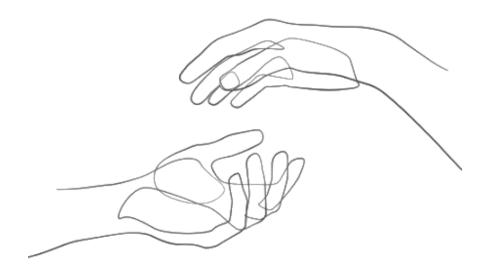


A dyadic approach: the predictive role of social support and physical independence on life satisfaction of persons with Spinal Cord Injury or Acquired Brain Injury and their significant others

Master Thesis

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Master Social Policy and Public Health, thesis based on existing data (201800155)

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June 27, 2021 wordcount: 7994

Abstract

Background: A decrease in life satisfaction is common among persons with Spinal Cord Injury (SCI) or Acquired Brain Injury (ABI) and for the person close to them: their significant other. This could have long-term impacts, such as psychological distress. The current study investigates if social support and physical independence of persons with SCI/ABI and their significant others (dyad) predict their life satisfaction six months after inpatient discharge.

Research question: Does perceived social support of the person with SCI/ABI and their significant other and physical independence of the person with SCI/ABI measured shortly after the start of inpatient rehabilitation, predict life satisfaction of both persons in a dyad six months after inpatient rehabilitation?

Method: Data were used from the POWER-study, a prospective quantitative longitudinal study conducted in 12 rehabilitation centres in the Netherlands among dyads between 2016 and 2018. Persons with SCI/ABI and their significant others filled in self-reported questionnaires separately at the start of inpatient rehabilitation and six months after inpatient discharge.154 dyads were included. Data were analysed using SPSS with independent t-tests, Pearson's chi-squared tests, Pearson correlations and MANCOVA.

Results: Dyads of the SCI-group scored lower on life satisfaction then dyads of the ABI-group. Life satisfaction of persons with SCI/ABI were correlated with life satisfaction of significant others. Perceived social support of the person with SCI/ABI and their significant others are not related to their life satisfaction. Physical independence is a predictor for the life satisfaction of the dyad.

Conclusion: The relationship of life satisfaction between the dyad indicates that dyadic health should be considered. Therefore, significant others should be included to a greater extent in the rehabilitation and predictors such as physical independence can serve as risk screening during rehabilitation.

Keywords: life satisfaction, acquired brain injury, spinal cord injury, dyads, significant others, social support, physical independence

Glossary

Spinal Cord Injury (SCI): SCI concerns damage or loss of the motor and/or sensory function of the spinal cord as a result of traumatic or non-traumatic damage to the neural elements in the spinal cord canal (Kirshblum et al., 2011). The most common causes of traumatic SCI are sport/traffic incidents and falls. Non-traumatic causes of SCI are, e.g., spinal degeneration, inflammation, tumors, or vascular diseases. The completeness and the neurological level of the injury determine the degree of impairment of an SCI. SCI could result in paralysis of the legs, along with higher injuries of the arms or even of the respiratory muscles (Kirshblum et al., 2011).

Acquired Brain Injury (ABI): ABI is a collective term referring to any brain injury that has occurred after birth. A distinction is made between brain damage from external causes; traumatic brain injury e.g., traffic- or sports accident, and brain damage caused by a condition or process in the body; non-traumatic brain injury e.g., stroke, TIA, brain tumors, or oxygen deficiency. Brain injury affects various areas of functioning such as cognition, mobility, communication, emotions, and behaviour (Zadoks, 2015).

Significant other: A significant other is someone close, usually a family member. One plays an important role in providing informal care (care outside the professional care system). This can be both practical support e.g., support in activities of daily living or bringing to a doctor, and emotional support e.g., learning how to live with the disability or comforting.

Dyad: A dyad is a couple. Within this study this includes the person with SCI/ABI and their significant other. Dyad studies are studies that conduct research among both the person with the condition and their significant other to analyse the interrelatedness of health outcomes.

Introduction

In 2015 the Dutch classic welfare state changed into a participatory society. Since then, everyone who is able is asked to take responsibility for his or her own life and environment (Tweede Kamer der Staten-Generaal, 2014). The number of informal caregivers expanded significantly due to this change (de Boer et al., 2020). The relationships between the people in a dyad are strengthened by the responsibility and growth of informal care (Springvloet et al., 2020). Considering this expansion and the fact that the chances of survival following SCI/ABI are increasing (Zadoks, 2015; Savic et al., 2017), persons with SCI/ABI and their significant others became an increasingly bigger group within society. A recent research by a Dutch research centre reported that people with a physical condition experience fewer opportunities to organize their lives freely (Vermeij & Hamelink, 2021). The life satisfaction of people with a condition and their relatives is an indicator of the extent to which they succeed in participating in society according to their wishes and needs (Meulenkamp et al., 2015; Springvloet et al., 2020). A decrease in life satisfaction is common among persons with SCI/ABI (Achten et al., 2012; Post & van Leeuwen, 2012), and for their significant others (Achten et al., 2012), and their lives are interrelated (Cox, 2020; Ostwald et al., 2009). This could have long-term impacts, such as psychological distress and a negative impact on wellbeing (Ergh et al., 2002; Middleton et al., 2014; Scholten et al., 2020). Strengthening the current scientific evidence of the interrelatedness of dyads (Achten et al., 2012; Eriksson et al., 2005; Kruithof et al., 2014) by using a dyadic approach and examine the predictive role of social support and physical independence on life satisfaction can contribute to development of rehabilitation interventions focussed on not only the person with the disability but also the person(s) next to them, which is increasingly important in today's society considering the increase of the role of informal care. This might allow identification of persons at risk for poor long-term adjustment.

Previous research

SCI and ABI

SCI/ABI are two large causes of a chronic condition. Globally, there were 0.9 million new cases with SCI and 43.6 million with ABI in 2016 (GBD, 2016). After onset of SCI/ABI, dyads must adjust to their new circumstances in life. People with SCI/ABI are the largest group who stay within a rehabilitation centre for longer term in the Netherlands to rehabilitate (inpatient rehabilitation) (Revalidatie Nederland, 2017). Optimal life satisfaction is considered an important long-term outcome after inpatient rehabilitation (Post & van Leeuwen, 2012).

Nevertheless, no studies so far tried to examine possible predictors of life satisfaction for both SCI and ABI. This study will contribute to fill this gap by analysing both conditions and comparing the life satisfaction. The comparison is made to provide knowledge that may be relevant for the development of diagnosis-specific care.

Predicting life satisfaction of persons with SCI/ABI

The association between demographic variables and life satisfaction among persons with SCI/ABI is inconsistent. Some studies found that demographic variables predict life satisfaction, most notably educational attainment, and age (Dowler et al., 2001; Ostwald et al., 2009). There are two relevant studies known that include SCI and Traumatic Brain Injuries (TBI) (ABI consists of more than half of TBI) (Hicken et al., 2002; Warren et al., 1996). In contrast to the other studies, they found that demographic variables were not related to life satisfaction. Persons with TBI scored significantly higher on life satisfaction than persons with SCI one year after onset of the condition (Hicken et al., 2002). Within the current study, demographic and injury-

related variables were included to control their influence on life satisfaction of both persons with SCI/ABI and their significant others. Physical functioning and psychosocial variables, such as social support, are more often related to life satisfaction for SCI (van Koppenhagen et al., 2009; van Leeuwen et al., 2011) and for ABI (Achten et al., 2012; Adriaansen et al., 2011; Resch et al., 2009).

The role of social support

Dyads often need social support to live a satisfactory life (Chan, 2000; Ergh et al., 2002). Social support can be defined as any support given outside formal settings, i.e., not by healthcare professionals or social services (Kruithof et al. 2014). Müller et al. (2011) conducted a systematic literature review that shows similar results the relationship between social support and life satisfaction is consistent among persons with SCI. Kruithof et al. (2014) conducted a similar review of literature about stroke survivors and concluded that perceived social support had a positive relation with health-related quality of life. A Dutch study among significant others of people with a disability show that significant others who experience more social support score higher on quality of life (Springvloet et al., 2020). Furthermore, significant others who provide care on their own experience lower quality of life ((Ergh et al., 2002; Springvloet et al., 2020). Perceived (i.e., subjective) social support has been reported as a better predictor for health outcomes than received (i.e., objective) social support (Ergh et al., 2002; Müller et al., 2011). Although various studies conclude that there is a relationship between perceived social support and life satisfaction in persons with SCI/ABI and for significant others (Chiou et al., 2009; Rodakowski et al., 2012), not much research is done into the predictive role of social support. Even though studies suggest that this is needed and should be considered for the design of rehabilitation interventions. Because of the aforementioned and because the role of social

support has become increasingly important in today's society, social support as a predictor for life satisfaction has been included in the present study.

