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MYASTHENIA GRAVIS PATIENTS HAVE A HIGHER PRODUCTIVITY LOSS AND LOWER UTILITY VALUES THAN A MATCHED SAMPLE OF THE GENERAL POPULATION: ANALYSIS OF DIGITALLY COLLECTED OBSERVATIONAL DATA FROM 9 COUNTRIES

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Introduction and objectives

- Myasthenia Gravis (MG) is a rare autoimmune neuromuscular disease resulting in muscle weakness affecting vision, swallowing, speech, mobility, dexterity and respiratory function [1, 2].
- MG is considered moderate or severe when multiple muscle groups are affected [3].
- The objective is to compare work productivity and medical resource utilization (MRU) of **moderate-to-severe MG (msMG) patients** with the general population.

Methods

- The MyRealWorld-MG (**MRW-MG**) study is a digital, observational, multi-country study (US, UK, Canada, Italy, Germany, Spain, Japan) among adult MG patients [4].
  - Patients entered personal and disease characteristics via a smartphone application, and provided data on work productivity, caregiver help and use of medical services.
  - Data from the third data cut (March 2022, n=1859) were used, where the MG-Activities of Daily Living (MG-ADL) total score was utilized to identify moderate (7-15) and severe (>=16) MG patients.
- The General Population Norms (**POPUP**) observational study collected similar data and was conducted in Canada, Belgium, Italy, Germany, Netherlands, Spain, UK and the US.
  - Members of the general public were enrolled, representative of age, gender, education and region.
  - POPUP data were age-gender matched to the proportions observed in MRW-MG.

Results

1. Population characteristics

- POPUP enrolled 9,000 persons whereas MRW-MG included 880 patients who completed the MG-ADL; of those, 431 had msMG.
- Almost 80% of msMG patients were women, which is over 10 percentage points more than in the total MRW-MG population.
- msMG patients were almost exclusively (97.6%) moderately affected by MG.
- A markedly higher comorbidity rate was found in msMG patients.

Table 1. Demographics

	POPUP (N=9,000)	MRW-MG (N=431)
Gender (% Female)	70.2%	79.3%
Age distribution		
18-34	27.6%	18.1%
35-54	36.9%	49.2%
55+	35.5%	32.7%
Activities of daily living MG-ADL		
0-6	96.8%	0%
7-15	2.7%	97.6%
≥ 16	0.5%	2.4%
VAS Mean (Std)	75.3 (17.6	50.9 (19.8)
Co-morbidities		
Diabetes	9.3%	9.2%
Respiratory disease	8.8%	20.7%
Thyroid problems	11.0%	30.1%
Cardiovascular dis.	4.3%	6.7%
Osteoporosis	2.9%	13.7%
Rheumatoid arthritis	4.7%	5.2%
Psoriasis	3.0%	3.1%
Psoriasis arthritis	0.8%	1.74%
Depression	12.8%	24.2%
Anxiety	16.2%	27.9%
Cancer	1.9%	4.8%
None of the above	40.1%	25.3%

Abbreviations: MG: myasthenia gravis, msMG: (moderate-to-severe) MG, MRW-MG: MyRealWorld-MG, POPUP: general population norms, MG-ADL: MG-Activities of daily living, EQ-5D-5L: five-level EuroQol five-dimensional questionnaire, VAS: visual analog scale, HUI: health utility index, HADS: Hospital Anxiety and Depression Scale, Std: standard deviation.

References:

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2. Living situation

- The majority of the general population lived at home without help from a caregiver, where this was 35.5% among msMG patients.
- Eight times more msMG patients needed help from a caregiver compared to the POPUP sample.

Table 2. Living situation

	POPUP (N=9,000)	MRW-MG (N=431)
Living situation		
At home without help from a caregiver	71.3%	35.5%
At home with help from a caregiver	2.4%	10.0%
With a family member	26.2%	49.2%
In a nursing home	0.2%	0.2%
In a long-term care rehabilitation facility	0.1%	0.7%
Caregiver		
% Needing help from a caregiver	7.1%	57.1%

3. Productivity loss

- The proportion of participants not being able to work or study was five times larger in msMG patients.
- Four times more msMG patients took sick leave in the past month compared to POPUP, with slightly higher average number of days.

Table 3. Proportion of respondents taking sick leave

	POPUP (N=9,000)	MRW-MG (N=431)
% Did not take time off in the past month due to illness	**89.8%**	**56.5%**
Not been ill	57.1%	26.4%
Been ill but did not take any time off	7.1%	
Chooses not to work/study	2.5%	0.7%
Cannot work/study because of an illness /MG	3.6%	17.3%
Retired	14.8%	8.0%
% Did take time off in the past month due to illness	**10.2%**	**43.5%**
Average number of days Mean (std)	13.1 (11.6)	14.8 (12)

4. Medical resource utilization

- The monthly rate of hospitalizations among msMG patients was seventeen times higher than the rate among the general population.
- ER visits were eleven times more frequent among msMG patients.
- Visits per month to specialists were four times higher for msMG patients.

Table 4. Medical resource use

Average number of visits in the past 4 weeks	POPUP (N=9,000)	MRW-MG (N=431)
Hospitalizations	0.009	0.158
Length of stay (days)	3.1	10.0
ER visits	0.014	0.151
Nurse/healthcare worker visit	0.127	0.131
GP visits	0.207	0.392
Specialist visit	0.188	0.811
Physiotherapist visit or visit to a rehabilitation center	0.097	0.172
Hospital outpatient visit	0.060	0.192

5. Utility values

- Both EQ-5D-5L [5] (based on the UK value set) and HUI3 [6] utility values (Canadian value set) were markedly lower (-0.246 and -0.479 respectively) among msMG patients compared to POPUP.
- Self-perceived health scores – as measured by the EQ VAS – were almost 25 points lower in msMG patients (75.3 vs. 50.9).
- Observed mean HADS [7] anxiety scores in msMG patients are considered “moderate” (>11) and their depression scores “mild” (>8) [8], contrasting the “normal” (0-7) scores in POPUP.

Table 5. Utility values, EQ VAS and HADS total scores

	POPUP (N=9,000)	MRW-MG (N=431)
	Mean, Std (Q1, Q3)	
EQ5D-5L utility	0.840, 0.202 (0.787 - 1)	0.594, 0.253 (0.487 - 0.754)
HUI3 utility	0.747, 0.269 (0.660 - 0.930)	0.268, 0.296 (0.030 - 0.490)
EQ-5D-VAS	75.3, 17.6 (69 - 90)	50.9, 19.8 (37 - 68)
HADS anxiety	6.5, 4.6 (3 - 10)	11.0, 2.3 (9 - 13)
HADS depression	5.0, 4.1 (1 - 8)	8.7, 2.2 (7 - 10)

Discussion & Conclusions

- **Suffering from msMG is associated with higher medical care and societal costs.**
- **When compared to the general population, a major impact of msMG on caregiver burden, productivity costs and MRU was observed.**

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