The Influence of Depression, Social Activity, and Family Stress on Functional Outcome After Stroke

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Background and Purpose: This study was designed to assess the quality of life after an active poststroke period of rehabilitation and to investigate the possibility of a return to a working environment for those still of working age.

Methods: The study was conducted on 180 consecutive patients affected by stroke who were hospitalized for the first time and discharged at least 1 year before the study. The group consisted of 65% men and 35% women with a mean age of 65.29 years (SD, 11.22). The period between the stroke and the interview ranged from 12 to 196 months, with a mean of 37.5 months. The average Rankin score on discharge from the rehabilitation center was 2.718 (moderate handicap). The interview took place at home after consent obtained by telephone. The questionnaire included general and personal information regarding the individuals, their socioeconomic position, and scales for daily activity, depression, social activity, and stress produced in the family. The control group consisted of 167 age-matched subjects.

Results: A close correlation was observed in all patients between depression, social activity, and stress caused to relatives. The scores on the individual scales were clearly worse than those for control subjects. The patients received approximately 5 months of rehabilitation after the stroke. Differences emerged between men and women for depression and social activities, with the women scoring worse. In reference to daily life, 70% of prestroke ability was required on average after rehabilitation. The daily activity score at the time of the interview was also strongly influenced by the discharge score. The majority of patients were retired. Of the total, 20.64% returned to work, but not always to the same job and often after readapting to new conditions. Of this population, only 31.5% were women. With regard to the population aged younger than 65 years, 21.42% returned to work. Lesions in the dominant hemisphere do not necessarily seem to rule out return to work, even if associated with aphasia. The main discriminating element was the ability to understand language. The patients were often criticized by their cohabitants; the criticisms most often raised concern about apathy, irritability, and self-centeredness. Sexual activity was depressed in almost all cases.

Conclusions: Despite the progress made in studying cerebral vasculopathies, patients in the aftermath of a stroke still seem to live unsatisfactorily, as they did many years ago. Useful measures include valid treatment against spasticity, psychological assistance, and greater social support. (Stroke. 1993;24:1478-1483.)

Key Words • activities of daily living • depression • rehabilitation

A discrepancy exists between the abundance of studies focusing on the acute phase of stroke and the scarcity of data collected on the later consequences at the end of a long, painful, and expensive period. The data furnished by the existing literature on the quality of life of patients with a stabilized poststroke condition are anything but promising. Cornes and Roy report that only a minority of patients of working age return to work. Drummond, in a questionnaire investigation, observes a decline in the number and frequency of leisure activities and social contacts after a stroke, confirming that the decrease in activity does not only result from the physical disability, as already observed by other authors. When the patient has to cope with daily problems, disability often turns into handicap.

The aim of the present study is fivefold: (1) to compare the quality of life between poststroke patients and age-matched control subjects; (2) to assess the possible interdependence of parameters considered essential for the quality of life, such as mood, activities of daily living (ADL), social activity, and stress produced in the family; (3) to evaluate the percentage of patients who return to work and identify the characteristics of such patients; (4) to identify any sex-dependent difference; and (5) to collect complementary data important in the patient's life, eg, income, type of housing, drugs used, and sexuality. Criticisms of the patient raised by the family have also been sought. All patients and

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control subjects were interviewed at home because the domestic setting was considered more productive than the outpatient surgery room.

