

# Assessing the suitability of the Neuro-QoL Fatigue to evaluate fatigue in patients living with Myasthenia Gravis

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## Introduction

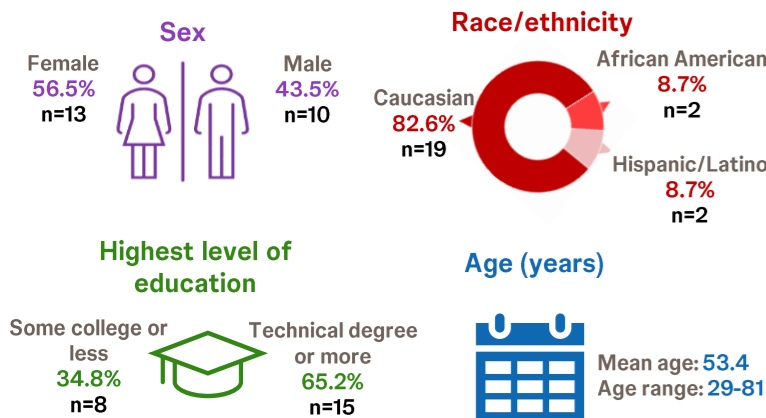
- Generalized myasthenia gravis (gMG) is a rare, chronic, autoantibody-mediated neuromuscular disease characterized by fluctuating weakness of skeletal muscles and fatigue.<sup>1-3</sup>
- The objectives of this research were to identify an appropriate patient-reported outcome (PRO) measure to assess fatigue in patients living with gMG and to conduct patient interviews to evaluate the content validity of the measure.

## Methods

- A targeted literature review identified the Neuro-QoL Fatigue<sup>4</sup> as a suitable candidate PRO to assess fatigue in gMG.
- The Neuro-QoL Fatigue is a 19-item PRO measure used to assess fatigue and its impact. It has a recall period of the past 7 days and uses a 5-point verbal descriptor scale.
- Twenty-three concept elicitation interviews were conducted with adults living with gMG. All participants were recruited from the United States via research partners following IRB approval.
- Each interview explored the symptoms and impacts of gMG on participants' daily lives.
- The final 8 interviews also included cognitive debriefing of the Neuro-QoL Fatigue to determine its appropriateness for use in gMG.
- Interviews were recorded and transcribed verbatim, and data was thematically analyzed.

## Sample Characteristics

- 23 participants were interviewed and included in the analysis. Demographic characteristics of the sample are summarized below.



## Results

### Concept Elicitation

- All participants (n=23, 100%) reported experiencing fatigue as part of their experience with gMG (Figure 1). Other commonly reported symptoms included double vision (n=13, 56.5%), and difficulty chewing/swallowing (n=8, 34.8%).
- Participants summarized the extensive impact fatigue had on their ability to carry out daily life activities, including not being able to participate in leisure activities and needing additional rest (Figure 2).
- Among those asked to provide bothersome ratings, 80% (n=12 of 15) reported that fatigue was their most bothersome symptom.

Figure 1. Frequently Reported Symptoms (n=23)

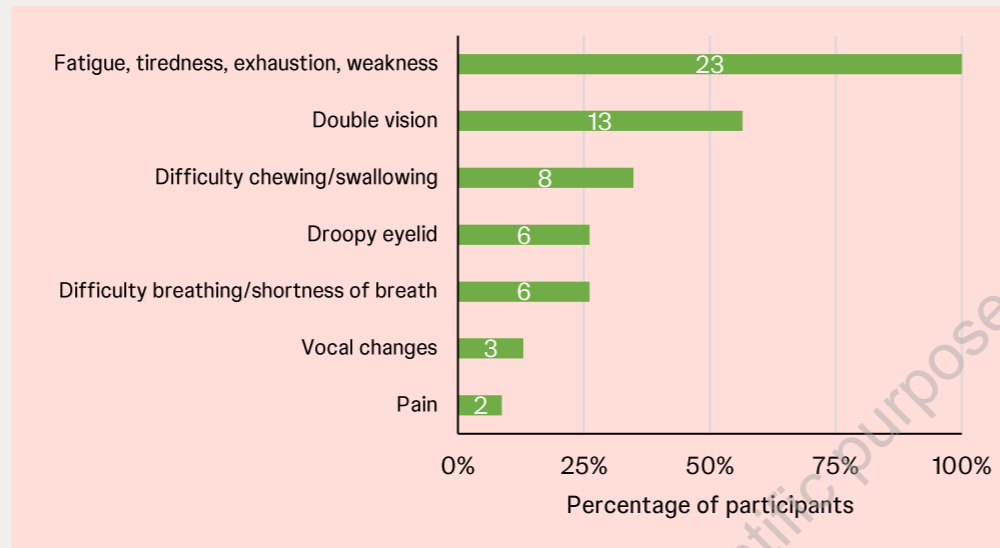
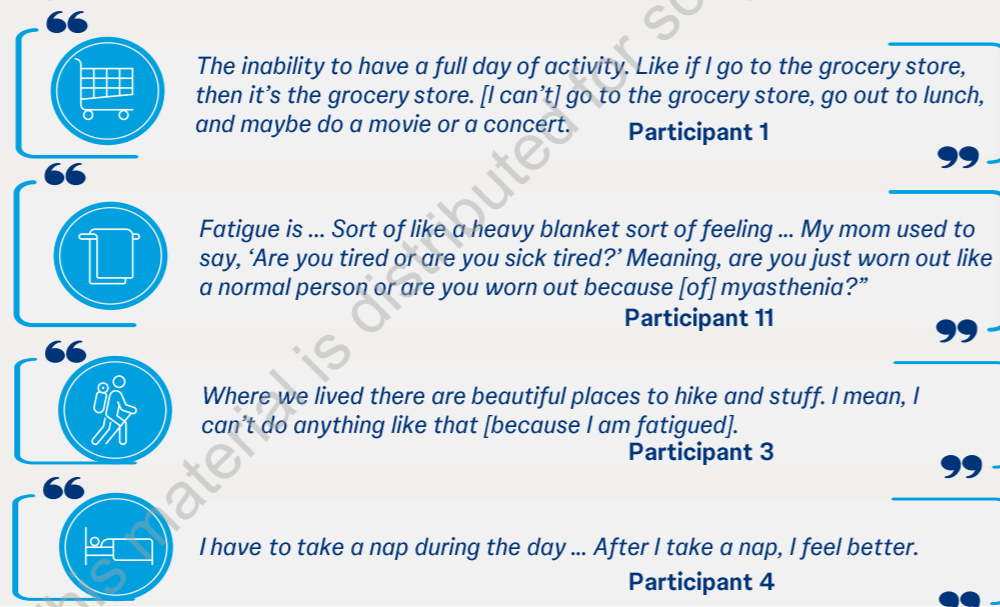


