



Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction



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ABSTRACT

Objectives: (a) To determine levels of and factors explaining partners' burden, anxiety and depressive symptoms at two months post-stroke, (b) to predict partners' burden, anxiety and depressive symptoms at one year post-stroke based on patient and partner characteristics available at two months post-stroke.

Methods: Prospective cohort study. Partners of stroke patients (N = 183) were included. Main outcome measures were the Caregiver Strain Index and the Hospital Anxiety and Depression Scale.

Results: Many partners experienced high burden, anxiety and depressive symptoms. At two months post-stroke, these outcomes were associated with the partner variables: age, relationship satisfaction, proactive coping, self-efficacy, everyday social support, burden, anxiety and depressive symptoms; and the patient variables: stroke severity and depressive symptoms.

Partner outcomes at one year post-stroke were mainly predicted by the level of these outcomes at two months post-stroke.

Conclusions: Partner outcomes at two months post-stroke predict to a large degree partner outcomes at one year post-stroke.

Practice implications: Measuring partners' burden and anxiety and depressive symptoms in the post-acute phase is recommended to trace partners at risk of long-term burden and emotional problems.

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1. Introduction

Many patients who survive the acute phase of stroke remain more or less physically or cognitively impaired and need help from professionals and/or family caregivers [1,2]. After a stroke, the partners' lives often also change considerably. Caring for a family member, takes time as well as physical and emotional efforts, and partners can experience high burden [3–5], anxiety [6] or depressive symptoms [1,2,4,7]. Many partners are capable of adjusting to their new situation. However, part of them show clinically relevant levels of distress that may require some form of support; and which may also persist over time [3,4,6].

To date, research has focused mainly on stroke characteristics and patients' and partners' demographic characteristics to explain burden, anxiety and depressive symptoms in partners of stroke survivors. There are three reviews focusing on partner outcomes as burden [3,8] and depressive symptoms [2]. In these reviews, patient characteristics that have been shown to be, although inconsistently, associated with these partner outcomes are younger age [3], poorer functional and mental status and ADL dependency [2,3,8] and cognitive impairment [2,3,8]. Further, partners' younger age [2,3,8], female gender [3,8], higher income [2] and having a spousal relationship [2,3,8] were, although also inconsistently, related with these partner outcomes. In our previous cohort study, partner depressive symptoms in the sub-acute phase was also a predictor of partner burden and depressive symptoms, at one year post-stroke [9].

A small number of publications have shown partners' psychosocial characteristics to be important predictors of partners'

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adverse health outcomes, like burden and depressive symptoms [4,9,10,11–13]. Coping was strongly associated with partner outcomes [4,10,11]. Ineffective coping strategies (i.e. passive coping or a negative problem orientation) were predictors of higher levels of burden and/or depressive symptoms [9,10]. Furthermore, disharmony in the relationship was associated with these partner outcomes [9]. Finally, mixed results concerning the associations between social support and partners' burden or depressive symptoms have been reported [10,12,13]. Consequently, there is a need for more research on partner psychosocial characteristics, like psychological resources, coping strategies and social support [2,3,8]. Knowledge on which psychosocial partner characteristics are associated with partner outcomes is relevant for rehabilitation practice since these factors may be changeable by therapeutic interventions, in contrast to demographic characteristics like age and gender.

In our previous cohort study we included partners of stroke patients admitted for inpatient medical rehabilitation [4,9]. However, this group represents only 10% of the Dutch stroke population. In the current study, we included stroke patients admitted to general hospitals and follow them up irrespective of their discharge destination, thereby re-presenting the general stroke population, we therefore aimed (a) to determine levels of and factors explaining partner outcomes (burden, anxiety and depressive symptoms) at two months post-stroke, and (b) to identify predictors of partner outcomes (burden, and anxiety and depressive symptoms) at one year post-stroke based on partner and patient characteristics available at two months post-stroke.

