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Original article

Exploring the mental strength of myasthenia gravis patients: A statistical and language learning model approach for understanding coping and adaptation

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Abstract. *Background and aim:* Myasthenia Gravis (MG) is a chronic autoimmune neuromuscular disorder characterized by muscle weakness and fatigue, significantly affecting physical abilities, emotional well-being, and social interactions. Coping strategies play a crucial role in disease management, yet there is limited knowledge on how MG patients adapt to their condition. This study aims to explore the coping mechanisms employed by individuals with MG to identify patterns that may inform targeted interventions for improving their overall well-being. *Methods:* We conducted an anonymous online survey from January to April 2023, recruiting MG patients through social media groups. The survey included socio-demographic questions and the validated Coping Orientation to Problems Experienced (COPE-NVI-25) questionnaire to assess coping strategies. Additionally, two open-ended questions allowed participants to express their concerns and suggestions regarding disease management. We analyzed structured responses using statistical methods, while open-ended responses were processed through a Large Language Model (LLM)-assisted sentiment analysis and clustering technique. *Results:* A total of 215 MG patients participated. Most respondents lacked prior knowledge of MG before diagnosis and reported dissatisfaction with available health education. COPE-NVI-25 results showed that Positive Attitude was the most frequently adopted strategy, while Avoidance Strategies and Transcendent Orientation were the least used. LLM-assisted analysis of open-ended responses highlighted patients' concerns regarding inadequate communication with healthcare providers, lack of guidance on coping strategies, and the desire for more patient-centered care. *Conclusions:* This study provides novel insights into the coping strategies of MG patients, highlighting the need for improved education and tailored interventions. (www.actabiomedica.it)

Key words: myasthenia gravis, coping impairment, COPE-NVI-25 questionnaire, large language model

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 (6,7), especially during COVID-19 pandemic (8–10). 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 (11). The disease manifests through various clinical dimensions, including cognitive deficits, depressive states, and sleep disturbances, all of which necessitate comprehensive clinical attention (12–15). 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 (16) and loneliness, which compromise their relative quality of life (17), 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 (18). 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, we aim to capture a nuanced understanding of how patients navigate the complexities imposed by MG. While analyzing structured questionnaire data with numerical or multiple-choice answers is relatively simple, deriving meaningful insights from open-ended responses presents significant challenges and lacks a universal method. Natural Language Processing (NLP) techniques such as sentiment and emotion analysis (19) offer some insight into the emotions of respondents but often fail to capture the subtle nuances in their expressions. Traditional NLP approaches can recognize basic sentiments like positive, negative, or neutral and identify emotions such as joy, anger, or sadness. However, they typically fall short in detecting complex moods and intentions, frequently oversimplifying the intricate language present in open-ended feedback. The development of AI-driven Large Language Models (LLMs) like ChatGPT (20), has significantly advanced NLP, enhancing the understanding of human language. These models are trained on extensive textual data from varied sources, enabling them to grasp contextual nuances, discern subtle tonal differences, and produce responses that are both coherent and context sensitive. Additionally, employing LLMs for analyzing open-ended questionnaire responses can streamline the data analysis process, considerably reducing the time and labor needed for manual evaluation. Through the automation of insight extraction, these models can manage vast quantities of qualitative data effectively, delivering timely and actionable information. Combining statistics and LLM, 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 (21).

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. The statistical analyses were conducted for all qualitative and quantitative variables using Matlab software, 2023b version. Statistical significance level was set at $p<0.05$.

Large language model for open-ended questionnaire processing

We opted to use for a semi-quantitative, automatic analysis of responses to two open-ended questions, following the methodology outlined in a prior study (10). Briefly, the process includes two primary stages: initially, vector embedding is applied to all text entries, followed by clustering these vectors using the k-means algorithm to discern patterns in the data. Subsequently, the content within each cluster is summarized to provide a comprehensive yet concise representation of the expressed moods.

We utilized a freely available embedding model (22), which features 768 variables, creating a matrix with dimensions 215 × 768, corresponding to the 215 respondents. The embedding vectors were then clustered, arbitrarily imposing 3 clusters as the target partitioning scheme. Post clustering, we manually polished the results to enhance clarity for publication and repeated the analysis to verify consistency. This method facilitated a refined depiction of the predominant emotional tones conveyed by the participants.

