

The background of the slide features a stylized, dark blue and purple cityscape of Seattle, with the Space Needle prominently visible on the left. The city is set against a bright yellow vertical bar on the far left. The text is overlaid on this background.

# SLEEP 2025

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A JOINT MEETING

**AASM** American Academy of  
SLEEP MEDICINE™

 Sleep Research Society®  
Advancing Sleep & Circadian Science

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

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# Learning Objectives

*Upon completion of this activity, participants should be able to:*

- Understand the residual symptom burden in people with type 1 narcolepsy who reported being satisfied with their current treatment
- Understand which factors differentiate those who were satisfied with their treatment from those who were not satisfied

# 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>
- Here we report a subgroup analysis of respondents reporting overall satisfaction with their current pharmacologic treatment to:
  - Quantify residual symptoms in this population
  - Understand which factors differentiate these patients from those who were not satisfied

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

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



# 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

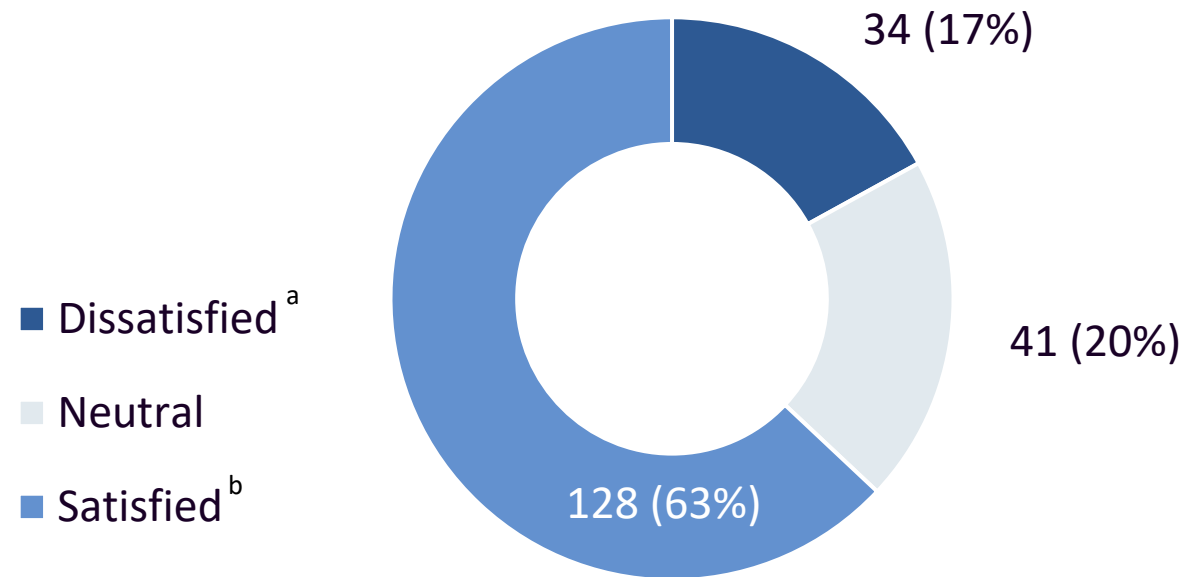


- Of 203 total respondents recruited, this subgroup analysis included 128 respondents who were satisfied and 75 who were not satisfied with their current narcolepsy treatment based on a 5-point categorical scale (1=very satisfied, 5=very dissatisfied)



# 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 "dissatisfied" and "very dissatisfied" categories.

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





# Baseline Demographics and Clinical Characteristics

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.

