Physician, Patient and Caregiver Concordance in a Real-World US Generalized Myasthenia Gravis Population

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BACKGROUND

- Generalized myasthenia gravis (gMG) is a rare, autoantibody-mediated condition of the neuromuscular junction[1]
- Symptoms of muscular weakness and fatigue impair a patient's ability to perform activities of daily living (ADL), affecting quality of life and potentially leading to reliance on caregivers[2,3]
- Treatment usually involves symptomatic or immunosuppressive drugs, although newer targeted therapies are also available[4]
- Despite treatment, symptoms persist for a portion of patients[5]

OBJECTIVE

- To explore concordance between physicians, patients and caregivers relating to overall quality of life (QoL), symptomology and treatment satisfaction in a United States gMG population

METHODS

- Data were drawn from the Adelphi gMG II Disease Specific Programme™ (DSP)[6-9], a cross-sectional survey conducted from February–August 2024 in the United States
  - Physicians with a primary specialty of neurology treating ≥1 patient with gMG provided patient-level data via an online survey
  - Patients independently self-reported data via pen and paper forms; caregiver data was obtained for patients willing but unable to provide data for themselves
- Data from patients aged <18 years or currently participating in a clinical trial were excluded
- Outcomes of interest were examined within matched physician-to-patient (PhysPat) and physician-to-caregiver (PhysCare) samples, including QoL, symptomology and treatment satisfaction
- Agreement between physician-reported outcomes and patient- or caregiver-reported outcomes was assessed using correlation analysis as well as weighted and unweighted Cohen's Kappa (**Table 1**)

Table 1. Cohen's Kappa analysis interpretation

Poor agreement	Slight agreement	Fair agreement	Moderate agreement	Substantial agreement	Almost perfect agreement
<0.00	0.00–0.20	0.21–0.40	0.41–0.60	0.61–0.80	0.81–1.00

RESULTS

Patient demographics and clinical characteristics

- There were 37 PhysPat matches, corresponding to a patient population that was 54.1% female, with a mean (SD) age of 59.1 (11.2) years and a mean (SD) time since diagnosis of 5.8 (4.8) years (**Table 2**)
- In addition, 23 PhysCare matches were evaluated, corresponding to a patient population that was 69.6% female, with a mean (SD) age of 46.1 (13.0) years and mean (SD) time since diagnosis of 3.4 (2.5) years (**Table 2**)
- PhysPat and PhysCare patients had a physician-reported mean (SD) Myasthenia Gravis – Activities of Daily Living (MG-ADL) score of 4.1 (2.8) and 6.3 (3.9), respectively, and Myasthenia Gravis Foundation of America (MGFA) classification breakdowns are shown in (**Table 2**)

Table 2. Physician-reported, patient-level demographics for PhysPat and PhysCare samples

	PhysPat (n=37)	PhysCare (n=23)
Age, mean (SD), years	59.1 (11.2)	46.1 (13.0)
Female gender, n (%)	20 (54.1)	16 (69.6)
MG-ADL total score; mean (SD)	4.1 (2.8)	6.3 (3.9)
MGFA classification, n (%)		
Class I	4 (10.8)	4 (17.4)
Class II	28 (75.7)	16 (69.6)
Class III	5 (13.5)	2 (8.7)
Class IV	0 (0)	1 (4.3)
Time since diagnosis (years), n	**29**	**18**
Time since diagnosis, mean (SD), years	5.8 (4.8)	3.4 (2.5)

MG-ADL, Myasthenia Gravis – Activities of Daily Living; MGFA, Myasthenia Gravis Foundation of America.

Quality of Life

- Overall patient QoL was reported as "good" or "very good" by 70.2% of physicians and 54.0% of patients in the PhysPat sample (k=0.6231, substantial agreement) (**Figure 1**), and by 56.5% of physicians and 52.1% caregivers in the PhysCare sample (k=0.6282, substantial agreement) (**Figure 2**)

Figure 1. Physician- and patient-reported patient's overall QOL at time of survey

