PicnicHealth

HSD100

Exploring The Path To Diagnosis For Patients With Myasthenia Gravis Using Real-World Data

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Background + Purpose

Background

- Myasthenia gravis (MG) is a neuromuscular autoimmune disorder that causes muscle weakness and fatigability.
- Symptoms can be limited to the eyes (ocular MG) or extend to other parts of the body (generalized MG).
- Symptoms can be vague and fluctuate over time, making MG difficult to diagnose.
- Diagnosis is usually made by a neurologist, after evaluating the presenting symptoms and conducting procedures such as autoantibody testing.
- Because diagnosis can be a complex, multi-step process, patient experiences differ.
- Few real-world studies to date have explored this diagnostic process.

Purpose: This study examines the time between initial presentation of MG symptoms and MG diagnosis using real-world data.

Methods

Data source

- Patients with MG enrolled in PicnicHealth's research platform beginning in August 2021 (enrollment ongoing, data evaluated as of January 2023).
- Participants consented to collection of their medical records across U.S. health systems.
- Structured and unstructured data were abstracted from medical records using human-validated machine learning.

Inclusion criteria

- MG diagnosis on or after January 1, 2010.
- Initial symptom presentation described in records.

Analysis methods

- Demographics were evaluated descriptively.
- Log transformed univariate linear regression models were used to examine the associations of time from symptom presentation to diagnosis, as mediated by:
  - Participant demographics
  - Type of presenting symptoms
  - Antibody status

Patient Presents with Symptoms → **Referral to Specialist** → **Clinical Exam** → **Diagnostic Testing** → **Possible Additional Testing** → **MG Diagnosis**

Table 1: Demographics & clinical characteristics of participants

	Female N = 145	Male N = 75	Overall N = 220
Age	47 (35, 60)	64 (52, 71)	52 (39, 66)
Age at symptom onset	41 (30, 53)	59 (47, 66)	47 (33, 61)
Race			
American Indian or Alaska Native	0 (0%)	1 (1.3%)	1 (0.5%)
Asian	2 (1.4%)	3 (4.0%)	5 (2.3%)
Black or African American	21 (14%)	4 (5.3%)	25 (11%)
More than one race	8 (5.5%)	2 (2.7%)	10 (4.5%)
Prefer not to say	1 (0.7%)	1 (1.3%)	2 (0.9%)
Unknown	3 (2.1%)	3 (4.0%)	6 (2.7%)
White	110 (76%)	61 (81%)	171 (78%)
Ethnicity			
Hispanic or Latino	10 (6.9%)	4 (5.3%)	14 (6.4%)
Not Hispanic or Latino	130 (90%)	67 (89%)	197 (90%)
Prefer not to say	5 (3.4%)	4 (5.3%)	9 (4.1%)
Autoantibody Status[1]	**N = 124**	**N = 61**	**N = 185**
AChR+	70 (56%)	46 (75%)	116 (63%)
AchR-	32 (26%)	14 (23%)	46 (25%)
LRP4+	4 (3.2%)	0 (0%)	4 (2.2%)
MuSK+	7 (5.6%)	1 (1.6%)	8 (4.3%)
Triple seronegative	11 (8.9%)	1 (1.6%)	12 (6.5%)

