Disagreement in Patient and Carer Assessment of Functional Abilities After Stroke

Peter Knapp, PhD; Jenny Hewison, PhD

Background and Purpose—The aims of this study were to describe differences between functional ability assessments made by stroke patients and their informal carers and to investigate the psychological associates of the difference in assessments.

Methods—A prospective design was used, with repeated assessments of function, mood, and carer strain. Thirty hospital stroke patients and their main carer were interviewed 3 times: within 1 month of stroke, 1 month after discharge, and 6 months after discharge.

Results—There were significant differences between patient and carer assessments at all 3 time points, with patient self-assessment less disabled than carer assessment (at least \( P < 0.02 \)). The disagreement in assessment was unrelated to patient or carer mood (\( P > 0.05 \)) but greater disagreement was associated with greater carer strain (\( P < 0.05 \)). The source of the disagreement in functional ability assessment remains unclear.

Conclusions—The method of assessment affects the rating of functional abilities after stroke. Carer strain is potentially increased when the patient or carer makes an unrealistic assessment of the patient’s level of independence. (Stroke. 1999;30:934-938.)

Key Words: activities of daily living ■ caregivers ■ mood disorders ■ neuropsychological tests ■ stroke

Research in the rehabilitation of people with stroke has led to a growth in the number of scales to measure functional abilities. Instruments such as the Nottingham Extended Activities of Daily Living scale\(^1\) and the Frenchay Activities Index\(^2\) have been established in stroke research and practice.

The problems of using proxy ratings of the patient’s functional abilities and the possible biases found in this method have been recognized for some time.\(^3,4\) The difference between patient and proxy ratings is important, because proxy ratings are used in both clinical and research work. This is particularly the case when patients have communication problems or their account is inconsistent or inconvenient to take.

The Barthel Index,\(^5\) one of the oldest and most often used measures in stroke research and practice, has been shown to be equally reliable in face-to-face and telephone interviews, although some moderate and severe disability may go undetected by telephone.\(^6\) Other studies suggest there may be differences in responses according to the method used. For example, carers tended to report lower patient abilities than the assessments made by occupational therapists.\(^7\) Similarly, doctors’ ratings of patient abilities from clinical interviews tended to be higher than nurses’ ratings from patient observation.\(^8\)

Despite these findings, there has been little attempt to search for explanatory factors. The only consistent finding is that discrepant ratings are more likely when patients are older.\(^7\)

The study reported here attempts to look for factors associated with discrepant ratings, as a means of understanding their origins. It does this in 2 ways: first, by asking patients and carers to make ratings of functional abilities over time (to see whether differences in ratings covary); and second, by looking at the association between discrepant ratings, mood, and carer strain. We have chosen mood disorder and carer strain because both are often reported after stroke and are said to influence patient function. We therefore wanted to evaluate their effects on reported function.

Subjects and Methods

Design

A prospective study of stroke patients and their carers was undertaken with repeated assessments of function, mood, and carer strain. Patients and carers were interviewed separately, and all data were collected by one of the authors (P.K.).

Sample

Recruitment was from consecutive admissions to 2 hospital wards (elderly care and neurology). Patients were approached if they met the following inclusion criteria: (1) the first-ever stroke occurred within the past month; (2) the patient was well enough to interview, with sufficient language (assessed by speech and language therapist) and cognition (assessed by Mini-Mental State Examination\(^9\)); (3) a named carer was also willing to participate; (4) the patient lived independently before the stroke, and (5) written consent was ob-
Patients’ participation in the study did not affect their care: they received treatment as usual.

Assessments

Physical Function

The patient’s functional ability was assessed with the Barthel Index. The scale is scored 0 to 20, with higher scores indicating greater functional ability.

Mood

The Hospital Anxiety and Depression (HAD) scale was used to measure mood. The HAD has subscales for anxiety and depression (scored 0 to 21) in which a higher score indicates a greater likelihood of clinical significance. The HAD has been shown to be reliable when used with the physically ill.

TABLE 1. Median Barthel Assessments Made by Patients and Carers at 4 Time Points

<table>
<thead>
<tr>
<th>Time Point</th>
<th>Carer</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>T0</td>
<td>20.0 (19.0–20.0)</td>
<td>20.0 (19.0–20.0)</td>
</tr>
<tr>
<td>T1</td>
<td>10.0 (7.75–18.25)</td>
<td>13.0 (10.75–18.25)</td>
</tr>
<tr>
<td>T2</td>
<td>17.0 (10.0–20.0)</td>
<td>18.0 (12.0–19.25)</td>
</tr>
<tr>
<td>T3</td>
<td>17.0 (10.75–20.0)</td>
<td>17.5 (14.0–20.0)</td>
</tr>
</tbody>
</table>

Values in parentheses are interquartile range. T0 indicates prestroke rating; T1, within 1 month of stroke; T2, 1 month after discharge; and T3, 6 months after discharge.

