Determinants of Quality of Life in Stroke Survivors and Their Informal Caregivers

Ann-Cathrin Jönsson, RN, MSc; Ingrid Lindgren, RPT, MSc; Björn Hallström, MD; Bo Norrving, MD, PhD; Arne Lindgren, MD, PhD

Background and Purpose—We examined longitudinal changes of quality of life (QOL) covering physical and mental factors in an unselected group of stroke patients and their informal caregivers. Our hypothesis was that informal caregivers would have better QOL than patients at both follow-ups, and that changes, if any, would be related to the patients’ status.

Methods—QOL of 304 consecutive stroke patients and their 234 informal caregivers from the population-based Lund Stroke Register was assessed 4 months after stroke onset with the Short Form 36 (SF-36) questionnaire. SF-36 was repeated for both groups after 16 months together with Mini Mental State Examination (MMSE) and Geriatric Depression Scale (GDS-20) for patients.

Results—The patients’ mean QOL scores improved between 4 and 16 months after stroke in the socio-emotional and mental SF-36 domains and decreased in the domain physical function. Multivariate analyses showed that the patients’ most important determinants of QOL after 16 months were GDS-20 score, functional status, age, and gender. Informal caregivers had better QOL than patients except for the domain role emotional and the mental component summary. The caregivers’ most important determinants of QOL were their own age and the patients’ functional status.

Conclusions—Our study highlights depressive symptoms in determining QOL of stroke patients. Despite self-perceived deterioration in physical function over time, several other components of QOL improved, suggesting internal adaptation to changes in their life situations. Informal caregivers of stroke patients may be under considerable strain as suggested by their lower emotional–mental scores. (Stroke. 2005;36:803-808.)

Key Words: caregivers % depression % disability evaluation % quality of life % stroke outcome

Survival and functional status are established outcome measures after stroke. However, quality of life (QOL), covering both physical and mental factors, has also been emphasized as an important outcome. A need for longitudinal research in this field has been recognized. Previous studies have found the Short Form 36 (SF-36) instrument useful for measuring QOL in stroke patients. SF-36 measures the patients’ perception of physical, mental, and socio-emotional factors affecting QOL, but it has been recommended that SF-36 should be supplemented by additional measurement of social functioning. SF-36 has been tested and found suitable also for older adults, if offered assistance with the questionnaire when necessary. An association between depression and QOL has been reported. The importance of obtaining the patients’ own views on QOL has been emphasized, because they do not always correlate with objective measures. The burden of stroke affects the patients’ informal caregivers and their QOL has been found generally worse than normative values, especially regarding psychological well-being. Previous studies have focused on patients only or on selected groups of patients or caregivers in general practice or rehabilitation units. Several studies have shown that patients’ QOL is worse compared with a general population in the first years after stroke, especially regarding physical factors and vitality. In hospital settings, a variable proportion of patients have been excluded for various reasons. There are no reports of QOL and its determinants in large population-based groups of stroke patients compared with their informal caregivers. Therefore, it would be interesting to study if interrelated groups of patients and caregivers influence each other and how.

The objectives of our study were to assess and compare QOL of a population-based group of patients and their informal caregivers 4 and 16 months after stroke and to analyze determinants affecting different domains of their QOL. Our hypothesis was that informal caregivers would have better QOL than patients at both follow-ups, and that changes, if any, would be associated with the patients’ status.

Materials and Methods

A total of 416 consecutive first-ever stroke patients included in Lund Stroke Register with stroke onset between March 1, 2001 and
TABLE 1. Functional Status

<table>
<thead>
<tr>
<th>Grade of Dependency, Barthel Index Before Stroke*, %</th>
<th>Follow-up I, %</th>
<th>Follow-up II, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independency (BI 95–100)</td>
<td>98</td>
<td>70</td>
</tr>
<tr>
<td>Moderate dependency (BI 60–90)</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Major dependency (BI 0–55)</td>
<td>1</td>
<td>10</td>
</tr>
</tbody>
</table>

*Level of dependency before stroke was determined by Swedish National Quality Register for Stroke Care questions on ambulation indoor and outdoor, dressing, and toileting (see Materials and Methods).

