Partners of patients with acquired brain injury

Impact, dyadic relationships and support

Vincent Cox

UMC Utrecht Brain Center

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Partners of patients with acquired brain injury

Impact, dyadic relationships and support

Partners van patiënten met niet-aangeboren hersenletsel
Impact, dyadische relaties en ondersteuning

(met een samenvatting in het Nederlands)

Proefschrift

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door

Vincent Cornelis Maria Cox

geboren op 3 februari 1984
te Eindhoven

Promotoren:	Prof. dr. J.M.A. Visser-Meily Prof. dr. C.M. van Heugten
Copromotor:	Dr. V.P.M. Schepers

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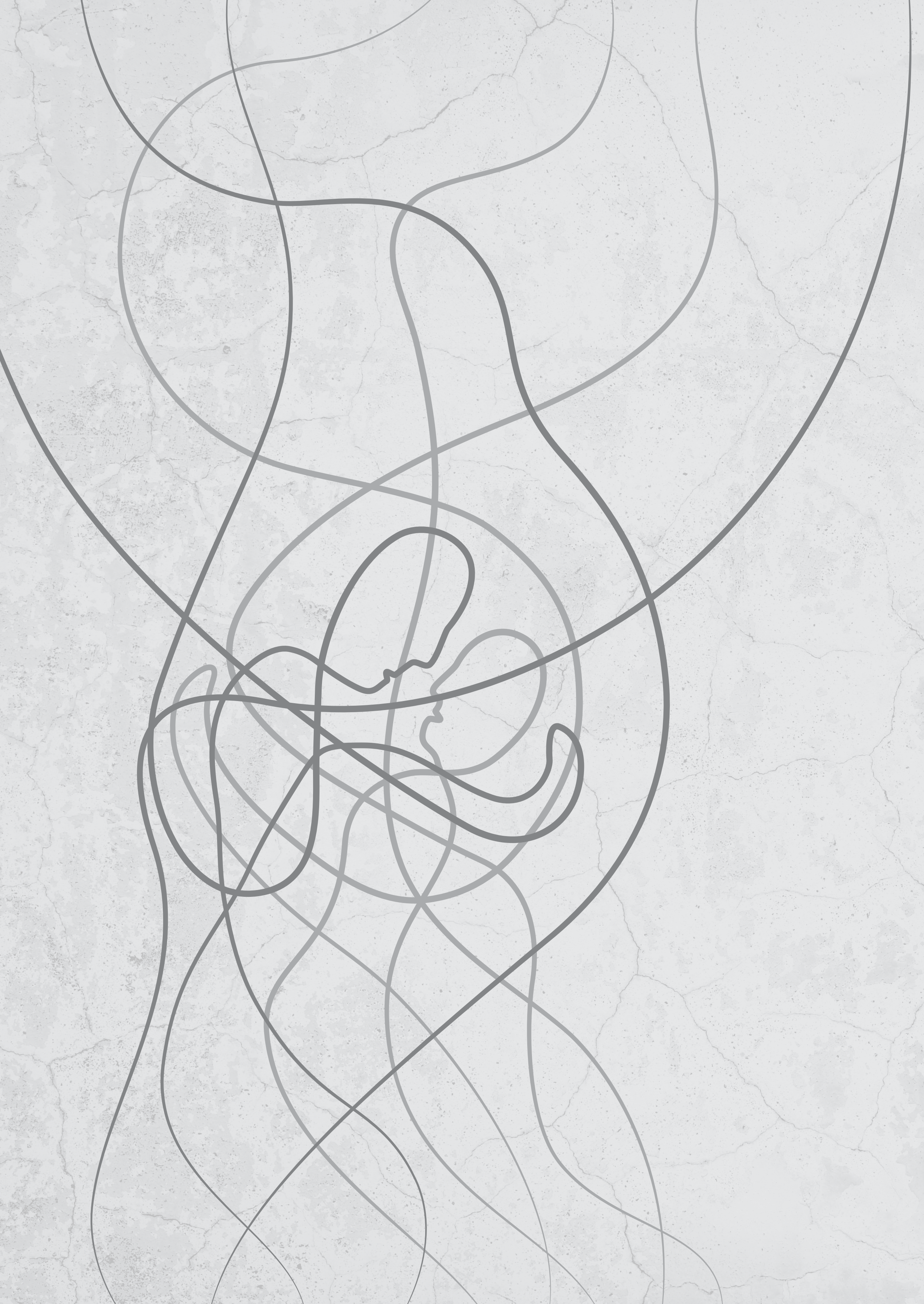
Contents



Chapter 1

General introduction

Acquired brain injury (ABI) refers to any type of brain damage that occurs after birth and is one of the most common causes of disability and death in adults.[1] Two of the primary causes of ABI are stroke and traumatic brain injury (TBI). Stroke is caused by the interruption of the blood supply to the brain.[2] TBI is an acute brain injury resulting from mechanical energy to the head from external physical forces such as a fall on the head.[3]

Every year about 45,000 people in the Netherlands suffer a first stroke.[4] The yearly incidence for TBI is estimated at 85,000.[4] Exact numbers for TBI are not available, because not every patient with TBI goes to a hospital, not even to their general practitioner. The number of people living with permanent limitations as a result of ABI in the Netherlands is estimated at 650,000.[5] Patients may experience symptoms in physical, behavioral, cognitive, communicative and psychosocial domains which can lead to loss of independence in everyday activities, reduced societal participation and poorer quality of life.[6]

The impact of ABI for the patients' partner

After hospitalization, approximately 35% of patients with stroke are referred to inpatient rehabilitation and 65% are directly discharged home from the hospital.[7] In case of traumatic brain injury, 90% of the patients are discharged to their homes.[8] Back home, it is up to the partners of the patients to resume their lives together with their loved ones. It is known from previous research that this new situation can have a significant impact on partners and that they experience various negative consequences. High percentages of burden have been reported by 25% up to 60% of the partners.[9-11] About one in three partners experience symptoms of anxiety,[9, 12] and depressive symptoms have been found in 13% to even 68% of the partners.[9, 10, 13] The percentages found vary widely and it is not yet fully known how these symptoms develop over time and which predictors contribute to this development. These results indicate that partners themselves also become patients with specific needs. Because of the ABI they must balance between their three roles as family member, caregiver, and patient.[14] The changed situation has led to more than half of the partners indicating that they are not satisfied with their lives and experience poor well-being.[15, 16] It has not been investigated in detail how this affects their daily lives and little is known about the impact on the partners' participation in society.

Patient and partner as a dyad

Even though the patient and the partner are two separate persons, each with their own problems after ABI, we should not solely consider them as individuals but also as a couple with interdependencies. There are characteristics of the partner which have an effect on outcomes of the patient and also patient characteristics that predict outcomes for the partner. For example, our research group found in previous research that the life satisfaction of patients was significantly related to the life satisfaction of their partner.[16] In addition, several studies have shown that depressive symptoms experienced by the patient are related to depressive symptoms of the partner.[16-18] These results indicate that there is an interdependent effect between patients and their partners and they should be viewed from a dyadic perspective. In this thesis we will therefore investigate the dyadic relationships within patient-partner couples.

A theoretical framework that has been developed for studying this dyadic perspective is the Actor–Partner Interdependence Model (APIM).[19, 20] This model encompasses actor effects and partner effects (Figure 1.1). An actor effect is the effect of someone's own characteristics on themselves, whereas a partner effect is the effect of this characteristic on the other person in the dyad. The terms 'actor' and 'partner' are generic terms and other terms can and should be used in different contexts.[21] The focus of this thesis is on patients with ABI and their partners and in order to avoid confusion of the word 'partner' the terms intrapersonal effects and interpersonal effects will be used instead of the actor and partner effects, respectively.

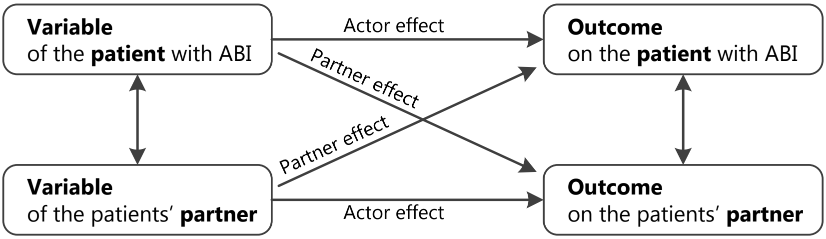


Figure 1.1. The Actor–Partner Interdependence Model (APIM).

Support for partners of patients with ABI

Because ABI has such an impact on the partner, it is clear that support for partners is needed. Therefore support for partners has been included in international and Dutch guidelines.[22, 23] Most interventions that have been developed were aimed at a broader population, including informal caregivers other than the partner. These interventions have been effective in reducing burden, anxiety, and depression among caregivers and improving their well-being.[24, 25] Psychoeducation, problem-solving therapy and skill building have been identified as effective components of such interventions.[24, 26-28]

Up to now, most interventions have been delivered face-to-face or as a combination of face-to-face with telephone counseling.[24] The Dutch healthcare system is undergoing a digital transformation and the government is encouraging the use of eHealth.[29] Using web-based interventions to support partners can be advantageous over the more traditional face-to-face methods since partners can keep their own pace and can participate at any time from any location with internet access, avoiding unnecessary travel time and costs.[30] Furthermore, web-based interventions proved to be feasible and effective in reducing negative outcomes for caregivers of patients with ABI.[24, 31, 32] By combining web-based interventions with face-to-face consultations, and thus creating a blended care intervention, participants remain more motivated to complete the intervention and that reduces the drop-out rate.[33] Blended care interventions appear suitable to support partners of patients with ABI and therefore research into their effects is necessary.

Interventions should be aimed at reducing the negative consequences that partners experience as a result of the patient's ABI. Improving their feelings of mastery seems important in achieving this.[34, 35] Mastery can be measured in caregivers using the Caregiver Mastery Scale.[36] Whether this instrument is valid in partners of patients with ABI is not yet known.

Aims of this thesis

The overall aim of this thesis was to gain more knowledge about the impact of ABI on the patients' partners in order to improve support for these partners.

The specific aims of this thesis were:

1. To in-depth investigate the impact of the patients' ABI on the partners
2. To investigate the dyadic relationships within patient-partner couples
3. To develop a blended care intervention for partners of patients with ABI and to validate a caregiver-specific instrument to evaluate the effect of the intervention

Outline of this thesis

The next two chapters of this thesis outline two studies that were conducted to in-depth investigate the impact of ABI on the partner. In the study described in **Chapter 2**, the participation restrictions and satisfaction with participation in partners of patients with stroke were investigated. Subsequently, as described in **Chapter 3**, we studied the courses and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke during the first two years after stroke.

The focus in the next two chapters is on the dyadic relationships within patient-partner couples. **Chapter 4** describes our study investigating the agreement and differences regarding family functioning between patients with ABI and their partners. In the study described in **Chapter 5** we have investigated the intra- and interpersonal effects of coping style and self-efficacy on anxiety, depression and life satisfaction in patient-partner couples after stroke.

Chapter 6 presents the protocol of a randomized controlled trial to evaluate a blended care intervention for partners of patients with ABI. **Chapter 7** describes the validation study of the Caregiver Mastery Scale for partners of patients with ABI.

Finally, **Chapter 8** presents a general discussion, where the results of the studies are integrated, theoretical and methodological considerations are discussed, suggestions for future research are made and clinical implications are provided.

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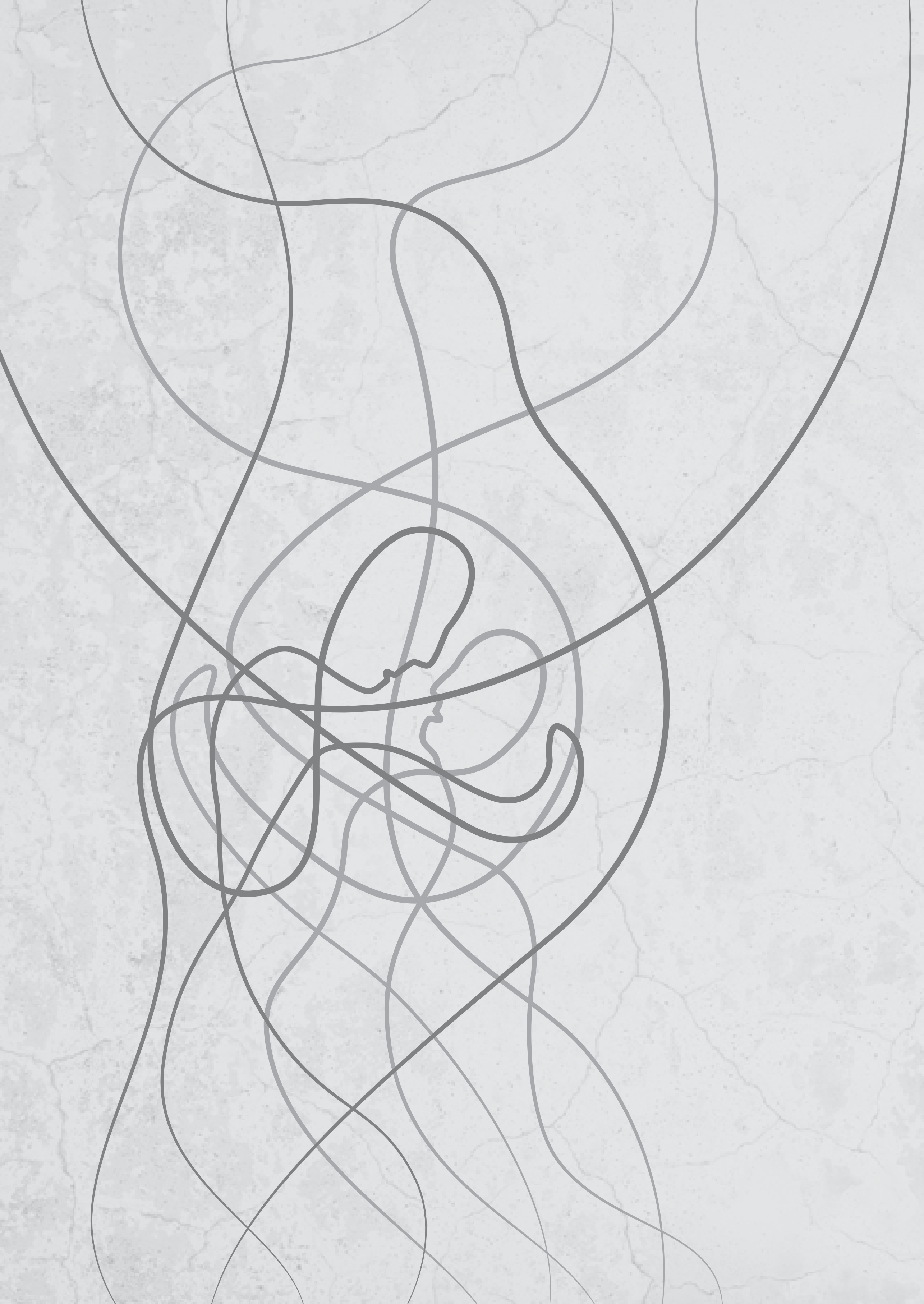

Chapter 2

Participation restrictions and satisfaction with participation in partners of patients with stroke

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Marjolijn Ketelaar

Caroline van Heugten

Anne Visser-Meily

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Abstract

Objective: To investigate participation restrictions and satisfaction with participation in partners of patients with stroke.

Design: Cross-sectional study.

Setting: Five rehabilitation centers and three hospitals in the Netherlands.

Participants: A consecutive sample of 54 partners of patients with stroke. The patients were participating in a multicenter randomized controlled trial.

Interventions: Not applicable.

Main outcome measures: Participation restrictions as a result of the patient's stroke and satisfaction with participation measured with the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P).

Results: The number of participation restrictions differed between partners of patients with stroke. The median number of participation restrictions experienced was 2 for the 11 activities assessed. Most participation restrictions were reported regarding *paid work*, *unpaid work*, *or education*, *relationship with partner (i.e. patient)*, and *going out*. Partners were least satisfied regarding going out, sports or other physical exercise, and day trips and other outdoor activities. The participation restrictions and satisfaction with participation were significantly correlated ($r_s = 0.65$; $p < .001$), although this relation between participation restrictions and satisfaction with participation differed for the various activities. Differences between satisfied partners with participation restrictions and dissatisfied partners concerned anxiety ($U = 93.0$, $p = .026$), depression ($U = 81.5$, $p = .010$), and the number of restrictions experienced ($U = 50.0$, $p < .001$).

Conclusions: There is great variety in restrictions experienced by partners regarding different activities and in their satisfaction with these activities. Specific assessment is therefore important when supporting partners of patients with stroke.

Introduction

Stroke is a major global health problem and a leading cause of serious long-term disability.[1] The physical and cognitive impairments, as well as changes in patients' emotions and behavior, also affect their informal caregivers.[2, 3] Caregivers of patients with stroke therefore experience numerous negative consequences such as high burden,[2, 4-6] anxiety,[5] depression,[2, 4-6] and poor quality of life.[2, 4, 6] Caregiving not only affects physical and psychological functioning, it also influences caregivers' social life, resulting in reduced social relations[4] and participation restrictions.[3, 7, 8]

Participation is defined in the International Classification of Functioning, Disability and Health (ICF) as 'involvement in a life situation'.[9 (p10)] These situations include vocational, leisure and social activities. Limitations regarding these activities are referred to as participation restrictions. Although caregivers of patients with stroke are known to experience participation restrictions, little is known in the current literature about the specific activities for which they experience restrictions. One study among 105 informal caregivers of patients with stroke showed that 47% of them experienced participation restrictions, with restrictions regarding cultural activities, sports, traveling for pleasure, and visiting restaurants and bars being mentioned most.[10]

Restricted participation is a negative consequence of caring for a loved one. One framework describing the negative caregiving outcomes and the underlying processes is Pearlin's Stress Process model,[11] which explains that caregivers who are exposed to the same stressors may experience different negative outcomes, determined by protective intrapersonal factors such as self-esteem and mastery. Some studies among caregivers of patients with stroke found that greater mastery correlates with greater psychological well-being and fewer participation restrictions.[3, 12]

In addition to negative consequences of caregiving, there are also positive aspects, which should be taken into account. Positive caregiving experiences can buffer the detrimental effects of negative consequences and are associated with greater life satisfaction in caregivers of patients with stroke.[13] It is therefore relevant for participation research to investigate not only the restrictions but also the level of satisfaction with the various participation items. Research among patients has shown that a person experiencing restrictions regarding a particular activity can still be satisfied with this activity.[14] In studies investigating satisfaction among partners of patients with stroke, partners indicated dissatisfaction with the relationship with their partner,[15, 16] their sex life,[15-17] occupational situation,[15] leisure time activities,[15, 16] social contacts,[15] and life as a whole.[15-17] However, these studies of satisfaction with participation did not investigate the participation restrictions they experienced.

It is important to support partners of patients with stroke regarding their participation because this can prevent depression and improve their quality of life.[5, 7, 8] Support programs should take participation restrictions as well as satisfaction with participation into account. To date, this has not been investigated in partners of patients with stroke. Furthermore, exploring differences between partners who are satisfied with participation despite the restrictions they experience and partners who are dissatisfied with participation may reveal factors that protect against the negative consequences of caregiving. Support programs for partners of patients with stroke can then target these factors.

The objectives of this study were to (1) identify the activities for which partners of patients with stroke experience restrictions; (2) investigate their satisfaction with these activities; (3) compare the restrictions and satisfaction for the various activities; and (4) explore the differences between those partners with participation restrictions who are satisfied and those with participation restrictions who are dissatisfied with their participation.

Methods

Participants

For this study, we used the baseline data of the Restore4Stroke Self-Management study, a multicenter randomized controlled trial conducted in three hospitals and five rehabilitation centers in the Netherlands.[18] This secondary data analysis was not part of the primary study objectives. Patients with stroke and their partners were included from February 2012 until May 2014 using consecutive sampling. Inclusion criteria for the patients were a clinically confirmed diagnosis of first or recurrent stroke, having problems regarding at least two items of the restriction scale of the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P), and being 18 years or over. Exclusion criteria for the patients were insufficient mental abilities to understand and benefit from the self-management intervention, disturbance in production or comprehension of language as determined with a score < 5 on the shortened version of the Aphasia Scale,[19] inability to function in a group because of behavioral problems, having major depression, and already taking part in structured psychological counseling aimed at proactive coping after stroke. A rehabilitation physician or nurse practitioner clinically judged these criteria.

Partners were included if they were living together with the stroke survivor taking part in the study and were 18 years or older. Clinically judged exclusion criteria for the partners were inability to function in a group because of behavioral problems and insufficient command of Dutch.

The medical ethics committee of the University Medical Center Utrecht and the ethics committees of the participating institutes approved the study. All participants gave written informed consent.

Procedure

Eligible patients with stroke were selected by rehabilitation physicians and nurse practitioners by means of case finding. Patients were invited to participate during regular consultations. Interested patients received an information letter, and their partners were also invited to participate. The researcher phoned the patients and partners after five days to check their willingness to participate. Baseline measurements were conducted by the researcher or a research assistant at the patients' home or at the participating institute. The researcher or research assistant provided examples for the various participation activities and made sure it was clear to the partner that the restrictions they reported should be a result of the patient's stroke.

Measures

The Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P)[20] was used to determine participation of the partners. The USER-P has been shown to be a valid[21] and responsive[22] instrument. In this study, we used the Restrictions and Satisfaction subscales of the USER-P. The Restrictions subscale consists of 11 items and assesses whether the caregiving partner experiences participation restrictions as a result of the patient's condition. The items cover 11 activities of daily life in different domains. Partners can indicate whether the activity is 'not possible' (0), 'possible with assistance' (1), 'possible with difficulty' (2) or 'possible without difficulty' (3). An option of 'not applicable' is available for each activity, which is selected when an activity is not relevant to the partner or when the restriction experienced is not related to the patient's health status. A total score for the Restrictions subscale can be calculated, and ranges from 0 to 100, with higher scores indicating fewer participation restrictions. The Satisfaction subscale consists of 10 items asking about satisfaction with participation in similar domains. Partners can indicate whether they are 'very dissatisfied' (0), 'dissatisfied' (1), 'neutral' (2), 'satisfied' (3) or 'very satisfied' (4). An option of 'not applicable' is available for the items *paid work*, *unpaid work*, *or education*, and *relationship with partner*. A total score for the Satisfaction subscale can be calculated, and ranges from 0 to 100, with higher scores indicating greater satisfaction. Both subscales are presented in Appendix 2.1.

Demographic characteristics (age, sex and educational level) were recorded for both partners and patients. Employment status was recorded for the partners. Depression and anxiety symptoms of the partners were assessed with the Hospital Anxiety and Depression Scale (HADS).[23] This instrument contains seven items measuring anxiety (HADS-A) and seven items measuring depression (HADS-D). Subscale total scores > 7 indicate an anxiety disorder or depression, respectively.[23] The HADS has shown good validity and reliability.[24] Stroke characteristics were derived from medical charts: type of stroke, first or recurrent stroke, and time since stroke. Cognitive functioning of the patient was determined with the Montreal Cognitive Assessment (MoCA), a screening instrument with scores ranging between 0 and 30.[25] Scores < 26 suggest cognitive impairment.[26, 27] Patients' performance in activities of daily living was assessed using the Barthel Index,[28] with scores ranging from completely dependent (0) to completely independent (20).

Statistical analyses

Data were analyzed using IBM SPSS Statistics version 22 for Windows. The normality of distribution was assessed using visual inspection and the Shapiro-Wilk test. Descriptive analyses were applied to describe the study sample with mean and standard deviation for normally distributed data and median with interquartile range for data with no normal distribution. Subscale total scores were calculated for the Restrictions and Satisfaction subscales of the USER-P. Spearman rank correlation was used for bivariate analysis of the relation between the total scores on the Restrictions and Satisfaction subscales. Each item of the USER-P was dichotomized to calculate the number of restrictions experienced and to link the restrictions with satisfaction scores. The restriction items were dichotomized into 'restriction' (1) for the answering options *not possible*, *with assistance* and *with difficulty*, and 'no restriction' (0) for the answering option *without difficulty*. The satisfaction items were dichotomized into 'satisfied' (1) for the answering options *satisfied* and *very satisfied*, and 'dissatisfied' (0) for the answering options *very dissatisfied*, *dissatisfied* and *neutral*. To link the activities in both subscales, we had to cluster items. The Restrictions subscale contains three items (i, j and k) on activities involving social contacts other than the partner, whereas the Satisfaction subscale contains two items (i and j) on these activities. Partners reporting a restriction for one or more of the three items were labeled as having 'restriction' regarding social contacts, and partners reporting to be satisfied with both items were labeled as 'satisfied' with social contacts. Two groups were distinguished: (1) partners who experienced participation restrictions but were nevertheless satisfied with all of these activities, and (2) partners who experienced participation restrictions and indicated being dissatisfied with one or more of these activities. Differences between these groups regarding partners' and patients' characteristics were explored using t-tests for normally distributed continuous data, Mann-Whitney U tests for continuous data with no normal distribution, and chi-square tests for categorical data.

Results

A total of 167 patients and 83 partners were recruited for the original study.[18, 29] One partner did not meet the inclusion criteria and 25 partners declined to participate, resulting in 57 partners. For our analyses we excluded three partners who had data missing on all items of the USER-P Restrictions subscale. Hence, the study sample consisted of 54 partner-patient pairs (Table 2.1). Patients and partners were relatively young, and half of the partners were in employment. More than a third of the partners had symptoms of anxiety, and almost a quarter of them experienced depressive symptoms. The majority of patients (n = 32) scored at ceiling on the Barthel Index. For the other patients scores ranged from 4 to 20. Almost two thirds of patients scored below the MoCA cut-off score suggesting cognitive impairment.

Participation restrictions

The median number of participation restrictions experienced was 2 for the 11 activities assessed (Figure 2.1). Twelve partners experienced no participation restrictions at all and four reported participation restrictions for nine activities. The mean total score for the Restrictions subscale was 86.6, with a standard deviation of 14.9.

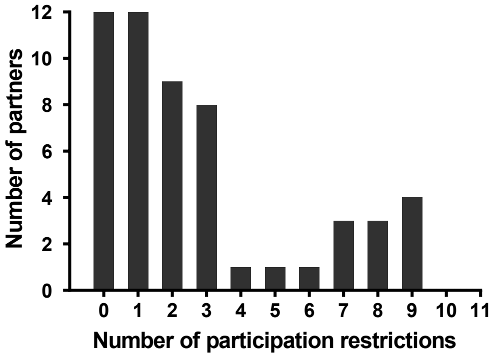

Figure 2.1. Number of activities for which participation restrictions were experienced (N = 54).

The largest number of participation restrictions was reported for *relationship with partner (i.e. patient)* (n = 25), followed by *going out* (n = 15) and *household duties* (n = 15). After correction for 'not applicable', the highest percentages of restrictions regarded *paid work, unpaid work, or education* (48.4%), *relationship with partner (i.e. patient)* (48.1%), and *going out* (42.9%). All participation restrictions are shown in Table 2.2.

Table 2.1. Partners' and patients' characteristics (N = 54)

Partner characteristics	
Age in years, mean (SD)	59.0 (8.4)
Sex, n (%)	
Male	23 (42.6)
Female	31 (57.4)
Educational level, n (%)	
Low	5 (9.3)
Medium	30 (55.6)
High	15 (27.8)
Missing data	4 (7.4)
Employed, n (%)	27 (50.0)
Anxiety (HADS-A), median (IQR)	6 (4.5)[a]
Anxiety (HADS-A > 7), n (%)	20 (37.0)
Depression (HADS-D), median (IQR)	5 (6.0)[a]
Depression (HADS-D > 7), n (%)	13 (24.1)
Patient characteristics	
Age in years, mean (SD)	58.6 (8.5)
Sex, n (%)	
Male	30 (55.6)
Female	24 (44.4)
Educational level, n (%)	
Low	4 (7.4)
Medium	35 (64.8)
High	15 (27.8)
Type of stroke, n (%)	
Ischemic stroke	46 (85.2)
Hemorrhagic stroke	7 (13.0)
Other	1 (1.9)
First or recurrent stroke, n (%)	
First	43 (79.6)
Recurrent	10 (18.5)
Missing data	1 (1.9)
Time after stroke in months, median (IQR)	6.8 (14.4)
Cognitive functioning (MoCA), mean (SD)	24.2 (2.8)
Cognitive functioning (MoCA < 26), n (%)	34 (63.0)
ADL-independence (Barthel Index), median (IQR)	20 (2)

SD: standard deviation; IQR: interquartile range; HADS-A: Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale – Depression subscale; MoCA: Montreal Cognitive Assessment.

Educational level: low = did not complete secondary school; medium = completed lower level secondary school; high = completed upper level secondary school and/or university degree.

[a] 1 missing.

