

Beyond income, education and insurance coverage: The utility of CORE-5 social risk screening in neuromuscular practice for Black patients with generalized myasthenia gravis

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Introduction

MG is a rare autoimmune neuromuscular disease that causes peripheral motor weakness with muscle fatigability¹

Analysis of US administrative claims data for ~30 million commercially- and Medicare-insured individuals found MG prevalence to be highest in Black patients (202.31 per million) and lowest in Hispanics (137.82 per million)¹

- Burden was most concentrated in Black females, who had the highest incidence and prevalence of all race-/ethnicity-by-sex subgroups analyzed (58.7 per million person-years and 221.04 per million, respectively)¹

Despite a higher MG prevalence in Black patients, their overall care experiences remain largely underexplored

Traditional SES indicators, such as education, income and occupation, are frequently used to measure overall social determinants of health;² however, among Black patients with gMG, these indicators alone may not be sufficient to help clinicians identify the presence of deleterious social risks relevant to neuromuscular health outcomes³

This study examines whether the CORE-5, a 5-item social risk screening tool (housing, food security, transportation, utilities and safety),⁴ may identify clinically relevant needs among Black patients not captured by traditional SES indicators

Methods



Design

A mixed-methods sequential study design was employed. Eligible patients completed an online quantitative survey via the Qualtrics platform; a subset of patients participated in one-on-one, in-depth, semi-structured interviews



Recruitment and eligibility

In October 2025, patients were recruited through a patient advocacy organization, the MG Holistic Society, via email campaigns and phone outreach. Data collection was conducted in November 2025. Patients completed eligibility screening based on self-reported gMG diagnosis, US residence, Black racial identity and age ≥18 years. Eligible patients reviewed study information and provided informed consent



Quantitative survey

The survey collected data on demographics, socioeconomic indicators, responses to PROMs (CORE-5, Brief Illness Perception Questionnaire, MG-QoL15r and Discrimination in Medical Settings Scale) and gMG care experiences



In-depth interviews

One-on-one interviews were conducted with a purposive subsample of survey respondents selected to ensure representation across geographic regions, age, gender and clinical characteristics. Qualitative data were analyzed until thematic saturation was achieved, resulting in 13 distinct themes



Data analysis

Descriptive statistics were used to summarize traditional SES indicators and all patient-reported outcomes, including CORE-5 item-level social risk scores. Qualitative interview data were thematically analyzed and integrated with quantitative findings

Abbreviations: CORE-5, 5-item social risk screening tool assessing housing, food security, transportation, utilities and safety; gMG, generalized myasthenia gravis; MG, myasthenia gravis; MG-QoL15r, Myasthenia Gravis Quality of Life 15-item revised; PROM, patient-reported outcome measure; SES, socioeconomic status.

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Summary and conclusions



- This mixed methods study examined social risks in Black adult patients with gMG
- Patients indicated unmet social risks on the CORE-5, with personal/family safety and housing/utility bills emerging as the highest specific concerns. These social risks persisted despite the study sample having high socioeconomic resources
- CORE-5 scores and in-depth interviews uncovered clinically meaningful risks not captured by traditional SES indicators – housing, food security, transportation, utilities and safety



- Documentation of only medical and clinical data may obscure how truly complex and challenging caring for a patient may be
- Socioeconomic markers like income or insurance coverage collected through administrative or claims data analysis often fail to fully account for patient-level vulnerabilities,⁸ while the CORE-5 tool uncovers hidden barriers for Black patients, particularly regarding patients' perception of safety⁴
- Capturing this comprehensive clinical picture through social risk documentation supports equitable quality

reporting, effective care coordination and broader population health initiatives within value-based care frameworks⁹

- Incorporation of CORE-5 screening during neuromuscular evaluation and management visits may support more equitable, patient-centered care⁷
- Future research must evaluate whether the 2026 shift toward physical activity and nutrition assessments¹⁰ obscures barriers such as food insecurity, safety or housing instability, thereby threatening equitable quality reporting and care coordination supported by social risk documentation

Results

The final quantitative survey sample included 207 patients, and a subset of patients (n=16) completed in-depth interviews

The study sample exceeded national averages in relation to educational attainment⁵, income⁵ and health insurance coverage⁶ for Black adults residing in the United States:



71% Held a bachelor's degree or higher

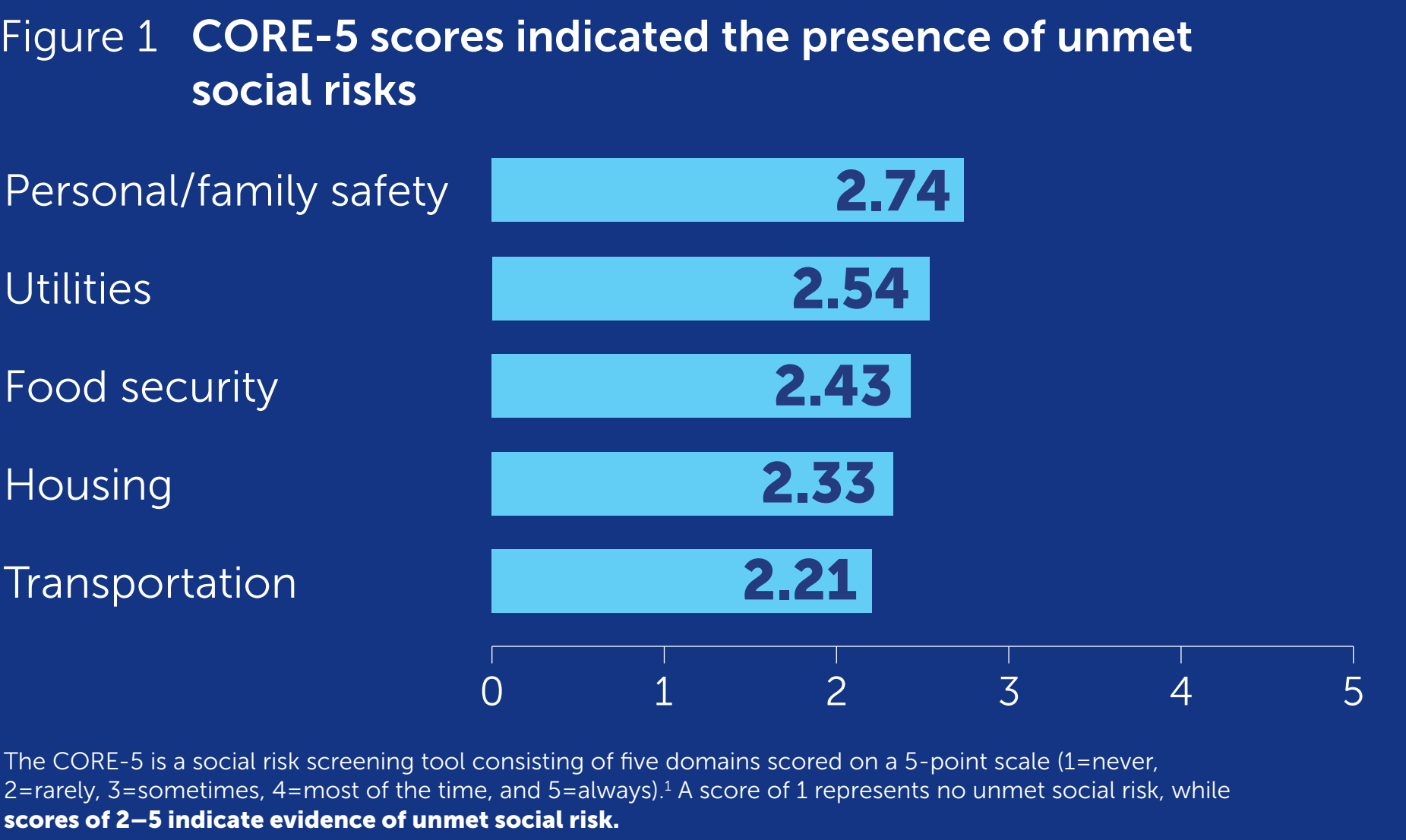


73% Reported an annual household income of >\$50,000



97% Reported having health insurance (with only 12.6% covered by Medicaid)

Despite being highly resourced across domains traditionally used to measure social determinants of health, overall CORE-5 scores indicated the presence of unmet social risks (Figure 1)



Patient quotes

Patients described feeling unsafe, having transportation challenges and experiencing sudden changes in employment and housing, bringing to light the psychosocial and financial burden of gMG despite high SES.



Safety

Safety concerns included forced exposure to overt racial hostility, geographic steering into unsafe areas and the chronic stress of navigating unwelcoming environments simply to access care.

"I have had experiences going to an Urgent Care clinic or the emergency room where I would feel stigmatized. They looked at me like I'm a drug addict just coming in to get drugs instead of seeking treatment. Nobody should be made to feel that way."

Patient 17
Female, age 51–55



"I don't wear a lot of makeup on a regular basis; I put on a hat. I dress simply because of my condition. So, the last two times I went to the hospital, they almost put me in a mental health hospital. They thought I was homeless and crazy. I kept telling them, 'I have MG, check the records. I need a neuro consult.' But they kept checking me for mental things. They weren't listening to me."

Patient 3
Female, age 46–50



"They sent me to some other place in a dangerous part of town, where I had to drive past a KKK headquarters – just because I'm Black. The way people treated me out in town was just so different. I could tell I wasn't really welcome. It felt like one of those movies where the new person comes to town, and everyone just starts staring as they walk around."

Patient 28
Male, age 46–50



Transportation

Health challenges related to gMG could cause significant transportation challenges that were not related to a lack of financial resources.

"There are challenges to walking and commuting. I started having droopy eyelids and a droopy neck, and driving became a challenge for me. [Another time], I was walking toward the train and my legs gave out; I just fell."

Patient 20
Female, age 71–80



Utility, bills and housing

Health challenges could swiftly change their employment status, having a domino effect on insurance coverage, ability to pay bills and even living situations.

"Even after the optometrist told me I have the signs of MG, the primary doctor refused to refer me to a neurologist because I did not have insurance."

Patient 21
Female, age 71–80



"Well, I always first of all think about the bills."

Patient 15
Male, age 46–50



"Well to be honest, right now I'm homeless. So, I live in a local homeless shelter right now."

Patient 10
Female, age 39–45

