HOW SOCIAL DETERMINANTS OF HEALTH IMPACT THE MYASTHENIA GRAVIS (MG) COMMUNITY

FINDINGS FROM A NATIONAL SURVEY

A FEBRUARY 2026 REPORT BY
THE RARE DISEASE DIVERSITY COALITION (RDDC)
IN PARTNERSHIP WITH THE MYASTHENIA GRAVIS
FOUNDATION OF AMERICA (MGFA) AND THE MG COMMUNITY

TABLE OF CONTENTS

DETAILED FINDINGS

Diagnostic Journey

Insurance & Access to Treatment

Patient-Provider Communication

Housing & Neighborhood

Non-Medical Barriers to Care

Employment Status

Managing Healthcare Costs

Access to Healthy Foods

Mental Health

Rare Disease Caregiving

BACKGROUND AND METHODOLOGY

ORGANIZATIONAL BACKGROUND AND RECOGNITIONS

About the Rare Disease Diversity Coalition (RDDC)

The Rare Disease Diversity Coalition (RDDC) is an organizational coalition launched by the Black Women's Health Imperative, dedicated to reducing health disparities and inequities within the rare disease community, particularly among historically marginalized populations. RDDC brings together experts in rare diseases, patients, caregivers, diversity and equity advocates, clinicians, researchers, and industry leaders to co-develop and advocate for evidence-based strategies that address the social, structural, and systemic barriers affecting access to diagnosis, treatment, and inclusion in research. Through targeted initiatives and coalition-driven research, RDDC aims to amplify underrepresented voices, inform policy reforms, and advance equity in all aspects of rare disease care and research.

About the Myasthenia Gravis Foundation of America (MGFA)

The Myasthenia Gravis Foundation of America (MGFA) is the leading U.S. patient advocacy organization solely dedicated to improving the lives of people living with myasthenia gravis (MG). Since its founding in 1952, MGFA has worked to create "A World Without MG" through funding research, advancing education, and supporting patients and caregivers. In addition to driving scientific discovery, MGFA is committed to addressing the broader social and structural factors that influence health outcomes — including access to care, health equity, and patient empowerment. Through its programs, community partnerships, and advocacy efforts, MGFA works to ensure that all individuals with MG have the resources, information, and support they need to achieve optimal health and quality of life.

Special Recognition of the MG Community

The following MG organizations also supported this work: Black with MG, Conquer MG, International Spanish MG Support Group, MG Association of Kansas City, MG Association of West PA, MG Corpus Christi, MG Georgia, MG Greater Houston, MG Holistic Society, MG Michigan, MG New York, MG Ohio, MG Rio Grande Valley, MG San Angelo, MG San Antonio, MG Texas, MG Wisconsin, and OwnMG.

RDDC acknowledges Links2Equity and Latina Health Collaborative for their significant contributions to this work.

The RDDC acknowledges with gratitude the generous support provided by Johnson & Johnson. This support was instrumental in enabling the design and execution of the research on social determinants of health for individuals living with myasthenia gravis. Their commitment to advancing health equity has made it possible to share these findings with the broader community.

METHODOLOGY

The RDDC and MGFA launched the nation's first Social Determinants of Health (SDOH)[0] survey specifically designed for the MG community. The purpose of this national survey was to systematically examine how SDOH—including housing stability, food security, transportation barriers, cultural competency, and financial burden—shape the experiences and well-being of individuals and families affected by MG.

To ensure a comprehensive understanding of these impacts, the survey also collected detailed demographic data, including age, gender, race, ethnicity, and education level, with a particular focus on capturing the voices of diverse and historically marginalized communities.

SurveyMonkey was selected as the survey platform for its ability to meet the Web Content Accessibility Guidelines (WCAG 2.1 AA), thereby ensuring that people with disabilities could fully participate. Recognizing the importance of community input, 23 leading MG and rare disease stakeholder organizations were asked to review and provide feedback on proposed survey questions and outcome measures. This collaborative approach ensured that the questionnaire was not only scientifically rigorous but also culturally relevant and responsive to the lived realities of the MG community.

OUTREACH AND PROMOTION STRATEGIES

To ensure inclusion and representation of individuals living with MG, we engaged the following patient advocacy organizations to validate and disseminate the survey to their members and network: Black with MG, Conquer MG, Eosinophilic & Rare Disease Cooperative, EveryLife Foundation for Rare Diseases, Hispanic Society for Rare Diseases, International Spanish MG Support Group, MGA KC, MGA West PA, MG Corpus Christi, MG Foundation of America, MG Georgia, MG Greater Houston, MG Holistic Society, MG Michigan, MG New York, MG Ohio, MG Rio Grande Valley, MG San Angelo, MG San Antonio, MG Texas, MG Wisconsin, National Organization for Rare Disorders (NORD), and OwnMG.

Following the integration of stakeholder feedback, the survey was opened for responses from May 15 to June 30, 2025. Additionally, the MG Foundation of America shared the survey with its members from September 4 to September 18, 2025. Participants were recruited using a "snowball sampling"[1] strategy due to challenges in recruiting survey respondents within rare disease populations. Partners were encouraged to share the survey information with MG patients and caregivers in their networks. To facilitate promotion, RDDC crafted a comprehensive social media toolkit, which included sample social posts, graphics, and newsletter-ready content for partner organizations.

---

0 This report addresses the social and environmental factors that can impact population health. Recognizing the federal government's renewed interest in the upstream drivers of health through programs like "Make America Healthy Again," this survey identifies factors that affect the health of the MG population.

1 Snowball sampling is a non-probability research method where initial participants refer new subjects from their social networks, creating a chain-like recruitment process. This helps researchers find and study hard-to-reach or hidden populations, like marginalized groups or those with rare conditions, growing the sample like a snowball rolling downhill.

Additionally, RDDC issued a targeted email newsletter announcing a gift card incentive for survey completion, incentivizing participation.
Recognizing the value of direct community engagement, RDDC and its partners also conducted in-person outreach at MG Holistic community health fairs in the Bronx, New York, and Atlanta, Georgia, where they collected responses directly from patients and caregivers. MG Holistic further supported participation by distributing a dedicated email blast to its membership base, ensuring widespread awareness of the survey opportunity.

RESPONDENT DEMOGRAPHICS AND DIVERSITY

The national survey garnered responses from 371 MG patients and 39 caregivers across 35 states (Appendix – Chart 1), yielding valuable insights into the lived experiences, diagnostic journeys, and barriers to care encountered by those affected by MG.

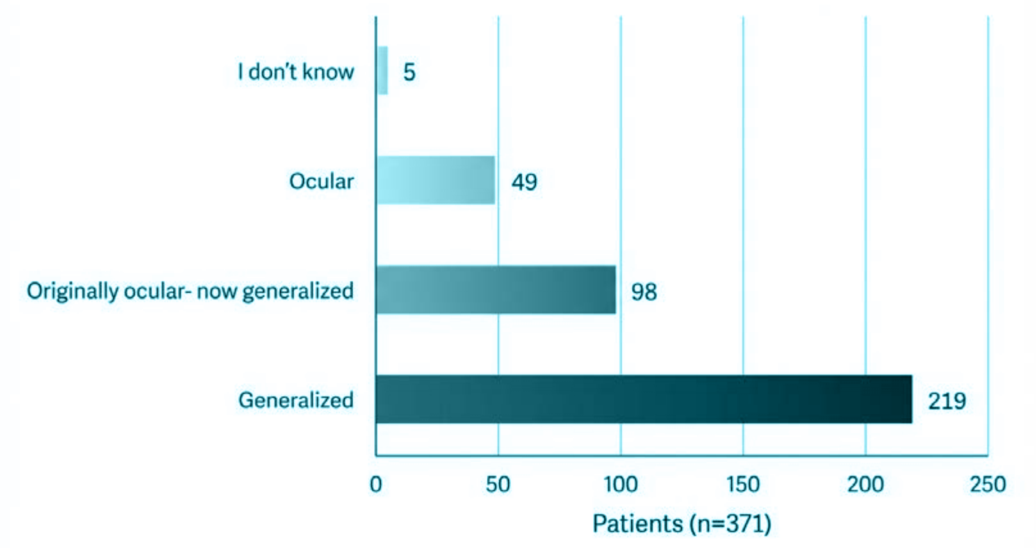
Because of this robust engagement with MG advocacy organizations nationwide, the survey also garnered strong participation from people with diverse racial and ethnic backgrounds, gender identities, and income levels.

- Of the 410 total respondents, nearly half (44%) identified as members of ethnic minority groups, compared to 56% who identified as White (Appendix – Chart 2).
- Most respondents were women between the ages of 45 and 54. (Appendix – Chart 3)

Despite a majority of respondents reporting at least partial higher education (some college or technical school, or completing college or advanced degrees), 46% (171 respondents) reported annual household incomes between $25,000 and $64,999 (Appendix – Chart 4).
The survey also reflected the diverse nature of MG. When the 371 patients were asked about their diagnosis:

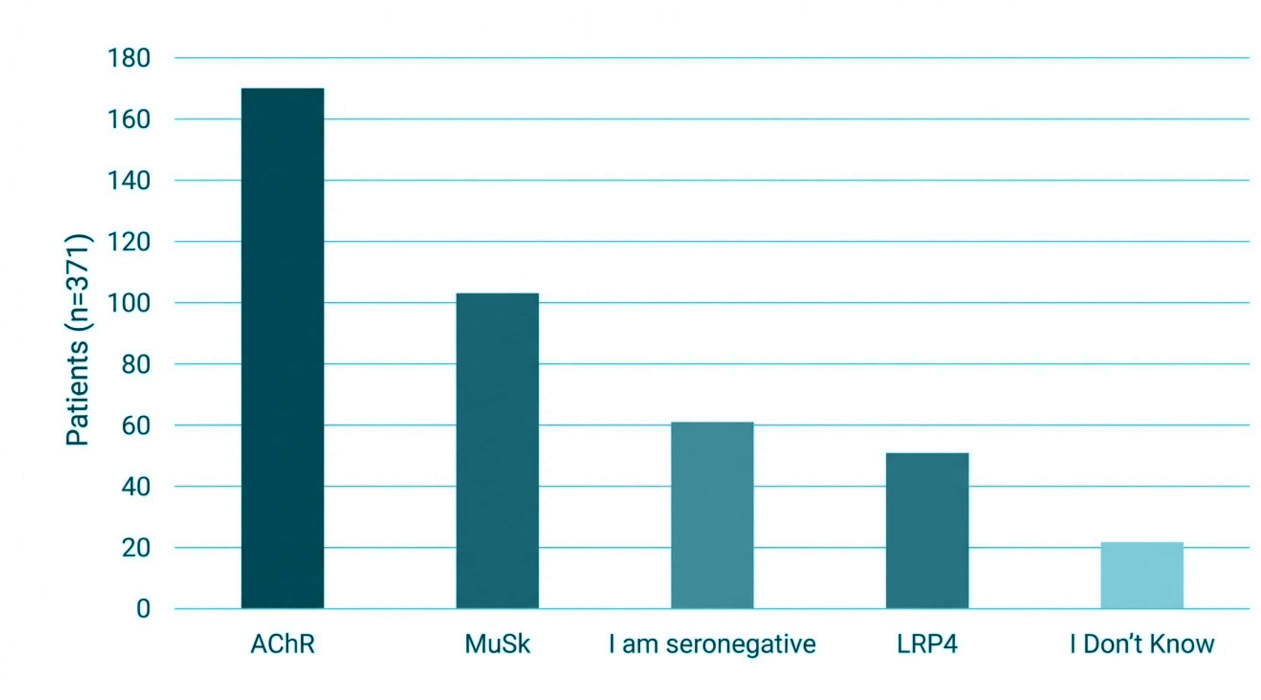
- 219 reported Generalized MG
- 98 reported progression from Ocular to Generalized MG
- 49 reported Ocular MG
- 5 were unsure of their MG type.

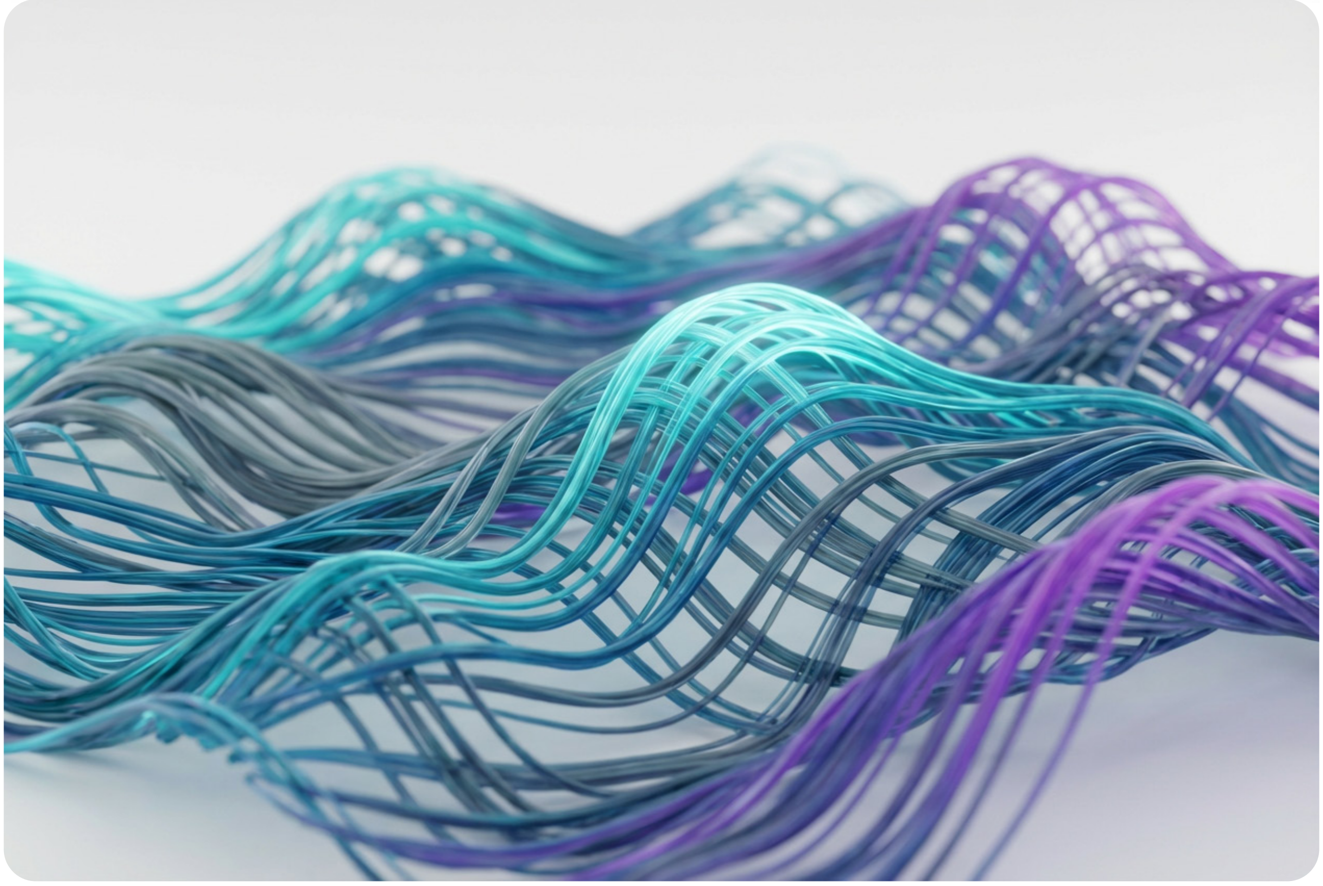
Chart 1: What type of MG do you have?



The survey also captured MG antibody subtypes for patients: acetylcholine receptors (AChR), muscle-specific kinase (MuSK), lipoprotein-receptor-related protein 4 (LRP4), seronegative, and "don't know." Some patients reported more than one antibody type.

Chart 2: Patients with positive antibodies by MG Type. (Patients selected all that applied.)





EXECUTIVE SUMMARY

The Rare Disease Diversity Coalition (RDDC), in partnership with Links2Equity and the Latina Health Collaborative, conducted the first nationwide Social Determinants of Health (SDOH) survey specifically designed for the Myasthenia Gravis (MG) community. The purpose of this national survey was to identify how individuals living with MG are affected by SDOH and to develop patient-centered interventions that meet the needs of this community. This collaborative effort engaged 23 MG and rare disease organizations in the survey's design, ensuring community-informed measures and broad dissemination.

Between May 15 and September 18, 2025, the survey received a total of 410 responses (371 MG patients and 39 caregivers) across 35 U.S. states. Nearly half (44%) identified as members of ethnic minority groups, reflecting RDDC's commitment to inclusivity and representation. Most respondents were women (predominantly ages 45–54), and 46% reported household incomes between $25,000 and $64,999. The diversity of respondents provides a robust snapshot of the MG community's experiences across demographic, socioeconomic, and geographic lines.

