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The Socio-Economic and Health-Related Quality of Life Impact of Myasthenia Gravis (MG) in Greece

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Objective / Aims

The present study, conducted in Greece, investigated the effect of MG on patients' everyday life and quality of life (QoL).

Methods

A cross-sectional study was performed between October and November 2022, via an electronic questionnaire. Survey questions included: demographics, clinical characteristics, questions on patients' everyday life, and the revised 15-item Myasthenia Gravis Quality of Life scale (MG-QoL15r), a disease-specific health-related quality of life (HRQoL) instrument [1]. The MG-QoL15r scale was translated and culturally adapted in Greek. Recruitment of participants was performed via the Hellenic MG Association. Specifically, participants received an invitation letter, containing all information regarding the study and a link to the electronic questionnaire. Patients could participate in the study if they fulfilled the following criteria: (1) Members of the H-MGA with an active e-mail address, (2) ≥ 18 years old, (3) had a confirmed diagnosis of MG. Questionnaire completion was anonymous, upon informed consent. The Research Ethics Committee of the University of West Attica approved the study protocol.

Results

In total, 323 invitations were sent; 123 respondents filled in the survey (response rate: 38.10%) and 99 questionnaires were included for analysis. The median (IQR) age of the participants was 48.50 (13.50) years, 76 (76.80%) were females and the majority of participants reported being married (57.60%). The median (IQR) number of children was 1 (2). The median (IQR) number of persons in the household was 2 (1). The majority (49.50%) of participants reported high educational level (University degree and higher).

Most participants (86.90%) reported a diagnosis of generalized MG. The median (IQR) time from diagnosis of MG was 13 (13.50) years. 54.50% of participants reported having additional chronic health conditions. Moreover, 58.60% of participants had a disability percentage greater than 50% as a result of MG, whereas 94.90% of patients reported taking medications for their condition.

The mean ± SD reported MG-QoL15r score was 13.50 ± 7.70 (the maximum score is 30 and corresponds to the highest impact of the disease on HRQoL).

For the vast majority of patients, MG has an impact on their everyday life (Table 1). Only a small proportion reported no impact of MG on their everyday routine. For patients with severe restriction of everyday routine, help is predominantly provided by a family member that lives with them (in 51.90% of cases).

Regarding MG's impact on employment status, 16.20% of participants reported that they cannot work due to MG, whereas 26.20% were forced to change jobs or work fewer hours as a consequence of MG. In addition, 22.20% retired due to MG-related disability (Table 1).

MG-related healthcare costs also had an effect on household economic status for 85.26% of respondents: among those, 18.20% mentioned an "Important/Very important" effect (Table 1).

Table 1: Impact of MG on participants' employment status, everyday routine and household economic status

Impact of MG diagnosis on patients' employment status		
	n	**%**
No impact on employment status	27	27.30
Stayed on the job but had to work fewer hours	14	14.10
Had to change job	12	12.10
Unable to work due to MG	16	16.20
Retired due to MG-related disability	22	22.20
Impact of MG diagnosis on patients' everyday routine		
	n	**%**
No change in everyday routine	19	19.20
Mild restriction in everyday routine	53	53.50
Severe restriction of everyday routine – help from another person/carer necessary	26	26.30
Inability to perform everyday routine without help from another person/carer	1	1.00
Perceived impact of MG-related healthcare costs on household economic status (during the last 12 months)		
	n	**%**
None	14	14.10
Minor impact	39	39.40
Some impact	24	24.20
Important impact	11	11.10
Very important impact	7	7.10
NA	4	4.00

Conclusions

This is the first study to use a MG-specific QoL questionnaire in Greece. Patients in our study reported a high MG-QoL15r score, highlighting the negative effect of MG on Greek patients' HRQoL. This is in accordance with other studies that used the same instrument [2] as well as the original MG-HRQoL scale [3,4]. The present study also highlights the significant impact of MG on many participants' ability to work and the dependence on a carer on an everyday basis. As MG tends to affect young people which are of working age, it is important to develop employment policies that promote inclusion of people with disability. Furthermore, households are burdened by disease-related health spending. The aforementioned findings were brought forward also in the case of Greek patients with Multiple Sclerosis [5]. Further analysis is needed to identify those most affected.

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References:

[1] Burns TM, Sadjadi R, Utsugisawa K, et al. International clinimetric evaluation of the MG-QOL15, resulting in slight revision and subsequent validation of the MG-QOL15r. Muscle Nerve. 2016 Dec;54(6):1015-1022. doi: 10.1002/mus.25198.

[2] Dewilde S, Philips G, Paci S, et al. Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG. BMJ Open 2023;13:e066445. doi:10.1136/bmjopen-2022-066445

[3] Contreras, JP, Salinas, R, Vidal, C, Hoffmeister, L, Wolfe, GI, Cea, G. Validation of Spanish version of 15-item myasthenia gravis quality-of-life questionnaire. Acta Neurol Scand. 2021; 144: 546–552. https://doi.org/10.1111/ane.13486

[4] Wu X, Li RY, Ye XB, Wang N. Reduced quality of life in myasthenia gravis patients: A study on 185 patients from China. Front Neurol. 2023 Jan 12;13:1072861. doi: 10.3389/fneur.2022.1072861. PMID: 36712441; PMCID: PMC9878687.

[5] Karampli E, Tsiantou, V, Koulierakis, G, et al. Healthcare utilisation and perceived health needs of multiple sclerosis patients in Greece: evidence from a qualitative study. Value in Health, Vol. 22, Supplement, S752, Published in issue: November, 2019