SIGNIFICANCE of the SIGNIFICANT OTHER

UMC Utrecht Brain Center

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Significance of the significant other

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(met een samenvatting in het Nederlands)

Proefschrift

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te Maarn

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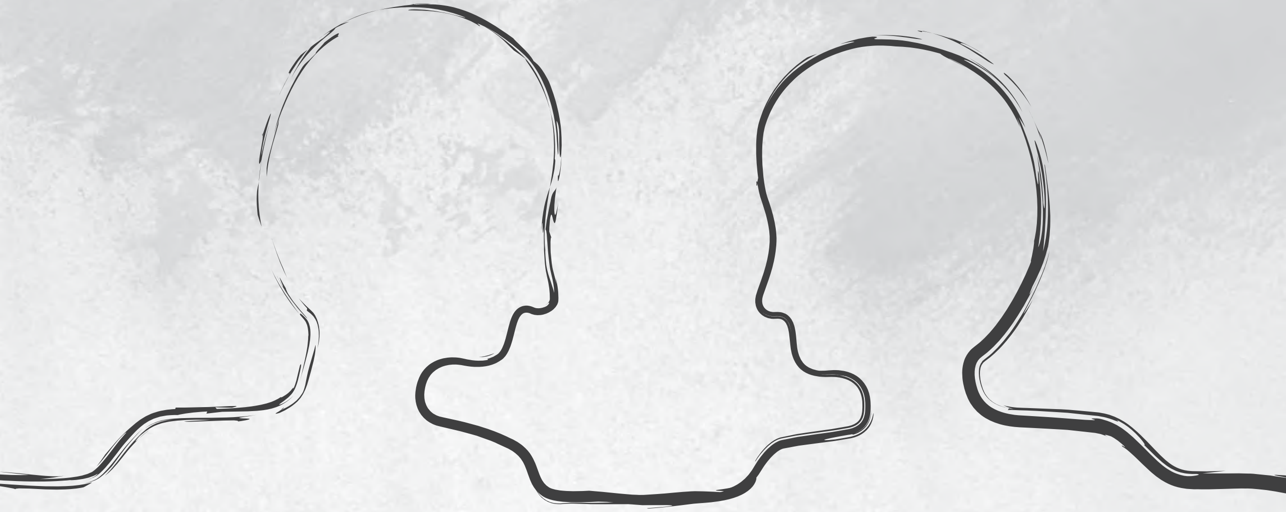
CHAPTER 1

General introduction



SPINAL CORD INJURY AND ACQUIRED BRAIN INJURY

Injuries resulting in chronic disabilities may not only have a major impact on the life of the person involved, but also on that of his significant other(s). Both have to rearrange their lives according to the changed circumstances.[1] This thesis focuses on the impact of chronic disabilities on the psychosocial well-being of individuals with a spinal cord injury (SCI) or acquired brain injury (ABI) and their significant others. SCI and ABI are two major causes of chronic disability worldwide and are the most common diagnoses among adults admitted in inpatient rehabilitation centers in the Netherlands.[2–4] Nearly two-thirds of all adult patients in inpatient rehabilitation have an SCI (11.0%) or ABI (53.2%).[4]

An SCI refers to impairment or loss of motor and/or sensory function of the spinal cord due to traumatic or non-traumatic caused damage of neural elements within the spinal canal. Falls, traffic and sports incidents are common reported causes of traumatic SCI.[5] Non-traumatic causes of SCI are, e.g., vascular diseases, spinal degeneration, inflammation or tumors.[6,7] The degree of impairment of an SCI is determined by the completeness and the neurological level of the injury. There are no reliable figures on the prevalence of SCI in the Netherlands.[8] The estimated incidence of traumatic SCI was 14.0 per million persons per year in 2010, or 11.7 for those surviving the acute phase.[5] Based on a study of characteristics of individuals with SCI admitted to inpatient rehabilitation, it is assumed that non-traumatic SCI is slightly more common than traumatic SCI.[8]

ABI is a collective term encompassing a range of brain pathologies that a person, previously intact from a neurological perspective, is being confronted with at a certain moment.[9] Causes of ABI are mostly subdivided in stroke, traumatic brain injury (TBI) and ‘other causes’ (e.g., meningitis or a brain tumor).[10] There is no exact information about the annual prevalence of ABI in the Netherlands. It is estimated that around 45,000 individuals suffer a first stroke yearly. Approximately 85,000 Dutch individuals are confronted with TBI, which also includes minor injuries such as a concussion. About 22,800 people suffer moderate to severe TBI (e.g., brain bruising or basilar skull fracture). Furthermore, circa 10,000 people suffer ABI by other reasons than stroke or TBI. In general, about thirty percent of the individuals with ABI experience chronic disabilities as a consequence.[10]

IMPACT ON INDIVIDUALS WITH SCI OR ABI

The proportion of people surviving after onset of SCI or ABI is increasing and most of them return to home after discharge from the hospital or a period of inpatient rehabilitation in a rehabilitation center.[11,12] However, they are often confronted with (long-term) physical or cognitive impairments which may restrict them in their daily life functioning and affect their well-being.[3]

The experienced consequences of a health condition such as an SCI or ABI are not equal for everyone. The International Classification of Functioning, Disability and Health (ICF) model is a framework that helps to classify the consequences of a health condition at the level of person's functioning (Figure 1.1).[13] The framework describes three levels of functioning: body functions and structure, activities, and participation. Besides the health condition itself, personal and environmental factors are important concepts in the ICF-model, interacting with person's functioning. Personal factors are characteristics of the individual which are not part of the functional health status, like sex, age, personality traits or coping styles. Environmental factors may be physical, like the place of living and the presence of aids, and social, like support of significant others and the existence of a broad social network. Personal and environmental factors vary from person to person and, in addition to the health condition itself, may explain differences in person's functioning. Although not specified in the ICF-model, a health condition like an SCI or ABI and its consequences on

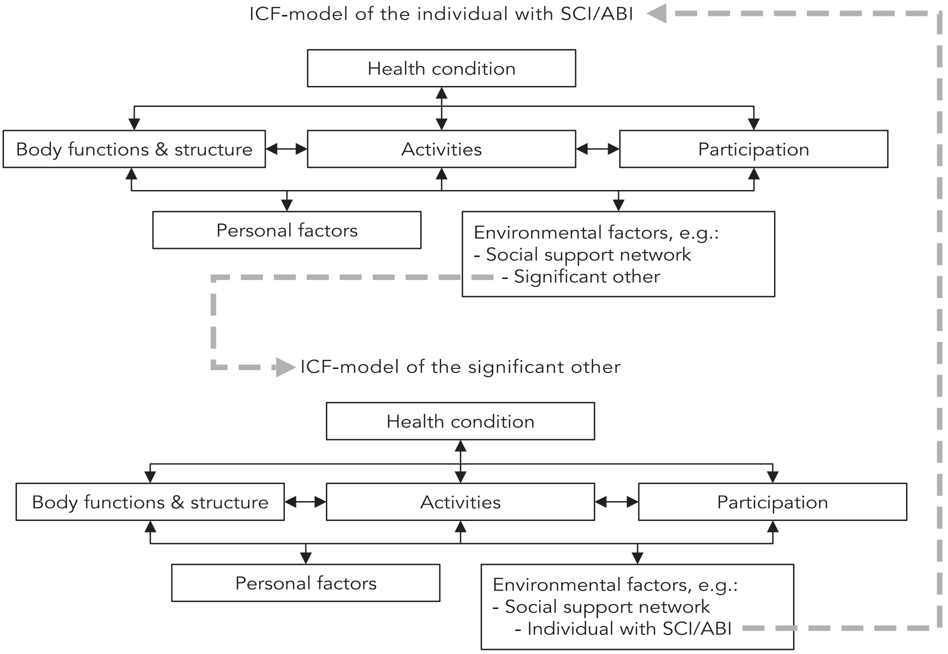


Figure 1.1 Interrelationship between individuals with SCI/ABI and significant others: two combined ICF-models.
In line with *Stroke, social support and the partner*, by Kruithof WJ. PhD thesis, University of Utrecht; 2016., p. 8.[18]

the functional level could also affect psychosocial well-being. Reduction of psychosocial well-being in terms of depressive feelings and decreased life satisfaction are common among individuals with SCI or ABI.[14–17] In this thesis, we use the concepts described in the ICF-model (health condition, personal and environmental factors) to explain psychosocial adjustment outcomes such as mental health, life satisfaction, psychological distress (i.e., anxiety and depression) and family functioning.

IMPACT ON SIGNIFICANT OTHERS

Significant others (i.e., persons close to the individual with a disability, mostly family members) often play a primary role in providing informal care to individuals with a chronic disability. Informal care refers to the care and support that is provided by persons outside the professional health care system.[19] The support could be practical (e.g., ADL-support like preparing meals and dressing) as well as emotional (e.g., comforting, learning how to live with the chronic health condition).[20] Support of significant others provides an important contribution on how individuals are able to deal with their health condition.[17,21] Therefore, based on the ICF-model, the significant other could be seen as an important environmental factor for the individual with a disability. On the other hand, the health condition of the individual with a disability could also be considered as an environmental factor that has an impact on the lives of the significant others (Figure 1.1). Significant others have to adapt to the changed circumstances and the new roles that they often (are expected to) fulfill.[22,23] Although the changed circumstances and the caregiving roles may have positive psychosocial consequences for significant others (e.g., self-esteem derived from caregiving and personal growth),[22,24] negative consequences (e.g., in terms of high levels of anxiety, depression and caregiver burden) are common.[25–27]

RISK FACTORS AND DYADIC IMPACT

As described in the ICF-model, besides the health condition and environmental factors, also personal factors are important to take into account in the investigation of how individuals deal with their situation.[13] In earlier studies was found that sociodemographic personal factors like age, sex and educational level are poor or inconsistent predictors of psychosocial adjustment outcomes.[28–32] Previous research conducted at our research institute indicates that in particular psychological personal factors are important to take into account. In the ‘Restoration of mobility SCI rehabilitation study’, started in 2000, was found that psychological personal factors like self-efficacy, neuroticism and appraisals were related to mental health and life satisfaction among individuals with an SCI up to five years after discharge from inpatient rehabilitation.[33–35] In the 'Functional prognostication and disability study on stroke' (FuPro-Stroke) cohort study, also started in 2000, was found that psychological personal factors like passive coping and symptoms of depression at the start of inpatient rehabilitation were important factors in the prediction of quality of life among spouses of individuals with stroke one year-post stroke.[36]

As a follow-up of the FuPro-Stroke study, in 2011 the Restore4Stroke cohort study has been started.[37] This study confirmed that psychological personal factors (such as anxiety, depression, coping and self-efficacy) two months post-stroke could predict adverse psychosocial adjustment outcomes (i.e., anxiety, depression and burden) among individuals with stroke and their partners up to two years post-stroke.[31,38,39] It was additionally found that psychological personal factors of one person in a dyad could predict psychosocial adjustment outcomes of the other person, which indicates a dyadic impact between individuals. Anxiety and depression among individuals with stroke two months after stroke could predict burden and anxiety among partners two years post-stroke.[31,38] Furthermore, a higher level of self-efficacy among partners in the subacute phase after stroke was related with lower levels of depression and higher life satisfaction among individuals with stroke up to one year post-stroke.[40] At the level of the dyad, it was found that lower self-efficacy among partners and less active coping among partners and stroke patients was associated with later symptoms of anxiety and depression in dyads.[40]

In the Restore4Stroke cohort study participants were included in a hospital setting in the acute phase after stroke. As a result a broad and general Dutch stroke population was included. Only part of the individuals with a stroke will be admitted to inpatient rehabilitation, mostly those patients more severely affected (approximately 15% of the total stroke patient population).[18] It is unclear whether the results found in the Restor4Stroke study do also apply to this more severely affected population. Furthermore, it is unclear if the results are specific for individuals with stroke and their significant others or if the results are also transferable to other populations in the adult inpatient rehabilitation setting. Therefore, we conducted a study focusing on the factors that may predict later psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others in an inpatient rehabilitation setting. In this study (the POWER study) a dyadic approach is used paying attention to dyadic impact between individuals.[16,41] The study provides insight into the intra-personal (own) and inter-personal (of the other person within a dyad) factors that may predict psychosocial adjustment outcomes (in here, psychological distress and family functioning). This insight may help to explain why some individuals or families are better able to adjust than others. Furthermore, this knowledge may help to identify individuals or families at risk for later psychosocial adjustment problems early during inpatient rehabilitation and offers opportunities for improving the support available to them during this period.

AIMS OF THIS THESIS

The general aims of this thesis are (Figure 1.2):

1. To enlarge the insight in the impact of an SCI or ABI on psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others;
2. To identify intra-personal and inter-personal risk factors that may predict later psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others.

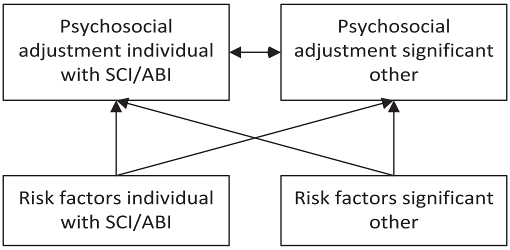


Figure 1.2 Schematic representation of the thesis aims.

STUDY DESIGNS

Data of the Umbrella project and the POWER study are used in this thesis.

Umbrella project

The Umbrella project is a prospective cohort study with the main aim to evaluate the restoration of mobility among individuals with SCI during active rehabilitation.[42] Individuals with SCI were included if they were aged between eighteen and sixty-five years, if they had a recently acquired SCI and when permanent wheelchair dependency was expected. They were excluded when they had a progressive disease, psychological disorder, SCI caused by a malignant tumor or insufficient understanding of the Dutch language. The study was conducted in the eight Dutch rehabilitation centers specialized in SCI. Recruitment took place between August 2000 and July 2003 and over 220 individuals with SCI have participated in the study. Participants were followed during their rehabilitation up to five years after discharge from first inpatient rehabilitation. In this thesis, data of the last assessment were used. At this assessment, the primary family caregivers of the participants were also invited to participate. The follow-up assessment of the Umbrella project was funded by ZonMw, the Netherlands Organisation for Health Research and Development (grant number: 14350003).

POWER study

In 2016 the POWER study started.[43] The first aim of this study was to identify predictors at admission to inpatient rehabilitation on later empowerment and adjustment by longitudinal follow-up of a cohort of adult individuals with physical disabilities and their adult significant others. The second aim was to implement and evaluate a family group conference intervention in adult rehabilitation care. This thesis focuses on the first aim. Therefore, a cohort study was conducted in twelve Dutch rehabilitation centers in which dyads of individuals with newly acquired SCI, ABI or leg amputation, and their significant others participated. Inclusion criteria for individuals with SCI, ABI or leg amputation were: first inpatient rehabilitation after the onset of SCI, ABI or amputation and expected stay in the rehabilitation center for at least four weeks. They were excluded when (nearly) full recovery was expected, no return to home was expected, if they had a limited life expectancy, when they were unable to complete the questionnaires due to severe cognitive or intellectual problems, or if they could not name a significant other. Significant others were usually the partner, but they could also be a child, parent, another family member, or friend. All participants had to be at least eighteen years of age. Recruitment ended in July 2018. Over 320 dyads were included in the study. All participants were asked to complete a self-report questionnaire (in print or electronically) four times: shortly after inpatient admission to one of the participating rehabilitation centers, shortly before discharge from inpatient rehabilitation, and three and six months after discharge. This thesis focuses on dyads of individuals with SCI or ABI and their significant others, and on part of the data collected in the cohort study (i.e., data regarding psychosocial adjustment and its predictors). The POWER study is financially supported by ZonMw, the Netherlands Organisation for Health Research and Development, Fonds Nuts Ohra and Revalidatiefonds (grant number: 630000003).

OUTLINE OF THIS THESIS

This thesis consists of two parts.

Part I The impact of SCI or ABI on psychosocial adjustment outcomes

Chapter 2 describes and compares levels of mental health and life satisfaction of individuals with SCI and their partners five years after discharge from inpatient rehabilitation. In **chapter 3**, a description is given of the type and regularity of the support provided by partners to individuals with SCI. Furthermore, their perceived levels of caregiver burden, mental health and life satisfaction and their determinants were investigated. For these two chapters, data of the Umbrella project has been used. **Chapter 4** describes the results of a systematic review that was conducted to investigate which existing measures were used in empirical studies conducted in the last decade to assess the impact of caregiving among significant others of individuals with an SCI, ABI or amputation. The quality of the measures was evaluated according to the COSMIN guidelines.[44–46]

Part II Factors to predict psychosocial adjustment outcomes

In **chapter 5**, a theoretical based mechanism was tested in order to explain psychological distress among significant others of individuals with SCI or ABI.[47] In **chapter 6** is investigated if self-efficacy at the level of the dyad (individual with SCI or ABI and significant other) contributes to the prediction of their both psychosocial adjustment outcomes (in here psychological distress and family functioning). In **chapter 7**, intra-personal and inter-personal risk factors for psychological distress were examined. In the second part of the thesis, data of the cohort part of the POWER study were used.

General discussion

The final part of this thesis, **chapter 8**, contains a general discussion of the most important results, methodological considerations, the main clinical implications and directions for future research.

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PART I

The impact of SCI or ABI on psychosocial adjustment outcomes

CHAPTER 2

Mental health and life satisfaction of individuals with spinal cord injury and their partners five years after discharge from first inpatient rehabilitation

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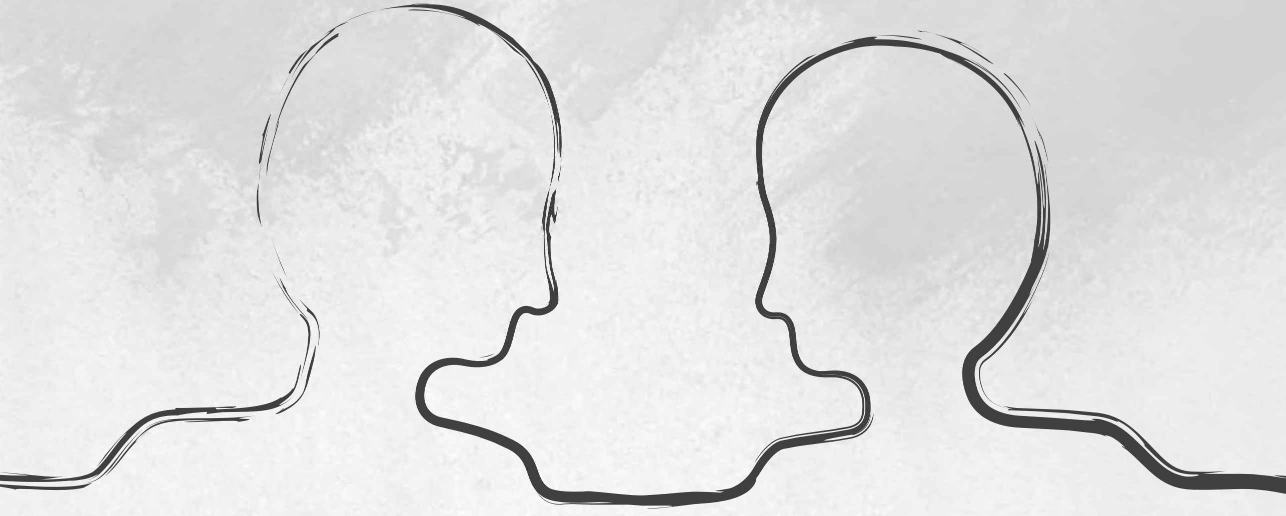
Spinal Cord. 2018;56:598–606



Abstract

Study design: Cross-sectional study.

Objectives: To describe and compare mental health and life satisfaction between individuals with spinal cord injury (SCI) and their partners five years after discharge from first inpatient rehabilitation; and to examine if injury severity moderates the association between individuals' with SCI and their partners' mental health and life satisfaction.

Setting: Dutch community.

Methods: Sixty-five individuals with SCI and their partners completed a self-report questionnaire. Main outcome measures were the mental health subscale of the Short-Form Health Survey and the Life Satisfaction Questionnaire.

Results: Levels of mental health and life satisfaction of individuals with SCI and partners were similar, with median scores of 76 and 4.8 versus 76 and 4.6, respectively. Moderate to strong correlations between individuals with SCI and their partners were found for the mental health ($r_S = .35$) and life satisfaction scores ($r_S = .51$). These associations were generally stronger in the subgroup of individuals with less severe SCI. Associations between scores on separate life domains ranged from negligible (.05) to moderate (.53). Individuals with SCI and their partners were least satisfied with their 'sexual life'. Compared with their partners, individuals with SCI were significantly more satisfied in the domains 'leisure situation', 'partnership relation', and 'family life', and less satisfied in 'self-care ability'.

Conclusions: This study showed similarities but also differences in mental health and life satisfaction between individuals with SCI and their partners. In clinical practice, attention on mental health and life satisfaction should, therefore, focus on different domains for individuals with SCI and partners.

INTRODUCTION

Individuals with spinal cord injury (SCI) are confronted with challenges regarding their physical health,[1,2] mental health and life satisfaction,[3] and social functioning.[4] Systematic reviews have estimated a prevalence of depressive mood and anxiety problems in this group of 22% and 27%, respectively.[5,6] In general, life satisfaction is lower in individuals with tetraplegia compared to those with paraplegia, but no differences with respect to mental health were found.[3] Studies also report life satisfaction in people with SCI to be substantially lower compared to the general population.[3] However, people close to them, in particular their partners, also experience the impact of SCI, have to adapt their pre-injury lifestyle and to undertake a caregiving role and responsibilities.[7,8] Partners often express ongoing feelings of anxiety, depression and low levels of life satisfaction.[9–12]

It is conceivable that mental health and life satisfaction of individuals with SCI and their partners interact mutually. Insight in the reciprocal influences between individuals with SCI and their partners may therefore contribute to the professionals' understanding of the complex situation of couples after SCI and may provide opportunities to support both individuals with SCI, their partners, and together as a couple. Only two SCI studies on this topic were found. In a Turkish study, it was found that emotional status of patients with traumatic SCI and that of their family caregivers was equal.[13] An Iranian study reported that partners score better on physical life domains (e.g., physical functioning, bodily pain), whereas patients were more satisfied on domains such as mental health and general health.[14] In research among stroke patients and their spouses it was found that their levels of life satisfaction were significantly related and that in general patients were less satisfied than spouses.[15–18] These studies suggest potential reciprocal influences of patient and partner responses of the chronic illness on well-being outcomes. However, it is still largely unclear how mental health and life satisfaction scores of persons with SCI and their partners are related.

The aim of this study is therefore to describe and compare mental health and life satisfaction (overall and in different life satisfaction domains) between individuals with SCI and their partners five years after discharge from first inpatient rehabilitation; and to examine if lesion characteristics moderate the association between partners' and patients' mental health and life satisfaction.

METHODS

Design

Data of the Dutch Umbrella project were used,[19] in which individuals with SCI were followed during their rehabilitation up to five years after discharge from first inpatient rehabilitation. Recruitment took place between August 2000 and July 2003 in the eight Dutch rehabilitation centers specialised in SCI. At the assessment five years after discharge from inpatient rehabilitation, we also asked the main informal caregivers of the participants to participate in the study.

Participants

Individuals with SCI were included in the Dutch Umbrella project if they (1) were aged between eighteen and sixty-five years, (2) had a recent onset of SCI and (3) if permanent wheelchair dependency was expected. Exclusion criteria were (1) a progressive disease (e.g., cancer), (2) SCI caused by a malignant tumour (3) a psychological disorder or (4) insufficient understanding of the Dutch language (last two according to clinical judgement).[19] In the current study, we used data from couples of individuals with SCI and their main informal caregivers who were also their partner (e.g., not siblings, children or neighbours), and who lived together at the time of the assessment five years after discharge.

Procedure

Both individuals with SCI and their partners were asked to complete a self-report questionnaire. Data about the type of SCI was extracted from data earlier collected in the Dutch Umbrella project.[19] A research assistant determined functional independence at time of assessment five years after discharge.

Measures

Dependent variables

Mental health was measured with the mental health subscale of the Short-Form Health Survey (SF-36),[20] which is often used as a screener for mood problems.[21] The total score of the nine items ranges from 0 (poor mental health) up to 100 (very good mental health). Scores of ≤ 60 indicate low mental health.[22] The SF-36 is formerly used by individuals with SCI and their caregivers.[23] With a Cronbach's alpha of .75–.86 in the present study, the internal consistency of the scale was interpreted as good (≥ .7).[24]

Life satisfaction was measured with the Life Satisfaction Questionnaire (LiSat-9).[25] The nine items address various domains of life satisfaction: 'life as a whole', 'self-care ability', 'leisure situation', 'vocational/daily occupation', 'financial situation', 'sexual life', 'partnership relation', 'family life' and 'contacts with friends'. LiSat-9 item scores range from 1 (very dissatisfying) to 6 (very satisfying). Item scores were dichotomised into 'dissatisfied' (score 1–4) and 'satisfied' (score 5–6).[26] The total score is the average of the item scores. Scores of < 4.5 were interpreted as 'low life satisfaction', scores of ≥ 4.5 as 'high life satisfaction'. The LiSat-9 has shown to be a valid measure to assess life satisfaction in individuals with SCI[23] and in partners from stroke survivors.[27] Cronbach's alpha in the present study was .77–.82.

Independent variables

Demographic information included gender, age, participation in paid work (0 versus ≥ 1 hour/week),[28] having children and experienced health with one item from the SF-36, which was dichotomised into 'good' (excellent, very good and good) or 'poor' (fair and poor).

A research assistant assessed the SCI characteristics.[29] Level of SCI was dichotomised as paraplegia or tetraplegia. Completeness of SCI was dichotomised as motor complete or motor incomplete. Functional independence was measured with Functional Independence Measure motor score (FIM-Motor).[30–32] This scale consists of thirteen items and the sum score ranges from 13 to 91. Higher scores indicate higher levels of functional independence. FIM scores were dichotomised in ≤ 70 or > 70 in order to get two groups of more or less equal size. Cronbach's alpha in the present study was .97.

Statistical analyses

We used descriptive statistics to describe the study population and outcome variables. Most scores were of ordinal level and therefore non-parametric tests were performed. We computed Spearman's rho correlations to assess the relationship between total scores of mental health and life satisfaction between individuals with SCI and their partners, in the whole sample and in subgroups based on the level and completeness of SCI and the FIM-score. Significant differences in correlation coefficients were tested using Fisher *r*-to-*z* transformation.[33] Wilcoxon signed-rank tests were performed to explore differences in mental health and life satisfaction scores between individuals with SCI and partners. We determined associations between individuals with SCI and partners in dichotomised life satisfaction domains using Cramer's *V* values and differences were assessed using McNemar's tests. We analysed the data with IBM SPSS Statistics 24. A significance level of $p < .05$ (two-tailed) was used. We used Cohen's standards to interpret the correlations ($r = .10–.29$ weak, $r = .30–.49$ moderate, and $r \geq .50$ strong).[34]

At baseline, 225 individuals with SCI participated in the study and 146 of them completed the follow-up measurement five years after discharge from inpatient rehabilitation. Group differences between individuals at baseline and a measurement one year after discharge (*n* = 154) are formerly analysed.[35] In that study was found that participants were less likely to participate one year after discharge when the duration of hospitalisation and inpatient rehabilitation was longer, when they had a low level of education and when they had a lower level of life satisfaction at the start of active rehabilitation (which was partly explained by exclusion due to psychiatric problems). We assume that these findings also apply to the measurement used in the current study, since the participants on the measurements one and five years after discharge were highly comparable.

RESULTS

Participants

Of the 146 participating individuals with SCI, eighty lived together with a partner, and of them, sixty-nine partners participated the study, which is 70.4% of all participating primary informal caregivers (*n* = 98). Twenty-nine informal caregivers were no partner (e.g., parent, child or other family) or did not live together at time of the measurement. Four couples of individuals with SCI and their cohabiting partners were excluded because of missing scores on the SF-36 mental health or LiSat-9, resulting in a sample of sixty-five couples. Table 2.1 displays characteristics of the individuals with SCI and their partners.

Table 2.1 Background characteristics

Characteristics	Individuals with SCI	*n*	Partners	*n*
Gender (female)	32.3%	65	64.6%	65
Age in years (Mdn; IQR)	50.0; 36.0–59.0	65	47.5; 34.5–59.8	64
Paid work (yes)	37.5%	64	76.6 %	64
Child (at least 1)	78.1%	64	78.1%	64
Resident child (at least 1)	45.8%	64	45.8%	64
Non-resident child (at least 1)	36.2%	64	36.2%	64
Experienced health (good)	80.0%	65	90.5%	63
Level of SCI (paraplegia)	73.8%	65	–	–
Completeness of SCI (motor complete)	76.9%	65	–	–
FIM-Motor score (Mdn; IQR)	72.0; 42.0–77.5	65	–	–

Note: Mdn: median; IQR: interquartile range; FIM: Functional Independence Measure.

Mental health and life satisfaction

Persons with SCI and their partners had the same median mental health scores of 76.0 and their mental health scores were moderately and positively correlated (Table 2.2). It was found that 26.1% of the partners and 13.8% of the individuals with SCI had low mental health.

Life satisfaction scores of individuals with SCI (median (Mdn) = 4.8, interquarquartile (IQR) = 4.2–5.0) and their partners (Mdn = 4.6, IQR = 4.0–5.1) were not significantly different from each other and were positively correlated. It was found that 47.7% of the partners and 32.3% of the individuals had low life satisfaction.

Table 2.2 Mental health and life satisfaction (*n* = 65)

	Mental health (1–100)[a]		Life satisfaction (1–6)[b]	
	Individuals with SCI	Partners	Individuals with SCI	Partners
Mean (SD)	78.6 (13.8)	74.3 (16.6)	4.6 (0.7)	4.6 (0.8)
Mdn (IQR)	76.0 (68.0–92.0)	76.0 (60.0–88.0)	4.8 (4.2–5.0)	4.6 (4.0–5.1)
% Below norm score	13.8%	26.1%	32.3%	47.7%
Z-score Wilcoxon test	1.53		1.15	
Spearman's rho correlation	.35**		.51***	

** $p < .01$, *** $p < .001$.

[a] A cut-off of ≤ 60 indicates severe mental health problems.

[b] A cut-off score of < 4.5 indicates low life satisfaction.

Table 2.3 shows that the correlations between mental health and life satisfaction of patients and partners were different between the subgroups based on SCI characteristics. Mental health scores of individuals with paraplegia and their partners were strongly and significantly related, but this was not found among individuals with a tetraplegia and their partners. The correlation between life satisfaction of individuals with SCI and their partners was stronger in the subgroup with a > 70 FIM-score (compared with a score of ≤ 70).

Table 2.4 shows the associations between life satisfaction scores of individuals with SCI and their partners in separate life satisfaction domains. Moderate positive and significant correlations were found with respect to the domains ‘life as a whole’, ‘financial situation’, ‘sexual life’, ‘partnership relation’ and ‘family life’. No associations were found in the other domains. Furthermore, Figure 2.1 shows many differences in (dis)satisfaction between partner and individual with SCI per life satisfaction domain. McNemar’s test demonstrated that compared with their partners, individuals with SCI were more satisfied with their ‘leisure situation’ (patients satisfied 68.8%, partners 51.6%), ‘partnership relation’ (patients satisfied

90.3%, partners 67.7%) and 'family life' (patients satisfied 90.6%, partners 68.8%), and less satisfied with their 'self-care ability' (patients satisfied 50.8%, partners 85.2%). Overall, individuals with SCI and their partners were most often dissatisfied with their 'sexual life'.

Table 2.3 Correlations between patients' and partners' mental health and life satisfaction in subgroups based on SCI characteristics

	Mental health			Life satisfaction		
	Median individuals with SCI	Median partners	*r*	Median individuals with SCI	Median partners	*r*
Lesion level						
Tetraplegia (*n* = 17)	84	76	-.07	4.5	4.3	.45
Paraplegia (*n* = 48)	76	76	.50***	4.9	4.6	.54***
Difference	8	0	.57*	.4	.3	.09
Completeness of SCI (motor complete)						
Complete (*n* = 50)	76	76	.36*	4.8	4.7	.45**
Incomplete (*n* = 15)	80	76	.36	4.7	4.3	.67**
Difference	4	0	0	.1	.4	.22
FIM						
≤ 70 (*n* = 30)	76	74	.30	4.7	4.3	.24
> 70 (*n* = 35)	80	76	.41*	4.8	4.7	.73***
Difference	4	2	.11	.1	.4	.49**

* *p* < .05, ** *p* < .01, *** *p* < .001.

Table 2.4 Association and comparison of life satisfaction domains between individuals with SCI and partners

Domains LiSat-9	*n*	Individuals with SCI satisfied *n* (%)	Partners satisfied *n* (%)	McNemar's test *p*-value	Cramer's *V*
Life as a whole	64	39 (60.9)	35 (54.7)	.52	.30*
Self-care ability	61	31 (50.8)	52 (85.2)	< .001	.05
Leisure situation	64	44 (68.8)	33 (51.6)	.04	.22
Vocational situation	64	43 (67.2)	33 (51.6)	.09	.12
Financial situation	64	46 (71.9)	43 (67.2)	.63	.38**
Sexual life	60	16 (26.7)	18 (30.0)	.77	.51***
Partnership relation	62	56 (90.3)	42 (67.7)	< .001	.36**
Family life	64	58 (90.6)	44 (68.8)	< .001	.36**
Contacts with friends	65	57 (87.7)	47 (72.3)	.05	.02

* *p* < .05, ** *p* < .01, *** *p* < .001.

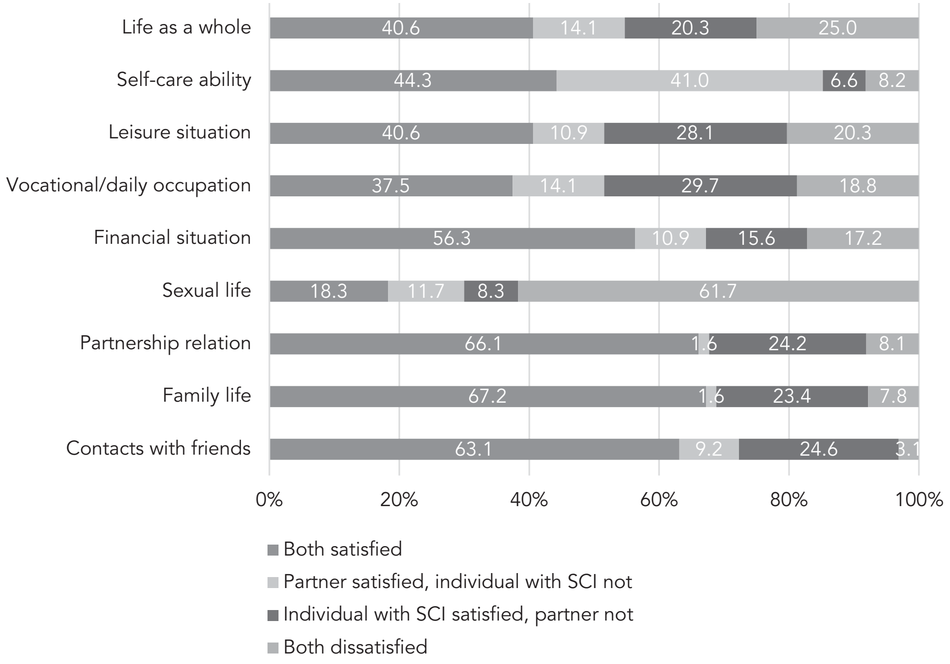


Figure 2.1 Comparison of satisfaction in life satisfaction domains between individuals with SCI and partners.

DISCUSSION

This study provides insight into the differences and associations in mental health and life satisfaction scores of persons with SCI and their partners five years after discharge from inpatient rehabilitation. Median total mental health and life satisfaction scores of individuals with SCI and their partners were similar and moderately to strongly related to each other. However, the differences found on individual life domains also indicate that there may be considerable differences in appreciation between partners in a relationship.

This study has several strengths. First, this is one of the first studies to gather data of both partners and individuals with SCI and provides insight into the impact of SCI on families instead of on different persons independently. Secondly, data were collected at a uniform point of time (five years after discharge from first inpatient rehabilitation). In former studies, large variations in duration since SCI may have had impact on the results.

Mental health and life satisfaction: levels

Median mental health and life satisfaction levels found in our study were comparable to those of the generic Dutch country population.[22,36] In our study, 13.8% of the individuals with SCI and 26.1% of the partners reported low mental health. In the Dutch adult population, 13.7% reported low mental health, with females reporting low mental health more often than males (respectively 16.7% and 10.5%).[37] In our study, most individuals with SCI were male (67.7%) and most partners were female (64.6%), which may partly explain the difference in mental health between individuals with SCI and their partners. However, considering this gender difference, the percentage of partners who report low mental health is still relatively high. In our study, 32.3% of the individuals with SCI and 47.7% of the partners report low overall life satisfaction. To compare, in the Dutch population 34% report low life satisfaction.[36] Again, gender differences may partly explain the difference.

Mental health and life satisfaction: relationship and comparison

In the literature, no studies on the relationships between mental health scores of individuals with SCI and their partners were found. Studies in other diagnostic groups showed similar results to our study findings.[38,39]

The association we found between life satisfaction of individuals with SCI and partners is consistent with previous findings found in research conducted with caregiver-patient dyads in other chronic illness groups.[15] Studies among individuals with stroke and their partners found that partners reported lower levels of life satisfaction[15,18] and higher anxiety compared to individuals with stroke.[16] However, and in accordance with our study, no differences in emotional status levels between SCI patients and their partners were found.[13]

Focusing on separate life domains, differences in life satisfaction between individuals with SCI and their partners were found. No association was found in domains which are not automatically shared by patients and partners ('self-care ability', 'leisure situation', 'vocational/daily occupation' and 'contacts with friends'). Moderate positive significant associations were found in more mutual life satisfaction domains ('financial situation', 'sexual life', 'partnership relation' and 'family life').

Individuals with SCI and their partners were both least satisfied with their 'sexual life', which is in accordance with earlier research.[15,18,40] It is likely that the SCI and related physical (e.g., bladder and/or bowel incontinence)[2] and mental (e.g., impaired body image)[41] problems influence their sexual relationship.[42]

We found that patients were significantly more often satisfied on the domains of 'leisure situation', 'partnership relation', and 'family life'; and partners significantly more often on the 'self-care ability' domain. This partly corresponds with the results of a former study among SCI patients and their partners in which was found that patients were more satisfied on mental domains and partners on physical domains.[14,43] Comparable results were also found in studies about life satisfaction among couples of stroke patients and their partners one and three years after stroke. In those studies was found that patients scored higher on the domain of 'partnership relation' and lower on the 'self-care ability' domain (only significant one year after stroke).[15,18] Higher satisfaction among the partners on the physical 'self-care ability' domain is not surprising because all patients with SCI experience a certain degree of physical impairment within their daily activities.[1,2] That partners were less satisfied than patients on the 'leisure time' domain corresponds with findings in caregiver studies in different diagnostic groups where it was found that more leisure time was one of the main needs of caregivers (of who most were partner).[44–46] Finally, lower satisfaction among partners in the 'partnership relation' and 'family life' domains may be explained by a change in role from spouse and lover to care provider and the new assumed responsibilities. Individuals with SCI are dependent and need support, partners provide support. In former research it was found that different stressors are negatively associated with caregiving and the evaluation of life satisfaction, like the changed relationship, anger or resentment toward partner with SCI, feeling trapped, loss of intimacy, lack of appreciation or respect from partner with SCI, and stress of multiple roles.[9,47]

We also, although not consistently, found that relationships between mental health and life satisfaction of individuals with SCI and partners appear to be stronger in individuals with a paraplegia and higher functional independence. This may just be a coincidence, but it may also reflect diminishing cohesion within the couple following a severe disability of one of the partners over time.[9,48]

Limitations

Our study has some limitations. First, this study concerned a selected group of individuals with SCI, since only wheelchair dependent individuals with SCI were included. Therefore, results are only representative for this selected group. However, the selection resulted in a homogenous group of individuals with a more severe SCI which is interesting since this group is highly dependent on rehabilitation care. Second, partners only participated in the measurement five years after discharge. Therefore, it is not possible to compare mental health and life satisfaction of individuals with SCI and their partners earlier after SCI onset in order to conclude anything about the course of mental health and life satisfaction. Third, attrition bias must be taken into account when interpreting the results. In particular the finding that follow-up participants had higher life satisfaction may lead to an over-estimation of the life satisfaction by individuals with SCI five years after discharge.

