First Contact of Care for Persons With Spinal Cord Injury: A General Practitioner or a Spinal Cord Injury Specialist?

Dima Touhami (✉ dima.touhami@paraplegie.ch)  
Department of Health Sciences and Medicine, University of Lucerne, 6002 Lucerne, Switzerland  
https://orcid.org/0000-0003-4598-8932

Mirjam Brach  
Schweizer Paraplegiker Forschung

Stefan Essig  
Institute of Primary and Community Care- Luzern

Elias Ronca  
Schweizer Paraplegiker Forschung

Isabelle Debecker  
REHAB- Basel

Inge Eriks-Hoogland  
Swiss Paraplegic Centre: Schweizer Paraplegiker Zentrum

Anke Scheel-Sailer  
Swiss Paraplegic Centre: Schweizer Paraplegiker Zentrum

Nadja Münzel  
ParaHelp

Armin Gemperli  
University of Lucerne: Universitat Luzern

Research article

Keywords: General practitioner, SCI specialist, spinal cord injury, first contact of care, secondary health conditions, shared-care model

DOI: https://doi.org/10.21203/rs.3.rs-191655/v1

License: © This work is licensed under a Creative Commons Attribution 4.0 International License.  Read Full License
Abstract

Background. Inter-professional collaboration between general practitioners (GPs) and spinal cord injury (SCI) specialists is needed to improve the health outcomes of persons with SCI. The objective of this study is to understand the differences in long-term care provision by GPs and SCI-specialists, by examining (1) the first contact of care for SCI health problems, (2) the morbidity profile and use of health-care services in relation to first contact, and (3) the factors associated with the choice of first contact.

Methods. In this cross-sectional study based on data derived from the Swiss Spinal Cord Injury Cohort Study Community Survey 2017, the main outcome measure was the reported first contact for SCI-specific care. This information was analysed using the chi-square test and logistic regression analysis of groups based on patient characteristics, use of health-care services and secondary health conditions assessed using the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS).

Results. Out of 1294 respondents, 1095 reported their first contact for SCI-specific care; 56% indicated SCI-specialists and 44% specified GPs. The mean ± standard deviation of the total SCI-SCS was significantly lower in persons who initially consulted GPs (13.1±7.7) than SCI-specialists (14.6±7.3). On average, participants who first contacted a GP reported higher number of GP consultations (5.1±5.2 vs. 3.9±7.2), planned visits to ambulatory clinics (3.7±7.3 vs. 3.6±6.7) and hospital admissions (GP, 1.9±1.7 vs. 1.5±1.3), but lower number of hospital days (22.8±43.2 vs. 31.0±42.8). The likelihood to contact a GP first was significantly higher in persons ≥75 years old (OR= 4.78, 95%-CI= 1.99–11.50), Italian speakers (OR= 5.11, 95%-CI= 2.47–10.54), had incomplete lesions (OR 2.51, 95%-CI 1.78–3.54) or diabetes mellitus (OR= 1.81, 95%-CI= 1.03–3.18), but lower for those situated closer to SCI centers (OR= 0.69, 95%-CI= 0.51–0.93) or experiencing bowel dysfunction (OR= 0.71, 95%-CI= 0.52–0.98).

Conclusion. The choice of first contact for SCI-specific care may be partly explained by the complementary roles of GPs and SCI specialists, but the reasons for variation are still unclear. Developing a transparent shared-care model between GPs and SCI specialists, with defined roles and responsibilities, may improve the management of secondary health conditions.

Background

Chronic spinal cord injury (SCI) is a complex medical condition [1], as affected individuals experience limitations in their sensory, motor, and autonomic functions that put them at high risk of developing life-threatening complications [2]. Hence, persons with SCI require a first contact of care who can address their acute and chronic medical problems, as well as lifestyle problems [3, 4]. Primary care is recognized as the first point of entry into the health-care system [5]. Accordingly, the choice of which practitioner to contact initially relies on how primary care is defined [6]. According to the European definition of general practice/family medicine, general practitioners (GPs) are the first point of contact for ‘all health problems regardless of the age, sex, or any other characteristic of the person concerned’ [7]. However, persons with SCI may also choose to consult a practitioner other than a GP, such as an SCI specialist, for diverse health-
care needs, and the specialist may then be the one managing and coordinating all aspects of care throughout their lives [4].

Persons with SCI find various ways to receive care for their complex medical needs [4]. A study of the primary care of persons with SCI in the United States, Canada and Britain showed that GPs were more likely to be visited for the treatment of general health problems or for screening [8], and SCI specialists were mainly consulted for routine annual follow-ups or the treatment of SCI-specific conditions, such as bowel and bladder problems, urinary tract infections, and pressure injuries [8]. In Switzerland, GPs were consulted more often for acute problems, and SCI specialists were contacted for follow-up care [9]. However, specialist-focused health-care provision is problematic when the geographical distribution of physicians is not even across regions [10]. That is, SCI specialists are likely to be situated in urban areas or in close proximity to hospitals and specialized centres. This may lead to geographically variable, poorly distributed access to care and unmet health-care needs—a problem that is particular to those living in rural areas or those with limited access to long-distance transportation [11]. Further, relying mostly on GPs in the absence of regional specialized care may lead to disparities in caring for the complex conditions of persons with SCI [12].

The fragmentation of services and the lack of integrated care across physicians also pose a challenge to meeting the health-care needs of persons with complex medical conditions [13]. Therefore, greater medical support and the concept of ‘shared care’ are needed to achieve positive health outcomes [14–16]. Efforts have been made to reach a consensus on health concepts and modes of providing primary care for persons with SCI, but these have not been successful [4]. Nonetheless, some health organizations have succeeded in constructing models integrating primary and specialty care to improve access, care coordination and health outcomes for the SCI population [4, 17].

