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Luana Conte [1,2,*], Roberto Lupo [3], Pierluigi Lezzi [4], Ludovica Panzanaro [5], Francesco Rizzo [6], Antonio Fasano [7], Tania Lezzi [4], Elsa Vitale [8], Ivan Rubbi [7] and Giorgio De Nunzio [1,2]

[1] Laboratory of Biomedical Physics and Environment, Department of Mathematics and Physics, "E. De Giorgi", University of Salento, Lecce, Italy
[2] Laboratory of Advanced Data Analysis for Medicine (ADAM), University of Salento and Local Health Authority (ASL) of Lecce, Lecce, Italy
[3] "San Giuseppe da Copertino" Hospital, Local Health Authority (ASL) of Lecce, Lecce, Italy
[4] "Veris Delli Ponti' Hospital, Local Health Authority (ASL) of Lecce, Scorrano, Italy
[5] Comunità Riabilitativa Assistenziale Psichiatrica (CRAP) Carrubo, Sol Levante srl, Avetrana, Taranto, Italy
[6] Freelancer
[7] "Vito Fazzi" Hospital, Local Health Authority (ASL) of Lecce, Lecce, Italy.
[8] Department of Mental Health, Local Healthcare Company of Bari, Bari, Italy
[9] University of Bologna, Bologna, Italy
* Correspondence: Luana Conte, luana.conte@unisalento.it; University of Salento, via per Monteroni, 73100, Lecce, Italy

Abstract: Myasthenia Gravis (MG) is a chronic autoimmune neuromuscular disorder characterized by muscle weakness and fatigue, which can significantly impact various facets of daily life, including physical capabilities, emotional well-being, and social interactions. The prognosis, when supported by optimal symptomatic, immunosuppressive, and supportive treatment, is generally favorable. However, compelling evidence underscores the presence of diminished quality of life among patients with MG. Notably, cognitive impairment, depressive symptoms, and sleep disorders emerge as clinically pertinent dimensions in affected individuals, warranting careful scrutiny and investigation. Individuals with this condition often encounter challenges stemming from a lack of knowledge about effective coping strategies. The core objective of our research is to delve into the coping strategies adopted by patients with MG. To this end, we conducted an extensive inquiry, administering a series of personalized questions and utilizing the short version of the Coping Orientation to Problems Experienced questionnaire, (COPE-NVI-25) survey. Generative Artificial Intelligence was also employed to gain a better understanding of patient responses. The outcomes of our study hold the potential to steer the development of targeted interventions, strategic approaches, and valuable resources designed to assist patients with MG in proficiently managing their condition and enhancing their overall well-being.

Keywords: Myasthenia Gravis; Coping impairment; COPE-NVI-25 questionnaire

Introduction

Myasthenia Gravis (MG) is an autoimmune neuromuscular disorder that significantly hampers muscle strength and endurance, posing profound challenges to the daily lives of those affected [1,2]. It is estimated that over 700,000 people worldwide are affected by this condition [3]. This alteration is due to antibodies against the acetylcholine receptor (AChR), muscle-specific kinase (MuSK), or other AChR-related proteins in the postsynaptic muscle membrane. Localized or general muscle weakness is the predominant symptom and is induced by antibodies. Diagnosis is straightforward in most patients with typical symptoms and a positive antibody test, although a detailed clinical and neurophysiological examination is important in patients who test negative for antibodies. Comorbidity is common, especially in older patients [4].

The journey from diagnosis to management and care still involves many obstacles, starting with the lack of early diagnosis. The most important elements of diagnosis are the clinical history and the findings of fluctuating and fatigable weakness, particularly involving the extraocular and bulbar muscles. The period between the onset of symptoms and diagnosis can be very long, causing considerable anxiety and frustration in patients [5]. Even when the disease is diagnosed, the difficulty of accessing specialized care negatively impacts the experiences of the patients [6], especially during COVID-19 pandemic [7–9].

While the advancements in symptomatic, immunosuppressive, and supportive treatments have generally improved the prognosis, MG significantly impacts the quality of life with substantial psycho-physical consequences [10]. The disease manifests through various clinical dimensions, including cognitive deficits, depressive states, and sleep disturbances, all of which necessitate comprehensive clinical attention [11–14]. Moreover, the personal, social, and work spheres are affected, as well as physical and psychological well-being. A meta-analysis reveals that the employment rate is considerably low considering that the average age of patients with MG is about 48 years Often, in a family, caregivers are represented by family members who, lacking training and appropriate knowledge of the pathology, assist the patient in a rather approximate manner. All these conditions lead both caregivers and patients themselves to develop disorders such as depression [15] and loneliness, which compromise their relative quality of life [16], with a greater incidence in females [5].

A notable gap in existing research pertains to the coping strategies employed by these patients, which are crucial for managing the everyday implications of the disease effectively. Understanding these coping mechanisms is vital for devising targeted interventions that enhance patient resilience and overall well-being [17]. To address this knowledge gap, our study focuses on exploring the coping strategies utilized by patients with MG. By employing a methodological framework that integrates the Coping Orientation to Problems Experienced (COPE-NVI-25) questionnaire—a validated instrument tailored to assess coping orientations in response to health challenges—and the innovative use of Generative Artificial Intelligence, we aim to capture a nuanced understanding of how patients navigate the complexities imposed by MG. The findings from our study could contribute significantly to the development of specific therapeutic strategies and support systems, ultimately improving the quality of life for individuals with MG.

