Psychosocial Functioning of Spouses of Patients With Stroke From Initial Inpatient Rehabilitation to 3 Years Poststroke Course and Relations With Coping Strategies

Anne Visser-Meily, MD, PhD; Marcel Post, PhD; Ingrid van de Port, PhD; Cora Maas, PhD; Gunilla Forstberg-Wärleby, PhD; Eline Lindeman, MD, PhD

Background and Purpose—Few studies have focused on long-term changes in the caregiving experience after stroke. This study assessed changes in the psychosocial functioning of spouses (burden, depressive symptoms, harmony in the relationship between patient and spouse, and social relations) during the first 3 years after stroke and identified predictors of the course of spouses’ psychosocial functioning based on the characteristics of patients and spouses with special emphasis on coping style.

Methods—We examined 211 couples shortly after the patient’s admission to a rehabilitation center, 197 2 months after discharge, 187 1 year poststroke, and 121 3 years poststroke. Burden was assessed using the Caregiver Strain Index, depressive symptoms with the Goldberg Depression Scale, harmony in the relationship with the Interactional Problem Solving Inventory, and social relations with the Social Support List. Multilevel regression analyses were performed.

Results—A significant effect of time (P<0.01) was found for all 4 aspects of spouses’ psychosocial functioning. Although burden decreased, harmony in the relationship and social relations also decreased. The depression score showed a nonlinear pattern with an initial decrease but a long-term increase. All outcomes were significantly related to caregiver coping strategies. A total of 15% to 27% of the variance in psychosocial functioning could be explained.

Conclusions—Follow-up of spouses of patients with stroke requires not only assessment of burden, but also other aspects of psychosocial functioning like harmony in the relationship, depression, and social relations, because our results show negative long-term consequences of stroke for these aspects of caregiver quality of life. (Stroke. 2009;40:1399-1404.)

Key Words: burden ■ depression ■ quality of life ■ stroke care

Many patients who survive a stroke have persistent functional deficits and require assistance. Most of the informal care is usually provided by the spouses of these patients with stroke. Such caregivers may experience high levels of burden,1 emotional distress,2 and adverse effects on family relationships.3 Few studies have focused on long-term changes in the caregiving experience. Whereas some of these studies found a decrease in caregiver burden and depression over the first year after stroke,1,4-5 others found stable stress levels6-8 or deterioration of caregiver quality of life between 6 months after discharge from inpatient rehabilitation and 1 year poststroke.9 Although a chronic stressor may also have a delayed effect on quality of life, few studies2,10-12 have addressed changes in the caregiving experience beyond the first year after stroke. These studies found little change over time in burden, depressive symptoms, and quality of life.

In an earlier study,13 our research group identified “passive coping strategy” as the most important negative predictor of spouses’ quality of life 1 year poststroke. Coping styles are related to the psychosocial well-being of persons who are confronted with a negative or stressful life event.14 Coping has 2 major functions, namely to reduce the risk of harmful consequences that might result from a stressful event (problem-focused or active coping) and to regulate the distressing emotional reactions to the event (emotion-focused coping). The sparse other studies showed that caregivers who used more active coping strategies experienced less depression15 and greater participation levels.16 Coping strategies of spouses were stable during the first months after stroke.16

Research on coping strategies of spouses of patients with stroke may contribute to an improved understanding of the way caregivers manage the changes over time as well as to the development of coping-focused interventions. The objectives of our study were (1) to assess the changes in psychosocial functioning of spouses (in terms of burden, depressive symptoms, relationship, and social relations) during the first...
3 years after stroke; and (2) to identify predictors of the course of psychosocial functioning of spouses based on the characteristics of patients and spouses with special emphasis on coping style.

Subjects and Methods

Subjects

Patients with stroke and their spouses consecutively admitted to 9 Dutch rehabilitation centers between April 2000 and July 2002 were included in the FuPro-Stroke cohort. Inclusion criteria for patients were: first-ever stroke, supratentorial and one-sided lesion, and age >18 years. Exclusion criteria for patients were disabling comorbidity (prestroke Barthel Index <18) and inability to speak Dutch. Exclusion criteria for spouses were Barthel Index <16 and very serious chronic illness. The study was approved by the medical ethics committees of the University Medical Center Utrecht and the participating rehabilitation centers. Informed consent was obtained from all participating patients and spouses.