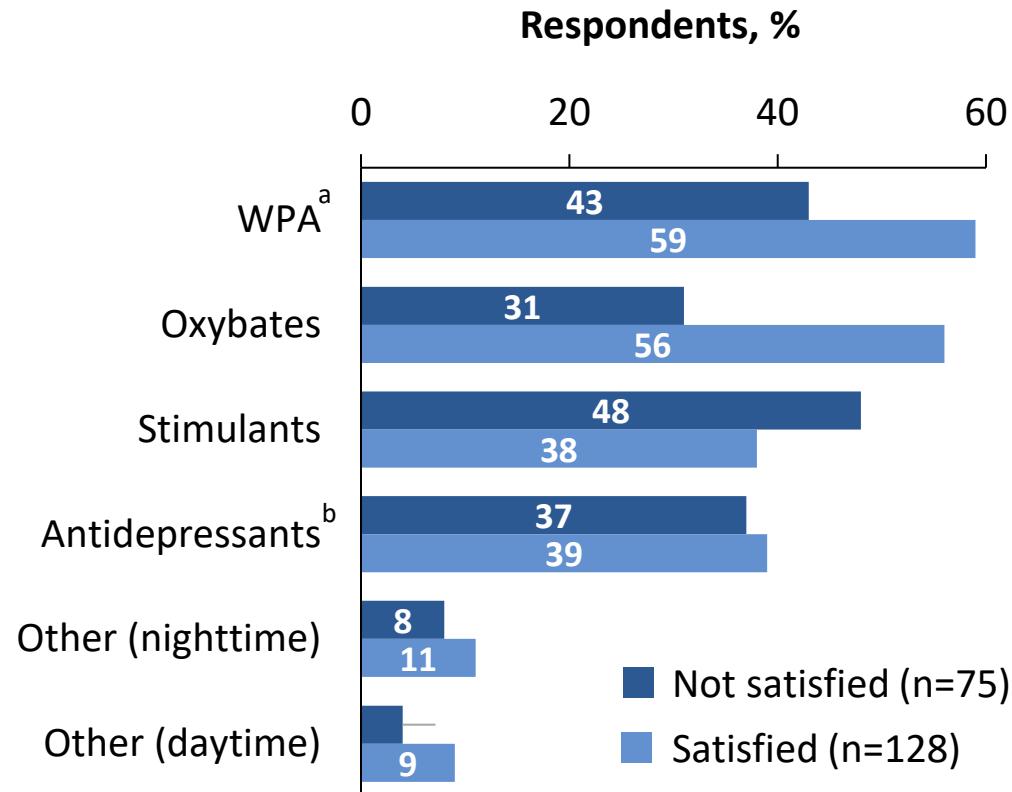
<sup>b</sup>Includes “satisfied” and “very satisfied” categories.





# Classes of Medications Patients Are Currently Taking for Narcolepsy

*Question: Which medications do you currently take for the treatment of your narcolepsy symptoms?*



A greater proportion of respondents who were satisfied with their current treatment were receiving WPAs and oxybates than those who were not satisfied with treatment

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

<sup>a</sup>WPAs included armodafinil, modafinil, pitolisant, and solriamfetol.

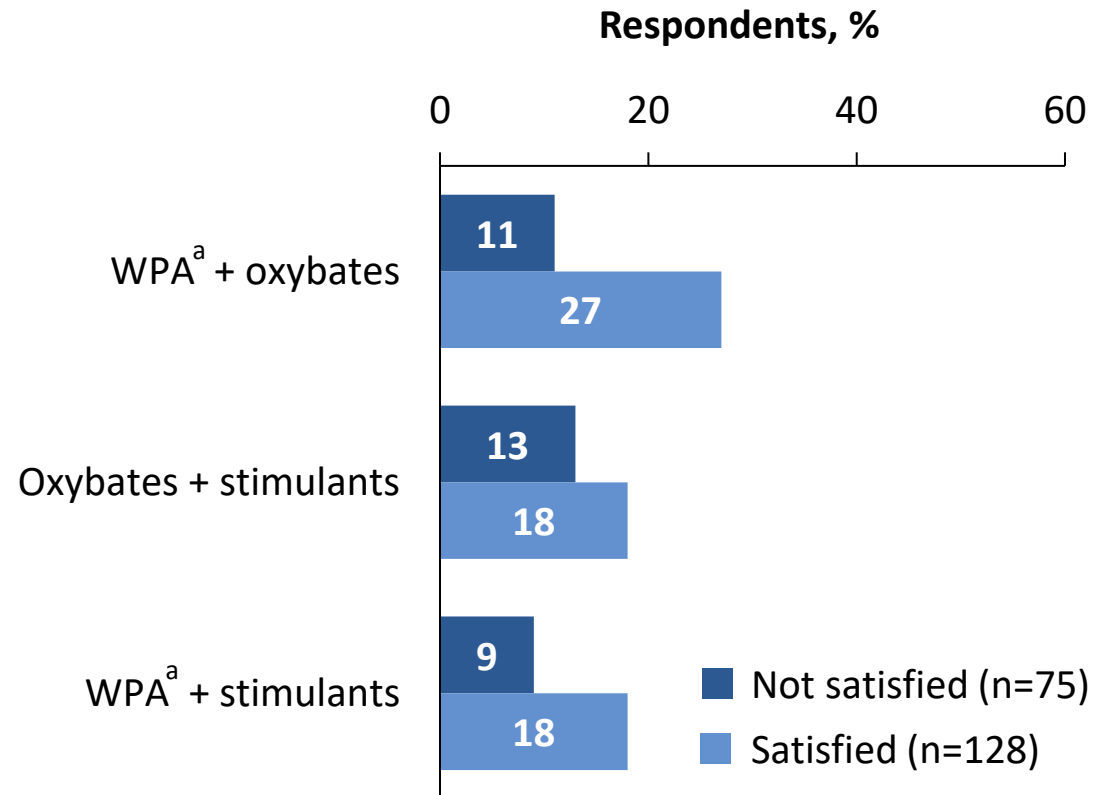
<sup>b</sup>Antidepressants for narcolepsy.