RESPONDENT CHARACTERISTICS

Total Respondents	**410 (371 patients, 39 caregivers)**
States Represented	35
Minority Respondents	44%
Median Age Range	45–54
Median Household Income	$25,000–$64,999
Delays in Diagnosis	47% required consultations with at least **three physicians** before receiving an accurate **diagnosis**

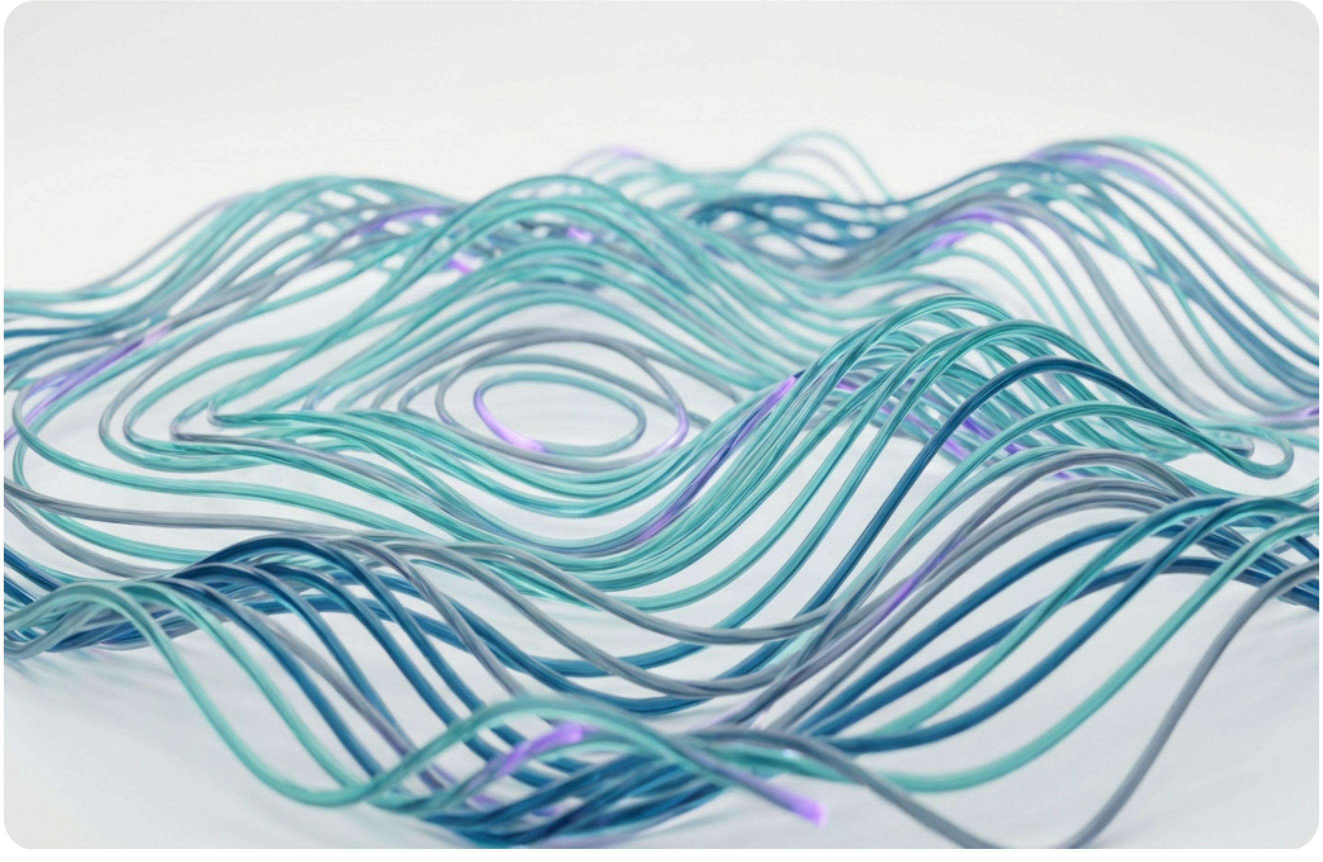
Key Findings

- **The diagnostic journey for MG patients remains long and inequitable:** Nearly half of MG patients reported significant diagnostic delays, with 39% waiting five years or more for an accurate diagnosis. Many experienced multiple misdiagnoses. The complexity and rarity of MG contribute to these barriers, underscoring the need for improved clinician education and care coordination.
- **Insurance coverage alone has not eliminated barriers to care:** Most patients are covered by public insurance (Medicare/Medicaid), yet face substantial hurdles getting access to treatment, including step therapy requirements and frequent insurance denials for necessary treatments. One-third reported that insurance did not cover critical treatments, and many faced high out-of-pocket costs.
- **Lack of support for Social Determinants of Health drives poor outcomes:** Respondents reported widespread challenges related to housing instability, food insecurity, and lack of reliable transportation, all of which negatively impacted health outcomes. Nearly half of patients in the survey rent their homes, one in three (37%) worry about running out of food, and one in four (26%) experienced care delays due to transportation barriers.

- **Financial strain and employment challenges are pervasive:** MG significantly affects employment, with only 28% of respondents able to work full-time and 17% unable to work due to poor health. The vast majority (75%) of patients reported having financial difficulty paying at least one healthcare cost, including medications, equipment, or medical bills.
- **MG patients and caregivers face high levels of stress and social isolation:** More than half of MG patients reported feeling stressed or lonely "always" or "usually." While 63% said they could access mental health services, many emphasized the need for more comprehensive mental health and peer support. Among caregivers, over half (53%) felt stressed or overwhelmed.
- **Caregivers shoulder substantial burdens:** Most caregivers provide substantial weekly support, 21 to 40 hours per week, often with little formal training. Many face their own mental and physical health challenges in managing the unpredictable nature of MG.

Recommendations from the MG Community

- Expand mental health resources and support group access immediately upon diagnosis.
- Improve education for healthcare providers and emergency clinicians on MG diagnosis and management.
- Advocate for greater recognition of MG as a qualifying condition for disability benefits and workplace accommodations.
- Develop a national MG specialist network and improve insurance coverage for MG-specific treatments and supportive services.



DETAILED FINDINGS

DIAGNOSTIC JOURNEY

Many rare disease patients and their families face a long and difficult journey to receive an accurate diagnosis and access to treatment. The symptoms of MG frequently mimic those of other neurological or autoimmune conditions—such as stroke, amyotrophic lateral sclerosis (ALS), or Lyme disease—which can lead to misdiagnoses and significant diagnostic delays.

Chart 3: How long did it take to get the correct diagnosis after your first symptoms?

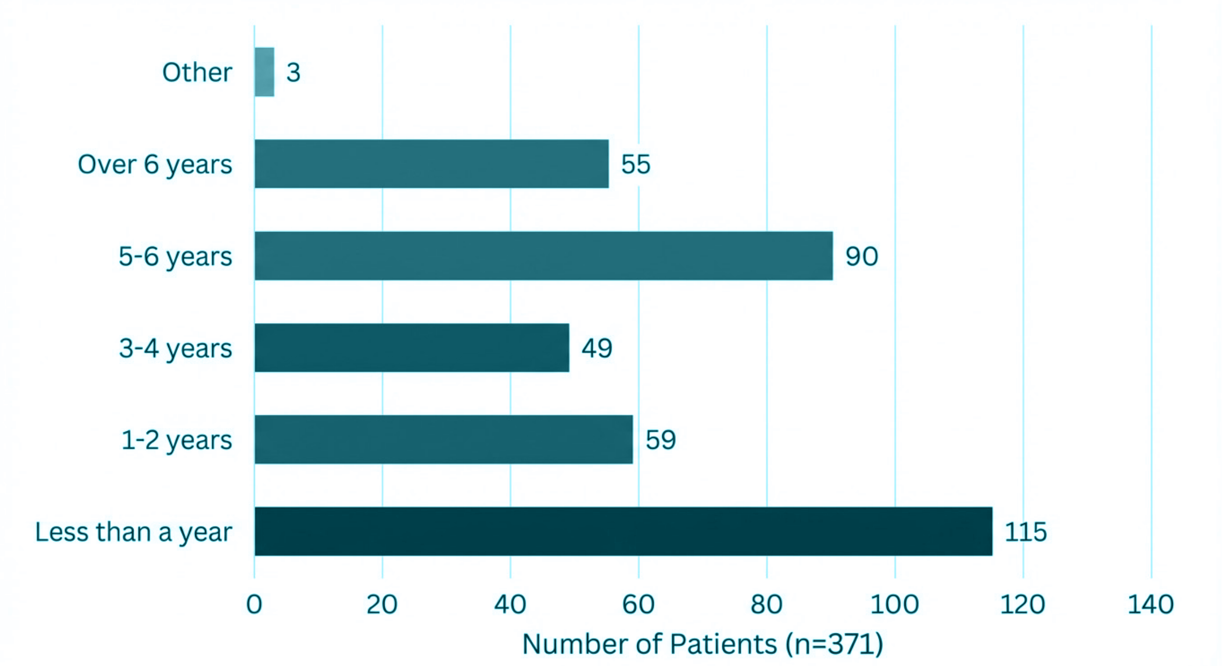
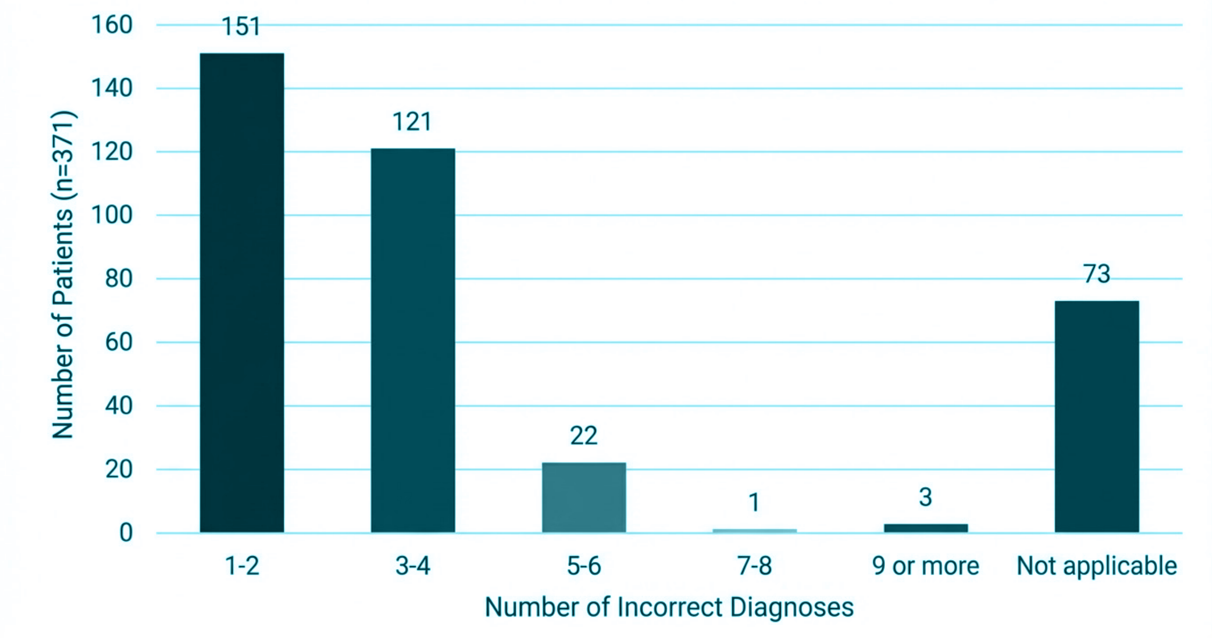


Chart 4: How many incorrect diagnoses did you receive prior to getting the right one? (n=371)



Key Findings from the Survey

"Being seronegative means I am limited in the treatments I can access and how much doctors believe me when I describe my symptoms." – Patient

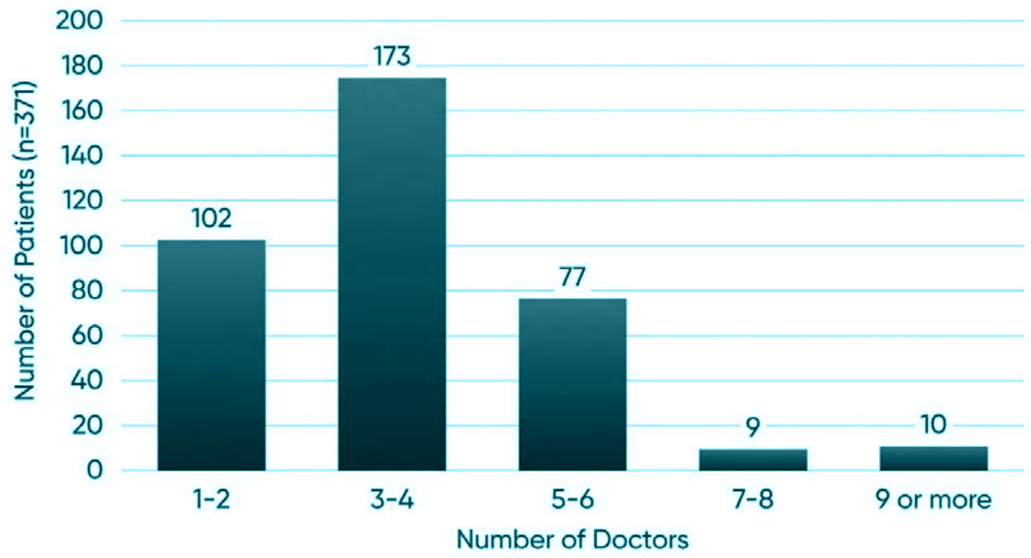
Diagnostic delays are common. Previous research has found that the average time for accurate diagnosis is more than 5 years for rare disease patients. Survey results reveal a stark divide for MG patients:

- 174 (47%) of respondents received an accurate diagnosis either "less than a year" or within "1–2 years" of symptom onset.
- 145 (39%) of respondents waited "5–6 years" or "more than 6 years" for an accurate diagnosis.
- 49 (13%) were accurately diagnosed within 3–4 years of symptom onset.

Multiple misdiagnoses are the norm. For most patients, getting to the right diagnosis requires face time with multiple physicians.

- 151 patients (41%) received "1–2 incorrect diagnoses"; an additional 121 patients (33%) received "3–4 incorrect diagnoses" before getting the right one.
- 26 patients (7%) received "5 or more incorrect diagnoses." Only 73 patients (20%) reported no history of misdiagnosis.
- 269 patients (73%) needed to see at least three doctors before getting the right diagnosis, and 19 patients needed to see 7 or more doctors.

Chart 5: How many doctors did you see before getting the correct diagnosis? (n=371)



Patient Voices

Open-ended survey responses highlighted the need for better coordination across specialists and primary care providers to improve health outcomes:

- *"Need more awareness and better education for primary care doctors."*
- *"Better coordination between neurologists and primary care doctors would help avoid mixed messages and treatment delays. I personally went through multiple misdiagnoses."*

INSURANCE & ACCESS TO TREATMENT

Insurance companies have authority to make medical coverage decisions that can significantly impact rare disease patients' access to healthcare, affecting both the quality and timeliness of care for patients. Selecting the right health insurance policy requires a thorough understanding of the benefits a patient will use, such as coverage for specialists, diagnostic testing, and off-label treatments. Rare diseases can be expensive to manage, with costs for therapies, medications, and specialized equipment not always covered by insurance.

Chart 6: What is your primary insurance type? (Patients selected all that applied.)

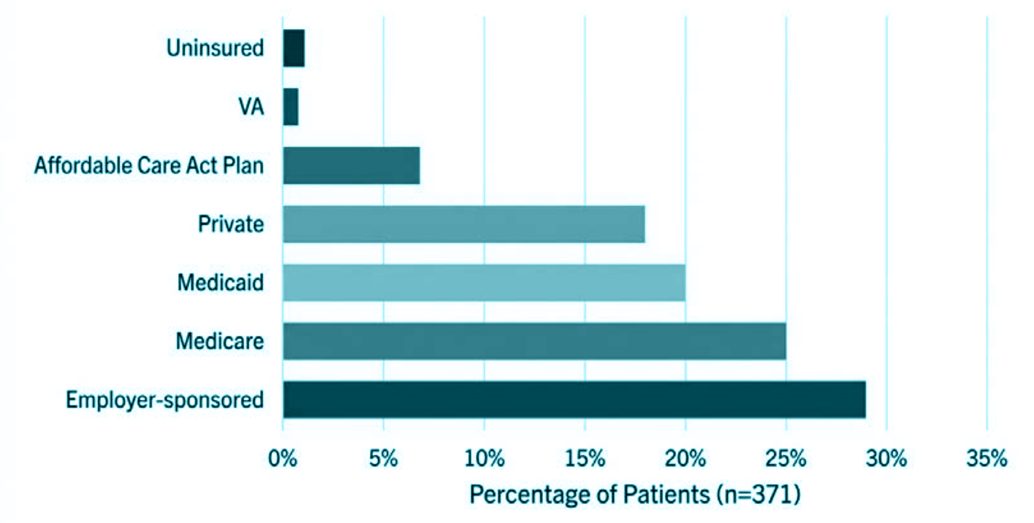


Chart 7: Did you get the following treatments when needed? (Respondents selected all that applied.)

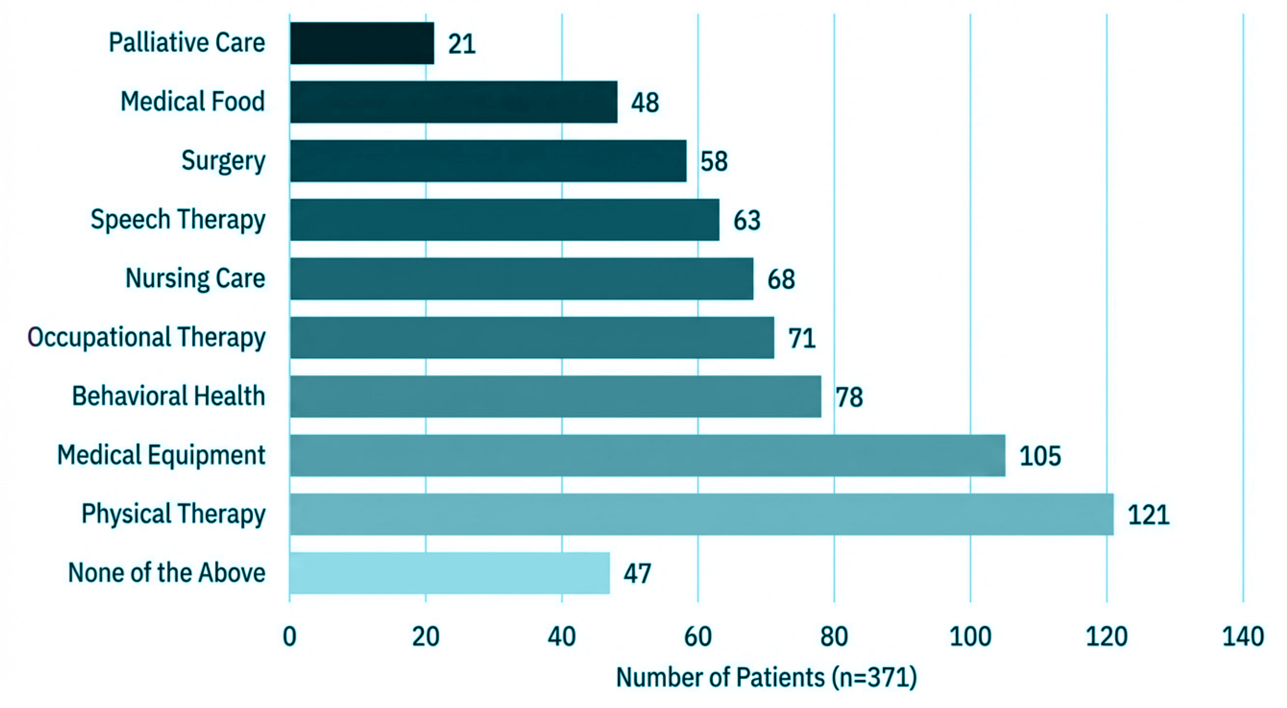
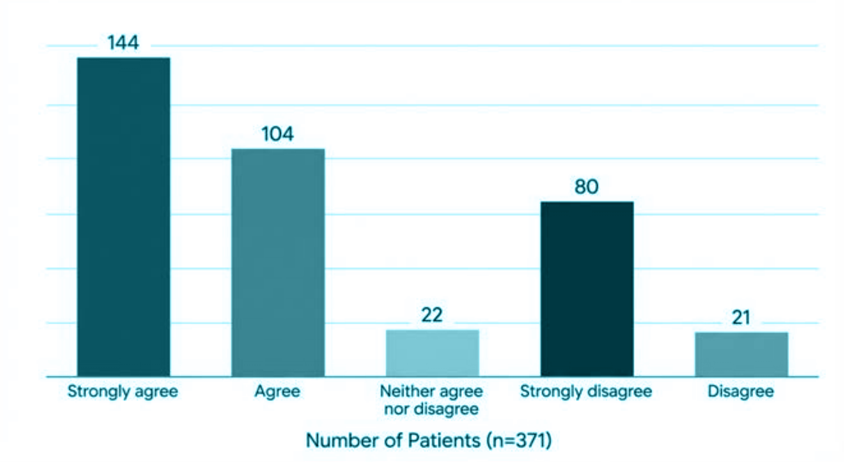


Chart 8: Did your insurance cover the treatments you needed after diagnosis?



