Age-related variation in mobility independence among wheelchair users with spinal cord injury: A cross-sectional study

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Objective: To evaluate age-related variation in mobility independence among community-living wheelchair users with spinal cord injury (SCI).
Design: Community Survey (2011–2013) as part of the Swiss Spinal Cord Injury Cohort Study.
Setting: Community.
Participants: Individuals aged 16 years or older with traumatic or non-traumatic SCI permanently residing in Switzerland and using a wheelchair for moving around moderate distances (10–100 m).
Interventions: Not applicable.
Outcome Measures: Mobility-related items of the Spinal Cord Independence Measure-Self Report were matched to the three principal domains 'changing basic body position', 'transferring oneself' and 'moving around'. Binary outcomes ('independence' vs. 'no independence') were created for every domain and analyzed using multivariable logistic regression (adjusted for sex, socioeconomic factors, SCI characteristics, and health conditions).
Results: Regression analyses ($N = 949$; 27% women; median age 51, interquartile range 41–61) showed a decline in the odds of independence (odds ratio; 95% confidence interval) with increasing age for 'changing basic body position' (age 16–30 (reference), 31–45 (0.99; 0.53–1.83), 46–60 (0.64; 0.33–1.21), 61–75 (0.45; 0.22–0.92), 76+ (0.18; 0.07–0.44); $P < 0.001$), 'transferring oneself' (age 16–30 (reference), 31–45 (0.77; 0.37–1.61), 46–60 (0.39; 0.18–0.84), 61+ (0.05; 0.02–0.14); $P < 0.001$), and 'moving around' (age 16–30 (reference), 31–45 (0.79; 0.42–1.48), 46–60 (0.49; 0.26–0.94), 61–75 (0.49; 0.24–1.01), 75+ (0.11; 0.04–0.30); $P < 0.001$).
Conclusions: Mobility independence was negatively associated with age in wheelchair users with SCI. Future longitudinal analyses are required to gain further insights into the causal factors for the age-related decline.

Keywords: Spinal cord injuries, Wheelchairs, Disabled persons, Movement, Moving and lifting patients

Introduction

For individuals with spinal cord injury (SCI), mobility independence is of great relevance for self-management[1] and community integration.[2] Functional independence with mobility tasks, such as transferring or moving around,[3] is partly determined by the characteristics of the spinal cord lesion such as level and completeness. The lesion can result in a number of motor, sensory, and autonomic impairments as well as in functional modifications of several biological systems (e.g. respiratory, cardiovascular, musculoskeletal).[4] Additional factors may include associated injuries, secondary health conditions, degenerative changes (e.g. of the shoulder region) resulting from overuse over time, and age-related changes (e.g. decline in muscle strength), and socioeconomic factors.[5–7] Given an increasing life expectancy of individuals with SCI,[8,9] maintaining

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mobility independence over the life course is a major concern in the organization of care. Knowledge of the association between age and mobility independence is necessary to enable healthcare professionals to anticipate and proactively counteract problems as well as maintain the maximum level of achievable independence.[10]

The majority of studies on functional independence of people with SCI focused on functional changes during the acute rehabilitation or within the first 1 to 5 years after the injury.[11,12] A few epidemiologic studies performed in samples of community-living people with SCI in the UK,[13] the US[14–16] and Australia,[17,18] demonstrated an increase of functional deficits and the need of assistance with age. To expand the existing knowledge of age-related variation in mobility independence among community-living people with SCI, the present study (1) evaluated the proportion of wheelchair users with SCI able to independently perform mobility tasks ('changing basic body position', 'transferring oneself' and 'moving around') in different age groups of a large and representative Swiss sample, and (2) examined the association between age and mobility independence, after accounting for sex, socioeconomic factors, SCI characteristics and a number of health conditions.

Methods

Study design and sample

The Swiss Spinal Cord Injury (SwiSCI) Cohort Study is an ongoing observational population-based cohort study that includes people (aged 16+) diagnosed with traumatic or non-traumatic SCI and permanently residing in Switzerland. People with congenital conditions leading to SCI, new SCI in the context of palliative care, neurodegenerative disorders or Guillain-Barré syndrome were excluded from the study. Details on study design and recruitment procedures have been reported previously.[19] SwiSCI was approved by the ethics committee of the Canton of Lucerne (the location of the main study center) and subsequently endorsed by the ethics committees of the Cantons Zürich, Basel-Stadt and Valais, who are liable for the other three participating rehabilitation centers. All participants signed written informed consent.

