Utilization of Myasthenia Gravis Quality of Life Revised 15 (MGQOL15r) Scale in India

Patient-reported health scores (for symptoms, outcomes, and quality of life) have become integral part of comprehensive disease evaluation and management. They provide patients' perspective regarding the burden of disease, which is still persistent in many neurological disorders including myasthenia gravis even after recent advances in treatment options. Health-related quality of life (HRQOL) measurement is important in myasthenia gravis as it is a fluctuating disease, patient may not have symptoms at the time of examination, and certain manifestations might be more evident to the patient (i.e., dysphagia, fatigue). Myasthenia Gravis Quality of Life scale-15 (MGQOL15) is one such disease-specific quality of life (QOL) scale, which has been derived from a 60-item MGQOL scale and has been validated for use in myasthenia patients.[1-3] After being used worldwide for around 7 years, it was revised (MGQOL15r) for improved clinimetrics and ease of use.[4] The scale has 15 questions regarding patient's symptoms, mobility, general contentment, and emotional well-being. The score ranges from 0–30, higher score indicates worse HRQOL.

The MGQOL15r has been validated and used in languages other than English.[5-8] Few studies from India have utilized the MGQOL15 in myasthenic patients. Study done by Kumar *et al*.[9] included 50 clinically stable adult myasthenia gravis patients. QOL was assessed by using MGQOL15. The patients read English version and marked the appropriate responses; the questions were read out loud in local language for the patients who were not proficient in English. The mean MGQOL15 scores correlated with Myasthenia Gravis Foundation of America (MGFA) clinical classification, with higher scores observed in class III/IV. Patients who were on pyridostigmine had higher scores (poor QOL, *P* 0.008). Age, sex, prior thymectomy status, type of steroid treatment (oral prednisone vs pulse dose methylprednisolone) did not affect the QOL scores. The authors did not check if there was any difference in scores between patients receiving steroids vs other immunosuppressive treatments.

Vemuri *et al*.[10] administered three different measures (MGQOL15, quantitative myasthenia gravis-QMG and myasthenia gravis composite score-MGC) in 54 myasthenia patients. The MGQOL15 questions were read out to the patients in local language. The authors reported strong correlation between MGQOL15 and other scores (QMG and MGC). They also measured differences in QMG and MGC at 3 and 6 months follow-up; MGQOL15 was not administered during follow-up.

The present study published in this isssue of journal, done by Majigoudra *et al* used Hindi translated version of MGQOL15r, along with other outcome measures including the Myasthenia Gravis Activities of Daily Living (MG-ADL) score and 36-Item Short Form Survey (SF-36, non-disease specific) in 55 adult myasthenic patients whose disease was clinically stable.[11] The Hindi translation was prepared as per guidelines described by Wild *et al*.[12] As expected, the mean QOL scores were higher in patients who were more symptomatic and were in higher MGFA class. The presence of diplopia, bulbar symptoms, limb weakness, and higher steroid doses negatively impacted MGQOL15r. Patients who have had thymectomy had better scores. The scores were not affected by gender, age of onset, antibody status, or a particular immunosuppressive therapy. The authors found MGQOL15r-Hindi to be quick and simple tool to access QOL in myasthenia patients.

The study has several limitations. First, the authors did not report how the translated version was validated. Several studies have described methods for cross-cultural adaptation and validation of a translated version of QOL by using specific statistical methods to check for reliability, reproducibility, concurrent validity, and construct validity.[5-8] Second, it is unclear how the results can be generalized because of selection bias. The patient cohort included clinically stable patients seen in a tertiary care center. It is not clear from the data for how long were they in remission/had crisis. Only 10.9% of patients had bulbar symptoms and around 40% of patients had thymectomy.

The current and prior studies as mentioned above show the feasibility of using patient-reported QOL scores in myasthenia patients in India, widespread use of which will help us know the impact of MG through patients' perspective and will increase their engagement in management by shared decision-making process. Further studies with the validated translated version of MGQOL15r and with longitudinal follow-up to access the effects of intervention would be welcomed.

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