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ARTICLE

SwiSCI 360° Perspective – Results from the Swiss SCI Survey 2017

Factors influencing specialized health care utilization by individuals with spinal cord injury: a cross-sectional survey

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Abstract

Study design Cross-sectional observational study using data from the second community survey of the Swiss Spinal Cord Injury Cohort Study (Survey 2017) conducted between 03/2017 and 03/2018.

Objectives To identify facilitators of and barriers to utilizing SCI-specialized outpatient clinic and inpatient care by individuals with spinal cord injury (SCI).

Setting Community.

Methods Multivariable logistic regression was used to identify factors influencing (1) the attendance at annual check-ups at SCI-specialized treatment facilities, (2) the utilization of SCI-specialized outpatient clinic care by those who utilized any outpatient clinic care, and (3) the utilization of SCI-specialized inpatient care by those who were hospitalized. Multiple imputation was used to account for missing data.

Results Out of 3959 eligible individuals, 1294 completed the questionnaire (response rate 33%). In the last 12 months, 51% of study participants attended the annual check-up, 33% of outpatient clinic care users utilized SCI-specialized outpatient clinic care, and 44% of those who were hospitalized were hospitalized at a SCI center. Annual check-ups were attended less by women, the elderly, and those with nontraumatic SCI. SCI-specialized outpatient clinic care was less likely to be utilized when individuals with SCI were living with cancer, lived farther away from SCI-specialized treatment facilities or in a minority language region. Specialized inpatient care was less likely to be utilized by women and those with incomplete lesions.

Conclusions SCI-specialized outpatient clinic care must be provided near the residence of individuals with SCI, otherwise non-specialized care is utilized. The reasons why women utilize SCI-specialized care less frequently than men merits further investigation.

Introduction

Individuals with a spinal cord injury (SCI) have complex secondary health condition that demand highly specialized knowledge and experience from a wide range of health care professionals [1, 2]. This experience is hard to gain since SCI is a rare condition, and most health care professionals do not frequently treat individuals with SCI [3]. Consequently, they may lack the necessary knowledge to adequately treat the secondary health conditions of individuals with SCI [4–6]. Therefore, the European Spinal Cord Injury Federation (ESCIF) promotes the centralization of acute care, rehabilitation, and life-long care of individuals with SCI in dedicated centers [1]. Care provided by a multidisciplinary team at SCI-specialized treatment facilities was found to result in better health outcomes [7–9] and is also generally the care preferred by individuals with SCI [2].

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In Switzerland, specialized SCI care is provided by 4 dedicated SCI centers and 2 outpatient clinics affiliated with the Swiss Paraplegic Centre, the largest of the SCI centers. The SCI centers offer acute care and initial rehabilitation for newly injured individuals as well as outpatient and inpatient care and annual check-ups for individuals with SCI living in the community [10]. The 2 affiliated outpatient clinics offer similar services, but to a lesser extent and exclude inpatient care. Check-ups are aimed at early detection and prevention of secondary health conditions and are recommended throughout the lifespan by the International Spinal Cord Society (ISCoS) [11]. The annual check-ups provided at Swiss SCI-specialized treatment facilities include assessments of neurological status, the spinal and musculoskeletal system, pain, skin, the urinary system, and functioning, including self-care, mobility, and bowel and bladder management. In addition, an assessment of the psychological, environmental, financial, and insurance situation is performed based on the bio-psycho-social model of functioning of the International Classification of Functioning, Disability and Health (ICF) [10].

Half of all individuals with SCI in Switzerland can reach one of the 6 SCI-specialized treatment facilities in less than 40 minutes (finding of the current study). However, our recent evidence suggests that some individuals report problems accessing SCI-specialized services and have unmet health care needs [12]. Access barriers were predominantly related to long travel distances to SCI-specialized treatment facilities or unavailability of long-distance transportation options [12]. Some individuals with SCI relocated near SCI-specialized treatment facilities probably due to an increased need for SCI-specialized care [13]. Environmental barriers to accessing SCI-specialized care have also been reported in countries such as Australia [2], Canada [14], and the United States of America [15, 16]. In the United States, a lack of private insurance [15] or low income [15] were both found to have a negative influence on access to SCI-specialized health care among individuals with SCI.

