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# ARTICLE Illness perception of individuals with spinal cord injury (SCI) during inpatient rehabilitation: a longitudinal study

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### STUDY DESIGN: Multicentre longitudinal study.

**OBJECTIVES:** To assess overall illness perception and specific illness representations at admission and discharge of inpatient spinal cord injury (SCI) rehabilitation, and to detect associations between demographic and injury-related variables, and illness perception. SETTING: Seven Dutch SCI-specialised rehabilitation centres.

METHODS: Participants aged >18 years with a recent SCI were screened for cognitive and emotional illness representations at admission and discharge with the Brief Illness Perception Questionnaire (B-IPQ). Differences between B-IPQ item scores at admission and discharge were analysed with the Wilcoxon signed-rank test. Differences between B-IPQ total scores were analysed with the paired-samples t-test. Associations between B-IPQ total scores and other variables were tested with bivariable and multivariable regression analyses.

RESULTS: B-IPQ results were available for 270 participants at admission (71% male, 59% paraplegia, 83% incomplete) and 119 at discharge (68% male, 50% paraplegia, 78% incomplete). The extent to which people experienced their SCI as a threat was highest for: 'consequences', 'symptom burden' and 'concern' both at admission and discharge. Participants generally experienced less threat at discharge. A more threatening illness perception was significantly associated with older age, complete SCI and a history of cognitive problems at admission. Age and completeness of injury, together, explained 12% of the variance of overall illness perception at admission.

CONCLUSIONS: For most individuals, illness perception positively changed during SCI rehabilitation. Measuring illness perception in inpatient rehabilitation could support the identification of specific treatment goals in order to improve adjustment after SCI.

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### INTRODUCTION

Living with spinal cord injury (SCI) and its secondary physical health consequences is associated with decreased mood and wellbeing [1, 2]. However, how people with SCI experience their condition, is diverse. Two individuals with similar severity of SCI may report very different levels of quality of life [3-5]. Psychological models, such as the Common-sense model of selfregulation (CSM), the Transactional model of stress and coping (TMSC) and the SCI adjustment model (SCIAM), reflect the various ways people react to certain situations or threats, including the onset of SCI [3, 6, 7]. A core element of all these psychological models concerns the individual's mental representations of their condition [3]. Such mental representations are referred to as 'reflections of illness perception' or 'illness cognitions' in the CSM, and as 'appraisals' in the TMSC and SCIAM [3, 6, 7].

Illness perception within the CSM is an umbrella term for the illness representations consequences (effect on life), timeline (permanency), (cure)control (effect of treatment), symptom burden (experience of symptoms), comprehensibility (understanding the health threat), emotions (emotionally affected) and concern (about the health threat). According to the CSM, these cognitive and emotional illness representations determine illness outcomes, mediated by the way an individual copes with a health threat, followed by an appraisal of the coping strategies used [8]. The constant feedback loop within the CSM suggests that the steps within this self-regulation process evolve over time. In other words, the CSM premises that not the situation itself, but how the individual experiences the situation, determine coping strategies and, thereby, illness outcomes.

According to the CSM, it seems meaningful to understand someone's illness representations to predict their coping reactions after a health threat. Likewise, it seems important to understand the alternation of these illness representations over time, because having insight into the patient's illness representations may contribute to the development of interventions that decrease experienced threats and promote coping strategies that are associated with positive adjustment after SCI. Moreover, illness perceptions might be highly relevant to decide where to focus with respect to cognitive behavioural therapy. For example, which illness perception/cognitions are limiting for the individual with SCI and which alternative, more helpful, illness perception can you formulate together. To date, however, we know of only one SCI

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study that has used a CSM-based measure to get insight into illness representations; the Illness Perception Questionnaire (IPQ), but with a substantially modified version [9]. To the best of our knowledge, no longitudinal SCI study assessing changes in illness representations with the IPQ exists. Additionally, interpretation of the level of experienced threat is lacking. Lastly, the association between demographic (e.g. age and marital status) and SCIrelated information (e.g. level and completeness of the injury) and experienced level of threat has not been explored.

