

Measurement of quality of life in stroke patients

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Summary. The quality of life after stroke and the methods of measuring this aspect of the disease have been viewed with a growing interest. The measurement has been focused on the physical, psychological, social, and functional aspects of living and is generally based on the patients' subjective perception of his/her general health and well-being. Seven generic measurement scales and three recently developed stroke-specific scales have been assessed and discussed. The stroke-specific quality of life measures described in this review are as follows: the Stroke Adapted Sickness Impact Profile, the Stroke Impact Scale, and the Stroke-Specific Quality of Life Measure. The various factors leading to a deterioration of the quality of life and influencing the quality of life scores are discussed and defined. Moreover, the necessity of further research is stressed.

The assessment of quality of life (QOL) after stroke is becoming common with the recognition that evaluation of treatment should include quality as well as quantity of survival (1). The results of treatment are appraised by applying tests that evaluate physical limitations and/or functional impairments (2–6). These tests, however, do not give us a measure of the patient's own perception of the mental and emotional effects of the bodily disabilities. Because of this, there has been a growing interest in tests that measure the health-related QOL of poststroke patients. This is used in addition to the scales of physical impairments. The combined scales are an indication of therapeutic effectiveness (7). Measuring QOL mostly comprises functional, physical, cognitive, psychological, and social elements. The results of these measures fairly accurately represent the patient's own perception of his/her functioning and general health. Taking into consideration the way in which patients view their own health situation is the most important element of patient-centered health care. Recording self-reported QOL must be integrated element of poststroke evaluation and treatment (8). It is, therefore, very important that physicians would increase their acquaintance with the selecting of trustworthy and pertinent QOL instruments and be aware of the factors that affect the results and the importance of the outcome.

General aspects of quality of life

The phrase "quality of life" is used in many different ways, and one of the major issues that face this

area of research is how the term should be defined and conceptualized. One of the essential aspects is to make a distinction between health-related and non-health-related quality of life (9). The starting point for a number of the health-related definitions was the well-known World Health Organization (WHO) (1948) (10) definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."

The inclusion of well-being in the WHO definition has led some researchers to focus too narrowly on self-reported psychological well-being as being the only aspect of QOL importance (11). However, "well-being" has to be seen as the narrower term; it is an important aspect of quality of life (12), but is not the only aspect that needs to be considered. It is important to specify the range of health-related and non-health-related aspects of quality of life that should also be included, such that "quality of life" is not simply another term for "well-being." In addition to the physical, mental, and social aspects, there is now a recognition that spiritual and religious aspects are needed to be included in health-related quality of life (9, 11, 13), and a range of aspects of the individual's physical environment needs to be included in non-health-related quality of life. The term "quality of life" is now widely used in the literature on the evaluation of health status and outcome. There are a considerable number of definitions of the term, but the definition that has been proposed by the WHO (1995) (13) is:

"An individuals' 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. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment."

Generic descriptions of quality of life measures

QOL instruments can be divided into generic and disease-specific scales: generic scales address general health concepts not specific to any age, disease, or treatment (14). The seven most stroke-relevant generic measures are as follows:

- *Medical Outcomes Short Form Health Survey (SF-36)*

This is an often-used measurement scale which was suggested by the Agency for Health Care Policy and Research in the Poststroke Rehabilitation Clinical Practice Guidelines (15). This instrument is a 36-item questionnaire completed by the patient him/herself. The items are grouped into eight domains which embrace a large range of physical activities and psychosocial cognition also including the evaluation of general health status (Table 1). The scores on a scale ranges from 0 to 100; a higher score indicates better health.

- *Medical Outcomes Short Form Health Survey (SF-12)*

In the middle of the 90s, an abbreviated version of the SF-36, the SF-12 (16), was developed. The SF-12 generates the physical and mental component summary (PCS and MCS, respectively) scores of the SF-36 with considerable accuracy, while imposing minimal burden on respondents. It was demonstrated that PCS and MCS scores of the SF-36 were replicable by the SF-12 (17).

