Handicap and Its Determinants of Change in Stroke Survivors
One-Year Follow-Up Study

Raymond S.K. Lo, MD; Joanna O.Y. Cheng, MS; Eric M.C. Wong, MA; Wai Kwong Tang, MD; Lawrence K.S. Wong, MD; Jean Woo, MD; Timothy Kwok, MD

Background and Purpose—Stroke, a major health issue affecting the elderly, limits their participation in society. The aim of this study was to investigate changes in stroke survivors’ handicap levels and to identify their determinants in the subacute phase from 3 months to 1 year.

Methods—Data were collected from a prospective cohort of 303 Chinese stroke survivors with the use of questionnaires, including the Lawton Instrumental Activities of Daily Living–Chinese Version (IADL-CV), Barthel Index, Chinese Mini-Mental State Examination, Chinese Geriatric Depression Scale, and the Chinese version of the London Handicap Scale.

Results—A total of 297 and 268 patients were successfully followed up at 6 and 12 months, respectively. Whereas IADL remained unchanged throughout, we found an improvement in Barthel Index but a deterioration in the Chinese Geriatric Depression Scale score at 12 months. Multilevel modeling revealed improvements in the mobility and social integration handicap domains and a deterioration in the orientation domain at 12 months. Overall handicap remained unchanged. At 12 months, depression was most significantly and independently associated with poststroke handicap, and advanced old age alone (>80 years) was associated with clinically significant deterioration in handicap.

Conclusions—Even though IADL remained static at 1 year, mobility and social integration handicap dimensions can be improved in the early community phase after stroke. Nonphysical factors such as depression were confirmed to be significantly associated with handicap. Rehabilitation should target the high-risk group of very elderly stroke survivors who were 4 times more likely to deteriorate in handicap. (Stroke. 2008;39:148-153.)

Key Words: cerebrovascular accident ■ cohort studies ■ follow-up studies ■ handicap ■ rehabilitation

Stroke is a major health issue in the elderly population because it not only affects physical functioning but also leads to disability, handicap, and poor health-related quality of life.1-5 Elderly stroke survivors have a reduced ability to live independently in the community and an increased need for institutionalization. Long-term adverse psychosocial consequences have been reported in stroke survivors.6-8 Follow-up studies of long-term poststroke handicap found that the trend is toward slight improvement between 1 and 2 to 3 years,2 although 50% remained handicapped at 3 years.9 A thorough investigation of handicap changes in the subacute phase of stroke (from discharge at 3 months to 1 year) is needed to determine its immediate trajectory and to identify determinants that can be targeted early in community rehabilitation.

Handicap is an important outcome for postdischarge stroke patients in the community. Existing studies on the long-term handicap outcome of stroke survivors have included a variety of different measures, some generic and some disease-specific, but not all conformed to the International Classifications of Impairments, Disabilities, and Handicaps dimensions of handicap.10,11 The most commonly applied generic measure of handicap in stroke survivors2,12-14 is the London Handicap Scale (LHS),12 which assesses handicap severity. In the recent International Classification of Functioning, Disability, and Health framework of bodily function, activity, and participation,15 handicap was reconceptualized as participation, a component of health subject to influences of environmental factors, rather than as a consequence of disease, as defined in the early International Classifications of Impairments, Disabilities, and Handicaps. Although it is acknowledged that “handicap” is no longer a favored term because of its negative connotations, the LHS does measure the International Classification of Functioning, Disability,
and Health concept of “participation” because it describes the effects of diseases and contextual factors that limit an individual’s participation in life situations. The LHS stands as a health status scale widely applied across different disease populations with the advantage of cross-cultural validity, and it measures a relevant outcome of rehabilitation in its own right.

In the present study, we aimed to monitor long-term changes in handicap in Chinese first-ever stroke survivors at multiple time points at 3, 6, and 12 months after stroke. Significant factors associated with poststroke handicap were also identified.

