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REVIEW

Assesment of quality of life in neurological diseases

Nörolojik hastalıklarda yaşam kalitesi değerlendirilmesi

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ABSTRACT

Health-related quality of life shows how a person is affected physically, emotionally, perceptually, and socially by the disease, the consequent disability, and treatment and rehabilitation processes. It is important to evaluate the quality of life of patients and their caregivers with generic or specific scales during the diagnosis, treatment, and follow-up stages of neurological diseases. In studies conducted in our country, scales with Turkish validity and reliability must be used. Additionally, it should be noted that quality-of-life scales do not measure every parameter with the same sensitivity.

Keywords: Generic scales, neurological diseases, quality of life, specific scales.

ÖZ

Sağlıkla ilgili yaşam kalitesi, kişinin hastalıktan, onun yarattığı engellilikten, tedavi ve rehabilitasyon süreçlerinden bedensel, duygusal, algısal ve sosyal olarak nasıl etkilendiğini gösterir. Nörolojik hastalıkların tanı, tedavi ve takip aşamalarında, hastaların ve bakım verenlerin yaşam kalitesinin jenerik veya özgül ölçeklerle değerlendirilmesi önemlidir. Ülkemizde yapılan çalışmalarda, mutlaka Türkçe geçerlik ve güvenirliği yapılmış ölçekler kullanılmalıdır. Ayrıca, yaşam kalitesi ölçeklerinin her parametreyi aynı hassasiyetle ölçmediği unutulmamalıdır.

Anahtar sözcükler: Jenerik ölçekler, nörolojik hastalıklar, yaşam kalitesi, özgün ölçekler.

Quality of life (QoL) encompasses the concept of health but extends beyond it, forming a new concept comprised of various domains, including physical, psychological, environmental, social, cultural, and many others. Quality of life is not determined by a single parameter and enables a comprehensive evaluation of a patient's life, taking into account not only the loss of function due to illness but also mental impacts, interactions with family members at home, social status, and perceptions.[1]

Chronic illnesses constitute a change in QoL.[2] As in all areas of medicine, QoL is of great importance in neurological diseases. Quality of life parameters should be considered during the diagnostic phase, monitoring the effects of treatment and rehabilitation, and assessing prognosis; in short, QoL is considered at every stage of the disease.

The World Health Organization defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns."[3]

Health-related QoL reflects the impact of disease, disability, and treatment-related daily functional impairments on an individual's life.[4]

Health-related QoL scales can be categorized into three groups: self-reported scales, generic scales, and disease-specific scales.[5] Self-reported scales can provide more accurate information about how much

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the patient benefited from the treatment. Generic scales are validated scales used across a wide range of chronic diseases. However, these scales may not be compatible with the specific conditions created by a particular disease, leading to lower sensitivity. Disease-specific scales are precisely designed for the disease and can detect minor details. The advantage of the combined use of generic and disease-specific scales is to compare different diseases and observe the differences in disease-specific scales.[1,6]

The choice of scale depends on the study's aim. The goal should be to find a scale with good psychometric properties for every health condition. Although disease-specific QoL measurements reflect the specific impact of a disease in more detail, generic tools are preferred for comparing QoL across different diseases and control populations. It is crucial that the chosen scale is validated by considering the influence of cultural characteristics.[1]

Evaluating patients' QoL plays a decisive role in treatment continuity and changes in treatment processes and thus should not be overlooked.

The Short Form 36 (SF-36), EuroQol (EQ-5D), and the World Health Organization Quality of Life scale long form (WHOQOL-100) and short form (WHOQOL-BREF) are commonly used and validated generic scales used in Türkiye.[7-10]

This study reviewed QoL scales with Turkish validity and reliability for the following neurological diseases using open access sources available on the internet: Parkinson's disease (PD), dementia, stroke, neuropathic pain, myasthenia gravis (MG), amyotrophic lateral sclerosis (ALS), myopathies, multiple sclerosis (MS), epilepsy, and headache.

QUALITY OF LIFE IN PARKINSON'S DISEASE

In PD, besides motor and nonmotor symptoms, cognitive status, sex, age, duration of illness, social status, and coping skills affect QoL. Generic QoL scales used in PD include SF-36, Sickness Impact Profile (SIP), WHOQOL-BREF, Questions on Life Satisfaction-Movement Disorders, and 15D (15-dimensional instrument of health-related quality of life).[10] The following disease-specific scales validated in Turkish are used under appropriate conditions: Parkinson's Disease Questionnaire (PDQ-39), Parkinson's Disease Questionnaire Short Form (PDQ-8), Nonmotor Symptoms Questionnaire, and Scales for Outcomes in Parkinson's Disease (NMS-Quest)-Autonomic (SCOPA-AUT) and SCOPA-Sleep (SCOPA-S).[11-16] The motor symptoms that most significantly affect general QoL are gait disturbances and complications related to treatment.[17] Nonmotor symptoms are significant and independent causes of poor QoL in PD, with studies indicating that depression is the strongest predictor of low QoL among nonmotor symptoms.[18] However, various outcomes have been obtained with different QoL scales. In the study by Balzer-Geldsetzer et al.,[19] findings from three scales (EQ-5D, PDQ-39, and WHOQOL-BREF) were compared among patients with PD. Depression associated with PD was poorly assessed with EQ-5D, while it was better evaluated with PDQ-39 and WHOQOL-BREF. The EQ-5D, widely used for its conciseness and convenience, has been found insufficient in assessing depression in PD.[19] Therefore, when evaluating the impact of specific parameters on QoL in Parkinson's patients, using scales that adequately assess these parameters is crucial.

QUALITY OF LIFE IN DEMENTIA

Dementia encompasses a group of diseases with irreversible destruction in cognitive, social, and physical functions. Impaired insight, behavior, judgment, and perception, as well as anxiety and depression, are present to varying degrees in these patients. The generic scales validated for dementia patients in Türkiye include WHOQOL-100, WHOQOL-BREF, SF-36, and Nottingham Health Profile (NHP); disease-specific scales include the Alzheimer's Disease-Related Quality of Life (ADRQL), Disability Assessment for Dementia (DAD), and Quality of Life-Alzheimer's Disease (QOL-AD).[20-24] Neuropsychiatric symptoms are the most impactful on the QoL in dementia patients. An individual's physical health, psychological condition, level of independence, social relationships, personal beliefs, environmental support, and whether they have a caregiver affect the QoL.[25] Caregivers of patients with Lewy body dementia (LBD) were demonstrated to have a worse QoL compared to caregivers of patients with Alzheimer's disease, which was associated with the presence of hallucinations in patients with LBD.[26] Information about a dementia patient's QoL is obtained from the caregiver, and the caregiver's own QoL can influence the information provided about the patient.[27] As dementia patients' insight impairment related to their condition increases, the QoL of caregivers decreases.[28] Depression and anxiety in caregivers have been identified as the most significant factors for poor caregiver QoL.[29,30] Additionally, a caregiver's mental, physical, and

overall health parameters and sleep quality all impact their QoL.[31] The QoL of caregivers can be assessed with health-related, self-reported, caregiver-specific scales. In studies involving dementia patients, evaluating the general QoL of caregivers is crucial. While there are other scales that are not validated in Turkish, the commonly employed scales are the Zarit Caregiver Burden Interview.[21,32,33] However, assessing objective measures, such as the time spent on care and the duration of caregiving, would also be beneficial.[29,34] Providing financial and social support to caregivers, as well as freedom for their activities, enhances the caregiver's QoL.[35] The impact of pharmacological treatments for dementia on improving QoL is limited. Occupational therapies, such as art therapy, music therapy, exercise, and cognitive therapy, showing improvements in cognitive, emotional, behavioral, and social effects on QoL have been supported by studies.[36-38] Patients with early- and middle-stage Alzheimer's disease and their primary caregivers have been shown to acquire positive effects from these therapies, reducing the need for antipsychotics.[37,38] The impact of treatment and support approaches on QoL in dementia patients and caregivers require a comprehensive evaluation with appropriate scales.

STROKE AND QUALITY OF LIFE

Stroke causes significant functional limitations and is a prominent health issue that directly affects the QoL of the individual and their family. Generic scales validated in Turkish, such as the Multidimensional Scale of Perceived Social Support (MSPSS), EQ-5D, NHP, SF-36, Frenchay Activities Index, and WHOQOL–BREF, are used to assess QoL in these patients.[3,7-10,20,39,40] Stroke-specific validated scales include the stroke and aphasia QoL scale-39, Stroke Impact Scale version 3.0, and Stroke-Specific Quality of Life Scale (SS-QOL).[41-44] Generic scales and disease-specific scales, whether through self-reporting or assessment by another, may assess the same areas but do not show perfect correlation.[45] When evaluating QoL in these patients, it is necessary to consider physical, emotional, cognitive, and social aspects together. During the rehabilitation process, aspects such as mobility, language functions, occupation, productivity, personality, energy, depression, sleep disorders, roles in family and society, and reintegration into social life are important parameters to be investigated for QoL.[46] In the literature, there are few studies investigating the relationship between stroke subtypes and QoL, as well as studies evaluating QoL in relation to returning to work after a stroke. Generally, individuals in administrative positions and those who are self-employed have been found to have a higher frequency of returning to work.[47] Poor educational level, low family income, and living in remote rural areas must be considered since these factors complicate rehabilitation and affect QoL. Individuals with left hemisphere infarcts, as their language functions are affected, have weaker cognitive function, require more support in daily living activities, and, consequently, have lower QoL.[48]