Procedure

At the start of inpatient rehabilitation, patients and spouses were invited to participate in the study. The first assessment (T1) was made as soon as possible after informed consent had been given. Approximately 2 months after discharge from the rehabilitation center, caregivers, but not patients, were reassessed (T2). Approximately 1 year poststroke (T3) and approximately 3 years poststroke (T4), all patients and spouses were assessed at home.

Measures

Dependent Variables: Spouses’ Psychosocial Functioning

Four domains of psychosocial functioning were assessed: burden, depressive mood, harmony in the relationship between patient and spouse, and social relations. Burden was measured at T2, T3, and T4 only, because at T1, the patients were not living at home. Burden was measured using the Caregiver Strain Index, consisting of 13 items with a total score range of 0 to 13. A score of ≥7 indicates high perceived burden. Depressive mood was measured using the Goldberg Depression Scale. This scale consists of 9 questions with yes/no answers and has a total score range of 0 to 9 with higher scores indicating more depressive feelings. A cutoff score of 2 has been found to yield good specificity (93%) and sensitivity (82%) in terms of assessing depression.

Harmony in the relationship was measured using the 17-item Interactional Problem Solving Inventory, which has been found to yield good specificity (93%) and sensitivity (82%) in terms of assessing depression. Harmony in the relationship was assessed using the 17-item Interactional Problem Solving Inventory, with scores ranging from 17 to 85, higher scores indicating greater harmony (Cronbach’s alpha coefficient 0.79 to 0.80 on all measurements). The short form (12 items) of the Social Support List was used to measure the social relations of the caregiver. The total score ranges from 12 to 48, and higher scores indicate more support. The internal consistency reliability was good in all the measurements (α = 0.87 to 0.91).

Patient Characteristics

Data on age, gender, type of stroke, hemisphere involved, and time elapsed between stroke and admission to the rehabilitation center were obtained from medical charts. Activities of daily living dependence was assessed using the Barthel Index (BI). The ability to communicate was determined by the Utrecht Communication Observation (UCO), a rating scale ranging from 1 (no communication possible at all) to 5 (normal communicative ability). Cognitive impairments were assessed using the Mini-Mental State Examination. However, only communicative patients (UCO 4 or 5) completed the Mini-Mental State Examination. A cognition score for all patients was obtained by using a dichotomous variable for cognition; patients were scored as being cognitively impaired if the Mini-Mental State Examination score was ≤23 or if the UCO score was ≤3.

Spouses’ Characteristics

The first assessment documented data on age, gender, having children aged ≤18 years, employment status, and prevalent health problems. Spouses were scored as having health problems if they were taking medication. Coping strategy was measured using the Utrecht Coping List (UCL). The list showed an acceptable internal reliability and test–retest correlation. This instrument consists of 44 items in 7 subscales, each representing a coping strategy. The UCL is based on the assumption that coping strategies are not mutually exclusive but may be used in various combinations. Spouses have to respond the question “how often do the following behaviors apply to you?” by answering on a 4-point scale from never (1) to very often (4). The 7 subscales are: passive (7 items), active confronting (7 items), palliative (8 items), seeking social support (6 items), avoiding (8 items), expressing emotions (3 items), and reassuring (5 items). Raw total subscale scores were used in the analyses.

Statistical Analyses

Descriptive statistics were used to describe characteristics of patients and their spouses and responses to the measures used. Differences in psychosocial functioning between T1 and T2, T2 and T3, and T3 and T4 were identified using paired t-tests and McNemar tests for dichotomized scores. The longitudinal course of psychosocial functioning was analyzed using multilevel regression analysis, also called hierarchical linear modeling, a type of regression analysis that is suitable for longitudinal data and in which the numbers of observations and the observation times are allowed to vary per individual. One multilevel model was computed for each of the dependent variables.

