Self-Reported Clinical Characteristics of a US Generalized Myasthenia Gravis Population Treated with Standard of Care Therapy: Results from a Real-World Patient Survey

Authors: Jacqueline Pesa[1], Louis Jackson[1], Gregor Gibson[2], Hannah Connolly[2], Shiva Lauretta Birija[2], Beth Poirrette[2], Amy Foster[2], Raghav Govindarajan[3]
Affiliation: [1]Johnson & Johnson, Horsham, PA, [2]Adelphi Real World, Bollington, UK, [3]HSHS Medical Group Multispecialty Care - St. Elizabeth's, O'Fallon, IL, United States

Scan the QR code.
The QR code is intended to provide scientific information for individual reference, and the information should not be altered or reproduced in any way.

Objective

To explore characteristics among generalized myasthenia gravis patients treated with standard of care (SOC) therapies.

Key Takeaways

gMG patients treated with standard of care therapies self-reported high MG-ADL scores, frequent MG-related clinical events and persistent symptoms, highlighting an ongoing unmet medical need.

These findings suggest that a substantial proportion of gMG patients may benefit from consideration of advanced therapies to achieve sustained symptom control and reduce the frequency of MG-related clinical events.

Background

- Generalized myasthenia gravis (gMG) is a subtype of autoimmune myasthenia gravis, a rare chronic condition characterized by muscle weakness and fatigue.[1]
- There is no cure for MG and despite the availability of novel treatments, many patients are still managed with traditional standard of care (SOC) therapies, including acetylcholinesterase inhibitors, steroidal and non-steroidal immunosuppressants and immunoglobulins, despite clinically significant events, including myasthenic crises and symptom exacerbations.
- The Myasthenia Gravis Activities of Daily Living (MG-ADL) is a measure of functional status and is often used to measure treatment response in clinical trials and observational studies and may be included in the restrictions for use of certain novel therapies.[2]

Methods

- Data were drawn from an online survey of gMG patients conducted by Adelphi Real World in October 2024.
- Patients were recruited via the US-based Rare Patient Voice and confirmed their eligibility via an online screener. Patients were required to be over 18 years old and self-confirmed their diagnosis of gMG. For this study only those patients prescribed SOC at time of survey were included.
- Patients self-reported their demographics, clinical characteristics, including MG-ADL, MGFA Classification and crises/exacerbations in the 12 months prior to survey, currently prescribed treatment and treatment satisfaction.
- Descriptive statistics are presented.

- ***Overall, 157 patients were included with a mean (standard deviation; SD) age of 49.5 (14.4) years. Patients were 87.3% female and had a mean age of 38.7 (16.4) years at diagnosis.***
- ***Respectively, 38.9% reported being in Myasthenia Gravis Foundation of America class II, 50.3% reported being in class III and 10.8% in class IV.***
- ***Mean (SD) MG-ADL score was 8.5 (3.4) with 86.6% of patients reporting a calculated total score ≥5.***
- ***Demographics are also reported in Table 1 split by those reporting MG-ADL scores ≤4 and ≥5.***

Results

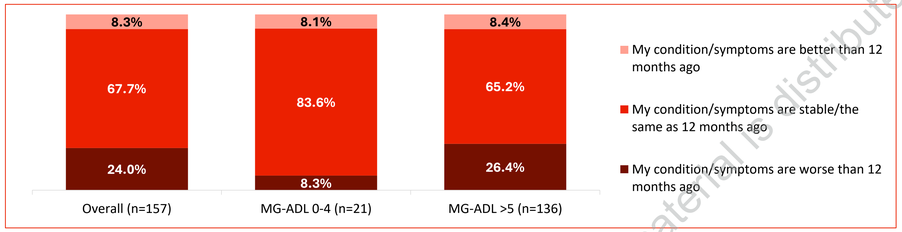
Table 1. Self-reported gMG patient demographics, MGFA classification and MG-ADL score at time of survey, split by MG-ADL scores ≤4 and ≥5:

