Original Article

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Health-related quality of life (HRQoL) and psychological impact of the COVID-19 pandemic on patients with myasthenia gravis

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SUMMARY The aim of this study was to compare the effects of the pandemic on health-related quality of life (HRQoL), anxious-depressive symptoms, feelings of loneliness, and fear of COVID-19 between people with myasthenia gravis (MG) and healthy controls. We also wanted to know in which group the variable fear of COVID-19 interfered the most with the results. This cross-sectional study involved 60 people with MG and 60 healthy controls. Participants using an online platform completed a sociodemographic questionnaire, the Short Form-36 Health Survey (SF-36), the Hospital Anxiety and Depression Scale (HADS), the revised UCLA Loneliness Scale and the Fear of COVID19 Scale (FCV-19S). The MG group reported worse levels in HRQoL indicators (p = 0.043- <.001), more severe anxiety-depressive symptoms (p = 0.002), and greater fear of COVID-19 (p < 0.001), but there were no differences in feelings of loneliness (p = 0.002). Furthermore, after controlling for the effect of the fear of COVID-19 variable, the differences remained for physical health indicators, but not for the most of psychosocial indicators (Social Functioning p = 0.102, η^2_p = 0.023; Role Emotional p = 0.250, η^2_p = 0.011; and HADS Total p = 0.161, η^2_p = 0.017). The harmful effect of the COVID-19 pandemic was greater in the MG group, and the perceived fear of COVID-19 had also a greater impact among this group, which has increased its negative effect on their psychosocial health.

Keywords MG, HRQoL, anxious-depressive symptoms, feelings of loneliness, fear of COVID-19

1. Introduction

Rare diseases (RDs) are clinical conditions that individually affect fewer than five people per 10,000 population (*1-3*). Together they affect more than 300 million people around the world (*2*). So far, about 7,000 different RDs have been recognised, which show great heterogeneity and are vastly dispersed geographically (*2-3*). Most of these diseases are chronic and lead to reduced life expectancy for those affected (*4*).

Myasthenia gravis (MG), also called myasthenia gravis acquisita, is a RD. This is a neuromuscular and autoimmune condition that affects the production of antibodies against acetylcholine receptor (AChR), muscle-specific kinase (MuSK) or other AChR-related proteins in the postsynaptic membrane of the neuromuscular junction, which impairs the muscle contraction (*5,6*). The overall prevalence of MG is around 150–250 cases per million people (*7*), affecting both sexes equally. In women it tends to develop before the age of 40, while in men it usually begins after the age of 50 (*8*). MG is characterised by weakness and fatigue affecting different muscle groups, with the most significant signs and symptoms in this population being ptosis, dysarthria, dysphagia, diplopia, fatigue, dyspnoea and weakness in arms and legs. In addition, weakness can become generalised and lead to a full paralytic crisis, also known as a myasthenic crisis, which can require hospitalisation (*5,8-9*).

In addition to physical health status, people with MG report high levels of depression, anxiety, loneliness, and isolation, as well as poorer health-related quality of life (HRQoL) compared to the general population (*10,11*). All of this interferes with the daily functioning of these individuals (*9,11*). Furthermore, the social stigma attached to visible symptoms, such as ptosis, can have a negative impact on the individual's self-perception (*9*). It is therefore essential to address the psychological aspects in people with MG (*9,12*).

Pandemic period due to the SARS-CoV-2 virus (COVID-19) brought a new and difficult challenge in this respect. Since it started in winter 2019, both its

impact on daily life and the resulting restrictions and lockdowns affected the physical and mental health of the population around the world (*13*). In Spain, due to the rapid spread of the virus, a state of alarm was declared in March 2020 and mandatory confinement was imposed for three months. Thereafter, until early 2022, Spain remained in a state of health emergency. During this time, there were some specific restrictions according to mobility (*e.g.* leaving your district and imposed curfew) and health/social measures, such as mandatory mask wearing, social distancing and limited capacity of people in both indoor and outdoor public settings. The demand for health care reached the point of saturation of health services (*14*). All these factors related to the pandemic situation, both during the state of alarm and the state of health emergency, were a major source of stress for the Spanish population, as in other countries around the world (*15*).

