

THE ECONOMIC BURDEN OF INDIVIDUALS LIVING WITH GENERALIZED MYASTHENIA GRAVIS AND SOCIAL DETERMINANTS OF HEALTH BARRIERS

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Introduction and objectives

- Generalized myasthenia gravis (gMG) is a rare autoimmune disease associated with failure of neuromuscular junction transmission, characterized by fluctuating and debilitating weakness in ocular, facial, bulbar, axial, and limb muscles.^{1,2} Despite available treatments, considerable unmet need remains in addressing clinical, humanistic, and economic burden for the >60,000 individuals currently affected with gMG in the US.³⁻⁷
- Growing evidence substantiates that individuals living with social determinants of health (SDOH) challenges experience increased economic burden, perpetuating historical health inequities.^{8,9} To holistically and inclusively address unmet economic needs in gMG, it is crucial to better understand the impact of SDOH on living with gMG from the patients' perspective. However, such evidence is limited in gMG.
- The objective of this study was to identify common economic challenges faced by individuals living with gMG and SDOH barriers, 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 from qualitative interviews conducted with individuals living with gMG and SDOH barriers, caregivers of such individuals, and 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 (Figure 1).



Quantitative web-based survey

- Multiple-choice questions and answers were designed based on insights gathered from the qualitative interviews
- The survey included questions regarding:
 - Overall concerns and challenges in living with gMG
 - Challenges by **phase** of the diagnosis and treatment experience



Figure 1. Study design.

Participant recruitment

- Individuals living with gMG and SDOH barriers (aged 18–75 years) were recruited into the study.

Key strategies utilized to overcome a challenging recruitment of individuals who historically do not participate in research studies:



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



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



Caregivers were allowed to assist individuals in completing the survey

Results

1. Study population

- A total of 38 individuals completed the survey. Diverse cohorts of individuals living with gMG were recruited, with a high proportion using Medicaid, using Medicare, and/or unemployed (Figure 2).

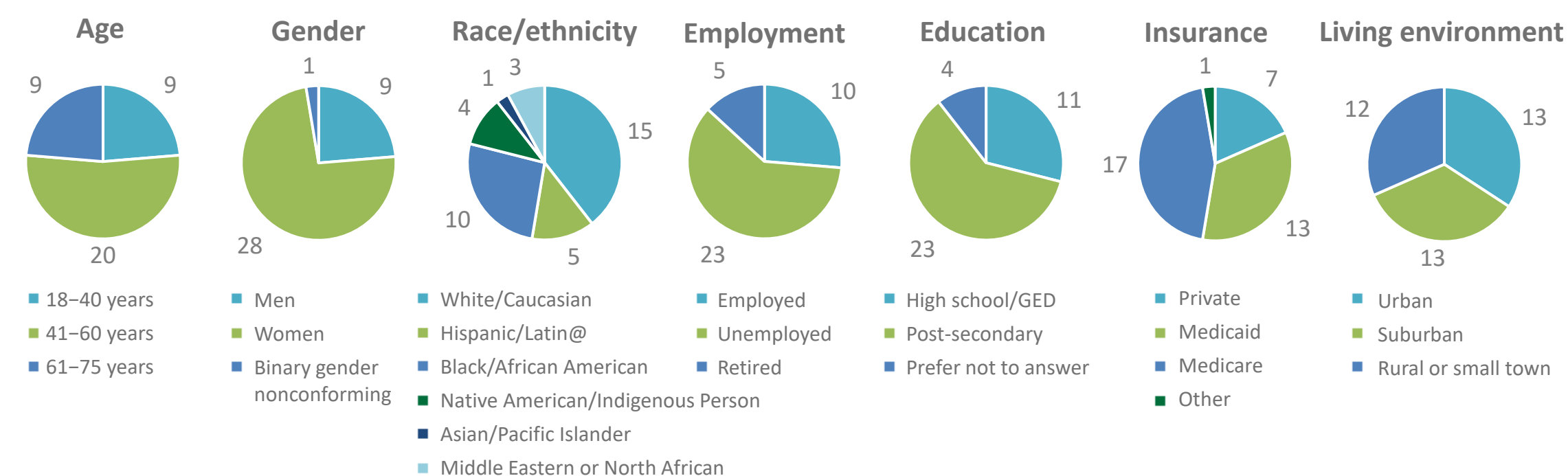


Figure 2. Self-reported participant demographics and characteristics of survey responders (N=38).

