Outcomes after Spinal Cord Injury

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Functional independence of persons with long-standing motor complete spinal cord injury in the Netherlands

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ABSTRACT

Context/Objective: Since life expectancy of persons with spinal cord injury (SCI) has improved, it is relevant to know whether this group is able to maintain functional abilities many years after onset of SCI. Objectives of this study were (1) to examine associations between time since injury (TSI) and functional independence in persons with long-standing SCI, and (2) to explore associations between functional independence and level of injury, comorbidities, mental health, waist circumference and secondary health conditions (SHCs).

Design: TSI-stratified cross-sectional study. Strata were 10-19, 20-29 and 30+ years.

Setting: Community.

Participants: 226 persons with long-standing SCI. Inclusion criteria: motor complete SCI; age at injury 18-35 years; TSI ≥10 years; current age 28-65 years; wheelchair dependency.

Interventions: Not applicable.

Outcome measures: The Spinal Cord Independence Measure III (SCIM) was administered by a trained research assistant. Level of injury, comorbidities, mental health, waist circumference and SHCs were assessed by a rehabilitation physician.

Results: Mean TSI was 23.6 (SD 9.1) years. No significant differences in SCIM scores were found between TSI strata. SCIM scores were lower for persons with tetraplegia, autonomic dysreflexia, hypotension, more than four SHCs and a high waist circumference. In linear regression analyses, TSI nor age were associated with the SCIM total score. Only level of injury (β -0.7; $P < 0.001$) and waist circumference (β -0.1; $P = 0.042$) were independent determinants (explained variance 55%).

Conclusion: We found no association between TSI and functional independence in persons with long-standing motor complete SCI. This study confirms the possible effect of overweight on functional independence.

INTRODUCTION

A primary goal of rehabilitation after spinal cord injury (SCI) is to attain an optimal level of functional independence. Since life expectancy of persons with SCI has considerably improved, it is relevant to know whether this group is able to maintain their functional abilities as they age.

Aging after SCI has been suggested to be determined by both growing age and time since injury (TSI).[1] Although it is often assumed that functional independence in this patient group decreases with aging, the literature on this topic shows conflicting results. Several cross-sectional studies did not find clues for a decline in functioning with a longer TSI or growing age.[2-6] Further, Whiteneck *et al*. found a decrease in mobility and physical independence with increasing age, but not with TSI.[7] However, several studies found that part of their participants had experienced a decline of functioning in the years preceding the study.[8-10] Amsters *et al*. reported participants experienced an increase in functioning in the first 10 years after SCI but a decrease in functioning after the first 10 years.[11]

Little longitudinal data on long-term functioning with SCI has been published to date. In one longitudinal study, no clear trend in functional independence with increasing age or duration of injury was found, although the participants reported a decline in their functioning.[2] Two other longitudinal studies reported a decrease in functioning with increasing age[12] or TSI,[12,13] although this only applied to higher functioning individuals in one of these studies.[13] In another longitudinal study, Functional Independence Measure (FIM) scores slightly increased when measured at 1, 5, 10 and 20 years after injury, although this was not tested for significance.[14]

In contrast to these conflicting results on TSI and age, the level of SCI demonstrates strong influence on long-term functioning.[3,4,6] Further, secondary health conditions (SHCs) are common in persons aging with SCI,[7,15,16] which may contribute to functional limitations. Little information has however been published on this subject.[3,17]

In most studies on long-term functioning, functional independence was measured using the FIM. The use of the more recently developed Spinal Cord Independence Measure III (SCIM III) is increasing. The SCIM III shows more responsiveness than the FIM to functional changes in sphincter management and mobility indoors and outdoors.[18] The SCIM III has been recommended as the primary outcome measure to assess functional recovery in SCI.[19] However, we found only one study in which this measure was used to describe long-term functioning.[6] Another study used the self-report version of the SCIM III, but only reported dichotomized scores of single mobility items.[17]

Since information on SCIM-scores in persons with long-standing SCI is sparse and it is relevant to know whether this group is able to maintain functional abilities many years after onset of SCI, the present study was performed to gain insight into long-

term functioning measured with the SCIM III of persons with a motor complete SCI in the Netherlands. The primary objective was to examine associations between TSI and functional independence. We hypothesized that persons with a longer TSI would function less independently. The secondary objective was to explore associations between functional independence and level of injury, comorbidities, mental health, waist circumference and SHCs.

