# **ORIGINAL ARTICLE**

# Impact of health problems secondary to SCI one and five years after first inpatient rehabilitation

P van der Meer<sup>1,2</sup>, MWM Post<sup>1,3</sup>, CMC van Leeuwen<sup>1,4</sup>, HJM van Kuppevelt<sup>5</sup>, CAJ Smit<sup>6</sup> and FWA van Asbeck<sup>1</sup>

**Study design:** This is a multicenter prospective cohort study.

**Objectives:** The objective of this study was to describe and compare the impact of health problems secondary to spinal cord injury (SCI) on functioning at home and on social activities at 1 and 5 years after discharge from first inpatient rehabilitation.

**Setting:** The study was conducted in a Dutch community.

**Methods:** Participants with SCI who use a wheelchair for everyday mobility (N=110) completed a self-report questionnaire as part of a larger cohort study including four items on extra time needed (body care, bladder and bowel regulation, 'organization' and transportation) and impact of 10 health problems on functioning at home and on social activities. The 10 health problems include secondary health conditions (bladder regulation, bowel regulation, decubitus, pain, spasticity, gain in body weight and edema), psychosocial problems (sexuality, having difficulty with being dependent on help from others) and handicap management.

**Results:** Median extra time needed for self-management and transportation was not significantly higher 1 year after discharge (16 (IQR 13.5) h per week) compared with 5 years after discharge (13 (IQR 17) h per week) (P=0.925). Participants reported slightly less impact, comparing the severity sum-score (range 10–50) of the 10 health problems on functioning at home and in social activities, 5 years post discharge (20 and 17, respectively) than 1 year post discharge (21 and 18, respectively; P<0.05). Most frequently mentioned health problems were handicap management, being dependent on help from others, bladder regulation, bowel regulation, pain and sexuality.

**Conclusions:** The impact of health problems after SCI is considerable and hardly diminishes over time. These results emphasize the need for structured long-term care for people with SCI.

Spinal Cord (2017) 55, 98-104; doi:10.1038/sc.2016.103; published online 19 July 2016

## INTRODUCTION

Health is a broad concept, encompassing aspects of physical, mental and social well-being.1 Health problems secondary to spinal cord injury (SCI), also called secondary health conditions (SHCs), include medical and psychological problems that are present in addition to the primary motor, sensory and autonomic problems due to the neurological damage to the spinal cord.<sup>2-4</sup> Medical problems secondary to SCI include neuropathic pain, urinary tract infections, obstipation, pressure ulcers, edema and spasticity. Other health problems secondary to SCI include problems of daily living, such as handicap management, extra time needed for body care, bladder and bowel regulation and transportation, as well as psychosocial problems such as sexuality and sadness.<sup>2,4–10</sup> Health problems are common after SCI. Anson and Shepherd<sup>2</sup> reported secondary problems to be present in 58% of the 348 people with SCI in their study group. Bloemen-Vrencken et al.4 reported an average of eight health problems per participant in their survey, and they reported that these health problems limited daily activities and social life of their participants. Kennedy et al.11 reported a significant impact of SHCs on independence and activities in a multicenter, cross-sectional study of SCI patients 3–18 months after discharge from three rehabilitation centers. Participants in the study by Cobb *et al.*<sup>12</sup> reported that because of SHCs their participation in 26 daily activities was restricted. Overall injury-related variables influence life satisfaction through functional health status, especially social functioning. To achieve and maximize social participation of people with SCI, Kennedy *et al.*<sup>14</sup> highlighted the main areas of unmet needs and some SHCs. Impact can also be expressed as the extra time that is needed because of the SCI to take care of SHCs, transportation and for 'organizing', such as applying for devices and home care. However, besides Schönherr *et al.*, To who reported a mean of 70 min a day of extra time on self-care activities, there is limited literature about this topic.

The cross-sectional study of Bloemen-Vrencken<sup>4</sup> and the study of Cobb *et al.*<sup>12</sup> and Calloway *et al.*<sup>10</sup> are the only studies we are aware of in which the participants were asked directly about the impact of a number of health problems on their activities of daily living and social activities. These were, however, cross-sectional studies.

