MEASURING QUALITY OF LIFE IN STROKE SURVIVORS

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Introduction. *The number of patients living with the consequences of stroke is increasing worldwide due to the improving stroke care and the modern differentiated treatment options for ischemic stroke — thrombolysis and thrombectomy. Hence, a significant interest has arisen in quality of life (QOL) measurement in post-stroke patients.*

Objectives. *Measuring QOL in stroke survivors can be achieved by using various generic and stroke specific questionnaires. All tools should assess different domains of health such as physical acting, communication, daily activities and others. This article describes the most commonly used scales for measuring post-stroke QOL.*

Methods. *We searched the PubMed electronic databases with the keywords — Quality of life, Stroke, Measuring for the period from January 2000 to May 2020.*

Results. *Various generic and specific scales for quality of life measuring are available. The advantages of the specific scales include high accuracy and detailed information for the assessed domains. The limitations are due to numerous items, long evaluation time and high dependency on patient’s compliance. The generic scales give the ability to compare the QOL in patients with different diseases. The disadvantage is lack of detailed information for the health status in certain disease or condition.*

Conclusion. *Measuring the different aspects of QOL in post-stroke patients is powerful tool in order to focus the further efforts to the most affected domains. A combination between generic and stroke-specific measure might be considered in order to overcome the limitations. The choice of measuring scales must be balanced in the terms of lengthy and repetitive surveys.*

Keywords: Quality of life, Stroke, Measurement, Scales, Review.

For citation: Tsalta-Mladenov M., Georgieva D., Andonova S. Measuring Quality of Life in Stroke Survivors. *Russian Neurological Journal (Rossijskij Nevrologicheskiy Zhurnal).* 2020;25(3):11–16 (Russian). DOI 10.30629/2658-7947-2020-25-3-11-16.

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Conflict of interest. The author declares no conflict of interest.

Acknowledgements. The study had no sponsorship.

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Received 24.05.20
Accepted 08.06.20

Introduction

Stroke is the second leading cause of death and disability worldwide. An increasing incidence of stroke with all its consequences is observed due to the aging population and the complicated comorbidity status. Besides the elderly, more young people are affected by different types of stroke as this is more common in the low- and middle-income countries [1].

The type of stroke, ischemic or hemorrhagic, further affects the mortality and disability rates. It is known that ischemic stroke (IS) is more frequent and leading to worse performance status in stroke survivors, but hemorrhagic stroke (HS) is related to greater mortality rates. In the recent decades the number of people surviving the acute stage of ischemic stroke is increasing. This is a result of the improving stroke care and the modern differentiated treatment options for patients with ischemic stroke — thrombolytic treatment and mechanical thrombectomy. This leads to a reduction in overall mortality and to increase in the prevalence of disabled patients [2]. Hence, a significant interest has arisen in quality of life measurement, as a tool to assess changes in patient's health throughout the length of its life [3].

According to the "Global Burden of diseases study" from 2016 the incidence of stroke worldwide is about 13,677 millions people (9556 IS and 4120 HS) as the number of those living with the consequences of stroke is much higher 79,574 millions (67,595 IS and 15,310 HS) [4].

As the number of patients surviving the acute stage of stroke is growing, the medical specialists and more precisely the neurologists are facing the problem with the quality of life (QOL). Measuring the quality of life is a key point for determining the following steps in order to improve the quality of care, treatment and post-stroke rehabilitation.

It is necessary to assess the general health of stroke-survivors and further to measure all aspects of their daily activity such as physical acting, communication skills, emotional, social functioning, daily activities and others. This can be achieved by using various questionnaires to measure the health-related quality of life.

What is quality of life?

In 1948 The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [5]. Later in 1984 The WHO declares in a revised statement that any health measure must take into account "the extent to which an individual or group is able to realize its aspirations, meet its needs and change or cope with the environment" [6].

In this regard, the WHO Quality of Life Group in 1993 defines "quality of life" as "the individual's perception of his/her position in life in the context of the cultural and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns" [7].

The subjective evaluation of the quality of life is nowadays accepted as a standard measure for health outcome in cases of different diseases including stroke. The fundamental characteristics of all QOL measures are subjectivity and multidimensional assessment of patient's well-being [8]. The tools used for assessment take into account the patient's self-esteem in terms of its well-being and limitations in various areas of life before, during and after the treatment of a disease [9].

Quality of life in patients with stroke, covers various areas of patients' lives, including physical, psychological and social functioning, perceptions of well-being and health, disability and life expectancy [10].

Why should we measure the QOL in stroke patients?

Routine measurement of QOL in stroke patients is time consuming, but useful for the clinical practice in different ways. First, it can describe the overall condition of the examined patient or group of patients. Second, it is used to identify the most affected aspects of daily functioning and to direct the treatment and rehabilitation process after stroke. Last but not least, it gives the possibility to monitor the long term effects and dynamics in stroke survivors by follow-up assessments of QOL with the same measurement tool [11].