Implications

The current main focus in clinical practice for the individual with SCI is on physical consequences. This study adds to the evidence suggesting that it is recommended to pay more attention to partner's perceived life satisfaction and mental health in order to promote their well-being, and it adds to this evidence that clinicians cannot assume that the partner's experienced life satisfaction is in line with the individual with SCI's life satisfaction. A focus on changing family roles, personal needs and responsibilities early in the rehabilitation process could possibly contribute to their life satisfaction, whereas it was found that partners were less satisfied in the life satisfaction domains 'partnership relation', 'family life' and 'leisure time'. Especially the finding that partners were less satisfied with their partnership relation than the individuals with SCI needs attention. Former research showed that partners who rate their partnership relation as low encounter more subjective caregiver burden and less caregiver satisfaction, which is a risk for burnout.[49]

Special attention also is needed for the domain of 'sexual life', whereas it was found that in 81.7% of all couples at least one person was dissatisfied. Our findings are in accordance with previous findings that people with more severe physical impairments report low sexual satisfaction[50] and that injury related changes could function as barriers to intimacy (for partner and patient).[51] Furthermore, former studies found that individuals with SCI were less satisfied with their sexual life compared with a general population group[36] and compared with their own situation before SCI.[40] All these findings emphasise the importance for more attention on sexual functioning and abilities in rehabilitation care.[52]

In rehabilitation care, attention for the caregiver and awareness of the importance of family-centered care is growing. However, overall more research on the specific needs of individuals with SCI and their partners/caregivers is needed in order to come to concrete recommendations for rehabilitation care. Qualitative research, like interviews, could be valuable in the exploration of personal needs of individuals with SCI and their partners and the individual differences in needs that do exist. Quantitative cohort and longitudinal research could contribute to a more general insight in needs and the changes in needs overtime. More insight in needs could be beneficial in the development of interventions aimed to promote mental health and life satisfaction of individuals with SCI and their partners. Existing interventions which focus on patients and their caregivers, like family conferences, are promising, however, there is still limited empirical evidence particular in the area of rehabilitation.[53,54] Future research is needed for the development, implementation, and evaluation of such interventions which are aimed to sufficiently equip families to cope with the effects of an SCI on their personal lives.

Conclusion

On average, individuals with SCI and their partners showed equal mental health and life satisfaction and their total scores on these measures were positively related to each other. However, these associations were only moderate, thereby suggesting considerable differences between individuals with SCI and their partners. Discrepancies between individuals with SCI and their partners were found with respect to various life domains. Therefore, the focus of attention on mental health and life satisfaction (domains) should be different for individuals with SCI and partners in clinical practice and in future research.

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Compliance with ethical standards

Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

We certify that we followed all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research. The Medical Ethics Committee of the University Medical Centre Utrecht approved this study.

Informed consent

Informed consent of the individuals with SCI was obtained at inclusion in the cohort. Partner’s informed consent was obtained at the measurement five years after discharge from inpatient rehabilitation (their first moment of participation).

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CHAPTER 3

Provided support, caregiver burden and well-being in partners of persons with spinal cord injury five years after discharge from first inpatient rehabilitation

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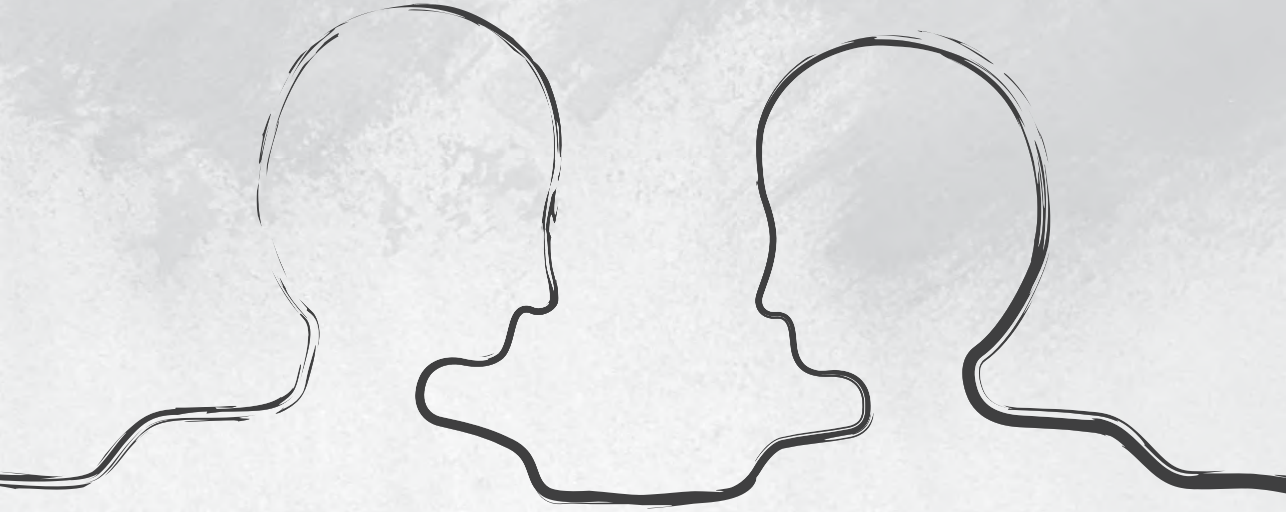

Abstract

Study design: Cross-sectional study.

Objectives: To describe type and regularity of support given by partners for individuals with paraplegia versus tetraplegia five years after discharge from first inpatient rehabilitation; to describe perceived caregiver burden, mental health and life satisfaction among partners; and to analyse determinants of perceived burden and the partner's mental health and life satisfaction.

Setting: The Netherlands.

Methods: Participants were partners of persons with spinal cord injury (SCI) five years after discharge from first inpatient rehabilitation (n = 67). Participants completed a self-report questionnaire. Provided support was assessed with an existing scale consisting of twenty-five activities for which partners could indicate how often they provide support to the patient. Caregiver burden was assessed with the Caregiver Strain Index. Mental health was measured with the Short-Form Health Survey 36 (mental health subscale), and life satisfaction was measured with the Life Satisfaction Questionnaire.

Results: Five years after inpatient rehabilitation, partners provided support with a large variety of activities. How often and in which activities partners provided support was associated with lesion level. About 43% of the partners experienced high levels of caregiver burden. Provided support was related to perceived burden (r_S = .58) and life satisfaction (r_S = -.24), and burden was negatively related to mental health (r_S = -.47) and life satisfaction (r_S = -.67).

Conclusions: High levels of perceived burden among partners and the associations between higher burden with lower well-being show the importance to prevent caregiver overload in partners of individuals with SCI. Monitoring burden during regular rehabilitation visits may help to early detect burden.

INTRODUCTION

Acquiring a spinal cord injury (SCI) not only has a major impact on the people with SCI themselves,[1] but also heavily affects the lives of their partners (often referred as spouses or significant others). They also have to adapt their pre-injury lifestyle and get a dual role as partner and caregiver, often without sufficient preparation.[2,3]

Most partners provide extensive support to individuals with SCI on a daily basis and for a long period.[4,5] Type and regularity of the support depend on the level and severity of the injury,[6] varying from support in activities of daily living (ADL) and other practical support, to more emotional support.[5] However, we only found one study describing the specific activities with which partners provide support.[5]

Providing support may be stressful for partners and result in the experience of caregiver burden. Burden is a highly individualised experience.[7] It is often defined as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, or spiritual functioning.[8] Previous studies showed that about 40–46 percent of the partners experience moderate to serious levels of caregiver burden.[5,9,10] Increased hours of care, more moderate or severe disabilities of the patient, residence with the patient, lack of choice in being a caregiver, providing more ADL support and social isolation are related to higher perceived burden.[5,10–12] Higher perceived burden has consequences for the caregiving partner in terms of lower general health,[13] lower participation,[9,14] lower well-being, loss of identity, or burnout,[2,15–17] but also for the individual with SCI, e.g., negative effect on the quality of their relationship[17] and society, e.g., financial consequences due to lost-productivity, absenteeism and burnout.[18]

At this time, only little is known about the specific activities with which partners provide support, how often they provide support and how this relates to caregiver burden.[5] Furthermore, it is unclear how to prevent and reduce caregiver burden and its consequences on partners' well-being. Research in other diagnostic groups, suggest interventions such as counselling, psycho-education, and family group interventions.[19–21] However, more research is needed to further develop and implement such interventions in SCI care.[22,23] Therefore, more insight in the determinants of burden and well-being is needed.[22] The aims of the present study, therefore, were: (1) to describe the type of activities and regularity with which partners provide support to individuals with paraplegia and tetraplegia five years after discharge from first inpatient rehabilitation, (2) to describe perceived levels of caregiver burden, mental health and life satisfaction in partners of individuals with SCI and (3) to analyse determinants of perceived burden, mental health and life satisfaction.

METHODS

Design

We used data from the Dutch Umbrella project.[24] In this study, individuals with SCI were included between August 2000 and July 2003, and they were followed during and after their first rehabilitation after onset of the lesion in one of the eight Dutch rehabilitation centers specialised in SCI.[24]

Participants

Individuals with SCI were included in the project if they met the inclusion criteria: (1) age between eighteen and sixty-five years, (2) recent onset of SCI, and (3) expectation of permanent wheelchair dependency. Exclusion criteria were: (1) progressive disease, (2) psychological disorder, (3) SCI caused by a malignant tumour or (4) insufficient understanding of the Dutch language.[24]

At the assessment five years after discharge, we also invited the primary family caregivers of the participants for the study. To get a more homogenous group, we selected only partners (e.g., no children, parents or other primary family caregivers) who lived together with the individual with SCI at time of measurement. In the current study, we used data from couples of individuals with SCI and their partners.

Procedure

We asked individuals with SCI and their partners to complete a self-report questionnaire. Information on the type of SCI was extracted from data collected by a rehabilitation physician at one year post-discharge. A research assistant administered the functional independence measure of individuals with SCI at time of assessment five years after discharge.

Measures

Dependent variables

Provided support by partners to individuals with SCI was measured with a scale developed in a previous study, consisting of twenty-five support activities.[5] Partners were asked: 'How often do you support your partner in the following activities?'. Answers were given on a four-point scale (never to always). Items were grouped into three subscales: ADL support (preparing meals, various helping hands, transfers, dressing, outdoors transportation, moving around outdoors, bladder control, bowel control, eating/drinking, toileting, washing/showering, communication, grooming, and moving around indoors), other practical support (visiting doctor, arranging for care or support, supplying medication, supplying ADL materials, arranging for supplies, arranging for adaptations, giving medication, putting on splints or orthoses, and performing exercises), and emotional support (learning to live with the SCI, and comforting, enlivening). Average scores (range 1–4) were computed for each subscale and for the total scale. Cronbach's alphas were, respectively, .89, .89, .83, and .94 in the present study.

We further asked individuals with SCI to report the average hours of support per week provided by the partner and by paid support providers.

Caregiver burden was assessed with the Caregiver Strain Index (CSI), consisting of thirteen dichotomous (yes or no) items.[25] We computed sum scores (range 0–13), where higher scores reflect higher levels of burden. Scores of ≥ 7 indicate high levels of burden and need for further assessment.[25] The CSI has shown good psychometric properties and was previously used in SCI research.[10] Cronbach's alpha in the present study was .84.

Mental health was assessed with the mental health subscale of the Short-Form Health Survey (SF-36).[26] This scale is an often used screening tool for mental health problems.[27] Items are scored on a six-point scale, summed and transformed to a 100-point scale. Higher scores reflect better mental health, scores of ≤ 60 indicate low mental health.[28] This scale showed validity in an SCI population[29] and is formerly used by caregivers from individuals with SCI.[30] Cronbach's alpha in the present study was .86.

Life satisfaction was assessed with the Life Satisfaction Questionnaire (LiSat-9).[31] Items were scored on a six-point scale ranged from 'very dissatisfying' to 'very satisfying'. This scale consists of nine items: one about 'life as a whole' and eight about the domains 'self-care ability', 'leisure situation', 'vocational/daily occupation', 'financial situation', 'sexual life', 'partnership relation', 'family life' and 'contacts with friends/acquaintances'. We calculated average scale scores, where higher scores reflect higher life satisfaction. Scores of < 4.5 were interpreted as 'low life satisfaction', scores of ≥ 4.5 as 'high life satisfaction'. The LiSat-9 has shown to be a valid measure to assess life satisfaction in partners from individuals with stroke.[16] Cronbach's alpha in the present study was .82.

Independent partner variables

Information was collected about age, gender (male = 0, female = 1) and the presence of children (none = 0, at least one = 1), for which a distinction was made in resident and non-resident children. In accordance with the definition of employment of the International Labour Organisation, participation in paid work was dichotomised in at least one hour per week (1) or not at all (0).[32] Experienced health was measured with a single item on general health from the SF-36, and the responses were dichotomised into 'good': excellent, very good and good (1); or 'poor': fair and poor (0).

Independent variables for individuals with SCI

Demographic information included age, gender, presence of children, participation in paid work, and experienced health. Furthermore, individuals with SCI reported their gross monthly family income in Euros.

We used established guidelines to assess SCI characteristics.[33] Level of SCI was dichotomised as tetraplegia (0) or paraplegia (1) and completeness of the SCI was dichotomised as motor complete (0) or motor incomplete SCI (1). A research assistant administered the thirteen-item motor score of the Functional Independence Measure (FIM-Motor) to measure independence in mobility and self-care.[34–36] Answers were given on a seven-point scale ranging from 'total assistance' to 'complete independence'. Sum scores were computed (range 13–91). The higher the score, the higher the level of functional independence. Cronbach's alpha in the present study was .97.

Statistical analyses

We used descriptive statics to describe study population, provided support, burden, mental health, and life satisfaction, in the total group and in the subgroups of partners from individuals with paraplegia and tetraplegia. We assessed internal consistency of scales by calculating Cronbach's alpha (a score of ≥ .7 is interpreted as good).[37] Mainly non-parametric analyses were conducted due to the ordinal level of most measures, Mann-Whitney *U*-tests for differences among persons with paraplegia and tetraplegia and Spearman's rho correlations to detect which variables related to burden, mental health, and life satisfaction. Linear regression analyses (Enter method) were conducted to analyse determinants of perceived burden, mental health, and life satisfaction. All independent variables which were significantly correlated ($p < .05$) with the respective dependent variable in bivariate analyses were included in the regression model. In the correlation and regression analyses, only age and gender of the partners were taken into account, because of the high correlations between age and gender of partners and age and gender of individuals with SCI. We did not include completeness of the SCI as determinant because only those expected to remain wheelchair-dependent were included in the study. In the regression analysis, we used transformed scores of mental health (square root transformation) because of the skewness of the score distribution. We assumed an unidirectional association between burden and mental health and life satisfaction, therefore, burden was included as a predictor in the analyses with mental health and life satisfaction as outcomes, but mental health and life satisfaction were not included as predictors in the model with burden as outcome. To reduce the number of predictors in the regression analyses, we only included total provided support. Data were analysed with IBM SPSS Statistics 24. A significance level of $p < .05$ (two-tailed) was used. We used Cohen's standards to evaluate the correlation coefficients (r = .10–.29 weak, r = .30–.49 moderate, and $r \geq .50$ strong).[38]

Statements of ethics

We followed all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research. The Medical Ethics Committee of the University Medical Center Utrecht approved the study protocol. At inclusion in the cohort, individuals with SCI signed informed consent. Partners signed informed consent at their entry in the study.

RESULTS

Participants

One-hundred forty-six of the 225 individuals with SCI who participated at baseline, completed the follow-up measurement five years after discharge. Of them, eighty lived together with a partner. In total, ninety-eight primary informal caregivers participated in the study, of who sixty-nine were a cohabiting partner (70.4%). Two partners were excluded because of missing scores on the dependent variables, resulting in a sample of sixty-seven couples of individuals with SCI and their partners. Table 3.1 displays demographic and injury characteristics.

Support

Figures 3.1–3.3 graph the percent frequency distribution of providing support 'often' to 'always' by type of support listed from frequent to infrequent. Overall, partners provided support in all three support categories often. Partners of individuals with tetraplegia provided more often support with total support, ADL support and other practical support, compared to partners of individuals with paraplegia. Only the regularity of provided emotional support did not differ significantly between the two groups (Table 3.2).

Table 3.1 Background characteristics

Characteristic	Partners	*n*	Individuals with SCI	*n*
Age in years (Mdn; IQR)	47.0 (35.0–59.5)	65	50.0 (36.0–59.0)	66
Gender (female)	64.2%	67	31.8%	66
Paid work (yes)	75.8%	67	36.9%	65
Gross monthly family income (Euro)	–	–	–	59
< 1000	–	–	5.1%	
1000–1999	–	–	13.6%	
2000–2999	–	–	22.0%	
3000–3999	–	–	30.5%	
4000–4999	–	–	5.1%	
≥ 5000	–	–	23.7%	
Children (at least 1)	78.5%	65	78.5%	65
Resident child (at least 1)	46.7%	65	46.7%	65
Non-resident child (at least 1)	37.3%	65	37.3%	65
Experienced health (good)	89.2%	65	80.3%	66
Level of SCI (paraplegia)	–	–	73.1%	67
Completeness of SCI (Motor complete)	–	–	77.6%	67
FIM-Motor score (Mdn; IQR)	–	–	73.0 (42.0–78.0)	62

Note: Mdn; median; IQR: interquartile range; FIM: Functional Independence Measure.

Table 3.2 Burden, support, hours of support, mental health and life satisfaction

	All (*n* = 67)	Paraplegia (*n* = 49)	Tetraplegia (*n* = 18)	*z*	*p*
Burden (0–12)[a]	6.0 (3.0–8.0)	5.0 (2.0–7.5)	7.0 (5.0–9.3)	1.86	.063
Support					
Total support (1–4)	1.8 (1.4–2.3)	1.6 (1.3–2.0)	2.3 (1.9–2.7)	-3.72	< .001
ADL support (1–4)	1.7 (1.4–2.2)	1.5 (1.3–1.9)	2.3 (2.1–2.7)	-4.52	< .001
Other practical support (1–4)	1.6 (1.3–2.3)	1.4 (1.2–2.0)	2.0 (1.6–2.9)	-2.57	.010
Emotional support (1–4)	2.0 (1.9–3.0)	2.0 (1.5–3.0)	2.5 (2.0–3.1)	-1.78	.075
Hours of support (per week)					
By partner	2.0 (0.0–12.25)	0.0 (0.0–7.3)	13.0 (1.0–21.0)	-2.72	.007
Paid support	2.3 (0.0–9.3)	0.0 (0.0–5.3)	15.0 (4.0–35.5)	-3.82	< .001
Mental health (0–100)[b]	76.0 (60.0–88.0)	76.0 (62.0–88.0)	78.0 (60.0–85.0)	.02	.983
Life satisfaction (1–6)[b]	4.6 (4.0–5.1)	4.6 (4.0–5.2)	4.6 (4.0–4.9)	.33	.750

Note: values are medians and interquartile range.
[a] A higher score indicates more burden.
[b] A higher score indicates higher mental health / life satisfaction.

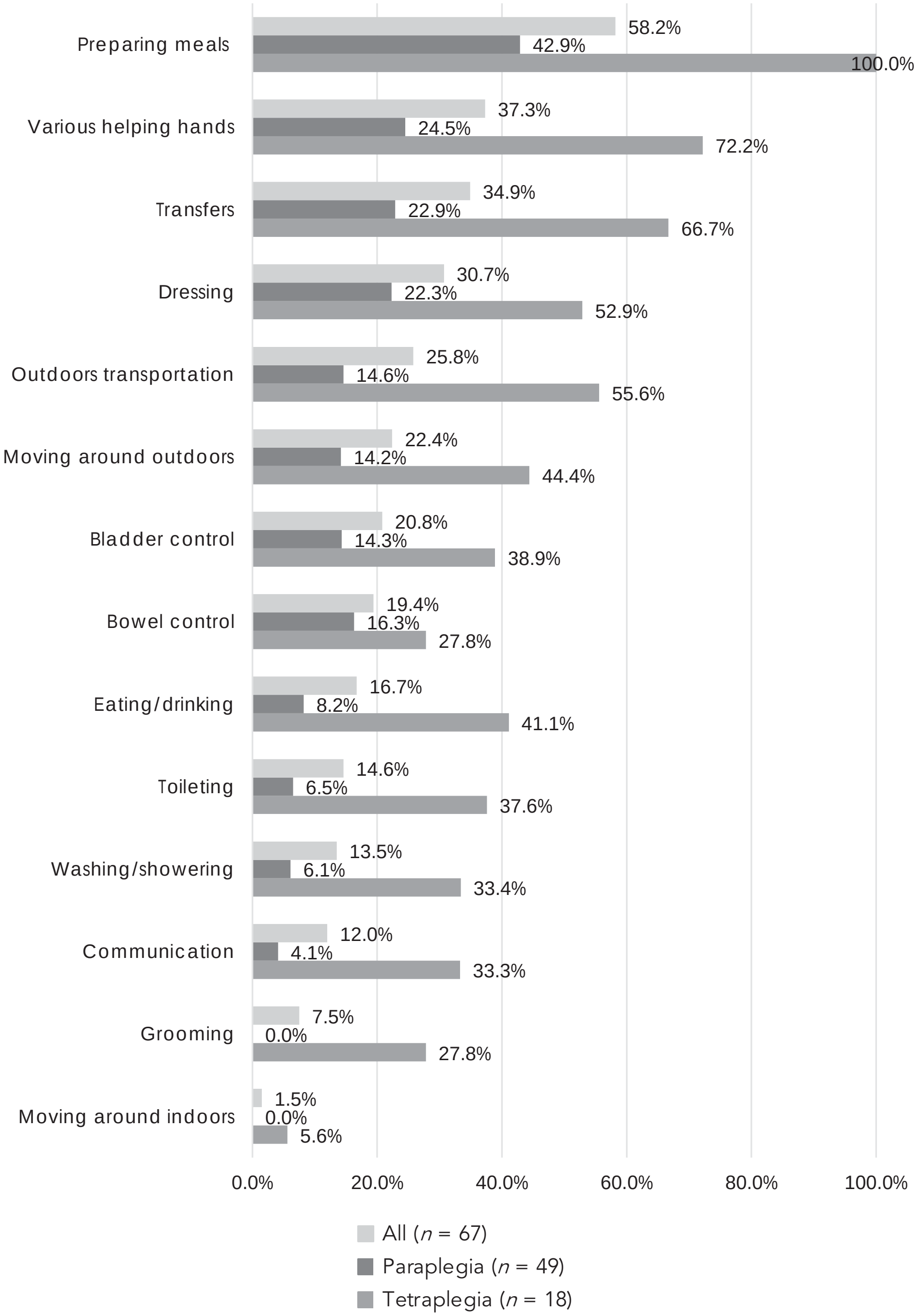

Figure 3.1 The percent frequency distribution of providing ADL support 'often' to 'always' by type of support are listed from frequent to infrequent.

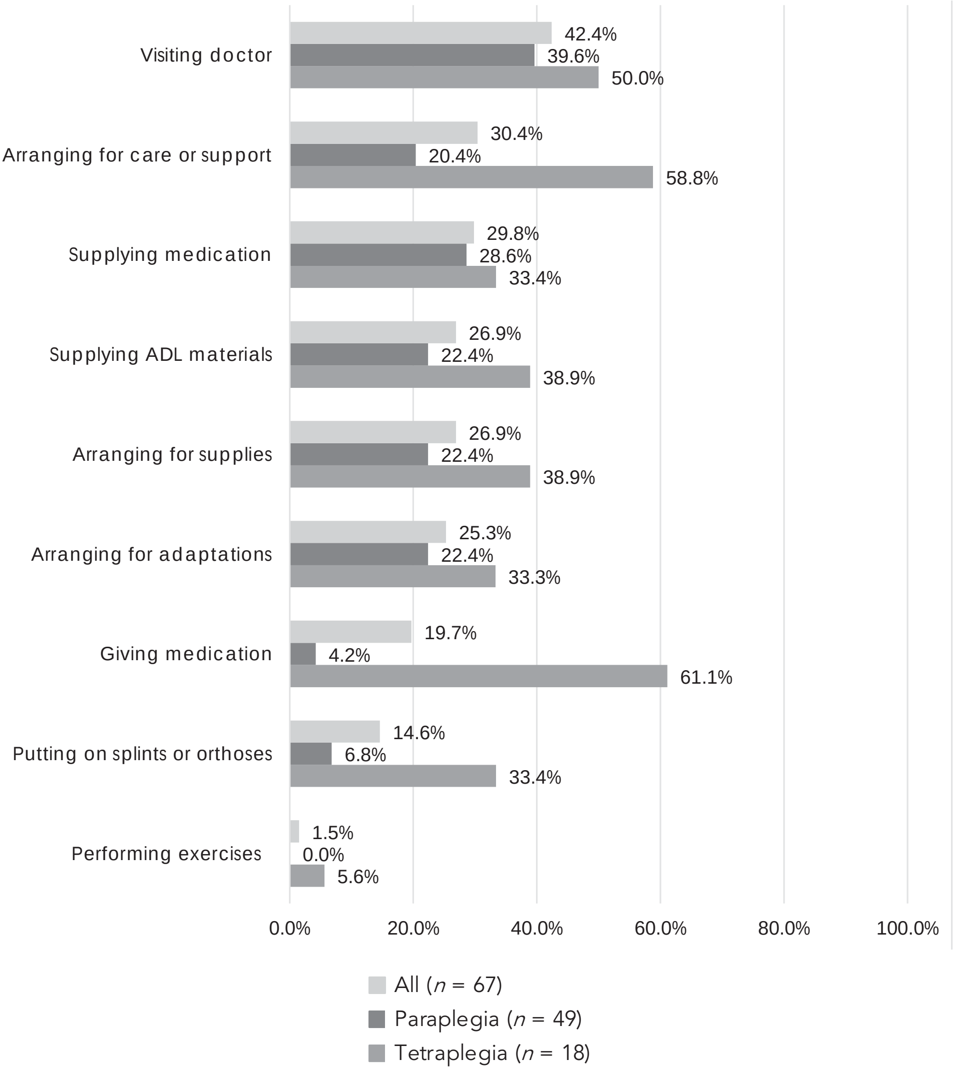

Figure 3.2 The percent frequency distribution of providing other practical support 'often' to 'always' by type of support are listed from frequent to infrequent.

The number of hours of support by the partner and paid support showed a large variation. Individuals with tetraplegia received significantly more hours of support provided by their partners (median 13) as well as paid support (median 15), than individuals with paraplegia (median 0 and 0, respectively). Higher number of hours of support provided by partners was moderately related with more hours of paid support ($r_S = .48$, $p < .001$).

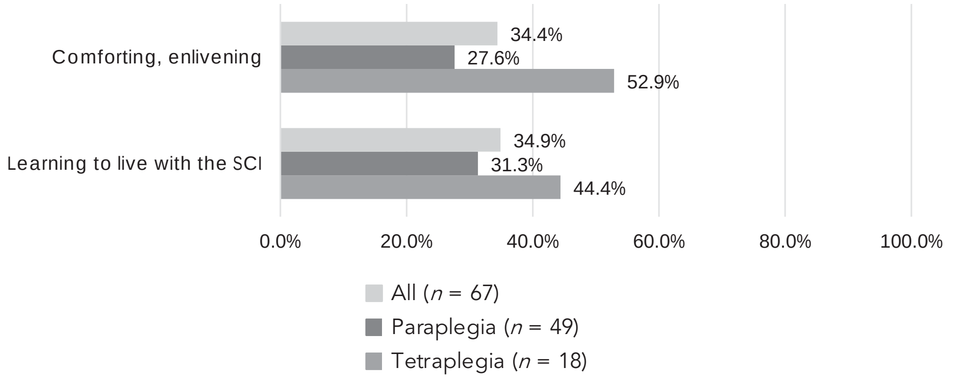

Figure 3.3 The percent frequency distribution of providing emotional support 'often' to 'always' by type of support are listed from frequent to infrequent.

Burden, mental health and life satisfaction

Partners had a median burden score of 6.0 (Table 3.2). We found no differences in perceived burden levels between partners of individuals with a paraplegia or tetraplegia. Overall, 43.3% of the partners had a burden score of ≥ 7.0, 38.8% in the paraplegia and 55.6% in the tetraplegia subgroup.

Table 3.2 shows mental health and life satisfaction scores. We found no significant differences between the paraplegia and tetraplegia subgroups. It was found that 25.4% of the partners reported low mental health and 47.8% low life satisfaction.

Relationships burden, mental health and life satisfaction

Table 3.3 shows the correlations between burden, mental health, life satisfaction and other partner and SCI-related independent variables. The first rows show the associations between the dependent variables. Higher perceived burden was related to lower mental health and life satisfaction. Mental health and life satisfaction were positively related.

We found significant moderate to strong associations between higher burden and more often provided support (total, and all three subscales), more partner support hours, higher partners' age, lower experienced health of the individual with SCI and a lower FIM-Motor score. Better mental health showed a moderate association with better partners' experienced health and higher gross monthly family income. Higher life satisfaction was weakly to moderately associated with more total and ADL support, lower partners' age and better experienced health of the individual with SCI.

Table 3.3 Spearman's rho correlations (n = 60–69)

	Burden		Mental health		Life satisfaction	
	r_S	p	r_S	p	r_S	p
Mental health	-.47	< .001	—	—	—	—
Life satisfaction	-.67	< .001	.73	< .001	—	—
Provided support by partner (total)	.58	< .001	-.20	.104	-.24	.048
ADL support	.59	< .001	-.17	.163	-.25	.042
Other practical support	.50	< .001	-.23	.061	-.24	.055
Emotional support	.42	< .001	-.09	.446	-.09	.460
Hours of support (per week)						
By partner	.41	.001	-.02	.867	-.14	.268
Paid support	.24	.054	-.13	.306	-.08	.548
Partner variables						
Age	.35	.005	-.16	.217	-.35	.004
Gender (female)	-.02	.902	-.11	.369	-.00	.995
Paid work (yes)	-.05	.705	.10	.430	.11	.397
Children (total)	.34	.007	.00	.990	-.18	.180
Experienced health (good)	-.14	.277	.28	.023	.24	.057
Characteristics individuals with SCI						
Gross monthly family income (Euro)	.14	.298	.28	.034	.21	.120
Experienced health patient (good)	-.24	.049	.13	.304	.30	.013
FIM-Motor	-.36	.003	.19	.132	.19	.123
Lesion level (paraplegia)	-.23	.066	.03	.813	.02	.880

Table 3.4 displays regression models. The strongest and only significant determinant of higher burden was more total provided support by the partner. The model explained 43.2% (R^2) of the variance in burden ($F(6) = 6.6$, $p < .001$). Lower burden, higher partners' experienced health and higher gross monthly family income were significant determinants of mental health and together they explained 40.9% (R^2) of the variance in mental health ($F(3) = 12.2$, $p < .001$). The strongest determinant of higher life satisfaction was lower burden, followed by a higher amount of total provided support by the partner. The regression model explained 52.4% (R^2) of the variance in life satisfaction ($F(4) = 16.5$, $p < .001$).

DISCUSSION

In our study, we found that, five years after clinical discharge, above 40% of the partners from individuals with SCI perceived high levels of burden, that they often provide support in various different tasks, and that providing support and perceiving burden were strongly

Table 3.4 Linear regression analyses to detect variables associated with burden, mental health and life satisfaction ($n = 65$)

	Beta	t-value	p-value	Explained variance (R^2)
Dependent variable: burden				43.2%
Provided support by partner (total)	.54	3.23	.002	
Hours of support provided by partner	.09	.59	.560	
Partner age	.06	.46	.646	
Children (total)	.16	1.29	.203	
Experienced health patient (good)	-.06	-.51	.612	
FIM-Motor	.05	.36	.723	
Dependent variable: mental health (square root transformed)				40.9%
Burden	-.50	-4.48	< .001	
Experienced health partner (good)	.24	2.20	.032	
Gross monthly family income (Euro)	.25	2.29	.026	
Dependent variable: life satisfaction				52.4%
Burden	-.76	-6.63	< .001	
Provided support by partner (total)	.27	2.46	.017	
Partner age	-.11	-1.14	.259	
Experienced health patient (good)	.13	1.38	.172	

related. Higher burden also showed strong associations with worse mental health and life satisfaction.

Strengths of the study are the detailed description of partners support tasks and the focus on the consequences of an SCI on the lives of partners from individuals with SCI. Furthermore, as far as we know this is the first study in which the relationships between provided support, experienced burden, and mental health and life satisfaction are investigated.

Support

That partners provide much support to individuals with SCI five years after discharge, confirms earlier research findings.[4,6,39] Compared to partners of individuals with paraplegia, partners of individuals with tetraplegia provide significantly more frequently support and more hours of support. Levels of support found in this study are similar to the results found in a study among partners on average thirteen years after SCI.[5] This indicates that levels of support provided by partners of individuals with SCI remain high on the long-term.[40]

In our study, we also found a strong association between partner and paid support, which is consistent with previous research findings in which it was also found that paid care was received in addition to care given by family or friends.[5,6,41] This association indicates that support given by partners is not a substitute for professional care, but that it is supplemental.

Further, it is noticeable that the range of provided support is large, particularly in individuals with tetraplegia, with 1–21 hours a week for partner support and 4–35.5 hours a week for paid support. Large variance in this subgroup is not surprising, due to the large difference in level of functional independence. In our study, no information was collected on the time distribution of given support, so further research is needed in order to get more insight in how much time partners and/or professionals spend on specific different tasks.

Burden

In the present study, 43.3% of the partners showed serious levels of burden.[25] This percentage is comparable to the 46% Middleton et al.[10] found among caregivers of patients with SCI two years post discharge, which may indicate that burden is not a temporarily experienced feeling. Comparable percentages of 43%–46% were also found among partners of stroke patients two to three years post stroke.[42,43] However, even higher levels of burden (51%–80%) were found in studies among caregivers of patients with amyotrophic lateral sclerosis[44] or dementia.[45]

Only a trend towards significance (p = .06) was found for the differences in the levels of perceived burden between partners of individuals with paraplegia and tetraplegia. In previous research, a comparable but significant, difference in perceived caregiver burden was found among partners of persons with minor (mean = 1.6, range 1–4) and serious (mean = 2.3) disabilities. The absence of significance in the current study is probably due to the low number of individuals with tetraplegia (n = 18).

Mental health and life satisfaction

While mental health and life satisfaction levels of partners from individuals with SCI were relatively low in previous research,[12,46] median mental health and life satisfaction scores in the present study were similar to the scores in the general Dutch population.[47,48] However, individual differences were large and 25.4% of the partners reported low mental health and 47.8% low life satisfaction, which are high proportions compared with the Dutch population (13.7% and 34%, respectively).[49,50] Only part of the differences may be explained by gender differences, where females in the Dutch population report more often low mental health than males (respectively 16.7% and 10.5%),[49] and the majority of the partners in our study was female.

Determinants of burden

We found that higher burden was strongly and independently related to worse mental health and life satisfaction, which is consistent with earlier findings.[15,16,51]

All three types of support were significantly related to burden, indicating that not only the more practical kinds of support like ADL (e.g., preparing meals and transfers) and other practical support (e.g., visiting a doctor and supplying medication), but also emotional support (comforting and learning to live with the SCI) relates with burden levels experienced by partners. We entered the total support variable in the regression analysis of burden, to restrict the number of independent variables and because all types of support were significantly related to burden. This variable turned out to be the only significant determinant of burden in the regression analysis with other variables, with a high explained variance (43.2%), indicating the importance of total support provided by the caregiver in understanding perceived burden of the caregiver.

Determinants of mental health and life satisfaction

We found no significant differences in the experienced levels of mental health and life satisfaction between the paraplegia and the tetraplegia subgroups. This is unexpected, because we found strong correlations between total support and burden on the one hand, and between burden and mental health and life satisfaction on the other hand. While there were no or weaker correlations between support and mental health and life satisfaction, perceived burden seems to be the connecting factor.

More provided support by the partner was associated with lower life satisfaction in the bivariate analysis. Information about this association is not found in SCI research, but a study among caregiving elderly showed that providing daily care had a negative impact on caregiver's life satisfaction.[52] However, in the regression analysis provided support was positively related to life satisfaction, again suggesting that experienced burden rather than the amount of provided support is key to explain partner's mental health and life satisfaction.

Bivariate analyses showed that lower age and higher general health of the partner were related with higher life satisfaction, but these associations were not present in the regression analysis when burden was included as independent variable. Higher age and lower general health are both indicators of lower physical capacity, which may result in higher burden and thereby in lower life satisfaction.

In the regression analysis of mental health, besides burden, gross monthly family income and general health of the partner were related to mental health (positively, weak to moderate effect). In former research economic status is also found to be a determinant of mental health.[53] Mental health and general health are partly overlapping concepts,[54] therefore it is not surprising that these concepts are related.

Limitations

This study has some limitations. Firstly, the sample size; especially the tetraplegia group is small. Due to the limited sample size, we reduced the number of predictors in the regression analyses as much as possible. Secondly, this study concerned a group of selected partners of wheelchair dependent individuals with SCI. Therefore, our results were not representative for all partners of individuals with SCI. Thirdly, partners only participated in the study during the measurement five years after discharge, which makes it impossible to conclude anything about the course of providing support, perceived burden, and well-being in the period between SCI onset and five years after discharge. However, in comparison with a former study, it appears that these results may be representative for a longer period.[5] Fourthly, no data were available about other determinants of burden, mental health and life satisfaction. Most consistent determinants of these constructs are patients behavioural problems, quality of the relationship between patient and partner,[2] caregiver coping,[19,46] personality traits (resilience,[55] neuroticism, self-efficacy), and caregiver competencies.[21] In future research, these determinants should be taken into account in order to get a more complete insight.

Implications

The high levels of burden among partners five years after discharge indicate that burden is not a temporarily experienced feeling. This emphasises the importance to regularly monitor burden among partners, in order to detect well-being problems. The CSI seems an useful tool which is easy to administer by a physician assistant during regular rehabilitation visits and quickly gives an indication of perceived burden.[25,43] More attention from professionals is needed for partners who report high burden levels, and therefore are at risk for well-being problems.

The strong associations between burden with mental health and life satisfaction, as well as the consequences of caregiver burden on the individuals with SCI[17] and the society[18] found in former research, indicate the importance to prevent and treat caregiver burden. In order to reduce experiences of caregiver burden, it seems useful to develop interventions which help to reduce the levels of support provided by partners (e.g., relieving tasks). However, the weaker correlations between support and mental health and life satisfaction show that it may also be effective to relieve feelings of burden among partners even if the amount of support they provide does not change. Such interventions should focus on increasing partners' ability to cope with caregiver burden (e.g., such as counselling, psycho-education, and family group interventions). To relieve feelings of burden it seems important for future research to focus on individual characteristics, since in previous research it was found that personal characteristics like resilience,[55] sense of control and coping style,[46] influence how people deal with the situation they are in.

Conclusion

Partners often provide support in various tasks and perceive high levels of burden five years after discharge from inpatient rehabilitation. Burden was negatively related with mental health and life satisfaction in the predictive models including various independent partner and SCI characteristics, which indicates the potential negative consequences of burden on well-being and shows the importance to prevent caregiver overload in partners of individuals with SCI.

Funding

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Compliance with ethical standards

Conflicts of interest

The authors declare that they have no conflict of interest.

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CHAPTER 4

Measures used to assess impact of providing care among informal caregivers of persons with stroke, spinal cord injury, or amputation: A systematic review

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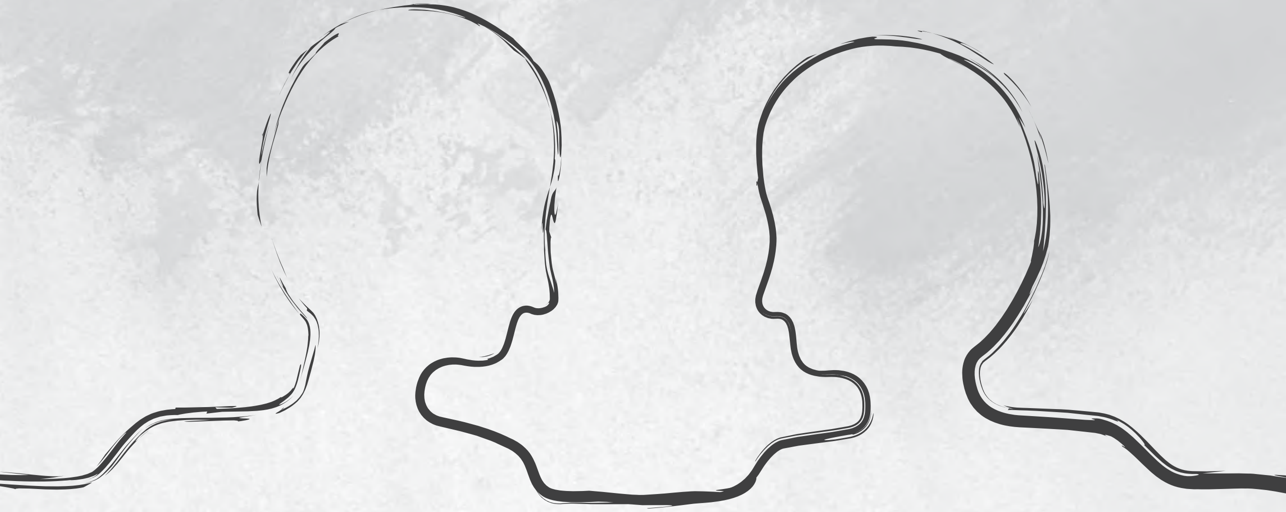

Abstract

Purpose: (1) To identify measures used to evaluate the impact of caregiving among caregivers of persons with stroke, spinal cord injury and amputation, and (2) to systematically evaluate their clinimetric properties reported in validation studies.