In Switzerland, a shift towards inter-professional collaboration between GPs and SCI specialists is being realized [18] with the aim of providing integrated long-term care for persons with SCI living in the community. The present study focuses on this model, with the aim of understanding the differences in long-term care provision by GPs and SCI specialists. To this end, it examines (1) the first contact of care for SCI-related health problems, (2) the morbidity profile and use of health-care services in relation to the first contact, and (3) the factors associated with the choice of first contact.

**Methods**

*Study Design*

Cross-sectional data were derived from the national community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) conducted between March 2017 and March 2018. Persons with SCI aged over 16 years and living in Switzerland (N = 3959) were invited to participate. Details on the methodology and study population of the Swiss national community survey of functioning after SCI are described by Gross-Hemmi et. al. [19].
Measures

Outcome Variables

First contact of care was determined based on the survey question ‘Who is your first point of contact for health problems related to your spinal cord injury?’ The choices provided were GP, SCI specialist, and other. A binary variable was then constructed with GPs comprising one group and SCI specialists comprising the other group.

Explanatory Variables

1. Participants’ characteristics

The sociodemographic characteristics of the participants used in the study were sex, age groups according to the International Spinal Cord Society recommendations [20], civil status, availability of informal caregivers, place of birth, years of formal education and employment status [21]. Subjective social status was defined using the MacArthur scale and constructed as a categorical variable based on the level of social status: low (rungs 1–3), middle (rungs 4–7) and high (rungs 8–10) [22]. The geographical information recorded included the national language of responses to the questionnaire (German, French or Italian) and distance travelled by vehicle to personal GP and nearest SCI centre. Time to the nearest SCI centre was calculated using the Google Maps Directions API and constructed as a binary variable [23]. The SCI characteristics included were time since injury in years, level of injury in patients with tetraplegia (cervical spine level) or paraplegia (damage at the level of the thorax or below), and lesion severity (complete or incomplete loss of sensory and/or motor functions below the level of injury). Cause of SCI was categorized as traumatic (insult caused by an external force) or non-traumatic (injury caused by an underlying pathology) [20].

2. Morbidity profile

The morbidity profile of the study participants was examined using the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) [24]. Participants were asked to report their health problems over the previous three months on a scale of 0 (non-existent or mild) to 3 (major or chronic). The morbidity profile represented secondary health conditions, which were self-rated as a moderate or major concern, and other existing conditions, such as coronary heart disease, cancer, depression and sleep problems.

3. Use of health-care services

Participants were asked to indicate if during the 12 months prior to the survey they had visited: (1) any of eight providers (GP, SCI specialist, other specialist, nurse or midwife, psychologist, speech therapist, occupational therapist or physiotherapist) and the frequency of visits; (2) ambulatory clinics (for planned or emergency care) and the frequency of visits; (3) specialized centres (for periodic check-up or ambulatory treatment); and (4) in-patient facilities (such as a hospital or an SCI centre), the frequency of visits, and the total number of days in hospital.
4. Factors associated with the choice of first contact

Sociodemographic and geographic features, SCI characteristics, secondary conditions, and other chronic conditions were analysed as predictors of the first contact of care.

Statistical Methods

Descriptive statistical data about participants’ characteristics, their morbidity profile and use of health-care services were reported as absolute and relative frequencies, means and standard deviations, medians, and 1st and 3rd quartiles. To measure the association of first contact for SCI-specific care and use of services, the $t$-test and Pearson's chi-square test were used respectively. Univariate and multivariable logistic regression analyses were conducted to identify factors related to first contact of care. Multiple imputation (MI), assuming missing at random, was used to account for potential biases caused by item non-response and missing values. Odds ratios (ORs) and 95% confidence intervals (CIs) were reported. All statistical findings were compared at a significance level of $P < 0.05$, and all statistical analyses were performed using Stata® version 16.0 (Stata Corp LP, College Station, Texas, USA).

Results

Out of the 3959 patients who were invited, 1294 (response rate, 33%) participated in the SwiSCI community survey. Of those, 1095 (85%) reported a first contact for SCI-specific care and were included in the analysis.

Participants’ Characteristics

The baseline characteristics of the study population are shown in Table 1. Of the 1095 participants, 72% were male, and the mean age was 55.8 years ($\pm14.5$). German was the language of response for 70% of the participants. With regard to the geographical data, 86% and 31% of the participants were living within 25 minutes of vehicle-driving distance of their personal GP ($12 \pm 11.7$ min) and the nearest SCI centre ($38 \pm 21.1$ min) respectively. Overall, 30% of the participants reported having tetraplegia, 33% reported complete lesions, and 80% reported trauma-induced SCI.

Morbidity Profile

Table 2 shows the self-reported health problems persons with SCI had experienced within the previous three months. Overall, the mean SCI-SCS score was 14 ($\pm7.5$). For SCI-specific care, 56% ($n = 612$) of the participants reported that their first contact was an SCI specialist and 44% ($n = 483$) stated their first contact was a GP.

The SCI-SCS mean score for persons who initially consulted a GP ($13.1 \pm 7.7$) was significantly lower than that in the SCI specialist group ($14.6 \pm 7.3$). The majority of SCI persons with autonomic dysreflexia (64%), postural hypotension (63%), muscle spasm (61%), sexual dysfunction (60%), urinary tract infections (60%), bowel (60%) and bladder dysfunctions (59%), pressure injuries (59%), contractures (57%) and pain (56%) contacted an SCI specialist first for SCI-related health problems. With regard to other health conditions,
more than half of the participants with diabetes mellitus (63%) and coronary heart disease (55%) consulted a GP first for SCI-specific care.

Use of Health-care Services

Table 3 shows the use of health-care services within the previous 12 months based on first contact of care. Almost all participants (96%) consulted a GP in this period (mean 4.5, SD ± 6.4). More than half of the participants who sought an SCI specialist for SCI-specific care visited SCI specialists (78%), occupational therapists (70%), physiotherapists (60%), ambulatory clinics for emergency care (59%), GPs (53%) and SCI centres for ambulatory treatment (80%), in-patient stays (77%) or periodic check-ups (75%).