The present study refers to cross-sectional data collected between September 2011 and March 2013 in a community survey.[19] Paper and web-based questionnaires and telephone interviews were used as assessment methods. Potential participants ($n = 3144$) were identified through cooperation with the national association for persons with SCI (Swiss Paraplegics Association), three specialized SCI-rehabilitation centers, and an SCI-specific home care institution (ParaHelp). The questionnaire modules that were relevant for the present study were returned by 1549 out of 3144 subjects (response rate: 49%). Finally, only those participants who reported using a wheelchair (manual or electric) to move around moderate distances of 10 to 100 m were included ($n = 949$); participants stating to walk ($n = 526$) or not answering the relevant question ($n = 74$) were excluded from further analyses.

Mobility independence

For the present study of wheelchair users, mobility independence was defined as being able to perform mobility-related activities without personal assistance, supervision or assistive devices other than the manual wheelchair (such as motorization of the wheelchair, hoists, lifting poles, sliding boards or grab rails). It was assessed by using the self-report version (SCIM-SR) of the (observer-rated) Spinal Cord Independence Measure (SCIM III). The SCIM-SR has previously shown good criterion validity.[20] SCIM-SR mobility items were matched to three domains each representing an ICF category within Chapter 4 'Mobility' of the ICF[3]: (1) 'changing basic body position', (2) 'transferring oneself', and (3) 'moving around' (Table 1). The domain 'changing basic body position' included a single item asking the participant for the number of activities (from a given set of 4) that he or she was able to perform without assistance or electrical aids at the time of the survey. The domain 'transferring oneself' included 4 activities, covered by 4 items asking the participant for the need of assistance or adaptive devices for performing the activity. The domain 'moving around' included 3 activities, covered by 3 items asking the participant for the need of an electric wheelchair or assistance for performing the activity.

For the logistic regression analyses we created binary outcomes for all 3 mobility domains: 'independence' (i.e. independence in *all* of the activities of the relevant domain) vs. 'no independence' (i.e. need of assistance/supervision/devices in *at least one* of the activities of the relevant domain). Table 1 shows the possible answers to all questions and the respective coding. SCIM items do not differentiate between the need of partial personal assistance and the need of adaptive devices, therefore both were coded as 'no independence' (see limitations).

Covariables

Covariables were selected *a priori* based on considerations on potential predictors of mobility independence. All covariables (Table 2) were assessed by self-report.

Table 1 Categorization of SCIM-SR mobility items and classification of answers to create the binary outcome: 'independence' (i.e., independence in *all* of the activities of the relevant domain) vs. 'no independence' (i.e., need of assistance/supervision/devices in *at least one* of the activities of the relevant domain)

Mobility domain (ICF codes)	SCIM-SR item numbers[a]	Activities	Answers coded as 'no independence'	Answers coded as 'independence'
Changing basic body position (d410)	9	• Turning upper body in bed • Turning lower body in bed • Sitting up in bed • Doing push-ups in wheelchair	I can perform… • none of those four activities • one of those four activities • two or three of those activities …without assistance or electrical aids.	I can perform… • all of those four activities …without assistance or electrical aids.
Transferring oneself (d420)	10, 11, 16	• Transfer from the bed to the wheelchair • Transfer from the wheelchair to the toilet/tub • Transfer from the wheelchair into the car	• I need total assistance. • I need partial assistance, supervision or adaptive devices.	• I do not need any assistance or adaptive devices. • I do not use a wheelchair.
	17	• Transfer from the floor to the wheelchair	• I need assistance.	• I do not need any assistance. • I do not use a wheelchair.
Moving around (d455, d460, d465)	12, 13, 14	• Moving around indoors • Moving around moderate distances (10 to 100 m) • Moving around outdoors for more than 100	• I use a wheelchair and need total assistance • I need an electric wheelchair or partial assistance to operate a manual wheelchair.	• I am independent in a manual wheelchair. • I walk.

