Depression Among Caregivers of Stroke Survivors

Anu Berg, Lic Psych; Heikki Palomäki, MD; Jouko Lönqvist, MD; Matti Lehtihalmes, Lic Phil; Markku Kaste, MD

Background and Purpose—We aimed to assess the prevalence of depressive symptoms among caregivers of stroke survivors and to determine which patient- or stroke-related factors are associated with and can be used to predict caregiver depression during an 18-month follow-up after stroke.

Methods—We examined 98 caregivers of 100 consecutive patients experiencing their first ischemic stroke in Helsinki University Central Hospital. The caregivers were interviewed at the acute phase and at 6 months and 18 months. Depression was assessed with the Beck Depression Inventory. The neurological, functional, cognitive, and emotional status of the patients was assessed 5× during the follow-up with a comprehensive test battery.

Results—A total of 30% to 33% of all caregivers were depressed during the follow-up; the rates were higher than those of the patients. At the acute phase, caregiver depression was associated with stroke severity and older age of the patient, and at 18 months the older age of the patient was associated with depression of the spouses. In later follow-up, caregiver depression was best predicted by the caregiver’s depression at acute phase.

Conclusions—Identifying those caregivers at highest risk for poor emotional outcome in follow-up requires not only assessment of patient-related factors but also interview of the caregiver during the early poststroke period. (Stroke. 2005;36:639-643.)

Key Words: caregivers ■ depression ■ stroke

Despite the extensive interest shown in depression occurring in stroke patients, little attention has been focused on the emotional outcome and depression of caregivers of stroke survivors. The majority of survivors continue to live at home and often need practical help and emotional support. Considerable stress is experienced by many caregivers from the early poststroke period1 to 3 to 5 years after stroke.2,3 In some previous studies, 11% to 42% of caregivers showed signs of depression.4–8

Caregiver depression may be associated with several patient-related variables. Spouses or other caregivers of patients with more severe stroke or greater physical dependency were more often depressive in many studies.5,7–9 However, not all researchers4,10,11 agree on these findings. If patients are emotionally distressed themselves, caregivers also tend to be more depressive.5 In a study by Anderson et al,4 dementia and behavioral abnormalities were the characteristics of stroke patients that were the most predictive of emotional illness among caregivers, but Dennis et al5 could not distinguish the effects of patients’ cognitive functions from those caused by other factors. However, cognitive abilities are assessed only with a single score or a brief screening battery, and detailed studies of the impact of cognitive defects are still lacking. Of caregiver-related factors, the physical health of the caregiver,6,11,12 perceived control over the emotions when solving problems,13 and lack of social contacts or support,6,11 among others, are critical to caregiver well-being. Little is known of the changes occurring in caregiver depression and the factors associated with it. Follow-up studies of caregiver depression are rare.8,9

This follow-up study aimed to (1) assess the prevalence of depression and exhaustion among caregivers of stroke survivors during the recovery process and (2) determine which patient- and stroke-related factors are associated with and can be used to predict caregiver depression and exhaustion. Family support can significantly improve the psychosocial outcome for caregivers.14 Knowledge of the risk factors for caregiver depression may aid in providing support for those caregivers who most need it.

Subjects and Methods

We examined 100 consecutive patients admitted to the Department of Neurology, Helsinki University Central Hospital after their first ischemic stroke. Patients >70 years of age and those with known histories of alcohol abuse, dementia, psychosis, current antidepressant treatment, or severe concomitant disease were excluded as well as confused patients unable to cooperate. A person providing the closest contact with the patient was identified in 98 cases. We referred to this person as the caregiver, regardless of the level of handicap or the independence of the patient.

The caregivers were interviewed at the acute phase (mean 26.6 days after stroke with SD of 10.9 days) and at 6 months and 18...
months, and caregivers completed the Beck Depression Inventory (BDI) at each appointment. We used 10 points in the BDI as the criteria for mild depression. Assessment of caregiver exhaustion was based on the 6- and 18-month interview by the psychologist.