Materials and methods: Two separate systematic reviews (Embase, PsycINFO, CINAHL, Pubmed/Medline) were conducted. COSMIN guidelines were used to assess clinimetric properties and methodological quality of studies.

Results: (1) 154 studies published between 2008 and May 2019 were included, in which forty-eight measures were used, mostly describing negative impact. Thirty measures were used only once and not further described. (2) In general, structural validity, internal consistency, and hypothesis testing were often investigated. Reliability, cross-cultural and criterion validity to a lesser extent, and scale development and content validity were rarely described. Tests of measurement error and responsiveness were exceptional. Most supporting evidence was found for the Zarit Burden Interview Short Form, Caregiver Burden Scale and Positive Aspects of Caregiving Questionnaire.

Conclusions: There is a wide variety of impact of caregiving measures. The present study provided a detailed overview of what is known about clinimetric characteristics of eighteen different measures repeatedly used in research. The overview provides clinicians a guidance of appropriate measure selection.

PROSPERO registration: CRD42018094796.

INTRODUCTION

Acquired brain injury, spinal cord injury and amputation are important diagnostic groups in medical rehabilitation. These three diagnostic groups together represent nearly three-quarters of the patients admitted to inpatient medical rehabilitation in the Netherlands.[1] Over 90% of all people with physical disabilities return to independent living in the community, either directly from the hospital or after a period of inpatient rehabilitation. Many of them, however, will need care or support and most of this care is provided by informal caregivers. Informal caregivers are persons, whether relatives or not, who provide unpaid care to a person with disabilities. Informal caregiving is not simply an imposition but arises from emotional bonds with the person with disabilities.[2,3] Care provided by informal caregivers may include practical tasks (e.g., ADL support, visiting a doctor, or arranging exercises), but also emotional support (e.g., comforting or looking after).[4] Performing informal care may have negative and positive consequences for the informal caregiver. It is known that many caregivers perceive high levels of caregiver burden on the short term as well as on the long term,[5–7] which often has negative consequences for their health and well-being (quality of life, physical and psychological impact),[8] but also for the patients,[9] and society.[10] At the same time, providing care may also have positive consequences, e.g., increased self-esteem and mental health, feelings of rewards or meaningfulness, and feeling of satisfaction.[11,12]

In the scientific literature, the measures used to assess the negative and positive impact of providing informal care are diverse. In 2004 Visser-Meily et al. published a review of measures used to assess burden among informal caregivers of patients with stroke.[13] These authors concluded that the many identified burden scales all lacked sufficient evidence for reliability and responsiveness.

Three more recent reviews published in 2012,[2] 2016[3] and 2017[14] provide overviews of tools to measure caregiving-related consequences on health,[2,3] quality of life[3] and feelings of burden[14] among caregivers of elderly people[2,3] or of patients with chronic conditions (in this case Parkinson's Disease, heart failure, Multiple Sclerosis and Chronic Obstructive Pulmonary Disease).[14] Although many different scales measuring caregiving impact were described in these reviews, only limited information on the clinimetric properties of these scales was reported. Users need information about the (dis)advantages and clinimetric properties of the measures to be able to make well-informed choices.[14] The use of valid and reliable measures is important to reduce the chance that impact of caregiving will be unnoticed.

In the present study, we aim to provide an overview of recently (last decade) used measures to evaluate negative and positive caregiving impact among caregivers of persons with stroke, spinal cord injury or amputation. We focus on these diagnostic groups because measure use may be sample-dependent and together these groups comprise a large part of the adult rehabilitation population. Furthermore, we want to evaluate clinimetric properties of the found measures in a comprehensive and systematical way. Our research questions are:

- Research Question 1 (RQ1): Which measures evaluating the negative and positive impact of caregiving reported by informal caregivers of persons with stroke, spinal cord injury, and amputation have been used in empirical studies published between 2008 and 27 May 2019?
- Research Question 2 (RQ2): For the measures used in more than one study: what are their clinimetric properties, as described in validation studies of these measures published before 3 June 2019?

MATERIALS AND METHODS

We followed the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) methodology for systematic reviews of patient-reported outcome measures,[15–17] including the PRISMA statement (online Supplementary Table S4.1).[18] The protocol of this systematic review has been registered in the International Prospective Register of Systematic Reviews (PROSPERO, ID: CRD42018094796).

RQ1

Search strategy RQ1

The electronic databases Embase, PsycINFO, CINAHL and Pubmed/Medline were systematically searched for the period between 2008 and 2019 (27 May). The search string consisted of three components – 'caregiving,' 'caregiver-reported negative and positive impact of caregiving,' and an indication of 'diagnosis.' To develop our search strategy, an information specialist was consulted. The search string was adapted for the use of different bibliographic databases. Details of the search string are shown in online Supplementary Table S4.2. Searches were restricted to studies published in the English language. To make sure that no relevant publications were missed, references of relevant publications were checked, as well as publications that used these relevant publications as a reference ('cited-by' function).

Eligibility criteria RQ1

Publications were included when at least one measure was used to assess the negative or positive impact of caregiving among informal caregivers of adult (≥ eighteen years) persons with stroke, spinal cord injury or amputation. Informal caregivers had to have a minimum age of eighteen years and had to provide informal, not paid, care. Publications were only included when at least fifteen caregivers of persons with stroke, spinal cord injury or amputation participated in the study. The study was restricted to empirical studies written in English, published in scientific journals (in print or online) and published between 1 January 2008, and 27 May 2019. Publications were only included if a measure was used that includes a 'caregiving component' in its questions, such as the Caregiver Strain Index.[19] If only more general measures of distress or other outcomes of caregivers were used without the 'caregiving component', e.g., the Hospital Anxiety and Depression Scale,[20,21] which items do not refer to caregiving, the publication was excluded. Publications were also excluded if only measures were used which do not include a negative or positive evaluation, like measures used to assess objective burden in terms of time spent, frequency and tasks, such as the Caregiver Assistance Scale.[22] Measures which assess several dimensions of impact were included if at least one dimension reflects subjective perception, e.g., the Oberst Caregiving Burden Scale which focus on time spent on caregiving tasks and caregivers perceptions of the difficulty of caregiving tasks.[23] Measures that focused only on evaluation or use of professional care and services, such as the Caregivers' Satisfaction with Stroke Care Questionnaire,[24] or on caregivers' knowledge (Caregiving Knowledge Level Scale[25]), were excluded. Furthermore, in RQ1, publications were excluded when a qualitative study, review or validation study was reported, or when no full-text was available in a situation where all needed information was not found in the abstract. Variants of measures, e.g., modified, revised or expanded versions, were counted as separate instruments.

Study selection RQ1

Reference management program Mendeley was used to merge all retrieved publications into one main file and to remove duplicates. The systematic literature review web application Rayyan QCRI was used for categorizing and labelling publications based on title and abstract, and later on, full-text.[26] Titles and abstracts were screened by one reviewer (ES), with a double check by another reviewer (CH) in the initial phase of screening. Disagreements were discussed until consensus was reached and the discussion was used to improve the screening process. In total, 10% of the titles and abstracts were double checked. Given the high level of interrater agreement (94.6% consensus, Kappa = .78),[27] we evaluated the 10% double check as sufficient. Relevant publications were read in full-text (ES), again with a 10% double check (CH) in the initial screening phase. The interrater agreement in the full-text screening (96.3% consensus, Kappa = .91) was even better.[27] Therefore, again, we decided that a 10% double check was sufficient.

Data extraction RQ1

We made an overview of all identified measures, including names of the authors, year of publication and number of studies in which the measure has been used, including references.

RQ2

Search strategy RQ2

For the second research question, a separate search was conducted. The same databases were searched as we did in RQ1 (Embase, PsycINFO, CINAHL, and Pubmed/Medline). In the search string, two components were combined: the name of the measure and terms indicating clinimetric properties. For the first component, all measures were included which have been used in at least two studies found in RQ1. For the second component, we used the sensitive PubMed, Embase and CINAHL (also adapted for PsycINFO) search filters for finding studies on measurement properties of measurement instruments developed by the COSMIN group.[28] Details of the search string are shown in online Supplementary Table S4.3.

Eligibility criteria RQ2

In RQ2, validation studies were included which reported clinimetric properties of one or more of the included measures. Only full-text articles, published in scientific journals (in print or online) before 3 June 2019, and written in English were considered eligible. We did not limit our search to specific diagnostic groups. Publications were excluded when the measure was used as an outcome instrument (not to validate the measure) or to validate another measure.[29] Publications in which the development of an included measure was described were included afterwards if such a publication was not identified in the search.

Study selection RQ2

The study selection method of RQ2 was identical to the method used in RQ1. The 10% double title/abstract and full-text screening in the initial phase resulted in a good to very good interrater agreement (respectively 99.0% consensus, Kappa = .93 and 90.9% consensus, Kappa = .62).[27] Consensus and improvement of the screening process were reached by discussion and, based on the good interrater agreement scores, we evaluated a 10% double check as sufficient.

Data extraction RQ2

We first compiled a table with the main characteristics of the measures: construct, original target population, original mode of administration, number of items, completion time, question example, response categories, subscales, score calculation, score interpretation, original language, available translations, and copyright. From all selected publications, we extracted information about the study population (*n*, age and gender), study design, administration mode, disease characteristics (disease, duration and severity), background (caregiving setting, country and language), response rate, distribution of scores, information about missing items, and floor/ceiling effects. Extraction was conducted by one author (ES).

Evaluation of measurement properties RQ2

All measurement properties reported in the included publications were evaluated. We used definitions of measurement properties as described in COSMIN guidelines (see online Supplementary Table S4.4).[15–17] We used the Risk of Bias checklist for systematic reviews of patient-reported outcome measures (as part of the COSMIN guidelines) to evaluate the methodological quality of single studies.[16] A four-point rating system was used in which each clinimetric standard was rated as 'very good' (V), 'adequate' (A), 'doubtful' (D) or 'inadequate' (I). The overall rating of the quality of each measurement property of each study was determined by taking the lowest rating of any standard (i.e., the 'worst score counts' principle). One author (ES) scored the checklist for the found studies. Difficulties in scoring were discussed with all authors. In the next step, we evaluated the results against COSMIN criteria for good measurement properties. Each result is rated as either 'sufficient' (+), 'insufficient' (-), or 'indeterminate' (?).

Data synthesis RQ2

After scoring the separate validation publications reporting clinimetric properties, we summarized, rated and graded the overall results for the different measures. For each measure, we decided whether the results found in different studies were 'consistent' ('sufficient' (+) or 'insufficient' (-)), 'inconsistent' (±) or 'indeterminate' (?). Finally, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to grade the quality of evidence.[30] Measurement properties were graded as 'high' when we were very confident that the true measurement property lies close to that of our findings. Grading's can be lowered to 'moderate', 'low' or 'very low', based on concerns regarding (1) risk of bias (methodological quality), (2) inconsistency in results between studies, (3) imprecision (refers to the total sample size of studies combined) and (4) indirectness (differences in populations or context). Finally, to come to evidence-based and transparent recommendations, measures were categorized into three categories:[15–17]

A. Measures with evidence for sufficient content validity and at least low quality for sufficient internal consistency;

B. Measures categorized not in A or C;

C. Measures with high quality evidence for an insufficient measurement property.

A-categorized measures will be recommended for use and results obtained with these measures can be trusted. B-categorized measures have potential, but require further research to assess the quality of the measure. C-categorized measures will not be recommended for use.

RESULTS

Selection of studies RQ1

The search of RQ1 identified a total of 4865 publications. Removal of duplicates, title and abstract screening and full-texts screening resulted in 192 included publications (see Figure 4.1).

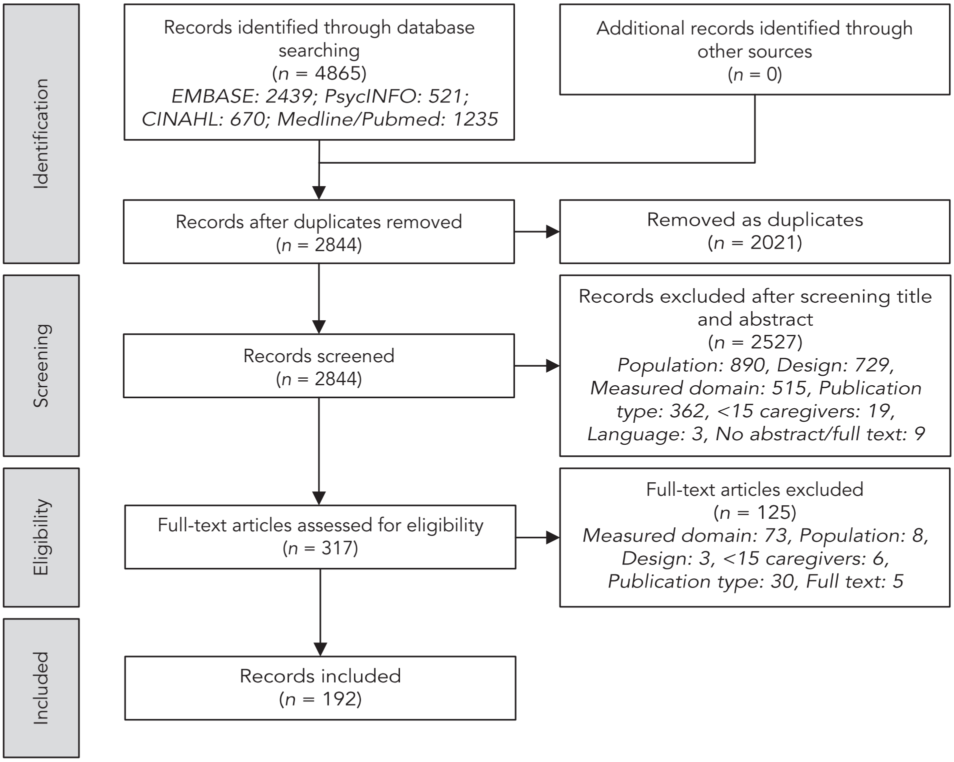

Figure 4.1 Flowchart search and selection process RQ1.

In the 192 included publications, 221 times measures were used which evaluated the negative or positive impact of providing care among informal caregivers (Table 4.1). Caregiving impact measures were mostly used in research among caregivers of persons with stroke (194 times), followed by spinal cord injury (twenty-six times) and amputation (two times). All publications describe 154 different studies in which forty-eight different measures were found, of which eighteen were used in at least two different studies.

Selection of studies RQ2

The search of RQ2 identified a total of 3013 publications reporting validation studies. Addition of other references, removal of duplicates, title/abstract and full-text screening resulted in ninety-six included publications (Figure 4.2). The ninety-six studies reported 101 measurement validations since three studies reported the validation of two different measures and one study reported the validation of three different measures.

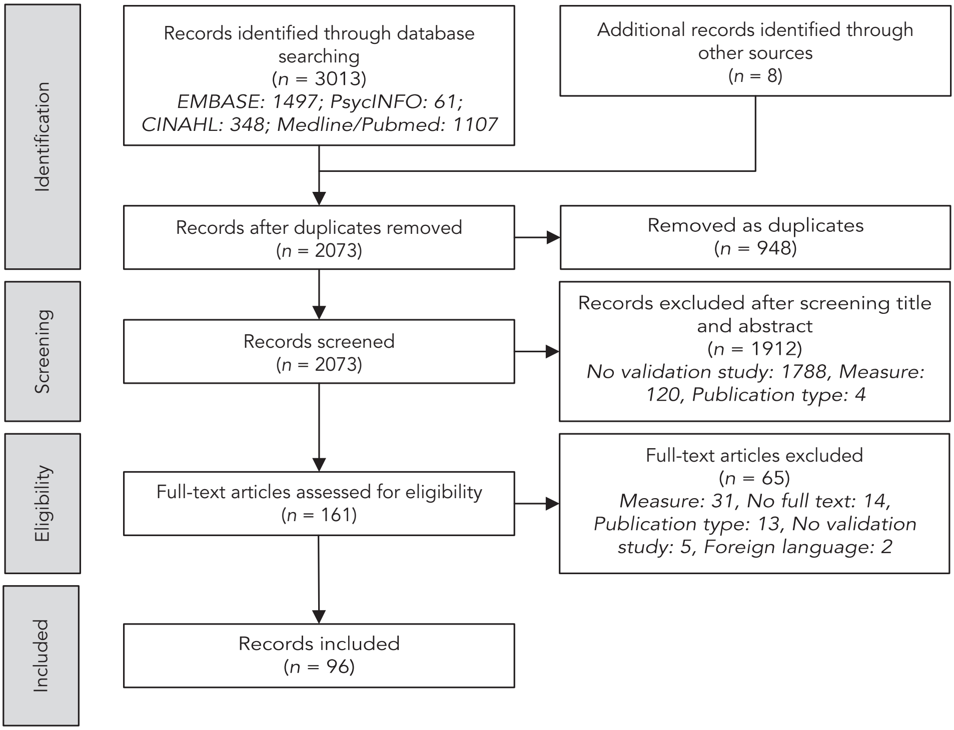

Figure 4.2 Flowchart search and selection process RQ2.

Table 4.1 Measures used to assess negative or positive caregiver impact

			Number of publications in which the measure has been used			
Measure	Author	Year of publication measure	Stroke	Spinal cord injury	Ampu-tation	Total
Strain / distress						
Caregiver Strain Index	Robinson[19]	1983	44[5,31–73]	3[74–76]		47
Modified Caregiver Strain Index (1)	Thornton & Travis[77]	2003	3[78–80]			3
Modified Caregiver Strain Index (2)	Teasdale, Emslie, Quirk, Evans, Fish, & Wilson[81]	2009	1[81]			1
Caregiver Strain Index Expanded	Al-Janabi, Frew, Brouwer, Rappange, & Van Exel[82]	2010	1[83]			1
Relative Stress Scale	Greene, Smith, Gardiner, & Timbury[84]	1982	1[85]	1[86]		2
Caregiving strain question	Schulz, & Beach[87]	1999	1[88]			1
Burden						
Zarit Burden Interview	Zarit, Reever, & Bach-Peterson[89]	1980	30[25,79,90–117]	8[118–125]		38
Zarit Burden Interview Short Form	Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell[126]	2001	1[127]	4[9,11,128,129]		5
Caregiver Burden Scale	Elmståhl, Malmberg, & Annerstedt[130]	1996	18[6,131–147]	2[148,149]		20
Caregiver Burden Inventory	Novak, & Guest[150]	1989	10[151–160]	3[160–162]		13
Oberst Caregiving Burden Scale	Carey, Oberst, McCubbin, & Hughes[23]	1991	8[10,69,163–168]	1[169]		9
Modified Pearlin Burden Scale	Pearlin, Mullan, Semple, & Skaff[170]	1990	3[171–173]			3
Burden Assessment Scale	Reinhard, Gubman, Horwitz, & Mintz[174]	1994	1[175]		1[176]	2
Burden Assessment Schedule Modified	Das, Hazra, Ray, Ghosal, Banerjee, Roy, Chaudhuri, Raut, & Das[177]	2010	2[177,178]			2
Montgomery Caregiver Burden scale	Montgomery, Stull, & Borgatta[179]	1985	1[180]			1
Family Burden Scale	Suh, & Oh[181]	1993	1[182]			1
Burden Scale for Family Caregivers	Nikolaus, Specht-Leible, Bach, Oster, & Schlierf[183]	1994	1[184]			1

Caregiving Burden Scale	Lee, & Wu[185]	1998	1[186]			1
Evaluation Questionnaire on Informal Caregiver's Burden	Martins, Ribeiro, & Garret[187]	2003	1[188]			1
Family Caregiver Burden Tool	Kim, & Roh[189]	2005	1[190]			1
Family Strain Questionnaire - Short Form	Vidotto,Ferrario, Bond, & Zotti[191]	2010		1[162]		1
Self-Rated Burden VAS	Vluggen, Van Haastregt, Verbunt, Keijsers, & Schols[192]	2012	1[192]			1
Caregiver Burnout Scale	Kim, & Kim[193]	2015	1[182]			1
Caregivers quality of life and burden	Menon, Salini, Habeeba, Conjeevaram, & Munisusmitha[194]	2017	1[194]			1
Life changes / reactions						
Bakas Caregiving Outcomes Scale	Bakas, & Champion[195]	1999	1[196]			1
Revised 15-item Bakas Caregiving Outcomes Scale	Bakas, Champion, Perkins, Farran, & Williams[197]	2006	18[10,163–166,168,198–209]			18
Caregiver Reaction Assessment	Given, Given, Stommel, Collins, King, & Franklin[210]	1992	8[12,104,211–216]			8
Caregiving Impact Scale	Cameron, Franche, Cheung, & Stewart[22]	2002	4[217–220]			4[a]
Difficulty / needs						
Family Caregiving Factors Inventory	Shyu[221]	2000	1[104]			1
Caregiver Needs and Concerns Checklist	Bakas, Austin, Okonkwo, Lewis, & Chadwick[222]	2002	1[223]			1
Family Caregiver Conflict Scale	Clark, Shields, Aycock, & Wolf[224]	2003	1[108]			1
Caregiver Needs Questionnaire	Arango-Lasprilla, Plaza, Drew, Romero, Pizarro, Francis, & Kreutzer[118]	2010		1[118]		1
Competence						
Sense of Competence Questionnaire	Vernooi-Dassen[225]	1993	8[226–233]			8
Carer Assessment Scale	Mackenzie, Holroyd, & Lui[234]	1998	2[47,229]			2
Carer's Assessment of Managing Index	Nolan, Grant, & Keady[235]	1998		1[149]	1[176]	2

Table 4.1 continues on next page.

Table 4.1 *Continued*

Measure	Author	Year of publication measure	Number of publications in which the measure has been used			
			Stroke	Spinal cord injury	Ampu-tation	Total
Mishel Uncertainty in Illness Scale for Family Members	Mishel, & Epstein[238]	1997	1[239]			1
Caregiving Competency Scale	Cheng, Chair, & Chau[240]	2017	1[66]			1
Positive aspects / benefits / rewards						
Positive Aspects of Caregiving Questionnaire	Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson[241]	2004	3[151,152,242]			3
Positive Aspects of Caregiving Scale	Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson[243]	1997	1[88]			1
Rewards of Caregiving Scale	Archbold, Stewart, Miller, Harvath, Greenlick, Van Buren, Kirschling, Valanis, Brody, Schook, et al.[244]	1995		1[169]		1
Appraisal / satisfaction						
Appraisal of Caregiving Scale	Oberst[245]	1991	4[164,198,199,246]			4
Caregiving satisfaction Scale	Strawbridge[247]	1991	1[248]			1
Carer's Assessment of Satisfaction Index	Grant, & Nolan[249]	1993	1[250]			1
Caregiver Quality of Life Index	McMillan, & Mahon[251]	1994	1[68]			1
Caregiving Appraisal Scale - Revised	Lawton, Moss, Hoffman, & Perkinson[252]	2000	1[253]			1
Caregiver Reciprocity Scale II	Carruth, Holland, & Larsen[254]	2000	1[215]			1
CarerQol	Brouwer, Van Exel, Van Gorp, & Redekop[255]	2006	1[192]			1
Total			194	26	2	221

[a] Four different publications, but one study, therefore not included in RQ2.

Scale characteristics, feasibility and interpretability

Table 4.2 reports general characteristics of the eighteen measures which were used in at least two different studies found in RQ1 (see online Supplementary Table S4.5 for a detailed version of Table 4.2). Most measures examine negative caregiver impact (e.g., strain or burden) and could be administered as self-report questionnaires. The completion time range from a few to twenty minutes. For most measures, total (sub-scale) scores are calculated by summing item scores, where higher total scores indicate greater impact. The original language of most scales is English.

Study characteristics RQ2

Table 4.3 provides information about the characteristics of the included clinimetric studies. See online Supplementary Table S4.6 for detailed information per publication.[19,77,84,89,126,130,150,174,177,197,210,234,241,256–338] The Zarit Burden Interview[89] and its short form[126] were most often evaluated in clinimetric studies, followed by the Caregiver Reaction Assessment,[210] the Caregiver Strain index[19] and the Caregiver Burden Inventory.[150] No validation studies were found for the Modified Pearlin Burden Scale[170] and the Oberst Caregiving Burden Scale.[23] Sample sizes of the studies ranged from small (*n* = 14) to very large (*n* = 1229). Age of the caregivers differed greatly, most caregivers who reported caregiver impact were female. Measures of caregiver impact were mostly studied in cross-sectional self-report designs. Diseases of patients differed, but stroke and dementia were most common. Information about response rate, missing scores, and floor/ceiling effects was often not reported.

Measure development and content validity

Table 4.4 describes the methodological quality of the development and the content validity of the measures. Publications reporting measure development were not found for three measures (Carer’s Assessment of Managing Index,[235] Modified Pearlin Burden Scale,[170] and Oberst Caregiving Burden Scale[23]). In the found publications, measure development was not described for four measures, content validity not found for eight measures. Based on the ‘worst score counts’ principle of the COSMIN Risk of Bias criteria, all of the measures scored ‘doubtful’ or even ‘inadequate’ on methodological quality of measure development and content validity. The terms ‘doubtful’ and ‘inadequate’ do not mean that the measure is doubtful or inadequate, but that in the interpretation of the findings awareness is required regarding the ‘doubtful’ or ‘inadequate’ way in which the specific property has been investigated.

Table 4.2 Characteristics of the eighteen measures used to assess negative or positive caregiver impact

Measures (year)	Construct impact of caregiving	Original target population	# items	Question example	Response categories	Subscales (# items)	Score (min–max)
Appraisal of Caregiving Scale (1991)[245]	Benefit, benign, threat, caregiving appraisal	Caregivers of patients receiving radiotherapy for cancer	27	This situation does not affect how I feel about myself	5-point-scale (very true to very untrue)	Threat, general stress, benefit (# items per subscale not found)	Mean score per subscale (1–5)
Burden Assessment Scale (1994)[174]	Burden	Family related to individuals with severe mental disorders	19	Would you tell me to what extent you have had any of the following experiences in the past 6 months? Felt trapped by your caregiving role	4-point-scale (not at all to a lot)	Objective (10) and subjective burden (9)	Sum per subscale (10–40 and 9–36) and total score (19–76)
Burden Assessment Schedule Modified (2010)[177]	Burden	Caregivers of persons with stroke	20	Has your workload increased after patient's illness	3-point-scale (not at all to very much)	Financial situation, physical and mental stress, family and social relationships (# items per subscale not found)	No scale scores, interpretation items
Caregiver Burden Inventory (1989)[150]	Burden	Caregivers of patients with Alzheimer	24	My care receiver needs my help to perform many daily tasks	5-point-scale (never to nearly always)	Time-dependence burden (5), developmental burden (5), physical burden (4), social burden (5), emotional burden (5)	Sum per sub-dimension (0–20; physical burden weighted by a factor of 1.25), no total score

Caregiver Burden Scale (1996)[130]	Burden	Caregivers of persons with stroke	22	Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?	4-point-scale (not at all to frequently)	General strain (8), isolation (3), disappointment (5), emotional involvement (3), environment (3)	Average of sub-dimensions, no total score
Caregiver Reaction Assessment (1992)[210]	Experiences with providing care	Caregivers of persons with physical impairments and Alzheimer's disease	24	My activities are centered around care for…	5-point-scale (strongly disagree to strongly agree)	Caregivers' self-esteem (7), lack of family support (5), impact on finances (3), impact on schedule (5), impact on health (4)	Mean subscale scores (1–5), no total score
Caregiver Strain Index (1983)[19]	Strain	Caregivers of patients recently hospitalized for hip surgery or heart problems	13	Feeling completely overwhelmed (e.g., because of worry about … concerns about how you will manage)	Yes/no	N.a.	Sum (0–13)
Modified Caregiver Strain Index (modernization) (2003)[77]	Strain	Long-term family caregivers	13	I feel completely overwhelmed	Yes/on a regular basis/yes, sometimes/ or no	N.a.	Sum (0–26)
Carer Assessment Scale (1998)[234]	Level of difficulty in caring	Caregivers of persons with stroke	14	Indicate the extent to which the following areas cause difficulty in caring for a relative with stroke: Inner conflict caused by responsibilities	4-point-scale (no problem to great problem)	N.a.	Sum (0–42)

Table 4.2 continues on next page.

Table 4.2 *Continued*

Measures (year)	Construct impact of caregiving	Original target population	# items	Question example	Response categories	Subscales (# items)	Score (min–max)
Carer's Assessment of Managing Index (1998)[235]	Carer ratings of helpfulness of management strategies and their own effectiveness	Carers involved in chronic care	38	Please circle the number that best describes your experience: Talking over your problems with someone you trust	4-point-scale (I do not use this, to very helpful)	N.a.	No scale score, profile
Modified Pearlin Burden Scale (1990)[170]	Burden	Caregivers of community-dwelling individuals with Alzheimer's disease	6	Exact formulation not found	5-point-scale (not at all to to a great extent)	N.a.	Sum (6–30)
Oberst Caregiving Burden Scale (1991)[23]	Difficulty associated with caregiving	Caregivers of patients with cancer	15	Exact formulation not found	5-point-scale (not difficult to extremely difficult (first subscale) or none to a great amount (second subscale))	Perceptions of the difficulty (15) and time spent (15) (same items for both subscales)	Sum per subscale (15–75)
Positive Aspects of Caregiving Questionnaire (2004)[241]	Positive aspects of caregiving	Caregivers of patients with Alzheimer's disease	9	Helping your relative … makes you feel more useful	5-point-scale (disagree a lot to agree a lot)	Self-affirmation (6), outlook on life (3)	Sum per subscale (6–30 and 3–15) and total sum (9–45)

Relative Stress Scale (1982)[84]	Stress	Relatives supporting elderly psychogeriatric patients living in the community	15	Do you ever feel you can no longer cope with the situation?	5-point-scale (never/not at all to always/ considerably)	Personal distress (6), life upset (5), negative feelings (4)	Sum per subscale (0–24; 0–20; 0–16) and total sum (0–60)
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	Life changes resulting from providing care	Caregivers of persons with stroke	15	As a result of providing care for the person with stroke: My self-esteem…	7-point-scale (changed for the worst to changed for the best)	N.a.	Sum (15–105)
Sense of Competence Questionnaire (1993)[225]	Feelings of being capable of caring	Caregivers of patients with dementia	27	I feel that I cannot leave my … alone, he/she needs me continuously	5-point-scale (agree to disagree)	Satisfaction with the patient as recipient of care (7), satisfaction with own performance as caregiver (12) and consequences of involvement in care for the personal life (8)	Sum per subscale (7–35, 12–60, 8–40) and total sum (27–135)
Zarit Burden Interview (revised) (1980)[89]	Burden	Caregivers of elderly persons with senile dementia	22	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	5-point-scale (never to nearly always)	N.a.	Sum (0–88)
Zarit Burden Interview Short Form (2001)[126]	Burden	Caregivers of patients with a memory disorder	12	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	5-point-scale (never to nearly always)	Personal strain (9) and role strain (3)	Sum (0–48), no information found about subscale score calculations

Table 4.3 Characteristics of the included clinimetric studies

Measure (year of first publication)	# publications	*N* range	Range mean age	Gender % female, range	Study design	Mode of administration	Disease characteristics	Country
Appraisal of Caregiving Scale (1991)[245]	2	47–484	53.3–56.5	56.8–77.0	Cross-sectional (1); repeated administration (1)	Self-report (2)	Cancer (2)	United States of America (2)
Burden Assessment Scale (1994)[174]	5	94–300	32.0–58.0	68.1–88.0	Cross-sectional (4); cross-sectional and repeated administration (1)	Self-report (4), interview based and self-report (1)	Mental disorder (3); psychiatric, behavioural or emotional disorder (1); schizophrenia (1)	Canada (1); Germany (1); Sweden (1); United States of America (2)
Burden Assessment Schedule Modified (2010)[177]	1	199	42.5	76.0	Cross-sectional (1)	Self-report (1)	Stroke (1)	India (1)
Caregiver Burden Inventory (1989)[150]	7	113–505	56.2–60.1	52.2–87.1	Cross-sectional (5), repeated administration (2)	Interview based (3); self-report (4)	Dementia (2); elderly (1); first-episode psychosis (1); heart failure (1); paediatric acute-onset neuropsychiatric syndrome (1); various diseases (1)	Brazil (1); Canada (1); Italy (2); Spain (1); United States of America (2)
Caregiver Burden Scale (1996)[130]	3	110–161	37.6–83.3	46.3–89.2	Cross-sectional (1); repeated administration (2)	Self-report (3)	Dementia and stroke (1); haemodialysis (1); spinal cord injury (1)	Iran (1); Sweden (1); Turkey (1)

Caregiver Reaction Assessment (1992)[210]	8	21–1190	55.6–63.4	55.5–81.4	Cross-sectional (6); repeated administration (1); both (1)	Interview based (1); self-report (7)	Cancer (2); dementia (1); elderly (1); malignant disease, dementia and physical impairment (1); physical impairments, Alzheimer's disease and cancer (1); stroke (2)	Germany (1); Japan (1); Singapore (1); Sweden (1); The Netherlands (3); United States of America (1)
Caregiver Strain Index (1983)[19]	8	14–148	42.7–61.0	45.5–83.0	Cross-sectional (5); repeated administration (3)	Interview based (3); self-report (5)	Cancer (2); hip surgery and heart failure (1); multiple sclerosis (1); stroke (3); not reported (1)	Malaysia (1); Spain (1); Taiwan (1); The Netherlands (2); Turkey (1); United States of America (2)
Modified Caregiver Strain Index (2003)[77]	2	158–219	54.7–61.0	71.7	Cross-sectional (1); repeated administration (1)	Interview based (1); self-report (1)	Chronic illness (1); patients who took medications (1)	Hong Kong (1); United States of America (1)
Carer Assessment Scale (1998)[234]	1	14	Not reported	Not reported	Cross-sectional (1)	Self-report (1)	Stroke (1)	Hong Kong (1)
Carer's Assessment of Managing Index (1998)[235]	1	295	18–62% ≥ 65	18.0–79.0	Cross-sectional (1)	Self-report (1)	Elderly (1)	Italy, Poland and United Kingdom (1)
Modified Pearlin Burden Scale (1990)[170]	0	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991 [23]	0	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.

Table 4.3 continues on next page.

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Table 4.3 *Continued*

Measure (year of first publication)	# publications	*N* range	Range mean age	Gender % female, range	Study design	Mode of administration	Disease characteristics	Country
Positive Aspects of Caregiving Questionnaire (2004)[241]	3	141–1229	58.3–62.9	76.7–81.4	Cross-sectional (3)	Interview based (1); self-report (1), both (1)	Acquired brain injury (1); dementia (1); dementia and cognitive impairment (1)	Hong Kong (1); Spain (1); United States of America (1)
Relative Stress Scale (1982)[84]	2	38–196	63.8; not reported in 1 study	65.0; not reported in 1 study	Cross-sectional (1); repeated administration (1)	Self-report (2)	Dementia (2)	Scotland (1); Norway (1)
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	2	100–147	51.6–52.9	76.0–78.6	Repeated administration (2)	Interview based (1); interview based and self-report (1)	Cancer (1); stroke (1)	Greece (1); United States of America (1)
Sense of Competence Questionnaire (1993)[225]	5	93–198	60.0–66.0	61.7–77.1	Cross-sectional (4); cross-sectional and repeated administration (1)	Interview based (3); self-report (2)	Dementia (2); stroke (3)	Germany (1); The Netherlands (4)

Zarit Burden Interview (1980)[89]	34	28–523	35.3–80.9	51.1–100.0	Cross-sectional (27); repeated administration (7)	Interview based (10); self-report (20); both (1); unclear (3)	Acquired brain injury (1); amyotrophic lateral sclerosis (1); cancer (1); cancer, cardiovascular disease, neurological disease and orthopedic condition (1) chronic heart failure (1); dementia (14); Duchenne muscular disease (1); elderly (4); neurological disease, orthopedic disease and traumatology (1); obsessive-compulsive disorder (1); Parkinson's disease (2); schizophrenia (3); stroke (1); stroke, chronic obstructive pulmonary disease and general disabilities (1); not specified (1)	Brazil (3); Canada (1); China (3); France (1); Germany and Switzerland (1); Hong Kong (2); Italy (1); Japan (4); Mexico (1); Scotland (1); Singapore (3); South Korea (1); Spain (2); Sub-Saharan Africa(1); Sweden (1); Taiwan (1); Turkey (1); United Kingdom (2); United States of America (3); United Kingdom and United States of America (1)

Table 4.3 continues on next page.

Table 4.3 *Continued*

Measure (year of first publication)	# publications	*N* range	Range mean age	Gender % female, range	Study design	Mode of administration	Disease characteristics	Country
Zarit Burden Interview Short Form (2001)[126]	17	45–770	38.1–69.6	53.8–81.0	Cross-sectional (13); repeated administration (3); secondary analysis pooled data (1)	Interview based (7); self-report (8); unclear (2)	Advanced cancer, dementia, and acquired brain injury (1); cancer (1); cognitive deficits and dementia (1); cognitive or physical impairment (1); cognitively impaired elderly (1); dementia (5); dementia, mild cognitive impairment and subjective memory complaint (1); elderly (1); Parkinson's disease (1); physical frail elderly (1); schizophrenia (1); spinal cord injury (1); terminally ill (1)	Brazil (1); Canada (5); Canada and Israel (1); China (2); Iran (1); Israel (3); Singapore (1); Sweden (1); United Kingdom (2)

Note: N.a.: not applicable.

Table 4.4 Quality of measure development and content validity of the eighteen selected measures

Measure	Design						Cognitive interview study					Content validity					
	General design requirements					Concept elicitation	General design requirements	Comprehensibility	Comprehensiveness	Total CI study		Asking patients			Asking experts		
	Clear construct	Clear origin of construct	Clear target population	Clear context of use	Developed in sample representing the target population		CI study performed in sample representing the target population				Total development	Relevance	Comprehensiveness	Comprehensibility	Relevance	Comprehensiveness	Total content validity
Appraisal of Caregiving Scale (1991)[245]	V	V	V	V	V	D	I	I	I	I	I	–	–	–	–	–	–
Burden Assessment Scale (1994)[174]	–	–	–	–	–	–	D	D	D	D	D	D	D	D	–	–	D
Burden Assessment Schedule Modified (2010)[177]	I	D	V	V	V	I	–	–	–	–	I	–	–	–	D	D	D
Caregiver Burden Inventory (1989)[150]	V	V	V	V	I	–	I	I	–	I	I	D	D	D	–	D	D
Caregiver Burden Scale (1996)[130]	–	–	–	–	–	–	D	D	D	D	D	D	–	D	D	D	D

Table 4.4 continues on next page.

Table 4.4 *Continued*

Measure	Design						Cognitive interview study					Content validity					
	General design requirements					Concept elicitation	General design requirements	Comprehensibility	Comprehensiveness	Total CI study		Asking patients			Asking experts		
	Clear construct	Clear origin of construct	Clear target population	Clear context of use	Developed in sample representing the target population		CI study performed in sample representing the target population				Total development	Relevance	Comprehensiveness	Comprehensibility	Relevance	Comprehensiveness	Total content validity
Caregiver Reaction Assessment (1992)[210]	V	V	V	V	V	D	V	D	D	D	D	–	–	–	D	D	D
Caregiver Strain Index (1983)[19]	V	V	V	V	A	D	V	D	D	D	D	–	–	–	D	D	D
Modified Caregiver Strain Index (2003)[77]	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–
Carer Assessment Scale (1998)[234]	I	D	V	V	I	–	V	D	D	D	I	–	–	–	–	–	–
Carer's Assessment of Managing Index (1998)[235]	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–
Modified Pearlin Burden Scale (1990)[170]	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–

Oberst Caregiving Burden Scale (1991)[23]	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–	–
Positive Aspects of Caregiving Questionnaire (2004)[241]	–	–	–	–	–	–	D	D	D	D	D	–	–	–	D	D	D
Relative Stress Scale (1982)[84]	I	D	V	V	I	–	I	–	–	I	I	–	–	–	–	–	–
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	V	V	V	V	I	–	–	–	–	–	I	–	–	–	–	–	–
Sense of Competence Questionnaire (1993)[225]	V	V	V	V	I	I	–	–	–	–	I	–	–	–	D	D	D
Zarit Burden Interview (1980)[89]	I	D	V	V	I	–	D	D	D	D	I	D	D	D	D	D	D
Zarit Burden Interview Short Form (2001)[126]	–	–	–	–	–	–	D	D	D	D	D	–	–	–	D	D	D

Note: V: very good; A: adequate; D: doubtful; I: inadequate. Total ratings of the quality of each measurement property was determined by taking the lowest rating of any standard ('worst score counts' principle).