Therefore, there is a need for prospective long-term follow-up studies with a focus on the extra time needed and the degree of the experienced impact on functioning at home and social activities

<sup>1</sup>Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands; <sup>2</sup>Spinal Cord injury Department, Sophia Rehabilitation, Den Haag, The Netherlands; <sup>3</sup>University of Groningen, University Medical Center Groningen, Department of Rehabilitation Medicine, Groningen, The Netherlands; <sup>4</sup>Spinal Cord injury Department, De Hoogstraat Rehabilitation, Utrecht, The Netherlands; <sup>5</sup>Spinal Cord Injury Department, Reade Rehabilitation and Research Center, Amsterdam, The Netherlands Correspondence: Professor MWM Post, De Hoogstraat Rehabilitation, PO Box 85238, 3508 AE Utrecht, The Netherlands. E-mail: m.post@dehoogstraat.nl

Received 16 February 2016; revised 14 May 2016; accepted 28 May 2016; published online 19 July 2016

because of SHCs to study the influence of health problems on daily life and social functioning in persons with SCI.

Research questions for the current study were as follows:

- 1. What is the extra time needed for body care, bladder and bowel regulation, 'organization' and transportation because of the SCI one and five years after discharge from first inpatient rehabilitation.
- 2. Which of the SCI characteristics are associated with the amount of extra time needed one and five years post discharge?
- 3. How many health problems are experienced by each participant, and what is the degree of the impact of these health problems on functioning at home and social activities one and five years post discharge?

We hypothesized that participants would report more extra time at 1 year post discharge compared with 5 years post discharge, and that participants with tetraplegia and/or complete SCI would report more extra time compared with participants with paraplegia and/or incomplete SCI. For the second research question, we expected that all health problems would negatively have an impact on functioning at home and on social activities. We also expected that the impact would be lower 5 years post discharge compared with 1 year post discharge, because of a certain learning curve during the years post discharge.

## **SUBJECTS AND METHODS**

#### **Participants**

This study uses data from a multicenter cohort study on the restoration of mobility in the rehabilitation of persons with SCI.<sup>16</sup> Participants were recruited in all eight rehabilitation centers with a specialization in SCI rehabilitation in the Netherlands between August 2000 and July 2003. Participants were included if they fulfilled the following criteria: (1) a recently acquired SCI; (2) aged between 18 and 65 years; (3) grades A, B, C or D on the American Spinal Injury Association Impairment Scale; and (4) expected permanent wheelchair dependency, at least for long distances. Participants were excluded if they had (1) an SCI caused by a malignant tumor, (2) a progressive disease, (3) psychiatric problems or (4) insufficient command of the Dutch language (unable to understand the goal of the study and test instructions). For the current study, only those participants were selected who completed self-report measures on the impact of health problems at 1 and 5 years post discharge. The research protocol was approved by the Medical Ethics Committee of the Rehabilitation Limburg/Institute for Rehabilitation Research, Hoensbroeck and the Medical Ethics Committee of University Medical Centre Utrecht. All participants have given written informed consent. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

### Procedure

Participants completed a self-report questionnaire including the impact of health problems, measured at 1 and 5 years after discharge from initial inpatient rehabilitation. In addition, the measurement at the start of the research program was relevant for this study. This comprised a medical examination, to define the lesion characteristics, and an oral interview with a trained research assistant to define demographic characteristics.

## Instruments and definitions

The impact of health problems secondary to SCI was assessed using two self-report measures developed in an earlier study.<sup>4</sup>

(1) The first measure consists of four items on the extra time (in hours/week) participants need after their SCI for their body care, bladder and bowel regulation, 'organization', such as arranging home care and devices, and transportation, in comparison with the situation before SCI. A sum-score of these four items was computed.

