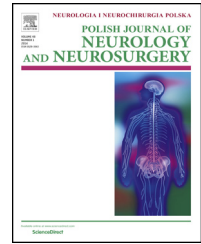


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Original research article

Validity and reliability of the Polish version of myasthenia gravis – Quality of life questionnaire – 15 item

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ABSTRACT

Aim: The myasthenia gravis-quality of life questionnaire 15 item (MG-QOL15) is a short, and easy to use disease-specific quality of life (QOL) tool in myasthenia gravis. The aim of this study was to validate and adapt the Polish version of the MG-QOL15.

Materials and methods: The total number of 50 patients with MG were qualified for the examination. Each patient underwent neurological examination and completed the quality of life evaluation questionnaire MQ-QOL 15 after translation and back-translation. Additionally, each patient was asked to evaluate the quality of his/her life by means of questionnaire SF-36 in Polish language version.

Results: The MG-QOL15 was found to have high internal consistency, test-retest reliability, and concurrent validity.

Conclusion: The MG-QOL15 is accepted to be a valid, reliable, valuable tool for measuring disease-specific QOL in Polish patients with MG.

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1. Introduction

Myasthenia gravis (MG) jest acquired autoimmune disease, the basic pathomechanism of which is based on production of auto antibodies directed against acetylcholine receptors (anti-AchR) of post-synaptic membrane of neuromuscular junction. The major symptom of MG is progressive myasthenia, for which the following are typical: symptoms of apocamnosis of extremities muscles and facial mimetic

muscles, diplopia, eyelid dropping, dysphagia, dysarthria [1,2]. Myasthenia gravis is characterized by big diversity of its course. Some patients complain about numerous clinical symptoms, which to a smaller or bigger extent make everyday functioning difficult, however, the majority of patients remain in the disease remission period due to the applied treatment. The remission condition is often not a condition without occurrence of neurological symptoms [3]. Even small MG symptoms may cause deterioration of the patients' life quality by influencing both their private and professional lives. The

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evaluation of the quality of life can be conducted using questionnaire MG-QOL 15 (MG – quality of life 15) [4]. The obtained results together with the assessment of neurological condition provide a possibility of holistic approach to a patient, and thus applying a more efficient therapy.

In our paper we want to present the obtained results of validation of the quality of life evaluation scale MG-QOL 15 of patients with myasthenia gravis, conducted on Polish population.

2. Materials and methods

2.1. Patients

The examination was conducted in Clinic of Neurology in years 2015–2016. The criteria of inclusion covered patients with diagnosed myasthenia gravis (ocular and generalized) confirmed by neurological examination and on the grounds of assessment: presence of antibodies against acetylcholine receptors, electro physiological examinations (electrostimulation and single-fibre electromyography studies), neuroimage examinations results (mediastinum MR or TK). The group was representative as regards age and gender. The specific characteristics of patients covered by the examination were presented in Table 1.

The total number of 50 patients with MG were qualified for the examination. Each patient underwent neurological examination and completed the quality of life evaluation questionnaire MQ-QOL 15 [4]. Additionally, each patient was asked to evaluate the quality of his/her life by means of questionnaire SF-36 in Polish language version [5,6]. For reliability assessment (test-retest) all the examined persons were asked to complete questionnaire MG-QOL 15 again during the follow-up visit after four weeks. The examined patients were qualified to selected groups in MGFA classification depending on the neurological evaluation of their condition [7]. The work described in this article has been carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans No. KNW/0022/KB1/68/15; uniform requirements for manuscripts submitted to biomedical journals. Each patient expressed a written consent to participation in the research.

2.2. Adaptation procedure questionnaire MG-QOL 15

Before the initiation of the validation process we obtained a permission from the author's scale to conduct translation and examinations using questionnaire. The MG-QOL 15 questionnaire was prepared in the USA by Professor Ted Burns et al. in 2008 on the grounds of myasthenia gravis (MG)-specific quality-of-life (QOL). Instrument was reduced from 60 items to 15 items while maintaining potential usefulness in the clinic and in prospective treatment trials. The quality of life evaluation form MG-QOL 15 consists of 15 questions. Each question is assigned from 0 to 4 points, the maximum number of obtainable points is 60. The particular questions constitute the evaluation of physical, emotional, social functioning as well as influence on professional and family life and pleasures.

Table 1 – Demographic and clinical characteristic of patients enrolled into the study.

Patients with myasthenia gravis (n)	50
Myasthenia character:	
Ocular (%)	48
Generalized (%)	52
Mean age (years)	60.66 ± 12.41
Average age (years)	30–81
Mean duration of disease (years)	9.48
Average of disease (years)	0.5–34
Gender:	
Female (%)	56
Male (%)	44
Mean antibodies against rec. Ach (nmol/l)	8.79
Average antibodies against rec. Ach (nmol/l)	0.1–85
Thymoma (%)	10
Residual thymus (%)	56
Tymectomy (%)	58
Electrical activity in repetitive nerve stimulation (%)	
86	
Treatment:	
Anticholinesterase drugs (%)	98
Steroids (%)	16
Azathioprine (%)	6
Mean doses of anticholinesterase drugs (mg per day)	197.8
Mean BMI	24.96
Average BMI	21.15–32.75
Main neurological symptoms:	
Diplopy (%)	44
Eyelids drooping (%)	72
Difficulty chewing (%)	10
Dysphagia (%)	16
Dysarthria (%)	20
Dyspnoea (%)	4
Apokamnosis symptoms of limbs and mimetics muscles (%)	40

The higher the score of the examination the worse the patient perceives the quality of his/her life [4,8].

In conformity with the requirements double translation from English to Polish and again to English was made. The translation was made by two bilingual teachers (Polish and English languages) in collaboration with Polish medical doctors fluent in spoken and written English. Two independent versions of translation of the original version of MG-QOL 15 were created and on their grounds the discrepancies were corrected, with particular interest in grammatical and linguistic conditionings. Finally, a Polish language version of questionnaire MG-QOL 15 was obtained, the content of which preserved the original meaning. The next stage was to retranslate or translate again the newly obtained scale back into the original language by a translator whose native language is English but who is also fluent in Polish. The Polish version form prepared in the above manner was subjected to evaluation of linguistic correctness by having it completed by healthy Polish language speakers. The questionnaire was completed by 30 persons, who were a representative group in the aspect of gender, age and education. This procedure allowed the confirmation of proper linguistic construction necessary to understand the questions correctly.

In the next stage 50 patients again completed questionnaire MG-QOL 15 during the follow-up visit after 4 weeks from the

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