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Problems and Benefits Reported by Stroke Family Caregivers: Results from a Prospective Epidemiological Study

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Abstract

Background and Purpose—Stroke symptoms can be very stressful for family caregivers, but most knowledge about the prevalence and stressfulness of stroke-related patient problems is derived from convenience samples. In addition, little is known about perceived benefits of the stroke caregiving experience. The purpose of this study was to determine the prevalence and stressfulness of stroke-related problems, and perceived benefits of caregiving, as reported by an epidemiologically-derived sample of caregivers of stroke survivors.

Methods—Stroke survivors (N=75) from a prospective epidemiological study of stroke, the REasons for Geographic and Racial Differences in Stroke (REGARDS) study, and their family caregivers were followed. Caregivers were given a comprehensive telephone interview 8 to 12 months after the stroke, using measures of stroke patient problems, caregiver appraisals of the stressfulness of these problems, and perceived benefits of caregiving.

Results—Caregivers rated patient problems with mood (depression, loneliness and anxiety), memory, and physical care (bowel control), as the most stressful, but reported prevalence of these problems was lower than those reported previously in studies using clinical samples. Caregivers also reported many benefits from caregiving, with over 90% reporting that caregiving enabled them to appreciate life more.

Conclusions—Epidemiologically based studies of stroke caregiving provide a unique picture of caregiver strains and benefits compared with clinical studies, which tend to over-represent more impaired patients. Support for caregivers should include interventions to aid their coping with highly

stressful mood, physical care, and cognitive problems of stroke patients, but should also attend to perceived benefits of caregiving.

Keywords

Family caregiving; Stroke; Epidemiological studies; Caregiving stress; Benefits of caregiving

Many stroke survivors experience long-term impairments in physical, psychosocial, and cognitive function^{1,2} that are formidable challenges to family caregivers^{3,4}. Caregiving demands in the home can place care recipients at risk for subsequent institutionalization^{5,6}. Caregivers of stroke survivors tend to have elevated levels of depression during both acute and chronic phases of care^{7,8}.

Most research on problems faced by stroke caregivers comes from convenience samples recruited through clinical settings^{1,8-11}. Patients and caregivers recruited through clinical/convenience likely have greater impairment and distress than those not seeking care. In addition, most convenience samples of stroke caregivers include very few ethnic minority participants even though African Americans have higher rates of stroke than Whites¹².

Many studies have examined patient problems reported by stroke caregivers and the impact of caregiving stress on caregivers' depression, anxiety, and quality of life^{5,8, 13-16}, but very few studies have assessed caregiver reports of the occurrence of specific problems over a given time and assessed appraised stressfulness. Researchers are also increasingly focusing on benefits of caregiving¹⁷, with findings suggesting that benefit finding is an important way that caregivers cope even while facing very difficult caregiving situations^{17,18}. Unfortunately, little is known about the perceived benefits of caring for stroke survivors.

We identified only one epidemiologically - based study of stroke focused on caregiver reports of the prevalence of problems during a specific time period after stroke. Anderson and colleagues¹⁹ assessed the prevalence of activity of daily living problems, other activity limitations, and abnormal behaviors in 84 stroke patients identified from a stroke registry, one year following their stroke. Dressing (52%), bathing (48%), and feeding (36%) were the most common activity of daily living (ADL) impairments. The most common abnormal behaviors included being slowed down (86%), excessive worries (63%), and forgetfulness (63%). This study did not report caregivers' appraisals of the stressfulness of these problems, or study perceived benefits of caregiving.

Studies examining perceived benefits of stroke caregiving are few. One qualitative study²⁰ found that caregivers reported successes as well as problems, and identified themes in these successes, but did not report the prevalence of specific positive experiences.