Measurement properties

Table 4.5 and 4.6 report summarized measurement properties results for each measure, including an overall rating and an indication of the quality of evidence based on a GRADE rating (see online Supplementary Table S4.7 for the results of separate publications).[19,77,84,89,126,130,150,174,177,197,210,234,241,256–338]

Structural validity

The degree to which scores of a measure are an adequate reflection of the dimensionality of the construct to be measured, i.e., the structural validity,[15–17] was often examined, mostly by factor analysis. However, ratings of structural validity were often lowered due to the absence of indicators of goodness of fit or due to 'inconsistent' findings in different studies. The Caregiver Burden Scale,[130] Positive Aspects of Caregiving Questionnaire[241] and Zarit Burden Interview Short Form[126] showed 'sufficient' structural validity based on high quality. On the other hand, 'insufficient' structural validity was found for the Burden Assessment Scale,[174] Revised 15-item Bakas Caregiving Outcomes Scale[197] and Zarit Burden Interview.[89]

Internal consistency

Relatively much information is available about internal consistency of measures: internal consistency was studied for fourteen of the eighteen measures. Nevertheless, for many measures, the rating of the internal consistency was 'indeterminate' due to the absence of evidence for 'sufficient' structural validity. The COSMIN guidelines state that for 'sufficient' internal consistency, besides Cronbach's alpha(s) of ≥ .70, at least low-quality evidence for 'sufficient' structural validity is needed, or else the rating will be 'indeterminate'.[15–17] Positive Aspects of Caregiving Questionnaire[241] and Relative Stress Scale[84] showed overall 'sufficient' results of high-quality evidence.

Cross-cultural validity

Cross-cultural validity was studied for only three measures. The Caregiver Reaction Assessment[210] showed 'sufficient' cross-cultural validity with high-quality evidence in terms of language (English, Chinese and Malay), group factors (disease and relationship caregiver) and over time. Results for the Zarit Burden Interview[89] were 'indeterminate' due to lack of multiple group factor analysis or differential item functioning analysis. Results suggest cross-cultural validity for the Japanese, Hebrew and German version of the scale, however, the quality of evidence was moderate. The Zarit Burden Interview Short Form[126]

Table 4.5 Summary of measurement properties of the eighteen selected measures

Measurement	Structural validity			Internal consistency			Cross-cultural validity/ measurement invariance			Reliability		
	Summary or pooled result, # factors	Rating	Quality evidence	Summary or pooled result	Rating[a]	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Appraisal of Caregiving Scale (1991)[245]	3	?	M	α = .72–.89	?	H	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Burden Assessment Scale (1994)[174]	2 to 5	?/-	L	α = .64–.94	?	M	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Burden Assessment Schedule Modified (2010)[177]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	ICC = .80–.84 (inter-rater and intra-rater; for every item)	+	L
Caregiver Burden Inventory (1989)[150]	4 or 5	±	M	α = .72–.96	+/?	M				ICC = .87–.94	+	M
Caregiver Burden Scale (1996)[130]	5	+	H	α = .61–.91; excepted environment subscale: α = .53–.63	±	H	N.a.	N.a.	N.a.	Cohen's Kappa = .69–1.00; ICC = .75–.90	+	H

Table 4.5 continues on next page.

Table 4.5 *Continued*

Measurement	Structural validity			Internal consistency			Cross-cultural validity/ measurement invariance			Reliability		
	Summary or pooled result, # factors	Rating	Quality evidence	Summary or pooled result	Rating[a]	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Caregiver Reaction Assessment (1992)[210]	5	?/+/-	M	α = .62–.90	+/?	M	Partial language invariance (Chinese, English, Malay), no important differences between group factors (disease and relationship) and over time	+	H	ICC = .58–.86	±	VL
Caregiver Strain Index (1983)[19]	1, 3 or 4	±	M	α = .66–.91	±	L	N.a.	N.a.	N.a.	ICC = .56–.93	±	L
Modified Caregiver Strain Index (2003)[77]	1	?	M	α = .88– .91	?	H	N.a.	N.a.	N.a.	ICC = .88	+	L
Carer Assessment Scale (1998)	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.

Carer's Assessment of Managing Index (1998)[235]	10	?	M	α = .64–.80 (only reported for the seven subdimensions with the highest α)	?	VL	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Modified Pearlin Burden Scale (1990)[170]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991)[23]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Positive Aspects of Caregiving Questionnaire (2004)[241]	2	+	H	α = .74–.89	+	H	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Relative Stress Scale (1982)[84]	3	?	M	α = .70–.86	+	H	N.a.	N.a.	N.a.	Correlation coefficient = .72–.88	+	L
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	1	-	H	α = .83–.90	?	H	N.a.	N.a.	N.a.	ICC = .66–.99	±	M

Table 4.5 continues on next page.

Table 4.5 *Continued*

Measurement	Structural validity			Internal consistency			Cross-cultural validity/ measurement invariance			Reliability		
	Summary or pooled result, # factors	Rating	Quality evidence	Summary or pooled result	Rating[a]	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Sense of Competence Questionnaire (1993)[225]	3	?	H	α = .50–.89	?/-	M	N.a.	N.a.	N.a.	ICC = .84–.93	+	M
Zarit Burden Interview (1980)[89]	1 to 6	-	L	α = .67–.95 / α = .89	+/?	M	Findings suggest cross-cultural validity	?	M	ICC = .88–1.00; correlation coefficient = .72–.76	+	H
Zarit Burden Interview Short Form (2001)[126]	2 or 3 (10 of the 11studies found 2 factors and were rated + or ?, one study found 3 factors and this study was rated -)	+	H	α = .67–.95 / α = .84	+/?	M	Generally reliable translation from English to Hebrew	+	M	ICC = .78	+	L

Note: N.a.: not applicable; -: ‘insufficient’; +: ‘sufficient’; ±: ‘inconsistent’; ?: ‘indeterminate’; ?/-: ‘inconsistent’ based on ‘indeterminate’ and ‘insufficient’ scores; +/?: ‘inconsistent’ based on ‘sufficient’ and ‘indeterminate’ scores; ?/+/-: ‘inconsistent’ scores based on ‘indeterminate’, ‘sufficient’ and ‘insufficient’ scores; α: Cronbach's alpha; ICC: intra-class correlation coefficient; H: high; M: moderate; L: low; VL: very low.

[a] Internal consistency is rated '+' when there is at least low evidence for ‘sufficient’ structural validity and α ≥ .70 for each unidimensional scale or subscale. Internal consistency is rated '?' if α ≥ .70, but when the criteria for at least low evidence for ‘sufficient’ structural validity have not met. Often rated ‘indeterminate’ due to ‘insufficient’ evidence of structural validity.

Table 4.6 Summary of measurement properties of the eighteen selected measures

Measurement	Measurement error			Criterion validity			Hypotheses testing			Responsiveness		
	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Appraisal of Caregiving Scale (1991)[245]	N.a.	N.a.	N.a.	Correlation gold standard < .7	-	H	7+ and 5-	±	M	N.a.	N.a.	N.a.
Burden Assessment Scale (1994)[174]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	3+	+	H	1+	+	M
Burden Assessment Schedule Modified (2010)[177]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Caregiver Burden Inventory (1989)[150]	N.a.	N.a.	N.a.	AUC = .67–.81	+	High	10+ and 5-	±	M	N.a.	N.a.	N.a.
Caregiver Burden Scale (1996)[130]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	6+ and 1-	+	H	N.a.	N.a.	N.a.
Caregiver Reaction Assessment (1992)[210]	SDD = .8–1.0; SEM = .3 and .5	-	VL	N.a.	N.a.	N.a.	42+ and 7-	+	H	N.a.	N.a.	N.a.

Table 4.6 continues on next page.

Table 4.6 *Continued*

Measurement	Measurement error			Criterion validity			Hypotheses testing			Responsiveness		
	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence	Summary or pooled result	Rating	Quality evidence
Caregiver Strain Index (1983)[19]	SEM = 1.00; SDD = 2.80	?	VL	AUC = .77	+	Moderate	13+ and 5-	±	M	N.a.	N.a.	N.a.
Modified Caregiver Strain Index (2003)[77]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	2+	+	H	N.a.	N.a.	N.a.
Carer Assessment Scale (1998)[234]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Carer's Assessment of Managing Index (1998)[235]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Modified Pearlin Burden Scale (1990)[170]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Oberst Caregiving Burden Scale (1991)[23]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.
Positive Aspects of Caregiving Questionnaire (2004)[241]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	18+ and 5-	+	M	N.a.	N.a.	N.a.

Relative Stress Scale (1982)[84]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	3+ and 1-	±	L	N.a.	N.a.	N.a.
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	N.a.	N.a.	N.a.	AUC = .94; sensitivity = 91%; specificity = 86%	+	H	6+	+	H	N.a.	N.a.	N.a.
Sense of Competence Questionnaire (1993)[225]	N.a.	N.a.	N.a.	N.a.	N.a.	N.a.	16+ and 11-	±	M	N.a.	N.a.	N.a.
Zarit Burden Interview (1980)[89]	N.a.	N.a.	N.a.	AUC = .69; specificity = 59.0–79.0%; sensitivity = 47.0–77.0%	±	M	41+ and 7-	+	H	1+	+	H
Zarit Burden Interview Short Form (2001)[126]	N.a.	N.a.	N.a.	Correlations = .70–.99; specificity = 72.2–94.0%; sensitivity = 49.0–92.0%; AUC = .86–.99	+	H	44+ and 4-	+	H	N.a.	N.a.	N.a.

Note: N.a.: not applicable; -: ‘insufficient’; +: ‘sufficient’; ±: ‘inconsistent’; ?: ‘inteterminate’; SDD: smallest detectable difference; SEM: standard error of measurement; AUC: area under the curve; H: high; M: moderate; L: low; VL: very low.

showed 'sufficient' cross-cultural validity for a Hebrew translation (quality of evidence was rated as moderate).

Reliability

In general, results regarding test-retest reliability demonstrated that most measures were 'sufficiently' reliable. For only two measures, the Caregiver Burden Scale[130] and Zarit Burden Interview,[89] the quality of evidence was rated as high.

Measurement error

The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured, i.e., measurement error,[15–17] was only evaluated in two scales, both with very low-quality evidence.

Criterion validity

Criterion validity, defined as the degree to which the scores of a measure are an adequate reflection of a 'gold standard',[15–17] was only evaluated for six measures. Results were 'sufficient' and with high-quality evidence for the Caregiver Burden Inventory,[150] Revised 15-item Bakas Caregiving Outcome Scale[197] and Zarit Burden Interview Short Form.[126] The Caregiver Strain Index[77] showed 'sufficient' criterion validity of moderate quality. 'Indeterminate' results (moderate quality evidence) were found for the Zarit Burden Interview.[89] The Appraisal of Caregiving Scale[245] showed 'insufficient' criterion validity.

Hypotheses testing for construct validity (convergent, discriminative and known-groups validity)

Hypotheses testing was done in thirteen of the eighteen measures. Overall, hypotheses regarding construct validity were mostly supported. Seven measures revealed 'sufficient' construct validity based on high-quality evidence (Burden Assessment Scale,[174] Caregiver Burden Scale,[130] Caregiver Reaction Assessment,[210] Modified Caregiver Strain Index,[77] Revised 15-item Bakas Caregiving Outcomes Scale,[197] Zarit Burden Interview,[89] Zarit Burden Interview Short Form[126]).

Responsiveness

Few studies on responsiveness of the measures were found. Results of two studies indicated responsiveness in sense of hypotheses testing about scores before and after intervention. Results indicate responsiveness for the Burden Assessment Scale (moderate quality of evidence)[174] and the Zarit Burden Interview (high quality of evidence).[89]

Overall results and recommendations for measure use

In line with the COSMIN guidelines, A-categorized ('sufficient' content validity and at least low quality evidence for 'sufficient' internal consistency) measures should be recommended for use. However, none of the measures were categorized as A, since none of the measures showed 'sufficient' content validity. The Carer Assessment Scale,[234] Modified Pearlin Burden Scale[170] and Oberst Caregiving Burden Scale,[23] were applied in empirical studies for respectively two, three and eight times in the last decade (RQ1), however, no information about measurement properties was found for these scales (RQ2). For the Burden Assessment Schedule Modified,[177] only reliability was evaluated ('sufficient' score, low quality of evidence). Based on the lack of clinimetric information, no statements can be made about the quality of these four scales. The Appraisal of Caregiving Scale[245] and Revised 15-item Bakas Caregiving Outcomes Scale[197] had both one 'insufficient' rating of high-quality evidence, and therefore were categorized as C and were recommended not to use. All other measures were categorized as B, which means that they may have potential, but more research is required. Table 4.7 gives an overview of the number of measurement properties evaluated and rated as 'sufficient', 'inconsistent' or 'insufficient' per measure, including statements of the quality of the evidence. 'Sufficient' ratings based on relatively high-quality evidence and absence of 'insufficient' ratings were found for the Caregiver Burden Scale,[130] Positive Aspects of Caregiving Questionnaire,[241] and Zarit Burden Interview Short Form.[126] The Caregiver Reaction Assessment[210] and the Zarit Burden Interview[89] had also three 'sufficient' ratings of high quality, but also had 'inconsistent' and 'insufficient' ratings based on very low, low or moderate quality evidence. Alternately 'sufficient', 'indeterminate' and sometimes even 'insufficient' (but based on low to moderate quality evidence) results regarding measurement properties were found for the Burden Assessment Scale,[174] Caregiver Burden Inventory,[150] Caregiver Strain Index,[19] Modified Caregiver Strain Index,[77] Carer's Assessment of Managing Index,[235] Relative Stress Scale,[84] and Sense of Competence Questionnaire.[225]

Table 4.7 Summary of ratings of 8 (maximum) psychometric properties[b]

Measure	+[a]	+/-/?[a]	-[a]
Appraisal of Caregiving Scale (1991)[245]	0	3 (moderate–high)	1 (high)
Burden Assessment Scale (1994)[174]	2 (moderate–high)	1 (moderate)	1 (low)
Burden Assessment Schedule Modified (2010)[177]	1 (low)	0	0
Caregiver Burden Inventory (1989)[150]	3 (moderate–high)	2 (moderate)	0
Caregiver Burden Scale (1996)[130]	3 (high)	1 (high)	0
Caregiver Reaction Assessment (1992)[210]	3 (moderate–high)	2 (very low–moderate)	1 (very low)
Caregiver Strain Index (1983)[19]	2 (moderate)	4 (very low–moderate)	0
Modified Caregiver Strain Index (2003)[77]	2 (low–high)	2 (moderate–high)	0
Carer Assessment Scale (1998)[234]	0	0	0
Carer's Assessment of Managing Index (1998)[235]	0	2 (very low–moderate)	0
Modified Pearlin Burden Scale (1990)[170]	0	0	0
Oberst Caregiving Burden Scale (1991)[23]	0	0	0
Positive Aspects of Caregiving Questionnaire (2004)[241]	3 (moderate–high)	0	0
Relative Stress Scale (1982)[84]	2 (low–high)	2 (low–moderate)	0
Revised 15-item Bakas Caregiving Outcomes Scale (2006)[197]	2 (high)	2 (moderate–high)	1 (high)
Sense of Competence Questionnaire (1993)[225]	1 (moderate)	2 (moderate–high)	1 (moderate)
Zarit Burden Interview (1980)[89]	4 (moderate–high)	2 (moderate)	1 (low)
Zarit Burden Interview Short Form (2010)[126]	6 (low–high)	0	0

Note: +: 'sufficient'; +/-/?: 'inconsistent'; -: 'insufficient'.

[a] Between brackets the GRADE level of evidence.

[b] Rated clinimetric properties are: structural validity, internal consistency, cross-cultural validity/measurement invariance, reliability, measurement error, criterion validity, hypotheses testing, responsiveness.

DISCUSSION

This article extends upon earlier reviews of measures used to assess caregiver impact.[2,3,13,14] We provided an overview of measures used in the last decade to evaluate negative and positive caregiving impact among informal caregivers of persons with stroke, spinal cord injury or amputation (RQ1). We found forty-eight different caregiving impact measures, mostly measuring negative impact. Only eighteen measures were used in at least two studies. The Caregiver Strain Index,[19] Zarit Burden Interview[89] and the Caregiver Burden

Scale[130] were used most often. The second aim was to systematically evaluate the clinimetric properties reported in validation studies of the measures which were at least used in two different studies (RQ2). The Caregiver Burden Scale,[130] Positive Aspects of Caregiving Questionnaire[241] and Zarit Burden Interview Short Form[126] showed the most supportive evidence. Overall we found that structural validity, internal consistency and hypotheses testing were often studied, whereas, measure development and content validity were often minimally described, and tests of measurement error and responsiveness were exceptional.

Measure development and content validity

In the last decade significant progress has been made in establishing standards for measure development and testing, which resulted in the development of standards like the COSMIN guidelines.[15–17] We used these guidelines to evaluate psychometric studies mostly executed (long) before the guidelines were established. As a result, most studies did not meet the high standards of the guidelines. In particular, the methodological quality of measure development and content validity were often rated as 'doubtful', maybe mainly due to lacking or incomplete information. COSMIN prescribes to apply a 'worst score counts' principle. This automatically resulted in ratings of 'doubtful' or worse methodological quality. Since measure development cannot be optimized retroactively, it is not possible to improve this characteristic of existing measures. Furthermore, in the COSMIN guidelines content validity is considered as the most important property. For the measures described in the present study this would mean that none of the measures can be recommended for use. However, with the awareness of changing insights over time, we instead recommend to interpret the quality ratings regarding measure development and content validity with caution and also take into account findings regarding other (clinimetric) characteristics of measures.

The need of closing gaps

Our study showed substantial knowledge gaps regarding clinimetric properties of – sometimes extensively – applied measures to assess caregiver impact. For recently developed measures it could be argued that there was less time and opportunity to be carefully tested. However, also for the older measures information on some clinimetric properties is largely lacking. Especially responsiveness and measurement error have rarely been investigated. This is alarming since reliable and responsive measures are needed to successfully monitor caregiver impact and low responsiveness may result in incorrectly assessing interventions as ineffective. Therefore, we want to emphasize the importance to conduct future research, in line with current standards, to be able to close the existing knowledge gaps regarding clinimetric properties.

Development of new measures

In the last two decades many caregiving measures were developed (twenty-three of the forty-eight found measures found in RQ1 were developed in 2000 or later). This would not be a problem in a highly developed field in which new constructs are being investigated and when measures are developed and tested regarding the current standards. However, in accordance with a previous review, our results showed that recently developed measures assess highly similar constructs (e.g., burden) compared to older measures, that many measures were used only once or just a few times, and that many clinimetric shortcomings exist.[2] We recommend researchers who develop and publish new measures to always compare their newly developed measure with more established measures, to show what their new measure adds. Furthermore, with the recent description of clear guidelines, it is now possible to report scale development and to evaluate measurement properties of existing measures in a standardized way. We strongly recommend researchers to use such guidelines. This makes it easier for other researchers and clinicians to objectively assess the quality aspects of a measure. At this moment low-quality evidence often relates to incomplete descriptions, which limits objective evaluation.

Measure selection

Our study provided a clear overview of the currently available knowledge with regard to measure development, content validity and measurement properties of measures used to assess caregiver impact among caregivers of persons with stroke, spinal cord injury or amputation. Since most publications describing measure development or investigation of measurement properties did not meet the current high reporting standards, we cannot clearly recommend a specific measure to evaluate caregiver impact. However, taken this into account, we think that the overview is nevertheless valuable and useful, because it does help to distinguish measures based on a comprehensive quality assessment. For measures evaluating negative caregiver impact, we found most supportive evidence for the Zarit Burden Interview Short Form[126] and the Caregiver Burden Scale.[130] The Positive Aspects of Caregiving Questionnaire[241] revealed to be a relatively good measure to evaluate positive caregiving impact. Hopefully, our overview will help researchers and clinicians in their selection of measures in addition to consideration of other important aspects, e.g., conceptual considerations, practical aspects like feasibility (e.g., completion time, costs, ease of administration), and interpretability (degree to which one can assign qualitative meaning to quantitative scores or change in scores).[15–17,339]

Limitations

In RQ1 we decided to focus on caregiving impact among caregivers of persons with stroke, spinal cord injury and amputation, because these groups comprise the largest part of the adult inpatient rehabilitation population.[1] Therefore, we missed caregivers of persons with progressive disabilities, like Multiple Sclerosis and Amyotrophic Lateral Sclerosis. In RQ2 we did not limit our search to specific diagnostic groups because we wanted all available clinimetric information. In the interpretation of the results, caution is advised when transferring results to specific subgroups. Furthermore, in RQ2 we only searched for clinimetric properties of the measures which were used in at least two empirical studies in the last decade (RQ1). Therefore, recently developed measures were less likely to be selected. In RQ2 we only included publications which primarily focused on clinimetric properties. However, sometimes results of empirical studies, e.g., randomized controlled trials or longitudinal studies, can be used as evidence of certain clinimetric properties. In our search, we missed these publications. However, it was practically not achievable to screen all empirical studies in which one of the selected measures was used for information that could be relevant from a clinimetric point of view. Finally, in our evaluation of measurement properties in RQ2, we did not report results for individual subscales or items. The COSMIN guidelines describe that each subscale of a multi-dimensional measure should be considered separately.[15–17] We chose to report results at measure level because most validation studies also report their findings only on the level of total measures.

Strengths

By conducting this review we obtained a clear overview of the different measures used in the last decade to measure caregiver impact among caregivers of persons with stroke, spinal cord injury or amputation, three main groups in clinical adult rehabilitation. Secondly, we used the COSMIN guidelines[15–17] in order to evaluate clinimetric properties in a comprehensive and systematical way. By using this method, not only the findings itself, but also the quality of evidence underlying the findings are taken into account, which resulted in weighted conclusions about clinimetric properties.

Conclusions

Many measures have been developed and used in empirical research to evaluate caregiver impact among caregivers of persons with stroke, spinal cord injury or amputation. The present study provided a detailed overview of what is known about clinimetric characteristics of eighteen different measures repeatedly used in research. The overview provides clinicians a guidance of appropriate measure selection.

Implications for rehabilitation

- Clinicians should be aware that information about measure development and clinimetric properties for most measures used to assess impact of informal caregiving is incomplete.
- Most supporting evidence was found for the Zarit Burden Interview Short Form, Caregiver Burden Scale and Positive Aspects of Caregiving Questionnaire.
- This overview of clinimetric properties provides clinicians guidance for selection of an appropriate measure.

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Disclosure statement

The authors report no conflicts of interest.

Ethical approval

We certify that we followed all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research.

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PART II

Factors to predict psychosocial adjustment outcomes

CHAPTER 5

Appraisals and coping mediate the relationship between resilience and distress among significant others of persons with spinal cord injury or acquired brain injury: A cross-sectional study

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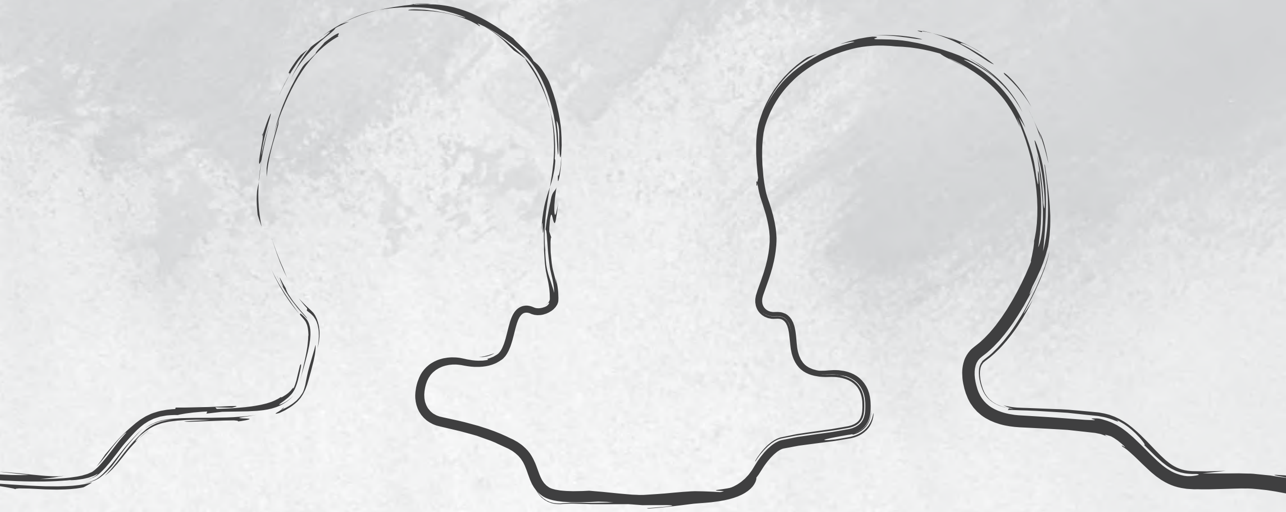

Abstract

Background: Many significant others of persons with serious conditions like spinal cord injury (SCI) and acquired brain injury (ABI) report high levels of psychological distress. In line with the stress-coping model, the aim of the present study was to investigate the relationship between personal resource resilience and psychological distress, and whether appraisals of threat and loss, and passive coping mediate this relationship.

Methods: Significant others (*n* = 228) of persons with SCI or ABI completed questionnaires shortly after admission to first inpatient rehabilitation after onset of the condition. The questionnaire included measures to assess psychological distress (Hospital Anxiety and Depression Scale), resilience (Connor-Davidson Resilience Scale-10), appraisals (Appraisals of Life Events scale, threat and loss) and passive coping (Utrecht Coping List). The PROCESS tool was used to test the presence of mediation. Confounding and differences between SCI and ABI were investigated.

Results: High levels of psychological distress among significant others were found (34–41%). Fifty-five percent of the variance in psychological distress was explained by the relationship between resilience and psychological distress. This relationship was mediated by appraisals of threat and loss, and passive coping. The relationship between resilience and psychological distress was similar in the SCI and ABI groups.

Conclusions: The results of our study indicate that appraisals of threat and loss and passive coping are mediating factors in the relationship between resilience and psychological distress. It seems useful to investigate if interventions focussing on psychological factors like resilience, appraisal and coping are effective to prevent or reduce psychological distress among significant others of persons with SCI or ABI.

Trial registration: Dutch trial register NTR5742. Registered January 9, 2016.

BACKGROUND

Spinal cord injury (SCI) and acquired brain injury (ABI) are two major causes of chronic disability worldwide.[1] Both conditions often have long-term effects that impact the lives of the persons themselves, but also that of the persons close to them, their significant others.[2–4] Although the new situation may have some positive aspects for significant others (e.g., self-esteem derived from caregiving),[5] they often report high levels of psychological distress in terms of anxiety and depression, and these levels of psychological distress remain high on the long term.[6,7] To be able to support significant others with substantiated interventions to treat psychological distress, it is important to understand the mechanism underlying caregiving-related psychological distress. There is a very long history of stress-response theory which has resulted in numerous theoretical models explaining well-being outcomes.[8,9] The stress-coping model, originally proposed by Lazarus and Folkman, is a widely recognized theoretical model often used to explain psychological distress and has been primarily used to explain emotional well-being among persons with SCI.[10,11]

Stress-coping model

According to the model, in situations of stress, a person's health-related quality of life (e.g., emotional well-being) is the outcome of the interplay between several factors. The trigger in this interplay is the stressful situation. How the stressful situation is evaluated depends on the person's own personal resources, health-related factors and the social and physical context. The cognitive process of evaluation is called appraisal. Coping refers to how persons tend to react, based on this appraisal, to solve personal and interpersonal problems in order to try to master, minimize or tolerate stress and conflict.[10] How the person copes with the stressful situation affects the adjustment outcomes.

The stress-coping model to explain psychological distress among significant others

Being a significant other of a person with SCI or ABI can be considered as a stressful situation.[4] This suggests the possible applicability of the stress-coping model in the explanation of adjustment outcomes among significant others. The application of the model can provide theoretical based insight which is important to be able to substantiate the support for significant others. However, there is still little evidence which support the applicability of the model on significant others of persons with SCI or ABI. Some evidence is found in research conducted in other diagnosis groups. Among caregivers of patients with prostate cancer was found that personal resources (including self-efficacy) were longitudinally associated with quality of life, and that this relationship was partly mediated by negative appraisals and avoidant coping.[12] Among caregivers of individuals with traumatic brain injury some support for the stress-coping model was found in a study using regression analysis to predict quality of life, which had demonstrated that appraisal was a strong predictor.[13] However, in this study the association between coping and quality of life disappeared after controlling for other variables, and the mediating effect of appraisal and coping in the explanation of quality of life was not tested.

Indications for the applicability of the stress-coping model to explain psychological distress among significant others are predominantly found in bivariate relationships between separate elements of the model. First, resilience – which reflects one's ability to thrive in the face of adversity – seems to be an important expression of personal resource.[14,15] Previous research among significant others of persons with SCI or cancer showed that resilience is a strong predictor of psychological distress.[16–18] Furthermore, negative appraisals and passive coping strategies were found to be correlated with higher levels of psychological distress among significant others with stroke.[19–21] If appraisals and coping mediate the relationship between resilience and psychological distress, as can be expected based on the stress-coping model, is still unclear.

Present study

Based on the stress-coping model, the objective of this study is to test if psychological distress – as indicator of emotional well-being outcomes – among significant others can be explained by the personal resource resilience, and if this relation is serially mediated by appraisals and coping. This study targeted significant others of persons with SCI or ABI in the subacute phase during first inpatient rehabilitation. We focus on SCI and ABI because these are two major causes of chronic disability which differ in presence and consequences.[1] Therefore, we will also investigate the relationships in both subgroups separately.

METHODS

Design

We used baseline data of the cohort part of the POWER-study.[22] The aim of this cohort study is to identify predictors at admission to inpatient rehabilitation of long-term empowerment problems among persons with SCI or ABI and their significant others. Recruitment took place between April 2016 and July 2018. The Medical Ethics Committee of the University Medical Center Utrecht declared that this study did not need approval according to the

Dutch Law on Medical Research (protocol number 15-617/C). Permission to execute the study was granted by the boards of all twelve participating Dutch rehabilitation centers. We certify that we followed all applicable institutional and governmental regulations concerning the ethical use of human volunteers during the course of this research.

Participants

In the POWER-study couples of persons with SCI or ABI and their significant others were included.[22] Inclusion criteria for the person with SCI of ABI were: first inpatient rehabilitation after onset of injury and expected stay in the rehabilitation center for at least four weeks. Because POWER was designed to investigate the long-term impact of chronic injuries, persons with SCI or ABI were excluded when (nearly) full recovery was expected, no return to home was expected, or if they had a limited life expectancy. Persons with severe cognitive or intellectual problems were excluded due to their inability to complete the questionnaires. Cognitive or intellectual problems were defined as restrictions in the expression and/or understanding of language and were assessed by nurses based on their clinical view and the Dutch aphasia scale.[23] Persons with SCI or ABI named their significant other, usually their partner, but it could also be a child, parent, sibling, other family member, or friend. Persons were excluded if they could not name a significant other or if this significant other declined participation. All participants had to be ≥ eighteen years of age. The present study focused exclusively on significant others.

Procedure

Shortly after admission of the person with SCI or ABI to one of the participating rehabilitation centers and after signing informed consent, significant others were asked to complete a self-report questionnaire (print or electronically). Diagnosis-specific information of the person with SCI or ABI was extracted from the patient’s file.

Measures

Dependent variable

Psychological distress was measured with the Hospital Anxiety and Depression Scale (HADS),[24,25] which is considered an effective measure of general psychological distress.[26] The HADS consists of fourteen items reflecting symptoms of anxiety and depression by seven items each. Every item is scored on a four-point scale, ranging 0 (‘no symptoms’) to 3 (‘maximum impairment’). A total sum score was calculated (range 0–42), where higher scores indicate higher psychological distress. Cut-off scores for the HADS focus on sum scores of anxiety and depression subscales separately (range 0–21), where scores of ≥ 8 indicate high anxiety or depressive symptoms.[27] The HADS has shown good psychometric properties in different populations.[25] Cronbach's alpha of the total scale was .91 in the current study.

Independent variable

Resilience was measured with the ten-item version of the Connor-Davidson Resilience Scale (CD-RISC-10).[14,28] Participants rated ten statements on a five-point scale ranging 0 ('not true at all') to 4 ('true nearly all the time'). Total scores range between 0 and 40, where higher scores indicate higher resilience capacity. The CD-RISC-10 has shown good internal consistency and construct validity.[28] In the current study, we found a Cronbach's alpha of .92.

Mediators

Appraisal is the first potential mediator. Three common appraisal patterns have been identified in response to stressful situations: appraisals of threat (potential for harm), loss (potential for disintegration of friendships, health, or self-esteem), and challenge (potential for growth, gain, and mastery).[29] Previous research showed that in particular negative appraisals predict greater negative outcomes, e.g., anxiety.[20] Based on that, in the design of the study we have decided only to assess appraisals of threat and loss, and not appraisals of challenge. In addition, we found it undesirable to confront significant others of persons recently confronted with SCI or ABI with questions such as: 'I find my current circumstances enjoyable'. So, we decided to focus on appraisals of threat and loss. Appraisals were measured with the threat (six items) and loss (four items) subscales of the Appraisals of Life Events (ALE) scale.[29] Participants rated the extent to which different adjectives describe their perceptions of their current life circumstances (0 = 'not at all' to 5 = 'very much so'). Subscale scores were computed as the mean item scores in that subscale. For this study a total score was computed as the mean of the two subscale scores (range 0–5) so that both subscales contributed equally to the total score. Higher scores indicate higher appraisals of threat and loss. The complete ALE has shown good psychometric properties.[29] Cronbach's alpha was .93 in the current study.

Coping is the second potential mediator. Previous research has shown that a passive coping strategy was most strongly associated with negative psychological outcomes.[12,19] Therefore, we decided to focus on passive coping which was operationalized as the tendency of being completely absorbed by and unable to deal with a stressful situation, retreating into oneself, and worrying about the past.[30] Passive coping was measured with the passive reaction pattern subscale of the Utrecht Coping List (UCL).[30,31] This subscale consists of seven items, scored on a four-point scale ranging from 1 ('rarely true') to 4 ('true nearly all the time'). The total sum score ranged from 7 to 28, where higher scores indicated a greater tendency to adopt a passive coping style. The UCL has shown good reliability and validity.[32] Cronbach's alpha was .75 in the current study.

Potential confounders

Demographic information included: sex (male = 0, female = 1), age (years), nationality (Dutch = 0, non-Dutch = 1), higher education (i.e., finished bachelor degree or higher) (no = 0, yes = 1), and relationship with the person with SCI or ABI (0 = no partner (e.g., child, parent, sibling or friend), 1 = partner). Health-related factors included diagnosis (SCI = 0, ABI = 1) and cause of injury (0 = traumatic, 1 = non-traumatic). For SCI, the American Spinal Injury Association (ASIA) Impairment Scale (AIS) score was determined by a trained rehabilitation physician.[33] The AIS provides information about sensory/motor completeness of the SCI. Furthermore, the level of injury (paraplegia (0) or tetraplegia (1)) was assessed, where paraplegia was defined as a lesion at or below the first thoracic segment, tetraplegia as a lesion at or above the first thoracic segment.[34] For ABI, location of injury was specified in left hemisphere, right hemisphere, both hemispheres, or brainstem. Physical independence for both diagnosis groups was measured with the physical independence subscale of the Utrecht Scale for Evaluation of Rehabilitation (USER).[35] This subscale consists of fourteen items on independence in mobility and self-care which are scored on a six-point scale (range 0–5) by an involved professional. The total score ranged from 0 to 70. A higher score represents better physical independence.[36] The USER is a valid and responsive scale.[36] Total USER scores were extracted from patients' files. We did not have the USER data at item level, therefore we were not able to calculate the Cronbach's alpha based on our own data. In a former Dutch study, Cronbach's alphas showed satisfactory internal consistency (.89–.90).[35]

Statistical analyses

We used descriptive statistics to describe the study population and outcome variables. Differences between SCI and ABI groups were tested with independent samples *t*-tests and Pearson's *r* correlations were computed to assess the relationships between the dependent, independent, (possible) mediating variables and the potential confounders. The stress-coping model assumes serial mediation. However, it is difficult to test serial mediation with standard linear regression. Therefore, as an application of regression, we used the PROCESS tool which provides a serial multiple mediation model that can be used to investigate the direct relationship between a predictor (resilience) and outcome (psychological distress) as well as indirect relationships via one or more mediators (appraisals of threat and loss, and passive coping).[37] Unstandardized regression coefficients were calculated for each path in the mediation model, displayed in Figure 5.1. The total effect of resilience on psychological distress without mediating variables is represented in *c*, and *c'* represents the direct effect of resilience on psychological distress while partialling out the effects of both mediators (appraisals of threat and loss, and passive coping). The indirect effect of resilience on psychological distress is calculated as the sum of the effects of different pathways including mediators: effect of resilience on psychological distress via appraisals only, via coping only, and via appraisals and coping. The effects are calculated by multiplying the coefficients of the pathways, so, the pathway via appraisals only is calculated by multiplying a^1 and b^1. Of the indirect effects, the bias-corrected 95% confidence intervals were based on 10,000 bootstrapped resamples.[37,38] When zero is not included in a bias-corrected 95% confidence interval, it can be concluded that in 95% of the bootstrapped samples the effect is significant.

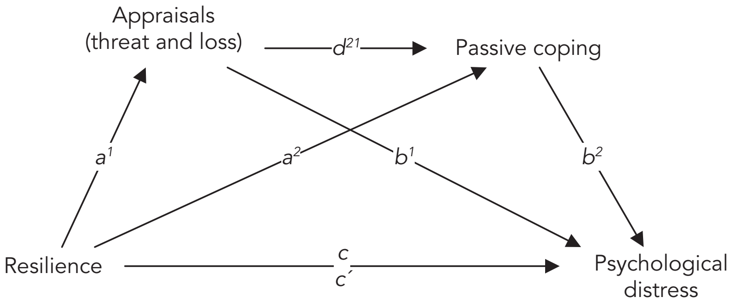

Figure 5.1 Serial multiple mediation model.
Adapted from Hayes AF. Multiple mediator models. In: Hayes AF, editor. Introduction to mediation, moderation, and conditional process analysis: A regression-based approach. New York, USA: Guilford Publications; 2013. p. 446.

Possible confounders, namely demographic (sex, age, nationality, education, and relationship with the person with SCI or ABI) and health-related factors (diagnosis and physical indepencence) were added as covariates in de mediation model if they were significantly correlated with the main outcome variable psychological distress and the predictor (resilience) or mediator(s) (appraisals of threat and loss and/or passive coping). Afterwards, the serial multiple mediation model was tested separately for the SCI and ABI groups to explore the differences between these groups.

We analysed the data with IBM SPSS Statistics 25. The internal consistencies of the used scales were assessed by calculating the Cronbach's alphas. Although the alpha of the UCL was somewhat lower than the alphas of the other scales, all scales had a value of ≥ .7 and, therefore, were interpreted as satisfactory.[39] A significance level of $p < .05$ (two-tailed) was used. We used Cohen's standards to interpret the correlations ($r = .10$, weak; $r = .30$, moderate; and $r = .50$, strong).[40] Individuals with missing scale scores were excluded from further analyses. We have checked the regular assumptions for multiple regression analysis: normality of the error terms (normal probability plot), linearity and homoscedasticity (plot of the residuals versus the predicted values of the dependent variable), independence of the error terms (Durbin Watson statistic) and collinearity (values of the variance inflation factors).[41,42] We found no indications of violation of one of the assumptions.

RESULTS

Sample characteristics

Data of 237 significant others were available, of which nine were excluded because of missing scores on the HADS (four cases), CD-RISC-10 (three cases) or ALE (two cases), resulting in a sample of 228 caregivers. The median number of weeks between onset of injury and completing the questionnaire was five weeks and did not differ between diagnoses. Table 5.1 displays characteristics of the significant others and persons with SCI or ABI. The most common traumatic cause of SCI was a fall (17.2% of all persons with SCI), and the most common non-traumatic cause was spinal degeneration (18.9%). The large majority of ABI were of non-traumatic origin, and in about half of all persons with ABI, the cause was a cerebral infarction (54.3%). Most significant others were partner (72.4%), others were child (13.2%), parent (8.8%), other family member (3.1%), friend (2.2%) or neighbor (0.4%).

Psychological distress

Mean variable scores, standard deviations, and independent samples *t*-tests between SCI and ABI groups are shown in Table 5.2. For the anxiety and depression subscales of the HADS respectively, 40.8% and 33.8% of the total group of significant others had a score of ≥ 8, indicating high anxiety or depressive symptoms (in the SCI group respectively 45.9% and 39.3%; in the ABI group 34.9% and 27.4%). Significant others of persons with ABI showed to be more resilient and had fewer appraisals of threat and loss compared with significant others of persons with SCI.

