THE BURDEN OF INFORMAL CAREGIVERS OF PEOPLE DIAGNOSED WITH MYASTHENIA GRAVIS

Dewilde S[1], Tollenaar NH[1], De Ruyck F[2], Phillips G[3], Paci S[2]

[1] Services in Health Economics (SHE), Brussels, Belgium, [2]argenx Gent, Belgium, [3]argenx US Inc., Boston, MA, USA

Introduction and objectives

- Informal caregivers play a vital role in supporting individuals via Myasthenia Gravis (**MG**).
- The responsibilities of informal caregivers may range from assisting with daily activities to offering emotional support and coordinating medical appointments.
- In general, caregivers often experience a significant burden due to their responsibilities.
- The caregiver burden (**CB**) of MG is currently understudied.
- **This analysis aimed to assess the burden experienced by informal caregivers of patients suffering from MG and explore its association with disease severity.**

MG Myasthenia Gravis

- Is a chronic autoimmune disorder characterized by muscle weakness.
- Symptoms usually progress from eyelid droop and double vision to problems with swallowing, speaking, breathing, dexterity, and mobility over time [1, 2].

CB Caregiver Burden

"The level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" [3].

Methods

- The CB study recruited pairs of adult MG patients and their informal caregivers from Germany, Italy, Spain and the UK via the MyRealWorld-MG study [4].
- These data were combined with a similar, paper-based survey in France.
- Besides patient and caregiver characteristics, caregiving and disease-specific data were collected.
- Patients were categorized based on their MG-Activities of Daily Living (**MG-ADL**) total score as **mild (0-4)**, **moderate (5-9)** or **severe (>=10)**.
- Caregiver burden was assessed using the Zarit Burden Interview (**ZBI-22**) total score.
- For paired analysis, maximum 7 days were allowed between patient and caregiver data collection.

Results

1. Population characteristics

- The study included **69** caregivers and patients (**Table 1**).
- For paired analyses of the CB presented by categories of MG-ADL, the sample size is reduced to N=39.
- The mean daily caregiving hours were 5.1 h, with 20% of caregivers providing care for 15h-49h and 30% for 50+ hours per week (**Figure 1**).
- A quarter of MG patients had severe MG, and 36% had moderate MG (**Figure 2**).

Table 1. Patient and caregiver demographics

	Caregivers (N=69)	Patients (N=69)
% Female	39%	75%
Mean age (SD)	53.7 (14.1)	50.6 (14.6)
Mean number of hours of caregiving per day (SD)	5.1 (6.5)	

Figure 1. Total hours of caregiving per week

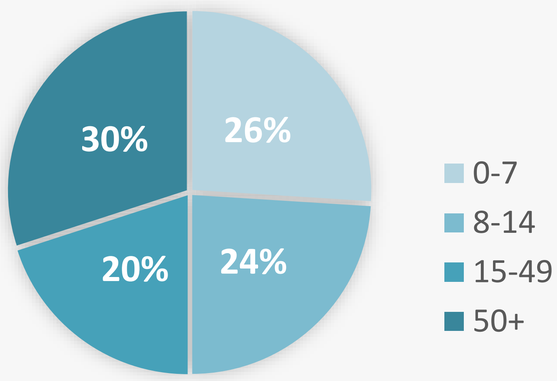
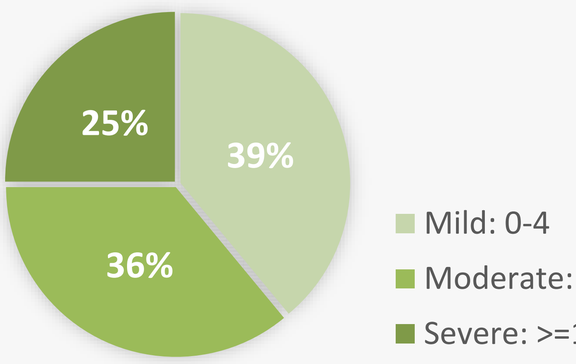


