Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/neurofrontiers/how-diagnostic-delays-in-gmg-impact-disease-severity-outcomes-and-quality-of-life/35492/

ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

How Diagnostic Delays in gMG Impact Disease Severity, Outcomes, and Quality of Life

Announcer:

This is *NeuroFrontiers* on ReachMD. On this episode, we'll discuss how diagnostic delays in generalized myasthenia gravis can worsen patient outcomes and quality of life with Dr. John Morren. He's the Program Director of the Neuromuscular Medicine Fellowship at Cleveland Clinic and an Associate Professor of Neurology at Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. Let's hear from Dr. Morren now.

Dr. Morren:

There are several factors, and if you think about the key clinical features of myasthenia gravis, you might realize where there is some vulnerability. In other words, myasthenia gravis is typically manifested with fluctuating fatigue, or this generalized weakness that tends to be worse with repeat or sustained exertion. So quite often, patients are worse at the end of the day, for example. And then, they seem to be inconsistent to the doctor, or if they're not having these impressive signs on the physical exam at the time, they may be dismissed or less aggressively worked up at the moment. So because it has that very fluctuating feature, it lends itself to that delay.

Initial misdiagnosis is also very common. There is this study that showed that about 70 percent of patients with gMG experience diagnosis delay of more than one year. They were given a wrong diagnosis, things like chronic fatigue syndrome, psychosomatic disease, and stroke, instead of myasthenia gravis. There are also some patients that will have prolonged periods where they don't have symptoms at all, so these are prolonged asymptomatic periods. And again, if they're being assessed by their doctor during those times, they will be shelved or say, "Well, you come back when things are worse," and things like that, and the can gets kicked down the road.

There's study data that supports that 40 percent of patients with a more than one year delay in diagnosis have a significant severity of disease. So if you use the MGFA classification, the Myasthenia Gravis Foundation of America classification, a class III, which is not mild but at least moderate generalized weakness, that may include bulbar muscle weakness. So in other words, you might be teetering on the edge of issues like aspiration and breathing issues, so there's that. You're also having reduced quality of life. Some studies show that patients with longer delays have a higher MG-QOL15r. That's the scale that we use for quality of life specific to myasthenia. So a higher score means lower quality of life, and delayed symptom control and remission is another aspect. If you delay diagnosis, one study showed that from diagnosis to symptom control, you had over 400 days—over a year—if you were diagnosed later as opposed to somebody who had prompt diagnosis, so you really do run the risk of long-term worse outcomes with a delay in diagnosis, not to mention increased burden on healthcare. So for those who have a delay in diagnosis, one study showed that they would need an average of five healthcare providers as opposed to just three healthcare providers as part of the team required to take good care of that patient.

A lot of the evolving data on this is from a few large studies. I would mention three. And if our listenership wanted to do a deeper dive, I would recommend reading the paper entitled "Factors Affecting the Diagnostic Delay of Myasthenia Gravis." This was published in the *Journal of Neurology* in 2024. Another one is "The Impact of Diagnosis Delay on European Patients with Generalized Myasthenia Gravis," and that was published in the *Annals of Clinical and Translational Neurology* in 2024. And the last I would recommend is a paper published in 2022 in *Neurology and Therapy* entitled, "Physician-Reported Perspectives on Myasthenia Gravis in the United States: A Real-World Survey." Each of these particular studies involved about 400 patients, so it was a pretty good sample size, and some of the statistics that I've shared came out of these papers. It's eye-opening. Again, the delay with myasthenia gravis is linked to poorer patient outcome, so us addressing this will have a very material impact on the quality of care we provide for our patients, the burden of morbidity and mortality associated with myasthenia gravis, and, of course, quality of life.

Announcer:
That was Dr. John Morren discussing the impacts of diagnostic delays on patients with generalized myasthenia gravis. To access this and other episodes in our series, visit *NeuroFrontiers* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening!