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Quality of Life and its Predictors Among Neurosurgical Patients — Systematic Review of Research

Jakość życia oraz jej predyktory wśród pacjentów neurologicznych — systematyczny przegląd badań

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Abstract

Quality of life is an important aspect in the fields of medicine and health sciences. It is presented as a complex concept. Therefore, it is presented in various ways. Its interpretation and definition depends mainly on the discipline and area of study. Very often, the quality of life is also defined in the context of the well-being that a person experiences during his life. It depends on the state of health. It can take into account a wide variety of problems, because neurological diseases bring about such unwanted effects as pain, the need for medical and rehabilitation stays, social isolation, and one of the worst consequences, i.e. shortening life expectancy. Therefore, it is important to conduct research on the quality of life among neurological patients. The results obtained from the conducted and continued research on large groups of patients could constitute a specific compendium of knowledge about the situation of patients, their needs and the perceived quality of life. Therefore, the aim of this study is to present research on the assessment of quality of life and its predictors among neurological patients. (JNNN 2020;9(3): 114–118)

Key Words: neurology disease, patients, predictors, quality of life

Streszczenie

Jakość życia jest ważnym aspektem w dziedzinie medycyny i nauk o zdrowiu. Ukazywana jest ona jako pojęcie złożone. Dlatego też prezentowana jest w różnorodny sposób. Jej interpretacja oraz definiowanie zależy w głównej mierze od dyscypliny i obszaru nauki. Bardzo często jakość życia definiowana jest także w kontekście dobrostanu jakiego człowiek doświadcza w ciągu swojego życia. Uwarunkowana jest ona od stanu zdrowia. Może uwzględniać dużą różnorodność problemów, ponieważ choroby neurologiczne przynoszą tak niechciane skutki jak ból, konieczność pobytów w placówkach medycznych oraz rehabilitacyjnych, izolację społeczną, oraz jedną z najgorszych konsekwencji, czyli skrócenie przewidywanej długości życia. Istotne jest zatem prowadzenie badań nad jakością życia wśród chorych neurologicznych. Uzyskane wyniki z prowadzonych oraz kontynuowanych badań na dużych grupach pacjentów mogłyby stanowić swoiste kompendium wiedzy na temat sytuacji chorych, ich potrzeb oraz odczuwanej jakości życia. Dlatego też celem prezentowanej pracy jest przedstawienie badań dotyczących oceny jakości życia oraz jej predyktorów wśród chorych neurologicznych. (PNN 2020;9(3):114–118)

Słowa kluczowe: choroby neurologiczne, pacjenci, predyktory, jakość życia

Introduction

Quality of life (QOL) has become an essential aspect in both medicine and health sciences. QOL is presented as a complex concept that is interpreted and defined in a variety of ways depending on the discipline and area of science [1]. Many attempts have been made in the literature to define the concept of quality of life. The main problem is the lack of a uniform definition in the literature. The variety of definitions presented reflects the diverse approach to this topic. According to the World Health Organization (WHO), quality of life is defined “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” [2]. What’s more, quality of life is also defined as “...a state of well-being which is a composite of two components: 1) the ability to perform everyday activities which reflects physical psychological, and social well-being and 2) patient satisfaction with levels of functioning and the control of disease and/or treatment related symptoms” [3]. The overall joy of life also appears in literature as a definition of the quality of life [4]. Additionally, the literature also uses the term “health-related quality of life” (HRQOL). The definition of the HRQOL term is as follows: “A term referring to the health aspects of quality of life, generally considered to reflect the impact of disease and treatment on disability and daily functioning; it has also been considered to reflect the impact of perceived health on an individual’s ability to live a fulfilling life. However, more specifically HRQOL is a measure of the value assigned to duration of life as modified by impairments, functional states, perceptions and opportunities, as influenced by disease, injury, treatment and policy” [5].

The quality of life can be assessed using:

- direct interview with the patient (standardized or not),
- psychometric tests,
- standardized questionnaires,
- indirect measures, e.g. the number of patients who consequently give up therapy [1,6].

The aim of the study is to present the perceived quality of life in particular neurological diseases.

