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Disease Burden, Impact on Daily Functioning, and Psychological Well-being in Patients with Ocular Myasthenia Gravis: Insights from a U.S. Patient Panel

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KEY TAKEAWAYS

Persistent OMG symptoms cause significant physical and daily activity limitations

- N=19/23 (83%) patients experienced both ptosis and diplopia; additional symptoms included eye fatigue, blurred vision and migraines.
- N=15/23 (65%) reported persistent ocular symptoms
- Over half of patients experienced ongoing pain, fatigue, and sleep disturbances

Work and personal life are heavily disrupted by OMG

- Among working-age participants (16-64 years), (N=16/23) 94% reported work-related impacts, particularly in roles requiring prolonged computer use or sustained visual focus. Reduced productivity and changes in employment status due to the condition were common.
- N=21/23 (91%) reported that OMG affects daily activities or hobbies. 9% had access to formal caregiving support.
- N=9/22 (41%) described experiencing strain in family relationships related to OMG.

Emotional well-being is severely affected by OMG

- Nearly all patients reported frustration, anxiety or fear of progression to generalized MG.
- N=15/23 (65%) reported reduced self-confidence and social withdrawal while 58% experienced stigma or misunderstanding.
- The majority reported a moderate to significant negative impact on mental health.
- Unmet needs include inadequate information on OMG and more OMG-specific support groups

BACKGROUND | METHODS

Ocular myasthenia gravis (OMG)

- Ocular myasthenia gravis (OMG) is an autoimmune condition driven by antibodies that disrupt neuromuscular transmission in the extraocular and eyelid muscles.[1-3] It is classified as Myasthenia Gravis Foundation of America (MGFA) class I, which refers to weakness limited to the ocular muscles while strength in all other muscle groups remains unaffected.
- The annual incidence of ocular myasthenia gravis is approximately 1.13 per 100,000 people, and about 50–70% of patients test positive for acetylcholine receptor autoantibodies.[3,4]
- OMG is characterized clinically by diplopia and/or ptosis; additional features may include photophobia, Cogan lid twitch, and, in rare cases, complete ophthalmoplegia.[5-8]
- Progression to generalized MG varies from 11% to 84%, especially in those with positive sfEMG findings or AChR antibodies, with risk of progression being the highest in the first 1 to 3 years.[9,10]
- There are no approved therapies targeting the underlying antibody-mediated pathology; pyridostigmine is the only approved symptomatic treatment.[11]

Objective

- The objective of this study was to examine disease burden, impact on daily functioning and psychological well-being of OMG patients.

Study type and dataset

- A qualitative, interview-based study conducted in the United States
- The researchers recruited 23 patients with OMG through patient advocacy groups
- To ensure diagnostic accuracy, participants were required to submit a healthcare provider's clinical note confirming the OMG diagnosis before enrolment. Each participant then completed a 60-minute semi-structured telephone interview, during which a secure screen-sharing platform was used to facilitate discussion and capture detailed insights
- The study was carried out over a short, defined period (February–March 2025)
- Patients reported their disease experience at the time of interview

RESULTS

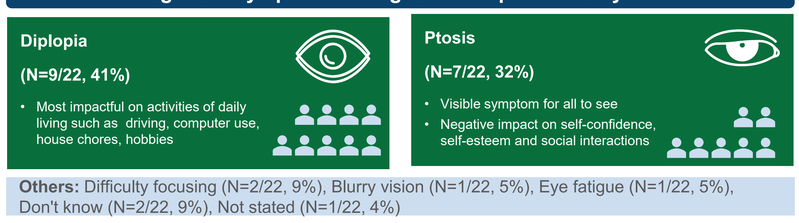
Patient demographics for the 23 individuals with OMG are presented in **Table 1**.