Methods

Design

From January to April 2023 a survey was administered among MG patients. The study involved an anonymous survey administered through a voluntary questionnaire. All questionnaire sections were digitalized using a pre-set format on the Google Drive platform, and the research was carried out via electronic distribution. We reached out to different Facebook groups and Instagram pages to share the digital questionnaires. The sampling technique employed was virtual snowball sampling until data saturation was achieved.

Survey Instrument

The survey comprised a set of questions designed to outline the socio-demographic characteristics of the sample and to investigate existential coping strategies of patients with MG by means the Coping Orientation to the Problems Experienced questionnaire (COPE-NVI-25).

Socio-demographic characteristics include gender, age, nationality, marital status, level of education, and employment status. Additionally, it gathers information related to patients knowledge about the disease and how the patient manages the illness, the treatments, and the management of difficulties. Two more questions were administered with the possibility of adding open-ended responses from the participants. These questions are: *"If you find the treatments you are* *receiving unsatisfactory, can you indicate the reasons why?*" and "*Write freely what you would recommend or believe is essential to change in the management of the disease*".

The COPE-NVI-25 survey consisted of 25 items, each linked to a Likert scale ranging from 1 to 6, where 1 represented "I never do" and 6 represented "I always do." These items were categorized into 5 sub-dimensions: Avoidance Strategies, Transcendent Orientation, Positive Attitude, Social Support, and Problem Orientation. Summing the items within each sub-dimension yielded a total score, with higher values indicating a stronger inclination towards a particular sub-dimension. The questionnaire validation was established through previous research, which demonstrated favorable psychometric properties [18].

Statistical Analysis

Data were collected in an Excel sheet and the answers of all respondents to the questionnaire items were reported using descriptive statistics. Continuous variables were summarized using the mean and standard deviation (SD), and categorical variables were summarized using frequencies and percentages. For the validated questionnaire, descriptive statistics for the item responses, such as the item median, standard deviation, skewness, floor and ceiling effects, and 95% confidence intervals, were assessed and reported for each scale score. Cronbach's alpha was used to measure the scale internal consistency reliability. COPE-NVI-25 subscales' scores were registered as means (μ) ± standard deviations (SD). To determine the factors that influence the coping strategies, a one-way ANOVA was performed. To further analyze the influencing factors of the coping strategies, Multiple linear regression analysis was performed. Each subscale score was used as the dependent variable and the influencing factors of the coping strategies in the Univariate analysis were used as the independent variables. For questions with open-ended responses, the generative artificial intelligence (ChatGPT version 4) was used to group similar answers together and to gather a summary of the results. The statistical analyses were conducted for all qualitative and quantitative variables using Matlab software, 2023b version. Statistical significance level was set at $p<0.05$.

Ethical Considerations

The study ethical concerns were explicitly explained in the questionnaire introduction. The questionnaire structure followed the guidelines established by the Italian Data Protection Authority (DPA). It was emphasized that taking part in the study was entirely optional, and participants had the freedom to discontinue their involvement at any point. Individuals who indicated their willingness to participate were provided with an informed consent form that reiterated the voluntary nature of their participation and guaranteed the confidentiality and anonymity of the gathered data. Additionally, to enhance the protection of participants privacy, all responses in the questionnaire were anonymized.

Results

Sample Demographics and Baseline Characteristics

A total of 215 patients were recruited in this study. Baseline characteristics were collected and reported in Table 1. Patients were 83% females and 17% males. The mean age of the responders was 46.17 years (SD 14.59), with a range of 19-82 years. Seventy-one percent of the sample was from Italy and the majority of the participants were married (64%). A predominant portion of the participants (34%) had achieved education at the higher secondary level, and 35% held a university degree. Among the participants, 66% were either students or employed, while 33% were without employment or retired.

Table 1. Sampling characteristics of all respondents (socio-demographics data and information about the patients) (n=215).

BASELINE CHARACTERISTICS	N	%
Socio-demographics		
Gender		
Female	178	83
Male	37	17
Age		
Range	19-82	
Mean	46.17	
SD	14.59	
Nationality		
Italians	152	71
Non-Italians	63	29
Married status		
Married	137	64
Single/Celibate	66	31
Separated/Divorced	10	5
Widower	2	1
Level of education		
No title	4	2
Lower secondary school certificate	14	7
Higher Diploma	73	34
Degree	76	35
Postgraduate training	48	22
Employment status		
Civil servant	31	14
Private employee	62	29
Freelancer	33	15
Unemployed	33	15
Retired	32	15
Student	17	8
Invalid	7	3

Questionnaire Items

The questionnaire items were evaluated for all respondents and data were collected (Tables 2-4).

Table 2. Information about patients' knowledge and training about the disease (n=215).

	N	%
Before your diagnosis, had you ever heard of MG?		
No	179	83
Yes	36	17
If you answered YES to the previous question, in which field did you hear about it?		

