A Quantitative Study of the Emotional Outcome of People Caring for Stroke Survivors

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Background and Purpose—Although the physical and, to a lesser extent, emotional outcome of stroke survivors has been well documented, there are far fewer data relating to the outcomes of those who care for them. We aimed to describe the outcome of those caring for stroke patients and to identify both patient and caregiver factors that are associated with poor caregiver outcomes.

Methods—As part of a randomized trial to evaluate a stroke family care worker, we identified 417 patients (67% of all referrals to our institution). We followed up 376 survivors of whom 246 identified a caregiver at a 6-month follow-up interview. The patients and caregivers were asked to complete 2 measures of emotional distress (30-item General Health Questionnaire [GHQ-30] and Hospital Anxiety and Depression [HAD] Scale). A regression analysis was used to identify factors that were independently associated with poor caregiver outcomes.

Results—Fifty-five percent of responding caregivers scored more than 4 on the GHQ-30, indicating that emotional distress is common in this group. Caregivers were more likely to be depressed if the patients were severely dependent (P<0.01) or emotionally distressed themselves (P<0.01). Female caregivers reported more anxiety (median HAD=8) than male caregivers (median HAD=5; P<0.01) but caregivers’ levels of anxiety were not so clearly related to the patients’ degree of physical disability as their levels of depression. Caregivers suffered more emotional distress if the patients had been dependent before their strokes.

Conclusions—These data may help to identify those caregivers at greatest risk of poor emotional outcomes and thus help in the planning of trials and delivery of interventions aimed at preventing or treating distress among caregivers. (Stroke. 1998;29:1867-1872.)

Key Words: stroke ■ caregivers ■ outcome ■ depression ■ anxiety ■ mood disorders

Stroke patients who survive the acute illness and are discharged from the hospital frequently depend on informal caregivers for practical and emotional support. Although the physical and, to a lesser extent, emotional outcome of patients has been well documented, there are far fewer data relating to the emotional outcome of those caring for stroke patients. The well-being of caregivers is important because the patients depend on these people to maintain them in the community.

Previous studies have documented the physical burden placed on stroke caregivers and the impact that this may have on their physical and psychological well-being.1-4 Carnwath and Johnson3 found that spouses of stroke patients, especially of those who were dependent, were more likely to have symptoms of depression than age- and sex-matched control subjects from the same community. Two community-based studies found that caregivers were often anxious and depressed and were limited in their social activities. However, the frequency of these problems differed considerably because one study2 included all those living with patients, whereas the other1 was restricted to those living with dependent survivors.

After it had been established that problems among caregivers are common, some studies described and evaluated interventions designed to prevent or alleviate these problems.5,6 One difficulty in planning such studies is the lack of quantitative data regarding the outcomes of caregivers that were measured using valid and reliable measures. Without these data, and some idea of the likely treatment effect, it is impossible to estimate the numbers of caregivers required to demonstrate a worthwhile benefit. It is also unclear which caregivers are at greatest risk of adverse emotional outcomes and therefore which are likely to have the most to gain from any effective intervention. This study aimed to describe the outcome of a large group of persons identified by stroke patients as their caregivers and to identify those characteristics of both patients and caregivers that are associated with a poor emotional outcome.

Subjects and Methods
We identified stroke patients as part of a randomized trial to evaluate the effectiveness of a stroke family care worker.7 This trial had broad entry criteria and included 417 patients (67% of all referrals) assessed within 30 days of a stroke at a teaching hospital over a 2-year period. The main reasons for exclusion were as follows: (1)
Results

Selection of Caregivers

Of the 417 patients randomized, 41 (10%) died before follow-up, 2 refused follow-up, 1 emigrated, and 1 was found to have a brain tumor and not a stroke. We identified 246 with stroke, 13 (5%) refused follow-up, and 2 were not assessable because of cognitive problems. Two-hundred thirty-one caregivers (94%) returned the first questionnaire, and 222 (90%) returned the second. Inevitably, some of their responses were incomplete, which accounts for the variable numbers for which we had complete data (Table 1). Although data were incomplete, this was due mainly to caregivers overlooking individual questions or turning over 2 pages at once. It seemed unlikely that this would have introduced significant bias. To verify this, we compared the baseline characteristics of the 229 patients whose caregivers completed 1 or more measures with the 17 who completed none and also the caregivers who did (n=187) or did not (n=59) complete the GHQ-30. The only significant differences were in the patients’ smoking habits (96/229 versus 1/17; P<0.01) and the proportion of patients with a prior disabling stroke (21/187 versus 1/59; P=0.03).

