Family Caregiving for Patients With Stroke
Review and Analysis
Beth Han, MA; William E. Haley, PhD

Background—The literature on family caregiving for stroke patients is reviewed with the goals of (1) evaluating the effects of stroke caregiving on caregivers’ well-being, (2) outlining deficiencies and methodological limitations of current research, and (3) outlining policy and practice implications of current studies.

Summary of Review—A total of 20 published stroke caregiving research articles were included in this review. Across studies, the effects of stroke caregiving on caregivers’ well-being and the significant predictors of caregivers’ depression were analyzed. Current evidence suggests that stroke caregivers have elevated levels of depression at both the acute stroke phase and the chronic stroke phase. However, major gaps are apparent in this literature, with few studies addressing such areas as caregiver physical health, ethnicity, and caregiver interventions.

Conclusions—Given the increasing prevalence of stroke as well as the increasing pressures on families to provide care, more research is needed to guide policy and practice in this understudied topic. (Stroke. 1999;30:1478-1485.)

Key Words: caregivers ▪ depression ▪ stress ▪ stroke outcome

Stroke is the third leading cause of death1 and the leading cause of adult disability2 in the United States. The high incidence and high prevalence of stroke have a major impact on society.2 After initial hospitalization and stroke rehabilitation, 80% of stroke survivors return to the community, relying on their family members’ emotional, informational, and instrumental support for daily living.3 Among the 3 million stroke survivors in 1989, approximately 23% had multi-infarct dementia.4 Stroke caregivers have to deal with not only stroke patients’ difficulties in mobility, self-care, and communication, but also their cognitive impairment, depression, and personality changes.5

The support of family caregivers for their relatives with stroke have an important impact on whether patients can remain outside of rehabilitation care.3,6 There is evidence that depression in stroke caregivers worsens the patients’ depressive symptoms7 and predicts poor responses of patients to rehabilitation.7–9 Moreover, the continuing shift from institutional care to community care makes the impact of stroke caregiving more profound than ever.

Despite the high prevalence of stroke and the potentially high burden of family caregiving for the stroke survivors, few studies have systematically addressed the consequences of stroke on family members and other informal caregivers. For example, 2 recently published articles on Alzheimer’s disease (AD) caregiving identified more than 60 articles published between 1986 and 199510,11; however, there were only about 20 published empirical articles related to stroke caregiving between 1986 and 1998.

Given the high and increasing prevalence of stroke, the high risk of developing dementia after stroke onset, the large number of family caregivers coping with stroke, and the evidence that caregivers’ adjustments have important implications for patients’ quality of life, a current review of the state of knowledge about stroke caregiving is needed. Thus, the purpose of this article is to provide a review and analysis of published empirical studies that have examined the outcomes of caregiving for stroke caregivers. Specifically, our goals are to (1) evaluate the effects of stroke caregiving on caregivers’ well-being, (2) outline deficiencies and methodological limitations of current research, and (3) outline policy and practice implications of current studies.

Methods of Search Strategy

Only published research articles were included in this review. Several methods were applied to search the literature. First, articles were limited to those published in English since 1986. Second, the search strategy excluded articles that focused on more generalized chronic disease caregiving rather than stroke-specific studies. Third, the search strategy excluded articles that were not peer reviewed, such as dissertations. Fourth, a computer search was conducted in June 1998 to review the databases of MEDLINE and PsychINFO by using the following key words: caregivers of stroke patients, care for stroke survivors, and stroke caregiving. Of the more than 200 articles identified, there were only 15 empirical articles that focused on the caregivers of stroke patients and measured caregivers’ well-being. Finally, 5 more articles were identi-
Prevalence of Caregiver Depression

Seven studies provided estimates of the prevalence of depression among stroke caregivers. These estimates ranged from as low as 34%,12 measured by the Center for Epidemiologic Studies Depression Scale (CES-D),13 to as high as 40% to 52%,3,6,14 measured by the General Health Questionnaire.15 Some other studies also reported similar results despite the use of different instruments. In these studies, 39% to 42% of stroke caregivers were depressed,1,7,16 as measured by the Hamilton Depression Rating Scale (HDR),17 Beck’s Depression Inventory (BDI),18 or the Wakefield Assessment of Depression Inventory.19

