Informal Care for Stroke Survivors

Results From the North East Melbourne Stroke Incidence Study (NEMESIS)

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Background and Purpose—Informal caregivers play an important role in the lives of stroke patients, but the cost of providing this care has not been estimated. The purpose of this study was to determine the nature and amount of informal care provided to stroke patients and to estimate the economic cost of that care.

Methods—The primary caregivers of stroke patients registered in the North East Melbourne Stroke Incidence Study (NEMESIS) were interviewed at 3, 6, and 12 months after stroke, and the nature and amount of informal care provided were documented. The opportunity and replacement costs of informal care for all first-ever-in-a-lifetime strokes (excluding subarachnoid hemorrhages) that occurred in 1997 in Australia were estimated.

Results—Among 3-month stroke survivors, 74% required assistance with activities of daily living and received informal care from family or friends. Two thirds of primary caregivers were women, and most primary caregivers (90%) provided care during family or leisure time. Total first-year caregiver time costs for all first-ever-in-a-lifetime strokes were estimated to be A$21.7 million (opportunity cost approach) or A$42.5 million (replacement cost approach), and the present values of lifetime caregiver time costs were estimated to be A$171.4 million (opportunity cost approach) or A$331.8 million (replacement cost approach).

Conclusions—Informal care for stroke survivors represents a significant hidden cost to Australian society. Because our community is rapidly aging, this informal care burden may increase significantly in the future. (Stroke. 2002;33:1028-1033.)

Key Words: Australia ▪ caregivers ▪ cerebrovascular disorders ▪ costs and cost analysis ▪ incidence
interrupted by surgery or death) with no apparent cause other than of vascular origin. 16 Cases of subarachnoid hemorrhage were excluded "Checking up" on the patient Completing errands, eg, collecting library books, posting mail, arranging services Providing transport or accompanying the patient to appointments Shopping Domestic activities Gardening, handyman tasks, grounds and home maintenance Heavy housework, eg, vacuuming, laundry, cleaning bathrooms Light housework, eg, washing up Meal preparation Medication supervision Supervision or assistance with walking outside Personal activities of daily living Eating; grooming; bathing; dressing; toilet use; incontinence management; moving from bed to chair and chair to chair; walking inside the house, including stairs

Definitions
Stoke was defined according to the World Health Organization definition as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function lasting more than 24 hours (unless interrupted by surgery or death) with no apparent cause other than of vascular origin."16 Cases of subarachnoid hemorrhage were excluded from all cost estimates. First-ever-in-a-lifetime strokes were defined as those strokes occurring in patients without any prior stroke event. Primary caregiver was defined as “that person who was most closely involved in helping the person with stroke to live independently at home (where home could be a form of supported accommodation).”

Stroke cases registered in NEMESIS were interviewed at 3, 6, and 12 months after stroke as part of the follow-up protocol. At each time point, we identified those survivors who were receiving any assistance with any activities of daily living. These people (or their next of kin) were asked to nominate their primary caregiver. The primary caregiver was then interviewed at ~3, 6, and 12 months after the stroke by use of a structured questionnaire, and the nature and amount of assistance provided with community, domestic, and personal activities of daily living were documented (Table 1). At each interview, the caregiver was asked whether specific types of assistance had been provided during the previous 3- or 6-month period and how much time was spent providing that assistance every week. At the 3-month interview, caregivers were also asked about the care provided in the month before stroke and at 2 weeks after stroke. Whenever possible, the same interviewer conducted all follow-up interviews.

Efforts were taken to include only care that was specifically for the well-being of the stroke patient. Activities regularly undertaken for the whole household, eg, meal preparation or using the washing machine, were not included as specific caregiving activities. To ensure that only additional care as a consequence of stroke was included, the respondents were asked whether they would be performing the task if the person with whom they live had not had a stroke. For example, if one partner traditionally took sole responsibility for domestic tasks such as cooking and cleaning and this situation did not change after the stroke (even if the other partner was now incapable of performing these tasks), these activities were not included as informal care.

Demographic details about the caregivers, eg, relationship to the patient and whether the caregiver was in paid employment before and after the stroke, were also recorded. Information about any additional secondary caregivers and the care that they provided was also obtained from the primary caregiver.

