Care Received by Elderly US Stroke Survivors May Be Underestimated

Lesli E. Skolarus, MD, MS; Vicki A. Freedman, PhD; Chunyang Feng, PhD; Jeffrey J. Wing, PhD, MPH; James F. Burke, MD, MS

Background and Purpose—Previous studies exploring stroke-related caregiving focused solely on informal caregiving and a relatively limited set of activities. We sought to determine whether, and at what cost, stroke survivors receive more care than matched controls using an expanded definition of caregiving and inclusion of paid caregivers.

Methods—Data were drawn from the National Health and Aging Trends Study (NHATS), a nationally representative survey of Medicare beneficiaries. NHATS personnel conducted in-person interviews with respondents or proxies to determine the weekly hours of care received. We compared hours of assistance received between self-reported stroke survivors (n=892) and demo-graphics- and comorbidity-matched nonstroke controls (n=892). The annual cost of stroke caregiving was estimated using reported paid caregiving data and estimates of unpaid caregiving costs.

Results—Of community-dwelling elderly stroke survivors, 51.4% received help from a caregiver. Stroke survivors received an average of 10 hours of additional care per week compared with demography- and comorbidity-matched controls (22.3 hours versus 11.8 hours; P<0.01). We estimate that the average annual cost for caregiving for an elderly stroke survivor is ≈$11 300 or ≈$40 billion annually, for all elderly stroke survivors, of which $5000 per person, or $18.2 billion annually, is specific to stroke.

Conclusions—Although stroke survivors are known to require considerable caregiving resources, our findings suggest that previous assessments may underestimate hours of care received and hence costs. (Stroke. 2016;47:2090-2095. DOI: 10.1161/STROKEAHA.116.012704.)

Key Words: caregivers ■ cost of disease ■ stroke ■ survivor

Stroke is a common condition in later life affecting an estimated 9% of the US population aged 65 to 79 years and 15% of those aged ≥80 years.1 Currently, there are an estimated 5.4 to 6.6 million stroke survivors in the United States, which is more than the prevalence of Alzheimer disease dementia (estimated 5.3 million) and Parkinson disease (estimated 630 000) combined.2,3 The number of US stroke survivors is projected to increase to 10 million by 2030, given the aging baby boom generation.3,4 The vast majority of strokes occur in those aged ≥65 years.3

Most stroke survivors return from the hospital to community or residential care settings,3 where many receive help with activities of daily living and instrumental activities of daily living.5,9 For example, 48% of elderly American stroke survivors receive help with activities of daily living and 52% receive help with instrumental activities of daily living from informal (ie, unpaid) caregivers.7 A previous national study of elderly stroke survivors estimated that 8.5 hours per week of informal caregiving was attributable to stroke.9 Estimates of societal stroke-related caregiving costs range from $6 to $27 billion per year depending on whether all elderly stroke survivors were considered or only those with stroke-related health problems.9,10

Previous studies of stroke caregiving focused on a relatively limited set of activities and only included informal care, which may underestimate the total amount and cost of care received. For example, accompaniment to physician appointments and transportation (for purposes other than grocery shopping) were not included in previous national estimates. Researchers have recently found that >10% of elderly Americans are accompanied by a caregiver to their doctor visits.11 Moreover, because many stroke survivors do not return to driving, transportation assistance may be important for stroke survivors and time consuming for stroke caregivers. In addition, previous studies have only focused on informal care and have not included formal (ie, paid) caregiving,8,10 despite the fact that ≥30% of elderly Americans who receive informal care also receive formal care.12

Given the rising prevalence of stroke survivors, it is important to understand the amount and the associated costs of care provided to this population. These estimates provide a basis for planning interventions and implementing government...
policy to support stroke survivors and their caregivers. Furthermore, a better understanding of the extent and specific activities for which help is provided to stroke survivors may identify particularly vulnerable populations that may benefit from increased caregiving. In this context, for a broader definition of care than previously considered and the inclusion of formal caregiving, we compare the proportion of elderly stroke survivors and demographics- and comorbidity-matched controls who received help. We then determine the weekly hours of care received by stroke survivors, overall and by type of care received. Finally, we estimate the average and national costs of care received by elderly stroke survivors.