These findings were generally consistent despite the specific instruments used, and the proportion of depressed caregivers was much higher than comparable noncaregiver populations. For instance, only 12% of a noncaregiving control group were depressed,7 as measured by the HDR; 16.5% of a comparable noncaregiver population were depressed,10 as measured by the CES-D. Moreover, 1 study20 demonstrated that stroke caregivers were statistically more depressed than the control group by comparing the group mean scores measured by the Zung Self-Rating Depression Scale. However, the proportions of depression among caregivers and the control group were not reported in the study.20

In summary, the literature consistently documented high rates of depression in stroke caregivers, which were higher than both available norms and comparison of control groups. However, most stroke caregiving studies have the common characteristics of small sample sizes and opportunistic samples with self-selection bias. Thus, it was possible that biased samples of these studies were more likely to include the more depressed caregivers. No research was identified that has randomly drawn a sample from a stroke caregiver population, which would provide better estimates of the prevalence of depression in stroke caregivers.

Predictors of Caregiver Depression

A variety of caregiver and patient factors have been studied as possible predictors of the degrees of caregiver depression. A summary of the association between predictors and caregiver depression is presented in Table 2. Across multiple studies, Table 2 shows the numbers of the study results reporting significant positive, negative, or no relationship between the predictors and caregiver depression. Because factors related to caregiver depression might function differently at different critical time intervals, the same study may report 2 different relationships between the predictors and caregiver depression at 2 different times; in such instances, both sets of predictors were noted in the table.

Caregiver Demographics

Several studies examined the correlation between caregiving outcomes and demographic characteristics of stroke caregivers, including the caregiver’s age, income, caregiving duration, and spousal or other relationship with the patient. Three studies found the age of the caregiver was not related to the caregiver’s depression.6,12,21 However, the mean time intervals between data collection and stroke onset were unknown in the first 2 studies.6,21 The third study12 found that the time interval was critical for the relationship, because older caregivers were less likely to have depression at 6 to 9 months after stroke but not at 3 to 10 weeks after stroke.

Two studies did not find a relationship between caregivers’ income and caregivers’ depression.12,21 The mean time interval between data collection and stroke onset was unknown for the second study,21 while the mean time interval was 3 to 10 weeks for the first study. However, the first study12 found that caregivers who had higher income were less likely to be depressed at 6 to 9 months after stroke.

Two studies did not find a relationship between longer duration of care and caregiver depression.6,21 Two studies found that spousal caregivers were more likely to be depressed during the acute care phase.12,22 However, during the chronic care phase, these 2 studies found that being a spousal caregiver was not a significant predictor for caregiver depression.12,22

Caregiver Psychosocial Factors

At the acute stroke phase, 2 studies found that caregivers’ concern for future care was the most important predictor of caregivers’ depression.12,16 However, after the acute stroke phase, 1 study12 found that caregivers’ concern for future care was no longer a significant predictor of caregivers’ depression at the chronic phase.

Two studies found that caregivers with fewer social contacts were more likely to be depressed.7,22 Moreover, caregivers with fewer social network members were more likely to be depressed during either the acute phase or the chronic phase.22

Caregiver Physical Health

Four of 20 articles used a self-rated global health item to evaluate caregiver current health on a scale from excellent to poor. None of these 4 studies6,12,14,22 found a significant relationship between caregivers’ self-rated health and their depression. However, 3 studies using the measures of physical symptoms7,12,22 found that caregivers with more physical symptoms were more likely to be depressed.

Stroke Patient Symptoms

In 6 studies, the physical disability of stroke patients, measured by the Barthel Index (BI),23 was not related to caregiv-
### TABLE 1. Summary of Stroke Caregiving Studies Published Since 1986