The degree of the physical independence

Persons with SCI/ABI typically suffer from physical problems (Kirshblum et al., 2011; Zadoks, 2005), affecting both themselves and their significant others (Cox, 2020; Eriksson et al., 2005; van Leeuwen et al., 2011), resulting in loss of independence in everyday activities and their life satisfaction (Cox, 2020). Various studies measure a form of to what extent someone is self-dependent such as physical independence, mobility, functional disability, or ADLdependency, and are used for comparison. Studies that were conducted within the first-year post injury report that a higher degree of physical independence correlates with a higher degree of life satisfaction (Hicken et al., 2002; Resch et al., 2009). The only unique predictor for life satisfaction within the comparative study of Hicken et al. (2002) among persons with SCI and TBI was functional disability. In the study of van Leeuwen et al. (2011) and Resch et al. (2009) decreased mobility/functional independence was a predictor for less life satisfaction one year after onset of SCI/ABI. Not much studies examined the role of physical independence on the life satisfaction of the significant others. A notable exception is the study of Pucciarelli et al. (2017), which shows that the physical functioning of a stroke survivor influence caregiver's quality of life.

Although previous studies show that there is a relationship between physical independence and life satisfaction, studies that include both conditions and their significant other (dyadic research) are scarce. The current study provides knowledge on the predictive role of physical independence of the person with SCI/ABI on life satisfaction for both members of the dyad and investigates diagnosis-specific differences among both persons within a dyad.

The interrelatedness between the person with SCI/ABI and their significant other

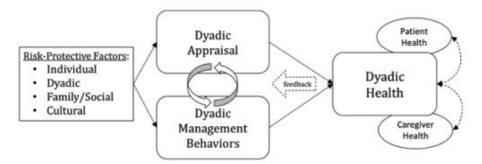
The important role as an informal care significant others now fulfil means that knowledge about their influence on, and the interrelatedness with their loved ones (in this case persons with SCI/ABI) can be important for the development of care. Results of dyad studies in the chronic phase show that the life satisfaction of couples was below average (Achten et al., 2012; Eriksson et al., 2005). Achten et al. (2012) also concluded that life satisfaction of both members of the dyads with a stroke survivor were significantly related. Although studies indicate that within the first year after onset of the injury life satisfaction can improve (de Groot et al., 2006; Warren et al., 1996), it remains unclear which factors contribute to life satisfaction of dyads within the first year and if these factors are interrelated between the two members of the dyad. Therefore, the current study will include both the person with SCI/ABI and their significant other to analyse their interrelatedness.

The dyadic approach: Theory of Dyadic Illness Management

To investigate the interrelatedness the theoretical framework guiding the current study is the Theory of Dyadic Illness Management (TDIM). The basic principle of the TDIM states that illness management is a dyadic phenomenon (Lyons & Lee, 2018). The theory suggests that various risk and protective factors (individual, dyadic, family/social, and cultural) influence how persons in a dyad experience their situation (dyadic appraisal) and how they together cope with the situation (dyadic management behaviours), which influence the dyadic health, including life satisfaction (see Figure 1).

Figure 1

The Theory of Dyadic Illness Management Model



Note. Taken from "The Theory of Dyadic Illness Management", by K.S. Lyons and C.S. Lee, 2018, Journal of Family Nursing, 24(1), p. 15.

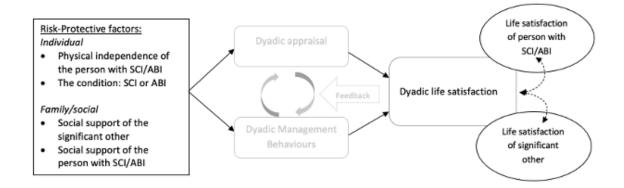
Relevance of the TDIM

The most frequently used theory within dyadic studies is the Actor-Partner

Interdependence Model (APIM) (Cook & Kenny, 2005). Although the APIM does demonstrate a dyadic approach, it does not take the collective health of a dyad into account, where the TDIM does (dyadic health). The current study will not only look at the influence on life satisfaction of both members but also of them together, by using a form of analysis that allows this and therefore fits well with the TDIM. Additionally, the APIM focuses on 'individual' variables that influence the health of both members of the dyads. The current study goes beyond the individual characteristics and also takes social factors into account. The TDIM is specifically designed for the dyadic relationship between a person with a disability and their caregiver (Lyons & Lee, 2018) and therefore relevant for the current study. Figure 2 shows the adapted version of the TDIM guiding the current study. Dyadic appraisal and dyadic management behaviours are reflected in the measurement of the perception of social support but are not the main focus of the current research. This adapted model is the explanatory mechanism for the relationship between the risk and protective factors on life satisfaction.

Figure 2

Adapted TDIM guiding the current study



Note. Adapted from "The Theory of Dyadic Illness Management", by K.S. Lyons and C.S. Lee, 2018, Journal of Family Nursing, 24(1), p. 15.

Research question and hypotheses

Drawing on the literature and the TDIM it is estimated that both persons within a dyad can influence the outcome of both members in a dyad. In the current study it is expected that the life satisfaction of the person with SCI/ABI and the life satisfaction of the significant others are interrelated, and it is tested whether the perceived social support of both persons and the physical independence of the person with SCI/ABI positively affects the life satisfaction of both persons in the dyad and the dyad itself six months after rehabilitation. Additionally, the differences in life satisfaction between the two conditions will be examined. This led to the following research question and hypotheses:

'Does perceived social support of the person with SCI/ABI and their significant other and physical independence of the person with SCI/ABI measured shortly after the start of inpatient rehabilitation, predict life satisfaction of both persons in a dyad six months after inpatient rehabilitation?'

- Hypothesis 1: Persons with SCI and their significant others score lower on life satisfaction then persons with ABI and their significant other.
- Hypothesis 2: The life satisfaction of the person with SCI/ABI is related to the life satisfaction of the significant other and vice versa.
- Hypothesis 3: Higher perceived social support of the person with SCI/ABI and the significant other measured shortly after the start of inpatient rehabilitation, positively contributes to a higher level of life satisfaction of a person with SCI/ABI and the significant other six months after inpatient rehabilitation.
- Hypothesis 4: Higher physical independence of the person with SCI/ABI measured shortly after the start of inpatient rehabilitation of the person with SCI/ABI contributes to a higher life satisfaction of a person with SCI/ABI and the significant other six months after inpatient rehabilitation.

Methods

Study design

Data of the POWER-study were used (Hillebregt et al., 2018). This prospective quantitative longitudinal study was conducted in 12 rehabilitation centres in the Netherlands between 2016 and 2018 among dyads of persons with SCI/ABI and their significant others. The POWER-study aims to identify predictors at admission to inpatient rehabilitation of long-term empowerment and adjustment problems among dyads (Hillebregt et al., 2018). Participants completed self-reported questionnaires, the first shortly after the start of rehabilitation (baseline measurement) and the last six months after inpatient discharge (follow-up measurement). In every centre, a designated research assistant was responsible for the course of the study. The questionnaires included sociodemographic information and questions about perceived social support and satisfaction with life (Appendix A). Injury-related information were taken from the patient file. These provided the data that was used to answer the research question.

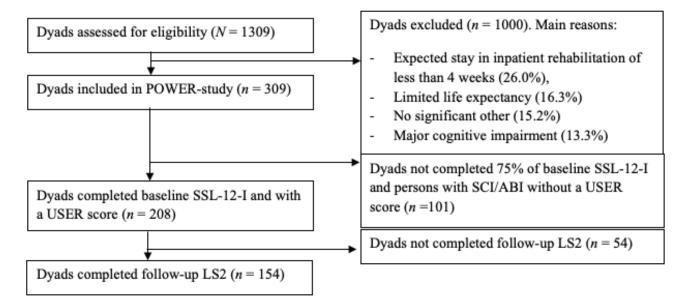
Participants and recruitment

The population for this study consists of persons with a recent onset of SCI/ABI who were admitted between April 2016 and July 2018 to inpatient rehabilitation in one of the participating rehabilitation centres (N=1309). Within the POWER-study, people with an expected stay of 4 weeks or longer were eligible to participate. The person with SCI/ABI had to be able to name a significant other since only dyads (of 18 years or older) were included. Exclusion criteria were expectation of full or nearly full recovery, discharge to a long-term care facility, or limited life expectation based on clinical judgment 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 (Deelman et al., 1981). All 12 rehabilitation

centres granted permission to execute the POWER-study. Persons with SCI/ABI and their significant others both had to sign informed consent. For the current study, dyads were not included in the analyses if there was no score on the measurement of physical independence of the person with SCI/ABI, and if less than 75% of the scale items of the independent (social support = SSL-12-I) and dependent variable (life satisfaction=LS2) were filled in (n = 155). The flowchart in Figure 3 shows the inclusion of dyads that are analysed within the current study.

Figure 3

Flowchart inclusion of dyads of persons with SCI/ABI and significant others of the current study



Measurements of study variables

Sociodemographic and injury-related variables

Sociodemographic variables were extracted from the baseline measurement. Injury-related variables were contracted from the patient file (Table 1).

