Quality of Life After Stroke

İnme Sonrası Yaşam Kalitesi

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Several studies have shown that many stroke survivors experience a decline in their Quality of life (QOL) in terms of impaired physical, functional, psychological, and social health. Quality of life is most often assessed by means of either structured interviews or written questionnaires. Many questionnaires have been developed recently for the evaluation of QOL in stroke and many studies have been done on this subject. In this study QOL changes in stroke patients, the evaluation of QOL, the QOL measuring instruments and the results of clinical studies on the subject were discussed.

Key words: Stroke; quality of life; measurement.

İnme geçiren birçok kişide, bozulan fiziksel, fonksiyonel, psikolojik ve sosyal sağlık durumları açısından yaşam kalitelerinde düşme gözlemlendiği çeşitli çalışmalar tarafından gösterilmiştir. Yaşam kalitesi çoğu kez ya yapılandırılmış görüşme ya da yazılı anketler aracılığıyla değerlendirilmektedir. Son zamanlarda inme geçiren hastalarda yaşam kalitesinin ölçülmesi için birçok anket geliştirilmiş ve bu konu üzerine birçok çalışma yapılmıştır. Bu makalede, inmeli hastalarda yaşam kalitesindeki değişimler, yaşam kalitesinin ölçülmesi, yaşam kalitesi ölçüm araçları ve konu hakkındaki klinik çalışmaların sonuçları tartışıldı.

Anahtar sözcükler: İnme; yaşam kalitesi; ölçüm.

According to the World Health Organization (WHO), stroke can be defined as: "Rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin".[1] Stroke is a clinical situation which has a very rich symptomatology (Table 1).[1] The heterogenic characteristics of stroke patients depend on wide ranges in demographic properties, various aetiologies of vasculary involvement, side of brain involvement and concordance, progress variability in natural motor recovery, richness of clinical findings, variability of co-morbidities and nature of therapy provided.

Stroke is a very prevalent clinical condition and exposes society a great economic burden. According to a study, 600 000 stroke attacks come about per year, and there are 4 600 000 stroke survivors in United States.[2] It is the third (sometimes the second) common cause of death and the leading cause of serious, long-term disability.[2-4] Stroke survivors have the third highest length of stay in rehabilitation following spinal cord injuries and brain dysfunction.[5]

Approximately 1/3 of stroke victims will die in the medium term. Another 1/3 will recover completely or with minor impairments. So the remaining 30-40% will experience moderate to severe impairments requiring special care and skilled care or long-term care facility.[6] The overwhelming majority of economic resources are spent for the last mentioned groups with moderate or severe disease. In order to ameliorate this big health problem and avoid irrationale expenditures, what should be made first is to prevent stroke attacks.

Table 1. Symptomatology of stroke

- Weakness or paralysis of an extremity-face
- Loss of memory
- Spastiscity, contracture
- Vertigo, loss of balance and coordination
- Pain
- Personality changes
- Altered sensation, neglect
- Mood changes (depression, apathy)
- Vision changes, eyelid droping
- Drowsiness, lethargy, or loss of consciousness
- Inability to speak or understand speech
- Incontinence
- Difficulty reading or writing
- Added complications
- Swallowing difficulties or drooling
- Co-morbities

If it occurs, the current condition of every patient must be well measured individually despite the very heterogenous characteristics of the patients and be estimated correctly what will happen in the future. According to this baseline data plan a rationale therapy programme should be planned. The great plan depends on proper evaluation of the real status and needs of a given patient. Cost effectiveness studies are emerging not only on stroke patients but on all other disease conditions for optimising the management costs.

THE IMPORTANCE OF QUALITY OF LIFE MEASUREMENT IN STROKE

Definition of quality of life and health related quality of life

Quality of life (QOL) has been defined as "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." Quality of life is a superordinate term when compared with health related quality of life (HRQOL), a subset that refers QOL in relation to health status of patients.[7]

Why quality of life measurements should be used in stroke?

For a rationale individual management programme, outcome measurement is highly important in stroke. The care of a stroke patient requires objective measurements of outcome, which are critical to assessment and evaluations of treatment regimens. In stroke, traditional outcome assessment focuses on prevention of deaths, alleviation of symptoms and restoration of function. These tests, however, do not give us a measure of the patient's own perception of the mental and emotional effects of the physical disabilities. For instance, stroke patients who are fully independent according to Barthel Index may nevertheless experience limitations in employment and leisure activities or in emotional adjustment. Measures like the modified Rankin Scale or the Barthel Index are relatively insensitive to change over time, can exhibit ceiling or floor effects in a given study population, and may poorly represent the impact of stroke on a patient's subsequent life.[8]

Quality of life measures should be used in stroke patients because they are multidimensional instruments which comprise functional, physical, cognitive, psychological and social elements. Additionally they are patient centered which fairly accurately represent patients perspective of health and a given treatment. Quality of life instruments also measure quality as well as quantity of the further life.[9]

One of the most frequently used classification methods for outcome measurements is the "International Classification of Impairments, Disabilities and Handicaps (ICF). Quality of life is said to lie beyond this disease-handicap continuum. Although ICF offers an important theoretical perspective, it neglects some QOL issues. Although handicap is the most relevant clinical outcome for patients and impairment the least, QOL may be even more pertinent from the patient's point of view.[10]

Which outcome instruments should be used during inpatient stroke rehabilitation? Functional status or HRQOL ?