Quality of Life of Patients after Stroke

One of the most important issues of public health is the assessment of the quality of life of patients after a stroke. In most patients, stabilization of the neurological state after a stroke occurs within 5 weeks of the onset of the disease. In turn, the functional state — before 3 months. The greatest neurological improvement occurs

in the first 6 weeks, while the functional improvement lasts 2 weeks longer. According to scientists and specialists in the field of neurology, having a stroke reduces the quality of life of patients in both functional and mental dimensions [7,8]. The study by Im et al. [9] assessed the quality of life of patients after stroke after 3 months (N=181), 6 (N=175) and 12 months (N=89). The work uses the EuroQol-5D three level (EQ-5D3L) tool. The mean value of the index was 0.68, 0.65 and 0.69, respectively after 3, 6 and 12 months. It was also shown that the decline in physical fitness 3 months after the stroke had a statistically significant influence on the lower EQ-5D values of the respondent also after 3 months ($\beta=-0.583$, 95% confidence interval [CI]: -1.045 to -0.120 , $R^2=0.491$). In addition, in people who, after 6 months, observed deterioration of physical fitness and communication, lower EQ-5D values were noted (mobility: $\beta=-0.170$; 95% CI: -0.305 to -0.034 , communication: $\beta=-0.164$; 95% CI: -0.309 to -0.020 , $R^2=0.666$). Moreover, functional ambulation categories turned out to have a statistically significant impact on the assessed quality of life in each observation period (post-stroke 3 months: $\beta=0.095$; 95% CI: 0.055 to 0.134 , post-stroke 6 months: $\beta=0.118$; 95% CI: 0.070 to 0.167). Interestingly, the most frequently diagnosed and worsening problems was mood disorders (reported by 8.8%, 16.0% and 13.5% of respondents 3, 6 and 12 months after stroke, respectively). The study by Szöcs et al. [10] also assessed the predictors influencing the quality of life among patients after stroke. It was shown that the degree of disability at discharge, age, length of acute hospital stay and re-hospitalization, satisfaction with care and the type of social housing after stroke had a statistically significant influence on the perceived quality of life. The elderly and those with deficits in self-care reported worse quality of life. It is interesting that single people reported a better quality of life than those living with their family or with a medical carer. It has also been shown that the longer the period of acute hospitalization, the lower the quality of life. The study by De Wit et al. [8] also assessed HRQOL in people 5 years after the first stroke in their lives. The mean of the obtained results in the EQ-5D scale after 5 years was 63.74 (SD=19.33). It has been shown that nearly 40% of the respondents had a result below the average norm, approximately 50% obtained a result within the average norm, and the remaining 8% qualified above the norm. The degree of disability, anxiety and depression decreased the examined quality of life. On the other hand, the study by Sangha et al. [11] showed that 38.5% of respondents after a transient ischemic attack or a minor ischemic stroke experienced a reduction in the quality of life. The independent predictors lowering the quality of life after 3 months included: the initial result of the National Institutes of Health Stroke Scale (adjusted odds

ratio [OR]=1.39, 95% CI: 1.17–1.64); age (adjusted OR=1.02, 95% CI: 1.01–1.04) and recurrent stroke (adjusted OR=2.10, 95% CI: 1.06–4.13).

Quality of Life in Parkinson's Disease

Parkinson's disease (PD) from many diseases and disorders of the nervous system deserves special attention, because its specific effects affect the possibility of undertaking various forms of professional activity. Moreover, the disease has both clinical and social consequences. As PD develops, patients develop a disability that causes QOL to decline. In addition, patients often develop depressive disorders and anxiety that worsens their well-being. The studies conducted by Lo Buono et al. [12] assessed the occurrence of anxiety, depression and quality of life in people with PD. It has been shown that mobility and communications significantly affect QOL. On the other hand, Santos-García and de la Fuente-Fernández [13] determined the impact of non-motor symptoms using the Non-Motor Symptoms Scale (NMSS) in people with PD on the quality of life. It has been shown that the increase in the results obtained in the NMSS has a statistically significant influence on the deterioration of the quality of life. PD-specific motor dysfunction had a more negative effect on perceived health-related quality of life than non-mechanical symptoms (2.8% vs 0.7%, respectively). On the other hand, non-motor symptoms negatively correlated with the perceived QOL. This impact was much greater than for specific motor dysfunctions (2.8% vs 0.9%, respectively). Also, Kadastik-Eerme et al. [14] conducted a study on the quality of life among people with PD. The leading predictors of low HRQOL values were motor and non-motor aspects of everyday life and depressive disorders. The performed Spearman's correlation analysis showed the following influence of certain factors on HRQOL: disease duration ($R=0.30$, $p<0.001$), tremor dominant ($R=-0.17$, $p=0.006$), MMSE ($R=-0.25$, $p=0.0001$), cognitive impairment ($R=0.38$, $p<0.0001$), depressed mood ($R=0.35$, $p<0.0001$), anxious mood ($R=0.29$, $p<0.0001$), apathy ($R=0.33$, $p<0.0001$), night-time sleep problems ($R=0.29$, $p<0.0001$), daytime sleepiness ($R=0.35$, $p<0.0001$), pain and other sensations ($R=0.38$, $p<0.0001$), urinary problems ($R=0.30$, $p<0.0001$), constipation problems ($R=0.13$, $p=0.0281$). In addition, Fan et al. [15] also assessed the determinants of quality of life in patients with PD. It was shown that the most severe determinant of the QOL was The Epworth Sleepiness Scale ($R^2=0.02$, $\beta=0.44$, $p=0.0099$), GDS score ($R^2=0.35$, $\beta=1.05$, $p<0.0001$), female ($R^2=0.01$, $\beta=3.38$, $p=0.0257$) and disease duration ($R^2=0.04$, $\beta=0.83$, $p=0.0116$).

