Retrospective longitudinal assessment of MG-ADL score with treatment of myasthenia gravis

Matthew Varon, Mamatha Pasnoor, Tamara Winden, Suzanne Hunt,

Omar Jawdat, Constantine Farmakidis, Duaa Jabari, Melanie Glenn,

Jeffrey Statland, Richard J. Barohn, Mazen M. Dimachkie.

Neuromuscular Division – Department of Neurology
The University of Kansas Medical Center, Kansas City, Kansas, USA

Objective

- To assess the feasibility of retrospectively extracting the Myasthenia Gravis Activities of Daily Living (MG-ADL) score from the electronic medical record (EMR) for purposes of monitoring clinical improvement of large populations of myasthenia gravis (MG) patients.

Background

- The MG-ADL scale (range 0-24) is a validated eight-item questionnaire which assesses the symptoms and activities of patients with MG.

- Developed in 1999 by Dr. Wolfe, Laura Herbelin, and Dr. Barohn in Dallas.

- A two-point change in the MG-ADL is thought to be clinically meaningful, with higher scores indicating worse function.

- Patient reported outcome measures such as MG-ADL have been utilized frequently as an outcome measure in MG research.

- More recently these have been used in routine clinical care.

Methods

- MG-ADL scores are obtained during rooming and inserted in the EMR at clinic visits for MG patients in the KUMC neuromuscular clinics.

- At each clinic visit where MG-ADL scores were obtained we abstracted MG-ADL values, demographic information, serology, and interventions received.

- Descriptive statistics were used to describe baseline characteristics and analyze the data.

- MG-ADL values at specific time points; 0, 3, 6, 9, 12, 18, and 24 months were analyzed to assess for change over time.

Results

- Data abstraction yielded 845 MG-ADL values for 334 patients.
- The initial visit was identified for 61 of 334 patients.

Demographics	
N	61
Female, n(%)	21 (34.4%)
Age at first encounter	
median (IQR)	66.0 (53.0, 73.0)
mean (SD)	62 (15)
Race, n(%)	
Asian	1 (1.6%)
Black or African Ame	1 (1.6%)
Other	3 (4.9%)
White or Caucasian	56 (91.8%)
Thymectomy, n(%)	2 (3.3%)
MUSK Serology, n(%)	
negative	9(14.8%)
positive	1(1.6%)
not tested	51(83.6%)
AChR Serology, n(%)	
high	17(27.9%)
low	0
not tested	44(72.1%)

Results

- MG-ADL scores for 61 subjects with known first encounter.

	N	minimum	25th %tile	median	mean	Std deviation	75th %tile	maximum
baseline	61	0.0	3.0	7.0	6.6	4.1	10.0	15.0
month 3	23	1.0	4.0	6.0	5.8	2.5	8.0	11.0
month 6	9	0.0	2.0	4.0	4.6	3.1	7.0	8.0
month 9	11	2.0	4.0	6.0	6.6	3.1	10.0	11.0
year 1	15	0.0	2.0	4.0	4.4	2.8	6.0	11.0
year 1.5	5	2.0	2.0	2.0	3.0	1.4	4.0	5.0
year 2	2	4.0	4.0	6.0	6.0	2.8	8.0	8.0