Table 2.2. Participation restrictions among partners (N = 54)

	Participation restricted			Participation not restricted	
	Not possible n (%)	Possible with assistance n (%)	Possible with difficulty n (%)	Possible without difficulty n (%)	Not applicable n (%)
Paid work, unpaid work or education (n = 52)	2 (3.8)	4 (7.7)	9 (17.3)	16 (30.8)	21 (40.4)
Household duties	0 (0)	4 (7.4)	14 (25.9)	33 (61.1)	3 (5.6)
Outdoor mobility	0 (0)	4 (7.4)	5 (9.3)	42 (77.8)	3 (5.6)
Sports or other physical exercise (n = 53)	1 (1.9)	1 (1.9)	6 (11.3)	32 (60.4)	13 (24.5)
Going out	5 (9.3)	1 (1.9)	12 (22.2)	24 (44.4)	12 (22.2)
Day trips and other outdoor activities	2 (3.7)	1 (1.9)	12 (22.2)	31 (57.4)	8 (14.8)
Leisure activities at home	1 (1.9)	0 (0)	7 (13.0)	39 (72.2)	7 (13.0)
Relationship with partner (i.e. patient) (n = 53)	2 (3.8)	1 (1.9)	22 (41.5)	27 (50.9)	1 (1.9)
Going to visit family or friends	1 (1.9)	1 (1.9)	13 (24.1)	37 (68.5)	2 (3.7)
Family or friends coming to visit at your home	1 (1.9)	0 (0)	11 (20.4)	39 (72.2)	3 (5.6)
Contacting other by phone or computer (n = 53)	0 (0)	1 (1.9)	6 (11.3)	44 (83.0)	2 (3.8)

Table 2.3. Satisfaction with participation among partners (N = 54)

	Not satisfied			Satisfied		
	Very dissatisfied n (%)	Dissatisfied n (%)	Neutral n (%)	Satisfied n (%)	Very satisfied n (%)	Not applicable[a] n (%)
Paid work, unpaid work or education	1 (1.9)	2 (3.7)	6 (11.1)	17 (31.5)	8 (14.8)	20 (37.0)
Household duties	0 (0)	5 (9.3)	19 (35.2)	23 (42.6)	7 (13.0)	-
Outdoor mobility (n = 53)	0 (0)	4 (7.5)	4 (7.5)	33 (62.3)	12 (22.6)	-
Sports or other physical exercise (n = 53)	1 (1.9)	9 (17.0)	18 (34.0)	17 (32.1)	8 (15.1)	-
Going out	3 (5.6)	7 (13.0)	19 (35.2)	19 (35.2)	6 (11.1)	-
Day trips and other outdoor activities	2 (3.7)	6 (11.1)	19 (35.2)	22 (40.7)	5 (9.3)	-
Leisure activities at home (n = 53)	0 (0)	4 (7.5)	11 (20.8)	28 (52.8)	10 (18.9)	-
Relationship with partner (i.e. patient)	0 (0)	6 (11.1)	10 (18.5)	12 (22.2)	26 (48.1)	0 (0)
Relationship with your family (n = 53)	0 (0)	2 (3.8)	15 (28.3)	15 (28.3)	21 (39.6)	-
Contacts with friends and acquaintances	0 (0)	4 (7.4)	11 (20.4)	24 (44.4)	15 (27.8)	-

[a] This option is only available for the items paid work, unpaid work or education and relationship with partner.

Satisfaction with participation

Partners indicated to be least satisfied regarding *going out*, *sports or other physical exercise* and *day trips and other outdoor activities*. They were most satisfied with *outdoor mobility*, followed by *paid work*, *unpaid work*, *or education* and *leisure activities at home*. The mean total score on the Satisfaction subscale was 68.6 (standard deviation 15.7). The satisfaction with participation is displayed for each activity in Table 2.3.

Relationships and comparisons between participation restrictions and satisfaction with participation

The total scores on the Restrictions and Satisfaction subscales were significantly correlated (r_s = 0.65; p < .001). Experiencing fewer participation restrictions was positively related to greater participation satisfaction. In comparing participation restrictions and satisfaction with participation differences were noted. The majority of the partners who experienced restrictions regarding *outdoor mobility* and *social contacts* reported being satisfied with these activities. Partners who experienced restrictions regarding *day trips and other outdoor activities* and *household duties* were least satisfied. An overview of the comparisons between participation restrictions and satisfaction with participation is displayed in Table 2.4.

Differences between satisfied and dissatisfied partners with participation restrictions

There were 42 partners who experienced participation restrictions for one or more activities. Eleven of these partners reported being satisfied with all of these activities. The other 31 partners reported dissatisfaction with one or more of these activities. We explored whether these two groups differed in terms of partner and patient characteristics. Differences were found for the partner characteristics of anxiety (U = 93.0, p = .026), depression (U = 81.5, p = .010), and number of restrictions experienced (U = 50.0, p < .001). Satisfied partners experienced fewer participation restrictions and had lower anxiety and depression scores. No significant relations were found regarding patient characteristics (first or recurrent stroke, time after stroke, cognitive functioning and ADL-independence) and other partner characteristics (age, sex, educational level and employment status).

Discussion

In this study we examined the reports of participation restrictions and satisfaction with participation in partners of patients with stroke and without aphasia who were in outpatient

Table 2.4. Partner reports of participation restrictions and satisfaction with participation (N = 54)

	Activity restricted, not restricted or not applicable N (%)	Satisfied with activity[a] N (%)
Paid work, unpaid work or education (n = 52)[b]		
Restricted	12 (23.1)	6/12 (50.0)
Not restricted	16 (30.8)	15/16 (93.8)
Not applicable	24 (46.1)	
Household duties		
Restricted	18 (33.3)	4/18 (22.2)
Not restricted	33 (61.1)	24/33 (72.7)
Not applicable	3 (5.6)	
Outdoor mobility (n = 53)[c]		
Restricted	8 (15.1)	5/8 (62.5)
Not restricted	42 (79.2)	39/42 (92.9)
Not applicable	3 (5.7)	
Sports or other physical exercise (n = 53)		
Restricted	8 (15.1)	3/8 (37.5)
Not restricted	32 (60.4)	20/32 (62.5)
Not applicable	13 (24.5)	
Going out		
Restricted	18 (33.3)	5/18 (27.8)
Not restricted	24 (44.4)	18/24 (75.0)
Not applicable	12 (22.2)	
Day trips and other outdoor activities		
Restricted	15 (27.8)	3/15 (20.0)
Not restricted	31 (57.4)	23/31 (74.2)
Not applicable	8 (14.8)	
Leisure activities at home		
Restricted	8 (14.8)	3/8 (37.5)
Not restricted	39 (72.2)	34/39 (87.2)
Not applicable	7 (13.0)	
Relationship with partner (i.e. patient) (n = 53)		
Restricted	25 (47.2)	9/25 (36.0)
Not restricted	27 (50.9)	27/27 (100.0)
Not applicable	1 (1.9)	
Social contacts (n = 53)		
Restricted	20 (37.7)	12/20 (60.0)
Not restricted	32 (60.4)	29/32 (90.6)
Not applicable	1 (1.9)	

[a] Numbers do not match with the numbers in Table 2.3; partners who reported to be satisfied but indicated 'not applicable' on the restriction item are categorized as 'not applicable'.

[b] 3 partners reported restriction but answered 'not applicable' to the satisfaction item are categorized as 'not applicable'.

[c] 1 partner reported restriction but had missing data on the satisfaction item.

rehabilitation facilities because of participation problems. We found that participation restrictions differed considerably between partners. Some partners experienced restrictions for 9 of the 11 activities we considered, whereas others reported no participation restrictions at all. The largest numbers of restrictions were reported regarding the relationship with the patient. Almost half of the partners who were in work or education reported restrictions for these activities. This is in agreement with previous research, in which 40% of the stroke caregivers reported reductions in the amount of work they were able to perform.[30]

Our second objective was to investigate satisfaction with activities. Although the most commonly reported restriction regarded the relationship with the patient, 70% of the partners were satisfied with this relationship. Comparable results were found in previous research, where 65% of the partners were satisfied with their relationship 4 months after stroke and 76% were satisfied after 7 years.[15, 16] In our study 72% of the partners were satisfied with their contacts with friends and acquaintances, which is slightly higher than in previous research: 67% after 4 months and 62% after 7 years.[15, 16]

Regarding the relation between participation restrictions and satisfaction with participation, we found that, on the whole, fewer participation restrictions were associated with greater participation satisfaction. The correlation we found (0.65) is much stronger than the 0.31 value found by Bergstrom et al.[10] Whereas they used one question about overall life satisfaction, we assessed satisfaction for individual activities, namely the same activities we used to measure the participation restrictions. Partners can experience a restriction regarding a particular activity and still be satisfied with this activity. For example, the majority of the partners in our study were satisfied with their outdoor mobility and social contacts, despite their restrictions for these activities. On the other hand, partners who experienced restrictions regarding household duties or day trips and other outdoor activities were less satisfied with these activities. These results emphasize the importance of determining both participation restrictions and satisfaction with participation when supporting partners for their participation problems. This is in line with previous research among patients.[10, 14, 31] Moreover, it is important to not merely measure them as general concepts but to assess the restrictions and satisfaction at the level of specific activities. A noteworthy finding is the number of partners who were dissatisfied with particular activities, even though they did not experience restrictions for these activities. This was reported most frequently for household duties and sports or other physical exercises. These same results, however, are found in the general population.[32]

The results relating to our last objective showed that among the partners with participation restrictions, the satisfied partners had lower anxiety and depression scores and fewer participation restrictions compared with dissatisfied partners. These analyses were explorative, and the results should be interpreted with caution because multiple comparisons were made. Although the differences in anxiety and depression scores between the two groups are interesting, the causal relationship is unclear because this was a cross-sectional study. Partners with anxiety and depression symptoms may be less resilient and therefore less satisfied when they experience participation restrictions. On the other hand, partners who are less satisfied with their participation may be more susceptible to developing an anxiety disorder or depression. In a study investigating only participation restrictions, Grigorovich et al. found depression to be a determinant,[3] while Nieboer et al. concluded that participation restrictions lead to more depressive symptoms.[8] It is conceivable that there is a reciprocal influence between participation restrictions and depression. A similar reciprocity may exist between depression and the combination of participation restrictions and satisfaction with participation. However, our cross-sectional data cannot confirm or refute this hypothesis, and additional longitudinal research is needed to elucidate this relation.

Our findings can be related to the Stress Process model by Pearlin,[11] which describes how exposure to the same stressors may have different effects on different caregivers. If we consider participation restrictions to be a stressor, we can conclude that its effect on partners of patients with stroke differs in terms of their satisfaction with participation. Some partners may be dissatisfied with certain participation restrictions, while others with the same restrictions may be satisfied. We found that partners who experienced participation restrictions and were dissatisfied with their participation experienced more symptoms of anxiety and depression. Dissatisfied partners may differ from satisfied partners concerning additional characteristics, which we did not investigate. Differences may be found in intrapersonal factors such as self-esteem, resilience, or mastery.[11] These factors should be taken into consideration to get a more complete picture of the problems partners of patients with stroke encounter and to uncover the mechanisms behind it, which in turn is important for effective support for partners.

Study limitations

The USER-P allows measurement of both participation restrictions and satisfaction with participation for various activities. A limitation, however, is that participants are able to report a certain activity as applicable on one of the subscales and answer 'not applicable' for the corresponding item on the other subscale. Furthermore, the USER-P has hardly been used in partners.[33] The psychometric properties of the USER-P in partners of patients with stroke require further investigation.

Patients were only included in the original study when they experienced at least two participation restrictions and had no aphasia. Partners of these patients may experience different participation problems than partners of patients with less participation restrictions or with aphasia. Our results can be generalized to partners of patients with stroke and without aphasia who are in outpatient rehabilitation facilities because of participation problems. Our study sample was rather small, which may have influenced the power of our analyses. The available data was cross-sectional, which prevented us from drawing conclusions about causal relationships. To enable stronger conclusions, a study should be conducted in a larger sample. Moreover, longitudinal research is needed to investigate the development of participation problems over time and to determine the causal relations between participation problems and other factors, such as burden, anxiety, depression, quality of life, coping, and mastery.

Conclusions

Partners of patients with stroke experience participation restrictions that vary for different activities. Satisfaction with participation is also different for the various activities. It is therefore important to measure both the participation restrictions and satisfaction with participation. When health care professionals want to support partners in coping with the negative consequences of caregiving, they should take restrictions and satisfaction for individual activities into account.

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Appendix 2.1

Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P)

Restrictions subscale

Does your partner's condition currently limit your daily life?

Explanation:
NA (not applicable): You do not take part in this activity, but this is not because of your partner's condition.
Not possible: You cannot not take part in this activity, and this is because of your partner's condition.
With assistance: You perform this activity partly by yourself, but need assistance because of your partner's condition. Such as: a home help to perform heavy household duties, your family helps by taking you to places etc. This includes paid help and unpaid help from family or friends.
Difficulty: This activity is considerably more difficult for you because of your partner's condition. Such as: it takes much more time, you need to rest halfway through an activity, you now do it less frequently, for a shorter time or in a less taxing way.

Answer options:
NA   Not possible   With assistance   With difficulty   Without difficulty

---

a Paid work, unpaid work or education
b Household duties
Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening
c Outdoor mobility
Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc
d Sports or other physical exercise
Such as: tennis, cycling, gym, long walks
e Going out
Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others
f Day trips and other outdoor activities
Such as: shopping, attending events, going to the beach, church or mosque
g Leisure activities at home
Such as: crafts, needlework, reading, puzzles, playing computer games
h Your relationship with your partner
Such as: communication, sexuality
i Going to visit family or friends
j Family or friends coming to visit at your home
k Contacting others by phone or computer
Such as: talking on the phone, texting, e-mailing

Satisfaction subscale

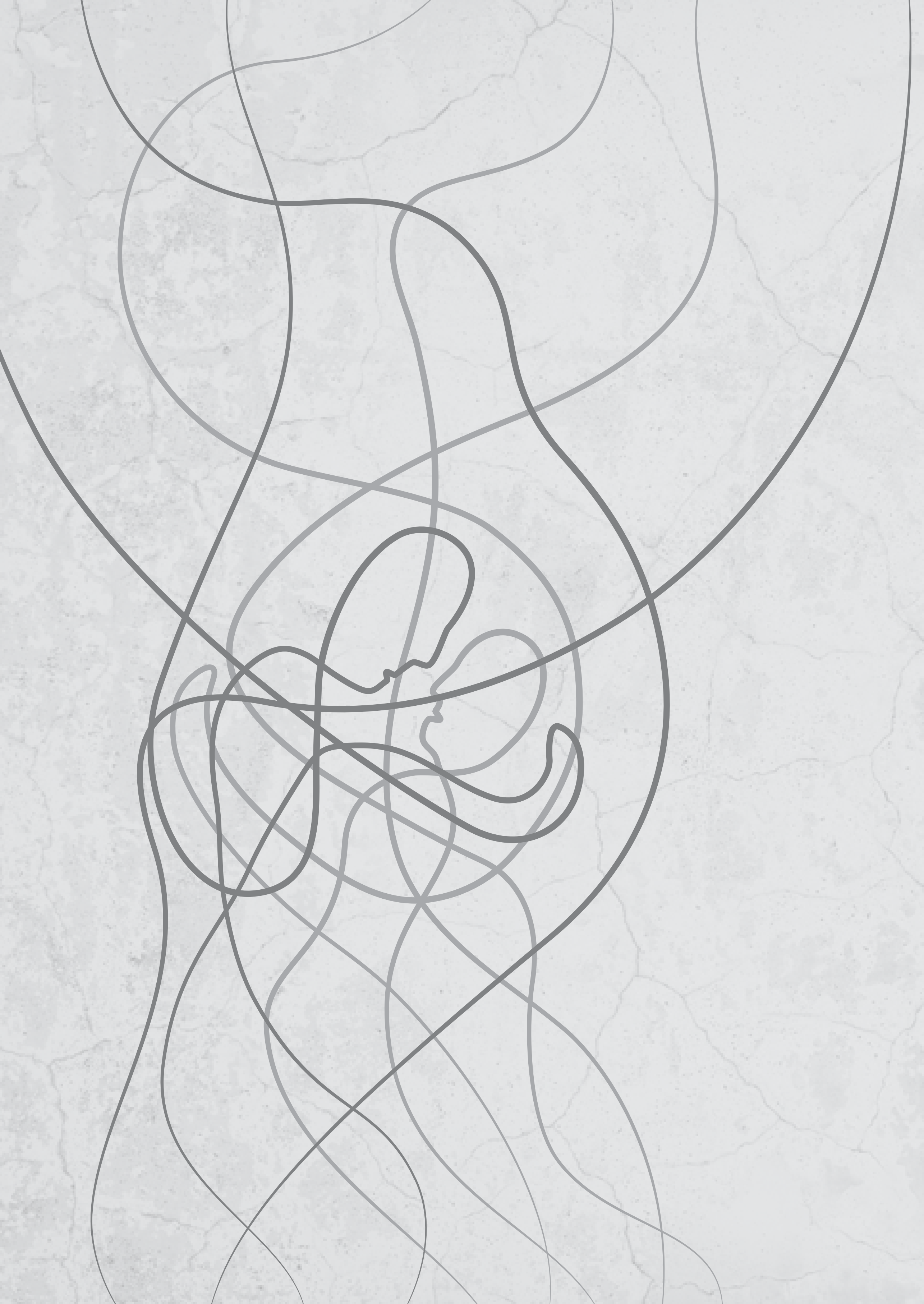
How satisfied are you with your current daily life?

Answer options:
Very dissatisfied   Dissatisfied   Neutral   Satisfied   Very satisfied

NA (not applicable): only enter this if you are unable to work or study or do not have a partner.

---

a Paid work, unpaid work or education
Please note: complete for the most important activity
b Household duties
Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening
c Outdoor mobility
Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc
d Sports or other physical exercise
Such as: tennis, cycling, gym, long walks
e Going out
Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others
f Day trips and other outdoor activities
Such as: shopping, attending events, going to the beach, church or mosque
g Leisure activities at home
Such as: crafts, reading, computer
h Your relationship with your partner
i Your relationship with your family
j Your contacts with friends and acquaintances



Chapter 3

Burden, anxiety and depressive symptoms in partners – course and predictors during the first two years after stroke

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Abstract

Background and purpose: Partners of patients with stroke are at high risk for burden, anxiety and depressive symptoms. Previous studies have reported contradictory results concerning the course and predictors of these symptoms, as they did not take the complexity of symptom development over time sufficiently into account. Our aim was to comprehensively study the courses and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke during the first two years after stroke.

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

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

Conclusions: Burden, anxiety and depressive symptoms become chronic in partners of patients with stroke. It is important to pay attention to partners themselves and not only concentrate on patient characteristics to identify partners at risk.

Introduction

Stroke is a leading cause of serious long-term disability,[1] and partners of patients with stroke are at high risk for burden, anxiety and depressive symptoms.[2-5] However, it is not clear how burden, anxiety and depressive symptoms develop in partners from the moment of stroke through the long-term caregiving situation over the years. Several studies have shown that burden remains elevated over time, while others reported a decrease or increase of burden as more time passes since the stroke.[4, 6-13] Such mixed results have also been reported for the courses of anxiety[2, 3, 13] and depressive symptoms among partners.[3, 4, 10, 13-17] The contradictory results illustrate that the development of burden, anxiety and depressive symptoms over time is complex. Previous studies did not take this complexity sufficiently into account. First, burden, anxiety and depressive symptoms were not studied together, although they are highly interrelated.[5, 6, 8, 13] Second, the individual differences between partners regarding the courses of their symptoms were not taken into account. Third, predictors proven to be important in previous research were not included when studying the courses of burden, anxiety and depressive symptoms, and the effects of these predictors were not investigated longitudinally for time-varying outcomes, i.e. over the entire course of burden, anxiety and depressive symptoms.

Previous research indicates which predictors are important. Predictors have been found in terms of demographic characteristics of either patient or partner, such as age, sex and education;[2, 3, 7, 9, 11, 13-15, 17-21] stroke-related characteristics such as stroke severity, cognitive impairments and ADL dependency;[2-4, 7-9, 13-15, 18, 19, 22] stroke patients' anxiety and depressive symptoms;[3, 6, 7, 9, 15, 17] and personal characteristics of the partners, such as coping and self-efficacy.[4, 19, 22]

We found only one study that investigated all three courses of burden, anxiety and depressive symptoms. This study showed that burden decreased in the first 3 months after discharge, then increased up to 9 months, while anxiety and depressive symptoms decreased up to 9 months.[13] Higher burden was predicted by the partner being male and not living with the stroke patient, and by greater ADL dependence of the patient. Higher anxiety was predicted by stroke patients' younger age, and more depressive symptoms were predicted by partners being older and by patients being younger. This study was limited to the first year after stroke, and burden, anxiety and depressive symptoms were studied separately.

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

Methods

Data used in this study (available on request from the authors) was available from the Restore4Stroke Cohort, a general hospital-based multicenter longitudinal cohort study.[23] Six general hospitals across the Netherlands participated and recruited patients with stroke and their partners between March 2011 and March 2013. Patients were included when they had had a clinically confirmed diagnosis of stroke within the last seven days. Partners were included when they were married to the stroke patient or were in a steady relationship with them. Patients and partners were eligible if they were least 18 years of age. Patients and partners were excluded if they (1) had a serious other condition that was likely to interfere with the study outcomes (e.g. neuromuscular disease), (2) were already dependent regarding activities of daily living before their stroke, as defined by a Barthel Index score of 17 or lower,[24] or (3) had insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgement). Furthermore, patients were excluded if they had already been suffering from cognitive decline before their stroke, as defined by a score of 1 or higher on the Heteroanamnesis List Cognition.[25] Post-stroke aphasia was not an exclusion criterion. If this problem made it difficult for patients to complete the questionnaires, only the observational measures were applied.

The medical ethics committees of all participating hospitals approved the Restore4Stroke Cohort study and informed consent was obtained from all participants.

Measures

Dependent variables

Burden experienced by the partner was measured with the Caregiver Strain Index (CSI).[26, 27] This instrument consists of 13 items, which can be answered with ‘yes’ or ‘no’. The total score ranges from 0 to 13, with higher scores reflecting a higher caregiver burden. A score of 7 or higher indicates a substantial burden. The CSI is a reliable[26] and valid[27] instrument and is the most commonly used instrument to assess burden in caregivers of patients with stroke.[28] Partners’ anxiety and depressive symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS).[29] This instrument contains seven items measuring anxiety (HADS-A) and seven items measuring depression (HADS-D). Subscale total scores range from 0 to 21, with scores above 7 indicating an anxiety disorder or depression, respectively.[29] The HADS has shown good validity and reliability.[30]

Independent variables

Demographic characteristics (age, sex and educational level) were recorded for both partners and patients. Educational level was dichotomized into higher education, for participants who had completed upper level secondary school and/or university degree, and lower education. Partners' proactive coping was measured with the Utrecht Proactive Coping Competence Scale (UPCC).[31] The UPCC has good psychometric properties.[31] Self-efficacy of the partners was determined with the General Self-Efficacy Scale (GSES).[32] Psychometric properties of the GSES are satisfactory to good.[33] Stroke characteristics (type of stroke, first or recurrent stroke and stroke severity) were obtained from medical charts. Stroke severity was measured using the National Institutes of Health Stroke Scale (NIHSS).[34] Independence in activities of daily living (ADL) was assessed with the Barthel Index (BI).[24] Cognitive functioning was determined with the Montreal Cognitive Assessment (MoCA).[35] The discharge destination was recorded as home, rehabilitation center or nursing home. Anxiety and depressive symptoms of the patients were measured with the HADS.

Procedure

Patients and their partners were included within the first week after stroke. Demographic characteristics of patients and partners (age, sex and educational level), as well as stroke characteristics, stroke severity and ADL independence, were recorded at inclusion. At two months after stroke, a research assistant visited the couples at the institution where the patient was residing or at home, to assess the patient's cognitive functioning. To assess their anxiety and depressive symptoms, both patients and partners were asked to complete questionnaires on paper independently from each other. Additionally, partners evaluated their burden, proactive coping and self-efficacy. At six months, one year and two years after stroke, questionnaires were again administered to patients and partners to assess their anxiety and depressive symptoms and for partners also their burden. At these measurement moments, patients and partners were given the choice to complete the questionnaires on paper or online.

Statistical analyses

Normality of distribution of the data was assessed by Shapiro-Wilk tests and visual plots. Descriptive statistics were used to describe the baseline characteristics of patients and their partners. Stroke severity was categorized into 'no stroke symptoms' (NIHSS 0), 'minor stroke symptoms' (NIHSS 1–4), 'moderate stroke symptoms' (NIHSS 5–12), and 'moderate to severe symptoms' (NIHSS > 12). BI and MoCA scores were dichotomized according to their cut-off scores to describe the ADL-dependent (BI < 19) and cognitively impaired (MoCA

< 26) patients, respectively. The prevalence of burden, anxiety and depressive symptoms among partners was described using means and standard deviations, as well as the number of partners scoring above the cut-off values (CSI ≥ 7, HADS-A > 7 and HADS-D > 7). Mixed model analyses were performed with burden, anxiety and depressive symptoms as dependent variables in three separate models. This statistical technique identifies both within-subject effects and between-subject effects, to account for the individual differences in partners as well as the effects at group level. Mixed model analyses allowed us to use all available data even when dropout occurred or data from previous time points was missing. In these models, random intercepts across persons were used to account for the fact that repeated measures are correlated within individuals. The course of the outcome variables was determined by adding the linear, quadratic and cubic functions of time in sequence, with time entered as the exact number of days after stroke. Random effects of time were added to the fixed effects to represent the individual differences in rates of change. Model fit was assessed using the deviance statistic (-2 log likelihood). Covariance structures were specified as unstructured random effects.

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

Results

A total of 215 patient-partner couples were included in the study. Their baseline characteristics are presented in Table 3.1. Partners' mean age was 62.6 years and most partners were women (78.1%). The majority of the partners were low educated (71.7%). Most patients had had an ischemic stroke (94.9%), had minor stroke symptoms (55.8%) and were ADL-independent (63.7%). Almost two thirds of the patients scored below the MoCA cut-off score, suggesting cognitive impairment.

Table 3.1. Partners' and patients' baseline characteristics (N = 215 dyads)

Partner characteristics	
Age in years, mean (SD)	62.6 (10.8)
Male sex, n (%)	47 (21.9)
Higher education[a] (n = 198), n (%)	56 (28.3)
Patient characteristics	
Age in years, mean (SD)	64.3 (11.0)
Male sex, n (%)	169 (78.6)
Higher education[a] (n = 210), n (%)	65 (31.0)
Ischemic stroke, n (%)	204 (94.9)
Recurrent stroke, n (%)	26 (12.1)
Stroke severity (NIHSS), median (IQR)	2.0 (3.0)
No stroke symptoms (NIHSS 0), n (%)	51 (23.7)
Minor stroke symptoms (NIHSS 1–4), n (%)	120 (55.8)
Moderate stroke symptoms (NIHSS 5–12), n (%)	37 (17.2)
Moderate to severe symptoms (NIHSS > 12), n (%)	7 (3.3)
ADL independence (Barthel Index), median (IQR)	20.0 (4.0)
ADL-dependent (Barthel Index < 19), n (%)	78 (36.3)
Cognitive functioning (MoCA) (n = 192), median (IQR)	24.0 (5.8)
Cognitively impaired (MoCA < 26) (n = 192), n (%)	122 (63.5)
Destination after discharge from hospital, n (%)	
Home	163 (75.8)
Rehabilitation center	34 (15.8)
Nursing home	18 (8.4)

NIHSS: National Institutes of Health Stroke Scale; ADL: Activities of Daily Living; MoCA: Montreal Cognitive Assessment.
[a] Completed upper level secondary school and/or university degree.

Presence of burden, anxiety and depressive symptoms

The presence of burden, anxiety and depressive symptoms in partners at the four time points is shown in Table 3.2. There was great variation in the presence of burden, anxiety and depressive symptoms, as shown by the high standard deviations. At two months and

Table 3.2. Partners' burden, anxiety and depressive symptoms

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

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

two years, anxiety was reported more often than burden or depressive symptoms. At six months and one year, the highest percentage was found for burden.

Course and predictors of burden, anxiety and depressive symptoms

The results of the three linear mixed models for burden, anxiety and depressive symptoms are displayed in Table 3.3.

