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ORIGINAL REPORT

THE RELATIONSHIP OF COPING STYLE WITH DEPRESSION, BURDEN, AND LIFE DISSATISFACTION IN CAREGIVERS OF PATIENTS WITH SUBARACHNOID HAEMORRHAGE*

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Objective: **To assess the relationship of coping style with depression, burden and life satisfaction in caregivers of patients with subarachnoid haemorrhage.**
Design: **Cross-sectional study.**
Participants: **Forty-one primary caregivers of patients with subarachnoid haemorrhage.**
Methods: **Caregivers completed several questionnaires within the first year after subarachnoid haemorrhage. Coping style was assessed using the Utrecht Coping List, depression with the Goldberg Depression Scale (GDS), burden with the Sense of Competence Questionnaire, and life satisfaction with the Life Satisfaction Questionnaire.**
Results: **Caregivers had a mean burden score of 37.8 (standard deviation (SD) = 7.4) and a life satisfaction score of 5.0 (SD = 0.6). Nine caregivers (23%) had depressive symptoms (GDS ≥2). A palliative coping style was positively associated with the presence of depressive symptoms (odds ratio (OR) = 1.45, *p* = 0.016). A passive coping style was positively related to burden (ß = 1.61, *p* = 0.024), adjusted for morbidity of the caregiver (ß = 11.90, *p* = 0.013), and inversely related to life satisfaction (ß = –0.10, *p* = 0.025).**
Conclusion: **In caregivers of patients with subarachnoid haemorrhage palliative or passive coping styles are related to depressive symptoms, higher burden and life dissatisfaction. This implies that rehabilitation programmes for patients with subarachnoid haemorrhage should also include caregiver support programmes that focus on coping style.**

Key words: subarachnoid haemorrhage; caregiver; coping style.

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INTRODUCTION

Subarachnoid haemorrhage (SAH) is a subtype of stroke, which accounts for 5% of all cases of stroke. A SAH is caused, in approximately 85% of cases, by a ruptured aneurysm in one of the cerebral vessels. The incidence of SAH in the Netherlands is 5.7 for men and 9.9 for women per 100,000 persons per year (1, 2). Compared with stroke in general, SAH occurs at a fairly young age: 50% of patients are younger than 55 years of age (3). Three months after SAH, 47% of patients experience mild cognitive impairments, 25% severe cognitive deficits and 40% depressive symptoms (4). One to 5 years after SAH, even in patients with good and fair recovery (Glasgow Outcome Score 5 and 4, respectively), there can still be cognitive deficits in all neuropsychological domains, with a high percentage of patients experiencing depression and reduced life-satisfaction (5). In research SAH is often clustered with other forms of stroke, whereby it is difficult to distinguish the unique consequences of this subtype (6).

Persistent psychosocial consequences are reported by the primary caregivers of patients with SAH, affecting quality of life, personal lives, family relations, financial situation and mood. Hop et al. (7, 8) found that after 4 months, and even after 18 months, SAH had considerable impact on the quality of life of the partners. Buchanan et al. (9) studied patients with SAH who underwent surgery. Their relatives reported psychological distress and 66% reported moderate or high levels of family burden (9). Forty percent of caregivers found it easier to deal with the initial crisis than to cope with the consequences after hospital discharge (10). Financial problems are reported by one-third of caregivers (10). Two to 3 years after SAH, 54% of caregivers experienced social or emotional stress (11). A study by Noble et al. (12) showed that 3.5 months after SAH, almost 26% of caregivers had post-traumatic stress disorder (PTSD). Because caregivers play an important role in the recovery of a patient with SAH (e.g. in maintaining treatment and emotional support) (7–11), the consequences above imply that post-acute rehabilitation after SAH should focus not only on the patient but also on his or her caregiver. To our knowledge there is no literature about specific caregiver support programmes for caregivers of patients with SAH.

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Little is known about coping in relation to psychosocial functioning of the primary caregivers of patients with SAH. There is evidence that a passive coping style is related to quality of life and burden in acquired brain injury (ABI) in general, and more specifically, in stroke and traumatic brain injury (TBI) populations (13–17). Only one study of caregivers of patients with SAH was found: Noble et al. (12) concluded that maladaptive coping strategies seem to be a predictor of PTSD in caregivers of patients with SAH. This study also suggests that these caregivers need greater attention and support, for example, by teaching them better coping strategies.

Another reason for studying caregivers of patients with SAH is that they differ from caregivers of patients with general stroke. Caregivers of patients with SAH are much younger and in different stage of life when the haemorrhage occurs compared with carers of patients with other types of stroke (18). In order to improve caregiver support programmes, it is important to understand which caregivers are at risk of long-term psychosocial distress. If the coping style of the caregiver relates to psychosocial distress and quality of life, training active coping styles could be a target for improving caregiver support programmes. The current study therefore assesses the relationship of the caregiver's coping style with depression, burden and quality of life of primary caregivers of patients with SAH.

METHODS

Participants

Between May 2006 and May 2009 patients diagnosed with SAH, admitted to the neurology or neurosurgery department of the Erasmus University Medical Center Rotterdam (Erasmus MC), and their primary caregivers were asked to participate in a prospective cohort study on long-term functional outcome after SAH. This study in caregivers is a cross-sectional sub-study of a longitudinal study in patients with SAH. Patients were included if they were diagnosed with SAH and were 18 years of age or older. Caregivers were included if they were the primary caregiver of the patient and if they were at least 18 years of age. Exclusion criteria for patients and caregivers were: inability to complete the questionnaires because of aphasia or cognitive impairment, no mastery of the Dutch language, or a short life expectancy (less than 1 year) due to co-morbidity. Written informed consent was obtained from all participants. The study was approved by the medical ethics committee of the Erasmus MC.

Data collection

Clinical characteristics and socio-demographic data of the patients with SAH were collected during hospital stay by the staff of the neurology or neurosurgery department. Within one year post-onset, patients and their primary caregivers were visited at home by a trained research psychologist to complete a set of validated questionnaires. Data collected from the caregivers were: age, gender, education level and morbidity. Morbidity of the caregiver is designed as a dichotomous variable where the caregiver was asked if he or she had health problems and/or relational stressors requiring treatment. The outcome measures assessed with validated questionnaires included depression, quality of life, coping style and burden.

Measurement instruments

Glasgow Coma Scale (GCS) scores were collected as a measure of the severity of the patients' SAH. The GCS score is composed of 3 components of impaired consciousness and coma: motor response, verbal response and eye opening. The total score ranges from 3 to 15, of which the higher scores represent a higher level of consciousness (19). The GCS scores, in combination with absent or present motor deficits, are transformed into World Federation of Neurological Surgeons (WFNS) scales, which is a universal SAH grading scale in 5 categories, ranging from 1 (no symptoms) to 5 (severe symptoms) (20, 21). The Barthel Index (BI) was used to measure physical functioning of the patient based on the independence of performing activities of daily living; it ranges from 1 (severe disabilities) to 20 (without disabilities) (22). The Mini-Mental State Examination (MMSE) was used to evaluate cognitive functioning of the patient (23).

The Goldberg Depression Scale (GDS) was used to assess symptoms of depression in the primary caregivers of patients with SAH. This scale consists of 9 questions with yes/no answers and has a total score range of 0–9, with higher scores indicating more depressive feelings. A cut-off score of 2 or more has been found to yield good specificity (93%) and sensitivity (85%) in terms of assessing depression in a general population (24).

The Sense of Competence Questionnaire (SCQ) was used to assess the burden of the caregivers. This questionnaire has been proven to be a reliable and valid instrument for assessing the burden of care-giving as experienced by caregivers of patients with stroke (25). The SCQ consists of 27 items on 3 sub-scales: satisfaction with the patient as a recipient of care (7 items), satisfaction with one's own performance as a caregiver (12 items) and consequences of involvement in care for the personal life of the caregiver (8 items). Each item was graded on a 4-point rating scale, ranging from 1 to 4. The burden scores for the total and the 3 sub-domains are represented as the sum of the item scores. The total score ranges from 27 to 108, with a higher score representing a higher level of perceived burden (26). To differentiate between high and low burden, we used a cut-off score of > 42 for high burden. This cut-off score is based on the description of normal cognitive functioning given by Scholte op Reimer et al. (25).

Life satisfaction was measured with the Life Satisfaction Questionnaire (LiSat-9). This questionnaire consists of 9 items: satisfaction with life as a whole, and 8 life domains. The scores range from 1 (very dissatisfying) to 6 (very satisfying). Scores of 1–4 depict degrees of dissatisfaction, and scores of 5–6 depict degrees of satisfaction. The total score consists of the mean of all 9 items scores and has shown good internal consistency and reliability (Cronbach's alpha coefficient = 0.82) (15, 27, 28). The Dutch version has been validated in an ABI population (29).

