

ORIGINAL REPORT

## ANXIETY AND LOW LIFE SATISFACTION ASSOCIATE WITH HIGH CAREGIVER STRAIN EARLY AFTER STROKE

Daniëlla M. Oosterveer, MD, PhD<sup>1</sup>, Radha Rambaran Mishre, MD<sup>1</sup>, Andrea van Oort<sup>2</sup>, Karin Bodde<sup>3</sup> and Leo A. M. Aerden, MD, PhD<sup>3</sup>

From the <sup>1</sup>Sophia Rehabilitation Centre, <sup>2</sup>Department of Neuropsychology, Reinier de Graaf Gasthuis, Delft and <sup>3</sup>Department of Neurology, Reinier de Graaf Gasthuis, Delft, The Netherlands

**Objective:** Caregivers play an important role in the well-being of stroke patients, and are known to experience considerable strain 3 months or more after patient discharge. The aim of this study was to determine the prevalence and determinants of caregiver strain early after discharge.

**Methods:** Six weeks after discharge from the hospital or rehabilitation setting stroke-surviving patients and their caregivers were seen by a specialized nurse. Several screening lists, including the Caregiver Strain Index (CSI), were completed. Step-wise logistic regression was used to analyse which determinants independently contribute to caregiver strain.

**Results:** A total of 284 stroke-surviving patients were included in the study. Of the 179 caregivers who completed the CSI, 23 (12.8%) experienced considerable strain. A higher level of anxiety symptoms and lower life satisfaction in patients are independently associated with higher caregiver strain ( $p=0.000007$  and  $p=0.0031$ , respectively).

**Conclusion:** High strain is experienced by 12.8% of caregivers shortly after discharge of a stroke-surviving patient. More anxiety symptoms and lower life satisfaction in patients are independently associated with a higher level of strain in caregivers. Treating patient anxiety at an early stage might therefore lead to a decrease in long-term caregiver strain.

**Key words:** caregiver strain; stroke; caregiver strain index; anxiety; life satisfaction.

J Rehabil Med 2014; 46: 139–143

Correspondence address: Radha Rambaran Mishre, Sophia Rehabilitation Centre, Reinier de Graafweg 1, 2625 AD Delft, The Netherlands. E-mail: r.rambaran@sophiarveelidatie.nl

Accepted Sep 3, 2013; Epub ahead of print Nov 8, 2013

### INTRODUCTION

Stroke is an important healthcare problem worldwide. In the Netherlands there were 11.7 surviving patients with stroke per 1,000 inhabitants on 1 January 2007 (1). Most patients return home after discharge from the hospital or after temporary rehabilitation in a nursing home or rehabilitation centre.

Care for these stroke patients at home is largely provided by their spouses or other relatives. These caregivers play an important role in preserving the rehabilitation gains and well-

being of stroke survivors (2). It has been shown that caregivers experience considerable strain 3 or more months after stroke (3). The highest level of help from the caregiver is needed during the first few weeks after discharge, during which period most functional recovery occurs. In addition to providing physical help, a review has shown that the caregivers' perception of their identity is challenged by changes in their roles and relationships and loss of taken-for-granted futures (4). Accepting and coping with the changed situation might also play a more prominent role in the first few weeks, for both patients and caregivers. Our hypothesis is supported by a study by Visser-Meiley et al. (5) demonstrating that the prevalence of caregiver strain decreases over time. However, studies examining the strain experienced by caregivers shortly after discharge of the patient are sparse and include a relatively low number of patients (6, 7). Knowledge of the prevalence of high strain in caregivers shortly after discharge and its determinants would allow rehabilitation physicians, general practitioners and neurologists to detect high strain in caregivers more easily at an earlier stage and to provide direction regarding necessary interventions.

The aims of this study were: (i) to determine the prevalence of high strain in caregivers shortly after discharge; and (ii) to identify the determinants of high strain in caregivers; determining whether patient characteristics, type of rehabilitation, presence of anxiety, depression or fatigue in the patient, or the level of participation and life satisfaction of stroke patients influence the strain experienced by caregivers.

