

# Quality Of Life of Patients with Symptomatic Ocular MG: Comparison with the General Population

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## Introduction

- Myasthenia Gravis (MG) is a rare autoimmune disorder characterized by muscle weakness.
- Ocular muscles are typically affected first, but most patients progress to generalized MG over time.
- Generalized MG symptoms (problems with chewing, swallowing, etc.) are well known to be associated with impaired health-related quality of life (HRQoL). The impact of symptomatic ocular symptoms on the HRQoL of non-generalized patients is less well documented.

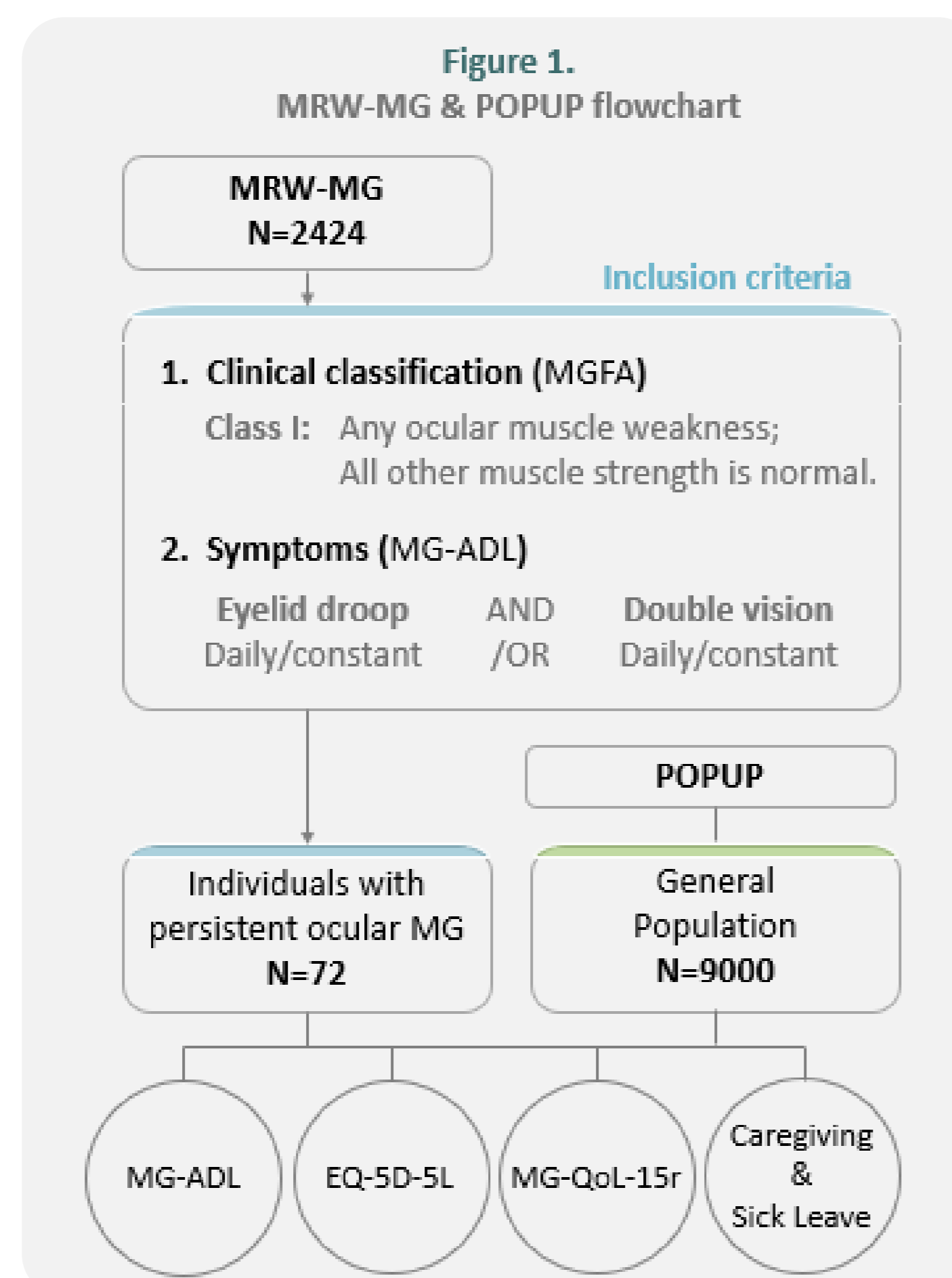
## Objective

To compare the HRQoL and symptom burden of symptomatic ocular MG patients to the general population.

