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ORIGINAL RESEARCH

Patient Perceptions of Needs and Expectations Regarding the Current Management of Myasthenia Gravis: A Biopsychosocial Study

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ABSTRACT

Introduction: Information on the biopsychosocial needs and healthcare experiences of people living with myasthenia gravis (PwMG) in Spain remains limited. This study aimed to describe self-reported experiences and provide an overview of the condition's physical, psychological, and social impact.

Methods: A multicenter cross-sectional epidemiological study was conducted through a nationwide online survey completed by a geographically stratified sample of PwMG across 13 of Spain's 17 Autonomous Communities.

Results: A total of 208 valid responses were analyzed (mean age 58.8; SD 15.2 years; range 16–94; 55.8% men). Nearly half (49.5%) reported generalized myasthenia gravis (MG), and 36.4% held a disability certificate. Although most respondents perceived their health as good or very good (45.2%), pain or discomfort affected 51.5%, and half reported emotional symptoms such as anxiety or depression. The mean EQ-VAS score was 66.1 (SD 20.6), reflecting a reduced health-related quality of life (HRQoL) compared with the general population. While satisfaction with access to and quality of medical care was generally high, many patients expressed concerns about limited psychological support and

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insufficient social care for themselves and their caregivers.

Conclusion: PwMG in Spain generally perceive their health positively, but significant unmet needs persist in psychological care and social protection. These findings underscore the importance of comprehensive patient-centered strategies that integrate medical, emotional, and social support to improve quality of life in MG.

Keywords: Myasthenia gravis; Biopsychosocial impact; Healthcare experiences; Psychological support; Social support

Key summary points

Why carry out this study?

Myasthenia gravis (MG) is a chronic autoimmune neuromuscular disease with a substantial biopsychosocial burden that remains under-recognized, particularly among individuals in active personal and professional stages of life.

This study explored how people living with MG in Spain perceive and experience their condition, examining its impact on daily functioning, quality of life, emotional well-being, work and finances, and the social and healthcare support they receive.

What has been learned from the study?

Health-related quality of life (HRQoL) in people with myasthenia gravis is lower than in the general Spanish population, particularly among women and those with more severe disease. Despite therapeutic advances, many physical symptoms remain, and psychological and social challenges (particularly those related to employment and financial impact) are still insufficiently addressed. Nevertheless, most respondents did not feel stigmatized.

The study highlights that although most patients have adequate access to medical care, many continue to experience unmet psychosocial needs, emphasizing the importance of holistic, patient-centered management and coordinated health and social policies to improve quality of life.

INTRODUCTION

Myasthenia gravis (MG) is a chronic autoimmune condition characterized by fluctuating skeletal muscle weakness due to antibody-mediated interference at the neuromuscular junction [1, 2]. It is a relatively uncommon condition, with an estimated annual incidence of 1.7–21.3 cases per million people and a worldwide prevalence of 15–179 cases per million people [3, 4]. The disorder affects essential muscle groups responsible for eye movement, facial expressions, chewing, swallowing, and breathing. MG can range from mild to life-threatening, with symptoms worsening as muscles are used throughout the day [1, 2]. While it affects people of all ages, there are two peaks of incidence: in women under 40 and men over 60 [1, 2].

MG has a profound impact on patients' quality of life, influencing their physical abilities [5, 6] as well as their emotional and social well-being [7]. Studies consistently show patients with MG face challenges in basic activities such as walking, self-care, and daily tasks due to muscle weakness and fatigue [7–15]. Additionally, many MG participants report significant emotional strain, including anxiety and depression, linked to the unpredictability of symptom flare-ups and the chronic nature of the condition [7–16]. The psychosocial aspects of MG are further compounded by the lack of sufficient social support and inadequate healthcare resources, which leave many patients feeling underserved and unsupported in managing their condition [7, 9, 14]. In recent years, there have been significant advancements in the treatment of MG [17–20]. However, its overall impact on patient's quality of life has not been thoroughly studied. Furthermore, only a few studies have examined

the first-person perspective of patients regarding the complex experience of living with MG [5–7]. This type of research could lead to a more comprehensive understanding of how MG impacts various aspects of life and, consequently, assist in developing strategies to address the biopsychosocial elements of the condition.

Building on this context, the present study seeks to advance understanding of the lived experience of PwMG in Spain through a comprehensive evaluation of the self-perceived biopsychosocial burden. The primary objectives are: (1) to assess the impact of MG on daily functioning, health-related quality of life (HRQoL), and disability; (2) to examine patients' perspectives on the effectiveness of current treatments; and (3) to evaluate the availability and adequacy of healthcare and social support systems. Together, these aims are intended to provide an epidemiological perspective on the holistic impact of MG in contemporary Spain, thereby supporting the development of more patient-centered and integrated management approaches.

METHODS

The study methods are described according to the STROBE statement guidelines [21].

Study Design

This was an observational, descriptive, and cross-sectional study conducted across multiple healthcare centers nationwide. Data were collected using a self-administered patient questionnaire.

The study adhered to the ethical principles outlined in the Declaration of Helsinki (Fortaleza revision) and Spanish Law 14/2007 on biomedical research. The protocol was reviewed and approved by the Ethics Committee of Hospital de la Santa Creu I Sant Pau, Barcelona, Spain (Code UCIS-MG-2022-03).

All participants provided written informed consent prior to inclusion. Participation was voluntary, and participants were informed of their right to withdraw at any time without consequence. The survey posed no risk to participants, as it collected self-reported information without any intervention or modification of ongoing treatments. Data confidentiality was strictly maintained, and all identifying information was anonymized in accordance with the European Union's General Data Protection Regulation (GDPR).

The study protocol was not preregistered, as it formed part of a broader national observational initiative to evaluate the current standard of care for PwMG in Spain.

Context

The study was conducted in 28 public and private hospitals throughout Spain, with the collaboration of 53 neurologists from the Neuromuscular Diseases Study Group of the Spanish Society of Neurology.

