

Knowledge and perceptions of the COVID-19 pandemic among patients with myasthenia gravis: follow up survey

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ABSTRACT

Introduction: We previously conducted a survey study in April 2020 at the beginning of the SARS-CoV-2 (COVID-19) pandemic to understand how it affected patients with myasthenia gravis (MG). Since then, significant advances have occurred in the following areas: knowledge about the SARS-CoV-2 virus, infection risk mitigation, patient management, risks for MG patients, and a global vaccination program. We conducted a follow-up survey in February 2021 to assess how these advances impacted the care and perception of MG patients.

Methods: We conducted a prospective online survey study of MG patients at a large academic practice in the Duke Health System.

Results: Seventy-eight patients participated in the survey, including 55 from the previous survey and 23 newly identified patients. The top reported change in the interaction with healthcare providers was an increase in telemedicine visits (74%). Telemedicine visits' median satisfaction score (0-100 scale) was 74. Ninety-six percent of survey participants expressed concern about the pandemic, and nearly half showed anxiety based on the Generalized Anxiety Disorder-7 score. The top 3 concerns related to COVID-19 were getting hospitalized (62%), exacerbation (62%), and death (53%).

Discussion: Although the follow-up survey results were similar to the previous study, most patients switched from in-person clinic visits to telemedicine. The overwhelmingly large portion of patients continue to have concern and anxiety about the pandemic, but the patients with severe symptoms have higher anxiety scores.

Conclusion: This follow-up survey demonstrated the adjustment of MG patients to new methods of communication, the significant psychological impact of COVID-19 on them, and their good healthcare literacy.

Introduction

As of September 2021, more than 4.5 million people worldwide have died due to COVID-19.¹ Information during the pandemic has evolved more rapidly than any other health crisis in human history. There has been a need for real-world data regarding how the pandemic has affected the care of MG patients. In April 2020, we surveyed to understand how patients with MG were experiencing the COVID-19 pandemic, where they got their information, and how it affected their medical care. The measures they took to protect themselves.³ To understand how changes in our understanding of COVID-19 have changed the care of MG patients and their perception of COVID-19, we conducted a follow-up survey in February 2021.

Methods

This is a prospective observational cohort study. Patients in the Duke Health System (Durham, North Carolina) were surveyed using REDCap. Details of our methods, eligibility criteria and statistical analysis were the same as described previously.³

Results

Survey timing and MG participant characteristics

The initial study approached 1,413 patients, and 75 patients completed the survey.³ Among the original 75 participants, 55 (71%) completed the follow-up survey. We also sent the survey to 937 patients who did not respond to our first survey invitation on February 10, 2021, and 23 of them consented and completed the survey, resulting in 78 total participants in the follow-up survey. Participant demographics in the initial and follow-up surveys were similar (Table 1).

Information sources regarding COVID-19

The top five sources of COVID-19 information were other federal government sources (the U.S. Center for Disease Control (CDC), Food and Drug Administration (FDA), Dr. Anthony Fauci (director of the National Institute of Allergy and Infectious Diseases), and the U.S. Surgeon General), local healthcare providers, state governments, television news, and websites (Figure 1), respectively. The top three most-trusted sources were federal government sources (73%), local healthcare providers (64%), and state government (52%). The most remarkable change was a 19% increase in participants who rated state government as

one of the most trusted sources of info. The top three least-trusted sources were unchanged from the initial survey:

- Facebook/Twitter/other social media (59%)
- Presidential news conferences and addresses (52%)
- Word of mouth from friends and family (40%) (Supplemental table 1)

Interaction with the healthcare system

Compared to the initial survey, participants reported that the use of telemedicine visits increased (44% vs. 74%), fewer patients had appointments postponed or canceled (72% vs. 64%), and messaging through the electronic health record was essentially stable (43% vs. 49%). The median satisfaction score (0-100 scale) for telemedicine visits increased from 67 to 74 (IQR: 61, 92.5). We further analyzed the telemedicine satisfaction score among different follow-up visits and found that the scores increased with time (Figure 3A).

