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## Introduction and objectives

- Generalized myasthenia gravis (gMG) is a rare autoimmune disease characterized by fluctuating and debilitating muscle weakness. Despite available treatments, considerable burden and unmet need remains for the >60,000 individuals affected with gMG in the United States (US).<sup>1-7</sup>
- Social determinants of health (SDOH) challenges pose an additional layer of burden for individuals navigating the healthcare system.<sup>8,9</sup> Though better understanding the impact of SDOH on living with gMG is crucial to holistically and inclusively address unmet needs, such evidence is limited in gMG.
- The objective of this study was to evaluate the real-world burden of individuals living with gMG in the US who are facing SDOH challenges based on their race/ethnic background, insurance type, and/or employment status, to highlight potential key areas of unmet need for which additional support can be proactively targeted.

## Methods

### Study design

- A cross-sectional survey was designed based on insights gathered from 15 qualitative 1-on-1 interviews conducted with pre-screened individuals, of whom 11 were living with gMG and SDOH barriers, 2 were caregivers of such individuals, and 2 were representatives of gMG patient advocacy groups in the US. Protocols and materials used in the study received Institutional Review Board approval (IRB#20220823, WCG IRB, Puyallup, WA, USA), and all participants received compensation for their time.



#### Quantitative web-based survey

- Respondents were presented with **10 potential challenges encountered while living with gMG and SDOH challenges** (prompts designed based on insights gathered from the qualitative interviews) in randomized order and requested to select all statements that were relevant to their experience during the last 6 months.

### Participant recruitment

- Adults living with gMG and SDOH barriers (aged 18–75 years) in the US were recruited.

#### Key strategies utilized to boost recruitment and survey completion rates for individuals living with both gMG (rare disease) and SDOH challenges, who are historically difficult to reach:

Directly partnered with vendors with robust networks of patients with rare disease, and gMG patient advocacy groups

Screener and quotas were customized to capture diversity among pre-defined SDOH dimensions

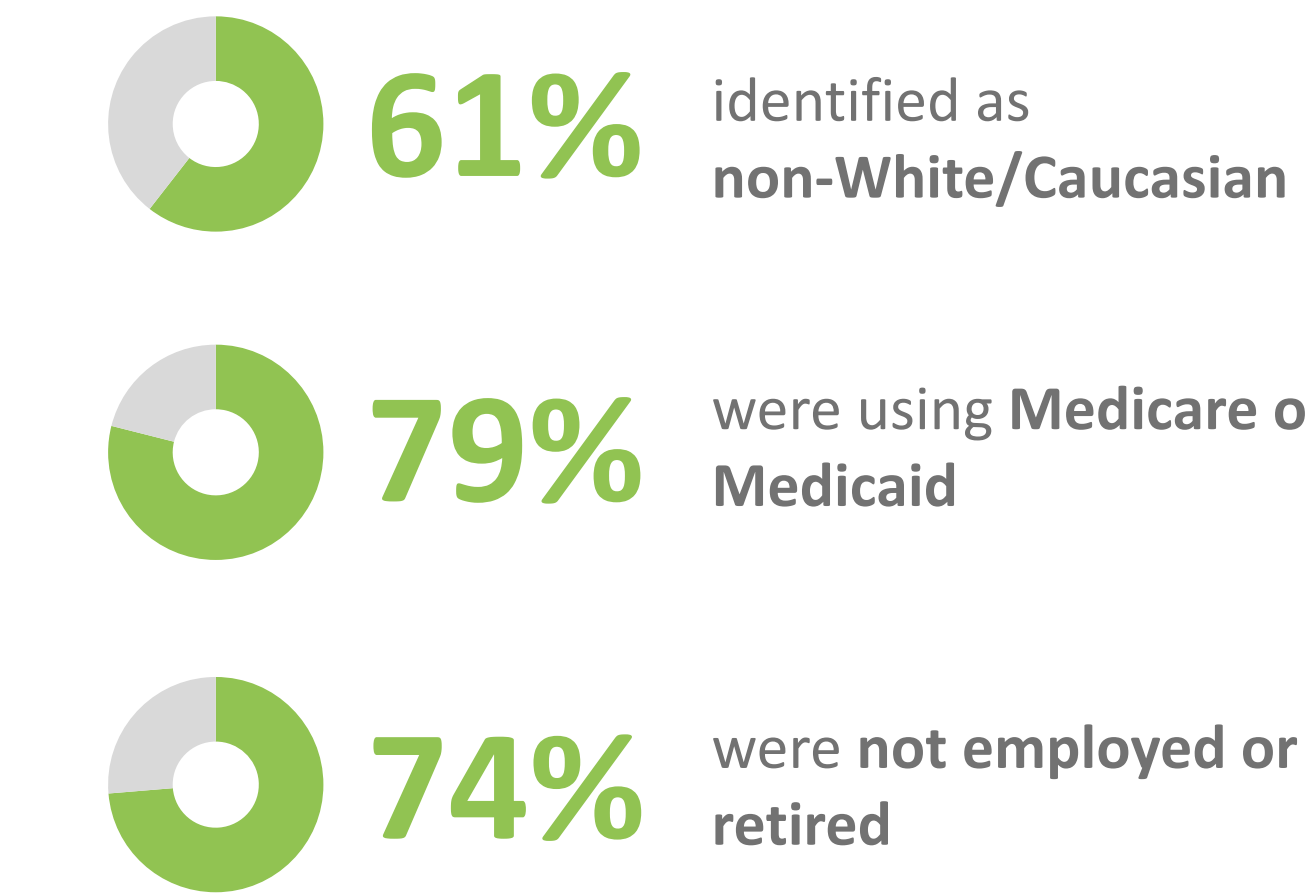
Caregivers were allowed to provide technical support in using the survey platform

