Handicap After Stroke: How Does It Relate to Disability, Perception of Recovery, and Stroke Subtype?
The North East Melbourne Stroke Incidence Study (NEMESIS)

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Background and Purpose—Knowledge of patterns of handicap after stroke and of the relationship among handicap, disability, perception of recovery, and stroke subtype is limited. The aim of this study was to assess handicap 3 and 12 months after first-ever stroke in a community-based study.

Methods—All strokes occurring in a population of 133,816 people were found and assessed. Patients were classified as having cerebral infarction (CI) or intracerebral hemorrhage (ICH) according to imaging or autopsy findings. Cases of CI were categorized using the Oxfordshire stroke classification. Handicap, disability, and perception of recovery were assessed 3 and 12 months after stroke using the London Handicap Scale, Barthel Index, and the question “Have you made a complete recovery from your stroke?” The association between disability and handicap was examined using Pearson’s correlation. Differences in handicap among subtypes of CI were evaluated using one-way ANOVA.

Results—There were 264 cases of CI or ICH. Of surviving patients, 113 (59%) were assessed at 3 months and 107 (64%) at 12 months. The domains of handicap most affected were physical independence and occupation. Only half the variance in handicap was due to disability. Of patients without disability, those who claimed complete recovery were less handicapped than those who claimed incomplete recovery. Patients with total anterior circulation infarction were more handicapped at 3 and 12 months than those with other subtypes of CI.

Conclusions—Stroke patients were handicapped across many domains. Handicap is only partly explained by disability. Stroke subtype should be considered in the interpretation of outcome data. (Stroke. 2002;33:762-768.)

Key Words: cerebral infarction ■ cerebrovascular disorders ■ incidence ■ outcome

Stroke is a common disease with high mortality and high levels of disability and handicap among survivors.1,2 Handicap is the disadvantage for an individual resulting from an impairment or disability that limits or prevents the fulfillment of a role (depending on age, sex, and social and cultural factors) that is normal for that individual. Disability is the lack of ability to perform an activity or task in the range considered normal for a human being.3 While poststroke disability has been the subject of much discussion in the literature, handicap has received little attention. Handicap is likely to be more important to the patient than disability3,4 and is an important target of rehabilitation.5 Some domains of handicap are potentially modifiable,6 but knowledge of which aspects of handicap are most affected in stroke survivors is limited. A better understanding of patterns of handicap after stroke and the relationship of disability, handicap, and patients’ overall perception of recovery may help in the planning of rational and cost-effective interventions in the setting of limited resources.

Stroke has usually been regarded as a global entity when the outcome of survivors has been assessed.7–10 However, mortality patterns differ with stroke subtype, and there is evidence that outcome in survivors differs among subtypes of cerebral infarction (CI).2,11,12 Natural history data for stroke subtypes is limited, particularly with respect to handicap. While the overall burden of stroke-related dependency is a key measure in public health prevention and medical service planning, studying patterns of disability and handicap for stroke subtypes may prove useful. If specific stroke subtypes are shown to have differing outcomes (and hence, needs), then the likely future public health burden of stroke, including need for community and rehabilitation services, could be better informed by studying incidence patterns among stroke subtypes. Natural history data may suggest that the patterns of handicap differ between subtypes, and this may aid the cost-effective targeting of limited resources. Prognostic information could be used to inform patients. Finally, if stroke subtypes differ in outcome, stratification of patients accord-

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ing to subtype would allow interventions to be assessed in homogenous populations.

The aims of this study were (1) to determine handicap patterns and the relationship of handicap to disability and to patient perception of recovery after first-ever stroke in a defined population and (2) to determine whether the outcome of survivors differs significantly among subtypes of CI.

Subjects and Methods

The investigation formed part of the North East Melbourne Stroke Incidence Study (NEMESIS), a community-based study in which the incidence, risk factors, and outcomes of stroke in the northeastern suburbs of Melbourne are being investigated. The methods used in NEMESIS have previously been described in detail.13 Briefly, NEMESIS was conducted in a defined area of inner northeast Melbourne, Australia, between May 1, 1996, and April 30, 1997. At the time of this initial survey, the study population comprised those residents in an 8-postcode region and contained a population of approximately 133 816. NEMESIS was expanded in May 1997 to survey a larger region containing a population of approximately 306 631. The methodology used to obtain stroke cases was based on the recommendations for the conduct of “ideal” stroke incidence studies.14,15 Cases were recruited prospectively from multiple overlapping sources, with emphasis on obtaining those cases not admitted to hospital for acute management. Case ascertainment was complete (or near-complete).13

All cases meeting the World Health Organization (WHO) definition of stroke were registered.16 After informed consent was obtained, potential cases were interviewed and examined by a trained research nurse as soon as possible after stroke. Additional clinical details were obtained from medical records and, if required, from the treating doctor. When potential cases had died or could not be examined by a nurse, appropriate medical records were reviewed and, when necessary, the treating doctor contacted to obtain clinical information. All potential cases of stroke were reviewed by a panel of at least 2 neurologists and an epidemiologist before inclusion in the study. Pathological subtype of stroke (CI, intracerebral hemorrhage [ICH], subarachnoid hemorrhage [SAH]) was determined on the basis of neuroimaging, lumbar puncture, or autopsy findings as described previously.17 Patients who had neither neuroimaging nor autopsy were classified as undetermined. Cases of CI were further categorized by the expert panel employing the Oxfordshire Community Stroke Project (OCSP) stroke classification11 using symptoms and signs at the time of maximal deficit and blinded to imaging findings. The OCSP classification system defines 4 distinct syndromes of CI with identifiable patterns of acute mortality, risk of recurrent, and staged 1 to 5 to predict the site of infarction with reasonable precision18,19 and to provide some indication of the likely mechanisms of stroke.20–22 The classification has acceptable interrater reliability.23,24 Consensus of the panel members was required for both inclusion and final OCSP subtype. Cases of SAH were not assessed further.

Surviving patients were assessed by trained research nurses at face-to-face interview 3 and 12 months after stroke. If a patient was unable to complete the interview due to dementia or aphasia, a proxy interview was sought from the best available informant, usually the next of kin or, if necessary, a professional carer. Patient perception of recovery was assessed with a simple question similar to that developed for use in large, randomized clinical trials: “Have you made a complete recovery from your stroke?”23 Disability was assessed using the Barthel Index.26,27 Patients were scored according to current actual performance of activities of daily living rather than potential ability. Frequency of disability was determined by classification of patients as disabled (Barthel score <20/20) or nondisabled (Barthel score ≥20/20). Severity of disability was determined by categorizing patients as very severely disabled (Barthel =0 to 4), severely disabled (5 to 9), moderately disabled (10 to 14), and mildly disabled (15 to 19).10 Patients with a disability (Barthel score <20) were asked whether this was due to stroke, not due to stroke, or partly due to stroke. Handicap was assessed using the London Handicap Scale.28 This scale is based on the domains of handicap described in the WHO international classification of impairments, disabilities, and handicaps.3 The London Handicap Scale provides a descriptive profile of disadvantages experienced in the domains of mobility, physical independence, occupation, orientation, social functioning, and economic self-sufficiency. A weighted total handicap score is produced with scores ranging from 0 (maximum disadvantage) to 100 (no disadvantage). Scale weights were derived from interviews with a general population sample, using conjoint analysis.28 The association between disability and handicap after stroke was determined using Pearson’s rank correlation and by comparing handicap scores between categories of severity of disability (as defined above) at 3 and 12 months poststroke. Differences in outcome of subtypes of CI were determined by comparing Barthel and handicap scores at 3 and 12 months after stroke. The study was not powered to determine a difference in outcome between survivors with CI and ICH. A retrospective version of the London Handicap Scale administered at the first poststroke assessment was used to obtain a measure of prestroke handicap. The Barthel Index26,27 and London Handicap Scale26–29 are well-validated outcome measures.

Statistical Methods

Data on questionnaires were coded and entered into a database designed for this study. One-way ANOVA was used to examine differences in handicap between patients with different levels of disability severity, and in evaluating differences in handicap and disability among subtypes of CI at 3 and 12 months after stroke.

Because the residuals from one-way ANOVA suggested nonnormality and heterogeneity of variance, we checked the outcomes by a Monte Carlo permutation test (10 000 permutations) for equality of means.20 The analyses were undertaken using StatXact version 3.1 (Cytel Software Corporation) and SYSTAT version 9 (SPSS Inc.). The level of statistical significance was set at 2-sided P=0.05.

Ethics

Ethics committees at each participating institution approved the study. Informed consent was obtained from each participant before any interview or examination was conducted. When the participant was cognitively impaired, was dysphasic, or had altered consciousness, consent was obtained from the next of kin.