The research network was stratified by autonomous communities according to regional population distribution. Participating neurologists consecutively invited eligible patients to complete the online self-administered questionnaire between October 2023 and February 2024.

Eligibility Criteria and Participant Selection Methods

Inclusion criteria: Patients aged ≥ 18 years, of either sex, with a confirmed diagnosis of MG and routine outpatient follow-up by participating neurologists were eligible for inclusion.

Exclusion criteria: Patients unable to complete the questionnaire independently (due to linguistic, cognitive, or functional limitations) were excluded.

Participants could withdraw their data at any point, even after completing the questionnaire, if they no longer wished to participate.

Variables

A 93-item closed-ended questionnaire assessed multiple aspects of the impact of MG on daily activities, healthcare access, and quality of life. The survey addressed seven key domains: 1. demographic information; 2. independence and empowerment; 3. access to healthcare and

treatments; 4. support for relatives, friends, and unpaid caregivers; 5. work flexibility and accessibility, volunteering and education; 6. financial resources; and 7. policies and practices promoting equality.

The survey primarily consisted of closed-ended items ($n = 92$) designed for self-administration, minimizing potential interviewer or provider influence on responses. One additional open-ended question invited participants to describe, in their own words, what it means to live with MG.

Questionnaire development followed a structured three-phase process:

1. Formation of the Scientific Committee: Six members (including neurologists specializing in MG, research methodologists, and representatives from patient associations) reviewed and approved the initial draft based on a targeted literature review. The committee also referenced a previously validated biopsychosocial impact questionnaire, developed and applied by the same methodological team in an earlier study on another neurological disorder, to inform the structure and content of the present draft [22].

2. Qualitative Research Phase: A face-to-face session with MG specialists, patients, and family members was conducted, using a nominal group technique (Crawford Slip Method) [23] to gather structured feedback on the draft questionnaire.

3. Pilot Testing: A small group of 9 patients completed the electronic version to evaluate comprehensibility, completion time, and usability. Minor linguistic and layout adjustments were made based on their feedback.

Additionally, the EuroQoL-5D-3L (EQ-5D-3L) instrument was used to measure HRQoL across five dimensions—mobility, self-care, usual activities, pain/discomfort, and anxiety/depression—and included a visual analogue scale (EQ-VAS) for overall health [24].

Data Sources and Measurements

Data collection was conducted using an electronic self-administered questionnaire accessible via a secure, restricted-access website. All personal data were dissociated from responses to preserve anonymity and confidentiality. Each participant received an individual access code, preventing duplicate submissions.

Survey responses were provided through dichotomous (yes/no) items and 5-point Likert-type scales assessing frequency (1 = never; 5 = always) or perceived importance (1 = not at all; 5 = totally). An additional open-ended question at the end of the survey invited participants to describe what it means to live with MG; responses are summarized in Table 5 (see below).

The questionnaire was completed online via a web platform, allowing participants to respond at their convenience, while built-in validation checks ensured accuracy and completeness. All questionnaires were completed exclusively by patients, without any external assistance or interference, thereby ensuring that all data reflected participants' own perceptions and experiences.

As described in the Variables section, the online questionnaire included multiple thematic blocks addressing different aspects of patients' experiences. A total of 208 participants initiated the survey, with completion decreasing slightly across sections (203 for block 2, 199 for block 3, 197 for blocks 4 and 5, and 194 for blocks 6 and 7). This progressive attrition was expected given the survey length and voluntary nature of participation. Missing or incomplete responses were addressed through case-wise exclusion, and all analyses were based on valid data only. No data imputation was applied.

Biases

To minimize selection bias, investigators were instructed to consecutively recruit the first eligible patients attending routine follow-up consultations, beginning from a randomized start date assigned to each geographic region. Recruitment continued until each investigator reached a minimum quota of five patients.

Sample Size

A minimum nationwide sample size of 196 patients was calculated to ensure adequate precision (± 7%) and a 95% confidence level for estimates of categorical variable proportions.

The calculation was based on the formula $n = 1.96^2 \times (0.5^2/\varepsilon^2)$, assuming the most conservative scenario ($p = q = 0.5$). Ultimately, 208 patients who met all inclusion criteria were enrolled, exceeding the required minimum and thereby reinforcing the precision and reliability of the study findings.

Statistical Analysis

Descriptive statistical methods were used to analyze the collected data. Quantitative variables were summarized using measures of central tendency and dispersion, including the mean, median, range, and standard deviation, which provided an overview of average values and variability. Categorical variables were described as absolute and relative frequencies, including both absolute frequencies and proportions, facilitating interpretation of the prevalence and distribution of specific categories within the dataset.

To compare and identify potential differences in the distribution of responses among subgroups of interest (such as sex, age, and disease severity), the Student's *t* test was applied for continuous variables (e.g., EQ-VAS scores), while the chi-square test was used for categorical variables, including Likert-scale and dichotomous items. A p value < 0.05 was considered statistically significant.

Missing data were handled as missing for analytical purposes. All analyses were performed using SPSS Statistics, version 25.0 (IBM, Armonk, NY, USA).

In addition to the quantitative analysis, qualitative data obtained from the open-ended question were examined through an inductive thematic content analysis. All responses were read repeatedly and segmented into units of meaning, which were manually assigned initial codes. These codes were then grouped into categories and, through an iterative process, organized into seven overarching thematic dimensions describing how participants characterized myasthenia gravis: disease definition, symptomatology, variability, impact on daily life, emotional aspects, treatment and management, and personal experiences or advice.

Coding was conducted independently by two researchers with experience in qualitative research. Discrepancies were discussed on a case-by-case basis until consensus was reached, and a third researcher was consulted when agreement could not be achieved. The analysis was supported by MAXQDA 24 (VERBI Software, Berlin, Germany), maintaining an audit trail to ensure transparency and methodological rigor.

