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Background + Objective

Background

 Myasthenia gravis (MG), a neuromuscular disorder, results in muscle weakness that fluctuates daily, leading to difficulty in determining overall disease burden.

Objective

 This study investigates the feasibility of collecting patient reported outcomes virtually to quantify disease burden and severity.

Methods

Data Source

- The first patient was enrolled in August 2021 with the most recent enrollment in April 2023.
- U.S. patients with MG were enrolled in PicnicHealth's research platform and consented to collection of their medical records
- Structured and unstructured data were abstracted using human-validated machine learning
- Eligible patients completed the MG Activities of Daily Living Profile (MG-ADL) on PicnicHealth's virtual patient portal within 90 days of enrollment

Methodology

- Patients with baseline MG-ADL responses (scored 0-normal to 24-most severe) were used to categorize disease burden and severity (0-4, mild; 5-9, moderate; 10-24, severe)¹
- Medications prescribed to manage MG that were either ongoing, or started within 90 days of baseline, were used to determine treatment patterns
- Demographics were summarized with descriptive statistics

Table 1: Patient Demographics

Characteristic	Female, N = 173 ¹	Male, N = 76 ¹	Overall, N = 249 ¹	
Race				
American Indian or Alaska Native	1 (0.6%)	0 (0%)	1 (0.4%)	
Asian	6 (3.5%)	2 (2.6%)	8 (3.2%)	
Black or African American	33 (19%)	5 (6.6%)	38 (15%)	
More than one race	5 (2.9%)	1 (1.3%)	6 (2.4%)	
Prefer not to say	2 (1.2%)	0 (0%)	2 (0.8%)	
Unknown	5 (2.9%)	0 (0%)	5 (2.0%)	
White	121 (70%)	68 (89%)	189 (76%)	
Ethnicity				
Hispanic or Latino	13 (7.5%)	3 (3.9%)	16 (6.4%)	
Not Hispanic or Latino	156 (90%)	70 (92%)	226 (91%)	
Prefer not to say	4 (2.3%)	3 (3.9%)	7 (2.8%)	
Age at Enrollment	50 (37, 62)	64 (57, 69)	55 (39, 66)	
Age at Diagnosis	39 (26, 53)	58 (46, 64)	47 (28, 59)	
Total Years of Clinical Documents	7.4 (4.8, 13.1)	6.9 (4.2, 9.5)	7.2 (4.7, 11.5)	
Total Years of Visits	9 (5, 15)	7 (4, 11)	8 (5, 13)	
Number of Providers	21 (10, 41)	19 (7, 33)	20 (10, 38)	
Number of Care Sites	7 (4, 12)	6 (4, 10)	6 (4, 12)	
Number of Hospitalizations	2 (1, 6)	1 (0, 4)	2 (1, 5)	
Total Hospital Days	4 (1, 11)	4 (0, 12)	4 (1, 11)	



