The relationship between illness perception and anxiety and depression: The mediating effect of passive coping

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Summary

A spinal cord injury (SCI) is a traumatic life-event with significant physical and psychological consequences. SCI patients are found to experience more psychological distress and to be more at risk for developing anxiety or depressive disorders. It is important to reduce these psychological problems, because they may limit physical recovery. This study investigated the effect of illness perception (i.e. cognitive representation of an illness) on anxiety and depression, and whether passive coping mediates this effect. Illness perception was expected to have a direct effect on anxiety and depression, as well as an indirect effect via passive coping. A total of 273 SCI patients admitted to eight Dutch rehabilitation centers with specialized SCI units completed the Brief Illness Perception Questionnaire (BIPQ), Utrechtse Coping Lijst (UCL) and Hospital Anxiety and Depression Scale (HADS) within 2 weeks of admission. The PROCESS tool was used to test the presence of mediation. Results confirmed the expectations; the effect of illness perception was partially mediated by passive coping. Effects of illness perception however were small, whereas the direct effect of the mediator passive coping on anxiety and depression was much larger. Results indicate that the effect of passive coping may be more important than the (mediated) effect of illness perception, and that interventions aimed at improving coping may therefore be more useful than those aimed at improving illness perception.

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Introduction

A spinal cord injury (SCI) is a traumatic life-event with significant consequences, both physical and psychological. Causes include incidents such as crashes and falls, but also medical/surgical complications (Chen et al., 2013), resulting in compressing, laceration or stretching of the spinal cord. Depending on the location of damage to the cord, injury may result in tetraplegia or paraplegia, and physical consequences include (partial) loss of bladder/bowel function and (partial) loss of motor and/or sensory functions (Kennedy, 2007). Research on psychological consequences has found patients to experience higher levels of distress (Post & Van Leeuwen, 2012) and to be more at risk for anxiety and depressive disorders (Craig, Tran & Middleton, 2009) than healthy individuals.

Although full physical recovery is highly unlikely in patients with SCI, psychological problems might limit recovery; Cassidy et al. (2014) found patients with more psychological distress to recover slower and emphasize the possible benefit from more focused clinical attention for those at risk. Determining who is at risk may be possible by looking at certain factors at admission. Treatment can then be focused on adjusting these factors, thereby reducing psychological distress and optimizing recovery. Factors that have been found to influence the development of anxiety and depression are passive coping and illness perception.

The first factor, coping, is a well-studied subject in the development of anxiety and depression (Blalock & Joiner, 2000; Compas et al., 2014; Cooper et al., 2008). Studies have found that interventions aimed at coping are effective in reducing anxiety and/or depressive symptoms (Duchnick, Letsch & Curtiss, 2009; Kennedy et al., 2003). Coping is found to influence the development of both anxiety and depression. For example, Pollard and Kennedy (2007) found that early coping is vital to the reduction of patients who develop psychological problems after an SCI. Therefore, they emphasize that coping strategies are critical in the adjustment to acquired SCI. Similarly, Kennedy et al. (2000) found that a high level of variance in depression and anxiety at year 1 and 2 after SCI was predicted by coping strategies at week 12. Passive coping in particular has a negative effect on anxiety and depression. In a study by Bonanno et al. (2012) findings clearly suggests a passive and less adaptive pattern of coping for chronically depressed SCI patients. Notably, Zyrianova et al. (2011) found passive coping to be a better predictor of depression and anxiety than functional disability. Based on these studies, passive coping is expected to have a direct effect on both anxiety and depression.

The second factor, illness perception, is also found to be directly related to anxiety and depression. Illness perceptions are cognitive representations of an illness, shown to predict

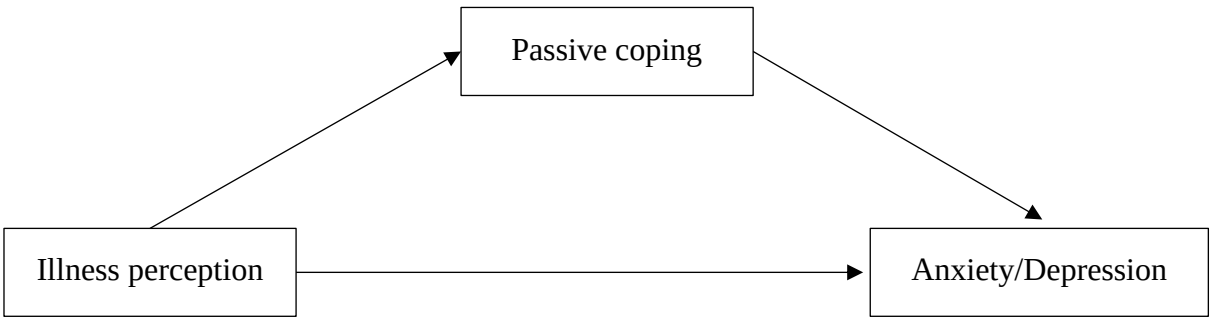
health-related outcomes (Morganet al., 2014). The model developed by Leventhal, Nerenz & Steele (1984) proposes that situational stimuli, such as symptoms, generate both an emotional and a cognitive representation of an illness. Dimensions of the cognitive representation are identity, consequences, cause, timeline and cure or control. Part of the emotional representation are negative emotions such as fear, anger and distress. Morgan et al. (2014) found significant correlations between dimensions of illness experience and depression scores and concluded that a significant proportion of variance in depression and anxiety scores could be accounted for by illness perceptions. Sararoudi et al. (2016) implemented an intervention aimed at illness perception, which led to a significant reduction in anxiety and depression. It is therefore expected that more negative illness perceptions will be found to be associated with higher levels of anxiety and depression.