Key Findings from the Survey

"Insurance coverage is a challenge because I am seronegative. There is a lack of support and knowledgeable resources." – Patient

Most patients are covered by Medicare or Medicaid.

When combined, 45% of patients use Medicare, Medicaid, or both (dual eligible enrollees).

- 29% are covered by employer-sponsored insurance.
- 19% are covered by private insurance.
- Only 7% are covered by an Affordable Care Act plan.
- Small percentages are covered under the VA (1%) or are uninsured (1%).

Most patients, but not all, can get additional treatments covered by health insurance.

Many rely on additional treatments such as physical therapy, occupational therapy, or medical equipment to manage their MG.

- When combined, 67% "agreed" or "strongly agreed" that their insurance covered additional treatments.
- However, nearly one-third (28%) of patients "disagreed" or "strongly disagreed" that insurance covered needed treatments.

Most patients faced administrative hurdles like "step therapy."

Step therapy is a process where insurance companies can require a patient to try a lower cost prescription drug or treatment before "stepping up" to a similar-acting, but more expensive drug or treatment.

- 55% were required to go through step therapy before accessing MG-specific treatments.
- 39% were not required to go through step therapy.
- 6% were unsure.

Patient Voices

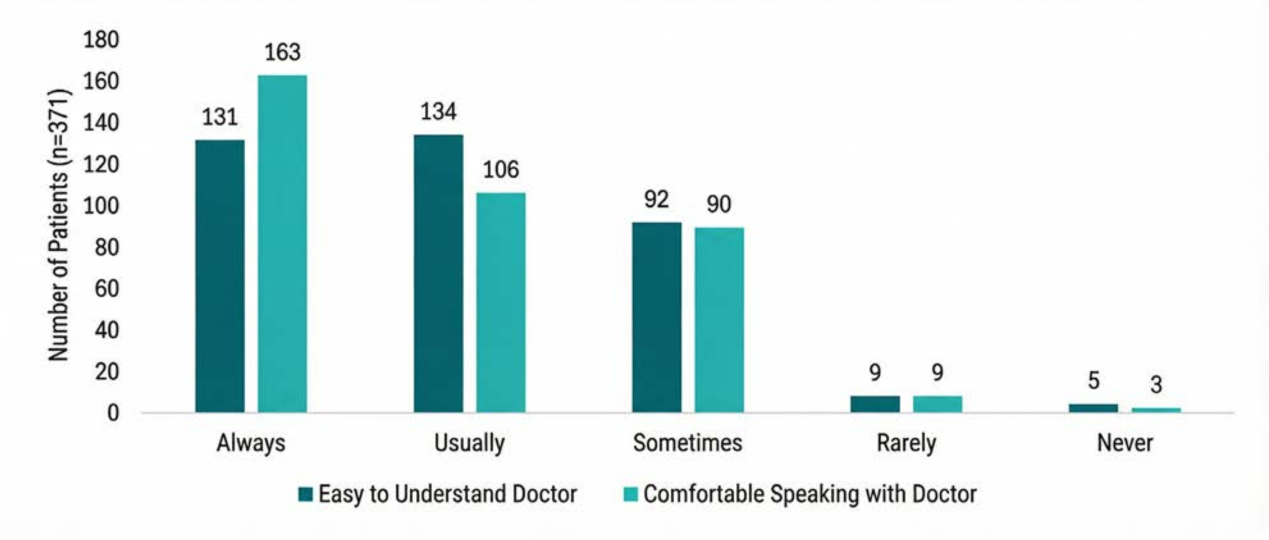
Open-ended survey responses highlight how patients navigate access to care through health insurance:

- *"I had to fail multiple treatments before getting MG-specific medications."*
- *"Medical providers treat me in a discriminatory manner, and health insurance does not pay for medications (and I have the best insurance available – traditional Medicare)."*
- *"My insurance company has repeatedly denied IVIG treatment...How can my insurance company dictate my treatment and not my doctor?"*

PATIENT-PROVIDER COMMUNICATION

The doctor-patient relationship is critical in supporting patients as they navigate a rare disease diagnosis and treatment plan. Using empathy and cultural competence during treatment and when educating patients about MG can improve patient outcomes by increasing patient engagement and adherence to treatment plans.

Chart 9: Patients reporting on their ability to communicate with their doctor. (n=371)



Key Findings from the Survey

"Finding the right doctor who will treat me has taken over four years." – Patient

Most patients think their doctor explains things in a way that they can understand.

- 71% of patients think their doctor "always" or "usually" explains things in a way they can understand.
- One in four (25%) find their doctor only "sometimes" explains things in a way they can easily understand.

Most patients are comfortable discussing their MG experience with their doctor.

- 73% of patients are "always" or "usually" comfortable speaking with their doctor.
- 24% of patients only "sometimes" feel comfortable speaking with their doctor.

Most MG patients are aware of clinical trials. (Appendix – Chart 5)

- 48% of patients were asked to participate in a clinical trial by their doctor.
- 40% of patients participated in clinical trials.

Patient Voices

Open-ended survey responses highlight common challenges with doctor-patient communication:

- *"Educating doctors on the heterogeneous nature of MG, that patients don't all check every box, and we don't always 'look' like we have MG."*
- *"Doctors make me feel like I'm crazy."*
- *"Although I'm positive for antibodies, I'm being told that it is in my head."*

HOUSING & NEIGHBORHOOD

Access to affordable housing is a crucial social determinant of health. Research finds that housing status has a greater impact on health outcomes than other demographic factors, drug and alcohol use, or mental health status. Housing stability, housing conditions, and the quality of the neighborhood and environment all play a critical role in achieving better health outcomes.

Chart 10: What is your current living situation? (n=371)

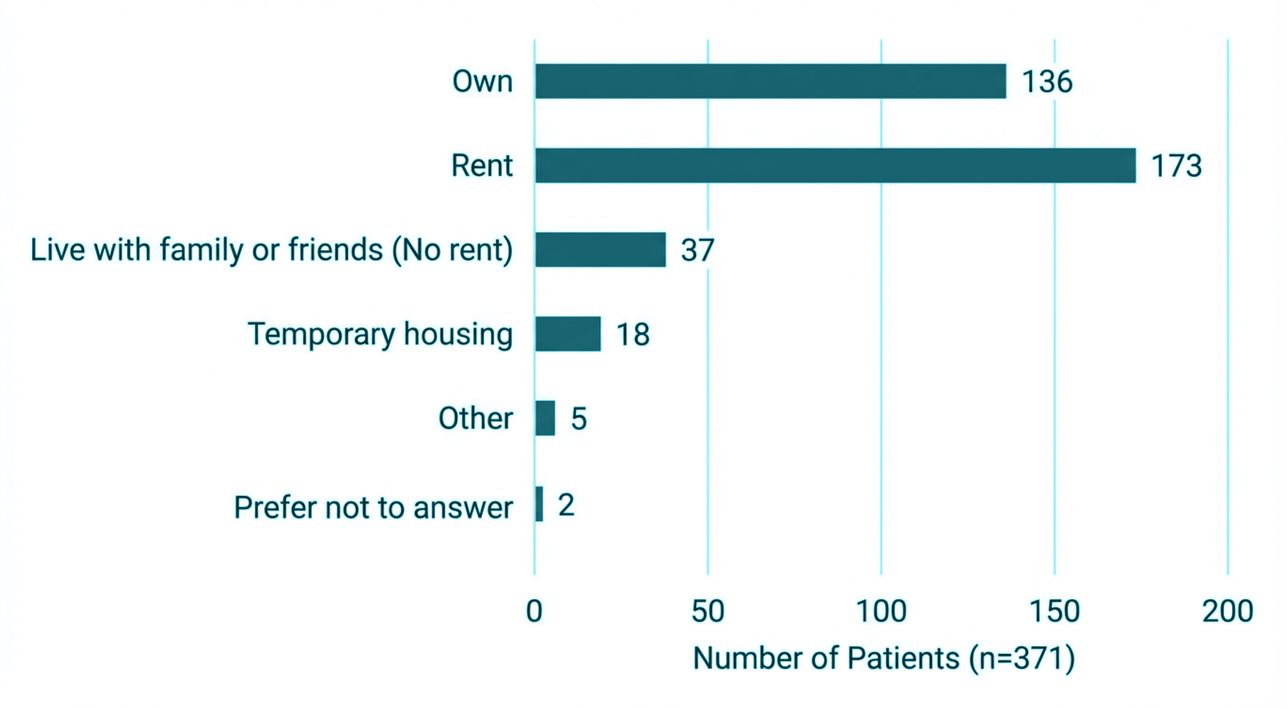
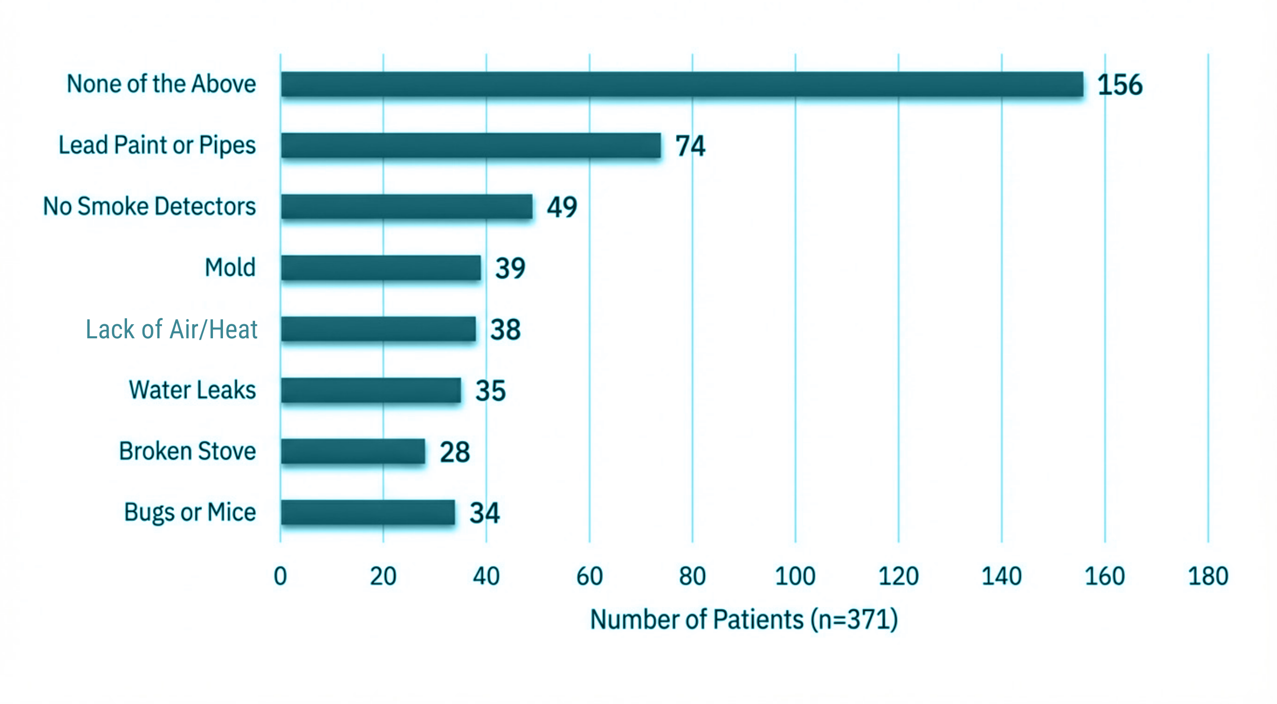


Chart 11: Do you have problems with any of these in your home?
(Patients selected all that applied.)



Key Findings from the Survey

Half of MG patients are renting their home. Patients who lived with family or friends did not have the option to indicate whether their friends or family owned the home or rented. "Temporary housing" included patients who were in a skilled nursing facility.

- 37% of patients own their home.
- 47% of patients are renting a home.
- Approximately 10% of patients live with family or friends (without paying rent).
- 6% of patients are in temporary housing, preferred not to say, or responded "other".

Most MG patients feel safe in their neighborhood.

- 239 patients (64%) "always" feel safe in their neighborhood.
- 120 patients (32%) feel safe only "sometimes."
- 12 patients (3%) said they "don't feel safe" in their neighborhood.

Most patients experience at least one problem with housing.

The majority of patients (58%) reported having at least one problem related to housing:

- 74 patients reported having issues with lead paint or pipes. This is nearly 20% of all patients.
- 49 patients have missing smoke detectors.
- 39 patients have problems with mold.
- 38 patients lack central air/heat.
- 35 patients have water leaks.
- 28 patients have broken stoves.
- 34 patients have problems with bugs or mice.

Only 156 of the 371 patients reported no problems with housing.

- This represents less than half (42%) of all MG patients.

Patient Voices

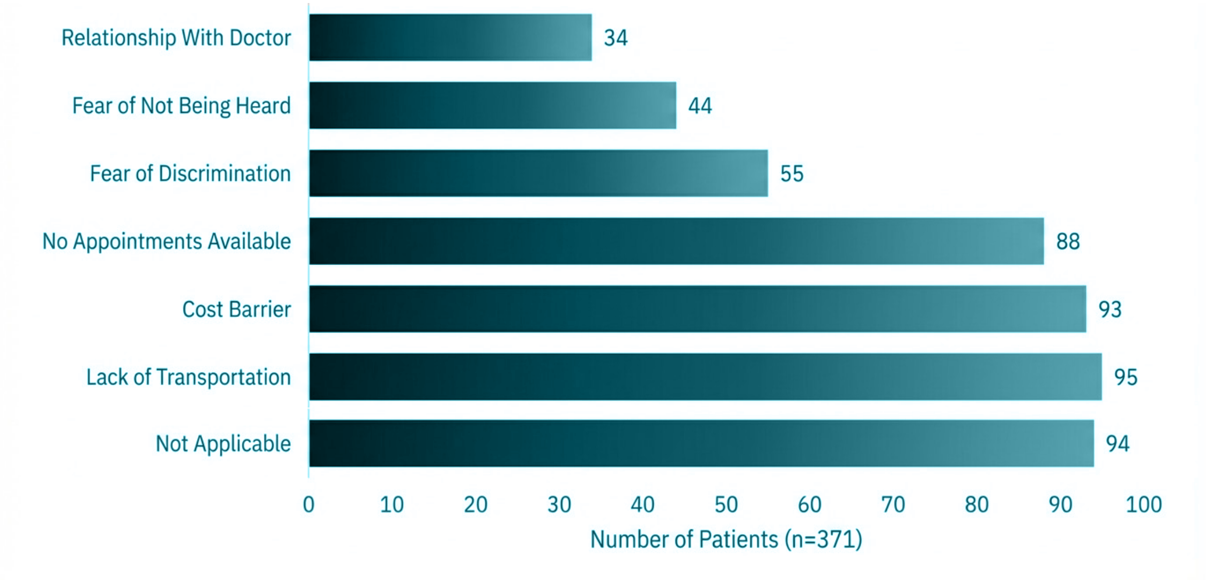
Open-ended survey responses emphasize the challenges related to housing conditions MG patients face:

- *"I very recently found possible mold exposure."*
- *"I have no air conditioning."*
- *"We have the occasional problem with bugs and mold but that's normal for the Miami area."*
- *"… Live in a high wildfire area and fear I would not be able to evacuate. Always try to leave early."*
- *"Not able to make the repairs and modifications to my home."*
- *"Need a list of contractors that can do some work either pro-bono or at very reduced rates."*
- *"…I live in a building for individuals with disabilities and seniors. I receive government assistance programs."*

NON-MEDICAL BARRIERS TO CARE

Non-medical barriers to care encompass a range of challenges beyond direct medical costs and treatments. These include financial burdens, transportation, availability of specialists, systemic discrimination, and unconscious provider bias.

Chart 12: In the past year, have you delayed or avoided medical care due to:
(Patients selected all that applied.)



Key Findings from the Survey

Most patients with MG (276 patients or 75%) reported experiencing at least one non-medical barrier to care. Only 95 patients, or 25%, faced no barriers to care.

Most patients can receive their MG care within 60 minutes of their home. A recent survey by the EveryLife Foundation for Rare Diseases found that 39% of patients with rare diseases had to travel more than 60 minutes for care.[2] (Appendix – Chart 6)

- 35% get their MG care within 20 miles of their home.
- 51% get their MG care within 20–40 miles of their home.

Lack of transportation is the most significant barrier to care. Despite most patients being able to receive their MG care within 60 minutes of their home, 95 patients (26%) reported that a lack of transportation to medical appointments caused a delay in care.

Cost is a leading barrier to care.
93 patients (25%) reported cost as a reason for delayed care.

- *"Greatest challenge is the cost of medications, hospital visits, and therapies." – Patient*
- *"Cost of monitoring and adjusting treatments is a challenge." – Patient*

---

[2] EveryLife Foundation https://everylifefoundation.org/access-to-expert-care/

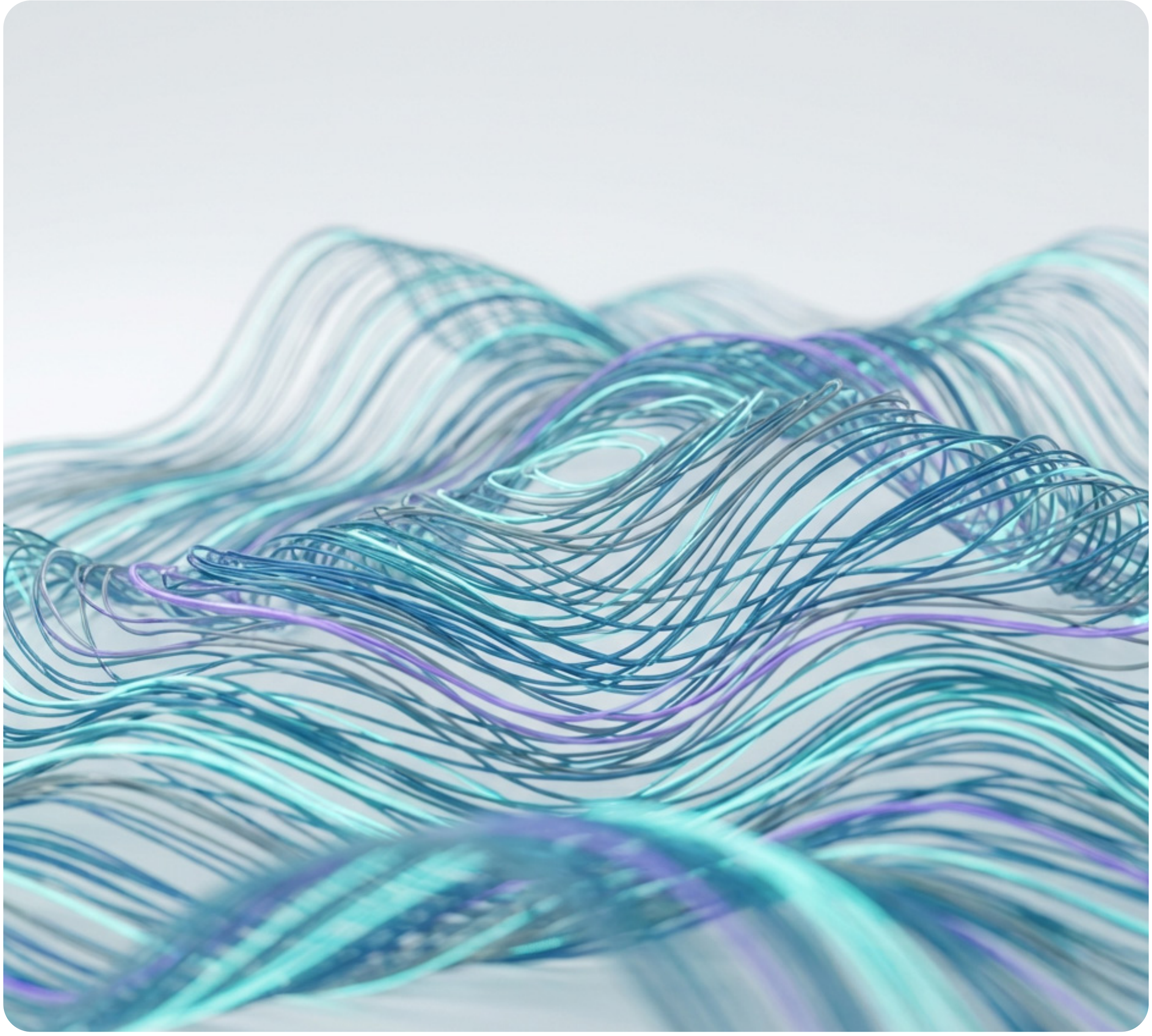
Lack of available appointments led to delayed care. 88 patients (over 24%) reported having to delay care due to a lack of available appointments.

