Quality of Life 4 Years After Stroke

Marja-Liisa Niemi, MA, Ritva Laaksonen, MA, Mervi Kotila, MD, and Olli Waltimo, MD

The quality of life for 46 stroke survivors under the age of 65 years in a stroke register was studied 4 years after their first stroke. A questionnaire covering four domains of life (working conditions, activities at home, family relationships, and leisure time activities) was used for investigation of the quality of life. The results showed that in spite of a good recovery in terms of discharge from the hospital, activities of daily living, and return to work, the quality of life of most patients (83%) had not been restored to the prestroke level. Deterioration among the several domains of life ranged from 39% to 80%, the lowest being in the domain of activities at home and the highest in the domain of leisure time activities. Hemispheral localization of the lesion, paresis, coordination disturbances, and especially subjective tendency to depression were highly correlated with a deterioration in the quality of life. Dependence in activities of daily living and an inability to return to work were also associated with the lack of restoration. Our results suggest that much more attention should be paid to the quality of life of stroke patients.

(Stroke 1988;19:1101–1107)

Stroke is a major, chronically disabling neurologic disease that often radically and permanently changes the lives of its victims. Medical treatment and occupational and physical therapy have been used to help stroke patients. Discharge from the hospital and the degree of independence achieved in activities of daily living (ADL) have been the usual criteria used to measure the success of rehabilitation. Although many studies have shown that stroke rehabilitation can help a patient to regain and maintain functional abilities, the efficacy of therapeutic interventions has been questioned. However, little attention has been given to the quality of life following expensive, often long treatment. As Feigenson points out, “unless this factor is considered, any statistics used in analysing the benefits of treatment are incomplete and misleading.”

Although the concept has been only loosely defined, there is agreement that quality of life refers to a person’s subjective well-being and life satisfaction and that it includes mental and physical health, material well-being, interpersonal relationships within and outside the family, work and other activities in the community, personal development and fulfillment, and active recreation. Despite the fact that the basic definition of quality of life seems to apply to most people, there is a need to focus its evaluation directly on the problems created by illness and disability. The aim of our study was to investigate the quality of life in relation to recovery from stroke.

Subjects and Methods

A stroke register was maintained in southern Finland in the towns of Espoo and Kauniainen from April 1, 1978, to March 31, 1980. A total of 255 cases of first stroke were registered. Details of the register are described elsewhere. Young patients (under the age of 65 years) were chosen for detailed follow-up examinations. Due to poor health, refusal, or other reasons, all young patients were not investigated. As described elsewhere, 66 of the 77 surviving young patients were examined neurologically and neuropsychologically 3 months after their stroke. Seven of the 66 patients died after the first year, and 52 of the 59 surviving patients were examined again 4 years after their stroke. Our study is based on the 46 surviving patients who were able to reply to the quality of life questionnaire at the 4-year examination. Of the six patients who could not answer the questions, three had severe aphasia, two were demented, and one refused. In all, we studied 27 (59%) men and 19 (41%) women. Their ages ranged from 17 to 64 years at the time of their stroke, with a mean of 48 years. The distribution of diagnoses and lesion locations are presented in Table 1.

The outcome used in assessing the recovery from stroke were 1) discharge from the hospital, 2) inde-
TABLE 1. Distribution of Diagnoses and Lesion Locations in 46 Patients With First Stroke

<table>
<thead>
<tr>
<th>Lesion location</th>
<th>Subarachnoid hemorrhage</th>
<th>Intracerebral hemorrhage</th>
<th>Brain infarction</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right hemisphere</td>
<td>0</td>
<td>1</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Left hemisphere</td>
<td>2</td>
<td>2</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>Brainstem</td>
<td>1</td>
<td>0</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>No localized lesion</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>3</td>
<td>32</td>
<td>46</td>
</tr>
</tbody>
</table>

Data are number of patients.

Results

The outcome of the 46 patients between the 3-month and the 4-year examinations indicated a high grade of recovery. At the 4-year examination, 98% (45) of the patients were living at home, 87% (40) were independent in ADL, and 54% (21) of the 39 patients gainfully employed before their stroke had returned to work.

Despite the good recovery indicated, the quality of life of the patients was not restored, but showed deterioration in 83% (38) of the patients. In 2% (one patient) there was restoration, and in 15% (7) there was improvement in the quality of life (Figure 1). Deterioration among the domains ranged from 39% in activities at home to 80% in leisure time activities.

Table 4 summarizes the main findings in relation to the quality of life. When recovery was analyzed, patients who were independent in ADL almost as often had a deteriorated quality of life over all four domains as did the dependent patients (32 of 40 vs. 6 of 6). However, when the severity of the deterioration (end-measure) was considered, the beneficial effect of independence showed clearly (Table 4). The beneficial effect of independence was seen in each of the four domains.

Four years after their stroke, 89% (eight of nine) employed patients with subarachnoid hemorrhage (SAH), 67% (two of three) employed patients with intracerebral hemorrhage, and 41% (11 of 27) employed patients with brain infarction had returned...
TABLE 2. Domains of Life and Questions in Each Domain—Questionnaire on Quality of Life After Stroke

<table>
<thead>
<tr>
<th>Working conditions</th>
<th>Activities at home</th>
<th>Family relationships including close personal relationships and sexual patterns</th>
<th>Leisure time activities in and outside home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working conditions</td>
<td>Activities at home</td>
<td>Family relationships including close personal relationships and sexual patterns</td>
<td>Leisure time activities in and outside home</td>
</tr>
<tr>
<td>(-6 to 6)</td>
<td>(-11 to 11)</td>
<td>(-11 to 11)</td>
<td>(-17 to 17)</td>
</tr>
<tr>
<td>Employment</td>
<td>Participation in preparation of meals</td>
<td>Participation in family decision-making (major investments, loans, and so on)</td>
<td>Participation or interest in:</td>
</tr>
<tr>
<td>Work satisfaction</td>
<td>If living alone, preparation of meals</td>
<td>If living alone, independent decision-making (major investments, loans, and so on)</td>
<td>Outdoor activities (walking, camping, swimming, games, etc.)</td>
</tr>
<tr>
<td>Attitudes of fellow workers toward you</td>
<td>Participation in cleaning</td>
<td>If living alone, cleaning</td>
<td>Family festivities or other occasions arranged by relatives</td>
</tr>
<tr>
<td>Attitudes of supervisors toward you</td>
<td>Participation in laundry</td>
<td>Participation in laundry</td>
<td>Parties arranged by friends or acquaintances</td>
</tr>
<tr>
<td>Own attitudes toward fellow workers</td>
<td>Participation in shopping and major purchases</td>
<td>Participation in important family matters (educational affairs, future plans, use of free time)</td>
<td>Going dancing</td>
</tr>
<tr>
<td>Own attitudes toward supervisors</td>
<td>If living alone, laundry</td>
<td>Participation in taking care of family business (paying bills, financial matters)</td>
<td>Going to movies, theaters, concerts, etc.</td>
</tr>
<tr>
<td></td>
<td>Participation in shopping and major purchases</td>
<td>If living alone, taking care of family business (paying bills, financial matters)</td>
<td>Attending clubs, meetings of professional organizations or charitable societies</td>
</tr>
<tr>
<td></td>
<td>Participation in child care (supervision of homework, free-time activities, and so on)</td>
<td>Participation in important family matters (educational affairs, future plans, use of free time)</td>
<td>Political activities or occasions</td>
</tr>
</tbody>
</table>

Poststroke questions are same as prestroke questions with altered verb tense. Difference (before stroke—after stroke) for each question was coded as -1, deterioration; 0, restoration; and 1, improvement. Coded differences within each domain were totaled, indicating amount of restoration within each domain. Cumulative sum of differences in all domains gave end-measure of quality of life (-45 to 45).

to work. All previously employed patients who were unable to return to work had a deteriorated quality of life; the frequency and severity of deterioration differed significantly from that of patients who had returned to work (Table 4).

In the diagnostic groups, patients with SAH significantly more frequently had a restored or improved quality of life than patients with brain infarction. The SAH patients also had significantly milder deterioration (higher end-measure) than did the brain infarction patients (Table 4). The same difference was also seen in the individual domains of family relationships and leisure time activities.

The patients with right- and left-hemisphere lesions had most often, and most severely, a deteriorated quality of life. Patients with no localizable lesion and patients with a brainstem lesion had only mild deterioration (Table 4). In regard to individual

**TABLE 3. Changes in Quality of Life 4 Years After Stroke by Domain**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Deteriorated</th>
<th>Restored</th>
<th>Improved</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Mean</td>
<td>No.</td>
</tr>
<tr>
<td>Working conditions*</td>
<td>-6 to 3</td>
<td>-2.4</td>
<td>23</td>
</tr>
<tr>
<td>Activities at home</td>
<td>-8 to 5</td>
<td>-1.2</td>
<td>18</td>
</tr>
<tr>
<td>Family relationships including close personal relationships and sexual patterns</td>
<td>-9 to 8</td>
<td>-1.5</td>
<td>25</td>
</tr>
<tr>
<td>Leisure time activities in and outside home</td>
<td>-16 to 3</td>
<td>-4.3</td>
<td>37</td>
</tr>
<tr>
<td>Overall quality of life</td>
<td>-31 to 15</td>
<td>-9.1</td>
<td>38</td>
</tr>
</tbody>
</table>

*39 of 46 patients were gainfully employed before stroke.
TABLE 4. Findings of Central Variables in Relation to Quality of Life After Stroke

<table>
<thead>
<tr>
<th>Variables</th>
<th>Quality of life over all four domains</th>
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<th></th>
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<tr>
<td></td>
<td></td>
<td>Deteriorated</td>
<td>Restored/Improved</td>
<td>Total</td>
<td>End-measure</td>
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<tr>
<td>Recovery</td>
<td></td>
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<td>%</td>
<td>No.</td>
<td>%</td>
<td>No.</td>
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<tr>
<td>Activities of daily living</td>
<td></td>
<td>32</td>
<td>80</td>
<td>8</td>
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<td>40</td>
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<tr>
<td>Independent</td>
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<td>0</td>
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<tr>
<td>Work§</td>
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<td>15</td>
<td>71</td>
<td>6</td>
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<tr>
<td>Returned</td>
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<tr>
<td>Diagnosis (intracerebral hemorrhage not included)</td>
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<td>Subarachnoid hemorrhage</td>
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<td>6</td>
<td>55</td>
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<td>45</td>
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<td>Brain infarction</td>
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<td>30</td>
<td>94</td>
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<td>Lesion localization</td>
<td></td>
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<td>Right hemisphere</td>
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<td>11</td>
<td>92</td>
<td>1</td>
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<tr>
<td>Left hemisphere</td>
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<td>16</td>
<td>94</td>
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<tr>
<td>Brainstem</td>
<td></td>
<td>8</td>
<td>89</td>
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<td>9</td>
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<tr>
<td>No localizable lesion</td>
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<td>3</td>
<td>37</td>
<td>5</td>
<td>63</td>
<td>8</td>
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<tr>
<td>Age</td>
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<td></td>
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<tr>
<td>Younger (17-50 yr)</td>
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<td>18</td>
<td>78</td>
<td>5</td>
<td>22</td>
<td>23</td>
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<tr>
<td>Older (51-64 yr)</td>
<td></td>
<td>20</td>
<td>87</td>
<td>3</td>
<td>13</td>
<td>23</td>
</tr>
<tr>
<td>Sex</td>
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<td></td>
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<td></td>
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<td>85</td>
<td>4</td>
<td>15</td>
<td>27</td>
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<tr>
<td>Female</td>
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<td>15</td>
<td>79</td>
<td>4</td>
<td>21</td>
<td>19</td>
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<td>Residual neurologic disturbances</td>
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<tr>
<td>Hemiparesis</td>
<td></td>
<td>29</td>
<td>78</td>
<td>8</td>
<td>22</td>
<td>37</td>
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<tr>
<td>Yes</td>
<td></td>
<td>9</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>9</td>
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<tr>
<td>Coordination disturbances</td>
<td></td>
<td>15</td>
<td>65</td>
<td>8</td>
<td>35</td>
<td>23</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>23</td>
<td>100f</td>
<td>0</td>
<td>0</td>
<td>23</td>
</tr>
<tr>
<td>Dysphasia</td>
<td></td>
<td>33</td>
<td>83</td>
<td>7</td>
<td>17</td>
<td>40</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>5</td>
<td>83</td>
<td>1</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>Tendency to depression</td>
<td></td>
<td>32</td>
<td>67</td>
<td>8</td>
<td>33</td>
<td>24</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>22</td>
<td>100f</td>
<td>0</td>
<td>0</td>
<td>22</td>
</tr>
</tbody>
</table>

*tp<0.001, 0.01, 0.05, respectively.
§39 of 46 patients were gainfully employed before stroke.

domains, patients with right- and left-hemisphere lesions also had marked deterioration in family relationships and leisure time activities.

Older patients (51-64 years) had a deteriorated quality of life as often as younger patients. However, the deterioration for older patients was significantly more severe than that for younger patients (Table 4). Age especially affected leisure time activities.

Men had a more severe deterioration in the quality of life than women, but the difference was not significant (Table 4). The most marked difference between men and women was in the domain of leisure time activities.

At the 4-year examination only 20% (nine) of the patients had marked residual hemiparesis; all nine had a deteriorated quality of life, and the deterioration was much more severe than that of patients with no paresis (Table 4). The effect of paresis was seen in all four individual domains.

Although hemiparesis had mostly disappeared, half the patients still had coordination disturbances. All 23 patients with coordination disturbances also had a deteriorated quality of life, but of those without such disturbances, only 63% (15) had deteriorated. The difference in the severity of the deterioration between these groups was very highly significant (Table 4). This trend was also seen within each domain.

At the 4-year examination, nine of the 52 patients examined had dysphasia; three had such severe aphasia they could not fill out the questionnaire and were excluded from this study. For the six patients with dysphasia who were included, the mean end-measure for quality of life was not different from that of patients without speech difficulties (Table 4); one patient with mild dysphasia had a restored quality of life.

Analysis of the additional questions concerning subjective changes in behavioral competence and personality showed that the symptoms most often reported were tiredness (65% of the patients), difficulties in ambulation (57%), irritability (50%), and tendency to depression (48%); persistent depres-
The amount of variance of the quality of life explained

<table>
<thead>
<tr>
<th>Variables in the equation</th>
<th>0.10</th>
<th>0.20</th>
<th>0.30</th>
<th>0.40</th>
<th>0.50</th>
<th>0.60</th>
<th>0.70</th>
<th>0.80</th>
<th>0.90</th>
<th>1.0 RSQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>tendency to depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Discussion
The aim of our register-based study was to provide information about variables influencing the quality of life after stroke. Of 52 patients in the 4-year follow-up, 46 were able to fill out the questionnaire. Of the six patients who could not answer the questions, three had severe aphasia, two were demented, and one refused. The questionnaire used for the study of the quality of life was comprehensive, with a high degree of reliability and good validity.

Our results showed that despite good recovery in terms of discharge from the hospital, ADL, and return to work, the quality of life of most patients was not restored to the prestroke level. The high percentage deterioration (83%) may to some extent be an overestimation because even the smallest negative differences (−1 to −5 in nine patients, Figure 1) were considered deterioration.

The percentage deterioration of the quality of life in our series is in good agreement with recent results.18,20–22 Using a visual analogy scale, Ahlsio and coworkers20 found that 2 years after cerebrovascular accident 77% of the patients reported a decrease in the quality of life, a decrement which had been seen at the acute stage. In a long-term follow-up study, Trudel and coworkers21 found that only 20% of 50 carotid endarterectomy patients met the criteria for normal functional level as measured by the Carey and Posavack Level of Rehabilitation Scale (LORS); 74% reported early retirement, loss of leisure time activities, or loss of driver’s license as the most frequent problems. In another long-term follow-up study, Viitanen et al22 reported a decrease in the subjective quality of life in 61% of stroke patients and an equally high decrease in
satisfaction with leisure and sexuality. Ahlsiö et al.20
and Viitanen et al.22 used only one item for estimat-
ing the global quality of life. Thus, the reliability of
their results are somewhat problematic. Further,
the patients in all of the studies20-22 cited above
were much older than ours.
In our study, deterioration within the domains of
life ranged from 39% for activities at home to 80%
for leisure time activities. Previously, Labi et al.18
reported decreases in the social functioning of 121
stroke survivors as follows: socialization outside
the home, 50.4%; hobbies and other interests, 38%;
and socialization in the home, 37.2%. In our study,
leisure time activities can be considered analogous
to the categories socialization outside the home and
hobbies and other interests.17,18 Therefore, the
decrease in satisfaction with leisure time activities
(80%) and activities at home (39%) in our patients is
similar to that found by Labi et al.18
The effect of the type of stroke and the localiza-
tion of the lesions was not considered in the above-
mentioned studies.18,20-22 In our study, more severe
deterioration of the quality of life was seen in
patients with hemispheric lesions.
Younger and older patients differed in severity of
the deterioration of the quality of life, probably due to
increasing disability and health problems in old age.
Men had a slightly more deteriorated quality of life
than women, due mostly to the fact that five of the six
patients dependent in ADL were men. When ADL
capacity was kept constant, Ahlsiö et al.20 found no
differences between men and women or between
older and younger patients. In the study of Labi et
al.,18 the effects of age and sex varied somewhat.
Speech disturbances had no effect on the quality
of life. However, three of nine patients with severe
aphasia could not deal with the questionnaire and,
thus, our results probably underestimate the impor-
tance of aphasia.
The incidence of depression reported by
patients is in agreement with recent studies.25-27 A
tendency to depression was one of our central
predictors of the quality of life. Ahlsiö et al.20 also
reported results emphasizing the importance of depression. Parikh et al.28 reported a strong correla-
tion between long-standing depression and social
functioning 2 years after stroke.
The patients whose quality of life was restored or
improved had significantly higher IQs and MQs
than those whose quality of life had deteriorated.
Minor hemispherical involvement and residual dis-
ability may explain this in part. The findings of
Lehmann et al.22 and Levin et al.24 support this view.
In our study, the typical patient with deteriorated
quality of life had a hemispherical lesion and neuro-
logic and neuropsychological deficits. Although the
patients had recovered in terms of discharge from
the hospital, ADL, and return to work, most (83%)
reported deterioration in the quality of life. It seems
that the severity of stroke and disability did have a
clear-cut impact on deterioration of the quality of
life, but even with this in mind the most important
variable seems to be the patient’s subjective expe-
rience of disability and insufficiency. Our results
suggest that, in addition to conventional rehabilita-
tion of stroke patients, more attention should be
paid to their quality of life. The patients need
encouragement, psychological support, adjustment
training after their stroke, and enough neuropsycho-
logical information to enable them to be realistic in
their self-evaluation of poststroke restrictions and
their chances of fulfilling their responsibilities and
enjoying life to the fullest.

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**KEY WORDS** • cerebrovascular disorders • depression • rehabilitation
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