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**The International Spinal Cord
Injury Survey and the Learning
Health System for SCI**

Jerome Bickenbach, PhD
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C O N T E N T S

Editorial

- S1 The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury**
Alarcos Cieza, PhD, MSc, MPH

Guest Editorial

- S2 The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury**
Gerold Stucki, MD, MS, and Jerome Bickenbach, PhD, LLB

Research Articles

- S5 A Structured Approach to Capture the Lived Experience of Spinal Cord Injury: Data Model and Questionnaire of the International Spinal Cord Injury Community Survey**
Christine Fekete, PhD, Marcel W.M. Post, PhD, Jerome Bickenbach, PhD, LLB, James Middleton, PhD, Birgit Prodingier, PhD, Melissa Selb, MSc, and Gerold Stucki, MD, MS, on behalf of the International Spinal Cord Injury Community Survey (InSCI) group
- S17 Stakeholder Dialogue as Deliberation for Decision Making in Health Policy and Systems: The Approach from Argumentation Theory**
Sara Rubinelli, PhD, and Per Maximilian von Groote, MA
- S23 Study Protocol of the International Spinal Cord Injury (InSCI) Community Survey**
Mirja H. Gross-Hemmi, PhD, Marcel W. M. Post, PhD, Cristina Ehrmann, PhD, Christine Fekete, PhD, Nazirah Hasnan, PhD, MRehabMed, MBBS, James W. Middleton, MD, PhD, Jan D. Reinhardt, PhD, Vegard Strøm, PhD, and Gerold Stucki, MD, MS, on behalf of the International Spinal Cord Injury Community Survey (InSCI) Group
- S35 Rehabilitation Services Provision and Payment**
Christoph Gutenbrunner, MD, PhD, Melanie Blumenthal, MA, Veronika Geng, MNSc, and Christoph Egen, Dipl-Soz-Wiss, Dipl-Päd



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S41 The Cross-Cultural Societal Response to SCI: Health and Related Systems

SDC Diana Pacheco Barzallo, PhD, and Mirja H. Gross-Hemmi, PhD

S55 The Implementation Challenge and the Learning Health System for SCI Initiative

Gerold Stucki, MD, MS, and Jerome Bickenbach, PhD, LLB

Country Reports

S61 People with Spinal Cord Injury in China

Jan D. Reinhardt, PhD, Yu Zheng, MD, Guangxu Xu, MD, Xiao Lu, MD, PhD, Yong Yin, MD, Shouguo Liu, MD, Qiang Gao, PhD, Xianghu Xiong, MD, PhD, Chengqi He, MD, Hao Li, DPT, and Jianan Li, MD

S66 People with Spinal Cord Injury in Germany

Melanie Blumenthal, MA, Veronika Geng, MSc, Christoph Egen, Dipl-Soz-Wiss, Dipl-Päd, and Christoph Gutenbrunner, MD

S71 People with Spinal Cord Injury in Greece

Christina-Anastasia Rapi, MD, PhD, SFEPRM, and Athanasios Kyriakides, MD, FEBPRM

S74 People with Spinal Cord Injury in Indonesia

Angela Bibiana Maria Tulaar, MD, PhD, Muhammad Karyana, MD, MPH, Luh Karunia Wahyuni, MD, Anitta Florence Stans Paulus, MD, Damayanti Tinduh, MD, Fitri Anestherita, MD, and Grace Wangge, MD, MSc, PhD

S78 People with Spinal Cord Injury in Israel

Manuel Zwecker, MD, Julie Wolff, MD, Tamara Shaoul, MSW, Gabi Zeilig, MD, and Iuly Treger, MD

S80 People with Spinal Cord Injury in Italy

Alessio Baricich, MD, Angelo Paolo Amico, MD, Mauro Zampolini, MD, Francesca Gimigliano, MD, Carlo Cisari, MD, and Pietro Fiore, MD

S83 People with Spinal Cord Injury in Korea

Zee-A Han, MD, PhD, Bum Suk Lee, MD, MPH, Wanho Kim, MD, Seong Jae Lee, MD, PhD, Hyun Jeong Im, Changsoo Kim, MD, PhD, Kijun Song, PhD, Hyun-Yoon Ko, MD, Moon Suk Bang, MD, PhD, and Chang-il Park, MD, PhD

S86 People with Spinal Cord Injury in Lithuania

Alvydas Juocevicius, MD, PhD, Ieva E. Jamontaite, PhD, and Ausra Adomaviciene, MSc

S90 People with Spinal Cord Injury in Malaysia

Julia Patrick Engkasan, MRehabMed(Mal), MBBS(Mal), Nazirah Hasnan, PhD, MRehabMed(Mal), MBBS(Mal), Yusniza Mohd Yusuf, MRehabMed(Mal), MBBS(Mal), and Lydia Abdul Latif, MRehabMed(Mal), MBBS(Mal)

S93 People with Spinal Cord Injury in the Netherlands

Marcel W.M. Post, PhD, Carla F. Nooijen, PhD, Karin Postma, PT, PhD, Jos Dekkers, Frans Penninx, Rita J.G. van den Berg-Emons, PhD, and Henk J. Stam, MD, PhD

S96 People with Spinal Cord Injury in New Zealand

Maria van den Heuvel, RN BN, MHealSc(Rehab), Lincoln Jansz, MB, BS, FAFRM(RACP), Xianghu Xiong, MB, BS, FAFRM(RACP), and Balraj Singhal, MB, BS, FAFRM(RACP), FRCS

S99 People with Spinal Cord Injury in Norway

Vegard Strøm, PhD, Grethe Månrum, PhD, Annelie Leiulfstrud, MA, Pia Wedege, MSc, Tiina Rekand, PhD, Annette Halvorsen, MD, Leif Arild Fjellheim, and Johan K. Stanghelle, PhD

S102 People with Spinal Cord Injury in Poland

Piotr Tederko, MD, PhD, Robert Jagodziński, Marek Krasuski, MD, PhD, and Beata Tarnacka, MD, PhD

S106 People with Spinal Cord Injury in Portugal

Ines Campos, MD, MSc, Paulo Margalho, MD, Arminda Lopes, MD, Catarina Branco, MD, Filipa Faria, MD, MSc, Jorge Caldas, MD, Maria Cunha, MD, Maria João Andrade, MD, PhD, and Jorge Lains, MD

S109 People with Spinal Cord Injury in Republic of South Africa

Conran Joseph, PhD, Ernst Scriba, MD, Virginia Wilson, MD, Joyce Mothabeng, PhD, and Francois Theron, MD, MMed

S112 People with Spinal Cord Injury in Spain

Merce Avellanet, MD, PhD, and Miguel Angel Gonzalez-Viejo, MD, PhD

S116 People with Spinal Cord Injury in Switzerland

Mirja H. Gross-Hemmi, PhD, and Diana Pacheco Barzallo, PhD

S120 People with Spinal Cord Injury in Thailand

Apichana Kovindha, MD

S124 People with Spinal Cord Injury in the United States

Christine Richards, Neil MacKenzie, Shawn Roberts, and Reuben Escorpizo, DPT, MSc, PT

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The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury

Alarcos Cieza, PhD, MSc, MPH

It is a pleasure for me to write this editorial on the Learning Health System for Spinal Cord Injury Initiative, and in particular the International Spinal Cord Injury Survey (InSCI) that is the essential data platform for this initiative.

The LHS-InSCI initiative is important to the World Health Organization (WHO) for 3 reasons. First, the initiative, and especially InSCI, is built on the understanding of functioning and disability contained within WHO's *International Classification of Functioning, Disability and Health (ICF)*¹; second, the initiative follows directly from the extensive work done at WHO and the World Bank in the development of the *World Report on Disability (2011)*² and the joint production of WHO with the International Spinal Cord Society of the report *International Perspectives on Spinal Cord Injury (2013)*³; third, the development of the InSCI has been based very closely on the *Model Disability Survey*, a major initiative of my unit.⁴

The current work of WHO on disability since 2014 has been guided by the WHO *Global Disability Action Plan 2014–2021 Better Health for All People With Disability*.⁵ The Action Plan has 3 objectives:

1. To remove barriers and improve access to health services and programs;
2. To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation; and
3. To strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.

The initiative, even though it is focused on a single health condition, namely, spinal cord injury (SCI), is linked to each of these 3 objectives. First, the information collected from InSCI and the anticipated analyses of the participating countries societal responses to SCI needs will identify—in terms that are far more detailed and concrete than is possible with standard population data collection exercises—information about the nature of barriers that limit access by persons experiencing disability to health services and programs. The initiative will also be able to expand our knowledge about global needs to strengthen rehabilitation services, within health systems, and the best strategies for doing so. One of the primary lessons learned from the IPSCI report is that SCI, although of low prevalence, can serve as a kind of “canary in the mine” to highlight barriers to accessing rehabilitation services: SCI calls up the full range of rehabilitation services, from acute all the way to community-based services. Finally, the urgent need to reform how we collect data about disability, and in particular the important role that the *ICF* can play as an information reference system for internationally comparable functioning and disability data, will be thoroughly tested and confirmed by the multicountry implementation of the *ICF*-based InSCI survey. Because InSCI is linked to the *Model Disability Survey*, it will be possible to compare the small SCI population with the general population of a country in order, for example, to assess whether in the implementation of the *Sustainable Development Goals*⁶ persons with SCI are not left behind.

I am very optimistic about the success of the initiative and the value of the InSCI survey. I would like to wish all participating countries continuing success.

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From the Blindness and Deafness Prevention, Disability and Rehabilitation, World Health Organization, Geneva, Switzerland.

All correspondence and requests for reprints should be addressed to: Alarcos Cieza, PhD, MSc, MPH, World Health Organization, Avenue Appia 20, CH-1211 Geneva 27, Switzerland. Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article. Copyright © 2017 Wolters Kluwer Health, Inc. All rights reserved.

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The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury

Gerold Stucki, MD, MS, and Jerome Bickenbach, PhD, LLB

The experience of living with spinal cord injury (SCI) has fundamentally changed in recent years, across the world. In part because of improvements in emergency response to injury, clinical care, and acute rehabilitation, people with SCI, especially in high-resource countries, are living longer and in part because of the growing recognition that what matters to people living with SCI is the extent to which they can live independently and fully participate in all aspects of their community life.¹ This need to focus on optimal functioning is part of the fundamental paradigm shift incorporated within the World Health Organization's (WHO's) *International Classification of Functioning, Disability, and Health in Rehabilitation (ICF)*.² The *ICF* conceptualizes the lived experience of a health condition such as SCI both in terms of *biological health*—the impairments that are experienced—and in terms of *lived health* understood as the outcome of a complex interaction between the health condition and environmental and personal factors.³ This focus, moreover, is reflected in the political domain by the explicit recognition that persons with disabilities enjoy human rights to full inclusion and participation in all areas of social life, on an equal basis with others.⁴

This shift in focus also calls for a new kind of information that can capture, not only the individual's lived experience, in all of its range and complexity, but also information about how societies respond to the needs of persons with a lifetime, chronic, and multifaceted health condition such as SCI. The challenge is, in light of the conceptual model of the lived experience of SCI offered by the *ICF*, to collect robust and relevant information both about the biological capacity of individuals with SCI and the actual performance of activities and domains of participation, given environmental and personal determinants that may facilitate or hinder that performance. Compounding this challenge is the need to not only faithfully record the societal response to the perceived needs of persons with SCI, but also evaluate the extent to which this response effectively enhances the individual's performance in domains of personal and social life. The societal response will include not only essential health services, and especially the full range of rehabilitation services and psychological and psychosocial supports, but also a wide range of social supports and services designed to enhance social participation.

The Learning Health System for Spinal Cord Injury Initiative is being conducted under the auspices of the Disability and Rehabilitation Team at the WHO, led by Prof Alarcos Cieza, and responding to the need to ensure the universal challenge of access to health care embodied in Goal 3 of the *Sustainable Development Goals*,⁵ as well as the specific objectives of the *Global Disability Action Plan 2014–2021 Better Health for All People With Disability*.⁶ Operationally, this initiative is a collaborative initiative between WHO, the International Spinal Cord Society, and the International Society of Physical and Rehabilitation Medicine—both of the latter are international organizations in official relationship with WHO—and hosted by the Swiss Paraplegic Research (Nottwil, Switzerland).

The normative framework of the initiative is provided by the WHO–International Spinal Cord Society report, *International Perspectives on Spinal Cord Injury (IPSCI)*,⁷ published by WHO on December 3, 2013, World Disability Day. The IPSCI report summarizes the best available evidence on SCI from both the personal and societal perspectives and around the globe. Based on WHO's own *World Report on Disability*, published in 2011,⁸ IPSCI takes the next step to focus on a specific health condition and provides concrete and actionable recommendations aimed at improving the lived

From the Department of Health Sciences and Health Policy, University of Lucerne, Lucerne; and Swiss Paraplegic Research, Nottwil, Switzerland.

All correspondence and requests for reprints should be addressed to: Jerome Bickenbach, PhD, LLB, Swiss Paraplegic Research, Guido Zäch Institute, Guido Zäch-Strasse 4, CH-6207 Nottwil, Switzerland.

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experience of SCI by means of an evidence- and human rights-informed research and policy effort. The IPSCI recommendations focus attention on structural features of the health sector response to SCI, as well as cross-sectorial issues of accessible and empowerment of persons with SCI and their families. Other recommendations focus on employment as a key area of social participation, address negative attitudes toward persons with SCI, and encourage research and improved data collection.

At the core of the initiative is the International Spinal Cord Survey (InSCI), a community survey that will be conducted in 2017 in 28 countries, across 6 WHO regions. Several of the participating countries are currently planning to develop and field national modules focusing on additional issues, for example, participation in sports activities, more focused detail on employment, or the level of social integration and acceptance experienced by the individual. A follow-up survey is proposed for 2022. The survey is fully grounded in the *ICF*, both in terms of the dimensions of the experience of SCI that are covered and the domains upon which the questions are based and also and more fundamentally in terms of the underlying conceptualization of functioning that provides the rationale and inherent structure of the survey. Because of this, InSCI is likely to be the first national-level, health condition-specific survey entirely structured and linked to the *ICF* and implemented across a variety of countries.

The overall objective of InSCI is to identify the factors that explain functioning and well-being of people living with SCI within and across countries in the context of health, health-related, and other social and political systems, policies, services, and care provision and accounting for differences in the health condition of SCI and environmental factors and personal characteristics. The survey will provide comprehensive and comparable information about the lived experience of disability—the perspective of the person. In light of detailed information from each participating country collected and analyzed at the study center at the Swiss Paraplegic Research, the complementary perspective of society will also be developed, comparatively across participating countries.

The scope of the Learning Health System for Spinal Cord Injury Initiative, however, extends beyond these substantial data generation activities, fundamental though they are. In addition, the initiative relies on, and takes the preliminary steps of implementing, a fundamental approach to reforming the societal response to SCI. This is called the learning health system approach, originally proposed and described by the US National Academy of Medicine (formerly the Institute of Medicine) beginning in 2007.^{9–14} This approach recognizes that health systems “learn” when they can rely on cyclical dynamics to identify issues, create responses, implement change, observe the consequences, respond to the results of the implementation, and revise and reshape the response: that is, learn from success and failure. A health system can only learn when it has the capacity to identify and understand weaknesses and constraints, successes and innovations, and craft and implement interventions that avoid or mitigate the effects of what does not work and enhance synergies that encourage what does work. In a recent discussion paper, the need for the kind of information InSCI will collect is described as essential for the learning health system approach.¹⁴ It is hoped that the initiative, and

InSCI in particular, will become a model for how health systems can “learn” for other specific health conditions.

Guided by these insights, the Learning Health System for Spinal Cord Injury Initiative proposes to use the multicountry data collection platform in order to generate an analysis of the gaps between the recognized needs for persons with SCI—across the entire lived experience of the condition and taking account of environmental and personal factors and their impact on the experience—and the societal response to these needs. Guided by the specific IPSCI recommendations, and more distally by the human rights set out in the United Nations *Convention on the Rights of Persons with Disabilities*,⁴ the initiative will propose an implementation strategy to close the fundamental gap between research and policy change and concrete implementation. This important aspect of the initiative is based on strategies developed and reformed through practical experience and grounded in the current state of the art in implementation science, in particular policy briefs and national stakeholder dialogues. It is anticipated that this phase of the initiative will begin in 2019.

This Special Issue begins by introducing the components of the learning health system for SCI, focusing primarily on the technical aspects of the InSCI survey and its implementation. For context, and to give the reader a sense of the overall scope and full context of the survey, an introduction to the learning health system approach, as applied in this initiative, as well as the implementation strategy of stakeholder dialogues, will also be included. The second part of the issue provides an opportunity for a sample of the participating countries to provide a baseline of the SCI experience in their countries, a brief review of their understanding of the societal response, and a description of their own survey strategy and supplementary national modules.

In the first article in the issue the innovative data model of the questionnaire used for the survey is described in detail. The challenge of collecting internationally comparable data on the lived experience of persons with SCI—data that can then be coordinated with information about the societal response of countries—is addressed, both in principle and technically. The standard balance of survey feasibility and data comprehensiveness is shown to pose a particular challenge in this survey, and the response to this challenge is described.

The first part of the issue ends with the the guiding rationale of the initiative, namely, the implementation challenge and the learning health system (pages x–y). The article reviews the components of the learning health system for SCI, and the role of the InSCI community survey is designed to play in the implementation endeavor, in light of the underlying learning health system approach. The point is underscored here that every aspect of the development of the InSCI survey was motivated, and in some instances specifically designed, to meet the objectives of the initiative as a whole.

Between these 2 end points in the first part, a discussion of the background rationale and the work that is in progress to develop an implementation strategy, grounded in the state of the science, which is tailored to the specific objectives of the initiative is outlined. In this original work, the authors use the resources of argumentation theory to enhance the effectiveness, in a policy implementation context, of the stakeholder dialogue methodology. The resource and training implementation of this

phase of the initiative are also discussed here. In the second article the specific survey methodological features of the InSCI survey are set out in detail. The article describes in detail the design of InSCI as a multinational community survey, grounded in the ICF. The overall aims, guiding principles on sampling strategies, data collection modes, reminder management, and other operational details are elucidated.

The remaining 2 articles set the stage for developing the analytical framework in terms of which data from countries outlining the societal response to SCI population needs will be analyzed during the course of the next 2 years of the initiative. The first of these articles focuses on rehabilitation services, both from the perspective of the provision and the payment of services. Based on the country-level reports and a systematic review of the literature, the article presents a preliminary analysis of the impact of rehabilitation services and payment on the societal response to SCI. These results will help to develop other systems models for comparative purposes as more data, from the InSCI survey and subsequent focused, country-level key informant reports are available from the participating countries. The next article discusses the challenges of analyzing cross-cultural societal responses to SCI, focusing on the basic health and health-related systems. The article describes a preliminary concurrent mixed-methods study to identify key macroeconomic indicators that can be used to describe the social situation of persons with SCI in the 28 participating countries, as well as the general societal response. Data were derived both from existing international sources of country-level macroeconomic information and also from a country template completed by researchers representing the participating country. Preliminary analysis suggests that there is a correlation between the efficiency of the health and social care systems and the extent of a country's investment of those sectors, but shows that unmet SCI need cannot entirely be explained in this manner.

As mentioned, in the second part of this Special Issue, 19 participating countries take the opportunity to describe their SCI experience and societal response prior to the implementation of the InSCI study, in part to provide a baseline for later analysis. The represented countries in this part are China, Germany, Greece, Indonesia, Israel, Italy, Korea, Lithuania,

Malaysia, the Netherlands, New Zealand, Norway, Poland, Portugal, South Africa, Spain, Switzerland, Thailand, and the United States. In each short report, country researchers describe recruitment procedures and other survey implementation issues that are of particular relevance to their country situation. They describe what they hope to learn from their participation in the initiative and, where relevant, outline their anticipated national modules and the research questions they hope to answer.

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A Structured Approach to Capture the Lived Experience of Spinal Cord Injury

Data Model and Questionnaire of the International Spinal Cord Injury Community Survey

Christine Fekete, PhD, Marcel W.M. Post, PhD, Jerome Bickenbach, PhD, LLB, James Middleton, PhD, Birgit Proding, PhD, Melissa Selb, MSc, and Gerold Stucki, MD, MS, on behalf of the International Spinal Cord Injury Community Survey (InSCI) group

Abstract: The International Spinal Cord Injury (InSCI) community survey has been developed to collect internationally comparable data on the lived experience of persons with spinal cord injury (SCI) in all 6 WHO regions. The InSCI survey provides a crucial first step to generate evidence on functioning, health maintenance, and subjective well-being in persons with SCI globally. A major challenge in setting up the InSCI community survey was to develop a data model and questionnaire that comprehensively captures what matters to people and, at the same time, is feasible and parsimonious in terms of participant's burden. This paper outlines the components of the InSCI data model and presents the question selection to operationalize the data model along the 4 guiding principles of efficiency, feasibility, comparability, and truth and discrimination. The data model consists of 6 components operationalized with 125 questions including functioning (n = 28 body functions and structures; n = 42 activities and participation), contextual factors (n = 26 environmental; n = 19 personal factors), lesion characteristics (n = 2), and appraisal of health and well-being (n = 8). The InSCI questionnaire presents an efficient and feasible solution with satisfying comparability to other populations; however, its validity and reliability still needs to be confirmed.

Key Words: Spinal Cord Injury, Data Collection, Questionnaire Design, Community Survey, Survey Methodology, International Classification of Functioning, Disability and Health

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The World Health Organization's (WHO's) Global Disability Action Plan 2014–2021 *Better Health For All People With Disability*¹ identifies as 2 objectives the reduction of barriers to access to health services, assistive technology, and community-based rehabilitation, and the strengthening of data collection to enable international comparative analysis of information about disability. The Learning Health System for Spinal Cord Injury (LHS-SCI) is an initiative aligned with these objectives of the action plan and consists of 3 complementary pillars: generating evidence, implementing recommendations,

and building capacity. The International Spinal Cord Injury (InSCI) community survey has been developed as a crucial first step to support the LHS-SCI initiative through the collection of internationally comparable data on the lived experience of community-dwelling persons with spinal cord injury (SCI) globally and to describe their situation in relation to functioning, health maintenance, and subjective well-being.

A major challenge in setting up the InSCI community survey is that of developing a data model that comprehensively captures what matters to people and, at the same time, is feasible in participant burden. As a result, the definition of what to measure and how to measure is crucial, and this requires a well-defined and structured approach in order to develop a comprehensive and parsimonious questionnaire. The International Classification of Functioning, Disability and Health (ICF)² provides a valuable framework to guide researchers in selecting the most relevant ICF components (ie, sets of variables) to measure, ensuring that appropriate data on relevant aspects of people's lived experience are collected.^{3,4} Since the ICF is built on a comprehensive model, it is a practical tool for determining a data model by means of selecting ICF categories that are relevant for the specific health condition.⁵ Once the components and specific ICF categories to be included in the data model are defined, researchers then face the challenge of operationalization, that is, the selection of data collection tools that adequately represent each of the predefined categories.

The objective of this paper was to report on the development of the InSCI data model and the InSCI questionnaire. More specifically, we aim to 1) present the components of the

From the Swiss Paraplegic Research, Guido A. Zäch Institute, Nottwil, Switzerland (CF, MWMP, JB, BP, MS, GS); University of Groningen, University Medical Center Groningen, Department of Rehabilitation Medicine, Center for Rehabilitation, Groningen, the Netherlands (MWMP); Brain Center Rudolf Magnus and Center of Excellence in Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat, Utrecht, the Netherlands (MWMP); Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland (JB, BP, GS); ICF Research Branch, Guido A. Zäch Institute, Nottwil, Switzerland, a cooperation partner within the WHO Collaborating Centre for the Family of International Classifications (at DIMDI) (JB, BP, MS, GS); and John Walsh Centre for Rehabilitation Research, Kolling Institute, Northern Sydney Local Health District and Sydney Medical School Northern, University of Sydney, Sydney, Australia (JM).

All correspondence and requests for reprints should be addressed to: Christine Fekete, PhD, Swiss Paraplegic Research, Guido A. Zäch Institute, 6207 Nottwil, Switzerland.

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InSCI data model and the resulting ICF categories; 2) outline the selection of questions that operationalize the InSCI data model based on guiding principles; and 3) describe the operational procedures and key process steps in the InSCI questionnaire development.

METHODS

The InSCI Data Model: Defining Components and Categories of “What To Measure”

The process of determining what to measure in the ICF components body functions and structures, activities and participation, and environmental factors was guided by the conceptually and scientifically driven selection of health condition–specific ICF categories in the ICF core sets. The ICF core sets are short lists of categories from the entire ICF classification that have been demonstrated through the core set methodology to be the most relevant for describing the functioning of persons with specific health conditions (www.icf-core-sets.org). Brief ICF core sets include a minimal set of categories to describe the typical spectrum of functioning in persons with specific health conditions.^{5,6} As the comprehensive core sets tend to be too large to be feasible for survey purposes, the brief core sets were selected. For the InSCI data model, all ICF categories defined in the brief ICF core set for SCI, long-term context,⁵ were selected. Importantly, the process of developing health condition–specific core sets also includes affected persons, thus reflecting their subjective perspective on the relevance of domains for their lives.⁷ In addition, the ICF rehabilitation set,⁸ including a minimal set of categories most relevant across health conditions, was selected to enable comparisons with general and clinical populations. The ICF rehabilitation set was developed as reference framework to harmonize information on disability across

clinical populations.⁸ In addition, the ICF rehabilitation set includes 7 categories from the ICF generic set⁹ relevant for general populations, thus providing information for general population comparisons. Information on ICF categories of the InSCI data model as well as their source (ICF core set for SCI; ICF rehabilitation set) is provided in Tables 2 to 4 in the “Results” section.

As the component of personal factors is not classified in the ICF, although it should be measured in the context of functioning, a recent systematic literature review by Geyh et al.¹⁰ was relied on for the identification of plausible categories to be included. The authors extracted data from a pool of 1246 items from SCI studies to establish a psychologic personal factor structure that includes relevant research constructs. The result of a preliminary classification proposal resulted in the identification of 7 categories, which were included in the InSCI data model (see “Results” section). Further components of the InSCI data model include lesion characteristics and the appraisal of health and well-being (Fig. 1).

As defined in the InSCI study protocol (Gross-Hemmi et al.¹¹ in this issue), the collaborating countries are invited to add national modules on key topics they wish to assess in more detail. The development of national modules is not the subject of this paper and is described in each of the national study protocols. In addition, design issues such as the operational implementation of the questionnaire in data collection are described in detail elsewhere in this issue (Gross-Hemmi et al.¹¹ for general guidelines; national study protocols for description of country-specific implementation of the survey).

Operationalization of the Data Model: Defining “How To Measure” and Selecting Questions

Based on earlier work on guiding principles to select data collection tools for epidemiological studies on functioning,⁴

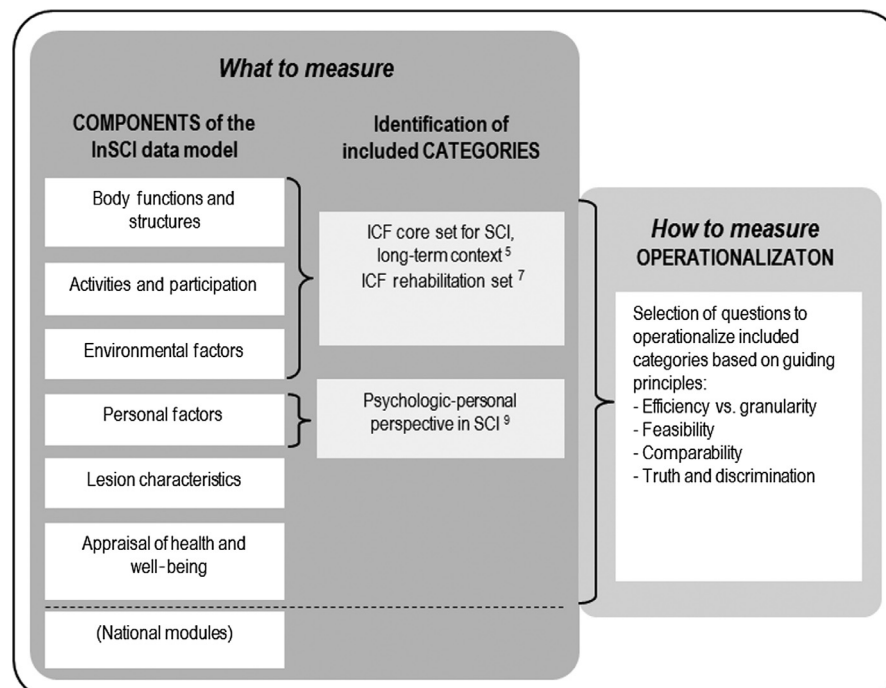


FIGURE 1. The structured approach of the InSCI data model and questionnaire development.

the four principles that guided the argumentative process of question selection are presented below.

Efficiency Versus Granularity

The procedure of linking questions to an ICF category^{12–14} (or just a category in case no ICF category exists) provides a useful tool to assess measurement efficiency. For example, the ICF category *d850 Remunerative employment* is assessed with 11 questions, thus indicating high granularity of information (ie, a high level of detail of information), but low efficiency, as 11 questions only cover a single ICF category. An example of efficient measurement would be the assessment of category *e225 Climate*, where a single question is used to capture the impact of unfavorable climatic conditions on a persons' life. The granularity of the information from this single question is limited, but the coverage of the ICF category is most efficient, as only one question is used to assess the category. However, the decision on a suitable number of questions to include per category, and therefore the efficiency of assessment, largely depends on the topic prioritization and study objective, with the trade-off between granularity and efficiency needing careful consideration.

Feasibility

Feasibility concerns include issues important for researchers (eg, legal aspects and availability of translations) and participants (eg, length and comprehensibility). The length of the questionnaire is one of the most important feasibility issues since willingness to complete a survey varies considerably by its length.^{15,16} Besides length, other factors such as question complexity and structure may add to participant's cognitive burden and affect data quality and completion. For example, simplicity can be enhanced by using similar style and response options throughout a section and by using a language that is familiar to participants (eg, avoiding technical terms).

Comparability

In addition to using condition-specific instruments, it is important to incorporate established generic data collection tools that allow the pooling and comparison of data with reference values from general populations. Moreover, interpretation of results and communication with the scientific community may be facilitated if well-known tools are used. Comparisons with SCI populations will be more relevant in some cases than in others. For example, a SCI-specific tool is needed for the assessment of body functions, since prevalent problems such as pressure sores or spasticity are usually not assessed in generic tools. However, the challenge remains that as there is no criterion standard in data collection, widely used tools, might not be the best ones or do not meet the needs of a specific survey. In some cases, it is useful to introduce newer or less frequently used tools that are shorter (and thus more efficient). Again, the use of newly developed questions may violate the principle of comparability and needs careful considerations.

Truth and Discrimination

Data collection tools should meet required standards for validity and reliability, summarized as truth and discrimination criteria by a recent initiative on the improvement of Outcome

Measures in Rheumatology.¹⁷ Validity is the extent to which a tool measures what is intended. Content and face validity assess whether questions adequately address the domain of interest, and reliability concerns whether a tool is internally consistent, reproducible, and free from measurement error (ie, the difference of responses and real values). Sensitivity to change is another aspect of reliability that should be taken into account.¹⁷ There are numerous approaches to assess these psychometric properties; extensive literature exists that describes these approaches in detail.^{18,19} However, validity and reliability should not be seen as fixed properties and must be assessed in relation to the specific population and measurement objectives. Again, there is a trade-off between using psychometrically tested data collection tools and new tools with less evidence of validity and reliability that may be preferred because of feasibility or efficiency reasons or a better fit to research questions. A pilot test of the InSCI questionnaire with the focus on inter-rater reliability of the ratings and cognitive debriefing of the questions has been performed (see also Gross-Hemmi et al.¹¹ in this issue).

Furthermore, a high standard of translation and cultural appropriateness must be ensured.²⁰ To attain appropriate linguistic translation and cultural adaptation and to maintain consistency and content validity of the InSCI questionnaire across different countries, guidelines for cross-cultural adaptation suggested by Beaton et al. and Epstein et al.^{21,22} are applied. These guidelines are designed to maximize semantic, idiomatic, experiential, and conceptual equivalence between the reference InSCI questionnaire (English version) and its translated versions. The order of questions and response categories cannot be changed, and altering content or design components are only allowed if substantial improvement in a specific socio-cultural context is attained. In general, the maintenance of the semantics equivalence of a phrase has priority over literal translation. The questions are translated in a process involving 2 independent translations, which are then harmonized, discussed and approved by the Expert Committee of each National Study Group.^{21,22}

Development of the InSCI Questionnaire: Operational Procedure

A first draft of the InSCI questionnaire was developed by researchers from the InSCI Study Center at Swiss Paraplegic Research (Nottwil, Switzerland), the chair of the Scientific Committee of InSCI, and 2 international advisors in March and April 2015. This draft was then been discussed with the national leaders and coordinators of participating InSCI countries at the conferences of the International Spinal Cord Society (ISCOS, Montréal, May 2015) and the International Society of Physical and Rehabilitation Medicine (ISPRM, Berlin, June 2015). There was general agreement on the inclusion of established data collection tools such as SF-36 or Brief Pain Inventory (see "Results" section); however, most critical feedback was related to newly designed questions or questions that have been adapted from existing tools in case of nonexistence of any suitable tool. In addition, the selection of questions to cover key topics (ie, the work situation and health care services) was discussed. Feedback from these discussions was incorporated in a revised version of the questionnaire and a final draft

discussed with experts in respective fields in July 2015. All participating countries received a final version of the questionnaire and had the opportunity to give feedback again. The translation process in all participating countries and the U.S. pilot test of the English reference questionnaire with SCI persons provided additional feedback that helped to improve the InSCI questionnaire. The pilot test included focus group interviews to test content validity, and the assessment of test-retest reliability. Based on the issues raised during translation and pilot testing, decisions on the final version of the InSCI questionnaire have been taken by researchers from the InSCI Study Center (Swiss Paraplegic Research, Nottwil, Switzerland), the chair of the Scientific Committee, and 2 international advisors by the end of August 2016. The development of the InSCI questionnaire has therefore been an iterative consensus process in which experts from different countries as well as persons with SCI have been involved.

RESULTS

In this section, the operationalization of the InSCI data model is presented with regard to the six components (Fig. 1). The source of the question, the category covered, and the rationale for the selection based on the guiding principles are given. The InSCI questionnaire as well as detailed information on the original questions and the ICF linking (if applicable) are all available on request at inSCI@paraplegie.ch.

Table 1 provides a summary on the total number of questions per component, the number of questions that assess categories from the InSCI data model, and the number of questions that assess categories beyond the InSCI data model. In total, the InSCI questionnaire includes 125 questions, of which $n = 70$ (56.0%) assess functioning ($n = 28$, body functions and structures; $n = 42$, activities and participation); $n = 45$ (36.0%) contextual factors ($n = 26$, environmental factors; $n = 19$, personal factors); $n = 2$ (1.6%) lesion characteristics, and $n = 8$ (6.4%) appraisal of health and well-being. Whereas an average of 1.9 questions were used to assess ICF categories on functioning, environmental factors were assessed more efficiently

with an average of 1.5 questions per category as defined in the data model. However, approximately one quarter of the questions assessing body functions and environmental factors cover ICF categories that are not part of the data model. With only one question covering an ICF category that is not in the data model, the component activities and participation is assessed most efficiently. The 19 personal factors questions covered 7 categories, thus indicating an average of 2.7 questions to cover one category.

Body Functions

A total of 12 ICF categories from the component of body functions are included in the InSCI data model, operationalized with 21 questions. Seven questions address ICF categories that are not part of the InSCI data model; therefore, a total of 28 questions address body functions (Tables 1 and 2). The selected data collection tools to operationalize the component of body functions are presented below.

SF-36 Mental Health and Vitality Subscale (Version 2)

The SF-36 is one of the most widely used generic data collection tools to assess health aspects including 8 dimensions of physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, vitality, pain, and general health perceptions.^{23–26} The 4 questions from the SF-36 Vitality Subscale were selected to cover the ICF category *b130 Energy and drive functions*, and the 5 questions from the SF-36 Mental Health Subscale were chosen to assess the ICF category *b152 Emotional functions*. The main reason for the inclusion of the 2 SF-36 subscales is not only its international comparability and the availability of general population reference values but also the availability of comparable data for SCI populations.²⁷ In addition, the SF-36 subscales were validated and translated into different languages, thus providing feasible and culturally adequate versions for most of the participating InSCI countries.

TABLE 1. Components, questions, and measurement efficiency in the InSCI questionnaire

Component	ICF Categories in Data Model	No. Questions...			Efficiency	
		Total	...Assessing ICF Categories in Data Model	...Assessing Extra ICF Categories (Not in Data Model)	Average of Questions to Assess One ICF Category From Data Model	% of Questions to Assess Additional Category (Not in Data Model)
Body functions	12	28	21	7	21/12 = 1.8	$(7/28) \times 100 = 25.0\%$
[Body structures] ^a	[4]	—	—	—	—	—
Activity and participation	22	42	41	1	41/22 = 1.9	$(1/41) \times 100 = 2.4\%$
Environmental factors	13	26	20	6	20/13 = 1.5	$(6/26) \times 100 = 23.1\%$
Personal factors	7 ^b	19	19	0	19/7 = 2.7	0.0%
Lesion characteristics	N.d.	3	N.d.	—	—	—
Appraisal of health and well-being	N.d.	8	N.d.	—	—	—
Total	47	125				

^aAssessed by body functions as indicators for body structures.

^bPersonal factors are not classified in the ICF. Selection of categories based on Geyh et al. (2011).⁹

N.d., not defined.

TABLE 2. Overview of the InSCI questions to assess body functions

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
b130	✓		Energy and drive functions	SF-36 vitality subscale	4	Frequency of feelings of vitality
b134	✓		Sleep problems	New (SCI-SCS format)	1	Sleep problem and treatment
b152	✓	✓	Emotional functions	SF-36 Mental Health Subscale	5	Frequency of positive and negative emotions
b270			Sensory functions related to temperature and other stimuli	SCI-SCS	1	Problem and treatment of injury caused by loss of sensation
b280	✓	✓	Sensation of pain	Brief Pain Inventory (BPI); Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)	2	Pain severity (BPI); Problem of pain interference and treatment (SCI-SCS)
b410–b429			Functions of the cardiovascular system	SCI-SCS	1	Problem and treatment of autonomic dysreflexia
b420			Blood pressure functions	SCI-SCS	1	Problem and treatment of postural hypotension
b430			Hematological system functions	SCI-SCS	1	Problem and treatment of circulatory problems
b440			Respiration functions	SCI-SCS	1	Problem and treatment of respiratory problems
b455	✓		Exercise tolerance functions	Model Disability Survey (MDS) ^a	1	Problem and treatment of shortness of breath during physical exertion
b525		✓	Defecation functions	Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) ^b	1	Problem and treatment of bowel dysfunction
b620	✓	✓	Urination functions	SCI-SCS	2	Problem and treatment of urinary tract infections; Problem and treatment of bladder dysfunction
b640	✓	✓	Sexual functions	SCI-SCS	1	Problem and treatment of sexual dysfunction
b710	✓	✓	Mobility of joint functions	SCI-SCS	1	Problem and treatment of contractures
b735		✓	Muscle tone functions	SCI-SCS	1	Problem and treatment of spasticity
b810		✓	Protective functions of the skin	SCI-SCS	1	Problem and treatment of pressure sores
b730	✓	✓	Muscle power functions	New	2	Level and completeness of lesion
N.a.			N.a.	New	1	Additional health problems
				Total number	28	

ICF categories printed in **bold** are part of the InSCI data model.^aTo group questions with the same style and response options, this question is placed in the section “Activity and Participation” within a sequence of MDS items.^bQuestions on joint and muscle pain; heterotopic bone ossification; and diabetes mellitus were dropped for feasibility reasons.N.a., not applicable; RS, ICF rehabilitation set⁷; SCI LT, brief ICF core set for SCI, long-term context.⁵

Question from the Brief Pain Inventory (BPI)

Similar to the SF-36, the BPI is a generic tool to assess pain in different settings (eg, clinical, epidemiologic, or effectiveness research) and populations (eg, general population, populations with specific conditions) that is widely used all over the world.²⁸ A single question on pain severity from the BPI was selected to assess *b280 Sensation of pain*. As outlined below, pain interference is assessed with an additional question. By using a BPI question, the availability of population reference values as well as reference values from SCI populations is largely given and presents an efficient and feasible solution. The fact that the BPI is translated into more than 40 languages is an additional advantage of the tool, as many InSCI countries can rely on available translations.

Questions from the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)

The Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) was specifically developed for the self-report of the prevalence and severity of secondary conditions in persons with SCI.²⁹ The SCI-SCS measures 16 SCI-relevant conditions, from which 9 questions cover ICF categories from the InSCI data model. For feasibility reasons, 2 questions that assess ICF categories beyond the InSCI data model were covered elsewhere (“diabetes” was gathered by an open question on additional health conditions, and “joint and muscle pain” was captured by a question on pain more generally), and one question was removed (“heterotopic bone ossification” as it is an uncommon condition). To harmonize the question style and reduce the number of response options, new questions on *b134 Sleep functions*, and *b280 Sensation of pain* (interference with day-to-day activities) were added to the group of questions derived from the SCI-SCS. As the original response options of the SCI-SCS were identified as problematic (severity and frequency in one option; difficulties in translation), the 5-point response options suggested by the Model Disability Survey (see below) ranging from 1, “no problem,” to 5, “extreme problem” were chosen. In addition to the modified 5-point scale on the extent of a problem, the question on “do/did you receive treatment for it?” was derived from the Self-Administered Comorbidity Questionnaire (SCQ).³⁰ This treatment-question may provide important information on the quality of a health care system. For example, highly prevalent problems that are rarely treated may point to unmet health care needs.

To cover additional health problems that are not part of the SCI-SCS, a question was added that gives respondents the option of listing up to 5 additional health problems in free text format. The free text format was chosen, as health problems vary considerably between persons and countries.

Body Structures

From the component of body structures, 4 ICF categories from the brief ICF core set for SCI⁵ are included in the InSCI data model. These 4 ICF categories are covered as follows: *s120 Spinal cord and related structures* is assessed with 2 questions on level and severity of the spinal cord lesion; *s430 Structure of respiratory system* is measured with a question from SCI-SCS²⁹ on the severity and treatment of respiratory problems; *s610 Structure of urinary system* is covered with a

question from Spinal Cord Independence Measure for Self-Report (SCIM-SR)³¹ on the independence and the use of assistive devices in bladder management; and *s810 Structure of areas of skin* is assessed with an SCI-SCS²⁹ question on the severity and treatment of pressure sores.

Activities and Participation

Twenty-two categories from the component of activities and participation are part of the InSCI data model. These 22 categories are operationalized with 41 questions. One extra category that is covered by a single question has been added, resulting in a total of 42 questions addressing activities and participation (Tables 1 and 3).

Questions from the Model Disability Survey (MDS)

The Model Disability Survey (MDS) was developed by the WHO and the World Bank to provide a platform to collect comprehensive, generic, comparable, and relevant information on disability for a variety of national purposes, including to monitor the United Nations Convention on the Rights of Persons with Disabilities in the general population.^{32–34} Eleven MDS questions were selected to cover *d* categories from the InSCI data model as they present an efficient and feasible solution. For 2 ICF categories where no MDS questions and no feasible alternatives were available, new questions in MDS format were developed (Table 3). By collaborating with the coordinators of the MDS, synergistic effects may be created during the period of translation and cultural adaptation. Furthermore, the use of MDS questions creates the opportunity to obtain data for SCI that is internationally comparable with the general population.

Questions from Spinal Cord Independence Measure for Self-Report (SCIM-SR)

The Spinal Cord Independence Measure (SCIM) III was specifically designed to assess independence in self-care, mobility, and respiration/sphincter management in persons with SCI.^{35,36} Originally developed for the clinical setting, it is also available as self-report version for the community setting (SCIM-SR).³¹ The SCIM for Self-Report (SCIM-SR) has been prioritized over other data collection tools, as it is recommended by ISCoS³⁷ and is used in SCI research worldwide. The SCIM-SR provides international comparability and captures more granular information than other tools, including information on the use of assistive devices in activity performance. To reach highly efficient coverage of ICF categories from the InSCI data model, 7 SCIM-SR questions that cover ICF categories that are not part of the data model were omitted.

Questions from Spinal Cord Injury-Functional Index, Assistive Technologies (SCI-FI AT)

The Spinal Cord Injury-Functional Index (SCI-FI) is an SCI-specific data collection tool to assess activity limitations in persons with SCI and the impact of assistive technology (AT) in 5 distinct functional domains.³⁸ Two of the categories, *d445 Hand and arm use*, and *d410 Changing basic body position*, have a potentially high impact on the independence of a person with SCI and the reason why 3 questions were selected from the SCI-FI AT item battery for more granular information.

TABLE 3. Overview on the InSCI questions to assess activities and participation

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
d230	✓	✓	Carrying out daily routine	New (Model Disability Survey, MDS-format)	1	Problem in carrying out daily routine
d240	✓	✓	Handling stress and other psychological demands	MDS	1	Problem in handling stress
d410	✓	✓	Changing basic body position	SCIM-SR; SCI-FI AT	3	Independence in moving body positions (SCIM-SR); Get up from lying; Get up from sitting to lying (SCI-FI AT)
d415	✓	✓	Maintaining a body position	MDS	2	Ability to sit (MDS modified); ability to stand (MDS)
d420	✓	✓	Transferring oneself	SCIM-SR	1	Independence in transfer from bed to wheelchair
d445	✓	✓	Hand and arm use	MDS; Spinal Cord Injury-Functional Index – Assistive Technology (SCI-FI AT)	2	Problems in hand and finger use (MDS); Problem in opening a door (SCI-FI AT)
d450	✓	✓	Walking	SCIM-SR	[1, same as d455]	Independence in moving around moderate distances
d455	✓	✓	Moving around	MDS; Spinal Cord Independence Measure for Self-Report (SCIM-SR)	2	Problem in getting where one wants to go (MDS); Independence in moving around moderate distances (SCIM-SR)
d465	✓	✓	Moving around using equipment	SCIM-SR	[1, same as d455]	Independence in moving around moderate distances
d470	✓	✓	Using transportation	MDS	2	Problem in using public transportation; private transportation
d510	✓	✓	Washing oneself	SCIM-SR	2	Independence in washing upper body and head; independence in washing lower body
d520	✓	✓	Caring for body parts	SCIM-SR	1	Independence in grooming
d530	✓	✓	Toileting	SCIM-SR	3	Independence in bladder management; independence in bowel management; Use of the toilet
d540	✓	✓	Dressing	SCIM-SR	2	Independence in dressing upper body; independence in dressing lower body
d550	✓	✓	Eating	SCIM-SR	1	Eating & drinking
d570	✓	✓	Looking after one's health	MDS; new	2	Problem of looking after one's health; smoking status
d640	✓	✓	Doing household work	MDS	1	Problem in getting household tasks done
d660	✓	✓	Assisting others	MDS	1	Problem in providing care or support for others
d710	✓	✓	Basic interpersonal interactions	New (MDS-format)	1	Problem in interaction with people
d770	✓	✓	Intimate relationships	MDS	1	Problem in intimate relationships
d845	✓	✓	Acquiring, keeping and terminating a job	MDS	1	Problems in job fulfillment
d850	✓	✓	Remunerative employment	SwiSCI community survey; MDS; Effort-Reward Imbalance Questionnaire (ERI)	11	Description of job before SCI (SwiSCI modified); duration until job entry after SCI (SwiSCI); current work situation (MDS modified); paid work yes/no (SwiSCI). <i>Persons in paid work:</i> Description of current job (SwiSCI modified); desired amount of work (SwiSCI modified); reward at work (2 items, ERI); <i>Persons without paid work:</i> wish to work (SwiSCI); work ability (SwiSCI); reasons for unemployment (MDS modified)
d920	✓	✓	Recreation and leisure	MDS	1	Problem in doing things for relaxation
			Total number		42	

ICF categories printed in **bold** are part of the InSCI data model.RS, ICF rehabilitation set⁷; SCI LT, Brief ICF core set for SCI, long-term context.⁵

Question to Assess d570, Looking After One's Health

As evidence points to the detrimental effect of smoking on health, a single question on current smoking status is used to assess health behavior linked to *d570 Looking after one's health*.

Questions to Assess the Work Situation

As highlighted in the WHO report International Perspectives on Spinal Cord Injury (IPSCI), paid employment is a major determinant of health and well-being in persons with SCI³⁹ and therefore a key topic of the InSCI community survey. In total, 6 questions assess the work situation in all persons, irrespective of their work status. An additional 7 questions are only asked in employed persons and 3 questions in persons who are not employed. Questions are drawn from several sources. Four MDS questions are used to collect basic information on the work situation, and 7 questions are assumed from the Swiss Spinal Cord Injury Cohort Study (SwiSCI).⁴⁰ The SwiSCI survey has been developed by SCI experts, thus providing valid questions that allow for comparison to other SCI populations. As an input from the conferences in Berlin and Montreal, a measure of work stress is included. Two questions from the internationally established Effort-Reward Imbalance Questionnaire⁴¹ that were used in its 2-question composition⁴² are selected to assess reward at work as an indicator for psychosocial work stress. In total, 11 work questions are linked to ICF category *d850 Remunerative employment*, 1 to *d845 Acquiring, keeping and terminating a job* (Table 3) and 4 questions to environmental factors (Table 4).

Environmental Factors

The InSCI data model includes 13 categories from the component of environmental factors. A total of 26 questions are used to operationalize the identified ICF categories of which 20 assess ICF categories in the data model and 6 questions assess additional ICF categories (Tables 1 and 4).

Questions from the Nottwil Environmental Factors Inventory Short Form (NEFI-S)

Based on the ICF core set for SCI, the Nottwil Environmental Factors Inventory Short Form (NEFI-S) was developed to assess perceived environmental barriers.⁴³ The NEFI-S is the only validated instrument specifically designed for SCI, covering a large spectrum of ICF categories defined in the InSCI data model. Therefore, it offers an efficient and feasible tool to assess *e* categories and allows for comparisons with other SCI populations such as the SwiSCI population.⁴⁴

Questions on Health Care Services (e355, e450, e580)

As stated in the Global Disability Action Plan¹ and the IPSCI report,^{45,46} improving the access and quality of health care services is a major target of future health policy. Assessment of health care services is therefore a key topic in the InSCI survey requiring more granularity. In addition to NEFI-S questions, MDS questions were selected to gather information on health care services. MDS questions offer the advantage of comparability with the general population. Based on expert feedback from Montreal and Berlin, a single question on support from other persons in activities of daily living was created.

Personal Factors

Seven categories determined as essential for capturing the psychological-personal perspective in SCI research are included in the InSCI data model.¹⁰ A total of 19 questions were included to assess these 7 categories (Table 5).

Sociodemographic and Personal Characteristics

Model Disability Survey questions are used to assess basic sociodemographic and socioeconomic characteristics including age, country of birth, highest level of education, and household income. A new item on total years of education was created, separating years of education before and after SCI. The country-specific response options for a highest level of education are based on the United Nations Educational, Scientific and Cultural Organization's guidelines for categorizing education into primary, secondary, and tertiary education.⁴⁷ Similarly, the 10 country-specific response categories for household income are based on the recommendations published by the European Social Survey 2012.⁴⁸

Position in the Immediate Social and Physical Context

Subjective social status is described with the McArthur Scale of subjective social status, using a 10-rung ladder to visualize social position.⁴⁹ Information on marital status is collected by using an MDS item with modified response options. A new item on household composition was created to weight household income based on the age cutoffs presented by the Organisation for Economic Co-operation and Development.⁵⁰

Personal History and Biography

Since most data collection tools to capture critical life events are lengthy, a single question with an open answer format was developed to assess critical life events during the past 12 months as operationalization of the category personal history and biography.

Feelings

This category is covered by the SF-36 Mental Health Subscale on *b152 Emotional functions* (see "Results", body functions).

Thoughts and Beliefs

Self-efficacy, personal growth, optimism, and autonomy were chosen to operationalize the category of thoughts and beliefs. The Generalized Self-Efficacy Scale (GSES) is a widely used tool that delivers comparable and reliable data,⁵¹ and the Moorong Self-Efficacy Scale (MSES) was developed specifically for SCI.⁵² Two GSES and 2 MSES questions were selected to assess self-efficacy, thus providing a feasible solution with good comparability both to the general population and SCI populations. With 4 questions, the concept of self-efficacy is assessed with more granularity, as evidence shows its importance for health and well-being in persons with SCI.⁵³⁻⁵⁵ Model Disability Survey questions are used to assess personal growth and optimism with one question each, an efficient solution. The single question on autonomy originates from the WHOQoL disabilities module⁵⁶ and is also used in the MDS.

TABLE 4. Overview on the InSCI questions to assess environmental factors

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
e110	e115	✓	Products or substances for personal consumption; Products and technology for personal use in daily living	Nottwil Environmental Factors Inventory short form (NEFI-S)	1	Insufficient medication, medical aid and supplies
e120	✓	✓	Products and technology for personal indoor and outdoor mobility	NEFI-S	2	Insufficiently adapted assistive technology for moving around short distances; Insufficiently adapted means of transportation for long distances
e125			Products and technology for communication	NEFI-S	1	Insufficient communication devices
e135	✓		Products and technology for employment	Swiss Spinal Cord Injury Cohort Study (SwiSCI)	1	Coverage of assistive work devices
e150	✓	✓	Design, construction and building products and technology of buildings for public use	SwiSCI; NEFI-S	2	Problem in accessing workplace (SwiSCI); Insufficient accessibility of public places (NEFI-S)
e155	✓	✓	Design, construction and building products and technology of buildings for private use	NEFI-S	1	Insufficient accessibility to homes of friends and relatives
e165			Assets	NEFI-S	1	Problematic financial situation
e225	✓		Climate	NEFI-S	1	Unfavorable climatic conditions
e310	✓	✓	Immediate family	NEFI-S	1	Negative attitudes of family and relatives
e320	✓		Friends	NEFI-S	1	Negative attitudes of friends
e340	✓	✓	Personal care providers and personal assistants	NEFI-S; New	2	Insufficient nursing care and support services (NEFI-S); home care situation (New)
e355	✓	✓	Health professionals	Model Disability Survey (MDS)	2	Visited health care providers; explanation received by health care providers
e460			Societal attitudes	NEFI-S	1	Negative societal attitudes
e425			Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	NEFI-S	1	Negative attitudes of neighbors, acquaintances and work colleagues
e450	✓		Individual attitudes of health professionals	MDS	2	Experience of respectful treatment; involvement in decision making for treatment
e580	✓	✓	Health services, systems and policies	MDS; NEFI-S	4	Frequency of inpatient hospitalization (MDS); unmet health care needs (MDS); satisfaction with health care services (MDS); insufficient state services (NEFI-S)
e570				MDS	1	Disability pension (MDS modified)
e590				SwiSCI	1	Vocational rehabilitation (SwiSCI modified)
				Total number	26	

ICF categories printed in **bold** are part of the InSCI data model.RS, ICF rehabilitation set²; SCI LT: Brief ICF core set for SCI, long-term context.⁵

TABLE 5. Overview on InSCI questions to assess personal factors

Category ⁹	Data Collection Tool	No. Questions	Operationalization of Category
Sociodemographic personal characteristics	New	1	Gender
	New	1	Total years of education or training before and after SCI
	Model Disability Survey (MDS)	4	Age; country of birth. highest level of education (country-specific response options according to UNESCO guidelines); household income (country-specific response options according to European Social Survey 2012)
Position in the immediate social and physical context	McArthur Scale of subjective social status	1	Subjective social position
Personal history and biography	New	1	Living situation
	MDS, modified	1	Marital status
	New	1	Major adverse life events
Feelings	N.a.	N.a.	(covered by b152 emotional functions)
Thoughts and beliefs	Moorong Self-Efficacy Scale (MSES)	2	Self-efficacy in maintaining contacts; Self-efficacy in maintaining health
	General Self-Efficacy Scale (GSES)	2	General self-efficacy
	MDS	1	Personal growth
	MDS	1	Optimism
	WHOQoL-Disability	1	Autonomy
Motives	MDS	1	Purpose in life
Patterns of experience and behavior	General Belongingness Scale (GBS)	1	Belongingness
	Total number	19	

Motives

A single question on purpose in life was selected from the MDS to operationalize the category of motives. Selecting this question was mainly based on feasibility and efficiency reasons, as many established measures of purpose in life contain several questions.

Patterns of Experience and Behavior

Patterns of experience and behavior are covered by a question from the General Belongingness Scale (GBS).⁵⁷ The GBS is a valid and reliable tool that was used in the general population to assess belongingness. For feasibility and efficiency reasons, a single question from the GBS was selected by expert discussion.

To reduce participant burden and to enhance cross-cultural validity, the same response options, derived from the MDS (1 'not at all' to 5 'completely') were chosen for all the questions on thoughts and beliefs, motives, and patterns of experience and behavior.

Lesion Characteristics

Besides the assessment of level and completeness of lesion level (paraplegia; tetraplegia; complete lesion; incomplete lesion) described in body functions and structures (*b730 Muscle power functions; s120 Spinal cord and related structures*), information on etiology and date of SCI is collected. Etiology of SCI is assessed based on the Spinal Cord Injury Demographics Template developed by the International Spinal Cord Society (ISCoS).

Appraisal of Health and Well-Being

Questions on General Health

The SF-36 questions on general health and health transition are used in the InSCI questionnaire owing to their comparability with population reference values and ability to deliver reliable and valid data^{23,26} (see "Results", body functions).

Questions on Subjective Well-Being

The WHO Quality of Life (WHOQoL)-BREF was developed by the WHO and provides an internationally and cross-culturally comparable assessment of well-being consisting of 26 questions. Owing to feasibility and efficiency reasons, a 5-question selection that showed good reliability and validity within the SCI-community is used.⁵⁸ Additionally, a question on the satisfaction with oneself is added from the WHOQoL BREF, as this dimension seems particularly important for persons with disabilities.

DISCUSSION

Implementing the InSCI community survey is a first step to support the LHS-SCI initiative through the collection of internationally comparable data on the lived experience of persons with SCI and to describe their situation in relation to functioning, health maintenance, and subjective well-being on a global level. In this paper, a structured approach to capture what matters to persons with SCI is described by providing details on the development of the InSCI data model and the InSCI questionnaire. In summary, the InSCI data model consists of 6 components (body functions and structures; activities and

participation; environmental factors; personal factors; lesion characteristics; and appraisal of health and well-being) and includes ICF categories from the brief ICF core set for SCI long-term context,⁵ the ICF rehabilitation set,⁸ and 7 categories for personal factors.¹⁰ Although the ICF² provides a valuable framework to guide the selection of relevant components to measure,^{3,4} the major challenge was to develop a questionnaire that comprehensively captures the most relevant aspects and, at the same time, is feasible and parsimonious with regard to participant burden. To attain this goal, the guiding principles of efficiency, feasibility, comparability, and truth and discrimination were defined and applied.

