Patient and Caregiver Experiences of Symptom Instability and Unpredictability from a Myasthenia Gravis Patient Engagement Research Council: A Generative Al-Assisted Analysis

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Background

Generalized myasthenia gravis (gMG) is a chronic, immunoglobulin G autoantibody-mediated neuromuscular disease associated with unpredictable, fluctuating muscle weakness^{1,2}

Patient Engagement Research Councils (PERCs) can be utilized to gather the perspectives of people living with and affected by a disease³

While qualitative interview data are crucial to understanding the patient perspective and lived experience of gMG, analysis of these data is often complex and time-consuming⁴

Recent advancements in generative artificial intelligence (GenAl) and its underlying large language models (LLMs) may provide a promising opportunity to expedite the qualitative analysis of textual data^{4,5}

Objective

To use GenAl to explore patient and caregiver experiences of gMG symptom instability and unpredictability, and experiences with healthcare providers (HCPs)

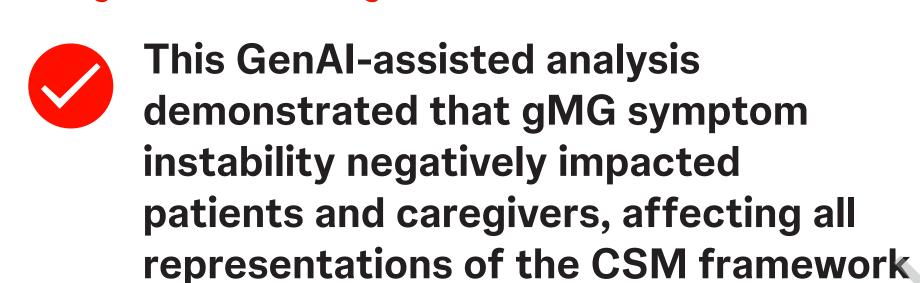
Methods

This study was an in-depth qualitative analysis of focus group interviews involving individuals living with gMG or their caregivers who participated in a PERC

- Fifteen focus groups were conducted with patients with gMG or their caregivers; focus group discussions were recorded and transcribed
- Interview transcripts were qualitatively analyzed to identify themes related to the experience of living with gMG
- Data analysis guided by Leventhal's Common-Sense Model of Self-Regulation (CSM) framework^{6,7} (**Figure 1**) was assisted using Johnson & Johnson's private and proprietary GenAl tool
- Emotional and cognitive representations of the CSM framework were applied to analyze the transcripts in relation to participants' gMG experience (**Table 1**)
- GenAl outputs were validated using a balanced method with human supervision and manual checking to ensure outputs were appropriate and accurate



Key Takeaways





Predictable treatment programs may be utilized to address poor cognitive and emotional responses to gMG, thereby enhancing treatment experience and resulting in sustained symptom control for patients with gMG