The purpose of the present study was to determine caregiver-reported prevalence and stressfulness of stroke-related problems among an epidemiologically-derived sample of family caregivers of stroke survivors experiencing a first stroke. We are conducting a prospective study of stroke caregiving by recruiting individuals previously enrolled in the REasons for Geographic and Racial Differences in Stroke (REGARDS) study²¹, an ongoing epidemiologic investigation of stroke incidence and mortality using a large national sample of African American and White adults over the age of 45 years. Our ancillary caregiving project, the Caring for Adults Recovering from the Effects of Stroke (CARES) study, collects additional information beyond REGARDS on stroke survivors and their primary family caregivers. We examined caregiver reports of the prevalence and stressfulness of a variety of patient impairments related to ADL, instrumental activities of daily living (IADL), mood, language, and sensory and motor functioning, and perceived benefits of caregiving.

Materials and Methods

Participants

Family caregivers of community-dwelling stroke survivor participants of the REGARDS study were invited to participate in the CARES study. Participants for the REGARDS study were randomly selected from a commercially available nationwide list. A total of 30,214 participants, 45 years of age or older, have completed the full REGARDS intake interview, including both a telephone and in-home assessment and are being followed longitudinally every six months with telephone interviews asking about stroke symptoms and hospitalizations. The sampling, recruitment, and telephone interviewing procedures for REGARDS have been described elsewhere²¹⁻²³.

The present analyses focus on primary family caregivers of stroke survivors, who self-reported a first stroke which was subsequently confirmed by review of medical records. Index hospitalization event medical records were obtained and were reviewed and adjudicated by two board certified neurologists with expertise in stroke. Stroke subtype was confirmed by the same physician experts using imaging and other diagnostic data abstracted from the index stroke event hospitalization record. World Health Organization criteria were used²⁴. Potential caregiver participants were excluded if they (1) were less than 21 years of age; or (2) unable to comprehend or respond to study questions.

Based on the stroke risk of the REGARDS participants²⁵ and the number of follow-up calls completed for eligible participants, we project that there were 230 eligible stroke survivor-caregiver dyads available for recruitment during the enrollment period. Of these, we contacted both members of the dyad in 95 cases (41%) and successfully enrolled 75 (79%) of the contacted dyads. The sample consisted of 75 stroke survivors and their family caregivers who were enrolled in the study over 36 months from August of 2005 to July of 2008.

Study Design

A cross-sectional, observational design was used. Stroke survivors from REGARDS were first contacted by telephone by trained research interviewers to establish eligibility, including confirming the date of the reported stroke event and the availability of a primary family caregiver for participation. The interviewer then provided more information about the study to the caregiver and obtained verbal informed consent to participate in CARES.

Procedures

All data reported in the present manuscript come from the baseline CARES telephone interview for the caregivers except for clinical data about the stroke event, which come from the REGARDS adjudication process. All telephone interviewing was conducted by trained interviewers with primary caregivers. Each stroke survivor and family caregiver received \$20 for completing the telephone interview.

The CARES baseline telephone interview was collected between 8 and 12 months after the stroke event ($M=267.68$ days, $SD=39.57$). Caregivers reported on stroke survivor ADL and IADL problems; memory and emotional problems; communication, motor, and sensory impairments; and caregiver stressfulness appraisals and perceived benefits of caregiving.

Instruments

Data related to stroke survivor and caregiver demographic characteristics were collected using standard interview questions. Data from the REGARDS consensus diagnosis were used to describe the location and type of stroke and data on hospitalization.

Stroke Survivor Impairments and Problems—We developed a 28 item instrument assessing caregiver report of the occurrence of a variety of stroke survivor impairments and problems. These items were drawn from widely used instruments including the Frenchay Activities Index²⁶, Barthel index²⁷ and the Revised Memory and Behavior Problems Checklist (RMBPC)²⁸. Items assessed stroke survivor problems with ADL (e.g. incontinence, bathing), IADL (e.g. managing money), mood (e.g. sadness, loneliness, anxiety), cognition (e.g. memory), motor and sensory impairment (e.g. problems using their arm or hand, hearing and vision problems), and communication (expressing themselves or participating in conversations). Caregivers were asked whether the impairment or problem had occurred during the previous week. Coefficient alpha for the scale was .92. The total number of problems was also related with the Barthel index and the Rankin²⁹ index obtained during a subsequent home visit for 59 participants ($r_s > .62$), suggesting excellent reliability and concurrent validity.