<table>
<thead>
<tr>
<th>Date of Publication</th>
<th>Sample Size, n</th>
<th>Time From Stroke</th>
<th>Characteristics of Caregivers</th>
<th>Major Domains Examined</th>
<th>Key Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aug 1986⁴</td>
<td>302</td>
<td>At 3 mo, 6 mo, 1 y, and 2 y</td>
<td>85% of caregivers were spouses; 72% of spousal caregivers were wives.</td>
<td>Patients: disability, cognitive impairment, depression, level of social activities. Caregivers: depression.</td>
<td>Caregivers’ depression was significantly related to patient’s disability up to 1 y after stroke but not at 2 y. At six mo, caregivers’ depression is related to patients’ depression, the level of social activities but not to cognitive impairment. At 2 y after stroke, none of measured factors were related to caregivers’ depression.</td>
</tr>
<tr>
<td>Sep 1986¹⁴</td>
<td>89</td>
<td>Average 11 mo</td>
<td>84% of caregivers were female; 59% were black; 55% were spouses.</td>
<td>Patients: functional status, severity of stroke. Caregivers: social activities, general and emotional health.</td>
<td>There was no significant difference between caregivers caring for patients at homes and caregivers caring for patients in institutions regarding their general, social, and emotional health. Patient’s functional status and the presence of additional life stress were related to caregivers’ decreased social activity and psychiatric distress.</td>
</tr>
<tr>
<td>Feb 1987⁷</td>
<td>Stroke group: 101, Control group: 59</td>
<td>1–3 y</td>
<td>100% of caregivers were spouses. There were no significant differences between groups regarding past medical or psychiatric history.</td>
<td>Patients: functional status, symptoms of stroke. Caregivers: depression, physical symptoms.</td>
<td>Stroke caregivers group was more depressed and had more physical symptoms than control group. Depression increased with the severity of stroke. Depressed spouses were more likely to be taking tranquilizers than nondepressed spouses but no more likely to be taking antidepressants. Social rehabilitation after stroke was less successful when the spouses were depressed.</td>
</tr>
<tr>
<td>Dec 1987³⁷</td>
<td>89</td>
<td>Average 11 mo</td>
<td>84% of caregivers were female; 59% were black.</td>
<td>Caregivers: social activities, general and emotional health.</td>
<td>The majority of caregivers were satisfied with their roles as caregivers and would do it again if faced with that decision. They relied on family and friends for help with caregiving but not on formal services.</td>
</tr>
<tr>
<td>Apr 1988¹¹</td>
<td>20</td>
<td>Unknown</td>
<td>60% of caregivers were females; mean age was 67.7 y.</td>
<td>Patients: level of dependency. Caregivers: psychiatric disorders; caregiving strain, communication functions.</td>
<td>The level of depression in spousal caregivers was only significantly related to problems of dependency. Caregivers’ strain was negatively related to family economics and communication functions and positively related to level of dependency.</td>
</tr>
<tr>
<td>Aug 1988²²</td>
<td>Time 1: 162, Time 2: 140, Time 3: 128</td>
<td>Time 1: 3–10 wk, Time 2: 7–9 mo, Time 3: 13–15 mo</td>
<td>86% of caregivers were white, 78% were female; mean age of caregivers at time 1 was 56.31 y.</td>
<td>Caregivers: perceived severity of stroke, concern for future care, social network/support, depression, caregiver burden.</td>
<td>Caregivers who were at risk at time 3 had higher initial depression scores, were less optimistic, were more likely to be married to the patients, and named fewer network members than at time 2.</td>
</tr>
<tr>
<td>Jun 1988¹²</td>
<td>Time 1: 162, Time 2: 140</td>
<td>Time 1: 3–10 wk, Time 2: 7–9 mo</td>
<td>86% of caregivers were white, 78% were female; mean age of caregivers at time 1 was 56.31 y.</td>
<td>Patients: functional status, personality characteristics. Caregivers: perceived severity of stroke, concern for future care, social network/support, depression, caregiver burden.</td>
<td>In acute stroke phase, the level of depression and perceived burden of caregivers were related to stroke patients’ functional impairments, relationship to the patients, and concern for future care. In chronic stroke phase, the level of depression and perceived burden of caregivers were related to caregivers’ age and their perceived severity of caregiving, and patients’ personality changes. Controlling for time 1 level of depression, time 2 depression was significantly related to caregivers’ change in satisfaction of social contact and reciprocal confiding.</td>
</tr>
<tr>
<td>Feb 1989²⁷</td>
<td>40</td>
<td>Average 9 mo</td>
<td>80% of caregivers were spouses; 69% were female.</td>
<td>Patients: depression, physical and cognitive impairment. Caregivers: depression.</td>
<td>Patients who were more depressed felt either more overprotected by their caregivers, had more negative perceptions of their caregivers, or had caregivers who saw them more negatively. However, patients’ depression and motivation were not related to caregivers’ depression.</td>
</tr>
<tr>
<td>Summer 1990³⁴</td>
<td>41</td>
<td>Average 14.63 mo</td>
<td>83% of caregivers were female; mean age was 67.6 y.</td>
<td>Patients: functional status. Caregivers: caregiving strain, depression.</td>
<td>Caregiver strain is significantly related to caregiver depression. Caregiver anxiety increased concomitantly with caregiving duration. Caregivers’ depression, hostility, and strain were not significantly related to caregiving duration.</td>
</tr>
</tbody>
</table>
### TABLE 1. Continued