In a previous study the relation between functional status and HRQOL during inpatient stroke rehabilitation was assessed. All Functional Independence Measure (FIM) scores, four of eight Short Form-36 (SF-36) domains, and one summary component score showed statistically significant improvement during the course of rehabilitation. Functional status and HRQOL improved considerably over the course of rehabilitation. However changes in SF-36 were not strongly associated with changes in FIM score, with only 6 of 90 correlations attaining statistical significance. This suggests a poor association between patients' perceptions of their health status and the health professionals' assessment of function. Both instruments offer insights into outcomes of inpatient rehabilitation, but they are complementary rather than overlapping.[7] So recording self-reported QOL must be an integrated element of poststroke evaluation and treatment. Quality of life scales should be used in addition to the scales of physical impairments.

EVALUATION OF HRQOL

Although there is no single, accepted definition of HRQOL, the literature is rich of studies performed discussing and identifying important domains to be included within this construct. Fitzpatrick et al.[11] systematically

Table 2. Generic and stroke-spesific measures in stroke

SF 36 / SF-12[1]
SIP[2]
EQ-5D[3]
NHP[4]
HUI[5]
LHS[6]
SA-SIP 30[7]
SIS[8]
SSQOL[9]

[1]Short Form 36&12; [2]The Sickness Impact Profile; [3]EuroQOL; [4]Nottingham Health Profile; [5]Health Utilities Index; [6]London Handicap Scale; [7]Stroke Adapted Sickness Impact Profile-30; [8]Stroke Impact Scale; [9]Stroke spesific QOL.

reviewed this literature and proposed a list of nine dimensions identified as relevant for HRQOL assessment. These are physical functioning, symptoms, global judgments of health, psychological well-being, social well-being, cognitive functioning, role activities, personal construct, satisfaction with care. The resulting framework reflects the complexity and diversity of domains implicated in the assessment of HRQOL. Although numerous tools are available to measure HRQOL, it is unclear which of the domains are more relevant.

Generic QOL instruments

There are several validated and useful QOL scales as outcome measures (Table 2).[9] Because poststroke quality of life is highly correlated with disability and motor function, these scores (or subscores) can be used as functionality indexes. Some contain additional items that measure domains of poststroke care such as vision or language impairments. For example SF-36 is the most often-used self completion measurement scale with a 36-item questionnaire. The items are grouped into eight domains which assesses a large range of physical activities and psychosocial cognition also including the evaluation of general health status.

Stroke-specific QOL measures

The health care areas specific to stroke necessiates some different domains to be included in the scales specific to stroke.[12] For example the Stroke Impact Scale (SIS) is a stroke-specific assessment of health status having domains of strength, hand function, activities of daily living, mobility, communication, memory, emotion, social participation. The other example is the Stroke Specific Quality of life (SSQOL) which was developed by Williams et al.[13] specific to stroke survivors consisting 49 items and 12 domains which are mobility, energy, upper extremity function, work-productivity, mood, self care, social roles, family roles, vision, language, thinking and personality.

Stroke Specific Quality of life measuring instruments which have been developed recently can be seen in Table 2.[14] Most items included in all SSQOL measurement scales fit into the adopted framework based on the examples provided by Fitzpatrick et al.,[11] but also they assess various dimensions. There is no evaluation of their ability to provide a comprehensive or adequate assessment.

Advantages-limitations of generic and SSQOL measures

An advantage of generic scales is the possibility to compare the relevant effects of different illnesses and interventions on the QOL. An inadequacy of the generic scales is that they have so called floor and ceiling effects. The SSQOL instruments have an exclusive advantage over generic scales. The stroke-specific scales have, however, also some disadvantages which should be watched carefully. Most of the weakness comes from the fact that these scales are still relatively new and there are still not enough data available from clinical trials.[9]

Role of proxy ratings

Quality of life is mostly assessed by instruments depending on self-reports. But many patients are not able to communicate effectively or to understand what they are being asked. One way to avoid this methodological problem is to use so-called proxy ratings. Interestingly research has revealed that patients perceived their QOL better than those of their proxies. Proxy scores are systematically lower. Patient depression and proxy perception of burden are important factors that influence agreement between patients and proxies.[13]

