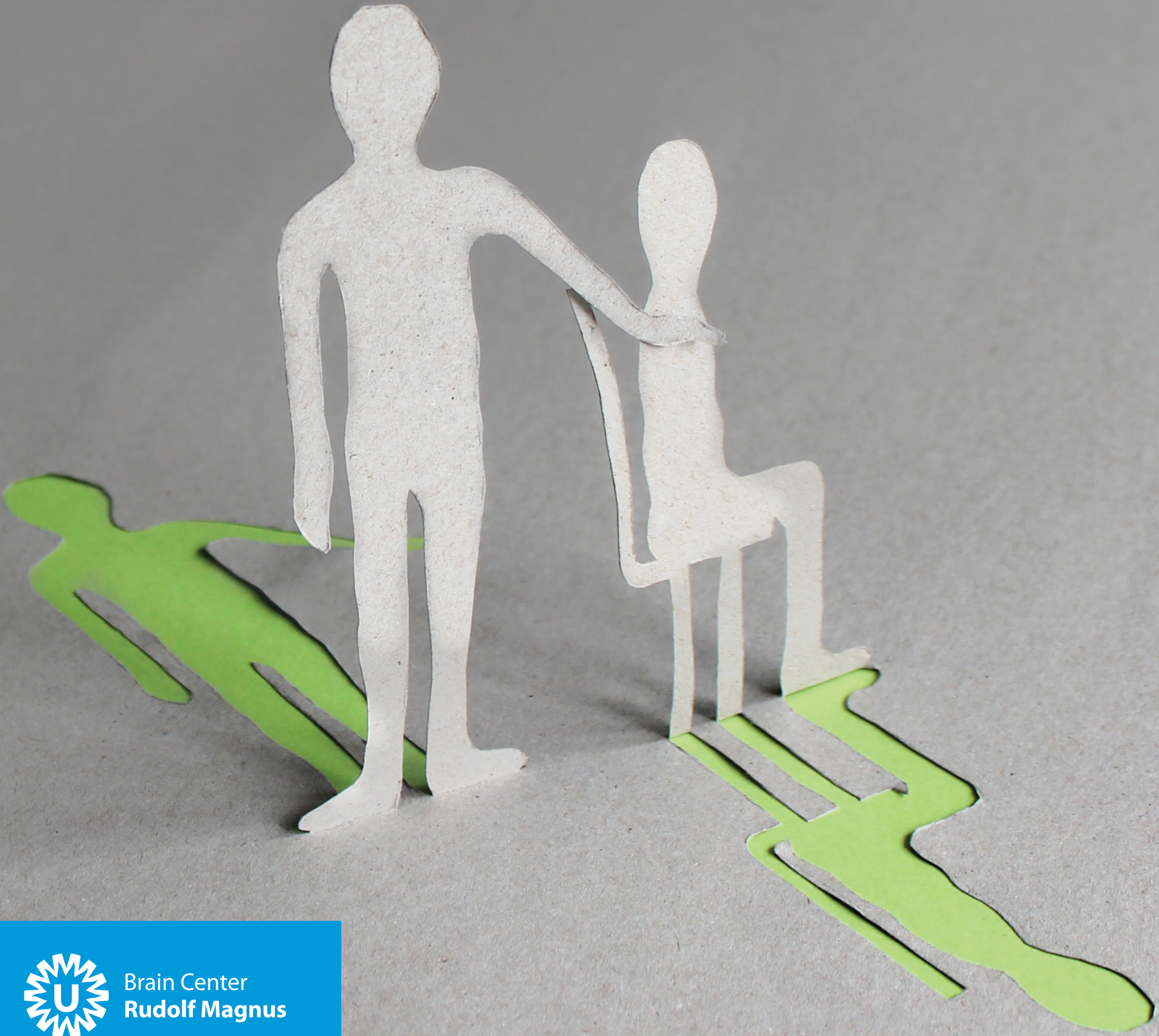
Stroke, Social Support and the Partner

Willeke Kruithof



Brain Center
Rudolf Magnus

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Stroke, social support and the partner

Beroerte, sociale steun en de partner

(met een samenvatting in het Nederlands)

Proefschrift

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Universiteit Utrecht op gezag van de rector magnificus,
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door

Willemtje Jansje Kruithof

geboren op 18 augustus 1986
te Zwolle

Promotoren:	Prof.dr. J.M.A. Visser-Meily Prof.dr. M.W.M. Post

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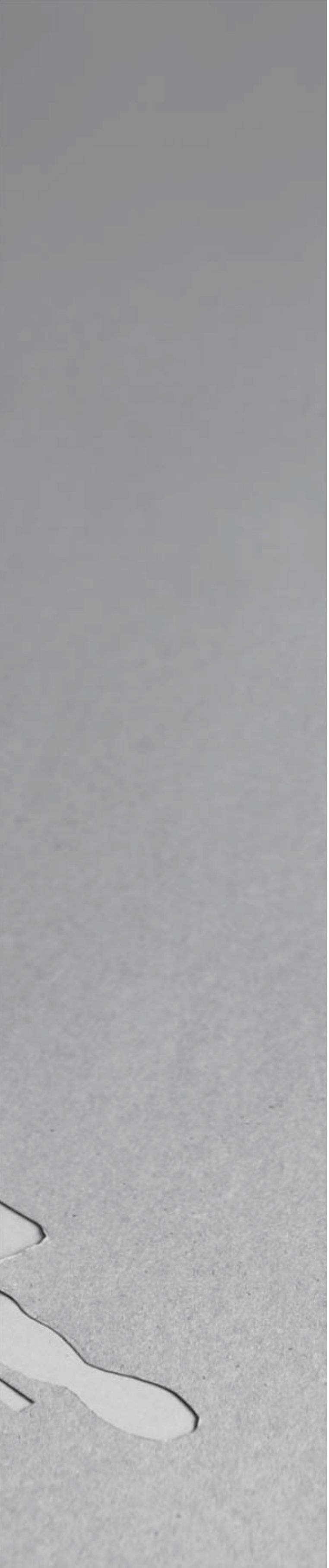
Contents

Chapter 1



General introduction

Stroke and the consequences for the patient

Each year, about 45,000 people suffer a first stroke in the Netherlands.[1] Although most patients return home, a substantial part of the patients who survive the acute phase of stroke remain more or less physically or cognitively impaired. The consequences of stroke affect many domains of life, as described in the International Classification of Functioning, Disability and Health (ICF).[2] The ICF-model provides a framework for the description of health and describes human functioning at three levels: body functions and structure, activities and participation. These levels are influenced by contextual factors, which are divided into personal factors (such as age, history and psychological characteristics) and environmental factors (such as social support or financial and economic resources). All these aspects interact with each other (Figure 1.1).

At the level of body functions and structure, the physical consequences of stroke can be quite obvious, such as hemiparesis or spasticity, but more often they are less visible.[3,4] The possible less visible consequences include cognitive impairments, such as memory loss or executive functioning, behavioural problems or complaints of fatigue.[3,5,6]

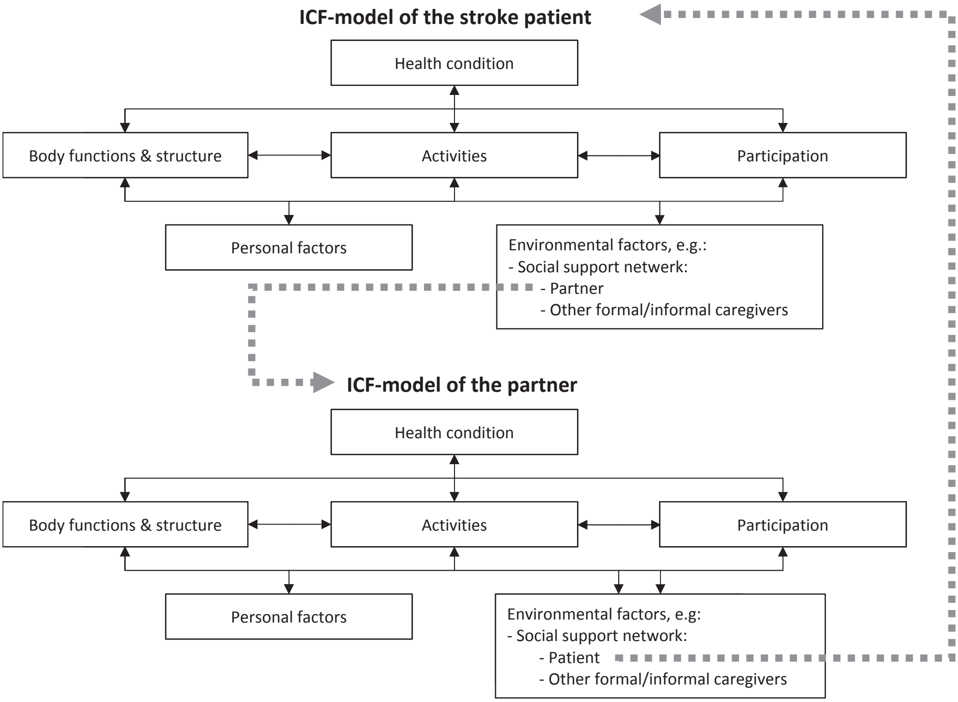


Figure 1.1 Interrelationship between stroke patient and partner: two combined ICF-models.

As a result of the brain damage itself but also as a result of the impairments, patients may experience mood problems (such as depressive symptoms)[7] as well as a reduced quality of life.[3,8,9] The ICF-model does not specify quality of life, but we considered quality of life to be a superordinate construct including aspects of functioning, health and well-being. Consequently, quality of life includes the three levels of the ICF: body functions and structure, activities, participation.

Altogether, stroke is an overwhelming event and stroke survivors face the challenge of adapting to a new situation.

Stroke and the consequences for the partner

From the perspective of the ICF-model, environmental factors, such as the patient's social system, influence the consequences of the stroke, but are also influenced by the consequences of the stroke for the patient. One of the main persons in the patient's environment is the partner. Consequently, support given by the partner may influence the patient's health condition, but the partner's life also changes considerably and this may influence the partner's own health condition (Figure 1.1).

In literature, three roles of the partner of a stroke patient have been distinguished: the role of caregiver, the role of client, and the role as family member.[10] Many partners become caregiver, because many patients need support as a consequence of their physical and/or cognitive impairments.[11,12] Informal care refers to the help and support which is given to a patient by persons outside the formal service system (i.e. not by health professionals or social services).[11] This informal care is mainly given by significant persons near the patient, usually partner, if there is a partner. Caring for a patient takes time as well as physical and emotional effort. Many partners are capable of managing the new situation, but others experience adjustment problems including high burden,[13,14,15] anxiety,[16] or depressive symptoms,[11,12,14,17] which may persist over time.[13,14,16] Hence, the partner may become a client and in need of formal/informal support as well. Besides being caregiver and client, most partners are first and foremost the partner of the stroke patient. This last role may also change due to the fact that stroke affects the interpersonal relationship between patient and partner (or other family members) as well. For instance, communication or behavioural problems may interfere with the emotional and sexual relationship between partners.[10]

Although informal care is most often unpaid and voluntary, this does not imply that it is free of economic impact. When valuing informal care by using standard cost prices based on the average hourly wages of healthcare professionals doing the same tasks (e.g. domestic help), economic studies revealed that informal care represents about 7–33% of the one-year post-stroke societal costs.[18,19,20] A Dutch hospital-based study showed that about half of the stroke patients received informal care (from partner or others) for an average of 11 hours a week, representing an economic value of 7% of the total societal costs of, on average, 29,484 Euro/patient in the first year post-stroke.[18] According to these findings and an incidence of 45,000 Dutch stroke patients, informal care due to stroke might represent a total economic value of almost 93 million Euros annually. Considering the impact of caregiving for the caregiver and the high economic value, it has become even more necessary for health professionals to pay attention to caregivers of stroke patients in the sub-acute and chronic phase post-stroke, and to qualify caregivers more for their 'informal care job'.

Although most studies have focused on the negative impact of caregiving, positive caregiving experiences, such as enhanced self-esteem and satisfaction, have also been reported.[21] Positive caregiving experiences may influence partner outcomes such as mood and life satisfaction and may lessen the impact of caregiver burden or distress.[22] However, only few studies into positive caregiving experiences of caregivers of stroke patients are available.[21]

Social support

Managing the new situation post-stroke is a challenge. Patients and partners might need social support from their environment. Social support is a broad concept and can be defined as any support given outside formal settings, i.e. not by health professionals or social services.[23] In literature, social support has been divided into several subtypes to make this concept more concrete. Langford and colleagues divide social support into four subtypes: (a) 'emotional support', involving the provision of care, empathy, love and trust, (b) 'instrumental support', including the provision of tangible goods and services (c) 'informational support', for instance receiving advice, and (d) 'appraisal support', involving information in the form of affirmation, feedback and social comparison.[24] Another regularly used way to categorize the concept of social support is the division into three subtypes: (a) 'everyday support', in which social companionship and daily emotional support are involved, (b) 'support in problem situations', including instrumental support, informative support, and emotional support in times of trouble, and (c) 'esteem support', which includes support resulting in improved self-esteem and approval.[25] Besides defining support by subtype, a different but also important perspective is the source of social support, i.e. the partner, children, other relatives or friends.

In patients, social support promotes the development of functional independence[26] and enhances quality of life.[26,27] Examples of social support are: assisting the patient with household activities and helping the patient to overcome grief over, for instance, the loss of mobility as a result of paralysis or the loss of communication subsequent to aphasia.

As mentioned above, the partner has also to deal with a new situation and might need social support as well. Almost the same examples as reported for the patient can be brought up: like needing assistance with household activities or emotional support to overcome grief over the life event.

Lack of social support is not only consistently associated with patients' post-stroke depression,[28,29] but with partners' mood as well.[30] An adequate social support network is, therefore, important for both patient and partner. To make it even more complicated, the stroke patient and partner are interrelated. The patient can be a part of the social network of the partner and vice versa, resulting in being the receiver and the giver at the same time (Figure 1.2). Consequently, it is important to take patients' psychosocial factors into account when examining partners' outcomes, and reciprocally, when examining stroke patients' outcomes (Figure 1.1).

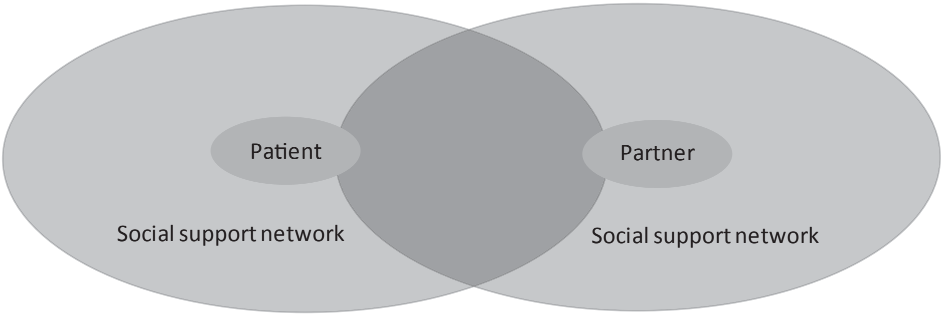


Figure 1.2 Interrelationship between patient and partner: overlapping social support networks.

The Functional Prognosis of Stroke study and Restore4Stroke Cohort study

This Thesis is founded in previous research at our institute. The 'Functional prognostication and disability study on stroke' (FuPro-stroke) was a cohort study designed to investigate outcome measures and prognostic factors of patients' functional outcome and recovery;[31,32] and to investigate prognosis in terms of burden, depression and satisfaction with life among family caregivers of patients admitted to rehabilitation centres.[14,30]

The FuPro-stroke study has shown that a large proportion of partners of stroke patients experience serious burden (51%), depressive symptoms (51%) and decreased life satisfaction (46%) at one year post-stroke as well as three years post-stroke.[33] Only burden diminished significantly over time, although, 44% of the partners still reported significant burden at three years post-stroke. Depressive symptoms remained stable, and life satisfaction even deteriorated.[33] Furthermore, at three years post-stroke, partners received significantly less social support from their social network in comparison to one year post-stroke.

Only 19% of burden and 22% of depressive symptoms at one year post-stroke could be explained with patient and partner factors, in which psychosocial factors seem to be the most important (i.e. passive coping and depressive symptoms in the sub-acute phase).[30] When analysing the course of partner outcome, psychological factors of partner themselves, namely coping strategies, were most strongly associated with partner outcome.[33] These findings resulted in the recommendation to examine the possible role of other patients' and partners' psychosocial factors, like depressive symptoms, social support and personality, as determinants of partner outcome.[33]

Based on the abovementioned results it can be concluded that functioning of stroke patients and partners cannot be viewed independently from each other. The patient might influence the partner's outcome (for instance burden or quality of life) and vice versa. More research into these interrelationships between patients and partners is needed.

As a follow up project of the FuPro-stroke study the Restore4Stroke Cohort Study was designed.[34] The FuPro-stroke study and Restore4Stroke Cohort Study show important similarities, focusing both on the quality of life (in terms of burden and depression) of stroke patients and their partners. However, one of the main differences is the setting at time of inclusion. The FuPro-stroke study included participants from rehabilitation centres, resulting in a narrowed, and a more severely affected, stroke patient population (approximately 15% of the total stroke patient population). In the Restore4Stroke cohort study participants were included in the acute (hospital) phase and were followed irrespective of discharge setting, resulting in a broad and more general Dutch stroke population. Furthermore, the Restore4Stroke study included more psychosocial factors of the patient and partner to complement the lack of knowledge remaining from the FuPro-stroke study. These two studies therefore complement each other well.

The Restore4Stroke Cohort study aims to investigate the quality of life of stroke patients and partners during the first two years post-stroke.[34] It was divided in two parts: one part focused on the patient (Restore4Stroke Patient Cohort study) and one focusing on the partners of stroke patients (Restore4Stroke Partner Cohort study). The first is published in a Thesis by Van Mierlo.[35] The latter is described in the present Thesis.

Aims of this Thesis

The general aim of this Thesis is to explore the interrelationship between the stroke patient and partner. The following research questions will be answered:

1. What is the association between the stroke patient and his or her environment, by focusing on patient's social support?
2. What is the association between the stroke patient and his or her environment, by focusing on the partner's experienced burden and quality of life?

Study designs

The Functional Prognosis of Stroke study

Participants were selected from stroke patients consecutively admitted to four Dutch rehabilitation centres for an inpatient rehabilitation programme in the period April 2000 to July 2002, and were followed up to three years post-stroke. Their spouses or young children were also included. The inclusion criteria for the patients were: (1) a first-ever stroke, (2) a one-sided supratentorial lesion and (3) age above 18 years. Exclusion criteria were: (1) disabling comorbidity (pre-stroke Barthel Index below 18) and (2) a premorbid inability to speak Dutch. Data were collected as soon as possible after admission to the rehabilitation centre, six months, one year and three years post-stroke. A total of 308 stroke patients and 211 spouses were included, in the following rehabilitation centres: De Hoogstraat (Utrecht); Rehabilitation Centre Amsterdam (Amsterdam); Heliomare (Wijk aan Zee); and Blixembosch (Eindhoven).

The FuPro-stroke study was embedded within the research programme entitled 'Functional prognostication and disability study on neurological disorders' (FuPro), and was supported by the Netherlands Organisation for Health Research and Development (ZonMw programme on Rehabilitation Medicine, grant no. 1435.0001).

The Restore4Stroke Cohort study

Included in the Restore4Stroke Partner Cohort study were partners of patients with clinically confirmed diagnoses of stroke (ischaemic or intracerebral haemorrhagic lesion). 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 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. A total of 395 stroke patients and 215 partners were included, in the following Dutch hospitals: St. Antonius hospital (Nieuwegein); Diakonessenhuis (Utrecht); Canisius Wilhelmina hospital (Nijmegen); Elisabeth hospital (Tilburg), TweeSteden hospital (Tilburg) and Catharina hospital (Eindhoven).

Restore4Stroke Cohort study is a result of a collaboration between Brain Centre Rudolf Magnus and Centre of Excellence for Rehabilitation Medicine of the University Medical Centre of Utrecht and De Hoogstraat Rehabilitation. The Restore4Stroke Cohort study is also a part of the larger Dutch national consortium programme called Restore4Stroke, funded by the VSB Fonds (#89000004) and was coordinated by the Netherlands Organisation for Health Research and Development (ZonMw).

Outline of this Thesis

This Thesis presents results of the FuPro-stroke study and Restore4Stroke Cohort Partner study, while focusing on the interrelationship between patient and partner. It consists of the following parts:

Part I Social support in the stroke population

- **Chapter 2** reviews the literature regarding the influence of social support on stroke patients' health-related quality of life.

- **Chapter 3** utilizes data from the FuPro-stroke study to investigate the associations between social support and patients' depressive symptoms in the first three year post-stroke.

Part II The partner of the stroke patient

- **Chapter 4** describes the psychometric properties of the Caregiver Strain Index expanded, an instrument measuring both negative and positive caregiving experiences. (Data used from the Restore4Stroke Partner Cohort study.)
- **Chapter 5** examines the associations between negative and positive caregiving experiences and partners' life satisfaction at three years post-stroke. (Data used from the FuPro-stroke study.)
- **Chapter 6** aims to identify associations between patient and partner variables, and adverse partner outcome (burden, and anxiety and depressive symptoms). It also aims to find predictors two months post-stroke to identify caregivers at risk for caregiver burden, and anxiety and depressive symptoms at one year post-stroke. (Data used from the Restore4Stroke Partner Cohort study.)

General discussion

- **Chapter 7** presents a general discussion describing the main findings of the studies, theoretical and methodological considerations, and recommendations for clinical practice and further research.

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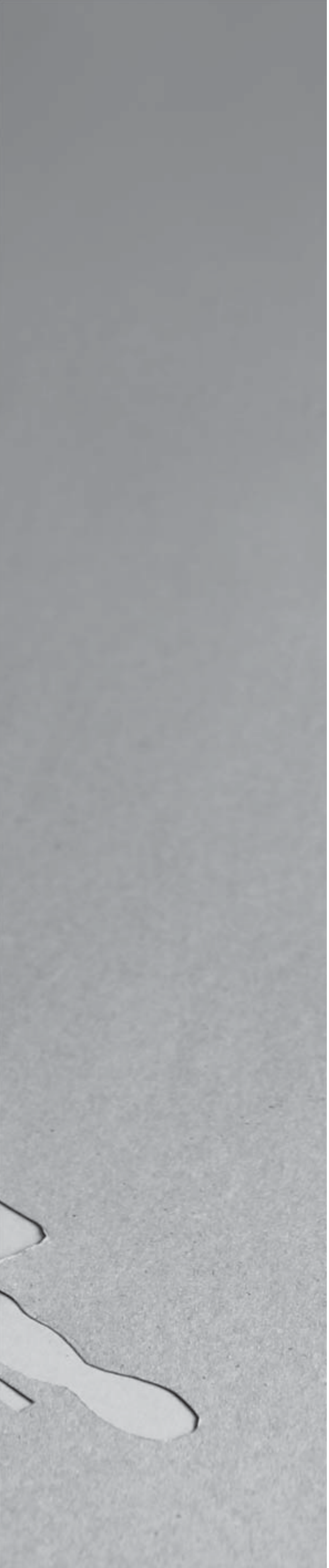
Part I

Social support in the stroke population

Chapter 2



Associations between social support and stroke survivors' health-related quality of life: A systematic review

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Johanna M.A. Visser-Meily

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Marcel W.M. Post

Patient Educ Couns. 2013; 93: 169-176

Abstract

Objective

Social support to stroke survivors has been recognized as an important determinant of their health-related quality of life (HRQoL), but this relationship is not clarified to date. More insight in the relationships between various types (i.e. emotional, instrumental, or informational support) and sources (i.e. partner, children) of social support and HRQoL might target post-stroke educational and counselling interventions to strengthen patient's social networks and supportive relationships.

Methods

Systematic review.

Results

A total of 11 original articles could be included. Most of these articles studied the overall perceived social support without further specification of type or source. They show a positive relation between perceived social support and stroke survivors' HRQoL. Relations between perceived social support and HRQoL seems to be more often significant and were stronger than relationships between specific social support types or sources and HRQoL.

Conclusion

Due to the small number of studies and the heterogeneity in methods of assessing social support, a clear statement about the specific influence of social support source or type could not be made.

Practice implications

Attention should be paid to promoting social support on the short and long term. Further research is needed to clarify the influence of social support type and source.

Introduction

Stroke survivors often experience physical or cognitive disabilities[1] which may have a negative impact on their health-related quality of life (HRQoL).[2-4] HRQoL is a broad concept, which focuses on the aspects of quality of life directly related to patients' post-stroke health. The concept of health-related quality of life is multidimensional, including different domains of one's life, such as physical, functional, mental, psychosocial and social health.[2] Demographic factors, stroke-related factors and physical impairments have been found consistent determinants of HRQoL of stroke patients.[4,5] However, these factors only explain a small part of the variance of HRQoL, and, consequently, other factors gained more attention as possible determinants of HRQoL. Social support is among these factors.[2,3,6,7] Social support can help to deal with the consequences of stroke and promote functional independence and quality of life.[8] For example, emotional support can help a person with stroke to overcome grief over, for example, the loss of mobility as a result of paralysis or the loss of communication as a result of aphasia, or may enhance self-confidence and self-efficacy by encouraging the stroke survivor.[8]

Social support can be defined as any support given outside formal settings, i.e. not by health professionals or social services.[6] Langford et al. divided social support in four types: (1) 'emotional support', involving the provision of caring, empathy, love and trust, (2) 'instrumental support', including the provision of tangible goods and services (e.g. getting help to get to and from the hospital), (3) 'informational support', providing information (e.g. receiving advice), (4) 'appraisal support' (e.g. involving information in the form of affirmation, feedback and social comparison).[9] Social support can be described from a qualitative (i.e. satisfaction with social support) and a quantitative (i.e. the amount of social support, or network size) view. Another perspective is the source of social support, i.e. the partner, children, other relatives or friends. Furthermore, social support can be distinguished in the received (i.e. objective) or the perceived (i.e. subjective) social support that have been offered.

In the stroke literature, only two reviews on social support are available.[2,10] The first is a narrative review describing social support as an important determinant on HRQoL, but the authors did not quantify associations between social support and HRQoL reported in the literature and did not specify social support by type or source. The second review reported the generally disappointing effectiveness of 10 social support interventions for post-stroke depression and did not investigate the effects on HRQoL.[10] These trials varied widely with regard to the types and sources of social support provided, which may have contributed to this counter-intuitive result but which could not be explored due to lack of data.

In conclusion, although HRQoL and social support have been recognized as important factors in stroke research, their inter-relationship is not clarified to date. More insight in the relationships between various types and sources of social support and HRQoL might target post-stroke educational and counselling interventions to strengthen patient's social networks and supportive relationships.[11] The present study aims to supplement the literature by systematically reviewing the literature on relationships between social support and stroke survivors' HRQoL.

Methods

Search strategy

Electronic searches of the literature published up to the 8th November 2011 were performed in Pubmed, Embase, Psycinfo and CINAHL. The following search term keywords were combined: stroke (and synonyms), social support (and synonyms) and health-related quality of life (and synonyms). Appendix 2.1 provides an overview of the search strategy used in Pubmed, compiled together with an information specialist. An update of the search up to March 2013 did not reveal new articles.

Selection criteria and process

Articles were included if they met the following criteria:

1. More than 50% of the investigated patients suffered from stroke (ischemic or haemorrhagic lesion).
2. The patients were ≥ 18 years at the time of stroke.
3. The study measured HRQoL with one or more standardized questionnaires.
4. The study reported quantitative relationships between social support and patients' HRQoL.
5. The study was an original empirical study (e.g. not an abstract, review, proceeding or letter) published in English.
6. The study was published in a peer-reviewed journal.

After removing duplicates, two authors (WJK and MM) independently checked the abstracts on the inclusion criteria, and compared their results. The level of agreement between the two raters was calculated using Cohen's kappa. After that and in case of disagreement, both authors reassessed and discussed that abstract until consensus was reached. The same procedure was followed for final in- or exclusion after reading the full text articles. The references of the included articles were studied to trace relevant studies not identified by the primary search.

Quality assessment

The assessment of methodological quality of the individual studies was conducted using a brief 8-point checklist (Appendix 2.2).[12] The scores ranged from 0 (lowest quality) to 8 (highest quality). The assessment was conducted independently by the same authors (WJK and MM) and the level of agreement between these authors was established using the Intraclass Correlation Coefficient (ICC). After calculating the ICC, consensus on a final rating was reached between both raters (WJK and MM).

Data extraction and analysis

Information on author, country, study population, sample size, follow up period, study design, assessment of HRQoL, assessment of social support, and associations between HRQoL and social support were extracted. Social support variables were classified as consistent determinants if more than one study investigated the variable, all bivariate associations reported were statistically significant and if most of these associations were higher than .30 (moderate).[13] Variables were classified as inconsistent determinants if only some of the associations were statistically significant or if most significant associations were weak. Variables were classified as unrelated to health-related quality of life if all, or nearly all, associations were nonsignificant.[12] Due to the low number of studies retrieved and the wide range of assessment of HRQoL and social support measures used, a meta-analysis was not possible.