Subjects and Methods

The study was conducted on 180 consecutive patients affected by stroke who were hospitalized for the first time and discharged at least 1 year before the study. The clinical diagnosis of stroke in the acute phase of the disease was always confirmed by neuroimaging examination (computed tomography and/or magnetic resonance imaging) that allowed us to distinguish between ischemic infarctions and hemorrhagic lesions. Transient ischemic attacks were not included in the research. The group consisted of 65% men and 35% women with a mean age of 65.29 years (SD, 11.22; age range, 35 to 93 years). The peak of the frequency distribution by age occurred between 58 and 76 years. Of the 180 patients studied, 84 had been treated in rehabilitation centers in the metropolitan area of Rome and 96 in centers within the Marche, a region of central Italy. On average each patient spent 158 (SD, 68) days in rehabilitation centers (about 5 months). The men received rehabilitation for an average of 156 days (SD, 72; range, 22 to 283 days), while the women averaged 163 days (SD, 48; range, 76 to 225 days). The interval between the stroke and the interview ranged from 12 to 196 months, with an average of 37.5 months (SD, 36.76). On average, patients were discharged from the hospital with a Rankin score of 2.718 (SD, 0.899), ie, moderate handicap typical of patients who can walk without help but with impairment and who need assistance to look after themselves. However, on discharge the sample studied covered the entire range of scores, from 1 to 5.

The lesion was located in the right hemisphere in 43.22% of the patients sampled and in the left in 50.96%. In 2.58% the location could not be determined precisely; 1.29% were brain-stem lesions. Finally, in 1.93% multi-infarct cerebral neuroimaging were found after the critical event. No scale was applied to assess hemispheric dominance. The question as to which hand was preferred for daily activities showed that five were ambidextrous, with no one claiming to be left-handed. Expressive aphasia was found in 16.77% of patients, with 3.87% exhibiting global aphasia. Only 0.64% had fluent aphasia of the Wernicke type. Only one of the patients who had a right hemisphere lesion exhibited aphasia. The mean schooling was 8.62 years (SD, 4.59).

The investigation was performed at home after telephoning to obtain the consent of the participants in both the city and suburbs of Rome and in the Marche region.

The interviewers had been specifically trained. They were authorized to conduct the study when the agreement between their scores for a given patient reached 95%.

The questionnaire included the following: (1) information supplied by the hospital: personal details, age, address and telephone number, diagnosis, hemisphere involved, Rankin score on discharge, date of discharge; (2) individual and socioeconomic information: schooling, body lateralization (right-handed, left-handed, ambidextrous), past and present work and hobbies, cohabitants, type of housing (luxury, medium-high, low-medium, low, rudimentary), ease of access to the apartment, space available to the patient (in square meters), links with the locality, other hospitalization for the same or other causes, rehabilitation (in a state-subsidized outpatient department, private, hourly cost, or no assistance), number of rehabilitation sessions per week, means of support (disability pension, private pension, etc), return to previous job or possible new job; (3) Northwestern University Disability Scale (NUDS) for ADL; (4) Beck Depression Scale (not applied to aphasic patients); (5) Linn Social Dysfunction Rating Scale; and (6) Greene Scale of family stress.

One hundred sixty-seven age-matched control subjects (100 in the provinces and 67 in Rome) were studied in the same way, of course omitting the questions referring to the disease. They had no previous pathological history, no current treatments, and led an active life.

The data were analyzed statistically using rigorous methods (mean, standard deviation, standard error, minimum, maximum, distribution, skewness, kurtosis, integral of the distribution function), one-way analysis of variance (ANOVA) with the Kruskall-Wallis test, and the Mann-Whitney U test. A multiple correlation statistical analysis was also performed, considering the scores of the NUDS, Beck, Linn, and Greene scales as an expression of the “quality of life.” Since no significant differences were found between the geographic areas for patients or control subjects, we proceeded to combine the data. The study was carried out on 180 patients and 167 control subjects.

Results

Activities of Daily Living

A clear difference existed between hemiplegics and control subjects in regard to daily life (P<.0001, Fig 1). In control subjects the mean NUDS value was 48.850 (SD, 1.473) with a rather limited range (minimum, 45; maximum, 50). In patients the frequency distribution of the NUDS values was uniform, since almost all patients had a score above 30/50. A number of patients (30%) had autonomy scores above 40/50, ie, slight impairment in their ADL.

The mean NUDS score was 34.7 (SD, 9), with three subjects scoring the maximum of 50. The mean score found for the men (35.08; SD, 9.08) matched that of the women (33.90; SD, 10.71).