**Subjects and Methods**

**Procedure**

The study used a prospective cohort design. The setting was the Prince of Wales Hospital, a regional university hospital with 1500 beds serving a population of 0.7 million people. Consecutive patients with acute stroke admitted to the Prince of Wales Hospital during a 2-year period were prospectively identified and followed up at 3, 6, and 12 months after stroke. Stroke types were clinically determined by neurologists after reviewing computed tomography and/or magnetic resonance imaging scans; and stroke severity was determined by the National Institutes of Health Stroke Scale (NIHSS) score administered by a stroke specialist nurse within 3 days of admission.

All patients included in the study were ethnic Chinese. Because we aimed to follow up on handicap outcomes only of those with a first disabling stroke, patients with a moderate or severe premorbid handicap level (modified Rankin scale score >2) were excluded. Patients who had recurrent stroke during follow-up time points were also excluded, because our study aim was to investigate longitudinal psychosocial changes after a single stroke episode. To ensure minimal loss to follow-up, those who lived too far outside Hong Kong and whose life expectancy was <6 months (ie, those with end-stage diseases) were excluded.

Eligible patients and their families were verbally informed about the study before discharge. At 3 months after stroke, all subjects were arranged to be followed up in Neurology or Geriatric specialist outpatient clinics at the Prince of Wales Hospital. Those who refused outpatient attendance were interviewed in their own homes. Recruited patients had been briefed on the purpose of the study and provided written consent to participate. For those who were unable to give consent, consent from a family member was obtained. The study was approved by the clinical research ethics committee of the Chinese University of Hong Kong.

**Measures**

Relevant baseline and outcome measures included the Barthel Index (BI), Lawton Instrumental Activities of Daily Living—Chinese Version (IADL-CV), Chinese Geriatric Depression Scale (GDS), Chinese Mini-Mental State Examination (MMSE), and the LHS. The BI has 10 items of ADLs, and the maximum score of 20 indicates full independence in these activities. The IADL-CV has been validated with Hong Kong Chinese and has 8 items of non–sex-specific activities, with a scoring range from 0 to 3. An average across these 8 items was used as the final score, where a higher figure indicates more independence. The GDS has 15 items, with a score of 8 or more indicating depression, and the Hong Kong Chinese version has been validated. The Hong Kong Chinese version of MMSE has been validated, with low scores indicating more cognitive impairment. The optimal cutoff for dementia varies from 18 in illiterate subjects to 22 for those with more than 2 years of schooling. The LHS has been translated into Chinese and validated in Hong Kong. It consists of 6 questions measuring the levels of handicap (scores ranging from 1 to 6) in 6 dimensions, including mobility, independence, occupation, social integration, orientation, and economic self-sufficiency. Higher scores indicate more severe levels of handicap.

When participants were deemed to be unreliable in answering a questionnaire because of dysphasia, cognitive impairment, or communication problems, family members were asked to give surrogate answers on the BI, IADL-CV, and LHS only.

**Statistical Analysis**

Among the subjects successfully followed up at 6 and 12 months, we compared their BI, IADL, GDS, and LHS domain scores with those at 3 months by the Wilcoxon signed-rank test with Bonferroni adjustment. In addition, multilevel multivariate models were used for comparing the LHS domain scores between 3 months and their corresponding follow-up values at 6 and 12 months, after adjusting for potential risk factors (including sex, age, home for the elderly residence, education, welfare assistance, BI total score, GDS, MMSE, physical exercise per day, pain in the affected side, dysphagia, and diet), with an analysis of multicollinearity. When 2 or more potential factors were highly correlated, the covariate that was clinically most important was selected for entry into the model. Death was also coded and included as a variable in the multilevel analysis. Multilevel models were random-effects models that took into account the hierarchical nature of the data and the within- and between-subject heterogeneity. For longitudinal data, such models allow for measurements made at unequal intervals and with a varied number of measurements (ie, subjects who may have 1 or several measurements). The models were fitted by the method of maximum marginal likelihood, expectation and maximization algorithm, and Fisher scoring solution of MIXREG computer software. The likelihood ratio test was used to assess the statistical significance of the estimates. The ability of variables at 3 months to predict clinically significant deterioration in the 6 LHS domain scores at 12 months was also determined by multivariate logistic regression. An 8% point change, ie, ~3 of 36 points, was generally regarded as a clinically significant change on the total LHS. The analysis was performed by SPSS for Windows. The level of significance was set at 5% in all comparisons.

