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Background and Purpose—Few reliable estimates of the long-term functional outcome after stroke are available. This population-based study aimed to describe disability, dependency, and related independent prognostic factors at 5 years after a first-ever stroke in patients in Perth, Western Australia.

Methods—All individuals with a suspected acute stroke who were resident in a geographically defined region (population, 138,708) of Perth, Western Australia, were registered prospectively and assessed according to standardized diagnostic criteria over a period of 18 months in 1989 to 1990. Patients were followed up prospectively at 4 and 12 months and 5 years after the index event.

Results—There were 370 cases of first-ever stroke, and 277 patients survived to 30 days. Of these early survivors, 152 (55%) were alive at 5 years, and among those who were neither institutionalized (n = 146) nor disabled (n = 129) at the time of their stroke, 21 (14%) were institutionalized in a nursing home, and 47 (36%) were disabled. The most important predictors of death or disability at 5 years were increasing age, baseline disability defined by a Barthel Index score of <20/20 (odds ratio [OR], 6.3; 95% confidence interval [CI], 2.7 to 14), moderate hemiparesis (OR, 2.7; 95% CI, 1.1 to 6.2), severe hemiparesis (OR, 4.5; 95% CI, 1.1 to 19), and recurrent stroke (OR, 9.4; 95% CI, 3.0 to 30). A low level of activity before the stroke was a significant predictor of institutionalization, and subsequent recurrent stroke was a consistent, independent predictor of institutionalization, disability, and death or institutionalization, increasing the odds of each of these 3 adverse outcomes by 5- to 15-fold.

Conclusions—Among 30-day survivors of first-ever stroke, about half survive 5 years; of survivors, one third remain disabled, and 1 in 7 are in permanent institutional care. The major modifiable predictors of poor long-term outcome are a low level of activity before the stroke and subsequent recurrent stroke. Efforts to increase physical activity among the elderly and to prevent recurrent stroke in survivors of a first stroke are likely to reduce the long-term burden of cerebrovascular disease. (Stroke. 2002;33:1034-1040.)

Key Words: Australia ■ disability evaluation ■ outcome ■ prognosis ■ stroke

Having survived the immediate aftermath of a stroke, patients are often concerned about their potential for recovery, whether they will be able to return home, and the likelihood of surviving in the long term free of being dependent on others. This information is, understandably, also of interest to families and to those providing or planning health care. Ideally, the information should be based on predictive models derived from data sets that include complete follow-up of cases of first-ever stroke from large, community-based inception cohorts in which the standard diagnostic criteria and details of disease severity, comorbidity, and sociodemographic factors are described adequately; valid, reliable, objective, and standardized measures of functional outcome are recorded; and actuarial methods of survival analysis are used. 1

Although the number of “ideal” prospective population-based studies of stroke is improving, 2 few have examined outcome in terms of survival free of disability 3–18 (Table 1), and only 3 have examined the patterns of disability among survivors of stroke at 5 years. 3–5 The largest is the Auckland Stroke Study, in which information on disability and health-related quality of life (HRQOL) was available on nearly all of the 639 six-year survivors (36%) of the original cohort of 1761 patients registered in 1991 to 1992. 3 In that study, 42%
of patients were dependent in at least 1 aspect of (basic care) activities of daily living (ADL), whereas overall they had lower scores for the physical health, general health, vitality, and social function components of HRQOL compared with the general population. No predictive modeling of functional outcome was undertaken in this report.

Using data from the 492 patients registered in the Perth Community Stroke Study (PCSS) in 1989 to 1990, we sought to determine the frequency and predictors of disability at 5 years among those patients who had survived to 30 days after stroke.