Psychometric and other properties of generic outcome measures used in stroke QOL research

The selection of the QOL measure must be based on its psychometric attributes, which include reliability, validity, precision and acceptability. Reliability is the extent to which measurements for the same individual on separate occasions or by different observers produce similar results. Validity is the extent to which an instrument measures what it is meant to measure. A responsive QOL will be able to detect even small differences within an individual over time. Precision is concerned with the number of response categories and the capacity of a measure to report the most favorable or poorest health states (in other words, the extent of floor and ceiling effects). Acceptability: Average completion times, previous response rates, suitability of a measure for use with proxy respondents, intended mode of administration of the measure are very important for the acceptability of the measure.

The Sickness Impact Profile (SIP) and Nottingham Health Profile (NHP) are found to be the only two generic measures to exhibit all three psychometric properties of reliability, validity, and responsiveness.[12] Suitability

for use with proxy respondents in stroke studies is evident for the SIP, EuroQol, and Health Utilities Index (HUI), SF-36 Health Survey and most of the other generic measures, can be either self- or interviewer-administered.[15]

Although coverage is broad in some of the generic QOL measures, certain issues relevant to stroke, such as concentration and memory are not covered at all. Average completion times ranged from 2 to 30 minutes, being SIP the longest. Overall response rates to the measures in stroke populations were acceptable in most cases, Response rates to individual items were good for the HUI and London Handicap Scale (LHS), moderate for the SF-36, but not known for the other generic measures. Evidence of acceptability in terms of pretesting with stroke patients exists only for the HUI.[15]

The level of precision also varies widely between measures. The SIP and NHP have only 2 response categories, for example, whereas the SF-36 has a combination of between 2 and 6 response categories depending on the domain, and the LHS has 6 response categories. Floor and ceiling effects in stroke populations are not known for most of the generic measures identified, but the SF-36 was reported to have high ceiling effects on some domains. But the results of SF-36 study has been criticised.[15]

Quality adjusted life years

Quality Adjusted Life Years (QALYs) has been used as a common metric useful for capturing both health-related QOL and length of life in the same measure. Thereby each year of life is adjusted for its quality (value assigned to the particular health state) x (time spent). With QALYs, each year of life after a stroke is adjusted for its quality. For example; man with stroke, QOL value: 0.3, lived six years after stroke had two QALYs (0,3 x 6). But let us assume that stroke prevented in the same man, and he lived ten more years with full health (QOL value: 1), then he had ten QALYs (10x1). Incremental public health gain from preventing the stroke made up eight QALYs. Although this example is for prevention, QALYs can also be used to quantify the value of how an intervention can change the natural course of QOL effected by the disease.[16,17]

QUALITY OF LIFE PERCEIVED AFTER STROKE

Variation in QOL assessments depends on severity of stroke. Quality of life weights for major stroke range from -0.02 (indicating that major stroke is worse than death) up to 0.71; for moderate stroke range from 0.12 to 0.81, for minor stroke from 0.45 to 0.92, and for general stroke from 0.29 to 0.903.[17] There is considerable overlap in the distributions: some QOL estimates for major stroke are greater than some estimates for moderate or minor stroke. This variation in QOL weights for stroke perhaps may be due to the analysis methods chosen. A large assesment of QOL weights for stroke would be very useful.

To investigate the distribution of Assessment of Quality of life (AQOL) utility scores in survivors at two years after first-ever stroke, 225 stroke survivors were assessed. The distribution of scores provides evidence that HRQOL is impaired for most survivors at two years poststroke. The obtained utilities are similar to those reported elsewhere of 0.5 to 0.7 for mild to moderate stroke and 0 to 0.3 for major stroke. Eight percent of patients had HRQOL assessed as equivalent to, or worse than, death; and nearly one-quarter had a utility score of 0.1. These patients more often had proxy assessments than did patients with higher scores. The authors have also found that physical well-being is the component of HRQOL most affected after stroke.[18]

A previous study has shown that despite five years passed after stroke many individuals are still greatly affected and they have poor HRQOL. In addition, the distribution of AQOL scores for stroke survivors compared with the Australian population show that they more often have poor HRQOL and less often have favorable HRQOL. A major finding is that a substantial proportion of 5-year survivors of stroke had very poor HRQOL. Such individuals cannot live independently, because they require daily help with Activities of Daily Life (ADL). Furthermore, many such individuals also suffer from diminished psychological well-being.[19] Jönsson et al.[20] assessed QOL at 4 and 16 months after stroke in 304 patients and 234 caregivers using SF-36 mean scores (domain and component summary) of stroke patients and their caregivers. Although the patients' self-perceived physical function deteriorated, they appeared to adapt to the new life situation and their QOL in socioemotional and mental domains improved during the year between the follow-up. Surprisingly, the caregivers were on a lower level in emotional and mental domains, and their most important determinants of QOL were their own age and the patients' functional status.