Methods

Study Population

Data were drawn from the National Health and Aging Trends Study (NHATS), an ongoing nationally representative cohort study of >8000 Medicare beneficiaries aged 265 years. NHATS was designed to support secondary data analysis of late-life disability and its consequences, including caregiving, such as performed in this study. In 2011, face-to-face interviews were conducted by trained NHATS personnel in study participants’ place of residence. Self-reported questions and cognitive and physical performance tests were administered. Proxy respondents were interviewed in cases where a study participant was unable to respond for themselves. Survey weights that adjust for differential probabilities of selection and nonresponse are provided (and used in all analyses described below) so that findings represent the elderly Medicare population.

This cross-sectional study compares stroke survivors with a matched group of nonstroke controls. Nearly 900 stroke survivors living in traditional community dwellings or residential care settings (ie, supportive care facilities and assisted living) other than nursing homes were identified (738 by self-report and 154 by proxy-report) based on an affirmative response to: “Has a doctor ever told you that you had a stroke?”

A comparison group of respondents without a history of stroke was created using one-to-one propensity matching on demographic characteristics (age, race, and marital status) and presence of comorbidities (hypertension, myocardial infarction, coronary heart disease, diabetes mellitus, cancer, lung disease, dementia, osteoporosis, and arthritis).

Caregiver Identification and Hours of Care

Respondents were asked whether they received help in the past month with mobility, self-care, and household activities, and if so, from whom. Self-care activities included eating, bathing/showering, toileting, and dressing. Mobility activities included getting outside one’s home, getting around inside, and getting out of bed. These activities correspond to activities of daily living. In addition, the study asked whether anyone else did household activities with or for the older adult in the past month, and if so, who did that and whether that was because of their health and functioning or some other reason. Household activities (which are common instrumental activities of daily living) included laundering, preparing hot meals, grocery shopping, handling bills and banking, and handling medications. In addition, NHATS asked about help with less common money matters (eg, opening, closing or cashing in certificates of deposit, checking, money market or retirement accounts, or applying for loan) in the past month.

We also created an indicator of type of help received: (1) help with only household activities, and (2) help with only self-care or mobility activities, but not household activities, (3) help with self-care or mobility activities, but not household activities, (4) help with only household activities, (5) help with only self-care or mobility activities, (6) open small objects and open sealed objects. Respondents received 1 point for every easy task and 2 points for every more challenging task performed (scores 0–12 being the best). Cognitive capacity was summarized as the sum of correct immediate and delayed recall of 10 words with scores (0–20) and the categorical NHATS clock-drawing scoring system (0: unrecognizable to 5: accurate).

Type of Help

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Analyses

Characteristics of the study population were reported using survey-weighted frequencies or means. Comparisons were made using Wald tests for continuous variables and χ² tests for categorical variables; survey sampling and design were taken into account.

Given the frequent occurrence of zero hours of help, we fit a zero-inflated Poisson model to explore differences in weekly hours of help between stroke survivors and controls. The zero-inflated Poisson model simultaneously examined the covariates attributable for: (1) the probability of not receiving help and (2) the expected weekly hours of help in total, for those who had hours of help greater than zero. We then constructed a set of models to determine differences in hours of caregiving by sequentially adding possible confounders and mediators to the model in the following order: (1) sociodemographics (age, race, sex, education, mean income, and marital status), comorbidities, and self-reported physical capacity; (2) cognitive capacity and whether the respondent and helper(s) lived together. For respondents with missing cognitive capacity data, mean imputation was used. To compare goodness of fit among a set of potential models, likelihood ratio tests, Akaike information criterion, Bayesian information criterion, adjusted McFadden R², and Vuong test statistics were computed.

Cost Estimation

To estimate the economic costs of caregiving for stroke, we included both informal (ie, unpaid) and formal (ie, paid) caregivers. For informal caregivers, we multiplied each respondent’s weighted hours of unpaid help per week by the national median wage for a home health aide in 2011 ($9.90). For formal caregivers, average wages observed in the sample (stroke: $8.50 per hour; control: $9.00 per hour) were multiplied by each respondent’s weighted hours of paid care per week. We then calculated average costs for each group and defined the stroke-related costs of caregiving as the costs for additional weighted mean hours and per day were reported. For caregivers with only monthly data, we derived a weekly average.