<table>
<thead>
<tr>
<th>Date of Publication</th>
<th>Sample Size, n</th>
<th>Time From Stroke</th>
<th>Characteristics of Caregivers</th>
<th>Major Domains Examined</th>
<th>Key Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb 1991&lt;sup&gt;32&lt;/sup&gt;</td>
<td>135</td>
<td>Time 1: initial hospitalization after stroke</td>
<td>93% of caregivers were female; 76% were spousal caregivers.</td>
<td>Caregivers: knowledge about stroke care, depression, family dysfunction assessment.</td>
<td>Patients who were at risk for less-optimal home care had caregivers who were (1) more likely to be depressed, (2) less likely to be married to patients, (3) below average in knowledge about stroke care, and (4) reporting more family dysfunction.</td>
</tr>
<tr>
<td>Sep 1992&lt;sup&gt;6&lt;/sup&gt;</td>
<td>Stroke caregivers: 48, Dementia caregivers: 51</td>
<td>Unknown</td>
<td>Stroke caregivers: Females (54%), Mean age (74.6). Dementia caregivers: Females (61%), Mean age (78.2).</td>
<td>Caregivers: depression, caregiving burden.</td>
<td>Caregiver burden was significantly correlated with psychological morbidity in both caregiver groups. The positive correlation between measure of burden and psychological morbidity was stronger in the dementia caregivers than in the stroke caregivers. Psychiatric aspects of chronic disability rather than physical aspects were found to be more stressful to caregivers.</td>
</tr>
<tr>
<td>Aug 1994&lt;sup&gt;20&lt;/sup&gt;</td>
<td>AD caregivers: 25, Stroke caregivers: 25, Controls: 25</td>
<td>Unknown</td>
<td>AD caregivers: mean age 56.3 y. Stroke caregivers: mean age 63.9 y. Control group: mean age 60.9 y.</td>
<td>Caregivers: immunology function, social resources, depression.</td>
<td>AD and stroke caregivers were more depressed than the control group. AD caregivers reported having fewer social resources than the stroke caregivers and control group; stroke caregivers had fewer social resources than control group. These differences still remained after ruling out the age and SES effect. However, with respect to immunologic function, there were no differences among the 3 groups.</td>
</tr>
<tr>
<td>Dec 1994&lt;sup&gt;38&lt;/sup&gt;</td>
<td>44</td>
<td>Range 6 mo to 4 y</td>
<td>66.7% of spousal caregivers were wives.</td>
<td>Patients: functional independence, morale. Caregivers: morale, caregiving impression.</td>
<td>Morale of caregivers and care receivers was positively correlated. Functional independence of patients predicted patient and spouse morale levels. Impression of caregiving and morale of caregivers are positively correlated.</td>
</tr>
<tr>
<td>Mar 1995&lt;sup&gt;28&lt;/sup&gt;</td>
<td>78</td>
<td>Average 14.7 mo</td>
<td>75.6% of caregivers were female; 93.6% were white.</td>
<td>Caregivers: caregiving daily stresses, caregiving satisfaction, well-being.</td>
<td>Daily stresses of caregivers were negatively associated with their well-being. caregiving satisfaction of caregivers was not significantly related to their well-being. However, when caregiving satisfaction outweighed caregiving stresses, caregivers reported lower levels of distress.</td>
</tr>
<tr>
<td>May 1995&lt;sup&gt;3&lt;/sup&gt;</td>
<td>84</td>
<td>1 y</td>
<td>82% of caregivers were female; mean age was 58 y.</td>
<td>Patients: physical disability, and abnormal behaviors. Caregivers: emotional distress.</td>
<td>There was no significant relationship between emotional distress among caregivers and the degree of patients’ physical disability. However, the abnormal behaviors of stroke patients were significantly related to their caregivers’ emotional distress.</td>
</tr>
<tr>
<td>Feb 1996&lt;sup&gt;47&lt;/sup&gt;</td>
<td>35</td>
<td>3 y after stroke</td>
<td>71% of caregivers were female; mean age was 82 y.</td>
<td>Patients: personality, functional status. Caregivers: caregiving burden.</td>
<td>A higher burden was related to a closer relationship but not to the living situation. The highest caregiver burden was found among patients showing the greatest improvement of functional status.</td>
</tr>
<tr>
<td>Winter 1996&lt;sup&gt;36&lt;/sup&gt;</td>
<td>38</td>
<td>6 mo after stroke</td>
<td>82% of caregivers were female; mean age was 59 y; 59% were black.</td>
<td>Patients: level of handicap, life satisfaction, disability. Caregivers: life satisfaction.</td>
<td>Caregivers’ life satisfaction was directly related to caregivers burden, which was in turn related to patients’ level of handicap.</td>
</tr>
<tr>
<td>Nov 1996&lt;sup&gt;48&lt;/sup&gt;</td>
<td>50</td>
<td>12 mo after stroke</td>
<td>68% of caregivers were female; mean age was 63.8 y.</td>
<td>Caregivers: age, physical health, caregiving responsibilities, caregiving stress, satisfaction with service provision.</td>
<td>Caregivers’ age, gender, and caring responsibilities were not related to caregivers’ well-being at 12 mo after stroke. Caregivers’ physical health, appraisal of caregiving stress, and satisfaction with service provision were related to caregivers’ well-being.</td>
</tr>
<tr>
<td>Feb 1998&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Time 1: 125 in active group, 70 in control group, Time 2: 115 in active group, 69 in control group.</td>
<td>Time 1: at 3 mo Time 2: at 12 mo</td>
<td>63% of caregivers were spouses; 37% were adult children.</td>
<td>Patients: level of handicap, cognitive impairments, depression. Caregivers: depression.</td>
<td>There was no significant difference in the depression rate of caregivers between districts with active programs and those without such programs at 3 mo and 12 mo. There were significantly more severely depressed caregivers in districts without active programs than those with such programs at 12 mo. The level of handicap of patients is related to caregivers’ depression at 3 mo.</td>
</tr>
</tbody>
</table>
ers’ depression at the chronic stroke phase. However, 2 studies reported that patients’ physical disability measured by the BI was positively related to caregivers’ depression at the acute phase.12,16

