

Quality of Life after Stroke in Croatian Patients

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ABSTRACT

In order to evaluate the microsocial factors affecting quality of life in stroke victims, 100 survivors of ischemic stroke and the same number of their relevant family members (key persons, controls) were interviewed using Stroke Specific Quality of Life Scale (SS-QOL)¹ questionnaire. Total SS-QOL score did not differ significantly between post-stroke patients and key persons ($z=0.64$, $P=0.524$). Relevant family members ranked the patients' family ($P=0.022$) and social role ($P=0.08$), and their mobility ($P=0.09$) slightly higher than the patients themselves. However, male patients rated their »family role« ($z=-2.82$, $P=0.005$), »mobility« ($z=-2.28$, $P=0.023$) and »social role« ($z=-1.86$, $P=0.063$) higher than their female peers. Recent (≤ 33 months) and remote (>33 months after the ischemic accident) stroke patients did not differ substantially in total SS-QOL score, social role and hand function assessment but in mobility ($z=-1.90$, $P=0.057$) and family role estimation ($z=-2.47$, $P=0.014$) the difference was in favor of recent stroke patients. The domain scores and total SS-QOL score did not differ by gender between recent stroke patients and their controls either. It is concluded that assessment of general functioning and global quality of life among post-stroke patients provided by relevant patients' family members could be accepted with confidence. Male patients slightly overestimate their mobility and social role. No significant impact of post-stroke time span on quality of life estimation was observed.

Key words: stroke, quality of life, family members

Introduction

Cardiovascular diseases in general, and stroke in particular, constitute a major public health problem in the last decades. Several prospective studies, including the WHO MONICA project² have been designed to estimate the coronary and stroke morbidity and mortality trends in several countries. In 1990 stroke was the second leading cause of death worldwide, in that very year it took 4.4 million lives^{3,4}.

Epidemiological data show that stroke is the third leading cause of death in USA and the main cause of disability⁵. According to Croatian data from 1999, stroke was the commonest cause of death among the cardiovascular diseases, with a peak incidence in the 65–74 years age group, and an 80% dominance of the ischemic subtype⁶. Nevertheless, the crude death rates still underestimate the complexity of stroke consequences. Indeed, at variance to other, e.g. coronary or malignant diseases, among stroke victims permanent disability presents a much bigger burden to the affected individuals and to the entire society than the death itself. The Croatian census in 2001 showed that 15.6% of the population was elderly (at or above 65 years of age). Since stroke rate is highest in the third age, and the favorable trend of extended life

span continues, an increasing role of stroke is expected in the morbidity and mortality structure, as well as a growing prevalence of long-term survivors after stroke, due to better care and effective secondary prevention, particularly with antihypertensive agents⁷. The incidence of stroke in Croatia increased from 202 per 100 000 inhabitants in 1972 to 250 in 1988 (relative increase by some 24% in 16 years), with a mortality rate of 30%, i.e. with 70% of the victims surviving the acute phase⁸.

Family physician is supposed to give the bulk of medical and rehabilitative support to stroke patients after the hospital phase, but at the same time is assumed to function as a first-line cost-containment officer or »gatekeeper« against unnecessary and expensive entrance into the health system. For several reasons family physician is therefore the person which in everyday practice has the opportunity to experience all the medical, social and economic intricacies of the post-stroke care, including the quality of life perception among the stroke survivors and among persons taking care of them and giving them permanent care and psychosocial support. Proxies, determined also »significant others«, »key persons«, permanent caregivers or more simply controls, are mostly but

not exclusively the patient's spouses or close relatives, sharing the same household. Talking to stroke patients and their controls we have observed that sometimes their quality of life judgements may differ.

Few studies by other researchers investigated the level of agreement between chronically ill patients and their controls in assessing different areas of functional health status. Some compared psychosocial functioning assessment between the two using different scales^{9–11}.

We assumed that differences in quality of life self-assessment by post-stroke patients and assessment by their proxies could be important and decided to evaluate them in our setting. Croatian family physicians were invited to participate in this study as interviewers by announcement published on a forum web page of Croatian Family Medicine Association. SS-QOL questionnaire^{1,12} originally used for longitudinal follow-up of post-stroke patients was used in our survey to interview patients and their relevant family members.