### METHODS

#### Study population

The study population included patients with a stroke who were admitted to the department of neurology at the Reinier de Graaf Gasthuis, Delft, The Netherlands, between 2009 and 2011. There were 5 treatment options after discharge, from which the neurologist, together with the patient, his or her relatives and future caregivers, the rehabilitation physician and the therapists from the hospital choose. The treatment options were: (i) the patient returns home without therapy; (ii) the patient receives mono-disciplinary therapy at home; (iii) the patient attends an outpatient rehabilitation programme at the rehabilitation centre; (iv) the patient receives a rehabilitation programme in a rehabilitation centre; and (v) the patient receives a rehabilitation programme in a nursing home. With the exception of the patients who stayed permanently in a nursing home after a rehabilitation programme, between 2009 and 2011 all patients were seen 6 weeks after discharge or after finishing

the rehabilitation programme by a nurse and a neurologist with special interest in stroke care. Before this appointment patients and their caregiver completed 5 screening questionnaires at home. A standardized history and the results of the screening questionnaires were used in order to record any complaints from the patient and caregiver. The answers to the screening questionnaires that patients completed at home were not changed or completed by the nurse or neurologist.

All patients were diagnosed with a stroke, defined as: (i) acute onset of one or more neurological deficits indicating central dysfunction; (ii) the neurological deficits were present for more than 24 h; and (iii) presence of recent haemorrhage or infarction on computed tomography (CT) imaging or the absence of another explaining cause on CT imaging of the brain executed on the day of admission. If there was any doubt about the diagnosis, magnetic resonance imaging (MRI) of the brain was carried out in order to confirm the diagnosis. Patients with dementia and terminal patients (malignancy) were excluded from the study. The medical ethics committee approved the study protocol.

#### Measurements

**Caregiver characteristics.** Caregiver strain was measured using the Caregiver Strain Index (CSI). This questionnaire comprises 13 items that assess the subjective care load of the caregiver. A score of 7 or more indicates a high level of strain (8). In an earlier comparison of instruments that measure caregiver strain, the CSI was found to be one of the most valid (9). In the present study patients were asked to agree to their caregiver completing this questionnaire. Both the caregivers who lived with the patient and those who did not live with the patient were allowed to complete the questionnaire.

**Patient and stroke characteristics.** Patient characteristics and stroke-related characteristics were collected retrospectively by the principal investigator, using the medical documents available for the patients. The following patient characteristics were recorded: date of birth, sex, presence of hypertension and diabetes, smoking habits, adiposity (defined as body mass index  $>25$  kg/m<sup>2</sup>), type of house (with or without stairs), presence of a partner or other house-mate, and presence of children. The stroke-related characteristics collected were: type and location of the stroke, duration of the hospital stay, policy after discharge, Barthel Index (BI) during hospital stay and score on the Berg Balance Scale (BBS) during hospital stay, and Modified Rankin Score (MRS) (at admission, at discharge, and after 3 months).

Fatigue was measured using the Fatigue Severity Scale (FSS), a validated self-report questionnaire that measures the severity of fatigue (10). The final score is the mean of the 9 items of the FSS. Each item is graded between 1 (strong disagreement) and 7 (strong agreement).

Anxiety and depression was measured using the Hospital Anxiety and Depression Scale (HADS), a questionnaire comprising 14 items (11).

Life satisfaction was measured using the Life Satisfaction Questionnaire (LiSat-9), a validated instrument that is frequently used in stroke patients. The final score consists of the mean of 9 questions and can vary between 1 (low level of life satisfaction) and 6 (high level of life satisfaction) (12–14).

Activities and participation after discharge was measured using the Frenchay Activities Index (FAI). This reliable test scores the frequency of 15 activities and is validated for measurement at 3 and 6 months (13, 15–17). In the present study a shortened version was used, in which the frequency of 10 activities after discharge were measured, leading to a score between 0 (inactive) and 30 (highly active).