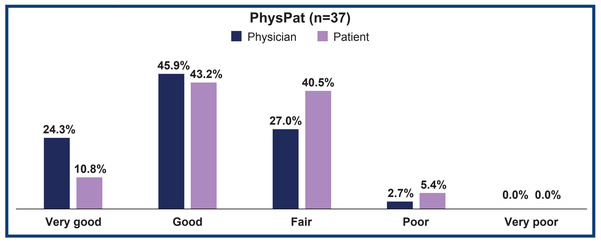
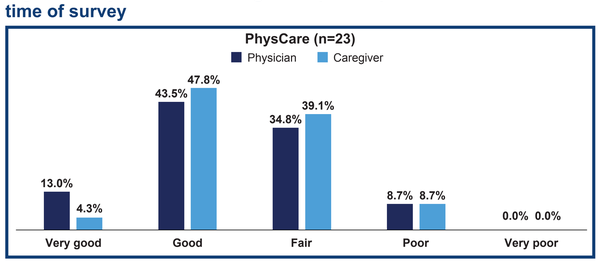


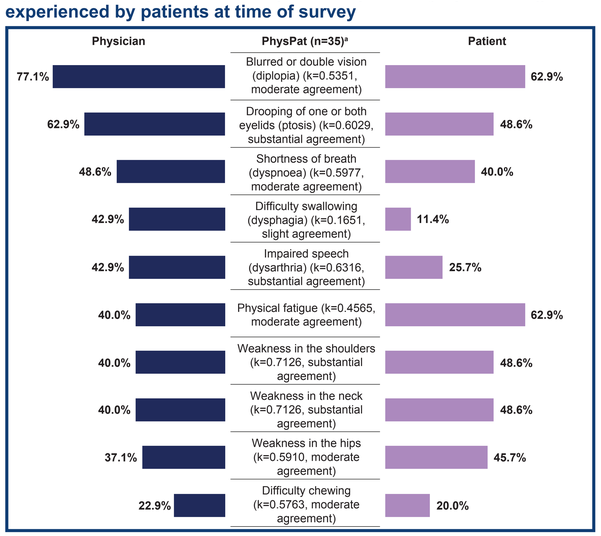
Figure 2. Physician- and caregiver-reported patient's overall QOL at time of survey



Symptomology

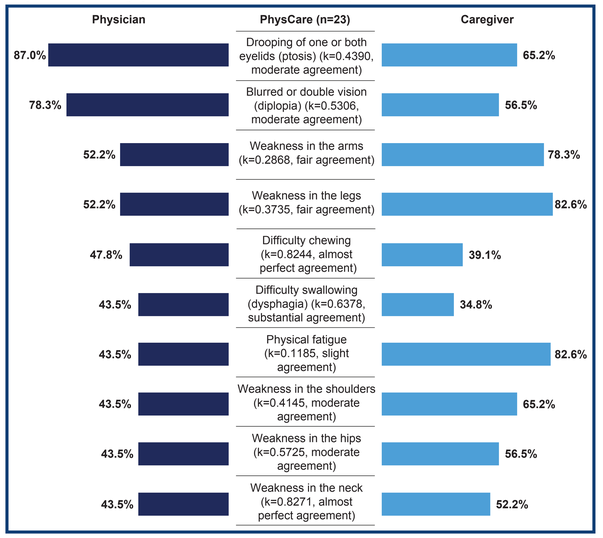
- Patient physical fatigue was reported by 40.0% of PhysPat physicians vs 62.9% of patients (k=0.4565, moderate agreement); in the PhysCare sample, 43.5% of physicians vs 82.6% of caregivers reported physical fatigue (k=0.1185, slight agreement) (**Figures 3 and 4**)
- Diplopia was reported in 77.1% of patients by PhysPat physicians vs 62.9% of matched patients (k=0.5351, moderate agreement); in the PhysCare sample, 78.3% of physicians and 56.5% of caregivers reported patient diplopia (k=0.5306, moderate agreement) (**Figures 3 and 4**)

Figure 3. Top 10 physician- and patient-reported symptoms of gMG experienced by patients at time of survey



[a]Excludes 2 patients who chose not to answer this question. gMG, generalized myasthenia gravis.

