ABSTRACT 1347 – POSTER PRESENTATION 006, NEIGHBORHOOD 9

PATIENT SUPPORT PROGRAM ENHANCEMENTS FOR PATIENTS DIAGNOSED WITH GENERALIZED MYASTHENIA GRAVIS FACING SOCIAL DETERMINANTS OF HEALTH CHALLENGES

Hughes T[1]*; Zvosec C[2]; Anderson AEL[3]; Habib AA[4]; Perez K[1]; Bergin C[1]; Suchotliff S[2]; Phillips G[1]
[1]argenx US Inc., Boston, MA, USA; [2]ZS Associates, New York, NY, USA; [3]Houston Methodist Neuromuscular Clinic, Houston, TX, USA; [4]UCI Health MDA ALS & Neuromuscular Center, University of California, Irvine, Orange, CA, USA. *Correspondence: thughes@argenx.com.

Introduction and objectives

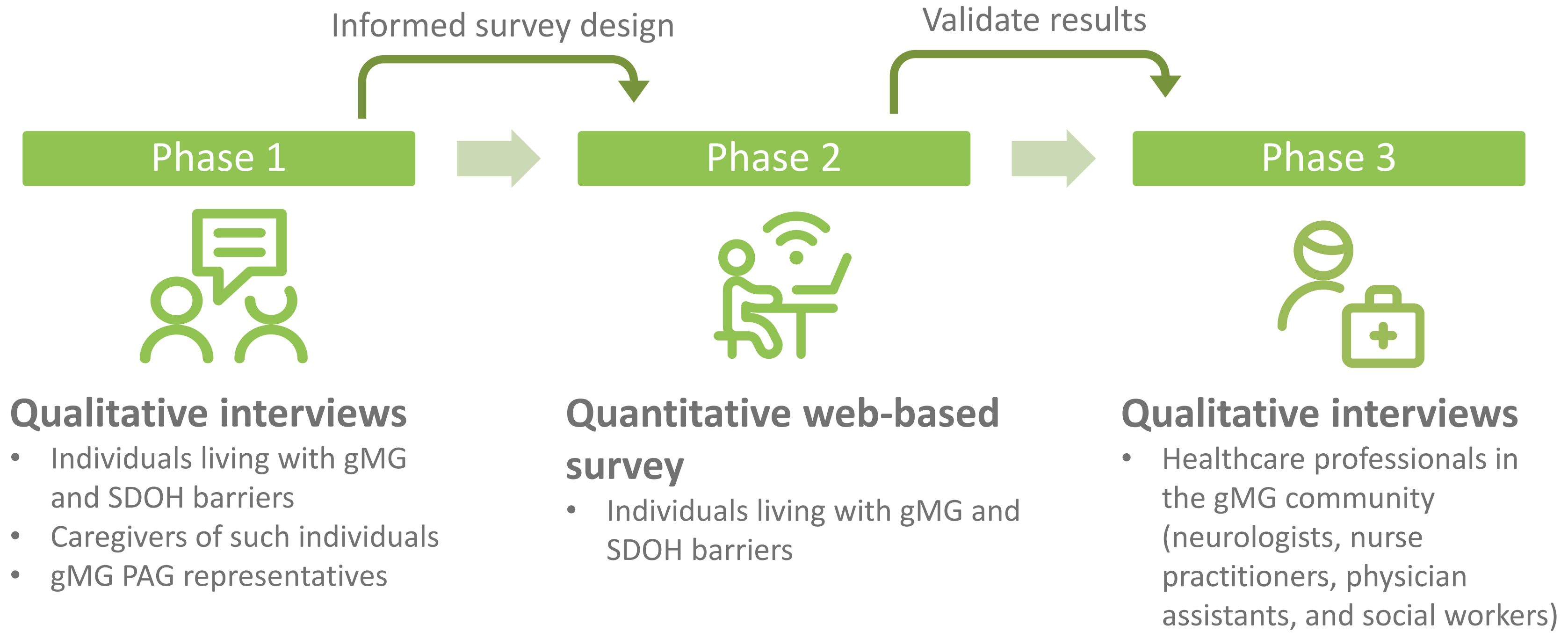
- Myasthenia gravis (MG) is a rare autoimmune disorder impacting neuromuscular junction transmission that affects ~60,000 individuals in the United States (US).[1,2] Most MG cases progress to generalized MG (gMG) affecting bulbar, limb, trunk, and respiratory muscles,[3] which contribute to significant patient burden.[4]
- Social determinants of health (SDOH) are important contributors to health outcomes,[5,6] and better understanding their impact on individuals diagnosed with rare, chronic diseases with high burden and unmet need is critical. Characterizing SDOH burden can help improve the design of patient support programs (PSPs), which offer interventions that aim to improve access to treatments and disease management.[7,8]
- The objective of this study was to better characterize how SDOH barriers impact individuals living with gMG in the US. We investigated their awareness and utilization levels of existing PSP resources, with the aim of identifying and prioritizing interventions that can help mitigate specific challenges associated with SDOH barriers.