Table 1
Sociodemographic and injury-related variables

Sociodemographic variables	Value	
Sex	male, 0; female, 1	
Age	у	
Education	low, 0 [ie, <bachelor's 1<="" degree];="" high,="" td=""></bachelor's>	
Nationality	Dutch, 0; non-Dutch, 1	
Living status	alone, 0; not alone, 1	
Relationship with person with SCI/ABI (only for significant others)	r partner, 0; not the partner, 1	
Injury-related variables		
Diagnosis	SCI, 0; ABI, 1	
Cause of injury	traumatic, 0; non-traumatic, 1	
Level of SCI ¹	paraplegia, 0; tetraplegia, 1	
Completeness of SCI ¹	A-D	
Location (only for ABI)	left, right, both sides, brainstem, unknown	

¹a trained physician determined the level and completeness according to the International Standards for the Neurological Classification of SCI (Kirshblum et al., 2011).

Table 2

Scale measurements information and internal consistency scores

Variable	Scale measure	No. of items, range score	Internal consistency
Life satisfaction for persons with SCI/ABI	LS2 ¹	2, 2-13	α=.65
Life satisfaction for significant others	LS2 ¹	2, 2-13	α=.78
Social Support for persons with SCI/ABI	SSL-I-12 ²	12, 12-48	α=.93
Social Support for significant others	SSL-I-12 ²	12, 12-48	α=.94

¹Life satisfaction was measured with two life satisfaction questions: LS2 (Post et al., 2012).

Operationalisation of the theoretical concepts

Table 2 shows the scale variables used with the numbers of items, ranges, scores, and all were tested for internal consistency. The calculation of the total scores of the scale measurements can be found in Appendix C.

Life satisfaction was measured at baseline and six months after inpatient discharge using the two life satisfaction questions (LS2) (Post et al., 2012), operationalised as satisfaction with overall quality of life. The LS2 has been used in several previous studies with participants with SCI (van Koppenhagen et al., 2009; van Leeuwen et al., 2010; van Leeuwen et al., 2011). The LS2 has been tested for reliability within this study (Table 2) and has been measured as a valid instrument (Post et al., 2012).

Social support was operationalised as the subjective appraisal of received social support (perceived social support) before onset of the injury and was measured at baseline (during

² Social support was measured using the Social Support List: SSL-I-12 (van Eijck, Kemperen & Sonderen, 1994).

inpatient rehabilitation) with the Social Support List (SSL-12-I) (van Eijck, Kemperen & Sonderen, 1994). The SSL-12-I has been used in similar previous studies (den Daas et al., 2019; van Leeuwen et al., 2012). Within the current study the SSL-12-I has been tested for reliability (Table 2) and have been measured as a reliable and valid scale (van Eijck, Kempen & Sonderen, 1994).

Physical independence

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) (Post et al., 2009). The score of the USER was taken from the patient file. The USER has been developed to measure physical independence in people with SCI/ABI by a total of 14 items. Higher sum scores indicate higher physical independence (0–70). The USER is a responsive, reliable, and valid measurement (Post et al., 2009).

Statistical analysis

Data were analysed using IBM SPSS Statistics 27. The variable 'living status' for those with SCI/ABI and significant others was recoded into a dichotomous variable (alone, 0; not alone, 1). All other dichotomous variables were already included in the database. A significant level of P < .05 (two-tailed) was used.

For the analyses missing demographic data were imputed with the score of the other person in the dyad (total 2 points). Dropped-out dyads that did completed baseline but not the follow-up measurement of life satisfaction (n = 54) were included to analyse sociodemographic, injury-related and scores on life satisfaction, social support and physical independence with a t-test or Pearson's chi-squared test, to see whether the group is significantly different to the analysed dyads which provides insight into whether there is a selective bias.

Before interpreting analyses, assumptions were tested on violations. The results of these tests can be found in Appendix D. The first hypothesis was assessed with t-tests to compare the LS2 between dyads with SCI and dyads with ABI. The second hypothesis was tested by conducting a Pearson correlation to identify correlation between baseline and follow-up measurements of life satisfaction of the persons with SCI/ABI and their significant others. To test the third and fourth hypotheses firstly Pearson correlations were conducted to identify potential predictors from the baseline measurement that relate to life satisfaction six months after inpatient discharge. Only the significant correlated variables were included in the Multivariate analyses of covariance (MANCOVA) model. MANCOVA was used instead of multiple ANOVA's to account for the possibility of increasing type 1 errors. Additionally, MANCOVA considers nonindependence between individuals within a dyad with the possibility to analyse two interdependent outcome variables simultaneously, in this case life satisfaction of persons with SCI/ABI and their significant others.

Results

Descriptive statistics

Table 3 (p.19-20) shows participant characteristics and descriptive statistics, including differences between SCI and ABI, and those who dropped out during follow-up. Almost all (90.6%) of the participants did not live alone. 77.9% of the significant others were the partner of the person with SCI/ABI (child, 7.8%; a friend, 2.6%; other, 2.6%). There were no significant differences between the demographic characteristics of persons with SCI and ABI. Persons with SCI scored significantly lower on physical independence (M=28.38, SD=17.7) then people with ABI (M=43.86, SD=17.2) (t(152)=-5.487, p<.001) and the cause of the injury for persons with SCI is more often traumatic (χ 2(1) = 23.261; p<.001). Compared to ABI significant others, there were more women among the significant others of persons with SCI (χ 2(1) = 6.045; p=.014).

Differences between dropped out and analysed dyads

To see whether there is a selective bias, dropped out and analysed dyads are compared (Table 3). Independent sample t-tests and Pearson's $\chi 2$ tests showed no significant difference between dropout and analysed persons with SCI/ABI. Among significant others differences between age (t(204) = -2.169, p=.031) and if the significant other is the partner or not ($\chi 2(1) = 5.809$; p=.016) were found. Although partners still were the largest group among the dropped out significant others (61.1%), they were more likely the child (22.2%) compared to the analysed significant others (7.8%). No significant differences were found within the scale variables that were included in the analyses (Table 4, p. 21).

 $\label{thm:conditional} \textbf{Table 3}$ Sociodemographic and injury-related characteristics of persons with SCI/ABI and their significant others

Persons with SCI/ABI	Analysed dyads	Dropped out dyads	SCI (n=82)	ABI (n=72)
	(n=154)	(n=54)	n (%) or Mean \pm SD,	n (%) or Mean \pm SD,
Variable	n (%) or Mean \pm SD,	n (%) or Mean \pm SD,	range	range
	range	range		
Sex (female)	66 (42.9)	15 (27.8)	30 (36.6)	36 (50.0)
Age, y	56.4±15.4, 18-87	56.6±14.9, 22-84	55.3±16.9, 18-81	57.6±13.6, 26-87
Education (high1)	56 (36.4)	14 (25.9)	29 (35.4)	27 (37.5)
Nationality (Dutch)	133 (86.4)	49 (90.7)	71 (86.6)	62 (86.1)
Living status (not alone)	135 (87.7)	43 (79.6)	73 (89.0)	62 (86.1)
Cause of injury (non-traumatic)	49 (31.8)	15 (27.8)	40 (48.8)*	9 (12.5)*
Physical independence ²	35.6±19.1, 1-70	30.6±16.2, 1-70	28.4±17.7, 1-70°	43.9±17.2, 1-70°
AIS3(SCI only)	-	-		-
A	-	-	11 (13.5)	-
B	-	-	13 (15.9)	-
C	-	-	16 (19.5)	-
D	-	-	42 (51.2)	-
Tetraplegia (SCI only)	-	-	43 (52.)	-
Location (ABI only)				
Left	-	-	-	30 (42.3)
Right	-	-	-	26 (36.6)
Both sides	-	-	-	11 (15.5)
Brainstem	-	-	-	2 (2.8)
Unknown	-	-	-	2 (2.8)

Significant others				
Sex (female)	97 (63.0)	41 (75.9)	59 (72.0)*	38 (52.8)*
Age, y	55.5±12.7,23-82*	51.0±13.2,25-79*	56.6±13.6, 25-82	54.2±11.8, 23-75
Education (high1)	63 (40.9)	17 (33.3)	32 (39.0)	31 (43.1)
Nationality (Dutch)	143 (92.9)	48 (90.6)	77 (93.9)	66 (91.7)
Living status (not alone)	144 (93.5)	48 (88.9)	76 (92.7)	68 (94.4)
Relationship with the person with	120 (77.9)*	33 (61.1)*	61 (74.4)	59 (81.9)
SCI/ABI (partner)				

¹High education indicates a bachelor's degree or higher.

² Physical independence was measured with the Utrecht Scale for Evaluation of Clinical Rehabilitation (range, 0-70).

³ 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 (Kirshblum et al., 2011).

^{*} Independent sample t-test or Pearson χ^2 test shows a significant difference between analysed and dropped out dyads.

^{*}Independent sample t-test or Pearson χ^2 test shows a significant difference between SCI and ABI.

