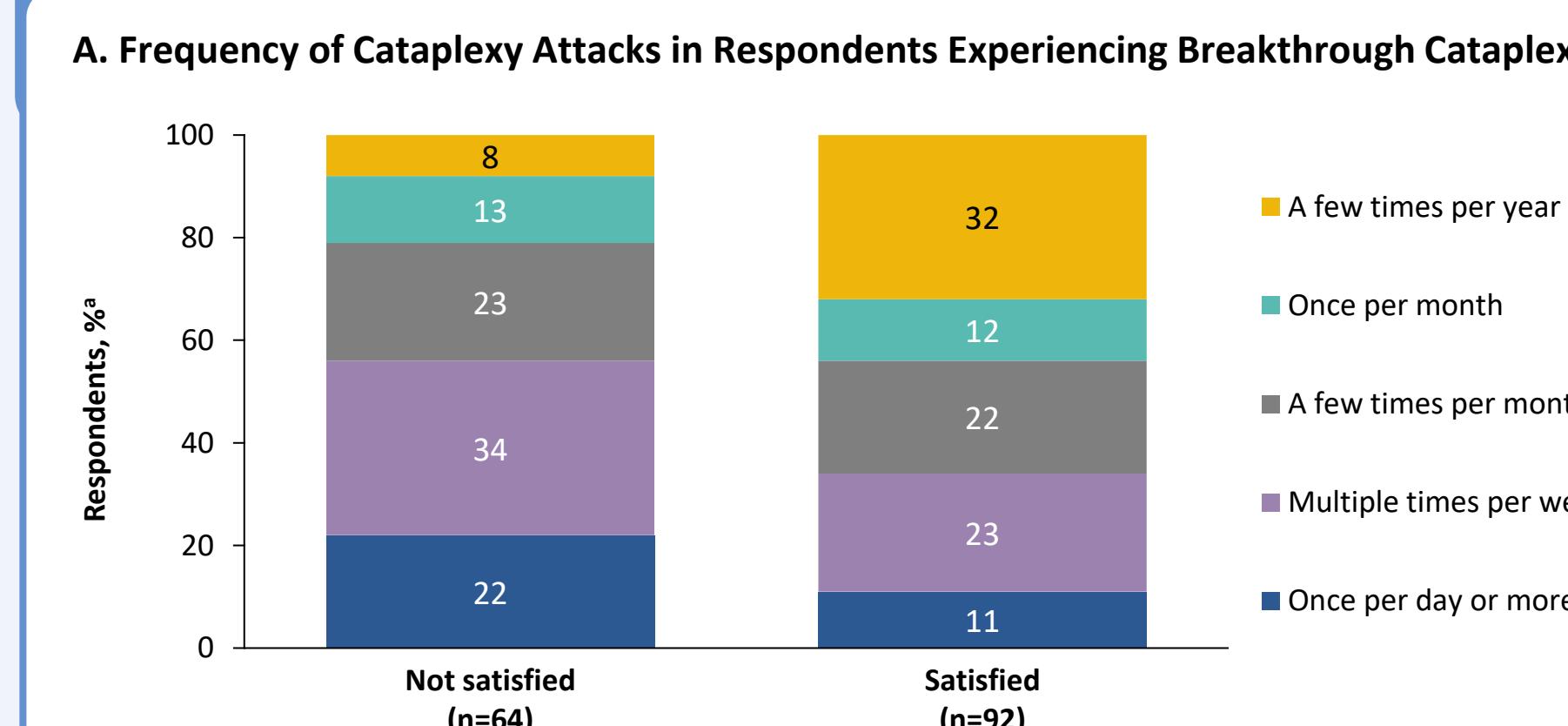
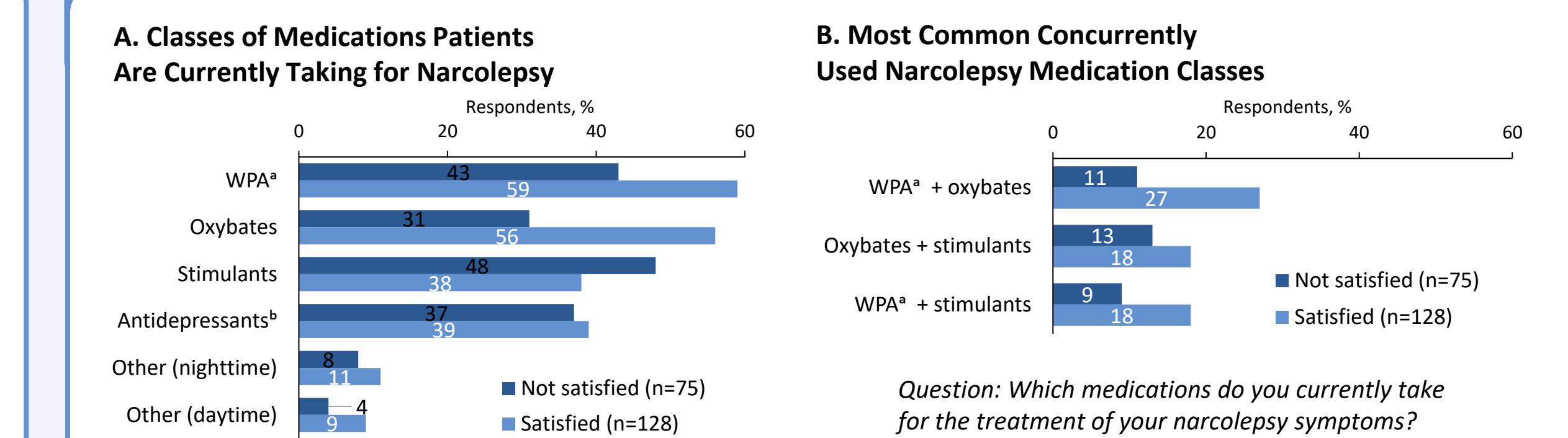


