

The Burden MG Patients Experience In Terms Of Utilities And Health Care Utilization: Comparison With The General Population

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BACKGROUND & AIM

- Myasthenia Gravis (MG) is a rare, IgG-mediated, autoimmune disease.
- MG is characterized by muscle weakness affecting vision, swallowing, speech, mobility, dexterity and breathing.
- Multiple studies concluded that MG patients have an impaired health-related quality of life (HRQoL).
- This analysis aims to explore the effect of disease severity on HRQoL of MG patients.
- MG-specific and generic outcome measures will be compared between patients with mild, moderate, and severe disease, and with the general population.

METHODS

Study design & Data sets

- This analysis compared data from two digital observational studies. One study was conducted among the general population, the other among MG patients.

General Population Norms (POPUP)

- POPUP established reference data in 9 countries: US, UK, Canada, Italy, Germany, Spain, France, Denmark and Japan.
- Participants were representative of age, gender, education and region in each country.

MyRealWorld-MG (MRW)

- The MRW-MG study explored the impact of MG in the real world from the patient perspective.
- The study was conducted in the US, UK, Canada, Japan, France, Germany, Italy, Spain, and Denmark.

Data collection

Both studies collected the following data:

- EuroQol (EQ-5D-5L);
- Health Utility Index (HUI3);
- MG-Activities of Daily Living (MG-ADL);
- Any sick leave taken (yes/no) in the past month;
- Need for a caregiver (yes/no) in the past month;
- Use of medical services (yes/no) in the past month.

RESULTS

Demographic characteristics

- MRW included 2074 MG patients, whereas POPUP enrolled 9000 respondents (**Table 1**).
- In the MRW-MG study, 68.8% were female; 58.4% of MG patients had moderate-to-severe MG.
- Mean EQ VAS values were meaningfully lower in MRW.

TABLE 1. Patient characteristics

		POPUP	MRW
		N=9000	N=1859
Gender	Female	51.2%	68.8%
	Male	48.8%	31.2%
	Age category		
	18-34	27.6%	17.0%
Age	35-54	36.9%	44.6%
	55 +	35.5%	38.4%
	Mean (SD)	47.1 (15.5)	49.9 (14.8)
MG-ADL	Mild: 0-4	93.6%	41.7%
	Moderate: 5-9	3.5%	39.6%
	Severe: >= 10	2.9%	18.7%
	Mean (SD)	75.7 (17.4)	61.7 (22.1)
VAS	Q1 - Q3	69 - 90	48 - 80

TABLE 2. Utilities per subgroup

		POPUP	MRW	Mild	Moderate	Severe
				0-4	5-9	10-24
MG-ADL	EQ-5D-5L	0.843	0.739	0.872	0.707	0.511
	HUI3	0.746	0.493	0.695	0.443	0.168

ABBREVIATIONS

EQ-5D-5L: EuroQoL 5-Dimension 5-Level, HUI3: Health Utility Index Mark 3, MG-ADL: MG-Activities of Daily Living, VAS: Visual Analogue Scale, SD: Standard deviation, Q1/Q3: First/Third quartile.

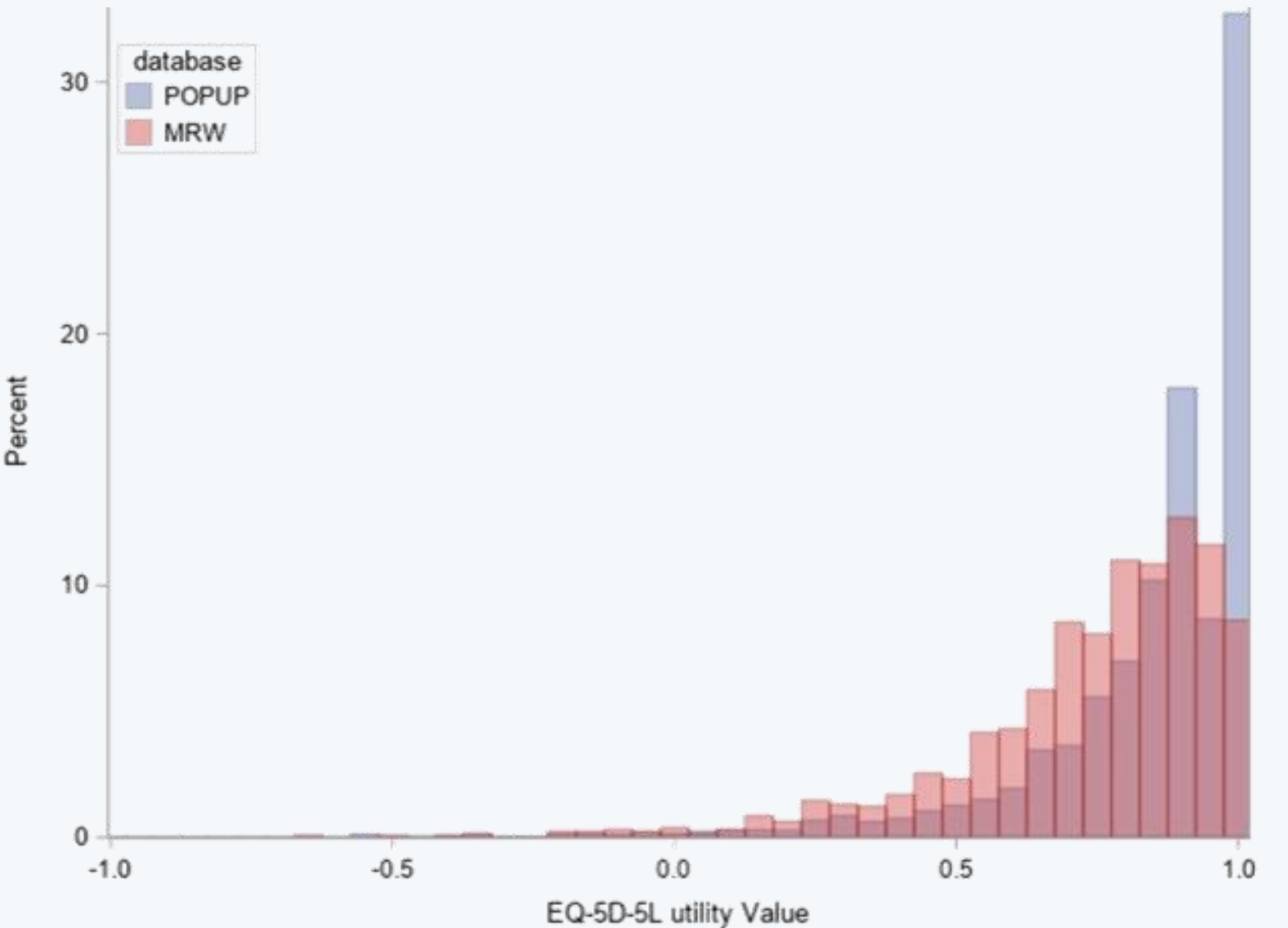
EQ-5D-5L utility values

- MG patients had significantly lower mean utility values than POPUP respondents (0.739 vs. 0.843, **Table 2**).
- Significant decline in mean utility values were found between patients with mild, moderate, and severe MG.
- Figure 1** displays the distribution of EQ-5D-5L utility values for MG patients and the general population.
- 32.7% of the POPUP population had a utility value of 1 (perfect health) vs. 9.9% of the MRW sample.
- The proportion of negative values (representing health states worse than death) was similar (1.5% vs. 1%).

HUI3 utility values

- Mean HUI3 utilities were also markedly lower in MRW compared to POPUP (0.493 vs 0.746) and decreased significantly with higher MG-ADL scores (**Table 2**).
- The distribution of MRW and POPUP respondents across utility values is displayed in **Figure 2**.
- The proportion of patients reporting to be in “perfect health” was ten times larger in the POPUP sample (1.9% vs. 11.8%).
- The proportion of negative utilities was three times higher in MRW than in POPUP (9.3% vs. 3.6%).

FIGURE 1. Distribution of MRW and POPUP respondents across EQ-5D-5L utility values



Sick leave

- One-third of MG patients took sick leave in the past month, compared to one in eight members of the general population (**Table 3**).

Need for a caregiver

- Four times more MG patients reported needing help from a caregiver (**Table 3**).
- Caregivers were mostly family members.