Depression

In control subjects the mean Beck value was 8.46 (SD, 4.9) (Fig 2A), which was slightly above the upper limit of the norm. In patients the frequency distribution of the Beck scale values showed a notable dispersion. The mean was 16, corresponding to moderate depression. However, 17.41% of the subjects scored over 25, corresponding to serious depression. The maximum score found was 38. Only 17.41% of the population scored less than 7, representing the cutoff point of the initial depression. Also, 6.45% of the patients interviewed lived alone in their homes. The mean score for this subgroup was 9.2 (SD, 5.52). Thus, in our cases solitude did not worsen the depression.

Social Activity

In control subjects the mean value of the Linn scores was 29.58 (SD, 9.31) (Fig 2B). According to the Linn
scale a subject with normal social activity has a score of 21, and a slight reduction increases the score to 42. In patients the frequency distribution profile of the Linn scores showed a consistent recurrence in the range of 47 to 81, indicating conspicuous abnormal social behavior. The mean score was 57.6 (SD, 21). The results of one-way ANOVA using the Kruskall-Wallis test showed that the greatest score (108) was found in a male patient with no motor impairment.

Family Stress

In control subjects the mean value of the Greene scores was 7.89 (SD, 6.28) (Fig 2C). On the Greene scale a normal subject has a score of 0, and a slight reduction changes the score to 21. In patients the frequency distribution profile of the Greene scores, related to stress within the family, was one of the most uniform, peaking near 40. Only 10% had values above 58. In fact, the mean value was 36.9 (SD, 16), indicating moderate stress.

![Fig 1. Plot shows correlation between Rankin scores on hospital discharge and Northwestern University Disability Scale (NUDS).](image)

![Fig 2. Bar graphs show mean scores for 180 poststroke patients (PP) and 167 age-matched healthy control subjects (HC) obtained using the Beck Depression Scale (A), Linn Social Dysfunction Rating Scale (B), and Greene Scale of family stress (C). **P<.01, ***P<.001 for men (M) vs women (W) (PP) and HC vs PP.](image)

**Male-Female Differences**

Our results showed that depression was greater in women than in men (P<.001), as was reduction in social activity (P<.001). There were no differences with regard to the stress caused to relatives. The sex-dependent Beck Scale scorings obtained from men, women, and control subjects are shown in Fig 2A through 2C.

**Correlation Between Scales**

The Table lists the results of one-way ANOVA using the Kruskall-Wallis test. The highest score (75) was found in a 78-year-old male patient affected by persistent left hemiplegia with hemineglect on the same side.

The coefficient of correlation between the NUDS and Beck scales was found to be .407 (P<.05). Considering the NUDS scale as the dependent variable with the Beck, Linn, and Greene scales together with age as the independent variables, multiple correlation analysis gives the following regression equation: NUDS=49.7 −0.14 (age)−0.4 (Beck value)+0.02 (Linn value)−0.03 (Greene value).

It can be observed that weight of the Beck is far greater than that of the other variables. Using z-transformed values to combine the scales (thus zeroing the means) and taking 1 as SD, the regression equation becomes: NUDS=0.15 (age)−0.35 (Beck value)+0.05 (Linn value)−0.06 (Greene value). This confirms that

**Correlation Between Daily Life, Depression, Social Activities, and Family Stress in 180 Poststroke Patients by One-Way Analysis of Variance Using the Kruskall-Wallis Test**

<table>
<thead>
<tr>
<th>NUDS</th>
<th>Beck</th>
<th>Linn</th>
<th>Greene</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>−0.525</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>0.495</td>
<td>0.826</td>
<td>1</td>
<td></td>
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<tr>
<td>−0.556</td>
<td>0.622</td>
<td>0.715</td>
<td>1</td>
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NUDS indicates Northwestern University Disability Scale; Beck, Beck Depression Scale; Linn, Linn Social Dysfunction Rating Scale; and Greene, Greene Scale of family stress. *All values P<.001.*
the weight of the Beck is greater than for the other variables.

