PCR69

UNDERSTANDING DETERMINANTS OF THE BURDEN EXPERIENCED BY INFORMAL CAREGIVERS OF MYASTHENIA GRAVIS PATIENTS

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Introduction and Aim

- Informal caregivers play a vital role in supporting individuals via Myasthenia Gravis (**MG**) however their caregiving burden (**CB**) is understudied.
- The responsibilities of informal caregivers may range from assisting with daily activities to offering emotional support and coordinating medical appointments. As a result, caregivers often experience a significant emotional, financial, and time burden, which may impact their health-related quality of life (**HRQoL**).
- AIM 1: **To investigate which caregiver and patient characteristics are determinants for a high CB.**
- AIM 2: **To determine whether CB affects caregiver's utility values.**

Methods

- Pairs of adult MG patients and their informal caregivers from Germany, Italy, Spain and the UK contributed data in the digital, observational MyRealWorld-MG study [4].
- These data were combined with a similar, paper-based survey in France.
- Patient and caregiver HRQoL was measured using the **EQ-5D-5L**.
- The **MG-ADL** total score was used to classify MG symptom severity as mild (0-4), moderate (5-9) or severe (>=10).
- The caregiver burden was assessed using the **Zarit Burden Interview** (**ZBI-22**) total score.

LB Low Burden

- The burden of caregivers was considered low when they have a ZBI-22 total score of 0-23.
- This definition applied to N=38 (58%) of all caregivers.

HB High Burden

- A ZBI-22 total score of 24 or higher was defined as having a high burden.
- This definition applied to N=29 (42%) of all caregivers.

Results

1. Population characteristics

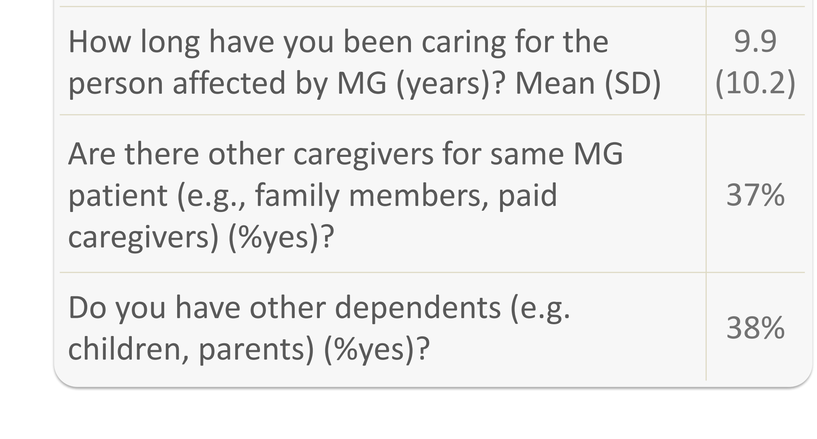
- The study included 69 pairs of patients and their caregivers (**Table 1**).
- The mean ages of caregivers and patients were similar (53.7 and 50.6 years), but patients were more often female (75% vs. 39%).

Table 1. Caregiving circumstances	N=69
Living together with the person affected with MG (%yes)?	90%
How long have you been caring for the person affected by MG (years)? Mean (SD)	9.9 (10.2)
Are there other caregivers for same MG patient (e.g., family members, paid caregivers) (%yes)?	37%
Do you have other dependents (e.g. children, parents) (%yes)?	38%

2. Caregiver burden measured by ZBI-22

- The distribution of caregivers among the scores of the ZBI-22 scale are display in **Figure 1.**
- The mean ZBI-22 score was 24.3 (SD 15), with a median of 23.
- The ZBI score can be divided by the median value of 23 into 2 categories: **HB**: "High burden" scores 24-88 (42%) and **LB**: "Low burden" with scores 0-23.(58%)

Figure 1. Kernel distribution of ZBI-22 scores



Mean	24.3
SD	15
Q1	14
Median	23
Q3	29

3. Caregiver characteristics influencing high versus low CB

- The caregiver age distribution was not different between HB and LB, but HB caregivers were considerably more often female (**Table 2)**.
- When the caregiver is a parent, a child, a sibling or a friend of the patient, they are more likely to be in the HB group.
- HB caregivers reported a significantly greater impact on their ability to work.

