Caregiver Assessment of Personal Adjustment After Stroke in a Veterans Administration Medical Center Outpatient Cohort

Ron L. Evans, ACSW, William Craig Noonan, MSW, Duane S. Bishop, MD, and Robert D. Hendricks, PhD

We evaluated 80 stroke patients to examine the contributions of caregiver anxiety, self-care ability, age, time since onset, marital and residential status, and need for health care services on personal adjustment as reported by caregivers. Mean age of the patients was 65.4 years, and the average time from stroke onset to evaluation was 415 days. Multiple regression analyses indicated that a significant amount of variance in patient adjustment was accounted for by caregiver anxiety ($R^2=0.28$, $p<0.05$) and patient self-care ability ($R^2=0.13$, $p<0.05$). Compared with community norms, stroke patients were reported to be more depressed, confused, and anxious and they demonstrated fewer household management skills. Stroke patients were not different from a normative sample on measures of interpersonal involvement or social activity. Caregivers had high levels of anxiety compared with norms. Our results may aid in developing methods for identifying stroke patients and caregivers at risk for suboptimal adjustment.

(Stroke 1989;20:483-487)

Clinical experience and research data suggest that stroke can be devastating to interpersonal relationships and can cause severe personal problems. Outcome, however, has most frequently been measured in terms of physical ability without assessing satisfaction or other aspects of patient adjustment. While research has increased our knowledge of many biomedical disorders, the consequences of stroke on everyday life are inadequately described and poorly understood.

Many stroke studies evaluate outcome in terms of functional ability or narrowly defined psychometric properties. Whereas many studies have described the cognitive abnormalities and social needs that often occur after stroke, no study has adequately addressed the personal impact of the disorder. The prevalence of stroke disabilities, other than physical limitations and depression, remains vaguely defined. We measured stroke adjustment from a caregiver perspective to determine the contribution of typical outcome variables to patient behavior.

Two decades ago, Anderson et al. noted an increase in the percentage of stroke patients reporting good adjustment and thought that education might be responsible for such a trend. Since that time, attention has been given to the many survivors who may have psychological or social problems, and personal adjustment has been defined largely in terms of mood disorders, coping styles, and practical resources. Theoretical perspectives suggesting why adjustment after stroke may be difficult have been developed. However, measures used to evaluate adjustment vary widely and are often based on indirect observations, such as reports of altered social or leisure activities. It is noteworthy that satisfactory adjustment is considered possible in spite of physical impairment for a variety of conditions, such as multiple sclerosis and arthritis.

Adjustment after stroke is difficult to measure because of the lack of consensus in defining good adjustment. Shontz suggested that adjustment to disability be considered poor if pathologic behavioral or emotional reactions persist and disrupt social interaction. Cognitive and perceptual dysfunction associated with stroke affect adjustment and make valid experimental inquiry difficult. Studies have often excluded patients with cognitive problems due to reliability issues, have omitted evalu-
We investigated only variables that have been shown to be significantly related to stroke outcome. By having a "significant other" as the primary informant, we attempted to reduce problems in measuring adjustment that would be confounded by cognitive or perceptual difficulties. Brocklehurst et al. found that caregivers experience as much or more difficulty in coping with stroke as stroke patients and express excessive amounts of anxiety in the process. Therefore, we included a measure of caregiver anxiety in our analysis and evaluated their expressed need for additional home health care services, using the technique described by Kraft et al. Limitations of our study include the fact that patient adjustment and caregiver anxiety were rated by the caregiver. The tendency for our method of data collection to result in correlation must be considered when interpreting results. Respondents who report anxiety may also tend to report adjustment problems, and results may reflect test-taking style rather than the actual constructs being measured.

Personal adjustment, as it applies to disability, was first defined by Katz et al. as "freedom from psychopathology as manifested in social behavior, performance of community and home responsibilities, and family satisfaction with the patient’s condition and activities." We accepted this definition of personal adjustment and selected the Personal Adjustment and Role Skills (PARS) scale to measure it because, compared with other scales, the PARS best reflects this definition and can be used to evaluate persons with language impairment.

The PARS is a 54-item scale completed by a caregiver, yielding a mean T score indicating positive adjustment (mean 50, SD 20) and individual scores (range 5–20) reflecting positive adjustment in interpersonal involvement, household management, and social activity. In the remaining areas (depression, confusion, and anxiety), higher scores connote poor adjustment. Ellsworth demonstrated the validity of PARS for samples of institutionalized and noninstitutionalized patients from Oregon via comparison with improvement judged by professionals (r=0.87). Reliability was estimated to be >0.85 on test–retest comparisons.

