

Unmasking the Iceberg: Quality of Life in Myasthenia Patients

समदोषः समाग्निश्च समधातुमलक्रियः।

प्रसन्नात्मेन्द्रियमनाः स्वस्थ इत्यभिधीयते ॥ ~सुश्रुत संहिता (15:47)

Ayurveda (Sushrut Samhita, 1200-600 BC) defined health as a “happy and balanced state of soul, senses and mind”, in addition to physical equilibrium.^[1] World Health Organization also incorporated the aspects of mental and social wellbeing in defining health in 1946. So, not only an absence of disease or disability but “realising aspiration and coping up the environment” forms the basis of quality of life (QoL) considerations of health.^[2] It is still a desirable but often elusive goal in an individual’s medical management of diseases.

The impact of chronic neurological illness on patients is huge but often overlooked. On focusing on the tip of symptomatic treatment, one may easily miss the iceberg (‘psycho-social implications’). The more chronic and severe the disease, the more chance it gets to evoke social and mental issues. Lifestyle changes made by the patients of chronic diseases may vary from subtle adjustments in day-to-day work schemes to a transformative alteration like substitutions of life goals, employment, and social makeup. Myasthenia Gravis (MG) is an example of such a disease, where a patient has to change one’s plan as per his disease status.

However, measuring QoL is an arduous task, as parameters for social and mental health are difficult to define. The scales must be validated as per community, social customs, occupation, and recreational activities. Various general and disease-specific QoL scales have been developed over the last 50 years, which try to figure out a person’s conceptual domains beyond the patient’s functional status, symptoms, disease process, or treatment-related changes.^[3]

As we are aware, MG causes fluctuating weakness of skeletal muscles, due to immune-mediated dysfunction of neuromuscular junction. Symptoms may vary from intermittent mild ptosis to a critical bulbar or limb weakness, causing dependency. MGQoL-15 scale is an abbreviated version of a 60-item questionnaire, validated, easy to use, and retains high sensitivity to clinical improvement.^[4] It measures scores ranging from 0 to 30, with a higher score indicating worse health-related QoL.

In this issue of the journal, Majigoudra G, *et al.* studied “Clinical profile and Quality of Life in Myasthenia Gravis using MGQOL-15-R (Hindi version)” from an Indian perspective. Fifty five stable myasthenia patients were

enrolled from a single outpatient center. Short Form (SF-36), a nondisease-specific, patient-reported QoL questionnaire, and Myasthenia-specific scale, MGQoL-15-R (modified, Hindi version) were implemented. In SF-36 survey, steroid use was found to have a negative correlation between physical health scores and bodily pain. In the MGQoL-15-R scale, the “I am frustrated by MG” was the most reported element and had the maximum mean score. From the management aspect, steroid dosage negatively and thymectomy status positively affects QoL scoring.^[5] The limitation of the MGQoL-15-R use in the assessment is twofold: not a good measure for a cross-sectional study, as MG has fluctuating clinical course; and there are no cut-off values for the level for different levels of impairment.

Myasthenia patients do deserve an approach to a better quality of life, besides symptom control and independence. In routine clinical practice, let us develop a positive viewpoint for the same, to unmask the iceberg.

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Submitted: 06-Jun-2023 **Accepted:** 11-Jun-2023

Published: 11-Sep-2023

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DOI: 10.4103/aian.aian_506_23