[1] Limited to patients with at least one antibody test result

Figure 1: Geographic distribution of participants

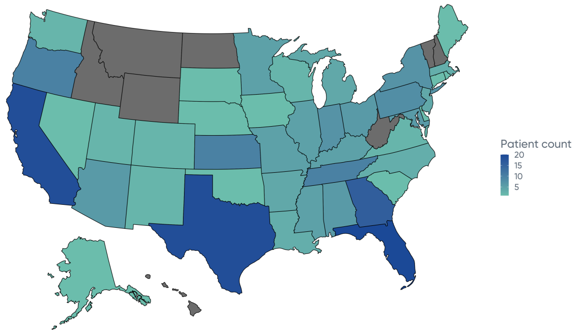


Figure 2: Time to diagnosis by patient characteristics

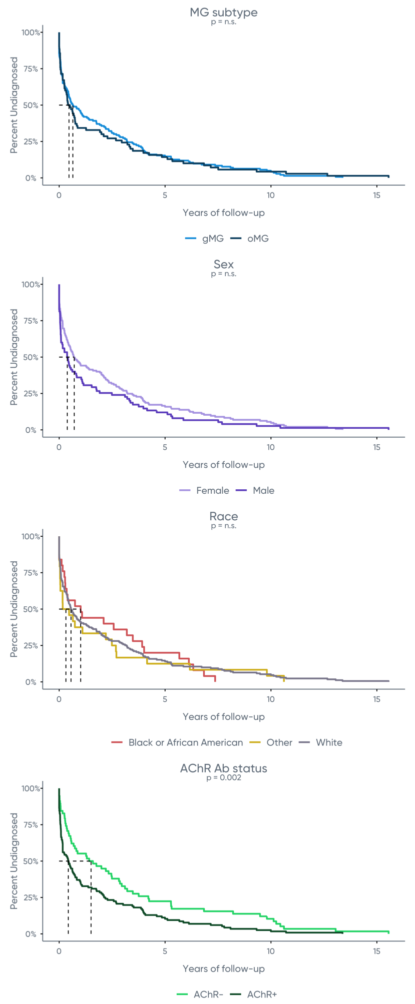


Figure 3: First presenting MG symptoms by sex

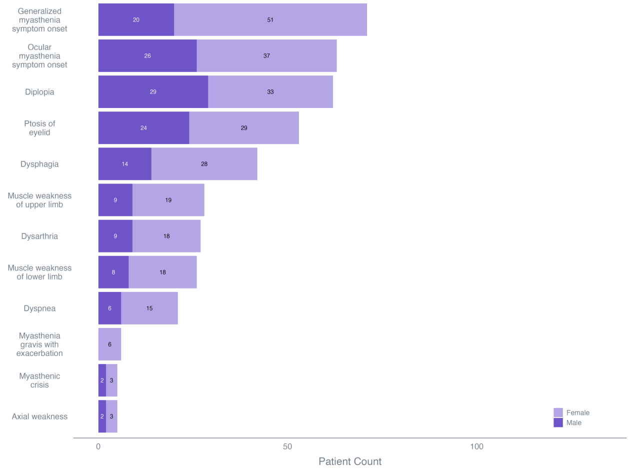
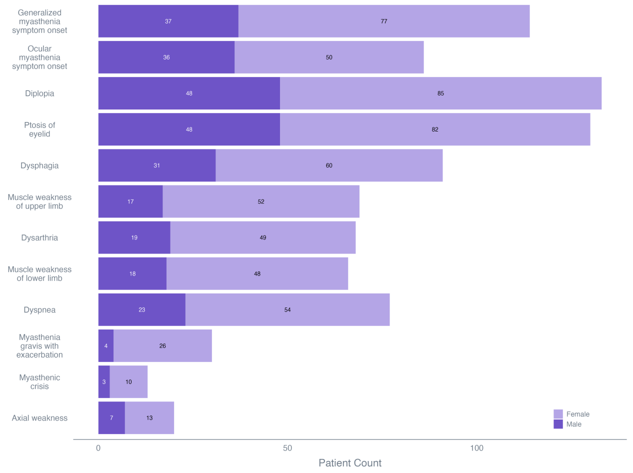


Figure 4: Most common symptoms by sex



Results

- **220 participants** met eligibility criteria [*Table 1*]
  - 66% female, 78% white
  - Median age at enrollment: 52 (IQR: 39-66) years
- **Symptom presentation:**
  - Median age at symptom onset is earlier for females (41) than males (59) [*Table 1*]
  - Most common first symptoms: broad symptoms of generalized MG, broad symptoms of ocular MG, diplopia [*Figure 3*]
  - Most common symptoms over time: Diplopia, ptosis, broad symptoms of generalized MG [*Figure 4*]
- **Median time to diagnosis:**
  - 158 days, but with wide variation (IQR: 16-909)
  - Did not significantly differ by sex, race, or type of symptoms (ocular vs generalized) [*Figure 2*]
- **Antibody data:**
  - ≥1 test available for 185 (84%) participants [*Table 1*]
  - AChR+ status associated with significantly shorter time to diagnosis compared to AChR- ($\beta = -1.24$, $p = 0.002$; median days to diagnosis 103 vs. 450) [*Figure 2*]

Conclusion

- This study suggests that diagnosing MG in real-world clinical practice is a complex and variable process.
- Diagnosis often takes >5 months from symptom presentation.
- Participants with AChR+ MG received more expedient diagnoses.
  - Participants with AChR- MG took an average of 11.5 months longer to diagnose.
- Having symptoms and waiting for a diagnosis can be a stressful time for patients. This study provides some insight into the path to diagnosis for patients with MG across the United States.

Acknowledgements + Disclosures

- The authors would like to acknowledge the participants who made this study possible.
- The authors are employees of PicnicHealth.