Data Analysis
All data on questionnaires were coded and entered into a Microsoft Access database. The proportion of patients receiving informal care for community, domestic, and personal activities of daily living and the average time spent providing that care was calculated for each time point (before stroke and 2 weeks and 3, 6, and 12 months after stroke). Only care that was additional to that provided before the stroke was included in the cost estimate. To estimate the costs of informal care for all first-ever-in-a-lifetime stroke cases occurring in Australia in 1997, informal care data (proportion of patients receiving each category of care and the average hours of care) were incorporated into an incidence-based model for the costs of stroke in Australia [Model of Resource Utilization, Costs and Outcomes for Stroke (MORUCOS)].17 The design of this model and lifetime cost estimates for all first-ever-in-a-lifetime stroke cases that occurred in Australia in 1997 that were obtained from the model have been previously reported.17,18 Briefly, the model was constructed with an incidence-based, “bottom-up” costing approach from a societal perspective. The incidence-based approach estimates the present value of the lifetime costs for all incident (first-ever-in-a-lifetime) strokes during a given reference year, even though many of the costs will actually be incurred during future years. It was assumed that the incidence rates, mortality, and resource-use data obtained from NEMESIS were representative of the general situation in Australia.12,18 It was further assumed that the level of informal care provided during the 6- to 12-month period after stroke remained the same for the rest of the stroke patient’s life unless death or a recurrent stroke event intervened. It was also assumed that stroke patients living in a nursing home at the time of their stroke did not receive any additional informal care after their stroke.

The time cost of informal care was valued according to both the opportunity and replacement cost approaches. Economists aim to offer guidance on making choices between alternative uses for scarce resources so that the benefit obtained for the resources used can be maximized (ie, efficiency). The notion of opportunity cost is based on the concept that the benefit from the preferred use of any resource should be greater than the benefits that would have been achieved if that same resource had been used for an alternative purpose. The opportunity cost of any commodity purchased is thus the amount of other commodities that could have been purchased with the same money or resources instead. Similarly, the opportunity cost of time spent in any activity is equivalent to the value of the best alternative use of that time. Thus, if providing informal care reduces leisure time rather than paid work, the valuation of caregiver time should reflect the opportunity costs of leisure time. In contrast to the opportunity cost approach, the replacement cost approach values productive activity according to the cost of substituting unpaid activity with a paid worker.

Unit Costs
The opportunity cost of informal care was valued at one third of the average Australian weekly wage in 1997 (A$58.86 per hour). This was considered to be a conservative estimate of the opportunity cost of leisure.

The replacement cost of assistance with community and domestic activities was valued according to the Victorian Health and Community Services Industry Award pay rate for unqualified healthcare workers (A$11.20 per hour). Personal care assistance was valued according to the hourly rate of nursing employees at level 2 (A$13.45 per hour). All care provided by secondary caregivers was valued at A$11.20 per hour. All costs were estimated in 1997 Australian dollars. Future costs were discounted by use of a 5% discount rate. Discounting is basically a compound interest calculation performed in reverse and is required because, as a society, we have a "positive rate of time preference"; ie, we generally prefer to postpone costs and enjoy benefits now.19 A 5% discount rate has recently been considered appropriate.20–22

TABLE 1. Categories of Informal Care

<table>
<thead>
<tr>
<th>Community-based activities</th>
<th>Informal Care for Stroke Survivors in Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advising on financial matters</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>“Checking up” on the patient</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Completing errands, eg, collecting library books, posting mail, arranging services</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Providing transport or accompanying the patient to appointments</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Shopping</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Domestic activities</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Gardening, handyman tasks, grounds and home maintenance</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Heavy housework, eg, vacuuming, laundry, cleaning bathrooms</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Light housework, eg, washing up</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Meal preparation</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Medication supervision</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Supervision or assistance with walking outside</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
<tr>
<td>Personal activities of daily living</td>
<td>Dewey et al</td>
</tr>
<tr>
<td>Eating; grooming; bathing; dressing; toilet use; incontinence management; moving from bed to chair and chair to chair; walking inside the house, including stairs</td>
<td>Informal Care for Stroke Survivors in Australia</td>
</tr>
</tbody>
</table>
Ethics committees at each of the participating institutions approved this study. Informed consent was obtained from each participant before any interview was conducted. When the participant was cognitively impaired, was dysphasic, or had altered consciousness, consent was obtained from the next of kin. Caregivers were interviewed only with the consent of the stroke patients or their next of kin.

Statistical Analysis
We used t tests and \( \chi^2 \) tests to compare all the major characteristics of subgroups of stroke cases who had caregivers\(^ \text{23} \) (Table 2). Differences in proportions of first-ever and recurrent cases receiving informal care and confidence intervals for the differences between these proportions were calculated with the methods outlined by Gardner and Altman.\(^ \text{24} \)

Results
A total of 340 individuals with stroke were included in the analysis. Of these, 247 were still alive 3 months after their first registered stroke. A total of 166 3-month survivors (67%) consented to the study and were interviewed. Of these, 127 (77%) had experienced a first-ever-in-a-lifetime stroke. There were some differences between the characteristics of interviewed and noninterviewed cases. Stroke patients who were male, who were managed in private hospitals, who were born overseas, and whose preferred language was not English were all underrepresented in the interviewed group. The majority of all 3-, 6-, and 12-month follow-up interviews (71%, 66%, and 76%, respectively) were carried out within 14 days of the ideal interview date.