RESULTS

Participant Characteristics

A total of 208 PwMG were recruited from 13 of Spain's 17 Autonomous Communities. The mean age of the participants was 58.8 years (SD 15.2), and 55.8% were men. Sociodemographic characteristics are summarized in Table 1. Most participants were married (65.4%) and had at least a secondary school education (74%), while nearly one-third were retired and 21.2% received disability pensions. Only 17.5% were affiliated with MG-related associations or foundations.

Clinical Profile and Quality of Life

Clinical characteristics and quality-of-life measures are summarized in Table 2. The mean time since symptom onset was 8.5 years (SD 9.7). Almost half (49.5%) had generalized MG, while one-third (32.2%) presented with ocular MG. More than one-third (36.4%) held a certified disability status, mainly between 33 and 66%.

Regarding perceived health, around half of PwMG (45%) rated their health as 'good' or 'very good'. The average self-rated health score was 3.3 (SD 0.9) on a 1–5 scale, and the mean EQ-VAS score was 66.1 (SD 20.6). According to the EuroQoL-5D-3L assessment, pain/discomfort or some degree of anxiety or depression were each reported by about half of participants (51% and 44%, respectively) and mobility limitations by 32%.

As illustrated in Table 3, participants with ocular MG reported markedly better quality-of-life scores than those with generalized MG: 74.3 (SD 15.7) versus 59.2 (SD

Table 1 Sociodemographic characteristics of participants

n	208
Men; *n* (%)	116 (55.8)
Age, mean (SD), years	58.8 (15.2)
Education level; *n* (%)	
Can read and write	7 (3.4)
Primary education	25 (12.0)
Secondary education or equivalent	22 (10.6)
High school or equivalent	64 (30.8)
University degree(s)	87 (41.8)
Doctorate	3 (1.4)
Marital status; *n* (%)	
Single	27 (13.0)
Married	136 (65.4)
Cohabiting	14 (6.7)
Separated	4 (1.9)
Divorced	16 (7.7)
Widowed	11 (5.3)
Employment status; *n* (%)	
Don't know/no answer	2 (1.0)
Others	6 (2.9)
Retired	68 (32.7)
Disability pensioner	44 (21.2)
Unemployed	8 (3.9)
Temporary work disability	13 (6.3)
Leave of absence	1 (0.5)
Student	6 (2.9)
Part-time employed	7 (3.4)
Full-time employed	53 (25.5)

21.7); $p < 0.001$. Mean EQ-VAS scores were slightly higher among men than women: 68.6 (SD 19.1) versus 62.9 (SD 22.1); $p = 0.025$, whereas no differences were observed by age group: < 50 years 65.2 (SD 21.6) versus ≥ 50 years 66.4 (SD 20.3); $p = 0.359$.

Overall, these results suggest that quality of life was significantly lower among participants with generalized MG and among women, while remaining largely similar across age groups. Complementary analyses of other variables by sex, age, and disease severity are provided in Supplementary Material (Tables S1–S3).

Independence, Empowerment and Information Access

The World Health Organization defines empowerment as "a process through which people gain greater control over decisions and actions affecting their health" and emphasizes that it should be understood as both an individual and a community process. In the context of myasthenia gravis and other chronic conditions, empowerment reflects the patient's ability to develop knowledge, confidence, and self-management skills, thereby becoming an active participant in their own care [25].

According to Fig. 1a, b, most participants (60.6%) did not feel isolated or stigmatized because of MG, although around one in five reported some degree of isolation. In this context, stigma refers to the social discredit or sense of shame attached to a health condition, which may lead to withdrawal or negative societal reactions [26]. Nearly two-thirds (64%) expressed no fear of professional or social rejection. MG was perceived to interfere moderately with daily activities by 60% of participants, with specific limitations in education, social participation, and mobility outside the home. Two-thirds stated that their quality of life depended on medication use, and almost 60% relied on medical aids. While only 10% frequently required physical rehabilitation, 64% considered psychological rehabilitation important for well-being.

Regarding healthcare communication, 86% felt their neurologist considered patients' and families' opinions during treatment decisions, but this proportion dropped with other

Table 2 Clinical characteristics and quality-of-life measures

n	**208**
Time since first MG symptom, mean (SD), years	8.5 (9.7)
Self-identified MG situation; *n* (%)	
Remission	26 (12.5)
Refractory MG	13 (6.3)
Ocular MG	67 (32.2)
Manifest myasthenic crisis	9 (4.3)
Imminent myasthenic crisis	0 (0.0)
Generalized MG	103 (49.5)
Unknown	17 (8.2)
Disability certificate, *n* (%)[a]	
No	131 (63.6)
Yes, less than 33%	7 (3.4)
Yes, between 33 and 64%	53 (25.7)
Yes, 65% or more	15 (7.3)
Self-assessment of health status; *n* (%)[a]	
Very bad	6 (2.9)
Bad	33 (16.0)
Fair	74 (35.9)
Good	76 (36.9)
Very good	17 (8.3)
EuroQoL-5D-3L; *n* (%)[b]	
Mobility; *n* (%)[b]	
I have no problems in walking about	139 (68.1)
I have some problems in walking about	64 (31.4)

Table 2 continued

n	**208**
I am confined to bed	0.5 (1.0)
Self-care; *n* (%)[b]	
I have no problems with self-care	171 (83.8)
I have some problems washing or dressing myself	29 (14.2)
I am unable to wash or dress myself	4 (2.0)
Usual activities (e.g. work, study, housework, family or leisure activities); *n* (%)[b]	
I have no problems with performing my usual activities	94 (46.1)
I have some problems with performing my usual activities	100 (49.0)
I am unable to perform my usual activities	10 (4.9)
Pain/discomfort; *n* (%) [b]	
I have no pain or discomfort	99 (48.5)
I have moderate pain or discomfort	95 (46.6)
I have extreme pain or discomfort	10 (4.9)
Anxiety/depression; *n* (%)[b]	
I am not anxious or depressed	113 (55.4)
I am moderately anxious or depressed	78 (38.2)
I am extremely anxious or depressed	13 (6.4)
EQ-VAS [c]; mean (SD)	
66.1 (20.6)	