Ethical considerations

The study ethical concerns were explicitly explained in the questionnaire introduction. The questionnaire adhered to the Helsinki principles and was approved by the Ethical committee of the General hospital of Policlinic of Bari, Italy, with id number n. 7766 of 11/01/2023. 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	19-82
Range 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 Higher	14 (7)
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 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

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
Often	0
Occasionally	15 (7)
Rarely	19 (9)
Never	181 (84)
FAMILY	
Always	2 (1)
Often	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
Often	0
Occasionally	7 (3)
Rarely	11 (5)
Never	197 (92)
SANITARY	
Always	4 (2)
Often	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)

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

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)

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.

Large Language Model results

The use of LLMs to analyze open-ended responses provided significant insights into respondent perspectives, in which they provided suggestions and highlighted perceived essential changes required in the management of MG. We analyzed responses to two open-ended questions from our survey using vector embedding and clustering methods. Table 4 displays comprehensive results for each question, including a representative example from each of the two clusters and a summary of the findings. Figure 1 visually represents the placement of clustered vectors, which were derived from the 215 responses, in a two-dimensional space using principal component analysis (PCA). PCA was utilized to simplify the visualization of the variable space.

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 2.

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 (23).

Table 4. Semi-automatic analysis of responses for two open-ended questions. For each question, the table includes a representative example from each of the three clusters and a summary of the findings.

<table>
<tr><td colspan="3">Open-ended question A:
<i>Write freely what you would recommend or believe is essential to change in the management of the disease</i></td></tr>
<tr><td>Cluster</td><td>Representative Example</td><td>Summary</td></tr>
<tr><td>1
Cardinality 113</td><td>More attention from physicians, less rush during check-ups</td><td>This cluster is characterized by a strong desire for greater attention from physicians and a less rushed approach during medical check-ups. Participants express a clear need for better listening and understanding from medical staff. Many responses highlight the necessity to improve communication and information regarding the disease, as well as the importance of personalized treatment and more adequate moral and material support. The recurring theme is dissatisfaction with the current level of care and the need for a more human and informed approach from physicians.</td></tr>
<tr><td>2
Cardinality 67</td><td>More information by the physician/ neurologist</td><td>This cluster highlights a significant need for better communication and information from healthcare providers, especially when a patient is newly diagnosed. Respondents frequently mention the importance of a more attentive and less formal physician-patient relationship. There is a strong desire for a multidisciplinary approach that includes psychological support, faster diagnosis, and better education for both patients and healthcare professionals. The recurring theme is the necessity of comprehensive care that addresses not only the medical but also the psychological and social aspects of the disease.</td></tr>
<tr><td>3
Cardinality 35</td><td>Nothing</td><td>This cluster primarily consists of responses that are non-informative or indicate a lack of opinion or knowledge. Examples include responses like “N/A,” “Nothing,” “I don’t know”. The overall theme is a neutral or unclear sentiment, with participants either choosing not to provide a meaningful answer or indicating they have no specific feedback or suggestions to offer.</td></tr>
<tr><td colspan="3">Open-ended question B:
<i>If you find the treatments you are receiving unsatisfactory, can you indicate the reasons why?</i></td></tr>
<tr><td>Cluster</td><td>Representative Example</td><td>Summary</td></tr>
<tr><td>1
Cardinality 97</td><td>I would like more information about alternative therapies and the disease</td><td>This cluster is predominantly characterized by a strong desire for more information regarding alternative therapies and the disease itself. The repetition of the phrase “I would like more information about alternative therapies and the disease” indicates a widespread sentiment among respondents that the information currently provided is insufficient. One notable response also mentions that the overall information given was not adequate, reinforcing the need for better communication and education. This cluster highlights a significant gap in patient knowledge that could be addressed through enhanced informational resources and patient education initiatives.</td></tr>
<tr><td>2
Cardinality 68</td><td>Dissatisfied</td><td>This cluster reflects a significant level of dissatisfaction among respondents, as indicated by numerous mentions of “Dissatisfied”. This cluster reflects a significant level of dissatisfaction among respondents, as indicated by numerous mentions of “Dissatisfied”. Many participants express frustration with various aspects of their treatment experience, ranging from the perceived inadequacy of care to a lack of responsiveness from healthcare providers.</td></tr>
<tr><td>3
Cardinality 50</td><td>I would like to be involved in therapeutic decisions</td><td>This cluster centers around the desire for greater involvement in therapeutic decision-making, with many respondents expressing a wish to have more input in their treatment plans. A recurring theme is the dissatisfaction with the brevity of medical visits, as indicated by several mentions of “The short visit is too short.” Additional concerns include difficulty in finding the right therapy and challenges related to long wait times and inadequate specialist availability. While a few responses indicate satisfaction with the care received, the predominant sentiment is a need for more thorough and collaborative medical care.</td></tr>
</table>

