Spouses of Stroke Survivors Report Reduced Health-Related Quality of Life Even in Long-Term Follow-Up

Results From Sahlgrenska Academy Study on Ischemic Stroke

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Background and Purpose—The consequences for the family of stroke survivor are generally studied in a short-term perspective. The aim of this study was to assess long-term aspects of health-related quality of life among spouses of stroke survivors.

Methods—Data on stroke survivors, controls, and spouses were collected from the 7-year follow-up of the Sahlgrenska Academy Study on Ischemic Stroke (SAHLSIS). The health-related quality of life of spouses was assessed by the Short Form-36, and the characteristics of stroke survivors were assessed using the National Institutes of Health Stroke Scale, the Mini-Mental State Examination, the Hospital Anxiety and Depression Scale, the Barthel Index, and the modified Rankin Scale.

Results—Dyads of 248 stroke survivors aged <70 at stroke onset and 245 dyads of matched controls were included. Spouses of stroke survivors and spouses of controls had a median age of 64 and 65, respectively; proportion of men was 35% and 34%, respectively. The spouses of stroke survivors reported lower scores in all the mental domains (P=0.045; P<0.001), as well as in the domains of general health (P=0.013) and physical role (P=0.006), compared with the spouses of controls. Predictors of poor physical health of the spouses were their own age and the level of global disability of the stroke survivor. Predictors of poor mental health of the spouses were depressive symptoms, cognitive impairment, and global disability among the stroke survivors.

Conclusions—The health-related quality of life of spouses of stroke survivors is reduced not only during the first years but also in the long-term perspective. (Stroke. 2015;46:2584-2590. DOI: 10.1161/STROKEAHA.115.009791.)

Key Words: cross-sectional studies ■ follow-up studies ■ outcome assessment (health care) ■ spouses ■ stroke

A stroke has often a wide-spread effect on the daily life of the family. Because of its heterogeneity, stroke may affect the lives of the spouses differently. The situation for spouses as caregivers during the first 2 years after the stroke is well studied, whereas less is known about the lives of younger families. The spouse of a midlife stroke survivor often has responsibilities related to family and a professional life; therefore, their lives are affected differently. Supporting a partner is often perceived as natural and important, but it may also be demanding and affect the health of the caregiver.

Subjects and Methods

Subjects

Data on stroke survivors, controls, and spouses were collected from the 7-year follow-up of the Sahlgrenska Academy Study on Ischemic Stroke (SAHLSIS). The database covers 600 consecutively recruited patients diagnosed with ischemic stroke before the age of 70 within 4 stroke units in western Sweden between 1998 and 2003 and 600 age- and sex-matched controls who were selected randomly from a group of participants in a population-based health survey. For both stroke cases and controls, recurrent stroke and deaths between SAHLSIS baseline and follow-up have been identified using the Swedish Cause of Death Register and the National Patient Register. For the 7-year follow-up,
stroke survivors and controls were invited to respond to a questionnaire with questions concerning background variables and self-rating instruments concerning health issues. In addition, stroke survivors included in the Sahlgrenska University Hospital were invited to a visit to the research nurse and the research physician. If the stroke survivor had difficulties concerning travel to the hospital, the nurse and physician made home visits. Stroke survivors included at the stroke units at other hospitals were interviewed by the research nurse over the phone.

From the 7-year follow-up, the spouses of stroke survivors and spouses of controls were recruited for this study. After approval by the stroke survivor or by the control, their spouse was invited to participate through responding to a questionnaire concerning sociodemographic measures and completing a self-rating instrument for HRQoL. All respondents gave informed consent and approved merging of data from the different sources. This study was approved by the Regional Ethical Review Board in Gothenburg (reference numbers, 413-04 and 622-06).

Assessments
Sociodemographic data about the stroke survivors were collected from the SAHLSIS database, and similar data on spouses were obtained using caregiver survey questions from the national quality register, Riks-Stroke, by permission.

HRQoL of spouses was assessed using the Short Form-36 (SF-36) questionnaire in an approved Swedish version, with 8 domains covering the subjective evaluation of general health, as well as physical (physical functioning, physical role, and bodily pain) and mental health (vitality, social functioning, emotional role, and mental health).

For stroke survivors, the physical impairment was assessed using the National Institutes of Health Stroke Scale (NIHSS). The global disability was assessed by the modified Rankin Scale (mRS). These data were collected prospectively at 3 months after stroke onset and at the 7-year follow-up. The ability to perform basic activities of daily living was assessed by the Barthel Index (BI). The cognitive impairment was assessed by the Mini-Mental State Examination (MMSE), and depression and anxiety were self-assessed by the Hospital Anxiety and Depression Scale. With regard to mRS and BI, for patients included at the Sahlgrenska University Hospital, the research nurse performed these evaluations in face-to-face interviews, whereas for the patients from the other stroke units, assessments were performed by telephone interviews. The NIHSS and MMSE were scored by the research physician, and for practical reasons, data on these impairments could only be obtained from patients recruited at the Sahlgrenska University Hospital.

Statistical Analyses
The distribution of the variables is given as mean, SD or median, and Q1 and Q3 for continuous variables and as number and percentage for categorical variables. Most of the instruments yielded skewed data distributions; thus, nonparametric statistics were used. However, because SF-36 domains are usually presented as mean values, our results were presented both as mean and median values. For comparison between 2 groups, Mann–Whitney U test was used for continuous variables. All significance tests were 2-sided and conducted at the 5% significance level. Spearman rank order correlation was used to study the strength of associations between the separate SF-36 domains for spouses and the age, sex, education level, and social support of the spouses, as well as stroke-related variables assessed with NIHSS, MMSE, Hospital Anxiety and Depression Scale, BI, and mRS. Variables displaying correlations with P values of ≤0.10 were included in a stepwise logistic regression to evaluate predictors of the HRQoL of the spouses. Odds ratios with 95% confidence interval were presented for descriptive purposes, and the area under the receiver operating characteristic curve was calculated for a description of the model’s goodness of fit. Data for the NIHSS and MMSE instruments were collected for a subgroup, and the stepwise logistic regression analysis was performed in 2 steps. The first step was carried out for the population from the Sahlgrenska University Hospital (n=170). If the analysis only included independent variables for the entire study population (n=248), then, the second step was carried out with only those independent variables. Analyses were conducted using SPSS software (version 20; SPSS, Inc, Chicago, IL).

Results
Figure illustrates the recruitment of participators for this study. At SAHLSIS baseline, 422 stroke survivors and 437 controls were cohabitant. Between baseline and the 7-year follow-up, 131 stroke survivors and 108 controls became single, deceased, or were excluded. Of those who were single at baseline, 8 stroke survivors and 15 controls became cohabitant, and accordingly, they were included in the study. Thus, at the 7-year follow-up, 299 cohabitant stroke survivors and 344 controls were available for this study. Of these, 20 stroke survivors and 46 controls denied contact with the spouses. Furthermore, 31 spouses of stroke survivors and 53 spouses of controls denied participation. A total of 248 spouses of stroke survivors and 245 spouses of controls and their cohabitants were included in this study (Figure). Spouses of stroke survivors and spouses of controls had a median age (Q1–Q3) of 64 (58–70) and 65 (59–70), respectively; proportion of men was 35% and 34%, respectively. Stroke survivors and controls had a median age (Q1–Q3) of 66 (60–71) and 66 (61–72), respectively (Table 1). No statistically significant differences between the stroke survivors and controls on sex or education were found. However, the controls were significantly older than the stroke survivors (P<0.010), and a larger proportion of the controls lived in their own home compared with the stroke survivors (P<0.001). No statistically significant differences between the 2 spouse groups on sex, age, or other background variables were found. At the 7-year follow-up, 41 (16.5%) of the 248 stroke survivors included in the study had a recurrent stroke. The stroke survivors with recurrent stroke displayed more impaired activities of daily living function (BI: P=0.030), worse global disability (mRS: P=0.021), and more cognitive impairment (MMSE: P<0.001), compared with the stroke survivors who did not have a recurrent stroke. Four (1.6%) of the 245 controls had a stroke at the 7-year follow-up.

The stroke survivors who were lost between baseline and the 7-year follow-up had worse global disability at 3 months after stroke onset than those who were eligible for this study (mRS: P<0.001). More male than female stroke survivors were lost to follow-up, but there were no age differences between those who were lost and those who were eligible for inclusion.

Seventeen percent of the remaining stroke survivors and 29% of the remaining controls refused contact with their spouses or their spouses declined participation. There were no age or sex differences between the stroke survivors and controls who refused contact and those whose spouses declined participation compared with the included spouses. Also, there were no differences in the stroke-related variables between stroke survivors included in the study and those who declined.

Differences in the HRQoL scores between the spouses of stroke survivors and the spouses of controls showed that the spouses of stroke survivors scored lower on all the mental domains, physical role, and general health compared with the spouses of controls (Table 2).

The age of the spouses was correlated with their HRQoL, such that older spouses of stroke survivors scored
significantly lower on all 8 SF-36 domains than younger spouses of stroke survivors; however, older spouses of controls scored significantly lower on physical functioning ($P<0.001$) and general health ($P=0.003$) than younger spouses of controls. No statistically significant differences in HRQoL related to sex were found in the spouses of stroke survivors group. In contrast, female spouses of controls scored significantly lower than male spouses of controls on physical role ($P=0.017$), bodily pain ($P=0.036$), and mental health ($P=0.033$).

The scores of spouses of stroke survivors concerning the SF-36 physical domains were correlated with the age of the spouses of stroke survivors and the stroke survivors physical and cognitive impairment, ability in self-care, and global disability. The scores of spouses of stroke survivors in the SF-36 mental domains were correlated not only with the same variables but also with the stroke survivors’ level of depression and spouses of stroke survivors perceived lack of social support (Table I in the online-only Data Supplement).

The results from stepwise logistic regression analysis evaluating predictors of the HRQoL domains of spouses of stroke survivors are shown in Table 3. The main predictors of the physical domain scores were the age of the spouses of stroke survivors and the global disability of the stroke survivor. Predictors of the scores concerning the mental domains were the stroke survivors’ depressive symptoms, global disability, cognitive impairment, and spouses of stroke survivors perceived lack of social support.

**Discussion**

In this long-term follow-up, we found that spouses of stroke survivors compared with spouses of controls experienced highly reduced HRQoL 7 years after the stroke episode. Domains where spouses of stroke survivors scored low were related to vitality, mental and general health, social functioning, and physical and social roles. However, the main predictor of the spouses’ HRQoL at this point in time was the global disability of the stroke survivors.
In the present sample of younger stroke survivors, the majority had a mild stroke on motor function and basic activities of daily living. However, several years after the stroke event, the spouses had poorer mental health compared with the controls. Previous findings have shown that supporting a family member with stroke primarily has an effect on the mental health of the caregiver. The spouses’ mental health has been shown to be related to experiences such as the practical and social consequences of the stroke, as well as own health and coping ability, all of which are factors that may change over time. Furthermore, increased depression over time is also associated with long-lasting negative changes post stroke. Our results highlight the effect on the spouses’ mental health because of demanding changes in the life situations of younger families, not only during the first years after stroke onset but also in the long-term perspective.

The spouses of stroke survivors scored lower on general health compared with spouses of controls. According to Salter et al., there is evidence for an effect on the mental health of caregivers, whereas the evidence for an effect on physical health is less clear. Furthermore, high strain on caregivers increases their risk for coronary heart disease, stroke, and premature death. Therefore, it can be assumed that long-lasting strain has an effect on general health. However, in line with previous studies, age also affected spouses’ ability to perform physical activities in daily life. This also has implications for their ability to provide support to the stroke survivor and should be noted when tailoring support for caregivers.

The main predictors of the physical domains of the HRQoL of the spouses of stroke survivors were their own age and the global disability of stroke survivors. Predictors of the mental domains on the other hand were depressive symptoms, cognitive impairment, and global disability of the stroke survivor, as well as lack of social support for the spouses of stroke survivors. The results are consistent with previous studies indicating that the functional status, depressive symptoms, and neurological deficits of the stroke survivor are determinants and predictors of the caregiver’s experienced burden during the first year after stroke onset. The amount of available social support may also be an important factor in lowering the psychological distress of the informal caregiver. We found that these predictors remain even in a long-term perspective. This highlights the importance of treating depression and implementing interventions at an early stage because the depression of the stroke survivor tends to affect the mental health of the partner. Furthermore, in this sample of stroke survivors with physically mild stroke, MMSE scores indicated that a large proportion showed cognitive impairments. It is obvious that these impairments and changes in emotional reactions affect the level of global disability among the stroke survivors.
survivors.27 Such impairments may become increasingly burdensome for the caregivers in a long-term perspective. This underlines the importance of detecting and following up over time also hidden cognitive impairments to provide a basis for education of the family on strategies to handle everyday life.

In our study, the HRQoL of spouses to stroke survivors was compared with that of a control group, although the matches were done concerning the age and sex of the stroke survivors but not of the spouses. However, because the age, sex, and other demographic characteristics were similar in the 2 groups, they were considered adequately comparable.28 Our results showed no differences in HRQoL between the sexes in the spouses of stroke survivors group, in contrast to the spouses of controls group. This finding indicates that caregiving has the same effect on the HRQoL of men and women at 7 years after stroke onset.

A main strength of this study is the well-described study population of consecutively included stroke survivors. Despite the long-term follow-up, the study has a response rate of 80%, and in addition, information is available concerning the cause of exclusions from baseline until the 7-year follow-up, illustrated in the Figure, such as if the stroke survivor had become deceased or single, that is, divorced or widowed.

A limitation of this study is that longitudinal data were not collected, and thereby, no information is available for spouses where the stroke survivor who had become deceased, single, or excluded. However, comparison between stroke survivors who were lost to follow-up and those stroke survivors recruited for this study showed that stroke survivors with higher levels of global disability at 3 months after stroke onset were lost to follow-up, probably underestimating the required support. Furthermore, 16.5% of the remaining stroke survivors had a new stroke episode since baseline, which reflects the variability of stroke disease over time, as well as the variability

| Table 2. Quality of Life Domains for Spouses of Stroke Survivors and Spouses of Controls |
|---------------------------------|---------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|
|                                | Spouses of Stroke Survivors (n=248) | Spouses of Controls (n=245) |
|                                | Mean (SD) | Median (Q1–Q3) | Mean (SD) | Median (Q1–Q3) | PValue* |
| Physical functioning           | 83.8 (20.5) | 90 (75–100) | 87.0 (17.5) | 95 (80–100) | 0.177 |
| Physical role                  | 78.9 (35.5) | 100 (75–100) | 85.6 (31.6) | 100 (100–100) | 0.006 |
| Bodily pain                    | 72.4 (26.7) | 74 (51–100) | 76.0 (26.1) | 84 (52–100) | 0.149 |
| General health                 | 71.5 (23.1) | 77 (55–92) | 76.5 (21.4) | 82 (66–95) | 0.013 |
| Vitality                       | 66.1 (24.0) | 70 (55–85) | 73.3 (21.8) | 80 (60–90) | <0.001 |
| Social functioning             | 86.7 (21.1) | 100 (75–100) | 90.6 (18.5) | 100 (88–100) | 0.045 |
| Emotional role                 | 80.5 (34.8) | 100 (67–100) | 89.8 (26.9) | 100 (100–100) | <0.001 |
| Mental health                  | 78.3 (20.0) | 84 (64–92) | 84.2 (15.9) | 88 (76–96) | <0.001 |
|                                | 77 (55–92) | 82 (66–95) | 76.5 (21.4) | 82 (66–95) | 0.177 |

Source: domains are from the Short Form-36 scale.10
*Mann–Whitney U test.

| Table 3. Predictors of Poor Health-Related Quality of Life for Spouses of Stroke Survivors |
|---------------------------------|---------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|------------------|
| Outcome Variable                | Predictor                        | PValue | OR (95% CI)‡    | Area Under ROC curve |
| Physical functioning*           | Age (spouse)                     | <0.001 | 0.91 (0.88–0.94) | 0.79 |
| Physical role*                  | mRS                              | 0.016  | 0.73 (0.57–0.94) | 0.66 |
| General health*                 | Age (spouse)                     | 0.026  | 0.96 (0.94–1.00) | 0.67 |
| Vitality*                       | mRS                              | 0.039  | 0.76 (0.61–0.99) | 0.69 |
| Social functioning†             | HADS-D                           | 0.006  | 0.89 (0.81–0.97) | 0.61 |
| Emotional role*                 | MMSE                             | 0.006  | 1.21 (1.06–1.38) | 0.65 |
| Mental health*                  | mRS                              | 0.028  | 0.74 (0.57–0.97) | 0.72 |
|                                | Lack of social support            | 0.023  | 0.63 (0.43–0.94) | 0.72 |
|                                | HADS-D                           | 0.013  | 0.91 (0.84–0.98) | 0.72 |
|                                | mRS                              | 0.005  | 0.67 (0.51–0.89) | 0.72 |
|                                | Lack of social support            | 0.007  | 0.59 (0.40–0.87) | 0.72 |

Source: domains are from the Short Form-36 scale.10 CI indicates confidence interval; HADS, Hospital Anxiety and Depression Scale; MMSE, Mini-Mental State Examination; mRS, modified Rankin Scale; OR, odds ratio; and ROC, receiver operating characteristic.
*Models are based on the total study population (n=248).
†Models are based on subgroup from the Sahlgrenska University hospital (n=170).
‡OR is associated with 1-unit increase in the predictor. For HADS-D and mRS, higher scores indicate more severe outcome. For the MMSE instrument, higher scores indicate less severe outcome.
with regard to its effect on the HRQoL of spouses over time. Further longitudinal studies of the effect of stroke disease on the HRQoL of spouses are needed. In addition, the use of the SF-36 to assess the HRQoL of spouses of stroke survivors and controls may be criticized because the instrument assesses self-reported health status on that particular day. On the other hand, HRQoL is multidimensional, and thereby, it provides a broader scope than assessments of medical symptoms. The generalizability is limited to ischemic stroke at ages <70. Data for the NIHSS and MMSE could only be obtained from patients recruited at the Sahlgrenska University Hospital, which resulted in a smaller sample size for these analyses. Furthermore, data for BI and mRS from the other hospitals were collected by the same trained research nurse but based on telephone interviews. However, these instruments are robust, and there were no indications that the data were any different between those who were assessed face-to-face by the research nurse compared with those assessed by telephone interview, results which are in accordance with a previous study.

In conclusion, we report that spouses of stroke survivors experienced impaired HRQoL also at 7 years after stroke onset. The disability level of the stroke survivors has an effect on the HRQoL of the spouses of stroke survivors and may be caused by cognitive, physical, and emotional factors, and thus, it may be perceived and coped with differently. Further longitudinal studies are needed to better understand the effect of the stroke survivors’ disability on the HRQoL of their spouses. Among the various recognized disabilities of stroke survivors, it is notable that the depressive symptoms of stroke survivors may adversely affect the mental health of the spouses. Long-lasting support of the family seems to be a challenge for societal efforts.

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Disclosures
None.

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**Supplemental Table I.** Correlations between the SF-36 scores of the spouses of stroke survivors and demographic features of the spouses and stroke-related variables of the stroke survivor.

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<th>Physical functioning</th>
<th>Role, physical</th>
<th>Bodily Pain</th>
<th>General Health</th>
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*Spearman’s Rank Order Correlation Coefficient.
¹ Subgroup from the Sahlgrenska University hospital (n=170).
² Total study population (n=248).