Uncontrolled myasthenia gravis can contribute to additional stress burden and adverse mental health experiences

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Sex/LGBTQ+

"But I [the Doctor] want to test you for

myasthenia gravis, but there is no way you

30 or a man over 60. And I'm like, OK, which

one isn't true in general and two it was very

apparent she hadn't read my chart because

I was assigned female at birth, so the

Male participant, age not disclosed

"I'm not going to lie to you, I'm really scared.

It's all - it's not new, but it's more right now.'

I'm really scared. ... I want to keep having hope tha

emotional stuff, anxiety, extreme anxiety, panic attacks

Symptom instability/uncertainty

"At first, I couldn't; I would get stressed out

to me, stress makes the myasthenia worse

If I get stressed out, I'm definitely going to

- Female participant, 60–69 years

symptoms as anything else."

and upset when I couldn't do things. ... Because

"The stress can be just as triggering to

- Male participant, 50-59 years

I can live a good life and not deal with all of this

LGBTQ+, lesbian, gay, bisexual, transgender, and queer or questioning

statement didn't even make sense."

have it because you're not a woman under

Background

- Myasthenia gravis (MG) is a rare autoimmune neuromuscular disorder characterized by fluctuating periods of muscle weakness and muscle fatigue¹
- Those with generalized MG (gMG) have a more severe form of the disease
- In the United States, individuals with MG have a higher prevalence of anxiety and depression compared with the general population²

Objective

 To investigate potential factors that may contribute to adverse mental health experiences (including, but not limited to, depression and anxiety) in individuals with gMG

Methods

- Individuals with a self-reported gMG diagnosis from the sponsor's existing Patient Engagement Research Council (PERC) were invited to participate in two 2-hour, virtual focus groups in February 2023
- PERCs include demographically diverse US-based individuals with gMG who provide insights into shared diagnoses through structured activities^{3,4}
- Focus groups were moderated by a patient experience research specialist (CorEvitas, LLC, Waltham, MA) using a semi-structured discussion guide
- Individuals described their personal experiences from initial symptom onset through recent treatments
- Sessions were audio-recorded and transcripts were analyzed to identify themes related to stressors and adverse mental health experiences
- All transcripts were coded using a qualitative research software (MAXQDA)

Results

Participants

- Twelve US-based adults with a selfreported diagnosis of gMG participated in the focus groups
- Six participants identified as female and six as male
- Six participants identified as white, three as Black, one as Hispanic/Latino, one as Asian, and one as Native Hawaiian or Pacific Islander
- Participants were aged between 38 and ~70 years of age
- Participants had been diagnosed with gMG between 2 and 35 years previously

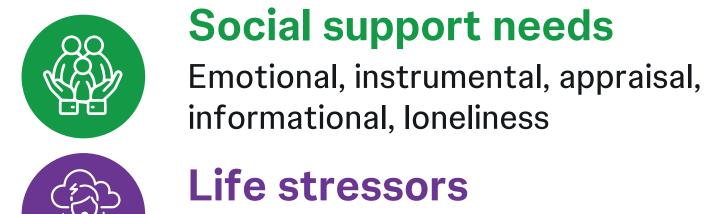
Stressors

- All participants described experiencing chronic stress as a result of their gMG
- Stressors were categorized into six themes: medical care and barriers; social support needs; life stressors; and discrimination (Figure 1)

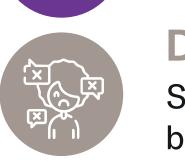
FIGURE 1: Stressor themes and subthemes



Medical care and barriers HCP, insurance, treatments



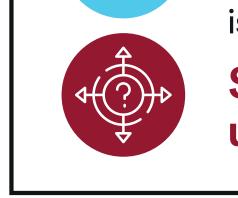
informational. Ioneliness Life stressors Family, work, daily activities



Discrimination Sex, LGBTQ+, race/ethnicity, body type, comorbidities



Anxiety, depression, and other Symptom instability/ uncertainty and resilie



uncertainty and resilience

HCP, healthcare professional; LGBTQ+, lesbian, gay, bisexual, transgender, and queer or questioning.