MASS MEDIA		
Always	0	0
Often	0	0
Occasionally	15	7
Rarely	19	9
Never	181	84
FAMILY		
Always	2	1
Often	0	0
Occasionally	9	4
Rarely	7	3
Never	197	92
SCHOOL		
Always	1	0
Often	2	1
Occasionally	9	4
Rarely	12	6
Never	191	89
FRIENDS		
Always	0	0
Often	0	0
Occasionally	7	3
Rarely	11	5
Never	197	92
SANITARY		
Always	4	2
Often	0	0
Occasionally	20	9
Rarely	28	13
Never	163	76
For the management of the condition, have you ever received health education from the nurse practitioner at the outpatient clinic you go to?		
No	155	72
Yes	60	28
Have you ever received home health education from the nursing professional?		
No	198	92
Yes	17	8
In the outpatient clinic, does the nurse advise you on what strategies to implement on a daily basis and whether there are alternative solutions to alleviate your symptoms?		
No	173	80

Yes	42	20
In your opinion, is MG still an unknown or under-recognised pathology compared to other diseases?		
No	4	2
Yes	175	81
In part	36	17
Do you believe that new forms of telecommunication can help to better manage MG- related problems?		
No	11	5
Yes	204	95

Table 3. How the patient manages the illness, the treatments, and the management of difficulties (n=215).

	N	**%**
Do you live alone?		
No	186	87
Yes	24	11
Yes, but I have children/neighbours who help me	5	2
Are you autonomous?		
Yes but only at home, while I need help going out	19	9
Yes, I am completely autonomous	142	66
No, I totally need help	24	11
No I need help in part	30	14
To move around, do you need an aid?		
No, I don't need anything	174	81
Yes, I use the stick	23	11
Yes, I use the wheelchair	10	5
Yes, I use the walker	8	4
What signs and symptoms did you experience in the early phase of the disease (more than one answer possible)		
Unsteady gait	67	31
Blurred or double vision	145	67
Eyelid ptosis	138	64
Limb weakness	142	66
Difficulty breathing	81	38
Nothing	6	3
Do you attend a centre and/or outpatient clinic that deals with the disease?		
No	27	13
Yes	156	73
In part	32	15
If you attend the centre and/or clinic, are you satisfied with the care you receive?		
No	29	13
Yes	114	53

In part	71	33
missing	1	0
Do you think that your life will now burden your family's?		
No	40	19
Yes	89	41

Table 4. Generative Artificial Intelligence (ChatGPT) of open-ended responses and result summary.

	ChatGPT-found categories:	**ChatGPT Summary of Results**
If you find the treatments you are receiving unsatisfactory, can you indicate the reasons why?	**Improvement of Therapies and Treatments:** • Customizing therapies based on individual symptoms • Exploring alternative therapies alongside traditional medications • Accessible experimental treatments for all patients • Targeted and personalized physical therapies • Provision of psychological and physical support • Integration of complementary medicines **Enhanced Medical Communication and Support:** • Improving doctor-patient relationships • Active listening to patients and increased engagement • Enhanced understanding and support from medical professionals • Collaboration among different specialists and therapists • Basic physician education about MG • Telemedicine and online consultations Information and Awareness: • Increased awareness about the disease and its symptoms • Awareness campaigns to raise public consciousness • Educating both the public and professionals about MG	Questionnaire participants expressed a range of suggestions and opinions regarding the management of MG. The majority emphasized the importance of personalized therapies, including alternative treatments and experimental interventions. Furthermore, they highlighted the need for open and collaborative communication with medical professionals, emphasizing active listening and psychological support. A common theme was the lack of information about the disease, with a call for greater awareness campaigns and education for both medical professionals and the general public. Participants stressed the significance of swift and accurate diagnosis, along with improved access to specialized tests and therapies. The social and economic dimensions emerged as relevant factors, with requests for increased financial support and legal recognition for patients. Participants also indicated the need for patient support networks and groups, in addition to underscoring the importance of a multidisciplinary approach to treatment. Overall, the responses underscore the importance of a holistic approach to managing MG, encompassing personalized therapies, effective communication, accurate information, and adequate social and economic support.

	• Official recognition of the disease as debilitating **Diagnosis and Access to Care:** • Quicker and more accurate diagnoses • Streamlined access to tests and specialized therapies • Specialized centers with multidisciplinary teams • Scheduled follow-up visits and regular check-ups **Social and Economic Support:** • Financial support from institutions • Legal recognition and assistance for patients • Support groups and patient networks	
Write freely what you would recommend or believe is essential to change in the management of the disease	**Therapies and Treatments:** • Cortisone • Access to exams and therapies • Symptom-targeted therapy • Experimental treatments • Traditional and alternative medicine **Communication and Support:** • Patient listening • Improvement of doctor-patient relationship • Psychological support • Awareness and mindfulness • Medical education **Diagnosis and Research:** • Speed of diagnosis • Increased research • Detailed information • Information about experimental treatments	In the collected responses, a series of key points and suggestions for improving the management of MG emerge: Patients are calling for a more targeted and personalized approach to therapy, taking into account the variation in symptoms and their severity among patients. There is hope for a more effective therapy and the provision of innovative and personalized therapeutic options. Improving access to exams and treatments is a crucial aspect, reducing wait times for diagnoses and treatments. This could be facilitated through the implementation of specialized centers and the creation of medical support networks. A greater understanding of the disease among doctors from various specialties is requested, as well as better training for primary care physicians to promptly recognize symptoms and initiate the diagnostic process.