METHODS

Design

Data for this study was derived from the research program 'Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)', a TSI-stratified cross-sectional study performed in eight rehabilitation centers in the Netherlands. TSI-strata were 10-19, 20-29 and 30 years or more after the onset of SCI.[20]

Study population

Inclusion criteria of ALLRISC were: traumatic or non-traumatic SCI, age at injury between 18 and 35 years, TSI at least 10 years, current age between 28 and 65 years and using a wheelchair (hand-rim propelled wheelchair or electric wheelchair), at least for longer distances (>500 m). Persons were excluded when their mastery of the Dutch language was insufficient.[20,21] The age inclusion criteria were applied to limit the confounding effects of age-related comorbidities and thereby to be better able to study the long-term consequences of SCI.[17,18]

For the current study, participants with a motor complete SCI were selected and persons with incomplete data on SCIM III scores or lesion characteristics were excluded.

Procedure

Eligible persons were identified in databases from all eight Dutch rehabilitation centers specialized in SCI rehabilitation. Participants were asked to complete a self-report questionnaire and invited for a one-day visit to the rehabilitation centre. This visit included an extensive medical assessment with a structured interview and a physical examination by an SCI rehabilitation physician, and an oral interview by a trained research assistant.

The study protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All subjects signed an informed consent form prior to participation.

Instruments

Functional independence

Functional independence was measured with the SCIM III, which was administered by the research assistant. The SCIM III consists of three subscales with a total score range of 0-100: 'Self-care' including six items (range 0-20), 'Respiration and sphincter management' including four items (range 0-40) and 'Mobility' including nine items (range 0-40). The items are weighted in terms of their assumed clinical relevance.[18,19,22] The SCIM III showed good reliability and validity.[18,23,24]

Demographics

The self-report questionnaire included information on age, sex, marital status and level of education. For statistical analysis level of education was dichotomized in 'high level of education' (at least a college degree) and 'low level of education'.

Injury characteristics

The patients were neurologically examined by the rehabilitation physician according to the International Standards for the Neurological Classification of Spinal Cord Injury (ISNCSCI).[25] American Spinal Injury Association (ASIA) Impairment Scale (AIS) A and B were considered motor complete. The lowest intact motor level was used to describe the level of injury. Levels of injury C1-C8 were defined as tetraplegia, levels below C8 as paraplegia.

Mental health

Mental health was measured with the Mental Health Inventory-5 (MHI-5), which was part of the self- report questionnaire, and consists of five questions to screen on depression and anxiety over the last four weeks.[26] A sum-score was calculated and converted to a 0 – 100 scale. The MHI-5 scores were dichotomized to "mental health problems" (<60) and "no mental health problems" (≥ 60).[27]

Waist circumference

Waist circumference was measured by the rehabilitation physician in supine position.

Secondary health conditions

As part of the structured interview, the rehabilitation physician asked whether participants had suffered from hypotension, pneumonia, autonomic dysreflexia (AD), pressure ulcers, problematic spasticity, urinary tract infections (UTI), musculoskeletal pain and neuropathic pain in the last 3 months. Also the presence of neurogenic heterotopic ossification (NHO) was recorded. The SHCs were defined as follows:

AD: a sudden reaction of the autonomic nervous system triggered by a stimulus below the level of the injury, causing an increase in blood pressure accompanied by other symptoms as pallor, piloerections, cold extremities and profuse sweating below the level of the injury, and severe headaches, flushing of the skin, bradycardia and nasal congestion above the level of injury.
Pneumonia: a lower respiratory tract infection treated with antibiotics.
Pressure ulcers: category I, II, III or IV pressure ulcers according to the classification of European Pressure Ulcer Advisory Panel (EPUAP).[28]
Problematic spasticity: spasticity interfering moderately or extensively with activities in daily life.
Hypotension: a decrease in blood pressure that was assessed according to symptoms as light-headedness or fainting.
UTI: a urinary tract infection treated with antibiotics, and the presence of one or more of the following symptoms: fever, increased spasticity, discomfort or pain during urination, onset of urinary incontinence, malaise, AD, mucus or gritty particles in the urine or cloudy urine with increased odour.
NHO: the presence of bone tissue in soft tissue surrounding paralyzed joints, confirmed by radiological examination.
Neuropathic pain: at- or below-level pain, originating from spinal cord ischemia, syringomyelia or trauma.[29]
Musculoskeletal pain: nociceptive pain originating from muscle, bone or joint trauma or overuse.[30]

SHC sum-score
A sum-score of the number of SHCs (0-9) was calculated to obtain insight into the effect of having multiple SHCs in relation to functional independence.