Depression is considered the most common poststroke psychiatric condition of stroke patients.25 Depending on the diagnostic criteria and the duration of stroke, the prevalence of depression of stroke patients ranges from 23% to 63%.25,26 Three studies found that depression of stroke patients was positively associated with the caregivers’ depression; the third study found this positive relationship at the acute stroke phase, but the first 2 studies did not specify the time interval between data collection and stroke onset. One study did not find a relationship between stroke patients’ depression and caregivers’ depression at the chronic stroke phase. Moreover, 1 study found that the severity of the patients’ depression was positively associated with the severity of the caregivers’ depression at 3 months after stroke.1

Objective measures of patient cognitive function were not related to caregiver depression at the acute16 or the chronic stroke phase. However, 1 study indicated that caregivers with greater perception of patients’ “cognitive hassles” had higher depression at a mean interval of 14.7 months after stroke. Furthermore, all 3 studies reported that the abnormal or disruptive behavior of stroke patients was positively related to caregivers’ depression.3,6,28

### TABLE 2. Predictors of the Stroke Caregivers’ Depression:
Number of Study Results Reporting Positive, Negative, or No Relationship Between Predictor Variables and Caregiver Depression

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Positive</th>
<th>Negative</th>
<th>None Found</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver demographics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older age</td>
<td>0</td>
<td>112</td>
<td>36,12,21</td>
</tr>
<tr>
<td>Higher income</td>
<td>0</td>
<td>112</td>
<td>21,22,21</td>
</tr>
<tr>
<td>Longer duration of caregiving</td>
<td>0</td>
<td>0</td>
<td>25,21</td>
</tr>
<tr>
<td>Relationship with patient (spouse)</td>
<td>21,22</td>
<td>0</td>
<td>21,22</td>
</tr>
<tr>
<td>Caregiver psychosocial factors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More concern for future care</td>
<td>21,16</td>
<td>0</td>
<td>112</td>
</tr>
<tr>
<td>Fewer social contacts</td>
<td>21,22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Caregiver physical health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor self-rated health</td>
<td>0</td>
<td>0</td>
<td>46,12,14,22</td>
</tr>
<tr>
<td>More physical symptoms</td>
<td>37,22,22</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Stroke patient symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More physical disability</td>
<td>21,16</td>
<td>0</td>
<td>61,3,6,12,16,24</td>
</tr>
<tr>
<td>More depression</td>
<td>3,6,16</td>
<td>0</td>
<td>127</td>
</tr>
<tr>
<td>Poor cognitive function</td>
<td>128</td>
<td>0</td>
<td>21,16</td>
</tr>
<tr>
<td>More abnormal behavior</td>
<td>3,6,28</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
research. Most stroke caregiving studies were cross-sectional. Only 5 of the 20 studies were longitudinal. One study reported that 42% of stroke patients were still alive after a mean interval of 4.9 years after stroke. Poststroke patients are more likely to develop dementia over time, which may make caregiving more difficult over time. Due to the stroke patients’ prolonged survival and high risk of developing dementia, it is important to know of factors related to caregivers’ depression and other outcomes beyond 2 or 3 years after stroke. However, based on the current stroke caregiving literature, little is known about the factors related to caregivers’ outcomes at several years after stroke. In fact, it will be important to study the trajectories of stroke caregiving, which helps in understanding the dynamic interaction relationship between caregivers and stroke patients and the dynamic effect of emotional, social, physical, and mental disabilities on caregivers’ well-being. Moreover, it might enable researchers to find and provide the different interventions according to the different critical periods.