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

Over the course of two years, higher burden was predicted by partners' younger age, higher educational level, and more symptoms of anxiety and depression, and by patients' greater stroke severity, lower cognitive functioning and more symptoms of anxiety and depression. More anxiety symptoms were predicted by partners' higher burden, more depressive symptoms, and lower self-efficacy. Patient characteristics had no significant effect on the partners' anxiety. More depressive symptoms were predicted by partners' older age, higher burden, more symptoms of anxiety, and less proactive coping strategies, and more

Table 3.3. Predictors of partner's burden, anxiety and depressive symptoms

	Burden		Anxiety		Depressive symptoms	
Predictors	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value
Intercept	4.35 (-0.39; 9.10)	.072	**5.74 (0.61; 10.87)**	.028	2.83 (-1.08; 6.74)	.156
Time (months)	0.01 (-0.01; 0.04)	.246	**-0.23 (-0.43; -0.03)**	.023	0.01 (-0.01; 0.02)	.341
Quadratic effect of time	-		**0.01 (0.00; 0.01)**	< .001	-	
Cubic effect of time	-		-		-	
Partner characteristics						
Age in years	**-0.03 (-0.06; 0.00)**	.049	-0.03 (-0.06; 0.01)	.155	**0.04 (0.01; 0.06)**	.006
Age in years*time	-		0.00 (0.00; 0.00)	.308	-	
Male sex	-0.39 (-1.12; 0.35)	.303	-0.25 (-0.99; 0.50)	.512	0.21 (-0.41; 0.84)	.505
Male sex*time	-		-		-	
Higher education	**0.86 (0.17; 1.55)**	.014	0.08 (-0.62; 0.78)	.819	-0.10 (-0.68; 0.49)	.745
Higher education*time	-		-		-	
Burden (CSI)			**0.28 (0.19; 0.36)**	< .001	**0.16 (0.09; 0.24)**	< .001
Burden (CSI)*time			-		-	
Anxiety (HADS-A)	**0.22 (0.15; 0.29)**	< .001			**0.42 (0.36; 0.48)**	< .001
Anxiety (HADS-A)*time	-				-	
Depressive symptoms (HADS-D)	**0.18 (0.10; 0.27)**	< .001	**0.56 (0.48; 0.64)**	< .001		
Depressive symptoms (HADS-D)*time	-		-			
Proactive coping (UPCC)	0.01 (-0.69; 0.72)	.967	-0.04 (-0.86; 0.79)	.930	**-1.27 (-1.86; -0.68)**	< .001
Proactive coping (UPCC)*time	-		0.01 (-0.02; 0.05)	.488	-	
Self-efficacy (GSES)	0.07 (-0.01; 0.16)	.096	**-0.12 (-0.20; -0.03)**	.006	0.00 (-0.07; 0.07)	.967
Self-efficacy (GSES)*time	-		-		-	

Table 3.3 continues on next page.

Table 3.3. *Continued*

	Burden		Anxiety		Depressive symptoms	
Predictors	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value
Patient characteristics						
Stroke severity (NIHSS)	**0.15 (0.02; 0.29)**	.026	-		-	
Stroke severity (NIHSS)*time	-0.01 (-0.01; 0.00)	.108	-		-	
ADL independence (BI)	-0.07 (-0.15; 0.02)	.127	0.02 (-0.06; 0.10)	.557	0.02 (-0.05; 0.08)	.642
ADL independence (BI)*time	-		-		-	
Cognitive functioning (MoCA)	**-0.10 (-0.19; -0.01)**	.027	0.08 (-0.01; 0.17)	.067	-0.05 (-0.13; 0.02)	.154
Cognitive functioning (MoCA)*time	-		-		-	
Anxiety (HADS-A)	**0.09 (0.02; 0.16)**	.013	0.06 (-0.02; 0.13)	.148	-0.03 (-0.09; 0.04)	.446
Anxiety (HADS-A)*time	-		-		-	
Depressive symptoms (HADS-D)	**0.16 (0.10; 0.23)**	< .001	0.05 (-0.05; 0.15)	.346	**0.08 (0.01; 0.15)**	.019
Depressive symptoms (HADS-D)*time	-		-0.01 (-0.01; 0.00)	.064	-	

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

depressive symptoms in the patients. No significant effects were found for the interactions of the predictors with time in any of the three models. The strongest effect was found for proactive coping as a predictor of fewer depressive symptoms.

Discussion

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

As regards the courses of burden, anxiety and depressive symptoms, we found that burden and depressive symptoms remained elevated during the first two years after stroke, whereas symptoms of anxiety initially decreased, but increased towards previous levels during the second year after stroke. The stable course of burden we found is in line with previous studies and a review about caregiver burden following stroke.[9-12] As regards the course of symptoms of anxiety, Pucciarelli and colleagues also found a decline followed by an increase, albeit in the first year after stroke.[13] Our finding that the level of depressive symptoms did not change over time is in disagreement with the findings of Pucciarelli and colleagues, who found that depressive symptoms decreased in the first nine months and stabilized or tended to increase after that.[13] We were less likely to find a decline, since the level of depressive symptoms in our sample was already much lower. Their study found a mean HADS-D score of 7.1 at three months after discharge, whereas our sample had HADS-D scores of 3.1 and 3.3 at two months and six months after stroke, respectively.

Our examination of the predictors found that burden, anxiety and depressive symptoms are interrelated, since they all predicted each other. However, multicollinearity was not present and there were no high correlations between the measures of burden, anxiety and depressive symptoms. We can therefore conclude that they are different concepts. There are also theoretical differences between the concepts: whereas the CSI is a measure of practical burden, the HADS determines emotional burden. The HADS can be used both as a measure of general distress and as an assessment of anxiety and depression using the individual subscales.[30] An explanation for the interrelations between burden, anxiety and depressive symptoms might be found in personal factors, which make partners more vulnerable for more negative outcomes. We found that anxiety and depressive symptoms were predicted by the coping and self-efficacy characteristics of the partners themselves, with higher self-efficacy being associated with lower anxiety and more proactive coping associated with less depressive symptoms. Stroke severity and cognitive functioning of the patient predicted partners' burden, but not their anxiety and depressive symptoms. It seems that practical burden is mainly determined by patient characteristics, whereas emotional burden is mostly a result of partner characteristics.

Additionally, we found that patients' anxiety predicted a higher burden for the partners, while depressive symptoms in the patients predicted higher burden and more depressive symptoms in the partners. There seems to be a dyadic influence within patient-partner couples concerning emotional distress. For depressive symptoms, this reciprocal association between patients with stroke and their partners is confirmed by previous studies and a recent review.[36]

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

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

Strengths

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

Limitations

This study has several limitations. First, our study sample included a higher percentage of male patients and female partners than the Dutch stroke population.[37] Since sex was not a significant predictor in either of the models, this probably did not influence the results. Second, we did not record whether partners had received any professional support. Our results might be an underestimation if such interventions had lowered the partners' levels of burden, anxiety and depressive symptoms. Third, certain personality traits and skills of the partners were not available in our data, while they might have been important predictors. In a previous study by our research group, passive coping was the strongest predictor of burden and depressive symptoms in partners of patients with stroke.[4] Although passive coping has a strong negative correlation with proactive coping, other coping strategies might have been important predictors as well.[38] Furthermore, optimism, self-esteem and mastery have been found to be related to emotional distress in caregivers of patients with stroke.[15, 39] These variables and others should be included in future research.

Clinical implications

The burden, anxiety and depressive symptoms experienced by partners of patients with stroke become chronic. Special attention should be given to anxiety, because although it decreases first, it increases again later on. Health care professionals should monitor both patients and partners and pay particular attention to the partners of patients with severe stroke, low cognitive functioning and depressive symptoms. Partners should be screened for burden, anxiety and depressive symptoms, since each of these is a risk factor for developing the other two negative outcomes. CSI and HADS are not time-consuming, and both are very easy to administer and could easily be integrated in standard care. Screening partners early after stroke may help health care professionals to identify partners who are at risk for negative outcomes. These partners can then receive support through interventions that use psychological techniques, such as cognitive-behavioral therapy, coping-skill training, and problem-solving therapy. These interventions have proven their usefulness and efficacy in reducing burden, anxiety and depressive symptoms in partners of patients with stroke.[40] Currently we are investigating a blended care support intervention for partners in a randomized controlled trial.[41]

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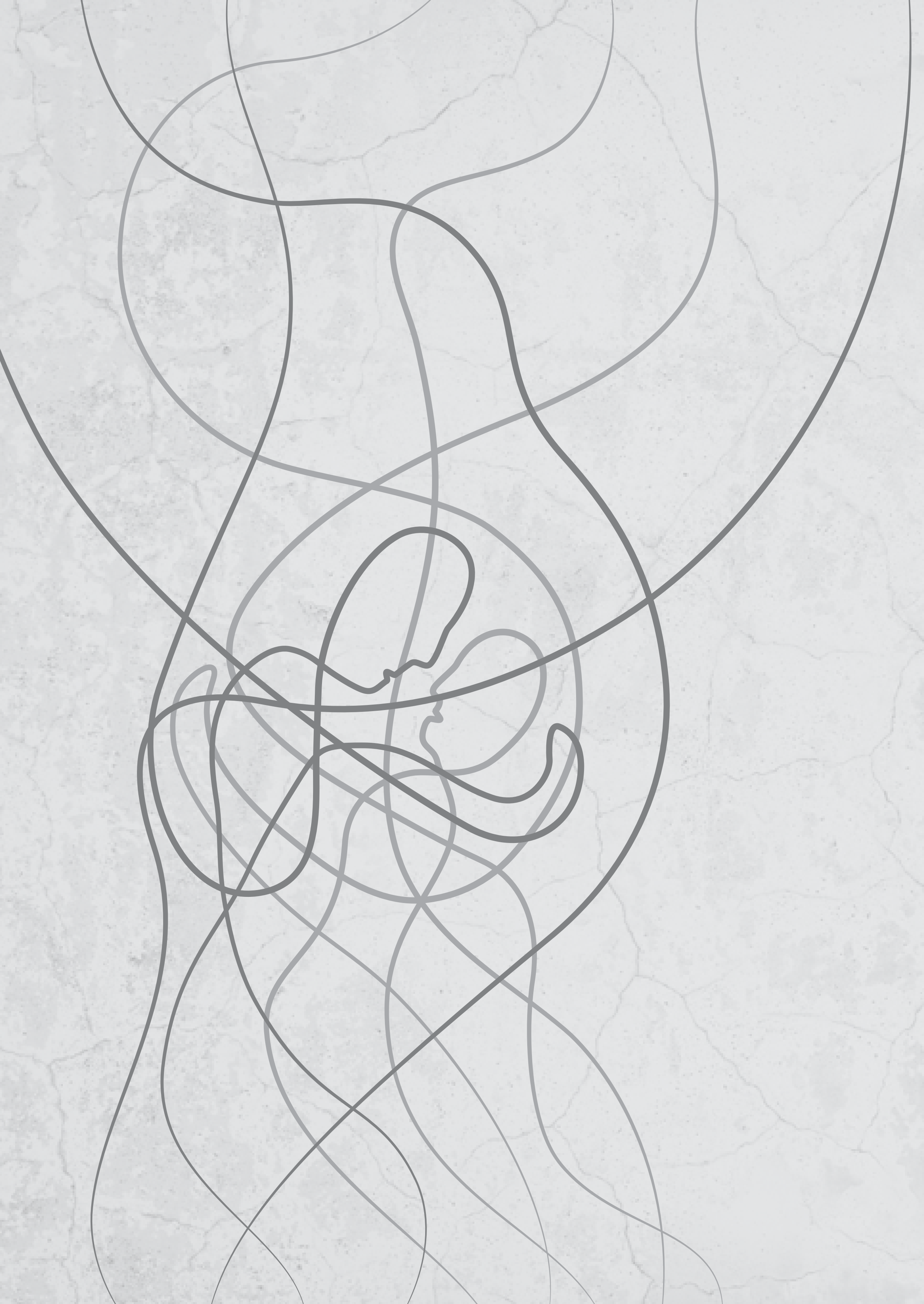

Chapter 4

Agreement and differences regarding family functioning between patients with acquired brain injury and their partners

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Abstract

Primary objective: To investigate the level of agreement and differences regarding the perception of family functioning between patients with acquired brain injury and their partners. Our hypothesis was that patients would report better family functioning than their partners.

Research design: Cross-sectional study.

Methods and procedures: Baseline data were used from 77 patient-partner dyads (87.0% stroke) who were participating in the ongoing CARE4Patient and CARE4Carer trials. Family functioning was assessed using the General Functioning subscale of the McMaster Family Assessment Device (FAD-GF). Agreement was assessed with intraclass correlation coefficient, a Bland-Altman plot, percentages absolute agreement and weighted kappa values. Differences were tested with Wilcoxon signed-rank tests.

Main outcomes and results: Patients and their partners differed in their perception of family functioning. Within-dyad agreement was poor regarding the overall FAD-GF scores with partners reporting significantly poorer family functioning compared to the patients (32.5% versus 18.2%). Agreement regarding the individual items ranged from slight to moderate.

Conclusions: Health care professionals should assess family functioning after stroke in both patients and their partners, and any discrepancies should be discussed with both members of the patient-partner dyad.

Introduction

Patients with acquired brain injury (ABI) typically suffer from complex problems, affecting both themselves and their caregivers. These may include physical, behavioral, cognitive, communicative and psychosocial problems, which can lead to loss of independence in everyday activities, reduced societal participation and poorer quality of life.[1]

After inpatient care, most patients with stroke eventually return to their own home, and about 70% will be dependent on informal caregivers, usually family members.[2] The burden of care has a great impact on caregivers' physical and psychosocial well-being[2, 3] with up to 65% of caregivers reporting health problems, high levels of strain and a decline in the quality of their social life.[4] Among caregivers, partners in particular have difficulties coping with the consequences of a brain injury.[5] Partners experience a sense of loss and need to adjust to a new relationship with the patient.[6, 7]

Changes in the relationship, lack of social support and changed roles of patients and partners may result in conflict, stress or even separation.[5, 7] Both patients and caregivers experience negative consequences and there is an interdependent effect between patients with stroke and their caregivers on outcomes such as stress and quality of life.[8, 9]

Family-centered interventions, aimed at both patients and caregivers, can result in better outcomes for the individual members of the dyad.[10-12] Evidence for outcomes concerning both members of the dyad together, such as family functioning, is still scarce. Family functioning comprises how family members work together and communicate with each other.[13] In patients with ABI, a negative perception of family functioning is associated with more depressive symptoms,[14] lower levels of activity,[15] and increased dependence in daily self-care[15] and home activities.[16] Poor family functioning, as perceived by caregivers, is associated with increased symptoms of anxiety and depression.[13, 17-21]

After an ABI, family functioning is often only assessed in caregivers, since patients may suffer from cognitive and communicative disorders.[11] Whether such a single measure is a valid representation of the perspectives of both members of the dyad is not clear, since little is known about the level of agreement and differences regarding perceived family functioning within dyads. To our knowledge, only two studies have reported on family functioning as perceived by both members of the patient-caregiver dyad, and their results are conflicting. One study found that patients reported better family functioning than their partners,[22] while another study found the opposite.[13] These contradictory results may be attributable to differences in the population they studied, e.g. the first study included only male patients and female partners, while the second study included not only partners but also other caregivers.

The further development of family-centered interventions for patients with ABI and their partners requires insight into the agreement about and differences in family functioning between these patients and their partners.

The objective of the present study was to examine how patients with ABI and their partners perceive their family functioning and to investigate agreement and differences regarding their perception of family functioning. We hypothesized that patients would report better family functioning than their partners.

Materials and methods

Design

For this cross-sectional investigation, data from two randomized controlled trials, CARE4Carer (NTR6197) and CARE4Patient (NTR5055), were combined. Designs, inclusion and exclusion criteria and trial interventions have been described in detail elsewhere and are briefly summarized here.[23-25] The medical ethics committee of the University Medical Center Utrecht approved the CARE4Carer study. The CARE4Patient study was approved by the medical ethics committee of the Slotervaart Hospital and Reade. Reporting in this cross-sectional study follows the STROBE statement.[26]

Participants

In the ongoing CARE4Carer trial, patients with ABI (mostly stroke) and their partners are recruited during outpatient rehabilitation from hospitals and rehabilitation centers in the Netherlands. In the CARE4Patient trial, patients with ABI (mostly stroke) and their caregivers were recruited during inpatient rehabilitation from rehabilitation centers and nursing homes in the Netherlands. For the purpose of this study, only patient-partner dyads were selected. Participants, recruited until the end of 2018, were included in the current study. Inclusion criteria for patients and partners in both trials included: (1) aged 18 years or older, and (2) able to understand Dutch. Inclusion criteria for patients included: (1) having an ABI, and (2) living independently prior to the injury. Patients with neurodegenerative or progressive ABI were excluded from both trials. Additional in- and exclusion criteria were specified to ensure safety or determine suitability for the experimental interventions of the trials. Additional inclusion criteria for patients in the CARE4Patient trial were: (1) planned to be discharged home, (2) able to follow instructions (Mini-Mental State Examination > 18), (3) having limited mobility (Functional Ambulation Category < 5), and (4) no significant symptoms of depression (depression subscale of the Hospital Anxiety and Depression Scale

≥ 11). In addition, patients and partners were excluded from CARE4Patient if they reported a serious comorbidity that interfered with participation or were medically unstable. Partners were excluded from the CARE4Carer trial if they: (1) were unable to use a computer, or (2) had no internet access. All participants gave written informed consent.

Measurements

In this study, we used baseline data from patients and partners participating in the CARE4Patient and CARE4Carer trials. Baseline measurements for CARE4Patient were taken during inpatient rehabilitation and those for CARE4Carer during outpatient rehabilitation.

Family functioning was assessed using the General Functioning subscale of the McMaster Family Assessment Device (FAD-GF).[27] Patients and partners indicated their level of agreement (i.e., strongly disagree, disagree, agree, strongly agree) with 12 statements. Each statement was scored from 1 to 4, with higher scores reflecting poorer family functioning. A mean score of 2.0 or higher is defined as ineffective family functioning.[28] The Family Assessment Device (FAD) has good psychometric properties.[27-29] The FAD-GF has good reliability and validity[30] and the Dutch translation has good internal consistency.[31] Patient and partner characteristics included demographics (age, sex, education, and employment), type of ABI, first or recurrent stroke, time since injury, being inpatient at a rehabilitation facility or living at home, communicative ability, anxiety and depression, and caregiver burden. Level of education was dichotomized into 'higher education' if participants had completed at least upper-level secondary school, and 'lower education' if they had completed lower-level secondary school or less. Communicative ability of the patients was dichotomized into presence or absence of communication restrictions, as indicated by a score of 3 or less on the Utrecht Communication Observation (UCO).[32] Anxiety and depression among both patients and partners were assessed using the Hospital Anxiety and Depression Scale (HADS).[33] The HADS consists of a 7-item anxiety and a 7-item depression subscale. Subscale scores above 7 suggest a mood disorder. Caregiver burden was assessed among partners with the Caregiver Strain Index (CSI).[34, 35] The CSI consists of 13 items which can be scored as 'yes' or 'no'. The total score ranges from 0 to 13, with higher scores reflecting higher caregiver burden. A score of 7 or higher indicates substantial caregiver burden.

Statistical analyses

Normality of distribution of the data was assessed by Shapiro-Wilk tests and visual plots. Descriptive analyses were applied to describe the study sample, using means and standard deviations for normally distributed data and medians and interquartile ranges for non-normally distributed data.

Independent samples t-tests, chi-square tests or Mann-Whitney U tests were conducted to test differences in demographic and psychosocial variables between effective and ineffective family functioning, in both patients and partners.

The Intraclass correlation coefficient (ICC) was used for measuring agreement within patient-partner dyads on their perception of family functioning. ICC estimates and their 95% confidence intervals (CIs) were calculated based on a single-rating, absolute agreement, two-way mixed-effects model. ICC values below 0.50 indicate poor agreement, values between 0.50 and 0.75 moderate agreement, values between 0.75 and 0.90 good agreement, and values greater than 0.90 excellent agreement.[36] A Bland-Altman plot was used to graphically display the level of agreement.[37]

Agreement on individual items was evaluated as the percentage absolute agreement (exact patient-partner score matches). Weighted kappa values with quadratic weights were also calculated to determine item-level agreement within dyads. Kappa values below 0.00 indicate poor agreement, values between 0.00 and 0.20 slight agreement, values between 0.21 and 0.40 fair agreement, values between 0.41 and 0.60 moderate agreement, values between 0.61 and 0.80 substantial agreement, and values over 0.81 almost perfect agreement.[38] Wilcoxon signed-rank tests were used to test differences in the perception of general family functioning and regarding individual items.

A two-tailed significance level alpha of 0.05 was used for all statistical tests. Data were analyzed using IBM SPSS Statistics version 25 for Windows.

Results

By the end of 2018, a total of 104 patients and their caregivers had been included in the ongoing CARE4Carer and CARE4Patient studies, 97 of whom provided complete data on family functioning for both members of the patient-caregiver dyad. CARE4Carer recruited 43 patients and their partners. CARE4Patient recruited 54 patients and their caregivers, of which 20 included other caregivers than partners. Those patient-caregiver dyads were excluded from the current study, resulting in a total of 77 patient-partner dyads. A description of their characteristics is presented in Table 4.1. Most patients had been diagnosed with stroke (87.0%), 8 of whom had had a recurrent stroke.

Table 4.1. Patients' and partners' characteristics (N = 77 dyads)

Characteristics	Patients	Partners
Age in years, mean (SD)	59.4 (8.7)	57.9 (9.1)
Male sex, n (%)	51 (66.2)	26 (33.8)
Higher education, n (%)	34 (44.2)	24 (31.2)
Employed before ABI, n (%)	53 (68.8)	47 (61.0)
Type of ABI, n (%)		
Ischemic stroke	45 (58.4)	
Hemorrhagic stroke	22 (28.6)	
Traumatic brain injury	8 (10.4)	
Oncology post-surgery	1 (1.3)	
Encephalitis	1 (1.3)	
Time since ABI in days, median (IQR)	80.0 (48.5−133.0)	
Living at home, n (%)	43 (55.8)	
Communication restrictions (UCO < 4), n (%)	5 (6.5)	
Anxiety (HADS-A) [0–21], median (IQR)	5.0 (3.0−7.0)	5.0 (3.0−8.0)[a]
Anxiety (HADS-A) > 7, n (%)	18 (23.4)	21 (27.3)[a]
Depression (HADS-D) [0–21], median (IQR)	5.0 (2.0−8.0)	4.0 (2.0−7.0)
Depression (HADS-D) > 7, n (%)	25 (32.5)	17 (22.1)
Caregiver burden (CSI) [0–13], mean (SD)		6.9 (2.6)
Caregiver burden (CSI) ≥ 7, n %		48 (62.3)

FAD-GF: McMaster Family Assessment Device-General Functioning; ABI: Acquired Brain Injury; UCO: Utrecht Communication Observation; HADS: Hospital Anxiety and Depression Scale; CSI: Caregiver Strain Index.

[a] 1 missing.

Family functioning as reported by ABI patients and their partners

The median FAD-GF score of the patients was 1.50 (IQR = 1.17–1.83) reflecting a positive perception of family functioning. Fourteen patients (18.2%) had a score of 2.0 or higher, indicating ineffective family functioning. No significant differences were found between patients reporting effective and those reporting ineffective functioning (Table 4.2).

The median FAD-GF score of the partners was 1.75 (IQR = 1.17–2.00) reflecting a positive perception of family functioning. Twenty-five partners (32.5%) reported ineffective family functioning. Partners reporting ineffective family functioning had significantly higher scores on caregiver burden (t(75) = -3.84; p < .001, d = 0.92), anxiety (U = 306.0; p < .001, r = -0.42) and depression (U = 297.0; p < .001, r = -0.44). In addition, partners reported ineffective family functioning when more time had passed since the brain injury (U = 377.0; p = .003, r = -0.34) and the patients were more often living at home (X^2 = 15.5; p < .001, r = 0.45).

Table 4.2. Characteristics of patients and partners reporting effective versus ineffective family functioning (N = 77)

	Patients		Partners	
	Effective family functioning (n = 63)	Ineffective family functioning (n = 14)	Effective family functioning (n = 52)	Ineffective family functioning (n = 25)
Age in years, mean (SD)	59.4 (8.4)	59.3 (10.2)	58.7 (9.3)	56.1 (8.6)
Male sex, n (%)	40 (63.5)	11 (78.6)	21 (40.4)	5 (20.0)
Higher education, n (%)	27 (42.9)	7 (50.0)	16 (30.8)	8 (32.0)
Employed, n (%)	44 (69.8)	9 (64.3)	29 (55.8)	18 (72.0)
Time since ABI in days, median (IQR)	73.0 (46.0–131.0)	110.5 (72.3–137.8)	61.0 (37.0–117.3)	106.0 (80.5–153.0)**
Living at home, n (%)	32 (50.8)	11 (78.6)	21 (40.4)	22 (88.0)**
Anxiety (HADS-A) [0–21], median (IQR) (n = 76)	5.0 (3.0–7.0)	4.5 (2.8–9.8)	4.0 (3.0–6.0)	9.0 (5.0–11.5)**
Depression (HADS-D) [0–21], median (IQR)	5.0 (2.0–8.0)	5.0 (3.5–8.3)	3.0 (1.0–6.0)	7.0 (4.0–10.0)**
Caregiver burden (CSI) [0–13], mean (SD)			6.2 (2.4)	8.4 (2.4)**

HADS: Hospital Anxiety and Depression Scale; CSI: Caregiver Strain Index.
* Significant at p < .05; ** Significant at p < .01.

The perception of family functioning within dyads

Poor agreement within patient-partner dyads was observed for the FAD-GF scores (ICC = .45, 95% CI [.25, .61]). The Bland-Altman plot shows the difference between the FAD-GF scores of patients and partners (Figure 4.1). The mean difference between the scores was 0.11 and the 95% limits of agreement ranged from -0.85 to 1.07. The agreement between patients' and partners' scores was independent of the value of the mean score. A significant difference was observed between the FAD-GF scores of the patients and those of their partners (Z = 2.274, p = .023), with partners reporting poorer family functioning.

Agreement and differences regarding individual items of the FAD-GF are presented in Table 4.3. Within-dyad agreement for the individual items ranged from slight agreement on three items, to fair agreement on eight items and moderate agreement on one item, viz. '4. Individuals are accepted for what they are'. The lowest percentage of absolute agreement

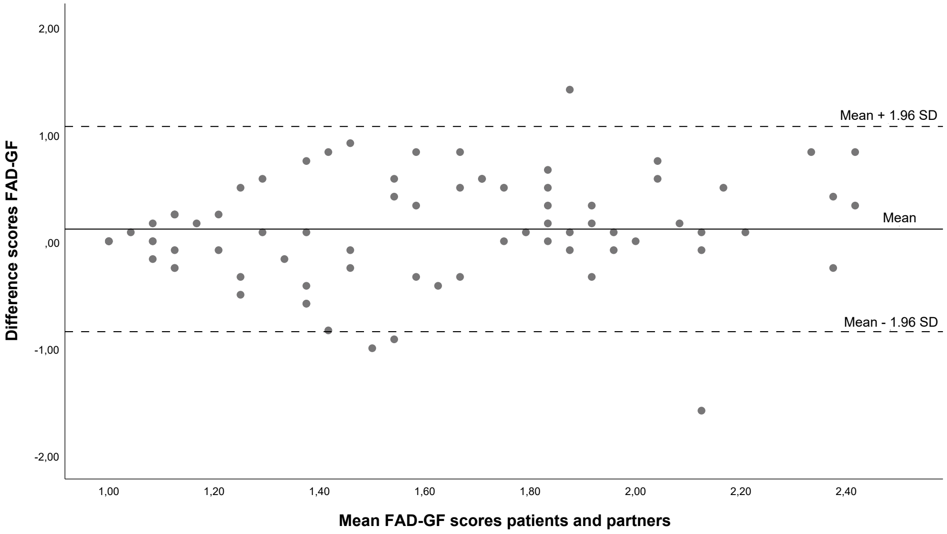

Figure 4.1. Bland-Altman plot of FAD-GF scores from patients and partners.

(36.4%) was found for item 5 ‘We avoid discussing our fears and concerns’. The item ‘We don’t get along well together’ had the highest percentage of absolute agreement (71.4%) and a low weighted kappa (0.12). Further investigation revealed that the dyads showing less than perfect agreement on this item had a greater discrepancy: in 5.2% of the dyads one member reported ‘strongly agree’ while the other member reported ‘strongly disagree’. Significant differences were found for items 2, 3 and 8, with partners reporting poorer family functioning than patients.

Discussion

This is the first study to investigate agreement and differences between patients and their partners regarding their perception of general family functioning following a brain injury. We found that agreement within patient-partner dyads was poor. The perception of patients, primarily post-stroke, and their partners differed, with partners reporting significantly poorer family functioning.