Status of Patients for Whom We Successfully Collected Information on Caregivers

Twenty-two patients (10%) had had a previous disabling stroke, and 15 (7%) were dependent in everyday activities (modified Rankin score ≥3) before the index stroke. Of the 231 patients with caregivers who responded to our first questionnaire, 29 (13%) had a total anterior circulation syndrome, 89 (41%) had a partial anterior circulation syndrome, 61 (28%) had a lacunar syndrome, 40 (18%) had a posterior circulation syndrome, and 12 were undefined. Ninety-nine (43%) of the 228 patients with known outcomes were dependent (modified Rankin score ≥3) at follow-up. Sixty-two (27%) were unable to walk independently, 36 (16%) had some degree of urinary incontinence, 11 (5%) were fecally incontinent, 30 (13%) needed help with transfers, 59 (26%) with stairs, 29 (13%) with toileting, 85 (37%) with bathing, 58 (25%) with feeding, 65 (29%) with dressing, and 28 (12%) with grooming. Their median Barthel Index (available for 227) was 19 (interquartile range, 17 to 20) and their median Frenchay Activities Index (available for 171) was 48 (interquartile range, 43 to 52). We had no measure of behavioral problems.

Characteristics of Caregivers

The mean age of the caregivers was 60 years (range, 27 to 88 years), and 66% were women. One-hundred eighty-two (79%) were spouses, 32 were children of the patients (including in-laws), and the remaining 15 (7%) were siblings, parents, or friends. Most of the caregivers (n=208, 91%) were living with the patient.

Status of Caregivers 6 Months After Stroke

The median scores (interquartile ranges) for each of our measures of caregiver outcome are shown in Table 1. In this sample, 102 caregivers (55%) scored more than 4 (the recommended cutoff is 4/5) on the GHQ-30, indicating a likelihood of greater than 50% of them having a diagnosable psychiatric disorder. If one applies the recommended cutoff of 8/9 for the HAD subscales, 33 (17%) and 69 (37%) of caregivers were depressed or anxious, respectively (Table 2).

Predictors of Caregivers’ GHQ-30

We examined the associations between the caregivers’ emotional status at 6 months with respect to their own characteristics and those of the patient at baseline. The results of these univariate analyses for the caregivers’ GHQ-30 are shown in Tables 3 and 4. This indicated that prestroke handicap (P<0.01) and the presence of a visual field defect (P=0.04) were significantly associated with more emotional distress in the caregivers. However, it is apparent that there was a consistent but statistically nonsignificant trend for caregivers of patients with symptoms, suggestive of a more severe stroke and thus a greater likelihood of disability at 6 months, to have more emotional distress. Thus, one might predict that caregivers of patients with worse functional outcomes at 6 months would themselves have poor outcomes. Table 5 shows the

**TABLE 1. Completion Rates for Caregiver Questionnaires and Caregiver Outcomes (n=231)**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Completed</th>
<th>Caregiver Outcome</th>
<th>Interquartile Range</th>
<th>Possible Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHQ-30</td>
<td>187</td>
<td>81</td>
<td>6</td>
<td>1–13</td>
</tr>
<tr>
<td>HAD (anxiety)</td>
<td>186</td>
<td>81</td>
<td>7</td>
<td>4–11</td>
</tr>
<tr>
<td>HAD (depression)</td>
<td>189</td>
<td>82</td>
<td>4</td>
<td>1–7</td>
</tr>
</tbody>
</table>

GHQ-30 indicates General Health Questionnaire (30 item); HAD = Hospital Anxiety and Depression Scale.
TABLE 2. Summary of Studies of Caregiver Outcome

