Determinants of Caregiving Burden and Quality of Life in Caregivers of Stroke Patients

Emily McCullagh, MRCP; Gavin Brigstocke, MBBS; Nora Donaldson, PhD; Lalit Kalra, PhD, FRCP

Background and Purpose—A large proportion of disabled stroke survivors live at home and are supported by informal caregivers. Identification of determinants of caregiver burden will help to target caregiver interventions.

Methods—Data on patient, caregiver, and health and social support characteristics were collected prospectively over 1 year in 232 stroke survivors in a randomized trial of caregiver training. The contribution of these variables to caregiver burden score (CBS) and quality of life (QOL) measures at 3 months and 1 year was analyzed using regression models.

Results—Stroke patients had a mean age of 74±11 years, and 120 (52%) were men. The mean age of caregivers was 65.7±12.5 years, 149 (64%) were females, and 116 (50%) had received caregiver training. The mean CBS was 48±13 and 38±11 (score range of bad to good 88 to 22) and QOL score was 75±16 and 75±15 (score range of bad to good 0 to 100) at 3 months and 1 year, respectively. CBS and QOL correlated with each other and with patient (age, dependency, and mood), caregiver (age, gender, mood, and training), and support (social services and family networks) variables. Of these, only patient and caregiver emotional status, caregiver age and gender, and participation in caregiver training were independent predictors of either outcome at 3 months. Patient dependency and family support were additional independent predictors at 1 year. Social services support predicted institutionalization but not caregiver outcomes.

Conclusion—Advancing age and anxiety in patients and caregivers, high dependency, and poor family support identify caregivers at risk of adverse outcomes, which may be reduced by caregiver training. (Stroke. 2005;36:2181-2186.)

Key Words: caregivers ■ quality of life ■ rehabilitation ■ stroke ■ stroke management ■ stroke outcome

Stroke rehabilitation has concentrated successfully on patient-focused interventions to reduce severe disability and institutionalization, which has resulted in increasing the number of disabled patients being managed at home.1,2 Recent years have seen increasing awareness of the role of caregivers in the long-term management of stroke patients, and there is growing literature on the caregiving burden, poor caregiver outcomes, lack of caregiver support, and equivocal success, with interventions aimed at alleviating the caregiving burden.2–5 It is also becoming clear that the emphasis in stroke rehabilitation needs to shift from a patient-focused approach to a combined patient- and caregiver-focused approach because these individuals are central in preserving rehabilitation gains and the long-term well-being of stroke survivors.4,5 However, the success of early attempts to support caregivers has been limited, largely because the determinants of caregiving burden and the needs of caregivers remain poorly understood.6 Little research has been devoted toward understanding the complex and multilayered phenomenon of caregiving, beyond patient dependence and the emotional or psychological aspects of caregiving after stroke.4–10 Very few studies have investigated the interactions between patient characteristics, caregiver attributes, and support mechanisms, which eventually determine burden of care and quality of life (QOL) experienced by caregivers.11,12 Furthermore, literature on longitudinal changes in caregiver perceptions of burden and QOL is conflicting and suggests that these outcomes and their determinants may vary between the acute and chronic phases of stroke.8,12,13 There is no study that has systematically investigated how patient, caregiver, and support determinants contribute to changing perceptions of caregiver burden and QOL at different time points after stroke in a large sample. This information is important because strategies directed at caregivers are likely to be more successful if they target modifiable determinants of the caregiving burden and address specific caregiver needs.14 Knowledge of these determinants would also help to identify caregivers most at risk of poor outcomes and deliver specific interventions at the appropriate time.4,8–10

The objective of this study was to identify patient, caregiver, and support characteristics that influence caregiving burden, caregiver QOL, and institutionalization in the first year after stroke.

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TABLE 1. Patient and Caregiver Characteristics, Including QOL and Caregiver Burden at 3 Months and 1 Year in 232 Patients Included in the Study