Two sets of limitations need to be addressed: limitations related to the approach of selecting questions based on guiding principles, and second, methodological limitations of the InSCI questionnaire. Although guiding principles provide a valuable tool to direct the decision-making process in question selection, some challenges concerning their application remain. Guiding principles cannot be prioritized in importance, and prioritization largely depends on the purpose of a study and its key topics. In addition, guiding principles strongly interact, and the decision for specific questions often claims a trade-off between different guiding principles, as already highlighted for the efficiency versus granularity issue. In the InSCI questionnaire development, efficiency and feasibility issues were often-times prioritized, which led to the violation of comparability or truth and discrimination issues. This situation arose whenever new items were created to efficiently cover a category with a single question in case established data collection tools were too comprehensive and thus not feasible in the context of the InSCI survey. These trade-offs need careful consideration, and justification for prioritization should be provided by the questionnaire developers.

The main limitation of the resulting InSCI questionnaire described in this paper, however, concerns truth and discrimination issues. As a result of the effort to enhance feasibility and efficiency, single questions were chosen from existing and psychometrically tested data collection tools. This might be criticized, as validity is not confirmed for the use of single questions. In addition, questions from the MDS were designed for the general population and have not yet been validated. However, MDS questions provided an efficient and feasible solution in the context of the InSCI community survey and have the advantage of worldwide comparability with general population data. Furthermore, the modification of style and response options of some questions to reduce complexity for participants (and thus enhance feasibility) limits comparability to other surveys. Consequently, the modified questions lack validation, and their comparability with other data sources is decreased. Statistical methods of calibration of response options present a potential solution to address the comparability issue in upcoming data analysis. However, there are reasons to believe that the cognitive debriefing in the pilot test of the questionnaire would have identified critical issues.

Besides these limitations, our approach to develop the InSCI data model and questionnaire has several strengths. The selection of what to measure, that is, the definition of the InSCI data model, was based on established ICF core sets and thus presents a structured, transparent, and reasoned selection of relevant categories. By additionally involving worldwide experts,

the iterative decision-making process reduced the risk of missing important categories. In addition, the application of guiding principles to operationalize the data model stimulated an argumentative process in which pros and cons of different questions were carefully considered. In conclusion, the InSCI community survey comprehensively captures what matters to people and, at the same time, is feasible and parsimonious with regard to participant burden. Moreover, the InSCI questionnaire offers satisfying comparability to general and SCI populations, although its validity and reliability still need to be confirmed.

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Stakeholder Dialogue as Deliberation for Decision Making in Health Policy and Systems

The Approach from Argumentation Theory

Sara Rubinelli, PhD, and Per Maximilian von Groote, MA

Objective: The literature on knowledge translation and dissemination in health care highlights the value of the stakeholder dialogue, namely, a structured process where stakeholders interact to identify the best solution to a given problem. By analyzing the stakeholder dialogue as a form of deliberative argumentation, this article identifies those factors that may hinder or facilitate reaching agreement among stakeholders on options to target problems.

Design: Conceptual analysis based on the descriptive and evaluation methods of argumentation theory.

Results: When stakeholders have a difference of opinion, confrontation alone does not lead to agreement. A normative model of critical discussion is needed to facilitate stakeholders in reaching this agreement and to prevent barriers to it that can result from personal factors (e.g., attitude and beliefs) or communication moves. This type of dialogue requires a training of stakeholders about the preconditions of argumentation and its different stages. The figure of the moderator is crucial in ensuring that the dialogue fulfills standards of reasonableness.

Conclusion: This article offers a reading of the stakeholder dialogue rooted in the tradition of critical thinking. It instructs on how to promote a collaborative exchange among stakeholders as a way to go beyond any expression of views.

Key Words: Knowledge Translation, Translation, Implementation Research, Stakeholder Dialogue, Deliberation, Argumentation Theory

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The role of research findings in policy decision making is recognized worldwide. This applies especially to the field of health policy and systems.^{1,2} There is, indeed, much value in supporting innovations and changes through scientific evidence in formats that include “informed choice” and “evidence-based policy.”^{3,4} The field of knowledge translation (or knowledge transfer) focuses exactly on how to synthesize and integrate scientific evidence, while the field of implementation works on how to integrate evidence-based recommendation in a specific setting.⁵

Bridging between research and policy and practice is, however, not a linear process. As Walt and Gilson⁶ emphasized, it is not just the scientific content to be translated in policies that matters. The assumption that researchers amass the right evidence and policymakers receive it and implement it is short cited. Researchers analyze and make recommendations about the evidence and prepare it for translation. The actual translation of evidence is, however, highly impacted by the actors involved (the stakeholders), what they think and believe, and by their attitudes, the processes of implementation, and

the contexts at the macrogovernment and microinstitutional level. Moreover, the production and dissemination of large amounts of scientific health care information make it difficult to adequately identify and retrieve what evidence matters for a specific context.⁷

This context testifies to the importance of the so-called “learning health system”, where the research agenda is collaboratively developed and it is responsive to the need for a coherent, “seamless” and dynamic flow of information across the health system.⁸ A learning health system can enhance a culture of shared responsibility creating a learning environment that links all “actors” in the health system—patients, health care providers, insurers, researchers, and policy makers—in the common cause to improve the nature and practical applicability of high-quality health evidence.

Lavis et al.⁹ developed a set of tools for evidence-informed policymaking in health that addresses the need both to identify evidence that matters and to account for the “human factor” involved in the actual decision making over the evidence. They conceptualized a process for finding and evaluating evidence in systematic reviews,¹⁰ for assessing the applicability in a specific context,¹¹ and to deliberate over these findings by means of a policy dialogue that involves all the relevant stakeholders, the “stakeholder dialogue.”¹²

This article focuses on the communication process behind the stakeholder dialogue as structured interaction where stakeholders work collaboratively toward a common understanding and toward reaching an agreement over a solution to a proposed problem. On the day of the dialogue, stakeholders are guided by a moderator in reaching agreement on the best solution (in regard to ethics, efficacy, and efficiency) to solve the issue at stake.

From the Department of Health Sciences and Health Policy, University of Lucerne and Swiss Paraplegic Research, Lucerne; and Swiss Paraplegic Research, Nottwil, Switzerland.

All correspondence and requests for reprints should be addressed to: Sara Rubinelli, PhD, Swiss Paraplegic Research, Guido Zäch Institute, Guido Zäch-Strasse 4, CH-6207 Nottwil, Switzerland.

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Thus, for instance, a stakeholder dialogue could be on the following topic:

Projections from the World Health Organization show that health care systems need to prepare for the increasing numbers of patients experiencing noninfectious chronic health conditions. A main strategy for Switzerland involves the creation of comprehensive information and care programs run by teams of nonphysician experts in disease self-management, disease prevention, and health promotion to assist people and families with chronic diseases. The main questions for decision making include: Who should be part of these teams and with what responsibilities? What training would these teams need and which institution should provide it? What would the implementation steps be for setting up these teams nationally?

The identification of this topic would lead to the creation of a policy brief collecting evidence from the literature on whether and how this issue has been addressed in Switzerland or in other countries. On the basis of the evidence collected, the policy brief would suggest a maximum of 3 solutions to the issue and an analysis of barriers and facilitators to the implementation of each solution in the Swiss context.

On the day of the dialogues, stakeholders (including physicians, nurses, social workers, health educators, and representatives of patients and their families) would be invited to decide on the best options with the aim of reaching agreement.

The stakeholder dialogue implements deliberation as its form of communication, that is, “a collaborative type of dialogue in which parties collectively steer actions toward a collective goal by agreeing on a proposal that can solve a problem affecting all of the parties concerned, taking all their interests into account.”^{13,14}

Deliberation as a form of communication was a main topic in classic Greece for its crucial value for democracy. Indeed, from a sociohumanistic perspective, deliberation has two main characteristics that fulfill the requirement of democratic decision making. First, it is essentially a participatory process in which the views of all stakeholders can be expressed and taken into consideration.¹⁵ Moreover, it is a reason-giving process¹⁶; participants are asked not to simply present their views but to give a reason pro or contra for what they intend to support or refute. Indeed, deliberation is not just dialogue as participants focus on the pros and cons of various options in order to agree on the best (or most valuable) one.

Deliberation entails argumentation, defined as “the communicative process of advancing, supporting, criticizing, and modifying claims so that appropriate decision makers, defined by relevant spheres, may grant or deny adherence.”¹⁷ People involved in a deliberation exchange reasons. Moreover, deliberations entail argumentation aimed at reaching agreement among people. This aspect reveals two main characteristics of deliberation highlighted by Walton et al.¹⁸: (1) deliberation is not a one-to-one dialogue in which one speaker tries to persuade another speaker; it aims at collective agreement; (2) deliberation differs from negotiation as it is not the personal interest of a specific participant that matters but the identification of the “action-option that is optimal for the group.”

Argumentation as the core of deliberation is the field of study of argumentation theory, a branch of knowledge that has been developed within the philosophical-humanistic and linguistic traditions.¹⁹ Over the years, argumentation theory has developed a set of analytic and evaluative tools to examine argumentation. Moreover, it has identified the challenges that speakers encounter when trying to reach agreement over something.

In light of this and by focusing on the stakeholder dialogue, the objective of this article is to identify those factors that may hinder or facilitate reaching agreement among stakeholders on options to target problems. More specifically, this article will shift from theoretical to practice implications. The focus of the theoretical parts will be on the complexity of reaching agreement through argumentation, the preconditions for this argumentation, and the rules resulting from an ideal model of critical discussion. The practice-implication parts will provide advice on the preparation and conduct of a stakeholder dialogue.

Overall, this article is expected to bring to stakeholder dialogue studies a currently unexplored perspective from communication sciences, linked to its deliberative-argumentative nature. This will complement the achievements of Lavis et al.¹² in the field.

PRECONDITIONS OF ARGUMENTATION

Argumentation is a natural process of communication as people support and refute claims on an almost daily basis on a variety of different issues that involve different opinions. As van Eemeren et al.²⁰ remark, “It is unusual [...] for two people to simply accept the fact that their opinion differ and just leave it at that.” Yet, exchanging reasons does not per se lead to reaching agreement and resolving the difference. When people engage in argumentation, they make “an explicit or implicit appeal to reasonableness,”²¹ but often ordinary argumentation does not end in agreement because speakers might not want to reconcile different views; they might argue for the sake of arguing and have vested interests that hinder the resolution of the difference of opinion.

As highlighted by van Eemeren et al.,²² reaching agreement requires certain preconditions, among which are the following:

- (1) Interlocutors must share their knowledge of the issue at stake to avoid lack of understanding because of fragmentary or different knowledge;
- (2) Interlocutors must have the opportunity to cast doubt on a certain point of view, and the other party must respond to them; and
- (3) Interlocutors should be disinterested in the outcome of a discussion and be willing to relinquish their standpoints if those of the other party can be better defended.

In the context of a stakeholder dialogue, the first requirement can be fulfilled by preparing what Lavis et al.²³ call a policy brief and by requesting stakeholders to read it carefully before taking part in the dialogue. A policy brief is a document that (a) describes the problem at stake by explaining all the relevant contextual factors; (b) presents a number of evidence-based

solutions to the problem and for each possible solution explains relevant aspects, including the expected benefits, eventual arms, and the costs; and (c) identifies barriers and facilitators to the implementation of each solution.²³

An example of a policy brief can be found in Lavis et al.²³ for the problem “low coverage rates for artemisinin-based combination therapies (ACTs) to treat uncomplicated falciparum malaria in sub-Saharan Africa.” The following three solutions are presented to stakeholders²³:

- (1) “Enlarge the scope of practice for community health workers to include the diagnosis of malaria and prescription of ACT (governance arrangements), introduce target payments for achieving a defined coverage rate for ACT treatment (financial arrangements), and provide them with training and supervision for the use of both rapid diagnostic tests and prescribing (delivery arrangements).”
- (2) “Introduce partial subsidies for both rapid diagnostic tests and ACT within the private sector where much care is provided in urban areas (financial arrangements).”
- (3) “Restrict the types of antimalaria drugs that can be imported and introduce penalties for those found dispensing counterfeit or substandard drugs (governance arrangements) and make changes to the national malaria control policy and drug formulary to ensure that ACT is the recommended first-line treatment.”

A policy brief starts by clearly identifying a priority issue and has the main advantage of being context specific. The framing of the issue, the options to address it, and the options for implementation are to be supported by research evidence (within the Lavis and colleagues’ approach, this is mainly by systematic reviews).

As for the second precondition of argumentation, stakeholders have to be clearly informed (ideally in a predialogue section) of the argumentative nature of the dialogue. During its conduct, the moderator has to ensure that all stakeholders have the opportunity to present any point of view they might have. In case they doubt or reject a point of view, the moderator will require that any objection is supported by a justification.

The third precondition has an ethical flavor, as speakers are invited to free their argumentation from biases, vested interest, and conflict of interest. Although this precondition can hardly be verified during the argumentative exchange, it would be important to at least ask speakers at the beginning of the dialogue to adhere to some principles of collaboration. A principle that could work for this purpose is that by the linguist Gricce as the maxim of quality, stating that speakers should be truthful, “They should not say what they believe to be false or what lacks adequate evidence.”²⁴

STAGES OF ARGUMENTATION

As explained by van Eemeren and Grootendorst,²⁵ reaching agreement over a certain issue is a process that requires different stages. In their theory of argumentation, known as pragma-dialectics, they identified four stages:

- (1) The confrontation stage: where speakers establish that they have a difference of opinions. Thus, going back to

the example presented previously, each stakeholder declares whether he/she favors solution 1, 2, or 3 (or an eventual fourth solution, or a combination of them, when it is possible).

- (2) The opening stage: here speakers determine whether there are common starting points to engage toward the resolution of the difference. Stakeholders state if, for instance, they share similar view points in relation to some aspects of the issue at stake.
- (3) The argumentation stage: this stage involves the actual argumentation. The different parties advance their reasons in support of their standpoints and discuss what is not acceptable or those aspects where there are doubts. Any time a party has doubts, that party has to support the reason for the doubts, and the other party will engage in further argumentation. Individual stakeholders or groups of stakeholders (if they share the same opinion on the best solution) present their reasons to favor a certain solution and their reasons against the other possible solutions. The presentation of arguments pro/contra continues until the different parties have doubts or do not accept the reasons against their own standpoints or in support of the other standpoints.
- (4) The concluding stage: the difference of opinion is considered resolved if all parties agree on one point of view. The different views have to be retracted. If such a stage is not reached, the discussion has failed to reach a resolution. In an ideal stakeholder dialogue, stakeholders agree on one solution as the best option. This agreement will be the starting point for implementing that solution, as often the identification of the best option goes together with an evaluation of the modalities of its implementation.

When operationalized in the context of a stakeholder dialogue, these stages can inform its performance. The policy brief highlights a set of options and implementation characteristics to a given issue to be resolved. Thus, in the first part of the dialogue, stakeholders should be invited to express what option each supports. This stage leads to the identification of the actual difference of opinions among the stakeholders and its nature. Once it is clear which stakeholder supports which options, those who hold similar views should be grouped together and invited to act as one party. As promoted by the opening stage, the different parties should agree on a set of shared starting points to base the actual argumentation.

In the argumentation stage, each stakeholder or a group of stakeholders who hold similar positions is asked to provide evidence for their points of view on the best options. If the other stakeholders or a group of stakeholders is not convinced or has doubts about this evidence, the dialogue continues with further argumentation. When there is general agreement on the point of view of one stakeholder or group of stakeholders, the dialogue has reached a successful conclusion; it has identified how to solve a certain issue and how to implement the solution. Yet, in practice, agreement may not be reached, in which case there are at least two possible ways to continue an interaction among stakeholders toward a resolution that will then come in a second stage. More specifically, agreement might not be reached

- because there is not enough evidence to support an option that convinces all stakeholders. Further research would be needed to fill this gap and to eventually inform another stakeholder dialogue;
- because the disagreement depends on different perspectives that, given the context of decision making in health care, might involve institutional constraints. Here a possibility of resolution would be for stakeholders to engage in negotiation and to reach a compromise.

PRINCIPLES OF CRITICAL DISCUSSION

In addition to the stages of an argumentative exchange, the theory of pragma-dialectics focuses on another main aspect of argumentation that is important to consider when examining the features of a stakeholder dialogue.

This type of dialogue is designed to make people collaborate on the identification of a solution to a given problem. In practice, however, the different parties, although instructed on the need to discuss by supporting their points of view with reasons, may act to serve their “rhetorical interests” toward their advantage and success. Van Eemeren²⁶ speaks of this tension between reasonableness and rhetoric as strategic maneuvering as “the continual efforts made in all moves that are carried out in argumentative discourse to keep the balance between reasonableness and effectiveness.” Basically, a stakeholder dialogue, to be a tool for policy making, should underline stakeholders’ efforts to have a genuine intellectual exchange, based on evidence and not on having a point of view accepted for reasons other than its value in solving the problem at stake. Because of this potential tension, it is important to moderate a stakeholder dialogue so as to preserve its dialogical standards.

Van Eemeren and Grootendorst,²⁵ reflecting on these standards, created a set of ten rules of critical discussions, which, when violated, could threaten the resolution of a difference of opinion and thus threaten reaching an agreement. For the purpose of being usable within a stakeholder dialogue and with an audience that might not be trained in argumentation theory, it is important that stakeholders consider the characteristics of the dialogue according to four dimensions:

- (1) Freedom of expression. The dialogue has to run in a collaborative atmosphere where all stakeholders feel free to present their standpoints and doubts about those of others.
- (2) Types of evidence accepted. When a standpoint is presented and supported, it has to be based on evidence that the group of stakeholders recognize as such. In the framework of Lavis et al.,¹⁰ evidence is often and mainly linked to systematic reviews, but there are other sources of evidence, including individual studies that apply to the context at stake (e.g., quantitative and qualitative studies that apply to a specific country or a specific institution) and institutional features of a specific country or context (e.g., existing regulations, laws, and policies). For this purpose, it is very important to define with stakeholders at the beginning of a dialogue what evidence the group will accept.
- (3) Quality of argumentation. It is important to avoid those arguments known in argumentation theory as fallacies. They are faulty arguments that, as such, violate the rules

of critical discussion and are used to win over the interlocutors at all costs. Thus, for instance, argumentation during the dialogue should refer to the merits of the points of views expressed and not to the speakers. Typical fallacies to avoid are the abuse of authority—when a person falsely claims to have expertise on a topic—and the argument *ad hominem*, which is based on implicitly or explicitly attempting to undermine the credibility of a person through personal attacks.

There are many different classifications of fallacies, and speakers cannot be trained on how to avoid them all. However, it would be valuable to give speakers a list of the main fallacies that should not be used in the dialogue and to control their quality of argumentation accordingly.

- (4) Intellectual honesty. Each stakeholder should be willing to acknowledge publicly when his/her own point of view is weak, wrong, or generally suboptimal versus when the point of view of someone else is good and valid. This acknowledgment is instrumental for the dialogue to conclude with agreement. Indeed, unless all stakeholders agree on the best solution from the start, there will be points of views to reject and others to support.

ON THE DAY OF THE DIALOGUE

This article examined the process known in policy making as stakeholder dialogue and attempted to show at least three main aspects.

First, a stakeholder dialogue, to be a tool for reaching agreement, cannot simply be conducted as a confrontation of points of view. Second, the application of a normative model of critical discussion is required to facilitate stakeholders in reaching this agreement and to prevent barriers to it that can result from personal factors (e.g., attitude, beliefs, and knowledge) or communication moves. Third, this type of dialogue is demanding for stakeholders as it requires ethical, conceptual, and procedural collaboration, regardless of their professional and institutional roles and positions.

The focus on the preconditions, the stages of argumentation, and the principles of critical discussion show that a stakeholder dialogue, to result in agreement, has three main requirements: following a clear structure, training of stakeholders, and a strong moderation.

The dialogue can be structured according to the stages of argumentation, thus starting with a presentation of the problem at stake, the possible solutions, and the points of view of the stakeholders on the best solution. The argumentation has to be conducted by discussing each point of view, that is, by providing evidence and objections to them, until all stakeholders agree on accepting or rejecting them. Subsequently, all evidence collected should be summarized, and those views considered to be suboptimal discharged. The conclusion should highlight whether agreement has been reached or whether additional research or negotiation has to be conducted beyond the dialogue.

Stakeholders should not engage in the dialogue without training as there are main ethical and communication principles to accept and apply in order to conduct a dialogue within the standards of critical discussion; this training can be done at the beginning of the dialogue. It is also important to

distribute together with the policy brief an overall framework that explains all preconditions and processes of the dialogue, including what speakers are asked to do and to what standards and rules of discussion they are asked to comply.

Overall, it appears that the role of the moderator is fundamental to ensure that the dialogue is conducted with respect to those standards needed to promote collaboration and to reach agreement among stakeholders. The tasks of the moderator include the following:

- conducting the dialogue from the preparation stage to the conclusion stage;
- soliciting the expression of points of view of all stakeholders by clearly highlighting the difference in opinions among stakeholders and why, what the areas of agreement are, and what the gray zones are;
- ensuring that reasons are provided when supporting or objecting to a point of view;
- ensuring the quality of the argumentative exchange by highlighting eventual fallacies and ensuring that reasons are grounded in relevant evidence;
- when agreement is not reached, underlying why it has been so difficult to decide, what stakeholders are willing to accept or not accept to solve the problem, and what steps can be taken after the dialogue.

The moderator will be trained in deliberative dialogue and will be assisted by note takers who record all points of views and their argumentation. In order to facilitate stakeholders in their discussions, it is ideal to show on a board their discussion results, including their stage of argumentation and the points of agreement and disagreement. Figure 1 summarizes the overall process of a stakeholder dialogue.

It has to be noticed that the approach proposed for the stakeholder dialogue might have practical limitations. First, a stakeholder dialogue might become a very technical form of interaction, according to the complexity of the issue at stake and the difficulties in identifying a solution that can be implemented. Second, stakeholders might find it unnatural to interact in such a structured process, and the short training before the dialogue might not be sufficient to empower them in following the normative standards of the dialogue. The involvement of all stakeholders might become particularly challenging when different groups of people, with different knowledge and expertise, are involved. Thus, for instance, in confronting the views of patients with those of health professionals and representatives of pharmaceutical companies, it is important that eventual differences in technical knowledge do not discourage patients from presenting their standpoints. Third, stakeholders might have hidden goals and agendas and might not be willing to declare them or to give them up for the sake of collaboration. Fourth, it might be very difficult to moderate argumentation toward reaching of agreement when stakeholders have sharp differences of opinion, and these opinions are inconsistent among themselves. Fifth, in the above paragraphs, it was implicitly assumed that any issue might be resolved by using appropriate scientific evidence. This assumption is, however, an empirical claim that has to

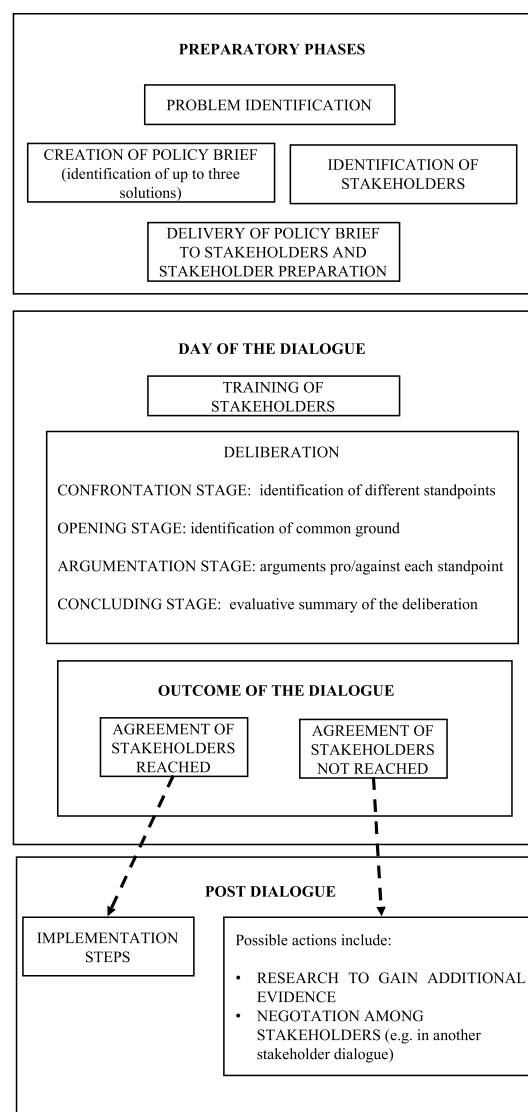


FIGURE 1. The process of the stakeholder dialogue.

be verified; it might be the case that the resolution of certain issues will not be in line with the available scientific evidence.

CONCLUSIONS

As Barbara Charline Jordane (1936–1996) once said, “it is reason, and not passion, which must guide our deliberation, guide our debate, and guide our decision.” By supporting the role of the stakeholder dialogue as a tool for policy making, this article has emphasized its essential rational nature. As a form of deliberation, based on argumentation, a dialogue can be valuable for reaching consensus over a best decision, but to serve this purpose, it has to be conducted under parameters of critical discussion. Stakeholders can express any point of view, and these have to be supported by evidence that the group recognizes as such. There is freedom of thought and expression, as this is essential to enable creativity and to stimulate solutions, but not every thought is likely to be accepted, and stakeholders have to be willing to accept an evaluation

of optimal–suboptimal, applicable–not applicable, and, ultimately, right or wrong.

A stakeholder dialogue is a communication process that is inherently linked to the tradition of critical thinking founded in ancient Greek society. Socrates (460/470–399 BC) initiated the conceptualization of critical thinking by inviting people to distinguish beliefs that are reasonable and logical versus those that lack adequate evidence. Indeed, in stakeholder dialogues, participants are invited to evaluate what counts as a good argument and what conclusions follow from the different types of supporting evidence.

Although designed to facilitate participants' expression of points of view, a stakeholder dialogue requires a kind of top-down moderation. The moderator has to implement and ensure that stakeholders hold to standards of discussion that relate to the various phases of the dialogue. This feature shows that, from an epistemological point of view, stakeholder dialogue is a process designed to go beyond any expression of views. Decision making presupposes a decision to be made. A dialogue will be successful when this decision is the best one for the context at stake and everybody agrees on this.

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Study Protocol of the International Spinal Cord Injury (InSCI) Community Survey

Mirja H. Gross-Hemmi, PhD, Marcel W. M. Post, PhD, Cristina Ehrmann, PhD, Christine Fekete, PhD, Nazirah Hasnan, PhD, MRehabMed, MBBS, James W. Middleton, MD, PhD, Jan D. Reinhardt, PhD, Vegard Strøm, PhD, and Gerold Stucki, MD, MS,
on behalf of the International Spinal Cord Injury Community Survey (InSCI) Group

Objective: The Learning Health System for Spinal Cord Injury (LHS-SCI) is an initiative embedded in the World Health Organization's (WHO's) Global Disability Plan and requires the statistical collection of data on the lived experience of persons with SCI to consequently formulate recommendations and policies. The International Spinal Cord Injury (InSCI) community survey has been developed as an initial step to gain information about the lived experience of persons with SCI within and across diverse nations.

Design: InSCI is a multinational community survey based on the International Classification of Functioning, Disability and Health Core Sets for SCI and involves 28 countries from all six WHO regions. The study will be implemented in 2017. Overall aims, guiding principles on sampling strategies, data collection modes, and reminder management are described.

Conclusions: InSCI will be the first survey to be conducted simultaneously in many countries and in all six WHO world regions that identifies the factors associated with functioning, health, and well-being of persons living with SCI. Expected results of the survey will be used for the basis of conducting stakeholder dialogs for policy reforms designed to improve the functioning, health maintenance, and well-being of persons with SCI.

Key Words: Spinal Cord Injuries, Community Survey, International Classification of Functioning, Disability, Health

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Spinal cord injury (SCI) is a relatively low-prevalence, high-cost health condition that affects between 250,000 and 500 000 persons worldwide each year. An SCI has far-reaching consequences for a person's functioning and health, as affected persons experience impairments of sensory and motor function below the lesion level.¹ SCI and associated health problems lead to premature mortality and increased risk for lower physical and mental health compared to the general population.^{1,2} In interaction with environmental factors and personal resources, an SCI may lead to lower participation in social and economic activities.^{3,4} As a result, the lived experience

of persons with SCI has increasingly become the focus of research, going beyond the description of one's health state into domains of functioning and disability, as characterized by the WHO's International Classification of Functioning, Disability and Health (ICF)⁵ and summarized in the International Perspectives on SCI (IPSCI) report.¹ Weaknesses in health and rehabilitation systems can worsen the burden of disability and lead to poorer health outcomes; reduced well-being; and increased risk of poverty, dependence, and restricted participation.⁵

Yet, owing to inconsistent or inadequate data sources, comparable figures on the incidence and functional consequences of SCI, as well as health services and social provisions for persons with SCI, are largely unavailable for most countries.¹ As recommended by the IPSCI report, systematic data collection and evaluation of the lived experience of SCI, as well as the state of SCI-relevant health and rehabilitation systems, provide essential information on what society can do to improve the situation of persons with SCI and enhance their health, functioning, and well-being.¹

The Learning Health System for Spinal Cord Injury (LHS-SCI)⁶ is an initiative rooted in the WHO's Global Disability Action Plan 2014–2021 *Better health for all people with disability* and in particular with its main objectives of reducing barriers and improving access to health services, assistive technology, and community-based rehabilitation as well as strengthening relevant and internationally comparable data collection.⁷ The LHS-SCI achieves its overall goal of continuously improving the lived experience of persons with SCI in three ways: (i) generating data by means of an international SCI (InSCI) community survey and description of the societal response to SCI; (ii) implementing recommendations

From the Swiss Paraplegic Research, Guido A. Zäch Institute, Nottwil, Switzerland (MHG-H, MWMP, CE, CF, JDR, GS); University of Groningen, University Medical Center Groningen, Department of Rehabilitation Medicine, Center for Rehabilitation, Groningen, the Netherlands (MWMP); Brain Center Rudolf Magnus and Center of Excellence in Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat, Utrecht, the Netherlands (MWMP); Department of Rehabilitation Medicine, University of Malaya, Kuala Lumpur, Malaysia (NH); John Walsh Centre for Rehabilitation Research, Kolling Institute, Northern Sydney Local Health District and Sydney Medical School Northern, University of Sydney, Sydney, Australia (JWM); Institute for Disaster Relief and Reconstruction, Sichuan University and Hongkong Polytechnic University, Sichuan, Chengdu, China (JDR); Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland (JDR, GS); Sunnaas Rehabilitation Hospital, Nesoddtangen, Norway (VS); and ICF Research Branch (a cooperation partner within the WHO Collaborating Centre for the Family of International Classifications at the German Institute of Medical Documentation and Information (DIMDI), Germany (GS).

All correspondence and requests for reprints should be addressed to: Mirja H. Gross-Hemmi, PhD, Swiss Paraplegic Research, Guido A. Zäch Institute, Nottwil, Switzerland.

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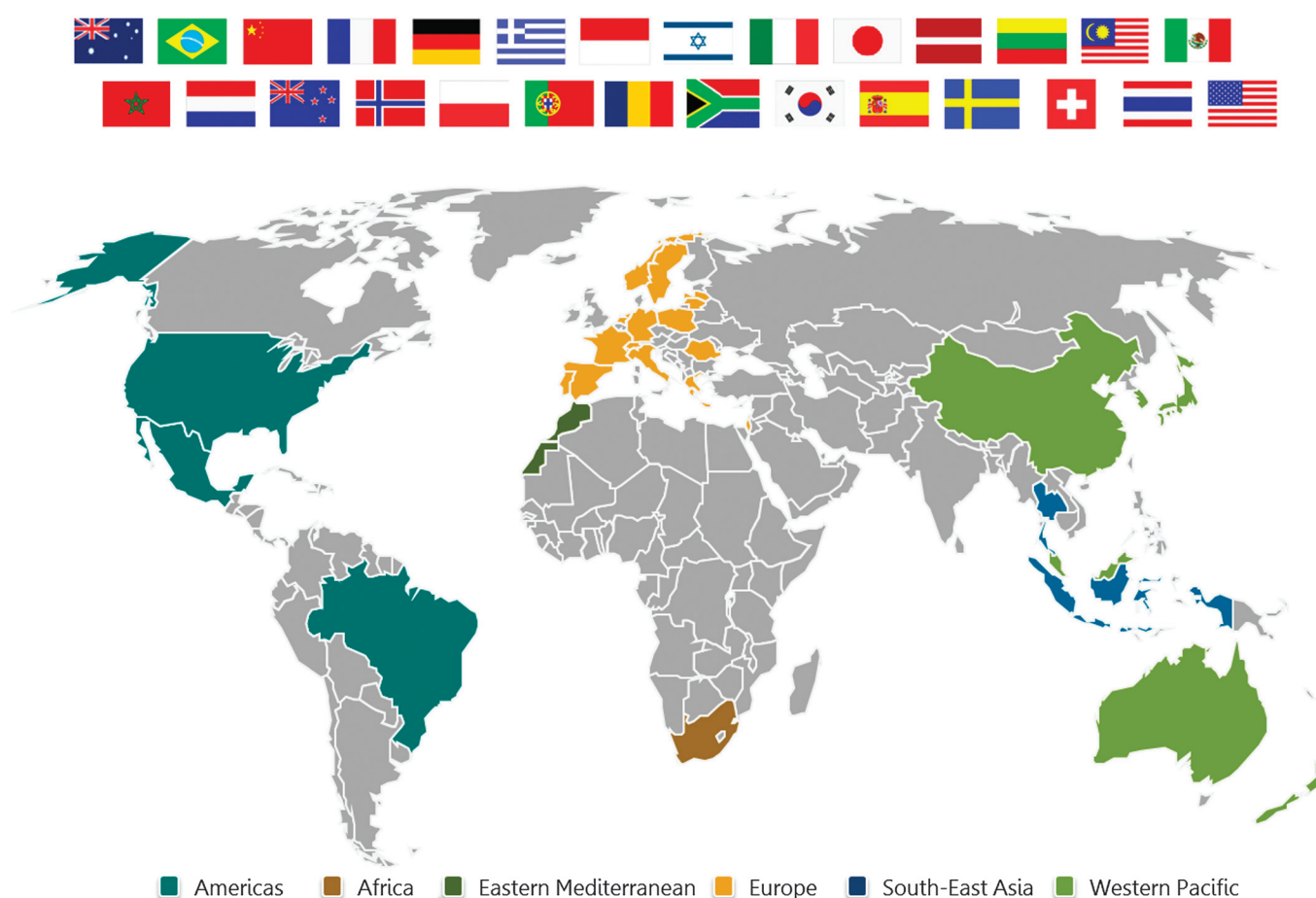
by means of national stakeholder dialogs; and (iii) building SCI-relevant policy and research capacity.

A comprehensive description of the lived experience of SCI in different cultural settings is urgently needed as stated by the IPSCI report¹ and constitutes the starting point for an international learning experience among diverging health systems within LHS-SCI. InSCI will be implemented in 28 countries (as of February 2016) in 2017 and potentially be repeated at 5-year intervals to obtain longitudinal and contemporary information of the lived experience of persons with SCI across these nations. The participating countries are from all of the six WHO regions (Fig. 1) and represent different stages of economic development and health care systems, allowing for comparative analysis. The first community survey of the Swiss Spinal Cord Injury (SwiSCI) cohort study served as model for the development of the InSCI study protocol.^{8–11} As with SwiSCI, InSCI will use the ICF,¹² which provides a framework for data generation by conceptualizing functioning, disability, and health as a dynamic interaction between an individual's health condition and contextual

factors.^{12,13} The study aim of InSCI is to comprehensively describe the lived experience of persons with SCI on an international level. More specifically, InSCI tries to describe and identify the determinants of levels of functioning, health, and well-being of persons living with SCI within and across countries. The guiding hypotheses for the analysis of the InSCI survey are the following:

- Functioning, health, and well-being vary between countries and WHO regions.
- Variation in functioning, health, and well-being is related to variation in self-reported environmental factors.
- Variation in functioning, health, and well-being is related to variation in self-reported personal factors.
- Variation in functioning, health, and well-being between countries and WHO regions is partly attributable to macrolevel differences in health systems and policies and general economic characteristics.

In this paper, we report on the overall methodology of the first InSCI survey, including the recruitment rationale, the



The InSCI community survey includes the following countries: Australia, Brazil, China, France, Germany, Greece, Indonesia, Israel, Italy, Japan, Latvia, Lithuania, Malaysia, Mexico, Morocco, The Netherlands, New Zealand, Norway, Poland, Portugal, Romania, South Africa, South Korea, Spain, Sweden, Switzerland, Thailand, USA.

FIGURE 1. Participating countries of the InSCI community survey.

logistic aspects, and the general analysis plan, recognizing that in some countries, the operational implementation may vary according to local conditions.

METHODS

Design

The InSCI community survey is a cross-sectional multinational survey including 28 countries from all six WHO regions and is scheduled for 2017, with the potential to be repeated at 5-year intervals. Researchers from various countries were invited for the study during conferences of the supporting societies: *International Society of Physical and Rehabilitation Medicine* (ISPRM) and *International Spinal Cord Society* (ISCoS); and all who volunteered to do so participate in the study. Data will be collected using a self-report questionnaire with mixed-mode data collection options (e.g., paper-pencil, telephone interviews, online). National study centers are responsible for the conduct of the survey in their respective country. Besides the development of country-specific sampling and data collection strategies, each national study center develops a strategy for reminding nonresponders. Swiss Paraplegic Research in Nottwil, Switzerland, acts as coordinating institute providing guidance and support to the national study centers with regard to sample design, data collection, storage and archiving, and analysis. Details of each country's national study protocol and optional additional modules are briefly described elsewhere in this issue (see individual country reports).

Target Population and Sampling Frame

Eligible persons are adults 18 years or older having sustained a traumatic SCI (including cauda equina syndrome) or nontraumatic SCI. Selection of participants adheres to a two-step process: First, potential participants will be identified based on selected codes from the International Classification of Diseases (ICD-10). Selected codes for SCI are in accordance with two studies^{14,15} that showed that these ICD-10 codes are the most commonly used and reliable codes associated with SCI (Table 1). In a second step, available medical information of selected patients will be reviewed, and upon confirmation of an SCI, patients will be included in the study. Eligible subjects are residents of the respective country who live in the community with SCI, are able to respond in one of the available language translations of the questionnaire, and have provided informed consent. Excluded are persons with spinal cord damage due to congenital etiologies such as spina bifida, or neurodegenerative disorders such as multiple sclerosis, amyotrophic lateral sclerosis (ALS), or peripheral nerve damage such as Guillain-Barré Syndrome. Persons who are inpatients receiving first rehabilitation or first acute care at the time of the study are also excluded owing to lack of community experience with SCI.

Owing to unavoidable differences between countries in existence and access to contact databases for individuals living with SCI in the community, InSCI allows for multiple sampling frames for the recruitment of participants. Each country defines its sampling design process. To ensure high scientific

TABLE 1. Selection criteria for SCI

ICD-10 Code	Description
G82	Paraplegia and tetraplegia
G82.0	Flaccid paraplegia
G82.1	Spastic paraplegia
G82.2	Paraplegia, unspecified
G82.3	Flaccid tetraplegia
G82.4	Spastic tetraplegia
G82.5	Tetraplegia, unspecified
G83.4	Cauda equina syndrome
S12	Fracture of the neck
S12.0	Fracture of first cervical vertebra
S12.2	Fracture of other specified cervical vertebra
S13.0	Traumatic rupture of cervical intervertebral disk
S13.2	Dislocation of other and unspecified parts of neck
S13.4	Sprain and strain of cervical spine
S14	Injury of nerves and spinal cord at neck level
S14.0	Concussion and edema of cervical spinal cord
S14.1	Other and unspecified injuries of cervical spinal cord
S17	Crushing injury of neck
S19	Other and unspecified injuries of neck
S22	Fracture of rib(s), sternum and thoracic spine
S22.0	Fracture of thoracic vertebra
S23.1	Dislocation of thoracic vertebra
S24	Injury of nerves and spinal cord at thorax level
S24.0	Concussion and edema of thoracic spinal cord
S24.1	Other and unspecified injuries of thoracic spinal cord
S28	Crushing injury of thorax and traumatic amputation of part of thorax
S29	Other and unspecified injuries of thorax
S32	Fracture of lumbar spine and pelvis
S32.0	Fracture of lumbar vertebra
S33.1	Dislocation of lumbar vertebra
S34.0	Concussion and edema of lumbar spinal cord
S34.1	Other injury of lumbar spinal cord
S34.3	Injury of cauda equina
S38	Crushing injury and traumatic amputation of part of abdomen, lower back and pelvis
S39	Other and unspecified injuries of abdomen, lower back and pelvis
T02.0	Fractures involving head with neck
T02.1	Fractures involving thorax with lower back and pelvis
T04.1	Crushing injuries involving thorax with abdomen, lower back and pelvis
T04.2	Crushing injuries involving multiple regions of upper limb(s)
T06.0	Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
T06.1	Injuries of nerves and spinal cord involving other multiple body regions
T09.3	Injury of spinal cord, level unspecified
T09.4	Injury of unspecified nerve, spinal nerve root and plexus of trunk
T91.1	Sequelae of fracture of spine
T91.3	Sequelae of injury of spinal cord

quality standards, the study center will evaluate the sampling design process of each collaborating country to optimize procedures and harmonize data collection if needed. After approval of the process, national standard operational procedures are developed to attain high standardization of processes and ultimately high scientific quality. To counteract potential selection bias, a hierarchy of defined sampling frames is proposed as follows: national or regional registry of persons with SCI, databases of academic or level I trauma hospitals, databases from specialized rehabilitation centers, databases from disabled people's organizations or insurance agencies, samples from previous cohort studies or a combination of the aforementioned databases. Countries are advised to refrain from opportunistic recruitment strategies with unidentified sampling frames (e.g., open access internet links; social media; snowball sampling), since these methods prevent an evaluation of sampling bias and correction for nonresponse. In addition, countries are advised to collect all eligible persons and, after a check of their survival status, draw a random sample of the desired size from this group based on the estimated minimal sample size (see next paragraph). Details on the recruitment in the various countries, if different, are described in the individual country reports in this issue.

Based on a power analysis using data from the SwiSCI community survey,⁸ a minimal target sample size of 200 participants per country is expected to provide sufficient power for comparative analysis of functioning outcomes across countries. Expecting a response rate of 50%, the sampling frame by country should at least contain 400 individuals.⁸ The power analysis used person ability scores in five ICF domains (b1 mental functions, b2–b8 functions of body systems, d4 mobility, d5 self-care, and d6–d9 involvement in life situations), which were calculated using Rasch analysis.¹¹ To estimate minimal sample size, a 10% difference on these ability scores between subgroups was defined as the minimal important difference, with a power of 80% and α error of 0.05. Since subgroups may not be of equal size, the consequences of variations in the relative size of two comparative samples were considered for sample size

calculation (Table 2).^{8,16} For subgroups of equal size, sample sizes vary between 74 and 194 and are moderately sensitive to size ratio.

Medical Ethics

As an international survey, InSCI adheres to universal ethical standards, such as the Declaration of Helsinki¹⁷ and national regulations governing research involving human subjects. Compliance with national laws and regulatory approvals by institutional review board or ethical committee are mandatory for all countries. Informed consent will be sought from each subject or the subject's legally authorized representative, in accordance with national regulations. Each country will specify whether informed consent will be obtained written or verbally. All data will be de-identified before being uploaded to a common database.

Data Collection Tools

The InSCI Questionnaire—The Person's Perspective

The study aim of the InSCI community survey is to comprehensively describe the lived experience of persons with SCI on an international level. The underlying InSCI data model is based on a similar approach as the WHO's World Health Survey, which used key components for health as basis for questionnaire construction.¹⁸ For the InSCI data model, the ICF framework¹² acts as guidance in selecting the most appropriate ICF categories to fully describe the lived experience of SCI, that is, to capture what matters most to affected persons. The InSCI data model is based on categories included in the Brief ICF core set for SCI, long-term context,¹⁹ and ICF rehabilitation set⁷ complemented by selected psychological-personal factors,²⁰ lesion characteristics, and appraisal of health and well-being. This resulted in a total of 47 ICF categories to be covered by the InSCI questionnaire (Table 3). The goal was to develop a data model that comprehensively captures the lived experience of persons with SCI but at the same time is practicable in participant burden (i.e., not too lengthy).^{21,22} To date, no single measurement instrument exists that covers all relevant ICF domains to comprehensively measure the lived experience of SCI. Existing and sound measurement instruments often focus on specific domains; and hence, the InSCI source questionnaire had to be compiled from various existing data collection tools and original questions. The argumentative process of question selection to operationalize the data model was guided by the four principles of efficiency, feasibility, comparability, and truth and discrimination.²³ Entire scales of sound and short data collection tools were used whenever applicable (e.g., Short Form (SF)-36 for the assessment of vitality and mental health). If the use of entire data collection tools was not feasible, for example, because they involved too many questions, single questions from general disability or SCI-specific tools were preferred, which comprised at least cognitively tested questions. The selection of questions for the InSCI questionnaire has been an iterative consensus process of internationally renowned experts in the field of SCI. A detailed description of the data model and the development of the InSCI questionnaire is described in detail elsewhere in this issue.²⁴

Briefly, *body functions* are covered by subscales of the SF-36 (vitality and mental health),²⁵ questions from the Brief

TABLE 2. Sample size estimates

ICF-based Scale	Standard Deviation of Standardized Scale	Ratio of Two Subgroup Samples				
		1	2	3	4	5
b1 Mental functions	0.177	102	114	136	160	180
b2–b8 Functions of body systems	0.151	74	84	100	115	132
d4 Mobility	0.217	150	168	200	235	270
d5 Self-care	0.246	194	219	256	300	348
d6–d9 Involvement in life situations	0.194	122	138	164	190	216

Estimated minimum sample sizes to detect a 10% difference for five standardized ICF-based scales using two samples (subgroups) of varying relative size (ratio range, 1–5) with power 0.8 and alpha 0.05 for the five ICF-based scales.

Estimates were derived using the power and sample size application in Stata (version 13.1; Stata Corp). The gray area indicates minimal sample size estimations of 200 or less.

TABLE 3. The InSCI data model and data collection tools

ICF Code	ICF Category	RS	SCI LT	Data Collection Tool	No. Questions
Body Functions					
b130	Energy and drive functions			SF-36 Vitality Subscale	4
b134	Sleep functions			New (SCI-SCS-format)	1
b152	Emotional functions			SF-36 Mental Health Subscale	5
b270	Sensory functions related to temperature and other stimuli			SCI-SCS	1
b280	Sensation of pain			SCI-SCS (1), BPI (1)	2
b410–b429	Functions of the cardiovascular system			SCI-SCS	1
b420	Blood pressure functions			SCI-SCS	1
b430	Hematological system functions			SCI-SCS	1
b440	Respiration function			SCI-SCS	1
b455	Exercise tolerance functions			MDS	1
b525	Defecation functions			SCI-SCS	1
b620	Urination functions			SCI-SCS	2
b640	Sexual functions			SCI-SCS	1
b710	Mobility of joint functions			SCI-SCS	1
b730	Muscle power functions			Level and completeness of lesion	2
b735	Muscle tone functions			SCI-SCS	1
b810	Protective functions of the skin			SCI-SCS	1
b	[General question on body functions]			Open question on additional health problems	1
Total questions body functions					28
Body structures:					
s120	Spinal cord and related structures			Level and completeness of lesion	—
s430	Structure of respiratory system			SCI-SCS	—
s610	Structure of urinary system			SCIM-SR	—
s810	Structure of areas of skin			SCI-SCS	—
Activities & Participation					
d230	Carrying out daily routine			New (MDS-format)	1
d240	Handling stress and other psychological demands			MDS	1
d410	Changing basic body position			SCIM-SR (1), SCI-FI AT (2)	3
d415	Maintaining a body position			MDS (1), MDS-format (1)	2
d420	Transferring oneself			SCIM-SR	1
d445	Hand and arm use			MDS (1), SCI-FI AT (1)	2
d450	Walking			SCIM-SR	
d455	Moving around			SCIM-SR + MDS	2
d465	Moving around using equipment			SCIM-SR	
d470	Using transportation			MDS	2
d510	Washing oneself			SCIM-SR	2
d520	Caring for body parts			SCIM-SR	1
d530	Toileting			SCIM-SR	3
d540	Dressing			SCIM-SR	2
d550	Eating			SCIM-SR	1
d570	Looking after one's health			MDS (1), new (1)	2
d640	Doing housework			MDS	1
d660	Assisting others			MDS	1
d710	Basic interpersonal interactions			New (MDS-format)	1
d770	Intimate relationships			MDS	1
d850	Remunerative employment			ILIAS (6), SwiSCI (1), MDS (2), ERI (2)	11
d845	Acquiring, keeping and terminating a job			MDS	1
d920	Recreation and leisure			MDS	1
Total activity and participation					42

(Continued on next page)

TABLE 3. (Continued)

ICF Code	ICF Category	RS	SCI LT	Data Collection Tool	No. Questions
Environmental Factors					
e110	Products or substances for personal consumption			NEFI-SF	
e115	Products and technology for personal use in daily living				1
e120	Products and technology for personal indoor and outdoor mobility and transportation			NEFI-SF	2
e125	Products and technology for communication			NEFI-SF	1
e135	Products and technology for employment			SwiSCI	1
e150	Design, construction and building products and technology of buildings for public use			NEFI-SF (1), SwiSCI (1)	2
e155	Design, construction and building products and technology of buildings for private use			NEFI-SF	1
e165	Assets			NEFI-SF	1
e225	Climate			NEFI-SF	1
e310	Immediate family			NEFI-SF	1
e320	Friends			NEFI-SF	1
e340	Personal care providers and personal assistants			NEFI-SF (1), new (1)	2
e355	Health professionals			MDS	2
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors and community members			NEFI-SF	1
e460	Societal attitudes			NEFI-SF	1
e450	Individual attitudes of health professionals			MDS	2
e570	Social security services, systems and policies			MDS	1
e580	Health services, systems and policies			MDS (3), NEFI-SF (1)	4
e590	Labour and employment services, systems and policies			SwiSCI	1
Total environmental factors					26
Personal Factors					
	Sociodemographic and personal characteristics			MDS (5), new (1)	6
	Position in the immediate social and physical context			MA SSS (1), MDS (1), new (1)	3
	Personal history and biography			New	1
	Thoughts and beliefs			MSES (2), GSES (2), MDS (2), WHOQoL Disability (1)	7
	Motives			MDS	1
	Patterns of experience and behavior			GBS	1
Total personal factors					19
Appraisal of health and well-being					
	Subjective well-being			WHOQoL-BREF	6
	General health			SF-36	2
Total appraisal of health and well-being					8
Lesion characteristics					
	Etiology, time of SCI			ISCoS (1), SwiSCI (1)	2
Total SCI characteristics					2
Total InSCI questionnaires					125

ICF categories printed in bold are part of the InSCI data model.

RS, ICF rehabilitation set; SCI LT, Brief ICF Core Set for SCI, long-term context.

Abbreviations for data collection tools: BPI, Brief Pain Inventory; ERI, Effort-Reward Imbalance Questionnaire; GBS, General Belongingness Scale; GSES, General Self-Efficacy Scale; ILIAS, International Labour Market Integration Assessment for Spinal Cord Injury; ISCoS, International Spinal Cord Association, Template for Demographics; MA SSS, McArthur Scale of Subjective Social Status; MDS, Model Disability Survey; MSES, Moorong Self-Efficacy Scale; SCI-FI AT, Spinal Cord Injury—Functional Index—Assistive Technology; NEFI-S, Nottwil Environmental Factors Inventory, Short form; SCIM-SR, Spinal Cord Independence Measure for Self-Report; SCI-SCS, Spinal Cord Injury Secondary Conditions Scale; SwiSCI, Swiss Spinal Cord Injury Cohort Study; WHOQoL-BREF, World Health Organization Quality of Life-BREF.

Pain Inventory,²⁶ and adapted questions from the Spinal Cord Injury Secondary Conditions Scale.²⁷ *Activity and participation* are mainly assessed by questions from WHO's Model Disability Survey (MDS),²⁸ the Spinal Cord Independence Measure for Self-Report,²⁹ and the Spinal Cord Injury Functional Index.³⁰ Evaluation of *work integration and health care services* involve questions taken from different tools. *Environmental factors* will mainly be assessed by the Nottwil Environmental Factors Inventory Short Form³¹ and questions from the MDS.²⁸ Relevant *personal factors* will be measured using questions from the General Self-Efficacy Scale,³² the Moorong Self-Efficacy Scale,³³ the General Belongingness Scale,³⁴ and the MDS.²⁸ Additionally, *basic sociodemographic and socioeconomic characteristics* will be gathered as personal factors. Information on *lesion characteristics* include self-reported severity and completeness of lesion, etiology, and date of SCI. *Appraisal of health and well-being* will be assessed with the General Health scale of the SF-36²⁵ and a 5-item selection of World Health Organization Quality of Life-BREF,³⁵ respectively. In total, the InSCI questionnaire comprises 125 questions, and its estimated time for completion is 30 to 45 minutes.

A multidisciplinary team with expertise in measurement, statistics, survey research, information technology, and documentation developed a paper-pencil version of the InSCI questionnaire that serves as template for all countries. The InSCI questionnaire can be self-administered (paper-pencil or online questionnaires, available for use on desktop, tablet, or smartphone) or interviewer-administered (face-to-face or telephone interview). A first draft of the questionnaire was discussed with the national leaders and coordinators of the participating InSCI countries at the ISCoS (Montréal, 2015) and ISPRM (Berlin, 2015) conferences. Feedback from these conferences has been incorporated, and a final draft of the questionnaire has been discussed with experts in respective fields.

For the various translations of the InSCI questionnaire, cross-cultural adaptation based on the guidelines proposed by Epstein et al.³⁶ will be applied. These guidelines are designed to maximize the attainment of semantic, idiomatic, experiential, and conceptual equivalence between the English InSCI reference questionnaire and the translated versions. This guarantees both appropriate linguistic translation and cultural adaptation to maintain consistency and the content validity of the InSCI questionnaire across the different participating countries. As a general translation guideline of the InSCI questionnaire, participating countries are advised to only adapt the questionnaire (e.g., altering content or design components) when substantial improvement for a specific sociocultural context is attained. The order of questions and response categories cannot be changed. Maintaining equivalence of the semantics of a phrase has priority above literal translation. Therefore, if a phrase cannot be properly translated by simply translating the words, the appropriate viable translation may be a translation that includes adaptation of content, format, or other feature. Unless validated translations of data collection tools are available, the instructions, questions, and response options will be translated in a

three-step process involving two independently translated questionnaire versions, which will be synthesized, checked, discussed, and approved by an expert committee within the national study group.³⁶

In a consecutive pretesting phase, difficulties in the questionnaire and study design have been assessed in each country to ensure comparability and equivalence of data. The pretest of the English reference version of the InSCI questionnaire has been performed in the United States and included focus group interviews to test content validity, and the assessment of test-retest reliability. Pretesting of the translated InSCI questionnaire including persons with SCI in all other countries has been recently completed and additionally helped improve the final version of the InSCI questionnaire. Based on the issues raised during translation and pilot testing, decisions on the final version of the InSCI questionnaire have been discussed by researchers from the study center, the chair of the scientific committee, and two international advisors at the end of August 2016.

Variables of the Health System and Economic Resources—The Societal Perspective

The InSCI research framework allows both national (within country) and cross-national (between countries) analyses. To make this possible, information on specific variables of the health system and economic resources variables, such as community rehabilitation and return-to-work programs, health and accident insurance, and social welfare systems, will be collected to describe the current stage of economic development and health care systems in each country. These variables are potentially important environmental factors or interest to the outcomes of the InSCI study and can be used as factors in the quantitative analyses of functioning, health, and well-being of persons living with SCI. For a detailed list of these variables, see Pacheco Barzallo and Gross-Hemmi³⁷ in this issue.

Data Entry, Management, and Access

For data entry, password-secured web-based entry forms will be used. To guarantee data security, only study participants and dedicated staff of the respective national study centers will have access. This allows both continued data entry on a case-by-case basis and real-time monitoring of accrual rates. In addition, the study center may advise individual countries on operational issues to ensure maximal subject participation.

Study data will be de-identified, harmonized, and centrally stored on a password-protected database server. The study center will be entrusted with the monitoring and coordination of the data collection process, the combining of national data files, and archiving of the data. For country-specific national modules, the countries may use either the central database or their own local database. Personal data of participants will be stored in each country's local database. Both study data and personal data will contain a unique identifier (InSCI ID number) allowing for the linkage of the data sets when required. In addition to the strict de-identification of study data,

country-level information will also principally be de-identified in reporting of functioning outcomes.

Access to the central database will be password-protected, monitored, and restricted to registered users. Access to the national study database holding personal data will be restricted to a small group of authorized study personnel under the responsibility of the national study center. All study staff will sign a declaration of adherence to data protection regulations.

Upon closure of the InSCI community survey, all data will be systematically checked to ensure that the subject was eligible and the informed consent was signed, and nonsensical responses will be resolved based on standardized operating procedures. The national data will be available to the research teams of each participating country at any time. All researchers intending to use InSCI survey data will have to submit a formal research proposal to the InSCI scientific committee.