<table>
<thead>
<tr>
<th>Study (First author)</th>
<th>Source</th>
<th>Definition of Caregiver</th>
<th>n</th>
<th>Spouse</th>
<th>% Living with Pt</th>
<th>Follow-up Time</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>This study</td>
<td>Hospital referred</td>
<td>Identified by pt</td>
<td>231</td>
<td>80</td>
<td>91</td>
<td>6 mo</td>
<td>HAD 17%; 55% = 4</td>
<td>HAD 37%; 8</td>
</tr>
<tr>
<td>Carnwath3</td>
<td>Community sample</td>
<td>Spouse</td>
<td>103</td>
<td>100</td>
<td>100</td>
<td>1–3 y</td>
<td>Present State Exam 39%</td>
<td>N/A</td>
</tr>
<tr>
<td>Wade6</td>
<td>Community based</td>
<td>Living with pt</td>
<td>302</td>
<td>85</td>
<td>100</td>
<td>6 mo</td>
<td>Wakefield 13% Def 7% Prob; GHQ-28 21% “abnormal”</td>
<td>N/A</td>
</tr>
<tr>
<td>Anderson4</td>
<td>Community based</td>
<td>Caring for disabled pt</td>
<td>84</td>
<td>59</td>
<td>89</td>
<td>1 y</td>
<td>HAD 25%; 42% = 4</td>
<td>HAD 44%; 8</td>
</tr>
<tr>
<td>Evans5</td>
<td>Hospital referred</td>
<td>Significant other</td>
<td>80</td>
<td>N/A</td>
<td>N/A</td>
<td>415 d</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

N/A indicates not available; pt, patient.

median values of the caregivers’ GHQ-30 depending on the patients’ modified Rankin score at 6 months. This demonstrates quite clearly that caregivers of patients with more disability at 6 months have significantly worse emotional outcomes. The association between the patients’ Barthel Index and the caregivers’ GHQ-30 was less apparent (slope of regression line, \(-0.25; P=0.1\)). This was probably due to the well-recognized ceiling on the Barthel Index that resulted in a large number of patients scoring 20/20. However, patients’ dependency in any of the 10 activities of daily living included in the Barthel Index were associated with worse scores on the caregivers’ GHQ-30 and were statistically significant \(P<0.05\) for all except grooming, bowel function, and toileting. We could not identify any single disability that was associated with greater distress in the caregiver. The patients’ score on the Frenchay Activities Index was significantly, but not strongly, related to the caregivers’ GHQ-30 (slope of regression line, \(-0.25; P<0.01\)). Interestingly, the patients’ and caregivers’ scores on the GHQ-30 at 6 months were positively correlated, although the relationship was not very strong (Spearman correlation = 0.38; \(P<0.01\)). We did not have any direct measure of patients’ cognitive ability at the 6-month follow-up. However, we took the patients’ ability or inability to complete the GHQ-30 as a surrogate measure of cognition. Those caregivers of patients who were unable to complete the GHQ-30 (\(n=25\)) generally had worse scores than the remainder on the GHQ-30 (median 9.0 versus 5.0), but this difference was not statistically significant \((P=0.2)\).

Regression Analyses

We modeled the caregiver GHQ-30 score using the caregivers’ age and sex and whether they lived with the patient (cohabitation) as explanatory variables; we used the following variables for the patient: age, previous stroke, prestroke modified Rankin scale score, living alone before stroke, employed before stroke, cigarette smoking within 12 months of the stroke, Glasgow Coma Score (verbal score), visuospatial dysfunction, visual field defect, arm power, and ability to walk (all at baseline assessment). From forward selection, caregivers had worse scores on the GHQ-30 at 6 months if the patient had a visual field defect at baseline or if they had a modified Rankin score before the stroke of 3 to 5, confirming the results of our univariate analyses. Once these terms had been entered into the model, no other baseline terms were significant, but these 2 terms only explained 5% of the observed variance in GHQ-30 score (\(R^2=0.05\)). Then the patient’s modified Rankin scale and GHQ-30 scores at 6 months were considered for inclusion into the model. This resulted in the patient GHQ-30 score at 6 months being included \((R^2=0.14)\), so that 14% of the variance in caregiver GHQ-30 score was explained. Because certain patient baseline factors (ie, visual field defects and prestroke function) were likely to predict the patients’ functional status at 6 months, we wondered whether a model that included the patients’ 6-month modified Rankin scale score might explain more of the variance in caregiver outcome. We repeated our modeling, first entering the patients’ modified Rankin and GHQ-30 scores at 6-month follow-up. This resulted in a model that explained 12% \((R^2=0.12)\) of the variance in the caregivers’ GHQ-30 score. Two baseline terms that were of borderline statistical significance and appeared to add to the predictive power of this model were the patients’ prestroke modified Rankin scale score \((P=0.055; R^2=0.13)\) and being female \((P=0.059; R^2=0.13)\). The former raises the question of whether the chronicity of disability is important in influencing the caregivers mood. Including both of these terms increased the percentage of variance explained to 15%.