The patients were examined 5 times during the 18-month follow-up, at the acute phase ~2 weeks after stroke, and at 2, 6, 12, and 18 months after stroke. The neurological, cognitive, and emotional status of the patients was assessed. Stroke severity was measured with the Scandinavian Stroke Scale (SSS) and activities of daily living (ADL) with the Barthel Index (BI) at each assessment. Cognitive functions were assessed at the acute phase and 6 months, and 12 months with a neuropsychological battery. The battery included 3 subtests of the Wechsler Adult Intelligence Scale (WAIS), 2 subtests of the Wechsler Memory Scale-Revised (WMS-R) (logical memory and verbal learning), and right- and left-hand tapping. The more comprehensive assessment was performed at the acute phase and at 12 months as described in detail earlier. Aphasia was assessed with the Western Aphasia Battery (WAB) at the acute phase and at 6, 12, and 18 months. Depression was assessed each time with the BDI.

A total of 69 of the caregivers were spouses; in 17 cases the next of kin was a child of the patient and in 6 cases a sibling, whereas 5 were friends or other relatives and 1 was a neighbor. Seventy-five of the caregivers were women and 23 were men. The BDI was completed by 95 of the 98 caregivers at the acute phase. Two patients died before the 6-month follow-up and 2 others declined to participate at the follow-up; their caregivers could no longer be contacted. At 6 months, 86 caregivers continued in the study and completed the BDI. Two more patients died before the 18-month follow-up and 4 patients declined to participate at the follow-up, during which we received the BDI from 79 continuing caregivers.

**Statistical Analysis**

We first described the associations with univariate statistics. The analyses were performed using Student 2-tailed t test, Pearson correlations, and ANOVA. Linear regression analysis was used to identify factors independently associated with depressive mood in the caregivers. Logistic regression analysis was used to identify factors associated with exhaustion. A value of P<0.05 was considered significant. The data were analyzed with the SPSS statistical package.

**Results**

**Description of Caregivers and Patients**

Of the 98 patients with caregivers, 66 were men and 32 were women with a mean age of 55.3 (±10.7) years. Seventy-seven lived with a spouse, a relative, or a friend, and 21 lived alone. Thirty-eight of the patients had a right-hemispheric infarct, 41 a left-hemispheric infarct, and 19 an infarct in the brain stem region. At the acute phase, 82.1% of the remaining patients needed at least some help in ADL functions (BI score <20). The rates were 38.4% at 6 months and 28.2% at 18 months. The SSS and BI scores of the patients are presented in Table 1 together with the percentages of the independent patients at each time point. The neurological, neuropsychological, and psychiatric findings of the patients were earlier described in detail.

**Prevalence of Depressive Symptoms**

During the follow-up, 30% to 33% of caregivers were defined as depressive. The rates for all caregivers, spouses, and other caregivers separately are presented in Table 2. Only 2% of caregivers scored 20 points or more (at least moderate depression) at the acute phase, 6% at 6 months, and 9% at 18 months. The mean BDI scores for spouses were significantly higher than those for other caregivers (7.6 versus 5.2 at the acute stage, 7.9 versus 4.3 at 6 months, and 7.6 versus 4.6 at 18 months, P<0.05 at all stages).

**Acute-Stage Factors Associated With Caregiver Depression**

We first analyzed whether caregiver depression (BDI) during the follow-up was associated with patient- and stroke-related factors and caregiver BDI in the acute stage. The correlations, and ANOVA. Linear regression analysis was used to identify factors independently associated with depressive mood in the caregivers. Logistic regression analysis was used to identify factors associated with exhaustion. A value of P<0.05 was considered significant. The data were analyzed with the SPSS statistical package.

We then performed a series of linear regressions to identify the independent contribution of the correlating variables to caregiver BDI. In the following analyses, we used the simultaneous SPSS enter method with the caregiver BDI score as the dependent variable. At the acute stage, stroke severity (SSS), functional disability (BI), and poor right-hand tapping correlated significantly with caregiver BDI, whereas caregivers of male patients had more depressive symptoms. Caregiver BDI at the acute phase was strongly correlated with caregiver BDI both at 6 and 18 months. Acute-phase BI and the male sex continued to correlate with caregiver BDI at 6 months. At 18 months, caregivers of male patients continued to have more depressive symptoms, and patient age, poor acute-phase BI, and poor left-hand tapping correlated with caregiver depression. Neuropsychological scores in the acute phase did not correlate with caregiver BDI, nor was caregiver depression associated with lesion location (left hemisphere, right hemisphere, or brain stem region) by ANOVA.