Figure 2. MG-ADL total score of MG patients



2. Mean ZBI-22 scores & distribution of the 5 ZBI dimensions

- Mean ZBI-22 total scores increased from 21.0 among caregivers for patients with mild MG to 29.9 in caregivers for patients with severe MG (**Figure 3**).
- 11% of caregivers for patients with severe MG experienced a severe CB, compared to none for patients with mild and moderate MG.
- Only 22% of caregivers for patients with severe MG caries little or no burden, compared to 50% of caregivers for patients with mild MG.

3. ZBI-22 scores per MG-ADL category

- The proportion of maximal burden (range 0-100%) for each ZBI-22 dimension increased with MG severity, except for the dimension "Finances" (**Figure 4**).

4. Highlighted ZBI-22 items

- About 18% of caregivers reported feeling frequently or almost constantly **stressed** due to their caregiving responsibilities (**Figure 5**).
- 44% expressed constant **fear** about the future.
- Additionally, 36% felt that their patient was highly **dependent** on them
- 30% reported that their patient **relied** on them as if they were the sole source of support.
- **Financial** strain was another notable aspect, with 26% of caregivers frequently or almost always feeling financially ill-equipped to cover both the costs of caregiving and their regular expenses.

Figure 3. ZBI scores by MG-ADL

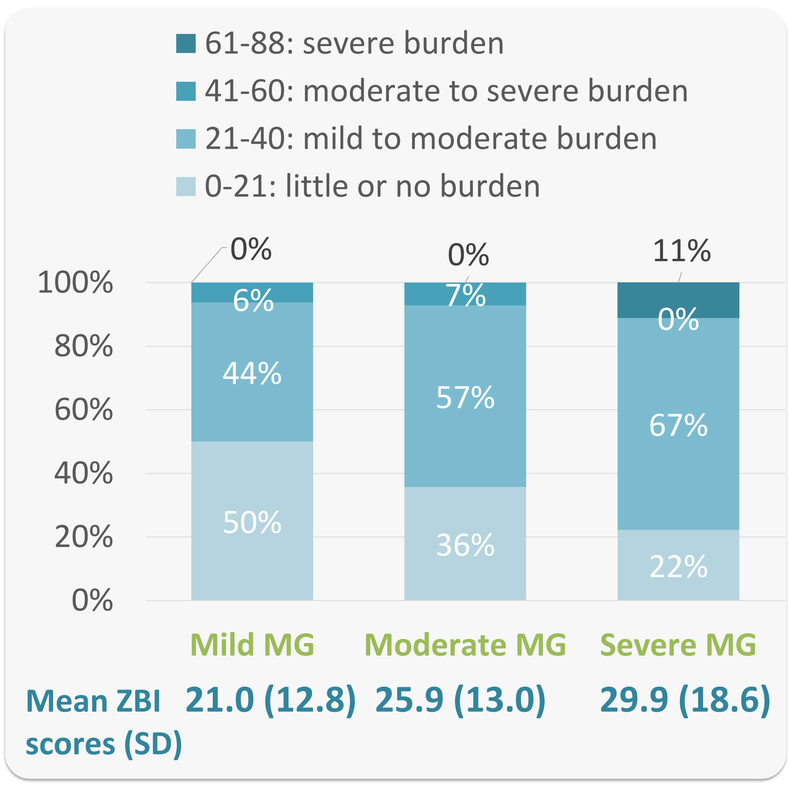
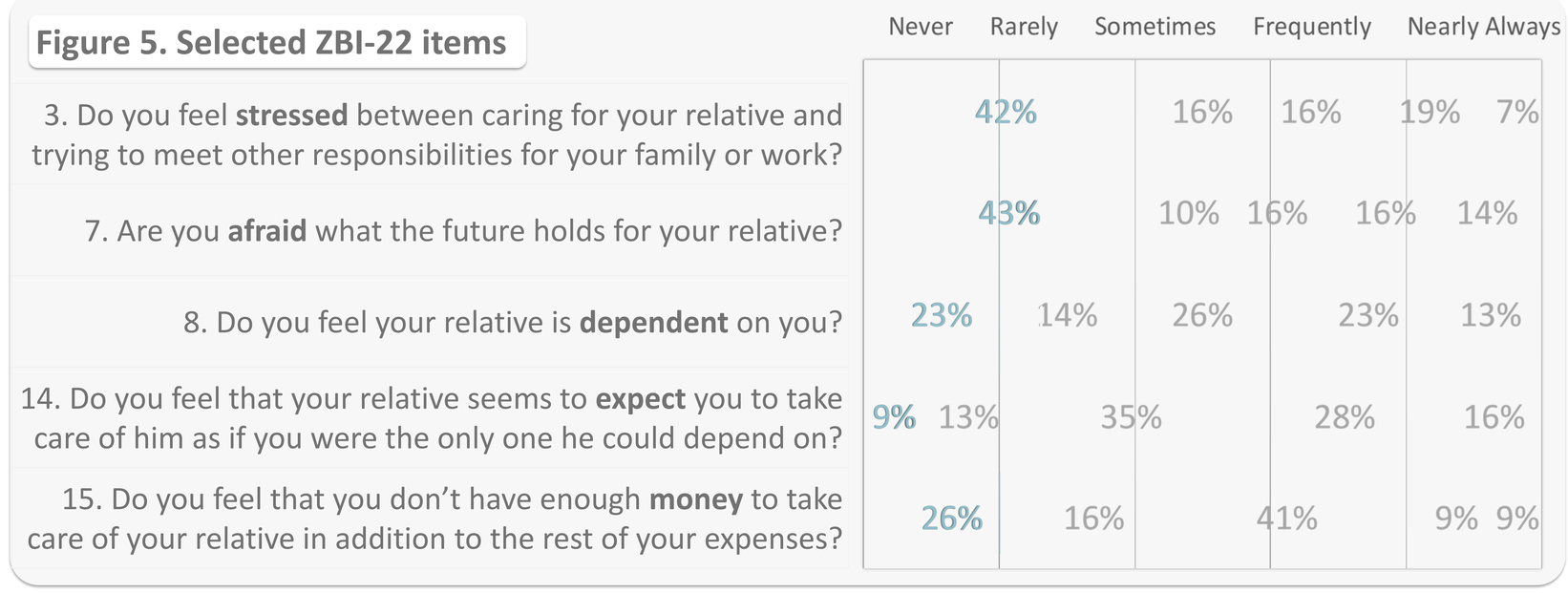


Figure 4. ZBI-22 Dimensions

ZBI-22 Dimensions	Mild MG (N=16)	Moderate MG (N=14)	Severe MG (N=9)
	Proportion of max burden (range 0-100%)		
Burden on relationship	28%	31%	39%
Emotional wellbeing	20%	26%	34%
Social and family life	20%	23%	26%
Finances	25%	43%	19%
Loss of control over life	28%	37%	38%

Figure 5. Selected ZBI-22 items



Conclusions

- Informal caregivers of patients with MG experience a considerable burden across multiple domains.
- The caregiver burden is strongly associated with the disease severity of the person with MG.

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

References:

[1] Gilhus NE et al., Nat Rev Dis Primers, 2019; 5:30

[2] Hehir and Silvestri, Neurol. Clin., 2018; 36:2

[3] Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. Int J Nurs Sci. Oct 10 2020;7(4):438-445.

[4] Berrih-Aknin S et al., BMJ Open, 2021;11

Funding: This study was funded by argenx BV (Gent, Belgium).

Acknowledgments and disclosures: The material in this poster has not been previously presented or published. SP, FDR and GP are employees of argenx. SD, and NT are paid consultants for and receive grant support from argenx.