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ABSTRACT

Background: Partners of patients with stroke are at high risk for burden, anxiety and depressive symptoms. Previous studies have reported contradictory results and did not investigate these three courses simultaneously. In this study we comprehensively studied the courses and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke during the first two years after stroke. They were analyzed as outcomes as well as predictors for each other.

Methods: Six general hospitals recruited 215 patients with stroke and their partners for a longitudinal cohort study. Mixed model analyses were performed for burden (CSI), anxiety (HADS-A) and depressive symptoms (HADS-D) as time-varying outcome variables, measured at four time points during two years after stroke.

Results: Burden and depressive symptoms did not significantly change over time, whereas anxiety symptoms initially decreased followed by an increase. Higher burden was predicted by partners' younger age, higher education, more symptoms of anxiety and depression, and by patients' greater stroke severity, lower cognitive functioning and more symptoms of anxiety and depression. More anxiety symptoms were predicted by higher burden, more depressive symptoms, and lower self-efficacy of the partner. More depressive symptoms were predicted by older age, higher burden, more symptoms of anxiety, less proactive coping strategies of the partner, and more depressive symptoms of the patients.

Conclusions: Burden, anxiety and depressive symptoms are interrelated and become chronic in partners of patients with stroke. It is important to screen partners early after stroke to identify partners who are at risk for negative outcomes.

Introduction

Stroke is a leading cause of serious long-term disability,[1] and partners of patients with stroke are at high risk for burden, anxiety and depressive symptoms.[2–5] In turn, such psychological distress can lead to reduced outcomes such as decreased quality of life, participation and life satisfaction.[6] However, it is not clear how burden, anxiety and depressive symptoms develop in partners from the moment of stroke through the long-term caregiving situation over the years. This knowledge is necessary to be able to properly support partners through psychosocial interventions. Several studies have shown that burden remains elevated over -time,

while others reported a decrease or increase of burden as more time passes since the stroke.[4,7–14] Such mixed results have also been reported for the courses of anxiety[2,3,14] and depressive symptoms among partners.[3,4,11,14–18] The contradictory results illustrate that the development of burden, anxiety and depressive symptoms over time is complex. Previous studies did not take this complexity sufficiently into account. First, burden, anxiety and depressive symptoms were not studied simultaneously, although they are highly interrelated.[5,7,9,14] Second, the individual differences between partners regarding the courses of their symptoms were not taken into account. Third, predictors proven to be important in previous

research were not included when studying the courses of burden, anxiety and depressive symptoms, and the effects of these predictors were not investigated longitudinally for time-varying outcomes, i.e. over the entire course of burden, anxiety and depressive symptoms.

Previous research indicates which predictors of caregiver burden, anxiety and depression are important. Predictors have been found in terms of demographic characteristics of either patient or partner, such as age, sex and education [2,3,8,10,12,14–16,18–22]; stroke-related characteristics such as stroke severity, cognitive impairments and ADL dependency[2–4,8–10,14–16,19,20,23]; stroke patients' anxiety and depressive symptoms[3,7,8,10,16,18]; and personal characteristics of the partners, such as coping and self-efficacy.[4,20,23] This large variety of predictors may vary across outcomes, but such comparisons are scarce.

We found only one study that investigated all three courses and predictors of burden, anxiety and depressive symptoms. This study showed that burden decreased in the first three months after discharge, then increased up to nine months, while anxiety and depressive symptoms decreased up to nine months.[14] Higher burden was predicted by the partner being male and not living with the stroke patient, and by greater ADL dependence of the patient. Higher anxiety was predicted by stroke patients' younger age, and more depressive symptoms were predicted by partners being older and by patients being younger. This study was limited to the first year after stroke, and burden, anxiety and depressive symptoms were studied separately. The current literature lacks studies investigating these courses and predictors simultaneously, while predictors may vary across outcomes and over time. Such knowledge is important when developing psychosocial interventions for caregivers which should be integrated in stroke rehabilitation programs.[24]

The aim of our study was to determine the courses and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke during the first two years after stroke and to analyze burden, anxiety and depressive symptoms as outcomes as well as predictors for each other.