Results

A total of 276 “first-ever-in-a-lifetime” stroke cases were registered in the study. Twelve (5%) had SAH and were not further studied. There were 40 cases (14%) of ICH. Two hundred patients had CI (72%), and of these, total anterior cerebral infarction (TACI) accounted for 17%, partial anterior cerebral infarction (PACI) for 36%, posterior cerebral infarction (POCI) for 22%, and lacunar infarction (LACI) for 25%. Twenty-four cases (9%) were classified as undetermined stroke.

Seventy-one (27%) of the 264 cases (excluding SAH) died within 3 months of their stroke. At 3 months 39 (20%) patients with CI, 19 (48%) with ICH and 13 (54%) with undetermined strokes were deceased. Of those alive at 3 months, 113 (59%) were assessed, 38 (20%) were notified to the study later than 3 months, 40 (21%) refused, and 2 (0.01%) could not be contacted.

Ninety-eight (37%) of the 264 cases had died by 12 months. At 12 months 62 (31%) patients with CI, 20 (50%) with ICH and 16 (67%) with undetermined strokes were deceased. Of those alive at 12 months, 107 (64%) were assessed, 11 (7%) were notified to the study after 12 months, 46 (28%) refused, and 2 (0.01%) could not be contacted.
characteristics of those assessed at 3 months versus those alive and not assessed are shown in Table 1. Survivors not assessed were significantly more likely to be born overseas and to have been admitted to a private hospital. Proxy interviews were performed in 23% of 3-month and 13% of 12-month assessments.

Have You Made a Complete Recovery From Your Stroke?

At 3 months poststroke, 82 patients were asked, “Have you made a complete recovery from your stroke?” Twenty-six (32%, 95% confidence interval [CI] 28% to 35%) indicated that they had made a complete recovery while 56 (68%, 95% CI 64% to 73%) had not. Of those who indicated incomplete recovery, 21 (38%, 95% CI 34% to 41%) scored 20/20 (not disabled) on the Barthel Index performed at the same assessment. Of those who claimed complete recovery, 7 (27%, 95% CI 25% to 29%) scored <20: 5 (19%, 95% CI 18% to 21%) later said that their disability was partly due to stroke and 2 (8%, 95% CI 7% to 9%) stated their disability was due to another condition.

At 12 months poststroke, 107 patients were assessed, 36 (34%, 95% CI 30% to 38%) reported a full recovery, and 71 (66%, 95% CI 61% to 72%) did not. Of those who indicated incomplete recovery, 26 (37%, 95% CI 33% to 40%) scored 20/20 on the Barthel Index. Among those who claimed complete recovery, 10 (28%, 95% CI 26% to 30%) scored <20: 7 (19%, 95% CI 18% to 21%) later stated that their disability was due to stroke or partly due to stroke and 3 (8%, 95% CI 7% to 10%) stated their disability was not due to stroke.

For patients who scored 20 on the Barthel Index, handicap measured at the same assessment was significantly less for those who said they had recovered than for those who indicated incomplete recovery (mean score 93 versus 82, \( P=0.007 \) at 3 months; 87 versus 76, \( P=0.003 \) at 12 months).

Handicap

There was a significant proportion of cases with disadvantage in each domain examined: mobility, physical independence, occupation (which includes hobbies), social functioning, orientation, and economic self-sufficiency. Physical independence and occupation were the most severely affected (Figure 1).

Handicap was increased at both 3 and 12 months after stroke compared with prior to stroke (\( P<0.001 \) at 3 and at 12 months). Mean total handicap score for stroke overall prior to stroke was 84; at 3 months, 69, and at 12 months, 72. Handicap was greater in patients who had proxy assessments compared with those directly interviewed (mean score 45 versus 76 at 3 months, \( P<0.001 \); 44 versus 76 at 12 months, \( P<0.001 \)). London Handicap Score correlated substantially with Barthel score at 3 months after stroke (\( r=0.8 \)) and at 12 months (\( r=0.7 \)). Mean handicap scores differed significantly among categories of disability at both 3 and 12 months after stroke (\( P<0.001 \)) (Figure 2).

Stroke Subtypes

There were no significant differences in age, sex, prestroke disability, or frequency of proxy respondents among subtypes of CI. Handicap of stroke subtypes at 3 and 12 months after stroke are shown in Figure 3 and disability in Table 2. One-way ANOVA revealed that differences in disability among the subtypes were significant at 3 months (\( P=0.004 \)) and at 12 months (\( P=0.02 \)). Patients with TACI were more handicapped than those with other subtypes at 3 and 12 months.

