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Comprehensive measurement of long-term outcomes and costs of rehabilitation in patients with stroke

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Chapter 6

Caregiver burden after stroke: changes over time?

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Abstract

Introduction and aim

Many caregivers of stroke patients experience a high burden. This study aims to describe the course of burden in individual caregivers in the first year after stroke.

Methods

This study is part of the Stroke Cohort Outcomes of REhabilitation study, a multicentre, longitudinal cohort study including consecutive stroke patients admitted to two rehabilitation facilities. Caregivers were asked to complete the Caregiver Strain Index and questions on their sociodemographic characteristics 6 and 12 months post admission. Patients' sociodemographic and clinical characteristics were extracted from medical records.

Results

A total of 129 caregivers were included, 72 completed the Caregiver Strain Index twice. Of them 19 (26.4%) were men, median age 59 (range 27-78) years. A consistently high or low burden was reported by 15 (20.8%) and 49 (68.1%), respectively, whereas 8 (11.1%) reported a high burden at either 6 ($n = 3$) or 12 months ($n = 5$).

Discussion

In the majority of caregivers of stroke patients the perceived caregiver burden is consistent over time. However, as in 11.1% caregiver burden changes from 6 to 12 months, caregiver burden should be measured repeatedly until 12 months after stroke. Caregivers living together with a patient who suffered a haemorrhagic stroke seem to be more at risk for a high burden.

Introduction

Worldwide 15 million people suffer a stroke each year¹. Of all patients who survive the acute phase of stroke (62% after 1 year), the majority (80%) remains to some extent physically or cognitively impaired and needs help from professionals and/or caregivers^{2,3}. Caregiving can be defined as task-oriented assistance provided by individuals, usually family or friends⁴, with this assistance not being part of formal community support services. At 12 months post stroke 69% of first-ever stroke patients in Australia received informal care from a caregiver⁵. On the longer term, over a third of all patients were found to be dependent on others in Australia and the UK^{6,7}. A South African study in community-dwelling stroke patients found that 6 months post stroke according to the Nottingham Extended Activities of Daily Living scale, many participants were dependent in housework (60.9%), food preparation (52.2%), shopping (80.4%) and the use of public transport (65.2%), suggesting the need for caregiver assistance⁷.

Caring for a family member takes time as well as physical and emotional efforts⁸. Caregiving is often experienced as a burden⁹⁻¹¹ and can thereby lead to anxiety¹² or depressive symptoms in caregivers^{2,3,8,13}. Caregiver burden is a term used to describe the weight or load carried by caregivers as a result of caring for their relative⁹. It can be divided into a subjective and objective burden. Objective burden refers to the physical assistance provided by caregivers. Subjective burden refers to the psychological, social, and emotional impact on caregivers as a consequence of objective burden⁹.

The proportion of caregivers of stroke patients experiencing significant burden at a certain point ranges from 25% (moderate or considerable burden on nine or more items on the Relatives Stress Scale in two Norwegian studies with 68 and 36 caregivers, respectively, at 6 months post stroke)^{14,15} to 54% (total score on the Caregiver Strain Index (CSI) ≥ 7 in a Dutch study with 187 caregivers 1 year post stroke)¹⁶. There are numerous instruments available to measure caregiver burden, of which the Caregiver Strain Index¹⁷, the Caregivers Burden Scale¹⁸, the Caregiver Reaction Assessment¹⁹, the Sense of Competence Questionnaire²⁰, the Relatives Stress Scale²¹, and the Zarit Burden Interview²² are most frequently cited²³. A study comparing the CSI, Sense of Competence Questionnaire, and Caregiver Reaction Assessment in caregivers of stroke patients found that the CSI proved to be more feasible and at least as valid as the longer and more complex Sense of Competence Questionnaire and Caregiver Reaction Assessment²⁴. For the CSI validation studies specifically in stroke patients show good reproducibility (k 0.93, CI 0.84-0.97) (25) and high reliability with a Cronbach's α of 0.83²⁶. On the basis of a review on measures used to assess burden among caregivers of stroke patients the CSI is recommended in Dutch guidelines on the measurement of stroke outcomes^{26,27}.

