

Diagnosis and Symptoms of Narcolepsy From the Patient Perspective: Results From In-Depth Qualitative Interviews

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INTRODUCTION

- Narcolepsy is a rare, chronic neurological condition characterized by excessive daytime sleepiness (EDS) and sleep-onset rapid eye movement periods^{1,2}
- Narcolepsy is categorized into type 1 (NT1) and type 2 (NT2)²
 - Both types are characterized by EDS (including sleep attacks), sleep inertia, and sleep paralysis and/or hallucinations²
 - In addition, NT1 features cataplexy, which is a sudden, spontaneous, and temporary loss of muscle control triggered by strong emotional stimuli (e.g., fear, anger, laughter, or stress)^{2,3}
- Symptoms of narcolepsy often start in adolescence or early adulthood, but can occur at any time⁴
- Lack of symptom recognition by clinicians may lead to misdiagnosis, potentially delaying effective treatment and further exacerbating disease burden⁵
- Previous studies that identified symptoms of narcolepsy have largely relied on quantitative methods, which may provide limited insight into the patient experience compared with qualitative methods

OBJECTIVE

- The objective of this study was to use qualitative research methods to characterize the patient experience of adults living with NT1 and NT2
 - The data presented herein reflect the diagnosis journey and symptom burden of narcolepsy