Comorbidities
Comorbidities were assessed by the rehabilitation physician in the structured interview. The presence was established according to the Charlson Comorbidity Index.[31]

Statistical analysis

Cronbach's alpha and Skewness of the total SCIM III score and subscale scores were calculated to examine their internal consistency and normality. Internal consistency was excellent for the total SCIM III score (0.91) and Self-care (0.93), good for Mobility (0.83), but questionable for Respiration and sphincter management (0.66). The Skewness was 0.73 for the total SCIM III and 0.51-0.62 for the subscale scores, showing no strong deviations from the normal distribution. Descriptive statistics of demographics, injury characteristics, SCIM III scores, SHCs and comorbidities were calculated for the

total group as well as for the three TSI strata. Analysis of variance (ANOVA) and the Chi-square test were used to determine differences between the three TSI strata. A Pearson's correlation was calculated between TSI and the total SCIM III score.

Possible determinants of the total SCIM III scores were tested using t-tests. For these analyses, age was dichotomized to <55 and ≥55 years, comorbidities to "no" and "one or more", waist circumference to "high" (male≥102; female≥88) and "normal" (male<102; female<88) and the SHC sum-score in <4 or ≥4.

Furthermore, to obtain more insight in the influence of level of injury on SCIM III scores we calculated a bar chart with SCIM III scores per single level of injury.

Finally, linear hierarchical regression analyses were performed to identify independent determinants of the total SCIM III score. In these analyses the dichotomized SHC sum-score was used instead of the separate SHCs to minimize the number of potential determinants. Demographics (age and sex) and level of injury were analyzed in the first step of the model, while all other determinants with a $P < 0.1$ in bivariate analyses were added to the model in the second step.

Missing data were dealt with using pairwise deletion. All analyses were performed using the SPSS statistical software program (SPSS 21.0 for windows, IBM; Armonck NY).

RESULTS

Descriptives

Between November 2011 and February 2014, 566 persons were invited of whom 282 participated in ALLRISC. For the purpose of this study, 54 persons were excluded because they had a motor incomplete injury, one person because of missing injury characteristics and one because of missing SCIM data, leaving a total of 226 participants. Characteristics of participants are displayed in Table 1. The mean age was 48.0 years (SD 8.9; median 47.3; range 29.1-66.5). The mean TSI was 23.6 years (SD 9.1; 21.5; range 10-47).

Differences between time since injury strata

The mean ages of persons in the three TSI strata (10-19 years, 20-29 years and 30+ years) were respectively 40.4 (SD 5.0), 48.5 (SD 5.6), and 58.1 (SD 5.3) years ($F=203.0$, $P < 0.001$).

The three TSI-groups were similar with regard to level of injury, comorbidities and most SHCs. Only the presence of problematic spasticity (respectively 52.3%, 39.5% and 27.4%, $P < 0.01$) and AD (respectively 30.7%, 13.2% and 12.9%, $P < 0.01$) was lower for persons with a longer TSI. In the group with the shortest TSI the fewest people had a high waist circumference, respectively 33.7%, 52.2% and 50%, $P < 0.05$.

Table 1. Participant characteristics

Characteristic	**%**
Demographics	
Sex (male)	76.1
Marital status (partner) (n=214)	36.9
Level of education (high) (n=215)	40.5
Injury characteristics	
Cause of injury (traumatic)	93.8
Level of injury (tetraplegia)	37.6
Comorbidities (1 or more) (n=225)	45.3
High waist circumference (m≥102;f≥88) (n=208)	44.2
Mental health problems (MHI-5<60) (n=212)	22.3
Secondary Health Conditions	
Musculoskeletal pain	61.5
Neuropathic pain	45.1
Problematic spasticity	41.2
Urinary tract infections	35.0
Pressure ulcers	33.6
Neurogenic heterotopic ossification	27.9
Hypotension	20.4
Autonomic dysreflexia	19.9
Pneumonia (n=217)	6.0

Abbreviations: m: male; f: female; MHI-5: Mental Health Index.