### Methods

#### Study Design

The design of the PCSS has been described elsewhere. Briefly, the study registered all episodes of possible acute cerebrovascular disease in a geographically defined segment of the inner metropolitan region of Perth, Western Australia, during an 18-month period in 1989 to 1990. Based on the Australian Bureau of Statistics 1986 census, the estimated population of the study area (on June 30, 1989) was 138,708 people (69,008 male, 69,700 female). Comparison with census figures for the remainder of Perth showed that the study population contained proportions of elderly persons and those born overseas (particularly from southern European countries) that were

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**TABLE 1. Summary of Previous Studies of Disability or Handicap at Least 6 Months After Stroke**

<table>
<thead>
<tr>
<th>Study</th>
<th>Strokes, n</th>
<th>Follow-Up Time</th>
<th>Outcomes Measured</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community based</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Auckland, New Zealand</td>
<td>1761</td>
<td>6 y</td>
<td>Disability (ADL) HRQOL (SF-36)</td>
</tr>
<tr>
<td>Rochester, Minn</td>
<td>292</td>
<td>5 y</td>
<td>Survival</td>
</tr>
<tr>
<td>Akita, Japan</td>
<td>97</td>
<td>5 y</td>
<td>Handicap (Rankin Scale)</td>
</tr>
<tr>
<td>Oxfordshire, UK</td>
<td>675</td>
<td>1 y</td>
<td>Survival</td>
</tr>
<tr>
<td>Melbourne, Australia</td>
<td>508</td>
<td>6 mo</td>
<td>Survival</td>
</tr>
<tr>
<td>Bristol, UK</td>
<td>976*</td>
<td>6 mo</td>
<td>Disability (Katz Scale)</td>
</tr>
<tr>
<td>Auckland, New Zealand</td>
<td>680</td>
<td>6 mo</td>
<td>Survival</td>
</tr>
<tr>
<td>Newcastle, UK</td>
<td>229</td>
<td>3 y</td>
<td>Disability (Katz Scale)</td>
</tr>
<tr>
<td>South England, UK</td>
<td>456</td>
<td>1 y</td>
<td>Survival</td>
</tr>
<tr>
<td>L'Aquila, Italy</td>
<td>819</td>
<td>1 y</td>
<td>Survival</td>
</tr>
<tr>
<td>Tartu, Estonia</td>
<td>519</td>
<td>6 mo</td>
<td>Disability (undefined)</td>
</tr>
<tr>
<td><strong>Hospital based</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hong Kong</td>
<td>304</td>
<td>20 mo</td>
<td>Survival</td>
</tr>
<tr>
<td>Iowa</td>
<td>296‡</td>
<td>15–45 y</td>
<td>Disability (Barthel Index)</td>
</tr>
<tr>
<td>Southeast London, UK</td>
<td>291</td>
<td>4.9 y</td>
<td>Survival</td>
</tr>
</tbody>
</table>

*Includes recurrent events.‡Ischemic stroke only.
slightly higher than average. Otherwise, the sociodemographic characteristics and patterns of hospital use for stroke were broadly representative of those of the population of the whole city (total population, 1.2 million). Stroke was defined with the use of the standard World Health Organization definition of stroke, and each event during the study period was classified as being the patient’s first-ever or recurrent stroke.

Baseline Assessment
All patients with a suspected stroke underwent a standardized assessment by a physician (C.S.A.). The time between stroke onset and assessment ranged from 0 to 827 days because there were some very late notifications (8% of notifications were >1 year after the event). The mean was 75 days, the median was 4 days, and the mode was 1 day. Furthermore, 40% of assessments were done within 48 hours, 62% within 7 days, 71% within 30 days, and 83% within 90 days of the event.