Table 5.1 Characteristics of significant others and injury information

	Total (*n* = 228)		SCI (*n* = 122)		ABI (*n* = 106)	
Significant others	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range
Sex (female)	228	149 (65.4)	122	92 (75.4)*	106	57 (53.8)*
Age in years	224	54.1 (12.8), 23–82	120	54.4 (13.7), 25–82	104	53.9 (11.8), 23–75
Nationality (non-Dutch)	226	17 (7.5)	121	9 (7.4)	105	8 (7.5)
Education level (high)	223	86 (38.6)	118	41 (34.7)	105	45 (42.9)
Relationship with person with SCI/ABI (partner)	228	165 (72.4)	122	86 (70.5)	106	79 (74.5)
Injury information	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range
Physical independence	218	34.6 (18.8), 0–70	120	27.7 (17.4), 0–70*	98	43.0 (17.0), 5–70*
Cause (non-traumatic)	227	154 (67.8)	122	65 (53.3)*	105	89 (84.8)*
AIS[a] (SCI only)	–	–	121		–	–
A	–	–	–	15 (12.4)	–	–
B	–	–	–	18 (14.9)	–	–
C	–	–	–	23 (19.0)	–	–
D	–	–	–	65 (53.7)	–	–
Level	–	–	122		–	–
Paraplegia	–	–	–	59 (48.4)	–	–
Tetraplegia	–	–	–	63 (51.6)	–	–
Location injury	–	–	–	–	99	–
Left	–	–	–	–	–	41 (41.4)
Right	–	–	–	–	–	35 (35.3)
Both sides	–	–	–	–	–	18 (18.2)
Brainstem	–	–	–	–	–	5 (5.1)

Note. SCI: spinal cord injury; ABI: acquired brain injury; SD: standard deviation; *n*: number of participants.
* Independent samples *t*-test showed a difference in sex ($t(209.0) = 3.5$, $p < .01$), physical independence ($t(209.2) = -6.5$, $p < .001$) and cause of injury ($t(215.5) = 5.3$, $p < .001$) between SCI and ABI. [a] AIS: American Spinal Injury Association Impairment Scale. A: complete; B: sensory incomplete; C: motor incomplete with less than half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3; D: motor incomplete with at least half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3.[33]

Table 5.2 Means, standard deviations and independent samples *t*-tests between SCI and ABI groups (*n* = 228)

	Total (*n* = 228)		SCI (*n* = 122)		ABI (*n* = 106)		Independent samples *t*-test[a]		
Variable (range of scores)	M	SD	M	SD	M	SD	*t*	*df*	*p*
1. Resilience (0–40)	28.3	5.9	27.5	6.0	29.1	5.8	-2.02	226	< .05
2. Appraisals (threat and loss) (0–5)	1.3	1.1	1.6	1.2	1.0	1.0	4.01	225.6	< .001
3. Passive coping (7–28)	10.5	2.8	10.8	2.9	10.2	2.6	1.61	226	.11
4. Psychological distress (0–42)	13.1	7.8	14.0	7.6	12.0	7.8	1.95	226	.05

Note. SCI: spinal cord injury; ABI: acquired brain injury; M: mean; SD: standard deviation; *n*: number of participants; *t*: *t*-value; *df*: degrees of freedom; *p*: *p*-value.

[a] Independent samples *t*-test to test differences in scale scores between SCI and ABI.

Correlations and mediation model

Correlations between resilience, appraisals of threat and loss, passive coping, and psychological distress were all moderate to strong (.40–.67), and in the expected direction based on the stress-coping theory (see Table 5.3). None of the potential confounders was significantly related with the dependent variable psychological distress and the predictor (resilience) or one of the mediators, and therefore no covariates were added in the serial multiple mediation model.

Table 5.3 Pearson's *r* correlation coefficients of the study variables (*n* = 228)

Variable	1.	2.	3.	4.
1. Resilience	–	–	–	–
2. Appraisals (threat and loss)	-.40***	–	–	–
3. Passive coping	-.44***	.54***	–	–
4. Psychological distress	-.42***	.67***	.61***	–
5. Sex (female)	-.06	.05	.05	.02
6. Age	-.01	.01	-.19**	.03
7. Nationality (non-Dutch)	.09	-.07	-.02	-.04
8. Education (high)	.14*	-.08	-.05	-.11
9. Relationship with person with SCI/ABI (partner)	.09	.07	-.09	.09
10. Diagnosis (ABI)	.13*	-.23***	-.11	-.13
11. Physical independence (person with SCI/ABI)	.04	-.12	.04	-.04

Note. SCI: spinal cord injury; ABI: acquired brain injury; *n*: number of participants.
* *p* < .05; ** *p* < .01; *** *p* < .001.

Table 5.4 Regression coefficients, standard errors, and model summary information for the presumed serial multiple mediator model ($n = 228$)

		Appraisals of threat and loss				Passive coping				Psychological distress		
		Coeff.	SE	p		Coeff.	SE	p		Coeff.	SE	p
Resilience	a^1	-.08	.01	< .001	a^2	-.13	.03	< .001	c'	-.12	.07	.07
Appraisals of threat and loss		–	–	–	d^{21}	1.04	.21	< .001	b^1	3.17	.38	< .001
Passive coping		–	–	–		–	–	–	b^2	.88	.19	< .001
Constant	i_{M1}	3.49	.36	< .001	i_{M2}	12.70	.89	< .001	i_Y	3.20	2.99	.29
		$R^2 = .16$ $F(2,226) = 43.29$, $p < .001$				$R^2 = .35$ $F(2,225) = 50.71$, $p < .001$				$R^2 = .55$ $F(3,224) = 86.62$, $p < .001$		

Note. Coeff.: unstandardized regression coefficient; SE: standard error; p: p-value; n: number of participants.

Table 5.4 and Figure 5.2 show the results of the mediation analysis. The complete model explained 55% of the variance in psychological distress. Without the mediators, the regression coefficient between resilience and psychological distress was -.55 (p < .001) (Figure 5.2 and Table 5.5). After adding the mediators to the model, this coefficient decreased and was no longer statistically significant (c' = -.12, p > .05). The original relationship between resilience and psychological distress was explained by indirect pathways, mostly by the indirect relationship via appraisals of threat and loss only ($a^1 * b^1 = -.24$), followed by the indirect relationship via passive coping only ($a^2 * b^2 = -.11$), and the indirect relationship via appraisals of threat and loss, and passive coping ($a^1 * d^{21} * b^2 = -.07$).

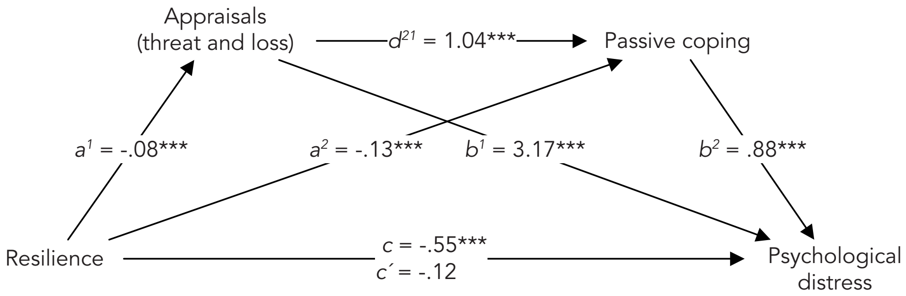

Figure 5.2 Serial multiple mediation model (with coefficients).

Table 5.5 Total, direct and indirect effects of resilience on psychological distress (n = 228)

		Effect[a]	SE	95% CI
Total effect	c	-.55	.08	-.70–-.40
Direct effect	c'	-.12	.07	-.26–.01
Indirect effect				
Via appraisals only	$a^1 * b^1$	-.24	.05	-.34–-.16
Via coping only	$a^2 * b^2$	-.11	.03	-.18–-.06
Via appraisals and coping	$a^1 * d^{21} * b^2$	-.07	.02	-.12–-.03

Note. Indirect effect standard errors (SE) and confidence intervals are based on 10,000 bootstrap samples; CI: confidence interval; n: number of participants.
[a] Unstandardized regression coefficients.

Differences between subgroups (SCI and ABI)

The mediation analyses were repeated for significant others of persons with SCI versus ABI separately. All coefficients were in the same direction and absolute values were largely similar. The model of significant others of persons with SCI explained 60% of the variance in psychological distress ($F(3,118) = 65.09$, $p < .001$) and the direct relationship between resilience and psychological distress remained statistically significant after adding the mediators in the model ($c = -0.54$, $p < .001$; $c' = -.16$, $p < .05$). In the ABI group, the model explained 47% of the variance in psychological distress ($F(3,102) = 21.15$, $p < .001$). In this group, the direct relationship between resilience and psychological distress was completely explained by indirect relationships ($c = -.53$, $p < .001$; $c' = -.08$, $p > .05$).

DISCUSSION

The purpose of this study was to test if psychological distress among significant others of persons with SCI or ABI in the subacute phase during first inpatient rehabilitation can be explained by the personal resource resilience, and if this relation is serially mediated by appraisals and coping. It was found that fifty-five percent of the variance in psychological distress was explained by its relationship with resilience. Furthermore, results of the serial mediation model indicate that significant others with high resilience show less psychological distress because they make less negative appraisals (threat and loss) and use less passive coping compared to significant others with low resilience. The relationship between resilience and psychological distress, and the mediation via appraisals coping, showed a similar pattern in both diagnosis groups (SCI and ABI).

Psychological distress

The mean psychological distress score in our sample (13.1, SD = 7.8) was considerably higher than the mean score found in the general Dutch population (8.4, SD = 6.3; persons aged eighteen to sixty-five),[25] indicating that significant others of persons with SCI or ABI on average experience higher levels of psychological distress than persons in the general Dutch population. Respectively 40.8% and 33.8% of the significant others reported high symptoms of anxiety or depression (45.9% and 39.3% in the SCI group; 34.9% and 27.4% in the ABI group). A literature review focusing on caregivers of persons with stroke showed that 21.4% had anxiety symptoms and 40.2% depressive symptoms.[7] In our study, symptoms of anxiety were more common than symptoms of depression, while in the review the opposite was found. Probably this difference could be explained by differences in the time of assessment. There are indications that, in contrast to levels of depression, levels of anxiety are higher in the subacute phase and decline over time.[21] This may explain the higher percentages of significant others reporting symptoms of anxiety in the current study (in the subacute phase) and the lower percentages found in the review (mostly in the chronic phase).[7]

Mediation model

This is the first study focusing on psychological determinants of psychological distress among significant others of persons with SCI or ABI using a serial multiple mediation model. First of all, correlations between resilience, appraisals of threat and loss, passive coping, and psychological distress were all moderate to strong and in the expected direction based on the stress-coping theory,[10] and previous research findings among significant others.[16–18,21,30] Furthermore, we found support for the mediating effect of appraisals of threat and loss, and passive coping in the explanation of psychological distress among significant others, as was previously found among caregivers of patients with cancer, and which is in line with results found among persons with SCI.[11,12] This seems to support the idea that the adaptation process of significant others of persons with SCI or ABI is essentially the same as that of significant others in other diagnosis groups and patients. This suggest the general applicability of the stress-coping modal as a behavioral model.

Based on the stress-coping model, health-related factors of patients could be considered as a (extra) stress factor.[10] Therefore, it seems noteworthy that in our study the level of physical independence of the person with SCI or ABI was not found to be related with psychological distress, resilience, appraisals and coping. However, also in previous studies no strong relationships were found between physical independence of the patient and anxiety, depression or mental health of caregivers.[21,43] This could indicate that the objective severity of disabilities is subordinate to the subjective experience of the situation.[43]

In the ABI group, the direct relationship between resilience and psychological distress disappeared after adding the indirect relationships via appraisals of threat and loss, and passive coping in the model, while this direct relationship remained significant after adding the mediators in the model in the SCI group. However, also in the SCI subgroup the main part of the relationship between resilience and psychological distress was explained by mediation. The regression coefficients in both subgroups were all in the same direction and differences in absolute values between the models in the ABI and SCI groups were small. So, overall, we conclude that the mediation model is similar in both subgroups. Because this is the first study in which the applicability of the theoretical stress-coping model is tested among significant others of persons in different diagnosis groups, we were not able to compare our results with previous results.

Implications

To be able to support significant others to handle psychological distress early after onset of injury, it is important to understand the underlying mechanism. The present study indicates that resilience, appraisals of threat and loss, and passive coping are psychological factors that should be taken into account. Based on these findings it seems useful to examine the changeability of resilience, appraisals and coping and to investigate the effectiveness of interventions focusing on these psychological factors. In the prevention or reduction of psychological distress, interventions could aim to increase resilience, to reduce negative appraisals and to deploy less passive coping strategies in problematic situations. Programs for counseling family members that have been developed and are being applied in recent years for carers in other diagnosis groups, mainly consist of psychoeducation, using techniques focusing on problem-solving, self-management, coping with the new situation and stress reduction.[44] Such interventions seem to fit well with our findings. Among carers of persons with dementia evidence was found that psychoeducational programs based on the Cognitive Behavioral Theory or Acceptance and Commitment Therapy seemed beneficial for treating psychological distress.[45] However, more controlled studies on the application of these programs during the transitions from hospital or rehabilitation center to home are needed before clear recommendations to healthcare professionals can be made regarding optimal time, format, dosage, and characteristics of the target population of programs to support caregivers of persons with SCI and ABI.[44]

Strengths and limitations

Unique to the present study is that we measured outcomes among a large group of significant others shortly after admittance of the person with SCI or ABI to first inpatient rehabilitation in one of the twelve participating rehabilitation centers spread across the Netherlands. Furthermore, testing a serial multiple mediation model based on the stress-coping model of Lazarus and Folkman[10] in a sample of significant others of persons with SCI or ABI is new. Our study has some limitations. First, this study concerned a selective group of significant others of persons with SCI or ABI who were admitted to rehabilitation facilities. Significant others of persons who were discharged home or to a nursing home after their stay in the hospital were not included. Second, results should be interpreted cautiously given the cross-sectional design of the study which makes it impossible to make any statements about causality or seriality. Our interpretations of the findings are based on the theoretical assumptions of the stress-coping model. A longitudinal study is needed to confirm our findings over time. Third, there are several personal resource factors that could be relevant. However, only one independent variable could be added in the mediation model. We have chosen to include resilience because previous research had demonstrated that resilience is a strong predictor of psychological distress.[16–18] We realize that we are not yet aware of the possible role of other factors such as self-efficacy.[21] Fourth, besides demographic variables, we only included physical independence and diagnosis of the person with SCI or ABI as potential confounders. For instance, we did not include cognition in the analyses, because we only got information about cognition for the group of persons with ABI (not for SCI). However, especially in the ABI group, cognition may be a stress factor, that may be more of a burden for the significant other over time. We decided not to include cognition in the ABI model, in order to keep the models for SCI and ABI comparable. Fifth, we did not include health-related factors of the significant others and factors representing their social and physical context in our model, while health-related factors and social and physical context are part of the stress-coping model of Lazarus and Folkman.[10] Previous research showed that, for instance, social support relates with resilience,[46] appraisals,[47] coping,[48] and psychological distress.[21,49] So in further investigation of the theoretical model, it is recommended to take these factors into account. Last, we have used the stress-coping model as theoretical framework in the explanation of psychological distress. There may also be other factors of interest in the explanation of distress that do not feature in this theoretical model and which we have not assessed. However, the mediation model tested in the present study already explained a relative large part of the variance in psychological distress (fifty-five percent).

Conclusions

Psychological distress is common among significant others of persons with SCI and ABI. Resilience, appraisals of threat and loss, and passive coping seem to be important psychological factors in the explanation of psychological distress. Therefore, it seems useful to investigate if such psychological factors are changeable and if intervention programs which focus on these factors are effective in order to prevent or reduce psychological distress among significant others.

Declarations

Ethics approval and consent to participate

The Medical Ethics Committee of the University Medical Center Utrecht declared that this study did not need approval according to the Dutch Law on Medical Research (protocol number 15-617/C). All participants have provided written informed consent prior to participation.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

CH, MK, JV-M, MP and ES designed the study and wrote the protocol. JS, MP and ES drafted the manuscript. TvD, CH, MK, KHW, RO and JV-M critically revised the manuscript, read, and approved the final version.

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CHAPTER 6

Self-efficacy predicts personal and family adjustment among persons with spinal cord injury or acquired brain injury and their significant others: A dyadic approach

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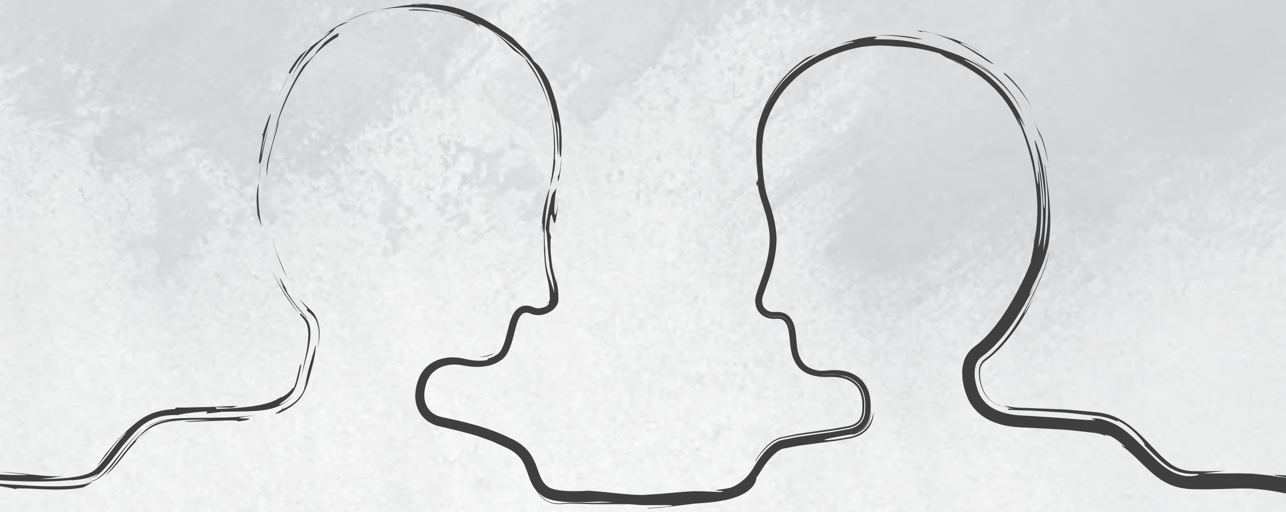

Abstract

Objective: To investigate if the combination of self-efficacy levels of persons with spinal cord injury (SCI) or acquired brain injury (ABI) and their significant others, measured shortly after the start of inpatient rehabilitation, predict their personal and family adjustment six months after inpatient discharge.

Design: Prospective longitudinal study.

Setting: Twelve Dutch rehabilitation centers.

Participants: Volunteer sample consisting of 157 dyads of adult persons with SCI/ABI admitted to inpatient rehabilitation, and their adult significant others.

Interventions: Not applicable.

Main outcome measures: Self-efficacy (General Competence Scale), personal and family adjustment (Hospital Anxiety and Depression Scale and McMaster Family Assessment Device General Functioning).

Results: In twenty dyads, both persons with SCI/ABI and their significant others showed low self-efficacy at baseline, and in sixty-seven dyads both showed high self-efficacy. In the low-self-efficacy dyads, 61% of the persons with SCI/ABI and 50% of the significant others showed symptoms of anxiety six months after discharge, versus 23% and 30% in the high-self-efficacy dyads. In the low-self-efficacy dyads, 56% of persons with SCI/ABI and 50% of the significant others reported symptoms of depression, versus 20% and 27% in the high-self-efficacy dyads. Problematic family functioning was reported by 53% of the persons with SCI/ABI and 42% of the significant others in the low-self-efficacy dyads, versus 4% and 12% in the high-self-efficacy dyads. MANOVA analyses showed that the combination of levels of self-efficacy of persons with SCI/ABI and their significant others at the start of inpatient rehabilitation predict personal ($V = .12$ $F(6, 302) = 2.8$, $p = .010$) and family adjustment ($V = .19$ $F(6, 252) = 4.3$, $p < .001$) six months after discharge.

Conclusions: Low-self-efficacy dyads seem to be more at risk for personal and family adjustment problems after discharge. Screening for self-efficacy may help healthcare professionals to identify and support families at risk for long-term adjustment problems.

INTRODUCTION

Chronic conditions like spinal cord injury (SCI) or acquired brain injury (ABI) affect not only the persons with SCI or ABI (pwABI/SCI) themselves, but also their significant others (often family members, but a close friend can also be a significant other).[1,2] The Theory of Dyadic Illness Management suggests that the ways in which dyads appraise the illness of the person as a unit influences the ways in which they engage in behaviors to manage the illness together.[3] Adjustment outcomes are the results of how dyads manage the illness. At personal level, an often reported negative adjustment outcome among pwSCI/ABI and significant others is psychological distress (i.e., anxiety and depression).[4] At family level, problems regarding family functioning (e.g., when they were not able to support each other) are common.[5]

Previous research among pwSCI/ABI and their informal caregivers has shown that personal adjustment outcomes like stress, mental health, and quality of life of persons in a dyad are inter-related.[6–8] Furthermore, it is known that persons with low self-efficacy (i.e., the belief about one's ability to cope with a variety of difficult situations in life)[9] are more at risk for later distress.[10,11] Based on the Theory of Dyadic Illness Management, it can be supposed that characteristics of both persons within a dyad will influence the adjustment outcomes of both. However, whether self-efficacy of both persons within a dyad contributes to the explanation of personal and family adjustment within the dyad is still unclear. In this study it is hypothesized that the combination of levels of self-efficacy of pwSCI/ABI and their significant others, measured shortly after the start of inpatient rehabilitation, predict both personal and family adjustment six months after clinical discharge. Exploratory, differences with respect to subgroups (SCI/ABI; partners only) will be investigated. Results provide insight in the dyadic impact between persons within a dyad in the prediction of adjustment which will help to develop a substantiated family-centered approach. This is in line with the increasing awareness of the need to adopt a family-centered approach to support pwSCI/ABI and significant others in rehabilitation care.[2]

METHODS

Design

Data of the cohort part of the POWER study were used, which is a study conducted in twelve Dutch rehabilitation centers.[12] The overall aim of this cohort study is to identify predictors at admission to inpatient rehabilitation of long-term empowerment and adjustment problems among dyads of pwSCI/ABI and significant others (usually the partner, but sometimes a child/

parent/sibling/other family member/close friend). Between April 2016 and July 2018, dyads were recruited. The Medical Ethics Committee of the University Medical Center Utrecht declared that this study did not need approval according to the Dutch Law on Medical Research (protocol number 15-617/C). Boards of all study sites granted permission to execute the study.

Participants

Inclusion criteria for pwSCI/ABI were: first inpatient rehabilitation after onset of injury, expected stay in rehabilitation center ≥ four weeks, ≥ eighteen years of age and able to name a significant other. They were excluded when the level of physical and cognitive functioning was expected to return to the level as it was before onset of the recently acquired injury, when no return to home was expected, in case of limited life expectancy, all based on clinical judgement by rehabilitation physicians, or when they were not able to complete the questionnaires due to severe cognitive/intellectual problems. Cognitive/intellectual problems were defined as restrictions in expression and/or understanding of language and were assessed by nurses based on their clinical view and the Dutch aphasia scale.[13] Significant others had to be ≥ eighteen years. PwSCI/ABI and significant others were included as dyads and both signed informed consent.

Procedure

Shortly after admission of the pwSCI/ABI to one of the participating rehabilitation centers, pwSCI/ABI and significant others completed a self-report questionnaire (print or electronically). Follow-up questionnaires were completed shortly before discharge from inpatient rehabilitation and three and six months after discharge. In this study baseline and six-month follow-up data were used. Diagnosis-specific information was extracted from the patient's file at baseline.

Measures

Dependent

Dependent variables were assessed at six months after discharge from inpatient rehabilitation. Personal adjustment was operationalized as psychological distress and measured with the Hospital Anxiety and Depression Scale (HADS),[14] which is considered an effective measure of general psychological distress.[15,16] The HADS consists of fourteen items reflecting symptoms of anxiety (HADS-A) and depression (HADS-D) (seven items each), scored on a four-point scale ranging 0–3 ('no symptoms' – 'maximum impairment'). We aimed to focus on personal adjustment in general, therefore in our assessment of psychological distress, we included anxiety and depression in a combined total HADS score (0–42).[15,16] Higher scores indicate higher distress. The HADS has shown good psychometric properties in various populations.[17] The anxiety and depression subscales were strongly correlated and Cronbach's alpha of the total score in the current study was .86 and .91 for the pwSCI/ABI and significant others respectively. Because no clear cut-off score exists for the total HADS, we used cut-off scores of the anxiety and depression subscales. Scores of ≥ 8 indicate symptoms of anxiety/depression.[18]

Family adjustment was measured with the General Functioning subscale of the McMaster Family Assessment Device (FAD-GF),[19] which has been widely used as a brief method of assessing overall family functioning. The subscale consists of twelve questions rated on a four-point scale ranging 1–4 ('strongly agree' – 'strongly disagree'). An example item is: 'In times of crisis we can turn to each other for support'. Total mean scores were calculated (1–4), where higher scores indicate poorer family functioning. A score of > 2 indicates problematic family functioning.[20,21] The FAD-GF has shown to be reliable and valid.[22,23] Cronbach's alpha was .86–.87 in the current study. Participants only completed the FAD-GF if they did not live alone. They were instructed to answer the questions with their own family in mind.

Independent

Self-efficacy was assessed at baseline with the ALCOS-12,[24,25] which is the abbreviated Dutch version of the Sherer's General Self Efficacy Scale.[9] The ALCOS-12 assesses the extent to which someone beliefs to be able to cope with a variety of difficult situations and consists of twelve questions scored on a five-point scale ranged 1–5 ('disagree' – 'agree'). A total sum score was calculated (12–60), where higher scores indicate higher self-efficacy. Scores were dichotomized in low (≤ 46) or high (≥ 47) self-efficacy based on a mean score of 46.3 found in a Dutch community study.[26] The ALCOS-12 showed good internal consistency among elderly.[25] Cronbach's alpha was .75–.80 in the current study.

Demographic and injury-specific information

Demographic information was assessed at baseline: sex (male = 0, female = 1), age (years), nationality (Dutch = 0, non-Dutch = 1) and education (low = 0, high = 1, i.e., bachelor degree or higher). Significant others indicated their relationship with the pwSCI/ABI (no partner (e.g., child/parent/sibling/other family member/friend) = 0, partner = 1).

Cause of disability was assessed (traumatic = 0, non-traumatic = 1). For SCI, a trained physician determined the level (paraplegia versus tetraplegia) and completeness (A–D) according to the International Standards for the Neurological Classification of SCI.[27] For ABI, location of injury was specified in left/right/both hemispheres, or brainstem. In both SCI/ABI, independence in mobility (e.g., sitting, standing) and self-care (e.g., eating, dressing) was measured with the fourteen-item Physical Independence subscale of the Utrecht Scale for Evaluation of Rehabilitation (USER).[28] Items were scored on a six-point scale (0–5). Higher total sum scores (0–70) represent better physical independence. The USER is a valid, responsive and reliable scale.[28]

Statistics

Dyads in which the ALCOS-12 and HADS or FAD-GF scores of both persons were available were included. Independent samples *t*-tests and Pearson Chi-square tests were conducted to investigate demographic and injury-specific differences between dropped and included dyads and between SCI/ABI. The HADS scores were transformed because of a positively skewed distribution (square root). Descriptive statistics (e.g., means) report raw data, statistical analyses were conducted on transformed data.

Dyads of pwSCI/ABI and significant others were divided into four groups based on the combinations of their self-efficacy scores (ALCOS-12) at admission: (1) both low self-efficacy (≤ 46), (2) pwSCI/ABI low self-efficacy and the significant other high (≥ 47), (3) pwSCI/ABI high self-efficacy and the significant other low, or (4) both high self-efficacy. Multivariate analyses of variance (MANOVA) were performed to test differences in HADS and FAD-GF scores six months after discharge between these four groups. Pillai's trace *F*-ratio was used to test the overall effect, and Tukey HSD post hoc tests to investigate group differences. Effect sizes of differences between groups were calculated by dividing the differences in means by the standard deviation of the total group. We used Cohen's standards to interpret the effect sizes (.10 = weak, .30 = moderate, .50 = strong).[29] MANOVA analyses were repeated for both diagnose groups (SCI/ABI) separately and for a selection including only dyads in which the significant other was the partner. Data were analysed with IBM SPSS Statistics 25. A significance level of $p < .05$ (two-tailed) was used.

RESULTS

Participants

Figure 6.1 shows a flowchart of the inclusion of dyads of pwSCI/ABI and significant others in the study. Of the 157 dyads which completed the last questionnaire, 155 completed the HADS and 130 completed the FAD-GF. Main exclusion reasons were: expected stay in

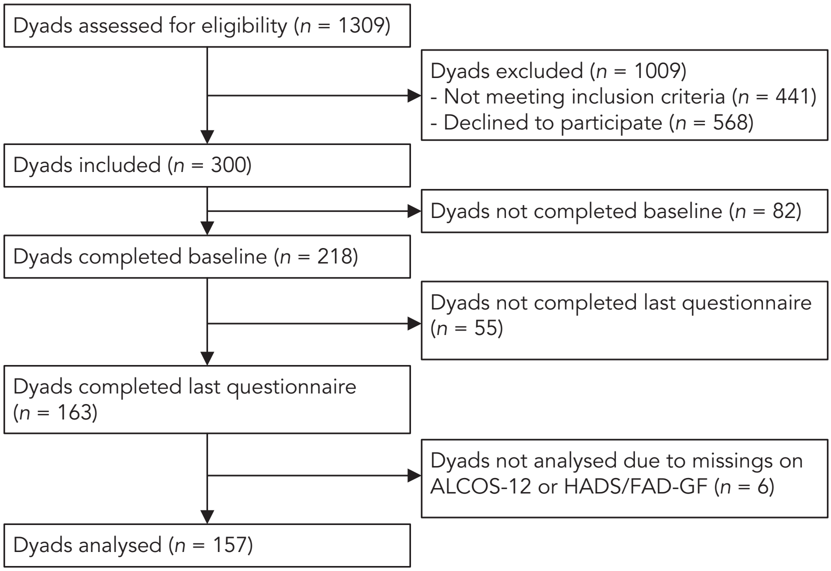

Figure 6.1 **Flowchart inclusion of dyads of pwSCI/ABI and significant others.**

inpatient rehabilitation < four weeks (26.0%), limited life expectancy (16.3%), no significant other (15.2%) or severe cognitive/intellectual problems (13.3%). Main reasons to decline participation were 'no interest' (45.2%) or 'to burdensome' (34.0%). Significant others of dyads included in the analyses were more often male, of higher age and more often partner than significant others of dyads who dropped out during follow-up of the study. PwSCI/ABI included in the analyses reported higher physical independence and had more often ABI compared to those who dropped-out during follow-up. Table 6.1 displays demographic and injury-specific information of the included dyads. In half of the cases the person with a disability had an SCI. The median number of weeks between onset of injury and completing the questionnaire was five weeks (for both diagnoses). Most significant others were partner (78.1%), followed by parent (9.3%), child (7.3%), or other family member/friend (5.3%).

Psychological distress, family functioning and self-efficacy

Of all pwSCI/ABI, 34.4% showed anxiety symptoms and 34.4% depressive symptoms six months post discharge. Of all significant others, this was 39.6% and 34.9%, respectively. In total 16.2% of the pwSCI/ABI and 23.1% of the significant others reported problematic family functioning. In a minority of the dyads (*n* = 20, 12.9%), both persons reported low self-efficacy. In sixty-seven (43.2%) dyads, both persons reported high self-efficacy. The

Table 6.1 Characteristics of persons with SCI/ABI and their significant others at the start of inpatient rehabilitation

	Total (*n* = 157)[d]		SCI (*n* = 79)		ABI (*n* = 78)	
PwSCI/ABI	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range
Sex (female)	157	66 (42.0)	79	28 (35.4)	78	38 (48.7)
Age in years	157	56.7 (14.9), 18–87	79	55.0 (16.8), 18–81	77	58.5 (12.4), 29–87
Nationality (non-Dutch)	149	25 (16.4)	76	13 (16.5)	76	12 (15.8)
Education (high)[a]	151	58 (38.4)	75	25 (33.3)	76	33 (43.4)
Physcical independence[b]	150	36.8 (18.9), 1–70	77	29.5 (17.5), 1–70*	73	44.5 (17.2), 5–70*
Cause of injury (non-traumatic)	157	107 (68.2)	79	39 (49.4)*	78	68 (87.2)*
AIS (SCI only)[c]						
A	–	–	79	9 (11.5)	–	–
B	–	–	–	11 (13.9)	–	–
C	–	–	–	16 (20.3)	–	–
D	–	–	–	43 (54.4)	–	–
Level (tetraplegia, SCI only)	–	–	79	35 (44.3)	–	–
Location (ABI only)						
Left	–	–	–	–	78	31 (39.7)
Right	–	–	–	–	–	26 (33.3)
Both sides	–	–	–	–	–	14 (17.9)
Brainstem	–	–	–	–	–	3 (3.8)
Unknown	–	–	–	–	–	4 (5.1)

Significant other	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range	*n*	*n* (%) / mean (SD), range
Sex (female)	157	98 (62.4)	79	55 (69.6)	78	43 (55.1)
Age in years	149	55.9 (12.2), 25–82	77	56.4 (13.1), 25–82	72	55.5 (11.3), 27–75
Nationality (non-Dutch)	149	12 (8.1)	76	6 (7.6)	73	6 (8.2)
Education (high)	149	61 (40.9)	76	30 (39.5)	73	31 (42.5)
Partner of pwSCI/ABI	151	118 (78.1)	77	58 (75.3)	74	60 (81.1)

Note. SCI: spinal cord injury; ABI: acquired brain injury; PwSCI/ABI: persons with SCI or ABI; SD: standard deviation; *n*: number of participants.

*Independent samples *t*-test and Pearson chi-squared tests showed a difference in physical independence of the pwSCI/ABI ($t(148) = -5.3$, $p < .001$) and cause of injury ($\chi^2(1) = 22.8$, $p < .001$) between SCI and ABI.

[a] Finished bachelor degree or higher.

[b] Utrecht Scale for Evaluation of Rehabilitation (0–70).

[c] American Spinal Injury Association Impairment Scale. A = complete SCI; B = sensory incomplete; C = motor incomplete with less than half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3; D = motor incomplete with at least half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3.[27]

[d] Total overall $n = 157$, regarding personal adjustment (HADS) $n = 155$ and regarding family adjustment (FAD-GF) $n = 130$.

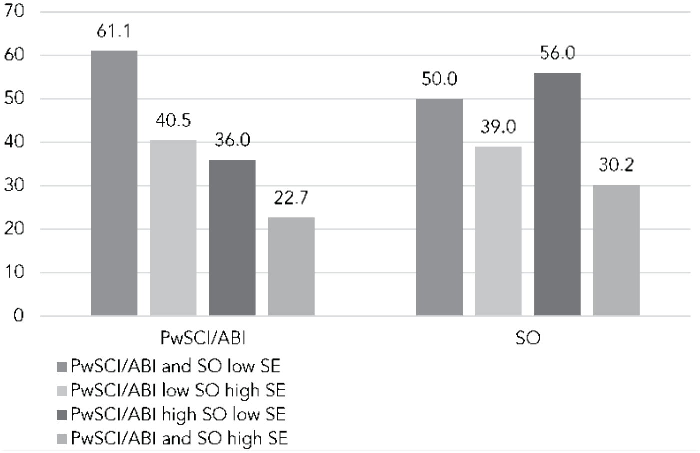

Figure 6.2 Symptoms of anxiety (%) among persons with SCI or ABI and their significant others at six months after discharge by self-efficacy group (*n* = 155).
Note. PwSCI/ABI: person with SCI or ABI; SO: significant other; SE: self-efficacy.

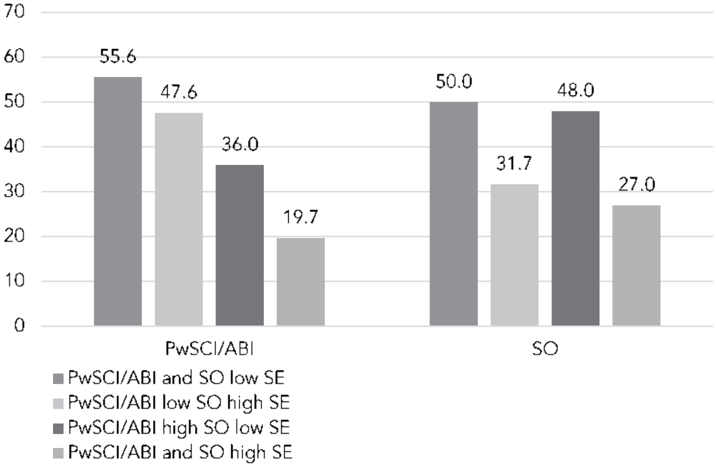

Figure 6.3 Symptoms of depression (%) among persons with SCI or ABI and their significant others at six months after discharge by self-efficacy group (*n* = 155).
Note. PwSCI/ABI: person with SCI or ABI; SO: significant other; SE: self-efficacy.

percentages of pwSCI/ABI and significant others per self-efficacy group who reported anxiety or depressive symptoms and problematic family functioning are shown in Figures 6.2–6.4. Score distributions of the independent and dependent variables are shown in Table 6.2.

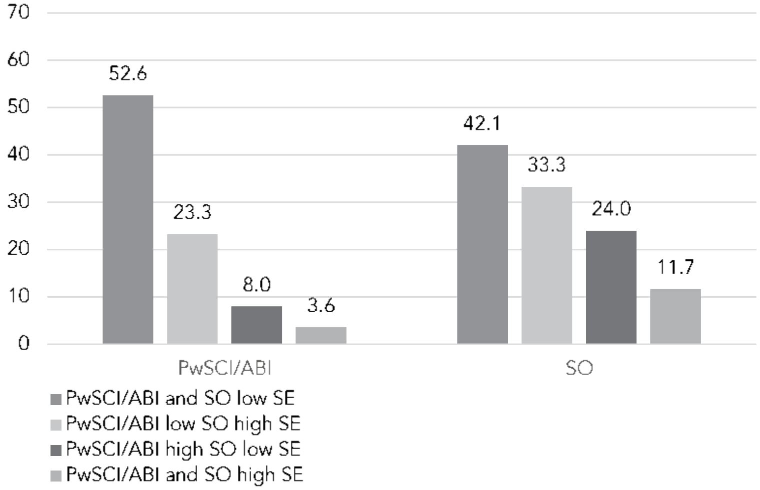

Figure 6.4 Problematic family functioning (%) among persons with SCI or ABI and their significant others at six months after discharge by self-efficacy group (n = 130).
Note. PwSCI/ABI: person with SCI or ABI; SO: significant other; SE: self-efficacy.

Self-efficacy as predictor of psychological distress

Psychological distress scores of pwSCI/ABI and significant others per self-efficacy group are shown in Table 6.3. MANOVA analysis showed significant differences in psychological distress between the four self-efficacy groups (V = .12 F(6, 302) = 2.8, p = .010). Results of the post hoc tests investigating which self-efficacy groups differed from each other with the corresponding effect size are shown in Table 6.3.

Repeating the MANOVA analysis in the two diagnostic groups separately showed no main effect of self-efficacy on psychological distress (SCI: V=.10 F(6, 150) = 1.4, p = .236; ABI: V = .11 F(6, 144) = 1.4, p = .240), which was also the case when including only dyads with partners (V = .10 F(6, 226) = 2.1, p = .058).

Self-efficacy as predictor of family functioning

Family functioning scores of pwSCI/ABI and their significant others per self-efficacy group are shown in Table 6.4. MANOVA analysis showed significant differences in family functioning between the four self-efficacy groups (V = .19 F(6, 252) = 4.3, p < .001). Results of the post hoc tests investigating which self-efficacy groups differed from each other with the corresponding effect sizes are shown in Table 6.4.

Table 6.2 Scores and differences in self-efficacy (at the start of inpatient rehabilitation), psychological distress and family functioning (at six months after discharge)

		PwSCI/ABI		Significant others	
Variabele (range of scores)	*n*	Mean	SD	Mean	SD
Total group (*n* = 157)					
Self-efficacy (12–60)[a]	157	48.1	8.1	49.6	6.6
Psychological distress (0–42)[b]	155	11.6	7.4	10.1	7.2
Family functioning (1–4)[c]	130	1.6	.4	1.7	.5
SCI (*n* = 79)					
Self-efficacy (12–60)[a]	79	49.1	7.9	48.8	6.6
Psychological distress (0–42)[b]	79	11.2	7.6	11.4	7.0
Family functioning (1–4)[c]	66	1.7	.4	1.7	.4
ABI (*n* = 78)					
Self-efficacy (12–60)[a]	78	47.1	8.3	50.3	6.6
Psychological distress (0–42)[b]	76	11.9	7.3	8.7	7.3
Family functioning (1–4)[c]	64	1.6	.4	1.7	.5

Note. SCI: spinal cord injury; ABI: acquired brain injury; pwSCI/ABI: persons with SCI or ABI; *n*: number of participants; SD: standard deviation.

