



Gender differences in patient experience among persons with spinal cord injury: A comparison across 22 countries

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ABSTRACT

Background: Due to the majority of males within the population of persons with spinal cord injuries (SCI), a male-oriented perception of persons with SCI might affect care provision in the way of prioritizing male needs.

Objective: The objective of this cross-sectional study is to describe the patient experience of persons with SCI by gender.

Methods: This study was based on the International Spinal Cord Injury Survey with 12,588 participants from 22 countries. An interval-based patient experience score was attained by partial credit model. Regression analysis was used in exploring the association between patient experience and gender.

Results: Participants reported very good and good patient experience. Respectful treatment was reported by 78 % of participants; clear explanations by 75 %; involvement in decision-making by 71 %; satisfaction with services by 62 %. The average patient experience score was equal among males and females (average: 64, range: 0–100), with the highest score in participants from the USA (78) and the lowest – in Morocco (44). Patient experience score was not associated with gender. Females had lower odds of reporting better decision-making involvement, yet higher odds of better satisfaction. Older participants, with higher household income and better self-rated health, had lower odds of being satisfied.

Conclusion: The majority of persons with SCI rated their experience as good or very good. Females were more likely to report higher satisfaction with services and lower involvement in decision-making. For other patient experience categories and the overall patient experience score, no association with gender was found.

Introduction

Spinal cord injury (SCI) is a complex and costly health condition, which requires continuous care from multiple health services

providers.¹ Women, representing one-fifth of the SCI population, constitute a “minority within a minority”.² The experience of disability and health care needs are different between males and females.^{3,4} On average, women with SCI tend to visit a broader range of providers and

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more frequently rely on primary rather than specialist care.⁵ Individuals with disabilities face social (e.g. negative attitudes, being ignored, being judged, abused), financial, and structural barriers (e.g. lack of insurance coverage, inaccessible equipment or transportation facilities) in their efforts to participate in their communities and receive care, which were described as more pronounced for women.⁶ Women were more likely than men to have problems finding an accessible service that would fit their needs.^{7,8} Persons with disability are four times more likely to report being treated badly in the health system, twice as likely to report the facilities or providers' skills to be inadequate, and three times more likely to report being denied health services,⁹ in addition to reporting inadequate information provision and feelings of being diminished and viewed as incompetent.¹⁰

Patient experience with health services refers to the process of patient interaction with the health system and interpersonal aspects of the received care. It reflects the perspective of the patient and patients' accounts of what happened during the episode of care.^{11,12} There is a research need to understand the patient experience of persons with SCI and the role of gender. Due to the majority of males within the population of individuals with SCI, particularly among those with SCI of traumatic origin, a male-oriented perception of individuals with SCI, might affect care provision in the way of prioritizing male needs.¹³ A Swiss study found no significant relationship between gender and patient satisfaction.¹⁴ Yet the broader concept of patient experience, and not just satisfaction has to be explored while including the perspectives from various countries in order to better understand care for individuals with SCI.^{11,15} The aim of this study is to describe the patient experience with health services of persons with SCI by gender across 22 countries.

Methods

Study design and data collection

The study used data collected by the International Spinal Cord Injury Community Survey (InSCI), a cross-sectional, community-based, questionnaire survey conducted during 2017–2019.¹⁶ It was the first systematically collected data describing the lived experience of persons with SCI.¹⁷ InSCI was part of the International Learning Health System for Spinal Cord Injury Study (LHS-SCI), embedded in the World Health Organization's Global Disability Plan¹⁸ and launched in 2017 with the support of the World Health Organization (WHO), the International Society for Physical and Rehabilitation Medicine (ISPRM), and the International Spinal Cord Society (ISCoS).¹⁸ Details on sampling and recruitment for each country can be found in previous InSCI publications.^{16,19,20} The study population was adults with chronic, non-traumatic or traumatic SCI, living in the community. Study participants have completed their first rehabilitation after the injury. Participants were living across the following 22 countries: Australia, Brazil, China, France, Germany, Greece, Indonesia, Italy, Japan, Lithuania, Malaysia, Morocco, the Netherlands, Norway, Poland, Romania, South Africa, South Korea, Spain, Switzerland, Thailand, and the United States.

