Family Intervention After Stroke: Does Counseling or Education Help?

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Two interventions for improving stroke caregiver knowledge, stabilizing family function, promoting patient adjustment, and enlisting the use of social resources after stroke were compared with routine medical and nursing care of stroke patients (n = 61) at a 440-bed Veterans Administration Medical Center. The education intervention (n = 64) consisted of classroom instruction for caregivers about basic stroke care principles. The counseling condition (n = 63) consisted of education plus seven follow-up problem-solving sessions with a social worker (for the caregiver). Six months and 1 year after the stroke, both interventions significantly improved caregiver knowledge and stabilized some aspects of family function better than routine care. Counseling was consistently more effective than education alone and resulted in better patient adjustment at 1 year. Neither intervention influenced the use of social resources. (Stroke 1988;19:1243-1249)

Family adjustment to stroke has confounded the interpretation of outcome studies and has made it difficult to determine what family intervention might be appropriate. Mazzuca suggests that didactic interventions are as therapeutic as more intensive approaches for families coping with disability, and the effectiveness of family education in vascular conditions has been demonstrated. Family dynamics may change as a result of cognitive or perceptual stroke deficits, but whether education or counseling offset such difficulties or improve family function after stroke has not been verified by research.

Family dysfunction can result directly or indirectly from stroke-related problems. The effects of aphasia on marital satisfaction, for instance, can be dramatic and long-standing; usual coping mechanisms, communication patterns, and social roles are disrupted. Family involvement in stroke rehabilitation, a common means of addressing these issues, is cited as an important factor that facilitates the patient's returning home. Although the family can promote rehabilitation, it can also have a negative influence if the family members are uninformed or uninvolved.

Providing instruction for home care of the stroke patient has been considered as important to social adjustment after stroke as physical rehabilitation.

Deteriorating relationships after stroke are common. Caregivers report that communication is the most stressful issue, but changes in social activities, avocational interests, and role assignments also affect the family system. There is a positive correlation between available social support and favorable outcome after stroke, suggesting that family involvement in rehabilitation is important to recovery.

Assessment of family function after stroke has been disappointing, perhaps because many variables interact with family behavior. The most common rationale for involving spouses in stroke rehabilitation is their potentially critical role in the operant reinforcement of patient behavior. Spouses may need help in coping emotionally, in grieving over losses incurred by the patient but shared by the family, in financial planning, or in dealing with shifted burdens of responsibility. Since the family is ultimately responsible for home care of the patient, including family members in rehabilitation may structure the support system to function more effectively and may influence other outcomes.

Although it is generally accepted that the majority of physical recovery occurs 6–12 months after the stroke, family function can deteriorate for years. We wished to determine the effects of stroke on family interaction, to assess the extent to which intervention might influence any family dysfunction, and to compare the effects of education alone
and education with supportive counseling for the principal caregiver with a control group of patients receiving routine medical and nursing care. The three conditions are referred to as education, counseling, and control. We hypothesized that education, resulting in an informed caregiver, would stabilize family function after a stroke, would promote patient adjustment, and would foster the use of social resources in a home care program. If education could improve knowledge about stroke, it was further hypothesized that counseling would sustain the effects.

Subjects and Methods

For 2 years, caregivers of all (233) stroke patients on inpatient wards at the Seattle Veterans Administration Medical Center from any referring service (provided the patients were hospitalized primarily for stroke) were asked to participate in family evaluation; 17 patients did not have a caregiver, and 213 caregivers signed informed consent to participate. A primary caregiver, defined as the principal supportive person with whom the patient lived (usually a wife), was identified by interviews with the patient and ward staff. Interested caregivers attended an initial appointment at which the study was explained and consent was obtained. More than 94% of the stroke patients were living outside an institution before stroke onset.

Patients were randomly assigned to conditions after minimizing the differences for variates known to predict stroke recovery; mood, self-care ability (Barthel Index), mental status, age, and location of the lesion. The method of Taves was used.

Seven patients died before assignment to condition. Four patients in the control, four in the education, and five in the counseling condition died during our study. Three families in the control and two in the education condition could not be located for follow-up. The resulting sample size is 188 (63 in the control, 64 in the education, and 61 in the counseling condition). Control patients differed from those in the education or counseling conditions with regard to marital status (more controls were single) and number in household (controls comprised fewer two-person households). Characteristics of the patients and caregivers before the stroke are listed in Table 1.

We assessed 1) caregiver knowledge of stroke care, 2) family function, 3) use of social resources, and 4) patient adjustment.

The Stroke Care Information Test (SCIT) consists of 36 four-part, forced-choice questions about physical loss, cognitive and perceptual disorders, language impairment, and effects on sexuality. The range of possible scores is 0 to 36. The SCIT has adequate reliability and differentiates participants in stroke education from nonparticipants.