Caregiver anxiety was measured using the State-Trait Anxiety Inventory (STAI). We analyzed only trait because it varies less and represents anxiety that might result from an ongoing caregiving process. The STAI consists of 20 questions that evaluate the respondents' emotions. Test–retest correlations are high, ranging from 0.73 to 0.86 over 30 days, and construct validity was demonstrated by discrimination of psychiatric patients from medical patients. One month after interviews were complete, we again administered the PARS and STAI to a random sample of 25 respondents from the original cohort. Test–retest correlations were computed for both the PARS (r=0.82) and STAI (r=0.71). Reliability of these measures was comparable with standardization samples.

**TABLE 1. Descriptive Variables of Study Sample**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean±SD</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barthel Index (self-care, mobility)</td>
<td>78.7±23.2</td>
<td></td>
</tr>
<tr>
<td>Age (yr)</td>
<td>65.4±11.8</td>
<td></td>
</tr>
<tr>
<td>Education (yr)</td>
<td>11.9±2.1</td>
<td></td>
</tr>
<tr>
<td>Income &lt;$12,000/yr</td>
<td>80.0</td>
<td></td>
</tr>
<tr>
<td>Lesion site</td>
<td>42.5</td>
<td></td>
</tr>
<tr>
<td>Reporting unmet health care needs</td>
<td>36.3</td>
<td></td>
</tr>
<tr>
<td>Male Patients</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Caregivers</td>
<td>8.8</td>
<td></td>
</tr>
</tbody>
</table>

*Any possible effects of neural recovery were assumed to have already occurred.
†Most prevalent conditions: congestive heart failure, pulmonary disorder, and arthritis.

Attention of "reaction to disability," or have defined adjustment problems vaguely as "psychosocial dysfunction." We address some of these methodologic problems by using a reliable and valid scale of adjustment that is conceptually related to problems reported by stroke patients and can be used to evaluate patients with language or cognitive problems. Based on the findings of previous studies, we hypothesized that specific characteristics (caregiver anxiety, self-care ability, age, time since onset, marital status, residential status, need for health care services) contribute to poststroke adjustment.

**Subjects and Methods**

The sample comprised 95 male stroke outpatients seen during 1 year at a Veterans Administration medical center. Five female patients were excluded because low prevalence would not permit meaningful interpretation of the effects of sex. All 95 male patients had completed 3 weeks of inpatient rehabilitation as part of their index hospitalization. Military veteran populations are predominantly male; hence, our results may not be generalizable to the total community. Six caregivers refused to participate in the subsequent data collection, and nine patients did not have a caregiver to complete the inquiry. The final sample size was, therefore, 80. All persons agreeing to participate completed the entire interview protocol. Descriptive variables of the sample are listed in Table 1. Patients who were included did not differ significantly in any variable from those who refused.
Sample Findings

Table 2. Comparison of PARS Community Norms With Study Sample Findings

<table>
<thead>
<tr>
<th>PARS subscale</th>
<th>Community norm (n=151)</th>
<th>Stroke study sample (n=80)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal</td>
<td>12.08±3.64</td>
<td>12.98±3.65</td>
<td>1.57</td>
<td>NS</td>
</tr>
<tr>
<td>involvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>10.98±2.14</td>
<td>15.16±3.78</td>
<td>5.45</td>
<td>0.01</td>
</tr>
<tr>
<td>Confusion</td>
<td>11.59±3.79</td>
<td>13.51±2.90</td>
<td>3.41</td>
<td>0.01</td>
</tr>
<tr>
<td>Household management</td>
<td>14.90±4.40</td>
<td>6.79±3.91</td>
<td>11.13</td>
<td>0.01</td>
</tr>
<tr>
<td>Social activity</td>
<td>7.07±2.60</td>
<td>6.19±3.74</td>
<td>1.71</td>
<td>NS</td>
</tr>
<tr>
<td>Patient anxiety</td>
<td>9.40±2.85</td>
<td>12.40±3.54</td>
<td>4.77</td>
<td>0.01</td>
</tr>
<tr>
<td>PARS total</td>
<td>50.44±9.54</td>
<td>44.23±8.34</td>
<td>4.31</td>
<td>0.01</td>
</tr>
</tbody>
</table>

PARS, Personal Adjustment and Role Skills scale; data are mean±SD. Two-tailed t test using Dunn’s multiple comparison procedure.

Results

Caregivers indicated that patients were more confused, depressed, and anxious and had fewer household management skills than persons in the PARS normative sample (Table 2). The only PARS subscales for which stroke patients were not significantly less adjusted were interpersonal involvement and social activity. Caregiver anxiety for the study sample measured on the STAI was significantly greater than that for normative age-matched samples (Table 3).

Results of regression analyses are summarized in Table 4. Increased caregiver anxiety was significantly correlated with increased patient confusion and patient anxiety. Low caregiver anxiety was significantly correlated with more interpersonal involvement and increased patient depression. Self-care ability was significantly correlated with better patient adjustment (total PARS). Patient anxiety was significantly related to time since stroke onset. Marital status accounted for 25% of the variance in household management scores and 22% of the variance in social activity scores; that is, unmarried patients did more household chores and were more socially active than married patients. Need for health care services was significantly correlated with patient depression and patient anxiety.

