The goals of treatment of myasthenia gravis (MG) are to (1) keep patients safe and alive, (2) allow them to do what they want to do when they want to do it, (3) limit symptoms, (4) minimize effect of the disease on quality of life, and (5) give patients a better future. There are now a handful of excellent MG-specific outcome measures, including the Myasthenia Gravis Impairment Index (MGII), which can assist us in our efforts.¹

As described in the article by Barnett et al., “Development and validation of the Myasthenia Gravis Impairment Index,” the MGII comprises 22 patient-reported items and 6 items from the examination. This MG-specific scale estimates ocular, bulbar, breathing, limb and neck strength, and endurance, and in that sense, it is similar to other validated MG-specific scales.²,³ Where its development and validation differ somewhat from other MG scales is in the use of now widely accepted modern clinimetric methods and use of recent scale development guidelines—including the late 2009 Food and Drug Administration (FDA) Guidance on patient-reported measures.⁴ In contrast, for example, colleagues and I initially developed and validated the MG-specific quality of life measure, the MG-QOL15, without using Rasch analysis and before publication of the 2009 FDA Guidance. And because of this, it was important to subject the MG-QOL15 to later scrutiny, including Rasch analysis, through an international collaboration, an effort that resulted in minor revisions to the current MG-QOL15r.⁵ Barnett et al. instead built their scale from the ground up using the latest methods and guidelines, as well as an appropriate amount of old-fashioned common sense. Because of their judicious efforts, the MGII appears well-positioned to be used in MG clinical trials, possibly as a primary outcome.

The MGII also deserves strong consideration for everyday clinical practice, which is where the power of these tools can be best realized. This is because patient-reported measures, especially disease-specific measures for chronic, symptomatic diseases, can supplement the interview and examination. These measures help provide a “high-definition video” that complements the “standard definition” interview and the “snapshot” examination. While these surveys do not substitute for the interview, they often preserve precious time, allowing more time to get to know the patient as a person, for drilling down on manifestations whenever necessary, and for counseling and education. I find that asking patients to complete a disease-specific, patient-reported survey while I am doing something else, such as completing my mandated clicks in the electronic health record, improves my efficiency and results in a more satisfying interaction for everyone. These validated surveys also provide a consistent, standardized approach to the assessment, which both patients and providers find beneficial. Furthermore, the wording of items has already been optimized. Thus, disease-specific, patient-reported surveys help you ask the right questions the right way, at each and every visit.

The items of a disease-specific, validated scale have been carefully selected by considering their relevance, meaningfulness, reliability, and responsiveness, among other qualities. Thus, by including the essential questions that should be asked at an encounter, they provide a cheat sheet for clinicians. Barnett et al. have done an admirable job working with patients to create, select, and later validate the items they chose for their MGII. It is noteworthy that the MGII includes an item for generalized fatigability, something patients thought was too important to exclude but MG specialists cautioned might be perilously nonspecific. And while there are dozens of different physiologic dimensions and causes, personally, as a cancer survivor, attempting to measure fatigue resonates because of my own experiences with debilitating fatigue. Not unlike patients recovering from cancer, many patients with MG also experience profound fatigue, and so I hope this item in the MGII holds up under future scrutiny.

Accepting that patient-reported measures can be a good thing and that there is more than one way to measure disease status, the selection of measures should consider statistical performance and other factors: ease-of-use and ease-of-interpretation; the use of the measure (e.g., to estimate severity that day or for measuring changes in status over time); logistical considerations (e.g., time available, who is administering); and, for patient-reported measures, the clinician’s estimate of
the reliability of the responses, judged on a patient-by-patient basis. This last challenge is an excuse some clinicians give for their reluctance to incorporate patient-reported surveys into their clinical practice. This has always perplexed me and strikes me as akin to “throwing out the baby with the bath water.” We already know that there is no substitute for putting patient responses in their proper clinical context and for judging their reliability during every encounter—we already do this with any patient interview. Throwing out unreliable responses, such as sometimes happens with the disability seeker or someone with substantial comorbidities, is simply part of everyday patient care and, thus, is not unique to patient-reported measures.

Despite limitations, these outcome measures can provide invaluable insight into how most patients are actually doing. For example, I never felt like complaining to my doctor about my chemotherapy-induced peripheral neuropathy (CIPN); however, I always thought that my answers to the 15 items on the Chronic Acquired Polyneuropathy Patient-Reported Inventory (CAP-PRI), another disease-specific measure, told my CIPN story. Furthermore, at no point did I find any meaningful value in the status of my ankle reflexes, toe flexion or extension strength, or sural sensory amplitude; nor did the 0 to 10 pain scale seem useful in expressing how CIPN was affecting me. My struggle expressed itself clearest in my CAP-PRI responses, and I believe the struggle of living with MG often expresses itself clearest in MG-specific, patient-reported scales, including the MGII.

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**REFERENCES**