NEUROPATHIC PAIN AND QUALITY OF LIFE

Most neuromuscular diseases require lifelong management. Pain, physical weakness, intensive rehabilitation, respiratory support, and surgical interventions affect patients' daily life activities and their QoL.[49] Neuropathy impacts both mental and physical well-being, leading to low QoL and physical disability through paresthesias, allodynia, autonomic disorders, anxiety, sleep disorders, fatigue, and depression. Sensory loss leads to the development of pressure ulcers, balance disorders, and a varying degree of gait disturbance, which, in turn, increases the potential risk of falls. The decrease in physical activity results in less participation in social activities, dependence on others, social isolation, depression, and a more sedentary lifestyle.[50] There are studies investigating the effects of various physiotherapy techniques, different etiologies of neuropathy, type of fibers affected, drug treatments, and acupuncture or other techniques on QoL parameters.[51-53] The generic QoL scales NHP, SF-36, SIP 68, and the Functional Assessment of Cancer/Gynecologic Oncology Group-Neurotoxicity (FACT-GOG-Ntx) are validated and used for neuropathies.[7,20,54,55] Scales validated in Turkish for neuropathic pain include the Neuropathic Pain Impact on Quality of Life Questionnaire (NEPIQoL), Brief Pain Inventory (BPI), Pain Self-Efficacy Questionnaire (PSEQ), and the short form of the Leeds Assessment of Neuropathic Symptoms and Signs (S-LANSS).[56-59]

MYASTHENIA GRAVIS AND QUALITY OF LIFE

In generalized MG, overall QoL is more affected compared to ocular MG and MG in remission. The affected parameters primarily are physical function, physical roles, pain, energy, and social

functions.[60-62] The MG-specific scale validated in Turkish is the 15-item MG Quality of Life scale (MG-QOL15).[63] Difficulty in chewing solid foods and difficulty breathing at rest were identified as the parameters most negatively affecting QoL in MG when disease-specific scales were used.[64] Physical impairments leading to changes in profession or jobs and depression were also noted as factors that reduce QoL.[65] Successful treatment of MG positively influences QoL.[66] However, the reduction in QoL persists in patients receiving aggressive treatment to prevent a myasthenic crisis, those who are treatment-resistant, and those with ongoing active disease.[67]

AMYOTROPHIC LATERAL SCLEROSIS AND QUALITY OF LIFE

Amyotrophic lateral sclerosis affects patients' functionality and QoL by having a significant impact on various domains, such as economic, social, emotional, and family life, in addition to causing a gradual decrease in physical capacity, falls, difficulties in breathing, eating, and communication and increasing dependency in daily life activities.[49,68] Generic scales that primarily assess functional status, such as SF-36, SIP, and EQ-5D, are most commonly used in QoL studies on these patients.[7-9] Disease-specific scales that have been validated include the Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ) and the revised Amyotrophic Lateral Sclerosis Functional Rating Scale.[49,69,70] Despite the disease's progressive nature that leads to physical disability, rehabilitation is stated to positively affect QoL and contribute to self-care capability.[68,71,72] Although it does not improve muscle strength, a mild to moderate exercise regimen is beneficial and it is important to prepare a therapeutic plan according to the patient's functional independence and the stage of the disease.[73,74] Cardiopulmonary exercise tests are useful in determining the appropriate intensity of exercise for the patient and have a positive contribution to functional status[75] The impact of noninvasive ventilation on QoL in ALS patients has controversial results. The use of BPAP (bilevel positive airway pressure) has been found to yield positive outcomes in terms of vital capacity, have good patient compliance when applied at home, and extend life expectancy with early initiation; however, no direct correlation with QoL has been identified.[76]

MYOPATHIES AND QUALITY OF LIFE

In myopathies, the generic scales SF-36, SIP, and NHP are used,[7,20,54] whereas the Individualized Neuromuscular Quality of Life questionnaire (INQoL) is utilized as a disease-specific scale.[77] In myopathies, the effect of other approaches, such as pain management, fatigue management, special orthoses, and rehabilitation, on QoL becomes significant due to the lack of sufficient treatment options against progressive muscle weakness.[78] Various studies have found that despite having a lower QoL compared to healthy controls, some myopathy patients with moderate to severe disability still report good QoL.[79,80] This has been suggested as a possible intuitive coping mechanism and described by researchers as the "disability paradox." In Becker muscular dystrophy and myotonic dystrophy, although the prevalence of depression is high, some researchers have noted that psychological and emotional functions appear adequate regardless of the severity of the disease, with mood disorders having a 14% impact on QoL.[81,82] It has been emphasized that the experience of receiving a diagnosis, the feeling of uncertainty about the future, and the burden of having a hereditary disease have similar psychosocial outcomes in different muscle diseases.[83]