Score Range | Baseline | 3 Months | 1 Year |
---|---|---|---|
**Patient characteristics** | | | |
Mean age in years (SD) | 74.2 (10.5) | | |
Male gender (%) | 120 (51.7) | | |
Median premorbid RS (IQR) | 6–0 | 0 (0–1) | |
Median BI (IQR) | 0–20 | 9 (5–12) | 18.5 (14–20) | 20 (17–20) |
Median RS (IQR) | 6–0 | 4 (3–5) | 2 (2–3) | 2 (2–3) |
Median Hospital Anxiety Score (IQR) | 21–0 | ... | 7.0 (4.0–8.0) | 4.0 (3.0–5.0) |
Median Hospital Depression Score (IQR) | 21–0 | ... | 5.0 (3.0–7.0) | 3.0 (2.0–5.0) |
Mean EQ-VAS Score (SD) | 0–100 | ... | 53.6 (21.1) | 61.1 (19.8) |
No. of patients institutionalized (%) | | | 6 (3%) |
Mortality over 1 year (%) | | | 0 |
**Caregiver characteristics** | | | |
Relationship with patient | | | |
Spouse/partner (%) | 164 (70.6) | | |
Children (%) | 53 (22.8) | | |
Relative/friend (%) | 15 (6.6) | | |
Mean age in years (SD) | 65.7 (12.5) | | |
Male gender (%) | 83 (35.8) | | |
Caregiver training (%) | 116 (50) | | |
Median baseline RS (IQR) | 6–0 | 0 (0–1) | | |
Median Hospital Anxiety Score (IQR) | 21–0 | ... | 6.0 (5.0–8.0) | 3.0 (2.0–5.0) |
Median Hospital Depression Score (IQR) | 21–0 | ... | 4.0 (2.0–8.0) | 2.0 (1.0–4.0) |
Mean EQ-VAS Score (SD) | 0–100 | ... | 75.2 (16.0) | 75.4 (15.2) |
Mean CBS (SD) | 88–22 | ... | 48.2 (13.2) | 38.3 (11.1) |

IQR indicates interquartile range.

**Methods**

**Subjects**

The study was undertaken in stroke patients undergoing rehabilitation and their caregivers participating in a randomized controlled trial (RCT) of caregiver training on a stroke rehabilitation unit.14 Patients were included if they were independent in daily living activities before the stroke (defined as Rankin score [RS] of 0 to 2), medically and neurologically stable at the time of baseline assessments, and expected to return home with residual disability (defined as need for supervision or physical assistance for core activities of daily living). All participants were required to have caregivers with no significant disability (defined as RS of 0 to 2) who were willing and able to provide support after discharge from hospital. The study was approved by the Bromley Research Ethics Committee.

**Assessments**

Data were collected prospectively for patient, caregiver, and support characteristics. Baseline assessments were performed at the time of inclusion into the RCT, which was within 10 days of stroke onset. Patient data included age, gender, estimated premorbid modified RS, and Barthel Index (BI) at the time of inclusion (Table 1).15 Patients were graded as mild (BI score 15 to 20), moderate (BI score 8 to 14), and severe (BI score 0 to 8) disability on the basis of initial Barthel scores.16 Caregiver assessments included age, gender, relationship to the patient, presence of any illness or disability, and 5D Euroqol (EQ-5D) and the Euroqol Visual Analogue Scale (EQ-VAS)17 for QOL. The number of caregivers participating in a structured training program that provided basic nursing and personal care skills, essential for the day to day management of disabled stroke survivors, was recorded. Support characteristics included family support network,18 community health input, and social services support. Data on therapy provision were recorded prospectively by treating therapists. Data on community health and social services use were collected at 3 and 12 months during patient assessment interviews using the Client Service Receipt Inventory.19 The completeness and accuracy of these data were verified against records of service providers.

Follow-up assessments were undertaken at 3 and 12 months after stroke onset. Variables of primary interest were caregiver burden and caregiver QOL, assessed using the caregiver burden score (CBS) and Euroqol VAS scales, respectively. CBS measures general strain (items 1 to 8), isolation (items 9 to 11), disappointment (items 12 to 16), emotional involvement (items 17 to 19), and environment (items 20 to 22), which together encompass important domains of the caregiving burden.20 These items are all scored from 1 to 4 (not at all, seldom, sometimes, often). The reliability, sensitivity, and various aspects of validity have been established in stroke patients and caregivers.20 Other measurements undertaken were institutionalization, RS, and BI in patients and Hospital Anxiety and Depression Scale (HADS)21,22 and EQ-5D/VAS in patients and caregivers. The HADS is commonly used in stroke research and has been validated against other instruments of emotional morbidity.22 It comprises 14 questions, of which half make up the anxiety subscale and half the depression subscale. Response options include “not at all,” “occasionally,” “quite often,” and “very often,” which are scored 0, 1, 2, or 3. A higher number indicates a more negative response, and a score of >8 is considered indicative of need for further assessment.

Assessments were undertaken by a researcher not involved in randomization or patient care. Patients and caregivers were inter-
viewed separately whenever possible; participants were encouraged to self-complete questionnaires without prompts, but caregivers were allowed to assist patients, if required.