Patients and Methods

Sample

This survey started on September 15, 2004, and ended on January 15, 2005. The interviewers were ten Croatian general practitioners (from Bukovlje, Dubrovnik, Postira, Sinj, Slavonski Brod, Split, Zadar, Zagreb, Trogir) who were previously group instructed. Each of them was taking care of a population averaging 1800 persons, and polling on average 10 patients and 10 family member responders. Patient inclusion criteria were: age above 18 years and history of only one clinically and CT proven ischemic stroke. Patients with hemorrhagic or recurrent stroke, hardly contactable (e.g. aphasic), frankly demented psychotic persons or those with comorbidities limiting the expected survival below 6 months were not included. Sampling of family members (controls, proxies, key persons, relevant others) was a convenient one: included were permanent caregivers found living with post-stroke patients and providing care for them. Those were mostly a spouse, an offspring or a close relative. The pollees were informed in detail about the aim of the survey, and all of them signed an informed consent form, attached to the questionnaire. Enrolled were 100 stroke survivors, 51 men and 49 women, and 100 controls, 67 women and 33 men. Patients and their controls were interviewed individually and independently face to face by family physicians, in their homes. It took approximately 20 minutes to fill an individual questionnaire. The response rate in both groups was absolute (100%).

Questionnaire

The survey form was written according to a validated instrument, Stroke Specific Quality of Life Scale (SS-QOL) questionnaire¹². It consisted of 49 questions grouped in 12 domains (energy, family role, hand function, mobility, pep, personality, productivity, sight, speech, self-sufficiency, social role, thinking). The original authors¹

used this questionnaire one month and three months after stroke. We decided to use it in all our examinees, irrespective of the time span after the accident, since it was the most appropriate and comprehensive form available. Each domain was rated on a 1–5 point Lykert type scale, according to the degree of agreement with a particular statement, ranging from full agreement (1) to full disagreement (5). The domain results were registered on a score-sheet, and later summed-up to get the global result (maximal score 260 points). Lower scale results indicated worse condition and higher patient's dependency in daily life activities. Concomitant diseases (e.g. diabetes, coronary heart disease, arterial hypertension), and the time interval (in months) since the acute phase were registered. Sociodemographic characteristics of patients (age, gender, marital status, living alone or in a family) were noted.

Total results and the particular data on four characteristic domains (»family role«, »mobility«, »social role«, »hand function«) have been analyzed for patients and controls.

Statistics

Chi-square test was used for comparison of frequencies, while t-test and Mann Whitney U test for independent samples were used to assess whether there was a statistically significant difference in quality of life assessment (between patients and their family member responders and among patients according to gender).

All statistical data were interpreted according to statistical significance of 95% ($P < 0.05$). Statistical analyses were conducted using Statistica 6.0 (StatSoft®, Inc., Tulsa, USA).

Results

Among the 100-post stroke patients there were 51 men and 49 women, and among the controls there were 67 women and 33 men. The mean age was 72 years, women were younger than men ($t = 2.65$, $P = 0.009$). According to marital status, there were more married males but 2.2 times more widows or unmarried females than widowers or unwedded males ($\chi^2 = 8.4$, $P = 0.004$). According to living conditions (alone, in a family) there were no significant gender differences ($\chi^2 = 1.4$, $P = 0.239$). The main comorbidities were grouped in five categories: coronary heart disease and hypertension, diabetes only, diabetes and coronary heart disease, diabetes and hypertension, the rest. Neither in this respect there were significant gender differences ($\chi^2 = 3.3$, $P = 0.771$). The time span from acute stroke was significantly longer in female patients ($z = 2.14$, $P = 0.033$).

No significant difference was observed between patients and their family members in SS-QOL total score ($z = 0.64$, $P = 0.524$), nor in domains »family role« ($z = -1.55$, $P = 0.122$), »mobility« ($z = -1.14$, $P = 0.254$) »social role« ($z = -1.20$, $P = 0.231$) and »hand function« ($z = -0.81$, $P = 0.417$; Table 1).

