

The Burden of Living With Narcolepsy: Patient Perspectives From In-Depth Qualitative Interviews

Michael J. Doane,¹ Meaghan O'Connor,² Miranda Lauher-Charest,² Laura Tesler Waldman,² Wilbur P. Williams, III¹

¹Alkermes, Inc., Waltham, Massachusetts; ²QualityMetric Incorporated, LLC, Johnston, Rhode Island

Poster No: 126

INTRODUCTION

- Narcolepsy is a rare, chronic neurological disorder that affects the brain's ability to regulate sleep-wake cycles, resulting in excessive daytime sleepiness (EDS).^{1,2}
- There are 2 major types of narcolepsy: narcolepsy type 1 (NT1), which includes cataplexy, and narcolepsy type 2 (NT2), which does not include cataplexy.³
- Narcolepsy may be associated with negative impacts to patients' lives, including impaired mental and physical health, increased stigma, and difficulty obtaining an education or maintaining employment.⁴⁻⁷
- Previous studies that have identified the burden associated with narcolepsy have largely relied on quantitative methods (eg, surveys), providing limited insights into the patient experience.

OBJECTIVE

- The objective of this study was to use qualitative research methods (ie, in-depth interviews and thematic analysis) to understand the experience and burden of narcolepsy directly from patients with NT1 or NT2.

METHODS

- This was a qualitative, cross-sectional, observational study
 - Using a semi-structured interview guide, interviewers used a concept elicitation approach 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, and social media outlets
 - Participants could also refer other participants to this study (ie, snowball sampling).
- 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 DISPOSITION

- A total of 22 adults with narcolepsy participated in this study (NT1 = 12; NT2 = 10) (Figure 1).
- Overall, over 70% of participants were female and over 60% of participants were White (Figure 1).
- 83% of participants with NT1 and 50% of participants with NT2 were diagnosed with narcolepsy within the last 10 years (Figure 1).

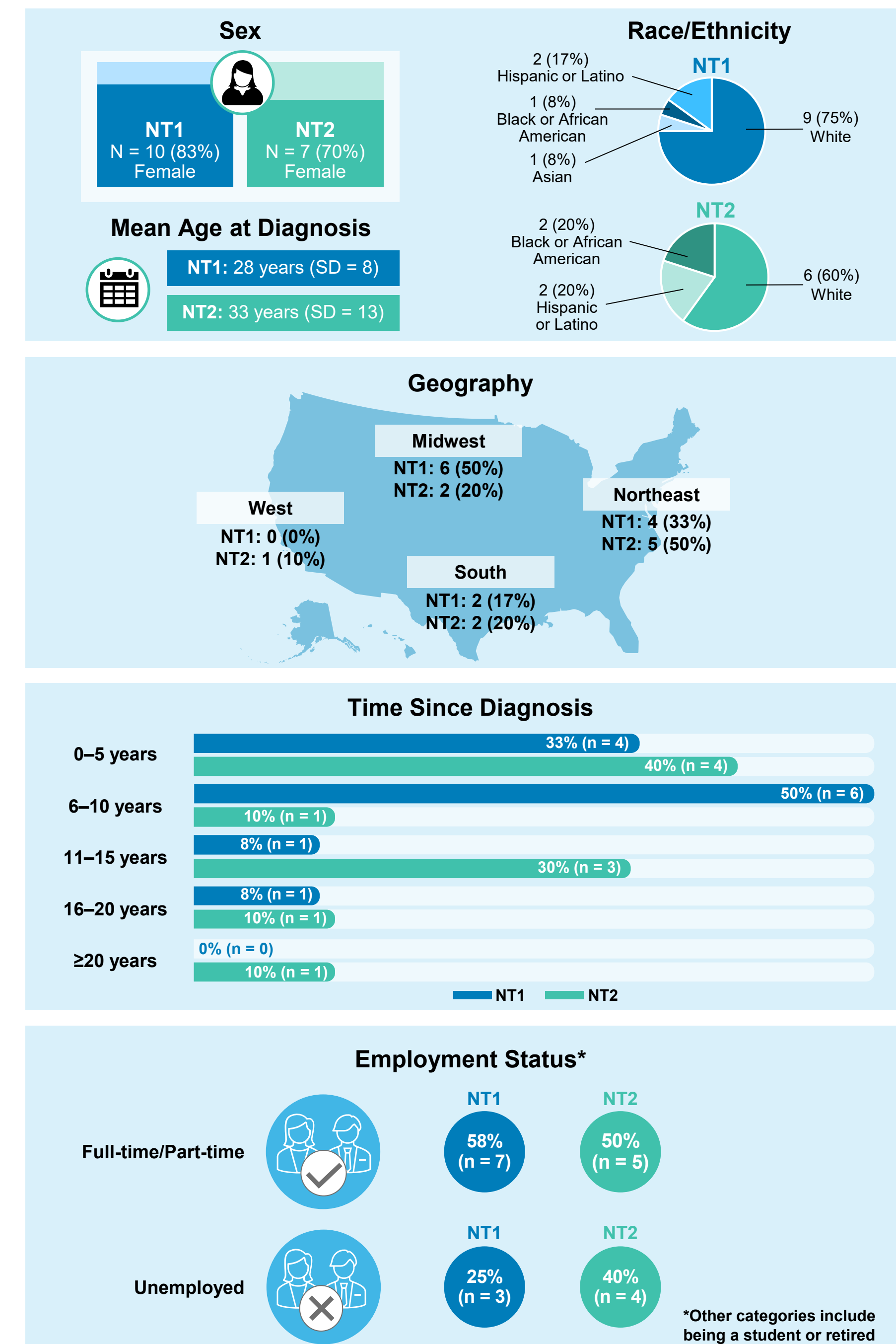
PATIENT PERSPECTIVE – IMPACT ON QUALITY OF LIFE