Compared to those who initiated contact with an SCI specialist, participants who first contacted a GP reported a higher number of GP consultations (GP, 5.1 ±5.2; specialist, 3.9 ± 7.2), planned visits to ambulatory clinics (GP, 3.7 ± 7.3; specialist, 3.6 ± 6.7) and hospital admissions (GP, 1.9 ± 1.7; specialist, 1.5±1.3), but a lower number of hospital days (GP, 22.8 ± 43.2; specialist, 31.0 ± 42.8), but the difference was not statistically significant.

Factors Associated with Choice of GP as the First Contact for SCI-specific Care

Multivariate logistic regression (Table 4) showed that the likelihood of the first contact being a GP rather than an SCI specialist for SCI-specific care was significantly higher in those who were ≥75 years old (OR = 4.78, 95% CI = 1.99–11.50) or Italian speaking (OR = 5.11, 95% CI = 2.47–10.54), as compared with persons below 29 years of age and German-speaking individuals. SCI individuals with incomplete lesions (OR = 2.51, 95% CI = 1.78–3.54) or a history of diabetes mellitus (OR = 1.81, 95% CI = 1.03–3.18) were significantly more likely to first contact a GP than individuals with complete lesions or no diabetes respectively. Those residing in close proximity to SCI centres (OR = 0.69, 95% CI = 0.51–0.93) or experiencing bowel dysfunction (OR = 0.71, 95% CI = 0.52–0.98) were significantly less likely to initially consult a GP for SCI-related health problems.

Although statistically not significant at 95% significance level, individuals experiencing spasticity (OR = 0.79, 95% CI = 0.59–1.06), contractures (OR = 0.85, 95% CI = 0.62–1.16), autonomic dysreflexia (OR = 0.87, 95% CI = 0.55–1.39) or pressure injuries (OR = 0.89, 95% CI = 0.61–1.32) were more likely to consult an SCI specialist first rather than a GP. Conversely, individuals experiencing an injury due to loss of sensation (OR = 1.04, 95% CI = 0.63–1.72) or pain (OR = 1.23, 95% CI = 0.91–1.67) were more likely to contact a GP first than those who did not experience either.

Discussion

Main Findings

Our study findings demonstrate that individuals with SCI who initially contact an SCI specialist for SCI-specific care have greater overall problems with secondary conditions and tend to use health-care services more often than those who first consult a GP. Further, persons with SCI who are 75 years of age and older,
Italian speakers, those with incomplete lesions and diabetes, and those living farther from SCI centres are more likely to contact a GP first than an SCI specialist for SCI-specific care.

**Interpretation and Comparison with Existing Literature**

In line with previous studies, SCI specialists were found to be the first contact of care for more than half of the study participants [25, 26]. The reasons for the choice of first contact and the specific conditions for which they sought care were not investigated in our study. However, the findings do indicate that individuals with more severe secondary conditions seek SCI specialists, while GPs are the first contact for those who require general medical attention or present with mild secondary conditions. This finding may be explained by the limited experience of GPs with SCI-specific care: individuals with SCI previously reported unmet information needs, and they often felt more knowledgeable about the management of SCI-specific conditions than their GPs [3, 27]. Lack of physical access, inadequate space and the unavailability of specialized equipment may further hinder individuals with SCI from seeking care from their GP, and this may consequently influence their choice of first contact [8, 28]. In addition, personal preferences for specialized care, familiarity with specialized rehabilitation centres for SCI, long-term relationship with SCI specialists, coordinated interdisciplinary care, and the availability of resources and information relating to one's health condition may inform the choice of first contact [4, 26].

Although more than half of our study participants considered the SCI specialist to be their first contact for SCI-specific care, they still consulted a GP based on the average of 3.9 visits per year. The reasons for visiting a GP were not investigated in this study, but a previous study on the use of and access to primary care in Canada, the United States and Britain demonstrated that the majority of individuals with SCI consulted GPs for health problems that require faster access and preventive care [8]. An additional explanation may be the specialist's reluctance to manage complex conditions that are far from their own specialties [29]. Nonetheless, the present finding indicates the complementary role of GPs in the continuity of long-term care for persons with SCI and the difference in expertise between GPs and SCI specialists with regard to provision of care for those with complex conditions. This finding also provides insights into the diverse health-care needs of persons with SCI that necessitate consulting different providers and a possible overlap in care due to a lack of clarity about who provides what care.

In this study, those who initiated contact with SCI specialists tended to make greater use of health-care services than those who consulted GPs. Although this finding may simply denote that specialists more frequently suggest additional referrals than GPs, it is plausible that age, comorbidities [30], severity of injury and the rehabilitation stage of participants necessitate more referrals, thereby contributing to the higher frequency of service use [31]. An additional factor may be the greater understanding of SCI specialists about the indications for long-term therapies, such as speech and occupational therapy, counselling and physiotherapy, and the need for comprehensive care. This premise may further explain the two- to three-fold higher use of specialized services in this population than in individuals who initiate contact with a GP. Conversely, the lower use of health services by those initially seeking a GP for SCI-specific care may be explained by the GP's management of complex conditions and referrals. In Switzerland, GPs were reported to manage 94.3% of health problems presented to their practices, with a
specialist referral rate of 9.4% [32]. The reasons influencing the referral of complex conditions were concerns about the treatment or the implications of the referral on the GP-patient relationship. Shared responsibility and delegation of tasks between GPs and specialists were described as additional reasons to refer [33]. Yet, the lower frequency in the use of health-care services and the higher rate of hospital admissions pose important questions regarding the needs of this group and whether these were met, particularly for SCI-specific care and periodic comprehensive health evaluations. Another influencing factor might be the health insurance schemes purchased by persons with SCI. Although this factor is not addressed in our study, research shows that people with chronic disabilities who have fee-for-service health plans tend to receive specialist care more often than those in managed-care organizations [34].

