Long-Term Outcome in the North East Melbourne Stroke Incidence Study
Predictors of Quality of Life at 5 Years After Stroke

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Background and Purpose—Although much is known about the long-term outcome of stroke patients in terms of mortality and disability, there has been little research on the patient-centered outcome of health-related quality of life (HRQoL). There are limited natural history data on HRQoL beyond 2 years after stroke and no data on those factors present at stroke onset that predict HRQoL beyond 2 years after stroke. For these reasons, we aimed to examine these aspects of HRQoL in an unselected population of stroke patients.

Methods—All cases of first-ever stroke from a prospective community-based stroke incidence study (excluding subarachnoid hemorrhage) were assessed 5 years after stroke. HRQoL was measured with the assessment of quality of life instrument. ANOVA was used to determine baseline predictors of HRQoL.

Results—In total, 978 cases were recruited, 45% were male, and the mean age (±SD) was 75.5±13.8 years. Five years after stroke, 441 (45.1%) were alive and 356 were assessed (80.7%). Those assessed were more often born in Australia and older in age (both \( P < 0.05 \)). Seventy-one survivors (20%) had a very low HRQoL (score \( \leq 0.1 \)). The independent baseline predictors of low HRQoL at 5 years after stroke were increasing age, lower socioeconomic status, and markers of stroke severity.

Conclusion—At 5 years after stroke, we found that a substantial proportion of survivors were suffering from poor HRQoL. As our population ages, the number of strokes and, thus, stroke survivors with poor HRQoL is likely to increase. Therefore, strategies to improve HRQoL should be vigorously pursued. (Stroke. 2005;36:2082-2086.)

Key Words: health status ■ quality of life ■ stroke incidence ■ stroke outcome

Stroke has a multitude of negative consequences on an individual’s life ranging from death, institutionalization, and loss of independence\(^1\)-\(^3\) to cognitive and communication difficulties.\(^4\) It is, therefore, understandable that stroke impacts an individual’s health-related quality of life (HRQoL). HRQoL instruments include assessment of mental health, social, and physical functioning. Within studies that have included assessment of HRQoL after stroke, many are limited to hospital-based samples of patients\(^5\)-\(^12\) or include HRQoL measures that have not been validated\(^5,12,13\).

Long-term HRQoL of stroke patients has been examined in 2 population-based studies. In the Auckland Stroke Study\(^14\) HRQoL was investigated at 6 years after stroke, and survivors were reported to have relatively good HRQoL compared with population norms and controls. In contrast, at an earlier time point 2 years after stroke, in the North East Melbourne Stroke Incidence Study (NEMESIS),\(^15\) it was found that more than a quarter of stroke survivors had a poor HRQoL. A novel aspect to this earlier study was the derivation of those factors present at baseline that predicted the level of HRQoL at 2 years after stroke.\(^15\) Despite the obvious value in being able to identify those individuals at stroke onset who may be at risk of poor HRQoL, there have been no other investigations of predictors of HRQoL in the longer term.

The aim of this study was to establish the level of HRQoL among an unselected population of stroke patients 5 years after stroke. In addition, we aimed to investigate those factors present at the time of stroke that could predict the level of HRQoL at 5 years after stroke.

Methods
This study was completed as part of the follow-up of patients from NEMESIS. The details of case ascertainment and baseline assessment have been described previously.\(^16\) Briefly, the study adhered to the criteria for an “ideal” stroke incidence study.\(^17,18\) From May 1, 1997, to April 30, 1999, all of the possible cases of first-ever stroke were ascertained from a region of North Eastern Melbourne with a
population of 306,631. Multiple overlapping sources were used to identify all of the cases of stroke in the study region. Sources included both hospital (admission and discharge lists) and nonhospital sources (general practitioner and nursing homes referrals). Stroke was defined using the World Health Organization clinical definition. All of the potential cases of stroke were assessed by a panel of stroke experts before inclusion in the study. Classification of strokes according to subtype [ischemic stroke, intracerebral hemorrhage, and subarachnoid hemorrhage (SAH)] was established by examining neuroimaging or autopsy findings, and when these were not available, the stroke was classified as undetermined. In addition, cases of ischemic stroke were categorized using the Oxfordshire Community Stroke Project classification. Although cases of SAH were included in incidence counts, they were not followed up.