- *"Original doctor did not listen & canceled scheduled appointment, so I had to find a different doctor." – Patient*
- *"There are long wait times for appointments." – Patient*

Patient Voices

Open-ended survey responses emphasize the geographic access barriers MG patients face:

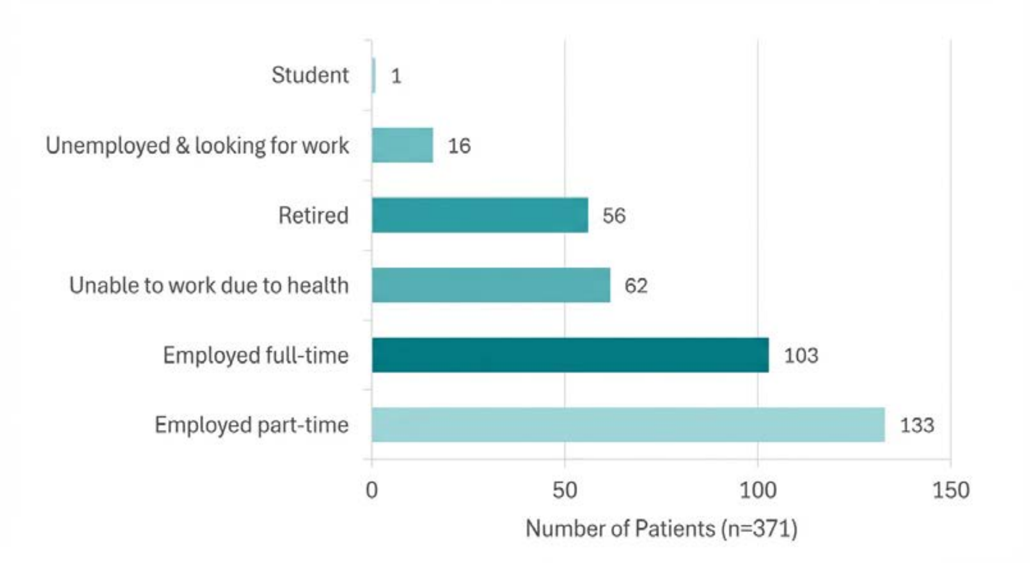
- *"I only get four round-trip rides a month with a ride service. I have not been to the bank in 5 years, and I only get to go to a store and post office one to two times a year. I must reschedule doctor's appointments constantly."*
- *"I live in a decent-sized city, but I feel like my options for doctors with appropriate knowledge of MG are limited."*
- *"The distance makes it hard, but I can discuss most things via the patient portal. In the beginning, I would have answered cost, lack of transport, fear of not being heard, and distance. Now it's more about distance."*



EMPLOYMENT STATUS

Patients with rare diseases have lower employment rates and greater disability rates than the general population.[3] Symptoms and disease management make it difficult for MG patients to work full-time without adequate workplace accommodations.

Chart 13: What is your employment status?



Key Findings from the Survey

"In less than 3 years, I've lost my job, independence, mobility, speech, and sight."
– Patient

Most MG patients (36%) are employed part-time.

- 103 patients (28%) work full-time.
- 62 patients (17%) are unable to work due to health conditions.
- 56 patients (15%) are retired.
- The remaining 17 patients (4%) are either "unemployed" or a "student."

Most patients can take paid time off from work for medical care. (Appendix – Chart 7)

- 55% of patients reported access to paid time off through sick leave or other paid leave for medical appointments.
- 12% reported they could not get time off.
- 33% of patients stated this did not apply to them.

Nearly half of MG patients (43%) receive financial or disability benefits. (Appendix – Chart 8)

- 57% do not receive financial or disability benefits.

Patient Voices

Open-ended survey responses highlight the struggles of MG patients who work:

- *"Having the ability to work – mid shift, you feel like you can't complete the shift."*
- *"Exhaustion– getting up in the morning takes a while to get moving, pushing myself to make it through work, then trying to have enough energy to make it through the evening with kids."*

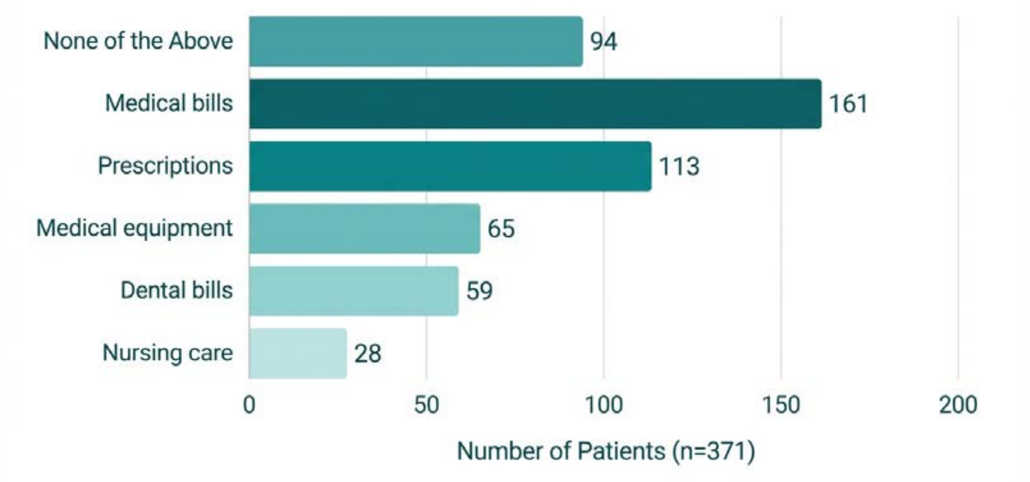
---

[3] Orphanet J Rare Dis. 2025 Apr 23; 20:193. https://doi.org/10.1186/s13023-025-03691-7

MANAGING HEALTHCARE COSTS

An NIH study indicated that healthcare costs for people with a rare disease are three to five times greater than the costs for people living without a rare disease.[4] This is often true for MG patients, who require more frequent and specialized medical services. They often face high out-of-pocket expenses for specialty tier prescription drugs and high co-pays for specialists. Other cost drivers include hospitalizations and emergency visits during a myasthenia crisis, as well as rehabilitation care. These factors can make it difficult for MG patients to pay for a variety of medical care and equipment.

Chart 14: In the past year, have you had trouble paying for:
(Patients selected all that applied.)



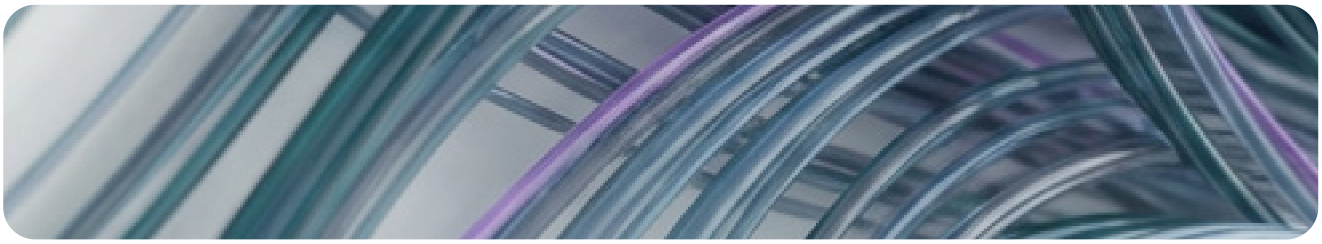
Key Findings from the Survey

"The cost of MG treatment and medication is a significant financial burden." – Patient

Only 94 patients stated that they had no difficulty paying for these healthcare services. This represents 25% of all patients (n=371).

The vast majority (75%) of patients reported having financial difficulty paying for at least one of the following healthcare costs:

- 161 patients (43%) had trouble paying their medical bills.
- 113 patients (30%) experienced difficulty paying for their prescription medicine.
- 65 patients (18%) had trouble paying for medical equipment.
- 59 patients (16%) had difficulty paying dental bills.
- 28 patients (8%) had difficulty paying for nursing care.



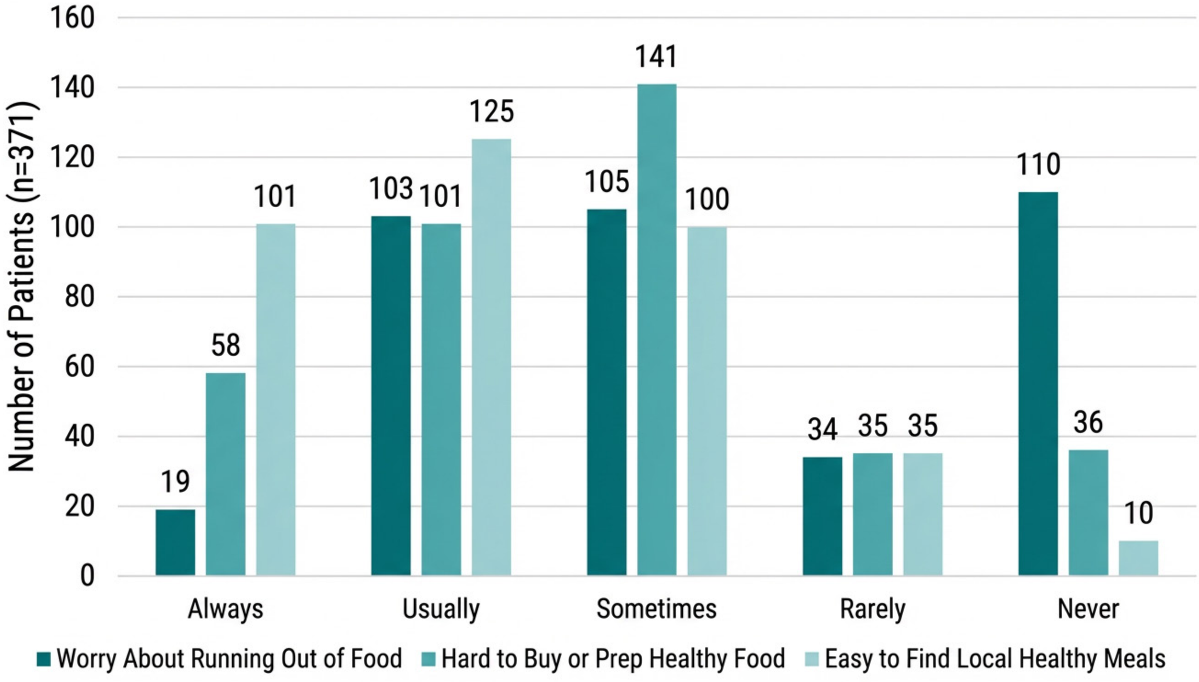
---

[4] Tisdale, A., Cutillo, C.M., Nathan, R. et al. The IDeaS initiative: pilot study to assess the impact of rare diseases on patients and healthcare systems. Orphanet J Rare Dis 16, 429 (2021). https://doi.org/10.1186/s13023-021-02061-3

ACCESS TO HEALTHY FOODS

Studies have found that access to healthy food and nutrition can improve health outcomes and lower healthcare costs.[5] Healthy foods are more expensive and less accessible in low-income communities. Food insecurity, including limited access to affordable, nutritious food, is a key SDOH that contributes to health disparities.[6]

Chart 15: Combined worry about running out of food, difficulty preparing healthy foods, and easy to find healthy meals in local stores or restaurants. (n=371 in each category)



Key Findings from the Survey

While most MG patients reported easy availability of healthy food at local stores or restaurants, the survey indicated disparities in access.

Most MG patients worry about running out of food before they can afford to buy more.

- When combined, 122 patients (32%) are either "always" or "usually" worried.
- 105 patients (28%) are "sometimes" worried.

Having MG makes it harder to buy and prepare healthy meals.

- When combined, 159 patients (43%) either "always" or "usually" have difficulty.
- 141 patients (38%) say they "sometimes" have difficulty.

It is easy to find healthy foods in local restaurants or stores.

- When combined, 226 patients (61%) stated it is "always" or "usually" easy to find healthy foods locally.
- 100 patients (27%) stated it is "sometimes" easy to find healthy foods locally.

---

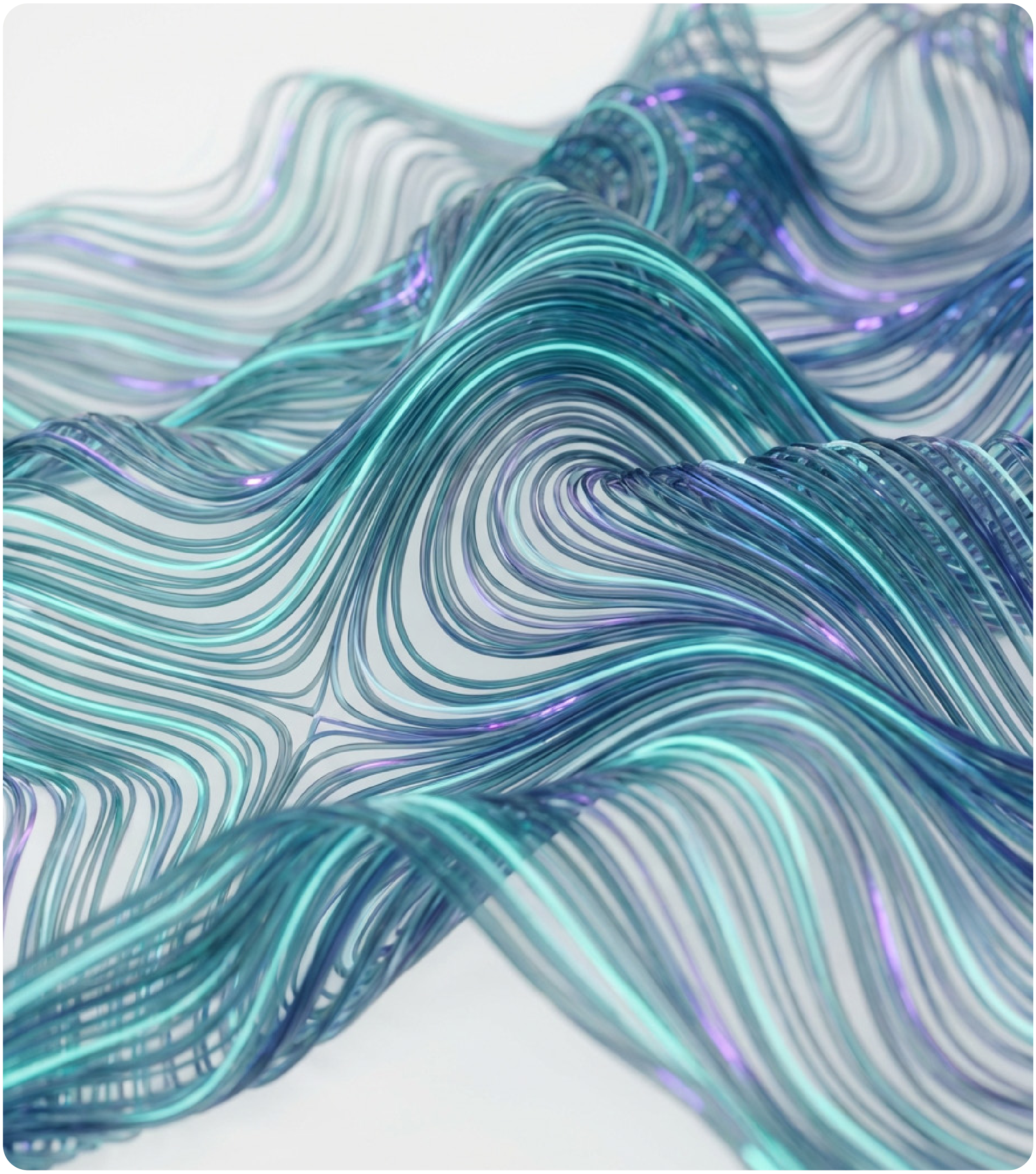
[5] https://aspe.hhs.gov/sites/default/files/documents/6ba4bbb2e9c9551355a6926f023f1585/SDOH-Evidence-Review.pdf

[6] https://www.aecf.org/blog/food-deserts-in-america

Patient Voices

Open-ended survey responses highlight the dietary challenges MG patients face due to common symptoms like trouble swallowing, trouble eating, and the risk of choking:

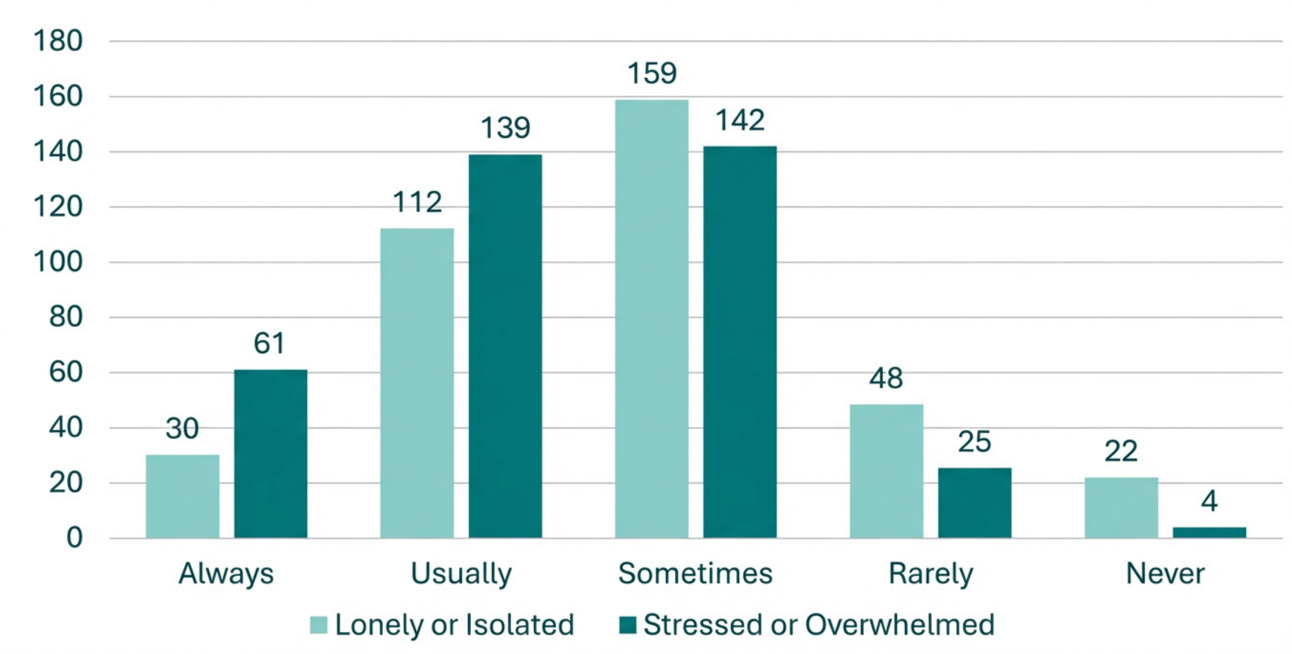
- *"Getting enough protein intake in food is a concern."*
- *"Advocate for coverage of liquid/soft food/meals (not enteral) by insurance for us because sometimes we need those because we cannot swallow anything but pureed/soups/ etc. type foods, but don't need enteral formula. But that diet is expensive to adapt to, especially if we need elemental-type diets."*



MENTAL HEALTH

Rare disease patients face unique mental health challenges stemming from the widely misunderstood nature of their rare condition and the journey to diagnosis.[7] Additional stress comes from navigating health insurance coverage of treatments and limited access to specialists and support services needed to live independently.