Results

Search

The search strategy yielded 2065 articles (Figure 2.1). After filtering 825 duplicates, a further 1195 articles were removed after screening title and abstract. Agreement on selection of titles and abstracts between both raters was high (Cohen's kappa .88). Four articles that appeared eligible could not be retrieved in full text, even after contacting the authors. Of the 41 full

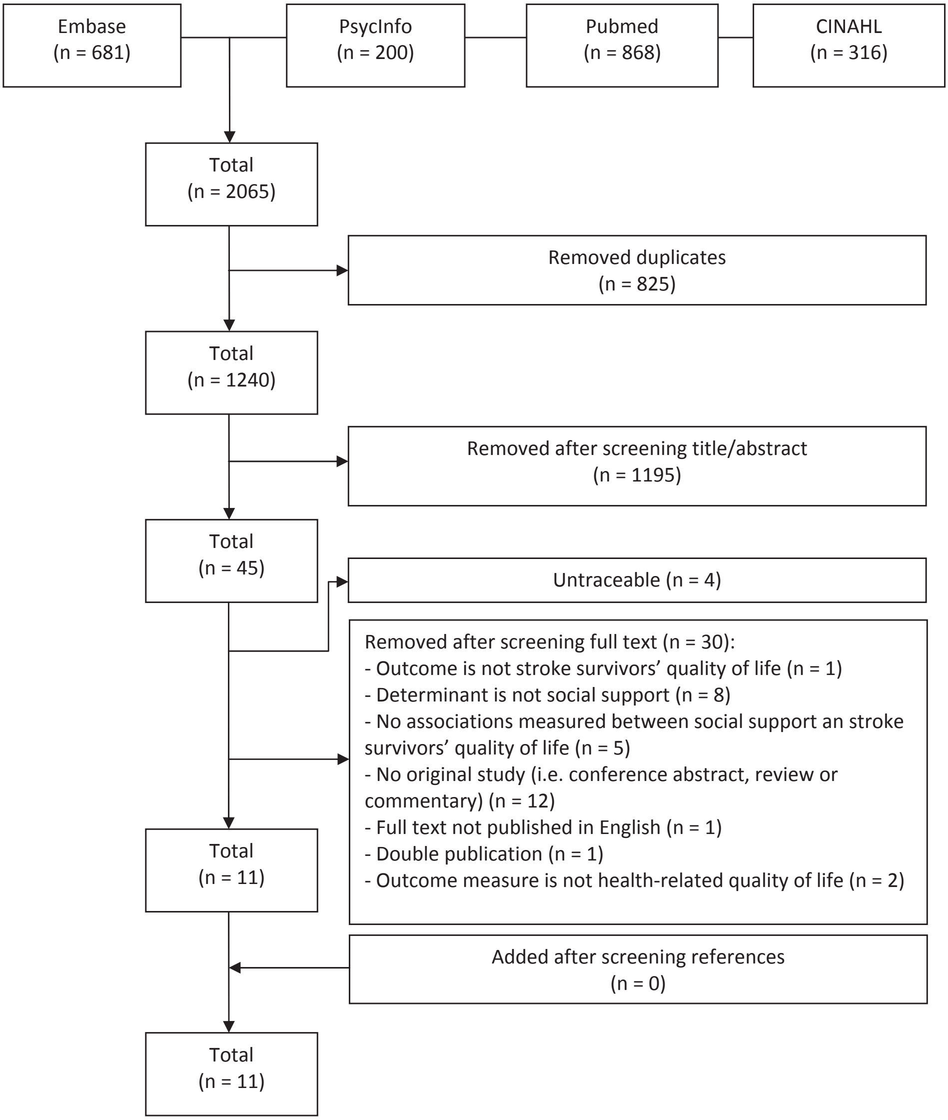

Figure 2.1 Search flowchart.

text articles available, 11 met all inclusion criteria.[3,14-23] Screening of the reference lists did not reveal additional relevant articles. The characteristics of the 11 included studies are shown in Table 2.1. The same cohort data were used in two different publications, but the statistical analysis of the data was different.[15,16] It respectively investigated the bivariate and the multivariate associations. Most studies were recently published, had a cross-sectional design, and concerned stroke in the chronic phase. Only, two studies used longitudinal data.[20,23] The various social support instruments used are displayed in Table 2.2. In the 11 articles ten different social support instruments were used.

Interrater agreement on methodological assessment of the individual studies was moderate (ICC .58). Most studies had a score between 4 and 7 out of maximum 8 points, with a moderate average score of 5.5 (Table 2.3).

Bivariate relationships between social support and HRQoL are shown in Table 2.4. In Table 2.4 on the left the bivariate associations and on the right the multivariate associations are reported. Most studies focused on perceived social support without further specification of type or source. Three studies[15,17,18] specified social support by type and two studies[15,20] by source. Most studies investigated amount of experienced support, one study investigated satisfaction with social support, and two studies investigated network size or (change in) contact frequency.

All included studies showed one or more significant associations between social support and HRQoL. In total, 45 bivariate correlations were tested, of which 21 were significant and 14 were > .30. Further, three F-tests were performed of which two were significant. Studies performing both bivariate correlations and regression analyses showed little differences between bivariate and multivariate associations. An overview of the bivariate associations by HRQoL domain, by social support domain, and finally the multivariate results is now presented.

HRQoL domains

Four articles presented associations between social support and physical and psychosocial HRQoL. These associations were similar to those between social support and overall HRQoL.[3,14,17,22]

Social support domains

Perceived social support. Fifteen bivariate correlations between perceived social support and HRQoL were tested, of which 11 were significant and 9 were > .30, indicating social support as an inconsistent determinant of HRQoL. Two studies tested a subscale Socioeconomic HRQoL and reported significant correlations of .45 and .51 (not shown in Table 2.4).[3,22]

Table 2.1 Study characteristics

Author (date)	Study population: (a) number of participants (male) (b) mean age (SD)* (c) country of research	Time post-stroke	Outcome: Health-related quality of life	Determinant: Social support
Dayapoglu (2010)[14]	(a) 70 (42) (b) 50–60 yr: 26 patients 61–71 yr: 28 patients + 71 yr: 16 patients (c) Turkey	> 3 months	SF-36 – mental health subscale	Perceived Social Support from the Family Scale
Hilari (2011)[15]	(a) 83 (52) (b) 61.7 (SD 15.5) (c) United Kingdom	3.5 years (SD 3.1, range 1–20 years)	Stroke and aphasia quality of life scale – 39	Medical Outcomes Studies Social Support Survey Social network (size and frequency of contacts)
Hilari (2011)[16]	(a) 83 (52) (b) 61.7 (SD 15.5) (c) United Kingdom	3.5 years (SD 3.1, range 1–20 years)	Stroke and aphasia quality of life scale – 39	Medical Outcomes Studies Social Support Survey
Huang (2010)[17]	(a) 102 (58) (b) 64.9 (SD 11.8) (c) Taiwan	29.8 months (SD 73.4)	Quality of Life Index-Stroke Version	Social Support Inventory
Jaracz (2003)[18]	(a) 72 (26) (b) 65.1 (range 33–85) (c) Poland	6 months	Quality of Life Index-Stroke Version	Satisfaction with emotional support (= item 16 from the Quality of Life Index-Stroke Version)
Kim (1999)[19]	(a) 50 (58%) (b) 75 (SD 6.1) (c) Canada	12 to 36 months after discharge from the rehabilitation	Quality of Life Index-Stroke Version	Social Support Inventory for Stroke Survivors

Table 2.1 continues on next page.

Table 2.1 *Continued*

Author (date)	Study population: (a) number of participants (male) (b) mean age (SD)* (c) country of research	Time post-stroke	Outcome: Health-related quality of life	Determinant: Social support
King (1996)[3]	(a) 86 (45%) (b) 69 (SD 13.2) (c) United States of America	12 to 33 months (SD 5.5)	Quality of Life Index-Stroke Version	Social Support in the Elderly Scale
Mackenzie (2002)[20]	(a) 215 (52%) (b) 70.5 (SD 8.3) (c) China	t1: 2 weeks t2: 3 months	Sickness Impact Profile	Social Support Questionnaire short form
Manders (2010)[21]	(a) 43 (25) (b) 61.9 (SD 12.4) (c) Belgium	4 months (SD 3.0)	Stroke and aphasia quality of life scale – 39 item version	Combination of the 'General health inquiry-Belgium' and the 'Medical Outcomes Studies Social Support Survey'
Owolabi (2010)[22]	(a) 100 (43) (b) 58.9 (SD 10.7) (c) Nigeria	> 1 month	HRQoL in stroke patients questionnaire SF-36 – mental health subscale	Self-developed questionnaire (5-item Likert response scale)
Teoh (2009)[23]	(a) 135 (92) (b) 67.5 (SD 14.3) (c) Australia	11.7 months (SD 4.9), and after ± 14 months and 18 months post-stroke	Assessment of Quality of Life Stroke Impact Scale Version 3.0	Medical Outcomes Studies Social Support Survey

* Mean age combined with standard deviation was considered as preferable. If this is not reported than respectively the median or range is given.
Only two studies used longitudinal data,[20,23] the other studies used cross-sectional data.
SF-36: Medical outcomes study 36-item short form health survey.

Table 2.2 Social support variables and questionnaires

Questionnaire	Number of items	Description	Possible answers and scoring system
Perceived Social Support from the Family Scale[24]	20	Statements refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. No subcategories.	Yes/no/don't know. Summary score from 'no perceived social support' (0) to 'maximum perceived social support' (20).
Medical Outcomes Studies Social Support Survey[25]	19	Four subcategories: *Emotional*: the expression of positive affect, empathic understanding and the encouragement of expressions of feelings. *Informational*: the offering of advice, information guidance or feedback. *Instrumental*: the provision of material aid or behavioural assistance. *Social companionship*: positive social interaction, the availability of other persons to do fun things with you. *Affectionate support*: involving expressions of love and affection**.	5-point scale going from 'none of the time' (1) to 'all of the time' (5). The developing authors recommend combining emotional and informational support as one category.
Social Support Inventory[17]	19	Four subcategories: *Emotional*: focusing on the individual qualities or behaviour of a supporting person, including empathy, caring, love and trust. *Appraisal*: affirms one's actions or statements. *Informational*: involves the provision of advice, suggestions and information that a person can use to address problems. *Instrumental*: providing support in a physical way that assists and individual in meeting their role responsibilities.	4-point scale going from 'never' (1) to 'always' (4), subscales were summed.
Satisfaction with emotional support[18]	1	Single item from the Quality of Life Index-Stroke: 'How satisfied are you with the emotional support you get from others'.	6-point scale from 'very unsatisfied' (1) to 'very satisfied' (6).
Social Support Inventory for Stroke Survivors[19]	75	Five subcategories: Personal ties, family/friends, community, group and professional ties. Each subcategory includes questions that correspond to dimensions of quality, quantity and satisfaction with both quality and quantity.	Total scores are generated by summing the three informational support categories (personal, family and close friends, and community individuals).

Table 2.2 continues on next page.

Table 2.2 ***Continued***

Questionnaire	Number of items	Description	Possible answers and scoring system
Social Support in the Elderly Scale[26]	18	Two subcategories: *Satisfaction* with various aspects of social support (9 items). *Importance* of each aspect to the subjects (9 items).	6-point scale from 'very dissatisfied' (1) to 'very satisfied' (6) and 'very unimportant' (1) to 'very important' (6). An index score is obtained by multiplying each satisfaction item with the corresponding importance item.
Social Support Questionnaire short form[27]	6	Two subcategories per item: *The perceived amount of social support*: the number of persons who the patient can count on for help or support with a maximum of nine people. *The satisfaction* with the overall support the patient has.	*Perceived amount*: add all items for all persons (max 54). *Satisfaction*: 6-point scale from 'very dissatisfied' (1) to 'very satisfied' (6), Total score 6–36.
Combination of the 'General health inquiry-Belgium' and the 'Medical Outcomes Studies Social Support Survey'[21]	Unknown	*General health inquiry – Belgium* – not available. *Medical Outcomes Studies Social Support Survey* – see above.	
Self-developed questionnaire[28]	Unknown	Questions on perceived support from relations and friends, access to social support, and satisfaction with support from friends.	5-item Likert response scale, an average score was calculated (not further specified by author).
Social network size and frequency of contacts[15]	2	*Social network size*: consisting of the spouse/partner, number of children, number of relatives, number of friends, number of group memberships. *Frequency of contacts*: patients were asked how often they saw their children, relatives and friends compared to before the stroke.	*Social network size*: adding number of persons together. *Frequency of contacts*: much less, less, the same, more, much more.

* One study assessed 2 questionnaires. ** In our analysis affectionate support was considered as part of emotional support, because of the similarity in definitions.

Table 2.3 Methodological quality assessment

Reference	Year	Internal validity	Control of drop out	External validity	Statistical validity	Proportion sample size: determinants	Multi-collinearity	Confounding bias	Reporting	Total (max 8 points)
Dayapoglu[14]	2010	1	0	1	1	1	1	0	0	5
Hilari[15]	2011	1	0	1	1	1	1	0	1	6
Hilari[16]	2011	1	0	1	1	1	1	0	1	6
Huang[17]	2010	1	0	1	1	1	0	0	1	5
Jaracz[18]	2003	1	1	1	1	1	0	0	1	6
Kim[19]	1999	1	0	1	1	0	0	0	1	4
King[3]	1996	1	1	1	1	0	0	0	1	5
Mackanzie[20]	2002	1	1	0	1	1	1	0	1	6
Manders[21]	2010	1	0	0	1	1	1	0	1	4
Owolabi[22]	2010	1	0	1	1	1	1	0	1	6
Teoh[23]	2009	1	1	1	1	1	0	1	1	7

Internal validity: use of validated and reliable measures, Control of patient drop out: including nonresponse analysis, external validity: specifying in/exclusion criteria and demographic characteristics, statistical validity: testing for statistical significance, adequate sample size in relation to the number of determinants (univariate ratio 20:1 and multivariate ratio 10:1), control for multilinearity, control for potential confounding variables, clearly description of main findings (Appendix 2.2).[12]

Satisfaction with social support. One study tested the correlation between satisfaction with social support and HRQoL.[20] It resulted in four bivariate correlations, of which two were significant and one was > .30. Social support satisfaction at two-weeks and three-months post-stroke was associated with better HRQoL at three months post-stroke.

Type of social support

The different types of social support were emphasized to five main categories (emotional, informational, instrumental, appraisal support and social companionship).

Emotional support. Six bivariate correlations between emotional support and HRQoL were tested.[15,17,18] All showed a relationship between more emotional support and better HRQoL, but only one was significant and also > .30.[18]

Informational support. Two studies associated informational support and HRQoL,[15,17] of whom one showed a significant association between more informational support and better HRQoL (< .30).[15]

Instrumental support. Associations between instrumental support and overall HRQoL were reported in two studies. Inconsistent results were found: one study found a non-significant association between more instrumental support and worse HRQoL,[15] whereas the other study found a significant association between more instrumental support and better HRQoL (> .30).[17] One study reported also a mediating effect of instrumental support between the psychosocial and physical subscale of HRQoL (not shown in Table 2.4).[17]

Appraisal support. Three bivariate correlations were tested between appraisal support and HRQoL, none of which was significant.[17]

Social companionship. Hilari et al.[15] found a significant association between more social companionship and better HRQoL (< .30).

Source

Network size. A larger network size (calculated by adding the presence of spouse/partner, number of children, number of relatives, number of friends, number of group members) was associated with a higher HRQoL (< .20) in one study.[15] Four bivariate correlations were tested between the number of supporting persons at different moments post-stroke and HRQoL, of which one was significant (< .21).[20]

Table 2.4 Results of the bivariate and multivariate associations between social support and stroke survivors' health-related quality of life

	Overall HRQoL			HRQoL subscale Psychosocial			HRQoL subscale Physical		
	Bivariate	Multivariate	Ref	Bivariate	Multivariate	Ref	Bivariate	Multivariate	Ref
Overall social support									
Perceived social support	.60**		14					F = 2.378**	22
	.39**		14				.57**		14
	.17		15						
	.19*	β = .06	16						
	.33*	unique R^2 = 9%*	19						
	.48***	β = .33*** unique R^2 = 9%	3	.42*	β = .24* unique R^2 = 5%	3	.35*	β = .23* unique R^2 = 4%	3
	.18*		21						
	ns§	ns	23						
Satisfaction with social support	.11^{a}	removed	20						
	.09^{b}	removed	20						
	.26***^{,c}	β = -.19***	20						
	.41***^{,d}	removed	20						
Type									
Emotional	.17		15						
	.08		17	.05		17	.11		17
	.60**	β = .36*** unique R^2 = 18%	18						
	.05		15						
Informational	.26*		15						
	.16		17	.15		17	.15		17

Table 2.4 continues on next page.

Table 2.4 ***Continued***

	Overall HRQoL			HRQoL subscale Psychosocial			HRQoL subscale Physical		
	Bivariate	Multivariate	Ref	Bivariate	Multivariate	Ref	Bivariate	Multivariate	Ref
Instrumental	-.06		15						
	.33**		17	.32**		17	.30**		17
Appraisal	.06		17	.03		17	.09		17
Social companionship	.24*		15						
Source									
Network size	.20*		15						
Number of supporting persons	.13[a]	removed	20						
	.04[b]	removed	20						
	.12[c]	removed	20						
	.21**,[d]	removed	20						
Change of frequency of contacts									
Children	F = 4.58*		15						
Relatives	F = 3.257*		15						
Friends	F = .138		15						

To make comparison more clear the minus sign from the Sickness Impact Profile[20] was removed. In this scale the higher the score the lower health-related quality of life. In all other scales a more positive (high) score indicates a higher quality of life and vice versa. Some subscales were more or less comparable. Therefore, the following subscales were combined: Mental[17] and Psychological;[3] Physical,[17,22] Health and functioning[3] and Functional capacity.[14] Furthermore the subscale 'General Health'[14] was inserted in the Overall HRQoL. Affectionate support was considered as part of emotional support, because of the similarity in definitions.

[a] Social support at 2 weeks and HRQoL at 2 weeks; [b] Social support at 3 months and HRQoL at 2 weeks; [c] Social support at 2 weeks and HRQoL at 3 months; [d] Social support at 3 months and HRQoL at 3 months.

B, beta value (regression analysis); R^2, explained variance (regression analysis); F, F value (analysis of variance).

* $p < .1$, ** $p < .01$, *** $p < .001$, [§] no significant relation between social support and HRQol at 11.7 months, 14 months and 18 months post-stroke, ns not significant.

Change of frequency of contacts with children, relatives and friends was investigated in one study.[15] A change of frequency of contact with their children and relatives was associated with a lower HRQoL.

Multivariate associations

Multivariate analyses were reported in seven publications. They were reported as adjusted and as non-adjusted explained variance and therefore, comparison was impossible. Four studies reported significant Beta values for overall perceived social support[3,19] or emotional support.[18] Two studies reported non-significant results[16,23] and one study reported only one significant associations out of eight tested.[20]

Discussion and conclusion

Discussion

This first systematic review on social support and HRQoL post-stroke shows positive, but not consistent, relations between social support and stroke survivors' HRQoL. Unfortunately, due to the small number of included studies and the heterogeneity in methods of assessing social support, a clear statement about the influence of social support source or type could not be made. It appears that the relation between social support and overall HRQoL was similar to the relation between social support and the Psychological or Physical HRQoL domains. Beside this, the relations between perceived social support and HRQoL seems to be more often significant and stronger than when social support was divided in source or type.

Approximately half of the bivariate associations were significant, indicating inconsistent results. The results of the multivariate analysis were also inconsistent. The explanation for these deviating results is unclear. Probably, this is due the large variation in study designs. Firstly, the sample size ranged from 43 to 215, which is acceptable. However, small sample size studies will show more often a non-significant result in comparison to a large sample size due to a lack of power. Secondly, the time post-stroke was variable, ranging from two weeks to 3.5 years. Probably, the amount of social support changes over time and influences the significant associations between social support and stroke survivors' HRQoL. Thirdly, two studies included only chronic aphasia patients, which is a different population than stroke survivors in general.[15,16] Fourthly, the heterogeneous measurements used have influenced the associations. Fifthly, only one study mentioned controlling for confounders.[23] Future studies should include possible confounding variables in the statistical analyses. Possible confounding variables could be the work status of stroke survivors (employed stroke survivors might have a broader social network and a better quality of life) or educational level (highly educated stroke survivors might have better social skills and might have a better quality of life).

Nine studies were cross-sectional and only two studies used a longitudinal design. Therefore, a causal-effect direction could not be established. More longitudinal studies are needed to study the course of social support over time, changes in associations between social support and HRQoL over time, and causal connections.

The exact pathway through which social support influences HRQoL is still unclear, but several theoretical models have been proposed. Uchino theorized that social support and physical health (morbidity and mortality) are linked by two different pathways.[29] The first pathway involves behavioural processes, like health behaviours and adherence to medical regimens. Social support would be health-promoting by facilitating healthier behaviours like exercise, diet, not smoking etc. The second pathway involves psychological processes that are linked to appraisals, emotions or moods, and feelings of control.[29]

Two other theoretical models that have been put forward to explain the effect of social support are the 'main effect model' and the 'stress-buffering model'. The main effect model suggests that, regardless of the level of stress, high levels of support promote general good health and therefore less risk of developing illness.[6,7,30] The stress-buffering model acts by an indirect way. Social support buffers or compensates the negative effect of stress, thereby lessening the risk of developing illness or speeds recovery after illness.[6,7,30] In this review, most studies implicitly used the direct effects model, although a mediating or buffering effect of instrumental support on HRQoL was found in one study.[17] This is consistent with literature of other diseases, like chronic pain[6] and heart diseases.[31,32]

Even if the exact pathway in which social support influences HRQoL is still unclear and no studies examined causal pathways, our review shows that 21 out of the 45 bivariate correlations that were tested were significant, of which 14 were > .30. Therefore, the results of this review show that it is reasonable to assume that promoting social support improves HRQoL. In a narrative study on the long-term needs of stroke survivors,[33] emotional and practical support was a key facilitator of functioning, buffering the reported impact of disabilities and mediating perceived needs. Lack of support was mentioned as a barrier to maintain independence in activity of daily living and social participation.

Although maintaining an adequate social network is important, it can be a major challenge for stroke survivors. The consequences of stroke in many different health aspects, like cognitive or behavioural changes, chronic fatigue, communication and mobility problems make maintaining a social network more difficult. Supporting a stroke survivor can be burdensome[34] and social contacts seems to decline over time. Three years post-stroke, elderly stroke survivors maintained their contacts with their children, but they had fewer contact with friends and neighbours in comparison with a general population of similar age.[35] One study in our review investigated the changes in frequency of contacts post-stroke in comparison with the situation before stroke,[15] and surprisingly showed that more frequent contacts with children or relatives was negatively associated with HRQoL. It is possible that this increase in contacts is elicited by dependence on others after a severe stroke. More social support could also be the result of overprotection (i.e. providing too much support), unintended support failures (i.e. when the intention is good, but the effect is not helpful at all) or when a support relationship is otherwise a source of conflict or tension.[36] Stroke survivors who saw their children or relatives in the same frequency had the highest HRQoL.

Limitations of this systematic review

Firstly, the search strategy used in this review was comprehensive, with a wide-ranging search of electronic databases, supplemented by hand-searches of the reference lists. However, the review included only studies written in English. Relevant studies in other languages might have been neglected, although the included articles were produced worldwide and represented a diversity of populations. Secondly, only few studies could be included. Consequently, it was impossible to classify all social support variables as either consistent, inconsistent or unrelated determinants of HRQoL.[12] A meta-analysis was not possible for the same reason. Thirdly, the heterogeneity in methods of assessment and types of social support made between study comparisons and overall conclusions difficult. Fourthly, this review focuses only on HRQoL and excluded depression or participation. In our view these subjects are different from HRQoL, so that they require an own systematic review.

Conclusion

Social support is significantly associated with stroke survivors' HRQoL. The subtype emotional support is most often investigated and shows the strongest relationships with HRQoL in contrast to the subtypes informational, instrumental and appraisal. Although,

(a) the evidence is inconsistent due to the small number of studies and its heterogeneity in designs, (b) the specifications by type or sources are not well investigated, this has implications to clinical practice both in the subacute phase (rehabilitation phase) as in the chronic phase (community level).

Practice implications

Social support should be a substantial aspect of the acute and chronic rehabilitation programme. Individual professionals in primary and secondary care should discuss social support with stroke survivors, like the different possibilities of social support (i.e. types and sources), the importance of gaining and maintaining an adequate social network, and how to maintain this network.

Furthermore, attention should be paid to promoting social support on the short and long term. Social support from family and friends can overcome fear and loss of self-esteem.[37] It can reduce the gap between functional abilities and task demands in order to improve HRQoL and participation.[37] One possible way to promote social support is by making interventions more targeted. These interventions should involve the social networks in a broad spectrum, for instance by promoting support networks through family or friends, a patient organization or voluntary bodies. Interventions should not focus on increasing the frequency of contacts, but on increasing the quality of it. Until nowadays, as Salter et al. showed in their review, most intervention programs focus on practical help and providing information,[10] whereas our review shows that the subtype emotional support is most often investigated and shows the strongest relationships in comparison to the subtypes informational, instrumental and appraisal.

Further research should focus on larger study groups; and should gain in uniformity of the social support and health-related quality of life questionnaires. A social support questionnaire which subdivides social support by source and/or type would be preferable, such as the Medical Outcomes Social Support Survey.[25] Furthermore, possible confounding variables should be defined. Most of the studies insert all significant variables in their multivariate analysis without any hypothesis about which variables could be confounders. A longitudinal design is recommended to clarify the cause-effect relation. It would also be useful to measure the pre-stroke situation of social support to reveal changes over time.

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Appendix 2.1

Pubmed search strategy

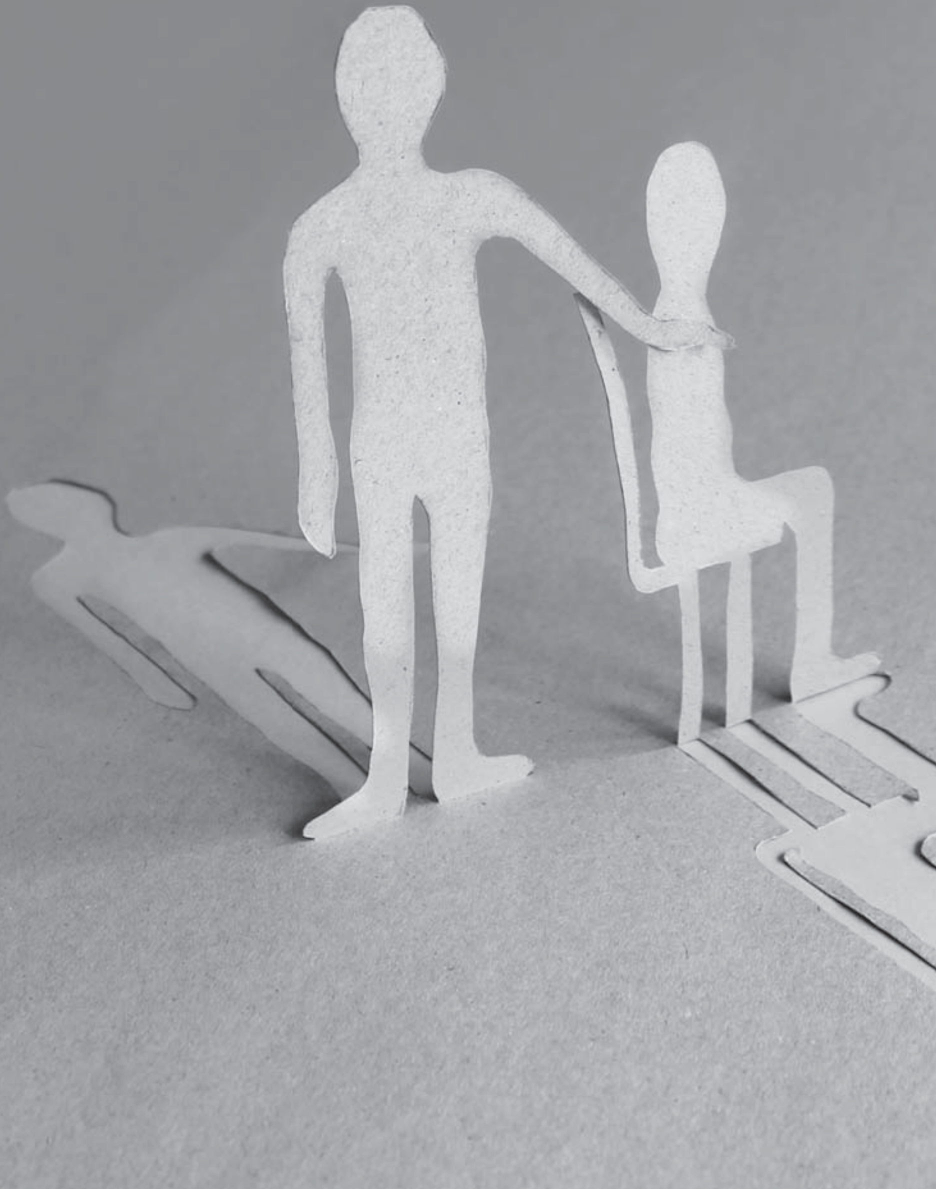
((“stroke”[Title/Abstract] OR “strokes”[Title/Abstract] OR “CVA”[Title/Abstract] OR “CVAs”[Title/Abstract] OR “vascular accident”[Title/Abstract] OR “vascular accidents”[Title/Abstract] OR “cerebrovascular”[Title/Abstract] OR “cerebro vascular”[Title/Abstract] OR “apoplexy”[Title/Abstract] OR “brain infarction”[Title/Abstract] OR “brain infarctions”[Title/Abstract] OR “cerebral infarction”[Title/Abstract] OR “cerebral infarctions”[Title/Abstract] OR “brain ischemia”[Title/Abstract] OR “cerebral ischemia”[Title/Abstract] OR “cerebral hemorrhage”[Title/Abstract] OR “cerebral haemorrhage”[Title/Abstract] OR “brain hemorrhage”[Title/Abstract] OR “brain haemorrhage”[Title/Abstract] OR “stroke”[MeSH Terms] OR “brain infarction”[MeSH Terms] OR “cerebral infarction”[MeSH Terms] OR “brain ischemia”[MeSH Terms] OR “cerebral hemorrhage”[MeSH Terms]) **AND** (“quality of life”[Title/Abstract] OR QOL[Title/Abstract] OR “life quality”[Title/Abstract] OR “life qualities”[Title/Abstract] OR “health related quality of life”[Title/Abstract] OR “hrqol”[Title/Abstract] OR “perceived health”[Title/Abstract] OR “health status”[Title/Abstract] OR “quality of life”[MeSH Terms] OR “health status”[MeSH Terms]) **AND** “partner”[Title/Abstract] OR “partners”[Title/Abstract] OR “spouse”[Title/Abstract] OR “spouses”[Title/Abstract] OR “husband”[Title/Abstract] OR “husbands”[Title/Abstract] OR “wife”[Title/Abstract] OR “wives”[Title/Abstract] OR “caregiver”[Title/Abstract] OR“caregivers”[Title/Abstract] OR “child”[Title/Abstract] OR “children”[Title/Abstract] OR “family”[Title/Abstract] OR “families”[Title/Abstract] OR “significant other”[Title/Abstract] OR “relatives”[Title/Abstract] OR “married persons”[Title/Abstract] OR “married person”[Title/Abstract] OR “spousal notification”[Title/Abstract] OR “care giver”[Title/Abstract] OR “care givers”[Title/Abstract] OR “carer”[Title/Abstract] OR “carers”[Title/Abstract] OR “stepfamily”[Title/Abstract] OR “stepfamilies”[Title/Abstract] OR “filiation”[Title/Abstract] OR “parent”[Title/Abstract] OR “parents”[Title/Abstract] OR “sibling”[Title/Abstract] OR “siblings”[Title/Abstract] OR “friend”[Title/Abstract] OR “friends”[Title/Abstract] OR “brother”[Title/Abstract] OR “brothers”[Title/Abstract] OR “sister”[Title/Abstract] OR “sisters”[Title/Abstract] OR “social support”[Title/Abstract] OR “neighbor”[Title/Abstract] OR “neighbors”[Title/Abstract] OR “neighbour”[Title/Abstract] OR “neighbours”[Title/Abstract] OR “social network”[Title/Abstract] OR “social networks”[Title/Abstract] OR “community support”[Title/Abstract] OR “support system”[Title/Abstract] OR “spouses”[MeSH Terms] OR “caregivers”[MeSH Terms] OR “child”[MeSH Terms] OR "family"[MeSH Terms] OR "parents"[MeSH Terms] OR "siblings"[MeSH Terms] OR "friends"[MeSH Terms] OR "social support"[MeSH Terms] OR "social participation"[MeSH Terms]))

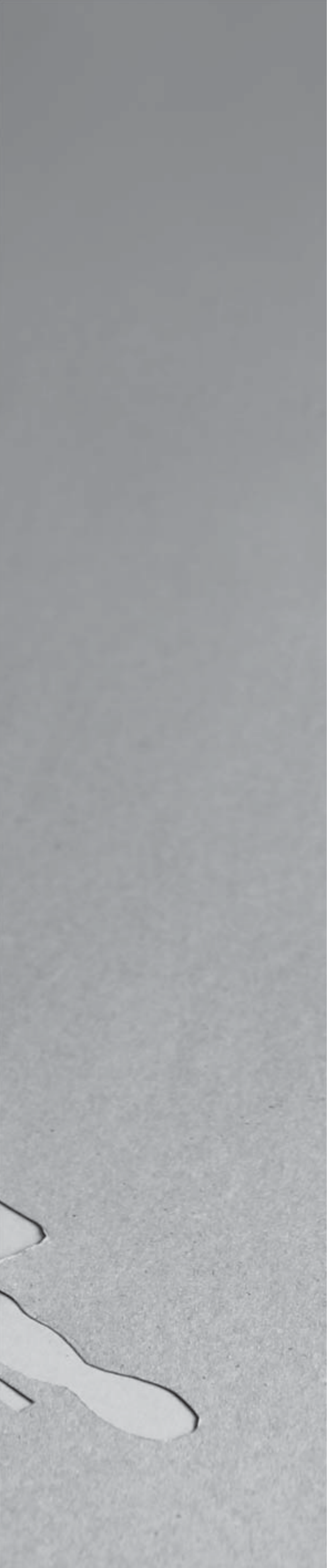
Appendix 2.2

Methodological quality assessment list

Item	Outcome strategy	Criteria (positive = 1, otherwise = 0)
1	To evaluate internal validity: Were the main outcome measures valid and reliable?	Positive, if the study tests the validity and reliability of the measurements used, or refers to other studies which have established the validity and reliability.
2	Control of patient-drop-out	Positive, if specified how many persons were approached, how many persons participated, and a nonresponse analysis is done to compare participants and non-participants.
3	To evaluate external validity: Were the relevant patient characteristics specified (in- and exclusion criteria)?	Positive, if age, gender, number and type or localization of stroke, and time since stroke were specified.
4	To evaluate statistical validity: Was the relationship between dependent and independent variables statistically valid?	Positive, if the relationship between a dependent and independent variable is tested for statistical significance.
5	Was the sample size (n) adequate in relation to the number of determinants (K)?	Positive, if univariate ratio [n: K] exceeds [20:1] and if multivariate ratio [n:K] exceeds [10:1].
6	Was there a control for multicollinearity?	Positive, if specified that multicollinearity between variables has been tested, or if not applicable.
7	To evaluate bias: Were potentially confounding variables controlled?	Positive, if specified that the design accounts for and analysis are corrected for confounders.
8	To evaluate reporting: Are the main findings of the study clearly described?	Positive, if purpose is described, results are related to the purpose, and data tables are explained in the results.