all MG-ADL values for those with known first encounter
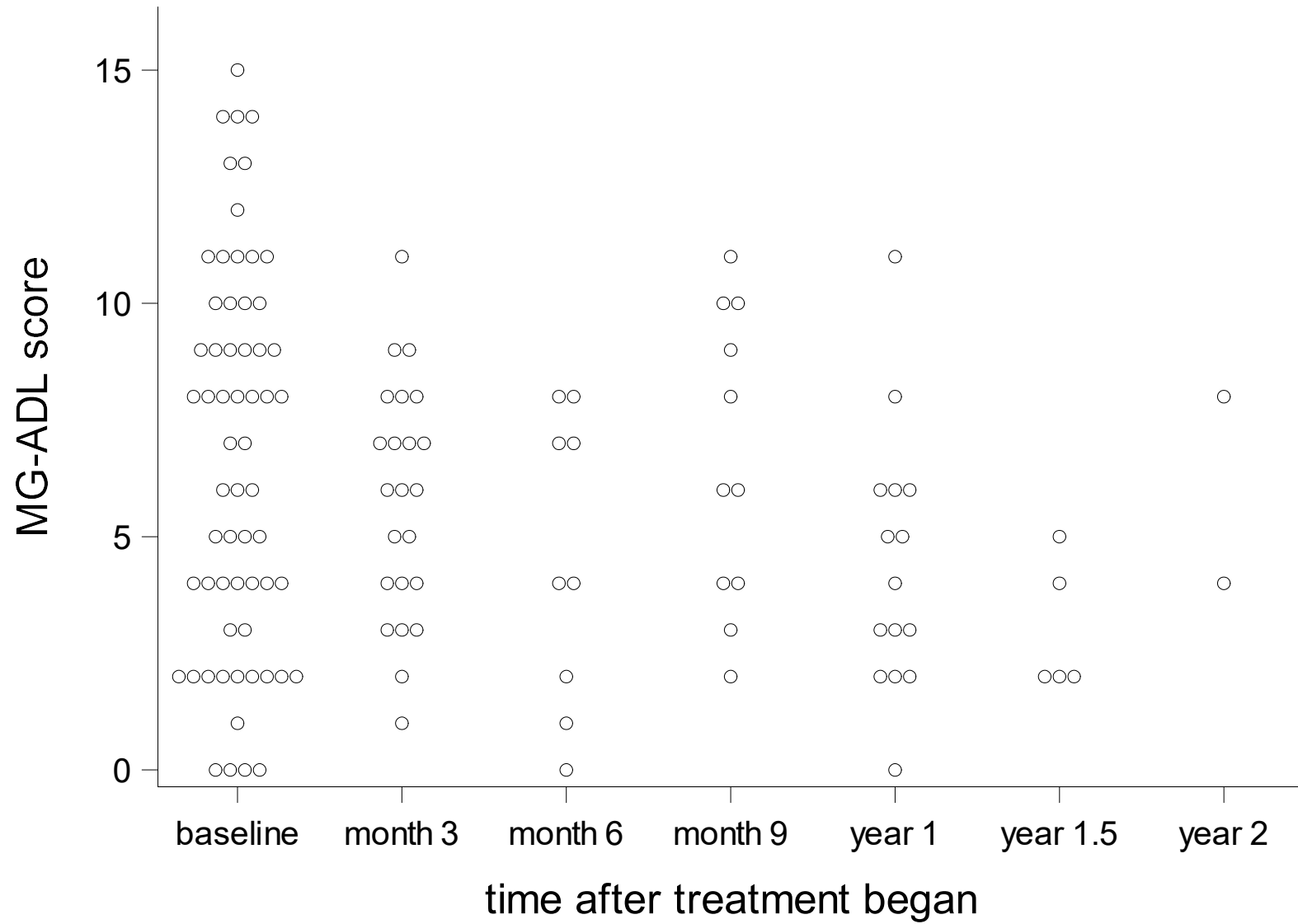
Change in MG-ADL from baseline, N=61