#### Statistical analysis

All data were anonymized when entered in a database and were analysed with SPSS for Windows. A 2-sided *p*-value of 0.05 was considered statistically significant.

The general characteristics of the stroke patients with a caregiver with no high strain (CSI  $<7$ ) were compared with those with a caregiver

Table I. Responses to individual questions on the Caregiver Strain Index (CSI)

CSI question	Positive answer <i>n</i> (%)
Disturbed sleep	29 (14.9)
Inconvenient	37 (19.3)
Physical strain	28 (14.5)
Confining	46 (24.2)
Family changes	65 (33.9)
Changes in personal plans	51 (26.6)
Other demands	84 (44.9)
Emotional adjustments	42 (22.1)
Upsetting behaviour	52 (27.4)
Patient has changed	43 (22.8)
Work adjustment	22 (11.6)
Financial strain	25 (13.2)
Feeling overwhelmed	15 (7.9)

experiencing high strain (CSI  $\geq 7$ ). The mean age of both groups was compared with the independent sample *t*-test. Dichotomous variables were analysed using the  $\chi^2$ -test.

Step-wise backward logistic regression was used to identify determinants that are independently associated with caregiver strain. In this analysis the CSI was used as a continuous variable.

## RESULTS

A total of 284 stroke-surviving patients were included in the study. The CSI data were complete for 179 (63%) patients and partially complete for 15 (5%) patients. There were no CSI data for the remaining 90 patients. Table I shows the responses to the individual questions. Twenty-three (13%) caregivers experienced considerable strain. Table II shows the general characteristics of patients for whom the caregiver experienced strain and those for whom the caregiver experienced no strain. There was no significant difference in stroke risk factors or type of stroke between the 2 groups. Of the 90 patients for whom there were no CSI data, 59 patients lived alone and therefore might not have had a caregiver.

Although all screening lists and type of house were correlated with caregiver strain, only a low score on the Life Satisfaction Questionnaire (i.e. low life satisfaction in the patient) and a high HADS anxiety score (i.e. more signs of

Table II. General characteristics of patients with a caregiver who experiences strain and of those with a caregiver who experiences no strain

	No caregiver strain <i>n</i> =156	High caregiver strain <i>n</i> =23	<i>p</i> -value
Type of stroke, <i>n</i> (%)			0.56
Ischaemic	144 (92.3)	22 (95.7)	
Haemorrhagic	12 (7.7)	1 (4.3)	
Thrombolysis, <i>n</i> (%)	19 (12.3)	2 (9.1)	0.67
Mean age stroke, years	68.8	70.1	0.64
Males, <i>n</i> (%)	97 (62.2)	13 (56.5)	0.60
Diabetes, <i>n</i> (%)	32 (20.5)	5 (21.7)	0.89
Hypertension, <i>n</i> (%)	89 (57.1)	14 (60.9)	0.73
Adiposity, <i>n</i> (%)	84 (60.4)	9 (47.4)	0.28

Table III. Association of patient characteristics and outcome of screenings lists with caregiver strain

Variable	Beta	p-value
Full model		
Life Satisfaction Questionnaire	-0.40	0.0012
Fatigue Severity Scale	0.09	0.49
Frenchay Activity Index	0.11	0.34
Hospital Anxiety and Depression Scale – anxiety score	0.28	0.023
Hospital Anxiety and Depression Scale – depression score	0.02	0.89
Age of the patient	0.00	0.98
Sex of the patient	-0.01	0.90
Type of stroke (presence of haemorrhagic stroke)	0.00	0.96
Presence of stairs in the patient's house	-0.14	0.16
Children	-0.12	0.23
Model after stepwise backward regression		
Life Satisfaction Questionnaire	-0.48	0.000007
Hospital Anxiety and Depression Scale – anxiety score	0.30	0.0031
Presence of stairs in the patient's house	-0.17	0.059

anxiety in the patient) were independently associated with caregiver strain ( $p=0.000007$  and  $p=0.0031$ , respectively). The absence of stairs in the patient's home was associated with more caregiver strain in this model after stepwise backward regression, however this association was not significant ( $p=0.059$ ). The complete model and the model after stepwise backward regression are shown in Table III.