The assessment included gathering information on all known classic risk factors for cerebrovascular disease, associated illnesses, and patterns of disability and function within the immediate premorbid period. Smoking status at baseline was characterized as never smoked, ex-smoker, current smoker of <21 cigarettes per day, and current smoker of ≥21 cigarettes per day. The physical signs recorded for each patient at presentation (or at onset in those with late presentation) included level of consciousness, severity of limb paresis, and the presence of urinary incontinence, cardiac failure, or atrial fibrillation. Level of consciousness was measured with the Glasgow Coma Scale, in which scores of 3 to 9 and 10 to 14 were defined as comatose and drowsy, respectively, compared with a top score of 15 (alert and without paresis). Severity of limb paresis was measured only in patients who were assessed within 2 weeks of the onset of stroke with the Motricity Index. Scores of 0 to 50 and 51 to 95 were defined as severe and moderate paresis, respectively, whereas scores of 96 to 100 were defined as normal (or minimal) paresis. Urinary incontinence was diagnosed if the patient had definite incontinence or needed an indwelling catheter during the acute stay in hospital. The presence of heart failure was based on clinical criteria that included ≥1 of the following: raised venous pressure, gallop cardiac rhythm, and crepitations at the lung bases. The presence of atrial fibrillation needed to be confirmed by an ECG at presentation (or at onset in those with late presentation).

Follow-Up
All patients were followed up prospectively at 4 and 12 months in the initial study and then at 5 years as part of the present study. Vital status at 5 years (censoring date of June 24, 1994) was ascertained initially by electronic linkage of the study records with mortality data supplied by the Registrar General of Births, Marriages and Deaths for the State of Western Australia and computerized records obtained from the Australian Bureau of Statistics. Patients not known to have been deceased were sent a letter of invitation, which was followed by a telephone call or home visit. Those who agreed to participate were assessed at their usual place of residence by the study nurse (S.F.). In addition to information regarding recurrent vascular events, major illnesses, and medications, this assessment included grading the current level of disability according to the modified Rankin Scale.

This follow-up study was approved by the Committee for Human Rights at the University of Western Australia and by the Confidentiality of Health Information Committee of the Health Department of Western Australia. Patients or their next of kin gave permission for review of medical records pertaining to suspected vascular events that occurred during follow-up.

Statistical Analysis
Crude associations between the occurrence of the binary end points of death, institutionalization, and disability (dependency) and each of 26 independent categorical variables at baseline were assessed by preliminary cross tabulations with the χ² test and SAS software.

Institutional care was defined as residence in a nursing home or private hospital in which full nursing care was required. Disability was defined as a modified Rankin score of ≥3 at 5 years.

Standard methods of imputation were used to investigate the effect of missing variables. Records with missing values were included in the analyses to make use of all available information, even though this has occasionally led to minor inconsistencies in totals. When the proportion of missing values for a possible prognostic factor was small (ie, <6%), we assumed that they were missing by chance, and therefore the missing values were reassigned to a valid code that corresponded to the level of “least harm,” ie, the most conservative category, which may have been the median or mean. When the proportion of missing values for a variable was large (ie, >6%), we considered it important to ascertain whether they were missing by chance or for some other reason that may be identifiable. They were therefore included in the analysis and fitted to the models as a specific, valid level of the prognostic factor (eg, 1=yes, 2=no, 3=unknown). If the missing value level did not produce a significant effect on the model, as proved to be the case in all such analyses, then we considered it reasonable to assume that the values were missing at random. If, however, the missing value level were to produce a significant effect, this would have suggested that these individuals had a different level of risk, and the effect would have been reported.

Models of predictors of the occurrence of death, institutionalization, and disability within 5 years of first stroke were developed through the use of multiple logistic regression and EGRET software.

Initially, the 26 independent variables were screened by their individual associations with the outcome of interest after adjustment for sex and age, each of which was forced into the model. Those that were significant at the 0.05 level were entered into the initial multivariate model. When the most parsimonious model was obtained by backward stepwise elimination of the nonsignificant factors, each of the excluded variables was again entered separately into the model to test its contribution to the final model. Results are given as odds ratios (ORs) as estimates of relative risks with 95% confidence intervals (CIs).