**Sample Size and Statistical Power**
To increase the sample size, 14 of the 20 studies did not control the different impacts of caregiving for first-time stroke patients and second-time stroke patients. The sample sizes of the 20 stroke caregiving studies ranged from 20 to 302 (median, 86; mean, 96; SD, 64.5). None of the 20 studies reported their statistical power for testing the stated hypothesis, raising concern about the reliability and generalizability of these findings.

**Statistical Methods**
Many stroke caregiving studies used relatively simple methods, such as ANOVA, t test, or simple correlation analysis. To truly understand the complexity of stroke caregiving outcomes, it is helpful to apply more advanced methods that are often applied in other caregiving research, such as multivariate analytical strategies, and structural equation models, to assess complex theory-based models and hypotheses.

**Measures**
The measurements used in stroke caregiving studies are very diverse, and some researchers raised concerns about the validity and reliability of measures used in the studies. Moreover, many measures are self-reported instruments, and little is known the clinical significance of these outcomes. For example, 6 of the 20 studies reported caregivers burden with 6 different measures. These burden scales did not have established cutoff points. Moreover, it would be inappropriate to use these burden scales for noncaregiver comparison. Thus, assessment of the estimates of burden rate is problematic.

**Comparison of Caregivers and Noncaregivers**
It is necessary to compare caregivers and noncaregivers in order to differentiate unique stroke caregiving impacts. Without inclusion of noncaregivers, it is difficult to define the extent of caregiver outcomes beyond or below those found in the general population having demographic status similar to that of stroke caregivers.

**Neglected Topics**
**Caregiver Physical Health**
The physical health of stroke caregivers is as important as their mental health. Although caregiving stress in AD has been shown to affect caregiver physical health, little is known from current literature about whether stroke caregiving affects caregivers’ physical health. One study did not find any differences regarding the immunological functioning among the AD caregivers, stroke caregivers, and noncaregivers. Two studies reported the mean scores of caregivers’ self-rated health. However, without comparison to a noncaregiver group, it is hard to know to what extent caregiver physical health is affected by stroke caregiving. Future research is needed to systematically identify the factors related to stroke caregivers’ physical health and its changes in order to prevent caregivers’ physical health from declining.

**Ethnicity**
Black Americans have higher risks of developing stroke than white Americans. Moreover, both Native Americans and Hispanic Americans have significant lower mean age at stroke onset than white Americans. Several factors were striking in their absence as variables studied as potential predictors. In particular, none of the projects assessed whether ethnicity predicts caregiver depression. Ethnicity is an especially important issue to investigate, given the consistent findings in AD caregiving literature that ethnicity has profound effects on caregiving.

Among the 20 stroke caregiving articles, only 3 indicated having black caregivers, ranging from 59% (n=89) to 61% (n=38) of the sample size. In addition, 3 article identified having “nonwhite” caregivers, ranging from 4.5% (n=44) to 14% (n=162) of the sample size. Unfortunately, none of the studies investigated the differences in depression between white and black stroke caregivers. No empirical evidence was reported about the effects of race, culture, and/or ethnicity on the stroke caregiving experience.