2. Methods

2.1. Participants

The current study was part of Restore4Stroke Cohort, a general hospital-based multi-centre longitudinal cohort study [14]. Stroke patients, admitted to six general hospitals across the Netherlands, and their partners were included in the Restore4Stroke cohort between March 2011 and March 2013. Included were partners of patients with clinically confirmed diagnoses of ischemic or intracerebral haemorrhagic. Exclusion criteria for partners and patients were: (1) age < 18 years, (2) having a serious other condition whereby interference with the study outcomes could be expected (e.g. neuromuscular disease), (3) pre-stroke dependency in activities of daily living (Barthel score [15] of 17 or lower), and (4) having insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment). For patients there was one additional exclusion criteria: showing symptoms of cognitive decline before their stroke, as measured by the Heteroanamnesis List Cognition [16]. Post-stroke aphasia was not an exclusion criterion. If this problem hindered patients to complete the questionnaires during the follow-up assessments, only the observational measures were administered.

The Medical Ethics Committee of the St. Antonius Hospital, Nieuwegein, approved the Restore4Stroke Cohort study. All participants gave informed consent.

2.2. Measures

2.2.1. Outcome variables

Burden experienced by the partner was assessed using the Caregiver Strain Index (CSI) [17]. This questionnaire consists of 13 items, which can be answered with yes or no. A score of 7 or more on the CSI indicates a high level of burden. The CSI has a good validity [18,19], and is commonly used in clinical practice [20].

Partners' anxiety and depressive symptoms were assessed with the Hospital Anxiety and Depression scale (HADS), which consists of 7 items on anxiety and 7 items on depressive symptoms [21]. Every item is rated on a 4-point scale; 0 (no symptoms) to 3 (maximum impairment). A score of 8 or more on each subscale indicates high anxiety or depressive symptoms, respectively [22]. The HADS has good psychometric properties [23].

2.2.2. Independent variables

2.2.2.1. Partner characteristics. Data on age, gender, education level and pre-stroke working status were collected. The educational level was classified according to the standard Dutch classification system [24] and afterwards dichotomized into low and high education, the latter including senior secondary education and higher. Pre-stroke working status was assessed in hours of paid work per week and dichotomized in less than 24 h a week or 24 h a week or more.

Partners' satisfaction with their relationship was asked for with a single item ("How satisfied are you with your relationship with your partner?") on a 0 (very dissatisfied) up to 4 (very satisfied) scale. Partners were considered to be satisfied with their relationship if they scored 3 (satisfied) or 4 (very satisfied). Proactive coping was assessed using the Utrecht Proactive Coping Competence Scale (UPCC) [25]. A higher score indicates higher levels of perceived proactive coping competencies. The UPCC showed good internal consistency, test-retest reliability and sensitivity to changes after education interventions in people in middle and late adulthood [25]. Self-efficacy was measured with the General Self-efficacy Scale (GSES) [26]. Higher scores indicate higher levels of self-efficacy. The GSES has satisfactory to good psychometric properties [26]. Partners' perceived social support was measured with the Social Support List-Interaction (SSL-12-I) [27]. The SSL-12 measures support given to the partner themselves from persons in their social environment. It contains three subscales: 'everyday social support' (social companionship and daily emotional support), 'support in problem situations' (instrumental support, informative support, and emotional support in times of trouble), and 'esteem support' (support resulting in self-esteem and approval), and has good psychometric properties [27].

2.2.2.2. Patient characteristics. Data on age, gender, educational level were obtained from the patient. Type of stroke, affected hemisphere and stroke severity were obtained from medical charts. Stroke severity was measured using the National Institutes of Health Stroke Scale (NIHSS) four days post-stroke [28]. Discharge destination was registered and categorized as home (with or without outpatient rehabilitation) or inpatient rehabilitation (in a rehabilitation centre or nursing home).

The Barthel Index was used to assess the patients' independence in activities of daily living (ADL) [15]. This instrument is valid and reliable in stroke populations [15]. The Montreal Cognitive Assessment (MoCA) was used to measure cognition of the stroke patient at two months post-stroke [29]. The MoCA is a screening test with good sensitivity and specificity to detect cognitive dysfunction [29]. Anxiety and depressive symptoms were assessed with the HADS [21].

2.3. Procedure

Patients and partners were included in the study within the first week post-stroke. Demographic characteristics of the patients and partners, i.e. age, gender, educational level, partners' pre-stroke working status, and stroke characteristics were documented at inclusion. At two months post-stroke, a research assistant visited the couples at home or at the institution the patient was residing at

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