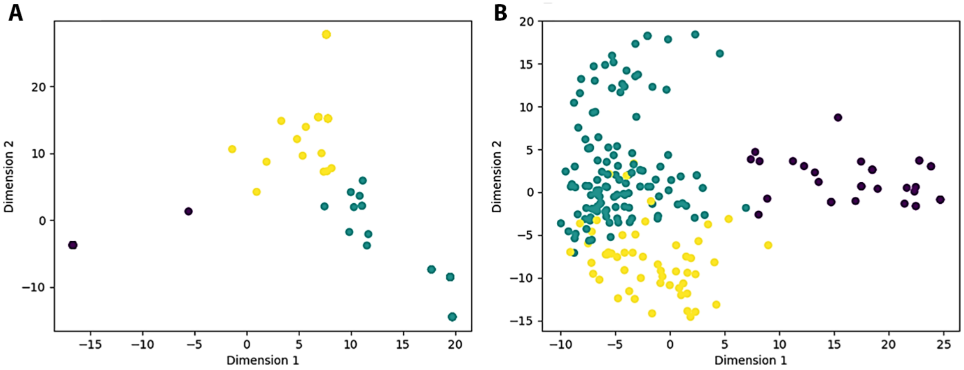

Figure 1. Responses from the two open-ended questions, coded by vector embedding and processed through PCA, are displayed in the two most representative dimensions. The points are color-coded based on the clusters to which they belong. Each panel represents one question (from A to B).

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	17 (8)
2	22 (10)
3	42 (20)
4	50 (23)
5	42 (20)
6	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)

COPE-NVI-25 QUESTIONNAIRE ITEMS	N (%)
9. I do what needs to be done, one step at a time	
1	8 (4)
2	7 (3)
3	16 (7)
4	33 (15)
5	54 (25)
6	97 (45)
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	
1	33 (15)
2	32 (15)
3	38 (18)
4	49 (23)
5	28 (13)
6	35 (16)

COPE-NVI-25 QUESTIONNAIRE ITEMS	N (%)
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	
1	53 (25)
2	31 (14)
3	40 (19)
4	33 (15)
5	34 (16)
6	24 (11)
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	19 (9) 15 (7)
1	39 (18)
2	48 (22)
3	39 (18)
4	55 (26)
5	
6	
21.I recognise that I cannot do anything about it and abandon all attempts to act	
1	115 (53)
2	41 (19)
3	27 (13)
4	13 (6)
5	4 (2)
6	15 (7)
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)

Table 5 (*Continued*)

COPE-NVI-25 QUESTIONNAIRE ITEMS	N (%)
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)

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.

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.

Discussion

In this study, we explored the coping patterns among patients with Myasthenia Gravis (MG), leveraging a validated questionnaire, COPE-NVI-25 (24), 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 (25,26). The application of the COPE-NVI-25