The objective of this study was to identify factors that influence whether individuals with SCI utilize SCI-specialized care (any care from one of the 6 SCI-specialized treatment facilities) or non-specialized care (any care from any other health care provider) for their health conditions in order to identify potential facilitators and barriers to accessing SCI-specialized care. The specific aims were to identify sociodemographic, injury, medical, and geographic characteristics that influence (1) whether the annual check-up at a SCI-specialized treatment facility is taken advantage of, (2) whether SCI-specialized outpatient clinic care is utilized when outpatient clinic care is required, and (3) whether SCI-specialized inpatient care is utilized when inpatient care is required.

Methods

Survey sample

The present study relied on data from the second community survey of the nationwide Swiss Spinal Cord Injury Cohort Study (Survey 2017) [17]. The survey was conducted between March 2017 and March 2018 [17]. A mixed-mode data collection design including paper-and-pencil, online questionnaire, telephone or face-to-face interviews was employed to achieve optimal response rates [17]. Individuals considered eligible were living in Switzerland, with traumatic or nontraumatic SCI, and aged 16 years or older. As per study protocol, "individuals with congenital conditions leading to SCI (e.g., spina bifida), those with neurodegenerative disorders (e.g., multiple sclerosis or amyotrophic lateral sclerosis), and Guillain-Barré syndrome" were excluded [17].

Outcome measures

The first variable of interest was "attendance of the annual check-up at a SCI-specialized treatment facility in the last 12 months". The second was "utilization of SCI-specialized outpatient clinic care at least once in the last 12 months among those who utilized any outpatient clinic care in the last 12 months", and the third was "utilization of SCI-specialized inpatient care at least once in the last 12 months among those who were hospitalized, in any hospital, in the last 12 months". An English translation of the Survey 2017 questionnaires is available online [18].

Predictor variables

The following candidate variables were evaluated for their effect on the utilization of SCI-specialized health care services: sex, age, lesion severity, SCI etiology, time since onset of SCI, health conditions, living arrangement (living alone, with other people, or in an institution such as a retirement home, nursing home, assisted living), language region, driving time by car from the place of residence to the nearest SCI-specialized treatment facility as well as the 2 variables "lack of, or inadequate, adapted means of transportation for long distances" and "financial hardship" from the Nottwil Environmental Factors Inventory Short Form (NEFI-SF) [19]. Further candidate variables evaluated included the number of visits to any outpatient clinic (only used for predicting SCI-specialized outpatient clinic care utilization), number of inpatient hospital stays in any hospital, and number of days in hospital in the last 12 months (only used for predicting SCI-specialized inpatient care utilization).

Table 1 Sociodemographic, medical, and geographic characteristics of the sample populations.