Chart 16: Patients asked how often they feel "stressed or overwhelmed" and "lonely or isolated"? (n=371)



Key Findings from the Survey

"MG patients and their caregivers need to be supported to get mental health services because sometimes the journey feels lonely and overwhelming."– Patient

Roughly half of all patients reported often feeling stressed or lonely.

- 142 patients (38%) either "always" or "usually" feel lonely or isolated.
- 200 patients (54%) either "always" or "usually" feel stressed or overwhelmed.

63% of patients reported accessing mental health services when needed.

- *"Counseling has been essential in managing the emotional impact of MG on me and my family." – Patient*

Most patients and caregivers rely on MG support groups.

Support groups, both local and online, play a vital role in helping to manage their MG symptoms as well as their mental health.

- *"I've found several Facebook groups for MG patients, and they've become my go-to for advice on managing symptoms and meds. The real-time feedback and empathy from other patients are things I can't get from a clinic visit." – Patient*
- *"I joined a local MG support group that meets once a month at the community center. Talking with people in person who face similar struggles has helped me open up emotionally and learn practical coping tips." – Patient*

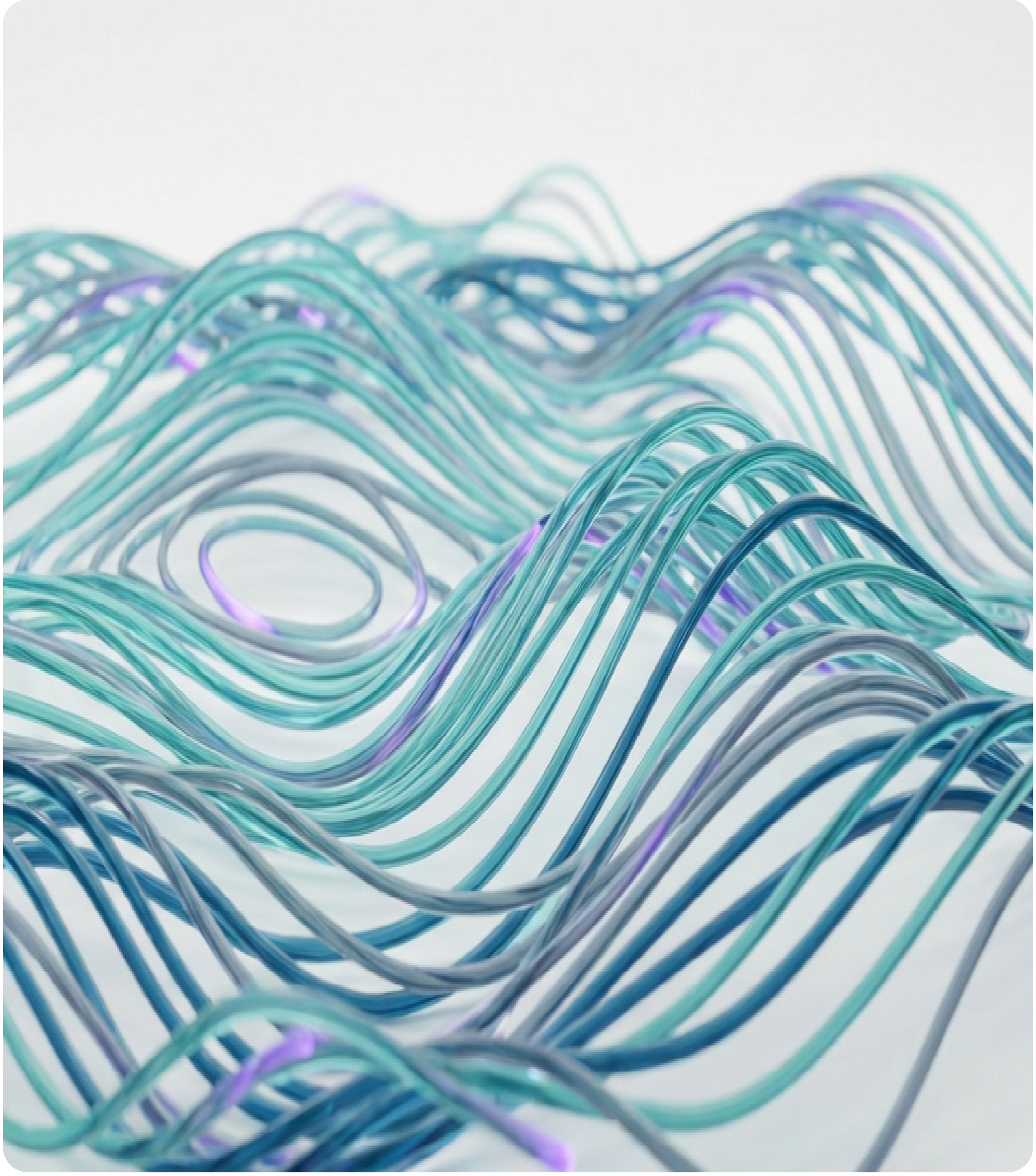
---

[7] RDDC Inequities in the Rare Disease Community Report https://bit.ly/45FDS5C

Patient Voices

Open-ended survey responses validate the need for mental health services:

- *"MG has led to social isolation, making it hard to participate in activities and connect with others."*
- *"Many people don't understand MG, leading to feelings of isolation and frustration."*
- *"Stress exacerbates MG symptoms, and finding ways to manage stress is crucial."*



RARE DISEASE CAREGIVING

Caregivers of individuals living with a rare disease are almost always family members. The inherent uncertainty surrounding rare diseases can be stressful for caregivers. Studies show that the poor mental and physical health of caregivers has a direct impact on the person they are caring for and how they provide care.[8] From in-person meetings to social media communities, patients and caregivers consistently emphasize the importance of peer connection in addressing both their physical health and mental well-being.

Chart 17: When patients need help with daily activities, do they get the help they need? (n=371)

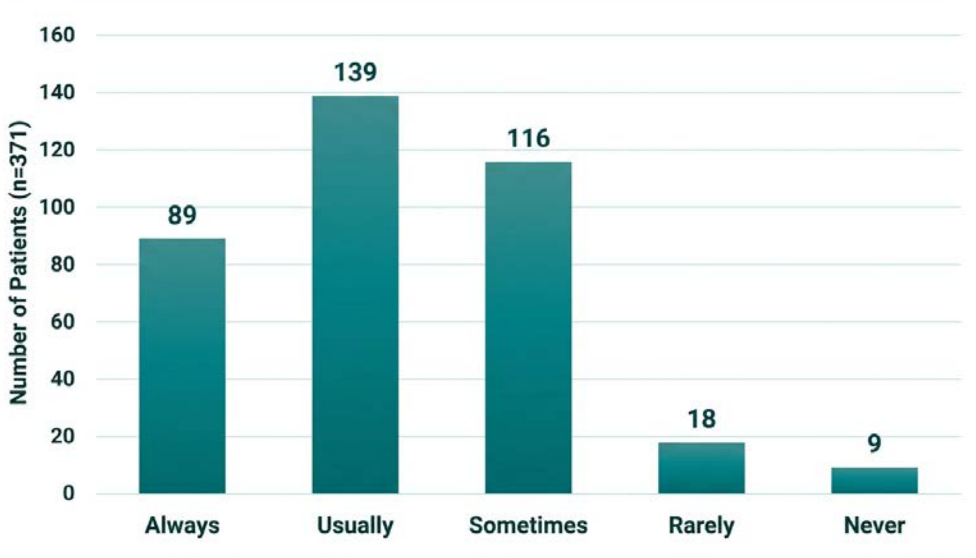
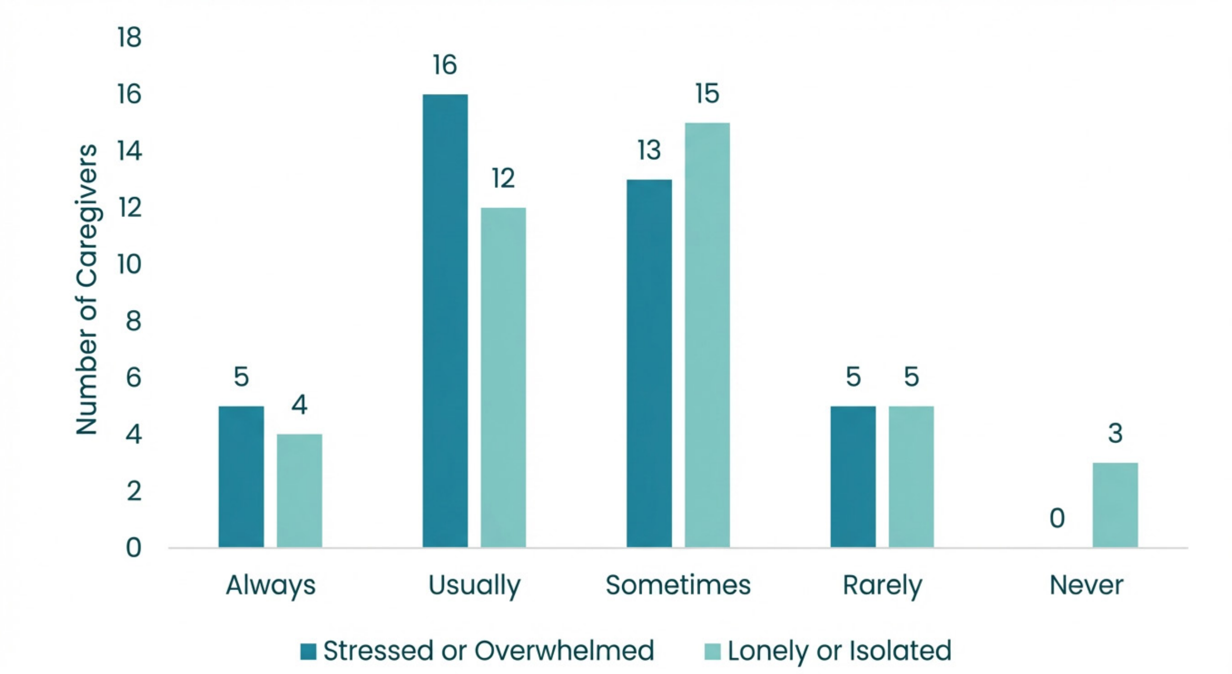


Chart 18: Number of caregivers who feel "stressed or overwhelmed" and "lonely or isolated." (n=39)



---

[8] Orphanet J Rare Dis 19, 319 (2024). https://doi.org/10.1186/s13023-024-03327-2

Key Findings from the Survey

"One of the biggest challenges as an MG caregiver is accurately grasping the changes in the patient's condition at different stages. The condition of MG is prone to fluctuations. For example, the severity of muscle weakness symptoms in patients may vary at different times of the day. It is rather difficult to accurately determine when to adjust the care methods and assist patients with rehabilitation activities." – Caregiver

Most MG patients get help with daily activities from family, friends, or support groups.

- 62% "usually" or "always" get the help they need.

Most caregivers provide care for 21 to 40 hours per week.

- Most caregivers have a college education or advanced degree.
- The average caregiver age is between 35 and 44 years old.

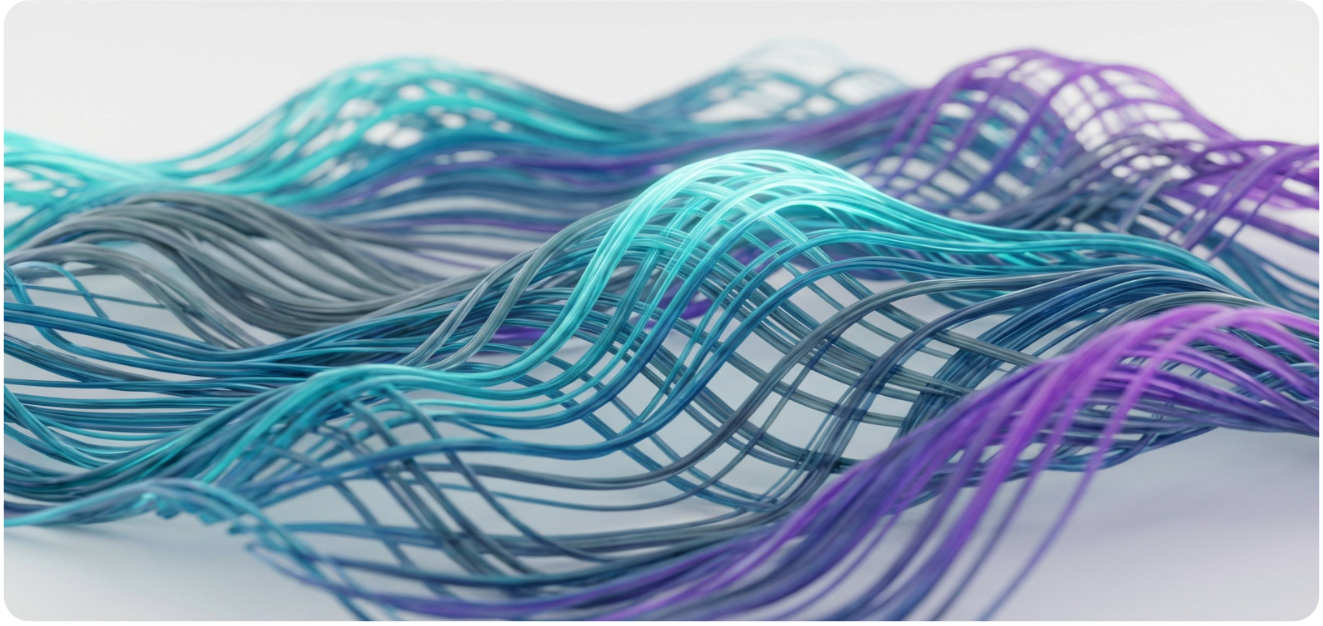
Approximately half of the caregivers surveyed expressed feeling "stressed or overwhelmed." Fewer caregivers feel "lonely or isolated."

- 21 caregivers (53%) reported that they "always" or "usually" feel stressed or overwhelmed.
- Only 16 caregivers (40%) reported that they "always" or "usually" feel lonely or isolated.

Caregiver Voices

Open-ended survey responses highlight the most significant challenges for MG caregivers:

- *"As an MG caregiver, the biggest challenge is the unpredictability of sudden illness episodes. Patients may experience myasthenic crisis without warning, affecting breathing and swallowing functions. We need to respond quickly for first aid, which brings huge psychological pressure."*
- *"Caregivers need to have certain medical knowledge and skills to accurately implement complex medication schedules (including the timing and dosage of different drugs). This is a significant challenge for non-professional caregivers."*



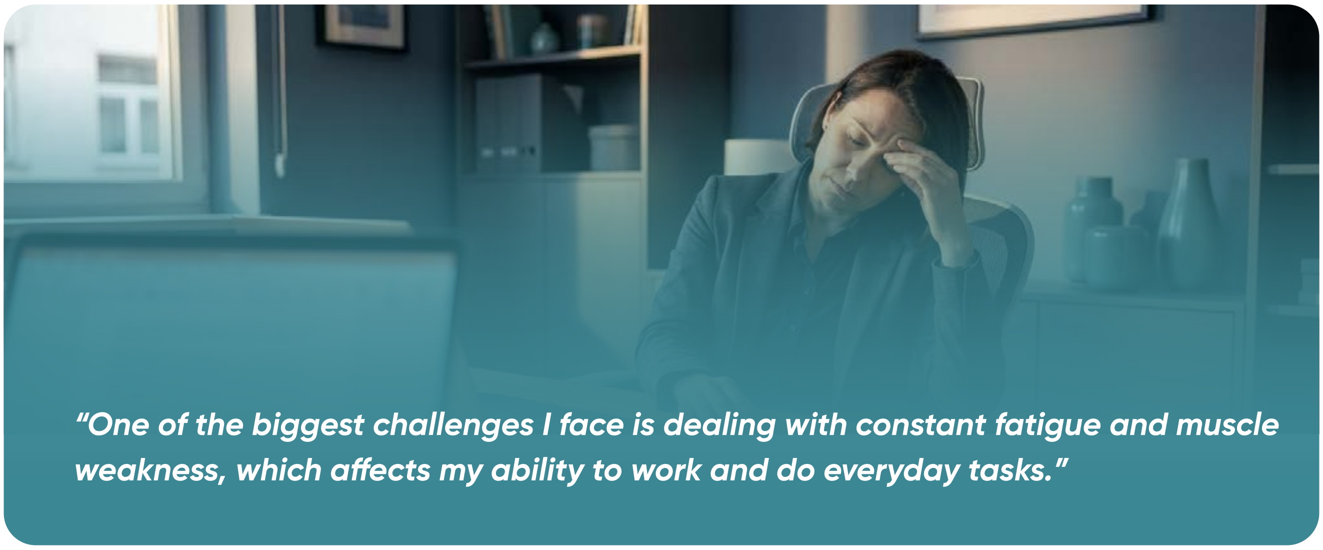
GREATEST MG COMMUNITY CHALLENGES

The survey asked open-ended questions to gather real stories in the voice of the MG community. These open-ended responses help us to understand how these challenges impact the daily lives of patients and families with MG, and provide recommendations for improved resources to support families and patients with MG.

The unpredictable nature of the disease wears on MG patients and caregivers. Many respondents listed fluctuating symptoms, unpredictable muscle weakness and fatigue, and treatment and medication side effects among the greatest challenges.