The survey, with optional telephone assistance, was offered in both English and Spanish

## Results

### 1. Diverse cohorts of individuals living with gMG completed the survey

- A total of 38 individuals completed the survey, with a high proportion being non-White/Caucasian, using public health insurance, and being unemployed or retired (Figure 1).



Baseline demographics and characteristics (N=38)					
	n		n		n
Race/ethnic background	White/Caucasian	15	Gender	Men	9
	Hispanic/Latin@	5		Women	28
	Black/African American	10	Binary gender nonconforming	1	
	Native American/Indigenous Person	4	Age	18 to 40 years	9
	Asian/Pacific Islander	1		41 to 60 years	20
Middle Eastern or North African	3	61 to 75 years		9	
Insurance type	Medicaid	13	Living environment	Urban	13
	Medicare	17		Suburban	13
	Private	7	Rural or small town	12	
	Other	1	High school or GED	11	
Employment	Employed	10	Level of education	Post-secondary education	23
	Not employed or retired	28		Prefer not to answer	4

Figure 1. Self-reported demographics and characteristics of survey responders (N=38).

### 2. Pronounced SDOH burden was highlighted in 3 of the challenges related to finances and securing stable and safe housing

- Overall, across the 10 potential challenges presented, the proportion of respondents expressing each statement as a concern ranged from 0% to 76% (Figures 2 and 3). Across 3 of the concerns particularly related to financial challenges and securing stable and safe housing, individuals living with gMG who identified as non-White/Caucasian, using Medicaid, and/or unemployed or retired expressed pronounced challenges compared with the overall study cohort (Figure 2).