In accordance with other studies, we imposed a 16-hour limit on help per day for any given caregiver. We calculated weekly hours of care from each caregiver for each respondent and total hours of care per week if a study participant had >1 caregiver. Caregivers who provided care for <1 hour were assigned zero hours (3.7% of stroke survivors and 3.8% of controls). We also created a dichotomous variable indicating whether the respondent lived with any of their caregiver(s). Respondents who did not receive help with mobility or self-care activities or with household activities for health or functioning reasons were assumed to receive zero hours of help (42% of stroke cohort and 60% of the sample matched control cohort).

Physical and Cognitive Capacity

A summary self-reported physical capacity (ie, function) index was created that determined whether the respondent could perform a set of tasks independently and without the use of assistive devices in the past month. Tasks were paired into less and more challenging functions. The 6 pairs were (1) walking 3 and 6 blocks, (2) going up 10 and 20 stairs, (3) lifting and carrying 10 and 20 pounds, (4) bending over and kneeling down, (5) reaching overhead and reaching overhead with a heavy object, and (6) open small objects and open sealed objects. Respondents received 1 point for every easy task and 2 points for every more challenging task performed (scores 0–12 being the best).

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hours of help for stroke survivors compared with controls. Finally, to obtain annual economic costs, we multiplied the total costs of help to stroke survivors per week and the excess costs of help to stroke survivors (over the average cost for the matched cohort) per week by the weighted number of stroke survivors and by 52 weeks.

**Results**

Stroke survivors and controls were well matched on demographics and comorbidities (Table 1). Compared to demographic and comorbidity-matched controls, stroke survivors had less income and were more likely to have Medicaid (18.9% versus 12.8%, P<0.01). There was no difference in education, receipt of supplemental security income or long term care insurance. The vast majority of stroke survivors and controls (90.7% versus 92.8%, P=0.17) live in traditional community housing. Stroke survivors had lower physical and cognitive capacity than controls.

**All Stroke Survivors and Controls Including Those Who Did Not Receive Care**

Characteristics of care received by all stroke survivors and controls, including those without a caregiver, are shown in Table 2. More than half of elderly US stroke survivors and one third of matched controls received care from a caregiver (51.4% versus 34.6%; P<0.01). Stroke survivors had more caregivers (1.2 versus 0.8; P<0.01) and were more likely to live with a caregiver than controls (33.7% versus 21.4%; P<0.01). Stroke survivors received an average of ≈10 more hours of help per week than controls (22.3 versus 11.8; P<0.01; Figure). There was no difference among stroke survivors and controls in the proportion of respondents with paid help or hours of paid help received.

Table 3 shows the average hours of care received by stroke survivors and controls after accounting for demographic characteristics, comorbidity, physical and cognitive capacity, and whether the respondent lived with a caregiver. Stroke survivors averaged more hours of care than controls after accounting for sociodemographic characteristics, comorbidity, and physical capacity (19.7 versus 13.4; P<0.001). This difference was attenuated only slightly after adjusting for cognitive capacity and living situation (19.0 versus 14.3; P≤0.01).

**Stroke Survivors and Controls Who Received Care**

Among stroke survivors and controls who received help, overall, the average number of hours of help per week was greater than that of controls (43.4 versus 34.0; P<0.01; Table I in the online-only Data Supplement). The vast majority of help was unpaid (37.4 versus 26.3; P<0.01). There was no difference in the number of caregivers between stroke survivors and controls (2.3 versus 2.3; P=0.99). For stroke survivors who received help, the majority of stroke survivors received help with self-care or mobility and household activities (Table 4). The 11.6% of stroke survivors who had help with only self-care or mobility activities (but not household activities) received 19.3 (95% confidence interval, 12.6–26.1) hours of help per week. In contrast, the 59.1% of stroke survivors who received help with both self-care or mobility and household activities received 57.3 (95% confidence interval, 50.5–64) hours of help per week.
Stroke Caregiving Cost Estimates
The 892 stroke survivors in NHATS represent ≈3.5 million community-dwelling stroke survivors aged ≥65 years in 2011. Within this population, ≈1.8 million stroke survivors had informal caregivers and >390,000 stroke survivors had formal caregivers. We estimate that the average annual costs of help to a stroke survivor living in the community or residential care setting other than nursing homes in 2011 was $11,300, of which ≈$9,800 was unpaid. The average annual cost of help among controls was $6,180, of which $4,600 was unpaid. Thus, the costs attributable to stroke were >$5,000 per year. The total annual US cost of stroke caregiving in this population was $40 billion, of which $18.2 billion was specific to stroke.