Illness perception not only has an effect on anxiety and depression, but it can also influence coping (Hopman & Rijken, 2015; Petrie et al., 2002; Sararoudi et al., 2016). Hopman and Rijken (2015) suggest that illness perceptions act as a framework for selecting coping strategies, and that illness perceptions determine the degree in which certain coping strategies are adopted. Interventions can then change these perceptions and therefore result in more adaptive coping styles (Petrie et al., 2002), reducing psychological distress (Keeling, Bambrough & Simpson, 2013). Hopman & Rijken (2015) also found that patients who perceived their illness as more emotionally burdening, long-lasting and having more negative consequences often used more passive ways of coping. Therefore, negative illness perceptions are expected to result in more passive coping.

Research had been done to investigate the effects of passive coping and illness perception in various patient groups, such as patients with traumatic brain injury (Rogan, Fortune & Prentice, 2013), cancer patients (Hopman & Rijken, 2015), heart patients (Nahlén Bose et al., 2016; Sararoudi et al., 2016; Steca et al., 2013) and patients with arthritis (Rezaei et al., 2014; Zyrianova et al., 2011). However, no research has been done for SCI patients, although results concerning the effects of illness perception and passive coping similar to those described above may be found for this patient group. This has yet to be verified, so interventions can be formed accordingly. Therefore, this study aims to investigate how passive coping and illness perception might play a role in the development of anxiety and depression in SCI patients. A model as shown in Figure 1 is hypothesized.

Figure 1

Model depiction of hypotheses: mediation models with passive coping as mediator



Methods

Design

The study used a between-subjects design. The independent variable was illness perception, and passive coping was included as a mediator. Dependent variables were anxiety and depression.

Participants

A total of 303 patients aged between 18 and 91 (M = 59.69, SD = 16.52) admitted to eight Dutch rehabilitation centers with specialized SCI units between May 2018 and May 2019 participated in the study (Table 1). One of the centers was forced to discontinue their participation because of staff shortage and organizational issues. Participants were included if they met the following criteria: (1) age 18 or higher, and (2) treated for a recent SCI (< 6 months) in one of the participating centers. Participants were excluded if they met one or more of the following criteria: (1) psychiatric issues affecting the reliability of answers on the psychological screening; (2) cognitive or intellectual issues affecting the reliability of answers, (3) one or more missing values on the IPQ, UCL or HADS scales at intake.

Table 1

Number of patients per participating center at admission

Center	City	N
Adelante	Hoensbroek	27
Beatrixoord	Haren	35

Heliomare	Wijk aan Zee	32
De Hoogstraat	Utrecht	68
Reade	Amsterdam	43
Rijndam	Rotterdam	0
Het Roessingh	Enschede	29
St. Maartenskliniek	Nijmegen	69
Total		303

Instruments

This study used data collected through a novel psychological screening instrument, composed of several questionnaires. It is meant to screen for psychological characteristics or problems and is being tested for its usefulness and usability in SCI patients' psychological treatment. Included questionnaires were a result of professional knowledge and experience of involved investigators and psychologists, and of psychological research in the same or comparable populations. Only the questionnaires relevant to variables in this study are described below. The other questionnaires used in the psychological screening are the Quality of Life (QoL) Basic Data Set, the University of Washington Self-Efficacy Scale (UW-SES) and the Brief Connor-Davidson Resilience Scale (CD-RISC).

Demographics

The first part of the screening instrument consisted of questions regarding demographic information including age, gender, education levels, marital status and main language. Questions were included on the screening form and filled in by the participant with or without assistance. Information on the SCI, such as the level and ASIA score, was provided by the psychologist, as well as information on comorbidity such as psychiatric issues and brain damage. ASIA scores are used to quantify the severity of the SCI, ranging from A (indicating a complete SCI; no sensory or motor function) to E (normal sensory and motor functions; Maynard et al., 1997).

Hospital Anxiety and Depression Scale (HADS)

For the independent variables anxiety and depression, the HADS anxiety and depression subscales were used. The HADS measures mental issues (Zigmond & Snaith, 1983) and consists of 14 statements concerning emotions in the past week with four response categories

which are scored from 0 to 3. The response categories vary per item. Examples of items are "I feel cheerful" (not at all/every now and then/sometimes/most of the time) and "I look forward to things" (just as much as before/a little less than before/a lot less than before/almost never). The questionnaire is used often for patients with SCI and was found valid (Sakakibara et al., 2009; Woolrich, Kennedy, & Tasiemski, 2006). A score of 0 to 7 for either subscale is regarded as being in the normal range, a score of 8 to 10 is considered suggestive of the presence of either anxiety or depression, and a score of 11 or higher indicates the probable presence of either mood disorder (Snaith, 2003).

