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Diagnosis Journey, Treatment, and Management of Patients with Ocular Myasthenia Gravis: Insights from a U.S. Patient Panel

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KEY TAKEAWAYS

Diagnosis of ocular myasthenia gravis (OMG) is frequently delayed, with neurologists most consistently establishing the diagnosis

- N=13/23 (57%) of patients sought care within 1 week of symptom onset, but time to diagnosis ranged from 1 day to 12 months (mean: 2.4 months)
- Initial assessments by HCPs (8/23) and ophthalmologists (7/23) were often linked to delays
- 26% of patients reported insufficient OMG knowledge among non-neurologists

Current treatment is dominated by pyridostigmine, often combined with corticosteroids (CS), but disease burden remains high:

- All patients (N=23) used pyridostigmine; N=13/23 (57%) combined it with CS
- 52% spontaneously reported experiencing side-effects from treatment, most commonly with Prednisone or pyridostigmine
- 82% had received CS since diagnosis, with 2 declining due to safety concerns.
- Among those treated with CS, 37% were on ≥20 mg/day for extended periods, and N=9/19 (47%) reported side effects.

Patients' unmet needs call for quicker diagnosis, greater awareness, and more tolerable treatments

- Only 3 of 23 (13%) patients achieved full symptom resolution; still symptoms recurred if treatment was missed
- Interest expressed in treatments with fewer side effects (43%) and longer-lasting effects (35%)

BACKGROUND | METHODS

Ocular myasthenia gravis (OMG)

- Ocular myasthenia gravis (OMG) is an antibody-mediated autoimmune disorder that impairs neuromuscular transmission in extraocular and eyelid muscles, classified as MGFA class I.[1-3] OMG is categorised as Myasthenia Gravis Foundation of America (MGFA) class I, meaning any ocular muscle weakness, while all other muscle strength is normal.
- About 50–70% of OMG patients have acetylcholine receptor autoantibodies, with an annual incidence of 1.13 per 100,000 people.[3,4]
- OMG is characterized clinically by diplopia and/or ptosis with uneven ocular involvement; 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.[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 explore diagnosis, treatment and management 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 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)

RESULTS

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

Table 1.Patient Demographics, N=23

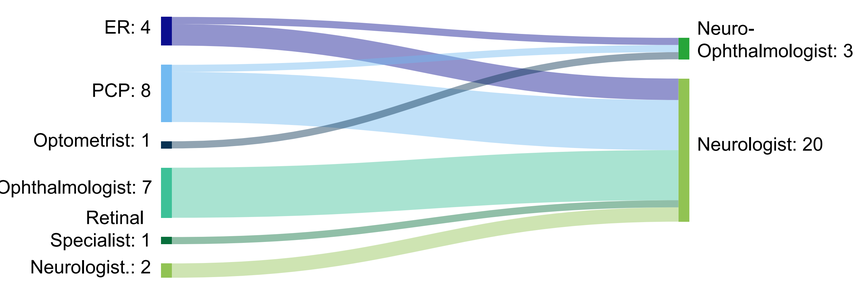
Gender	
Male	N=10/23 (43%)
Female	N=13/23 (57%)
Age	
18-30 years	N=1/23 (4%)
31-60 years	N=13/23 (57%)
61+ years	N=9/23 (39%)
Race	
White	N=13/23 (57%)
Black or African American	N=9/23 (39%)
Prefer not to say	N=1/23 (4%)
Education	
Basic or none	N=1/23 (4%)
Secondary	N=3/23 (13%)
College and above	N=19/23 (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

Diagnosis journey

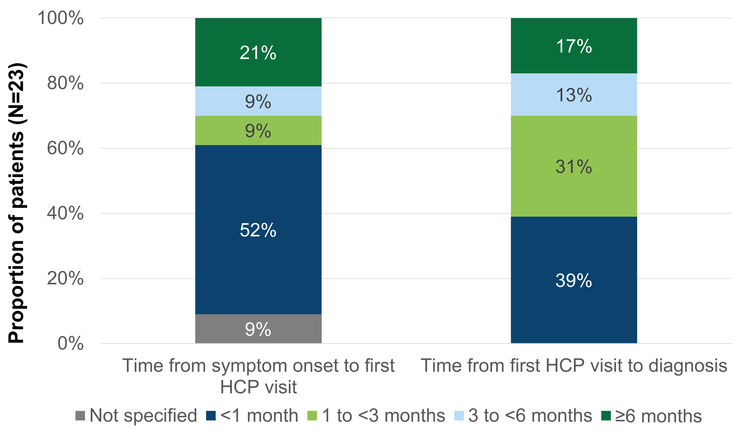
- Diplopia and ptosis occurred in 83% of patients; other symptoms included eye fatigue, blurred vision, misalignment, and photosensitivity
  - N=2/23 (9%) patients had double vision only and N=2/23 (9%) had eyelid droop only
- Common diagnosis routes are from primary care or eye doctor(s) to neurologist and/or neuro-ophthalmologist; some are referred to, or present directly to ER
- N=20/23 (87%) patients were diagnosed by neurologist and N=3/23 (13%) were diagnosed by neuro-ophthalmologist (**Figure 1**)

