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

This GenAl-assisted analysis demonstrated that gMG symptom instability negatively impacted patients and caregivers, affecting all

**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

representations of the CSM framework

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## Background

Generalized myasthenia gravis (gMG) is a chronic, immunoglobulin G autoantibody-mediated neuromuscular disease associated with unpredictable, fluctuating muscle weakness<sup>1,2</sup>

Patient Engagement Research Councils (PERCs) can be utilized to gather the perspectives of people living with and affected by a disease<sup>3</sup>

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-consuming<sup>4</sup>

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<sup>4,5</sup>

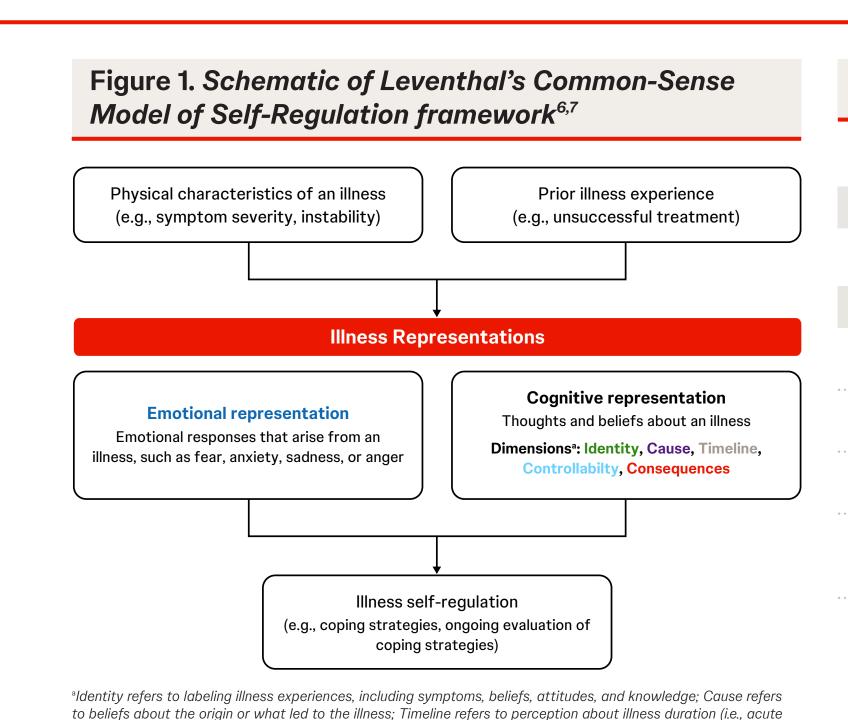
## Objective

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<sup>6,7</sup> (**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



vs chronic); Controllability refers to beliefs about if illness can be cured or controlled; Consequences refers to beliefs

about illness impact, including emotional, occupational, physical, and social.<sup>6</sup>

Table 1. CSM framework applied to gMG and GenAl constructs CSM Illness Representation Description Applied to gMG **Example GenAl Prompt Emotional Representation** Impact of gMG on emotions (such as What are the ways patients describe the impact of gMG on mental health or emotions? fear, anxiety, sadness, or anger) **Cognitive Representation** What are patients' perspectives on gMG illness experiences, including most common symptoms, most troubling symptoms, patient knowledge gMG illness experiences, including Identity about symptoms and triggers for symptoms, communication from care provider regarding symptoms? symptoms, beliefs, and knowledge Beliefs about the origin of gMG symptom What are patients' beliefs about the origin of gMG symptom uncontrollability such as gender, race, education, socioeconomic status, insurance, Cause work, family responsibility, medication dose, antibody status? uncontrollability What are patients' perspectives on the difficulty of managing healthcare needs, hospital visits (doctor visits, ER, travel, hospitalization, etc.), Perceptions about the duration **Timeline** scheduling visits for treatment, etc.? (chronicity) and burden of gMG What are the ways patients describe symptom & experience of instability or uncontrolled symptoms? What are the ways patients describe how Individuals' sense of controllability of Controllability satisfied or dissatisfied patients are with overall effectiveness of medication, ease of use, uptake, form of medication, type & route of drug gMG symptoms, including treatment administration (intravenous, subcutaneous, oral), drivers for wanting to switch medication? What are the ways patients describe the impact of the overall disease on relationships (social function), on ability to function, on ability to sleep and feel rested, on their frustration with MG, on social activity, on ability to enjoy hobbies and fun activities, on meeting the needs of Impact of gMG on physical, social, and Consequences their family, on having to make plans around their MG, on how they are bothered by limitations in performing their work (include work at home) psychological functioning of individuals because of their MG, on losing some personal independence because of their MG (e.g., driving, shopping, running errands), regarding trouble getting around public places because of their MG, and regarding having trouble performing their personal grooming needs due to MG? CSM=Leventhal's Common-Sense Model of Self-Regulation, ER=emergency room, GenAl=generative artificial intelligence, gMG=generalized myasthenia gravis, MG=myasthenia gravis.