**Time**
The neurological recovery of stroke often improves significantly within the 3-week period immediately after stroke, and the functional recovery may continue to improve up to 18 months after stroke. Thus, stroke patients who are at different time periods after stroke generally have different severity and manifestation of neurological deficits, and different levels of functional impairments and depression status. Moreover, short-term coping for medical crisis is different from long-term coping.

The impact of caregiving is more likely to be affected differently over time due to the coping process of caregivers and changing status of patients. Thus, the measurement of time interval of poststroke is a critical variable for study design, interpretation, and generalization of stroke caregiving. However, most studies paid little attention to time as a factor for caregivers’ adaptation. Many stroke caregiving
studies even did not report the mean time interval after stroke so that it was hard to compare the results of these studies to others. Some studies reported the mean time interval poststroke, however, the standard deviations of the mean interval were as long as eight months in these studies.

Positive Aspects of Caregiving

Current research has emphasized the negative impacts of stroke caregiving. Even though stroke caregivers have to deal with the huge amount of physical, emotional, and financial burden, most caregivers are satisfied with their current life, and have positive feeling about caregivers roles. About 17% of caregivers in one study reported that caregiving improved their relationship with care recipients. Further studies are needed to systematically examine both negative aspects and positive aspects of caregiving.

Special Problems in Stroke

The impacts of specific problems on stroke caregiving need to be examined. For example, incontinence is a significant predicator of stroke severity because of its association with mortality and disability and its influence on the institutionalization of stroke survivors. However, little is known about the effect of incontinence on caregiving outcomes.

Only one of the 20 studies examined the caregiving outcomes of aphasia patients. Patients with severe aphasia and cognitive impairments cannot be readily interviewed. Taking care of aphasia patients might have unique impacts on caregiving outcomes. Future research is needed to test the effect of communication deficits on caregiving outcomes.

Policy and Practice Implications of Current Studies

Stroke caregivers appear to be at substantial risk for depression. Many AD caregiving studies have demonstrated that psychosocial intervention had the potential to improve caregivers’ depression. Early intervention for the depression of stroke caregivers may be more effective in preventing subsequent psychological morbidity. There were various interventions developed to reduce caregivers’ psychiatric morbidity, such as visits by a specialist nurse, or long-term counseling and early involvement of caregivers in the planning of patients’ discharge. However, there was no clear evidence that these interventions were effective. Thus, it is necessary to investigate which intervention or combination of interventions meets the most caregivers’ needs at different critical periods. Intervention targeting stroke patients may also yield beneficial effects on caregivers due to the psychological and social interactions between stroke patients and their caregivers.

Recently published poststroke rehabilitation guidelines recommended that physicians and other health care professionals maximize the well-being of both patients and caregivers. However, one study reported that 22% of stroke caregivers felt that the physicians of stroke patients had not been particularly helpful to them. In fact, physicians’ attention to caregivers is important for both caregivers and stroke patients. The rate of diagnosis and treatment for depression of stroke patients and caregivers was very low. Only 17.4% of depressed stroke patients were undergoing antidepressant drug treatment at 12 months after stroke onset. The depressed caregivers were taking more sedatives and nonpsychotropic drugs and were less likely to be taking antidepressants. If caregivers are depressed, then social rehabilitation of stroke patients may be less successful. Unless clinicians monitor both stroke patients and caregivers more closely to prevent and treat the adverse psychiatric outcomes, any other interventions might not be as effective.

In summary, it is unfortunate that researchers have paid little attention to family caregiving for elderly stroke patients. Evidence to date clearly suggests that stroke caregiving is highly stressful and leads to clinically significant depression in caregivers. Caregiving stress has the potential to hamper rehabilitation of the patients and is of vital importance both as a research topic and the focus of clinical care. Stroke caregiving studies may help us not only to better understand caregiving impact, but also to find the most effective interventions to improve the quality of life of stroke patients and their caregivers, reduce the burden and depression of caregivers, and decrease the need for long-term institutionalization.

References


Family Caregiving for Patients With Stroke: Review and Analysis
Beth Han and William E. Haley

*Stroke*. 1999;30:1478-1485
doi: 10.1161/01.STR.30.7.1478

*Stroke* is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 1999 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/30/7/1478

**Permissions**: Requests for permissions to reproduce figures, tables, or portions of articles originally published in *Stroke* can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

**Reprints**: Information about reprints can be found online at:
http://www.lww.com/reprints

**Subscriptions**: Information about subscribing to *Stroke* is online at:
http://stroke.ahajournals.org/subscriptions/