Data Analysis

Statistical Adjustment for Response Bias, and Data Analysis Plan

Possible country-specific response bias will be estimated by the study center through a unit nonresponse analysis that looks at targeted participants who did not participate in the survey, based on existing personal participant's characteristics (e.g., sex, age, lesion level, date of onset of SCI). To account for nonresponse bias, inverse probability weights based on the propensity of response will be computed for each country. The study center will also account for item nonresponse (missing item response data). If possible, logical imputations with values unambiguously inferred from other response options will be made. Otherwise, data will be imputed both with single imputation and multiple imputation methods,^{38,39} as the preferred use of single imputation or multiple imputation data may depend on the application and previous experience of the researchers. Rasch analysis is the principal validation tool in InSCI to compute and ensure conceptual coherence and cross-national equivalence of ICF-based scores.^{11,31}

Data Analysis Plan for the Lived Experience Across Countries

The data analysis of the InSCI survey consists of a twofold approach. First, the perceived lived experience of people with SCI (the person's perspective) will be analyzed with regard to items of the InSCI questionnaire, which will then be contrasted to variables of the health system to determine the influence of the countries' health systems on the lived experience (the societal perspective).⁴⁰ To achieve this, the analysis plan will analyze both the person's perspective and the societal perspective separately, as follows:

- 1) Data analysis plan for the lived experience and participation in the society—the person's perspective

First, functioning profiles across all functioning domains based on the prevalence of functioning problems among the population with SCI will be created. Heat

graphs⁴¹ will be used to visualize the extent of functioning problems in both, SCI samples and SCI subgroups identified as meaningful for comparing information across different countries, namely, SCI type (tetraplegia, paraplegia), etiology (traumatic and nontraumatic), SCI degree (complete/incomplete), age (16–30 years, 31–45 years, 46–60 years, 61–75 years, and 76 years or older), and sex (male, female).⁴²

Second, the complexity of functioning in relation to SCI will be explored using graphical models. Based on this innovative statistical approach, we will be able to examine the association between aspects of functioning and identify the areas of the lived experience that are most influential for optimizing the health of people with SCI.

A graph is defined as a visualization of (V, ϵ) , where V denotes the vector of the functioning variables of interest (also called the nodes of the graph) and ϵ a set of edges representing the dependence between those functioning variables. The edges can be undirected ($x-y$) or directed ($x \rightarrow y$ or $x \leftarrow y$). Undirected graphs will be used to visualize mutual association between functioning variables, whereas directed acyclic graphs will be used to represent the effect of hypothetical interventions in each functioning variable on people's health. The undirected graph, called a skeleton, will be estimated using the PC algorithm implemented by Kalisch et al.⁴³ In this algorithm, a series of conditional independence tests (starting with three functioning variable and then increasing the set of functioning variables step by step) are carried out for eliminating the edges from a complete graph, that is, one within which all variables (nodes) are connected. The final edges in the skeleton indicate some strong dependence that cannot be explained by conditioning on other variables.

To identify which aspects of functioning may most importantly contribute to optimizing health, intervention calculus developed by Peter Sprintes and Clark Glymour and implemented in the *pcalg* R package will be applied.⁴⁴ Setting in the skeleton all edges connected with the self-reported health variable so that they are directed toward the self-reported general health variable at the end will allow us, by using observational data, to quantify the effect on health that is achieved by setting one functioning variable to a particular value (in this case, the value “no problem because of a hypothesized intervention”). Third, we will investigate the relation between different aspects of functioning and contextual factors. Aspects of functioning and environmental barriers will be aggregated into clinically meaningful domains of functioning (e.g., mobility, self-care, domestic life) by maintaining conceptual coherency with the ICF and ensuring robust psychometric properties of the metric obtained following the approach developed for the SwiSCI community survey.⁴⁵ The Rasch measurement model will be applied to derive interval scales for the identified subdomains.⁴⁶ For existing associations between body functions and activities and participation subdomains, the effect of environmental barriers will be studied by comparing moderator hypothesis, mediator hypothesis, and direct effect hypothesis. In addition, we will adjust for variation in age (in years), time since injury, sex, SCI type (paraplegic/tetraplegic), etiology (traumatic/nontraumatic), SCI degree (complete/incomplete),

and education. Personal factors evaluated with various measurement instruments will also be considered once their Rasch scores have been estimated.⁴⁷

2) Data analysis plan for the influence of the health system on the person's lived experience—the societal perspective

Owing to the hierarchical structure of the expected data, a multilevel approach is inevitable to determine the societal influence on the lived experience of SCI across and within countries.^{48,49} The most appropriate way to handle such a data structure is to use extensions of standard regression models that allow for clustering of outcomes between individuals in the same cohort. For example, individual data are nested in different levels, such as the community level, country region level, and country level. One main obstacle of ordinary least squares regression analysis applied to a nested data structure to ensure that the standard errors of the regression coefficients are valid (as these will most likely be too small or too large depending on the level of the variable (within or between cluster variable) because of unobserved heterogeneity if the hierarchical data structures are ignored). Consequently, random-effects (also known as “subject-specific”, “conditional”, “mixed”, or “multilevel”) regression models will be used, which allow us to account for sources of heterogeneity that may arise at the different group and/or individual level by portioning the error term of the regression equation.⁴⁹ These models are also particularly suitable for the analysis of incomplete and/or unbalanced data.

For all analyses, well-established statistical software packages such as STATA (StataCorp, Texas) and R (The R Foundation for Statistical Computing) will be used.

GOVERNANCE STRUCTURE

The InSCI governance structure aims to ensure ethical and scientific excellence, good partnership with the community of persons living with SCI, and efficient and sustainable daily and

long-term study operations. The governance structure consists of six principal organizational units: a steering committee, an executive committee, a scientific committee, the study center, national study groups, and interest groups (Fig. 2). These are each described.

- *Steering committee:* consists of the country study leaders and representatives from individuals living with SCI, the supporting societies of ISPRM and ISCoS, the scientific committee, and the study center. It will meet twice a year. The steering committee sets the principles governing the quality and management of the overall project including the work progress of the entire LHS-SCI initiative, and oversees the results, outcomes, and dissemination of all activities performed. In addition, the steering committee approves the creation of interest groups to guide and supervise project groups within a theme of scientific content and feasibility aspects.
- *Executive committee:* consists of eight individuals from the steering committee who will oversee the daily operations performed by the study center. The committee meets on a regular basis, and the decision making competence lies within the framework approved by the steering committee.
- *Scientific committee:* consists of a chairperson, chosen national leaders, ISPRM and ISCoS representatives, and senior advisors and will be responsible for the scientific content of InSCI and all other following activities. The scientific committee will meet twice a year.
- *Study center:* provides operational infrastructure in administrative, statistical, and technical support. The study center reports to the executive and scientific committee.
- *National study groups:* are composed of the national leaders, study coordinators, delegates of the national ISCoS and ISPRM societies, patient organizations, and local persons considered beneficial for the success of the project in each country. This group unanimously decides on country-specific issues and coordinates all activities within the LHS-SCI initiative in their respective country.

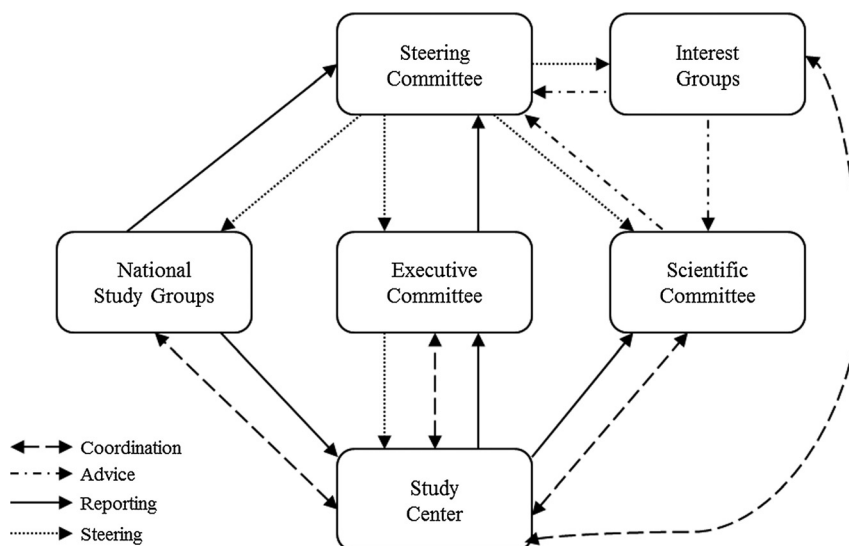


FIGURE 2. Governance structure of the LHS-SCI initiative.

- *Interest groups:* provides an informal forum to develop the research agenda and funding plans as well as the implementation of nested and joint projects. Upon request, experts for a defined subject area provide scientific expertise and advice within the LHS-SCI initiative.

DISCUSSION

In this protocol paper, the overall aims and design of the InSCI community survey are detailed. InSCI will be the first standardized survey on health, functioning, and well-being of persons with SCI to be executed simultaneously in 28 countries across all six WHO world regions. As an important first step within the LHS-SCI initiative, InSCI serves as a platform to generate evidence on the lived experience of persons with SCI on an international level. To monitor goal achievement of the LHS-SCI, the InSCI community survey is foreseen to be repeated at 5 yearly intervals to evaluate progress in the health system development and service provision.

As an international survey, InSCI involves several methodological challenges that need careful consideration and planning. Each will be reviewed in turn.

Representativeness of the Sample

For cross-country comparisons, as planned for InSCI, population-based random samples would be ideal. However, as comprehensive registries on persons with SCI are lacking in many countries, such random samples are hard to obtain; and this limits the representativeness of the sampling frames.⁴⁰ To guarantee feasibility and best possible adjustment to local conditions, national study groups develop country-specific strategies regarding sampling frames and sampling modes within the given InSCI guidelines. This flexibility ensures that the targeted minimal sample size of 200 eligible participants per country can be reached. This may, however, create a risk of nonrepresentative samples owing to suboptimal sampling frames. To address this issue, guidelines concerning target populations have been clearly defined, and a hierarchical suggestion of defined sampling frames have been developed. Moreover, for analysis, countries with similar sampling frames will be clustered and different scenarios and sensitivity analyses of functioning outcomes will be applied. All analyses will be adjusted for demographics and SCI characteristics, and random effects models will be used to account for unobserved heterogeneity.

Addressing Nonresponse Bias

The use of a Web-based data entry form for immediate data entry will allow the real-time monitoring of the response status of eligible subjects to ensure reminder management to nonresponders by national study groups. Each national study center develops a strategy for reminding nonresponders. As the experience of SwiSCI has shown, an elaborate reminder strategy can effectively increase participation rates. In the SwiSCI community survey, a first written reminder was followed by a telephone reminder, and this combination was an efficient way to optimize response rates.¹⁰ Based on this experience, a nonresponse rate of approximately 50% can be expected,⁸ and all participating countries are advised to collect survival status and basic data of

eligible subjects to address and correct for unit nonresponse by inverse probability weights based on the propensity of response.

Data Collection

Whereas the InSCI questionnaire was designed to comprehensively capture the lived experience of persons with SCI considering the four guiding principles (efficiency, feasibility, comparability, truth, and discrimination) that directed the argumentative process of question selection, the validity and reliability of the InSCI questionnaire still needs to be confirmed. A first approach toward content validity of the questionnaire was established by using well-established ICF domains for SCI research purposes. Moreover, the recently completed US pilot study that assessed content validity and test-retest reliability in a sample of SCI persons as well as the country-specific pretests with SCI persons provided us with additional data on psychometric evidence and cross-cultural adaptation of the InSCI questionnaire and helped improve the final InSCI questionnaire.

Furthermore, as cross-national comparison is an aim of InSCI, data collection has to be harmonized to a certain extent so as to be comparable across countries. Thanks to the Web-based data, entry mask harmonization among the countries is possible, which may prevent unexpected bias due to different data entry layout or mechanism. The survey is planned for a common starting point in 2017 so that health systems and service provision to SCI of the participating countries can be integrated. For example, world affairs and/or significant changes in health systems affecting the countries can be integrated as covariate into the statistical modeling of outcomes. Finally, the InSCI questionnaire was developed to be culturally sensitive and understandable across countries.

Comparability of Results Across Countries (Variables of the Health System and Economic Resources)

As reported in the IPSCI report, specific data on the use of health-care services and the unmet needs of persons with SCI are often lacking and difficult to obtain, particularly in low-income countries. This results in high variability of available information.¹ Yet, data about health system performance and economic resources of a country are of particular importance to understanding the societal response and may point to possible inequalities between countries.⁴⁰ To determine the societal response to the lived experience of persons with SCI, variables on the health care and rehabilitation system as well as economic resource variables of the 28 participating countries have been collected and will be integrated into the statistical modeling to determine the influence of the health system on the lived experience of SCI within and between countries.²⁴

Finally, it is important to mention that insights gained from InSCI alone will not be a complete guide to reforming practice, research, and policy in the field of disability and rehabilitation. The role of InSCI in the context of the LHS-SCI is to provide comparable evidence on the lived experience and needs of persons living with SCI. Continued research in the

field with detailed in-depth analysis is necessary to guide further developments.

CONCLUSIONS

InSCI provides an international platform to gather evidence on the lived experience of persons with SCI and supports the LHS-SCI initiative for planning, implementing, and monitoring improvements in health care systems and service delivery. Results of the InSCI survey will provide the basis for continued research and, in particular, will support the background for stakeholder dialogs – the second pillar of LHS-SCI—that will be used to identify potential targets for interventions to improve the situation of persons living with SCI.

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Rehabilitation Services Provision and Payment

Christoph Gutenbrunner, MD, PhD, Melanie Blumenthal, MA,
Veronika Geng, MNSc, and Christoph Egen, Dipl-Soz-Wiss, Dipl-Päd

Abstract: Persons with spinal cord injury (SCI) experience disability and have significant need for rehabilitation. To deliver appropriate rehabilitation, interventions and programs suitable services must exist. A prerequisite for system improvement is a description of rehabilitation services. The aim of this paper was to develop a rehabilitation service framework for SCI. Additionally, principles and models of payment of rehabilitation services will be discussed. Health-related rehabilitation services should be available along the continuum of care and implemented at all levels of health care. The three most important types of services are acute, postacute, and long-term rehabilitation services. Health-related rehabilitation services for patients with SCI must be able to provide high-quality equipment and a well-trained, highly specialized and multiprofessional team of rehabilitation workers. The principles of payment for SCI rehabilitation services vary according to the organization of health care systems, which primarily depends on the sources of money (eg, from national health care systems, other health insurances, or out of pocket). Funding systems and payment criteria may influence service provision and justice in service delivery. It is important to analyze the provision of rehabilitation services and the related funding system using uniform assessment and evaluation tools.

Key Words: Spinal Cord Injury, Rehabilitation Services, Service Organisation, Payment Systems

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There is no doubt that persons with spinal cord injury (SCI) experience disability and have significant need for rehabilitation.¹ It has been shown that an early onset of rehabilitation leads to better outcomes^{2,3} and that postacute rehabilitation interventions are crucial for persons with disabilities to achieve maximum independence.^{4,5} It is also obvious that persons with SCI have a need for long-term rehabilitation care (including assistive devices) that should be delivered near their place of residence (ie, in the community).⁶ Consequently, the report *International Perspectives of Spinal Cord Injury* recommends that “access to rehabilitation should be as early as possible, i.e. during the acute phase of injury, and provided on a continuum to maximize functional outcomes and facilitate transition to community living” and “access to a range of assistive technologies will help accommodate changes in function and will maximize independence”.¹

As functioning problems in patients with SCI concern all aspects and determinants of functioning (body structures and functions, activities, participation, and environmental and personal factors), rehabilitation must target all these domains.^{7,8} This requires a team of well-trained and specialized rehabilitation professionals (including physical and rehabilitation medicine doctors (PRM doctors), physiotherapists (PTs), occupational therapists (OTs), psychotherapists (PSTs), social workers (SWs), and others),^{9,10} and demonstrates that rehabilitation services are in need of highly specialized professionals working in an

efficient team. This also applies to technical resources (eg, equipment for therapies) and an appropriate barrier-free environment.¹¹ Standardized rehabilitation programs and rehabilitation guidelines clearly reflect these requirements.^{3,12}

To deliver appropriate rehabilitation interventions and programs to persons in need, suitable services must exist. In many countries, in particular, high-resource countries, highly specialized acute, postacute, and long-term services are available; yet the standards of care vary considerably between and, in some cases, also within countries.¹³ In many low and lower middle-income countries, such services are absent, and an appropriate infrastructure must be built up to deliver high-quality rehabilitation.¹⁴

A prerequisite for system improvement is a description of rehabilitation services and service models (optimally based on existing services).¹⁵ Thus, the aim of this paper was to develop a rehabilitation service framework for SCI based on the *International Classification of Functioning, Disability and Health* conceptual description of rehabilitation services¹⁶ and the proposed classification of service organization in rehabilitation.¹⁷ Additionally, principles and models of payment of rehabilitation services will be discussed.

Types of Rehabilitation Services

Rehabilitation services are conceptually described as “personal and non-personal intangible products offered to persons with a health condition experiencing or likely to experience disability or to their informal care-givers within an organizational setting in interaction between provider and person addressing individual functioning needs that aim at enabling persons to achieve and maintain optimal functioning considering the integration of other services addressing the individual’s needs including health, social, labor and educational services and delivered by rehabilitation professionals, other health professionals, or appropriately trained community-based workers”.¹⁶ According to the World Health Organization (WHO) *Global Disability Action Plan 2014-2021* “Better Health

From the Department of Rehabilitation Medicine, Hannover Medical School, Hannover, Germany (CG, MB, CE); and Manfred-Sauer-Stiftung, Lobbach, Germany (VG).

All correspondence and requests for reprints should be addressed to: Christoph Gutenbrunner, MD, PhD, Department of Rehabilitation Medicine, Hannover Medical School, Carl-Neuberg-Str. 1, D-30525 Hannover, Germany.

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for all People with Disability” health-related rehabilitation services should be available along the continuum of care and implemented at all levels of health care.¹⁴ The three most important types of services are:

- A. *Acute rehabilitation services:* Acute rehabilitation services are delivered in hospitals at the secondary and tertiary levels. The target group is composed of patients with severe disease or injury in risk of long-term disability. Acute rehabilitation services should start even during intensive care and should be performed in multiprofessional teams (including PRM doctors, PTs, OTs, and other rehabilitation professionals). Acute rehabilitation services may be delivered in specialized acute rehabilitation wards or in mobile acute rehabilitation teams.¹⁸
- B. *Postacute rehabilitation services:* Postacute rehabilitation services should be delivered immediately or shortly after discharge from acute care hospitals. The target groups are patients with persisting impairment activity limitations and participation restrictions after acute care or trauma.¹⁹ Postacute rehabilitation services improve functioning (including participation) and can contribute to an earlier discharge from hospital. For more severe cases (with limitations in mobility and activities of daily living) postacute rehabilitation should be done in in-patient postacute rehabilitation units. Patients with fewer restrictions can also be referred to outpatient postacute rehabilitation units. For patients with minor deficits single intervention services may be sufficient. Postacute rehabilitation services should be specialized for the specific disease or trauma and also must have a multiprofessional rehabilitation team.
- C. *Long-term rehabilitation services:* Long-term rehabilitation services aim to improve functioning for persons with long-term disability including congenital disability, acquired disability, and chronic diseases. They also are the main entrance point for more specialized rehabilitation if needed. Long-term rehabilitation can be performed by rehabilitation professionals (eg, PRM doctors, PTs, OTs). In many cases, primary health care professionals (eg, family doctors, primary health care rehabilitation workers) may take an important role in long-term rehabilitation. Long-term rehabilitation can be delivered in primary care rehabilitation centers and as monoprofessional long-term rehabilitation services.^{11,20} If no specialized rehabilitation exists, community-based rehabilitation (CBR) is a model to provide some rehabilitation service to persons in need.²¹ Community-based rehabilitation should be closely connected to an inclusive community development policy (CBD). Intermittent in-patient rehabilitation services can be used to induce and boost rehabilitation effects in patients with chronic health conditions, in particular, if they are related to psychosocial stress and vocational problems.

To classify rehabilitation services, Gutenbrunner et al.¹⁷ proposed a framework (*International Classification System for Service Organization in Health-related Rehabilitation [ICSO-R]*) that uses the following dimensions¹⁷: provider (location, organization, context, facility, human resources, technical resources and equipment, quality assurance, profit-orientation,

and other categories of provider), funding (source of money, criteria of cost refund, and other criteria of funding), and service delivery (strategy, target groups, service goals, aspects of time, intensity, team structure, mode of production, and other categories of service delivery). These dimensions can be used as a framework to describe rehabilitation services for patients with SCI. The most relevant services are described in Table 1.

Generally speaking, health-related rehabilitation services for patients with SCI must be able to provide high-quality equipment and a well-trained, highly specialized, and multiprofessional team of rehabilitation workers. At the level of medical doctors, a close collaboration between different specialists (neurosurgeons, neurologists, physical and rehabilitation specialists, urologists, and others) is required to manage the complex health condition.^{22,23} Therapists must have a wide range of qualification and must be trained in treatment methods for SCI. Multiple specializations are required (physiotherapy, occupational therapy, speech and language therapy, bowel and bladder management, prosthetics and orthotics, and others). Nurses must be specialized in rehabilitation issues and familiar with the problems of patients with SCI. As mental problems often occur and integration into social life (including labor and education) is one major goal of rehabilitation, psychotherapists and social workers should be part of the rehabilitation team. It is crucial that all these professionals work in patient-centered teams and include the relatives of the patient into the rehabilitation process. Ideally, adaptations of the home of the patients and return-to-work issues should be addressed as early as possible (the latest in the postacute rehabilitation phase). Thus, rehabilitation teams must have capacity to reach out into the community or collaborate with community-based services.²³

Rehabilitation after SCI must start immediately after onset of the SCI and needs lifelong continuation.²³ The acute and postacute rehabilitation phase can be organized within one center, and the long-term rehabilitation services will be delivered by several service providers.

This heterogeneity must be managed by coordinating structures, which could be done by case managers, family doctors, or personnel in the specialized rehabilitation centers. Case management should include information to the care providers (eg, family doctors, physiotherapists, and occupational therapists working at primary care level) on special knowledge for the treatment and management of SCI. Patient organizations can take a central role here, too. Case management should also link to other services, such as vocational rehabilitation and training, education, adaptation of the living environment, and assistive technologies. Most assistive devices should be directly chosen by the rehabilitation team, and training to handle and use of them must be an integrated part of the rehabilitation service.

Despite these basic principles, variations of care provision are possible. For example, the ownership of services (states, insurance companies, private sector, and nongovernmental organizations) may vary, as may payment systems (per diem, per intervention, per case, or for the entire service), the specialization and role of the single team members, and the referral and case management system. Because systematic comparative studies on the service provision for patients with SCI in different countries are missing, only a few points from narrative descriptions can demonstrate some principles.

TABLE 1. Most relevant types of health-related rehabilitation services classified within the framework of the ICSO-R¹⁷

Phase Service ICSO-R Dimension	Acute Care		Postacute Care		Long-Term Care		
	A. Acute (<i>Early</i>) Rehabilitation Unit	B. In-Patient Post Acute Rehabilitation Unit	C.1 Primary Care Health Services	C.2 Community-Based Rehabilitation Service	C.3 Intermittent In-Patient Rehabilitation Service		
Provider							
1.1.1. Location	Centralized (<i>within hospital</i>)	Centralized (<i>may be in other community than hospital</i>)	Decentralized	Decentralized, community based	Centralized or decentralized (<i>can be provided in same units as postacute services</i>)		
1.2. Organization	Integrated in hospital services	Integrated in hospital services or independent organization with structure referral system	Health care centers or single practices	Community	Depends on health system and local situation		
1.3. Context	Within hospital	Stand alone in-patient center or within hospital	Stand alone primary health care center or within community	Within community	Specialized units (<i>in-patient clinics</i>)		
1.4. Facility	Hospital ward and mobile rehabilitation team (<i>eg, for very early interventions on ICU's</i>)	In-patient service structure	Facilities for single treatments	Facilities for single treatments and/or home-based interventions	In-patient service structure		
1.5. Human resources	PRM doctor, neurosurgeon, nurses, physiotherapists, occupational therapists, speech and language therapist, dysphagia therapist, rehabilitation nurse, psychologist, social worker. Other medical specialists (<i>eg, neurologists, urologists, Internal medicine specialists</i>) should be in reach (<i>same hospital</i>)	PRM doctor, nurses, physiotherapists, occupational therapists, speech and language therapist, dysphagia therapist, rehabilitation nurse, psychologist, social worker. Other medical specialists (<i>eg, neurologists, urologists, internal medicine specialists</i>) should be in reach (<i>optimally in same center</i>)	PRM doctor, other specialist, or primary care physician, nurses, therapists	Therapists, nurses, community workers	PRM doctor, nurses, physiotherapists, occupational therapists, speech and language therapist, dysphagia therapist, rehabilitation nurse, psychologist, social worker. Other medical specialists (<i>eg neurologists, urologists, internal medicine specialists</i>) should be in reach (<i>optimally in same center</i>)		
1.6. Technical resources and equipment	Barrier-free ward structure (<i>feasible also for wheel chair users</i>), therapy room, devices for early mobilization, activities of daily living, splinting, and material for other therapies. (<i>Diagnostic equipment of hospital also required</i>)	Diagnostic equipment (<i>including MRI, neurophysiology, urodynamic unit, clinical laboratory</i>) for patients follow-up, comprehensive specialized treatment facilities, medical training, return to normal life are, vocational training, gym, pool and others	Specialized treatment facilities and basic diagnostics	Room, basic treatment facilities	Comprehensive specialized treatment facilities and diagnostic equipment (<i>including MRI, neurophysiology, urodynamic unit, clinical laboratory</i>) for patients follow-up		
1.7. Quality assurance	Rehabilitation assessment, regular documented team meetings on the patients' functioning	Rehabilitation assessment, regular documented team meetings on the patients' functioning	Monoprofessional assessment	Basic assessment	Rehabilitation assessment, regular documented team meetings on the patients' functioning		
1.8. Profit orientation	Depending on health system and ownership	Depending on health system and ownership	Depending on health system and ownership	Depending on health system and ownership	Depending on health system and ownership		
1.9. Other categories of provider	—	—	—	In many cases provided by communities and/or NGOs			
Funding							
2.1. Source of money	Depends on health funding system	Depends on health funding system	Depends on health funding system	Depends on health funding system (<i>or in many cases funded by communities and/or NGOs</i>)	Depends on health funding system		

(Continued on next page)

TABLE 1. (Continued)

Phase Service ICSO-R Dimension	Acute Care		Postacute Care		Long-Term Care	
	A. Acute (<i>Early</i>) Rehabilitation Unit	B. In-Patient Post Acute Rehabilitation Unit	C.1 Primary Care Health Services	C.2 Community-Based Rehabilitation Service	C.3 Intermittent In-Patient Rehabilitation Service	
2.2.2. Criteria of cost refund	Depends on health funding system	Per-day or single therapies refund or other funding systems	Single therapies refund	Depends on 2.1	Per-day or single therapies refund or other funding systems	
2.2.3. Other criteria of funding	—	—	—	—	In some countries funded by pension insurance	
Service delivery						
3.1. Strategy						
3.1.1. Strategy	Early rehabilitation (<i>mainly training body functions and activities, preparing for participation, support coping with disease</i>), prevention of complications of treatments and immobilization, maintenance of body functions. In cases with unclear prognosis overlap with palliation	Postacute rehabilitation (<i>treatment of impaired functions and activities, independent living, return to normal life and/or ob. empowerment</i>)	Treatment of functions and training of activities, rehabilitation (<i>independent living</i>)	Independent living	Rehabilitation, health promotion, return-to-work, independent living	
3.2. Target	SCI patients in the acute phase (<i>with severe impairment and at risk of long-term disability</i>). Patients must have capacity for active treatments	SCI patients with persisting complex rehabilitation needs (<i>mostly with need of more than two therapies</i>), and need of medical supervision and nursing	SCI patients experiencing long-term disability and other health conditions	SCI patients experiencing long-term disability	SCI patients experiencing disability (<i>including incapability for work</i>)	
3.3. Service goals	Basic mobility (<i>indoor</i>) and independent self-care. Patients at discharge must be medically stable and meet admission criteria for postacute rehabilitation or treatment in nursing home	Independent living, optimal functioning, ability to work	Improvement and maintenance of functions and activities (<i>and participation</i>), treatment of diseases	Maintenance (<i>or improvement</i>) of functions and activities (<i>and participation</i>), treatment of diseases	Achieve optimal functioning	
3.4. Aspects of time	Acute and early postacute phase	(<i>Immediately</i>) after discharge from hospital (<i>or maximum one to 2 weeks later</i>), mostly for several weeks or months of treatment	3 to 6 weeks or (<i>in complex cases</i>) long-term treatments, mostly from 2 interventions per week or single visits	Very variable	3 to 6 weeks, treatment 5 days per week, mostly more than 2 treatments per day	
3.5. Intensity	High intensity (<i>two or more types of treatment, treatments 7 days per week, mostly more than two treatments per day</i>)	More than two treatments per day, mostly 5 days a week	Low intensity (<i>single treatments or visits</i>)	Low intensity, service on demand	More than two treatments per day, mostly 5 days a week	
3.6. Team structure	Interdisciplinary team structure with all professions involved in treatment process (<i>see 1.5</i>)	Interdisciplinary team structure with all professions involved in treatment process (<i>see 1.5</i>)	One or more professions	Single workers or team of community workers	Interdisciplinary team structure with all professions involved in treatment process (<i>see 1.5</i>)	
3.7. Mode of production	In-patient service in specially dedicated wards (<i>Acute Rehabilitation Unit; ARU</i>) as well as within ICUs and intermediate care units	In-patient service in specialized units	Out patient	Outpatient or home based	In-patient service	
3.8. Other categories of service delivery	Depending on technical equipment and team structure SCI patients with mechanical ventilation can be treated too	Services must be specialized for SCI	Referral systems to more specialized rehabilitation interventions needed	Referral systems to outpatient health services and more specialized rehabilitation interventions needed	Should be linked to primary care and vocational medicine	
MRI, magnetic resonance imaging.						

The number of rehabilitation centers specialized in SCI ranges from approximately 0.007/1 million inhabitants (Indonesia) to 0.8/1 million inhabitants (Portugal).^{24,25} In some countries, these specialized centers are exclusively run by the private sector (eg, Greece),²⁶ whereas in other countries, they are state owned (eg, Thailand or Portugal)^{24,27} or run by public insurance (eg, Norway).²⁸ There are also countries that have mixed systems of service funding and ownership (eg, Germany).²⁹ However, in some countries there are no specialized rehabilitation centers for SCI patients (eg, Korea or Israel).^{30,31} Often, the rehabilitation of SCI patients takes place in universal rehabilitation departments or in hospitals that are specialized in all phases of SCI care (eg, Poland or Italy).^{32,33}

Furthermore, it might be reasonably assumed that the length of stay in hospitals and postacute rehabilitation centers or units and the number of physicians specialized in SCI also vary to a great extent. Unfortunately, evidence-based data do not exist.

With regard to long-term care, the differences are also enormous. Whereas in Germany long-term care is mainly coordinated by family doctors with frequent referrals to specialists (eg, neurologists, PRM physicians) and prescription of PT and OT,²⁹ in Thailand, long-term care is mainly delivered by nurses and nonmedical volunteers.²⁷ In many countries, nongovernmental organizations play an important role in long-term care, too (eg, Indonesia or Israel).^{25,31}

In some countries, professionals who are seen important as part of a multiprofessional rehabilitation team are not trained or accredited. This occurs in particular in occupational therapy, which is not established in the education system in some countries (eg, in Egypt). The availability of vocational training for persons with SCI in some countries is well developed (eg, in Germany)²⁹ but is almost missing in others (eg, in Greece).²⁶

Thus, it can be assumed that care provision is highly dependent on the country in which a person lives. In general, owing to a different structure of health care systems and gaps in data collection, there is still a lack of useful information for a systematic comparison of national rehabilitation systems. For this reason, the need for collection of comparable data is of major importance to assess the differences in health and rehabilitation care for persons with SCI and to develop concepts of good practice.

Payment Systems

As mentioned before, the principles of payment for SCI rehabilitation services may vary according to the organization of health care systems. The sources of money could be as follows:

- Tax based (eg, national health care systems, regional governments, and communities)
- Contribution based (eg, health insurance, accident insurance, pension insurance, and others)
- Transfer payment (eg, in case of work accidents)
- Out of pocket (eg, by patients or families; as in Morocco)

The most frequent criteria or factors of payment can be as follows:

- Payment for the whole service
- Payment per case
- Per diem payment
- Payment per intervention

Of course, combinations of sources of money and payment criteria can be used; and in some countries, for different cases, different payment systems are applied. Furthermore, in some countries, unofficial payment systems are a reality, for example, paying cash for access to services or for single interventions.

Funding systems and payment criteria may influence service provision and the equity of service delivery. State payment systems in most cases lead to equal services for all patients. However, even here, inequalities are frequently observed (eg, different or no services for ex-patriots of migrants).³⁴ The same applies to insurance that, for example, can cover the whole service (needs oriented) or only parts of it. Additionally, there is variation in insurance status and cause of injury (eg, in accident insurances). The criteria of payment can also influence service provision. Payment in lump sums, for example, may decrease outcome orientations and intensity of care, whereas per-case payments may lead to shorter length of stay and services.³⁵

As another article in this series on service delivery has shown, comparable data on funding are missing. However, narrative descriptions of the rehabilitation care financing systems obviously show huge differences. For instance, in some countries, all inhabitants who reside in the country will be automatically registered to the single public health insurance (eg, in Sweden).³⁶ In other countries, the system of health insurance is very heterogeneous. In the United States, 64% have contracts with private health insurance, and 13% do not have any health insurance at all.³⁷ These differences have considerable influence on health care provision, as many doctors only accept insured patients in their practice. Furthermore, the catalog of interventions and the health-related outcomes (such as life expectancy after SCI) vary according to the insurance covering.³⁸ With regard to cost-reward system, different systems might be applicable even within the same country. For example, in Germany, in acute care, a diagnosis-related payment system is applied; in rehabilitation, the principle of per diem payment is used; and in long-term and outpatient care, the payment is given per intervention.^{21,39,40} Lack of public funding of rehabilitation may also lead to insufficient care provision. In Greece, for instance, owing to the present crisis of state finance, only approximately 25% of existing rehabilitation beds are in use.²⁶ However, it can be assumed that the variety of funding principles has effects on health care provision.

DISCUSSION

In the WHO documents and experts consensus papers, a strong consensus exists that for patients with SCI, in addition to timely and highly qualified first interventions, rehabilitation services must be provided for all patients. These services must be provided in the acute, postacute, and long-term phases and should be delivered by well-trained health professionals working in multiprofessional teams. These services can be described according to the setting, technical and human resources, service goals, and other parameters. For comparison and service planning, the use of a matrix with the dimensions "acute, postacute, and long-term care" and "primary, secondary, and tertiary levels of health care" is applicable and suitable. The proposal of an International Classification of Service Organisation on Rehabilitation (ICSO-R) may be a useful tool

to systematically describe rehabilitation services.^{15,17} It can be also used to describe model services that should be implemented if these services do not yet exist.

Narrative descriptions of rehabilitation services in different countries suggest that the variety of service provision for persons with SCI is huge. The variety involves the number of specialized services and personnel, the length of stay in rehabilitation units, and the payment system as well as the coverage of costs for the individuals in need. However, in most countries, at least some acute rehabilitation services exist in tertiary level hospitals, and postacute services are implemented at the secondary level. A large variety of options can be seen in the provision of long-term rehabilitation services that are not well defined in many countries. The spectrum of service models ranges from community-based services to primary health care centers to specialized rehabilitation units delivering intermittent in-patient rehabilitation services.

This variety shows the need for a normative approach to describe model services that can be used as references for comparison and as good practice examples for service planning and implementation. Definitions are a precondition for the evaluation of outcomes of rehabilitation services, and research on this is vital for the development of rehabilitation services guidelines.

To address these issues, a systematic analysis of the provision rehabilitation services and the related funding system is required using uniform assessment and evaluation tools. The International SCI Survey (InSCI) and the Learning Health System for SCI will provide data that can contribute to a clearer picture on factors for a good rehabilitation service provision for SCI.^{41,42} Additionally, it is recommended to apply the International Classification of Service Organisation in Rehabilitation (ICSO-R) in a stakeholder dialog or similar approach to evaluate its applicability and to develop model services.

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The Cross-Cultural Societal Response to SCI

Health and Related Systems

Diana Pacheco Barzallos, PhD, and Mirja H. Gross-Hemmi, PhD

Objective: The Learning Health System for Spinal Cord Injury (LHS-SCI) is an initiative aligned with the World Health Organization's (WHO) Global Disability Action Plan. Based on the outcomes of this initiative, countries will be able to shape their health systems to better respond to the needs of persons with SCI. This paper describes and compares the macroeconomic situation and societal response to SCI across 27 countries from all 6 WHO regions that will participate in the LHS-SCI initiative.

Methods: A concurrent mixed-methods study was conducted to identify key indicators that describe the situation of persons with SCI, the general societal response, the health and rehabilitation system, and the experience for a SCI person after discharge from inpatient rehabilitation.

Results: A strong correlation was found between the efficiency of a healthcare system and the amount a country invests in health. Higher availability of resources does not necessarily imply that unrestricted access to the healthcare system is warranted. Variations in the health systems were found for various domains of the health and rehabilitation systems.

Conclusions: The evaluation and comparative analysis of the societal response to SCI raise the awareness of the need of more standardized data to identify current needs and gaps in the quality and access to SCI-specific health system.

Key Words: Spinal Cord Injury, Data Collection, Qualitative Research, Macroeconomic Factors

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The highest attainable physical and mental health, independent living, and full participation in all aspects of life are basic rights for all people, irrespective of their sociocultural background or physical or mental health status. These and other human rights are guaranteed by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD).¹ The environment in which a person lives and his or her experience with it play a crucial role for community participation as it has the power to "enable" or "disable" a person in the light of a chronic health condition.² To facilitate the attainment of these basic human rights, States that have ratified the CRPD are obliged to target the social environment persons live in and rely on, including the social environment governed by the health and social policy.

The Learning Health System for SCI (LHS-SCI), which is aligned with the World Health Organization's (WHO) Global Disability Action Plan 2014–2021 "*Better health for all people with disability*," foresees the continuous improvement of the lived experience of people living with spinal cord injury (SCI).³ The initiative consists of three interlocking phases: (1) evidence generation from an international community survey and combined description and analysis of the societal response to the needs of persons with SCI, (2) use of policy

briefs and stakeholder dialogues as implementation tools to bring the evidence before relevant stakeholders, and (3) research and policy capacity-building. These three phases will jointly achieve the LHS-SCI mission of continuous improvement of the lived experience of people with SCI, through identifying unmet needs and policy options to meet these needs, by means of an international evidence- and rights-informed research and policy effort.

A key feature of the LHS-SCI program is to make it possible for countries to learn from each other's experiences, successes, and failures, and to remodel their healthcare and rehabilitation systems to better respond to the need of persons with SCI. This can also be summarized as "*The Societal Response to SCI*"—namely all state actions and inactions that have a direct impact on people's lives and their lived experience of SCI. As emphasized in the *International Perspectives on Spinal Cord Injury* report (IPSCI report, 2013),⁴ health system responses have a tremendous impact on the health outcomes of mortality, morbidity, and functioning as they provide not only healthcare and rehabilitation services but also social assistance and opportunities in education, employment, and other areas of life.

Inadequate or insufficient responses to the needs of SCI persons have been reported in many countries, and this has resulted in poorer health outcomes, reduced quality of life, higher incidence of poverty, and restricted participation and increased dependence on social resources of SCI persons.^{4,5} For this reason, an in-depth evaluation of the current structure and function of health systems at the national and comparative international level is important to lay the evidentiary basis for a better understanding not only how these systems work but also where and how to intervene to remodel them to meet currently unmet needs and to thereby improve health and quality of life outcomes for people with SCI.

From the Swiss Paraplegic Research, Guido A. Zäch Institute, Nottwil, Switzerland. All correspondence and requests for reprints should be addressed to: Diana Pacheco Barzallos, PhD, Swiss Paraplegic Research, Guido A. Zäch Institute, Strasse 4, 6207 Nottwil, Switzerland.

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The objective of this paper is to characterize and compare the manner in which health and rehabilitation systems operate in the context of SCI across the participating countries of LHS-SCI. This analysis is one of the first LHS-SCI programmatic steps towards the goal of generating evidence through a comparative analysis of the cross-cultural societal response to SCI. Micro data about the specific situation of each country comes from profiles where relevant information was collected about the socioeconomic situation of the country and, in particular, how the overall health system operates in the light of the lived experience of individuals with SCI. Because of data scarcity, country's specialists described the patient pathway in the health system just after discharge. The data collection includes information of 27 countries (as of December 2015) participating in the International Spinal Cord Injury (InSCI) community survey supplemented by macroeconomic information intended to give a snapshot of the situation, and the place each country has respect to others in the sample. Therefore, the aim of this study is twofold: first, to describe and compare the macroeconomic situation across 27 countries participating in the InSCI study; and second, describing the societal response to SCI across these countries. The macroeconomic analysis is required to set the scene to fully understand any potential impact the various health system states may have on the outcomes of the societal response to SCI. The macroeconomic indicators come from international sources such as OECD, World Bank, and WHO.

The overall goal of this paper is to identify patterns of unmet needs and gaps in health and health-related systems that can serve as the evidentiary basis for general guidance in the elaboration of specific policy recommendations designed to improve the systems that will be part of the policy implementation phase of LHS-SCI.

METHODS

Study Design and Setting

To fully capture the societal response to SCI across countries, we conducted a concurrent mixed-method study using a country template that covered both components of data collection and analysis, i.e., a quantitative component with closed questions that allows for numerical analysis and a qualitative component with open-ended questions and narrative sections that allows for a content analysis.^{6,7} To set the societal response to SCI into a wider perspective, data collection was supplemented by additional quantitative macroeconomic information. The sequence of data collection was aimed at identifying key indicators that describe the situation of persons with SCI, the general societal response in terms of a description of the health and rehabilitation systems, and the experience of a SCI person after discharge from inpatient rehabilitation. The mixed-method approach was favored because the sole numerical description of a country's health system (and especially the patient journey through the continuum of care) was insufficient to capture all aspects of the societal response and lived experience of SCI. The hallmark of this approach is that elements of the quantitative and qualitative parts complement each other, and this allows for a thorough investigation of the research topic rather than limiting it to a specific research method.^{8,9} Qualitative

data, captured through open-ended questions, give a direct view into a respondent's attitudes and beliefs,¹⁰ and these can give insights into complex issues where a predetermined set of responses or simply numerical tables may not do the job as informatively.^{7,11}

Data Collection

Using a methodological approach similar to that used by the WHO in its periodically published health system reviews,^{12,13} a country template was devised that included a comprehensive set of questions that gave the countries the opportunity to evaluate their national health and rehabilitation systems in general and with the SCI context in mind in particular. The country template consisted of 59 items of which 27 were closed and 32 were open-ended questions (see Electronic Appendix 1, <http://links.lww.com/PHM/A354>). The questions were developed using well-known general and SCI-specific health system indicators from various sources, such as the six building blocks of health system proposed by the WHO,^{14,15} IPSCI report,⁴ and OECD statistics.

In brief, the country template included questions intended to evaluate the following indicators: (1) health statistics on workforce and infrastructure; (2) basic SCI epidemiology data; (3) the lived experience of SCI, including accessibility to public buildings and transportation, employment situation and poverty prevalence, public campaigns for the prevention of SCI, and education achievement, access to health and rehabilitation services including assistive technologies, and workplace regulations on health and safety; and (4) general societal response to SCI through health and health-related systems (health system performance). Questions in this section considered the type, number, and description of the specialized care persons with SCI receive, such as specialized care facilities, healthcare coverage and disability-related social protection measures, national health strategies and campaigns, disability persons' organization, and specific laws for vocational integration. Finally, the last section (5) focused on the continuity of care after a traumatic SCI (complete/incomplete) with six predefined milestones: (1) injury, (2) rescue, (3) acute care—stabilization, (4) specialized centers, (5) rehabilitation, and (6) community and outpatient care. The questionnaire template provided detailed guidelines and examples needed to compile a reliable country report. To allow for comparison of the collected data across countries, the source and year of publication has to be indicated for each question.

The country template was sent to 27 countries (as of December 2015) that committed to participate in the International Spinal Cord Injury (InSCI) community survey.¹⁶ Covering all six WHO regions, these countries represent different cultural backgrounds and stages of economic development and hence give a unique insight into their societal response to SCI. Either the national leader, study coordinator, or any other dedicated person among the InSCI research team of the respective country filled in the template.

To supplement these data, we included a macroeconomic perspective, as the analysis involves a comparison across heterogeneous countries. As the healthcare system is a key element in the dynamics of a society, general socioeconomic characteristics of the population have a significant effect on

how that system functions. Also, characteristics of the social environment, such as the health and rehabilitation system and on a broader level a country's economic resources and distribution, create a background scaffold that may be determinative of the level of individual functioning.^{17,18} To better understand how all of these systems work and what the problems and potential gaps are, it is necessary to know each country's status in terms of production, employment, inequality, population growth, and finances. In that way, inequities and gaps in access to the health system may be detected in particular countries, which may then be hypothesized to account for reduced functioning, health maintenance, and wellbeing of persons with SCI.¹⁸

Data Extraction and Analysis

Quantitative Data

For the macroeconomic analysis of the countries, standard indicators related to the economic context (income disparities, general unemployment rate, and debt-to-GDP ratio), sociodemographic characteristics, and life expectancy/health system status were included.

Economic Context

Because of the heterogeneous characteristics of the 27 countries and to best describe the economic context, the income classification from the World Bank from 2012 was used: lower-middle (USD 1046 to USD 4126), upper-middle (USD 4126 to USD 12735), and high income (USD 12736 or more). This classification is based on estimates of the gross national income (GNI) per capita in US dollars, converted to local currency. To correct for income inequalities, the analysis includes the Gini coefficient, a popular indicator for income inequalities, which ranges from 0 (complete economic equality) to 1 (complete inequality).

Data on unemployment rates were retrieved from OECD data statistics. Debt-to GDP ratio is from the Trading Economics indicators webpage (2014). This ratio was used as a standard indicator to reflect the health of a country's finances. It shows, to some extent, the maneuver capacity, in terms of national income, a government has in case they need extra resources either because of an emergency requirement or to impose a long-term development agenda.

For comparability purposes, the analysis included data from the year 2012. For countries with missing observations, the study used the latest available information, which in very few cases was more recent data. The use of different years does not represent an issue for comparability purposes because all macro indicators, within a country, do not show great variability over time. The majority of internationally performed studies (e.g., WHO, World Bank, OECD), using the same type of indicators, employ different sources and years of data. In general, at macro level, exogenous and/or endogenous shocks will have a temporal effect in the economy that could take several periods to show an effect in the global indicator.

Demographic Characteristics

Three indicators were used to describe the composition and trends of the population to capture the demographic characteristics of the InSCI countries: the fertility rate, the

percentage of the elderly population, and the population level. These data were retrieved from the UN's biennial World Population Prospects.²² By contrasting the fertility rate with the elderly population and weighting them by the population level, a proxy of the growth and replacement rate of the population is obtained.

Health System Status

Healthcare coverage (WHO Health Statistics, 2013) was compared to out-of-pocket expenditure (OECD data) as this composition better estimates the extent to which households depend on their income in case of a health event. This was done as healthcare coverage does not take into account the accessibility level in terms of financial possibilities or physical barriers. In fact, healthcare coverage mostly reflects the situation of the general population, but is detached from the actual use and quality of the services.

Age-standardized disability-adjusted life years (DALYs), an indicator to measure the burden of one year lost of healthy life, shows the gap between the current health and the "ideal" status. DALYs are computed at a global level and, for comparability purposes, by different diseases. Because DALYs are sensitive to differences in a populations' growth and age composition, age-standardized DALYs were used for the comparative analysis across countries.

In the macroeconomic analysis, scatter plots were produced to highlight important patterns. In case of a marked correlation, the graphs included a smooth line. All graphs were constructed using STATA 12 (College Station, TX).

Qualitative Data

We used documentary analysis as strategy for analyzing the qualitative data on the societal response to SCI in the country templates.⁷ For this, each country template was thoroughly reviewed, and data were entered into a database. For the qualitative data, a coding protocol was established to aid transparency and reduce inter-rater variability.^{6,19,20} In a next step, data were a priori grouped according to themes based on the IPSCI report recommendations⁴ and WHO's six building blocks of the health system¹⁴ to crystallize information about the societal response to SCI and health system performance across countries.²⁰ The data was clustered as follows: global epidemiology of SCI, long-term rehabilitation systems and services and associated integrative measures (vocational rehabilitation and education programs), access to assistive health technology (AHT) and infrastructure and transportation, and health system performance (financing, social protection measures and financing, community care, and government). This categorization allows for the standardized comparison of different health systems based on commonalities, differences, and the identification of gaps in the health systems. Double data extraction was performed, and for nondescriptive categories (e.g., epidemiological data), additional literature review was done so that no important information was missed. Disagreement between coding was intensively discussed between DPB and MGH until consensus was reached. For each country report, the national team was contacted if disagreement could not be resolved by the authors. Of note, rehabilitation systems are described on a macro level in this paper. A detailed analysis

TABLE 1. Countries by income group

Income Group	Country
Lower-middle income economies (USD 1046 to USD 4126)	Indonesia (IDN), Morocco (MAR)
Upper-middle income economies (USD 4126 to USD 12,735)	Brazil (BRA), China (CHN), Malaysia (MYS), Mexico (MEX), South Africa (ZAF), Thailand (THA)
High-income economies (USD 12,736 or more)	Australia (AUS), France (FRA), Germany (DEU), Greece (GRC), Israel (ISR), Italy (ITA), Japan (JPN), Korea (KOR), Latvia (LVA), Lithuania (LTU), Netherlands (NLD), New Zealand (NZL), Norway (NOR), Poland (POL), Portugal (PRT), Spain (ESP), Sweden (SWE), Switzerland (CHE), United States (USA)

Source: World Bank (2012 classification).

of the rehabilitation system based on the templates is reported elsewhere in this issue.²¹

RESULTS

For the macroeconomic analysis, data from all 27 countries were available. For the description of the societal response, data from 18 country templates were available and analyzed.

Country Characteristics (Macroeconomic Perspective)

Economic Context

Income Disparities

The economic context varies widely between countries (Table 1). Countries in the high-income group reported an average income per capita of USD 37,258, and those in the lower-income group reported almost five times less (USD 8235).

As income per capita does not allow any conclusions on income distribution as it only reflects the “average” individual in a country, the Gini coefficient was used to give a more

detailed picture of income disparities. Figure 1 shows the distribution of the InSCI countries according to their GDP per capita and Gini coefficient. The numbers suggest important differences between and within income groups, with a strong pervasive effect of inequality on economic growth. For example, countries in the high-income group have a more equal income distribution, and at the same time this group has the highest level of income per capita. Within income groups, Norway shows the highest level of income and the most equal distribution. In contrast, the USA with a lower income level shows the highest level of inequality in this group. The income distribution in the USA is comparable to China (upper-middle income country), and it is more unequally distributed than in some lower-income countries like Indonesia or Thailand. Similarly, in the upper-middle income group, countries with comparable income levels, such as Thailand, Mexico, and Brazil, show significant variations in their income distribution. The highest income disparity is found in South Africa. Even though the country is classified as upper-middle income, it shows the highest level of inequality among all countries. This result suggests that most of the country's income is in a few hands

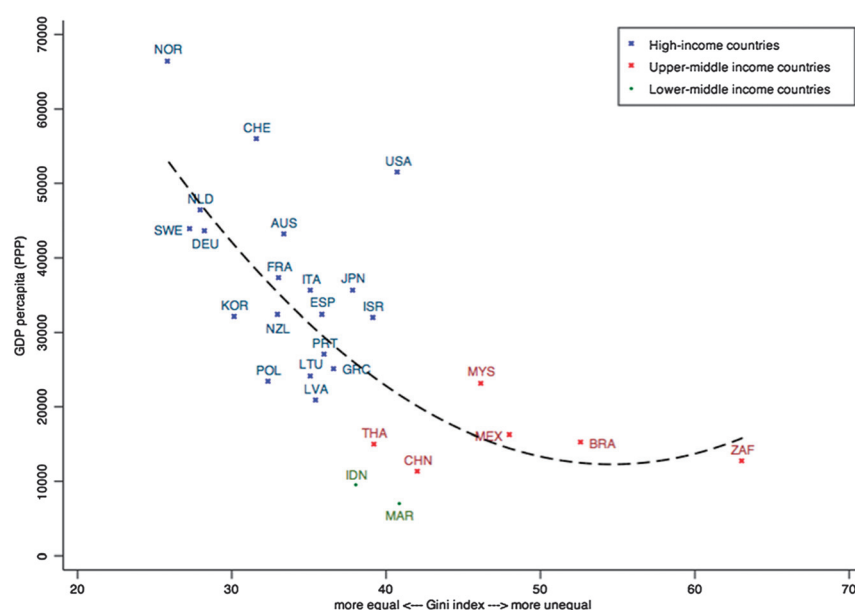


FIGURE 1. GDP per capita and Gini index (source: World Bank, 2012). Notes: The GDP per capita is in PPP terms (purchasing power parity). The PPP GDP is the gross domestic product converted to international dollars using PPP rates. The information for NZL corresponds to 2011.

and a greater part of its population is still poor, which may have an important impact on health outcomes.

General Unemployment Rate

The unemployment rate significantly varies among income groups (Fig. 2). It is important to emphasize that after the 2008 economic crisis, this rate dramatically increased worldwide with a strong impact on the most vulnerable groups: young people and older individuals. Countries like South Africa, Spain, and Greece reported unemployment rates close to 25% of the active population. Interestingly, lower-income groups showed significantly lower unemployment rates; however, these numbers should not be overinterpreted as they strongly depend on the type and quality of employment in each country. For example, Thailand reported the lowest unemployment rate (0.7%), and this result may be explained by the composition of its productive sector. Thailand's economy relies on international trade, and most of the active population is employed in the agricultural sector, a structure which made the country considerably less vulnerable to the latest worldwide crisis.²³ Among the wealthy countries, Norway has the lowest rate of unemployment rate with 3.2%.

Debt-to-GDP Ratio

The International Monetary Fund (IMF) suggests in their policy rule recommendation that a prudential limit for a debt-to-GDP ratio should not pass the 60% level in developed economies and 40% in developing economies—otherwise, the fiscal sustainability in a country may be threatened.²⁴ As the results suggest, few economies comply with this rule. Figure 3 suggests that most of the high-income countries are heavily indebted, and most of the lower-income economies have an important portion of their income compromised. Japan, for example, has accumulated debts 2.3 times its total yearly income. The same applies to Greece, Italy, and Portugal, countries that

would have to allocate more than their entire yearly income to repay their debts. The USA, Spain, and France are almost in the 1-to-1 limit. In contrast, Norway and Indonesia are countries with a low debt-to-GDP ratio, which is close to 20%.

Sociodemographic Characteristics

The Population Department at the United Nations suggests that an optimal replacement-level fertility of 2.1 children per woman is needed. This number represents the average number of children a woman would need to have to reproduce herself by bearing a daughter who survives to childbearing age. If replacement level fertility is sustained over a sufficiently long period, each generation will exactly replace itself in the absence of migration.²⁵ Consequently, countries with a high share of old population and a low fertility rate might face serious problems in the long run, especially in terms of developing strategies to finance their budgets. In fact, a growing old population implies a steady increase in the pensions and health costs. This situation requires, at the same time, a steady increase in the working population, which a low fertility rate does not guarantee. If continuing with this pattern, the next generations might face serious financial problems, which can be either solved by a reduction of the pensions, a more restrictive use of health services, or an increase in the working population by other means, such as a relaxation of the migration regulations.

Within the InSCI countries, Japan seems to have a growing problem because almost one in every four people is over 64 years old (Fig. 4). At the same time, the country has one of the lowest fertility rates, with less than 1.5 children per woman. A similar situation, at a lower scale, can be observed in most of the countries in the high-income group. In contrast, the upper-middle income group still shows acceptable rates for population replacement. However, it is important to keep track of their fertility trends: most of the countries in this group have relatively low old populations, but they still show rather low

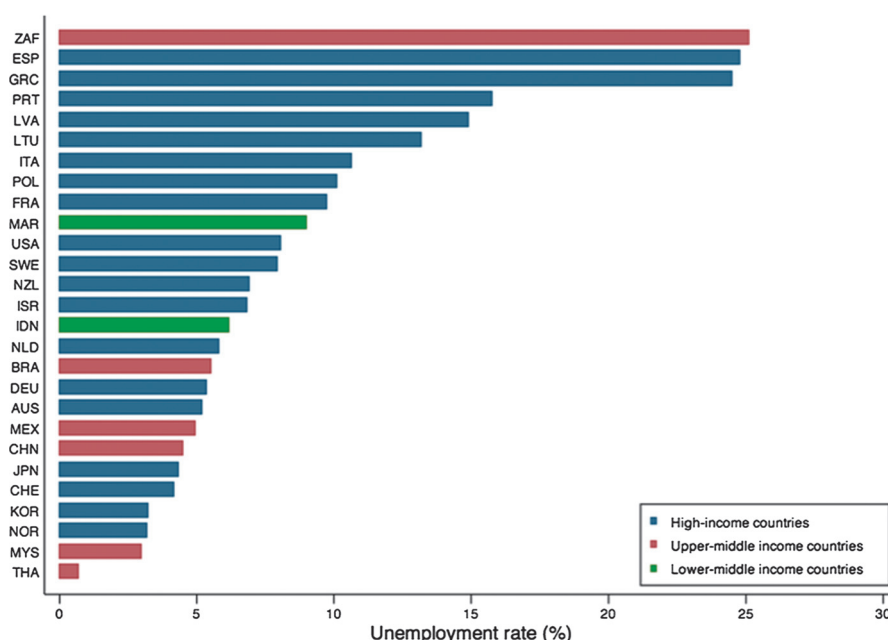


FIGURE 2. Unemployment rate (source: OECD statistics, 2012).

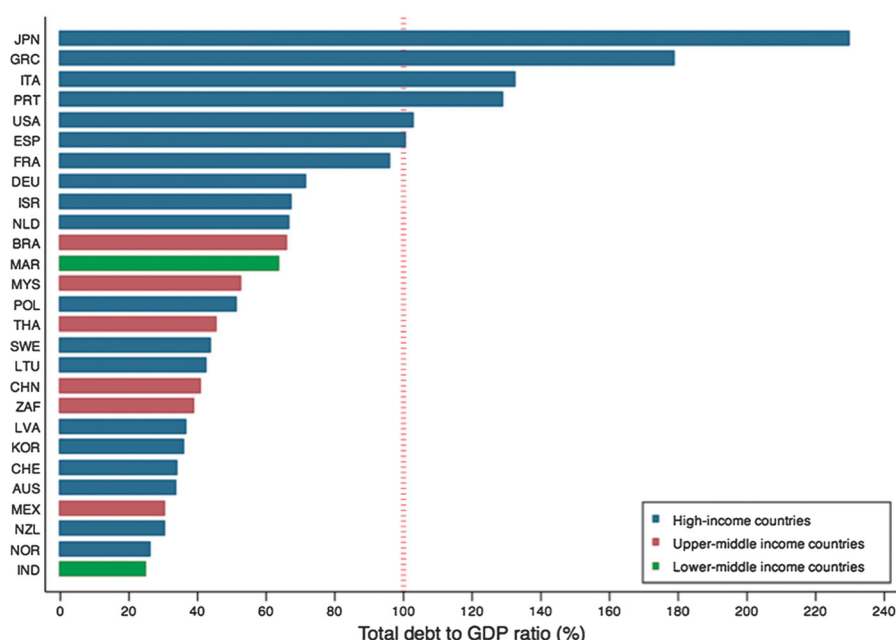


FIGURE 3. Debt-to-GDP ratio (source: Trading Economics webpage, 2014).

fertility rates, with the exception of Israel, a country that reported a low share of elderly population and a high fertility rate (3 children per woman). Finally, lower-middle and low-income countries show growing populations with a low number of old people.

