Symptom Burden and Quality of Life in Patients With Narcolepsy Who Experience Residual Cataplexy: Subgroup Analysis From the CRESCENDO Survey

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Key Objective

To describe the treatment experience and unmet need in patients with a diagnosis of, and being treated for, narcolepsy type 1 (NT1) who report residual cataplexy using data from a patient-reported survey

Introduction

- People living with NT1 often continue to experience symptoms, including excessive daytime sleepiness (EDS), cataplexy, and cognitive difficulties, even when taking multiple medications[1,2]
- Although cataplexy is a core symptom of narcolepsy, it often goes underrecognized and can cause limitations to daily life[3]
- The CRESCENDO survey examined the patient experience in patients with NT1, providing a detailed characterization of symptom burden[2]
- 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 residual cataplexy to better understand the burden and impact on quality of life of residual cataplexy in this patient population

Methods

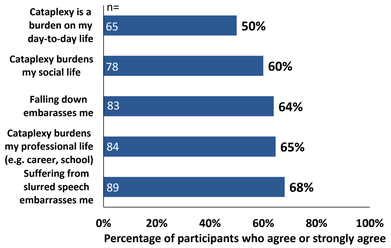
- The CRESCENDO survey was conducted from October–December 2023 in adults diagnosed with NT1 who were currently taking an FDA-approved medication for narcolepsy and included assessments of symptom burden and impact on quality of life
- CRESCENDO was developed and executed in partnership with the patient 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 156 respondents who reported residual cataplexy and 47 who reported no residual cataplexy
- Residual cataplexy was defined as reported presence of any cataplexy events

Results

Table 1. Demographic and Clinical Characteristics	Residual Cataplexy (n = 156)	No Residual Cataplexy (n = 47)
Age, mean (range)	43 (18–82)	37 (18–61)
Age at symptom onset, mean (range)	18 (1–63)	19 (3–47)
Age at diagnosis, mean (range)	29 (10–67)	27 (8–48)
Gender, n (%)		
Female	110 (71)	20 (43)
Male	24 (15)	8 (17)
Decline to answer	12 (8)	19 (40)
Race, n (%)		
White	119 (76)	24 (51)
Decline to answer	13 (8)	21 (45)

Figure 1. Frequency of Cataplexy and Impact on Quality of Life[a]

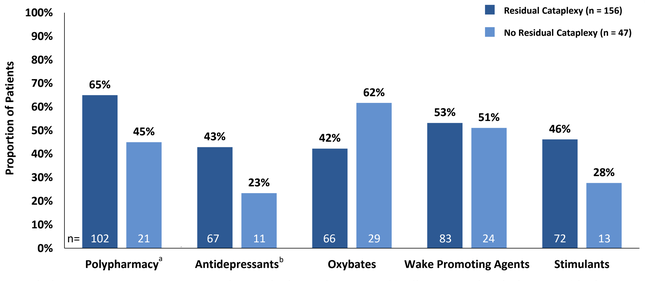
- Of the respondents reporting residual cataplexy (n = 156), 43% reported experiencing it daily or multiple times per week



- A majority of respondents felt that residual cataplexy caused them embarrassment or impacted their profession/social life

[a]Of the 156 participants with residual cataplexy.

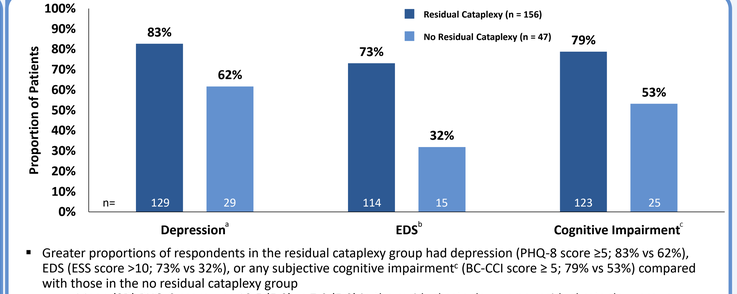
Figure 2. Rates of Medication Use



- Polytherapy[a] was more common in the residual cataplexy group (65%) compared with the no residual cataplexy group (45%)
- Greater proportions of respondents in the residual cataplexy group were currently treated with antidepressants (43 % vs 23%) or stimulants (46% vs 28%) compared with the no residual cataplexy group

[a]Defined as ≥2 medication classes; [b]Antidepressants used for the treatment of cataplexy.