Categorical variables [n missing responses in all participants]	All participants *n* (%)	Users of any outpatient clinic care *n* (%)	Users of any inpatient care *n* (%)
Study participants	1294 (100.0)	713 (100.0)	406 (100.0)
Sex [0], male	918 (70.9)	509 (71.4)	299 (73.6)
Age [0]			
16–30	54 (4.2)	34 (4.8)	17 (4.2)
31–45	253 (19.6)	145 (20.3)	69 (17.0)
46–60	443 (34.2)	246 (34.5)	128 (31.5)
61–75	431 (33.3)	228 (32.0)	144 (35.5)
>75	113 (8.7)	60 (8.4)	48 (11.8)
Lesion severity [142]			
Incomplete paraplegia	484 (42.0)	242 (38.4)	137 (38.2)
Incomplete tetraplegia	252 (21.9)	128 (20.3)	67 (18.7)
Complete paraplegia	327 (28.4)	203 (32.2)	116 (32.3)
Complete tetraplegia	89 (7.7)	57 (9.0)	39 (10.9)
Etiology [11]			
Traumatic	1,027 (80.2)	571 (80.5)	333 (82.6)
Nontraumatic	256 (19.9)	138 (19.5)	70 (17.4)
Health conditions			
Sexual dysfunction [155]	520 (45.7)	314 (49.2)	190 (53.2)
Heterotopic ossification [188]	22 (2.0)	15 (2.4)	11 (3.1)
Spasticity [90]	292 (24.3)	188 (27.7)	112 (29.8)
Cancer [16]	85 (6.7)	46 (6.5)	31 (7.8)
Language region [17]			
German	897 (70.2)	462 (65.4)	242 (60.2)
French	320 (25.1)	220 (31.2)	138 (34.3)
Italian	60 (4.7)	24 (3.4)	22 (5.5)
Driving time to nearest SCI-specialized treatment facility [15]			
≤30 min	465 (36.4)	265 (37.5)	113 (28.1)
31–60 min	538 (42.1)	313 (44.3)	106 (26.4)
61–90 min	262 (20.5)	123 (17.4)	122 (30.3)
>90 min	14 (1.1)	5 (0.7)	61 (15.2)
Continuous variables	**Median (Q1–Q3)**	**Median (Q1–Q3)**	**Median (Q1–Q3)**
Age	57 (46–67)	56 (45–66)	60 (48–70)
Years since SCI [79]	16 (8–28)	16 (7–28)	17 (8–31)
Driving time[a]	38 (25–56)	37 (24–52)	52 (28–78)

Health conditions were defined as present when declared to be of significant or chronic concern during the last 3 months.

SCI spinal cord injury, *Q1* lower quartile, *Q3* upper quartile

[a]Driving time by car from the place of residence to the nearest SCI-specialized treatment facility (4 SCI centers + 2 affiliated outpatient clinics) in minutes. For inpatient care users the driving time to the nearest SCI center was calculated.

Age and time since onset of SCI categories were created using the ISCoS-recommended cut-offs [20]. Lesion level and completeness were combined into the variable lesion severity with the categories, incomplete paraplegia, incomplete tetraplegia, complete paraplegia, and complete tetraplegia. The information on lesion severity was either derived from patient records (if available) or through self-report. Health conditions included were conditions that are commonly encountered by individuals with SCI (secondary health conditions) as well as conditions that are highly prevalent in the general population [21]. These were pressure sores, urinary tract infections, sexual dysfunction, spasticity, respiratory problems, injury caused by loss of sensation, contractures, heterotopic ossification, bladder dysfunction, bowel dysfunction, autonomic dysreflexia, postural hypotension, circulatory problems, sleep problems, pain, diabetes, heart disease, cancer, and depression. These were defined as present when declared to be of significant concern during the last 3 months. The variable language region was created based on the language predominantly spoken in the place of residence of the study participant. The driving time by car from the place of residence to the nearest SCI-specialized treatment facility was estimated using the Google Maps Distance Matrix API [22]. All variables except for lesion severity, language region and driving time were self-reported. More detailed information about the predictor variables can be found in the online version of the survey questionnaire [18].

Missing data and imputation

Multiple imputation was used to create 8 imputed datasets. All predictor variables with missing data were imputed, using the default settings of the R (language for statistical computing) package "mice" (version 3.6.0) [23]. Continuous variables were imputed using predictive mean matching, binary variables were imputed using logistic regression imputation, unordered categorical variables were imputed using polytomous regression imputation, and ordered categorical variables were imputed using the proportional odds model. The variables, age, driving time by car from the place of residence to the nearest SCI-specialized treatment facility, number of outpatient clinic visits, number of inpatient hospital stays, and number of days in hospital were imputed as continuous variables and subsequently categorized. The variables lesion level and completeness of injury were imputed separately and then combined into the variable lesion severity.

Statistical analysis

Predictor variables to be included in the final multivariable logistic regression were selected from the candidate pre-

dictor variables in a two-step procedure described by van Buuren [24]. The first step involved performing a logistic regression separately on each imputed dataset, followed by the construction of a new supermodel that contained all variables that were associated with the outcome variable at a 5% level of significance in at least half of the initial models. Secondly the pooled likelihood ratio p value was calculated. If the largest p-value was greater than 0.05, the corresponding variable was removed, and the procedure was repeated on the reduced model. The procedure stopped when all p-values were less than 0.05. Parameters were pooled according to Rubin's rules [24, 25]. For each predictor variable, estimated relative frequencies (estimated marginal means) were computed, adjusted for the other predictor variables in the regression model using the R package "emmeans" (version 1.4.4) [26]. Data preparation and statistical analyses were performed using R (version 3.6.2).