Chapter 3





Course of social support and relationships between social support and patients' depressive symptoms in the first three years post-stroke

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Abstract

Objective

To describe the course of social support (everyday support, support in problem situations and esteem support) from initial inpatient rehabilitation till three years post-stroke and to examine the cross-sectional and longitudinal relationships of social support with depressive symptoms.

Design

Prospective cohort study.

Subjects

A total of 249 stroke patients.

Methods

Depressive symptoms were measured with the Center of Epidemiologic Studies Depression Scale. Perceived social support was assessed with the Social Support List-Interaction. Pearson correlations and multilevel analysis were performed.

Results

More than one-third of the participants were suffering from depressive symptoms. Social support and its three subtypes declined significantly over time. Divergent relationships between subtypes of social support and depressive symptoms were seen. Everyday support and esteem support showed negative associations with depressive symptoms, whereas support in problem situations showed a positive association. Social support in problem situations was a predictor of depressive symptoms over time. Effect-modification by participants with physical or cognitive limitations could not be shown.

Conclusions

Stroke survivors experience a decline of social support over time. Various subtypes of support show distinct relationships with depressive symptoms. Health care professionals should focus on the various subtypes of support when supporting patients to improve and maintain an adequate social support network.

Introduction

Post-stroke depression is a major problem;[1-3] approximately one-third of all stroke survivors worldwide suffer from depression.[1] The underlying aetiology of post-stroke depression is poorly understood; both biological and psychological mechanisms are thought to play a role.[4-6] The biological mechanism may include several neurological factors, such as lesion location (left hemisphere, basal ganglia), neurotransmitters and inflammatory cytokines.[4,6] Stroke is, however, also an overwhelming psychological event and stroke survivors face the challenge of adapting to a new situation. This may trigger depressive feelings.

Lack of social support is consistently associated with post-stroke depression.[4,5] Social support seems to have a 'protective effect' against developing post-stroke depressive symptoms, buffering the negative consequences of stroke and reducing depressive symptoms.[5,7] It is a broad concept and can be defined as any support given outside formal settings, i.e. not by health professionals or social services.[8] To make this concept more concrete, social support can be divided into three different subtypes: 'everyday support', 'support in problem situations' and 'esteem support'.[9]

It is important to consider both the type and the timing of social support.[10,11] However, most stroke studies measure social support with a single total score, as if it were a one-dimensional factor. Consequently, there is insufficient knowledge about the impact of different subtypes of social support. Furthermore, most studies are cross-sectional, so that the course of social support and the longitudinal relationships of social support with stroke outcome are rarely investigated. It is possible that this this lack of detailed knowledge about type and timing of social support have resulted in the generally disappointing effectiveness of social support interventions for post-stroke depression published in a review in 2010.[12]

The aims of this study are therefore (a) to describe the course of stroke survivors' social support and three subtypes of social support (i.e. everyday social support, social support in problem situations and esteem support) from the start of initial inpatient rehabilitation until three years post-stroke; (b) to examine the cross-sectional relationships between social support, including the three subtypes, and depressive symptoms at various times post-stroke; and (c) to examine the longitudinal relationships between social support, including the three subtypes, and depressive symptoms over time, correcting for potential confounding and effect modification.

Our first hypothesis is that social support and the three subtypes will decline over time, because the disabilities resulting from stroke (e.g. sensomotoric, communicative and cognitive) make it a major challenge for stroke survivors' to maintain an adequate social network. Furthermore, we expect that less social support is associated with more depressive symptoms at all measurement occasions.[4,5] However, because of the different aspects of the subtypes the strength of the associations might differ. Until now, this has not yet been investigated. With regard to the third aim of our study, we hypothesize that all subtypes of social support are negatively associated with depressive symptoms over time. Finally, the theory that social support buffers the negative consequences of stroke[5,7] predicts that the association between social support and post-stroke depression will be stronger in stroke survivors with relatively severe disabilities than in stroke survivors with relatively minor disabilities. Therefore, we hypothesize that the association between social support and depression will be stronger in stroke survivors scoring below established cut-off points for physical and cognitive disability than in stroke survivors scoring above these cut-off points.

Methods

Participants

Study subjects were selected from stroke patients who participated in the 'Functional prognosis after stroke' (FuPro-Stroke) study.[13] They were recruited through four Dutch rehabilitation centres between April 2000 and July 2002. Inclusion criteria were: first-ever stroke, one-sided supratentorial lesion and age above 18. Exclusion criteria were: disabling comorbidity (defined as a pre-stroke Barthel Index < 18) and inability to speak Dutch.

For the present analysis patients with aphasia were excluded, since they were unable to complete the Center of Epidemiologic Studies Depression Scale. The presence of aphasia was operationalized as a score in the clinical range of either the Token Test (short version, score ≥ 9) or the Utrecht Communication Observation (Utrechts Communicatie Onderzoek, score < 4).[13] Each assessment the presence of aphasia was measured again.

The study was approved by the medical ethics committees of the University Medical Centre Utrecht and the participating rehabilitation centres. Informed consent was obtained from all participants.

Procedure

At the start of inpatient rehabilitation, stroke patients were invited by their rehabilitation specialists to participate in the study. The first assessment was conducted as soon as possible after informed consent was given. Other assessments followed at one and three years after stroke. Patients were assessed at home or at the institution where they lived by trained research assistants.

Measures

Perceived social support was measured with the Social Support List-Interaction (SSL-12-I) (Appendix 3.1). This questionnaire measures the patients' subjective experience of social support. The SSL-12-I consists of 12 items in three scales: '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).[9] The score ranges from 12 to 48, and higher scores indicate more social support. It has good psychometric properties.[9]

Depressive symptoms were measured using the Center of Epidemiologic Studies Depression Scale (CESD). The total score of this 20-item scale ranges between 0 and 60, and a score of ≥ 16 indicates a clinically relevant presence of depressive symptoms. It has a good reliability and validity.[14,15]

Cognition was assessed with the Minimal Mental State Examination (MMSE), which is a screening test with good validity and reliability.[16] Participants were scored as having cognitive disability if the MMSE score was ≤ 23 points or if they were not able to complete this test due to aphasia.

Independence in activities of daily living (ADL) was assessed using the Barthel Index,[17] which is a valid and reliable instrument.[18,19] Participants were scored as dependent if the Barthel Index score was ≤ 18.

Demographic characteristics, like age, gender and type of stroke, were obtained from medical charts. Other data on marital status, pre-stroke employment and educational level were documented at start of the inpatient rehabilitation.

Statistical analysis

All participants who completed at least one of the three measurement occasions were included in the analyses. Descriptive statistics were used to describe the demographic characteristics of the stroke survivors. Pearson correlations were used to investigate the cross-sectional associations between social support, its three subtypes and depressive symptoms.

To examine the course of social support (and its subtypes) and depressive symptoms up to three years post-stroke, random coefficient analysis (multi-level analysis) was used. Two advantages of this method in longitudinal studies are: (1) the number of observations per stroke survivor and the temporal spacing of these observations can be varied, (2) this method considers dependency of repeated measures within the same person.[20]

First, the course of social support was studied with time as the only determinant. Time was entered in the model as a set of two dummy variables with T1 (at baseline) as reference. Total social support and the three subtypes were separately used as the dependent variable, resulting in four different models.

To analyse the relationships between social support and depressive symptoms over time, again four different basic multi-level linear regression models were used with depressive symptoms as the dependent variable (T1, T2 and T3), one model for each subtype of social support and total support as the independent variable (also T1, T2 and T3).

Effect modification, related to level of disability, of the relation between social support and depressive symptoms was also investigated. Effect modification occurs if the association between social support and depressive symptoms is different in participants with disability than in participants without disability. Since the MMSE and the Barthel Index scores were strongly inter-correlated and the MMSE score was highly skewed, both variables were combined in one new variable. This new variable was dichotomized to indicate the presence of problems in ADL or cognition (MMSE ≤ 23 or Barthel Index ≤ 18) or the absence of these problems, and to facilitate the clinical interpretation of the findings. Both, the new variable and the interaction term between the social support variable and this new variable were added to the basic models.

To test for confounding the demographic (age, gender, having a partner, having children, educational level, pre-stroke employment) and clinical characteristics (type of stroke, hemisphere affected, post-stroke time, dependence in ADL and cognitive impairment) were added one by one to each model. A characteristic was considered a confounder if the

B values of the above independent variables or interactions changed more than 10% after adding them to the model.

SPSS statistical program for Windows (version 16.0) and the MLwiN program of the Centre for Multi-level Modelling of the Institute of Education in London (version 1.1) were used for the analyses.

A p-value of < .05 was considered statistically significant.

Results

Participants

A total of 308 stroke survivors were recruited in the FuPro-stroke study. At baseline (T1) 206 participants, at one year post-stroke (T2) 210, and at three years post-stroke (T3) 174 participants completed the measurement on social support at T1, T2 and T3 respectively. A total of 249 participants (response percentage 81%) completed at least one measurement on social support in three years and were included for the current analyses.

Fifty-nine of the 308 stroke survivors could not complete any measurement on social support. A non-response analysis revealed that these stroke survivors were more often male, had more often a lesion in the left hemisphere and a lower average educational level than the 249 participants.

Table 3.1 displays the demographic and stroke characteristics of the participants at admission for inpatient rehabilitation. The majority were men (57%) and their mean age was 56.7 years. The majority had suffered from an infarction. More than one-third (36.9%) showed clinically relevant depressive symptoms. At baseline 76.7% were dependent in ADL and 17.1% reported cognitive impairments.

Course of social support

Table 3.2 shows the descriptives of social support and depressive symptoms at each time point and Figure 3.1 displays the course of the three subtypes of social support over time as estimated using random coefficient analysis. It shows a similar decrease in each subtype of social support over time. This decline of social support was significant in both time periods (T2–T1 and T3–T1, respectively) (Table 3.3).

Table 3.1 Baseline characteristics (n = 249)

	Included stroke patients[a]
Demographic characteristics	
Age, mean (SD), median (IQR)	56.7 (10.8), 56.0 (49.0–65.0)
Female gender, %	43.0
Living with a partner, %	72.3
Having children, %	81.5
Educational level (higher education)[b], %	19.3
Pre-stroke employment status (employed), %	42.2
Place of residence three years post-stroke, % at home	91.4
Stroke characteristics	
Type of stroke (infarction), %	71.9
Hemisphere (right), %	54.6
Post-stroke time in days, mean (SD)	50.5 (24.0)
Barthel Index, mean (SD), median (IQR), % dependent[c]	13.9 (4.6), 14.0 (10.0–18.0), 76.7
Minimal mental state examination, mean (SD), median (IQR), % present[d]	26.0 (2.8), 27.0 (24.5–28.0), 17.1
Dependence in ADL and/or cognitive impairment, %	78.0
Depressive symptoms, mean (SD), median (IQR), % present[e]	13.7 (9.3), 12.0 (6.0–18.0), 36.9

[a] Stroke patients are included when at least one out of three social support lists is completed.
[b] Senior secondary education, university preparatory education, higher professional education, and university.
[c] Dependent in activities of daily living if Barthel index is ≤ 18.
[d] Cognitive impairments are present if MMSE ≤ 23.
[e] Depressive symptoms are present if CESD ≥ 16.
Abbreviations: n, number of patients; SD, standard deviation; IQR, interquartile range; ADL, activities of daily living; CESD, Center of Epidemiologic Studies Depression Scale.

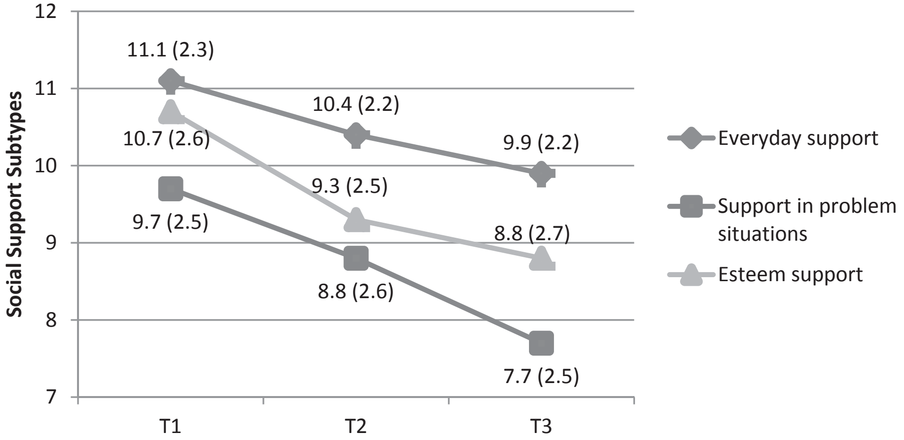

Figure 3.1 Course of subtypes of social support over time.
Figures represents mean (SD).
T1: at admission; T2: at one year post-stroke; T3: at three years post-stroke.

Table 3.2 Descriptives of stroke patients' total social support, everyday social support, support in problem situations, esteem support, depressive symptoms at T1–T3 (n = 249)

	T1		T2		T3	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Total social support	31.6 (6.1)	31.0 (27.8–36.0)	28.4 (6.0)	28.0 (24.0–32.0)	26.4 (6.1)	26.0 (22.0–31.0)
Everyday social support	11.1 (2.3)	12.0 (10.0–12.0)	10.4 (2.2)	10.0 (9.0–12.0)	9.9 (2.2)	10.0 (8.0–11.3)
Support in problem situations	9.7 (2.5)	9.5 (8.0–12.0)	8.8 (2.6)	9.0 (7.0–10.0)	7.7 (2.5)	7.0 (6.0–9.0)
Esteem support	10.7 (2.6)	11.0 (9.0–12.0)	9.3 (2.5)	9.0 (8.0–11.0)	8.8 (2.7)	8.0 (7.0–11.0)
Depressive symptoms	13.7 (9.3)	12.0 (6.0–18.0)	11.7 (8.9)	10.0 (4.0–17.0)	10.0 (8.1)	8.0 (4.0–14.0)

T1: at admission; T2: at 1 year post-stroke; T3: at 3 years post-stroke. Abbreviations: SD, standard deviation; IQR, interquartile range.

Table 3.3 Multilevel linear regression model for the course of social support between baseline and three years after stroke (n = 249)

	Model for total social support			Model for everyday support			Model for support in problem situations			Model for esteem support		
Variables	Beta	SE	p	Beta	SE	p	Beta	SE	p	Beta	SE	p
Constant	31.354	0.407		11.051	0.150		9.699	0.171		10.623	0.170	
Time T2–T1	-3.054	0.384	< .001	-0.807	0.144	< .001	-0.913	0.180	< .001	-1.343	0.161	< .001
Time T3–T1	-5.269	0.411	< .001	-1.304	0.154	< .001	-2.030	0.192	< .001	-1.931	0.202	< .001

Beta stands for a non-standardized regression coefficient in multi-level analysis. All 4 models had random intercepts. All time-dependent covariates had a fixed slope, except for time (T3–T1) in the model for esteem support, which had a random slope.
T1: at baseline; T2: one year after stroke; T3: three years after stroke.
Abbreviations: SE, standard error; p, p-value.

Social support and depressive symptoms

Some bivariate correlations between social support, its three subtypes and depressive symptoms were significant, although weak and without an apparent relationship with measurement occasion (Table 3.4). The three subscales had opposite coefficients in their relation with depressive symptoms. Everyday support and esteem support showed negative associations with depressive symptoms, whereas support in problem situations showed a positive association.

Table 3.4 Pearson correlations between social support and depressive symptoms at the three different measurements (n = 249)

	Total social support	Everyday social support	Support in problem situations	Esteem support
Depressive symptoms				
T1	0.022 (.756)	-0.077 (.274)	0.146 (.037)*	-0.024 (.730)
T2	-0.109 (.116)	-0.181 (.009)*	0.019 (.780)	-0.124 (.073)
T3	-0.079 (.301)	-0.140 (.067)	0.103 (.178)	-0.156 (.040)*

Figures are Pearson correlations with p-values. * P-value < .05.
T1: at baseline; T2: one year after stroke; T3: three years after stroke.

In the random coefficient analyses, only social support in problem situations showed a significant positive direct relationship with depressive symptoms over time, indicating that social support in problem situations is a predictor of depressive symptoms (Table 3.5). No significant confounders were found for this model.

Effect modification

None of the interaction terms tested were significant. This means that the associations between social support and depressive symptoms in participants with relatively severe disabilities were not significantly different from these associations in stroke survivors with relatively minor disabilities.

Table 3.5 Multilevel linear regression models for the direct relationship between different types of social support and depressive symptoms (n = 249)

	Model for total social support			Model for everyday support			Model for support in problem situations			Model for esteem support		
Variables	Beta	SE	p	Beta	SE	p	Beta	SE	p	Beta	SE	p
Constant	10.385	2.148		14.112	1.752		7.792	1.251		11.934	1.805	
Social support variable	0.094	0.059	.112	-0.203	0.162	.211	0.479	0.131	< .001	0.127	0.138	.358
Confounders												
Cognitive impairment	-1.738	1.401	.215	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	-1.701	1.413	.230
Educational level (higher education)	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	-0.239	1.316	.857
Hemisphere (right)	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	n.e.	1.620	1.019	.112

All 4 models had random intercepts. All time-dependent covariates had a fixed slope for the direct relationship. Beta, a non-standardized regression coefficient in multilevel analyses. Abbreviations: SE, standard error; p, p-value; n.e., not entered.

Discussion

The present study describes the course of social support, as a total scale and as divided in three subtypes, and depressive symptoms in stroke survivors up to three years post-stroke. As hypothesized, social support and depressive symptoms declined over time. Our hypotheses about the cross-sectional and longitudinal relationship between social support and depressive symptoms were partly confirmed. Social support was associated with post-stroke depressive symptoms, although we had expected more consistent and stronger relationships. The advantage of examining subtypes of social support instead of a total scale was established: Depressive symptoms over time are predicted by social support in problem situations and not by everyday support or esteem support. No significant interactions were found; consequently, our hypothesis on effect modification could not be established. Above all, this study reveals that social support cannot be seen as a one-dimensional factor and should be assessed within subtypes.

Course of social support

Levels of social support decreased over time in this study for all subtypes. A decrease in contacts with other persons over time has also been suggested by earlier cross-sectional studies.[21-23] In the chronic phase, contacts with children seem more or less the same after stroke,[21-23] but a majority of stroke survivors had less contact with friends,[22] suggesting that it is difficult for persons with stroke to maintain friendships. Our study adds a longitudinal description of different subtypes of social support in a general stroke population over time to the stroke literature.

The levels of total social support and the three subtypes reported at baseline and at one year post-stroke were higher than those reported in the general elderly Dutch population (26.4, 9.7, 8.0 and 8.7, respectively).[9] At three years post-stroke the support levels of the stroke survivors were approximately the same as in the elderly population. However, ‘average’ does not necessarily equal ‘sufficient’, since stroke survivors might need more social support than healthy elderly, and a lack of social support is common in the elderly population.[24]

Social support and depression

Our study shows that social support, including its three subtypes, is related to post-stroke depressive symptoms. There were significant correlations, although not at each measurement, in line with what was reported by other studies,[5,7] and adding an analysis of support subtypes and a follow-up period of three years to the literature.

Furthermore, our study shows, on the one hand, that more support in problem situations is associated with more depressive symptoms and, on the other hand, that more everyday support and esteem support are associated with less depressive symptoms. This partly corresponds to the literature, in which a systematic review presented that low social support was consistently associated with depression,[5] and instrumental and emotional support were associated with depressive symptoms at one month post-stroke (instrumental and emotional support) and three months post-stroke (emotional support).[25]

Social support can increase the autonomy of stroke survivors (positive effect) but can also confirm the dependency of the stroke survivor to others (negative effect).[10] Perhaps, everyday support and esteem support have both effects in it (and more positive than negative effects), resulting in a non-significant positive association. On the other hand, support in problem situation confirms the dependency of the stroke survivor to others more, resulting in a significant negative association with post-stroke depressive symptoms.

These opposed directions might also explain the lack of significant association between total social support and depressive symptoms. Therefore, social support should not be measured as a total scale, but in subscales.

Social support, including its three subtypes, was associated with post-stroke depressive symptoms, although we had expected more consistent and stronger relationships. This finding may be explained by the disability profile of the participants. Our participants had relative high Barthel (mean 13.9 at baseline) and MMSE scores (mean 26.0 at baseline) suggesting a relatively moderately disabled group. Lewin and colleagues also focused in their study on former inpatient rehabilitation patients and showed that high levels of social support were a protective factor for depressive symptoms.[7] In comparison with this study, our study population was younger, was less dependent in ADL and had a slightly lower score on the MMSE.[7]

Effect modification

No effect modification of disability (in terms of having physical or cognitive disability) in the relationship between social support, its three subtypes and depressive symptoms, that is no significant interaction term, was found. No other studies focusing on effect modification in the relationship between social support and depressive symptoms after stroke were found. Our results imply that no stronger association between social support and depressive symptoms in stroke survivors who experience problems in ADL or cognition was found. This finding suggests that social support is always important, whether or not there are problems in ADL or cognition. An alternative explanation is that our study group consisted of persons with a relatively high Barthel score and high score on the MMSE, making it difficult to analyse this factor.

Strengths of the study

It is important to investigate social support in the subacute and chronic phase of stroke in a relatively young and moderately disabled population, because this support could be needed for many years or even lifelong. Therefore, one of the strengths of this study is its longitudinal design with a follow up of three years. Furthermore, we specified social support by type. Patients may need different types of support at different times post-stroke. If the course of different types of support is clarified further, interventions could be better targeted.

Limitations of the study

Firstly, our participants had a relatively high Barthel score and high MMSE score, suggesting a relatively moderately disabled study group. This may jeopardize generalization of the results to all stroke patients and their partners.

Secondly, we assumed a causal relationship between social support and depressive symptoms, but we cannot prove causality in this observational research. In the literature, the association between these variables has already been proven[4,5] and a 'protective effect' for developing post-stroke depressive symptoms has been suggested.[5,7]

Thirdly, a non-response analysis revealed that the non-responders differ in gender, hemisphere affected and educational level. However, in our statistical analyses we have also put these variables in each model to correct for the possible effect on the relationship between social support and depressive symptoms.

Fourthly, we performed linear regression analysis on the Social Support List-Interaction, which is a rating scale that has not yet undergone Rasch validation and transformation.

Finally, the study results should be interpreted with care beyond the Dutch culture and (in) formal care system.

Conclusion

Stroke survivors experienced a decline of social support, as a total scale and as divided in three subtypes, over time. Although we had expected stronger relationships, social support was related to post-stroke depressive symptoms. Social support in problem situations was a predictor of depressive symptoms over time, but not specifically in stroke survivors with disability. Above all, this study reveals that social support could not be seen as a one-dimensional factor due to the opposite coefficients of the support subscales in their relation with depressive symptoms.

Practice implications

Attention should be paid to improving and maintaining adequate social support for stroke survivors from the beginning of the inpatient rehabilitation process up to the chronic phase. Healthcare professionals should focus on the various subtypes of social support, especially support in problem situations when dealing with depressive symptoms, both in practical healthcare and in designing interventions to enhance social support.

Further research

Further research could be focused on developing interventions to strengthen social support networks and decreasing depressive symptoms post-stroke. Therefore, it is important to reveal which stroke survivors could maintain their social network and which are at risk for social isolation and unmet needs. In elderly people, it has already been suggested that interventions to reduce social isolation should have a theoretical basis and offer social activity and/or support within a group format.[24] Furthermore, interventions in which people are active participants also appeared to be effective.[24] It would be worth investigating these interventions in the stroke population.

As mentioned before, social support is a broad concept and various aspects should be taken into account when targeting interventions. The type of support needed may vary over time and the people who give support may also vary over time or by type of support.[10,11] Therefore, next to dividing social support by subtype, as in this study, dividing it by source (i.e. partner, relatives or friends) and timing may also be of benefit in targeting interventions for strengthening social networks and decreasing post-stroke depression.

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Appendix

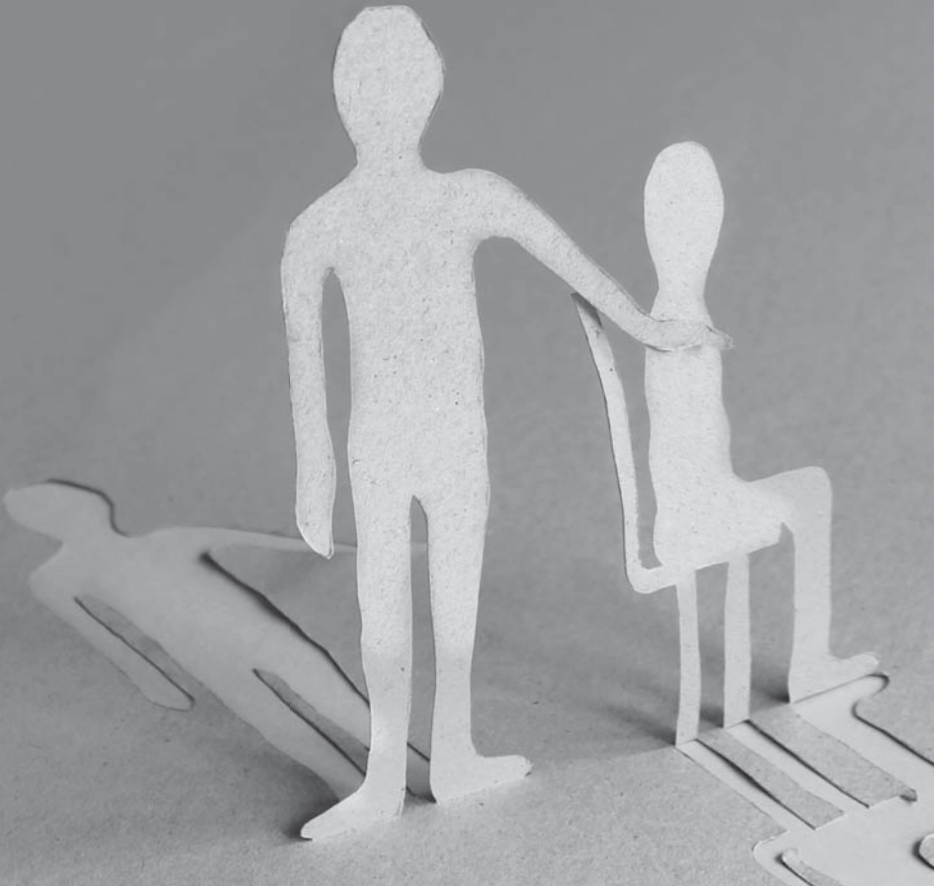
Appendix 3.1 SSL-12-I; Questions are arranged by subtypes

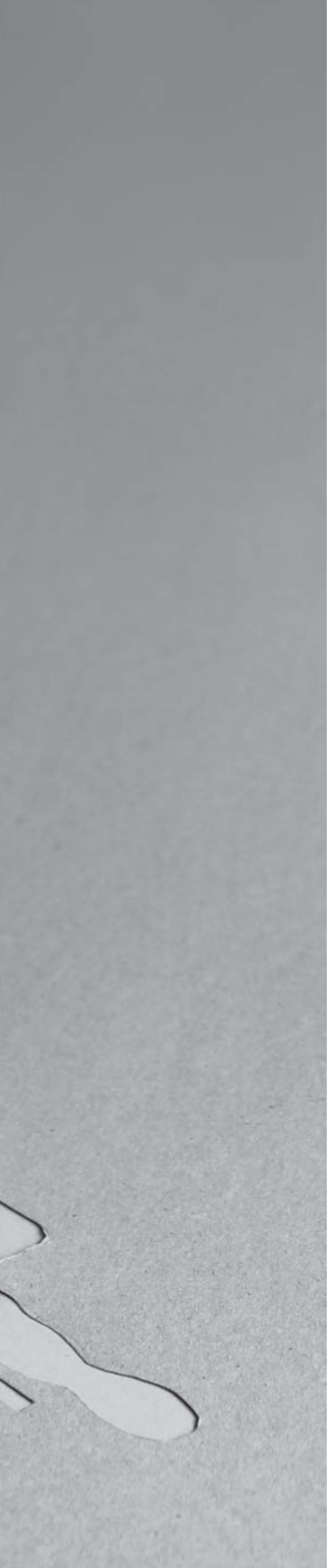
Dimensions of social support
Everyday social support Does it ever happen to you that people… - invite you to a party or to dinner? - drop in for a (pleasant) visit? - show you that they are fond of you? - just call you up or just chat to you?
Social support in problem situations Does it ever happen to you that people… - comfort you? - provide you with help in special circumstances such as illness or moving home? - reassure you? - give you good advice?
Esteem support Does it ever happen to you that people… - pay you a compliment? - confide in you? - ask you for help or advice? - emphasize your strong points?