Methods

Study design

- This cross-sectional mixed-methods study included 3 phases and involved individuals living with gMG and SDOH barriers, caregivers of such individuals, healthcare professionals, and representatives of gMG patient advocacy groups (PAGs) in the US (Figure 1). Protocols and materials used in the study received Institutional Review Board approval (IRB#20220823), and all participants received compensation for their time.

Figure 1. Study design.



Qualitative interviews
- Individuals living with gMG and SDOH barriers
- Caregivers of such individuals
- gMG PAG representatives

Quantitative web-based survey
- Individuals living with gMG and SDOH barriers

Qualitative interviews
- Healthcare professionals in the gMG community (neurologists, nurse practitioners, physician assistants, and social workers)

Participant recruitment and inclusion criteria

To overcome a challenging process of recruiting individuals who historically do not participate in research studies:

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

We directly partnered with vendors with robust networks of patients with rare disease, and gMG PAGs

The screener questionnaire was customized to capture diversity among several SDOH dimensions:

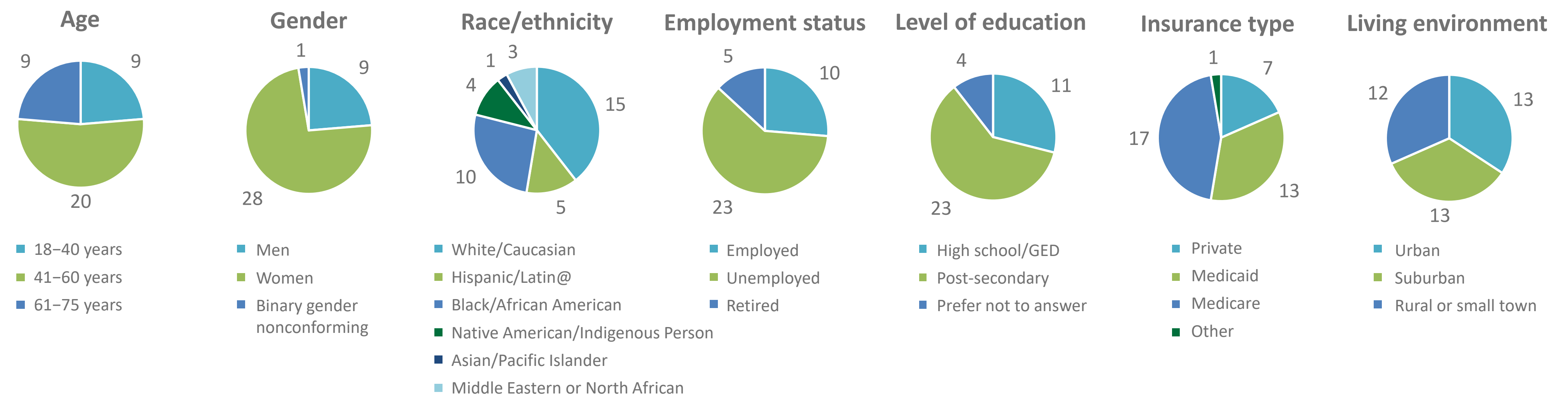
Age
Gender
Racial/ethnic background
Employment status
Level of education
Insurance type
Living environment

Results

1. Study population

- Phase 1: N=15, including 11 individuals living with gMG and SDOH barriers, 2 caregivers, and 2 PAG representatives.
- Phase 2: N=38 individuals living with gMG and SDOH barriers (Figure 2).
- Phase 3: N=11, including 7 neurologists, 2 nurse practitioners, 1 physician's assistant, and 1 social worker who have managed ≥3 individuals with gMG in the past 12 months.

Figure 2. Self-reported participant demographics and characteristics in Phase 2 (N=38).



