

Healthcare provider perspectives on barriers and challenges to equitable care among patient subpopulations with generalized myasthenia gravis: A US national survey

Amanda Guidon¹, Ashley Anderson², Yaacov Anziska³, Gretchen Ayer⁴, Michael Hehir⁵, Ehtesham Khalid⁶, Shaida Khan⁷, Hannah Machemehl⁸, Rodrigo Rodriguez Jr.⁹, Brienne Stairs¹⁰, Grace Stelter¹⁰, and Judith Thompson¹¹

¹Massachusetts General Hospital, Boston, MA, USA; ²Department of Neurology, Houston Methodist, Houston, TX, USA; ³Downstate Health Sciences University, Brooklyn, New York, NY, USA; ⁴UCB, Middlebury, VT, USA; ⁵University of Vermont, Burlington, VT, USA; ⁶Ochsner Medical Center, New Orleans, LA, USA; ⁷Department of Neurology, UT Southwestern Medical Center, Dallas, TX, USA; ⁸UNC Health, Arden, NC, USA; ⁹Keck School of Medicine of USC, Los Angeles, CA, USA; ¹⁰MEDUCOM Health Inc., Guelph, Ontario, Canada; ¹¹UCB, Smyrna, GA, USA

MGFA Scientific Session at AANEM 2026, Orlando, FL, USA; September 29, 2026

Introduction

- MG is a rare chronic autoimmune neuromuscular disorder characterized by fluctuating weakness in the skeletal muscles^{1–3}
- Although treatment options for MG have expanded in recent years, disparities in care persist^{4–8}
- Many patients experience inequitable access to patient-centered care, exacerbated by SDoH including insurance coverage, geographic location, language proficiency, and socioeconomic status^{4–8}
- Limited evidence on HCPs' perspectives on drivers of healthcare inequities for gMG in the US hinders development of informed and impactful population health strategies
- This study aims to characterize expert perspectives on barriers and challenges to care for patients with gMG, with a focus on disproportionately affected subpopulations**

Methods

- Cross-sectional survey conducted from March 23, 2026 to April 10, 2026 among US HCPs (**Table 1**)
- Measures
 - HCPs were asked what they thought is the most significant barrier and primary underlying challenge contributing to inequitable care in gMG for the following populations:
 - Ethnic or racial minorities
 - People on Medicaid or other publicly subsidized insurance
 - People who are uninsured
 - People with limited healthcare options due to geography
 - People with limited English proficiency
 - People with limited English proficiency
 - Women of childbearing age

Table 1 Participant screening criteria

All survey participants	<ul style="list-style-type: none">Clinical practice experience in MG for ≥3 years (including fellowship training)Treated or managed ≥5 patients with gMG (MGFA Clinical Class >I) within the past 12 months
Neurologists	<ul style="list-style-type: none">Board-certified or board-eligible in neurology
Neuromuscular specialists	<ul style="list-style-type: none">Board-certified or board-eligible in neurologyCompleted fellowship/equivalent training in neuromuscular medicine or electrophysiology, or hold recognized subspecialty certification in this field
Neurology APPs	<ul style="list-style-type: none">Board-certified or board-eligible as a Nurse Practitioner or Physician AssistantPrimarily manage patients in a neurology practice setting

Table 2 HCP respondent clinical specialty, professional degree, practice type, and gMG experience

Clinical specialty	n	Professional degree	n	Primary practice	n	Clinical experience managing gMG	n	Estimated number of patients with gMG managed in past 12 months ¹	n
Neuromuscular medicine	112	MD	114	Academic medical center	96	<3 years ²	1	<5 ³	3
General neurology	5	DO	6	Private practice	13	3–5 years	17	5–10	8
Other*	8	NP	4	Community hospital	9	6–10 years	27	11–25	29
		PA	1	Veterans Affairs	2	11–20 years	45	26–75	37
				Other ⁴	5	>20 years	35	76–150	28
								>150	20