Figure 2. Medication Usage Patterns



- A greater proportion of respondents who were satisfied with their current treatment were receiving wake-promoting agents (WPA) and oxybates than those who were not satisfied (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

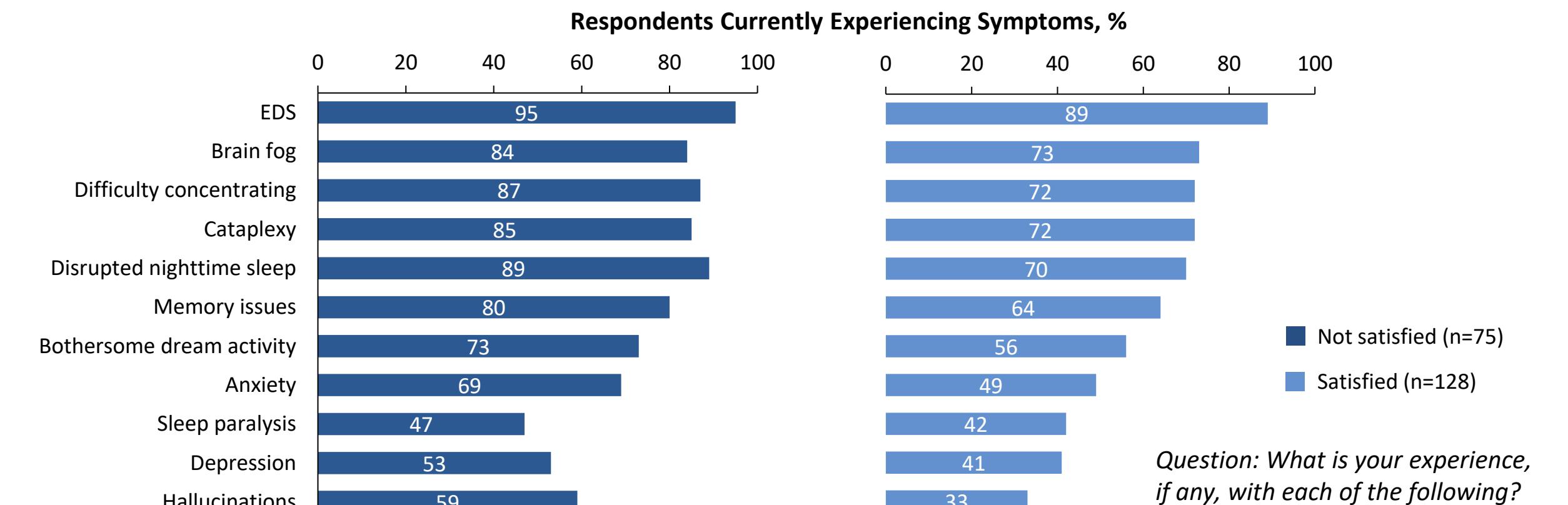
Patients could receive more than one medication in the same class.