Table 4

Scores on life satisfaction, social support, and physical independence

Variable	Analysed ($n = 154$)	Dropped out (n=54)	SCI (n=82)	ABI (n=72)
	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Persons with SCI/ABI				
Life satisfaction ¹ - Baseline	5.73±2.2	5.81±2.2	5.16±2.1**	6.39±2.1**
- Follow up	6.72±2.3	6.38±2.6	6.24±2.4*	7.26±2.0*
Social Support ²	37.24±7.3	37.26±8.3	37.62±7.7	36.80±6.9
Physical Independence ³	35.6±19.1	30.61±16.2	28.38±17.7**	43.86±17.2**
Significant others				
Life satisfaction ¹ - Baseline - Follow up	7.09±2.1	7.54±2.2	6.66±2.3*	7.6±1.7*
	7.76±2.2	7.92±1.7	7.39±2.1*	8.18±2.3*
Social Support ²	36.76±7.6	38.53±7.8	37.04±8.5	36.45±6.3

¹Life satisfaction was measured with two life satisfaction questions (Post et al., 2012).

²Social Support was measured using the Social Support List (van Eijck, Kemperen & Sonderen, 1994).

³Physical independence was measured at baseline with the Utrecht Scale for Evaluation of Clinical Rehabilitation (USER) (Post et al., 2009).

^{*}Independent sample t-tests show a significant difference between SCI and ABI <.05.

^{**}Independent sample t-tests show a significant difference between SCI and ABI <.001.

Hypothesis 1: differences between SCI and ABI life satisfaction

At baseline, life satisfaction differed significantly among persons with SCI and ABI (t(152) = -3.661, p = <.001), whereby persons with SCI scored lower (M=4.98, SD=2.2) than persons with ABI (M=6.69, SD=1.9). This also applies to the follow-up measurement of life (SCI: M=6.67; SD=3.1 and ABI: M=7.61; SD=1.9) (t(152) = -2.864, p = .005). Likewise, significant others of persons with SCI scored lower for baseline (M=5.15, SD=2.1) (t(152) = -2.810, p = .006) and follow-up (M=6.24, SD=2.4) (t(152) = -2.251, p = .026) measurement of life satisfaction then significant others of persons with ABI at baseline (M=7.58, SD=1.7) and follow up (M=7.26, SD=2.0) measurements. This indicates that dyads of the SCI-group scored lower on life satisfaction then dyads of the ABI-group.

Hypothesis 2: life satisfaction interrelated within dyads

Table 5 (p.23) shows the results of the bivariate correlation with the life satisfaction scores six months after inpatient discharge. Both the baseline and the follow-up measurement of life satisfaction correlated between the person with SCI/ABI and their significant other. Additionally, the MANCOVA (Table 7, p.28) showed that life satisfaction at baseline of persons with SCI/ABI(Λ = .870, F(2, 143) = 10.639, p =<.001, partial η 2 = .130) and that of significant others (Λ = .737, F(2, 143) = 25.550, p =<.001, partial η 2 = .265) are significant predictors for life satisfaction at dyad level six months after inpatient discharge. One's own life satisfaction measured at baseline is a significant predictor for one's own life satisfaction six months later for persons with SCI/ABI (F(1,82) = 20.597, p = <.001, partial η 2=.125) and for significant others (F(1,17) = 50.554, p = <.001, partial η 2=.260). The results indicate that their life satisfaction is not only interrelated but that the life satisfaction of both members of the dyad is predictive of their life satisfaction six months after inpatient discharge.

Table 5

Bivariate correlations coefficients between baseline and follow-up measurement of life satisfaction with follow-up measurement of life satisfaction of persons with SCI/ABI and their significant others (n=154)

Variable	Life satisfaction of persons with SCI/ABI ¹	Life satisfaction of significant others ¹
	Correlation coefficient (P value)	Correlation coefficient (P value)
Life satisfaction baseline ² :		
- persons with SCI/ABI	.417 (<.001) **	.211 (.008) **
 significant others 	.207 (.010) *	.525 (<.001) **
Life satisfaction follow-up1:		
persons with SCI/ABIsignificant others	NA	.416 (<.001) **
	.416 (<.001) **	NA
NA= not applicable Assessed at six months after patient	discharge	
² Assessed during inpatient rehabilita *P<.05	ition	

**P<.01

Table 6

Bivariate correlations coefficients between sociodemographic + injury-related variables and social support for life satisfaction six months after discharge from inpatient rehabilitation for persons with SCI/ABI and significant others (n=154)

Variable	Life satisfaction of persons with SCI/ABI ¹	Life satisfaction of significant others ¹	
	Correlation coefficient (P value)	Correlation coefficient (P value)	
Diagnosis persons with SCI/ABI	.226 (.005) **	.180 (.026) *	
Sex persons with SCI/ABI	.067 (.411)	.119 (.143)	
Sex significant others	047 (.560)	108 (.181)	
Age persons with SCI/ABI	110 (.173)	065 (.426)	
Age significant others	148 (.066)	135 (.094)	
Education persons with SCI/ABI	.028 (.732)	120 (.138)	
Education significant others	.150 (.063)	135 (.094)	
Living status persons with SCI/ABI	152 (.060)	194 (.016) *	
Living status significant others	.049 (.544)	101 (.213)	
Nationality persons with SCI/ABI	.041 (.614)	.095 (.240)	
Nationality significant others	.046 (.574)	016(.848)	

Variable	Life satisfaction of persons with SCI/ABI ¹	Life satisfaction of significant others ¹
	Correlation coefficient (P value)	Correlation coefficient (P value)
Cause of injury persons with SCI/ABI	070 (.387)	065 (.424)
Physical independence persons with	.249 (.002) **	.204 (.011) *
SCI/ABI		
Social support of persons with SCI/ABI ²	.068 (.399)	.107 (.188)
Social support of significant others ²	051 (.532)	.025 (.760)
Relationship with person with SCI/ABI	101 (.213)	165 (.041) *
¹ Assessed at six months after patient discharge		
² Assessed during inpatient rehabilitation		
*P<.05		
**P<.01		

Hypotheses 3 and 4: prediction of life satisfaction

Correlations with life satisfaction six months after inpatient discharge

In preparation for hypotheses 2 and 3, variables which correlated with life satisfaction six months after inpatient discharge were examined with a Pearson correlation (Table 5 and 6, p.23-25). In addition to the results above where life satisfaction measured at admission correlates with life satisfaction six months after inpatient discharge, physical independence and diagnosis were also related to both the life satisfaction of the persons with SCI/ABI as for the significant others. For significant others the living status of the person with SCI/ABI and if they are the partner or not of the person with SCI/ABI, correlated with their life satisfaction.

Hypothesis 3: the predictive role of social support on life satisfaction

No significant correlations were found between social support and life satisfaction for both the persons with SCI/ABI as for the significant others. Therefore, social support is not included in the final MANCOVA model where the prediction of life satisfaction was investigated. In contrast to what was expected the results indicated that within this study no (predictive) relationship between social support and life satisfaction was found.

Hypothesis 4: the predictive role of physical independence on life satisfaction

The MANCOVA model (Table 7, p.28) included all significant correlated variables with life satisfaction of the persons with SCI/ABI or/and of the life satisfaction of the significant others: diagnosis, physical independence, life satisfaction at baseline of both members of the dyads, living status of the person with SCI/ABI and relationship with the person with SCI/ABI. Adjusted for these variables physical independence is a significant predictor for life satisfaction of the dyad ($\Lambda = .955$, F(2, 143) = 3.403, p = .063, partial $\eta 2 = .045$). Physical independence is also a significant predictor for the life satisfaction of persons with SCI/ABI (F(1, 17) = 4.367, p = .063).

- = .038, partial η 2 = .029), and for life satisfaction of significant others (F(1,15) = 4.636, p
- = .033, partial η 2= .031). The MANCOVA model explained 25.7% (adjusted R² = 21.1%) of the total variance of the LS2 score of the persons with SCI/ABI and 34.6% (adjusted R²= 30.4%) for significant others' total LS2 score.

 Table 7

 MANCOVA to predict life satisfaction six months after discharge from inpatient rehabilitation (n=154)

		Between Subjects Effects		
Independent variables Multivariate		Life satisfaction persons with SCI/ABI ³	Life satisfaction significant others ³	
	V ¹(P value)	F (P Value)	F (P Value)	
Diagnosis	.997 (.787)	.248 (.619)	.09 (.205)	
Living status of the person with SCI/ABI ²	.963 (.066)	2.38 (.125)	4.76 (.031) *	
Physical independence	.955 (.036) *	4.37 (.038) *	4.64 (.033) *	
Partner or not	.988 (.412)	.75 (.389)	1.55 (.215)	
Life satisfaction of persons with SCI/ABI baseline ²	.870 (<.001) **	20.60 (<.001) **	.312 (.577)	
Life satisfaction of significant others baseline ²	.737 (<.001) **	1.76 (.186)	50.55 (<.001) **	
Explained variance (%)	NA	25.7	34.6	

NA= not applicable

¹Wilks' Lambda value

²Assessed at the start of inpatient rehabilitation

³Assessed six months after discharge from the rehabilitation centre

^{*}P<.05

^{**}P<.01

Discussion

The aim of this study was to investigate if social support of the person with SCI or ABI and significant others, and physical independence of the person with the condition measured shortly after the start of inpatient rehabilitation, predict their life satisfaction six months after inpatient discharge from the rehabilitation centre.