(2) The second measure consists of 10 items on restrictions in functioning at home and restrictions in social activities (e.g., work, leisure, visiting someone) because of certain health problems in the past 12 months.<sup>4</sup> The 10 health problems include SHCs (bladder regulation, bowel regulation, decubitus, pain, spasticity, gain in body weight and edema), psychosocial problems (sexuality, having difficulty with being dependent on help from others) and handicap management (such as the extra time needed for body care and the organization of activities and issues because of the SCI). Answers could be given on a 5-point scale (no, some, moderate, considerable or complete impediment). Each item score was also dichotomized to reflect the absence or presence of impediment because of a health problem (no, complete).

Two sum-scores for restrictions in functioning at home and two sum-scores for restrictions on social activities were computed, the first reflecting the number of health problems per participant (the sum-score of the dichotomized items with a range between 0 and 10) and the second reflecting the severity sum-score of the impact of all health problems with a range between 10 and 50.

Lesion characteristics. Lesion characteristics were assessed according to the International Standards for Neurological Classification of SCI. Neurologic levels below T1 were defined as paraplegia; neurologic levels at or above T1 were defined as tetraplegia. American Spinal Injury Association Impairment Scale grades A and B were considered motor complete and American Spinal Injury Association Impairment Scale grades C and D were considered motor incomplete. Cause of injury was dichotomized in traumatic versus nontraumatic etiology.

Demographic characteristics. The demographic characteristics were age, sex, marital status (being married or living together versus living alone), children (yes, no) and level of education (low, middle and high).

## Statistical analyses

Descriptive statistics were calculated. A nonresponse analysis was performed, using the Fisher's exact test or Pearson's  $\chi^2$  test where appropriate.

The nonparametric Wilcoxon signed rank test and the Mc Nemar test were used to compute differences in the amount of extra time, and the number and severity of health problems at 1 versus 5 years post discharge. Similarly, associations between demographic and injury characteristics and these three impact variables were analyzed using the Mann–Whitney test or the Kruskall–Wallis test

Significance was set at a *P*-value less than 0.05. SPSS statistical program for Windows (version 22; SPSS Inc., Chicago, IL, USA) was used for all analyses.

## **RESULTS**

# Respondent characteristics

A total of 156 persons participated in the study 1 year post discharge, and 110 participated also at 5 years post discharge. The mean age of the participants was 40.2 years (s.d. 13.2) 1 year post discharge, ranging from 19.6 to 67.3 years. Other characteristics are shown in Table 1. Participants in the measurement 5 years after inpatient rehabilitation did not significantly differ from the nonparticipants with respect to gender, age, level and completeness of SCI, cause of injury, marital status, children and level of education.

### Extra time

Table 2 shows the average hours/week extra time participants reported to need compared with their situation before onset of the SCI at 1 and 5 years after first inpatient rehabilitation. There were no significant differences for each of the four health problems (body care, bladder and bowel regulation, organization and transportation) between 1 and 5 years post discharge. The Median sum-score at 5 years (with 13 h per week) was lower than at 1 year post discharge (16 h per week), but this difference was not significant.

Table 1 Descriptive characteristics of participants and nonparticipants in the study 1 and 5 years after first inpatient rehabilitation (N=156)

Characteristics	Particip	ants	Nonparti	_	
	N = 110	(%)	N = 46	(%)	Р
Gender					
Male	76	69.1	36	78.3	0.329
Type of injury, AIS					
A, Complete tetraplegia	58	52.7	20	44.4	0.520
B, Complete paraplegia	23	20.9	9	20	
C, Incomplete tetraplegia	20	18.2	13	28.9	
D, Incomplete paraplegia	9	8.2	3	6.7	
N	110		45		
Cause of injury					
Traumatic	85	77.3	33	71.7	0.540
Age (year)					
19.62-29.99	30	27.3	12	26.1	0.456
30-49.99	50	45.5	17	37.0	
50–67.33	30	27.3	17	37.0	
Marital status					
Married/together	59	53.6	24	54.5	1.000
N	110		44		
Children					
Yes	54	49.1	22	50	1.000
N	110		44		
Education					
Low	8	7.7	8	19.0	0.097
Middle	72	69.2	28	66.7	
High	24	23.1	6	14.3	
N	104		42		
Paid work before the SCI					
Yes	90	81.8	38	44.4	0.446
Ν	110		46		

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.