Healthcare Services: • Specialized centers • Telemedicine • Multidisciplinary support • Holistic treatments • Personalized treatments	The desire for better communication and interaction between doctors and patients is evident, with increased patient involvement in the decision-making process and greater attention to their needs.
Social and Economic Support: • Family and friend support • Financial support • Rights of disabled individuals • Support groups	Psychological support, both in the form of therapy and counseling, is considered important for addressing the emotional aspects of the disease. Patients want to be treated with humanity and sensitivity by healthcare providers.
Medical Awareness: • Improved doctor training • Greater medical knowledge • Enhancement of basic medical care • Holistic patient treatment	Information and awareness are deemed crucial for both patients and society at large. MG is often poorly understood, so increased awareness could help combat ignorance and promote better understanding.
Other themes: • Stress management • Nutritional education • Invisible symptoms • Patient experience	Work-related concerns are evident, with requests for workplace support and potential adjustments to working conditions. Access to experimental treatments and alternative therapies is an interest, emphasizing the need for diverse therapeutic options. Lastly, patients desire to be treated with respect, understanding, and attention by medical staff, and they hope that the disease will be recognized as disabling to facilitate legal and social support. These suggestions and patient desires reflect the importance of a comprehensive and personalized approach to managing MG, aiming to improve patients’ quality of life and ensure adequate support in all aspects of their battle against the disease.

Table 2 delves into patients awareness and training regarding MG, as well as the sources of information they encountered about the condition. It also investigates whether participants received health education from nurses at the clinic and their perspectives on utilizing telecommunication for addressing challenges associated with MG. A noteworthy proportion of participants (83%) had not been familiar with MG prior to their diagnosis. Among those who responded positively, intriguingly, the impact of mass media, family, friends, school, and even the healthcare setting appeared to be relatively limited.

Participants reported that they do not receive health education from clinical professionals (72%) or from home nurses (92%). Additionally, 80% of patients indicated that nurses did not provide recommendations for daily strategies or alternative solutions to alleviate symptoms. Lastly, the majority of patients (81%) perceived MG as being less recognized compared to other conditions. Moreover, there was a consensus among patients that innovative forms of telecommunication could contribute to managing challenges associated with the disease. These findings underline the need for more comprehensive health education strategies, highlighting the potential of telecommunication to bridge informational gaps and enhance management approaches for MG.

Table 3 presents various aspects related to how patients manage their illness, treatment, and challenges, including living situation, autonomy, mobility aids, initial symptoms, medical care, and psychosocial support in relation to MG. While a substantial proportion of participants (87%) indicated that they do not live alone, the majority (66%) expressed being completely autonomous. Concerning mobility aids, the largest group (81%) stated that they did not require any aids, while smaller percentages used a walking stick (11%), wheelchair (5%), or walker (4%).

Participants detailed diverse initial symptoms: unstable gait (31%), blurred or double vision (64%), drooping eyelids (64%), limb weakness (66%), and breathing difficulties (38%). Moreover, 41% believed that their condition could impact their family. A notable number of participants (73%) attended a specialized center or clinic for the disease, with 15% doing so partially. Among those who attended, only half (53%) expressed satisfaction with the care they received.

Regarding psychological support, 56% of participants considered it essential for individuals with MG to cope with challenges, while 36% regarded it as partially necessary. These findings underscore the diverse experiences and perspectives of individuals living with MG, encompassing various aspects such as living arrangements, autonomy, medical care, and psychosocial needs.

Generative Artificial Intelligence was then utilized to categorize similar responses and generate a comprehensive summary of the outcomes for open-ended responses. The responses were derived from participants answers to the questionnaire, in which they provided suggestions and highlighted perceived essential changes required in the management of MG. This encompassed their recommendations and beliefs regarding pivotal alterations in disease management. This analysis facilitated the recognition and organization of various themes, which are delineated and presented in Table 4. Additionally, an inclusive summary of the results inferred by ChatGPT has been incorporated.

COPE Score Analysis

Table 5 presents the responses to the COPE-NVI-25 questionnaire along with their respective percentages. The distribution of scores for the subscales, expressed in percentages, is shown in Figure 1.

Table 5. The Coping Orientation to the Problems Experienced (COPE-NVI-25) questionnaire items. The survey consisted of 25 items, each linked to a Likert scale ranging from 1 to 6, where 1 represented "I never do" and 6 represented "I always do.".

COPE-NVI-25 QUESTIONNAIRE ITEMS	N	%
1. I try to get advice from someone on what to do		
1	32	15
2	25	12
3	49	23
4	39	18
5	34	16

6	36	17
2. I learn to live with the problem		
1	10	5
2	10	5
3	24	11
4	25	12
5	51	24
6	95	44
3. I concentrate on dealing with this problem and, if necessary, put other things aside		
1	14	7
2	17	8
3	45	21
4	49	23
5	45	21
6	45	21
4. I do not put much effort into solving the problem		
1	101	47
2	37	17
3	33	15
4	21	10
5	13	6
6	10	5
5. I try to prevent other things from interfering with my coping efforts		
1		
2	17	8
3	22	10
4	42	20
5	50	23
6	42	20
	42	20
6. I look for something positive in what happened		
1	27	13
2	18	8
3	25	12
4	41	19
5	41	19
6	63	29

7. I refuse to believe that this happened		
1	121	56
2	33	15
3	21	10
4	17	8
5	9	4
6	14	7
8. Seeking help in God		
1	96	45
2	13	6
3	18	8
4	23	11
5	17	8
6	48	22
9. I do what needs to be done, one step at a time		
	8	4
1	7	3
2	16	7
3	33	15
4	54	25
5	97	45
6		
10. I talk to someone to do something concrete to solve the problem		
1	33	15
2	17	8
3	41	19
4	34	16
5	40	19
6	50	23
11. I pray more than usual		
1	104	48
2	17	8
3	32	15
4	28	13
5	7	3
6	27	13
12. I try to learn something from experience		
1	13	6
2	13	6
3	26	12
4	28	13