Stressfulness Appraisals—Caregivers' subjective reactions to impairments and problems of the stroke survivor were assessed by asking caregivers to rate the stressfulness of all endorsed problems on the preceding instrument. Using a five-point scale (0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely), caregivers reported how much they were bothered or upset by the problem when it occurred. The stressfulness rating was calculated only for caregivers who reported the problem occurred within the previous week²⁸.

Perceived Benefits of Caregiving—The Positive Aspects of Caregiving Scale contains 11 items³⁰ and is designed to assess the caregiver's perception of benefits associated with the caregiving experience. The respondents were asked to respond “yes” or “no” to each of the 11 questions.

Overall strain and depressive symptoms—Caregivers were asked to provide an overall rating of the amount of strain they experienced due to the caregiving role. Response options for the caregiving strain question were the same as those used in previous research³¹ and included “no strain,” “some strain,” or “a lot of strain.” Caregivers also reported on the number of hours of care provided per week. The 20-item Center for Epidemiological Studies-Depression scale³² was used to assess depressive symptoms. Items were rated on a 4-point scale ranging from “rarely or none of the time (less than once a day)” to “most of the time (5-7 days)”. Total scores ranged from 0 to 60, and a score of 16 or more is suggestive of a high likelihood of a clinically significant depressive disorder³².

Statistical Analyses

Demographic and study data were analyzed using mean and standard deviations or frequencies and percentages for nominal variables.

Results

Descriptive characteristics of the stroke survivors and the family caregivers are presented in Table 1. In terms of site, 56% were left hemisphere, 39% right hemisphere, and 5% bilateral. For type of stroke, 85% were infarctions and 15% were hemorrhages. The majority of stroke patients (89%) were hospitalized after their stroke events, and the average length of those hospitalizations was 11.1 days (SD = 16.5). Caregivers provided an average of 36.9 hours of care per week (SD = 44.2). When asked about overall levels of strain, 44.00% of caregivers reported no strain, 41.33% reported some strain, and 14.67% reported a lot of strain. The average CES-D score for caregivers was 7.32 (SD = 9.15), with only 13.7% scoring at or above the commonly used clinical cut point of 16--well below levels of depressive symptoms typically reported in studies of stroke caregiving¹⁰.

Table 2 shows the 28 stroke-related patient problems assessed and their caregiver-reported prevalence (i.e., percent of caregivers reporting the problems occurred in the previous week) as well as the rank order of problem stressfulness. Caregivers reported an average of 6.61 (SD = 6.55) patient problems, with 61 reporting at least one current problem. The average stressfulness rating was 0.91 (SD = 0.96) across problems.

While 82% of caregivers did report the stroke patient having problems, no single problem was reported by 50% or more of caregivers. Patient problems reported by at least one third of caregivers included patient anxiety (45%), needing help with transportation (45%), trouble remembering recent events (37%), difficulty walking or climbing stairs (37%), and problems with vision or hearing (37%). As can be seen in Table 2, stroke-related patient problems rated as most stressful by caregivers were appearing sad or depressed, loneliness, having problems with bowel control, feeling worthless, anxiety, asking repeated questions, and trouble remembering recent events. Among the items with the lowest stressfulness ratings were those assessing higher level IADLS.

Caregivers reported an average of 9.00 (SD = 3.13) benefits from caregiving. As depicted in Table 3, the percentage of caregivers reporting positive aspects of caregiving was quite high, with over 90% of caregivers reporting their experience as a stroke caregiver had increased their appreciation of life. All items were endorsed by at least 66% of caregivers. Other common reported benefits included feeling needed and appreciated and developing a more positive attitude toward life.