According to the worldwide COVID-19 psychological impact, some meta-analyses conducted during pandemic confirmed an increase in the prevalence of anxious and depressive symptoms (*16-18*), as well as an increasing number of people with post-traumatic stress disorder (*16,18*). Other clinical variables that have also become important due to their impact include feelings of loneliness and HRQoL (*19,20*).

However, the impact of the COVID-19 pandemic on people living with RD, especially in terms of their mental health, has been and continues to be under-represented (*21,22*). In this regard, it is important to understand that people with MG often manifest respiratory muscle weakness, which leaves them in a position of increased vulnerability as a population group who are more at risk if they contract COVID-19. In addition, immunosuppressive treatment for MG may limit the immune response to viral infection, and even drugs to combat COVID-19 infection may have adverse effects on the neuromuscular system. Therefore, the pandemic has become a potential stressor for these individuals, which adds to the long list of concerns and needs related to their health (*21,23-30*). Specifically, some studies conducted in Spain highlighted the importance of considering the perspective of patients with chronic diseases during the pandemic era, as the quality and continuity of care for the management of their clinical condition was interrupted or disrupted by the lack of health resources (*31,32*). The preliminary findings of one of the few studies conducted in a small MG sample have shown that the COVID-19 pandemic is particularly associated with anxious-depressive symptoms and poorer HRQoL (*33*).

This study aims to analyse the effects and psychological impact of the COVID-19 pandemic after lockdown and during health emergency state on people living with MG as a pre-existing rare and chronic condition, and to address the urgent need for better understanding of their situation (*34,35*). Specifically, in terms of HRQoL, anxiety-depressive symptoms, feelings of loneliness and fear of COVID-19. Furthermore, given the psychological effect that the pandemic has had across the world's population, the influence that the COVID-19 fear variable may have had on the rest of the clinical variables reported was controlled for. This led to a more detailed analysis of the differences found between a sample with MG and a sample from the general population. Based on the objectives, we expected to find a greater psychological impact of the pandemic among people with MG. Secondly, it was hypothesised that the perception of fear of COVID-19 would also increase the other variables studied to a greater extent in the MG group.

2. Materials and Methods

2.1. Participants

This cross-sectional study was performed on a quasi-control group of 120 Spanish participants, who were recruited in the first half of 2021 (during the state of emergency for COVID-19 in Spain). The total sample consisted of 60 patients diagnosed with MG and 60 control-matched participants. Table 1 shows the sociodemographic data.

The inclusion criteria for the clinical group were: *i*) a diagnosis of MG given by a neurologist, *ii*) being aged 18 or over, *iii*) informed consent provided prior to participation, *iv*) being resident in Spain, and *v*) speaking Spanish as one of their main languages. The exclusion criteria were a diagnosis of any clinical condition

Table 1. Socio-demographic characteristics of the total sample

Variable	Clinical group (n = 60) M (SD) / n (%)	Control group (n = 60) M (SD) / n (%)
Sex		
Female	44 (77.3%)	44 (77.3%)
Male	16 (26.7%)	16 (26.7%)
Age (years)	51.90 (14.73)	51.93 (14.60)
Educational level		
Primary education or equivalent	5 (8.3%)	16 (26.7%)
Secondary education or equivalent	11 (18.3%)	10 (16.7%)
Baccalaureate or equivalent	13 (21.7%)	13 (21.7%)
Higher Level of Vocational Training	7 (11.7%)	3 (5%)
University degree or equivalent	17 (28.3%)	13 (21.7%)
Master's degree	5 (8.3%)	5 (8.3%)
Doctorate	2 (3.3%)	0 (0%)
Employment status		
Employed	24 (40%)	33 (55%)
Self-employed	3 (5%)	2 (3.3%)
Unpaid work	1 (1.7%)	2 (3.3%)
Unemployed for health reasons	3 (5%)	1 (1.7%)
Unemployed (for other reasons)	2 (3.3%)	4 (6.7%)
Retired	26 (43.3%)	14 (23.3%)
Student	1 (1.7%)	4 (6.7%)