## Methods

### 1. Data sources

- The **MyRealWorld-MG study (MRW-MG)** is a digital, observational, real-world multi-country survey (US, UK, Canada, Italy, Germany, Spain, Japan) among **adult MG patients (N=2424)**. The objective of this study was to provide a detailed view of the impact of MG and its treatment on patients in the real-world setting. A mobile application was used for data collection.
- POPUP** is a digital study aimed to estimate population norms in the US, Canada, UK, Italy, Spain, Germany, the Netherlands, and Belgium for the EQ-5D-5L with six bolt-on dimensions (vision, breathing, tiredness, sleep, social relationships, self-confidence). The study was conducted using an online questionnaire among **9,000 general population participants**, representative of age, gender, education, and region within each country.



### 2. Outcome measures

- In both studies, data collection included:
  - Background characteristics.
  - EQ-5D-5L** with six bolt-on dimensions (vision, breathing, tiredness, sleep, social relationships, self-confidence). Utility values are calculated using the UK value set.
  - MG-Activities of Daily Living (MG-ADL)**, assessing MG severity through the following symptoms: talking, chewing, swallowing, breathing, impairment of ability to brush teeth/comb hair, impairment of ability to rise from a chair, double vision, and eyelid droop. The total score ranges from 0: no impact to 24: severe impact on daily living. The MG-ADL is an MG-specific tool but was also measured in POPUP to provide population norms.
  - MG Quality Of Life 15-item revised scale (MG-QoL-15r)** is an MG-specific HRQoL questionnaire, which assesses the impact of MG on the following domains: emotions, physical health, self-care, social life, and role. The MG-QoL-15r was adapted and measured in POPUP to provide population norms.
  - Number of days of **sick leave** in the previous month.
  - Caregiver** data (need for a caregiver, amount of caregiving per week).
- Symptomatic ocular MG** was defined as having MGFA Class I, and daily/constant eyelid droop and/or daily/constant double vision, based on the MG-ADL scale.
- Besides the total MG-ADL score (all items), We distinguished between the MG-ADL ocular score (sum of *Eyelid Droop and Double Vision*), and the MG-ADL generalized score (sum of remaining items).

### 3. Statistical analysis

- Two-sided t-tests and Chi-squared tests were used to test for significance.

Abbreviations: MG: Myasthenia Gravis, HRQoL: Health-related quality of life, EQ-5D-5L: EuroQoL 5-Dimension 5-Level, VAS: Visual analogue scale, MG-ADL: MG-Activities of daily living scale, MG-QoL-15r: MG-Quality of Life 15 items scale, MGFA: MG Foundation of America, MO: Mobility, SC: Self-Care, UA: Usual activities, PD: Pain/Discomfort, AD: Anxiety/Depression, N: Sample size, SD: standard deviation.

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### 1. Participant characteristics

- The characteristics of patients with symptomatic ocular MG from MRW-MG are shown in **Table 1**.
- The characteristics of the general population participants from POPUP are shown in **Table 2**.

Number of patients	N	72
<b>Age (years)</b>	Mean (SD)	49.29 (14.18)
	18-34 years	17%
	35-54 years	45%
	>55 years	38%
<b>Sex</b>	Male	39%
	Female	61%
<b>Years since diagnosis</b>	Mean (SD)	6.55 (10.57)
<b>Current treatment</b>	Proportion of patients taking routine treatment for MG	88%
	Of which:	
	Anticholinesterase medication	76%
	Corticosteroids	33%
	Azathioprine	19%
	Mycophenolate	6%
	Ciclosporin	2%
	Tacrolimus	3%
	Intravenous immunoglobulin (IVIG)	6%
	Thymectomy	10%
<b>Comorbidities</b>	Proportion of patients with at least one comorbidity	54%
	Of which:	
	Diabetes	13%
	Respiratory disease	13%
	Thyroid problems	31%
	High blood pressure	28%
	High cholesterol	31%
	Osteoporosis	10%
	Rheumatoid arthritis	10%
	Psoriasis	5%
	Thyroid disorder	10%
	Gastrointestinal problems	23%
	Depression	10%
	Anxiety	13%
	Liver disease	3%
	Kidney disease	3%
	HIV/AIDS	3%
	Food intolerance	10%
	Other	31%

