Quality of Life After Stroke

The North East Melbourne Stroke Incidence Study (NEMESIS)

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Background and Purpose—Health-related quality of life (HRQoL) data are scarce from unselected populations. The aims were to assess HRQoL at 2 years poststroke, to identify determinants of HRQoL in stroke survivors, and to identify predictors at stroke onset of subsequent HRQoL.

Methods—All first-ever cases of stroke in a population of 306 631 over a 1-year period were assessed. Stroke severity, comorbidity, and demographic information were recorded. Two-year poststroke HRQoL was assessed using the Assessment of Quality of Life (AQoL) instrument (deceased patients score=0). Handicap, disability, physical impairment, depression, anxiety, living arrangements, and recurrent stroke at 2 years were documented. If necessary, proxy assessments were obtained, except for mood. Linear regression analyses were performed to identify factors independently associated with HRQoL.

Results—Of 266 incident cases alive at 2 years, 225 (85%) were assessed. The mean AQoL utility score for all survivors was 0.47 (95% CI, 0.42 to 0.52). Almost 25% of survivors had a score of ≤0.1. The independent determinants of HRQoL in survivors were handicap, physical impairment, anxiety and depression, disability, institutionalization, dementia, and age. The factors present at stroke onset that independently predicted HRQoL at 2 years poststroke were age, female sex, initial NIHSS score, neglect, and low socioeconomic status.

Conclusions—A substantial proportion of stroke survivors have very poor HRQoL. Interventions targeting handicap and mood have the potential to improve HRQoL independently of physical impairment and disability. (Stroke. 2004;35: 2340-2345.)

Key Words: cerebrovascular disorders ■ epidemiology ■ outcome ■ quality of life ■ stroke

Quality of life is defined as "individuals' perceptions 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." Health-related quality of life (HRQoL) refers to those aspects of quality of life affected by disease. The importance of measuring HRQoL when assessing the efficacy of interventions is recognized; however, HRQoL outcomes have been used in few stroke trials. Apart from HRQoL data for patients at 6 years after stroke in New Zealand, information from unselected populations using rigorous case ascertainment methodology is lacking.

We have previously published data on handicap in stroke survivors.³ In the same cohort, we now focus on HRQoL. In this unselected population at 2 years poststroke, our specific aims were: (1) to assess HRQoL; (2) to identify factors that explain HRQoL in survivors; and (3) to identify factors present at stroke onset that predict subsequent HRQoL.

Methods

This was a substudy within the community-based North East Melbourne Stroke Incidence Study (NEMESIS).⁴ Detailed methods for case ascertainment, baseline assessment, and follow-up at 2 years after stroke have been described previously.³

Case Ascertainment

All cases of first-ever stroke occurring in a population of 306 631 between May 1, 1998 and April 30, 1999 were ascertained. Patients with subarachnoid hemorrhage were included in incidence counts but not followed-up. Case-finding methodology met criteria for "ideal" stroke incidence studies.⁵ Potential cases were reviewed by a panel of stroke experts before inclusion. Ethics committees at each participating institution approved the study and informed consent was obtained from all participants.

Baseline Data

Cases were assessed by a research nurse as soon as possible after stroke. Additional clinical details were obtained from medical records and, if required, from treating doctors. Pathological stroke

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subtype (ischemic stroke [IS], intracerebral hemorrhage) was determined using neuroimaging or autopsy findings.6 Patients without neuroimaging or autopsy were classified as undetermined. IS cases were further categorized using the Oxfordshire Community Stroke Project classification.7

Demographic data recorded included age, sex, country of birth, preferred language, living alone, and institutionalization (nursing home, hostel, or supported accommodation). Occupations of the patient and spouse were used to classify socioeconomic status (SES).8 The categories for SES ranged from 1 (highest) to 6 (lowest).