TABLE 2. Number of Disagreements in Patient-Carer Assessments at 4 Time Points

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Time Point</th>
<th>Patient Carer</th>
<th>Carer Patient</th>
<th>Ties</th>
</tr>
</thead>
<tbody>
<tr>
<td>T0</td>
<td>6 (1.0)</td>
<td>3 (2.0)</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>15 (2.0)</td>
<td>5 (1.0)</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>T2</td>
<td>13 (2.0)</td>
<td>4 (1.0)</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>T3</td>
<td>14 (2.0)</td>
<td>5 (1.0)</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>

Values in parentheses are median difference in Barthel Index score. T0 indicates prestroke rating; T1, within 1 month of stroke; T2, 1 month after discharge; and T3, 6 months after discharge.

Mean patient-carer Barthel Index assessment and absolute difference in patient-carer Barthel assessment at 4 time points: T0, T1, T2, and T3.
### Carer Strain

The scale developed by Greene et al.\(^2\) was used to assess carer strain. This scale was originally developed for carers of people with dementia, although its items are not illness specific. The scale has 3 subscales: personal distress, domestic upset, and negative feelings. The total scale is scored 0 to 60, with higher scores indicating greater carer strain.

### Timing

All participants were interviewed 3 times: at the hospital within 1 month of stroke (T1); at home 1 month after discharge (T2); and at home 6 months after discharge (T3). All participants completed the HAD and the Barthel scales at each interview (T1, T2, and T3) and also rated the prestroke Barthel (T0) at the first interview. Patients used the Barthel Index to assess themselves while carers used the instrument to assess the patient. Carers completed the Carer Strain measure at T2 and T3.

### Results

The sample of thirty stroke patients (14 women, 16 men) was recruited over 5 months. Twenty-seven patients with stroke did not meet the inclusion criteria, and 4 patients who did meet the criteria refused to participate. Patients were aged 47 to 85 (median, 72) years. The 30 carers (19 women, 11 men) were aged 30 to 81 years. More than half the carers were spouses of the patients, while 9 were children of the patients. Before the stroke, 20 patients and carers were coresident; after stroke, 22 lived together. Median length of hospital stay was 37 days (interquartile range, 10 to 97 days).

### Barthel Index Scores

The Barthel scores for the sample of patients showed the expected pattern of high prestroke scores, followed by low scores after stroke and then a recovery in the following months. The pattern was similar for assessments made by patients and carers (see Table 1). The patients reported significantly higher scores than carers at all poststroke time points (Wilcoxon signed matched-pairs test; T1: \(Z=2.42, P=0.016\); T2: \(Z=2.92, P=0.003\); and T3: \(Z=2.69, P=0.007\)). Patients’ and carers’ scores were not significantly different on the prestroke assessment (T0: \(Z=-0.72, P=0.47\)). Agreement between patient and carer assessments was greatest at the prestroke time point (T0), but more than half the patient-carer pairs disagreed at the 3 poststroke time points (see Table 2). At each time point a small number of pairs disagreed, but against the main trend, in that the carer made a higher Barthel assessment. The magnitude of the disagreement between patient and carers was small at all time points, with median disagreements of 2 Barthel points or less.

Altman-Bland plots\(^2\) were drawn to see whether the discrepancy in Barthel Index scores was biased toward a particular range of scores. These plots comprised the mean Barthel assessment of each patient-carer pair on 1 axis and the absolute difference in assessment. The variables were associated at T2 and T3 but not at T0 or T1 (Spearman ranks, T0: \(r=-.38, P=0.06\); T1: \(r=-.06, P=0.74\); T2: \(r=-.66, P<0.001\); and T3: \(r=-.64, P<0.001\)). These results suggest that discrepancy was more likely when the Barthel score was lower, although the scatterplots show that there is not a straightforward linear relationship between the 2 variables (see the Figure).

### Table 3. Median Total HAD Scale Scores of All Patients and Carers and the Two “Agreement/Disagreement” Groups After Stroke

<table>
<thead>
<tr>
<th>Carer Group</th>
<th>All patients</th>
<th>Patients in pt-&gt;carer group</th>
<th>Patients in agreeing and carer-&gt;pt group</th>
<th>Mann-Whitney U Value (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>12.5 (9.0–17.25)</td>
<td>15.0 (11.0–18.0)</td>
<td>12.0 (8.0–13.0)</td>
<td>68.5 (&gt;0.05)</td>
</tr>
<tr>
<td>T2</td>
<td>11.5 (8.75–17.0)</td>
<td>13.0 (10.0–14.5)</td>
<td>11.0 (7.5–17.0)</td>
<td>95.0 (&gt;0.05)</td>
</tr>
<tr>
<td>T3</td>
<td>12.5 (6.0–15.25)</td>
<td>11.5 (6.0–14.5)</td>
<td>13.0 (6.0–15.75)</td>
<td>105.5 (&gt;0.05)</td>
</tr>
</tbody>
</table>

Values in parentheses are interquartile range unless otherwise designated. Pt indicates patient.

