

Characterizing and quantifying impacts of neuromyelitis optica spectrum disorder (NMOSD) on patients and caregivers

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INTRODUCTION

- Anti-aquaporin-4 antibody-positive (AQP4-Ab+) NMOSD is a rare autoimmune disease characterized by repeated, unpredictable relapses, often leading to irreversible neurological disability.^{1,2}
- The impact of rare diseases, such as NMOSD, is often defined by clinical outcomes of patients and direct medical costs. However, most studies do not address indirect costs to patients and their caregivers.³⁻⁷
- Beyond economic costs, qualitative impacts are also crucial to evaluate; however, consequences such as the loss of health-related quality of life for patients with NMOSD and their caregivers are typically overlooked.⁸

OBJECTIVE

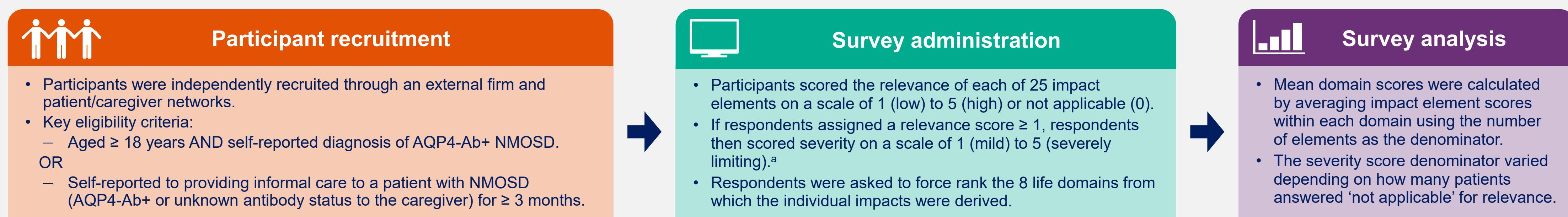
- To quantitatively assess the impacts of NMOSD in the daily lives of US patients and caregivers reported across life domains.

CONCLUSIONS

- NMOSD imposes a significant burden on patients and caregivers across a broad range of life domains, including impacts on finances, physical health, and planning and autonomy. Severity of impact across elements of the various life domains differed both within and between patient and caregiver cohorts by age, sex, relapse history (among patients), and employment status.
- These impacts should be considered when assessing overall disease burden, as well as patient outcomes and treatment benefits, and future evaluation will be important to better understand the potential benefits associated with NMOSD treatments.
- Collectively, these findings emphasize the importance of measuring perspectives from both patients and caregivers to fully understand the burden of NMOSD.