Part II

The partner of the stroke patient

Chapter 4





Measuring negative and positive caregiving experiences: A psychometric analysis of the Caregiver Strain Index Expanded

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Abstract

Objective

To compare the psychometric properties of the Caregiver Strain Index Expanded with those of the original Caregiver Strain Index among partners of stroke patients.

Design and subjects

Cross-sectional validation study among 173 caregivers of stroke patients six months post-stroke.

Main measures

Outcome measure: Caregiver Strain Index Expanded. *Reference measures:* Hospital Anxiety and Depression Scale, two questions on life satisfaction, Barthel Index and Montreal Cognitive Assessment. Additionally, National Institutes of Health Stroke Scale.

Results

Neither the Caregiver Strain Index Expanded nor the original Caregiver Strain Index showed floor or ceiling effects. The sum score of the positive items showed a ceiling effect and was skewed to the right (2.20). Principal component analysis revealed no clear underlying item clustering. Alpha values of the Caregiver Strain Index Expanded and the original Caregiver Strain Index were good (.82 and .83), but the alpha value of the positive subscale of the Caregiver Strain Index Expanded was too low (.51). Convergent validity was confirmed for the Caregiver Strain Index Expanded, the original Caregiver Strain Index and the positive subscale. The Caregiver Strain Index Expanded and the original Caregiver Strain Index showed nearly identical correlations with the reference measures. Negative caregiving experiences were more strongly related to partners' mood and life satisfaction than positive caregiving experiences. In the regression analyses, the positive subscale showed little added value in predicting partners' mood and life satisfaction.

Conclusion

The addition of five positively phrased items does not improve the psychometric properties of the Caregiver Strain Index.

Introduction

Although most patients survive the acute phase of a stroke, many of them remain more or less physically or cognitively impaired and need help from professional and/or family caregivers to perform activities of daily living.[1,2] Caring for a family member takes time and physical and emotional effort and can be burdensome, resulting in feelings of depression[1-5] and a decreased quality of life.[2,6-8]

In recent years however, there is growing awareness of positive experiences associated with caregiving.[9-11] Research showed that negative and positive caregiving experiences can co-exist, and positive experiences can even compensate or buffer the negative effects of caregiving on life satisfaction.[11,12]

Several measurement instruments have been developed that include items on both negative and positive experiences of caregivers.[13-17] One of these is the Caregiver Strain Index Expanded, in which the original Caregiver Strain Index[18] is enlarged with five additional items to assess the positive aspects of caregiving (Appendix 4.1). The Caregiver Strain Index Expanded is a recently developed measure, which is potentially very relevant, as the Caregiver Strain Index[18] is the most frequently used questionnaire to measure caregiver burden. In stroke research, it has good reproducibility[20] and validity,[19,21] and it is recommended in the Dutch stroke care guidelines.[22-24] An initial validation study of the Caregiver Strain Index Expanded found good feasibility and validity for caregivers who applied for support.[17] Until now, however, the added value of the Caregiver Strain Index Expanded over the Caregiver Strain Index to assess caregiving experiences has not been established in caregivers of patients with stroke. We therefore tested the hypotheses that (a) the Caregiver Strain Index Expanded would also have good validity in the stroke population and (b) that the more comprehensive measurement of caregiving experiences would mean that the Caregiver Strain Index Expanded is more strongly correlated with reference measures of caregivers' mood and life satisfaction than the Caregiver Strain Index.

Methods

Participants

Participants in the current analysis were the partners of stroke patients included in the Restore4Stroke Cohort Study, who completed the Caregiver Strain Index Expanded at six months post-stroke.[25] Six general Dutch hospitals participated and stroke patients were recruited between March 2011 and March 2013. The patients were included in the study within seven days after suffering a clinically confirmed ischemic or intracerebral haemorrhagic stroke. Partners of these stroke patients were included if they were married to the patient or in a steady relationship with them. Exclusion criteria for patients and partners were: (1) age < 18 years, (2) having a serious other condition that could be expected to interfere with the study outcomes (e.g. neuromuscular disease), (3) pre-stroke dependency in activities of daily living (Barthel score of 17 or lower), and (4) having insufficient command of Dutch to understand and complete the questionnaires (based on clinical judgment). Patients were also excluded if they had shown symptoms of cognitive decline before their stroke, as assessed by the Heteroanamnesis List Cognition.[26] The study was approved by the Medical Ethics Committee of the Antonius Hospital Nieuwegein. Informed consent was given by all participating stroke patients and their partners.

Data collected at baseline and at six months post-stroke were analysed for the present study. The observational measurement instruments were administered by a research assistant who visited the stroke patients at home or at the institution in which they were residing at that moment. Partners completed their questionnaires either online or in paper/pencil format.

Measures

At the first assessment, the demographic characteristics of the patient and their partner were documented, as well as the patient's stroke characteristics and functioning. The other variables used in the current study were collected at six months post-stroke.

Measurements for the partner

Negative and positive caregiving experiences of the partner were assessed using the Caregiver Strain Index Expanded.[17] This questionnaire comprises 18 items, 13 items measuring the caregiver's negative subjective care burden (the original Caregiver Strain Index) and five items measuring positive experiences (referred to as the 'positive subscale of the Caregiver Strain Index Expanded'). Each negative item rated as present adds 1 point to the total score, whereas each positive item rated as present is scored as -1, so subtracts 1 point from the total score. The developers of the Caregiver Strain Index Expanded did not propose a separate positive subscale, but the current study explored the possibility of using the sum score of the positive items as a separate score. The positive subscale ranges from -5 to 0, with the lowest possible score of -5 representing the best possible score (many positive experiences).

A score of 7 or more on the original Caregiver Strain Index indicates a high level of caregiver burden. A cut-off point for the Caregiver Strain Index Expanded has not yet been defined.

Mood was assessed by the Hospital Anxiety and Depression scale,[27] which has good psychometric properties[28] and is commonly used for the stroke population.[29]

Life satisfaction was assessed with two items.[30] The first item measures current life satisfaction on a 6-point scale ranging from 1 ('very dissatisfied') to 6 ('very satisfied'). The second item asks participants to compare their current life satisfaction with their pre-stroke life satisfaction on a 7-point scale ranging from 1 ('much worse') to 7 ('much better'). A total life satisfaction score was computed by summing the two scores. This life satisfaction questionnaire has shown good validity in a population with spinal cord injury.[30]

Measurements for the patient

Stroke severity at baseline was measured using the National Institutes of Health Stroke Scale.[31]

The Barthel Index[32,33] was used to assess the patients' independence in activities of daily living, ranging from 0 ('total dependence') to 20 ('total independence'). This instrument has been identified as valid and reliable.[32,34]

The Montreal Cognitive Assessment was used as a cognitive screening test, and is known to have good sensitivity and specificity.[35,36]

Statistical analyses

Data were analysed using SPPS version 19.0 for Windows (IBM Corporation, Armonk, NY, USA).

The score distributions of the Caregiver Strain Index Expanded (including the original Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded), Hospital Anxiety and Depression scale and life satisfaction were recorded. Skewness was considered to be present if the skewness value was below -1.0 or above 1.0. Floor and ceiling effects were considered to be present if at least 15% of the participants achieved the worst or the best score, respectively.

Construct validity was evaluated by means of a principal component analysis with Oblimin rotation, and internal consistency was assessed. We also used principal component analysis to explore any underlying clustering of items. The number of factors was identified on the basis of eigenvalues above 1.0, visual inspection of the scree plot and Parallel Analysis with corresponding criterion values for a randomly generated data matrix of the same size (18 items x 173 participants). After the subscales had been established, internal consistency was calculated for each subscale and the total score using Cronbach's α coefficient, with and without reverse scoring of the five positive items. Internal consistency was considered acceptable if Cronbach's α was between .70 and .95.[37]

Convergent validity of the Caregiver Strain Index Expanded was examined by calculating Spearman correlations between the Caregiver Strain Index Expanded, the original Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded on the one hand and the measures of partners' mood and life satisfaction and the stroke patients' physical and cognitive functioning on the other. We tested the following four hypotheses:

- Caregiver Strain Index Expanded and Caregiver Strain Index: (1) a moderate positive correlation with partners' mood score and (2) moderate negative correlations with the patients' physical and (3) cognitive functioning and (4) the partners' life satisfaction scores.
- Positive subscale of the Caregiver Strain Index Expanded: (1) a moderate positive correlation with partners' mood score and (2) a moderate negative correlation with life satisfaction scores, but weak or no correlations with patients' (3) physical and (4) cognitive functioning.

If at least 75% of these four hypotheses were confirmed for each scale, that scale was considered to have convergent validity.[37]

We further hypothesized that all four associations between partner burden and partner outcomes would be significantly stronger for the Caregiver Strain Index Expanded than for the Caregiver Strain Index. The difference between the correlations was tested using an online tool (http://vassarstats.net/index.html).

Finally, linear regression analyses were performed to explore the individual and combined effects of the Caregiver Strain Index Expanded, the Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded on partners' mood and life satisfaction. $P < .05$ was considered statistically significant.

Results

A total of 395 stroke patients and 196 partners participated in the Restore4Stroke study. At six months post-stroke, 173 partners (88.3%) completed the Caregiver Strain Index Expanded and were included in the present analyses. Table 4.1 presents the demographic and stroke characteristics of the participants at baseline and at six months post-stroke. Relatively few patients were dependent in activities of daily living, but about half showed cognitive dysfunction.

For each positive item, more than four out of five partners responded affirmatively (Table 4.2). The mean score of the Caregiver Strain Index Expanded was -0.46, showing that positive caregiving experiences slightly outweighed caregiver burden (Table 4.3). No less

Table 4.1 Participants' characteristics (n = 173)

Partner characteristics	
Age, mean (SD)	62.1 (11.0)
Female gender, n (%)	136 (78.6)
Educational level (higher education)*, n (%)	48 (29.8)
Pre-stroke working status, n (%) employment ≥ 24 hours/wk	42 (25.0)
Outcome variables six months post-stroke	
Caregiver Strain Index Expanded, mean (SD)	-0.46 (3.6)
Caregiver Strain Index, mean (SD), n (%) high burden (≥ 7)	4.06 (3.2), 40 (23.2)
Positive subscale of the Caregiver Strain Index Expanded, mean (SD)	-4.52 (0.9)
Life satisfaction, mean (SD)	8.15 (1.8)
Hospital Anxiety and Depression scale score, mean (SD), n (%) many symptoms (≥ 11)	7.72 (6.4), 53 (30.6)
Patient characteristics	
Age, mean (SD)	64.0 (11.3)
Female gender, n (%)	36 (20.8)
Infarction, n (%)	164 (94.8)
Right hemisphere affected, n (%)	68 (39.5)
National Institutes of Health Stroke Scale score at baseline, mean (SD)	2.69 (3.2)
Barthel Index at baseline, mean (SD), n (%) dependent (≤ 18)	17.24 (4.6), 63 (36.4)
Barthel Index at six months, mean (SD), n (%) dependent (≤ 18)	19.44 (1.8), 19 (11.0)
Montreal Cognitive Assessment score at six months, mean (SD), n (%) dysfunction (≤ 25)	24.91 (3.3), 87 (51.5)
Post-acute inpatient rehabilitation post-stroke, n (%) yes	36 (20.8)
Living at home at six months post-stroke, n (%) yes	169 (97.7)

Abbreviations: SD, standard deviation, n, number.
* Senior secondary education, university preparatory education, higher secondary professional education, and university education.

Table 4.2 Item response distribution of the Caregiver Strain Index Expanded six months post-stroke (n = 173)

		n (%) yes
Item 18	**Care is important**	**160 (92.5)**
Item 14	**Happy to care**	**157 (90.8)**
Item 3	**Recipient appreciates care**	**156 (90.2)**
Item 11	**Handle the care fine**	**155 (89.6)**
Item 6	**Enough time for oneself**	**153 (88.4)**
Item 9	Other demands on time	118 (68.2)
Item 7	Family adjustments	91 (52.6)
Item 8	Changes in personal plans	88 (50.9)
Item 12	Behaviour upsetting	71 (41.0)
Item 10	Emotional adjustments	69 (39.9)
Item 13	Recipient's change upsetting	58 (33.5)
Item 5	Confining	51 (29.5)
Item 1	Sleep disturbed	38 (22.0)
Item 17	Financial strain	34 (19.7)
Item 4	Physical strain	26 (15.0)
Item 16	Feeling completely overwhelmed	21 (12.1)
Item 2	Inconvenient	20 (11.6)
Item 15	Work adjustments	17 (9.8)

Abbreviations: n, number. Positive items in bold.

Table 4.3 Score distributions of the Caregiver Strain Index Expanded (n = 173)

	Caregiver Strain Index Expanded	Caregiver Strain Index (original)	Positive subscale of the Caregiver Strain Index Expanded
Items	18	13	5
Range of scale	-5 – 13	0 – 13	-5 – 0
Mean score (SD)	-0.46 (3.6)	4.06 (3.2)	-4.52 (0.9)
Range of scores	-5 – 13	0 – 13	-5 – 0
Median	-1.0	3.0	-5.0
IQR	5.0	5.0	1.0
Skewness (SE)	0.92 (0.2)	0.64 (0.2)	2.21 (0.2)
Kurtosis (SE)	0.76 (0.4)	-0.34 (0.4)	5.87 (0.4)
% with worst score	0.6	1.2	0.6
% with best score	9.8	12.7	68.2
Cronbach's α	.82	.83	.51

Abbreviations: SD, standard deviation; IQR, interquartile range; SE, standard error.

than two-thirds of all partners responded affirmatively to all five positive items, resulting in a large ceiling effect. Skewness values of the Caregiver Strain Index Expanded and the original Caregiver Strain Index were acceptable, and no floor or ceiling effects were detected.

The data for the Caregiver Strain Index Expanded satisfied the assumptions for principal component analysis with a Kaiser-Meyer-Olkin Measure value of .782, a significant Bartlett's Test of Sphericity, and inter-item correlation coefficients of ≥ .30.

Principal component analysis of the total scale revealed the presence of six components with eigenvalues exceeding 1.0, together explaining 63.1% of the total variance. Inspection of the Scree Plot suggested no clear break. Parallel analysis showed only three components with eigenvalues exceeding the corresponding criterion values. Hence, three components were retained for further analysis. Table 4.4 presents the pattern matrix. The three-component solution explained a total of 44.2% of the variance. Since this analysis did not reveal clear components, the principal component analysis was repeated separately for the original Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded. These results are also presented in Table 4.4. The Kaiser-Meyer-Olkin Measure values of the Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded were .825 and .571, respectively, showing that the positive subscale did not exceed the recommended value of .60. Both the Caregiver Strain Index and the positive subscale included two components in the final analysis, explaining 44.5% and 58.4% of the total variance, respectively.

Cronbach's alpha of the Caregiver Strain Index Expanded was good, with .73 in the original form and .82 with reversed positive items. The alpha value of the Caregiver Strain Index was .83, also indicating good internal consistency. The internal consistency of the positive subscale of the Caregiver Strain Index Expanded was unacceptable, however, with a value of .51.

The results of the convergent validity analyses are shown in Table 4.5. There were no significant differences between the correlation coefficients of the Caregiver Strain Index Expanded with partners' mood and life satisfaction and those of the Caregiver Strain Index with partners' mood and life satisfaction ($p > .05$). All hypotheses regarding the correlations between the Caregiver Strain Index Expanded, Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded on the one hand and partners' mood and life satisfaction scores and stroke patients' physical and cognitive functioning on the other were confirmed, showing convergent validity.

Table 4.4 Principal component analyses of the Caregiver Strain Index Expanded (n = 173)

		Component Pattern Matrix Caregiver Strain Index Expanded			Component Pattern Caregiver Strain Index (original)		Component Pattern Positive subscale of the Caregiver Strain Index Expanded	
		Component 1	Component 2	Component 3	Component 1	Component 2	Component 1	Component 2
Item 18	**Care is important**	-.02	.81	-.13			.82	.05
Item 14	**Happy to care**	-.05	.83	-.13			.85	-.09
Item 3	**Recipient appreciates care**	.05	.45	.06			.49	.04
Item 11	**Handling the care fine**	.06	.34	.47			.18	.70
Item 6	**Enough time for oneself**	.10	-.02	.59			-.14	.85
Item 9	Other demands on time	.54	.12	.06	-.05	-.58		
Item 7	Family adjustments	.87	.10	.10	.06	-.81		
Item 8	Changes in personal plans	.86	.01	.14	.03	-.82		
Item 12	Behaviour upsetting	.47	-.14	-.25	.58	-.18		
Item 10	Emotional adjustments	.32	-.19	-.28	.57	-.05		
Item 13	Recipient's change upsetting	.53	-.09	-.26	.56	-.25		
Item 5	Confining	.57	-.14	-.04	.11	-.59		
Item 1	Sleep disturbed	.31	-.02	-.43	.47	-.25		
Item 17	Financial strain	.33	-.17	-.23	.55	-.05		
Item 4	Physical strain	.01	.01	-.76	.78	.15		
Item 16	Feeling completely overwhelmed	.12	-.26	-.61	.64	-.06		
Item 2	Inconvenient	.01	.25	-.71	.77	.26		
Item 15	Work adjustments	.23	.13	-.34	.33	-.16		

The pattern matrix shows the regression coefficients for each Caregiver Strain Index Expanded item on each factor, with grey boxes indicating loadings > .4. The positive items are shown in bold.

Table 4.5 Convergent validity (n = 173)

	Caregiver Strain Index Expanded	Caregiver Strain Index (original)	Positive subscale of the Caregiver Strain Index Expanded
Partner			
Mood	.60**	.58**	.27**
Life satisfaction	-.60**	-.58**	-.28**
Patient			
Dependency in activities of daily living	-.24**	-.26**	-.01
Cognitive impairments	-.09	-.10	-.05

Regression coefficients calculated by Spearman correlations.
** $p < .01$.

As can be seen from Table 4.6, regression analyses showed no additional value of the positive items: the Caregiver Strain Index Expanded explained about the same percentage of the variance of partners' mood and life satisfaction as the Caregiver Strain Index, and even entering the Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded as separate determinants in the analysis did not increase the percentage of explained variance.

Discussion

The Caregiver Strain Index Expanded and the original Caregiver Strain index showed no floor or ceiling effects. However, the positive subscale of the Caregiver Strain Index Expanded showed a ceiling effect and was skewed to the right. In contrast to the study by Al-Janabi,[17] our principal component analysis revealed no clear underlying clustering of items. The internal consistency of the Caregiver Strain Index Expanded and the Caregiver Strain Index was good, but it was unacceptable for the positive subscale. Convergent validity was confirmed for the Caregiver Strain Index Expanded and the Caregiver Strain Index. However, the addition of positive items to the Caregiver Strain Index did not increase its convergent validity.

Apart from the study by Al-Janabi, no other studies have evaluated the Caregiver Strain Index Expanded.[17] In comparison to Al-Janabi, our study showed a different item response distribution, the percentages of affirmative answers on the negative items being substantially lower in our study population. Furthermore, all positive items except 'care is important' were more often endorsed in our study. This suggests that our study population had less negative caregiving experiences and more positive caregiving experiences.

Table 4.6 Linear regression analyses of the Caregiver Strain Index Expanded at six months post-stroke (n = 173)

	Partners' mood			Partners' life satisfaction		
	Standardized coefficients	P-value	R-square	Standardized coefficients	P-value	R-square
Univariate linear regression						
Caregiver Strain Index Expanded	.60	.000	.36	-.58	.000	.34
Caregiver Strain Index	.61	.000	.37	-.56	.000	.32
Positive subscale of the Caregiver Strain Index Expanded	.25	.001	.06	-.31	.000	.10
Multiple linear regression						
Caregiver Strain Index Expanded	.59	.000	.37	-.52	.000	.34
Positive subscale of the Caregiver Strain Index Expanded	.05	.418		-.14	.038	

Mood was measured with the Hospital Anxiety and Depression Scale.

The component analyses in both Al-Janabi's study and ours revealed three components. The three positive items 'recipient appreciates care', 'happy to care', and 'care is important' were included in one component in both analyses. However, the distribution over the two other components differed between the two studies.

The strengths of the correlations of the Caregiver Strain Index with the reference measures in this study are in line with the literature.[19] However, the positive subscale added little value to the Caregiver Strain Index. Several explanations can be suggested. First, the positive subscale consists of only five positive items with dichotomized scores, resulting in only six total score levels. This restricts the opportunity to identify variability of caregiver experiences. Other instruments scoring positive caregiving experiences, like the Caregiver Reaction Assessment or the Sense of Competence Questionnaire, use 5-point Likert scales.[15,16] Second, our study population was an average stroke hospital population and consisted of mildly affected stroke patients and their partners. The study population examined by Al-Janabi included caregivers who had applied for support by informal care centres or the Dutch association of personal care budget holders,[17] resulting in a study population with more negative experiences and more variety in terms of positive experiences. Finally, social desirability bias, in which participants tend to answer questions in a manner that will be regarded favourably by others, could have occurred. However, most questionnaires were self-administered.

We found a weak correlation between caregiving experiences and patients' cognition and independence in activities of daily living, which has also been reported in previous studies.[11,38] Apparently, there is no linear association between the amount of care given to a stroke patient and the experienced negative and positive impact of caregiving.

The positively phrased items of the Caregiver Strain Index Expanded showed little added value over the Caregiver Strain Index. Nonetheless, positive caregiving experiences are clinically important.[11] Two options to measure positive caregiving experiences could be considered: (1) improving the Caregiver Strain Index Expanded, either by adding more positive items or by adding more answer categories, for example a 5-item Likert scale ranging from completely disagree to completely agree, or (2) using a different questionnaire to measure positive caregiving experiences. Candidates would be the Caregiver Reaction Assessment or the Sense of Competence Questionnaire, although these questionnaires also have limitations (e.g. moderate reliability and reproducibility of the Caregiver Reaction Assessment and less focus on positive aspects in the Sense of Competence Questionnaire).[19,20]

Focusing on negative and positive consequences of caring for a stroke patient is important, and this study has explored the validity of the brief and easily administered Caregiver Strain Index Expanded, which measures both negative and positive caregiving aspects.

Nevertheless, some limitations should be considered. We investigated some aspects of the psychometric properties of the Caregiver Strain Index Expanded, but did not assess its test-retest reliability or responsiveness. A second limitation is that the participants were selected from a Dutch stroke population admitted to a general hospital, and inclusion took place within seven days post-stroke. The most seriously affected patients might not have been able to give their informed consent in the first week post-stroke, and this may make it difficult to generalize the results to all stroke patients and their partners.

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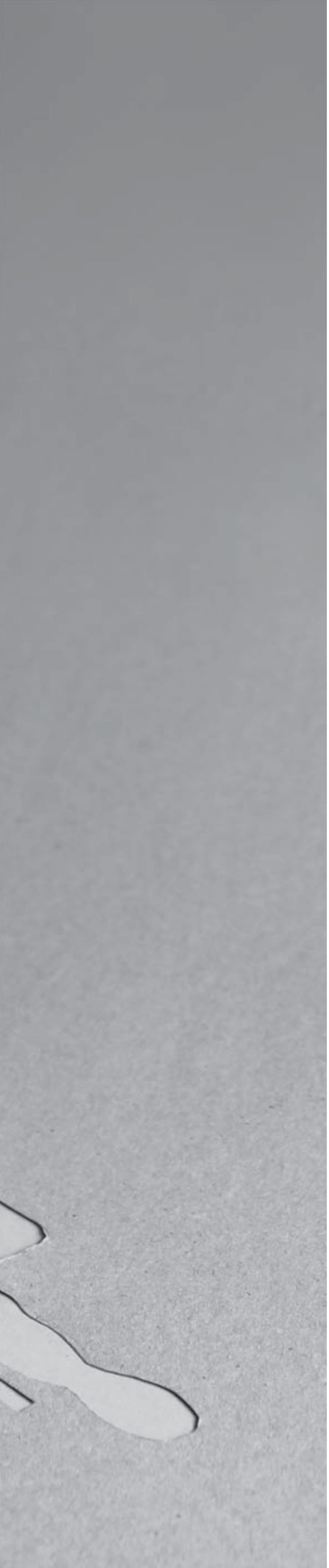
Appendix

Appendix 4.1 The Caregiver Strain Index Expanded

		Yes	No
1.	Sleep is disturbed (e.g. because ____ is in and out of bed or wanders around at night)		
2.	It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)		
3.	The ____ appreciates everything I do for him/her		
4.	It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)		
5.	It is confining (e.g. because helping restricts free time or cannot go visiting)		
6.	Besides the care I provide to ____ I have enough time for myself		
7.	There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)		
8.	There have been changes in personal plans (e.g. because had to turn down a job; could not go on vacation)		
9.	There have been other demands on my time (e.g. from other family members)		
10.	There have been emotional adjustments (e.g. because of severe arguments)		
11.	I can handle the care for ____ fine		
12.	Some behaviour is upsetting (e.g. because of incontinence; ____ has trouble remembering things; concerns about how you will manage)		
13.	It is upsetting to find ____ has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)		
14.	I am happy to care for ____		
15.	There have been work adjustments (e.g. because of having to take time off)		
16.	Feeling completely overwhelmed (e.g. because of worry about ____; concerns about how you will manage)		
17.	It is a financial strain		
18.	Taking care for ____ is important to me		

Chapter 5



Positive caregiving experiences are associated with life satisfaction in spouses of stroke survivors

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J Stroke Cerebrovasc Dis. 2012; 21: 801-807

Abstract

Background

Studies into caregivers usually have been focused on negative caregiving experiences. This study is based on the hypotheses that positive caregiving experiences (i.e., self-esteem derived from caregiving) of spouses of stroke patients also need to be taken into account, and that these are related to life satisfaction in two ways: first, by a direct association with life satisfaction, and second, indirectly by way of a buffer effect (i.e., by compensating for the impact of negative caregiving experiences on life satisfaction).

Methods

In this cross-sectional study (n = 121) three years post-stroke, the Caregiver Reaction Assessment was used to assess caregiver burden (Burden) and self-esteem derived from caregiving (Self-esteem scale). Life satisfaction was measured with the Life Satisfaction Questionnaire (LiSat-9). Spearman correlations and regression analyses were performed.

Results

Both Self-esteem and Burden scores were associated with life satisfaction (correlation coefficients .35 and -.74, respectively). An interaction effect was also found (p = .006); spouses who perceived both high Burden and high Self-esteem reported significantly higher life satisfaction scores (mean 4.2, SD 0.5) than spouses who perceived high Burden but low Self-esteem (mean 3.6, SD 0.7).

Conclusions

Positive caregiving experiences are related with spouses' life satisfaction three years post-stroke and mediate the impact of burden on life satisfaction. Positive caregiving experiences should get more attention in rehabilitation research and practice.

Introduction

Stroke is a leading cause of disability in the Western world. The burden of stroke is expected to increase considerably as a consequence of our rapidly ageing population and the better survival rates in the acute phase. A scenario analysis in the Netherlands revealed that demographic changes will result in an increase of 28% in the prevalence of stroke between 2000 and 2020 – that is, > 150,000 people in 2020.[1]

Most patients survive the acute phase of the stroke, but many survivors remain more or less physically or cognitively disabled and need support from formal or informal caregivers. Consequently, stroke affects not only the patients but also their family members.[2] Caring for a stroke patient has been linked to higher rates of depression[3-6] and a decreased quality of life.[6-8] A poorer self-rated physical health has also been reported, although a recent review suggests that informal caregiving does not necessarily result in reduced physical health.[9]

Although most studies have focused on negative caregiving experiences, positive caregiving experiences have also been reported.[10-15] Positive experiences can be described in several ways, such as self-esteem, positive aspects, rewards, benefits, uplifts, gains and satisfaction.[10,11] The influence of positive caregiving experiences in spouses of stroke patients has rarely been examined.[16-18] In nonstroke studies, it has been suggested that almost half of the caregivers derive positive utility from caring and that their happiness would even decline if someone else would take over their informal care tasks.[19] Caregivers' positive caregiving experiences were related to better caregivers' mental and physical health[13] and higher quality of life.[15] The importance of positive caregiving experiences might look obvious, but research on caregivers of stroke patients has almost exclusively focused on negative caregiving experiences,[4] and, consequently, clinical practice guidelines pay little or no attention to enhancing positive caregiving experiences.[20]

As was shown for social support,[21,22] positive caregiving experiences might influence spouses' life satisfaction in two different ways: first, by a direct association with life satisfaction and second, indirectly, by compensating for the impact of negative caregiving experiences on life satisfaction (also known as the buffer effect). The first aim of this study was to describe the direct associations between both positive and negative caregiving experiences in spouses of chronic stroke patients and spouses' life satisfaction. The second aim of this study was to investigate the existence of an indirect or buffer effect. The hypothesis is that if caregivers experience many negative caregiving experiences but also many positive caregiving experiences, their life satisfaction will be higher than if caregivers experience many negative caregiving experiences and few positive caregiving experiences.

Methods

Subjects

Subjects were the spouses of stroke patients included in the Functional Prognosis after Stroke (FuPro-stroke) study.[6] All stroke patients had been admitted to the participating Dutch rehabilitation centres between April 2000 and July 2002. Inclusion criteria for patients were: first-ever stroke, a one-sided supratentorial lesion and age ≥ 18 years. Exclusion criteria for patients were: disabling comorbidity (pre-stroke Barthel Index < 18) and/or inability to speak Dutch. Exclusion criteria for spouses were: Barthel Index below 16 and/or very serious progressive illness. The study was approved by the medical ethics committee of the University Medical Centre Utrecht and the participating rehabilitation centres. Informed consent was given by all participating patients and spouses.