National study centers have conducted the questionnaire translation, cultural adaptation, and data collection, while Swiss Paraplegic Research in Nottwil, Switzerland coordinated the survey.¹⁶ Ethical approval was granted to each national study center for conducting the survey, where applicable. Informed consent was obtained from each participant, where applicable. The questionnaire was offered in multiple response options, i.e., paper-pencil or online questionnaires, face-to-face and telephone interviews.

In this study, 65 % of the data came from predefined sampling frames used by eight countries Australia, China, Germany, the Netherlands, Norway, Poland, South Africa, and Switzerland. Various data sources were used for creating the sampling frames: national registries of individuals with SCI, databases of academic or level I trauma hospitals,

clinical records of specialized rehabilitation centers, membership registries of organizations for persons with disability, or insurance agencies. Collected data were de-identified and saved in a central database.¹⁶

Measurements

Socio-demographic, SCI, and health status characteristics

For the questionnaire item asking about the participant's gender as identity and social role ("Please indicate your gender"), two response options, "male" and "female", were provided. While the interpretation of this question may depend on the specific country, we assume that those identifying as a male would choose the option "male", and those identifying as female the option "female". Those who do not identify as either were assumed to not have chosen an option. Total years of formal education, including school and vocational training were summed up according to the definition provided by the International Standard Classification of Education.^{19,21} Income was represented by an equivalent total household income translated to country-specific income deciles, which divides the population into ten income-ranked groups.²²

The Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)²³ score (range: 0–56) was used to describe health problems experienced in the past three months, with higher scores indicating greater problems with secondary conditions. It was based on the following 14 health conditions: sleep problems, bowel dysfunction, urinary tract infections, bladder dysfunction, sexual dysfunction, contractures, muscle spasms or spasticity, pressure sores or decubitus, respiratory problems, injury caused by a loss of sensation, circulatory problems, autonomic dysreflexia, postural hypotension, and pain. Each health condition was rated from 0 (no problem) to 4 (extreme problem), for all countries except for Switzerland where a four-point scale was used. The answers in the four-point scale were weighted as 0, 1.3, 2.3, and 4, respectively, to align with the 0 to 4 weighting in the five-point scale.

The Spinal Cord Independence Measure (SCIM-III self-report) score (0–66) was used as a measure of independence in activities of daily living, with higher scores indicating greater independence. It contained the following questionnaire items: eating and drinking, washing the upper body and head, washing the lower body, dressing the upper body, dressing the lower body, grooming, use of an indwelling catheter, intermittent bladder catheterization, use of external drainage instruments, bowel assistance, bowel movement, fecal incontinence, toileting, turning the upper body in bed, turning the lower body in bed, sitting up in bed, doing push-ups in a chair or a wheelchair, transfer from bed to a wheelchair, moving around moderate distances. The recoding and creating a single score by summing up the items was done according to Fekete et al.²⁴ Self-rated health was measured by four five-point Likert scale survey items with response categories: "excellent", "very good", "good", "fair", "poor").

Patient experience

Experience while receiving health services during the last provider visit was measured by four five-point Likert scale survey items (response categories: "very good", "good", "neither good nor bad", "bad", "very bad"): respectful treatment of the patient by the provider; clear explanations for the patient by the provider; patient's involvement in decision-making by the provider; patient's satisfaction with service. To attain an individual interval-scaled, total experience score scaled to a 0–100 range (worst experience – best experience), a partial credit model was applied. The following tests were performed to check the assumptions of the partial credit model: ordered categories check via graphs; local independence test; unidimensionality test by principal component analysis and factor analysis on polychoric correlations; differential item functioning test on the different characteristics (gender, age, SCI type, and SCI degree).