Regarding the course of caregiver burden over time as measured with the CSI, in multiple studies no significant changes of the average CSI score over time were found^{8,28-30}. However, two longer-term follow-up studies showed that 3 and 5 years after admission to a neurological department or inpatient rehabilitation facility caregiver burden of stroke patients significantly declined^{10,31}. However, if proportions of caregivers under considerable burden are considered, in longitudinal studies using the CSI one study showed an increase in the prevalence of caregiver burden over time³², whereas four other studies did not show a change in its prevalence over time, with measurements done from 2 months post stroke until 1 year post stroke^{8,28-30}. The proportions of caregivers under significant burden at specific time points varied among the studies, with 22.7% and 42.0% of caregivers reporting high burden at 12 months on the CSI^{8,30}.

All of these studies reported the percentages of caregivers under considerable burden over time or average scores of measures of caregiver burden but did not show the course of caregiver burden in individual caregivers. It is conceivable that caregivers who initially experience low caregiver burden experience high burden later in time and vice versa. The prevalence of high burden can be constant, whereas for individual caregivers burden could increase or decrease. It is also conceivable that caregivers with an initial low burden will be missed when the CSI is not repeated. More insight into the course of caregiver burden in individual caregivers is important. Regarding factors associated with caregiver burden in stroke, two systematic reviews on caregiver burden found patients characteristics that, although inconsistently, were related to caregiver burden, that is, age, gender, cognitive impairment, mental health, functional status, ADL dependency, and communication deficits^{3,9,33}. In addition, Jaracz et al.³¹ found that not only patient characteristics, but also caregiver characteristics, such as time spent caring, self-rated health, depressive symptoms, sense of coherence, and anxiety were significantly related to caregiver burden³¹.

Therefore, the aims of the present study were to describe the proportions of caregivers experiencing low burden, high burden, or a change from high to low burden and vice versa at 6 months and 12 months post stroke; and to explore the patient and caregivers characteristics of caregivers with a high burden at some point in time, to make recommendations for the screening of burden of caregivers in clinical care. We hypothesized that on average general caregiver burden would remain the same over time, whereas in some individual caregivers the burden increases or decreases.

Methods

Design and setting

This study is part of the Stroke Cohort Outcomes of REhabilitation (SCORE) study; a multicentre longitudinal inception cohort study, which is currently executed in two Dutch specialized rehabilitation facilities in the western part of the Netherlands.

Multidisciplinary rehabilitation is offered to patients who have multiple and complex impairments and are expected to be discharged to their homes. Stroke patients are admitted to the rehabilitation facilities for inpatient rehabilitation if they had a recent stroke preventing the patient from living independently at home, being able to take part in at least two therapy sessions of 30 min each per day, having some learning ability, and expecting to live independently, whether or not with spouse or caregiver, with a life expectancy of at least 1 year. Patients with dementia or (neuro)psychiatric conditions do not qualify for admission. Stroke patients receive outpatient rehabilitation if they meet the same criteria, but are able to live at home.

Caregivers are actively involved in the rehabilitation process by means of meetings with the rehabilitation physician and care providers, partner courses/discussion groups, meetings with a social worker, and the possibility to join the patient during treatment³⁴.

The study protocol of the SCORE study was approved by the Medical Ethics Board of the Leiden University Medical Centre (LUMC), P13.249. This study is registered in the Netherlands National Trial Register (NTR) under number 4293.

Study population

We included caregivers of stroke patients who started inpatient or outpatient rehabilitation and participated in the SCORE study³⁴. Stroke patients were eligible for the SCORE study if they met the admission criteria and were 18 years or older, and had a first or recurrent stroke not longer than six months ago. Exclusion criteria were being unable to complete questionnaires in Dutch or not providing written informed consent. The patients were asked whether they had a caregiver and if so, whether they agreed with inviting their caregiver. In case of agreement, they were asked to hand over an invitation letter to their caregiver, in most cases their spouse. If the patient had more than one caregiver, he or she was asked to invite the person they spent most of the time with. All caregivers willing to participate provided written informed consent. For this caregiver burden study, data from caregivers who agreed to participate in the study and who completed questionnaires on caregiver burden at 6 and/or 12 months after the start of the rehabilitation period of the stroke patient were used.

Sample size calculation

The SCORE study is collecting data that are also used in clinical practice so that a sample size calculation for the study as a whole was not deemed appropriate. To answer the particular research questions on the caregiver burden we assumed that a description of at least 100 caregivers would be needed to reflect sufficiently the potential heterogeneity in the group and allow the analysis of a limited number of factors associated with caregiver burden.