Discussion

Our results are one of the first from an epidemiologically based study to identify the most common and stressful stroke-related patient problems reported by family caregivers. Understanding stroke-related patient problems reported by caregivers is important because they are risk factors for caregiver depression, which also is a known risk factor for a negative impact on the stroke survivor⁶, and because they increase risk of nursing home placement³³.

Caregivers rated mood disturbances of the stroke survivors, including sadness and anxiety, among the most stressful problems they faced. Many survivors have depression and anxiety a year post stroke, even after participating in usual post-discharge programs³⁴. Anxiety symptoms are present in both acute and non-acute stages (i.e., 3 yrs.) of stroke and are often associated with fear of stroke recurrence³⁵. Interventions to help caregivers manage depression and anxiety in persons with stroke should be a high priority. Research suggests that care management of poststroke depression is a promising intervention deserving further attention³⁶.

Memory related patient problems, including asking repeated questions, and trouble remembering recent events, were also rated as highly stressful. Caregivers can learn strategies to cope with such impairments, including distraction and avoiding arguing with the patient.³⁷

Problems with dressing and bowel-related difficulties were rated as the most stressful ADL problems. A variety of sensory, motor, and communication problems were also rated as highly stressful. In general, these findings are consistent with previous research^{8,10,11} and emphasize the necessity of developing interventions to manage these common and stressful problems. Assistance with IADLs was among the least stressful caregiving problem, because they are more within the normal range of adult helping behaviors, activities often done not only for disabled persons.

One important finding from this project is that, as a whole, caregivers in our sample appeared to be coping quite well and better than reported previously. Only 16% of caregivers reported

high levels of strain and CES-D scores were similar to those found in non-caregiving samples. Although caregivers reported dealing with a number of common and highly stressful care-recipient problems, caregiver reports of the percentage of patients with these problems were lower than in previously reported for clinically-based samples¹⁰. Such clinically-based convenience samples are probably more impaired than the general population of first-time stroke survivors.

Another positive finding from our epidemiologic sample of first-time stroke survivors and their family caregivers was that many caregivers reported benefits from caregiving, such as feeling a greater appreciation for life. Perceived benefits from caregiving may be an important psychological resource for caregivers. The ability to find benefits in stressful circumstances such as caregiving is increasingly seen not as a form of denial, but as a beneficial form of coping. Benefit finding may be a product of the ability to find meaning through positive reappraisals, spiritual beliefs, or other adaptive coping mechanisms in the face of stress¹⁸. One recent study of dementia caregivers found that finding benefits from caregiving predicted a better response to a caregiver intervention over a 12 month period³⁸. This is not to minimize the problems faced by caregivers, but we need to acknowledge that caregiving is not an entirely negative experience.

Current research supports that telephone social problem-solving partnerships between health providers and caregivers may be effective in improving caregivers' mental health³⁹. Future research needs to also explore whether these skills can be used to improve caregivers' subjective well-being, long-term.

This project had a number of strengths, including use of an epidemiological sample that was designed to be as representative as possible of Whites and African Americans over the age of 45 in the United States, focus on first strokes, and careful medical confirmation of self reported stroke. Limitations of the study include a lack of representation from other minority groups, the relatively small sample size, reliance on caregiver report, and the cross sectional nature of the data. Finally, although we had a high response rate of agreement to participate in our project (79%), our rigorous selection criteria meant that we could not include cases for whom medical data were unavailable or inconclusive, and we cannot know how individuals who participated differ from those not included in the sample. Finally, the measure of stroke patient impairment and problems, while having excellent reliability and concurrent validity, was a brief composite and did not sample some areas of impairment that might be of interest.

In conclusion, clinicians should make it a high priority to assess and intervene with caregivers on these highly stressful problems but also to identify perceived benefits of caregiving. Application of this framework has the potential to benefit future intervention efforts by identifying gaps in caregiver education, training, and support.