Regression analyses were then performed to determine whether the acute-stage variables (patient age, sex, SSS, and caregiver BDI) could predict later caregiver depression. The model was highly significant (P<0.001), accounting for 41% of the variance at 6 months and 41% at 18 months, and the only independent predictor was caregiver BDI at the acute stage.

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**Table 1. SSS and BI Scores of the Patients**

<table>
<thead>
<tr>
<th>No.</th>
<th>SSS (Mean ± SD)</th>
<th>BI (Mean ± SD)</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>95</td>
<td>43.8 ± 11.6</td>
<td>14.5 ± 4.6</td>
</tr>
<tr>
<td>6 mo</td>
<td>86</td>
<td>51.1 ± 7.6</td>
<td>18.8 ± 2.4</td>
</tr>
<tr>
<td>18 mo</td>
<td>79</td>
<td>51.5 ± 7.3</td>
<td>19.1 ± 2.2</td>
</tr>
</tbody>
</table>

Independence is defined as a score of 20/20 in the BI.

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**Table 2. Prevalence of Depression (%; BDI=10) Among Spouses and Other Caregivers**

<table>
<thead>
<tr>
<th>All Caregivers</th>
<th>Spouses</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>33</td>
<td>38</td>
</tr>
<tr>
<td>6 mo</td>
<td>30</td>
<td>34</td>
</tr>
<tr>
<td>18 mo</td>
<td>30</td>
<td>33</td>
</tr>
</tbody>
</table>
Both the univariate analyses and series of linear regression analyses were repeated with only spouses included. The correlative results are presented in Table 5. At the acute stage, we chose a linear regression model with 3 predictors: patient age, sex, and stroke severity. At the acute stage, the model ($P<0.001$) accounted for 21% of the variance. Stroke severity and patient age were significant independent variables. Adding right-hand tapping did not improve the model. Similarities and WAB reading were not included because of strong correlation with the tapping score.

Regression analyses were then performed to determine whether the acute-stage variables (patient age, sex, SSS, and spouse BDI) could predict spouses’ later depression. The model was highly significant ($P<0.001$), accounting for 37% of the variance at 6 months, whereas the only independent predictor was spouse BDI ($P<0.001$). At 18 months, the model accounted for 39% of the variance ($P<0.001$), with spouse BDI ($P=0.56$, $P<0.001$) and patient age ($P=0.24$, $P<0.05$) being the independent predictors (Table 6).

### Table 3. Caregiver Depression and Its Acute-Stage And Later Associates

<table>
<thead>
<tr>
<th>Caregiver BDI</th>
<th>Acute</th>
<th>6 Mo</th>
<th>18 Mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>NS</td>
<td>NS</td>
<td>0.23*</td>
</tr>
<tr>
<td>Patient sex</td>
<td>male*</td>
<td>male*</td>
<td>male†</td>
</tr>
<tr>
<td>SSS</td>
<td>−0.28†</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>BI</td>
<td>−0.30†</td>
<td>−0.29†</td>
<td>−0.26*</td>
</tr>
<tr>
<td>Tapping, right</td>
<td>−0.21*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Tapping, left</td>
<td>NS</td>
<td>NS</td>
<td>−0.23*</td>
</tr>
<tr>
<td>Patient BDI</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver BDI</td>
<td>0.65‡</td>
<td>0.63‡</td>
<td></td>
</tr>
</tbody>
</table>

Univariate analysis including only variables with significant correlation. NS indicates nonsignificant.
* $P<0.05$.
† $P<0.01$.
‡ $P<0.001$.

### Table 4. Acute-stage Predictors of Caregiver Depression

<table>
<thead>
<tr>
<th></th>
<th>Acute</th>
<th>6 Mo</th>
<th>18 Mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>0.22*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Male patient</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>SSS</td>
<td>−0.32†</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Patient BDI</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver BDI</td>
<td>0.61‡</td>
<td>0.60‡</td>
<td></td>
</tr>
</tbody>
</table>

Univariate analysis including only variables with significant association. NS indicates nonsignificant.
* $P<0.05$.
† $P<0.01$.
‡ $P<0.001$.