Independent variables measured at T1 were selected based on an earlier study: BI, cognitive impairment and UCO (patient), age, gender, UCL, educational level, and having young children (spouse). Time (in years from T1) and time squared were entered in the analysis to analyze changes over time. Just as in ordinary linear regression, this resulted in a regression equation. For each independent variable, a regression coefficient B was estimated and tested for significance. This coefficient is a combination of both between-subjects and within-subjects effects. A coefficient of, for example, 0.31 indicates that an increase of 1 point of the independent variable is associated with a 0.31-point increase of the dependent variable. The amount of variance explained by all independent variables together, but without the 2 time variables, was computed to indicate how well each dependent variable was explained. The time variables are part of the benchmark model for calculating explained variances. A backward elimination technique was used to filter significant main relations (P≤0.05). The analyses were performed using MlwIN.

Results

Subjects

A total of 338 patients were included, 68% of whom had a spouse (n=229). Of these spouses, 211 (92%) participated in the study. Of the 211 couples at baseline, 197 participated in the measurement 2 months after discharge, 187 in the measurement 1 year poststroke, and 121 in the last measurement 3 years poststroke. Seventeen persons died (15 patients and 2 spouses), 33 patients had a recurrent stroke or other disabling disease, and 8 couples divorced and were excluded from the study. Another 18 refused further participation, and 14 were lost to follow-up. Patients and spouses were relatively young (mean, 56 and 54 years) and patients were moderately disabled (mean BI of 13; Table 1). Approximately 25% of the patients had communication problems and 42% had cognitive impairments. One in 4 couples had young children (≤18 years of age) at home.
Changes Between Measurements

Caregiver burden decreased significantly between T2 and T3 and between T3 and T4 (Table 2). The percentage of spouses with depressive symptoms decreased significantly, from 68% at the first assessment to 53% at T2, but showed no significant change between T2 and T3 or between T3 and T4. The mean scores for depression (Goldberg Depression Scale) improved significantly between T1 and T2 and between T2 and T3, but did not change significantly between T3 and T4. The Interational Problem Solving Inventory score showed a decreasing harmony in the relationship between T1 and T2 and between T3 and T4. The largest difference was between T3 and T4 (P<0.01). Social relations showed no change between T1 and T2, but decreased between T2 and T3 and declined further between T3 and T4. Patient functioning (BI and UCO score) improved significantly between T1 and T3 and a drop in the percentage of patients with cognitive impairments. Patient functioning did not change significantly between 1 and 3 years poststroke (T3 to T4).

Course of Psychosocial Functioning Over Time

A significant effect of time (P<0.01) was found for all 4 aspects of spouses’ psychosocial functioning (Table 3). Although the burden decreased, the harmony in the relationship and the social relations also decreased. The depression score showed a nonlinear pattern with an initial decrease but a long-term increase with a turning point between T3 and T4 (time [negative B] and time squared [positive B] as significant predictors).

Predictive Models

Results of the multilevel regression analyses are displayed in Table 3.

Burden

A favorable course of burden (lower Caregiver Strain Index scores) was associated with less passive coping, more avoiding coping, and higher BI scores.

Depressive Symptoms

Less depressive symptoms were associated with less passive coping and more expression of emotions.

Relationship

A favorable course of the quality of the relationship (higher Interactional Problem Solving Inventory scores) was associated with being male (as a spouse), not having a family with young children, more active coping, more support-seeking, and less passive coping.

Social Relations

Six significant predictors were identified for the course of social relations. Predictors of better social relations were being female, more active coping, more palliative coping, more social support-seeking, less expression of emotions, and better communicative ability of the patient with stroke. The variance explained by all independent variables, without time, was between 15% for caregiver burden and 27% for social relations.