Patel et al.,[21] concluded that disability and handicap remain highly prevalent up to 3 years after stroke. Patients' perception of physical health is persistently low, but mental health perception is satisfactory up to 3 years. Due to variable correlations between different HRQOL domains with disability and handicap, it is suggested that disability, handicap and HRQOL should all be assessed to acquire a broader measure of stroke outcome.

In a study assessing changes in SF-36 scores from admission to discharge and from discharge to six-months follow-up (n=85), it was found out that inpatient rehabilitation has a strong, positive impact on physical, cognitive, emotional, and social aspects of a patient's function and well-being, as expected. Patients may not do well when they return to their own environment. There were improvements in all eight domains of the SF-36, although only five were statistically significant during rehabilitation. After discharge there were marked

and statistically significant declines in the other five domains of the SF-36 in the six months after discharge opposite to the results of the preceeding study despite the concomittant use of SF-36. Declines after discharge suggests that patients may not do well when they return to their own environment.[22]

Stroke unit treatment improves long-term QOL. In a randomized controlled trial, 110 patients with symptoms and signs of an acute stroke were allocated to the stroke unit and 110 to general wards. Assessment with the NHP showed better results in the stroke unit group for the dimensions of energy (p=0.0323), physical mobility (p=0.0415), emotional reactions (p=0.0290), social isolation (p=0.0089), and sleep (p=0.0436), although there was no difference in pain (p=0.3186). This study shows for the first time that stroke unit care improves different aspects of long-term QOL for stroke patients.[23]

DETERMINANTS OF QUALITY OF LIFE AFTER STROKE

The investigation of relevant factors with HRQOL after stroke will provide valuable information about strategies that can address to improve HRQOL for stroke patients. Another study investigating factors independently associated with physical health summary scale (PHSS) at 1 year after stroke showed that female sex (coefficient [β], −3.26), manual workers (β, −3.15), diabetes (β, −4.23), urinary incontinence (β, −7.83) and cognitive impairment (β,−2.70) independently predicted worse PHSS. Compared to Total Anterior Circulation Infarcts (TACI), Partial Anterior Circulation Infarcts (PACI) had better PHSS (β, 5.95). In the same study, factors independently predicting mental HSS revealed that being older was associated with better Mental Health Summary Scale (MHSS): subjects aged 65–75 (β, 5.41) and over 75 (β, 6.29) had better MHSS than those <65 years. Other predictors of poor MHSS were being Asian (β, −11.8), ischaemic heart disease (β, −2.72) and cognitive impairment (β, −3.04).[24]

In another study performed on 225 alive cases, the independent concurrent determinants of HRQOL at two years after stroke were two-year handicap, disability and impairment, age, anxiety, and depression. When recurrent stroke and the markers of initial stroke severity were added to the multivariable models, none was retained as independent determinants of HRQOL. The evaluation of factors present at stroke onset revealed that stroke severity markers, female sex, dementia, institutionalization, cardiac failure, low summary effect size (Socioeconomic Status) and TACI subtype were significantly associated with worse HRQOL on univariable analysis. The independent determinants on multivariable regression were age, sex, initial NIHSS score, neglect, and SES.[18]

According to Paul et al.,[19] five-year AQOL score was associated with gender, age, socioeconomic status, whether the individual lived independently before stroke, and country of birth after univariate analysis. Comorbidities and risk factors present at stroke onset that were associated with poor five-year HRQOL were dementia and smoking. The baseline stroke-related variables of initial impairment (NIHSS), loss of consciousness, aphasia, hemiplegia, incontinence and neglect on admission. Multivariate analysis using ANOVA revealed that the independent predictors of five-year HRQOL were age, socioeconomic status, initial NIHSS score, and hemiplegia at onset.

CONCLUSION

Emphasis on the assessments of individual QOL which provide valuable information in deciding upon appropriate treatments and allocation of resources is increasing. However, universally accepted definitions of HRQOL do not yet exist. The need remains for a patient-centered, psychometrically robust, stroke-specific QOL measure. Today, selecting carefully seems more important.

The magnitude of deterioration of QOL in stroke cases of various severity is roughly proportional, however substantial overlaps exist (large surveys and sophisticated evaluation methods needed). Substantial proportion of stroke survivors still have very poor HRQOL even after years from onset. Physical well-being is the most affected component and deterioration is more permanent than that of mental health. Structured and comprehensive rehabilitation is benefical to improve HRQOL.

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