Utrechtse Coping Lijst (UCL; passive coping items)

For the mediator passive coping the UCL was used. The complete UCL consists of 7 subscales and a total of 47 items. A four-point scale is used to indicate how often a certain response is used in a difficult or unpleasant situation. Response categories are "rarely/never", "sometimes", "often" and "very often". The validity was found to be average to good (Schreurs et al., 1993). For this study, only the 7 items of the passive coping subscale were used to measure passive coping. An example of an item on this subscale is "Completely isolate yourself from others". The UCL has been used previously for patients with SCI (Kilic, Dorstyn & Guiver, 2013; Van Diemen et al., 2018).

Brief Illness Perception Questionnaire (BIPQ)

The Dutch version of the Brief Illness Perception Questionnaire (BIPQ) was used to measure the independent variable illness perception. The Dutch version was cross-culturally adapted in 2012 (de Raaij et al., 2012) and validated in 2017 (Timmermans et al., 2017). This questionnaire contains 9 questions concerning the patient's thoughts and expectations regarding the SCI. It assesses cognitive representations (5 items; consequences, timeline, personal control, treatment control, identity), emotional representations (2 items; concern, emotion), illness comprehensibility (1 item; coherence) and causal representation (1 item). A study by van Oort et al. (2011) showed that item 3 was often misinterpreted and rephrasing was advised. The suggested rephrased item was used in this study. Furthermore, item 9 concerning causal representation was removed.

An example of an item is "How worried are you about your spinal cord injury?". Possible responses range from 0 (not at all/none etc.) to 10 (a lot/very etc.) (Weinman et al.,

1996). The responses to item 3, 4 and 7 were recoded to be in the same direction as the others for statistical analysis. A higher score represented a more negative perception of the SCI.

Procedure

Data was gathered in purpose of testing a novel psychological screening instrument. During admission, participants were verbally informed about the psychological screening and given a letter containing additional information. The organization of the screening was determined by the concerning center; in some centers the screening was conducted by the psychologist, in others by the psychological assistant. Most subjects filled in the screening by themselves in the presence of a psychologist or psychological assistant who assisted if needed. The total duration of the screening was between 30 to 60 minutes.

In all centers, the screening was conducted within 2 weeks of admission. At the end of the intake, subjects were asked for a written consent for anonymous use of their screening results. Only data for which was given written consent was used in the study. Answers on the screening questions and additional patient data were collected in an Excel file by the treating psychologist and sent periodically to the researchers.

Analysis

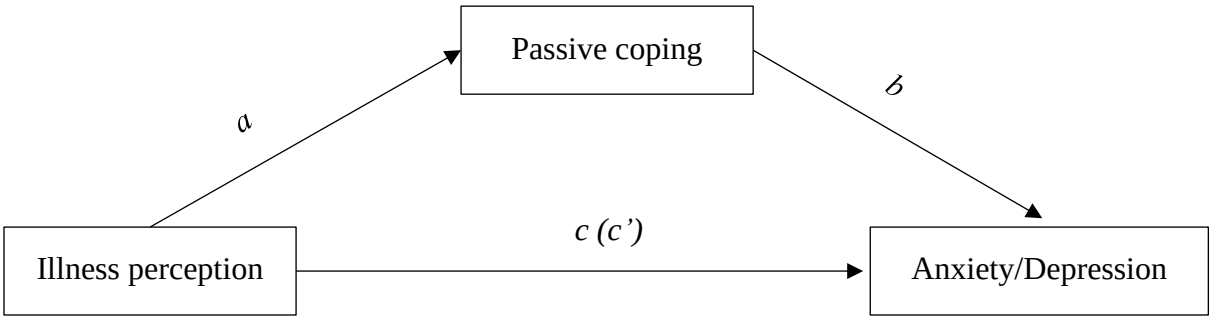
Data was analysed using IBM SPSS Statistics 23. Two mediation analyses were performed using the PROCESS v3 macro for SPSS (Hayes, 2017). It provides a mediation model that can be used to investigate the direct relationship between a predictor (illness perception) and outcome (anxiety/depression), as well as indirect relationships via one or more mediators (passive coping). In the first analysis, passive coping was entered as a mediator, illness perception as an independent variable and anxiety as a dependent variable. The same was done for the second analysis, but with depression as the dependent variable. The regular assumptions for multiple regression analyses were checked and no violations were found.

For each path in the model unstandardized regression coefficients were calculated (see Figure 2): *a* represents the direct effect of illness perception on passive coping, *b* represents the direct effect of passive coping on anxiety and depression and *c* represents the total effect of illness perception on anxiety and depression. Indirect effects are calculated by multiplying the coefficients of the pathways, so the indirect effect of illness perception on anxiety and depression via passive coping (c') is $a \times b$. For the indirect effects, 95% confidence intervals

were based on 5,000 bootstrapped resamples. The true indirect effect is estimated to lie between CL and CR with a 95% confidence, and when zero is not included, it can be concluded that the indirect effect is significantly different from zero at $p < .05$ (two-tailed; Preacher & Hayes, 2004).