The assessment of QOL in stroke survivors must be multidimensional and cover different areas (domains) — physical (motor deficit, spasticity, ataxia, dysarthria, dysphagia, pain, sleep disorders and fatigue), functional (mobility, hygiene and basic activities), mental (mood, memory, satisfaction and self-perception) and social (work, social activities and social role) [12].

By covering different areas of functioning QOL can be used to identify and prioritize the most affected aspects of the life of stroke patients. Quality of life data improves patient-physician relationship, reveals hidden problems and meliorates the clinical decision-making process [13].

How to measure the quality of life in stroke patients

There are many measuring tools and scales for quality of life. In general they can be divided in two main groups according to their specificity — generic (broad spectrum) or disease specific. Regardless of the type of scales, each of them is composed of different subscales (domains) that assess different aspects of the life of the subjects such as motor activity, communication skills, emotional, social sphere, daily activities and others [9].

The generic QOL measures are applicable to patients with different diseases, while the specific measures are intended for a certain part of the population suffering from one distinct disease [11]. It should be noted that each type of measures has its advantages and limitations, and the choice of measuring scale is based on the objectives and the context of the study [8].

Generic measures are appropriate for assessment of people with severe comorbidity status or heterogeneous populations. In such cases, they will allow direct comparison of the results between groups with different diseases. The main disadvantage is that they might be missing specific indicators that are uniquely important to some special disease groups [14]. The second limitation is inadequate sensitivity and responsiveness which may lead to misreading of the results [15].

Specific scales are more accurate, targeting specific group of patients with a certain disease. These measuring tools do not allow direct comparison of the quality of life between groups with different illnesses [16].

In the recent years the majority of the developed QOL measures are disease specific. The stroke specific measures have the advantage to detect the multidimensional concerns of patients who suffered from stroke [17]. They also tend to be more sensitive and with higher responsiveness than the generic measures [14, 15]. The main limitation of the specific tools is that they contain many items on specific symptoms which makes the evaluation time-consuming and relies on the patient's current status and compliance [8].

It is widely accepted that none of these instruments is ideal. They are much more informative for a group of patients than for the individual. All measuring tools might be used not only for single time point assessment but for tracking the minimal significant differences in time. This gives the opportunity to detect mild problems, which are not distinguishable in the routine neurological examination. These minimal detectable differences found in the follow up process of the patients are actually of great importance for improving the quality of life [18].

The overall score of quality of life from different stroke specific scales or between specific and generic scales could not be directly compared. Only in specific cases with strong enough statistical correlation this could be considered [8]. A combination between generic and stroke-specific measure might be considered in order to overcome the limitations, but this must be balanced in cases with lengthy and repetitive survey [19].

Generic scales for measuring QOL

There are dozens of different generic scales for measuring the quality of life, but still not all of them are widely used [11]. The most commonly used and cited instruments in the European literature are Short Form 36 (SF-36), EuroQOL (EQ-5D), Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP), Quality of Well-Being (QWB) Scale and the Health Utilities Index (HUI). All of them have different characteristics — reliability, validity, respondent and administrative burden, alternative (short) forms and translations [20].

The SF-36 health survey is the most widely used tool for QOL measuring. It is used in numerous surveys and research works including the area of stroke [21]. The time required to complete SF-36 is approximately 10 minutes. This tool is formed by 36 questions, assessing eight aspects of health (sub-scales) — physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, energy, social functioning, role limitations due to emotional problems, and mental health [22]. Each question has five-point ordinal choices based on the concept of the Likert scale. The final score is formed by summing the scores for all items in the different sub-scales and later the results are rescaled with a standard range from 0 to 100, where a score of 100 denotes the best health [23]. The validity and reproducibility of the information obtained through this measuring tool has been proven and described in various research articles. This is the most pronounced for the assessment of physical and mental health, and to a lesser extent for social activities [21]. The SF-36 scale is valid, reliable, and sensitive to change in stroke populations. It is sensitivity is high enough even when the responses are provided by family member or caregiver [24]. Due to the presence of many questions, a shorter version called SF-12 has been developed, which has the same qualities, without significant loss of information in the individual subscales [25].

The second most used tool is The EuroQOL (EQ-5D) questionnaire. It is a standardized measure of health status developed by the EuroQOL group in order to provide a simple generic measure for wide range of conditions and populations [26]. Time spent to complete this questionnaire is approximately 18 minutes. This measure is assessing five aspects of health — mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The level of function in each dimension is assessed by the patient from a three-point ordinal choice scale. It is accompanied by a Visual Analogue Scale (VAS) for self-assessment of the patient's own heal from 0 (the worst health state) to 100 (the best health state) [27]. EQ-5D differs from other tools by its simplicity and accessibility to the patient [28]. In an international survey the quality of data collected by SF-36 and EQ-5D showed no significant differences according to validity and reproducibility [29].