We used the Family Assessment Device (FAD), based on the McMaster model of family relationships, to evaluate seven areas of family function: problem solving, role assignments, communication, behavior control, affective involvement, affective responsiveness, and global family function. The FAD has adequate test–retest reliability, moderate correlations with other self-reported measures of family function, and differentiates clinician-rated healthy from dysfunctional families. Persons use a four-point scale (range 1 to 4) to indicate agreement for 60 statements about their family; high scores connote dysfunction.

We measured the use of social resources with the ESCROW profile, which evaluates suitability of the environment, reliance on social agencies, available help in the home, financial resources, ability to make decisions, and vocational status.

To determine patient adjustment, caregivers completed the Personal Adjustment and Role Skills scale (PARS), which has adequate reliability and validity. The PARS yields a standardized score measuring patient adjustment in the areas of interpersonal involvement, agitation, confusion, household management, and social activities.

Clinical, pretreatment, and caregiver assessments (SCIT, FAD, ESCROW, and PARS) were completed by the third hospital week. Evaluations were completed at 6 months and again 1 year after the stroke.

Patients in the control condition were assessed, but their caregivers were not scheduled for education or counseling. Some caregivers received social services as part of the patient’s hospital course, but contacts were limited, dealt with finances or placement, and were similar to services offered to all patients. At the end of the study, the control patients’ families were offered the education described below.

Caregivers of patients assigned to the education condition attended two 1-hour classes. All but 13 of 125 classes occurred during the third week of hospitalization. The first hour was a lecture and videotape entitled “Living with Stroke.” The lecture followed a specific outline of information that was developed from constructs prioritized by physiatrists and included basic information about the consequences of stroke (language impairment, physical and perceptual loss, memory and learning ability, emotional consequences, and sexuality) presented by an occupational therapist. The second hour, facilitated by a social worker within 3 working days after the first class, was used to explain treatment unique to the family’s situation and to respond to questions.

Caregivers of patients assigned to the counseling condition participated in 2 hours of education as described above and received seven additional individual 1-hour counseling sessions with one of two social workers trained in the use of a cognitive behavioral format of counseling as outlined by Meichenbaum. The first counseling session was scheduled for the third week of hospitalization, and at discharge six more biweekly sessions were scheduled. The counseling sessions were monitored for uniformity as described. The intent of the counseling was for the caregivers to apply
TABLE 1. Characteristics of 188 Stroke Patients and Caregivers Before Treatment

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control (n = 63)</th>
<th>Education (n = 64)</th>
<th>Counseling (n = 61)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yr)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>63.4 ± 10.3</td>
<td>62.4 ± 9.6</td>
<td>61.1 ± 10.2</td>
</tr>
<tr>
<td>Caregiver</td>
<td>50.7 ± 15.2</td>
<td>48.7 ± 15.2</td>
<td>47.9 ± 15.4</td>
</tr>
<tr>
<td>Education (yr)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>10.9 ± 1.6</td>
<td>11.4 ± 1.1</td>
<td>11.5 ± 1.4</td>
</tr>
<tr>
<td>Caregiver</td>
<td>11.6 ± 1.7</td>
<td>12.0 ± 1.8</td>
<td>11.6 ± 1.9</td>
</tr>
<tr>
<td>Household annual income ($)</td>
<td>12,300 ± 3,300</td>
<td>12,200 ± 3,280</td>
<td>11,900 ± 3,140</td>
</tr>
<tr>
<td>Patient depression (range 0–36)</td>
<td>14.4 ± 5.2</td>
<td>14.7 ± 5.2</td>
<td>15.0 ± 5.4</td>
</tr>
<tr>
<td>Patient self-care (Barthel Index scores 5–100)</td>
<td>50.0 ± 29.0</td>
<td>52.8 ± 27.9</td>
<td>49.6 ± 28.5</td>
</tr>
<tr>
<td>Hospital days (range 7–89)</td>
<td>40.3 ± 21.8</td>
<td>37.1 ± 22.3</td>
<td>37.7 ± 21.4</td>
</tr>
<tr>
<td>Lesion location</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>36.5</td>
<td>37.5</td>
<td>37.7</td>
</tr>
<tr>
<td>Left</td>
<td>34.9</td>
<td>35.9</td>
<td>34.4</td>
</tr>
<tr>
<td>Bilateral/brainstem/unknown</td>
<td>28.6</td>
<td>26.5</td>
<td>27.9</td>
</tr>
<tr>
<td>Patients employed at onset</td>
<td>15.8</td>
<td>17.2</td>
<td>13.1</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients</td>
<td>93.7</td>
<td>95.3</td>
<td>95.1</td>
</tr>
<tr>
<td>Caregivers</td>
<td>11.1</td>
<td>7.8</td>
<td>8.2</td>
</tr>
<tr>
<td>Patients cognitively intact</td>
<td>58.3</td>
<td>59.4</td>
<td>57.4</td>
</tr>
<tr>
<td>Patients married</td>
<td>74.1</td>
<td>79.7</td>
<td>78.5</td>
</tr>
<tr>
<td>Two-person households</td>
<td>85.7</td>
<td>87.5</td>
<td>90.2</td>
</tr>
<tr>
<td>Patients hospitalized again at least 1 day during year after stroke</td>
<td>47.6</td>
<td>42.3</td>
<td>41.0</td>
</tr>
<tr>
<td>Discharged by service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicine</td>
<td>12.7</td>
<td>10.9</td>
<td>9.8</td>
</tr>
<tr>
<td>Neurology</td>
<td>23.8</td>
<td>25.0</td>
<td>26.2</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>63.5</td>
<td>64.0</td>
<td>63.9</td>
</tr>
</tbody>
</table>