Data collection

Caregivers

Six and twelve months after the start of the rehabilitation of their nearest, the participating caregivers received a questionnaire. On the basis of the caregivers' preference, the questionnaires were sent by regular mail or by e-mail. They were asked to complete and return it within 1 week. If the caregiver did not return the questionnaire, the principle investigator (WP) called the caregiver once to remind him/her to fill in the questionnaire.

Caregiver burden

Caregiver burden was assessed using the generic CSI¹⁷. The CSI aims to identify problems with work, finances, and emotional burden that could rise from caregiving. It determines objective and subjective impact using 13 items with dichotomous outcome categories (yes/no). A score of 7 or more indicates a high level of burden¹⁷.

Sociodemographic characteristics and work status

Sex, date of birth, and relation to the stroke patient (partner, parent, child, friend, sibling or other) were derived from the caregivers' consent form. At 6 months, the level of education of the caregiver was measured using a 6-point scale ("not finished primary school" to "finished university") and divided into lower, middle, and higher educated. In addition, caregivers were asked about their work status (paid employment yes or no).

Patients

Sociodemographic and clinical characteristics

Sociodemographic characteristics of the patients were derived from a questionnaire filled in at the start of the rehabilitation. Type of stroke, stroke localisation, type of rehabilitation (inpatient or outpatient), and the Barthel Index at the start of the rehabilitation were extracted from the patients' medical file. The Barthel Index is a 10-item measurement instrument that scores independence in Activities of Daily Living (ADL) and yields a score between 0 and 20, with higher scores indicating more independency³⁵.

Data analyses

Data analyses were performed in IBM SPSS version 22 v02 (IBM Corp: Armonk NY, 2013). The characteristics of the patients and the characteristics and CSI scores of the caregivers were presented as percentages, means, and standard deviations (SD) for normally distributed values or medians with 25-75% percentiles (interquartile range [IQR]) and minimum and maximum values for non-normally distributed variables.

For the computation of the CSI score, missing values were imputed if the missing value(s) was or were of influence on the total score being below or above the cut-off point of 7, the value(s) of the other questionnaire for that item(s) was or were imputed.

The CSI scores at 6 and 12 months for caregivers who filled in the CSI at both points in time were compared by means of the Wilcoxon signed rank test.

Characteristics of patients who did and did not provide informed consent to invite their caregiver, and of patients of whom the caregiver did and did not agree to participate in the study, were compared by means of the Mann-Whitney U test, the Fisher's exact test, or the independent samples t-test, where appropriate. The same analyses were conducted for participating caregivers who filled in the CSI at either 6 or 12 months and those who completed it at both measurement points.

Caregivers who filled in the CSI at both 6 and 12 months were divided into 4 groups. The first group consisted of caregivers with a high score (≥ 7) on the CSI at both 6 and 12 months (high-high), the second group consisted of caregivers with a high score on the CSI at 6 and a low score at 12 months (high-low), the third group consisted of caregivers with a low score on the CSI at 6 and a high score at 12 months (low-high), and the fourth group (low-low) consisted of caregivers with a low score on the CSI at both 6 and 12 months. The characteristics of caregivers with a high CSI score at some point in time were compared to those with a low CSI at both measurement points by means of the Mann-Whitney U test or Fisher's exact test, where appropriate.

With all statistical analyses a p values of <0.05 was considered as statistically significant.