[a] Higher scores indicate higher self-efficacy.

[b] Higher scores indicate higher psychological distress.

[c] Higher scores indicate poorer family functioning.

Table 6.3 Psychological distress among persons with SCI or ABI and their significant others at six months after discharge based on their self-efficacy levels at the start of inpatient rehabilitation (*n* = 155)

Self-efficacy		Psychological distress		
PwSCI/ABI	Significant other	*n*	PwSCI/ABI	Significant other
			Mean (SD)	Mean (SD)
Low	Low	20	14.1 (7.4)	14.5[a] (8.5)
	High	43	12.9 (7.5)	8.8[a] (6.9)
High	Low	25	12.2 (7.3)	10.1 (6.6)
	High	67	9.7 (7.1)	9.6 (7.0)

Note. PwSCI/ABI: person with spinal cord injury or acquired brain injury; SE: self-efficacy; *n*: number of dyads; SD: standard deviation.

[a] Indicates significant difference based on Tukey HSD post hoc test, effect size = .79.

Repeating the MANOVA analysis in the two diagnostic groups separately, showed a main effect of self-efficacy on family functioning in the SCI-group (V = .31 *F*(6, 124) = 3.8, *p* = .002), but not in the ABI-subgroup (V = .15 *F*(6, 120) = 1.6, *p* = .155).

Table 6.4 Problematic family functioning among persons with SCI or ABI and their significant others at six months after discharge based on their self-efficacy levels at the start of inpatient rehabilitation (n = 130)

Self-efficacy		Problematic family functioning		
PwSCI/ABI	Significant other	*n*	PwSCI/ABI	Significant other
			Mean (SD)	Mean (SD)
Low	Low	19	1.9[a,b] (.5)	1.9[d] (.5)
	High	30	1.8[c] (.4)	1.8 (.4)
High	Low	25	1.6[b] (.4)	1.7 (.5)
	High	56	1.5[a,c] (.4)	1.6[d] (.4)

Note. PwSCI/ABI: person with spinal cord injury or acquired brain injury; SE: self-efficacy; *n*: number of dyads; SD: standard deviation.
[a]/[b]/[c]/[d] Indicates significant differences based on Tukey HSD post hoc tests between the groups marked with the symbol. Effect sizes were: [a]1.00; [b].75; [c].75; [d].60.

Repeating the MANOVA analysis including only dyads with partners showed a similar main effect of self-efficacy on family functioning (V = .22 $F(6, 214) = 4.3$, $p < .001$) as was found in the total group.

DISCUSSION

In this study it was hypothesized that the combination of levels of self-efficacy of pwSCI/ABI and significant others, measured shortly after the start of inpatient rehabilitation, predict personal and family adjustment of both six months after clinical discharge. MANOVA results showed a dyadic effect of self-efficacy in the prediction of later psychological distress and family functioning among pwSCI/ABI and significant others, supporting our hypothesis. To our knowledge, this is the first study in which the combination of levels of self-efficacy among affected persons and their significant others on adjustment outcomes is investigated.

Two previous reviews demonstrated that self-efficacy is an important predictor of personal adjustment among pwSCI/ABI.[10,11] Our study adds the insight that there is a combined effect of self-efficacy of pwSCI/ABI and that of their significant others on personal adjustment, and also on family adjustment, of both pwSCI/ABI and significant others. These results emphasize the importance to focus on both persons in a dyad and to consider dyadic relationships.[8,30,31] Regarding family adjustment, post hoc tests showed that pwSCI/ABI and significant others in the low-self-efficacy dyads reported higher levels of problematic family functioning than persons in the high-self-efficacy dyads. The found effect sizes were strong.

Regarding personal adjustment, only one post hoc tests showed significant differences in means between groups. However, the apparently small differences in mean scores hide large differences in the percentages of persons within the different self-efficacy groups reporting symptoms of psychological distress. These percentages were considerably higher in the low self-efficacy group compared to the percentages in the high self-efficacy group. This seems to indicate that low self-efficacy dyads are more at risk for personal and family adjustment problems six months after discharge from inpatient rehabilitation.

According to the Theory of Dyadic Illness Management, it was assumed that adjustment among pwSCI/ABI and significant others is the result of how they together appraise and manage the illness.3 In the theory it is further described that factors at different levels (e.g., individual, dyad, family/social, or cultural) within which the patient and care partner are situated may act as risk or protective factors in this dyadic interaction. Our study showed that low self-efficacy could be seen as a risk factor at personal level which may have an effect on adjustment outcomes among both persons within a dyad. Theoretically reasoned, this effect of self-efficacy on adjustment is caused by the effect of self-efficacy on the dyadic interaction.

When focusing on diagnostic groups separately, or when only partners were included as significant others, significant effects of the combination of levels of self-efficacy scores were found on family adjustment in the SCI-group and in the partner-dyads. No significant effect of the combination of levels of self-efficacy scores on family adjustment was found in the ABI-group, nor in any of the subgroups regarding to personal adjustment. However, patterns of absolute values (mean scores on the HADS and FAD-GF) in the subgroups were highly similar to the values in the total group. This may indicate that the absence of significant effects in the subgroups could probably be explained by the lower number of dyads in the subgroups. Future studies examining larger samples are needed to confirm this.

Limitations

This study has some limitations. Firstly, regarding the representativeness of our sample we should note that excluding pwSCI/ABI with an expected stay in inpatient rehabilitation of < four weeks will have led to an overrepresentation of more severely affected pwSCI/ABI, although the majority of the inpatient rehabilitation trajectories in the Netherlands take longer than four weeks.[32] On the other hand, pwSCI/ABI with severe cognitive/intellectual problems or a limited life expectancy were excluded, which could result in the opposite effect. Furthermore, pwSCI/ABI having a significant other were over overrepresented, since participants were included as dyads resulting in the exclusion of pwSCI/ABI who did not have a significant other. Unfortunately, we do not have any information about the excluded dyads which limits the possibilities to compare their characteristics with the characteristics of the included dyads. We have compared some basic baseline characteristics such as age, sex and injury-specific information (completeness and level of injury (SCI), physical independence (ABI)) with the characteristics found in the general Dutch SCI and stroke population in an inpatient rehabilitation setting.[33,34] Based on these characteristics, our sample seems to be representative. Furthermore, prevalence of symptoms of psychological distress found in the present study were highly comparable to results found in earlier research among pwSCI/ABI and significant others.[1,35,36] Mean scores of family functioning in the present study were a bit lower compared to the mean score found in a study among caregivers of pwABI in the chronic phase after onset, indicating better family functioning in our sample.[37] However, results of a recent study among pwABI and partners during inpatient and outpatient rehabilitation were highly comparable to our results.[38] Secondly, no clear cut-off score for the ALCOS-12 exist. We pragmatically based our cut-off score of 46 on the mean score of 46.3 found in a Dutch community study.[26] However, mean self-efficacy scores in the present study were slightly higher (48.1–49.6), indicating relatively high self-efficacy in our sample. Since combined self-efficacy was found to be a predictor of later adjustment, our results may underestimate adjustment problems. The relatively high self-efficacy scores could probably be explained by the relatively high educational level of our participants.[9] Thirdly, we decided to use total HADS scores because we wanted to assess general psychological distress instead of anxiety and depression separately. However, since there are no clear cut-off scores for the total scale, we decided to use subscale cut-off scores in the calculation of percentages.[18] Repeating the MANOVA analyses with the anxiety and depression subscales separately, however, revealed the same results as with the total scale. Fourthly, participants answered the FAD-GF for their own family. So, although exceptional, it was possible that persons within a dyad had answered the questions for different families (e.g., when the significant other was a friend). Fifthly, despite the longitudinal design, we were not able to rule out confounding or reverse causation. When a certain variable has impact on the dependent and independent variable, this may disrupt study results (i.e., confounding). We think confounding is not likely in our study, because self-efficacy is assumed to be a highly stable characteristic which is not or hardly subjected to the influence of confounders.[39,40] For that reason, also reverse causation seems to be unlikely. Lastly, we are not able to present figures on the received psychological care by pwSCI/ABI and significant others because we have not monitored the specific services received by our participants during inpatient and outpatient rehabilitation. In general, pwSCI/ABI in our study received regular care, which includes psychological assessment and intervention by psychologists (if needed) during inpatient rehabilitation and sometimes also during outpatient rehabilitation. Significant others are usually in contact with social work and only occasionally receive psychological support.

Implications

The main clinical message for healthcare professionals is to recognize the interdependence between pwSCI/ABI and their significant others.[8] Therefore, in addition to individual attention for pwSCI/ABI, attention is also required for the dyadic relationships, e.g., by introducing a joint anamnesis. Furthermore, since our results indicate that combined self-efficacy scores shortly after the start of inpatient seem to predict later personal and family adjustment, it is advised to implement a screening for low self-efficacy of both pwSCI/ABI and significant others, e.g., by administering a short self-report questionnaire which is a relatively easy and inexpensive way to quickly assess self-efficacy. Screening may help healthcare professionals to identify and support families more at risk at an early stage, which may help to prevent later adjustment problems and related costs. Using the ALCOS-12 as screening tool seems useful, but other measures of self-efficacy are available, and more knowledge is desirable about clear cut-off scores.[10,26]

In research more attention for dyadic relationships between people is desirable to get more insight in how people interact and influence each other.[31] This information may also help to give direction to the development of family-based interventions which take into account the interdependence of persons. Effective family-centered interventions are still limited.[41,42]

Conclusion

There is a dyadic relationship between self-efficacy of pwSCI/ABI and that of their significant others at the start of inpatient rehabilitation and personal and family adjustment six months after discharge. Low self-efficacy seems to be a risk factor for adjustment problems. It is important to identify and support persons for whom it is difficult to adjust to changed conditions as a result of disease with a chronic impact.

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Conflicts of interest

The authors report no conflicts of interest.

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CHAPTER 7

Prediction of psychological distress among persons with spinal cord injury or acquired brain injury and their significant others

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Abstract

Objective: To identify intra-personal and inter-personal sociodemographic, injury-related and psychological variables measured at admission of inpatient rehabilitation that predict psychological distress among dyads of persons with spinal cord injury (SCI) or acquired brain injury (ABI) and their significant others (i.e., persons close to the individual with a disability, mostly family members) others six months after discharge. Differences in predictors were investigated for persons with SCI/ABI and significant others, and between diagnoses.

Design: Prospective longitudinal study.

Setting: Twelve Dutch rehabilitation centers.

Participants: 157 dyads of adult persons with SCI/ABI admitted to inpatient rehabilitation and their adult significant others.

Interventions: N.a.

Main outcome measures: Psychological distress (Hospital Anxiety and Depression Scale).

Results: Sociodemographic and injury-related variables were not or only weakly associated with psychological distress among persons with SCI/ABI or significant others six months after discharge. Bivariately, higher baseline psychological distress, lower scores on adaptive psychological characteristics (combination of self-efficacy, proactive coping, purpose in life, resilience) and higher scores on maladaptive psychological characteristics (combination of passive coping, neuroticism, appraisals of threat and loss) were related to higher psychological distress, also, although less strongly, crosswise between persons with SCI/ABI and significant others. Combined prediction models showed that psychological distress among persons with SCI/ABI was predicted by educational level of the significant other, own baseline psychological distress and own maladaptive psychological characteristics (explained variance = 41.9%). Among significant others, only their own baseline psychological distress predicts psychological distress (explained variance = 40.4%). Results were comparable across diagnoses.

Conclusions: Although a dyadic connection was shown, primarily one's own baseline psychological distress and psychological characteristics are important in the prediction of later psychological distress among both individuals with SCI/ABI and significant others. Screening based on these variables could help to identify persons at risk for psychological distress.

INTRODUCTION

Chronic conditions such as spinal cord injury (SCI) or acquired brain injury (ABI) are two important causes of chronic injury. In 2016 there were 0.9 million new cases with SCI worldwide and 43.6 million with ABI (traumatic brain injury / stroke / meningitis).[1,2] In the Netherlands, nearly two-thirds of all adult patients in inpatient rehabilitation have SCI (11.0%) or ABI (53.2%).[3]

Having SCI or ABI may have consequences on the well-being of the persons involved and their significant others (i.e., persons close to the individual with a disability, mostly family members). Compared to the general population, persons with SCI or ABI (pwSCI/ABI) and significant others more often experience psychological distress,[4–7] often defined as 'a state of emotional suffering characterized by symptoms of depression or anxiety'.[8] It is important to pay attention to psychological distress among pwSCI/ABI, but also among their significant others, more so because they play an important role in supporting the pwSCI/ABI.[9–11] To be able to support pwSCI/ABI and significant others properly it is important to identify those persons with a higher risk of psychological distress.

Literature has shown that injury-related (e.g., pain severity, physical impairment and motor function) and sociodemographic variables (e.g., age, sex, educational level) are poor/inconsistent predictors of psychological distress among pwSCI/ABI and significant others.[10–14] Early post-injury symptoms of anxiety and depression were found to be important predictors of later psychological distress.[10,12,13,15] Furthermore, psychological factors including neuroticism, appraisals, coping, optimism, resilience and self-efficacy were found to be related to psychological distress among pwSCI/ABI and significant others in previous studies.[10–14,16–19]

Most research on psychological distress after the onset of SCI/ABI focuses on either pwSCI/ABI or significant others. However, it is also important to focus on the inter-dependence of persons within a dyad.[20] For example, previous research showed that anxiety and depression of pwABI were related with later anxiety and depression among caregivers.[10,21] A dyadic relation was also found between stroke survivors' self-esteem and partner depression.[22] These findings underline the importance to investigate distress among pwSCI/ABI and significant others in relation to each other. Furthermore, more insight is needed in the variables that are most important in the prediction of psychological distress. SCI and ABI are both conditions characterized by a sudden onset, but with diverging commonly reported consequences. For example, pain is an often reported consequence among pwSCI, pwABI often experience problems regarding cognitive functioning. Therefore, it is also important to investigate diagnosis-based differences in predictors of psychological distress.

The present study aimed to identify intra-personal and inter-personal sociodemographic, injury-related and psychological factors measured at admission of inpatient rehabiltation that predict psychological distress among dyads of pwSCI/ABI and significant others six months post-discharge. The hypotheses were:

1. Psychological variables relate more strongly to psychological distress among pwSCI/ABI and significant others than sociodemographic and injury-related variables.
2. Intra-personal and inter-personal psychological variables are both significant predictors of psychological distress.

Exploratory, differences in predictors between diagnoses (SCI/ABI) were investigated. Insight in predictors and differences between diagnoses, can contribute to the early identification of individuals vulnerable for psychological distress post-discharge from inpatient rehabilitation and, therefore, provides knowledge to optimize rehabilitation care.

METHODS

Design

The current analyses are part of the POWER study.[23] The overall aim of the cohort part of this study was to identify predictors of empowerment and adjustment among dyads of pwSCI/ABI and significant others. The study was executed in twelve Dutch rehabilitation centers. Dyads were included between April 2016 and July 2018. The Medical Ethics Committee of the University Medical Center Utrecht declared that this study did not need approval according to the Dutch Law on Medical Research (protocol 15-617/C). Boards of all participating rehabilitation centers provided approval for study execution.

Participants

PwSCI/ABI were eligible to participate if they met the inclusion criteria: first inpatient rehabilitation after the onset of injury (no inpatient readmission), expected inpatient stay ≥ four weeks, ≥ eighteen years of age and able to name a significant other (partner/other family member/close friend). Exclusion criteria were: expectation of (nearly) full recovery, discharge to a long-term care facility, or limited life expectation based on clinical judgement by rehabilitation physicians, or when they were not able to respond to questionnaires due to severe cognitive disabilities, as assessed by nurses based on their clinical view and the Dutch aphasia scale.[24] Significant others had to be ≥ eighteen years of age. All participants signed informed consent. Data of dyads in which both individuals completed the baseline and follow-up assessments were used in the current study.

Procedure

Soon after admission, dyads were informed about the study and a few days later their willingness to participate was investigated. Participants completed self-report questionnaires (print/online, according to personal preference). The baseline assessment was completed on average two weeks after inpatient admission. Baseline injury-related information was obtained from the medical file. The follow-up assessment was conducted six months after discharge (print/online).

Measures

At baseline and follow-up, psychological distress was measured with the Hospital Anxiety and Depression Scale (HADS),[25] which is an effective measure of general psychological distress.[26,27] Fourteen questions answered on a four-point scale assess symptoms of anxiety and depression. A total HADS sum score was computed in which higher scores reflect higher psychological distress (0–42). The HADS has been used in various populations and has shown good clinimetric properties.[28]

Baseline sociodemographic variables included: sex (male = 0, female = 1), age (years), and education (low = 0, i.e., < bachelor degree, high = 1, i.e., ≥ bachelor degree) and type of relationship with the pwSCI/ABI (partner/parent/child/other family/friend/other).

Baseline injury-related variables included: diagnosis (SCI = 0, ABI = 1), level of SCI (paraplegia = 0, tetraplegia = 1), completeness of SCI (A–D = 0–3),[29] and location of ABI. Physical independence was measured with the sum score of the mobility and self-care scales of the Utrecht Scale for Evaluation of Clinical Rehabilitation (USER).[30] Higher scores indicate higher physical independence (0–70). Causes of SCI/ABI were categorized in traumatic (= 0) or non-traumatic (= 1).

The psychological measures assessed at baseline are shown in Table 7.1.[31,32,41–43,33–40] All measures were found to be valid and reliable[28,32,37,42–45] and internal consistency figures of all measures were satisfactory (Cronbach's alpha ≥ .7) in the current study.[46]

Table 7.1 Psychological variables and the used measures

Independent variable	Measure	# items	Range score	Higher score indicates
Self-efficacy	ALCOS[31,32 a]	12	12–60	Higher self-efficacy
Proactive coping competencies	Shortened Utrecht Proactive Coping Competence scale[34]	7	1–4	Better proactive coping competency
Purpose in life	Purpose in Life Scale-Short Form[35,36]	4	4–28	Higher purpose in life
Resilience	Connor-Davidson Resilience Scale[37,38]	10	0–40	Higher resilience capacity
Passive coping	Passive reaction pattern subscale of the Utrecht Coping List[39,40]	7	7–28	Greater tendency to adopt a passive coping style
Neuroticism	Neuroticism subscale of the Eysenck Personality Questionnaire-Revised Short Form[41,42]	12	0–12	Higher levels of neuroticism
Appraisals	Threat and loss subscales of the Appraisals of Life Events scale[43 b]	10	0–5	More appraisals of threat and loss

[a] The ALCOS is the Dutch version of the General Self Efficacy originally developed by Sherer.[33]
[b] The threat subscale contains six items and the loss subscale four. Subscale scores were computed as the mean of the respective item scores. A total score was computed as the mean of the two subscale scores, so that both subscales contributed equally to the total score.

Statistical analysis

Data were analyzed with IBM SPSS Statistics 25. A significance level of $p < .05$ (two-tailed) was used. To reduce the number of psychological variables, we clustered these in two scales based on exploratory factor analysis (principal components extraction, oblim rotation) using data of all participants who had completed the baseline assessment (n = 223), similar to the method used in a previous study.[47] The adaptive psychological characteristics scale (A-PC) included self-efficacy, proactive coping, purpose in life, and resilience (pwSCI/ABI: Eigenvalue: 3.58, 51.14% explained variance, factor loadings: .64–.87; significant others: Eigenvalue: 3.66, 52.26 % explained variance, factor loadings: .59–.85). The maladaptive psychological characteristics scale (M-PC) included passive coping, neuroticism, and appraisals of threat and loss (pwSCI/ABI: Eigenvalue: .95, 13.55% explained variance, factor loadings: .72–.90; significant others Eigenvalue: .94, 13.48% explained variance, factor loadings: .72–.96). Both psychological variables were calculated as the mean of the scores of the underlying scales, which were first standardized into *z*-scores to obtain a common metric. A maximum of one missing score on an underlying scale was allowed.

The HADS scores were positively skewed and were transformed (square root). Descriptive statistics report raw data, statistical analyses were carried out on transformed data.

Missing sociodemographic data (total: eight data points) were imputed with the score of the other person in the dyad. Other missing baseline scores (six USER, one HADS and one A-PC and M-PC scores) were imputed with the mean score within the corresponding scale, adjusted for diagnose. Missing follow-up HADS-scores were not imputed.

Independent samples *t*-tests and Pearson Chi-square tests were conducted to investigate sociodemographic, injury-related, and psychological differences between dropped-out and analyzed dyads, and between SCI/ABI.

To investigate hypothesis 1, we calculated Pearson correlations between potential predictors and follow-up psychological distress among pwSCI/ABI and significant others. Multivariate analyses of covariance (MANCOVA) were used to investigate hypothesis 2. MANCOVA takes into account non-independence between persons within a dyad with the possibility to analyze two inter-dependent outcome variables simultaneously, in our case psychological distress of pwSCI/ABI and significant others.[20] The results provided insight into the independent predictors of psychological distress at dyad level (multivariate effects) and at the level of pwSCI/ABI and significant others separately (between-subjects effects). Only variables that were bivariately significantly related with at least one dependent variable (follow-up HADS of the pwSCI/ABI or significant other) were added in the MANCOVA. In the first model, only sociodemographic and injury-related variables were entered as predictors. In Model 2a–c, respectively early post-injury psychological distress, A-PC and M-PC were additionally entered. The final model (Model 3) contains all variables together in one model. All analyses were repeated for SCI and ABI separately to explore diagnosis-based differences.

RESULTS

Background: participants and main outcomes

Data of 157 dyads were analyzed (Figure 7.1). Main reasons to exclude dyads were: expected stay in inpatient rehabilitation < four weeks (26.0%), limited life expectation (16.3%), no significant other (15.2%) or severe cognitive disabilities (13.3%). Main reasons to decline participation were ‘no interest’ (45.2%) or ‘too burdensome’ (34.0%). Table 7.2 shows sociodemographic and injury-related information of the analyzed dyads. Cause of SCI was in half of the cases traumatic (fall 21.5%; sport/leisure accident 15.2%; traffic accident 12.7%; occupational accident 1.3%). Non-traumatic causes were: spinal degeneration

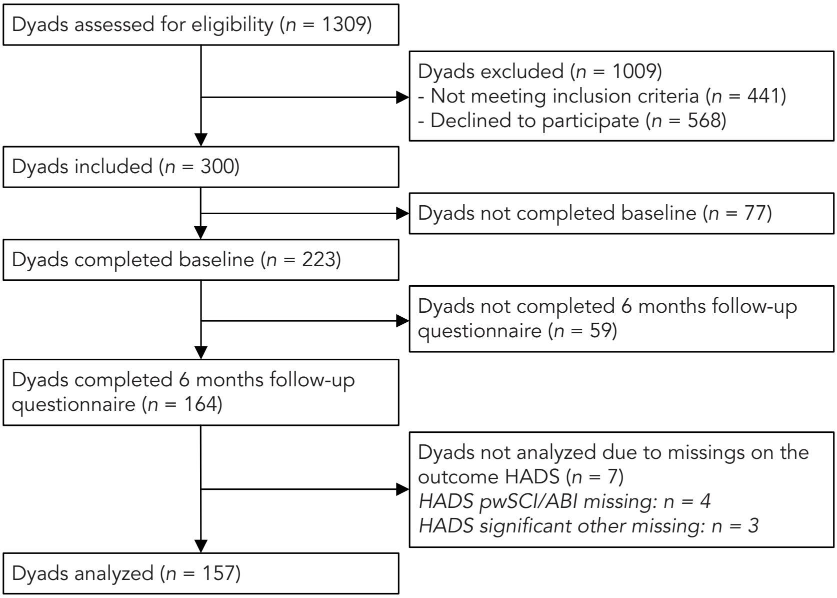

Figure 7.1 Flowchart inclusion of dyads of pwSCI/ABI and significant others.

11.4%; tumor 11.4%; inflammation 10.1%; medical complication 8.9%; vascular diseases 7.6%. ABI causes were mostly non-traumatic (infarction 48.7%; hemorrhage 26.9%; or 'other' such as meningitis 11.5%). Table 7.2 shows differences between sociodemographic and injury related variables between analyzed and dyads who dropped-out during follow-up. Score distributions of the psychological variables are shown in Table 7.3. No differences were found regarding psychological variables between analyzed and dropped-out dyads.

Hypothesis 1: correlations

Of all sociodemographic and injury-related variables, only higher educational level of the significant other was related to lower psychological distress among pwSCI/ABI, and a diagnosis of ABI was related to lower psychological distress among the significant others (Table 7.4). With respect to psychological factors, higher early post-injury psychological distress, higher M-PC, and lower A-PC were related to higher psychological distress at follow-up, both intra-personal as (although less strongly) crosswise between pwSCI/ABI and significant others.

Hypothesis 2: prediction at dyad level (multivariate effect)

The first MANCOVA model (Table 7.5) included only educational level (significant other) and diagnosis. Both variables were significant predictors of psychological distress at dyad level. Model 2a–c show that respectively early post-injury psychological distress (of pwSCI/ABI and significant others), A-PC (of both) and M-PC (of both) were significant predictors of psychological distress at dyad level, adjusted for significant others' educational level and diagnosis. The final model, which contained all variables together, shows that only diagnosis, early post-injury psychological distress (of both), and M-PC (of the pwSCI/ABI) remain significant predictors of psychological distress at dyad level.

Hypothesis 2: predictors for pwSCI/ABI (between-subjects effects)

Adjusted for educational level of the significant other and diagnosis, early post-injury psychological distress, A-PC and M-PC among pwSCI/ABI were significant predictors of psychological distress among pwSCI/ABI when tested in separated models (Table 7.5, Model 2a–c). The final model shows that, adjusted for other variables, educational level of the significant other, early post-injury psychological distress (pwSCI/ABI) and M-PC (pwSCI/ABI) were significant predictors of psychological distress at follow-up (explained variance: 41.9%).

Hypothesis 2: predictors for significant others (between-subjects effects)

Adjusted for significant others' educational level and diagnosis, significant others' scores on early post-injury psychological distress, A-PC and M-PC were significant predictors of follow-up psychological distress when tested in separated models (Table 7.5, Model 2a–c). The final model shows that, adjusted for other variables, early post-injury psychological distress of the significant others themselves was the only significant predictor of psychological distress at follow-up (explained variance: 40.4%).

Exploratory: SCI versus ABI

Differences between SCI/ABI were found in level of physical independence (SCI lower), cause of injury (SCI more often traumatic) and sex of the significant other (SCI more often female) (see Table 7.2). Significant others of pwSCI reported higher baseline and follow-up psychological distress than significant others of pwABI (see Table 7.3). PwSCI and their significant others reported higher levels of appraisals of threat and loss (resulting in higher M-PC scores) than persons in the ABI subgroup.

Table 7.2 Sociodemographic and injury-related characteristics of persons with SCI/ABI and their significant others (n = 157)

	Total (n = 157)		Dropped-out (n = 66)	SCI (n = 79)	ABI (n = 78)
PwSCI/ABI	*n*	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range
Sex (female)	157	67 (42.7)	18 (27.3)	28 (35.4)	39 (50.0)
Age in years	157	56.3 (14.9), 18–87	57.8 (14.4), 22–84	55.3 (16.3), 18–81	57.3 (13.3), 26–87
Education (high)[a]	154	58 (37.7)	15 (23.4)	25 (32.9)	33 (42.3)
Physical independence (USER, 0–70)[b]	151	36.4 (19.0), 1–70)	29.3 (15.8), 1–70[e]	28.8 (17.9), 1–70[f]	44.4 (16.9), 5–70[f]
Cause of injury (non-traumatic)	—	—	—	39 (49.4)[f]	68 (87.2)[f]
AIS[c] (SCI only)					
A	—	—	—	10 (12.7)	—
B	—	—	—	12 (15.2)	—
C	—	—	—	17 (21.5)	—
D	—	—	—	40 (50.6)	—
Tetraplegia (SCI only)	—	—	—	44 (55.7)	—
Location (ABI only)					
Left	—	—	—	—	31 (39.7)
Right	—	—	—	—	27 (34.6)
Both sides	—	—	—	—	13 (16.7)
Brainstem	—	—	—	—	3 (3.9)
Unknown	—	—	—	—	4 (5.2)
Weeks between admission and completing baseline assessment	157	2.0 (2.0)[d]	2.0 (2.0)[d]	2.0 (2.0)[d]	2.0 (2.0)[d]

Significant others	*n*	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range	*n* (%) / mean (SD), range
Sex (female)	157	97 (61.8)	52 (78.8)	55 (69.6)[f]	42 (53.8)[f]
Age in years	155	55.5 (12.4), 23–82)	51.0 (13.1), 25–79[e]	56.6 (12.9), 25–82	54.4 (11.9), 23–75
Education (high)[a]	155	64 (41.3)	19 (30.6)	31 (39.7)	33 (42.9)
Relationship with pwSCI/ABI					
Partner	157	123 (78.3)	40 (62.5)[e]	60 (75.9)	63 (80.8)
Parent		14 (8.9)	5 (7.8)	9 (11.4)	5 (6.4)
Child		11 (7.0)	16 (25.0)	5 (6.3)	6 (7.7)
Other family		5 (3.2)	2 (3.1)	2 (2.5)	3 (3.8)
Friend		3 (1.9)	—	2 (2.5)	1 (1.3)
Other		1 (.6)	1 (1.6)	1 (1.3)	—

Note. SCI: spinal cord injury; ABI: acquired brain injury; pwSCI/ABI: person with SCI or ABI; SD: standard deviation.

[a] High education ≥ bachelor degree.

[b] Physical independence is measured with the Utrecht Scale for Evaluation of Clinical Rehabilitation. Higher scores indicate higher physical independence (0–70).

[c] American Spinal Injury Association Impairment Scale. A = complete SCI; B = sensory incomplete; C = motor incomplete with less than half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3; D = motor incomplete with at least half of key muscle functions below the single neurological level of injury having a muscle grade ≥ 3.[29]

[d] Median and interquartile range instead of mean and standard deviation.

[e] Independent samples *t*-tests or Pearson Chi-square test showed a significant difference between analyzed and dropped-out dyads.

[f] Independent samples *t*-tests or Pearson Chi-square test showed a significant difference between SCI and ABI.

Table 7.3 Psychological scores of persons with SCI/ABI and their significant others (*n* = 157)

	Total (*n* = 157)		Dropped-out (*n* = 66)[d]	SCI (*n* = 79)	ABI (*n* = 78)
PwSCI/ABI	*n*	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Psychological distress (HADS, 0–42)					
Baseline[a]	156	12.0 (11.0)[c]	12.0 (11.5)[c]	13.0 (11.0)[c]	12.0 (10.3)[c]
Follow-up[b]	157	11.0 (11.0)[c]	N.a.	11.0 (12.0)[c]	11.0 (10.5)[c]
Adaptive psychological characteristics[b]					
Total	157	-.0 (.8)	-.0 (.8)	.0 (.8)	-.0 (.7)
Self-efficacy (ALCOS-12, 12–60)	155	48.1 (8.1)	48.9 (8.0)	49.1 (7.9)	47.1 (8.3)
Proactive coping (UPCC-SF, 1–4)	157	2.9 (.5)	2.9 (.5)	2.9 (.5)	3.0 (.4)
Purpose in life (PIL-SF, 4–28)	156	22.8 (3.8)	22.9 (3.5)	23.0 (3.9)	22.5 (3.7)
Resilience (CD-RISC-10, 0–40)	157	27.7 (6.9)	27.2 (6.8)	27.6 (7.0)	27.8 (6.8)
Maladaptive psychological characteristics[b]					
Total	157	-.0 (.8)	.1 (.9)	.1 (.9)[e]	-.1 (.8)[e]
Passive coping (UCL, 7–28)	156	10.5 (2.9)	10.9 (3.3)	10.8 (3.1)	10.1 (2.7)
Neuroticism (EPQ-RSS-N, 0–12)	155	3.1 (3.1)	3.1 (3.4)	3.3. (3.2)	2.9 (3.0)
Appraisals of threat and loss (ALE, 0–5)	157	1.8 (1.2)	2.0 (1.4)	2.0 (1.3)[e]	1.5 (1.1)[e]

Significant others	*n*	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Psychological distress (HADS, 0–42)					
Baseline[a]	157	12.0 (11.0)[c]	12.0 (11.0)[c]	13.0 (13.0)[c,e]	10.7 (11.0)[c,e]
Follow-up[b]	157	9.0 (11.0)[c]	N.a.	11.0 (11.0)[c,e]	8.0 (9.0)[c,e]
Adaptive psychological characteristics[b]					
Total	156	-.0 (.8)	.1 (.8)	-.1 (.7)	.1 (.8)
Self-efficacy (ALCOS-12, 12–60)	156	49.7 (6.9)	48.8 (8.0)	48.8 (6.7)	50.5 (7.1)
Proactive coping (UPCC-SF, 1–4)	156	3.0 (.4)	3.1 (.4)	3.0 (.4)	3.0 (.4)
Purpose in life (PIL-SF, 4–28)	154	22.7 (3.6)	23.0 (3.8)	22.4 (3.4)	23.0 (3.7)
Resilience (CD-RISC-10, 0–40)	155	28.2 (6.1)	28.2 (6.0)	27.4 (6.2)	29.1 (5.8)
Maladaptive psychological characteristics[b]					
Total	156	.0 (.8)	.1 (1.0)	.2 (.9)[e]	-.2 (.7)[e]
Passive coping (UCL, 7–28)	156	10.4 (2.7)	10.6 (3.0)	10.7 (2.9)	10.0 (2.4)
Neuroticism (EPQ-RSS-N, 0–12)	153	2.8 (2.6)	3.6 (3.4)	3.0 (2.7)	2.7 (2.5)
Appraisals of threat and loss (ALE, 0–5)	155	1.3 (1.1)	1.4 (2.3)	1.6 (1.1)[e]	.9 (.9)[e]

Note. SCI: spinal cord injury; ABI: acquired brain injury; pwSCI/ABI: person with SCI or ABI; SD: standard deviation; N.a.: not applicable.

[a] Assessed at the start of inpatient rehabilitation (baseline).

[b] Assessed at six months after inpatient discharge (six months follow-up).

[c] Median and interquartile range instead of mean and standard deviation.

[d] Independent samples *t*-tests showed no significant difference between analyzed and dropped-out dyads for any of the variables

[e] Independent samples *t*-tests or Pearson Chi-square test showed a significant difference between SCI and ABI.

Table 7.4 Bivariate correlation coefficients between independent variables and psychological distress of the pwSCI/ABI and significant others six months after discharge from inpatient rehabilitation (*n* = 157)

	Psychological distress pwSCI/ABI[b] Correlation coefficient (*p*-value)	Psychological distress SO[b] Correlation coefficient (*p*-value)
Sex (female)		
PwSCI/ABI	.10 (.20)	-.08 (.33)
SO	-.04 (.61)	.05 (.56)
Age		
PwSCI/ABI	-.06 (.46)	.07 (.41)
SO	.02 (.83)	.10 (.24)
Education (high)		
PwSCI/ABI	-.13 (.12)	.03 (.72)
SO	-.24 (< .01)**	-.07 (.40)
Significant other is partner	.02 (.85)	.04 (.60)
Diagnosis (ABI)	.01 (.94)	-.22 (< .01)**
Physical independence	.02 (.78)	-.12 (.14)
Psychological distress[a]		
PwSCI/ABI	.57 (< .001)***	.12 (.12)
SO	.21 (< .01)**	.61 (< .001)***
Adaptive psychological characteristics[a]		
PwSCI/ABI	-.46 (< .001)***	-.19 (.02)*
SO	-.25 (.001)**	-.37 (< .001)***
Maladaptive psychological characteristics[a]		
PwSCI/ABI	.57 (< .001)***	.21 (< .01)**
SO	.17 (.03)*	.49 (< .001)***

Note. SCI: spinal cord injury; ABI: acquired brain injury; pwSCI/ABI: person with SCI or ABI; SO: significant other.
* *p*-value < .05; ** *p*-value < .01; *** *p*-value < .001.
[a] Assessed at the start of inpatient rehabilitation (baseline).
[b] Assessed at six months after inpatient discharge (six months follow-up).

Correlation and MANCOVA analyses were repeated for SCI and ABI separately (see supplementary Tables S7.1–S7.3). In SCI, in the final MANCOVA model, early post-injury psychological distress of the pwSCI and that of the significant other were found to be significant predictors of psychological distress at dyad level. Among pwSCI, own early post-injury psychological distress and M-PC were found to be significant predictors. Among significant others, own early post-injury psychological distress was found to be the only significant predictor.

Table 7.5 MANCOVA to predict psychological distress six months after discharge from inpatient rehabilitation (n = 157)

	Model 1: Basic model[b]			Model 2a: Psychological distress[a]		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwSCI/ABI	Distress SO		Distress pwSCI/ABI	Distress SO
	V^c (*p*-value)	F (*p*-value)	F (*p*-value)	V^c (*p*-value)	F (*p*-value)	F (*p*-value)
Education (high)						
PwSCI/ABI	–	–	–	–	–	–
SO	.06 (< .01)**	9.78 (< .01)**	.54 (.47)	.03 (.08)	4.90 (.03)*	.14 (.71)
Diagnosis (ABI)	.06 (.01)*	.05 (.83)	7.63 (< .01)**	.04 (.05)*	.74 (.39)	3.68 (.06)
Psychological distress[a]						
PwSCI/ABI	–	–	–	.32 (< .001)***	61.95 (< .001)***	.00 (.96)
SO	–	–	–	.35 (< .001)***	2.96 (.09)	80.73 (< .001)***
Adaptive psychological characteristics[a]						
PwSCI/ABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Maladaptive psychological characteristics[a]						
PwSCI/ABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Explained variance	N.a.	6.0%	5.2%	N.a.	36.0%	38.6%

Table 7.5 continues on next page.

Table 7.5 *Continued*

	Model 2b: Adaptive psychological characteristics[a]			Model 2c: Maldaptive psychological characteristics[a]		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwSCI/ ABI	Distress SO		Distress pwSCI/ ABI	Distress SO
	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)	V[c] (p-value)	F (*p*-value)	F (*p*-value)
Education (high)						
PwSCI/ABI	–	–	–	–	–	–
SO	.04 (.04)*	6.33 (.01)*	.00 (.99)	.05 (.02)*	8.21 (< .01)**	.41 (.52)
Diagnosis (ABI)	.04 (.04)*	.02 (.89)	5.89 (.02)*	.05 (.03)*	3.23 (.07)	2.09 (.15)
Psychological distress[a]						
PwSCI/ABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Adaptive psychological characteristics[a]						
PwSCI/ABI	.16 (< .001)***	29.72 (< .001)***	1.54 (.22)	–	–	–
SO	.10 (< .001)***	1.73 (.19)	16.24 (< .001)***	–	–	–
Maladaptive psychological characteristics[a]						
PwSCI/ABI	–	–	–	.32 (< .001)***	70.20 (< .001)***	1.65 (.20)
SO	–	–	–	.20 (< .001)***	1.09 (.30)	36.53 (< .001)***
Explained variance	N.a.	25.5%	17.7%	N.a.	37.8%	26.0%

Table 7.5 *Continued*

	Model 3: Final model		
	Multivariate	Between-subjects effects	
		Distress pwSCI/ABI	Distress SO
	V[c] (p-value)	F (p-value)	F (p-value)
Education (high)			
PwSCI/ABI	–	–	–
SO	.04 (.07)	5.23 (.02)*	.05 (.82)
Diagnosis (ABI)	.05 (.03)*	1.75 (.19)	3.27 (.07)
Psychological distress[a]			
PwSCI/ABI	.07 (< .01)**	6.07 (.02)*	1.43 (.23)
SO	.18 (< .001)***	.29 (.59)	31.46 (< .001)***
Adaptive psychological characteristics[a]			
PwSCI/ABI	.01 (.45)	.84 (.36)	1.27 (.26)
SO	.01 (.55)	.31 (.58)	1.15 (.29)
Maladaptive psychological characteristics[a]			
PwSCI/ABI	.07 (< .01)**	10.90 (< .01)**	.41 (.52)
SO	.00 (1.00)	.00 (1.00)	.00 (.98)
Explained variance	N.a.	41.9%	40.4%

Note. SCI: spinal cord injury; ABI: acquired brain injury; pwSCI/ABI: person with SCI or ABI; SO: significant other; N.a.: not applicable.
* p-value < .05; ** p-value < .01; *** p-value < .001.
[a] Assessed at the start of inpatient rehabilitation (baseline).
[b] Only bivariately significant variables ($p < .05$) were added in the MANCOVA models.
[c] Pillai's Trace Value.

In ABI, the final MANCOVA model shows that early post-injury psychological distress of the significant other was the only predictor of psychological distress at dyad level. Among pwABI, none of the variables was a significant predictor of psychological distress when adjusted for other variables. Among significant others, own early post-injury psychological distress was found to be the only significant predictor.

DISCUSSION

By using a dyadic approach and comparing two diagnostic groups, this study extends upon earlier research aimed to identify sociodemographic, injury-related and psychological predictors of later psychological distress among pwSCI/ABI and significant others.

