

MYASTHENIA GRAVIS QUALITY OF LIFE-15 REVISED (MG-QOL15R)

Instructions

Introduction

The MG-QOL15r is a 15-item quality of life scale designed to assess important aspects of the patient's experience related to MG. The MG-QOL15r is a validated modification of the MG-QOL15 and scores each of 15 items 0-2 (max score 30), while the MG-QOL15 scores items 0-4 (max score 60). In addition, the wording of some items was modified in the MG-QOL15r compared to the MG-QOL15.

The MG-QOL15r component items were chosen to reflect physical, psychological, and social domains of patient well-being. The scale was developed as a patient reported outcome measure and the consensus among experts is that the MG-QOL15r should be self-reported by the patient.

Procedures for Administration

The patient should be provided with the MG-QOL15r form that includes instructions for self-completion. Remind the patient to answer items based on the impact MG has had their quality of life over the past 4 weeks. The patient with MG should complete the MG-QOL15r without evaluator input or guidance. Similarly, no family members or other visit attendees should provide input to the patient on how to answer the items.

Evaluator Review

The evaluator should review the MG-QOL15r once the patient has completed the form.

- If any MG-QOL15r item is not completed by the patient, inquire whether the omission was intentional or not. If omitted in error, then ask the patient to complete.
- If a patient asks for clarification about a question, please simply remind the patient to answer questions based on the impact of their MG-related symptoms. Do not help the patient to tease apart relative contributions from MG and non-MG causes.
- If a patient makes a mark on the boundary line between two scores or marks two scores, ask the patient to clearly select only one score.

Revised Myasthenia Gravis Quality of Life-15 (MG-QOL15r)

This form includes 15 questions related to how your quality of life is affected by MG-related symptoms.

For each item, please read the question, and then choose the one answer that best describes the average impact of your MG on your quality of life over the past 4 weeks. You may have had good days and bad days. Please select the answer that best describes how you felt on average.

Please answer all questions by circling the response that best describes your MG-related symptoms. Do not leave any item blank. If an item does not seem to apply to you, score as 0.

Please keep in mind the following as you complete the form:

- Score each item based on how you feel given that you are taking your current MG medications. Do not try to imagine how severe your symptoms might be if you were not taking your MG medication.
- You may be in doubt about how to answer a question. If this happens, choose the option that is most appropriate for you most of the time over the past 4 weeks.
- Sometimes it can be difficult to determine whether a particular symptom is related to MG or to some other condition. When responding, please use your best judgement and try to consider only symptoms related to your MG. Exclude symptoms arising from any other illness you might have.
- Complete the form without input or guidance from family members or other attendees.

Participant ID: _____

Visit ID: _____

Date of Evaluation: _____

MG-QOL15r Scale

Please indicate how true each statement has been (over the past 4 weeks).

- 1. I am frustrated by my MG
- 2. I have trouble with my eyes because of my MG (e.g. double vision)
- 3. I have trouble eating because of MG
- 4. I have limited my social activity because of my MG
- 5. My MG limits my ability to enjoy hobbies and fun activities
- 6. I have trouble meeting the needs of my family because of my MG
- 7. I have to make plans around my MG
- 8. I am bothered by limitations in performing my work (include work at home) because of my MG
- 9. I have difficulty speaking due to MG
- 10. I have lost some personal independence because of my MG (e.g. driving, shopping, running errands)
- 11. I am depressed about my MG
- 12. I have trouble walking due to MG
- 13. I have trouble getting around public places because of my MG
- 14. I feel overwhelmed by my MG
- 15. I have trouble performing my personal grooming needs due to MG

Not at all 0	Somewhat 1	Very much 2

Evaluator Signature: _____ Date: _____

Total MG-QOL15r score