ICF – International Classification of Functioning Disability and Health.
SCIM-SR – Spinal Cord Independence Measure-Self Report.
[a]Item numbers according to Fekete *et al.*[20]

Table 2 Participants' characteristics (*N* = 949; 27.2% women)

	N[a] (missing)		Total	Male	Female
Socio-demographic and -economic factors					
Age (years)	949 (0)	median (IQR)	51 (41–61)	51 (41–61)	51 (40–61)
16–30		*n* (%)	84 (8.9)	62 (9.0)	22 (8.5)
31–45		*n* (%)	256 (27.0)	186 (26.9)	70 (27.1)
46–60		*n* (%)	367 (38.7)	266 (38.5)	101 (39.2)
61–75		*n* (%)	195 (20.6)	145 (21.0)	50 (19.4)
76+		*n* (%)	47 (5.0)	32 (4.6)	15 (5.8)
Education (years)	932 (17)				
Compulsory school (≤9)		*n* (%)	74 (7.9)	49 (7.2)	25 (9.8)
Vocational training (10–12)		*n* (%)	229 (24.6)	145 (21.4)	84 (33.1)
Secondary education (13–16)		*n* (%)	455 (48.8)	350 (51.6)	105 (41.3)
University education (≥17)		*n* (%)	174 (18.7)	134 (19.8)	40 (15.8)
Net equivalent income (CHF/month)	853 (96)				
Low (≤3500)		*n* (%)	333 (39.0)	246 (39.3)	87 (38.3)
Medium (>3500 to ≤4643)		*n* (%)	220 (25.8)	154 (24.6)	66 (29.1)
High (>4643)		*n* (%)	300 (35.2)	226 (36.1)	74 (32.6)
Spinal cord injury characteristics					
Etiology traumatic	942 (7)	*n* (%)	792 (84.1)	607 (88.5)	185 (72.3)
Lesion level	944 (5)				
Tetraplegia		*n* (%)	294 (31.1)	220 (32.1)	74 (28.7)
Paraplegia		*n* (%)	650 (68.9)	466 (67.9)	184 (71.3)
Completeness of injury	944 (5)				
Complete		*n* (%)	603 (63.9)	464 (67.6)	139 (53.9)
Incomplete		*n* (%)	341 (36.1)	222 (32.4)	119 (46.1)
Time since injury (years)	931 (18)	median (IQR)	18 (8–29)	19 (9–29)	17 (7–27)
Health conditions					
Spasticity	904 (45)				
No problem		*n* (%)	226 (25.0)	166 (24.9)	60 (25.2)
Mild/moderate problem		*n* (%)	437 (48.3)	330 (49.6)	107 (45.0)
Severe problem		*n* (%)	241 (26.7)	170 (25.5)	71 (29.8)
Chronic pain	907 (42)				
No problem		*n* (%)	255 (28.1)	187 (28.2)	68 (28.0)
Mild/moderate problem		*n* (%)	324 (35.7)	250 (37.7)	74 (30.5)
Severe problem		*n* (%)	328 (36.2)	227 (34.2)	101 (41.6)
Contractures	905 (44)				
No problem		*n* (%)	481 (53.2)	360 (54.2)	121 (50.2)
Mild/moderate problem		*n* (%)	280 (30.9)	203 (30.6)	77 (32.0)
Severe problem		*n* (%)	144 (15.9)	101 (15.2)	43 (17.8)
Diabetes	934 (15)	*n* (%)	58 (6.2)	48 (7.0)	10 (4.0)
Heart disease	930 (19)	*n* (%)	78 (8.4)	56 (8.2)	22 (8.8)

IQR – interquartile range; CHF – Swiss Francs; SCI – Spinal Cord Injury
[a]Numbers of participants with data for the respective variable.

SCI etiology was classified as traumatic/non-traumatic. Injury level and completeness were assessed by two separate questions on the level of paraplegia/tetraplegia and complete/incomplete. Health conditions were assessed by using the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS; spasticity, chronic pain, contractures)[21] and the Self-Administered Comorbidity Questionnaire (SCQ; diabetes, heart disease).[22] It has previously been suggested that socioeconomic factors are predictive of functional limitations in the general population[23,24] and in populations with specific chronic health conditions.[25,26] A cross-sectional study in people with SCI found an association between financial hardship and various health outcomes including morbidity, pain and quality of life.[7] We included income and education as covariables to account for socioeconomic influences. Education was measured as total years of formal education[27] and classified into four levels.[28] Net equivalent income (based on self-report of disposable household income, household size, and number of adults and children[29]) was classified into low/medium/high using tertiles of the whole sample (wheelchair-users and others).