Statistical analysis

To establish the association between gender and patient experience, regression analysis was used: multilevel linear regression for patient experience score with gender as fixed- and country as a random effect; and multilevel ordinal regression analysis for patient experience categories with gender as fixed and country as a random effect. The analysis was adjusted by the non-modifiable socio-demographic characteristics (age, migration background, living arrangement, assistance received with day-to-day activities from family, friends or professionals, education, household income, having paid work) and SCI and health status characteristics (tetra- or paraplegia, complete or incomplete lesion, traumatic or nontraumatic etiology, years lived with injury, SCI-SCS score, self-rated health). The proportional odds assumption was assessed by visual inspection of the predicted probabilities of each outcome category for different values of the predictor variable. The level of statistical significance was set to 5 %. All statistical analyses were conducted using Stata 16.1 and R 4.2.2. All statistical analyses were based on a predefined data analysis protocol approved by the InSCI Committee before the study started.

Results

Basic characteristics of the study participants

Socio-demographic characteristics of study participants

The analysis was conducted among 12,588 participants. The response rates were only available for countries with predefined sample frames: South Africa (54 %), Norway (42 %), Switzerland (39 %), Netherlands (33 %), Germany (32 %), Poland (32 %), Australia (27 %), China (23 %).¹⁹

Table 1

Socio-demographic, spinal cord injury and health status characteristics.

	Total	Gender	
		Male	Female
<i>Total participants, n (%)^a</i>	12,588 (100.0)	9165 (72.8)	3391 (26.9)
<i>Socio-demographic characteristics, n (%)^a</i>			
Age – mean (min, max)	51.3 (18.0, 96.0)	51.0 (18.0, 96.0)	52.0 (18.0, 94.0)
Migrant background	951 (7.6)	666 (7.3)	285 (8.4)
Living in institution	413 (3.3)	299 (3.3)	113 (3.3)
No assistance	3095 (24.6)	2305 (25.2)	786 (23.2)
No education	152 (1.2)	92 (1.0)	60 (1.8)
Income decile ^b			
1-3	5578 (44.3)	4054 (44.2)	1517 (44.5)
4-7	3380 (26.9)	2472 (27.0)	902 (26.6)
8-10	2085 (16.6)	1540 (16.8)	543 (16.0)
No paid work	8046 (63.9)	5812 (63.4)	2215 (65.3)
<i>Spinal cord injury and health status characteristics, n (%)^a</i>			
Tetraplegia	4582 (36.4)	3515 (38.4)	1055 (31.1)
Incomplete lesion	7599 (60.4)	5378 (58.7)	2208 (65.1)
Nontraumatic etiology	2397 (19.0)	1354 (14.8)	1037 (30.6)
Years since injury – mean (min, max)	13.1 (0.0, 81.0)	13.4 (0.0, 81.0)	12.5 (0.0, 73.0)
SCI-SCS ^c – mean (min, max)	17.1 (0.0, 56.0)	17.2 (0.0, 56.0)	16.8 (0.0, 56.0)
SCIM ^d – mean (min, max)	40.0 (0.0, 66.0)	39.7 (0.0, 66.0)	41.0 (0.0, 66.0)
Self-rated health			
Excellent/very good	1872 (14.9)	1397 (15.2)	474 (14.0)
Good	4853 (38.6)	3518 (38.4)	1332 (39.3)
Fair/poor	5590 (44.4)	4062 (44.3)	1519 (44.8)

^a Missing values: Gender: 0.3 %, Age: 0.6 %, Migrant background: 1.1 %, Living arrangement: 1.6 %, Assistance: 0.9 %, Education: 1.3 %, Income: 12.3 %, Paid work: 7.5 %.

^b Income: equivalent total household income translated to country-specific income deciles, which divides the population into ten income-ranked groups.

^c Spinal Cord Injury Secondary Health Conditions Scale (range: 0–56) based on self-rated question about 14 health problems.

^d Spinal Cord Independence Measure (range: 0–66): a measure of independence in activities of daily living score.

Socio-demographic, SCI and health status characteristics are presented in [Table 1](#). The female population was similar to the male population in terms of sociodemographic characteristics. There were 27 % female participants, on average 1 year older compared to the male participants (52 versus 51 years old). Eight percent of female participants had a migrant background, with 3 % living in an institution, 23 % having no assistance and 65 % having no paid work (2 % more than the males). Among female participants, 31 % had tetraplegia (vs. 38 % in males) of nontraumatic etiology with an incomplete lesion (65 %) for 13 years on average.

Patient experience

The majority of the responders, regardless of country, rated their health experience as good or very good across all four experience categories: provider's attitude towards the patient – 78 %; provider's clarity of explanations – 74 %; patient's involvement in the decision-making – 71 %; satisfaction with the service – 62 %. Patient experience score (0–100) was the highest score in the USA (78), Spain (77), and Brazil (74) while the lowest score was in Morocco (44), South Korea (49), and Lithuania (55). ([Table 2](#)).

Comparable shares of respondents among both males and females reported very good/good patient experience: provider's attitude towards the patient (both: 78 %); provider's clarity of explanations (males: 75 %, females: 74 %); patient's involvement in the decision-making (both: 71 %); satisfaction with service health (males: 63 %, females: 61 %). The average patient experience score of females was equal to the one of males (64). The biggest difference in these patient experience scores among males and females was in Greece (males: 60, females: 55), Norway (69, 63), South Africa (63, 69), and Lithuania (58, 50).

Table 2
Patient experience by gender.

	Gender		
	Total	Male	Female
<i>Experience score, mean (standard deviation)^{a,b}</i>	63.8 (20.3)	63.7 (20.2)	64.2 (20.6)
<i>Experience score, by country, mean (standard deviation)^c</i>			
Australia	72.5 (21.1)	72.9 (20.8)	71.4 (15.3)
Brazil	74.4 (16.2)	73.9 (16.3)	76.0 (16.1)
China	54.9 (16.2)	54.6 (15.9)	55.6 (7.0)
France	69.7 (19.4)	69.7 (19.5)	69.8 (19.3)
Germany	63.5 (18.8)	63.8 (17.8)	63.2 (18.6)
Greece	58.3 (20.5)	59.8 (20.8)	54.6 (19.2)
Indonesia	61.5 (14.3)	61.5 (14.9)	61.6 (12.9)
Italy	57.0 (20.0)	57.3 (20.0)	57.7 (19.7)
Japan	61.1 (16.4)	61.0 (16.3)	62.1 (17.9)
Lithuania	54.8 (19.9)	57.8 (19.6)	49.6 (19.5)
Malaysia	72.1 (18.2)	72.5 (18.6)	70.5 (16.2)
Morocco	44.4 (20.1)	43.7 (20.6)	46.1 (18.8)
The Netherlands	69.9 (18.5)	69.6 (16.5)	70.5 (22.0)
Norway	69.0 (20.7)	68.8 (20.8)	69.3 (20.4)
Poland	57.2 (18.6)	57.2 (18.4)	57.7 (19.7)
Romania	59.7 (20.8)	58.9 (20.7)	62.0 (21.1)
South Africa	64.9 (17.4)	63.4 (17.7)	69.1 (15.9)
South Korea	48.5 (16.6)	48.9 (16.8)	47.4 (47.4)
Spain	76.6 (19.0)	77.5 (19.3)	74.3 (18.2)
Switzerland	71.0 (16.9)	70.4 (16.8)	72.5 (17.1)
Thailand	68.8 (16.8)	68.0 (16.5)	70.1 (17.6)
United States	77.7 (19.6)	78.4 (18.9)	76.9 (20.7)
<i>Provider's attitude towards the patient, n (%)^d</i>			
Very good/good	9821 (78.0)	7157 (78.1)	2647 (78.1)
Neither good nor bad	1505 (11.9)	1115 (12.1)	386 (11.4)
Bad/very bad	432 (3.4)	102 (1.1)	120 (3.5)
<i>Provider's clarity of explanations, n (%)^d</i>			
Very good/good	9440 (74.5)	6901 (75.3)	2524 (74.4)
Neither good nor bad	1676 (13.3)	1222 (13.3)	450 (13.3)
Bad/very bad	579 (4.6)	416 (4.5)	161 (4.5)
<i>Patient's involvement in the decision-making, n (%)^d</i>			
Very good/good	8896 (70.7)	6469 (70.6)	2414 (71.2)
Neither good nor bad	2099 (16.7)	1568 (17.1)	526 (15.5)
Bad/very bad	639 (5.1)	453 (4.9)	184 (5.4)
<i>Patient's satisfaction with the service, n (%)^d</i>			
Very satisfied/satisfied	7849 (62.4)	5766 (62.9)	2071 (61.1)
Neither satisfied nor dissatisfied	2747 (21.8)	1981 (21.6)	758 (22.4)
Dissatisfied/very dissatisfied	1420 (11.3)	1016 (11.1)	400 (11.8)

^a Missing values: Experience score 3.7 %, Attitude: 6.6 %, Clarity: 7.1 %, Involvement: 7.6 %, Satisfaction: 4.5 %.

^b Interval-scaled patient experience score (range: 0–100).

Association between patient experience and gender

Gender was not associated with the patient experience score either in the univariable or multivariable analysis (Table 3). The provider's attitude towards the patient and the provider's clarity of explanations were as well not associated with gender. Patient involvement in decision-making was associated with gender in the univariable but not in multivariable analysis, with females having lower odds of reporting better involvement in the decision-making. Satisfaction was associated with gender in both uni- and multivariable regression. Females had higher odds of reporting better satisfaction with services. Older participants, with higher household income and better self-rated health, had lower odds of reporting satisfaction with care services. Other characteristics showed no association with patient experience. The proportional odds assumption was considered satisfied in all models.

Discussion

This study examined the association between patient experience and gender among persons with SCI. Persons with SCI reported predominantly good or very good patient experience. Females had lower odds of reporting better involvement in decision-making than males, yet higher odds of reporting better satisfaction with services. Older participants, with higher household income and better self-rated health, had lower odds of reporting satisfaction with care.

Females with SCI were previously found to be more likely to experience unmet needs,^{9,13} which could suggest lower service satisfaction. Yet we found that females were more likely to be satisfied with the health services they received, contrary to our hypothesis. We also did not find that females had a higher involvement in decision-making compared to

Table 3
Association between patient experience and gender.

	Patient experience score ^a		Provider's attitude towards the patient ^b		Provider's clarity of explanations ^b		Patient's involvement in the decision-making ^b		Patient's satisfaction with the service ^b	
	Coef.	95 % CI, Sign ^e	Odds ratio	95 % CI, Sign ^e	Odds ratio	95 % CI, Sign ^e	Odds ratio	95 % CI, Sign ^e	Odds ratio	95 % CI, Sign ^e
Unadjusted model										
Male	Ref.		Ref.		Ref.		Ref.		Ref.	
Female	0.02	(-0.71, 0.75)	0.94	(0.87, 1.02)	0.95	(0.87, 1.03)	0.92	(0.85, 0.99)*	1.12	(1.04, 1.21)*
Adjusted model										
<i>Socio-demographic characteristics</i>										
Male	Ref.		Ref.		Ref.		Ref.		Ref.	
Female	-0.25	(-1.18, 0.68)	0.99	(0.88, 1.09)	0.98	(0.86, 1.09)	0.92	(0.84, 1.03)	1.18	(1.07, 1.31)**
<i>Age, years</i>										
18–35	Ref.		Ref.		Ref.		Ref.		Ref.	
36–45	0.52	(-0.76, 1.79)	1.00	(0.87, 1.16)	1.04	(0.90, 1.20)	1.03	(0.89, 1.18)	0.82	(0.71, 0.94)*
46–55	1.81	(0.54, 3.07)	0.92	(0.79, 1.06)	1.96	(0.84, 1.11)	0.93	(0.80, 1.06)	0.68	(0.59, 0.78)***
56–65	2.44	(1.08, 3.79)	0.85	(0.73, 0.98)	0.88	(0.76, 1.03)	0.97	(0.84, 1.14)	0.60	(0.52, 0.69)***
66+	3.45	(1.89, 5.01)	0.81	(0.68, 0.97)	0.86	(0.71, 1.02)	0.91	(0.77, 1.09)	0.51	(0.43, 0.60)***
<i>Migrant background</i>										
Living in institution	-0.41	(-2.27, 1.45)	1.13	(0.90, 1.41)	1.22	(0.98, 1.52)	0.99	(0.79, 1.22)	0.90	(0.73, 1.06)
No education	-4.62	(-11.78, 2.53)	1.37	(0.60, 3.14)	2.21	(0.95, 5.13)	1.89	(0.77, 4.25)	1.09	(0.50, 2.37)
<i>Income deciles</i>										
1–3	Ref.		Ref.		Ref.		Ref.		Ref.	
4–7	1.00	(0.01, 1.99)	0.93	(0.83, 1.04)	0.97	(0.86, 1.07)	0.93	(0.84, 1.04)	0.83	(0.75, 0.93)**
8–10	2.26	(1.03, 3.50)	0.87	(0.76, 1.06)	0.85	(0.74, 0.98)	0.76	(0.67, 0.87)	0.81	(0.70, 0.93)*
No paid work	0.26	(-0.74, 1.33)	0.9	(0.83, 1.06)	0.95	(0.84, 1.07)	1.01	(0.90, 1.13)	0.98	(0.88, 1.09)
<i>Spinal cord injury and health condition characteristics</i>										
Tetraplegia	0.03	(-0.94, 0.88)	1.04	(0.93, 1.15)	1.05	(0.94, 1.16)	0.97	(0.87, 1.07)	0.98	(0.88, 1.09)
Incomplete lesion	-0.06	(-1.0, 0.88)	0.95	(0.85, 1.06)	0.98	(0.88, 1.09)	0.96	(0.86, 1.06)	1.02	(0.92, 1.13)
Nontraumatic etiology	0.23	(-0.86, 1.33)	1.01	(0.89, 1.14)	1.09	(0.96, 1.23)	1.04	(0.92, 1.17)	0.90	(0.80, 1.02)
<i>Years lived with SCI, years</i>										
<1	Ref.		Ref.		Ref.		Ref.		Ref.	
0–10	-2.91	(-6.62, 0.79)	1.42	(0.93, 2.17)	1.48	(0.98, 2.5)	1.29	(0.85, 1.94)	1.13	(0.75, 1.70)
11–20	-3.04	(-6.87, 0.78)	1.45	(0.94, 2.25)	1.47	(0.96, 2.25)	1.26	(0.83, 1.92)	1.14	(0.74, 1.74)
21–30	-3.80	(-7.74, 0.14)	1.53	(0.98, 2.40)	1.65	(1.06, 2.57)	1.31	(0.85, 2.03)	1.22	(0.78, 1.89)
31–40	-3.68	(-7.82, 0.45)	1.63	(1.01, 2.61)	1.39	(0.88, 2.22)	1.26	(0.79, 1.99)	1.19	(0.75, 1.88)
≥41	-2.64	(-6.91, 1.63)	1.57	(0.96, 2.55)	1.56	(0.96, 2.51)	1.26	(0.73, 1.88)	0.96	(0.59, 1.53)
SCI-SCS ^c	-0.31	(-0.46, -0.26)	1.02	(1.02, 1.03)	1.03	(1.02, 1.03)	1.02	(1.02, 1.03)	1.03	(1.03, 1.04)***
SCIM ^d	0.04	(0.01, 0.07)	0.99	(0.99, 0.99)	0.97	(0.99, 0.99)	0.99	(0.99, 0.99)	0.99	(1.99, 1.00)
<i>Self-rated health</i>										
Fair/poor	Ref.		Ref.		Ref.		Ref.		Ref.	
Moderate	11.45	(10.14, 12.76)	0.35	(0.29, 0.41)	0.39	(0.34, 0.46)	0.37	(0.32, 0.43)	0.30	(0.26, 0.35)***
Excellent/very good	4.92	(3.98, 5.87)	0.69	(0.63, 0.8)	0.68	(0.61, 0.76)	0.67	(0.60, 0.74)	0.55	(0.49, 0.61)***
Constant	54.52	(28.91, 102.81)	0.53	(0.28, 1.01)	0.48	(0.26, 0.92)	0.34	(0.17, 0.65)	0.65	(0.34, 1.23)

^a Interval-scaled patient experience score (range: 0–100 (worst experience – best experience)).

^b Modeled via the following categories “Very good/good”; “Neither good nor bad”; “Bad/very bad”), with “Very good/good” as a reference category.

^c Spinal Cord Injury Secondary Health Conditions Scale (range: 0–56) based on self-rated question about 14 health problems.

^d Spinal Cord Independence Measure (range: 0–66): a measure of independence in activities of daily living score.

^e * p < 0.05, **p < 0.01, ***p < 0.001.

males, while in other studies higher involvement in decision-making was found to be contributing to higher satisfaction with services.²⁵ Females could be reporting higher satisfaction due to the type of services they mostly use, as they tend to use more primary care services.⁷ Alternatively, satisfaction differs from experience and represents the overall evaluation of the service received rather than the process of service delivery.^{11,15} This overall evaluation may often differ from the evaluation of specific process elements by being general and overly optimistic.²⁶

Despite previous findings that older individuals with SCI have higher satisfaction with the services due to lower expectations,^{14,27} we found satisfaction to be decreasing with age. Those with higher household income and better health were as well less satisfied. Both males and females with higher household income can utilize a wider range of services and tend to have higher expectations, hence, might perceive some services as less valuable.²⁸ This finding suggests that even among those who consider themselves to be in good health and supposedly experiencing fewer health problems, there are still areas for improvement in the quality of care and overall patient experience.²⁶

This study had several limitations to take into consideration. Firstly, the study relied on survey data, which can be subject to recall bias and selection bias in differences in expectations related to patient experience. Additionally, the sampling frames primarily focused on specific regions and health settings within each country (rehabilitation facilities (Brazil, Germany, the Netherlands, Norway) or general or acute hospitals (China, Spain)), limiting the representativeness of the findings. Convenience sampling was used in certain countries, which is subject to self-selection and potential exclusion of individuals who more frequently face barriers to health access. Lastly, the response rate (ranging from 27 % to 54 %) suggests that individuals also face greater challenges in survey participation.

Conclusion

Persons with SCI reported positive patient experiences, with a majority rating their experiences as good or very good. Females were more likely to report better satisfaction with services while reporting lower involvement in decision-making. For other patient experience categories and the general patient experience score, no association with gender was found.

Authors' contributions

Study conceptualization and development.

Data availability statement

The data that support the findings of this study are available from InSCI Study Group, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of InSCI Study Group.

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Ethics approval and consent to participate

Ethical approval was granted in each participating country based on their regulations. Each study participant signed an informed consent

form. The InSCI Study Group approved the present study based on its protocol.

Consent for publication

Not applicable.

CRediT authorship contribution statement

Olena Bychkovska: Conceptualization, Formal analysis, Methodology, Visualization, Writing – original draft, Writing – review & editing. **Sintip Pattanakuhar:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Mohit Arora:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Karin Postma:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Vegard Strøm:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Conran Joseph:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Piotr Tederko:** Conceptualization, Formal analysis, Methodology, Writing – review & editing. **Armin Gemperli:** Conceptualization, Formal analysis, Methodology, Supervision, Visualization, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare no conflict of interest relevant to this article.

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Abbreviations

SCI	Spinal Cord Injury
InSCI	International Spinal Cord Injury Survey
LHS-SCI	International Learning Health System for Spinal Cord Injury Study
WHO	World Health Organization
ISPRM	International Society of Physical and Rehabilitation Medicine
ISCoS	International Spinal Cord Society
SCI-SCS	Spinal Cord Injury Secondary Health Conditions Scale

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