Figure 1. Patient journey: initial HCP contact to diagnosing HCP



- Over half of patients sought care from an HCP within one week of symptom onset (**Figure 2**).
- Time from first HCP visit to diagnosis ranged from one day to 7 months (one patient reported 12 months); median is 1 month
  - Among patients with a 6–12 months time to diagnosis, reported challenges included missed eyelid droop, misdiagnosis by PCP, multiple referrals, and improperly conducted SFEMG
- In total, 13 out of 23 patients (57%) reported unmet needs with the diagnostic process, including the need for greater knowledge of OMG among HCPs

Figure 2. Time from first symptoms to diagnosis: duration of each step in OMG



Treatment and management

- Most common treatment regimens:
  - All patients (N=23) used mestinon (pyridostigmine)
  - **Pyridostigmine + CS, N=13/23 (57%)**: was the most common regimen, often both prescribed at diagnosis (N=11), but some patients required treatment breaks or discontinuation due to toxicity (N=2), insomnia (N=1), or limited efficacy (N=1). 2 were recommended but refused CS, due to safety concerns
  - **Mestinon + CS + mycophenolate mofetil, N=4/23 (17%)**: Triple therapy was less frequent and typically used to reduce long-term steroid exposure, with patients adjusting treatment based on side-effects or response
  - **Pyridostigmine alone, N=3/23 (13%)**: A minority of patients remained on monotherapy, often due to concerns about steroid-related side-effects, comorbidities or perceived remission
  - One patient underwent surgery for ptosis bilaterally.

Side effects

- N=12/23 (52%) spontaneously mentioned experiencing side-effects with treatment, most commonly with CS or pyridostigmine
  - N=9/19 (47%) on CS reported side-effects, among those weight gain (N=2), bone loss/ osteoporosis (N=2). N=7/19 (37%) were prescribed high dose CS (≥20 mg/day)
  - N=8/23 (35%) reported side effects with mestinon/pyridostigmine, among those drooling (N=5), GI disturbance (N=4)

Supportive management techniques

- Majority of patients use visual aids (70%) like eye patches, dark or prism glasses. They also use resting, or reduce/stop activity to help manage OMG
- Patients may also use counselling (26%), eye physical therapy (22%), and try to avoid stress and eat healthily to manage OMG

Unmet needs

- The most cited unmet treatment needs were for therapies with fewer or minimal side-effects (43%), less frequent dosing (35%), improved efficacy (35%), a wider range of treatment options (26%), and faster-acting therapies (13%)
- N=3/23 (13%) reported full symptom resolution with current therapies, but they still report experiencing side effects (N=1) or some minor disturbances (N=1). Symptoms tended to return if the dose is missed.

Patient quotes about treatment

Side-effects

"A lot of things that bothered me were side-effects, I think it's mestinon. It seems like every possible way that my body could be exuding some kind of fluid… It's just like sometimes the faucets would turn on. I'll be sweating unnecessarily. I wake up with big old piles of drool coming out of my mouth. Or when I spoke, I would see saliva coming out. I felt my watering eyes were from the Mestinon, but the doctor thinks not. Leading to urinate a lot more. I think the best thing was that we've recently cut that down by a third and I've been able to sleep better at night, not getting up as much."

Effect not sustained

"If I was to complain about prednisolone, I'd say it's working but when I stop for some time, I feel like the eye drooping is coming back. Pyridostigmine is working; symptoms do not go off completely but it's something that is manageable. The vision is okay. You don't have to strain very much. But I wouldn't say that it's working 100%. If there is another medication that is better than this, I'll go for it."

Dosing and effect not sustained

"I wish Mestinon lasted longer, but I don't have the side effects that I would have with long-term steroid use. If it means I have to take it more often, then I guess I'm happy with that. But it would be nice if I just took it once a day and it'll last all day."

Slow acting

"My management is very good. And my treatments, you know, it was something which I hoped would be faster but at the end of the day, I'm kind of seeing results, even though it's not something which is very big at once. So, I'm kind of happy about that and just trust in the process. It's not the best, but it's a very good one." (patient currently taking mestinon/prednisone)

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ABBREVIATIONS: OMG = 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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