The current study addresses these research gaps by focussing on people with recently acquired SCI who were inpatients of SCI rehabilitation centres, with the following specific aims: (1) to gain insight into their level of experienced threat according to the illness representations and overall illness perception as defined within the CSM and the B-IPQ at admission and at discharge, to (2) to assess changes in the level of experienced threat between admission and discharge and (3) to detect demographic and injury-related associations with the experienced level of threat. We hypothesised that illness perception will become less threatening over time. We also expected that people with a more severe injury have a more threatening illness perception compared to people with a lower and/or incomplete injury [10].

### METHODS

### Participants and procedure

Included were inpatients of seven Dutch SCI-specialised rehabilitation centres. Recruitment took place from May 2018 to May 2019. Inclusion criteria were: (1) a minimum age of 18 years at the time of the study, (2) inpatient rehabilitation after recent SCI and (3) sufficiently fluent in the Dutch language to fill out the questionnaires. Participants with significant psychological or cognitive problems were excluded.

Illness perception data were collected by rehabilitation psychologists as part of the standard psychological screening of every individual with a recently acquired SCI. The self-administered screening took place within the first two weeks of rehabilitation after SCI ('admission') and in the last week of rehabilitation ('discharge'). Data were collected by the researcher in de-identified form. Demographic and injury variables, including information about the psychological history, were obtained from medical files by the psychologists and de-identified before linking these data to the psychological data. Informed consent for sharing this anonymous data was obtained from all participants. National and institutional regulations for the ethical involvement of participants that volunteered in this study have been followed. The Medical Ethics Review Board of the University Medical Centre Groningen concluded that this study did not need approval according to the Dutch law on Medical Research Involving Human Subjects (number 201800303). Permission to perform this study was granted by the boards of directors of all seven rehabilitation centres.

#### Measures

Illness perception and illness representations were assessed using the Brief Illness Perception Questionnaire (B-IPQ) [11]. The B-IPQ is a short screening instrument that can contribute to the regular investigation of the level of threat of specific illness representations (i.e. B-IPQ item scores) and overall illness perception (i.e. B-IPQ total score) [11]. The B-IPQ has frequently been used and validated in various populations and settings [12]. Together, eight items cover the illness representations described by the CSM [13]. For our study, items were tailored to the target group of individuals with SCI by replacing the word 'illness' with 'spinal cord injury' (Appendix). Further, two introductory sentences were added to the B-IPQ to contextualise the questions: 'People can have different ideas about the spinal cord injury. Please, for each of the following questions, circle the number that best reflects your opinion.'

Each B-IPQ item can be answered on a 0 to 10 scale. Scores on items 3, 4 and 7 were reversed so that for all eight items a higher score indicated a more threatening representation. A single-item approach of the B-IPQ is most common, but B-IPQ total scores can be used as well [14]. Hence, total scores of the B-IPQ were computed, with a range from 0 to 80. If a maximum one item score was missing, this score was imputed by the mean of the seven other items to calculate a B-IPQ total score. Though, single missing items scores were indicated as missing. In our sample, B-IPQ total scores at admission and discharge were normally distributed and showed sufficient internal consistency (Cronbach's alpha: 0.74 at admission and 0.77 at discharge). Within a previous study, B-IPQ cut-off scores were determined for low (<42), moderate (42–49), and high ( $\geq$ 50) experienced threats associated with the SCI [14].

Demographic characteristics included in the current analyses were: gender (0: male, 1: female), age, marital status (0: single, 1: living with a partner) and educational level (0: lower, up to completed high school education, 1: higher, college or university education). SCI level (0: paraplegia, 1: tetraplegia) and SCI severity (0: complete (American Spinal Injury Association (ASIA) impairment scale (AIS A)), (0: complete (AIS A), 1: incomplete (AIS B, C and D)) were recorded according to the International Standards for Neurological Classification of Spinal Cord Injury [15]. Additionally, information about having a history of psychological or cognitive problems (0: no problems, 1: (possible) problems) was collected.