February 28, 2002 participated in this study. Lund Stroke Register covers the population of Lund-Orup, including 8 municipalities with 234,505 inhabitants (December 31, 2001), representing the local catchment area of Lund University Hospital. Several overlapping sources were used to detect stroke patients. The major source was the daily admission list at the Department of Neurology. Patients with a wide range of admitting diagnoses, including transient ischemic attack, as well as patients at the outpatient clinic, were also screened for stroke. Stroke was diagnosed according to the World Health Organization definition.12 The nurse specialist inquired at other hospital departments once per month and at nursing homes in the Lund Stroke Register area every 3 months, if any new cases of stroke had been found. All patients but 1 with a final diagnosis of first-ever stroke underwent computed tomography scan of the brain.

Informal caregivers were considered eligible if they were in contact with the patient at least twice per week. The group “caregivers” consisted of the following categories: spouses or living together with the patient 71%, children 22%, parents or siblings 5%, and close friends 2%.

Informed consent was obtained from each participant. When patients were confused or had sensory dysphasia, the caregivers gave consent on their behalf, if they thought this was in line with the patients’ will. The study was approved by the Ethics Committee of the Faculty of Medicine, Lund University.

All surviving patients were contacted 4 (follow-up I) and 16 months (follow-up II; median) after stroke onset and given an appointment with a nurse specialist and a physical therapist. Approximately 70% of the 304 patients alive at follow-up II were able to come to the outpatient clinic; whereas the remainder were examined in primary care centers (~10%), nursing homes (~10%), or their own homes (~10%).

Assessments

QOL for patients and caregivers was assessed using the SF-36 questionnaire, which has been validated for use in stroke patients13 and evaluated in a Swedish version.14 SF-36 provides a general assessment of the respondent’s subjective views on different aspects of life.14 It consists of 8 health domains, each with a score range between 0 and 100, with 100 being the best possible score: physical functioning (PF); role limitations because of physical problems (RP); bodily pain (BP); general health (GH); vitality (VT); social functioning (SF); role limitations because of emotional problems (RE); and mental health (MH). We also analyzed 2 summary scores of SF-36, the Physical Component Summary (PCS) and Mental Component Summary scores (MCS).18 The investigators read the questions with the patients and the caregivers separately, unless they wanted to complete the questionnaires on their own. The questionnaires were checked for missing items and supplemented when necessary. Caregivers or personnel assisted 27 patients at follow-up I and 36 patients at follow-up II. To find determinants of QOL, we also used the following instruments, which have been found suitable in previous studies. Patients’ functional status was assessed with Barthel Index (BI)14 and divided into 3 grades of dependency15 (Table 1). We assessed functional status before stroke onset using items from the Swedish National Quality Register for Stroke Care16 corresponding to BI questions about dressing, toilet use, transfer, and mobility.

Social participation was assessed using a 10-item question, with 10 being the best possible score (1 point each given for: attendance at study circle, club/association, theater/cinema, exhibition, religious activity, sports activity/game, family gathering, private party, writing letters/e-mails, or any other activity).17

At follow-up II, we tested cognitive function in 275 patients (29 patients could not respond because of severe cognitive dysfunction or impaired vision) using the Mini Mental State Examination (MMSE), range 0 to 30,20 with a score <24 indicating cognitive impairment.21,22

The presence of depression was tested at follow-up II in 294 patients (10 patients could not respond because of cognitive dysfunction) with the Swedish adapted Geriatric Depression Scale (GDS-20), range 0 to 20. A score of ≥6 indicates possible depression.23–24

Statistical Analysis

Mean scores of the SF-36 domains and the PCS and MCS summary scores were calculated for patients and caregivers. We tested for significant changes between the 2 follow-ups for patients and caregivers separately and compared the scores of patients and caregivers with Wilcoxon Signed Ranks tests. Multivariate analyses (stepwise linear regression analyses) examined if the separate SF-36 domains and summary scores for patients and caregivers were influenced by age or gender. The following items regarding patients only were also included in multivariate analyses for both groups: BI score; MMSE score; GDS-20 score; and social participation. Thus, nonresponders to GDS-20 and/or MMSE (n=30) were excluded.