 Participant perspectives for each stressor are shown in Figures 2–7

FIGURE 2: Participant perspectives on stressors related to medical care and barriers

Medical care and barriers

"...And so I couldn't see anyone of my choice There's only one neuromuscular specialist I cou see and it became very apparent, very quickly that she did not believe me, because the bloodwork was not abnormal. ... They didn't want to listen ... I filed a number of grievances because they were refusing to treat me." Male participant, age not disclosed

HCP

"My first neurologist got tired of dealing with me after like three years because I kept popping up with more symptoms." - Male participant, 50-59 years

"He [the Doctor] says to me, 'I can now treat you because you have different insurance.' I wo so upset because I went three additional year untreated because insurance wouldn't allow hi - Female participant, age not disclosed

"And even when I was working having insurance I would have to put off the treatment because even as a state employee and having good insurance, I still couldn't afford some of it." - Male participant, 70-79 years

"It had got to the point where none was working for me. So I was going into ICU every six months because I was having flares and the MG was getting worse. ... The best case for me

Treatments

taking so many medications in order to have a - Female participant, 40-49 years

to live my life is to not have to worry about

HCP, healthcare professional; ICU, intensive care unit; MG, myasthenia gravis.

FIGURE 4: Participant perspectives on life stressors

FIGURE 3: Participant perspectives on stressors related to social support needs

Social support needs

Life stressors

"I was so much in the hospital that I lost my job.

"I had to stop working for a number of months at a

"I had to end up leaving my job because I wasn't ab

to perform as I was before I started having flares."

They put me on full-time disability."

- Female participant, 40-49 years

- Male participant, age not disclosed

emale participant, 40-49 years

"I'm more fortunate than others becau

I'm in a self-help group and support group. Male participant, 60-69 years

"I'm part of a support group on social media

"I've lost a lot of friends. I've isolated

- Female participant, 40-49 years

Family

"And the last couple years have been physically

do some stuff yesterday and just the stress of

them ... I just can't do it. ... It's very physically and

emotionally taxing ... the stress can be just as

triggering to symptoms as anything else."

- Male participant, 50-59 years

devastating. I mean I tried to take my kids out and

"My younger son said, 'Dad, you need to move in with me so I can watch you.'... but I just have the fear that, hey, I can't push myself and no have someone there actively there with me to watch and see what's going on." Male participant, 60–69 years "I had a roommate who just couldn't put up with me not doing anything. He asked me to leave, and I did. So I ended up staying in hotels for

a year. ... There's a lot of things I just can't do

for myself, so it's kind of difficult."

- Male participant, 50-59 years

"But what's so cool is I have people that I live with that do see it, ... And so it's important to have those type of people in your life who will tell you, you might want to

not overdo it to get to the point ... He [the Doctor] knows I live by medication if I'm having any side effects or anything like that. And he's one that I can actually get on

Informational

"It's hard because I live by myself, so I have to really watch my energy, where I can't do anything. ... I live by myself. I don't have much support. myself and he will ask me about the the phone and call if I'm having

Female participant, 40–49 years "Everything was just so heavy. I was having a hard time reaching up. I broke several dishes. And I was told I was just anxious. I was nervous." Female participant, 30–39 years

and resilience

"Everything became completely unstable

for me. ... And I just kind of felt like I wasn'

Female participant, age not disclose

"... just want to be able to do things that

brought me great joy and I could do those

again if my symptoms were better."

Male participant, age not disclosed

going to make into the next year."

FIGURE 6: Participant perspectives on the impact of stressors on mental health

FIGURE 5: Participant perspectives on stressors related to discrimination

Mental health

Body type

"I was told I need to lose some weight.

It was me being heavier that was causing

the problems, and that I was anxious. ... the

then he [the Doctor] dismissed me and said

you know, you can Google those symptoms

anything about your shortness of breath.

You need to lose weight. ... And I ended up

emale participant, 30–39 years

realized, whoa, she's sick."

getting a septic meningitis ... And then they

... my neurologist basically told me I can't do

"And so it's - one of the hardest things I think with myasthenia gravis is your ment I've gone to deep depression. I've been admitted into mental hospitals. It's just

- Female participant, 40-49 years "I do take anti-anxiety medication,

anti-depression." Female participant, 40–49 years

"I think that hardly nobody talks about past traumas. Like how - why is all our immune system attacking ourselves? ... that I wish we, as a group, would discuss. That mental part of it, like past traumas ..."

Resilience

. I have mv agenda and I set mv davs ... is just having a goal. Even if it's

focus on than on the pain. ... And that is helping my mental - the depression

Despair "And I gave up. I was like, this is it. This is the way I'm going

unattainable, it gives you purpose and it gives you something else to

- Female participant, 40-49 years

to live. Everybody thinks I'm crazy ..."