Values are mean ± SD or % (rounded). Control, routine medical and nursing care of patient; education, classroom instruction for caregiver about basic stroke care; counseling, education plus seven problem-solving sessions for caregiver.

Results

We used univariate analysis of variance (ANOVA) and \( \chi^2 \) analysis to determine that patients in the three conditions did not differ significantly \( (p > 0.10) \) in any variable before treatment (Table 1). There were no differences for the education and counseling conditions in the time from stroke onset to classes (mean ± SD 26.2 ± 3.1 days). To determine the maintenance of treatment gains, we used repeated-measures ANOVA of the dependent measures, with the independent variables condition and time (6 months and 1 year after the stroke) yielding significant multivariate main effects \( (p < 0.001) \).

Six Months After Stroke

We performed univariate ANOVAs to determine if the conditions differed before treatment and 6 months after the stroke (Table 2). We found significant relations \( (p < 0.001) \) for caregiver knowledge about stroke; the family functions problem solving, communication, and global family function; and patient adjustment (use of social resources not shown). Thus, conditions differed significantly for three of seven family function subscale variables and two of the three remaining variables.

We used Scheffé’s test\(^{24}\) to assess differences between conditions 6 months after the stroke (Table 3). All three conditions showed worsening family function after the stroke, but both the education and counseling conditions demonstrated significantly less deterioration than control on problem solving, communication, and global family function. Both conditions improved caregiver stroke knowledge, but only the counseling condition significantly improved patient adjustment relative to control. No condition was significantly different in the use of social resources.

One Year After Stroke

Univariate ANOVAs demonstrated significant differences between conditions on scores 1 year after the stroke on caregiver stroke knowledge; the family functions problem solving, communication, behavior control, affective involvement, and global family func-
tion; and patient adjustment (use of social resources not shown) (Table 2). Thus, the initial effects were maintained, and a delayed effect on behavior control and affective involvement was obtained.

Using Scheffé's test to compare conditions 1 year after the stroke, we found that both the education and the counseling conditions were significantly better than control on caregiver stroke knowledge and the family functions problem solving, communication, affective involvement, and global family function (Table 3). Although family function deteriorated initially in both conditions, it had deteriorated significantly less than control at 1 year on four of the seven FAD subscales and had not changed or had made minor gains on the remaining three subscales.

The hypothesized long-term benefits of counseling over education were observed for five of 10 variables: the family functions problem solving, communication, behavior control, and global family function and patient adjustment.

Comparison With Normative Data

Table 3 gives cutoff scores for the FAD. Scores below the cutoff are considered healthy; scores greater than or equal to the cutoff are dysfunctional. For all conditions family function (except behavior control) was healthy during the 3 months before stroke onset. Family function for the control condition 1 year after the stroke was dysfunctional on six of the seven FAD subscales, whereas family function for the education and counseling conditions were usually healthy.

Ellsworth reported normative data for the PARS (n = 151, mean ± SD 51.63 ± 6.78). One year after the stroke (Table 3), the PARS score for the counseling condition was not different from normal (t = 1.7, not significant), whereas scores for the control (t = 13.8, p < 0.01) and education (t = 11.7, p < 0.01) conditions indicated significantly less adjustment.