Methods

This study was a secondary data analysis on data available from the Restore4Stroke Cohort, a general hospital-based multi-center longitudinal cohort study.[25] Six general hospitals across the Netherlands participated and recruited patients with stroke and their partners between March 2011 and March 2013. Patients were included when they had had a clinically confirmed diagnosis of stroke within the last seven days. Partners were included when they were married to the stroke patient or were in a steady relationship with them. Patients and partners were eligible if they were least 18 years of age. Patients and partners were excluded if they (1) had a serious other condition that was likely to interfere with the study outcomes (e.g. neuromuscular disease), (2) were already dependent regarding activities of daily living before their stroke, as defined by a Barthel Index score of 17 or lower,[26] or (3) had insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment). Furthermore, patients were excluded if they had already been suffering from cognitive decline before their stroke, as defined by a score of 1 or higher on the Heteroanamnesis List Cognition.[27] Post-stroke aphasia was not an exclusion criterion. If this problem made it difficult for patients to complete the questionnaires, only the observational measures were applied.

The medical ethics committees of all participating hospitals approved the Restore4Stroke Cohort study and informed consent was obtained from all participants. This manuscript conforms to the STROBE guidelines.

Measures

Dependent variables

Burden experienced by the partner was measured with the Caregiver Strain Index (CSI).[28,29] This instrument consists of 13 items, which can be answered with "yes" or "no." The total score ranges from 0 to 13, with higher scores reflecting a higher caregiver burden. A score of 7 or higher indicates a substantial burden. The CSI is a reliable[28] and

valid[29] instrument and is the most commonly used instrument to assess burden in caregivers of patients with stroke.[30]

Partners' anxiety and depressive symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS).[31] This instrument contains seven items measuring anxiety (HADS-A) and seven items measuring depression (HADS-D). Subscale total scores range from 0 to 21, with scores above 7 indicating an anxiety disorder or depression, respectively.[31] The HADS has shown good validity and reliability.[32]

Independent variables

Demographic characteristics (age, sex and educational level) were recorded for both partners and patients. Educational level was dichotomized into higher education, for participants who had completed upper level secondary school and/or university degree, and lower education. Partners' proactive coping was measured with the Utrecht Proactive Coping Competence Scale (UPCC).[33] The UPCC has good reliability, validity and responsiveness.[33] Self-efficacy of the partners was determined with the General Self-Efficacy Scale (GSES).[34] Psychometric properties (reliability and validity) of the GSES are satisfactory to good.[35] Stroke characteristics (type of stroke, first or recurrent stroke and stroke severity) were obtained from medical charts. Stroke severity was measured using the National Institutes of Health Stroke Scale (NIHSS).[36] Independence in activities of daily living (ADL) was assessed with the Barthel Index (BI).[26] Cognitive functioning was determined with the Montreal Cognitive Assessment (MoCA).[37] The discharge destination was recorded as home, rehabilitation center or nursing home. Anxiety and depressive symptoms of the patients were measured with the HADS.

Procedure

Patients and their partners were included within the first week after stroke. Demographic characteristics of patients and partners (age, sex and educational level), as well as stroke characteristics, stroke severity and ADL independence, were recorded at inclusion. At two months after stroke, a research assistant visited the couples at the institution where

the patient was residing or at home, to assess the patient's cognitive functioning. To assess their anxiety and depressive symptoms, both patients and partners were asked to complete questionnaires on paper independently from each other. Additionally, partners evaluated their burden, proactive coping and self-efficacy. At six months, one year and two years after stroke, questionnaires were again administered to patients and partners to assess their anxiety and depressive symptoms and for partners also their burden. At these measurement moments, patients and partners were given the choice to complete the questionnaires on paper or online.