The hypothesis that psychological variables relate more strongly to psychological distress among pwSCI/ABI and significant others than sociodemographic and injury-related variables was supported and in line with previous research findings.[10–14,16–19] It was additionally hypothesized that intra-personal and inter-personal psychological variables are both important in the prediction of psychological distress. As an indication of inter-dependence between pwSCI/ABI and significant others,[20] correlations were found between psychological variables of one person in a dyad and outcome psychological distress of the other person and at dyad level psychological variables of both persons within a dyad did indeed add in the prediction of psychological distress. On the other hand, the crosswise correlations were relatively weak ($r < .3$) and in combination with the own psychological variables, they were not of added value in the prediction of psychological distress at individual level, which contradicts our hypothesis. Possibly, this could be explained by the strong correlation between own baseline and follow-up psychological distress in combination with a relatively small change in psychological distress scores over time which might limit the impact of other variables in the explanation.

Separately, early post-injury psychological distress, A-PC and M-PC were all significant predictors of psychological distress, both at dyad and individual level. However, altogether, early post-injury psychological distress and M-PC were the most important predictors of psychological distress among pwSCI/ABI, and early post-injury psychological distress among significant others. Possibly, the concept of 'maladaptive psychological characteristics' measured with the M-PC is more similar to the HADS (measuring anxiety and depression), than the concept measured with the A-PC, which may explain why A-PC was found to be a less important predictor of psychological distress. This idea is supported by the relatively strong correlation between the baseline HADS and M-PC (pwSCI/ABI: $r = .76$; significant others: $r = .80$).

Exploratory, differences between diagnostic groups were investigated. We did find some diagnosis-based differences in levels of variables and in correlations, but not in the predictors of psychological distress. In both diagnosis-subgroups, own early post-injury psychological distress and M-PC seem to be the most important predictors. Results were less consistent in the ABI subgroup due to absence of significant predictors to predict psychological distress among pwABI. However, *F*-values found among pwABI were comparable to those found among pwSCI and *p*-values were close to .05. Future research should be conducted to explore if the differences do reflect diagnosis-based differences in the prediction of psychological distress, or if the differences could be explained e.g., by limited power in our sample.

Study limitations

Firstly, to increase the power, we have combined different psychological scales, with the result that no statements can be made about the predictive value of individual psychological variables. Exploratory factor analysis and a comparable application in previous research supported our choice to cluster the scales.[47] Secondly, relatively large part of the dyads did not meet the inclusion criteria or declined to participate which may have resulted in selection or non-response bias. Unfortunately, we have no information on the excluded/declined dyads. However, regarding age, sex and injury-specific information (completeness SCI, level of SCI, physical independence pwABI) our sample seems to be highly comparable to the general Dutch SCI and stroke population in inpatient setting.[48,49] Thirdly, selective loss to follow-up may have disrupted the results. However, this seems to be unlikely since scores on the significant predictors of psychological distress did not differ between the analyzed and dropped-out dyads. Fourthly, half of the pwSCI had an AIS D score. They have a better prognosis than pwSCI with a score of A–C, possibly resulting in lower psychological distress levels at baseline and follow-up. However, since we found that injury-related factors did not add to the prediction of psychological distress, we do not expect major differences in the results when a smaller proportion of the pwSCI would have had an AIS score of D. Fifthly, different kinds of significant others have participated in the study. Most significant others (78.3%) were partner, therefore, the results mainly apply to the situation in which the significant other is the partner. Lastly, previous research has shown that a history of pre-injury psychological problems is an important predictor of post-injury psychological distress.[11–14] We have not assessed pre-injury psychological problems, alternatively, we included the HADS at baseline which was considered as an indicator for vulnerability at admission.

Implications

Our results highlight the importance of one's own early post-injury psychological distress and adaptive and maladaptive psychological characteristics in the prediction of later psychological distress. A screening based on these variables, conducted at the start of inpatient rehabilitation, could help to identify persons more at risk for psychological distress earlier. Screening only the pwSCI/ABI does not seem enough to accurately predict psychological distress among both persons within the dyad. It is also important to get insight into distress among significant others since significant others play an important, often necessary, role in providing practical and emotional support to pwSCI/ABI.[50,51] If significant others become overloaded, this has adverse consequences for themselves, but also for the pwSCI/ABI, possibly even institutionalisation.[52,53] Therefore, we recommend to screen both pwSCI/ABI and their significant others.

Risk screening also helps to personalize the support provided to pwSCI/ABI and significant others, thereby making the most efficient use of available resources.[54] Previous research has shown that tailored interventions provide more positive outcomes than the application of standard interventions.[55] Interventions that apply psychological techniques (e.g., cognitive behavioral therapy, coping skill-training, problem-solving therapy) seem to be most effective in the reduction of psychological distress.[55]

Finally, identifying pwSCI/ABI and significant others at greater risk for psychological distress earlier and providing them appropriate support could be crucial in reducing healthcare system burden and costs.[56–58]

Conclusions

There is a dyadic connection between early post-injury psychological distress, psychological variables, and follow-up psychological distress among pwSCI/ABI and significant others. However, primarily one's own early post-injury psychological distress and psychological variables were important in the prediction of follow-up psychological distress. The results were comparable for SCI and ABI. A psychological screening of patients and significant others could help to early identify persons more at risk for later psychological distress.

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Conflicts of interest

The authors report no conflicts of interest.

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SUPPLEMENTARY TABLES

Supplementary Table S7.1 Bivariate coefficients between independent variables and psychological distress of the pwSCI/ABI and significant others six months after discharge from inpatient rehabilitation, separated by diagnosis

	Spinal cord injury		Acquired brain injury	
	Psychological distress pwSCI[b]	Psychological distress SO[b]	Psychological distress pwABI[b]	Psychological distress SO[b]
	Correlation coefficient (*p*-value)	Correlation coefficient (*p*-value)	Correlation coefficient (*p*-value)	Correlation coefficient (*p*-value)
Sex (female)				
PwSCI/ABI	.30 (< .01)**	.03 (.79)	-.10 (.41)	-.12 (.29)
SO	-.18 (.11)	-.08 (.50)	.10 (.39)	.09 (.42)
Age				
PwSCI/ABI	-.09 (.41)	-.01 (.92)	-.02 (.89)	.20 (.08)
SO	-.04 (.76)	.03 (.80)	.08 (.50)	.12 (.29)
Education (high)				
PwSCI/ABI	.05 (.64)	.07 (.55)	-.31 (< .01)**	.03 (.79)
SO	-.22 (.05)	-.07 (.56)	-.27 (.02)*	-.05 (.65)
Significant other is partner	-.00 (.97)	.07 (.56)	.04 (.74)	.05 (.69)
Physical independence	.13 (.26)	-.07 (.52)	-.10 (.40)	.01 (.94)
Psychological distress[a]				
PwSCI/ABI	.59 (< .001)***	.20 (.08)	.55 (< .001)***	-.00 (.99)
SO	.30 (< .01)**	.64 (< .001)***	.13 (.28)	.55 (< .001)***
Adaptive psychological characteristics[a]				
PwSCI/ABI	-.49 (< .001)***	-.30 (< .01)**	-.43 (< .001)***	-.10 (.37)
SO	-.19 (.09)	-.41 (< .001)***	-.32 (< .01)**	-.31 (< .01)**
Maladaptive psychological characteristics[a]				
PwSCI/ABI	.63 (< .001)***	.31 (< .01)**	.53 (< .001)***	.04 (.75)
SO	.25 (.02)*	.52 (< .001)***	.08 (.49)	.40 (< .001)***

Note. SCI: spinal cord injury; pwSCI: person with SCI; SO: significant other.
* *p*-value < .05; ** *p*-value < .01; *** *p*-value < .001.
[a] Assessed at the start of inpatient rehabilitation (baseline).
[b] Assessed at six months after inpatient discharge (6 months follow-up).

Supplementary Table S7.2 SCI: MANCOVA to predict psychological distress six months after discharge from inpatient rehabilitation ($n = 79$)

	Model 1: Basic model[b]			Model 2a: Psychological distress[a]		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwSCI	Distress SO		Distress pwSCI	Distress SO
	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)
Sex (female)						
PwSCI	.10 (.02)*	7.43 (< .01)**	.07 (.79)	.08 (.04)*	6.36 (.01)*	.02 (.88)
SO	–	–	–	–	–	–
Psychological distress[a]						
PwSCI	–	–	–	.31 (< .001)***	29.85 (< .001)***	.02 (.88)
SO	–	–	–	.39 (< .001)***	1.82 (.18)	47.32 (< .001)***
Adaptive psychological scale[a]						
PwSCI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Maladaptive psychological scale[a]						
PwSCI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Explained variance	N.a.	8.8%	0.1%	N.a.	40.9%	41.0%

Supplementary Table S7.2 *Continued*

	Model 2b: Adaptive psychological scale^a			Model 2c: Maldaptive psychological scale^a		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwSCI	Distress SO		Distress pwSCI	Distress SO
	V^c (*p*-value)	F (*p*-value)	F (*p*-value)	V^c (*p*-value)	F (*p*-value)	F (*p*-value)
Sex (female)						
PwSCI	.07 (.06)	5.01 (.03)*	.09 (.77)	.05 (.15)	3.19 (.08)	.18 (.67)
SO	—	—	—	—	—	—
Psychological distress^a						
PwSCI	—	—	—	—	—	—
SO	—	—	—	—	—	—
Adaptive psychological scale^a						
PwSCI	.20 (< .001)***	18.33 (< .001)***	4.20 (.04)*	—	—	—
SO	.13 (< .01)**	.47 (.50)	11.06 (< .01)**	—	—	—
Maladaptive psychological scale^a						
PwSCI	—	—	—	.32 (< .001)***	35.89 (< .001)***	2.54 (.12)
SO	—	—	—	.22 (< .001)***	.36 (.55)	20.61 (< .001)***
Explained variance	N.a.	29.1%	20.9%	N.a.	42.0%	29.3%

Table S7.2 continues on next page.

Supplementary Table S7.2 *Continued*

	Model 3: Final model		
	Multivariate	Between-subjects effects	
		Distress pwSCI	Distress SO
	V^{c} (*p*-value)	F (*p*-value)	F (*p*-value)
Sex (female)			
PwSCI	.06 (.12)	3.83 (.05)	.02 (.89)
SO	—	—	—
Psychological distress^{a}			
PwSCI	.10 (.03)*	4.23 (.04)*	1.45 (.23)
SO	.18 (< .01)**	.092 (.762)	14.72 (< .001)***
Adaptive psychological scale^{a}			
PwSCI	.02 (.43)	.01 (.94)	1.53 (.22)
SO	.02 (.53)	.11 (.74)	.88 (.35)
Maladaptive psychological scale^{a}			
PwSCI	.07 (.07)	5.43 (.02)*	.14 (.71)
SO	.00 (.95)	.09 (.76)	.00 (.99)
Explained variance	N.a.	45.8%	44.2%

Note. SCI: spinal cord injury; pwSCI: person with SCI; SO: significant other; N.a.: not applicable.

* *p*-value < .05; ** *p*-value < .01; *** *p*-value < .001.

[a] Assessed at the start of inpatient rehabilitation (baseline).

[b] Only bivariately significant variables ($p < .05$) were added in the MANCOVA models.

[c] Pillai's Trace Value.

Supplementary Table S7.3 ABI: MANCOVA to predict psychological distress six months after discharge from inpatient rehabilitation (*n* = 78)

	Model 1: Basic model[b]			Model 2a: Psychological distress[a]		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwABI	Distress SO		Distress pwABI	Distress SO
	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)
Education (high)						
PwABI	.06 (.09)	3.27 (.08)	.39 (.54)	.05 (.19)	2.74 (.10)	.01 (.91)
SO	.02 (.54)	1.11 (.30)	.52 (.47)	.02 (.45)	1.47 (.23)	.01 (.93)
Psychological distress[a]						
PwABI	–	–	–	.35 (< .001)***	32.89 (< .001)***	.00 (.98)
SO	–	–	–	.31 (< .001)***	1.66 (.20)	31.47 (< .001)***
Adaptive psychological scale[a]						
PwABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Maladaptive psychological scale[a]						
PwABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Explained variance	N.a.	11.1%	0.8%	N.a.	39.8%	30.7%

Table S7.3 continues on next page.

Supplementary Table S7.3 *Continued*

	Model 2b: Adaptive psychological scale[a]			Model 2c: Maldaptive psychological scale[a]		
	Multivariate	Between-subjects effects		Multivariate	Between-subjects effects	
		Distress pwABI	Distress SO		Distress pwABI	Distress SO
	V^c (*p*-value)	F (*p*-value)	F (*p*-value)	V^c (*p*-value)	F (*p*-value)	F (*p*-value)
Education (high)						
PwABI	.04 (.22)	2.34 (.13)	.18 (.67)	.03 (.28)	1.95 (.17)	.06 (.80)
SO	.01 (.61)	.95 (.33)	.26 (.61)	.04 (.23)	3.05 (.09)	.53 (.47)
Psychological distress[a]						
PwABI	–	–	–	–	–	–
SO	–	–	–	–	–	–
Adaptive psychological scale[a]						
PwABI	.09 (.03)*	6.70 (.01)*	.02 (.88)	–	–	–
SO	.10 (.03)*	3.33 (.07)	6.56 (.01)*	–	–	–
Maladaptive psychological scale[a]						
PwABI	–	–	–	.31 (< .001)***	30.34 (< .001)***	.16 (.69)
SO	–	–	–	.16 (< .01)**	1.46 (.23)	13.52 (< .001)***
Explained variance	N.a.	27.9%	10.1%	N.a.	38.3%	16.5%

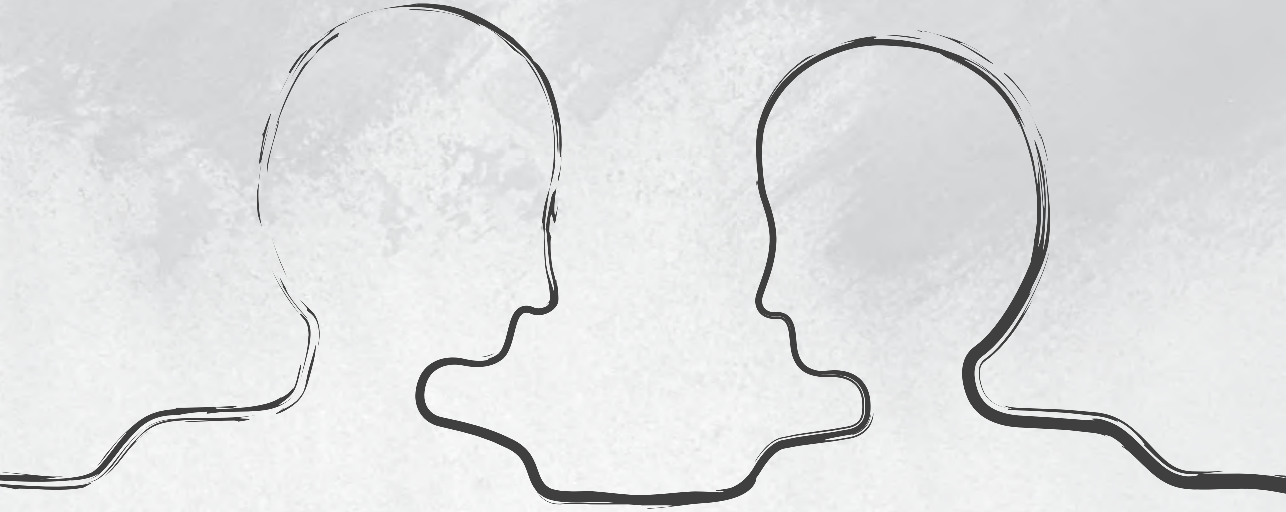
Supplementary Table S7.3 *Continued*

	Model 3: Final model		
	Multivariate	Between-subjects effects	
		Distress pwABI	Distress SO
	V[c] (*p*-value)	F (*p*-value)	F (*p*-value)
Education (high)			
PwABI	.04 (.30)	1.91 (.17)	.03 (.87)
SO	.03 (.35)	1.86 (.18)	.00 (.97)
Psychological distress[a]			
PwABI	.08 (.07)	3.81 (.06)	.23 (.63)
SO	.18 (< .01)**	.24 (.63)	14.37 (< .001)**
Adaptive psychological scale[a]			
PwABI	.01 (.85)	.29 (.59)	.16 (.69)
SO	.03 (.42)	1.71 (.20)	.62 (.43)
Maladaptive psychological scale[a]			
PwABI	.06 (.12)	3.94 (.05)	.03 (.88)
SO	.00 (.95)	.08 (.77)	.07 (.80)
Explained variance	N.a.	45.6%	31.8%

Note. ABI: acquired brain injury; pwABI: person with ABI; SO: significant other; N.a.: not applicable.
* *p*-value < .05; ** *p*-value < .01; *** *p*-value < .001.
[a] Assessed at the start of inpatient rehabilitation (baseline).
[b] Only bivariately significant variables ($p < .05$) were added in the MANCOVA models.
[c] Pillai's Trace Value.

CHAPTER 8

General discussion



The general objective of this thesis was specified in two aims:

1. To enlarge the insight in the impact of an SCI or ABI on psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others;
2. To identify intra-personal and inter-personal risk factors that may predict later psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others.

The following paragraphs provide an overview of the main findings, a discussion of the main findings, methodological considerations, clinical implications and suggestions for further research. The general discussion ends with the final conclusions.

MAIN FINDINGS

Part I The impact of SCI or ABI on psychosocial adjustment outcomes

The studies described in **chapter 2** and **3** focused on the impact of an SCI on individuals with SCI and their partners five years after the onset of SCI. **Chapter 2** showed that overall levels of mental health and life satisfaction were similar for individuals with SCI and their partners. However, differences in satisfaction were found when focusing on specific life domains such as 'leisure situation', 'partnership relation', 'family life' and 'self-care ability'. **Chapter 3** described that partners provided support often and in a large variety of activities. More support provided was related to higher perceived burden and lower life satisfaction among partners. Furthermore, burden was related to lower mental health and life satisfaction. In **chapter 4**, a literature review was conducted aiming to identify and evaluate measures used to assess the impact of caregiving among caregivers of individuals with stroke, SCI or amputation. In the last decade, forty-eight measures were used of which only eighteen in more than one unique study. In general, the evidence on the clinimetric quality of the found measures was not optimal, especially regarding measurement error and responsiveness of measures.

Part II Factors to predict psychosocial adjustment outcomes

In **chapter 5, 6** and **7** was investigated which intra-personal (one's own) and inter-personal (of the other person in a dyad) variables are important in the explanation of psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others. **Chapter 5** described that 55% of the variance in psychological distress (measured shortly after the start of inpatient rehabilitation) among significant others of individuals with SCI or ABI was explained by the relationship between resilience and psychological distress. This relationship was mediated by appraisals of threat and loss, and passive coping. **Chapter 6** provided insight into the dyadic impact between individuals with SCI or ABI and their significant others. It was found that the combination of self-efficacy levels of individuals with SCI or ABI and their significant others, measured shortly after the start of inpatient rehabilitation, predicted personal and family adjustment six months after discharge. Individuals in the low-self-efficacy dyads were more at risk for personal and family adjustment problems. **Chapter 7** showed that sociodemographic and injury-related variables did add little in the prediction of psychological distress among individuals with SCI or ABI and significant others six months after discharge from inpatient rehabilitation. There was a dyadic connection between early post-injury psychological distress, psychological variables, and follow-up psychological distress, however, primarily one's own post-injury psychological distress and psychological variables were important in the prediction of follow-up psychological distress.

DISCUSSION OF THE MAIN FINDINGS

Two main themes will be discussed in this section: 'impact on significant others' and 'personal and dyadic risk factors for psychosocial adjustment outcomes'.

Impact on significant others

In line with results found in previous studies conducted in our own research institute and internationally, this thesis showed that adverse psychosocial adjustment outcomes in terms of low mental health, low life satisfaction (**chapter 2** and **3**), high levels of caregiver burden (**chapter 3**), high levels of psychological distress (**chapter 5–7**) and problematic family functioning (**chapter 6**) are frequent among significant others of individuals with SCI or ABI.[1–8] Significant others play an important role in providing (long-term) support to individuals with SCI or ABI, both practical and emotional (**chapter 3**).[9,10] Although, providing support may have positive psychosocial consequences (e.g., self-esteem derived from caregiving and personal growth),[11,12] it was also found that providing support was related to higher caregiver burden and lower life satisfaction (**chapter 3**).

In recent years, in the Netherlands the normative discourse regarding care has shifted resulting in a stronger call for solidarity, a strengthened norm of providing informal care to close relatives and decreased reliance on the government as care provider.[13,14] This, combined with budgetary cuts in public services prioritizing home care above institutional care (resulting in shorter stays in hospitals and inpatient rehabilitation settings), enlarged the importance that is attached to the contributions of significant others in providing informal care.[15–17] Different studies and our own study (**chapter 3**) showed that significant others of individuals with SCI or ABI do indeed provide much informal support (as they also did before this normative discourse shift), both practical and emotional, and also on the long-term.[9,10] By providing informal care, significant others play an essential role in maintaining the health and psychosocial well-being of individuals coping with chronic health conditions.[17] Most significant others are intrinsically motivated to provide informal support, however, they are only able to do so when they are doing well themselves. When they experience high levels of caregiver burden, this may have far-reaching adverse consequences. Their own health, functioning and psychosocial well-being can be compromised, as well as that of the individuals with chronic health conditions.[17–20] Significant others may feel restricted socially and economically (e.g., having less leisure time, social isolation due to inability to maintain social relationships, reduction or loss of work, loss of income).[17,21,22] Not rarely, dropout among significant others as a consequence of overload is reason for institutionalization of the individual with chronic health conditions.[19,22] At community level adverse consequences of overload among significant others can be found in, for example, increasing welfare payments for governments, increasing demand on home health services and higher costs for employers (e.g., costs due to absenteeism, workday interruptions and replacement of employees who are no longer able to work).[17,23,24] Various studies tried to economically value informal care and they show that the economic value of informal care is substantial.[24] This underlines the importance to pay attention to the psychosocial well-being of significant others during and after (inpatient) rehabilitation and facilitates a social debate focusing on the responsibilities regarding the psychosocial well-being of significant others of individuals with chronic health conditions, which may guide policy development.[17]

Personal and dyadic risk factors for psychosocial adjustment outcomes

The hospital-based Restore4Stroke study already showed that in particular psychological characteristics provide an important contribution in the prediction of psychosocial adjustment outcomes among individuals with stroke and their significant others.[3,4,25] Sociodemographic and injury-related factors were found to be less contributory. The POWER study (**chapter 5–7**) extends these results by presenting figures on individuals with ABI and significant others in an inpatient rehabilitation setting, representing a population generally having more severe injuries, by measuring potential risk factors at the start of inpatient rehabilitation instead of two months post-stroke, and by also focusing on individuals with SCI and their significant others. The importance of psychological factors in the prediction of later psychosocial adjustment outcomes is also found in international studies focusing on SCI or ABI,[26–29] and in studies focusing on other diagnostic groups (e.g., cancer, dementia, heart disease, or Parkinson's disease).[30–34] These findings and our own comparisons between SCI and ABI (**chapter 5–7**) do not suggest important differences between diagnoses in the prediction of later psychosocial adjustment outcomes among individuals with chronic health conditions and among significant others.

Just as in the Restore4Stroke study, but with a more tailored statistical technique, we also found support for the existence of dyadic associations between individuals with a chronic health condition and significant others. Levels of mental health and life satisfaction were found to be related among individuals with SCI and their partners (**chapter 2**), baseline self-efficacy levels of both individuals within a dyad were found to be important in the prediction of their both personal and family adjustment (**chapter 6**) and crosswise relationships exist between baseline psychological characteristics and later psychological distress (**chapter 7**). Insight into the dyadic relationships between individuals shows that individuals interact and that the family cannot be ignored if we want to explain why some individuals or families are better able to adjust than others.[35] However, in the prediction of psychosocial adjustment outcomes, it is found that persons' own psychological variables proved to be of greater predictive value than the psychological variables of the other person within the dyad (**chapter 7**), which is in line with results found in previous studies.[3,36,37]

METHODOLOGICAL CONSIDERATIONS

Doing research is accompanied by making methodological choices that may strength or limit the findings of the study. Methodological considerations regarding the study population and the inclusion of participants are discussed below.

Study population

The Umbrella project has focused on a selective group of wheelchair-dependent individuals with SCI admitted to one of the eight Dutch rehabilitation centers specialized in SCI care.[38] Study results cannot be generalized to the total SCI population, but do provide insight into the situation of a relatively homogenous group of individuals with a more severe SCI. It is valuable that primary family caregivers also have participated, although only at the last measurement.

In the POWER study, we have included a large group of individuals with disabilities and their significant others in three different diagnosis groups which together represent major causes of chronic disability: SCI, ABI and amputation.[39,40] The number of individuals with an amputation included in the study was remarkably lower than the number of individuals with SCI or ABI, mainly because there were less individuals with an amputation and they were less often admitted to inpatient rehabilitation. In total, 329 dyads were included in the POWER study, of which 146 in the SCI subgroup, 160 in the ABI subgroup and only 23 in the amputation subgroup. The last group was too small to be included in statistical analyses and therefore we decided to focus only on SCI and ABI in this thesis. As a consequence, we were not able to conclude anything about the amputation subgroup.

Secondly, we have excluded individuals with SCI, ABI or an amputation when (nearly) full recovery was expected, return to home was not expected, and in case of limited life expectancy or severe cognitive or intellectual problems. This selection has consequences for the generalizability of our results. It is possible that the presence and levels of psychosocial adjustment problems varies between included and excluded dyads. For example, in previous research is found that cognitive impairment (which was an exclusion criterion in severe cases) after stroke is an important predictor of post-stroke anxiety.[26]

A third point to note is the relatively high drop-out of participants between inclusion and completion of the first questionnaire. Of the 329 included dyads, 276 individuals with a disability and 260 significant others completed the first questionnaire. The most important reason to decline participation after signing informed consent was that participants on second thoughts found it too hard to complete the questionnaires besides everything else that came up their way in the first phase of inpatient rehabilitation. Unfortunately, we do not have information about the characteristics of the dropped-out individuals which disables the possibility to compare the individuals who dropped-out with the individuals who have participated. Therefore, we cannot exclude that selective dropped-out has disrupted our results. For example, when the dropped-out individuals were characterized by having relatively high levels of psychological distress at the start of inpatient rehabilitation, this may have led to an underestimation of adverse psychosocial adjustment problems six months after discharge from inpatient rehabilitation, since early distress turned out to be an important predictor of later psychosocial adjustment. Regarding the representativeness of our study sample, we were only able to compare some basic baseline characteristics such as age, sex and injury-specific information (completeness of injury (SCI), level of injury (SCI) and physical independence (ABI)) with the characteristics found in the general Dutch SCI and stroke population in an inpatient rehabilitation setting.[41,42] Regarding these characteristics, our sample seems to be representative.

Inclusion

We are proud of the high number of participating rehabilitation centers in the Umbrella project and the POWER study. In both studies, all eight rehabilitation centers specialized in

SCI have participated. In the POWER study, four additional rehabilitation centers were willing to participate. This shows the importance Dutch rehabilitation centers attach to (participation in) scientific research. However, in the POWER study, a disproportionate number of the participating dyads (172 out of 329) came from *De Hoogstraat*. *De Hoogstraat* is a relatively large rehabilitation center and in this center SCI, ABI and amputation units participated in the study, which was not the case in all participating centers. However, this cannot completely explain the large differences in inclusion numbers between centers. In *De Hoogstraat* the researchers themselves were, in collaboration with research assistants, responsible for the inclusion. In most other participating rehabilitation centers, health care professionals (e.g., physiotherapists or social workers) fulfilled the role of research assistant besides their own job. They often reported to experience practical restrictions (e.g., time) and other broad challenges (e.g., priorities, reduced involvement) which restricted them in the execution of the study and which in some centers has limited the inclusion process. The constant presence of researchers or research assistants in *De Hoogstraat* helped to keep everyone involved in the study. The study was less visible in the other centers, which sometimes reduced the urgency and motivation to continue the recruitment of new participants.

IMPLICATIONS FOR REHABILITATION CARE

Based on the described and discussed study results we have formulated implications that may help to improve inpatient rehabilitation care for individuals with SCI or ABI and their significant others.

Attention for significant others

For multiple reasons it is important that significant others are doing well.[17–20,23,24] Therefore, in (rehabilitation) care more attention is needed for their functioning and well-being. This is particularly relevant in the current society in which is given a great call upon the contributions of significant others.[18]

In the Netherlands, the organization of rehabilitation care is described in diagnosis-specific guidelines. In the stroke rehabilitation guideline, the importance of paying attention to significant others is already endorsed in 2008, e.g., by the recommendation to screen for caregiver burden.[43,44] However, the current SCI rehabilitation guideline does not yet include any recommendations regarding the involvement of significant others or the family in rehabilitation care.[45] Also, in the most recent vision paper describing the main themes of interest and ambitions for medical specialists in 2025, published by the Dutch Federation of Medical Specialists, attention for significant others is not even mentioned.[46] To our opinion, it is important that all rehabilitation guidelines and vision documents which guide formal care provision should include recommendations that generate more attention for significant others.

Recommendations in health care guidelines is an important step, however broader changes in the organization of care are needed. Current systems of care provision are organized and financed at patient-level. As a consequence, attention for and the involvement of significant others in care programs is not always easy (or even possible). Structural changes in the organization and financing of care are needed. This calls for a political discussion about the responsibilities regarding the well-being of significant others. It would be even better to adopt a care provision model in which individuals with a health condition and their significant others are not considered individually, but as dyads (or even broader families) which can be supported as a system.[47]

Furthermore, even when more general purposes of family-orientated care are clear and relevant, for health care professionals it appears to be difficult to integrate this perspective in health care services.[48] Therefore, it is also important to integrate family-oriented principles into the training of health care professionals, i.e., to include these principles in the (para-) medical curriculums.[48]

Screening for psychological distress

Our results showed that in particular psychological distress at the start of inpatient rehabilitation is an important predictor for later psychosocial adjustment outcomes. Other psychological factors do also relate to adjustment outcomes, but they do not seem to be of substantial additional value in the prediction of adjustment outcomes besides baseline psychological distress. Based on these findings we recommend health care professionals to screen psychological distress among individuals with SCI or ABI and their significant others as part of regular inpatient rehabilitation care. Screening offers possibilities to identify vulnerable people at an early stage and to support them during inpatient rehabilitation.

Screening of psychological distress among individuals with SCI is already recommended in the SCI rehabilitation guideline.[45] Since 2018 a comprehensive psychological screening focusing on psychological distress and other psychological characteristics (e.g., self-efficacy, coping and resilience) has been implemented. This screening is applied in most of the Dutch rehabilitation centers specialized in SCI.[49] Also in the stroke rehabilitation guideline it is advised to screen for psychological distress, in this case as part of a more comprehensive neuro-psychological screening. However, the screening is not systematically administered everywhere and therefore we recommend adhering to the guidelines regarding the screening of psychological distress.

We also recommend to screen for psychological distress among significant others (SCI and ABI). More so, because there is a potential to improve the health and well-being of the whole family by attending the psychological needs of significant others.[50,51] In the stroke rehabilitation guideline it is already recommended to screen caregiver burden among significant others, however, this is not conducted systematically everywhere.[43] Screening significant others is not described in the current SCI rehabilitation guideline.[45] In the current organization of care, which is organized at patient-level, it could be difficult to implement a screening for significant others. However, our study showed that only screening the individual with SCI or ABI is not enough to accurately predict psychosocial adjustment problems among significant others.

In different meetings of Dutch rehabilitation care professionals specialized in SCI or ABI (*Nederlands Vlaams Dwarslaesie Genootschap* and *Werkgroep Hersenletsel Revalidatie*) we have discussed the willingness and opportunities to systematically implement a short psychological distress screening for significant others (SCI and ABI) during inpatient rehabilitation. In general, the need to pay attention to significant others is recognized as well as the potential benefits of screening. The seven guidelines described by Cadman et al. determining whether a screening program is likely to be effective provide a valuable framework to discuss the most important doubts.[52] Based on our results we reflect on these seven topics.

Firstly, the screening has to be effective. Given our results (in particular those described in **chapter 7**), screening for psychological distress appears to be suitable for identifying and predicting psychosocial adjustment problems among significant others.

Secondly, there should be efficacious treatments available. In the current organization of care it is difficult to treat significant others in rehabilitation care, other than referring them to e.g., the general practitioner. The primary purpose of the screening is signaling and awareness of psychosocial problems. Recognition of experienced problems and providing reassurance can already be helpful for significant others.[53] Furthermore, in the political discussion the screening results may emphasize the importance of paying more attention to significant others in rehabilitation care.

Thirdly, the burden of suffering needs to warrant the screening. All significant others who are confronted with chronic health conditions among someone close to them have to adjust to the changed situation.[47,54] This makes them all potentially vulnerable for psychosocial adjustment problems. This thesis shows that adverse psychosocial adjustment outcomes are frequent among significant others and the impact could be large at different levels.[18–20] Therefore, it seems to be useful to screen all significant others. Screening psychological distress by completing a short questionnaire is not very burdensome and can quickly provide insight into experienced problems.

Fourthly, there should be a good screening test. Based on our experiences we would recommend the Hospital Anxiety and Depression Scale (HADS) in the assessment of psychological distress.[55] The HADS is a commonly used scale to assess general psychological distress.[56,57] The use of the HADS is already recommended in the rehabilitation guidelines for individuals with SCI or stroke.[43,45] The fourteen-item self-report questionnaire is easy to complete in just a few minutes.[43,45] However, there are also other scales available to assess psychological distress.[58]

Fifthly, the screening has to reach those who could benefit. In rehabilitation care, it is usual to have contact with significant others. Likely, these significant others are also those persons who are and will be most intensively involved. Therefore, significant others can be easily reached for screening during the rehabilitation phase.

Sixthly, the health care system should be able to cope with the screening. The implementation of the psychological distress screening does not have to be very complicated. The screening can even be offered without face-to-face contact with a health care professional. Face-to-face contact could be a next step when the significant other reports to experience psychological distress. Innovations, such as digitizing of the screening, can help to better facilitate the screening and processing of the screening results.

Seventhly, individuals with positive screenings should comply with advice and interventions. In the intervention part of our study we experienced that it might be difficult to motivate significant others (and also individuals with SCI or ABI) during inpatient rehabilitation to take part in an intervention focusing on their own problems regarding psychosocial well-being and participation. Often they do not expect problems on the long term or otherwise think that they are able to deal with the problems by themselves. It is important to develop interventions that meet their needs and also to carefully consider the best time to offer an intervention.[59,60] Initially, the screening will mainly function as a tool to start a conversation about psychological distress among significant others.

To conclude, we recommend to systematically screen psychological distress early during inpatient rehabilitation among individuals with SCI or ABI and their significant others. Screening appears to be a relatively easy way to generate more attention for and recognition of psychosocial adjustment problems. Screening can help to identify and provide support to those individuals experiencing psychological distress already at an early stage during inpatient rehabilitation. In the box below, all our recommendations are briefly summarized.

More attention for significant others of individuals with SCI or ABI in rehabilitation care

- Include recommendations that generate more attention for significant others in relevant guidelines that guide formal (rehabilitation) care.
- Current systems of care provision are organized and financed at patient-level, which limits the possibilities of health care professionals to be able to have attention for and to involve significant others in rehabilitation care. Structural changes in the organization of care are needed.
- Integrate family-oriented principles into the medical curriculums of health care professionals.

Systematically screen psychological distress

- Adherence to the SCI and stroke rehabilitation guidelines to screen psychological distress among individuals with SCI or ABI is recommended.
- Also screen significant others and include this in relevant guidelines.

DIRECTIONS FOR FUTURE RESEARCH

Scientific research is important in order to be able to improve the care available for individuals with SCI or ABI and their significant others. Based on our results, we have formulated directions for future research.

Qualitative research

The current thesis is based on the quantitative analysis of questionnaire data. As noticed before, in the POWER study part of the participants dropped-out directly after inclusion, mostly because the high burden they experienced in completing the (long) questionnaires in the intense first phase of inpatient rehabilitation. Possibly, other research methods, for example more qualitative ones (e.g., interviews) would have been less burdensome for them. Applying qualitative research methods would also have been valuable to get a more in-depth insight in the experiences and needs of individuals with SCI or ABI and their significant others. Such research may further have had benefits in the interpretation of the results and provide concrete directions for improving the support available for them.[61]

For example, previous qualitative studies showed that caregivers of individuals with SCI or stroke wanted to feel cared for with regard to their own emotional needs, but timing is an important factor to consider.[59,60] Therefore, for future research it is recommended to combine quantitative and qualitative research methods.

Furthermore, qualitative research may also beneficial to gain insight into the barriers and facilitators related to the implementation of the psychological distress screening. For example, a previous evaluation of the psychological screening for individuals with SCI showed that time required to perform the screening, data safety and privacy issues, logistics of the screening and the burden they assumed it would be for participants were considered as the main important barriers for conducting the screening from the point of view of health care professionals (i.e. psychologists). Support among those persons involved in the performance of the screening is essential to successfully implement the screening, so it is important to take their opinions and experiences into account.[49]

Psychological screening: further development and evaluation

Since 2018, a more extensive psychological screening is implemented for individuals with SCI, including psychological distress and other psychological characteristics (e.g., coping, resilience and self-efficacy).[49] In our study we also found evidence supporting that other psychological characteristics (e.g., appraisals, coping, resilience and self-efficacy) may be important in the prediction of later psychosocial adjustment outcomes (**chapter 5, 6** and **7**). However, in **chapter 7** was also found that such other characteristics add less in the prediction of psychological adjustment outcomes additional to baseline psychological distress. Therefore, in this thesis we recommended only to screen psychological distress among individuals with SCI or ABI and their significant others. However, this is a preliminary recommendation because we have not yet been able to analyze all our study data. There is also evidence that does support the importance of other psychological characteristics, for example when focusing on participation as adjustment outcome.[62] Future research and further evaluation of the SCI screening can provide insight into whether a more extensive psychological screening is more effective in identifying psychosocial complaints and the later risks of subsequent problems. In particular, it is important to investigate which psychological characteristics should be taken into account. Additionally, it may be interesting to explore whether kind of a triage-model is effective, for example a two-stage model in which the extensive psychological screening is only conducted when a first short screening (e.g., a psychological distress screening) indicates problems.

Family-orientated care

Being confronted with a chronic health condition has impact on the whole family. It is therefore important to involve the whole family as a unit in rehabilitation care, so that they together can be supported to deal with the situation.[47] This is the aim of family-orientated interventions, which embrace the view of the care-client as the patient and their family, rather than just the patient, and is characterized by the goal to develop and implement patient treatment plans within the context of families.[18] Existing family-orientated intervention models are most commonly available for pediatric patient populations and have not yet proven to be effective in adult rehabilitation health care.[18,63,64] There are different initiatives in adult health care (e.g., family meeting interventions),[63,64] but future research is needed to demonstrate the benefit of family-orientated interventions. High-controlled trials have long been recognized as the gold standard for assessing intervention effect.[65] However, such trials are challenging in real-world settings and for complex behavioral treatments that predominate in rehabilitation care.[66,67] Therefore, applying innovative or adaptive study methods may be promising. For example comparative effectiveness research which is characterized by a direct comparison of interventions in typical day-to-day clinical care, with the aim of tailoring decisions to the needs of individual patients.[65,67,68] The purpose is to assist consumers, clinicians, and policy makers to make informed decisions that will improve health care at both the individual and population level.[68]

CONCLUSIONS

SCI or ABI may have a large impact on the psychosocial well-being of the individuals involved, but also on that of their significant others. Adverse psychosocial adjustment outcomes regarding mental health, life satisfaction, caregiver burden, psychological distress (i.e., anxiety and depression) and family functioning are frequent among significant others. Despite previous attempts, in the current rehabilitation care is still limited attention for the psychosocial well-being of significant others.[69,70] The importance of a well-functioning significant other (for themselves, the individuals with SCI or ABI and at community level) is not yet widely recognized in (all) health care guidelines and in health care practice, and there are still limited options to support significant others. More attention for the psychosocial well-being of significant others is needed.

In the prediction of psychosocial adjustment outcomes, sociodemographic and injury-related variables were found not to be as important as psychological characteristics. Especially one’s own level of psychological distress was found to be important. Screening psychological distress among individuals with SCI or ABI and their significant others may help to early identify those individuals at risk for psychosocial adjustment problems and provides opportunities to support them already during inpatient rehabilitation.