	Overall	MG-ADL ≤4	MG-ADL ≥5
Base, n=	**157**	**21**	**136**
Demographics			
Age; years, mean (SD)	49.5 (14.4)	53.5 (18.0)	48.9 (13.7)
Female, n (%)	137 (87.3)	15 (71.4)	122 (89.7)
MGFA classification			
Class II, n (%)	61 (36.1)	14 (69,9)	47 (31.0)
Class III, n (%)	79 (57.5)	6 (26.8)	73 (62.1)
Class IV, n (%)	17 (6.4)	1 (3.3)	16 (6.9)
MG-ADL			
Total score, mean (SD)	8.5 (3.4)	3.0 (1.0)	9.4 (2.7)
Age at diagnosis, n	154	21	133
Age at diagnosis, years; mean (SD)	38.7 (16.4)	42.3 (19.7)	38.1 (15.8)

gMG; Generalized Myasthenia Gravis, MGFA; Myasthenia Gravis Foundation of America, MG-ADL; Myasthenia Gravis Activities of Daily Living, SD; Standard Deviation

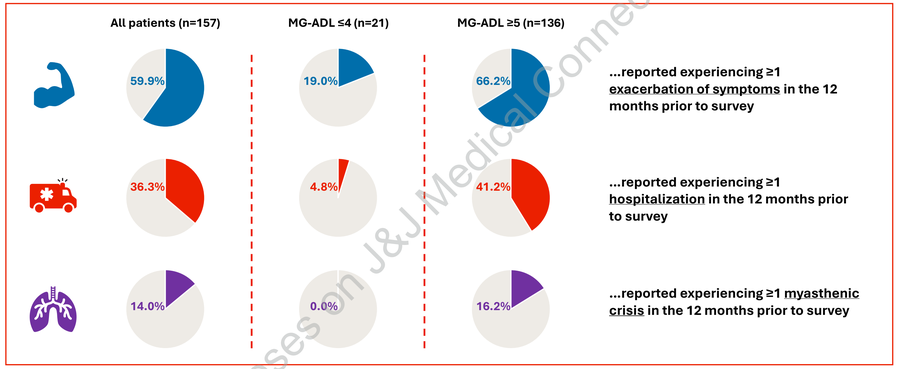
- ***The most frequently reported symptoms were physical fatigue (91.7%), weakness in arms (72.0%) and weakness in legs (72.0%).***
- ***Compared to 12 months prior to survey, 26.4% of patients with an MG-ADL score of >5 felt that their condition/symptoms had worsened, compared to 8.3% of those with an MG-ADL score of ≤4 (figure 1).***
- ***In the 12 months prior to survey, 59.9% of patients reported experiencing at least one symptom exacerbation, 36.3% reported at least one hospitalization and 14.0% reported a myasthenic crisis (figure 2).***
- ***The mean (SD) number of exacerbations in the 12 months prior to survey for patients with a MG-ADL score >5 was 6.8 (13.2) and 1.0 (3.9) for those with a MG-ADL score of ≤4.***

Figure 1. Self-reported gMG condition/symptom status compared to 12 months prior, split by MG-ADL scores ≤4 and ≥5:



gMG; Generalized Myasthenia Gravis, MG-ADL; Myasthenia Gravis Activities of Daily Living

Figure 2: Percentage of gMG patients self-reporting to have experienced at least one symptom exacerbation, hospitalization and myasthenic crisis in the 12 months prior to survey by MG-ADL≤4 and ≥5:

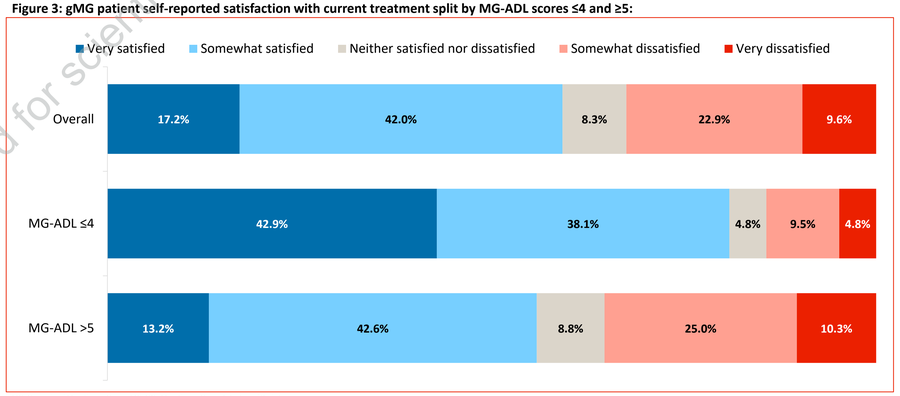


gMG; Generalized Myasthenia Gravis, MG-ADL: Myasthenia Gravis Activities of Daily Living.