Table 3 shows the associations between demographic and SCI characteristics and the amount of extra time spent on the four domains. For most of the activities, participants with motor incomplete SCI needed less extra time compared with participants with motor complete SCI. Participants with paraplegia and younger participants needed less extra time for body care than participants with tetraplegia and older participants, respectively. Gender and etiology of SCI did not make much of a difference in the reported extra time.

# Impact on functioning at home and social activities

Figures 1 and 2 show the proportions of participants experiencing restrictions because of certain health problems at 1 and 5 years post discharge. The health problems that were reported by a majority of the participants to have an impact on functioning at home were handicap management (89 and 85%), pain (65 and 75.7%), dependency (75.2 and 69.3%), bladder (73.5 and 64.7%) and bowel (72.8 and 68.0%)

Table 2 Descriptive characteristics of the extra time (in hours per week) needed for certain activities in comparison with the situation before the SCI at 1 and 5 years post discharge

Health problem		ne year post discharge		re years post discharge	Wilcoxon signed rank test	
	N	Median (IQR)	N	Median (IQR)	N	Р
Body care	101	7 (4.75)	105	6 (8.3)	96	0.058
Bladder and bowel regulation	97	4 (5)	102	4 (5)	92	0.248
Organization	95	2 (4)	95	1 (3)	84	0.243
Transportation	93	2 (3)	93	1 (2)	81	0.123
Sum-score	101	16 (13.5)	107	13 (17)	98	0.925

Abbreviation: IQR, interquartile range, expressed in hours. Median expressed in hours. N, number of participants. Statistically significant at P<0.05.

regulation, sexuality (67.3 and 58.2%) and spasticity (65.0 and 57.3%) at 1 and 5 years post discharge, respectively.

The health problems reported by a majority of the participants to have impact on social activities were handicap management, bladder regulation, dependency, bowel regulation and pain. The percentages of participants who experienced the impact of a health problem were generally slightly lower at 5 years compared with 1 year, but these differences were not statistically significant. Seven health problems had an impact on functioning at home, and five health problems had an impact on social activities for more than 50% of the participants at 5 years post discharge (see Figures 1 and 2).

A median of six health problems having an impact on functioning at home was reported both 1 and 5 years post discharge for the impact on functioning at home, but with a significant decline over time (P=0.022; N=103). A median of five health problems was reported at 1 year post discharge, and a median of four health problems was reported 5 years post discharge for the impact on social activities, but this decline was not significant (P=0.075; N=102). Three or more health problems on functioning at home were experienced by 94.2% of the participants at 1 year post discharge and 92.6% at 5 years post discharge, respectively. Three or more health problems on social activities were experienced by 83.6% of the participants at 1 year post discharge and 79.6% at 5 years post discharge, respectively. Eight or more health problems on functioning at home and social functioning were experienced by 30.8 and 9.6% of the participants at 1 year post discharge and 22.1 and 9.3% at 5 years post discharge, respectively.

Table 4 demonstrates the impact expressed as a sum-score of the severity scale (1 to 5) for all 10 health problems in the previous year on functioning at home and social activities 1 and 5 years after first inpatient rehabilitation.

A significant negative association (P=0.014; N=103) was found comparing the severity sum-score of the impact on functioning at home, between 1 and 5 years post discharge, using the Mc Nemar test. In addition, a significant negative association (P=0.032; N=102) was found for the severity sum-score of the impact on social activities, between 1 and 5 years post discharge, using the Mc Nemar test.

# **DISCUSSION**

This study describes the amount of extra time needed to perform four core activities and the impact of health problems on functioning at home and in social activities, 1 and 5 years post discharge from initial

Table 3 Comparison of the SCI and demographic variables between 1 and 5 years post discharge, for the items body care, bladder and bowel regulation, 'organization' and transportation, in contrast to the situation before the SCI