### Table 5. Spouses’ Depression and Its Acute-Stage and Later Associates

<table>
<thead>
<tr>
<th>Spouses’ BDI</th>
<th>Acute</th>
<th>6 Mo</th>
<th>18 Mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>0.30*</td>
<td>0.32†</td>
<td>0.39†</td>
</tr>
<tr>
<td>Patient sex</td>
<td>NS</td>
<td>male*</td>
<td>male*</td>
</tr>
<tr>
<td>SSS</td>
<td>−0.36†</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>BI</td>
<td>−0.33†</td>
<td>−0.34†</td>
<td>−0.32*</td>
</tr>
<tr>
<td>WAIS similarities</td>
<td>−0.24*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Tapping, right</td>
<td>−0.24*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Tapping, left</td>
<td>NS</td>
<td>−0.34†</td>
<td>−0.32*</td>
</tr>
<tr>
<td>Patient BDI</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver depression</td>
<td>0.61‡</td>
<td>0.61‡</td>
<td></td>
</tr>
</tbody>
</table>

Univariate analysis including only variables with significant association. NS indicates nonsignificant.
* $P<0.05$.
† $P<0.01$.
‡ $P<0.001$.

### Correlations at Different Time Points

The correlations between caregiver depression and patient-related factors are presented in Table 3 and (with only spouses included) in Table 5. The associations between stroke severity or functional impairment and caregiver depression were no longer significant at 6 and 18 months. Of the cognitive measures, a poorer digit symbol from the WAIS correlated with caregiver depression at 18 months. The
Inclusion of caregiver depression increased the explanatory power of the model. At 6 months, 85% were correctly predicted, with caregiver depression (P<0.001) and patient’s dependence in ADL (P<0.05) as significant independent predictors. At 18 months, 84% were correctly predicted, with only caregiver depression as an independent predictor (P<0.001). When only spouses were included at 6 months, 88% were correctly predicted, with spouse depression (P<0.001) and patient’s dependence in ADL (P<0.05) as significant independent predictors. At 18 months, 70% were correctly predicted, with only spouse depression as an independent predictor (P<0.001).

**Discussion**

Our study is one of the few follow-up investigations available on depression of stroke caregivers and enabled us to examine the dynamic changes occurring in caregiver depression and its associated factors. In generalizing the results, the inclusion criteria must be considered; our patients may have been younger and healthier than stroke patients in general, and the caregivers were included regardless of the help needed or the living conditions.

In this study, the percentages of depressive caregivers are of average level compared with the rates observed in previous studies.4-7 The rates of depression remained similar throughout the 18-month follow-up. Caregiver depression was even more common than patient depression (23% to 29%) in our earlier study.22 Spouses had more depressive symptoms than other next of kin. This finding is best seen in the acute phase, which is in line with an earlier study.9

The association between stroke severity and caregiver depression was strongest at the acute stage and no longer significant at 18 months. Time may be a critical factor behind the differences in earlier studies: Dennis et al8 and Kotila et al7 also found an association between stroke severity and caregiver depression, but Anderson et al4 and Stein et al10 did not. In the former studies, caregivers were examined 3 to 6 months after stroke and in the latter only once 1 year poststroke. Our study, together with earlier longitudinal investigations,8-9 supports the idea that at least a moderate association occurs between stroke severity and caregiver depression soon after stroke, but that this association decreases during longer follow-up times. We found no cognitive impairments that were independent predictive factors; the overall stroke severity covered these impairments. From the caregivers’ points of view, the overall stroke severity is better able to describe the status of the patient than specific cognitive deficits. We cannot exclude the possibility that some other measures of behavioral defects would have revealed interaction between them and caregiver depression. Interestingly, the association between stroke severity and depression is seen earlier among caregivers than among patients themselves. We found previously that the association between stroke severity and patient depression first became significant at 2 months.22 We suggest that caregivers can recognize the problems earlier than patients who may be unaware of their impairments at the acute stage.