Statistical analyses

The three binary outcomes: 'independence' (vs. 'no independence') in 1) 'changing basic body position', 2) 'transferring oneself', and 3) 'moving around', were analyzed descriptively, stratified by age groups. Results of the descriptive analyses refer to the number of participants with a valid value for the respective item.

Multivariable logistic regression analyses on the three binary outcomes were used to evaluate the association with age; while adjusting for education, net equivalent income, SCI etiology, lesion level, completeness, time since injury (TSI), spasticity, chronic pain, contractures, diabetes, and heart disease. Results are reported as odds ratios (ORs) and 95% confidence intervals (95% CIs). To account for potential bias due to item non-response in individuals who did not respond to a particular question (see Table 2 for missing data), we performed multiple imputation analysis, combining results from 20 imputed data sets using Rubin's rules.[30] To further handle unit nonresponse in individuals who did not respond to the entire survey, we used inverse probability weights (IPWs) that were derived from a propensity score model for survey participation.[30] All commonly available information on individuals of the source sample was included in the propensity scores model, including sex, age, membership of the Swiss Paraplegics Association, language of response to the questionnaire, lesion level, and time since injury. Corresponding to the overall response rate of 49.3%, the average inverse probability weight was 2.03. Individual weights ranged from 1.02 to 6.65, indicating that the identified sampling bias was small. Results of regression analyses that account for item non-response as well as unit non-response are presented as main results. Complete case analyses without propensity scores were performed as sensitivity analyses and only conflicting results are reported.

Statistical analyses were performed with STATA Version 13 (StataCorp LP, College Station, Texas, USA).

Results

Nine hundred forty-nine wheelchair users (27.2% women) with a median age of 51 (IQR 41–61; range 17–90) participated in the study (Table 2). Eighty-nine percent of men reported a traumatic SCI etiology compared to 72% of women. About two thirds of participants reported to have paraplegia. The most frequently reported severe health condition was chronic pain (36% of participants), followed by spasticity (27%), and contractures (16%).

Results of the descriptive analyses of the binary outcomes for the total sample and stratified by age groups are shown in Table 3 (see Supplementary Table 1 for results of descriptive analyses of the individual SCIM-SR items, available at http://www.maneyonline.com/doi/suppl/10.1179/2045772315Y.0000000008.). Fifty-three percent of participants were independent in 'changing basic body position', 15% were independent in 'transferring oneself', and 55% were independent in 'moving around'.

Table 3 Proportions of independent participants within the three mobility categories (in the total sample and stratified by age groups)

	Independence in...					
	1) ...changing basic body position		2) ...transferring oneself		3) ...moving around	
	N	***n* (%)**	***N***	***n* (%)**	***N***	***n* (%)**
Total	941	497 (52.8)	940	144 (15.3)	945	519 (54.9)
Age (years)	941		940		945	
16–30		50 (59.5)		20 (24.1)		54 (64.3)
31–45		153 (59.8)		57 (22.5)		159 (62.6)
46–60		194 (53.3)		58 (15.9)		198 (54.1)
61–75		85 (44.3)		9 (4.6)		97 (50.0)
76+		15 (33.3)		0 (0)		11 (23.4)

Results of the multivariable logistic regression analyses are shown in Table 4. Men had higher odds (OR; 95% CI) of being independent in 'transferring oneself' (3.79; 1.99–7.22) and in 'moving around' (1.95; 1.35–2.82) than women. The odds of being independent decreased with age in all mobility domains. SCI lesion level and completeness had a major impact on mobility independence. Participants with paraplegia had markedly higher odds of being independent in 'changing basic body position' (10.24; 6.97–15.04), in 'transferring oneself' (27.06; 11.42–64.12), and in 'moving around' (7.51; 5.20–10.85) compared to those with tetraplegia. SCI completeness affected independence (with higher odds for those with an incomplete lesion) in 'changing basic body position' (2.06; 1.42–2.98) and in 'transferring oneself' (4.28; 2.60–7.04). Differences between complete case analyses and multiple imputation analyses combined with use of propensity scores were minimal and did not affect the conclusions.