EuroQoL-5D-3L European Quality of Life-5 Dimensions-3 Levels, EQ-VAS European Quality of Life Visual Analogue Scale, *MG* myasthenia gravis

[a] $n = 206$

[b] $n = 204$

[c] Respondents' overall assessment of their health on a scale ranging from 0 (worst imaginable health) to 100 (best imaginable health)

Table 3 Comparison of QoL for PwMG based on severity, age and gender

		QoL*	*P***
Severity of MG	Ocular MG	74.5 (15.7)	**< 0.001**
	Generalized MG	59.2 (21.7)	
Sex	Men	68.6 (19.1)	**0.025**
	Women	62.9 (22.1)	
Age (years)	< 50	65.2 (21.6)	0.359
	> 50	66.4 (20.3)	

Significant values in bold

*Mean (SD)

** Student's *t* test

specialists (60%) and other health professionals (53%). Most received treatment information from neurologists, though fewer than 40% had been informed about clinical trial participation opportunities.

Information sources on MG management are shown in Fig. 2: healthcare professionals were the primary source (68%), followed by digital channels and journal articles.

Access to Care and Treatment Perceptions

Overall satisfaction with healthcare services was high: 73% were satisfied or very satisfied with their access to services, and a similar proportion rated care quality as good (Fig. 3). Most participants (68%) reported improved quality of life as a result of the healthcare received.

Specific MG treatments were perceived as quite or completely effective by about 70% of participants, whereas treatments for other symptoms were rated as moderately effective or better by less than half. Table 4 details perceived

Fig. 1 a, b Questions about independence and empowerment

Fig. 1 continued

treatment effectiveness by symptom category. In general, therapies for vision disturbances and fatigue were considered most effective, while those for anxiety and depression were less so.

Fewer than 20% had received physical or occupational rehabilitation, though nearly 90% of these found it at least moderately effective. Most participants did not require home or respite services, but 14% reported needing such services without access. Preventive care (e.g., vaccinations) was consistently available to roughly two-thirds.

At diagnosis, 60% felt healthcare staff were sensitive to the emotional impact of the disease, and 64% reported sufficient time for questions. However, more than half (57%) said they were not adequately informed about access to psychological treatment. Most considered their neurologists experienced in MG management (77%), compared with 44% for nurses. Coordination between healthcare professionals was considered good or excellent by 51% of participants. Over half had never needed to change neurologists due to organizational reasons, suggesting good continuity of care.

Awareness of MG patient associations was limited (75% had received no information at diagnosis), though nearly all agreed that greater visibility of these associations could improve care coordination.

Family and Caregiver Support

As shown in Fig. 4, most participants reported limited institutional support for family members and informal caregivers. Nearly two-thirds (63%) stated that families received little or no assistance, and around half (43%) believed caregivers lacked adequate training or resources to help them manage the disease effectively.

Psychological support for families was scarce: approximately three-quarters (73%) of

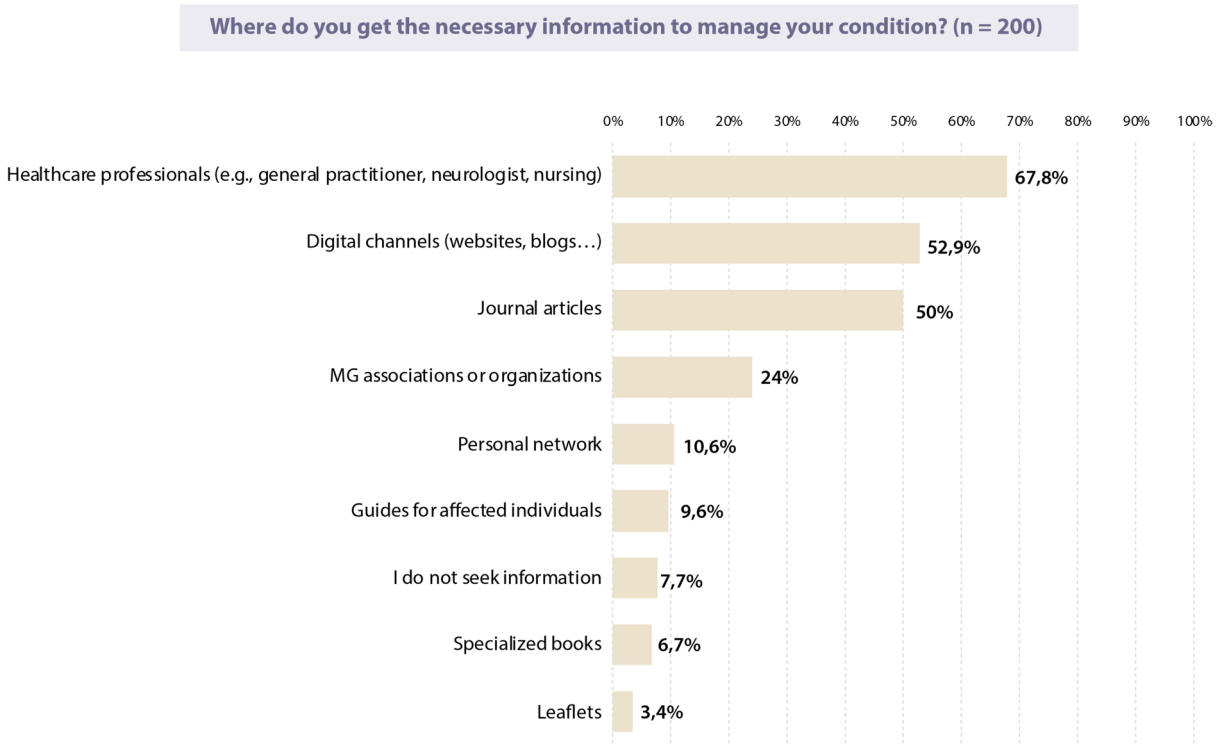


Fig. 2 Information sources utilized by patients regarding the management of myasthenia gravis

respondents reported that caregivers did not have access to mental health services. A large majority (88%) expressed the need for joint educational programs for patients and caregivers.