In this study, those who were aged 75 or over were most likely to initially consult a GP for their SCI-related health problems. This finding may be explained by the heightened risk of chronic conditions in older persons with SCI, which often requires frequent visits to GPs. As a result, a personal relationship with their physician is developed, and this may, in turn, govern their choice of first contact and trump their need for a disease-specific care approach [29]. Qualitative research in the general population also revealed that the elderly tend to appreciate the social and emotional behaviour exhibited by GPs during visits, and focus less on how care is provided [35]. They appeared to value the information and communications they received about their medical conditions and treatment, and described the care as individualized and tailored to meet their needs [36].

Consistent with previous findings on the same population, our results show that Italian speakers were five times more likely to initiate contact with a GP for SCI-specific care than German and French speakers [12]. It was previously suggested that SCI individuals from Italian-speaking regions favoured care by GPs who spoke the same language over specialized treatment in different language settings [37]. Moreover, the geographical dispersal of services, mainly in rural areas, lack of specialized clinics with SCI expertise, and general culture may also contribute to the choice of first contact among Italian speakers.

The present findings indicate that study participants with incomplete lesions were more likely to first seek contact with a GP for SCI-specific care than those with complete lesions. This finding is surprising, as it was previously reported that individuals with incomplete lesions expressed dissatisfaction with the quality of primary care services in terms of the fulfilment of SCI-specific care needs [11]. However, differences in the need for SCI-specific care and for a broader range of services between persons with incomplete and complete lesions might explain their choice of first contact [38]. An additional aspect may be the local availability of specialized care and the travel distance to SCI centres. As described by Ronca et al., persons living farther from SCI centres tend to prefer proximate but less specialized care over comprehensive services at SCI centres [11, 39]. Moreover, persons with more severe lesions are more likely to be situated closer to specialized SCI centres [40]. This further explains the choice of first contact based on proximity to SCI centres.

**Weaknesses And Strengths**
To our knowledge, this is the first study to examine the morbidity profile and the use of health-care services in relation to the first contact for SCI-specific care. Nevertheless, this study has several limitations, including a low response rate and the exclusion of 199 participants from the analysis due to missing values for the outcome measure. In addition, as this is a cross-sectional study, we can only build our assumptions by means of associations: that is, we are not in a position to determine the impact of first contact on the use of health-care services and health outcomes for persons with SCI. The study design simplified the complex question of who was the first contact for SCI-specific health problems in individuals with SCI. However, the correct choice of first contact is context-dependent and relies on factors that were not captured in our study, such as health insurance plans and gatekeeping schemes, the level of integration and coordination between GPs and specialists, and remoteness of the place of residence. Moreover, this study lacked key information on health-care needs, reasons for visiting providers and satisfaction with the quality of care in relation to the choice of first contact. Finally, as our results are based on self-reported data, recall bias and inaccuracies cannot be dismissed. Despite these limitations, our data are derived from the largest SCI survey in Switzerland, and this has made it possible to include those who may not be properly identified in the Swiss health-care system owing to the lack of a national registry.

Implications

The findings of this study demonstrate that the choice of first contact, severity of secondary conditions and use of health-care services are interrelated. They also reveal the predominance of GPs in the provision of care to the vast majority of individuals with SCI, irrespective of first contact. Nonetheless, the specific reasons for which individuals with SCI seek GP care remain unclear. This information would provide better insights into which health problems GPs are consulted for, as well as reflect patients’ views on the competence levels of their GPs. In addition, our results could inform new approaches to primary-care delivery that foster well-defined roles of providers and structured referral pathways for both preventive and follow-up SCI care and take into account the complementary roles of both providers in the long-term care of persons with SCI [11].

Conclusions

The choice of first contact for SCI-specific care may be partly explained by the complementary roles of GPs and SCI specialists, but there is still some unwarranted variation that remains unclear. Developing a transparent shared-care model between GPs and SCI specialists, with defined roles and responsibilities, may improve the management of secondary health conditions.

Abbreviations

SCI = spinal cord injury

GP = general practitioner
Declarations

Ethics approval and consent to participate

Ethical approval for the survey was granted by the leading ethical institution Ethikkommision 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. The study protocol has been approved by the Steering Committee of the Swiss Spinal Cord Injury Cohort Study. All study participants have signed a document to provide their written informed consent.

Consent for publication

Not applicable

Availability of data and material

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 on reasonable request (contact@swisci.ch).

Competing interests

Seven of the authors (DT, MB, ER, IE, NM, AS and AG) are salaried employees of organizations financially supported by the Swiss Paraplegic Foundation.

Funding

Swiss Paraplegic Research provided a stipend to the first author. SwiSCI is hosted and funded by Swiss Paraplegic Research.

Authors’ contributions

DT, SE and AG were involved in the conception and design of the study. SE, ER, MB, ID, IE, NM, AS and AG reviewed and approved the study methodology. DT conducted the analysis, with the support of AG. DT and AG performed the statistical analyses. SE, ER, MB, ID, IE, NM, AS and AG critically reviewed the interpreted data. All the authors read and approved the final draft of the manuscript before submission.