TABLE 1
STROKE-SPECIFIC QUALITY OF LIFE (SS-QOL) IN
POST-STROKE PATIENTS AND IN THEIR CONTROLS

Domain	Groups		P*
	Patients (n=100) Mean ± SD	Controls (n=100) Mean ± SD	
»Family role«	7.4 ± 4.18	8.3 ± 4.40	0.122
»Mobility«	11.6 ± 6.89	12.6 ± 7.05	0.254
»Social role«	8.7 ± 5.80	9.4 ± 5.61	0.231
»Hand function«	12.7 ± 7.07	13.5 ± 7.09	0.417
SS-QOL total	121.5 ± 46.82	125.8 ± 46.96	0.542

*Mann-Whitney U test

TABLE 2
STROKE SPECIFIC QUALITY OF LIFE (SS-QOL) IN
POST-STROKE PATIENTS ACCORDING TO GENDER

Domain	Groups		P*
	Women (n=49) Mean ± SD	Men (n=51) Mean ± SD	
»Family role«	6.3 ± 4.05	8.5 ± 4.07	0.005
»Mobility«	10.1 ± 6.48	13.0 ± 7.05	0.023
»Social role«	7.9 ± 5.82	9.5 ± 5.73	0.063
»Hand function«	12.2 ± 7.35	13.3 ± 6.83	0.348
SS-QOL total	116.8 ± 47.65	126.1 ± 46.02	0.267

*Mann-Whitney U test

Total score in the domain »family role« ($z=-2.82$, $P=0.005$) and »mobility« ($z=-2.28$, $P=0.023$) was significantly higher in male patients, while in the »social role« domain the score resulted marginally higher ($z=-1.86$, $P=0.063$). Regarding patients' gender, there were no significant differences in the total SS-QOL ($z=-1.10$, $P=0.267$) and »hand function« score ($z=-0.94$; $P=0.348$; Table 2).

According to median time span from the stroke, which was 33 (range 1–120) months, we have split our patients in two subgroups: 33 male and 17 female patients with 33 months from the accident (recent stroke) and 18 male and 32 female patients with >33 months from the acute event (remote stroke). A significant difference was observed in the domain »family role« ($z=-2.47$, $P=0.014$), and a marginal one in the domain »mobility« ($z=-1.91$, $P=0.057$) in favor of the recent stroke group. No significant differences between these two subgroups were observed in domains »social role« ($z=-1.45$, $P=0.147$), »hand function« ($z=0.60$, $P=0.548$) or total SS-QOL score ($z=-0.99$; $P=0.324$).

Comparing these subgroups with the respective controls, no significant differences were noted between recent stroke male patients and their proxies in any of the domains (»family role« $z=-0.56$, $P=0.576$, »mobility« $z=-0.31$, $P=0.753$, »social role« $z=-0.15$, $P=0.881$, »hand function« $z=-0.50$, $P=0.615$) or in total SS-QOL score

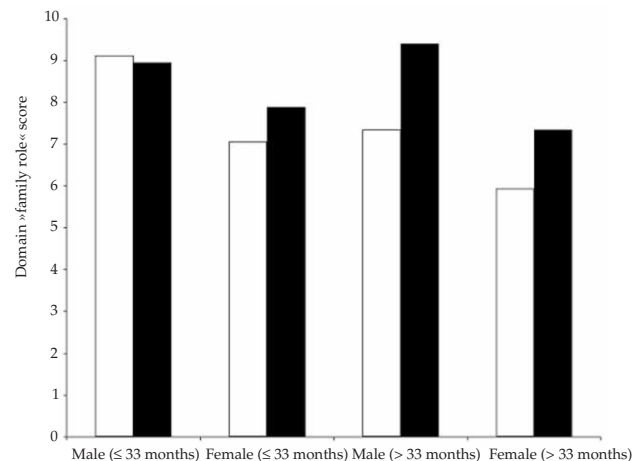


Fig. 1. »Family role« domain scores: post-stroke patients (according to gender and time elapsed from CVI) and controls (light bars-patients, dark bars-controls).

($z=-0.67$, $P=0.505$). The differences were tiny between recent stroke female patients and their key persons in domains »family role« ($z=-0.66$, $P=0.499$), »mobility« ($z=-2.24$, $P=0.809$), »hand function« ($z=-0.50$, $P=0.615$), »social role« ($z=-1.12$, $P=0.263$) or total SS-QOL score ($z=-0.45$, $P=0.654$) as well.

