

Financial and mental health burden on caregivers of patients with neuromyelitis optica spectrum disorder (NMOSD) in the United States

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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 such as vision loss or paralysis.¹
- Patients with AQP4-Ab+ NMOSD report financial and quality of life impacts due to NMOSD, and in a survey of patients with AQP4-Ab+ NMOSD, 53% of respondents reported needing a caregiver.²

- Caregiving for patients with AQP4-Ab+ NMOSD is associated with substantial cost and psychological burden,^{2,3} and patients with AQP4-Ab+ NMOSD who experience relapse require increased caregiver involvement and dependency.⁴ Therefore, there is still a need for further investigation into the financial and mental health burdens of caring for patients with AQP4-Ab+ NMOSD.

OBJECTIVES

- To assess the incremental income losses associated with caregiving for patients with AQP4-Ab+ NMOSD who reported a relapse in 2023 versus those who did not.
- To evaluate the financial tradeoffs and mental health burdens for caregivers to patients with AQP4-Ab+ NMOSD.

CONCLUSIONS

- Caregivers linked to patients with AQP4-Ab+ NMOSD with a relapse reported increased earning loss due to care responsibilities compared with caregivers of patients without a relapse.
 - These findings underscore the economic impact of AQP4-Ab+ NMOSD on caregivers and highlight the potential for effective relapse-preventing therapies to substantially reduce caregiver burden.
- Overall, caregivers of patients with AQP4-Ab+ NMOSD experience a substantial burden impacting their employment, educational opportunities, and mental health.
- To our knowledge, this study is among the first to provide a comprehensive assessment of caregiver burden across various domains for patients with AQP4-Ab+ NMOSD.

METHODS

- An electronic survey was administered to patients with AQP4-Ab+ NMOSD and caregivers to patients with AQP4-Ab+ NMOSD between January and April 2024 to gather data regarding demographics, their relationship to the patient/caregiver, and cost data for 2023.
 - Eligible patients were adults living in the United States who self-reported to having a diagnosis of AQP4-Ab+ NMOSD.
 - Eligible caregivers were adults living in the United States who self-reported to providing informal care to a patient with NMOSD (AQP4-Ab+ or unknown antibody status to the caregiver) on a regular basis for ≥ 3 months.
 - Patients and caregivers were unpaired.
- Record linkage was performed to integrate patient information with caregiver information to determine the impact of relapse status of the patient on the caregiver. Each caregiver was paired with a patient who most closely matched the caregiver's description of the individual for whom they provided care.
- Impacts on caregivers' income, employment, educational opportunities, and mental health due to AQP4-Ab+ NMOSD were evaluated.

RESULTS AND INTERPRETATION

Caregiver characteristics

- A total of 49 caregivers completed the survey; the majority of caregivers were employed full time with a mean age of 42.1 (SD \pm 13.6) years (Table 1).
- Males provided care to their partners or spouses more frequently compared with females whereas females more frequently provided care to parents or children.

Table 1. Baseline demographics and characteristics

| Characteristic | All caregivers (N = 49) | Male (n = 21) | Female (n = 28) |
|--|-------------------------|---------------|-----------------|
| Patient age, mean (SD) | 48.7 (11.2) | 46.7 (11.4) | 50.1 (11.0) |
| Caregiver age, mean (SD) | 42.1 (13.6) | 41.2 (13.4) | 42.7 (14.0) |
| Weekly average caregiving time, mean (SD), hours | 39.7 (23.3) | 41.6 (27.3) | 38.3 (20.3) |
| Years of caregiving, mean (SD) | 6.7 (6.6) | 5.6 (4.7) | 7.6 (7.8) |
| Education, n (%) | | | |
| Bachelor's degree | 19 (38.8) | 6 (28.6) | 13 (46.4) |
| Graduate degree or higher | 13 (26.5) | 6 (28.6) | 7 (25.0) |
| Prefer not to answer | 3 (6.1) | 1 (4.8) | 2 (7.1) |
| Other | 14 (28.6) | 8 (38.1) | 6 (21.4) |
| Relationship type, n (%) | | | |
| Parent(s)/parent(s)-in-law | 12 (24.5) | 4 (19.0) | 8 (28.6) |
| Spouse/partner | 24 (49.0) | 13 (61.9) | 11 (39.3) |
| Child(ren) | 4 (8.2) | 1 (4.8) | 4 (14.3) |
| Sibling(s) | 7 (14.3) | 3 (14.3) | 4 (14.3) |
| Other | 2 (4.1) | 1 (4.8) | 1 (3.6) |
| Marital status, n (%) | | | |
| Married | 32 (65.3) | 16 (76.2) | 16 (57.1) |
| Other | 2 (4.1) | 0 | 2 (7.1) |
| Prefer not to answer | 4 (8.2) | 1 (4.8) | 3 (10.7) |
| Single (never married) | 11 (22.4) | 4 (19.0) | 7 (25.0) |
| Employment status, n (%) ^a | | | |
| Employed full time | 28 (57.1) | 16 (76.2) | 12 (42.9) |
| Full-time homemaker | 6 (12.2) | 0 | 6 (21.4) |
| Other | 6 (12.2) | 3 (14.3) | 3 (10.7) |
| Employed part-time | 9 (18.4) | 3 (14.3) | 6 (21.4) |
| Part-time caregiver | 4 (8.2) | 1 (4.8) | 3 (10.7) |
| Retired | 5 (10.2) | 2 (9.5) | 3 (10.7) |

