

ORIGINAL REPORT

## FROM THE PERSON'S PERSPECTIVE: PERCEIVED PROBLEMS IN FUNCTIONING AMONG INDIVIDUALS WITH SPINAL CORD INJURY IN SWITZERLAND

Sara Rubinelli, PhD<sup>1,2</sup>, Andrea Glässer, PhD<sup>1</sup> and Mirjam Brach, MPH<sup>1,2</sup>

From the <sup>1</sup>Swiss Paraplegic Research (SPF), Nottwil and <sup>2</sup>Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland

**Objective:** To report the main problems in functioning cited by people with spinal cord injury in Switzerland.

**Study design:** Post-coding analysis was conducted based on the open-ended question, "What causes you the most problems since your spinal cord injury?" from the Starter Module of the community survey of the Swiss Spinal Cord Injury Cohort Study, administered between September 2011 and March 2013.

**Study participants:** Out of 3,144 eligible subjects, 1,762 answered the open-ended question and cited problems.

**Methods:** Thematic analysis was used, based on the coding system from the International Classification of Functioning, Disability and Health.

**Results:** The study identified the 10 problems cited most by the participants, and the 5 most-cited problems mentioned by participants from each of the relevant subgroups subdivided by factors including gender and aetiology. Problems linked to complications in body functions (e.g. pain), activities and participation (e.g. leisure) and environment (e.g. design of public buildings) were reported as important.

**Conclusion:** This study contributes to priority setting in spinal cord injury by accounting for the person perspective within a large-scale quantitative survey. The results support the value of a comprehensive approach to spinal cord injury.

**Key words:** spinal cord injury; qualitative research; life experiences; functioning; International Classification of Functioning, Disability and Health.

J Rehabil Med 2016; 48: 235–243

Correspondence address: Sara Rubinelli, Swiss Paraplegic Research, CH-6207 Nottwil, Switzerland. E-mail: sara.rubinelli@paraplegie.ch

Accepted Dec 22, 2015; Epub ahead of print Feb 1, 2016

### INTRODUCTION

Setting the correct priorities in research and practice is a main goal for strengthening healthcare systems and services. As explained by Hammell (1), in priority setting there is the need to integrate qualitative and quantitative perspectives that account both for users' involvement and researchers' knowledge.

Until the late 1990s quantitative methods dominated research in healthcare. However, nowadays the paradigm of person-

centred healthcare argues for the integration of the viewpoints of both individuals experiencing health conditions and their families into healthcare research and practice (2). This paradigm calls for the involvement of individuals' views about what matters to them as an essential source of information for researchers and policymakers interested in identifying potential targets of interventions to enhance the quality of life of people with disabilities (3). People living with health conditions are confronted daily with functioning problems caused by their health issues interacting with the environment. As a result of this direct and day-to-day experience, people develop an experiential knowledge of health conditions that put them in a good position to be able to identify interventions and management strategies that work for them.

This experiential knowledge is best captured in research by means of qualitative methodologies that elicit the meaning that people living with a health condition attach to their experiences of the world and their lives, in settings that are natural for them (4). In the case of spinal cord injury (SCI), several qualitative studies have examined the person's perspective on specific aspects of functioning, including the experience of fatigue (5) and how to manage it (6), bladder management (7), neuropathic pain (8), participation in society (9) and in care and rehabilitation (10), leisure time (11), parenting (12), and work reintegration (13), access to health and support services (14), the experience of living with SCI (15) and more specifically, hopes (16), post-traumatic growth (17), coping strategies (18), and autonomy (19).

These studies have shown that SCI is a complex health condition that is linked to several problems at the level of body functions and activities and participation, as well as problems linked to the individual's environment and their own personal factors. This complexity is well portrayed in a qualitative study by Kirchberger et al. (20), who illustrated a comprehensive range of functioning domains that individuals with SCI viewed as problems for them in the early post-acute and long-term care settings. A qualitative study by Lüthi et al. (21) also gives an overview of aspects of functioning and disability that matter to people living in the German-speaking part of Switzerland.

This type of research provides an important basis for generating working hypotheses for research about the experience of SCI and strategies for care and management. However, these studies lack the generalizability of quantitative research that would identify priorities for intervention.

A main study in priority setting for SCI is that of Anderson (22), which aimed at determining which of the 7 areas of functional recovery mattered most to individuals with SCI in the USA. Although quantitative in nature, this study only partially captures the person perspective of people, since its participants were merely asked to rank 7 pre-determined areas of functioning in order of importance to their quality of life. Acknowledging this limitation, Hammell (1) attempted to provide a synthesis of qualitative and quantitative studies on patient priorities for rehabilitation research. As the author concludes, however, there is the need to focus on issues and outcomes of relevance and importance for individuals with SCI.

This paper combines the important need to give participants an independent voice on what matters to them with the scientific need to obtain results that are generalizable. Its objective is to identify which domains of functioning and issues in the environment are most reported by individuals with SCI in Switzerland when asked to indicate freely what causes them most problems since their SCI.