Results
In the PCSS register of 492 patients with acute stroke, there were 370 (75%; 95% CI, 71 to 79) with first-ever stroke (the Figure). For this report, follow-up data concerning survival and institutionalization were available for 362 of these patients (98%) over a range of 3.9 to 5.3 years. Overall, their mean ± SD age at baseline was 73 ± 13 years (median, 76 years), whereas the 194 men (53.6%) were younger (median age, 72.5 years) compared with the 168 women (median age, 78 years). Of the 277 who survived to 30 days after stroke (76.5%), 213 (77%) were known to have been free of disability before the onset of stroke; 51 (18.4%) were known to have been disabled, and the functional status of 13 (4.7%) was not known. By 5 years, 125 (45%) of the 277 survivors at 30 days had died; the 152 long-term survivors represented 42% of the initial cohort of 362 patients with first-ever stroke and 55% of the 277 patients alive at 30 days after stroke (the
Institutional Care at 5 Years

Among the 152 survivors at 5 years, 27 were living in a nursing home (institutionalized), but 6 of these patients had been in this level of care at the time of their index stroke. Thus, the cumulative risk of new institutionalization in survivors of first-ever stroke at 5 years was 14.4% (21 of 146).

Table 2 shows the multivariate prediction model for institutionalization at 5 years after first-ever stroke among the 146 survivors who had not been institutionalized before their stroke. After adjustment for sex, the significant prognostic factors present at baseline for institutionalization at 5 years were older age, prestroke Frenchay Activities Index score of 15 to 29, indicating a very low premorbid level of activities, moderate or severe hemiparesis, coma, and recurrent stroke during follow-up.

Death or Institutional Care at 5 Years

Among the 152 survivors with known outcomes at 5 years, 27 were living in a nursing home (institutionalized), but 6 of these patients had been in this level of care at the time of their index stroke. Thus, the cumulative risk of new institutionalization at 5 years was 14.4% (21 of 146).

Table 2 shows the multivariate prediction model for institutionalization at 5 years after first-ever stroke among the 146 survivors who had not been institutionalized before their stroke. After adjustment for sex, the significant prognostic factors present at baseline for institutionalization at 5 years were older age, prestroke Frenchay Activities Index score of 15 to 29, indicating a very low premorbid level of activities, moderate or severe hemiparesis, coma, and recurrent stroke during follow-up.

Disability at 5 Years

Of the 152 survivors at 5 years, 23 either were disabled at the time of their stroke or had incomplete data for disability status at 5 years. The cumulative risk of new major disability
after a first-ever stroke was 36% (47 of 129) at 5 years. After adjustment for sex, the significant prognostic factors for disability at 5 years were age 65 to 74 years, age 75 to 84 years, drowsiness at baseline assessment, moderate hemiparesis, and recurrent stroke (Table 4).

### Death or Disability at 5 Years

Of the 254 survivors at 30 days who were included in this analysis (because 23 of the 277 patients either were disabled at the time of their stroke or had incomplete data for disability status at 5 years), 172 were dead (n = 129) or disabled (n = 47) at 5 years after the stroke. The cumulative risk of death or disability among 30-day survivors of stroke was 68% (172 of 254) at 5 years. Table 5 shows that after adjustment for sex, the significant prognostic factors were age (supralinear relationship), baseline Barthel Index score of <20/20, indicating some disability, moderate hemiparesis, severe hemiparesis, and recurrent stroke.

### Discussion

We conducted a population-based study using premorbid and baseline clinical data to determine the frequency and predictors of disability in the long term after stroke. In the cohort of 277 patients with first-ever stroke who survived ≥30 days, 125 (45%) had died within 5 years. Among the 152 five-year survivors who were not living in an institution (n = 146) or were not disabled before their stroke (n = 129), 14% (21 of 146) were in a nursing home, and 36% (46 of 129) were disabled in terms of ADL. The most important predictors of poor outcome at 5 years after stroke (death, institutionalization, or disability; Tables 3 and 5) were increasing age, prestroke disability, severe stroke-related deficits at onset (severe hemiparesis, urinary incontinence), the presence of risk factors for recurrent stroke (current smoking and intermittent claudication), and the occurrence of recurrent stroke. The major predictors of surviving in a disabled or dependent state (Tables 2 and 4) were increasing age, low level of prestroke activity, moderate and severe hemiparesis, mild impairment of consciousness, and recurrent stroke. Thus, once a stroke has occurred, the only modifiable predictors of a poor long-term functional outcome that we could determine were a low level of activity before the stroke and subsequent recurrent stroke. We were not able to assess the additional impact of organized multidisciplinary care in a stroke unit, which was available to a minority of the patients.