Stroke severity markers recorded were dysphasia, loss of consciousness, neglect, and dense hemiparesis (loss of power against gravity in at least 1 limb) as determined using medical records and the National Institutes of Health Stroke Scale (NIHSS) examination. An acute NIHSS score was recorded prospectively when the patient was seen within 7 days, or retrospectively from the medical records. Comorbidities recorded were the presence of dementia, prestroke disability, and stroke risk factors (hypertension, diabetes, smoking, cardiac failure, atrial fibrillation, peripheral vascular disease, previous transient ischemic attack, and previous myocardial infarction). Dementia, hypertension, cardiac failure, peripheral vascular disease, previous transient ischemic attack, and previous myocardial infarction were defined as a known history. Smoking status was classified as current, ex, or never. Prestroke disability was defined as a prestroke Barthel Index score of <20/20. Diabetes was defined as either a known history or a current presentation with fasting blood glucose ≥7.0 mmol/L. Atrial fibrillation was defined as either a known history or a current presentation confirmed on electrocardiography.

Follow-up

Participants were assessed in a standardized face-to-face interview at 2 years after their index stroke. If severe cognitive impairment or dysphasia was present, proxy interviews from reliable informants were used, except for mood assessments. Interpreters were provided when required.

Instruments

HRQoL was assessed using the Assessment of Quality of Life (AQoL) instrument,9 a generic HRQoL utility instrument that includes 5 dimensions of HRQoL: independent living, social relationships, physical senses, psychological well-being, and illness. Scores from the first 4 dimensions, but not the illness dimension, are used to calculate an overall utility score. Each individual scale is weighted to extend between 0.0 (death) and 1.0 (full health). However, the overall utility score ranges from -0.04 (worst possible HRQoL state) to 0.00 (death equivalent HRQoL state) to 1.00 (full HRQoL). The AQoL has been validated for use in the general population^{9,10} and in people with stroke.11

Handicap was assessed using the London Handicap Scale (LHS);¹² physical impairment with the NIHSS;13 and disability with the Barthel Index.¹⁴ Disability the patient stated as not caused by stroke was also recorded. Mood impairment was assessed with the Irritability, Depression, Anxiety scale (IDA),15 a self-assessment measure of depression, anxiety, and "inward" and "outward" irritability.

Stroke-like events in the previous 2 years were identified using a questionnaire. A panel of experts verified recurrent strokes using information from medical or nursing home records and from treating doctors.

Analyses

Student t test or 1-way ANOVA was used to determine the significance of differences in 2-year HRQoL scores between patients categorized according to demographic, stroke severity, comorbidity, and stroke subtype variables; 2-year impairment and disability scores; and presence of recurrent stroke.

Univariable linear regression analyses were performed to identify factors present concurrently (ie, at the time HRQoL was assessed) associated with HRQoL in survivors. Multivariable linear regression analyses were performed, including those factors significant on

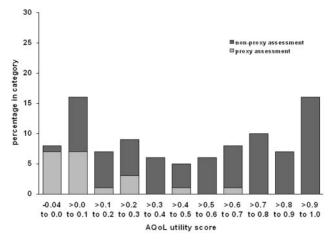


Figure 1. Distribution of AQoL utility scores in survivors at 2 years after first-ever stroke (n=225).

univariable analysis, to identify factors independently associated with HRQoL. First, all assessments (proxy and nonproxy) were examined, and then nonproxy assessments alone were used to examine the effects of mood. Once the most parsimonious model was obtained by backwards stepwise regression, each excluded variable was entered again separately to test its contribution to the final model. NIHSS, Barthel, IDA and LHS scores, and age were entered as continuous variables.

Similarly, univariable and then multivariable linear regression were performed to identify factors, present at stroke onset, that were independent predictors of HRQoL at 2 years after stroke. For these analyses, patients deceased at 2 years after stroke have a utility score of 0.0.

Results

Of 516 cases of first-ever stroke, 27 had subarachnoid hemorrhage and were ineligible for this study. The remaining 489 comprised 223 deceased at 2 years after stroke (46%) and 266 survivors. Of these survivors, 4 were found >2 years after stroke, 38 refused participation, and 225 (85%) were assessed. The mean time to interview was 737 days (median, 731; range, 646 to 898). Of those assessed, 51% were male, 23% were institutionalized, 22% were living alone, 85% had IS, 12% had intracerebral hemorrhage, 3% had undetermined subtype, and the mean age was 71 years (95% CI, 69 to 73). Forty-seven (21%) had proxy assessments. There were no significant differences between those assessed and those eligible but not assessed in terms of age (P=0.7; Student t test) or sex, country of birth, stroke subtype, and stroke severity markers (all $P \ge 0.9$; χ^2). No significant colinearity or interaction among variables entered into regression analyses was found.