Figure 1: Severity Group by Sex

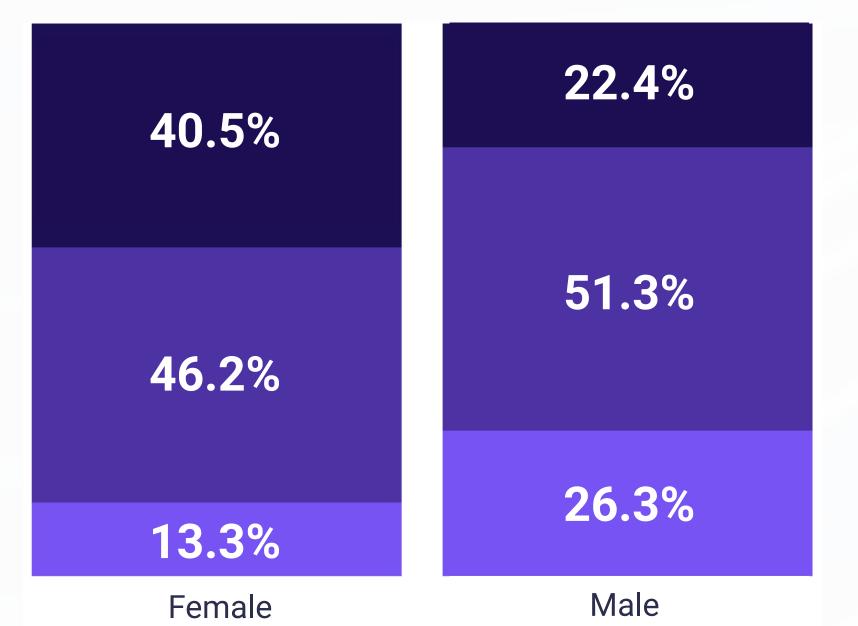
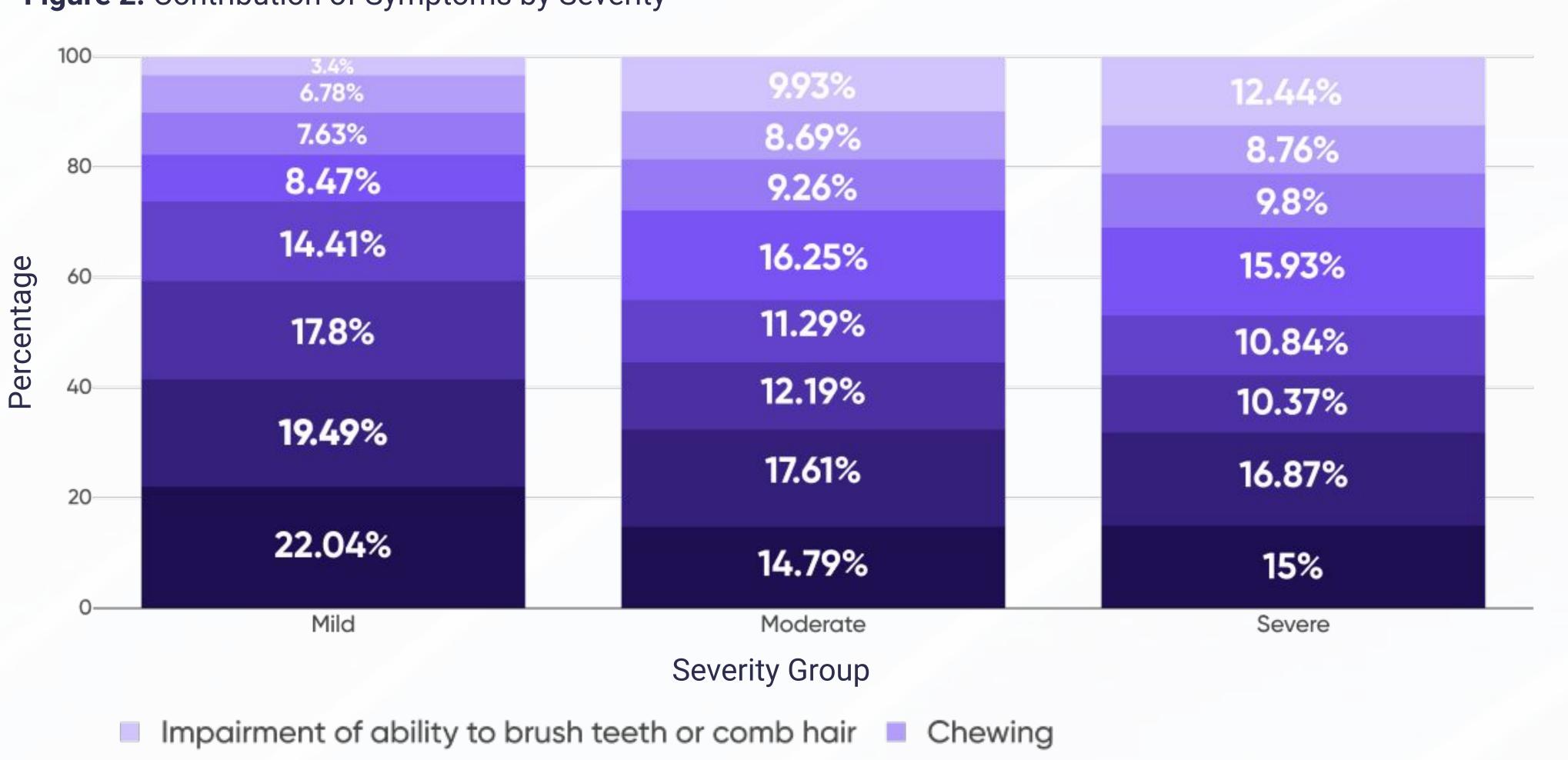


