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

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Key Takeaways

- **This GenAI-assisted analysis demonstrated that gMG symptom instability negatively impacted patients and caregivers, affecting all representations of the CSM framework**
- **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**

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 disease[3]
- 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[4]
- Recent advancements in generative artificial intelligence (GenAI) and its underlying large language models (LLMs) may provide a promising opportunity to expedite the qualitative analysis of textual data[4,5]

Objective

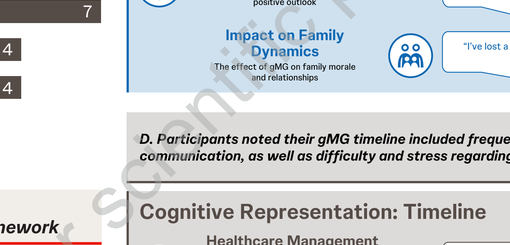
To use GenAI to explore patient and caregiver experiences of gMG symptom instability and unpredictability, and experiences with healthcare providers (HCPs)

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 GenAI tool
- Emotional and cognitive representations of the CSM framework were applied to analyze the transcripts in relation to participants' gMG experience (**Table 1**)
- GenAI outputs were validated using a balanced method with human supervision and manual checking to ensure outputs were appropriate and accurate

Figure 1. ***Schematic of Leventhal's Common-Sense Model of Self-Regulation framework***[6,7]



*Identity refers to labeling illness experiences, including symptoms, beliefs, attitudes, and knowledge; Cause refers to beliefs about the origin or what led to the illness; Timeline refers to perception about illness duration (i.e., acute 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.[6]

Table 1. ***CSM framework applied to gMG and GenAI constructs***

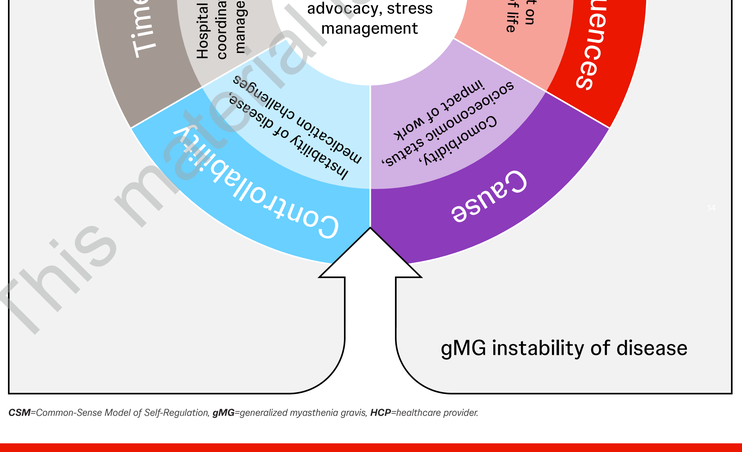
CSM Illness Representation	Description Applied to gMG	Example GenAI Prompt
Emotional Representation		
	Impact of gMG on emotions (such as fear, anxiety, sadness, or anger)	What are the ways patients describe the impact of gMG on mental health or emotions?
Cognitive Representation		
Identity	gMG illness experiences, including symptoms, beliefs, and knowledge	What are patients' perspectives on gMG illness experiences, including most common symptoms, most troubling symptoms, patient knowledge about symptoms and triggers for symptoms, communication from care provider regarding symptoms?
Cause	Beliefs about the origin of gMG symptom uncontrollability	What are patients' beliefs about the origin of gMG symptom uncontrollability such as gender, race, education, socioeconomic status, insurance, work, family responsibility, medication dose, antibody status?
Timeline	Perceptions about the duration (chronicity) and burden of gMG	What are patients' perspectives on the difficulty of managing healthcare needs, hospital visits (doctor visits, ER, travel, hospitalization, etc.), scheduling visits for treatment, etc.?
Controllability	Individuals' sense of controllability of gMG symptoms, including treatment	What are the ways patients describe symptom & experience of instability or uncontrolled symptoms? What are the ways patients describe how satisfied or dissatisfied patients are with overall effectiveness of medication, ease of use, uptake, form of medication, type & route of drug administration (intravenous, subcutaneous, oral), drivers for wanting to switch medication?
Consequences	Impact of gMG on physical, social, and psychological functioning of individuals	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 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) 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, **GenAI**=generative artificial intelligence, **gMG**=generalized myasthenia gravis, **MG**=myasthenia gravis.*

Results

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

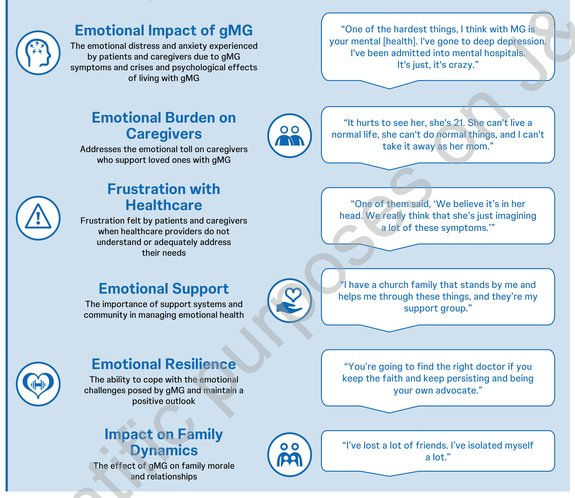
17 Participants
11 patients with gMG, 6 caregivers