Acknowledgements

Not applicable
References

1. Chrvala CA, Sharfstein SS. Definition of serious and complex medical conditions. ProQuest, editor. Washington, DC: National Academy Press; 1999.
2. Sezer N, Akkuş S, Uğurlu FG. Chronic complications of spinal cord injury. World J Orthop. 2015;6(1):24-33.
3. McColl MA, Aiken A, McColl A, Sakakibara B, Smith K. Primary care of people with spinal cord injury: scoping review. Can Fam Physician. 2012;58(11):1207-e635.
4. Ho CH. Primary care for persons with spinal cord injury - not a novel idea but still under-developed. J Spinal Cord Med. 2016;39(5):500-3.
5. World Health Organization. Primary health care, main terminology. https://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology. Accessed 11 November 2020.
6. Yang H, Huang X, Zhou Z, Wang HH, Tong X, Wang Z, et al. Determinants of initial utilization of community healthcare services among patients with major non-communicable chronic diseases in South China. PLoS One. 2014;9(12):e116051.
7. Wonca Europe. The European definition of general practice/family medicine. Austria, Switzerland: WHO Europe Office; 2002. https://www.woncaeurop.org/file/7c9ad67-0ec6-4c79-920e-96fe0310c345/EUROPAISCHE_DEFINITION%20DER_ALLgemeinmedizin_Hauserztmedizin.pdf. Accessed 16 September 2020.
8. Donnelly C, McColl MA, Charlifue S, Glass C, O'Brien P, Savic G, et al. Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. Spinal Cord. 2007;45(1):25-36.
9. Gemperli A, Ronca E, Scheel-Sailer A, Koch HG, Brach M, Trezzini B. Health care utilization in persons with spinal cord injury: part 1-outpatient services. Spinal Cord. 2017;55(9):823-7.
10. Wanzenried G, Nocera S. The Evolution of Physician Density in Switzerland. SJES. 2008;144:247-82.
11. Ronca E, Scheel-Sailer A, Koch HG, Essig S, Brach M, Munzel N, et al. Satisfaction with access and quality of healthcare services for people with spinal cord injury living in the community. J Spinal Cord Med. 2020;43(1):111-21.
12. Ronca E, Scheel-Sailer A, Koch HG, Gemperli A. Health care utilization in persons with spinal cord injury: part 2-determinants, geographic variation and comparison with the general population. Spinal Cord. 2017;55(9):828-33.
13. Kodner DL. All together now: a conceptual exploration of integrated care. Healthc Q. 2009;13 Spec No:6-15.
14. Schmitz C, Atzeni G, Berchtold P. Challenges in interprofessionalism in Swiss health care: the practice of successful interprofessional collaboration as experienced by professionals. Swiss Med Wkly. 2017;147:w14525.
15. Schusselé Filliettaz S, Berchtold P, Kohler D, Peytremann-Bridevaux I. Integrated care in Switzerland: Results from the first nationwide survey. Health Policy. 2018;122(6):568-76.

16. Buzzell A, Chamberlain JD, Eriks-Hoogland I, Jordan X, Schubert M, Zwahlen M, et al. Etiology-specific variation in survival following non-traumatic spinal cord injury: a causal inference approach using data from a population-based cohort. Spinal Cord. 2020.

17. Newman ED, Simonelli PF, Vezendy SM, Cedeno CM, Maeng DD. Impact of primary and specialty care integration via asynchronous communication. Am J Manag Care. 2019;25(1):26-31.

18. ClinicalTrials.gov [Internet]. Bethesda (MD): National Library of Medicine (US). 2000 Feb 29 -. Identifier NCT04071938, Shared Responsibility Between General Practitioners and Highly Specialized Hospitals in Spinal Cord Injury (SCICO); 2019 Aug 28 [cited 2020 Sep 22]; [about 4 screens]. https://www.clinicaltrials.gov/ct2/show/NCT04071938. Accessed 17 September 2020.

19. Gross-Hemmi MH, Gemperli A, Fekete C, Brach M, Schwegler U, Stucki G. Methodology and study population of the second Swiss national community survey of functioning after spinal cord injury. Spinal Cord. 2020.

20. Biering-Sørensen F, DeVivo MJ, Charlifue S, Chen Y, New PW, Noonan V, et al. International Spinal Cord Injury Core Data Set (version 2.0)—including standardization of reporting. Spinal Cord. 2017;55(8):759-64.

21. Biering-Sørensen F, Noonan VK. Standardization of Data for Clinical Use and Research in Spinal Cord Injury. Brain Sciences. 2016;6(3):29.

22. Chen B, Covinsky KE, Stijacic Cenzer I, Adler N, Williams BA. Subjective social status and functional decline in older adults. J Gen Intern Med. 2012;27(6):693-9.

23. Google Developers. The Google Maps Distance Matrix Application Programming Interface. 2020. https://developers.google.com/maps/documentation/distance-matrix/start. Accessed 17 September 2020.

24. Spinal Cord Injury Research Evidence. Spinal Cord Injury Secondary Conditions Scale (SCI-SCS). 2020. https://scireproject.com/outcome-measures/outcome-measure-tool/spinal-cord-injury-secondary-conditions-scale-sci-sss/#1467983894080-2c29ca8d-88af. Accessed 17 September 2020.

25. Munce SE, Guilcher SJ, Couris CM, Fung K, Craven BC, Verrier M, et al. Physician utilization among adults with traumatic spinal cord injury in Ontario: a population-based study. Spinal Cord. 2009;47(6):470-6.

26. Bockenek WL. A Fragmented Model of Care for Persons with Spinal Cord Injuries1. Am J Phys Med Rehabil. 1997;76(3):43-6.

27. DeJong G, Tian W, Hsieh CH, Junn C, Karam C, Ballard PH, et al. Rehospitalization in the first year of traumatic spinal cord injury after discharge from medical rehabilitation. Arch Phys Med Rehabil. 2013;94(4 Suppl):S87-97.