No significant differences between the TSI strata were found for the total score and sub-scores of the SCIM III (Table 2). Furthermore, no correlation was found between TSI as a continuous variable and the total SCIM III score (R= -0.02, P = 0.175). However, SCIM III scores for persons with paraplegia decreased with a longer TSI (R= -0.20, P < 0.05), in contrast to persons with tetraplegia (R=-0.04, P = 0.737).

Table 2. SCIM III scores of TSI strata

	Total group (n= 226)	TSI 10-19 yrs (n= 88)	TSI 20-29 yrs (n=76)	TSI ≥30 yrs (n=62)		
SCIM scale	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**ANOVA F**	**P**
SCIM self-care	12.9 (5.8)	12.8 (5.6)	12.9 (6.4)	12.9 (5.4)	0.0	0.989
SCIM respiration and sphincter management	27.7 (7.8)	27.3 (7.9)	28.3 (7.6)	27.7 (7.9)	0.3	0.728
SCIM mobility	14.1 (6.1)	14.5 (6.1)	14.2 (6.5)	13.6 (5.5)	0.4	0.649
SCIM Total	54.9 (18.5)	54.6 (18.5)	55.7 (19.3)	54.2 (17.7)	0.1	0.888

Abbreviations: SCIM: Spinal Cord Independence Measure; TSI: time since injury

Other determinants of the SCIM III

As the internal consistency of the total SCIM III score was excellent and analyses per subscale did not reveal substantial information, analyses of determinants of the SCIM III were performed with the total SCIM III score. Further, these analyses were not performed for separate TSI strata but for all participants, regardless of TSI. SCIM III scores were significantly lower for persons with a tetraplegia, AD, hypotension, less than four SHCs and a high waist circumference. No significant difference was found between the two age categories (Table 3).

Figure 1 shows the SCIM III scores per level of injury. There was one person with a C1 level of injury. This person had a zone of partial preservation (right sensory C3, left sensory T3, right motor C7, left motor C7). SCIM III scores of persons with C4-T1 level of injury increased with each lower level of injury. We found more or less similar scores for participants with levels of injury across the range T1-L1 (Figure 1).

Regression analysis

The results of the linear hierarchical regression analyses are displayed in Table 4. The adjusted R square of the first step of the analyses (including sex, age and level of injury) was 0.534. The R-square change of the second step in the regression analyses was small (0.011), indicating the variables added in the second step (waist circumference and SHC sum-score) had little added value in explaining long-term functioning. Level of injury was the strongest independent determinant of long-term functioning (R square 0.469). Waist circumference was the only other independent, but weak, determinant (R square 0.010).

Table 3. Determinants of the SCIM III

Determinant		N	SCIM total Mean (SD)	T	P
Demographics					
Age	< 55 years	175	54.6 (18.9)	0.4	0.662
	≥ 55 years	51	55.8 (17.1)		
Sex	Male	172	54.4 (18.8)	0.6	0.562
	Female	54	56.1 (17.5)		
Education	High	87	55.6 (19.3)	-0.5	0.623
	Low	128	54.3 (17.9)		
Marital status	Partner	135	52.2 (19.1)	1.6	0.100
	No partner	79	56.5 (18.0)		
Injury characteristics					
Cause of injury	Non-traumatic	14	51.8 (19.6)	0.6	0.522
	Traumatic	212	55.1 (18.4)		
Level of injury	Paraplegia	141	65.3 (7.8)	-13.4	<0.001
	Tetraplegia	85	37.5 (18.1)		
Comorbidities	No	123	53.4 (19.6)	1.5	0.144
	One or more	102	56.9 (16.7)		
Waist circumference	m<102; f<88	116	59.5 (16.4)	-3.4	0.001
	m≥102; f≥88	92	51.0 (18.9)		
Mental Health	MHI-5 ≥60	186	55.7 (18.1)	-1.6	0.110
	MHI-5 <60	26	49.5 (20.3)		
SHCs					
Musculoskeletal pain	No	87	53.1 (19.7)	1.1	0.280
	Yes	139	55.9 (17.6)		
Neuropathic pain	No	124	55.7 (17.7)	-0.8	0.427
	Yes	102	53.8 (19.4)		
Problematic spasticity	No	133	56.2 (17.9)	-1.3	0.206
	Yes	93	53.0 (19.2)		
Urinary tract infections	No	147	55.4 (18.3)	-0.6	0.560
	Yes	79	53.9 (18.8)		
Pressure ulcers	No	150	56.1 (17.8)	-1.5	0.140
	Yes	76	52.3 (19.5)		
NHO	No	163	54.7 (18.5)	0.2	0.828
	Yes	63	55.3 (18.5)		