Results

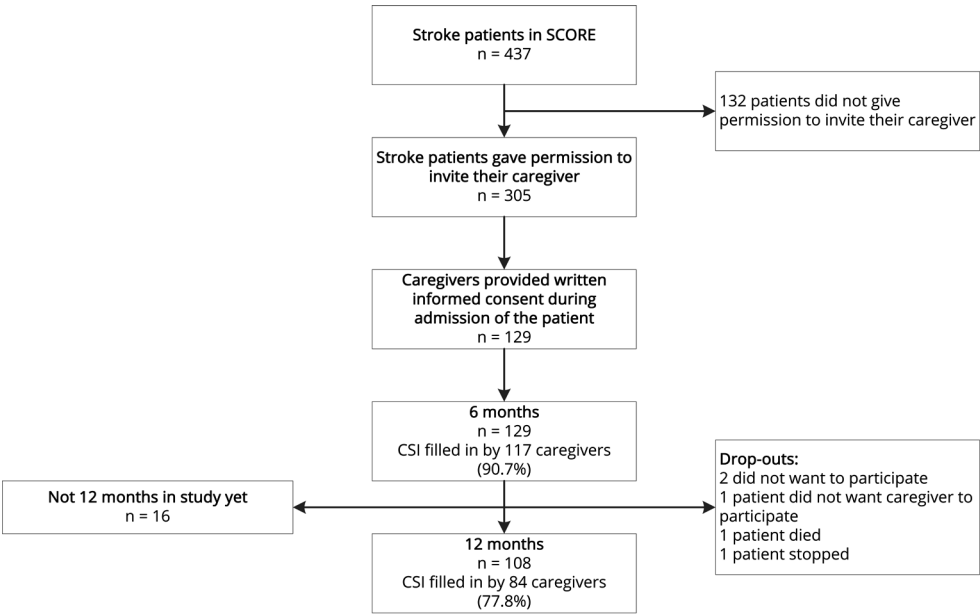
Characteristics of stroke patients and their caregivers

In the two rehabilitation facilities, ~200 and 130 stroke patients are admitted for inpatient rehabilitation per year, respectively. Counting up to 934 patients in the study period. As 339

patients of the SCORE study started in the clinic, the participation rate of clinical patients is 36%. Total number of patients immediately starting outpatient stroke rehabilitation could not be retrieved, as these data turned out to be contaminated with patients dismissed from clinical rehabilitation and follow-up consultations after termination of rehabilitation. Figure 1 displays the flow of participants in the study. Between 10 March 2014 and 1 January 2017, 436 stroke patients (~47% of the total population), admitted to inpatient or outpatient rehabilitation, provided informed consent to participate in the SCORE study. Of the patients participating in the SCORE study, 305 (70% of the SCORE population) gave permission to invite their caregiver. Patients who provided informed consent to invite their caregiver had a significantly lower Barthel Index than patients who did not provide informed consent to invite their caregiver (median 14.0, range 0.0-20.0 versus median 16.5, range 4.0-20.0; $p = 0.04$), whereas all other characteristics did not differ between these two groups (results not shown).

Of the 129 participating caregivers, 117 (90.7%) completed the CSI at 6 months, 84 (77.8%) at 12 months, and 72 (66.7%) at both time points.

Figure 1. Flow chart of caregivers of stroke patients in the SCORE-study.



Among the 305 caregivers invited, written informed consent was provided by 129 (42.3%). Table 1 shows the patient characteristics related to the caregivers who were invited and who did and did not complete one or more CSIs. In the group of patients of whom a caregiver participated in the study, significantly more patients had outpatient rehabilitation (37, 28.7%)

than in the group of whom the caregiver did not participate in the study (31, 17.6%, $p = 0.03$). None of the other patient characteristics were significantly different between the two groups.

The comparisons of the sociodemographic characteristics of the 72 caregivers who completed both CSIs versus those 57 only filling it in at 6 or 12 months, showed no significant differences between these two groups.

Table 1. Characteristics of stroke patients admitted for inpatient and outpatient rehabilitation in two rehabilitation facilities.

| | Patients of whom the caregiver participated | Patients of whom the caregiver did not participate | <i>p</i> value |
|----------------------------------------|------------------------------------------------|-------------------------------------------------------|----------------|
| | n = 129 | n = 176 | |
| Sex (male) (n,%) | 80 (62.0) | 102 (58.0) | |
| Age (median, [IQR, min-max]) | 61 (52-68; 19-68) | 62 (54-69; 18-83) | |
| Education level (n,%) | n = 122 | n = 153 | |
| Low | 55 (45.1) | 64 (41.8) | |
| Medium | 30 (24.6) | 43 (28.1) | |
| High | 37 (30.3) | 46 (30.1) | |
| Type of stroke (ischemic) (n,%) | 99 (78.6) | 127 (72.2) | 0.23 |
| | n = 126 | | |
| Stroke localisation (n,%) | n = 123 | n = 171 | |
| Left | 58 (47.2) | 87 (50.9) | 0.50 |
| Right | 50 (40.7) | 69 (40.4) | |
| Stem | 8 (6.5) | 4 (2.3) | |
| Posterior | 5 (4.1) | 7 (4.1) | |
| Multiple | 2 (1.6) | 4 (2.3) | |
| Inpatient rehabilitation (n,%) | 92 (71.3) | 145 (82.4) | 0.03 |
| Barthel Index (median, [IQR, min-max]) | 15 (9-18; 1-20) | 13 (9-18; 0-20) | 0.56 |
| | n = 61 | n = 123 | |

p Values of Mann-Whitney U test or Fisher's Exact Test, comparison of patient characteristics.