Procedure

At the start of inpatient rehabilitation, patients and spouses were invited by their rehabilitation specialists to participate in the study. The first assessment was conducted as soon as possible after informed consent was given. Other assessments followed until three years post-stroke. The present analyses focused on data at three years after patients' stroke, when all patients and spouses were assessed at home.

Measures

Stroke characteristics were obtained from medical charts. At three years post-stroke, cognition and physical disability were assessed using the Mini Mental State Examination (MMSE) and the Barthel Index. The MMSE is a screening test with good validity and reliability.[23] However, only communicative patients can complete this test. Cognition was therefore dichotomized; patients were scored as cognitively impaired if the MMSE score was ≤ 23 points or if they were not able to complete this test because of an inability to communicate. Independence in activities of daily living (ADL) was assessed using the Barthel Index, and patients were scored as dependent if the Barthel Index score was ≤ 18.[24]

In spouses, the first assessment documented data on age, gender, education level, employment status, and having children ≤ 18 years of age.

At three years post-stroke, depressive symptoms, prevalent health problems and new caregiving tasks were assessed. Depressive symptoms were measured using the Goldberg Depression Scale.[25] This brief scale consists of 9 items with yes or no answers, in which the last five items need to be administered only when there are positive answers to the first four. The total score ranges from 0 ('no depressive symptoms') to 9 ('high chance of having clinically important depressive symptoms').

To describe caregivers' perceived health, spouses were asked to rank their own health on a scale ranging from 1 ('poor') to 5 ('excellent').

The 16-item Care Task List was used to determine objective burden.[26] Every positive answer indicates a new caregiving task post-stroke. A higher score demonstrates more caregiver load.

The Caregiver Reaction Assessment (CRA) was used to measure positive and negative caregiving experiences. The CRA is one of the few instruments with which both positive and negative experiences can be assessed,[11,27] and is considered a valid, feasible and reliable instrument.[11,28] It consists of 24 items in four subscales measuring negative caregiving experiences: Disrupted schedule (5 items), Financial problems (3 items), Lack of family support (5 items), and Health problems (4 items), and one subscale measuring positive caregiving experiences called Self-esteem (7 items). Each item is scored on a 5-point Likert scale ('completely disagree' to 'completely agree'). All subscales scores are the average of the item scores, ranging from 1 to 5. A high score on Self-esteem indicates that the caregiver derives more positive experiences from caregiving. High scores on the negative subscales indicate more negative caregiving experiences. To simplify the analyses, the four negative subscales (Disrupted schedule, Financial problems, Lack of family support and Health problems) were merged into one scale of negative caregiving experiences, further called Burden. The internal consistency of this scale was high (Cronbach's alpha .89).

Spouses' life satisfaction was rated with the Life Satisfaction Questionnaire (LiSat-9).[8,29] The LiSat-9 consists of 1 item about satisfaction with 'life as a whole' and 8 items about satisfaction with life domains. LiSat-9 item scores range from 1 ('very dissatisfying') to 6 ('very satisfying'). To interpret individual item scores, a score of ≤ 4 was considered as 'dissatisfied' and a score of ≥ 5 as 'satisfied'.[29] In addition, a LiSat-9 total score was computed as the average of all nine items.[5,30] This score showed good internal consistency reliability in the current study (Cronbach's alpha .83).

Statistical analyses

Spearman correlations were calculated to evaluate the bivariate relationships between the CRA subscales, LiSat-9, and patients' and spouses' characteristics. Patients' age and gender were not analysed because of their strong correlations to spouses' age and gender.

The spouses were categorized into four groups to illustrate the relationships between Burden, Self-esteem, their interaction, and spouses' life satisfaction. Using the median score as cut-off, the Burden and Self-esteem scores were dichotomized into conditions of high or low Self-esteem and high or low Burden.

Finally, a multiple linear regression was performed to identify the combined effect of all the variables on caregivers' life satisfaction. Patients' characteristics, spouses' characteristics, and the Burden and Self-esteem scores were entered as independent variables in a stepwise backward regression model if they were bivariately associated with life satisfaction ($p < .2$). The Burden and Self-esteem scores were centred to obtain a valid interaction term. P-values $< .05$ were considered statistically significant. All statistical analyses were conducted with SPSS (Version 16.0; SPSS Inc, Chicago, IL).

Results

At the start of the study, 211 couples of patient and spouse were included. During the follow-up period until three years post-stroke, 15 patients and 2 spouses died, and 33 patients had a recurrent stroke or other serious disabling disease and were therefore excluded from the FuPro-Stroke study. In addition, 8 couples were divorced, 18 spouses refused further participation, and 14 spouses were lost to follow-up. This resulted in a study population of 121 spouses still participating three years post-stroke.

Patient and spouses characteristics

The patient and spouses characteristics are shown in Table 5.1. Only 6% of the caregivers received professional home care. Other resources were children (54%), neighbours/acquaintance (28%), family other than children (29%), general practitioner (25%), self-paid domestic help (24%) or social worker (16%).

Caregiving experiences and life satisfaction

Descriptive statistics of caregiving experiences at three years post-stroke are presented in Table 5.1. The negative CRA subscales showed largely comparable mean values. The mean score of the subscale Self-esteem was higher, indicating a relatively high level of positive caregiving experiences.

Table 5.1 Characteristics of stroke patients and their spouses, three years post-stroke (n = 121)

Patients	
Demographic characteristics	
Age, mean (SD)	54.7 (10.0)
Female gender, %	40
Stroke characteristics	
Type of stroke (infarction), %	68.7
Hemisphere (right), %	41.5
Cognitive impairment (present)§, %	21
Dependent in activities of daily livingµ, %	43
Spouses	
Age, mean (SD)	53.4 (9.5)
Female gender, %	60
Education level (higher education)†, %	27.5
Employment ≥ 20 hours/week, %	45
Family with children ≤ 18 years old, %	27.5
Health (good or excellent), %	79.3
Depressive symptoms (≥ 1), %	49.2
New caregiving tasks, mean (SD)	6.1 (4.5)
Caregiver reaction assessment (CRA)	
Disrupted schedule, mean (SD)	2.8 (1.1)
Financial problems, mean (SD)	2.6 (0.8)
Lack of family support, mean (SD)	2.6 (0.8)
Health problems, mean (SD)	2.6 (0.9)
Self-esteem, mean (SD)	3.9 (0.6)
Burden, mean (SD)	2.7 (0.7)
Spouses' life satisfaction	
LiSat-9, mean (SD)	4.4 (0.8)

Abbreviations: SD standard deviation; CRA, Caregiver Reaction Assessment; Burden, negative caregiving experiences (all negative CRA subscales were added up to one scale); Self-esteem, positive caregiving experiences.

Note: On CRA Self-esteem and LiSat-9, higher score is favourable; on other subscales of CRA, a lower score is favourable. † Senior secondary education, university preparatory education, higher professional education and university. § Mini Mental Status Examination ≤ 23 or not completed because of communication problems. µ Barthel Index ≤ 18.

The mean life satisfaction score was 4.4, which is between 'rather satisfied' and 'satisfied' (Table 5.1). Almost half of the spouses (48.8%) were satisfied with 'their life as a whole'. Satisfaction was lowest for 'sexual life' (28%), and highest for 'family life' (72.9%) and 'self-care ability' (85%).

Relationships between CRA subscales

Table 5.2 shows the correlations between the CRA subscales. Most correlations were significant, except for the correlations between Self-esteem and Disrupted schedule, and Self-esteem and Lack of family support. The CRA Self-esteem score was negatively correlated with the other subscales. The subscales Disrupted schedule and Health problems showed the strongest correlations with the total Burden scale (Table 5.2).

Table 5.2 Correlation coefficients between Caregiver Reaction Assessment subscales

CRA subscales	Disrupted schedule	Financial problems	Lack of family support	Health problems	Self-esteem	Burden
Disrupted schedule	1.00	.40**	.42**	.76**	-.10	.88**
Financial problems	-	1.00	.25**	.44**	-.25**	.58**
Lack of family support	-	-	1.00	.46**	-.17	.70**
Health problems	-	-	-	1.00	-.30**	.86**
Self-esteem	-	-	-	-	1.00	-.24**
Burden	-	-	-	-	-	1.00

Abbreviations: CRA, Caregiver Reaction Assessment; Burden, negative caregiving experiences (all negative CRA subscales were added up to one scale); Self-esteem, positive caregiving experiences. Spearman rho was used, and significance was two-tailed: ** p < .01.

Relationships between patients' and spouses' characteristics, caregiver experiences and life satisfaction

Correlations between patients' and spouses' characteristics with spouses' caregiver experiences and life satisfaction are displayed in Table 5.3. The Self-esteem score was not significantly related with any patients' or caregivers' characteristics. A high Burden score was significantly related with lower Barthel Index scores, cognitive impairments, worse spouses' perceived health and more newly obtained tasks. Higher Burden was strongly related to lower caregivers' life satisfaction. Higher life satisfaction was significantly related

Table 5.3 Correlation coefficients between patients' and spouses' variables with caregiving experiences and life satisfaction

	Self-esteem	Burden	Life satisfaction
Patients			
Cognitive impairment	.00	.25**	-.22*
Barthel Index	.03	-.33**	.23*
Spouses			
Age	-.05	-.01	.17
Gender	.01	-.09	.12
Education level	-.04	.08	-.22*
Employment ≥ 20 hours/week	.05	-.09	-.00
Family with children ≤ 18 years	-.10	.06	-.12
Health	.17	-.49**	.41**
New caregiving tasks	.01	.57**	-.46**
Spouses' life satisfaction	.35**	-.74**	1.00

Abbreviations: CRA, Caregiver Reaction Assessment; Burden, negative caregiving experiences (all negative CRA subscales were added up to one scale); Self-esteem, positive caregiving experiences. Spearman rho was used, and significance was two-tailed: * p < .05, ** p < .01.

with higher Barthel Index scores, higher MMSE scores, lower spouses' education level, better spouses' perceived health and fewer newly obtained caregiving tasks. Both the Burden and Self-esteem scores were significantly associated with life satisfaction, although Burden was more strongly associated with life satisfaction than the Self-esteem score was.

The interrelationships between Burden, Self-esteem and life satisfaction are shown in Figure 5.1. This figure shows that in the condition of low Burden, life satisfaction scores of spouses who reported high on the Self-esteem subscale were similar to those of spouses who reported low on the Self-esteem subscale (both LiSat-9 scores 4.9, SD 0.5). In the condition of high Burden, however, spouses who reported high on Self-esteem reported higher life satisfaction (LiSat-9 score 4.2, SD 0.5) than spouses who low on Self-esteem (LiSat-9 score 3.6, SD 0.7).

For multivariate regression analyses, the variables employment status, and having children ≤ 18 years were not selected because of a p-value > .2 (Table 5.4). Two patient variables, five spouse variables and the two caregiving experiences determinants were entered for stepwise backward regression analyses. The final regression model showed Burden to be the strongest predictor for spouses' life satisfaction. In addition, a significant interaction between Self-esteem and Burden with life satisfaction (p = .006) was present. The other significant predictors of life satisfaction were all spouses' characteristics: age, education level, health

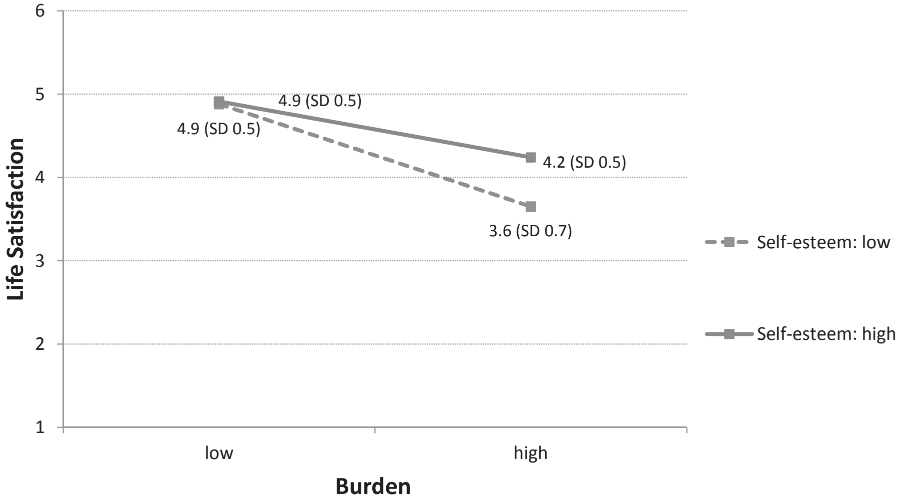

Figure 5.1 Indirect (buffer) relationship between life satisfaction and caregiving experiences.†
† Self-esteem and Burden, respectively positive and negative caregiving experiences, were dichotomized according to the median score on each scale. Low Self-esteem/Burden scores are scores below their median score, high Self-esteem/Burden indicate scores above the median score.

Table 5.4 Multivariate linear regression for the direct and indirect relationship between life satisfaction and caregiving experiences

Characteristics	Coefficients Beta-value	p-value
Patients		
Cognitive impairment	Dropped	
Barthel Index	Dropped	
Spouses		
Age	.12	.042
Gender	Dropped	
Education level	-.13	.045
Employment ≥ 20 hours/week	Not selected	
Family with children ≤ 18 years	Not selected	
Health	.18	.013
New caregiving tasks	-.13	.087
Measuring instruments (CRA)		
Self-esteem	.23	.000
Burden	-.55	.000
Interaction term	.17	.006

Abbreviations: CRA, Caregiver Reaction Assessment; Burden, negative caregiving experiences (all negative CRA subscales were added up to one scale); Self-esteem, positive caregiving experiences.
Note: Adjusted R^2 for multivariable regression = .616 (F = 27.810; constant factor 4.734). Stepwise backward regression was performed. Initial set of variables selected from list of characteristics, if univariable associations were significant at $p < .2$. Variables were dropped if $p > .1$ in the multivariate analysis.

and the number of new caregiving tasks. Together, these variables predict 61.6% of the total variance of spouses' life satisfaction (Table 5.4).

Discussion and conclusion

This study showed that positive and negative caregiver experiences were both associated with life satisfaction. We also demonstrated a buffer effect, namely, spouses who reported both many negative and many positive caregiving experiences reported higher life satisfaction than spouses who reported many negative and few positive caregiving experiences.

Caregiving experiences

Like other studies using the CRA,[15-17,31] the mean score of the Self-esteem scale, measuring positive caregiving experience, was relatively high in comparison with the mean scores of the burden scales. Apparently, spouses derive many positive experiences from caring for their spouse.[18] An alternative explanation, however, is that it might be easier to confirm positively formulated questions than negatively formulated questions.[8] Moreover, both scores are of ordinal level, so that a score of, for example, 2.5 does not have the same meaning in both scales.

The Self-esteem subscale was not significantly related to the negative subscales Disrupted schedule and Lack of family support. Previous research also reported the absence of correlations between the CRA subscale Self-esteem and most other subscales.[17,28] Van Exel et al. interpreted this as a less important role of Self-esteem to define overall caregiver burden in comparing to the other subscales.[16] However, based on the results of the current study, it might be more appropriate to consider Burden and Self-esteem as partly independent components that can coexist in the caregivers' experience. Interestingly, and unlike earlier studies,[13-15] we found no significant relationships between spouses' characteristics and positive caregiving experiences. The reason for this difference is unclear. Additional research is necessary to identify determinants of positive caregiving experiences.

Similar to the findings by Nijboer et al.,[15] the Burden and Self-esteem subscales were both significantly related with spouses' life satisfaction, although Burden was stronger related with life satisfaction than Self-esteem.

This first study on the buffer effect in caregiving experiences and life satisfaction, showed a compensating effect of positive caregiving experiences on spouses' life satisfaction in high Burden circumstances. In the few positive caregiving experiences condition, the mean LiSat score was 3.6 (i.e. between 'rather dissatisfied' and 'rather satisfied'), against 4.2 (i.e. between 'rather satisfied' and 'satisfied') in the many positive caregiving experiences condition. This mean difference of 0.6 points is substantial, compared to the standard deviation of 0.8 (Effect Size .75) in this study. In social support studies, this 'buffer effect' has been shown more often.[21,22] For example, a recent study, in patients with spinal cord injury revealed that social support was stronger related with life satisfaction in functionally dependent persons than in functionally independent persons.[32] Nevertheless, burden was more strongly related to spouses' life satisfaction than positive caregiving experiences.

In the multivariate regression analysis, spouses' life satisfaction was mainly influenced by spouses' characteristics and caregiving experiences. None of the patients' characteristics tested were significantly related to life satisfaction. Other researchers did not find associations between life satisfaction and patients' age,[12,19] patients' gender,[12,19] spouses gender,[12,19] education level[12,15] or spouses' health.[19] Forsberg et al. did find a bivariate relation with the stroke patients' ADL-dependency and cognitive impairment,[8] but they did not perform a multivariate analysis.

Although spouses' age was not significantly related to life satisfaction in the bivariate analyses ($p < .2$), in the multivariate analyses it was significantly related with life satisfaction. In the literature, there is no consensus between studies about the influence of spouses' age on life satisfaction; some researchers confirm our findings[33,34] and some do not.[8,31]

We found that having more new caregiving tasks post-stroke correlates with decreased life satisfaction. This is consistent with our expectation that more obligations results in higher Burden.[31] However, having a family with young children and employment ≥ 20 hours/week were not significantly related with life satisfaction. The reason for this is unclear, because it was expected that having children and employment would elevate the amount of obligations and therefore were expected to be related to a decreased life satisfaction.[12]

Strengths and limitations of the study

This study is the first to describe a buffer effect of positive caregiving experiences (i.e., self-esteem derived from caregiving) on life satisfaction in stroke caregivers. Investigating caregiving experiences in the chronic phase of stroke in a relatively young population is important, because the caregiving situation could persist for many years. Also, our study included a relatively large group of caregivers, and, by conducting both patients' and spouses' variables in multivariate analyses, we carefully investigated the relation between caregiving experiences and life satisfaction.

Despite these strengths, some limitations should be considered when interpreting the results. First, the study was carried out in a selected stroke population, namely those admitted for inpatient rehabilitation. This hampers generalization of the results to the entire stroke population. The rehabilitation population has specific characteristics. The patients, and thereby the spouses, are relatively young in comparison with other (stroke) populations.[11,28,31] The patients were further on average moderately disabled, because inpatient rehabilitation is not necessary for patients with the best outcome, and is not very beneficial for patients with very severe stroke or comorbidity. Our patients were also more often living with young children compared to other studies.[15] Second, the study population is Dutch and the results might not be generalized beyond the Dutch culture and (in)formal care system. However, the results of this study were comparable with the literature, although this literature stems from Western countries only. Research in non-Western populations should examine whether our conclusions could be maintained in the non-Western world. Third, the cross-sectional nature of this study does not allow to asses intra-individual changes and how these changes influence the buffer effect over time. Future research is recommended to examine these relationships in a longitudinal design. Finally, selection bias could have occurred because of nonresponse and refusing further participation. Perhaps these couples were the ones with the highest Burden, lowest Self-esteem and least life satisfaction, which might have influenced the results. In another study, however, based on the same study population, no selection bias was observed on the basis of patients' and spouses' characteristics, except for a lower Barthel Index in the response group.[5]

Practice implications

Professional attention should not only be paid to minimize negative caregiving experiences (i.e. Burden) – if possible, but also to enhance positive experiences. Programs addressing active coping styles, problem-focused and positive relationship-focused coping strategies of caregivers are promising.[2,33,35] In caregiver studies, cognitive behavioural therapy seemed to be helpful to reduce and cope with negative caregiving experiences.[36,37] Psychological interventions, such as cognitive behavioural and psychoeducation programs, might transform caregivers' view from 'the glass half empty' to 'the glass half full' and could thereby improve the capacity of spouses to deal with their load. A family-centred approach can be helpful to focus on the problems and needs of the whole family, learning to set goals and to use adequate coping strategies.[2]

Conclusion

The present study has shown that positive and negative caregiving experiences are two relatively independent constructs. Both are related to spouses' life satisfaction, and positive experiences can buffer the negative caregiving experiences to some degree. Future research into caregivers should not only focus on caregiver burden, but should also include measures of positive caregiving experiences. Future research is necessary to identify factors that positively impact caregiving experiences and to identify strategies to enhance positive caregiving experiences.

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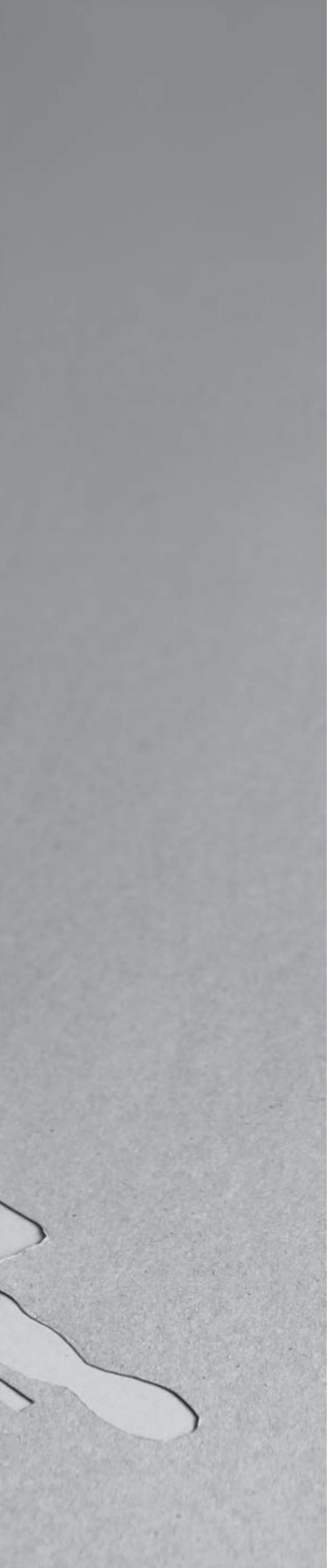
Chapter 6



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, pro-active 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. 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.

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' adverse health outcomes, like burden and depressive symptoms.[4,9-13] 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 15% 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.

Methods

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.

Measures

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]

Independent variables

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 hours a week or 24 hours 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]

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]

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 that moment to administer the observational measures and the questionnaires. Partners and patients completed the questionnaires independently on paper. For the assessment of the outcome variables at one year post-stroke, partners and patients were given the choice to complete the questionnaires on paper or online.

Statistical analyses

Partners were included for analyses when they completed at least one of the three outcome measures at one year post-stroke. Descriptive statistics were used to describe partner and patient characteristics. A non-response analysis was conducted using independent t-tests for continuous variables and chi-square test for dichotomous variables.

The outcome variables were normally distributed. Differences in partners' burden, anxiety and depressive symptoms between two months and one year post-stroke were tested for significance with paired t-tests. These analyses were performed in the total study group and separately in two subgroups (discharge home versus discharge to inpatient rehabilitation). Pearson correlations were calculated to evaluate the bivariate relationships between the patient and partner characteristics and the outcome measures at two months and one year post-stroke. Point-biserial correlations were used when a correlation between a dichotomous and a continuous variable had to be calculated. Patients' age, gender and educational level were not included in these analyses because of the strong correlations between the patients' and the partners' age, gender and educational level. The pre-stroke working status was used as an indicator of other responsibilities partners could have at the moment of patients' stroke onset.

Multiple linear regression analyses were performed to identify independent determinants of the outcome measures at two months post-stroke and one year post-stroke from all independent variables available at two months post-stroke. Bivariately significant independent variables ($p < .10$) were entered in a stepwise backward regression model. This liberal significance level increased the power for the selection of true predictors. The candidate determinants were checked for multicollinearity to prevent overparameterization of the prediction model. If multicollinearity was suggested (correlation coefficient > .70), the variable with the highest correlation coefficient with the outcome measure was included in the regression analyses.

In the multiple regression analyses, burden, anxiety and depressive symptoms were used as both dependent and independent variables. As mentioned before, depressive symptoms at the sub-acute phase are known as a strong predictor for this partner outcome at one year post-stroke.[9] Therefore, we have chosen to use burden, anxiety and depressive symptoms as an independent variable that explain the level of the other two variables at two months post-stroke and predicts the level of all three variables at one year post-stroke.

In all other statistical analyses a p-value of < .05 was considered as statistically significant. Data were analysed using SPSS version 21.0 for Windows (IBM Corporation, Armonk, NY, USA).

Results

Baseline characteristics

A total of 215 partners were included. At one year post-stroke, 183 partners (85.1%) completed at least one of the three outcome measures and were included in the present analyses. If the patient dropped out, the partner was excluded. Two patients died, and 30 partners and/or patients did not respond or declined to participate. The number of completed outcome questionnaires of these 183 partners at two months post-stroke varied per measure, which resulted in 171/172 partners at two months post-stroke.

Table 6.1 Partner and patient characteristics

	Participants (n = 183)		Drop outs (n = 32)	
	Mean (SD)	%	Mean (SD)	%
Partner characteristics				
Age	62.5 (10.9)		63.6 (10.6)	
Female gender		78.7		75.0
Higher educational level		27.5		33.3
Pre-stroke working status, % employment ≥ 24 hours/week $^{\mu}$		24.7		26.6
Satisfaction with their relationship, range 0–4, % satisfied	3.2 (0.9)	84.2	3.3 (0.6)	90.5
Proactive coping (UPCC), range 1–4	3.1 (0.6)		3.3 (0.4)	
Self-efficacy (GSES), range 10–40	32.6 (4.6)		34.2 (6.1)	
Social support (SSL-12-I), everyday support, range 4–16	11.0 (2.1)		11.2 (2.4)	
Social support (SSL-12-I), support in problem situations, range 4–16	10.3 (2.5)		10.6 (2.4)	
Social support (SSL-12-I), esteem support, range 4–16	10.4 (2.2)		10.5 (2.8)	
Patient characteristics				
Age	64.1 (11.0)		65.6 (11.4)	
Female gender		20.8		25.0
High educational level		28.6		46.4
Infarction		95.1		93.8
Right hemisphere affected		39.6		53.1
Stroke severity (NIHSS) $^{\mu}$	2.6 (3.0)		4.2 (4.8)	
No stroke symptoms (NIHSS 0)		24.0		23.7
Minor stroke symptoms (NIHSS 1–4)		57.9		55.8
Moderate stroke symptoms (NIHSS 5–12)		15.8		17.2
Moderate to severe stroke symptoms (NIHSS ≥ 13)		2.2		3.3
Aphasia (NIHSS item 9), % yes		11.5		18.8
ADL independency (BI), % dependent (≤ 18), range 0–20	19.5 (1.7)	11.0	18.7 (3.4)	25.0
Cognitive functioning (MoCA), % dysfunction (≤ 25), range 0–30	24.1 (3.4)	63.5	22.3 (6.0)	63.6
Discharged to home after hospital		78.1		62.5
Anxiety symptoms (HADS), range 0–21	4.8 (4.0)	19.5	4.4 (4.3)	14.3
Depressive symptoms (HADS), range 0–21	4.2 (3.0)	17.8	4.6 (4.1)	19.2

Abbreviations: SD, standard deviation; UPCC, Utrecht Proactive Coping Competence Scale; GSES, General Self-efficacy Scale; SSL, social support list; HADS, Hospital Anxiety and Depression scale; NIHSS, national institutes of health stroke scale; ADL, activities of daily living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment.

Variables marked with $^{\mu}$ are assessed at baseline.

Table 6.1 displays the demographic and stroke characteristics of the participants at baseline and at two months post-stroke. A non-response analysis revealed no significant differences between participants and drop-outs.

Partner outcomes at two months and one year post-stroke

High levels of burden were reported by 24.6% and 22.7% of all partners at two months and one year post-stroke respectively (Table 6.2). The proportion of partners experiencing high levels of anxiety was even larger at two months post-stroke (32.0%) and declined significantly to 19.2% at one year post-stroke. Almost 13% of all partners reported high levels of depressive symptoms at two months post-stroke. Levels of partners' burden and depressive symptoms did not change between two months and one year.

We found better outcomes in partners of patients discharged home compared to partners of patients discharged to a rehabilitation setting (Table 6.2).

(Psychosocial) factors explaining partner outcomes at two months post-stroke

Partners' burden was associated with the following partner variables: younger age, less satisfaction with their relationship, high self-efficacy, anxiety symptoms at two months post-stroke; and the following patient variables: stroke severity and depressive symptoms. This final model explained 53.4% of the variance in partners' burden (Table 6.3).

Partners' anxiety symptoms were only associated with partner variables: less self-efficacy, high burden and depressive symptoms. This final model explained 57.6% of the variance (Table 6.4).

Partners' depressive symptoms were associated with the following partner variables: higher age, less satisfaction with their relationship, less proactive coping, less everyday social support and high anxiety symptoms, and one patient variable: depressive symptoms. This final model explained 61.2% of the variance (Table 6.5).

The psychosocial factors: partners' satisfaction with the relationship, proactive coping, self-efficacy and everyday support showed significant bivariate correlations with all three outcome measures. However, not every psychosocial variable reached significance in all multivariate analyses.

Table 6.2 Partner outcomes at two month and one year post-stroke (Mean, SD)

	At two months post-stroke		At one year post-stroke	
	Total study population (n = 183)			
	n = 171–172	% high symptoms[≠]	n =181–182[α]	% high symptoms[≠]
Burden	4.1 (3.4)	24.6	4.0 (3.3)	22.7
Anxiety symptoms	5.6 (4.0)	32.0	4.9 (3.6)**	19.2
Depressive symptoms	3.2 (3.2)	12.8	3.3 (3.2)	12.6
	Selection of the partners of which the patient was discharged home after hospital stay (n = 143)			
	n = 135–136	% high symptoms[≠]	n = 141–142[¥]	% high symptoms[≠]
Burden	3.7 (3.2)	18.5	3.5 (3.2)	17.0
Anxiety symptoms	5.2 (3.7)	27.9	4.6 (3.5)**	16.2
Depressive symptoms	2.8 (2.9)	11.0	2.8 (3.0)	9.9
	Selection of the partners of which the patient was discharged to a rehabilitation setting after hospital stay (n = 40)			
	n = 36	% high symptoms[≠]	n = 40[±]	% high symptoms[≠]
Burden	5.9 (3.3)	47.2	5.6 (3.3)	42.5
Anxiety symptoms	7.1 (4.8)	47.2	5.7 (3.8)*	30.0
Depressive symptoms	4.8 (3.9)	19.4	4.9 (3.3)	22.5

Abbreviations: n number of partners included in the specific descriptive or test; n.a. not applicable.