Statistical analyses

Normality of distribution of the data was assessed by Shapiro-Wilk tests and visual plots. Descriptive statistics were used to describe the baseline characteristics of patients and their partners. Stroke severity was categorized into "no stroke symptoms" (NIHSS 0), "minor stroke symptoms" (NIHSS 1–4), "moderate stroke symptoms" (NIHSS 5–12), and "moderate to severe symptoms" (NIHSS > 12). BI and MoCA scores were dichotomized according to their cutoff scores to describe the ADL-dependent (BI < 19) and cognitively impaired (MoCA < 26) patients, respectively. The prevalence of burden, anxiety and depressive symptoms among partners was described using means and standard deviations, as well as the number of partners scoring above the cutoff values (CSI ≥ 7, HADS-A > 7 and HADS-D > 7).

Mixed model analyses were performed with burden, anxiety and depressive symptoms as dependent variables in three separate models. This statistical technique identifies both within-subject effects and between-subject effects, to account for the individual differences in partners as well as the effects at group level. Mixed model analyses allowed us to use all available data even when dropout occurred or data from previous time points was missing. In these models, random intercepts across persons were used to account for the fact that repeated measures are correlated within individuals. The course of the outcome variables was determined by adding the linear, quadratic and cubic functions of time in sequence, with time entered as the exact number of days after stroke. Random effects of time were

added to the fixed effects to represent the individual differences in rates of change. Model fit was assessed using the deviance statistic (−2 log likelihood). Covariance structures were specified as unstructured random effects.

For each outcome variable, the predictors were determined by adding independent variables to the best fitting model with time. Independent variables concerning partner characteristics were age, sex, educational level, proactive coping, and self-efficacy, all treated as constant predictors, and burden, anxiety and depressive symptoms as time-varying predictors (measured at four time points). Independent variables concerning patient characteristics were stroke severity, ADL independence and cognitive functioning, treated as constant predictors, and anxiety and depressive symptoms as time-varying predictors (measured at four time points). For each of the three outcome variables, we tested which independent variables showed model improvement over the model with time, and added these variables to the final model. When the main effect of an independent variable improved the model, the interaction effect of this variable with time was tested to determine whether the effect differed over time. When the interaction effect improved the model, it was added to the final model. Effect sizes and their 95% confidence intervals were estimated with restricted maximum likelihood. These estimates are a combination of both between-subject and within-subject effects. All outcome variables and possible predictors were checked for multicollinearity (variance inflation factor > 4 or tolerance < 0.2), which was not present. A two-tailed significance level alpha of 0.05 was used for all statistical tests. Data were analyzed using IBM SPSS Statistics version 25 for Windows.

Results

A total of 215 patient-partner couples were included in the study. Their baseline characteristics are presented in Table 1. Partners' mean age was 62.6 years and most partners were women (78.1%). The majority of the partners were low educated (71.7%). Most patients had had an ischemic stroke (94.9%), had minor stroke symptoms (55.8%) and were ADL-independent (63.7%). Almost two thirds of the patients scored below the MoCA cutoff score, suggesting cognitive impairment.

Table 1. Partners' and patients' baseline characteristics (N = 215 dyads).

Partner characteristics	Mean (SD)	n (%)
Age in years, mean (SD)	62.6 (10.8)	
Male sex		47 (21.9)
Higher education[a] (n = 198)		56 (28.3)

Patient characteristics	Mean (SD) Median (IQR)	n (%)
Age in years, mean (SD)	64.3 (11.0)	
Male sex		169 (78.6)
Higher education[a] (n = 210)		65 (31.0)
Ischemic stroke		204 (94.9)
Recurrent stroke		26 (12.1)
Stroke severity (NIHSS), median (IQR)	2.0 (3.0)	
No stroke symptoms (NIHSS 0)		51 (23.7)
Minor stroke symptoms (NIHSS 1–4)		120 (55.8)
Moderate stroke symptoms (NIHSS 5–12)		37 (17.2)
Moderate to severe symptoms (NIHSS > 12)		7 (3.3)
ADL independence (Barthel Index), median (IQR)	20.0 (4.0)	
ADL-dependent (Barthel Index < 19)		78 (36.3)
Cognitive functioning (MoCA) (n = 192), median (IQR)	24.0 (5.8)	
Cognitively impaired (MoCA < 26) (n = 192)		122 (63.5)
Destination after discharge from hospital		
Home		163 (75.8)
Rehabilitation center		34 (15.8)
Nursing home		18 (8.4)