**Working and Environmental Features**

Almost all the patients were retired, since the stroke occurred after the age of 65. At the time of interview 17.41% of the total group had a disability pension with a supplement if the patient needed constant assistance in ADL. The percentage without a pension was 14.19%, either because these subjects still received a salary or because they had their own income (a minority of cases).

The homes of 15.48% had difficult access. Links with commercial centers and outpatient clinics appeared difficult in 13.54% of the cases studied. In particular, dividing the data by geographic area, the links in the metropolitan area of Rome were judged as more difficult than in the Marche (9.03% and 4.51%, respectively; total, 13.54%).

**Return to Work**

We found that 20.64% of patients returned to work, but not always to the same job, and often after readapting to new conditions. Calculating the percentages of the number of patients who returned to work, we found that 37.50% had a left hemisphere lesion with nonfluent aphasia; 15.62% had a left hemisphere lesion with fluent aphasia; 53.12%, therefore, had a left hemisphere lesion; 43.75% had a right hemisphere lesion; and 3.12% had a brain-stem lesion.

Women formed 31.5% of the working population. This calculation includes housewives who returned to manage their own homes, either wholly or partially.

**Housing**

Most patients interviewed were not poor and had homes that were well situated, well furnished, and comfortable. Twenty-six percent of patients still paid for monthly rehabilitation sessions, which cost the equivalent of $270 to $900 per month. More women than men had practiced rehabilitation at home (55% versus 46%). Many of them had expressed a preference for “home” therapy, away from onlookers and therefore offering greater privacy. However, most patients no longer practiced rehabilitation, and less than one third had found state rehabilitation facilities.

**Drugs Used**

A mean of 3.20 (SD, 1.79) drugs were used per patient. Only 5.16% of patients were not on any drug therapy. We counted up to nine various specialized drugs taken by the same patient. The most heavily used category of drugs was the platelet antiaggregants, taken by 46.45% of patients. By far the most common hypotensive drugs were the angiotensin converting enzyme inhibitors (used by 15.48% of all patients) and nifedipine (14.83%). Diuretics were used by 9.03% of patients, and other hypotensive drugs were used by a smaller percentage of patients. Digital cardiokinetic drugs also were heavily used (in 14.83% of patients). At least one antiepileptic drug was taken by 12.25% of patients. Since this percentage exceeds that for post-stroke epilepsy, one may deduce that most of these drugs were administered as preventive measures. However, only 3.22% of the patients took antidepressants. This percentage is well below the percentage of depressed patients, as previously noted.

**Criticisms of the Patients**

The patients were often criticized by their cohabitants. The most common criticisms were apathy, irritability, and self-centeredness. Sexual function was found to be depressed in almost all cases. Only 2% showed increased sex drive, sometimes with sexual deviations.

**Discussion**

The aim of our research was to investigate the effects of the aftermath of a stroke on the patient and on the family. Although interviews by telephone appear valid, we preferred a direct interview at home because an impersonal telephone call did not seem an appropriate means to ask questions on certain delicate subjects.

The problem of reintroducing the patient into society appears at the bottom of the scale of our understanding of strokes. Few controlled studies have been performed on this topic, despite the many studies on cerebral vasculopathies and even if stroke involves social and economic issues. In the area of Boston, for example, it has been calculated that the cost per patient exceeds $4 million, including the acute phase (23%), rehabilitation (52%), rehospitalization (13%), and various outpatient services (12%), but excluding medical fees and personal expenses.7, 8

Despite the high cost of rehabilitation, it is clear that a great discrepancy exists between the interest dedicated to rehabilitative techniques (and technology) and the true purpose of neurorehabilitation, ie, the integration of the patient into his/her family, work, and social environment, as recommended by the World Health Organization.9 There is a great information gap on the final results of this costly chain of events and possible ways to reduce the physical and social hardships of stroke patients. Observations limited to the purely physical and motor aspects of patient rehabilitation have been criticized; the result seen by the therapist as satisfactory does not necessarily parallel the satisfaction of the stroke victims and their families.10 Prolonged physiotherapy may provide advantages for many patients. Yet, Wade et al11 maintain that the risk-benefit ratio is not clear. Moreover, the patient may become dependent on the therapist, thus perpetuating the mental concept of being “sick” and “different.”