5	51	24
6	84	39
13. I make every effort to act on the situation		
1	7	3
2	7	3
3	24	11
4	33	15
5	55	26
6	89	41
14. I try to find solace in my religion		
1	102	47
2	20	9
3	20	9
4	23	11
5	13	6
6	37	7
15. I ask people how they have acted when faced with similar experiences	33	15
1	32	15
2	38	18
3	49	23
4	28	13
5	35	16
6		
16. I try to use this experience to grow as a person		
1	16	7
2	11	5
3	29	13
4	33	15
5	48	22
6	78	36
17. I act as if it never happened		
1	101	47
2	35	16
3	31	14
4	23	11
5	12	6
6	13	6
18. Seeking moral support from friends and relatives	53	25
1	31	14

2	40	19
3	33	15
4	34	16
5	24	11
6		
19. I put my hope in God		
1	95	44
2	24	11
3	19	9
4	20	9
5	15	7
6	42	20
20. I think hard about what moves to make to deal with the problem		
1	19	9
2	15	7
3	39	18
4	48	22
5	39	18
6	55	26
21. I recognise that I cannot do anything about it and abandon all attempts		
to act	115	53
1	41	19
2	27	13
3	13	6
4	4	2
5	15	7
6		
22. I tend to fantasise to distract myself		
1	80	37
2	35	16
3	35	16
4	30	14
5	23	11
6	12	6
23. I accept the reality of the facts		
1	15	7
2	13	6
3	20	9
4	39	18
5	48	22
6	80	37

24. Trying to get used to the idea that this happened		
1	12	6
2	13	6
3	21	10
4	47	22
5	51	24
6	71	33
25. Seeking someone's understanding and solidarity		
1	49	23
2	34	16
3	38	18
4	41	19
5	28	13
6	25	12

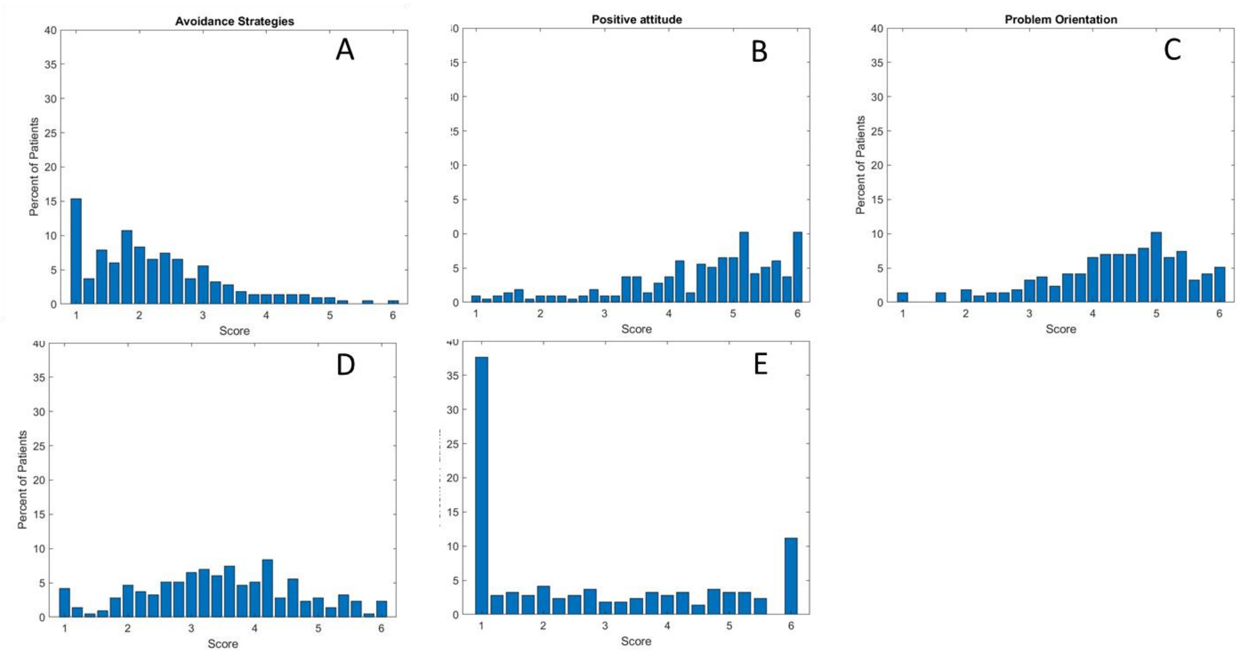

Figure 1. Frequency distributions (percent) for the five subscales of the COPE-NVI-25 questionnaire (panels A to E).

In Table 6, descriptive statistics provide insights into the score distribution for the COPE-NVI-25 questionnaire, shedding light on how participants employ coping strategies and orientations in the context of MG. Patients scores are moderately reported, ranging from 2.25 (Avoidance Strategies) to 4.50 (Positive Attitude). Notably, the lowest mean scores are observed in the Avoidance Strategies and Transcendent Orientation subscales, displaying positive skewness, indicating a leaning toward higher scores. These two subscales also exhibit a higher percentage at the floor (9.64% and 11.54%, respectively), suggesting certain patients tend toward lower scores. Conversely, other subscales demonstrate negative skewness, implying a slight leftward distribution. The internal consistency reliability, as measured by Cronbach's alpha, is 0.87 for all items. The minimum Cronbach's alpha exceeds 0.70. For 3 out of 5 scales, Cronbach's alpha exceeds 0.80, while the Transcendent Orientation subscale surpasses 0.90, thus satisfying Nunnally's criterion of 0.7 [19].