Results

Participant characteristics

Out of 3959 eligible individuals, 1294 completed the questionnaires (response rate 33%) [17]. Participants were predominantly male (71%), had a median age of 57 years, and a mean time since SCI of 16 years (Table 1). The predominantly reported etiology was traumatic SCI by ~80% of participants. Incomplete paraplegia was the most commonly reported lesion severity (42%), followed by complete paraplegia (28%), incomplete tetraplegia (22%), and complete tetraplegia (8%). The number of individuals from each of the three language regions was roughly representative of the distribution in the general population. The average travel time to the nearest SCI-specialized treatment facility was 38 min, and only 14 individuals (1%) lived further than 90 min from a SCI-specialized treatment facility. Individuals who had been hospitalized in the last 12 months were slightly older, more likely to be male, and more often had a complete lesion. Overall, the participant characteristics of individuals who utilized outpatient clinic care and of those who were hospitalized were similar to those of the whole study population.

Health care utilization

Approximately half of the responding individuals attended the annual check-up at a SCI-specialized treatment facility (51%) (Table 2). More than half (55%) utilized outpatient clinic care in the last 12 months, and those reporting to do so averaged two visits during that time. Additionally, one-third (33%) of the individuals who utilized any outpatient clinic care did so at least once at a SCI-specialized treatment facility. Those individuals with SCI who utilized any inpatient care (31%) had, on average, one hospital stay lasting ten days during the last 12 months. Somewhat fewer than half of the individuals who were hospitalized received inpatient care in a SCI center at least once (44%).

Table 2 Health care utilization in the last 12 months.

$N = 1294$ participants [n missing responses]	Total n (%)
Annual check-up attendance at SCI-specialized treatment facility	657 (50.8%)
Utilization of care from any outpatient clinic	713 (55.1%)
Number of visits[a] [159]	
1	256 (46.2%)
2–4	209 (37.7%)
≥5	89 (16.1%)
At SCI-specialized treatment facility	235/ 713 (33.0%) 235/ 1,294 (18.2%)
Utilization of inpatient care from any hospital	406 (31.4%)
Number of hospital stays[a] [80]	
1	219 (67.2%)
2–4	95 (29.1%)
≥5	12 (3.7%)
Number of days in hospital [62]	
1–5 days	118 (34.3%)
6–20 days	108 (31.4%)
>20 days	118 (34.3%)
At SCI-specialized treatment facility	178/ 406 (44.2%) 178/ 1,294 (13.8%)
Median (Q1–Q3)	
Number of outpatient visits	2 (1–3)
Number of hospital stays	1 (1–2)
Number of days in hospital	10 (4–30)

SCI spinal cord injury, *Q1* lower quartile, *Q3* upper quartile.

[a]Applies to those who have utilized outpatient clinic or inpatient care.

Predictors of SCI-specialized care utilization

Women were less likely than men to attend the annual check-up (44 vs. 53%, respectively) at a SCI-specialized treatment facility (Fig. 1, Supplementary Tables 1 and 2). Also, when being hospitalized, more men (47%) than women (31%) obtained care at a SCI center. The utilization of SCI-specialized care was similar across all age groups except for individuals aged 75 years and older, who were less likely to attend the annual check-up. Individuals with more severe lesions were more likely to attend annual check-ups and more likely to utilize SCI-specialized inpatient care. The utilization of SCI-specialized outpatient clinic care was similar across individuals with different lesion severities. Individuals with nontraumatic SCI were

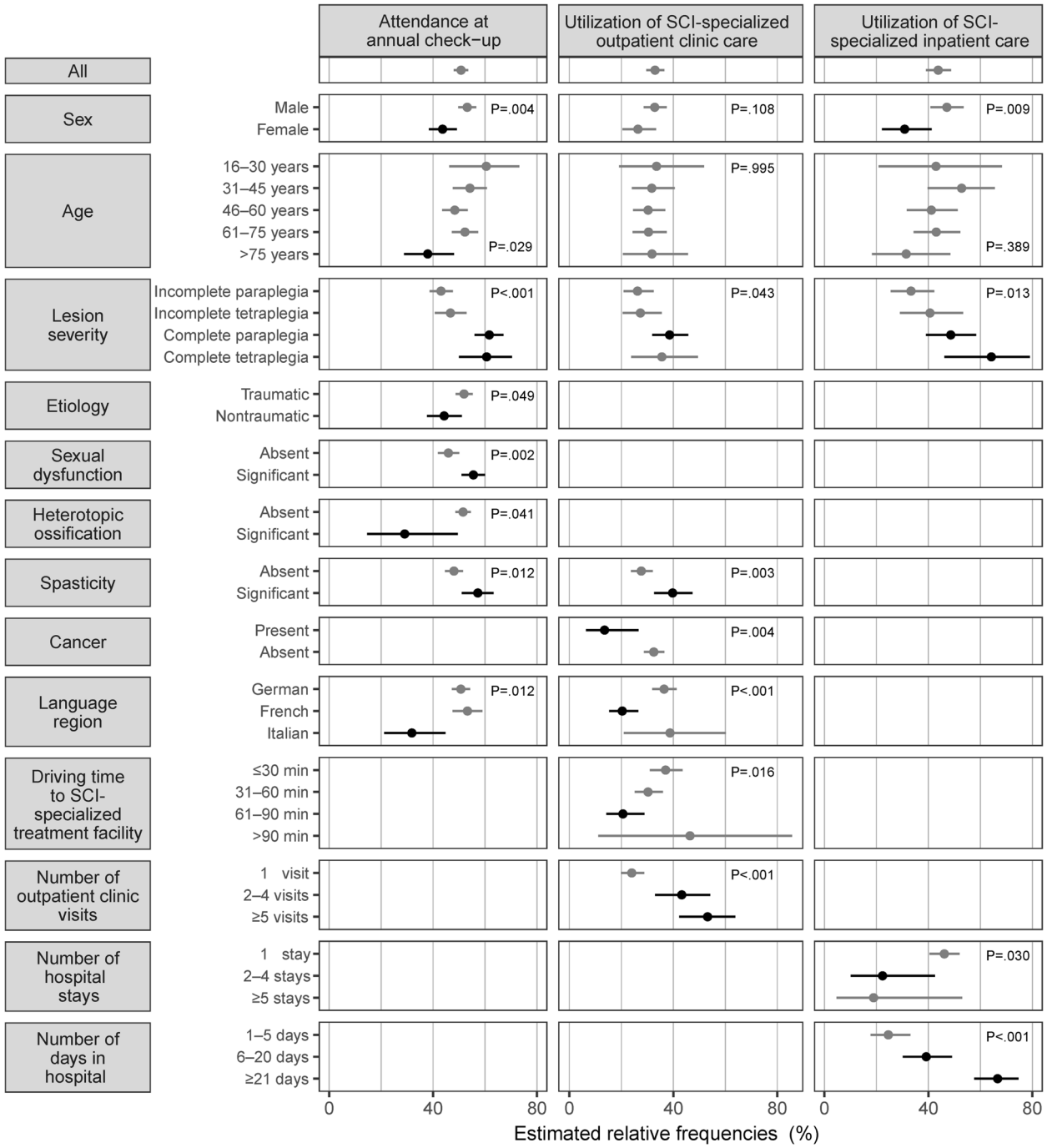

Fig. 1 Estimated relative frequencies of individuals with SCI who utilized SCI-specialized health care at least once in the last 12 months by health care type and individual characteristics. Note: Estimated relative frequencies (estimated marginal means) are based on multivariable logistic regression and adjusted for all predictor variables. The dots represent the point estimates and the bars the 95% confidence intervals. The p-values are based on a likelihood ratio test and indicate how much the model fit improved when the predictor variable was included. Empty boxes indicate that including the variable did not improve the model and, therefore, that the variable was not included in the model. The variables age, sex, and lesion severity were always included. The variable "number of outpatient visits" was only included in the model investigating the utilization of SCI-specialized outpatient clinic care. In contrast, the variables "number of inpatient stays" and "number of days in hospital" were included only when investigating the utilization of SCI-specialized inpatient care. The estimates depicted in black are different (at the five percent significance level) from the reference group (the first category for each variable) as estimated by the logistic regression model.

less likely to attend the annual check-up (check-up attendance rate of 44% compared to 52% for those with a traumatic SCI).

Of the 19 health conditions evaluated, only 4 were associated with attendance at the annual check-up or with utilization of SCI-specialized outpatient or inpatient care. We found higher attendance than average for the entire sample (51%) by individuals with significant sexual dysfunction (56%) and lower attendance by individuals with significant heterotopic ossification (29%). Compared with the average rate of SCI-specialized outpatient clinic care utilization (33%), we found reduced utilization among individuals with cancer (14%) and increased utilization among individuals with significant spasticity (40%). The presence of a health condition in the last three months did not influence whether SCI-specialized inpatient care was utilized in the last 12 months.

Living in an Italian-speaking region was associated with a lower annual check-up attendance rate, while living in a French-speaking region or farther away from SCI-specialized treatment facilities was associated with reduced utilization of SCI-specialized outpatient clinic care. On the other hand, neither the distance to SCI centers nor the language region influenced whether individuals utilized SCI-specialized inpatient care.

The more outpatient clinic care visits individuals had, the greater the chance that they also utilized SCI-specialized outpatient clinic care at least once in the last 12 months. The opposite was observed for inpatient care utilization. The more often individuals were hospitalized, the less likely they were to utilize SCI-specialized inpatient care, and the longer they remained hospitalized, the more likely they were to visit a SCI center for inpatient care.

Discussion

The considerably lower propensity to utilize SCI-specialized care of women was not entirely unexpected but the size of the difference was surprising. In a previous study, we found that women were about 1.5 times less likely than men to be admitted to a SCI center for early acute management and initial rehabilitation after a traumatic SCI [27]. We previously interpreted this finding with caution because it was based on hospital discharge data, which were not collected for research purposes and are known for coding inaccuracies [28]. Now that the same trend has been observed again among individuals with chronic SCI, there is increasing evidence that women are indeed less likely to utilize SCI-specialized care. Regarding check-up attendance, the finding might be explained by a potentially better health status of women or because they get regular check-ups by gynecologists [29]. If individuals with SCI are in good condition, the interval between check-ups is sometimes prolonged from annual to biannual by the physician in consultation with the patient. It is, however, unlikely that a better health status alone explains the differences in check-up attendance since the rates were adjusted for differences in health conditions. The reasons why women were less likely to utilize SCI-specialized care in general and particularly when being hospitalized remain unknown.

The higher propensity to utilize SCI-specialized care among younger individuals, those with higher lesion severity, and those with a traumatic etiology aligns with the results of previous research using administrative inpatient hospital discharge records [27, 30]. The current study confirms the previous research related to inpatient care and in addition found a similar trend for annual check-up attendance and utilization of outpatient care. Many individuals with nontraumatic SCI have undergone treatment at different institutions for their underlying disease that caused SCI. They might therefore have weaker connections to SCI-specialized treatment facilities and may visit them less often for follow-up care. The reasons why individuals with cancer utilized SCI-specialized care less might be similar to those of individuals with nontraumatic SCI. The treatment of cancer is probably given a higher priority than specialized SCI care. Individuals with significant spasticity, on the other hand, were above-average users of SCI-specialized care. Potential reasons might be the lack of clarity about how to best manage spasticity among different health care providers and variations in knowledge and availability of interdisciplinary resources [31, 32]. These problems might be reduced when spasticity is evaluated as part of a comprehensive interdisciplinary, neurological, and physiological assessment in a SCI-specialized setting. The refilling of the baclofen pump or the injection of botulinum toxin is often part of this procedure. Heterotopic ossification often limits activities of daily living [33], which could explain why individuals with significant heterotopic ossification were considerably less likely to attend annual check-ups at SCI-specialized treatment facilities. This observation is supported by a previous finding that individuals with significant heterotopic ossification reported unmet health care needs and insufficient access to SCI-specialized care [12].

Individuals with SCI from minority language regions (French and Italian speaking regions) were less likely to visit SCI-specialized treatment facilities. This finding might be partly explained by a combination of a lower density of SCI-specialized care supply in these regions (longer traveling distances to SCI-specialized treatment facilities) and language barriers. The distance to SCI-specialized treatment facilities alone however did not hinder the attendance at the annual check-up or the utilization of SCI-specialized inpatient care.

Individuals with SCI seemed willing to travel long distances for check-ups that were only scheduled annually or when complications were severe and required hospitalizations. The utilization of SCI-specialized outpatient clinic care, however, seemed to be dependent on the travel distance to SCI-specialized treatment facilities. This finding is in line with previous research where the willingness to utilize SCI-specialized care was considerably reduced with longer travel times [12]. The previous study showed that individuals with SCI who lived 70+ minutes away from a SCI center preferred to utilize local health care providers.

Frequent users of outpatient clinic care likely had more severe health conditions and were more likely to utilize SCI-specialized care. Interestingly, the opposite was noted for inpatient care, where the propensity to visit a SCI center was reduced as the number of hospitalizations increased. This finding might be related to repeated hospitalizations for health conditions that are not related to SCI such as, for example, cancer.

No effect on the utilization of SCI-specialized care was found for financial hardship, time since injury, or whether somebody was living alone, with other persons, or in an institution.

Limitations

This study is subject to several limitations. Since SwiSCI participants were predominantly recruited through SCI-specialized treatment facilities, it might be that they were more likely to utilize care from SCI-specialized treatment facilities than other individuals with SCI in Switzerland. Therefore, the rates of SCI-specialized care utilization reported in the current study might be overestimated. Conversely, the Survey 2017 was subject to minimal non-response bias [17], and therefore we expect the findings of the current study to be mostly representative of the group of all individuals with SCI. Second, the health conditions that were used as predictor variables only provided information about the health status in the last three months, while health care utilization was recorded over 12 months. A further problem with the health conditions variables was that they were self-rated. Third, the medical conditions for which individuals with SCI utilized health care are not known. It is possible that medical conditions, not related to SCI and thus not requiring SCI-specialized care, were unevenly distributed across the groups studied (e.g., study participants from different language regions). Lower utilization of SCI-specialized health care could then be incorrectly interpreted as underuse of appropriate care. It is, however, unlikely that the significant differences in SCI-specialized care utilization between the groups studied were fully explained by an uneven distribution of conditions that do not require SCI-specialized care.

Conclusion

Women were much less likely to utilize specialized SCI care than men, particularly when needing hospitalization. Given the evidence that SCI-specialized care is preferred for SCI-associated health problems and might lead to a better health outcome, it is important to further investigate this finding in order to remove potential barriers to accessing SCI-specialized care. Longer travel distances to SCI-specialized treatment facilities did not seem to hinder the annual check-up attendance or utilization of SCI-specialized inpatient care but reduced the utilization of SCI-specialized outpatient clinic care. The introduction of additional SCI-specialized outpatient clinics in underserved regions should be considered to support equal access to SCI-specialized services for individuals living in remote and minority language regions.

Data availability

Owing to our commitment to SwiSCI study participants and their privacy, datasets generated during the current study are not made publicly available but can be provided by the SwiSCI Study Center based on reasonable request (contact@swisci.ch).

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Author contributions ER, AG, ID, and AKS were responsible for conceptualization of the analysis. ER and AG were responsible for data analysis and ER, AG, AKS, ID, IEH, and MB were responsible for the interpretation of results.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical statement Ethical approval was granted by the Ethikkommission Nordwest- und Zentralschweiz (EKNZ, Project-ID: 11042 PB_2016-02608, approved Dec 2016). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

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