Costs and Health-Related Quality of Life in Patients With NMO Spectrum Disorders and MOG-Antibody–Associated Disease

CHANCE NMO Study

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Study Question
What are the socioeconomic burden and the health-related quality of life (HRQoL) of patients with neuromyelitis optica spectrum disorders (NMOSD) and MOG-antibody–associated disease (MOGAD)?

What Is Known and What This Paper Adds
Few studies have examined the costs and HRQoL of patients with the rare autoimmune disease NMOSD, but to date, there is a lack of specific data considering the clinical presentation, its impact on the personal and professional lives of patients, including the need for (informal) care, and the overall costs of the disease. For MOGAD, there are no relevant data on costs and HRQoL to date. The results of this investigation from the era without approved preventive immunotherapies for NMOSD and MOGAD show enormous effects of the disease on costs and quality of life and might be helpful for estimating the impact and cost-effectiveness of new therapeutic approaches.

Methods
This nationwide multicenter cross-sectional study used a paper-based questionnaire to collect detailed data from 212 adult patients with NMOSD diagnosed according to the 2015 International Panel for NMO Diagnosis criteria and MOGAD on demographics, professional activity, retrospective consumption of medical and nonmedical resources, and HRQoL captured by the EuroQoL EQ-5D-5L questionnaire. Additional clinical data were retrieved from the NEMOS database. Costs were analyzed from the societal perspective and by use of a microcosting method. For statistical analyses, patients were stratified by disease severity and serostatus. Multivariate analyses were performed to identify influencing factors on costs and HRQoL.

Results and Study Limitations
Of 275 available patients, analysis of 212 patients showed that total annual costs rose significantly with increasing disease severity, from €34,992 (US $41,291) in the mildly affected group (Expanded Disability Status Scale [EDSS] score 0–3) to €129,687 (US $153,031) in the severely affected group (EDSS score 6.5–8.5) (Figure). The most important cost driver was informal care with 28% of total costs. The HRQoL was substantially impaired with a mean EQ-5D-5L index value of 0.693 (95% CI 0.65–0.73) and exhibited a negative correlation with disease severity (ρ = −0.69, 95% CI −0.76 to −0.61). The antibody status did not influence total annual costs or HRQoL. Limitations of the study include the risk of recall bias due to patient self-report in the questionnaire and possible selection bias due to the possible refusal to participate of more severely affected patients.

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This study did not receive targeted funding. Some authors report receiving speaking fees, personal compensation, research support, and travel funds from commercial interests. Go to Neurology.org/N for full disclosures.
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