### TABLE 1. Comparison of Survivors Assessed Versus Not Assessed at 3 Months Poststroke

<table>
<thead>
<tr>
<th>Assessed</th>
<th>Not Assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=113</td>
<td>n=80</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Assessed</th>
<th>Not Assessed</th>
<th>( P ) Value†</th>
<th>( P^1 ) Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male sex</td>
<td>113</td>
<td>80</td>
<td>0.32</td>
<td>0.999</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>113</td>
<td>80</td>
<td>0.85</td>
<td>0.999</td>
</tr>
<tr>
<td>Born overseas</td>
<td>113</td>
<td>74</td>
<td>&lt;0.01</td>
<td>0.022</td>
</tr>
<tr>
<td>Private hospital admission</td>
<td>113</td>
<td>80</td>
<td>&lt;0.01</td>
<td>0.019</td>
</tr>
<tr>
<td>TACI</td>
<td>113</td>
<td>80</td>
<td>0.506</td>
<td>0.999</td>
</tr>
<tr>
<td>PACI</td>
<td>113</td>
<td>80</td>
<td>0.057</td>
<td>0.510</td>
</tr>
<tr>
<td>POCI</td>
<td>113</td>
<td>80</td>
<td>0.646</td>
<td>0.999</td>
</tr>
<tr>
<td>LACI</td>
<td>113</td>
<td>80</td>
<td>0.822</td>
<td>0.999</td>
</tr>
<tr>
<td>PICH</td>
<td>113</td>
<td>80</td>
<td>0.043</td>
<td>0.438</td>
</tr>
<tr>
<td>Undetermined</td>
<td>113</td>
<td>80</td>
<td>0.124</td>
<td>0.992</td>
</tr>
<tr>
<td>Prestroke disability</td>
<td>108</td>
<td>80</td>
<td>0.689</td>
<td>0.999</td>
</tr>
<tr>
<td>Onset NIH score (mean)</td>
<td>81</td>
<td>12</td>
<td>0.833‡</td>
<td>0.999</td>
</tr>
</tbody>
</table>

*Number for whom this information is available. †Chi-square was used unless otherwise indicated. ‡Student’s t test. \( P^1 \) value=adjusted for 12 comparisons by the Ryan Holm stepdown procedure. TACI=total anterior cerebral infarction; PACI=partial anterior cerebral infarction; POCI=posterior cerebral infarction; LACI= lacunar infarction.
months. Difference in handicap across subtypes was significant at 3 months (P=0.03) but not at 12 months (P=0.09).

In the statistical methods we noted that analysis of residuals from one-way ANOVA revealed heterogeneity of variance among groups. Because of this we also employed a permutation test for equality of group means. This is proof against non-normality and heterogeneity of variance. The outcomes of classic one-way ANOVA and its permutation equivalent were virtually identical in terms of probability value.

Discussion

In this study, stroke survivors were found to be handicapped over a wide range of domains. The most disadvantage occurred in the domains of physical independence and occupation. Handicap increased with severity of disability. Patients with TACI were the most disabled and handicapped of the subtypes of CI at 3 and 12 months after stroke.

We used the London Handicap Scale as our measure of poststroke handicap. This scale has been used previously in stroke populations. The modified Rankin Scale is easy
to use and has been widely adopted as a measure of handicap for use in stroke trials, but it is a fairly blunt instrument that measures a mix of impairment, disability, and handicap.4,35 The relationship of impairment, disability, and handicap is complex, and measures relating to a single level are easier to interpret when assessing natural history data and the effects of intervention on outcome. At 12 months poststroke, the mean total handicap score was 72 in our population, which implied our patients were far less handicapped than those in a southeast London study, in which the mean total score was 49.33 A possible explanation is that the latter was a hospital-based study and mild cases not requiring admission would not be included. The two populations come from different cultural and socioeconomic backgrounds with differing health care systems, all of which may influence handicap. In a sample of mild, nonhospitalized stroke patients who were not in supported care, median handicap score 6 months after stroke was 76 in those who received occupational therapy and 65 in those who did not.6 The mean total handicap score in a community survey of people 65 years of age was 83,28 similar to the prestroke score of 84 in our cohort. A typical patient with a score of 72 would be able to get to most (but not all) places that he or she wanted to; would require help with tasks such as housework and shopping; would be limited in work and leisure activities (gardening, hobbies); would have a slightly limited social life; would hear, speak, and think clearly; and would cope with expenses fairly easily. As was shown in a previous hospital-based study,32 we found that while the domains of physical independence and occupation were most severely affected, stroke survivors were handicapped over a wide range of domains. Patients were more handicapped in all domains in the hospital-based study when compared with patients in our community-based study and scored particularly worse in the areas of mobility, social integration, and economic self-sufficiency. While handicap in the domain of orientation is likely to be nonmodifiable in most cases, much of poststroke handicap can potentially be improved. Good medical care for acute stroke will reduce impairment and disability and thus have some impact on handicap. Rehabilitation services through the provision of mobility and communication aids and environmental modification (eg, ramps) may reduce handicap in the domains of mobility, physical independence, and social relationships without improving disability. Occupational therapy can reduce occupational handicap.6 There are, however, considerable practical barriers to patients resuming their normal roles in life, including inadequate access to aids, equipment, and transport; inadequate personal finances; and underresourced and fragmented community services.36,37 While the role of medical services is important, many of these issues have to be addressed at the level of government policy. We also explored the relationship of disability, handicap, and patients’ perception of recovery. When asked simply, “Have you made a complete recovery from your stroke?” approximately 20% of stroke survivors at both 3 and 12 months who answered “yes” later stated that their disability (identified with the Barthel Index) was stroke-related. In contrast, approximately 30% of survivors at 3 and 12 months who said they had incomplete recovery scored full marks on the Barthel Index but were more handicapped than patients who claimed complete recovery. Clearly, among these patients, independence with basic activities of daily living did not equate with full recovery, as illustrated by the greater handicap measured in those who indicated an incomplete recovery. Patients’ answers may differ depending on whether their perception of recovery from stroke relates to persisting
impairment, disability, or handicap. The interpretation of “recovery” may also differ among age groups, cultures, and social class. The accuracy of this simple question was similar in our community-based study to that reported previously among a hospitalized sample.