As part of the Swiss Spinal Cord Injury Cohort study (SwiSCI), this study applies a robust qualitative methodology to ensure inter-rater reliability within a thematic analysis, including an embedded post-coding exercise using data from an open-ended question in a large-scale epidemiological survey. Open-ended questions of this sort, in epidemiological surveys, are rarely rigorously analysed, given that they are neither truly quantitative nor qualitative in nature and it is not clear what analytical tools should be used. However, in principle they provide important information that enables us to view the quantitative information derived from the survey from a patient-centred perspective that highlights what, from the person's point of view, are perceived as important problems.

## METHODS

### *Study design and participants*

The SwiSCI is an ongoing national observational cohort study that includes individuals (aged 16 years and over) who reside in Switzerland and who have been diagnosed with traumatic or non-traumatic SCI. Exclusion criteria include congenital conditions leading to SCI, new SCI in the context of palliative care, neurodegenerative disorders, and Guillain-Barré syndrome. This national cohort study follows a questionnaire-based modular structure. The study design and recruitment procedures have been reported in detail elsewhere (23). The SwiSCI was approved by the ethics committee of the Canton of Lucerne and subsequently endorsed by the ethics committees of the Cantons of Zürich, Basel-Stadt, and Valais. Written informed consent was signed by all participants.

The present study refers to the cross-sectional data collected in a community-based survey between September 2011 and March 2013. The participants were identified through cooperation with the national association for persons with SCI (Swiss Paraplegics Association), a SCI-specific home care institution, and 3 specialized SCI-rehabilitation centres.

The data for this paper were extracted from the first module (called the Starter Module), a 19-item questionnaire on basic socio-demographic data, lesion characteristics, and information about the care situation, as receiving support from others, what kind of support and whether this support is sufficient. Data were extracted specifically

from one open-ended question, the last question of the questionnaire, which asked the participants: "What causes you the most problems since your spinal cord injury?"

### *Data analysis*

The participants' answers to the open-ended question were examined through a 3-step thematic analysis, based on meaning condensation, unit identification, and theme categorization (24). First, through meaning condensation, the response texts were shortened while maintaining their integrity. Secondly, through unit identification, data were divided into units of meaning, units of words or sentences with a common theme. Thirdly, themes were extracted from the units of meaning and post-coded into categories of the International Classification of Functioning, Disability and Health (ICF) as the underlying framework (25). The World Health Organization (WHO) developed this classification for many purposes, including the provision of a common, standardized language to describe the aspects of functioning and lived experiences of people with health conditions. The ICF contains 1,454 categories, subdivided into 4 major components: *body functions* (labelled "b" in the ICF), *body structures* ("s"), *activity and participation* ("d"), and *environmental factors* ("e"). Each component consists of chapters (first-level categories), and each chapter comprises second-level categories, which can be further broken down into third- and sometimes fourth-level categories. Examples are as follows:

- d5 chapter 5 – *self-care* (first-level category),
- d510 – *washing oneself* (second-level category), and
- d5102 – *washing body parts* (third-level category).

In the context of the present study, the ICF was chosen as an ideal framework to categorize the problems mentioned by respondents as impairments at the level of body functions and structures, limitations in activities and restrictions in participation, and barriers in the environment.

The units of meaning extracted from the response texts were linked to the most precise first- and second-level ICF categories, based on specific linking rules (26). If a response's content was not linkable to any ICF category, it was coded as "not covered."

To give an example of the analytical procedures, one participant answered:

*I have physical pain caused by paraplegia* (male, age 32 years, complete paraplegia [para]).

Through meaning condensation and unit identification, the unit of meaning "physical pain" was identified and then linked to the first-level category *chapter 2 – sensory functions and pain*, under the ICF component *body functions*, and to the second-level category *b280 – sensation of pain*, defined as the "sensation of unpleasant feeling indicating potential or actual damage to some body structure."

The overall linking process was conducted by 2 researchers following a previously established methodology in studies with a similar design (20, 21). The answers of the first 50 participants, transcribed verbatim, were analysed for meaning extraction and linked to the ICF by the 2 researchers (multiple coding). Agreements and special cases of meaning extraction and of the linking rules were documented. After this phase of adjustment, the other answers were analysed and linked by 1 researcher. Then 35% of these answers were independently analysed and linked by the other researcher (peer review). The degree of agreement between the 2 researchers, calculated by the Kappa statistic, was 0.83, with 95%-bootstrapped confidence intervals (27, 28) ranging from 0.82 to 0.84.

STATA for Windows was used for frequency analysis of the various problems identified by the participants. To enrich the data analysis according to the population's specific characteristics, the SwiSCI sample was subdivided according to the International Spinal Cord Injury Society (ISCoS) subgroup recommendations (29, 30), specifically age (at injury and current age), gender, aetiology, years since injury and severity of injury.

## RESULTS

*Study population and general insight*

A total of 3,144 eligible subjects were identified. The relevant Starter Module for this study was returned by 1,922 subjects (61% response rate). Of these 1,922 participants, 147 (7.6%) did not answer the open-ended question, and 13 (0.6%) stated not having problems. Table I presents the characteristics and sociodemographic data of the questionnaire respondents ( $n = 1,922$ ).