The results indicate that dyads of the ABI-group score significantly higher on life satisfaction than dyads of the SCI-group. Social support is not related to life satisfaction. Physical independence of the person with the condition is a significant predictor for life satisfaction six months after inpatient discharge for the dyad and for persons with SCI/ABI and significant others separately. Furthermore, the life satisfaction of both members of the dyad measured during inpatient rehabilitation is a significant predictor for the life satisfaction six month after inpatient discharge. Additionally, the living status of the person with SCI/ABI was a significant predictor for significant others' life satisfaction.

Differences between SCI and ABI

In line with the first hypothesis life satisfaction was found to be significantly lower in dyads of the SCI-group then in dyads of the ABI-group. Although there are no known studies in which both SCI and ABI groups were included to measure life satisfaction, the results are in line with results from previous study that included persons with both SCI and TBI (Hicken et al.,2002). The extent to which this result can be explained based on the diagnosis itself might be questionable. Other studies with different diagnoses show that mostly the physical functioning or condition severity were related to life satisfaction (Hickens et al., 2002; Pucciarelli et al., 2017; Warren, 1996) The current study did show that the degree of physical dependence is a clear predictor of life satisfaction while diagnosis itself is not. Additionally, the physical independence

was significantly lower among persons with SCI then among persons with ABI. Taken this in consideration, the difference in diagnosis is possibly explained by the difference in physical dependence. This could mean that it is not diagnosis itself that is predominant, but that physical independence explains the difference. On the other hand, these results indicate that diagnosis differences exist, which can be relevant for diagnosis specific treatment whereby for the dyads of the SCI-group requires more attention to life satisfaction then to those from the ABI-group. It is then recommended to conduct further research into these differences and diagnosis-specific characteristics before drawing further conclusions.

The interrelatedness of life satisfaction between the person with SCI/ABI and their significant other

It was hypothesised that the life satisfaction of dyads are related. By using a dyadic approach, it was shown that life satisfaction at the start at inpatient rehabilitation and six months after inpatient rehabilitation are related between the person with SCI/ABI and their significant other and that their life satisfaction at baseline predict their life satisfaction six months after inpatient discharge. Studies that have looked at life satisfaction on a dyadic level in the chronic phase also confirm these findings (Achten et al., 2012; Cox, 2020). Based on the TDIM the results of the interrelatedness between the life satisfaction of persons with SCI/ABI and their significant others was expected as the TDIM states that the mental health of both members of the dyad are inextricably linked (Lyons & Lee, 2018). This emphasizes the importance of including both the person with the condition and their significant other right at the start of rehabilitation.

The role of perceived social support

A remarkable result of this study was that social support did not correlate with the life satisfaction for the person with SCI/ABI and their significant other separately, since this is in

contrasts with other studies where this relationship was found (Adriaansen et al., 2011; Ergh et al., 2002; Müller et al., 2011; Rodakowski et al., 2012). Furthermore, it was what was expected from the TDIM, which cites that social support is the largest and most protective factor (Lyons & Lee, 2018). Possibly, the current results relate to the way social support was questioned in the present study, which asked about perceived social support before the onset of the condition, whereas other studies specifically asked about the actual received social support received after the onset of the condition (Ergh et al., 2002; Rodakowski et al., 2012). The experience of social support before onset of the condition may be a difficult aspect because it deals with past experiences, which is less accurate. Especially after onset of SCI/ABI, experiencing social support can be a very important aspect for people (Kruithof et al., 2014; Post et al., 1999) and may therefore be more related to their life satisfaction. However, another study that also used the SSL-12-I found no significant main effect between social support and life satisfaction, and this study did ask about social support after the onset of the condition (van Leeuwen et al., 2011). The subscales of the SSL-12-I were also analysed within the study of van Leeuwen et al. (2011) it emerged that 'social support in problem situations' was a significant predictor of life satisfaction.

The role of physical independence

As hypothesised physical independence of the person with SCI/ABI is a predictor for life satisfaction of persons with SCI/ABI and their significant others. Several studies did find the comparable relationship between physical independence and life satisfaction among stroke patients and persons with TBI/SCI (Achten et al., 2012; Hicken et al., 2002; Pucciarelli et al., 2017; Resch et al., 2009). A similar study to the current study of van Leeuwen et al. (2011) shows that significant correlations exist between a higher life satisfaction and higher functional

independence among persons with SCI, during, just after one year and five years after inpatient discharge. The present results and previous studies show that physical independence thus plays a role in predicting life satisfaction right from the start and also later in life following SCI/ABI. Possibly this influence their functioning and participation within society, which is important for this target group since this seems to contribute to their life satisfaction (Meulenkamp et al., 2015; Springvloet et al., 2020).

Strengths and limitations

A strength is that the current study used a dyadic approach which resulted in scientific knowledge about the identification of possible predictors of life satisfaction of persons with SCI/ABI, their significant others and at dyad level. These results can be relevant for the development of family-centred rehabilitation care.

Additionally, all rehabilitation centres in which people with SCI are treated throughout the Netherlands are included. The inclusion of different diagnostic groups (SCI and ABI) which together form the majority of the adult inpatient rehabilitation population contributes to the generalisability of the results.

Although it is a strength that a comparison is made within the study between dropouts and analysed dyads it does reveal a limitation. It showed a significant different between age and the relationship with the person with SCI/ABI for significant others. The results show that dropped out significant others were more often a child of the person with SCI/ABI than the analysed significant others. This probably explains the significant age difference. Despite this difference, in comparison to the general population, the sample of significant others used is representative as the majority of informal carers are the partner (Waverijn & Heijmans, 2015).

Additionally, there remains quite a large group that dropped out due to inclusion criteria or refusal to participate. This may have caused selection or nonresponse bias. Unfortunately, no data are available for this group. Nevertheless, the group seems to correspond to the sociodemographic data known of the general Dutch SCI and stroke population (Post et al., 2012; Ten Brink et al., 2017).

Due to missing scores on the main variables and the different measurement moments a large proportion of dyads were excluded from the analyses. It was decided not to impute these data, because it concerns subjective scores, other than, for example, gender or age. Although supplementing the scores means a larger sample, it is believed that this does not contribute to generalizability because of uncertainty about the correct interpretation of the scores.

Additionally, although this has resulted in fewer participants, it is something that is always something to consider when using different measurement moments, as this is a well-known problem in these types of studies.

Furthermore, the LS2 for persons with SCI/ABI showed poor internal consistency.

Nevertheless, it is of limited value when applied to scales with very few items, because it depends on the number of items in a scale. The obvious way to increase internal consistency is to increase the number of items. However, this would negate the advantage of a very short instrument. Considering the target group with regard to impaired cognition problems, it is not desirable to implement a longer questionnaire.

Lastly, measuring social support with the SSL-12-I by asking for the perceived social support before onset of the condition seems to produce conflicting results compared to other measurement methods or when using the subscales, as described above. This is seen as a

limitation. A follow-up study would encourage the measurement of different aspects of social support after the onset of the condition to investigate its predictive role for life satisfaction.

Implications and recommendations

Further research

Since life satisfaction can be an important indicator of people with a condition like SCI/ABI and their significant others of the extent to which they succeed in participating in society according to their wishes and needs, further research could be focused on developing interventions to strengthen life satisfaction for dyads after onset of SCI/ABI. Therefore, it is important to reveal which factors (personal, social, cultural, and environmental) predict their life satisfaction. The present study has contributed to this by showing that dyadic life satisfaction exists and that research into further aspects that may influence dyadic life satisfaction may therefore be valuable. The use of the TDIM can contribute to further research. By using this model consistently, it is possible to determine what influences the life satisfaction of dyads over time after onset of SCI/ABI. These further studies will contribute to targeted rehabilitation care with a focus on the dyadic relationship an improvement of life satisfaction for both the person with SCI/ABI their and their significant other.

As social support is a broad concept with various aspects and the type of social support may vary over time, further research among dyads should encounter for these different aspects of social support and the timing of measurement so that aspects of social support that contribute to the life satisfaction of dyads can be further examined.

Practical implications

Rehabilitation interventions

This study shows that focusing only on the person with SCI/ABI is not sufficient enough. A focus on dyadic health recognizes the complexity of roles within dyads and does not hold the health of one member of the dyad as more important than the other. Previous research has shown that interventions targeting not only the person with the injury but also relatives lead to more positive outcomes than the application of standard interventions and results in faster recovery which contributes to less care costs (Lindhout et al., 2016). Moreover, the efficacy of such interventions are not just dyads based (i.e., both members are included) but should be dyad focused (i.e., the dyad is the target). Risk screening based on the results of the current study helps to provide dyadic care and thereby providing care that is more effective with results in less time and with less costs.

