

Research Article

Satisfaction with access and quality of healthcare services for people with spinal cord injury living in the community

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Objective: To identify barriers to access healthcare services and reveal determinants of satisfaction with healthcare services in people with chronic spinal cord injury (SCI).

Design: Cross-sectional survey.

Setting: Community setting in Switzerland.

Participants: People with chronic SCI.

Interventions: Non-applicable.

Outcome Measures: Questionnaire-based evaluation of availability and quality of healthcare services for secondary health conditions, satisfaction with fulfillment of healthcare needs, and preference for care from a hypothetical service provider with limited specialized SCI care expertise but in close proximity over comprehensive care from an existing specialized SCI center located at a greater distance.

Results: Close to three-quarter of participants (70%) indicated satisfaction with healthcare services received for SCI related health conditions. Elderly individuals (61+ years old) rated the availability and quality of healthcare 6% to 11% higher than younger individuals. The perceived fulfillment of healthcare needs was lower in people with incomplete paraplegia (odds ratio (OR) 2.11, 95%-credibility interval (CI) 1.18–3.84), chronic pain (OR 1.85, CI 1.12–3.08), insufficient access to long distance transportation (OR 5.81, CI 2.74–12.82), and longer travel distances to specialized SCI centers.

Conclusion: Perceived inadequateness of access to healthcare services was partly related to transportation barriers, suggesting that outreach services or support with transportation are possible solutions. People with incomplete paralysis and pain consistently rated the fulfillment of care needs associated with SCI less favorably, pointing to the need for enhanced advocacy for this vulnerable groups.

Keywords: Spinal cord injury, Healthcare availability, Healthcare quality, Patient satisfaction, Spatial analysis

Introduction

People with spinal cord injury (SCI) are confronted with a wide range of adverse health conditions specific to SCI,¹ leading to more frequent visits to general

practitioners (GPs), outpatient clinics and inpatient hospitals compared to the general population.^{2,3} SCI is a relatively rare and complex health condition; therefore, local healthcare providers may lack the knowledge to adequately meet the healthcare needs of people with SCI. For this reason, the European Spinal Cord Injury Federation (ESCI) promotes the centralization of the treatment, rehabilitation, and life-long care of people with SCI,⁴ which may result in negative consequences

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for individuals living in remote areas. The majority of people with SCI in Switzerland depend on mobility devices (68%) and have experienced environmental barriers to receiving treatment.⁵ Previous research has reported that the utilization of specialist care is reduced with increasing distance from the specialized healthcare facilities,⁶ leading to the use of inadequate services located in close proximity when appropriate care is not readily available or accessible.⁷

The objective of this study was to investigate the perceived availability and quality of care for SCI-related health conditions with the goal to identify barriers of access to adequate healthcare services. The specific aims were to reveal the sociodemographic, medical, and geographic factors that influence (1) the perceived availability of SCI-related care in the region in which people reside, (2) the perceived quality of SCI-related services in primary care in the region in which people reside, (3) the perceived fulfillment of SCI-related care needs, and (4) the preference for care from a hypothetical service provider with limited specialized SCI care expertise but in close proximity over comprehensive care from an existing specialized SCI center located at a greater distance.

Our research complements and extends recent research in the field. Stillman and Hamilton, when studying barriers to healthcare utilization in individuals with SCI, mention small sample sizes and potentially low representativeness when recruiting participants from a single clinic as study limitations.^{8,9} By contrast, the present study relied on a diverse and representative sample of almost five hundred individuals living in the community in an entire country.^{10,11} Bell *et al.*, in their study on healthcare service utilization, emphasize the importance of geography and care access in health of individuals with SCI. They report that these were largely under-investigated determinants.¹² Finally, Bell *et al.* concluded that “[it] requires further discussion whether there is an ‘ideal travel distance’ benchmark for which to evaluate whether there is adequate utilization and availability of healthcare resources”. We sought to address this question in our study.

Methods

Design, setting, and population

The study was based on a community survey within the Swiss Spinal Cord Injury (SwiSCI) cohort study,^{10,13} conducted in Switzerland between late 2011 and early 2013, and involving individuals with traumatic or non-traumatic SCI, 16 years or older, and living in the community. The study was approved by the respective cantonal ethics committees and each participant gave their

consent. Participants were recruited through the national association for people with SCI, three specialized SCI centers, and a SCI-specific professional home-care institution. Individuals with limited hand function could answer the questionnaires by telephone, whereas others chose between paper-and-pencil and online questionnaires.

Outcome variables

Outcome variables that measure dissatisfaction with healthcare services were evaluated according to questions adapted from the Swiss Health Survey 2007 and were assessed according to self-ratings.¹⁴ The outcome “dissatisfaction with availability of SCI-related care in the residential region” was constructed from the two questionnaire items “satisfaction with availability of SCI-related medical care services in the region in which people reside” and “satisfaction with availability of SCI-specific therapy in the region in which people reside” using a generalized partial credit model (gpcm).^{15,16} In this way, the two similar and correlated items on an ordinal scale were combined into a single construct on an interval scale. Rasch residuals of the gpcm model were inspected for unidimensionality by means of principal component analysis, and for local item independence. Differential item functioning was investigated for age, sex, and lesion level using logistic regression conditional on observed scores. Item characteristic curves were inspected for item discrimination. The derived interval scale was reversed and projected on a new scale from 0 to 100 in which a change in dissatisfaction is expressed as percentage of the data range and higher values represent higher dissatisfaction.

The same approach was used to assign the outcome “dissatisfaction with quality of SCI-related services in primary care in the residential region” from the two questionnaire items “satisfaction with quality of SCI-related care provided by general practitioners in the region in which people reside” and “satisfaction with quality of SCI-related care provided by home care professionals in the region in which people reside”.

The outcome “dissatisfaction with fulfillment of SCI-related care needs” was assigned by dichotomizing the item “satisfaction with fulfillment of SCI-related care needs” into dissatisfaction (i.e. no, low and partial fulfillment of care needs) versus satisfaction (i.e. complete, large fulfillment of care needs, and no use of SCI-related services) with fulfillment of healthcare needs. The outcome “preference for care from a hypothetical service provider with limited specialized SCI care expertise but in close proximity over comprehensive care from an existing specialized SCI center located at a greater

distance” was dichotomized by omitting the “no opinion” answer category from the analysis.

Explanatory variables

Individual-level variables

Age, sex, severity of SCI, financial hardship, availability of short and long-distance transportation, and the secondary health conditions chronic pain, bladder dysfunction, bowel dysfunction, urinary tract infection, and heterotopic ossifications were used as explanatory variables in the statistical analysis. Age categories were created following the recommendations of DeVivo *et al.* and Hinrichs *et al.*^{17,18} The two lowest age categories (16–30 and 31–45 years) were combined due to small sample size in the youngest category ($n = 29$). Financial hardship was defined as those participants reporting to have experienced financial difficulties over the past four weeks.

Secondary health conditions were included in the analysis if comprised in the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) and when significantly associated with one of the four outcome variables in a univariable regression analysis ($P < 0.05$).^{19,20} Secondary health conditions were defined as absent when declared to be of no or mild concern, and present when declared to be of moderate or significant concern, during the last 3 months. Participants were considered to face major problems with short distance transportation when they reported having experienced inadequate access to adapted assistive technology for moving short distances (e.g. stair lift, walking aids). Major problems with long distance transportation was defined as inadequate access to adapted means of transportation for long distances (e.g. no adapted car or hard to use public transport).⁵

Aggregate-level geographic variables

Participants’ place of residence was referenced to MedStat regions, a subdivision of Switzerland into 705 zones each containing between 3,500 and 10,000 inhabitants.²¹ The degree of urbanization in each MedStat region was defined equivalent to the municipality with the highest degree of urbanization according to the Swiss Federal Statistical Office.²² Travel times by car from the place of residence (centroid of MedStat region) to the closest of four specialized SCI centers were estimated using the Google Maps Directions API.²³ For the spatially structured part of the regression models, regions with at least five participants were included. Regions with fewer participants were iteratively merged with the neighboring region with the

highest number of participants until a minimum of five participants per region was reached.

Statistical analysis

Spatially structured linear and logistic regression models were computed using the R-INLA library in the R programming language.²⁴ This suite of functions allow for fast Bayesian inference using Laplace approximation. The two Rasch-constructed interval-scaled response variables were investigated using linear regression analyses, and the binary response variables were examined using logistic regression models. The regression models accounted for residual spatial autocorrelation by including region-specific random effects with conditional autoregressive prior distribution within the hierarchical Bayesian model.²⁵ The effect of travel time was modelled as smoothed curve using a random walk of order 2.²⁶ Missing covariate values were imputed using the missForest library with all variables used in the imputation process.²⁷ Statistical analyses were performed using the R programming language version 3.3.2.²⁸

Results

Sociodemographic and injury characteristics

The 492 study participants (86% response rate) were on average 57 years old and predominantly male (71%) (Table 1). Twice as many participants had paraplegia (43% had a complete loss of sensory and motor function, 57% incomplete) as had tetraplegia (30% complete and 70% incomplete). The median car travel time from the place of residence to the closest SCI center was 50 minutes. The availability of appropriate short- and long-distance transportation was identified as a major problem for 11% and 14% of the participants, respectively.

Satisfaction with SCI-related care

Close to two-thirds of participants (60% and 64% for medical care and therapy availability, respectively) reported high or very high satisfaction with the availability of SCI-related healthcare in the region in which they reside (Table 2). Similarly, over half (55%) of the participants perceived the service quality of GPs as high or very high. Professional home care services were not utilized by more than half (54%) of the participants. The majority of professional home care users reported a high or very high satisfaction with the quality of services provided in the region in which they reside (70%). Of those who required SCI-related healthcare, 68% reported their needs as largely or completely met. When asked whether the study participants would rather visit one of four existing specialized SCI centers with a full

Table 1 Characteristics of the SCI population.

	N = 492
Age in years – median (Q1, Q3)	57 (44, 67)
Sex – male, n (%)	350 (71.1)
Lesion level, n (%)	
Paraplegia	338 (69.3)
Tetraplegia	150 (30.7)
Severity, n (%)	
Complete	192 (39.3)
Incomplete	297 (60.7)
Financial hardship, n (%)	
None	356 (74.8)
Little	83 (17.4)
Major	37 (7.8)
Secondary health condition	
Chronic pain	266 (59.2)
Bladder dysfunction	191 (43.1)
Urinary tract infection	175 (39.9)
Bowel dysfunction	187 (41.6)
Heterotopic ossification	10 (2.3)
Language region, n (%)	
German	347 (70.5)
French	122 (24.8)
Italian	23 (4.7)
Residential area, n (%)	
Urban	125 (25.7)
Suburban	225 (46.3)
Rural	136 (28.0)
Availability of short distance transportation, n (%)	
Major problem	54 (11.2)
Availability of long distance transportation, n (%)	
Major problem	65 (13.6)
Driving time to closest specialist SCI center in minutes – median (Q1, Q3)	50 (29, 75)

The number of missings was less than 3.3 percent in all items except for the health conditions (8.7–11.8 percent). SCI, spinal cord injury; Q1, lower quartile; Q3, upper quartile.

range of services versus preferring treatment at a hypothetical closer SCI clinic with limited specialist SCI care, approximately 40% equally preferred either option.

Verification of interval scale variables

Unidimensionality in the ordinal items was verified for both constructs in a confirmatory factor analysis based on polychoric correlations (variance explained 0.84 and 0.70, respectively), and was substantiated in a principal component analysis of Rasch residuals. Correlation analysis on Rasch residuals confirmed that the assumption of local item independence was not violated. We found no evidence of differential item functioning, and examination of the item characteristic curves suggested good discrimination and ordered thresholds. The interval scale of the two constructed response variables, the frequency distribution of dissatisfaction scores on this scale, and the corresponding ordinal categories of the four items used to construct the two outcome variables are depicted in [supplemental Figure S1](#).

Table 2 Satisfaction with care for SCI-related health conditions.

	N = 492
Satisfaction with availability of SCI-related medical care services in the region in which people reside, n (%)	
Very high	123 (26.2)
High	160 (34.1)
Neutral	103 (22.0)
Low	63 (13.4)
Very low	20 (4.3)
Satisfaction with availability of SCI-related therapy in the region in which people reside, n (%)	
Very high	124 (26.7)
High	172 (37.1)
Neutral	111 (23.9)
Low	46 (9.9)
Very low	11 (2.4)
Satisfaction with quality of SCI-related care provided by general practitioners in the region in which people reside, n (%)	
Very high	103 (22.3)
High	152 (33.0)
Neutral	134 (29.1)
Low	60 (13.0)
Very low	12 (2.6)
Satisfaction with quality of SCI-related care provided by home care professionals in the region in which people reside, n (%)	
Very high	59 (12.1)
High	78 (16.0)
Neutral	51 (10.5)
Low	25 (5.1)
Very low	9 (1.8)
Services not used	266 (54.5)
Satisfaction with the fulfillment of SCI-related care needs, n (%)	
Complete	164 (34.5)
Large	114 (24.0)
Partial	67 (14.1)
Low	43 (9.1)
No	20 (4.2)
Services not used	67 (14.1)
Preference for care from a hypothetical service provider with limited specialized SCI care supply but in close proximity over comprehensive care from an existing specialized SCI center located at a greater distance, n (%)	
Preference for closer care	192 (40.2)
Preference for more specialized care	199 (41.6)
No opinion	87 (18.2)

SCI, spinal cord injury.

Determinants of dissatisfaction and preference

Elderly participants rated the availability of SCI-related care in the region in which they reside more favorably compared to participants aged 45 years and younger (6% and 11% higher satisfaction in 61-75 and 76+ years' old participants, respectively) ([Table 3](#)). The elderly were also found to report higher satisfaction with the quality of SCI-related services in primary care (8% and 9% higher in 61-75 and 76+ years' old participants, respectively). Neither sex nor financial hardship was significantly associated with any of the four studied outcomes. Of the five secondary health conditions that were significantly associated with any of the outcomes in univariable regression models, chronic

pain, urinary tract infection, and heterotopic ossification remained statistically significant in the multivariable regression models. Participants with chronic pain were almost twice as likely to report that their SCI-related care needs were not met (odds ratio (OR) 1.85, 95%-credibility interval (CI) 1.12–3.08) compared to participants without chronic pain. The preference for care from a hypothetical service provider with limited specialized SCI care expertise in close proximity was 1.74 times higher (CI 1.06–2.89) for participants who suffered from urinary tract infections. Reported satisfaction with availability of SCI-related care services in the residential region was 15% (CI 0% – 31%) lower when participants were suffering from heterotopic ossification. Participants living in rural areas were twice as likely to be satisfied with how their SCI-related care needs were met (OR 0.50, CI 0.26–0.97) as compared to participants from urban areas. Those participants

who reported insufficient access to short distance transportation rated the regional availability of SCI-related care services and the quality of primary care services in the region in which they reside less favorably (13%, CI 4% – 21% and 11%, CI 4% – 18%, respectively). When examining the raw numbers, people with insufficient access to short distance transportation were more likely to report low or very low satisfaction with the regional availability of SCI-related medical care services and with the quality of SCI-related care provided by regional GPs (43.4% and 29.6%, respectively), as compared to people with good access to short distance transportation (14.5% and 13.8%, respectively). Reported satisfaction with quality of primary care services was also lower (7% CI 1–14%) when access to long distance transportation was insufficient. A lack of accessibility to long distance transportation was strongly associated (OR 5.81, CI 2.74–12.82) with a perception of unmet

Table 3 Individual and geographical determinants of satisfaction with and preference for SCI-related healthcare.

	Dissatisfaction with			Preference
	availability of SCI-related care in the residential region Percent change (95%-CI)	quality of SCI-related services in primary care in the residential region Percent change (95%-CI)	fulfillment of SCI-related care needs OR (95%-CI)	to visit a closer but smaller SCI center OR (95%-CI)
Age, ref: 16–45 years				
46–60 years	-3.0 (-8.8–2.8)	-2.3 (-6.9–2.4)	1.66 (0.90–3.12)	1.05 (0.58–1.91)
61–75 years	-5.9 (-11.6 – -0.2)*	-8.0 (-12.6 – -3.5)**	1.44 (0.78–2.71)	1.32 (0.74–2.37)
76+ years	-10.5 (-19.8 – -1.2)*	-8.7 (-16.2 – -1.1)*	0.84 (0.28–2.31)	1.31 (0.44–3.87)
Sex, female	-0.1 (-5.1–4.9)	-1.9 (-5.9–2.1)	1.21 (0.73–2.00)	1.54 (0.93–2.56)
Severity, ref: Complete paraplegia				
Incomplete paraplegia	-0.4 (-5.9–5.0)	2.5 (-1.9–6.9)	2.11 (1.18–3.84)*	0.44 (0.25–0.77)**
Complete tetraplegia	5.5 (-2.8–13.8)	6.3 (-0.4–12.9)	1.62 (0.65–3.88)	0.55 (0.25–1.23)
Incomplete tetraplegia	1.9 (-4.3–8.2)	4.4 (-0.6–9.4)	1.38 (0.69–2.74)	0.90 (0.49–1.65)
Financial hardship, ref: None				
Moderate	1.4 (-4.5–7.2)	-0.4 (-5.1–4.3)	1.37 (0.75–2.44)	0.94 (0.52–1.70)
Major	5.9 (-2.5–14.4)	-0.7 (-7.5–6.1)	1.35 (0.59–3.01)	1.64 (0.66–4.25)
Secondary health condition, ref: Absence				
Chronic pain	-1.1 (-5.9–3.6)	-0.2 (-4.0–3.6)	1.85 (1.12–3.08)*	0.69 (0.43–1.12)
Bladder dysfunction	2.7 (-2.5–8.0)	0.3 (-3.9–4.6)	1.47 (0.85–2.53)	0.65 (0.38–1.11)
Bowel dysfunction	4.6 (-0.5–9.6)	-0.2 (-4.2–3.9)	1.51 (0.92–2.50)	1.37 (0.83–2.29)
Urinary tract infection	4.0 (-1.0–9.1)	4.0 (-0.1–8.1)	0.85 (0.50–1.43)	1.74 (1.06–2.89)*
Heterotopic ossification	15.4 (0.1–30.7)*	1.9 (-10.4–14.3)	3.52 (0.86–15.71)	1.45 (0.34–7.64)
Language region, ref: German				
French	4.6 (-0.9–10.1)	3.5 (-1.0–8.0)	0.96 (0.53–1.72)	1.83 (0.89–3.74)
Italian	-2.8 (-16.4–11.3)	2.0 (-9.2–13.9)	0.41 (0.09–1.72)	0.49 (0.09–2.44)
Residential area, ref: Urban				
Suburban	-1.8 (-7.2–3.7)	-2.1 (-6.5–2.3)	0.87 (0.51–1.52)	1.05 (0.59–1.87)
Rural	-3.0 (-9.1–3.1)	-0.8 (-5.7–4.2)	0.50 (0.26–0.97)*	0.84 (0.43–1.64)
Availability of short distance transportation, ref: No or minor problem				
Major problem	12.6 (3.8–21.4)**	10.9 (3.9–18.0)**	0.99 (0.40–2.31)	0.94 (0.37–2.41)
Availability of long distance transportation, ref: No or minor problem				
Major problem	2.4 (-5.6–10.4)	7.4 (1.0–13.8)*	5.81 (2.74–12.82)**	1.63 (0.70–3.88)

Parameter estimates based on multivariable mixed-effects logistic or linear regression, adjusted for all shown variables and driving time by car to the closest specialized SCI center, modelled as smoothed curve (presented in figures 1A, B, C and D).

SCI, spinal cord injury; ref, reference population; OR (95%-CI), Odds ratio with 95% credibility interval.

* P < 0.05; ** P < 0.01.

SCI-related care needs. In other words, the risk of experiencing unmet SCI-related healthcare needs was almost three times as high for those with problems accessing long distance transportation (61.9%) than for those without (22.2%).

In general, participants who lived further away from SCI centers rated the availability of SCI-related care, the quality of services in primary care, and the fulfillment of SCI-related healthcare needs less favorably (Figures 1A, B, and C). The longer the participants were required to travel to a SCI center, the more likely they would diminish benefits of comprehensive services at an existing specialized SCI center in favor of more proximate services at a smaller less specialized SCI clinic (Figure 1D). The majority of people with SCI who were required to travel less than 69 minutes to an existing SCI center preferred treatment at one of these centers, whereas participants who travelled for longer periods reported a desire to obtain services from a closer but smaller SCI clinic. Geographic variation in satisfaction with care and preference are shown in Figures 2A, B, C and D.

Discussion

Satisfaction with healthcare

Satisfaction with the regional availability of SCI-related care services, with the quality of SCI-related services in primary care and with the fulfillment of SCI-related healthcare needs, was high or very high in 55 to 70% of participants. Several other studies evaluated primary care services in people with SCI and reported higher satisfaction (66-80%) compared to our study.^{8,29-31} In a recent study, Stillman *et al.* found a similar degree of satisfaction (54%) for participants in the United States.⁹ However, their participants felt much more often that they had been provided incomplete care related to their disability (66% as compared to 13% in our study). Another study by Beatty *et al.*, also conducted in the United States, found that 23% of people with a disability did not receive needed primary care, and 18% did not receive needed specialist care.³² Similarly, two more studies from the United States, by Meyers *et al.* and Godleski *et al.*, reported problems obtaining necessary care in 25% and 20% of people with SCI, respectively.^{29,33}

Age effect on satisfaction with healthcare

Positive associations between elderly people and favorable perception of care, as found in our study, is well reported in the general population.^{34,35} In SCI, this finding is consistent with that of a Norwegian study

by Hagen *et al.* who found that the elderly reported the highest degree of satisfaction with their GP among all age groups.³¹ It was presumed that a higher utilization of primary care services result in more opportunities to be favorably influenced by the services provided.^{3,31,34} Another explanation is that elderly people have fewer expectations regarding the SCI-related knowledge of their primary care provider. Furthermore, it is possible that elderly people with SCI have accumulated valuable experience during the management of their secondary conditions that ultimately compensates for a lack of knowledge among GPs.

Lesion characteristics and satisfaction with healthcare

Individuals with incomplete paraplegia most often reported dissatisfaction with the fulfillment of SCI-related care needs. This finding is consistent with the study of Hagen *et al.* who found that individuals with incomplete paraplegia were the least satisfied with GP services among all individuals with SCI.³¹ This could be caused by a discrepancy between the physician's evaluation and how the patients perceive their health condition.³¹ Individuals with incomplete paraplegia suffer from similar secondary health complications as people who comply with the stereotypical image of an individual with SCI. However, anecdotal evidence from conversations of specialists with patients at SCI centers suggested that non-specialist physicians are often unaware of these complications. Raising awareness for these problems among physicians may serve to prevent frustration, increase treatment quality, and reinforce more trusting relationships between physicians and individuals with incomplete paraplegia.

Our study found that individuals with incomplete paraplegia prefer to obtain care at specialized SCI centers rather than seeking care in smaller, more proximate, but less specialized SCI clinics. This signifies a higher awareness of the many difficulties related to incomplete lesions by specialists at SCI centers. However, this does not translate to higher utilization of services at specialized centers in individuals with an incomplete lesion as compared to those with a complete lesion.³⁶

Secondary health conditions and satisfaction with healthcare

Chronic pain was the only investigated secondary health condition that demonstrated a statistically significant association with unmet healthcare needs. Ten

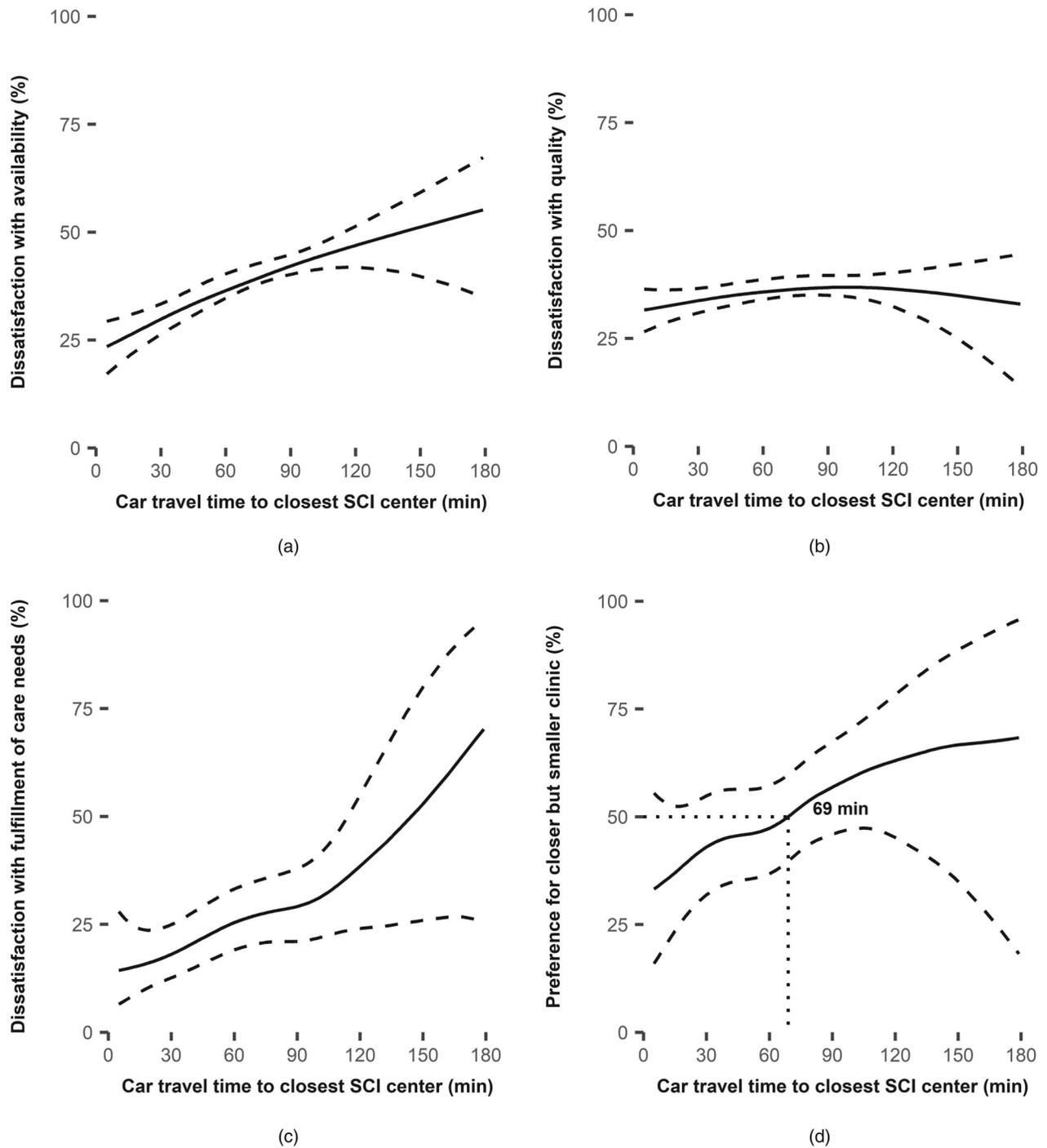


Figure 1 (a) Influence of car driving time to the closest SCI center on dissatisfaction with availability of SCI-related care in the residential region. (b) Influence of car driving time to the closest SCI center on dissatisfaction with quality of SCI-related services in primary care in the residential region. (c) Influence of car driving time to the closest SCI center on dissatisfaction with fulfillment of SCI-related care needs. (d) Influence of car driving time to the closest SCI center on preference for closer less specialized care over care from an existing SCI center.

participants reported instances where they did not receive the needed care for their pain problems, and three participants explicitly stated that neither specialist interventions at SCI centers nor high doses of painkillers were able to relieve pain. Our findings suggest that the

inadequate treatment of neuropathic pain causes a feeling of frustration, perceived injustice, and dissatisfaction with healthcare.³⁷ The strong association between having pain and experiencing unmet healthcare needs demonstrates the urgent need for new treatment options.

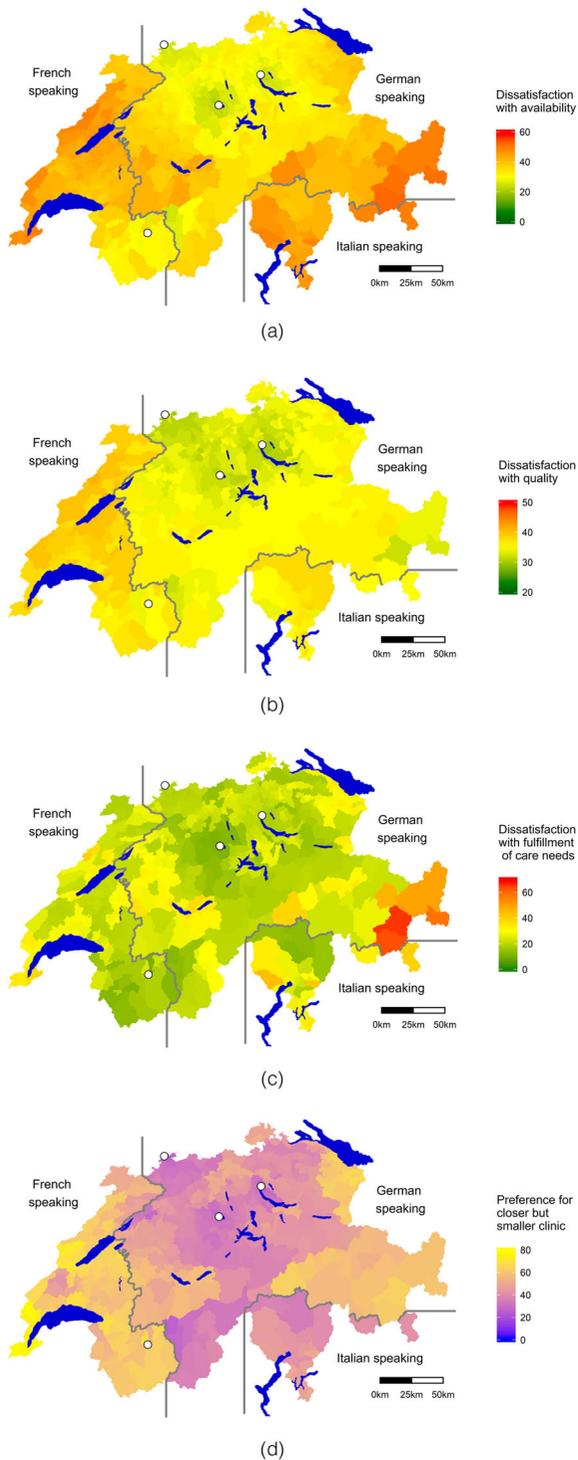


Figure 2 (a) Map of absolute dissatisfaction with availability of SCI-related care in the residential region. Grey lines: Language borders. Circles: locations of the four centers for spinal cord injury. From north to south: Rehab Basel; University clinic Balgrist, Zurich; Swiss Paraplegic Centre, Nottwil; Clinique romande de réadaptation, Sion. (b) Map of absolute dissatisfaction with quality of SCI-related services in primary care in the residential region. (c) Map of absolute dissatisfaction with fulfillment of SCI-related care needs. (d) Map of absolute preference for closer less specialized care over care from an existing SCI center.

Individuals with urinary tract infections preferred closer but smaller SCI clinics over more comprehensive specialist care at large SCI centers located at greater distances from their place of residence. The requisite understanding and training of urinal tract management and the equipment to perform urodynamics are unlikely to be available at general hospitals. Frequently uncomplicated urinary tract infections without fever can be treated empirically with oral antibiotics and people with SCI might be less willing to travel to distant SCI centers for urinary tract management.^{38,39}

We found that individuals with heterotopic ossification perceived the availability of SCI-related care in the region in which they reside as insufficient. However, we caution that this result is based on a relatively small sample ($n = 10$), thus limited statistical power precludes making robust conclusions from this finding.

Geographical characteristics

As expected, satisfaction with the availability of SCI-related care in the region in which people reside was higher when specialized SCI centers were located in close proximity. Furthermore, the quality of SCI-related services provided by local primary care professionals (i.e. GPs and home care professionals) was rated more favorably by participants living closer to SCI centers. It is possible that GPs and home care professionals near SCI centers are collaborating more closely with specialists, resulting in greater knowledge of SCI. Individuals who required to travel more than 69 minutes to an existing specialized SCI center would more likely forgo comprehensive specialist care at one of those centers in exchange for less extensive local care from a hypothetically smaller, less specialized SCI clinic.

Geographic patterns in the survey data suggests that particularly in the French-speaking regions located far away from SCI centers, people with SCI were dissatisfied with the availability and quality of SCI-related services and desire SCI-related care that is closer to where they live. This finding has a number of implications for resource allocation. A possible way to reduce unmet healthcare needs is to introduce outreach services or small outpatient SCI clinics, especially for those living in minority language regions and further away than 69 minutes by car from a SCI center. People from rural areas reported less unmet healthcare needs than people living in urban areas. This result is supported by Goodridge *et al.* who found that people with SCI living in a rural areas valued the benefits of the region in which they reside more so than greater availability of care in urban centers.⁴⁰

The present study is the first to investigate access to adequate healthcare services for follow-up care for individuals with SCI using spatial statistical methods. By doing so we determined the willingness (with respect to time) that people with SCI will travel for specialized care. This new information informs more optimal resource allocation and can serve as an “ideal travel distance” benchmark for the identification of appropriate locations for new specialized clinics. The unexpected finding that people with incomplete paraplegia were the least satisfied with the fulfillment of their healthcare needs has previously only been described in a small sample of individuals with incomplete paraplegia and was restricted to GP services.³¹ Our results warrant the attention of physicians in order to prevent frustration with healthcare provision in the future.

Study limitations

It is important to discuss a number of potential study limitations. Satisfaction is highly subjective as expectations and personal characteristics play an important role in how people experience healthcare services.⁴¹ Furthermore, the lesion level, lesion completeness, and secondary health conditions were self-reported and therefore are not as accurate as those contained in healthcare records. However, the lesion characteristics of the survey participants were reported to be highly reliable, with substantial agreement between self-report and medical record data.¹⁰ There are potential barriers to care that were not addressed in this study, including long waiting times, unavailability of services at a specific time, high costs, lack of knowledge on who needs to be contacted or a lack of SCI expertise of the healthcare provider. These barriers have been previously discussed for the present study population.⁴²

Conclusion

We found that satisfaction with healthcare was strongly related to long travel time to SCI centers and lack of access to suitable transportation. Outreach services or support with transportation options (e.g. provision of disability friendly taxi services, stair lift, walking aids) are suggested solutions. In regions where individuals with SCI are required to travel longer than 69 minutes to specialized SCI centers, the introduction of decentralized SCI outpatient clinics could improve access to healthcare. Individuals with incomplete paralysis and pain were the least satisfied with the fulfillment of SCI-related care needs, which points to the need for prioritization of more comprehensive care for this vulnerable groups.

Abbreviations

CI	Credibility Interval
ESCIF	European Spinal Cord Injury Federation
GP	General Practitioner
GPCM	Generalized Partial Credit Model
INLA	Integrated Nested Laplace Approximations
OR	Odds Ratio
Q1, Q3	Lower, Upper Quartile
SCI	Spinal Cord Injury
SCI-	Spinal Cord Injury Secondary Conditions
SCS	Scale
SwiSCI	Swiss Spinal Cord Injury Cohort Study

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