**Results**

A total of 303 patients were recruited 3 months after acute stroke, with 297 participants successfully followed up at 6 months and 268 participants at 12 months. The numbers of participants who dropped out for different reasons at each time point are shown in the Figure. Twenty-four patients were excluded from the study because of a premorbid handicap (modified Rankin Scale score >2), and 14 patients were excluded owing to recurrent stroke between 0 and 3 months. When compared with those with complete data, dropouts at 12 months were older (median age, 77 vs 72.5 years), had a higher median NIHSS score (8 vs 6), and had a lower median BI score (15 vs 19). All differences were significant at P<0.001. Patients who required proxy interviews and those who died during follow-up had worse LHS outcomes when compared with patients who self-reported on those measures (LHS=25.0 for proxy, 28.0 for death, 15.0 for self-report). Those lost to follow-up for other reasons had scores similar to those of the self-report group (LHS=13.0 for lost to follow-up). By 12 months, 35 (11.5%) proxy responses were gathered.

As shown in Table 1, 282 (93.1%) subjects had ischemic strokes among the 303 recruited at 3 months; 174 (57%) had moderate stroke (NIHSS between 3 and 8); and 80 (26%) patients had severe stroke (NIHSS ≥8). Among all participants, 10 patients were admitted to nursing homes between the 3- and 12-month follow-up.
Table 1 shows that at 3 months, 139 (46%) patients were independent in all basic ADLs and achieved the maximum BI score of 20; 94 (36%) patients supplying reliable data had a GDS cutoff score of at least 8, indicating clinical depression. LHS data at 3 months were available for all 303 patients. Table 2 shows that the median LHS scores for the 6 domains ranged from 2 to 3, with the worse scores in the mobility, independence, and occupation domains.

Univariate changes in functional status, mood, and handicap level of subjects from 3 to 12 months after stroke are also shown in Table 2. Participants were significantly less disabled (P < 0.05) and less cognitively impaired (P < 0.005) at 12 months, with increased BI and MMSE scores. There was no significant change in IADL scores, but there was a significant increase in GDS score, indicating more depression at 12 months (P < 0.005). There was a significant improvement in the mobility domain (P < 0.005) and a significant deterioration in the orientation domain (P < 0.005) at 12 months.

Multilevel modeling that adjusted for all confounding variables revealed that there was a significant improvement in mobility (P < 0.05) and social interaction (P < 0.05) handicap domain scores at 12 months and a deterioration of orientation scores (P < 0.05) at 12 months when compared with scores at 3 months (Table 3), although there were no significant changes in overall handicap. Factors associated with handicap severity are shown in Table 3. Depression was the strongest factor, as it was significantly associated with all handicap domains and total handicap. The next most significant factor was disability. Other significant factors for more severe handicap were old age, receipt of financial assistance, moderate to severe pain on the affected side, female sex, proxy interview, and death during follow-up.

Among the 268 patients who completed the 12-month follow-up and supplied LHS information, 54 (17.8%) showed a clinically significant increase in handicap severity, with the total LHS score having increased by 3 points or more. In
multivariate logistic-regression analyses of baseline variables for the 54 patients, age 80 years or older was the only factor associated with an increase in the total LHS score, with an odds ratio of 4.39 and a 95% CI of 1.56 to 12.37.