2. Over 75% of respondents expressed economic concerns over the past 6 months



76% had problems making ends meet at the end of the month



50% felt worried that they may not be able to maintain stable housing

32% had neglected treatments or healthcare visits due to financial reasons

29% had been threatened with cutoff of their household utilities (e.g., electric, gas, oil, water)

21% felt worried that the place they are living now is making them sick or unsafe

Figure 3. Proportions of respondents expressing economic concerns. Respondents were shown a list of 10 pre-defined potential overall concerns in a randomized order and asked to select all statements that were relevant in their day-to-day lives over the past 6 months (N=38).

3. Economic concerns were highlighted when accessing treatment

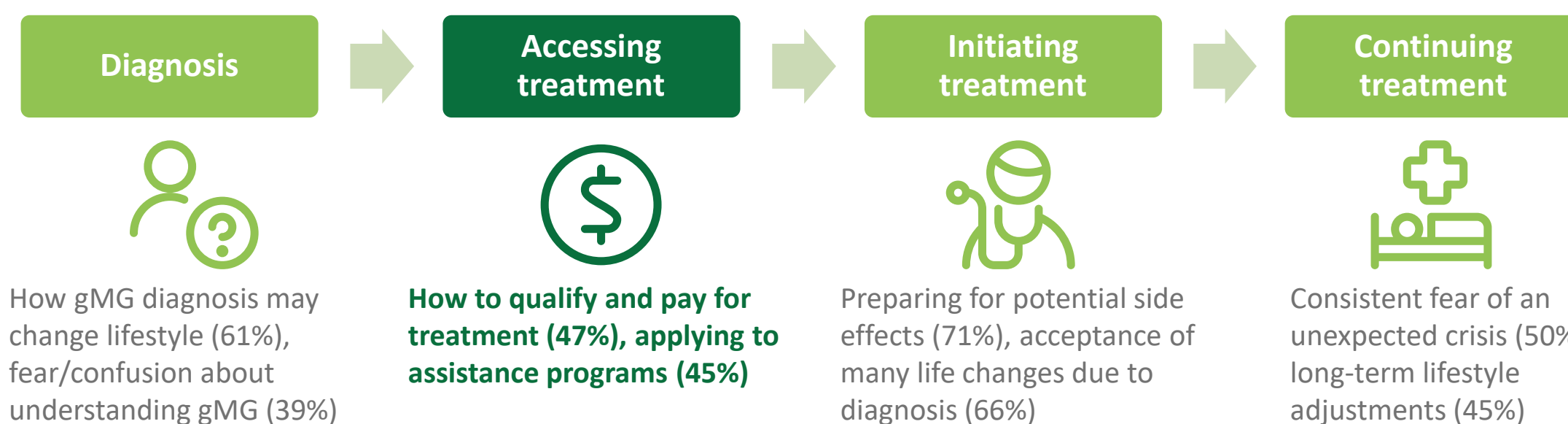


Figure 4. The 2 most common concerns expressed in relation to each phase. Respondents were asked to select 3 out of 10 pre-defined concerns (shown in randomized order) that were most relevant in each phase. The 2 most common concerns for each phase are shown (N=38).

4. In addition to costs related to accessing treatment, a wide range of other cost types were expressed as a major concern

- In addition to direct medical costs related to accessing treatment, top major concerns included indirect and direct non-medical costs. Loss of income was a major concern for 61% of respondents, representing the high impact of indirect costs (Figure 5).