Coping style was measured with the Utrecht Coping List (UCL), a questionnaire with an acceptable internal reliability and test-retest correlation. The UCL has 44 items in 7 sub-scales, each representing a coping strategy. Caregivers have to respond to the question "How often do the following behaviours apply to you?" by answering on a 4-point scale from never (1) to very often (4). The 7 sub-scales are: "Passive" (7 items), which includes isolating oneself from others, worrying about the past and taking refuge in fantasies; "Active confronting" (7 items), described as tackling a problem at once, seeing problems as a challenge and remaining calm in difficult situations; "Palliative" (8 items), which represents seeking distraction by trying to relax, going out or decreasing pressure by smoking or drinking alcohol; "Seeking social support" (6 items), which includes asking for help and sharing worries with someone; "Avoiding" (8 items), which means to let things take their course and wait to see which way the wind blows; "Expressing emotions" (3 items), which represents showing anger and letting off steam; and "Reassuring thoughts" (5 items) to encourage and telling oneself that everything will be alright. Sum-scores were used per sub-scale (30, 31).

Data analysis

Statistical analyses were performed using SPSS version 19 (SPSS Inc., Chicago, IL, USA). Descriptive analyses were used to express the patient and caregiver characteristics. The coping style mean scores were compared with the normal ranges in the norm tables (1 and 2) in the UCL manual (30). Multivariate linear and logistic regression analyses were performed to estimate the relation of coping style with depression, burden and life satisfaction in caregivers of patients with SAH. The model assumptions of linearity, normality and homoscedasticity were checked. Because the residuals of the depression variable were not normally distributed, due to the high number of zero scores, this variable

(GDS) was dichotomized into yes/no for the presence of depression, based on the cut-off score of at least 2. The relation of coping style with the presence of depression was assessed with a logistic regression analysis, and burden and life satisfaction were analysed using linear regression analyses. The following potential confounders were taken into account: the severity of SAH of the patient measured with the GCS, and age, gender, education level and presence of morbidity of the caregiver.

First, each variable was analysed separately with univariate regression analysis. If a significant relationship was found at a p-value < 0.05, the variable was entered into a multivariate regression analysis using forward variable selection. If the p-value was > 0.10 the variable was removed from the multivariate regression model.

RESULTS

Patient and caregiver characteristics

During the inclusion period, a total of 228 patients with SAH were admitted to the neurology or neurosurgery department of the Erasmus University Medical Center, of which, 63 patients died. All 165 surviving patients were asked to participate in the study before hospital discharge. Of these, 20 patients refused to participate, 30 did not meet the inclusion criteria and 48 were discharged before informed consent was obtained. A total of 67 SAH patients agreed to take part in the study. The primary caregiver of each included patient was also asked to participate in the study. Of these, 41 (61%) agreed to participate. The caregiver study population mainly consisted of spouses (n=35; 85%), with the remainder comprising of children (n=3; 7%) or parents (n=3; 7%) of the patients. The majority of the caregivers were men (59%). Ages ranged from 27 up to 79 years (mean 56.3, SD 13.4 years). The patient and caregiver characteristics are shown in Table I.

Table I. *Patient and caregiver characteristics (n = 41)*

	n (%)	Mean (SD)	Median (IQR)
Patient characteristics			
Age, years		54.8 (12.0)	
Gender, male	16 (39)		
Time post-SAH, months		6.8 (10.5)	
Type of SAH			
Aneurysmal	37 (90)		
Perimesencephalic	4 (10)		
WFNS grade			
I	22 (54)		
II	11 (27)		
III	0 (0)		
IV	4 (10)		
V	4 (10)		
Treatment SAH			
Clipping	12 (29)		
Coiling	23 (56)		
Other	6 (15)		
Discharge destination			
Home	30 (73)		
Inpatient rehabilitation centre	6 (15)		
Nursing home	4 (10)		
Other	1 (2)		
GCS		13.2 (3.3)	15 (13–15)
Barthel Index		18.8 (2.2)	20 (19–20)
Depression Score (CES-D)		12.1 (9.2)	10 (4.8–17.8)
MMSE (total score)		26.7 (3.8)	28 (25.5–29.4)
Caregiver characteristics			
Age, years		56.3 (13.4)	
Gender, male	24 (59)		
Relation to the patient			
Partner	35 (85)		
Parent	3 (7)		
Child	3 (7)		
High education	12 (29)		
Employed	15 (37)		
Morbidity	5 (12)		

SAH: subarachnoid haemorrhage; WFNS: World Federation of Neurological Surgeons Scales; GCS: Glasgow Coma Scale score; CES-D: Center for Epidemiologic Studies – Depression Scale score; MMSE: Mini-Mental State Examination; SD: standard deviation; IQR: inter quartile range.