Improvement at policy level

The Dutch government is striving for increasing inclusion of people with disabilities with the program 'Onbeperkt Meedoen' (Vermeij & Hamelink, 2021) in which the aim is for everyone to be able to participate and live a fulfilled life in society without hampered by a disability. Life satisfaction of people with a condition and their relatives is an indicator of the extent to which they succeed in participating in society according to their wishes and needs (Meulenkamp et al., 2015; Springvloet et al., 2020). As mentioned in the introduction people with a physical condition experience fewer opportunities to organize their lives freely (Vermeij & Hamelink, 2021). The results of the present study highlight a possible missing element in this programme: the inclusion of the significant other in the efforts to achieve participation and to live a satisfactory life. In addition, significant others do not feel involved enough in the care process (Wiersema, 2017), this research shows the importance of doing so because their life satisfaction is related. Successful rehabilitation and thus integration starts not only with the person with the

condition but also with their significant other. Knowledge of this dyadic relationship should be further embedded in measuring and improving the lives of people with disabilities such as SCI/ABI so that they can lead a fulfilled life.

Conclusion

Perceived social support does not predict life satisfaction of persons with SCI/ABI and their significant other. In contrast, physical independence of the person with SCI/ABI does predict life satisfaction for the dyad as well as for the person with SCI/ABI and their significant other separately. The relationship of life satisfaction between persons with SCI/ABI and significant others indicate that dyadic health should be considered. Significant others should be included to a greater extent in the rehabilitation and predictors such as physical independence can serve as risk screening during rehabilitation.

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Appendix A: instruments

** = from the questionnaire six months after inpatient discharge

Questionnaire POWER-study: for the person with ABI (Dutch)





POWER

Vragenlijst – Revalidant

Eerste meting

Bij opname – niet-aangeboren hersenletsel

Deelnemernummer:	
Datum:	//
P. WER STUDY	
Contactgegevens on	derzoekers

Invulinstructie

Het invullen van deze lijst duurt ongeveer 25 tot 40 minuten. Het is de bedoeling dat u bij elke vraag het hokje aankruist, of het cijfer omcirkelt, bij het antwoord dat (het meest) op u van toepassing is. Een open vraag beantwoordt u door uw antwoord op te schrijven. Indien u opmerkingen heeft over een bepaalde vraag of uw antwoord wilt toelichten, kunt u deze aan het einde van de vragenlijst met vermelding van bladzijde en vraagnummer, aangeven.

Er zijn geen goede of verkeerde antwoorden: vul deze vragenlijst zo veel mogelijk in naar uw huidige situatie tenzij anders vermeld. Denk niet te lang na over uw antwoord: uw eerste ingeving is vaak de beste.

Geef bij elke vraag één antwoord, tenzij aangegeven is dat meerdere antwoorden mogelijk zijn.

We verzoeken u deze vragenlijst zelfstandig en zonder hulp van een naaste in te vullen. De vragen gaan over u. We zijn geïnteresseerd in uw eigen antwoorden. Indien u hulp nodig heeft dan kan de onderzoeksassistent u helpen.

Persona	ilia
Geboor	tedatum:/ (dag / maand / jaar)
	Man Vrouw
Wat is u	w geboorteland?
	w hoogste afgeronde opleiding?
	Lager onderwijs (6 of 8 klassen lagere school)
	Lager beroepsonderwijs (o.a. LBO, LTS, ITO, LEAO, LHNO,
	Huishoudschool, Hogere Landbouw/Tuinbouw, VMBO praktijk)
	Middelbaar algemeen voortgezet onderwijs (MAVO, IVO (M)ULO,
	Middenschool, 3 jaar HBS/VWO, VHMO/Atheneum/Gymnasium, VMBO theoretische leerweg)
	Middelbaar Beroepsonderwijs (o.a. MBO, MTS, UTS, MEAO, Middelbare
	Landbouw/Tuinbouw/Detailhandelschool/MBA/SPD)
	Hoger algemeen en voorbereidend wetenschappelijk onderwijs (HAVO,
П	VWO, MMS, HBS, Gymnasium, Lyceum, Atheneum) Hoger beroepsonderwijs en wetenschappelijk onderwijs (o.a. HBO, HTS,
_	HEAO, NLO, MO-A, MO-B, KMA, universiteit)
Wat is u	w burgerlijke staat?
	Alleenstaand
	Partner, niet samenwonend
_	Gehuwd/duurzaam samenwonend
_	Gescheiden
	Weduwe/weduwnaar

Algemeen welbevinden

De volgende vragen hebben betrekking op de wijze waarop u uw leven beoordeelt op dit moment en in vergelijking met uw leven voor het hersenletsel.

1.	ger	nsen kunnen meer of minder tevreden zijn over hun leven als geheel, ook wel noemd hun kwaliteit van leven. Wat is op dit moment uw oordeel over uw aliteit van leven? Kruis het hokje aan dat het beste bij u past.		
		Zeer onbevredigend Onbevredigend Enigszins onbevredigend Enigszins bevredigend Bevredigend Zeer bevredigend		
 Als u uw leven vergelijkt met uw leven vlak voor het hersenletsel, vindt u dan kwaliteit van leven op dit moment beter of slechter dan uw leven voor het hersenletsel? Kruis 1 hokje aan dat uw situatie het beste weergeeft. 				
	000000	Veel slechter Slechter Beetje slechter Ongeveer hetzelfde Beetje beter Beter Veel beter		

**

Sociale steun

Nu volgen 12 vragen waarin telkens over 'men' gesproken wordt. Het is de bedoeling dat u bij elke vraag onder 'men' steeds de mensen verstaat waar u mee omgaat (dus het geheel van familieleden, vrienden, kennissen, buren, collega's etc.). Wilt u telkens het antwoord dat het meest op u van toepassing is aankruisen?

Beantwoord deze vragen over uw situatie voor het hersenletsel.

	Gebeurt het weleens dat men	Zelden of nooit	Af en toe	Regel matig	Erg vaak
1.	u uitnodigt voor een feestje of etentje?				
2.	gezellig bij u op bezoek komt?		۵	۵	
3.	genegenheid voor u toont?				
4.	u troost?	_			
5.	u complimenten geeft?	_			
6.	interesse voor u toont?				
7.	u hulp biedt in bijzondere gevallen zoals bij ziekte en verhuizing?	_		П	
8.	u geruststelt?	_			
9.	u goede raad geeft?			□	
10.	u in vertrouwen neemt?	_			
11.	u om hulp of advies vraagt?	_			
12.	uw sterke punten naar voren haalt?				

Questionnaire person with SCI (Dutch)





POWER

Vragenlijst - Revalidant

Eerste meting

Bij opname - dwarslaesie

Deelnemernummer:					
Datum:		1	/	 	
P. WER STUDY					
Contactgegevens onderz	oeke	ers			

Invulinstructie

Het invullen van deze lijst duurt ongeveer 25 tot 40 minuten. Het is de bedoeling dat u bij elke vraag het hokje aankruist, of het cijfer omcirkelt, bij het antwoord dat (het meest) op u van toepassing is. Een open vraag beantwoordt u door uw antwoord op te schrijven. Indien u opmerkingen heeft over een bepaalde vraag of uw antwoord wilt toelichten, kunt u deze aan het einde van de vragenlijst met vermelding van bladzijde en vraagnummer, aangeven.

Er zijn geen goede of verkeerde antwoorden: vul deze vragenlijst zo veel mogelijk in naar uw huidige situatie tenzij anders vermeld. Denk niet te lang na over uw antwoord: uw eerste ingeving is vaak de beste.

Geef bij elke vraag één antwoord, tenzij aangegeven is dat meerdere antwoorden mogelijk zijn.

We verzoeken u deze vragenlijst zelfstandig en zonder hulp van een naaste in te vullen. De vragen gaan over u. We zijn geïnteresseerd in uw eigen antwoorden. Indien u hulp nodig heeft dan kan de onderzoeksassistent u helpen.

Persona	lia
Geboort	edatum:/ (dag / maand / jaar)
_	t Man Vrouw
Wat is u	w geboorteland?
	w hoogste afgeronde opleiding?
	Lager onderwijs (6 of 8 klassen lagere school) Lager beroepsonderwijs (o.a. LBO, LTS, ITO, LEAO, LHNO, Huishoudschool, Hogere Landbouw/Tuinbouw, VMBO praktijk)
	Middelbaar algemeen voortgezet onderwijs (MAVO, IVO (M)ULO, Middenschool, 3 jaar HBS/VWO, VHMO/Atheneum/Gymnasium, VMBO theoretische leerweg)
	Middelbaar Beroepsonderwijs (o.a. MBO, MTS, UTS, MEAO, Middelbare Landbouw/Tuinbouw/Detailhandelschool/MBA/SPD)
	Hoger algemeen en voorbereidend wetenschappelijk onderwijs (HAVO, VWO, MMS, HBS, Gymnasium, Lyceum, Atheneum)
	Hoger beroepsonderwijs en wetenschappelijk onderwijs (o.a. HBO, HTS, HEAO, NLO, MO-A, MO-B, KMA, universiteit)
	w burgerlijke staat?
_	Alleenstaand Partner, niet samenwonend
	Gehuwd/duurzaam samenwonend
	Gescheiden
	Weduwe/weduwnaar

Algemeen welbevinden

De volgende vragen hebben betrekking op de wijze waarop u uw leven beoordeelt op dit moment en in vergelijking met uw leven voor de dwarslaesie.