a Completed upper level secondary school and/or university degree.
NIHSS: National Institutes of Health Stroke Scale; ADL: activities of daily living; MoCA: Montreal Cognitive Assessment.

Presence of burden, anxiety and depressive symptoms

The presence of burden, anxiety and depressive symptoms in partners at the four time points is shown in Table 2. Numbers vary across time points and between instruments due to drop-out of dyads, partners not filling in a measurement at a specific time point, or not correctly completing a specific instrument. There was great variation in the presence of burden, anxiety and depressive symptoms, as shown by the high standard deviations. At two months and two years, anxiety was reported more often than burden or depressive symptoms. At six months and one year, the highest percentage was found for burden.

Course and predictors of burden, anxiety and depressive symptoms

The results of the three linear mixed models for burden, anxiety and depressive symptoms are displayed in Table 3.

Burden and depressive symptoms did not significantly change over time. Anxiety showed a quadratic effect of time, decreasing between two and six months and increasing again between one and two years after stroke.

Table 2. Partners' burden, anxiety and depressive symptoms.

	n	Mean	Standard deviation	Above cutoff*n (%)
Burden (CSI) [Possible range: 0–13]				
2 months	192	4.0	3.3	46 (24.0)
6 months	193	4.1	3.3	47 (24.4)
1 year	181	4.0	3.3	41 (22.7)
2 year	176	4.2	3.4	44 (25.0)
Anxiety (HADS-A) [Possible range: 0–21]				
2 months	193	5.5	4.0	58 (30.1)
6 months	193	4.7	3.6	40 (20.7)
1 year	182	4.8	3.6	35 (19.2)
2 year	176	5.6	4.0	51 (29.0)
Depressive symptoms (HADS-D) [Possible range: 0–21]				
2 months	193	3.1	3.1	22 (11.9)
6 months	193	3.3	3.4	25 (13.0)
1 year	182	3.3	3.2	23 (12.6)
2 year	176	3.6	3.4	27 (15.3)

CSI: Caregiver Strain Index; HADS-A: Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale-Depression subscale.
* cutoff points CSI ≥ 7, HADS-A > 7, HADS-D > 7.

Over the course of two years, higher burden was predicted by partners' younger age, higher educational level, and more symptoms of anxiety and depression, and by patients' greater stroke severity, lower cognitive functioning and more symptoms of anxiety and depression. More anxiety symptoms were predicted by partners' higher burden, more depressive symptoms, and lower self-efficacy. Patient characteristics had no significant effect on the partners' anxiety. More depressive symptoms were predicted by partners' older age, higher burden, more symptoms of anxiety, and less proactive coping strategies, and more depressive symptoms in the patients. No significant effects were found for the interactions of the predictors with time in any of the three models. The strongest effect was found for proactive coping as a predictor of fewer depressive symptoms.

Discussion

In this study, the courses and predictors of burden, anxiety and depressive symptoms were examined in partners of patients with stroke and these factors were investigated as outcomes as well as predictors for each other. Results showed that burden, anxiety and depressive symptoms remained present in partners during the first two years after stroke. The strongest predictors were the burden, anxiety and depressive symptoms themselves, which turned out to predict each other. In addition, the partners' burden was mainly predicted by patient characteristics, while anxiety and depressive symptoms were particularly predicted by the characteristics of the partners themselves.