WPA, wake-promoting agent.



# Most Common Concurrently Used Narcolepsy Medication Classes

*Question: Which medications do you currently take for the treatment of your narcolepsy symptoms?*



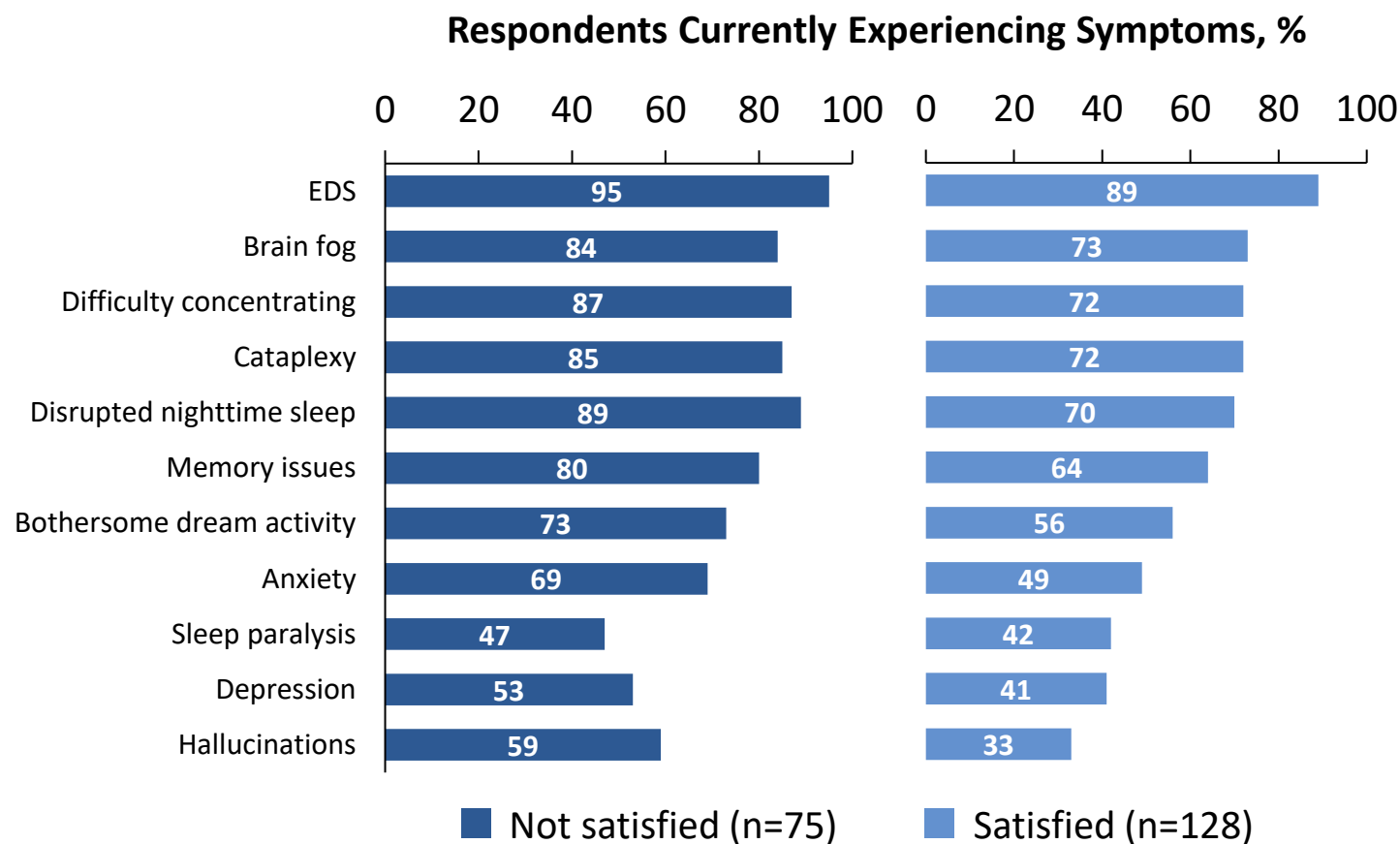
Polypharmacy was more common in respondents who were satisfied with treatment vs not satisfied; 65.6% of satisfied respondents reported taking medications from 2 or more classes vs 52.0% of not satisfied respondents