Contrasting the male patients with remote stroke to their family members, a minor difference was observed in the domain »family role« ($z=-1.70$, $P=0.088$), while in the rest (»mobility« $z=-0.62$, $P=0.536$, »social role« $z=-0.58$, $P=0.561$, »hand function« $z=-1.00$, $P=0.316$ and total SS-QOL score $z=-1.08$, $P=0.282$) it was slight indeed. Similar results have been obtained in female subgroup of remote stroke victims (»social role« $z=-1.66$, $P=0.098$, »hand function« $z=-0.55$, $P=0.580$, total SS-QOL score $z=-0.61$, $P=0.541$, »family role« $z=-1.65$, $P=0.098$ and »mobility« $z=-1.64$, $P=0.102$; Figures 1 and 2).

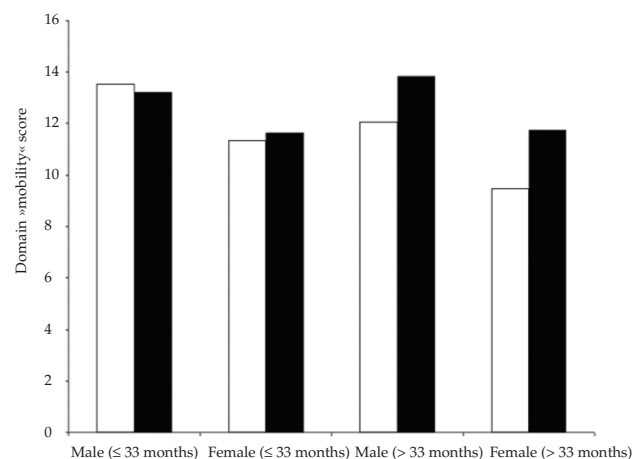


Fig. 2. »Mobility« domain scores: post-stroke patients (according to gender and time elapsed from CVI) and their controls (light bars-patients, dark bars-controls).

Discussion

The results of this study suggest that relevant family members are reliable in assessing global quality of life of post-stroke individuals; their assessment was comparable to self-assessment provided by the patients. A close patient-proxy agreement was achieved about the functional quality of life peculiarities and in evaluating specific life quality traits such as »family role«, »mobility« and »social role« of a disabled person. Family physicians may rely with confidence on family member's evaluation of a post-stroke patients' quality of life.

Limitation of this survey is lack of matched sampling (pairing patients with their caregivers by age, gender etc.), which would be rather difficult to achieve. Another one is absence of an objective, parallel assessment of the patients' functional status (e.g. using the Barthel index), since functional and emotional circumstances, including depression, have decisive impact upon the patient's perception and judgment about his/her quality of life. Which is the prevalence of depression in our post-stroke patients? It should be assessed with a validated questionnaire, such as Hamilton Depression Rating Scale¹³. Lacking from our questionnaire were also some relevant sociodemographic data about the subjects, particularly those concerning their schooling, job, revenue and possible return to work. Do educational level, income or occupation influence the patient's (or the family member responder's) quality of life assessment?

On the other hand, a relevant study, comparing rural and urban families, may stem from our results, as the way of living and family structure in Croatia are still quite different in these two settings. A correlation between specific impairments and quality of life estimation should be sought as well in order to identify the lesions that mostly affect the perception of good life. The patient's appraisal of the quality of medical and paramedical care (nurse, physiotherapist, psychologist, social worker) should be comparably evaluated¹⁴. In the projected large, prospective study, these drawbacks will hopefully be overcome.

No significant association was found between socio-demographic characteristics (age, gender marital status, way of living) of the examined post-stroke patients and their estimated total quality of life. A closer examination of the questionnaire's domains revealed that male survivors were more optimistic in the assessment of some quality of life components than their female counterparts. These were notably »family role« (decision making, entertainment within family), »mobility« (walking, standing, gait and balance, climbing stairs) and »social role« (getting out, recreation, visits to friends, social life). The literature data also indicate that male patients often overestimate their mobility after stroke¹⁵. The reason possibly lies in the fact that men are less engaged in everyday activities, which include walking and climbing, being more oriented towards car usage. Women have more problems in their declining family role after stroke, presumably because their house part in our society is tra-

ditionally more important, and the decline is more severe. On the other side, depressed hand function was evenly (critically) judged by both genders, presumably because it is equally crucial for daily activities.