<sup>a</sup>WPAs included armodafinil, modafinil, pitolastant, and salsamifetol.

<sup>b</sup>Antidepressants for narcolepsy.

WPA, wake-promoting agent.

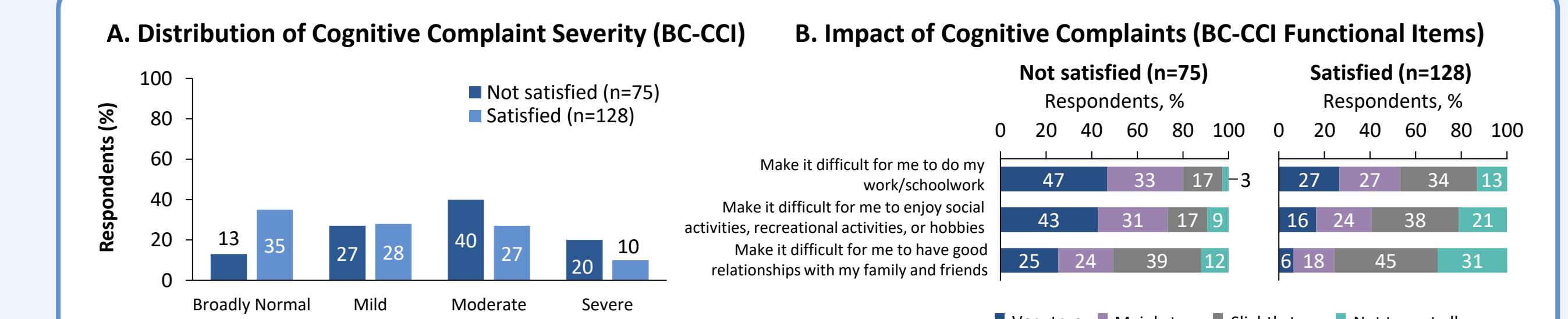
Figure 3. Prevalence of Breakthrough Symptoms Experienced



- 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

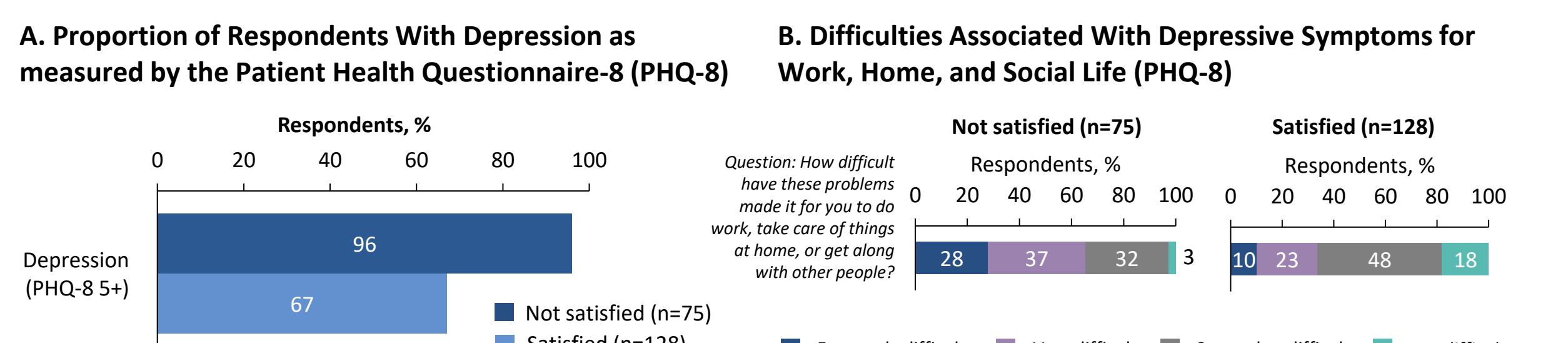


- Respondents who were satisfied with treatment reported less severity of cognitive complaints and less of an impact on quality of life vs those who were not satisfied
- Most respondents who were satisfied with treatment still indicated at least some difficulty with work or social life due to their cognitive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

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

BC-CCI, British Columbia Cognitive Complaints Inventory.

Figure 5. Depressive Symptoms and Impact on Quality of Life



- 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
- 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.

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 patient-reported 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

<sup>a</sup>Percentages based on the population experiencing breakthrough cataplexy with non-missing data.