Psychological Well-Being 3 Years After Severe Stroke

Britta Löfgren, OT, MSc; Yngve Gustafson, MD, DMSc; Lars Nyberg, RPT, PhD

Background and Purpose—Stroke often has a very negative influence on the victims’ perception of their life situation. The aim of this study was therefore to assess the subjects’ long-term psychological well-being and to explore associations between subject characteristics, impairments, disabilities, and psychological well-being.

Methods—Of 100 subjects rehabilitated at a specialized geriatric stroke ward after the acute phase, 47 survivors were assessed in their homes 3 years after discharge and interviewed regarding their psychological well-being with the Philadelphia Geriatric Center Morale Scale (PGCMS).

Results—Sixty-four percent of the subjects were classified as having high scores for psychological well-being or fell within the middle range. In a cluster analysis, depression was shown to have the strongest association with the subjects’ PGCMS scores. Variables including the subjects’ social situation and functions as well as age, gender, ability to communicate, and need for help showed a much weaker association with the PGCMS.

Conclusions—More than half of the stroke subjects were classified as having levels of psychological well-being that were good or fairly good. The strong association between PGCMS scores and depression indicates the importance of detecting and treating depression and of following up initiated therapy after stroke. (Stroke. 1999;30:567-572.)

Key Words: depression ■ follow-up studies ■ morale ■ rehabilitation

Stroke brings a sudden and unexpected change to the victims’ life situation, with more or less serious and lasting disabilities, functional impairments, and complications as its consequences contributing to these changes. Furthermore, the victims’ roles in the family and among friends may change because of these consequences, which may in turn lead to further distress. Studies describing stroke victims’ quality of life or life satisfaction from a long-term perspective have been performed, and it has been shown that they are less satisfied than the nonstroke control groups. These studies have found that depression, functional disability, impaired social network, gender, larger volume of infarcts, and severity of aphasia contributed to poor quality of life. However, comparisons among studies of quality of life are difficult because different kinds of measurements with varying conceptual bases, terminology, and definitions are used when these aspects are measured. The subject selection criteria also constitute an additional problem when results are compared. This study focuses on severely affected stroke victims because one would assume that the consequences of a severe stroke will strongly influence a person’s quality of life or psychological well-being.

The fact that, after a stroke, the life situation changes rapidly and often involves major consequences for the affected person implies that the ability to find any future life meaningful is important in mobilizing energy for rehabilitation. This ability probably depends on individual morale, one important aspect of an individual’s psychological well-being.

Lawton has developed a multidimensional measure to assess morale, namely, the Philadelphia Geriatric Center Morale Scale (PGCMS). This scale is intended to be practicable in the assessment of very old people since it uses simple wording and has only 2 response alternatives. The definition of morale used by the authors is “freedom from distressing symptoms and a basic sense of satisfaction with oneself.” The latter part is explained as that in which a person has “a feeling of having attained something in his life, of being useful now, and thinks of himself as an adequate person.” Another component of the definition of high morale is a “feeling of syntony between self and environment,” which means “a fit between personal needs and what the environment offers.” An additional component is the “ability to strive appropriately while still accepting the inevitable,” meaning “a certain acceptance of what cannot be changed.” Additional characteristics of many people who are of high morale are also that they are active, sociable, and optimistic in outlook.

In view of the stress to which stroke victims are exposed, one would assume that their capacity to handle their new life situation would be closely dependent on their morale. It would therefore be interesting to assess the subjects’ long-term psychological well-being, on the basis of the above definition of morale, and to explore associations between subject characteristics, impairments, disabilities, and psychological well-being.
Subjects and Methods
The study comprised a 1-year sample of stroke patients admitted consecutively from November 1991 to October 1992 to a specialized geriatric stroke rehabilitation ward at the University Hospital, Umeå, Sweden.7 These severely affected survivors, accounting for approximately one third of those admitted as emergency cases to the hospital for stroke in the Umeå catchment area, usually had extensive pareses and/or cognitive problems, such as recurrent episodes of delirium.8 They could not be discharged without further rehabilitation after the acute phase. Their median Katz activities of daily living (ADL) score on admission to the rehabilitation ward, an average 3 weeks after the onset of stroke, was E, ie, dependent in 4 of the 6 ADL activities.9 They could not be discharged without further rehabilitation because of mobility and balance problems. Of 100 subjects followed up, 57 were still alive and eligible for follow-up 3 years after their stroke. The reliability estimate including only 1 of the ADL activities. One of these fairly ADL-independent subjects had episodes of delirium, and 2 had problematic social or living situations, which meant that they needed further support in solving these problems. The remaining 4 needed further rehabilitation because of mobility and balance problems. Of 100 subjects discharged from the unit during 1 year, 57 were still alive and eligible for follow-up 3 years after their stroke.