- Improved
  - Decrease of ≥ 2 points.
- Worsened
  - Increase of ≥ 2 points.
- Stable
  - Change < to 2 points.
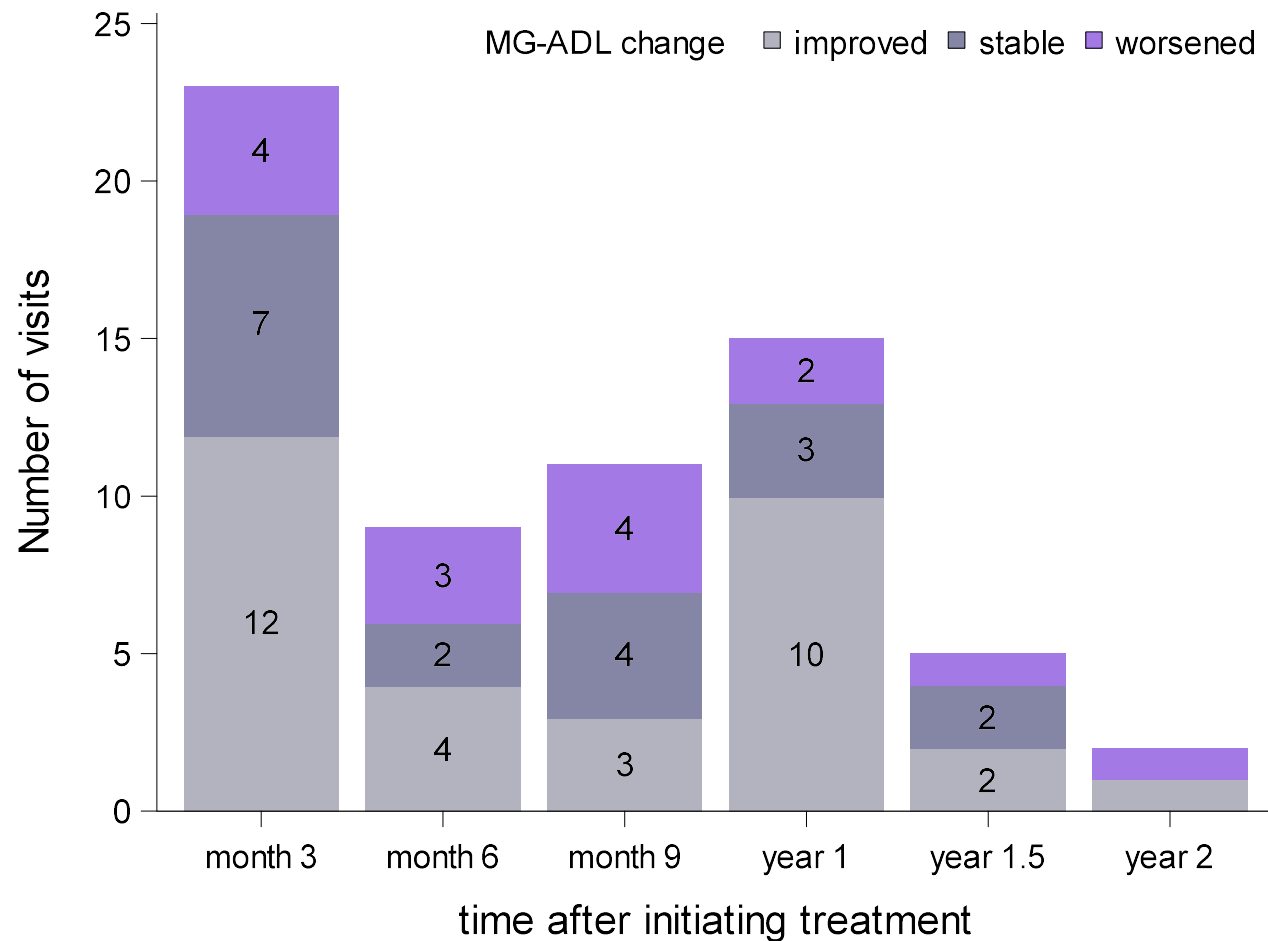
Results

- 29 of 61 subjects had only a baseline visit.
- 32 of 61 had at least 1 follow up visit.
- 26 subjects had at least 1 follow up visit within 12 months.

MG-ADL at last visit within year 1, N=26

	N	Median	25th %tile	75th %tile	Mean	Std dev.
MG-ADL baseline	26	8.0	4.0	10.0	7.3	3.8
MG-ADL last visit	26	4.0	2.0	8.0	5.0	3.3
Change in MG-ADL	26	-2.0	-5.0	1.0	-2.3	3.7

Limitations

- Retrospective design
- Inconsistency in availability MGADL on every patient / every visit
- Different roomer assessing MGADL
- Difficulties in extracting meaningful data (Ab status, etc)
- Bias due to less frequent follow up for improved patients

Conclusion

- It is feasible to extract MG-ADL scores from our EMR, though with challenges.

- MG-ADL values should be systematically documented for all MG patient visits.

- Most MG patients are stable or improved over the follow up duration.

- 26 subjects had at least 1 follow up visit within 12 months, mean MG-ADL improved by > 2 points

- Future real-world multisite studies to compare changes in MG-ADL with therapeutic interventions in the clinic.