Discussion

This cross-sectional study quantified the prevalence of mobility independence in different age groups in a large, community-dwelling sample of wheelchair users with SCI. Differences in independence between participants belonging to different age groups were apparent already among younger and middle-aged subjects, which suggests that age-related decline of mobility independence may not be limited to old age but extend throughout adult life. However, this would have to be confirmed by longitudinal studies. The maximum need of personal assistance seems to occur in old age at a time when caregiving spouses might experience age-

Table 4 Multivariable regression analyses for the binary outcomes 'independence' (yes vs. no) in 1) 'changing basic body position', 2) 'transferring oneself', and 3) 'moving around' (imputed dataset; $N = 949$)

	Independence in…											
	1) …changing basic body position				2) …transferring oneself				3) …moving around			
		95% CI				95% CI				95% CI		
	OR[a]	Lower	Upper	*P*	OR[a]	Lower	Upper	*P*	OR[a]	Lower	Upper	*P*
Socio-demographic and -economic factors												
Sex				0.200				<0.001				<0.001
Female	1				1				1			
Male	1.25	0.89	1.77		3.79	1.99	7.22		1.95	1.35	2.82	
Age (years)				<0.001				<0.001				<0.001
16–30	1				1				1			
31–45	0.99	0.53	1.83		0.77	0.37	1.61		0.79	0.42	1.48	
46–60	0.64	0.33	1.21		0.39	0.18	0.84		0.49	0.26	0.94	
61–75	0.45	0.22	0.92		0.05[b]	0.02[b]	0.14[b]		0.49	0.24	1.01	
76+	0.18	0.07	0.44						0.11	0.04	0.30	
Education (years)				0.105				0.098				0.759
Compulsory school (≤9)	1				1				1			
Vocational training (10–12)	1.55	0.83	2.89		0.71	0.20	2.52		1.10	0.58	2.11	
Secondary education (13–16)	2.00	1.10	3.64		1.52	0.46	4.99		1.27	0.68	2.38	
University education (≥17)	2.01	1.03	3.93		1.26	0.37	4.28		1.35	0.67	2.73	
Net equivalent income (CHF/month)				0.106				0.592				0.598
Low (≤3500)	1				1				1			
Medium (>3500 to ≤4643)	1.43	0.97	2.10		1.08	0.63	1.84		1.12	0.76	1.65	
High (>4643)	1.49	0.97	2.30		1.32	0.75	2.33		1.25	0.81	1.92	
SCI characteristics												
Etiology				0.395				0.143				0.086
Non-traumatic	1				1				1			
Traumatic	1.23	0.77	1.96		1.75	0.83	3.71		1.52	0.94	2.46	
Lesion level				<0.001				<0.001				<0.001
Tetraplegia	1				1				1			
Paraplegia	10.24	6.97	15.04		27.06	11.42	64.12		7.51	5.20	10.85	
Completeness of injury				<0.001				<0.001				0.229
Complete	1				1				1			
Incomplete	2.06	1.42	2.98		4.28	2.60	7.04		0.81	0.58	1.14	
Time since injury (per year)	1.01	0.99	1.02	0.237	1.02	1.00	1.04	0.018	1.01	0.99	1.02	0.238
Health conditions												
Spasticity				0.638				0.047				0.157
No problem	1				1				1			
Mild/moderate problem	0.92	0.63	1.35		0.72	0.45	1.17		0.82	0.55	1.21	
Severe problem	0.80	0.51	1.27		0.45	0.24	0.85		0.64	0.41	1.01	
Chronic pain				0.059				0.232				0.680
No problem	1				1				1			
Mild/moderate problem	1.03	0.69	1.54		1.24	0.73	2.08		0.93	0.62	1.40	
Severe problem	0.66	0.43	1.02		0.78	0.43	1.41		0.83	0.54	1.28	
Contractures				0.270				0.068				0.002
No problem	1				1				1			
Mild/moderate problem	0.75	0.53	1.08		0.57	0.34	0.96		0.53	0.37	0.76	
Severe problem	0.79	0.49	1.27		0.60	0.30	1.23		0.61	0.37	0.99	
Diabetes				0.005				0.077				<0.001
No	1				1				1			
Yes	0.39	0.20	0.76		0.31	0.85	1.13		0.32	0.17	0.61	
Heart disease				0.720				0.765				0.948
No	1				1				1			
Yes	0.90	0.52	1.58		0.89	0.40	1.95		1.02	0.55	1.91	