Table 6. Descriptive statistics of score distributions for COPE-NVI-25 questionnaire. Cronbach's alpha was used to measure the scales' internal consistency reliability.

Subscale COPE-NVI-25	**No. of items**	**Score**	**95% CI**	**Median**	**SD**	**% floor†**	**% ceiling‡**	**Skewness**	**Cronbach's α* Total items = 0.87**
Avoidance_Strategies	5	2.25	2.25-2.26	1.6	0.0501	9.64	1.19	1.07	0.71
Transcendent_Orientation	4	2.75	2.75-2.77	2	0.12	11.54	4.48	0.59	0.96
Positive Attitude	6	4.50	4.50-4.51	0.093	1.57	1.20	6.09	-0.84	0.88
Social Support	5	3.54	3.46-3.46	3.6	0.036	3.72	3.16	-0.00403	0.76
Problem Orientation	5	4.36	4.36-4.37	4.4	0.104	1.21	6.10	-0.68	0.81

†Percentage of patients with worst possible score. ‡Percentage of patients with best possible score. *Measure of internal consistency.

Univariate analysis was employed to discern factors influencing coping strategies and reported in Table 7. Notable differences in the Problem Orientation subscale were observed based on age ($p<0.05$). Additionally, the Transcendent Orientation subscale was influenced by the geographical area of origin ($p<0.01$). Several factors were significantly associated with various subscales. These factors include having received home health education and autonomy, which were both linked to Transcendent Orientation, Social Support, and Problem Orientation. Awareness of the disease existence and advice on daily strategies from healthcare professionals were associated with Avoidance Strategies ($p<0.05$). Hearing about the disease through mass media and friends influenced the Transcendent Orientation subscale ($p<0.01$) and Problem Orientation subscale ($p<0.05$), respectively. Intriguingly, learning about the disease at school demonstrated a strong association with nearly all subscales.

Table 7. Univariate analysis of the COPE-NVI-25 subscales (n=215) according too socio-demographic characteristics, Information about patients' knowledge and training about the disease and How the patient manages the illness, the treatments they receive, and the management of difficulties. A p-value <0.05 was considered statistically significant (*$p<0.05$; **$p<0.01$; ***$p<0.001$).

	μ±s.d	**COPE-NVI-25 subscales *p-value***				
COPE-NVI-25/ Socio-demographic characteristics		**Avoidance Strategies**	**Transcendent Orientation**	**Positive attitude**	**Social Support**	**Problem Orientation**
Gender						
Female	112.1 ± 61.8	0.315	0.468	0.755	0.476	0.722
Male	88 ± 60.8					

Age						
<20	93.3 ± 40.2	0.209	0.545	0.334	0.260	**<0.05***
20-30	100.8 ± 71.5					
31-40	90.09 ± 64.9					
41-50	110.31 ± 3.26					
51-60	115.37 ± 53.2					
61-70	119.3 ± 62.04					
71-80	109.2 ± 50.7					
>81	130.5 ± 14.8					
Geographic area						
Argentina	186.5 ± 0.7	0.895	**<0.01***	0.841	0.566	0.786
Australia	179.5 ± 17.6					
Bulgaria	193 ± 0					
Canada	204 ± 0					
Egitto	164 ± 0					
Germania	171 ± 0					
Giordania	179 ± 0					
Grecia	194.3 ± 18.9					
India	190.6 ± 22.5					
Inghilterra	185 ± 14.1					
Italia	77.3 ± 45.7					
Libia	177 ± 0					
Macedonia	185.6 ± 29.5					
Malta	111 ± 0					
Paesi Bassi	185.5 ± 3.5					
Portorico	200 ± 0					
Scozia	182 ± 23.06					
Sud Africa	174.5 ± 28.9					
USA	181.06 ±					
	20.01					
Level of education						
No title	88.2 ± 39.8	0.09	0.608	0.772	0.200	0.775
Lower secondary	84.6 ± 48.7					
school	78.9 ± 49.9					
Higher Diploma	111.5 ± 4.3					
Degree	155.06 ±					
Postgraduate training	51.4					
Employment status						
Employee	125.6 ±	0.362	0.08	0.837	0.560	0.428
Freelancer	63.09					
Student	96.6 ± 59.3					

Retired	96.5 ± 62.2					
Unemployed	126.5 ± 63.3					
	93.7 ± 62.8					
Marital status						
Married	110.4 ± 59.8	0.125	0.3006	0.229	0.292	0.219
Single/Celibate	99.07 ± 66.2					
Separated/Divorced	131 ± 61.7					
Widower	122 ± 100.4					
Before your diagnosis, had you ever heard of MG?	103.3 ± 60.7	**<0.05***	0.828	0.364	0.626	0.217
No	131 ± 65.01					
Yes						
If you answered YES to the previous question, in which field did you hear about it?	0	0.253	**0.01****	0.905	0.483	0.523
	0					
MASS MEDIA	84.7 ± 49.8					
Always	114.7 ± 70.6					
Often	106.01 ± 61.2					
Occasionally						
Rarely						
Never	133.5 ± 37.4	0.409	0.109	0.348	0.349	0.199
	0					
FAMILY	89 ± 39.8					
Always	81.8 ± 74.3					
Often	107.3 ± 62.1					
Occasionally						
Rarely						
Never	71 ± 0	0.552	**<0.05***	**<0.05***	**<0.05***	**<0.01***
	190 ± 11.3					
SCHOOL	134 ± 0					
Always	136.6 ± 65.05					
Often	102.1 ± 60.5					
Occasionally						
Rarely						