28. Milligan J, Lee J, Hillier LM, Slonim K, Craven C. Improving primary care for persons with spinal cord injury: Development of a toolkit to guide care. J Spinal Cord Med. 2020;43(3):364-73.
29. Koopman R, May K. Specialist Management and Coordination of "Out-of-domain Care". Fam Med. 2004;36:46-50.
30. Rizza A, Kaplan V, Senn O, Rosemann T, Bhend H, Tandjung R. Age- and gender-related prevalence of multimorbidity in primary care: the Swiss FIRE project. BMC Fam Pract. 2012;13:113.
31. Noonan VK, Fallah N, Park SE, Dumont FS, Leblond J, Cobb J, et al. Health care utilization in persons with traumatic spinal cord injury: the importance of multimorbidity and the impact on patient outcomes. Top Spinal Cord Inj Rehabil. 2014;20(4):289-301.
32. Tandjung R, Hanhart A, Bartschi F, Keller R, Steinhauer A, Rosemann T, et al. Referral rates in Swiss primary care with a special emphasis on reasons for encounter. Swiss Med Wkly. 2015;145:w14244.
33. Tzartzas K, Oberhauser P-N, Marion-Veyron R, Bourquin C, Senn N, Stiefel F. General practitioners referring patients to specialists in tertiary healthcare: a qualitative study. BMC Fam Pract. 2019;20(1):165.
34. Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: patterns and predictors. Arch Phys Med Rehabil. 2003;84(10):1417-25.
35. Marcinowicz L, Pawlikowska T, Oleszczyk M. What do older people value when they visit their general practitioner? A qualitative study. Eur J Ageing. 2014;11(4):361-7.
36. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. Patient Educ Couns. 2007;68(1):33-42.
37. Ronca E, Scheel-Sailer A, Koch HG, Metzger S, Gemperli A. Inpatient migration patterns in persons with spinal cord injury: A registry study with hospital discharge data. SSM Popul Health. 2016;2:259-68.
38. Trezzini B, Brach M, Post M, Gemperli A. Prevalence of and factors associated with expressed and unmet service needs reported by persons with spinal cord injury living in the community. Spinal Cord. 2019;57.
39. Ronca E, Scheel-Sailer A, Eriks-Hoogland I, Brach M, Debecker I, Gemperli A. Factors influencing specialized health care utilization by individuals with spinal cord injury: a cross-sectional survey. Spinal Cord. 2020.
40. Ronca E, Brunkert T, Koch HG, Jordan X, Gemperli A. Residential location of people with chronic spinal cord injury: the importance of local health care infrastructure. BMC Health Serv Res. 2018;18(1):657.

Tables

Table 1. Characteristics of the study population
| Variable                                      | Value          |
|----------------------------------------------|----------------|
| N = 1,095                                    |                |
| Males, n (%)                                 | 787 (72)       |
| Age groups, n (%)                            |                |
| 16–29 years                                  | 48 (4)         |
| 30–44 years                                  | 204 (19)       |
| 45–59 years                                  | 376 (34)       |
| 60–74 years                                  | 358 (33)       |
| ≥75 years                                    | 109 (10)       |
| Married¹, n (%)                              | 590 (54)       |
| Informal caregiver², n (%)                   | 498 (46)       |
| Born in Switzerland, n (%)                   | 909 (83)       |
| Years of education, n (%)                    |                |
| Less than 10 years                           | 65 (6)         |
| 10–12 years                                  | 206 (20)       |
| 13–15 years                                  | 438 (42)       |
| ≥16 years                                    | 342 (32)       |
| Employed, n (%)                              | 510 (47)       |
| Subjective social status³, n (%)             |                |
| Low (rungs 1–3)                              | 144 (14)       |
| Middle (rungs 4–7)                           | 738 (70)       |
| High (rungs 8–10)                            | 166 (16)       |
| Language, n (%)                              |                |
| German                                       | 769 (70)       |
| French                                       | 279 (26)       |
| Italian                                      | 47 (4)         |
| Travel distance to health-care provider      |                |
| ≤25 minutes travel distance to personal GP⁴, n (%) | 913 (86) |
| ≤25 minutes travel distance to nearest SCI centre⁴, n (%) | 334 (31) |
| Characteristics                                      | Value     |
|------------------------------------------------------|-----------|
| Time since SCI in years, median (Q1–Q3)              | 15.7 (7.8–27.2) |
| Tetraplegia, n (%)                                   | 324 (30)  |
| Complete injury, n (%)                               | 361 (33)  |
| Missing                                              | 120 (11)  |
| Traumatic SCI, n (%)                                 | 872 (80)  |

SCI: Spinal cord injury, Q1–Q3: 1\textsuperscript{st} to 3\textsuperscript{rd} quartile

The number of missing observations is less than 5% for all characteristics, unless indicated otherwise.

1 Married denotes those reporting being married or in a registered partnership.

2 Informal caregiver is a family member or friend who provides unpaid care.

3 SSS is the subjective social status based on MacArthur Scale classification.

4 Travel distance is the distance by motor vehicle.

**Table 2. Morbidity profile of the study participants according to the first contact of care**
| First contact of care | GP (n = 483) | Specialist (n = 612) |
|----------------------|-------------|---------------------|
| N = 1,095            | Moderate/Major problem¹ | Treated² | Moderate/Major problem¹ | Treated² | Statistical significance³ |
| SCI-SCS score, (mean±SD) | (14.0±7.5) | (13.1±7.7) | (14.6±7.3) | ** |
| Genitourinary and bowel | | | |
| Bowel dysfunction, n (%) | 469 (43) | 187 (40) | 103 (55) | 282 (60) | 148 (52) | * |
| Bladder dysfunction, n (%) | 488 (45) | 200 (41) | 140 (70) | 288 (59) | 227 (79) |
| Sexual dysfunction, n (%) | 608 (56) | 242 (40) | 47 (19) | 366 (60) | 83 (23) | ** |
| Urinary tract infections, n (%) | 389 (36) | 155 (40) | 128 (83) | 234 (60) | 201 (86) | * |
| Muscle structure and pain | | | |
| Contractures, n (%) | 378 (35) | 162 (43) | 106 (65) | 216 (57) | 125 (58) |
| Pain, n (%) | 620 (57) | 274 (44) | 167 (61) | 346 (56) | 222 (64) |
| Muscle spasm (spasticity), n (%) | 518 (47) | 204 (39) | 118 (58) | 314 (61) | 180 (57) | ** |
| Skin, breathing and metabolism | | | |
| Pressure injuries, n (%) | 176 (16) | 73 (41) | 56 (77) | 103 (59) | 81 (79) |
| Diabetes mellitus, n (%) | 71 (6) | 45 (63) | 37 (82) | 26 (37) | 24 (92) | ** |
| Respiratory problems, n (%) | 111 (10) | 49 (44) | 40 (82) | 62 (56) | 40 (65) |
| Condition                                                                 | GP 1 | GP 2 | GP 3 | GP 4 | GP 5 |
|---------------------------------------------------------------------------|------|------|------|------|------|
| Injury due to loss of sensation, n (%)                                    | 100  | 39   | 15   | 61   | 30   |
| Circulatory and autonomic problems                                        |      |      |      |      |      |
| Autonomic dysreflexia, n (%)                                              | 145  | 52   | 27   | 93   | 32   |
| Postural hypotension, n (%)                                               | 87   | 32   | 17   | 55   | 24   |
| Circulatory problems, n (%)                                               | 219  | 92   | 58   | 127  | 65   |
| Heterotopic bone ossification, n (%)                                      | 42   | 22   | 14   | 20   | 7    |
| Other chronic conditions                                                  |      |      |      |      |      |
| Coronary heart disease, n (%)                                             | 112  | 62   | 54   | 50   | 48   |
| Cancer, n (%)                                                             | 73   | 37   | 32   | 36   | 34   |
| Depression, n (%)                                                         | 154  | 72   | 61   | 82   | 67   |
| Sleep problems, n (%)                                                     | 384  | 158  | 64   | 226  | 75   |