Table 2: MG-ADL Score by Sex

Characteristic	Female, N = 173 ¹	Male, N = 76 ¹	p-value ²
Total MG-ADL Score	9.0 (7.0, 11.0)	7.0 (4.0, 9.0)	<0.001
Severity Group			0.005
Mild	23 (13%)	20 (26%)	
Moderate	80 (46%)	39 (51%)	
Severe	70 (40%)	17 (22%)	

¹ Median (IQR); n (%) ² Wilcoxon rank sum test; Pearson's Chi-squared test

Figure 2: Contribution of Symptoms by Severity



Talking

Swallowing Eyelid droop Double vision

Breathing

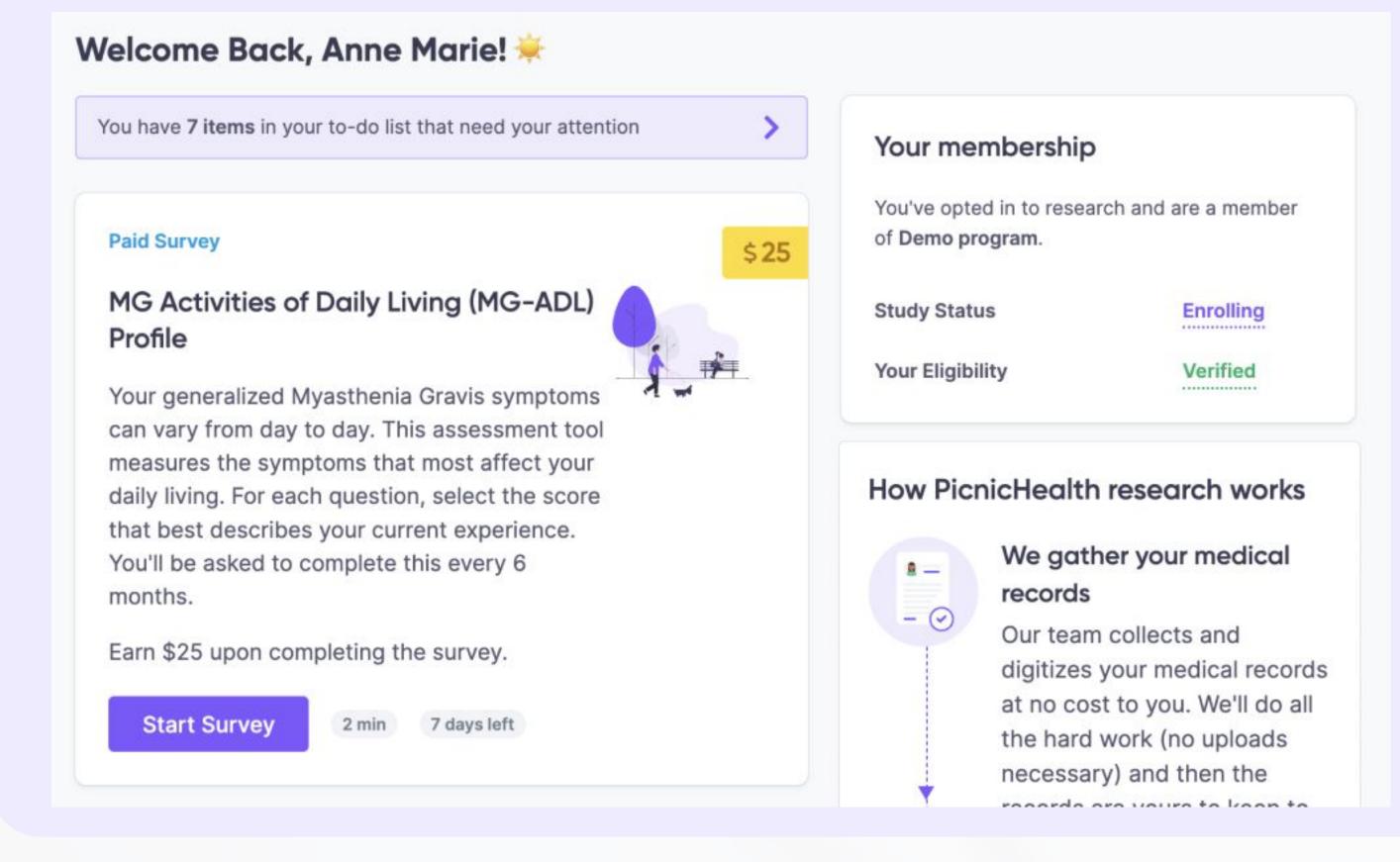
Impairment of ability to arise from a chair