Patients could receive more than one medication in the same class.  
<sup>a</sup>WPAs included armodafinil, modafinil, pitolisant, and solriamfetol.  
 WPA, wake-promoting agent.



# Prevalence of Breakthrough Symptoms Experienced

*Question: What is your experience, if any, with each of the following?*

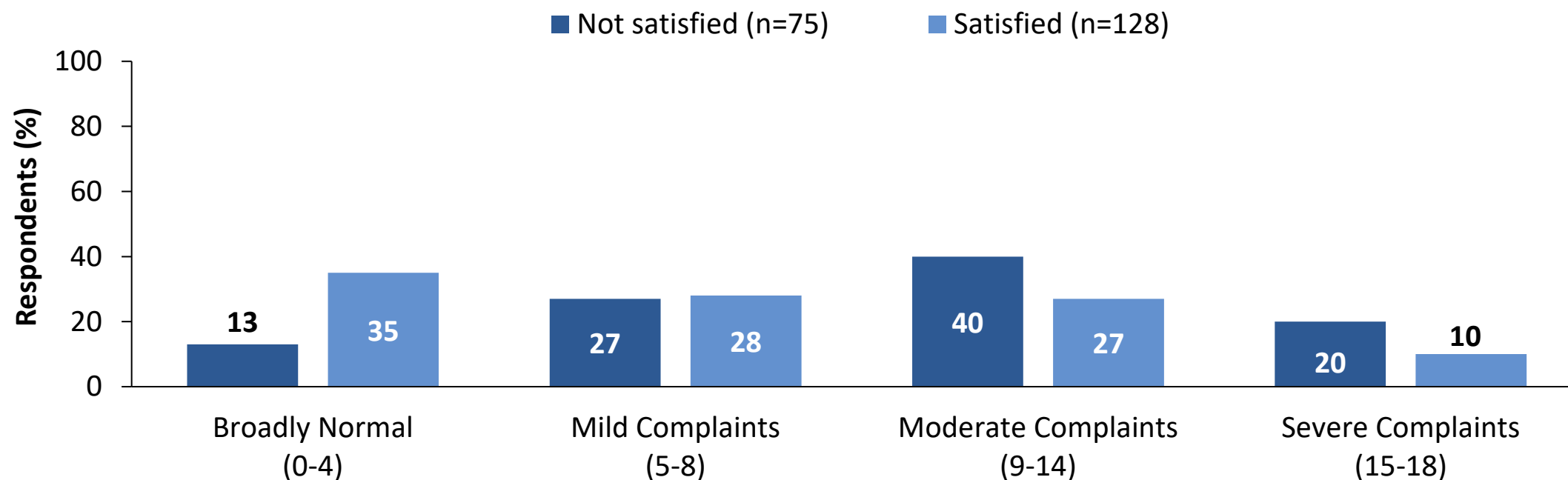


Although breakthrough symptoms were less common in respondents who were satisfied with treatment vs not satisfied, the prevalence of breakthrough symptoms remained high

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%)