Discussion
In the present study, overall handicap levels did not show deterioration with time. Improvements in the mobility and social domains could have offset the effects of deteriorating orientation, thus contributing to no change in overall handicap when all domains were considered at the same time. For the 17.8% of participants who showed a clinically significant increase in handicap severity over 12 months, such deterioration was associated with advanced old age (>80 years) alone. Multivariate multilevel modeling showed that depression, disability, old age, receipt of financial assistance, moderate to severe pain on the affected side, female sex, proxy interview, and death during follow-up were all significant factors associated with different domains of handicap severity.

The results of our study showed that disability and cognitive ability could be improved between 3 and 12 months, yet more depression was reported at 12 months. Depression emerged as a crucial factor affecting overall handicap.

Table 2. Changes in Functional Status and Handicap in the First Year of Stroke

<table>
<thead>
<tr>
<th>Measure</th>
<th>3 Months</th>
<th>6 Months</th>
<th>12 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Score</td>
<td>n</td>
</tr>
<tr>
<td>BI</td>
<td>303</td>
<td>19 (15, 20)</td>
<td>297</td>
</tr>
<tr>
<td>IADL</td>
<td>303</td>
<td>1.1 (0.1, 1.4)</td>
<td>297</td>
</tr>
<tr>
<td>MMSE</td>
<td>285</td>
<td>24 (19, 28)</td>
<td>271</td>
</tr>
<tr>
<td>GDS</td>
<td>263</td>
<td>5 (2, 10)</td>
<td>254</td>
</tr>
<tr>
<td>LHS domains</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>303</td>
<td>3 (1, 3)</td>
<td>296</td>
</tr>
<tr>
<td>Independence</td>
<td></td>
<td>3 (2, 4)</td>
<td>296</td>
</tr>
<tr>
<td>Occupation</td>
<td>303</td>
<td>3 (1, 5)</td>
<td>296</td>
</tr>
<tr>
<td>Social</td>
<td>303</td>
<td>2 (1, 3)</td>
<td>296</td>
</tr>
<tr>
<td>Orientation</td>
<td></td>
<td>3 (2, 4)</td>
<td>296</td>
</tr>
<tr>
<td>Economic</td>
<td>303</td>
<td>2 (2, 4)</td>
<td>296</td>
</tr>
<tr>
<td>Total (maximum = 36)</td>
<td>303</td>
<td>16 (11, 20)</td>
<td>296</td>
</tr>
</tbody>
</table>

Values are presented as median (interquartile range).
*P<0.05, †P<0.005 by Wilcoxon signed-rank test with Bonferroni adjustment.

Table 3. Factors Associated With LHS Domain Scores: Results of Multivariate Multilevel Modeling

<table>
<thead>
<tr>
<th>Risk Factors</th>
<th>Mobility</th>
<th>Independence</th>
<th>Occupation</th>
<th>Social</th>
<th>Orientation</th>
<th>Economic</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow-up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 month vs 3 month</td>
<td>-0.38</td>
<td>-0.38</td>
<td>-0.23</td>
<td>0.39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (GDS&gt;8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BI</td>
<td>0.54</td>
<td>0.54</td>
<td>0.86</td>
<td>0.77</td>
<td>0.78</td>
<td>2.96</td>
<td></td>
</tr>
<tr>
<td>15–19 vs 20</td>
<td>0.79</td>
<td>1.28</td>
<td>3.01</td>
<td>0.58</td>
<td>3.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;15 vs 20</td>
<td>1.92</td>
<td>3.52</td>
<td>5.98</td>
<td>0.95</td>
<td>5.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70–79 vs &lt;70 years</td>
<td>0.59</td>
<td>1.21</td>
<td>0.57</td>
<td>1.33</td>
<td>1.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;80 vs &lt;70 years</td>
<td>0.95</td>
<td>1.55</td>
<td>1.12</td>
<td>1.65</td>
<td>1.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>CSSA vs non-CSSA</td>
<td>0.62</td>
<td>0.63</td>
<td>2.12</td>
<td>2.29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Moderate/severe vs mild</td>
<td>0.82</td>
<td>0.82</td>
<td>1.56</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
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<tr>
<td>Female vs male</td>
<td>0.65</td>
<td></td>
<td>1.43</td>
<td>2.54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proxy interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Death during follow-up</td>
<td>1.14</td>
<td>1.14</td>
<td>2.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CSSA indicates comprehensive social security assistance. Total number of subjects was 269. Values are odds ratio (95% CI). Only significant factors are shown. Nonsignificant factors were 6-month follow up, marital status, and education. Because BI is highly associated with residence in a home for the elderly, dysphagia, MMSE score <20, exercise, and a soft/pureed diet, only BI was selected to enter the model to avoid multicollinearity.