Baseline Assessment

After verification of stroke, each case was assessed by a research nurse. Information regarding demographics, medical history, and clinical details of the stroke were gathered from medical records, the treating physicians, and the cases themselves. Demographic data collected included age, gender, country of birth, occupation, and whether or not they were institutionalized. Occupation was used as a marker for socioeconomic status divided into manual and nonmanual occupations. Data relating to comorbid conditions and vascular risk factors were collected. The presence of diabetes, dementia, hypertension, previous myocardial infarction, atrial fibrillation, other cardiac disease, and peripheral vascular disease was established from medical records and recorded as a dichotomous outcome. In addition, information regarding the individuals smoking status, defined as never, former, and current smoker, and their level of alcohol consumption, defined as never, moderate (≤ 4 standard drinks a day for females and ≤ 6 standard drinks a day for males), heavy, and ex-heavy consumption, was ascertained.

Stroke severity was assessed using the National Institutes of Health Stroke Scale (NIHSS). This measure of neurological impairment is valid and reliable when administered by either neurologists or trained nurses. Where possible, the NIHSS was completed within 7 days of the stroke; however, if this was not possible, the NIHSS was completed retrospectively from medical records. In addition, we recorded the presence at onset of dysphasia, neglect, hemiparesis, urinary incontinence, and loss of consciousness.

Follow-Up Assessment

Survivors were contacted 5 years after stroke, and a face-to-face interview was conducted. When severe cognitive impairment or dysphasia was present, a reliable source was used as a proxy respondent. HRQoL was assessed with the Assessment of Quality of Life (AQoL) instrument.

AQoL Instrument

The AQoL is a generic HRQoL utility instrument that provides a single utility score representing the general population preference for a given health state. The AQoL comprises 15 items over 5 subscales: independent living, social relationships, physical senses, psychological well-being, and illness. A score between 0 (worst health state) and 1 (best health state) is obtained for each subscale. Scores from each subscale (except the illness subscale) are then converted to a single weighted utility score. Weights were derived using the time trade-off technique within an Australian community-based sample. Utility scores range from −0.04 (state worse than death) through 0.00 (death-equivalent) to 1.00 (full health). The AQoL is valid and reliable in stroke patients. Furthermore, it is reliable when completed by proxy. Patients who are deceased can be included in outcome measures by assigning an AQoL utility score of 0. Normative data for the Australian population aged 70 to 79 years (n = 936) were provided by an author of the AQoL (Graeme Hawthorne personal communication, 2005).

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. With Available Data</th>
<th>% With Variable*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean±SD)</td>
<td>892</td>
<td>75.5±13.8</td>
</tr>
<tr>
<td>Female</td>
<td>892</td>
<td>55%</td>
</tr>
<tr>
<td>Country of birth: Australia</td>
<td>880</td>
<td>67%</td>
</tr>
<tr>
<td>Socioeconomic status: nonmanual occupation</td>
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<td>60%</td>
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<tr>
<td>Current smoker at onset</td>
<td>773</td>
<td>14%</td>
</tr>
<tr>
<td>Institutionalized before stroke</td>
<td>891</td>
<td>17.8%</td>
</tr>
<tr>
<td>Stroke subtype</td>
<td>892</td>
<td>16%</td>
</tr>
<tr>
<td>TACI</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>PACI</td>
<td>26%</td>
<td></td>
</tr>
<tr>
<td>POCI</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>LACI</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>ICH</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>Undetermined</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>LOC at onset</td>
<td>888</td>
<td>31%</td>
</tr>
<tr>
<td>Incontinence at onset</td>
<td>873</td>
<td>22%</td>
</tr>
<tr>
<td>Aphasia at onset</td>
<td>885</td>
<td>35%</td>
</tr>
<tr>
<td>Hemiplegia at onset</td>
<td>888</td>
<td>41%</td>
</tr>
<tr>
<td>Neglect at onset</td>
<td>755</td>
<td>21%</td>
</tr>
</tbody>
</table>

Data Analysis

To determine univariate associations between variables and 5-year AQoL scores, Student t tests and \( \chi^2 \) cross-tabulations were used. All of the analyses were conducted using Stata 8.0. Baseline factors that were independent predictors of 5-year HRQoL were determined by ANOVA. A full model with all of the variables significant on univariate analysis was fitted with serial removal of the least significant variables until all of the variables in the model had a \( P < 0.05 \). When this was achieved, each excluded variable was then entered separately into the model to determine its contribution to the final model.