[≠] Cut-off points Burden ≥ 7, Anxiety symptoms ≥ 8, Depressive symptoms ≥ 8, Anxiety and depressive symptoms Total score ≥ 11; [α] The number of partners in the T-test is 169–171; [¥] The number of partners in the T-test is 133–135; [±] The number of partners in the T-test is 36; * Significant paired T-test between two months and one year post-stroke, p < .05; **Significant paired T-test between two months and one year post-stroke, p < .01.

Table 6.3 Bivariate and multivariate correlation coefficients between partner and patient variables, and partners' burden at two months and one year post-stroke (n = 183)

	Burden at two months post-stroke		Burden at one year post-stroke	
	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)
Partner characteristics				
Age	-.196 (.010)*	-.129 (.021)*	.020 (.786)	Not entered
Female gender	.033 (.664)	Not entered	.026 (.723)	Not entered
Higher educational level	.085 (.285)	Not entered	.061 (.434)	Not entered
Pre-stroke working status, > 24 hrs/ week $^{\mu}$	.138 (.076)	Dropped	-.026 (.735)	Not entered
Satisfaction with their relationship	-.456 (.000)*	-.173 (.006)*	-.319 (.000)*	Dropped
Proactive coping	-.213 (.006)*	Dropped	-.199 (.010)*	Dropped
Self-efficacy	-.184 (.017)*	.153 (.014)*	-.111 (.153)	Not entered
Social support, everyday support	-.280 (.000)*	Dropped	-.249 (.001)*	Dropped
Social support, support in problem situations	-.087 (.255)	Not entered	-.061 (.432)	Not entered
Social support, esteem support	-.014 (.853)	Not entered	-.029 (.710)	Not entered
Burden	n.a.	n.a.	.696 (.000)*	.544 (.000)*
Anxiety symptoms	.598 (.000)*	.447 (.000)*	.515 (.000)*	.139 (.051)
Depressive symptoms	.493 (.000)*	Dropped	.428 (.000)*	Dropped
Patient characteristics				
Infarction	.069 (.369)	Not entered	.073 (.330)	Not entered
Right hemisphere affected	.089 (.250)	Not entered	.065 (.387)	Not entered
Stroke severity $^{\mu}$	.261 (.001)*	.244 (.000)*	.153 (.039)*	Dropped
ADL independency	-.271 (.000)*	Dropped	-.255 (.003)*	Dropped
Cognitive functioning	-.063 (.419)	Not entered	-.150 (.052)	-.117 (.036)*
Discharged to home after hospital	-.267 (.000)*	Dropped	-.263 (.000)*	Dropped
Anxiety symptoms	.413 (.000)*	Dropped	.436 (.000)*	.150 (.016)*
Depressive symptoms	.468 (.000)*	.271 (.000)*	.455 (.000)*	Dropped
Explained variance (R square)		53.4% (Adjusted R square 51.6%)		53.3% (Adjusted R square 52.1%)

Abbreviations: ADL, activities of daily living; n.a. not applicable.
* P-value < .05. Variables marked with $^{\mu}$ are assessed at baseline.

Table 6.4 Bivariate and multivariate correlation coefficients between partner and patient variables, and partners' anxiety symptoms at two months and one year post-stroke (n = 183)

	Anxiety symptoms at two months post-stroke		Anxiety symptoms at one year post-stroke	
	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)
Partner characteristics				
Age	-.110 (.152)	Not entered	.026 (.729)	Not entered
Female gender	.107 (.163)	Not entered	-.007 (.925)	Not entered
Higher educational level	.105 (.183)	Not entered	.099 (.197)	Not entered
Pre-stroke working status, > 24 hrs/ week $^{\mu}$	.062 (.425)	Not entered	.009 (.900)	Not entered
Satisfaction with their relationship	-.453 (.000)*	Dropped	-.264 (.001)*	Dropped
Proactive coping	-.395 (.000)*	Dropped	-.258 (.001)*	Dropped
Self-efficacy	-.420 (.000)*	-.202 (.000)*	-.315 (.000)*	Dropped
Social support, everyday support	-.288 (.000)*	Dropped	-.234 (.002)*	Dropped
Social support, support in problem situations	-.091 (.234)	Not entered	-.112 (.145)	Not entered
Social support, esteem support	-.148 (.053)	Dropped	-.055 (.477)	Not entered
Burden	.598 (.000)*	.354 (.000)*	.459 (.000)*	Dropped
Anxiety symptoms	n.a.	n.a.	.653 (.000)*	.601 (.000)*
Depressive symptoms	.667 (.000)*	.418 (.000)*	.439 (.000)*	Dropped
Patient characteristics				
Infarction	-.026 (.734)	Not entered	.005 (.950)	Not entered
Right hemisphere affected	.098 (.204)	Not entered	.041 (.584)	Not entered
Stroke severity $^{\mu}$	.051 (.506)	Not entered	-.035 (.635)	Not entered
ADL independency	-.192 (0.013)*	Dropped	-.140 (.068)	Dropped
Cognitive functioning	.071 (.362)	Not entered	.049 (.529)	Not entered
Discharged to home after hospital	-.192 (.011)*	Dropped	-.131 (.078)	Dropped
Anxiety symptoms	.398 (.000)*	Dropped	.370 (.000)*	.131 (.044)*
Depressive symptoms	.406 (.000)*	Dropped	.357 (.000)*	Dropped
Explained variance (R square)		57.6% (Adjusted R square 56.8%)		44.0% (Adjusted R square 43.3%)

Abbreviations: ADL, activities of daily living; n.a. not applicable.
* P-value < .05. Variables marked with $^{\mu}$ are assessed at baseline.

Table 6.5 Bivariate and multivariate correlation coefficients between partner and patient variables, and partners' depressive symptoms at two months and one year post-stroke (n = 183)

	Depressive symptoms at two months post-stroke		Depressive symptoms at one year post-stroke	
	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)	Bivariate correlation coefficients (p-value)	Multivariate regression coefficients, Beta (p-value)
Partner characteristics				
Age	.132 (.085)	.155 (.003)*	.188 (.011)*	.138 (.038)*
Female gender	.009 (.907)	Not entered	-.050 (.504)	Not entered
Higher educational level	-.033 (.673)	Not entered	.060 (.440)	Not entered
Pre-stroke working status, > 24 hrs/ week $^{\mu}$	-.076 (.328)	Not entered	-.124 (.101)	Not entered
Satisfaction with their relationship	-.508 (.000)*	-.157 (.008)*	-.259 (.001)*	Dropped
Proactive coping	-.525 (.000)*	-.191 (.001)*	-.392 (.000)*	Dropped
Self-efficacy	-.364 (.000)*	Dropped	-.321 (.000)*	-.135 (.058)
Social support, everyday support	-.360 (.000)*	-.103 (.057)	-.315 (.000)*	-.157 (.028)*
Social support, support in problem situations	-.170 (.026)*	Dropped	-.138 (.073)	Dropped
Social support, esteem support	-.204 (.008)*	Dropped	-.150 (.051)	Dropped
Burden	.493 (.000)*	Dropped	.341 (.000)*	Dropped
Anxiety symptoms	.667 (.000)*	.440 (.000)*	.373 (.000)*	Dropped
Depressive symptoms	n.a.	n.a.	.514 (.000)*	.352 (.000)*
Patient characteristics				
Infarction	-.032 (.678)	Not entered	-.101 (.173)	Not entered
Right hemisphere affected	.127 (.097)	Dropped	.049 (.515)	Not entered
Stroke severity $^{\mu}$	.109 (.156)	Not entered	.090 (.229)	Not entered
ADL independency	-.230 (.003)*	Dropped	-.164 (.032)*	Dropped
Cognitive functioning	-.126 (.104)	Not entered	-.146 (.058)	Dropped
Discharged to home after hospital	-.251 (.001)*	Dropped	-.270 (.000)*	-.151 (.028)*
Anxiety symptoms	.406 (.000)*	Dropped	.288 (.000)*	Dropped
Depressive symptoms	.488 (.000)*	.167 (.004)*	.348 (.000)*	Dropped
Explained variance (R square)		61.2% (Adjusted R square 59.7%)		34.1% (Adjusted R square 31.9%)

Abbreviations: ADL, activities of daily living; n.a. not applicable.
* P-value < .05. Variables marked with $^{\mu}$ are assessed at baseline.

(Psychosocial) factors predicting partner outcomes at one year post-stroke

Partners' burden was predicted by partner burden and anxiety symptoms (although not significantly) at two months post-stroke, less cognitive functioning of the patient and anxiety symptoms of the patient, explaining 53.3% of the variance (Table 6.3).

Partners' anxiety symptoms were predicted by anxiety symptoms of the partner and anxiety symptoms of the patient at two months post-stroke, explaining 44.0% of the variance (Table 6.4).

Partners' depressive symptoms were predicted by the following partner variables: higher age, less self-efficacy, less everyday social support, depressive symptoms at two months post-stroke, and one patient variable: discharge to rehabilitation setting. Together these predictors explained 34.1% of the variance (Table 6.5).

The partners' psychosocial factors: satisfaction with their relationship, proactive coping and everyday social support were significant predictors of partner outcomes one year after stroke in the bivariate analyses, but, except for self-efficacy and everyday social support in the prediction of partners' depressive symptoms, were not independent predictors of these outcomes.

Discussion and conclusion

Discussion

The results of the current study show that a substantial part of the stroke partners experience high burden, anxiety and depressive symptoms.

Partner outcomes at two months post-stroke can be well explained by several partner and patient variables: partners' burden and emotional problems on the other outcomes (burden, anxiety and depressive symptoms), partners' psychosocial factors (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support) and patients' depressive symptoms are of substantial importance.

Moreover, in contrast with the levels of anxiety, the levels of burden and depressive symptoms did not decline over time. The levels of burden, anxiety or depressive symptoms at two months post-stroke were the strongest predictors of the level of burden, anxiety and depressive symptoms at one year post-stroke, respectively. We were, to a large degree, able to identify in the sub-acute phase (i.e. two months post-stroke) partners at risk for adverse partner outcomes in the chronic phase (i.e. one year post-stroke).

Partner outcomes at two months and at one year post-stroke

The levels of partners' burden found in our study were in line with results reported by a hospital-based[30] as well as an inpatient rehabilitation-based study.[4] We found higher levels of anxiety symptoms in comparison to levels of depressive symptoms. The levels of depressive symptoms in our study were lower in comparison to other stroke partner studies.[2,4] This differences may be caused by the use of a different measure.[2,4] Our scores of depressive symptoms were substantially higher compared to HADS depression scores in the general Dutch population.[31] A review on psychosocial functioning after spinal cord injury showed that estimations of the occurrence of depressive symptoms after spinal cord injury may vary with the screening instruments used.[32]

Partners of patients discharged home had better outcomes compared to partners of patients discharged to a rehabilitation setting. This might be explained by the fact that patients discharged to an inpatient rehabilitation setting are more severely affected which might result in more negative consequences for the partners. However, even in the subgroup of partners of patients who were discharged home, still a part of the partners experienced high burden, anxiety symptoms and/or depressive symptoms at one year post-stroke.

(Psychosocial) factors explaining partner outcomes at two months post-stroke

Psychosocial factors, especially satisfaction with their relationship, proactive coping, self-efficacy and everyday social support, were determinants of partners' burden, anxiety and depressive symptoms in the cross-sectional analyses. The finding of low partner relationship satisfaction as a predictor of partners' burden[9] and caregivers' depression[33] confirms results from other studies.

Diverging findings on the association between social support and caregiver outcomes have been reported in the literature. Our study added to this literature by showing that only everyday social support was associated with partner outcomes. These results align with the growing awareness, in stroke literature, that social support cannot be considered to be a one-dimensional factor. Everyday social support, is support given in the 'normal daily situation' to provide the recipient with a feeling of protection.[27] This subtype of social support differs from, for instance, support in problem situations, in which support is given in problem situations to comfort, to give help and advice.[27] To enhance adverse partner outcomes, focusing on maintaining and improving everyday social support might be more effective than focusing on social support as a whole.

High self-efficacy was associated with lower burden in the bivariate analysis, but with higher burden at two months post-stroke in the multivariate analyses, which seems to be counterintuitive. One possible explanation might be that, corrected for the other determinants in the regression analysis, people with high self-efficacy set themselves higher goals, invest more effort and persist longer than those with low self-efficacy,[26] which might result in higher level of burden. In the other multivariate analyses self-efficacy is negatively related to anxiety and depressive symptoms, resulting in an association of low self-efficacy with the outcome measure, which seems to be more rational. In literature, a low sense of self-efficacy has also been related to more anxiety and depressive symptoms.[26]

In our study, 20.8% of the patients and almost 80% of the partners is female. An association between partners' female gender and higher levels of adverse partner outcomes has been, although inconsistently, described.[3,8] However, in our multiple regression analyses, female gender did not reach significance. Therefore, a dis-balance of gender cannot explain why depressive symptoms in our study were lower in comparison to other stroke partner studies.

(Psychosocial) factors predicting partner outcomes at one year post-stroke

Apparently, partners with adverse outcomes at two months post-stroke are at high risk for adverse outcomes at one year post-stroke. Our comprehensive analysis of predictors, including partners psychological and environmental factors and patients anxiety and depressive symptoms, revealed that both the level of partners' anxiety and patients' anxiety symptoms were the strongest factors in the prediction of partners' anxiety symptoms at one year post-stroke.

Although sparsely, psychosocial factors in relation with adverse partner outcome were investigated before.[9,10,12,13] Relationship satisfaction in the chronic phase after stroke was significantly correlated with positive aspects of the caregiver role.[9,34] In a study of partners of patients discharged to a rehabilitation setting more passive coping and reassuring as coping style were associated with partners' burden, and more passive coping, less seeking social support and more avoiding with partners' depressive symptoms at one year post-stroke.[9]

Everyday social support was an independent predictor of partners' depressive symptoms at one year post-stroke, but not of partners' burden or anxiety symptoms. However, in the study of McCullagh, concerning the prediction of partners' burden, social support was a predictor at one year post-stroke.[12] The fact that we have chosen to analyse social support in different subtypes may explain some of the differences found when comparing with the existing literature.

In our study, not every psychosocial variable reached significance in the multivariate analyses. Probably because, in the multiple linear regression analyses, we also included the partner outcome variable at two months post-stroke. So, at first glance, the psychosocial factors did not have an important role in the prediction of adverse outcome at one year post-stroke. However, partners' satisfaction with their relationship, proactive coping, and everyday social support were significant bivariately related to all three outcome measures and partners' self-efficacy with anxiety and depressive symptoms at one year post-stroke

The use of the variables burden, anxiety and depressive symptoms as both dependent and independent variables can be questioned. Although intercorrelation exist between these variables, we are convinced that it is acceptable because no multicollinearity was found. Furthermore, the levels of burden, anxiety and depressive symptoms remained more or less stable during the first year post-stroke (except anxiety symptoms which decreased significantly), which might suggest that these factors remain important during the post-stroke phase. And therefore, making it worthwhile to include it in the multivariate regression analyses.

A dyadic approach to patients and partners post-stroke

Besides partners' burden or anxiety symptoms at two months post-stroke, *patients*' anxiety symptoms at two months post-stroke was a significant predictor in the prediction of partners' burden and anxiety symptoms at one year post-stroke. This underlines the upcoming appeal in literature, that patient and partner outcomes should be viewed from a dyadic perspective,[35] and care should be family centred instead of patient centred.[36,37] Couples' emotional health seems to be interdependent, probably because of the intimate connection that patients and partners share before, during and after stroke.[35] Therefore, also patient variables (i.e. anxiety symptoms at two months post-stroke) should be taken into account when assessing partners' burden or anxiety symptoms at one year post-stroke.

Strengths of the study

One of the strengths of this study is the inclusion of a large number of patients and partners of a general hospital-based stroke population directly after stroke and following them up to one year post-stroke irrespective of discharge destination. A non-response analysis revealed no difference between participants and non-responders.

Furthermore, we approached the concept of partner outcome from a dyadic perspective. Therefore, we included a broad range of patients' and partners' variables which could possibly explain and predict partners' burden, anxiety and depressive symptoms, resulting in a respectable percentage of explained variance of the outcome measures.

Also, this is one of the few study focussing on symptoms of anxiety in partners of stroke patients.

Limitations of the study

Firstly, we did not have data on comorbidity and premorbid scores on partners' and patients' anxiety or depressive symptoms. Inclusion of these factors might have raised the amount of explained variance. However, we excluded partners and patients with a serious other condition whereby interference with the study outcomes would be expected, hampering the analysis of this variable.

Secondly, although we did not exclude patients suffering a severe stroke in advance, most patients included in the study experienced a mild stroke which might influence partner outcomes and the mild stroke group is the largest segment of all stroke patients.

Thirdly, information bias could have been occurred, because no researcher was present at the assessment at one year post-stroke. It cannot be ruled out that partners (or others) helped the patients to complete the questions, and/or that certain momentary conditions were of influence on the answers, without the possibility to check these.

Fourthly, a risk of mass significance as a result of the multiple correlations analyses could have been occurred. Therefore, the observed values should be interpreted carefully.

Finally, subdividing the participants regarding to discharge setting revealed a substantial higher level of burden, and anxiety and depressive symptoms in the group of partners with a patient discharged to an inpatient rehabilitation setting. Unfortunately, the group was too small (n=40) for further subgroup analyses.

Conclusion

This study adds knowledge of determinants of partner outcome in the sub-acute and chronic phase post-stroke to the literature.

A substantial part of the stroke partners experience high levels of burden, anxiety or depressive symptoms in the sub-acute and the chronic phase post-stroke. Especially, the levels of anxiety symptoms are high. In contrast with the levels of anxiety, the levels of burden and depressive symptoms did not decline over time.

Partners with long-term (one year) adverse outcomes can be identified in the sub-acute phase (i.e. two months post-stroke), by measuring these outcomes in the sub-acute phase in combination with patients' depressive symptoms and partners' psychosocial factors (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support).

Practice implications

In clinical practice it is important to identify partners experiencing high burden, and anxiety and depressive symptoms during the sub-acute phase (i.e. two months post-stroke) and to provide them with appropriate support or counselling. This study identified partners' psychosocial factors associated with partner outcomes (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support) and screening on these factors is also recommended, because these factors can be changed by counselling or therapeutic interventions and thereby such interventions may help to improve partner outcomes.[38,39] Also, *patients*' anxiety and depressive symptoms at two months post-stroke should be taken into account, which underlines the upcoming appeal that patient and partner outcomes should be viewed from a dyadic perspective.

In conclusion, an assessment at two months post-stroke is important, and might be easy to implement, because most patients will be seen in this period at the hospital or general practice to monitor and evaluate cardiovascular risk management. Brief self-report measures such as the HADS and CSI used in this study are easy to administer and can be used as screening instruments to identify patients and partners at risk of adverse outcomes in these settings.

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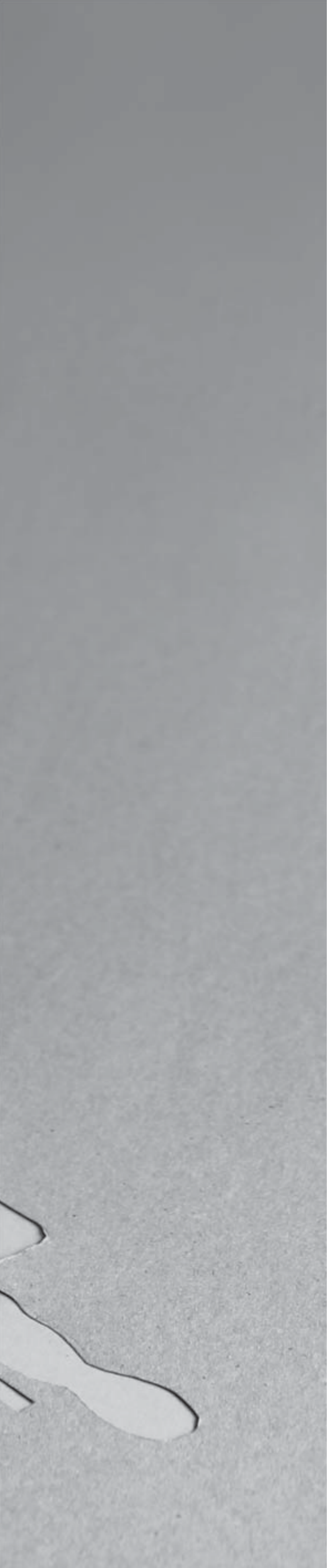
Chapter 7



General discussion

As expressed in the ICF-model (**chapter 1**, Figure 1.1) personal and environmental factors may facilitate or hinder stroke outcomes. Therefore, it is important to take a wide range of personal and environmental factors into account in stroke research. In this Thesis, social support and the partner are the focus of attention. We examined associations between the stroke patient and his or her environment, by focusing on patient's social support and on the partner. The results of our studies are presented in the previous chapters. This final chapter starts with an overview of the main findings and conclusions of this Thesis, followed by a discussion of the main findings and methodological considerations. Finally, clinical implications and recommendations for future research are suggested.

Main findings

Part I Social support in the stroke patient

Chapter 2 consists of a systematic review of the literature on associations between perceived social support and patients' health-related quality of life. A total of 11 articles could be included. Most of these articles studied overall perceived social support without further specification of type or source of support. The results show positive, but not consistent, relations between social support and patients' health-related quality of life. Emotional support was the most often investigated subtype of social support and showed the strongest relationships with health-related quality of life, compared to other subtypes such as informational or instrumental support. However, due to the small number of studies and the heterogeneity in methods assessing social support, a clear statement about the specific influence of social support type or source could not be made.

In **chapter 3** we tried to elucidate the relationship between social support to stroke patients and stroke patients' depressive symptoms further. Social support is a broad concept and the measure we used divides it into three subtypes; 'everyday social support' (in which social companionship and daily emotional support are involved), 'support in problem situations' (including instrumental support, informative support, and emotional support in times of trouble) and 'esteem support' (which includes support resulting in improved self-esteem and approval). Firstly, we described the course of social support as perceived by the patients from the start of initial inpatient rehabilitation until three years post-stroke. Secondly, we examined the cross-sectional and longitudinal relationships between social support and patients' depressive symptoms at various times post-stroke.

More than one-third of the participants showed depressive symptoms. Total perceived social support and its three subtypes declined significantly from inpatient rehabilitation until three years post-stroke. Although we had expected stronger relationships, we found significant associations between social support and patients' post-stroke depressive symptoms. The advantage of examining subtypes of social support in addition to a total score was established since divergent relationships were found between the three subtypes and patients' depressive symptoms. More everyday social support and esteem support were associated with less patients' depressive symptoms, whereas social support in problem situations was associated with more patients' depressive symptoms. A characteristic of assessing associations is that it does not clarify the direction of the association; for instance, more everyday social support was related to less depressive symptoms, but this does not indicate whether more everyday social support leads to less depressive symptoms or that having more depressive symptoms leads to less everyday social support.

In the longitudinal analysis, however, only social support in problem situations showed a significant positive relationship with patients' depressive symptoms over time; more social support in problem situations was a predictor of more depressive symptoms.

Part II The partner of the stroke patient

The second part of this Thesis focuses on the stroke patient's partner. In **chapter 4** we compared the psychometric properties of the Caregiver Strain Index Expanded with those of the Caregiver Strain Index. The potential benefit of the Caregiver Strain Index Expanded is that it measures positive experiences of caregiving in addition to negative experiences. However, the addition of five positively phrased items did not improve the psychometric properties of the Caregiver Strain Index and did not show other added value. Therefore, we do not advise the Caregiver Strain Index Expanded to measure positive caregiver experiences.

Nonetheless, positive caregiving experiences are clinically important as we show in **chapter 5**. This chapter focuses on the direct and indirect ('buffer effect') associations between both positive and negative caregiving experiences in partners of stroke patients and partners' life satisfaction. Positive and negative caregiver experiences can co-exist and were both related to partners' life satisfaction at three years post-stroke. Furthermore, positive caregiving experiences mediate the impact of negative caregiving experiences ('burden') on life satisfaction. This means that partners who reported many negative and many positive caregiving experiences reported higher life satisfaction than partners who reported many negative and few positive caregiving experiences.

Chapter 6 focuses on partner outcomes in terms of partners' burden, anxiety and depressive symptoms. We revealed that many partners suffered from high levels of burden, anxiety and depressive symptoms in the sub-acute and chronic phase. Partners' anxiety, but not burden and depressive symptoms, decreased between two months and one year post-stroke. At two months post-stroke, these outcomes were associated with the partner variables: age, relationship satisfaction, pro-active coping, self-efficacy, everyday social support, burden, anxiety and depressive symptoms; and the patient variables: stroke severity and depressive symptoms. The strength of the correlation, but occasionally also the direction (positive or negative) of the correlation, differed between the three partner outcomes. With regard to the psychosocial factors of the partner: less proactive coping, less self-efficacy, less satisfaction with the relationship and less everyday social support were also determinants of adverse partner outcomes one year post-stroke, but, except for self-efficacy and everyday social support in the prediction of partners' depressive symptoms, were not independent predictors of these outcomes. Partner outcomes, in terms of burden, anxiety and depressive symptoms, at one year post-stroke could be predicted to a large degree in the sub-acute phase at two months post-stroke; high levels of partner burden, anxiety and depressive symptoms at two months were de strongest predictors of high levels of partner outcomes at one year post-stroke.

Discussion of the main findings

This Thesis complements other research on social support and caregiving in the stroke population. Three main results will be discussed in this section; namely, 'social support after stroke', 'positive caregiving experiences' and 'stroke from a dyadic perspective'.

Social support after stroke

As described in the General Introduction (**chapter 1**) and in the other chapters concerning social support (**chapter 2, 3 and 6**), the concept of social support is broad.

To measure social support and to target interventions to improve the social support network, social support should be considered from different perspectives. The most studied perspective is the type of received social support as experienced by the patients involved, as we did in this Thesis. Other perspectives focus on the actual support given (i.e. hours or tasks), the source of support (e.g. partner, children, neighbours) or satisfaction with the social support received. Ideally, multiple perspectives are taken into account in the same social support research.

We used the classification by Langford in the review (**chapter 2**)[1] and measured patients' and partners' social support with the Social Support List-12 as developed by Van Eijk et al.[2] in the studies described in **chapter 3 and 6**. Although Langford used four subtypes (respectively, 'emotional support', 'instrumental support', 'informational support' and 'appraisal support') and Van Eijk three subtypes (respectively, 'everyday support', 'support in problem situations' and 'esteem support'), these classifications show important similarities. Both concern perceived social support. Esteem support in the Social Support List-12 includes both emotional support and appraisal support according to Langford's classification. Support in problem situations includes Langford's categories of instrumental support and informational support. These were distinct scales in the long version of the Social Support List, but were merged in the Social Support List-12.

In this Thesis, social support was associated with patients' post-stroke depressive symptoms (**chapter 3**) and was a predictor of partner outcomes in terms of partners' burden, anxiety and depressive symptoms (**chapter 6**). However, based on the literature,[3-7] we had expected more consistent relationships between social support and both patients' depressive symptoms[3,4] and partner outcomes.[5-7] Several explanations can be suggested: Firstly, the stroke patients in our studies were mostly mildly to moderately disabled, as shown by high mean Barthel Index scores at follow-up in both the FuPro-stroke study and the Restore4Stroke study. Probably (partners of) patients with a higher level of ADL-independency (i.e. higher Barthel Index scores) may need less support in comparison to (partners of) patients with a lower level of ADL-independency. Secondly, we measured only the perceived social support. Probably, we would have found stronger relations if we would have assessed other aspects of social support, for instance the satisfaction with perceived social support. Thirdly, the Social Support List-12 has been validated for use in elderly in the general community,[2] but not yet in a stroke population so that it is unclear whether all aspects of social support relevant to stroke patients are included in this instrument.

We think that the need of social support post-stroke may change for both patient and partner over time.[8] Cameron and colleagues have developed a framework in which the changing needs of stroke caregivers and the changing need for education and support are elucidated.[8]

Although this framework was developed for caregivers, we assume that an almost similar changes in patients' needs can be expected. Recovery, relearning skills and/or change in environmental setting (e.g. being at a hospital, at inpatient rehabilitation or at home) all may change patient's demands of social support and, consequently, result in corresponding changes in the caregiver role.[8] For instance, in the acute phase, the focus may be at motor impairments, but in the chronic phase cognitive and behavioural problems may become more apparent. In this acute phase, patients and caregivers might need especially informational support ('What has happened and what are the consequences?').[8] During hospitalization or inpatient rehabilitation, health professionals provide substantial care. Patients and caregivers will need informational support and training to become more prepared for returning home, and consequently need appraisal to become more confident with their patient or caregiver role.[8] At home, fewer health care professionals are available and the stroke patient and caregiver rely more on themselves. Patients and caregivers may still need emotional, instrumental, informational and appraisal support, but the focus will be on how the couple manage with the reduced functioning of one of them within their own environment.[8]

When focusing on patients' social support, in **chapter 3**, our results show that the amount of all subtypes of patients' perceived social support declined significantly over time. This is not in line with the framework by Cameron and colleagues, in which it is assumed that the need of a specific subtype of support may vary over time like described above.[8] However, we did not investigate changes in subtypes of social support in relation to the setting but only to time post-stroke. Perhaps this explains some of the differences found. Furthermore we did not assess satisfaction with social support, so, it is not possible to determine if the decline in social support is due to reduced social support needs or if it represents a gap between the need for social support and the fulfilment of these needs. Most of patients' physical, emotional and cognitive recovery takes place in the first three months post-stroke, although additional improvements may occur in the following three to six months. After these months stroke-related disabilities remain more or less stable and persist over time, suggesting that social support may also be persistently needed over time. Therefore, it is alarming that all social support subtypes declined over time.

In this Thesis, we have not examined the change in partners' social support over time, but further exploration of the Restore4Stroke data is in progress.

Positive caregiving experiences

The notion of the negative and positive impact of caregiving, and the concept that positive and negative aspects of caregiving are not simply the opposite ends of the same continuum, is not new.[9,10] We have confirmed this in **chapter 4 and 5** by showing that most partners experience at least some positive aspects of caring and that negative and positive caregiving experiences can co-exist.

However, there is an important difference between the methodology in **chapter 4** and **chapter 5**: in **chapter 4** we used the Caregiver Strain Index Expanded and in **chapter 5** the Caregiver Reaction Assessment to measure positive caregiving experiences. This allows us to discuss the issue of how to measure positive caregiving experiences.

In literature, many different terms of positive caregiving experiences have been used, such as positive aspects, satisfactions, self-esteem, benefits, gains, uplifts or rewards.[9,10] Furthermore, our results of **chapter 5** suit the stress buffering hypothesis of Cohen and Wills,[11] which has been described in **chapter 1**. However, a clear understanding of how positive caregiving experiences are related to caregiver outcomes does not exist. A theory on both negative and positive caregiving experiences and patient and partner outcome would be helpful to understand how these experiences and outcomes can be changed.