Discussion

This study found a heterogeneous course of the psychosocial functioning of spouses of patients with stroke during 3 years

Table 1. Baseline Characteristics of Patients With Stroke and Their Spouses at Admission for Inpatient Rehabilitation (n=211)

<table>
<thead>
<tr>
<th>Patients</th>
<th>Spouses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female gender, %</td>
<td>39</td>
</tr>
<tr>
<td>Age, mean (median, IQR)</td>
<td>56 (55, 15)</td>
</tr>
<tr>
<td>Days poststroke, mean (median, IQR)</td>
<td>51 (45, 24)</td>
</tr>
<tr>
<td>Type of stroke (infarction), %</td>
<td>74</td>
</tr>
<tr>
<td>Hemisphere (right), %</td>
<td>44</td>
</tr>
<tr>
<td>UCO, mean (median, IQR)</td>
<td>4 (5, 1)</td>
</tr>
<tr>
<td>BI, mean (median, IQR)</td>
<td>13 (12, 8)</td>
</tr>
<tr>
<td>Cognitive impairment, %</td>
<td>42</td>
</tr>
<tr>
<td>Family with children ≤18 years, %</td>
<td>28</td>
</tr>
<tr>
<td>Employment ≥20 hours/week, %</td>
<td>42</td>
</tr>
<tr>
<td>Health problems (yes), %</td>
<td>23</td>
</tr>
<tr>
<td>Educational level (higher education), %</td>
<td>25</td>
</tr>
</tbody>
</table>

UCO indicates Utrecht Communication Observation (range 1–5); BI, Barthel Index (range 0–20); IQR, interquartile range.

*Senior secondary education, university preparatory education, higher professional education, and university.

Table 2. Scores for Spouses’ Burden, Depression, Harmony in the Relationship, and Social Relations (dependent variables) at T1, T2, T3, and T4; and Comparison of Mean Values at Different Measuring Times (T1–T2, T2–T3, T3–T4)

<table>
<thead>
<tr>
<th>Spouse</th>
<th>T1 (N=211)</th>
<th>T2 (N=194)</th>
<th>T1–T2 P Value (N=194)</th>
<th>T3 (N=184)</th>
<th>T2–T3 P Value (N=184)</th>
<th>T4 (N=121)</th>
<th>T3–T4 P Value (N=121)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSI, mean (SD)</td>
<td>7.1 (3.4)</td>
<td>6.7 (3.6)</td>
<td>6.7 (3.6)</td>
<td>6.7 (3.6)</td>
<td>6.7 (3.6)</td>
<td>6.7 (3.6)</td>
<td>6.7 (3.6)</td>
</tr>
<tr>
<td>Percent ≥7</td>
<td>59%</td>
<td>52%</td>
<td>52%</td>
<td>52%</td>
<td>52%</td>
<td>52%</td>
<td>52%</td>
</tr>
<tr>
<td>GDS, mean (SD)</td>
<td>3.4 (2.8)</td>
<td>2.6 (2.8)</td>
<td>0.000</td>
<td>2.4 (2.7)</td>
<td>0.012</td>
<td>2.5 (2.8)</td>
<td>0.338</td>
</tr>
<tr>
<td>Percent depressive symptoms</td>
<td>68%</td>
<td>53%</td>
<td>54%</td>
<td>54%</td>
<td>54%</td>
<td>54%</td>
<td>54%</td>
</tr>
<tr>
<td>IPSI, mean (SD)</td>
<td>670.2 (11.4)</td>
<td>656.6 (12.1)</td>
<td>0.047</td>
<td>647.2 (12.9)</td>
<td>0.281</td>
<td>626.2 (13.2)</td>
<td>0.002</td>
</tr>
<tr>
<td>SSL, mean (SD)</td>
<td>30.1 (6.2)</td>
<td>29.8 (6.9)</td>
<td>0.567</td>
<td>29.1 (6.8)</td>
<td>0.011</td>
<td>25.5 (6.0)</td>
<td>0.000</td>
</tr>
</tbody>
</table>

CSI indicates Caregiver Strain Index (CSI ≥7 = stressed); GDS, Goldberg Depression Scale (GDS ≥2 = depressive symptoms); IPSI, Interactional Problem Solving Inventory; SSL, Social Support List.

CSI and GDS: lower score is favorable; IPSI and SSL: lower score is unfavorable.
after stroke. This is one of the few longitudinal studies of the long-term psychosocial functioning of spouses of patients with stroke. The multilevel modeling allowed us to analyze the course of psychosocial functioning and to test relations with independent variables for all 4 measurements simultaneously.