CSI: Caregiver Strain Index; SD: Standard Deviation; IQR: inter quartile range.

Caregiver burden

In 14 of the 117 (12.0%) CSIs at 6 months and 9 out of 84 (10.7%) CSIs at 12 months 1 to 3 items were missing. In all but two cases the missing values had no influence on whether a caregiver would have a total score on the CSI below or above 7. For two caregivers, the values of the previous questionnaire were imputed.

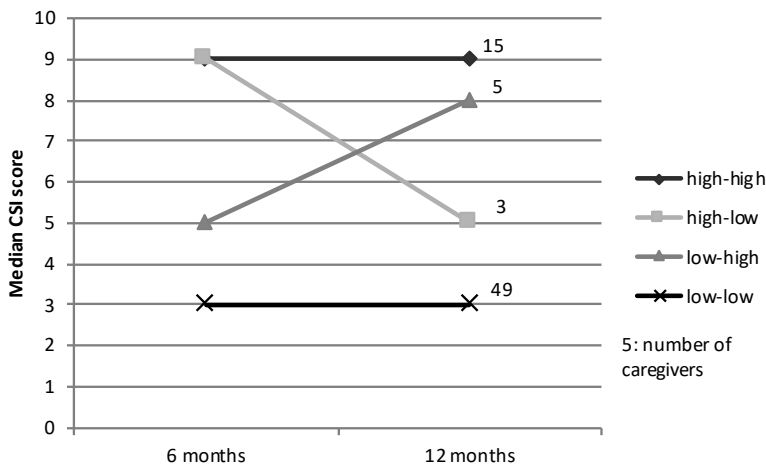
Overall, the median CSI scores at 6 or 12 months of caregivers completing the CSI twice were in the same range as those from caregivers completing at only at 6 or 12 months. Within the group of 72 caregivers completing the CSI twice, there was no significant difference between

the median scores on the CSI at 6 and 12 months. The proportions of caregivers with a high CSI score and the CSI scores at 6 and 12 months did not differ significantly in the groups of caregivers completing it at both time points or only at 6 or 12 months (all $p > 0.05$).

Caregiver burden in individual caregivers over time

Figure 2 shows the median CSI scores at 6 and 12 months past admission for the caregivers divided into four groups. Fifteen caregivers (20.8%) had a consistent high level of caregiver burden over time, whereas three caregivers (4.2%) perceived a high burden at 6 months and low at 12 months, five caregivers (6.9%) had a low burden at 6 months and high at 12 months, and 49 (68.1%) had a consistent low burden.

Figure 2. Median Caregiver Strain Index scores 6 and 12 months past admission in the SCORE study for caregivers of stroke patients divided into four groups.



Because we were primarily interested in characteristics of caregivers and patients with a high score on the CSI, and because of the small group sizes, the caregivers with a high score at some point in time were joined together and compared with the group with a low score at both time points.

Table 2 shows the characteristics of the 23 (31.9%) caregivers experiencing a high burden at both or one-time point and 49 (68.1%) caregivers with a consistent low burden. Perceiving a high burden at any time point was connected to living together with the patient and a haemorrhagic nature of stroke.

Table 2. Characteristics of caregivers of stroke patients and patients among groups of caregivers with high and low levels of caregiver burden.