^aRespondents were allowed to check more than one option.

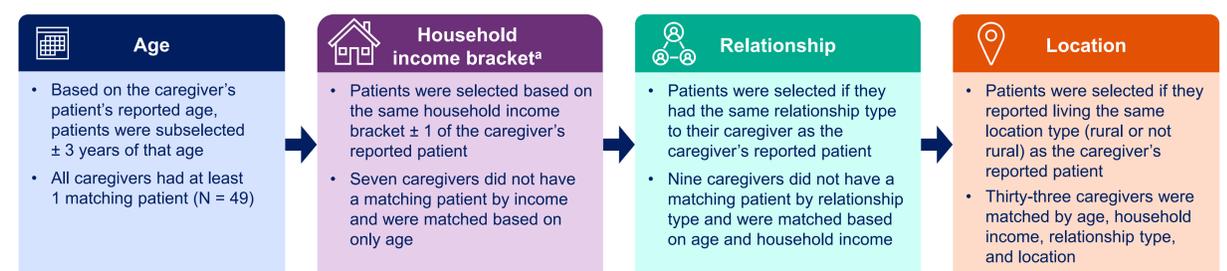
Record linkage and caregiver financial loss associated with patient relapse

- All caregiver respondents were matched with a patient respondent by at least age; 33 were matched by age, household income, relationship type, and location (Figure 1).
- Caregivers linked to patients with a relapse lost approximately US \$171 more weekly per hour of caregiving compared with caregivers linked to patients without a relapse, amounting to an average income loss of US \$7,079/year (Figure 2).

Financial tradeoffs and mental health impacts for caregivers

- For every hour invested in caring per week, the expected yearly caregiver income is reduced by US \$930 ($P = 0.004$, $r = -0.31$) and by US \$1,142 ($P = 0.013$, $r = -0.44$) in the household.
- Principal (main) caregivers report 71% higher impact on their own risk and experience of falls and injuries while providing care than secondary caregivers (Figure 3).
- Providing > 35 hours/week of care was associated with an increased likelihood of occupational change ($P = 0.0018$).
- Of the caregivers who reported stopping work or retiring, 25% (3/12) reported that NMOSD influenced their decision.
- Of caregivers for patients aged > 45 years, 26% (6/23) reported lost educational opportunities due to caregiving.
- Caregivers aged < 40 years reported more frequent loss of personal identity and mistrust of other caregivers or disproportionate sense of responsibility compared with caregivers aged > 40 years (Figure 4).
- Compared with men, women tended to report a higher frequency of impact of downstream health effects due to caregiving (Figure 5).

Figure 1. Record linkage between caregivers and patients



^aIncome brackets in USD: None or insignificant; \$1,000 to \$14,999; \$15,000 to \$24,999; \$25,000 to \$49,999; \$50,000 to \$74,999; \$75,000 to \$99,999; \$100,000 to \$149,999; \$150,000 to \$199,999; and \$200,000 or more.