*Other specialties included neuroimmunology (n=4), neuro-ophthalmology (n=1), neuroimmunology and neuro-ophthalmology (n=1), PM&R with certification in NM medicine and electrodiagnostic medicine (n=1) focused on MG (n=1). ¹Other primary practice settings (n=1 for each) included a non-academic medical center, academic tertiary care, outpatient healthcare system, academic medical center/safety net hospital and multispecialty group practice. ²A sensitivity analysis excluding these respondents will be conducted during manuscript development. ³Based on survey question: 'In the past 12 months, approximately how many patients with gMG have you managed in your practice?'. ⁴

Figure 1 HCP respondent state of practice

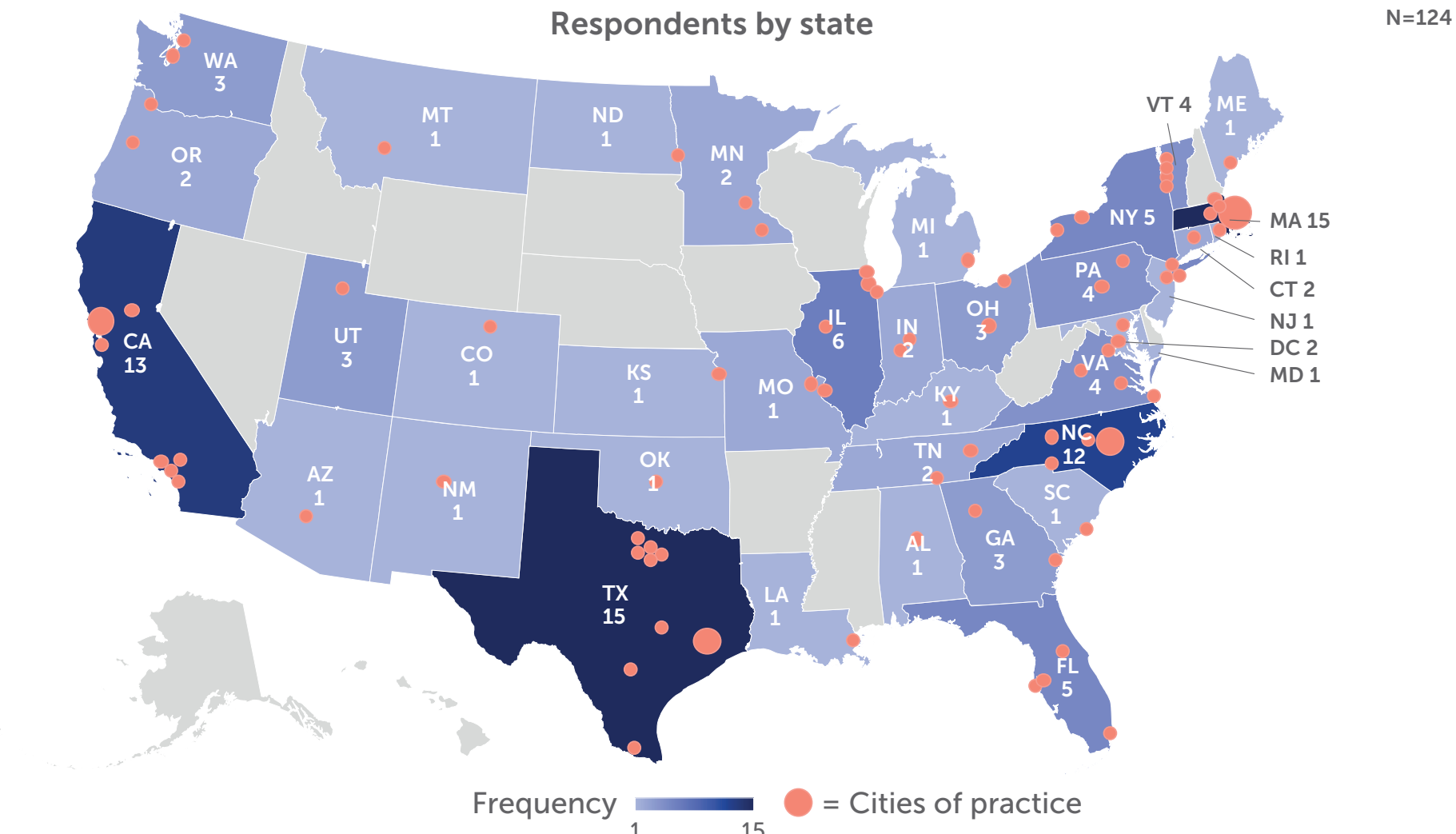
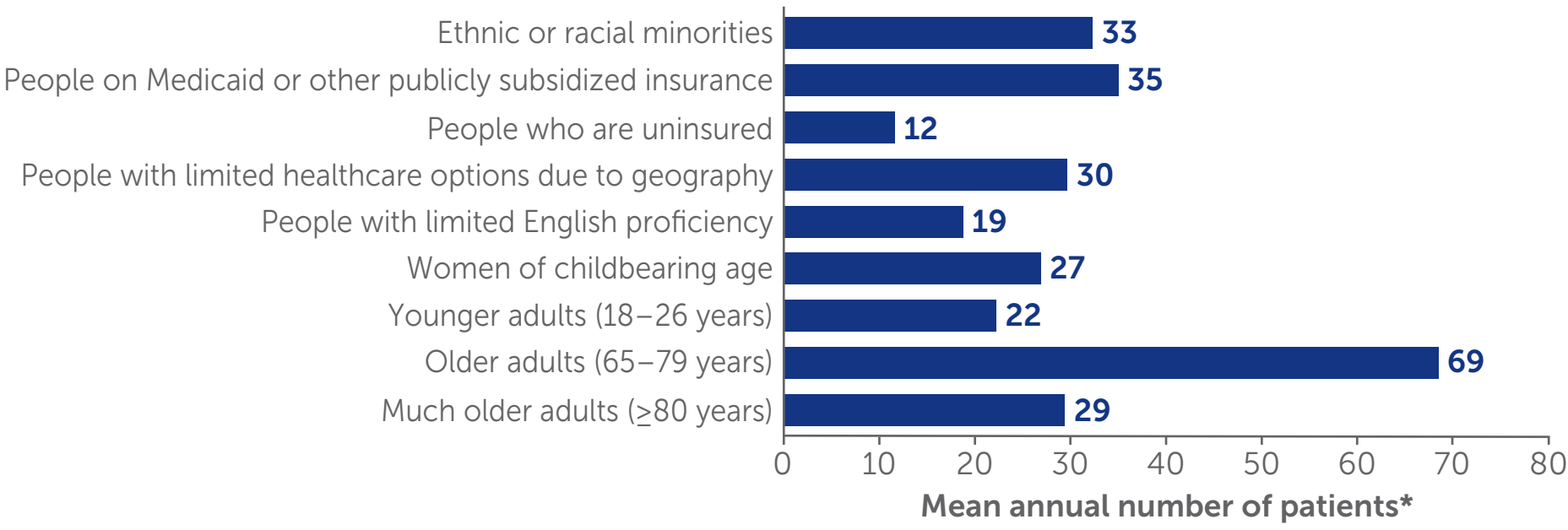