Discussion

We evaluated the effects of caregiver education, caregiver education with counseling, and only routine care of the patient (control) on the variables caregiver stroke care knowledge, family function, use of social resources, and patient adjustment. We hypothesized that in households in which one member had suffered a stroke, caregiver education would positively affect family function, would foster better use of social resources, and would promote patient adjustment. We further hypothesized that counseling would facilitate greater gains than education alone and would sustain the effects by reinforcing adaptive patient behavior. Our hypothesis, that caregiver education would facilitate and maintain adaptive changes in family function, was supported. Further, counseling helped maintain the benefits of education in several areas of family function and resulted in better patient adjustment 1 year after the stroke than either control or education alone.

Our results suggest that both interventions were effective. Compared with control, the education and counseling conditions gave significantly better outcomes 6 months after the stroke on measures of caregiver stroke knowledge and the family functions problem solving, communication, and global family function. Gains were maintained for 1 year, with the counseling condition outperforming the control and education conditions on four of seven family function subscales, as well as on caregiver stroke knowledge and patient adjustment.
Differences in family function among conditions are significant both clinically and statistically. For instance, families in all conditions were healthy before the stroke with regard to most subscales based on FAD cutoff scores. One year after the stroke, only the control families had deteriorated; the majority were dysfunctional. Further, areas of family function that were positively influenced by intervention are areas associated with stroke deficits (e.g., problem solving and communication).

Healthy family problem solving was reported in families of both intervention conditions at the 6-month and 1-year assessments. We have demonstrated that family problem solving is important in adherence to treatment after stroke and in patient adjustment to stroke after 1 year. Reiss suggested that family problem solving is associated with the members’ interactions with the health care system. Our intervention conditions were intended to improve the caregivers’ abilities to solve problems by applying stroke care principles in practical situations and by responding to health care suggestions. Effective problem solving may have an impact on family integration by improving the handling of stressful situations and in dealing with the rehabilitation process and by facilitating the lifestyle changes often associated with stroke. Reiss warns that stronger families may tend to coalesce around illness, resulting in “paradoxical vulnerability” and eventual poor outcome.

The interventions also helped families to communicate more clearly and directly. Difficulties understanding the stroke patient’s speech have been linked to behavioral and sexual problems, and communication is a central factor in recovery from stroke. The education condition promoted better family communication but did not promote better behavior control. The education intervention was effective in maintaining healthy affective involvement among family members. Other studies have indicated that poor affective involvement is associated with deterioration...
after stroke and that healthy affective involvement is associated with adherence to treatment recommendations during a medical crisis and in stroke specifically. Preoccupation with the disabled family member to the exclusion of the needs of other family members interferes with the autonomy required for optimal adjustment. Gaining information about home care may optimize involvement of the caregiver by promoting compliance and subsequently better family function.

We thought patient adjustment would be contingent on caregiver knowledge about stroke care. Both interventions improved caregiver knowledge, but education was not sufficient to promote even short-term changes in patient adjustment; counseling resulted in better patient adjustment at follow-up. Thus, education may be necessary, but not sufficient, for retaining and applying rehabilitation principles.

Education is more common than counseling as a strategy to promote patient adjustment in stroke rehabilitation. However, evaluation of the effectiveness of either intervention is scarce. Rehabilitation programs contemplating family intervention should consider the added benefits of counseling. The counseling we used specifically addressed caregiver education as it related to home care; other types of counseling may not be as effective. Insight therapy, for instance, has been found inappropriate for medically ill or recently disabled clientele.

Our method of evaluating family function after stroke represents improvement over previous work. Most studies cited by Lind, for instance, relied heavily on patient self-report of only a few dimensions of family and social variables. No study cited by Jongbloed addressed family function in predicting stroke outcome.

We did not assess the utility of including only caregivers in education or counseling; results would likely differ if other family members were included. Further study is needed to determine which components of intervention are responsible for changes in family function after stroke. Assessing patient compliance and measuring caregivers' acquisition of skills would aid in identifying the active ingredients of the intervention. Also, while our high proportion of men is typical of a military veteran cohort, additional clinical trials are needed before generalizations can be made to other populations.

Future research should assess changes in the caregivers themselves. Caregiver involvement may be crucial for particular patients or unique to specific interventions. It is evident, however, that planned, family-oriented intervention, not just involvement, is worthwhile and may be necessary to help generalize rehabilitation efforts to a home setting.

Our positive results, in spite of the fact that >40% of the patients had cognitive limitations, suggest that education and counseling should be pursued routinely with families of stroke patients. Clinical assessment of family function can be useful in evaluating rehabilitation effectiveness and in predicting outcome. These are encouraging findings with a subgroup of patients considered by some clinicians to have poor prognoses for home care.

Acknowledgment

Statistical review was provided by Robert D. Hendricks, PhD.

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**KEY WORDS** • cerebrovascular disorders • family therapy
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Stroke. 1988;19:1243-1249
doi: 10.1161/01.STR.19.10.1243
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 1988 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/19/10/1243

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