Spouses of First-Ever Stroke Patients
Psychological Well-Being in the First Phase After Stroke

Gunilla Forsberg-Wärleby, OTR, BS; Anders Möller, PhD; Christian Blomstrand, MD, PhD

Background and Purpose—A stroke affects not only the patient but also the spouse. To better support the spouse during the acute phase of stroke, knowledge is needed about his or her experience with the situation. The aim of the present study was to study the well-being of the spouses of stroke patients during the acute state of stroke and to identify factors that may influence their well-being.

Methods—Eighty-three consecutively enrolled spouses of first-ever stroke patients <75 years old participated. Their psychological well-being, measured by the Psychological General Well-Being Index 10 days after the stroke, was compared with norm values. Multiple analyses of correlation were performed to investigate the effects on psychological well-being of (1) age and sex, (2) level of impairment of the stroke patient, and (3) intrapersonal variables such as previous life satisfaction and view of the future.

Results—The study group showed significantly lower psychological well-being compared with norm values except for the dimension of general health. The variables that correlated significantly with the Psychological General Well-Being total score were the sensorimotor impairment of the stroke patient and the “view of the future.” This view of the future also correlated significantly with the level of functional ability of the stroke patients.

Conclusions—During the acute phase of stroke, the severity of the stroke has an impact on the spouse’s image of his or her future life, whereas the individual appraisal of personal consequences and of his or her own coping capacity seems to have a greater impact on the psychological well-being of the spouses than does the objective state of disability. (Stroke. 2001;32:1646-1651.)

Key Words: caregivers ■ quality of life ■ stroke, acute

Strokes are one of the most common disabling diseases.1 When a family member is affected by an illness perceived as life threatening or potentially disabling, this is often experienced as a critical event in life.2 The meaning and coherence of life are broken and the situation can be perceived as chaotic.3 It is well known from stress research, however, that the same type of event may evoke a marked variation in the amount of perceived stress among different persons. The appraisal of the event and the coping capacity of the individual are important factors behind the variations.3,4 Acute illness in a family member will affect the emotional well-being of the remainder of the family. Relatives of patients in intensive care units experience emotional turmoil.5 It is not well known how families of stroke patients experience their situation during the acute stage. The impact of stroke on the psychological health of caregivers has been investigated mostly from the perspective of 3 to 6 months,5–9 1 to 3 years,6,7,10,11 and >3 years,12,13 after the stroke, showing that 20% to 50% of caregivers experience emotional disturbance, especially depression. To our knowledge, only 2 studies have systematically investigated the emotional impact of the caregiver during the first weeks after stroke. Wade et al7 found that 23% of caregivers were depressed or probably depressed, and Shultz et al8 showed that the mean level of depression in support persons was higher than that for national samples of persons of similar ages. The spouse plays an important role in the rehabilitation process of the stroke patient. The emotional and practical support of the caregiver is known to affect the functional and psychosocial outcome of the stroke patient.14,15 The risk for depression seems to be higher for spouses than for other support persons.8 To better support the spouses of stroke patients during the acute stage, there is a need for greater knowledge about their psychological well-being and experience of their new life situation.

A longitudinal study was conducted to investigate the impact of stroke on spouses’ everyday life and adaptation process. In a previous study, we investigated the spouses’ “view of the future” during the acute phase of stroke.15a The results assumed an association between the view of the future and well-being at the present time, which called for further investigation.
The main purposes of the present study were to (1) describe spouses’ perceived psychological well-being during the acute stage of stroke and (2) investigate the extent to which psychological well-being was associated with objective variables, such as level of impairment of the stroke patient, and with subjective variables, such as previous life satisfaction and view of the future.

Subjects and Methods

Study Group

The study group consisted of spouses of individuals (1) with medical evidence of a first completed stroke, including minor stroke (patients with subarachnoid hemorrhage were excluded), (2) with no evidence of coexisting known malignant or other rapidly progressive medical disease, (3) who were aged <75 years, (4) who were hospitalized at the Neurological Department, Sahlgrenska University Hospital, Göteborg, (5) who were living in Göteborg or the surrounding areas, and (6) who spoke and understood Swedish. Spouses who had experienced a stroke or had cognitive impairment were excluded. The subjects were included consecutively from September 1994 to October 1997, except during holidays. Of a total of 342 consecutively admitted stroke patients, 130 were single, 33 were >75 years old, 44 had a recurrence of stroke, 16 did not live in the geographic area, 3 did not speak Swedish, and 4 had a coexisting malignant disease. Two patients were personal friends of the investigators. Three spouses were excluded because they had had a stroke or had dementia, and 1 spouse did not speak Swedish. One hundred six stroke patients were therefore eligible. The stroke patient was contacted 3 to 5 days after the stroke for informed consent, after which the spouse was invited to participate. The initial refusal rate was 22% (n = 23). Two stroke patients did not give permission to contact their spouses. 2 stroke patients died, 18 spouses refused to participate, and 1 spouse was not available. Eighty-three participants were included in the study group. There were no significant differences between the stroke patients in the study group and the 23 patients who did not participate with respect to age, sex, localization of the brain lesion, or level of disability. The Ethics Committee of the Faculty of Medicine, Göteborg University, Sweden, gave approval for the study.

Measurements

Data About the Stroke Patients

Information on the stroke patients included demographic data such as age and sex, localization of the brain lesion as recorded with CT scanning, and status of the patient as recorded by the neurologist on duty at the ward. The presence of cognitive symptoms was assessed by a speech therapist and a neuropsychologist. Neurological deficits were categorized (by C.B.) according to (1) a disturbance of consciousness during the first days after the onset, (2) the presence of cognitive impairment such as aphasia, apraxia, neglect, or visuospatial impairment, and (3) the level of sensorimotor impairment. Inability to use the limbs was classified as “severe sensorimotor impairment,” ability to use the limbs but with impaired force and/or coordination was classified as “moderate impairment,” and impaired fine motor ability was classified as “slight impairment.” The BI score ranges from 0 (total dependence) to 100 (total independence). The BI has been found to be a valid instrument for the functional abilities of stroke patients. The assessment was made an average of 7 days after stroke (range 2 to 27 days) by occupational therapists experienced in neurological rehabilitation.

Data About the Spouse

Information on the spouses included (1) demographic data such as age, sex, family members, occupation, and length of relationship and (2) a semistructured interview consisting of open questions about previous experience with traumatic life events, experience concerning the onset of the stroke, and ongoing life situation, as well as coping strategies and resources used (G.F-W.). The interviews were taped with informed consent, transcribed, analyzed according to contents, and categorized according to the spouses’ perception of stressors and coping in the future.

The analysis resulted in the variable of view of the future, which consisted of 3 subcomponents: perception of the disease and its impact on the future health and abilities of the stroke patient; perception of changes in daily activities, roles, and life circumstances; and perception of one’s own coping capacity. The participants were then classified into 4 categories of optimism/pessimism according to their view of the future. An intrarater assessment was made by G.F-W. The interview data and the self-rating scale were kept separate until the assessment was completed. A completely blind intrarater assessment was made by A.M. and C.B. The intrarater and the intrarater assessments showed strong agreement. In addition, 3 self-rating scales were used. The sense of psychological well-being during the most recent week was measured with the Psychological General Well-Being (PGWB) Index. This index includes 22 items that can be added to provide a global overall score and can be divided into 6 dimensions: anxiety, depressed mood, positive well-being, self-control, general health, and vitality. There are 6 response options for each item that are scored on a scale from 1 (most negative option) to 6 (most positive option). The index has shown high validity and reliability in previous studies. Normal values for a Swedish population are available.

Satisfaction with life before the onset of stroke was rated with the Life Satisfaction Questionnaire. This questionnaire consists of 9 items for which satisfaction is rated: life as a whole, ability to manage self-care, leisure situation, vocational situation, financial situation, sexual life, partner relations, family life, and contacts with friends and acquaintances. The study group included persons who were employed, homemakers, or retired, the original item “satisfaction with occupational situation” was expanded to cover “satisfaction with vocational/occupational situation,” which means satisfaction with ordinary daily occupation (K.S. Fugl-Meyer, personal communication, 1995). Each item is rated on a 6-point scale that ranges from 1 (“very dissatisfied”) to 6 (“very satisfied”).

The interviews took place an average of 10 days after the stroke (range 3 to 29 days) at the Occupational Therapy Department. The participants rated their psychological well-being and life satisfaction in the course of the interview. One participant was unable to complete the rating scales but participated in the interview. There were internal dropouts in some items of the Life Satisfaction Questionnaire. The interviews lasted an average of 1 hour 45 minutes (range 45 minutes to 3 hours).

Statistical Analysis

Differences between the stroke patients in the study group and those who did not participate were analyzed with Fisher’s exact test and Pitman’s test.

Owing to the data distribution and the ordered categorical data characteristics of the instrument, the data are described by frequency, median, and interquartile ranges. However, because results of the BI and the PGWB are given as mean and SD values in reference studies, we present such data to facilitate comparisons.

To compare the PGWB of the study group with that of a normal population, a statistical calculation was made on the basis of normal distribution after a transformation (A. Odén and E. Dimenas, unpublished data, 2000). The transformation was determined by use of a large population sample, previously described by Dimenas et al.

To study (1) the associations between the stroke patients’ neurological impairments and disability and the spouses’ psychological well-being and view of the future and (2) the associations between the spouses’ age, sex, psychological well-being, view of the future, and life satisfaction, Spearman’s rank correlation coefficient was calculated. To reduce the risk of type I errors in multiple correlation analysis, P < 0.01 was chosen as a level of significance.

Power analysis was computed to determine that a sample size of 83 had the sufficient power of 80% provided that the correlation
coefficient was $0.36$ (or $20.36$), being of a level of significance of $0.01$.

Results

Stroke Patients

Sixty-two of the stroke patients were men ($75\%$), and $21$ were women ($25\%$). The average age was $58$ years (age range $23$ to $75$ years). The neurological symptom profiles were heterogeneous. The mean of the BI was $80.4$ (SD $27.5$), and the median was $100$ (range $0$ to $100$). The average age of the spouses was $57$ years (age range $27$ to $79$ years). Forty-seven spouses ($57\%$) were employed on a part-time or fulltime basis. Sixteen ($19\%$) of the couples had responsibility for children. The mean length of the relationship was $30$ years (range $2$ to $54$ years). Details on the stroke patients and the spouses are given in a previous report.15a

Psychological Well-Being of the Spouses

All dimensions in the PGWB except “general health” and the total score were significantly lower than normal population values with respect to age and sex (Table 1).

Multiple analyses of correlation were performed to study the association with (1) age and sex, (2) level of impairment of the stroke patients, and (3) intrapersonal variables such as psychological well-being, previous life satisfaction, and view of the future. The main results are outlined in the Figure.

The first analysis was conducted to investigate the associations between the neurological impairments and the BI of the stroke patients and the PGWB and view of the future of the spouses. The severity of sensorimotor impairment was associated with the PGWB dimensions of anxiety ($r_s=0.32$, $P=0.003$, 95% CI 0.11 to 0.50) and depressed mood ($r_s=0.36$, $P<0.001$, 95% CI 0.16 to 0.54), PGWB total score ($r_s=0.29$, $P=0.008$, 95% CI 0.08 to 0.48), and view of the future ($r_s=0.38$, $P<0.001$, 95% CI 0.18 to 0.55). The presence of apraxia was associated with the PGWB dimension of positive well-being ($r_s=0.32$, $P=0.004$, 95% CI 0.11 to 0.50). The BI was associated with the PGWB dimension of depressed mood ($r_s=0.32$, $P<0.003$, 95% CI 0.11 to 0.50) and view of the future ($r_s=0.41$, $P<0.001$, 95% CI 0.21 to 0.58). For details, see Table 2.

Most of the participants were satisfied with their previous life situation. The median score of life satisfaction ranged

<table>
<thead>
<tr>
<th>TABLE 1. Score for the PGWB Dimensions Versus Norm Values With Respect to Age and Sex (Transformed Data)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PGWB</td>
</tr>
<tr>
<td>--------------------</td>
</tr>
<tr>
<td>Total score</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>Depressed mood</td>
</tr>
<tr>
<td>Positive well-being</td>
</tr>
<tr>
<td>Self-control</td>
</tr>
<tr>
<td>General health</td>
</tr>
<tr>
<td>Vitality</td>
</tr>
</tbody>
</table>

n=82.
between 5 and 6 (satisfied/very satisfied) in all items of the scale.

The second analysis of correlations was concerned with the association between the spouses’ age, sex, psychological well-being, life satisfaction, and view of the future.

There were no associations between age or sex and the PGWB, view of the future, and satisfaction with life as a whole. However, there was a correlation between age and satisfaction with sexual life (younger persons were more satisfied than older persons) ($r = 0.32$, $P = 0.005$, $95\%$ CI $0.10$ to $0.51$) and between sex and satisfaction with one’s ability for self-care (women were more satisfied than men) ($r = 0.30$, $P = 0.006$, $95\%$ CI $0.09$ to $0.49$).

There were no associations between life satisfaction before the onset of stroke and PGWB or view of the future (Table 3). However, the association between the view of the future and all the dimensions of the PGWB was high (Table 4).

**Discussion**

Most of the spouses felt a decreased psychological sense of well-being during the first phase after the stroke. Although there were correlations between the sensorimotor impairment of the stroke patient and the spouse’s state of anxiety and depressed mood, the correlation between the BI and the PGWB total score was weak. In a previous study, the severity of stroke was found to be a predictor of caregivers’ depression during the first weeks after stroke. In contrast, another study did not show a correlation between the severity of injuries after trauma and well-being of the family. Thus, additional factors other than the objective state of impairments seem to be involved in the well-being of the spouse. Wade et al offered the hypothesis that caregivers of more disabled patients may be more upset initially because severe stroke would engender greater worry for the future. We found that the spouses’ cognitive appraisal of the future life situation and coping capacity had a strong association with their PGWB. This association may be an interrelated one. According to Lazarus, the cognitive activity of appraisal of the situation precedes emotions and the cognitive activity is later affected by the emotions. Spouses with an optimistic view of the future felt greater well-being. In previous studies, level of optimism has been found to be a predictor of depression in the acute state and in the long-term perspective.

The most common source of concern was uncertainty about the severity and prognosis of the disease and concerns about the impact on daily occupations. Schultz et al also

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### TABLE 2. Correlations Between the PGWB Index, View of the Future, and Neurological and Functional Characteristics of the Stroke Victims

<table>
<thead>
<tr>
<th>Neurolgical Characteristics</th>
<th>PGWB</th>
<th>Unconsciousness</th>
<th>Sensorimotor</th>
<th>Hemianopia</th>
<th>Visuospatial</th>
<th>Neglect</th>
<th>Aphasia</th>
<th>Apraxia</th>
<th>Barthel Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>0.02</td>
<td>-0.32*</td>
<td>-0.04</td>
<td>0.02</td>
<td>0.23</td>
<td>-0.03</td>
<td>-0.05</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>Depressed mood</td>
<td>0.23</td>
<td>0.36†</td>
<td>-0.07</td>
<td>0.04</td>
<td>0.12</td>
<td>-0.12</td>
<td>0.16</td>
<td>0.32*</td>
<td></td>
</tr>
<tr>
<td>Positive well-being</td>
<td>0.23</td>
<td>-0.25</td>
<td>-0.07</td>
<td>0.08</td>
<td>0.18</td>
<td>-0.19</td>
<td>0.32*</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>Self-control</td>
<td>0.11</td>
<td>-0.18</td>
<td>0.09</td>
<td>0.04</td>
<td>0.21</td>
<td>-0.09</td>
<td>0.09</td>
<td>0.18</td>
<td></td>
</tr>
<tr>
<td>General health</td>
<td>0.02</td>
<td>-0.13</td>
<td>0.04</td>
<td>0.02</td>
<td>0.13</td>
<td>-0.09</td>
<td>0.16</td>
<td>0.26</td>
<td></td>
</tr>
<tr>
<td>Vitality</td>
<td>0.02</td>
<td>-0.17</td>
<td>-0.08</td>
<td>0.08</td>
<td>0.13</td>
<td>-0.14</td>
<td>0.19</td>
<td>0.09</td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td>0.11</td>
<td>-0.29*</td>
<td>-0.06</td>
<td>0.03</td>
<td>0.21</td>
<td>-0.12</td>
<td>0.17</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>View of the future</td>
<td>0.23</td>
<td>-0.38†</td>
<td>0.06</td>
<td>0.11</td>
<td>0.26</td>
<td>-0.23</td>
<td>0.26</td>
<td>0.41†</td>
<td></td>
</tr>
</tbody>
</table>

Statistical analysis: Spearman’s rank correlation coefficient ($r_s$).

* $P<0.01$, † $P<0.001$, n=82.

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### TABLE 3. Correlations Among Satisfaction With Life Before the Onset of Stroke, the PGWB Index, and View of the Future

<table>
<thead>
<tr>
<th>Satisfaction With</th>
<th>PGWB, $r_s$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Anxiety</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>0.07</td>
</tr>
<tr>
<td>Ability to manage self-care</td>
<td>0.19</td>
</tr>
<tr>
<td>Leisure situation</td>
<td>0.18</td>
</tr>
<tr>
<td>Vocational/occupational</td>
<td>0.13</td>
</tr>
<tr>
<td>Financial situation</td>
<td>0.11</td>
</tr>
<tr>
<td>Sexual life</td>
<td>0.09</td>
</tr>
<tr>
<td>Partnership relations</td>
<td>0.07</td>
</tr>
<tr>
<td>Family life</td>
<td>0.09</td>
</tr>
<tr>
<td>Contacts with friends and</td>
<td>0.03</td>
</tr>
<tr>
<td>acquaintances</td>
<td></td>
</tr>
</tbody>
</table>

Statistical analysis: Spearman’s rank correlation coefficient ($r_s$).

* $P<0.01$, † $P<0.001$.  

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showed the negative impact that uncertainty has on well-being. Concern about future care has been found to be a predictive variable for depression during the first weeks, as well as 6 months, after a stroke.\(^6,25\) In contrast to a previous study,\(^26\) we did not find any significant correlation between the presence of aphasia and the PGWB, nor did we find any correlation between the spouses’ PGWB and impairment of the stroke patients such as visuospatial impairment and neglect. Persons with such impairments are often unaware of these during the acute stage.\(^27\) The impact of cognitive impairments on daily occupations is often first recognized by the family when the stroke patient enters a more complex context than the ward. This may also affect the perception of the spouses during the first phase of stroke. It may be assumed that the information the spouses received from the medical staff can have an impact on their view of the future. About 60% of the spouses in general, but the majority of the spouses of moderately/severely disabled stroke patients, perceived that they had received medical information about the stroke. However, regardless of whether the spouses reported that they had received information, about half of the study group still felt that they lacked information on the consequences of the stroke.

There was no association between age and well-being in the acute phase, which was also shown by Schultz et al.,\(^8\) nor was there any association between the PGWB and life satisfaction. The proportions of participants who were satisfied/very satisfied with life as a whole, ability for self-care, sexual life, partnership relation, and family life were similar to those of a large population sample.\(^28\) The feeling of satisfaction with the previous life might be affected by psychological well-being in the current situation. In a stressful life situation, the perception of the previous life may be more satisfying in contrast to the current situation. Our study did not indicate such associations, however.

A previous study has shown that refusal to participate was more common among persons with the highest level of stress and among those who did not feel themselves to have any symptoms.\(^29\) Similar reasons for refusal was given in the present study. It may be assumed that the level of the PGWB would have been even lower if all possible participants had been recruited into the study. The self-rating scales used in this study are frequently used in research, but no test for validity or reliability is available concerning the spouses of stroke patients. In several interviews, the spontaneous description of their experience indicated more emotional disturbance than is offered in the PGWB. This may depend on the well-known discrepancy between answering items in a questionnaire and in an interview, when the issues may stir up unpleasant or ambivalent emotions. Accordingly, it is less distressing to talk about the issue than to write down the answer on a piece of paper.\(^30\) This may have caused a bias in the result of the PGWB and affected the results in a more positive direction.

The data were collected during a long period of time. However, there were no major changes in the health care system or hospital organization that could have had an effect on the stroke population enrolled in the study. All participants were in the same ward during the time of data collection. Generally, data about the stroke patients were collected during the first week after stroke and the spouses were interviewed a few days later. The measurements made 19 to 27 days after the onset for 5 stroke patients were made so much later because these patients had been admitted to other hospitals in Europe in the first weeks. The medical records of these patients were collected from these hospitals. The functional ability of the stroke patients had not increased significantly, and the spouses perceived themselves to have a similar emotional status as during the first week after onset. We thus decided to include these stroke patients and spouses in the study. The perception of the future is a process that changes constantly over time. During the first period after a stressful event such as stroke, the perception of the consequences for the future may change from day to day as the status of the stroke patient changes and the coping process of the spouses continues. However, there was no trend in the spouse’s perception of his or her view of the future in association with time, during the first weeks after the event.

It should also be mentioned as a limitation to this study that it is not representative of an elderly stroke population. The reasons for including only patients younger than 75 years is that there is high comorbidity rate in elderly populations and changes in the social networks are common. We planned the study to focus on spouses’ experiences in the younger portion of the stroke population.

The main results of the study were that the study group showed significantly lower psychological well-being compared with norm values except for the dimension of general health. The level of disability of the stroke patients correlated with the spouses’ view of the future. The correlation between the view of the future and the PGWB was high. The results of the study agree with earlier results concerning spouses’ well-being during the first phase of stroke.\(^24\)

Tompkins et al.\(^25\) showed that caregivers’ depression during the first phase of stroke predicts later depression. It is therefore important to prevent any deterioration in psychological health at an early stage. To support an optimistic but realistic view of the future, the staff must take into account the spouses’ individual appraisal of the disease, of the impact on their daily activities, and of their own coping capacity.

Other variables that require further investigation may also affect the well-being of the spouses, such as the impact of

<p>| TABLE 4. Correlations Between the PGWB Index and View of the Future |
|--------------------------|--------------------------|</p>
<table>
<thead>
<tr>
<th>PGWB</th>
<th>View of the Future</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score</td>
<td>0.79* 69%–69%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.68* 54%–78%</td>
</tr>
<tr>
<td>Depressed mood</td>
<td>0.74* 62%–83%</td>
</tr>
<tr>
<td>Positive well-being</td>
<td>0.73* 61%–82%</td>
</tr>
<tr>
<td>Self-control</td>
<td>0.69* 56%–79%</td>
</tr>
<tr>
<td>General health</td>
<td>0.56* 39%–69%</td>
</tr>
<tr>
<td>Vitality</td>
<td>0.58* 41%–71%</td>
</tr>
</tbody>
</table>

Statistical analysis: Spearman’s rank correlation coefficient (rs).

\(^*P<0.001, n=82.\)
one’s own health, experience of previous critical life events, and internal and external coping resources. There also is a need for longitudinal studies to follow up the changes in daily life and for coping resources during different stages in the coping process.

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References
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