Figure 2

Mediation model with illness perception as the independent variable, passive coping as the mediator and anxiety/depression as the dependent variable



Results

Sample characteristics

Patients with one or more missing items on the UCL, IPQ or HADS scales were excluded. The final sample consisted of 273 patients, aged 18 to 91 (M = 59.43, SD = 16.68). Descriptive statistics of participants can be found in Table 2, as well as the means and standard deviations of BIPQ scores per gender and ASIA score.

Table 2

Descriptive statistics of participants

			BIPQ scores	
Variable	Total (Missing)	%	*M*	*SD*
Age	260 (13)			
Gender	270 (3)			
Male	185	68.51	46.48	14.38
Female	85	31.48	44.07	12.85
Education level	265 (8)			
Primary	60	21.0		
Secondary	103	37.8		
Higher	102	37.3		
Marital status	261 (12)			

Single	56	20.5		
Partner, living apart	12	4.4		
Married	155	56.8		
Divorced	20	7.3		
Widow(er)	18	30.0		
Centre	273 (0)			
Adelante	27	9.89		
Beatrixoord	30	11.00		
De Hoogstraat	63	23.08		
Heliomare	26	9.52		
Het Roessingh	26	9.52		
Reade	41	15.02		
St. Maartenskliniek	60	21.98		
ASIA	251 (22)			
A	40	15.94	54.05	14.40
B	17	6.77	48.59	16.37
C	27	10.76	45.81	14.98
D	167	66.53	43.60	13.15

Illness perceptions

The means and standard deviations per BIPQ item can be found in Table 3. Total illness perception scores ranged from 1 to 71 (N = 273; M = 40.93, SD = 12.40). Patients score lowest on item 4 (treatment control; M = 1.94, SD = 1.66) and highest on item 1 (consequences; M = 7.72, SD = 2.21).

Table 3

Brief Illness Perception Questionnaire (BIPQ) dimension scores (N = 273)

Dimension	Description	Mean	Standard Deviation
BIPQ1 (consequences)	How much does your illness affect your life?	7.72	2.21
BIPQ2 (timeline)	How long do you think your illness will continue?	5.63	3.29
BIPQ3 (personal control)[a]	How much control do you feel you have over your illness?	4.82	2.85
BIPQ4 (treatment control)[a]	How much do you think your treatment can help your illness?	1.94	1.66
BIPQ5 (identity)	How much do you experience symptoms from your illness?	6.44	2.41
BIPQ6 (concern)	How concerned are you about your illness?	6.27	2.74
BIPQ7 (emotion)[a]	How well do you feel you understand your illness?	3.46	2.73
BIPQ8 (coherence)	How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	4.66	2.91

[a] recoded items

Anxiety and depression

HADS total scores ranged from 0 to 38 (*N* = 273; *M* = 11.02, *SD* = 7.44). The number of patients scoring above cut-off scores can be found in Table 4. More than a quarter (25.3%) of patients (*N* = 273) scored 8 or higher on the anxiety subscale, which suggests (8-10) or indicates (≥11) the presence of an anxiety disorder (*M* = 5.23, *SD* = 4.10). Almost one third (32.3%) of patients (*N* = 273) scored 8 or higher on the depression subscale, which suggests (8-10) or indicates (≥11) the presence of a depressive disorder (*M* = 5.79, *SD* = 4.04).

Table 4

Hospital Anxiety and Depression Scale (HADS) subscale scores (N = 273)

Subscale	*M*	*SD*	n (%) of patients scoring 8-10[a]	n (%) of patients scoring 11 or higher[b]
Anxiety	5.23	4.10	31 (11.4)	38 (13.9)
Depression	5.79	4.04	54 (19.8)	34 (12.5)

[a]considered suggestive of the presence of either anxiety or depression

[b]indicates the probable presence of either mood disorder

Passive coping

The means and standard deviations per UCL item can be found in Table 5. Total UCL passive coping scores ranged from 7 to 28 (N = 273; *M* = 10.26, *SD* = 3.07). Scores were divided into categories using the UCL manual and results can be found in Table 6. Almost 20% of patients score above average on the passive coping scale.