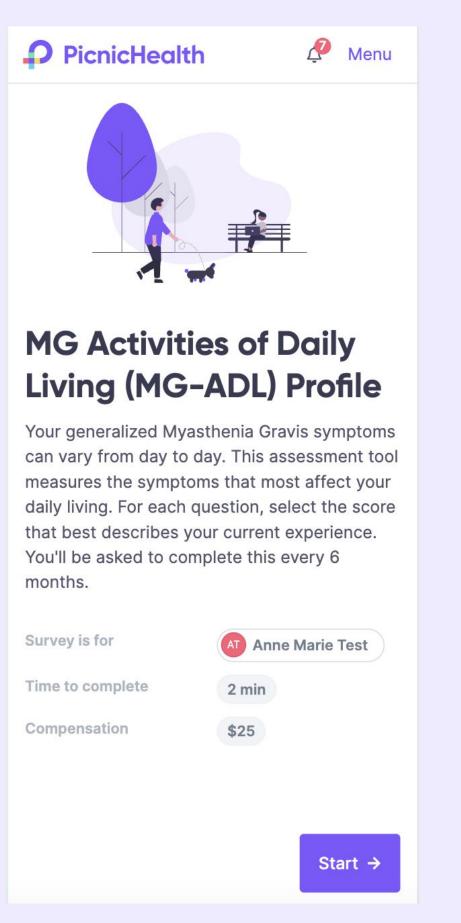
Table 3: MG-related Medication use by Severity Group

Characteristic	Mild, N = 43	Moderate, N = 119	Severe, N = 87	p-value ¹
Number of Unique Medications				0.036
Mean (SD)	1.60 (1.35)	2.11 (1.41)	2.17 (1.42)	
Median (IQR)	2.00 (0.50, 2.00)	2.00 (1.00, 3.00)	2.00 (1.00, 3.00)	

¹ Kruskal-Wallis rank sum test

Patient Portal Views of MG-ADL Surveys





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6. Impairment of ability to arise from a chair
0 - Normal
1 - Mild, sometimes uses arms
2 - Moderate, always uses arms
3 - Severe, requires assistance
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Acknowledgements & Disclosures

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

Results

- Of the 249 eligible patients 70% were female and 77% were White
- Median (IQR) age at diagnosis was 39 (26, 53) for females and 58 (44, 70) for males
- The median total MG-ADL score was 9, with 17%, 48%, and 35% of the cohort classified as mild, moderate and severe, respectively
- The median (IQR) total MG-ADL score was higher for women than men (9 (7, 11) vs. 7 (4, 9), p<0.001)
- Distribution of severity differed between men and women, with women having 13% mild, 46% moderate, and 40% severe, compared to 26% mild, 51% moderate, and only 22% severe in men (p = 0.005).
- Patients classified as mild attributed breathing difficulties, eyelid droop, and rising from a chair most strongly to their total score
- Moderate and severe patients reported symptoms more evenly across domains and the contribution of double vision and impairment with brushing teeth and hair increased
- Mild patients utilized fewer unique treatments than moderate and severe patients with mild patients using on average 1.63 medications, compared to 2.13 medications for moderate patients, and 2.20 mean medications for severe (p = 0.036)

Conclusion

- The MG-ADL survey is an effective way to classify patients with MG into severity categories
- Patients' daily disease burdens can be effectively monitored virtually
- MG-ADL offers valuable insights into patient experiences including sex differences, symptom burden, and medication use, and can potentially supplement RWD studies
- Given frequent variations in these burdens, future studies will aim to quantify trends in disease burden over time

. Dewilde S, Phillips G, Paci S, De Ruyck F, Tollenaar NH, Janssen MF. People Diagnosed with Myasthenia Gravis have Lower health-related quality of life and Need More Medical and Caregiver Help in Comparison to the General Population: Analysis of Two Observational Studies. Adv Ther. 2023;40(10):4377-4394. doi:10.1007/s12325-023-02604-z