Delayed diagnosis amongst Generalized Myasthenia Gravis patients: Results from a European real-world study

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OBJECTIVE

- To explore the impact of delayed diagnosis on gMG patient's health-related quality of life and health care resource utilization across five European countries.

CONCLUSIONS

- Physicians reported patients with a diagnosis taking longer than a year experienced more fatigue, anxiety, and prolonged burden on health-related quality of life, leading to higher health care resource utilization in patients with gMG.
- gMG patients with a delayed diagnosis typically required a greater number of healthcare professionals involved in their overall management and consulted them more frequently compared to those diagnosed within one year. This highlights a need for faster diagnosis to limit the burden on the patient and healthcare providers.
- These findings underscore the importance of a timely diagnosis of gMG after symptom onset and the need to properly educate all stakeholders on optimal disease management strategies.

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INTRODUCTION

- Generalised Myasthenia Gravis (gMG) is a chronic, autoantibody neuromuscular disease.
- Diagnosis can be difficult as symptoms, such as fatigue and muscle weakness, are often mistaken for a range of other disorders[1].
- A timely diagnosis is important to effectively manage the disease, reduce patient anxiety, improve patient quality of life, and limit additional healthcare resource use.

METHODS

- The Adelphi MG Disease Specific Programme (DSP™) collected point-in-time data from a cross-sectional cohort of physicians and their consulting patients.
- Data was collected across France, Germany, Italy, Spain and the UK between March – September 2020.
- The DSP methodology has been previously published[2]
- Physicians provided data including demographics, diagnostic pathway and their perception of disease impact..
- Patients were invited to complete a follow-up form, paired to their physicians, which included the MG-QoL-15r and EQ5D PRO instruments.
- Only patients with gMG (defined as MGFA class II-IV at the time of survey), a known diagnosis date and a self-completed patient form were included.
- Delayed diagnosis was defined as when the time between symptom onset and diagnoses were known to take over one year.

LIMITATIONS

- Patients included in the DSP sample may not be truly representative of the overall population of patients, as patients who consult more frequently are more likely to be included.
- The quality of the data depends on the reporting accuracy of information by physicians and patients which maybe subject to recall bias.
- Patients complete on a voluntary basis and so may reflect a more motivated sub population.

RESULTS AND INTERPRETATION

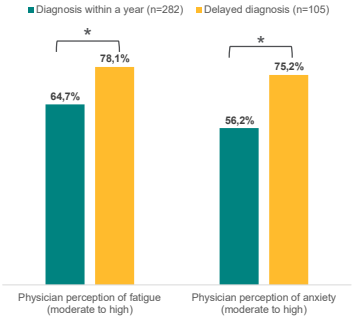
- 191 physicians provided data for 387 gMG patients with a known diagnosis date.
- 54.0% of the patients were female, mean age was 52.5 (SD±15.69) and mean time from diagnosis to survey was 4.2 years (SD±5.66, ***Table 1***).
- Mean time from symptom onset to gMG diagnosis was 1.0 years (SD±1.43).
- 105 patients (27.1%) received a gMG diagnosis more than a year after the onset of symptoms.
- Those in the 'delayed diagnosis' group were more likely to be initially misdiagnosed (68.6%, ***Table 1***).
- Patients who were diagnosed more than a year after symptom onset were more likely to experience moderate or higher levels of fatigue (78.1%, *p<0.05*) and anxiety (75.2%, *p<0.05*) than those diagnosed within a year from symptom onset (64.5% and 56.0% respectively, ***Figure 1***).