The correlation between ages of the patients and spouses’ depression became stronger throughout the follow-up. The

### TABLE 6. Linear Regression Analyses With Best Predictors and Only Spouses Included

<table>
<thead>
<tr>
<th></th>
<th>Acute 6 Mo</th>
<th>18 Mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>0.30†</td>
<td>NS</td>
</tr>
<tr>
<td>Male patient</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>SSS</td>
<td>−0.37†</td>
<td>NS</td>
</tr>
<tr>
<td>Spouse BDI</td>
<td>0.53‡</td>
<td>0.56‡</td>
</tr>
<tr>
<td>Model</td>
<td>P&lt;0.001</td>
<td>P&lt;0.001</td>
</tr>
<tr>
<td>Adjusted $R^2$</td>
<td>0.21</td>
<td>0.37</td>
</tr>
</tbody>
</table>

NS indicates nonsignificant.
*P<0.05.
†P<0.01.
‡P<0.001.

regression models could predict only 9% to 14% of the variance, and none of the variables appeared to be independent predictors of caregiver depression.

**Change in Depression of Caregivers**

Finally, we determined whether the change in caregiver depression was associated with the change in SSS and other variables in the patient. Although there was a significant negative correlation ($−0.30$, P<0.01) between the change in SSS and the change in caregiver BDI from the acute phase to 18 months, the regression model was not significant.

**Exhaustion**

A total of 38% of the spouses were exhausted at 6 months and 29% at 18 months. The rates were lower (21% at 6 months and 5% at 18 months) when caregivers other than the spouses were assessed. The difference was significant at 18 months (P<0.05).

At 6 months, spouses of patients who were not independent in ADL functions were more often exhausted than spouses of independent patients (Pearson $χ^2$, P<0.01). A total of 47% of the wives of male patients were exhausted; in contrast only 8% of the husbands of female patients were exhausted (Pearson $χ^2$, P<0.01). These differences were no longer significant at 18 months. Exhaustion did not differ significantly when different lesion locations were compared and when older patients were compared with younger patients. Spouses who were exhausted were also significantly more often depressed than those who were not, both at 6 and 18 months (Spearman $χ^2$, P<0.001).

We performed a series of logistic regressions with exhaustion (present or not) as the dependent variable and dependence on ADL, patient sex, and patient age as predictors. When all caregivers at 6 months were included, 72% were correctly predicted, with dependence in ADL as the only significant (P<0.01) predictor. When only spouses were included, 75% were correctly predicted using patient’s dependence in ADL (P<0.01) and female sex of the caregiver (P<0.05). At 18 months, this model did not predict exhaustion.

In this study, the percentages of depressive caregivers are of average level compared with the rates observed in previous studies.4-7 The rates of depression remained similar throughout the 18-month follow-up. Caregiver depression was even more common than patient depression (23% to 29%) in our earlier study.22 Spouses had more depressive symptoms than other next of kin. This finding is best seen in the acute phase, which is in line with an earlier study.9

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The correlation between ages of the patients and spouses’ depression became stronger throughout the follow-up. The
caring needs may become truly overwhelming when the patient and his or her spouse are older. We do not know whether patient age or caregiver age is more important, and we cannot comment on age association at more advanced ages. The correlation between patient depression and caregiver depression at 18 months suggests a possibility of some interaction between these variables in longer follow-up.

In later follow-up, caregiver depression was best predicted by caregiver’s acute-phase depression. We focused on patient- and stroke-related factors, but the importance of caregiver-related factors cannot be ignored. The few earlier follow-up studies do not report the association between acute-phase and later follow-up caregiver depression.

The factors associated with exhaustion were not identical to those of depression. When age was significantly associated with spouse depression, the female sex of the caregiver was an important factor in exhaustion. Stroke severity and/or dependency were associated with caregiver depression and exhaustion during the first 6 months, which is in line with Bugge et al, but thereafter other factors became more important. When Bugge et al found that caregiver stress appeared to increase in the early poststroke period, our study showed a slightly descending rate of exhaustion from 6 to 18 months. Exhaustion and depression were associated with each other 18 months after stroke. It is possible that exhaustion is one cause of depression.

The depressive symptoms of caregivers are frequent. If the financial burden and future responsibility for organizing health care shift more to community care, these questions may become even more important. Stroke severity is an important determinant of caregiver depression, and spouses of older patients are at risk of developing depressive symptoms not only at the acute stage but also during long follow-ups. The best predictor of caregiver depression at later stages is caregiver depression at the acute stage. This suggests that assessment of caregivers’ medical, social, and emotional needs should be included as part of the general rehabilitation plan of the stroke patient.

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References
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