| | All Caregivers n = 129 | Group 1: high-high, high-low or low-high n = 23 (31.9%) | Group 2: low-low n = 49 (68.1%) | p value |
|-----------------------------------|---------------------------|---------------------------------------------------------------|------------------------------------|---------|
| Caregiver characteristics | | | | |
| Age (median, [IQR, min-max]) | 59 (52-68; 15-80) | 55 (52-65; 46-73) | 59 (49-71; 27-78) | |
| Sex (male) (n,%) | 41 (31.8) | 6 (26.1) | 13 (26.5) | |
| Education level (n,%) | n = 121 | | | |
| Low | 46 (39.0) | 7 (30.4) | 21 (42.9) | |
| Medium | 37 (31.4) | 6 (26.1) | 14 (28.6) | |
| High | 35 (29.7) | 10 (43.5) | 14 (28.6) | |
| Relationship with patient (n,%) | | | | |
| Partner | 102 (79.1) | 20 (87.0) | 36 (73.5) | |
| Parent | 7 (5.4) | 2 (8.7) | 5 (10.2) | |
| Child | 12 (9.3) | 1 (4.3) | 5 (10.2) | |
| Friend | 2 (1.6) | | 1 (2.0) | |
| Sibling | 5 (3.9) | | 2 (4.1) | |
| Unknown | 1 (0.8) | | | |
| Living with relative | 95 (89.5) | 22 (95.7) | 37 (75.5) | |
| Paid employment | 55 (46.6) | 13 (56.5) | 23 (46.9) | |
| Patient characteristics | | | | |
| Age (median, [IQR, min-max]) | 61 (51.5-68; 19.0-68) | 60 (51-66; 21-82) | 61 (49-69; 19-80) | |
| Sex (male) (n,%) | 80 (62.0) | 16 (69.6) | 32 (65.3) | |
| Education level (n,%) | n = 122 | n = 21 | n = 47 | |
| Low | 55 (45.1) | 7 (33.3) | 25 (53.2) | |
| Medium | 30 (24.6) | 5 (23.8) | 10 (21.3) | |
| High | 37 (30.3) | 9 (42.9) | 12 (25.5) | |
| Type of stroke (ischemic) (n,%) | 99 (78.6) n = 126 | 13 (59.1) n = 22 | 43 (87.8) | 0.01 |
| Stroke localisation (n,%) | n = 123 | n = 21 | n = 48 | |
| Left | 58 (47.2) | 11 (52.4) | 24 (50.0) | 0.86 |
| Right | 50 (40.7) | 9 (42.9) | 16 (33.3) | 0.45 |
| Stem | 8 (6.5) | 1 (4.8) | 5 (10.4) | 0.44 |
| Posterior | 5 (4.1) | | 1 (2.1) | |
| Both sides | 2 (1.6) | | 2 (4.2) | |
| Inpatient rehabilitation | 92 (71.3) | 16 (69.6) | 36 (73.5) | 0.78 |
| Barthel Index (median, [min-max]) | 15 (1.0-20.0) n = 61 | 8 (4-20) n = 11 | 16 (5-20) n = 22 | 0.17 |

IQR: inter quartile range.

p Values of Mann-Whitney U test or Fisher's Exact test, comparison of caregivers experiencing low burden or high burden at some point in time.

Discussion and conclusion

Findings

The results of the current study show that in the majority of caregivers of stroke patients who were admitted to inpatient or outpatient rehabilitation the perceived caregiver burden does not change over time, with 20.8% reporting a high burden at both 6 and 12 months. In 4.2% the burden decreases, but in 6.9% of caregivers the burden increases. Caregiver burden is subject to change, therefore it would be recommended to measure caregiver burden up to and including 12 months.

Comparison and interpretation

For the large majority of the caregivers of stroke patients (N = 64, 88.9%) the burden they experienced over time was consistent (either low or high). These results are in line with previous studies in which was found that caregiver burden at 6 months or 1 year post stroke can be predicted based on the caregiver burden at 2 or 3 months post stroke^{8,30}. The added value of the present study is that there is more insight in the course of individual burden over time. In only a small proportion of caregivers (6.3%) the burden increased over time, nevertheless this percentage is clinically relevant. It indicates that even if at 6 months a caregiver is not reaching the cut-off value for considerable strain, the considerable strain may develop over time so that all caregivers should be followed up. Extra attention should be given to caregivers living together with the patient who had a haemorrhagic stroke, because all of the caregivers for whom burden increased were living with the patient and 80% of the patients had a haemorrhagic stroke.

In the present study on average, no significant change in caregiver burden was found in the first year post stroke. However, previous longer-term follow-up studies 3 and 5 years after admission to a neurological department or inpatient rehabilitation facility showed that caregiver burden significantly declined^{10,31}. It could be hypothesized that it takes more than one year for caregivers to adjust to the new situation and find ways to cope with the change in the patients' health and the changed situation¹⁰.

