

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:
- 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

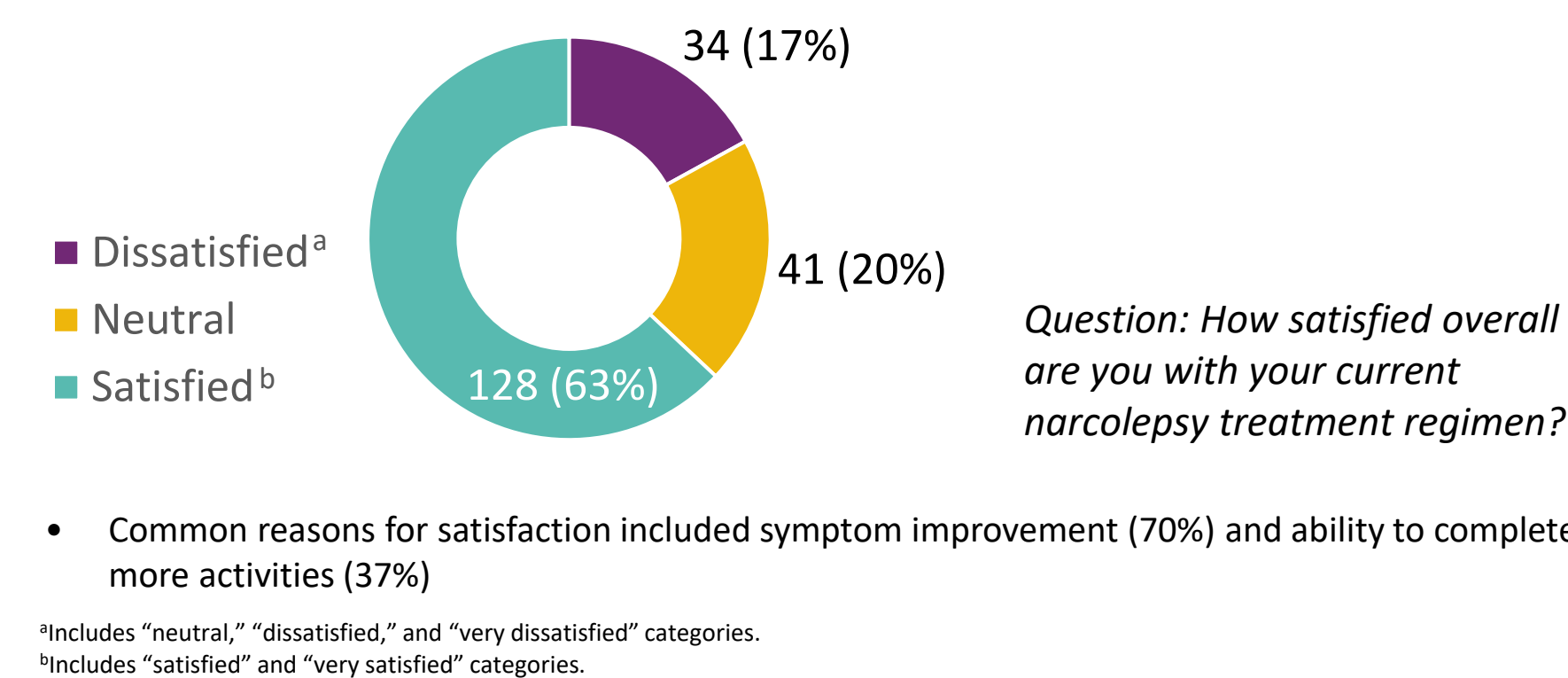


Table 1. Baseline Demographic and Clinical Characteristics	Not satisfied ^a (n=75)	Satisfied ^b (n=128)
Age, mean (range)	43 (18–82)	41 (18–78)
Age at symptom onset, mean (range)	18 (5–51)	18 (1–63)
Age at diagnosis, mean (range)	30 (10–67)	27 (8–64)
Gender, n (%)		
Female	49 (65)	81 (63)
Decline to 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)

^aIncludes "neutral," "dissatisfied," and "very dissatisfied" categories.
^bIncludes "satisfied" and "very satisfied" categories.