### Statistical analysis

Statistical analyses were performed with SPSS, version 25 (IBM, Armonk NY). Participant characteristics and B-IPQ scores were reported using descriptive statistics. Differences in participant characteristics between those who completed the screening at admission and at discharge and participants who only completed the screening at admission were analysed using Chi-square tests. Differences between B-IPQ item scores at admission and discharge were analysed with the non-parametric Wilcoxon signed-rank test, since B-IPQ items 1 and 4 at admission and items 3 and 4 at discharge, were skewed. The difference between the B-IPQ total scores at admission and discharge were analysed with the paired-samples t-test because these variables were normally distributed. The proportion of participants experiencing a decrease, no change, or increase of threat at discharge compared to discharge were assessed with McNemar's test. Associations between demographic and injury-related variables, and B-IPQ total scores at admission, discharge, and change in B-IPO total scores between admission and discharge, were tested with bivariable regression analyses. Additional multivariable regression analyses were performed with variables that showed a significant (p < 0.05) [16] association in the previous bivariable analyses. Standardised Beta coefficients ≥0.10, ≥0.30 and ≥0.50, were indicated as 'weak', 'moderate' and 'strong', respectively [17].

### RESULTS

### Participant characteristics

Screening data, at admission, were available for 279 participants. Of them, nine were excluded from the current study since they completed less than seven of the eight B-IPQ items. Of these 270 participants, 119 (44%) completed at least seven B-IPQ items at discharge as well. Their characteristics are displayed in Table 1. There were no significant differences in characteristics between participants who completed the B-IPQ at admission only and those who completed the B-IPQ at admission and discharge.

### **B-IPQ scores**

Table 2 shows median (IQR) scores on the single B-IPQ items and mean (SD) on the B-IPQ total score at admission and discharge. At admission, the highest item scores were found for 'consequences', 'symptom burden' and 'concern'. The lowest item scores (least threat) were found for 'treatment control' and 'comprehensibility'. Indicating that, at admission, people reported that they: experienced severe consequences of the SCI in their lives, experienced severe symptoms, were worried about their injury, had high expectations about how much their treatment would help, and felt that they understood their injury. At discharge, the highest item scores (highest threat) were found for 'consequences' and 'timeline'. Conversely, 'personal control', 'treatment control' and 'comprehensibility' showed the lowest item scores at discharge. This means that, at discharge, people reported that they: experienced severe consequences of the SCI (however, slightly lower compared to admission), thought their SCI would be permanent, felt that they had quite some control over their injury, had high expectations about how much their treatment would help, and felt that they understood their injury. All changes in B-IPQ scores between admission and discharge were significant.

	All participants	Participants who completed B-IPQ at admission <u>and</u> at discharge	Participants who completed B-IPQ data at admission only	Difference between admission and discharge
	N (%)	N (%)	N (%)	P value Chi-square test
Gender				0.568
Male	188 (70)	85 (71)	103 (68)	
Female	82 (30)	34 (29)	48 (32)	
Age (Years)				0.748
18–29	20 (7)	9 (7)	11 (7)	
30–49	36 (13)	18 (15)	18 (12)	
50–69	123 (46)	52 (44)	71 (47)	
>70	87 (32)	38 (32)	49 (33)	
Missing	4 (2)	2 (2)	2 (1)	
Living situation				0.928
Single	105 (39)	46 (38)	59 (39)	
Living with partner	160 (59)	71 (60)	89 (59)	
Missing	5 (2)	2 (2)	3 (2)	
Educational level				0.763
Lower	173 (64)	75 (63)	98 (65)	
Higher	95 (35)	43 (36)	52 (34)	
Missing	2 (1)	1 (1)	1 (1)	
Level injury				0.197
Paraplegia	145 (54)	70 (59)	75 (50)	
Tetraplegia	119 (44)	48 (40)	71 (47)	
Missing	6 (2)	1 (1)	5 (3)	
Completeness injury				0.482
Complete	38 (14)	15 (13)	23 (15)	
Incomplete	217 (80)	99 (83)	118 (78)	
Missing	15 (6)	5 (4)	10 (7)	
History of psychological problems				0.998
Yes or possibly	32 (12)	14 (12)	18 (12)	
No	233 (86)	102 (86)	131 (87)	
Missing	5 (2)	3 (2)	2 (1)	
History of cognitive problems				0.285
Yes or possibly	41 (15)	21 (18)	20 (13)	
No	225 (83)	95 (80)	130 (86)	
Missing	4 (2)	3 (2)	1 (1)	

 Table 1.
 Demographic and injury-related characteristics at the time of admission, admission and discharge, and admission data only.