The sickness impact profile (SIP) scale is the third most commonly used tool for measuring QOL. It is evaluating the effect of the disease in two aspects of health — physical and emotional functioning [30]. This measure has total 136 questions divided in 12 categories including sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, and communication [31]. It is used for measuring and follow-up of the QOL in broad specter of diseases including post-stroke patients [32]. Major disadvantage of this tool is the large number of questions — 68, complicating its routine use. It is also a time-consuming tool, as it requires approximately 30 minutes for completing the questionnaire. Therefore, a shorter version of the questionnaire was developed — SA-SIP, which contains a total of 30 questions assessing the QOL in eight aspects [33]. The authors of the questionnaire emphasize its applicability in everyday practice. However, its sensitivity cannot be determined when tracking the minimal changes over time in stroke patients, as all questions are dichotomous — yes/no type. This leads to major difficulties in the general interpretation of the results [31].

Specific scales for measuring HR-QOL

Various specific instruments for assessing post-stroke QOL have been developed over the years. All of them offer the advantage of assessing different specific domains relevant to stroke, such as vision or language. These measuring tools, however are not always available in all languages and some of them are addressed to the family members or caregivers [34].

The two most commonly used stroke-specific scales for assessing QOL are the Stroke-Specific Quality of Life Scale (SS-QOL) and the Stroke Impact Scale (SIS). They are comprehensive and reliable tools, providing a vast information for the health status of patients recovering from stroke [35].

SS-QOL is a tool designed for self-assessment of stroke survivors. It might be completed by the patient or its caregiver, as the time required to complete SS-QOL is approximately 10–15 minutes [36]. The questionnaire consists of 49 items divided in 12 domains — energy, family role, language, mobility, mood, personality, self-care, social role, thinking, upper extremity function, vision and work. Each of the domains is scored separately and a total quality of life score is also being provided [16]. The SS-QOL is evaluating the past week and it is being rated on five-point Likert scale. The results are later rescaled to fit the 0 to 100 scale where 100 is being the best health state [37]. The validity, sensitivity and reproducibility of the scale have been proven in many different studies in Europe [38]. This measure is broadly used for monitoring the quality of life in patients who survived ischemic, hemorrhagic stroke or subarachnoid hemorrhage [39]. The data collected by this measuring tool shows a high correlation with other questionnaires like SF-36 and SIS. The SS-QOL domains are being also in negative correlation with the stroke severity assessed by the National Institutes of Health Stroke Scale (NIHSS) and the level of disability measured by the modified Rankin Scale (mRS), indicating the lower QOL among patients with worse functional status and greater clinical severity of stroke [40].

Stroke impact scale (SIS) is developed primarily as a comprehensive specific measure for quality of life in post-stroke patients. Time required to complete SIS 3.0 is approximately 15–20 minutes [41]. The questionnaire consists of 59 items divided in 8 domains — strength, hand function, activities of daily living, mobility, communication, emotion, memory and thinking, participation. The first four of the domains are combined in a composite physical domain score [42]. Each item is being rated on five-point Likert scale and the domain results are later rescaled by the following equation-Domain score = [(Mean item score – 1) / 5 – 1] × 100. The calculated final scores have a standard range from 0 to 100, where a score of 100 denotes the best health [23]. Stroke impact scale is suitable for a post-stroke patient follow-up, as it has high reliability, sensitivity and reproducibility, for each domain [43]. There is also a good correlation between results of SIS and other generic QOL measures like SF-36, EQ-5D and specific tools — SS-QOL [41].

There is evidence that the psychometric performance of the SIS is better than this of SS-QOL. The stroke impact scale has higher sensitivity for the minimal detectable changes in hand function and recovery domains. Despite the similar validity of these scales, the SIS hand function domain shows better predictive validity than SS-QOL upper-extremity function domain.

There-fore currently SIS appears to be a better measuring tool for assessing stroke-specific quality of life [44].

Conclusion

The advantage of the specific scales is their high accuracy and detailed determination of the various aspects of quality of life in stroke-survivors. The main drawback is the inability to conduct a comparative analysis with other diseases.

A combination between generic and stroke-specific measure might be considered in order to overcome the limitations. This must be balanced in cases with lengthy and repetitive survey.

Measuring the different aspects of health in post-stroke patients is powerful tool in order to focus the further efforts to the most affected domains.

Conflict of interest

The authors declare no conflict of interest.

Acknowledgments

The study had no sponsorship.

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Received 24.05.20
Accepted 08.06.20