Mapping Out the Patient Journey of Generalized Myasthenia Gravis: Insights and Challenges

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Background

Generalized myasthenia gravis (gMG) is a rare, autoantibody-driven disease; it causes fluctuating, fatigable, often debilitating muscle weakness[1,2]

It is well understood that the variability and unpredictability of gMG can negatively affect patients' quality of life;[3] however, there is limited research characterizing the patient experience

Patient journey maps can be used to visualize the patient experience and provide healthcare providers (HCPs) with information to help optimize care[4]

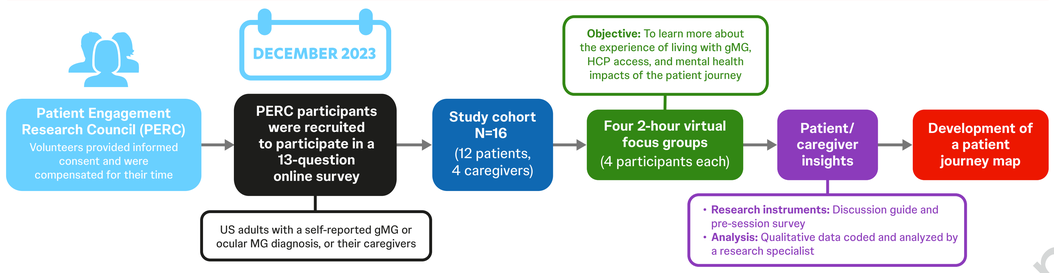
Objective

The aim of this study was to develop a patient journey map and further characterize the experience of living with gMG

Methods

- A Johnson & Johnson Patient Engagement Research Council (PERC) program was established to gather the perspectives of people living with and affected by gMG. PERCs represent diverse groups of disease-aware adults with chronic health conditions who provide insights to inform research[5]
- US adults with a self-reported gMG or ocular myasthenia gravis diagnosis were recruited to participate in a 13-question online survey (**Figure 1**). Caregivers providing support to patients meeting these criteria were also included in the study
  - Survey topics were selected based on prior research and publications regarding the patient journey and included identification/first symptoms, diagnosis, treatment, HCP relationships, and mental health impacts
- Survey responses guided and facilitated four 2-hour virtual focus group discussions held in December 2023
  - Discussions were moderated by a professional research specialist using a semi-structured discussion guide to elicit open and honest feedback and opinions
  - Sessions were audio recorded and transcribed; they were then coded, analyzed, and distilled into key insights
- Key patient and caregiver insights from the pre-session survey and focus group discussions were used to develop a patient journey map
- Additional insights about HCP access and mental health impacts during the patient journey were analyzed to further characterize the experience of living with gMG

Figure 1. ***Study overview***



gMG=generalized myasthenia gravis, HCP=healthcare provider, MG=myasthenia gravis.

Results

Participant Characteristics

- Of 16 total participants, 12 were patients and 4 were caregivers
- The highest proportion of participants were White, identified as female, were aged 50–59 years, and had a bachelor's degree (**Table 1**)

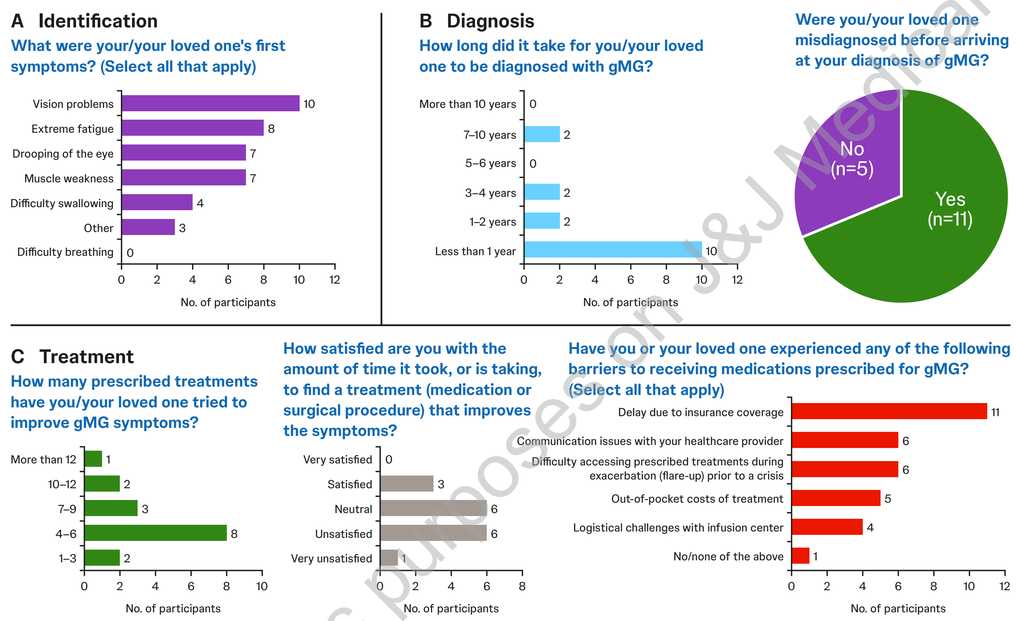
Table 1. ***Participant characteristics (N=16)***