Figure 6. Breakthrough Cataplexy

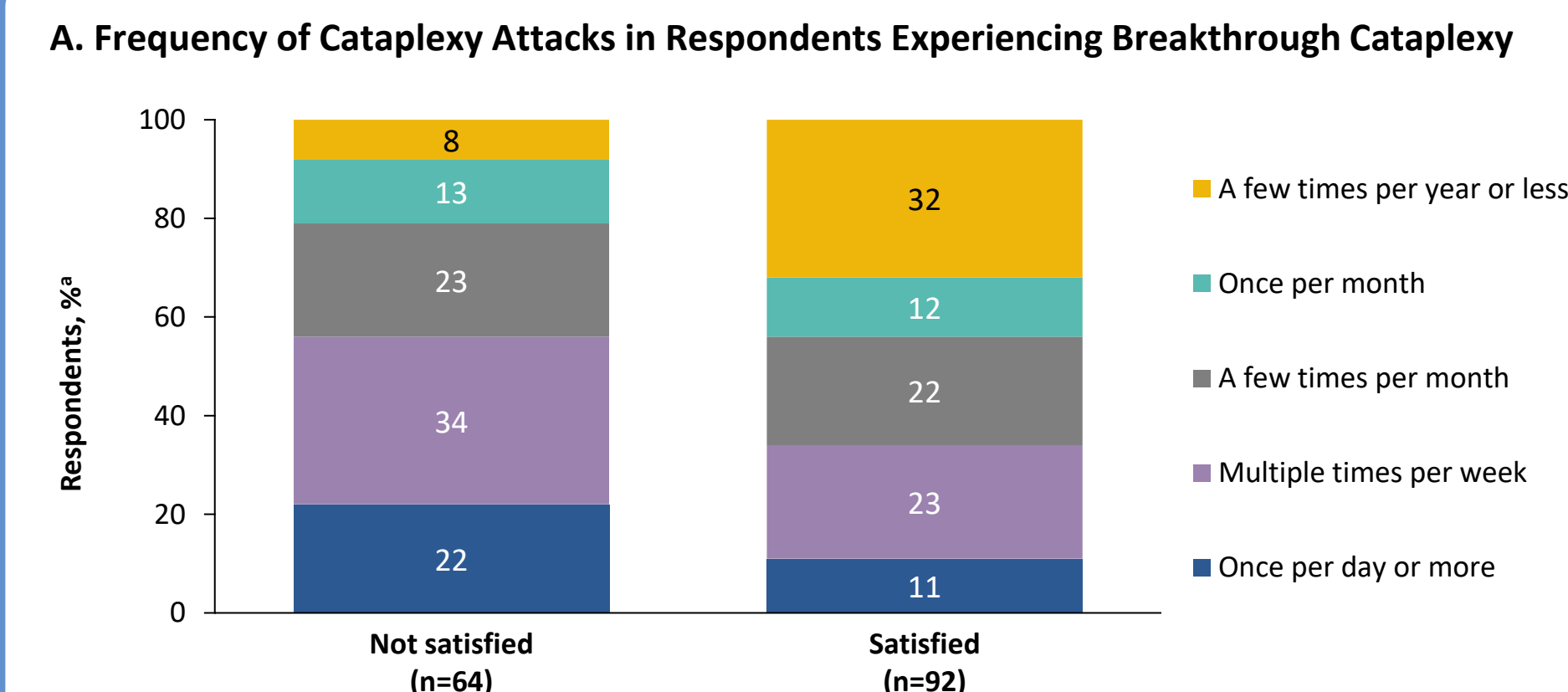


Figure 2. Medication Usage Patterns