The impact of MG on family dynamics was also evident. Many participants noted that caregiving responsibilities were often undervalued or invisible, and that a general lack of awareness about MG in workplaces and society increased caregivers' stress. Around two-thirds (65%) of respondents felt that poor societal understanding of the disease had a substantial impact on caregivers. MG affected the relationships and family leisure time of two-thirds (63%) of PwMG. Nevertheless, MG was not perceived to have significantly influenced decisions about having children.

Work, Volunteering, and Educational Accessibility

Nearly all participants (93%) had previous work experience and as illustrated in Fig. 5, many indicated that stopping work due to MG had negatively affected their self-esteem and sense of purpose. Although more than half (53%) had not yet changed their employment status, a considerable proportion (18%) reported reducing their working hours or adapting their roles because of MG-related symptoms.

Barriers in the workplace were common. Around one-third (33%) of PwMG reported difficulties commuting to work, while nearly three in ten (28%) indicated that medical appointments or treatments interfered quite a bit or completely with their job performance. Only a small minority reported that their employers had implemented accommodations or adjustments to facilitate continued employment. Professional advancement was often perceived as limited (38%), reflecting the broader challenges of maintaining stable employment with MG.

Support for alternative forms of engagement—such as volunteering, educational courses, or recreational activities—was minimal.

Around one in four (26%) participants had pursued educational opportunities after the

Fig. 3 Questions about access to effective treatments

onset of MG, and most (82%) noted that institutions rarely adapted to their physical or cognitive needs.

Financial Resources and Support

As detailed in Fig. 6a, b, financial strain was common among respondents. About one-third (30%) reported experiencing economic difficulties after the onset of MG. Nevertheless, most (89%) indicated that they had not had to abandon medical treatments, rehabilitation, or care programs for financial reasons.

Information about available financial aid was scarce. Only a small minority (13%) of participants were aware of public assistance for home adaptations, medications, or assistive devices. Nearly all (99%) described the application processes for financial aid as complex and time-consuming, and only a few (1.5%) considered the eligibility criteria fair.

Access to standard financial products such as insurance or bank loans was also limited (88%), suggesting that MG can negatively affect long-term financial security.

Policies and Practices Promoting Equality

Most participants (87.1% of 194) perceived insufficient institutional and political initiatives to address the inequalities associated with MG. Just over half (53.6%) were aware of the existing legal frameworks designed to protect the rights of people with disabilities against social discrimination, suggesting limited awareness and weak implementation of current regulations.

When asked about the development of public policies addressing the vulnerability and social exclusion of individuals affected by MG, nearly half (48.8%) perceived that no such initiatives were being developed.

Table 4 Perceived treatment effectiveness for most common myasthenia gravis symptoms

Do you believe that effective treatments are provided to manage the most common symptoms of MG? ($n = 198$)							
		I don't need it (%)	Not at all (%)	Slightly (%)	Moderately (%)	Quite a bit (%)	Completely (%)
Sensory symptoms	Vision disorders	17.2	4.0	15.7	18.7	24.2	20.2
	Sensory disorders	42.4	5.1	12.6	18.2	14.1	7.6
Physical symptoms	Fatigue	21.2	7.6	16.7	24.7	22.2	7.6
	Pain	50.0	6.6	11.1	16.2%	11.6	4.5
	Loss of strength	21.8	6.6	20.3	20.3	22.8	8.1
	Balance disturbances	40.9	9.1	13.1	19.2	10.6	7.1
	Gait disorder	43.4	10.1	9.6	17.7	13.1	6.1
	Motor coordination disorders	51.3	7.6	10.2	14.7	10.2	6.1
	Swallowing difficulties	35.0	5.6	13.7	18.8	14.7	12.2
	Speech disturbances	39.4	7.6	13.1	15.7	13.6	10.6
Emotional symptoms	Depression	45.5	15.2	21.2	7.6	6.6	4.0
	Anxiety	42.9	14.6	22.2	9.1	7.6	3.5
Other symptoms[a]		71.7	6.1	7.6	7.1	4.5	3

[a]Additional reported symptoms included respiratory difficulties ($n = 10/198$, 5.1%), sleep disturbances ($n = 4/198$, 2.0%), and memory impairment ($n = 3/198$, 1.5%)

Awareness of disability-related legislation was generally low, and most participants (71%) believed that public policies aimed at reducing social exclusion or promoting equality for PwMG were either poorly developed or inadequately implemented. These findings underscore a clear perception of insufficient institutional commitment and limited political action to ensure equality, visibility, and protection for individuals living with MG and their families.

Open-ended responses are summarized in Table 5. Based on the participants' narratives, the way they described myasthenia gravis can be summarized across seven thematic dimensions: disease definition, most frequent symptoms, variability of the condition, impact on daily life, emotional and psychological aspects, treatment and management, and personal advice or experiences. Participants emphasized the unpredictable and disabling nature of MG, the resulting emotional burden, and the need for greater social visibility and coordinated care.

DISCUSSION

This national study provides a comprehensive overview of the personal, social, and healthcare impact of MG in Spain, derived from patient-reported outcomes. The design enabled collection of patient experiences across multiple

Fig. 4 Questions about support for family members, friends, loved ones, and unpaid caregivers

regions, enhancing the generalizability of the findings.

The results show that MG affects multiple dimensions of daily life beyond physical symptoms, including emotional well-being, family dynamics, work participation, and perceived equality in access to care and social resources. Despite generally positive evaluations of medical treatment, many participants reported unmet psychological and social needs, insufficient support for caregivers, and limited institutional initiatives to address the inequalities associated with MG.