"One of the hardest things about living with MG is feeling like a stranger in your own body. Some mornings, I wake up and can't even lift my arms to comb my hair, or my eyes are so heavy I can barely keep them open. It's frustrating because the day before, I might've felt totally fine. That unpredictability wears on you — mentally and emotionally."

Most MG patients have difficulty with daily tasks. Most patients with MG struggle with everyday tasks, like cooking, cleaning, or grooming. Vision problems, such as ptosis (drooping eyelids) or double vision, can impact daily tasks like driving or reading. MG patients also struggle with speaking (dysarthria), breathing, and chewing or swallowing (bulbar symptoms), which can lead to choking risks.



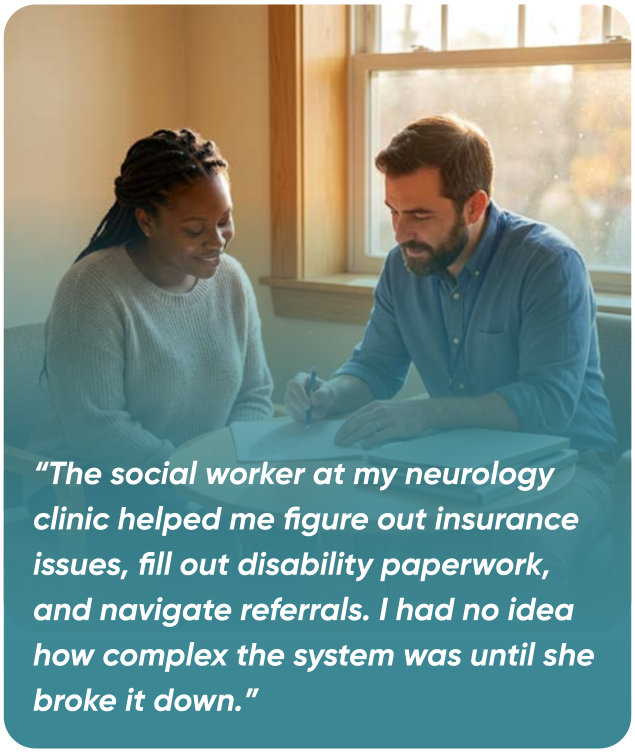
"One of the biggest challenges I face is dealing with constant fatigue and muscle weakness, which affects my ability to work and do everyday tasks."

Specialists and medical treatments are not widely available. Many patients shared their challenges with finding specialists, surgeons, and access to appropriate treatments.

“Increase access to specialized care (neuromuscular specialists are not available everywhere).”

“It’s been a challenge to find a doctor who understands MG and can provide effective treatment.”

Most struggle to access disability benefits and accommodations. Due to the functional limitations of the disease, many MG patients need help applying for disability and a range of support services—such as meal delivery, paratransit, and employment accommodations—and frequently rely on patient financial assistance programs, rehabilitation services, and legal aid.

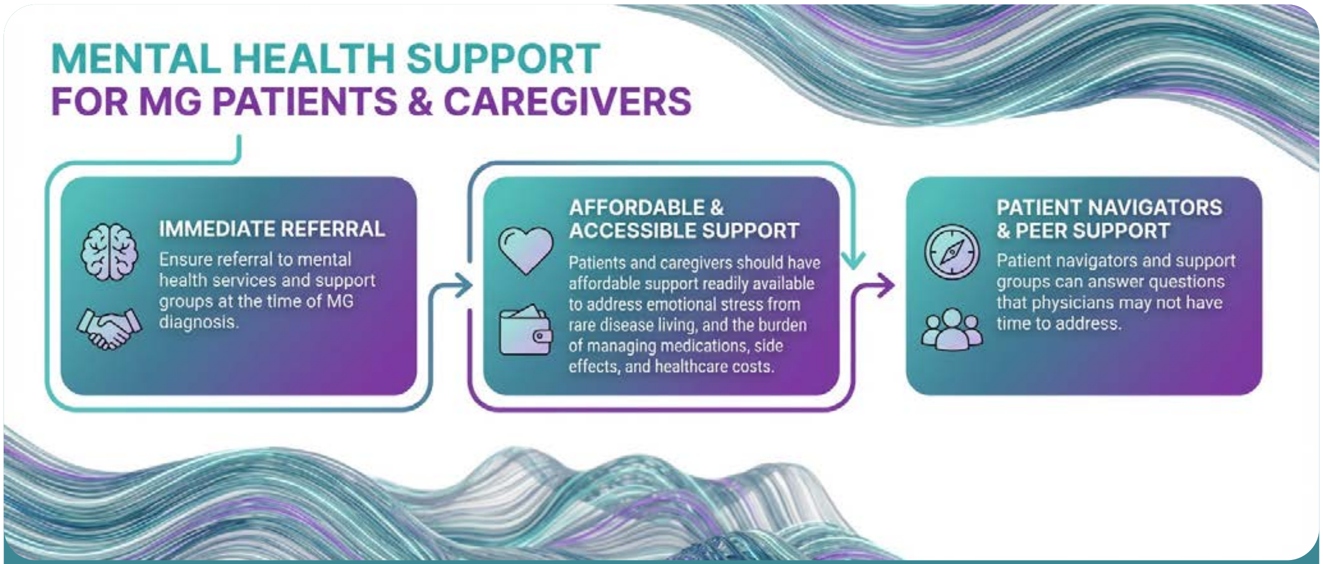


“The social worker at my neurology clinic helped me figure out insurance issues, fill out disability paperwork, and navigate referrals. I had no idea how complex the system was until she broke it down.”

“I need assistance with housing, transportation, and navigating disability benefits.”

RECOMMENDED INTERVENTIONS

The survey's findings directly inform these interventions to address barriers and patient-reported needs. They are designed to address the full spectrum of medical, social, financial, and emotional challenges faced by the MG community.



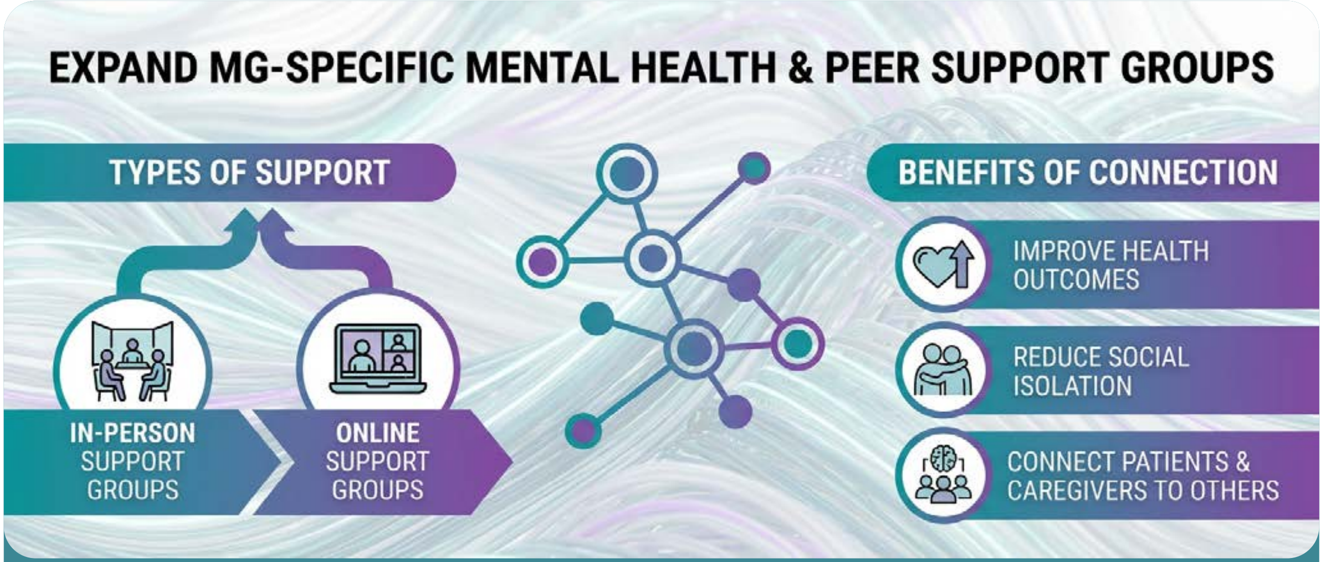
MENTAL HEALTH SUPPORT
FOR MG PATIENTS & CAREGIVERS

IMMEDIATE REFERRAL
Ensure referral to mental health services and support groups at the time of MG diagnosis.

AFFORDABLE & ACCESSIBLE SUPPORT
Patients and caregivers should have affordable support readily available to address emotional stress from rare disease living, and the burden of managing medications, side effects, and healthcare costs.

PATIENT NAVIGATORS & PEER SUPPORT
Patient navigators and support groups can answer questions that physicians may not have time to address.

Ensure immediate referral to mental health services and support groups at the time of MG diagnosis. Patients and caregivers should have affordable mental health support readily available to help address the emotional stress from living with a rare disease, and the burden of managing medications, side effects, and healthcare costs. Patient navigators and support groups can answer questions that physicians may not have time to address.



EXPAND MG-SPECIFIC MENTAL HEALTH & PEER SUPPORT GROUPS

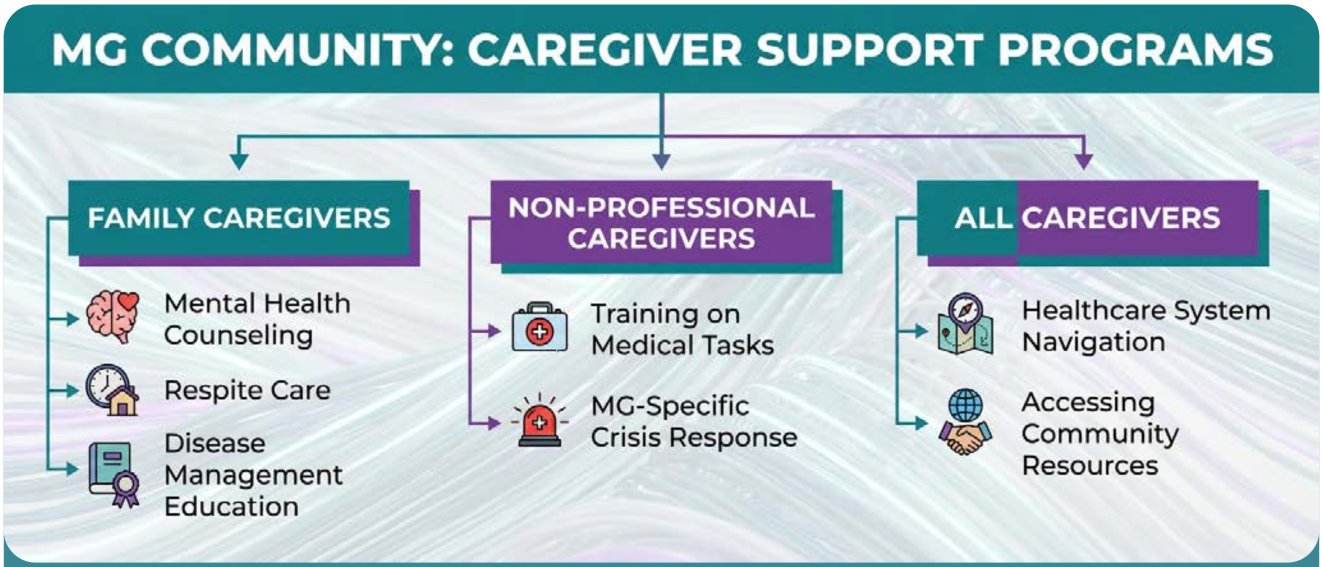
TYPES OF SUPPORT
IN-PERSON SUPPORT GROUPS
ONLINE SUPPORT GROUPS

BENEFITS OF CONNECTION
IMPROVE HEALTH OUTCOMES
REDUCE SOCIAL ISOLATION
CONNECT PATIENTS & CAREGIVERS TO OTHERS

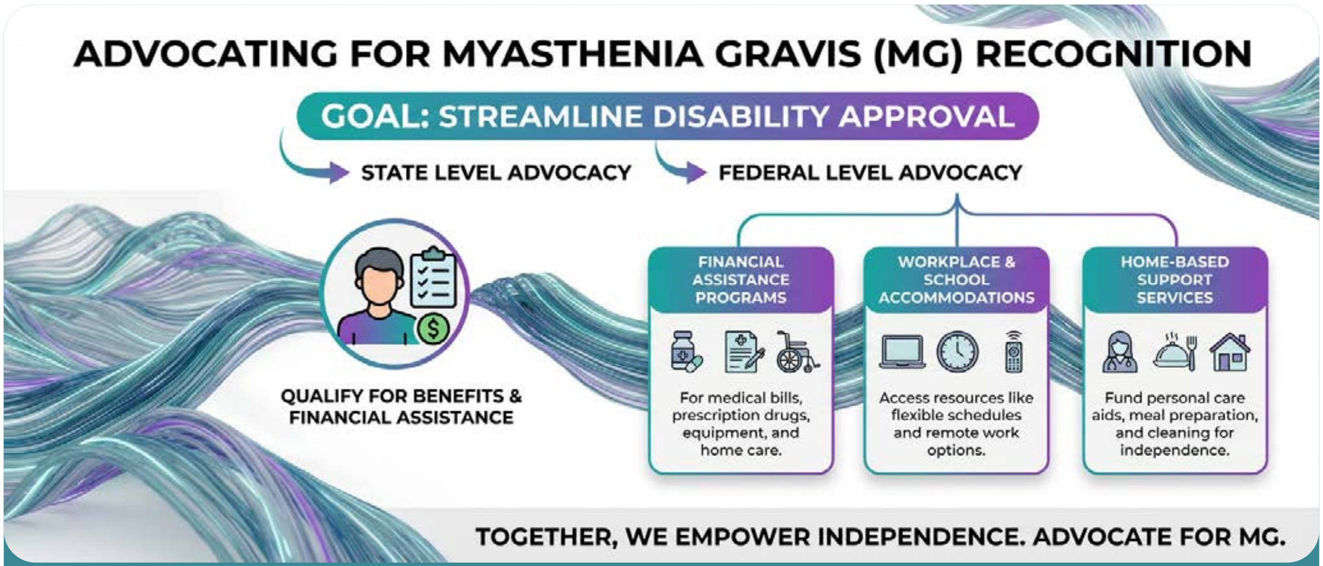
Expand the availability of MG-specific mental health and peer support groups. Both in-person and online support groups can improve health outcomes, reduce social isolation, and connect individuals to others living with a similar disease.[9]

---

[9] Family Practice, Volume 39, Issue 5, October 2022, Pages 903–912, https://doi.org/10.1093/fampra/cmac004



Provide caregiver support programs. Family caregivers in the MG community should be offered mental health counseling, respite care, and education on disease management. Non-professional caregivers should be offered training on medical tasks and emergency response for MG-specific crises. All caregivers need information on navigating the healthcare system and accessing community resources.

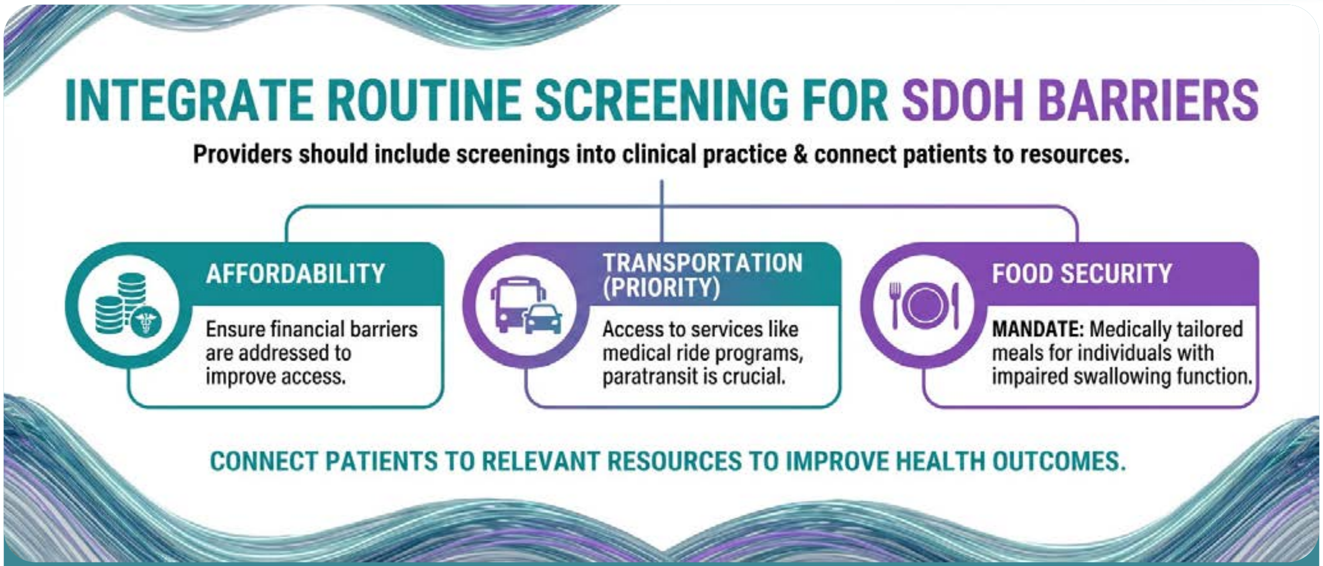


For medical bills, prescription drugs, equipment, and home care.

Access resources like flexible schedules and remote work options.

Fund personal care aids, meal preparation, and cleaning for independence.

Advocate for MG to be more broadly recognized as a qualifying disability.
There is a need for advocacy at the state and federal level to streamline the approval for MG patients to qualify for disability benefits and financial assistance. MG patients, like other rare disease patients, need financial assistance programs for medical bills, prescription drugs, equipment, and home care. Disability guidance will also help MG patients access school and workplace accommodation resources (e.g., flexible schedules, remote work options), and fund home-based support services (e.g., personal care aids, meal preparation, cleaning) to help patients maintain their independence.



INTEGRATE ROUTINE SCREENING FOR SDOH BARRIERS

Providers should include screenings into clinical practice & connect patients to resources.

