Original Report

PHYSICAL HEALTH CONDITIONS IN PERSONS WITH SPINAL CORD INJURY ACROSS 21 COUNTRIES WORLDWIDE

Vegard STRØM, PHD[1], Grethe MÅNUM, PHD[1,2], Mohit ARORA, PHD[3,4], Conran JOSEPH, PHD[5], Athanasios KYRIAKIDES, PHD[6], Marc le FORT, PHD[7], Rutger OSTERTHUN, PHD[8,9], Brigitte PERROUIN-VERBE, PHD[10], Karin POSTMA, PhD[9,10] and James MIDDLETON, PHD[3,4]

From the [1]Department of Research, Sunnaas Rehabilitation Hospital, Nesoddtangen, [2]Institute of Clinical Medicine, Faculty of Medicine, University of Oslo, Oslo, Norway, [3]John Walsh Centre for Rehabilitation Research, Kolling Institute of Medical Research, Royal North Shore Hospital, [4]Sydney Medical School – Northern, Faculty of Medicine and Health, The University of Sydney, Australia, [5]Faculty of Medicine and Health Science, Department of Health and Rehabilitation Sciences, Physiotherapy Division, Stellenbosch University, Cape Town, South Africa, [6]Spinal Cord Injuries Rehabilitation Department, Medical University of Patras, Patras, Greece, [7]Nantes Université, Centre Hospitalier Universitaire de Nantes, Service universitaire de Médecine Physique et de Réadaptation neurologique, F-44000 Nantes, France, [8]Rijndam Rehabilitation Center, Rotterdam, The Netherlands, [9]Department of Rehabilitation Medicine, Erasmus Medical Center, University Medical Center Rotterdam, The Netherlands, [10]Université de Médecine Physique et Réadaptation, France Nantes, Université de Nantes-Service Universitaire de Médecine Physiqueet Réadaptation Neurologique; l'Institut national de la santé et de la recherche médicale (INSERM) 1235,"the enteric nervous system in gut and brain disorders", F-44000, France

Objectives: **To describe the 3-month prevalence and correlates of self-reported physical health conditions in persons with spinal cord injury (SCI) worldwide.**

Study design: **Multinational cross-sectional survey.**

Subjects: **Community-living persons with traumatic or non-traumatic SCI aged >18 years from 21 countries representing all the 6 World Health Organization regions.**

Methods: **The study used data from 11,058 participants in the International SCI Community Survey (InSCI). The survey, based on the International Classification of Functioning, Disability and Health (ICF) Core Sets for SCI, was conducted in 2017–19 simultaneously in the participating countries. The health conditions were reported on a modified version of the SCI Secondary Conditions Scale.**

Results: **Overall, 95.8% of the participants reported having experienced 1 or more health problems secondary to SCI. Having pain was the most prevalent problem (77.3%), followed by spasticity/muscle spasms (73.5%) and sexual dysfunction (71.3%), and the least prevlent was respiratory problems (28.8%). The participants reported a mean of 7.4 concurrent health conditions. Unmet healthcare needs, being a smoker, being a female, having a complete lesion, and a traumatic injury exhibited significant associations with comorbidity.**

Conclusion: **Physical health problems secondary to SCI are extremely common worldwide and demand investment in appropriate management, medical care and preventative measures.**

Key words: spinal cord injury; health conditions; comorbidity; prevalence.

Accepted: 6 May 2022; Epub ahead of print: 6 June, 2022

J Rehabil Med 2022; 54: jrm00302

DOI: 10.2340/jrm.v54.2040

LAY ABSTRACT

More than 500,000 people experience a spinal cord injury (SCI) every year. Because of the impairments of having SCI, many experience co-occurrence of additional health conditions, called comorbidity. This study describes the 3-month prevalence, and associated factors of self-reported physical health conditions secondary to SCI across 21 countries worldwide. The study uses data from 11,058 adults with SCI participating in the International SCI Community Survey in 2017–19. The results showed that physical health problems secondary to SCI are extremely common worldwide. Having pain, muscle spasms/spasticity, sexual dysfunction and bowel dysfunction were the most common, all with rates above 70%. The participants experienced a mean of 7 concurrent health conditions in addition to their SCI. Those reporting unmet healthcare needs, being a smoker, female, and having a complete lesion were most at risk for having comorbidity. These findings demand investment in appropriate management, medical care and preventative measures.

Correspondence address: Vegard Strøm, Sunnaas Rehabilitation Hospital, 1450 Nesoddtangen, Norway. E-mail: vegard.strom@sunnaas.no

Global incidence data suggest that more than 500,000 people experience a spinal cord injury (SCI) every year (1). Following SCI, people are at risk of a number of health conditions (2), either as a direct or indirect result of the impairments and activity limitations of having a SCI (3). These conditions, often referred to as secondary health conditions (SHCs) can substantially affect functioning, independence, emotional well-being and quality of life, as well as be a major cause of morbidity and mortality

(4). Over recent decades, there has been a major shift in principal causes of death for people with SCI in high-income countries, from secondary conditions of SCI, such as urosepsis or renal failure, to causes of death similar to the general population, such as respiratory problems, especially pneumonia and influenza (4). In contrast, in low-income countries, people with SCI continue to die prematurely from preventable secondary complications resulting from SCI, often due to the absence of adequate medical care and equipment (4, 5).

A range of SHCs have been reported in persons with SCI, such as cardiovascular and respiratory problems (including autonomic dysreflexia and postural hypotension), bladder and bowel disorders, sexual dysfunction, pressure injuries, spasticity, contractures, osteoporosis, sleep disorders and chronic pain (2, 4, 6, 7). The most prevalent SHCs in SCI are reported to be chronic pain, spasticity, sexual dysfunction, bowel and bladder problems, urinary tract infections, osteoporosis, and pressure ulcers (2, 6, 7). Furthermore, SHCs seem to occur with higher frequency in older individuals or those with longer duration of SCI, relative to younger individuals or those with shorter post-injury duration (2). SHCs are also found to be higher among women and in individuals with complete tetraplegia (8), as well as in individuals with lower income status (9). SHCs commonly occur in the initial years post-discharge following SCI, after which their course seems to be relatively stable (6, 10).

Co-occurrence of additional health conditions to the index condition (SCI), that is comorbidity (11), is common and more pronounced with increasing age at injury (7, 12). Comorbidity is found also to be significantly associated with lack of access to appropriate healthcare, poorer health status, and lower quality of life (13). In a previous study, however, there was wide variability in the proportions of individuals who reported receiving treatment (7), which may be attributed to reduced accessibility and poor healthcare seeking behaviour compounded by low levels of health literacy and self-efficacy, especially in low- and middle-income countries (4). Identifying the conditions that are the most common and important to people with SCI is essential in order to select those that should be the primary targets of treatment for enhancing community participation and quality of life (4). To our knowledge, there have been no comparative studies across the World Health Organization (WHO) regions estimating the distribution of health conditions secondary to SCI. The aim of the current study was to describe the 3-month prevalence, severity and correlates of self-reported physical health conditions secondary to SCI across 21 countries representing all 6 WHO regions.

METHODS

Study design and setting

The International SCI Community Survey (InSCI) is a cross-sectional study comprising data from 22 countries worldwide representing all the 6 WHO regions (14). The participating countries per WHO region were: *Africa* (South Africa); *Americas* (Brazil and USA); *Eastern Mediterranean* (Morocco); *Europe* (France, Germany, Greece, Italy, Lithuania, the Netherlands, Norway, Poland, Romania, Spain, and Switzerland); *South East Asia* (Indonesia and Thailand); *Western Pacific* (Australia, China, Japan, Malaysia, and South Korea). The InSCI study allowed for using either random or convenience sampling frames, based on local conditions (15). Random sampling based on predefined sampling frames was applied in 7 of the included countries with access to hospital or patient organization databases. Fourteen of the countries applied convenience sampling (i.e. asking eligible visitors to healthcare facilities or patient organization events to participate in the study) (14). A power analysis indicated a minimal target sample size of 200 participants per country to provide sufficient power for comparative analysis of outcomes across countries (15). Ethical approval was obtained from ethics committees in the respective study countries, and informed consent sought from each participant in accordance with national regulations. InSCI was conducted simultaneously in the participating countries between 2017 and 2019 and its item selection is based on the International Classification of Functioning, Disability and Health (ICF) Core Sets for SCI (14, 15).