One strength of this study was that it was designed to meet the criteria for optimal investigations of clinical outcome, as described by Sackett et al. It provides prognostic data from a large, unselected, community-based inception cohort of patients with first-ever stroke who were assessed early after the onset of the illness through standardized diagnostic criteria and well-validated and reliable instruments. In addition to measures of the extent and severity of the index event, information was obtained on premorbid levels of activity, comorbid conditions, and sociodemographic details of the patients. Outcome events were carefully defined; only 2% of patients were lost to follow-up; and use of multiple regression in the analyses allowed adjustment for confounding.

There are some methodological weaknesses of this study, however, that frequently occur with investigations of this kind. Not all of the baseline data were collected on all patients; some patients were lost to follow-up; and changes in risk factors and treatments were not reassessed over time. However, we did include recurrent stroke in the prognostic model, together with baseline factors. Overall, the models achieved a better fit with the inclusion of recurrent stroke, and in most cases the other predictive factors remained the same, with only slightly altered (generally decreased) ORs. In 2 of the models, slight adjustments were made to the number of other factors in the model of best fit. There was some instability in the ORs for several of the risk factors in the final model of the institutionalization analysis in that they increased markedly after the inclusion of recurrent stroke. More important, though, is the small number of cases with outcomes of interest, which limits the statistical power and robustness of the prediction models, particularly the models for new institutionalization (only 21 cases) and new disability (only 47 cases). It has been suggested that for each prognostic variable examined in a multiple regression analysis, there should be at least 5, and preferably 10, outcome events or cases of interest. Because we examined 26 potential prognostic variables, we would have liked at least 260 cases with the outcome of interest in each model. Although the models

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**TABLE 4. Multivariate Prediction Model for Disability at 5 Years After First-Ever Stroke***

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Prevalence, %</th>
<th>OR 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 65–74 y</td>
<td>31.8</td>
<td>3.6</td>
</tr>
<tr>
<td>Age 75–84 y</td>
<td>29.5</td>
<td>5.7</td>
</tr>
<tr>
<td>Baseline clinical features</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild coma</td>
<td>15.5</td>
<td>3.8</td>
</tr>
<tr>
<td>Moderate hemiparesis</td>
<td>31.8</td>
<td>3.4</td>
</tr>
<tr>
<td>Follow-up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent stroke</td>
<td>12.4</td>
<td>14.4</td>
</tr>
</tbody>
</table>

*Model based on the 129 patients who survived ≥30 days after stroke, who were not chronically disabled before their stroke, and who survived 5 years.

**TABLE 5. Multivariate Prediction Model for Death or Disability at 5 Years After First-Ever Stroke***

<table>
<thead>
<tr>
<th>Prognostic Variables</th>
<th>Prevalence, %</th>
<th>OR 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (mean, 72.0 y; median, 74.0 y)</td>
<td>0.82</td>
<td>0.68–0.99</td>
</tr>
<tr>
<td>Age squared</td>
<td>1.002</td>
<td>1.001–1.004</td>
</tr>
<tr>
<td>Baseline clinical features</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate hemiparesis</td>
<td>28.7</td>
<td>2.7</td>
</tr>
<tr>
<td>Severe hemiparesis</td>
<td>10.6</td>
<td>4.5</td>
</tr>
<tr>
<td>Baseline disability†</td>
<td>76.7</td>
<td>6.3</td>
</tr>
<tr>
<td>Follow-up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent stroke</td>
<td>19.3</td>
<td>9.4</td>
</tr>
</tbody>
</table>

†As defined by a score of <20/20 on the Barthel Index.