- Female participant, 30–39 years

... I was able to go to college, I held a job. I was able to drive

"My suspicion is that because I have a pretty

stigmatized psych diagnosis that that was

part of the issue as far as her [the Doctor]

believing me. But I have had that diagnosis

since I was 12 and my mental health up until

that point was actually doing probably the

Male participant, age not disclosed

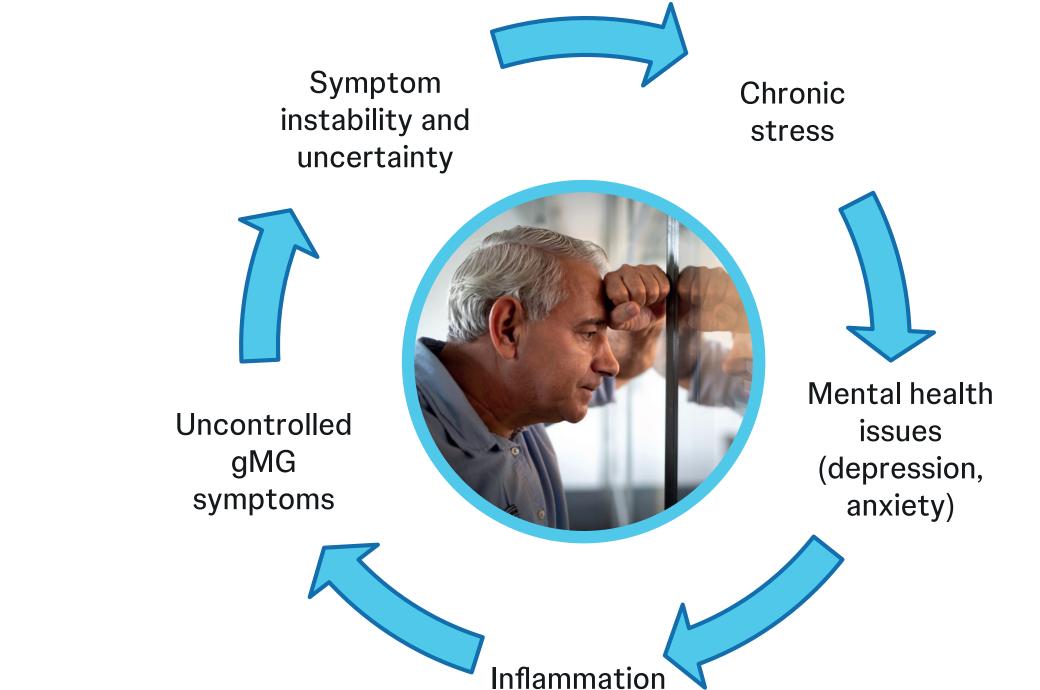
it had anything to do with the

psych diagnosis ..."

best it's been in my life, so I really didn't think

"I feel guilty. I feel like I'm not pitching into society the way I want to." Male participant, 50-59 years

FIGURE 7: Participant perspectives on the influence of stressors on symptom instability/uncertainty



^aThis is a hypothesized conceptual model. The cycle has been proposed based on the insights of this study and prior research,5-7 but warrants further evaluation. **gMG**, generalized myasthenia gravis.