"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."

lized me. And that's how

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

have anyone that can call for me."

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."

how vou're feeling

long time is bad."

## 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

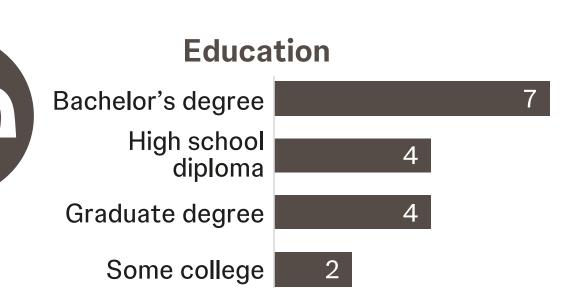
Hispanic or Latino

Native Hawaiian or Other Pacific Islander



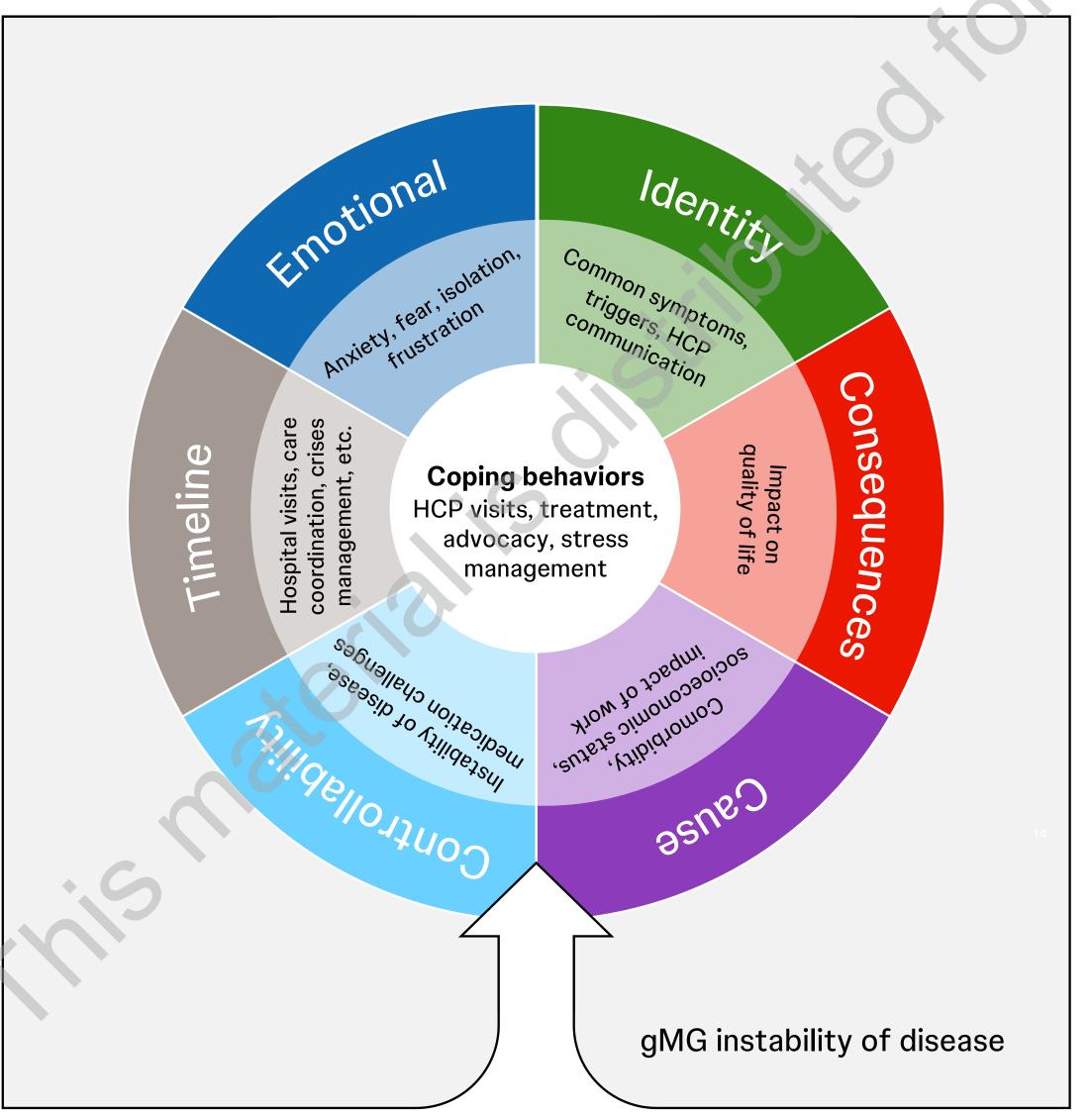
Age (years) 60-69





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

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

symptoms and crises and psychological effects of living with gMG **Emotional Burden on** 