Table 1. Physician and patient reported impact of delayed diagnosis of gMG

	All patients	Diagnosis within a year (from symptom onset)	Delayed diagnosis (Over a year from symptom onset)	*p* Values
Physician reported base, N	**387**	**282**	**105**	
Age; mean (SD)	52.5 *(15.69)*	52.1 *(16.51)*	53.6 *(13.24)*	-
Gender, Female; n (%)	209 *(54.0)*	151 *(53.5)*	58 *(55.2)*	-
Time from diagnosis to survey, Years; mean (SD)	4.2 *(5.66)*	4.1 *(5.51)*	4.5 *(6.08)*	-
Time from symptom onset to diagnosis, Years; mean (SD)	1.0 *(1.43)*	0.4 *(0.29)*	2.7 *(1.85)*	-
Initially misdiagnosed, Yes; n (%)	117 *(30.2)*	45 *(16.0)*	72 *(68.6)*	-
Physician perception, moderate or higher fatigue; n (%)	264 *(68.2)*	182 *(64.5)*	82 *(78.1)*	*0.01**
Physician perception, moderate or higher anxiety; n (%)	237 *(61.2)*	158 *(56.0)*	79 *(75.2)*	*<0.01**
Number of different healthcare professionals involved in patient management currently, mean (SD)	*3.6 (1.92)*	*3.2 (1.68)*	*4.6 (2.17)*	*<0.01**
Number of consultations in the last 12 months (all healthcare professionals), mean (SD)	*8.2 (6.90)*	*6.9 (5.62)*	*11.9 (8.52)*	*<0.01**
Patient self-reporting MG-QoL-15r base, N	**117**	**74**	**43**	
MG-QoL-15r score, mean (SD)	13.3 *(7.10)*	12.6 *(7.84)*	14.4 *(5.50)*	*0.18*
Patient self-reporting EQ-5D-5L base, N	**122**	**76**	**46**	
EQ-5D-5L score, mean (SD)	0.67 *(0.24)*	0.68 *(0.26)*	0.67 *(0.19)*	*0.88*
Patient self-reporting EQ-5D-VAS base, N	**120**	**73**	**47**	
EQ-5D-VAS score, mean (SD)	61.8 *(19.89)*	60.2 *(21.98)*	64.2 *(16.02)*	0.27

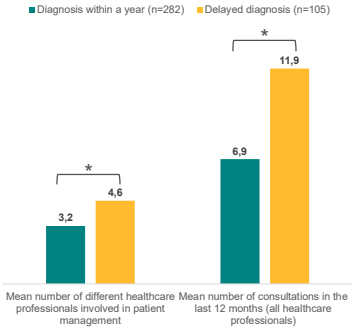
* Statistically significant; *p* value <0.05

Figure 1. Physician reported levels of moderate to high fatigue and anxiety



* Statistically significant; *p* value <0.05

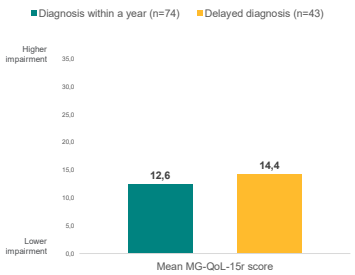
Figure 2. Number of healthcare professionals involved and number of consultations in the last 12 months



* Statistically significant; *p* value <0.05

- Patients with a delayed diagnosis had a significantly greater number of healthcare professionals involved in their overall patient management (4.6, *p*<0.05) compared to those diagnosed within a year (3.2, ***Figure 2***).
- Patients with a delayed diagnosis consulted significantly more frequently with healthcare professionals (11.9, *p*<0.05) than those diagnosed within a year (6.9, ***Figure 2***).
- 117 patients completed the MG-QoL-15r. Those with a delayed diagnosis (n=43) had higher impairment (14.4,SD±5.50) than those diagnosed within a year (***Figure 3***). The difference was not statistically significant (*p*=0.18).
- Among the 122 patients completing an EQ-5D-5L questionnaire there was little variation in the utility score between those with a delayed diagnosis (0.68) and a diagnosis within a year (0.67, *p*=0.88). However the EQ-5D-5L has limitations in capturing the overall health state of a patient and may lack adequate sensitivity analysis[3].
- However when asked to rate their health that day out of 100 using the visual analogue scale, those with a delayed diagnosis (n=105) rated their health lower (60.2) than those diagnosed within a year from symptom onset (n=282). This difference was also not statistically significant (*p=0.27*).

Figure 3. Mean MG-QoL-15r score



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DISCLOSURES

AB, RN, CG, WN, JL, JM, QZ, AEB and MV are employees of Janssen JdC, EC, OT and GG are employees of Adelphi Real World

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