*P<0.05, †P<0.01, ‡P<0.001.
pression was more associated with social handicap domains (social integration and occupation), whereas disability was more associated with physical domains (mobility, independence, and orientation). Tackling disability alone to reduce handicap is not sufficient without considering the effects of depression on the social aspects of handicap. A survey revealed that depressive disorders occurred in 17.2% of first-time stroke survivors in Hong Kong. A high prevalence of depressed mood had been reported after 5 years of stroke, and other studies confirmed the association between depression and handicap severity in long-term follow-up. The present study showed that at 1 year after stroke, survivors were already depressed, although they may not have completed community rehabilitation. Further rigorous research is required to prove the benefits of routine depression screening and prompt treatment in the early stages of stroke rehabilitation.

Disability and cognitive impairment were also confirmed to be independent factors associated with multiple handicap domains. Disability had been reported to be strongly associated with handicap in other studies and perceived control was found to moderate the effects of disability on handicap. Whereas day hospital rehabilitation has been shown to bring about significant improvements in mobility, independence, and occupational domains of handicap in stroke survivors, intensive community-based multidisciplinary rehabilitation has been shown to improve social participation in stroke survivors. Future studies should investigate the benefits of exercise and activity groups collaborating with family caregivers and social services in facilitating social integration and reducing handicap.

One of the other important findings in this study was that advanced old age alone had an independent effect on handicap, both cross sectionally and prospectively. Very old participants (those >80 years) were more than 4 times as likely to deteriorate in terms of handicap. Our multivariate analysis indicated that deteriorating handicap in the very elderly patient is likely to be abetted by worsened orientation. The association between old age and decreased orientation in handicap has also been reported in other studies. The smaller social network of older people, as well as vision and hearing loss, may all contribute to handicap in orientation. Previous studies have also found that for the very old, prestroke institutionalization, paralysis, swallowing problems, and incontinence in the acute phase of stroke were associated with more severe handicap.

The present study has the advantage of a low dropout rate and inclusion of a wide range of disabilities among the cohort. However, the sample consisted of mostly mild to moderate stroke survivors, and results may not apply to severe stroke survivors. A few subjects who experienced recurrent stroke during follow-up were excluded because our primary intention was to study the psychosocial adjustment to disabilities resulting from a single stroke episode. In addition, patients lost to follow-up were older and more severely disabled than those who completed the study. To minimize the bias toward more favorable outcomes, the statistical method of multilevel modeling was used. Although the use of proxy interviews enabled us to include patients with severe stroke, cognitive impairment, or communication difficulties, data from proxy interviews and data collected for death during follow-up cases were also included in the analyses as confounders. Although proxy interview cases and death during follow-up cases were more handicapped and disabled than self-report subjects at the 12-month follow-up, they were found to have no significant association with most handicap domains when included as variables in multilevel modeling, mainly because most of the variance in poststroke handicap was accounted for by factors such as depression and disability.

Conclusions
Results from the present study support the view that some handicap dimensions (eg, mobility) improve during the first year after stroke as the survivor becomes less disabled. Furthermore, our study clearly illustrates that handicap is not only related to disability but also determined by many other physical and psychosocial factors. Depression is strongly associated with poststroke handicap, more so than disability. Residence in a home for the elderly emerged as an interesting factor in poststroke handicap. Future research is needed to identify specific rehabilitation interventions for high-risk groups to prevent deteriorating handicap levels.

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Disclosures
None.

References


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