The objective of our study was to describe how patients with ABI and their partners perceive their family functioning. A previous study reported higher median scores on the FAD-GF in patients with stroke, indicating poorer family functioning, compared to our study.[14] King et al.[14] reported a significant association between patients’ poorer family functioning and

Table 4.3. Agreement and differences on FAD-GF items within patient-partner dyads

	Patients	Partners	Agreement within dyads		Differences within dyads
FAD-GF Items	Ineffective family functioning (%)	Ineffective family functioning (%)	Absolute agreement (%)	Weighted kappa (95% CI)	Wilcoxon signed-rank, p-value
1. Planning family activities is difficult because we misunderstand each other	7.8	14.3	50.6	0.21 (0.01–0.41)	.053
2. In times of crisis we can turn to each other for support	5.2	13.0	59.7	0.29 (0.07–0.50)	.031*
3. We cannot talk to each other about the sadness we feel	5.2	14.3	51.9	0.22 (0.00–0.45)	.026*
4. Individuals are accepted for what they are	7.8	11.7	58.4	0.45 (0.24–0.66)	.170
5. We avoid discussing our fears and concerns	20.8	15.6	36.4	0.15 (-0.08–0.37)	.509
6. We can express feelings to each other	10.4	11.7	54.5	0.34 (0.12–0.55)	.588
7. There are lots of bad feelings in the family	5.2	6.5	59.7	0.37 (0.16–0.58)	.654
8. We feel accepted for what we are	6.5	15.6	50.6	0.29 (0.04–0.53)	.022*
9. Making decisions is a problem for our family	3.9	9.1	44.2	0.10 (-0.07–0.28)	.097
10. We are able to make decisions about how to solve problems	3.9	2.6	62.3	0.27 (0.00–0.54)	.157
11. We don't get along well together	2.6	3.9	71.4	0.12 (-0.09–0.33)	.297
12. We confide in each other	3.9	7.8	55.8	0.21 (-0.04–0.46)	.180

* Significant at $p < .05$.

depressive symptoms, 2 years after discharge. We did not find this association, which may be attributable to the lower proportion of patients with ineffective family functioning in our sample (18.2% versus 33%). As regards the family functioning of partners, our findings are in accordance with previous research, which reported ineffective family functioning in about 30% of stroke caregivers.[13, 18] Partners reporting ineffective family functioning in our study perceived higher burden and had more symptoms of anxiety and depression. This is also in line with previous studies, which reported associations between family functioning and anxiety and depression in partners.[13, 17-21]

Agreement on general family functioning between the patients and their partners was poor (ICC = .45), which is lower than the agreement found in healthy dyads (ICC = .65).[39] A significant difference was observed between the FAD-GF scores of the patients and their partners, which is in accordance with a study which also reported poorer family functioning in partners compared to patients with stroke.[22] By contrast, our findings run counter to those from a previous study which reported significantly poorer family functioning in patients with stroke compared to their caregivers.[13] That study, however, also included caregivers other than partners. Partners may perceive poorer family functioning than other caregivers of patients with stroke.[40] Reports on the agreement and differences regarding individual items of the FAD-GF between patients with ABI and their partners have not been found in the current literature.

Our findings add to the scarce existing knowledge on the agreement and differences regarding family functioning. Low agreement between the perception of patients and their partners is also found in other concepts, such as physical functioning of the patient, cognitive, emotional and behavioral changes and activities in daily living, where the partners are again more pessimistic.[41, 42] The reason for this is unclear and requires further investigation.

The limitations of the current study should be mentioned. First, our study sample mainly consisted of patients with stroke (87.0%) and therefore these findings cannot be generalized to a broader population of patients with ABI and their partners. Second, this was a cross-sectional investigation and therefore the course of family functioning over time remains unclear. Third, patients and partners were excluded from the CARE4Patient trial if they reported significant symptoms of depression (HADS-D ≥ 11). Depressive symptoms may influence the agreement about and differences in perceived family functioning within dyads. Although few participants have been excluded due to symptoms of depression, our findings should be confirmed in a more heterogeneous sample with respect to depressive symptoms.

Patients with ABI (mostly stroke) and their partners differed in their perception of family functioning. Health care professionals should therefore assess family functioning in both patients with stroke and their partners. When family functioning can only be assessed in one member of a dyad, it is important to realize that perceptions within dyads may differ. We found that partners perceived poorer family functioning when more time had passed since the injury and when the patient had been discharged home. Family functioning is dynamic and likely to vary over time, as a result of changes in roles (e.g. from partner to caregiver) or depending on the post-injury phase (acute versus chronic).[14, 19, 43, 44] Agreement about and differences in family functioning between patients and partners may also change over time. Family-centered interventions should be started early in the rehabilitation process, with repeated monitoring of the family functioning in both members of the dyad. Health care professionals should explore any discrepancies in the perception of family functioning and discuss these with both patient and partner.

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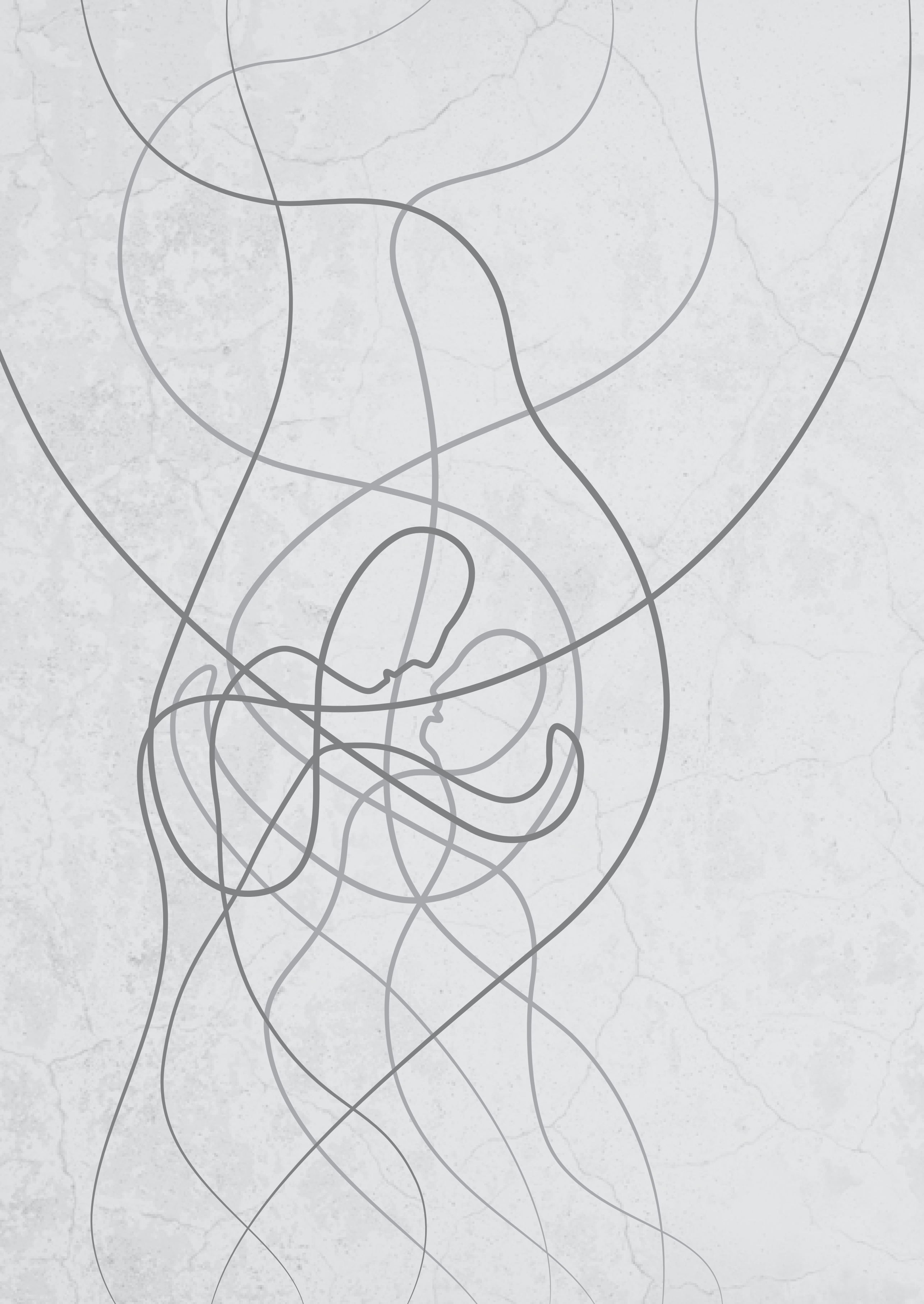

Chapter 5

Intra- and interpersonal effects of coping style and self-efficacy on anxiety, depression and life satisfaction in patient-partner couples after stroke

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Abstract

The close relationship between patients with stroke and their partners suggests interdependence in functioning. The aim of this study was to examine anxiety, depression and life satisfaction in patient-partners couples and how they differ in coping style and self-efficacy. Inter- and intrapersonal effects of coping style and self-efficacy on emotional health in couples were examined.

Data was used from 215 patient-partner couples in the Restore4Stroke Cohort at two and twelve months post-stroke. Independent and outcome variables were assessed using questionnaires. Effects within couples were assessed with an Actor–Partner Interdependence Model.

Twelve months post-stroke, anxiety was present in at least one member of 33.9% of couples. Depressive symptoms were present in 31.1% of couples. Dissatisfaction with life was present in 24.9% of couples. Less active coping by patient and partner, and lower self-efficacy of the partner were associated with anxiety and depression in couples. Pro-active coping by the patient was associated with lower anxiety of the partner. Higher self-efficacy of the partner was associated with lower depression scores and higher life satisfaction of the patient.

Our study adds to accumulating evidence for the importance of a dyadic approach to post-stroke functioning. It supports a family-based approach for treating post-stroke emotional problems.

Introduction

Stroke, with its myriad of symptoms ranging from physical impairments to cognitive and behavioral changes, has a great impact on the lives of patients and their partners. After a stroke, patients show increased symptoms of anxiety and depression and decreased life satisfaction.[1-5] Psychological factors, such as coping styles, can protect against the negative consequences of stroke. Studies have shown that coping styles with more negative problem orientation and avoidance (passive coping) are associated with post-stroke depression in patients.[6] In contrast, pro-active coping is associated with lower depression and anxiety scores.[7] High self-efficacy was shown to be associated with better quality of life.[7]

The negative effects of stroke on the anxiety, depression and life satisfaction of the partner, who often becomes the primary informal caregiver, are also increasingly being studied.[8-10] The coping styles and self-efficacy of the partners of patients with stroke have also been shown to be associated with symptoms such as anxiety and depression. A passive coping style of the partner was identified as an important predictor of life satisfaction and depressive symptoms in partners.[11] Anxiety and depression in the partner were associated with less pro-active coping and less self-efficacy of the partner.[8]

Patients with stroke and their partners will need to adjust together to life after stroke. The close relationship between them implies interdependence of patient and partner functioning. Several studies have found associations between patient and partner or caregiver depressive symptoms and between patient and partner or caregiver life satisfaction.[12-14] This suggests a need to view the effect of stroke on anxiety, depression and life satisfaction from a couple-based (dyadic) perspective. A few studies have so far looked into the associations between patient and partner factors and the functioning of both individuals within the couple. These studies found that the quality of life of patients with stroke was associated with their caregivers' burden, anxiety and depression.[15, 16] In addition, the psychological factors of low self-esteem and low optimism of the partner were shown to be associated with stroke survivor depression.[17]

It is not known whether pro-active coping styles or perceived self-efficacy,[18] which were shown to be protective features in the individual functioning of patients and partners as described above, are associated with the anxiety, depression or life satisfaction that occurs in both individuals within a couple. More knowledge about these dyadic relationships could guide family-centered rehabilitation care by healthcare professionals. Therefore, we aimed to determine how many couples suffer from anxiety, depression and low life satisfaction at two months and one year post-stroke. We also aimed to determine whether these couples have different characteristics as regards coping styles and self-efficacy. Thirdly, we aimed to determine if the coping style and self-efficacy of one member of the couple is related to the anxiety, depression and life satisfaction of the other member. We expected to find interdependence of these factors between patients and partners, as suggested by the intimate relationship between patient and partner/primary caregiver.

Methods

Participants

This study used data collected in the Restore4Stroke Cohort, a general hospital-based multicenter longitudinal study,[19] in which patients with stroke, at least 18 years old, with a clinically confirmed diagnosis of stroke, were included within seven days after their stroke. They were admitted to six general hospitals across the Netherlands between March 2011 and March 2013. Their partners were also included, and were also at least 18 years old. The couples were married or in a steady relationship. Exclusion criteria for patients and their partners were: having another serious health condition that could be expected to interfere with study outcomes (such as neuromuscular disease), a Barthel index (BI) of 17 or lower, indicating pre-stroke dependency in activities of daily living, and having insufficient command of Dutch to complete the questionnaires. Patients were also excluded if they had shown signs of cognitive decline before their stroke, as measured by the Heteroanamnesis List Cognition.[20]

The Restore4Stroke study was approved by the Medical Ethics Committee of the St. Antonius Hospital in Nieuwegein. Informed consent was obtained from all participants.

Variables

Outcome variables

Symptoms of anxiety and depression were assessed with the Hospital Anxiety and Depression scale (HADS).[21] This questionnaire consists of 7 items on anxiety (HADS-A) and 7 items on depression (HADS-D), and each item is rated on a 4-point scale, ranging from '0' (no symptoms) to '3' (maximum impairment). When a score of 8 or more is reached on either subscale, this can be interpreted as indicative of a high level of anxiety or high depressive symptoms.[22] The HADS is known to have good psychometric properties.[23]

Life satisfaction was determined by having patients and partners rate their current life satisfaction on a 6-point scale ranging from '1' (very dissatisfied) to '6' (very satisfied). This score can be dichotomized, in which a score of 3 or lower is classified as 'dissatisfied', whereas as score of 4 or higher is classified as 'satisfied'.

Independent variables

At baseline, data on age, gender, education level, stroke characteristics and pre-stroke functioning were collected. Stroke severity was measured using the National Institutes of Health Stroke Scale (NIHSS).[24] For patients, the Barthel Index (BI) was used to assess their independence in activities of daily living.[25] In addition, the Montreal Cognitive Assessment (MoCA) was used to assess the patient's cognition.[26]

Coping style was determined using the Utrecht Proactive Coping Competence Scale (UPCC), in which a higher score indicates higher levels of self-perceived proactive coping styles.[27] The UPCC is known to have good internal consistency and test-retest reliability when used in middle and late adulthood.[27]

Self-efficacy was measured using the General Self-Efficacy Scale (GSES), in which higher scores indicate higher levels of self-efficacy.[28] Psychometric properties of the GSES are satisfactory to good.[28]

Procedure

Patients and their partners were included within the first week post-stroke. Demographic characteristics such as age, gender and educational levels, as well as stroke characteristics, were documented at inclusion. Patients and their partners were visited by a research assistant two months post-stroke, to administer observational measurements and questionnaires. Questionnaires were completed by patients and partners independently from each other. At one year post-stroke, patients and partners were given the choice to complete the questionnaires online or on paper.

The MoCA was applied two months post-stroke. The HADS, life satisfaction, UPCC and GSES were all applied at two months and one year post-stroke, for both patients and partners.

Statistical analysis

Descriptive statistics were used to describe patient and partner characteristics. For each couple, the outcomes were determined at two months and one year post-stroke. Using the cut-off points for the HADS-A, HADS-D and life satisfaction as described above, percentages of couples with and without symptoms of anxiety, depression or low life satisfaction were calculated (e.g. a couple with symptoms has at least one member of the dyad who scores above the cut-off point). The couples were then divided into two subgroups, one consisting of couples in which both members were symptom-free on either of the HADS subscales or were both satisfied with life, the other consisting of couples in which at least one member showed symptoms of anxiety or depression, or was dissatisfied with life. Independent samples t-tests were used to test for significant differences in independent variables measured at two months post-stroke between these subgroups of couples.

An Actor–Partner Interdependence Model (APIM) was used to determine the effects of coping style and self-efficacy of patient and partner on their own and each other's anxiety, depression and life satisfaction.[29] The APIM uses structural equation modelling to determine the interdependence of the effects of variables measured at two months post-stroke on outcomes measured at one year post-stroke for patients with stroke and their partners. This allowed us to calculate intrapersonal effects (effects of one individual's variables on that same individual's outcomes, e.g. effects of patient variables on patient outcomes and effects of partner variables on partner outcomes), but also of interpersonal effects (effects of one individual's variables on the other person's outcomes, e.g. effects of patient variables on partner outcomes, and effects of partner variables on patient outcomes). This statistical method is well suited to test for dyadic correlations, as it takes into account the interdependence between the two members of a dyad. Effect sizes were standardized per standard deviation, for both determinants and outcomes. R^2 indicates the amount of variance explained by determinants included in the model. Models were corrected for age and sex of the patient.

Data were analyzed using IBM SPSS version 24. Mplus version 6.1 was used for the structural equation modeling. In all statistical analyses, a p-value of $< .05$ was considered statistically significant.

Results

Patient and partner characteristics

A total of 215 couples were included in the study. At two months post-stroke, 189 couples (87.9%) completed at least one of the questionnaires regarding the three outcome measures. At one year post-stroke, 180 couples (83.7%) completed at least one of the questionnaires regarding the three outcome measures. Two patients died and 33 patients and/or partners did not respond, declined to participate, or did not fill out the relevant part of the questionnaire.

Patients were on average 64 years (SD = 11.1) old, and the majority (78.6%) were male. Partners were on average slightly younger, 62 years (SD = 10.8), and 21.9% were male. The vast majority of patients (94.9%) had suffered an ischemic stroke (Table 5.1).

The presence of anxiety, depressive symptoms and life satisfaction in patients and partners at two months and one year post-stroke is shown in Table 5.2. There was great variation in the presence of anxiety and depressive symptoms, as shown by the high standard deviations.

Table 5.1. Predictors of partner's burden, anxiety and depressive symptoms

	Patients	Partners
Demographic factors		
Age in years, mean (SD)	64.3 (11.1)	62.6 (10.8)
Male sex, n (%)	169 (78.6)	47 (21.9)
Higher educational level, n (%)	65 (31.0)[a]	56 (28.3)[b]
Stroke-related factors		
Ischemic stroke, n (%)	204 (94.9)	
Left hemisphere, n (%)	87 (40.7)[c]	
Stroke severity (NIHSS), mean (SD)	2.6 (3.4)	
No symptoms (NIHSS 0), n (%)	51 (23.7)	
Minor symptoms (NIHSS 1–4), n (%)	120 (55.8)	
Moderate symptoms (NIHSS 5–12), n (%)	37 (17.2)	
Severe symptoms (NIHSS ≥ 13), n (%)	7 (3.3)	
ADL independence (BI), median (IQR)	20.0 (4.0)	
ADL dependency (BI ≤ 18), n (%)	78 (36.3)	
Cognitive functioning (MoCA), median (IQR)	24.0 (5.8)[d]	
Cognitively impaired (MoCA ≤ 25), n (%)	122 (63.5)[d]	
Psychological factors at two months post-stroke		
UPCC[e], mean (SD)	65.8 (11.2)[f]	66.5 (11.9)[g]
GSES[h], mean (SD)	32.1 (6.0)[f]	32.8 (4.8)[i]

ADL: Activities of Daily Living; BI: Barthel Index; GSES: General Self-Efficacy Scale; IQR: Interquartile Range; NIHSS: National Institutes of Health Stroke Scale; UPCC: Utrecht Proactive Coping Competence Scale.

[a] n = 210; [b] n = 198; [c] n = 214; [d] n = 192; [e] Pro-active coping, on a scale from 21 to 84 (high pro-active coping); [f] n = 191; [g] n = 188; [h] Self-efficacy score, on a scale from 10 to 40 (high self-efficacy); [i] n = 190.

Table 5.2. Mean outcome measures at 2 and 12 months post-stroke

	Patients		Partners	
	2 months	12 months	2 months	12 months
HADS-anxiety[a], mean (SD)	4.8 (3.8)[b]	4.9 (3.7)[c]	5.5 (4.0)[d]	4.8 (3.6)[e]
Symptoms present (%)	18.5	25.0	29.1	19.4
HADS-depression[a], mean (SD)	4.3 (3.7)[b]	5.0 (3.8)[c]	3.1 (3.1)[d]	3.3 (3.2)[e]
Symptoms present (%)	18.0	26.7	10.6	12.8
Life satisfaction[f], mean (SD)	4.3 (1.2)[d]	4.4 (1.1)[g]	4.6 (0.9)[h]	4.5 (1.0)[i]
Dissatisfied (%)	20.4	14.1	12.4	18.1

HADS: Hospital Anxiety and Depression Scale.

[a] HADS-subscale, on a scale of 0 (no symptoms) to 21; [b] n = 191; [c] n = 189; [d] n = 193; [e] n = 182; [f] Life satisfaction on a scale of 1 ('very dissatisfied') to 6 ('very satisfied'); [g] n = 192; [h] n = 188; [i] n = 179.

Table 5.3. Prevalence of anxiety, depression and life satisfaction in patient-partner couples

2 months after stroke					12 months after stroke				
HADS-Anxiety									
		Partner					Partner		
		Symptom-free	Symptoms present	Total			Symptom-free	Symptoms present	Total
Patient	Symptom-free	118 (62.4)	36 (19.0)	154 (81.5)	Patient	Symptom-free	119 (66.1)	16 (8.9)	135 (75.0)
	Symptoms present	16 (8.5)	19 (10.1)	35 (18.5)		Symptoms present	26 (14.4)	19 (10.6)	45 (25)
	Total	134 (70.9)	55 (29.1)	189 (100)		Total	145 (80.6)	35 (19.4)	180 (100)
HADS-Depression									
		Partner					Partner		
		Symptom-free	Symptoms present	Total			Symptom-free	Symptoms present	Total
Patient	Symptom-free	141 (74.6)	14 (7.4)	155 (82.0)	Patient	Symptom-free	124 (68.9)	8 (4.4)	132 (73.3)
	Symptoms present	28 (14.8)	6 (3.2)	34 (18.0)		Symptoms present	33 (18.3)	15 (8.3)	48 (26.7)
	Total	169 (89.4)	20 (10.6)	189 (100)			157 (87.2)	23 (12.8)	180 (100)
Life satisfaction									
		Partner					Partner		
		Satisfied	Dissatisfied	Total			Satisfied	Dissatisfied	Total
Patient	Satisfied	139 (74.7)	9 (4.8)	148 (79.6)	Patient	Satisfied	133 (75.1)	19 (10.7)	152 (85.9)
	Dissatisfied	24(12.9)	14 (7.5)	38 (20.4)		Dissatisfied	12 (6.8)	13 (7.3)	25 (14.1)
	Total	163 (87.6)	23 (12.4)	186 (100)		Total	145 (81.9)	32 (18.1)	177 (100)

Results show numbers (percentage of total).
HADS: Hospital Anxiety and Depression Scale.

Symptoms of anxiety or depression and dissatisfaction with life in couples after stroke

Table 5.3 shows the percentages of couples with none, one or both members experiencing symptoms of anxiety, depression or decreased life satisfaction. At two months post-stroke, 37.6% of couples had at least one member experiencing symptoms of anxiety. At 12 months post-stroke, 33.9% of couples had at least one member experiencing symptoms of anxiety.

At two months post-stroke, 25.4% of couples had at least one member experiencing symptoms of depression. This increased to 31.1% of couples a year post-stroke.

At two months post-stroke, 25.3% of couples had at least one member dissatisfied with life. At 12 months post-stroke, this was true for 24.9% of the couples.

Self-efficacy and coping styles in couples

At two months and 12 months post-stroke, couples with symptoms of anxiety had a less active coping style by patient (at two months: t = 3.38, p = .001; at 12 months, t = 3.35, p = .001) and partner (at two months, t = 3 .53, p = .001; at 12 months, t = 2.31, p = .022), and more self-efficacy of the partner (at two months, t = 4.60, p < .001; at 12 months, t = 2.55 p = .012), when compared to couples without symptoms of anxiety (Table 5.4).

At two months and 12 months post-stroke, couples with symptoms of depression had less pro-active coping by patient (at two months, t = 4.04, p < .001; at 12 months, t = 2.89, p = .004), and partner (at two months, t = 2.87, p = .005; at 12 months, t = 2.28 p = .024) and less self-efficacy of the partner (at two months, t = 3.05, p = .003; at 12 months, t = 2.05, p = .042), when compared to couples without symptoms of depression. Additional associations with the presence of depression in the couples at two months post-stroke were worse cognitive functioning of the patient (t = 3.01, p = .003) and lower self-efficacy scores of the patient (t = 2.73, p = .007).

In couples of which at least one member was dissatisfied with life, patients showed less pro-active coping (t = -2.06, p = .041) and their partners showed lower self-efficacy (t = -2.75, p = .007) at two months post-stroke, compared to couples of which both members were satisfied with life. One year after stroke, there were no significant differences between the two groups.

Table 5.4. Comparison of coping styles and self-efficacy between couples with/without symptoms

	2 months after stroke			12 months after stroke		
HADS-Anxiety	Symptoms present, mean (SD) (n = 69–71)	Symptom-free, mean (SD) (n = 115–118)	p-value	Symptoms present, mean (SD) n = 54–61	Symptom-free, mean (SD) (n = 110–119)	p-value
NIHSS	2.45 (3.5)	2.45 (2.4)	.997	2.39 (2.3)	2.68 (3.4)	.552
MOCA	23.6 (3.9)	23.9 (3.8)	.618	23.9 (2.7)	24.2 (3.7)	.568
UPCC patient	62.6 (12.3)	68.1 (9.9)	**.001****	61.9 (11.1)	67.7 (10.1)	**.001****
UPCC partner	62.9 (13.2)	69.1 (10.4)	**.001****	63.0 (12.9)	67.6 (11.4)	**.022***
GSES patient	31.1 (6.0)	32.8 (6.0)	.060	31.5 (5.5)	32.5 (6.2)	.296
GSES partner	30.9 (5.2)	34.0 (4.0)	**< .001****	31.3 (5.0)	33.1 (4.2)	**.012***
HADS-Depression	Symptoms present, mean (SD) (n = 45–48)	Symptom free, mean (SD) (n = 139–141)	p-value	Symptoms present, mean (SD) (n = 50–56)	Symptom free, mean (SD) (n = 114–124)	p-value
NIHSS	2.02 (2.6)	2.6 (2.9)	.231	2.75 (2.9)	2.51 (3.1)	.624
MOCA	22.4 (4.3)	24.3 (3.5)	**.003****	23.6 (3.1)	24.3 (3.6)	.213
UPCC patient	60.6 (11.8)	67.9 (10.3)	**< .001****	62.3 (11.5)	67.3 (10.0)	**.004****
UPCC partner	62.4 (14.1)	68.2 (10.7)	**.005****	62.8 (13.1)	67.5 (11.4)	**.024***
GSES patient	30.1 (5.6)	32.9 (6.1)	**.007****	31.3 (5.0)	32.5 (6.4)	.232
GSES partner	31.0 (5.6)	33.4 (4.3)	**.003****	31.4 (5.4)	33.0 (4.1)	**.042***
Life satisfaction	Dissatisfied, mean (SD) (n = 46–47)	Satisfied, mean (SD) (n = 136–139)	p-value	Dissatisfied, mean (SD) (n = 39–44)	Satisfied, mean (SD) (n = 124–133)	p-value
NIHSS	2.62 (3.3)	2.41 (2.7)	.671	2.57 (2.8)	2.56 (3.1)	.994
MOCA	23.1 (4.4)	24.1 (3.6)	.138	24.1 (3.1)	24.1 (3.5)	.934
UPCC patient	63.4 (11.1)	67.2 (10.8)	**.041***	65.2 (10.7)	66.3 (10.6)	.570
UPCC partner	64.4 (13.5)	67.7 (11.2)	.102	63.7 (11.7)	67.2 (11.4)	.097
GSES patient	30.7 (5.5)	32.8 (6.2)	.050	32.0 (5.5)	32.3 (6.0)	.794
GSES partner	31.3 (5.4)	33.4 (4.4)	**.007****	31.7 (4.5)	32.9 (4.5)	.142

GSES: General Self-Efficacy Scale; HADS: Hospital Anxiety and Depression Scale; MOCA: Montreal Cognitive Assessment; NIHSS: National Institutes of Health Stroke Scale; UCL: Utrecht Coping List; UPCC: Utrecht Proactive Coping Competence Scale.
* Significant at p < .05; ** Significant at p < .01.