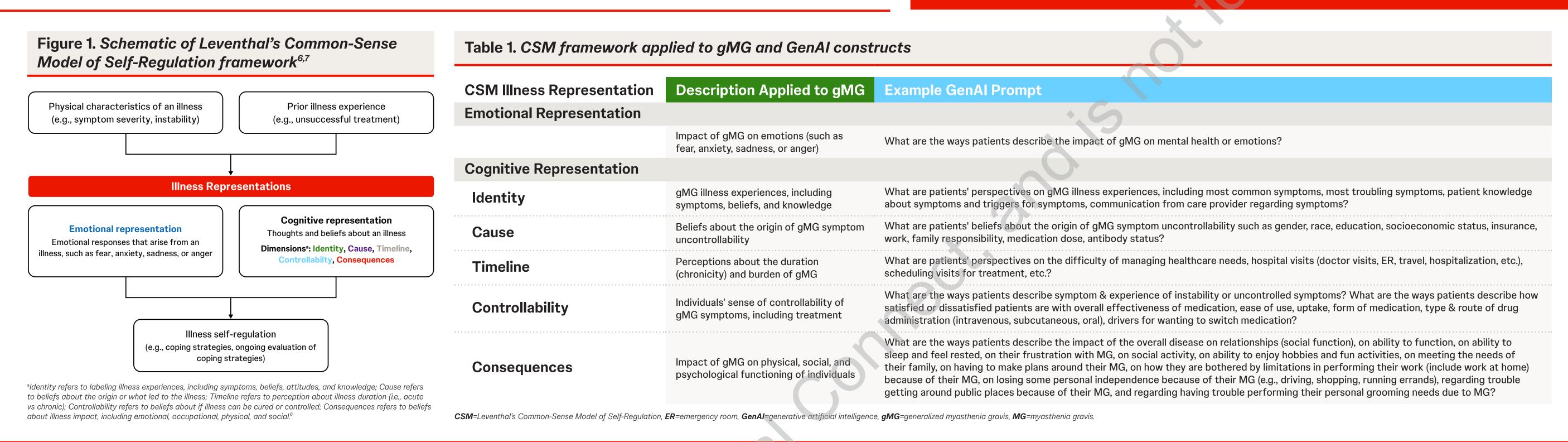


Figure 3. Insights, themes, and representative participant quotes related to the experience of living with gMG in the context of the emotional and cognitive representations of the CSM framework

B. Perspectives on gMG disease experience involved common symptoms, triggers,

Results

Figure 2. The majority of participants were White, female, and over 50 years old

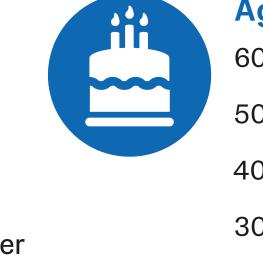
17 Participants

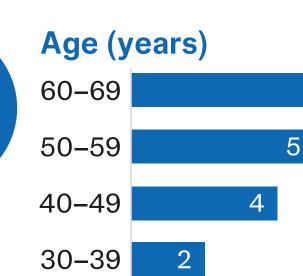
11 patients with gMG, 6 caregivers



Race/Ethnicity

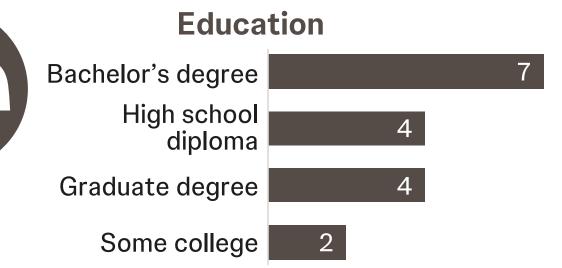
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander







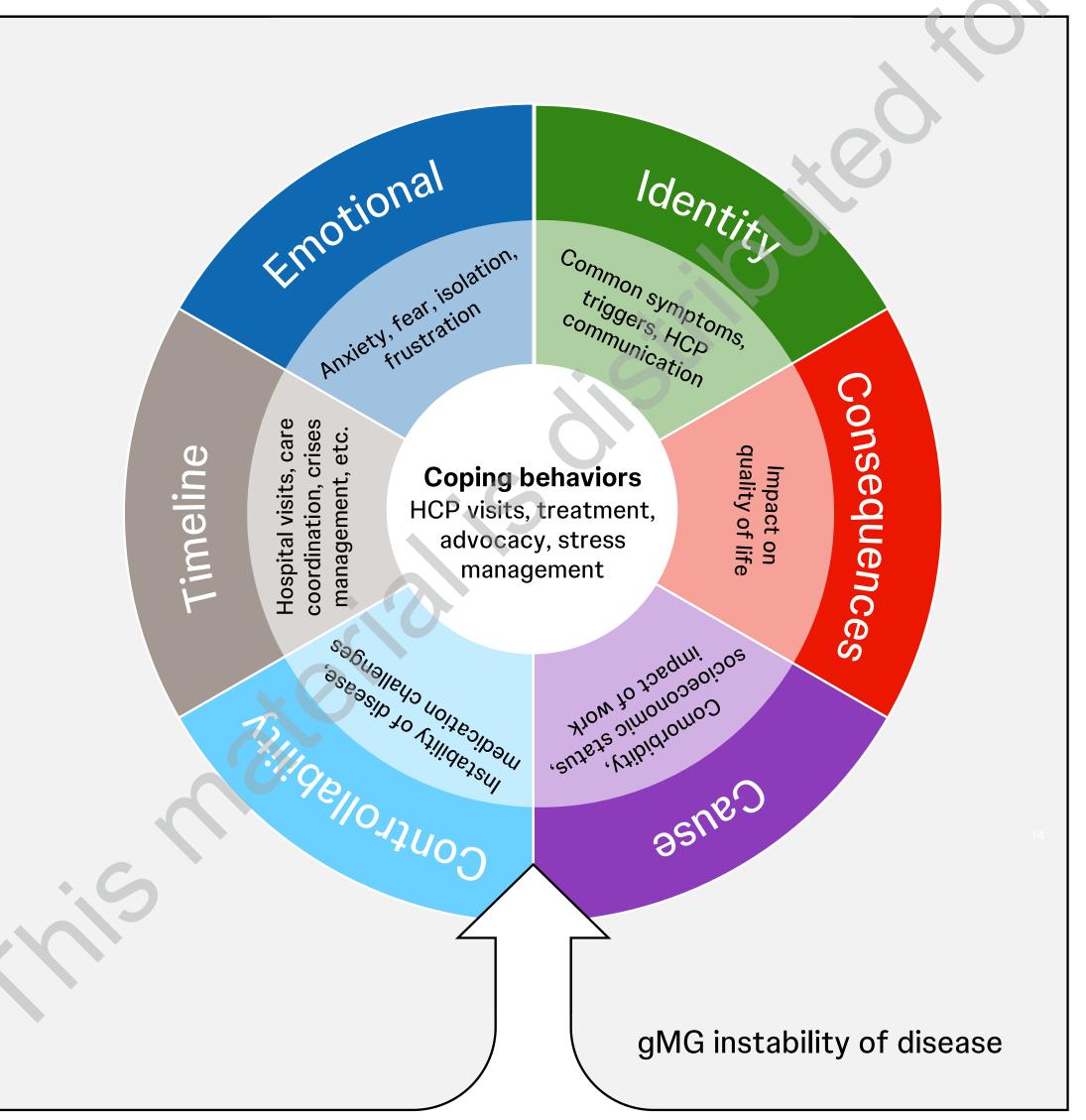




Data shown are number of participants. **gMG**=generalized myasthenia gravis.

Gender

Figure 4. The unstable nature of the symptoms gMG had impact on the participants' lives and affected all the representations of the CSM framework



CSM=Common-Sense Model of Self-Regulation, **gMG**=generalized myasthenia gravis, **HCP**=healthcare provider.

A. Participants described a range of negative emotions related to gMG symptom instability, including anxiety, depression, fear, isolation, and frustration; positive

emotions were associated with support groups, resilience, and self-advocacy

Emotional Impact of gMG The emotional distress and anxiety experienced by patients and caregivers due to gMG symptoms and crises and psychological effects of living with gMG

Emotional Representation

Addresses the emotional toll on caregivers who support loved ones with gMG **Frustration with**

Emotional Burden on

Frustration felt by patients and caregivers when healthcare providers do not understand or adequately address their needs **Emotional Support**

The importance of support systems and

community in managing emotional health

Emotional Resilience The ability to cope with the emotiona challenges posed by gMG and maintain a

Impact on Family The effect of gMG on family morale

Cognitive Representation: Timeline

Healthcare Management

Challenges

Difficulties faced by patients in managing

and medication

Hospital Visits

Experiences related to doctor visits,

emergency room visits, and hospitalizations

Scheduling Treatment Visits

attending treatment sessions, including

infusions and appointments

Insurance and Financial

Barriers

Challenges related to insurance coverage,

costs of treatment, and financial implications

Emotional Impact

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

"One of the hardest things, I think with MG is

our mental [health]. I've gone to deep depression

I've been admitted into mental hospitals.

It's just, it's crazy."

ormal life, she can't do normal things, and I can't take it away as her mom."