SCI – spinal cord injury; OR – odds ratio; CI – confidence interval; yrs – years; CHF – Swiss Francs.
[a]Model adjusted for all variables in the table and corrected for non-response-bias by using propensity scores.
[b]Age group 61+ (none of the participants aged 75+ was independent in transferring oneself (see Table 3), therefore the categories 61–75 and 76+ were merged).

related decline in health and functioning as well, and therefore might find it difficult to provide the additional support required.[31–33]

In line with our findings, it has been suggested by previous longitudinal[16,18,34] and cross-sectional studies[13,14,17] that physical independence and mobility of people with SCI decrease with age, that there is an increasing need of assistive devices with age, and that changes seem to occur at an earlier age than would be expected in non-disabled individuals. However, different methodologies make it difficult to compare studies directly. A retrospective study[14] with a convenience sample of rehabilitation center outpatients found 24% of participants reported a decline in general physical function or ability to perform activities of daily life over the preceding 5 years, with those reporting a decline being significantly older than their counterparts without a decline. Participants began experiencing declines at a mean age of about 40 years. Another retrospective study[13] of individuals with long-term SCI—identified through record screening in two SCI treatment centers—found a subgroup of 22% of respondents reporting that they needed more physical assistance as they aged with their SCI. Among a set of various self-care and mobility activities, transfers were the greatest concern for this subgroup. A majority (71%) of the subgroup made durable medical equipment changes in response to their physical status changes. The mean age when additional assistance was first needed was about 50 years. Findings presented by Amsters *et al.*[17] offer some insight into the long-term course of functional independence after the injury. They asked their participants—a sample of individuals with a mean age of 52 who had sustained their SCI more than 20 years previously—to retrospectively rate their functional independence at three points in time: post discharge from initial rehabilitation, about 10 years post SCI, and currently. While mobility independence improved between discharge and midpoint in 25% and declined in only 2%, it improved in only 2% and declined in 27% of participants between midpoint and current point. These findings suggest that the period of initial functional restoration in primary rehabilitation is usually followed by a period of maintenance or further improvement before the onset of functional decline, supporting Menter's[35] theoretical 3-phase model of functional change after SCI.

Sex differences in functional deficits in terms of a higher prevalence of mobility limitation in women have been documented in the general population[32,33,36] which supports the present findings in the SCI population. Findings can probably partly be explained by basic physiological differences between the sexes, for example in muscle strength,[37] and their association with functioning.[38] Furthermore, authors frequently hypothesize that higher prevalence of mobility limitation in females found in cross-sectional studies can partly be attributed to longer survival with disability in females.[39] While there are a few studies that investigated sex differences in functional recovery within the first year after SCI (so far with inconclusive results[12,40–42]), reports that focus on sex differences in functional independence in community-living people with SCI are scarce. In a survey of a population-based sample of men and women with SCI, Shackelford *et al.*[43] compared hours participants spent out of bed and number of days participants left their house, both as possible indicators of independence. The authors found no difference between sexes in average time spent out of bed per day, but the average number of days per week on which persons left their house was lower in women compared to men (3 versus 4 days). While similar rates of men and women reported limitations in joint range of motion, a higher rate of women reported that these limitations interfered with their activities of daily living. In a cross-sectional study conducted by Weitzenkamp *et al.*[44] sex did not predict daily hours of personal care assistance.