Concern and anxiety level among survey participants

Ninety-four percent of survey participants reported being either very concerned (62%) or somewhat concerned (32%) about COVID-19. The top concerns among participants were getting hospitalized (62%), MG exacerbation (62%), and dying from COVID-19 (53%) (Figure 2). Nearly half (49%) of survey participants had Generalized Anxiety Disorder (GAD)-7 scores suggestive of anxiety (33% mild anxiety, 11% moderate anxiety, and 5% severe anxiety) (Supplemental figure 1A). Patients with moderate symptoms had significantly higher GAD-7 scores than patients with no or mild symptoms (Supplemental figure 1B). When comparing the GAD-7 score changes among different follow-up visits, we found that the score decreased with the visits (Figure 3D). In addition, the ADL and Qol-15r scores dropped with time (Figure 3B, C).

Discussion and Conclusion

This follow-up survey showed interesting changes between April 2020 and February 2021. There was an increasing trend for the use of telemedicine and an improvement in patient satisfaction scores for telemedicine visits. The implementation of telemedicine was investigated even before the pandemic. Multiple studies showed favorable outcomes for patient care by allowing better communication and reducing the burdens of travel, especially for those with chronic neurological diseases.^{4,5} However, it had not been put into routine practice, likely due to the lack of incentive to change practice and concerns about the legality of telemedicine.⁶ Because of the need for social distancing and stay-home orders placed in many regions in

the countries, telemedicine has been widely implemented as an efficient way to reduce the transmission of the virus in the United States. Its feasibility and effectiveness for treating various neurological diseases were also reported during the COVID-19 pandemic.⁷ While the first survey showed that 44% of the first participants reported telemedicine visits, 74% of the second survey participants used it. Similarly, Mayo Clinic reported an increase in telemedicine use by 2,000% by June 15, 2020, compared to before the COVID-19 pandemic.⁸ There was also increased satisfaction among patients with telemedicine; the median satisfaction score was increased from 67 (IQR 50-79) to 74 (IQR 61-92.5), and the average of the score was increased with different follow-up visits in our survey, presumably on account of rising familiarity of providers and patients with the use of video communication modalities over time.

On the other hand, there were essentially no interim changes in participants' concern for COVID-19 and anxiety levels. Sixty-two percent of participants were very concerned, and 32% were somewhat worried about COVID-19 in present survey. This is similar to our first survey, where 69% of patients were very concerned.³ Regarding their GAD-7 scores, 49% of survey participants showed anxiety, a 10% increase from the initial survey. Within different follow-up visits, the GAD-7 scores decreased gradually, but the ADL and Qol-15r scores increased with time. Also, we continued to see the correlation between the severity of symptoms and anxiety that we reported in the first survey. The top 3 issues they were concerned about were unchanged between the two surveys. Compared to April 2020, when we first conducted the survey, our community has learned more about how COVID-19 can affect the disease course of MG and its risks for MG patients from published works of literature and direct clinical experiences.⁹⁻¹⁷ Our participants' concerns are scientifically reasonable from a medical perspective. It is likely because our study participants obtain information from trustable resources such as the federal or state government, health care providers, and the Myasthenia Gravis Foundation of America. Multiple studies consistently showed that the risk of contracting COVID-19 for MG patients appears to be no higher than that of other general populations.^{11,14} Businaro et al. interviewed 162 patients with MG and identified COVID-19 infection in 3 patients confirmed by PCR testing and eight without test.¹¹ The prevalence did not differ from the general population in the Pavia district.¹¹