GP: General practitioner; SCI: Spinal Cord Injury; Specialist represents SCI-specialist with own office or specialist of one of the SCI centers.

SCI-SCS score: Spinal cord injury secondary conditions scale score.

1 Represents [the percentage of] participants with moderate or major health condition who choose GP/specialist as first contact of care. 100% is the overall number of participants with the corresponding moderate or major health condition.

2 Represents [the percentage of] participants with moderate or major health condition who choose GP/specialist as first contact care, and received treatment. 100% is the number of participants with the corresponding moderate or major health condition based on their first contact of care.

3 Pearson’s Chi² test is used to test significance between first contact of care and major health conditions. T-test is used for significant difference of SCI-SCS score means between the two groups. * P-value <0.05, ** P-value <0.01, *** P-value <0.001.
Table 3. Use of health-care services in total and according to the first contact of care

| Utilization of health-care services in the previous year | First contact of care | Specialist¹ | Statistical significance² |
|--------------------------------------------------------|-----------------------|-------------|---------------------------|
| n (%) | Visits² | Number of visits (SD) | Number of days (SD) | n (%) | Visits² | Number of visits (SD) | Number of days (SD) | |
| Total, n (%) | 1,095 (100) | 483 (44) | 612 (56) | | | | |
| Health-care professionals | 1,051 (96) | 456 (43) | 596 (57) | | | | |
| General practitioner | 909 (87) | 430 (47) | 5.1 (5.2) | 479 (53) | 3.9 (7.2) | **rs** | |
| Specialist for paraplegia | 463 (44) | 101 (22) | 1.7 (1.8) | 362 (78) | 2.6 (3.7) | **rs** | |
| Other specialist | 561 (53) | 235 (42) | 5.3 (9.8) | 326 (58) | 4.5 (7.2) | | |
| Nurse or midwife | 60 (6) | 30 (50) | 105.1 (196.0) | 30 (50) | 40.7 (86.7) | | |
| Psychologist | 97 (9) | 44 (45) | 10.5 (12.2) | 53 (55) | 11.9 (14.3) | | |
| Speech therapist | 15 (1) | 6 (40) | 19.8 (17.3) | 9 (60) | 31.3 (43.9) | | |
| Occupational therapist | 176 (17) | 52 (30) | 18.6 (25.1) | 124 (70) | 21.3 (29.7) | **rs** | |
| Physiotherapist | 665 (65) | 273 (40) | 44.1 (36.6) | 412 (60) | 47.9 (35.0) | **rs** | |
| Ambulatory or polyclinic visits | 567 (53) | 205 (36) | 382 (64) | | | | |
| Planned | 446 (79) | 151 (34) | 3.7 (7.3) | 295 (66) | 3.6 (6.7) | **rs** | |
| Unplanned | 204 (36) | 83 (41) | 1.6 (1.1) | 121 (50) | 1.9 (3.7) | | |
| Specialized centres | 639 (59) | 169 (26) | 470 (74) | | | | |
| Control visit | 570 (89) | 141 (25) | 420 (76) | | | | |
| Ambulatory treatment | 197 (31) | 40 (20) | 157 (80) | | | | |
| Inpatient stay | 344 (31) | 133 (39) | 211 (61) | | | | |
| Hospital | 331 (96) | 129 (39) | 22.8 (43.2) | 202 (61) | 1.5 (1.3) | | |
| SCI centre | 151 (44) | 35 (23) | 116 (77) | | | | |
| No visits to any health service provider | 35 (3) | 21 (60) | 14 (40) | | | | |

¹GP: general practitioner, SCI: spinal cord injury, SD: standard deviation
²Statistical significance: **p < 0.001, *p < 0.01, **p < 0.05
³100% represents the overall number of participants with the corresponding visits to health-care services.
⁴Pearson’s chi-square test was used to analyse the significance of differences in the choice of first contact of care and visits to health-care services.