Note: n = number of participants; M = mean; SD = standard deviation.

other than MG. The control group consisted of healthy participants from the general Spanish population. Both groups were homogeneous with respect to gender, $\chi 2$ (1) = 0, p = 1, and age (U = 1818.000, p = 0.925).

2.2. Instruments

Socio-demographic and participants' exposure experience to the pandemic data were collected through an ad hoc questionnaire. The items related to exposure experience to COVID-19 refer to the following information: *If the person…i*) Has been infected by COVID-19 at any time; *ii*) Has gone into voluntary lockdown after the end of the alarm state / during state of health emergency; *iii*) Has lived with someone infected; and *iv*) Have relatives, friends or colleagues who have been infected.

The following variables were included in the assessment protocol: HRQoL, anxiety-depressive symptoms, feelings of loneliness and fear of COVID-19. All tests were adapted to Spanish and had appropriate psychometric properties.

2.2.1. Short Form-36 Health Survey (SF-36)

The Short Form-36 Health Survey (SF-36) (*36*; Spanish version: *37*) is an instrument designed to assess HRQoL. It consists of 36 items that are made up of eight different scales ("Physical Functioning", "Role Physical", "Bodily Pain", "Vitality", "Social Functioning", "Role Emotional", "Mental Health" and "General Health"). Administration time is around 10 minutes and the range of scores is between 0 and 100 points, with 0 being the worst possible health status for that dimension and 100 being the best. In addition, the instrument offers two standardized components summaries: Physical and Mental. The overall test-retest reliability is above 0.79, reaching a Cronbach's alpha of 0.94 for some scales (*38*).

2.2.2. Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) (*39*; Spanish version: *40*) consists of 14 items divided into two subscales (anxiety and depression). Each of these is made up of seven items that presented by alternating the order with a Likert-type choice of four responses to each item (ranging from 0 to 3 points). The total scores, which are obtained by adding the scores of each item, range from 0 to 21 points for each subscale and from 0 to 42 points for the overall test, with a higher score implying a higher level of anxious-depressive symptoms. The full scale has high values for internal consistency (α = 0.90) (*40*).

2.2.3. Revised UCLA (University of California, Los Angeles) Loneliness Scale

The revised UCLA Loneliness Scale (*41*; Spanish version: *42*) is a self-reporting measure that assesses feelings of loneliness. It is made up of 20 items, with Likert-type response options (1 = often, 2 = sometimes, 3 = rarely and 4 = never) and scores range from 20 to 80 points. A higher score suggests a greater feeling of loneliness. The instrument adapted for use with the Spanish population has high internal consistency (α = 0.94) (*42*).

2.2.4. Fear of COVID-19 Scale (FCV-19S)

The Fear of COVID-19 Scale (FCV-19S) (*43*; Spanish version: *44*) is a seven-item Likert-type test that assesses fear of COVID-19. The participant is asked to report their degree of agreement with some statements, 1 meaning "strongly disagree" and 5 meaning "strongly agree". The minimum possible score per question is 1 and the maximum 5. The total score is obtained by adding up the scores for each item (ranging from 7 to 35). Thus, the greater the score, the greater the fear of COVID-19. The psychometric validation of the Spanish version (*45*) achieved acceptable internal consistency (α = 0.82).