All of the values are presented as mean±SD. A \( P < 0.05 \) (2-sided) was considered statistically significant.

Results

Baseline Sample

A total of 978 cases of first-ever stroke (excluding SAH) were identified over a 24 month period. Of these cases, 45% were males, 67% were born in Australia, and the mean age was 75.5±13.8 years (Table 1).

5 Years After Stroke

At 5 years after stroke, 441 cases (45.1%) were alive, and 356 (80.7%) of these agreed to be interviewed. Proxy respondents were used in 18.5% of interviews. The mean age of interviewed survivors was 74.6±13.9 years. Those who were assessed were more likely to be born in Australia and were older in age (\( P < 0.05 \)) than those not assessed. Reasons for not being assessed included refusing participation (46%) or being uncontactable (21%).
Distribution of AQoL Utility Scores 5 Years After Stroke

The distribution of 5-year AQoL scores among survivors and a representative group of the Australian population (aged 70 to 79 years) is shown in Figure 1. The mean AQoL score among stroke survivors was 0.50 (95% CI, 0.46 to 0.54). Of note is that 20% of stroke survivors were found to have very poor HRQoL, with an AQoL score ≤0.1. In contrast, in the general population <3% had a score ≤0.1. The poorest utility was seen in the illness subscale of the AQoL (mean score, 0.28; 95% CI, 0.26 to 0.31). The other subscale in which HRQoL was substantially reduced was independent living (mean, 0.61; 95% CI, 0.57 to 0.65).

Baseline Predictors of HRQoL 5 Years After Stroke

Univariate Analysis
Five-year AQoL score was associated with gender, age, socioeconomic status, whether the individual lived independently before stroke, and country of birth (P≤0.05; Table 2; Figure 2). Comorbidities and risk factors present at stroke onset that were associated with poor 5-year HRQoL were dementia, never drinking alcohol, and never smoking (P≤0.05; Table 2; Figure 2). The baseline stroke-related variables of initial impairment (NIHSS), loss of consciousness, aphasia, hemiplegia, incontinence and neglect on admission were all associated with AQoL score at 5 years (P≤0.05; Table 2; Figure 2).

Multivariate Analysis
Using ANOVA, the independent predictors of 5-year HRQoL were age, socioeconomic status, initial NIHSS score, and hemiplegia at onset (Table 2).

Discussion
In this study we found that 5-year survivors of stroke have poor HRQoL. The low AQoL utility score of 0.50 indicates that the general population would prefer to halve their expected life span than have the life of the average stroke patient. This score is similar to the level of HRQoL found at 2 years after stroke (0.47; 95% CI, 0.42 to 0.52), but is considerably lower than that found among a representative sample of the Australian population aged between 70 and 79 years (0.75; 95% CI, 0.72 to 0.78). In addition, the distribution of AQoL scores for stroke survivors compared with the Australian population show they more often have poor HRQoL and less often have favorable HRQoL. Thus, it is evident that despite 5 years lapsing from the initial stroke event, the lives of many individuals are still greatly affected, and probably for many this low HRQoL has been present since the stroke.

When we examined the subscales of the AQoL, the worst scores were seen in the illness and independent living subscales (mean scores of 0.28 and 0.61, respectively). The low score in the illness subscale is unsurprising given that this subscale refers to the need and reliance on medical treatment, medications, and medical aids. Because a significant proportion of stroke patients require medications for secondary prevention and, therefore, require regular contact with their physician, a lower score in this subscale is to be expected. The low score in the independent living subscale is consistent with data from other studies. Among 5-year survivors in the Perth Community Stroke Study, disability, measured by the modified Rankin Scale (which shares similarities with “independent living”), was found to be present in 36% survivors at 5 years after stroke. Similarly, among 6-year survivors in the Auckland Stroke Study, the worst HRQoL was seen in the physical functioning scale of the Short Form-36. Of interest is that the same 2 AQoL subscales were found to be the most affected among 2-year survivors in the NEMESIS cohort.