On the other hand, COVID-19 can trigger the exacerbation of MG as seen in other infection.^{2, 15, 16} In a large cohort study of 93 patients with MG who developed COVID-19 symptoms, Jakubíková et al. reported 15% of patients developed MG exacerbation.¹⁴ In their study, 38%

had severe pneumonia, and 11% died due to COVID-19 infection. They also reported that MG patients treated with rituximab had a high risk of death due to COVID-19. At the same time, other immune therapies, including azathioprine, mycophenolate mofetil, and ciclosporin, did not appear to affect the course of COVID-19. They also reported unsatisfied condition of MG with lower forced vital capacity, previous long-term CS treatment, especially in higher doses, older age, and the presence of cancer as risk factors for severe COVID-19 symptoms. To provide further real-world evidence related to COVID-19 and MG, an international physician-reported registry, COVID-19 Associated Risk and Effects in MG (CARE-MG), was launched.¹⁸ The preliminary data from the registry revealed that among a total of 91 patients with MG, MG is worsening or crisis requiring rescue therapy, including intravenous immunoglobulin, plasma exchange, or steroid, was observed in 36 (40%) of patients. Although they reported a more significant proportion of patients developing worsening MG symptoms than other studies, these data should be interpreted with caution given the potential selection bias toward poor outcomes reporting.^{14, 18} Further studies will enable us to understand the relationship between COVID-19 and MG.

The limitation of the study is unchanged from the initial survey. It includes the meager participation from minorities more significantly impacted by the pandemic, and our clinic population has very few uninsured patients.

In conclusion, our follow-up survey suggests that many MG patients have well-adjusted to remote communication with providers in the pandemic era. Also, from the evaluation scales the MG patients took, they seem to have been well-educated about the risks and consequences of contracting COVID-19 over time, even though we didn't include the direct questions in our survey. Although these results are promising, the current survey probably could not obtain information from those with limited access to broadband internet, computers, or insufficient technology literacy. To improve the care of MG patients in the entire community, further studies should be conducted to investigate the impact of COVID-19 among patients with poor virtual healthcare access.

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Table 1. Characteristics of MG-COVID19 Survey Participants (N=78)			
	First batch follow-up	Second batch	Total
	N(%) or median (IQR)	N(%) or median (IQR)	N(%) or median (IQR)
N	55	23	78
Female sex (%)	26 (45%)	11 (47.8%)	37 (47.4%)
Age (y)	66(59-73.3)	65(55-71)	66(57.5-73)
Race			
Black or African American	1 (1%)	1 (4%)	2 (3%)
American Indian or Alaska Native	0 (0%)	0 (0%)	0 (0%)
Asian	0 (0%)	0 (0%)	0 (0%)
Native Hawaiian or Other Pacific Islander	0 (0%)	0 (0%)	0 (0%)
White	54 (99%)	22 (96%)	76 (97%)
Other	0 (0%)	0 (0%)	0 (0%)
Prefer not to respond	0 (0%)	0 (0%)	0 (0%)
Ethnicity (%)			
Hispanic or Latino	1 (1%)	1 (4%)	2 (3%)
Not Hispanic or Latino	54(98%)	22 (96%)	76 (97%)
Not reported	0(0%)	0(0%)	0(0%)
Antibody Status (%)			
AChR-Ab	17(31%)	5(22%)	22(28%)
MuSK-Ab	2(4%)	0(0%)	0(0%)
Other Ab	3(5%)	1(4%)	4(5%)
Sero negative	10(18%)	5(22%)	15(19%)
Did not know	23(42%)	12(52%)	35(45%)
Self-reported MG symptoms			
No symptom	14(25%)	10(43%)	24(31%)
Mild	27(49%)	7(30%)	34(44%)
Mod	11(20%)	0(0%)	0(0%)
Severe	3(5%)	6(26%)	9(12%)
Self-reported overall disease severity (0-100)	25(11-53)	19(9-53)	25(10.5-53)
MG-ADL (IQR)	4 (2-6.25)	6 (2-8)	4 (2-7.5)
MG-QOL15r (IQR)	5 (2-11.25)	8 (2.5-12.5)	6 (2-11.75)
MG treatments			
Pyridostigmine	32 (58%)	14 (61%)	46 (59%)
Corticosteroids	18(33%)	5 (22%)	23 (29%)
Other oral immunosuppressives	28(51%)	12(53%)	40(51%)
Eculizumab	1(1%)	0(0%)	1(1%)
Rituximab	0(0%)	0(0%)	0(0%)
No treatment	3(5%)	4(17%)	7(9%)
Education			
High school diploma or equivalency (GED)	6(11%)	2(9%)	8(10%)
Associate degree (junior college) or vocational degree/license	9(16%)	0(0%)	9(12%)
Bachelor's degree	20(36%)	12(52%)	32(41%)
Master's degree	16(29%)	5(22%)	21(27%)
Professional (MD, JD, DDS)	3(5%)	4(17%)	7(9%)
None of the above	1(2%)	0(0%)	1(1%)
Total household income			
<\$25,000	3(5%)	4(2%)	7(9%)
\$25,000-<\$50,000	6(11%)	2(9%)	8(10%)
\$50,000-<\$75,000	13(24%)	2(9%)	15(19%)
\$75,000-<\$100,000	8(15%)	3(13%)	11(14%)
\$100,000-<\$150,000	5(9%)	7(30%)	12(15%)
≥\$150,000	13(24%)	6(26%)	19(24%)
Prefer not to respond	7(13%)	2(9%)	9(12%)