Discussion
In this nationally representative sample of elderly Americans, we found that more than half of community-dwelling stroke survivors have a caregiver. We found that the number of hours of help received by stroke survivors is higher than in prior studies, higher than demographic-, comorbidity-matched controls, and that existing estimates of the costs of stroke caregiving may be underestimated. Stroke survivors received an average of 22.3 hours of care per week. Depending on the activities that stroke survivors received help with, help received ranged from 19.3 to 57.3 hours of care per week. To place this in context, this is equivalent to 0.5 to >1 full-time equivalent of help, the majority of which is unpaid. This substantial unpaid workforce may exert a disproportionate impact on stroke survivors and their families, given the greater hours of care received and lower income compared with controls. Further study into the positive and negative ramifications of caregiving to stroke survivors and caregivers, intervention, and policy implications should be considered.

We found that stroke survivors received ≈6 hours more help per week than previous national estimates of 16.1 hours per week. These previous estimates of help were based solely on informal care and explored a narrower list of activities. About half of the difference, 3 hours per week, can be explained by our inclusion of formal caregiving in addition to informal caregiving. Remaining differences are likely attributable to the expanded set of activities included in our definition of

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**Table 1.** Continued

<table>
<thead>
<tr>
<th>Table 1. Characteristics of Care Received by All Stroke Survivors and Nonstroke Controls, Including Those Who Did Not Receive Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke Survivors (n=892), %</td>
</tr>
<tr>
<td>Carer</td>
</tr>
<tr>
<td>Any unpaid carer</td>
</tr>
<tr>
<td>Any paid carer</td>
</tr>
<tr>
<td>Average number of caregivers, n (SE)</td>
</tr>
<tr>
<td>Carer lives with recipient</td>
</tr>
<tr>
<td>Average amount of care received, h/wk (SE)</td>
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<tr>
<td>Unpaid</td>
</tr>
<tr>
<td>Paid</td>
</tr>
</tbody>
</table>

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**Table 2.** Characteristics of Care Received by All Stroke Survivors and Nonstroke Controls, Including Those Who Did Not Receive Care

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**Figure.** Average weekly hours of care received by stroke and nonstroke controls.

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*Data were missing for 136 stroke survivors and 101 controls.*
†Data were missing for 161 stroke survivors and 120 controls.
help. It is also possible that the series of questions in NHATS was based on self-report, which has been shown to be reasonable and reliable. We do not have measures of stroke severity and time committed to caring for stroke survivors, but not a larger relative time commitment.

This study has several limitations. First, stroke diagnosis was based on self-report, which has been shown to be reasonably reliable. We do not have measures of stroke severity and time since stroke. In addition, hours of help were based on reports by the care recipient (or his/her proxy in the case of aphasia or cognitive deficits) rather than self-report from the caregiver. Our findings are limited to stroke survivors aged ≥65 years living in settings other than nursing homes. They do not extend to working age or institutionalized stroke survivors. Although we include informal help and non–staff–paid help provided in residential care settings, staff hours were not measured in these settings in NHATS and are therefore excluded. Thus, our findings underestimate the amount and cost of paid help to the 9% of stroke survivors residing in such settings. In addition, our wage estimate for home health care may be underestimated and, although consistent with previous studies, is subject to geographic variation, with some areas experiencing agency-based wages of $20.00 per hour.

Our results suggest that previous studies have underestimated the substantial amount and cost of care provided to stroke survivors. Our findings may assist in planning for the care of the increasing number of stroke survivors.

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## Disclosures

None.

## References


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Supplemental Table I: Characteristics of Care Received by Stroke Survivors and non-Stroke Matched Controls who Received Care

<table>
<thead>
<tr>
<th></th>
<th>Stroke Survivors %</th>
<th>Matched controls %</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Number of Caregivers, n (se)</td>
<td>2.3 (0.06)</td>
<td>2.3 (0.08)</td>
<td>0.99</td>
</tr>
<tr>
<td>Average Amount of Care Received, hrs/wk (se)</td>
<td>43.4 (2.5)</td>
<td>34.0 (2.9)</td>
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<tr>
<td>Unpaid</td>
<td>37.4(2.3)</td>
<td>26.3 (2.3)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Paid</td>
<td>6.0 (0.9)</td>
<td>7.7 (1.4)</td>
<td>0.40</td>
</tr>
</tbody>
</table>

Matched Controls who Received Care