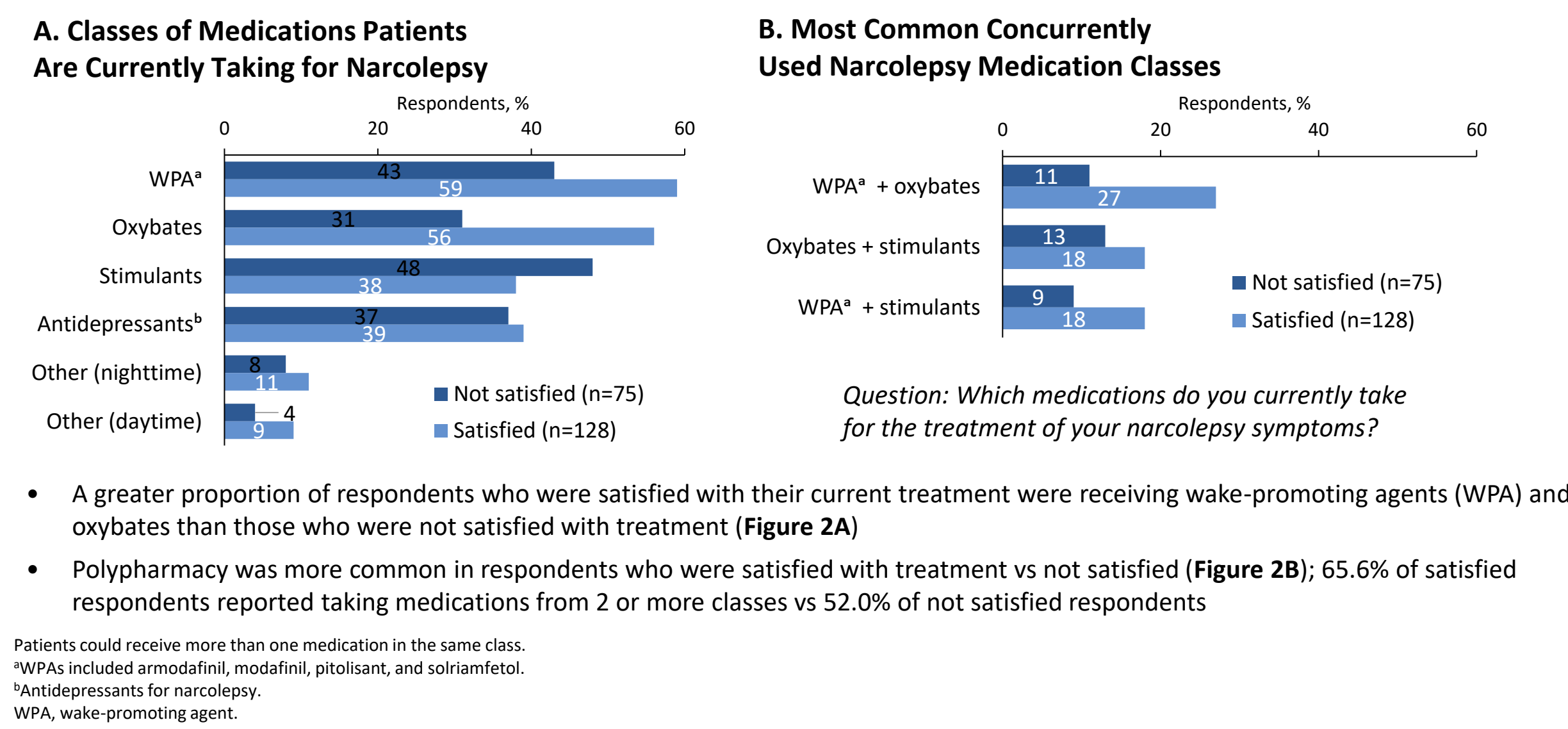


Figure 4. Cognitive Complaints and Impact on Quality of Life

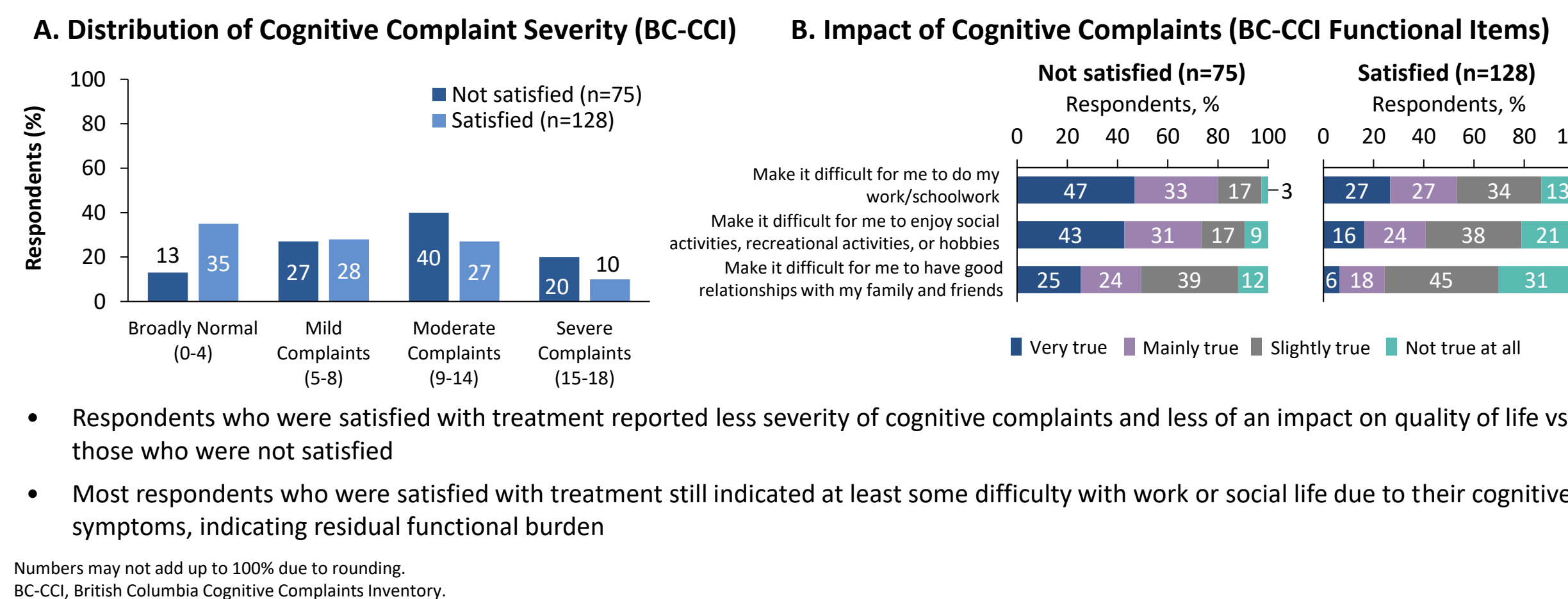