We found that burden and depressive symptoms remained elevated during the first two years after stroke, whereas symptoms of anxiety initially decreased, but increased toward previous levels during the second year after stroke. The stable course of burden is in line with previous studies and a review about caregiver burden following stroke.[10–13] Pucciarelli et al.[14] also found a decline in anxiety followed by an increase, albeit in the first year after stroke. Our finding that the level of depressive symptoms did not change over time is in disagreement with those of Pucciarelli et al.,[14] who

Table 3. Predictors of partner's burden, anxiety and depressive symptoms.

Predictors	Burden		Anxiety		Depressive symptoms	
	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value
Intercept	4.35 (−0.39; 9.10)	0.072	**5.74 (0.61; 10.87)**	0.028	2.83 (−1.08; 6.74)	0.156
Time (months)	0.01 (−0.01; 0.04)	0.246	**−0.23 (−0.43; −0.03)**	0.023	0.01 (−0.01; 0.02)	0.341
Quadratic effect of time	-		**0.01 (0.00; 0.01)**	< 0.001	-	
Cubic effect of time	-		-		-	
Partner characteristics						
Age in years	**−0.03 (−0.06; 0.00)**	0.049	−0.03 (−0.06; 0.01)	0.155	**0.04 (0.01; 0.06)**	0.006
Age in years*time	-		0.00 (0.00; 0.00)	0.308	-	
Male sex	−0.39 (−1.12; 0.35)	0.303	−0.25 (−0.99; 0.50)	0.512	0.21 (−0.41; 0.84)	0.505
Male sex*time	-		-		-	
Higher education	**0.86 (0.17; 1.55)**	0.014	0.08 (−0.62; 0.78)	0.819	−0.10 (−0.68; 0.49)	0.745
Higher education*time	-		-		-	
Burden (CSI)			**0.28 (0.19; 0.36)**	< 0.001	0.16 (0.09; 0.24)	< 0.001
Burden (CSI)*time			-		-	
Anxiety (HADS-A)	**0.22 (0.15; 0.29)**	< 0.001			0.42 (0.36; 0.48)	< 0.001
Anxiety (HADS-A)*time	-				-	
Depressive symptoms (HADS-D)	**0.18 (0.10; 0.27)**	< 0.001	**0.56 (0.48; 0.64)**	< 0.001		
Depressive symptoms (HADS-D)*time	-		-			
Proactive coping (UPCC)	0.01 (−0.69; 0.72)	0.967	−0.04 (−0.86; 0.79)	0.930	**−1.27 (−1.86; −0.68)**	< 0.001
Proactive coping (UPCC)*time	-		0.01 (−0.02; 0.05)	0.488	-	
Self-efficacy (GSES)	0.07 (−0.01; 0.16)	0.096	**−0.12 (−0.20; −0.03)**	0.006	0.00 (−0.07; 0.07)	0.967
Self-efficacy (GSES)*time	-		-		-	
Patient characteristics						
Stroke severity (NIHSS)	**0.15 (0.02; 0.29)**	0.026	-		-	
Stroke severity (NIHSS)*time	−0.01 (−0.01; 0.00)	0.108	-		-	
ADL independence (BI)	−0.07 (−0.15; 0.02)	0.127	0.02 (−0.06; 0.10)	0.557	0.02 (−0.05; 0.08)	0.642
ADL independence (BI)*time	-		-		-	
Cognitive functioning (MoCA)	**−0.10 (−0.19; −0.01)**	0.027	0.08 (−0.01; 0.17)	0.067	−0.05 (−0.13; 0.02)	0.154
Cognitive functioning (MoCA)*time	-		-		-	
Anxiety (HADS-A)	**0.09 (0.02; 0.16)**	0.013	0.06 (−0.02; 0.13)	0.148	−0.03 (−0.09; 0.04)	0.446
Anxiety (HADS-A)*time	-		-		-	
Depressive symptoms (HADS-D)	**0.16 (0.10; 0.23)**	< 0.001	0.05 (−0.05; 0.15)	0.346	**0.08 (0.01; 0.15)**	0.019
Depressive symptoms (HADS-D)*time	-		−0.01 (−0.01; 0.00)	0.064	-	