Dyadic relationships between patients with stroke and their partner

Figure 5.1 shows the dyadic relationships between pro-active coping at two months post-stroke and anxiety, depression and life satisfaction at one year post-stroke. Horizontal arrows indicate intrapersonal effects (effects of patient variables on patient outcomes, or effects of partner variables on partner outcomes). Diagonal arrows indicate interpersonal effects

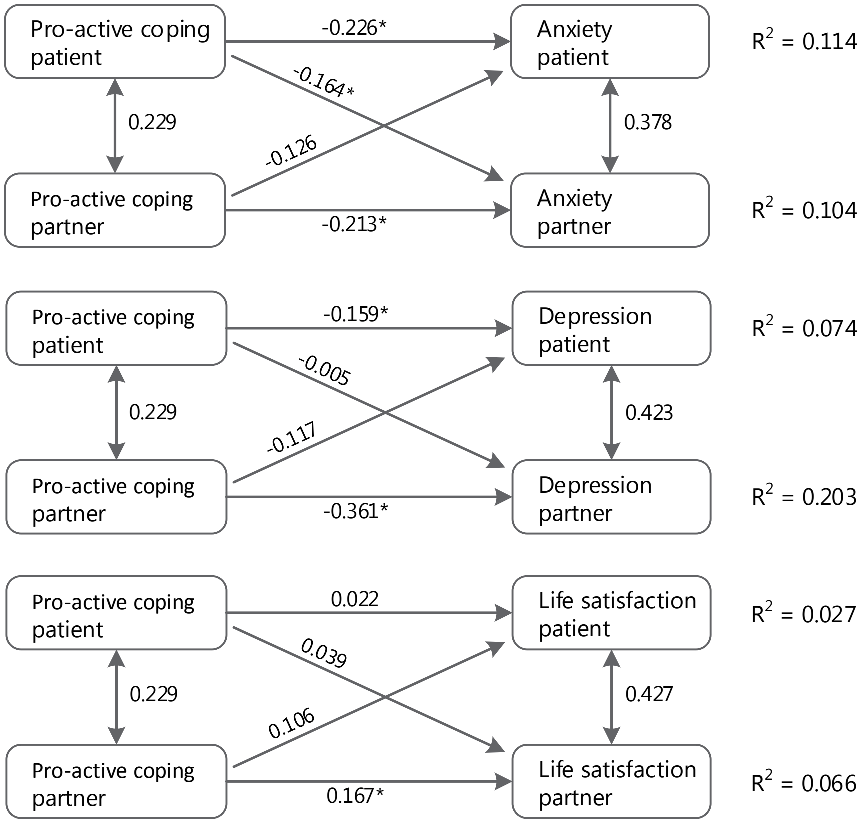

Figure 5.1. Dyadic relationships of pro-active coping with anxiety, depression and life satisfaction of the patient-partner couple.
Results were adjusted for age and sex of the patient. Single-headed arrows indicate inter- or intrapersonal effects, with effect size shown in SD of the outcome measure per 1 SD change in independent variables. Double-headed arrows indicate correlations between independent and outcome variables.
* Significant at $p < .05$.

(effects of partner variables on patient outcomes, or effects of patient variables on partner outcomes). Correlations between the same independent variables and outcome variables of patients and partners are indicated with vertical arrows. Figure 5.2 shows the dyadic relationships of self-efficacy and the outcome variables within the dyad.

Pro-active coping had multiple significant actor effects. Pro-active coping by the patient two months post-stroke was associated with lower anxiety scores (-0.226 SD, $p = .002$) and lower depression scores (-0.159 SD, $p = .037$) of the patient one year post-stroke. Pro-active coping by the partner was associated with lower anxiety scores (-0.213 SD, $p = .004$), lower depression scores (-0.361 SD, $p < .001$) and greater life satisfaction of the partner (0.167 SD, $p = .036$). A significant partner effect also occurred; pro-active coping by the patient

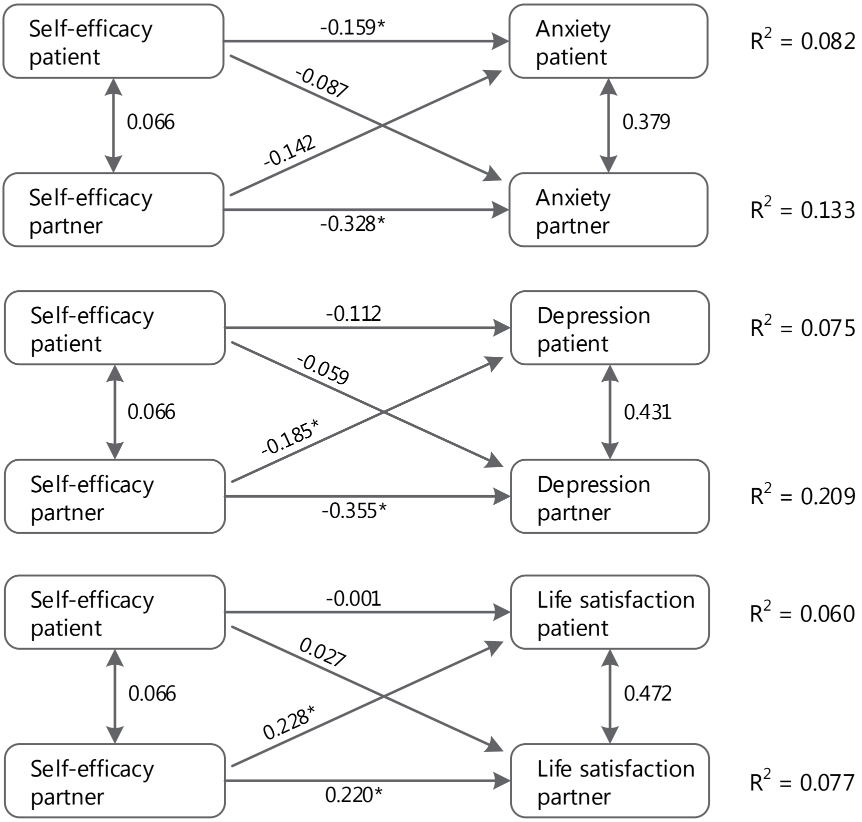

Figure 5.2. Dyadic relationships of self-efficacy with anxiety, depression and life satisfaction of the patient-partner couple.
Results were adjusted for age and sex of the patient. Single-headed arrows indicate inter- or intrapersonal effects, with effect size shown in SD of the outcome measure per 1 SD change in independent variables. Double-headed arrows indicate correlations between independent and outcome variables.
* Significant at $p < .05$.

was associated with lower anxiety scores of the partner (-0.164 SD, p = .029). The other five partner effects that were tested showed no significant associations (Figure 5.1).

Higher self-efficacy had multiple significant actor effects. Self-efficacy of the patient was associated with less anxiety of the patient (-0.159 SD, p = .029), and self-efficacy of the partner was associated with less anxiety (-0.328 SD, p < .001), less depression (-0.355 SD, p < .001) and higher life satisfaction (0.220 SD, p = .004) of the partner. Two significant partner effects occurred; self-efficacy of the partner was associated with less depression (-0.185 SD, p = .012) and higher life satisfaction (0.228 SD, p = .002) of the patient. The other four partner effects that were tested showed no statistical significance (Figure 5.2).

Discussion

The results of the current study show that in 37.6% of couples, one or both members showed signs of anxiety at two months post-stroke. At one year post-stroke, this had decreased slightly, to 33.9%. As regards depression, 25.4% and 31.1% of couples showed symptoms at two months and one year, respectively. In 25.3% of couples, at least one member was dissatisfied with life at two months post-stroke, while at one year post-stroke this was true for 24.9% of couples. Couples with no signs of depression or anxiety showed less passive coping styles of the patient, more active coping by both patient and partner, and higher self-efficacy scores of the partner. In couples in which both members were satisfied with life, patients had less passive coping styles compared to couples in which one or both members were not satisfied with life.

The Actor–Partner Interdependence Model (APIM) showed intra- and interpersonal effects of coping and self-efficacy in couples. In this model, pro-active coping style and self-efficacy were found to have interpersonal effects, with pro-active coping by the patient being associated with less anxiety of the partner. Higher self-efficacy of the partner was associated with patients having less depressive symptoms and higher life satisfaction. We found no individual psychological factors that were significantly related to both patient and partner outcomes.

Dyadic relationships in stroke research

The effect of coping style and self-efficacy of patient and partner on psychosocial functioning has been studied before.[7, 8, 30] However, an Actor–Partner Interdependence Model to determine the intra- and interpersonal effects of coping style and self-efficacy on anxiety, depression and life satisfaction has not been used before to our current knowledge. Our results are in line with findings from earlier studies that have looked specifically at the role that psychological factors play within the post-stroke dyad. Researchers found that stroke survivors' perceived stress affected caregivers' perceived stress in a significant interpersonal effect.[31] Patient distress was shown to be associated with both patients' and caregivers' illness representations.[32] Another dyadic approach to quality of life research in patient-caregiver couples after stroke showed that higher caregiver depression scores were associated with poorer quality of life in patients with stroke.[16] Associations have also been found between partners with lower self-esteem and low optimism and higher depression scores of stroke survivors. Similarly, low self-esteem in patients was associated with higher depression scores in spouses.[17] A linear regression study found associations between partners' high burden and depression and patients' depressive symptoms.[8] Overall, our current study and earlier studies show that patients and partners who appear to be handling their new situation well (e.g. through pro-active coping, high self-efficacy and self-esteem, or high optimism) can influence their partner in a positive way. Thus far, dyadic models have not been used extensively in stroke research. The use of Actor–Partner Interdependence Models for a dyadic approach to the functioning of patient-partner couples has been used more extensively and in large studies in other research fields, such as dementia research.[33-36]

Strengths and limitations of the study

A strength of the study is the inclusion of a large number of patients and their partners, shortly after stroke, independent of discharge destination. The one year follow-up allowed us to compare results in the subacute and chronic phases post-stroke. In this way, emotional health and life satisfaction in the chronic phase can be related to coping style and self-efficacy measured in the subacute phase.

Furthermore, our study involved a couple-based perspective of emotional health and life satisfaction of both patients and their partners. The APIM analysis gave us the opportunity to investigate the intra- and interpersonal effects within the dyad in one comprehensive model. Our study adds to the understanding of post-stroke functioning of not only the patient, but of the patient-partner dyad.

A limitation of our study is that both patients and partners were relatively young. A large proportion of the patients were male, whereas partners were for a large part female. Almost 95% of patients had suffered from ischemic stroke. These characteristics of our study population could limit generalizability to the general stroke population of patients and partners.

Another limitation is that baseline measurements of anxiety, depression and life-satisfaction were not included in the APIM analyses. However, anxiety, depression and life-satisfaction at baseline could well be an important predictor of anxiety, depression and life-satisfaction at 12 months.

Clinical implications for a family-based approach to stroke rehabilitation care

The current study has added to the growing body of evidence for the interdependence of patient and partner functioning. This implies that a family-based approach by clinicians is vital. In order for this approach to be successful, clinicians should know what to screen for in both patients and partners to identify couples at risk. Also, there must be relevant care interventions available for patients and partners.

Our study showed associations between the coping style and self-efficacy measured at two months post-stroke, and the anxiety, depression and life satisfaction measured at one year post-stroke. This points to an opportunity for early screening, assisting in identifying couples at risk and possibly leading to early intervention.

In 2014, the American Heart Association and American Stroke Association released a statement regarding evidence for family caregiver and dyad interventions post-stroke.[37] This statement was updated in 2017.[38] Although many of the studies they reviewed had methodological limitations, they recommended that caregiver and dyad interventions should combine a psychoeducational component with a skill building component, to improve psychosocial outcomes such as depression. Psychological interventions aimed at stroke caregivers, such as coping skill training, have been shown to reduce their anxiety and depressive symtomps.[39] A high refusal rate for support group formats was found, implying that large numbers of sessions with face-to-face contact may not be feasible for busy caregivers. Delivery of family-based approaches (partly) through telephone or web-based contacts may be easier to integrate in post-stroke care.[37, 38]

In conclusion, this study provides further insight into the dyadic functioning of patient-partner couples after stroke. Anxiety, depression and decreased life satisfaction are prevalent in these couples. When emotional functioning is viewed from a couple's perspective, both patient and partner psychological characteristics can play an important role. Interpersonal effects of coping style and self-efficacy on anxiety and depression were demonstrated.

We used coping and self-efficacy as the psychological determinants, and did not use other, sometimes related, psychological constructs, such as optimism, self-esteem, mastery, self-stigma or personality traits. Furthermore, genetic and biological factors, apart from sex and age, were not included in the models.

More research is needed to better understand patients with stroke and their partners from a dyadic perspective, to identify other relevant factors for early screening and to investigate if interventions aimed at psychological factors in both dyad members are clinically useful and effective.

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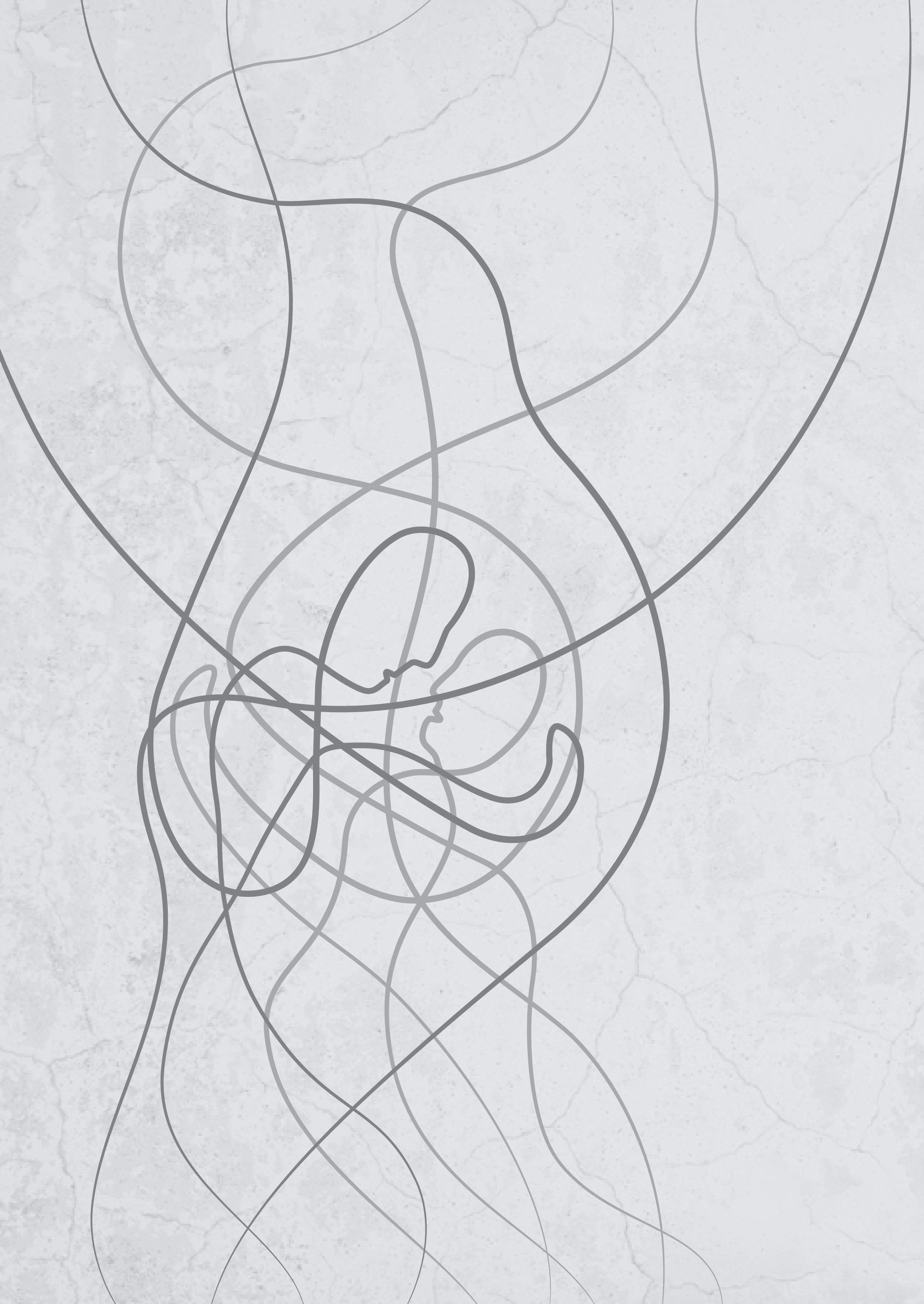

Chapter 6

Evaluating the CARE4Carer blended care intervention for partners of patients with acquired brain injury: protocol for a randomized controlled trial

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Abstract

Background: Support programs for partners of patients with acquired brain injury are necessary, since these partners experience several unfavorable consequences of caregiving, such as a high burden, emotional distress, and poor quality of life. Evidence-based support strategies that can be included in these support programs are psychoeducation, skill building, problem solving and improving feelings of mastery. A promising approach would seem to be to combine web-based support with face-to-face consultations, creating a blended care intervention.

Objective: This paper outlines the protocol of a randomized controlled trial to evaluate the CARE4Carer blended care intervention for partners of patients with acquired brain injury.

Methods: A multicenter two-arm randomized controlled trial will be conducted. A total of 120 partners of patients with acquired brain injury will be recruited from five rehabilitation centers in the Netherlands. The blended care intervention consists of a nine-session web-based support program and two face-to-face consultations with a social worker. Themes that will be addressed are: giving partners insight into their own situation, including possible pitfalls and strengths, learning how to cope with the situation, getting a grip on thoughts and feelings, finding a better balance in the care for the patient with acquired brain injury, thinking about other possible care options, taking care of oneself, and communication. The intervention lasts 20 weeks and the control group will receive usual care. The outcome measures will be assessed at baseline and at 24- and 40-week follow-up. The primary outcome is caregiver mastery. Secondary outcome measures are strain, burden, family functioning, emotional functioning, coping, quality of life, participation, and social network.

Results: The effect of the intervention on the primary and secondary outcome measures will be determined. Additional a process evaluation will be conducted.

Conclusions: The findings of this study will be used to improve the care for partners of patients with acquired brain injury. Barriers and facilitators that emerge from the process evaluation will be used in the nationwide implementation of the intervention.

Registration: Dutch Trial Register NTR6197, http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=6197 (Archived by WebCite at http://www.webcitation.org/6xHBAxx0y).

Introduction

Caregivers of patients with acquired brain injury (ABI), such as stroke and traumatic brain injury, often experience high levels of burden, which profoundly affects their physical and psychosocial well-being.[1-5] About half of the caregivers experience anxiety and emotional distress, and 65% report health problems and a decline in social life with high levels of strain.[6] The majority of caregivers of patients with ABI reporting psychological distress, are the partners of the patients.[7] Among partners of patients who were admitted for inpatient rehabilitation, 80% reported poor quality of life one year after stroke.[3] It is especially the return home after inpatient rehabilitation which appears to be a major hurdle for patients and their caregivers.[6]

Support programs for partners of patients with ABI are necessary and should be initiated as early as possible after discharge from the rehabilitation facility, so partners are better prepared for their new role as caregivers at home.[8] Several reviews show that evidence-based support strategies such as psychoeducation, problem-solving therapy and skill building are effective components of interventions.[9-13] Additionally, support programs should address condition-specific issues, such as the cognitive, emotional and personality changes of the patient.[1] Furthermore, interventions to increase feelings of mastery also seem important, since mastery can protect against the stressors of caregiving and improve caregivers' well-being.[14, 15]

Participating in a support program can be challenging for partners of patients with ABI, since being a caregiver already takes up much time and energy,[16] in addition to everyday activities such as having a job. Travelling to a rehabilitation center to attend a support program can be experienced as requiring too much time and energy. Web-based interventions may therefore be more suitable, since partners can participate at any time from any location with internet access, and they can keep their own pace.[17] Caregivers in various populations have reported being satisfied and comfortable with web-based interventions.[18] Previous research has shown that web-based interventions can improve family functioning, psychological well-being, coping, and quality of life among caregivers.[18, 19] Furthermore, web-based interventions for caregivers are feasible[19] and can save costs.[18] A disadvantage of web-based interventions, however, is that of the higher drop-out rates.[20] Participants of web-based interventions report that adherence can be increased by combining web-based interventions with face-to-face consultations, creating a blended care intervention.[21, 22] Another advantage of combining web-based interventions with face-to-face consultations is the opportunity for personalized treatment: elaborating on specific personal problems, which cannot be addressed through predefined responses, but require input from professional caregivers.[22]

This study aims to evaluate the effects and process of a blended care intervention, which includes psychoeducation, skill building and problem solving, on feelings of mastery in partners of patients with ABI. Our hypothesis is that the intervention group will have increased feelings of mastery compared to the control group. This paper describes the study protocol.

Methods

Design

This study is a multicenter two-arm randomized controlled trial investigating the CARE4Carer blended care intervention in addition to usual care, in comparison to usual care alone. The Medical Research Ethics Committee of the UMC Utrecht confirmed that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply to this study. The Dutch Agreement on Medical Treatment Act (WGBO) and Dutch Personal Data Protection Act (Wbp) do apply. All participating rehabilitation centers have approved the study protocol. Written informed consent is obtained from each participant. The study is registered in the Dutch trial register as NTR6197, registered 2 November 2016.

Participants

The study population consists of partners of patients with ABIs such as stroke, subarachnoid hemorrhage, traumatic brain injury, postanoxic encephalopathy (i.e. acute onset, no degenerative neurological diseases). Participants are recruited from five rehabilitation centers in the Netherlands (Adelante, Heliomare, Reade, Sint Maartenskliniek, Tolbrug). Inclusion criteria for both patient and partner are: (1) 18 years or older, and (2) written informed consent.

Additional inclusion criteria for the patient are: (1) having an ABI, (2) independent living in the community before the ABI, (3) having been admitted for inpatient rehabilitation, and (4) being scheduled to be discharged home after rehabilitation.

Additional inclusion criteria for the partner are: (1) being one of the patient's primary caregivers, and (2) being the patient's partner.

Exclusion criteria for the patient are: (1) neurodegenerative or progressive ABI and (2) insufficient command of Dutch, clinically judged by the health care professionals. Exclusion criteria for the partner are: (1) insufficient command of Dutch, clinically judged by the health care professionals, (2) being unable to work on a computer, and (3) having no internet access.

Partners can only participate when the patient signs informed consent. If the patient decides to stop study participation, the partner can continue to participate, but data of the patient will not be used in the analyses.

Procedure

The participants are recruited during regular consultations with a social worker during inpatient rehabilitation. The social workers, who are trained in the treatment protocol, check the eligibility criteria and explain the study. Both partner and patient receive an information letter and an informed consent form and are asked whether the researcher may contact them. After a few days the researcher calls the partner and asks if there are any questions about the study. When both partner and patient agree to participate, they sign their informed consent forms and return these to the researcher by mail. Reasons for exclusion and reasons to decline research participation are recorded. Randomization takes place after the informed consent forms have been received.

Demographic factors of the partners are recorded at baseline and those of the patients are retrieved from the patient records. The outcome measures for the partners are assessed at baseline, post-intervention and at follow-up, except for care consumption, which is not assessed at baseline. The outcome measures for the patients are assessed at baseline and at follow-up. Questions regarding process evaluation are presented after the intervention. All questionnaires are administered through the same platform, which also provides the web-based support program.

See Figure 6.1 for the flow diagram.

Randomization

Participants are randomly assigned to either the group receiving the CARE4Carer intervention or to the usual care control group, using an online randomization tool. Participants are stratified by rehabilitation center, and block randomization with two block sizes (2 and 4) is used to achieve a balance across the experimental and control groups. The block size and order of allocation are randomly chosen at the beginning of each block. This minimizes the risk of predicting group assignment and keeps the researcher blinded to the randomization process. Randomization takes place before the baseline measurement to be able to assign a certain route to the partner in the online platform. Partners in the intervention group automatically gain access to the web-based support program directly after completing the baseline measurement, which is only possible when this route is set beforehand.

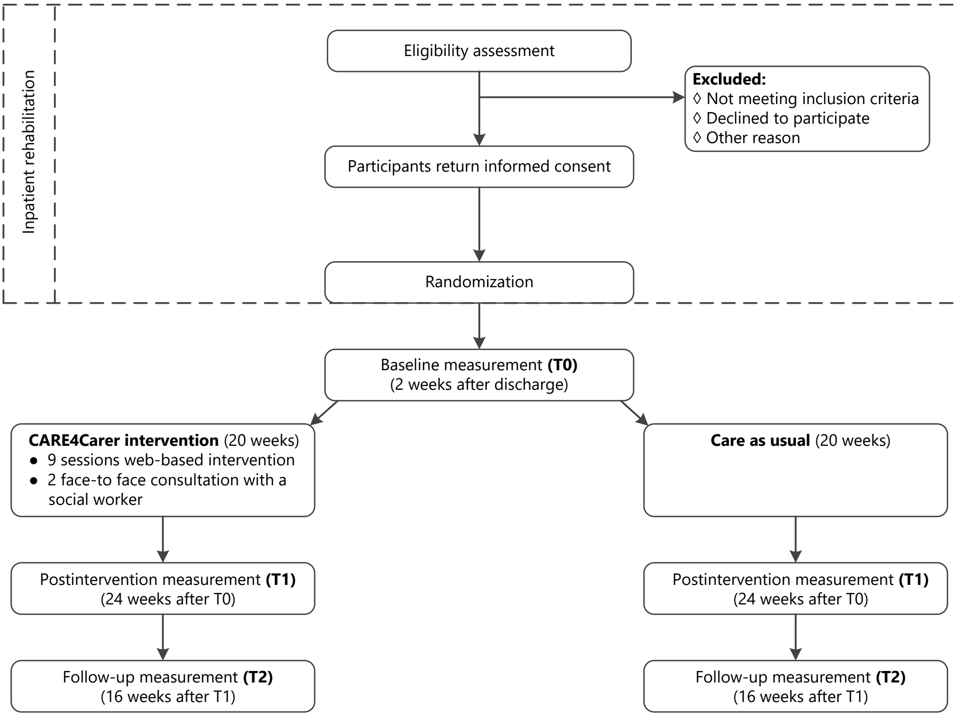

Figure 6.1. Flow diagram of the trial.

CARE4Carer intervention

The CARE4Carer intervention starts two weeks after the patient is discharged from inpatient rehabilitation and consists of a web-based support program and face-to-face consultations with a social worker.

Web-based support program

The intervention program, called Brain injury – Moving forward together (in Dutch: 'Hersenletsel – hoe samen verder?'), is a web-based support program for partners of patients with ABI. The program comprises 9 sessions, described in Table 6.1. It is based on an existing support program, which was developed by Minddistrict and Heliomare Rehabilitation Centre. They used principles of cognitive behavior theory[23] and solution-focused therapy,[24] as well as expert input from social workers, psychologists, and caregivers of patients with ABI. We have modified this program to tailor it specific to partners of patients with ABI. We have also carried out a pilot study, in which three partners of patients with ABI and

Table 6.1. Sessions of the CARE4Carer web-based intervention

#	Title
1.	Welcome
2.	Caring for your partner
3.	Burden and resilience
4.	Which care choices to make?
5.	Getting a grip on your thoughts and feelings
6.	Taking care of yourself
7.	Asking for support
8.	Communication
9.	And now?

a member of the patient association tested and evaluated the program. This has led to several further adaptations.

Themes within the program are: getting insight into one's own situation, including possible pitfalls and strengths, learning how to cope with the situation, getting a grip on thoughts and feelings, finding a better balance in the care for the patient with ABI, thinking about other possible care options, taking care of oneself, and communication.

Each session is informative and easy to use, and provides practical tips. The sessions consist of psychoeducation and assignments aimed at problem solving and skill building. Short videos featuring a social worker and videos of partners who are caregivers of patients with ABI are included in each session.

The partners can attend the program over a period of 20 weeks, in their own time, at their own pace and from any location with internet access. Partners are encouraged by automatic e-mail reminders and by the social workers to complete the sessions before the post-intervention measurement, although the program is still available for them after this period.

Face-to-face consultations

In addition to the web-based support program, partners are offered two consultations with a social worker at the rehabilitation center. The social workers prepare for the meetings by reviewing the completed assignments presented in the web-based sessions. Issues emerging from these answers are addressed and specific personal situations are discussed. The first consultation takes place 10 weeks after discharge, after the first 4 sessions of the web-based program have been completed; the second consultation is after the 9th session, 20 weeks after discharge. The duration of the consultations is about 45 minutes to one hour, depending on the need to elaborate.

Usual care

Partners randomized to the control group receive usual care. This can consist of consultations with a social worker and/or psychologist and peer support groups. Partners in the intervention group are also allowed to receive usual care in addition to the CARE4Carer intervention.

Measures

The primary outcome is caregiver mastery. Secondary outcome measures for the partners are strain, burden, family functioning, emotional functioning, coping, care-related quality of life, participation, social network and care consumption. Secondary outcome measures for the patients are family functioning, emotional functioning, and participation. Additionally, a process evaluation will be conducted. An overview of all instruments and the time of assessment is presented in Table 6.2.