1.	. Mensen kunnen meer of minder tevreden zijn over hun leven als geheel, ook w genoemd hun kwaliteit van leven. Wat is op dit moment uw oordeel over uw kwaliteit van leven? Kruis het hokje aan dat het beste bij u past.					
	□ O:	eer onbevredigend nbevredigend nigszins onbevredigend nigszins bevredigend evredigend eer bevredigend				
2.	kwalite	uw leven vergelijkt met uw leven vlak voor de dwarlaesie, vindt u dan uw eit van leven op dit moment beter of slechter dan uw leven voor de laesie? Kruis 1 hokje aan dat uw situatie het beste weergeeft.				
	□ SI □ Be □ OI □ Be	eel slechter lechter eetje slechter ngeveer hetzelfde eetje beter eter eel beter				

**

Sociale steun

Nu volgen 12 vragen waarin telkens over 'men' gesproken wordt. Het is de bedoeling dat u bij elke vraag onder 'men' steeds de mensen verstaat waar u mee omgaat (dus het geheel van familieleden, vrienden, kennissen, buren, collega's etc). Wilt u telkens het antwoord dat het meest op u van toepassing is aankruisen?

Beantwoord deze vragen over uw situatie voor de dwarslaesie.

	Gebeurt het weleens dat men	Zelden of nooit	Af en toe	Regel- matig	Erg vaak
1.	u uitnodigt voor een feestje of etentje?	_		_	0
2.	gezellig bij u op bezoek komt?			۵	-
3.	genegenheid voor u toont?			۵	-
4.	u troost?	_			
5.	u complimenten geeft?			۵	
6.	interesse voor u toont?		۵	۵	۵
7.	u hulp biedt in bijzondere gevallen zoals bij ziekte en verhuizing?	-			۵
8.	u geruststelt?				۵
9.	u goede raad geeft?				□
10.	u in vertrouwen neemt?				
11.	u om hulp of advies vraagt?		□		□
12.	uw sterke punten naar voren haalt?			_	۵

Questionnaire significant other of the person with SCI (Dutch)





Power

Vragenlijst - Naaste

Eerste meting

Bij opname - Dwarslaesie

Deelnemernummer:				
Datum:	 <i>l</i>	/ .	 	

Contactgegevens onderzoeker

Deelname

Voordat u de vragenlijst gaat invullen willen we u op de hoogte brengen van een aantal belangrijke punten:

- Meedoen is vrijwillig. U kunt altijd stoppen. Daar hoeft u geen reden voor te geven.
- De gegevens uit deze vragenlijst worden gebruikt voor wetenschappelijk onderzoek.
- Uw naam en contactgegevens worden niet gekoppeld aan de gegevens die u invult in de vragenlijst.
- Na afronding van het onderzoek worden alle onderzoeksgegevens 15 jaar bewaard. Daarna worden de onderzoeksgegevens vernietigd.
- Als u voorafgaand aan het invullen van de vragenlijst nog vragen heeft, neem dan contact op met de onderzoeker. Het is belangrijk dat al uw vragen beantwoord zijn. De contactgegevens van de onderzoeker staan op de voorkant van deze vragenlijst.

De it had de havenstaande nunten gelegen en it han haveid en een het

Vind u het goed om aan het onderzoek deel te nemen?

_	onderzoek deel te nemen. U kunt de vragenlijst invullen. Lees voorafgaand de onderstaande invulinstructie.
	Nee, ik wil liever niet deelnemen aan het onderzoek. U hoeft de vragenlijst niet verder in te vullen. U kunt de vragenlijst in de bijgeleverde envelop voegen en naar de onderzoekers opsturen. Het adres staat al op de envelop weergegeven. Postzegels zijn niet nodig.

Invulinstructie

Het invullen van deze lijst duurt ongeveer 20 tot 30 minuten. Het is de bedoeling dat u bij elke vraag het hokje aankruist, of het cijfer omcirkelt, bij het antwoord dat (het meest) op u van toepassing is. Een open vraag beantwoordt u door uw antwoord op te schrijven. Indien u opmerkingen heeft over een bepaalde vraag of uw antwoord wilt toelichten, kunt u deze aan het einde van de vragenlijst met vermelding van bladzijde en vraagnummer, noteren.

Er zijn geen goede of verkeerde antwoorden: vul deze vragenlijst zoveel mogelijk in naar uw huidige situatie tenzij anders vermeld. Denk niet te lang na over uw antwoord: uw eerste ingeving is vaak de beste.

Geef bij elke vraag één antwoord, tenzij aangegeven is dat meerdere antwoorden mogelijk zijn.

In de vragenlijst worden soms vragen gesteld waarin gesproken wordt over 'uw naaste' of over 'de aandoening van uw naaste'. Met uw naaste bedoelen we de persoon met dwarslaesie.

Personalia Geboortedatum: / (dag / maand / jaar) Geslacht □ Man □ Vrouw Wat is uw burgerlijke staat? Alleenstaand Partner, niet samenwonend □ Gehuwd/duurzaam samenwonend ☐ Gescheiden □ Weduwe/weduwnaar Wat is uw geboorteland? Wat is uw hoogste afgeronde opleiding? ■ Lager onderwijs (6 of 8 klassen lagere school) Lager beroepsonderwijs (o.a. LBO, LTS, ITO, LEAO, LHNO, Huishoudschool, Hogere Landbouw/Tuinbouw, VMBO praktijk) Middelbaar algemeen voortgezet onderwijs (MAVO, IVO (M)ULO, Middenschool, 3 jaar HBS/VWO, VHMO/Atheneum/Gymnasium, VMBO theoretische leerweg) Middelbaar Beroepsonderwijs (o.a. MBO, MTS, UTS, MEAO, Middelbare Landbouw/Tuinbouw/Detailhandelschool/MBA/SPD) Hoger algemeen en voorbereidend wetenschappelijk onderwijs (HAVO, VWO, MMS, HBS, Gymnasium, Lyceum, Atheneum) Hoger beroepsonderwijs en wetenschappelijk onderwijs (o.a. HBO, HTS. HEAO, NLO, MO-A, MO-B, KMA, universiteit) Wat is uw relatie tot de persoon met de dwarslaesie? Partner □ Ouder ☐ Kind ☐ Kleinkind □ Anderszins familie, namelijk ______

Ander belangrijk persoon uit het sociale netwerk, namelijk

□ Vriend/vriendin□ Buurtgenoot

Algemeen welbevinden

De volgende vragen hebben betrekking op de wijze waarop u uw leven beoordeelt op dit moment en in vergelijking met uw leven voor de dwarslaesie van uw naaste.

1.	Mensen kunnen meer of minder tevreden zijn over hun leven als geheel, ook wel genoemd hun kwaliteit van leven. Wat is op dit moment uw oordeel over uw kwaliteit van leven? Kruis het hokje aan dat het beste bij u past.
	 □ Zeer onbevredigend □ Onbevredigend □ Enigszins onbevredigend □ Enigszins bevredigend □ Bevredigend □ Zeer bevredigend
2.	Als u uw leven vergelijkt met uw leven vlak voor de dwarslaesie van uw naaste, vindt u dan uw kwaliteit van leven op dit moment beter of slechter dan uw leven voor de dwarslaesie van uw naaste? Kruis het hokje aan dat uw situatie het beste weergeeft.
	□ Veel slechter □ Slechter □ Beetje slechter □ Ongeveer hetzelfde □ Beetje beter □ Beter □ Veel beter

**

Sociale steun

Nu volgen 12 vragen waarin telkens over 'men' gesproken wordt. Het is de bedoeling dat u bij elke vraag onder 'men' steeds de mensen verstaat waar u mee omgaat (dus het geheel van familieleden, vrienden, kennissen, buren, collega's etc). Wilt u telkens het antwoord dat het meest op u van toepassing is aankruisen?

Beantwoord deze vragen over uw situatie voor de dwarslaesie.