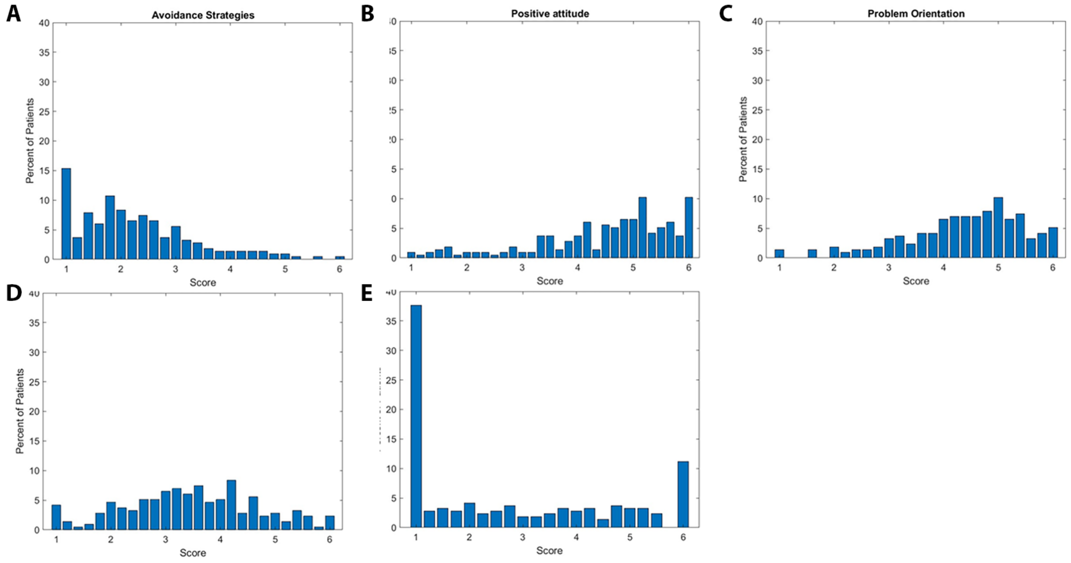

Figure 2. Frequency distributions (percent) for the five subscales of the COPE-NVI-25 questionnaire (panels A to E).

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

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 (27). 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

Table 7. Univariate analysis of the COPE-NVI-25 subscales (n=215) according to 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).

		COPE-NVI-25 subscales *p-value*				
COPE-NVI-25/ Socio-demographic characteristics	**μ±s.d**	**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 school	84.6 ± 48.7					
Higher Diploma	78.9 ± 49.9					
Degree	111.5 ± 4.3					
Postgraduate training	155.06 ± 51.4					
Employment status						
Employee	125.6 ± 63.09	0.362	0.08	0.837	0.560	0.428
Freelancer	96.6 ± 59.3					
Student	96.5 ± 62.2					
Retired	126.5 ± 63.3					
Unemployed	93.7 ± 62.8					

		COPE-NVI-25 subscales *p-value*				
COPE-NVI-25/ Socio-demographic characteristics	**μ±s.d**	**Avoidance Strategies**	**Transcendent Orientation**	**Positive attitude**	**Social Support**	**Problem Orientation**
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?						
No	103.3 ± 60.7	**<0.05***	0.828	0.364	0.626	0.217
Yes	131 ± 65.01					
If you answered YES to the previous question, in which field did you hear about it?						
MASS MEDIA						
Always	0	0.253	**0.01****	0.905	0.483	0.523
Often	0					
Occasionally	84.7 ± 49.8					
Rarely	114.7 ± 70.6					
Never	106.01 ± 61.2					
FAMILY						
Always	133.5 ± 37.4	0.409	0.109	0.348	0.349	0.199
Often	0					
Occasionally	89 ± 39.8					
Rarely	81.8 ± 74.3					
Never	107.3 ± 62.1					
SCHOOL						
Always	71 ± 0	0.552	**<0.05***	**<0.05***	**<0.05***	**<0.01***
Often	190 ± 11.3					
Occasionally	134 ± 0					
Rarely	136.6 ± 65.05					
Never	102.1 ± 60.5					
FRIENDS						
Always	0	0.400	0.258	0.222	0.423	**<0.05***
Often	0					
Occasionally	128.7 ± 15.9					
Rarely	103.1 ± 72.7					
Never	106.7 ± 62.01					
HEALTHCARE SECTOR						
Always	111.5 ± 30.1	0.07	0.403	0.267	0.305	0.287
Often	0					
Occasionally	80.3 ± 40.5					
Rarely	126.9 ± 63.6					
Never	102.3 ± 61.8					

Table 7 (*Continued*)