In general, our observations confirm that a high ADL score on hospital discharge indicates a favorable prognosis for the patient’s return home and quality of life.12 The most negatively affected activities on patient hospitalization are (in decreasing order) negotiating stairs, walking, clothing, and personal hygiene. The highest assessment indexes on hospital discharge were for sphincter control, feeding autonomy, and personal hygiene; the lowest score was for negotiating stairs.13 According to Thorngren et al,14 there are few domestic variations in the follow-up of patients affected by stroke. After 1 year 89% walk alone or with support (23%), and 81% are independent in their personal hygiene. However, 20% do not socialize, even though they are able to. It is not clear whether the stroke unit itself improves the recovery: Lincoln et al15 state that the equations used are useful for studying groups of patients but are not always reliable in predicting the decision to be made for
an individual. Other variables possibly influencing the final outcome include age, social resources, and personal autonomy.

Our investigation into the quality of life and leisure activities after a stroke also confirms the impression of hardship for many patients and their families. Sjogren observed a reduction in recreational activities even after the patients return home. Social activities also decline in the same way, whether or not the patient has made a complete recovery. Such studies on the long-term effects of stroke and their social impact are uncommon and often imprecise, according to Thorgren and Westling. Unmarried elderly people have the greatest probability of eventually being moved to a rest home.

Drummond observes that almost all activities are practiced to a lesser degree after a stroke. According to the patients, the causes of this reduction are (in decreasing order of importance) difficulties in walking, manual dexterity, and concentrating, followed by language defects, sphincter control, inadequate transport, and finally medical problems and lack of physical assistance. These results confirm the importance of factors not linked to the disability itself, such as fear of being criticized, depression, loss of social role, and lack of self-confidence and knowledge about the facilities and equipment available.

With regard to the incidence of poststroke depression, the data seem to be inconsistent. House et al found (1) no difference between patients and control subjects matched for age and social class (incidence less than 2%), (2) no correlation between depression and probable cerebral localization of the lesion, and (3) no trend toward improvement in the course of 1 year. On the contrary, according to Sjogren, depression affects 65% of patients, according to Robinson and Price 45%, according to Feibel and Springer and according to Santus et al 26%. The latter also observed problems of social integration in 59.9% of their patients studied 1 year after hospital discharge. Egelko et al observed that poststroke depression does not show any improvement even in the first year after stroke, thus maintaining the need for finalized therapeutic intervention.

Our data show that, on average, the Beck scale values indicate moderate depression. However, 17.41% of patients had scores corresponding to serious depression; only 17.41% had a normal score. Thus, poststroke depression does exist and is an important factor in the rehabilitative process; social activities, depression, and family stress proved to be strongly related in our patients. It is likely that psychological support is useful to counter such depression, although this type of approach to poststroke patients was never found in our interviews.

The difference between the scarcity of antidepressive therapy prescribed and the elevated number of unquestionably depressed patients suggests that many cases of depression are not recognized by the family doctor. This is regrettable, since the results show a correlation between depression, ADL, and social activities.

Few reports in the literature deal with the sex lives of poststroke patients. Our home interviews indicate that sexual activity decreases in almost all cases, although it is impossible to say whether such a decrease is the result of depression or one of its causes. Furthermore, it is still a matter of debate whether poststroke depression results from organic alterations or psychodynamic processes. With regard to sexual activity, we should point out that this important part of a person’s life has been largely ignored by studies on cerebral vasculopathies. However, according to the male patients interviewed, impotence is more difficult to tolerate than hemiparesis, since the latter can be compensated for with suitable strategies and is less mortifying.