Table 5

Utrechtse Coping Lijst (UCL) passive coping item scores (N = 273)

Item	Description	*M*	*SD*
UCL1	Completely isolate yourself from others	1.62	.73
UCL2	See things gloomy	1.62	.70
UCL3	Worry about the past	1.51	.71
UCL4	Use soothing remedies if you feel tense or nervous	1.31	.67
UCL5	Flee into fantasies	1.23	.52
UCL6	Letting yourself get completely occupied by problems	1.41	.65
UCL7	Feeling unable to do anything	1.56	.73

Table 6

Interpretation of Utrechtse Coping Lijst (UCL) passive coping subscale scores (N = 273)

Category	n (%)
Low use of passive coping (<7)	219 (80.2)
Above average use of passive coping (8-10)	39 (14.3)
High use of passive coping (>10)	15 (5.5)

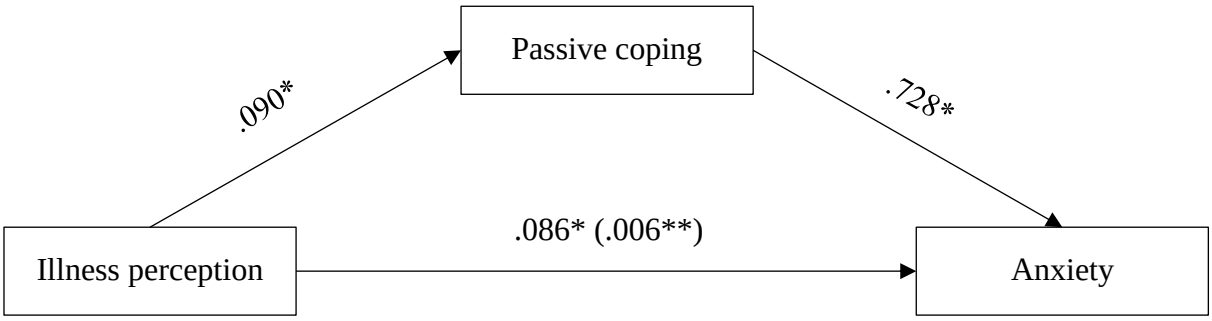
Mediation models

Illness perception, passive coping and anxiety

The model, as shown in Figure 3, explained 26.5% of variance in anxiety. A significant direct effect (without the mediator) of illness perception on anxiety was found, $b = .086$, $t(270) = 6.274$, $p < .001$. The effect of illness perception on passive coping was found to be significant, $b = .090$, $t(271) = 7.368$, $p < .001$, as well as the effect of passive coping on anxiety, $b = .728$, $t(270) = 11.737$, $p < .001$. Finally, the indirect effect of illness perception on anxiety was significant, $b = .006$, 95% CI [.042, .091]. Thus, the effect of illness perception on anxiety was partially mediated by passive coping, and both the direct and the indirect effect of illness perception on anxiety were significant. All found correlations were weak, except for the direct effect of passive coping on anxiety, which was strong.

Figure 3

Standardized regression coefficients for the relationship between illness perception and anxiety as mediated by passive coping



* $p < .001$; ** $p < .05$

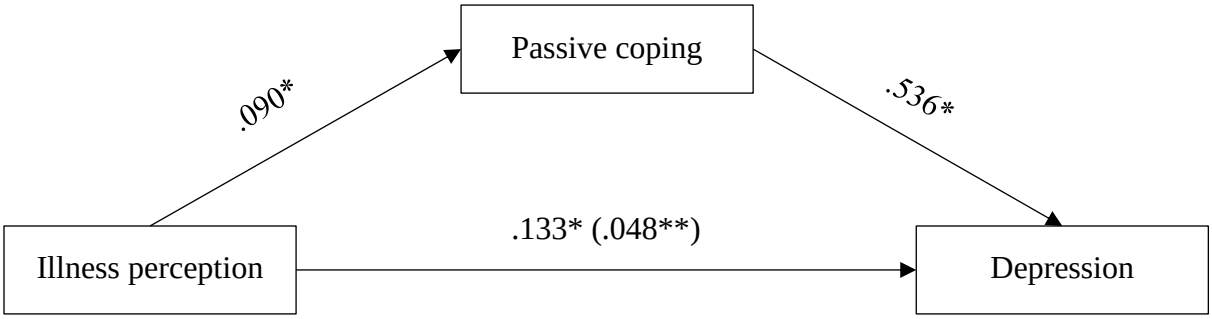
Illness perception, passive coping and depression

The model, as shown in Figure 4, explained 39.0% of variance in depression. A significant direct effect of illness perception on depression was found, $b = .133$, $t(270) = 10.010$, $p < .001$. The effect of illness perception on passive coping was found to be significant, $b =$

.090, $t(271) = 7.368$, $p < .001$, as well as the effect of passive coping on depression, $b = .536$, $t(270) = 8.878$, $p < .001$. Finally, the indirect effect of illness perception on depression was significant, $b = .048$, 95% CI [.030, .070]. Thus, the effect of illness perception on depression was partially mediated by passive coping, and both the direct and the indirect effect of illness perception on anxiety are significant. Again, all found correlations were weak, except for the direct effect of passive coping on depression, which was moderate.

Figure 4

Standardized regression coefficients for the relationship between illness perception and anxiety as mediated by passive coping



* $p < .001$; ** $p < .05$

Discussion

This research investigated the mediating role of passive coping in the relationship between illness perception and anxiety and between illness perception and depression. It was found that passive coping partially mediated both relationships. As hypothesized, illness perception was found to influence anxiety and depression both directly and through passive coping, though effects were weak. Higher scores on illness perception, i.e. more negative illness perception, resulted in significantly higher scores on passive coping, anxiety and depression. Since IPQ scores increase as the SCI severity increases (from D to A), patients with higher ASIA scores have a higher risk of developing anxiety and depression than those with lower ASIA scores. They are also more likely to use passive coping. Passive coping strongly influenced anxiety and depression scores: higher scores on passive coping resulted in significantly higher scores on anxiety and depression.