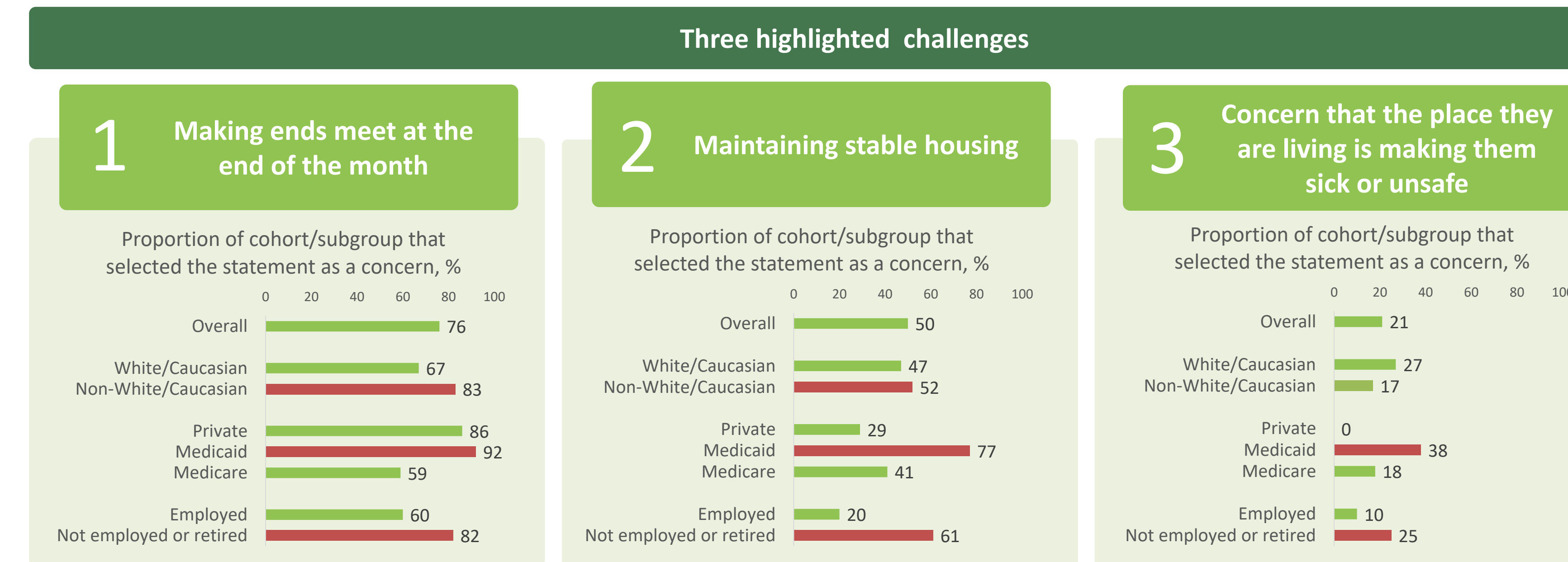


Figure 2. Proportion of each cohort or subgroup that selected the statement as a concern. Data for the 3 concerns with the most pronounced SDOH burden are shown. Red bars highlight where a greater proportion of the non-White/Caucasian, Medicaid, or not employed subgroup considered the statement as a concern compared with the overall study cohort. Data corresponding to the remaining 7 statements are shown in Figure 3.

### 3. Varied levels of SDOH burden were observed for other concerns

- Among each pre-specified SDOH subgroup, variations were observed in the proportion of respondents who expressed the statement as a concern (Figure 3).

Other challenges/concerns included in the survey	Overall	Race/ethnicity		Insurance			Employment	
		White/Caucasian	Non-White/Caucasian	Medicare	Medicaid	Private	Employed	Not employed/retired
Have felt unequal treatment due to socioeconomic status	32%	27%	35%	41%	31%	14%	20%	36%
Have had to skip treatments or doctor's appointments to save money	32%	27%	35%	29%	23%	43%	30%	32%
Have put off or neglected doctor's visit(s) because of distance or transportation	32%	27%	35%	24%	38%	43%	30%	32%
Utilities providers have threatened to shut off services to your home	29%	33%	26%	24%	38%	29%	30%	29%
Have felt judged by someone with more education	24%	33%	17%	35%	23%	0%	20%	25%
Have felt unequal treatment due to race/ethnicity/skin color	13%	7%	17%	12%	15%	14%	40%	4%
Have had difficulty communicating due to English not being first language	0%	0%	0%	0%	0%	0%	0%	0%
<b>n</b>	<b>38</b>	<b>15</b>	<b>23</b>	<b>17</b>	<b>13</b>	<b>7</b>	<b>10</b>	<b>28</b>

Figure 3. Proportion of each subgroup who selected the statement as a concern (results for the 7 remaining statements not depicted in Figure 2).

## Conclusions

- Overall, challenges experienced by individuals living with gMG and facing SDOH barriers were diverse. Pronounced burden was observed in managing finances and maintaining stable and safe housing among people of color, using Medicaid, or not employed.
- While our study sample comprised one of the most diverse groups of individuals living with gMG in the US, the cohort size limited the scope of the analysis. The results presented reflect descriptive trends, with further studies using larger datasets required to make statistical comparisons or generalizations.
- While these results improve our understanding of the burden of individuals living with gMG, key subgroups living with certain SDOH challenges may be facing disproportionate challenges for which additional support should be provided.

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