Never	0	0.400	0.258	0.222	0.423	**<0.05***
	0					
FRIENDS	128.7 ± 15.9					
Always	103.1 ± 72.7					
Often	106.7 ± 62.01					
Occasionally						
Rarely						
Never						
	111.5 ± 30.1	0.07	0.403	0.267	0.305	0.287
HEALTHCARE	0					
SECTOR	80.3 ± 40.5					
Always	126.9 ± 63.6					
Often	102.3 ± 61.8					
Occasionally						
Rarely						
Never						
Have you ever received home health education from the nursing professional?						
No	111.4 ± 61.6	0.07	0.203	0.435	0.09	0.345
Yes	99.08 ± 63.3					
Have you ever received home health education from the nursing professional?						
No	104.7 ± 61.8	0.06	**<0.05***	0.332	**<0.001*****	**0.05***
Yes	146.5 ± 53.8					
In the outpatient clinic, does the nurse advise you on what strategies to implement on a daily basis and whether there are alternative solutions to alleviate your symptoms?	108.1 ± 61.2	**<0.05***	0.334	0.289	0.114	0.874
	107.5 ± 66.8					
No						
Yes						

Are you autonomous?						
No, I totally need help	93.6 ± 62.2	0.759	**<0.05***	0.429	**0.01****	**<0.05***
No, I need help in part	164.7 ± 36.05					
Yes	103.3 ± 60.8					

To further investigate the factors influencing the coping strategies score of patients, a multiple linear regression analysis was conducted (Table 8). The results indicated that two key variables, namely participants prior awareness of MG and the guidance received from clinic nurses regarding strategies to alleviate symptoms, significantly contribute to explaining the variance in Avoidance Strategies ($p<0.01$). However, it is important to note that the overall explanatory capacity of the model remains limited, suggesting that additional unexamined factors may also contribute to the variation in Avoidance Strategies. Similarly, the same conclusion can be drawn for the Transcendent Orientation subscale and Social Support, as both exhibit notable associations with variables such as having received information about the condition at school, the guidance provided by clinic nurses for symptom-alleviating strategies (for both subscales), and geographical area of origin, autonomy, and exposure to mass media (for Transcendent Orientation only) ($p<0.01$). Just as observed with Avoidance Strategies, it becomes apparent that while these identified variables demonstrate significance, the potential exists for additional unexplored factors to contribute to the observed variability in both the Transcendent Orientation and Social Support subscales.

Table 8. Multiple linear regression analysis performed with the COPE-NVI-25 subscales as the dependent variable (n=215). A p-value <0.05 was considered statistically significant (*$p<0.05$; **$p<0.01$; ***$p<0.001$).

Dependent variable	**Independent variable**	**R^2**	**R^2 adj**	**F-statistic**	**p-value**
Avoiding strategies	Prior to diagnosis, had you ever heard of MG In the outpatient clinic, does the nurse advise you on strategies to alleviate your symptoms?	0.04	0.03	4.82	**<0.01****
Transcendent Orientation	Geographical area Heard about in the media Heard at School	0.07	0.05	3.38	**<0.01****

	Have you ever received home health education?				
	Autonomy				
Positive attitude	Heard at School	0.0004	-0.004	0.09	0.761
Social Support	Heard at School	0.05	0.04	3.9	<0.01**
	Have you ever received home health education?				
	Autonomy				
Problem Orientation	Age	0.03	0.01	1.58	0.168
	Heard at School				
	Sentito parlare da Amici				
	Have you ever received home health education?				
	Autonomy				

Discussion

In this study, we explored the coping patterns among patients with Myasthenia Gravis (MG), leveraging a validated questionnaire, COPE-NVI-25 [20], and a series of ad hoc administered questions, including open-ended ones designed to gather in-depth information on patients knowledge about their disease and how they manage its difficulties.

Most patients (72.6%) attend a centre where MG is treated, but the majority are not satisfied with the care they receive for several reasons. These concerns relate to the lack of health education provided by the nurse at the clinic they visit. The nurses responsible for managing MG do not implement any health education, even at home, lacking the necessary training to do so, and consequently, they are unable to advise patients on significant strategies to alleviate the symptoms of such pathology or how to deal with it. Among the few studies present in the literature, there emerges a lack of knowledge among nurses, enough to compromise the care [21].

The application of the COPE-NVI-25 survey enabled us to quantify coping strategies across five distinct sub-dimensions: Avoidance Strategies, Transcendent Orientation, Positive Attitude, Social Support, and Problem Orientation. The survey results revealed moderate use of coping strategies, with the highest scores in Positive Attitude and the lowest in Avoidance Strategies and Transcendent

Orientation. This suggests that patients are more inclined to adopt a positive outlook rather than avoid their problems, which can be seen as a proactive approach to managing their condition. This variation might indicate that while avoidance and spiritual coping are generally less favoured, they are significant for a subset of patients. These findings align with the broader literature that emphasizes the importance of a positive mindset in chronic disease management, where maintaining an optimistic outlook is associated with better quality of life and reduced depression and anxiety [22]. Conversely, the positive skewness in 'Avoidance Strategies' and 'Transcendent Orientation' indicates that there is a tail towards higher scores. There is a need to consider individual differences in coping preferences and effectiveness. Tailoring interventions to support each patient preferred coping style might help improve their overall management of the disease and enhance their quality of life.