- All, or nearly all, participants reported impacts on work or school (NT1 = 12, NT2 = 10, 100%), mental health (NT1 = 12, NT2 = 9, 95%), and instrumental activities of daily living (NT1 = 11, NT2 = 10, 95%) such as home maintenance, cooking/preparing meals, and driving (Figure 2).
- Most participants also described impacts on their relationships with family and friends (NT1 = 10, NT2 = 8, 82%), activities of daily living (NT1 = 11, NT2 = 6, 77%) such as eating, bathing, dressing/grooming, and toileting, and physical functioning (NT1 = 10, NT2 = 5, 68%) (Figure 2).

STUDY LIMITATIONS

- The rare nature of narcolepsy resulted in difficulty recruiting study participants
 - Participants included in this study were mostly female, White, and under 40 years of age.
 - It is unclear if results would have been different with a more diverse sample with respect to sex, race/ethnicity, and age.
 - 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.
- Confirmation of diagnosis was encouraged but not required; confirmation was provided by 4 participants with NT1 and 8 participants with NT2.

FIGURE 1: Demographics and Clinical Characteristics Among Participants



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

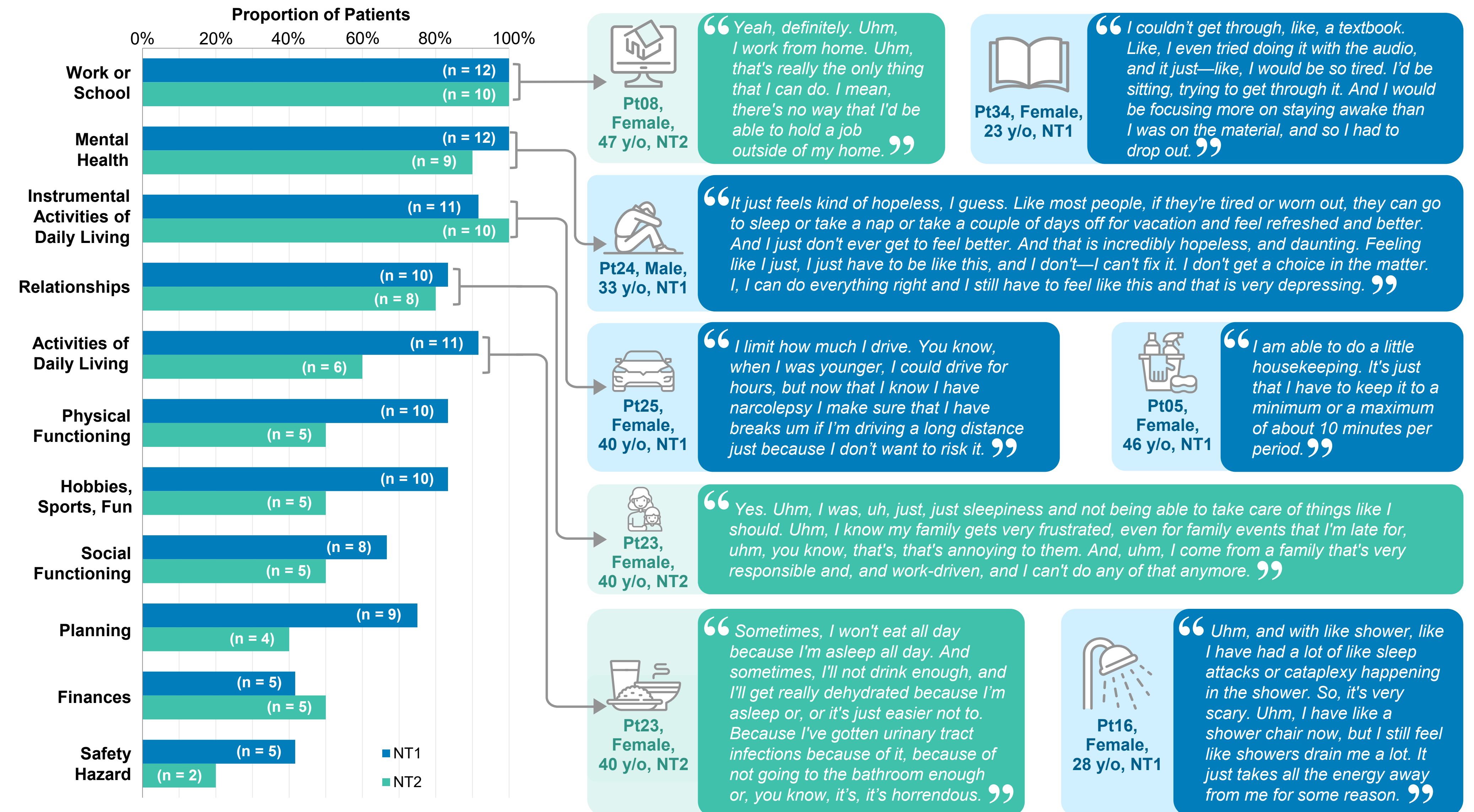
Key contributors

MJD and WPW III contributed to conceptualization, methodology, writing – reviewing and editing, visualization, and supervision. MO, MLC, and LTW contributed to project administration, methodology, data curation, formal analysis, validation, investigation, writing – reviewing and editing, and visualization.

Acknowledgments

The study was supported by Alkermes, Inc. Medical writing support was provided by Aparna Rao at 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.

FIGURE 2: Impact on Quality of Life Among Participants



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

CONCLUSIONS

- Results of this study provide a comprehensive description of the patient experience of narcolepsy.
- This study demonstrated the many facets of life that are impacted by narcolepsy, straining patients' work/school performances, relationships, and mental health.
- Future research should seek to understand predictors of the burden of narcolepsy, including whether burden differs based on type of diagnosis (eg, NT1 or NT2) as well as whether diagnostic delay exacerbates the burden associated with this condition.

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Disclosures

MJD and WPW III are employees and stockholders of Alkermes. MO, MLC, and LTW are employees of QualityMetric Incorporated, LLC.

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