Quality of Life in Epilepsy

Epilepsy is a heterogenous disease due to its clinical course, aetiology, and different psychological and health consequences. Undoubtedly, epilepsy is also a disease around which — despite the progress of medical knowledge — superstitions persist, as well as an atmosphere of fear and rejection, which is an additional burden for the patient, influencing the quality of life. Many studies emphasize the negative impact of stigmatization, anxiety and depressive disorders on the perceived quality of life among patients. The studies by Coleman et al. [16] assessed the quality of life among epileptic patients twice — at the start of the study (T1) and after 6 years (T2). The Quality of Life in Epilepsy Inventory-31 items (QOLIE-31) was used in the study to assess QOL. The authors indicate an increase in the mean total QOLIE-31 score obtained in T1 ($M=58.42$, $SD=16.94$, $N=93$) compared to the result obtained in T2 ($M=63.86$, $SD=15.71$, $N=92$). The obtained difference turned out to be statistically significant ($p=0.000$). The predictors affecting QOL in T1 and T2 were: stigma, depressive disorders, anxiety, number of seizures in the last 12 months. Moreover, depressive disorders and the assessment of QOL in T1 were included among the strongest prognostic factors of QOL in T2. Also McLaughlin et al. [17] assessed HRQOL among patients with epilepsy. The main predictors influencing HRQOL were: seizure frequency, depressive disorders, and dysthymia. Luoni et al. [18] also assessed HRQOL among patients diagnosed with drug-resistant epilepsy. The strongest predictors of HRQOL were: results obtained using the Beck Depression Inventory-II questionnaire ($\beta=-0.398$, $p<0.001$), treatment-related adverse events ($\beta=-0.451$, $p<0.001$), age ($\beta=-0.060$, $p=0.008$) and pharmacoresistance grade ($\beta=0.066$, $p=0.004$). On the other hand, in the study by Szafarski et al. [19], the leading predictors were age at the onset of epilepsy and the duration of the disease ($p=0.004$ and $p=0.012$, respectively). The shorter the disease duration and the higher the age of onset, the lower the HRQOL. The study by Freidman et al. [20] showed the following predictors that negatively affect the HRQOL of patients with epilepsy: depressive disorders (slope= -19.99 [95% CI -25.16 , -14.81]; $p<0.0001$), seizure frequency (-0.17 [-0.26 , -0.07]; $p=0.001$), recurrent seizure-related head injuries (-17.02 [-22.35 , -11.69]; $p<0.0001$).

Quality of Life for People with Multiple Sclerosis

Multiple sclerosis (MS) is a central nervous system disorder characterized by inflammatory demyelinating conditions. The underlying cause of the disease is still not fully known. This condition is in many cases the

leading cause of progressive disability. Therefore, there are disturbances in everyday functioning. One of the important elements of the therapy is social support, which helps to develop life goals in functioning with the disease entity [21]. Many studies show that this functional impairment of patients with MS significantly lowers QOL [22,23]. The leading predictors certainly include: progressive disease type [24,25], disease duration [26], relapses within the last 3 months [24], fatigue [23,27]. Other factors of decreased QOL include depressive disorders [23,27] and anxiety [28,29]. Also, a high level of perceived stress [29,30] and apathy [27] have a negative impact on QOL.

Conclusions

Quality of life is a field that is increasingly presented in the research of many sciences, namely in economics, sociology, pedagogy, and also medicine. In the literature on the subject, we can find many meanings of the concept of life, which may prove its interdisciplinary character. The lack of an unambiguous definition prompts researchers to try to clarify the term quality of life. Therefore, it is important to conduct research on the quality of life among neurological patients. Quality of life is a very personal category. Therefore, we cannot define it uniformly for the entire population. On the other hand, specific quality of life measures may be used by medical personnel to modify the goals of treatment and provided care [1,2,31].

Implications for Nursing Practice

Holistic care of nurses over the sick and proper interpersonal relations play an important role in the perceived quality of life by patients. Quality in nursing care is one of the elements of medical care, it relates directly to the activities and relationships between the nursing staff and the patient. In patient care, an important role is played by support and education about the disease, both for the patient and the family. It is also very important to continue research into the quality of life of patients with neurological diseases. The results of these studies could constitute a specific compendium of knowledge about the situation of patients, their needs and the perceived quality of life.

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