Number of participants	N	9000
<b>Age (years)</b>	Mean (SD)	47.09 (15.46)
	18-34 years	24%
	35-54 years	37%
	>55 years	39%
<b>Sex</b>	Male	49%
	Female	51%

## Results

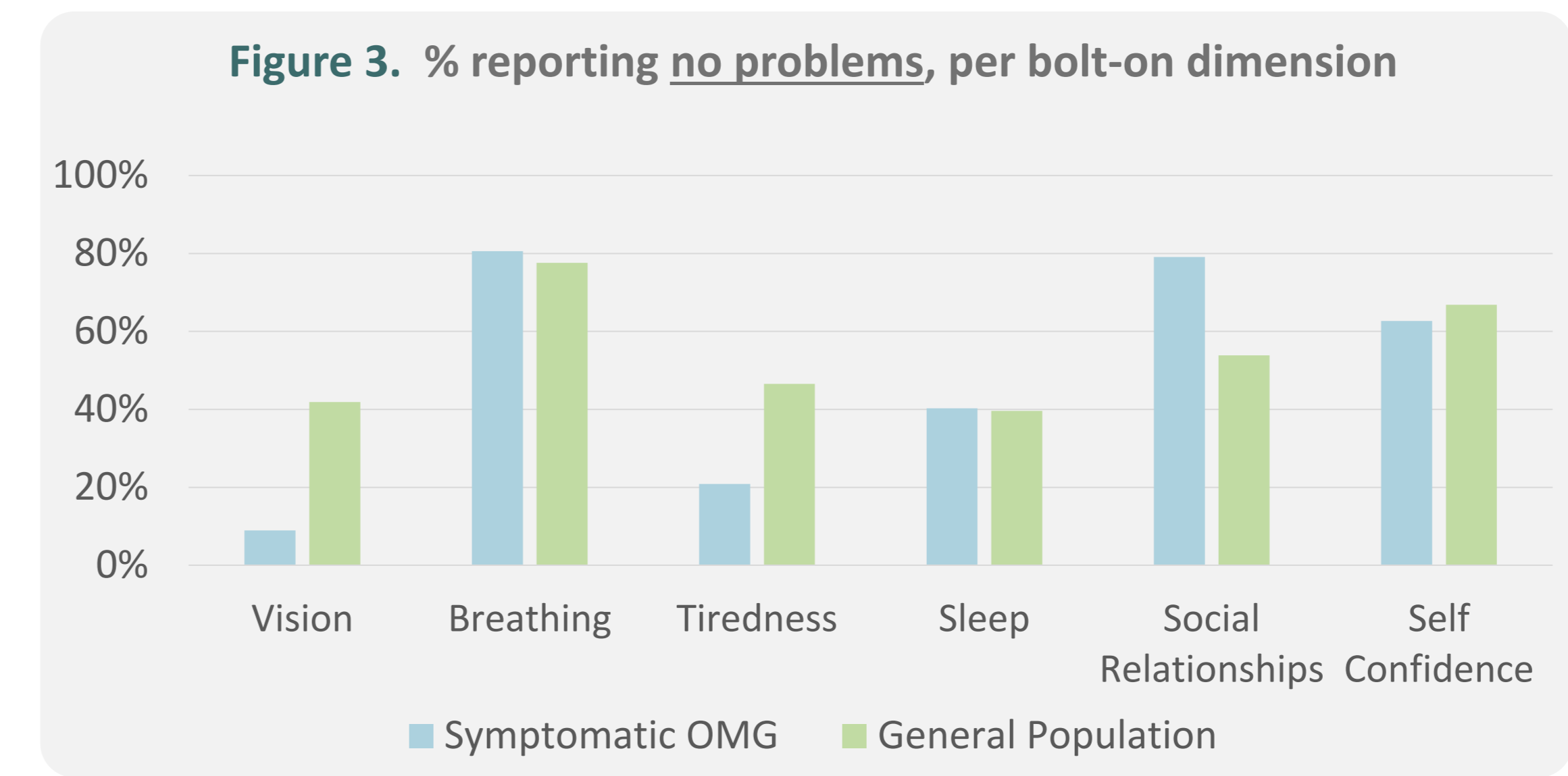
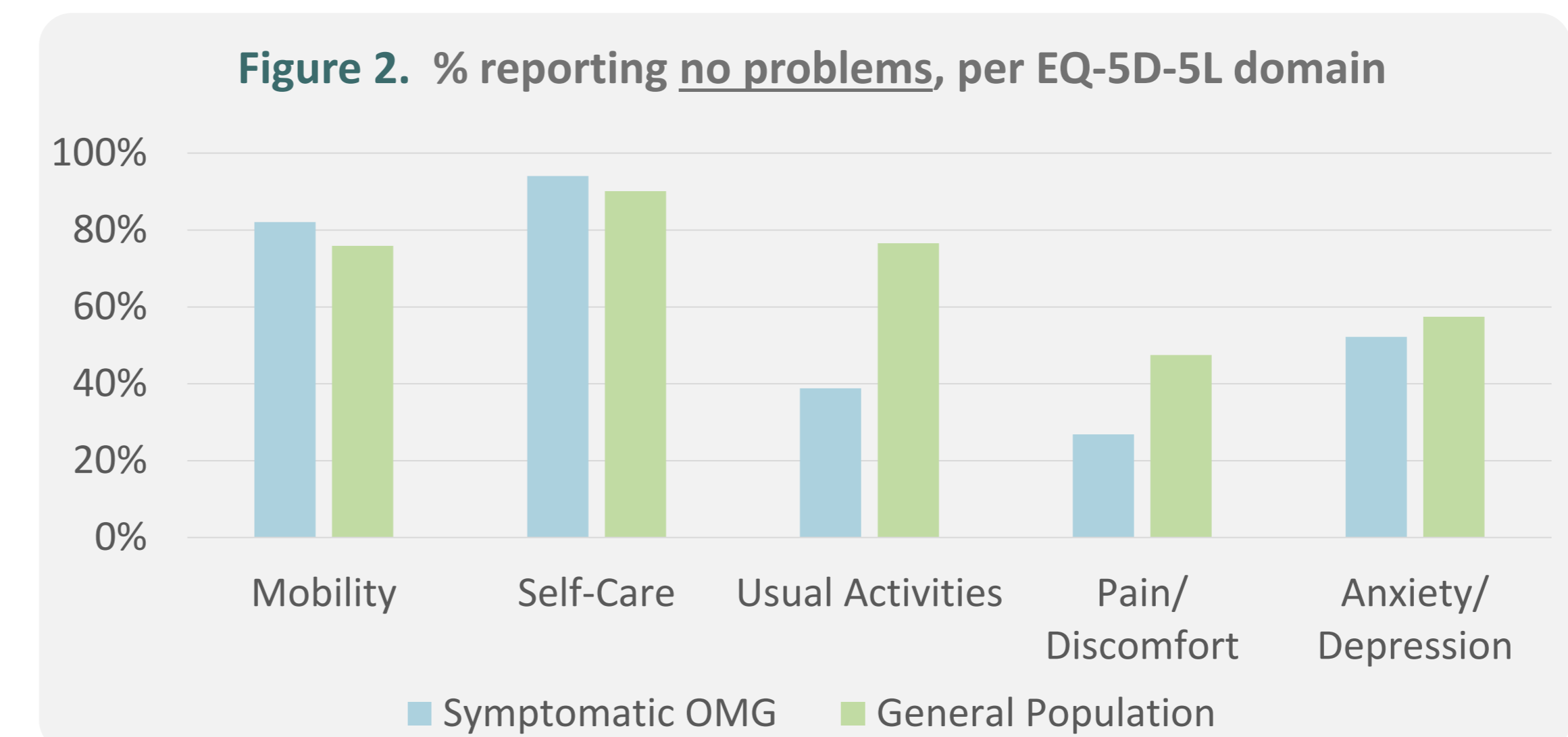
### 2. EQ-5D-5L

- The mean EQ-5D-5L utility value was significantly lower for patients with symptomatic ocular MG than for the general population (0.754 versus 0.799, p=0.023) (**Table 3**).
- Patients with symptomatic ocular MG reported more problems in the EQ-5D-5L dimensions *pain/discomfort* and *performing usual activities*, and for bolt-ons covering *tiredness* and *vision* (**Figure 2 and 3**).