### Data Analysis

Descriptive data are presented as proportions, means, or medians as appropriate. Patient, caregiver, and support characteristics were correlated with CBS, caregiver Euroqol score, and patient institutionalization at 3 months and 1 year. Because the domains of EQ-5D (mobility, self care, usual activities, pain and anxiety, and depression) were replicated in other assessments (eg, Barthel, RS, HADS in patients and HADS and CBS in caregivers), which were more sensitive to change than EQ-5D, this measure was not used further in analysis. Variables with $P\leq0.10$ and those that were considered clinically relevant were investigated further by constructing multiple regression models for 3 months and 1-year outcomes in 3 stages. In the first stage, the independent effects of patient characteristics and the extent to which these variables explained variation in outcomes was assessed. In the second stage, caregiver characteristics were added to the model and their impact on primary measures assessed after adjusting for patient characteristics. In the third stage, the independent effect on support characteristics was assessed after adjusting for patient and caregiver characteristics.

### Results

Complete data sets at 1 year were available for 232 (77%) of the 300 stroke patients and their caregivers included in the original study. Reasons for incomplete data included mortality ($n=32$), patients or caregiver unable or unwilling to complete assessments ($n=28$), and incorrectly filled out or illegible forms ($n=8$).

The mean age of patients was 74 years; half were men, and all were independent before stroke (Table 1). The baseline BI score for the majority of patients ranged between 4 and 14, consistent with moderate to severe disability. Most patients improved significantly by 3 months (median BI increased from 9 to 18.5; $P=0.013$). By the end of 1 year, there were further improvements in the BI, significant reductions in patients’ anxiety and depression levels from median HADS-A, and HADS-D scores of 7.0 and 5.0, respectively, at 3 months to HADS-A and HADS-D scores of 4.0 and 3.0 at 1 year ($P<0.0001$ for both), and improvements in QOL (median EQ-VAS change from 54 to 61; $P=0.0002$). A total of 226 (97%) patients were residents at home 1 year after stroke.

The mean age of the caregivers was 65.7 years, who, on average, were 10 years younger than patients (Table 1). More than 90% of caregivers were immediate family members, and nearly two thirds of caregivers were women, the majority of whom were spouse or partner. Of these, 50% had received formal training in caregiving during hospital rehabilitation of the patient. Caregiver anxiety and depression levels of caregivers reduced significantly between 3 months and 1 year ($P<0.0001$ for HADS-A and HADS-D). CBS also decreased significantly between 3 months and 1 year (48.2 versus 38.3; $P<0.0001$). Caregiver EQ-VAS scores did not change significantly between 3 and 12 months.

Frequent support from local family or friends was available for 69 of 232 (29%) subjects; 17 (8%) subjects had no local family but were supported by family members living in different towns. The majority of subjects, 146 of 232 (62%), were isolated in the community with limited informal support from family or friends. Although all patients received some form of community support after discharge, there were great variations in the type and the intensity of community health and social services use between patients (Table 2).

Pearson correlations showed a significant inverse relationship between caregiver burden and caregiver QOL ($r=-0.33; P<0.001$). Caregiver burden at 3 and 12 months correlated significantly with increased patient disability, anxiety, and depression. It also correlated positively with caregiver anxiety and depression but showed significant reduction after caregiver training (Table 3). There was no correlation with patient or caregiver age, gender, or relationship to the patient. Caregiver burden did not correlate with the family support or no support but was greater in those receiving therapy and day care input, probably reflecting the severity of residual disability. Caregiver burden was less at 1 year in patients receiving domiciliary care input. Caregiver QOL at 3 and 12 months correlated with the same patient and caregiver variables as caregiver burden (Table 3). In addition, there was a negative correlation between caregiver QOL and patient and caregiver age and increasing burden of caregiving. Institutionalization from home at the end of 1 year correlated with severity of residual disability and patient anxiety and depression but not with caregiver or support characteristics.

Multiple regression models showed that patient and caregiver anxiety were the only significant independent determinants of caregiver burden at 3 months and were equally important and explained 50% of caregiver burden at this time point (Table 4). At 1 year, caregiver depression and family support or no support also became important independent determinants of caregiver burden. Caregiver training had an independent effect on reducing caregiver burden, regardless of other patient and caregiver characteristics. Patient disability, increasing age of caregiver, and lesser personal care input from social services were independent determinants of institutionalization from home within 1 year of stroke. Independent determinants of poor caregiver QOL at 3 months included increasing caregiver age, male gender, and disability (Table 4). By the end of 1 year, the patient disability and caregiver depression became additional determinants of caregiver QOL. Participation in caregiver training was associated with better QOL at 3 months and 1 year. The addition of caregiver characteristics nearly doubled the explanatory