Kruithof et al.⁸ studied caregiver burden from the hospital to different discharge destinations. At 12 months post stroke, they found a lower percentage of high burden in the total population (22.7%), but a higher percentage for caregivers of patients discharged to a rehabilitation facility (42.5%) than we did 12 months post admission to the rehabilitation facility (30,9%)⁸. The difference may be explained by the fact that our population was not hospital-based but rehabilitation facility based, probably selecting patients with a more severe condition. Moreover, because our sample also included outpatients, the severity of impairments and

level of dependency may have been lower than in their sample of inpatients only. Previous studies showing that partners of patients who were discharged home experienced less burden than partners of patients discharged to a rehabilitation centre or nursing home confirm this hypothesis^{8,36}.

One might postulate that caregivers living together with the patient spend more time with actually assisting the patients with daily tasks. Indeed in the literature, it is reported in an Australian study, including 71 caregivers that at 6 months post stroke 61% of caregivers of stroke patients spend on average 4.6h helping the patient with basic and instrumental activities of daily living and household per day²⁹. At 12 months the same group of caregivers spend 3.6h per day helping stroke patients²⁹. This direct support is probably less in caregivers who do not live with the patients. In addition, there may be the additional burden of the changes or losses in the intimate relationship with one's spouse or partner. Given our findings, it would be interesting to focus on the difference between caregivers who do and do not live together with the patient in future research.

In the present study, it was also found that caregivers of patients with a non-ischemic nature of stroke experienced a high burden. Some previous studies did not include the nature of stroke in analyses of factors associated with high caregiver burden^{10,16}. One study showed that haemorrhagic stroke is not significantly associated with high caregiver burden³⁶. Another study showed that infarction is not related to burden at 2 months and 2 years post stroke⁸. A larger sample size and multivariate analyses are needed for better investigation of factors associated with high caregiver burden.

Strengths and limitations

A strength of this study is that it does not only describes the number of caregivers under considerable burden at specific time points but also whether caregivers shifted from low to high burden and vice versa over time.

A weakness of this study was the relatively small groups of caregivers, in particular, those with two completed CSI questionnaires. Among those, the groups of caregivers who experienced an increasing or decreasing burden were very small and therefore we were unable to find significant differences among subgroups. One of our main concerns was that caregivers with highest burden would not participate. For those not providing informed consent, this does not seem to be the case, as the Barthel Index of the corresponding patients was significantly higher (indicating less need of help) than that of those willing to participate. Besides, of the caregivers who did participate drop-out levels were relatively low. At 6 and 12 months past admission, 90.7% and 77.8% of the participants filled in the questionnaire, respectively.

Of the total population of stroke patients admitted for clinical rehabilitation, 36% participated in the SCORE-study. Of the SCORE-population, 70% gave permission to invite their caregiver. Patients who did and did not give permission to invite their caregiver did not significantly differ, apart from the observation that patients who gave permission to invite their caregiver were more dependent in ADL (as indicated by a lower Barthel Index) than patients who did not. Therefore, the results of the present study might not be applicable to caregivers of ADL independent patients.

Another limitation is that within the group of caregivers with a low burden, caregivers could also have experienced an increasing burden, even though they did not exceed the cut-off point of 7. In the present study, these caregivers with increasing burden were not identified.

Lastly, in the present study, we did not include the patients' (physical or mental) health status as a possible explanation for increasing caregiver burden. Several studies have been done where caregiver burden appeared related to patient outcomes⁹. However, caregiver burden has also been described to be predicted by caregiver characteristics³¹. In future studies on the course of caregiver burden, it might be interesting to include patient health outcomes as well.

Conclusions

The CSI score at 6 months is a good predictor for the score at 12 months. However, as in some caregivers, the high burden is not yet present at 6 months, monitoring caregiver burden throughout the first year after stroke seems warranted. Caregivers living together with a patient who suffered a haemorrhagic stroke seem to be more at risk for a high burden.

Implications for Rehabilitation

- Many caregivers of stroke patients experience a high burden.
- The Caregiver Strain Index score at 6 months is a good predictor for the score at 12 months.
- In some caregivers the high burden is not yet present at 6 months, therefore monitoring caregiver strain throughout the first year after stroke seems warranted.
- Caregivers living together with a patient that suffered an haemorrhagic stroke seem to be more at risk for a high burden.

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