On the items 'consequences', 'personal control' and 'concern', >50% of the participants showed a decrease in threat at discharge as compared to admission. In contrast, changes towards higher threat were found for 'timeline' and 'treatment control', indicating that more participants thought their SCI was permanent and fewer thought that treatment will help at discharge. The mean B-IPQ total score significantly decreased between admission and discharge, and 60% of the individuals experienced less threat at discharge. About one third (32%) of the individuals that completed the B-IPQ both at admission and at discharge, experienced moderate/high threat at both time points. Another 16% experienced moderate/high threat at admission only, 7% experienced moderate/high threat at discharge only, and 46% experienced low threat at both time points. The percentage of individuals that experienced moderate/high threat decreased from 48% at admission to 39% at discharge.

# Associations between demographic and injury-related characteristics and B-IPQ scores

Older age, a complete SCI, and a history of cognitive problems, all showed significant but weak ( $\beta < 0.30$ ) associations with a higher B-IPQ score at admission (Table 3). At discharge, no significant associations between individual characteristics and B-IPQ total scores were found. Subsequently, the variables that were significantly associated with the B-IPQ total score at admission (age, completeness of the injury and history of cognitive problems) were included in a multivariable analysis. Both age ( $\beta = 0.176$ , p = 0.005) and completeness of injury ( $\beta = -0.310$ , p = <0.001) demonstrated independent weak to moderate associations with illness perception at admission. Together, these variables explained 12% of the variance in the total scores on the B-IPQ at admission.

		-			'n			
	Admiss	sion	Disch	arge	Difference	Proportion of participants r	eporting change in threat betwee	en admission and discharge
B-IPQ items (range 0-10)	z	Median (IQR)	z	Median (IQR)	Wilcoxon signed-rank test p	% Decrease	% No change	% Increase
1) Consequences	270	8.0 (6.8-10.0)	119	7.0 (5.0-8.0)	<0.001	65	15	20
2) Timeline	270	5.5 (3.0-8.0)	118	7.0 (3.0-10.0)	0.003	23	27	50
3) Personal control*	268	5.0 (3.0-6.0)	118	3.0 (2.0-5.0)	<0.001	58	22	20
4) Treatment control*	269	2.0 (1.0-3.0)	116	2.0 (1.0-3.0)	<0.001	21	34	45
5) Symptom burden	268	7.0 (5.0-8.0)	119	6.0 (4.0-7.0)	0.014	50	20	30
6) Concern	269	7.0 (5.0-8.0)	118	5.0 (3.0-7.0)	<0.001	59	17	24
<ol> <li>Comprehensibility*</li> </ol>	267	3.0 (2.0-5.0)	114	3.0 (1.0-5.0)	0.001	50	25	25
8) Emotions	268	5.0 (2.0-7.0)	118	4.0 (2.0-7.0)	0.004	47	19	34
	z	Mean (SD)	z	Mean (SD)	Paired-samples <i>t</i> -test <i>P</i> % (95% Cl)	o Decrease	% No change	% Increase
B-IPQ total score (range 0–80)	270	40.9 (12.3)	119	36.5 (13.3)	<0.001 (2.6–6.3) 60	0	7	34
B-IPQ brief illness perception *Reversed score, lower score	n questior es indicat	inaire, <i>IQR</i> interq	quartile ra 1/ compre	ange, SD standard shensibility.	deviation, Cl confidence interval			

### DISCUSSION

This study identified levels of experienced threat according to the illness representations and overall illness perception at admission and at the discharge of SCI inpatient rehabilitation and sought out changes in the level of experienced threat between admission and discharge, and demographic and injury-related associations with the experienced level of threat. Almost half of the participants reported experiencing moderate to high levels of illness threat. As hypothesised, the extent to which people experienced their SCI as a threat was highest for: 'consequences', 'symptom burden', and 'concern' both at admission and discharge. Participants generally experienced less threat at discharge. Though over time, for some participants levels of threat increased and some illness representations showed an overall increase of threat. At discharge, participants indicated the treatment (i.e. rehabilitation) to be less helpful with their SCI and were more certain about their injury being permanent. A more threatening illness perception was significantly associated with older age, complete SCI and a history of cognitive problems at admission. Age and completeness of injury, together, explained 12% of the variance of overall illness perception at admission.