HRQoL in Survivors After Stroke

The mean utility score for survivors was 0.47 (95% CI, 0.42) to 0.52). 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 (Figure 1). Seventy-seven percent of patients with an AQoL utility score of ≤ 0.1 were not institutionalized at stroke onset. Patients' scores ranged between 0.0 and 1.0 for each of the subscales. The mean subscale scores (which, unlike the utility

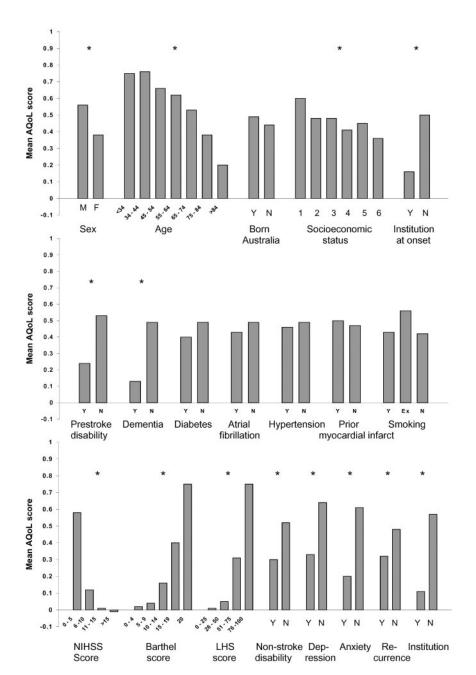


Figure 2. HRQoL of survivors grouped according to demographic factors, comorbidities and risk factors, and 2-year outcomes. **P*<0.05, univariable linear regression.

score, have not been transformed to reflect community preferences) were independent living 0.59 (95% CI, 0.54 to 0.64), social relationships 0.8 (95% CI, 0.77 to 0.83), physical senses 0.88 (95% CI, 0.86 to 0.90), and psychological well-being 0.86 (95% CI, 0.84 to 0.88). The mean score for the illness domain (not used in utility score calculation) was 0.27 (95% CI, 0.24 to 0.30).

Univariable Relationships Between HRQoL and Demographics, Comorbidities, and 2-Year Outcomes in Survivors

The relationships between HRQoL in survivors and demographic factors, comorbidities, and outcomes at 2 years after first-ever stroke are summarized in Figure 2 and Tables I-IV (available online at http://www.strokeaha.org). Worse

HRQoL was associated with female sex, increasing age, institutionalization at stroke onset, low SES, dementia, pre-existing disability,; and the presence at 2 years poststroke of greater physical impairment and disability, depression, anxiety, inward irritability, nonstroke-related disability, and institutionalization. Patients with recurrent stroke had worse HRQoL than those without further stroke; however, differences were not statistically significant.

Independent Concurrent Determinants of HRQoL in Survivors

In the first analysis, mood scores were excluded (ie, both proxy and nonproxy assessments were included). The independent determinants were 2-year handicap, institutionalization at 2 years, dementia, and age (adjusted R=0.74). The

TABLE 1. Independent Concurrent Determinants of HRQoL in Survivors at 2 Years After First-Ever Stroke, Including Mood Assessments

Variable	Mean Score	β (95% CI)	Multivariable, P
2-year LHS	81	0.009 (0.007, 0.010)	< 0.001
2-year NIHSS	1.5	-0.013 (-0.26 , -0.001)	0.028
Depression	4.0	-0.017 (-0.028 , -0.007)	0.001
Anxiety	3.9	-0.019 (-0.28 , -0.009)	< 0.001
2-year Barthel	17.8	0.012 (0.003, 0.020)	0.005
Age	68.6	-0.023 (-0.004 , 0.000)	0.019

LHS indicates London Handicap Scale; NIHSS, National Institutes of Health Stroke Score.

Adjusted R^2 for model=0.76, n=167.

second analysis included mood scores (ie, using only data from nonproxy respondents). The independent determinants were 2-year handicap, disability and impairment, age, anxiety, and depression (Table 1). When recurrent stroke and the markers of initial stroke severity were added to the multivariable models, none was retained as independent determinants of HRQoL.