The study was approved by the Ethics Committee of Umeå University. Informed consent was sought by telephone from the subjects themselves and in a few cases from their relatives. Two subjects declined to participate. The remaining 55 subjects were visited in their homes by a physician (Y. Gustafson or M. Mattsson) and an occupational therapist (B.L.). Comprehensive clinical assessments were made by the same physicians who had been responsible for the subjects during their inpatient rehabilitation. Forty-seven of the subjects followed up could answer the PGCMS questions, and their characteristics are shown in Table 1. Interviews were used in the assessment of the PGCMS. Five of the 8 subjects who could not answer the PGCMS questions had sustained severe dysphasia and thus could not be properly cognitively assessed either. One additional subject could not complete the Mini-Mental State Examination (MMSE) assessment and could not therefore be reliably assessed with the PGCMS. Six of these subjects were dependent in 4 of the 6 ADL activities.

Assessments at follow-up were made with the following instruments: (1) the British-English version of the PGCMS, translated into Swedish; (2) the Montgomery-Åsberg Depression Rating Scale (MADRS) for rating depression; (3) the Katz ADL index; (4) the MMSE; and (5) the Brunnström–Fugl-Meyer Scale.

The Royal College of Physicians, London, and the British Geriatrics Society recommend the PGCMS for assessment of subjective well-being in elderly subjects.10 It is designed to provide a measure of morale or psychological well-being appropriate for very old or less competent individuals. Three factors represent the dimensions of psychological well-being: agitation, attitude toward own aging, and lonely dissatisfaction. The agitation factor reflects symptoms of anxiety and dysphoric mood elements. The second factor concerns attitude toward the aging process experienced by the older person as well as the perception of changes in life and the evaluation of those changes. The factor lonely dissatisfaction represents the acceptance or dissatisfaction with the social interaction experienced. The scale includes 17 items, and the score ranges from 0 to 17. In the Administration and Scoring Instructions for the scale, the designer suggests that scores of 13 to 17 would fall within the middle of the scale, whereas 0 to 12 would fall within the low end of the scale. The scale was translated into Swedish according to a method especially developed for the cross-cultural adaptation of health-related quality of life measures.11 Interrater reliability estimates for the Swedish version, including use for patients in a geriatric clinic, were performed and found to be satisfactory (r = 0.86) (L. Nyberg, RPT, PhD, et al, unpublished data, 1999). In that study, almost half the patients had sustained a stroke, and the reliability estimate including only these patients was r = 0.91. Furthermore, the values for internal consistency, as determined by Cronbach's α, of the 3 factors agitation, attitude toward own aging, and lonely dissatisfaction have been found to be 0.85, 0.81, and 0.85, respectively.
The MADRS\textsuperscript{12} for rating depression consists of 10 items with a score ranging from 0 to 6 for each item. The higher the scores, the more severe is the depression. When comparing rating scales for depression in stroke victims, Agrell and Dehlin\textsuperscript{13} found the MADRS most valid and reliable. They reported an external validity of $r=0.86$, and the $\alpha$ coefficient of internal consistency was 0.89. Montgomery and Asberg have reported interrater reliability ranging from $r=0.89$ to $r=0.97$ in other patient groups.\textsuperscript{12} The criteria of MADRS and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition\textsuperscript{14} (DSM-IV) were used for diagnosing the variable “ongoing depression.” The subjects were then divided into 4 groups according to the presence of depression and pharmacological treatment for depression. These groups were (1) subjects with no symptoms or signs of depression, (2) subjects who were successfully treated for their depression, (3) subjects receiving antidepressant treatment but not responding (unsuccessfully treated), and (4) subjects who although depressed were not receiving treatment for depression.

The Katz ADL index\textsuperscript{9} included 6 items: bathing, dressing, toileting, transfer, continence, and feeding. The score ranges from A to G; A indicates independence in all 6 activities, and G indicates total dependence. O is used for unclassifiable cases.

The MMSE\textsuperscript{15} includes orientation, registration, attention and calculation, recall, language, and copying. The maximum score is 30, and a score of $\leq 23$ indicates significant cognitive impairment.

The Brunnström–Fugl-Meyer Scale\textsuperscript{16} includes motor function, postural stability, sensory function, and range of motion. The maximum scores for either side of the body are 100 for motor function, 24 for sensory function, and 40 for range of motion. In this study, scores from the right and left sides were added together. The maximum score for postural stability is 14.

In addition, the subjects’ gender, age, and living conditions were noted. The presence or absence of home help service or help from relatives or others was also recorded. Whether the subjects had impaired vision or hearing was recorded, ie, whether the subjects could not, with or without spectacles, read a 5-mm block letter text at reading distance or could not apprehend normal voice conversation at 1 m of distance. The presence of diabetes and dysphasia was also registered. Diabetes was diagnosed if a subject had any type of treatment for diabetes (diet, drug, or insulin), and dysphasia was defined as a defect (or loss) of the power of expression through speech, writing, or signs or of comprehending spoken or written language.

SPSS statistical software\textsuperscript{17} was used to analyze the data. The cluster analysis technique was preferred to conventional regression analyses since this was a cross-sectional explorative study aimed at identifying associations between variables rather than predicting the subject’s psychological well-being. Spearman correlation matrices were performed to discover correlations between the PGCMS and subject characteristics. Variables showing correlations of $>0.30$ and variables that, a priori, could be presumed to strongly affect one’s psychological well-being were then included in a hierarchic cluster analysis to find variables or homogeneous groups of variables that interacted with the PGCMS. The between-groups linkage cluster method measured with Pearson’s correlation was preferred because it uses information about all pairs of distances, not just the nearest or the farthest. The absolute value of the coefficient was used since as it uses information about all pairs of distances, not just the nearest or the farthest. The nearer the origin (0), ie, the farther to the left, the cluster combines, the stronger is the correlation between the variables. When the cluster analysis was performed, the PGCMS scores (range, 0 to 17) were used without their division into subscales.

### Results
It was possible to assess 47 subjects with the PGCMS. More than half of them (64%) showed high or middle-range scores for psychological well-being (Table 2).

The answers classified under the 3 factors suggested by Lawton—agitation, attitude toward own aging, and lonely dissatisfaction—are also shown in Table 2. These figures show that the factors agitation and lonely dissatisfaction had more answers indicating good psychological well-being than the factor attitude toward own aging.

The correlations between the PGCMS and the subjects’ characteristics are described in Table 1. The depression rating scale and the dichotomous rating of being or not being depressed emerged as the variables most closely correlated with the PGCMS scores. This study also showed that depression was a prevalent comorbidity 3 years after severe stroke ($n=26; 55\%$). This figure includes 8 subjects who were not depressed at follow-up but were receiving treatment for depression.

The hierarchical cluster analysis that was performed to discover associations between subject characteristics and the PGCMS is shown in the Figure. The analysis resulted in 6 identifiable groups or clusters of variables. The first cluster, encompassing psychological factors, consisted of the variables MADRS, being or not being depressed, and the PGCMS. The second included the social variables cohabiting and whether or not the subjects were living in their own houses or apartments. Functional variables formed the third cluster, comprising postural stability, motor function, ADL, range of motion, and cognition (MMSE). A fourth cluster included the variables gender and diabetes. The variables impaired vision, impaired hearing, and dysphasia, which could all be assumed to affect a person’s ability to communicate, were included in the fifth cluster. Finally, the sixth cluster comprised the variables age, home help service, and help from relatives or neighbors, of which the last 2 represents a person’s state of dependence. It appears from the cluster analysis that the MADRS scores and being depressed showed the strongest association with low PGCMS scores since they clustered in combination to the scale near the origin. The other variables showed a much weaker correlation to the scale since the 5 remaining clusters joined the first cluster, and thus the PGCMS, at a much greater distance from the origin.

The state of being or not being depressed was closely correlated to the PGCMS score. Table 3 shows the relationship between the PGCMS classification groups and depression. It can be seen that none of the subjects in the high

### Table 2. PGCMS Scores for Stroke Survivors at 3-Year Follow-Up ($n=47$)

<table>
<thead>
<tr>
<th>PGCMS, total score (range, 0–17)</th>
<th>Median</th>
<th>Q1–Q3</th>
<th>No. %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of persons with</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High PGCMS (scores 13–17)*</td>
<td></td>
<td></td>
<td>20 43</td>
</tr>
<tr>
<td>Middle-range PGCMS (scores 10–12)*</td>
<td></td>
<td></td>
<td>10 21</td>
</tr>
<tr>
<td>Low PGCMS (scores 0–9)*</td>
<td></td>
<td></td>
<td>17 36</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subscales</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitation (range, 0–6)</td>
<td>5 3–5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitude toward own aging (range, 0–5)</td>
<td>2 1–4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lonely dissatisfaction (range, 0–6)</td>
<td>5 3–6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*High, middle-range, and low PGCMS scores according to Lawton.\textsuperscript{6}
PGCMS group was depressed, while the corresponding figure for the subjects in the low group was 15 of 17.

Further analyses showed that people who were not depressed or were being successfully treated with drugs for depression had higher PGCMS scores than those who were depressed but were receiving no treatment and those who were not responding to treatment (Table 4).

Discussion
In this study, the main findings were that more than half the subjects had high or middle-range scores for psychological well-being. They seemed free from agitation and satisfied with their social interaction but were less content with their aging process. The results also showed that low scores seemed to be closely linked to depression.

We found that even if many of the subjects studied had high or middle-range PGCMS, there were also a significant number of subjects who were assessed as having poor psychological well-being. No other long-term follow-up studies of stroke victims could be found that used the PGCMS, as was done in this study. However, we have found 2 studies that examine stroke victims’ life satisfaction late after stroke. Åström et al2 reported that 64% of their subjects, 3 years after stroke, found their global life satisfaction fair or good, while Viitanen et al18 reported that 82% of their stroke population were very satisfied or rather satisfied with their life in general, 4 to 6 years after stroke. However, these studies included less affected and younger subjects and used other rating scales. Nevertheless, the psychological well-being of the stroke victims in this study must be considered reduced compared with a study of a general population19 using the PGCMS, which reported that 91% of the subjects had high scores or fell within the middle range. However, since more than half the subjects in this study were assessed as having high or middle-range scores for psychological well-being, it seems possible for even severely affected stroke victims to cope with life changes after stroke.

The subjects’ attitudes toward the aging process are reflected in the low frequency of answers indicating good psychological well-being to the questions concerning the factor attitude toward own aging. The consequences of their stroke may have contributed to changes in their earlier conceptions of their own aging. These changes can be hard to cope with since often one not only must reassess one’s roles in relation to the environment but must also accommodate the fact that the claims and expectations from the environment change. On the other hand, they seemed free from anxiety and satisfied with their social interaction, which indicates that they feel confident and are taken good care of in their daily lives. Their answers also indicate that they consider their relationships with relatives and friends to be satisfactory.

This study also showed that depression was closely linked to low psychological well-being, but low scores were also found in some subjects without depression. The negative impact of depression on stroke survivors’ quality of life or life satisfaction has also been described in earlier studies2,3,20 Our results indicate that it seems important to detect and treat depression to increase the psychological well-being of stroke victims.

### Table 3. Relationship Between PGCMS Scores and Depression* (n=47)

<table>
<thead>
<tr>
<th>PGCMS</th>
<th>Depressed</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td>High PGCMS (scores 13–17)</td>
<td>0</td>
<td>20</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Middle-range PGCMS (scores 10–12)</td>
<td>3</td>
<td>7</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Low PGCMS (scores 0–9)</td>
<td>15</td>
<td>2</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>29</td>
<td>47</td>
<td></td>
</tr>
</tbody>
</table>

*The definition of ongoing depression is in accordance with the DSM-IV criteria and measured by the MADRS.

### Table 4. Depression and Pharmacological Treatment for Depression in Relation to PGCMS Scores (n=47)

<table>
<thead>
<tr>
<th>PGCMS</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>No depression (n=21)</td>
<td>14</td>
<td>7–17</td>
</tr>
<tr>
<td>Successfully treated depression (n=8)</td>
<td>12.5</td>
<td>6–16</td>
</tr>
<tr>
<td>Unsuccessfully treated depression (n=4)</td>
<td>5.5</td>
<td>3–11</td>
</tr>
<tr>
<td>Untreated depression (n=14)</td>
<td>7</td>
<td>2–11</td>
</tr>
</tbody>
</table>
victims, especially since drugs with fewer side effects are now available. Depression is a common (30% to 60%) and long-lasting consequence of stroke, as was found in this study (55%). Recurrent assessment for depression should therefore be performed even several years after stroke. Furthermore, the findings show that it is equally important to follow up and evaluate the treatment for depression so that the best possible effect can be achieved.

However, other circumstances describing a person’s life, such as social situation, impairments, and disabilities, did not appear to influence stroke survivors’ psychological well-being to any great extent. If this were the case, one could presume that living with someone or managing to ambulate and to perform ADL independently would increase a person’s psychological well-being. Similarly, one might think that the ability to communicate and lack of dependence on other people would be associated with good psychological well-being, but the results of this study could not support this assumption.

Several measures with different conceptual bases have been used to describe psychological well-being. The terms morale, life satisfaction, quality of life, and psychological well-being have often been used interchangeably, which may lead to some confusion. In this study we have accepted Lawton’s concept of morale, which has been previously described in this article, as the definition of psychological well-being. Morris et al performed a study seeking common themes among morale (PGCMS) and depression and suggest that depression and low morale, to some degree, represent an equivalent mood. However, they also found that the questions in the factor concerning the attitude toward the aging process represented an independent theme. This latter finding and the fact that this study included subjects who had low PGCMS scores without being depressed indicate that the conceptual bases of psychological well-being and depression are not identical. Furthermore, depression is often considered in a dichotomous manner (depressed or not depressed) according to DSM-IV criteria, while psychological well-being is comprehended as spanning a range. Psychological well-being can also be understood from a social perspective rather than within a medical framework.

In research studies it is important to choose valid and reliable measures, but it is also essential to use measures that minimize loss of data. Assessing stroke victims with inappropriate measures involves risks of dropouts due to cognitive and communication impairments. This in turn causes an undesirable subject selection and thus less valid data. The PGCMS was constructed as an appropriate measure of morale among the very old. To make the questions comprehensible to very old subjects, they were phrased as simply as possible without multiple clauses, difficult vocabulary, or several response alternatives. The length of the scale was also limited so that it would not cause fatigue or inattention. Furthermore, a study including cognitively impaired persons who had retained verbal skills showed that most of the subjects were able to respond to a verbally administered assessment using the PGCMS. Therefore, it can probably be asserted that this scale is an appropriate measure of the psychological well-being of stroke victims. From assessments and interviews, the investigators also understood that the PGCMS score agreed with the subjects’ situations. The MADRS can also be regarded as an appropriate measure and has often been used when depression in cognitively impaired persons is assessed. However, 8 subjects could not be assessed, even with the PGCMS, in a manner that could be considered appropriate for this sample.

Although this study did not include a large number of subjects, it has provided information about stroke victims’ psychological well-being in the long term and has led to further questions about this issue that could not be answered here. For example, is psychological well-being as defined in this study stable or changeable over the course of time? In addition, do subjects with good psychological well-being improve more from initial stroke rehabilitation than subjects with lower scores? Future studies on this issue should therefore include assessments from the initial rehabilitation period as well as assessments of depression since this was found to be strongly associated with psychological well-being.

In conclusion, despite the fact that they were initially severely affected by stroke, more than half the subjects in this study seemed to have good or fairly good psychological well-being. However, the strong association between psychological well-being and depression indicates that it is important to detect and treat the latter to increase the psychological well-being of stroke victims. The fact that there were depressed subjects who were not responding to treatment also points to the necessity of following up the initiated therapy.

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References


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