Characteristic	Participants, n (%)
Age Range, years	
30–39	2 (13)
40–49	3 (19)
50–59	6 (38)
60–69	3 (19)
70+	2 (13)
Gender	
Non-binary	1 (6)
Male	7 (44)
Female	8 (50)
Race/Ethnicity	
Native Hawaiian/Other Pacific Islander	1 (6)
Hispanic or Latino	1 (6)
Black or African American	4 (25)
White	10 (63)
Education Level	
High school diploma	4 (25)
Technical or trade school	1 (6)
Some college	2 (13)
Bachelor's degree	6 (38)
Graduate degree	3 (19)

Patient Journey

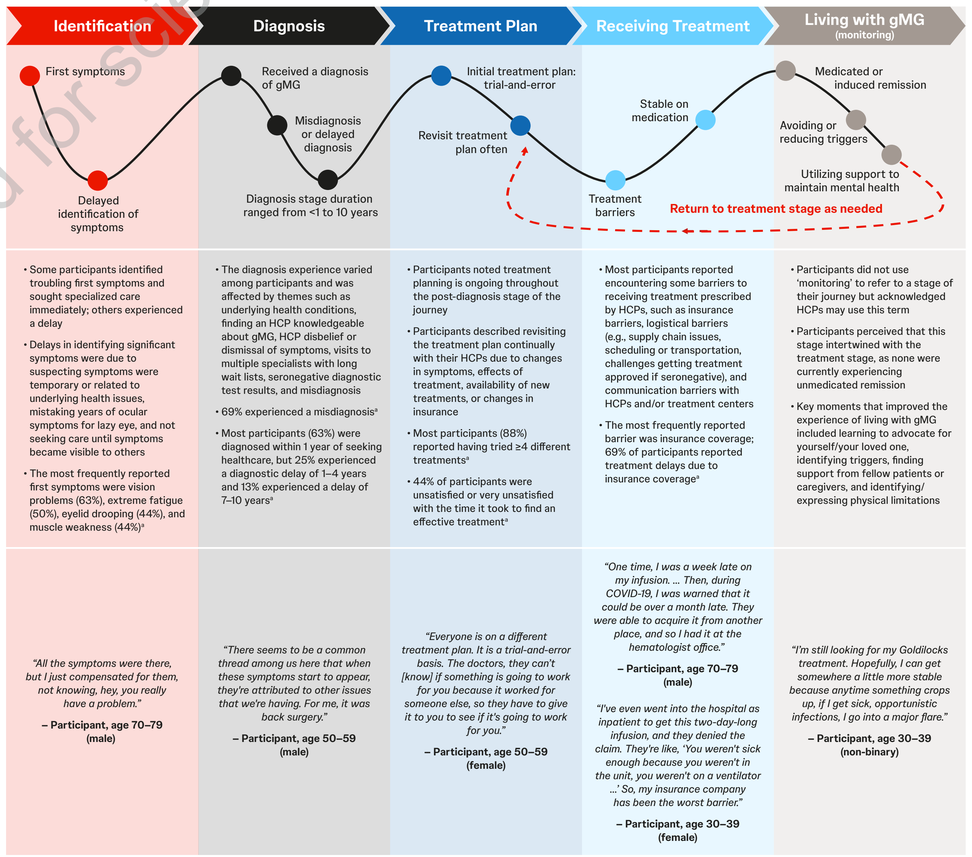
- The pre-session survey results for identification (**Figure 2A**), diagnosis (**Figure 2B**), and treatment (**Figure 2C**) topics were validated by the focus group discussions; common key insights from the survey and the focus groups were used to develop a patient journey map (**Figure 3**)
- Key insights included challenges of misdiagnosis, delays related to finding HCPs who have knowledge of gMG, insurance policy barriers, and the trial-and-error phase of finding treatments that work for the individual
- Factors deemed important for improving the patient experience included learning to advocate for yourself/ your loved one, identifying triggers, finding support from fellow patients or caregivers, and identifying physical limitations and expressing them to others
- Participants suggested mapping the patient journey in a non-linear format to reflect the cyclical nature of their treatment planning, receiving treatment, and monitoring of gMG
- Changing HCPs, experiencing new symptoms, and changing treatments were noted as events that can cause participants to revisit previous stages of the patient journey

Figure 2. ***Pre-session survey results for identification (A), diagnosis (B), and treatment (C) topics***



gMG=generalized myasthenia gravis.