Possible factors behind age-related decline of mobility independence are manifold, including health conditions (e.g. coronary heart disease, diabetes, osteoarthritis, pain, general fatigue) and impairments of muscle strength, endurance capacity or balance.[45–48] The rate of secondary health conditions has been shown to increase with age in the SCI population,[18,49] and we were able to adjust our regression models for some of them. Muscle strength declines with age[50] and it has been demonstrated that muscle strength is related to mobility independence, both in the general population[51] and in people with SCI.[52] More complex motor abilities such as those involved in handling and moving around in a wheelchair (e.g. transferring, crossing a doorstep, negotiating curbs or ascending slopes) are also affected by age.[53–55] Individual reasons for functional decline reported by people with SCI included weight gain, pain and stiffness, musculoskeletal injuries, muscle weakness and fatigue.[13,14] Unfortunately, information on body composition (e.g. body mass index or waist circumference) was not available in our study, thus we were not able to adjust our models for one of these parameters. Overweight would presumably also explain part of the association between diabetes and mobility independence detected in our study.

Even though not reaching statistical significance, it seems that the odds of being independent might increase with education and income in all mobility domains. This would be in line with previous reports on the association between socioeconomic factors and functional limitations.[7,23–26]

The present study refers to spinal cord injured wheelchair users. It has to be acknowledged however, that there is currently no consensus about the definition of a wheelchair user in scientific studies. The WHO defines a wheelchair user as 'a person who has difficulty in walking or moving around and uses a wheelchair for mobility'.[56] Authors of scientific articles often ambiguously specify this definition by describing a wheelchair user as a person who uses a wheelchair 'as primary means' of mobility.[57,58] Further specifications are based on defining a minimal period per day use, e.g. 'at least 4 hours each day',[59,60] or a specific location, e.g. 'necessitating wheelchair use for mobility outside the home'.[61] Recognizing that the 'International SCI Activity and Participation Basic Data Set'[62] includes the item 'mobility moderate distances (10 to 100 m)' which is consistent with the relevant SCIM item (whereas items on indoor mobility and mobility outdoors >100 m are not included), we chose to define wheelchair users as participants who stated to use a wheelchair at this item. This will facilitate future comparisons of our sample with samples of other studies.

Strengths and limitations

Some limitations result from the cross-sectional study design. Even though we statistically accounted for non-response, the association between age and mobility independence is presumably affected by a remaining degree of non-response bias in addition to the inevitable survival bias.[63] Bias would most likely be directed towards an overestimation of the proportion of people who are independent in mobility. Cohort effects are another limitation that concerns all cross-sectional and even longitudinal studies in SCI.[34] We adjusted for TSI, however cohort effects resulting from, e.g. changes in emergency medicine, survival, and rehabilitation throughout different inception eras, cannot be ruled out. There are also some limitations involved in the use of the SCIM. Unfortunately, SCIM items do not differentiate between the need of a device and the need of partial assistance. These two alternatives make a meaningful difference with respect to personal autonomy and the amount of necessary supervision, care and services, not only from the affected person's but also from the caregivers' and the service providers' point of view. When interpreting the presented prevalence of mobility independence, it has to be kept in mind, that our definition of 'independence' is very rigorous and that 'no independence' ranges between needing a simple device and being completely dependent on personal assistance. To obtain a better understanding of age-related changes in functional independence, assessment instruments are needed that capture different levels of (partial) independence and quantify the degree of personal assistance needed. Furthermore, SCIM items of the three mobility domains are very heterogeneous in the way that questions and answers are constructed; e.g. 'transferring oneself' is covered by four, 'changing basic body position' by a single question. As a consequence, the strengths of the detected associations are not directly comparable between the three domains. Despite these limitations, this study is the first to deliver reliable data on the prevalence of mobility independence of persons with SCI in Switzerland by analyzing a large nation-wide sample. Presented data will serve as a reference base for future studies using the SCIM-SR to assess mobility independence.

Conclusions

A systematic decrease in independence for performing mobility tasks when progressing from 16- to 30-year-old up to 76+ year-old wheelchair users with SCI was observed. Age was found to be one of the main predictors of mobility independence. However, longitudinal studies are necessary to confirm these findings and to answer the remaining questions on underlying causes and mechanisms of functional changes over time and on how best to prevent or delay their onset and progression.

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Disclaimer statements

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Ethics approval SwiSCI was approved by the ethics committee of the Canton of Lucerne (the location of the main study center) and subsequently endorsed by the ethics committees of the Cantons Zürich, Basel-Stadt and Valais.

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