The sample was slightly male-dominated (55.8% male) with a mean age of 58.8 years, aligning with MG's known bimodal age distribution, which tends to affect younger women and older men [1, 2]. Despite more than 70% of the participants having a secondary school education or higher and 40% holding a university degree, only 30% of the participants were actively employed, which may illustrate the disabling nature of MG and the need for frequent medical interventions or symptom management. This pattern is consistent with other previous studies that report high early retirement rates and reduced work capacity in patients with MG [5, 6, 14, 15, 27].

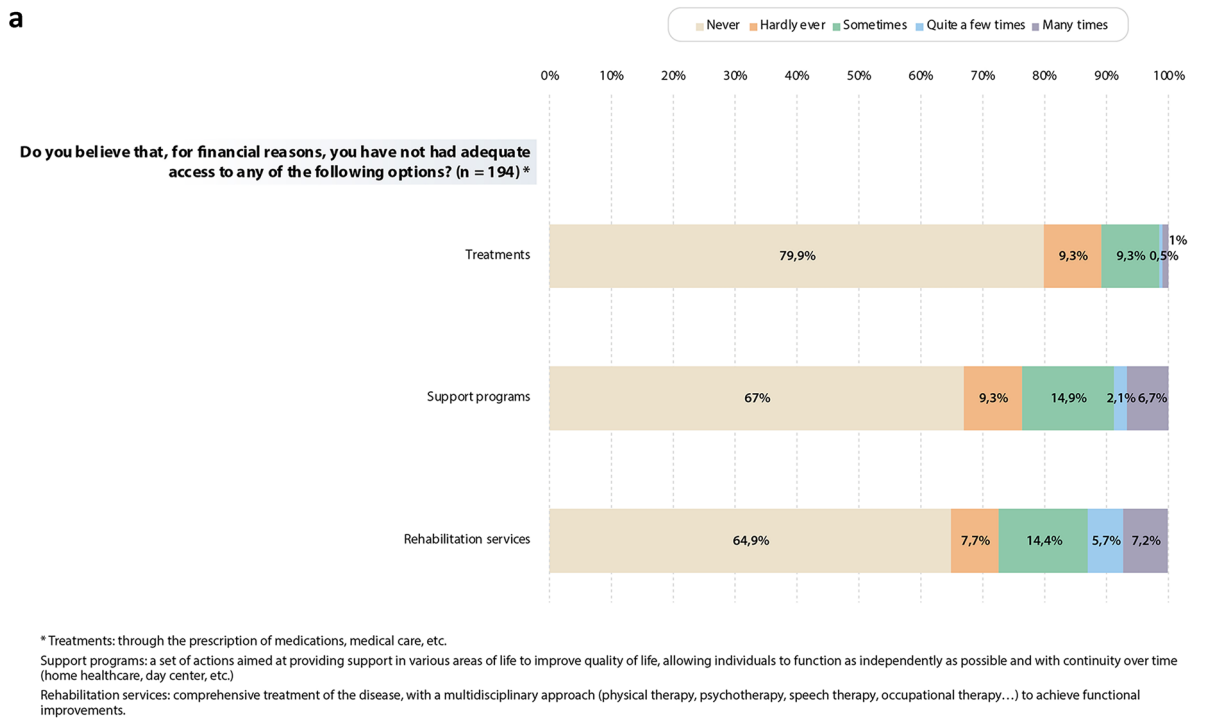
Our findings are consistent with previous studies showing that MG imposes a substantial physical and psychosocial burden on patients [5, 6, 9, 12–16, 28, 29]. More than 30% of participants reported mobility difficulties, 46.6% experienced moderate pain or discomfort, and 49% faced challenges in usual activities (such as work and household tasks), with 4.9% completely unable to perform such tasks due to MG's debilitating effects. Emotional health was also markedly affected, as many participants reported anxiety and depression. The mean EQ-VAS score of 66.1 reflects a lower HRQoL than that of the general Spanish population (75.0–77.1 depending on age and health status) [30, 31], with values particularly reduced among individuals with generalized MG compared to those with ocular forms and slightly lower in women.

Fig. 5 Questions about flexibility and accessibility to work, volunteering, and education

Together, these findings highlight the broad physical and emotional burden of MG and reinforce the need for comprehensive, multidisciplinary management strategies, encompassing pain control, psychological support, and interventions that promote autonomy in daily life, including rehabilitation and vocational training initiatives. Such an integrated approach is essential not only to address the physical manifestations of MG but also to mitigate its psychological and social consequences, aligning patient care with a holistic model of health.

Regarding independence and empowerment, the study indicates that, while most participants do not feel stigmatized by their condition (with 60.6% reporting no sense of isolation), there are significant limitations in the empowerment of patients with MG. For example, 39% reported reduced opportunities in education, and 44.5% noted limitations in community activities like sports or leisure. This pattern aligns with previous studies, which suggest that PwMG often face ongoing challenges in maintaining social participation and personal growth, even while managing physical symptoms [13, 28]. Additionally, most participants relied heavily on medications (66.5%) and medical aids (59.1%) to maintain their quality of life. While 10.4% required physical rehabilitation, a notable 64.4% found psychiatric rehabilitation important for improving their well-being.

In the section on access to effective treatments, the study emphasizes the variability in how well current treatments manage different symptoms of MG. While vision-related symptoms saw higher effectiveness, symptoms like fatigue, muscle weakness, and emotional disturbances (such as anxiety and depression) were not as well controlled. Several recent studies suggest that standard acetylcholinesterase inhibitors (AChEIs) and immunosuppressants, while effective in managing some symptoms of MG,