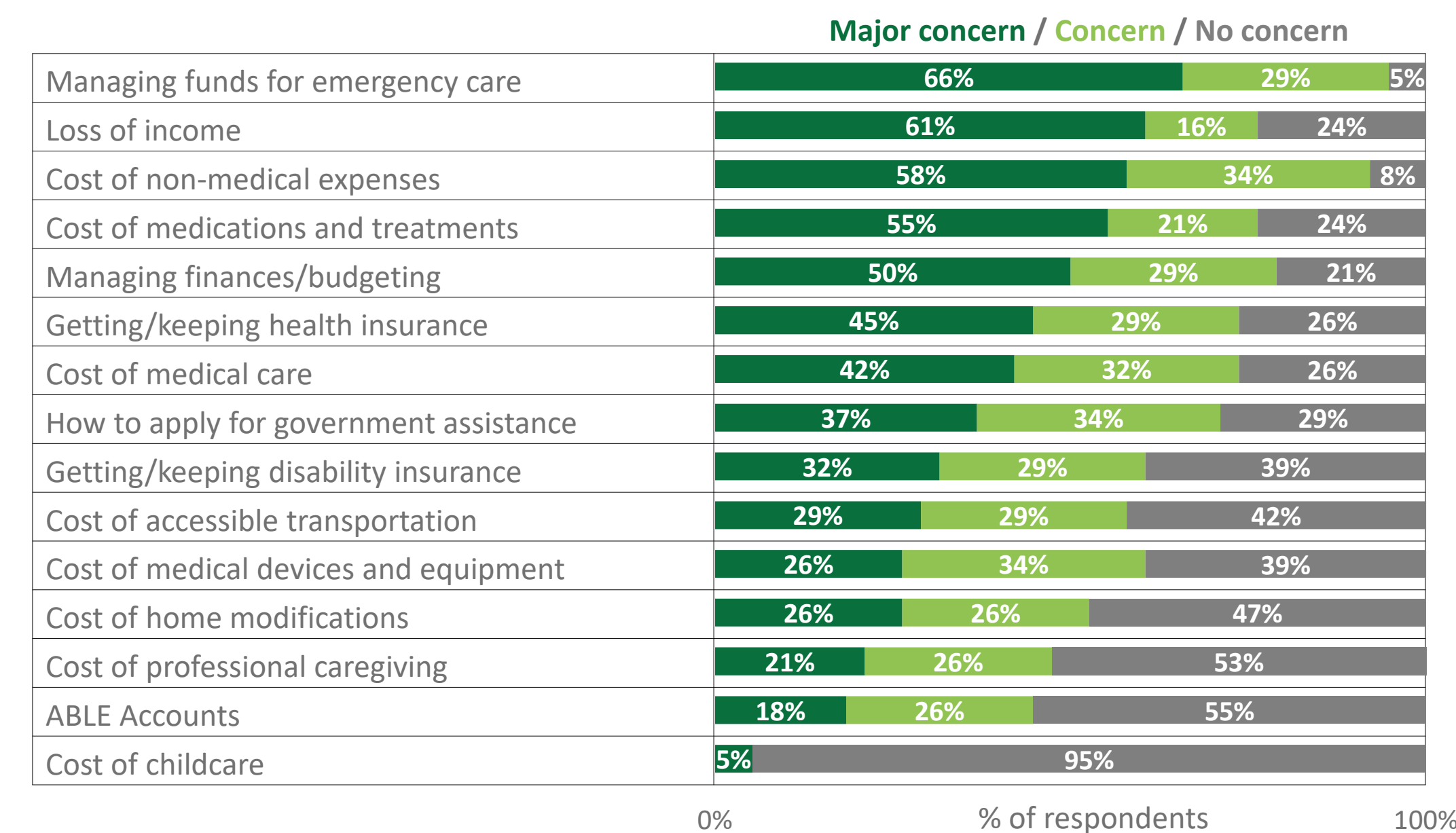


Figure 5. Proportions of respondents expressing degree of concerns. Respondents were shown the cost types (randomized order) and were asked to choose 1 of 3 options (major concern, concern, or no concern) indicating to what degree each had been a concern since being diagnosed with gMG. Percentages may not add up to 100% due to rounding.

Conclusions

- Economic challenges were common among individuals living with gMG and SDOH challenges, with particularly high impact when accessing treatment. Notably, however, indirect and direct non-medical costs were common major concerns in addition to direct medical costs.
- Although 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 larger datasets required to make statistical comparisons.
- Nevertheless, these results highlight specific areas of compounding economic burden faced by individuals living with gMG and SDOH barriers. Future research and economic models should be tailored to inclusively capture the real-world experience of individuals living with gMG who are facing SDOH barriers.

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Part of the material in this poster is currently in review for publication. TH and GP are employees of argenx. SC was an employee of ZS Associates at the time of research contribution. MS is a current employee of ZS Associates and serves as a paid consultant for argenx.

Abbreviations gMG, generalized myasthenia gravis; SDOH, social determinants of health.

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