After discharge from hospital patients received rehabilitation depending on their remaining neurological deficits: (i) they return home without therapy; (ii) they return home with mono-disciplinary therapy; (iii) they return home with an outpatient rehabilitation programme; (iv) they stay in a nursing home with a rehabilitation programme; or (v) they stay in a rehabilitation centre. Of the 179 patients, 25 stayed in an inpatient setting after hospital discharge (Table IV). When these patients had returned home, the caregivers tended to experience more strain than those of patients who returned home earlier (24% vs 11%,  $p=0.072$ ). The addition of clinical therapy did not change the stepwise-backward regression results.

Table IV. High caregiver strain and mean caregiver strain for each rehabilitation treatment

Rehabilitation treatment	n	High caregiver strain n (%)	Caregiver strain Mean (SD)
Home without therapy	76	6 (7.9)	2.2 (2.7)
Home with mono-disciplinary therapy	62	9 (14.5)	2.9 (3.3)
Home with outpatient rehabilitation programme	16	2 (12.5)	2.8 (2.5)
Clinical rehabilitation in a nursery home	22	5 (22.7)	4.0 (3.6)
Clinical rehabilitation in a rehabilitation centre	3	1 (33.3)	4.3 (5.8)

## DISCUSSION

In this study 12.8% of caregivers of stroke-surviving patients experienced considerable strain 6 weeks after patient discharge. Low life satisfaction in the patient and more signs of anxiety in the patient were found to be independently associated with more caregiver strain.

The reported prevalence of high caregiver strain varies widely in the literature. The time between stroke and measurement of the CSI is known to influence the prevalence: caregiver strain decreases over time (5). We therefore expected a higher prevalence of caregiver strain than the 12.8% measured. Perhaps the CSI does not measure all aspects of caregiver strain, particularly for those factors that play a role in caregiver strain during the first few weeks, such as coping and acceptance. Increased emotional lability, withdrawal from social life, and changes in leisure activities, for example, are not mentioned specifically in the CSI, but have been associated with higher caregiver strain (18). On the other hand, hope for improvement or actual improvement in the neurological deficits might decrease caregiver strain. In addition, the patient sample in which the prevalence is measured seems to be of influence. In our study there was a trend that caregivers of patients who received rehabilitation in an inpatient setting experienced more strain than caregivers of patients who received no therapy or outpatient rehabilitation. This is in line with the results of other studies: the mean CSI 1 year post-stroke of caregivers of stroke patients who received inpatient rehabilitation was 6.7, while, for caregivers of stroke patients who were recruited during admittance in the hospital, this was 4–5 (5, 19). We hypothesize that this is due to the severity of the neurological deficits, because the choice between inpatient and outpatient rehabilitation is based mainly on dependency in activities of daily living (ADL). ADL dependency can be measured using the BI or MRS. However, in our study there was an insufficient number of patients with complete data for the BI ( $n=41$ ) or MRS to be able to study the relationship between ADL dependency and caregiver strain. A correlation between these factors has been reported previously (5, 20, 21).

A recent review reports that anxiety symptoms occur frequently in patients after stroke (18–25%) (22). Anxiety about recurrence and because of helplessness or hopelessness contribute to these symptoms. In the literature, post-stroke agoraphobia, generalized anxiety disorders and post-traumatic stress disorder (PTSD) are mentioned as diagnoses (23–25). Anxiety in patients might place a higher strain on caregivers of stroke patients than would be expected based on the patients' neurological deficits alone. Previously, a positive Spearman's rank correlation has been measured between HADS anxiety score and caregiver strain, similar to our results; however, this correlation was not significant. This might be due to a lower number of patients and differences in inclusion criteria (26).