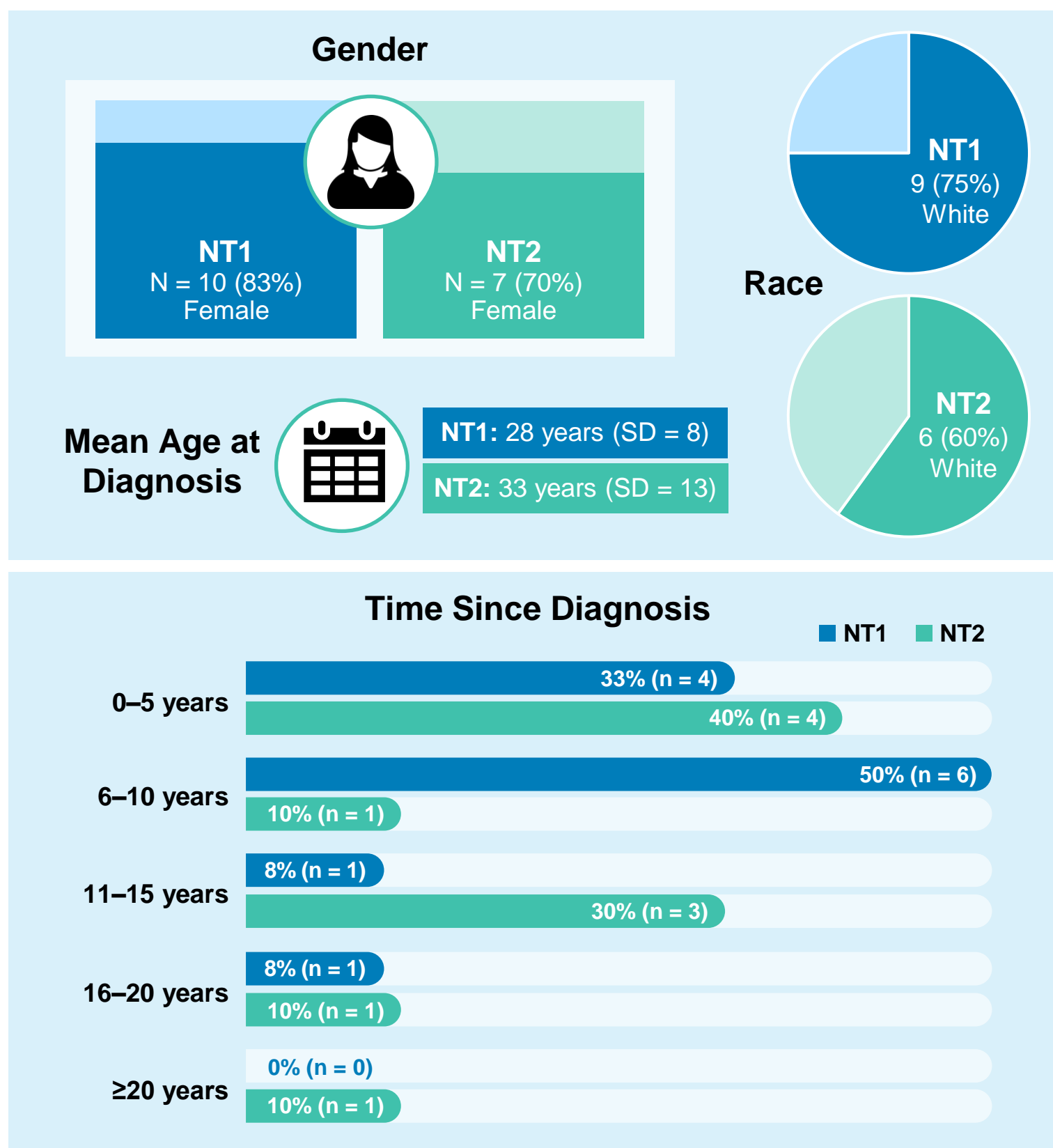
METHODS

- This was a qualitative, cross-sectional, observational study
 - Using a semistructured interview guide, interviewers asked open-ended questions to gather insights into people's experiences with NT1 or NT2
- Adult participants with NT1 or NT2 were recruited from panels of patients, physician referrals, social media outlets, and snowball sampling (participants could refer other participants to this study)
- Interview transcripts were coded and thematically analyzed using inductive and deductive approaches
- This study was approved by an Institutional Review Board and all participants provided informed consent