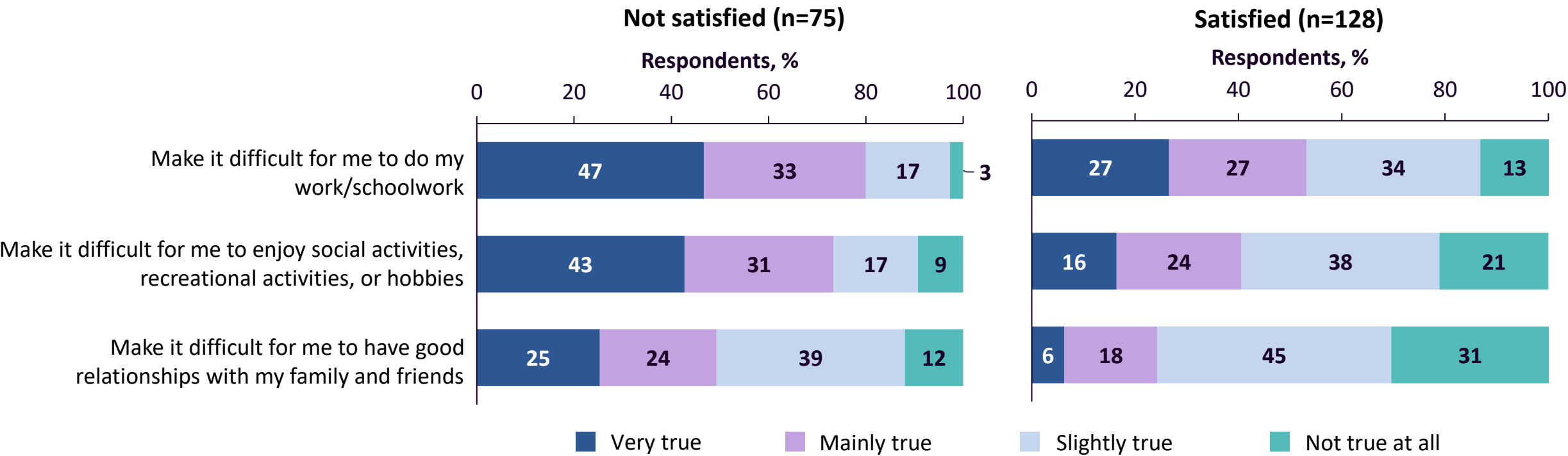
# Distribution of Cognitive Complaint Severity (BC-CCI)



Respondents who were satisfied with treatment reported lower severity of cognitive complaints, although 37% still reported moderate to severe complaints



# Impact of Cognitive Complaints (BC-CCI Functional Items)

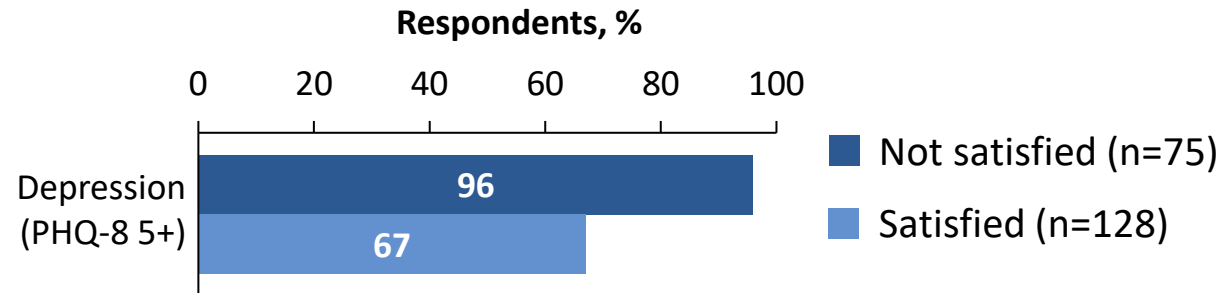


Respondents who were satisfied with treatment reported less of an impact on quality of life vs those who were not satisfied. Most respondents who were satisfied with treatment still indicated at least some difficulty with work or social life due to their cognitive symptoms, indicating residual functional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

Numbers may not add up to 100% due to rounding.  
BC-CCI, British Columbia Cognitive Complaints Inventory.