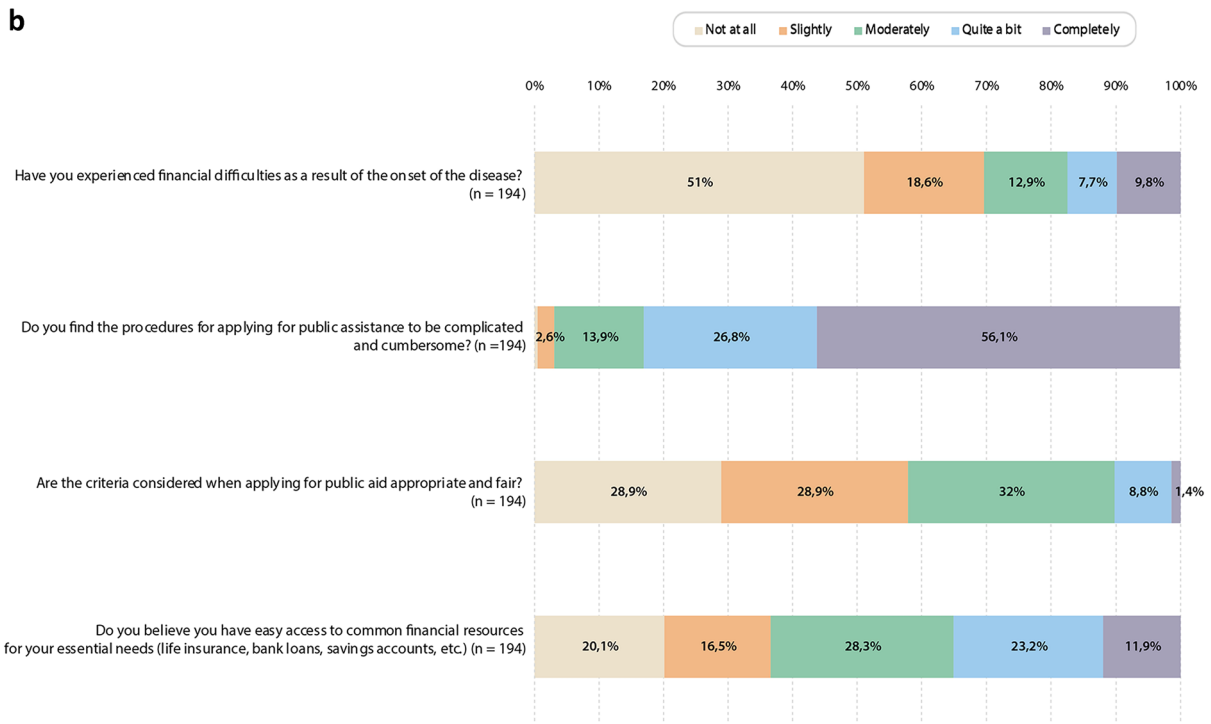


Fig. 6 a, b Questions about financial resources

Table 5 Categorized patient experiences of living with myasthenia gravis

Definition of the condition:	Myasthenia gravis is a neuromuscular and autoimmune condition that affects communication between the nerves and muscles, leading to muscle weakness and fatigue
The most frequent symptoms are:	Weakness in muscles anywhere in the body, especially in the eyes (ptosis, double vision), neck, limbs, and respiratory muscles Extreme fatigue, physical and mental exhaustion, difficulty chewing, swallowing, speaking, and breathing Impairment of the immune system, increasing susceptibility to infections *"It affects the muscles in any part of the body. In my case, it impacts speech, swallowing, hand coordination, vision, and causes general fatigue"*
Variability of the condition:	The severity and symptoms vary between individuals; some may experience mild symptoms while others face more severe symptoms that significantly affect their quality of life It can be chronic, with periods of exacerbation and remission The condition can limit personal and professional life due to the need to carefully schedule and manage daily activities Constant need for medication and frequent doctor visits to monitor the condition and adjust treatments *"It affects each person differently. In my case, I spent two years in poor condition, mainly due to vision problems—seeing double and struggling to keep my eyes focused—and muscle weakness, as my muscles often failed to respond"*
Impact on daily life:	The condition can limit personal and work life due to the need to carefully plan and manage daily activities Constant need for medication and frequent doctor visits to monitor the condition and adjust treatments *"With the diagnosis came a sudden and severe interruption of my working life, a partial loss and deterioration of my personal and family life, and physical limitations—especially in my case affecting vision, speech, mobility, and the side effects of medical and pharmacological treatment"*
Emotional and psychological aspects:	Frustration and constant worry about symptoms and myasthenic crises The importance of maintaining a positive attitude and adapting to the new limitations imposed by the condition *"Living in constant fear of choking on food, water, or even my own saliva. Being unable to ask for help because my tongue won't let me speak"*

Table 5 continued

Treatment and management:	Use of medications such as immunosuppressants and corticosteroids to control symptoms
	The importance of personalized treatment and close monitoring by neurology specialists
	"...From that point on, under the care of my first neurologist, I experienced no improvement (he only prescribed Mestinon). When I changed to another specialist, my treatment was expanded to include corticosteroids, which improved my quality of life, although the first 10 to 15 days were somewhat difficult"
Advice and personal experiences	The condition requires patience and adaptation; some participants have successfully managed symptoms through lifestyle changes and adherence to medical recommendations
	Early diagnosis and treatment are crucial to improving quality of life
	"...You need a great deal of patience and tolerance to face it with dignity"

Representative patient quotes illustrating selected thematic categories are included. Quotes have been translated from Spanish and lightly edited for clarity while preserving their original meaning

are often insufficient in addressing complex and chronic symptoms such as fatigue, muscle weakness, and emotional health [32, 33]. AChEIs, like pyridostigmine, are primarily used for symptomatic treatment, improving muscle weakness temporarily, but they do not modify the disease course or effectively manage chronic symptoms. Similarly, immunosuppressants such as corticosteroids and azathioprine are crucial in reducing condition activity but are associated with delayed onset and significant long-term side effects. These limitations underscore the importance of not only developing but also effectively implementing novel therapies, alongside strengthening multidisciplinary approaches to MG management that integrate psychological and rehabilitative support [7, 20, 32–35].

The section on support for family members and caregivers highlights significant gaps in institutional and psychological support for those assisting patients with MG. Many caregivers need access to proper resources and training, and there is a notable absence of psychological services for both families and caregivers. Additionally, there is limited workplace and societal awareness of MG, further burdening caregivers. Family dynamics are also impacted, with many participants reporting changes in family activities and relationships. These findings emphasize the need for improved support systems and awareness for caregivers and families affected by MG [28, 36, 37].