- *Sickness Impact Profile (SIP)*

The SIP is a reliable and validated 136-item instrument grouped into 12 sections or subscales (Table 1). Contrary to other QOL scales, the items concentrate on particular behavior that relates to restrictions or recent alterations in functionality instead of subjective feelings or perceptiveness (18). Individuals may for instance say "yes" or "no" to questions like, "I have less desire to talk to my friends and relatives," rather than to an abstract statement such as, "I experience a sense of isolation towards my environment." Total scores are converted to a percentage of the maximum possible impairment from 0% (representing no impairment) to 100% (representing maximal impairment) (8). There is a short version of this scale called SA (stroke adapted) SIP 30. A comparative survey conducted by A. van Straten *et al.* concludes that the

Table 1. Comparison of generic quality of life instruments (modified from L. K. Saladin (2000) (8))

| SF-36 (8 domains) | SIP (12 domains) | Euroqol (6 domains) | NHP (6 domains) |
|--|---|-------------------------------|--------------------|
| Emotional health | Gregarious interaction, emotional conduct | Mood (distress/despondency) | Emotional, social |
| Bodily performance | Mobility, ambulation | Mobility | Physical |
| Role-physical, emotional interaction, social functioning | Housekeeping ability, recreation and pastimes, employment | Daily practice | – |
| Pain | – | Pain and discomfort | Pain |
| General condition | – | Family and leisure activities | – |
| Vigor/vitality | Alertness behavior | – | Energy |
| – | Rest and sleep | – | Sleep |
| – | Self-care and mobility, eating | Self-maintenance | – |
| – | Communication | – | – |

SF-36 – Medical Outcomes Short-Form Health Survey; SIP – Sickness Impact Profile; NHP – Nottingham Health Profile.

SA-SIP30 should be preferred over the SIP136 (19).

- *Euroqol*

Euroqol is a measurement scale which has been developed by the Euroqol group. It was created as a standardized generic scale used for the evaluation of patient health status and has been used for this objective in varying clinical populations. The Euroqol questionnaire consists of only six items (1) and covers six domains (Table 1). The score for each item ranges from 1 to 3, whereby 1 signifies “no problems” and 3 represents “extreme problems.” In addition to this scale, the Euroqol uses a visual analogue scale from 0 to 100 to furnish a general estimate of health-related QOL, where 0 signifies “worst imaginable health” and 100 – “best imaginable health.”

There are four more generic scales which are used to evaluate poststroke QOL. None of these have been particularly validated (1, 8, 20).

- *Quality of Life Index (QLI)*

The QLI at first was designed to measure the QOL in people with chronic diseases such as cancer (21), but now it has been adjusted for stroke patients (22). The initial version was a questionnaire with 38 questions grouped into four subsections. For the stroke version of the QLI 3, sections were added: communication, self-care, and mobility. Satisfaction and importance are evaluated on a scale from 1 to 6. The total score ranges from 0 to 30; higher scores indicate better QOL.

- *Reintegration to Normal Living Index (RLNI)*

This instrument comprises a questionnaire of 11 items which measures patient’s satisfaction over six domains (23). The RLNI determines the overall functional state by recording the patient’s evaluations of his/her capabilities and by objectively assessing the indications of social, psychological, and physical state. As in the case of generic measurement scales, an overall score and domain-related subscores are obtained where a higher score signifies a higher QOL.

- *Nottingham Health Profile (NHP)*

The NHP scale is a generic instrument which at first was designed to measure the perception of health status in population surveys (24). The NHP questionnaire consists of 38 items necessitating a “yes” or “no” answer to questions grouped into six subscales (Table 1). The scores for each group range from 0 to 100, where 0 indicates perfect health (8).

Advantages and limitations of generic quality of life measures

To choose the most pertinent QOL instrument for clinical use, therapists should familiarize themselves

with the pros and cons of the various instruments. Generic QOL instruments were specifically developed to be used by a wide range of patient populations. An advantage of such scales is therefore the possibility to compare the relevant effects of differing illnesses and interventions on the QOL. Therefore, it is recommended to use a generic scale if the QOL needs to be compared across a range of illnesses and/or conditions (8). QOL is mostly assessed by instruments depending on self-reports. These methods of data collection are not very suitable for patients with cognitive or communicative disorders. One way to avoid this methodological problem is to use so-called proxy ratings, but the evidence from caregivers’ reports is contradictory (25). Because of the danger of significant distortions in the scores caused by the completion of the questionnaires by caregivers, using this method should be treated with considerable prudence. Another inadequacy of the generic scales is reduced accuracy of certain scales at the high and low end. When QOL scores are recorded as very low, there is a so-called “floor effect.” The scales are at that level not sensitive enough to detect differences among patients with such low scores although such differences may exist. Therefore, these scales do not correctly present the right scores of this type of patient, and they cannot determine precisely the effect of treatment. A “ceiling effect” is observed if there are a large number of persons with a very high score for a specific test. Instruments that are affected by this ceiling effect lack the necessary sensitivity to distinguish among patients with the highest scores for specific test. Significant floor and/or ceiling effects (Table 2) have been reported for the various SF-36 subscales (1, 26). The degree of accuracy also varies significantly among scales. The SIP and NHP use only two response groupings whilst the SF-36 has an arrangement of two and six response groupings depending on the relevant domain (1). Finally, a foremost criticism is the pertinence of generic QOL instruments when applied to stroke patients. The validity of content refers to the capacity of a test or scale to pinpoint meaningful and specific symptoms or problems inside a particular population (27). In order to eliminate these problems, the process of improvement and validation of more stroke-specific QOL scales has been started recently.