Table 3. Determinants of the SCIM III (continued)

Determinant		N	SCIM total Mean (SD)	T	P
Hypotension	No	180	56.3 (17.9)	-2.3	0.024
	Yes	46	49.4 (19.8)		
AD	No	181	56.6 (18.0)	-2.9	0.004
	Yes	45	47.8 (18.9)		
Pneumonia	No	204	55.0 (18.3)	-1.4	0.171
	Yes	13	47.7 (22.2)		
SHC sum-score (0-9)	<4	141	56.8 (17.9)	-2.5	0.014
	≥4	76	50.3 (19.2)		

Abbreviations: SCIM: Spinal Cord Independence Measure; SHC: secondary health condition; NHO: neurogenic heterotopic ossification; AD: autonomic dysreflexia, m: male; f: female; MHI-5: Mental Health Index.

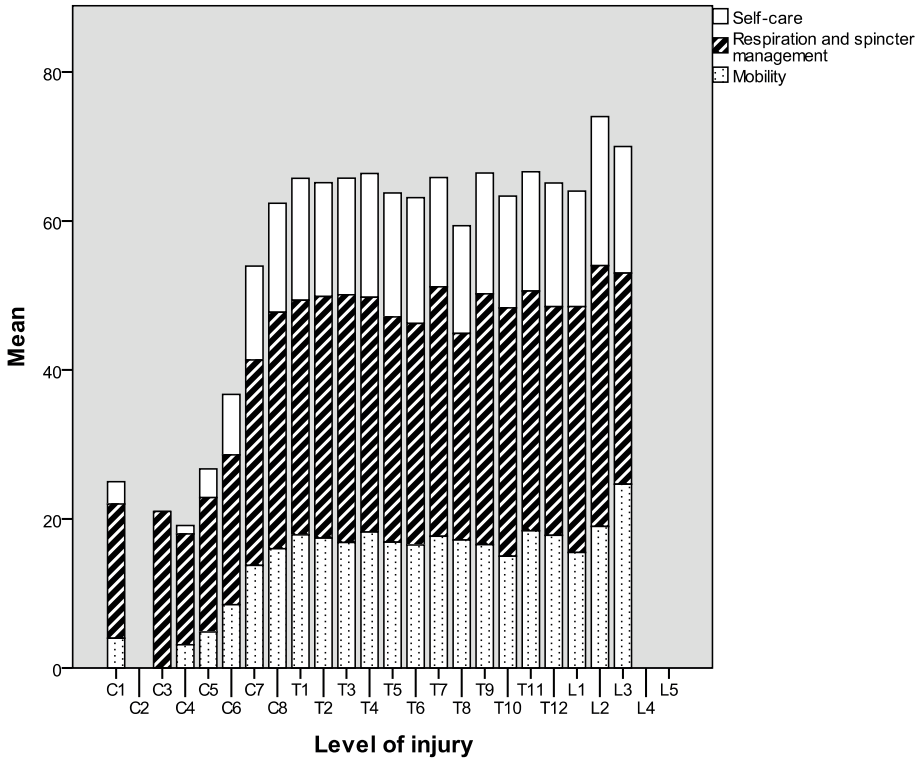

Figure 1. SCIM III scores per level of injury

Table 4. Linear hierarchical regression analyses (final model) of determinants of the SCIM III

Determinant	B (SE)	β	P	Uniquely explained variance (%)
Level of injury (tetraplegia)	-27.7 (1.9)	-0.7	<0.001	49.6
Age (older)	-0.2 (0.1)	-0.1	0.098	0.6
Sex (female)	-3.0 (2.1)	-0.1	0.153	0.5
SHC sum-score (≥4)	-1.6 (1.9)	-0.04	0.391	0.2
Waist circumference (m≥102; f≥88)	-3.7 (1.8)	-0.1	0.042	1.0
Adjusted R square 0.545 (F 48.6, p<0.001)				

Abbreviations: SHC: secondary health condition; m: male; f: female

DISCUSSION

In this cross-sectional study we found no differences in functional independence measured with the SCIM III between strata of TSI (10-19, 20-29, 30+ years) in persons under 65 years of age with a motor complete SCI in the Netherlands. The level of injury was the strongest determinant, and neither TSI nor age was associated with long-term functioning. Waist circumference was another weak, but independent determinant.