Figure 2 HCP reports of patients with gMG in subpopulations of interest



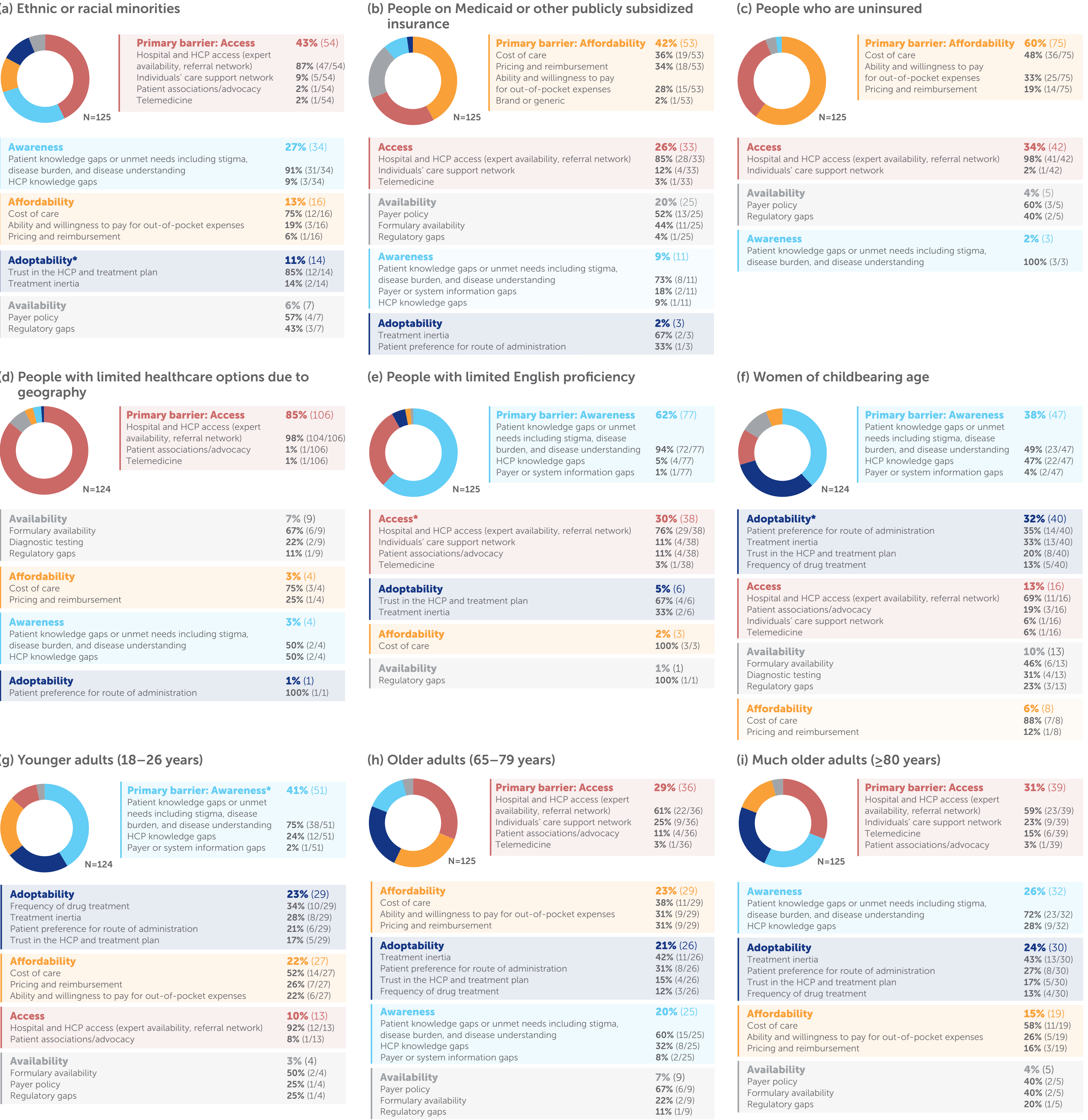
*To estimate subpopulation patient numbers, HCP-reported annual gMG patient volumes (categorical responses converted to representative numeric values >150, 150; 76–150, 150; 26–75, 75; 11–25, 25; 5–10, 10; <5, 4) were multiplied by reported proportions of patients within each subpopulation (range responses converted to midpoint values [0%, 0; 1–20%, 10; 21–40%, 30; 41–60%, 50; 61–80%, 70; 81–100%, 90; unsure, 0]). Estimated counts were calculated at the respondent level, aggregated across respondents, and averaged across the sample.

- Younger adults (18–26 years)
- Older adults (65–79 years)
- Much older adults (≥80 years)
- Barriers considered were access to provider or care network, affordability (care/treatment cost), awareness (patient/HCP knowledge gaps about the disease/system), availability (diagnostic, regulatory, supply), and adoptability (treatment acceptance/preferences)