CSI: Caregiver Strain Index; HADS-A: Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale-Depression subscale; UPCC: Utrecht Proactive Coping Competence Scale; GSES: General Self-Efficacy Scale; NIHSS: National Institutes of Health Stroke Scale; ADL: activities of daily living; BI: Barthel Index; MoCA: Montreal Cognitive Assessment.

found that depressive symptoms decreased in the first nine months and stabilized or tended to increase after that. We were less likely to find a decline, since the level of depressive symptoms in our sample was already much lower. Their study found a mean HADS-D score of 7.1 at three months after discharge, whereas our sample had HADS-D scores of 3.1 and 3.3 at two months and six months after stroke, respectively.

Burden, anxiety and depressive symptoms are interrelated, since they all predicted each other. However, multicollinearity was not present and there were no high correlations between the measures of burden, anxiety and depressive symptoms. We can therefore conclude that they are different concepts.

Additionally, we found that patients' anxiety predicted a higher burden for the partners, while depressive symptoms in the patients predicted higher burden and more depressive symptoms in the partners. There seems to be a dyadic influence within patient-partner couples concerning emotional distress. For depressive symptoms, this reciprocal association between patients with stroke and their partners is confirmed by previous studies and a recent review.[38]

Of all the variables we tested in the three models, proactive coping came out as the strongest predictor. Partners with less proactive coping were at risk for more depressive symptoms, and therefore also at risk for higher burden and more anxiety, since depressive symptoms in turn predicted these negative outcomes.

None of the predictors showed an interaction effect with time, meaning their effects were similar over the entire course of burden, anxiety or depressive symptoms from the early stages after stroke up to two years thereafter.

Strengths

In this longitudinal study we investigated the predictors of burden, anxiety and depressive symptoms at four time points up to two years after stroke. We included burden, anxiety and depressive symptoms in all three models as outcomes or as predictors, and we included other known important predictors in the analyses. The sophisticated statistical techniques used were able to deal with missing data and different intervals for different cases (e.g. the exact number of days between measurements).

Limitations

This study has several limitations. First, our study sample included a higher percentage of male patients and female partners than the Dutch stroke population.[39] Since sex was not a significant predictor in either of the models, this probably did not influence the results. Second, we did not record whether partners had received any professional support. Our results might be an underestimation if such interventions had lowered the partners' levels of burden, anxiety and depressive symptoms. Third, previous or comorbid mental health issues, medications, as well as certain personality traits and skills of the partners were not available in our data, while they might have been important predictors. In a previous study by our research group, passive coping was the strongest predictor of burden and depressive symptoms in partners of patients with stroke.[4] Although passive coping has a strong negative correlation with proactive coping, other coping strategies might have been important predictors as well.[40] Furthermore, optimism, self-esteem and mastery have been found to be related to emotional distress in caregivers of patients with stroke.[16,41] In addition, poor family functioning is associated with increased symptoms of anxiety and depression in stroke caregivers.[42–46] These variables and others should be included in future research.

Clinical implications

The burden, anxiety and depressive symptoms experienced by partners of patients with stroke become chronic. Health care professionals should monitor both patients and partners and pay particular attention to the partners of patients with severe stroke, low cognitive functioning and depressive symptoms. Partners should be screened for burden, anxiety and depressive symptoms, since each of these is a risk factor for developing the other two negative outcomes. CSI and HADS are not time-consuming, and both are very easy to administer and could easily be integrated in standard care. Screening partners early after stroke may help health care professionals to identify partners who are at risk for negative outcomes. These partners can then receive support through interventions that use psychological techniques, such as cognitive-behavioral therapy, coping-skill training, and problem-solving therapy. These interventions have proven their usefulness and efficacy in reducing burden, anxiety and depressive symptoms in partners of patients with stroke.[24] Currently we are investigating a blended care support intervention for partners in a randomized controlled trial.[47]

Disclosure statement

No potential conflict of interest was reported by the author(s).

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