Limitations and future research

In literature, most studies investigate the effect of illness perception on coping. However, coping was found to share a genetic basis (Kato & Pedersen, 2005) and to be strongly correlated with personality (Fickova, 2001; McWilliams, Cox & Enns, 2003). Since personality is stable over time and situations, coping might also be to some extent. It could therefore be hypothesized that coping style might influence how an illness is perceived. Since the opposite was investigated here, additional research could examine the effect in this other direction.

All used data was obtained within the first two weeks after intake. Patients differ vastly in time between onset of the SCI and intake, from 2 up to 300 days. This might influence the data in multiple ways. When there is little time between onset and intake, patients may not have had enough time to process or understand their situation. This can influence how they perceive their illness and prognosis (i.e. illness perceptions), and psychological problems might not have manifested yet. When there is a lot of time between onset and intake, patients may have already received some kind of therapy influencing both coping style and psychological problems. For example, in a study by Craig et al. (2015) with three assessments (initial, discharge and 6 months post discharge) HADS anxiety scores vary greatly over time. Thus, it would have been preferable to determine the ideal moment of data collection and collect data at roughly the same relative moment.

A factor that was not included in this research but seems of importance in the development of anxiety and depression is social support. Studies have found social support to act as a buffer, meaning that social support may have a protective effect in experiencing anxiety and depression. Depending on the stressor, social support was found to mediate or moderate the relationship with anxiety and depression (Paukert et al., 2010; Pisanti et al., 2014; Waqas et al., 2015; Zhou, Zhu, Zhang & Cai, 2013). More research is needed to determine the role of social support in SCI patients. When an effect is found, intervention or treatment can be aimed to increase the amount of social support, thereby reducing psychological problems.

On the IPQ, patients scored lowest on the treatment control item, which indicates that on average patients believe that treatment can help their illness. While this results in more positive illness perception scores, studies show that the effect of rehabilitation on physical improvement is small, especially for patients with complete lesions (ASIA scores A and B; Harkema et al., 2012; Lim & Tow, 2007; Schönherr et al., 1999). Though these high expectations might be unrealistic, they have been linked to better treatment outcomes in both physical and psychiatric disorders (Bialosky, Bishop & Cleland, 2010; Choi, Fiszdon &

Medalia, 2010; Hall et al., 2010; Vos-Vromans et al., 2016). Vos-Vromans et al. (2016) hypothesize that higher expectations and higher agreement to the content of treatment might result in larger treatment engagement and compliance. According to the expectancy-value model of achievement performance and choice by Eccles et al. (1983), reassessment of previously held expectations can either drive the individual toward continued engagement in rehabilitation, when it is viewed as worthwhile, or to disengagement, when it is judged as pointless. Summarizing, it seems important to monitor patients' treatment expectations, since high expectations contribute in treatment engagement, but can result in treatment drop-out when they are not met. Additional research is needed to examine how and when these expectations need adjusting.

Conclusion and implications

Despite these limitations, this study makes a significant contribution to the knowledge base about the relationship between illness perception, passive coping, and anxiety and depression. Both illness perception and coping were found to influence anxiety and depression. However, the effect of passive coping was found to be much stronger than that of illness perception. As mentioned before, psychological problems might limit recovery. It was hypothesized that illness perception influenced these problems both directly and via passive coping. It appears, however, that passive coping is a much more important factor in the development of psychological problems than illness perception. A short psychological screening at intake might help determine those with higher scores on both and therefore more at risk of developing these problems. To optimize recovery and the psychological health of patients, treatment should then be aimed to correct illness perceptions and improve coping for those at risk, though interventions aimed at the latter will presumably be most successful.

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Appendices

Appendix 1: Intake screening

Nummer revalidant:

Datum afname: _ _ / _ _ / _ _ _ _

Psychologische screening

Opname

Naam revalidant: ……

Invulinstructie voor de revalidant

Het invullen van deze lijst duurt ongeveer 15 tot 25 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. 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.

Personalia

Naam: ……

Geboortedatum: _ _ / _ _ / _ _ _ _ (dag / maand / jaar)

Geslacht
☐ Man
☐ Vrouw

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 burgerlijke staat?
☐ Alleenstaand
☐ Partner, niet samenwonend
☐ Gehuwd/duurzaam samenwonend
☐ Gescheiden
☐ Weduwe/weduwnaar

Welke taal wordt er meestal bij u thuis gesproken?

……

Tevredenheid

De volgende vragen hebben betrekking op uw tevredenheid.
U kunt dit op de onderstaande schaal aangeven door middel van een kruisje hoe tevreden u afgelopen week bent geweest.

Voorbeeld: Links staat 'Volledig ontevreden' en rechts staat 'volledig tevreden'. Als u in de afgelopen week ontevreden bent geweest, zet u het kruisje meer op het linker gedeelte bij een van de lagere cijfers dat het beste weergeeft hoe tevreden u was. Bent u daarentegen afgelopen wek tevreden geweest, dan zet u het kruisje meer naar rechts bij een van de hogere cijfers.