Life satisfaction in patients was not tested previously. Equivalent quality of life was shown to associate with caregiver strain (26).

Except for the CSI we did not collect other data about the caregivers. Visser-Meiley et al. (5) showed that characteristics of the caregiver, such as coping style, are also associated with caregiver strain.

High caregiver strain has a negative label; however, the influence of caregiver strain on stroke patients and their caregivers has not been evaluated fully. Nevertheless, there is some evidence of a negative impact of high caregiver strain in other patient groups. Caregivers of patients with a chronic disease or disability who reported high caregiver strain had significantly higher adjusted mortality rates than those with no strain or some strain (27). In addition, patients with cardiovascular disease more often did not achieve a heart-healthy diet and were less physically active when their caregiver experienced high caregiver strain (28). The severity of the strain experienced seems to play a role. We therefore used the results of the CSI as a continuous variable in our regression model.

We included in the study all patients who attended the appointment with the specialized nurse. However, these were not all of the consecutive patients admitted to the neurology department. Some patients died during their hospital stay or before the appointment. Other patients stayed permanently in the nursing home after a rehabilitation period. The spouses of these patients can experience strain, but because most caregiver tasks are performed by the staff of the nursing home we did not include these patients and spouses. In addition, not all patients who received an outpatient rehabilitation programme of clinical rehabilitation in a rehabilitation centre were included because follow-up was secured by a rehabilitation physician. After exclusion of this group ( $n = 19$ ), both patient life satisfaction and anxiety remain independently associated with caregiver strain.

Patients and caregivers who cancelled the appointment, or who did not have an appointment, due to miscommunication between the hospital and rehabilitation settings, are missing from our data-set. Thus, it is not known how many patients are missing. This may lead to higher or lower prevalence of caregiver strain; however, it is unlikely that the determinants of caregiver strain change, given the strong association.

The CSI data was complete of the caregivers of 179 patients (63%). Caregivers of another 15 patients completed the CSI, but did not answer all questions. The nurse and neurologist completed or changed answers to the screening questionnaires; thus we could not include these 15 patients in the analysis. Of the remaining 90 patients, 59 lived alone and therefore might not have had a caregiver. In addition to the absence of a caregiver, caregivers might not have had time to complete the questionnaire, might not have considered it necessary, or may not have regarded themselves as a caregiver. There was insufficient data on ADL independency to check the last point.

In conclusion, during the follow-up of stroke patients, attention should be paid to the high strain experienced by caregivers. High strain is present in over 10% of caregivers shortly after patient discharge and is associated with a higher level of anxiety symptoms and lower life satisfaction in stroke patients. Treating patient anxiety at an early stage might therefore lead to a decrease in long-term caregiver strain.

## ACKNOWLEDGEMENTS

No specific grant was received from any funding agency in the public, commercial, or not-for-profit sectors for this research.