Descriptive	Body care		Bladder and bowel regulation		Organization		Transportation		Sum-score	
	One	Five	One	Five	One	Five	One	Five	One	Five
	years po	st discharge	years posi	t discharge	years post	t discharge	years pos	t discharge	years post	t discharge
Lesion characteristics										
Incomplete—complete lesion										
P	0.094	0.006*	0.002*	0.001*	0.010*	0.027*	0.213	0.005*	0.002*	0.001*
Incomplete, median (IQR)	4 (4)	2 (8.3)	2 (4.5)	2 (5.5)	1 (3)	0 (2.3)	1 (2)	0 (1.3)	8 (14)	5 (19.6)
Complete, median (IQR)	7 (6)	7 (8.5)	5 (5)	5 (4)	2 (4)	1 (2)	2 (3)	1 (3)	16.5 (14.1)	14.5 (14.8)
N	101	105	97	102	95	95	93	93	101	107
Tetraplegia–paraplegia										
Р	0.014*	0.098	0.838	0.672	0.085	0.709	0.707	0.189	0.043*	0.469
Tetraplegia, median (IQR)	7 (10.5)	9 (9.8)	4 (5)	3.5 (5)	2.5 (6)	1 (3)	2 (3)	2 (4)	19 (16.5)	17 (21)
Paraplegia, median (IQR)	5 (3.25)	5 (8)	4 (5)	4 (5)	1 (3)	1 (3)	2 (3)	1 (2)	14 (12)	13 (16)
N	101	105	97	102	95	95	93	93	101	107
Gender										
Р	0.875	0.569	0.852	0.321	0.528	0.307	0.166	0.242	0.715	0.222
Male, median (IQR)	7 (5)	6.(8)	4 (5)	4 (5)	1 (3.75)	1 (2)	2 (4)	1 (2)	15.5 (13.5)	12.5 (16.3)
Female, median (IQR)	6 (6)	4.625 (12)	4 (5)	5 (4.3)	2 (5)	2 (3)	1.5 (1)	1 (4)	16 (15.3)	16 (17.8)
N	101	105	97	102	95	95	93	93	101	107
Age										
P	0.010*	0.027*	0.051	0.329	0.551	0.912	0.238	0.726	0.083	0.097
19.62–39.99, median (IQR)	4. (6)	4.5 (8)	3 (5)	4 (4)	1 (5)	1 (3)	1.5 (3)	1 (2)	11 (13.8)	12 (15.8)
40–67.33, median (IQR)	7 (6)	7 (10.5)	5 (4.75)	4 (4.3)	2 (4)	1 (2.3)	2 (3)	1 (3)	17 (13)	17 (16.3)
N	101	105	97	102	95	95	93	93	101	107
Cause of injury										
P	0.529	0.848	0.468	0.617	0.066	0.129	0.047	0.408	0.122	0.869
Traumatic, median (IQR)	7 (4.38)	6 (8)	4 (5)	4 (5)	2 (4)	1.25 (3)	2 (3.25)	1 (2)	16 (14.4)	13 (17.4)
Nontraumatic, median (IQR)	4 (7)	6.5 (11.5)	3 (5.5)	3.75 (6)	1 (3.5)	1 (2)	1 (2)	0.75 (2)	12.8 (14.3)	16 (18.4)
N	101	105	97	102	95	95	93	93	101	107

Abbreviation: IQR, interquartile range. Statistically significant at \*P<0.05.

inpatient rehabilitation. Overall, participants with a complete lesion needed more time for all activities. Patients with tetraplegia and older patients needed more time for body care. All health problems were shown to have an impact on daily life and social functioning, although on average the reported severity of this impact was moderate. Nevertheless, the impact of all health problems together is considerable for most participants. Importantly, this impact was not substantially lower at 5 years post discharge compared with 1 year post discharge.

#### Extra time

Participants with an SCI were reported to spend more time for body care, bladder and bowel management, 'organization' and transportation. Body care took the most extra time in comparison with the situation before the lesion. No significant differences were observed in the extra time needed for the above-mentioned items between 1 and 5 years post discharge. Only one other study investigated the extra time spent on self-care activities. Schönherr *et al.*<sup>15</sup> reported that significantly more time was spent on self-care activities, which was 4.5 h extra per week post injury, in a group of persons 2–12 years after

traumatic SCI, compared with a median of 7 and 6 extra hours per week for the item body care in our study, which included only wheelchair users.