		COPE-NVI-25 subscales *p-value*				
COPE-NVI-25/ Socio-demographic characteristics	**μ±s.d**	**Avoidance Strategies**	**Transcendent Orientation**	**Positive attitude**	**Social Support**	**Problem Orientation**
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?						
No	108.1 ± 61.2	**$<0.05^{*}$**	0.334	0.289	0.114	0.874
Yes	107.5 ± 66.8					
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					

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 behavior and coping strategies in chronic diseases (28). 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

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 Have you ever received home health education? Autonomy	0.07	0.05	3.38	**<0.01****
Positive attitude	Heard at School	0.0004	-0.004	0.09	0.761
Social Support	Heard at School Have you ever received home health education? Autonomy	0.05	0.04	3.9	**<0.01****
Problem Orientation	Age Heard at School Hear from friends Have you ever received home health education? Autonomy	0.03	0.01	1.58	0.168

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 confirms 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 sociocultural 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 employed an advanced analytical approach using LLMs to examine open-ended responses provided by questionnaire participants regarding the management of MG. The results offer significant insights into patient perspectives, highlighting several key themes that underscore the areas needing improvement in MG care and treatment (29–31). A central theme identified is the urgent need for better communication and information dissemination from healthcare providers. Cluster analyses reveal that many patients feel inadequately informed about their disease and the available treatment options, particularly alternative therapies. This gap in knowledge underscores the necessity for more comprehensive education efforts directed both at patients and the medical community. Addressing this need could enhance patient empowerment and lead to better treatment outcomes. Another prominent theme is patient dissatisfaction with current care practices. Many respondents expressed frustration with the level of attention and time they receive during medical visits, reflecting a broader dissatisfaction with the healthcare system's ability to meet their needs. This dissatisfaction highlights the importance of improving the clinician-patient relationship, particularly through more personalized and empathetic care. Respondents emphasized the importance of being involved in therapeutic decision-making, suggesting that a more collaborative approach could alleviate some of the dissatisfaction currently experienced. The analysis also pointed out the desire for greater involvement in decision-making. Patients are not just passive recipients of care; they want to play an active role in the decisions that affect their health. This finding suggests that healthcare providers need to foster a more inclusive environment where patient input is valued and considered integral to the treatment process. Enhancing patient involvement could not only improve satisfaction but also lead to more tailored and effective treatment plans (32). Lastly, the analysis revealed a subset of respondents who provided non-informative or neutral responses, indicating a potential lack of engagement or awareness regarding the management of their condition. This group's responses highlight the importance of ensuring that all patients are fully engaged in their care, which might require additional outreach or education efforts. In conclusion, the findings from this study emphasize the need for a more comprehensive, patient-centered approach to managing MG. The recurring requests for improved communication, better information, personalized care, and active patient involvement point to critical areas where the current system could be enhanced. Addressing these issues could lead to more effective management strategies and improved patient outcomes. Future research should explore the impact of these themes on long-term patient outcomes, potentially incorporating deeper psychological assessments, socio-economic factors, and broader community support systems. Understanding these additional layers could provide further insights into the complex nature of coping with MG and inform the development of more holistic management strategies.

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. In addition, due to the data collection through social media, this study does not have a big sample size but is a convenience sample. 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 provides valuable insights into the coping strategies and challenges faced by patients with MG, with a particular focus on the perspectives revealed through the use of LLM for analysing open-ended survey responses. The findings highlight the complex nature of this chronic autoimmune neuromuscular disorder and its significant impact on various aspects 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 and the desire for improved communication, more personalized care, and greater involvement in their treatment decisions. 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.

Ethic Approval: The questionnaire adhered to the Helsinki principles and was approved by the Ethical committee of the General hospital of Policlinic of Bari, Italy, with id number n. 7766 of 11/01/2023.

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

Authors' Contributions: R.L., P.L. conceived and designed the study. L.C. contributed to data collection and statistical analysis. L.C., L.P., F.R., and A.F. assisted in patient recruitment and data acquisition. L.C., T.L., I.R., and E.V. contributed to the interpretation of results and manuscript drafting. G.A. and D.C. provided critical revision of the manuscript. G.DN. supervised the study and provided methodological support. All authors reviewed and approved the final version of the manuscript.

Declaration on the Use of AI: We used ChatGPT to assist with English language refinement and grammar checking. No AI was used for data analysis, interpretation, or scientific content generation.

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