Among the 166 stroke patients who consented to follow-up interview, 7 provided no information about the existence of a primary caregiver, and the reason for this was not recorded. Of the remaining 159 stroke patients, 118 (74%) were identified as requiring assistance with activities of daily living and were receiving informal assistance from family or friends during follow-up periods after stroke. Overall, 88 patients (55%) had a relative or friend who had provided informal care assistance before the index stroke. One primary caregiver refused to be interviewed, and 1 primary caregiver died before being interviewed. For 5 patients, the primary caregiver changed between interviews, and at each interview, the primary caregiver for the time period of interest was interviewed. Of the 116 primary caregivers interviewed, 85 (73%) were providing care for patients who experienced a first-ever-in-a-lifetime stroke, and overall, 88 (76%) were providing informal care to the patient before stroke.

The characteristics of patients with informal caregivers are shown in Table 2 and compared with the total population of stroke patients registered in NEMESIS. Those patients with informal caregivers before stroke were older (t test, \( P=0.0007 \)) and more likely to be female (\( \chi^2, P=0.0007 \)) compared with the general stroke population. We could not compare patients with and without caregivers before stroke for the whole NEMESIS cohort because we do not know

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Patients With Prestroke Caregivers (n=88)</th>
<th>Patients With New Poststroke Caregivers (n=28)</th>
<th>All Stroke Patients* (n=340)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>20</td>
<td>162</td>
</tr>
<tr>
<td>Female</td>
<td>56</td>
<td>8</td>
<td>178</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>78§</td>
<td>69</td>
<td>74</td>
</tr>
<tr>
<td>Range</td>
<td>48–95</td>
<td>22–89</td>
<td>22–96</td>
</tr>
<tr>
<td>Prestroke place of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own home</td>
<td>73</td>
<td>24</td>
<td>253</td>
</tr>
<tr>
<td>Home of relatives</td>
<td>4</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Special accommodation</td>
<td>2</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Hostel</td>
<td>5</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>Nursing home</td>
<td>3</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>1</td>
<td>16</td>
</tr>
<tr>
<td>History of previous stroke</td>
<td>22</td>
<td>9</td>
<td>77</td>
</tr>
<tr>
<td>Prestroke ADL independent( \text{†} )</td>
<td>49</td>
<td>21†</td>
<td>81</td>
</tr>
</tbody>
</table>

ADL indicates activities of daily living.
*Excluding subarachnoid hemorrhage patients.
†Barthel Index score\(^ {22} \) = 20/20.
‡\( P=0.0007 \) (\( \chi^2 \)) for comparison with the total population of stroke patients in NEMESIS.
§\( P=0.0007 \) (t test) for comparison with the total population of stroke patients in NEMESIS.
¶Data about prestroke ADL available for 26 persons.
Data about prestroke ADL available for 83 persons.
| Data about prestroke ADL available for 183 persons.

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Comparison was made between informal care provided to first-ever-in-a-lifetime and recurrent stroke patients (data not shown in Table 2). Proportionally more recurrent than first-ever patients were receiving informal care before stroke (59% versus 54%). This difference was small and not statistically significant (difference in proportions, 5%; 95% CI, −13 to 23). Similarly, after stroke, proportionally more recurrent than first-ever cases were receiving informal care at 12 months after stroke (82% versus 69%), but again, this difference was not statistically significant (difference in proportions, 13%; 95% CI, −4 to 30).

Table 3 shows the proportion of first-ever-in-a-lifetime stroke patients receiving assistance with community, domestic, and personal activities of daily living among those with and without an informal caregiver before stroke, together with the mean hours of care provided in each category. Most informal caregivers (≥88% at each time point) provided assistance with community-based activities of daily living. Assistance with personal activities of daily living such as showering and dressing was provided to more than one third of patients.

In general, first-ever-in-a-lifetime stroke patients who were already receiving informal care before the index stroke demonstrated only a modest increase in the hours of care provided each week (on average, 1 to 2 hours). However, at each time point, the proportion of patients receiving care in each category was greater than in the prestroke situation.

The characteristics of the 116 interviewed primary caregivers are presented in Table 4. Overall, approximately two thirds of primary caregivers were women, most commonly wives or daughters, and about half of the caregivers lived with the stroke patient to whom they provided care. Of note, 79 primary caregivers (68%) were not employed in paid work at the time they began providing informal care for the stroke survivor. Of those in paid employment, 59% made no changes in their working arrangements, and cessation of paid work by the caregiver occurred in only 2 instances. Only 5 paid workers (14%) reduced their hours, and the remainder took available leave or rearranged their work schedules. Thus, although most stroke survivors received some informal care from relatives and friends, this care was generally provided during either leisure or family time or by using existing leave entitlements for those in the paid workforce.