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for death and institutionalization (146 cases) and death and disability (172 cases) are reasonably robust, only the consistent findings across the models can be interpreted with any degree of confidence. An unexpected result, such as coma as a predictor of survival free of institutionalization (Table 2), is likely to be a chance finding related to the small numbers. Clearly, in the absence of other similar studies, there is a need for larger prospective, community-based studies or a meta-analysis of “ideal” studies that have included the same outcomes assessed in the same way to reliably identify important predictors of long-term outcome after stroke.

Knowledge of the natural history and prognosis for recovery after stroke may help doctors and other health professionals manage patients more efficiently and appropriately. It is also important for counseling patients and their families and for planning health services, both type and amount. Most formalized instruments developed and used to measure disability after stroke emphasize or are limited to the constellation of physical variables known as ADL. The popularity of ADL scales, such as the Barthel Index, stems from the beliefs that ADL represents the key to functional independence and that the ability to participate in a broader range of activities, social or otherwise, usually requires the capacity for self-care. Accumulating data over recent decades indicate that nearly all patients are disabled at the time of the stroke, usually with some degree of paresis; that recovery is most rapid in the early weeks and nearly complete, if it is to be so, within the 6 months of onset; and that approximately half of all survivors of stroke remain dependent on others for ADL by the end of the first year.

Patients certainly may continue to improve in the long term after stroke, but the problem with ADL scales is that they are not sensitive enough to detect small changes that may occur later. Furthermore, summary scores based on aggregated data hide wide variations in the ability of individuals. Some patients make a rapid, early recovery; others have a late, quick recovery; and still others experience a slower, more prolonged recovery. Another problem is that in studies of large numbers of patients, the improvements seen for the group may simply reflect attrition of the most disabled. Alternatively, continuing improvement may be counteracted by the effects of ageing and the development of other disabilities that may or may not be stroke related.

With these caveats aside, ADL scales are a robust measure of disability as either a continuous or binary outcome. In keeping with studies undertaken in Auckland, Rochester, and Akita, we found that about one third of patients who survive to 5 years after a first stroke are disabled.1–5 Our data also add to the literature by showing that the more severe the stroke is (eg, severity of paresis, urinary incontinence, and loss of consciousness), the more severe the disability is, with less likelihood of recovery and a greater risk of long-term dependency. Despite the fact that advancing age was strongly associated with increasing levels of disability and an increasing number of comorbidities, few studies have examined the independent significance of age on outcome. In a Rochester (Minn) study,5 20% of patients were at least mildly dependent before their stroke. When multiple regression analysis was used to control for the level of disability and comorbidities before the onset of stroke, age had a highly significant positive correlation with poor scores on the Rankin Scale at 1 year. In the Oxfordshire Community Stroke Study, 15% of patients were dependent before their first-ever stroke.32 The likelihood of surviving to be independent at 6 months after a stroke dropped progressively with increasing age, from 64% for patients <65 years of age to 20% for patients ≥84 years of age. This reflected an increased risk of death, a reduced likelihood of improvement, and an increased risk of deterioration among the most elderly.

The chance of surviving free of disability after stroke is a complex function of the brain lesion per se and of many other associated or complicating factors. The size, location, and type of cerebral lesion have an impact on the immediate prognosis, whereas vascular disease and the complications of disability, eg, pulmonary embolism and bronchopneumonia, also determine whether a patient will survive the first few weeks after onset. The degree of residual disability and vascular disease also influences long-term survival and disability.

Long-term disability and institutionalization are common sequelae among survivors of stroke (affecting one third and one seventh of patients, respectively), and the most important modifiable adverse prognostic factors for these outcomes are low levels of activity before the stroke and subsequent recurrent stroke. It follows that encouraging older people to keep physically active and the immediate and sustained implementation of appropriate and effective strategies to prevent a new stroke among stroke survivors should be coupled with ongoing rehabilitation as major priorities for minimizing the burden of stroke on the patient, his or her caregiver(s), and the community.

Acknowledgments

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References


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