RESULTS

PARTICIPANT DEMOGRAPHICS AND CLINICAL CHARACTERISTICS

Figure 1. Demographics and Clinical Characteristics Among Participants

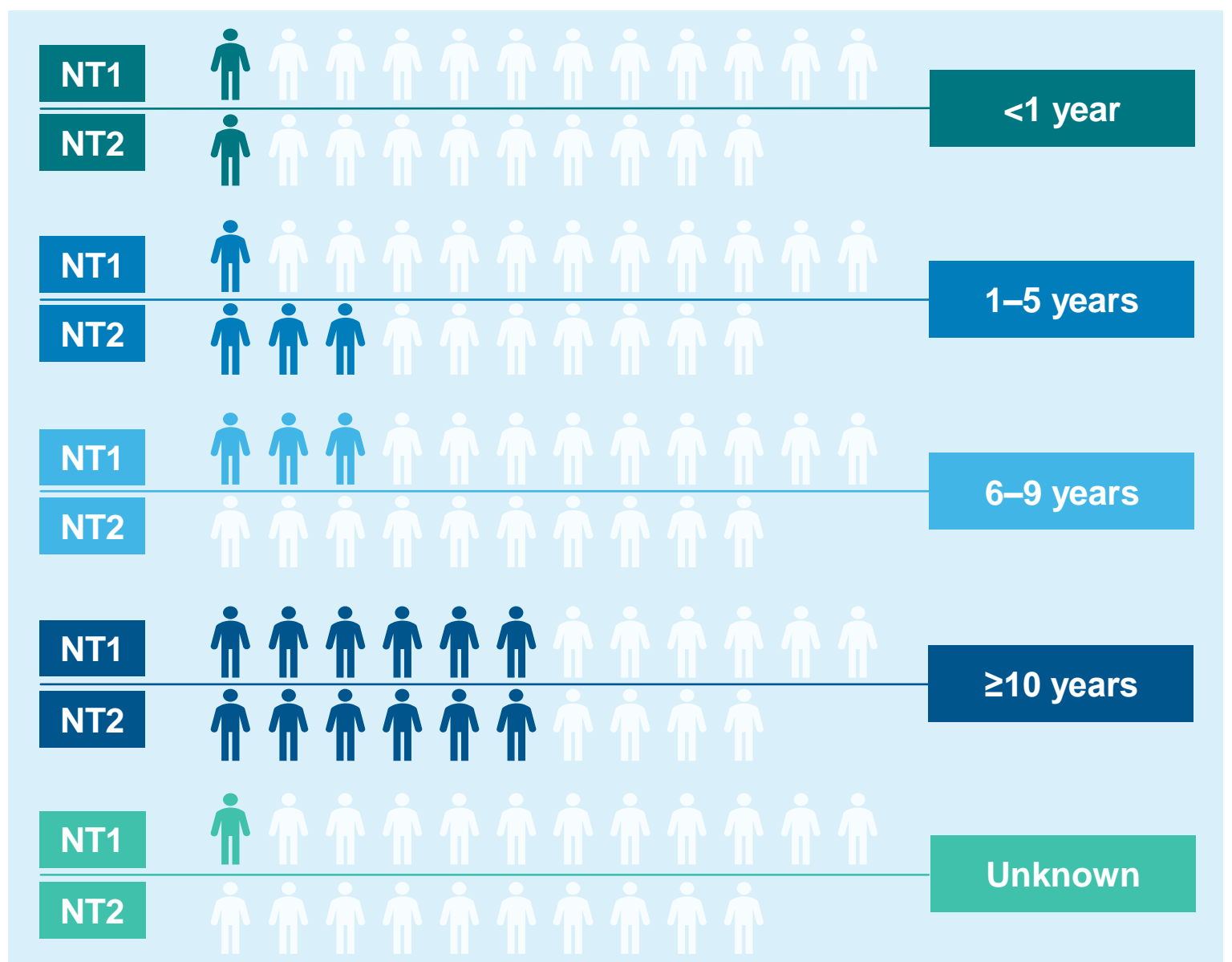


NT1, narcolepsy type 1; NT2, narcolepsy type 2.

- A total of 22 adults with narcolepsy participated in this study, including 12 adults with NT1 and 10 adults with NT2
- 58% (n = 7) of NT1 patients and half of NT2 patients (n = 5) were employed (full-time or part-time)
 - Other categories included being unemployed, student or retired