Using the simpler SF-12 scale instead of the SF-36 scale is of particular consequence for the research evaluation of stroke patients. Time and cost savings may be realized using a shorter array of questions included into a longitudinal questionnaire series, while

Table 2. Precision of generic measures used in stroke quality-of-life research (modified from D. Buck *et al.* (2000) (1))

| Measure | No. of response categories | Weighting of numerical values | Floor/ceiling effects* |
|---------|----------------------------|-------------------------------|---|
| SF-36 | Varies by domain (2–6) | No** | Large ceiling effects reported for some domains |
| SIP | 2 | Yes | Not reported |
| Euroqol | 3 | Yes | Not reported |
| NHP | 2 | Yes | Not reported |

SF-36 – Medical Outcomes Short-Form Health Survey; SIP – Sickness Impact Profile; NHP – Nottingham Health Profile.

* in studies of stroke populations; ** scores of 0–100 are generated for each domain.

providing essentially the same prognostic information as by applying the longer form. The shorter SF-12 questionnaire can substantially reduce the time spent by respondent and interviewer in an administered survey. Furthermore, by enabling responses from patients with poorer outcomes, a shorter, simpler instrument may provide more power to detect differences among groups because larger sample sizes will compensate smaller losses in precision. The total time to complete the SF-12 questionnaire is less than 2 minutes for the majority of individuals (28), while the corresponding time to respond to the SF-36 is 10 to 12 minutes. Average completion times ranged from 2 to 30 minutes (Table 3). These completion times are likely to be greater for both instruments in stroke patients. The SIP which scores well in the other respects such as accuracy and social and psychological aspects of QOL measurement is much more time demanding (Table 3). Compared with the SF-36, the disadvantages of using the SF-12 include less precise

estimate of individual health and an inability to calculate summary scores when one item is left unanswered (17).

The selection of the QOL measure must be based on its psychometric attributes, which include feasibility, validity, reliability, and sensitivity to change (20). The method of collecting data requires some trade-off between costs and response rates, non-response bias, and data quality (29).

Stroke-specific quality of life measures

Although stroke is a major problem, the best method for measuring the outcome of stroke is not clear, partly due to the heterogeneity of stroke signs and symptoms (7). Three disease-specific QOL measures were recently developed for the use in stroke survivors.

- *The Stroke Adapted Sickness Impact Profile (SA-SIP30)*

This instrument is an adaptation of the 136-ques-

Table 3. Generic measures used in stroke quality-of-life research: description of acceptability (modified from D. Buck *et al.* (2000) (1))

| Measure | No. of items | Average completion time | Response rates (of measure)* | Response rates (of items)* |
|---------|-----------------------------------|-------------------------|------------------------------|---|
| SF-36 | 36 | 5–10 min | 63–83% | <75% for all items in role-physical and role-emotional scales |
| SIP | 136 | 20–30 min | 83–98% | Not reported |
| Euroqol | 6 | 2–3 min | 63–80% | Not reported |
| NHP | 38 (or 45 if part II is included) | 5–10 min | 72–89% | Not reported |

SF-36 – Medical Outcomes Short-Form Health Survey; SIP – Sickness Impact Profile; NHP – Nottingham Health Profile.

* in studies of stroke populations.

tion SIP (30). The scale was principally designed to avoid the great length of the SIP, which was considered a major disadvantage. The SA-SIP30 is a 30-question instrument with eight subgroups created by eliminating the most irrelevant questions from the initial test. Although this scale is stroke specific and is much shorter than the original generic SIP, it will be necessary to further evaluate the dependability, sensitivity, and soundness of the SA-SIP30 poststroke scale.