The present study suggested that participants with a complete lesion needed more extra time than participants with an incomplete lesion. Bloemen-Vrencken *et al.* found few significant differences between persons with complete lesions and incomplete lesions, but the results were not comparable. Overall, differences between Bloemen-Vrencken *et al.*<sup>4</sup> and our study can be explained by a different study design (cross-sectional study) and study population consisting of fewer participants with tetraplegia and complete lesions, more older participants and participants with a long duration of the SCI. Besides, in our study only wheelchair-bound participants were included.

This study showed that not only the SHCs themselves but also organization and transportation have a serious impact on daily life because of the extra time these activities require in comparison with the situation before the SCI. It is necessary to take these aspects also into account to provide a comprehensive view of the extra time needed because of the SCI. We advise to do further research on these aspects.

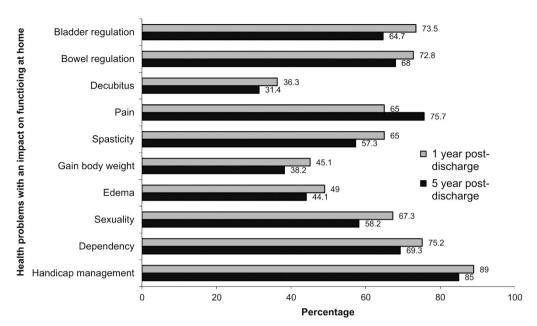


Figure 1 Health problems with an impact on functioning at home: 1 and 5 years post discharge.

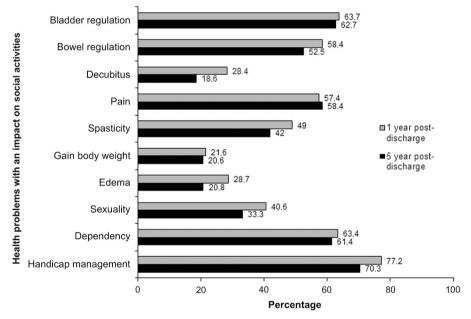


Figure 2 Health problems with an impact on social activities: 1 and 5 years post discharge.

## Impact on functioning at home and social activities

In our study, most participants experienced that one or more health problems interfered with functioning at home or social activities. An interesting result was the stable course of the impact of the health problems at 1 and 5 years post discharge. There was a slight reduction of experienced problems between 1 and 5 years post discharge, except for pain. Pain increased between 1 and 5 years post discharge. All differences were not significant.

To our knowledge, this is the first multicenter prospective cohort study in which patients were asked to rate the degree of impact of health problems on daily life. Similar questions on the impact of health problems were part of an earlier cross-sectional study, but in this study participants were only asked to rate the impact of their five most important health problems.<sup>4</sup> Therefore, it is not a surprise that higher levels of impact of health problems were reported in that study with respect to the health problems such as pain (91.1%; 94.5%), spasticity (86.7%; 80.0%) and decubitus (80.4%; 79.3%), followed by the degree of impact of bowel and bladder regulation. Hitzig *et al.*<sup>3</sup> found 56% of their participants to report impact of pain on their daily activities, which is similar to the results of our study. Cobb *et al.* found higher percentages for the amount of experienced SHCs. In contrast to our study, they included many more items: 21 SHCs and 26 Daily Activities.<sup>12</sup> Qualitative data analysis, a pilot study of Callaway *et al.*, focused on the SHCs spasm, pain, sexual dysfunction, pressure sores, fatigue and the impact of SHCs on life role participation. They

Table 4 Impact, as the sum-score of the severity scale (1 to 5) for all 10 health problems in the previous year, on functioning at home and social activities 1 and 5 years after first inpatient rehabilitation