A major finding is that a substantial proportion of 5-year survivors of stroke had very poor HRQoL (AQoL score ≤0.1). Such individuals cannot live independently, because they require daily help with personal care and household tasks and are unable to move around their home or the

<table>
<thead>
<tr>
<th>Variable</th>
<th>Univariate P Value</th>
<th>Multivariate P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of atrial fibrillation</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Age</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Level of alcohol</td>
<td>&lt;0.05</td>
<td>...</td>
</tr>
<tr>
<td>Aphasia at onset</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>History of cardiac failure</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>History of dementia</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Hemiplegia at onset</td>
<td>&lt;0.001</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Incontinence at onset</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Institutionalized at onset</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>LOC at onset</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Initial NIHSS score</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Neglect at onset</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Gender</td>
<td>&lt;0.001</td>
<td>...</td>
</tr>
<tr>
<td>Smoking</td>
<td>&lt;0.05</td>
<td>...</td>
</tr>
<tr>
<td>Socioeconomic status</td>
<td>&lt;0.05</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>

LOC indicates loss of consciousness.

*No. of cases included 654; r²=0.4.
community unaided. Furthermore, many such individuals also have difficulty fulfilling their family role and suffer from diminished psychological well-being. At this level of disability, patients either require costly nursing home care or considerable help from next of kin to undertake everyday tasks. With the ageing of our population and an expected increase in the prevalence of stroke survivors, there is likely to be an increase in the demand for nursing home care to support these people. Methods of improving HRQoL for patients after stroke, so that more patients that can be supported in the community rather than institutions, need to be urgently investigated.

We identified 4 independent predictors of poor HRQoL at 5 years after stroke: age, hemiplegia and impairment at onset, and socioeconomic status. These factors were also identified as predictors of 2-year HRQoL; however, the current data identifies hemiplegia, not neglect. Some investigators, using selected samples of stroke patients, have also found an association between older age and poor HRQoL, whereas other investigators found no such association. 

It is unsurprising that more severe strokes (measured by the NIHSS) were associated with poor HRQoL 5 years after stroke. In the long term, dependency in activities of daily living associated with such strokes can impact on all subscales of the AQoL and, therefore, reduce overall HRQoL. It was unexpected that gender was not a predictor of 5-year HRQoL, because it was a highly significant predictor of 2 year HRQoL (P<0.001). The weakening of this association may be attributed to a change in the distribution of mortality between genders from 2 to 5 years. At 2 years, 39.9% of males and 50.6% of females were deceased, whereas at 5 years, similar proportions of males and females were deceased (54.4% and 59.6%, respectively). The comparatively high proportion of females deceased at 2 years (having an AQoL score of 0) acts to reduce the mean AQoL score among females and, thus, strengthens the association between female gender and poor HRQoL. At 5 years, this gender-based mortality difference was reduced. Subsequently, the AQoL scores were more widely distributed across genders, and this may explain the reduced association between gender and HRQoL at 5 years.

This study has a number of advantages over existing studies of HRQoL in the literature. First, these data are from a large, prospective, community-based stroke incidence study that adopted the ideal criteria for stroke incidence studies. Second, the HRQoL utility instrument provides a single summary score enabling an inclusive predictive analysis of outcome. Furthermore, deceased patients can be included by assigning a score of 0, thereby permitting a prediction of outcome for all patients and not just those who survive. A limitation of the study is the 20% loss to follow-up, with those participating being older and more often born in Australia than those who were not assessed. However, we are confident that the community-based ascertainment and size of the cohort make it representative of stroke patients in general. It should be considered that because of the ethnic mix of our patients being different from those in other countries and because the perception of HRQoL can be affected by cultural factors, it is possible that these data are not generalizable to other ethnically diverse groups. Furthermore, the lack of assessment of rehabilitation and social support, which may influence HRQoL, is a limitation of this study, and additional
investigations of how these factors may influence the long-term HRQoL after stroke should be undertaken. We have demonstrated that at 5 years after stroke, a substantial proportion of survivors have very poor HRQoL. We found that being older, being of a lower socioeconomic status, and suffering a stroke of greater severity were independent factors in predicting a poor HRQoL 5 years after stroke. There are 2 possible avenues to improve HRQoL in stroke patients. First, stroke severity should be reduced via greater use of acute stroke treatments. Second, more effective strategies to combat the long-term deficits that contribute to poor HRQoL (particularly physical disability) must be actively sought. Together, these 2 approaches have the potential to greatly improve long-term HRQoL in stroke patients.

Acknowledgments

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References

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