Out of the 1,762 who responded to the open-ended question, 256 (14.5%) reported only 1 problem, while the others reported more, ranging from 2 to 4 problems.

Table I. Characteristics and socio-demographic data of questionnaire respondents

Variable	
Total number of participants	1,922
Total number of respondents	1,762
Male, $n$ (%)	1,258 (71.4)
Age, years, median (IQR)	52 (42–63)
Age classification cf. ISCoS guidelines, $n$ (%)	
16–30 years	148 (8.4)
31–45 years	430 (24.4)
46–60 years	636 (36.1)
61–75 years	425 (24.1)
≥76 years	123 (7.0)
Time since injury, years, median (IQR)	13.8 (6.2–24.6)
Time since injury classification cf. ISCoS guidelines, $n$ (%)	
<1 years	21 (1.2)
1–5 years	323 (18.7)
6–10 years	316 (18.2)
11–15 years	252 (14.6)
16–20 years	207 (12.0)
21–25 years	186 (10.7)
26–30 years	148 (8.5)
31–35 years	99 (5.7)
>35 years	180 (10.4)
Unknown (missing data)	30 (1.7)
SCI characteristics, $n$ (%)	
Paraplegia, incomplete	660 (37.8)
Paraplegia, complete	533 (30.5)
Tetraplegia, incomplete	367 (21.0)
Tetraplegia, complete	186 (10.7)
Unknown (missing data)	16 (0.9)
Aetiology, $n$ (%)	
Traumatic	1,373 (78.4)
Non-traumatic	378 (21.6)
Unknown (missing data)	11 (0.6)
Language of correspondence, $n$ (%)	
German	1,266 (71.9)
French	418 (23.7)
Italian	78 (4.4)
Living arrangements, $n$ (%)	
Single	576 (34.0)
With partner	1,120 (66.0)
Unknown (missing data)	66 (3.8)
Years of education (median, IQR)	13 (12–15)
Unknown (missing data)	36 (2.0)

ISCoS: International Spinal Cord Society; IQR: interquartile range; SCI: spinal cord injury.

Overall, the problems reported by the participants were linked to 168 ICF categories, more specifically, 54 categories under the component *body functions*, 16 under *body structures*, 56 under *activity and participation*, and 42 under *environmental factors*. As for the “non-covered” problems, those that could not be linked to the categories of the ICF, 158 (8.98%) participants reported problems generically linked to the ICF component *personal factors*, for example problems in motivation, autonomy and coping.

The full list of all problems linked to the ICF categories, together with the percentage of participants who mentioned the problems, is shown in Appendix I.

*Most common problems*

This section describes in detail the 10 most cited problems by the participants. They are linked to the following ICF categories: *sensation of pain, urination functions, toileting, defecation functions, walking, sensations related to muscles and movement functions, recreation and leisure, design construction and building products and technology of buildings for public use, structure of urinary system, and muscle tone functions*. The number of citations for each problem ranged from 438 occurrences (stated by 24.86% of participants) linked to the ICF category *sensation of pain* to 135 for the problem linked to the ICF category *muscle tone functions* (stated by 7.66% of participants). Table II presents the 10 ICF categories and underlying ICF components, as well as the number of citations for each problem and the percentage of participants who mentioned it.

Some examples more specifically illustrate the content and range of the problems mentioned in each category. For instance, *sensation of pain* was reported under a variety of types of pain and in different body parts, including:

- *pain in the buttocks and shoulders* (male, incomplete tetraplegia [tetra], age 57 years),
- *pain in the joints every day* (male, incomplete tetra, age 56 years),
- *phantom pain* (male, complete para, age 49 years),
- *nerve pain in the foot and left leg* (male, incomplete para, age 73 years), and
- *strong neuropathic pain* (female, incomplete tetra, age 36 years).

With respect to *toileting*, individuals with SCI experienced problems such as the use of toilets:

*The toilets for people with disabilities are often closed, and I have difficulties in using the regular one* (male, complete tetra, age 33 years).

and dressing:

*When I get dressed, I cannot find the buttons with my fingers, so I cannot wear shirts but only clothes with zippers* (male, complete para, age 42 years).

The ICF category *urination* and its related category *structure of urinary system*, as well as *defecation function*, were used to refer to impairments at the level of body functions, such as for *urination functions*:

Table II. The 10 most cited problems based on International Classification of Functioning, Disability and Health (ICF) categories

ICF component	ICF category	Problem, n	% of participants who mentioned the problem
Body Functions	b280 Sensation of Pain	438	24.86
Body Functions	b620 Urination functions	379	21.51
Activity and Participation	d530 Toileting	364	20.66
Body Functions	b525 Defecation functions	350	19.86
Activity and Participation	d450 Walking	168	9.53
Body Functions	b780 Sensations related to muscles and movement functions	163	9.25
Activity and Participation	d920 Recreation and leisure	158	8.97
Environmental Factors	e150 Design, construction and building products and technology of buildings for public use	152	8.63
Body Structures	s610 Structure of urinary system	146	8.29
Body Functions	b735 Muscle tone functions	135	7.66