Participants

Eligible for the study were individuals with traumatic or non-traumatic SCI (including cauda equina syndrome) who were aged 18 years or older, living in the community, being able to respond in 1 of the available language versions of the questionnaire, provided informed consent, and were residents in 1 of the participating countries. Those with congenital aetiologies (e.g. spina bifida), neurodegenerative disorders (e.g. multiple sclerosis, amyotrophic lateral sclerosis), or peripheral nerve damage (e.g. Guillain-Barré syndrome) were excluded (15). The total InSCI-sample comprises 12,591 participants from 22 countries. The current study, however, included data from only 11,058 participants, as 1 country (Switzerland) used different response options from the other countries for the health conditions outcome (see below).

Measures

The InSCI survey comprised a 125-item self-report questionnaire covering components of body function and structures, activities and participation, environmental and personal factors, lesion characteristics, and appraisal of health and well-being. The InSCI questionnaire was translated into national languages, in which the requisite cross-cultural adaptation process was based on the guidelines proposed by Epstein et al. (16). The current study used data on body function, namely health conditions, and demographic and lesion characteristics. A comprehensive description of the components of the questionnaire and the InSCI data model have been presented previously (15, 17).

Physical health conditions

The occurrence of self-reported health conditions following SCI was assessed using a modified version of the Spinal Cord Injury Secondary Conditions Scale III (SCI-SCS). The SCI-SCS was originally developed by Kalpakjian et al. (18) for the self-report of the prevalence and severity of secondary conditions in persons with SCI. The health conditions covered in the current study include: autonomic dysreflexia (e.g. sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache), bladder dysfunction (e.g. incontinence ("accidents"), bladder or kidney stones, kidney problems, urine leakage and vesicoureteral reflux), bowel dysfunction (e.g. diarrhoea, stool incontinence ("accidents") and constipation), circulatory problems (involves swelling of veins, feet, legs or hands, or the occurrence of blood clots), contractures (a limitation in the range of motion of a joint), injury caused by loss of sensation (e.g. burns from carrying hot liquids in the lap or sitting too close to a heater or fire), muscle spasm/spasticity (refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitches or spasms), pain (having pain in the day-to-day life), postural hypotension (involves a strong sensation of light-headedness following a change in position, which might be caused by a sudden drop in blood pressure), pressure sores/decubitus (develop as a skin rash or redness and may progress to an infected sore), respiratory problems (symptoms of respiratory infections or problems include difficulty in breathing and increased secretions), sexual dysfunction (e.g. difficulty with sexual arousal, erection, lubrication, and reaching orgasm), sleep problems (e.g. problems falling asleep or sleeping through the night and waking up early), and urinary tract infections (e.g. kidney or bladder infection). In the SCI-SCS the items are scored on an ordinal scale from 0 to 3, with the following definitions: 0 = Not experienced in the last 3 months or insignificant problem, 1 = Mild or infrequent problem, 2 = Moderate or occasional problem, and 3 = Significant or chronic problem. However, these response options were identified as problematic for the InSCI-study, in that both severity and frequency are rated under a single option. To address this, a 5-point scale utilized by the Model Disability Survey (19) was chosen. For each of the health conditions, participants were asked to rate on a 5-point numerical rating scale (NRS) ranging from 1 (no problem) to 5 (extreme problem) how much of a problem it was in the last 3 months. If the participants had experienced the health problem, they were asked to indicate whether they receive/had received treatment or not for the respective health condition (e.g. taking a medication or getting treatment by doctors or other health professionals). The question on "do/did you receive treatment for it?" (yes/no) was derived from the Self-Administered Comorbidity Questionnaire (SCQ) (20). This question may provide important information on the quality of a healthcare system. Since Switzerland used the original SCI-SCS response options (in order to align responses with their previous SwiSCI-study (21)), these participants were excluded from the current analyses.

Healthcare services

Healthcare seeking behaviour were surveyed by asking how many times over the last 12 months the participant had been a patient in a hospital or other care facility for at least 1 night, and by a general question about accessibility, asking if the participant in the last 12 months had needed healthcare but did not receive it (yes/no). If answering yes on the latter, the participant was asked to give the reason(s) for not getting the needed healthcare, with the following response options: Could not afford the cost of the visit; There was no service; No transport available; Could not afford the cost of transportation; Previously badly treated; Could not take time off work or had other commitments; The healthcare provider's drugs or equipment were inadequate; The healthcare provider's skills were inadequate; Did not know where to go; Tried but were denied healthcare; Thought I were not sick enough; and Other reason(s).

Socio-demographic and SCI-related variables

The socio-demographic variables included participant's age (years), sex (male/female), country of residence, WHO region (Africa, America, Eastern Mediterranean, Europe/South East Asia, Western Pacific), marital status (married, single, cohabiting or in partnership, separated or divorced, widowed), highest level of education (number of years, and primary school, lower secondary, higher secondary, post-secondary, short tertiary, bachelor or equivalent, master or equivalent, other), household (living alone, living together with others, living in an institution), getting assistance in day-to-day life (yes/no), and smoking status (never smoked, former smoker, current

or occasional smoker). The SCI variables (self-reported) included the level of SCI (paraplegia/tetraplegia), the severity of SCI (complete/incomplete), the aetiology of SCI (traumatic/non-traumatic), and the time since SCI (years; calculated from the reported date of onset of SCI).

Statistical analyses

Statistical analyses were conducted using SPSS v26.0 (IBM Corp. Armonk, New York, United States). The level of statistical significance was set at $p = 0.05$. Descriptive statistics (mean and standard deviation (SD) or median and quartiles), and frequency distributions (n and percentage) are used to describe the study population, e.g. demographics and SCI characteristics, and the outcomes. The 3-month prevalence measures are presented as proportions with 95% confidence intervals (95% CI). Differences in prevalence of self-reported health problems across socio-demographic and SCI variables were evaluated using cross-tabulations with Pearson χ^2 tests, and with Bonferroni-corrections when performing pairwise multiple comparisons of proportions. Prevalence of health conditions were based on the reporting on the 5-point NRS from 1 (no problem) to 5 (extreme problem). For the purpose, the NRS was recoded into 0 (no problem) to 4 (extreme problem), and further dichotomized into 0; having no problem (i.e. the lowest level of the NRS), and 1; having a health problem, classified as the upper 4 levels of the NRS. The severity of the self-reported health conditions was described based on the 0–4 NRS in which a summary score of the 14 conditions was calculated, ranging from 0 to 56, where a higher score indicates more severe problems. Having a substantial health problem was defined as rating the problem as an extreme problem (i.e. the highest level of the NRS; 4). Comorbidity was evaluated using the dichotomized scores added up for the number of health conditions to give a summary score ranging from 0 (no comorbidity) to 14 co-occurring conditions. To examine the association of the physical health conditions with comorbid SCI, unadjusted and adjusted binary logistic regression using generalized linear mixed models were performed. Models were run with random intercept for country to account for the clustering of data within countries due to the different sampling strategies adopted (14) (i.e. random or convenience sampling), and fitted with variance component covariance matrix.

RESULTS

Participant characteristics

The current study sample comprises 8,075 (73.2%) men and 2,951 (26.8%) women from 21 countries, representing all the 6 WHO regions. Participant characteristics are presented in Table I. In all countries, the majority of participants were men, ranging from 58.1% in the USA to 84.1% in Japan. Overall, the mean age of the participants at the time of the survey was 50.5 (SD 15.2) years, and at the age at injury 38.0 (17.0) years. Almost 81% of the participants reported having a traumatic SCI, with 61.7% of the sample having paraplegia. For a more comprehensive description of the study participants, see Table I and reference (14).

Prevalence of health conditions

Overall, 95.8% (95% CI 95.4–96.2) of the participants reported having experienced 1 or more health problems secondary to their SCI during the last 3 months. Experiencing pain in day-to-day life was the most prevalent self-reported health condition (prevalence rate 77.3%, 95% CI 76.5–78.1), followed by muscle spasms/spasticity (73.5%, 95% CI 72.7, 74.4), sexual dysfunction (71.3%, 95% CI 70.5–72.2) and bowel dysfunction (70.8%, 95% CI 69.9–71.6). The least prevalent self-reported health conditions were injury caused by loss of sensation (29.6%, 95% CI 28.8–30.5) and respiratory problems (28.8%, 95% CI 28.0–29.7) (Fig. 1).