Table 6.2. Overview of all instruments

	T0		T1		T2	
Instruments	C	P	C	P	C	P
Caregiver Mastery Scale (CMS)	x		x		x	
Caregiver Strain Index (CSI)	x		x		x	
Self-Rated Burden (SRB)	x		x		x	
McMaster Family Assessment Device (FAD) Subscale: General Functioning	x	x	x		x	x
Hospital Anxiety and Depression Scale (HADS)	x	x	x		x	x
Utrecht Coping List (UCL)	x		x		x	
CarerQol	x		x		x	
Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) Subscale: Restrictions	x	x	x		x	x
Social network	x		x		x	
Care consumption			x		x	
Process evaluation			x			

C: caregiving partner; P: patient.

Caregiver mastery

Caregiver mastery is measured by the Caregiver Mastery Scale (CMS).[25] This instrument is an adaptation of the Pearlin Mastery Scale,[26] in order to measure mastery in the caregiving situation instead of global mastery. This questionnaire consists of seven statements about caregiving, such as '*You believe you are mastering most of the challenges in caregiving*'. Partners are asked to indicate their level of agreement (i.e. strongly disagree – disagree – neither agree nor disagree – agree – strongly agree) with each statement. Three items with negative statements are reverse-scored. Total scores can range from 7 to 35, with higher scores reflecting greater caregiver mastery. Psychometric quality has been confirmed[25] and the instrument has proved to be able to detect change after intervention.[27]

Secondary outcome measures

Caregiver Strain Index (CSI) The amount of strain experienced by the partner is assessed with the CSI. This instrument contains 13 statements which are scored a 1 ('yes') or 0 ('no').[28] Total scores range from 0 to 13, with higher scores indicating higher strain. Scores of 7 or higher indicate substantial strain. The CSI is a reliable[28] and valid[29] instrument which is commonly used for caregivers of stroke patients.[30]

Self-Rated Burden (SRB) A single question enables the partners to indicate how burdensome caring for the patient with ABI is at that moment. A visual analogue scale is used, ranging from 0 ('not hard at all') to 100 ('much too hard').[29] The SRB has proved to be a valid instrument to assess the burden of caregiving for informal caregivers of patients with stroke.[29]

McMaster Family Assessment Device (FAD) Family functioning is assessed with the General Functioning subscale of the FAD.[31] Partners indicate their level of agreement (i.e. strongly disagree – disagree – agree – strongly agree) with 12 statements. Each statement is scored from 1 to 4, with 1 reflecting healthy functioning and 4 reflecting unhealthy functioning. A mean score of 2.0 or higher indicates problematic family functioning.[32] The FAD has good psychometric properties.[31-33]

Hospital Anxiety and Depression Scale (HADS) Emotional functioning is measured with the HADS. It consists of two 7-item subscales measuring anxiety and depression. Scores above 7 on the subscales indicate an anxiety disorder or depression, respectively.[34] The HADS has good psychometric properties and has proved to be responsive to change.[35, 36]

Utrecht Coping List (UCL) Coping is assessed with three subscales of the Utrecht Coping List: (1) active problem solving (7 items), (2) seeking social support (6 items), and (3) passive reacting (7 items).[37] A 4-point rating scale is used, ranging from 'seldom or never' to 'very often'. Higher scores on a subscale indicate a greater tendency to use that specific coping style. The UCL has good psychometric properties.[37, 38]

CarerQol The CarerQoL instrument measures the care-related quality of life of informal caregivers.[39] It determines the subjective burden in seven dimensions of the caregiving situation (CarerQol-7D) and includes a valuation component (CarerQol-VAS). Low scores on the CarerQol-7D indicate a poor caregiving situation, while high scores on the CarerQol-VAS reflect a higher level of happiness. The CarerQol is a valid tool to measure the impact of caregiving.[40]

Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) Participation restrictions are assessed with the USER-P instrument.[41] On 10 items, respondents indicate to what extent they are able to do the activity described. Scores range from 0 ('not possible') to 3 ('without difficulty'). Higher total scores indicate fewer participation restrictions. The USER-P has good psychometric properties.[42, 43]

Social network The social network (i.e. number of parents/step-parents, children/grandchildren, other family members, and friends/neighbors) is mapped using a newly developed questionnaire. It also includes items about how easy it is to get practical and emotional help from these persons. Partners answer on a 5-point scale ranging from 'very easy' to 'very difficult'.

Care consumption Care consumption is assessed during the post-intervention (T1) and follow-up (T2) measurements. Partners are asked whether and how often they have had contact with a psychologist, social worker, general practitioner, practice nurse and/or aftercare nurse, and whether they participated in peer support groups.

Process evaluation

At post-intervention (T1), the partners evaluate the intervention, the individual sessions, and the different elements of the intervention, by filling in the online questionnaire. The advantages, disadvantages, satisfaction and usability of the intervention are investigated.

Using interviews, we assess the experiences of the social workers with carrying out the intervention and working with a blended care program, as well as their views on facilitators and barriers for implementation. Every social worker who supported a caregiver in the intervention group will be interviewed.

Treatment fidelity is determined by reports from the social workers on the number of face-to-face consultations that have taken place, and by analyzing how many sessions of the web-based support program have been completed. Partners are obliged to fill in certain assignments to be able to complete a session.

Blinding

The baseline measurements (T0) are self-reported by partner and patient, who do not yet know the allocation outcome at this stage. Blinding to treatment allocation is not possible due to the nature of the intervention. The post-intervention (T1) and follow-up (T2) measurements are, therefore, not blinded, since these are self-reported by the partner and patient, who are aware of treatment allocation by that time.

Power analysis

The sample size has been calculated on the basis of the primary outcome measure, the Caregiver Mastery Scale. To detect a difference between the groups of 0.5 SD on the Caregiver Mastery Scale, with an alpha of 0.05 and a power of 80%, a total of 50 caregivers is needed in each arm of the trial. Assuming a drop-out rate of 20%, a total of 120 patient-partner couples will be included in the CARE4Carer trial.

Statistical analyses

Descriptive statistics including frequencies, means, standard deviations, and (for nonparametric data) medians and interquartile ranges will be calculated. Longitudinal data analysis will be performed using a generalized linear mixed model (GLMM), to evaluate differences in efficacy between the experimental and control groups. Data will be analyzed based on an 'intention-to-treat' analysis and with an alpha level of 0.05. The analysis software IBM SPSS Statistics version 22 for Windows will be used.[44]

Descriptive statistics will be used for the partners' process evaluation and for the treatment fidelity. The interviews with the social workers will be transcribed verbatim and qualitative analyses will be performed.

Results

Participant recruitment for this randomized controlled trial commenced in September 2016 and enrolment is on-going. The first results are expected to be submitted for publication in 2018.

Discussion

In this paper we have described the protocol of a randomized controlled trial to evaluate the CARE4Carer blended care intervention to improve feelings of mastery in partners of patients with acquired brain injury. We will also investigate the effect of the intervention on strain, burden, family functioning, emotional functioning, coping, quality of life, participation, social network and care consumption. A process evaluation will also be part of this study.

Brain injury – Moving forward together is an innovative partner support program. It was developed in co-creation with partners, social workers, and psychologists. Methods that have proved to be effective, such as those based on cognitive behavior theory and solution-focused therapy, have been integrated in the intervention. The program has been pilot-tested among partners of patients with ABI and modified in response to their comments. Another strength of this study is the use of blended care. Integrating the web-based support program with face-to-face therapy combines the best of two worlds, which can enhance the effect of the intervention.[22] To our knowledge, this is the first blended care intervention for partners of patients with ABI.

It is important to note that blended care is probably not suitable for everyone. Not every partner and health care provider may be ready for blended care. Some partners may not be comfortable with receiving support via a web-based program and might prefer to only have face-to-face contacts. Also, health care providers may resist offering support via the internet.[45] In addition, access to internet and possession of a computer, laptop, tablet or smartphone is not standard for everybody: 22% of the Dutch population aged 65 years or older has no internet access at home.[46]

The study may have some limitations. First, we only include partners of patients who are admitted for inpatient rehabilitation. Patients who go home after treatment at the hospital and patients who receive geriatric rehabilitation are not included. Second, the control group treatment is not standardized, because care as usual differs between rehabilitation centers.

Support for partners of patients with ABI is clearly needed. Blended care interventions that include psychoeducation, skill building and problem solving have not been investigated in this population yet. Our CARE4Carer intervention could help partners to better deal with their new role as a caregiver, after the patient has returned home. We hypothesize increased caregiver mastery among partners as a result of this intervention.

The findings of this study will be used to inform rehabilitation physicians, social workers, and psychologists and to improve the care for partners of patients with ABI. If the intervention proves to be superior to usual care, it will be made available for implementation nationwide, taking into account the barriers and facilitators that emerge from the process evaluation.

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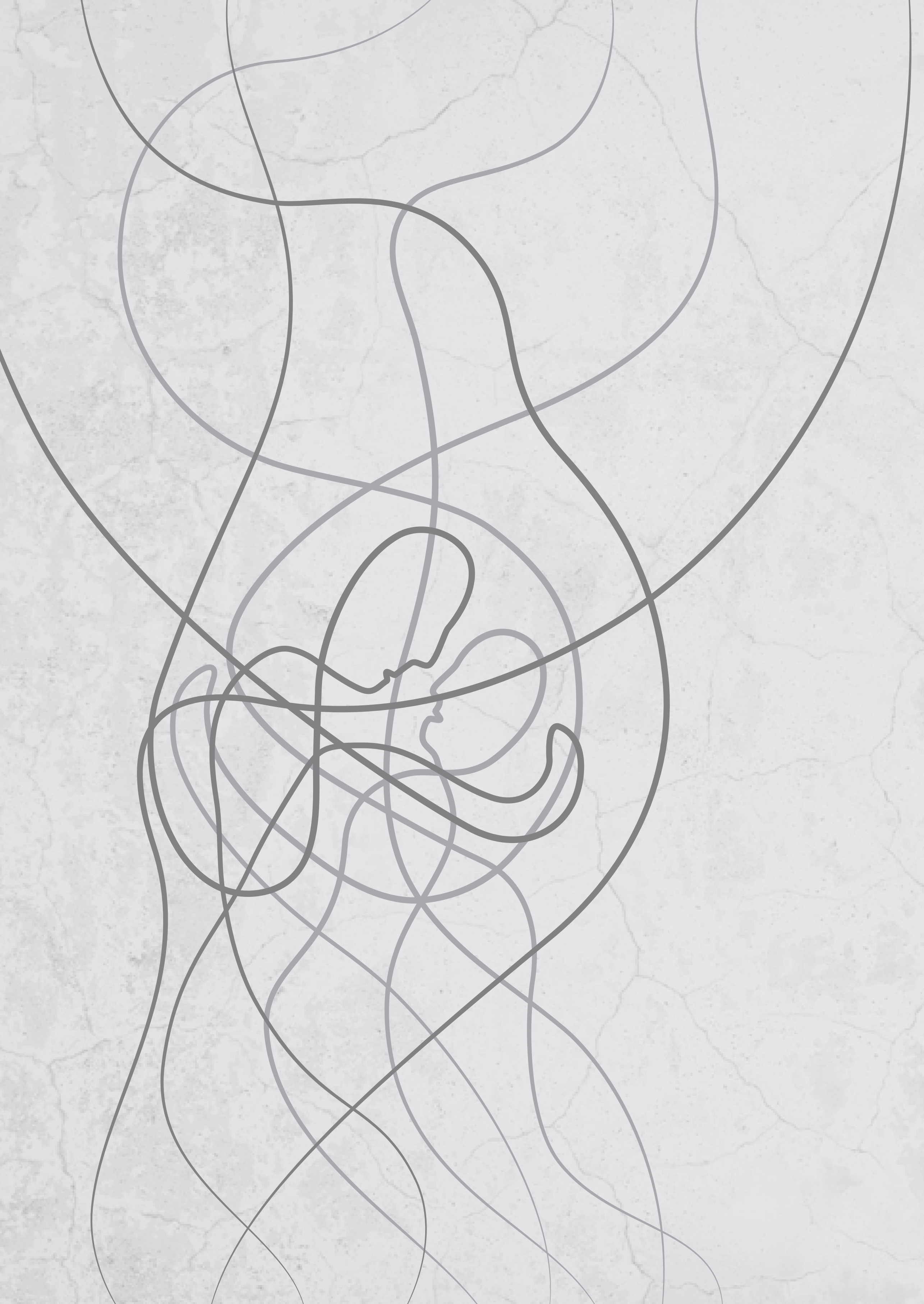

Chapter 7

A validation study of the Caregiver Mastery Scale for partners of patients with acquired brain injury

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Abstract

Objective: To validate the Caregiver Mastery Scale for partners of patients with acquired brain injury.

Design: The score distributions, internal consistency, and convergent validity of the Caregiver Mastery Scale were determined.

Subjects: A total of 92 partners (53% male, age 62 years) of patients with acquired brain injury (91% stroke) discharged from inpatient rehabilitation (time since injury 32 months).

Main measures: *Outcome measure:* Caregiver Mastery Scale. *Reference measures:* Caregiver Strain Index, Hospital Anxiety and Depression Scale and CarerQol.

Results: The Caregiver Mastery Scale has a normal distribution, with no floor or ceiling effects. Its internal consistency is acceptable (Cronbach's alpha: 0.75). The convergent validity analyses confirmed our hypothesis that higher scores on the Caregiver Mastery Scale correlate with less burden, lower levels of anxiety and depression and greater well-being. Furthermore, partners scoring high on the Caregiver Mastery Scale mostly scored below the clinical cut-off scores on the Caregiver Strain Index and the anxiety and depression subscales of the Hospital Anxiety and Depression Scale, whereas partners scoring low on the Caregiver Mastery Scale were more likely to score above the cut-off points.

Conclusion: The Caregiver Mastery Scale is a valid instrument to assess the caregiver mastery of partners of patients with acquired brain injury.

Introduction

Nowadays most people with acquired brain injury are discharged home where informal caregivers take care of them. The role of caregiving is often fulfilled by the partner, who is the most close to the patient, and may lead to negative consequences such as high levels of burden,[1-5] anxiety[3, 4] and depressive symptoms[1-4, 6] and poor well-being.[1, 4]

Several psychological resources and coping responses can protect against the negative consequences of stressors such as caregiving.[7] Mastery is considered to be one of these psychological resources and is defined as 'the belief that one is able to influence or control life events and that one is competent or effective in managing those events in order to produce desired outcomes'.[8 (p163)]

In 1978, Pearlin and Schooler[7] constructed a 7-item scale to assess mastery. Elaborating on this global mastery scale, Christensen et al.[8] created four specific mastery scales for women in their roles as mother, wife, employee and caregiver for their own parent. They found mastery in the caregiving role to be positively related to well-being and negatively correlated with depressive symptoms.[8] Little is known about the psychometric properties of this Caregiver Mastery Scale. The internal consistency and responsiveness have been investigated in a group of women taking care of their parent[8] and caregivers of glioma patients,[9] respectively. Whether the Caregiver Mastery Scale can be used to measure mastery in caregiving for other conditions, such as patients with acquired brain injury, is unknown. The aim of this study was therefore to determine the validity of the Caregiver Mastery Scale for partners of patients with acquired brain injury.

The objectives of this study were to (1) investigate the score distributions of the Caregiver Mastery Scale, (2) examine the internal consistency of the Caregiver Mastery Scale, and (3) test the convergent validity of the Caregiver Mastery Scale for partners of patients with acquired brain injury. The corresponding hypotheses were that higher scores on the Caregiver Mastery Scale would be related to (1) less burden,[4] (2) less anxiety,[4, 10] (3) less depression[4, 8, 10, 11] and (4) greater well-being.[4, 8]

Methods

Participants

Participants in this cross-sectional study were the partners of patients with acquired brain injury discharged from inpatient rehabilitation at De Hoogstraat Rehabilitation (Utrecht, the Netherlands). Partners were invited when (1) the patient had a non-progressive, non-neurodegenerative acquired brain injury, (2) the patient was admitted to the rehabilitation center between June 2013 and June 2015 and (3) the partner was at least 18 years old. Exclusion criteria were (1) absence of internet access and (2) insufficient command of the Dutch language.

Procedure

Letters signed by the attending physician were sent in April 2016 to inform the partners about the study and ask them to participate. Participants were invited to fill in online questionnaires, and the letter contained the URL and login credentials required to gain access. Reminder letters were sent after one month when partners had not responded to the first invitation. The participants consented to the use of their data for this study by logging in to the website. The medical ethics committee of The Hoogstraat approved the study and Good Clinical Practice Guidelines[12] were followed.

Measures

The demographic characteristics of the partner (e.g. age, gender, country of birth, educational level and employment), as well as the patient's diagnosis and the date of diagnosis, were self-reported by the partners.

The *Caregiver Mastery Scale*[8] is a 7-item self-report scale, indicating the extent to which respondents agree (5) or disagree (1) with each item. Three items with negative statements are reverse-scored. Total scores can range from 7 to 35, with higher scores reflecting greater caregiver mastery. The Dutch version used in this study was obtained from the researchers who investigated mastery among caregivers of patients with high-grade glioma.[9] The English and Dutch versions can be found in Appendix 7.1.

The following measures were used to assess the convergent validity:

The *Caregiver Strain Index*[13, 14] consists of 13 items which can be scored as 'yes' or 'no'. The total score ranges from 0 to 13, with higher scores reflecting a higher caregiver burden. A score of 7 or higher is considered to indicate a substantial burden. The Caregiver Strain Index is the most commonly used scale to assess burden among caregivers of patients with stroke[15] and is recommended in the Dutch stroke care guidelines.[16]

The *CarerQol*[17, 18] instrument determines the care-related quality of life of informal caregivers. It consists of the CarerQol-7D and the CarerQol-VAS. The CarerQol-7D uses 7 items to measure the subjective burden in various dimensions of the caregiving situation. Low scores indicate a high burden. The CarerQol-VAS assesses the caregivers' well-being, with higher scores indicating greater well-being.

The Hospital *Anxiety and Depression Scale*,[19-21] consists of a 7-item anxiety and a 7-item depression subscale. Subscale total scores above 7 indicate an anxiety disorder or depression, respectively.

Statistical analyses

Data were analyzed using IBM SPSS Statistics version 22 for Windows. The score distribution of the Caregiver Mastery Scale was examined. Skewness was considered to be present if the skewness value was below -1.0 or above 1.0. A kurtosis value between -1.0 and 1.0 was considered acceptable. Floor and ceiling effects were considered to be present if at least 15% of the participants achieved the worst or best score, respectively.[22]

To determine internal consistency, Cronbach's alpha and item-total correlation were calculated. Internal consistency was considered acceptable if Cronbach's alpha was between 0.70 and 0.90.[23] A corrected item-total correlation value below 0.3 indicates that the corresponding item does not correlate very well with the scale overall and may be dropped.[23]

The convergent validity of the Caregiver Mastery Scale was examined by investigating the correlations between the Caregiver Mastery Scale and the other measures. Since the Caregiver Mastery Scale is an ordinal scale, the Spearman rank-order correlation coefficient was used. Convergent validity was considered to be good if the correlation coefficient was greater than 0.6, moderate if the coefficient was between 0.3 and 0.6, and poor if the coefficient was below 0.3.[15] Moderate correlations were expected, since the instruments measure concepts that are related, but not identical, to caregiver mastery. If at least 3 out of 4 hypotheses were confirmed, the Caregiver Mastery Scale was considered to have convergent validity.[22]

Elaborating on the convergent validity, we investigated the relationship between Caregiver Mastery Scale scores and the burden, anxiety and depression outcomes with respect to their clinical cut-off scores. Two subgroups were created, consisting of the 25% of partners with lowest scores and the 25% with the highest scores on the Caregiver Mastery Scale. For both groups, the percentage of respondents scoring below and above the clinical cut-off scores of the Caregiver Strain Index and the anxiety and depression subscales of the Hospital Anxiety and Depression Scale were determined.

Results

A total of 255 partners were invited to participate, 95 of whom (37%) logged in to the online questionnaire. Three persons only answered a few demographic questions but quit before filling in the Caregiver Mastery Scale and were therefore excluded from the analyses. Hence, the study sample consisted of 92 partners. The age of the respondents and the patients' diagnosis in our study sample are similar to those of the invited population. Men were more likely to respond: 49 out of 92 (53%) of the study sample were male, compared with 111 out of 255 (44%) in the invited population.

Table 7.1 presents the acquired brain injury characteristics of the patients and the demographic characteristics of their partners.

Table 7.1. Acquired brain injury characteristics of the patients and demographics of their partners (N = 92)

Patient characteristics	
Diagnosis patient, n (%)	
Ischemic stroke	62 (67.4)
Hemorrhagic stroke	22 (23.9)
Traumatic brain injury	4 (4.3)
Other	4 (4.3)
Time since diagnosis in months, median (IQR)	32 (21)
Partner characteristics	
Age in years, mean (SD)	62.4 (10.2)
Gender, n (%)	
Male	49 (53.3)
Female	43 (46.7)
Country of birth, n (%)	
The Netherlands	88 (95.7)
Other	4 (4.3)
Educational level, n (%)	
High	37 (40.2)
Medium	20 (21.7)
Low	35 (38.0)
Employed, n (%)	
Full-time (≥ 32 hours per week)	25 (27.2)
Part-time (< 32 hours per week)	22 (23.9)
Unemployed	45 (48.9)

n: number; IQR: interquartile range; SD: standard deviation.

Score distributions

Table 7.2 presents the descriptive statistics of the Caregiver Mastery Scale for 92 partners of patients with acquired brain injury. No floor or ceiling effects were found and the skewness and kurtosis values showed a normal distribution of the Caregiver Mastery Scale.

Table 7.2. Descriptive statistics of the Caregiver Mastery Scale (N = 92)

	Caregiver Mastery Scale (range: 7–35)
Minimum	13
Maximum	34
Mean (SD)	23.63 (4.29)
Median (IQR)	24 (5)
Skewness (SE)	-0.45 (0.3)
Kurtosis (SE)	0.33 (0.5)

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

Internal consistency

The Caregiver Mastery Scale showed acceptable internal consistency, with a Cronbach's alpha value of 0.75. The item-total correlations are presented in Table 7.3. Item 5 showed an unacceptable item-total correlation. Removing this item from the scale, however, would only slightly improve the internal consistency.

Table 7.3. Item-total correlations of the Dutch version of the Caregiver Mastery Scale (N = 92)

		Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Item 1	You are usually certain about what to do in caring for your partner	0.42	0.73
Item 2	No matter what you do as a caregiver, it never seems to be enough	0.45	0.73
Item 3	In general, you are able to handle most problems in the care of your partner	0.57	0.70
Item 4	You are not doing as well as you would like as a caregiver	0.42	0.73
Item 5	You feel that you have a great deal of influence over the things that happen in caregiving	0.27	0.76
Item 6	You believe you are mastering most of the challenges in caregiving	0.70	0.67
Item 7	You have lost some control of your life since your partner's illness	0.47	0.72

Convergent validity

The results of the convergent validity analyses are shown in Table 7.4. Higher scores on the Caregiver Mastery Scale correlate with less burden, lower levels of anxiety and depression and greater well-being. All tested relations showed a moderate correlation.

Table 7.4. Correlations between the Caregiver Mastery Scale and the other measures

	Burden		Anxiety	Depression	Well-being
	CSI (n = 92)	CarerQol-7D[a] (n = 90)	HADS-A (n = 90)	HADS-D (n = 90)	CarerQol-VAS (n = 68)
Caregiver Mastery Scale	-0.58**	0.46**	-0.45**	-0.55**	0.57**

CSI: Caregiver Strain Index; CarerQol-7D: Care-related quality of life – seven dimensions of burden; HADS-A: Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale – Depression subscale; CarerQol-VAS: Care-related quality of life – visual analogue scale for well-being. Spearman rank correlation coefficients.

[a] Low scores indicate a high burden and reflect a poor care-related quality of life.

** Significant at $p < .01$ (two-tailed).

The correlations of the Caregiver Mastery Scale with the CarerQol-7D and the subscales of the Hospital Anxiety and Depression Scale were determined for a sample of 90 partners, because two respondents had missing data on these measures. The correlation of the Caregiver Mastery Scale with the CarerQol-VAS was tested for 68 respondents, due to missing data in 24 cases.

The percentages of respondents scoring below and above the clinical cut-off scores for burden, anxiety and depression are displayed in Table 7.5. Most partners scoring high on the Caregiver Mastery Scale scored below the clinical cut-off scores on the Caregiver Strain Index and the anxiety and depression subscales of the Hospital Anxiety and Depression Scale. Partners scoring low on the Caregiver Mastery Scale were more likely to score above the cut-off points.

Table 7.5. Subgroup analyses of the Caregiver Mastery Scale relative to clinical cut-off scores

	Burden		Anxiety		Depression	
	Below CSI < 7	Above CSI ≥ 7	Below HADS-A ≤ 7	Above HADS-A > 7	Below HADS-D ≤ 7	Above HADS-D > 7
25% lowest CMS scores	13.0%	87.0%	56.5%	43.5%	47.8%	52.2%
25% highest CMS scores	86.4%	13.6%	86.4%	13.6%	95.5%	4.5%

CMS: Caregiver Mastery Scale; CSI: Caregiver Strain Index; HADS-A: Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale – Depression subscale.

Discussion

The Caregiver Mastery Scale proved to be a valid instrument for partners of patients with acquired brain injury. In our study sample, the Caregiver Mastery Scale had a normal distribution, with no floor or ceiling effects. This means that the instrument can identify persons with extremely low or extremely high caregiver mastery. Our findings for partners of patients with acquired brain injury are in accordance with those in the study by Christensen et al.,[8] who reported a similar range, mean and standard deviation among women caring for their impaired parent.

The internal consistency of the Caregiver Mastery Scale is acceptable. The Cronbach's alpha found in this study is comparable to what Christensen et al.[8] found (0.75 vs. 0.68). In spite of the acceptable internal consistency, item 5 does not fit the scale very well. Careful analysis of this item has led to the conclusion that there may have been an incorrect translation from English to Dutch. The Dutch statement seems to concern all the care for the patient and could be interpreted to include care provided by health professionals and not merely informal caregiving. We suggest not to remove the item from the scale, as it provides useful information to indicate where the problems are experienced and enables support for the caregiver to be more targeted. Furthermore, deletion of the item hardly increases the internal consistency. Consequently, we recommend adjusting the Dutch item to make it more in accordance with the original English item. The suggested adjusted version of item 5 can be found in Appendix 7.1.

All hypotheses regarding the correlations between the Caregiver Mastery Scale and the other concepts were confirmed, proving convergent validity. Higher scores on the Caregiver Mastery Scale are related with less burden, less anxiety, less depression and greater well-being. As expected, the relations we tested showed a moderate correlation, since the concepts are related, but not identical, to mastery. As shown in Table 7.5, most partners scoring high on the Caregiver Mastery Scale scored below the clinical cut-off scores for burden, anxiety and depression, whereas the partners scoring low on the Caregiver Mastery Scale were more likely to score above the clinical cut-off scores. These findings support the clinical relevance of measuring caregiver mastery.

Our study design did not allow having missing items within a scale, as the measurements were conducted via a web-based application. However, two respondents quit before filling in all the pages, resulting in entire instruments being missed. Also, the visual analog scale (CarerQol-VAS) was not visible for all respondents due to unforeseen technical issues, resulting in missing data. The missing data resulted in smaller but still acceptable sample sizes for the convergent validity analyses. It did not affect the analyses for score distribution and internal consistency of the Caregiver Mastery Scale.

The results of this study are limited to the partners who chose to participate and might not be applicable for the ones who did not respond. We do not know whether they score differently on caregiver mastery. The patients' diagnosis and age of the partners in the study sample are, however, comparable with the invited population, but fewer women responded.

Furthermore, we excluded partners without internet access, as the questionnaires were delivered online. The results should, therefore, be interpreted with caution for partners without internet access, who are most likely older of age, lower educated and woman.[24]

The sample in this study was a large group of partners of patients with acquired brain injury who had been discharged from inpatient rehabilitation. Our results demonstrate that the Caregiver Mastery Scale is a valid instrument for this population. The generalizability of these findings to all caregivers may be limited. Results may differ for partners of patients with acquired brain injury who are not admitted to inpatient rehabilitation, for informal caregivers who are not the partner of the care receiver and for informal caregivers of other categories of patients. The validity of the Caregiver Mastery Scale for other informal caregivers, therefore, requires further research.

Negative caregiving consequences, such as burden and emotional problems, have been widely investigated. Positive aspects of caregiving have received less attention, although they are important since they can buffer the negative consequences.[25] Caregiving mastery is one of these positive aspects which may protect against the negative consequences of caregiving,[7] and assessing caregivers' mastery could provide greater insight into the caregiving situation. Additionally, interventions aimed at improving caregiver mastery should be developed in order to achieve better psychological well-being among caregivers.[26] The effect of these interventions can be determined with the Caregiver Mastery Scale, which is able to measure change in caregiving mastery.[9] Interventions are particularly relevant for partners of patients with acquired brain injury, a growing group experiencing numerous negative consequences of caregiving. Our study shows that the Caregiver Mastery Scale is a valid instrument to assess caregiver mastery in this population.