2.3. Procedure

Given the characteristics of the target population, convenience sampling was carried out in the first part. Participants were recruited by contacting the Spanish Myasthenia Gravis Association (*Asociación Española de Miastenia Gravis* (AMES)), which was responsible for disseminating the study information letter to its members. All questionnaires used in this research were adapted to an online format using the "Qualtrics platform (XM version)". In this way, each participant self-administered the survey *via* a link to the evaluation protocol. It took approximately 25 minutes to complete the questionnaire. The platform used allowed the protocol to be completed at different times by recording the information previously covered, provided that it was accessed from the same electronic device (smartphone, tablet, *etc*.). This protocol also contained an *ad hoc* questionnaire and an informed consent form for participation in the study. It was specified that participation would be voluntary and without financial remuneration. In the second part, the participants in the homogeneous control group were recruited and provided with the information included in the information letter. They also received the link to access the evaluation protocol in the same way as the clinical group. In addition, the study was carried out between 2021–2022. Finally, participants were informed that the study complied with the criteria of the Code of Ethics, ensured compliance with the international standards proposed in the Declaration of Helsinki and was approved by the Research Ethics Committee of the institution (Ref: ETK-39/20-21).

2.4. Data analysis

Statistical Package for Social Sciences (SPSS) version 28.0 was used for the analyses. The Kolmogorov-Smirnov test was applied to determine the normal distribution of the variables. The direct scores were converted into *z* scores to carry out the analyses.

The Mann-Whitney *U*-test for quantitative variables and the Chi-square statistic for categorical variables were used to compare sociodemographic data, COVID-19 exposure, and clinical variables between groups. Cramer's V and Pearson's r measures of effect size were taken as appropriate.

A multivariate analysis of covariance (MANCOVA) was also carried out to analyse the influence of the COVID-19 fear variable on the differences found in the rest of the clinical variables analysed between the clinical and control groups. As an indicator of effect size, the partial *eta* squared η^2_p was established. The significance level was set at $p < 0.05$.

3. Results

The data collected on exposure experience to COVID-19 for each group can be found in detail in Table 2. In this case, statistically significant differences were found only in the question about voluntary lockdown $\chi 2$ (1) = 5.507, $p = 0.025$, with participants in the clinical group going into voluntary lockdown more often in comparison to control ones.

Table 3 shows the scores obtained from the different psychometric instruments. The analyses carried out showed statistically significant differences between the clinical group and the control group. Specifically, people with MG reported a worse HRQoL in almost all indicators of the SF-36: "Physical Functioning" ($p < 0.001$, $r = 0.613$), "Role Physical" ($p < 0.001$, $r = 0.487$), "Bodily Pain" ($p = 0.003$, $r = 0.273$), "Vitality" ($p < 0.001$, $r = 0.579$), "Social Functioning" ($p = 0.002$, $r = 0.283$), "Role Emotional" ($p = 0.002$, $r = 0.287$), "General Health" ($p = 0.043$, $r = 0.184$), and "PCS" ($p < 0.001$, $r = 0.567$). In addition, higher levels of anxious ($p = 0.003$, $r = 0.269$) and depressive ($p = 0.006$, $r = 0.250$) symptoms in the different subscales and total score ($p = 0.002$, $r = 0.288$) of the HADS and greater fear of COVID-19 ($p < 0.001$, $r = 0.335$) assessed through the FCV-19S instrument. According to effect sizes, the magnitudes of the differences ranged from small to large. However, no statistically significant differences were found between the clinical group and the control group in the HRQoL indicator "Mental Health" and "MCS" of the SF-36 test nor in the variable of feelings of loneliness analysed using the UCLA test.