Table 4. Factors associated with choice of GP as the first contact for SCI-specific care
| Factors                                      | Univariate OR (95% CI) | Multivariable OR (95% CI) |
|---------------------------------------------|------------------------|---------------------------|
| **Sociodemographic factors**                |                        |                           |
| Males, *(ref: females)*                     | 0.88 (0.67–1.15)       | 0.99 (0.72–1.37)          |
| Age groups, *(ref: 16–29 years)*            |                        |                           |
| 30–44 years                                 | 0.99 (0.50–1.95)       | 1.07 (0.52–2.22)          |
| 45–59 years                                 | 1.49 (0.79–2.83)       | 1.41 (0.69–2.89)          |
| 60–74 years                                 | 2.14 (1.12–4.09) *     | 1.69 (0.79–3.62)          |
| ≥75 years                                   | 5.21 (2.48–10.94) ***  | 4.78 (1.99–11.50) ***     |
| Married¹, *(ref: single)*                   | 1.31 (1.03–1.65) *     | 1.09 (0.80–1.48)          |
| Informal caregiver, *(ref: paid assistance or none)² | 0.85 (0.67–1.08)       | 0.78 (0.58–1.05)          |
| Born in Switzerland, *(ref: foreign born)*  | 1.04 (0.75–1.44)       | 1.22 (0.83–1.80)          |
| Years of education, *(ref: <10 years)*      |                        |                           |
| 10–12 years                                 | 0.79 (0.45–1.39)       | 0.96 (0.51–1.79)          |
| 13–15 years                                 | 0.67 (0.39–1.14)       | 0.88 (0.49–1.58)          |
| ≥16 years                                   | 0.44 (0.25–0.76) ***   | 0.73 (0.39–1.37)          |
| Employed, *(ref: unemployed)*               | 0.59 (0.46–0.75) ***   | 0.90 (0.64–1.27)          |
| Subjective social status, *(ref: low SSS [1–3])³ |                        |                           |
| Middle SSS (4–7)                            | 0.63 (0.44–0.91) *     | 0.73 (0.47–1.14)          |
| High SSS (8–10)                              | 0.65 (0.42–1.03)       | 0.85 (0.48–1.50)          |
| Income in Swiss Francs⁴, *(ref: less than 2000)* |                        |                           |
| Between 2000 and 2999                       | 1.21 (0.68–2.17)       | 1.11 (0.55–2.25)          |
| Between 3000 and 3999                       | 0.95 (0.54–1.66)       | 0.92 (0.47–1.83)          |
| Between 4000 and 4999                       | 0.75 (0.42–1.35)       | 0.82 (0.41–1.65)          |
| Between 5000 and 6000                       | 0.62 (0.34–1.13)       | 0.60 (0.30–1.22)          |
| More than 6000                               | 0.62 (0.35–1.10)       | 0.67 (0.33–1.36)          |
| Geographical factors                        |                        |                           |
| Language, *(ref: German)*                   |                        |                           |
| French                                      | 1.10 (0.83–1.45)       | 1.05 (0.76–1.44)          |
| Italian | 2.53 (1.33–4.79) * | 5.11 (2.47–10.54) *** |
| Travel distance<sup>5</sup> to personal GP, *(ref: >25 minutes)*<sup>6</sup> |
| ≤25 minutes to personal GP | 1.17 (0.81–1.68) | 1.22 (0.82–1.81) |
| Travel distance<sup>5</sup> to SCI centre, *(ref: >25 minutes)* |
| ≤25 minutes to nearest SCI centre | 0.88 (0.68–1.14) | 0.69 (0.51–0.93) * |
| Injury-related factors |
| Time since injury | 0.99 (0.99–1.00) | 1.01 (0.99–1.02) |
| Lesion status, *(ref: paraplegia)* |
| Tetraplegia | 0.95 (0.73–1.23) | 0.89 (0.65–1.22) |
| Severity of injury, *(ref: complete)* |
| Incomplete | 2.64 (2.01–3.46) *** | 2.51 (1.78–3.54) *** |
| Cause of SCI, *(ref: non-traumatic)* |
| Traumatic | 0.55 (0.41–0.75) *** | 0.74 (0.52–1.07) |
| Secondary health conditions factors<sup>7</sup> |
| Genitourinary and bowel |
| Bowel dysfunction | 0.73 (0.57–0.94) * | 0.71 (0.52–0.98) * |
| Bladder dysfunction | 0.78 (0.61–0.99) * | 0.99 (0.72–1.37) |
| Sexual dysfunction | 0.69 (0.54–0.87) ** | 0.84 (0.63–1.14) |
| Urinary tract infections | 0.75 (0.58–0.96) * | 0.91 (0.67–1.24) |
| Muscle structure and pain |
| Contractures | 0.91 (0.71–1.17) | 0.85 (0.62–1.16) |
| Pain | 0.99 (0.78–1.26) | 1.23 (0.91–1.67) |
| Muscle spasm (spasticity) | 0.70 (0.55–0.89) ** | 0.79 (0.59–1.06) |
| Skin, breathing and metabolism |
| Pressure injuries | 0.87 (0.63–1.19) | 0.89 (0.61–1.32) |
| Diabetes mellitus | 2.25 (1.39–3.65) *** | 1.81 (1.03–3.18) * |
| Respiratory problems | 1.01 (0.67–1.51) | 0.96 (0.59–1.57) |
| Injury due to loss of sensation | 0.79 (0.51–1.22) | 1.04 (0.63–1.72) |
| Circulatory/autonomic problems |
| Condition                        | OR   | 95% CI          | Reference          |
|---------------------------------|------|-----------------|--------------------|
| Autonomic dysreflexia           | 0.67 | (0.46–0.97) *   | 0.87 (0.55–1.39)   |
| Postural hypotension            | 0.70 | (0.44–1.11)     | 0.73 (0.41–1.30)   |
| Circulatory problems            | 0.89 | (0.66–1.19)     | 0.92 (0.63–1.35)   |
| Heterotopic bone ossification   | 1.34 | (0.74–2.44)     | 1.44 (0.69–3.02)   |
| Other chronic conditions        |      |                 |                    |
| Coronary heart disease          | 1.63 | (1.11–2.40) *   | 1.19 (0.75–1.89)   |
| Cancer                          | 1.29 | (0.80–2.07)     | 0.92 (0.53–1.58)   |
| Depression                      | 1.10 | (0.79–1.55)     | 1.29 (0.87–1.92)   |
| Sleep problems                  | 0.83 | (0.65–1.06)     | 0.83 (0.61–1.14)   |

OR: Odd ratios of logistic regression, *P-value < 0.05, **P-value < 0.01, ***P-value < 0.001
CI: confidence interval, SCI: spinal cord injury; GP: general practitioner; ref: reference

1 Married includes persons in a registered partnership.
2 Informal caregiver is a family member or friend who provides unpaid care.
3 SSS is the subjective social status based on MacArthur Scale classification.
4 Represents the household's total net income from all sources divided by its equivalent size.
5 Represents motor vehicle driving distance.
6 Represents those who are at >25 minutes motor vehicle driving distance from their GP or report having no personal GP.
7 Reference is non-existent or mild.