**Course of Psychosocial Functioning**

Between admission and 3 years after stroke, perceived caregiver burden decreased, whereas depressive symptoms also decreased during the first year after stroke, but increased again between 1 and 3 years, and social relations and harmony in the relationship decreased consistently over time. Based on earlier studies, we expected improvement of expertise and competence grew over time. Depressive symptoms are common among patients and spouses in the early stages after stroke. In these stages, the patients’ future disability is uncertain, and uncertainty and anxiety are powerful stressors. The patients’ depressive symptoms usually decrease over time. However, as has also been found by others, our results suggest that spouses’ depressive symptoms take a different course. The slight but significant increase in depressive symptoms between 1 and 3 years after stroke might be related to the consistent decrease in social relations and harmony in the relationship seen in this study. Anderson et al described adverse effects on family relationships for a variety of reasons, including tension, misunderstandings, and feelings of neglect among family members. In addition, spouses in our study perceived a significant reduction in social relations from their social network over time.

**Table 3. Results of the Multilevel Analysis to Predict the Course of Burden, Depression, Harmony in the Relationship, and Social Relations Using Independent Variables Measured at T1 as Predictors**

<table>
<thead>
<tr>
<th></th>
<th>CSI</th>
<th>GDS</th>
<th>IPSI</th>
<th>SSL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (95% CI)</td>
<td>B (95% CI)</td>
<td>B (95% CI)</td>
<td>B (95% CI)</td>
</tr>
<tr>
<td>Time, years</td>
<td>–0.45 (–0.55, –0.35)†</td>
<td>–0.85 (–1.03, –0.67)†</td>
<td>–1.54 (–1.92, –1.16)†</td>
<td>–1.63 (–1.83, –1.43)†</td>
</tr>
<tr>
<td>Time²</td>
<td>0.41 (0.30, 0.52)†</td>
<td></td>
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<tr>
<td>Spouse</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>characteristics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (♂=man)</td>
<td></td>
<td></td>
<td>–3.86 (–5.41, –2.31)*</td>
<td>2.88 (2.11, 3.65)†</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
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<tr>
<td>Family of young</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>children</td>
<td></td>
<td>–5.78 (–7.54, –4.00)†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>UCL passive</td>
<td>0.31 (0.24, 0.38)†</td>
<td>0.49 (0.45, 0.53)†</td>
<td>–0.72 (–0.95, –0.49)†</td>
<td>0.28 (0.18, 0.38)†</td>
</tr>
<tr>
<td>UCL active</td>
<td>0.49 (0.29, 0.69)*</td>
<td></td>
<td></td>
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<tr>
<td>UCL reassuring</td>
<td></td>
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<tr>
<td>UCL palliative</td>
<td></td>
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<tr>
<td>UCL avoiding</td>
<td>–0.19 (–0.26, –0.12)*</td>
<td>–0.57 (–0.79, –0.34)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UCL seeking SS</td>
<td></td>
<td>0.82 (0.60, 1.04)†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UCL expressing E</td>
<td></td>
<td>–0.19 (–0.28, –0.10)†</td>
<td></td>
<td></td>
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<tr>
<td>Patient</td>
<td></td>
<td></td>
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<tr>
<td>characteristics</td>
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<tr>
<td>UCO</td>
<td></td>
<td></td>
<td></td>
<td>0.91 (0.59, 1.23)†</td>
</tr>
<tr>
<td>BI</td>
<td>–0.19 (–0.24, –0.14)†</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cognitive</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>impairment‡</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expl variance</td>
<td>15%</td>
<td>24%</td>
<td>19%</td>
<td>27%</td>
</tr>
</tbody>
</table>

*P < 0.05; †P < 0.01; ‡Cognitive impaired if Mini-Mental State Examination < 23.