- *The Stroke Impact Scale (SIS)*

This scale is a stroke-specific instrument for measuring QOL. It is version 2.0 of the SIS (31). The main difference from the SA-SIP30 scale is that it is not merely a simplified version of the generic scale, but that it was designed especially for stroke survivors. The SIS has 8 domains and 64 items which are the most appropriate for the evaluation of poststroke QOL. The questionnaire asks the patient to rate his/her own awareness of his/her recovery progress on an analogue graphical scale. There are four physical domains being hand function, strength, mobility, and Daily Life Activity/Instrumental Activity of Daily Life. When added together, these four domains represent one physical domain score. The other domains are scored individually (8). The domain score ranges from 0 to 100. The SIS score is a reliable and stable instrument and has been proved to have a good test-retest consistency. Research shows that most SIS domains sensitively reflect the progress of recovery.

- *The Stroke Specific Quality of Life Measure (SS-QOL)*

This instrument is the latest of the tools for poststroke-specific QOL scales (32). Interviews with stroke patients formed the basis for 49-item and 12-domain questionnaire. All questions were reviewed by specialists in physical medicine, rehabilitation, and neurology and thereafter again by different stroke patients. Further questions were checked and revisions were made using the data from poststroke persons after one to three months. However, further studies on the reliability, consistency, and sensitivity of the SS-QOL are needed involving larger patients' samples.

Advantages and limitations of stroke-specific quality of life measures

The stroke-specific QOL instruments, as the generic scales, have similar advantages in many ways. As in the case of generic scales, these stroke-specific tools are self-report questionnaires which can be completed within 10 to 15 minutes using varying techniques such as self-completion, personal interview,

telephone interview, e-mail or ordinary mail transmission. Besides these advantages, the SIS and the DSS-QOL scales have an exclusive advantage over generic scales and the SA-SIP30. They were developed to deal with the items which are most pertinent to stroke patients and are likely to become the more suitable measurement of poststroke QOL also because of the greater ability to pinpoint significant changes. The SIS has some extra and essential advantages when compared with the other two stroke-specific scales. The most noteworthy advantage is the link to a website (8). A database on the site enables medical personnel to enter and gather data resulting in a summary report for every patient. The stroke-specific scales have, however, also some disadvantages which should be watched carefully. Most of the weakness stems from the fact that these scales are still relatively new and there are still not enough data available from clinical trials. A specific problem with the use of the SS-QOL is its complexity. There are three response set possibilities available for answering the survey items, and items within the same domains use varying response sets. The possible misconstruction about the correct response set choice may be lessened if the format of the forms is changed to improve the clearness. Moreover, it seems that the descriptions of some of the items do not correspond with the response sets. Further clinical trials of the SS-QOL with larger samples are being conducted (27), and some of these weaknesses will likely be eliminated as the development progresses.

The use of proxies

Several studies have shown that many stroke survivors experience a decline in their QOL in terms of impaired physical, functional, psychological, and social health (33, 34). QOL is most often assessed by means of either structured interviews or written questionnaires. However, it has been recognized that these methods of data collection are not always suitable for studies of stroke survivors (35). Given the frequency of serious cognitive, speech, and language disorders, many patients are not able to communicate effectively or to understand what they are being asked. The inability of a highly relevant subgroup of patients to participate in such studies may yield results that cannot be generalized to the total patient population of interest (25). Research has been conducted on the differences of the perception of QOL by the patients themselves and proxies such as relatives or medical staff. It was concluded that patients perceived their QOL better than the same circumstances were perceived by proxies (36).