METHODS

Figure 1. Survey recruitment, administration, and analysis



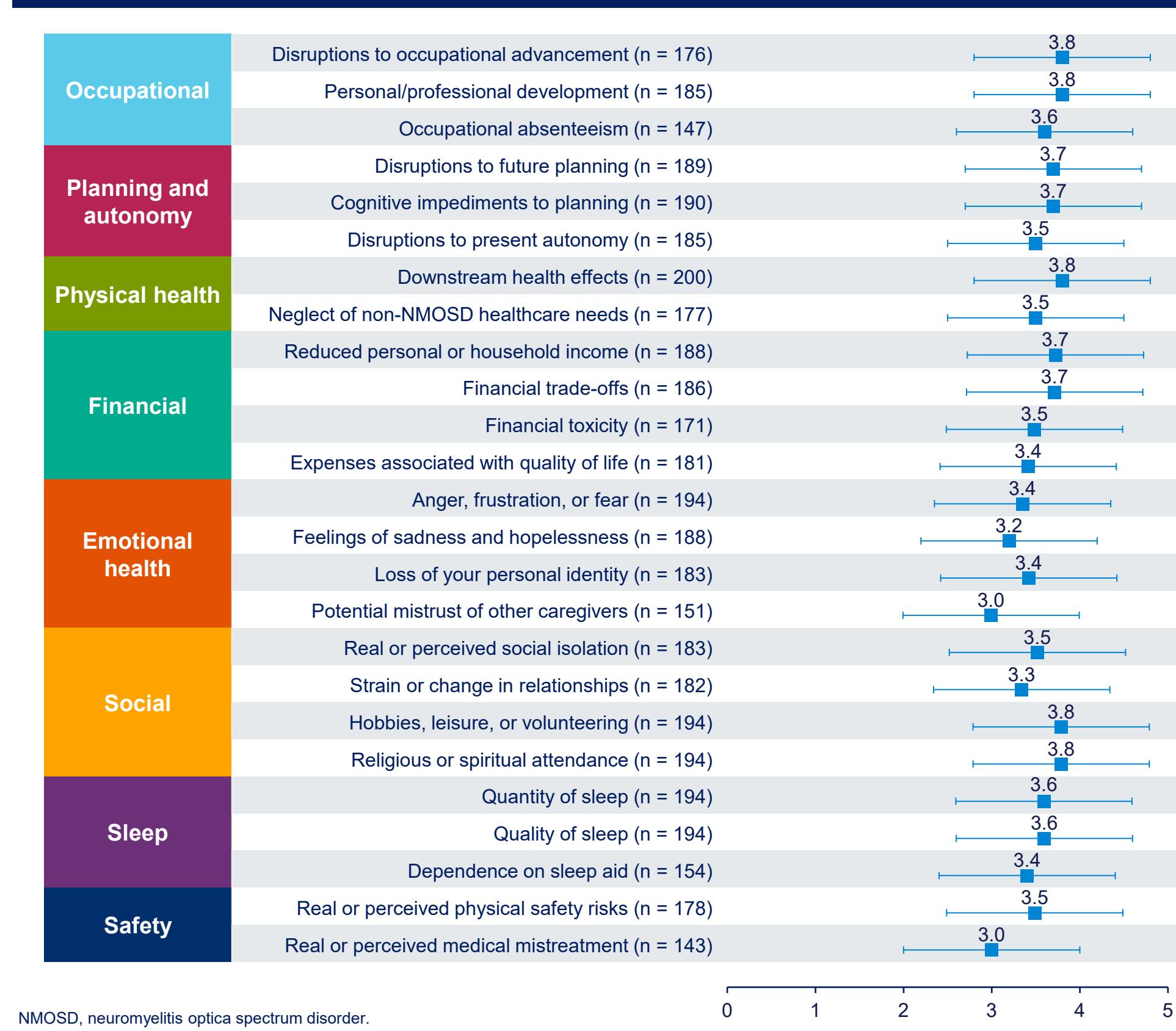
^aIf relevance was not applicable (0), severity was coded as 0.

AQP4-Ab+, anti-aquaporin-4 antibody-positive; NMOSD, neuromyelitis optica spectrum disorder.