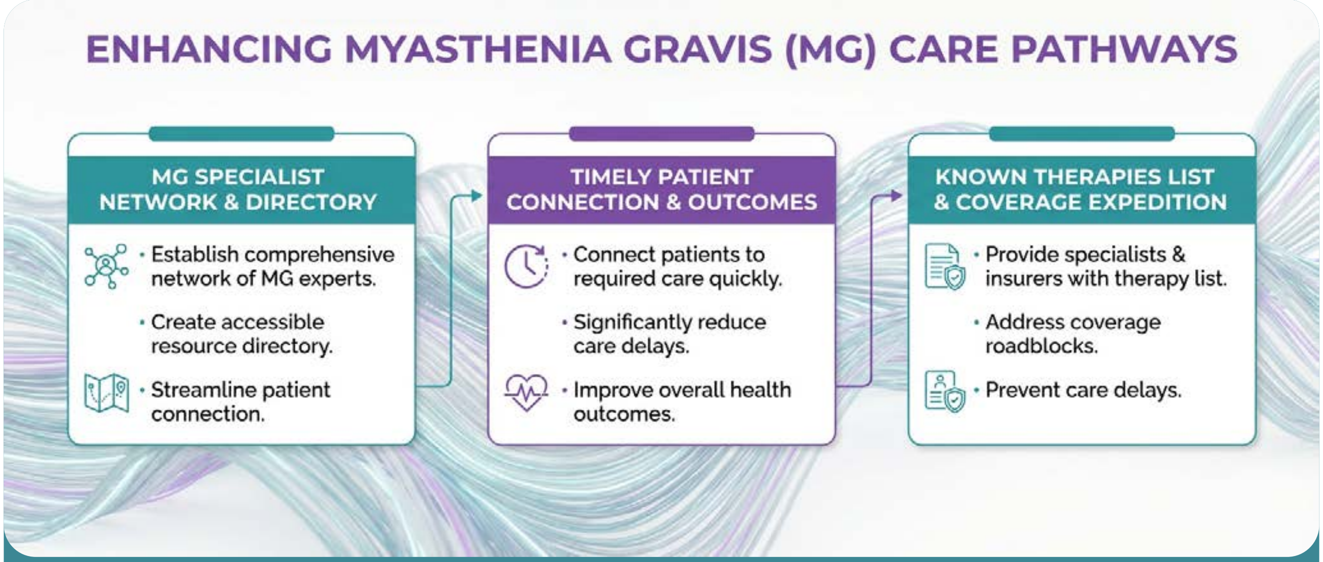
AFFORDABILITY
Ensure financial barriers are addressed to improve access.

TRANSPORTATION (PRIORITY)
Access to services like medical ride programs, paratransit is crucial.

FOOD SECURITY
MANDATE: Medically tailored meals for individuals with impaired swallowing function.

CONNECT PATIENTS TO RELEVANT RESOURCES TO IMPROVE HEALTH OUTCOMES.

Integrate routine screening for SDOH barriers. Providers should include screenings (for affordability, transportation, food security, etc.) in clinical practice and connect patients to relevant resources. Access to transportation services (e.g., medical ride programs, paratransit) is a priority for patients. It is necessary to mandate that food assistance programs include medically tailored meals designed for individuals with impaired swallowing function.



ENHANCING MYASTHENIA GRAVIS (MG) CARE PATHWAYS

MG SPECIALIST NETWORK & DIRECTORY
- Establish comprehensive network of MG experts.
- Create accessible resource directory.
- Streamline patient connection.

TIMELY PATIENT CONNECTION & OUTCOMES
- Connect patients to required care quickly.
- Significantly reduce care delays.
- Improve overall health outcomes.

KNOWN THERAPIES LIST & COVERAGE EXPEDITION
- Provide specialists & insurers with therapy list.
- Address coverage roadblocks.
- Prevent care delays.

Establish an MG specialist network and an MG care resource directory. Connecting patients to the care they need in a timely manner will reduce delays to care and improve overall health outcomes. Providing specialists and insurance companies with a list of known MG therapies and treatments will help to address coverage and care delays.

ADVOCATE FOR INSURANCE REFORM

ACCESSIBLE PATIENT NAVIGATION SERVICES

- Help patients understand insurance benefits.
- Manage denials or appeals for coverage.

LIMIT STEP THERAPY & ENSURE TIMELY APPROVAL

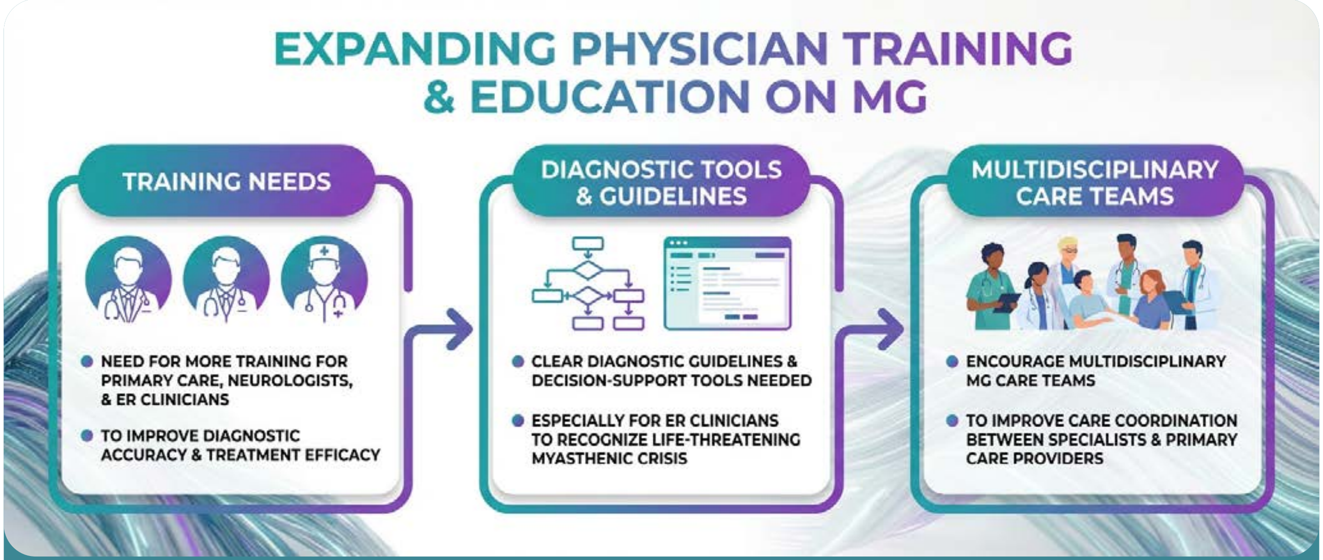
- Ensure timely approval of MG-specific treatments.
- Clinician-determined, not insurer-driven decisions.

STANDARDIZED MG TREATMENT LIST

- Develop and distribute a standardized list.
- Assist providers and insurers in coverage decisions.

Advocacy for a Better Future.

Advocate for insurance reform. Create accessible patient navigation services to help patients understand their insurance benefits and manage denials or appeals for coverage. Advocate to limit step therapy requirements and ensure timely approval of MG-specific treatments as determined by clinicians, not insurers. Develop and distribute a standardized list of approved MG treatments to assist providers and insurers in coverage decisions.



EXPANDING PHYSICIAN TRAINING & EDUCATION ON MG

TRAINING NEEDS

- NEED FOR MORE TRAINING FOR PRIMARY CARE, NEUROLOGISTS, & ER CLINICIANS
- TO IMPROVE DIAGNOSTIC ACCURACY & TREATMENT EFFICACY

DIAGNOSTIC TOOLS & GUIDELINES

- CLEAR DIAGNOSTIC GUIDELINES & DECISION-SUPPORT TOOLS NEEDED
- ESPECIALLY FOR ER CLINICIANS TO RECOGNIZE LIFE-THREATENING MYASTHENIC CRISIS

MULTIDISCIPLINARY CARE TEAMS

- ENCOURAGE MULTIDISCIPLINARY MG CARE TEAMS
- TO IMPROVE CARE COORDINATION BETWEEN SPECIALISTS & PRIMARY CARE PROVIDERS

Expand physician training and education on MG. Many patients expressed the need for more training for primary care, neurologists, and emergency room clinicians to improve diagnostic accuracy and treatment efficacy. There is a need for clear diagnostic guidelines and decision-support tools for clinicians to recognize suspected MG cases, especially for emergency room clinicians who need to treat MG patients experiencing a life-threatening myasthenic crisis. Encourage multidisciplinary MG care teams to improve care coordination between specialists and primary care providers.

CONCLUSION

The voices of the MG community, as captured in this survey, highlight the complex and deeply personal challenges faced by those living with myasthenia gravis. The unpredictable nature of the disease, struggles with daily tasks, and the emotional toll of living with fluctuating symptoms are recurrent themes in patient narratives. The survey results acknowledge the systemic barriers MG patients face, from delayed diagnoses and limited specialist access to insurance denials and issues driven by social determinants like food insecurity and transportation. Participants consistently identified significant gaps in access to specialized care, disability support, and financial assistance, emphasizing the need for broader systemic support. These lived experiences reveal not only the physical burdens but also the mental and emotional resilience required to navigate life with MG.

A clear and urgent call for enhanced education among healthcare providers resounds throughout patient feedback. From emergency room clinicians to neurologists, better awareness and understanding of MG are essential to improve diagnosis, treatment, and patient safety. Community resources, especially in-person and online support groups, serve as lifelines for many patients and caregivers. The community's suggestions highlight the need for more comprehensive training, improved coordination among care providers, and heightened awareness of rare diseases across the healthcare system.

Ultimately, these insights provide invaluable direction for advocacy, education, and resource development efforts. By centering the real stories and needs of MG patients and their families, we can work collectively to address gaps in care, expand support services, and foster a more informed and compassionate response to myasthenia gravis, helping every person with MG feel seen, supported, and empowered.

APPENDIX

Chart 1: States represented by patient and caregiver respondents. (n=410)

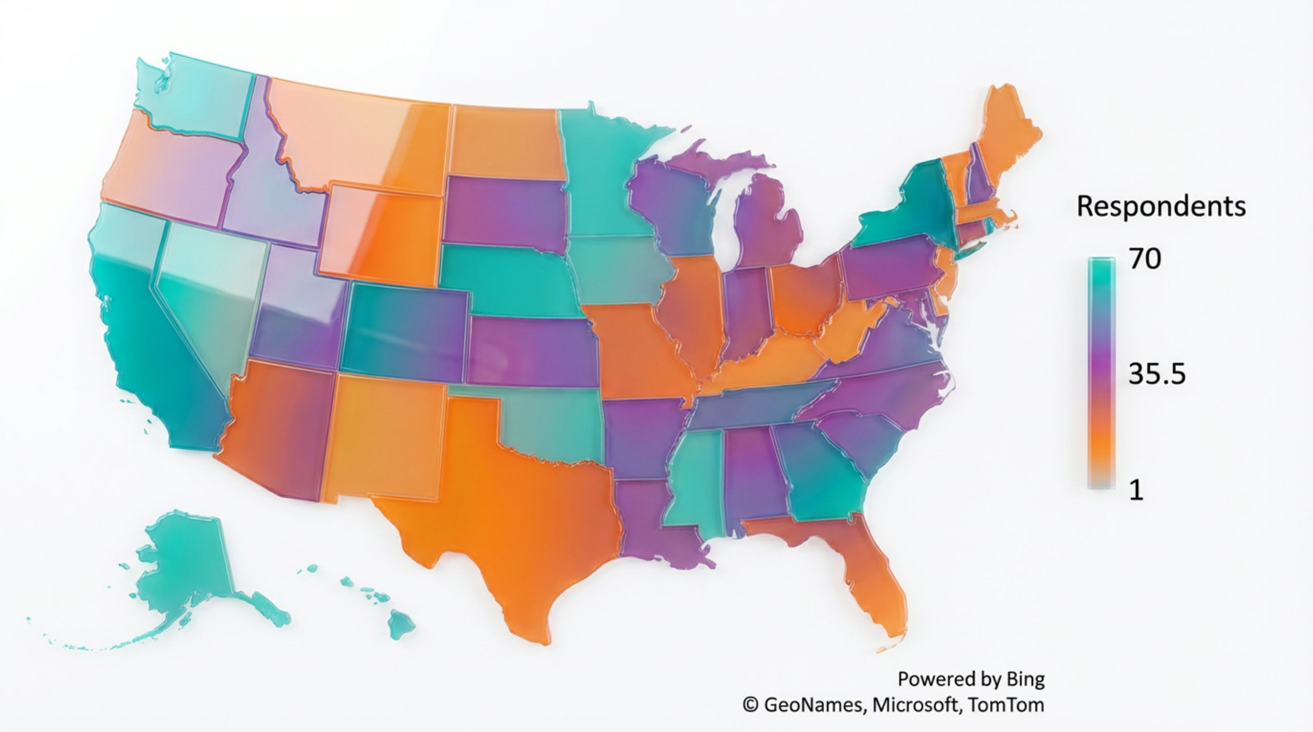


Chart 2: Total percentage of respondents (patients and caregivers) by race and ethnicity. (n=410)

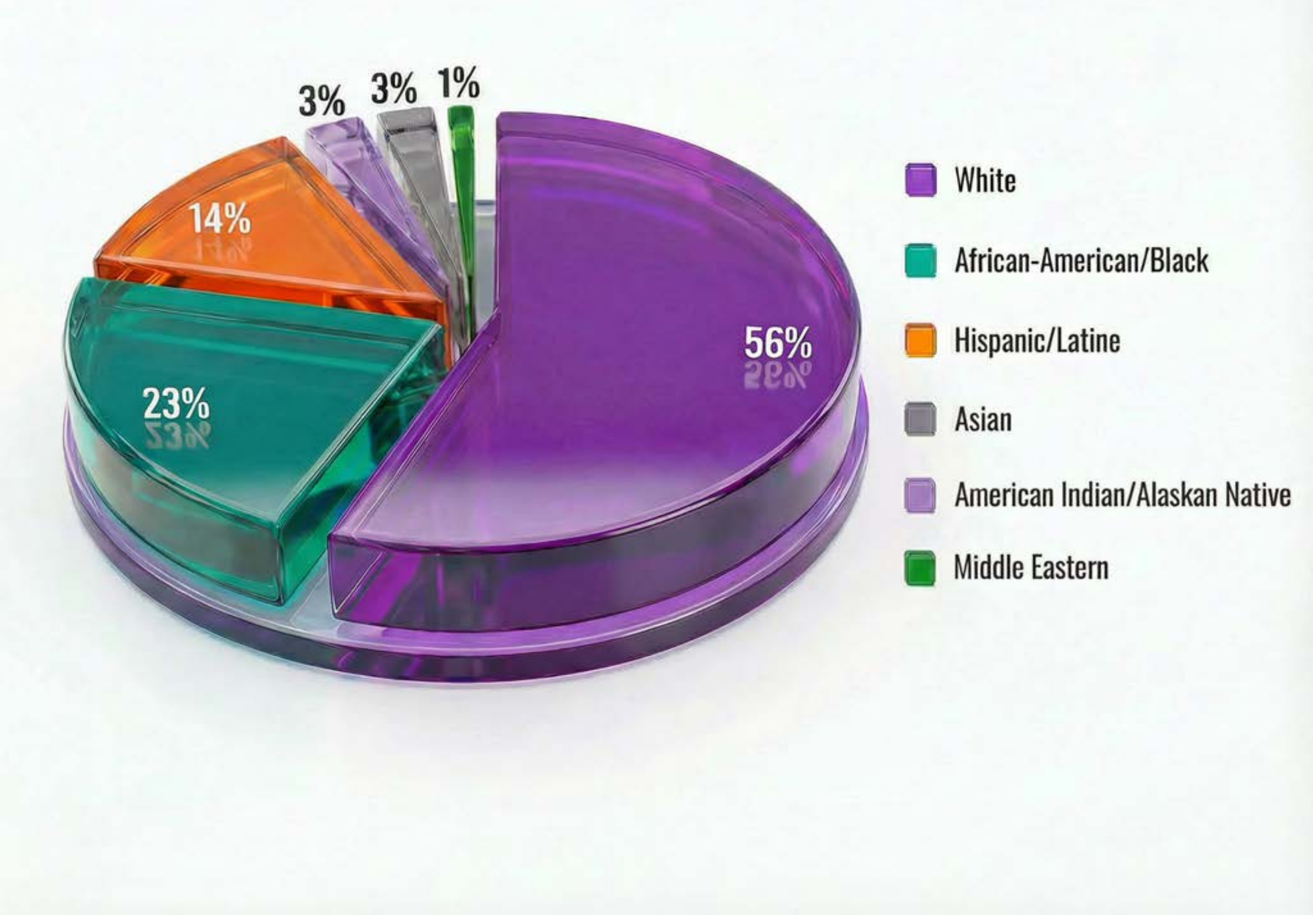


Chart 3: Total number of patients by age and gender. (n=371)

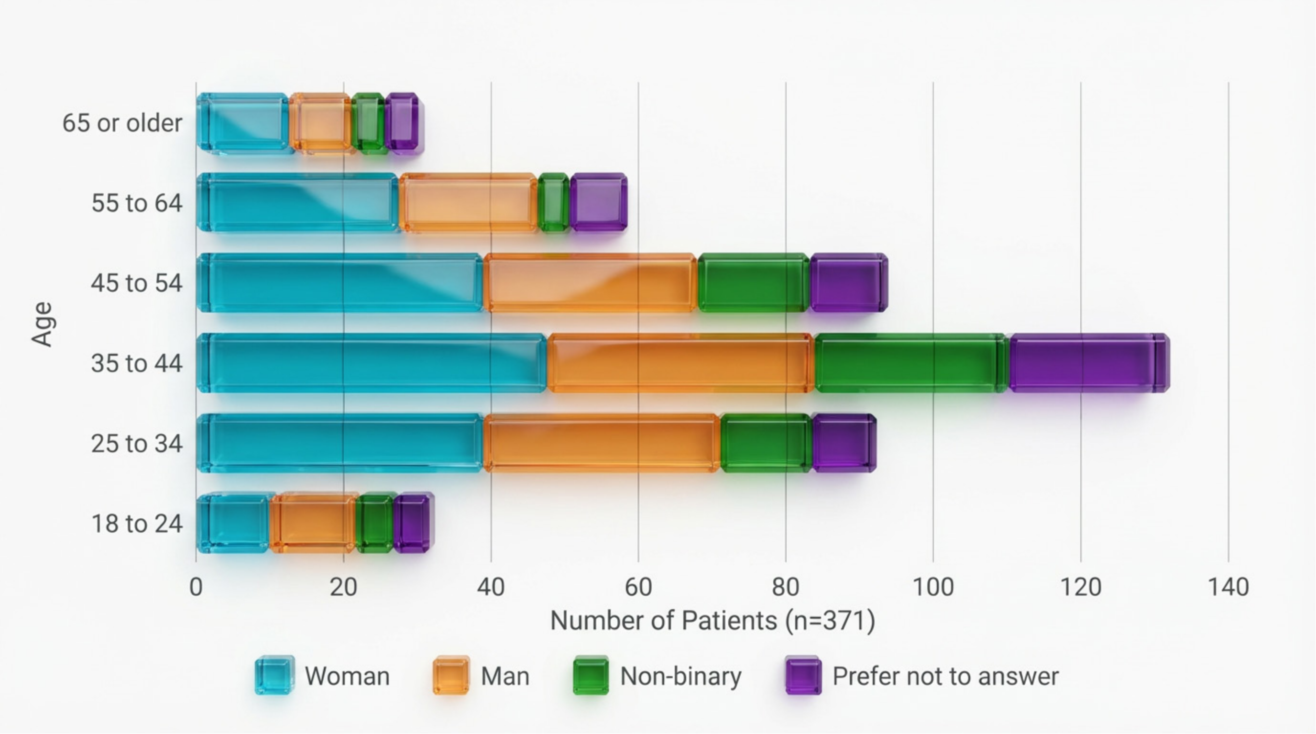


Chart 4: Total respondents patients by income and education. (n=371)