### Illness representations and illness perceptions of people with SCI

This study is the first to assess overall illness perception and specific illness representations with the B-IPQ at admission and discharge of inpatient spinal cord injury (SCI) rehabilitation, and to detect associations between demographic and injury-related variables, and illness perception. Only one other SCI study has used the IPQ, with substantial modifications to the questions, a different 1-7 point scale, and a cross-sectional design (median of 56 days after SCI onset) [9]. Illness representations with a similar question to our study were: 'timeline' and 'consequences' [9]. Comparable to our findings, Krause and Ede (2014) found the highest threat scores for 'consequences', with a mean score of 4.98 [9]. 'Timeline' threat was somewhat lower compared to our study, with a mean score of 3.41 [9]. B-IPQ results within other samples are more extensively available [12]. Very similar B-IPQ total scores have been found for the traumatic intensive care population; within that sample, the median (IQR) B-IPQ total score was 42.5 (25.0–51.0) [18]. A study among Dutch people with Diabetes Mellitus type 2 found a lower mean (SD) B-IPQ total score of 31.9 (11.2) [19]. The moderate level of threat due to stay in an intensive care department, compared to low threat due to Diabetes Mellitus type 2, may emphasise the drastic consequences of acquiring an SCI. Yet, slightly more than half of the individuals in our study experienced lower threat both at admission and at discharge. Unfortunately, within other samples, categorical results concerning the level of threat, i.e. low/moderate/high, are not available.

Our description of the responses to the B-IPQ highlight the complexity of change in illness representations over time. Although a decrease in median scores over time was found for most illness representations, such a decrease in threat was not found for every single participant or B-IPQ item. There was, for example, an increase in both the median 'timeline' threat score and the number of people that experienced a higher level of threat, indicating that more individuals at discharge thought that their SCI would be permanent. This increase could be explained by a more clear, or realistic outlook on the likelihood of complete recovery. It might also be that, at discharge, people may perceive that the end of inpatient SCI rehabilitation also means the end of further improvement (opportunities). The pattern of results indicating less threatening illness perception over time is consistent with a previous SCI study, which revealed significant decreases in threat and loss as measured with the Appraisal of life events at the start and after 12 weeks of SCI rehabilitation [20].

	Illness perception					
	Admission		Discharge		Change in illness percept	tion
	Standardised β coefficient	P value	Standardised β coefficient	P value	Standardised β coefficient	P value
Gender	-0.05	0.400	0.04	0.709	0.10	0.306
Age*	0.12	0.045	0.11	0.245	-0.06	0.536
Living with partner	0.03	0.581	0.04	0.692	-0.04	0.650
Educational level	0.07	0.252	0.15	0.100	0.04	0.678
Level of injury	-0.10	0.096	-0.04	0.693	0.04	0.671
Completeness of injury	-0.27	<0.001	-0.14	0.130	0.04	0.705
History of psychological problems	0.10	0.099	0.17	0.067	0.01	0.954
History of cognitive problems	0.13	0.040	0.11	0.230	-0.03	0.744

Gender (0: male, 1: female), marital status (0: single, 1: living with partner), educational level (0: lower, 1: higher), SCI level (0: paraplegia, 1: tetraplegia), SCI completeness (0: complete, 1: incomplete).

Coefficients in italic are significant p < 0.050.

B-IPQ brief illness perception questionnaire.

\*Continuous variable.

Results for 'timeline' and 'comprehensibility' B-IPQ items were mixed within our SCI sample. Notably, the earlier mentioned SCI study that modified their IPQ questions, omitted the comprehension item [9]. Deletion and modification of B-IPQ items, may not be necessary given that the original scale has demonstrated sound psychometric properties in SCI research [14].

## Associations of illness perception with demographic and injury-related characteristics

As expected, people with complete SCI had significantly more threatening illness perception at admission than people with incomplete SCI. This result is comparable to that of Eaton et al. (2018), who found that people with complete SCI showed more negative cognitive appraisal [10]. We had expected stronger associations because of the more severe consequences of a complete SCI compared to an incomplete SCI. Yet, the CSM implies that there is an inter-individual variation in the cognitive and emotional experience of SCI. This means that even when injuries and physical consequences are similar in nature, reactions to the disability could still be very distinct [3, 4]. A distinction in reactions to the SCI might be found in psychological factors that were not further assessed within this study, such as coping strategies and resilience [21]. The smaller sample size at discharge may also have played a role in the insignificance of this association at discharge. Finally, individuals with less severe injuries may have a shorter rehabilitation trajectory compared to individuals with more severe injuries.