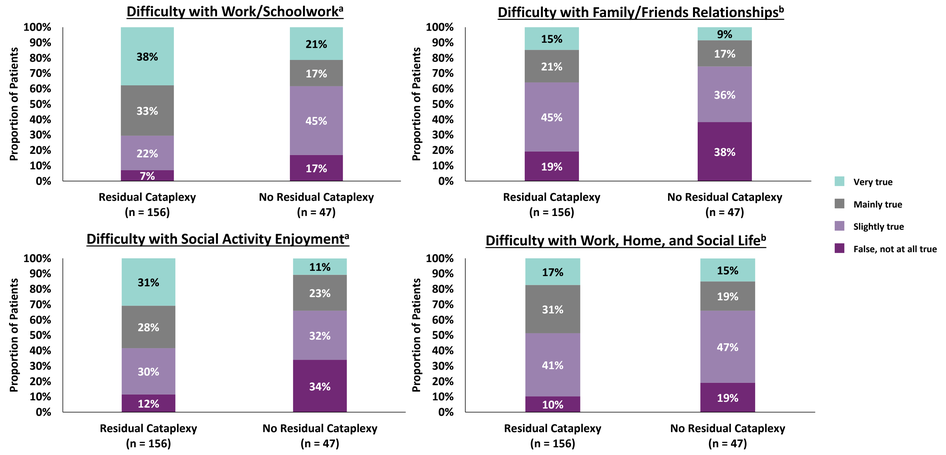
Figure 3. Rates of Depression, EDS and Cognitive Impairment



- Greater proportions of respondents in the residual cataplexy group had depression (PHQ-8 score ≥5; 83% vs 62%), EDS (ESS score >10; 73% vs 32%), or any subjective cognitive impairment[c] (BC-CCI score ≥ 5; 79% vs 53%) compared with those in the no residual cataplexy group
  - Mean (SD) PHQ-8 score was 10.5 (5.8) vs 7.0 (5.8) in the residual cataplexy vs no residual cataplexy group
  - Mean (SD) ESS score was 13.6 (4.6) vs 8.9 (4.5) in the residual cataplexy vs no residual cataplexy group
  - Mean (SD) BC-CCI score was 9.1 (5.0) vs 5.2 (4.0) in the residual cataplexy vs no residual cataplexy group

[a]Defined as PHQ-8 score >5; [b]Defined as ESS score >10; [c]Defined using BC-CCI scores as follows: 0–4, broadly normal; 5–8, mild cognitive impairment; 9–14, moderate cognitive impairment 15–18, severe cognitive impairment.

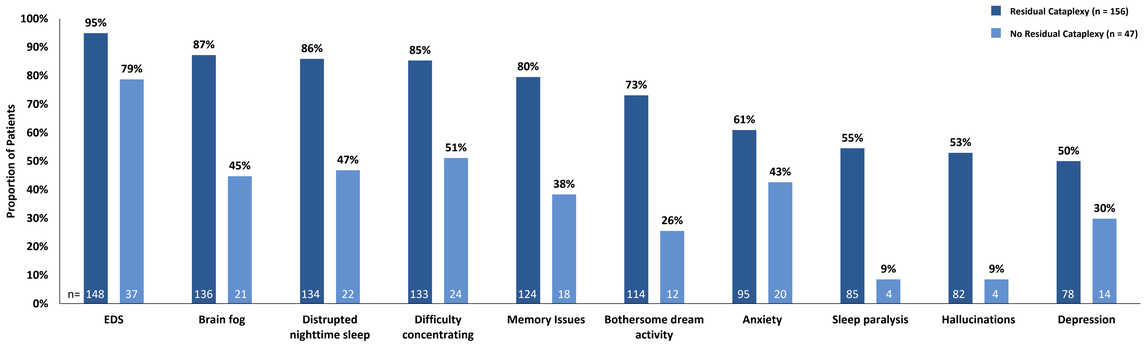
Figure 4. Functional Impairment Related to Cognitive and Depressive Symptoms



- Greater proportions of respondents in the residual cataplexy group reported functional impairment related to cognitive symptoms (any difficulty with work/school [93% vs 83%], family/friends relationship [81% vs 62%], or social activity enjoyment [89% vs 66%]) and depressive symptoms (49% vs 34% reporting very/extreme difficulty with work/home/social life)

[a]Evaluated using the functional impairment items of the BC-CCI; [b]Evaluated using the functional impairment items of the PHQ-8.

Figure 5. Patient-reported Symptoms



- All residual symptoms were more frequently self-reported in the residual cataplexy group compared with the no residual cataplexy group

References

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.
3. Hlodak J, et al. *Sleep Breath.* 2025;29(4):231.

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QR Code

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Disclosures

M.J. Thorpy serves as a consultant to Axsome Therapeutics
G.M.L. Eglit, S. Floam, and H. Tabuteau are current employees of Axsome Therapeutics

Conclusions

- Despite current treatment, residual cataplexy was common among patients with NT1, affecting the-majority of NT1 patient survey respondents
- Despite higher rates of polytherapy, those with residual cataplexy reported higher rates of depression and EDS compared with those with no residual cataplexy
- Furthermore, patients with residual cataplexy experienced a substantial symptom burden and psychosocial impact
- There is prevailing unmet need for additional treatment options to treat cataplexy and improve outcomes in this population