Health System Status

Expenditure on Health and Life Expectancy

There is a strong positive correlation between public health expenditure and life expectancy at birth of the population (in years) with important variations among income groups

(Fig. 5). In high-income countries public expenditure on health varies between 3.5% (Latvia) and 10% (the Netherlands), in upper-middle income countries it does not exceed the 5% cut-off, and in lower-middle income countries less than 2% of the GDP is spent on public expenditure on health. In terms of life expectancy, the population in high-income countries lives around 80 years, with Japan having the highest and Latvia the lowest life expectancy. For the rest of the income group, life expectancy fluctuates around 75 years with one exception: South Africa has the lowest life expectancy with 57 years, where 19.1% (2013) of deaths were caused by tuberculosis, influenza, and pneumonia (top leading natural

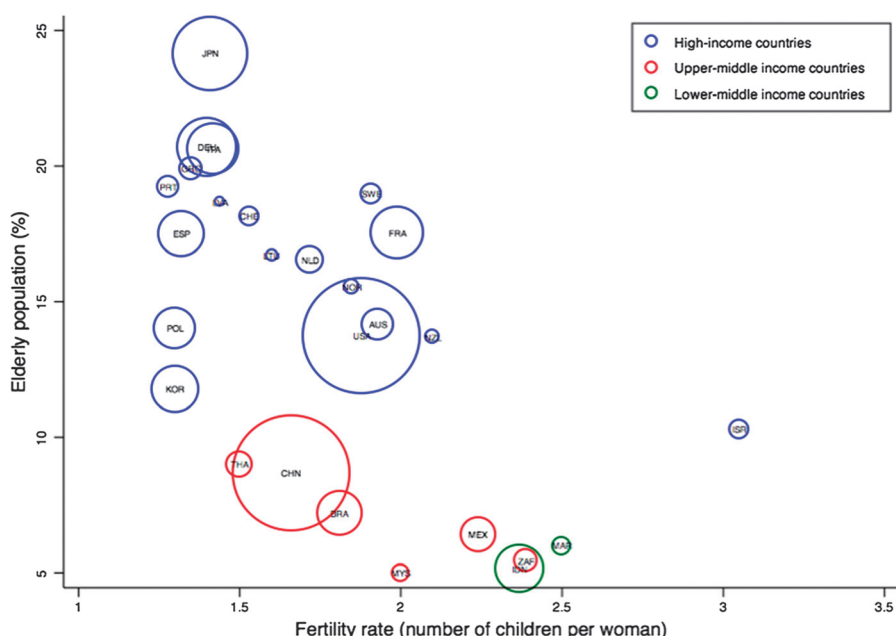


FIGURE 4. Sociodemographic composition (source: OECD statistics, 2012). The size of the circles correspond to the population size in each country.

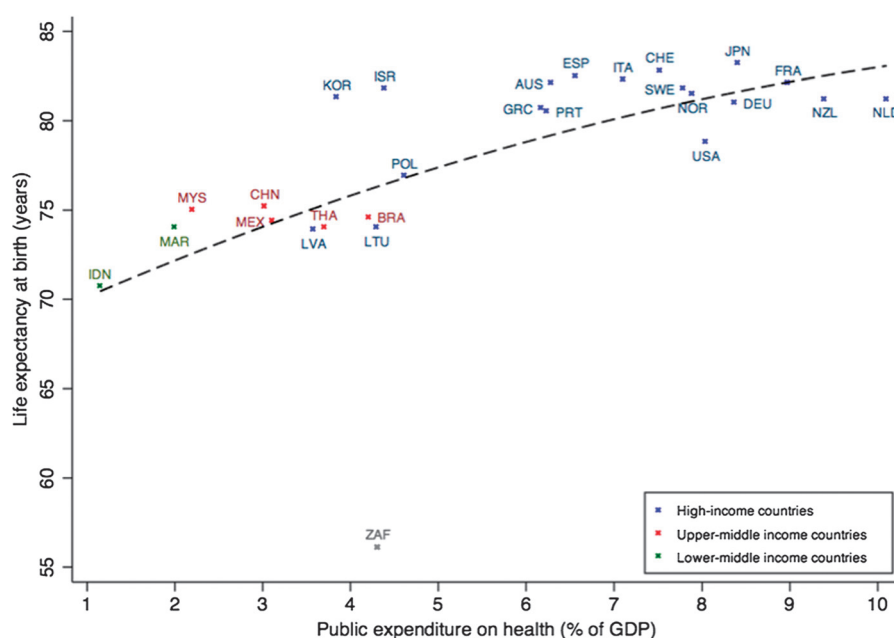


FIGURE 5. Life expectancy and public expenditure on health (source: OECD statistics, 2013. World Bank for Malaysia and Thailand).

causes of death). Among the non-natural causes, South Africa shows high rates of violence crime and accidents deaths.²⁶

Healthcare Coverage

In the InSCI country sample, most of the developed or high-income countries exhibit healthcare coverage rates close to 100%, with the exception of Greece (79%) and the USA (88.5%, Fig. 6). Within this group out-of-pocket expenditures were highest in Korea (36.6%) and Latvia (36.5%). Upper-middle income countries show, in general, high rates of coverage, with South Africa (84%) having the lowest coverage. Out-of-pocket expenditures were also highest in this country

together with Mexico (44.1%) and Thailand (42.6%). Finally, lower-middle income countries show the lowest level of coverage and the highest participation of households in their health expenditures. Morocco, for example, has an estimated healthcare coverage below 40%, and households have to pay almost 60% of their health expenditures. The same applies to Indonesia with coverage close to 72% and an out-of-pocket expenditure of 45.8%.

Age-Standardized Disability-Adjusted Life Years (DALYs)

The analysis between age-standardized DALYs and public expenditure on health reveals a marked negative correlation

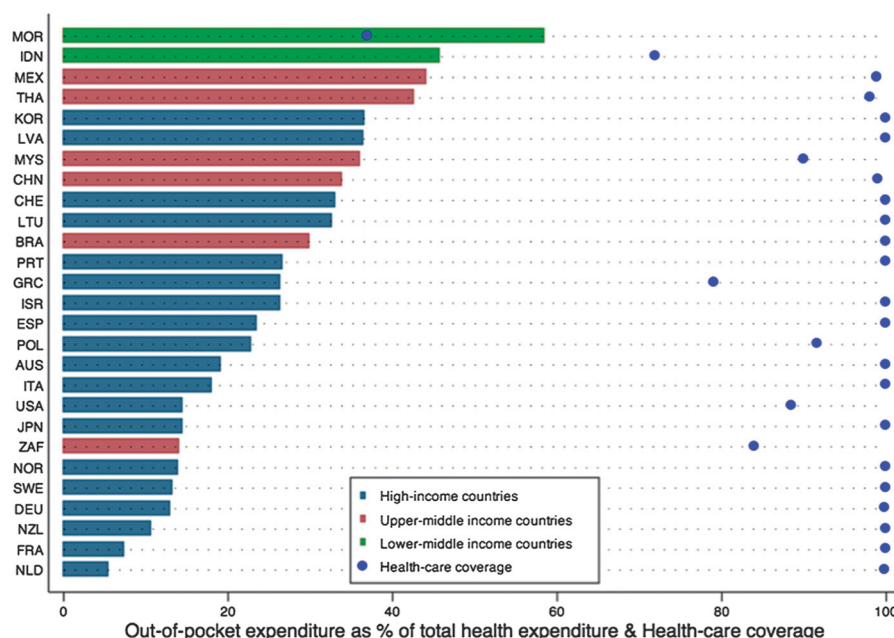


FIGURE 6. Out-of-pocket expenditures and healthcare coverage (source: OECD statistics, 2013).

with greater variability between income groups than within groups (Fig. 7A). High-income countries show generally significant lower age-standardized DALYs compared to lower-income countries, with the exception of South Africa, a country with similar expenditure on health as Brazil but with a more than twice as high age-standardized DALY (60.6). Also, the correlation between age-standardized DALYs and the Gini index yielded a marked result indicating that countries with high inequalities tend to have a higher loss in the years of healthy life because of a disability (Fig. 8A).

When adjusting for injuries, similar results are observed. The correlation between age-standardized DALYs and expenditure on health remains similar (Fig. 7B). Age-standardized DALYs, however, increase when correlated with the Gini index and adjusted for injuries (Fig. 8B). For example, inequality has a stronger negative effect on people with a disability as a result of an injury than people suffering from other diseases. From a global perspective, however, the estimated DALYs for injuries represent a small part in the global indicator (Fig. 9). Interestingly, all InSCI countries, with the exception of Mexico,

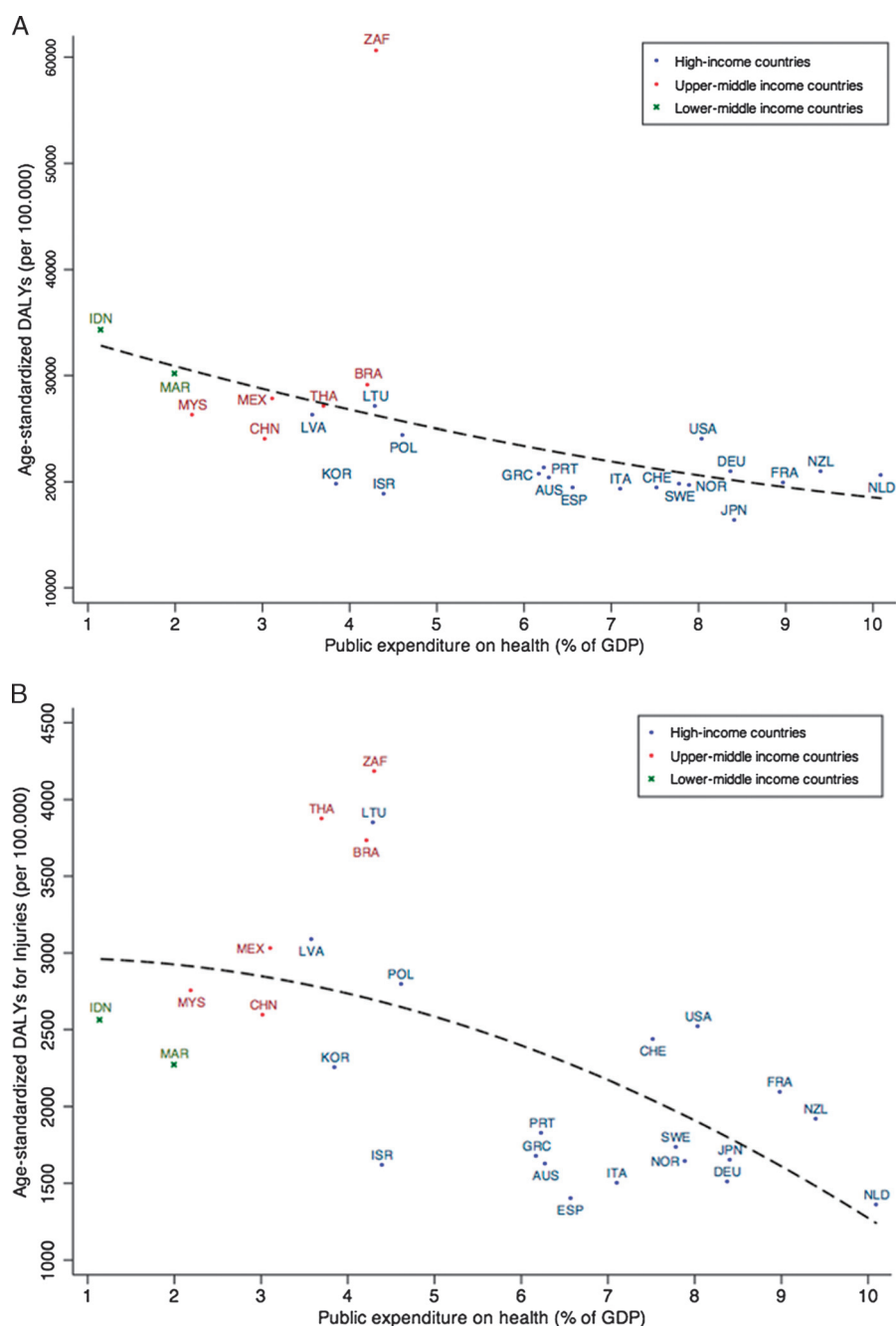


FIGURE 7. A, Age-standardized DALYs and expenditure on health. B, Age-standardized DALYs and expenditure on health, adjusted for injuries. (Source: Institute for Health Metrics and Evaluation. Global Burden of Disease Study 2013).

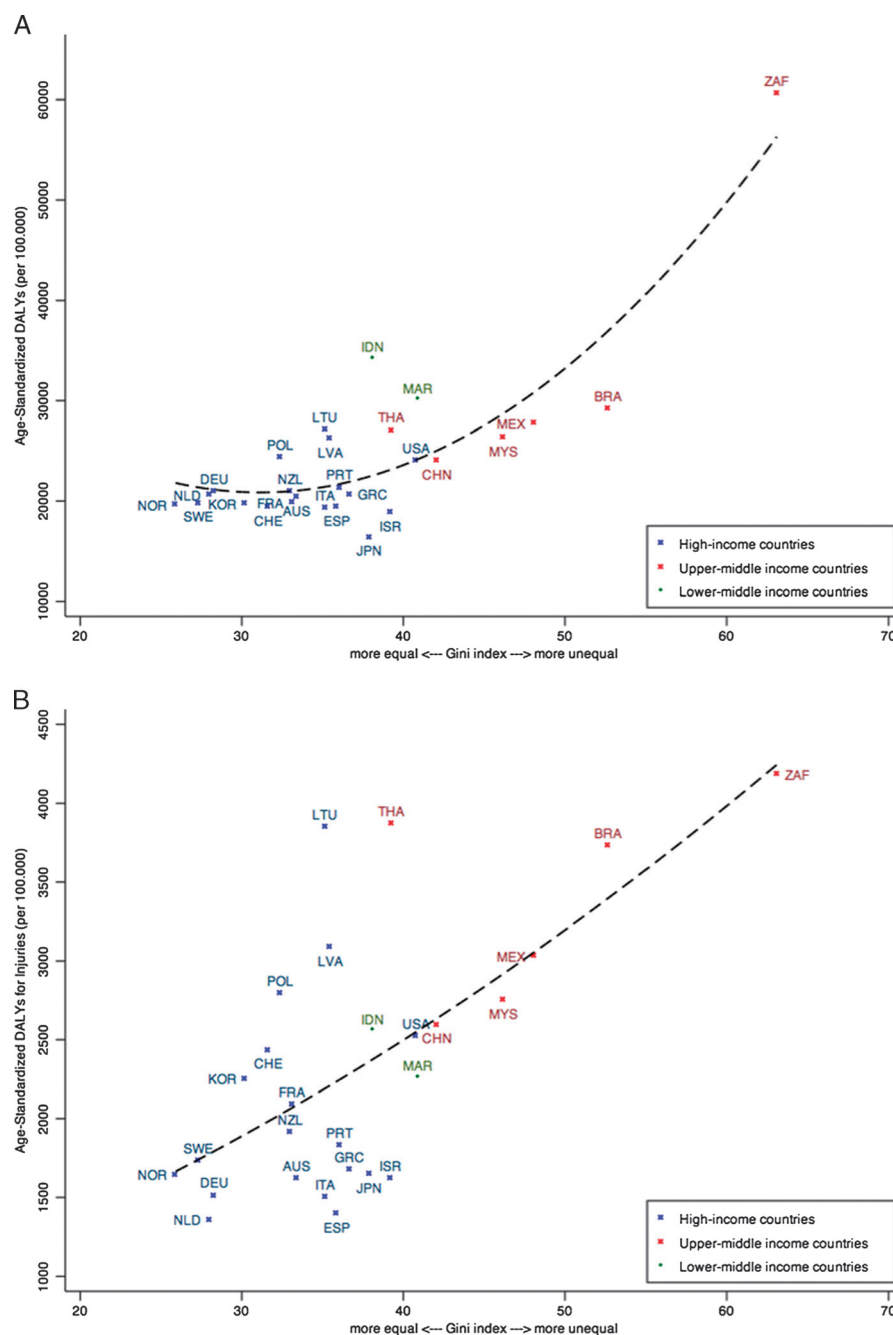


FIGURE 8. A, Age-standardized DALYs and Gini index. B, Age-standardized DALYs and Gini index, adjusted for injuries. (Source: Institute for Health Metrics and Evaluation. Global Burden of Disease Study 2013).

improved their DALYs between the period 2005 to 2013. In the case of Mexico, the age-standardized DALYs for injuries increased in more than 5% in that period.²⁷

A Global Picture on the Epidemiology of SCI of the Participating InSCI Countries

Epidemiological data on SCI are important proxies for gauging health services demands and social support and to inform policy- and decision-makers.^{4,28} By assessing prevalence and incidence of SCI and causes and long-term consequences

on the lives of persons, prevention strategies can be formulated and health services can be shaped according to the needs.

The global epidemiology of SCI has been recently described in various systematic reviews.^{4,29–36} However, data sources, publication dates, and methods to capture the epidemiology of traumatic and nontraumatic SCI vary greatly in the countries making it difficult to compare them and draw conclusions. Data on prevalence of SCI is scarce and does not allow for a global estimate.³⁶ Traumatic SCI prevalence rates for four InSCI countries are reported and range between 906 per million (USA) and 250 per million (France, Rhone-Alpes

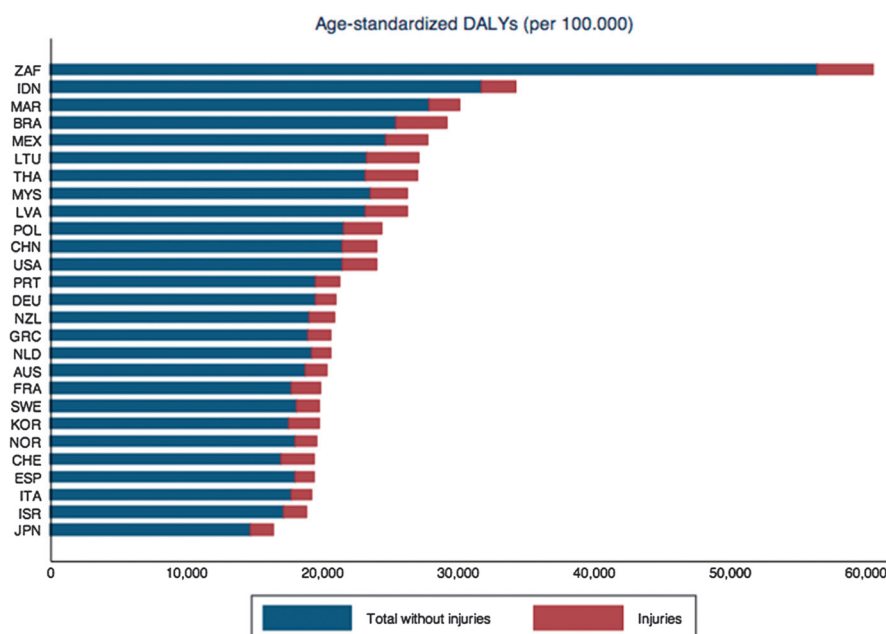


FIGURE 9. Age-standardized DALYs and injuries, global indicator (source: Institute for Health Metrics and Evaluation. Global Burden of Disease Study 2013).

Region).²⁹ In terms of nontraumatic SCI, there is no reliable data on the prevalence of the participating InSCI countries. Figures on the crude annual incidence of traumatic SCI greatly vary across the InSCI countries and range between 10.7 (Germany) and 75.6 (Cape Town, South Africa) per million population.^{32,33,36,37} Causality greatly varies across the countries, but data suggest that traffic-related accidents (13–75%) and falls (12–59%) were the primary causes for a traumatic SCI across nations.²⁹ Little is known about commonalities in incidence and causality of nontraumatic SCI as they greatly vary among the WHO regions and country income level.^{4,34}

Mortality and life expectancy are key indicators for individual health after SCI.^{4,30} For example, in-hospital mortality can be used as a proxy to assess the performance and quality of a country's healthcare system (e.g., timely emergency services response, capacity problems, or availability/unavailability of timely critical medical interventions and rehabilitation). As mortality and life expectancy usually vary between etiology, lesion level and severity, and associated comorbidity, it may be difficult to compare mortality rates among the different InSCI countries.³⁰ Data on mortality and life expectancy are restricted to some countries during acute phase and after rehabilitation. As reported by a recent meta-analysis, there is considerable variation according to the six WHO regions and country-income level with a reported in-hospital mortality ranging between 1.1% (Germany) and 26% (Brazil).³⁰

The Societal Response to SCI

Long-Term Rehabilitation

The extent to which health systems engage in a life-long care perspective and the rehabilitative success of a patient not only depends on the system's budget and availability of resources but also on other factors, such as physical accessibility, social inclusion, and communication of different health providers.^{5,38} Therefore, considering the variations of the

macroeconomic analysis, it is not surprising that a great variety of long-term rehabilitation approaches exist across countries. Depending on the structure and availability of resources of the respective national health systems, long-term rehabilitation services may include different personnel, such as medical assistants, nurses, physicians, or specialists. To allow for a crude comparison among the InSCI countries, long-term rehabilitation was continuously rated as *no long-term rehabilitation* with patients discharged home without regular check-ups of their health status and living situation to *comprehensive long-term rehabilitation*, which includes long-term rehabilitation services with regular check-ups by a specialized team.

In Indonesia, Malaysia, Thailand, Israel, and South Africa, no standardized long-term rehabilitation schedule after discharge from in-patient rehabilitation is reported. Patients are usually discharged home with the possibility of visiting primary care providers or local hospitals, which depends on the location and service availability. For patients without access to a service, like in Indonesia, the health system accommodates for regular home visits of nurses or health volunteers. Only patients with severe chronic conditions are rehospitalized in more specialized centers where they are regularly monitored.

The USA, Korea, Portugal, and Greece described a more structured long-term rehabilitation approach that integrates more specialized SCI units in the long-term care of SCI patients that is associated to a higher availability of physical and monetary resources. Most of the countries in this group refer their patients to general hospitals or specialized centers (the USA) equipped with trained personnel and technology for long-term rehabilitation. In general, there is no predefined health provider in the follow-up stage, and the number and frequency of check-ups are case-based. Although long-term rehabilitation is in a more structured way, problems of accessibility and health insurance are reported. For example, patients holding Medicaid or Medicare insurance in the USA

are reported to experience disadvantages in terms of service delivery.³⁹

The third group of countries (Lithuania, Poland, Italy, and Spain) reported a long-term rehabilitation consisting of a number of predefined check-ups by the medical provider, which in most cases is at a specialized center. Depending on the person's needs, the frequency of routine monitoring can vary. Generally, the medical visits are more frequent within the first year and decrease over the second and third year. The objective is to keep track of the individual rehabilitation progress and adjust treatments if necessary.

Germany and Switzerland reported a long-term care perspective. Long-term rehabilitation of SCI persons consists of regular medical check-ups in either specialized SCI centers or general hospitals with rehabilitation units. Depending on the person's preferences, one of the two options can be chosen. In general, SCI centers and hospitals are easily accessible.

Finally, the Netherlands, New Zealand, and Norway reported having a well-defined and structured follow-up plan. Their health systems are organized under a life-long follow-up where people have specific scheduled visits. As in other cases, the schedule can be adjusted to the person's needs. Beside specialized health services, the follow-up stages include home and community support, and providers focus on a long-term rehabilitation process. Individuals remain under the care of the spinal team for the duration of their lives. The health system goal is the full inclusion of the person into social, family, and professional life.

Types of Rehabilitation and Services

Comprehensive rehabilitation requires a multidisciplinary team with multimodal interventions.^{38,40} Availability of specialized care units and services is, however, often not warranted especially in low-resourced countries, and other facilities and models, such as service provision by public hospitals, arranged home-care visits, or community-based rehabilitation, come into play instead.

Most of the analyzed countries provide physical and psychological assistance during post-acute and long-term rehabilitation. However, the delivery of these services depends on the provider and the availability of specialized personnel. Owing to important shortage of medical personnel,⁴¹ Indonesia, for example, relies on community-based rehabilitation for patients. Also, in other countries, such as Israel, Thailand, and Malaysia, rehabilitation services are offered, which are primarily delivered by public hospitals, the community, or occasionally the family. South Africa shows a very strict approach in the context of limited resources. Its health system offers the possibility of rehabilitation depending on the age, motivation of the patient, and potential benefits a patient could gain in the process. Admitted patients focus their rehabilitation on personal goals that could facilitate inclusion and participation in the society.

Spain, Italy, Poland, Greece, and Portugal have a more complete offer of rehabilitation services, which includes vocational rehabilitation and support for assistive devices. The availability of the services has, however, reduced their scope because of the economic crisis. It seems that countries affected by the economic situation have rearranged their priorities, with a special focus on the costs. For this reason, in some of these

countries, assistance and reimbursement of technological devices are not covered anymore. This has created a problem in terms of accessibility. SCI patients without a wheelchair can easily be left out of the entire system. In some cases, if patients have private insurance, they have access to a more complete rehabilitation package.⁴² Also in these countries, services are mainly provided by community-based rehabilitation.

Korea, Germany, Switzerland, the Netherlands, New Zealand, and Norway administer comprehensive rehabilitation services to their patients. Depending on the location, patients either receive rehabilitation in general hospitals or specialized centers. In both cases, adequate infrastructure and specialists exist to guarantee optimal treatment. Work reintegration, family, and community life are important goals of rehabilitation. Therefore, SCI persons receive assistance in vocational rehabilitation or training to adjust their lives to the new situation. Psychological and medical support is warranted either through medical personnel or online forums.

Vocational Rehabilitation

Vocational rehabilitation programs are designed to support persons with SCI to adjust their capabilities to their new condition towards reintegration into the labor market. According to related literature, vocational rehabilitation should start early enough to increase the chances of a patient to obtain and sustain employment. However, physical and emotional recovery of the patient should be considered in advance.⁴

Most countries with comprehensive rehabilitation include vocational rehabilitation as a key feature. Some countries even invest in training programs that help persons to adjust their work opportunities to their new condition. By contrast, in countries with financial constraints, reintegration to work is taken care of only in specific cases. In countries where rehabilitation programs are still in development, assistance for work reintegration is not considered part of rehabilitation.

Education

Education is a key feature to employment and social participation. Equal access to an inclusive education system is a task of the government, and it includes environmental adaptations, counseling, and other preparatory supports (psychological support).⁴

SCI persons in school age are likely to continue with their studies according to the country reports. Depending on the country, parents may apply for financial assistance to help their children stay in school. The attendance level and school attainment depend on environmental barriers (building access, availability of assistive devices, transportation) and on the attitude peers have towards people with disabilities. Problems with accessibility and stigma are important determinants of school dropout rates.⁴

Accessibility

Assistive Devices

Assistive devices encompass any equipment that increase, maintain, or help a person to perform a task or activity. The type of an assistive device depends on lesion level and associated comorbidities, environmental factors, and personal factors.⁴ According to the IPSCI report, wheelchairs, environmental

control systems, and computer technology seem to be the main assistive technologies used in persons with SCI.

The provision and maintenance of assistive devices vary widely in the InSCI country sample. In most of the cases, the unique device that is fully or partly reimbursed by the health insurances is a wheelchair. The provision of assistive devices depends besides the type (public or private) and coverage of insurance on the severity of injury and income level of the person. In countries with public health insurance provision, patients have, to some extent, access to basic devices. Most private insurances do not cover assistive devices in their health plans.

In low-income countries, the provision of assistive devices mostly comes from nonprofit organizations, and it is estimated that a great portion of people in need still cannot access any type of technological device. In special cases, for example, when a person falls under a predefined poverty line, the funding for assistive devices relies on public funding. In Malaysia, Thailand, and Indonesia, for example, the public health insurance does not cover assistive devices in their plans. However, for people depending on social security, the provision of a wheelchair is funded by the government.

In Israel, Poland, the USA, Korea, Spain, Lithuania, Greece and Portugal, selected assistive devices are fully or partly covered by the health insurance. In some cases, persons receive a wheelchair free of charge within a year after the injury. Some health insurances provide additional services, such as home retrofitting or car adaptations. However, the coverage depends on the availability of resources. After the 2008 economic crisis, most countries adjusted their budgets by reducing their health expenditures on this category.

Finally, assistive devices and services are almost fully covered by the health insurances in countries with long-term rehabilitation services (Germany, Switzerland, the Netherlands, New Zealand, and Norway). In these countries, persons usually need a prescription of a certified specialist to access a determined device. In cases where persons have copayments, patients' organizations provide advice and financial support.

Infrastructure Access and Transportation

Adaptations to infrastructure, like parking spaces, automatic doors, elevators, adapted toilets, pedestrian paths, and public transportation, to improve access and mobility of people with disabilities are still rare. The main flaw seems to be the disparity reported between urban and rural areas. Persons living in areas with poorly designed public transportation service (less frequent buses, long distances between stops, ramps, space for wheelchairs) are very likely to stay at home and eventually completely lose contact with others. In most of these cases, patients cannot continue with the rehabilitation process because of their dependence on others for transportation.

Thailand, Indonesia, South Africa, Malaysia, Israel, and the USA have adopted the principle of universal design in many of their public buildings. Nonetheless, most of these countries still report problems in the public transportation system. Portugal, Poland, Spain, Greece, Italy, and Lithuania report better infrastructure in urban areas, but claim that there is still room for improvement. Korea, Germany, Switzerland, the Netherlands, New Zealand, and Norway have made important

improvements in terms of infrastructure, but they face some accessibility issues in old buildings without possibility for modifications.

Health Services Finance Management

All countries included in the analysis reported having a mixed financing healthcare system, which includes private and public providers. In every country, private and public insurers are available. In some cases, like in Norway and the Netherlands, the system is heavily publicly financed, but people still access private insurers to improve specific services. In Italy, Germany, Spain, Lithuania, Poland, Greece, Portugal, Malaysia, and Thailand, despite having an important intervention of the government in the administration of healthcare, citizens still have access to private insurers. It seems that private insurers significantly reduce the waiting times, which improves the quality perception of the services. Korea and Switzerland can be located in the same group; still, people have high out-of-pocket payments to access healthcare services.

The USA has a mixed composition of its system, where the insurers are mainly private. Depending on the type of insurance, people can access a great variety of services. In contrast, Israel has a public system, yet in general access to specialists is better with private insurers. In South Africa and Indonesia, most people access the public system. Nevertheless, the restriction of resources makes the coverage deficient. Most people complain about the waiting times and the availability of providers. For this reason, at least in Indonesia, the healthcare system has put in a lot of effort to improve primary care services.

Pension and Funds

Every country in the sample reported having some financial aid for people with disabilities. Some countries support patients with a disability insurance, whereas others help patients with cash grants or in the provision of technological devices. Nevertheless, this aid is not always a permanent stream of resources and can vary depending on the economic situation of the country and the personal situation of a person: working capacity and other income sources. The USA and Indonesia, for example, have financial support, but the resources tend to be temporary. In the case of Israel, Lithuania, Poland, Greece, Portugal, and Spain, the resources are intended to cover the basic necessities of SCI persons, but in most cases the money is not enough for a living. In general, patients receive the money as long as they are not working, or they do not receive more than a defined income level. In countries such as Italy, Malaysia, and Korea, people receive financial support to prevent them from falling into poverty. In most of the cases, people are registered in social welfare. In Switzerland, New Zealand, Germany, and Norway, the financial support corresponds to a fixed percentage of the working salary before the injury. However, if individuals require additional financial aid, other monetary resources exist to support them.

In general, in countries where health insurance and accident insurance are available, patients show a better financial situation during and after rehabilitation. It is common that pensions and financial aid are much higher.

Community Care

Community organizations are a key element in raising awareness and providing support to people with disabilities. In most countries, these organizations are managed and administered by peers who have successfully overcome their new situation. These organizations focus on the participation of individuals in social, political, and educational activities, and only a few offer financial supports to their members. In some cases, where these organizations receive public funding, their work is also related to scientific research.

Thailand and South Africa did not report any association to support SCI persons, and they also face negative attitudes against people with disabilities. In most of the cases, individuals may stay isolated. In Malaysia, Indonesia, and Korea, patients' organizations work to reduce stigma in the society. In some cases, and depending on the organization, they also support persons in their reintegration to work. Israel has an important participation of social workers and veterans supporting SCI persons. In the rest of the countries, several organizations that support patients in different areas exist. In most of the cases, these organizations are privately funded, but in some others, the government provides some financial aid.

Government

Almost every country included in the analysis has had some kind of regulations governing injury prevention, especially related to transit laws. Because traffic accidents is the leading cause of SCI in most countries, legislations related to speed limits, risk awareness, and car controls have significantly increased in recent years. In addition, most legislation also includes specific regulation for accessibility of people with disabilities. In general, the law targets infrastructure and transportation. Finally, some countries have worked on legislation intended to reduce discrimination by increasing the employment options of people with disabilities. Despite great efforts, however, the enforcement of the law is problematic.

DISCUSSION

This paper describes and compares the macroeconomic situation and societal response to SCI across 27 countries from all 6 WHO regions that are participating in the LHS-SCI initiative and InSCI survey. Even though the structure, functioning, availability of resources, and priorities of a society significantly vary across countries, it is possible to draw some conclusions about the key elements that will increase the chances that a health system will improve the living situation of a person with SCI.

In general terms, and not surprisingly, there is a high correlation between the efficiency of a healthcare system, in terms of supply and quality of the services, and the amount a country invests on healthcare. Nevertheless, this relation fails when looking at population coverage. For example, a higher availability of resources does not necessarily imply that the entire population can access the healthcare system. In fact, there are high-income countries that claim a 100% coverage, but access to the system is still restricted. By studying the patient pathway country by country, it is possible to point to some flaws in the systems that hamper a successful inclusion into society. The

findings of this paper are in line with the IPSCI report and will be outlined as follows.⁴

- *Access to assistive technologies.* It seems that, despite great efforts, many systems fail to provide adequate assistive devices, which is a key determinant of the success of the rehabilitation process. Irrespective of the country income level, the provision of a wheelchair is not always part of the rehabilitation system and, in most cases and depending on the availability of insurance, people have to find ways to finance a wheelchair.
- *Infrastructure and transportation.* Access to assistive technologies has a significant impact on a person's autonomy. Yet, if the infrastructure and availability of transportation is deficient, the mobility of a person with SCI will be restricted to specific spaces. Ramps, elevators, and buses/cars conditioned to wheelchairs can have an enormous impact on people's lives.
- *Insurance availability and coverage.* SCI requires an efficient and specialized healthcare system. The medical treatment and later rehabilitation imply long-term care, which is costly. If a person with SCI has to find ways to finance the process on his/her own, it will be very likely that he/she will fail and give up rehabilitation. Most countries with a good public system seem to have better outcomes in terms of rehabilitation and reintegration into the society of persons with SCI.
- *Rehabilitation system.* If a person can access the rehabilitation system and financing is guaranteed, the next key element in the patient pathway is the availability of a specialized and multidisciplinary team. For middle- and low-income countries, board-certified specialized doctors are not always available. In the best-case scenario, most of the patients receive support of general doctors, and often nurses attend patients in community care.
- *Work and education.* The inclusion of people into society very much depends on the level of social interaction they have with their peers. Support to continue with work and education after an SCI event can be decisive for a successful rehabilitation. The involvement of community organizations or the direct intervention of the government by the implementation of regulations intended to reduce stigma, or by creating incentives to employers to hire individuals with SCI have significant positive effects on the lives of people with SCI.
- *Pension and funds.* Even when a person with SCI can successfully adjust to the new situation, he or she will always require a constant stream of resources. A person with SCI will incur in a number of expenses during their entire life because of their need of continuous medical and personal care. Even when they work, it is very likely that their incomes will be reduced, either because the amount of time they work is reduced or because they had to change of professional activity. When this occurs, additional monetary resources need to be available. Pensions run by the government or funds managed by patient organizations can help in this regard.

Limitations

There are some limitations in this research that warrant mentioning. The sample of countries analyzed in this paper is highly

heterogeneous so that a clear comparison was not practicable. To address this issue in the best possible way, countries with similar health system provisions were grouped together, which allowed us to draw conclusions on the societal response to SCI. Moreover, little is known about individual functioning profiles in the light of a country's economic situation, and data on healthcare utilization and unmet needs of persons with SCI are often difficult to obtain, particularly in low-income countries.^{4,18} Also, lack of data, inconsistent reporting, and different sources and years make it difficult to draw conclusions as stated by the IPSCI report.⁴ Data on the person's perspective of the lived experience will be collected by the InSCI community survey in 2017 in 28 countries. Thanks to this genuine start of data collection, data can be compared to health system variables (macroeconomic variables) to obtain a clearer picture of strengths and limitations in the health and related systems across countries. Finally, most data were retrieved through country templates, which are in most cases filled in by the national leaders of the InSCI study team. Although these data were collected in a systematic way through templates, we cannot exclude potential biased or missed information. To counteract this, general databases such as OECD, ISCoS, or World Bank and published articles and reviews were consulted to complete any missing data. Nevertheless, by the applied mixed-method approach and having the national InSCI study team describing their health system, we gained unique insight into their experience and perception of strengths and weaknesses of the health and related systems of their country.

CONCLUSIONS

Systematic evaluation and comparative analysis of the societal response to SCI on a global level is necessary to identify issues and gaps in the quality and access to SCI-specific healthcare and rehabilitation systems. Currently, data on SCI-specific healthcare services and demands have not been collected in a systematic way. This study tries to identify gaps and weaknesses in the healthcare system as it strives to further the inclusion of persons with SCI into the society. Although a high heterogeneity was observed, the results of this paper point to potential weaknesses in health and related systems in some countries. Together with the results of the InSCI survey, this analysis will provide the information required for Policy Briefs that set the ground for Stakeholder Dialogues, the second pillar of the LHS-SCI initiative.

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The Implementation Challenge and the Learning Health System for SCI Initiative

Gerold Stucki, MD, MS, and Jerome Bickenbach, PhD, LLB

Abstract: The paper introduces the *special issue* by linking the International Spinal Cord Injury (InSCI) Community Survey study to the Learning Health System for SCI Initiative (LHS-SCI). The LHS-SCI was designed to respond to the implementation challenge of bringing about policy reform in light of the targeted policy recommendations of World Health Organization's *International Perspectives on SCI* report as well as the call for action of WHO's *Global Disability Action Plan*. The paper reviews the components of LHS-SCI relevant to internationally comparable information, a theory of change to guide for action, and the tools for evidence-informed policy. The interplay between persons, their health needs, and the societal response to those needs provides the foundation for the organization of the LHS-SCI Initiative. Moreover, as the other articles in this *special issue* describe in detail, the rationale, conceptualization, and study design of the InSCI study are also informed by the rationale, and mission, of the LHS for SCI Initiative. The LHS-SCI, and the implementation challenge that motivates it, is responsible for the design of the InSCI study and the overall mission of LHS-SCI to continuously improve the lived experience of people living with SCI around the world through an international evidence- and rights-informed research and policy reform effort.

Key Words: Spinal Cord Injury, Data Collection, Questionnaire Design, Community Survey, Survey Methodology, International Classification of Functioning, Disability and Health

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On December 3, 2013 (the International Day of Persons with Disabilities), the World Health Organization (WHO) launched the International Perspectives on Spinal Cord Injury (IPSCI), a joint production of the WHO and the International Spinal Cord Society.¹ The aims of the IPSCI report were to assemble the best available evidence on SCI—epidemiology, services, interventions, and policies—and to bring that together with information about the lived experience of people with SCI as the basis for recommendations for action, consistent with the United Nations' Convention on the Rights of Persons with Disabilities.² Following the format and structure of WHO's World Report on Disability (WRD), launched 2 years before,³ IPSCI not only brought together the state of the art in SCI worldwide epidemiology and reviewed best practices in prevention strategies, health, and rehabilitation service needs and health systems reforms to meet unmet needs, it also delved deeply into domains of the lives of persons with SCI—relationships and adjustment, enabling environments, education, and employment. Like the *World Report on Disability*, IPSCI makes recommendations about that experience (Fig. 1).

The IPSCI and the WRD face an implementation challenge. As the United Nations agency for health, the WHO has an extensive regional and country-level dissemination network to distribute these reports, and it can bring the world's attention to the recommendations they make. Yet, these efforts have proven to be insufficient to bring about at the levels of both policy and practice, reforms that implement the recommendations. It is challenging to find, evaluate, and analyze the best evidence and use it to create recommendations that are relevant and feasible. However, it is even more challenging to bring about change, to make a difference, by implementing the recommendations at the country level. Changing clinical practice with evidence-based clinical guidelines is hard enough. More difficult is implementing recommendations of a global report like IPSCI and WRD: recommendations that are multisectorial, that affect both policy and practice, require coordination between administrative levels, demand buy-in from a wide range of stakeholders, and require change in behavior.

Nonetheless, this is precisely the motivation behind WHO's Disability Global Action Plan 2014–2021.⁴ Focusing on the primary objectives of removing barriers to health services, strengthening rehabilitation and enhancing capacity to collect relevant and internationally comparable disability data, the *Action Plan* mandates WHO to identify concrete actions that can realistically achieve these objectives. The *Action Plan* is a call to meet the challenge of implementation.

The Challenge of Implementation

As a general matter, there are three requirements presupposed by this implementation challenge: there is a need for *information*, for a *theory of change* that can structure the implementation project, and for practical *implementation strategies and tools*.

From the Department of Health Sciences and Health Policy, University of Lucerne, Lucerne, Switzerland; and Swiss Paraplegic Research, Nottwil, Switzerland. All correspondence and requests for reprints should be addressed to: Jerome Bickenbach, PhD, LLB, Swiss Paraplegic Research, Guido Zäch Institute, Guido Zäch-Strasse 4, CH-6207 Nottwil, Switzerland.

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1. Improve health sector response to SCI
2. Empower people with SCI and their families
3. Challenge negative attitudes to people with SCI
4. Ensure that buildings, transport and information are accessible
5. Support employment and self-employment
6. Promote appropriate research and data collection.

FIGURE 1. International Perspectives on Spinal Cord Injury main recommendations.

Information

To initiate, monitor, evaluate, and adjust processes of implementation, valid and reliable data are essential. In the case of a global health report like WDR and IPSCI, these data must be relevant to the recommendations being implemented, international in scope, and longitudinal. To be relevant to the IPSCI recommendation, the data must encompass the complete lived experience of SCI, including environmental determinants and personal factor characteristics that explain the functioning and well-being of people living with SCI. In addition to information about the person, implementation requires information about the societal response to the needs of persons with SCI. These data must be international to learn from country-level successes (and failures) in shaping their own societal responses (at the policy level [macro-], the service administrative level [meso-], and the level of clinical and other dimensions of practice [micro-]). Finally, information about the person and societal response must be longitudinal to monitor change in the societal response to track implementation. This is an enormous informational demand, given the technical difficulties of ensuring international comparability.

Theory of Change

The processes of the implementation of complex and multisectorial recommendations will not work if they are fragmented, incoherent, and unsustainable. Implementation science is full of examples of attempts to change systems that failed because the strategy used ignored the potential impacts on other sectors, workforces, or institutions. For this reason, implementation researchers argue for the need to describe pathways for scaling up change to take into account the unpredictable behavior of “complex adaptive systems.”⁵ Failures can result from the naive assumption that planned actions will have clear consequences, when, at the level of the system, far more complex relationships are at work. What is needed, therefore, is a realistic theory of system change that accounts for feedback loops, patterns of cyclical change, and other properties of complex systems such as those found in health and social sectors.

Implementation Tools

Increasingly, health researchers are recognizing the importance of bringing *research into practice* and have, as a result, become more interested in *knowledge translation*. The rise of implementation science and implementation research is a

response to the realization that the promise of *evidence-based medicine* depends on implementation, and so the successful use of implementation tools to change behaviors, both at the clinical level and through policy reform.⁶ The WHO has fully invested in implementation research⁷ and has taken the lead in developing broad implementation strategies for making clinical and health systems reforms, primarily in low- and middle-income countries.⁸ Somewhat lagging behind are implementation strategies for implementing recommendations of world reports, such as IPSCI and WDR,⁹ but WHO is aware that the benefits of its guidelines and global reports will never be realized without the application of implementation strategies and tools.

One of the motivations behind The Learning Health System for Spinal Cord Injury (LHS-SCI) Initiative, of which the International Spinal Cord Injury (InSCI) Community Survey is a part, was to respond to this implementation challenge. The underlying rationale, conceptualization, and study design of the LHS-SCI Initiative reflect this motivation. The InSCI study addresses the need for evidence of the lived experience of persons with SCI in the InSCI participating countries. The overall mission of LHS-SCI is broader than this, as it includes processes of evidence- and rights-informed research and policy reform that respond to the implementation challenge.

The LHS-SCI is therefore informed by two major traditions in health research: the familiar tradition of evidence-based medicine, and, from within implementation science, evidence-informed policy. Whereas the former motivates the concern to ensure that clinical practice is governed by the best available evidence, the latter bridges this concern with the need to influence the policy and political domains to make change happen, sustainably, throughout the health system.

THE CONCEPT OF THE LEARNING HEALTH SYSTEM FOR SCI INITIATIVE

Our approach in this paper is to describe the mission, concept, and study design of LHS-SCI in light of the underlying motivation just described. Research initiatives of the ambition, scope, and complexity of LHS-SCI will address many objectives and research questions, but our aim here was to expose the reasoning behind some of the fundamental choices that went into the conceptualization and design of the initiative to provide the full context of the InSCI study, including the rationale for the data model and study design. At the core of the LHS-SCI is the aim of integrating evidence and policy. However,

this integration is not merely the traditional one of bringing evidence to the attention of policy makers; it is also a response to the implementation challenge: the LHS-SCI is embarking on a long-term initiative to create a sustainable, multicountry, integrated implementation strategy that brings together evidence generation, a theory of change, and implementation tools.

Normative Framework

The LHS-SCI initiative begins with a commitment to the recommendations of the IPSCI report. To ensure its success and effectiveness, it was decided to align the initiative with WHO's own research and policy agenda as specified in its *Global Disability Action Plan 2014–2021* and its three objectives:

- To remove barriers and improve access to health services and programs.
- To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation.
- To strengthen collection of relevant and internationally comparable data on disability, and support research on disability and related services.

As it was produced concurrently with the development of the *Disability Action Plan*, IPSCI also reflects these priorities in its recommendations. Hence, both the *Action Plan* and IPSCI (and indeed, WRD as well) focus on access to services and in particular to rehabilitation services, and emphasizes the importance of collecting internationally comparable data, both on the experience of SCI and the societal response to the needs of persons with SCI. Finally, both the *Action Plan* and IPSCI were shaped by the provisions of the *Convention on the Rights of Persons with Disabilities*, which, among other things, guarantees the rights to accessibility, health, and rehabilitation services, and full participation in education, employment, and community life. Every study design choice, including the selection of domains to be operationalized as survey questions for InSCI and the selection of data items to be collected for the cross-cultural societal response, was motivated by the normative framework created from the merging of these three sources.

Learning Health System

As mentioned, the successful integration of evidence and policy presupposes a theory of change for implementation across both the health sector and health-related sectors such as education and employment. The decision was made to use the notion of the “learning health system” as the theory of change that would be the blueprint for the study design.

Starting in 2007, the American Institute of Medicine (IOM) released the first of a dozen workshop reports and studies on the urgent need for better clinical health research and fundamental systems' reforms to put that research into practice.¹⁰ The term *learning health system* was used to describe a health system that *learns* through the application of *cyclical dynamics* for identifying issues, creating responses, implementing change, observing the consequences of the change, revising and reshaping that response: in short, a health system that learns from its successes and failures. A learning health system has the capacity to identify and understand—at the level of clinical practice,

administration of services, and overall, national health policy—weaknesses and constraints and develop and implement changes that avoid or mitigate the effects of what does not work and encourage what does work.

The United States, like all high-resource countries, faces the *health care imperative* of improving health care outcomes while reducing health care costs.¹¹ The United States spends considerably more per capita on health care than any other Organization for Economic Cooperation and Development country, but its population health care outcomes (eg, life expectancy) are well below the average in these countries.¹² Whereas some of the problems facing the United States are not readily transferable to other countries, much of what the IOM recommended in these reports is easily applicable to nearly all middle- and high-resource countries:

- In light of the increasing evidential complexity of modern health care, it is essential to narrow the research-practice divide for clinical decision support;
- National health care quality improvement process and data architecture are essential for a health care system to “learn” from successes and failures;
- Health care systems must take full advantage of the opportunities created by technological improvements in computing, information services, and connectivity;
- Patients, families, and communities must be better involved in health care;
- A “continuous improvement” culture of care must be created for systematic problem solving, the application of operational models that encourage and reward sustained quality and improved patient outcomes, and strong leadership.¹²

The path to a “continuously learning health care system,” in short, incorporates two infrastructural improvements. The first concerns information. It has been said that the learning health care system is the natural development from evidence-based medicine¹³ in that whereas the latter advocated the need for practice to be informed by the best evidence, the former addresses the persistent problem of getting that evidence to actually change practice. Getting the right information to inform health care services is a matter of research methodologies and strategies,¹⁴ exploiting the untapped value in translational and comparative effectiveness research,¹⁵ and implementing electronic health records to benefit from large clinical and administrative data sets.¹⁶ Of importance here, although not developed in the IOM reports, is the further need to ensure that health care outcomes reflect what actually matters to people, namely, the level of functioning in their daily lives.

The other infrastructural reform required for the learning health system is less technical, and considerably more challenging. A health care system learns when feedback loops between research and practice are strengthened so that research questions can be refined for timeliness and relevance to clinical decision making, and clinical data can be managed so that clinical success and failure can be monitored for lessons learned. The vision of the learning health care system is “one in which science and informatics, patient-clinician partnerships, incentives, and culture are aligned to promote and enable continuous and real-time improvement in both the effectiveness and efficiency of care.”¹⁷ To achieve this requires health care system remodeling along

several axes: engaging and empowering patients to ensure strong patient-clinician partnerships; creating financial and other incentives that are aligned with continuous improvement; and creating a continuous learning culture sustained by leadership committed to continuous improvement. All of this requires powerful implementation strategies to bring stakeholders together to develop a health care system remodeling plan and timetable.

As a theory of change, the learning health care system has been called “an enormous interdisciplinary challenge incorporating behavioral psychology, communication science, implementation science, behavioral economics, policy science, and organizational theory.”¹⁸ Effective change also depends on leveraging the expanded capacity of digital infrastructures, data collection, and innovative statistical and research techniques. Finally, change also requires a sustained application of implementation science to remodel the health care system at all levels: policy, service administration, and clinical practice.¹⁹

The LHS-SCI Initiative is an application of the learning health care system approach to the case of SCI and the experience of living with SCI. It is hoped that this initiative can become a model for health system redesign for other health conditions and to meet the growing needs of an aging population. The initiative provides the unique opportunity for stakeholders from the participating countries to learn from each other's successes and to build both research and policy capacity toward the implementation, at the national level, of a learning health care system.

The Informational Base: Person and Society

The LHS-SCI Initiative builds on a preexisting informational base for SCI. The evidence from the IPSCI report, supplemented by evidence from the WRD, provides a broad base of information about all aspects of the lived experience of SCI. Although the best research evidence available supports generalization about international perspectives on SCI, in many regions of the world, the gaps in evidence are substantial. We know almost nothing about the epidemiology of SCI across the African continent, for example.

Fortunately, more granular data about the lived experience of SCI are available from the community survey conducted in the context of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) in 2012,²⁰ results of which have been analyzed and recently published.²¹ The SwiSCI community survey was based on the conviction that the goals of the societal response to the needs of persons with SCI, with regard to rehabilitation services and social interventions, must be that of improving what matters to people, namely, optimizing functioning and participation in all aspects of community life. This conviction reflects the understanding of functioning in WHO's *International Classification of Functioning, Disability and Health* (ICF), which conceptualizes functioning and decrements in functioning, or disability, as the outcome of a complex interaction between a person's health condition and environmental and personal factors.²²

The ICF provides the shared framework for both the SwiSCI survey and the LHS-SCI Initiative. Moreover, the ICF conceptualization of functioning structures the evidence collected for both IPSCI and WRD and is presumed by the

WHO *Disability Action Plan* as well. In particular, the third objective of the *Plan*, to strengthen the collection of internationally comparable data on disability, is currently being implemented through the development and piloting of the Model Disability Survey (MDS).²³ The MDS is based on the ICF conception of functioning and uses a set of ICF domains that have been shown to be adequate for a complete description of functioning, both from the perspective of the intrinsic health capacity of the individual and his or her performance in actual environments. As described in detail in other papers in this *special issue*, the MDS was used as one of the sources of questions for the InSCI survey.

The ICF is fundamental to the LHS-SCI for another reason. The LHS-SCI Initiative follows the SwiSCI study in its commitment to the view that the lived experience can only be expressed in the ICF notion of functioning and that all data collected and used for the initiative must be based on the ICF domains and model of functioning. Thus, the SwiSCI community survey collects information on all of the ICF components—health condition, impairments, activities and participation, and environmental and personal factors—as does the MDS.

The information base provided by the InSCI evidence and SwiSCI data will be augmented during the course of the initiative by the InSCI community survey. As the parameters for both SwiSCI and InSCI surveys are described elsewhere, it need only be emphasized here that InSCI collects data about the person, and the person's lived experience of SCI, in an ICF-based data model. The overall objective of InSCI is to identify determinants of functioning, health, and well-being of people living with SCI within and across countries in relation to health and social service, systems, and policies. This will be done taking into account individual differences in the experience of health conditions, environmental factors, and personal characteristics. The collaborating countries cover the six WHO regions and represent countries with different stages of economic development, different political regimes and health systems, thereby providing the basis for comparison.

International Spinal Cord Injury data capture the determinants of functioning and participation. However, to get the complete picture of the interaction between the person and society, information about the overall societal response to the health and health-related needs of persons with SCI needs also to be collected. These data describe all state actions (and inactions) that have a direct impact on people's lives and their lived experience of SCI.

Information about the societal response will come from country profiles in which relevant quantitative and qualitative information about the general current socioeconomic state of the country is described. Of particular interest is how the health system operates with respect to SCI in general and the lived experience of SCI in particular. In addition to these profiles, the societal response analysis for LHS-SCI will develop a consolidated comparative analysis of the societal response to SCI based on these data and supplementary information collected from international sources. The goal of this analysis was to identify patterns of unmet needs to formulate policy recommendations designed to strengthen the capacity of these systems to meet these needs.

The combination of information about the person and, in particular, the health and health-related needs of individuals experiencing SCI, and information about the societal response to those needs captures the essential person-society interplay that is at the heart of the health sciences. Arguably, the evolution of the health sciences and, in particular, the astounding breadth and depth of interdisciplinary of health research is a recognition that the interplay between persons and their needs, and the societal response to those needs is at the core of what we now understand to be the aim of the health sciences.²⁴

The information base for the LHS-SCI Initiative, both existing data sources and those that will be arise during the course of the initiative, is both qualitatively broad and quantitatively extensive, providing a rich source of data for a wide range of comparative analyses. All participating countries will benefit not only from a more in-depth understanding of their own situation but also from a fully comparative understanding of the situation of other countries from which lessons can be learned. In the context of the LHS-SCI Initiative, these data will provide the essential informational base for the implementation of the normative framework provided by the IPSCI recommendation, the *Disability Action Plan* objectives, and the *Convention on the Rights of Persons with Disabilities*. This leads to the next component of the LHS-SCI Initiative.

Implementation Tools: Policy Briefs and Stakeholder Dialogs

As a theory of transformation action, the LHS is grounded in the need for the best clinical and research evidence for evidence-informed health policy making and an essentially participatory, multistakeholder process of implementation of research into practice. Implementation science is the natural source of this second mechanism, although much of implementation research is also focused on the nontrivial need to package information in a manner that is accessible to all stakeholders.²⁵ The LHS-SCI Initiative proposes to use the state-of-the-art implementation tools for application at the national level for each participating country. These tools are policy briefs and stakeholder dialogues.

The policy brief is a concise, accessible, but fully evidence-based discussion paper that identifies and gives evidentiary background for a specific issue concerning some aspect of the overall societal response to SCI needs. It is country specific, informed by all available data including the complete informational base that will be provided by the LHS-SCI Initiative and developed by country collaborators who can integrate their understanding of the specific political and cultural context for policy making in their country. The policy brief will include, based on a comparative analysis from other LHS-SCI collaborating countries, three or four policy reform options that address the issue raised. Although the preparation of a successful policy brief, relevant to the actual situation of the national setting, is a challenging task,²⁶ it is an essential preliminary step for the implementation mechanism of stakeholder dialogue.

A stakeholder dialogue is a structured communication process or a dialogue where representative stakeholders work collaboratively toward a common understanding and reach agreement about a practical, step-by-step implementation strategy designed to address and solve the issue fully described in

the policy brief. The dialogue is guided by a moderator who facilitates the interaction and stimulates participants to clearly express their positions and, using the policy brief as the basis, provides evidence and arguments for their position. The dialogue closes when (a) there is agreement over a course of action or (b) there is no agreement and either (i) there is need for a second stakeholder dialogue to foster agreement or (ii) more research is needed, as there is a lack of evidence to agree on a best solution. A full description of the version of stakeholder dialogue to be used in LHS-SCI, as well as a theoretical justification for the process, is provided in a paper in this *special issue*.

Research and Policy Capacity Program

A goal of the LHS-SCI and the final component of the concept of the initiative involves the perceived need to develop policy and research capacity across the network of participating countries. The research center in Nottwil will be the source of technical assistance for the initiative, including implementation tools. Capacity building will be achieved through a two-part policy and research capacity effort.

