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Beyond the Symptoms: The True Impact of gMG on Patients' Lives

Announcer:

Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

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Dr. Silvestri:

This is CME on ReachMD, and I’m Dr. Nick Silvestri. Here with me today is Dr. James Howard.

Dr. Howard, let’s dive right into our discussion by addressing the burden of generalized myasthenia gravis, or gMG, on the quality of life of patients and their caregivers.

Dr. Howard:

Thanks, Nick. I think we need to look at burden of myasthenia in two ways. One is the burden of disease, the impact of the weakness itself, as well as the burden of treatment. Both have tremendous impacts on the quality of life of the individual.

The burden of disease, the muscle weakness itself, fluctuates. That’s the semiquinone of myasthenia gravis. And because of its fluctuation, it’s not predictable to the patient when it’s going to come, to what degree of severity, and as such, we see this interfering with their ability to interact with family, interact with friends, to get out and socialize. The individual is fearful that the fact that they may develop significant weakness at a point in time where they’re not near home, do not have resources to rest, etc.

So this unpredictability is a significant problem for our patients with MG. Similarly, the double vision with a ptosis, which fluctuates, the proximal weakness, and I’ve had patients be accused of being intoxicated because they stagger. They’re fearful to be in crowds because of the instability that they have because of their weakness, etc., and with their double vision, to be able to manipulate in close quarters and read signs, etc.

And then we have to look at the burden of treatment. The adverse event profiles of many of our standard of care therapies are literally legion and tremendously affect the quality of life of the patient. For instance, corticosteroids often have difficulties with mood swings. And this clearly impacts social interactions, with spouse, with family, with coworkers, etc.

Patients with mycophenolate may be prone to have diarrhea. I have one patient who was having up to 20 stools a day and literally became a hermit in her home because she was fearful of soiling herself if she were out in public. The other adverse events, in terms of renal dysfunction, liver dysfunction, the necessity of having to have frequent laboratory assessments made, impact the quality of life for some.

And then there are the logistics of treatment. For some, getting therapeutic apheresis must be done in hospital rather than as an outpatient. In both instances, they must go to a facility to receive their care. Intravenous immunoglobulin in the United States may be administered at home, but often, one has to go to an outpatient infusion facility. And in Japan, one is hospitalized to receive intravenous immunoglobulin. All of these things impact the quality of life that the individual has to interact with family, grandchildren, children, etc. So it's a widespread problem.

It's for these issues that we're seeking new therapies to ameliorate both of the adverse event profiles of our patients but to work more quickly than our current standard of care does to provide them with a much better quality of life.

Dr. Silvestri:
Thanks, Chip. That was a great overview, and obviously, another thing that we have to think about is our symptoms that traditionally haven't been thought to be due to myasthenia but affect our patients. For example, fatigue. We can, in many cases, control patients' every other symptom except they have persistent fatigue.

Dr. Howard:
In fact, fatigue is one of the most singularly prominent complaints that our patients have.

Dr. Silvestri:
Another aspect of treating patients with myasthenia gravis is really enlisting the help of our colleagues in other disciplines, so using a multidisciplinary approach. And this differs from patient to patient depending on their symptoms, depending on their needs.

Well, Chip, this has been a great bite-size discussion, but our time is up. And thanks, everyone, for listening.