### 3. MG-QoL-15r

- The mean MG-QoL-15r score was significantly worse for patients with symptomatic ocular MG than for the general population (9.2 versus 4.9, p<0.0001) (**Table 3**).
- Patients with symptomatic ocular MG reported more problems on most MG-QoL-15r items, including *frustration* (72% vs 47%), *losing independence* (50% vs 16%), and *limitations in performing work* (74% vs 25%) and *enjoying hobbies* (74% vs 39%).

	symptomatic ocular MG	General population	p-value of test for difference
<b>EQ-5D-5L utility</b>			
Mean (SD)	0.754 (0.156)	0.799 (0.213)	p=0.023
Median (IQR)	0.768 (0.123)	0.837 (0.265)	
<b>EQ VAS</b>			
Mean (SD)	64.2 (20.8)	75.7 (17.4)	p<0.0001
Median (IQR)	70 (31)	80 (21)	
<b>MG-QoL-15r</b>			
Mean (SD)	9.2 (4.5)	4.9 (5.7)	p<0.0001
Median (IQR)	9 (6)	3 (7)	



### 4. MG-ADL

- As expected, patients with symptomatic ocular MG had a significantly higher ocular score (p<0.0001) compared to the general population (**Table 4**). In the general population, only 7% of individuals report problems with double vision or eyelid droop.
- Patients with symptomatic ocular MG had a significantly higher generalized score than the general population (p=0.04). Only 49% of patients with symptomatic ocular MG report no problems on the generalized items, compared to 66% in the general population. The most common generalized domains where symptomatic ocular MG patients report problems with are *talking*, *chewing* and *swallowing*.

MG-ADL	symptomatic ocular MG	General population	p-value of test for difference
<b>Total score, mean (SD)</b>	5.2 (2.4)	1.2 (2.6)	p<0.0001
Mild (0-4)	38%	94%	
Moderate (5-9)	58%	3%	
Severe (10+)	4%	3%	
<b>Ocular score, mean (SD)</b>	3.8 (1.4)	0.3 (0.8)	p<0.0001
0-1	0%	93%	
2-4	69%	6%	
5-6	31%	1%	
<b>Generalized score, mean (SD)</b>	1.4 (2.0)	0.9 (1.9)	p=0.04
0	49%	66%	
1-2	32%	24%	
3+	19%	10%	

### 5. Caregiving & Sick leave

- Compared to the general population, significantly more patients with symptomatic ocular MG took sick leave in the past month (28.2% versus 13.2%, p<0.0001) and more patients with symptomatic ocular MG needed regular help from a caregiver (14% versus 8%, p=0.118) (**Table 5**).

	symptomatic Ocular MG	General population	p-value of test for difference
<b>Sick leave</b>			
% Took sick leave	28.2%	13.2%	p<0.0001
Mean days of sick leave (SD)	13.7 (10.8)	12.4 (11.5)	
<b>Caregiving</b>			
% Needing a caregiver	14%	8%	p=0.118
Hours of caregiving/week*			
0-7	56%	42%	
8-14	33%	32%	
15-49	0%	19%	
50+	11%	7%	

\*among those who need a caregiver

## Conclusions

- Symptomatic ocular MG patients have significantly lower utility values, higher MG-QoL-15r scores and take more sick leave than the general population.**
- This indicates an **unmet need** for treatment in symptomatic ocular MG patients.
- The **limitations** of this study are the relatively small sample size (N=72) and the lack of validation of the MG-ADL and MG-QoL-15r scales in the general population. Furthermore, ocular MG is defined based on patient **self-reported MGFA status** at the time of the survey.