Our female patients were younger (nevertheless, all of them were >50) and had a longer mean interval from acute stroke than the males: on average they were hit by the stroke earlier but survived longer. The growing incidence of stroke in women may be explained by intensified exposure to stress at the working place and at home, and by the expanding cigarette consumption¹⁶. Longer average survival after stroke may be explained by a better observance of life-style and diet changes and better compliance with prescribed drug therapy: indeed, advice and support of family members in these general measures are more effective among female patients^{17–19}.

Family members estimated total quality of life, general »mobility«, »family role«, »social role« and »hand function« in both recent and remote stroke patients with surprisingly high concordance with patients themselves. In fact, we expected lower reliability in quality of life assessment by longtime caregivers of remote stroke patients, as shown by Sprangers and Aaronson²⁰. It is quite possible that the family member responders in our study will henceforth become exhausted from long-lasting support and care for post stroke patients. Overly bureaucratic, slow and ineffective today's health and social welfare system with more limited financial resources tomorrow could have even more negative impact on fragile patients and their loving proxies. Presumably such »burn-out« caregivers could overestimate their protégée's quality of life and self-sufficiency, because of their own fatigue and exhaustion. Such overoptimistic estimations began to appear in our study, among controls of remote stroke female patients when rating their »social role« and among family members of both male and female remote stroke patients when estimating their »family role«. Perhaps more noticeable difference may be expected in due time?

More pessimistic judgments of female stroke survivors may also be due to the often-overlooked development of depression, a frequent complication of long-term stroke survival. For example, Robinson²¹ revealed severe depression in 23.3% of post-stroke outpatients. Since depression further impairs the existing functional, social and psychological deficits, and possibly augments the risk of recurrent stroke, the family physician should periodically evaluate the psychological profile of such patients, using for instance one of the validated ranking scales^{22–25}.

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KVALITETA ŽIVLJENJA NAKON MOŽDANOG UDARA U HRVATSKIH BOLESNIKA

SAŽETAK

Radi procjene mikrosocijalnih čimbenika koji utječu na kvalitetu življenja nakon ishemijskog moždanog udara, anketirano je 100 bolesnika i 100 relevantnih članova njihovih obitelji (ključne, kontrolne osobe) pomoću SS-QOL (Stroke-Specific Quality of Life) upitnika. Nije opažena značajna razlika u ukupnom SS-QOL zbiru između bolesnika i ključnih članova njihovih obitelji ($z=0,64$, $P=0,524$). Ključne osobe su nešto više ocijenile obiteljsku ($P=0,022$) i društvenu ulogu ($P=0,08$) pacijenata, kao i njihovu pokretljivost ($P=0,09$). Bolesnici su bolje ocijenili svoju obiteljsku ulogu ($z=-2,82$, $P=0,005$), pokretnost ($z=-2,28$, $P=0,023$) i društvenu ulogu ($z=-1,86$, $P=0,063$) nego bolesnice. Pacijenti s razmjerno svježim inzultom (≤ 33 mjeseci od incidenta) nisu se bitno razlikovali od onih sa starijim (> 33 mjeseci) u ukupnim SS-QOL bodovima, u procjeni socijalne uloge i funkcije ruke, ali je procjena pokretnosti ($z=-1,90$, $P=0,057$) i obiteljske uloge ($z=-2,47$, $P=0,014$) bila povoljnija u prvih. Ove se podskupine nisu ni spolno razlikovale po ukupnim SS-QOL bodovima ili pojedinim domenama. Zaključuje se da je procjena sveukupnog funkcijskog statusa i opće kvalitete života koju pružaju ključne osobe bolesnika s preboljelim ishemijskim moždanim udarom pouzdana. Bolesnici za razliku od bolesnica malo precjenjuju svoju pokretnost i društvenu ulogu. Vrijeme proteklo od nastupa moždanog udara nema većeg utjecaja na prosudbu kvalitete življenja.