### Table 2. Support Characteristics of 232 Patients Included in the Study

<table>
<thead>
<tr>
<th></th>
<th>No. of Users (%)</th>
<th>Mean Use (SD)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community health input</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family doctor, contacts</td>
<td>227 (97.8)</td>
<td>2.9 (3.2)</td>
</tr>
<tr>
<td>Physiotherapy, hr</td>
<td>66 (28.4)</td>
<td>52.1 (27.2)</td>
</tr>
<tr>
<td>Occupational therapy, hr</td>
<td>75 (32.3)</td>
<td>31.6 (27.5)</td>
</tr>
<tr>
<td>Speech and language therapy</td>
<td>133 (57.3)</td>
<td>5.2 (8.9)</td>
</tr>
<tr>
<td>Social services input</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care for ADL tasks, hr</td>
<td>86 (37.1)</td>
<td>282.5 (349.8)</td>
</tr>
<tr>
<td>Domiciliary ‘sit in’ services, sessions</td>
<td>22 (9.5)</td>
<td>25.8 (33.4)</td>
</tr>
<tr>
<td>Day care center, sessions</td>
<td>40 (17.2)</td>
<td>18.6 (21.4)</td>
</tr>
</tbody>
</table>

*Means and SDs of input over the period of 1 year for users only.

ADL indicates activities of daily living.
Training caregivers in the management of disabled patients reduced caregiver burden and improved their QOL but had no effect on institutionalization.

Caregiving is a complex and multidimensional activity, the nature and determinants of which evolve over time. The study showed that despite a significant interaction between caregiver burden and caregiver QOL, there was a divergence at the end of 1 year with improvements in caregiver burden but not in caregiver QOL. This may be explained partly by the limitations of current measures of caregiver burden to capture the interactions between caregiving burden and the supporting capacity of the caregiver, which, if exceeded, may result in poorer QOL. Another possible explanation is the transition in caregiver experience as caregivers adapt to their new role and factors such as advancing age, level of disability, depression, and family support become important. Studies have shown that the awareness of a relative/loved one in ill health, changing roles, obligations, decreasing support, and changed life perspectives are associated with feelings of inadequacy and depression, which have adverse effects on QOL unrelated to caregiving burden.

A limitation of the study is that it was limited to willing caregivers participating in a randomized controlled study. Selection criteria would have excluded patients with severe disability or cognitive impairments; most patients made
TABLE 4. Independent Determinants of Caregiver Burden and QOL