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

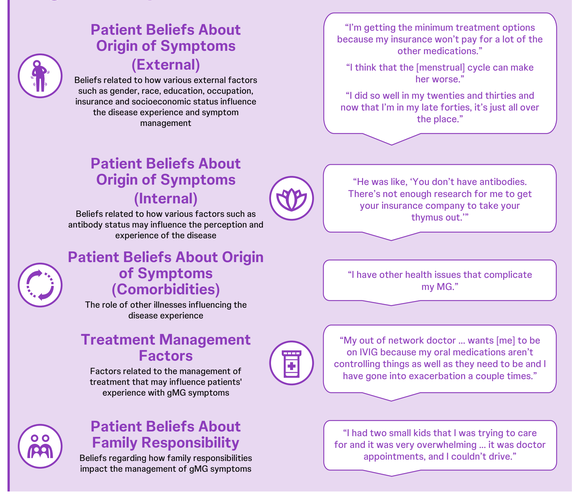
Figure 3. ***Insights, themes, and representative participant quotes related to the experience of living with gMG in the context of the emotional and cognitive representations of the CSM framework***

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



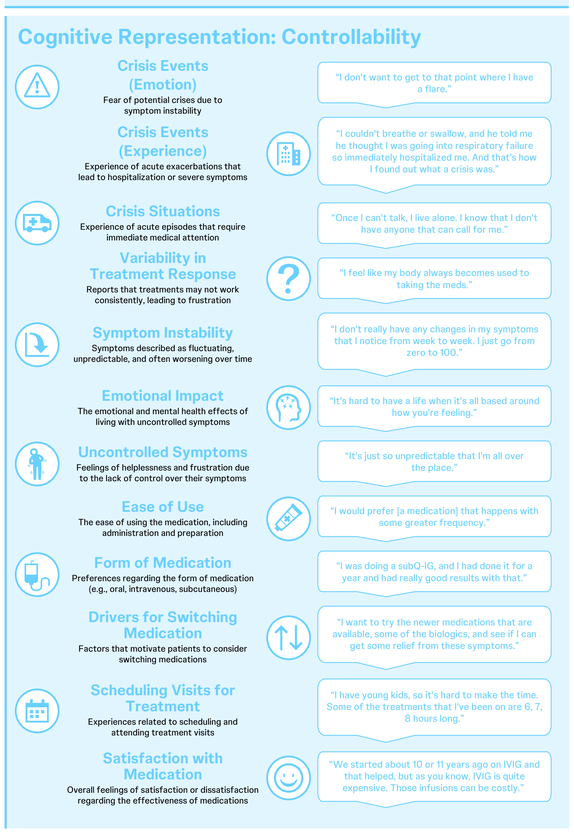
B. Perspectives on gMG disease experience involved common symptoms, triggers, and HCP communication

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



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

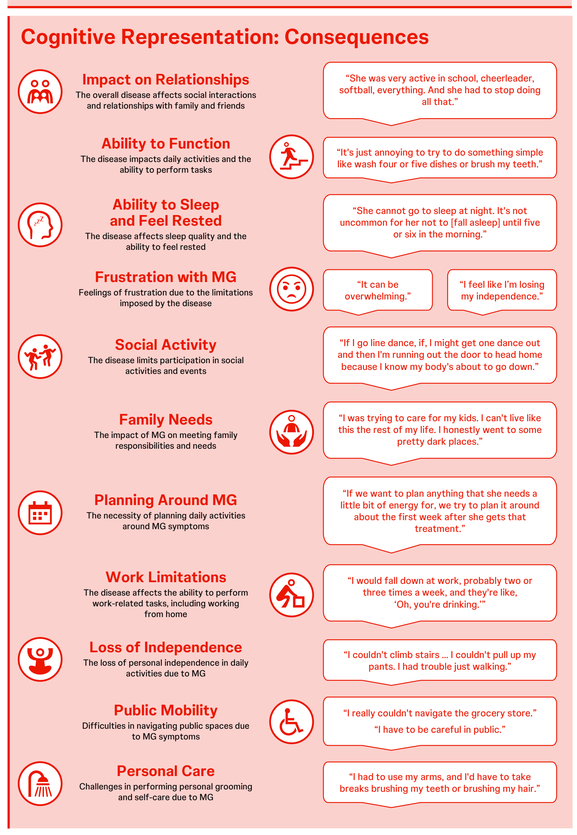


Figure 4. ***The unstable nature of the symptoms gMG had impact on the participants' lives and affected all the representations of the CSM framework***

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

***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.*

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