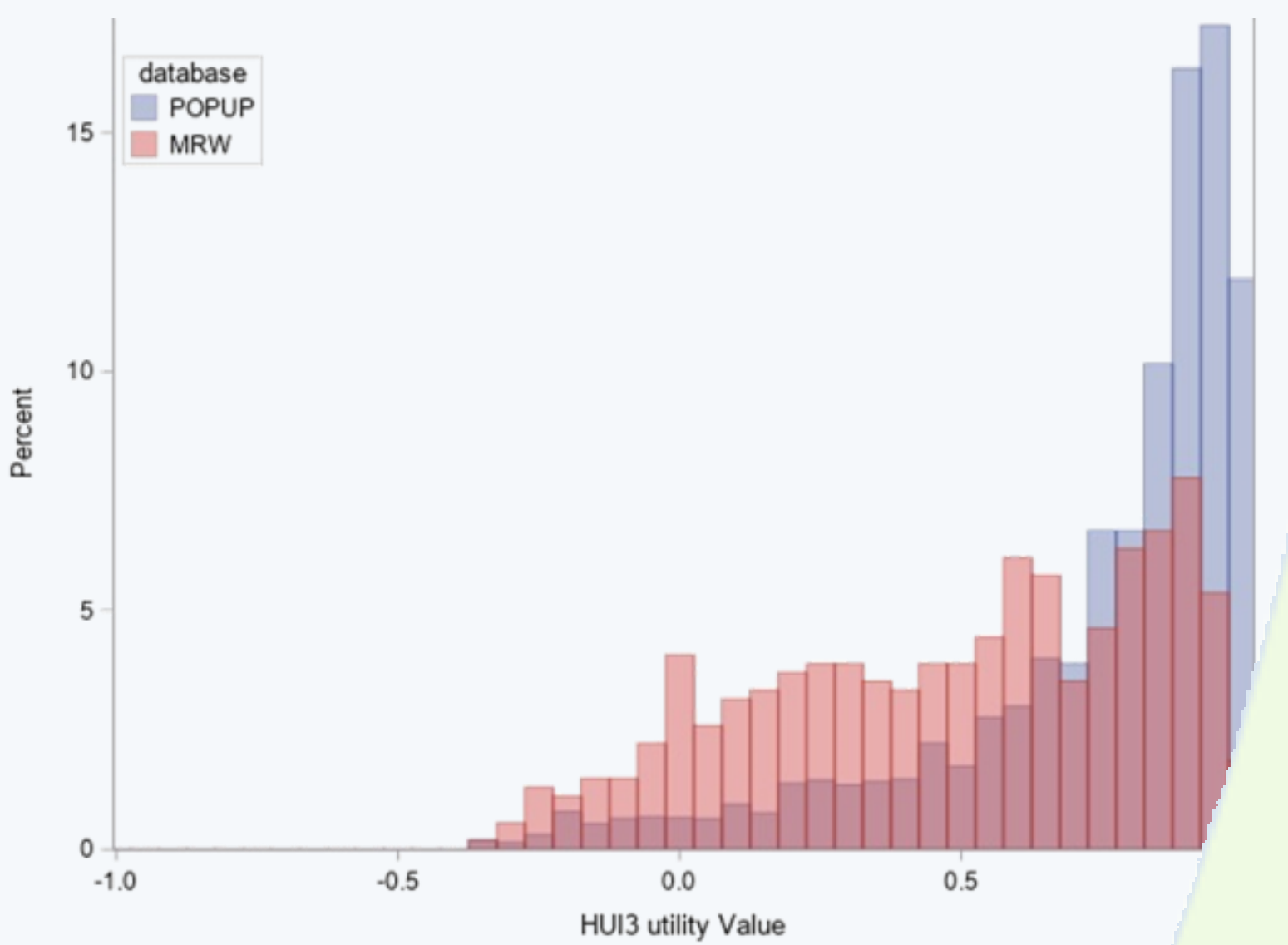
Medical resource use

- MG patients required twice as often any type of medical care in comparison with the general population (**Table 3**).

TABLE 3. Sick leave, Need for a Caregiver and Medical resource use in the past month

	POPUP	MRW
Sick leave	13.2%	34.4%
Needing help from a caregiver	8.3%	34.8%
Medical resource use	24.6%	51.9%

FIGURE 2. Distribution of MRW and POPUP respondents across HUI3 utility values



KEY TAKEAWAYS



People suffering from MG have lower utility values than the general population. The higher their symptom burden, the more their utility values are declining.



People diagnosed with MG need significant resources to help them manage their condition: medical resources, caregiver help and time off work.

LIMITATIONS

Different age and gender distribution

- The MRW age and gender distribution was different than that of the general population. This observed utility differences could be partially attributed to differences in baseline characteristics. However, when POPUP results were adjusted to the age and gender distribution of the MRW sample, only a minor effect on results was observed, and moreover it made the HRQoL difference even larger between the two populations.

Selection bias

- The results from these two digital studies are subject to all biases typical for digital studies, of which the most important is selection bias. People participating in online panels and patients contributing actively to studies on their disease may differ on several characteristics from people who do not participate, which may have an influence on the results.

CONCLUSIONS

- A large burden in MG patients was found in this direct comparison of HRQoL with the general population using two international studies.
- Results were consistent across all outcomes, in all countries.

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DISCLOSURES AND ACKNOWLEDGMENTS

SP is an employee of argenx BV, the sponsor of the study; FS has received public speaking honoraria from Almirall, Biogen, Mylan, Novartis, Roche, Sanofi and Teva; and served on advisory boards for Almirall, argenx BV, Avexis, Biogen, Forward Pharma, Lexeo, Merk, Novartis, Novatek, Pomona, Roche, Sanofi, and Takeda; RM has received speaking honoraria from Biomarin, Alexion and UCB, served on advisory boards for Alexion, argenx BV and UCB and received support for congress participation from Merck, Teva and Biogen; SD, the principal investigator of the study, NT and MFJ have been commissioned by argenx BV and received honoraria to design the study, analyze and write the abstract.