If the caregivers at follow-up II had any item with lower SF-36 score compared with the patients, we examined if this SF-36 item varied significantly between the 3 grades of dependency using Kruskal–Wallis test. We used the SPSS program for statistical analyses.

Results

Demographic features of the patients are shown in Table 2. At follow-up II, 88 of the 416 patients were deceased. These 88 patients were older, had more severe strokes, and more often intracerebral bleeding than those who survived. We assessed QOL at both follow-ups for 304 patients and 234 caregivers (Table 3). Follow-up could not be obtained for 21 patients declining to participate, 1 not being located, and 2 being very ill. Reasons for missing caregivers were: 8 being ill, 19 declining to participate, 25 not being eligible, and no caregivers existing for 18 patients.

QOL and BI at Follow-up II

We found a decrease in patients’ PF (P=0.017) and increases in SF (P=0.005), RE (P=0.012), MH (P=0.010), and MCS (P=0.001) compared with follow-up I. For caregivers, there were no significant changes between the 2 assessments. At follow-up II, the caregivers had higher mean scores than patients in 5 SF-36 domains and PCS (Table 3).

The caregivers had lower RE and MCS scores than the patients (Table 3). The caregivers’ mean scores for these 2 items were as follows for the 3 grades of dependency: independency, RE 76.9 and MCS 49.2; moderate dependency, RE 59.8 and MCS 44.8; and major dependency, RE 66.7 and MCS 44.2. Thus, the lowest mean RE score for caregivers was in the moderate dependency group and the highest mean scores for both RE and MCS were in the independent group. Kruskal–Wallis test showed significant differences between the caregivers’ RE (P=0.030) and MCS
scores in the 3 dependency groups. The patients’ grade of dependency is stated in Table 1.

**MMSE and GDS-20**

Fifty patients (18%) scored <24 points on the MMSE scale, indicating possible cognitive dysfunction. On the GDS-20 scale, 119 patients (41%) scored ≥6 points, indicating possible depression. The proportion of patients with depression was larger in women (45% of 119 women) than in men (37% of 175 men) \((P=0.016)\). This gender difference remained significant \((P=0.012)\) after adjustment for age.

**Determinants of QOL**

For patients, lower (ie, better) depression scores were associated with higher scores in all SF-36 domains and summary scores; BI influenced physical and social domains and also general health and mental score. Increasing age in patients was related to lower scores in physical domains and higher emotional and mental scores. Female gender in patients was associated with higher scores for physical role, emotional function, general health, and mental score. Higher social participation was associated with better physical function and vitality (Table 4).

Increasing age in caregivers was negatively related to their physical and emotional domains, general health, and bodily pain. Caregivers’ social and mental domains, and also bodily pain, were positively affected by better functional status in patients. Patients’ higher scores in social participation were associated with caregivers’ higher scores in physical domains. Caregivers’ social function and vitality were negatively influenced by patients’ increasing age. Female gender in patients was positively associated with vitality and mental health in caregivers.

**Discussion**

To our knowledge, this is the first report of QOL and its determinants for patients and their caregivers in a large population-based group of stroke survivors. A novel finding was that the mean values of the patients’ QOL improved significantly in 3 SF-36 domains and in MCS during the 16 months after stroke, whereas there were no significant changes for the caregivers. Another important finding was the impact of depression measured by GDS-20 on all SF-36 domains and summary scores for patients and that there was a considerably larger proportion of women with depression (45% versus 37% for men). Surprisingly, caregivers’ QOL was worse than for patients regarding emotional and mental factors at follow-up II.

An association between depression and QOL has been reported previously. In a recent report, depression also was a significant factor 2 years after stroke. The conclusion was that
interventions targeting mood might improve QOL regardless of physical disability.