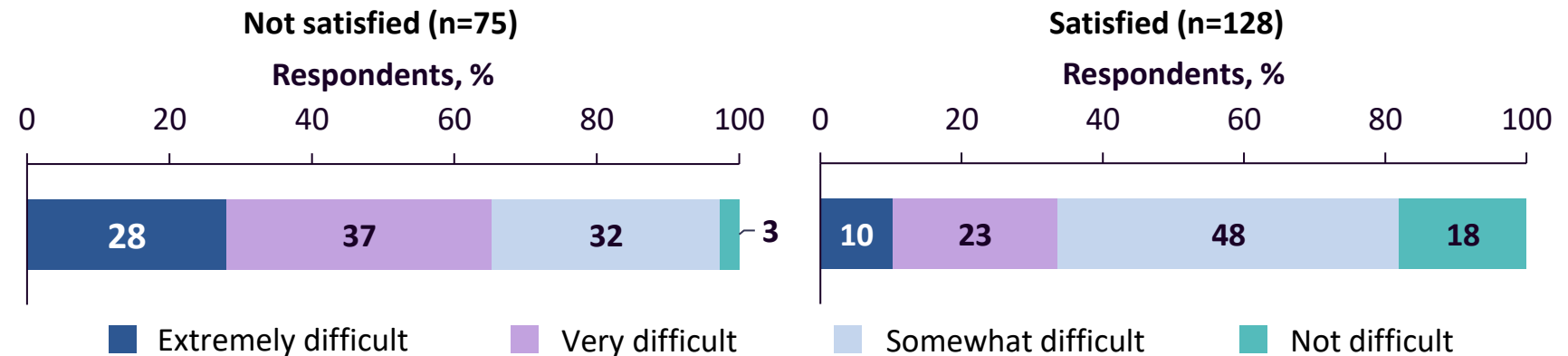


# Depressive Symptoms (PHQ-8) and Impact on Work, Home, and Social Life



The proportion of respondents with depression was higher as assessed by the PHQ-8 vs a self-report. 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

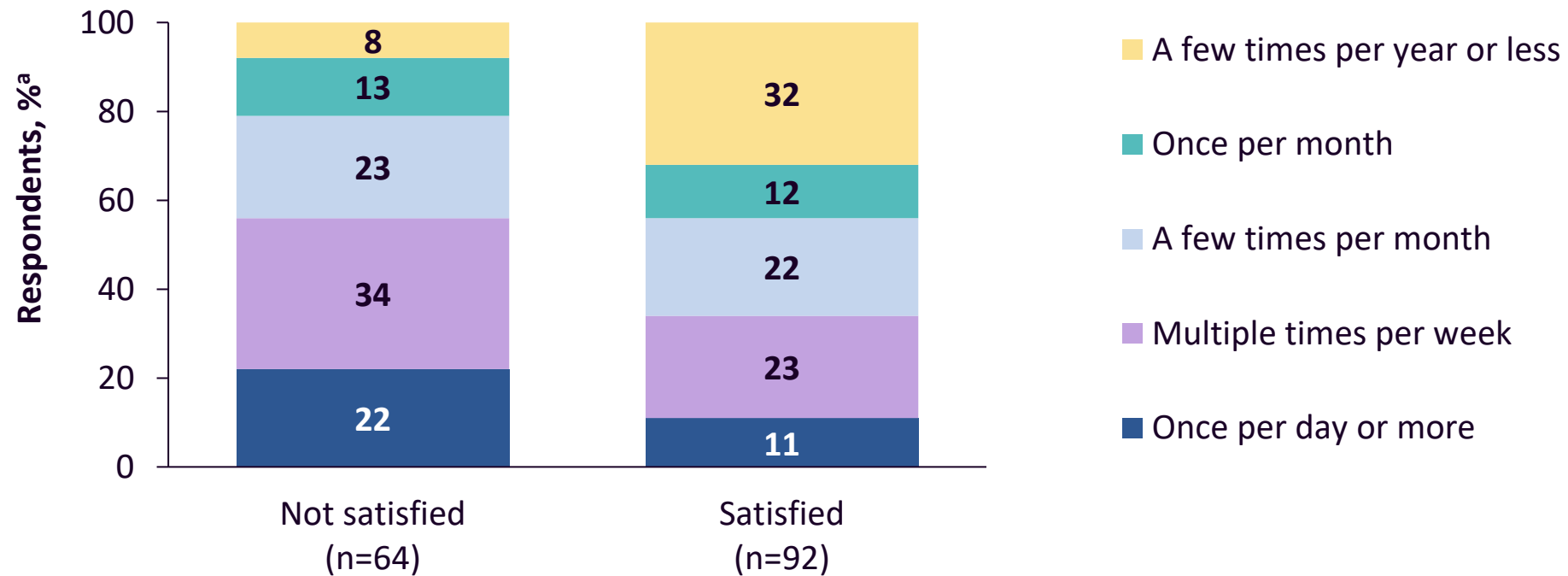
*Question: How difficult have these problems made it for you to do work, take care of things at home, or get along with other people?*



