



The Impact of Neuromuscular Diseases on Patients' Quality of Life: A Call for Action

Ivan Barbov¹⁻³ and Goce Kalcev^{3*}

¹University Clinic of Neurology, Skopje, Republic of North Macedonia

²Faculty of Medicine, St. Cyril and Methodius-Skopje, Skopje, Republic of North Macedonia

³National Alliance for Neuromuscular Diseases and Neuroscience, GANGLION Skopje, Skopje, Republic of North Macedonia

*Corresponding Author: Goce Kalcev, National Alliance for Neuromuscular Diseases and Neuroscience, GANGLION Skopje, Skopje, Republic of North Macedonia.

Received: August 31, 2023

Published: September 01, 2023

© All rights are reserved by **Ivan Barbov and Goce Kalcev.**

Keywords: Quality of Life; Neuromuscular Diseases; INQoL

Neuromuscular diseases (NMDs) are a broad category of illnesses that affect muscle function either directly through pathologies of the muscles or indirectly through pathologies of the nerves or neuromuscular junctions [1]. As a result of the progressive nature of NMDs, which can result in muscle spasticity or weakness, there is an increasing urgency for supportive devices as well as both medical and non-medical support [1]. These illnesses vary in terms of their features, including inheritance patterns, the nature of genetic mutations, incidence, symptoms, age at onset, rate of progression, and prognosis. Today, neurology, rehabilitation, rheumatology, immunology, cardiology, pulmonology, and gastroenterology are just a few of the medical specialties where neuromuscular diseases manifest [2]. The standard of care for the management of these patients includes an integrated and multidisciplinary approach. The majority of NMDs involve loss of sensory function as well as progressive physical deterioration caused by impairing muscles in the upper and lower extremities. These are the most typical signs, along with weakness in the muscles used for breathing, swallowing, and speaking [1,2]. As well, it is well known that individuals with neuromuscular diseases typically have unbalanced emotional and psychological functioning. However, the effect of NMDs on mental functioning is determined by the characteristics and severity of the symptoms associated with each NMD [2,3].

Regarding quality of life (QoL), the World Health Organization (WHO) started conceptualizing and creating measurement tools

for evaluating people's subjective QoL. The WHO defines QoL as an individual's perception of their state in life in relation to their goals, expectations, standards, and concerns, as well as the culture and value systems in which they live. NMDs outcomes have a significant negative impact on quality of life [4]. Hence the urgent need for instruments that will evaluate the impact of these disabilities on perceived quality of life. Another very important objective is the prevalence and severity of stigmatization in persons diagnosed with an NMD and its impact on their quality of life.

Considering the critical need for new innovative tools, one of the most promising is the Individualized Neuromuscular Quality of Life Questionnaire (INQoL), which is adapted for adults with neuromuscular diseases. This instrument is a muscle disease specific QoL measure which has been developed and validated in the United Kingdom on a diverse group of patients with neuromuscular disorders [5]. INQoL has also been validated in other countries, confirming that it is a reliable, valid, and practical measure for assessing QoL that can capture issues specific to the muscle condition. The INQoL is composed of 45 items. The impact of common muscle disease symptoms (weakness, myotonia (locking), pain, and fatigue) is discussed in four sections. Five examine the extent and significance of the impact of muscle disease on specific aspects of life (activities, independence, relationships, emotions, and body image). The final section discusses treatment, its effects, and expectations [5].

The area of QoL research in neuromuscular disease is complex and difficult for a variety of reasons, such as the large number of neuromuscular diseases under investigation, the large number of QoL outcome measures being used, and the dynamic nature of everything that affects one's QoL.

Funding

This research received no external funding.

Acknowledgment

This research has no acknowledgment.

Conflicts of Interest

The authors declare no conflict of interest.

Bibliography

1. Margeta M. "Neuromuscular disease: 2022 update". *Free Neuropathology* 3 (2022): 3-5.
2. Margeta M. "Neuromuscular disease: 2023 update". *Free Neuropathology* 4 (2023): 4-2.
3. Dewilde S., *et al.* "Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG". *BMJ Open* 3.1 (2023): e066445.
4. Siyazbekova Z., *et al.* "Using of the World Health Organization quality of life instrument, short form to patient after PCI or CABG surgery". *Bratislavské Lekárske Listy* 123.12 (2022): 891-896.
5. Vincent KA., *et al.* "Construction and validation of a quality of life questionnaire for neuromuscular disease (INQoL)". *Neurology* 68.13 (2007): 1051-1057.