In addition to these problems is stress produced within the family. The frequency distribution profile of the Greene scale values was quite uniform, with a peak at approximately 40 (indicating moderate stress) regardless of the sex of the patient. The patients were often criticized by their cohabitants, the most frequent criticisms being apathy, irritability, and egocentrism. Yet, it was a surprise not to find a very high mean stress score among the cohabitants. This leads us to be relatively optimistic about the possibilities of reintroducing the patient into the family as the final stage of the rehabilitation period. Moreover, it is a condition that can allow direct participation of family members in the functional recovery and a more extensive rehabilitative process, consistent with the advice of Evans et al. These authors also observe that the later consequences of a stroke in the family are often neglected by neurologists, who limit their attention to the clinical phase and the physiastic aspects.

In reference to the return to work, if we refer to the population aged younger than 65 years, the proportion of those returning to work is 21.42%, well below the 29.4% figure for those returning to a previously held job found by Friedland and McColl. These authors maintain that the buffer to attenuate the patient’s psychosocial distress cannot be provided (as is generally the case now) by the family alone and that there is a need for support from society to ensure that stroke sufferers feel cared for, loved, valued and esteemed, and ready to accept assistance from others if necessary. Social support may come from the family or from a variety of people and institutions, even after the period of active rehabilitation.

A stroke generates great stress, and its final effect depends on intermediate factors such as genetic characteristics, psychological defenses, general state of health, family environment, type of community, economic resources, standard of living, social support, and religious faith. Social support for stroke victims has not been defined by the literature, as it has for other pathological conditions.

In addition to the possible link between depression and the left hemisphere, in practice the aphasia translates into reduced social support because of difficulties in communication. Factors important for a return to self-employment include level of education, type of work, and the individual’s work motivation before the stroke. Our data are inconclusive in regard to the value of income, housing, and the general sociocultural level in predicting the eventual return to work. However, subjects who return to work improve considerably in their overall outlook on life, daily and leisure activities, working environment, and financial situation. Positive rehabilitative assistance leads subjects to face their problems more optimistically.
The correlation between return to work and aphasia has not been studied to any great extent. Our data suggest that a lesion in the dominant (left) hemisphere does not necessarily rule out an eventual return to work, even if accompanied by nonfluent aphasia. The paramount discriminating factor is the ability to understand language. Whereas an expressive aphasic subject has been able to work in an environment that does not involve communication with the public, in no case have we seen a return to work when the subject was unable to understand language.

The return to work did not always mean immediate productive activity; sometimes we observed prejudice against the stroke victim even when his/her recovery was more than satisfactory. If the patient returns to work, job satisfaction may then be considered an indicator of the quality of life. For this reason occupational rehabilitation should be considered an important part of the overall rehabilitation therapy. Rehabilitative medicine in Anglo-Saxon countries has always tried to help the patient to return to work but with only limited success, except in selected cardiological cases, as observed by Cornes and Roy. These authors describe the measures taken by politicians, administrators, and special centers set up to find appropriate work for stroke victims. Despite these attempts the failure rate is high in this field, with one of the reasons being, in our opinion, the generally high unemployment level. A proposal has been made to design a scale called the Vocational Rehabilitation Index, which would not be limited to victims of stroke.

In conclusion, studies on the long-term consequences of stroke deserve attention because they allow an ideal protocol to be worked out for assessing the process of rehabilitation and reinforcing its aims, i.e., improved quality of life for patients and family and improved working conditions for patients. Despite the progress made in studying cerebral vasculopathies, patients in the aftermath of a stroke still seem to live in the same unsatisfactory manner as they did years ago. Improved therapy for spasticity, psychological assistance for patients and those supporting them, greater social support, and better vocational rehabilitation for a return to work are all approaches to be developed to improve the living conditions of an unfortunate class of people.

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