Predictors of Caregivers’ HAD

We also examined the relationships between the variables shown in Tables 3 and 4 and the caregivers’ HAD at 6 months. Univariate analysis showed that caregivers of patients who were dependent before the stroke had worse outcomes with respect to both anxiety and depression than those of previously independent patients \((P<0.002)\). Older caregivers were more depressed on the HAD depression subscale (median 5 versus 4; \(P<0.01)\). Female caregivers scored worse on the HAD anxiety subscale than their male counterparts (median 8 versus 5; \(P<0.01)\). Caregivers of patients who had had a previous stroke were more depressed according to the HAD subscale (median 6 versus 4; \(P=0.01\)). Those caregivers of patients with symptoms of more severe strokes (ie, cognitive problems, inability to walk) had significantly worse scores on the HAD depression subscale.

There was a statistically significant, although only modest, association between the patients’ Barthel Index score and the caregivers’ HAD depression subscale score (slope of regression line, \(-0.19; P=0.01\) and little association with the HAD anxiety subscale score (slope of regression line, \(-0.12; P=0.2\)). However, patients’ dependency in feeding, ambulation, dressing, toileting, making transfers, and the presence of urinary incontinence were all significantly associated \((P<0.05)\) with worse scores on the HAD depression subscale. Patients who were dependent in the other activities included in the Barthel Index had higher scores on the HAD depression subscale, but these were not statistically significant. The caregivers’ scores on the HAD anxiety subscale were only significantly worse for caregivers of patients who were dependent in dressing \((P<0.01)\) compared with caregivers of those who were independent. There
there were only small differences in anxiety scores between caregivers of those who were dependent and independent in other activities of daily living. The patients’ scores on the Frenchay Activities Index was significantly but not strongly related to the caregivers’ scores on the HAD depression subscale (slope of regression line, $-0.23; P = 0.01$) but not for the anxiety subscale (slope of regression line, $-0.10; P = 0.08$). The results of our regression analyses with respect to the HAD are summarized (with those relating to the GHQ-30) in Table 6 and are similar to the results of the univariate analyses.

**Discussion**

In this study we have described the emotional outcome of caregivers of patients who had suffered a stroke 6 months earlier. Several methodological points have to be considered when interpreting our data. First, the patients were identified...
as part of a randomized trial and therefore may not be typical of stroke patients in general. However, 67% of referred patients were entered into this trial, and the main reasons for exclusion were that they lived outside our catchment area or were expected to die soon after the stroke. These factors are unlikely to have biased our results, but one must not overlook other selection pressures such as the original reason for referral to our hospital and refusal to complete or incomplete responses to questionnaires by caregivers. We adopted a definition of a caregiver that did not stipulate that the patients required physical help, so some caregivers may not have been responsible for much actual physical caregiving. We were not able to identify a suitable control group, so we cannot comment on whether our caregivers had different outcomes than caregivers of other types of patients or indeed than noncaregivers in the general population. For instance, our finding that female caregivers had higher levels of anxiety on the HAD subscale probably reflects a general difference between the sexes in the frequency of reported symptoms of anxiety.14 Finally, we examined the association between a large number of baseline and outcome variables. It is therefore possible that we might have obtained spurious results because of multiple testing. However, we found fairly consistent associations between the patients’ level of dependency and emotional state and the emotional distress of their caregivers.

Previous studies have reported various rates of emotional distress in caregivers (13% to 39% for depression), probably reflecting variations in methods (Table 2). Generally, the caregivers of more dependent patients (Barthel Index) have more distress.2,3 Anderson and colleagues demonstrated a nonsignificant trend for more distressed caregivers to be caring for more dependent, confused patients with more behavioral problems. We confirmed that caregivers of more severely disabled patients had more distress, although interestingly their level of anxiety did not seem to be related to the patients’ level of dependency. Importantly, the caregivers’ emotional outcome (both depression and anxiety) was associated with the patients’ emotional status, a finding consistent with previous studies.2,3 We assume that the patient influences the caregiver’s well-being, although the converse is possible.