Abbreviation: Y-year, Ab-Antibody, MG-ADL --myasthenia gravis activity daily life, MG-QOL15r --myasthenia gravis quality of life.

Figure 1. COVID-19 related concerns among survey participants.

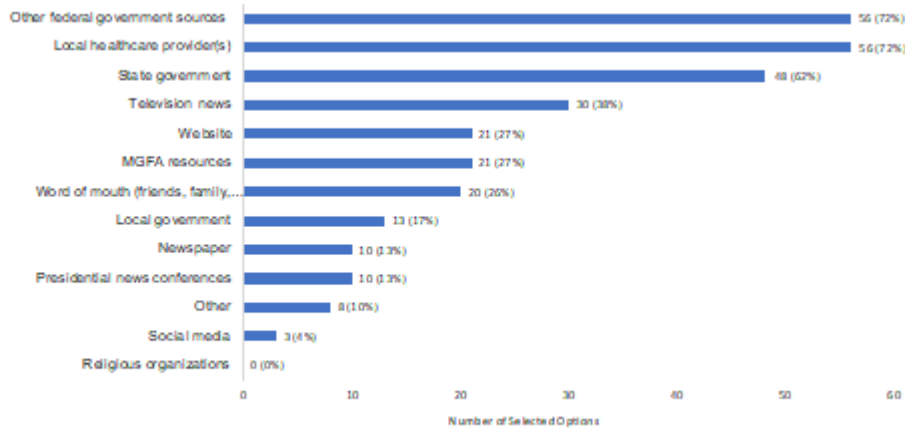


Figure 2. Top COVID-19 information sources used by responders

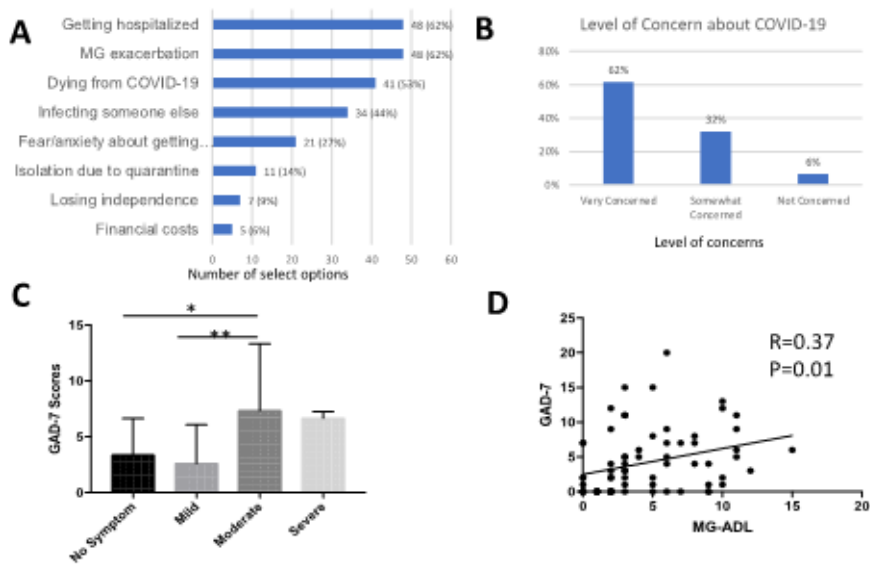
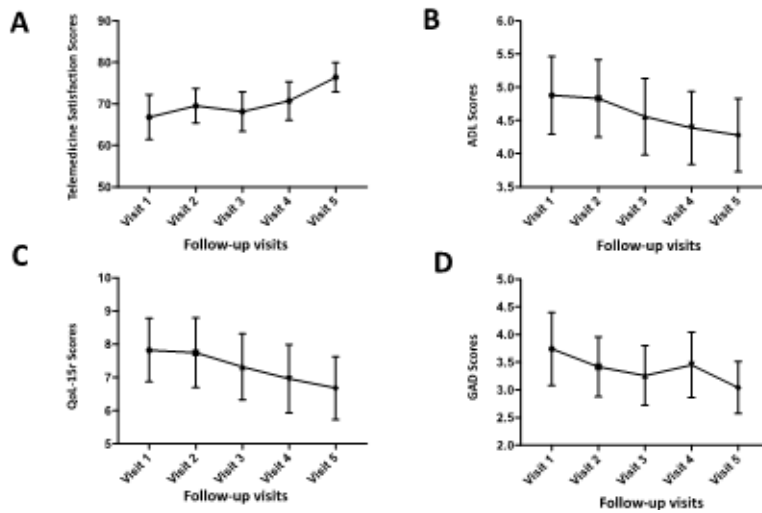


Figure 3. Scores change with follow-up visits.



A, Telemedicine satisfaction score changes with follow-up visits.

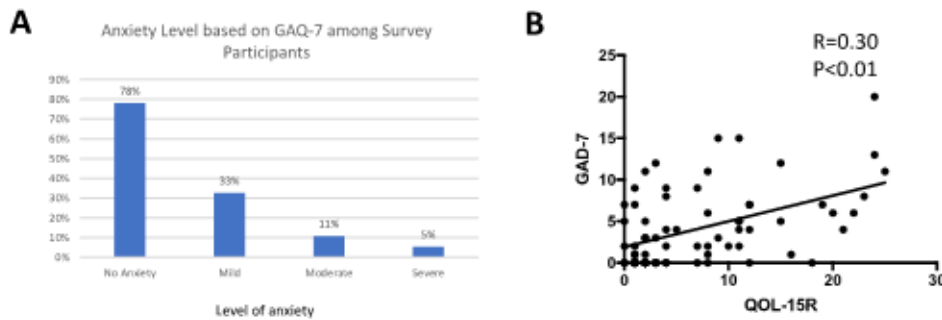
B, ADL score changes with follow-up visits.

C, QOL-15r score changes with follow-up visits.

D, GAD-7 score changes with follow-up visits.

Visit 1, the time of the first visit around April-2020; Visit 2, the time of the first visit around May-2020; Visit 3, the time of the first visit around June-2020; Visit 4, the time of the first visit around July-2020; Visit 5, the time of the first visit around October-2020.

Supplemental figure1. GAD-7 scores and QOL-15r scores.



A, GAD-7 scores among all participants.

B, GAD-7 scores and disease severity

C, Correlation between GAD-7 scores and MG-QOL-15r.

D, Correlation between GAD-7 scores and MG-ADL.

GAD-7 scores were grouped as No anxiety: 0-4; Mild anxiety: 5-9; Moderate anxiety 10-14; Severe anxiety: 15-21.

*, p value < 0.05.**, p value < 0.01.

Supplement table 1. Most trusted and least trusted sources of COVID-19 information according to survey participants*

Sources Rank	Most Trusted	Least Trusted
1	Other federal government sources (73%)	Facebook, Twitter, other social media (59%)
2	Your local healthcare provider(s) (64%)	Presidential news conferences and addresses (52%)
3	State government (governor, state health department) (52%)	Word of mouth (friends, family, etc.) (40%)
4	MGFA resources (27%)	Television news (29%)

*Total does not equal 100% patients selected 3 options.