Results

- 125 HCPs completed the survey. The majority were MDs and neuromuscular specialists, had >5 years of experience managing care for patients living with gMG, and had managed >25 patients with gMG in the past 12 months (**Table 2**)
- HCP respondents' practice locations spanned 37 states and districts (**Figure 1**), and they reported treating patients from all states in the US
- HCPs reported treating patients with gMG across all subpopulations of interest, with older adults (65–79 years) representing the largest volume of patients (**Figure 2**)
- Primary barriers and challenges to care were identified across subpopulations of interest (**Figure 3**)
 - Subpopulations classified by SDoH demonstrated distinct primary barriers to care, whereas age-related subpopulations had multiple barriers contributing to inequitable care
- The primary barriers to care identified by HCPs did not vary when compared to a subgroup of respondents who managed >25 patients with gMG per year and had >20% of their patients represented in the subpopulations of interest

Figure 3 Primary underlying challenges contributing to barriers to care in gMG



*Percentages may not total 100% due to rounding. Data presented as % (n).

Abbreviations: APP, Advanced Practice Provider; DO, Doctor of Osteopathic Medicine; gMG, generalized myasthenia gravis; HCP, healthcare provider; MD, Doctor of Medicine; MG, myasthenia gravis; MGFA, Myasthenia Gravis Foundation of America; NM, neuromuscular; NP, Nurse Practitioner; PA, Physician Assistant; PM&R, Physical Medicine and Rehabilitation; SDoH, social determinants of health. **Acknowledgments:** This study was funded by UCB. The authors acknowledge Lianne Holloway of Celity Health, London, UK, for editorial assistance, which was funded by UCB. The authors thank Kate Weatherall, PhD, CMPP for UCB, for publication and editorial support, and Danielle Quinn for UCB, for strategic and editorial support. The authors thank the HCPs, in addition to the investigators and their teams who contributed to this study. **Author disclosures:** Amanda Guidon is a member of Scientific Advisory or Data Safety Monitoring Boards for Amgen, argenx, Regeneron, and UCB. She is a Guest Editor for AAN - Continuum. She has received research support from NINDS (institution). She has received royalties from McGraw Hill. She has non-compensated relationships as a Committee Member with the Myasthenia Gravis Foundation of America and the Neuromuscular Study Group. An immediate family member of Dr. Guidon has received personal compensation for serving as an employee of GE Healthcare. Ashley Anderson and Yaacov Anziska have nothing to disclose. Gretchen Ayer is an employee of UCB. Michael Hehir has served as a paid consultant for argenx, Dianthus, Johnson & Johnson, and UCB. Ehtesham Khalid has received honoraria for speaking and advisory board participation from UCB. Shaida Khan has served as a paid consultant for UCB, served on advisory boards for argenx and UCB, and receives research support from the Fichtenbaum Charitable Trust. Hannah Machemehl has served on an advisory board for argenx and Octapharma, served on an advisory board and as a consultant for UCB, received grant funding from the ALS Association, and research funding from Vertex. Rodrigo Rodriguez Jr. has received consulting fees from UCB. Brienne Stairs and Grace Stelter are contracted by UCB to provide strategic and editorial support. Judith Thompson is an employee of UCB.

References: 1. Rodrigues E, et al. Muscle Nerve. 2024;69(2):166–71. 2. Alhajdar MK, et al. J Clin Med. 2022;11(6):1597. 3. Guo RJ, et al. Neurol Ther. 2022;11(1):73–86. 4. UCB Data on file. Thompson J, et al. 2023. MGFA SS. Poster 25. 5. UCB Data on file. Thompson J, et al. 2024. AANEM. Poster 287. 6. UCB Data on file. Thompson J, et al. 2024. AANEM. Poster 288. 7. Sirven J, et al. Epilepsy Behav. 2022;126:108473. 8. Neroda P, et al. Front Public Health. 2021;9:662876.



Please use this QR code to download a PDF of the poster.

Summary and conclusions



We surveyed 125 HCPs for their perspectives on the barriers to care for patients with gMG, especially for subgroups of the population that experience disparities in care



Key barriers to care differed by subpopulation and included:

- Access (hospital and expert availability/referral networks)
- Awareness (knowledge gaps or unmet needs including stigma, disease burden, and disease understanding)
- Affordability (cost of care)



Diverse barriers to high-quality, equitable care across patient subpopulations highlight the need for informed, targeted strategies to close care gaps and improve outcomes for people living with gMG