Not less than 91% of the men and 80% of the women were living in their own homes at follow-up II. This gender difference was in line with 72% men versus 62% women still being independent (BI), and also with other studies.3,18 A complete BI assessment regarding the prestroke status for comparison with follow-ups would have been useful. How-

<table>
<thead>
<tr>
<th>Table 4. Determinants for 8 SF-36 Domains and PCS and MCS (Stepwise Linear Regression Analysis)*</th>
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</thead>
<tbody>
<tr>
<td><strong>Patients</strong></td>
</tr>
<tr>
<td><strong>n=274</strong></td>
</tr>
<tr>
<td><strong>PF</strong></td>
</tr>
<tr>
<td><strong>B1 score</strong></td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td><strong>GDS-20</strong></td>
</tr>
<tr>
<td><strong>RP</strong></td>
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<tr>
<td><strong>BI score</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td><strong>BP</strong></td>
</tr>
<tr>
<td><strong>MMSE</strong></td>
</tr>
<tr>
<td><strong>Age, own</strong></td>
</tr>
<tr>
<td><strong>GH</strong></td>
</tr>
<tr>
<td><strong>BI score</strong></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td><strong>VT</strong></td>
</tr>
<tr>
<td><strong>Social participation</strong></td>
</tr>
<tr>
<td><strong>SF</strong></td>
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<tr>
<td><strong>BI score</strong></td>
</tr>
<tr>
<td><strong>RE</strong></td>
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<tr>
<td><strong>Age</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
<td><strong>MH</strong></td>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
<td><strong>PCS</strong></td>
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<tr>
<td><strong>GDS-20</strong></td>
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<td><strong>Age</strong></td>
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<tr>
<td><strong>Social participation</strong></td>
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<tr>
<td><strong>MCS</strong></td>
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<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td><strong>BI score</strong></td>
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<tr>
<td><strong>Gender</strong></td>
</tr>
</tbody>
</table>

*Only significant values shown. †indicates patient status.
ever, using questions from the Swedish National Quality Register for Stroke Care, we could compare the patients’ functional status before stroke and afterward (Table 1). Although the patients’ self-perceived physical function deteriorated, their QOL improved in social, emotional, and mental domains, which may relate to an adaptation to the new life situation. Such a “response shift” or internal adaptation was also reported in a previous study and may represent changing priorities in life.

We found significant differences between the caregivers’ emotional and mental scores in the patients’ 3 dependency groups, which may reflect the severity of the caregiver strain. Whereas the patients gradually adapt to the new situation, it may become more demanding for caregivers. Emotional scores were higher for caregivers of patients with major dependency compared with the moderate dependency group, which may be because of more support provided from the community for patients with severe strokes.

### Methodological Aspects

Strengths of our study are the population-based design, well-characterized patient material, and >90% follow-up, achieved by examining almost one-third of all patients in out-of-hospital settings. Proxies participated in the patient ratings of QOL in only 10% of cases. Proxy ratings may introduce bias, but they are preferable to exclusion of data from patients who cannot respond themselves.

Weaknesses include lack of a detailed assessment of depression, as well as absence of data on cerebrovascular or other main new events, and the use of antidepressant medication during follow-up. For depression, we used only the GDS-20, which is a screening scale. Of the 304 patients in our study, only 19 had ICH and 13 had SAH; therefore, the statistical power was too low for analyses of these subgroups. The clinimetric validity of SF-36 has been subject to debate. Using the recommendation by Taft, we included both subscales and summary scores in our study. Because our study also comprised assessments of QOL in caregivers, a stroke-specific scale like the recommended Stroke Impact Scale could not be used.

### Conclusions

Although the patients’ self-perceived physical function deteriorated, they appeared to adapt to the new life situation and their QOL in socio-emotional and mental domains improved during the year between the follow-ups. Surprisingly, the caregivers were on a lower level in emotional and mental domains, and their most important determinants of QOL were their own age and the patients’ functional status. A support for the caregivers could be a training program that may improve psychosocial outcomes for caregivers as well as patients. Future studies should preferably include screening for depression, which was the most important determinant of QOL for patients in our study.

### Acknowledgments

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