An exacerbation of symptoms was defined as the sudden flare-up of symptoms not needing breathing support and myasthenic crisis was defined as the sudden worsening of breathing and swallowing problems meaning breathing support was needed.

- ***Mean (SD) time from prescription of current treatment to survey was 2.9 (4.2) years.***
- ***Overall, 32.5% of patients reported being either dissatisfied or very dissatisfied with their current treatment (figure 3).***
- ***Amongst patients with MG-ADL scores ≤4, 81.0% reported being satisfied or very satisfied with their current treatment. In patients with a MG-ADL ≥5, 55.8% reportedly similarly.***

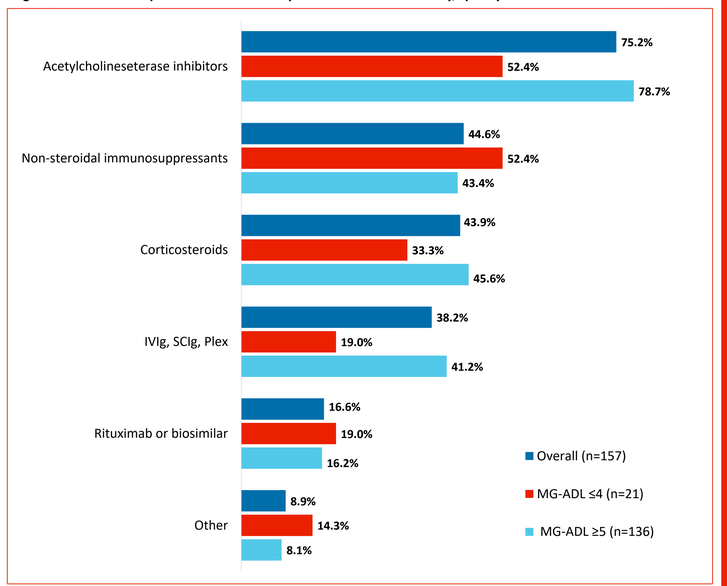
Figure 3: gMG patient self-reported satisfaction with current treatment split by MG-ADL scores ≤4 and ≥5:



gMG; Generalized Myasthenia Gravis, MG-ADL; Myasthenia Gravis Activities of Daily Living

- ***At time of survey, 75.2% of patients reported they were prescribed acetylcholinesterase inhibitors, more frequently among those with MG-ADL scores ≥5 (78.7%) than those with scores ≤4 (52.4%, figure 4).***
- ***Immunoglobulins and plasmapheresis were more frequently reported among those with MG-ADL scores ≥5 (41.2%) than those with scores ≤4 (19.0%, overall: 38.2%).***
- ***Overall, 26.9% of patients reported their current medication was the only one they had been prescribed for their gMG since diagnosis, more frequently among those with a MG-ADL ≥5 (28.1%) than those with MG-ADL scores ≤4 (19.0%)***

Figure 4: Patient self-reported SOC treatments prescribed at time of survey, split by MG-ADL scores ≤4 and ≥5:



SOC; Standard of Care therapies, MG-ADL; Myasthenia Gravis Activities of Daily Living, IVIg/SCIg/Plex; Intravenous immunoglobulins, Subcutaneous immunoglobulins or Plasmapheresis

This material is distributed for scientific purposes on J&J Medical Connect and is not for promotional use

PRESENTED AT: *American Academy of Neurology (AAN), April 18th - 22nd 2026, Chicago, Illinois.*

REFERENCES: *1. Phillips WD, Vincent A, F1000Res. 2016;5:F1000 2. Menon D, et al. Front Neurol. 2020;11:538.*

ACKNOWLEDGMENTS: *The data collected during this patient survey is owned by Adelphi Real World. This secondary analysis of the data was funded by Johnson & Johnson.*

DISCLOSURES: *JP and LJ are employees of Johnson & Johnson. GG, HC, SLB, BP and AF are employees of Adelphi Real World. RG is on the advisory board for Argenx, UCB and Janssen and serves as speaker for Argenx and Alexion.*