Scientific Capacity Building

The LHS-SCI Initiative requires a new kind of health researcher, one who appreciates that health systems and service research must be a cooperative endeavor involving multiple stakeholders and demands new skills and expertise including, in particular, implementation science. The research center in Nottwil, in collaboration with the academic institutions of the participating countries, will initiate and seek funding for a research scientist program that will bring in young researchers interested in developing the skills and capacity for a learning health system. LHS-SCI will also conduct short educational courses in protocol development and other interdisciplinary teaching modules focusing on the components of the LHS-SCI Initiative.

Management of Standardized Health Information

The LHS-SCI will lead in the development of data standards for structured reporting and, where appropriate, the collection of new multipurpose health information. This is fundamentally a collective goal, as it is impossible for any single researcher to be able to overcome the barriers to acquiring, and maintaining, relevant and comparable health information. What is required is the integrated participation of all LHS-SCI academic institutions as well as the additional resources of the WHO. This will require health information standardization and a health data warehouse.

The LHS-SCI will develop and propose national data standards in collaboration with the WHO, suitable to comprehensively describe both the health and functioning of persons and populations as well as the components of the health system as a foundation for sustainable decision making in national health care systems. Information about individual and population health includes, but extends beyond, basic medical or biological information to encompass information about the lived experience of a person with a health condition. Information about how a person's health plays out in their lives, how it, in interaction with the person's physical, interpersonal, and social

environment, helps or hinders the individual to live the kind of life and achieve the goals and aspirations he or she seeks is crucial for input into the learning health care system.

Finally, since data that are not available are data that cannot be used, it is central to the LHS-SCI goal of providing tools for the enhancement of communication between policy, research, and practice in national health care systems that access to relevant and usable health data. This requires standardization and the capacity to make data collected from a variety of health settings, registries, and administrative sources using a variety of data collection tools and methods that is comparable. In a next step, an accessible storage platform needs to be created so that data can be readily, efficiently, and cost-effectively disseminated.

CONCLUSION

It has been our aim to place the InSCI study in the context of the broader LHS-SCI Initiative and show that the initiative is motivated by the need to implement the targeted policy recommendations of WHO's IPSCI. The implementation challenge can be broken down into the need for relevant and internationally comparable information, the need for a theory of change that provides guidance for action, and the identification and application of implementation tools to ensure evidence-informed policy. Responding to the interplay between persons and their needs and the societal response to those needs, LHS-SCI Initiative includes a normative framework, a theory of action, a complex informational base capturing data on both the person and societal response, an implementation strategy, and an attempt to secure sustainability through capacity development. As the other articles in this Special Issue describe in detail, the rationale, conceptualization, and study design of the InSCI study is also informed by the rationale and mission of the LHS-SCI.

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People with Spinal Cord Injury in China

Jan D. Reinhardt, PhD, Yu Zheng, MD, Guangxu Xu, MD, Xiao Lu, MD, PhD, Yong Yin, MD, Shouguo Liu, MD, Qiang Gao, PhD, Xianghu Xiong, MD, PhD, Chengqi He, MD, Hao Li, DPT, and Jianan Li, MD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN CHINA

Only sparse epidemiological data on spinal cord injury (SCI) in mainland China is available. Epidemiological studies are predominantly based on retrospective chart reviews of selected hospitals in particular regions and cities. Prevalence data are currently not available and studies of nontraumatic SCI are largely lacking. China has no central registry for SCI. However, a nationwide trauma registry comprising all military hospitals exists.

Estimates of the incidence of SCI exist for Beijing,¹ Shanghai,² and Tianjin.^{3,4} Incidence rates ranged from 23.7 per million (Tianjin³) and 25 per million (Shanghai²) between 2004 and 2008 to 60 per million in Beijing.¹

Evidence suggests that the incidence of SCI in China increased dramatically during the past decade. A study based on data of the aforementioned trauma registry found a staggering increase of spinal trauma in the period from 2001 to 2007, which was mainly due to an increase of spinal trauma due to motor vehicle crashes and falls.⁵ Spinal trauma accounted for 4.68% of all trauma cases, and SCI accounted for 0.74%.⁵ A similar trend was found by Ning et al.³ for the annual incidence of traumatic SCI in Tianjin between 2004 and 2008 based on a retrospective chart review of 15 tertiary hospitals able to treat traumatic SCI. Yang et al.⁶ found that the percentage of patients hospitalized in second grade A hospitals located in Guangdong China increased from 7% to 14% from 2003 to 2011.

As in many other countries, males are more likely to have a traumatic SCI than women.^{1,3-5,7,8} Male-to-female ratios ranged from 3.1:1 in Beijing¹ to 5.6:1 in Tianjin.³ The mean age ranged from 41.7 years (SD not reported) in Beijing¹ to mean (SD) 46.0 (14.2) years in Tianjin,³ with the largest proportion in the age group between 30 and 50 years. Several studies also

reported on the occupational status at injury suggesting that most of patients with SCI are unemployed persons,⁴ peasants,^{1,8,9} or workers.⁶

Only one study from Guangdong reported on nontraumatic SCI⁶ indicating a proportion of 10% of nontraumatic cases of all known causes. Main etiologies of nontraumatic SCI in this study were ossification, spinal degeneration, tumors, and inflammation.

Leading etiologies of traumatic SCI were reported to be motor vehicle accidents and falls, both from a height and trivial falls. Evidence suggests that high falls particularly occur in men and in younger age groups, whereas trivial falls are the leading cause of traumatic SCI in the elderly.^{3,4,8} Notably, several studies report a relatively high proportion of SCI due to being hit by falling objects ranging from 4.9%⁸ to 19.5%,⁶ probably related to work accidents and natural disasters such as earthquakes.

Apart from one study from Beijing, which reported the highest proportion of SCI to have lumbosacral lesions,¹ all other studies report the highest proportion of patients with cervical lesions ranging from 44.4% in Guangdong⁶ to more than 80% in Tianjin.⁴ Most lesions seem to be complete, with American Spinal Injury Association (ASIA) Impairment Scale (AIS) Grade A accounting for up to 32%.⁴

No estimates for the life expectancy of people with SCI are available for study, and only few studies on mortality after SCI have been conducted. A study from Shang¹⁰ followed 131 patients with cervical SCI between 2004 and 2012 in Jinan, 11 (8.40%) died, of which nine were males. Leading cause of death was respiratory failure. Ning et al.³ looked at in-patient mortality of patients with SCI admitted to hospitals in Tianjin between 2004 and 2008. Twelve patients (1.4% of admitted cases) died; all were tetraplegics, and the leading cause (92 %) was respiratory failure.

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

Patients with SCI are transferred to the nearest hospital within 8 hours after injury in urban areas, whereas in some rural areas, it takes more than one day transferring to a hospital, which is capable of managing patients with SCI. Acute care mainly depends on professional knowledge and the skills of physicians and nurses. Multidisciplinary cooperation between emergency department, neurology department, and rehabilitation department is common in China and helps to provide better treatment during in-patient periods. Nonetheless, postacute SCI rehabilitation in China still has its limitations, that is, some patients are referred to rehabilitation only 2 to 3 months after the acute phase owing to the limited understanding of the importance of postacute rehabilitation. In-patient rehabilitation, which usually lasts for 1 to 2 months mainly, includes physical and occupational

From the Institute for Disaster Management and Reconstruction of Sichuan University and Hong Kong Polytechnic University, Chengdu, Sichuan Province, China (JDR, YZ, HL); Swiss Paraplegic Research, Nottwil, Switzerland (JDR); Department of Health Sciences and Health Policy, University of Lucerne, Switzerland (JDR); Department of Rehabilitation Medicine, Nanjing Medical University, Nanjing, Jiangsu Province, China (GX, XL, SL, JL); Department of Rehabilitation Medicine, Kunming Medical University, Kunming, Yunnan Province, China (YY); Department of Rehabilitation Medicine, West China Hospital, Chengdu, Sichuan Province, China (QG, CH); and Burwood Spinal Unit, Burwood Hospital, Christchurch, New Zealand (XX).

All correspondence and requests for reprints should be addressed to: Jianan Li, MD, The First Affiliated Hospital of Nanjing Medical University, 300 Guangzhou Road, 210029 Nanjing, Jiangsu Province, China; and Hao Li, DPT, Institute for Disaster Management and Reconstruction, Sichuan University and Hong Kong Polytechnic University, Hanghe Road Middle Section, 610207 Chengdu, Sichuan Province, China.

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therapy. Patients are discharged from hospitals and go back to the community when they acquired basic skills of daily living or complications have been cured. Readmission due to complications occurs frequently.

LIVING WITH SCI

Life after SCI in China is not well researched. Only one study on labor market participation of people with SCI living in China was available. The study from Xu et al.¹¹ followed 161 traumatic patients with SCI from Guangdong for 18 months after injury. The re-employment rate was 31% (80% full time, 20% part time) with a 4.4:1 ratio of paraplegia to tetraplegia.

THE HEALTH AND REHABILITATION SYSTEM

China has recently faced rapid economic growth and its estimated gross national income per head was \$11,860 international purchasing power parity in 2013 of which \$646 (international purchasing power parity) was spent on health care expenditure per inhabitant. Approximately 44% of health care expenditure was private in 2013 mostly involving out-of-pocket payments (76.7%). The life expectancy of both sexes has increased considerably from 69 years in 1990 to an estimated 75 years with a healthy life expectancy of 68 years in 2013.¹²

In 2009, China had approximately 15 physicians, 15 nurses and midwives, and 42 hospital beds per 10,000 population.¹² The Chinese health system faces challenges, in particular owing to a dramatic rise in noncommunicable disease in recent years resulting from an aging population, increasing income, and urbanization.¹³ It is envisioned to achieve universal health coverage by 2020 involving different strategies such as consolidating the fragmented social health insurance schemes to achieve equitable access, investing in training of general practitioners to improve the quality of primary health care delivery, enhancing health system's monitoring capacity, and strengthening the production of evidence to inform clinical decision making.¹⁴

China has increased investments in clinical rehabilitation massively after the 2008 Wenchuan earthquake.¹⁵ However, those have been mainly concentrated on urban areas.

WHAT IS THE STATE OF SPECIALIZED CARE?

In urban areas, specialized care for persons with SCI is provided in sufficient amounts, and appropriate treatments and devices are available. This is, however, less so in rural areas as well as in economically less developed provinces of China. A major problem regarding SCI treatment in China is that patients are often lost to follow-up upon return to the community, and continuous specialized health care is hardly provided. Additionally, psychological and vocational rehabilitation is rarely provided. Peer counseling is not well developed in China as is professional personal assistance. Thus, caring for and financing of persons with SCI largely depend on their relatives after discharge from in-patient rehabilitation.

THE SOCIAL RESPONSE TO SCI

In 1988, China founded the Chinese Disabled Persons Federation, which is the national umbrella organization for persons with different kinds of disability. China has also signed the United Nations Convention on the Rights of Persons with

Disability in 2007 and ratified it in 2008 by revising and amending the 1990 Law on the Protection of Persons with Disabilities (signed by President Jintao Hu on April 24, 2008, and entered into force on July 1, 2008).¹⁶ This law encompasses comprehensive provisions regarding rehabilitation, education, employment, cultural life, social security, and accessibility. Its implementation in practice is, however, another issue and has not been researched to our knowledge.

In China, most recently constructed government buildings, that is, museums, theaters, schools/universities, and hospitals as well as public facilities like subways are well accessible in most cities, but other buildings open to the public such as restaurants or shops and private buildings are not. Moreover, sidewalks are often difficult to maneuver in a wheelchair and streets difficult to cross.

The situation regarding attitudes toward disability and discrimination in employment and in social and community life is unclear owing to lack of research on these issues. Our understanding, however, is that employment is often difficult to find for persons with SCI.

RATIONALE OF THE STUDY

Whereas limited epidemiological data on SCI are available for specific cities and regions of China, research on the lived experience of persons with SCI living in the community, in particular, with regard to activity limitations, participation restrictions, and influencing environmental factors with regard to the International Classification of Functioning, Disability and Health (ICF)¹⁷ as well as quality of life, is, with the exception of some studies on small groups of spinal cord-injured earthquake victims,^{18,19} virtually nonexistent. Problems and needs of community dwelling persons with SCI are thus largely unknown for China. To identify the former is, however, a necessary condition to provide respective interventions on the services and policy level.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

The objective of the Chinese SCI Survey of the InSCI survey is to obtain basic epidemiological data and to better understand functioning, social integration, living situation, health care, and quality of life of persons with SCI in China and in comparison to other countries. Based on the results, the authors expect to trigger a policy dialogue in China to improve the living situation of persons with SCI.

THE NATIONAL STUDY PROTOCOL

Design and Ethical Procedures

This is a cross-sectional observational study with the possibility of follow-up after 5 years as indicated by the general design of the International SCI survey.²⁰

The study will be conducted according to the principles of the Declaration of Helsinki. The study protocol has been approved by the provincial ethical review boards of Jiangsu,

Yunnan, and Sichuan Province located at the respective provincial hospitals.

Setting

Three provinces representing different levels of economic development within mainland China have been purposefully selected to be able to compare the situation of people with SCI across provinces with differential economic resources: Jiangsu, Yunnan, and Sichuan Province (Fig. 1). Jiangsu province is located northeast of China and with a per capita gross domestic product (GDP) of 14,105 USD in 2014 is one of the higher resourced provinces of China. With a population of approximately 80 million living on an area of 102,600 km², it is relatively densely populated. Jiangsu is ethnically homogeneous, with Han Chinese comprising 99.6% of the population.²¹ In contrast, Yunnan Province located in the southwest of China is less economically developed (2013 per capita GDP of 4,156 USD) and less densely populated (approximately 46 million population on an area of 394,000 km²). It is also ethnically more heterogeneous, with Han Chinese making up only approximately 67% of the population.²² Sichuan Province is located in the middle west of China. It has 81 million inhabitants on an area of 485,000 km². It is more economically developed than Yunnan but less than Jiangsu (5,728 USD per capita GDP). Han Chinese make up approximately 95% of the population.²³ Sichuan is also interesting because it is prone to natural disasters, in particular, earthquakes, with the 2008 major Wenchuan earthquake being the most significant.¹⁵

Eligibility Criteria

Eligibility criteria largely follow the recommendations of the overall InSCI study protocol.²⁰

Eligible will be adults aged 18 years or older having sustained a traumatic SCI (including cauda equina syndrome), or SCI of certain nontraumatic etiologies, including vascular causes, infections, and benign tumors. Eligible subjects should be residents of China, able to respond in Mandarin Chinese or one of the dialects with which the interviewers are familiar, and having provided informed consent. Included furthermore are only patients of which electronic records in the succeeding specified databases are available (mostly those having sustained SCI in the past 10 years). Excluded are persons with congenital etiologies, such as spina bifida as well as progressive etiologies, such as autoimmune diseases, malignant tumors, toxic agents, radiation; multiple sclerosis; amyotrophic lateral sclerosis; or peripheral nerve damage, such as Guillain Barré syndrome. Persons who are in-patients receiving first rehabilitation at the time of the study are also excluded.

Sampling Frame

The sampling frame (Fig. 2) will primarily follow the hierarchically organized Chinese hospital system. In China, three levels of hospitals exist with level 3 hospitals (province level) providing the most specialist care according to highest standards. Moreover, it is envisioned to use available data from the Chinese Disabled Persons Federation (CDPF) of the participating provinces.

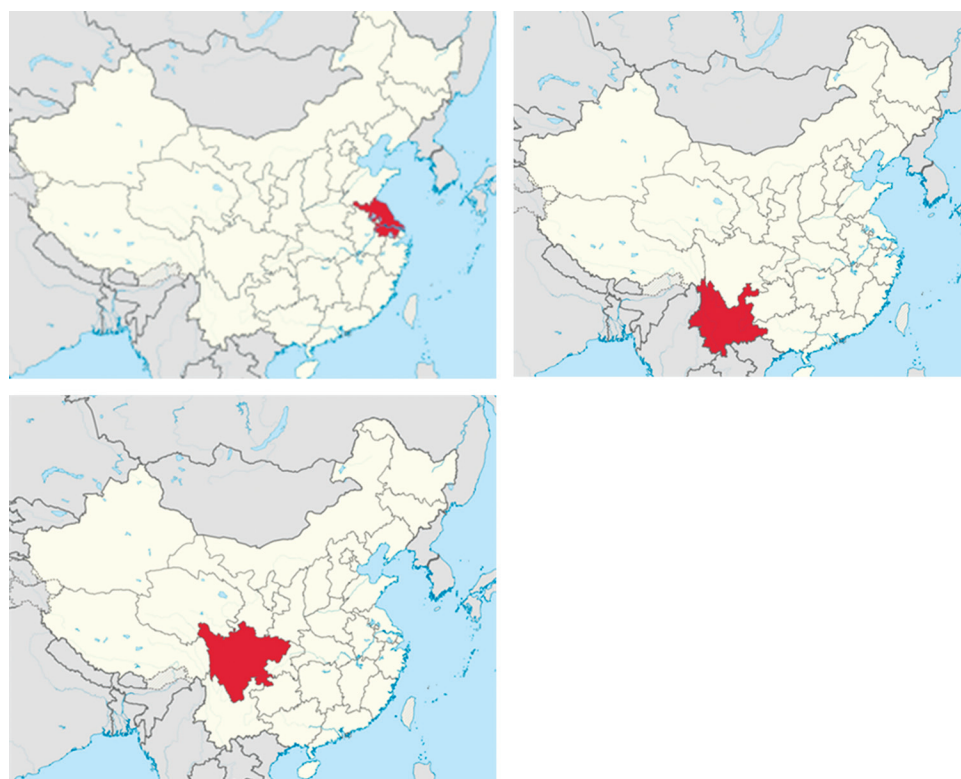


FIGURE 1. Geographical location of Jiangsu (left), Yunnan (right), and Sichuan (bottom left) within the People's Republic of China (source: wikipedia.org).

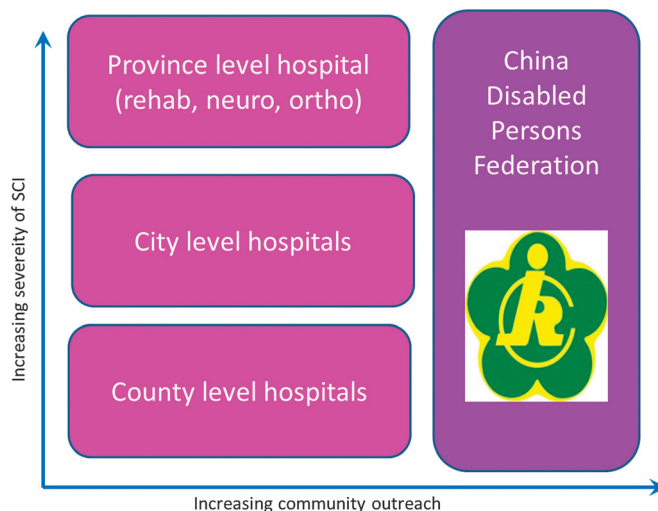


FIGURE 2. Sampling frame.

In each province, at least one provincial hospital, one city level hospital, and one county level hospital will be selected. The rationale behind this is to capture cases of different severity, as more severe cases are usually referred to higher-level hospitals. Moreover, the provincial disabled persons federations (DPFs) will be contacted to identify SCI cases from their databases. People with particular health conditions can apply for disability benefits at DPF.

In Jiangsu province, potential survey participants will be identified through combining databases from the Jiangsu Province Hospital's rehabilitation orthopedic and neurological ward, the International Tongren Rehabilitation Hospital, the Wuxi Rehabilitation Hospital, the Xuzhou Rehabilitation Hospital at the city level, the Zhoushi Community Hospital in Suzhou at the county level, and the Jiangsu Disabled Persons Federation.

In Yunnan, the Yunnan Province Hospital, the Zhaotong People's Hospital at city level, the Ludian Hospital at county level, and the Yunnan Disabled Persons Federation are envisioned sources of cases.

In Sichuan, the West China (Huaxi) Hospital at province level, the Mianyang Hospital at city level, and the Mianzhu People's Hospital at county level and the Sichuan Disabled Persons Federation have been envisioned as data sources.

In all provinces, potential SCI cases will be identified by searching the respective databases for relevant ICD codes²⁰ and SCI related keywords in Mandarin such as “spinal cord”, “paraplegia”, etc.

If necessary, charts will be reviewed in detail. Data on contact details (addresses and telephone numbers) of eligible cases will be extracted. Moreover, where applicable data on demographics (age, sex, education, and marital status) and SCI characteristics (level of lesion, etiology, rehabilitation [yes/no], date of onset, spinal stabilization method [surgical vs conservative]) will also be extracted, in particular, with respect to later analysis of unit nonresponse. Finally, the patients' Chinese national ID number will be extracted to serve as local unique and stable case identifier.

Data extracted from different sources will be combined in a new database and duplicates identified.

Recruitment Strategies and Reminder Management

Featuring posters of the upcoming survey in the participating hospitals and offices of the CDPF will sensitize the source population. Information on the upcoming survey will also be posted on the hospitals' and CDPF's website. Eventually, popular social media in China such as Weibo, QQ, and Wechat will be used.

Initial contact with the potential study participants identified from the databases as previously specified will be made by telephone. Informed consent will be obtained verbally and recorded. Per request of the participants, different data collection methods as detailed later will be offered.

Two reminders of participants who have not responded at 1 and 2 months, respectively, after dispatch of the mailed survey invitation are planned. The first reminder will be by mobile text message and the second reminder by telephone call. Up to five attempts to reach potential participants by telephone will be made before a case is considered a nonresponder. The telephone contact attempts also serve the inclusion of illiterate persons in the study.

Real-time monitoring of response based on a tracking system in the central local database will be used to identify persons who have not responded at predefined dates to accurately target the reminders.

To increase the response rate, a lottery among survey participants will be announced within which three iPads can be won.

A sample size of approximately 2,000 participants is envisioned. Given that we aim to extract data from three provinces including three major provincial hospitals, four city level hospitals, and four county level hospitals as well as provincial DPFs, this is a rather conservative estimate. Provincial hospitals alone usually treat at least 200 cases of SCI per year, which adds up to 6,000 cases for the past 10 years. A sample size of 2,000 means that we would be able to recruit one third of this population.

Data Model and Questionnaire

The data model and questionnaire follow the InSCI standard as detailed in an accompanying paper.²⁴ The data model is primarily based on ICF¹⁷ and the ICF core sets for SCI for the long-term context.²⁵ The questionnaire in English has been translated into simplified Mandarin Chinese (Hanyu) by two members of the national study team (Y.Z. and S.L.). In case of disagreement, a third member of the study team (X.L.) was consulted. Finally, the questionnaire was again reviewed by a fourth author who is a US citizen but has been born and raised in China (H.L.). All Chinese-speaking authors approved the final translation.

Data Collection

Data will be collected by mixed modes. Participants can choose to fill a paper-pencil or an app-based online version of the questionnaire. In addition, telephone interviews and visits at the participating hospitals for face-to-face interviews will also be offered. This is of particular importance to include illiterate persons and the elderly. Telephone and face-to-face

interviews will be computer assisted using the online data-entry tool.

Data Management

A local database with contact information, demographics, and SCI characteristics as extracted from the databases of the participating institutions will be established and hosted on the servers of the participating provincial hospitals. The Chinese national ID number will serve as the unique and stable person identifier. The local database will be password protected. There will be three levels of data input and access: (level 1) database access for student assistants and study nurses who are responsible for data input, for example, response status (permission for writing of data), (level 2) database access for two supervisors for each site (permission for reading and writing of data for site-specific database), and (level 3) database access to national study leader (permission for reading and writing for all data). Automated data backup on a second server will be performed on a daily basis.

In this local database, each local ID will be linked with a unique international survey ID provided by the international study center. A standard operating procedure for linking the local ID with the international ID will be developed. This unique international ID will be printed on the paper and pencil questionnaires and also be used for online data entry.

Anonymous survey data will be hosted by Swiss Paraplegic Research in Nottwil, Switzerland, which guarantees full-data confidentiality and security.

Data from paper-pencil questionnaires will be entered into the online system provided by Swiss Paraplegic Research. Two assistants will independently enter data from each questionnaire. Inconsistencies will be resolved by reviewing the original questionnaire or consultation of the responsible study supervisor. Swiss Paraplegic Research will provide the Chinese study team with a standard operating procedure for data entry.

Paper-pencil questionnaires will be sorted by international ID and filed. Apart from data entry (at hospital), they will be locked in the hospitals' archives at all times.

CONCLUSION

The upcoming study will be the first comprehensive research on functioning and living conditions of people with SCI in China. The study will provide an opportunity for discovering unmet needs of people with SCI with regard to functioning including social participation, health care, and environmental factors based on which a policy dialogue can be started to improve the living conditions of people with SCI in China. The contact database built for the purpose of this study can be used

for regular follow-up and monitoring of future interventions. It is also envisioned that additional hospitals and provinces will participate in future repetitions of the survey.

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People with Spinal Cord Injury in Germany

*Melanie Blumenthal, MA, Veronika Geng, MSc,
Christoph Egen, Dipl-Soz-Wiss, Dipl-Päd, and Christoph Gutenbrunner, MD*

EPIDEMIOLOGY OF SPINAL CORD INJURY IN GERMANY

In Germany, specific data reflecting the health and care situation on spinal cord injuries (SCIs) are very limited. The results of research primarily relate to diagnostic and therapeutic interventions. Routine data provided by the German Health Surveillance System do not give any information about new cases and their etiology. For that reason, neither the exact number of new cases per year nor the number of people affected by SCI in Germany is known. Furthermore, a nationwide registry like that in Australia¹ or the United States,² including all cases of SCI, does not exist. The extent of disability and rehabilitation needs in Germany is also unknown.

A German working group is providing the first indications about the current situation. They have been collecting data from most SCI-specialized centers in Germany since 1976. From this database, we know that 34,000 new cases of SCI were registered between 1976 and 2002, corresponding to an annual incidence rate of approximately 1,200 to 1,500 cases per year.³ Most patients (70%) were male. The main identified causes of SCI were traffic accidents (31%) and disease (30%), eg, tumor of the spinal cord, certain types of disc herniation, or prenatal impairments like spina bifida.⁴ Thirteen percent of cases involved occupational accidents, and 7% involved swimming and sport accidents. Regarding the paralysis level, there were 37% tetraplegics and 63% paraplegics. Children were rarely affected (1%).³ Currently, Germany lists approximately 80,000 cases of a total of 81.1 million inhabitants.⁵ However, the significance of these figures is limited owing to the partial response of the specialized SCI centers in Germany.

Recent data of the working group (1997–2010) indicate a strong increase in disease-related SCI and a slight decrease of accidental causes. Owing to an increase in age-related diseases in the population, an increase in disease-related SCI up to 50% is expected in the future. Moreover, an increasing percentage of women are expected owing to their higher life expectancy. The mean age of the entire population affected by SCI in 2010 was 60 years.⁵

Life expectancy after traumatic SCI is limited in Germany, despite comprehensive systems of rescue, treatment, and rehabilitation, and the implementation of lifelong aftercare. The mean survival time after the incidence of paraplegia is 29.2 years, the mean survival time after the incidence of tetraplegia, 13.7 years.⁶ A patient's prognosis was worse at the start of the 20th century owing to fewer medical and rehabilitation services.⁷ Today, patients with SCI who survived 20 years after injury have nearly the same life expectancy as the general population. If SCI with a high degree of paralysis is diagnosed, pulmonary complications often lead to premature death.⁶

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

In Germany, a well-developed and comprehensive system of emergency rescue exists to initiate first aid. Normally, in case of an accident, it can be assumed that a rescue team, consisting of paramedics and an emergency physician will arrive within a maximum of 15 minutes at the accident location to initiate the first medical interventions.⁸ Rescuers can acquire knowledge and skills in dealing with patients with a suspected SCI in special courses.⁹ The aim was to transfer the patients to one of the available specialized SCI centers. If this is not possible for reasons of capacity, transport to another emergency care hospital is initiated. Rescue vehicles and helicopters are always equipped to treat seriously injured patients. The choice of transportation, however, depends on availability.⁹

Subsequent intensive care can be carried out in 60% of all hospitals in Germany.¹⁰ Even surgical procedures are possible in many places. Twenty-five years ago, there were only a few hospitals where surgical interventions of the spine could be carried out. Today, even smaller hospitals have spinal surgery departments.¹¹

Transfer to an SCI center for subsequent rehabilitation is desirable. These centers are spread across the country and make regional medical care possible. The mean duration of transport is rather low because most of the large federal provinces in Germany (11/13) provide a specialized SCI center (Fig. 1).¹² The range of services at the facilities is nearly similar. All of them provide physical, occupational, and sports therapy as well as physical medicine. Furthermore, most of them perform surgeries (75%), have an intensive care unit (96%), and provide pain management (93%).¹² In addition, most of them offer all phases of rehabilitation: emergency treatment, integration into the social and professional environment and long-term care. A clear classification for becoming a specialized center for Spinal Cord Injury is not available. Possible criteria could be, for example, the number of SCI patients per year and the specialized know-how of the staff. Although many German

From the Department for Rehabilitation Medicine, Hannover Medical School, Germany (MB, CE, CG); and Manfred-Sauer-Foundation Lobbach, Germany (VG).

All correspondence and requests for reprints should be addressed to: Melanie Blumenthal, MA, Klinik für Rehabilitationsmedizin, Medizinische Hochschule Hannover, Carl-Neuberg-Straße 1, 30625 Hannover, Germany.

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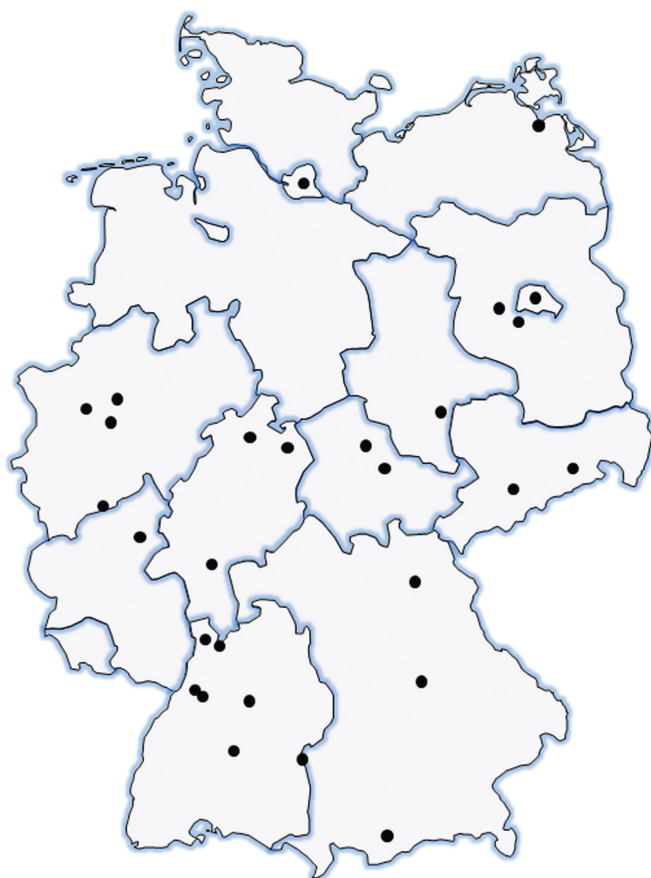


FIGURE 1. German SCI centers, modeled after DMGP 2015.

legal requirements for ensuring a needs-based medical care exist, the realization of these standards has not been explored. There are no studies that give an overview of the actual situation.

LIVING WITH SCI

During the first phase of rehabilitation after the occurrence of SCI, patients are provided with various support such as a wheelchair and aids for emptying the bladder and bowel, etc. The German insurance system bears (most of) the incurred cost, according to the SCI cause. For the period after the first rehabilitation, there are a number of stakeholder organizations, associations, and foundations that work for the interest of patients with SCI. They provide information, advice, and support. To lead an active life in the community, patients can obtain technical support (wheelchairs), support for integration into the environment, home maintenance, home care, as well as assistance to participate in cultural life.

THE HEALTH AND REHABILITATION SYSTEM

Health care in Germany is predominantly financed by the insurance system. Citizens and employers contribute to different obligatory health, nursing care, pension, and accident insurance. Federal grants contribute to the social contributions by tax revenue.¹³ This general legal obligation ensures that all people living in Germany pay into the health care system. In the case of unemployment, social welfare pays the costs. This

arrangement ensures adequate medical care for all people at any time, including in the case of SCI.

The compulsory health insurance covers the costs almost on an equal level. Differences in health care services exist if other institutions bear the incurred cost, such as a private accident insurance company or the employer's liability insurance association. The latter takes care of persons with SCI caused by work-related accidents and is very specific for Germany. With the principle of restoring human health by using all appropriate means, persons with a work-related SCI benefit from high-quality health care.

Table 1 shows the different phases of care of paraplegics and legal support.

WHAT IS THE STATE OF SPECIALIZED CARE?

As previously mentioned, in Germany there are a total of 28 SCI centers assigned to several payers (eg, employer's liability insurance association). They are specialized in medical treatment, rehabilitation, and follow-up care,¹² based on very good personnel and equipment facilities. Almost all centers or hospitals to which these specialized centers are attached provide intensive medical care. Surgical interventions of the spine can be performed in 11 centers directly and in another 9 centers of the attached hospitals over 24 hours. Special surgeries such as urological surgeries or hand surgeries are possible in most of the centers or may be performed nearby.¹³

Throughout the rehabilitation process, clinical psychological care is always provided. Psychologists form an integral part of the team.¹⁴ Social workers also support patients in adapting to their domestic and professional environment.¹⁵ Relatives can participate in care training and consulting services. In addition, the principle of lifelong follow-up care ensures the early detection of health problems and the greatest possible independence.¹⁶ These interventions are mainly carried out in specialized SCI centers because of their knowledge. The frequency of the examinations varies and is adapted to each case.

THE SOCIAL RESPONSE TO SCI

In Germany, the costs for medical care, rehabilitation, and the changing life circumstances are funded by various organizations and forms of insurance. In cases of disease or private accidents, the compulsory health insurance covers acute care, as well as financial support. Medical rehabilitation is financed by the pension fund as long as the patient is of working age.¹⁷ In case of accident at one's workplace or on the way to work or returning home from work, the employers liability insurance association assumes all costs associated with restoring health and capacity.¹⁸ The pension fund follows the principle of "rehabilitation before retirement" and includes medical care as well as vocational and social reintegration of the patient.¹⁹ Insurance provides benefits for participation in the work force as well as complementary services to alleviate the effects of disease on the patient's ability to work. If the ability to work and have income is limited owing to SCI, it is possible to obtain a disability pension. Patients with SCI can also retire earlier from work or reduce their weekly working time.²⁰ If the SCI is the result of a third party's fault, all costs are adopted by the private liability insurance of the person who was responsible for the accident. Regarding civil servants, there are special

TABLE 1. Overview of phases of care of paraplegics and legal support

Insurance Company or Support Institution		Health Insurance	Accident Insurance ^a	Pension Insurance	Long-term Nursing Care Insurance ^b	Social Welfare
Legal Basis		GSLC V, IV, IX	GSLC VII, IV, IX	GSLC VI, IV, IX	GSLC XI, IV, IX	GSLC XII, IV, IX
Phase of Care						
Acute Care	Intensive care/Hospital care	X	X			X
	Posttreatment rehabilitation	X	X	X		X
Post Acute Care/ Rehabilitation (mostly inpatient)	Vocational rehabilitation		X	X		X
	Assistive technologies (eg, prosthesis, wheelchairs, crutches)	X	X	X		X
	Community-based health care ^c	X	(X)		X	
Long-term Care/ Rehabilitation (mostly outpatient)	Adopted living and/or working environment	(X) ^d	X	X		X
	Home care/Outpatient care	X			X	(X)
	Retraining measures ^e		X	X		X
	Medical rehabilitation	X	X	X		X
	Vocational rehabilitation		X	X		X
	Assistive technologies	X	X	X		X
	Monetary compensation ^f	X	X		X	
Financial Protection	Reduced earnings capacity pension		X	X		X
	Pension payment		X	X		

The direct comparison of the phases is not given between the insurances, and for everything, there are various exemptions in the German Social Law Codes (GSLC). This list only represents an attempt of a schematic collection of *possible* phases of care and the corresponding responsibilities. Not every paraplegic runs through all phases.

For all legal insurances, there are also private insurances, which stand either in place of the legal insurances or as a supplement. Base is an individual contract. Moreover, it may get in case of liability claims to a recovery of financial expenditure of the legal insurance. E.g. in case of early retirement after an alien-inflicted accident: Not only the pension is taken from the opposing party liability insurance until official retirement age, also the outstanding pension contributions (see SGB X §115ff).

^aResponsible for the elimination of the consequences of an accident on the way to work, on the way from work to home or during work.

^bUsually not 100% financing, but exclusive own contribution.

^cCommunity-based health care is for people of all ages who need health care assistance at home. Community care services include home support, general practitioner, PRM specialist, nursing, physiotherapy, but also other rehabilitation services.

^dBrackets mean that this is only in exceptional cases applicable.

^eThis means retraining measures beyond the vocational rehabilitation.

^fFor example, sick pay, compensation for damages or care allowance.

GSLC, German Social Law Code (dt. Sozialgesetzbuch (SGB)).

arrangements in Germany.²¹ Social welfare takes over if the payment from all insurance is rejected. Nursing care insurance only assumes the costs if the need for care was formally confirmed.²²

There are a number of legal regulations regarding the lives of people with disabilities in Germany. The Act on Equal Opportunities for Disabled Persons, in place since 2002, ensures equality and accessibility in the public sector to prevent discrimination.²³ It regulates, that “buildings or other facilities, public ways, squares and streets as well as public traffic facilities and means of public transportation should be accessible.” Although the law was passed 13 years ago, it has not yet been fully implemented.²⁴

Finally, the ninth volume of the German Social Insurance Code mandates that disabled persons receive certain benefits to participate independently and adequately in social life.²⁵ This provision also deals with issues of participation in the work force, the redesign of the workplace, job assistance, wheelchair access, automobile assistance, and accessibility of facilities and homes. If re-entering into the primary profession is not possible, further education or retraining may be granted. Private and public employers with at least 20 jobs available monthly, per year on average, must offer 5% of their jobs to people with a severe disability. If this integration does not occur, a compensation charge must be paid. Despite these provisions, job integration after SCI has reached a proportion of 60%.²⁶

Since traffic accidents are the main cause of SCIs in Germany, the information campaign, “Slow down,” was initiated. Numerous posters on highways and country roads have promoted public awareness of the consequences of risky behavior to reduce the number of serious traffic accidents involving fatalities.²⁷ The prevention campaign of the German foundation for patients with SCI, “Risk makes no sense,” provides information about risks associated with sporting activities. School projects advise children and adults of the risks and consequences of risky behaviors.²⁸

A campaign to improve the folic acid intake of the German population to reduce neural tube defects was initiated in 2006 but was not implemented successfully.²⁹ Although the number of prenatal neural tube defects in Germany compared to other European countries is very high (12.36 new cases per 10,000 child births in Germany compared to 7.88 new cases per 10,000 child births in Europe),³⁰ there are only recommendations for folic acid supplementation before conception. A program for folic acid fortification for food has not yet been established.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

Although the overall situation for persons with SCI in Germany is fairly good, it is always possible to improve medical care and extend the social response to improve their lives. We eagerly await the information to be gathered from the German national study using the InSCI protocol so that gaps in the picture of those living with SCI in Germany are filled, and better policies can be devised.

The National Study Protocol

The German research project, “Spinal Cord Injury in Germany—A Study on the Health and Living Conditions of Affected People,” is a partial project of the ISPRM/WHO collaboration plan (2014–2017). It is designed as an exploratory cross-sectional study based on the design of the Swiss Spinal Cord Injury Cohort Study (SwiSCI-Study) of Swiss Paraplegic Research. It provides, for the first time, an overview of the general health situation, medical care, and job situation as well as social participation in Germany. This promotes the recognition of current problems as well as the implementation and control procedures of health and social policy.

For data collection, contact with cooperating partners, namely, the SCI specialized centers, is planned. The existing address database is used to invite those who meet the inclusion criteria. The use of the database will allow for the inclusion of a large number of patients, will probably establish confidence, and could increase the willingness to participate. Included are persons with SCI (traumatic or nontraumatic, including vascular, inflammatory, and tumor-related causes, as well as congenital SCI) who have already completed their first rehabilitation. Study participants must be at least 18 years old and live in Germany. The questionnaire will be available both in German and English.

Data collection is based on a semistandardized questionnaire, which will be Web-based or paper-based, depending on

the preference of the participants. It is also possible to complete the questionnaire with the help of the study staff by calling the study coordinators if an independent completion of the questionnaire is not possible owing to a functional limitation.

The cooperating SCI centers will send the study documents to their clients, including an invitation to participation in the study, subscriber information, the questionnaire, a Web link, and an online access code for the possibility of Web-based completion, and a return envelope. Study participants will decide which form—paper or online-based—they will use. Participating in the study means completing and sending the questionnaire to the center of the study, and participants agree to follow the study conditions. A written reminder will be sent 4 to 6 weeks after the first letter, depending on the response rate. If the online-based questionnaire is not completed in full, these incomplete questionnaires can be identified by the ID number. The cooperating partners then will inform the study participants again.

CONCLUSION

The improved medical care and social response allowed an independent and integrated life in Germany, even with spinal cord injury. Legal regulations make the realization of appropriate care possible, so that medical care as well as social participation is ensured. However, it is still unknown whether these regulations are being implemented. Furthermore, there is no reliable data about the subjective health or life situation of affected people. The planned study should offer a very first overview about the current situation and could be used to provide a hypothesis and to initiate new research projects.

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People with Spinal Cord Injury in Greece

Christina-Anastasia Rapidi, MD, PhD, SFEbPRM, and Athanasios Kyriakides, MD, FEBPRM

EPIDEMIOLOGY OF SPINAL CORD INJURY IN GREECE

There are no reliable epidemiological data regarding the incidence, prevalence, and mortality rate after spinal cord injury (SCI) in Greece.¹ The only evidence available comes from studies that cover only a small part of the total Greek population.^{2,3} The larger study available reports an annual incidence rate of 33.6 per million, and transportation accidents are reported as the leading causes of injury. (The study refers to the greater Thessaloniki region, consisting of Central and Western Macedonia. The reported data correspond to the years 2006–2007, where the population of this region was approximately 2 million inhabitants. In the same years, the Greek population was 11.16 million inhabitants.) The percentage of injured males was significantly higher than that of the females.²

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

There are emergency medical services available to all citizens in Greece, regardless of their financial or insurance status. The National Centre of Emergency Health Care (EKAB) was founded in 1985 (according to the law, no. 1579/1985) and is a public entity supervised by the Ministry of Health, responsible for coordinated first aid and emergency medical care to citizens and their transfer in health care units.⁴ Highly skilled health personnel trained in emergency services reach the place of injury by ambulance or helicopter depending on the geomorphology. Services of the EKAB services are established and operating in 12 regions all over Greece as stand-alone branches. Each EKAB branch is responsible for a particular geographical region.⁵ The geomorphology of Greece (several remote islands and mountains) has significant effect on mean transfer delay at hospital.⁶ In the areas the EKAB services can reach the injured person, acute care starts even before the patient reaches the emergency department, with spinal immobilization principles, which are well established in Greece, and are followed to prevent secondary injury to the cord (data provided by the EKAB medical service).

In Greece, given the absence of specialized centers for SCI, patients with acute SCI are admitted to orthopedic,

neurosurgery, or specialized spine surgery departments of general hospitals.

Rehabilitation services should begin in the intensive care setting.⁷ However, most of the times, owing to lack of rehabilitation teams providing health care in the acute SCI stage, initial rehabilitation management is limited to physiotherapy. After the acute phase, usually during the first month after injury, patients are transferred to public or private rehabilitation departments, where the interdisciplinary approach of the rehabilitation team is provided. According to Hellenic unpublished data, the average initial hospitalization in Rehabilitation Departments is 7 months.⁸

The prevalence of patients with SCI of traumatic and nontraumatic origin represents 5.7% of the total number of rehabilitation beds. Patients with SCI of traumatic or nontraumatic origin are dispersed in several rehabilitation centers, and the average number of patients with SCI is 3 patients per center.⁹ During inpatient rehabilitation, persons with SCI and their family members or significant ones receive information and training regarding bladder and bowel management and skills such as transferring, wheelchair skills, and assistance for activities of everyday living. Information concerning sexual function, fertility issues, and psychological burden is poorly addressed, however.¹⁰

Entering the chronic phase, a large percentage of Greeks with SCI have follow-up services provided by physical and rehabilitation medicine (PRM) physicians in rehabilitation departments. However, individuals with SCI (25.4%) seem to lose their initially gained independence with activities of daily living (ADL) during follow-up.⁸ In case of an emergency, these patients visit the emergency department of a general hospital, where physicians of specialties other than PRM treat them.¹¹

In addition, geographical region seems to affect the follow-up services. Distance from health facilities, lack of access to means of transportation, and unavailability of adequate infrastructure and human resources are reported as the main reasons.¹²

In general, Greeks with SCI are not adequately prepared for the transition to live in the community. There are no policies to facilitate housing modifications and return to work. Furthermore, in the current period of economic crisis, even basic issues like assistive devices are not considered priorities. Consequently, individuals with SCI use inappropriate equipment resulting in complications, many of which could have been prevented.^{13,14}

LIVING WITH SCI

A young person with SCI faces many obstacles to return to school. It is difficult to overcome feelings of low self-esteem, and there is not always organized counseling available, or other

From the PRM Department, General Hospital “G. Gennimatas”, Athens, Greece (C-AR); and PRM Department, University Hospital of Patras, Rio, Patras, Greece (AK).

All correspondence and requests for reprints should be addressed to: Christina-Anastasia Rapidi, MD, PhD, SFEbPRM, PRM Department, General Hospital “G. Gennimatas”, 154 Messogeion, 15669 Athens, Greece.

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preparatory supports. In addition, the lack of teachers trained in the needs of children with SCI, as well as bullying by other students can have a negative impact on their decision to return to school. Finally, exclusion of the educational system is often due to physical environmental barriers. Greece needs to prepare a practical education policy, strategies for making school buildings accessible, as well as to provide educators trained in the needs of children with SCI.

The State is making promising steps toward vocational reintegration, but it must be noted that vocational counselors do not participate in the rehabilitation team. As far as employment is concerned, obtaining a job or returning to a preinjury employment is also a challenge. Lack of vocational rehabilitation, counseling and preparation, and inappropriate work adjustments and accommodations exclude people with SCI from most jobs.¹

THE HEALTH AND REHABILITATION SYSTEM

A public-private combination of both funding and service delivery characterizes the Greek health care system. The National Health System provides universal coverage to everyone and operates according to the principles of equal access to health services for all. Insurance coverage of hospitalization costs in public rehabilitation centers is 100% in contrast to private rehabilitation centers, where only 50% or less is covered.

Greece has one of the highest rates of physicians (6.2 per 1000 population), and one of the lower rates of nurses (3.3 per 1000 population).¹⁵ Unfortunately, very few of them are trained in SCI rehabilitation issues.

Nowadays in Greece, inpatient rehabilitation facilities have significantly increased compared to some decades ago.^{1,9} Rehabilitation services for the acute and postacute phases of SCI are provided in general hospitals and rehabilitation centers, in the public and private sectors. Public rehabilitation structures are lacking: there are only 5 public PRM departments in general hospitals and the National Rehabilitation Center, all of which are located in Athens, with a total of 234 beds (data provided by the Hellenic Society of PRM). There are also several regional public rehabilitation departments in Greece, but owing to lack of qualified staff, they are not in use or they function below their capacity. More than 2000 rehabilitation beds have emerged in the private sector during the past decade, located in semi-urban areas and towns in different areas of Greece.⁹

WHAT IS THE STATE OF SPECIALIZED CARE?

No national health strategy for people with SCI has ever been designed in Greece.

The first Rehabilitation Department for people with SCI in Greece was founded by private sponsorship in 2010.¹⁶ It is part of the General University Hospital of Patras, the third largest city of Greece, covering a population of approximately 1 million people. Unfortunately, the foundation of the hospital coincided with the economic crisis in the country. As a result, it remains understaffed, and many inpatient and outpatient services are not fully developed. The lack of resources also affects the outpatient services and the efforts toward the prevention of secondary conditions and complications of SCI. Efforts for creating a proper interrelation between acute medical care, rehabilitation, and community integration are in development.¹⁷

In general, Greek health care system still faces problems related to lack of trained health staff. Very few of Greek rehabilitation therapists work as members of a rehabilitation team.¹⁸ Most work in their own private offices. Even fewer therapists are specialized in SCI rehabilitation. Although there are well-trained PRM physicians in SCI, the lack of specialized spinal cord units has a negative effect in the quality of care. Furthermore, the rehabilitation services provided by the general rehabilitation centers are not reliably assessed.¹⁹

People with SCI have access to assistive technology such as wheelchairs and home equipment. According to the legislation in force since 2012, approximately 50% of the actual cost of these devices is covered, whereas necessary home adaptations are not covered at all.²⁰

THE SOCIAL RESPONSE TO SCI

A telephone survey conducted in November 2013 revealed that persons with mobility impairments (including paraplegia and tetraplegia) face difficulties related to financial issues (51.6%), public services (49.1%), and discrimination and social exclusion (29.0%).²¹ Another recent study on wheelchair users reports significant poor quality of life.²²

Home accessibility represents a major challenge for people with SCI, and public means of transport (buses and trains) are often wheelchair inaccessible. In Athens, most metro stations are wheelchair accessible. Wheelchair-accessible private taxis are available, but their drivers must be informed in advance. Issues of accessibility are addressed in a very popular SCI community site: <http://www.rollout.gr>.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the International Spinal Cord Injury Study?

To improve SCI management, it is necessary to better understand rates of occurrence and to have a clear view of the incidence and prevalence of SCI. This knowledge will enable health care providers to estimate both the cost and psychosocial burden of SCI and the resources required for SCI management.

International spinal cord injury (InSCI) survey will help us toward this direction. The Greek translation of the InSCI survey questionnaire will be reviewed and approved by a research ethics committee before the operational phase of the survey. Patients with chronic SCI (≥ 1 year after injury), of sudden onset (traumatic or nontraumatic), age 18 years or older, community dwelling, residents of Greece, capable of answering the survey questionnaire, and without concomitant cognitive impairment will be included. Persons with progressive etiologies of SCI will be excluded. Participants will be informed through letters and telephone calls from member lists of associations of persons with disabilities and SCI and through hospitals' and associations' Web sites. Information will also be provided during their regular reassessment as outpatients in rehabilitation departments. Letters and telephone calls will be used as reminders. Means of contact (first contact and reminders) will be with mixed mode of written invitation letter, e-mail, postal mail, and telephone. Methods of data collection shall include online questionnaire, paper-and-pencil

questionnaire, interviews (possibly computer assisted), face-to-face (eg, hospital, at home), and telephone call. Data will be collected, stored, processed, and strictly protected by members of the Greek InSCI study. Local database should be organized and connected to the international database.

During our national PRM meeting in February 2016, in Athens, the Greek translation of the International Perspectives on SCI and the InSCI survey were presented to the scientific community and authorities. It is expected that successful IPSCI implementation and InSCI survey will give the opportunity to develop national data of people with SCI in Greece and encourage policy makers toward decisions that will improve the situation for persons with SCI in Greece.

CONCLUSION

As a consequence of the absence of specialized SCI units in Greece, patients with SCI are admitted to various rehabilitation centers, where the provision of health care services is often suboptimal with regard to specialization and comprehensive rehabilitation. Current challenges include the following: (1) the identification of the incidence and prevalence of individuals living with an SCI in Greece; (2) the identification of their needs during the chronic phase; (3) the provision of long-term follow-up and maintenance of their functional capacity during aging; (4) the appropriate training of health care professionals not specialized in SCI issues; and (5) the support of public initiatives that challenge negative attitudes to disability.

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People with Spinal Cord Injury in Indonesia

Angela Bibiana Maria Tulaar, MD, PhD, Muhammad Karyana, MD, MPH, Luh Karunia Wahyuni, MD, Anitta Florence Stans Paulus, MD, Damayanti Tinduh, MD, Fitri Anestherita, MD, and Grace Wangge, MD, MSc, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN INDONESIA

The epidemiological data of spinal cord injury (SCI) in Indonesia are now currently being collected. In 2014, 104 SCI cases were registered at the Fatmawati General Hospital whereat 37 had traumatic and 67 had non-traumatic SCI as origin. The most common etiologies of traumatic SCI were car accidents and falls from heights, whereas the major causes for nontraumatic SCI were infection and neoplasm.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

After an accident-related SCI occurred, the patients are referred to emergency services by the rescue team, where they are treated as cervical trauma cases. The patients are transported to the nearest hospital by ambulance, which is the major transportation of choice, or by helicopter, which is available only in the private sector. Upon arrival at the emergency room, the patients are received by the frontline staff who are certified physicians in Advanced Trauma and Cardiac Life Support—standard requirements for physicians working in hospitals in Indonesia. If the injury requires surgery and intensive care, the patients are assigned to a neurosurgeon or orthopedic surgeon to obtain further medical intervention. Afterward, they will be transferred to the intensive care unit (ICU) for stabilization. Every hospital has an ICU in Indonesia, but the units do not have special standard care for patients with SCI. Patients in stable condition are transferred to the acute care and usually need an average length of stay from 1 to 2 weeks. After discharge, patients are trained to continue with the rehabilitation program and to have regular medical consultation in a hospital every 3 months.¹

There are only 2 hospitals in Indonesia that have special units for SCI services, which are the Fatmawati General Hospital in Jakarta and Prof. Dr. R. Soeharso Orthopedic Hospital in Solo. Other hospitals that have qualified staff and facilities for neurosurgeons, vascular surgeons, cardiothoracic surgeons, orthopedics, intensive care, anesthesiology, and rehabilitation are also

allowed to provide medical services for SCI patients. Currently, Indonesia has 163 neurosurgeons, 65 cardiothoracic surgeons, and 19 vascular surgeons. Rehabilitation units are available in all types of hospitals, but still have limited human resources with specific SCI rehabilitation skills. Most of these hospitals provide only general medical rehabilitation services. When patients become outpatients, they are suggested to have regular medical evaluations (usually every 3 months) in a hospital.¹

Rehabilitation services in Indonesia have some limitations. Most SCI patients use health insurance provided by the Social Security Administrators (Badan Penyelenggara Jaminan Sosial [BPJS]) to cover for rehabilitation services. Nevertheless, BPJS covers only for limited types of orthosis, prosthesis, or assistive devices for patients. Rehabilitation facilities such as specialized rehabilitation wards are also limited. The numbers of medical staff with specialization in SCI medical care are limited, and they are not evenly distributed among hospitals in the country.

Patients with SCI face many problems in the society. They have problems with accessibility to travel from home to the outpatient care in assigned hospitals because of lack of facility, money, or caregiver. They also have problems with the availability of a qualified caregiver once they are discharged from hospital. Caregivers, who are usually a family member, do not have sufficient training or capabilities to care for the patient at home. In most cases, patients end up being treated at community care centers, which are still limited in Indonesia.

LIVING WITH SCI

Special education for people with disabilities is limited in Indonesia. Schools that accept students with disabilities are rare.² Indonesia has laws and regulations to facilitate return to work for the disabled. Law No. 4/1997 and Government Regulation No. 43/1998 detail specific efforts to improve social welfare of people with disabilities, including the obligation quota of 1% in public and private institutions with a minimum of 100 employees, support for rehabilitation, and job placement for workers with disabilities in the private sector (Circular Letter of the MOMT 2002).^{3,4}

There are some vocational rehabilitation premises available in Indonesia where many supporting facilities are provided and produced. For example, the Great Hall of Vocational Rehabilitation for Disabled by the Ministry of Social Affairs Republic of Indonesia (annual capacity: 140 people) in Cibinong, West Java, and the Great Hall of Social Rehabilitation for Disabled Prof. Dr. R. Soeharso, with a capacity of 300 people, in Solo, Central Java.

Despite the governmental regulations, nearly 70% of people with disabilities in Indonesia are unemployed. Contributing

From the Indonesian Physical Medicine and Rehabilitation Association (PERDOSRI), Pulo Gadung (ABMT, LKW, AFSP, DT, FA); National Institute of Health, Research and Development, Ministry of Health Indonesia, Johar Baru (MK); and Department of Community Medicine, University of Indonesia, Menteng (GW), Jakarta, Indonesia.

All correspondence and requests for reprints should be addressed to: Luh Karunia Wahyuni, MD, SpKFR(K), Indonesian Physical Medicine and Rehabilitation Association (PERDOSRI), Jl. Cakalang No. 28, Pulo Gadung, Jakarta 13220, Indonesia.

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factors to this situation are the lack of understanding and awareness of the potential and capabilities of people with disabilities, lack of opportunity to participate in education and training, and lack of confidence.⁵ The occupational profile of persons with SCI is not yet available, but there is an impression that the majority of people with SCI do not work as an employee, but they rather open independent handicraft business. In Indonesia, the majority of people with SCI have access to wheelchairs, but approximately 10% of the 24 million persons with disabilities who require assistive devices cannot afford them. These people must crawl, be carried, or simply stay at home. Many individuals with SCI who are fortunate to access mobility devices receive support from the United Cerebral Palsy Wheels for Humanity (UCP-Roda Untuk Kemanusiaan [UCPRUK]).⁵ UCPRUK focuses on providing appropriately designed, low-cost wheelchairs (standard, pediatric, rough terrain, and sport) and other mobility devices throughout the country with an emphasis on quality service and long-term sustainability. Their products enable children to go to school and to socialize, help adults to earn an income and participate in their communities, and help families to care for their loved ones. Manufactured in Jakarta, the wheelchairs are approved by ISO (International Organization for Standardization) and exported to the United States and Europe.

THE HEALTH AND REHABILITATION SYSTEM

Public and private health insurance companies are available in Indonesia. In the public sector, there are 2 insurance arrangements, *Jasa Raharja* and the universal health coverage provided by the newly created BPJS. The latter allows patients with SCI to be referred to advanced level of health services, including outpatient services (for medical examination, consultation, procedures, drugs, diagnostic tools, and rehabilitation) and inpatient services (for non-ICU and ICUs). Private insurers include Allianz Indonesia, Prudential Indonesia, Zurich Insurance Group in Indonesia, AXA General Insurance Indonesia, Panin Dai-ichi Life, and ANZ Indonesia. Primary care facilities are easy to access in the country, with nearly 9600 clinics scattered throughout the country.⁶ Nearly all primary health care services are covered by insurance. Currently, there are more than 561 physiatrists (data collected in July 2015), 3646 physiotherapists, 288 occupational therapists, 244 speech therapists, and 93 orthotics and prosthetics practitioners.⁷ The number of health workers nationwide is adequate, but their distribution is uneven.