We know little about the changes that may occur with respect to the caregivers’ emotional state over time. Some have suggested that caregivers go through stages of adjustment (ie, crisis, treatment stage, realization, and adjustment), implying that their emotional state may evolve.15 In this study we described their outcome at only 1 point in time. One study suggested that depression among caregivers became more common as more time elapsed after the stroke, although theirs was a cross-sectional study. Our finding that the patients’ prestroke dependency and the fact that they had had a previous stroke both had independent associations with the caregivers’ mood beyond that of the patients’ dependency at 6 months supports the idea that the duration of caring for a dependent person may be important. Using the Wakefield

### TABLE 4. Univariate Associations between Caregiver Characteristics and Caregiver Score on GHQ-30 at 6 Months

<table>
<thead>
<tr>
<th>Factor</th>
<th>Value</th>
<th>n</th>
<th>Upper Quartile</th>
<th>Median</th>
<th>Lower Quartile</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship of caregiver to patient</td>
<td>Spouse/partner</td>
<td>147</td>
<td>12</td>
<td>6</td>
<td>1</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>40</td>
<td>14.5</td>
<td>4.5</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Sex of caregiver</td>
<td>Male</td>
<td>62</td>
<td>11</td>
<td>6</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>123</td>
<td>14</td>
<td>5</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>2</td>
<td>10.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of caregiver, y</td>
<td>&gt;=65</td>
<td>62</td>
<td>11</td>
<td>6.5</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td>&lt;65</td>
<td>117</td>
<td>13</td>
<td>5</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>8</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Anx indicates anxiety; pts, patients; Dep, depression.

### TABLE 5. Caregiver Outcomes (Medians) Depending on Patient Modified Rankin Scale Score at 6-Month Follow-Up

<table>
<thead>
<tr>
<th>Patient Modified Rankin Scale Score at 6 Months</th>
<th>No. of Pts</th>
<th>GHQ-30</th>
<th>HAD (Anx)</th>
<th>HAD (Dep)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>12</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>43</td>
<td>2</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>74</td>
<td>6</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td>3</td>
<td>53</td>
<td>7</td>
<td>8.5</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>37</td>
<td>9.5</td>
<td>7.5</td>
<td>5.5</td>
</tr>
<tr>
<td>5</td>
<td>9</td>
<td>10</td>
<td>6.5</td>
<td>5.5</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Slope of regression line, P for slope 1.64 0.66 0.94 <0.01 0.02 <0.01

Anx indicates anxiety; pts, patients; Dep, depression.
scale, Wade et al\textsuperscript{2} tried to assess caregivers serially over 2 years, although the proportion of caregivers who completed the questionnaires varied considerably over this period (224/393, 57%, at 6 months; 235/302, 78%, at 1 year). At 6 months, 45 (20.1%) of 224 caregivers were depressed (Wakefield >14); at 1 year 57 (24.3%) of 235 were depressed, and at 2 years 31 (23.1%) were depressed. However, the variable rates of completion for the measures of mood over the follow-up period may have obscured any trend for depression to become more or less common.

Our findings, and those from previous studies, may be useful to researchers who are planning randomized trials to evaluate interventions aimed at improving caregiver outcomes. They suggest that emotional distress is common among those caring for patients who have suffered a stroke and that it is predominantly the caregivers of patients with poor physical and emotional states who are likely to have poor emotional outcomes themselves. Although studies in caregivers’ of patients with dementia have suggested that patients’ cognitive function and continence are particularly important in determining their caregivers’ emotional well-being, in this study we could not distinguish the effects of these impairments or disabilities from others.

Our regression models only explained a small proportion of the variance in mood scores, so that many caregivers will have a poor outcome even if these factors are not present. Thus, a caregivers’ emotional status is likely to also depend on other factors, such as their personality and environment, which we did not measure in this study. Patients with poor physical and emotional states are likely to attract more health and social service resources than those with better outcomes. These resources should also be targeted at their caregivers. The finding that the duration of caring may be important needs to be confirmed but suggests that follow-up of the patient and caregiver in the community may need to be prolonged.

### Acknowledgments

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### References

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