*The authors declare no conflicts of interest.*

## REFERENCES

1. Hoeymans N, Melse JM, Schoemaker CG. [Health and determinants. Report about the exploration of the future of public health 2010. From healthy to better.] RIVM report no. 270061006, Bilthoven; 2010 (in Dutch).
2. Low JT, Payne S, Roderick P. The impact of stroke on informal carers: a literature review. *Soc Sci* 1999; 49: 711–725.
3. Opara JA, Jaracz K. Quality of life of post-stroke patients and their caregivers. *J Med Life* 2010; 3: 216–220.
4. Greenwood N, Mackenzie A. Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas* 2010; 66: 268–276.
5. Visser-Meily A, Post M, van de Port I, Maas C, Forstberg-Wärleby G, Lindeman E. Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years post-stroke: course and relations with coping strategies. *Stroke* 2009; 40: 1399–1404.
6. King RB, Ainsworth CR, Ronen M, Hartke RJ. Stroke caregivers: pressing problems reported during the first months of caregiving. *J Neurosci Nurs* 2010; 42: 302–311.
7. Bugge C, Alexander H, Hagen S. Stroke patients' informal caregivers. Patient, caregiver, and service factors that affect caregiver strain. *Stroke* 1999; 30: 1517–1523.
8. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983; 38: 344–348.
9. van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg B, Koopmanschap MA, van den Bos GA. Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clin Rehabil* 2004; 18: 203–214.
10. Valko PO, Bassetti CL, Bloch KE, Held U, Baumann CR. Validation of the fatigue severity scale in a Swiss cohort. *Sleep* 2008; 31: 1601–1607.
11. Mykletun A, Stordal E, Dahl AA. Hospital Anxiety and Depression (HAD) scale: factor structure, item analyses and internal consistency in a large population. *Br J Psychiatry* 2001; 179: 540–544.
12. Melin R, Fugl-Meyer KS, Fugl-Meyer AR. Life satisfaction in 18- to 64-year-old Swedes: in relation to education, employment situation, health and physical activity. *J Rehabil Med* 2003; 35: 84–90.
13. Boosman H, Schepers VP, Post MW, Visser-Meily JM. Social activity contributes independently to life satisfaction three years post-stroke. *Clin Rehabil* 2011; 25: 460–467.
14. Fugl-Meyer A, Branholm IB, Fugl-Meyer K. Happiness and domain-specific life satisfaction in adult northern Swedes. *Clin Rehabil* 1991; 5: 25–33.
15. Post MW, de Witte LP. Good inter-rater reliability of the Frenchay Activities Index in stroke patients. *Clin Rehabil* 2003; 17: 548–552.
16. Wade DT, Legh-Smith J, Langton Hower R. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *Int Rehabil Med* 1985; 7: 176–181.
17. Holbrook M, Skilbeck CE. An activities index for use with stroke patients. *Age Ageing* 1983; 12: 166–170.
18. Oliveira AR, Rodrigues RC, Sousa VE, Costa AG, Lopes MV, et al. Clinical indicators of 'caregiver role strain' in caregivers of stroke patients. *Contemp Nurse* 2013; 44: 215–224.
19. Rudd AG, Wolfe CDA, Tilling K, Beech R. Randomised controlled trial to evaluate early discharge scheme for patients with stroke. *BMJ* 1997; 315: 1039–1044.
20. Krevers B, Öberg B. Support/services and family carers of per-

- sons with stroke impairment: perceived importance and services received. *J Rehabil Med* 2011; 43: 204–209.
21. Blake H, Lincoln NB, Clarke DD. Caregiver strain in spouses of stroke patients. *Clin Rehabil* 2003; 17: 312.
  22. Campbell Burton CA, Murray J, Holmes J, Astin F, Greenwood D, Knapp P. Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. *Int J Stroke* 2013; 8: 545–559.
  23. Bruvill PW, Johnson GA, Jamrozik KD, Anderson CS, Stewart-Wynne EG, Chakera TM. Anxiety disorders after stroke: results from the Perth Community Stroke Study. *Br J Psychiatr* 1995; 166: 328–332.
  24. Bruggimann L, Annoni JM, Staub F, von Steinbüchel N, van der Linden M, Bogousslavsky J. Chronic posttraumatic stress symptoms after nonsevere stroke. *Neurology* 2006; 66: 513.
  25. Astrom M. Generalized anxiety disorder in stroke patients. A 3-year longitudinal study. *Stroke* 1996; 27: 270–275.
  26. Ilse IB, Feys H, de Wit L, Putman K, de Weerd W. Stroke caregivers' strain: prevalence and determinants in the first six months after stroke. *Disabil Rehabil* 2008; 30: 523–530.
  27. Mochari-Greenberger H, Mosca L. Caregiver burden and non-achievement of healthy lifestyle behaviors among family caregivers of cardiovascular disease patients. *Am J Health Promot* 2012; 27: 84–89.
  28. Perkins M, Howard VJ, Wadley VG, Crowe M, Safford MM, Haley WE, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013; 68: 504–512.