JOURNEY TO DIAGNOSIS

Figure 2. Time From Symptom Onset to Narcolepsy Diagnosis

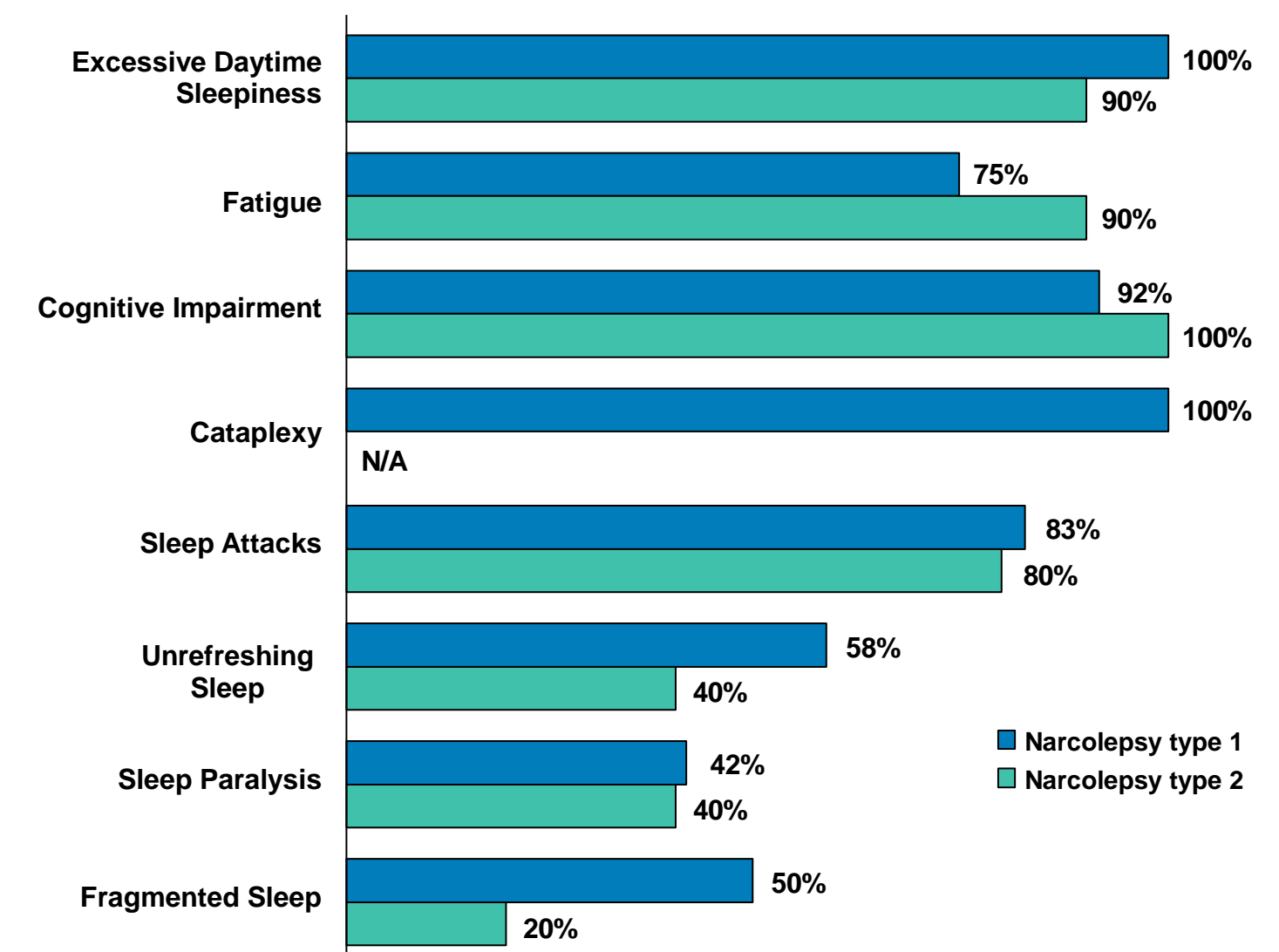


NT1, narcolepsy type 1; NT2, narcolepsy type 2.

- Initial symptoms included EDS (NT1 = 83%; NT2 = 80%), fatigue (NT1 = 42%; NT2 = 30%), oversleeping (NT1 = 33%; NT2 = 20%), sleep attacks (NT1 = 35%; NT2 = 50%), insomnia (NT1 = 35%; NT2 = 20%), and cataplexy (NT1 = 42%)
- Half of participants (n = 11, 50%) described being misdiagnosed prior to their diagnosis of NT1 or NT2; misdiagnoses included depression (27%), sleep apnea (18%), and attention-deficit/hyperactivity disorder (9%)
- While seeking a diagnosis, participants visited various healthcare professionals, including sleep specialists (NT1 = 7; NT2 = 4), neurologists (NT1 = 3; NT2 = 3), pulmonologists (NT1 = 2; NT2 = 2), psychiatrists (NT1 = 2; NT2 = 0), and primary care physicians (NT1 = 2; NT2 = 2)

