



Identifying patients with High Economic Burden Using Real-World Data – the case of Myasthenia Gravis (MG)

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Objective

- To utilise real-world data to identify MG patients with a high economic burden potential.

Background

- MG is a rare neuromuscular disease characterized by variable degrees of skeletal muscle weakness, with an incidence of 10-15 persons per million per year [1].
- There is a large variation in the severity of symptoms and disease progression in MG patients. Our previous research demonstrated an uneven distribution of health care needs and economic burden among MG patients [2].
- Generalised MG often requires long-term treatment with corticosteroids and immunosuppressants. Some patients need intravenous immunoglobulin (IVIg) treatment to control symptoms during myasthenic crises, before surgery, or in response to other medical challenges.
- For many novel treatments, reimbursement is restricted to patients with high economic burden. Thus, it is important to identify and understand different patient populations. This is particularly important for rare diseases where data availability is limited.
- We aimed to utilise mandatory, nationwide patient-level registry data from Norway to identify patients with high economic burden, using IVIg treatment as a marker for health care needs.

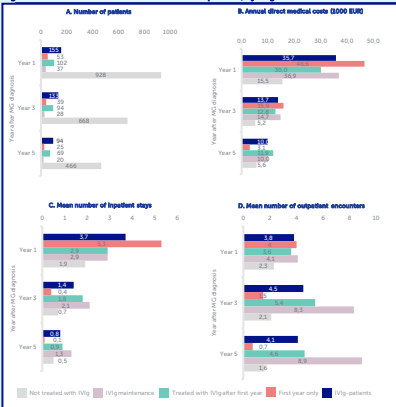
Methods

- Patient-level data were obtained from the Norwegian Patient Registry (NPR) for all MG patients in contact with a Norwegian hospital from 2008 through 2021.
- Incident MG patients were identified in the NPR based on the presence of at least two hospital encounters with an MG diagnosis code (ICD-10 G70.0) during 2010-2021, excluding patients with MG recorded in 2008 and 2009.
- IVIg treatment was identified by procedure (RPGM05) and ATC codes (J06BA02).
- Patients were divided into five groups based on treatment with IVIg following MG diagnosis:
 - all IVIg patients
 - patients treated with IVIg only during the first year
 - patients treated with IVIg the second year or later
 - patients treated with IVIg as maintenance treatment
 - non-IVIg patients
- Maintenance treatment was defined as IVIg treatment in at least three unique months during a 12-month period.
- Resource utilisation and direct medical costs were estimated using Diagnosis-Related Group (DRG) cost weights.

Results

- Among the 1,083 incident MG patients, 14% (N=155) were treated with IVIg. 4.9% (N=53) received IVIg only in the first year, 9.4% (N=102) were treated with IVIg in the second year or later, and 3.4% (N=37) received IVIg maintenance treatment.
- MG-related inpatient stays and outpatient encounters were 2.8-fold higher for IVIg patients compared with non-IVIg patients. IVIg patients had 3.3-fold higher direct medical costs during follow-up.
- Direct medical costs per patient were EUR 95,364 for all IVIg patients, EUR 71,934 for those receiving IVIg in the first year only, EUR 107,538 for patients treated with IVIg in the second year or later, EUR 111,148 for patients on IVIg maintenance treatment, and EUR 28,952 for non-IVIg patients.
- In the fifth year after diagnosis, IVIg-patients still had higher costs and resource utilisation than non-IVIg patients (EUR 9,953 vs. EUR 5,634) (Figure 1)

Figure 1 Health care utilisation and costs in MG patients, by IVIg use



Limitations

- Hospital encounters may be registered with an MG diagnostic code by mistake, or MG may be misdiagnosed. To avoid including non-MG patients, we applied strict criteria to identify MG patients (at least two encounters) that should favour diagnostic specificity over sensitivity.
- Subcutaneous immunoglobulin (SCiG) was not included as we were not able to link prescription data to NPR data. However, Norwegian prescription data alone show that only a small proportion (1.4%) of the Norwegian MG patients received SCiG during the study period.
- Our study only considered resource utilisation and health care costs related to hospital treatment. Primary care resource utilisation, prescription drug use, and other societal costs were not included due to lack of data. As a result, the overall health care utilisation and costs are likely to be higher.
- Our evaluation of costs was undertaken before any complement inhibitors and FcRn blockers were available in Norway.

Conclusions



IVIg treatment is a significant indicator of higher resource use and costs in MG.



Real-world data can identify patients with high economic burden that offer a greater scope to reduce costs, thereby facilitating access to innovation and optimising healthcare spending.



This approach can serve as a model for other conditions.

References: 1. Gilhus et al. Tidsskr Den Nor legforening 2016;136:1059-64. 2. Engebretsen et al. Eur J Neurol 2024;31(5).

Abbreviations: MG = myasthenia gravis, IVIG = intravenous immunoglobulin, SCiG = subcutaneous immunoglobulin, NPR = Norwegian Patient Registry, DRG = diagnosis related group, ATC = Anatomical Therapeutic Chemical Classification System, EUR = Euro, ICD-10 = International Statistical Classification of Diseases and Related Health Problems (10th revision).

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