Figure 2. Caregiver income based on weekly hours of caregiving and stratified by patient relapse

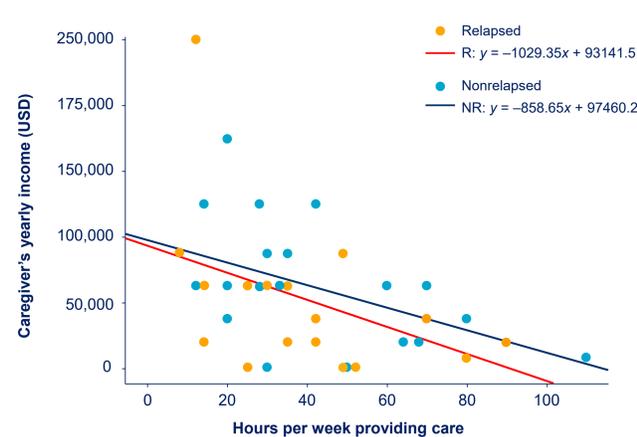
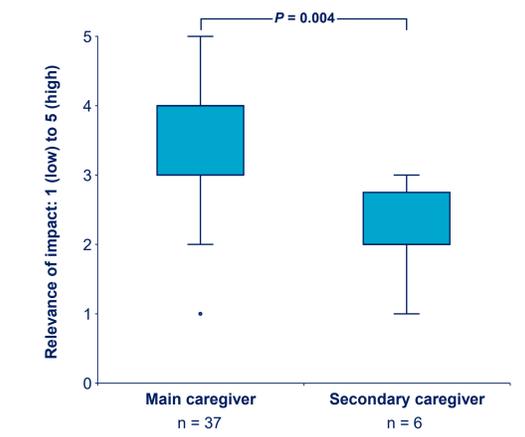
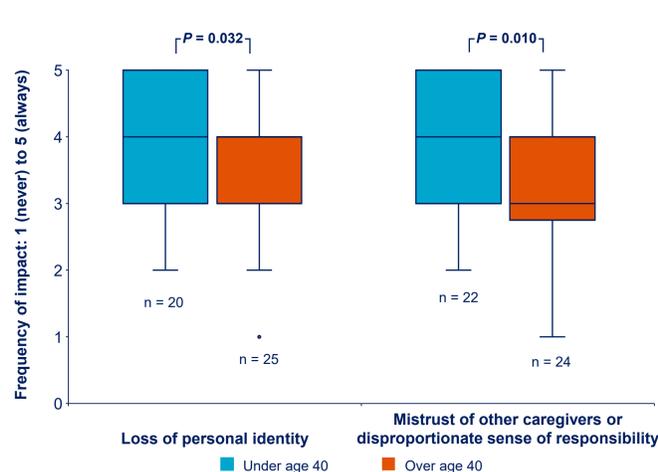


Figure 3. Relevance of perceived physical safety risks due to caring for someone with AQP4-Ab+ NMOSD



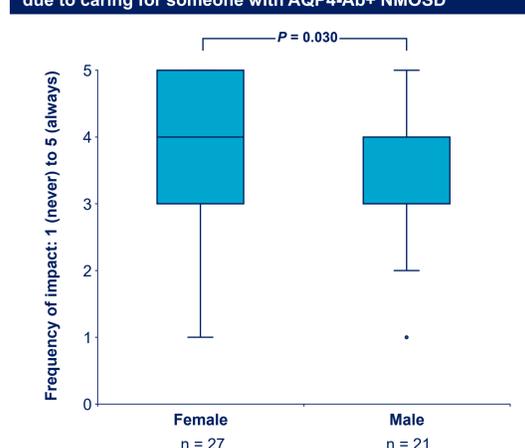
Single data points represent outliers. Data are shown for respondents with answers in the survey. AQP4-Ab+, anti-aquaporin-4 antibody-positive; NMOSD, neuromyelitis optica spectrum disorder.

Figure 4. Frequency of impacts by caregiver age group



Single data points represent outliers. Data are shown for respondents with answers in the survey.

Figure 5. Frequency of impact of downstream health effects due to caring for someone with AQP4-Ab+ NMOSD



Single data points represent outliers. Data are shown for respondents with answers in the survey. AQP4-Ab+, anti-aquaporin-4 antibody-positive; NMOSD, neuromyelitis optica spectrum disorder.

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