To our opinion, caregiving, or giving social support in general, can be conceptualised as an occupational task and thereby as a potential occupational stressor.[12] Potential helpful theories originating from occupational health research are the Effort-Reward Imbalance theory[13] and the Demand-Control theory.[14] The Effort-Reward Imbalance theory claims that work characterized with high efforts and low rewards (such as positive feedback, money or career opportunities) is imbalanced and may cause sustained stress reactions. Prolonged stress seems to evoke adverse health outcomes, such as higher cardiovascular risk or reduced well-being, by stimulating neurobiological, psychological and behavioural pathways.[15] It might take high efforts to give care (negative caregiving experiences, burden) and might give low rewards (few positive caregiving experiences). These imbalance between efforts and rewards will be maintained in case of overcommitment, which is when a person obliges himself to do more than he is capable of. Highly overcommitted employees will respond with more stress to an imbalance between efforts and demand in comparison to less overcommitted empolyees.[15] Probably, some partners might show signs of overcommitment as well. A feature of this model is that efforts and rewards are being seen as ends of one continuum instead of two relatively independent variables.

The Demand-Control theory of Karasek[14] complements the Effort-Reward Imbalance theory.[13] This model was also developed for work settings to study job strain in which stress, quality of life, job satisfaction and performance can be considered as indicators of strain. It assumes that job strain can be determined by physical and psychological demands and the level of control (job skills and decision authority) of fulfilling these demands. According to this model, caregivers who experience a high level of control of caregiving demands will experience less strain. The Demand-Control model has already been tested in a stroke caregiver population, and preliminary support for using this model in predicting caregivers' anxiety and depression post-stroke has been found.[12]

Until now, there is no consensus on measuring positive caregiving experiences and consequently, we measured in **chapter 4** positive caregiving experiences with the Caregiver Strain Index Expanded[16] and in **chapter 5** with the Caregiver Reaction Assessment.[17] In the FuPro-stroke study, we choose for the Caregiver Reaction Assessment as the instrument for measuring negative and positive aspects of caregiving. The Caregiver Reaction Assessment consists of 24 items in four subscales measuring negative caregiving experiences; Disrupted schedule, Financial problems, Lack of family support and Health problems, and one subscale measuring positive caregiving experiences called Self-esteem (example items of the subscale self-esteem are 'caregiving is important to me', 'caring makes me feel good', 'I enjoy caring').[17] Each item has to be scored on a 5-point Likert scale. Unfortunately, the Caregiver Reaction Assessment has showed moderate reliability and reproducibility,[18,19] in which the reliability of the subscale self-esteem and reproducibility of the subscales lack of family support and self-esteem were insufficient.[19]

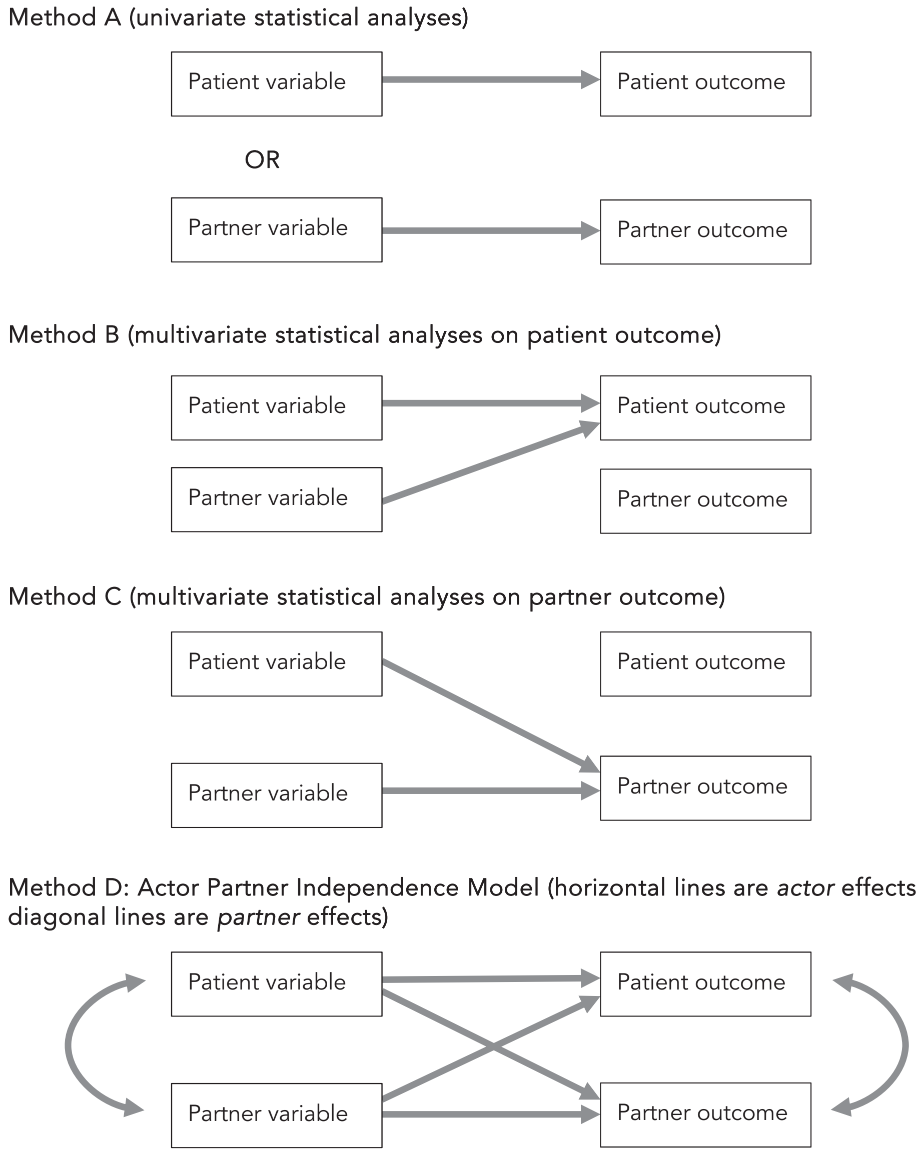
At the time the Restore4Stroke study was designed, the Caregiver Strain Index had become the most frequently used questionnaire to measure caregiver burden in stroke research, and showed good reproducibility[19] and validity[18] in stroke research. The expanded version of the Caregiver Strain Index, including five positively phrased items, had just been published at that time and it seemed to be a logical step to replace the Caregiver Reaction Assessment for the Caregiver Strain Index Expanded in the Restore4Stroke study. Unfortunately, the psychometric properties of the Caregiver Strain Index Expanded turned out to be insufficient (**chapter 4**), especially those of the positive subscale; it showed a huge ceiling effect and its internal consistency was unacceptable. In our analyses of the negative and positive subscale of the Caregiver Strain Index Expanded, we have determined the subscales as ends of one continuum (by summing up the scores of both subscales), as directed by its developers, but we have also evaluated the negative and positive caregiving experiences as two relatively independent variables (by testing the added value of the positive phrased items above the negative positive items). Both approaches showed unsatisfactory results, probably due to the ceiling effect of the positive subscale. It is therefore unclear which approach is the best. To explain these unsatisfactory results, it is important to examine the five items more closely: 'The … appreciates everything I do for him/her', 'Besides the care I provide to … I have enough time for myself', ' I can handle the care for … fine', 'I am happy to care for …', 'Taking care for … is important to me'. On one hand, people might have the intention to answer questions in a manner that will be regarded favourably by others (social desirability bias), but on the other hand, we think that the questions might not measure positive caregiving experiences in the best way. The two items measuring 'time for yourself' and 'handling care fine' seem to measure the opposite of burden, and suggest that negative and positive caregiving experiences are opposing ends of a spectrum. The other three items, seem to focus on a positive feeling as a result of caring, and might suit the concept of two relatively independent variables better.

Because of the disappointing psychometric properties of the Caregiver Strain Index Expanded we did not include the positively phrased items in the analyses presented in **chapter 6**. A good instrument to measure both negative and positive caregiving experiences in stroke has still to be developed. The review of Mackenzie and Greenwood might be a good start to determine which topics have to be included in such an instrument.[10] It focused on positive caregiving experiences and included both quantitative and qualitative studies. It provides an overview of the great variety of positive aspects of caregiving (like stroke patient's physical progress or recovery, improved or strengthened relationships, feelings of appreciation by the care recipient or community, and feeling needed) and positive results of caregiving (for instance giving meaning or purpose in life, increased self-esteem or inner strength) described in the literature. They found that coping was associated with positive aspects of caregiving, but the direction of the correlation was unclear. Furthermore other variables which may influence positive aspects of caregiving seemed not often studied and only three studies investigated changes in positive caregiving experiences over time. To elucidate the concept of positive caregiving experiences, a possible approach might be conducting qualitative research into stroke caregivers to add and specify the familiar topics. Another way might be to search beyond the stroke literature. Experiences of stroke caregivers may be, to some extent, similar to experiences of other caregivers, for instance multiple sclerosis.[20] In this Thesis, partner variables were more important than patients' stroke variables in the prediction of partner outcomes (**chapter 6**), which might suggest that caregiving experiences are not disease-specific.

Stroke from a dyadic perspective

In **chapter 6** we found that both partner and patient characteristics in the sub-acute phase post-stroke explain partner outcomes at two months post-stroke and predict partner outcomes at one year post-stroke. Strongest predictors of partner outcomes (in terms of burden, anxiety and depressive symptoms) were the levels of partner burden, anxiety and depressive symptoms at two months post-stroke. Besides these partner variables, patient variables were important: patients' anxiety symptoms at two month post-stroke was a significant predictor of partners' burden and anxiety symptoms at one year post-stroke. This underlines the upcoming appeal in literature, that patient and partner outcomes should be viewed from a dyadic perspective instead of focusing on the stroke patient and/or the partner solely.[21-26] Furthermore, this accentuates the importance of monitoring both patient's and partner's health in clinical practice. We think that the use of the combined ICF-models for both patient and partner, as described in **chapter 1** (Figure 1.1), might be helpful to clarify the interrelationship between patient and partner. Health professionals should pay attention to the question 'How the patient influences the partner, and vice versa?'.

In future research, the next step in investigating from a dyadic perspective is a challenging one: finding a good conceptual approach. In the literature, several approaches have been used. Probably, the most simple way is to sum up both patient and partner scores, but we think that is too simplistic. Another approach described in the literature is to categorize couples in three groups regarding dyadic outcome. This was done in studies on dyadic life satisfaction as dyadic outcome.[23,27] In these studies life satisfaction scores were dichotomized into 'satisfied' and 'dissatisfied', and used to identify three groups: 'a satisfied couple', 'a discordant couple' (i.e. not in agreement), and 'a dissatisfied couple'.[23,27] A shortcoming of the two aforementioned approaches is that they do not investigate the interrelationship between patient and partner. Perhaps, the Actor-Partner Interdependence Model (APIM),[28,29] which has already been used in several stroke research,[e.g. 24,25] will be more appropriate. In this model the *actor effect* represents how the individual's predictor variable affects his or her *own* outcome (e.g. the effect of perceived social support on depressive symptoms), while the *partner effect* represents how the individual's predictor variable affects his or her *partner's* outcome (e.g. the effect of perceived social support in the person on the partner's depressive symptoms). Both the actor and the partner predictor and outcome variables were included within the same mixed model analysis to account for the interdependence. In our opinion the last mentioned approach might be most promising. Therefore, we have tried to translate this model to stroke patient/partner research (Figure 7.1). In Figure 7.1 model A



Method A (univariate statistical analyses)

Method B (multivariate statistical analyses on patient outcome)

Method C (multivariate statistical analyses on partner outcome)

Method D: Actor Partner Independence Model (horizontal lines are *actor* effects, diagonal lines are *partner* effects)

Figure 7.1

shows an association between a patient variable and a patient outcome, or between partner variable and partner outcome, as we perform in univariate statistical analyses. Model B and C refers to a multivariate analyses in which both patient and partner variables are included to explain/predict patient or partner outcome (respectively, **chapter 3 and 6**). Lastly, Model D refers to the Actor-Partner Interdependence Model, in which horizontal lines are *actor* effects, diagonal lines are *partner* effects). We advise to use Model D (APIM) for future dyadic research.

Methodological considerations

Some methodological considerations have already been discussed above, e.g. the instruments used, but other methodological aspects will be debated below.

Study population

In the FuPro-stroke study we recruited patients and their partners at admission to the rehabilitation centre, whereas participants in the Restore4Stroke Cohort Study were included in the acute phase in acute care hospitals. The FuPro-stroke study thereby focused solely on the inpatient stroke rehabilitation population, which is about 15% of the total stroke population. The patients, and thereby the partners, in the FuPro-stroke study were relatively young in comparison with other (stroke) populations.[17,30,31] The patients were further on average moderately disabled.

In the Restore4Stroke Cohort Study we included patients (and partners) in the acute phase post-stroke and we followed them irrespective of discharge setting. Our inclusion criteria were broad and we did not exclude patients suffering a severe stroke in advance. Most patients included in the study however appeared to experience a mild stroke. The most seriously affected patients might not have been able to give their informed consent in the first week post-stroke, and could therefore be underrepresented in this study. This is reflected by the almost 80% of patients discharged home after hospitalization. This is more than expected based on data collected by Kennisnetwerk CVA,[32] which show that approximately 60–65% of the stroke patients return home after hospitalization. However, patients with a partner may be more likely to be discharged home because of the support which can be giving by the partner. In the Restore4Stroke Patient Cohort study, which included patients irrespective of having a partner, approximately 70% of the patients were discharged home, which is closer but not similar to the figures from the Kennisnetwerk CVA. We therefore seem to have missed the group of patients who were most seriously affected, especially the haemorrhagic strokes, and who might be admitted to long stay facilities such as a nursing home. Nevertheless, we feel that the FuPro-stroke study and the Restore4Stroke partner Cohort study complement each other well and together provide a broad overview of the stroke patient and partner outcome in the Netherlands.

Study design

In both the FuPro-stroke study and Restore4Stroke Partner Cohort Study large groups of stroke patients and their partners were included. The longitudinal design of these studies resulted in follow up assessments up to three and two years post-stroke respectively. As presented in **chapter 2**, few studies have examined the relationship between social support and patient outcome with a longitudinal design. Studies focusing on social support and caregiver outcomes after stroke used also most often a cross-sectional design.[33,34] Therefore, in this Thesis we added new information to the existing literature on social support and patient/partner outcome in the chronic phase after stroke.

Developments in stroke care

When considering the results of our Thesis, developments in stroke care have to be taken into consideration. Participants of the FuPro-stroke study and the Restore4Stroke Partner Cohort Study were recruited in two different eras, respectively 2000–2002 and 2011–2013. Medical care is constantly changing, which may result in changes in stroke characteristics and outcomes. In the era of FuPro-stroke study stroke units were being established and computed tomography (CT) had become more and more routinely administered. In the following period, secondary prevention in terms of statins and anti-hypertensives and intravenous thrombolysis has become a routine treatment for patients with acute ischemic stroke. Altogether, an increasing proportion of patients receiving thrombolysis, stroke unit care and secondary prevention may have contributed to better patient outcomes.[35,36]

Another change in the last decade, is the shortening of length of hospital stay.[32,37] Most likely, this has multiple causes, which, besides more effective acute care, also may include budgetary cuts in hospitals and a government which has prioritized the expansion of home care above institutional care. A shortened length of hospital stay does not necessarily have to result in a lower proportion of patients discharged to inpatient rehabilitation setting, because the decision about discharge destination has also to be made earlier after stroke. In a recent article,[36] a comparison between the inpatient rehabilitation stroke patient in the era of FuPro-stroke study and today was made: length of hospital stay and length of inpatient rehabilitation stay have shortened. However, stroke severity (assessed with the Barthel Index) of both patient groups was similar at start of the inpatient rehabilitation. The last finding implies that today patients similar to the FuPro-stroke participants are being discharged to inpatient rehabilitation, which confirms today's relevance of the results of the FuPro-stroke study. Moreover, it implies that these patients (and their partners) have less time to become prepared for being at home post-stroke, which makes the challenge to identify partners at risk for adverse outcome even more urgent.

Variables measured

As always in research, the number of factors taken into account could not be infinite. We did not assess the premorbid scores on partners' and patients' social support network or quality of life (in terms of anxiety or depressive symptoms, and partner burden). Inclusion of these factors might have raised the amount of explained variance and might have clarified unique stroke caregiving impacts better. However, assessing premorbid scores on subjective issues after an overwhelming event, like stroke, might be affected by recall bias. Furthermore, results of the Restore4Stroke Patient Cohort Study (focusing on the stroke patient) revealed that psychological factors (for instance, neuroticism) are more important in stroke patients' quality of life than demographic and stroke-related factors.[38] If we would have taken more psychological factors of partners into account, this would have been helpful in identifying even more relevant factors influencing partners' burden, anxiety or depressive symptoms.

Clinical implications

In this Thesis we have endorsed the stroke literature in that a substantial part of the stroke patients and partners show adverse outcomes (resp. patients' depressive symptoms in **chapter 3** and partners' burden, anxiety and depressive symptoms in **chapter 6**). So, how can we use the current knowledge about the interrelationships between the stroke patient and partner to improve their outcomes?

First, health care professionals should become more aware of this interrelationship. Stroke patients and their partners should be considered as a dyadic unit both by health professionals and researchers, as they are interdependent in their relationship; patient's outcome influences partner's outcome and vice versa. We believe that the use of combined ICF-models (**chapter 1**, Figure 1.1) can be helpful to educate professionals.

Second, our results imply that patients and their partners should be followed up to the chronic phase. Patients' perceived social support declines in the first three years post-stroke (**chapter 3**). Furthermore, the high levels of burden, anxiety or depressive symptoms experienced by partners in the sub-acute phase post-stroke are likely to become chronic problems since only anxiety symptoms declined in the first year post-stroke (**chapter 6**).

Monitoring the social support network of both patient and partner should be part of regular evaluation in post-stroke follow up. Ideally more perspectives of social support are taken into account, like the type, source and the satisfaction with the perceived support. Perhaps the sentence, 'Who needs what kind of support (type) when (timing) from who (source)?' may be helpful to keep in mind when assessing patient's or partner's needs. This attention is especially needed in today's Dutch society. The role of informal care from partners (and other relatives) is increasing due to a governmental paradigm shift focusing on increasing responsibilities for citizens in taking care of themselves (if necessary with help of other citizens). In a family with a person with a disability, such as stroke, the demands can be high and people are at risk of reduced quality of life, increased burden or emotional problems). In this situation it is extremely important for patients and partners to perceive they are equipped to the 'patient-job' or 'caregiver-job'. Education and training of partners already in the sub-acute phase may reduce partners' burden, anxiety and depressive symptoms and improve both patients' and partners' quality of life at three months and one year post-stroke.[39] Patients and partners have to be well informed on the long-lasting consequences of stroke, have to know how to monitor their own quality of life and how to ask purposeful for help. Respite care or financial support, such as a personal budget ('PGB'), to purchase care and support their selves, may be helpful as well. Furthermore, peer support or patient associations (like Hersenletsel.nl) could provide support to patients and their partners as well.

Third, as we show in **chapter 5**, negative and positive caregiving experiences can co-exist and therefore should be assessed separately. Even though a good measure of positive caregiving experiences does not exist to date (**chapter 4**), we recommend assessing both negative and positive caregiving experiences. Asking partners if they experience any positive aspects or rewards might be a start to further discuss the topic of positive caregiving experiences. Counselling should be targeted (for instance, enhancing the awareness of positive caregiving experiences might buffer negative experiences).

Fourth, with regard to partner outcome in terms of burden, and anxiety and depressive symptoms, partners should be monitored not only in the acute phase but also in the chronic phase. It is important to trace partners experiencing high burden, anxiety or depressive symptoms in the sub-acute phase (i.e. two months post-stroke), and to identify partners who are at risk of long-term (one year post-stroke) adverse outcome by measuring these outcomes in the sub-acute phase in combination with patients' depressive symptoms and partners' psychosocial factors (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support).

Recommendations for future research

Future research should focus on several aspects. First, more research is needed on subgroups of partners of stroke patients, such as partners of patients discharged home versus inpatient rehabilitation, and include sufficient numbers of participants in each subgroup. Furthermore, in order to identify unique stroke caregiving impacts it might be beneficial to compare caregivers with non-caregivers, or to compare the situation before and after stroke.

Second, research into social support and patient/partner outcomes should use a broad spectrum of social support measures. Recently, our study group started an intervention study into the effect of family group conferences for patients and their relatives on self-efficacy, participation and emotional functioning.[40] In this project, type, frequency and source of social support are all taken into account.

Third, in the present Thesis we provide a starting point for unravelling the prediction of partner outcome, especially by focusing on psychosocial factors. More research should be conducted to understand possible causal relationships between psychosocial factors and partner outcome. Furthermore, as mentioned above, research on patient and partner outcome should be conducted from a dyadic perspective.

Fourth, more knowledge is needed about ways to change psychosocial factors. For instance, it is unclear if and how positive caregiving experiences can be triggered or strengthened. As discussed above, the underlying concept of positive caregiving experiences should be clarified, for instance by conducting qualitative research. To the best of our knowledge, no intervention studies especially investigating improving partner outcome by focusing on positive caregiving experiences have been described in the literature to date. Theories like the Effort-Reward Imbalance theory and the Demand-Control theory provide some clues to improve partner outcome, in which improving positive caregiving experiences but also social support might act as mediating factors: improving the level of control (or reducing the loss of control), developing better coping strategies to learn to adapt and manage their new caregiver situation. In literature, a recent review has confirmed that focusing on coping and stress management is more promising than psycho-education only[41] and more and more studies are focusing on this topic.[e.g. 42,43]

Finally, we think that E-health interventions are promising and recently an intervention study focusing on psycho-education and learning problem solving strategies to help caregivers to deal with patients' cognitive and emotional consequences of stroke.[44]

Altogether, we recommend that further research into patient and partner outcome should contain a broad spectrum of social support measures, an adequate positive caregiving experience measure and caregivers' personal characteristics. Moreover, both patient and partner variables should be taken into account to investigate partner outcome from a dyadic perspective.

Conclusions

The present Thesis contributes to our understanding of the interrelationship between the stroke patient, social support and the caregiver (in our Thesis: the partner).

- Social support is a broad concept, which cannot be seen as a one-dimensional factor. Stroke patients experience a decline of social support. Patients' social support is significantly associated with patients' health-related quality of life and depressive symptoms.
- Positive and negative caregiving experiences are two relatively independent constructs. Both are related to partner outcome, and positive experiences can buffer the negative caregiving experiences to some degree.
- A substantial part of the stroke partners experience high levels of burden, anxiety or depressive symptoms in the sub-acute and the chronic phase post-stroke, in which the levels of burden and depressive symptoms did not decline over time.
- Partners with long-term (one year) adverse outcomes can be identified in the sub-acute phase (i.e. two months post-stroke), by measuring these outcomes in the sub-acute phase in combination with patients' depressive symptoms and partners' psychosocial factors (satisfaction with their relationship, proactive coping, self-efficacy and everyday social support). Patient and partner outcome should therefore be assessed from a dyadic perspective.

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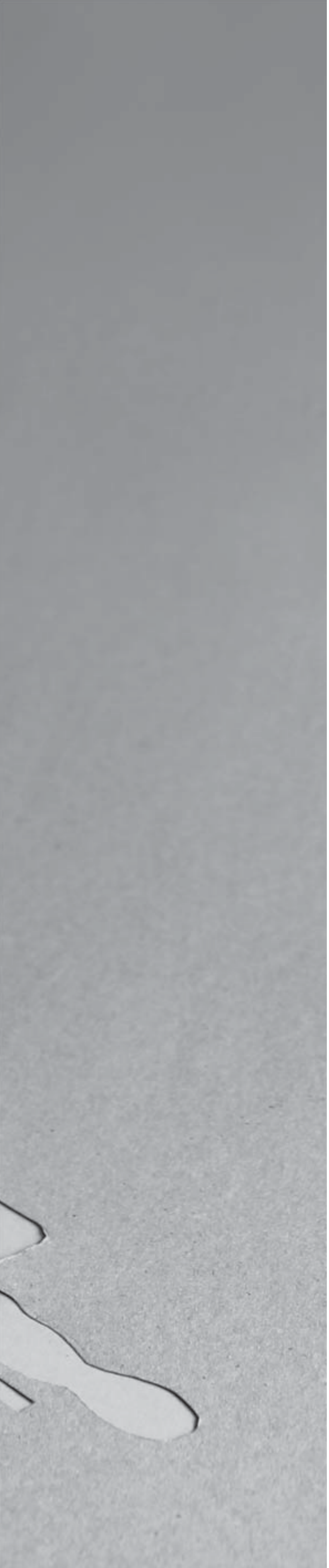


Summary

Stroke is an overwhelming event for both stroke patient and partner. Each year, about 45,000 people suffer a first stroke in the Netherlands, which can lead to death and to physical, cognitive and psychosocial consequences in the survivors. Stroke affects the interpersonal relationship between patient and partner (or other family members) as well. Many partners become caregiver, because many patients need support as a consequence of their physical and/or cognitive impairments. Support given by the partner may positively influence the patient's health, but the partner's own life also changes considerably and this may negatively influence the partner's own health (**chapter 1**, Figure 1.1) as caring for a stroke patient takes time as well as physical and emotional effort. Managing the new situation post-stroke is therefore challenging for both patients and partners, and both may need social support from their environment.

Most studies into caregiving of stroke patients have focused on the negative impact of caregiving. Positive caregiving experiences have also been reported. However, only few studies into positive caregiving experiences of caregivers of stroke patients are available.

In this Thesis, findings of two prospective cohort studies, the FuPro-stroke study (The Functional Prognosis of Stroke study, from start of inpatient rehabilitation up to three years post-stroke) and the Restore4Stroke study (from hospital setting up to two years post-stroke) are presented. The general aim of this Thesis was to explore the interrelationship between the stroke patient and partner by focusing on associations between social support experienced by stroke patients and their quality of life in Part I, and associations between characteristics of stroke patients and their partner with the partner's experienced burden and quality of life in Part II.

In **chapter 1** an overview of the context of this Thesis was given. The consequences of stroke for both patient and partner were discussed on the basis of the International Classification of Functioning, Disability and Health (ICF). The interrelationship between the stroke patient, social support and the partner was outlined by using a combined ICF-model (Figure 1.1 and 1.2). Also the study designs of the FuPro-stroke study and the Restore4Stroke study were presented. Finally, the main aims and the outline of this Thesis were described.

Part I Social support in the stroke patient

In **chapter 2** the results of a systematic review on associations between social support and patients' health-related quality of life are presented. A total of 11 articles were included in which the following aspects of social support were assessed: overall (perceived) social support, satisfaction with social support, emotional support, informational support, instrumental support, appraisal support, social companionship, network size, number of supporting persons and change of frequency of contacts. Most of these articles studied overall perceived social support without further specification of type or source of support. The results show positive, but not consistent, relations between social support and patients' health-related quality of life. Emotional support was the most often investigated subtype of social support and showed the strongest relationships with health-related quality of life, compared to other subtypes such as informational or instrumental support. However, due to the small number of studies and the heterogeneity in methods assessing social support, a clear statement about the specific influence of social support type or source could not be made. Important methodological limitations of this review were that only 11 articles could be included, none of them examined causal pathways, and that a meta-analysis was impossible. In conclusion, social support is significantly associated with stroke patients' health-related quality of life. Further research is needed to investigate cause-effect relationships.

Chapter 3 focused on the course of social support and the relationships between social support and patients' depressive symptoms in the first three years post-stroke. A total of 249 stroke patients from the FuPro-stroke study were included in this study. Social support is a broad concept and the measure we used divides it into three subtypes; 'everyday social support' (in which social companionship and daily emotional support are involved), 'support in problem situations' (including instrumental support, informative support, and emotional support in times of trouble) and 'esteem support' (which includes support resulting in improved self-esteem and approval). More than one-third of these stroke patients showed depressive symptoms at admission for inpatient rehabilitation. Total perceived social support and its three subtypes declined significantly from inpatient rehabilitation until three years post-stroke. The advantage of examining subtypes of social support in addition to a total score was established since divergent relationships were found between the three subtypes and patients' depressive symptoms. More everyday social support and esteem support were associated with less patients' depressive symptoms, whereas social support in problem situations was associated with more patients' depressive symptoms.

In the longitudinal analysis, only social support in problem situations showed a significant positive relationship with patients' depressive symptoms over time; more social support in problem situations was a predictor of more depressive symptoms.

No effect-modification by variables reflecting psychical or cognitive impairments was found. These results indicate that social support should be seen as a multi-dimensional factor. Ideally multiple perspectives on social support are taken into account, like the type, source and satisfaction with support. We advise to monitor stroke patients' social support network as part of regular follow-up visits.

Part II The partner of the stroke patient

The second part of this Thesis focused on the partner of the stroke patient. In **chapter 4** the psychometric properties of the Caregiver Strain Index Expanded were compared with those of the Caregiver Strain Index. The potential benefit of the Caregiver Strain Index Expanded is that it measures positive aspects of caregiving, by enlarging the original Caregiver Strain Index (13 items) with five positively phrased items. We conducted a cross-sectional validation study including 173 partners who participated in the Restore4troke study and completed the Caregiver Strain Index Expanded at six months post-stroke.

We compared the construct validity by means of a principal component analysis and assessing internal consistency, and convergent validity by examining the correlations between the Caregiver Strain Index Expanded, the original Caregiver Strain Index and the positive subscale of the Caregiver Strain Index Expanded on the one hand, and the measures of partners' mood and life satisfaction and the stroke patients' physical and cognitive functioning on the other. The results showed good internal consistency of the total Caregiver Strain Index Expanded, with Cronbach's alpha .73 in the original form and .82 with the scores on the positive items reversed. However, the internal consistency of the separate positive subscale was unacceptable with a value of .51. In addition, the five positive phrased items showed a large ceiling effect, because no less than two-thirds of all partners responded affirmatively to all five positive items. Although, convergent validity of the Caregiver Strain Index Expanded was shown, regression analyses showed no additional value of the positive items above the original Caregiver Strain Index; both showed about the same percentage of the explained variance of partners' mood and life satisfaction. Therefore, we do not advise the Caregiver Strain Index Expanded to measure positive caregiver experiences. As far as we know, the perfect measure of positive caregiving experiences does not exist to date, and we discuss in this chapter (and in **chapter 7**) possible directions for the development of a better measure of positive caregiving experiences.

Chapter 5 presents the direct and indirect associations between negative and positive caregiving experiences in partners of stroke patients and partners' life satisfaction at three years post-stroke. Data of 121 partners who participated in the FuPro-stroke study could be included in this study.