Table 1.Patient Demographics, N=23

Gender	
Male	N=10/23 (43%)
Female	N=13/23 (57%)
Age	
18-30 years	N=1/23 (4%)
31-60 years	N=13/23 (57%)
61+ years	N=9/23 (39%)
Race	
White	N=13/23 (57%)
Black or African American	N=9/23 (39%)
Prefer not to say	N=1/23 (4%)
Education	
Basic or none	N=1/23 (4%)
Secondary	N=3/23 (13%)
College and above	N=19/23 (83%)
Employment	
Full-time	N=12/23 (52%)
Part-time	N=1/23 (4%)
Unemployed	N=3/23 (13%)
Retired	N=7/23 (30%)
Health Insurance	
Private	N=17*/23 (74%)
Government-funded	N=6*/23 (26%)
Health exchange or marketplace	N=1/23 (4%)
Symptoms experienced	
Eyelid droop only	N=2/23 (9%)
Double vision only	N=2/23 (9%)
Both eyelid droop and double vision	N=19/23 (83%)
Nature of oMG symptoms	
My symptoms occur sporadically	N=8/23 (35%)
My symptoms are persistent	N=15/23 (65%)
Time since symptoms first began	
Less than a year	N=6/23 (26%)
1 to 2 years	N=5/23 (22%)
More than 2 years	N=12/23 (52%)

* One patient has both private and government-funded health insurance

Figure 1. Symptoms with greatest impact on daily life



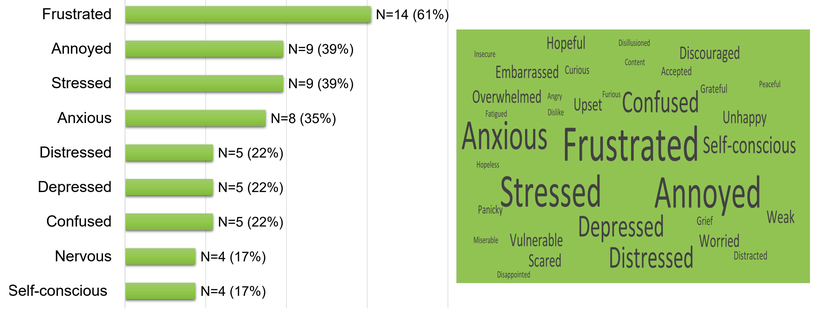
Others: Difficulty focusing (N=2/22, 9%), Blurry vision (N=1/22, 5%), Eye fatigue (N=1/22, 5%), Don't know (N=2/22, 9%), Not stated (N=1/22, 4%)

Number of patients mentioning symptom has greatest impact on life

Psychological impact: emotions and feelings

- Emotions and feelings associated with OMG are more intense at diagnosis and are mainly negative, including frustration, annoyance, stress, and anxiety (**Figure 2**).

Figure 2. Patients selecting emotion/word in association with oMG (N=23)



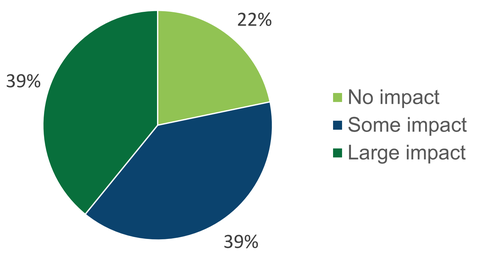
* Only words mentioned 4 or more times are shown in the bar chart.