Given the differences found in the level of perceived fear of COVID-19 between the two study groups, a MANCOVA analysis was performed in order to control for the effect of this variable on HRQoL and anxious-depressive symptoms, and to analyse whether fear of COVID-19 might exacerbate its impact on participants' physical and mental health. Table 4 shows how differences were eliminated for the SF-36 "Social Functioning" ($F = 2.718$, $p = 0.102$) and "Role Emotional" ($F = 1.337$, $p = 0.250$) variables and for the anxiety ($F = 1.497$, $p = 0.224$) and depression ($F = 1.197$, $p = 0.276$) subscales and the HADS total score ($F = 1.989$, $p = 0.161$), while for "Physical Functioning", "Role Physical", "Bodily Pain", "Vitality", "General Health" and "PCS" of SF-36 differences remained between the groups. In other words, the statistically significant differences in the physical health and in the "Vitality" psychosocial indicators between groups remained even after controlling for fear of COVID-19, but not in the other psychosocial variables. This means that the differences between the clinical and control group in psychosocial health were influenced by the perceived fear of COVID-19.

Table 2. Exposure experience to COVID-19 data of the total sample

Variable	Clinical group ($n = 60$) *n* (%)	Control group ($n = 60$) *n* (%)	$\chi 2(1)$	*p*	*V*
Have you been infected by COVID-19?			1.365	0.243	0.107
Yes	5 (8.3%)	2 (3.3%)			
No	55 (91.7%)	58 (96.7%)			
Have you gone into voluntary lockdown after the end of the state of alarm?			5.507	0.025*	0.205
Yes	22 (36.7%)	11 (18.3%)			
No	38 (63.3%)	49 (81.7%)			
Have you lived with someone who has been infected with COVID-19?			2.157	0.142	0.134
Yes	9 (15%)	4 (6.7%)			
No	51 (85%)	56 (93.3%)			
Has any member of your family been infected with COVID-19?			2.727	0.099	0.151
Yes	20 (33.3%)	12 (20%)			
No	40 (66.7%)	48 (80%)			
Have any of your friends or colleagues been infected with COVID-19?			0.037	0.847	0.018
Yes	39 (65%)	40 (66.7%)			
No	21 (35%)	20 (33.3%)			

Note: *n* = number of participants; $\chi 2$ = Chi-squared test; *$p < 0.05$; **$p < 0.001$; *V* = Kramer's *V* (effect size).

Table 3. Differences in HRQoL, anxiety-depressive symptoms, feelings of loneliness and fear of COVID-19 between the clinical group and the control group

Variable	Clinical group (n = 60) Mdn (Range)	Control group (n = 60) Mdn (Range)	U	Z	p	r
SF-36						
Physical Functioning	65.00 (95)	97.50 (75)	541.000	-6.704	< 0.001**	0.613
Role Physical	25.00 (100)	100.00 (100)	860.000	-5.341	< 0.001**	0.487
Bodily Pain	52.00 (100)	72.00 (90)	1233.500	-2.999	0.003*	0.273
Vitality	47.50 (85)	55.00 (90)	594.000	-6.345	< 0.001**	0.579
Social Functioning	68.75 (100)	87.50 (100)	1211.000	-3.101	0.002*	0.283
Role Emotional	67.70 (100)	100.00 (100)	1214.000	-3.149	0.002*	0.287
General Health	41.00 (82)	67.00 (75)	1454.000	-2.021	0.043*	0.184
Mental Health	60.00 (64)	64.00 (56)	1535.000	-1.397	0.162	-
PCS	38.13 (44.34)	54.64 (48.97)	620.000	-6.193	< 0.001**	0.567
MCS	42.19 (45.18)	44.89 (50.14)	1684.000	-0.609	0.543	-
HADS						
Total	18.50 (23)	15.00 (16)	1199.000	-3.161	0.002*	0.288
Depression subscale	9.00 (10)	8.00 (13)	1281.500	-2.748	0.006*	0.250
Anxiety subscale	9.00 (15)	7.00 (12)	1240.500	-2.949	0.003*	0.269
UCLA	39.00 (39)	37.00 (45)	1572.000	-1.198	0.231	-
FCV-19S	19.00 (27)	16.50 (19)	1101.500	-3.673	< 0.001**	0.335

Note: n = number of participants; Mdn = median; U = Mann-Whitney U test; Z = z scores; PCS = Physical Component Summary; MCS = Mental Component Summary; *$p < 0.05$; **$p < 0.001$; $r = r$ coefficient (effect size). Raw scores have been used in the Table.