WHAT IS THE STATE OF SPECIALIZED CARE

Several hospitals have SCI-related treatments in intensive care, surgery, and anesthesiology. They employ neurosurgeons, vascular surgeons, and orthopedic, for example. SCI rehabilitation services are provided in the Fatmawati General Hospital in Jakarta and Prof. Dr. R. Soeharso Orthopedic Hospital in Solo.¹

In Indonesia, rehabilitation services for people with SCI are provided by well-trained health professionals such as physiatrists, nurses, and allied health professionals, including physiotherapists, occupational therapists, speech therapists, social workers, orthosis-prosthesis practitioners, nutritionists, and psychologists.

Community care support for reintegration of patients with SCI is available in Indonesia, at, for example, the Prof. Suyoto Hospital-Rehabilitation Centre of the Ministry of Defense Indonesia, nongovernment organization: Cheshire, Sasana Bina Daksa Budi Bhakti Pondok Bambu, and YAKKUM Rehabilitation Center Yogyakarta.⁸ Even though there is a current good coordination with nongovernment organizations specializing in SCI, the amount and quality of cooperation should be further improved.

Spinal cord injury-relevant assistive devices available in Indonesia are sets for canes and crutches, standard walkers, reciprocal walkers, rolling/gliding walkers, reverse walkers, manual wheelchairs, electric wheelchairs, and spinal orthotics. The majority of people with SCI, like most others with disabilities, have limited access to assistive technology.⁵ However, there are some nonprofit organizations that facilitate the availability of wheelchair and other mobilization and ambulation aids to people in need.

THE SOCIAL RESPONSE TO SCI

Indonesia has social protection laws to reduce poverty and social isolation of persons with disabilities, such as Law No. 13/2011 about poverty management and Law No. 11: 4-6/2009 about social welfare. The Occupational Injuries Benefits Program (Jaminan Kecelakaan Kerja [JKK]) is expected to become a social protection law, which is designed to improve the independence of persons with disabilities.⁹ Participants of JKK with occupational injuries or diseases are entitled to receive JKK benefits in the form of health services according to medical needs and financial compensation. Financial compensation includes reimbursement for transportation cost to the hospital and/or work and first aid fees. Temporary compensation is also available for participants who are unable to work until they receive confirmation to be cured or impairment reduced based on a medical certificate.

Rehabilitation costs include orthosis or prosthesis reimbursement with a certain cost that is applied in the Rehabilitation Centre of Public Hospital plus 40% of the cost. Although the accessibility of wheelchairs distributed in public areas and buildings around urban areas in Indonesia is making progress, there are still many obstacles in other areas. Public spaces are still not taken into account for the ease of movement for persons with assistive devices such as wheelchair or crutches. Special parking spaces for the disabled are not available. Doors to public buildings are not designed to be easily opened and closed, locked, and traversed by people with mobility disabilities, nor are ramps, stairs, and elevators. Accessible toilets are rare; pedestrian paths are impassable and unsafe. Public transportation is equally inaccessible.² Because SCI cases in Indonesia are mostly caused by vehicle accidents, one of the existing prevention regulations is basically on vehicle safety and driver's behavior that are rigorously enforced by the Indonesian National Traffic Police Corps. In addition, with myelitis tuberculosis (TB) as the most common cause of nontraumatic SCI in Indonesia, the government has launched a national TB prevention program, which is part of the National Strategy for Controlling TB in the country in 2010-2014.¹⁰

In addition, approximately 370 organizations are available in Indonesia to support people with disabilities and their

families. Other agencies that provide funds to people with SCI are the Ministry of Social Affairs and JSPACA (Jaminan Sosial Penyandang Cacat Berat)–Cash Transfer for Disabled People.¹¹ There are also international and local private organizations that offer funding to people with SCI such as the Disability Rights Fund, Kick Andy Foundation, Handicap International Indonesia and Timor Leste Program, BILiC (Bandung Independent Living Center), Yayasan Wisma Cheshire (YWC), Kupu-Kupu Foundation, and the Bhakti Luhur Foundation.¹²

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

We expect to identify the response of the health system with respect to mortality, morbidity, and functioning by providing adequate emergency and acute care, and rehabilitation services, opportunities in education, employment, and lifelong support. We also expect to compare and learn from other countries' experiences that have been successful in increasing the quality of functioning and well-being of people living with SCI in relation to health and related systems, policies, services, and care provision.

The National Study Protocol

The Indonesian Physical Medicine and Rehabilitation Association (Perhimpunan Dokter Spesialis Kedokteran Fisik dan Rehabilitasi Indonesia [PERDOSRI]) will coordinate the national study protocol for the InSCI study. They collaborate with the Ministry of Health, Data Collection and Information Center, and 13 branches of PERDOSRI in acquiring the data.

The current research plan is divided into 3 phases. The first phase is creating the SCI profile data in Indonesia. The incidence and prevalence data of SCI in Indonesia have not yet been completed; thus, this research must be performed. The second phase includes the validation study of International Classification of Functioning, Disability and Health core set tabulation in Bahasa by 5 physical medicine and rehabilitation specialist education centers in Indonesia. The third phase is the International Classification of Functioning, Disability and Health core set implementation of measuring SCIs.

There are 510 registered physiatrists distributed in 33 provinces and working in the public and private hospitals. SCI rehabilitation is complicated; thus, physiatrists and a medical rehabilitation team working in types A and B hospitals will manage the treatment. Patients who are hospitalized in types A and B hospitals are selected based on different etiologies of SCI managed by orthopedics, neurosurgeons, and neurologists. Patients in type C hospitals will be referred to type A or B for acute management.

This research will use medical records and the data collection method that should receive ethical approval from the Ethics Committee of Research and Development, Ministry of Health Republic of Indonesia, and the medical committee of each hospital. Physiatrists record the data written on medical records in which the diagnosis was made based on the *International Classification of Diseases, 10th Revision*. Afterward, the data will be

delivered to the secretariat of PERDOSRI to be processed and recapitulated. Indonesia is a large country, and disability has not been a main public health issue. Acquiring the data, such as the mortality rate of SCI, case-fatality rate of traumatic SCI, and life expectancy postinjury data, is very challenging.

OPTIONAL NATIONAL MODULE

We are proposing to construct an additional module for Indonesia that will look at the following considerations:

1. Evaluate the SCI data and the following conditions because most SCI patients ($\pm 50\%$) who were suggested to have outpatient service did not continue the rehabilitation program or control regularly.
2. Determine the factors that prevent return to work and school for people living with SCI because the national number of persons with disabilities who work is estimated to be less than 30% of the total disabled population.

CONCLUSION

Persons with SCI require more attention from the Indonesian Government from the perspective of prevention, health promotion, and rehabilitation. Because the country is located in an archipelago with a tropical climate that shows a high incidence of acute and chronic infections, the government attention is focused on these health problems. Regarding this situation, SCI has not received serious attention, and the patients face different difficulties.

Although there are laws that regulate the protection of the rights of persons with disabilities, the government is committed to ensure that public health services throughout Indonesia incorporate people with SCI. Because of national campaigns, there are improving societal attitudes toward persons with SCI. However, many challenges remain:

1. The number of health professionals specialized in SCI and the number of specialized SCI centers are still limited.
2. Not all of the treatment costs and assistive devices, orthotics, and so on are covered by the BPJS.
3. The number of vocational rehabilitation training halls is limited.
4. The rate of persons with disabilities to return to work is very low.
5. Educational services have not been fully accessible to person with disabilities.
6. Public buildings, public areas, and public transportation are not fully accessible.

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People with Spinal Cord Injury in Israel

Manuel Zwecker, MD, Julie Wolff, MD, Tamara Shaoul, MSW, Gabi Zeilig, MD, and Iuly Treger, MD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN ISRAEL

There is currently no epidemiological database in Israel concerning spinal cord injury (SCI). The data presented here date back nearly 40 years and are reported in 2 studies carried out at an important site for spinal cord rehabilitation medicine in Israel, the Lowenstein Rehabilitation Hospital.¹⁻³ In 2009, it was estimated that there were 140 new cases of SCI per year. Traumatic SCI was mostly due to vehicular accidents,⁴ work accidents, war violence, and shallow water accidents. The incidence of traumatic cases was more common than nontraumatic cases in persons 40 years or younger. Mortality for all causes of SCI combined stood at 4.8% a year after injury and 13.6% 5 years after injury.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

The SCI patient's journey begins upon arrival of the paramedics at the scene of the accident. Paramedics are specifically trained to handle cases of SCI by providing immobilization of the patient and adequate transport and transfer. Transport to the nearest emergency room is relatively fast because Israel is a small country with a well-developed ambulance service. Rescue in areas without roads is done by means of a specialized helicopter service. The primary rescue team is very professional and well equipped in the provision of emergency treatment in the field. The general population is also educated in basic life support and the immobilization of people injured with suspicion of SCI.

After arriving in the emergency room, comprehensive medical assessments and radiological studies can be performed without delay. Appropriate insurance is checked only after the patient is hospitalized. At all major admitting hospitals, the ambulances are equipped with advanced intensive care facilities capable of stabilizing the survivor's medical condition. If the hospital is small and without a specialized neurosurgical department or orthopedic spine department, the patient is

transferred to the appropriate hospital for further treatment. Today the majority of SCI patients require further surgery for stabilization of the spine. Statistics reveal that 20% of patients with traumatic injuries of the spine have involvement of the spinal cord; 55% to 59% of them needed to be operated on. After the surgery and further medical stabilization, 45% of the SCIs were transferred to rehabilitation.¹

In Israel, 2 neurological rehabilitation departments are specialized in the management of SCI patients. One rehabilitation center is located within a general hospital, whereas the other is in the community. The rehabilitation process depends on the level and severity of SCI and can last up to 6 months. A comprehensive multidisciplinary team approach is provided in light of the patient's special medical needs. On the medical front, SCI-specific issues include deep vein thrombosis and osteoporosis prophylaxis, pain relief, bladder and bowel incontinence, treatment and prevention of pressure sores and contractures, and spasticity management.

The main goals of the inpatient rehabilitation are to achieve maximal functional independence in activities of daily living and to optimize mobility in light of the severity of the injury. The majority of the patients are discharged home, while continuing outpatient rehabilitation in a day care setting or physical therapy in the community. Each neurological rehabilitation department specialized in SCI provides medical regular life-long follow-up outpatient care services after discharge for individuals with SCI.

LIVING WITH SCI

The reintegration of the SCI population into the society is difficult in Israel both on a professional level and a personal level. Funds from the government are provided for education and reeducation purposes. Guidance is also provided for job placement. Unfortunately, we know very little about the everyday life of persons with SCI because there are few available data or research done on, for example, success rates for reentry to work. This lack of statistics also applies to the social and marital status of persons with SCI. In the case of housing, patients from a lower socioeconomic status are provided a stipend; otherwise, they receive a loan. The state also provides funds to help cover rental costs. The level of SCI activity in the community differs from person to person and is dependent on financial means, type of injury, and personality, but the unemployment rate may be as high as 50% of the working-age population with disabilities of all varieties.

THE HEALTH AND REHABILITATION SYSTEM

The health system in Israel is of a mixed type. Each person is covered for their basic needs by the public system. Those who choose to have more specialized insurance or wish to

From the Department of Neurological Rehabilitation, The Chaim Sheba Medical Center, Tel Hashomer and Sackler Faculty of Medicine, Tel-Aviv University, Tel-Aviv (MZ, JW, TS, GZ); Rehabilitation Department, Soroka Medical Center, Beer Sheva (IT); and Council of the Israel Association of Physical Rehabilitation Medicine, Ramat Gan (IT), Israel.

All correspondence and requests for reprints should be addressed to: Manuel Zwecker, MD, Department of Neurological Rehabilitation, The Chaim Sheba Medical Center, Tel Hashomer 52621, Israel.

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see specific doctors go into the private system, which exists alongside the public system. Some patients who use the private system are sometimes reimbursed by the public system. The public system is divided into 4 funding arrangements known as "kupat holim." Every person is obliged to choose 1 of the 4 plans to subscribe to. Israeli veterans are insured separately from the budget of the Ministry of Defense. As in many countries, Israel suffers from a lack of human resources in health care. Yet, help is always provided in emergent cases should it be needed.

WHAT IS THE STATE OF SPECIALIZED CARE?

There are no centers of specialized care in SCI in Israel. The National Insurance Institute in Israel and the Ministry of Health provide assistance in financing rehabilitation equipment, including the funds to adapt homes and to support caregivers. All benefits, health services, and insurances are provided according to the functional and medical needs of those with disabilities and are not specifically related to separate diagnosis such as SCI.

At the same time, SCIs are included in the general health services provided by the government and local institutions. SCI, as well as all other disabling conditions, is covered by the health insurance. According to the Israeli law, every citizen is covered by the public health insurance, whose services are provided by insurance at 1 of the 4 available levels. The insurance provides the population with a wide range of basic but comprehensive health services. More specialized and extended treatments, procedures, and medications, which are not included in the general health insurance, can be acquired only through additional private insurances.

There are a few nonprofit organizations that help survivors with SCI after discharge from post-acute rehabilitation to adjust to living in the community. Social workers in the health funds and veterans groups provide support to people after the injury.

THE SOCIAL RESPONSE TO SCI

On the prevention side, although there are many regulations regarding safety and driver behavior to prevent motor vehicle accidents, these regulations are difficult to enforce, and there are many motor vehicle accidents in the urban and outlying areas, often involving casualties. At the same time, social awareness of the needs of people with disabilities is quite high, particularly in the context of disability resulting from military service. Buses, trains, and train stations adapted the use of wheelchairs. Citizens are also socially aware on public transit.

There are several state programs designed to assist people with disabilities, generally although nothing specifically for persons with SCI. There are few public awareness campaigns, and these are usually initiated by prominent disabled individuals themselves. General awareness of people with disabilities is strong, but accessibility remains an issue.

Today, there are laws that aimed to facilitate the reintegration of people with disabilities to employment by adapting the workplace, providing sheltered employment, and protecting against discrimination. In 1998, for example, a law pertaining to the equality of rights for the disabled was passed. This law includes accessibility recommendations. It also provides the opportunity for government aid to help with the costs of adapting the workplace. An amendment to the law in 2009, which will be gradually implemented until 2022, further promises accessibility for people with disabilities in spheres of living such as education, public places, insurances, and communications. Another recent law from 2009 provides incentive to integrate people into the workplace by not cutting their government stipend after employment and allowing them to earn above minimum wage. Because foreign individuals are the primary caregivers in Israel, there is a strong infrastructure in place to regulate their employment. Private insurers, government funds, and personal funds contribute to the funding of these caretakers.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

We hope to be able to create and present a database representing Israel's current situation regarding SCI survivors, as well as their predominant medical, functional, and social issues. The Israeli national protocol that will be used to create this database will be in keeping with the international study protocol.

CONCLUSION

Currently, the initial care that the SCI population receives is within the hospital setting from the time of injury through to the time to outpatient rehabilitation. The greater challenge for the SCI patient is once he/she leaves the hospital and integrates into the society. The government makes many efforts toward the population of persons with disabilities as a group by providing funding and new laws to enable a smooth integration into the workplace and society, although these laws are not specific to SCI alone. On a practical level, there is still a lack of accessibility for the SCI patient. It is extremely difficult to find information about the patient's experience after hospitalization.

A key part of improving the patient's experience would be to have a better idea of what his/her daily challenges are on a practical level. Based on these analyses, a better plan could be put into place to meet these needs and create more specific programming. It is hoped that Israel's participation in the InSCI study will help to fill that gap.

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People with Spinal Cord Injury in Italy

Alessio Baricich, MD, Angelo Paolo Amico, MD, Mauro Zampolini, MD, Francesca Gimigliano, MD, Carlo Cisari, MD, and Pietro Fiore, MD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN ITALY

According to data from the Gruppo Italiano Studio Epidemiologico Mielolesioni study,¹ the incidence of spinal cord injury (SCI) is estimated to be 2500 cases per year with a prevalence of 60,000 to 70,000 cases for a population of 60 million in Italy. Main causes of traumatic SCI include traffic accidents (54.8%), falls (22%), sports (8%), and work-related (10%) accidents, whereas for nontraumatic SCI, neoplastic tumors (25%), vascular (25%), inflammatory (19%), degenerative (19%), and other diseases (12%) were the main etiologies. Of all SCI cases, 67% were of traumatic origin and 33% were of nontraumatic origin. Sixty percent of patients are paraplegic and 40% tetraplegic. Men are 3 times as often affected as women (4 times as much for traumatic SCI). The median age for SCI is 43 years with a median age of 34 years for traumatic SCI and 58 years for nontraumatic SCI. Fifty-two percent of the traumatic SCI and 24% of the patients with nontraumatic SCI present with a complete lesion.¹ There are no systematic data on mortality in the first year, but it seems that mortality is higher in patients with cervical injury and in ventilated patients.

As there is no national register for SCI in Italy contemporary and reliable information about incidence is lacking, it is difficult to assess epidemiological trends. However, preliminary data from the National Agency for Regional Health Systems study² (2013–2014) indicates that there is a higher mean age of traumatic SCI (48 years), a decrease of SCI from traffic accidents (41%), and an increase in incidence from falls (42%), with a total incidence of 12 to 22 SCI cases per million per annum. A study from the Istituto Studi Direzionali Foundation (2010) showed a relative increase in nontraumatic SCI (45% vs 55% of traumatic SCI).³

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

In the event of traumatic SCI, rescue is provided by an integrated emergency service, which allows the transportation of

the injured to a trauma center, and in particular, unipolar spinal units (USU) are designated for the complex treatment of patients with SCI. The main characteristic of a USU is its multidisciplinary and integrated intervention model. These units take in account clinical, social, and rehabilitative needs, and the acute care and stabilization phases are tightly linked to the rehabilitation phase, which is carried out immediately afterward in the same unit. Unfortunately, only a few USUs exist in Italy, and most of them are located in the Northern areas. In other cases, upon stabilization of the patient, non-unipolar spinal units or general rehabilitation departments provide inpatient rehabilitation. This phase, both in unipolar and non-unipolar spinal units, include medical assistance, nursing, physiotherapy, occupational therapy, psychological rehabilitation, and in some cases, vocational therapy.

On the other hand, in the event of nontraumatic SCI, a dedicated chain of care is still lacking. In particular, a clinical pathway for neoplastic patients with SCI is not available.

After discharge, outpatient rehabilitation is managed in both the spinal units and community-based services, and a follow-up program for long-term care is generally provided by the spinal units. Unfortunately, the links between spinal units and community services are often lacking, and this is an important problem that needs to be addressed.

LIVING WITH SCI

Spinal cord injury has a significant impact on the social life of patients. According to Franceschini et al.⁴ (2012), more than half of the people with SCI reported to be unemployed (57.9%), 34.7% reported to have a job, 7.2% were students, and 0.2% were working students at the time of the interview. Nevertheless, 43.7% had lost their previous employment, whereas 2.0% had gained a position of employment for the first time in their life. Furthermore, among the employed persons, many workers had changed their job type, job timetable, or other job characteristics. Among them, 62.0% reported a worsening in their income after injury. The main causes of unemployment included the difficulty to find a suitable job (31.9%), the public welfare subsidy (31.0%), or industrial accident insurance (34.1%). The source of the economic livelihood comprised of welfare subsidy and salary in 61.3% and 34.7% of the participants, respectively. Approximately 15% of the participants reported to have an underpaid job.⁴

THE HEALTH AND REHABILITATION SYSTEM

The Italian National Health System (NHS) is organized as a public insurance system that provides universal health care coverage. The NHS was created in response to Article 32 of

From the Spinal Unit, Maggiore della Carità University Hospital, Novara, Italy (AB, CC); Department of Health Sciences, Università del Piemonte Orientale, Novara, Italy (AB, CC); Spinal Unit, Policlinico di Bari University Hospital, Bari, Italy (APA, PF); Physical Medicine and Rehabilitation, ASL3 Umbria, Foligno, Italy (MZ); Physical and Rehabilitation Medicine, Seconda Università di Napoli, Italy (FG); and Physical Medicine and Rehabilitation, Università di Bari, Bari, Italy (PF).

All correspondence and requests for reprints should be addressed to: Alessio Baricich, MD, Spinal Unit, Maggiore della Carità University Hospital, Viale Piazza d'Armi 1, 28100 Novara, Italy.

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the Italian Constitution that asserts that the State is responsible for safeguarding the health of its citizens as an individual asset and a community interest. In addition, Article 32 requires that the State guarantees free care to the citizens in need. Reformation Act no. 833 (December 23, 1978) defined the aim of the functions, facilities, services, and activities of the NHS, namely, to promote, preserve, and recover the physical and mental health of population. The intent was to place the individual at the center of the NHS, who has the right to health.

National legislation from 1992 to 1993 and later amendments (1997 and 2000) radically transformed the NHS. Now the political, administrative, and financial responsibility for the health care was delegated to the 20 Italian regions. The result is a variety of health care systems, with predominantly private systems in Northern Italy and mainly public systems in the central and southern areas. This situation makes it difficult to describe the Italian NHS as a unique national system. The Italian State retains a limited general supervisory function, and its sole responsibility remains to ensure uniform and essential levels of health services and assistance across the whole country.

The first organization of physical and rehabilitative medicine (PRM) services took place in 1998, with the publication of the *Italian Guidelines for Physical and Rehabilitation Medicine Services*.⁵ This document established a PRM strategy and a general plan for the treatment of disease, functional and diagnostic assessment, and the development of an individualized PRM project performance evaluation for intervention programs. In this plan, treatments are organized in the following settings: acute inpatient PRM, postacute inpatient PRM (including day hospitals), long-term care and nursing homes, outpatient care, and home care. Reimbursement is based on the setting and the intensity of care, and the daily fee is independent of the severity of the disability. In the context of this very fragmented picture, in 2010, the health minister developed the Italian National Physical and Rehabilitative Medicine Plan to promote homogeneous development of physical and rehabilitative medicine in Italy.

In this plan, the definition of PRM needs is based on clinical complexity, disability, and multimorbidity. Disabled inpatients in the acute phase must be provided with an integrated plan for their individual rehabilitative project (IRP), which contains the various therapeutic settings of the PRM network. The decision-making process is led by a psychiatrist who drafts the IRP, taking into account the functional prognosis, the potential modification of the disability, the patient's degree of clinical stability, and his or her participation in the program. Areas of specific intervention; objectives; professionals involved; settings, methodologies, and methods of PRM; timing for realization; and verification of the intervention are also included in the IRP. The IRP also defines the role of the spinal units.

WHAT IS THE STATE OF SPECIALIZED CARE?

The previously published guidelines (1998) reported the definition of the USU, a multidisciplinary professional organization specialized for the therapeutic, rehabilitative, and psychosocial needs of people with SCI. The clinical pathway starts from the earliest stages of the SCI through prevention of immediate complications, toward the full

recovery of residual functions and the highest possible level of autonomy in the later stages.⁶ The activities that take place within the USU affect all aspects of disability resulting from the SCI: respiratory, neuromotor, bladder-sphincter, psychological, and sexual functions. In addition, in collaboration with the USU, rehabilitation of patients with SCI is also performed in emergency departments to assist clinically stabilized patients with bone marrow lesions of the traumatic and nontraumatic type (infective, vascular, and neoplastic) and without serious respiratory problems.^{6,7}

A critical point is the lack of ad hoc formation in postgraduate medical training. In fact, as recently pointed out in a document developed by the International Spinal Cord Society,⁸ there are several skills and competencies that a trainee would need to develop to work as a medical practitioner in a spinal cord unit, and Italian physical medicine and rehabilitation residency program should be upgraded by focusing on these specific items.

THE SOCIAL RESPONSE TO SCI

Social services provide the possible pathways for return to work for persons with SCI. Specific legislation (Legislative Decree No. 68/99) sets out a specific percentage of the overall work force of a company that must be dedicated to the employment of disabled people. Unfortunately, vocational rehabilitation and specific job training are not part of the Italian rehabilitation facilities except within the network of work injury insurance (National Institute of Insurance Against Work Accidents).

In everyday life, people with disabilities in Italy face several problems. Public buildings and areas are generally not easily accessible to people in wheelchairs, and there is only a limited accessibility to public transportation available. There is also a low awareness of the needs of people with SCI, despite public health campaigns directed specifically to SCI prevention. At the same time, however, several patient organizations for people with SCI exist in Italy, and they play an important role in helping to achieve integration and full participation for all persons with disabilities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

We are using the opportunity of the InSCI study to improve not only the epidemiological information about SCI in Italy but also, and more importantly, to get a sense of the needs and requirements of this group. In fact, even if several scientific societies such as SIMS (Italian Society for Spinal Cord), CNOPUS (Italian Organization of Spinal Unit Professionals) and SIPLeS (Italian Society of SCI Psychology) are actively involved in improving the standards of care and research in Italy, there has been very little amount of literature produced on the health and functioning of persons with SCI in Italy, and this study will help to fill gaps in this research.

We will focus on patients with SCI living in the community; both traumatic and nontraumatic (caused by vascular conditions, infections, benign tumors) cases, among Italian-speaking resident

adults (older than 18 years) who have completed their first rehabilitation. We will exclude nontraumatic, progressive SCI (caused congenitally or from inflammatory and autoimmune disease, malignant tumors, toxic agents, radiations, other neurological progressive conditions) and people with cognitive impairments. Our sampling frame will be drawn from patients' associations, sport associations, the Workers' Injuries Insurance Institute database, and clinical databases from Spinal Unit network. Partners will be contacted to obtain the patient's contact information. Disabled peoples' organizations are often linked to outpatient clinics, including spinal units, so their database will be used (although there may be some bias, since these patients tend to be more active and motivated). There is also a risk of missing data about nontraumatic patients who are often referred to departments other than rehabilitation. First contact will be made by letter or e-mail. Before this, to sensitize the SCI population, posters and flyers will be posted in participating hospitals and announcements made on patients' organization Web sites and newsletters. Before the start of the survey, information on sex, age, level of lesion, and educational level will probably be available for most of the patients.

First contact will be made by an invitation letter or by e-mail invitation letter (with written informed consent). A telephone reminder will be planned 1 month and 2 months after the letter or e-mail in case of nonresponse. We chose a mixed-mode data collection using paper-pencil and online questionnaire. An electronic informed consent form will be provided in the online version of the questionnaire. The paper-pencil questionnaire will be sent after receiving the signed informed consent form. In case of nonresponse after 1 month from the date of sending the paper pencil questionnaire, a telephone reminder will be made. Ethical approval will be carried following standard procedures.

The local database will include patients' personal data (name, age, sex, contacts, and local and international IDs) and basic clinical data (time of lesion and SCI level). The questionnaire data will be stored in a central database at Swiss Paraplegic Research, Nottwil, Switzerland. Data backup will be provided automatically for both databases. Paper-pencil questionnaire will be locally stored in locked rooms. Confidentiality of data will be guaranteed by the use of local and international IDs. Standard procedures will be required for ID assignments, data

entry, and data check and data protection, using local and international passwords.

Once an Italian version of the questionnaire is available, the survey will be conducted in a preparatory and operational phase. The preparatory phase will include fund raising, reaching agreement with envisioned partners, preparing documentation for ethics application, hiring study coordinator and investigators, preparing databases, and checking and preparing availability of information technology infrastructure and other resources. The operational phase includes ID management, mail order and reminder management, daily response management and documentation, systematical filing of paper questionnaires and consent forms, data entry in database, and data quality control.

CONCLUSION

The societal response to the health and social needs of people with SCI is still inadequate in Italy. The most relevant challenges to face include improving health services, in particular, the uneven distribution of spinal units in Italy, and responding to the social impact of the disability associated with SCI. Italy needs better implementation of accessibility to public services and a better integration with job placement services to improve employment after SCI. Nonetheless, some encouraging signals are present, in particular, the key role played by patients' associations that can highlight patient needs and raise awareness across the country.

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People with Spinal Cord Injury in Korea

Zee-A Han, MD, PhD, Bum Suk Lee, MD, MPH, Wanho Kim, MD, Seong Jae Lee, MD, PhD, Hyun Jeong Im, Changsoo Kim, MD, PhD, Kijun Song, PhD, Hyun-Yoon Ko, MD, Moon Suk Bang, MD, PhD, and Chang-il Park, MD, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN KOREA

Korea performs a national disability survey every 3 years, and epidemiological data concerning 15 official disability categories set by the government are provided in open access. It is estimated that 91.7% of the population of persons with disabilities are registered in the National Disability Registry system.¹ The most recent results of the National Disability Survey (2014) estimates the disability prevalence in Korea to be 5.59% (2,726,910 persons).

There is no national spinal cord injury (SCI) registry in Korea. However, the Korean government officially categorizes spinal cord injury–related paralysis into the paralysis section of “physical disability.” Physical disability is further divided into amputation, joint contracture, and deformities, but epidemiological data specific to spinal cord injury are lacking, and thus only an estimation of SCI persons in Korea is possible: According to the 2014 National Disability Survey, estimated persons with physical disability was 1,373,737 with a prevalence of 2.82%.¹ Among the diagnoses that make up Physical disability, the percentage of SCI (cervical, thoracic, lumbar) and myelitis add up to 4.9%, and thus a figure of 67,313 (excluding nonresponders) is a rough estimate of spinal cord injury persons. According to the Statistics Korea (KOSTAT), the total population in Korea is 50,617,000, and thus SCI persons would make up approximately 0.1% of the total Korean population.² (Because very mild SCI persons (ASIA impairment scale D, E) may not be included in these statistics, this figure is only an extremely rough estimate.)

There is no national demographic data specific to SCI. In 1999, Park et al. analyzed demographics of 590 SCI patients.³ Men accounted for 79.6% and the peak age group were those in their twenties (32.5%). Etiologically, 91.2% were traumatic in origin. The National Rehabilitation Center analyzed 3076 SCI patients admitted to the National Rehabilitation Center

between 1994 and 2014 to obtain a rough demographic picture of SCI persons. Among the patients analyzed, 72.9% were men and 27.1% were women. Etiological analysis showed that 80.9% (n = 2488) were of traumatic origin with the most frequent cause being traffic accidents (55.3%) followed by falls (32.1%), sports-related accidents (6.1%), and violence (0.9%). Among the 19.1% of nontraumatic origin, tumor (19.6%) was the most common etiology followed by myelitis (19.2%), spinal stenosis and herniated disc (15.3%), infection (12.9%), and arteriovenous malformation (4.2%).⁴

The National Rehabilitation Center performed an interval analysis of the data to investigate for etiological changes in traumatic SCI between years 1994–2000 and 2008–2014. Results showed that the most common cause of traumatic SCI was traffic accidents, but the percentage had fallen from 64% to 45% in 1994–2000 and 2008–2014, respectively. In contrast, falls, which was the second most common cause of traumatic SCI, had risen from 23% to 43% during the same time intervals implying a change in trends regarding etiology of SCI among SCI patients of traumatic cause. Furthermore, the percentage of incomplete injuries between the two time frames had risen from 70.5% to 82.6%, respectively.⁴

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

After an SCI, emergency services are available regardless of insurance schemes and trained personnel, who follow basic protocols for spinal cord protection, would take SCI patients to tertiary hospitals for acute care. Some tertiary hospitals have specialized SCI units, but the number of those that do is not known, although most tertiary hospitals have the capability to treat SCI in the acute stage with intensive care units and specialized spinal teams.

Most tertiary hospitals also have rehabilitation departments, and thus a transition to the subacute phase would typically include rehabilitation. After or during the subacute phase, patients would be transferred to rehabilitation departments in other tertiary, secondary, or rehabilitation-specific hospitals.

LIVING WITH SCI

The impact of SCI on an individual is multifaceted. However, with adequate health care and fulfillment of rehabilitation needs, the impact can be cushioned and minimized. Unfortunately, due to the lack of epidemiological and socioeconomic data regarding SCI, little is known about the lived experience. In 2012, the Korea Spinal Cord Injury Association (KSCIA), a nonprofit organization by SCI persons, conducted

From the Departments of Spinal Cord Injury Rehabilitation (ZAH, BSL), Public Rehabilitation Service (WHK, HJI), and Neurorehabilitation (SJL), National Rehabilitation Center, Seoul, Korea; Departments of Preventive Medicine (CSK) and Medical Informatics and Biostatistics (KJS), Yonsei University College of Medicine, Seoul, Korea; Department of Rehabilitation Medicine, Pusan National University School of Medicine, Busan, Korea (HYK); Department of Rehabilitation Medicine, Seoul National University, College of Medicine, Seoul, Korea (MSB); and Department of Rehabilitation Medicine, Konyang University, Daejeon, Korea (CIP).

All correspondence and requests for reprints should be addressed to: Chang-il Park, MD, PhD, Department of Rehabilitation Medicine, Konyang University, 158 Gwanggedong-ro, Seo-gu, Daejeon, Korea.

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a self-report survey with a randomized sampling of its members. Out of the 307 respondents, 303 were obtained and analyzed. According to the survey results, 69.6% responded that they were employed before SCI. These rates dropped to 13.0% after experiencing SCI.⁵ However, due to the scarcity of sampling, it is extremely difficult to say that these results reflect the whole SCI population in Korea.

THE HEALTH AND REHABILITATION SYSTEM

Korea does not have a single health care and rehabilitation policy regarding SCI. However, Korea is making enormous efforts to improve health care provision for persons with disabilities through reforms in policy and legislation, financing and affordability, service delivery, and human resources. Every 5 years, the Ministry of Health and Welfare reviews its legislation and policy in light of social welfare guidelines that help to raise awareness to the need for appropriate legislation to improve healthcare service delivery for persons with disabilities.⁶

Korea has universal health coverage managed by the National Health Insurance Corporation. Thus, all Korean citizens are enrolled in the National Health Insurance (NHI) of Korea. Moreover, 5–20% of inpatient and 30–60% of outpatient medical costs are paid out of pocket, and the remaining costs are reimbursed by the NHI, depending on the type and level of medical institution visited by the beneficiary.⁷ For those with the lowest income, both NHI insurance fees and out-of-pocket medical fees are exempt and covered by the government. Currently, about 17.1% of the population of people with disabilities and 12.4% of those registered as having physical disability (which includes SCI) are within this lowest income population and so qualified for exemption of these fees, compared with 3% of the general population.⁶

Most treatments after SCI including acute care, specialized treatment, and rehabilitation are reimbursed through the National Health Insurance. However, traffic accident insurances cover medical costs related to traffic accidents, and worker's compensation insurances reimburse for medical fees involving work-related accidents. The NHI also reimburses for assistive devices and 80% of the upper limit of standard costs defined by the NHI Corporation is reimbursed by the NHI.⁷

WHAT IS THE STATE OF SPECIALIZED CARE?

Korea has made efforts to improve service delivery in the subacute phase by evenly redistributing rehabilitation services in Korea. Currently, there is one National Rehabilitation Center (NRC) in Seoul that provides subacute rehabilitation services and research data regarding disability care. The NRC coordinates and guides rehabilitation services in the 6 provincial rehabilitation centers, 17 community rehabilitation hospitals, and 113 regional public health centers in Korea. There is also a university-affiliated hospital, Yonsei University Severance Rehabilitation Hospital, which provides coordinated rehabilitation services in various fields from the acute phase of rehabilitation and onward. The National Traffic Injury Rehabilitation Hospital is a hospital affiliated with the Ministry of Land, Infrastructure and Transport and is specialized in rehabilitation associated with traffic accident-related injuries. Korea has 82

training hospitals with rehabilitation departments that run comprehensive residency programs.

Korea has continually strived to increase the specialized pool related to rehabilitation. The Ministry of Health and Welfare currently certifies physicians specialized in rehabilitation through board examinations since 1983. Currently, there are 1855 certified specialists and 514 doctors in rehabilitation training residency programs. The certification process has been expanded to include physiotherapists, occupational therapists, orthotists and prosthetists, and speech-language therapists.

THE SOCIAL RESPONSE TO SCI

In light of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), Korea has strengthened health care service provision, including provision of assistive health products, ensuring barrier-free hospitals, providing caregiver support, and facilitating transportation. The significance of capturing the "lived experience" of people with disabilities within nations has been emphasized in Article 31 of the CRPD, according to which data collection relevant to the lives of persons with disabilities is no longer an option but a basic human right that must be undertaken by its member states.⁸ For Korea, the collection of data on persons with disabilities has been ongoing since 1980. Article 31 of the Korean Act on Welfare for Persons with Disabilities mandates a national disability survey where problems are identified and policies are formulated on the basis of such data to give effect on the identified shortcomings of the realities of persons with disabilities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain From Participating in the International Spinal Cord Injury Study?

The Korean team (KoSCI team) has been organized to lead The Korean Spinal Cord Injury Cohort Study (KoSCI) through the International Spinal Cord Injury (InSCI) study. The KoSCI team aims to develop a Korean protocol that will ultimately use the InSCI survey as a basis to formulate a Korean SCI database that will have common questions with the InSCI but also a set of questions specific and important to SCI persons in Korea.

Only community-dwelling SCI persons will be included in the initial Korean study protocol. The source population will be based on the approximately 3000 NRC SCI patient database, 2500 KSCIA member database, and the 2000 Korea Society for Industrial Disaster Victim member database. However, eliminating redundancy within the source population will be important. Hospital pools often overlap and the KSCIA pool will also have duplicate participants. Ways to overcome this may be to use the largest pool as the main source and carefully eliminate duplicates using name and birthdates.

Modes of data collection will be done through a combination of electronic survey and paper and pencil. All those who agree to be surveyed will receive both electronic and paper and pencil surveys via Email or postage. For those who respond

that they are unable to perform the surveys due to lack of caregiver or poor hand control, a face-to-face or telephone interview by educated interviewers will be performed. The KoSCI team will manage all data input using a central database coordinated by Swiss Paraplegic Research in Nottwil, Switzerland. Korea's data will be authorized by the Data Usage Committee within the KoSCI team.

CONCLUSION

International data encompassing all disabilities is important. However, for identification of concrete problems and formulation of realistic policies, there is also a need for condition-specific data. Collaborative efforts, such as the InSCI survey, must be initiated so that in the future this may act as an example for data formulation in other disability conditions. The Korean Team hopes to work in synergy with the international community to capture the lived experience of persons with SCI and ultimately contribute to bettering the lives of persons with SCI not just in Korea, but globally.

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People with Spinal Cord Injury in Lithuania

Alvydas Juocevicius, MD, PhD, Ieva E. Jamontaite, PhD, and Ausra Adomaviciene, MSc

EPIDEMIOLOGY OF SPINAL CORD INJURY IN LITHUANIA

Approximately 2500 people with spinal cord injury (SCI), both paraplegia and tetraplegia, live in Lithuania, divided between 1900 traumatic and 600 nontraumatic cases. The prevalence of traumatic SCI is 660 per million cases and 200 per million for nontraumatic.¹ According to a recent retrospective study, the mean annual incidence rate for traumatic SCI in 2015 was 24 per million persons, with men accounting for 18.8 per million and women 5.2 per million. This annual incidence rate appears to have decreased from 32 per million in the period 1994–2006 to the current 24 per million rate.^{2,3} Age-adjusted incidence rates, however, did not change for men or women from the period 1994 on, although the mean age at onset increased among men (from 34.6 to 42.4 years) and women (from 35.8 to 40.4 years). For men and women 55 years or older, the incidence rate per million was significantly higher in 2007–2015 than in 1994–2006. In another unpublished study, it was noticed that there has been since the early 1990s an increasing incidence rate of nontraumatic SCI (39%) among older persons with corresponding decreasing incidence rates of traumatic SCI (61%) for younger inhabitants.^{2,3}

The most common causes of SCI in Lithuania are road traffic crashes at 31.7%, falls at 41.6%, violence at 4.9%, and unspecified for 21.8% of cases.^{2,3} The proportion of traumatic SCI due to falls and household injuries increased among those 55 years or older but decreased in the case of diving accidents and weather among younger persons.³

Spinal cord injury lesion level-adjusted incidence rates during the 1994–2006 period were 60.6% for paraplegia and 39.4% for tetraplegia. During the 2007–2015 period, there was an increased incidence rate of tetraplegia to 45.9% and a decreased incidence of paraplegia to 54.1%.² Mortality at the early, acute phase ranges between 4.4% and 16.7%, with patients dying within the first days after the injury. The main causes of these deaths were reperfusion injury, respiratory system problems, and urological complications.⁴

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Lithuania provides a competent ambulance and emergency health service, and this service is free for everyone, including those who lack state health insurance. There are 63 ambulance services throughout the country, and their functions include that of assessing the injured person on site and setting care priorities after assessment. Ambulance workers are trained to undertake lifesaving and first-aid measures at the accident site and while transporting victims to hospitals. A decentralized dispatch system has been used for many years so that each city or district has a 24-hour nurse-based dispatch center. For trauma patients, there is only ground-based transportation from the scene of the event.^{5,6} Emergency treatment is provided at the emergency room of any hospital. These emergency services are available for anyone in need of immediate attention, when a general practitioner refers a patient, and even in cases where there is no general practitioner service available.⁷

After the injury, patients are transported to 1 of 6 specialized neurosurgery units located in the biggest towns. After stabilization and treatment, on average 10 days after the injury, they are referred to 1 of the 3 specialized SCI patient rehabilitation units (university hospitals in the eastern and central parts of the country and a rehabilitation hospital in the west), where multidisciplinary services are provided. The duration of the course of rehabilitation for inpatient units depends on the SCI level and functional status. In general, rehabilitation lasts on average between 70 and 130 days. For complicated cases, the patient's hospital stay can be prolonged after agreement is reached with his/her insurance fund that is paying for the rehabilitation care. If required, 22 to 24 days of rehabilitation treatment may be repeated once a year (and for the first 3 years at the same unit). Multidisciplinary rehabilitation services include physical and rehabilitation medicine physician assessment and coordination of the program, physiotherapy, occupational therapy, nursing, speech therapy, consultations with a psychologist or social worker, and other medical specialists.

There are 2 health check-ups during the first year after injury, and one check-up from the second year on. If needed, courses of rehabilitation can be repeated once a year from year 4 onward, and every person with SCI has the possibility to participate in supportive rehabilitation courses, which are also free of charge. For further medical or psychological support, persons with SCI may apply to specialized rehabilitation units, a general practitioner, or, for pain relief, to pain clinics that are hospital based.⁸

LIVING WITH SCI

An unpublished retrospective study has reported on the availability of educational and employment for persons with

From the Rehabilitation, Physical and Sports Medicine Department, Faculty of Medicine, Vilnius University; and Rehabilitation, Physical and Sports Medicine Center, Vilnius University Hospital Santariskiu Klinikos, Vilnius, Lithuania.

All correspondence and requests for reprints should be addressed to: Alvydas Juocevicius, MD, PhD, Rehabilitation, Physical and Sports Medicine Department, Vilnius University Hospital Santariskiu Klinikos, Santariskiu 2, Vilnius LT 08661, Lithuania.

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SCI for the years 1994 to 2012.² Persons who, before injury, had not already completed the level of education were successful doing so 5.4% for primary education, 14.6% secondary, 25.7% tertiary, and 23.8% for higher or college education. During both the periods 2007–2012 and 2012–2015, the percentage of those with SCI who completed tertiary education, if they had not already before injury, did not significantly change. In the case of employment the situation is somewhat less optimistic. During 2009–2015, only 6.2% of persons with SCI enjoyed permanent employment, 5.2% worked part time in a private business, 18.6% had short-term or fixed-term work, and 14.4% worked in the home (e.g., doing crafts, needlework, wood work, translation, computer repairing, management, and consulting); 7.9% of people were employed during the first 2 years after injury. Of these, 64% returned to their previous jobs, and the rest were employed at new jobs. Overall, 30.4% of persons with SCI participated in some form of vocational rehabilitation after injury, whereas 16% studied, and the remaining 45.7% did not work or never tried to find a job; 25.4% of those employed had tetraplegia and had the benefit of some form of environmental adaptation (adjusted working hours, assistive technology, or adapted working equipment). Of those who were employed, 75.6% lived in a town and had a partly adapted house, whereas 64.6% of them drove a special hand-controlled vehicle.⁹

The primary employment barriers that were reported in this study were as follows: 19 (18.8%), lack of environmental adaptation; 17 (16.8%), negative attitude of employers; 12 (11.9%), lack of available professional assistances; 10 (9.9%), problems with transportation; 9 (8.9%), personal, psychological problems; 12 (11.9%), lack of motivation to work; and 21 (20.8%), health, self-care, and mobility problems.¹⁰ The main functional problems that were experienced and that interfered with their capacity to work were emotional functions; self-confidence; sensory functions—especially the sensation of stabbing, aching pain localized in neck, back, or dermatome—mobility and movement organs functions, such as muscle power, muscle tone, or muscle endurance; and sensations of the skin. The kind of limitations in activities and participation that were reported were linked primarily to movement (changing and maintaining a body position, transferring oneself, lifting and carrying objects, fine hand use, and moving around in different locations). The functional independence measure score for those who were employed was 114.4 ± 7.7 ($P < 0.05$) as compared with unemployed at 94.4 ± 16.4 ($P < 0.05$).³

From the same study, it was found that 40.2% of persons with SCI were unmarried, 13.4% currently married, 6.2% divorced or separated, and 7.3% living out of wedlock; 12.6% of those who were married got married after their injury. The study showed that many people with SCI in Lithuania continued to participate in community life, with men working and doing sports, whereas most women participate in club activities.^{4,9}

THE HEALTH AND REHABILITATION SYSTEM

Health care in Lithuania includes mostly public-sector health care services financed primarily by the Statutory Health Insurance Fund. At the same time, there also exist private-sector

health care providers financed both by the Statutory Health Insurance Fund and by patients' out-of-pocket payments. The Ministry of Health is responsible for general supervision of the health care system, whereas the municipalities are responsible for providing primary health care to their local populations. Municipalities have been granted property rights for outpatient facilities and nursing homes and are engaged in running small and medium hospitals within their localities, in accordance with legislation. The private sector plays a significant role, especially in dental care, cosmetic and day surgery, gynecology, and primary health care. Private health insurance is permitted, and there are private insurance companies mainly dealing with coverage of health care expenditures of Lithuanian citizens during foreign travel and for foreigners residing in Lithuania.¹¹

Primary health care in Lithuania is provided in both state and private institutions. State institutions may be general practitioner offices, ambulatory clinics, and polyclinics—both general and specialized. Ambulatory clinics are usually available in smaller towns, whereas polyclinics are situated in bigger cities and provide more complex services, such as outpatient surgery. Paramedical centers (or medical posts) and health posts (i.e., a community nurse) in schools also provide primary care in rural areas. Family health care is provided by the family physician. This position in Lithuania has been recently introduced based on the experience of other countries. The family physician now plays the role of a counsellor or a coordinator guiding people through the health system, offering appropriate consultation, monitoring chronic diseases, and making referrals for necessary specialist consultations. A licensed family physician takes care of those registered at the primary health care facility (outpatient clinics and family doctor centers).^{10,12}

Although at present there are a sufficient number of family doctors in Lithuania, there is not enough community-based rehabilitation in rural areas, which may account for the limited participation in social life of the rural SCI population.

WHAT IS THE STATE OF SPECIALIZED CARE?

During the past 10 years, the waiting time between injury and surgery in specialized neurosurgery has decreased from 24 hours to 5 to 6 hours, mostly because of more specialized emergency services, intensive SCI care, the increasing supply of modern equipment, specialized emergency ambulance, and decreasing transportation time. The time from specialized neurosurgery to specialized rehabilitation has also decreased from approximately 30 days to 10 days. Also over this period, vocational rehabilitation institutions have been developed.

Currently, there are 6 specialized neurosurgery units in the biggest towns. Rehabilitation services for SCI patients are provided in 3 specialized SCI rehabilitation centers. A multidisciplinary team using a patient-centered and biopsychosocial approach handles rehabilitation of SCI patients in all 3 of these centers. Well-trained specialists are available and provide services for persons with SCI.¹³

Spinal cord injury–relevant assistive technology is available for all SCI patients during rehabilitation course under the supervision of rehabilitation team members. The ministries responsible for social security and labor provide services for the provision and maintenance of technical aids in Centres for Technical Aid for Disabled People. Branches of this service are spread across Lithuania. To prevent secondary conditions and complications, SCI patients can apply to their regional general rehabilitation services on an outpatient basis or to a specialized unit of rehabilitation.¹⁴

THE SOCIAL RESPONSE TO SCI

There are specific laws aimed at facilitating the reintegration of people with disabilities into employment in Lithuania: Law on Disabled Social Integration (1991, 2005), Law on Social Services (2006), Law on Employment Promotion (2006), Law on State support for Housing and Rental (2003), and Law on State Social Assistance Benefits (2011). Lithuania is also in the course of implementing its National Program for Social Integration of People With Disabilities 2012–2019.

The Law on Employment Promotion provides support for employers who are integrating people with disabilities into the labor market. Every company can receive state support for employing persons with disabilities, creating new jobs, or adapting the already existing workplaces to the disability of the unemployed person: They also organize vocational training and employ them after the vocational rehabilitation programs or other vocational programs designed to provide professional skills are concluded. According to this law, people with disabilities are able to participate in active labor market policy measures, such as subsidized employment, vocational training, support for the acquisition of professional skills, support for job creation, and support for self-employment.¹⁵ Support is also being provided to the employers who create new jobs or adapt existing workplaces to the disability of the unemployed person. Finally, there is support to employ unemployed persons under a more flexible, open-ended contract of employment.

Disability pensions are granted according to the Law on State Social Insurance pensions. State social insurance pensions are the major type of social security in cases of disability. The size of the pension depends on the level of disability and the special needs of the person. In order to provide additional funding for persons with SCI, the Department for the Affairs of the Disabled at the Ministry of Social Security and Labour annually publishes tenders to finance the various activities of the disabled persons. These tenders help to finance the activities of nongovernmental organizations (NGOs).

There are several NGOs or disabled persons' organizations associations that provide support to people after their injury, as well as their family. Among these are the Lithuanian Association of Paraplegics and the Lithuanian Union of the Disabled. National campaigns designed to reduce stigma against disability take place on a regular basis. The NGOs organized charity concerts and TV sponsorship campaigns in which people are encouraged to donate money to medical equipment and various kinds of assistive technology to improve the quality of life of persons with disability.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain From Participating in the InSCI Study?

We hope to conduct a comprehensive situation analysis and use the data to contribute to national and regional planning and to develop partnerships with other sectors, such as education, social, and transport and groups of persons with disabilities to affect future policy decisions. We hope also to establish effective coordination across all phases of care for the SCI population and to involve organizations of persons with disabilities and their family members in decision making, planning, and evaluation. We hope the study will also support opportunities for professional development for rehabilitation and medical care personnel specialized in SCI and to improve assistive technology services so that they respond more effectively to individual needs. Finally, we hope this study provides the information necessary to advocate for improved accessibility of environment surroundings for people with SCI, as well as to develop educational and vocational rehabilitation resources.

THE NATIONAL STUDY PROTOCOL

Our national study protocol will follow the general outlines of the overall protocol regarding eligibility and exclusive criteria. We expect a sample of 423 persons with SCI and will use the procedures recommended for contacting, and retaining contact with, the study population. Data management will be arranged consistent with the requirements of the Lithuanian Bioethical Committee. For data management, the central database at Swiss Paraplegic Research in Nottwil, Switzerland, will be used. The process of entering to the digital Excel database will take place in 2017, with coordinators submitting data collection from the survey. In order to contact the study population (and in particular to get addresses and personal information), we will use a database of specialized SCI units, the insurance fund database (which finances rehabilitation for both traumatic and nontraumatic SCI patients), and the databases of Lithuanian association of SCI patients. The modes of data collection will be paper-pencil questionnaire, face-to-face interview, and online questionnaire. Printed versions of the surveys will be securely kept in a locked file room. For personal data, local and international ID file protection guarantee additional security components will be implemented at the hospital information technology system.

CONCLUSION

The situation in Lithuania with regard to epidemiological trends and access to specialized and rehabilitative care is similar to those of other countries. We benefit from having a network of cooperation between different sectors and persons with SCI and their families members. A large proportion of the SCI population is fully integrated into Lithuanian social life. There is, however, a distinct lack of community-based rehabilitation services and support, which causes a lower level of participation in rural areas. Work must be done to ensure that accommodations for people's living and work surroundings are put into place to improve outcomes and achieve independence. Access

to community-based rehabilitation must be improved, and resources for education and vocational rehabilitation need to be improved.

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People with Spinal Cord Injury in Malaysia

Julia Patrick Engkasan, MRehabMed(Mal), MBBS(Mal), Nazirah Hasnan, PhD, MRehabMed(Mal), MBBS(Mal), Yusniza Mohd Yusuf, MRehabMed(Mal), MBBS(Mal), and Lydia Abdul Latif, MRehabMed(Mal), MBBS(Mal)

EPIDEMIOLOGY OF SPINAL CORD INJURY IN MALAYSIA

Very little is published on the demographics or epidemiological patterns of spinal cord injury (SCI) in Malaysia. Available studies show that most persons with SCI were males, aged younger than 40 years, and had paraplegia.¹⁻³ A related study showed a bimodal distribution of age, with peaks of incidence in the 25 to 34 and 55 to 64 age groups.² The most common cause of injury was caused by motor vehicle accident followed by fall from height.¹⁻³ Tumor-related cases made up 40% of nontraumatic causes of SCI.¹ No data are available on the mortality and life expectancy of persons with SCI in the Malaysian population.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

People with SCI receive prehospital care, acute care, inpatient rehabilitation, outpatient rehabilitation, and community care. Upon injury, first aid is usually provided either by bystanders, the police, or paramedics. Whereas paramedics are usually trained to be aware of the possibility of SCI and use spinal boards to transport people, the public is usually not so prepared. Emergency treatments are given at the nearest hospital and are accessible to everybody regardless of insurance status. A person suspected or diagnosed to have an SCI will be referred to the nearest general hospital with the necessary facilities and specialists. There is no specialized SCI center or unit in Malaysia; these cases are usually managed in the orthopedic or neurosurgical wards of general hospitals. Staffs in these wards generally have limited skills, expertise, and support to manage patients with SCI. To date, there is no clear pathway of transition from acute to rehabilitation care for patients with SCI.

General rehabilitation services are available mainly in the government hospitals: there are 16 state hospitals, 3 teaching hospitals, and a rehabilitation hospital throughout the country, with a total population of 29,714,700. Although all hospitals are equipped to deliver spinal rehabilitation care, not all of them have inpatient rehabilitation beds. In some, rehabilitation service is provided in the orthopedic ward; only the

rehabilitation hospital has a dedicated spinal ward with 25 beds. Owing to limited beds and opportunity for prolonged admission, most patients complete a basic inpatient spinal rehabilitation program that is followed by outpatient rehabilitation. The duration of inpatient rehabilitation varies widely between hospitals, ranging from 6 weeks to 6 months.

Most patients are discharged home directly from the hospital. Assistance to manage daily activities at home are usually given by family members or paid attendants. After discharge, patients continue their rehabilitation process by attending outpatient rehabilitation therapy at the admitting hospital. Patients are also followed up at the rehabilitation clinic to monitor progress and for any secondary complications. Readmission is possible for further rehabilitation or for management of complications. There is no community care available specifically for those with SCI; however, the health care system does provide home-nursing services that may be used by people with SCI.

LIVING WITH SCI

There is not much published information on how well people with SCI do in the community. Based on the authors' own experience, there is limited support available in the community and people living with SCI face various obstacles to re-integrate with the society. Access to wheelchairs and other rehabilitation equipment for home and work also varies. Those who are under the social security scheme will receive funding, and those who are registered with the Department of Social Welfare may receive support from the government. Most private insurance policies do not cover for such rehabilitation aids and technologies. There are significant variations on how return-to-work program is implemented throughout Malaysia. Some are carried out by individual hospitals, whereas some collaborate with the Social Security Organization (SOCO). Ramakrishnan et al.⁴ found a 57% employment rate in an urban sample, which is comparatively high to other available data.

THE HEALTH AND REHABILITATION SYSTEM

The Malaysian health care system consists of tax-funded and government-run universal services and is centrally administered by the Ministry of Health (MOH). Malaysian society places high importance on the expansion and development of health care, putting 5% of the government social sector development budget into public health care.⁵ The MOH offers a comprehensive range of services, including health promotion, disease prevention, and curative and rehabilitative care delivered through clinics and hospitals, whereas special institutions provide long-term care. The government hospitals have the country's best health care equipment and facilities apart from having specialists in the field. Most Malaysians rely on

From the Department of Rehabilitation Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia (JPE, NH, LAL); and Cheras Rehabilitation Hospital, Bandar Tun Razak, Kuala Lumpur, Malaysia (YMY).

All correspondence and requests for reprints should be addressed to: Julia Patrick Engkasan, MRehabMed(Mal), MBBS(Mal), Department of Rehabilitation Medicine, Faculty of Medicine, University of Malaya, 50603 Kuala Lumpur, Malaysia.

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government hospitals; they only need to pay very small fee. People with disabilities who are registered with the social welfare department received free inpatient and outpatient medical treatment and most of the medications. Malaysia generally has an efficient and widespread system of health care, and people generally have good physical access to health facilities, as 92% of the urban population and 69% of the rural population live within 3 km of a health facility.⁶ There is still, however, a significant shortage in the medical workforce, especially of highly trained specialists; thus, certain medical care and treatment is available only in large cities.

WHAT IS THE STATE OF SPECIALIZED CARE?

With regard to specialized care for people with SCI, Malaysia has spinal surgeons and neurosurgeons, rehabilitation physicians, and the technology to diagnose and manage SCI. All rehabilitation physicians received a 6-month clinical training to manage people with SCI during their residency, but there are few nurses trained in spine rehabilitation. A similar trend is seen with physiotherapists and occupational therapists: most become experts through the years spent treating people with SCI but not through formal training. There is no formal peer counseling support provided by the hospitals, but it is common for physicians to ask patients who are far beyond the rehabilitation stage to counsel the newly injured patients.

SOCIETAL RESPONSE

Social services for people with SCI are very limited, other than those generally available to all people with disabilities. No social service is automatically provided to people after an SCI. People who are employed by the government and their dependents, and those with social security coverage are entitled to medical rehabilitation and equipment support. Support ranges from inpatient and outpatient public health care needs, funding of equipment, disability pensions, caregiver allowance, return-to-work program, purchases of medicine and continence needs. The Department of Social Welfare in Malaysia also provides these services depending on the patient's economic status. The government policy states that 1% of employment positions are officially reserved for persons with disability, but this has never been achieved even in the government sector. Accessibility of public places for people with disabilities is spelled out under the Uniform Building By-Laws Act 133 amended in 2006 and the Persons with Disabilities Act 2008.⁷

There is also access to funding from nongovernmental organizations such as The Rotary Club, Lion's Club, and various religious associations. Nevertheless, none of this funding is specifically dedicated for people with SCI. Various disability-related advocacy groups have been active in raising awareness about disability and the need for an accessible environment, affordable health care, and equipment as well equal opportunities to education and employment.