Handicap differed significantly with severity of disability at 12 months. Although disability differed significantly among subtypes of CI at 12 months, handicap did not, suggesting that factors other than physical disability contribute to handicap. The correlation between Barthel and handicap scores after stroke was substantial, \( r^2 = 0.64 \) at 3 months and \( r^2 = 0.49 \) at 12 months, indicating that approximately half the variance in handicap scores is explained by disability. The strong association between disability and handicap is in line with previous reports.

We have used the OCSP classification to categorize cases of CI. This is ideal for community-based studies, as it allows classification into meaningful subtypes without the need for extensive investigation. Classifications requiring more detailed investigations, eg, the Trial of ORG 10172 in Acute Stroke Treatment (TOAST) classification, in a study such as this would result in a large proportion of cases being unclassifiable. Outcome data for survivors of CI according to OCSP subtypes are limited. Using the modified Rankin Scale, investigators in the Oxfordshire Community Stroke Project and in the Perth Community Stroke Study found that those patients with TACI had a negligible chance of living independently 12 months poststroke. Among subtypes of CI, people with TACI were most disabled, people with PACI and POCI had intermediate disability, and those with LACI were least disabled at 3 and 12 months after stroke. This is most likely due to differences in initial stroke severity, which is supported by the CI subtype mortality rates.

The main strength of this study was the community-based design that allowed results from an unselected and representative group of stroke patients to be assessed. The prospective recruitment of patients from multiple overlapping referral sources ensured complete ascertainment of stroke patients. Patients with milder strokes may not be admitted to hospital, which can introduce selection bias into hospital-based outcome studies. It is acknowledged that the refusal rate together with the rate of late notification to our study may have introduced bias. Analysis showed that those survivors assessed were more likely to have been born in Australia and less likely to have been admitted to a private hospital than those not assessed. There were no significant differences in age, sex, stroke subtype, preexisting disability, or stroke severity, although other unknown factors may also influence handicap. Barriers to timely follow-up of patients included the large number of government and private institutions that provide treatment for stroke patients in Melbourne, each of which have their own Research Ethics Committee. A number of private institutions had concerns about patient privacy that delayed access to information in many cases. Despite these limitations, the data provided offer insight into patterns of handicap poststroke and into the relationships of disability, handicap, and perception of recovery. Further evidence of the utility of the OCSP classification of CI is provided, and we suggest stroke subtype should be considered in the interpretation of outcome data, whether obtained from natural history studies or from trials of intervention after stroke, eg, rehabilitation or community support programs.

In conclusion, although many stroke survivors make a good recovery in terms of basic activities of daily living, the overwhelming majority experience handicap across a range of domains. The degree to which handicap may be improved through the provision of physical and economic resources and social support is unknown, and further evaluation of the effectiveness of rehabilitation and community support programs is required. Impairment and disability only partly explain handicap and patients’ perception of recovery, and future research should address novel approaches to reducing the disadvantage experienced by patients after stroke.

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References


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