Table 4. MANCOVA for HRQoL and anxiety-depression symptoms after controlling for the effect of fear of COVID-19 symptoms

Variable	Clinical group (n = 60) M (SD)	Control group (n = 60) M (SD)	F	p	η^2_p
SF-36					
Physical Functioning	-0.55 (0.99)	0.55 (0.63)	39.196	< 0.001 **	0.251
Role Physical	-0.48 (.095)	0.48 (0.79)	22.491	< 0.001**	0.161
Bodily Pain	-0.26 (0.98)	0.26 (0.95)	4.668	0.033*	0.038
Vitality	-0.28 (0.92)	0.28 (0.99)	5.629	0.019*	0.046
Social Functioning	-0.25 (0.99)	0.25 (0.94)	2.718	0.102	0.023
Role Emotional	-0.19 (1.06)	0.19 (0.90)	1.337	0.250	0.011
General Health	-0.58 (0.80)	0.58 (0.82)	37.988	< 0.001**	0.245
PCS	39.28 (9.90)	51.84 (9.60)	35.468	< 0.001**	0.233
HADS					
Total	0.29 (1.02)	-0.29 (0.89)	1.989	0.161	0.017
Depression subscale	0.22 (0.97)	-0.22 (0.98)	1.197	0.276	0.010
Anxiety subscale	0.27 (1.05)	-0.27 (0.86)	1.497	0.224	0.013

number of participants; M = mean; SD = standard deviation; F = MANCOVA; $\eta 2p$ = partial eta squared (effect size); PCS = Physical Component Summary; *$p < 0.05$; **$p < 0.001$. Raw scores have been used in the Table.

4. Discussion

The COVID-19 pandemic has had an impact on the mental health of the world's population. Therefore, it is particularly important to specifically address the psychological state of people who were already living with a pre-existing chronic disease (*46*). This becomes even more vital for RD patients, given the under-representation of scientific evidence on their situation in this health emergency (*21,22*). Therefore, the purpose of the present study was to analyse the impact on the mental health status of people diagnosed with MG compared to a healthy control group. This aimed to better understand the experience and care needs of people with MG during the COVID-19 pandemic.

According to the first hypothesis, the results obtained in this study confirmed that people with MG had poorer levels of HRQoL for most of the indicators analysed, as well as higher levels of anxiety-depressive symptoms and greater fear of COVID-19 compared to their healthy peers. On the one hand, results are consistent with the clinical psychopathology associated with the neuromuscular condition, which involves particularly impaired physical and psychosocial HRQoL and increased comorbidity with anxiety-depressive disorders (*16-18*). On the other hand, while there are no prior studies that have analysed fear of COVID-19 using the FCV-19S in the population with MG, some authors have used this instrument in patients with chronic diseases related to MG. For example, one study found that people with fibromyalgia reported significantly higher scores on the FCV-19S test compared to healthy controls, with

similar results to this study (*47*). Moreover, in the case of the population with MG, this greater fear could be justified by the consequences of being a vulnerable group, since they are at a greater risk. Treatment for MG may weaken their ability to fight the virus and their disease may worsen either as a result of it or because of the drugs prescribed to treat it (*21,23-30*). Furthermore, this study also found that people with MG had a greater tendency to go into voluntary lockdown, which also supports the idea that the impact of fear of COVID-19 is greater in the clinical population.

Nevertheless, no statistically significant differences were found between the clinical group and the control group for the HRQoL "Mental Health" indicator of the SF-36 test or for the variable of feelings of loneliness analysed by the UCLA test. These results may be due to the fact that the SF-36 test is a generic assessment instrument (*48*) and instruments such as the HADS are more sensitive to detecting psychological symptoms in people with MG compared to control subjects. This is evidenced by the fact that the HADS has been more widely used and recommended for studies in people with MG (*8,49-51*). Regarding feelings of loneliness, one possible explanation for the lack of statistically significant differences for this variable between the two groups could be that that the pandemic and lockdowns have posed a strong risk for the entire population; therefore, there has been overall isolation, causing feelings of loneliness to grow across the board. In fact, this problem elicited studies aimed at targeting urgent and effective interventions to prevent psychological and physical comorbidities, especially in vulnerable groups such as older adults (*20,52-54*).