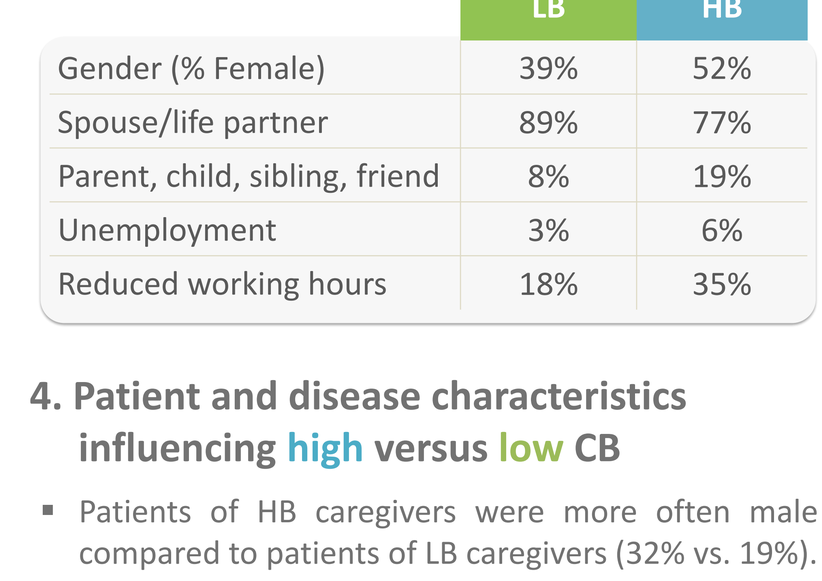
Table 2. Caregiver characteristics

	LB	HB
Gender (% Female)	39%	52%
Spouse/life partner	89%	77%
Parent, child, sibling, friend	8%	19%
Unemployment	3%	6%
Reduced working hours	18%	35%

4. Patient and disease characteristics influencing high versus low CB

- Patients of HB caregivers were more often male compared to patients of LB caregivers (32% vs. 19%).
- HB caregivers cared more often for patients with more severe disease compared to LB caregivers (moderate MG: 42% vs. 32%, severe MG: 32% vs. 18%).
- **Figure 2** clearly visualizes the effect of disease severity on the distribution of ZBI-score

Figure 2. Distribution of ZBI-22 scores by disease severity



5. EQ-5D-5L Dimensions and Utility values for high versus low CB

- Higher proportions of severe-to-extreme problems were reported for all five EQ-5D-5L dimensions, and for 4 selected bolt-on questions when comparing the CB group and the LB group.
- This proportion was significantly higher for anxiety/depression, tiredness, sleep and self-confidence.
- Due to the cross-sectional nature of the dataset, causality cannot be inferred from this analysis.

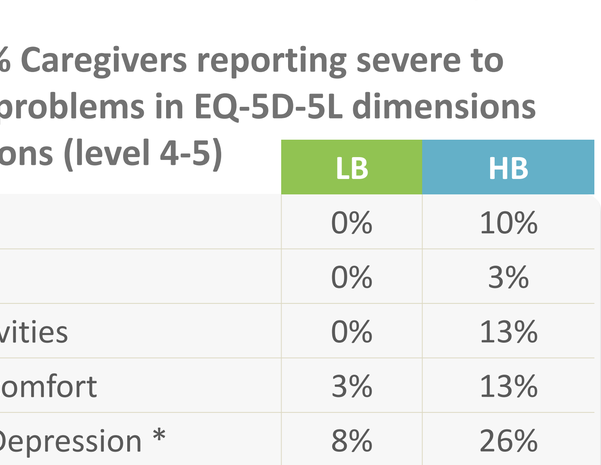
Table 3. % Caregivers reporting severe to extreme problems in EQ-5D-5L dimensions and bolt-ons (level 4-5)

	LB	HB
Mobility	0%	10%
Self-Care	0%	3%
Usual Activities	0%	13%
Pain / Discomfort	3%	13%
Anxiety / Depression *	8%	26%
Tiredness bolt-on *	8%	26%
Sleep bolt-on *	5%	13%
Self-Confidence bolt-on *	0%	31%
Social relationships bolt-on	3%	6%

Significant

- The mean EQ-5D-5L utility value declined with CG severity, but also showed more variability.
- HB caregivers had significantly lower mean EQ-5D-5L utility values (0.818 vs. 0.931, p=0.0234).

Figure 3. Scatter plot of utilities by ZBI-22 scores



Conclusions

- Various characteristics of both patients and caregivers contribute to a high caregiving burden for those supporting individuals with MG.
- This burden significantly impacts the utility values of caregivers, highlighting the need for targeted support and interventions in MG caregiving situations.

Abbreviations*: MG-ADL*: MG-Activities of daily living, *ZBI-22*: Zarit Burden Interview-22 items, *SD*: standard deviation, *N*: Sample size

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