Outcomes of the caregivers

Caregivers were measured within 1 year after patients' SAH (mean time 4.4 months, SD 3.8). Nine caregivers (23%) were classified as depressed (GDS ≥ 2). The mean score on the LiSat-9 of 5.0 (SD 0.6) indicates that, in general, the caregivers were satisfied with life. Ten caregivers (28%) scored < 5, indicating they were dissatisfied with life. Of the SCQ there were only 21 complete questionnaires, because this test was added later during the study. Of these 21 caregivers, 6 (29%) scored higher than 42, which indicates that they experienced high burden. All coping style sub-scores were in the normal ranges of age norm groups as described in the UCL manual (30). All total mean scores and frequencies of these caregiver outcomes are shown in Table II.

Relationships between coping styles and outcomes

Results of the logistic and linear regression analyses are shown in Table III.

Table II. *Outcomes for caregiver depression, burden, life satisfaction and coping strategy (n = 41)*

Outcome	*n* (%)	Mean (SD)	Median (IQR)
GDS (0–9)		1.0 (2.0)	0 (0–1)
Depression (GDS ≥ 2)	9 (23)		
SCQ total (27–108)		37.8 (7.4)	35 (32–44)
Satisfaction as recipient (7–28)		9.1 (1.8)	9 (8–10)
Satisfaction with own performance (12–48)		16.4 (4.9)	15 (13–19)
Consequences of involvement (8–32)		12.3 (3.6)	12 (9–16)
Presence of burden (SCQ > 42)	6 (29)		
LiSat-9 (1–6)		5.0 (0.6)	5.2 (4.9–5.4)
Dissatisfied (LiSat-9 < 5)	10 (28)		
UCL			
Active (7–28)		18.8 (3.4)	19 (16–21)
Palliative (8–32)		16.4 (2.9)	16 (14–17)
Avoiding (8–32)		14.4 (3.2)	14 (12–16)
Seeking social support (6–24)		12.7 (2.3)	12.5 (11–15)
Passive (7–28)		10.6 (2.3)	10 (9–12)
Expressing emotions (3–12)		5.6 (1.3)	6 (5–6)
Reassuring (5–20)		12.4 (1.9)	12 (11–14)

Missing data: GDS: n=2, SCQ: n=20, LiSat: n=5, UCL: n=1. SAH: subarachnoid haemorrhage; UCL: Utrecht Coping List; GDS: Goldberg Depression Scale; SCQ: Sense of Competence Questionnaire; LiSat-9: Life Satisfaction Questionnaire; SD: standard deviation; IQR: inter quartile range.

Table III. *Logistic and linear regression models for the 3 outcomes: presence of depression, burden score and life satisfaction score*

	OR (95% CI)	ß (95% CI)	*p*-value	R^2 change (%)	R^2 total (%)
Presence of depression					34.3[a]
Palliative coping style	1.45 (1.07; 1.97)		0.016		
Burden					48.3
Morbidity of caregiver		11.90 (2.84; 20.97)	0.013	29.8	
Passive coping style		1.61 (0.24; 2.99)	0.024	18.5	
Life satisfaction					14.3
Passive coping style		–0.10 (–0.18; –0.01)	0.025		

[a] R^2 Nagelkerke.

95% CI: 95% confidence interval; OR: odds ratio.

A palliative coping style was positively associated with the presence of depressive symptoms (OR = 1.45, *p* = 0.016). None of the potential confounders was significantly associated with the presence of depression.

Passive coping style (*p* = 0.025), morbidity of the caregiver (*p* = 0.010), and gender (*p* = 0.024) were significantly related to burden in univariate analyses. In the multivariate model, a passive coping style was positively related to burden (ß = 1.61, *p* = 0.024), adjusted for morbidity of the caregiver (ß = 11.90, *p* = 0.013). Gender dropped out of the final regression model (R^2change = 5.0%; *p* = 0.210).

Passive coping style was inversely related to life satisfaction (ß = –0.10, *p* = 0.025). None of the potential confounders was significantly associated with this outcome.