Most respondents who were satisfied with treatment indicated at least some difficulty with work, home or social life due to depressive symptoms



# Frequency of Cataplexy Attacks in Respondents Experiencing Breakthrough Cataplexy



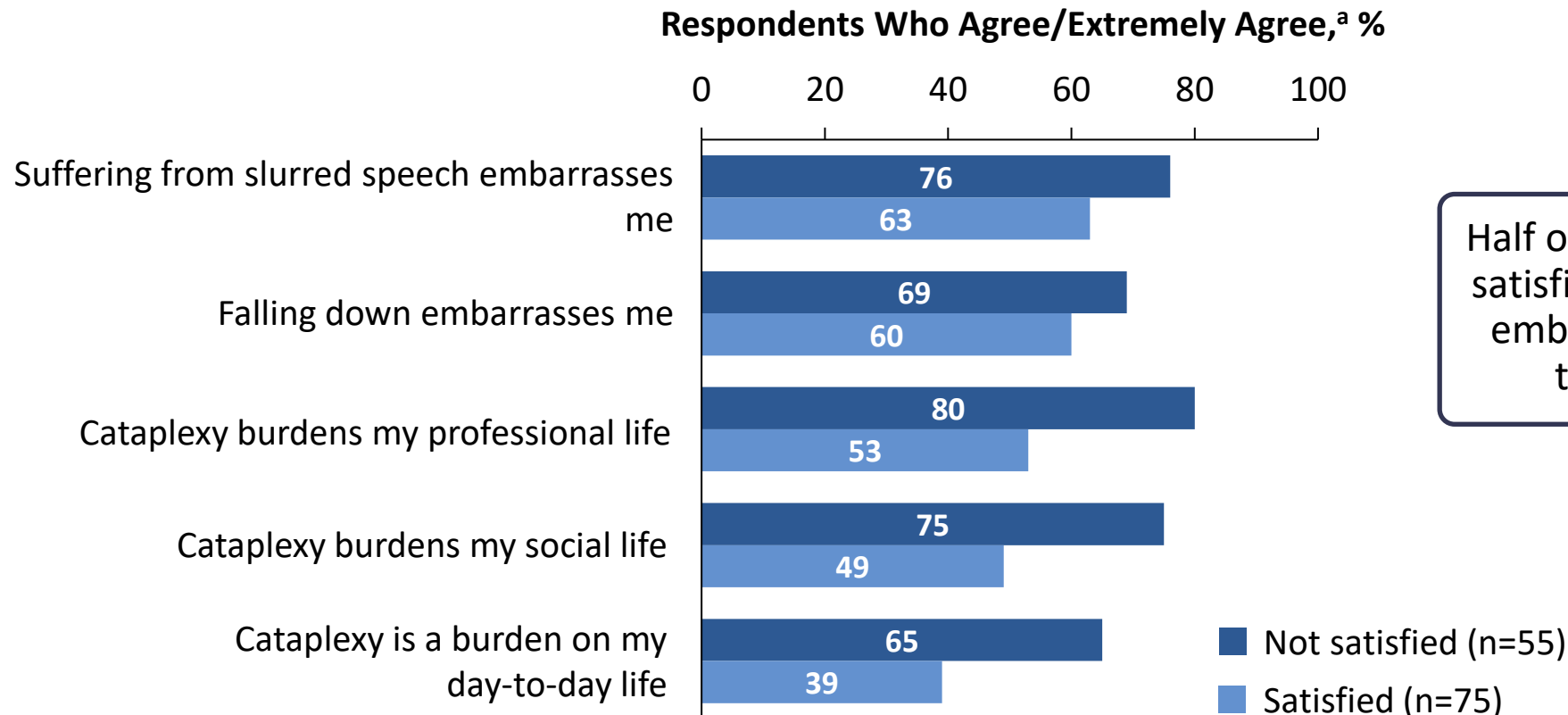
Over half of participants in both groups reported experiencing cataplexy at least a few times per month. In those not satisfied with treatment, over half experienced cataplexy multiple times per week





# Impact of Cataplexy on Quality of Life in Respondents Experiencing Breakthrough Cataplexy

*Question: Thinking of your cataplexy on a typical day, please indicate how much you agree or disagree with each of the following statements?*



Half or more of patients who were satisfied still report that cataplexy embarrasses them and burdens their work or social lives

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



# 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



# Acknowledgements and Disclosures

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