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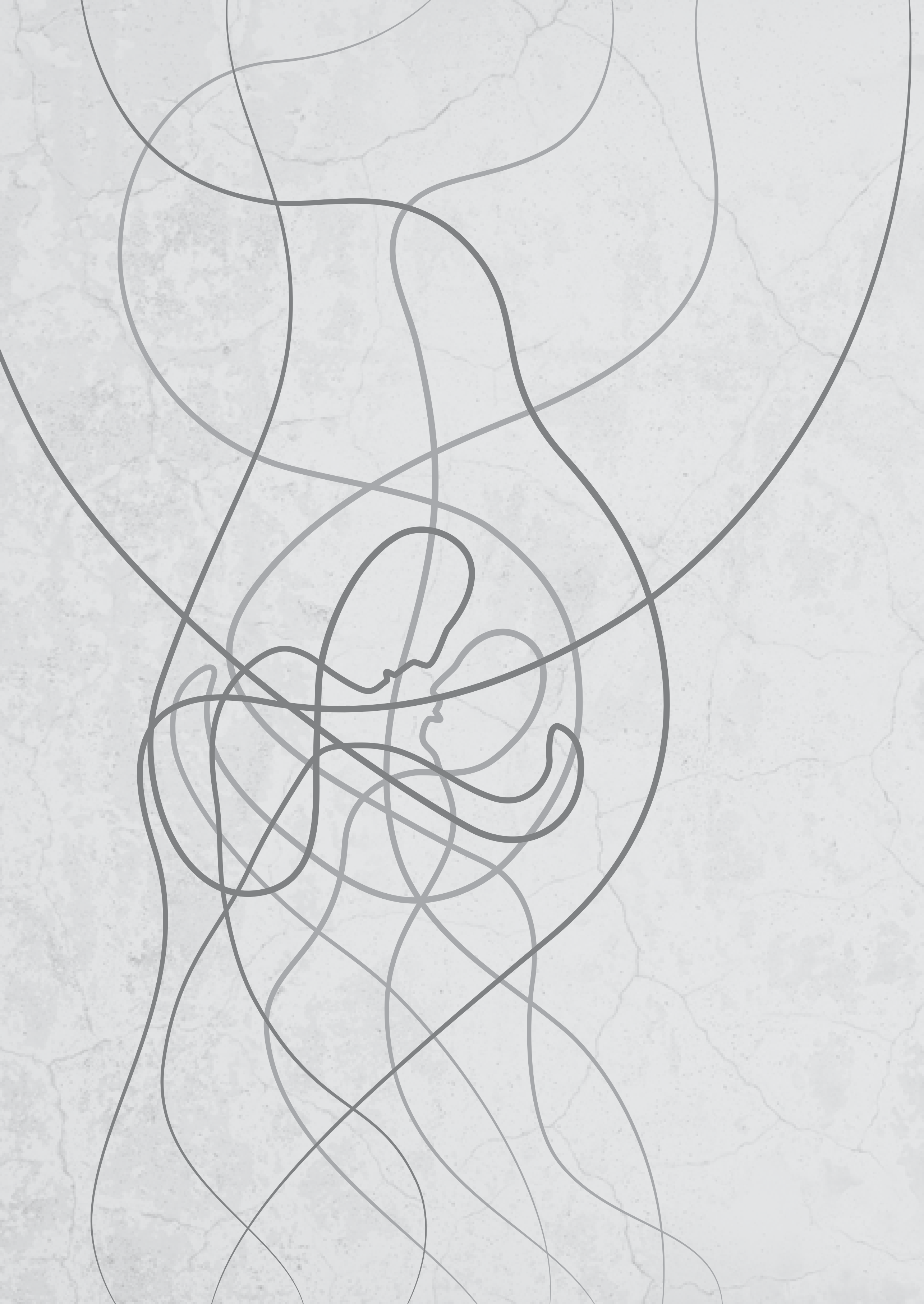
Appendix 7.1

The Caregiver Mastery Scale

	English statement	Dutch statement
Item 1	You are usually certain about what to do in caring for your partner	Je voelt je normaalgesproken zeker over wat je doet bij het zorgen voor je partner
Item 2*	No matter what you do as a caregiver, it never seems to be enough	Wat je ook doet als zorgverlener, het lijkt nooit genoeg te zijn
Item 3	In general, you are able to handle most problems in the care of your partner	Over het algemeen kun je de meeste problemen in de zorg voor je partner aan
Item 4*	You are not doing as well as you would like as a caregiver	Je doet het niet zo goed als je zou willen als zorgverlener
Item 5	You feel that you have a great deal of influence over the things that happen in caregiving	Je hebt het gevoel dat je veel invloed hebt op de dingen die gebeuren omtrent de zorg voor je partner
Item 6	You believe you are mastering most of the challenges in caregiving	Je bent ervan overtuigd dat je de meeste uitdagingen in het zorgen voor je partner onder de knie hebt.
Item 7*	You have lost some control of your life since your partner's illness	Je hebt enigszins de controle over je leven verloren sinds je partner ziek is geworden

* Negative statements.

Suggested adjustment of item 5 in the Dutch version:
Je hebt het gevoel dat je veel invloed hebt op de dingen die komen kijken bij het zorgen voor je partner.



Chapter 8

General discussion

The overall aim of this thesis was to gain more knowledge about the impact of acquired brain injury (ABI) on the patients' partners in order to improve support for these partners.

The specific aims of this thesis were to:

1. in-depth investigate the impact of the patients' ABI on the partners
2. investigate the dyadic relationships within patient-partner couples
3. develop a blended care intervention for partners of patients with ABI and to validate a caregiver-specific instrument to evaluate the effect of the intervention

This final chapter presents an overview of the main findings of the studies presented in this thesis, followed by a discussion of these findings. Subsequently theoretical and methodological considerations are discussed and suggestions for future research are made. Finally clinical implications are provided.

Main findings

The first aim, focusing on the impact of ABI for partners, is dealt with in **Chapters 2 and 3**. In **Chapter 2** we investigated the participation restrictions and satisfaction with participation in partners of patients with stroke. The highest absolute numbers of restrictions were reported on the relationship with the partner (i.e. patient), going out and household duties. Since not all partners have a job, relatively most of the restrictions were experienced regarding work or education, and in addition, the relationship with the partner (i.e. patient) and going out. Partners indicated to be least satisfied with going out, day trips and other outdoor activities, and sport or other physical exercise. They were most satisfied with their outdoor mobility, work or education, and leisure activities at home. Within the group of partners who experienced participation restrictions, we compared the characteristics of the satisfied partners with the dissatisfied partners. Satisfied partners with participation restrictions reported lower anxiety, less depression and fewer numbers of restrictions experienced compared to the dissatisfied partners with participation restrictions.

Chapter 3 presents the course and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke. During the first two years after stroke, burden and depressive symptoms did not significantly change over time. Symptoms of anxiety decreased between two and six months after stroke, but increased again between one and two years after stroke. Higher burden was predicted by partners' younger age, higher level of education, more symptoms of anxiety and depression, and by patients' greater stroke severity, lower cognitive functioning and more symptoms of anxiety and depression. More anxiety symptoms were predicted by higher burden, more depressive symptoms, and lower self-efficacy of the partner. Patient characteristics showed no significant effect on anxiety of the partner. More depressive symptoms were predicted by older age, higher burden, more symptoms of anxiety, less proactive coping strategies of the partner, and more depressive symptoms in the patients.

Chapters 4 and 5 present studies on the dyadic relationship between patients and their partners. **Chapter 4** revealed that agreement on family functioning within patient-partner dyads was poor. The agreement regarding individual items of a global measure of family functioning (the FAD-GF) ranged from slight to moderate. We found that patients with ABI and their partners significantly differed in their perceptions of family functioning, with partners reporting poorer family functioning compared to the patients.

In **Chapter 5** we investigated the intra- and interpersonal effects of coping style and self-efficacy on anxiety, depression and life satisfaction within patient-partner dyads. Among patients, coping had an intrapersonal effect on anxiety and depressive symptoms and self-efficacy on symptoms of anxiety. Among partners, intrapersonal effects on anxiety, depression and life satisfaction were revealed for both coping and self-efficacy. Regarding effects on the other member of the dyad (interpersonal), we found that pro-active coping of the patient was associated with lower anxiety of the partner, and higher self-efficacy of the partner was associated with lower depression scores and higher life satisfaction of the patient.

Chapters 6 and 7 address the third aim of this thesis concerned a blended care intervention to support partners and the validation of an instrument to evaluate the effect of this intervention. **Chapter 6** presents the protocol of a randomized controlled trial to evaluate a blended care intervention for partners of patients with ABI. We described the CARE4Carer intervention, which consists of a nine-session web-based support program and two face-to-face consultations with a social worker. The effect of the intervention is determined with caregiver mastery as the primary outcome measure. This study is still ongoing and results will be published at a later point in time when the study is finished.

In **Chapter 7** the validation study of the Caregiver Mastery Scale is presented. We investigated the score distributions, internal consistency and convergent validity of the Caregiver Mastery Scale. This study showed that the Caregiver Mastery Scale is a valid instrument to assess the caregiver mastery of partners of patients with ABI. The Caregiver Mastery Scale is the primary outcome measure in the RCT (**Chapter 6**).

Discussion of the main findings

In this section, the main findings are discussed in the light of the complexity of the impact for partners and the patient-partner dyadic relationship.

The complexity of the impact of ABI for partners

The first aim of this thesis was to investigate in-depth the impact of ABI for partners. The most important conclusion that we can draw based on our own studies and previous research is that the impact for partners is very complex in terms of their participation, burden, anxiety and depressive symptoms.[1-5] Our results showed that burden, anxiety and depressive symptoms not only become chronic in partners; these outcomes are also highly interrelated and predict each other. Studies that investigate only one of these concepts and do not include the other two concepts do not sufficiently take this interrelationship into account, which may have consequences for the study results. The complexity of the impact for partners is well reflected in the Stress Process Model.[6] Pearlin and colleagues have described a Stress Process in which life events can lead to symptoms of stress.[6] Examples of life events are divorce, personal illness or health problems of a spouse. The path between the disruptive event and the experienced stress is complex and can be mediated by concepts such as coping and feelings of mastery.[6] The Stress Process Model is not a fixed model that must always be used in the same way, but a conceptual model intended to give direction to researchers.[7] The model has already been applied to caregivers of patients with Alzheimer's disease, dementia and cancer.[8-11] In this paragraph we apply the Stress Process Model specifically to partners of patients with ABI. Figure 8.1 is a representation of the Stress Process Model for partners of patients with ABI.

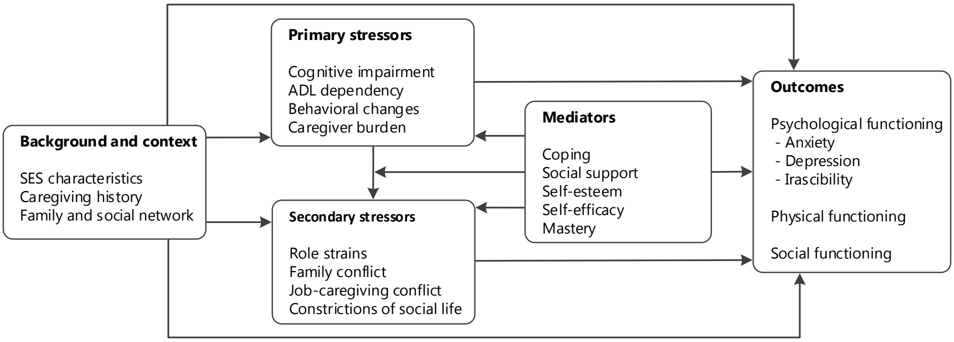


Figure 8.1. The Stress Process Model for partners of patients with ABI.

The process of stress can be viewed as linkages between three domains: sources of stress, mediators and outcomes.[12] The sources of stress can be divided into primary stressors and secondary stressors. In our case, when investigating partners of patients with ABI, the primary stressors are directly related to the person with ABI. For example, patients can be cognitively impaired as a result of the brain injury, they may be more dependent in their activities of daily living and their behavior can be changed.[13] Often patients are no longer the persons the partners fell in love with earlier in their lives. Moreover, partners have become caregivers and caring for their loved one can cause partners to experience caregiver burden.[14]

Secondary stressors are more indirectly related to the situation of the patient.[12] For example, the role between partner and patient within the family shifts; partners are no longer only partners, but have become caregivers as well. As a result partners can experience role strains and conflict within the family may arise.[15] Our study in **Chapter 4** shows that partners and patients can have different perspectives with regard to family functioning, which could lead to family conflict. In addition, it can be difficult for partners to continue to perform other roles, such as their jobs, and to continue their social lives and leisure activities in the same way as before the ABI of their partners. Our study in **Chapter 2** contributed to the knowledge about participation of partners, by specifically investigating the activities in which partners experience restrictions and by determining the partners' satisfaction with these activities.

Stress mediators are abilities or skills that can influence the direction of the stress process and can buffer the effect of stressors on the potential outcomes.[12] Examples of stress mediators are coping, social support, self-esteem, self-efficacy and mastery. These mediators have been extensively investigated in behavioral research to explain certain behavior and to develop interventions aimed at changing health behaviors.[16] We have included the mediators coping and self-efficacy in the longitudinal studies in this thesis (**Chapters 3 and 5**) and have chosen mastery as the primary outcome measure for the randomized controlled trial investigating the effect of the blended care intervention to support partners of patients with ABI.

Outcomes of the stress process can be found in changes in psychological functioning, physical functioning and social functioning of partners.[12] Partners can experience symptoms of anxiety or depression or become more irascible.[2, 17] In addition, partners can experience physical strain by providing informal care for patients with ABI.[18] Finally, the stress process can affect the social functioning of partners, such as their participation in everyday life (**Chapter 2**).[5]

Background and contextual factors can influence stressors as well as the outcomes. These can be aspects concerning the social and economic characteristics of partners, such as gender, age, and work status.

It is important to notice the interconnectedness of factors within the stress process model.[7] Stress does not follow a simple path from stressors to outcomes. Furthermore, stressors are not static; they develop over time and can change over time.[12] The same applies for the outcomes, as we have seen in our study regarding symptoms of anxiety which first decreased and later increased again (**Chapter 3**). Individual partners can be exposed to different stressors or to the same stressor, but in another degree. Even if partners are exposed to the exact same stressors, they can experience different outcomes as we showed in our study on participation where partners with the same participation restrictions were satisfied to a different extent (**Chapter 2**).[5] The impact of stressors on the way partners experience certain outcomes is influenced by factors such as their coping, self-efficacy or mastery. Just as with the stressors and outcomes, these mediators may not be stable traits, but can change over time, for example as a result of an intervention.[19-21] In conclusion, the impact of ABI on partners is very complex, as shown by this model of the stress process for partners of patients with ABI and is supported by the results of the studies in this thesis.

The dyadic relationship between patient and partner

The second aim of this thesis was to investigate the dyadic relationships within patient-partner couples. First, we investigated the agreement and differences between patients and partners regarding their perception of family functioning. Secondly, we investigated the dyadic influence between patients and partners.

For the first part, we found that patients and partners have a different perception of their family functioning (**Chapter 4**). A high percentage of patients and their partners disagree on several areas of their family functioning. This is not necessarily a consequence of the ABI, since low agreement on family functioning has also been found in healthy couples.[22] However, brain injury might affect the perception of family functioning, since we found that partners were more negative about family functioning compared to the patients. This difference in perception can be found in other areas than family functioning as well. Partners also had a more negative perception compared to patients, in studies investigating agreement on the functioning of patients with stroke, such as their activities of daily living and somatic, cognitive and behavioral complaints.[23, 24] Agreement between patients and partners in these studies was low and where significant differences were found, the partners had a more negative perception. It is important to realize that perceptions within patient-partner dyads differ and if only one of them is asked about the situation that will give an incomplete picture; not only on family functioning, but also on other areas. Assessment in both patients and partners can reveal any discrepancies in their perception, which can then be discussed to make them aware of these differences.

Two members within a dyad can perceive the same situation differently, but they also influence each other. We have shown that coping and self-efficacy in patients and partners influence their own, but also each other's anxiety, depressive symptoms and satisfaction with life (**Chapter 5**). Here too the ABI may affect this dyadic influence, but this is not restricted to patient-partner couples. In a large, nationally representative sample of the American population, researchers found an association between the partners' higher mastery and more physical activity, fewer functional limitations and better self-rated health.[25] Persons in a romantic relationship are intertwined in such extent, that the condition of their partner can have a beneficial, or conversely, detrimental effect on their own health.[26] Combining this knowledge about dyadic influence with the stress process model suggests that the stressors, mediators and outcomes of one member within a dyad can influence the stressors, mediators and outcomes of their partner. For patients with ABI and their partners, this implies that a dyadic perspective should be used when studying, providing care, or supporting either of the members of the dyad.

Theoretical and methodological considerations and future research

The studies in this thesis were designed carefully. However, as always in research, choices have to be made and sometimes concessions were made during the design of the study. In this paragraph we will discuss the theoretical and methodological considerations of our studies.

Studied populations

In this thesis we were interested in partners of patients with ABI. In the studies we conducted, the diagnoses of the patients were somewhat different. The RCT described in **Chapter 6** was designed for partners of patients with ABI and we validated the Caregiver Mastery Scale for this population (**Chapter 7**). For the study regarding family functioning (**Chapter 4**) we used baseline data from two intervention studies aimed at partners of patients with ABI and ended up with a sample in which 87% of the patients had had a stroke. The studies in **Chapters 2, 3 and 5** were secondary data analyses on existing data sets that consisted of nothing but patients with stroke. The results of these three studies can be generalized to the stroke population, but caution is advised when generalizing these results to other types of ABI, such as traumatic brain injury.

Study designs

The studies about participation (**Chapter 2**) and family functioning (**Chapter 4**) were conducted cross-sectional. As regards participation we were particularly interested in the relation between participation restrictions and satisfaction with participation for which a cross-section design is sufficient. However, it could be interesting to investigate this relation longitudinally in further research. As mentioned in the paragraph about the stress process above, outcomes such as participation can change over time. Moreover, the influence of mediators such as coping or mastery can change over time, which can influence the way partners perceive the outcomes. With regard to participation it could be the case that the dissatisfaction with a certain participation activity only occurs after that activity has been restricted for a longer period of time. Or, the opposite, the partner may have learned to cope with the participation restriction and has, therefore, become more satisfied with that participation activity. Future, longitudinal research is needed to clarify this.

As regards family functioning, we were interested in the agreement and differences within patient-partner dyads. Here a cross-sectional study was also sufficient to answer that research question. However, we could not determine how the family functioning changed over time and whether the agreement and differences within these dyads changed over time. This seems interesting to us and should be investigated with longitudinal studies.

For the validation study for the Caregiver Mastery Scale (**Chapter 7**) we also used a cross-sectional design, which was sufficient to study the score distributions, internal consistency and convergent validity. Other psychometric properties, such as test-retest reliability and responsiveness, could not be determined since this requires a longitudinal study design. Concerning the responsiveness of the Caregiver Mastery Scale, earlier research has shown improvement in caregiver mastery after participation in an intervention program for caregivers for patients with glioma.[27] Therefore we stand by our decision to use the Caregiver Mastery Scale as primary outcome measure for our RCT described in **Chapter 6**.

Instruments

For the studies described in this thesis we have used some instruments that were initially developed for screening purposes, i.e., the Caregiver Strain Index (CSI) and the Hospital Anxiety and Depression Scale (HADS). Screening instruments are designed to identify the potential presence of a particular problem, such as strain, anxiety or depression. Further assessment should confirm whether the problem is present and to what extent. The results of these more extensive assessments were not available for our studies. Ideally, certain psychometric properties, such as the responsiveness and measurement error, should be determined before using instruments like the CSI and HADS as outcome measures. The COSMIN guidelines were established for this purpose.[28] A recent study shows that measures that are used to assess the impact for caregivers often do not comply with these COSMIN guidelines.[29] To date, the cross-cultural validity, criterion validity, responsiveness and measurement error of many instruments for caregivers have not been investigated.[29] This does not necessarily mean that these psychometric properties are not sufficient; there is simply no information available about these properties. To determine whether the CSI and HADS can be used as reliable outcome measures, certain psychometric properties of these instruments, such as the responsiveness and measurement error, will need to be confirmed for partners of patients with ABI.

Variables measured

In **Chapter 5** we investigated the anxiety, depression and life satisfaction in patient-partner couples and our models only explained a small part of the variance in these outcome measures. In each model, variables of both patients and partners were included. However, per model either coping or self-efficacy was used as independent variable and only one of the three outcomes was included. The low number of variables per model could be the cause of the low explained variance. As mentioned above, the stress process is very complex. To be able to explain a larger part, more variables must be included in the statistical models at the same time. For future research, the Stress Process Model can be used to provide guidance for adding other concepts, such as social support, self-esteem and mastery.

Clinical implications

Rehabilitation care in the Netherlands has changed considerably over the past years. Initially, the focus was solely on recovery of patients and preparing patients to deal with an adapted life after the ABI. Gradually, partners became more involved in this process, which seems to have benefits for the patients' rehabilitation.[30, 31] Around the same time, more attention was paid to the negative impact of the patients' ABI on the partners, as well as on the positive aspects of being an informal caregiver.[4, 32] With this thesis we have contributed to the knowledge about the impact of ABI on the patients' partners. Moreover, we have added an extra aspect: the dyadic relationship between patient and partner. Recognizing this dyadic relationship implies that health care professionals must take into account the influence of the patients' partners in the rehabilitation treatment of the patients. In addition, when providing support for partners of patients with ABI, the influence of the patients must be acknowledged.

Early identification of partners at risk is necessary since negative outcomes are experienced by partners as early as two months after stroke and the symptoms remain present up to two years after stroke (**Chapter 3**). Since 2008, it has been recommended in the Dutch guideline for stroke to screen partners using the Caregiver Strain Index.[33, 34] Our recommendation is to expand this with screening for anxiety and depression, using the Hospital Anxiety and Depression Scale. Screening of partners is now usually done by health care professionals, but self-monitoring could be used for this. Self-monitoring allows partners to gain a better understanding of their own situation. Partners of patients with Amyotrophic Lateral Sclerosis (ALS) can already monitor themselves with an app that improves their feelings of mastering the caregiving situation.[35] Such an app could also be developed for partners of patients with ABI and the Caregiver Strain Index and the Hospital Anxiety and Depression Scale can be integrated into that app. This could reduce the pressure on healthcare, which is necessary since the demands on the Dutch healthcare system are ever-increasing.[36] This societal problem is reinforced by the fact that the number of elderly people will further increase in the coming years, which also puts more pressure on the informal caregivers.[37] It can therefore be beneficial to offer caregivers tools to increase their feelings of mastery.

It is very clear that partners need support. However, what kind of support should be provided at what moment is inconclusive.[38] There probably is no one-size-fits-all solution, since the need for support is different per partner and the support needs of a partner can change over time. The Dutch Association of Medical Specialists has stressed the importance for joint decision-making between health care professionals and patients, because every patient is unique.[36] Every patient is unique, every partner is also unique and every relationship between patient and partner is unique. Health care professionals must be aware of this when providing support to either patients or partners.

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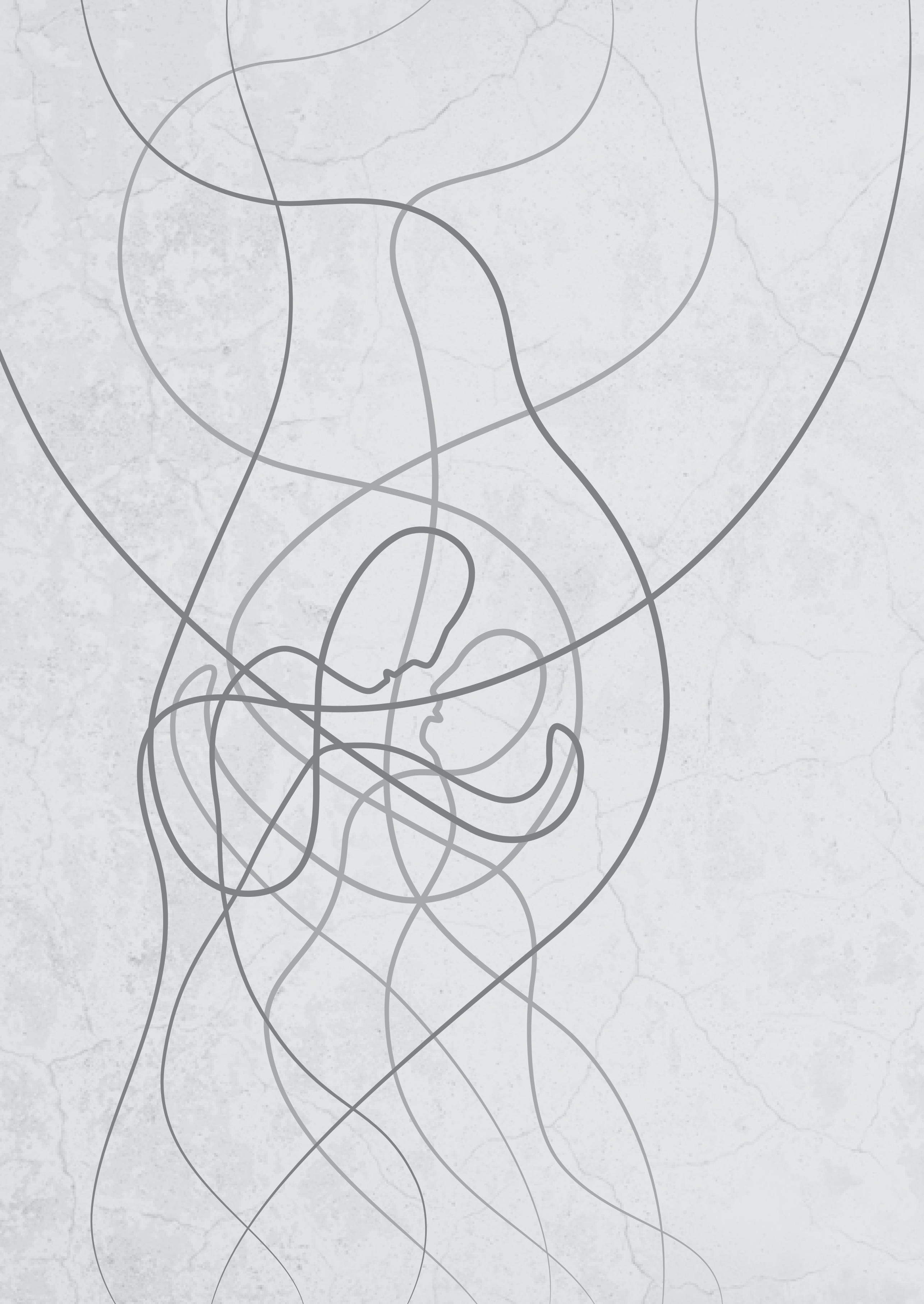


Summary

Acquired brain injury (ABI), including stroke and traumatic brain injury, can have a major impact on the lives of both patients and their partners. In the Netherlands, approximately 650,000 patients live with permanent limitations as a result of ABI. They experience problems on physical, behavioral, cognitive, communicative and psychosocial domains, which can lead to loss of independence in everyday activities, reduced societal participation and poorer quality of life. Partners of patients with ABI can experience high levels of burden, anxiety and depressive symptoms. How these symptoms develop over time and which predictors contribute to this development requires further investigation. An interdependent effect exists between patients and their partners. For example, depressive symptoms in patients are related to depressive symptoms in partners. Patients and partners should therefore be viewed from a dyadic perspective.

There is a need to support partners of patients with ABI and interventions have been effective in reducing their burden, anxiety, and depressive symptoms and improving their well-being. Blended care interventions, created by combining web-based interventions with face-to-face consultation, seem promising for supporting partners of patients with ABI. Interventions can aim to improve partners' feelings of mastery, which can subsequently reduce the negative consequences that partners experience as a result of the patient's ABI. Mastery can be measured with the Caregiver Mastery Scale. The Caregiver Mastery Scale has not yet been validated for partners of patients with ABI.

The overall aim of this thesis was to gain more knowledge about the impact of ABI on the patients' partners in order to improve support for these partners. In this thesis we aimed (1) to in-depth investigate the impact for partners of patients with ABI, (2) to investigate the dyadic relationships within patient-partner couples and (3) to develop a blended care intervention for partners of patients with ABI and to validate a caregiver-specific instrument to evaluate the effect of the intervention.