2. Key unmet needs for 38 individuals living with gMG and SDOH barriers (Phase 2)

1 Disease education

50% had low or neutral confidence in **navigating their healthcare and treatment experience with ease**

39% had low or neutral confidence in their ability to find **reliable health information**

2 "High-touch" support*

42% responded that the most valuable resource at diagnosis would be a **nurse navigator** who can provide support, including mental health resources

39% responded that the most valuable resource when initiating treatment would be a **nurse case manager**

3 Financial support

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

47% reported that one of their top 3 concerns when accessing treatment was **determining if they are qualified for their treatment and how they will pay for it**

4 Awareness of PSPs

84% were **unaware of free medication** available while waiting to hear if insurance will cover costs

79% were **unaware of nurse case managers available** to support the beginning of their treatment journey when initiating treatment

*"High-touch" support is a form of care that encourages frequent direct person-to-person interactions between individuals receiving and providing support.

3. Key unmet needs identified from 11 healthcare professionals (Phase 3)

Clinicians may not have adequate training to identify and address SDOH challenges that patients are facing

Clinicians have limited time/resources to support patients with holistic needs beyond the clinical realm

As a result, clinicians often lean on social workers/nurses to direct patients for SDOH support

Potential solutions for PSPs

- Synthesizing the results from all phases of the research, the following 4 recommendations were identified to help PSPs bolster support for individuals living with gMG and SDOH barriers, each corresponding to current unmet needs.

Bolster support for individuals living with SDOH barriers

1. Expand reach and accessibility of currently offered services, including informational hotlines and educational materials
2. Improve adoption and scale of personalized "high-touch" offerings, such as nurse case managers and 1:1 patient mentoring programs
3. Establish a long-term financial commitment using innovative strategies to support diverse individuals living with gMG
4. Increase awareness of PSP offerings amongst patient advocacy groups, clinicians, nurses, social workers, and the wider gMG care community

Conclusions

- Individuals living with gMG and SDOH barriers face a complex and compounding set of challenges. Disease education, 1-on-1 "high-touch" support, and financial support were especially highlighted as persisting unmet needs. Strikingly, their awareness and current usage of existing PSPs that offer such services were low.
- Some limitations of this study should be noted. Data from this cross-sectional descriptive analysis are not intended to be comparable to the perspectives of a general population of individuals living with gMG. Additionally, longitudinal studies in a larger population are needed to further contextualize or generalize how SDOH barriers may contribute to health inequities in gMG.
- Nevertheless, our study captured one of the most diverse cohorts of individuals living with gMG in the US, and based on their robust insights, 4 clear and actionable recommendations were formulated for PSPs to consider in improving their support for individuals living with SDOH barriers. To further improve the experiences of historically marginalized individuals, researchers should continue to spotlight these communities and work together to address their specific needs.

Financial support This study was funded by argenx US Inc. (Boston, MA, USA).

Acknowledgments The authors thank the individuals living with gMG, their caregivers, and PAG representatives for participating in the study. Manisha Lali, Pratik Raj, and Snimar Snimar (ZS Associates) performed data processing and analyses. Medical writing support was provided by Mai Sato, PhD (ZS Associates) and editorial support was provided by Katherine Gora (ZS Associates) in accordance with the Good Publication Practice 2022 (GPP 2022) guidelines (https://www.ismpp.org/gpp-2022).

Disclosures Part of the material in this poster is currently undergoing peer review for publication. TH, KP, CB, and GP are employees of argenx. AELA is a Patient Education Speaker for argenx. AAH receives research support from Alexion/AstraZeneca, argenx, UCB, Immunovant, Regeneron, Cabaletta Bio, Viela Bio/Horizon, and Genentech, and has received honoraria from UCB, argenx, Alexion, Immunovant, Regeneron, and Genentech/Roche. CZ and SS are employees of ZS Associates and serve as paid consultants for argenx.

Abbreviations gMG, generalized myasthenia gravis; PAG, patient advocacy group; PSP, patient support program; SDOH, social determinants of health; US, United States.

References 1. Conti-Fine BM, et al. *J Clin Invest.* 2006;116(11):2843-2854. 2. Howard JF. Clinical overview of MG. https://myasthenia.org. Accessed July 2, 2021. 3. Jani-Acsadi A, Lisak RP. *J Neurol Sci.* 2007;261(1-2):127-133. 4. Phillips G, et al. *Front Neurol.* 2021;12:809999. 5. World Health Organization. Social determinants of health (2022). https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1. Accessed November 5, 2022. 6. Dean HD, et al. *Public Health Rep.* 2013;128(Suppl 3):1-4. 7. Ganguli A, et al. *Patient Prefer Adherence.* 2016;10:711-725. 8. Brixner D, et al. *J Manag Care Spec Pharm.* 2019; 25(7):770-779.

American Academy of Neurology Annual Meeting 2023 | April 22–27, 2023 | Boston, MA, USA