The women had significantly higher prevalence than the men for several of the self-reported health conditions, particularly for bladder dysfunction ($p = 0.001$), circulatory problems ($p < 0.001$), pain ($p < 0.001$) and sleep problems ($p = 0.023$), while muscle spasms ($p < 0.001$), sexual dysfunction ($p < 0.001$) and pressure injuries ($p < 0.001$) were more prevalent among the men than the women (Table II). The participants with tetraplegia had more health problems than those with paraplegia, except for pain and urinary tract infections. Similarly, the presence of a complete lesion was associated with higher rates of health problems for all conditions ($p < 0.05$), apart from contractures ($p = 0.16$) and pain ($p = 0.64$), while sleep problems was more prevalent among those with incomplete lesions ($p = 0.049$). Furthermore, those with a traumatic SCI reported higher prevalence than those with non-traumatic SCI on all reported health conditions (Table II).

The prevalence of the health conditions varied both across the countries and across the WHO regions. Fig. 2 depicts the variation across countries for the health conditions pain, muscle spasms/spasticity, sexual dysfunction and bowel dysfunction, all with an overall prevalence rate above 70%. For pain, the prevalence varied from 58.0% in China to 89.7% in South Korea, and was the most prevalent condition in 10 of the 21 participating countries (Australia, Brazil, China, France, Indonesia, Morocco, Netherlands, Norway, South-Korea and Spain). The prevalence of muscle spasm/spasticity varied from 43.8% in Indonesia to

Table I. Characteristics of the study participants (n = 11 058) from 21 countries in the International Spinal Cord Injury (InSCI) community

	Sex n (%)			Age (years)	Age at SCI (years)	Time since SCI (years)	Lesion characteristics n (%)				SCI etiology n (%)		Marital status n (%)					Houshold situation n (%)			Education (years completed)	Smoking status n (%)	
							Tetraplegia (4 124 (38.3))		Paraplegia (6 649 (61.7))														
	n (%)	Female	Male	Mean (SD)	Mean (SD)	Median (Q1-Q3)	Complete SCI	Incomplete SCI	Complete SCI	Incomplete SCI	Traumatic	Non-traumatic	Single	Married	Widowed	Separated/ divorced	Cohabiting/ partnership	Living alone	Living together	Living in institution	Mean (SD)	Never smoked	Former or current smoker
Total	**11 058 (100)**	**2 951 (26.8)**	**8 075 (73.2)**	**50.5 (15.2)**	**38.0 (17.0)**	**9 (4-17)**	**1 111 (10.4)**	**2 986 (27.9)**	**3 011 (28,1)**	**3 593 (33.6)**	**8 834 (80.9)**	**2 085 (19.1)**	**3 115 (28.4)**	**5 665 (51.6)**	**396 (3.6)**	**975 (8.9)**	**821 (7.5)**	**1 870 (17.2)**	**8 665 (79.5)**	**361 (3.3)**	**11.9 (5.0)**	**5 171 (47,5)**	**5 707 (52,5)**
Countries				*Median (Q1–Q3)*	*Medan (Q1–Q3)*																*Median (Q1-Q3)*		
Australia	1 579 (14.3)	422 (26.7)	1 157 (73.3)	59 (48–68)	38 (24–55)	13 (6–25)	128 (8.6)	449 (30.3)	362 (24.4)	542 (36.6)	1 305 (83.5)	258 (16.5)	386 (24.5)	791 (50.3)	62 (3.9)	195 (12.4)	140 (8.9)	361 (22.9)	1 153 (73.5)	55 (3.5)	12 (8.1–16)	777 (50.0)	777 (50.0)
Brazil	201 (1.8)	42 (20.9)	159 (79.1)	43 (30–57)	40 (26.3–53)	2 (1–3)	15 (7.5)	66 (32.8)	27 (13.4)	93 (46.3)	141 (70.1)	60 (29.9)	78 (38.8)	92 (45.8)	14 (7.0)	6 (3.0)	11 (5.5)	13 (6.5)	186 (93.5)	0 (0)	11 (8–14.5)	111 (55.2)	90 (44.8)
China	1 354 (12.2)	391 (28.9)	963 (71.1)	50 (41–59)	46 (36–54)	4 (2–5)	68 (5.0)	389 (28.1)	277 (20.5)	629 (46.5)	899 (67.2)	438 (32.8)	130 (9.6)	1138 (84.0)	26 (1.9)	45 (3.3)	15 (1.1)	72 (5.3)	1 245 (92.3)	32 (2.4)	9 (6–12)	709 (52.4)	645 (47.6)
France	412 (3.7)	112 (27.2)	300 (72.8)	53 (41–62)	28 (20–44)	16 (6–26)	37 (9.2)	98 (24.4)	135 (33.6)	132 (32.8)	332 (81.2)	77 (18.8)	110 (26.9)	191 (46.7)	15 (4.2)	51 (12.5)	40 (9.8)	127 (31.6)	269 (66.9)	6 (1.5)	14 (11–17)	143 (35.5)	260 (64.5)
Germany	1 617 (14.6)	447 (28.0)	1 150 (72.0)	56 (46–65)	42 (25–56)	9 (4–17)	159 (10.5)	586 (38.7)	357 (23.5)	414 (27.3)	1 234 (79.1)	327 (20.9)	339 (21.6)	819 (52.1)	88 (5.6)	163 (10.4)	162 (10.3)	348 (22.6)	1 139 (73.9)	54 (3.5)	13 (12–16)	1 009 (63.9)	570 (36.1)
Greece	200 (1.8)	54 (27.0)	146 (73.0)	46.5 (38–56)	28 (20–40.3)	13 (6–22)	18 (9.1)	45 (22.8)	73 (37.1)	61 (31.0)	170 (85.9)	28 (14.1)	89 (44.7)	71 (35.7)	4 (2.0)	13 (6.5)	22 (11.1)	44 (22.1)	154 (77.4)	1 (0.5)	12 (12–16)	74 (37.8)	122 (62.2)
Indonesia	201 (1.8)	66 (32.8)	135 (67.2)	44 (35–52)	31 (22–41)	12 (3–12)	8 (4.1)	12 (6.2)	74 (37.9)	101 (51.8)	173 (87.8)	24 (12.2)	55 (27.6)	126 (63.3)	0 (0)	6 (3.0)	12 (6.0)	10 (5.1)	156 (78.8)	32 (16.2)	9 (6–12)	93 (47.7)	102 (52.3)
Italy	206 (1.9)	53 (25.7)	153 (74.3)	51 (40–60)	36 (25–51)	10 (5–17)	15 (7.5)	37 (18.5)	61 (30.5)	87 (43.5)	141 (69.8)	61 (30.2)	68 (33.0)	84 (48.8)	8 (3.9)	25 (12.1)	21 (10.2)	35 (17.1)	166 (81.0)	4 (2.0)	13 (8–13)	91 (46.0)	107 (54.0)
Japan	302 (2.7)	47 (15.9)	248 (84.1)	55 (44–67)	31 (21.3–49)	16 (8–30)	80 (27.3)	68 (23.2)	105 (35.8)	40 (13.7)	268 (89.9)	30 (10.1)	91 (30.7)	171 (57.8)	9 (3.0)	17 (5.7)	8 (2.7)	47 (15.7)	248 (82.7)	5 (1.7)	12 (12–14)	99 (32.9)	202 (67.1)
Lithuania	218 (2.0)	81 (37.2)	137 (62.8)	42 (35–49)	25 (20–33)	16 (7–22)	52 (24.0)	13 (6.0)	110 (50.7)	42 (19.4)	202 (93.5)	14 (6.5)	59 (27.1)	84 (38.5)	6 (2.8)	21 (9.6)	48 (22.0)	27 (12.4)	190 (87.6)	0 (0)	13 (12–16)	82 (38.0)	134 (62.0)
Malaysia	297 (2.7)	61 (20.5)	236 (79.5)	37.5 (29–50)	28 (20–40.3)	6 (3–13)	31 (10.8)	56 (19.6)	87 (30.4)	112 (39.2)	252 (85.4)	43 (14.6)	133 (44.8)	139 (46.8)	8 (2.7)	15 (5.1)	2 (0.7)	15 (5.2)	260 (90.0)	14 (4.8)	11 (7.8–13)	129 (44.9)	158 (55.1)
Morocco	385 (3.5)	106 (27.5)	279 (72.5)	37 (28–47)	28 (22–40)	4 (2–9)	35 (9.1)	65 (16.9)	137 (35.6)	148 (38.4)	298 (77.4)	87 (22.6)	189 (49.1)	163 (42.3)	8 (2.1)	23 (6.0)	2 (0.5)	17 (4.4)	365 (94.8)	3 (0.8)	9 (4–12)	248 (64.4)	137 (35.6)
Netherlands	260 (2.4)	87 (33.5)	173 (66.5)	59 (50.3–69)	45 (28–56.3)	10 (4–22)	22 (8.6)	76 (29.8)	50 (19.6)	107 (42.0)	159 (62.6)	95 (37.4)	48 (18.6)	149 (57.8)	12 (4.7)	19 (7.4)	30 (11.6)	59 (23.1)	191 (74.9)	5 (2.0)	14 (11–18)	94 (37.0)	160 (63.0)
Norway	609 (5.5)	192 (31.5)	417 (68.5)	60 (45–70)	51 (36–62)	8 (4–12)	34 (6.0)	205 (36.1)	71 (12.5)	258 (45.4)	420 (69.7)	183 (30.3)	103 (17.1)	297 (49.2)	38 (6.3)	70 (11.6)	96 (15.9)	174 (29.0)	418 (68.6)	15 (2.5)	13 (9–15)	263 (43.8)	337 (56.2)
Poland	971 (8.8)	164 (16.9)	807 (83.1)	45 (37–57)	29 (22–43)	11 (6–19)	110 (11.6)	332 (34.9)	322 (33.9)	187 (19.7)	861 (89.2)	104 (10.8)	328 (34.0)	426 (44.1)	32 (3.3)	98 (10.1)	82 (8.5)	119 (12.4)	806 (83.7)	38 (3.9)	12.8 (11–15)	293 (30.4)	671 (69.6)
Romania	216 (2.0)	60 (27.8)	156 (72.2)	37 (30–46)	28 (21–38)	5 (2–13)	8 (3.7)	58 (27.0)	62 (28.8)	87 (40.5)	180 (83.7)	35 (16.3)	108 (50.0)	78 (36.1)	5 (2.3)	14 (6.5)	11 (5.1)	23 (10.6)	192 (88.9)	1 (0.5)	12 (10–14)	86 (39.8)	130 (60.2)
South Africa	200 (1.8)	50 (25.0)	150 (75.0)	37 (28–48)	25 (20–33)	7 (4–16)	38 (19.5)	38 (19.5)	67 (34.4)	52 (26.7)	185 (92.5)	15 (7.5)	133 (66.8)	27 (13.6)	2 (1.0)	20 (10.1)	17 (8.5)	13 (6.5)	132 (66.0)	55 (27.5)	12 (9.2–13.8)	76 (38.2)	123 (61.8)
South Korea	890 (8.0)	214 (24.1)	673 (75.9)	49 (40–57)	31 (23–41)	15 (7–22)	157 (18.0)	191 (21.9)	348 (39.8)	178 (20.4)	815 (92.2)	69 (7.8)	327 (37.1)	426 (48.4)	26 (3.0)	96 (10.9)	6 (0.7)	249 (28.6)	613 (70.4)	9 (1.0)	12 (11–15)	355 (41.8)	494 (58.2)
Spain	417 (3.8)	125 (30.0)	291 (70.0)	51 (42–61)	31.5 (22–47)	14 (5–24)	54 (13.5)	93 (23.2)	129 (32.2)	125 (31.2)	320 (77.5)	93 (22.5)	119 (28.5)	195 (46.8)	14 (3.4)	42 (10.1)	47 (11.3)	65 (15.7)	341 (81.8)	8 (1.9)	12 (8–17)	149 (36.0)	265 (64.0)
Thailand	320 (2.9)	92 (28.8)	227 (71.2)	43 (33–58)	32 (23–50)	5 (2–12)	23 (7.3)	59 (18.8)	118 (37.6)	114 (36.3)	276 (86.3)	44 (13.8)	138 (43.1)	108 (33.8)	16 (5.0)	25 (7.8)	33 (10.3)	13 (4.1)	284 (88.8)	23 (7.2)	9 (4–14)	153 (48.7)	161 (51.3)
United States	203 (1.8)	85 (41.9)	118 (58.1)	42.5 (32–57)	26 (19–47.3)	10 (4–19)	19 (9.5)	59 (29.4)	39 (19.4)	84 (41.8)	203 (100)	0 (0)	84 (41.6)	90 (44.6)	1 (0.5)	11 (5.4)	16 (7.9)	39 (19.2)	163 (80.3)	1 (15)	16 (12–18)	137 (69.2)	61 (30.8)

Abbreviations: SCI; spinal cord injury, SD; Standard deviation, Q1; First quartile (= 25 percentile), Q3; Third quartile (= 75 percentile).

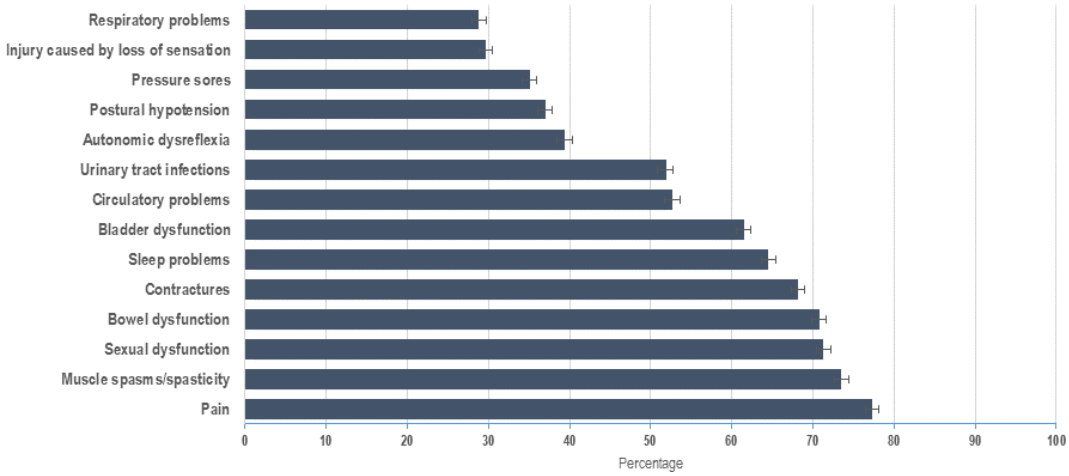

Fig. 1. Prevalence of health conditions. Three-month prevalence rates (percentage with 95% confidence intervals; 95% CI) of self-reported physical health conditions among 11,058 adults with spinal cord injury across 21 countries representing all the 6 World Health Organization regions participating in the International Spinal Cord Injury (InSCI) community survey.

88.2% in South Korea, and was the most common condition in 6 of the countries (Malaysia, Poland, Romania, South Africa, Thailand and the USA). Across the different WHO regions, pain exhibited the highest prevalence in Europe and significantly higher than in the Americas, South East Asia and Western Pacific ($p < 0.05$), while muscle spasms had the highest prevalence in the African region, and significantly higher than in South East Asia and Western Pacific regions ($p < 0.05$; Table SI). Participants from high-income countries based on gross national income (GNI) per capita, exhibited statistically significant ($p < 0.05$) higher prevalence rates than those in the upper-middle-income countries for all the self-reported health conditions (Table SII).

Severity and treatment of the health conditions

The mean sum-score on the 0–56 scale of the 14 conditions was 16.8 (SD 10.4). All countries exhibited mean sum-scores ranging between 10 and 20, except South Korea, which had a significantly higher mean score than all the other countries (26.1, SD 12.4, $p < 0.001$; Fig. 3). The severity of the health conditions, rated from no problem to extreme problem, showed that sexual dysfunction showed the highest self-reported level of severity, with 31.6% (95% CI 30.7–32.5%) rating this as an extreme health problem. This was followed by pain (17.0%, 95% CI 16.3–17.7%), bladder dysfunction (13.7%, 95% CI 13.0–14.4), muscle spasms/spasticity (13.5%, 95% CI 12.8–14.1) and contractures (13.4%, 95% CI 12.8–14.1). Postural hypotension (2.9%, 95% CI 2.6–3.2) and respiratory problems (2.5%, 95% CI 2.2–2.8) exhibited lowest rating on severity. Differences in the severity ratings of the health conditions and between countries are depicted in Fig. S1.

Of those rating sexual dysfunction as an extreme problem, only 16.2% reported that they received or had received treatment for it. However, this varied across the WHO regions, as participants from the Americas reported the highest treatment rate (27.4%), which was significantly higher than those in the Eastern Mediterranean region (8.4%, $p < 0.05$). In contrast, for pain, the majority (72.5%) of those rating this as an extreme problem received or had received treatment, which was similar across the WHO regions. Urinary tract infections was the health condition reported to have received the most treatment (88.4%; highest in Europe (91.4%) and lowest in Africa (50.0%).

Healthcare accessibility

Of the total current sample, 2,063 (19.3%) of the participants reported that they needed healthcare during the last 12 months, but did not get it. More women than men reported not receiving needed healthcare (20.9%, 95% CI 19.4–22.4 vs 18.7%, 95% CI 17.9–19.6), and more people in the Eastern Mediterranean and African countries reported issues with healthcare access than in the other WHO regions. The most commonly reported reason for not getting the healthcare required was that they could not afford the cost of the visit ($n = 727$), followed by no available transport ($n = 401$) and no available service ($n = 379$). The median number of times hospitalized for at least 1 night over the last 12 months was 0 (Q1–Q3; 0–1).

Comorbidity

The prevalence of comorbidity, involving co-occurrence of health conditions secondary to the SCI, was 93% (95% CI 92.6–93.5), highest in the age-group of 30–45 years (94.8%, 95% CI 94.0–95.6), and lowest among the 75 years+ group (89.4%, 95% CI 86.7–91.6).

Table II. Prevalence rates (%) of self-reported health problems stratified by demographic and SCI characteristics across participants (n = 11 058) from 21 countries in the International Spinal Cord Injury (InSCI) community survey.

	Sex						SCI level						SCI severity						SCI etiology					
	Female (*n* = 2 951)		Male (*n* = 8 075)		Missing (*n* = 32)		Paraplegia (*n* = 6 649)		Tetraplegia (*n* = 4 124)		Missing (*n* = 285)		Complete (*n* = 4 146)		Incomplete (*n* = 6 740)		Missing (*n* = 172)		Traumatic (*n* = 8 834)		Non-traumatic (*n* = 2 085)		Missing (*n* = 139)	
	%	95% CI	%	95% CI	n (%)	*P-value*[a]	%	95% CI	%	95% CI	n (%)	*p-value*[a]	%	95% CI	%	95% CI	n (%)	*p-value*[a]	%	95% CI	%	95% CI	n (%)	*p-value*
Autonomic dysreflexia	39.4	37.6–41.2	39.3	38.2–40.4	395 (3.6)	*.914*	33.7	32.6–34.9	48.8	47.3–50.4	602 (5.4)	***<.001***	47.1	45.6–48.7	34.6	33.5–35.8	493 (4.5)	***<.001***	41.6	40.5–42.6	29.8	27.8–31.8	465 (4.2)	***<.001***
Bladder dysfunction	64.0	62.3–65.8	60.5	59.5–61.6	407 (3.7)	***.001***	63.2	62.0–64.3	58.7	57.1–60.2	616 (5.6)	***<.001***	68.1	66.6–69.5	57.6	56.4–58.8	506 (4.6)	***<.001***	62.5	61.4–63.5	57.1	54.9–59.3	481 (4.3)	***<.001***
Bowel dysfunction	71.4	69.7–73.1	70.5	69.5–71.5	332 (3.0)	*.351*	69.8	68.7–70.9	72.4	71.0–73.8	545 (4.9)	***.004***	74.9	73.6–76.2	68.4	67.2–69.5	434 (3.9)	***<.001***	72.2	71.2–73.1	64.5	62.4–66.6	408 (3.7)	***<.001***
Circulatory problems	57.1	55.3–58.9	51.1	50.0–52.2	372 (3.4)	***<.001***	51.6	50.4–52.8	54.5	52.9–56.0	580 (5.2)	***.005***	58.4	56.8–59.9	49.3	48.1–50.5	469 (4.2)	***<.001***	54.0	52.9–55.0	46.6	44.5–48.8	446 (4.0)	***<.001***
Contractures	67.4	65.7–69.1	68.4	67.4–69.5	461 (4.2)	*.320*	64.2	63.0–65.4	74.0	72.7–75.4	669 (6.0)	***<.001***	67.4	65.9–68.8	68.7	67.6–69.8	558 (5.0)	*.161*	68.9	67.9–69.9	64.2	62.1–66.3	532 (4.8)	***<.001***
Injury caused by loss of sensation	29.1	27.4–30.8	29.8	28.8–30.8	421 (3.8)	*.479*	27.9	26.8–29.0	32.5	31.1–34.0	625 (5.7)	***<.001***	34.3	32.9–35.8	26.8	25.7–27.9	519 (4.7)	***<.001***	31.2	30.2–32.2	22.6	20.8–24.5	494 (4.5)	***<.001***
Muscle spasms	70.4	68.7–72.1	74.7	73.8–75.7	334 (3.0)	***<.001***	67.6	66.5–68.8	83.3	82.1–84.4	545 (4.9)	***<.001***	75.4	74.1–76.7	72.6	71.6–73.7	434 (3.9)	***.002***	75.6	74.6–76.5	64.9	62.8–66.9	409 (3.7)	***<.001***
Pain	80.8	79.3–82.2	76.0	75.1–77.0	343 (3.1)	***<.001***	76.7	75.6–77.7	78.2	76.9–79.4	551 (5.0)	*.073*	77.6	76.3–78.9	77.2	76.2–78.2	439 (4.0)	*.644*	78.2	77.4–79.1	73.3	71.3–75.2	414 (3.7)	***<.001***
Postural hypotension	38.4	36.6–40.2	36.4	35.3–37.5	431 (3.9)	*.059*	29.4	28.3–30.5	49.1	47.5–50.6	629 (5.7)	***<.001***	39.1	37.6–40.6	35.6	34.4–36.7	527 (4.8)	***<.001***	38.4	37.4–39.5	30.2	28.2–32.2	503 (4.5)	***<.001***
Pressure sores	29.5	27.8–31.1	37.1	36.1–38.2	374 (3.4)	***<.001***	36.1	34.9–37.3	34.1	32.6–35.8	583 (5.3)	***.035***	49.3	47.8–50.9	26.6	25.5–27.7	473 (4.3)	***<.001***	37.5	36.5–38.5	25.1	23.3–27.1	448 (4.1)	***<.001***
Respiratory problems	28.1	26.4–29.7	29.1	28.1–30.1	383 (3.5)	*.305*	24.3	23.3–25.4	36.2	34.7–37.7	588 (5.3)	***<.001***	31.0	29.6–32.5	27.5	26.5–28.6	480 (4.3)	***<.001***	29.6	28.7–30.6	25.3	23.5–27.3	456 (4.1)	***<.001***
Sexual dysfunction	55.7	53.8–57.6	76.7	75.7–77.6	761 (6.9)	***<.001***	72.1	71.0–73.2	70.1	68.6–71.5	955 (8.6)	***.031***	78.7	77.3–79.9	67.0	65.8–68.1	859 (7.8)	***<.001***	73.9	73.0–74.9	60.1	57.9–62.2	832 (7.5)	***<.001***
Sleep problems	66.2	64.5–68.0	63.9	62.8–64.9	300 (2.7)	***.023***	62.6	61.4–63.7	67.6	66.1–69.0	515 (4.7)	***<.001***	63.4	61.9–64.8	65.2	64.1–66.4	400 (3.6)	***.049***	65.4	64.4–66.4	60.5	58.4–62.6	377 (3.4)	***<.001***
Urinary tract infections	51.9	50.0–53.7	51.8	50.7–53.0	408 (3.7)	*.999*	52.5	51.3–53.7	51.3	49.8–52.9	611 (5.5)	*.249*	62.5	61.0–64.0	45.5	44.3–46.7	507 (4.6)	***<.001***	53.5	52.4–54.5	45.0	42.8–47.2	481 (4.3)	***<.001***

[a]Pearson Chi-Square test

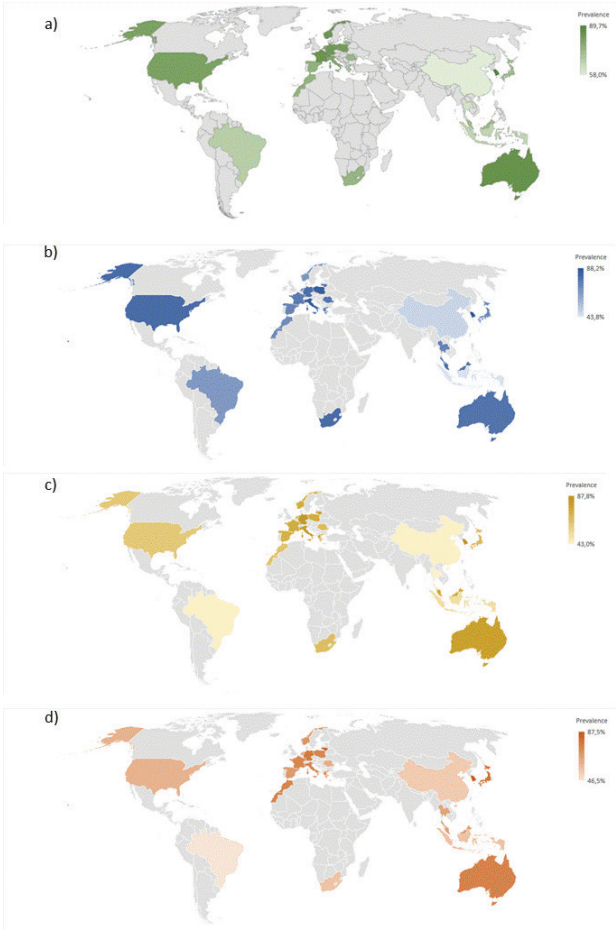

Fig. 2. Prevalence of the health conditions per country. Three-month prevalence rates (percentage) of the health conditions (a) pain, (b) muscle spasms/spasticity, (c) sexual dysfunction and (d) bowel dysfunction for the 21 countries of the International Spinal Cord Injury (InSCI) community survey (n = 11,058). *Darker colour* indicates higher prevalence.

The prevalence of comorbidity varied also across the WHO regions, from 97.4% in Eastern Mediterranean to 88.9% in South East Asia.

The participants reported a mean of 7.4 (SD 3.6) concurrent health conditions, although this varied considerably between countries. South Korea was the country with the highest mean number of co-occurring health conditions (10.1, 95% CI 9.9–10.3), while Brazil had the lowest (4.5, 95% CI 4.1–4.8), as shown in Fig. S2. Overall, men had more comorbidity than women (7.4 (3.6) vs 7.2 (3.6), p = 0.002), participants with tetraplegia more than those with paraplegia (7.8 (3.6) vs 7.1 (3.5), $p < 0.001$), those individuals with a complete lesion more than those with an incomplete lesion (8.0 (3.5) vs 7.1 (3.6), $p < 0.001$), and those with a traumatic injury had more comorbidity than those with a non-traumatic injury (7.6 (3.5) vs 6.5 (3.8), $p < 0.001$).

Adjusted estimates of the mixed model binary logistic regression analysis revealed that unmet healthcare needs (i.e. reporting not receiving needed healthcare), being a current or former smoker, being female, having a complete lesion and a traumatic cause exhibited statistically significant associations with comorbidity (Table III). In addition, age and SCI duration exhibited statistically significant negative associations with comorbidity. Marital status, household situation, education and type of SCI did not reach statistical significance for associations with comorbidity (Table III).

DISCUSSION

The current multi-national, comparative, cross-sectional study aimed to describe the prevalence, severity and correlates of self-reported health conditions among community-living persons with SCI across 21 countries worldwide representing all 6 WHO regions. The results showed high worldwide prevalence rates of health conditions, in which pain, muscle spasms/spasticity, sexual dysfunction and bowel dysfunction were most prevalent, with rates all above 70%. There were, however, significant differences across countries, between sexes and between the severity (complete vs incomplete) and the aetiology (traumatic vs non-traumatic) of SCI. Furthermore, sexual dysfunction exhibited the highest self-reported level of severity, but with the lowest treatment rate. Unmet healthcare needs, smoking status, sex, age, and SCI duration, severity and aetiology demonstrated statistically significant associations with comorbidity.

Prevalence of self-reported health conditions

The high prevalence rates of health conditions secondary to SCI found in the current study are consistent with previous findings from numerous national and single site studies during the last decades (3, 6, 8, 21–27). The prevalence rates, however, differed in this inquiry, across both countries and WHO regions. Interestingly, those in the high-income countries exhibited substantially higher prevalence rates on all, or most, of the reported health conditions than those in the upper-middle-income or lower-middle-income countries, respectively. For example, pain, which was the most prevalent condition in 10 of the 21 participating countries, exhibited rates varying from 58% in China to almost 90% in South Korea (Fig. 2). Few studies have, to our prior knowledge, reported prevalence rates of secondary health conditions in low- and middle-income countries. Some recent studies of people living with SCI in low- and middle-income countries reported lower prevalence rates of secondary health conditions (28, 29). Furthermore, a recent systematic review concluded that inequality in income in more developed countries lead to significantly higher odds of secondary outcomes (9). The heterogeneity in

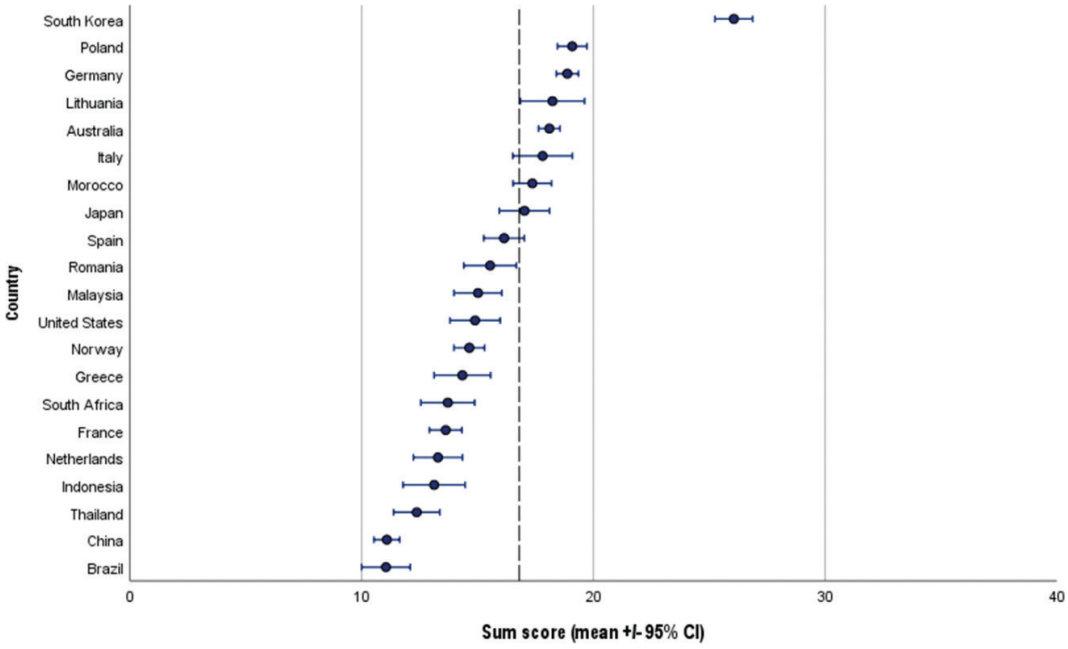

Fig. 3. Severity of health conditions per country. Summary scores (with 95% confidence intervals; 95% CI) of the health conditions (n = 14), ranging from 0 to 56, in which a higher score indicates more severe problems, for participants (n = 11,058) of the 21 countries of the International Spinal Cord Injury (InSCI) community survey. The rated health conditions were; Pain, Muscle spasms/spasticity, Sexual dysfunction, Bowel dysfunction, Contractures, Sleep problems, Bladder dysfunction, Circulatory problems, Urinary tract infections, Autonomic dysreflexia, Postural hypotension, Pressure sores, Injury caused by loss of sensation, Respiratory problems. *Vertical dotted line* indicates the overall mean value.

Table III. Unadjusted and adjusted coefficient estimates, odds ratios (OR) and 95% confidence intervals (CI) of comorbidity derived from binary logistic regression using generalized linear mixed models with random intercept for country to account for the clustering of data within countries due to the different sampling strategies adopted (i.e. random or convenient sampling), fitted with variance component covariance matrix. $N_{participants}$ = 11 058, $N_{countries}$ = 21.

		Unadjusted estimates				Adjusted estimates			
	Parameter	Coefficient	p-value	OR	95% CI	Coefficient	p-value	OR	95% CI
Age (years)		-0.018	***<0.001***	0.982	0.977–0.987	-0.010	***0.015***	0.990	0.982–0.998
Sex	Male	ref							
	Female	-0.081	*0.352*	0.922	0.778–1.093	0.244	***0.037***	1.276	1.015–1.604
Marital status	Married	ref							
	Single	0.075	*0.466*	1.078	0.880–1.321	-0.143	*0.370*	0.867	0.634–1.185
	Widowed	-0.153	*0.474*	0.858	0.564–1.305	0.137	*0.646*	1.147	0.639–2.060
	Separated or divorced	0.139	*0.410*	1.149	0.826–1.598	-0.043	*0.855*	0.958	0.606–1.516
	Cohabiting/partnership	0.347	*0.087*	1.415	0.951–2.102	0.168	*0.547*	1.183	0.684–2.046
Household	Living together with others	ref							
	Living alone	-0.175	*0.146*	0.839	0.663–1.063	-0.128	*0.473*	0.880	0.621–1.247
	Living in an institution	-0.263	*0.206*	0.769	0.511–1.156	-0.159	*0.551*	0.853	0.505–1.441
Years of education completed		0.016	*0.084*	1.016	0.998–1.034	0.008	*0.465*	1.008	0.987–1.030
Smoking	Never smoked	ref							
	Former or current smoker	0.424	***<0.001***	1.529	1.297–1.802	0.489	***<0.001***	1.630	1.327–2.002
SCI duration (years)		-0.008	*077*	0.992	0.984–1.001	-0.013	***0.018***	0.987	0.977–0.998
SCI level	Paraplegia	ref							
	Tetraplegia	0.063	*0.468*	1.065	0.899–1.260	0.184	*0.070*	1.202	0.985–1.468
SCI severity	Incomplete	ref							
	Complete	0.642	***<0.001***	1.901	1.572–2.300	0.639	***<0.001***	1.895	1.487–2.414
SCI etiology	Non-traumatic	ref							
	Traumatic	0.809	***<0.001***	2.246	1.896–2.662	0.745	***<0.001***	2.106	1.712–2.590
Unmet health care needs	No	ref							
	Yes	1.186	***<0.001***	3.273	2.470–4.335	1.492	***<0.001***	4.447	3.098–6.384

prevalence rates of health conditions across countries found in the current study, representing self-reported data, may reflect socioeconomic and cross-cultural differences in thresholds for reporting on health complaints (30), and as such probably also underestimate the real disease burden in some countries. The most common cause of mortality following SCI, both in short and long term, remains respiratory complications (31). In the current study, respiratory problems were the health condition exhibiting the lowest prevalence rate. This, in addition to the low reported hospitalization rate within the last year, might indicate that our respondents were not the ones with the most severe health conditions secondary to SCI.

Sexual dysfunction was reported more frequently among males than females, as also reported by others (21, 27). In addition, sexual dysfunction stood out as the health condition with the highest self-reported level of severity, and notably, of those who reported this to be an extreme problem, only approximately 16% reported receiving treatment for it. This was in clear contrast to other common conditions, such as urinary tract infections, in which almost 90% of those rating this as an extreme problem, received or had received treatment. The results might, however, be biased by missing data, as reporting on sexual dysfunction was the condition with a relatively high rate of missing data (6.7%), and more so among the women than the men (11.3.% vs 4.9%). A number of biological, psychological and social factors may play a role in reporting of sexual dysfunction (32), and barriers may exist to receiving treatment due to the sensitive nature of the condition (33).

Impact of the health conditions

The high prevalence of comorbidity (>90%) and the high number of concurrent health conditions reported (a mean of >7), was expected to vary across countries and WHO regions. A peculiar finding, however, was the much higher number of co-occurring health conditions reported by the participants from South Korea in comparison with that in the other countries (Fig. S2), and also the fact that they rated the health problems on almost all health conditions to be more severe than for their counterparts (Fig. S1). Brazil, in contrast, reported a significantly lower number of co-occurring health conditions and less severity than that in other countries. Interestingly, however, the participants from South Korea and Brazil exhibited similar values on quality of life measures, as shown in other analyses of the InSCI data (34). Different cultural perceptions or unobserved differences in sample characteristics might be possible contributing factors to the variations across countries.

Unmet healthcare needs showed the strongest association with comorbidity in the fitted binary logistic regression model. In fact, the odds for comorbidity for those not receiving healthcare was 4.45 times greater than the odds for those reporting having received healthcare when needed. Reported reasons for not getting the necessary healthcare included not being able to afford healthcare costs, as well as unavailability of healthcare services and transportation. The introduction of measures to increase access to healthcare services for people with SCI is pivotal (4) and should include lowering the costs, improving insurance coverage, making transportation accessible and available, and also possibly investing in increased use of telerehabilitation (35). Significant associations with comorbidity were found for SCI of traumatic origin, having a complete lesion, being a current or former smoker and being a female. The lower odds of comorbidity for those with an incomplete SCI lesion, and for those having a non-traumatic SCI, are in line with previously reported Swiss data (21). The results contrast, however, with findings from a recent Finnish study, in which differences between the groups for SCI severity did not reach statistical significance (27).

Methodological considerations

This study represents the largest and most comprehensive data-set on health conditions among community-living persons with SCI worldwide. Nevertheless, caution should be exercised when interpreting the current results, as there are certain study limitations to be considered. First, the self-reported data on health conditions were not verified by medical professionals, which may have introduced reporting bias. Secondly, the variation in the sampling frame might have introduced selection bias. The InSCI study was planned as a cross-country comparison study, and as such population-based random samples would be ideal. This was, however, feasible in only 7 of the countries, while most of the countries had to rely on convenience sampling, mainly due to lack of available and updated databases. The diversity in the sampling frame for the recruitment of participants has probably introduced sampling bias, thus the country-wise representativeness is limited. Furthermore, the response rate varied across countries, from 23% in China to 54% in South Africa. In most of the countries, however, the characteristics of the non-responders were, unknown, precluding accounting for non-response bias. Moreover, small samples in some countries, even though reaching the targeted minimal sample size of 200 participants per country, might limit the power to detect meaningful associations. This, in addition to the relatively large differences in the sample sizes across countries, ranging from 200 in

South Africa to 1,617 in Germany, might lead to limited generalizability to the population of persons with SCI in participating countries. The country-specific results should thus be interpreted cautiously. The overall sample, however, suggest key socio-demographics and lesion characteristics to be in line with current evidence (4), and in the analysis of associations, models were run accounting for the clustering of data within countries due to the different sampling strategies adopted. Thirdly, the nature of the cross-sectional study design used precludes any causal inference on the associations found in this study between characteristics of participants and health outcomes.

CONCLUSION

The current cross-national comparison offers a map of differences that increases knowledge and understanding of the prevalence of health conditions among community-living persons with SCI worldwide. Physical health problems secondary to SCI are extremely common and the high prevalence of comorbidity found demands investment in appropriate management, medical care and rehabilitation, as well as preventative measures to not only reduce the associated morbidity and mortality, but also assist persons with SCI towards fulfilling productive lives. The data from the current study indicate that many people with SCI across the world report not receiving the healthcare they require, and that there are unmet treatment needs in all of the reported secondary health conditions following SCI. Morbidity and mortality rates are thus likely to remain high without increased investment in appropriate management and medical care. Nonetheless, there is a need for continued research identifying potential targets for nationwide interventions to improve the situation for community living persons with SCI.

Data archiving

The use of InSCI survey data is currently restricted to participating countries. For further information or any request on future collaboration, please contact the InSCI study center at insci@paraplegie.ch.

ACKNOWLEDGEMENTS

This study is based on data from the International Spinal Cord Injury (InSCI) Community Survey, providing the evidence for the Learning Health System for Spinal Cord Injury (LHS-SCI, see Am J Phys Med Rehabil 25 2017;96(Suppl):S23–S34). The LHS-SCI is an effort to implement the recommendations described in the WHO report International Perspectives on Spinal Cord Injury (Bickenbach J et al. Geneva: WHO Press; 2013). The members of the InSCI Steering Committee are: Julia Patrick Engkasan (ISPRM representative; Malaysia), James Middleton (ISCoS representative; Member Scientific Committee; Australia), Gerold Stucki (Chair Scientific Committee; Switzerland), Mirjam Brach (Representative Coordinating Institute; Switzerland), Jerome Bickenbach (Member Scientific Committee; Switzerland), Christine Fekete (Member Scientific Committee; Switzerland), Christine Thyrian (Representative Study Center; Switzerland), Linamara Battistella (Brazil), Jianan Li (China), Brigitte Perrouin-Verbe (France), Christoph Gutenbrunner (Member Scientific Committee; Germany), Christina-Anastasia Rapidi (Greece), Luh Karunia Wahyuni (Indonesia), Mauro Zampolini (Italy), Eiichi Saitoh (Japan), Bum Suk Lee (Korea), Alvydas Juocevicius (Lithuania), Nazirah Hasnan (Malaysia), Abderrazak Hajjioui (Morocco), Marcel W.M. Post (Member Scientific Committee; The Netherlands), Anne Catrine Martinsen (Norway), Piotr Tederko (Poland), Daiana Popa (Romania), Conran Joseph (South Africa), Mercè Avellanet (Spain), Michael Baumberger (Switzerland), Apichana Kovindha (Thailand), Reuben Escorpizo (Member Scientific Committee; USA).

Conflicts of interest

The authors have no conflicts of interest to declare.

REFERENCES

1. Kumar R, Lim J, Mekary RA, Rattani A, Dewan MC, Sharif SY, et al. Traumatic spinal injury: global epidemiology and worldwide volume. World Neurosurg 2018; 113: e345–e363.
2. 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.
3. Jensen MP, Molton IR, Groah SL, Campbell ML, Charlifue S, Chiodo A, et al. Secondary health conditions in individuals aging with SCI: terminology, concepts and analytic approaches. Spinal Cord 2012; 50: 373–378.
4. Bickenbach JE, (editor), editors. International Perspectives on spinal cord injury: World Health Organization, WHO Library Cataloguing-in-Publication Data 2013.
5. Oderud T. Surviving spinal cord injury in low income countries. Afr J Disabil 2014; 3: 80.
6. Adriaansen JJ, Ruijs LE, van Koppenhagen CF, van Asbeck FW, Snoek GJ, van Kuppevelt D, et al. Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. J Rehabil Med 2016; 48: 853–860.
7. Brinkhof MW, Al-Khodairy A, Eriks-Hoogland I, Fekete C, Hinrichs T, Hund-Georgiadis M, et al. Health conditions in people with spinal cord injury: contemporary evidence from a population-based community survey in Switzerland. J Rehabil Med 2016; 48: 197–209.
8. Adriaansen JJ, Post MW, de Groot S, van Asbeck FW, Stolwijk-Swuste 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.
9. Jorge A, White MD, Agarwal N. Outcomes in socioeconomically disadvantaged patients with spinal cord injury: a systematic review. J Neurosurg Spine 2018; 29: 680–686.
10. Middleton JW, Lim K, Taylor L, Soden R, Rutkowski S. Patterns of morbidity and rehospitalisation following spinal cord injury. Spinal Cord 2004; 42: 359–367.
11. Harrison C, Fortin M, van den Akker M, Mair F, Calderon-Larranaga A, Boland F, et al. Comorbidity versus multimorbidity: why it matters. J Comorb 2021; 11: 2633556521993993.
12. Rivers CS, Fallah N, Noonan VK, Whitehurst DG, Schwartz CE, Finkelstein JA, et al. Health conditions: effect on function, health-related quality of life, and life satisfaction after traumatic spinal cord injury. A Prospective Observational Registry Cohort Study. Arch Phys Med Rehabil 2018; 99: 443–451.
13. Noonan VK, Fallah N, Park SE, Dumont FS, Leblond J, Cobb J, et al. Health care utilization in persons with traumatic spinal cord injury: the importance of multimorbidity and the impact on patient outcomes. Top Spinal Cord Inj Rehabil 2014; 20: 289–301.
14. Fekete C, Brach M, Ehrmann C, Post MWM, InSci, Stucki G. Cohort profile of the international spinal cord injury community survey implemented in 22 countries. Arch Phys Med Rehabil 2020; 10.1016/j.apmr.2020.01.022.
15. Gross-Hemmi MH, Post MW, Ehrmann C, Fekete C, Hasnan N, Middleton JW, et al. Study Protocol of the International Spinal Cord Injury (InSCI) Community Survey. Am J Phys Med Rehabil 2017; 96: S23–S34.
16. Epstein J, Osborne RH, Elsworth GR, Beaton DE, Guillemin F. Cross-cultural adaptation of the Health Education Impact Questionnaire: experimental study showed expert committee, not back-translation, added value. J Clin Epidemiol 2015; 68: 360–369.
17. Fekete C, Post MW, Bickenbach J, Middleton J, Prodinger B, Selb M, et al. A Structured approach to capture the lived experience of spinal cord injury: data model and questionnaire of the International Spinal Cord Injury Community Survey. Am J Phys Med Rehabil 2017; 96: S5–S16.
18. Kalpakjian CZ, Scelza WM, Forchheimer MB, Toussaint LL. Preliminary reliability and validity of a Spinal Cord Injury Secondary Conditions Scale. J Spinal Cord Med 2007; 30: 131–139.
19. World Health Organization (WHO). Model disability survey. 2020 [cited 23rd Sept 2021]. Available from: https://www.who.int/news-room/q-a-detail/model-disability-survey
20. Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. Arthritis Rheum 2003; 49: 156–163.
21. Brinkhof MW, Al-Khodairy A, Eriks-Hoogland I, Fekete C, Hinrichs T, Hund-Georgiadis M, et al. Health conditions in people with spinal cord injury: Contemporary evidence from a population-based community survey in Switzerland. J Rehabil Med 2016; 48: 197–209.
22. Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. Arch Phys Med Rehabil 1999; 80: 1429–1434.
23. 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. Top Spinal Cord Inj Rehabil 2014; 20: 277–288.
24. van der Meer P, Post MW, van Leeuwen CM, van Kuppevelt HJ, Smit CA, van Asbeck FW. Impact of health problems secondary to SCI one and five years after first inpatient rehabilitation. Spinal Cord 2017; 55: 98–104.
25. Anson CA, Shepherd C. Incidence of secondary complications in spinal cord injury. Int J Rehabil Res 1996; 19: 55–66.
26. New PW. Secondary conditions in a community sample of people with spinal cord damage. J Spinal Cord Med 2016; 39: 665–670.
27. Tallqvist S, Kauppila AM, Vainionpaa A, Koskinen E, Bergman P, Anttila H, et al. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord 2021; 10.1038/s41393-021-00704-7.
28. Hossain MS, Islam MS, Rahman MA, Glinsky JV, Herbert RD, Ducharme S, et al. Health status, quality of life and socioeconomic situation of people with spinal cord injuries six years after discharge from a hospital in Bangladesh. Spinal Cord 2019; 57: 652–661.
29. Bellet FD, Rashid SM, Jusabani MA, Dekker MCJ, Temu RJ. The characteristics of cervical spinal cord trauma at a North Tanzanian Referral Hospital: a retrospective hospital based study. Pan Afr Med J 2019; 33: 82.
30. Goren A, Mould-Quevedo J, daCosta DiBonaventura M. Prevalence of pain reporting and associated health outcomes across emerging markets and developed countries. Pain Med 2014; 15: 1880–1891.
31. Berlowitz DJ, Wadsworth B, Ross J. Respiratory problems and management in people with spinal cord injury. Breathe (Sheff) 2016; 12: 328–340.
32. McCool-Myers M, Theurich M, Zuelke A, Knuettel H, Apfelbacher C. Predictors of female sexual dysfunction: a systematic review and qualitative analysis through gender inequality paradigms. BMC Womens Health 2018; 18: 108.
33. Takeuchi Y, Otsuka R, Kojima H, Fetters MD. Comparison of self-report and objective measures of male sexual dysfunction in a Japanese primary care setting: a cross-sectional, self-administered mixed methods survey. Fam Med Community Health 2021; 9.
34. Pacheco Barzallo D, Gross-Hemmi M, Bickenbach J, Juocevicius A, Popa D, Wahyuni LK, et al. Quality of life and the health system: a 22-country comparison of the situation of people with spinal cord injury. Arch Phys Med Rehabil 2020; 10.1016/j.apmr.2020.04.030.
35. Irgens I, Bach B, Rekand T, Tornas S. Optimal management of health care for persons with disability related to spinal cord injury: learning from the Sunnaas model of telerehabilitation. Spinal Cord Series and Cases 2020; 6: 88.