Severity sum-score		Impact on fund	tioning at home		Impact on social activities			
	One year post discharge		Five years post discharge		One year post discharge		Five years post discharge	
	N = 104	%	N = 109	%	N = 104	%	N = 108	%
10	2	2	1	0.9	6	5.8	8	7.4
11–14	10	9.6	12	11.0	18	17.3	24	22.2
15-19	31	29.8	35	32.1	45	43.3	39	36.1
20–24	29	27.9	33	30.3	19	18.3	20	18.5
25–29	11	10.6	18	16.5	9	8.7	13	12.0
30-34	14	13.5	7	6.4	6	5.8	2	1.9
35–39	2	2	3	2.8	1	1	2	1.9
40-44	5	4.8	0	0	0	0	0	0
45-50	0	0	0	0	0	0	0	0
Median (IQR)	21 (9.8)		20 (8)		18 (7)		17 (7)	
Mean (s.d.)	22.6 (7.5)		20.9 (5.8)		18.7 (5.8)		18.0 (5.7)	

Abbreviation: IQR, interquartile range.

Severity sum-score ranges from 10 to 50. A severity sum-score of 10 means no impact. A severity sum-score of 50 is the most severe possible impact.

described an overall negative impact that these items can have on daily life.  $^{10}$ 

In our study, the degree of impact for each health problem seems to be relatively moderate. Kennedy *et al.* studied a group 3–18 months after discharge from rehabilitation centers. The majority of participants reported a rare/mild impact. Just 9% stated a moderate impact until significant disruption due to the effects of health problems.<sup>11</sup>

The stable course of the impact of health problems in our study reflects the stable course of the health problems itself at 1 and 5 years post discharge found in this cohort.<sup>6</sup> It is therefore not likely that this situation will improve after 5 years post discharge, as patients who had been injured for six or more years appeared to be at a greater risk for getting medical complications than those within 5 years of their injury.<sup>2</sup>

Besides, a response shift might have occurred. A response shift can be another explanation to what has contributed to the stable course of the impact of the health problems. In contrast to our study, Kennedy *et al.* showed that participants were quite satisfied about the areas activities of daily living (ADL), bowel, bladder, skin management, social activities and recreation. The needs they identified as being addressed the least satisfactory were in the areas of pain relief and sexuality. Forty-eight percent of their participants had a complete paraplegia and 31% an incomplete paraplegia, comparing with 23 and 9% in our study and their participants had been injured 21 years on average.

Besides the severity of the lesion, other lesion characteristics, age or socio-demographic factors seem to have no consistent role in experiencing the impact on functioning at home and social activities.

Strengths and limitations to this study. This is the first prospective follow-up study using patient ratings of the impact of several health problems on functioning at home and on social activities 1 and 5 years after first inpatient rehabilitation after an SCI.

The described health problems in our study met the expected problems elsewhere described in the first years after SCI.<sup>18</sup>

Some limitations should be mentioned. First, the present study included only Dutch patients with an SCI who were aged between 18 and 65 years at inclusion, who were wheelchair-dependent and admitted to an SCI rehabilitation center. Therefore, the results are not fully generalizable to the whole SCI population. Second, although

the measures used were developed and used in an earlier study,<sup>4</sup> these have not been formally validated. The 10 health problems are based on the impact of the health problem in an earlier study. It is not a complete list of the impact of all existing SHCs that can occur after SCI. In addition, participants were asked to compare their situation in the past 12 months to the situation before the SCI more than 5 years back in time. Their memory of the preinjury situation may not have been very accurate any more, or a response shift might have occurred. Regardless of these limitations, the findings of this study highlight an important topic and may have several implications.

Implications. The present study shows that SCI and health problems secondary to SCI have an impact on time expenditure and on functioning at home and in social activities in the first five years post discharge. It is important to minimize the impact of health problems, as this study showed that the impact of health problems does not diminish over time during this period. Not only common health problems such as bladder and bowel regulation need attention but also handicap management and dependency should be given special attention during long-term follow-up care.

These results emphasize that it is necessary to focus not only on health problems itself but also on the consequences of these health problems during post-discharge care. It should be a goal of clinicians of specialized rehabilitation centers and researchers to diminish the harm, as a consequence of the negative impact that health problems can have on an individual with an SCI, in a multidisciplinary approach. Special attention should be given to handicap management, dependency, bladder and bowel regulation and pain.