Our study is amongst the first studies to have used the SCIM III to evaluate long-term functional independence.[6] The results are thus mainly discussed in the light of studies that have used other outcome measures, mostly the FIM. Due to methodological differences with other studies, a comparison of the results must be interpreted with caution. Furthermore, factors related to the health care systems, e.g. the degree of initial rehabilitation or follow-up, add to the difficulties of comparing studies on (long-term) functioning.

Our finding that persons with a longer TSI did not function less independent compared to persons with more recent SCI is more or less in line with the inconsistent results of previous longitudinal studies[2,12,13] and also with several other cross-sectional studies that did not found a decline.[2-6] However, studies that measured the patient's perception of change in functioning found a decline in experienced functioning in a part of the participants.[8-10] Although this may be explained by the subjective measurement of functioning, the SCIM III may not be sensitive enough to detect small functional changes, since the effort needed to perform an activity is not evaluated. Further investigation is necessary to examine whether other measures, e.g., the recently developed Spinal Cord Injury-Functional Index would be more sensitive to detect changes in functional independence in persons with long-standing SCI.[32]

In contrast to our overall results on long-term functioning, we found a negative correlation between the SCIM III scores and TSI for persons with a paraplegia. This seems to match the results of a study performed with the FIM, in which a decline of functioning was described only for higher functioning individuals.[13] The difference in SCIM score between the first and last TSI stratum for persons with a paraplegia we found was however so small that it does not seem to be clinically relevant.[33] Altogether, more longitudinal data is needed for more solid conclusions on long-term functioning.

The level of injury has been described as strongest determinant of long-term functional independence.[3,4,6] The SCIM III showed sensitivity to detect differences in functioning across cervical levels of injury but not across thoracic level of injury. Due to the absence of key muscles in the thoracic area (Th2-L1), little functional changes would also be expected according to the level of injury within this range. Functional changes on the mobility subscale would be likely across levels L2-S1. As our inclusion criteria included wheelchair dependency and only few persons with a low level of injury were included, we were not able to analyze this.

Waist circumference was the only other independent determinant of long-term functioning. The role of body composition in long-term mobility has been suggested previously.[17] As an increased waist circumference is a modifiable determinant, this finding is relevant to clinical practice, although the association we found was only weak.

Study limitations

As a result of the cross-sectional study design no conclusions can be drawn on the true effects of aging. A longitudinal study design would be necessary to obtain more insight in these true effects of aging.[12]

A limitation concerning the representativeness of the study sample concerned absent information regarding the comparability between participants and non-participants. There may have been a survivor effect within our study, meaning that healthier subjects may have been more available or willing to participate.[34] However, we found similar SCI characteristics and SHCs in the three TSI strata, which does not indicate a survivor effect in those living with SCI for more than 10 years.

The inclusion of only motor complete injuries rendered more valid information on SCIM III scores per injury level, but restricts generalization of the results to all people living with SCI.

As a result of our inclusion criteria, all participants were injured as young adults and maximum 65 years of age at the time of the study. Therefore, our study is less suited to study the influence of age and age at injury on long-term functional independence. Age at injury has been previously described to be a determinant of long-term functioning; the older the age at the time of injury, the greater the influence of aging on disability.[35]

Further, our study population may have been too young to detect a relation between age and functional independence.

The SCIM III subscale "Respiration and sphincter management" contains information on two common SHCs, namely urinary and fecal incontinence. As spurious relations were expected between these SHCs and the SCIM subscale, we could not analyze these SHCs as possible determinant of functional independence.

Conclusions

Our study suggests that persons under 65 years of age with a motor complete SCI in the Netherlands seem to be able to maintain their level of functioning for quite a long period. However, longitudinal studies are necessary to reveal the effects of aging on functional independence. Our study further confirms the association between waist circumference and functional independence, and thereby the importance of a healthy lifestyle to prevent an increase in weight.

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