**Emotional Representation** 

**Emotional Impact of gMG** 

The emotional distress and anxiety experienced

by patients and caregivers due to gMG

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

**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

**Barriers** 

**Emotional Impact** 

of Healthcare

community in managing emotional health

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

D. Participants noted their gMG timeline included frequent hospital visits and HCP

communication, as well as difficulty and stress regarding managing treatment

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

"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."

"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

a lot of these symptoms."

#### keep the faith and keep persisting and being your own advocate.' **Communication with Care Provider**

#### The effectiveness and clarity of communication from healthcare providers regarding symptoms and treatment options

and HCP communication

**Cognitive Representation: Identity** 

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** 

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

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,

### **Cognitive Representation: Controllability Crisis Events**

### Fear of potential crises due to symptom instability **Crisis Events** Experience of acute exacerbations that lead to hospitalization or severe symptoms

"I was in the hospital for 45 days of the two-month period. "I had to plan, and we have one trip that's planned pre-diagnosis that's going to extend longer than two weeks."

**Insurance and Financial** 'The insurance companies love to mix it up and you have to pick a plan all of a sudden before a Challenges related to insurance coverage, certain door closes." costs of treatment, and financial implications "The waiting, I can't imagine ... That must have been a stressful nine months.'

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

would get everything set up for her [and] get

"A crisis has to be so weakening, and in such

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. regarding treatment and symptoms

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

**Travel for Treatment** 

The challenges associated with traveling for

a state where I will have to take them to the emergency room." "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 coordination among HCPs and caregivers 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

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

I found out what a crisis was."

Experience of acute episodes that require mmediate medical attention Reports that treatments may not work consistently, leading to frustration

that I notice from week to week. I just go from Symptoms described as fluctuating, zero to 100." unpredictable, and often worsening over time

living with uncontrolled symptoms Feelings of helplessness and frustration due to the lack of control over their symptoms

The emotional and mental health effects of

Ease of Use

**Drivers for Switching** 

The ease of using the medication, including some greater frequency." administration and preparation Form of Medication 'I was doing a subQ-IG, and I had done it for a Preferences regarding the form of medication year and had really good results with that." (e.g., oral, intravenous, subcutaneous)

Factors that motivate patients to consider switching medications **Scheduling Visits for** "I have young kids, so it's hard to make the time. **Treatment** 

Experiences related to scheduling and attending treatment visits Satisfaction with Overall feelings of satisfaction or dissatisfaction

regarding the effectiveness of medications

Some of the treatments that I've been on are 6, 7, 8 hours long." '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.'

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."

**Cognitive Representation: Cause** 

work, influenced their experience with gMG symptoms

C. Participants believed various factors, such as gender, race, comorbidities, and

**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'

experience with gMG symptoms **Patient Beliefs About Family Responsibility** 

Beliefs regarding how family responsibilities impact the management of gMG symptoms

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." "I had two small kids that I was trying to care for and it was very overwhelming ... it was docto

"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

thymus out."

'I have other health issues that complicate

"My out of network doctor ... wants [me] to be

"She was very active in school, cheerleader,

softball, everything. And she had to stop doing

'I was trying to care for my kids. I can't live like

this the rest of my life. I honestly went to some

treatment."

'Oh, you're drinking."

"I feel like I'm losing

my independence.'

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

other medications.

appointments, and I couldn't drive."

quality of life, ability to work, and social function

F. Perspectives on consequences of gMG included negative impacts on patient

# **Cognitive Representation: Consequences**

Impact on Relationships The overall disease affects social interactions and relationships with family and friends

**Ability to Function** 'It's just annoying to try to do something simple The disease impacts daily activities and the e wash four or five dishes or brush my teeth.' ability to perform tasks

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

"She cannot go to sleep at night. It's not uncommon for her not to [fall asleep] until five or six in the morning."

**Social Activity** he disease limits participation in social activities and events

**Planning Around MG** 

The necessity of planning daily activities

The loss of personal independence in daily

activities due to MG

Feelings of frustration due to the limitations

imposed by the disease

"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."

The impact of MG on meeting family responsibilities and needs

"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

around MG symptoms **Work Limitations** '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

I couldn't climb stairs ... I couldn't pull up my pants. I had trouble just walking."

Difficulties in navigating public spaces due

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

**Personal Care** Challenges in performing personal grooming and self-care due to MG

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

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