Regarding flexibility and accessibility to work, volunteering, and education, the study highlights that MG significantly impacts participants' ability to work and pursue education in line with other studies [14, 38]. Many participants reported challenges in continuing employment due to symptoms like fatigue and muscle weakness, and only a small percentage had access to workplace adaptations or support. The findings suggest the advisability of better employer awareness and improved support programs to help individuals with MG keep their jobs. Similar barriers have been described in other chronic neurological disorders, reinforcing the need for occupational and social interventions tailored to functional variability and fatigue [22]. In education, few participants received accommodations, indicating gaps in accessibility for those pursuing further studies.

Participants faced significant challenges when dealing with financial resources because of their diagnosis. Although most could access treatment and care programs without major barriers, applying for public assistance was described as

complex and difficult to navigate. Additionally, many participants struggled to access financial services like insurance and loans, underscoring the broader financial burden experienced by those living with MG. Spain's universal coverage and free public healthcare system [39] can help mitigate some of these challenges by providing consistent access to essential medical treatments and resources. However, these findings emphasize the necessity for more accessible financial aid and reforms to alleviate the economic burden on patients.

The study also reveals that most participants (87.1%) feel that legislative and political bodies do not adequately address the inequalities associated with MG. Additionally, while 53.6% were aware of existing regulations to protect individuals with disabilities, a significant portion believed that policies to reduce the vulnerability and exclusion of people with MG are not being developed at all.

Taken together, these results suggest that MG continues to be managed primarily through a biomedical lens, while the psychosocial consequences remain insufficiently addressed. The high prevalence of pain, fatigue, and anxiety/depression, together with patients' reports of inadequate emotional support, indicate that psychological distress is an integral part of the disease burden. Limited institutional and policy initiatives to promote equality may exacerbate these challenges. The perception that legislation and public resources fail to adequately protect patients with MG reflects a gap between formal disability frameworks and real-world implementation. Clinically, these findings highlight the importance of incorporating systematic psychological assessment, counseling, and caregiver education into MG care. Interdisciplinary management, including physiotherapy, occupational therapy, and vocational counseling, could help mitigate the secondary effects of chronic fatigue and role loss. From a policy perspective, improving coordination between healthcare and social services would facilitate more equitable access to support programs and financial aid.

The main strengths of this study are its nationwide scope and the inclusion of a large, diverse sample of PwMG. The study was conducted with the endorsement and collaboration of the Asociación Miastenia de España, whose participation in the scientific committee contributed to aligning the research objectives with patient perspectives and to promoting dissemination within the MG community. The questionnaire was structured and reviewed by a multidisciplinary panel of experts, including neurologists from different healthcare settings, which strengthened its clinical relevance and external validity. The use of a structured patient-centered design enabled exploration of domains rarely captured in clinical registries, such as social participation, employment, and perceived equality. The survey's online administration allowed broad geographic participation and ensured complete data through electronic validation mechanisms. Finally, the study's biopsychosocial framework provided a comprehensive perspective on MG, integrating medical, social, and emotional dimensions of the disease and enhancing the generalizability of its findings.

However, several limitations should be considered when interpreting the results. Firstly, cross-sectional design limits the ability to capture changes in patients' experiences over time. Although the sample was geographically diverse, the recruitment method may not fully represent all patient subgroups, potentially under-representing individuals with more severe symptoms or limited access to healthcare. The use of self-administered questionnaire and self-reported data introduces possible biases related to comprehension and subjective perceptions. The absence of clinical verification of diagnosis and disease severity could also contribute to variability, although all participants reported a confirmed medical diagnosis. Comorbidities were not systematically recorded and may have influenced the interpretation of symptoms (e.g., pain, fatigue). Finally, while the instrument was adapted and pilot-tested for comprehension and usability, it has not undergone formal psychometric validation.

Future studies should explore longitudinal changes in psychosocial and health-related outcomes among MG patients to better capture

the dynamic nature of the disease. Validation of disease-specific tools addressing emotional well-being, social participation, and caregiver impact would improve assessment precision. Qualitative studies could deepen understanding of patient and caregiver experiences, while complementing quantitative data. International comparisons, particularly within Europe, could help identify cultural or systemic factors influencing quality of life and access to care. Moreover, integrating patient-reported outcomes into routine clinical practice and registries would provide a more holistic view of disease management and facilitate evaluation of multidisciplinary interventions.

CONCLUSION

This study offers a comprehensive view of the biopsychosocial needs of patients with MG in Spain and reinforces the fact that MG substantially affects not only physical health but also the emotional, social, and economic dimensions of patients' lives. The findings highlight the significant physical, emotional, and social challenges this patient population faces, substantially impacting their quality of life and reveal a mismatch between medical management and psychosocial needs, emphasizing the importance of integrated multidisciplinary approaches. Policies and healthcare strategies that address both the medical and social determinants of health are essential to improving quality of life and promoting equality for PwMG. The results underscore the need for a more holistic and patient-centered approach to care, including improved access to psychological and rehabilitative services, enhanced healthcare coordination, and greater societal awareness of the condition. Addressing these unmet needs could lead to better health outcomes and improved quality of life for individuals affected by MG.

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Declarations

Conflict of Interest. Francisco Javier Campos-Lucas, Elena Cortés-Vicente, Antonio

Guerrero-Sola, Rodrigo Álvarez-Velasco, Raquel Pardo-Gómez, Juan Gómez-Salgado, Cristina Antón-Rodríguez and Fernando Caballero-Martínez declare no conflicts of interest.

Ethical Approval. The study adhered to the ethical principles outlined in the Declaration of Helsinki (Fortaleza revision) and Spanish Law 14/2007 on biomedical research. The protocol was reviewed and approved by the Ethics Committee of Hospital de la Santa Creu I Sant Pau, Barcelona, Spain (Code UCIS-MG-2022-03).

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