The Malaysian government response to SCI prevention has been limited to the provision of folic acid to expecting mothers and the implementation of seat belts for the driver and front passenger. The 10th National health strategy does not have specific health agenda related to people with SCI. Malaysia has strict road traffic rules and regulation, but

implementation has been inconsistent. Motorcycles are popular in Malaysia, and this has contributed to the high incidence of road traffic accidents.⁸

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain From Participating in the InSCI Study?

The InSCI study aims to describe the lived experience of persons with SCI in the participating countries including Malaysia, in particular, to collect comprehensive data on functioning, health, and well-being of people living with SCI in the community. Participating in the InSCI study gives us the opportunity to greatly increase our insight into the lived experience of people with SCI in Malaysia and will be used to raise some policy recommendations. This is a cross-sectional study that will be implemented in 9 state hospitals that provide SCI rehabilitation services in Malaysia.

The National Study Protocol

Each health facility will include all eligible participants from their hospital in-patient and outpatient registry. In addition, participants will be recruited from SCI associations throughout the country such as Malaysian Spinal Cord Injury Association, Sibul Spinal Cord Injury Association, Kuching Spinal Injury Association, and Persatuan Spinal Pantai Timur. This is in line with the recommended method of recruitment by the Coordinating Institute to ensure an unbiased sample. The eligible participants are people with SCI older than 18 years at the time of study, who have traumatic or nontraumatic SCI, who have lived with SCI in the community for at least a year after initial hospital discharge, reside in Malaysia and are able to answer the survey questionnaire (available in English and Bahasa Malaysia). We will exclude those with progressive disease (malignant/neuropalliative disease), congenital cases, or cognitive impairment. Every eligible participant will be getting a unique ID.

The sample size calculation performed by the Coordinating Institute stated a minimum number of 400 participants, considering that there would be 50% nonresponse rate. An invitation letter together with a study information leaflet will be sent to all participants who fulfill the inclusion/exclusion criteria. They are required to indicate their preferred method of participation in the survey: the choice of online data entry, pen and pencil, or face-to-face interview. Persons who prefer the online method will receive a package consisting of a log in ID, the consent form, and a return envelope. Persons who prefer to participate using a pen and pencil will receive the study package consisting of the consent form, the questionnaire, and a return envelope. Persons who prefer interviewer-administered survey will be contacted for appointments.

Once the invitations are sent out, an electronic reminder will be sent out 30 days later if there is no response. A second reminder will be done via telephone call 30 days after the first reminder. A maximum effort of 10 calls are planned to reach potential participants. Within the second stage after the participants have agreed to participate and have received the questionnaire, if the tracking tool does not see a response or have

not received the returned questionnaire within 30 days, an electronic message will remind the participants. In the same way, a second reminder will be done via telephone call 30 days later of nonreceipt of completed questionnaire.

At the country level, we will collect epidemiologic and preventive data on SCI, which will address the epidemiologic gap in the country, especially related to prevalence of SCI, the demographics of persons with SCI, and the characteristics of SCI and cause of SCI in Malaysia. These data are essential to define the magnitude and trend of SCI and to explore effective preventive strategies. We will use dual approach for data collection: (1) by means of a retrospective review of hospital records on all admissions due to SCI who were treated by the rehabilitation team; and (2) by a prospective study on patients admitted due to SCI. In relation to the existing InSCI modules, the proposed national module will take place during the initial hospital registry screening. All patients who are referred for SCI rehabilitation will be included in this epidemiologic data survey. The only exclusion criteria will be patients who do not have neurological deficits on initial assessment. Three data collection forms will be implemented for this exercise: (1) international SCI core data sets; (2) international SCI nontraumatic SCI data sets; and (3) minimum injury/safety data set.

CONCLUSION

The societal response to health and social needs of persons with SCI remains deficient in Malaysia, although the breadth and depth of services available for these patients have significantly improved over the past decade. Improved epidemiologic

data from the InSCI study will enable us to fill this gap and quantify the magnitude of SCI, information that will be essential for policymaking. In general, there is in Malaysia a need to create awareness among the general public of the importance of SCI prevention and the society requirement to respond to the unmet needs of people with SCI.

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People with Spinal Cord Injury in the Netherlands

Marcel W.M. Post, PhD, Carla F. Nooijen, PhD, Karin Postma, PT, PhD, Jos Dekkers, Frans Penninx, Rita J.G. van den Berg-Emons, PhD, and Henk J. Stam, MD, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN THE NETHERLANDS

The estimated incidence of traumatic spinal cord injury (SCI) was 14.0 per million per year in the Netherlands in 2010, or 11.7 per million per year for those surviving the acute phase.¹ The incidence of traumatic SCI seems rather stable as an earlier study reported an estimated incidence of 10.4 per million per year surviving the acute phase in 1994.² The incidence of nontraumatic SCI in the Netherlands is unknown. However, a study on characteristics of persons with SCI admitted to an SCI department for initial inpatient rehabilitation found 54.7% of persons with SCI to have a nontraumatic lesion.³ Therefore, we assume that the incidence of nontraumatic SCI is slightly higher than the incidence of traumatic SCI. There are no reliable figures on the prevalence of SCI in the Netherlands.

Most cases of traumatic SCI admitted to acute care hospitals were falls (53%) in 2010, followed by road traffic accidents (22%) and sports (14%).¹ Within this last category, diving (27%) and bicycling (23%) were most common. Violence applied to only 2% of cases. Reported etiologies for nontraumatic SCI admitted to specialized rehabilitation centers were vascular diseases (28%), spinal degeneration (26%), inflammation (17%), malignant tumor (17%), and benign tumor (11%).³

The most notable change between 1994 and 2010 was a strong increase in age at injury. The proportion of newly injured people older than 60 years was 30% in 1994 compared with 52% in 2010.^{1,2} This increase in age at injury was associated with a growing proportion of falls as a cause of SCI and of more people with incomplete and cervical SCI. The decreasing proportion of traumatic SCI due to traffic incidents from 31% in 1994 to 22% in 2010 mirrors a decline in death and wounded people in traffic accidents in recent years in the Netherlands.⁴

The mortality rate during acute hospitalization was estimated to be 16% in 2010.¹ In a cohort study of persons with SCI admitted to a specialized rehabilitation center who were expected to remain wheelchair dependent, the cumulative

mortality was 12% at 5 years after injury.⁵ Main causes of death were cardiovascular disease (37%), pulmonary disease (30%), and neoplasm (15%).⁵

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

The typical journey through the health care system in the Netherlands of an adult with thoracic SCI due to a traffic accident (let us call her “Jane”) begins with the injury. We may assume that Jane has the compulsory basic health insurance, which covers the costs (over the self-contribution level of 385 Euros a year) of trauma care and acute hospital care, rehabilitation and follow-up, most medical devices, and primary care (physician and registered nurse). Within 15 minutes after receiving the alarm, the emergency service should have arrived to provide Jane with first aid. In most cases, the emergency service will arrive by ambulance, but dependent on the location and the nature of the accident, it can also arrive by helicopter. The ambulance will convey Jane to the emergency department of a nearby hospital or trauma center. At this department, it is decided if and when Jane is referred to the intensive care.

A total of 94 intensive care units are spread over the country, including 8 university hospitals and 3 other level I trauma centers. Because Jane shows symptoms of spinal cord damage, she will be transported to one of these 11 level I trauma centers. She will probably receive stabilizing spinal surgery. Dependent on local arrangements, spinal surgery will be performed by orthopedic surgeons, trauma surgeons, or neurosurgeons, and Jane will stay at the respective ward afterwards. Median stay in the acute care hospital for patients with TSCI was 17 days (2010).¹

Once medically stable, Jane will likely be transferred to 1 of the 8 rehabilitation centers with a specialization in SCI rehabilitation. These centers are spread over the country, so that she will probably stay in a center within a 1-hour drive by car from home. Post-acute SCI rehabilitation in these centers is comprehensive and multidisciplinary, consisting of medical, functional, and psychosocial rehabilitation. All relevant disciplines are available, for example, physical therapy, occupational therapy, recreation and leisure therapy, sports therapy, psychology, and social work. Length of stay in the rehabilitation center is strongly dependent on the type of SCI, but will be approximately 4 to 6 months for someone with complete paraplegia and up to 6 to 9 months for someone with complete tetraplegia.

After discharge from inpatient rehabilitation, Jane will receive outpatient rehabilitation for a further few months. If applicable, advice concerning return to work, advice for the provision of a wheelchair, and domestic adaptations will be part of inpatient or outpatient rehabilitation.

From the Center of Excellence for Rehabilitation Medicine, the Brain Center Rudolf Magnus, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht (MWMP); University of Groningen, University Medical Center Groningen, Center for Rehabilitation, Groningen (MWMP); Department of Rehabilitation Medicine, Erasmus University Medical Center Rotterdam (CFN, KP, RJGB-E, HJS) and Rijndam Rehabilitation Center (KP), Rotterdam; and Spinal Cord Injury Association of the Netherlands (Dwarslaesie Organisatie Nederland), Groningen (JD, FP), the Netherlands.

All correspondence and requests for reprints should be addressed to: Marcel W.M. Post, PhD, De Hoogstraat Rehabilitation, Rembrandtkade 10, 3583TM Utrecht, the Netherlands.

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Reintegration of persons with disabilities into the workforce is a priority of the Dutch government, and a variety of community services are available to support this process.⁶ There is, however, no reintegration service specific for persons with SCI. If Jane needs basic medical care after completion of initial inpatient and outpatient rehabilitation, such as in the case of an uncomplicated urinary tract infection, this is taken care of by a general practitioner (primary care physician, family physician). Rehabilitation aftercare is available, and Jane will probably return to the rehabilitation center for follow-up consultation 1 or 2 times in the first year. After the first year, the frequency of follow-up is agreed upon by patient and doctor. Some rehabilitation centers are implementing a system of standard structured multidisciplinary follow-up. If distance between home and center is an issue, Jane may be referred for follow-up to a nonspecialized rehabilitation center.

LIVING WITH SCI

In general, people with SCI will return to school if they are of school age. Accessibility problems may occur, in particular in case of older buildings, but in general, buildings and classrooms are more or less wheelchair accessible. Parents can apply for a budget to allow for some assistance for their child during school time. In exceptional cases, say if a child requires much assistance or has cognitive disabilities too, children with SCI are eligible for placement in special schools for children with severe physical disabilities.⁷

Return to work after SCI is far from complete in the Netherlands. A recent survey among members of the patient's organization showed that 72% of those employed at the time of their SCI returned to work for some time after their SCI, and 51% of the participants of working age had paid work for more than 1 h/wk at the time of the survey. Of them, 27% worked full time (>35 h/wk), which is markedly less compared with 79% of those having paid work working full-time before SCI.⁸ The general Dutch unemployment rate of persons with disabilities is among the Organisation for Economic Co-operation and Development average, but the poverty rate in this group at 12% is relatively low.⁹

There are no particular hindrances for persons with SCI to get married and have children. In the same survey, the participants' current civil status was married (58%) or in a registered partnership (9%), single (20%), divorced (5%), and widowed/widower (8%).⁸ The proportion of married persons with SCI is higher than that in the general population 20 to 64 years of age (50%).¹⁰ Many persons with SCI have children, born before or after the SCI. Fertility treatment is covered by the basic health insurance.

From the same survey, we know that 48% of the participants performed unpaid (volunteer) work, and 13% were in education. Further 58% participated in sports, 84% performed outdoor leisure activities, 69% visited friends or family, 73% received visits from friends or family, and 93% had contacts by telephone or computer, all at least once a week.⁸

THE HEALTH AND REHABILITATION SYSTEM

Overall, the health care system in the Netherlands is well organized and of good quality. Health insurance is managed by private companies (usually nonprofit). Basic health

insurance is compulsory and reaches 99% of the population. The fee is approximately 100 Euros a month, and there is a compulsory self-contribution of minimum 385 Euros and maximum 500 Euros (primary care consultations are exempted from this deductible). Slightly less than 90% has some form of supplementary health insurance, for example, to cover physical therapy, dental care, some medical devices, or complementary medicine. Residential care, for example, nursing homes and long-stay psychiatry, is covered through taxation. Under certain conditions, it is possible for people in need of help with activities of daily living (showering, dressing, etc.) or other nursing care to apply for money to hire one's own help instead of care delivered by a home care agency. People who can handle the complexities of the system are thus able to organize their own maximally person-centered and flexible care.¹¹ Provision of wheelchairs and other transportation modalities and domestic adaptations is the responsibility of the local municipalities. There is 1 primary care physician per 2379 inhabitants and, including all specialties, 3 physicians per 1000 inhabitants.^{12,13}

WHAT IS THE STATE OF SPECIALIZED CARE?

In general, the specialized care for persons with SCI is sufficient, and necessary treatments and devices are available. Peer counseling is a recent development, and now half of the SCI centers have a paid peer counselor. A challenge the rehabilitation system is facing at the moment is the growing number of older persons with SCI. Elderly are more often than younger persons discharged to nursing homes for rehabilitation, which do not have the specialized care for persons with SCI.¹ It is, however, unclear whether treatment of the elderly with SCI is insufficient.

The economic crisis has led to budget cuts, and as a result, reimbursements of some services have become more limited, such as physical therapy in the community and sports wheelchairs. This has led to an increase of out-of-pocket costs. From January 2015, home care services have become the responsibility of local governments, together with a major budget cut, and the consequences of this change have to be awaited. Overall, it is a challenge to keep the services for people with disabilities from further deterioration.

THE SOCIAL RESPONSE TO SCI

The Netherlands have a complex social security system of the sort commonly found in high-resource European countries.¹⁴ Government buildings and (partly) publicly financed buildings, such as museums, theaters, and hospitals, are mostly well accessible. Other public buildings (restaurants, pubs, hotels, shops) are, however, poorly accessible in many cases. With the exception of the subways in the big cities, the public transport system is poorly accessible. Streets in the older cities and private buildings are often difficult to access by wheelchair.

Figures on social attitudes toward persons with SCI are lacking. Although discrimination of people with disabilities is prohibited by the law, they often have difficulty finding a job. Research into discrimination of persons with SCI in the Netherlands is sparse. The only data are the aforementioned survey in which participants were asked the question: "People with disabilities such as mine are discriminated against

in this country,” on which question 18% provided an affirmative response. It is not possible to put this into perspective as data from other countries are lacking.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

The topics of International Spinal Cord Injury (InSCI) are generally well researched in the Netherlands.^{8,15–17} The added value of participation in InSCI is in (1) the opportunity to compare the situation of persons with SCI in the Netherlands with that in other countries and (2) the options of more in-depth multinational analyses of add-on topics. Three rehabilitation centers with a specialization in SCI rehabilitation, Rijndam Rehabilitation in Rotterdam, De Hoogstraat Rehabilitation in Utrecht, and the Center for Rehabilitation of the University Medical Center Groningen, will participate in this study. With these 3 centers in the Western, Middle, and Northern part of the Netherlands, respectively, the combined catchment area covers a large and representative part of the country, including both urban and rural areas.

A database including all former patients of these centers will be compiled, and the survival status of these persons will be checked. The inclusion and exclusion criteria are described in the general InSCI protocol paper in this issue.¹⁸ From this database, a random sample of 500 survivors will be drawn, so that with an expected response rate of 50%, the target sample size of 250 will likely be reached. If necessary, an additional sample will be drawn.

Selected persons will be invited by postal mail. They will be provided with a link to a protected local Web site to complete the questionnaire online, or they can complete a pencil-and-paper version of the questionnaire and return it using a prepaid envelope. Unpublished data from a recent study showed that 98% of all people with long-standing SCI between 18 and 65 years of age have a computer and Internet access,¹⁵ but in another recent study in which participants were offered both response options, half chose the paper-and-pencil version.⁸ A maximum of 2 reminders will be sent. To enhance participation, the survey will be announced in various relevant magazines.

The National Study Protocol

Two options for a national module are under discussion. Dependent on the willingness of other InSCI countries and groups to join 1 or more of these topics, a final choice will be made.

- (1) Physical activity. In an earlier study in the Netherlands, (the course in) physical activity level has been assessed with an accelerometry-based activity monitor in a rather small group of wheelchair-dependent people with SCI (40 persons).¹⁹ In this add-on, we want to explore physical activity levels in a larger representative Dutch sample (with questionnaires and activity monitors) and in persons with SCI in other countries. This study will provide information on determinants of physical activity and on differences in physical activity level between countries.

- (2) Participation. Following up on previous research on participation^{20,21} and the previously mentioned finding that some people with SCI feel discriminated by society, we want to explore how perspectives on social integration vary between countries. Do persons with SCI feel stigmatized? What do they feel that persons with SCI should do themselves to reintegrate in society? How does this impact their quality of life? To answer these questions, a brief questionnaire on experienced stigma and attitudes toward society will be administered.

CONCLUSION

From the description given in this article, it should be clear that the health and social needs of persons with SCI appear to be well addressed. However, as also described previously, there remain, or have emerged in recent years, several challenges that have to be confronted. We hope participation in InSCI will put these themes on the agenda of policy makers.

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People with Spinal Cord Injury in New Zealand

*Maria van den Heuvel, RN BN, MHealSc(Rehab), Lincoln Jansz, MB, BS, FAFRM(RACP),
Xianghu Xiong, MB, BS, FAFRM(RACP), and Balraj Singhal, MB, BS, FAFRM(RACP), FRCS*

EPIDEMIOLOGY OF SPINAL CORD INJURY IN NEW ZEALAND

New Zealand (NZ) has an estimated population of just over than 4.5 million people. Currently, there exists no national registry for spinal cord injury (SCI) in NZ. As a result, the incidence of SCI is difficult to ascertain accurately, and the incidence of nontraumatic SCI is even more difficult to determine.¹ However, information collated up to 2012 from various sources suggests that approximately 100 to 170 persons each year had a diagnosis of some form of SCI in NZ, giving an estimated annual incidence of 30 to 40 SCI cases per million population.² More recent estimates put this figure closer to 45 per million.³ Data from the Derrett longitudinal study found the incidence to be 29 per million for European, 46 per million for Maori, 70 per million for Pacific Islands people, and 16 per million for other ethnicities.²

Spinal cord injury rates are very low in children (single digits per year). The average age at time of injury for traumatic SCI is 34 years. Cervical SCI is the most common level in NZ,⁴ with males between 15 and 29 years being most frequently affected, reflecting international trends.⁵ Traumatic SCI grading in New Zealand follows the International Standards for Neurological Classification of SCI (ISNCSCI), which assigns AIS (American Spinal Injuries Association Impairment Scale) categories A through E to paraplegia and tetraplegia. Reviewed SCI data from one SCI unit between 2005 and 2010 reveal 30% complete SCI, counting both tetraplegia and paraplegia (American Spinal Injury Association Impairment Scale), 36.2% incomplete tetraplegia (AIS B-D), and 33.8% incomplete paraplegia (AIS B-D).⁶ Motor vehicle accidents remain the leading cause of SCI in NZ, followed by falls, reflecting trends reported internationally. Sporting accidents (e.g., rugby football, horseback riding, skiing, mountain biking, diving) constitute the third most common cause. Recent data suggest a decrease in sports-related causes of tetraplegia, and a rapid increase in SCI from falls.⁷ Of note, there has been a 2,000% increase in the post-onset life expectancy of people with a SCI over the past 50 years.⁸

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

Patients with isolated SCI without hemodynamic instability are air-lifted directly from the scene of injury to one of the

two specialized regional SCI centers: Christchurch (facilities include Christchurch Public Hospital and Burwood Spinal Unit) or Auckland (facilities include Middlemore Hospital and Auckland Spinal Rehabilitation Unit). Children with acute SCI without hemodynamic instability from the South Island are air-lifted to Christchurch Public Hospital and from the North Island to Starship Hospital for acute management followed by rehabilitation at Wilson Centre in Auckland. This streamlined fast tracking of their management is in keeping with established international standards and is believed to constitute "best practice," whereby early admission not only saves lives but also reduces secondary complications common to this cohort of patients and therefore reduces total hospital length of stay. This has seen a dramatic reduction in injury-to-decompression/reduction times for acute spinal injuries. Patients presenting acutely with symptoms and signs consistent with SCI may make first contact with their general practitioner, and are then referred to secondary or tertiary services depending on their assessment, i.e., either to the nearest general hospital emergency department or to specialist orthopedic surgery or neurosurgery. For those presenting to emergency departments, spinal injury assessment and triage by the attending doctors is followed by rapid referral and transfer directly to a tertiary spinal trauma unit if indicated.

For patients with suspected/confirmed traumatic SCI and multitrauma who are transferred immediately to the nearest regional trauma center, assessment and initial management will involve early consultation with an orthopedic surgeon or spinal physician based in one of the two specialized regional SCI centers (see above). Admission to the intensive care unit or orthopedic unit usually comes next, followed by spinal team assessment and early surgical intervention if judged appropriate.

As soon as the patient is considered medically stable, with no further need of intensive medical or surgical care, he or she is transferred to the relevant specialist spinal rehabilitation unit. Nontraumatic SCI and neurological syndromes with similar presentation, such as epidural abscess, or transverse myelitis, will follow one or other of these pathways of assessment and triage as appropriate for their acuity of presentation, followed by a period of specialist management in a tertiary neurological, orthopedic, or neurosurgical unit as appropriate. If specialist inpatient rehabilitation is indicated for remaining neurological impairment, admission to a specialist SCI rehabilitation service or other neurorehabilitation service will follow.

Later, the patient receives ongoing services from one of various national outreach services and specialist home and community support services, where long-term rehabilitation can continue in a step-down model (if and when appropriate) either after a period of inpatient rehabilitation or directly after specialist orthopedic or neurological or neurosurgical treatment.

From the Burwood Spinal Unit, Christchurch, New Zealand (MH, LJ, XX); and Burwood Spinal Unit, Adult Rehabilitation, Christchurch, New Zealand (BS). All correspondence and requests for reprints should be addressed to: Maria van den Heuvel, RN BN, MHealSc(Rehab), Burwood Hospital, Christchurch, New Zealand. Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article.

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Community rehabilitation teams in NZ usually consist of occupational therapists, speech-language therapists, assistive technology consultants, psychologists and counsellors, social workers, vocational rehabilitation specialists, orthotists, and physiotherapists.

Generally, postacute inpatient rehabilitation for a person with incomplete tetraplegia may extend to 5 to 6 months, and with paraplegia to approximately 3 months. Thereafter, individuals remain under the care of the spinal team for the duration of their lives; commencing with a comprehensive 3-day reassessment 6 months after discharge from their initial postacute rehabilitation, followed approximately 12 months later (and again 12 months after that) by further reassessments. Thereafter, reassessment appointments with their spinal team occur at three-yearly intervals. Reassessments are made more frequently if clinically indicated. Readmission for periods of rehabilitation (even years after SCI onset) is often offered when changes, caused either by aging, SCI-related complications or new pathology, cause functional deterioration.

LIVING WITH SCI

Employment rates after SCI in NZ vary considerably, the average being approximately 35% within the first year after injury.⁹ Vocational rehabilitation is strongly supported in NZ, and persons who were employed or studying at the time of their injury are encouraged and assisted to engage with vocational rehabilitation counsellors during their postacute inpatient rehabilitation. Those on Accident Compensation Corporation (ACC) funding (described in detail in the next section) receive further support after discharge through a special scheme designed to help such people develop the skills and functional competence appropriate for their chosen work. A longitudinal study published in 2013 exploring socioeconomic outcomes for 169 participants in NZ 2.5 years after their SCI found that most retained their income and standard of living after sustaining an SCI, and high overall rates of returning to work.¹⁰ The authors attributed these results to the fact that most of the participants in this study were served by the ACC scheme.

Regardless of the funding stream that applies to their healthcare post-injury, all NZ residents have access to assistance to maximize their post-discharge function, which includes aids and equipment (both durable equipment and equipment needing regular renewal), environmental modification, transport options, assistance with personal and household tasks, and assistance with community reintegration once they are discharged into the community.

In 2013, a National SCI Initiative and Implementation Plan, outlining “an integrated and sustainable approach to supporting people with spinal cord impairment in meeting their goals,”¹¹ was developed by the Ministry of Health and ACC in collaboration with a wide range of stakeholders across the health system spectrum including customer groups, professional bodies, expert clinicians, District Health Boards, and researchers, the express aim of which was to improve treatment and rehabilitation outcomes for persons with SCI, and to signalize the achievement of better outcomes after SCI as a national health priority.

THE HEALTH AND REHABILITATION SYSTEM

All New Zealanders have access to free public hospital services; and since 1982, the ACC¹² has provided publicly

funded comprehensive, no-fault personal injury insurance cover for all NZ residents (and even for visitors to NZ) who suffer injury through an accident (e.g., a vehicular accident, assault, sporting accident, a fall, etc.) regardless of the legal, social, or personal context of its occurrence. Those whose injury is accepted under the ACC scheme receive a range of benefits: regular weekly payment of 80% of their weekly earnings (if they were employed at the time of their injury); payment of all rehabilitation and hospital care expenses; payment of all expenses relating to equipment and environmental modification needs; payment of all expenses for that portion of their postdischarge health care that relates to their SCI; and, depending on the degree of injury present, a large lump-sum payment that does not affect their other benefits under the scheme. In the case of traumatic SCI, the ACC covers a patient's medical and other ongoing care and function-related needs for life. Many New Zealanders also have private health insurance, and the extent to which this affects (if at all) their entitlement to ACC insurance cover for the same injury is determined by the terms of their private insurance.

Those whose SCI occurred before 1982, or was not the result of an accident, are supported by the general public health system (commonly referred to as “Ministry of Health funding”) during and after their hospital treatment. The latter group includes congenital and developmental pathologies, degenerative, ischemic, and inflammatory hemorrhagic, toxic, and neoplastic causes of SCI. These patients outnumber the “accident-generated” group served by the ACC scheme. For individuals under Ministry of Health funding, there is a limit to the funds available that may be spent on facilitating their continuing rehabilitation, functional and care needs after inpatient rehabilitation, and community reintegration. They will also be entitled to a disability allowance if they are unable to return to work, and an unemployment benefit (entitlement to this is means-tested).

In practice, this two-track system fosters potential inequality, and disparities are perceived commonly in the range and quality of resources available through public funding to people with SCI, such as for domestic and personal cares, equipment and transport needs, and environmental modifications. This is a source of considerable dissatisfaction among people in NZ with acquired disabilities.

THE SOCIAL RESPONSE TO SCI

People living with SCI in NZ have the same opportunities available to other New Zealanders to live a full and active life. All public buildings are required by law to be wheelchair accessible, and have accessible toilet facilities. Not-for-profit organizations such as the NZ Spinal Trust (a registered charity formed in 1994) were set up to address unmet needs of the rehabilitation journey for people with SCI, and task themselves with disseminating information, promoting research, providing resources, and providing advocacy and support to people with SCI throughout NZ through initiatives, projects, and programs that directly benefit them. To meet these objectives, the Trust works in collaboration with a number of entities, including government health boards, ACC, and the Ministry of Health.¹²

Independent living and community participation have become central goals in the rehabilitation process in NZ.^{13,14}

Therefore, a National Serious Injury Service supported by the ACC was initiated in 2008 that is dedicated to facilitating community participation, independent living, and work reintegration.¹³

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

New Zealand is participating in the InSCI Survey. Maria van den Heuvel is the study coordinator with the backup of Dr XH Xiong, who is national leader. Mr Balraj Singhal, currently the Clinical Director for Adult Rehabilitation in Christchurch (including the Spinal Service), will represent the Australian and New Zealand Spinal Cord Society. Mr Hans Wouters, CEO of NZ Spinal Trust, is the representative for the national SCI consumer organizations. The organization of New Zealand's health care delivery with respect to SCI puts it in a strong position to provide international leadership toward the implementation of International Perspectives on Spinal Cord Injury, and its current collaboration with Canada's Rick Hansen Institute may help improve standards of data collection in New Zealand.

CONCLUSION

New Zealand has established a comprehensive, unique health care system for people with SCI. The incidence of SCI in NZ is very similar to that of Australia and most of the Western world. The most common cause of traumatic SCI in NZ is still motor vehicle accidents, followed by falls and sports-related injuries. New Zealand has two comprehensive SCI services providing comprehensive inpatient rehabilitation, medical and surgical care for patients with spinal cord injuries, and facilitating their transition into the community. Furthermore, they provide for their lifelong follow-up at regular intervals. There exists a national strategy embodied in the NZ Spinal Cord

Impairment Action Plan to improve treatment and rehabilitation outcomes to foster well-being, independent living, and community integration for persons with SCI and support their family (commonly referred to as whānau in New Zealand) and caregivers. Progress also is being made toward more comprehensive data collection. With such initiatives assuring continual development of strategies to improve overall standards of care and support for people living with SCI, it is expected that improved survival, lower complication rates, and better quality of life will follow.

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People with Spinal Cord Injury in Norway

Vegard Strøm, PhD, Grethe Månrum, PhD, Annelie Leiulfstrud, MA, Pia Wedege, MSc, Tiina Rekand, PhD, Annette Halvorsen, MD, Leif Arild Fjellheim, and Johan K. Stanghelle, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN NORWAY

In 2014, 122 new cases of spinal cord injury (SCI) were registered in the Norwegian Spinal Cord Injury Registry (NorSCIR), of which 80 were traumatic and 42 were non-traumatic.¹ Written consent is obtained from the participants before entering data into the registry, and permission is only requested from SCI patients submitted to a specialized SCI unit in Norway. Such permissions are obtained from 91% to 93% of the relevant patients. Data from 419 individuals are included for the period 2011–2014: 250 with a traumatic SCI and 169 with a nontraumatic SCI. Historical data on incidence and prevalence of SCI in Norway are relatively sparse. In 1974–1975, the incidence of traumatic SCI was reported to be 16.5.² For the period 1952–2001, it was found to be 13.9 in western Norway.³ Thus, a relatively stable trend is found during the past 50 to 60 years. The etiology of SCI, based on the 2014 data from NorSCIR,¹ are nontraumatic causes, 34.4%; traumatic causes due to falls, 29.5%; sports, 13.9%; transport, 13.1%; other traumatic, 8.2%; and assault, 0.8%. The main causes of traumatic SCIs have been unchanged for the past 50 years,⁴ except for an increasing trend toward higher incidence of fall-induced SCI among persons older than 50 years.³ People with traumatic SCI have an increased mortality rate (1.85) compared with the Norwegian population.⁴ Women with SCI have a significant higher mortality rate than men.^{4,5}

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

The Norwegian emergency medical service system consists of specialized rescue teams for acute medicine and traumatology including SCI and provides assistance regardless of time, place, and insurance by a uniform alert and response system. A dedicated toll-free phone number, 113, routes calls to emergency medical dispatch centers (EMDCs). Ground ambulances, boats, and/or helicopters are dispatched with

specialized teams including medical doctors based on criteria in the Norwegian Index for Medical Emergencies,⁶ a decision tool to secure appropriate responses to medical emergencies. Each call is classified as either “acute” (highest priority), “urgent” (high, but lower priority), or “not urgent” (lowest priority). When “acute,” both ambulances and the medical staff on call are alerted. Together with the emergency medical dispatch centers and increasing competence of ambulance personnel, the emergency medical service of serious accidents and/or illnesses has improved.⁶

In cases of accidents where a traumatic SCI cannot be excluded, the patient is assessed and stabilized as soon as possible by specialized emergency medical staff and, with some exceptions, transported to 1 of 4 specialized trauma hospitals. These hospitals are located in the cities of Oslo, Bergen, Trondheim, and Tromsø and cover 20 emergency regions.⁷ In 6 of the emergency regions, the transport time is less than 2 hours. In northern Norway, it is more than 4 hours in 2 of 5 regions.⁸ If transport time is more than 45 minutes to a trauma hospital, the patient will be transported to the nearest acute care hospital.

In Norway, there are 3 specialized SCI rehabilitation units; these are located at Sunnaas Rehabilitation Hospital, Haukeland University Hospital, and St. Olav's University Hospital. Each SCI unit covers a designated part of Norway; Sunnaas Rehabilitation Hospital the southeastern part, Haukeland University Hospital the western part, and St. Olav's University Hospital the mid- and northern part of Norway.

LIVING WITH SCI

Norway has a number of laws and regulations aiming to reintegrate people with disability back to employment. Important regulations are the Disability Discrimination Act,⁹ The Working Environment Act,¹⁰ and the Agreement on Inclusive Working Conditions between the government, the labor unions, and the Norwegian Federation of Employers.¹¹ The UN Convention on Disability from 2006 was implemented into the Norwegian legal system in 2008.¹² Norway is among the top spenders on publicly sponsored reeducation and back-to-work programs in Europe.¹³

Studies of the Norwegian SCI population show that approximately 65% to 70% is employed at some time after injury (Leiulfstrud A, Solheim E, submitted for publication, 2015).¹⁵ Important factors predicting employment after injury are levels of education and the opportunity to continue working in the same organization as before the SCI (Leiulfstrud A, Solheim E, submitted for publication, 2015), and also age and severity of the injury.¹⁵ Women have been reported to have significant lower employment odds in the past,¹⁵ but more recent data

From the Sunnaas Rehabilitation Hospital, Nesoddtangen, Norway (VS, GM, PW, JKS); Spinal Cord Unit, St. Olav's University Hospital, Trondheim, Norway (AL); Department of Neurology, Haukeland University Hospital, Bergen, Norway (TR); Institute for Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Sweden (TR); Norwegian Spinal Cord Injury Registry, St. Olav's University Hospital, Trondheim, Norway (AH); The Norwegian Spinal Cord Injuries Association, Grønland, Oslo, Norway (LAF); and Faculty of Medicine, University of Oslo, Oslo, Norway (GM, JKS).

All correspondence and requests for reprints should be addressed to: Vegard Strøm, PhD, Sunnaas Rehabilitation Hospital, 1450 Nesoddtangen, Norway.

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show small sex differences in employment patterns (Leilufsrud A, Solheim E, submitted for publication, 2015). People with SCI are expected to marry and have children and to take part in social activities at the same level as other citizens.

THE HEALTH AND REHABILITATION SYSTEM

Norway has a universal public health system including all citizens with a permanent address in the country. Some have additional private health insurance coverage or health insurances sponsored by their employers.¹⁶ However, this only applies to less than 5% of the population. Moreover, neither is there a private hospital with acute services for SCI or other severe injuries, nor a private specialized rehabilitation facility for SCI. The public health system offers people with disabilities access to disability pension if they are unable to work.¹⁷ A national health strategy covers all citizens.¹⁸

Community services are available, and individual rights are protected by legislation. The act relating to municipal health services obliges municipalities to provide a number of health services including general practitioner arrangement, physiotherapy, home nursing, and nursing homes. The law provides the right to receive necessary health services for all who live in a municipality. The Social Service Act and the Patient's Rights Act also cover the rights as a recipient of health services and describe what the members of the community are entitled to.¹⁹ In addition, the Norwegian Labour and Welfare Administration will assist the users in returning to work and reintegrating to the community.¹¹

WHAT IS THE STATE OF SPECIALIZED CARE?

Specialized spinal cord rehabilitation units are integrated at Haukeland University Hospital and St. Olav's University Hospital, with 10 and 12 beds, respectively, dedicated to SCI. Oslo University Hospital transfers sub-acutely their patients with SCI to Sunnaas Rehabilitation Hospital, which has 34 beds available for primary rehabilitation and 17 beds for follow-up. The average length of stay in hospital from acute care until end of primary rehabilitation in 2014 for all SCI units was 121 days for traumatic SCI and 91 days for non-traumatic SCI.¹ The SCI units have well-trained multidisciplinary rehabilitation teams that may include physiotherapists, occupational therapists, social workers, psychologists, teachers, sports therapists, peer support specialists, nurses, and medical doctors. Examples of rehabilitation services provided are mobilization, pain and spasticity relief, urinary tract and bowel management, vocational training, patient education, strength and endurance training, wheelchair skills development, adaptation of assistive devices, adaptation of home environment, assistance with economic issues, nutritional advice, and psychological assessment and support.

All SCI units have a commitment to life-long follow-up for persons with SCI. After the primary rehabilitation, they will be admitted for regular checkups depending on their needs. In addition, the users can contact the hospitals if they have specific issues that need solving, or they can contact the ambulatory rehabilitation team, which will be able to support them, and the health care providers in the community.²⁰

THE SOCIAL RESPONSE TO SCI

According to Norwegian law, all people have equal rights to necessary health care, both in the primary and specialist health care services.²¹ All disabled people have access to assistive technology such as wheelchairs, equipment for home, and communication systems. To reduce social stigma against disability, campaigns are designed and all new public buildings and transportation, except flights and ships, are required to have a universal design according to the Anti-Discrimination Act.⁹

Most disability organizations in Norway operate under the umbrella of the Norwegian Association of Disabled²² or the Norwegian Federation of Organizations of Disabled People.²³ Persons with SCI may hold a membership of the Norwegian Spinal Cord Injured Association (Landsforeningen for Ryggmargsskade [LARS]). LARS is based on the philosophy of empowerment, and runs on a voluntary basis by their members, and is organized with a national executive board and 10 local autonomous branches. LARS arranges meetings, different activities, and is carrying out peer support at the SCI units. LARS has a good collaboration with the SCI units on different projects, and work for better rehabilitation, technical aid equipment, and research on SCI, among others.

There is no specific organization providing funding to persons with SCI in Norway, but LARS may apply for project-specific funding from a National Lottery (<http://www.extrastiftelsen.no/>), the Norwegian Directorate of Health, or get financial support to arrange meetings, etc., from private sponsors.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

The Norwegian international SCI Survey (InSCI-Nor) will supplement the already superior epidemiological data from NorSCIR, by adding information about the full-lived experience of SCI, and the perception on the part of patients with SCI of the nature and adequacy of the social response to their needs.

THE NATIONAL STUDY PROTOCOL

The survey questionnaire will be translated into Norwegian "bokmål", as this is the language used and understood by most of the population. Eligible persons for the study will be those with traumatic and nontraumatic SCI, age older than 18 years, who have completed primary rehabilitation since year 2000. In addition, they are required to have permanent residency in Norway and being able to respond to the questionnaire in Norwegian. Those with progressive etiologies, including other nontraumatic etiologies, such as congenital, inflammatory and autoimmune diseases, malignant tumors, and injury due to toxic agents and radiation, will be excluded. The electronic medical records at the 3 SCI units will be reviewed to identify eligible participants.

To recruit respondents, written invitation letters will be sent via the postal service. Reminders will be sent, either by post, telephone, or SMS. The invitation letter will contain information about the study, an informed consent form, the paper questionnaire, and a personal log-in code for the Web-based

questionnaire. Participants can choose between different response modes, either a self-administered paper- or a Web-based questionnaire or a telephone interview (upon request).

Each eligible participant will be assigned a unique anonymous international study ID. The paper questionnaire will contain this ID on each page. The key for linking the international ID to the national personal ID, as well as electronically scanned paper questionnaires, will be securely stored by the study coordinators at Sunnaas Rehabilitation Hospital. Data security and confidentiality will adhere to Norwegian legislations. A central international database is envisioned. The national leader and survey coordinators will have access to this password-protected central database.

Applications for approval will be sent to the regional committees for medical and health research ethics.

OPTIONAL NATIONAL MODULE

Additional modules for InSCI-Nor will be developed addressing issues such as employment, nutrition, physical activity, and shoulder pain. The modules will be part of PhD/postdoctoral or other research projects. Each module requires approximately 5 additional questions: questions on *employment* will be part of a postdoctoral project at St. Olav's University Hospital to get more in-depth information about the employment and work situation before and after injury; to assess the importance of work autonomy and empowerment at work; and to study the relative differences between occupational class groups in level of living and their overall life situation. Questions on *nutrition* will be part of a PhD project at Sunnaas Rehabilitation Hospital aiming to survey nutritional status in the SCI group. Questions on *physical activity and training* will be a continuation of previous research at St. Olav's University Hospital to study the overall importance in health and quality of life between those actively engaged in physical activity and training and those less active. Questions on *shoulder pain* will be part of a PhD project at Sunnaas Rehabilitation Hospital aimed at investigating prevalence of shoulder pain and exercise interventions in the management of upper extremity pain.

CONCLUSION

The present survey gives an overview of a relatively good health and social system for persons with SCI in Norway. The planned study is an excellent opportunity to compare the Norwegian system with many others around the world, thus establishing a basis for discussing current challenges concerning SCI, especially the most encouraging and discouraging signs for the future. In addition to the comparative dimension of the survey, the systematic sampling of

Norwegian data facilitates further studies of the Norwegian SCI population, and similar national studies can be made in participating countries.

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People with Spinal Cord Injury in Poland

Piotr Tederko, MD, PhD, Robert Jagodziński, Marek Krasuski, MD, PhD, and Beata Tarnacka, MD, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN POLAND

In the past 20 years, no systematic effort has been made to estimate the national spinal cord injury (SCI) incidence or prevalence. Epidemiologic data are mainly derived from hospital-based studies and different time points and may be outdated.¹ The incidence of SCI is estimated to be 14.5 for low urbanized regions and 20 per million population for highly industrialized areas in Poland.^{2,3} Currently, there are no studies investigating the prevalence of SCI in Poland.¹

More data have been retrieved from studies pertaining the etiology of SCI. Over the past decades, traffic accidents (24.5%), falls from a horse cart (24.3%), and diving accidents (19.8%) have been the predominant causes for an SCI.^{1,4-7} Cervical SCI prevailed among those younger than 40 years (particularly among children and adolescents) with the injury usually resulted from a diving or traffic accident, whereas falls from height and lumbar injuries were more frequent in older persons.^{2,4,7} Males were affected 2.8 to 6 times more frequently compared with females.^{2,8} A systematic review revealed that there are no studies concerning the epidemiology of SCI that resulted from conditions other than trauma.¹

Hospital mortality rate ranges between 8.9% (data from a specialized SCI center, 1965–1993) and 10.3% (regional hospitals, 2005–2008) in the acute phase of SCI^{2,5,9,10} and depends on injury location (18% of cervical, 7.5% of thoracic, and 2.4% of lumbar SCI), severity of neurological deficit on admission (17.9% in persons with a complete neural deficit), cause of injury (19%–21% among persons injured in falls from height, 16% in pedestrians struck by motor vehicles), and patient age.^{7,9,10} Deaths in the acute period after injury were most often due to pulmonary complications (74%), gastrointestinal bleeding (8%), urosepsis (7.4%), pulmonary embolism (6.2%), and irreversible brain injury (6%).¹⁰

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Upon the report of an injury, first aid is usually rendered by qualified rescue teams. Either ambulance or helicopter

transportation is used to refer the patient to the nearest emergency department of a hospital. First aid, transportation, and advanced care at the emergency departments are provided to all injured persons regardless of their insurance status.

In the hospital setting, standard surgical procedures are performed in neurosurgical and orthopedic departments. More complicated cases may be operated on in specialized centers and university hospitals. The average length of stay at a surgical department lasts between 7 and 14 days and may vary depending on a patient's dependency on mechanical ventilation in the intensive care unit. Pain treatment is usually provided at the neurosurgical centers and pain medicine units.

There are 2 centers providing comprehensive care for persons with SCI in Poland. The first and main spinal center, the Metropolitan Centre of Rehabilitation in Konstancin, is situated in central-eastern Poland and provides acute, post-acute, and chronic medical care for SCI patients in the entire country but mainly for those coming from the central-eastern provinces (with a population of 7.5 million).¹ The spinal unit has 45 beds and 10 beds for the specialized intensive care unit, and patients are admitted in the first hours after injury. Since the early 2000s, the care became less comprehensive because 3 important departments (neuro-urology, the orthopedic department for patients with septic complications, and social adaptation department) were closed. The second major rehabilitation center for SCI, the Upper Silesian Rehabilitation Centre Repty in Tarnowskie Gory, has 2 SCI departments with 50 beds each and admits patients from the entire country, but mainly from southern and central Poland (with a population of 13 million inhabitants). Patients from other areas, which are not admitted to 1 of the 2 specialized SCI centers, are treated in local hospitals under the supervision of specialists of the main spinal center.¹

Once a patient is discharged from inpatient rehabilitation, he/she undergoes a medical follow-up care plan. Because of the lack of a nationwide standard-of-care implementation, frequency of visits and schedules of diagnostic procedures vary between centers. Persons with chronic SCI may be referred to the outpatient rehabilitation by a physical and rehabilitation medicine specialist, which consists of 5 basic medical procedures for 10 days. In addition, day rehabilitation departments or inpatient rehabilitation exists and provides services, which can last for 15 to 30 days and 3 to 6 weeks, respectively. Persons with severe functional limitation in transferring oneself may avail of a home-based rehabilitation (up to 80 days a year, with 5 medical procedures daily).

LIVING WITH SCI

Despite advances in health and social care, persons with disabilities are still deprived of equal access to goods, services, institutions, and many rights in Poland. The percentage of

From the Department of Rehabilitation, First Medical Faculty, Medical University of Warsaw (PT, MK, BT); and Foundation of Active Rehabilitation (RJ), Warsaw, Poland.

All correspondence and requests for reprints should be addressed to: Piotr Tederko, MD, PhD, Department of Rehabilitation, Medical University of Warsaw, Pory 78, 02-757, Warszawa, Poland.

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persons with severe disabilities (including SCI) who felt discriminated is 11.7%, which is twice as high as in a group with milder disabilities.¹¹ According to self-reported data, 6.7% of disabled persons in Poland cannot satisfy their basic needs with the current income, 35.6% can hardly satisfy their basic needs, 53.4% can satisfy their basic needs, and 4.3% are well off. Poverty at the level of 4 of 9 factors of material deprivation is experienced by 21.4% of persons with disability.¹² There are sharp disparities in the financial situation among people with SCI depending on age, place of residence, and cause of the injury. Risk factors for worse material status include young age, living in rural areas, and injury due to a cause precluding compensation and disability pension.

The employment rate in the whole population of people with disabilities was 14.1% in 2014. After having sustained an SCI, the rate falls from 56% to 26%, which can be attributed to employer-related factors, such as the lack of workplace adaptation or negative attitudes and person-related factors, such as a low education level, motivation, and decreased attractiveness of persons with SCI in the labor market.¹³ Data collected between 2011 and 2015 showed that unemployment among persons with SCI of working age (females aged <60 years, males aged <65 years) exceeds 60%. Among those who work, 67% are employed in sheltered work facilities, 28% in the open market, and 5% run their own businesses.

The education level of persons with SCI is lower than that in the general population despite educational programs subsidized by the State Fund for Rehabilitation of the Disabled (PFRON). Ten percent of persons with SCI have a university degree, but only 18% continued education after acquiring the disability, reflecting limited educational opportunities close to their places of residence, lack of adapted infrastructure, or lack of motivation in individuals with SCI.¹³

While persons with newly acquired SCI express a strong demand for emotional support within the first 3 years after injury, veterans living with SCI for 10 to 15 years expect affirmative support (acceptation, esteem, trust). The shorter the time since SCI is, the more distinct is the discrepancy between support demanded and received.¹⁴ Recent findings showed that family life and relations with friends were the most satisfying domains of life of persons with SCI, whereas employment and sexual life were those areas with the least satisfaction. Overall life satisfaction was 4.1% for paraplegics and 3.9% for tetraplegics. Mean depression and anxiety scores among persons with SCI were comparable to the general population.¹⁵

THE HEALTH AND REHABILITATION SYSTEM

The socioeconomic transition that began in the late 1980s resulted in a decentralization of the mandatory health insurance system and a separation of health care financing from the provision of funding.^{12,16} In 2013, 4.6% of the Polish gross domestic product was spent on health care. Compulsory health insurance covers 98% of the population and guarantees access to a broad range of health services. The limited financial resources result in a restricted availability of services that patients are theoretically entitled to by the public payer. The problems most frequently encountered by users of public health services include insufficient availability of primary practitioners, limited access to diagnostic studies at the level of primary care,

and long waiting times in secondary specialized care (1–18 months, even for urgent cases). The number of per capita of health professionals employed in health care institutions providing publicly financed health care in Poland is lower than in most western European countries for all health professionals.^{16,17}

Financial shortages, inadequate allocation mechanisms for real health needs and lack of standards result in relatively high out-of-pocket expenditures (22%) for households.¹² According to 2010 data, the average health care expenditure per capita accounted for 4.8% of the household budget, nearly doubled for retirees.¹⁸

Rehabilitation services provided in spinal centers, as well as in the majority of neurorehabilitation centers, follow the assumptions of the Polish Model of Rehabilitation ensuring coordinated medical, psychological, social, and vocational aspects of patient's functioning and providing comprehensive care from the acute phase to social reintegration. Other hospitals present large disparities with regard to the quality of rehabilitation care. Some of them may provide comprehensive care comparable to that in the spinal centers, whereas others may limit their offer to several medical procedures, such as passive and active exercises, respiratory physiotherapy, adaptation to sitting and vertical position, and electrostimulation. All rehabilitation centers follow the limits of hospital stay: 12 weeks in acute and post-acute phase and 6 weeks in other cases.

The right to equal access to public health services has been guaranteed by 2 recent Constitutions of Poland (1952 and 1997). The centralized health care system basing on the Semashko model created after World War II guaranteed the establishment of medical institutions providing highly specialized care for large populations.¹⁶ The system of care for persons with SCI was based on 2 regional centers providing continued comprehensive treatment from the acute to chronic stage of SCI-related disability for patients from the entire country, covering medical, psychological, social, and vocational aspects of functioning.¹⁹

WHAT IS THE STATE OF SPECIALIZED CARE?

The systemic health care changes have resulted in a decentralization of care for persons with SCI in all stages. A significant number of public hospitals (including spinal centers) have suffered from ineffective financial management and the accumulation of debt. Being a well-paid surgical procedure, spinal fusion surgery has been widely introduced even in provincial hospitals. There are 373 hospitals with an orthopedic department and 99 hospitals with a neurosurgical department in Poland. Patients with SCI are now randomly referred to local rehabilitation facilities. Of the 356 inpatient rehabilitation facilities in Poland, 160 provide neurorehabilitation. Institutions providing rehabilitation services offer care of different quality, from comprehensive rehabilitation to a scanty repertoire of procedures imposed by the payer. Although guidelines exist for the treatment of persons with SCI,^{19–22} there are no nationwide programs of SCI care endorsed by the Ministry of Health.

Beyond spinal centers, there is a paucity of specialists experienced in the treatment of persons with SCI, particularly in the fields of urology, gastroenterology, sex and procreation medicine, and care of persons with pressure sores. There is limited access to specialized outpatient psychological support.

There are no private hospitals offering comprehensive care for persons with SCI, although some selected diagnostic and therapeutic procedures addressing specific SCI consequences, such as urological or orthopedic procedures or physiotherapy, can be obtained in the nonpublic sector.

THE SOCIAL RESPONSE TO SCI

The disability pension system in Poland covers all persons who pay an insurance premium themselves or have been registered by a family member, but the amounts provided are insufficient to live in dignity. Benefits for caregivers of disabled persons are also low. Several government and nongovernmental organizations (PFRON, District Employment Agencies, Career Initiative Companies, Social Welfare Centers [SWCs], and Family Support Centers [FACs]) provide financial, organizational, and advisory support for disabled persons.¹ The statutory activity of PFRON includes tasks related to subsidizing the employment of people with disabilities and cofinancing of projects targeted at social and professional mobilization of people with disabilities conducted by disabled people's organizations, financing Occupational Therapy Workshops and Vocational Activity Workshops.

Direct support for people with disabilities is offered by FACs, which run programs for the elimination of barriers and supply equipment and function-improving technologies. Family Support Centers provide financial support for the education for people with disabilities. In addition, SWCs provide financial benefits for caregivers of persons with disabilities. There are financial reliefs granted by the Polish law for employers who employ persons with disabilities, such as wage subsidies, support for workplace adaptation, and partial reimbursement of the costs of employing an assistant to the disabled.

Disabled people's organizations not only offer financial support but also provide activation programs and education, including assistance services. The Foundation of Active Rehabilitation (FAR) is the only disabled people's organization specifically concerned with long-term care of persons with SCI in Poland. Enrollment of beneficiaries of social and vocational activation programs starts by contacting potentially eligible patients with SCI at rehabilitation departments, where post-acute care is provided.¹ The support provided by FAR includes training camps where participants acquire practical skills and receive additional information for the future, free-of-charge wheelchair rental for persons in the first year after hospital discharge, education (e.g., computer skill courses), and vocational, social, and psychological counseling. Other forms of the FAR activity include education of medical and paramedical professionals about the disability related to SCI from the perspective of a disabled person, promoting sports for wheelchair-bound persons, campaigns to reduce the social stigma of disability, and efforts to facilitate inclusion of persons with disability in the public space. The 2 latter tasks are usually fulfilled in cooperation with the Government Plenipotentiary for Persons with Disabilities and medical institutions.

According to an Ordinance of the Minister for Infrastructure, all newly constructed and redeveloped buildings should be accessible to persons using wheelchairs. Since 1991, PFRON has been subsidizing targeted programs aimed to adapt public buildings for people with disabilities. There are still problems with accessibility of institutions and offices situated in older

buildings. Persons with SCI find it difficult to overcome architectural barriers in their places of residence. In bigger cities, this problem is reduced by the home exchange system endorsed by FACs and SWCs and social housing meeting the needs of persons with disabilities.

Regarding public transportation, there are large disparities between cities and villages. In most cities with more than 100,000 inhabitants, there are new adapted public buses and specialized mobility transport subsidized by local authorities. In rural areas and in small towns, it is difficult to get out of one's place of residence without one's own vehicle. Transport by train is becoming gradually more accessible as railway stations are adapted and the number of adapted railroad cars has been growing. All carriers providing air services are required to follow relevant procedures for people with disability. The lack of trained personnel at some airports is occasionally reported.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

As previously mentioned, basic epidemiologic information is of much need in Poland. Following the collapse of a previously well-functioning system of care of persons with SCI, it is important to develop a program of medical and social care fulfilling the biopsychosocial needs of this vulnerable group in the recent socioeconomic condition of Poland. Understanding how SCI influences biological, personal, and social functioning, together with updated morbidity and prevalence data, is the minimal set of evidence-based data necessary to formulate a program of changes. The need of a long-term research strategy on SCI may be at least partly addressed by this comprehensive cohort study.

The National Study Protocol

The Polish study within the InSCI project will target persons 18 years or older with a diagnosis of a traumatic or nontraumatic (vascular, infectious, related to degenerative spinal disease, and tumors) SCI, at least 3 months after discharge from a post-acute care rehabilitation facility, who permanently reside in Poland. Individuals with congenital conditions leading to SCI, new SCI in the context of palliative care, and progressive disorders of the spinal cord (multiple sclerosis, amyotrophic lateral sclerosis), as well as persons with mental and cognitive impairment, will be excluded.

To ensure a large and representative sample of the target population, a study database will be created. The database will include all persons with SCI identified by FAR in the years 1990–2016 and the corresponding records of 2 spinal centers and a regional rehabilitation institution admitting patients with SCI. Personal identification numbers in the combined database will be cross-verified to avoid double recording. Three thousand individuals randomly selected from the contact database will be invited by e-mail, ground mail, or telephone to participate in the survey. Nonrespondents will be approached again every 4 weeks up to 3 times, except for those who have explicitly refused participation. The diverse forms of survey data acquisition offered to participants (direct interview, telephone

interview, online questionnaire, paper version distributed by ground mail) should increase participation and representativeness of the study. Fifteen percent to 20% of the participants will be surveyed personally by interviewers. Selection of the participants to be visited by interviewers will be based on the preferences of the participants, for example, related to the willingness of participation in FAR programs and/or the expected difficulty with filling up the questionnaire. Interviewers will meet the participants at locations preferred by the participant to ensure personal comfort and privacy.

The expected need to visit 15% to 20% of the participants in their places of residence is based on the experience gained during previous programs^{13,14,23} and serves to reach the most vulnerable individuals (those with highest functional limitations, poor general health, complications, negative attitude toward oneself and the environment, worse financial situation, or living in remote rural areas). At each stage, nonresponse cases and causes will be recorded.

The FAR database was initiated in the 1980s and has been developed and managed in accordance with the Act on Personal Data Protection of August 27, 1997. The procedures of data collection and processing have been approved by the Inspector General for Personal Data Protection. The study protocol will be submitted for review to the Ethical Review Committee of the Medical University of Lodz. Informed consent will be obtained from all subjects prior to data collection. The data set designed for analysis will be kept separate from the participants' personal data.

Expected limitations of the study are related to the enrollment strategy. The FAR database as the largest nationwide prospectively collected database of persons with SCI serves as a good starting point for sample selection but brings the risk of bias. Persons who are older and less motivated to undertake social and vocational activity and those with nontraumatic SCI may be underrepresented. The addition of hospital records may be insufficient because not all persons with SCI are referred to spinal centers.

CONCLUSION

Spinal cord injury is a devastating condition to both an individual and the society.²⁴ The model of rehabilitation elaborated in Poland in the 1960s ensured comprehensive and continuous care of persons with SCI. However, decentralization of health services following the socioeconomic transition in Poland affected the performance of the model. Participation in the InSCI program is an opportunity to obtain epidemiologic data useful for the creation of a comprehensive nationwide program of SCI care and is an opportunity to form an evidence base for restoring comprehensive medical and social care of the population of persons with SCI living in Poland. The national study with a sampling frame of 3000 persons with traumatic and nontraumatic SCI identified between 1990 and 2016

will be based on the contact database of FAR in combination with medical databases acquired from the biggest hospitals dealing with SCI. The expected risk of bias is related to the underrepresentation of persons who are older and less motivated for social and vocational activity and individuals with nontraumatic SCI.

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People with Spinal Cord Injury in Portugal

Ines Campos, MD, MsC, Paulo Margalho, MD, Arminda Lopes, MD, Catarina Branco, MD, Filipa Faria, MD, MsC, Jorge Caldas, MD, Maria Cunha, MD, Maria João Andrade, MD, PhD, and Jorge Lains, MD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN PORTUGAL

In Portugal, there are no national data about spinal cord injury (SCI) or about most other health conditions that may cause disabilities. Since the last census (2011), there are general questions about “activity of daily living” (ADL) disabilities related to *vision, hearing, mobility, memory/concentration, hygiene and personal arrangement, and to be understood and to understand others*.¹ Eighteen percent of the population aged 5 or older mentioned having difficulty performing 1 of these 6 activities; in the population aged 65 or older, this number exceeded 50%. Portugal has no central registry of SCI cases nor has there been a national epidemiologic study on SCI.