DISCUSSION

In this study, we found that maladaptive coping styles, such as passive coping and palliative coping, are related to depression, burden and life dissatisfaction in caregivers of patients with SAH. This is in line with the results of other studies among the caregivers of patients with ABI, which concluded that psychosocial functioning is related to caregiver coping styles (13–15, 17, 31). In particular, a passive coping style of the caregiver has been associated with lower family functioning, lower quality of life and higher strain (17). Visser-Meily et al. (15) found that the passive coping style of the caregiver was the most important predictor of quality of life 1 year after stroke. In addition, 3 years after stroke, caregiver coping style seemed to be related to their psychosocial functioning: a passive coping style was related to negative outcomes, whereas an active coping style was related to positive outcomes (16). In caregivers of patients with TBI, a similar correlation was found between coping style and perception of burden and increased emotional distress (13, 14, 31). Surprisingly, in our study no significant associations were found between active coping styles and the caregiver outcomes, as in Visser-Meily et al. (15, 16). This may be explained by the problem of a small sample size in our study or by the different outcome measures that were used.

Our finding, about the correlation between coping style and caregiver outcomes, is important for the development and improvement of specific SAH caregiver support programmes in rehabilitation services and to target those persons who might benefit from such programmes. If it is possible to change maladaptive coping styles into effective coping styles through an intervention programme, both patients and caregivers might benefit from such a programme. A study analysing the burden of caregivers of chronic neurological patients showed that approximately 66% of the caregivers requested interventions aimed at reducing their burden (32). In order to select persons for caregiver support programmes, questionnaires could be used that measure the preference for certain coping styles. Our study shows that caregivers with high scores on palliative or passive coping styles may benefit the most from such programmes. Several intervention studies for patients with stroke or TBI and their caregivers have focused on improving emotional functioning and reducing caregiver burden after TBI or stroke (33, 34). Backhaus et al. (35) found that a Coping Skills Group intervention in a population of patients with TBI and their caregivers resulted in improved perceived self-efficacy directly after participating in the group. This result is promising for our population of patients with SAH and their caregivers. Although 23% of caregivers of patients with SAH seemed to be depressed in this study, we also found that, in general, the primary caregivers of patients with SAH were satisfied with life, had low depression and burden scores, and showed adequate coping styles. Only 28% of caregivers were dissatisfied with life. These numbers are much better than those reported for caregivers of patients with ABI. For these caregivers, Wolters Gregório et al.(17) found that 39% experienced high levels of strain and 38% reported a low quality of life. In spouses of patients with stroke, 52% reported depressive symptoms, 50% dissatisfaction with life and 54% strain (15). An explanation for this discrepancy might be that the studies of caregivers of stroke or ABI patients contained cohorts of patients that were more severely affected, both physically and mentally, by the injury in comparison with our cohort, in which the majority of the patients had maximal GCS scores and Barthel Index scores (13, 16, 31, 36). If a patient is severely affected by the injury this will have a greater impact on caretaking tasks and burden for their caregivers (34). Differences in injury severity can also be explained by the fact that our sample is a hospital-based cohort of patients with SAH, whereas other ABI cohorts are often rehabilitation cohorts and thus more severely affected (14, 16, 17, 36, 37). From our cohort only 25% were referred to inpatient rehabilitation centres or nursing homes and 75% were discharged directly to their homes.

Finally, the high scores on the GCS and low scores on WFNS in this study might be partly explained by the fact that patients with perimesencephalic SAH were not excluded (10% of the study population). The prognosis of these patients is considered much better compared with patients with aneurysmal SAH (18).

Study limitations

The study has some limitations. The first is that the sample size is relatively small. However, even with this small number, we did find significant differences in outcomes based on coping styles of caregivers. In further research a larger sample is required to confirm that palliative or passive coping styles in caregivers of patients with SAH are related to depressive symptoms, higher burden and life dissatisfaction. Another limitation is that the study has a cross-sectional design, which prevents us from drawing conclusions about causal relationships. No follow-up measurement was performed in this group of caregivers, and as such the change over time in coping styles, mood and life satisfaction was not studied. Finally, no distinction was made between the types of caregivers. All types of caregivers were grouped together, because the sample size in this study was too small to subdivide the group of caregivers into partners, parents and children. Further studies are required to determine whether there are different outcomes for these subgroups.

Conclusion

Palliative and passive coping styles are related to depressive symptoms, burden, and life dissatisfaction in caregivers of patients with SAH in the first year post-onset. To develop specific rehabilitation programmes for patients with SAH and their caregivers, more studies assessing the relationship between coping style, depression, burden and life dissatisfaction in caregivers of patients with SAH are required, with a longitudinal study design.

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