<table>
<thead>
<tr>
<th></th>
<th>3 Months</th>
<th></th>
<th>1 Year</th>
<th></th>
<th>Institutionalization</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver Burden</td>
<td>Coefficient (95% CI)</td>
<td>Caregiver QOL</td>
<td>Coefficient (95% CI)</td>
<td>Caregiver Burden</td>
</tr>
<tr>
<td>Model 1 (patient variables)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient age</td>
<td>NS</td>
<td>-0.4 (-0.7 to -0.2)</td>
<td></td>
<td>0.1 (0.002 to 0.3)</td>
<td>-0.6 (-0.8 to -0.3)</td>
</tr>
<tr>
<td>BI</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>1.9 (0.3 to 3.5)</td>
</tr>
<tr>
<td>Patient anxiety score</td>
<td>1.6 (0.8 to 2.4)</td>
<td>NS</td>
<td></td>
<td>2.2 (1.1 to 3.4)</td>
<td>NS</td>
</tr>
<tr>
<td>r²</td>
<td>0.26</td>
<td>0.16</td>
<td></td>
<td>0.30</td>
<td>0.21</td>
</tr>
<tr>
<td>Model 2 (patient+caregiver variables)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient age</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>BI</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>1.6 (0.16 to 3.1)</td>
</tr>
<tr>
<td>Patient anxiety score</td>
<td>1.1 (0.3 to 1.9)</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver age</td>
<td>NS</td>
<td>-0.3 (-0.6 to -0.07)</td>
<td></td>
<td>-0.3 (-0.6 to -0.1)</td>
<td>0.1 (0.02 to 0.2)</td>
</tr>
<tr>
<td>Caregiver gender (male)</td>
<td>NS</td>
<td>7.4 (0.9 to 13.9)</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver disability (RS)</td>
<td>NS</td>
<td>-5.2 (-8.9 to -1.5)</td>
<td></td>
<td>-6.1 (-9.7 to -2.5)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver training</td>
<td>NS</td>
<td>4.2 (0.8 to 9.1)</td>
<td>-2.9 (-5.9 to -0.2)</td>
<td>2.5 (0.01 to 5.1)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver anxiety score</td>
<td>2.4 (1.5 to 3.3)</td>
<td>NS</td>
<td></td>
<td>1.0 (0.1 to 1.8)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver depression score</td>
<td>NS</td>
<td>1.1 (0.1 to 2.2)</td>
<td>-1.6 (-3.2 to -0.02)</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>r²</td>
<td>0.49*</td>
<td>0.35*</td>
<td></td>
<td>0.47*</td>
<td>0.39*</td>
</tr>
<tr>
<td>Model 3 (patient+caregiver+support variables)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient age</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>BI</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>1.5 (0.1 to 3.1)</td>
<td>-0.08 (-0.12 to -0.05)</td>
</tr>
<tr>
<td>Patient anxiety score</td>
<td>1.2 (0.4 to 2.1)</td>
<td>NS</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver age</td>
<td>NS</td>
<td>-0.4 (-0.7 to -0.1)</td>
<td></td>
<td>-0.3 (-0.6 to -0.06)</td>
<td>0.1 (0.02 to 0.2)</td>
</tr>
<tr>
<td>Caregiver gender (male)</td>
<td>NS</td>
<td>7.3 (0.6 to 13.9)</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver disability</td>
<td>NS</td>
<td>-5.9 (-9.7 to -2.2)</td>
<td></td>
<td>-6.3 (-9.9 to -2.6)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver training</td>
<td>NS</td>
<td>4.3 (0.8 to 9.4)</td>
<td>-3.0 (-6.2 to -0.2)</td>
<td>-2.6 (-5.3 to -0.03)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver anxiety score</td>
<td>2.4 (1.5 to 3.4)</td>
<td>NS</td>
<td></td>
<td>1.0 (0.2 to 2.1)</td>
<td>NS</td>
</tr>
<tr>
<td>Caregiver depression score</td>
<td>NS</td>
<td>1.2 (0.03 to 2.3)</td>
<td>-1.1 (-2.8 to -0.6)</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Family support</td>
<td>NS</td>
<td>1.6 (0.4 to 2.9)</td>
<td></td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Social services support</td>
<td>NS</td>
<td>NS</td>
<td></td>
<td>-0.001 (-0.002 to -0.009)</td>
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</tr>
<tr>
<td>r²</td>
<td>0.51</td>
<td>0.41</td>
<td></td>
<td>0.50</td>
<td>0.41</td>
</tr>
</tbody>
</table>

*Significance of change in F value P<0.001.

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Significant physical recovery, and all caregivers were in good health. This may explain why variables such as patient disability, cognitive impairments, and patients’ or caregivers’ health, found to be significant in studies on caregivers of severely disabled patients,4,9,13,25 were not independent predictors of caregiver burden in this study. These factors make substantial difference in the level of caregiving burden and need to be considered in caregiver risk assessment. A weakness of the study is that the number of patients who required help from caregivers to fill in questionnaires was not recorded. Similar methods have been used previously and are often necessary in pragmatic studies in disabled subjects.26–28

Despite the fact that all patients received appropriate levels of community and social services input at discharge based on objective assessments during rehabilitation, patients’ and caregivers’ perceptions of adequacy of this support may have influenced caregiver burden as well as caregiver QOL but was not measured in this study. Anxiety and depression are common in stroke patients and their caregivers and determine caregiving burden.5,7,8–10,13

Studies show that social services support or interventions aimed at the emotional support of caregivers have little effect on reducing this burden.12,26–29 However, “hands on” training in the day to day management of stroke patients was associated with lower anxiety and burden of care levels.14

This suggests that a shift in rehabilitation philosophy for a patient-centered approach to a patient- and caregiver-centered approach, which empowers caregivers, may have better long-term outcomes. It is also important that assessments of rehabilitation interventions in clinical practice or research include measures of patient and caregiver outcomes in evaluating effectiveness. Whereas considerable advances have been made in the development of patient-centered measures, there are no instruments at present that reliably capture all important dimensions of the caregiving experience.23 It is possible a self-rated instrument, in which the domains are...
Acknowledgments

The project was supported by the NHS R&D Executive’s Primary Care and Support Variables being considered in this study, regression models could not predict >50% of caregiver outcomes. Other quantitative and qualitative studies have shown similar limitations in developing paradigms that accurately predict caregiver needs. Although caregiving will always be influenced by a range of subjective factors (eg, coping ability, personal beliefs, and social expectations), clinicians need some objective measures to identify those at risk of adverse outcomes. This study suggests that high physical dependence, advancing age, and increased anxiety in caregivers or patients and poor family support are simple and easily assessable measures of caregiver risk, which can be used in clinical practice to target caregiver interventions.

References

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