"One of them said, 'We believe it's in her

head. We really think that she's just imagining

have a church family that stands by me and

helps me through these things, and they're my

"You're going to find the right doctor if you

keep the faith and keep persisting and being

your own advocate.'

"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."

two-month period.

a lot of these symptoms."

D. Participants noted their gMG timeline included frequent hospital visits and HCP communication, as well as difficulty and stress regarding managing treatment

E. Discussions of disease control highlighted perceptions of disease instability, treatment challenges, and treatment inconsistency

Cognitive Representation: Controllability Crisis Events Fear of potential crises due to symptom instability **Crisis Events**

and HCP communication

qMG Illness Experience

Experiences and challenges faced by

patients living with gMG, including

symptoms and their impact on daily life

Common Symptoms

Most Troubling Symptoms

Symptom Fluctuation

Patient Knowledge

Understanding and awareness of symptoms

and their implications by the patient

Triggers for Symptoms

Communication with

Care Provider

The effectiveness and clarity of

communication from healthcare

providers regarding symptoms and

treatment options

Reports that treatments may not work

consistently, leading to frustration

Symptoms described as fluctuating,

unpredictable, and often worsening over time

The emotional and mental health effects of

living with uncontrolled symptoms

Feelings of helplessness and frustration due

to the lack of control over their symptoms

Ease of Use

The ease of using the medication, including

administration and preparation

Form of Medication

switching medications

"I was in the hospital for 45 days of the Experience of acute exacerbations that lead to hospitalization or severe symptoms "I had to plan, and we have one trip that's planned pre-diagnosis that's going to extend Experience of acute episodes that require mmediate medical attention

longer than two weeks." 'The insurance companies love to mix it up and you have to pick a plan all of a sudden before a certain door closes." "The waiting, I can't imagine ... That must have

We live five hours from the hospital ... so they

would get everything set up for her [and] get

of Healthcare been a stressful nine months.' Emotional stress and anxiety related to managing healthcare and treatment processes Advocacy and Support nad to rely on friends, people from our church, The need for advocacy in navigating healthcare my wife, my children taking time off of work to get me to the infusion center." systems and finding appropriate support **Communication with Providers** "I have a very close relationship with my doctor The importance of communication with HCPs and his nurses in his office.

The challenges associated with traveling for treatment (i.e., burden of logistics and transportation) **Crisis Management** How patients and caregivers define and manage crisis situations related to the disease

Coordination of Care

coordination among HCPs and caregivers

regarding treatment and symptoms

Travel for Treatment

"I want to make sure that all of them are talking, and before I start any new medication, I make sure all three [HCPs] are on the same page." The need for effective communication and The anesthesiologist actually took the time to all me and explained to me that my doctor had spoken to him, and we needed to have a conversation because I had myasthenia."

Treatment Management "We got it to every 6 weeks and then we decided The ongoing management of treatment plans to change it over to a subQ-IG." and adjustments based on patient response

Preferences regarding the form of medication "A crisis has to be so weakening, and in such (e.g., oral, intravenous, subcutaneous) a state where I will have to take them to the emergency room." **Drivers for Switching** Factors that motivate patients to consider

Scheduling Visits for Treatment Experiences related to scheduling and attending treatment visits Satisfaction with

Overall feelings of satisfaction or dissatisfaction regarding the effectiveness of medications

'We started about 10 or 11 years ago on IVIG and that helped, but as you know, IVIG is quite expensive. Those infusions can be costly.'

C. Participants believed various factors, such as gender, race, comorbidities, and work, influenced their experience with gMG symptoms

Cognitive Representation: Cause Cognitive Representation: Identity

"My symptoms started in about the summer

of 2017 ... double vision ... mostly happened in

"She started having these sort of weird episodes

where it'd be just walking across the room ...

legs kind of just give out."

"She couldn't spit when she'd brush her teeth,

[or] suck on a straw."

"When I start having symptoms, it goes really

quick, and [I] usually end up in the hospital."

"Heat does bother [my symptoms] ... If I go

outside in the heat and stay out in the heat, that

affects me."