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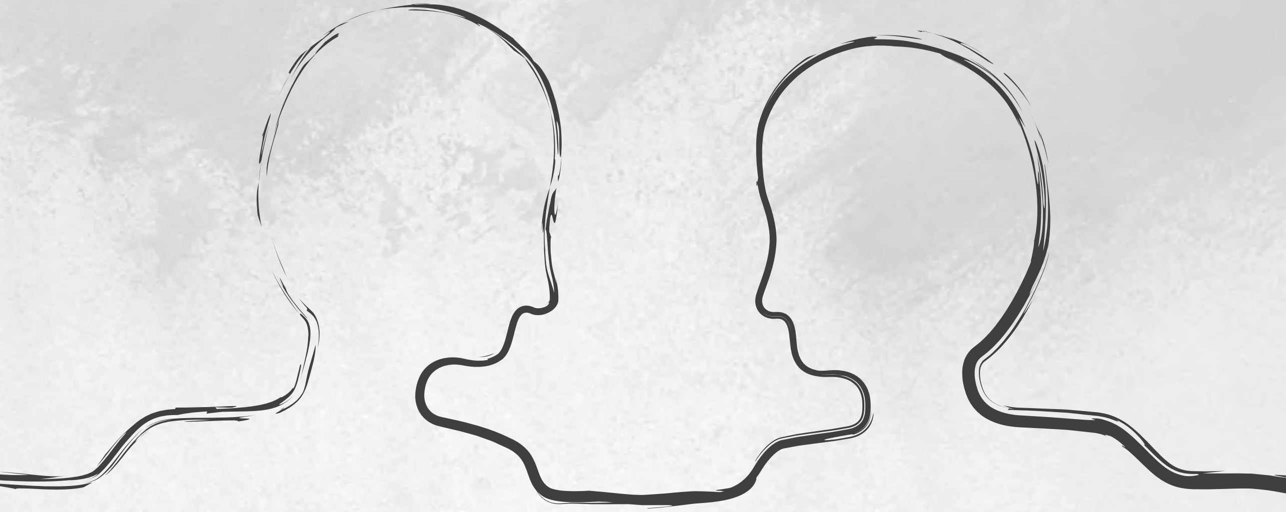
Summary



In this thesis we focus on the psychosocial well-being of individuals with a spinal cord injury (SCI) or acquired brain injury (ABI) and their significant others. SCI and ABI are two major causes of chronic disability worldwide and are the most common diagnoses among adults admitted to inpatient rehabilitation in the Netherlands. Individuals with SCI or ABI are confronted with (long-term) physical or cognitive impairments which may restrict them in their daily life functioning and affect their well-being. The International Classification of Functioning, Disability and Health (ICF) model is a framework that helps to classify the consequences of a health condition on a person's functioning in relation to personal and environmental factors. Personal and environmental factors vary from person to person and, in addition to the health condition itself, may explain differences in a person's functioning. A health condition like SCI or ABI and its consequences on the functional level often also affects psychosocial well-being. Reduced psychosocial well-being in terms of depressive feelings and decreased life satisfaction are frequent among individuals with SCI or ABI. The consequences on psychosocial well-being differ between persons as a result of functional problems and personal and environmental factors.

Support of significant others contributes to how individuals are able to deal with their health condition. Like individuals with SCI or ABI, significant others also have to adapt to the changed circumstances and the new roles that they often fulfill. As a consequence, significant others often report adverse psychosocial adjustment outcomes in terms of depression, anxiety or caregiver burden.

Our research was aimed to enlarge the insight in the impact of SCI or ABI on psychosocial adjustment outcomes among dyads of individuals with SCI or ABI and their significant others (part I), and to identify intra-personal (one's own) and inter-personal (of the other person in a dyad) risk factors that may predict later psychosocial adjustment outcomes (part II). This insight may help to explain why some individuals or families are better able to adjust than others. Furthermore, this knowledge may help to identify individuals or families at risk for later psychosocial adjustment problems early during inpatient rehabilitation and offers opportunities to better support them during this period. Results are derived from two prospective cohort studies, the Umbrella project and the POWER study. In the Umbrella project, individuals with a newly acquired SCI were followed from the start of inpatient rehabilitation up to five years after discharge. At the last follow-up assessment their primary family caregivers were also invited to complete a questionnaire. In the POWER study, we followed dyads of individuals with SCI or ABI and their significant others during inpatient rehabilitation up to six months after discharge. Both studies are introduced in **chapter 1**.

Part I The impact of SCI or ABI on psychosocial adjustment outcomes

The studies described in **chapter 2** and **3** focused on the impact of SCI on psychosocial adjustment outcomes among individuals with SCI and their partners five years after discharge from inpatient rehabilitation. We analyzed data of the Umbrella project in these chapters.

In **chapter 2** we compared levels of mental health and life satisfaction among individuals with SCI and their partners five years after discharge from inpatient rehabilitation. Data of sixty-five dyads were analyzed in this study. In general, the results showed that the levels of mental health and life satisfaction of individuals with SCI and their partners were similar and moderately to strongly inter-related. These associations were generally stronger in the subgroup of individuals with less severe SCI. Differences between individuals with SCI and partners were found in their satisfaction with specific life domains. Compared with their partners, individuals with SCI were significantly more often satisfied in the domains of ‘leisure situation’, ‘partnership relation’ and ‘family life’, and less often satisfied with their ‘self-care ability’. Both individuals with SCI and partners were least satisfied with the ‘sexual life’ domain. To conclude, this study showed similarities but also differences in mental health and life satisfaction between individuals with SCI and their partners five years after discharge from inpatient rehabilitation.

The aim of **chapter 3** was to describe the type of activities and regularity with which partners provided support to individuals with SCI five years after discharge from first inpatient rehabilitation. Furthermore, we investigated the levels and determinants of perceived caregiver burden, mental health and life satisfaction in partners. In this study, data of sixty-seven partners were available. We found that partners provided support in a large variety of activities. Partners provided more and different types of support to individuals with tetraplegia compared to those with paraplegia. Over forty percent of the partners experienced high levels of caregiver burden, a quarter low mental health and almost half low life satisfaction. More support provided was related to higher perceived burden and lower life satisfaction. Burden was further related to lower mental health and life satisfaction. To conclude, the high levels of perceived burden among partners and the associations between higher burden and lower well-being show the importance to prevent caregiver overload in partners of individuals with SCI. Monitoring burden during regular rehabilitation visits may help to early detect burden.

Chapter 4 reports the results of a systematic literature review aimed to identify measures used to evaluate the impact of caregiving among caregivers of persons with stroke, spinal cord injury, and amputation in the last decade; and to systematically evaluate their clinimetric properties reported in validation studies. We identified a total of 192 publications that reported the results of 154 unique studies, mostly focusing on caregivers of individuals with stroke. In these studies a total of forty-eight different measures were used to assess the impact of caregiving, mostly describing negative impact. Thirty measures were used only once and were not further described. We used the COSMIN guidelines to assess clinimetric properties and methodological quality of the eighteen measures that were used in at least two studies. We found that some clinimetric properties were often investigated, for example, the degree to which the scores of measures are an adequate reflection of the dimensionality of the construct to be measured (structural validity), the degree of the interrelatedness among the items of a measure (internal consistency), and the degree to which the scores of a measure are consistent with hypotheses for instance with regard to relationships to scores of other measurements (hypotheses testing for construct validity). The extent to which scores for individuals who have not changed are the same for repeated measurement (reliability) was less often investigated. This also applies to the degree to which a translated or culturally adapted measure is an adequate reflection of the original version (cross-cultural validity), or the degree to which the scores of a measure are an adequate reflection of a 'gold standard' (criterion validity). Aspects regarding measure development and the degree to which the content of the measure is an adequate reflection of the construct to be measured (content validity) were rarely described. Lastly, tests to investigate the systematic and random errors in measure scores (measurement error) and the ability of a measure to detect change over time (responsiveness) were exceptional. We concluded that there is a wide variety of impact of caregiving measures, but the evidence on the clinimetric quality of the found measures was not optimal.

Part II Factors to predict psychosocial adjustment outcomes

In the second part of this thesis, we reported results of the POWER study. An important aim of this study was to identify intra-personal and inter-personal variables that are important in the prediction of psychosocial adjustment outcomes among individuals with SCI or ABI and their significant others.

In **chapter 5** we investigated the relationship between resilience and psychological distress among significant others, and whether appraisals of threat and loss, and passive coping mediated this relationship. Variables were assessed shortly after the start of inpatient rehabilitation of the individual with SCI or ABI. We had complete data-sets of 228 significant others in this study. In total, 34–41% of all significant others reported to experience high levels of psychological distress at the start of inpatient rehabilitation. Over half of the variance in psychological distress was explained by the relationship between resilience and psychological distress. This relationship was mediated by appraisals of threat and loss, and passive coping. The relationship between resilience and psychological distress was similar for the SCI and ABI groups. We stated that it seems useful to investigate if interventions focusing on psychological factors like resilience, appraisal and coping are effective to prevent or reduce psychological distress among significant others of persons with SCI or ABI.

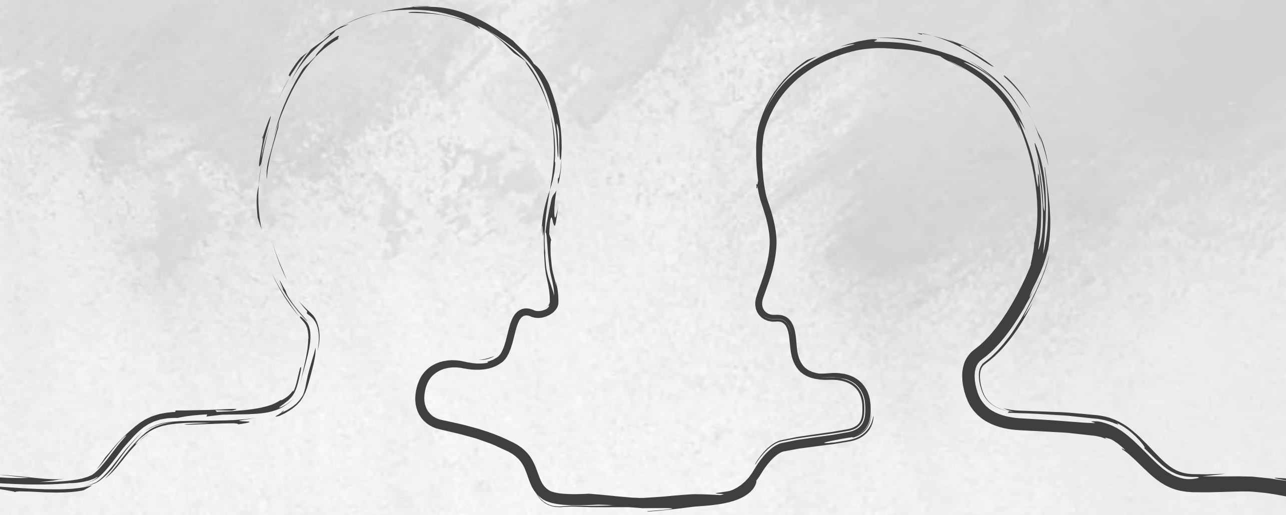
In **chapter 6** we investigated if the combination of self-efficacy levels of individuals with SCI or ABI and their significant others, measured shortly after the start of inpatient rehabilitation, predict their personal and family adjustment six months after inpatient discharge. We had complete data-sets of 157 dyads in this study. In general, the results showed that the combination of levels of self-efficacy of individuals with SCI or ABI and their significant others predict personal and family adjustment. In the low-self-efficacy dyads, 61% of the individuals with SCI or ABI and 50% of the significant others showed symptoms of anxiety six months after discharge, versus 23% and 30% in the high-self-efficacy dyads. In the low-self-efficacy dyads, 56% of individuals with SCI or ABI and 50% of the significant others reported symptoms of depression, versus 20% and 27% in the high-self-efficacy dyads. Problematic family functioning was reported by 53% of the individuals with SCI or ABI and 42% of the significant others in the low-self-efficacy dyads, versus 4% and 12% in the high-self-efficacy dyads. We concluded that individuals in the low-self-efficacy dyads seem to be more at risk for personal and family adjustment problems after discharge. Screening for self-efficacy may help healthcare professionals to identify and support families at risk for long-term adjustment problems.

The aim of **chapter 7** was to identify intra-personal and inter-personal sociodemographic, injury-related and psychological factors measured at admission of inpatient rehabilitation that predict psychological distress among dyads of individuals with SCI or ABI and their significant others six months after discharge from inpatient rehabilitation. We had complete data-sets of 157 dyads in this study. We found that sociodemographic and injury-related variables were not or only weakly associated with psychological distress. Bivariately, higher baseline psychological distress, lower scores on adaptive psychological characteristics (combination of self-efficacy, proactive coping, purpose in life, and resilience) and higher scores on maladaptive psychological characteristics (combination of passive coping, neuroticism, and appraisals of threat and loss) were related to higher psychological distress, also, although less strongly, crosswise between persons with SCI/ABI and significant others. Combined prediction models showed that psychological distress among individuals with SCI and ABI was predicted by educational level of the significant other, own baseline psychological distress and own maladaptive psychological characteristics. The explained variance was 41.9%. Among significant others, only their own baseline psychological distress predicts psychological distress. The explained variance was 40.4%. The results were highly comparable across diagnoses (SCI versus ABI). Although there is a dyadic association, it was concluded that primarily one's own baseline psychological distress and psychological characteristics are important in the prediction of later psychological distress among both individuals with SCI or ABI and significant others. Screening based on these variables could help to identify persons more at risk for psychological distress.

Finally, in **chapter 8** the main findings were summarized and discussed. Furthermore, we provided methodological considerations, clinical implications and suggestions for future research. In this thesis we described that SCI or ABI may have a large impact on the psychosocial well-being of the individuals involved, but also on that of their significant others. Adverse psychosocial adjustment outcomes are common among significant others. In the current rehabilitation care is still limited attention for the psychosocial well-being of significant others. We concluded that more attention for significant others is needed.

In the prediction of psychosocial adjustment outcomes, sociodemographic and injury-related variables were found to be not as important as psychological characteristics. Especially one's own level of psychological distress was important. Screening psychological distress among individuals with SCI or ABI and their significant others may help to early identify those individuals at risk for psychosocial adjustment problems and provides opportunities to support them already during inpatient rehabilitation.

Nederlandse samenvatting



In dit proefschrift richten we ons op het psychosociale welzijn van personen met een dwarslaesie of niet-aangeboren hersenletsel (NAH) en hun naasten. Dwarslaesie en NAH zijn de meest voorkomende aandoeningen onder volwassenen die opgenomen worden in een revalidatiecentrum in Nederland. Personen met een dwarslaesie of NAH worden vaak geconfronteerd met blijvende fysieke en/of cognitieve beperkingen die hen in hun dagelijks leven belemmeren en die hun psychosociale welzijn kunnen verminderen. Niet iedereen ervaart de gevolgen van een dwarslaesie of NAH op dezelfde manier. Het *International Classification of Functioning, Disability and Health* (ICF) model is een framework dat helpt bij het classificeren van de gevolgen van een aandoening op het functioneren van een persoon. Naast de aandoening zelf zijn ook persoonlijke factoren en factoren uit de omgeving van de persoon van belang om verschillen in functioneren tussen personen te verklaren. Het hebben van een dwarslaesie of NAH en de gevolgen daarvan op functioneel niveau hebben ook vaak gevolgen op het psychosociale welzijn van een persoon. Een verminderd psychosociaal welzijn, bijvoorbeeld in termen van depressie of een verminderde tevredenheid met het leven, komt regelmatig voor bij personen met een dwarslaesie of NAH. Niet voor iedereen zijn de gevolgen op psychosociaal welzijn gelijk.

Naasten spelen een belangrijke rol in het ondersteunen van personen met een dwarslaesie of NAH en hebben daarmee invloed op de manier waarop personen met een dwarslaesie of NAH kunnen omgaan met hun aandoening. Net als personen met een dwarslaesie of NAH moeten ook naasten zich aanpassen aan de veranderde omstandigheden en de nieuwe rollen die ze (vaak) vervullen. Dit is vaak lastig. Als gevolg rapporteren ook naasten regelmatig negatieve psychosociale uitkomsten zoals depressie, angst of overbelasting.

Het overkoepelende doel van het onderzoek beschreven in dit proefschrift was meer inzicht te krijgen in de impact van een dwarslaesie of NAH op psychosociale uitkomsten bij koppels van personen met een dwarslaesie of NAH en hun naasten (deel I), en om intra- (eigen) en interpersoonlijke (van de andere persoon in een koppel) risicofactoren te identificeren die latere psychosociale uitkomsten kunnen voorspellen (deel II). Dit inzicht kan helpen bij het verklaren waarom sommige personen of gezinnen beter in staat zijn om zich aan te passen dan anderen. Daarnaast kan deze kennis helpen om personen of gezinnen met een groter risico op latere psychosociale problemen al vroegtijdig in de revalidatie te identificeren en biedt het mogelijkheden om hen beter te ondersteunen in deze periode. De resultaten die in dit proefschrift beschreven worden zijn verkregen uit twee prospectieve cohortonderzoeken: het Koepelproject en het POWER onderzoek. In het Koepelproject werden personen met een recent ontstane dwarslaesie gevolgd vanaf het begin van de klinische revalidatie tot vijf jaar na ontslag. Bij de laatste meting voor het onderzoek werden ook hun primaire informele zorgverleners gevraagd een vragenlijst in te vullen. In het POWER onderzoek volgden we koppels van personen met een dwarslaesie of NAH en hun naasten gedurende de klinische revalidatie tot zes maanden na ontslag. Beide onderzoeken worden beschreven in **hoofdstuk 1**.

Deel I De impact van een dwarslaesie of NAH op psychosociale uitkomsten

De deelonderzoeken die beschreven zijn in **hoofdstuk 2** en **3** richten zich op de impact van een dwarslaesie op psychosociale uitkomsten bij personen met een dwarslaesie en hun partners vijf jaar na ontslag uit het revalidatiecentrum. In deze hoofdstukken hebben we data uit het Koepelproject geanalyseerd.

In **hoofdstuk 2** vergeleken we de mentale gezondheid en tevredenheid met het leven van 65 personen met een dwarslaesie en hun partners vijf jaar na ontslag uit het revalidatiecentrum. De resultaten laten zien dat de niveaus van mentale gezondheid en tevredenheid met het leven van personen met een dwarslaesie en hun partners ongeveer even hoog zijn en matig tot sterk met elkaar samenhangen. Deze samenhang was sterker in de subgroep van personen met een minder ernstige dwarslaesie. Er waren ook verschillen in de mate van tevredenheid tussen de personen met een dwarslaesie en hun partners. Personen met een dwarslaesie rapporteerden significant vaker dan hun partners tevreden te zijn met hun ‘vrije tijdbesteding’, ‘relatie met de partner’ en ‘gezinsleven’. Partners waren alleen significant vaker tevreden met hun ‘vermogen tot zelfverzorging’. Zowel personen met een dwarslaesie als hun partners waren het minst vaak tevreden met hun ‘seksleven’. We concludeerden dat er overeenkomsten maar ook verschillen in mentale gezondheid en tevredenheid met het leven zijn tussen personen met een dwarslaesie en hun partners vijf jaar na ontslag uit de klinische revalidatie.

Het doel van **hoofdstuk 3** was om het type en de frequentie van de ondersteuning die partners boden aan personen met een dwarslaesie vijf jaar na ontslag uit de klinische revalidatie te beschrijven. Daarnaast onderzochten we het niveau en de determinanten van ervaren zorglast, mentale gezondheid en tevredenheid met leven onder partners. We hadden beschikking over de data van 67 partners. We vonden dat partners ondersteuning boden bij een grote verscheidenheid aan activiteiten. Partners boden vaker ondersteuning aan personen met een tetraplegie (hoge dwarslaesie). In totaal gaf meer dan veertig procent van de partners aan een hoge mate van zorglast te ervaren, een kwart rapporteerde een lage mentale gezondheid en bijna de helft een lage mate van tevredenheid met het leven. Het verlenen van meer ondersteuning hing samen met een hogere ervaren zorglast en een lagere tevredenheid met het leven. Een hogere ervaren zorglast hing verder samen met een lagere mentale gezondheid en een lagere tevredenheid met het leven. De hoge ervaren zorglast onder partners en de samenhang tussen hogere zorglast en een lager welzijn onderstrepen het belang om overbelasting bij partners van personen met een dwarslaesie te voorkomen. Het monitoren van ervaren zorglast gedurende de revalidatie kan helpen om overbelasting bij partners vroegtijdig op te sporen.

Hoofdstuk 4 rapporteert de resultaten van een systematisch literatuuronderzoek met het doel om vragenlijsten te identificeren die gebruikt kunnen worden om de impact van zorgverlening te meten bij informele zorgverleners van personen met een beroerte, een dwarslaesie of een beenamputatie; en om de klinimetrische eigenschappen van deze vragenlijsten systematisch te evalueren. In totaal vonden we 192 publicaties die resultaten rapporteerden uit 154 verschillende onderzoeken. Het merendeel van de publicaties was gericht op informele zorgverleners van personen met een beroerte. In de 154 onderzoeken werden in totaal 48 verschillende vragenlijsten gebruikt om de impact van zorgverlening te meten. De meeste daarvan zijn gericht op het in kaart brengen van negatieve gevolgen voor de informele zorgverleners. Dertig vragenlijsten zijn slechts in één studie gebruikt en zijn verder niet beschreven in ons onderzoek. We gebruikten de COSMIN richtlijnen om de klinimetrische eigenschappen en de methodologische kwaliteit van de overige achttien meetschalen te beoordelen. We vonden dat sommige klinimetrische eigenschappen vaak onderzocht waren, bijvoorbeeld de dimensionaliteit van een vragenlijst (structurele validiteit), de mate van onderlinge samenhang tussen de vragen van een vragenlijst (interne consistentie) en de mate waarin de scores van een vragenlijst hypothesen bevestigen bijvoorbeeld met betrekking tot relaties met scores van andere vragenlijsten (construct-validiteit). In hoeverre vragenlijstscores gelijk blijven bij herhaalde metingen als personen niet veranderen (betrouwbaarheid) werd minder vaak onderzocht. Dit gold ook voor de mate waarin een vertaalde of cultureel aangepaste vragenlijst een goede weerspiegeling is van het origineel (cross-culturele validiteit) en de mate waarin de vragenlijstscores een goede weerspiegeling zijn van een ‘gouden standaard’ (criteriumvaliditeit). Aspecten met betrekking tot de ontwikkeling van vragenlijsten en de mate waarin de inhoud van een vragenlijst een goede weerspiegeling is van het construct dat je wilt meten (inhoudsvaliditeit) waren zelden nauwkeurig beschreven. Tot slot, systematische en toevallige fouten in de vragenlijstscores (meetfouten) en het vermogen van een vragenlijst om veranderingen in de tijd op te merken (responsiviteit), werden slechts een enkele keer onderzocht. We concludeerden dat er een brede variëteit is aan meetschalen om impact van zorgverlening bij informele zorgverleners te meten, maar dat het bewijs voor de klinimetrische kwaliteit van de gevonden meetschalen niet optimaal is.

Deel II Factoren om psychosociale uitkomsten te voorspellen

In het tweede deel van dit proefschrift rapporteerden we resultaten uit het POWER onderzoek. Een belangrijk doel van dit onderzoek was het identificeren van intra- en interpersoonlijke factoren die van belang zijn bij het voorspellen van psychosociale uitkomsten bij personen met een dwarslaesie of NAH en hun naasten.

In **hoofdstuk 5** onderzochten we de relatie tussen veerkracht en psychologische stress bij naasten. Daarnaast werd bekeken of deze relatie werd gemedieerd door de mate waarin een persoon zijn situatie als bedreigend of beangstigend ervaart en door de neiging tot het toepassen van een passieve copingstrategie (de manier waarop een persoon omgaat met een probleemsituatie). De variabelen werden gemeten kort nadat de persoon met een dwarslaesie of NAH was opgenomen in het revalidatiecentrum. Wij gebruikten voor dit deelonderzoek data van 228 naasten. In totaal gaf 34–41% van de naasten aan hoge niveaus van psychologische stress te ervaren aan het begin van de klinische revalidatie. Ongeveer de helft van de variantie van psychologische stress kon verklaard worden door de relatie met veerkracht. Deze relatie werd echter gemedieerd, want de relatie werd veel minder sterk wanneer gecontroleerd werd voor de mate waarin een persoon zijn situatie als bedreigend of beangstigend ervaarde en de neiging tot het toepassen van een passieve copingstrategie. De relatie tussen veerkracht en psychologische stress was gelijk voor de dwarslaesie en de NAH doelgroepen. We stelden dat het zinvol lijkt om te onderzoeken of interventies die zich richten op psychologische factoren zoals veerkracht, de manier waarop een individu zijn situatie beoordeelt (bijvoorbeeld als bedreigend of beangstigend) en copingstrategieën effectief zijn in het voorkomen of reduceren van psychologische stress bij naasten van personen met een dwarslaesie of NAH.

In **hoofdstuk 6** onderzochten we of gecombineerde niveaus van zelf-effectiviteit van personen met een dwarslaesie of NAH en hun naasten, gemeten kort na opname in het revalidatiecentrum, persoonlijke uitkomsten (angst en depressie) en gezinsuitkomsten (gezinsfunctioneren) kunnen voorspellen zes maanden na ontslag uit de klinische revalidatie. In dit deelonderzoek hadden we complete datasets van 157 koppels. In het algemeen lieten de resultaten zien dat de gecombineerde niveaus van zelf-effectiviteit van personen met een dwarslaesie of NAH en hun naasten zowel persoonlijke uitkomsten als gezinsuitkomsten kunnen voorspellen. De koppels werden op basis van hun beide niveaus van zelf-effectiviteit ingedeeld in vier verschillende groepen (beiden lage zelf-effectiviteit, beiden hoge zelf-effectiviteit, en de twee mengvormen). In de koppels met lage zelf-effectiviteit rapporteerde 61% van de personen met een dwarslaesie of NAH en 50% van de naasten symptomen van angst zes maanden na ontslag uit de klinische revalidatie, versus 23% en 30% in de koppels met hoge zelf-effectiviteit. In de koppels met lage zelf-effectiviteit rapporteerde

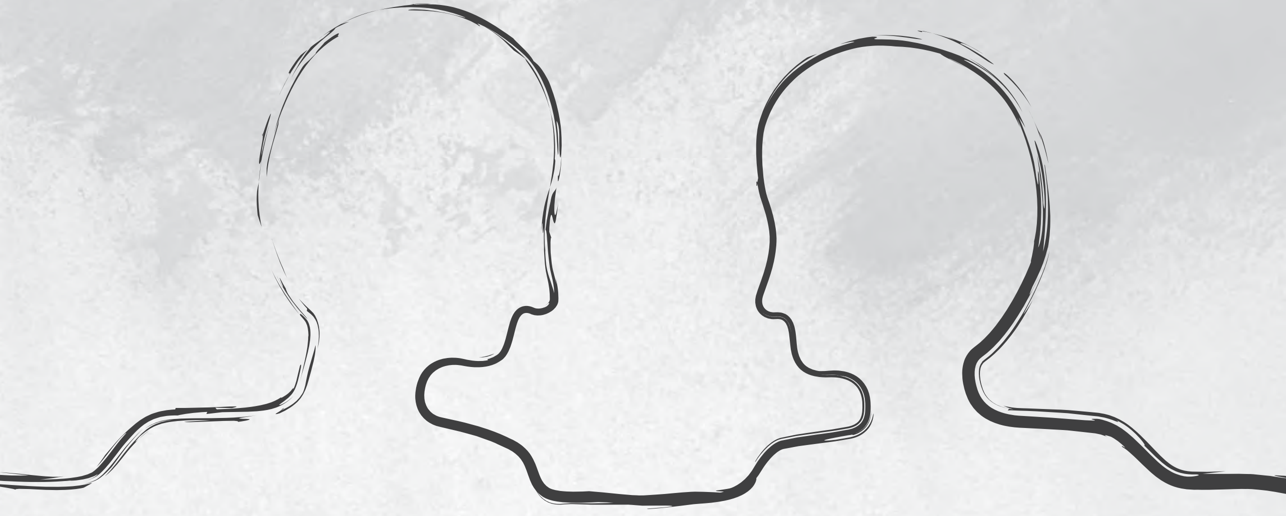
56% van de personen met een dwarslaesie of NAH en 50% van de naasten symptomen van depressie, versus 20% en 27% in de koppels met hoge zelf-effectiviteit. Problematisch gezinsfunctioneren werd gerapporteerd door 53% van de personen met een dwarslaesie of NAH en 42% van de naasten in de koppels met lage zelf-effectiviteit, versus 4% en 12% in de koppels met hoge zelf-effectiviteit. We concludeerden dat personen in de koppels met lage zelf-effectiviteit na ontslag uit de klinische revalidatie een groter risico lijken te hebben op persoonlijke problemen en gezinsproblemen. Screening op zelf-effectiviteit kan zorgprofessionals helpen bij het identificeren en ondersteunen van gezinnen die risico lopen op problemen op de lange termijn.

Het doel van **hoofdstuk 7** was om intra-persoonlijke (binnen een persoon) en interpersoonlijke (tussen personen in een koppel) factoren te identificeren die psychologische stress bij personen met een dwarslaesie of NAH en hun naasten kunnen voorspellen zes maanden na ontslag. In dit deelonderzoek hadden we complete datasets van 157 koppels. We vonden dat sociaal-demografische en aandoening-gerelateerde factoren die gemeten werden kort na opname in het revalidatiecentrum niet of beperkt gerelateerd waren aan latere psychologische stress. Psychologische factoren waaronder adaptieve psychologische factoren (een combinatie van zelf-effectiviteit, proactieve copingstijl, het hebben van een doel in het leven en veerkracht) en mal-adaptieve psychologische kenmerken (een combinatie van passieve copingstijl, neuroticisme en de mate waarin een individu zijn situatie als bedreigend of beangstigend ervaart) waren wel van belang. Bivariaat waren een hogere mate van psychologische stress bij opname, lagere scores op adaptieve psychologische kenmerken en hogere scores op mal-adaptieve psychologische kenmerken gerelateerd aan een hogere mate van psychologische stress zes maanden na ontslag. Er bestonden interpersoonlijke relaties tussen kenmerken van de ene persoon in een koppel en uitkomsten bij de andere persoon, maar de intra-persoonlijke relaties waren het sterkst. Gecombineerde predictiemodellen lieten zien dat psychologische stress bij personen met een dwarslaesie of NAH werd voorspeld door het opleidingsniveau van de naaste, eigen psychologische stress bij opname en de eigen mal-adaptieve psychologische kenmerken. De verklaarde variantie bedroeg 41,9%. Bij naasten voorspelde alleen het eigen niveau van psychologische stress bij opname psychologische stress zes maanden na ontslag. De verklaarde variantie bedroeg 40,4%. De resultaten waren in hoge mate vergelijkbaar tussen diagnoses (dwarslaesie versus NAH). Ondanks dat er sprake was van een dyadische associatie, concludeerden we dat vooral de eigen psychologische stress en psychologische kenmerken kort na opname in het revalidatiecentrum van belang zijn bij het voorspellen van latere psychologische stress, zowel bij personen met een dwarslaesie of NAH als bij hun naasten. Screening op basis van deze variabelen kan helpen om personen te identificeren die meer risico lopen op psychologische stress.

Tot slot werden in **hoofdstuk 8** de belangrijkste bevindingen samengevat en bediscussieerd. Daarnaast presenteerden we methodologische overwegingen, klinische implicaties en suggesties voor vervolgonderzoek. In dit proefschrift beschreven we dat een dwarslaesie of NAH een grote impact kan hebben op het psychosociaal welzijn van de personen zelf, maar ook op dat van hun naasten. Negatieve psychosociale uitkomsten komen ook bij naasten regelmatig voor. In de huidige revalidatiezorg is er beperkt aandacht voor het psychosociale welzijn van naasten. We concludeerden dat er meer aandacht voor naasten nodig is.

In de voorspelling van psychosociale uitkomsten bleken sociaal-demografische en aandoening-gerelateerde factoren van ondergeschikt belang ten opzichte van psychologische factoren. Vooral het niveau van psychologische stress van de persoon zelf bleek van belang. Het screenen van psychologische stress bij personen met een dwarslaesie of NAH en hun naasten kan helpen om vroegtijdig personen met een groter risico op psychosociale problemen te identificeren en het biedt mogelijkheden om hen al vroegtijdig gedurende de klinische revalidatie te ondersteunen.

Dankwoord



De afgelopen jaren heb ik met veel interesse en plezier meegewerkt aan het POWER onderzoek, wat in vele opzichten erg leerzaam voor mij was. Ik ben trots op het eindresultaat in de vorm van dit proefschrift. Hoewel mijn naam op de voorkant van het proefschrift gedrukt staat, is dit proefschrift geen persoonlijk resultaat, maar een gezamenlijk resultaat dat tot stand is gekomen dankzij de medewerking van een groot aantal betrokkenen. Uiteraard wil ik iedereen die een bijdrage geleverd heeft hartelijk bedanken. Een aantal personen wil ik in het bijzonder noemen.

Allereerst de vele revalidanten en hun naasten die zo trouw meermaals vragenlijsten hebben ingevuld. Zonder jullie bereidheid tot deelname was dit proefschrift er niet geweest.

Prof.dr. Visser-Meily, beste Anne, jij bent zowel een bevlogen onderzoeker als een betrokken revalidatiearts. Het is het bewonderenswaardig hoe jij deze rollen weet te combineren. Het resulteert erin dat jij uitstekend op de hoogte bent van alle wetenschappelijke ontwikkelingen in de revalidatiezorg voor mensen met hersenletsel en dat je een duidelijke klinische focus hebt, beide (en vooral in combinatie) erg waardevol. Ik heb dankbaar gebruik gemaakt van jouw kennis en ervaring. Dank voor het vertrouwen dat je mij gegeven hebt.

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Dr. Ketelaar, beste Marjolijn, wat vind ik het fijn dat jij onderdeel van ons team bent! Op onderzoeksvlak hield jij mij scherp in het interpreteren van resultaten. Leuk die resultaten, maar wat betekenen ze? Jouw enthousiasme en optimisme maakte dat ik uitdagingen ben aangegaan, ook al vond ik dat soms spannend. Daarnaast heb jij veel oog voor persoonlijke ontwikkeling. Jij spoorde mij aan om ook na te denken over mijn persoonlijke doelen en bood mij kansen in de realisatie daarvan. Veel dank daarvoor!

Chantal, wij zijn tegelijk als promovendi aan het POWER onderzoek begonnen. Hoewel onze wegen nu gescheiden zijn, wil ik je toch bedanken voor de samenwerking.

Tijn, onze onderzoeken waren gekoppeld waardoor we automatisch veel hebben samengewerkt. Ik heb deze samenwerking als heel prettig ervaren. Je bent een fijne collega, altijd bereid om mee te denken en te helpen. Dat waardeer ik erg. We kunnen onze samenwerking niet beter afsluiten dan met onze beide promoties, waarbij jij de rol van paranimf vervult bij mijn promotie en ik bij die van jou. Heel bijzonder! Ik hoop dat er in de toekomst nog mogelijkheden tot samenwerking zijn.

Naast de bovengenoemde personen hebben verschillende andere personen als coauteur een belangrijke bijdrage geleverd aan de artikelen in dit proefschrift. Sonja, wat fijn dat we de data van het Koepelproject hebben kunnen gebruiken voor twee artikelen. Madeleine, Anneroos en Julia, jullie scripties hebben aan de basis gestaan voor drie artikelen. Ik ben er trots op dat we dat voor elkaar hebben gekregen. David, Ellen, Ilse, Janneke, Kees Hein, Mirjam en Rutger, wat ontzettend leuk dat ook jullie een bijdrage hebben willen leveren. Met name jullie klinische input is erg waardevol gebleken!

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De projectgroep van het POWER onderzoek bestond naast de onderzoeksgroep uit vertegenwoordigers van de Nederlandse Vereniging van Revalidatieartsen, vertegenwoordigers van maatschappelijk werk, vertegenwoordigers van de patiëntenverenigingen Dwarslaesie Organisatie Nederland, Hersenletsel.nl en Korter maar Krachtig, en adviseurs Ellen, Ingrid en Janneke. De bijdrage van jullie allemaal is erg belangrijk geweest in de vormgeving van het POWER onderzoek. Het was waardevol om van jullie expertise gebruik te mogen maken.

Edward, Evelien en Jessica, als onderzoeksassistenten in De Hoogstraat hebben jullie mij ontzettend veel werk uit handen genomen. Jullie waren onmisbaar!

Naast De Hoogstraat hebben nog elf andere revalidatiecentra in Nederland meegewerkt aan het POWER onderzoek. Veel artsen, maatschappelijk werkers en andere professionals hebben een bijdrage geleverd, waarvoor mijn dank. In het bijzonder gaat mijn waardering uit naar alle onderzoeksassistenten die vaak naast hun eigen werk de inclusie voor het POWER onderzoek hebben verzorgd. Ank, Carla, Desiree, Esther, Hanneke, Iris, Joke, Joke, Jolanda, Jolien, Jos, Kristien, Linda, Martine en Tijn, dank voor jullie inzet!

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De data die verzameld zijn in het POWER onderzoek zijn nog lang niet uitgeput. Wat zou het mooi zijn als de data-analyse voortgezet wordt. Amy en Jennifer, fijn dat jullie hier al een start mee hebben gemaakt.

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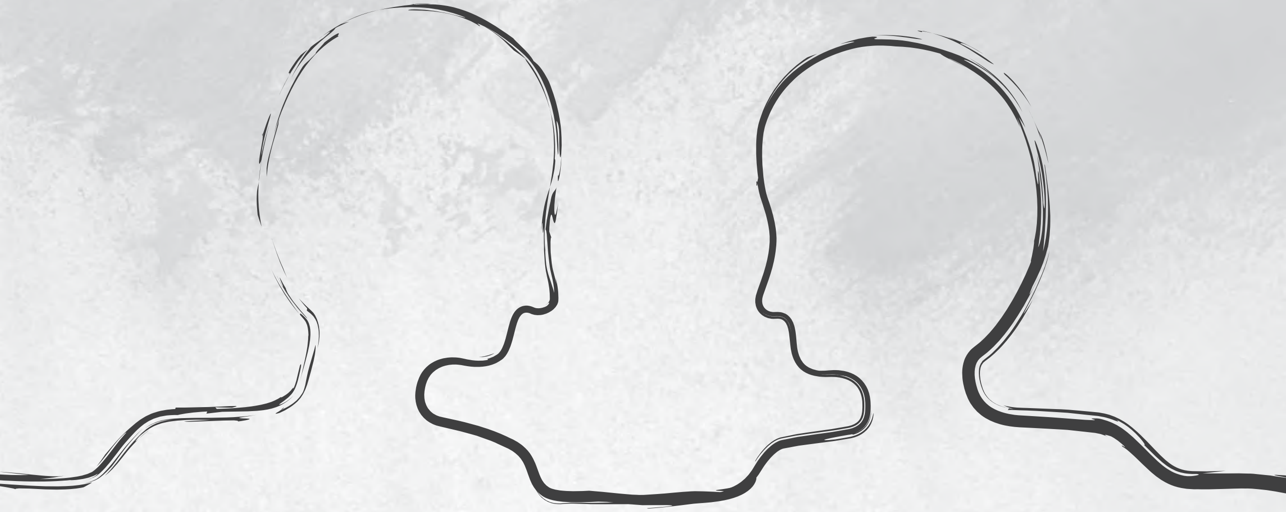
Lieve pap en lieve mam, het maakt niet uit waarvoor en het maakt niet uit wanneer, jullie zijn er áltijd voor mij. Dat is zo waardevol! Tijdens mijn promotietraject was dat niet anders. Of ik nu om half zeven 's ochtends de auto wilde ophalen omdat de trein plotseling niet reed, even mijn frustraties moest afreageren, een succes wilde vieren of motiverende woorden nodig had, jullie stonden klaar.

ABOUT THE AUTHOR

Curriculum Vitae

List of publications



CURRICULUM VITAE

Eline Scholten was born on October the 5th 1990 in Maarn, the Netherlands. In 2009 she finished secondary school at the Revius Lyceum in Doorn (VWO), thereafter she studied Interdisciplinary Social Science at Utrecht University. In 2012 she achieved her bachelor degree (cum laude) and started the master Youth Studies. In 2013 she did an internship at the IVO Addiction Research Institute where she wrote her master thesis, which was internationally published afterwards. During the internship her interest in research has grown. After achieving her master degree in 2013 (cum laude), she worked for one year as a junior researcher at the IVO Addiction Research Institute. In this period she got the opportunity to work on several projects. In April 2015 she started as PhD-student at the Center of Excellence for Rehabilitation Medicine, which has resulted in this thesis. During her PhD, she followed the research education program 'Clinical and Experimental Neuroscience' at the Graduate School of Life Sciences at Utrecht University. Currently, she is working at the Center of Excellence for Rehabilitation Medicine in the function of a postdoc researcher.

LIST OF PUBLICATIONS

International publications

Scholten EWM, Ketelaar M, Visser-Meily JMA, Stolwijk-Swüste J, Van Nes IJW, Gobets D, POWER Group, Post MWM. Self-efficacy predicts personal and family adjustment among persons with spinal cord injury or acquired brain injury and their significant others: A dyadic approach. Archives PMR. 2020, in press.

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