RESULTS AND INTERPRETATION

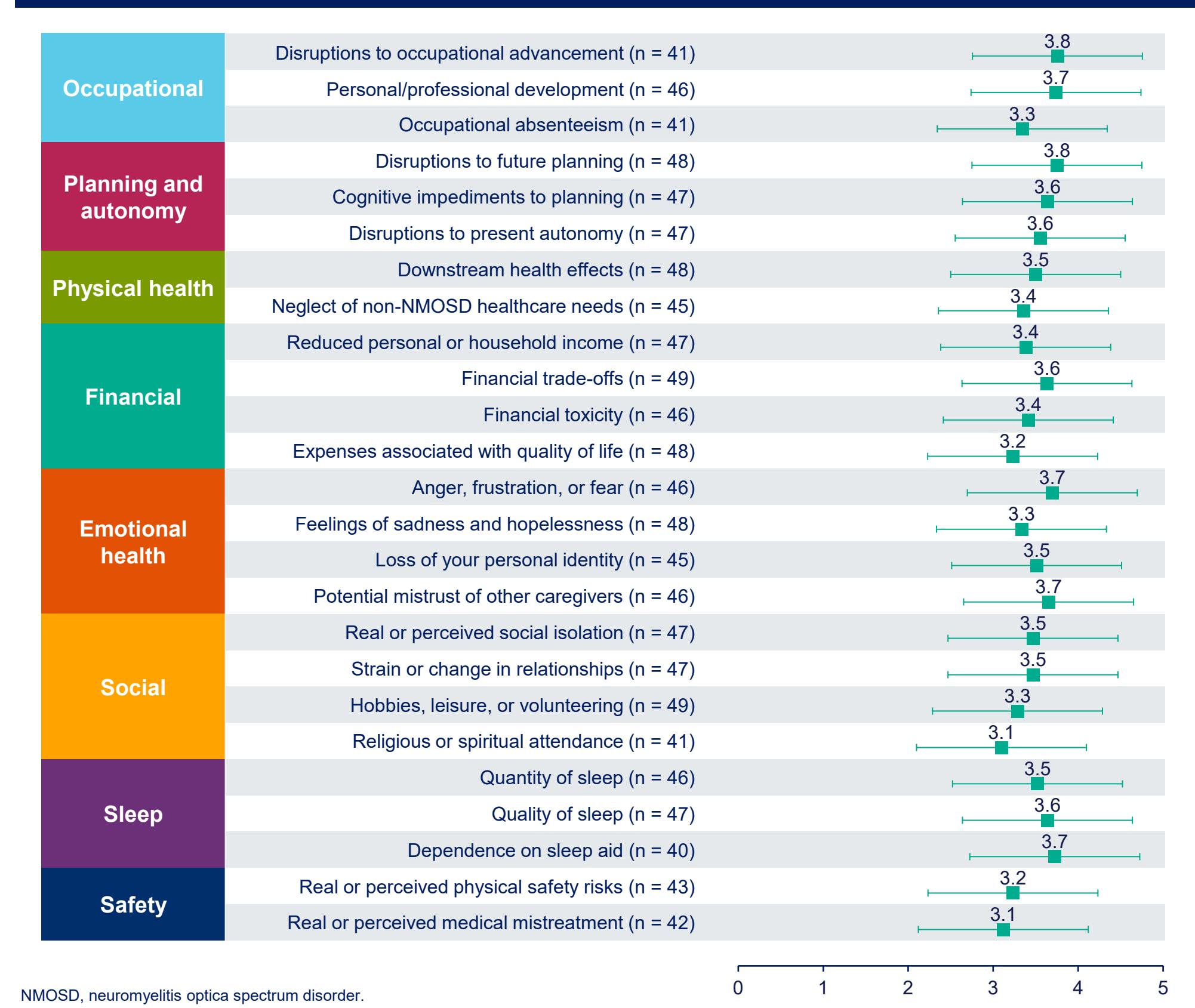
- Among patients, the impact elements with highest severity impact were: personal/professional development; downstream health effects; disruptions to occupational advancement; religious or spiritual attendance; and hobbies, leisure, or volunteering (Figure 2).
- Some variations in the number of elements with the highest severity of impact were observed across subgroups of patients by age (Figure 3A), sex (Figure 3B), and number of relapses (Figure 3C).
- Younger patients reported higher severity of impact on feelings of sadness and hopelessness, and anger, frustration, or fear, compared with older age groups; patients aged 65+ years reported higher severity of impact on real or perceived medical mistreatment and social isolation versus younger age groups (Figure 3A).
- Females reported being more severely impacted than males, with disruptions to occupational advancement and personal/professional development having the highest severity of impact compared with men, who had the highest severity impact in hobbies, leisure, or volunteering; and religious or spiritual attendance (Figure 3B).
- Patients with ≥ 1 relapse in 2023 reported higher severity across 76% (19/25) of impact elements compared with patients without relapse (4%, 1/25), with the largest differences observed in potential mistrust of caregivers; feelings of sadness and hopelessness, and anger, frustration, or fear (Figure 3C).
- Among caregivers, the impact elements with highest severity impact were disruption to occupational advancement and disruption to future planning (Figure 4).
- Disruptions to occupational advancement had increased severity of impact with increased caregiver's age (Figure 5A).
- Male caregivers reported higher severity of impact across more elements (44%, 11/25) compared with females (36%, 9/25) (Figure 5B).
- The impact with the highest severity was dependence on sleep aid for caregivers with full-time employment, personal/professional development for those employed part-time, and disruption to occupational advancement for those unemployed, on disability, or other (Figure 5C).