Baseline Predictors of HRQoL

For this analysis, patients deceased at 2 years poststroke were included (utility score=0.0). The factors present at stroke onset significantly associated with HRQoL regression analyses are summarized in Table 2. Initial stroke severity markers, subtype, institutionalization at stroke onset, dementia, risk factors, and demographics were considered. Stroke severity markers, female sex, dementia, institutionalization, cardiac failure, low SES, 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.

Discussion

This is the second community-based study, with ideal methodology to ensure complete case ascertainment, to provide HRQoL data on stroke patients.2 The AQoL utility scores provide an estimate of the general communities' views about the state of health the patient is experiencing. The distribution of scores (Figure 1) provides evidence that HRQoL is impaired for most survivors at 2 years poststroke. The mean utility for survivors (\approx 0.5) suggests that people in the general community would rather give up half of their remaining years of life to live in full health than continue living with the health status of the average stroke survivor. The utilities obtained are similar to those reported elsewhere of 0.5 to 0.7 for mild to moderate stroke and ≤ 0.0 to 0.3 for major stroke. ¹⁶ This is considerably lower than the median AQoL score of 0.86 found in a group of healthy elderly people living in the community in Melbourne (Graeme Hawthorne, Department of Psychiatry, The University of Melbourne, personal communication). Our findings are consistent with previous reports of reduced HRQoL poststroke, even among patients with good functional recovery. 16-26

A major finding was that 8% of patients had HRQoL assessed as equivalent to or worse than death, and that almost

TABLE 2. Baseline Predictors of HRQoL at 2 Years After Stroke Significant on Linear Regression

Variable	n*	Mean AQoL (95%Cl)	Univariable <i>P</i>	Multivariable <i>P</i>
Ischaemic subtype†				
TACI	76	0.06 (0.02, 0.11)	< 0.001	_
PACI	111	0.32 (0.25, 0.39)		
POCI	67	0.38 (0.28, 0.47)		
LACI	68	0.38 (0.29, 0.47)		
Dense hemiplegia				
Yes	205	0.08 (0.06, 0.11)	< 0.001	_
No	241	0.37 (0.32, 0.42)		
Impaired consciousness				
Yes	153	0.05 (0.02, 0.08)	< 0.001	_
No	294	0.37 (0.29, 0.38)		
Neglect				
Yes	90	0.13 (0.08, 0.18)	< 0.001	0.002
No	320	0.29 (0.25, 0.33)		
Urinary incontinence		(, ,		
Yes	132	0.05 (0.02, 0.07)	< 0.001	_
No	308	0.32 (0.28, 0.36)		
Dysphasia	-00	(), 0.00)		
Yes	139	0.15 (0.10, 0.20)	< 0.001	_
No	305	0.28 (0.24, 0.32)	×0.001	
Initial NIHSS	000	0.20 (0.24, 0.02)		
0–5	190	0.45 (0.39, 0.50)	< 0.001	< 0.001
6–10	75	0.20 (0.14, 0.27)	<0.001	<0.001
11–15	44	0.06 (0.01, 0.10)		
≥16	102	0.01 (-0.003, 0.03)		
Institution at onset	102	0.01 (0.003, 0.03)		
Yes	76	0.05 (0.01, 0.08)	< 0.001	
No	372	,	<u>\0.001</u>	_
	3/2	0.28 (0.24, 0.31)		
Sex	201	0.22 (0.27, 0.20)	<0.001	<0.001
Male	201	0.32 (0.27, 0.38)	< 0.001	< 0.001
Female	247	0.17 (0.13, 0.20)		
Age	44	0.01 (0.00, 0.00)	<0.004	-0.001
<34	11	0.61 (0.33, 0.89)	< 0.001	< 0.001
35–44	7	0.54 (0.16, 0.92)		
45–54	15	0.57 (0.39, 0.75)		
55–64	41	0.48 (0.36, 0.61)		
65–74	102	0.32 (0.25, 0.39)		
75–84	153	0.19 (0.14, 0.24)		
≥85	119	0.04 (0.01, 0.07)		
Socioeconomic status				
1	90	0.41 (0.33, 0.50)	0.005	< 0.001
2	65	0.29 (0.21, 0.38)		
3	32	0.23 (0.10, 0.36)		
4	66	0.28 (0.20, 0.36)		
5	26	0.23 (0.08, 0.37)		
6	61	0.25 (0.17, 0.33)		
Cardiac failure				
Yes	88	0.10 (0.06, 0.16)	< 0.001	_
No	354	0.27 (0.24, 0.31)		
Dementia				
Yes	60	0.02(-0.01, 0.06)	< 0.001	_
No	386	0.27 (0.23, 0.30)		
Alcohol		, , ,		
Never	141	0.21 (0.16, 0.26)	0.040	_
Mild	200	0.32 (0.27, 0.37)		
Heavy	19	0.30 (0.14, 0.46)		
Ex-heavy	15	0.29 (0.05, 0.53)		