"Stress is bad, heat is bad, riding in a car for a

"We had an awesome support system with the

doctors and nurses to get things taken care of.'

"Sometimes I think that, especially with

medical professionals, they do things by the book

as opposed to what we're saying we need."

'I don't want to get to that point where I have

I found out what a crisis was."

Once I can't talk, I live alone. I know that I don't

have anyone that can call for me."

that I notice from week to week. I just go from

zero to 100."

t's hard to have a life when it's all based around

"It's just so unpredictable that I'm all over

the place."

some greater frequency."

'I was doing a subQ-IG, and I had done it for a

I want to try the newer medications that are available, some of the biologics, and see if I can get some relief from these symptoms."

"I have young kids, so it's hard to make the time.

Some of the treatments that I've been on are 6, 7,

8 hours long."

year and had really good results with that."

how vou're feeling

lized me. And that's how

long time is bad."

Patient Beliefs About Origin of Symptoms Beliefs related to how various external factors such as gender, race, education, occupation,

nsurance and socioeconomic status influence the disease experience and symptom management **Patient Beliefs About** Origin of Symptoms

(Internal) Beliefs related to how various factors such as antibody status may influence the perception and experience of the disease **Patient Beliefs About Origin** of Symptoms

(Comorbidities) The role of other illnesses influencing the **Treatment Management**

Factors Factors related to the management of treatment that may influence patients'

Patient Beliefs About Family Responsibility Beliefs regarding how family responsibilities impact the management of gMG symptoms

thymus out." 'I have other health issues that complicate

"I'm getting the minimum treatment options

because my insurance won't pay for a lot of the

"I think that the [menstrual] cycle can make

"I did so well in my twenties and thirties and

the place.

There's not enough research for me to get

your insurance company to take your

'It's just annoying to try to do something simple

"She cannot go to sleep at night. It's not

uncommon for her not to [fall asleep] until five

"I feel like I'm losing

my independence.'

or six in the morning."

"If I go line dance, if, I might get one dance out

and then I'm running out the door to head home

because I know my body's about to go down."

"If we want to plan anything that she needs a

little bit of energy for, we try to plan it around

about the first week after she gets that

'Oh, you're drinking."

I couldn't climb stairs ... I couldn't pull up my

pants. I had trouble just walking."

e wash four or five dishes or brush my teeth.'

now that I'm in my late forties, it's just all over

other medications.

"My out of network doctor ... wants [me] to be on IVIG because my oral medications aren't controlling things as well as they need to be and I have gone into exacerbation a couple times."

experience with gMG symptoms

"I had two small kids that I was trying to care for and it was very overwhelming ... it was docto appointments, and I couldn't drive."

F. Perspectives on consequences of gMG included negative impacts on patient quality of life, ability to work, and social function

Cognitive Representation: Consequences Impact on Relationships "She was very active in school, cheerleader, softball, everything. And she had to stop doing

The overall disease affects social interactions and relationships with family and friends

Ability to Function The disease impacts daily activities and the ability to perform tasks

Ability to Sleep and Feel Rested The disease affects sleep quality and the ability to feel rested

> Feelings of frustration due to the limitations imposed by the disease **Social Activity**

he disease limits participation in social activities and events

> The impact of MG on meeting family responsibilities and needs

'I was trying to care for my kids. I can't live like this the rest of my life. I honestly went to some

Planning Around MG The necessity of planning daily activities around MG symptoms

'I would fall down at work, probably two or The disease affects the ability to perform three times a week, and they're like,

work-related tasks, including working from home The loss of personal independence in daily

Work Limitations

activities due to MG

Difficulties in navigating public spaces due

I really couldn't navigate the grocery store." "I have to be careful in public."



"I had to use my arms, and I'd have to take breaks brushing my teeth or brushing my hair."

CSM=Leventhal's Common-Sense Model of Self-Regulation, gMG=generalized myasthenia gravis, HCP=healthcare provider, IVIG=intravenous immunoglobulin, MG=myasthenia gravis, subQ-IG=subcutaneous immunoglobulin.