Our findings also highlight significant associations between coping strategies and various factors like age, geographic origin, prior awareness of the disease, and access to health education. For instance, younger patients and those from different geographic regions exhibited different coping patterns, possibly reflecting cultural and systemic differences in health education and disease management approaches. Younger patients might be more proactive or reactive in facing the challenges posed by MG, indicating a potential need for age-specific support strategies that cater to their unique coping styles. Previous studies have similarly noted the influence of cultural and systemic factors on health behaviour and coping strategies in chronic diseases [23].

The association between awareness of the disease and professional advice with 'Avoidance Strategies' highlights the role of knowledge and external support in shaping how patients cope with MG. Patients who are more aware of their condition and receive advice on daily management strategies may be better prepared to face their condition head-on rather than resorting to avoidance. In addition, the significant impact of information sources like mass media and schools on coping strategies such as 'Transcendent Orientation' and 'Problem Orientation' emphasizes the power of information dissemination methods. This finding suggests that the way patients learn about their disease—whether through formal education or media—can profoundly affect how they cope with their illness.

The multiple linear regression analysis offers further insights into the factors influencing coping strategies among MG patients. The analysis identifies prior awareness of MG and the guidance received from clinic nurses about symptom alleviation as significant predictors for the use of 'Avoidance Strategies'. This indicates that patients who are more informed about their condition and those who receive actionable advice from healthcare professionals are likely to avoid less effective coping mechanisms. For the 'Transcendent Orientation' and 'Social Support' subscales, the analysis again confirm the influence of education (information received at school) and healthcare interaction (guidance from clinic nurses) along with geographic and cultural factors (geographical area of origin and exposure to mass media). These findings suggest that both personal experiences and socio-cultural environments play significant roles in shaping coping behaviours, supporting the need for a multifaceted approach in patient education and support.

These insights are crucial for healthcare providers and policymakers as they highlight the need for targeted interventions that consider these various factors. By understanding the specific needs and influences of different demographic groups, interventions can be more precisely tailored to improve coping strategies among MG patients, ultimately enhancing their overall management and quality of life. This approach supports a more personalized medicine framework, where treatment and support are adapted to individual characteristics and needs.

In the present investigation, we also employed an innovative approach based on Generative Artificial Intelligence to analyze open-ended responses provided by questionnaire participants regarding the management of MG. The results highlight a range of key themes that reflect patients opinions and perspectives on enhancing care and treatment for this complex disease. A predominant theme emerging from the responses is the significance of personalized therapies. Participants underscored the need to consider variations in symptoms and severity among patients, calling for targeted therapeutic approaches and innovative options. This underscores the importance of tailored treatment that takes into account individual patient needs.

Another relevant theme pertains to communication and interaction between physicians and patients. Participants emphasized the necessity of improving the clinician-patient relationship through active listening and increased patient engagement in the decision-making process. The request for psychological support reflects the importance of addressing emotional aspects of the disease and ensuring empathetic and sensitive treatment.

Education and information emerged as crucial components. Participants expressed a desire for greater public awareness about MG and improved medical education regarding the disease. This highlights the importance of combating ignorance and promoting deeper understanding among both medical professionals and the general public.

The social and economic dimensions were equally significant. Patients called for increased financial support and legal recognition of the disease to ensure adequate safeguards. The importance of patient support networks and a multidisciplinary approach to care underscores the need for a holistic approach to addressing MG.

In conclusion, participants responses reflect the importance of a comprehensive, personalized, and interdisciplinary approach to managing MG. The requests for personalized therapies, effective communication, accurate information, and appropriate social and economic support underscore the need to comprehensively address this complex disease. This study provides further insights into patient perspectives and can inform the development of enhanced strategies for the management of MG.

Future research should explore additional factors that could influence coping strategies. This could include deeper psychological assessments, socio-economic factors, family dynamics, and broader community support systems, which might offer further insights into the complex nature of coping with chronic illnesses like MG.

Limits

While the study highlights the coping strategies and adaptation mechanisms employed by patients, it also acknowledges the limitations of the analysis. The use of virtual sampling and self-reported data may introduce bias, and the findings might not be generalizable to all MG populations. Furthermore, while our study provides insights into the associations between coping strategies and certain demographic and medical factors, it does not establish causality. Further research is warranted to explore additional factors that may influence coping strategies and to validate the observed patterns in larger and more diverse patient populations. Overall, our study highlights the importance of tailored interventions and resources aimed at empowering patients to manage their condition effectively.

Conclusions

Our study illuminates the coping strategies embraced by patients contending with the challenges posed by MG. The findings underscore the intricate nature of this chronic autoimmune neuromuscular disorder and its profound repercussions across various dimensions of daily life. Notably, our research unveils patients’ resolute determination to ameliorate the impact of the ailment across its diverse phases. However, a noteworthy proportion of participants encounter hurdles stemming from a dearth of knowledge regarding efficacious coping strategies. This underscores the imperative of tailored interventions and resources aimed at empowering patients in effectively managing their condition. In conclusion, this study contributes to a deeper understanding of how individuals with MG navigate the complexities of their condition. The insights gained have the potential to drive the development of more effective interventions, ultimately enhancing the quality of life for patients and improving their ability to cope with the challenges posed by this chronic disorder.

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Conflicts of interest: Authors declare no conflicts of interest.

Code availability: The code used in this study is available from the corresponding author on reasonable request.

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