Discussion

We evaluated a set of well-documented stroke outcome variables to determine if they could account for variance in personal adjustment after stroke. Five variables (caregiver anxiety, self-care ability, time since stroke onset, marital status, and need for health care services) accounted for a significant amount of variance in one or more aspects of personal adjustment.

Caregiver anxiety had the strongest and most consistent association with patient adjustment, but the association may be spurious because both the PARS and the STAI were obtained from the caregivers. High caregiver anxiety was associated with increased patient confusion and anxiety and with decreased patient depression and overall adjustment. If direct assessment of patient adjustment is not possible, reports by a caregiver and assessment of his or her emotional state may be helpful in predicting the patient’s adjustment to interpersonal problems. The negative correlation between caregiver anxiety and patient depression (r=-0.24, p<0.05) may have important clinical implications. Caregivers reporting minimal anxiety may be reacting to the patient’s affect by emotionally insulating themselves or denying patient depression. Lack of caregiver anxiety may be interpreted by the patient as an uncaring response and may subsequently spawn dysphoria, or perhaps caregivers with minimal anxiety are more adept at identifying a patient’s mood disorder. Anxious caregivers may also be active in care activities and may use their energy constructively to help resolve issues that affect patient depression. Clinical explanation of these findings would be enhanced by measuring caregiver and patient mood over several months to assess
how they covary. Caregiver anxiety accounted for 28% of the variance in overall patient adjustment, suggesting that the caregiver's psychological status influences his or her interpretation of how the patient is doing after rehabilitation. Caregivers expressed high levels of anxiety compared with a control group matched for age. This finding is supported by others, who found that caregiver mood is a main cause of social problems after stroke. Time since stroke onset was significantly correlated with both patient and caregiver anxiety (r=0.34), that is, recovery does not seem to explain why caregivers report anxiety and may reflect the chronic nature of anxiety after stroke.

Rehabilitation experts have tended to minimize the relation between severity of disability and adjustment based on physical activity limitations alone. Nonsignificant relations between physical status and psychological adjustment have been found for amputation, lupus and emphysema. One study suggests that psychological adjustment improves as physical ability worsens in multiple sclerosis. However, our finding that self-care ability accounted for significant variance in four of seven areas of adjustment is consistent with the findings of De Jong and Branch. That patient confusion and caregiver anxiety make self-care more difficult is logical, and self-care is an integral part of household management.

Stroke often limits social activity and self-care ability, and stroke deficits have been thought to create marital distress for language-impaired patients. Stroke has been associated with limited social activity and depression. We found no significant difference between stroke patients and a normative sample for interpersonal involvement or social activity. However, on other PARS subscales significant differences are noted, with the stroke patients being less adjusted. The largest difference was noted in household management; stroke patients were reportedly doing few household chores. The significant relation between household management and marital status may partially explain these results.

Married patients tended to let their wives manage the household. Age accounted for little variance in adjustment, which is consistent with other studies. Age has no apparent effect on coping with stroke-related problems. Older patients may experience as many disruptions in lifestyle as do younger persons.

Placement in a nursing home indicates negative stroke outcome. The fact that living at home did not explain variance in adjustment in our study may be useful in determining the consequences of institutionalization. In our study, caregiver reports of adjustment for nursing home patients were no different from those for patients at home or of a normative sample. Based on the literature, rehabilitation staff may assume that being in a nursing home leads to poor adjustment. However, a recent study notes that family function is not irreparably disrupted by such placement, and our study suggests that many patients can be viewed by family as being adjusted while living in a nursing home.

Being married was associated with patients' doing fewer household chores and being less socially involved. For the majority of adjustment variables, marital status was inconsequential. Having a spouse is usually associated with better stroke outcomes, such as reduced likelihood of institutionalization. We included only patients with a caregiver, which may have biased our results. On the other hand, having a satisfactory caregiver may contribute to adjustment regardless of marital status. Future research could include prospective studies to clarify the reasons for caregiver anxiety or how a caregiver's reactions might be treated if they are problematic. Evaluation of caregiver mood may help determine family characteristics that influence adjustment.

When comparing stroke patient adjustment with a normative sample, we found no significant differences for interpersonal involvement or social activity. Patients were reportedly more confused, depressed, and anxious and demonstrated fewer household management skills than persons in the...
normative group. Patient adjustment problems were evident in all but two PARS subscales, but other correlates of stroke outcome, such as being married or living at home, had little influence on adjustment. We encourage others to evaluate poststroke adjustment directly, using measures that accommodate a population with language or perceptual impairment. More research is needed to clarify which areas can be influenced by rehabilitation and how caregivers can be helped to foster better patient outcomes.

References

Key Words: cerebrovascular disorders • rehabilitation • social adjustment

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Stroke. 1989;20:483-487
doi: 10.1161/01.STR.20.4.483

Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 0039-2499. Online ISSN: 1524-4628

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