Secondary caregivers were also important for most stroke survivors receiving informal care. Among the 88 patients who had an informal caregiver before stroke, 41% also had ≥1 secondary caregivers before stroke (average, 2; range, 1 to 5) who, on average, contributed 4 hours of care per week (range, 1 to 28 hours). After stroke, 76 (66%) of those with primary caregivers had ≥1 secondary caregivers (average, 3; range, 1 to 6). After stroke, on average, secondary caregivers contributed 5 hours of care per week in the first 6 months after stroke and 6 hours of care per week in the second 6 months after stroke. Among the 146 secondary caregivers, assistance with domestic activities of daily living (68%) was just as common as assistance with community-based activities (61%), whereas assistance with personal activities of daily living was far less frequent (19%).

Most commonly, secondary caregivers were daughters (27%), sons (22%), or daughters-in-law (14%). A wide range of other relatives (including grandniece, granddauughter-in-law, and son’s fiancée), friends, and neighbors played roles in the care of some patients. Three spouses and 1 de facto spouse were identified as secondary rather than primary caregivers. For these 4 patients, the primary caregiver was a son for 2 patients, a daughter for 1 patient, and a friend for the remaining patient.

The total costs of informal care during the first year after stroke and the present value of the total costs of informal care over a lifetime for all first-ever-in-a-lifetime stroke cases that occurred in Australia in 1997 are presented in Table 5. The total first-year costs of all first-ever-in-a-lifetime strokes that occurred in Australia during 1997 have previously been estimated to be A$555 million, and the present value of lifetime costs was estimated to be A$1.3 billion. Depending on whether the opportunity or replacement cost approach is used, caregiver time costs represent between 4% and 7% of total stroke-related costs during the first year and between 14% and 23% of lifetime costs after first-ever-in-a-lifetime stroke.

**Discussion**

This is the first comprehensive, community-based study in which the nature, quantity, and economic value of the...
informal care provided to stroke survivors have been examined. In this study, 69% of 3-month survivors of first-ever-in-a-lifetime stroke were receiving informal care from relatives or friends. Primary caregivers were either the wife or the daughter of the patient in 53% of cases. Informal care was provided at the expense of family or leisure time rather than as an alternative to paid employment in >90% of cases. A larger network of secondary caregivers of up to 6 persons supported many patients. Although the hours of informal care provided each week varied widely between patients, the amount of care provided was substantial for many. When estimated with a conservative opportunity cost approach, the stroke-related time costs of informal care contributed between 14% and 23% of the present value of the total lifetime costs after first-ever-in-a-lifetime stroke and, except for nursing home care, represented the largest component of non-inpatient postacute care costs.\(^1\)

A note of caution should be applied to the interpretation of cost estimates in this study. First, the results are based on the patterns of informal care among stroke patients living in the NEMESIS area. This region of Melbourne is located in the inner suburbs of a major city and contains people who, on average, have a higher socioeconomic status as measured by the Education and Occupation Index (according to the 1996 Australian census) than Victoria or Australia as a whole. Second, not all stroke patients registered in NEMESIS were interviewed, and the interviewed group was not completely representative of the total stroke population. Thus, the type of informal support provided to patients in this study may not be representative of the situation elsewhere in Australia.

In this study, the opportunity cost of providing informal care to stroke survivors was valued at one third of the average weekly Australian wage in 1997. Given that most informal caring occurs at the expense of leisure or family time, it would appear appropriate to value informal care as equivalent to leisure. Previously, the UK Department of Transport used an estimate of 40% of the average hourly earnings of commuters for the value of time saved for nonwork activities.\(^2\) In this study, we have taken an even more conservative approach and used one third of the average weekly wage as the opportunity cost of leisure. We acknowledge that the valuation of leisure time is controversial and that a number of other approaches could be justified.\(^2,6,27\) Cost estimates through the replacement cost approach have also been provided because this is the method of valuation of unpaid production currently favored by the Australian Bureau of Statistics and the Statistical Office of the Commission of European Communities.\(^27\) However, because informal care for stroke patients includes both assistance with daily activities that is fundamental to survival in noninstitutional community accommodation and extra care that may be associated with positive utility for both the stroke patient and the caregiver, it is an ethical issue whether society would (or should) be prepared to pay for complete replacement of the informal care provided by family and friends.
The importance of informal care and its economic value is in its context. Although there is some evidence that stroke incidence rates are falling in Australia, at least in 1 population, this may not be the case more generally. Moreover, because Australia’s population is known to be rapidly aging, it is very likely that the absolute numbers of new stroke cases will increase substantially over the next several years. In addition, there is an increasing tendency for smaller and more fragmented family units in Australian society today. Therefore, in the face of increasing numbers of new stroke cases, there are likely to be fewer able-bodied people available to provide informal care. The result will be an increased burden for formal support services, the cost of which will need to be borne by Australian taxpayers.

Acknowledgments

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