Figure 2. Participant Descriptions of Fatigue Impacts



### Cognitive Debriefing

- All participants (n=8, 100%) interpreted the instructional text of the Neuro-QoL Fatigue as intended and found it to be clear and easy to understand.
- The debriefing exercise demonstrated that nearly all participants interpreted the Neuro-QoL Fatigue items as intended (Table 1). One participant had difficulty interpreting the item that assessed feeling the need to force oneself to get up and do things as this was not relevant to their experience with gMG.
- All participants (n=8, 100%) were able to easily report specific fatigue experiences over the past 7 days and found this recall period to be appropriate for measuring the concepts.
- Results showed that the concepts in the measure were confirmed relevant by the participants to their gMG disease experience (Table 1).

Table 1. Neuro-QoL Fatigue Cognitive Debriefing Item-Level Insights (n=8)

| Neuro-QoL Fatigue Concept                              | Item interpreted as intended | Reported as relevant to the patient's experience with gMG |
|--|------------------------------|---|
|  |                              | n (%)   |
| Felt exhausted   | 8 (100)                      | 8 (100)   |
| No energy  | 8 (100)                      | 8 (100)   |
| Felt fatigued  | 8 (100)                      | 8 (100)   |
| Too tired to do chores                                 | 8 (100)                      | 8 (100)   |
| Too tired to leave the house                           | 8 (100)                      | 8 (100)   |
| Frustrated by being too tired                          | 8 (100)                      | 8 (100)   |
| Felt tired   | 8 (100)                      | 8 (100)   |
| Limited social activity because too tired              | 8 (100)                      | 8 (100)   |
| Needed help doing usual activities because of fatigue  | 8 (100)                      | 8 (100)   |
| Sleep during the day                                   | 8 (100)                      | 8 (100)   |
| Trouble finishing things                               | 8 (100)                      | 8 (100)   |
| Too tired to walk                                      | 8 (100)                      | 8 (100)   |
| Too tired to eat                                       | 8 (100)                      | 8 (100)   |
| Needed to rest during the day                          | 8 (100)                      | 8 (100)   |
| Felt weak all over                                     | 8 (100)                      | 8 (100)   |
| Needed help doing usual activities because of weakness | 8 (100)                      | 8 (100)   |
| Limited social activity because physically weak        | 8 (100)                      | 8 (100)   |
| Trouble starting things                                | 8 (100)                      | 7 (87.5)  |
| Forced self to get up and do things                    | 7 (87.5)                     | 7 (87.5)  |

## Key takeaway

- Patients living with gMG experience troublesome levels of fatigue. The Neuro-QoL Fatigue includes concepts that are suitable and comprehensive for assessing fatigue in patients living with gMG.

## Conclusions

- Fatigue is a bothersome symptom of gMG that limits patients' abilities to participate in daily life.
- Concepts assessed by the Neuro-QoL Fatigue are relevant to patient experiences in gMG.
- The interview insights support the content validity of the Neuro-QoL Fatigue in gMG patients.
- Future research will focus on evaluating the psychometric properties of the Neuro-QoL Fatigue in the gMG population.

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## Disclosures

Sheryl Pease and Kayla Scippa are employees of Johnson & Johnson.

## Abbreviations

gMG, generalized myasthenia gravis; PRO, patient reported outcome

## References

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