Negative and positive caregiving experiences were measured with the Caregiver Reaction Assessment, which consists of four subscales measuring negative experiences and one subscale measuring positive experiences. This study revealed that most partners experienced at least some positive aspects of caring and negative and positive caregiving experiences can co-exist. Both negative and positive caregiving experiences were related to partners' life satisfaction at three years post-stroke (correlation coefficients -.74 and .35, respectively). Furthermore, positive caregiving experiences mediated the impact of negative caregiving experiences on life satisfaction; partners who perceived both many negative and positive caregiving experiences reported significantly higher life satisfaction scores than partners who perceived many negative and few positive caregiving experiences.

This study suggest that negative and positive caregiving experiences are two relatively independent constructs and should be assessed separately. In addition, counselling can not only be targeted at minimizing negative caregiving experiences, but also at enhancing the awareness of positive caregiving experiences to improve partner's life satisfaction.

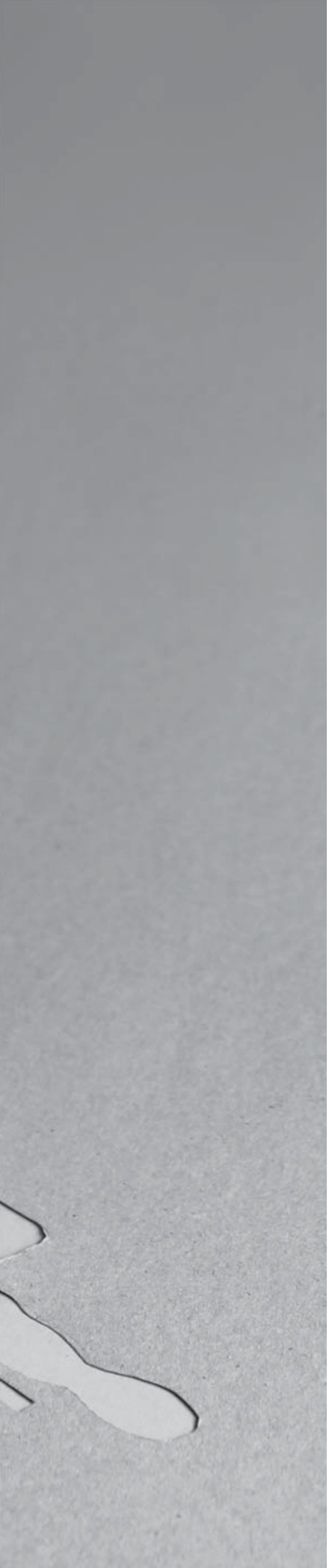
In **Chapter 6** we examined partner outcomes in terms of partners' burden, anxiety and depressive symptoms. First, the levels of and factors explaining partners' burden, anxiety and depressive symptoms at two months post-stroke were presented. Second, partners' burden, anxiety and depressive symptoms at one year-post stroke were predicted based on patient and partner characteristics available at two months post-stroke. Special attention was paid to partners' psychosocial variables; satisfaction with their relationship, proactive coping, self-efficacy and three subtypes of social support (everyday social support, social support in problem situations and esteem support). At one year post-stroke, 183 partners participating in the Restore4Stroke study completed at least one of the three outcome measures and were included in this study.

The study revealed that many partners suffered from high levels of burden, anxiety and depressive symptoms two months and one year post-stroke. Almost a quarter (24.6%) of the partners reported high levels of burden and 12.8% of all partners reported high levels of depressive symptoms at two months post-stroke. The proportion of partners experiencing high levels of anxiety was even larger at two months post-stroke (32.0%). Partners' anxiety (from 32.0% to 19.2%), but not burden and depressive symptoms, decreased between two months and one year post-stroke. At two months and one year post-stroke, these outcomes were associated with more partner variables than patient variables. The psychosocial factors of the partner: proactive coping, self-efficacy, relationship satisfaction and everyday support were also determinants of partner outcomes at two months and one year post-stroke.

Partner outcomes, in terms of burden, anxiety and depressive symptoms, at one year post-stroke could be predicted to a large degree in the sub-acute phase at two months post-stroke; high levels of partner burden, anxiety and depressive symptoms at two months were de strongest predictors of high levels of partner outcomes at one year post-stroke. Besides these partner variables, patient variables were important: patients' anxiety symptoms at two months post-stroke is a significant predictor in the prediction of partners' burden and anxiety symptoms at one year post-stroke.

Therefore, we recommend to monitor partners as well as patients in the sub-acute phase post-stroke to identify partners experiencing high burden, anxiety and depressive symptoms and to provide them with appropriate support or counselling.

Finally, in **chapter 7** we discuss our main findings by focusing on three main topics of this Thesis; namely, 'social support after stroke', 'positive caregiving experiences' and 'stroke from a dyadic perspective'. Methodological considerations related to the study population, study design, developments in stroke care and variables measured were debated. Finally, clinical implications and recommendations for future research were provided. The present Thesis contributes to our understanding of the interrelationship between the stroke patient, social support and the caregiver (in our Thesis: the partner). We revealed that both patients' and partner' variables are important predictors of partner outcome. Stroke patients and their partners should be considered as a dyadic unit both by health professionals and researchers, as they are interdependent in their relationship. Furthermore, social support and both negative and positive caregiving experiences should be taken into consideration during stroke care.



Samenvatting

Dit onderzoek richt zich op patiënten die leven met de gevolgen van een beroerte en hun partners. Elk jaar krijgen ongeveer 45.000 mensen een beroerte in Nederland. Een beroerte kan niet alleen leiden tot het overlijden van de patiënt, maar ook tot fysieke, cognitieve en psychosociale gevolgen bij hen die de beroerte overleven. Het krijgen van een beroerte heeft dan ook een grote impact op de patiënt, maar ook op zijn of haar partner. Veel partners worden mantelzorger, omdat veel patiënten hulp nodig hebben vanwege hun fysieke en/of cognitieve beperkingen. Steun van de partner kan de gezondheid van de patiënt positief beïnvloeden, maar verandert ook het leven van de partner. Het zorgen voor een patiënt kost vaak tijd en fysieke en emotionele inspanningen. Dit kan een negatieve invloed hebben op de fysieke en mentale gezondheid van de partner (**hoofdstuk 1**, Figuur 1.1). Het goed leren omgaan met de nieuwe situatie na een beroerte is daarom een uitdaging voor zowel patiënten als hun partners. Beiden zullen daarbij steun nodig hebben van hun omgeving.

De meeste studies over mantelzorg voor patiënten na een beroerte hebben zich gericht op de negatieve gevolgen voor de mantelzorger. Ondanks dat er ook positieve mantelzorgervaringen zijn gerapporteerd, is hier slechts weinig onderzoek naar gedaan.

In dit proefschrift presenteren wij de resultaten van twee prospectieve cohortstudies: De FuPro-stroke studie ('The Functional Prognosis of Stroke study'), waarbij patiënten en partners vanaf het starten van de klinische revalidatiebehandeling werden gevolgd tot drie jaar na de beroerte, en de Restore4Stroke studie, waarbij patiënten en hun partners vanaf de eerste week na de beroerte tot twee jaar later werden gevolgd. Het overkoepelende doel van de studies in dit proefschrift was om de onderlinge interacties tussen de patiënt en de partner te onderzoeken. In het eerste deel ligt de focus op de relaties tussen de ervaren sociale steun van de patiënt enerzijds en de kwaliteit van leven van de patiënt anderzijds. In deel 2 worden relaties tussen de karakteristieken van de patiënten en hun partner én de ervaren zorglast en kwaliteit van leven van de partner beschreven.

In **hoofdstuk 1** wordt een overzicht van de samenhang van dit proefschrift gegeven. De gevolgen van de beroerte voor zowel de patiënt als de partner worden beschreven met behulp van de Internationale Classificatie van Functie, Handicap en Gezondheid (ICF-model). Door het combineren van twee ICF-modellen, het ICF-model van de patiënt en dat van de partner, worden de onderlinge interacties tussen de patiënt, de sociale steun en de partner gespecificeerd (Figuur 1.1 en 1.2). Daarnaast wordt in dit hoofdstuk de studieopzet van zowel de FuPro-stroke studie als van de Restore4Stroke studie gepresenteerd en de belangrijkste doelstellingen van het onderzoek beschreven.

Deel I Sociale steun bij de patiënt na een beroerte

In **hoofdstuk 2** worden de resultaten van een systematisch literatuuronderzoek beschreven naar de samenhang tussen sociale steun en gezondheidsgerelateerde kwaliteit van leven van de patiënt. In totaal zijn er 11 artikelen gebruikt die de volgende aspecten van sociale steun hebben onderzocht: algemene ervaren sociale steun, tevredenheid met sociale steun, emotionele steun, informatieve steun, instrumentele steun, waarderingssteun, sociaal gezelschap, grootte van het netwerk, aantal personen dat steun geeft en verandering in frequentie en aantal contacten na een beroerte. In het merendeel van deze artikelen werd algemene ervaren sociale steun gemeten, zonder verdere specificatie van type of bron van steun. De artikelen lieten positieve, maar geen consistente, relaties zien tussen sociale steun en gezondheidsgerelateerde kwaliteit van leven van de patiënt. Het meest onderzochte subtype van sociale steun was emotionele steun en deze liet ook de sterkste relatie met gezondheidsgerelateerde kwaliteit van leven zien in vergelijking met andere subtypes van sociale steun, zoals informatieve of instrumentele steun. Door het kleine aantal artikelen en de heterogeniteit van de gebruikte methodes kon een duidelijke conclusie over de specifieke invloed van het subtype of de bron van sociale steun op gezondheidsgerelateerde kwaliteit van leven niet worden getrokken. Belangrijke methodologische beperkingen van deze review waren a) het kleine aantal geïncludeerde artikelen, b) dat in geen van de studies causale verbanden werden onderzocht en c) dat het uitvoeren van een meta-analyse niet mogelijk was. Concluderend kunnen wij stellen dat deze review het belang van sociale steun voor de gezondheidsgerelateerde kwaliteit van leven van de patiënt na een beroerte onderstreept, maar dat meer onderzoek nodig is om te weten te komen welke aspecten van sociale steun daarvoor belangrijk zijn en om causale verbanden te onderzoeken.

In **hoofdstuk 3** worden het beloop van sociale steun en de relatie tussen sociale steun en depressieve klachten van de patiënt in de eerste drie jaar na de beroerte beschreven. Voor deze studie includeerden wij een totaal van 249 patiënten na een beroerte uit de FuPro-stroke studie. Meer dan een derde van deze patiënten had depressieve klachten bij start van de klinische revalidatiebehandeling. Sociale steun werd gemeten met een vragenlijst voor ervaren sociale steun, met drie subschalen: ‘alledaagse sociale steun’ (waarin sociaal gezelschap en dagelijkse emotionele steun opgenomen zijn), ‘sociale steun in probleemsituaties’ (waarin instrumentele steun, informatieve steun en emotionele steun in probleemsituaties opgenomen zijn) en ‘waarderingssteun’ (steun die resulteert in toegenomen zelfvertrouwen en acceptatie). Zowel de totale sociale steun-score als de scores van de drie subtypes namen significant af in de periode vanaf de start van de klinische revalidatiebehandeling tot drie jaar na de beroerte. Verder vonden wij uiteenlopende relaties tussen de drie subtypes van sociale steun en depressieve klachten van de patiënt. De mate van alledaagse sociale steun en waarderingssteun hing negatief samen met depressieve klachten van de patiënt, terwijl sociale steun in probleemsituaties positief samenhing met depressieve klachten. Sociale steun in probleemsituaties was de enige voorspeller van meer depressieve klachten in de longitudinale analyses. Er werd geen effect-modificatie door fysieke of cognitieve beperkingen gevonden. Deze resultaten geven aan dat sociale steun beschouwd moet worden als een multidimensionale factor die samenhangt met het bestaan van depressieve klachten. Idealiter worden meerdere aspecten van sociale steun onderzocht, zoals type, bron of tevredenheid met steun. Wij adviseren om het sociale steun netwerk van patiënten na een beroerte in kaart te brengen en te evalueren tijdens de reguliere controleafspraken.

Deel II De partner van de patiënt na een beroerte

In het tweede deel van dit proefschrift gaat de aandacht uit naar de partner van een patiënt na een beroerte. In **hoofdstuk 4** worden de psychometrische eigenschappen van de Caregiver Strain Index Expanded vergeleken met die van de Caregiver Strain Index. Het potentiële voordeel van de Caregiver Strain Index Expanded is dat deze ook positieve mantelzorgervaringen meet. In deze schaal zijn namelijk vijf positief gefraseerde items toegevoegd aan de originele Caregiver Strain Index (welke van origine uit 13 items bestaat). Wij voerden een cross-sectionele validatiestudie uit bij 173 partners uit de Restore4Stroke studie die zes maanden na de beroerte de Caregiver Strain Index Expanded hadden ingevuld.

Hierbij onderzochten wij de constructvaliditeit met een principale-componentenanalyse en het bepalen van de interne consistentie. Daarnaast onderzochten wij de convergente validiteit aan de hand van de correlaties tussen de Caregiver Strain Index Expanded, de originele Caregiver Strain Index en de positieve subschaal van de Caregiver Strain Index Expanded enerzijds, en de scores op meetinstrumenten voor stemming en levenstevredenheid van de partner en de fysieke en cognitieve beperkingen van de patiënt anderzijds. De resultaten lieten een goede interne consistentie zien van de totale Caregiver Strain Index Expanded, met een Cronbach's alpha van .73 in de originele vorm en van .82 met de omgedraaide scores van de positieve items. Daarentegen was de interne consistentie van de positieve subschaal als losse schaal onacceptabel met een waarde van .51. De positieve subschaal liet ook een groot plafondeffect zien, waarbij niet minder dan tweederde van de partners positief antwoordde op alle vijf de positieve items. Alhoewel een goede convergente validiteit van de Caregiver Strain Index Expanded werd gevonden, lieten regressieanalyses geen toegevoegde waarde zien van de vijf positieve items bovenop de originele Caregiver Strain Index; beide verklaarden namelijk ongeveer hetzelfde percentage van de variantie van stemming en levenstevredenheid van de partner. Op basis van deze resultaten adviseren wij de Caregiver Strain Index Expanded niet te gebruiken om positieve mantelzorgervaringen te meten. Zover wij weten bestaat er tot nu toe geen perfect meetinstrument voor positieve mantelzorgervaringen. Daarom bediscussiëren wij in dit hoofdstuk (en in **hoofdstuk 7**) mogelijke richtingen voor het ontwikkelen van een beter instrument.

Hoofdstuk 5 presenteert de directe en indirecte associaties tussen negatieve en positieve mantelzorgervaringen van partners van patiënten na een beroerte en de levenstevredenheid van deze partners drie jaar na de beroerte. Wij gebruikten voor deze studie data van 121 partners die deelnamen aan de FuPro-stroke.

Negatieve en positieve mantelzorgervaringen werden gemeten met de Caregiver Reaction Assessment, welke bestaat uit vier subschalen die negatieve mantelzorgervaringen meten en één subschaal die positieve mantelzorgervaringen meet. Deze studie toonde aan dat de meeste partners op z'n minst enkele positieve aspecten van mantelzorg bemerkten en dat negatieve en positieve mantelzorgervaringen naast elkaar kunnen bestaan. Zowel negatieve als positieve mantelzorgervaringen waren gerelateerd aan de levenstevredenheid van de partner (respectievelijk correlatiecoëfficiënten van -.74 en .35). Daarnaast fungeerden positieve mantelzorgervaringen als een mediator in de relatie tussen negatieve mantelzorgervaringen en levenstevredenheid; partners die veel negatieve en veel positieve mantelzorgervaringen hadden, rapporteerden een hogere levenstevredenheid dan partners die veel negatieve en weinig positieve mantelzorgervaringen hadden.

De resultaten van de analyses in **hoofdstuk 5** impliceren dat negatieve en positieve mantelzorgervaringen twee relatief onafhankelijke constructen zijn en apart gemeten zouden moeten worden. Ook betekent dit dat counseling niet alleen gericht moet zijn op het minimaliseren van de negatieve mantelzorgervaringen, maar ook gericht dient te zijn op het bevorderen van het bewustzijn van positieve mantelzorgervaringen om zodoende de levenstevredenheid van de partner te verbeteren.

In de studie in **hoofdstuk 6** onderzochten wij de kwaliteit van leven van de partner in termen van ervaren zorglast, angst- en depressieve klachten. Allereerst werden de mate van ervaren zorglast, angst- en depressieve klachten op één jaar na de beroerte en de determinanten daarvan onderzocht. Ten tweede werd geprobeerd de ervaren zorglast, angst- en depressieve klachten op één jaar na de beroerte te voorspellen op basis van patiënt- en partnerkarakteristieken gemeten op twee maanden na de beroerte. Speciale aandacht werd besteed aan de psychosociale variabelen van de partner: de tevredenheid van de partner met zijn/haar relatie, proactieve coping, zelf-effectiviteit en drie subtypes van ervaren sociale steun (alledaagse sociale steun, sociale steun in probleemsituaties en waarderingssteun). Op één jaar na de beroerte hadden 183 partners minimaal één van de drie uitkomstmaten volledig ingevuld en werden geïncludeerd in deze studie.

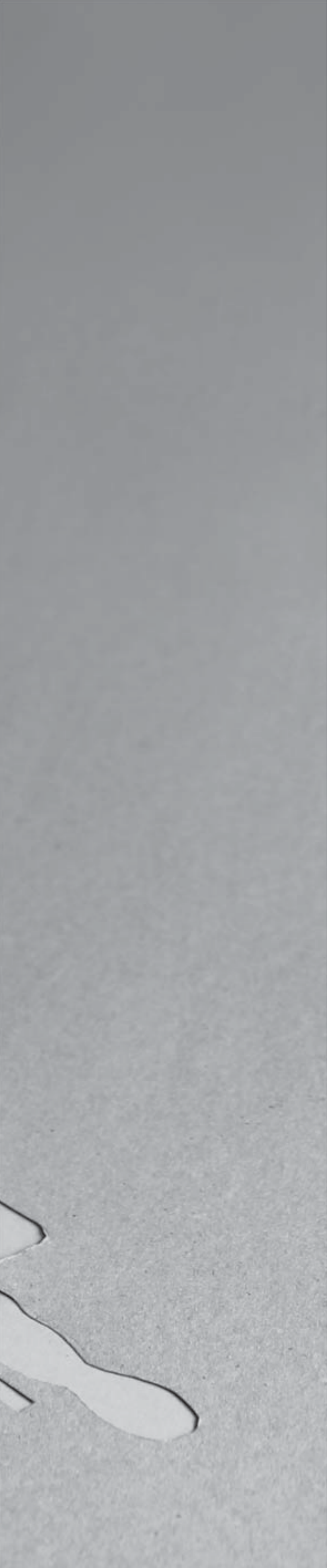
De resultaten van deze studie lieten zien dat veel partners een hoge ervaren zorglast, angst- en depressieve klachten bemerkten op twee maanden en één jaar na de beroerte. Bijna een kwart (24,6%) van de partners rapporteerde een hoge zorglast en 12,8% van de partners rapporteerde veel depressieve klachten op twee maanden na een beroerte. Het percentage partners dat een hoog niveau van angstklachten bemerkte op twee maanden na een beroerte, was zelfs nog groter (32,0%). Alleen het percentage partners met verhoogde angstklachten, maar niet de percentages van ervaren zorglast en depressieve klachten, daalde tussen twee maanden en één jaar na een beroerte (van 32,0% naar 19,2%). Op twee maanden en één jaar na een beroerte waren de uitkomstmaten sterker geassocieerd met partnervariabelen dan met de patiëntvariabelen. De volgende psychosociale factoren van de partner waren determinanten van partneruitkomsten op twee maanden en één jaar na een beroerte: de tevredenheid van de partner met zijn/haar relatie, proactieve coping, zelf-effectiviteit en alledaagse sociale steun.

De kwaliteit van leven van de partner in termen van ervaren zorglast, angst- en depressieve klachten op één jaar na een beroerte kon al voor een groot deel in de subacute fase, namelijk twee maanden, na een beroerte worden voorspeld. De sterkste voorspellers waren de mate van ervaren zorglast, angst- en depressieve klachten van de partner op twee maanden na een beroerte. Behalve partnervariabelen bleken ook variabelen van de patiënt belangrijk. Zo was de mate van angstklachten van de patiënt op twee maanden na een beroerte een significante voorspeller voor de ervaren zorglast en voor angstklachten van de partner op één jaar na een beroerte.

Daarom raden wij aan om naast patiënten ook partners in de subacute fase na een beroerte te monitoren, de partners te identificeren die een verhoogd risico lopen op een verhoogde mate van ervaren zorglast, angst- en depressieve klachten en deze te voorzien van passende steun en counseling.

Tenslotte worden in **hoofdstuk 7** de belangrijkste bevindingen samengevat en besproken aan de hand van drie belangrijke onderwerpen van dit proefschrift; namelijk ‘sociale steun na een beroerte’, ‘positieve mantelzorgervaringen’ en ‘beroerte vanuit een dyadisch perspectief’. Methodologische overwegingen gerelateerd aan de onderzoekspopulatie, de onderzoeksopzet en de gemeten variabelen worden bediscussieerd.

Tot slot worden klinische implicaties en aanbevelingen voor toekomstig onderzoek verstrekt. Wij laten in dit proefschrift zien dat zowel patiënt- als partnervariabelen belangrijke voorspellers zijn voor partneruitkomstmaten. Patiënten na een beroerte en hun partners zouden bezien moeten worden als een dyadische unit (‘een koppel’) door gezondheidsprofessionals en onderzoekers, omdat zij een eenheid vormen in hun relatie. Verder dient er tijdens de zorg na een beroerte meer aandacht te zijn voor zowel sociale steun als voor negatieve en positieve mantelzorgervaringen.



Dankwoord

Eén ding is zeker: Zonder sociale steun geen proefschrift!

Het leven is een reis, die je niet alleen maakt. Het krijgen van een CVA heeft grote impact op iemands leven en dat van hun naasten. Ik vind het daarom een voorrecht om als revalidatiearts een periode in hun leven mee te mogen wandelen en om tegelijkertijd als onderzoeker te proberen de zorg voor hen te verbeteren. De afgelopen jaren heb ik veel geleerd van allerlei mensen om mij heen; ik ben gesteund in de juiste richting maar ook bijgestuurd waar ik mis zat, en heb geprobeerd anderen steun te geven.

Graag wil ik op deze plek iedereen bedanken die de afgelopen op mijn pad meegewandeld heeft. Een aantal mensen wil ik in het bijzonder noemen:

Allereerst alle patiënten en partners die tijd en energie hebben besteed door deelname aan de FuPro-stroke studie of Restore4Stroke Cohort studie. Zonder jullie was dit hele proefschrift niet mogelijk geweest.

Prof. dr. Visser-Meily, geachte promotor, beste Anne, zonder jou had ik überhaupt nooit aan een promotietraject gedacht. Ik zie ons nog zo zitten in de kelder van het UMCU aan jouw bureau toen je die éne vraag stelde ‘Ooit gedacht aan promoveren?’. Na een enorme aarzeling van mijn kant uiteindelijk de stap gewaagd. Dank voor je vertrouwen, je input en onuitputtelijke stroom van energie.

Prof. dr. Post, geachte promotor, beste Marcel, een een rustige haven. Altijd zeer gedetailleerd, nauwkeurig én snel in de feedback. Een bewonderenswaardige combinatie. Dank ook voor je enorme hoeveelheid geduld om mij telkens weer het een en ander (over statistiek) uit te leggen.

Een artikel schrijf je gelukkig niet alleen. Naast mijn promotoren hebben verschillende coauteurs een bijdrage geleverd aan de artikelen in dit proefschrift. Marloes, ‘Restore4Stroke Cohort-partner’. Dank je wel dat ik bij jou op de rijdende trein mocht stappen en dat je je data met mij wilde delen. We hebben een heel aantal trein-, autoritten en zelfs vliegreizen gedeeld. Ik geloof dat er niet veel stiltes vielen. Vera, niet alleen co-auteur maar ook mijn opleider. Jouw kracht zat in het oog hebben voor mij als persoon in het geheel van promotie- en opleidingstraject. De gesprekken over wie ik ben en waar volgens jou mijn sterke kanten en uitdagingen als revalidatiearts liggen heb ik als zeer waardevol ervaren. Prof. dr. van den Bos, meedenkend, meeschrijvend met veel oog voor de betekenis van het onderzoek voor de dagelijkse praktijk. Prof. dr. van Heugten, het grondig doorlezen van een artikel: klopt de schrijfwijze wel, leggen we op de juiste dingen nadruk? Ik heb er veel van geleerd. Janneke, opvallend hoe snel en vaak we op één lijn zaten qua denkwijze. Ook nu in de gezamenlijke begeleiding van studenten is dit merkbaar. Christel, wat fijn dat je jouw kennis over statistiek met mij wilde delen en geduldig de analyses met mij wilde uitvoeren.

Dank aan alle leden van de beoordelingscommissie, Prof. dr. Verschuren, Prof. dr. Kappelle, Prof. dr. Trappenburg, Prof. dr. Geurts en Prof. dr. Broese van Groenou voor de bereidheid om mijn manuscript te lezen en te beoordelen.

De Restore4Stroke Partner Cohort studie maakte onderdeel uit van het grotere onderzoeksprogramma Restore4Stroke. Ik wil alle leden van het consortium bedanken voor hun kritische, maar vooral stimulerende input. Nienke, Istanbul was een ontdekkingsreis én enorm gezellig!

Meerdere revalidatiecentra en ziekenhuizen hebben meegewerkt aan de FuPro-stroke of Restore4Stroke studie. Op de achtergrond, of eigenlijk juist op de voorgrond, hebben vele artsen, verpleegkundig specialisten of andere professionals hun best gedaan patiënten en hun partners te motiveren voor deelname. Dank daarvoor! Marloes, Lenneke, Hanneke, Anne-Marije en Jetty, wat fijn dat jullie de metingen van Restore4Stroke op jullie hebben genomen.

De combinatie van een promotietraject en een specialisatie tot revalidatiearts is een (organisatorische) uitdaging. Zonder de flexibiliteit van alle supervisoren tijdens mijn opleiding zou het niet gelukt zijn om mijn onderzoekstijd zo optimaal mogelijk te benutten. Dank jullie wel voor alle ruimte!

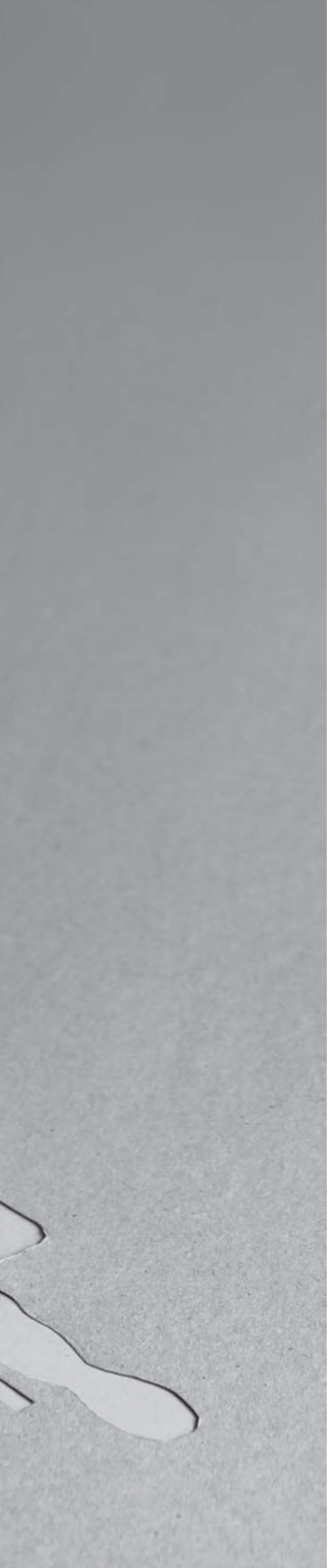
Mede-AIOS, ik hoop dat ik iets van mijn enthousiasme over wetenschappelijk onderzoek heb kunnen laten zien ('Het is leuker dan je denkt'). Maar vooral denk ik terug aan een mooie en gezellige tijd, op de werkvloer én tijdens de basiscursussen. Ondertussen verspreiden wij ons steeds meer over het land. Gelukkig is Nederland klein en de revalidatiewereld nog kleiner, dus de lijntjes zijn kort.

Lieve vrienden en naaste familieleden, jullie zullen wel eens gedacht hebben 'Nog steeds dat onderzoek?'. Ja nog steeds, maar nu kunnen jullie eindelijk iets concreets zien en horen. Dank jullie wel voor alle afleiding en ontspanning.

Lieve paranimfen, Geert en Gerrianne. Geert, op een dag besef je je plotseling dat ook kleine broertjes groot worden en wijs uit de hoek kunnen komen. In IJsland viel dus meer te ontdekken dan verwacht. Gerrianne, een jarenlange waardevolle vriendschap. En al zullen we het nooit eens worden over Oosterwolde, ik vind het heerlijk dat Jarno en ik van jullie levendige gezin mogen genieten. Bedankt dat jullie vandaag bij de verdediging van mijn proefschrift naast mij willen staan.

Lieve mam, jij en pap hebben altijd achter me gestaan en me geholpen te relativeren als ik me ergens druk om maakte. Wat ben ik blij dat jullie mijn ouders zijn. De afgelopen jaren zijn niet geheel gelopen zoals we verwacht en gehoopt hadden, maar ik weet dat jullie trots op me zijn. Samen staan we sterk!

En tot slot, lieve Jarno, je hebt me altijd gesteund in deze uit de hand gelopen hobby en vond het geen probleem weer een avond muziek te maken als ik met het onderzoek bezig was. Dank voor je liefde en belangstelling. Dit hoofdstuk is voorbij, de muziek blijft, maar laten we vooral op zoek gaan naar de volgende (gezamenlijke) hobby!



About the author

Curriculum Vitae

Willeke Kruithof was born on August 18th 1986 in Zwolle, the Netherlands. She grew up in Elburg and finished secondary school at the Lambert Franckens College in Elburg (VWO, with Honours). In 2004 she started her study Medicine at the University of Utrecht. During her study her interest in rehabilitation medicine and scientific research was aroused and she wrote her first article focusing on partners of stroke patients.

After obtaining her medical degree, she worked as a physician at rehabilitation centre De Vogellanden, Zwolle. In March 2011, she started as a resident in rehabilitation medicine at De Hoogstraat Rehabilitation, Utrecht. During this training she continued conducting research, which resulted in the work described in this Thesis. In 2014, she was awarded the Livit Orthepedie Award “Most promising trainee in Rehabilitation Medicine”. Willeke finished her specialisation in Rehabilitation Medicine in February 2015, and continued working at De Hoogstraat Rehabilitation. Currently she is attached to UMC Utrecht, with special interest in patients with acquired brain injury and neuromuscular diseases.

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