Regarding second hypothesis, this study also aimed to find out whether fear or perceptions about the pandemic might have a greater impact on the mental health of people with MG compared to their healthy peers. The results showed that, controlling for the effect generated by the fear of COVID-19 variable, significant differences remained only for the indicators of general health and the different indicators referring to physical health. This is consistent with the fact that it is mainly the physical sphere in MG that is compromised, given the muscle weakness and fatigue MG patients suffer, which limits their daily functioning and interferes with their HRQoL (*5,8-11*). However, differences in anxiety-depressive symptoms and socio-emotional health indicators were not maintained, which suggests that the fear of COVID-19 seems to have a stronger negative influence on the psychosocial aspects of people with MG. This finding may be reinforced by more recent scientific literature, as it was stipulated early in the pandemic that those with pre-existing chronic illnesses would be one of the groups most likely to suffer adverse psychosocial effects (*55*).

In addition, there are contextual variables that may have increased this fear and the way in which people with MG perceive the threat that COVID-19 poses to their health. In particular, there are currently no quality COVID-19 pandemic guidelines for patients with MG, and the continuous and sometimes variable media coverage of recommendations to prevent transmission of the virus may have hindered their awareness or perception, while contributing to their anxiety (*30*). However, it has been argued that the MG population is considered even more vulnerable, making it essential that they receive both specific health education, as a preventive measure against COVID-19, and psychological care and counselling (*33*). Undoubtedly, promoting the provision of accurate COVID-19-related and MG-specific information by healthcare authorities, as well as patient associations, would lead to more informed and therefore less anxious MG patients (*30*). In this sense, strengthening telehealth strategies and services is an ideal, safe, and efficient resource for managing MG patients during the pandemic (*30,56*); especially, telecare psychological interventions have proven to be effective in the neuromuscular patient group on previous occasions (*e.g.*, *10*).

Despite the importance of the evidence and conclusions drawn, this study had many limitations. Firstly, it did not have a large sample size, compared to other studies conducted during the pandemic with participants from the general population. However, the difficulty in recruiting patients to participate in research studies needs to be taken into consideration, which is even more complex in the case of RDs (*57*). Secondly, as this was a cross-sectional study, there were no "pre-COVID-19" measurements of the same subjects; if these had been available, the conclusions drawn about the impact of COVID-19 on people with MG could have more accurately reflected. In addition, although guidelines were considered to ensure the validity and ethical implications of the self-report instruments used, many of them did not have a proper adaptation to the remote model (*58*). Finally, the specific psychosocial intervention required was not offered during this study.

Therefore, it is hoped that future research will follow up the variables discussed here using longitudinal studies and larger numbers of participants. It would also be useful to conduct psychosocial interventional studies, especially through telecare, for people with MG with the aim of mitigating the harmful effects of the pandemic. It is also hoped that the issues highlighted in this study can be extended across the RD community to reach specific patient groups, so that evidence on their experience during the pandemic can be obtained and appropriate guidelines for action can be developed accordingly.

To conclude, this study has shown that, during the pandemic, people with MG have had poorer levels of HRQoL, stronger anxiety-depressive symptoms and greater fear of COVID-19 compared to their healthy peers. Perceived fear of COVID-19 has also had a greater impact among people with MG, with an increased negative impact on their psychosocial health. Therefore,

this study provides additional evidence, and joins the rest of the literature in calling for regular attention to the mental and psychosocial health of people with MG, especially in this time of unprecedented large-scale pandemic.

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