CSI indicates Caregiver Strain Index; GDS, Goldberg Depression scale; IPSI, Interactional Problem Solving Inventory; SSL, Social Support List; UCL, Utrecht Coping List; BI, Barthel Index; UCO, Utrecht Communication Observation; B, regression coefficient; Expl variance, percent of the variance of the dependent variable that is explained by the combined independent variables (without time or time²). CSi and GDS: lower score is favorable; IPSI and SSL: lower score is unfavorable.
ures such as caregiver depression scores as determinants of caregiver burden and obtained higher percentages of explained variance. However, burden, anxiety, and depression are closely related to each other, and in the stress-coping model, depression might also be seen as an outcome variable instead of a predictor. In view of the long timespan of our study, and the fact that the value of the outcome variable was not included at baseline as a predictor in the analyses, the amount of explained variance in this study is substantial.

Activities of daily living dependence and communicative disorders were the only patient characteristics significantly related to the course of psychosocial functioning of spouses and were each significant in only one of 4 analyses. This confirms the findings of previous studies showing that the severity of the stroke is of minor importance regarding spouses’ psychosocial functioning. We did not find that gender or age moderated the course of burden and depression. However, female gender was associated with a negative course of harmony in the relationship and a positive course of social relations. This result is in line with a meta-analysis showing that tension in the relationship with the patient caused more stress for women than for men and that women reported a greater need for social relations and support than men.

Coping was the most strongly associated with the course of psychosocial functioning; using a passive coping strategy was generally associated with negative outcomes, whereas using active coping strategies and seeking social support were associated with positive outcomes. Other caregiver studies also found that spouses who used more active coping strategies experienced less stress and showed higher levels of social participation. According to Table 3, active coping was not associated with reduced burden or depression, as it was not in our earlier study. Lazarus and Folkman suggested that the effectiveness of a coping style cannot be determined as straightforwardly as often is suggested. Active coping may prove to be effective in dealing with the changed situation after stroke but not in changing the impairments. Avoiding coping was associated with reduced burden in our study. Avoiding can be like escape and running away from the situation and it is possible that spouses with an avoiding style literally walk away from caring and in this way perceive lower stress. According to Table 3, expression of emotions was associated with reduced burden, depression, and social relations. It is possible that spouses who express more emotions may be able to reduce their perceived burden and depression, but may also reduce social relations and support as others begin to lose interest in hearing about the caregiver’s emotions over time.

Methodological Aspects

A limitation of this study is that we have no control group with noncaregivers, which means we cannot draw the conclusion that our findings specifically apply to spouses of patients with stroke. Nor can we compare the course of, for example, harmony in the relationship after stroke with the course in an age-matched group during these 3 years. Furthermore, we have no information on the prestroke psychosocial functioning of the spouses, so the course of psychosocial functioning after stroke might in part represent a restoration of the prestroke situation. The dropout rate during this study may have caused selection bias and may limit the generalizability of the results. However, the multilevel approach allowed us to use all available data of all respondents, including those who dropped out during the study, to minimize the consequences of such bias. Moreover, because only spouses of patients with stroke admitted to clinical rehabilitation were included, further research is required to examine the psychosocial functioning of spouses in other groups of patients with stroke.

Implications for Clinical Practice

After the acute and rehabilitation phases, patients with stroke and their spouses have to cope with permanent changes and their consequences for everyday activities. Stroke research is beginning to focus on adaptation in addition to survival and functional outcome. Experts have recommended integrating social science knowledge in stroke care and research. Our findings highlight the need to monitor the long-term psychosocial functioning of spouses of patients with stroke as part of a family-centered approach. Not only burden, but also depressive mood, harmony in the relationship, and social relations are aspects of psychosocial functioning that need more attention, because our results show negative long-term effects of stroke on these aspects of caregiver quality of life. Because passive and active coping strategies were more strongly associated with the course of psychosocial functioning, assessment of these spouses’ coping strategies should be a routine part of stroke care. Psychosocial interventions should, if applicable, teach spouses how to cope actively with the consequences of the stroke, how to decrease the negative consequences for family functioning and harmony in the relationship, and how to ask for support. Future studies are needed to examine the possible role of other psychological factors, like personality and self-efficacy, as determinants of the psychosocial functioning of caregivers.

Disclosures

None.

References

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