*My biggest problem is this incontinence (male, complete para, age 37 years).*

for structure of urinary system:

*Despite all my efforts, the bladder does not work (male, incomplete tetra, age 72 years),*

for defecation functions:

*I suffer from bowel incontinence (male, incomplete para, age 26 years).*

The ICF category *recreation and leisure* pertained to limitations in activities, including:

- *visiting friends (female, complete para, age 69 years),*
- *I cannot do a course in gymnastics; I cannot do nature walks. I can no longer visit all my grandchildren (female, incomplete para, age 81 years), and*
- *I can no longer engage in my favourite hobbies (play the clarinet, ski, and climb mountains) (female, complete para, age 37 years).*

Another most common problem, linked to the ICF category *walking*, involved limitations in walking-related activities, including: climbing stairs:

*I can no longer climb stairs (male, incomplete para, age 52 years),*

long-distance walking:

*I no longer have the power to walk for more than an hour (female, incomplete tetra, age 46 years),*

and running:

*I can no longer run (female, incomplete para, age 37 years).*

The ICF category *design, construction and building products and technology of buildings for public use* referred mainly to problems in wheelchair accessibility, such as:

*I have problems with the infrastructure of public spaces and with the accessibility of buildings and public transports (male, complete para, age 39 years), and*

*Wheelchair access to the public and semi-public areas is insufficient, for example, the post office, the bank, restaurants, cinemas, cultural centres, schools, swimming pools, shops, and public transport (female, incomplete para, age 47 years).*

*Sensations related to muscles and movement functions* and *muscle tone function* pertained to phenomena including tensions and spasms, as well as insensibility and spasticity, such as:

*I have tensions and spasms, and insensibility in the urogenital part of the body, partially in the legs and in the right foot, and totally in the left foot (male, complete para, age 46 years), and I constantly have leg tremor (female, incomplete para, age 79 years).*

#### Problems in the context of subgroups

In addition to the 10 most-cited problems by participants generally, the analysis showed that there are 5 main problems that were mentioned across all subgroups. These reported problems link to the following ICF categories and components:

- *defecation functions (ICF component body functions),*
- *sensation of pain (ICF component body functions),*
- *urination functions (ICF component body functions),*
- *toileting (ICF component body functions),*
- *recreation and leisure (ICF component activity and participation).*

The analysis also shows, however, that there are problems that occur among the 10 most cited in some sub-groups, but not in the others. More specifically, the problem linked to the ICF category *walking* is cited among the first 10 by all sub-groups, with the exception of individuals with complete paraplegia or tetraplegia.

Of the participants with complete paraplegia, 7.50% have among the 10 most-cited problems impairments linked to the ICF category *protective functions of the skin*, referring mainly to pressure sore-related problems

*I always have problems because I am [constantly] sitting, and I soon get pressure sores (male, complete tetra, age 54 years).*

These impairments do not appear among the most cited by participants of other sub-groups.

Of the participants with complete tetraplegia, 10.22% reported among the 10 most-cited problems barriers linked to the ICF category *health services, systems and policy*, referring mainly to reimbursement issues:

*When I need a different medicine, I always have to pay. If I want physiotherapy I also have to pay (female, incomplete para, age 33 years).*

Finally, aspects linked to the ICF categories *sensations related to muscles and movement functions* are cited among the first 10

problems by all sub-groups, with the exception of participants with complete paraplegia.

## DISCUSSION

This study presents the first large-scale investigation into the problems experienced and reported by individuals with SCI living in Switzerland. The results can be related to the existing literature in four main ways.

First, from a methodological point of view, this study shows the feasibility of applying a rigorous qualitative methodology, in the form of thematic analysis, to account for the frequency of problems mentioned by the participants in a generalizable way. It supports the use of the ICF as a coding system to process and drive the analysis of a large set of answers to an open-ended question. Unlike other types of analysis of open-ended questions, coded without a pre-determined conceptual scheme (31), the ICF enables the standardization and comparison of the units of meaning within the various answers given by the participants.

Secondly, from a content point of view, this study shows that, on the one hand, for the Swiss SCI population many of the problems that matter most to people refer to complications in body functions, as widely acknowledged in previous studies, namely, *pain* (32), *urination and defecation functions and structure of the urinary system* (33, 34), *sensations related to muscles and movement functions*, and *muscle tone function* (35). However, compared with data from studies from other countries, the occurrence and frequency of these problems in the Swiss population seems lower. For example, while most reports estimate that more than 60% of individuals with SCI have some form of chronic pain (36, 37), in the present study the highest occurrence of the problem is among individuals with incomplete paraplegia, 29.70% of whom report pain as a problem. Similarly, in the present study only 13.08% of the participants with incomplete tetraplegia comprise the highest percentage of reported problems in *sensations related to muscles and movement functions* compared with other reports' estimates that more than 65% of the SCI population have some amount of spasticity (38). Further research is needed to determine whether the difference observed between reported problems and presence of impairments in other studies reflects phenomena such as adaptation: an impairment does not necessarily lead to a problem as it might be fully accommodated, or the person may simply have become used to the impairment. The perceived problems might, thus, represent unmet needs for intervention, and the difference between the prevalence of the impairment and the remaining "problem" associated with that impairment might indicate the extent of adaptation.

On the other hand, other main problems perceived by individuals with SCI relate to their daily activities and can be influenced by environmental factors. Thus, problems linked to the ICF categories of *toileting*, *walking*, and *recreation and leisure* reveal the main types of limitations in activities and restrictions in participation that SCI individuals experience. These problems are partly determined by the decrease in body functions. Rehabilitation is therefore suggested as an optimal health strategy to overcome

some of the physical barriers (39), aided by technological devices (40). The fact that participants indicate problems linked to ICF environmental factor categories, such as *design, construction and building products and technology of buildings for public use* (8.63%) among the 10 most-cited problems supports the claim that some issues are environmentally caused.

Overall, this study supports the ideas expressed by the WHO World Report on Disability (41) and the WHO Report on SCI entitled "International Perspectives on Spinal Cord Injury" (42). Both reports emphasize the need for comprehensive research and a practice-oriented approach to disability in general, and SCI in particular, that accounts for all components of the ICF content-model, including environmental factors in particular.

Thirdly, some results of this study may have clinical implications consistent with the literature. More specifically, as suggested by previous studies (43), pressure ulcers appear to be an issue that is especially important in complete paraplegia; similarly, consistent with previous studies (44), spasticity appear to be less of a problem for individuals with complete paraplegia. This has implications for the Swiss healthcare system: the lifetime costs for a person with tetraplegia are higher than for a person with paraplegia (45). This might explain why problems at the level of healthcare services and policy appear among the 10 most-cited problems of participants with complete tetraplegia.

Lastly, the list of the 10 most-cited problems does not include 2 problems widely reported by other studies, namely work (46) and sexuality (47). The fact that work is not cited here might be explained by the relatively high employment rate of persons with SCI in Switzerland. A study by Marti et al. reported a 63.8% employment rate of individuals with SCI of working age (48). As for sexuality, the fact that it does not appear in the list of the most cited problems might be due to a bias in revealing potentially embarrassing personal details.

This study has some potential limitations. An open-ended question has the advantage of favouring participant's self-expression and avoiding suggestion of ideas that they might not have otherwise considered. However, it has limitations linked to the individual's perception, understanding, feelings, attitudes and experiences at the time of the interview/data collection (49). First of all, focus groups could help determine how the participants understood and interpret the expression "the most problems". Indeed, interpretation of the term "problem" could vary among participants. Secondly, respondents may not want to reveal sensitive personal details, such as their sexuality. Thirdly, participants might forget pertinent details or intentionally decide to mention only some of the issues that matter to them. This could explain why the reported problems linked to pain and spasticity occur at a lower level than in other studies.

In conclusion, this study sets out a method of capturing the perspective of people with SCI in Switzerland through a generalizable post-coding approach using the comprehensive framework of the ICF. The analysis identified a rich set of different perceived problems linked to SCI at the levels of body functions, activities and participation, and environmental factors. The insight provides an understanding of the breadth of the problems faced by people living with SCI in Switzerland, while offering an in-depth view of

what the most cited problems are in general, across all subgroups of individuals and in the specific context of some subgroups. While this study, using the comprehensive framework of the ICF, is presented as a basis for priority setting in SCI research and practice, its findings need to be compared with those from standardized questionnaires in order to gain mutual elucidation.

#### ACKNOWLEDGEMENTS

This study was financed in the framework of the Swiss Spinal Cord Injury Cohort Study (SwiSCI, [www.swisci.ch](http://www.swisci.ch)), supported by the Swiss Paraplegic Research.

#### REFERENCES

- Hammell KR. Spinal cord injury rehabilitation research: patient priorities, current deficiencies and potential directions. *Disabil Rehabil* 2010; 32: 1209–1218.
- People centred health care. A policy framework. WHO Western Pacific Region; 2007. Available from: [http://www.wpro.who.int/health\\_services/people\\_at\\_the\\_centre\\_of\\_care/documents/ENG-PCIPolicyFramework.pdf](http://www.wpro.who.int/health_services/people_at_the_centre_of_care/documents/ENG-PCIPolicyFramework.pdf).
- Dow B, Haralambous B, Bremner F, Fearn M. What is person-centred healthcare? A literature review. National Ageing Research Institute, State Government Victoria; 2006.
- Pope C, Mays N, editors. *Qualitative research in health care. Chapter 1: Qualitative methods in health research*. Malden, USA: Blackwell Publishing; 2006, p. 1–11.
- Hammell KW, Miller WC, Forwell SJ, Forman BE, Jacobsen BA. Fatigue and spinal cord injury: a qualitative analysis. *Spinal Cord* 2009; 47: 44–49.
- Hammell KW, Miller WC, Forwell SJ, Forman BE, Jacobsen BA. Managing fatigue following spinal cord injury: a qualitative exploration. *Disabil Rehabil* 2009; 31: 1437–1445.
- Engkasan JP, Mg CJ, Low WY. Factors influencing bladder management in male patients with spinal cord injury: a qualitative study. *Spinal Cord* 2014; 52: 157–162.
- Henwood P, Ellis JA. Chronic neuropathic pain in spinal cord injury: the patient's perspective. *Pain Res Manag* 2004; 9: 39–45.
- Rouranen K, Post MW, Juvalta S, Reinhardt JD. Participation and integration from the perspective of persons with spinal cord injury from five European countries. *J Rehabil Med* 2015; 47: 216–222.
- Lindberg J, Kreuter M, Teft C, Person LO. Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord* 2013; 51: 834–837.
- Williams TL, Smith B, Papathomas A. The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: a meta-synthesis of qualitative findings. *Health Psychol Rev* 2014; 8: 404–425.
- Duvdevany I, Buchbinder E, Yaacov I. Accepting disability: the parenting experience of fathers with spinal cord injury (SCI). *Qual Health Res* 2008; 18: 1021–1033.
- Willbanks SR, Ivankova NV. Exploring factors facilitating adults with spinal cord injury rejoining the workforce: a pilot study. *Disabil Rehabil* 2014; 8: 1–11.
- Goodridge D, Rogers M, Klassen L, Jeffery B, Knox K, Rohatinsky N, et al. Access to health and support services: perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disabil Rehabil* 2014; 21: 1–10.
- Wetzner E, Surca S, Wiese S, Dion A, Roussos Z, Renwick R, et al. Getting on with life: positive experiences of living with a spinal cord injury. *Qual Health Res* 2011; 21: 1455–1468.
- Lohne V. Back to life again – patients' experiences of hope three to four years after a spinal cord injury. A longitudinal study. *Can J Neurosci Nurs* 2009; 31: 20–25.
- Chun S, Lee Y. The experience of posttraumatic growth for people with spinal cord injury. *Qual Health Res* 2008; 18: 877–890.
- Babamohamadi H, Negarandeh R, Dehghan-Nayeri N. Coping strategies used by people with spinal cord injury: a qualitative study. *Spinal Cord* 2011; 49: 832–837.
- van de Ven L, Post M, de Witte L, van den Heuvel W. Strategies for autonomy used by people with cervical spinal cord injury: a qualitative study. *Disabil Rehabil* 2008; 30: 249–260.
- Kirchberger I, Sinnott A, Charlifue S, Kovindha A, Lüthi H, Campbell R, et al. Functioning and disability in spinal cord injury from the consumer perspective: an international qualitative study using focus groups and the ICF. *Spinal Cord* 2010; 48: 603–613.
- Lüthi H, Geyh S, Baumberger ME, Dokladal P, Scheuringer M, Mäder M, et al. The individual experience of functioning and disability in Switzerland – patient perspective and person-centeredness in spinal cord injury. *Spinal Cord* 2011; 49: 1173–1181.
- Anderson KA. Targeting recovery: priorities of the spinal cord-injury population. *J Neurotrauma* 2004; 10: 1371–1383.
- Brinkhof, MWG., Fekete, C., Chamberlain, JD., Post, MWM. Gemperli, A.: Swiss national community survey on functioning after spinal cord injury: Protocol, characteristics of participants and determinants of non-response. *J Rehabil Med* 2016; 48: 120–130.
- Kvale S. *Interview – an introduction to qualitative research interviewing*. CA: Sage; 1996.
- World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. WHO: Geneva; 2001.
- Cieza A, Geyh S, Chatterji S, Kostanjsek N, Stün B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005; 37: 212–218.
- Cohen J. A coefficient of agreement for nominal scales. *Educ Psychol Meas* 1960; 20: 37–46.
- Vierkant RA. A SAS macro for calculating bootstrapped confidence intervals about a kappa coefficient. Available from: <http://www2.sas.com/proceedings/sugi22/STATS/PAPER295.PDF>.
- DeVivo MJ, Biering-Sørensen F, Charlifue S, Noonan V, Post M, Stripling T, et al. Executive Committee for the International SCI Data Sets Committees. *International Spinal Cord Injury Core Data Set*. *Spinal Cord* 2006; 44: 535–540.
- DeVivo MJ, Biering-Sørensen F, New P, Chen Y. Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. *Spinal Cord* 2011; 49: 596–599.
- Schreier M. *Qualitative content analysis in practice*. London: SAGE Publications.
- Dijkers M, Bryce T, Zanca J. Prevalence of chronic pain after traumatic spinal cord injury: a systematic review. *J Rehabil Res Dev* 2009; 46: 13–29.
- Wolfe DL, Ethans K, Hill D, Hsieh JTC, Mehta S, Teasell RW, et al. Bladder health and function following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al, editors. *Spinal cord injury rehabilitation evidence, Version 4*. Vancouver: Spinal Cord Injury Rehabilitation Evidence (SCIRE); 2012.
- Krassioukov A, Claxton G, Abramson C, Shum S. Neurogenic bowel following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al., editors. *Spinal cord injury rehabilitation evidence, Version 3*. Vancouver: Spinal Cord Injury Rehabilitation Evidence (SCIRE); 2010, p. 1–41.
- Hsieh JTC, Wolfe DL, Townson AF, Short C, Connolly SJ, Mehta S, et al. Spasticity following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al., editors. *Spinal cord injury rehabilitation evidence, Version 4*. Vancouver: Spinal Cord Injury Rehabilitation Evidence (SCIRE); 2012.
- Demirel G, Yilmaz H, Gençosmanolu B, Kesikta N. Pain following spinal cord injury. *Spinal Cord* 1998; 36: 25–28.
- Felix ER, Cruz-Almeida Y, Widerström-Noga EG. Chronic pain after spinal cord injury: What characteristics make some pains more disturbing than others? *J Rehabil Res Dev* 2007; 44: 703–716.
- Adams MM, Hicks AL. Spasticity after spinal cord injury. *Spinal*

Cord 2005; 43: 577–586.

39. Kirshblum S, Bloomgarden J, McClure I, Nead C, Forrest G, Mitchell J. Rehabilitation of spinal cord injury. In: Campagnolo D, Kirshblum S, Nash MS, Heary RF, Gorman PH., editors. Spinal cord medicine. 2nd edn. Philadelphia, PA: Lippincott Williams & Wilkins; 2011.

40. Friesen EL, Theodoros D, Russell TG. Assistive technology devices for toileting and showering used in spinal cord injury rehabilitation – a comment on terminology. *Disabil Rehabil Assist Technol* 2014; 17: 1–2.

41. World Health Organization (WHO). World report on disability. Geneva: WHO; 2011.

42. World Health Organization. International Perspectives on Spinal Cord Injury. Geneva: WHO; 2013.

43. Hsieh J, McIntyre A, Wolfe D, Lala D, Titus L, Campbell K, et al. Pressure ulcers following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al., editors. Spinal Cord Injury Rehabilitation Evidence. Version 5.0. 2014, p. 1–90.

44. Sköld C, Levi R, Seiger A. Spasticity after traumatic cord injury: nature, severity and location. *Arch Phys Med Rehabil* 1999; 80: 1548–1557.

45. Access Economics for the Victorian Neurotrauma Initiative. The economic cost of spinal cord injury and traumatic brain injury in Australia; 2009. Available from: <https://www.tac.vic.gov.au/about-the-tac/our-organisation/research/tac-neurotrauma-research/vni/the20economic20cost20of20spinal20cord20injury20and20traumatic20brain20injury20in20australia.pdf>.

46. Noreau L, Escorpizo R, von Elm E, Miller C, Tawashy AE. Work and employment. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, et al, editors. Spinal cord injury rehabilitation evidence, Volume 3.0. Vancouver: Spinal Cord Injury Rehabilitation Evidence (SCIRE); 2010.

47. Consortium for Spinal Cord Medicine. Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for health-care professionals. Washington DC: Paralyzed Veterans of America; 2010.

48. Marti A, Reinhardt JD, Graf S, Escorpizo R, Post MW. To work or not to work: labour market participation of people with spinal cord injury living in Switzerland. *Spinal Cord* 2012; 50: 521–526.

49. Taylor B, Francis K. Qualitative research in health sciences. Abingdon, Oxon: Routledge; 2013.

APPENDIX I. International Classification of Functioning, Disability and Health (ICF) categories resulting from the linking of problems, and percentage of participants who mentioned the problems

ICF code	ICF category	% of participants who mentioned the problem linked to the ICF category
b280	Sensation of pain	24.86
b620	Urination functions	21.51
d530	Toileting	20.66
b525	Defecation functions	19.86
d450	Walking	9.53
b780	Sensations related to muscles and movement functions	9.25
d920	Recreation and leisure	8.97
e150	Design, construction and building products and technology of buildings for public use	8.63
s610	Structure of urinary system	8.29
b735	Muscle tone functions	7.66
b270	Sensory functions related to temperature and other stimuli	7.09
e580	Health services, systems and policies	6.75
b640	Sexual functions	5.62
e155	Design, construction and building products and technology of buildings for private use	5.16
s540	Structure of intestine	5.05
b730	Muscle power functions	4.99
d770	Intimate relationships	4.82
b298	Sensory functions and pain, other specified	4.71
e165	Assets	4.60
b152	Emotional functions	4.48
e120	Products and technology for personal indoor and outdoor mobility and transportation	4.37
b130	Energy and drive functions	4.31
e115	Products and technology for personal use in daily living	4.09
e515	Architecture and construction services, systems and policies	4.03
e570	Social security services, systems and policies	4.03
e160	Products and technology of land development	3.97
d230	Carrying out daily routine	3.92
s750	Structure of lower extremity	3.92
d850	Remunerative employment	3.86
b126	Temperament and personality functions	3.80
b455	Exercise tolerance functions	3.80
d410	Changing basic body position	3.63
b810	Protective functions of the skin	3.58
s810	Structure of areas of skin	3.52
d870	Economic self-sufficiency	3.46
d570	Looking after one's health	3.29
b820	Repair functions of the skin	3.18

APPENDIX I *contd.*


---

d455	Moving around	3.06
e110	Products or substances for personal consumption	3.06
d415	Maintaining a body position	2.95
e540	Transportation services, systems and policies	2.84
e460	Societal attitudes	2.78
s730	Structure of upper extremity	2.78
b235	Vestibular functions	2.21
d470	Using transportation	2.04
b710	Mobility of joint functions	1.99
d640	Doing housework	1.93
e355	Health professionals	1.87
d440	Fine hand use	1.76
e310	Immediate family	1.70
b180	Experience of self and time functions	1.65
e530	Utilities services, systems and policies	1.59
e550	Legal services, systems and policies	1.59
b515	Digestive functions	1.53
d845	Acquiring, keeping and terminating a job	1.53
e590	Labour and employment services, systems and policies	1.53
e225	Climate	1.48
d430	Lifting and carrying objects	1.42
d465	Moving around using equipment	1.42
e565	Economic services, systems and policies	1.42
d460	Moving around in different locations	1.36
d540	Dressing	1.36
b134	Sleep functions	1.25
d910	Community life	1.25
e340	Personal care providers and personal assistants	1.25
s720	Structure of shoulder region	1.25
d510	Washing oneself	1.19
d445	Hand and arm use	1.14
d475	Driving	1.14
e445	Individual attitudes of strangers	1.14
b530	Weight maintenance functions	1.08
b535	Sensations associated with the digestive system	0.96
b770	Gait pattern functions	0.85
s760	Structure of trunk	0.85
e325	Acquaintances, peers, colleagues, neighbours and community members	0.79
d620	Acquisition of goods and services	0.74
d710	Basic interpersonal interactions	0.74
b164	Higher-level cognitive functions	0.68
b265	Touch function	0.68
d420	Transferring oneself	0.68
s530	Structure of stomach	0.62
s770	Additional musculoskeletal structures related to movement	0.62
b440	Respiration functions	0.57
d520	Caring for body parts	0.57
b140	Attention functions	0.51
b720	Mobility of bone functions	0.51
b760	Control of voluntary movement functions	0.45
d550	Eating	0.45
d630	Preparing meals	0.45
d760	Family relationships	0.45
b144	Memory functions	0.34
b435	Immunological system functions	0.34
d720	Complex interpersonal interactions	0.34
d750	Informal social relationships	0.34
e320	Friends	0.34
e360	Other professionals	0.34
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	0.34
e450	Individual attitudes of health professionals	0.34
e575	General social support services, systems and policies	0.34
s740	Structure of pelvic region	0.34
b420	Blood pressure functions	0.28
b450	Additional respiratory functions	0.28
b765	Involuntary movement functions	0.28

---

APPENDIX I *contd.*

b240	Sensations associated with hearing and vestibular function	0.23
b415	Blood vessel functions	0.23
b610	Urinary excretory functions	0.23
b715	Stability of joint functions	0.23
b755	Involuntary movement reaction functions	0.23
d360	Using communication devices and techniques	0.23
d840	Apprenticeship (work preparation)	0.23
e595	Political services, systems and policies	0.23
s620	Structure of pelvic floor	0.23
b114	Orientation functions	0.17
d170	Writing	0.17
d240	Handling stress and other psychological demands	0.17
d350	Conversation	0.17
d560	Drinking	0.17
d650	Caring for household objects	0.17
e430	Individual attitudes of people in positions of authority	0.17
s710	Structure of head and neck region	0.17
b260	Proprioceptive function	0.11
b445	Respiratory muscle functions	0.11
b510	Ingestion functions	0.11
b630	Sensations associated with urinary functions	0.11
b830	Other functions of the skin	0.11
d155	Acquiring skills	0.11
d610	Acquiring a place to live	0.11
d855	Non-remunerative employment	0.11
e330	People in positions of authority	0.11
e345	Strangers	0.11
e455	Individual attitudes of health-related professionals	0.11
e585	Education and training services, systems and policies	0.11
s120	Spinal cord and related structures	0.11
b147	Psychomotor functions	0.06
b156	Perceptual functions	0.06
b160	Thought functions	0.06
b167	Mental functions of language	0.06
b210	Seeing functions	0.06
b230	Hearing functions	0.06
b520	Assimilation functions	0.06
b550	Thermoregulatory functions	0.06
b670	Sensations associated with genital and reproductive functions	0.06
d150	Learning to calculate	0.06
d175	Solving problems	0.06
d177	Making decisions	0.06
d330	Speaking	0.06
d340	Producing messages in formal sign language	0.06
d355	Discussion	0.06
d435	Moving objects with lower extremities	0.06
d660	Assisting others	0.06
d740	Formal relationships	0.06
d820	School education	0.06
d825	Vocational training	0.06
d830	Higher education	0.06
d930	Religion and spirituality	0.06
d940	Human rights	0.06
e125	Products and technology for communication	0.06
e210	Physical geography	0.06
e240	Light	0.06
e255	Vibration	0.06
e335	People in subordinate positions	0.06
e420	Individual attitudes of friends	0.06
e525	Housing services, systems and policies	0.06
e555	Associations and organizational services, systems and policies	0.06
e560	Media services, systems and policies	0.06
s410	Structure of cardiovascular system	0.06
s630	Structure of reproductive system	0.06
s798	Structures related to movement, other specified	0.06