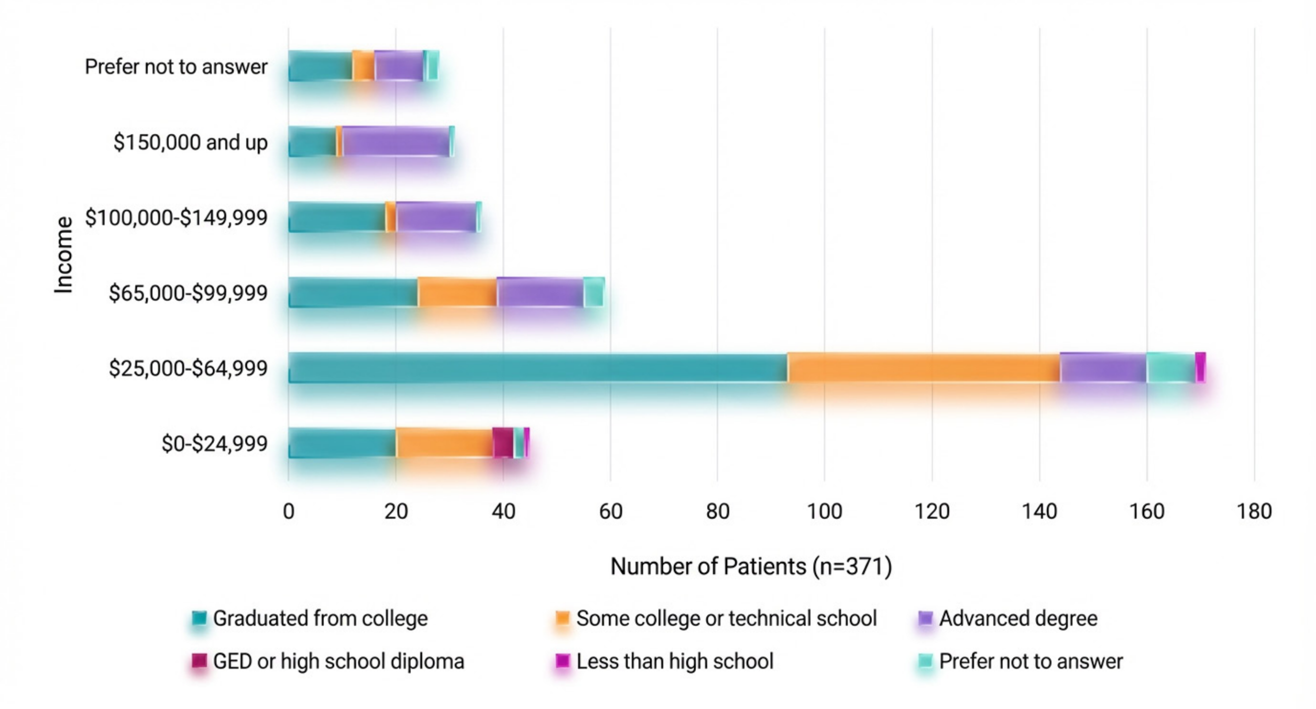


Chart 5: Patients reporting on awareness and participation in clinical trials. (n=371)

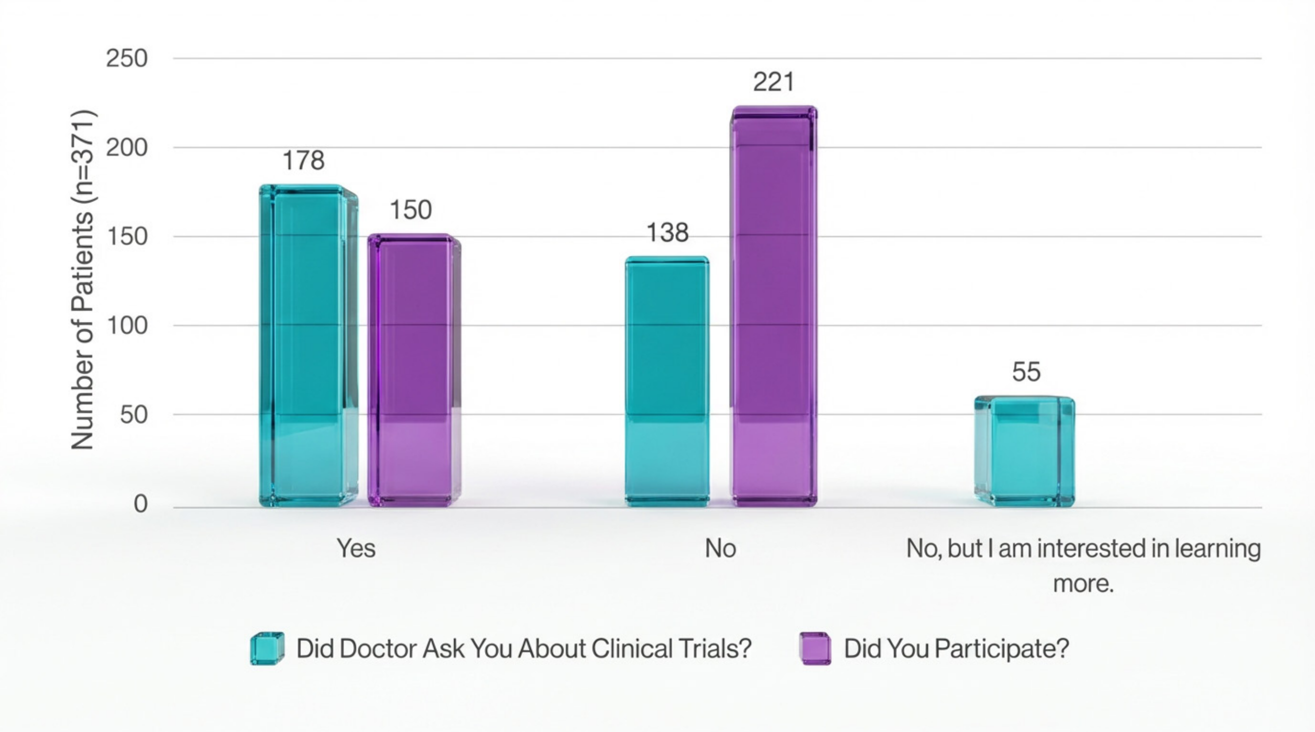


Chart 6: How far patients travel for MG care. (n=371)

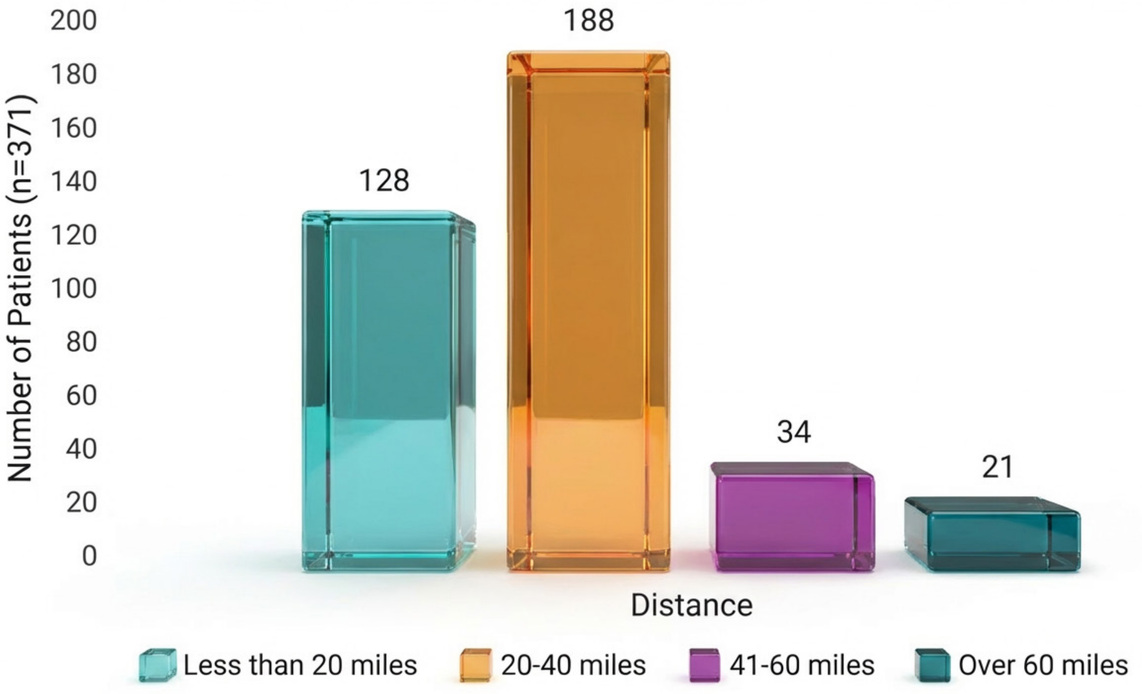


Chart 7: Patients who get time off from work for medical care. (n=371)

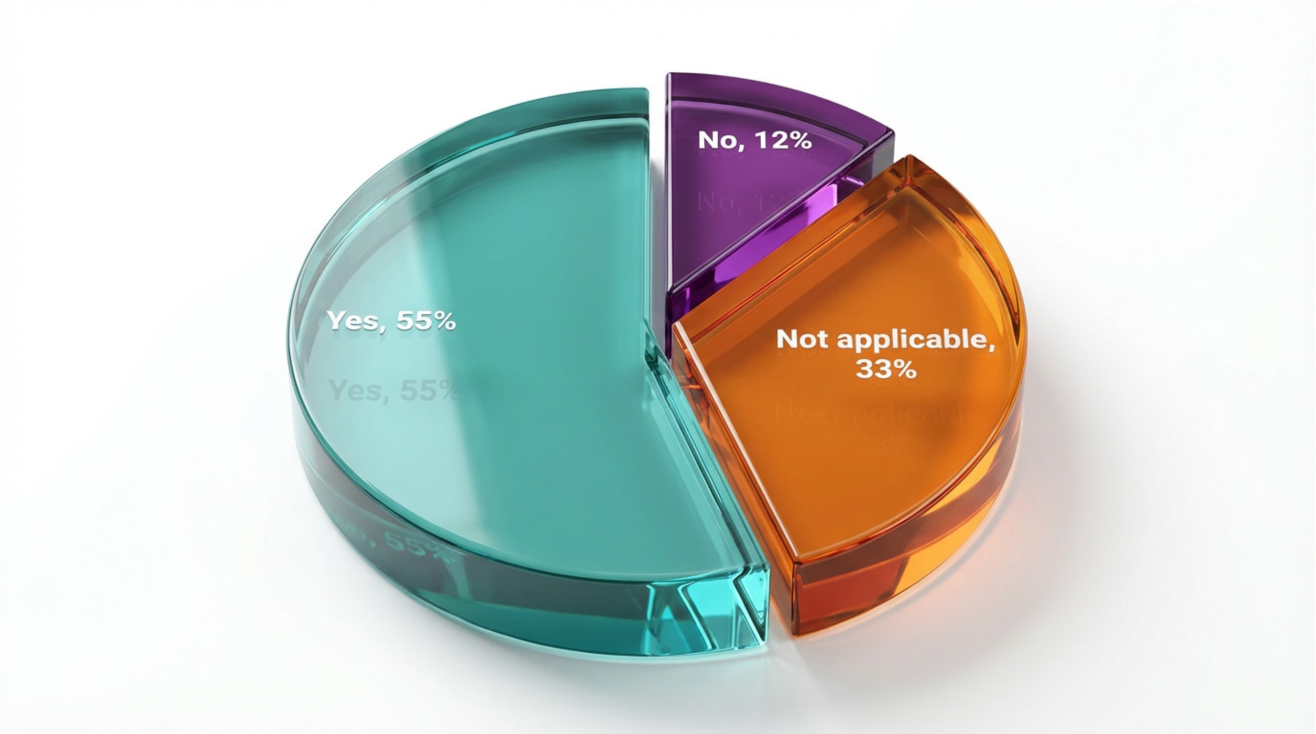
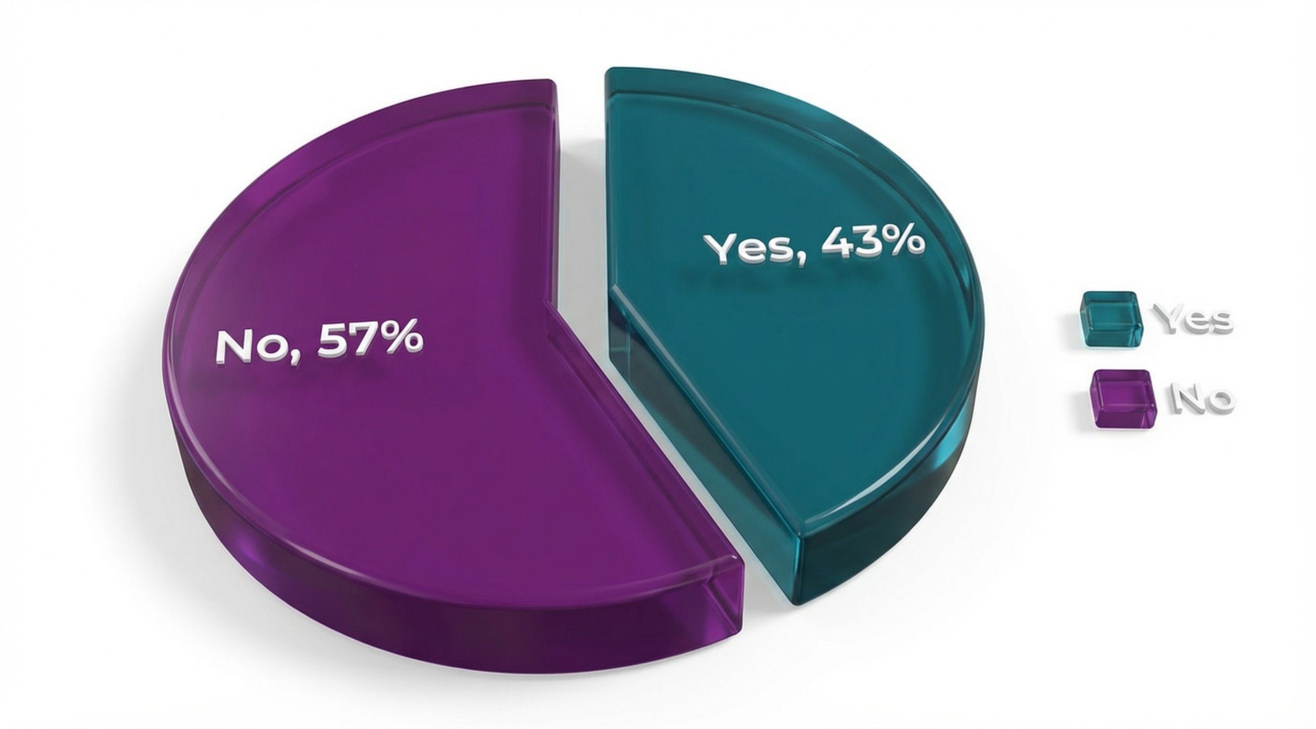
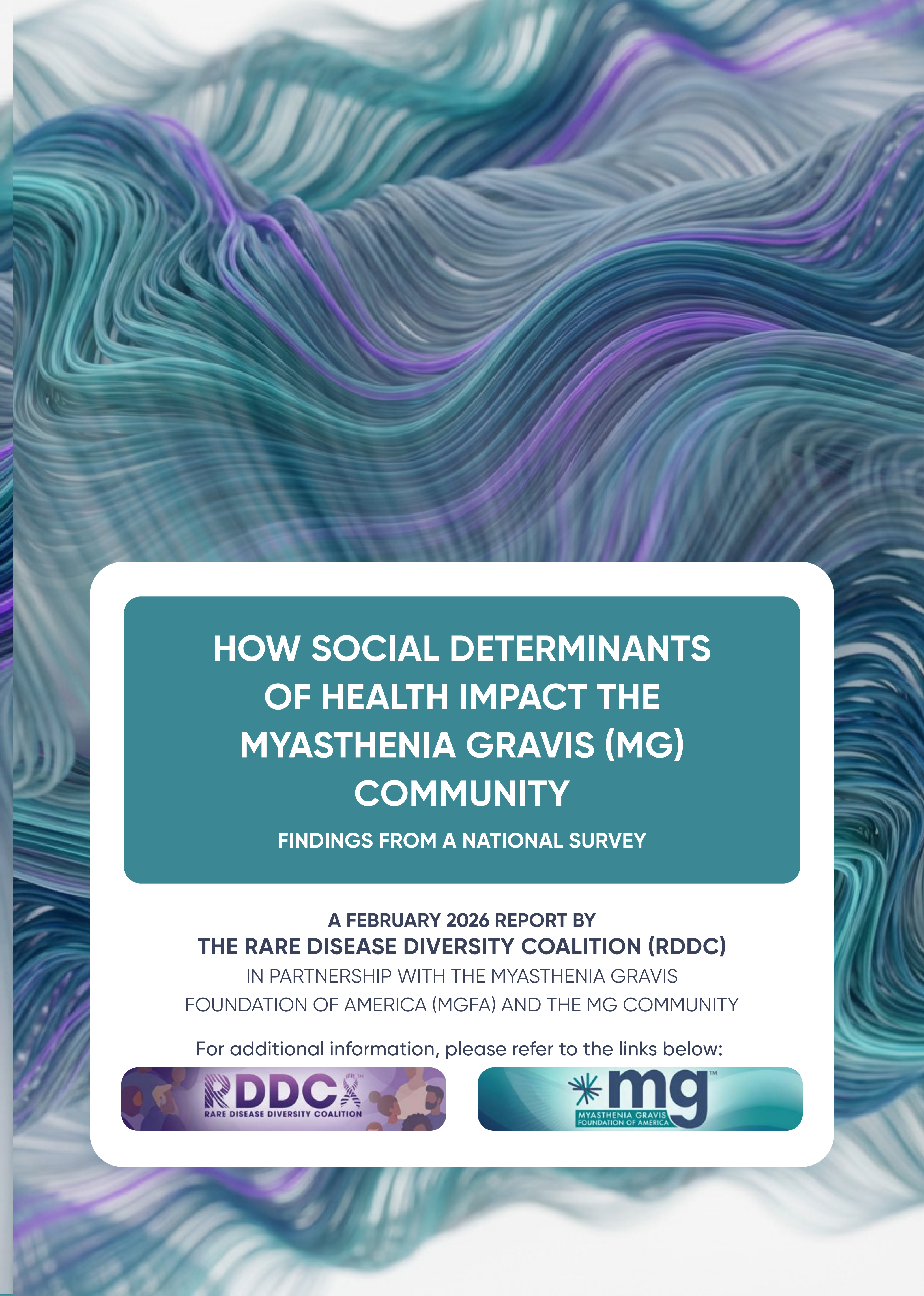


Chart 8: Patients who receive disability benefits. (n=371)





HOW SOCIAL DETERMINANTS OF HEALTH IMPACT THE MYASTHENIA GRAVIS (MG) COMMUNITY

FINDINGS FROM A NATIONAL SURVEY

A FEBRUARY 2026 REPORT BY
THE RARE DISEASE DIVERSITY COALITION (RDDC)
IN PARTNERSHIP WITH THE MYASTHENIA GRAVIS
FOUNDATION OF AMERICA (MGFA) AND THE MG COMMUNITY

For additional information, please refer to the links below:

RDDC™
RARE DISEASE DIVERSITY COALITION

mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA