DISABLEMENT AND QUALITY OF LIFE AFTER STROKE

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SUMMARY  This study concerns the quality of life of patients after stroke and how this is influenced by disablement and emotional factors. Ninety-six consecutive patients of mean age 71 years were followed for two years. At the end of that time 23% had experienced a recurrence of stroke and 27% were deceased. Of the survivors 76% were independent as regards activities of daily life (ADL) and lived in their own homes. Age as well as initial function were prognostically important factors. Patients who could participate in interviews marked on a visual analogue scale their evaluation of quality of life before and after stroke. Most of them had experienced a decrease and no improvement was observed during the two years. The deterioration was more pronounced in ADL dependent patients than among the independent. However, depression and anxiety were found to be of similar importance for quality of life as was physical disablement. These findings call for a greater emphasis on psychological support in the care of post stroke patients. The visual analogue scale can be a useful tool for detecting special needs.

THERE HAVE BEEN SEVERAL REPORTS on the prognosis of stroke patients as regards mortality and risk of recurrence.1,2 There is less knowledge about the frequency with which long-standing disability develops. Most information stems from studies of selected patients referred to rehabilitation centers.3 Also the question of the quality of life of the average stroke survivor needs exploration. Our intention was therefore to study these factors in consecutive patients treated in a stroke unit.

Material and Methods

In a defined catchment area of Stockholm with 120,000 inhabitants, all patients who sought acute medical advice were taken care of in the Serafimer Hospital. Stroke cases, including transient ischemic attacks (TIA), were transferred to the Stroke Unit according to availability of beds. It has previously been shown that the unit treats about half, and a representative part, of all strokes admitted to the hospital.4 Furthermore, patient mean age, distribution of previous diseases and diagnoses as well as mortality were similar to those of stroke patients in population studies.5,6,7 Criteria for the different diagnostic categories, as well as the organization and routines of the unit, have been described elsewhere.8 During the year 1979, 113 patients were admitted. Of these, 9 died during the acute phase and 8 were not included in the follow-up for other reasons: 5 moved to other parts of the country or abroad; 2 refused; 1 was transferred to another hospital for uremia treatment.

Among the 96 patients participating in the study, 60% were male and 40% female. Their mean age was 71 years (range 35–90). One fifth had previously had stroke or TIA. The present diagnoses were: Hemorrhage 5%, thrombosis 60%, embolism 11%, TIA 22% and unspecified 2%.

The treatment program in the unit included medical measures, rehabilitative nursing, physical and occupational therapy. This was continued to various extents for patients transferred to geriatric hospitals and for those who returned home and still needed training.

The capacity of the patients as regards activities of daily life (ADL) was recorded according to the index worked out by Katz.9 This estimates the degree of care needed by a subject and is one of the most carefully tested indices available. The best ADL group A consists of patients independent in feeding, continence, locomotion, toileting, dressing and bathing. The letters B-F signify gradually increasing disablement and G stands for dependence in all the mentioned functions.

At each follow-up, patients were also interviewed by means of a structured questionnaire. The concept quality of life can be defined as the experienced degree of satisfaction of human needs.9 In our opinion, and that of some others,10 this must be a subjective measure, a person's own appreciation of his life situation. This will usually depend on his physical well-being, psychological situation, living conditions, relations and opportunities for meaningful activities. These items were therefore explored during the interviews.

The aim was to study how much a stroke, with various degrees of subsequent disablement, affected the long-term situation for a person. However, it appears impossible to decide which factors, and their relative priority, are of importance for another individual's evaluation of his life. Thus, rather than applying a rating scale constructed for use by physicians,11 we wanted to know how a patient, with his/her own operational definitions, perceived the global quality of life before and after stroke. The questionnaire therefore ended with a summing-up graph in the form of two bars graded with "worst possible" at the bottom and "best possible" at the top (fig. 1). The patient was asked to mark on the left bar his/her quality of life before the stroke and on the right bar his/her present one. He had no access to earlier graphs when reexamined. The difference in height before and after stroke was calculated. This technique builds upon the visual analogue scale suggested by Huskisson.12 Our modification consisted of a measure of change rather than static conditions.

The understanding of the analogue scales was tested in the following way: Changes in quality of life marked on the bars were validated against interview answers (three questions about the total life situation with 5-
moved home. Others, mostly due to new strokes or accidents, had to move in the other direction. At the end of the study 26 (27%) of the patients were deceased, 54 (56%) were living at home and the remaining 16 (17%) were in geriatric hospitals.

On most instances, ADL capacity was decisive for a patient’s opportunity to live at home. Those who needed constant care by others for the basic ADL usually had to be treated in a geriatric hospital. Only six such patients could eventually be transferred home. They were all male and had an able wife who had accepted the nursing task, sometimes supported by a day care center. Eleven patients were at some time during follow-up treated in a geriatric clinic although they belonged to the best ADL group. Eight needed care due to severe aphasia or disorientation, qualities not evaluated in Katz index unless influencing ADL. Five patients had gradually improved and were just about to leave hospital at the time of investigation.

New Strokes and Mortality

During the study period 22 patients (23%) suffered new strokes. Twenty-six patients died (27%). Causes of death were: complication to the initial stroke (5 patients); new stroke (10); ischemic heart disease (5); aortic aneurysm, gangrene (3); neoplasm, uremia (3).

ADL Capacity

For the whole group the ADL capacity improved gradually with time after stroke. At the acute stage 55% were in group A compared to 76% of the survivors at the end of the study. The 26 patients who died had been more disabled initially than those who survived for two years. Part of the total improvement, therefore, was due to the death of the worst struck. As can be seen from table 1, however, another part was due to a favorable change of ADL in many cases, especially during the first 6 months after stroke.

At 19 follow-up investigations a deterioration of ADL was noted (table 1). Two patients in a bad condition, with gradual worsening, accounted for five of these deteriorations. The remaining 14 occurred in as many patients: 7 had a new stroke; 2 broke a leg; 2 were injured in accidents; 2 had a leg amputated. Movements between independent and dependent ADL generally resulted in transfers between home and geri-
At the acute stage older patients had a non-significant tendency to be somewhat worse with regard to ADL. For the outcome at two years both age and initial ADL were of statistically significant importance (table 2). Thus younger patients with independent ADL had the best prognosis and older, dependent the worst regarding mortality as well as independent function (p < 0.001). This does not mean that a great number of disabled patients remained in a bad condition for two years. In fact, this happened in only seven of initially 43 cases. The remainder either improved to independence or died.

### Quality of Life

At each examination 20–24% of the patients could not be meaningfully interviewed nor asked about their quality of life (table 3). Seventy per cent of them were severely disabled compared to 23% of those questioned. Among patients independent in ADL isolated severe aphasia or dementia were reasons for non-participation.

As can be seen from table 3, most patients reported a decrease of quality of life after stroke. The decrease remained rather constant during the follow-up period. This was confirmed when only the 50 patients interviewed on all four occasions were considered. Their estimation of quality of life before stroke did not vary statistically significantly between the investigations nor did the reported deterioration, although their physical function improved.

Less than one third of the subjects reported unchanged or improved quality of life after the stroke. Most of them were not at all disabled. Of the 12 improvements noted, seven were slight. In the remaining five patients specified reasons for a positive change were given, such as: "Felt happier, having been able to slow down", "appreciated life more after the illness".

The importance of age, sex and social factors was studied. For patients on the same level of ADL rating there were no statistically significant differences between the means of quality of life changes for men and women, nor for patients below or above 71 years of age. The socioeconomic group made no difference and those who had expressed complaints about the social situation did not evaluate their quality of life lower than the remainder.

There was, however, a correlation between changes in quality of life and ADL capacity (fig. 3). Thus, as a mean, quality of life deteriorated progressively with increasing degree of disablement. In figure 3 the results from all four follow-ups are presented together. When diagrams for each investigation were plotted separately, the results were similar. At two years, for instance, the differences were statistically significant between the two A groups and between A and the two worst groups.

Although ADL capacity thus seems to be of importance for quality of life, it must be pointed out that there was great variation and much overlap. Quality of life failed to improve with time as ADL did. Most patients without any recorded disability reported a decrease. Among these subjects (A plus = Independent ADL and no disorientation, dysphasia or walking aids)
the following reasons were spontaneously given during the interviews:

**Physical Impairment**
- Fine motor function (10 patients);
- Walking ability (5);
- Outdoor leisure/Travels (7);
- Balance/Vertigo (10);
- Therapy (e.g. anticoagulants) limits freedom (3);
- Investigations/Operations (8).

**Psychological Difficulties**
- Worries about a new stroke (16);
- Depression (12);
- Concentration (8);
- Memory (6).

**Medical Effects**
- Therapy (e.g. anticoagulants) limits freedom (3);
- Investigations/Operations (8).

Thus quality of life as marked on the scales seemed to be influenced by physical as well as psychological factors. Further, to study the last mentioned, answers to structured interview questions were compared with the change in quality of life marked on the bars at the investigation two years after the stroke. Five questions regarding anxiety and five regarding depressive reactions were selected. For each question there were five alternative answers graded from 1 = absent to 5 = pronounced. As can be seen from table 4, it had a great impact on change in quality of life if the patient felt anxious or depressed. These psychological reactions seemed as important as physical disablement for the evaluation of quality of life. To ensure that ADL differences between groups did not explain the impact of emotional factors, patients independent in ADL were studied separately. The observations regarding depression and anxiety were thereby confirmed. Furthermore, from a predictive standpoint, those patients who were either "depressed" or "anxious" during the acute phase showed more deterioration of quality of life after 24 months than other patients (−34,8 versus −19,2, p < 0.05).

**Discussion**

Mortality and stroke recurrence rates in the present patients were comparable to those of other stroke studies. The prognosis for life as well as functional capacity was dependent on age and severity of disablement in the acute phase. However, even among the older and worst affected only few remained in a bad condition for two years. An equally small group of patients improved to independence and the majority died.

When compared with data from stroke rehabilitation studies, recently summarized, the following similarities and discrepancies emerged. Our patients were somewhat older but more often independent at onset. This is due to the fact that in the other studies disabled patients suitable for training programs had been selected, whereas our material also consisted of patients beyond such aims and of cases with mild symptoms or TIA.

The rationale for including TIA patients was that they, like the others, had been hospitalized for threatening disease symptoms, after which fear for future recurrences might develop. The question was how their quality of life was affected compared to that of patients who were disabled as well. The boundary between the two groups was found artificial. Cerebral infarction and lasting metabolic disturbances have been revealed after TIA. Some patients with manifest stroke recovered slightly later than those with TIA or had very mild residues. Occasionally such residues were also noted after what had been named TIA. New diseases, accidents and death occurred during follow-up in both groups. For these reasons we have not treated TIA separately.

Despite dissimilarities of materials there was a common experience in all the studies. Unless a new stroke

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**TABLE 4** Means of Changes in Quality of Life for Patients with and without Anxiety or Depression two years after Stroke.

<table>
<thead>
<tr>
<th>Category</th>
<th>Change in quality of life, mean</th>
<th>Difference between yes and no</th>
<th>Significance of diff.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety, yes</td>
<td>14</td>
<td>−43</td>
<td>26</td>
</tr>
<tr>
<td>Anxiety, no</td>
<td>39</td>
<td>−17</td>
<td></td>
</tr>
<tr>
<td>Depression, yes</td>
<td>15</td>
<td>−47</td>
<td>32</td>
</tr>
<tr>
<td>Depression, no</td>
<td>38</td>
<td>−15</td>
<td></td>
</tr>
<tr>
<td>Anxiety or depression, yes</td>
<td>23</td>
<td>−42</td>
<td>31</td>
</tr>
<tr>
<td>Anxiety or depression, no</td>
<td>30</td>
<td>−11</td>
<td></td>
</tr>
<tr>
<td>ADL Worse than A plus</td>
<td>20</td>
<td>−39</td>
<td>24</td>
</tr>
<tr>
<td>A plus</td>
<td>33</td>
<td>−15</td>
<td></td>
</tr>
</tbody>
</table>

For comparison the mean is also given for the very best ADL group (A plus) and those worse.

- Anxiety, yes = At least one 5-point answer (pronounced) to five anxiety questions.
- Depression, yes = At least one 5-point answer (pronounced) to five anxiety questions.
or other accidents occurred, disabled patients improved gradually with time, most pronouncedly during the first six months.

Our findings regarding age and initial function as prognostically important factors for recovery support those of Marquardsen and WHO. In rehabilitation studies this is more questionable. One possible reason for the discrepancy is that age and function are already involved in their selection of patients. Furthermore, a weakness of this, and the rehabilitation studies, is the relatively small sample size. Particularly this regards subgroups. Therefore, negative findings must be interpreted with due caution.

As claimed by its designer, Katz’ score used for ADL measurements turned out to be a good instrument for assessing the degree of care needed by a patient. However, independent ADL does not mean absence of physical disablement, which many complaints during the interviews stressed. Adding information about dysphasia, disorientation and need of walking aids substantially improved the estimation of a patient’s situation. Even so, the measures must be considered crude. Vertigo, tiredness, memory and cognitive difficulties, impairment of fine motor function and walking, often limited opportunities for leisure and intellectual or social functions. Thus, physical factors might be of importance for quality of life also in ADL independent patients.

However, quality of life was not influenced by these factors alone. Signs of depression, and also of anxiety, were of similar importance. This seems highly plausible and is supported by recent reports showing depression to be a common and serious problem in the post-stroke period. Somewhat surprising was the observation that perceived quality of life did not improve during follow-up, although ADL function did.

Against this background there is too great a discrepancy between efforts invested in physical rehabilitation and in psychological support. The care of stroke patients calls for trials in answering questions like: Would individual or group psychotherapy be beneficial? Should this be arranged prophylactically as an integrated part of post-stroke care? Is there a role for antidepressive drugs as indicated? If so, for whom, when, and for how long?

Under all circumstances more emphasis needs to be placed on the importance of psychological reactions for a patient’s quality of life after stroke. An easy way to evaluate this in routine clinical practice is therefore needed. We found the graphs very useful in this context. They were as well understood by the patients as verbal questions on the matter. The fact that the levels marked on the graphs correlated both to degree of disablement and to emotional status supports the hypothesis that the method was reasonable and reflected what most people would put into the concept ‘quality of life’. We therefore suggest the use of the two visual analogue scales a short-cut for detecting when a patient’s life situation is seriously affected. This can serve as a basis for further discussions about the underlying causes and what rehabilitative measures may be appropriate.

Acknowledgments

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