Impact of stressors on mental health in gMG

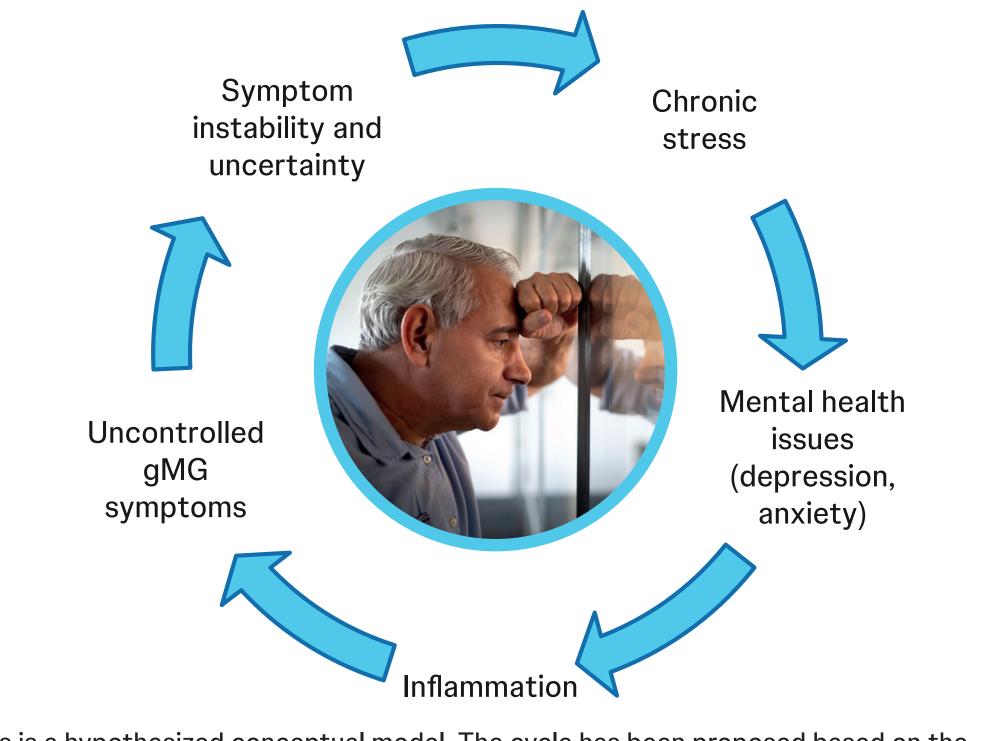
- Participants described how stressors generally had an adverse effect on their mental health (Figure 6)
- Two individuals self-reported they had experienced depression
- Five individuals self-reported they had experienced Trauma, guilt, and controlling emotions were each
- Some factors (e.g., good relationships with healthcare providers) had a positive impact on mental health

experienced by one individual

Mental health issues can worsen gMG symptoms

- Adverse mental health resulting from gMG-related stressors can add to gMG symptoms, or make them worse
- Half of the focus group participants (n=6) mentioned the negative impact of stress and/or emotions on their gMG (**Figure 7**)
- Many individuals described challenges associated with uncontrolled gMG symptoms (n=9)
- Participants described how they felt chronic stress and resulting adverse mental health experiences contributed to their gMG symptoms (Figure 8)
- More than half of the participants (n=7) talked about
- Resilience was described in positive or negative terms (i.e., hope vs despair)
- Resilience was considered protective Social support may alleviate stressor impact and mental health burden

FIGURE 8: Conceptual cycle of chronic stress, mental health burden, and uncontrolled gMG symptoms^a



Conclusions



with gMG described chronic stressors related to gMG medical care, social support, activities of daily living, and discrimination, and their impact on mental health and symptom control



inform clinicians to better understand, monitor, and manage their patients with gMG

Acknowledgments

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Disclosures

AUTOANTIBODY: MG

KG reports consulting for Argenx, UCB, and Alexion, and speaking engagements for Alexion. RR, ZC, LJ, GG, SR, and MAT are employees and stockholders of Johnson & Johnson. WP is employed by CorEvitas, LLC, Philadelphia, PA, USA. NG is employed by Stanford Neuroscience Health Center, Palo Alto, CA, USA, and reports advisory and consulting engagements from Alexion, Argenx, UCB/Ra Pharma, Janssen, Amgen, and Lycia, and grant support from Argenx.

Daily activites

"Generally speaking, the more I do, the weaker I am."

"And I progressed greatly for about 20 years with

little flare-ups here and there depending on my stress

level. ... I still have to make sure that I don't overdo it

"There's the anxiety of wanting to work out or

walk or whatever, but then there's that fear that I

- Male participant, 60-69 years

- Male participant, 70-79 years

because my body will get weak."

- Female participant, 40-49 years

can't go too far."

1. Dresser L, et al. J Clin Med. 2021;10:2235. 2. Nadali J, et al. Brain Behav. 2023;13:e2840. 3. Chakravarty SD, et al. Rheumatol Ther. 2021;8:609–20. 4. Janssen Patient Engagement Research Councils. Available from: https://www.janssenpatientcouncils.com/index.html (accessed March 4, 2024). 5. Roberts BL, et al. Fac Rev. 2021 Dec 16;10:83. 6. Sharif K, et al. Autoimmun Rev. 2018;17:967–83. 7. Stojanovich L, et al. Autoimmun Rev. 2008;7:209–13.