- Patients fear progression to generalized MG, with anxiety most heightened around the time of diagnosis and during the critical first 3 years when the risk is the highest
  - All patients were aware of the risk of progression to GMG, either from their neurologist (N=22/23, 96%) at the time of diagnosis, and/or through their personal research. 2 patients had a family history of generalized MG
  - N=15/23 (65%) mentioned searching for more information on gMG

Impact on personal life

- Almost all OMG patients reported that condition affects their daily activities and hobbies (N=21/23, 91%). Patients tend to shift to indoor or less visually demanding hobbies.
- N=15/23 (65%) report that OMG impacts their self-confidence and social interactions, associated with reduced confidence during social situations, social withdrawal, and experiences of embarrassment.
- Many patients describe their family or partners as a source of strength and support, but N=9/22 (41%) described some level of strain on or with their families
- Although most patients reported that OMG symptoms impacts their daily lives, only 9% have formal caregiver support. Typically, help comes from family or friends as needed, mainly with driving, household chores, morning routines, and online tasks.
- Patients primarily rely on neurologists (N=15/23, 65%) and social media (social media support groups or targeted searches) (N=14/22, 64%) for support. N=9/22 (41%) report unmet needs, including a demand for more information on OMG and a broader range of OMG support groups.

Figure 3. Impact on mental health



- OMG has a moderate to significant impact on mental health for the majority of patients (**Figure 3**)
- N=15/23 (65%) report oMG impacts their self-confidence and level of social interaction
- 58% reported experiencing stigma or misconceptions related to oMG due to lack OMG awareness, misunderstanding of the disease and negative social perception

Disease burden and symptoms

- N=19/23 (83%) patients experienced both ptosis and diplopia
  - N=2/23 (9%) patients had double vision only and N=2/23 (9%) had eyelid droop only
  - Other symptoms included eye fatigue, blurred vision, migraines, eye misalignment
  - N=15/23 (65%) had persistent symptoms
- Double vision and ptosis were perceived to have the greatest impact on daily life by N=9/22 (41%) and N=7/22 (32%) patients, respectively (**Figure 1**)
- N=12/23 (52%) report experiencing pain or to a lesser extent discomfort with OMG
  - *"Like nerve pain in eye socket, long lasting" – selected quote*
  - "*Irritated, like a grain of sand in my eye all the time*" *– selected quote*
- N=11/21 (52%) report that oMG impacts general fatigue and/or sleep. Many patients feel persistent tiredness and sleep disruptions are common.

Impact on productivity and ability to work

- Among working-age participants (16-64 years), N=16/23 (94%) reported impacts on work—particularly in roles requiring prolonged computer use or sustained visual focus. Patients commonly experienced reduced productivity, frequent breaks, increased sick leave, and missed opportunities for promotion due to their condition.
  - N=5/15 (33%) reported that OMG led to the change of their work status or made them considered quitting/retiring due to oMG symptoms or concerns about underperformance and how they might be perceived by others
  - 44% reported they receive support from their colleagues and bosses in relation to OMG and few reported feeling unsupported (20%)

Selected patient quotes about OMG

Fear of progression to GMG

"I was overwhelmed with the unknown because day-to-day you didn't know whether you were going to wake up with breathing problems or going to the hospital. I was told that if you use your muscles, you're going to be in trouble, so you need to shut down all your activity. What am I going to do? I mean, is it just don't lift more than 5 lbs of weight?"

Impact on self-confidence

"I definitely feel a lot less confident, especially when my eyelid droop is really noticeable. I try to hide it. It's my right eye, so if I'm talking to somebody, I'll kind of shift my body to where they see more of the left side of my face. And I'll rub my eyes a lot to try to make it seem like they look like that because they're dry. It's so stupid."

Impact on work

"I stopped working as an electrical engineer due to OMG. My last day at work was after my depth perception started being affected, though I didn't realize it was OMG at the time. I almost stepped off a roof, and that ended my career.

Vision impairment impact

"The double and blurry vision messed with everything. I couldn't drive for two months. I have to drive every day going to and from work, so that was a big, big issue for me. But thankfully, my mother-in-law, she lives with us, she is my Uber."

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ABBREVIATIONS: **O**MG = ocular myasthenia gravis; MGFA = Myasthenia Gravis Foundation of America; AChR = acetylcholine receptor; GMG = generalized myasthenia gravis; sfEMG = single-fiber electromyography; ER = emergency room; HCP = healthcare professional.

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