

# Impact of NMOSD on Employment: A Global Survey

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## Background & Objectives

- Neuromyelitis optica spectrum disorder (NMOSD) is characterized by recurrent episodes of optic neuritis and transverse myelitis that often lead to chronic neurologic symptoms and disability.
- NMOSD could have a significant impact on employment and personal income but this has yet to be characterized, particularly globally.
- This study aims to depict the impact of NMOSD on employment, job loss, work hours, and wages internationally.

## Methods

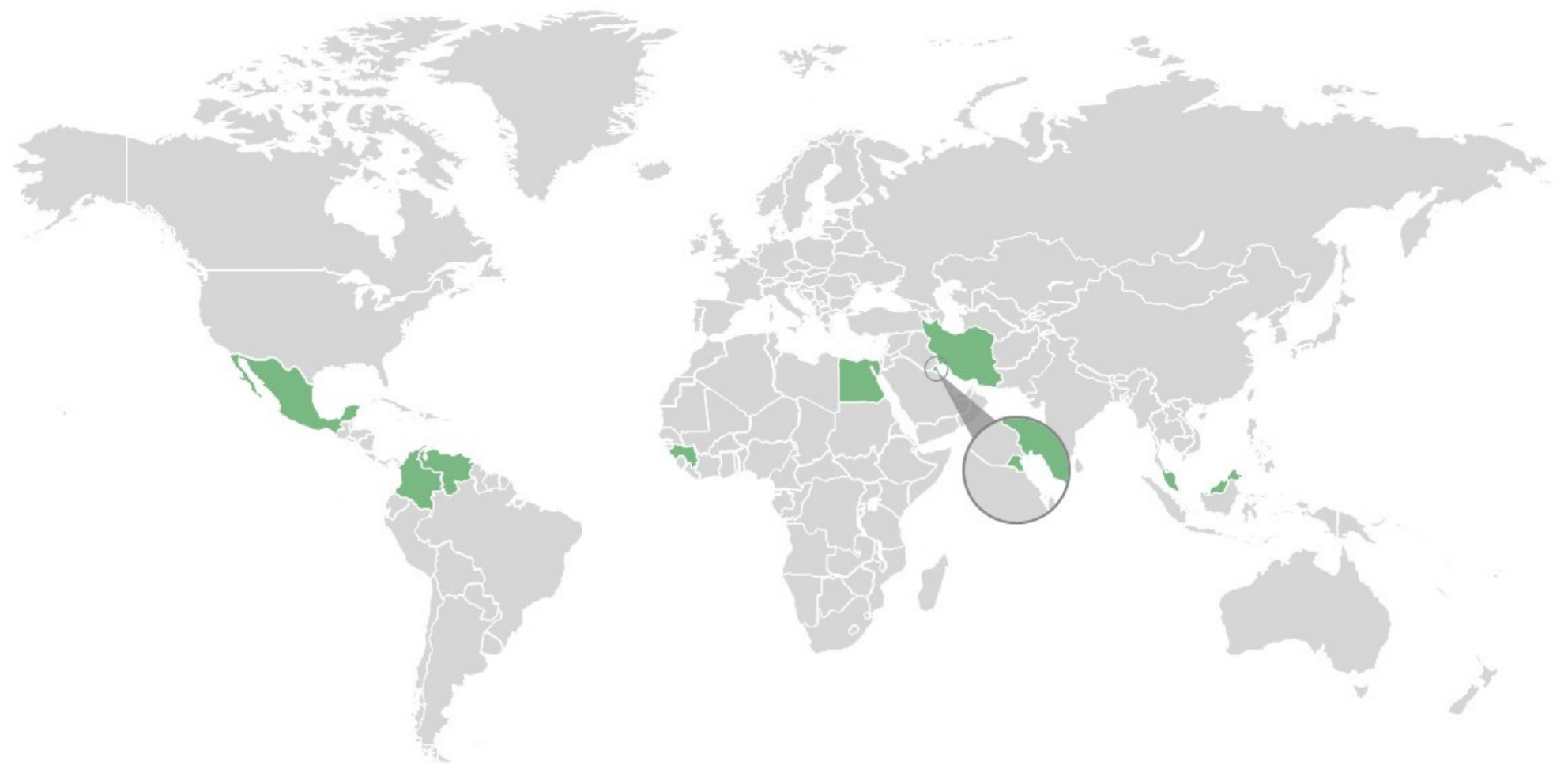
- People ages 18 to 70 years old, diagnosed with NMOSD by a clinician, were asked to complete a one-time survey of approximately 80 questions on REDCap, requiring approximately 30 minutes.
- Participants could be aquaporin-4 antibody seropositive, myelin oligodendrocyte glycoprotein antibody positive, or double seronegative.
- The survey was translated into multiple languages, and inquired about sociodemographic (e.g., age, gender, and education), clinical (e.g., NMOSD disease course), and household economic factors (e.g., employment history, wages, work hours).
- The study aims to enroll up to 500 NMOSD participants, following the same eligibility criteria.
- Data from hospital-based sites in countries of all income levels are targeted.
- Surveys from other countries will also be collected.
- Enrollment for this interim analysis occurred between July 18 to November 3, 2022.
- Descriptive data analyses were performed using Python and Minitab.

## Results

- 158 patients (132 female, 26 male) are enrolled.
- On average, patients have been living with NMOSD for 8.2 years, were diagnosed with NMOSD at 32 years old, and experienced 7.4 attacks since diagnosis.
- 59% were aquaporin-4 antibody seropositive positive, while 12% were myelin oligodendrocyte glycoprotein antibody positive.
- The mean work hours lost per month was 35.6.



**Figure 3.** The number of patients employed dropped 23% after NMOSD diagnosis (from 59.3% pre-diagnosis to 36.1% currently employed).



**Figure 1.** Data from the Republic of Colombia, the Arab Republic of Egypt, the Republic of Guinea, the Islamic Republic of Iran, the State of Kuwait, Malaysia, the United Mexican States, and the Bolivarian Republic of Venezuela have been gathered to date.



**Figure 2.** 58% of patients have lost a job due to symptoms or obligations related to NMOSD, and 65% report reducing their work hours since diagnosis. On average, patients lost more than half of their income after diagnosis (55%).

- Excluding patients who completely lost their job, those who are currently able to work outside the home saw a mean estimated income loss of 36%.
- Only 15% of patients reported disability status.
- At home, 70% of patients report having a regular unpaid caretaker, of whom almost half (49%) changed their work hours or job to support the patient.
- 20% of caretakers reduced their work hours (mean = 17.2 hours less per week), while 9% increased their work hours (mean = 10.4 hours more per week).

## Conclusions

- In a global sample of patients, NMOSD leads to increased unemployment as well as decreased income.
- Among those who remain employed, NMOSD is also associated with decreased work hours.
- There is also a secondary negative impact on household employment.

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