In **Chapter 2** we performed a cross-sectional study that examined participation restrictions and satisfaction with participation in partners of patients with stroke. Baseline data was used from the Restore4Stroke Self-Management Study, a multicenter randomized controlled trial in five rehabilitation centers and three hospitals in the Netherlands. The study sample consisted of 54 partners of patients with stroke. The Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) was used to assess partners' participation restrictions as a result of the patient's stroke and satisfaction with participation. Most participation restrictions were reported regarding work or education, relationship with the partner and going out. Partners were least satisfied regarding going out, sports or other physical exercise, and day trips and other outdoor activities. The participation restrictions and satisfaction with participation were significantly correlated, but differed for the various activities. Satisfied partners with participation restrictions differed from dissatisfied partners with participation restrictions when it comes to anxiety, depression and the number of restrictions experienced. We concluded that a specific assessment of the participation restrictions and satisfaction with participation is important when supporting partners of patients with stroke.

Chapter 3 presents the courses and predictors of burden, anxiety and depressive symptoms in partners of patients with stroke during the first two years after stroke. Data was used from the Restore4Stroke Cohort, a hospital-based multicenter longitudinal cohort study in six hospitals across the Netherlands. The study sample consisted of 215 patients with stroke and their partners. Mixed model analyses were performed with burden, anxiety and depressive symptoms as time-varying outcome variables, measured at four time points during the first two years after stroke. We found that burden and depressive symptoms did not significantly change over time, whereas anxiety symptoms initially decreased followed by an increase. Higher burden was predicted by partners' younger age, higher education, more symptoms of anxiety and depression, and by patients' greater stroke severity, lower cognitive functioning and more symptoms of anxiety and depression. More anxiety symptoms were predicted by higher burden, more symptoms of depression, and lower self-efficacy of the partner. More depressive symptoms were predicted by older age, higher burden, more symptoms of anxiety, less proactive coping strategies of the partner, and more depressive symptoms of the patients. We concluded that it is important to pay attention to partners themselves and not only concentrate on patient characteristics to identify partners at risk.

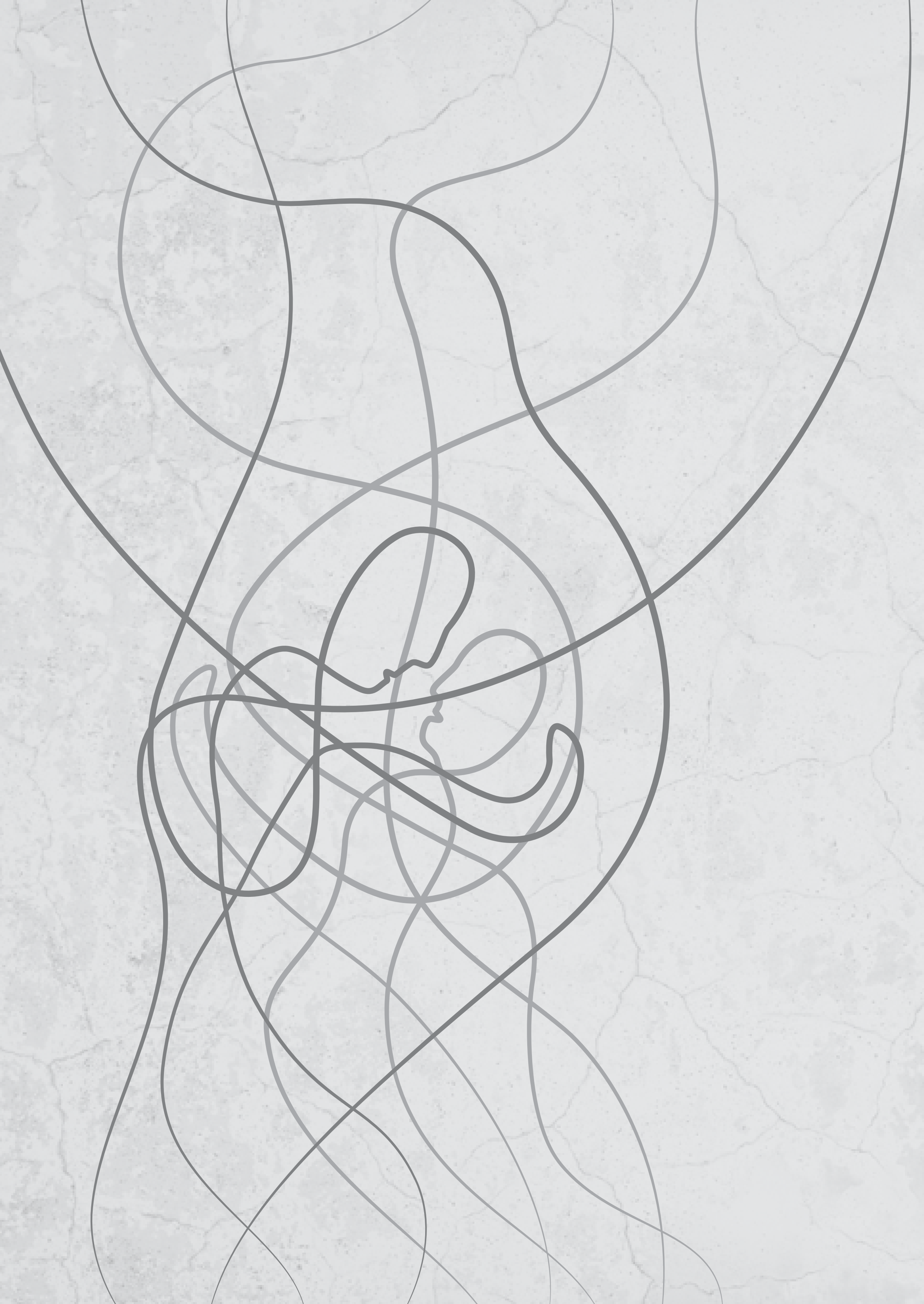
Chapter 4 describes the results of our cross-sectional study aimed at investigating the level of agreement and the differences regarding the perception of family functioning between patients with ABI and their partners. Data were used from 77 patient-partner dyads who were participating in the ongoing CARE4Patient and CARE4Carer trials. Family functioning was assessed using the General Functioning subscale of the McMaster Family Assessment Device (FAD-GF). Agreement within dyads was poor regarding the overall FAD-GF scores with partners reporting significantly poorer family functioning compared to the patients. Agreement regarding the individual items of the FAD-GF ranged from slight to moderate. Patients and their partners differed in their perception of family functioning. We concluded that health care professionals should assess family functioning in both patients and their partners, to explore any discrepancies in the perception of family functioning and to discuss these discrepancies with both members of the patient-partner dyad.

Chapter 5 presents the intra- and interpersonal effects of coping style and self-efficacy on anxiety, depression and life satisfaction in patient-partner couples after stroke. Data was used from 215 patient-partner couples from the Restore4Stroke Cohort. Among patients, coping had an intrapersonal effect on anxiety and depressive symptoms and self-efficacy on symptoms of anxiety. Among partners, intrapersonal effects on anxiety, depression and life satisfaction were revealed for both coping and self-efficacy. Regarding effects on the other member of the dyad (interpersonal), we found that pro-active coping of the patient was associated with lower anxiety of the partner, and higher self-efficacy of the partner was associated with lower depression scores and higher life satisfaction of the patient. These results add to the accumulating evidence for the importance of using a dyadic perspective in patients with stroke and their partners.

Chapter 6 presents the protocol of the randomized controlled trial to evaluate a blended care intervention for partners of patients with ABI. The CARE4Carer intervention combines web-based support with face-to-face consultations, creating a blended care intervention. The intervention consists of a nine-session web-based support program and two face-to-face consultations with a social worker. Addressed themes are: giving partners insight into their own situation, including possible pitfalls and strengths, learning how to cope with the situation, getting a grip on thoughts and feelings, finding a better balance in the care for the patient with ABI, thinking about other possible care options, taking care of oneself, and communication. Caregiver mastery is the primary outcome measure. Secondary outcomes are strain, burden, family functioning, emotional functioning, coping, quality of life, participation, and social network. The results of this trial will be published at a later point in time when the study is finished.

Chapter 7 focused on the validation of the Caregiver Mastery Scale (CMS) for partners of patients with ABI. A total of 92 partners of patients with ABI were recruited for this validation study. We determined the score distributions, internal consistency and convergent validity of the CMS. The CMS has a normal distribution, with no floor or ceiling effects. The internal consistency was acceptable and the convergent validity confirmed our hypothesis that higher scores on the CMS are related with less burden, lower levels of anxiety and depression and greater well-being. We concluded that the CMS is a valid instrument to assess the caregiver mastery of partners of patients with ABI.

Chapter 8, the general discussion, provides an overview of the main findings and a reflection on these main findings. The findings are discussed in the light of the complexity of the impact for partners, related to the Stress Process Model, and the patient-partner dyadic relationship. Theoretical and methodological considerations are discussed with the topics: study populations, study designs, instruments and variables measured. Recommendations for future research are also described. Finally, clinical implications were provided. This thesis contributes to the knowledge about the impact of ABI on the patients' partners. Our results emphasize the complexity of this impact and the interrelationship between the negative consequences that partners experience. In addition, we have provided more evidence for the dyadic relationship between patients and partners. When health care professionals provide support for partners, they should take the complexity of the impact for partners and the patient-partner dyadic relationship should into account.



Samenvatting

Niet-aangeboren hersenletsel (NAH), waaronder beroerte en traumatisch hersenletsel, kan een enorme impact hebben op het leven van zowel patiënten als partners. In Nederland kampen ongeveer 650.000 patiënten met blijvende beperkingen als gevolg van NAH. Ze ervaren fysieke, cognitieve, psychosociale, gedrags- en communicatieproblemen, die kunnen leiden tot verlies van onafhankelijkheid bij alledaagse activiteiten, een vermindering van maatschappelijke participatie en een verminderde kwaliteit van leven. Partners van patiënten met NAH kunnen overbelasting, angst en depressieve klachten ervaren. Hoe deze symptomen zich ontwikkelen gedurende de tijd en welke voorspellende variabelen bijdragen aan deze ontwikkeling, moet nader worden onderzocht. Er is een wederzijdse beïnvloeding tussen patiënten en hun partners. Depressieve symptomen bij patiënten zijn bijvoorbeeld gerelateerd aan depressieve symptomen bij partners. Patiënten en partners zouden daarom vanuit een dyadisch perspectief moeten worden bekeken.

Er is behoefte aan ondersteuning voor partners van patiënten met NAH en interventies zijn effectief gebleken in het verminderen van gevoelens van overbelasting, angst en depressieve symptomen én in het verbeteren van welzijn. *Blended care* interventies, die ontstaan door online interventies te combineren met fysieke consulten, lijken veelbelovend in het ondersteunen van partners van patiënten met NAH. Deze interventies kunnen zich richten op het verbeteren van het gevoel van grip op de mantelzorgsituatie bij partners, wat vervolgens de negatieve gevolgen die partners ervaren vanwege het NAH van de patiënt kunnen verminderen. Grip op de mantelzorgsituatie kan worden gemeten met de *Caregiver Mastery Scale*. De *Caregiver Mastery Scale* is nog niet gevalideerd voor partners van patiënten met NAH.

Het algemene doel van dit proefschrift was om meer kennis te verzamelen over de impact van NAH op partners van patiënten om vervolgens de ondersteuning van deze partners te kunnen verbeteren. In dit proefschrift wilden we (1) diepgaand onderzoek doen naar de impact op partners van patiënten met NAH, (2) de dyadische relaties binnen patiënt-partnerkoppels onderzoeken en (3) een *blended care* interventie voor partners van patiënten met NAH ontwikkelen en een instrument valideren voor mantelzorgers om het effect van de interventie te kunnen bepalen.

In **hoofdstuk 2** wordt aan de hand van een cross-sectionele studie gekeken naar ondervonden beperkingen bij participatie en de tevredenheid over deze participatie bij partners van patiënten met NAH. Hiervoor zijn de gegevens van de nulmeting van de *Restore4Stroke* zelfmanagementstudie gebruikt, een RCT die is uitgevoerd in vijf revalidatiecentra en drie ziekenhuizen in Nederland. De steekproef bestond uit 54 partners van patiënten die een beroerte hebben gehad. De *Utrecht Scale for Evaluation of Rehabilitation – Participation* (*USER-P*) is gebruikt om de participatiebeperkingen die partners ervaren als gevolg van de beroerte en hun tevredenheid over deze participatie te meten. De meeste participatiebeperkingen werden ondervonden op het gebied van werk of opleiding, de relatie met de partner en uitgaan. Partners waren het minst tevreden over uitgaan, sporten of andere lichaamsbeweging, en dagtripjes of andere activiteiten buitenshuis. De participatiebeperkingen en de tevredenheid met participatie waren significant gecorreleerd, maar verschilden voor de diverse activiteiten. Tevreden partners met participatiebeperkingen verschilden van ontevreden partners met participatiebeperkingen op het gebied van angst, depressie en het aantal beperkingen dat werd ervaren. Wij concludeerden dat een specifieke bepaling van de participatiebeperkingen en de tevredenheid met participatie belangrijk is bij het ondersteunen van partners van patiënten die een beroerte hebben gehad.

Hoofdstuk 3 beschrijft het beloop en de voorspellende factoren van overbelasting, angst en depressieve klachten bij partners van patiënten gedurende twee jaar na de beroerte. Hiervoor zijn de gegevens gebruikt van het *Restore4Stroke Cohort*, een multicenter longitudinaal cohortonderzoek dat in zes ziekenhuizen in heel Nederland is uitgevoerd. De steekproef bestond uit 215 patiënten die een beroerte hebben gehad en hun partners. Er zijn analyses met gemengde modellen uitgevoerd met overbelasting, angst en depressieve symptomen als tijdsafhankelijke uitkomstvariabelen, gemeten op vier momenten gedurende de eerste twee jaar na de beroerte. Hier kwam uit dat overbelasting en depressieve symptomen niet significant veranderden met de tijd, terwijl angstklachten eerst afnamen en daarna toenamen. Er is een hogere kans op overbelasting als de partner jonger en hoogopgeleid is en als deze meer symptomen van angst en depressie vertoont en bij een ernstigere beroerte, verminderd cognitief functioneren van de patiënt en diens verhoogde symptomen van angst en depressie. Er is een hogere kans op angstklachten wanneer de partner hogere belasting ervaart, meer symptomen van depressie vertoont en een lagere eigen effectiviteit heeft. Het ervaren van meer depressieve klachten werd voorspeld door een hogere leeftijd, hogere ervaren overbelasting, meer angstklachten en minder proactieve copingstrategieën aan de kant van de partner en meer depressieve klachten aan de kant van de patiënt. Wij concludeerden dat het belangrijk is om aandacht te besteden aan de partners zelf en niet alleen te concentreren op de kenmerken van de patiënt, om partners met een hoog risico op negatieve uitkomsten op te sporen.

Hoofdstuk 4 laat de resultaten zien van onze cross-sectionele studie die was gericht op het onderzoeken van de mate van overeenstemming en op de verschillen tussen patiënten met NAH en hun partners bij hun visie op het familiefunctioneren. De gegevens die zijn gebruikt komen van 77 patiënt-partnerdyades die deelnamen aan de lopende CARE4Patient en CARE4Carer studies. Familiefunctioneren werd beoordeeld door middel van de *General Functioning subscale* van het *McMaster Family Assessment Device* (*FAD-*

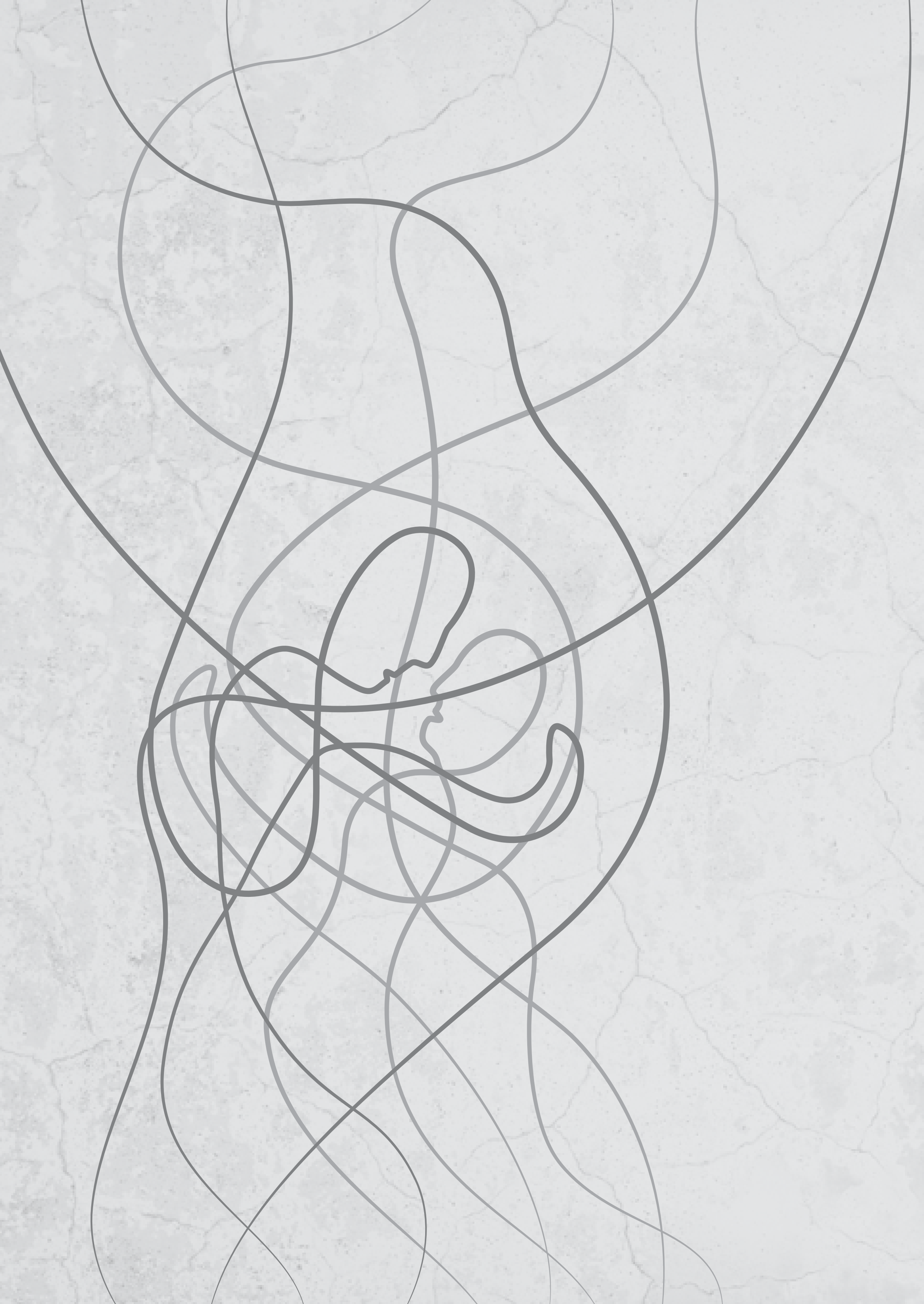
GF). Er was weinig overeenstemming binnen de dyades wat betreft de algehele FAD-GF scores, waarbij de partners significant lagere scores gaven aan het familiefunctioneren dan de patiënten. De overeenstemming op individuele onderwerpen van de FAD-GF varieerde van weinig tot matig. Patiënten en hun partners verschilden in hun perceptie van het familiefunctioneren. Wij concludeerden dat zorgprofessionals het familiefunctioneren door zowel de patiënt als de partner moeten laten beoordelen, om discrepanties in de perceptie van familiefunctioneren te verkennen en deze discrepanties te bespreken met beide individuen van de patiënt-partnerdyade.

Hoofdstuk 5 behandelt de intra- en interpersoonlijke effecten van copingstijl en eigen effectiviteit op angst, depressie en tevredenheid met het leven binnen patiënt-partnerkoppels na een beroerte. Hiervoor zijn de gegevens gebruikt van 215 patiënt-partnerkoppels uit het *Restore4Stroke Cohort*. Bij patiënten had coping een intrapersoonlijk effect op angst en depressieve klachten en eigen effectiviteit op angstklachten. Bij partners werden intrapersoonlijke effecten op angst, depressie en tevredenheid over het leven vastgesteld voor zowel coping als eigen effectiviteit. Kijkend naar de effecten op het andere individu binnen de dyade (interpersoonlijk), vonden we dat een proactieve coping van de patiënt werd geassocieerd met minder angstklachten bij de partner en dat een hogere eigen effectiviteit van de partner gerelateerd was aan minder depressieve klachten en een hogere tevredenheid met het leven bij de patiënt. Deze resultaten dragen bij aan het groeiende bewijs dat het belangrijk is om een dyadisch perspectief te gebruiken bij patiënten die een beroerte hebben gehad en hun partners.

Hoofdstuk 6 presenteert het protocol van de RCT om de *blended care* interventie voor partners van patiënten met NAH te evalueren. De CARE4Carer interventie combineert online ondersteuning met fysieke consulten, waardoor het een *blended care* interventie wordt. De interventie bestaat uit een programma met negen online sessies en twee fysieke consulten met een maatschappelijk werker. Thema's die worden behandeld zijn: partners inzicht geven in hun eigen situatie (inclusief mogelijke valkuilen en sterke punten), leren hoe ze kunnen omgaan met de situatie, grip krijgen op gedachten en gevoelens, een betere balans vinden in de zorg voor de patiënt met NAH, nadenken over andere zorgmogelijkheden, voor jezelf zorgen en communicatie. Grip op de mantelzorgsituatie is de primaire uitkomstmaat. Secundaire uitkomstmaten zijn overbelasting, familiefunctioneren, emotioneel functioneren, coping, kwaliteit van leven, participatie en het sociale netwerk. De resultaten van deze studie zullen later worden gepubliceerd, wanneer het onderzoek is afgerond.

Hoofdstuk 7 focust op de validatie van de *Caregiver Mastery Scale* (*CMS*) voor partners van patiënten met NAH. In totaal zijn er 92 partners van patiënten met NAH geworven voor deze validatiestudie. We hebben de verdeling van scores, interne consistentie en convergente validiteit van de CMS vastgesteld. De CMS heeft een normale verdeling, zonder plafond- of vloereffecten. De interne consistentie was acceptabel en de convergente validiteit bevestigde onze hypothese dat hogere scores op de CMS samenhangen met minder overbelasting, een lager niveau van angst en depressie en een beter welzijn. We concludeerden dat de CMS een valide instrument is om de grip op de mantelzorgsituatie te meten bij partners van patiënten met NAH.

Hoofdstuk 8, de algemene discussie, geeft een overzicht van de belangrijkste bevindingen en een reflectie hierop. De bevindingen worden besproken in het kader van de complexiteit van de impact op partners, gerelateerd aan het *Stress Process Model* en de dyadische relatie tussen patiënt en partner. Theoretische en methodologische overwegingen worden besproken met als onderwerpen: steekproeven, onderzoeksopzetten, instrumenten en gemeten variabelen. Ook worden aanbevelingen voor verder onderzoek besproken. Ten slotte worden er klinische implicaties gegeven. Dit proefschrift draagt bij aan de kennis over de impact van NAH op partners van patiënten. Onze resultaten benadrukken de complexiteit van deze impact en de onderlinge verbanden tussen de negatieve gevolgen die partners ervaren. Bovendien hebben we meer bewijs aangedragen voor de dyadische relatie tussen patiënten en hun partners. Wanneer professionele zorgverleners ondersteuning bieden aan partners van patiënten met NAH, zouden zij daarbij rekening moeten houden met de complexiteit van de impact voor partners en de dyadische relatie binnen patiënt-partnerkoppels.

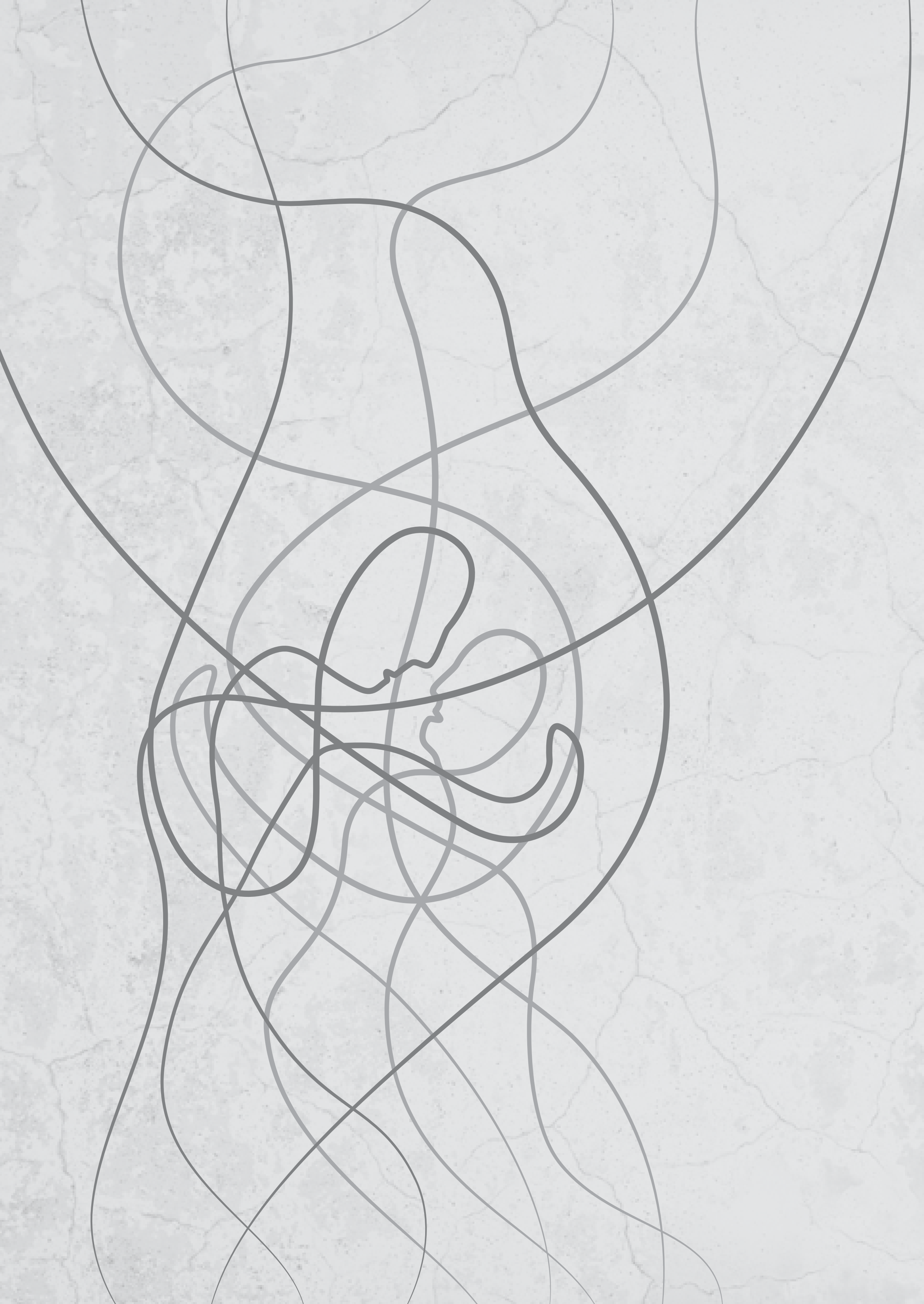


Curriculum vitae

Vincent Cox was born on the 3rd of February 1984 in Eersel, the Netherlands. After secondary school (gymnasium) at Rythovius College, he went to study Public Health at Maastricht University. In 2008 he obtained his Master's degree in Health Education and Promotion.

From 2007 until 2010 Vincent worked as a research and teaching assistant at the department of Health Promotion at Maastricht University, where he assisted several PhD students with their eHealth projects in preventive medicine. In 2011 he started as a product developer and researcher at Vision2Health BV, a startup company founded by Maastricht University and OverNight Software Europe. Here he implemented proven effective web-based interventions, developed new tailor-made advisory products and conducted research into the effectiveness and usability of these interventions. In February 2015 he started his PhD trajectory at the Centre of Excellence for Rehabilitation Medicine Utrecht (a collaboration between University Medical Center Utrecht and De Hoogstraat Rehabilitation) on the CARE4Carer project, in order to develop and evaluate a blended care intervention for partners of patients with acquired brain injury.

Since February 2020 Vincent is working as an advisor at the Knowledge Institute of the Dutch Association of Medical Specialists.



Dankwoord

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Ook al konden de resultaten van het CARE4Carer onderzoek niet worden meegenomen in dit proefschrift, het is een belangrijk onderdeel geweest van mijn promotietraject. De betrokkenen binnen Adelante, Heliomare, Reade, de Sint Maartenskliniek, Tolbrug, De Hoogstraat Revalidatie, het St. Antonius Ziekenhuis, Meander Medisch Centrum en het UMC Utrecht wil ik erg bedanken voor hun betrokkenheid bij CARE4Carer. Van jullie heb ik veel geleerd over de revalidatiezorg in Nederland.

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