1. Denkend aan uw leven en uw persoonlijke omstandigheden, hoe tevreden bent u met uw leven als geheel de afgelopen week?

Volledig ontevreden	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Volledig tevreden

2. Hoe tevreden bent u met uw lichamelijke gezondheid de afgelopen week?

Volledig ontevreden	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Volledig tevreden

3. Hoe tevreden bent u met uw mentale gezondheid, emoties en stemming in de afgelopen week?

Volledig ontevreden	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Volledig Tevreden

Omgaan met de dwarslaesie

De wijze waarop mensen omgaan met hun dwarslaesie verschilt van persoon tot persoon. Wilt u bij de onderstaande uitspraken aangeven in hoeverre deze voor u nu in deze fase van uw leven gelden, door een van de hokjes achter iedere uitspraak aan te kruisen.

Hoeveel vertrouwen heeft u erin dat …		Helemaal niet	Een beetje	Nogal wat	Veel	Helemaal
1.	u kunt doen wat u zou willen doen, ondanks het lichamelijke ongemak van uw dwarslaesie?	☐	☐	☐	☐	☐
2.	u om kunt gaan met onverwachte gebeurtenissen ondanks uw dwarslaesie?	☐	☐	☐	☐	☐
3.	u nu kunt voorkomen dat uw dwarslaesie uw sociale leven belemmert?	☐	☐	☐	☐	☐
4.	u nu kunt voorkomen dat uw dwarslaesie uw gehele leven beheerst?	☐	☐	☐	☐	☐
5.	u nu de frustratie, ontmoediging of teleurstelling te boven kunt komen, die uw dwarslaesie kan veroorzaken?	☐	☐	☐	☐	☐
6.	u nu effectieve oplossingen kunt bedenken voor problemen die met de dwarslaesie samenhangen?	☐	☐	☐	☐	☐

Stemming

Het is bekend dat emoties bij de meeste ziektes en aandoeningen een belangrijke rol spelen. Deze vragenlijst dient als hulpmiddel om te weten te komen hoe u zich voelt. Lees iedere vraag goed door en geef uw antwoord aan met een kruisje in het hokje dat het beste weergeeft hoe u zich gedurende de afgelopen week gevoeld heeft.
Denk niet te lang na over uw antwoord. Het gaat bij al deze uitspraken om uw eigen indruk. Er bestaan geen foute antwoorden, elk antwoord is goed, zolang het maar uw eigen indruk weergeeft.

1 Ik voel me gespannen:
☐ Meestal
☐ Vaak
☐ Af en toe, soms
☐ Helemaal niet

2 Ik geniet nog steeds van de dingen waar ik vroeger van genoot:
☐ Zeker zoveel
☐ Wel wat minder
☐ Duidelijk minder
☐ Eigenlijk nauwelijks nog

3 Ik heb een soort angstgevoel alsof er iets vreselijks zal gebeuren:
☐ Jazeker, en vrij erg
☐ Ja, maar niet zo erg
☐ Een beetje, maar het hindert me niet
☐ Helemaal niet

4 Ik kan best lachen en de dingen van de vrolijke kant zien:
☐ Net zoveel als vroeger
☐ Nu wel wat minder
☐ Duidelijk minder
☐ Helemaal niet

5 Ik maak me ongerust:
☐ Heel erg vaak
☐ Vaak
☐ Af en toe, maar niet zo vaak
☐ Heel soms

6 Ik voel me opgewekt:
☐ Helemaal niet
☐ Heel af en toe
☐ Soms
☐ Meestal

7 Ik kan best rustig zitten en me ontspannen:

☐ Jazeker
☐ Meestal
☐ Af en toe
☐ Helemaal niet

8 Ik heb het gevoel dat alles moeizamer gaat:

☐ Bijna altijd
☐ Heel vaak
☐ Soms
☐ Helemaal niet

9 Ik heb een soort angstig, gespannen gevoel in mijn buik:

☐ Helemaal niet
☐ Soms
☐ Vrij vaak
☐ Heel vaak

10 Het interesseert me niet meer hoe ik eruitzie:

☐ Inderdaad, helemaal niet meer
☐ Niet meer zoveel als eigenlijk zou moeten
☐ Het interesseert me wel, maar minder dan vroeger
☐ Het interesseert me nog net zoveel als vroeger

11 Ik ben onrustig en voel dat ik iets te doen moet hebben:

☐ Inderdaad, heel duidelijk
☐ Duidelijk
☐ Enigszins
☐ Helemaal niet

12 Ik verheug me van tevoren op dingen die komen gaan:

☐ Net zoveel als vroeger
☐ Een beetje minder dan vroeger
☐ Veel minder dan vroeger
☐ Bijna nooit

13 Ik raak plotseling in paniek:

☐ Inderdaad, zeer vaak
☐ Tamelijk vaak
☐ Soms
☐ Helemaal nooit

14 Ik kan van een goed boek genieten, of van een radio- of televisieprogramma:

☐ Vaak
☐ Tamelijk vaak
☐ Af en toe
☐ Heel zelden

Omgaan met problemen

Mensen reageren vaak heel verschillend als zij met problemen of onplezierige gebeurtenissen te maken krijgen. Wat men in een bepaalde geval doet hangt sterk af van de aard van het probleem of de gebeurtenis en de ernst ervan. Toch reageert men over het algemeen wat vaker op de ene dan op de andere manier.