## **DATA ARCHIVING**

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

## **ACKNOWLEDGEMENTS**

We thank the participating Dutch rehabilitation centers and research assistants in these centers who collected all data: De Hoogstraat Rehabilitation Center (Utrecht), Reade, centre of rehabilitation and rheumatology (Amsterdam),

Rehabilitation Centre Het Roessingh (Enschede), Adelante (Hoensbroek), Rehabilitation Center Sint Maartenskliniek (Nijmegen), Center of Rehabilitation – Location Beatrixoord (Haren), Rehabilitation Center Heliomare (Wijk aan zee) and Rehabilitation Center Rijndam (Rotterdam).

- 1 Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946.
- 2 Anson CA, Shepherd C. Incidence of secondary complications in spinal cord injury. Int J Rehabil Res 1996; 19: 55–66.
- 3 Hitzig SL, Tonack M, Campbell KA, McGillivray CF, Boschen KA, Richards K et al. Secondary health complications in an aging Canadian spinal cord injury sample. Am J Phys Med Rehabil 2008; 87: 545–555.
- 4 Bloemen-Vrencken JH, Post MWM, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disabil Rehabil* 2005; 27: 1381–1389.
- 5 Post MWM, van Leeuwen CM. Psychosocial issues in spinal cord injury: a review. Spinal Cord 2012; 50: 382–389.
- 6 Adriaansen JJE, Post MWM, de Groot S, van Asbeck FW, Stolwijk-Swüste JM, Tepper M et al. Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge. J Rehabil Med 2013; 45: 1016–1022.
- 7 Haisma JA, van der Woude LH, Stam HJ, Bergen MP, Sluis TA, Post MWM et al. Complications following spinal cord injury: occurrence and risk factors in a longitudinal study during and after inpatient rehabilitation. J Rehabil Med 2007; 39: 393–398.
- 8 Hitzig SL, Campbell KA, McGillivray CF, Boschen KA, Craven BC. Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. Spinal Cord 2010; 48: 330–335.

- 9 Noreau L, Proulx P, Gagnon L, Drolet M, Laramée M-T. Secondary impairments after spinal cord injury: a population-based study. Am J Phys Med Rehabil 2000; 79: 526–535.
- 10 Callaway L, Barclay L, McDonald R, Farnworth L, Casey J. Secondary health conditions experienced by people with spinal cord injury within community living: implications for a National Disability Insurance Scheme. *Aust Occup Ther J* 2015; 62: 246–254.
- 11 Kennedy P, Sherlock O, McClelland M, Short D, Royle J, Wilson C. A multicentre study of the community needs of people with spinal cord injury: the first 18 months. Spinal Cord 2010: 48: 15–20.
- 12 Cobb J, Dumont FS, Leblond J, Park SE, Noonan VK, Noreau L. An exploratory analysis of the potential association between SCI secondary health conditions and daily activities. Spinal Cord Inj Rehabil 2014; 20: 277–288.
- 13 Post MWM, de Witte LP, van Asbeck FWA, van Dijk AJ, Schrijvers AJP. Predictors of health status and life satisfaction in spinal cord injury. *Arch Phys Med Rehabil* 1998; 78: 395–402.
- 14 Kennedy P, Lude P, Taylor N. Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. Spinal Cord 2006; 44: 95–105.
- 15 Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. *Spinal Cord* 2005; 43: 241–248.
- 16 de Groot S, Dallmeijer AJ, Post MWM, van Asbeck FWA, Nene AV, Angenot ELD et al. Demographics of the Dutch multicenter prospective cohort study 'Restoration of mobility in spinal cord injury rehabilitation'. Spinal Cord 2006; 44: 668–675.
- 17 Marino RJ, Barros T, Biering-Sorensen F, Burns SP, Donovan WH, Graves DE et al. International standards for neurological classification of spinal cord injury. ASIA Neurological Standards Committee 2002. J Spinal Cord Med 2003; 26: 50–56.
- 18 Jensen MP, Truitt AR, Schomer KG, Yorkston KM, Baylor C, Molton IR. Frequency and age effects of secondary health conditions in individuals with spinal cord injury: a scoping review. Spinal Cord 2013; 51: 882–892.