Figure 4. Top 10 physician- and caregiver-reported symptoms of gMG experienced by patients at time of survey

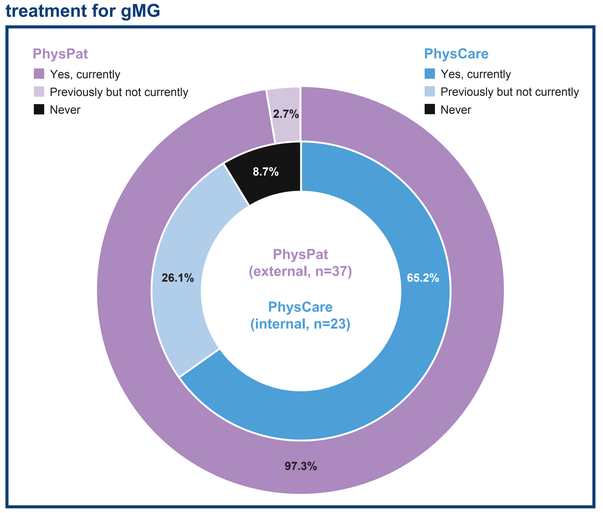


gMG, generalized myasthenia gravis.

Treatment

- Prescriptions for treatment were reported by 97.3% and 65.2% of physicians in the PhysPat and PhysCare samples, respectively (**Figure 5**)
  - Of those, 25.0% (PhysPat) and 53.3% (PhysCare) reported prescriptions for complement inhibitors or neonatal fragment crystallizable receptor inhibitors
- Treatment satisfaction was reported as "neutral" or "dissatisfied" by 13.9% of physicians and 19.5% of patients in the PhysPat sample (k=0.3294, fair agreement), and by 26.6% of both physicians and caregivers in the PhysCare sample (k=0.9032, almost perfect agreement) (**Figures 6 and 7**)
  - Inadequate long-term efficacy was reported as a reason for dissatisfaction by 60.0% and 50.0% of physicians of the PhysPat and Phys Care sample, respectively
  - Patients in the matched PhysPat sample reported availability of better treatment options (n=7, 57.1%) as a reason for dissatisfaction with their current treatment, whereas caregivers reported frequency of administration (n=2, 100%)

Figure 5. Physician-reported status of prescribed maintenance treatment for gMG



gMG, generalized myasthenia gravis.

Figure 6. Physician- and patient-reported satisfaction with patient's maintenance treatment for gMG

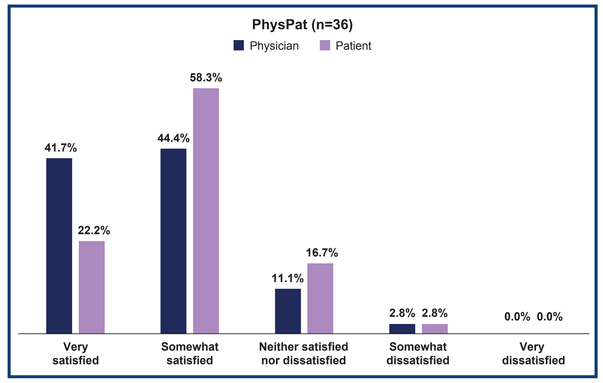
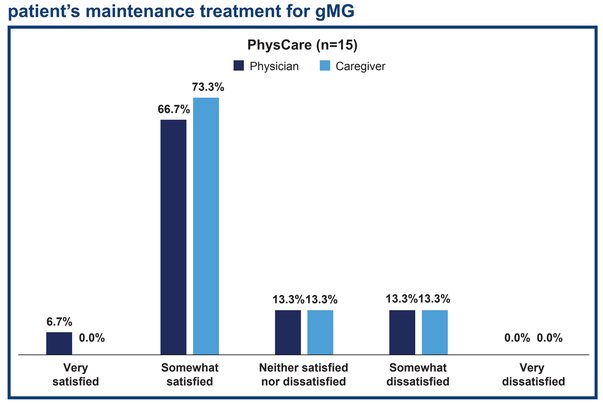


Figure 7. Physician- and caregiver-reported satisfaction with patient's maintenance treatment for gMG



CONCLUSIONS

- **Discordant reporting of QoL and symptoms suggests improvement is needed in the communication between physicians, patients, and caregivers**
- **More treatment options are needed to optimize patient care and improve treatment satisfaction**

LIMITATIONS

- The survey was not based on a true random sample although minimal inclusion criteria governed the selection of the participating physicians, participation was influenced by the physician's willingness to complete the survey, and is therefore considered a convenience sample
- The quality of the data obtained relies on how accurately physicians, patients and caregivers were able to recall and report information

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DISCLOSURES

LAMW, LL and **YE** are employees of Immunovant, Inc. **JC, SLB, HC** and **GG** are employees of Adelphi Real World. Immunovant, Inc., was a subscriber to the survey and did not influence the original survey through either contribution to the design of questionnaires or data collection

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