^{*}Number with available data.

Adjusted R^2 for model=0.41, n=321

^{†71} ICH, 55 undetermined subtypes, differences among pathological subtypes non-significant.

NIHSS indicates National Institutes of Health Stroke Score.

one-quarter had a utility score of \leq 0.1. Clearly, the outcome for a substantial proportion of patients who survive to 2 years is poor.

The impairment in HRQoL of survivors was pronounced in the independent living domain of the AQoL that is used to assess basic and instrumental activities of daily living and ease of getting around the home and community. The low score in the illness domain implies that this group of patients is heavily reliant on medications, medical aids, and health professionals. Patients scored better, on average, in the domains of social relationships, physical senses, and psychological well-being. Other authors using the SF-36 have also found that physical well-being (ie, SF-36 Physical Functioning and Role Physical scales) is the component of HRQoL most affected after stroke.^{2,18,20,26}

Similar to previous work at other time points, the factors present at 2 years poststroke that independently influenced HRQoL in survivors were physical impairment, 21,22,25,27,28 disability, 18,27-31 depression, 18,22,25,29-31 and age. 18,21,28 We also found that handicap, anxiety, institutionalization, and dementia were independently associated with HRQoL, whereas others reported that cognition was an important factor.³² Social support has been identified as a determinant of HRQoL;^{29–31} however, this was not specifically assessed in our study. We have previously found that disability, physical impairment, anxiety, and depression were also independent determinants of handicap.3 Therefore, addressing these factors may influence HRQoL either directly or indirectly through reducing handicap. Alleviating poststroke handicap (eg, rehabilitation, poststroke services, occupational and leisure therapy, environmental modification) may improve HRQoL; however, the effectiveness of these interventions is unclear.

The factors at stroke onset that independently predicted HRQoL at 2 years poststroke (in deceased and surviving patients) were age, sex, initial NIHSS score, neglect, and low SES. These baseline factors did not add additional independent explanation of HRQoL in survivors when included in analyses with factors measured concurrently with HRQoL. However, the identification of these indicators of subsequent poor HRQoL may be useful to the clinician.

That surviving TACI patients had significantly worse HRQoL than other subtypes is consistent with previous reports of increased mortality,⁷ dependence,⁷ impairment,³³ and handicap³⁴ in these patients. The lack of significant difference in HRQoL between survivors with IS and intracerebral hemorrhage is consistent with reports at 6 months²¹ and at 1 to 3 years poststroke.³⁰

Because of our community-based design and high follow-up rate, it is likely that our sample population is representative of stroke patients as a whole. HRQoL was assessed with the AQoL for which validity in cross-sectional stroke studies has been demonstrated.¹¹ Weaknesses of our study include lack of assessment of the influence of rehabilitation and social support on outcomes. Analyses were exploratory; therefore, some associations may be significant by chance, and results need validation in other cohorts. Patients may rate health status better than their proxies do;³⁵ therefore, HRQoL may have been underestimated in our

proxy assessments. Furthermore, the relationship between mood and HRQoL was not examined in patients with proxy assessments and may differ from that observed in patients responding themselves.

The AQoL has several advantages as an outcome measure, providing a valid and sensitive measure of HRQoL and utility scores that can be used to calculate quality-adjusted life-years in economic analyses. Disability and handicap instruments do not allow death to be considered when baseline factors are used to predict outcome. The design of the AQoL means deceased patients score equals 0.0 (HRQoL equivalent to death), allowing an unbiased assessment of predictors of HRQoL. This makes the AQoL an attractive measure for stroke clinical trials. Additional validation of the instrument, particularly in use of proxy assessments, may further enhance its usefulness.

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