Figure 3. Prevalence of Breakthrough Symptoms Experienced

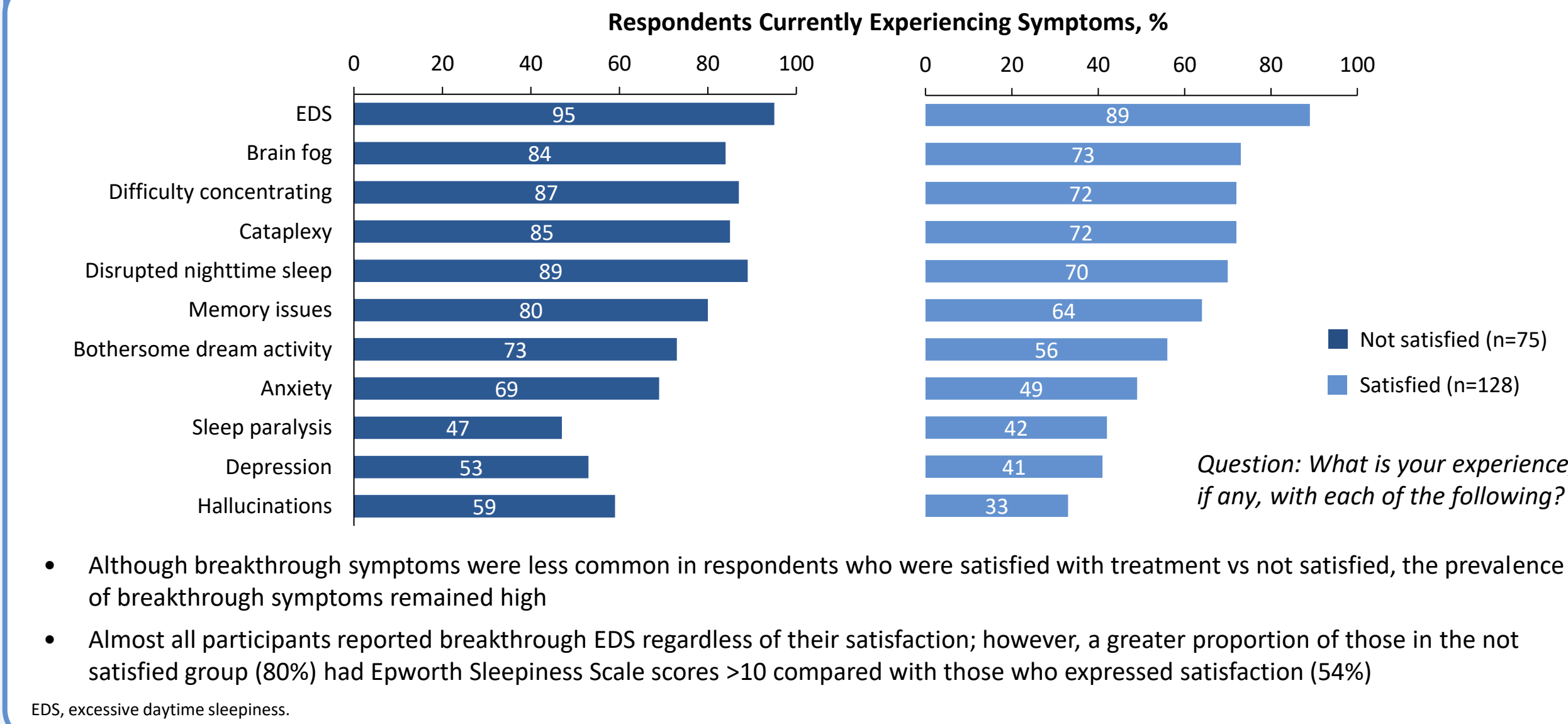
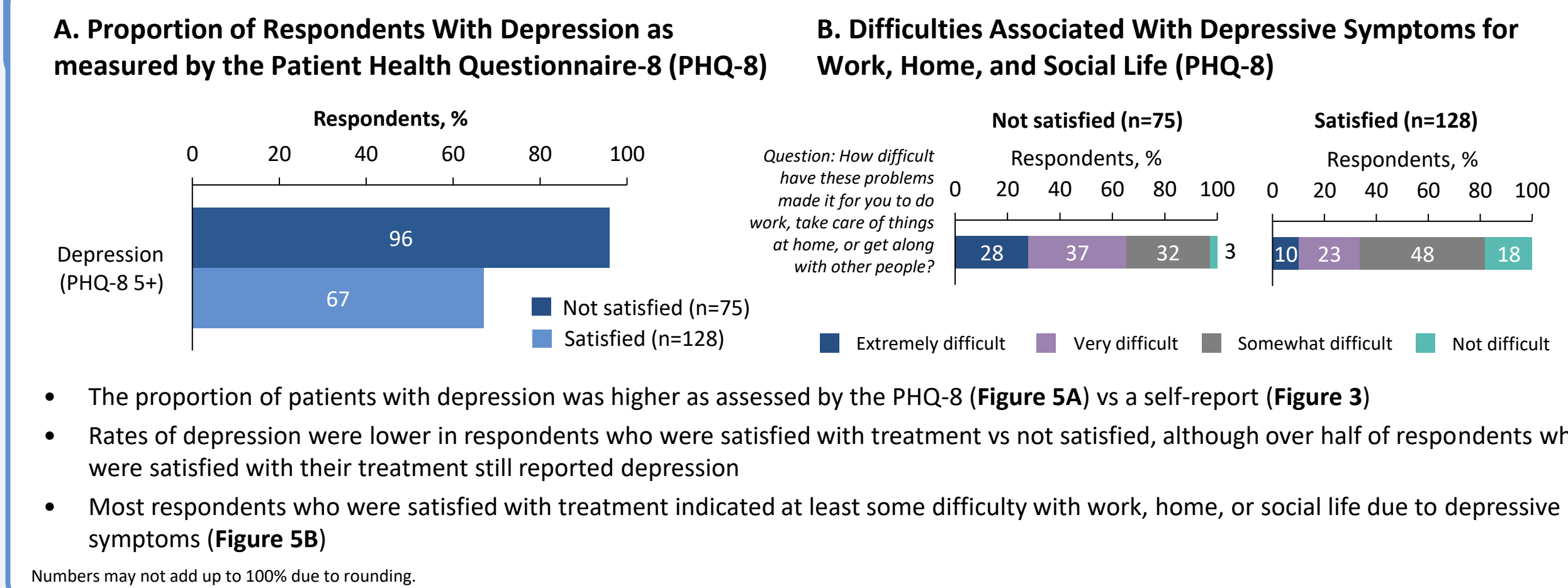


Figure 5. Depressive Symptoms and Impact on Quality of Life



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