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Table 1

Demographic Information for Caregivers

Variable	Description
Family caregiver's age: mean, \pm standard deviation	63.69 (13.62)
Family caregiver's race	42 White Americans (56%) 33 African Americans (44%)
Family caregiver's education	5 less than high school (7%) 19 high school graduate (25%) 27 some college (36%) 23 college graduate (31%)
Family caregiver's relationship to stroke survivor	40 Spouses (53%) 23 Child (31%) 12 Other (16%)
Family caregiver's gender	59 Female (79%) 16 Male (21%)

Table 2
Prevalence and Stressfulness of Problems Reported by Stroke Caregivers, Ranked by Stressfulness

Rank	Problem	Prevalence Percent	Stressfulness rating (M ± SD)
1	Appeared sad or depressed	29.33	1.71 ± 1.31
2	Talked about feeling lonely	14.67	1.55 ± 1.57
3	Had a problem controlling his/her bowels	13.33	1.50 ± 1.27
4	Commented about feeling worthless or being a burden to others	20.00	1.47 ± 1.30
5	Appeared anxious or worried	45.33	1.44 ± 1.26
6	Been asking the same question over and over	25.68	1.42 ± 1.35
7	Had trouble remembering recent events	37.33	1.41 ± 1.25
8	Had problems using the arm or hand that was most affected by the stroke	32.00	1.38 ± 1.38
8	Needed help with toileting	10.81	1.38 ± 1.06
10	Needed help with dressing	20.00	1.33 ± 1.29
11	Had difficulty understanding what had been said to him/her in conversations	22.67	1.24 ± 1.35
11	Had difficulty expressing him/herself or participating in conversations	22.67	1.24 ± 1.25
13	Had difficulty concentrating on a task	17.33	1.15 ± 1.07
14	Been starting, but not finishing things	21.33	1.13 ± 1.20
15	Needed help getting in and out bed	13.33	1.10 ± 1.29
16	Needed help with bathing	21.33	1.06 ± 1.34
17	Had problems with vision or hearing	37.33	1.04 ± 1.04
18	Had difficulty walking or climbing stairs without assistance	37.33	1.00 ± 1.31
18	Needed help with eating or feeding himself/herself	4.00	1.00 ± 0.00
20	Needed help managing his/her money	29.33	0.95 ± 1.25
20	Needed help preparing meals	25.33	0.95 ± 1.03
22	Needed help with travel or transportation	45.33	0.91 ± 1.23
23	Needed help with grooming such as brushing teeth or combing hair	10.67	0.88 ± 0.83
24	Needed help using the telephone	9.33	0.86 ± 0.90
25	Had a problem controlling his/her bladder	21.33	0.81 ± 0.91
26	Needed help doing housework	25.33	0.79 ± 1.13
27	Needed help taking his/her medications as prescribed	26.67	0.75 ± 1.16
28	Needed help with shopping	30.67	0.65 ± 0.93

Note: In cases where average stressfulness ratings were identical across items, rankings indicate ties.

Table 3
Prevalence of Positive Aspects of Caregiving by Stoke Caregivers, Ranked by Percent Endorsing

Rank	Item	Prevalence/n	Percent
1	.. enabled you to appreciate life more?	68/75	90.67
2	.. made you feel needed?	66/75	88.00
3	.. strengthened your relationship with others?	64/74	86.49
4	.. enabled you to develop a more positive attitude toward life?	62/73	84.93
5	.. made you feel appreciated?	63/75	84.00
6	.. made you feel good about yourself?	61/75	81.33
6	.. made you feel strong and confident?	61/75	81.33
8	.. given more meaning to your life?	69/73	80.82
9	.. made you feel more useful?	60/75	80.00
10	.. made you feel important?	50/72	69.44
11	.. enabled you to learn new skills?	50/75	66.67