Determinants of poststroke quality of life

Several studies have shown that by far the largest part of the patients experience and report a decline in QOL after stroke (37–41), and this even applies to persons who have suffered only a minor stroke (37, 38, 42). There are a number of factors which seem to be contributing towards a decline in QOL of stroke patients. Advanced age (34, 39, 41), the severity of motor impairment or paralysis (40, 43), lack of perceived social supports (44), inability to return to work (45), supratentorial lesion locations (46), impaired cognition, and the presence of comorbid health problems (43) have been associated with a decline in QOL and should be taken into account when making an analysis of stroke results. Several authors have reported a strong association between physical disability, dependency in activities of daily living and QOL (34, 43, 47). Dependency in activities of daily living has been shown to be associated with physical functioning and the general health domains of QOL (22, 47), but not to predict psychological and socio-economic aspects of QOL (22). The correlation between age, sex and QOL has remained obscure. C. S. Anderson *et al.* showed that women had a better stroke outcome in terms of social functioning and mental health (47), but most authors report QOL either to be independent of gender (43) or lower in females (33). Failure to maintain or re-establish social ties, except for those with family members, seems to be an important determinant of poor QOL in long-term survivors of stroke (34), whereas high levels of social support have been shown to be related to a better outcome (48). On the other hand, too much support from the spouse may lead to overprotection and understimulation and lead to a less favorable outcome (49). To ensure a good outcome, the support of the family is not enough; the support of society is also needed (33), so that stroke victims feel cared for, loved, valued, and esteemed and are ready to accept assistance from others if needed. An aspect that has not been sufficiently investigated is the effect of aphasia. It is an important fact that the major part of the studies has excluded patients with severe aphasia (37, 40, 44, 50). The results of a few investigations, which studied this correlation, were unconvincing (43), so more investigations and re-

search should be conducted to establish the impact of communication disorders on poststroke QOL sufficiently. A decrease in the independence of function has been linked to a declined QOL in most studies (37–39, 43, 44). It is, however, very important to note that stroke survivors, even if they are independent in their daily activities, report a decline in their QOL (37). This seems to indicate that functional measurements only are not sufficient for determining stroke results. It is necessary too, in addition to the impartial assessment of physical impairments, to measure the QOL to provide a more accurate and complete picture of the poststroke level of disability. The existence of depression has a strong correlation with the prognosis of declined QOL after stroke (38, 40, 44, 45). From 23 to 41% of stroke patients feel an immediate inception of depression in the period of the few months after the event of the stroke (51). QOL is not a fixed measure, but it may change in the course of time as new as the patient has to deal with new situations. The effect of the after-stroke time factor on QOL is still contentious. A decline in the QOL over a 6- to 24-month period after the stroke event has been documented (41). The aspects of QOL which suffered the strongest deterioration included dealing with life events (50), private relationships, and self-care necessities but also recreation and housekeeping. Nevertheless and in contradiction with these findings, a light improvement in the overall QOL during the first 1 to 3 years after the stroke event has also been recorded. These findings point to the need for a long-term follow-up of patients after stroke to achieve a complete evaluation of these data (8). A decrease in the QOL as time progresses may point to an inadequate strategy for helping patients with their reintegration in the community and the readjustment of their lives and that more efforts and means should be applied to improving this facet of after stroke care.

Conclusions

The need remains for a patient-centered, psychometrically robust, stroke-specific quality of life measure. Patients should be involved in each stage of instrument development. Caution is needed in the selection of an instrument to measure quality of life after stroke.

Insultu persirgusių pacientų gyvenimo kokybės vertinimas

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Raktažodžiai: gyvenimo kokybė, insultas, vertinimas.

Santrauka. Pastaraisiais metais vis daugiau domimasi tyrimais, skirtais ligonių po insulto su sveikata susijusiai gyvenimo kokybei, kaip pagrindinei ligos padarinių nustatymo priemonei ir gydymo veiksmingumo rodikliui, vertinti. Gyvenimo kokybės vertinimas paprastai apima fizinius, funkcinus, psichologinius, kognityvius ir socialinius gyvenimo veiksnus. Gyvenimo kokybė rodo subjektyvų individo savų funkcijų ir bendros sveikatos būklės suvokimą. Straipsnyje apžvelgiamos septynios bendrosios priemonės, naudojamos gyvenimo kokybei po persirgto insulto tirti, taip pat trys naujai sukurtos gyvenimo kokybės nustatymo priemonės, pritaikytos insultą patyrusiems ligoniams, aptariami jų privalumai bei trūkumai. Apžvelgiamos šios gyvenimo kokybės vertinimo priemonės, pritaikytos insultą patyrusiems asmenims: 1) insultui pritaikyta ligos poveikio anketa; 2) insulto poveikio skalė; 3) insultui pritaikytas gyvenimo kokybės vertinimas. Aprašomi veiksniai, lemiantys gyvenimo kokybės pablogėjimą po persirgto insulto ir galintys turėti įtakos gyvenimo kokybei. Nurodomas ir tolesnių tyrimų poreikis.

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