Figure 2. Patient severity of impact elements



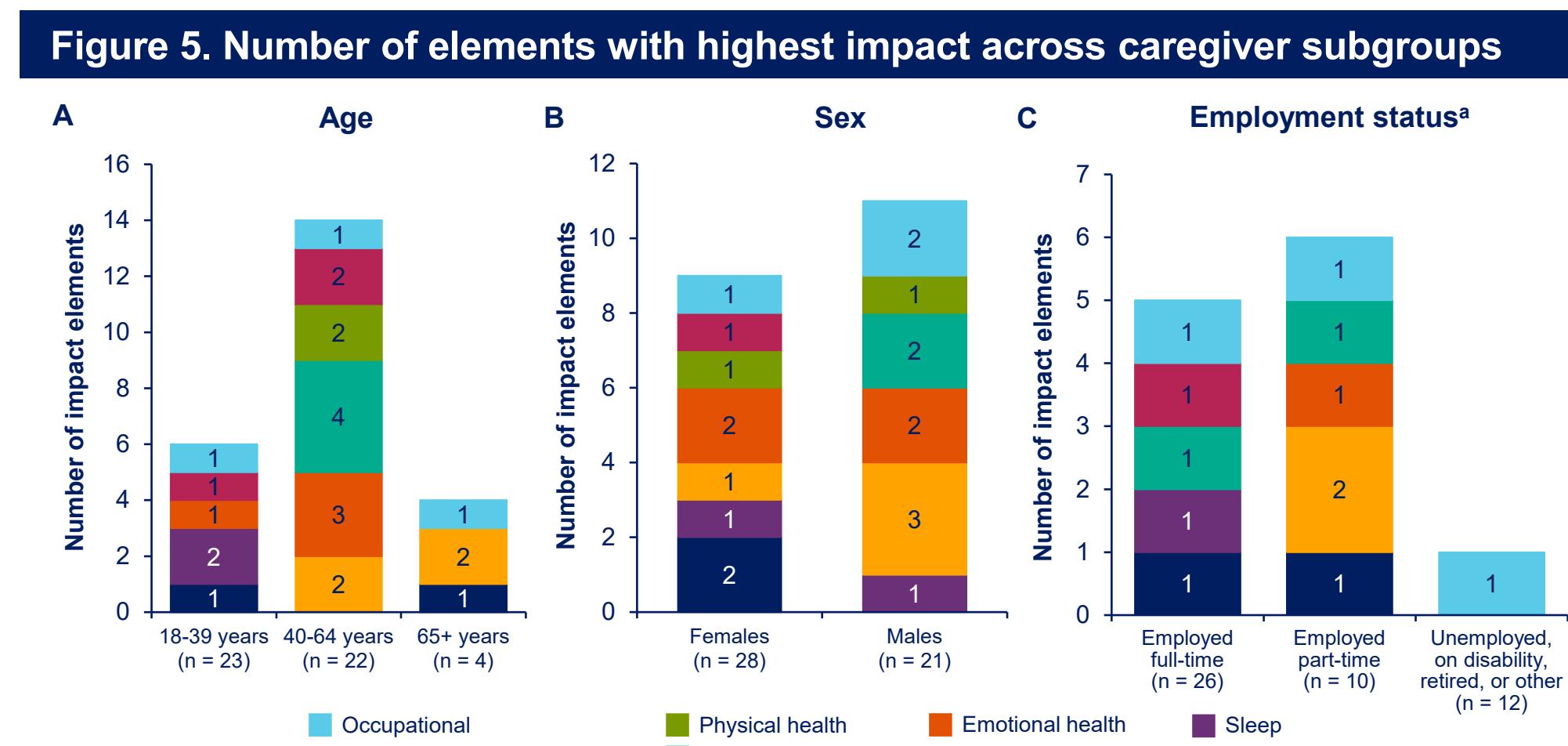
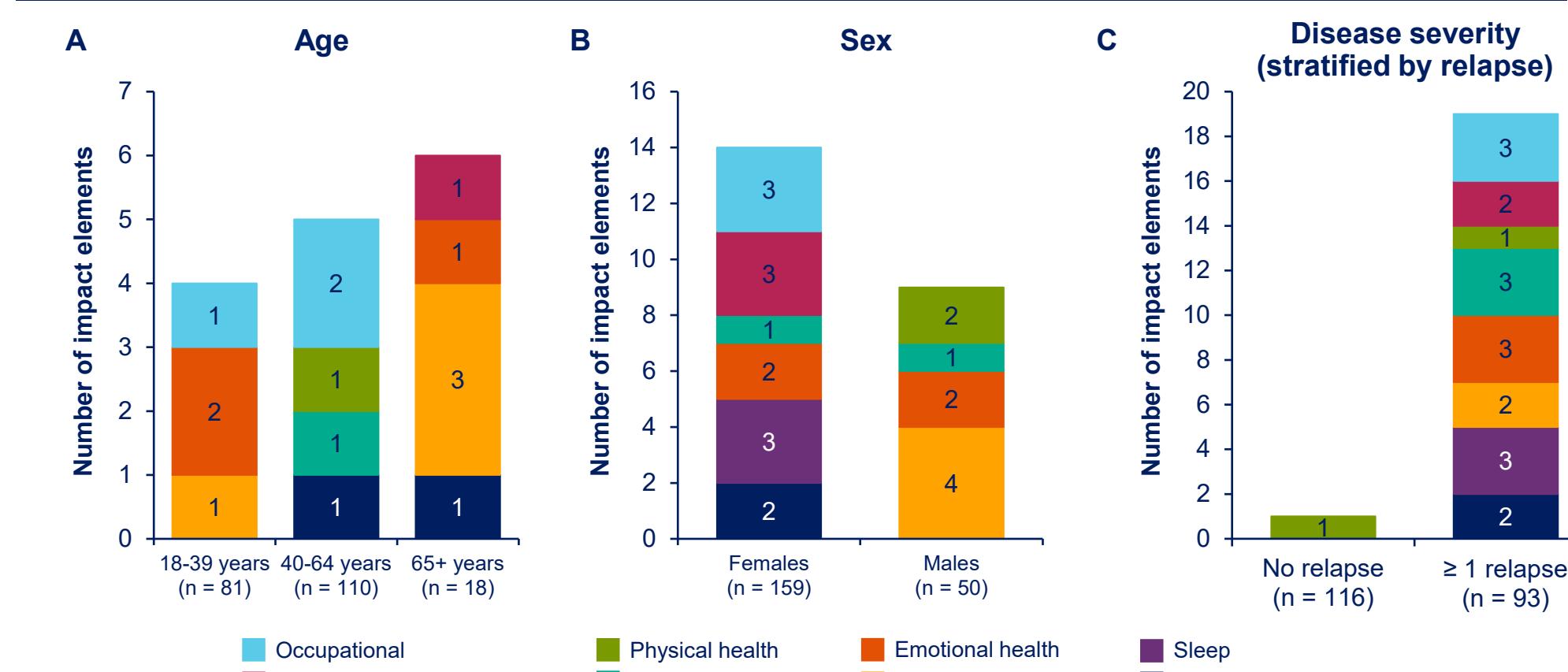
NMOSD, neuromyelitis optica spectrum disorder.

Figure 4. Caregiver severity of impact elements



NMOSD, neuromyelitis optica spectrum disorder.

Figure 3. Number of elements with highest impact across patient subgroups



^aThe seeking work or in school subgroup (n=1) was not included due to small sample size.

Study limitations

- Limitations include convenience sampling, possible variability in interpretation of survey questions, potential of NMOSD symptom variability to influence responses, and ability of respondents to independently complete the survey or recall relevant impacts.
- Efforts were made to mitigate the risks of these study limitations through thoughtful survey question wording, broad outreach, and analytic decisions.

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