FREQUENCY OF SYMPTOMS

Figure 3. Frequency of Symptoms Identified by Participants

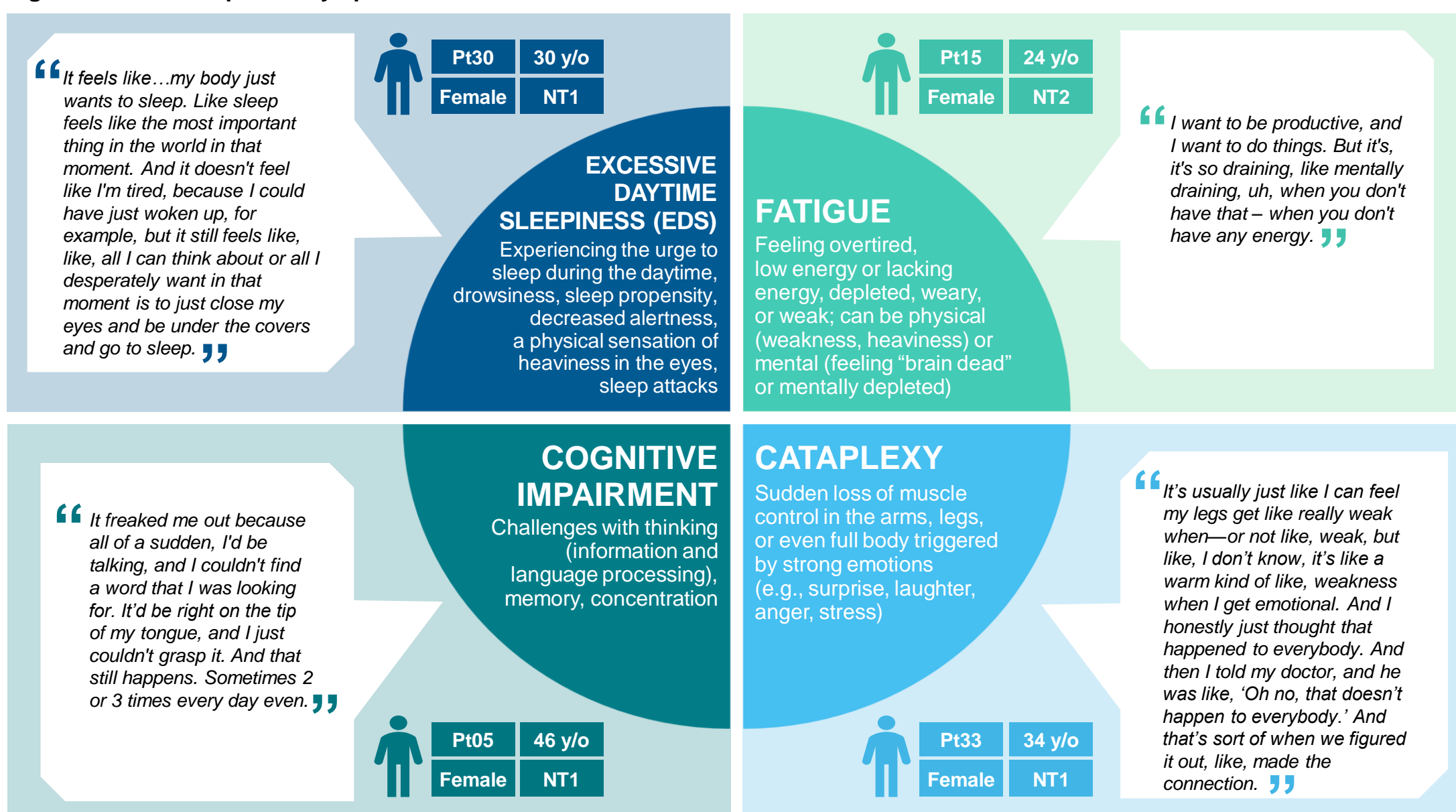


- Almost all participants (n = 21; 95%) described experiencing EDS
 - Over three-fourths of participants (n = 18; 82%) reported sleep attacks
- 82% of participants (n = 18) reported fatigue, describing it as a feeling of low or depleted energy that left them constantly "exhausted," "dragging," and "drained" during the day
- Among participants who experienced cognitive impairments (n = 21; 95%), more than half described lapses in short-term memory (NT1 = 9; NT2 = 5) and difficulties with focus and attention (NT1 = 5; NT2 = 7); nearly half described trouble thinking through and processing information (NT1 = 6; NT2 = 3)
- Cataplexy (NT1 = 100%) was triggered by strong emotions/reactions such as laughter (n = 6; 50%), anger (n = 5; 42%), stress (n = 5; 42%), and surprise (n = 3; 25%)
 - Almost all participants with NT1 (n = 11; 92%) described experiencing cataplexy within a specific body part, whereas one-third of NT1 participants (n = 4; 33%) described full-body cataplexy
- Fatigue was the most frequently cited bothersome symptom (NT1 = 5; NT2 = 4), followed by EDS (NT1 = 5; NT2 = 2) and cognitive impairment (NT1 = 2; NT2 = 1)

FROM THE PATIENT PERSPECTIVE

- The 4 most common symptoms were EDS, cognitive impairment, fatigue, and cataplexy

Figure 4. Patient-Reported Symptoms: In Their Own Words



STUDY LIMITATIONS

- The rare nature of narcolepsy resulted in difficulty recruiting study participants
 - Despite this, a saturation analysis suggested saturation of concepts was reached for NT1 and NT2 participants and additional interviews would likely not have yielded new information
- It is unclear if results would have been different with a more diverse sample with respect to gender, race/ethnicity, and age

CONCLUSIONS

- Study results provide a comprehensive description of the patient experience of narcolepsy and highlight the often long and complicated journey these individuals experience while seeking a diagnosis for their symptoms
- The rich descriptions provided by participants for each symptom have contributed to a deeper understanding of how each may be experienced
 - From the patient perspective, NT1 and NT2 are characterized by a constant desire to sleep during the day, challenges with focus, concentration, and memory, and overwhelming and debilitating fatigue



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ACKNOWLEDGMENTS

The study was supported by Alkermes, Inc. Medical writing support was provided by Envision Pharma Group and was funded by Alkermes, Inc. This poster was developed in accordance with Good Publication Practice (GPP4) guidelines. Authors had full control of the content and made the final decision on all aspects of this poster.

DISCLOSURES

MJD, BR, and WPW III are employees and stockholders of Alkermes, Inc. MOC, ML-C, and LTW are employees of QualityMetric Incorporated, LLC.

