

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/quality-of-life-challenges-in-gmg-care-navigating-the-invisible-burden/35493/>

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Quality-of-Life Challenges in gMG Care: Navigating the Invisible Burden

Announcer:

This is *NeuroFrontiers* on ReachMD. On this episode, we'll hear from Dr. Maxwell Levy, who will discuss how we can optimize the quality of life for patients with generalized myasthenia gravis. Dr. Levy is an Assistant Professor of Neurology and the Residency Program Director at Tulane University in Louisiana. Let's hear from him now.

Dr. Levy:

When it comes to quality of life in generalized myasthenia gravis, there are many unmet needs in clinical practice today. The first of these is very patient centered. This is a not easily visible disability. Obviously, if a patient is very weak, it can be seen clearly in their movements and their gait. People around them can tell. But one of the hallmarks of myasthenia is its variability. There are good moments and bad moments as well as good days and bad days. Patients have ways of predicting these, but they have a much better intuition of this than people around them. Their friends, their family, and their employers may not get a good sense of what really drives that variability. They see them on a good day because that's when they can get out and see people in their lives, but they don't necessarily see it on a bad day. They don't understand what the progression or exacerbation of weakness means.

Another thing that very much is an unmet clinical need is in terms of physical activity and exercise. Exercise is something that is still indicated for patients with generalized myasthenia gravis, even though it may be a little bit more difficult. Because of their weakness, patients are at a higher risk for falls or having other physical injuries when they're not able to access the kind of strength that they need. If they require physical therapy, this may require closer discussion with their physical therapists. The role of a physical therapist often is to push patients to the extent of their abilities, but this is something that is a little bit tricky in myasthenia gravis. If you work in a densely populated area, you may have a physical therapist that you can work with on a repeated basis and establish a rapport, and they may have the ability to specialize in some sorts of neurologic therapy. However, if your patients come from a further distance, you may need to reach out to individual therapists to discuss their plan of treatment more in depth than you would with patients that have more conventional conditions.

There are many different clinical, psychological, and social strategies that can be effective in supporting patients' quality of life. One of the most important ones that I've found is having patients follow some sort of objective marker of their strength and well-being at home. As patients get onto treatment and as their myasthenia comes under better control, they may find that they're able to do more, exercise more, exert themselves more, and get out more, and this, in turn, induces fatigue. So even though the patient is doing better, they still feel the same level of fatigue. If they have some sort of referential marker that they can look at or have some sort of benchmark, this can help them gain some perspective, and it's really helpful in having patients feel better and understand the quality of life that they have gained. This may be something about how far they can walk without resting, whether it's around their block or in the grocery store, or it may be more event-driven. Can they sit through their child's whole baseball game in the summer heat, or do they need to go into the car and take a break in the air conditioning?

Announcer:

That was Dr. Maxwell Levy sharing strategies for optimizing patients' quality of life in generalized myasthenia gravis care. 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!