	Gebeurt het weleens dat men	Zelden of nooit	Af en toe	Regel- matig	Erg vaak
1.	u uitnodigt voor een feestje of etentje?	_		_	0
2.	gezellig bij u op bezoek komt?			۵	-
3.	genegenheid voor u toont?			۵	-
4.	u troost?	_			
5.	u complimenten geeft?			۵	
6.	interesse voor u toont?		۵	۵	۵
7.	u hulp biedt in bijzondere gevallen zoals bij ziekte en verhuizing?	-			۵
8.	u geruststelt?				۵
9.	u goede raad geeft?				□
10.	u in vertrouwen neemt?				
11.	u om hulp of advies vraagt?		□		□
12.	uw sterke punten naar voren haalt?			_	۵

Questionnaire significant other of the person with ABI (Dutch)



Power

Vragenlijst - Naaste

Eerste meting

Bij opname - niet-aangeboren hersenletsel

Deelnemernummer:							
Datum:	//						
Contactgegevens onde	rzoeker						

Deelname

Voordat u de vragenlijst gaat invullen willen we u op de hoogte brengen van een aantal belangrijke punten:

- Meedoen is vrijwillig. U kunt altijd stoppen. Daar hoeft u geen reden voor te geven.
- De gegevens uit deze vragenlijst worden gebruikt voor wetenschappelijk onderzoek.
- Uw naam en contactgegevens worden niet gekoppeld aan de gegevens die u invult in de vragenliist.
- Na afronding van het onderzoek worden alle onderzoeksgegevens 15 jaar bewaard. Daarna worden de onderzoeksgegevens vernietigd.
- Als u voorafgaand aan het invullen van de vragenlijst nog vragen heeft, neem dan contact op met de onderzoeker. Het is belangrijk dat al uw vragen beantwoord zijn. De contactgegevens van de onderzoeker staan op de voorkant van deze vragenlijst.

Vind u het goed om aan het onderzoek deel te nemen?

_	onderzoek deel te nemen. U kunt de vragenlijst invullen. Lees voorafgaand de onderstaande invulinstructie.
	Nee, ik wil liever niet deelnemen aan het onderzoek. U hoeft de vragenlijst niet verder in te vullen. U kunt de vragenlijst in de bijgeleverde envelop voegen en naar de onderzoekers opsturen. Het adres staat al op de envelop weergegeven. Postzegels zijn niet nodig.

Invulinstructie

Het invullen van deze lijst duurt ongeveer 20 tot 30 minuten. Het is de bedoeling dat u bij elke vraag het hokje aankruist, of het cijfer omcirkelt, bij het antwoord dat (het meest) op u van toepassing is. Een open vraag beantwoordt u door uw antwoord op te schrijven. Indien u opmerkingen heeft over een bepaalde vraag of uw antwoord wilt toelichten, kunt u deze aan het einde van de vragenlijst met vermelding van bladzijde en vraagnummer, noteren.

Er zijn geen goede of verkeerde antwoorden: vul deze vragenlijst zoveel mogelijk in naar uw huidige situatie tenzij anders vermeld. Denk niet te lang na over uw antwoord: uw eerste ingeving is vaak de beste.

Geef bij elke vraag één antwoord, tenzij aangegeven is dat meerdere antwoorden mogelijk zijn.

In de vragenlijst worden soms vragen gesteld waarin gesproken wordt over 'uw naaste' of over 'de aandoening van uw naaste'. Met uw naaste bedoelen we de persoon met het hersenletsel.

Personalia					
Geb	oorl	tedatum:/ / (dag / maand / jaar)			
Ges					
		Man Vrouw			
	_	Violaw			
Wat	is u	w burgerlijke staat?			
		Alleenstaand			
		Partner, niet samenwonend			
		Gehuwd/duurzaam samenwonend Gescheiden			
		Weduwe/weduwnaar			
	_	Weddwe/ Weddwilaal			
Wat	is u	w geboorteland?			
	•••••				
Wat	is u	w hoogste afgeronde opleiding?			
		Lager onderwijs (6 of 8 klassen lagere school)			
		Lager beroepsonderwijs (o.a. LBO, LTS, ITO, LEAO, LHNO,			
	_	Huishoudschool, Hogere Landbouw/Tuinbouw, VMBO praktijk)			
		Middelbaar algemeen voortgezet onderwijs (MAVO, IVO (M)ULO,			
		Middenschool, 3 jaar HBS/VWO, VHMO/Atheneum/Gymnasium, VMBO			
		theoretische leerweg) Middelbaar Beroepsonderwijs (o.a. MBO, MTS, UTS, MEAO, Middelbare			
	_	Landbouw/Tuinbouw/Detailhandelschool/MBA/SPD)			
		Hoger algemeen en voorbereidend wetenschappelijk onderwijs (HAVO,			
		VWO, MMS, HBS, Gymnasium, Lyceum, Atheneum)			
		Hoger beroepsonderwijs en wetenschappelijk onderwijs (o.a. HBO, HTS,			
		HEAO, NLO, MO-A, MO-B, KMA, universiteit)			
Wat	is u	w relatie tot de persoon met het hersenletsel?			
		Partner			
		Ouder			
		Kind			
		Kleinkind			
		Anderszins familie, namelijk			
		Vriend/vriendin Buurtgenoot			
		Ander belangrijk persoon uit het sociale netwerk, namelijk			

Algemeen welbevinden

De volgende vragen hebben betrekking op de wijze waarop u uw leven beoordeelt op dit moment en in vergelijking met uw leven voor het hersenletsel van uw naaste.

1.	Mensen kunnen meer of minder tevreden zijn over hun leven als geheel, ook wel genoemd hun kwaliteit van leven. Wat is op dit moment uw oordeel over uw kwaliteit van leven? Kruis het hokje aan dat het beste bij u past.				
	□ Zeer onbevredigend □ Onbevredigend □ Enigszins onbevredigend □ Enigszins bevredigend □ Bevredigend □ Zeer bevredigend				
2.	Als u uw leven vergelijkt met uw leven vlak voor de dwarslaesie van uw naaste, vindt u dan uw kwaliteit van leven op dit moment beter of slechter dan uw leven voor de dwarslaesie van uw naaste? Kruis het hokje aan dat uw situatie het best weergeeft.				
	□ Veel slechter □ Slechter □ Beetje slechter □ Ongeveer hetzelfde □ Beetje beter □ Beter □ Veel beter				

**

Sociale steun

Nu volgen 12 vragen waarin telkens over 'men' gesproken wordt. Het is de bedoeling dat u bij elke vraag onder 'men' steeds de mensen verstaat waar u mee omgaat (dus het geheel van familieleden, vrienden, kennissen, buren, collega's etc.). Wilt u telkens het antwoord dat het meest op u van toepassing is aankruisen?

Beantwoord deze vragen over uw situatie voor het hersenletsel.

	Gebeurt het weleens dat men	Zelden of nooit	Af en toe	Regel matig	Erg vaak
1.	u uitnodigt voor een feestje of etentje?				
2.	gezellig bij u op bezoek komt?		۵	۵	
3.	genegenheid voor u toont?				
4.	u troost?	_			
5.	u complimenten geeft?	_			
6.	interesse voor u toont?				
7.	u hulp biedt in bijzondere gevallen zoals bij ziekte en verhuizing?	_		П	
8.	u geruststelt?	_			
9.	u goede raad geeft?			□	
10.	u in vertrouwen neemt?	_			
11.	u om hulp of advies vraagt?	_			
12.	uw sterke punten naar voren haalt?				

Appendix B: syntax

The syntax will be sent to the supervisor via a secured environment

Appendix C: Calculations of the scale measurements

Life satisfaction (LS2)

The LS2 consist of two questions: 1. What is your quality of life at the moment (1= very unsatisfying, 6= very satisfying)? 2. If you compare your life now with your life before the SCI/ABI, is your quality of life at the moment worse, equal, or better than before the SCI/ABI (1=much worse, 7=much better)? A total life satisfaction score was computed by summing the two scores, leading to a total score between 2 and 13. A higher score indicates a higher degree of life satisfaction.

Social Support (SSL-12-I)

The SSL-12-I consists of 12 items which can be answered on a four-point scale (1= rarely or never, 4= very often). The total SSL-12-I score was calculated by summing up the scores of the 12 items, with a higher score referring to more perceived social support. A total score was calculated when at least 75% of the questions have been answered. Corrections were made for missings by first calculating the mean of the total score by 75% of the items (9) and then multiplying by the total number of items (12).

Appendix D: assumption tests results

The two LS2 Total scores (of the persons with SCI/ABI and significant others) were normally distributed at each measurement (skewness, 0.0–0.5). A linear relationship was found with scatterplot matrices between the two groups (SCI and ABI) of the independent variables. Based on the histograms and skewness (all between 0.0 and 0.5) the dependent variables are normally distributed. No extreme outliers were found within the boxplots. To test linearity between the dependent and the independent variables scatter plots were used, which showed that there are linear relationships. The test for homogeneity covariances matrixes was met with a nonsignificant Box's M test (p=.142). Wilks' Lambda showed a non-significant result (p=.705) indicating that the variances and covariances of the two total LS2 scores are equal in groups of the dependent variables. With z-scores not higher than 3.20 (Tabachnick & Fidell, 2013) there were no significant univariate outliers. Additionally, multivariate outliers were tested with mahalanobis distance. With no case higher than critical chi-squared value of 13.82 (maximum=10.21) for df=2 at a critical alpha value of .001 indicated no multivariate outliers. To test multivariate normality for both LS2 scores the residuals were calculated and Shapiro-Wilk tests show a non-significant result for the residuals of life satisfaction of persons with SCI/ABI (p=.320) but a significant result for the residuals of life satisfaction of significant others (p=.033). Nevertheless, the two cases causing the significant result of Shapiro-Wilk with an extreme low value have not been removed since the histogram and Q-Q plot gave a normal impression.