Hieronder staan een aantal beschrijvingen die aangeven wat men zoal kan denken of doen als er problemen zijn. Wilt u achter iedere zin aangeven hoe vaak u in het algemeen op de beschreven manier reageert. U kunt dit doen door bij iedere zin in een van de hokjes een kruis te zetten. Er zijn geen goede of foute antwoorden.

	Zelden of nooit	Soms	Vaak	Zeer vaak
1. Je volledig afzonderen van anderen	☐	☐	☐	☐
2. De zaken somber inzien	☐	☐	☐	☐
3. Piekeren over het verleden	☐	☐	☐	☐
4. Rustgevende middelen gebruiken als je je gespannen voelt of nerveus bent	☐	☐	☐	☐
5. Wegvluchten in fantasieën	☐	☐	☐	☐
6. Je geheel en al in beslag laten nemen door problemen	☐	☐	☐	☐
7. Je niet in staat voelen om iets te doen	☐	☐	☐	☐

Omgaan met moeilijke situaties

Geef bij de onderstaande stellingen aan in welke mate deze van toepassing zijn voor u in de afgelopen maand.

Als een bepaalde situatie zich niet recent heeft voorgedaan, geef dan antwoord hoe u denkt dat u zich gevoeld zou hebben.

		Helemaal niet waar	Zelden waar	Soms waar	Vaak waar	Bijna aldoor waar
1.	Ik ben in staat om me aan te passen als er veranderingen optreden	☐	☐	☐	☐	☐
2.	Ik kan goed omgaan met alles wat op mijn pad komt	☐	☐	☐	☐	☐
3.	Ik probeer de humoristische kant te zien als ik met problemen word geconfronteerd	☐	☐	☐	☐	☐
4.	Het hoofd bieden aan stressvolle situaties kan me sterker maken	☐	☐	☐	☐	☐
5.	Ik heb de neiging om weer op te veren na ziekte, blessures of andere moeilijke situaties	☐	☐	☐	☐	☐
6.	Ik geloof dat ik mijn doelen kan bereiken, zelfs als er obstakels zijn	☐	☐	☐	☐	☐
7.	Als ik onder druk sta, blijf ik mijn doel voor ogen houden en helder nadenken	☐	☐	☐	☐	☐
8.	Ik laat me niet snel uit het veld slaan bij tegenslagen	☐	☐	☐	☐	☐
9.	Ik zie mezelf als een sterke persoon bij het omgaan met de uitdagingen en moeilijkheden in het leven	☐	☐	☐	☐	☐
10.	Ik kan omgaan met onplezierige gevoelens als verdriet, angst en boosheid	☐	☐	☐	☐	☐

Denkbeelden over de dwarslaesie

Mensen kunnen verschillende denkbeelden hebben over de dwarslaesie. Hieronder staan een aantal vragen. Omcirkel alstublieft bij elke vraag het getal dat uw mening het beste weergeeft.

1. Hoeveel beïnvloedt uw dwarslaesie uw leven?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal geen invloed	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer veel invloed

2. Denkt u dat uw dwarslaesie blijvend zal zijn?

	0	1	2	3	4	5	6	7	8	9	10	
Zeker niet	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeker wel

3. Hoeveel controle vindt u dat u heeft over uw dwarslaesie?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal geen controle	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer veel controle

4. In hoeverre heeft u zelf invloed op uw dwarslaesie?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal geen invloed	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer veel invloed

5. Hoeveel denkt u dat uw behandeling kan helpen bij uw dwarslaesie?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal niet	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer veel

6. Hoe sterk ervaart u klachten door uw dwarslaesie?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal geen klachten	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Veel ernstige klachten

7. Hoe bezorgd bent u over uw dwarslaesie?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal niet bezorgd	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer bezorgd

8. In welke mate vindt u dat u uw dwarslaesie begrijpt?

	0	1	2	3	4	5	6	7	8	9	10	
Helemaal geen begrip	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Zeer veel begrip

9. Hoeveel invloed heeft de dwarslaesie op uw stemming? (Bijvoorbeeld: maakt de dwarslaesie u boos, bang, van streek of somber?)

Helemaal geen invloed	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Zeer veel invloed

Heeft u hulp gehad bij het invullen van de vragenlijst? Zo ja, wie heeft u geholpen?

☐Nee

☐Ja, namelijk van…….

<u>Dit is het einde van de vragenlijst. Hartelijk dank voor het invullen.</u>

Eventuele opmerkingen kunt u hieronder noteren.

Als u een opmerking heeft over een bepaalde vraag, noteert u dan ook het paginanummer en het vraagnummer.

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