Figure 3. ***Patient journey map for gMG***

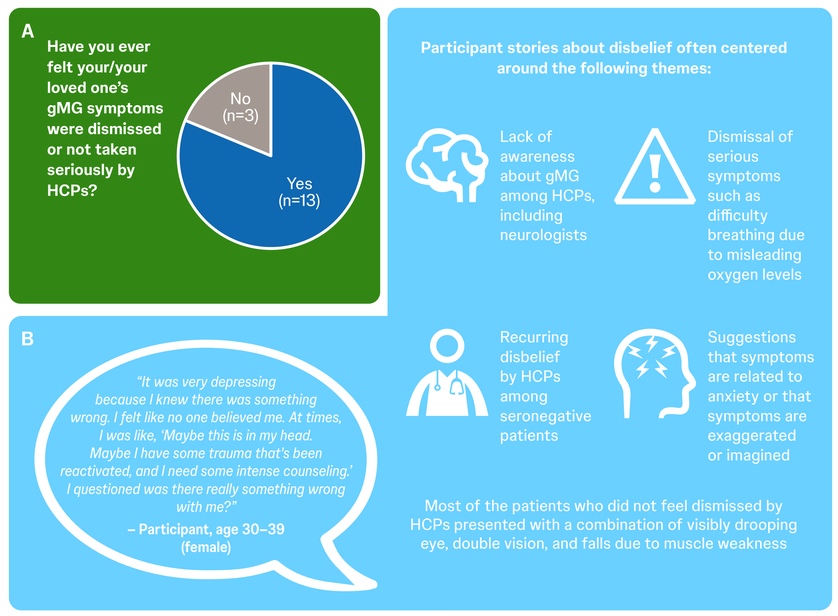


[a]*Insight from the pre-session survey.* ***gMG****=generalized myasthenia gravis,* ***HCP****=healthcare provider.*

HCP Access and Mental Health Impacts

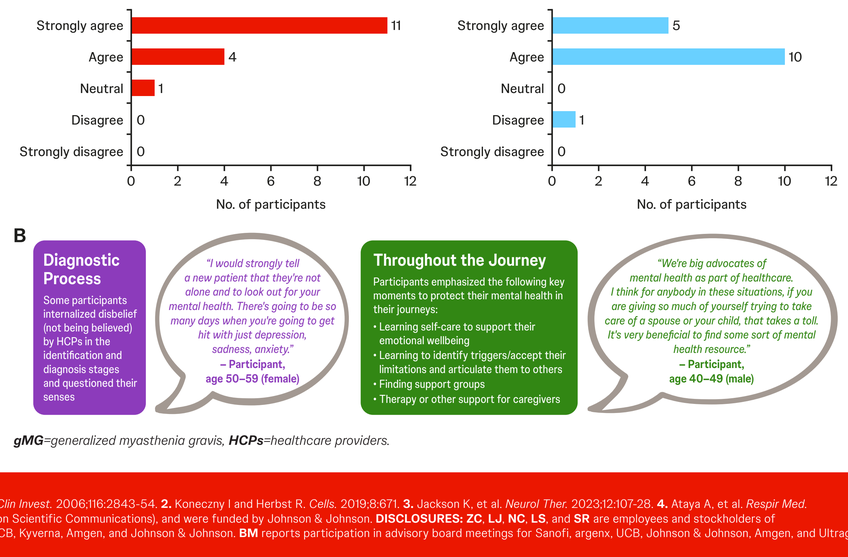
- The majority of patients (13/16 [81%]) experienced disbelief or dismissal by HCPs during their journey (**Figure 4A**), with stories centered around themes such as lack of gMG awareness among HCPs and suggestions that symptoms were related to anxiety (**Figure 4B**)
- Most participants (15/16 [94%]) reported that they agreed or strongly agreed that living with gMG was emotionally challenging and that they felt persistent fear or anxiety about having a gMG crisis (**Figure 5A**)
- Participants emphasized the importance of protecting their mental health through self-care and support groups (**Figure 5B**)

Figure 4. ***Pre-session survey results (A) and focus group insights (B) for discussions about HCPs***



gMG*=generalized myasthenia gravis,* ***HCPs****=healthcare providers.*

Figure 5. ***Pre-session survey results (A) and focus group insights (B) for discussions about mental health impacts***



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Key Takeaway

The patient journey map and insights generated from this study demonstrated that the gMG patient journey is cyclical and emotionally challenging

Conclusions

- **This study provided a visualization of the patient journey and detailed insights into the experience of living with gMG**
- **Common challenges participants faced in the gMG patient journey included misdiagnosis or delayed diagnosis, insurance barriers, and the trial-and-error nature of finding effective treatments**
- **Most participants described gMG as an emotionally challenging disease, due in part to self-doubt caused by HCPs not believing them, grief for lost abilities, and the emotional toll on caregivers of patients with gMG**
- **Implementing self-care practices, finding support groups, and learning to identify limitations and triggers and express them to others were strategies participants utilized to improve their patient journey and protect their mental health**
- **Leveraging these insights may help to improve gMG management and patient outcomes, as US patients with gMG continue to experience substantial disease instability despite currently available treatment options**

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