MULTIPLE SCLEROSIS AND QUALITY OF LIFE

Multiple sclerosis is a neurological condition that significantly impacts the QoL of young adults due to muscle weakness, visual problems, sensory changes, balance disorders, fatigue, and cognitive, urological, sexual, psychological, and social issues, resulting in lower QoL compared to healthy controls. Females experience more problems than males in terms of depression, fatigue, and bladder function disorders. Additionally, pregnancy, childbirth, and the postpartum period can negatively affect QoL in females.[84] When assessing QoL in MS, it is crucial to consider both subjective and objective factors. Objective factors include the clinical picture, social status, living conditions, and social contacts, while subjective factors cover disease perception, self-image, sense of well-being, and satisfaction with family, work, and social relationships.[85] The SF-36, EQ-5D, SIP, and WHOQOL-BREF are used as generic scales.[7-10,54] The SF-36, although useful in predicting the course of the disease, has disadvantages such as having lower sensitivity in detecting changes in QoL due to its upper and lower limits.[86] The EQ-5D is less sensitive to changes in QoL in patients with an Expanded Disability Status Scale (EDSS) score >5.[8] The SIP is more sensitive but has the disadvantage of being lengthy.[87] Disease-specific

scales that have been validated for use include the Multiple Sclerosis Quality of Life-54 (MSQOL-54) and the Multiple Sclerosis Monitoring Scale.[88,89] For assessments of depression in young individuals, the Beck Depression Inventory (BDI) is commonly used. Significant parameters affecting QoL in patients include severe disability, depression, poor sleep quality, and fatigue, with depression being notable as the primary factor. Periodical reassessment of QoL is crucial in the management of these patients.[90]

QUALITY OF LIFE IN EPILEPSY

In a systematic study conducted on children and adolescents with epilepsy, the strongest determinants of QoL were identified as the age of onset, the number of antiepileptic drugs, and parental depression, while moderate determinants were attention issues, intelligence, family structure, and parental anxiety.[91] Studies in adults have found that increased levels of seizure frequency, seizure severity, depression, and anxiety and the presence of comorbid diseases are factors determining QoL.[91,92] In older individuals with epilepsy, cerebrovascular diseases, neurodegenerative diseases, brain tumors, and head injuries account for two-thirds of cases as etiological factors, often accompanied by physical and mental disorders, and with significant impact of primary causes on QoL.[93] Furthermore, this age group has distinct features such that they tend to use multiple drug therapies and are particularly sensitive to drug side effects.[93,94] Living alone, decreased mobility, reduced participation in daily activities, and lower income levels are other factors that affect QoL. In the elderly, the recent onset of seizures, frequency of seizures, higher incidence of injuries and complications, prolonged postictal confusion, and fear and anxiety about having seizures are strong determinants of QoL. There is no definitive evidence regarding the impact of seizure type on QoL.[94] Disease-specific QoL scales used for epilepsy with Turkish validity and reliability are the QOLIE-89 (Quality of Life in Epilepsy Inventory) and QOLIE-31 (the short form of Quality of Life in Epilepsy Inventory).[95,96]

QUALITY OF LIFE IN HEADACHE DISORDERS

Headache disorders, with their increasing intensity, are neurological conditions that lead to loss of work and impact social life.[97] Migraine, chronic headaches, and drug-overuse headaches affect QoL in specific areas such as physical and mental health, social functions, and vitality. In addition, inability to control pain during attacks, productivity loss, and fear of the next attack also affect QoL. Treatments aimed at reducing headache attacks improve patients' QoL. Chronic tension headaches have been found to have a lower QoL compared to migraines, with depression and anxiety being more prominent in those with chronic tension headaches.[98] The generic scales SF-36, EQ-5D, and WHOQOL-BREF are used to assess QoL in headaches.[7-10] Disease-specific scales include the Migraine Disability Assessment (MIDAS), the 24-h Migraine Quality of Life Questionnaire (24s MQoLQ), and the Headache Impact Test (HIT-6).[99,100]

In conclusion, monitoring the QoL of both patients and caregivers in neurological diseases is essential at every stage, including diagnosis, treatment, monitoring, and rehabilitation. It is important to use validated scales in QoL studies and to employ both generic and disease-specific scales together. Care should be taken to select scales that can better assess the symptoms of interest. For bachelor or specialist theses, utilizing scales that have undergone validity and reliability studies but have not been used in other studies is another crucial aspect of research on QoL in neurological diseases.

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