Our results suggest that characteristics such as gender, age, living alone or together, educational level, level, completeness of the injury, and history of psychological and cognitive problems, do not play a highly important role in illness perception over time. According to the literature, it seems plausible that there could have been other aspects that did play a more important role, however, were not assessed in the current study. These aspects include anxiety, depression, quality of life, coping strategies and resilience [9, 10, 14, 21–25]. The relevance of such aspects to changes in mental representations is emphasised by previous research that has demonstrated an association between changes in illness cognitions, as measured with the Illness Cognition Questionnaire, and mental health [24].

### Limitations

This study has some limitations. First, most illness representations are represented with only one item in the B-IPQ. Therefore these illness representations may not be covered as accurate and reliable as is done within the Revised IPQ [26]. Nevertheless, a systematic review of studies using the B-IPQ found that the B-IPQ total score as well as all individual items showed sensitivity to changes in the level of threat over time [12]. The total B-IPQ score further showed good reliability and validity in our sample, as reported elsewhere [12, 14]. A second limitation is the loss of participants between admission and discharge. Organisational reasons were the main cause for this loss and no significant differences between participants with and without discharge data were found. Therefore, systematic drop-out, and consequently selection bias, is not likely. Finally, precise information about the duration of the inpatient rehabilitation at discharge was lacking. As such, we could not analyse the contribution of time to the change of illness perception. Indeed, the duration of inpatient rehabilitation is typically longer for people with more severe SCI, yet the severity of SCI was not associated with illness perception.

### **Clinical implications**

Considering the theoretical background of the CSM, the previous findings that confirmed the associations within the CSM [9, 10, 22–25, 27], and the current finding that revealed that half of the participants experienced moderate to high experienced threat, the importance of insight in illness perception during inpatient SCI rehabilitation, is supported. Moreover, answers to the B-IPQ questions seem useful for initiating conversation, indicating specific needs and developing interventions that decrease experienced threats, to improve adjustment after SCI. Therefore, the results of this study could be used by healthcare workers to enhance their understanding and possibilities for the improvement of adjustment after SCI. Additionally, our results indicate that regardless of demographic, injury-related characteristics, or history of psychological or cognitive problems, illness perception is critical to adjustment and should be routinely screened with a validated tool such as the B-IPO.

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### Conclusions

Among inpatients of SCI rehabilitation, the level of overall experienced threat, as measured with the B-IPQ, varied over time, between individuals, and between illness representations. Overall, the level of threat decreased over time. Age and completeness of the injury were the only demographic and injury-related variables within our study that were significantly associated with the level of threat and only at admission. A scientific implication of these findings is that illness perception should be taken into account when studying adjustment after SCI.

### DATA AVAILABILITY

The datasets analysed during the current study are available from the corresponding author on reasonable request.

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### AUTHOR CONTRIBUTIONS

HK designed the study, performed the data analysis and drafted the paper. CMCvL collected parts of the data and provided feedback on the data analyses and the paper. JMS-S provided feedback on the data analyses and the paper. MWMP provided feedback on the data analyses and the paper.

#### **COMPETING INTERESTS**

The authors declare no competing interests.

### ETHICS APPROVAL

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

### APPENDIX

Illness representations are based on the Brief Illness Perception Questionnaire and adapted for individuals with spinal cord injury (Broadbent et al. 2006)

ltem	Illness	representations	(B-IPQ	questions)
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- 1 **Consequences** (How much does your spinal cord injury affect your life?)
- 2 **Timeline** (Do you think your spinal cord injury will be permanent?)
- 3 Personal control (How much control do you feel you have over your spinal cord injury?)
- 4 **Treatment control** (How much do you think your treatment can help with your spinal cord injury?)
- 5 **Symptom burden** (How much do you experience symptoms from your spinal cord injury?)
- 6 **Concern** (How concerned are you about your spinal cord injury?)
- 7 **Comprehensibility** (How well do you feel you understand your spinal cord injury?)
- 8 Emotions (How much does your spinal cord injury affect you emotionally? (e.g. does it make you angry. scared. upset or depressed?)

### ADDITIONAL INFORMATION

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