### Table 4. Median Carer Strain Scores of All Carers and Carers According to “Agreement/Disagreement” Groups After Stroke

<table>
<thead>
<tr>
<th>T2 Time Point</th>
<th>Whole Group</th>
<th>Carers in Agree and Carer &gt;Pt Group</th>
<th>Mann-Whitney U Value (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Whole Group</td>
<td>Carers in Agree and Carer &gt;Pt Group</td>
<td>Mann-Whitney U Value (P)</td>
</tr>
<tr>
<td>T2 Time Point</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Whole Group</td>
<td>Carers in Agree and Carer &gt;Pt Group</td>
<td>Mann-Whitney U Value (P)</td>
</tr>
<tr>
<td>T1 Time Point</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Values in parentheses are interquartile range unless otherwise designated. T2 indicates 1 month after discharge; T3, 6 months after discharge; Pt, patient; PD, personal distress; DU, domestic upset; and NF, negative feelings.
Discrepant Assessments and Other Variables
To see whether other variables were associated with the patient-carer discrepancy in Barthel assessment, the 30 pairs were split, post hoc, into 2 groups. The first group comprised those pairs in which the patient’s assessment of functional abilities was higher than that of the carer; the second group comprised the pairs who agreed on their assessment, as well as the small number whose disagreement was in the opposite direction. This split was used because the pairs making up the first group were the main interest of the study. The sizes of the 2 groups formed by this split varied: at T1 the split was 15:15; at T2 it was 13:17; and at T3 it was 14:16.

Patient and Carer Mood Scores
The median HAD scores for all patients and carers and the 2 groups at the 3 poststroke time points are summarized in Table 3. Neither patient nor carer mood, as measured by total HAD scores, was associated with the discrepant or agreement groups. Separate analyses of the anxiety and depression subscores showed the same pattern and are not shown in the table.

Carer Strain
The scores obtained at both poststroke time points were lower than the mean total strain score reported by the Greene et al study12 of carers of people with dementia. The total and subscale carer strain scores of the 2 groups of pairs were compared in the same way as for the mood scores.

Table 4 shows that carers in discrepant pairs (ie, those in which the carer thought the patient less able than the patient’s own assessment) had higher strain scores. This difference was more marked at T3, 6 months after discharge, than at T2, some 5 months earlier. Only the total scale and 1 of the subscales, personal distress, were significantly higher at T2. At T3 the total strain score and 2 subscale scores were significantly higher among carers in discrepant pairs.

Discussion
This study has both confirmed previous work and generated new findings. Stroke patients and their carers made different assessments of stroke-related restrictions in activities of daily living, as measured by the Barthel Index. The difference in assessment was consistent over 3 time points after stroke, including the time after discharge from hospital when patient and carer had most contact. The difference in scores was small, approximately 1 to 2 points on a 20-point scale, and patient-carer assessments were highly correlated. The high positive correlation suggests that neither party was being globally unrealistic in their assessment.

That different assessments of abilities might be a source of difficulty was tested by analyzing discrepancy and mood and then discrepancy and carer strain. Patient and carer mood scores were not associated with the discrepancy in assessments. Carer strain, however, was associated with discrepancy at both time points after discharge from hospital.

Previous work has shown that carer strain tends to persist and is associated with negative patient outcomes.14 Measurement error is a possible explanation of differences in assessment, but the Barthel Index is reliable,15,16 and measurement error cannot explain the systematic differences in patient and carer assessments.

This study is small, and its findings are in need of replication. Another, larger study will need to separate the effects of discrepancy in assessments and severity of disability in their association with carer strain. Both carer strain and discrepant ratings were greater in more disabled patients. This may be a real effect, but the problem of confounding needs to be tackled. A larger study would also clarify the relationship between disagreement and level of disability. In this study, the ratings of a few highly disagreeing pairs may have affected the statistical relationship between the 2 variables (see the Figure). The Barthel Index is popular but relatively insensitive. It would be useful to know whether carers and patients differ in their assessment on another activities of daily living scale, and how meaningful small magnitude differences are in clinical practice.

The finding that carers and patients differed consistently in their ratings of functional abilities is important, because the score obtained may depend on whom is asked. This is particularly relevant to the repeated assessment of a patient’s progress in rehabilitation.

The main finding of this study is the association of carer strain with discrepant assessments, suggesting 2 explanations: first, that different perceptions of the patient’s abilities can be a source of conflict and potentially long-lasting problems, and second, that a distorted estimate of abilities on the part of patient or carer is a result of carer strain. The study cannot identify the source of the discrepancy but has shown that the difference in assessment of functional abilities can be a problem in itself. Different perceptions might result from a misunderstanding of the nature and consequences of stroke or, alternatively, from unrealistic expectations about recovery. Both these problems should be responsive to clinical intervention.

Acknowledgments
Dr Knapp’s work on this study was supported by a postgraduate studentship grant from the United Kingdom Economic & Social Research Council. We should like to thank the patients and their carers, without whose participation this study could not have taken place. We wish to thank Dr Allan House, Dr John Young, and 2 anonymous reviewers for their helpful comments on an earlier version of this paper.

References
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Stroke. 1999;30:934-938
doi: 10.1161/01.STR.30.5.934
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
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