In 1998, Martins et al.² (1998) claimed that the epidemiology of SCI in Portugal’s central region was not representative of the country overall SCI population. They identified 398 cases, with a predominance of males (3.4–1 ratio) and a bimodal age distribution in 2 peaks (15–24 and 55–74 years). The major causes of the injury were traffic accidents (57.3%) and falls (37.4%). The annual incidence rate was estimated at 57.8 per million inhabitants, and the annual survival rate was 25.4 per million inhabitants. We are not aware of new publications regarding the subject.

There are some single-center studies on their own SCI population, but they are not representative.^{3–5} One study³ evaluated 178 paraplegic patients followed for neurogenic sexual dysfunction and found a predominance of males (87.1%) aged between 18 and 81 years; traumatic etiology was the main cause of SCI (79.2%), with a similar number of complete ($n = 90$) and incomplete lesions ($n = 88$). Another study⁴ analyzed demographic data of patients with nontraumatic SCI admitted for rehabilitation between 2007 and 2009, and 69 patients were included; there was a small predominance of males (55.1%), with a mean age of 58 years; 79.9% were paraplegic and 89.9% had incomplete lesions. One small retrospective study⁵

included 16 patients with iatrogenic SCI admitted for rehabilitation between 2004 and 2009; 9 women and 7 men, with a mean age of 58.3 years.

Nowadays, based on our experience, we think that the survival rate significantly improved, and there is a decrease in traffic accidents and a trend to increase in falls and nontraumatic cases. In parallel, the SCI population is aging along with the overall Portuguese population and is experiencing better survival rates. Although we have no data, we believe that patients with SCI are living longer, with a life expectancy close to the general Portuguese population (except for those with high-level, complete injuries).

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Since 1981, every injured person was rescued by an emergency specialized team. All emergency team members have the skills to deal with major trauma and advanced life support. The emergency system may use rescue helicopters, or the patient will be driven to the nearest hospital with neurosurgery or orthopedic acute care and intensive care. After clinical stability, the patient is transferred to the ward (neurosurgery or orthopedics, depending on the hospital and clinical condition). Rehabilitation care starts as soon as the medical condition allows it.

After the acute phase, most patients with SCI are transferred to a rehabilitation center for a comprehensive rehabilitation program conducted by a physical and rehabilitation medicine physician, supplemented with physical therapy, occupational therapy, rehabilitation nursing, psychological support, social service counseling and assistive devices prescription and adaptation, and adapted sports. Most of the patients with SCI return to their homes after discharge.

As outpatients, they have access to physiotherapy treatments in local rehabilitation clinics (financed by the national health system, NHS, or insurance companies), and maintain follow-up appointments on the rehabilitation center or rehabilitation unit. For those who are able and wishing to work after the injury, there are 2 institutions in Portugal dedicated to vocational rehabilitation (www.cmra.pt and www.crpg.pt). Other institutions are dependent on fund raising to provide this service.

Overall, the rescue and acute care are in a very high standard quality, whereas access to comprehensive rehabilitation care has improved over the years by increasing the number of beds for inpatient rehabilitation. Portugal has 4 major rehabilitation centers covering the entire country. However, the number of rehabilitation beds remains low, approximately a total of 450 beds. Another gap is in the area of social integration and the availability of vocational rehabilitation and professional (re)integration.

From the Centro de Medicina de Reabilitação da Região Centro - Rovisco Pais, Tocha, Portugal (IC, PM, JL); Centro de Medicina de Reabilitação do Sul, São Brás de Alportel, Portugal (AL); Centro Hospitalar de Entre Douro e Vouga - Hospital de São Sebastião, Santa Maria da Feira, Portugal (CB); Faculty of Dentistry Porto University, Porto, Portugal (CB); Centro de Medicina de Reabilitação de Alcoitão, Alcoitão, Portugal (FF); Centro Hospitalar Tondela-Viseu, Viseu, Portugal (JC); Centro de Reabilitação do Norte, - Dr Ferreira Alves, Vila Nova de Gaia, Portugal (MC); Centro Hospitalar do Porto - Hospital de Santo António, Porto, Portugal (MJA); ICBAS Medical School, Porto University, Porto, Portugal (MJA); and Medical Dentistry School Catholic University, Viseu, Portugal (JL).

All correspondence and requests for reprints should be addressed to: Ines Campos, MD, MsC, Centro de Medicina de Reabilitação da Região Centro - Rovisco Pais, Tocha, Portugal.

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LIVING WITH SCI

Portugal has legislation concerning accessibility to public buildings and transportation, although these laws are not yet widely applied. Outside major cities, sidewalks, public transportation, and many public buildings are not wheelchair accessible, but the picture is improving.

For students with SCI, it is easy to return to school. Usually, the school tries to eliminate barriers to accessibility. On the other hand, it remains difficult for a person with SCI to return to work or to get a paid job; the unemployment rate for people with disabilities is estimated to be 2.5 times as much as the general unemployment rate.⁶ Portugal signed and ratified the Convention on the Rights of Persons with Disabilities. The “Initial report of Portugal on the implementation of the Convention on the Rights of Persons with Disabilities, August 2012” describes the work that has been done. In the report, Portugal commits itself to guarantee that employers and insurance companies will help to adapt the working place and provide needed vocational rehabilitation up to 36 months. In fact, most people with disabilities are unemployed in Portugal because of their low educational level and the lack of work adaptations. Specific legislation is still missing to oblige employers to hire a percentage of workers with disabilities, or to apply penalties for employers that refuse to adapt the workplace or prepare the employee with disabilities for shifting to alternative jobs after injury. If the SCI was suffered as a result of an accident at work, however, there is legislation that provides for both professional rehabilitation and reintegration.

Although there are no data concerning divorce rates for SCI persons, we feel that they have a higher percentage than the general population. Yet, they generally have good family support and a caregiver and are socially integrated with a good social network.

THE HEALTH AND REHABILITATION SYSTEM

The Portuguese National Health System, financed by the state budget, is a hierarchized system, and the facilities have levels of responsibility and capabilities, from the local hospital to the regional and central hospitals (named group 2 and 3).⁷ Access to required health service is generally easy but depends on geographic and bureaucratic issues of the NHS and insurance companies. All the patients with disabilities have priority in the access to primary care. The number of physicians, nurses, rehabilitation therapists, and other health professionals are generally enough to fulfill the demands. The country’s 13 hospitals have the equipment and staff, including a rehabilitation department, with the abilities to manage patients with SCI in the acute phase. Many patients with SCI are financed by insurance companies (mainly for traffic and work accidents) and have easy access to health care and assistive technology. For patients assisted through the NHS, access may be delayed, but medical appointments, treatments, and assisting technology are available across the country, nearly free of charge. The removal of architectural barriers in the person’s house is generally on their own expenses (except for those assisted through insurance companies).

WHAT IS THE STATE OF SPECIALIZED CARE?

Portugal has 4 rehabilitation centers covering the entire country, and 5 physical and rehabilitation medicine departments

inside acute care hospitals that provide comprehensive and intensive rehabilitation, with the complete technological equipment needed to screen and treat patients with SCI. All the group 2 and group 3 hospitals have rehabilitation departments for acute SCI rehabilitation and follow-up appointments. Some treatments, such as medically assisted procreation, are only available in specialized centers resulting in that not all the patients have access to it. Local outpatient clinics have a physiatrist who may or may not be specialized in SCI. There are a few centers where individuals with SCI have free access to assistive devices. Although the access is unequal across the country, generally all patients with SCI have at least a wheelchair and assistive devices for activities of daily living. In Portugal, there are qualified professionals to fit and repair the assistive devices.

THE SOCIAL RESPONSE TO SCI

There is no national health strategy specifically designed for SCI, although most of the health coverage is public (the rest is covered by work or traffic insurance). There are no national organized campaigns designed to reduce stigma against disability, but there are campaigns during the summer to prevent SCI diving accidents. There are national campaigns to prevent car accidents, and the Portuguese law remains very strict concerning safety equipment (in particular, seat belts), speed limits, and alcohol consumption.

Portugal has laws that state tax benefits for the employers of disabled workers, but most of the persons with SCI do not work, so the national government provides pensions for all the persons with disabilities with at least 60% of disability, which is much lower than the country’s minimum salary. There are patients’ associations for persons disabled by motor accidents, and some of these provide very limited and scarce funds to people with SCI. Social attitudes toward persons with SCI are very positive, with special parking places, supermarket queue priority, and public institutions’ preferential attendance for persons with motor disabilities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain From Participating in the InSCI Study?

As noted, in Portugal, there are no national data about SCI, so we are extremely hopeful that the InSCI in Portugal will be the first step to closing that important epidemiological gap. We intend to use the national survey data we get from the study to assisting in raising awareness in Portugal about persons with disabilities in general and persons with SCI in particular and to use that momentum to try to influence politicians and the opinion and decision makers.

THE NATIONAL STUDY PROTOCOL

As patient’s associations are not very active, nor do they focus on SCI in particular; our sampling frame will rely on multicenter hospital databases, based on *International Classification of Diseases* codes, to contact patients from the 4 rehabilitation centers and 5 physical and rehabilitation medicine departments that provide specific care for inpatients with

SCI. We will also recruit through social media. We acknowledge that this approach may underrepresent those with less disability who do not attend regular medical appointments. The inclusion criteria are the following: adult patients with traumatic SCI and nontraumatic nonprogressive etiologies, living in a community in Portugal, able to respond in Portuguese, with the informed consent given any time since injury. The exclusion criteria are the following: progressive etiologies such as inflammatory and autoimmune diseases, malignant tumors, toxic agents, radiation, and congenital SCI. First contact will be conducted by their physiatrist to obtain consent; the patient will receive by post the invitation letter, the informed consent, and the paper-and-pencil questionnaire; an online response will be given as an option. There will be 2 reminders for nonresponders at the 30th and the 90th days and the possibility of a telephone interview.

A local database will be established and hosted by *Rovisco Pais*, with username and password protection and limited access. The contact details and personal data database will be matched for repeated patients. The survey data will be hosted by the Swiss Paraplegic Research in Nottwil.

OPTIONAL NATIONAL MODULE

The National module will address issues concerning patient's accessibility to rehabilitation health care, namely, access to assistive devices, urinary catheters, physiotherapy treatments, specific appointments for SCI, and adapted sports. It is presumed that the access to rehabilitation health care and physical activity, as well as for the entire Portuguese population, is very unequal across the country, but there are no reliable data. The national module may allow the national authorities to update health policies.

CONCLUSION

Generally, the societal and health response to persons with SCI is good and universal. The exception is mechanisms for returning to work or getting a paid employment for the first time. Portuguese legislation is fairly advanced in the area of

human rights and anticipates a proactive social response to remedy discrimination. For some reason, however, the rules and regulations that put these laws into practice are still missing. The same is happening with the legislation about architectural barriers in public and private buildings. As a people, the Portuguese have a positive and inclusive attitude toward people with motor disabilities, in particular, toward the persons with SCI.

The discouraging signs for the future concern the national, and European, economic crisis. Unemployment and poverty are growing among the Portuguese population and may become even worse for disabled persons. Although Portugal has a good public health system, the basic needs depend on the country's economy. The lack of national data avoids comparison of these variables for the SCI population. Additionally, the absence of a powerful and active association of patients with SCI makes even more difficult for the patients to claim their rights and to get attention from the health authorities.

The most encouraging signs are the positive cultural and social attitude toward those with disabilities, the respect to those that are "different" and needing special social support, mainly due to the tremendous growth of the educational level of the Portuguese population. We aim that this survey will allow the promotion of an active and representative organization of patients with SCI.

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People with Spinal Cord Injury in Republic of South Africa

*Conran Joseph, PhD, Ernst Scriba, MD, Virginia Wilson, MD,
Joyce Mothabeng, PhD, and Francois Theron, MD, MMed*

EPIDEMIOLOGY OF SPINAL CORD INJURY IN REPUBLIC OF SOUTH AFRICA

In South Africa, epidemiological data on spinal cord injury (SCI) are scarce, partly owing to the lack of a national registry and a coordinated system of care. A recent study by Joseph et al. provided the first population estimates of the incidence of traumatic spinal cord injury (TSCI), reporting a staggering rate of 75.6 per million persons. The main cause of TSCI in South Africa was found to be assault, which accounted for approximately 60% of all cases, followed by transport-related causes (26%) and falls (12%).¹ This recent report provides an optimal platform for prevention because of its population-based design; however, the data only represent the City of Cape Town and not the entire nation of South Africa. The only other epidemiological study of South Africa, conducted 2 decades ago in Johannesburg, found similar mechanisms of injury² but a lower incidence rate that is probably due to the hospital-based design. Taken together, the 2 studies show a disproportionately high incidence of violent injuries in South Africa, compared to the rest of the world, which is believed to be precipitated by the sociopolitical climate.^{2,3} With regard to prevalence and mortality of TSCI, and nontraumatic spinal cord injury, (NTSCI) generally, there are no available reliable reports, although the QuadPara Association of South Africa estimated in 2009 that approximately 50,000 people in South Africa are living with an SCI.⁴

With the restructuring of the health care system in South Africa, moving toward a universal health insurance, it is essential to firmly establish the epidemiological profile of SCI to redistribute resources for improved service delivery. Many gaps concerning the epidemiology of TSCI and NTSCI remain, especially for mortality and life expectancy after SCI.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

The management of SCI in South Africa has transformed tremendously, having moved toward the provision of

comprehensive care of those who survived the initial ordeal. Having said that, only a few of the 9 provinces in South Africa have the organizational capacity and resources to provide a more comprehensive package of care for survivors of SCI. Typically, those in urban settings and those with private health care insurance have access to better care.

Consistent with the acute clinical practice guidelines of managing SCI, in South Africa, acute survivors are first transferred to the closest Level I trauma unit—hospitals with the capacity and expertise to ensure that persons are medically stable.⁵ However, a recent report found that stabilization surgery for newly injured persons is delayed, with 10 days as the average time to surgery after injury. This is likely due to pressure on specialized services such as neurosurgery and orthopedics. Subsequently, this delay resulted in an increased prevalence of pressure ulcers during acute care.⁶

Specialized inpatient rehabilitation is available for both public and private systems. The public-funded center situated in Cape Town manages approximately 420 persons with SCI annually, constituting 40% of all admissions for the year. Owing to the high need of rehabilitation, persons with SCI are often admitted based on factors such as age, potential to benefit optimally from rehabilitation, and motivation. The length of inpatient rehabilitation of those with tetraplegia and paraplegia is 86 and 68 days, respectively.⁷ The benefits of those selected for rehabilitation are evident in their functional independence and experience of becoming reconnected with and integrated in society.^{7,8}

Based on the emerging evidence-based foundation for developing SCI care in South Africa, it is important to aggressively target primary prevention of SCI, followed by secondary prevention of adverse events that may lengthen acute hospital stay in an already pressurized health care system. Additionally, access to comprehensive care to persons with SCI living in rural areas of South Africa needs to be improved.

LIVING WITH SCI

Inaccessibility of the environment had been identified as the chief barrier to social participation and integration of persons with SCI in South Africa. Already in 1982, a time when little legislation concerning the demands of equalizing employment opportunities existed for persons with disabilities,⁹ a coordinated approach between state departments, provincial and local authorities, and private welfare organizations had been proposed to address this need—equalization of opportunities and effective participation—among persons with SCI. Now, more than 30 years later, the same challenges, including accessibility of the environment and the lack of recreational facilities and transport, persist today with no SCI-specific employment legislation in place. A recent qualitative study

From the Division of Physiotherapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden (CJ); Physiotherapy Department, Faculty of Community and Health Sciences, University of the Western Cape, Cape Town (CJ); Western Cape Rehabilitation Centre, Cape Town (ES); Netcare Rehabilitation Hospital, Johannesburg (VW); Faculty of Health Sciences, School of Healthcare Sciences, Physiotherapy Department, University of Pretoria, Pretoria (JM); and Tswane Rehabilitation Centre, Pretoria (FT), South Africa.

All correspondence and requests for reprints should be addressed to: Conran Joseph, PhD, Karolinska Institutet, Department of Neurobiology, Care Sciences and Society (NVS), 17 Division of Physiotherapy, 23100, SE-141 83 Huddinge, Sweden.

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by Joseph et al. focusing on the path to *participation* of long-term survivors of TSCI found that participants acknowledged that barriers are always present and *participation* and integration depended on the ability of dealing with the “new-self,” negotiating challenges, identifying facilitators, and becoming an agent.¹⁰ Survivors of SCI generally expressed their need to be seen as equals in society, people who can contribute in a meaningful way, and people who would like responsibility and not only rights. This understanding is, however, not always observed in the able-bodied persons of society. Participants further expressed that their personal relationships are affected after an SCI, owing to the fact that the consequences of injury can negatively affect intimacy, mobility, and energy. Survivors of SCI further describe their involvement in community life as much less than in the past, mainly due to physical barriers, lack of adequate transport, and negative attitudes of the general population.¹⁰

THE HEALTH AND REHABILITATION SYSTEM

In South Africa, both public- and private-funded health care systems are available, with approximately 80% of South Africans using the public system. The public health care system of South Africa has undergone radical changes after 1994 in the aftermath of apartheid, with core principles and concepts focusing on the availability of health care as a basic human right and having access to affordable care that is of quality. Primary health care has been identified as the primary vehicle for health services delivery (especially to those in rural areas), with rehabilitation as an important component of the primary health care service.¹¹ It is against this backdrop that the National Rehabilitation Policy was developed and published in 2000.¹² A national report of 2014 revealed that 94% of persons with private medical aid were very satisfied with services and facilities compared to only 60% using public care.¹³ A recent community-based study by Maart and Jelsma¹⁴ concerning access to public health and medical rehabilitation services found a high percentage of unmet rehabilitation needs. The proportion of unmet needs for services was as follows: 54% for home-based care; 34.5% for assistive devices; 28.9% for medical rehabilitation services; and 2.5% for health services. The main problems with accessing services included inadequate finances (71%) and transport problems (72%).

WHAT IS THE STATE OF SPECIALIZED CARE?

Specialized health care and SCI rehabilitation services in the larger urban areas are available, although the public sector has major transport problems.¹² There are also large discrepancies between the public and the privately funded SCI sector regarding accessibility: there are only a few public SCI rehabilitation centers and even fewer public acute SCI care facilities, while multiple privately funded rehabilitation and acute care centers are available throughout the country. Owing to the lack of specialized SCI health and rehabilitation services in other areas of the country, patients are screened based on their potential to benefit, with the result that not all spinal cord-injured persons will receive specialized rehabilitation. Recently, the country made available an Integrated Disability

Management and Rehabilitation Pathway document indicating that persons with SCI should receive adequate acute care, followed by 15 to 90 days of high-intensity rehabilitation. Furthermore, outpatient rehabilitation should be received between 1 and 3 hours per week, focusing on individualized goals and development of strategies to facilitate integration and social participation.¹⁵

Assistive technology is available to people with SCI, but this differs from facility to facility, with excellent services being available at some and, mostly in rural areas, no available budget for assistive devices. Training in the use of assistive devices occurs, but this is still in the developmental stages. Furthermore, national wheelchair-seating guidelines are available, and most therapists working with SCI and other neurological health conditions are encouraged and subsidized to complete these courses that are offered at a basic, intermediate, or advanced level. Concerning peer support for newly injured survivors of SCI, this model had been found to assist acute survivors to make a positive adjustment in the light of the new body; however, rehabilitation centers are no longer able to afford the appointment of this level worker. In a recent qualitative study, participants, including founders of nonprofit organizations, expressed the need to continue this service and counseling platform, since survivors are more willing to share their stories with their peer that made a positive adjustment to life.¹⁰

THE SOCIAL RESPONSE TO SCI

South Africa developed its own National Rehabilitation Policy and ratified the UN Convention on the Rights of Persons with Disabilities in November 2007, with the focus of promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. South Africa remains committed to accelerate its national agenda for the progressive realization of rights of persons with disabilities by, among others, strengthening its mainstreamed legislative and policy framework and by accelerating the implementation of policies and programs that aim to provide equal access to persons with disabilities, including disability-specific programs aimed at addressing barriers to participation. Many challenges remain today as survivors of SCI echo the inaccessibility of public spaces, for example, lack of elevators at train stations and the narrow aisle of supermarkets. Public transport is another major issue, since the lack of accessible transport resulted in numerous survivors not being able to attend health and rehabilitation appointments or their jobs.¹⁰ Another issue that persists is the portrayal of negative attitudes toward persons with SCI and disability in general. A need exists to sensitize the public toward inclusion of persons with disabilities as equal members of society. Concerning prevention of SCI, 3 SCI-related campaigns have been launched, one for diving accidents,¹⁶ one accentuating the use of seatbelts and road safety,¹⁷ and the other the BokSmart National Rugby Safety Programme (rugby-related).¹⁸ We have seen a low incidence of diving and sport-related injuries in the latest epidemiological study.¹ However, no local or national campaign concerning the main cause of injury, namely, assault (gunshot and stabs), has been launched.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

Limited research investigating health and functioning of survivors of SCI has been conducted in South Africa. A description of TSCI in South Africa is emerging, whereas little remains known about NTSCI. Participating in the InSCI Survey affords the opportunity to gain information on the health and rehabilitation requirements to respond to the unmet needs of survivors of SCI. The survey items for this purpose were selected from current criterion standard measures in the SCI field, which cover the entire spectrum of ICF domains and the prototypical aspects often altered after injury. Furthermore, having other countries, both high- and middle-income participating in this endeavor, much is to be learned about the successes of restructuring and reallocating resources for survivors of SCI. Our team that consists of academics, clinicians, consumers of health services, and the management of the South African Spinal Cord Association has a clear vision of promoting and ensuring full participation, and is committed to improving the lives of those with SCI. We will further use other data sets for SCI to gain a broader perspective on functioning and the needs of survivors in South Africa. We remain confident that our participation in this study may contribute to the long-term aim of developing a national competence guideline for SCI care in South Africa.

THE NATIONAL STUDY PROTOCOL

We plan to include the entire sample from an ongoing regional population-based epidemiological study in Cape Town, South Africa, among survivors of TSCI. With the start of the International Survey in 2017, this cohort will be 3 years after injury, providing the additional benefit of investigating mortality and factors affecting it, data that are much needed for South Africa. In addition, we will recruit eligible participants from Pretoria, Durban, and the Eastern Cape, which is likely to represent the SCI population in South Africa. This sampling frame will result in the recruitment of survivors from urban, periurban, and rural localities, which will account for the presence or absence of health care services both with regard to accessibility and quality. Furthermore, the recruitment of subjects from these provinces will ensure variation with regard to personal factors, such as ethnicity and socioeconomic status, which need to be addressed within the South African context. We will include adults with TSCI, older than 18 years, surviving 3 years or more. We will also endeavor to include a sample that received private medical care with the same inclusion criteria.

Since knowledge available on NTSCI in South Africa is limited, we strive to retrospectively and prospectively learn concerning its epidemiology. Similarly, inclusion of participants will be based on survival time after diagnosis. We will also include the centers in the 4 provinces.

Contact details of eligible participants will be retrieved from the hospital records, upon approval of the study, and participants will be contacted by telephone to ascertain their intention to participate. Owing to the numerous official languages spoken in South Africa, and high levels of illiteracy (because

of no education), participants will be asked to complete the questionnaire in their preferred language and whether a proxy will be available to assist with its completion. Questionnaires will be sent to participants via postal mail, and 2 to 4 weeks will be given to return completed measures to the Secretary of the South Africa Spinal Cord Association in Durban, where it will be safely stored in accordance with good practice.

CONCLUSION

The South African Department of Health adopted various frameworks and policies to ensure the health and well-being of those with disabilities. This is further evident with the establishment of a limited number of specialized acute and rehabilitation facilities in the country. However, these services are not easily accessible for persons residing in rural areas. It is promising to see the first reports of TSCI epidemiology in a region in South Africa, which could be used to advocate for the adequate distribution of resources and facilities. To date, no epidemiological data are available for the rest of the country (8 of the 9 provinces) and none for NTSCI, which are thought to be on the rise. More studies are needed, especially in the rural areas, to investigate aspects concerning access to health and rehabilitation care, long-term unmet needs, and participation and integration. Participation in this international project may be the platform that is required for strengthening the health care system for SCI in South Africa.

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People with Spinal Cord Injury in Spain

Merce Avellanet, MD, PhD, and Miguel Angel Gonzalez-Viejo, MD, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN SPAIN

The incidence of traumatic spinal cord injury (SCI) has increased from 8 cases per million population (1984–1985) to 23.5 cases per million population (2000–2009) in Spain.¹ Currently, it is estimated that 38,000 persons live with SCI in Spain.²

According to data from the Spanish Ministry of Health (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2014), hospital mortality rate from first admission is 1.4%.³ Mortality rate after hospital discharge is not available. Among traumatic SCI, 39% are due to road accidents, 55% are a result of falls during sporting or leisure activities, 1% are caused by violence, and 5% result from other miscellaneous reasons mainly attributed to accidents at the workplace. Traffic accidents are represented as follows: 40%, car; 40%, motorbike accidents; and 20%, pedestrian-related incidents.^{3,4} Other important data on SCI epidemiology are missing. Currently, a National Register System on epidemiological data does not exist, although it is expected that one will be operative in the future.

Over the last decades, the assistance to road traffic accidents and the acute care of SCI have improved notably in Spain. Moreover, after a specific report of the situation in 2005, the Ministry of Health implemented a national protocol in 2010.⁵ That is why a lesser number of complete injuries and a longer life expectancy have been observed.^{2,4} Similar to other countries, there is also a progressive increase in the mean age of patients with SCI. This is most likely caused by a shift from traumatic to nontraumatic cases. Moreover, improvement in acute and subacute care implies that people with SCI are living longer.¹

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Emergency care is provided 24 hours a day, both within and outside health care centers, including home emergency care, “in situ” care, and emergency transportation. It involves medical and nurse resources, as well as other professionals. Coordination across different emergency resources and mobilization according to need is centralized in emergency call centers.⁶

Once an injury has occurred, emergency services can be contacted by dialing 112. This call is free and initiates an immediate rescue process based on the information provided. The Emergency Medical System (EMS) coordinates a specialized medical rescue team. Medicalized ambulances as well as helicopters are available. Because the EMS covers all Spanish geographical areas, the average response time is usually fast. Depending on the information given to the EMS, trained and specialized technicians and/or physicians will attend the injured patients. If firefighters are required, they are trained to deal with SCI, too. The time between calling and the arrival of the medical team depends on the location of the accident, but generally it is no longer than 30 minutes.⁵

There are more than 200 intensive care units (ICUs) located in general hospitals throughout Spain.⁷ Only hospitals designated by the National Health System at the upper level (level III), which provide advanced care, can offer all surgical techniques such as neurosurgery, spine surgery, general surgery, thoracic surgery, cardiac surgery, and pediatric surgery. Most patients are initially admitted to an SCI specialized acute care unit within a level III hospital. If the person who contacted the emergency services mentions the possibility of an SCI, the patient is taken directly to the specialized hospital with ICU and SCI unit. If the information provided is not accurate, the injured patient would be initially taken to a level III hospital without SCI or even a general hospital. Once physicians are aware of an SCI, the patient is immediately transferred to a specialized SCI unit. This may mean a delay of a few hours, less than 24 hours. In total, there are 11 hospitals throughout the country with both ICU and SCI units; these cover 11 of the 17 autonomous communities. Terrestrial ambulances are usually used for transportation; however, when the journey is expected to take longer than 30 minutes, a helicopter is used. Regarding the therapeutic approach of physiatrists who take care of acute SCI, the Spanish Paraplegia Society⁸ recommends that they follow the clinical guidelines published in the 2013 Neurosurgery issue.⁹ Moreover, the Spanish Paraplegia Society has recently published an evidence-based review guideline on the use of corticosteroids.¹⁰ High-dose therapy is not recommended in acute traumatic SCI as part of a routine therapeutic approach.

All of the 11 specialized SCI centers have rehabilitation units, and there are also 2 SCI rehabilitation hospitals. All of these centers provide medical and psychological rehabilitations; however, vocational rehabilitation is currently not sufficiently covered.² The length of stay will depend on the neurological level and the American Spinal Injury Association classification. For persons with paraplegia, the length of stay is 120 days; that for persons with tetraplegia is 189 days, including the period of acute ICU admission.¹¹ Rehabilitation services include physiotherapy, occupational therapy, pain management, spasticity treatment, and the use of technical aids.

From the PMR Department, Hospital Nostra Senyora de Meritxell, Andorra (MA); and SCI Unit, Hospital Universitari Vall d'Hebron, Barcelona, Spain (MAG-V). All correspondence and requests for reprints should be addressed to: Merce Avellanet, MD, PhD, PMR Department, Hospital Nostra Senyora de Meritxell, Fiter i Rossell 1-13, Escaldes-Engordany AD700, Andorra.

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LIVING WITH SCI

One of the most important gaps in the SCI care process is preparing patients to return to work. There are many difficulties facing a person with SCI. Apart from the disability itself, employment prospects are very low and are additionally hindered by the general high unemployment rate in the Spanish population (25%).¹² Moreover, patients usually receive a monthly payment from the government, which may deter persons with SCI from searching employment.

Community resources to improve the lives of persons with SCI depend on the geographical location, which shows a great variability within different autonomous communities. The availability of techniques or devices required for support in daily life activities for disabled people is subject to the existence of specific bilateral agreements between central and regional administrations.⁶ There are numerous factors influencing these differences, many of which are beyond the scope of this report. For example, like in other European countries, the Spanish population has a high life expectancy, with an increasing ratio of people older than 60 years old with SCI.¹³ Community reintegration in this subset of patients is therefore very difficult, which explains the fact that 30% of people with SCI patients are institutionalized.²

All patients have regular checkups in SCI units at least once a year to monitor functional and urological conditions, neurogenic bowel dysfunction, pain, spasticity, and accompanying morbidities, such as bedsores and syringomyelia. A percentage of patients following discharge are likely to be readmitted to an SCI unit because of a variety of conditions, most of them because of infections, bedsores, autonomic dysreflexia, or acute respiratory disease. In primary care, access to medical and psychological services is the same as that for the general population. There are no special support services for people with SCI in Spain.

Very few studies are available that focus on the quality of life in the Spanish SCI population. A prospective and observational study of 91 SCI patients leaving in Catalonia concluded that in men sexual function was the main concern of most patients, followed by bowel dysfunction, urinary incontinence, and ambulation or gait problems, whereas in women the main concerns were urinary incontinence, bowel dysfunction, and ambulation or gait.¹⁴

Returning to community life is still a challenge for most people with SCI. In most cases, continuing with school or university courses is possible, and there are programs for students with disabilities in different universities all over the country. For instance, the Universitat Autònoma de Barcelona developed in 2011 an action plan composed of 32 measures to foster the inclusion of students with disabilities. However, as mentioned earlier, employment is a different matter. Even though it is not uncommon to see people with SCI active within the community, there are still many barriers, both physical and psychological, to achieve complete integration.^{15,16} Limited access to health technologies such as innovation or assistive devices provides a paradigmatic example of those barriers. Furthermore, not all disability needs are financially covered by the Spanish National Health System. Regarding assistive devices and technologies, the common benefits basket includes, for example, wheelchairs, cushions, and orthoses, but

do not include vehicle adaptation. Vocational rehabilitation remains largely underdeveloped. Accessibility to the workplace itself is often not available, and there is often little or no assistance given to SCI patients when trying to adapt back into their previous roles. Generally speaking, employers still believe that persons with physical disabilities are considerably less capable in their role than an able-bodied employee. In addition, the monthly compensation provided by the government has proved to be another barrier to return to work because it is attached to the household income. If the household income surpasses a specific limit, the disabled person stops receiving the money.¹⁷

THE HEALTH AND REHABILITATION SYSTEM

Spain is a devolved country, with 17 decentralized regions, known as autonomous communities. Local communities currently administer health management policy decisions. Consequently, within each community, there may be different criteria regarding health decisions. Since 1989, the National Health System has been publicly financed, and universal coverage is offered as a constitutionally guaranteed right.⁶ Patients do complain, however, about long delays for an appointment with medical specialists.¹⁸ Recent data from the Ministry of Health state a 65-day delay for external consultation and 38% of patients waiting for more than 60 days, data for all patients in first consultation, and basic medical specialties.¹⁹ Although the private health system does not play any relevant role in Spain, the number of people opting for private health care varies significantly between different autonomous communities (in Catalonia 20%–30% of patients seek private care, whereas in Andalucía only 10% do).

Regarding specialized care, well-trained specialists are available for everyone with SCI. There are 1313 physical medicine and rehabilitation physicians and 50 SCI expertise fellows. The number of physical medicine and rehabilitation physicians is sufficient, but they are not evenly spread over the autonomous communities.²⁰ Both specialized nurses and allied health professionals develop their work in the SCI centers.

WHAT IS THE STATE OF SPECIALIZED CARE?

There are a total of 11 SCI units across the country. These units together with the 2 SCI rehabilitation hospitals (Hospital Nacional de Paraplégicos de Toledo and Institut Guttmann) provide a wide range of medical and psychological rehabilitation from physiotherapy and occupational therapy to pain management, spasticity treatment, and use of technical aids.

THE SOCIAL RESPONSE TO SCI

Welfare coverage is available for all patients with SCI. Those patients injured through road traffic accidents or accidents at work may also be covered by private insurances. People with SCI have limited access to assistive technology such as wheelchairs, equipment for the home, and communication systems, because the public health service contributes only to part of that economic burden. Within the legal framework,²¹ autonomous communities are free to approve their respective health benefits baskets, supplementing the common benefits

package of the Sistema Nacional de Salud. Both common and regional benefits baskets are updated on a regular base. Consequently, family support and social support are still essential for people with an SCI. Eighty percent of them receive help or support for their daily lives, mainly provided by people living in the same house.²

Advocacy groups for persons with SCI are important. There are several national and local SCI patient groups and associations (e.g., Asociación nacional de Lesionados Medulares y Grandes Discapacitados Físicos). One of 4 SCI persons belongs to a disability association.² Some of these associations also act as foundations that support research in SCI, such as the Step by Step Foundation in Barcelona, Catalonia (<http://www.fundacionstepbystep.com/>).

Although laws and regulations aim to reduce discrimination against people with disabilities, a recent survey noted 25% of people with SCI had complained of discrimination at least once in the last year.² The main problems cited were related to difficulties in transportation or when trying to participate in cultural or leisure activities.

Progress in providing social care is far behind the improvement in the quality of medical care. In 2006, the role of “carer” was recognized by law for promoting personal autonomy and attention to dependant persons (Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las personas en Situación de dependencia y el Sistema para la Autonomía y Atención a la Dependencia).²¹ However, the implementation by the law has been difficult because of the economic crisis.^{22,23} Therefore, taking into account the aging population, the government has now to cope with an increasing number of elderly patients with SCI and should plan and allocate resources accordingly.^{24,25}

The National Health Strategy includes general health recommendations.²⁶ In order to reduce accident rates and following a cross-sectoral collaboration, some preventive measures have been implemented to reduce both traffic accidents and accidents in the workplace, for instance, the inclusion of security professionals in companies or labor inspectors monitoring periodically.²⁷ However, these strategies do not focus on SCI. The government has promoted accident prevention programs, such as the use of seatbelts when driving, as well as regulations and advice for sporting activities.

On April 7, 2014, the latest amendment to the Law on Traffic, Motor Vehicle Traffic, and Road Safety, was released.²⁸ The Spanish traffic laws are very strict on speed limits by means of radar control, alcohol and drug use, the wearing of seatbelts, placement and use of child seats, and yearly technical evaluation of any traffic vehicle. Generally, roads are well maintained in Spain, although there are some notable differences to be found between urban and rural areas. Rural roads are often narrower than the former but still reasonably well maintained.

Social attitudes toward persons with SCI are generally positive in Spain. A few public and private campaigns have promoted social inclusion of people with disabilities. A good illustration of this was a recent TV series in which the main character had suffered a complete SCI (<http://www.ccma.cat/tv3/ventdelpla/>). The program centered on her life following the accident and detailed her rehabilitation progress, which took place at a specialized SCI center.

Existing regulations encourage employers to employ people with disabilities by offering tax benefits. Overall, Spanish society is quite sympathetic to people with disabilities.^{29,30}

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain From Participating in the InSCI Community Survey?

We recognize the importance of having accurate information about SCI characteristics, patients' environment, their emotional wellbeing, how active they are, and how much they are able to participate in everyday life. We believe it to be highly beneficial to participate in this study as it will provide an accurate assessment of the situation in Spain regarding all aspects of the patient's life.

The National Study Protocol

There are 4 SCI units taking part in the study: Hospital Universitari Vall d'Hebron (Barcelona), Hospital Universitario Virgen del Rocío (Sevilla), Hospital Universitario Insular Materno-Infantil de Gran Canaria (Canarias), and Complejo Hospitalario Universitario A Coruña (La Coruña). With these 4 units located in Western, Eastern, and Southern Spain and the Canary islands, a large and representative part of the country is covered, including both urban and rural areas. All admitted patients in these SCI units will be invited to participate in the InSCI community survey. These patients will be interviewed sequentially starting with those patients admitted in 2008. The Minimum Basic Data Set of Hospital Discharge and the database of each SCI unit will provide the information. Patients will be contacted by telephone and will attend the interview in person.

We will seek approval from the local ethical committee ensuring that the criteria on the Spanish Data Protection Act are met. The following drawbacks are anticipated: transportation of patients because the interview is a face-to-face procedure and financial assistance as the development of the study will be time consuming.

CONCLUSION

Generally speaking, the health needs of persons with SCI are adequately met throughout Spain including acute care, the rehabilitation process, and other comorbidities, which occur during a patient's life. The lack of a national SCI register prevents us from having a better knowledge of the epidemiological characteristics of these patients, including life expectancy.

It is expected that a significant increase in older people having an SCI will be seen over the next 2 decades. This fact has to be considered by the administration, not only in terms of economic expenses, but also as a social burden. Specific measures to cope with this burden need to be implemented now. Although the social feeling is sympathetic to people with SCI, the social needs are far from met, mainly because of the lack of economic resources and the effects of the economic crisis. Finally, the economic recovery together with the political would help to implement the existing laws with regard to social care. More resources are needed to reintegrate people with SCI to the fullest.

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People with Spinal Cord Injury in Switzerland

Mirja H. Gross-Hemmi, PhD, and Diana Pacheco Barzallo, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN SWITZERLAND

Epidemiological data of spinal cord injury (SCI) for Switzerland is limited, although 2 studies based hospitalization and rehabilitation data from specialized SCI centers for SCI incidence until 2002.^{1,2} More recent evidence comes from the Swiss Spinal Cord Injury Cohort (SwiSCI),³ which, using data from a rehabilitation-based study of medical files for 2005 to 2012, estimates 18.0 (95% confidence interval [CI], 16.9–19.2) traumatic SCI (TSCI) cases per 1 million population per year. This seems intermediate to the annual TSCI incidence in other European countries.⁴ Incidence rates in Switzerland typically vary by age and sex. The elderly have the highest incidence rate, with 22.4 (18.5–27.3) per 1 million population per year, with males higher (27.5; 25.5–29.6) than females (9.0; 7.9–10.2). Between 2005 and 2012, 932 new TSCI cases were registered; and falls (37.1%), sports and leisure-related activities (26.5%), and transport-related accidents (22.9% due to bicycle crash, car crash, motorcycle, moped, pedestrian hit by vehicle, and other/unspecified transport accident) were identified as the leading causes. In the youngest cohort (16–30 years), sports and leisure and transport-related activities are predominant causes, whereas falls are the most common cause in persons 76 years and older.⁴

Data on the prevalence of SCI have not been published so far, but from the medical files study, paraplegia is 3 times more frequent than tetraplegia, and the latter is more prevalent in the elderly.⁴ The epidemiological evidence for nontraumatic SCI is less complete as both acute care and rehabilitation of new cases less frequently occur in specialized SCI centers and so is missed by the SwiSCI study. This is because in these cases, SCI is a complication of the primary disease (eg, tumors or infections) and requires a comprehensive medical-therapeutic approach that is usually provided in specialized units other than SCI rehabilitation centers. As in other European countries, it is mostly the elderly that are affected by nontraumatic SCI in Switzerland (median age, 64 years, according to SwiSCI data).⁵ Owing to the higher age and prevailing multimorbidity character of nontraumatic SCI compared to TSCI, patients have worse prognosis for rehabilitation, and some cases are treated in a palliative care setting that is outside the scope of the specialized SCI centers in Switzerland.⁶ As the Swiss

population, like Europe in general, is aging, increase in incidence and prevalence of nontraumatic SCI is expected.

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

Since the early 1990s, Switzerland has had a comprehensive emergency service available irrespective of the health care insurance, and emergency treatment is fully covered by mandatory health care insurance.^{7,8} Rescue and transportation are partially covered up to an annual ceiling that can be increased by voluntary health insurance.⁹ The Swiss Institute for Rescue Medicine is specialized in the training of SCI rescue specialists such as paramedics and physicians, and recovery of persons suspecting a TSCI.¹⁰ Approximately 90% of urban and rural rescue sites can be reached within 15 minutes after an emergency call.^{11,12} Since in sparsely populated or uninhabited mountain areas rescue may take longer, Swiss Institute for Rescue Medicine also trains police officers and volunteers who can render first aid until the arrival of specialists.¹³ Both ambulance and helicopters are used for transportation, although helicopters are the preferred mode of transport in case of SCI.¹⁴

Newly injured patients with SCI are stabilized immediately to avoid further damage, and patients are admitted either to one of the 10 acute hospitals specialized in spine and neurosurgery¹⁵ or one of the 4 specialized SCI rehabilitation centers.⁶ In the case of multitrauma injuries, primary care commonly occurs in specialized trauma centers and intensive care units (eg, at university hospitals). Initial diagnostic steps are usually performed within the first 2 hours after injury, followed by surgery within 6 hours after injury.

Patients with SCI initially treated in an acute care hospital are usually referred to 1 of the 4 specialized SCI rehabilitation centers upon stabilization within a few days after injury (median duration from SCI onset to start of acute rehabilitation was 10 days).¹⁶ Each of the specialized SCI center offers comprehensive rehabilitation service including medical, psychological, and social rehabilitation. The duration of the rehabilitation phase depends on the lesion level, severity, and occurrence of accompanying problems.¹⁷ Patients with paraplegia stay for an average of 5 to 6 months; patients with tetraplegia for approximately 8 to 10 months in the specialized SCI rehabilitation centers. Data on multitrauma cases and length of stay are currently being collected through the inception cohort of the SwiSCI study. This phase of acute inpatient rehabilitation aims at enabling people with SCI to regain a maximum of autonomy, independence, and the best possible inclusion into social, family, and professional life.

LIVING WITH SCI

In Switzerland, considerable effort is made to reintegrate individuals with SCI into society. During the rehabilitative

From the Swiss Paraplegic Research, Nottwil, Switzerland.

All correspondence and requests for reprints should be addressed to: Mirja H. Gross-Hemmi, PhD, Swiss Paraplegic Research, Guido A. Zäch Strasse 4, 6207 Nottwil, Switzerland.

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process, integrative measures such as vocational rehabilitation, assistance with housing and building adaptations are initiated to ease the patient into community inclusion immediately after discharge from the inpatient phase. After discharge from acute inpatient rehabilitation, regular medical checkups are 3, 6, and 12 months after discharge and subsequently, on a yearly basis. The outpatient clinic of the specialized SCI centers provides continuous medical care and psychological support. Psychological support is provided by trained psychologists in each of the 4 major SCI rehabilitation centers. Core of the psychological counseling is to foster quality of life, self-reliance, and self-confidence in the SCI person. Cotreatment of secondary health conditions, such as chronic pain, sleep problems or sexual dysfunction, and coping with the new situation and associated functional limitations are additional parts of the psychological support. In addition, psychotherapeutic interventions are provided to treat preceding or prevent secondary psychological disorders (eg, anxiety, depression, or posttraumatic stress disorder). Partner, family, and relatives of the SCI patient will usually be involved in the course of the psychological support, and support of health care personnel (eg, physicians, nurses, or physiatrists) with regard to health information or evaluation of problematic situations is also provided, which complements the interdisciplinary approach of the specialized SCI rehabilitation centers.

There are 2 organizations that play an important role in community inclusion: The Swiss Paraplegic Association (SPA), which is the largest association for persons living with SCI in Switzerland, and ParaHelp, an SCI-specific home care institution. The SPA provides comprehensive support with regard to everyday life situations, legal and financial issues, housing, return to work, leisure, and sports. Peer counseling and an Internet chat platform (ParaForum) is also provided and complements the rehabilitative process. The Internet platform ParaForum is an interactive platform for communication and information exchange among persons with SCI and their families and caregivers. It provides access to reliable health information for self-management and peer support.

The Swiss Paraplegic Association supports 27 regional wheelchair clubs across Switzerland, and ParaHelp provides information and support for people living with SCI in the community in all aspects of daily living. In addition, the Swiss Association of Rehabilitation (www.sar-reha.ch) provides a platform for interdisciplinary exchange of evidence-based information and training for health professionals involved in the rehabilitative process and care of patients with SCI. Despite these measures, many persons with SCI continue to experience restrictions because of inaccessible public spaces and private buildings, problems with transportation, policies and services, and finance.¹⁸

THE HEALTH AND REHABILITATION SYSTEM

In Switzerland, individuals, private associations of health insurers, and health care providers and federal, cantonal, and municipal governments help to finance the health care system.⁹ Since 1996, everyone residing in Switzerland is required to contract a basic health insurance from an authorized private insurer. The insurer charges the same premium for everyone within a canton (community rating), and individuals contribute

to the cost of the services through deductible medical expenses, coinsurance, and copayments (out-of-pocket expenditure) up to an annual ceiling.

The government (mainly the canton) supports the system by subsidizing the institutional providers. For individuals with low income, the canton provides financial support to reduce the cost of premiums.¹⁹

The basic health insurance benefit basket includes a wide range of goods and services for curative and rehabilitative care. In principle, all medical treatments and diagnostics prescribed by licensed professionals are covered, unless they are explicitly excluded from the benefit basket. The benefit basket also includes costs of medical care for patients receiving long-term care in institutions or at home. The medicines and other medical goods, including assistive devices, which are listed in a positive list, are eligible for reimbursement. Only dental care, prosthesis, and vision products are excluded from the benefit package, unless they respond to specific medical needs.²⁰ Swiss residents can access supplementary health insurances, which typically cover one or several of the following services: private room in hospitals, dental care, alternative medicines, and cash benefits for sickness absence. The supplementary insurances cannot cover benefits included in the mandatory health insurance, or cost sharing for mandatory health insurance.²¹

Parallel to the basic health insurance, other insurance schemes help individuals finance potential health care costs: accident insurance, sponsored by employers, covers accident on the job; old age and disability insurance covers disability-related pensions and allowances; and military insurance covers military personnel.⁹

Swissmedic is the authority to oversee and regulate the introduction of medical devices onto the market in Switzerland. Its work includes clinical trial approvals, market surveillance, export certificates, materiovigilance, and inspections. The health insurance companies have a means and items list (MiGel) created by the Federal Office of Public Health together with other Federal advisory bodies with medical product categories that must be reimbursed. The general conditions for reimbursement are the following: (1) the product must be admissible in the Swiss market and (2) must fulfill the required therapeutic purpose of an illness and its consequences, and (3) the approved delivery point must hand the product directly to the insured. Products and performances not specifically listed in MiGel are nonetheless entitled to reimbursement if they are rational and financially justifiable.²²

In general, the Swiss health care system is quite efficient and shows high-quality outcomes.⁹ Nevertheless, some concerns related to the costs exist. For example, the health expenditure as a share of the gross domestic product was 11.1% in 2013, just below the Netherlands and the United States. In addition, out-of-pocket spending is 26%, which is relatively high compared to the OECD average (19.5%). In per capita terms, the country spent USD 6325 per head in 2013, compared to USD 3453, which was the OECD average.²³

Looking closer to the functioning of the system, there may be still some room for improvement regarding costs in the rescue phase. The use of an ambulance or helicopter, depending on the case, is not fully covered by the health insurance. Patients have an important participation on the service's costs. As the rescue phase is a key step toward patient survival and

rehabilitation, the health insurance should include its costs in the basic package. Another downside of the otherwise good working Swiss health system is related to skill nursing homes and the home care organization, Spitex. Most of these facilities and care structures are designed for the elderly and not specifically tailored to the needs of young people with SCI. Finally, most of the infrastructure and equipment are not designed for people with chronic conditions, which is the case for people with SCI.¹⁸

WHAT IS THE STATE OF SPECIALIZED CARE?

By 2013, Switzerland had 18,945 board-certified specialist medical practitioners, 5657 medical groups of specialists, and 5972 surgical specialists that corresponded to 1.1x, 0.7x, and 0.74x specialists per 1000 population, respectively. In infrastructure, the country has one of the highest numbers of hospitals relative to the population in OECD countries (36.3 hospitals per million people) with 293 hospitals, of which 113 are general hospitals and 180 are specialized clinics.⁹ The specialized clinics include psychiatric clinics (52), rehabilitation clinics (43), and others (85).²⁴ There are 66 hospitals in Switzerland with at least one intensive care unit, and 10 hospitals are able to provide initial care to newly injured patients with SCI.¹⁵

Switzerland has 45 rehabilitation hospitals of which 4 deliver specialized SCI rehabilitation.²⁵ The SCI centers provide comprehensive rehabilitation service including medical (eg, spine surgery, neurological, urological, pain management, ventilation, and circulation management and management of secondary health conditions), psychological and social rehabilitation (eg, vocational rehabilitation, nutrition, and social counseling, use and adaptation of assistive devices for communication and activities of daily living, leisure and sports, work, housing, and support of financial and legal aspects). An interdisciplinary team consisting of physicians, nurses, physiotherapists, occupational therapists, speech therapists, nutritionists, psychologists, music therapists, art therapists, hippotherapists, sports therapists, social and legal counselors, vocational counselors, and orthopedic technicians guarantee a high level and evidence-based rehabilitative approach.

THE SOCIAL RESPONSE TO SCI

Owing to advancements in the health and rehabilitation system, life expectancy of people with SCI has markedly increased in high-income countries such as Switzerland.²⁶ Therefore, inclusion into the society is of utmost importance after discharge from acute inpatient rehabilitation to guarantee independent living and community participation. Although disability insurance supports and personnel at specialized SCI rehabilitation centers guide patients in labor market inclusion, currently, there is no law or regulation governing employment reintegration of persons with disabilities in Switzerland. Employers can be supported financially and administratively if they employ a person with SCI.

Switzerland ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2014, after several years of legislative review to ensure that Swiss law and policy was aligned with its provisions. Like many high-resource countries in Europe, issues of public accessibility are high on

the political agenda. The issue of adverse attitudes and stigma, however, is an ongoing issue. The disability organization Pro Infirmis Switzerland recently launched a campaign ("Because who is perfect? Get closer") to reduce stigmatization of people with disabilities. The campaign placed mannequins with disabilities in fashion stores of one of the busiest districts in Zurich. Alongside the able-bodied mannequins, there were figures with scoliosis and brittle bone disease modeling the latest fashions. The objective of the campaign was to provoke reflection on the acceptance of people with disabilities. All public awareness campaigns were initiated by nongovernmental associations. There are also governmental prevention campaigns designed to reduce injuries from traffic crashes directed to cyclist, drivers, pedestrians, and children.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

As a participating country in the InSCI community survey, we contribute to the global research of the lived experience in the light of identifying factors linked to functioning, health, and well-being of persons with SCI.²⁷ Such a research endeavor will allow us to compare and discuss our clinical and community approach toward individuals with SCI within an international framework and identify overarching problems that affect people with SCI experience in their daily lives on both, at national and international level. In the context of Switzerland, the InSCI questionnaire will be collapsed with the SwiSCI community survey 2017 (follow-up measurement at 5 years). This allows the study of longitudinal data; and hence, more in-depth insights into the factors that foster functioning in persons with SCI can be gained. Recent evidence from the SwiSCI community survey (baseline, cross-sectional data) suggests that secondary health conditions (eg, spasticity or chronic pain) or psychological-personal factors can negatively affect a person's functioning.^{28,29} In what way these problems may persist over time will be subject to the research of the longitudinal data of the SwiSCI and InSCI study in Switzerland.

THE NATIONAL STUDY PROTOCOL

The InSCI survey will be part of the SwiSCI community survey 2017. The baseline assessment of the SwiSCI community survey was conducted between March 2011 and September 2013 and will be periodically repeated every 5 years. The aim of the community survey is to establish an epidemiological database on functioning, disability, and health for SCI that serves as a platform for the evaluation of rehabilitation or policy interventions and as an evidence base to inform Swiss social and health policy.³⁰ Details on the study design of SwiSCI are reported elsewhere.^{3,30,31} As participants of the InSCI survey come from the SwiSCI community, InSCI will adopt the same evidence-based recruitment and mixed-mode response and reminder as well as data management strategy for the SwiSCI community survey.

The SwiSCI community survey consisted of 3 successive International Classification of Functioning, Disability and Health-based questionnaire modules, which were sent out in intervals of 3 months: (i) a starter module covering

sociodemographic data, lesion characteristics, and the care situation; (ii) a basic module including core measurement instruments to assess mood, activity limitations, participation, and quality of life; and (iii) 1 of 3 thematically specific modules assessing psychological factors and health behaviors: labor market participation, the care situation, and health service utilization.³ The next questionnaire wave for the SwiSCI community survey using the starter and basic modules as well as selected questions on psychological factor and self-management, labor market participation, the care situation and health service utilization, disability policy, and health information is planned for early 2017. Since most items of the InSCI questionnaire will be covered by the SwiSCI basic module, only supplementary items not part of the SwiSCI community survey basic module will be evaluated in the InSCI national module.

CONCLUSION

Epidemiologic data on SCI are scarce in Switzerland. However, owing to the SwiSCI study, the epidemiological picture will eventually evolve, giving more precise numbers of persons living in the Swiss community. According to a recent report of the European Observatory on Health Systems and Policies 2015, the Swiss health system performs very well, and public satisfaction is high concerning the quality, although its costs exceed the EU average.⁹ According to the CRPD highest attainable physical and mental health, independent living and full inclusion in community life are basic rights for all people. With the ratification of the CRPD, Switzerland is obliged to warrant these rights for persons with disabilities. With regard to SCI rehabilitation, Switzerland enables a comprehensive rehabilitative approach for individuals with an SCI to fully include them into the community life. The InSCI study will provide us with much needed information to improve the social response to the needs of persons with SCI in Switzerland, with the overall aim of improving both their health and well-being and to increase their participation and full inclusion in Swiss society.

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People with Spinal Cord Injury in Thailand

Apichana Kovindha, MD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN THAILAND

There are few epidemiologic studies of people with spinal cord injury (SCI) in Thailand, predominantly coming from the Chiang Mai province, as no national data for the whole country exist. Most studies that have been done come from university hospitals with rehabilitation wards. This report is mainly based on studies done at Maharaj Nakorn Chiang Mai Hospital, a tertiary/advanced level and university hospital with a dedicated rehabilitation ward for SCI. Over the past 30 years, most SCI cases in the northern region were referred to this hospital for treatment and rehabilitation. According to a 5-year study (1977–1981) of patients with spinal injuries admitted, 48% of 577 patients had SCI.¹ During 1985–1991, there were 398 new patients with SCI admitted, and when counting only those living in Chiang Mai, the incidence of SCI was approximately 23 cases per million per year.²

According to a 6-month survey of road traffic accidents done by the National Rehabilitation Center in 2006 to study the incidence of disability and impact of these collisions,³ data were collected from 8 of 28 trauma centers operated by the Ministry of Public Health. When extracting data from this survey, there were 9,737 victims with major injuries. Of these, 82% used a motorcycle, 32% drank alcohol before the collision, and 3.2% became disabled. Among those with disabilities, 10.4% had SCI (tetra-AB, 26%; tetra-CD, 55%; para-AB, 12%; and para-CD, 7%). From these data, 0.3% of major injuries or 3 of 1,000 severely injured road traffic accident victims had SCI. In addition, the economic loss of more than 2.6 million baht per case with disability was reported.³

When comparing data between 2 previous studies (1977–1981 and 1985–1991),^{1,2} causes of SCI have changed: falling from height, the main cause 30 years ago, declined from 42.8% to 33%, whereas the prevalence of road traffic accidents increased from 28.4% to 47%. Among road traffic accidents, 54% were collisions involving motor cycles. In addition, later data in 2006 indicate that 67.5% of new patients with SCI were caused by road traffic accidents.⁴ Two studies from Siriraj Hospital in Bangkok showed that the prevalence of road traffic accidents increased from 50.7% of SCI causes in 1989–1994 to 74.8% in 1997–2000.^{5,6} Clearly, road traffic accident-related injury is a major cause of SCI in Bangkok.

Concerning mortality during the acute phase, in the study covering the years 1987–1991, 31 patients (8%) of 398 cases died² compared to only one of 91 new SCI cases admitted in 2013.⁷ There are no studies on mortality of chronic SCI individuals living in the community.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

During 1985–1991, only 30% were admitted within 6 hours after injury, 57% were admitted within 24 hours, 12% had neurological deterioration before admission, 12% had urinary infection, 11% had pressure ulcers, and 7% had respiratory complication.² During the past decade, the prehospital service has been much developed after the National Emergency Medical Service (EMS) Act, enacted in 2009. Most of the injured victims from road traffic accidents are now transferred to a nearby hospital by a hospital ambulance in the EMS system, as this can be accessed by a nationwide phone call: 1669. According to the survey of road traffic accidents in 6 trauma centers in 2006, 92.4% arrived at the hospital within 24 hours.³

Based on the SCI model at Maharaj Nakorn Chiang Mai Hospital, one of the trauma centers with facilities for advanced imaging and treatments, new patients with spinal injuries and SCI are admitted to the acute spinal orthopedic ward. Those with associated injuries are admitted to neurosurgical or trauma wards. As surgical instruments had been developed, more cases have been operated on: less than 50% in 1985–1991² and more than 75% in 2006.⁴ Two or 3 weeks after surgery, when the medical and surgical conditions are stable, patients with SCI are then transferred to a rehabilitation ward. A spinal surgery is performed at the tertiary-/advanced-level hospital where at least one rehabilitation physician/consultant and physical and occupational therapists provide rehabilitation services. However, if there is no rehabilitation ward and the rehabilitation consultant decides that the patients with SCI need further rehabilitation, they will be referred to another hospital, where a dedicated in-patient rehabilitation service for SCI is available.

At the rehabilitation ward, patients receive a comprehensive medical rehabilitation program provided by rehabilitation team consisting of rehabilitation consultants (physiatrists), in-training rehabilitation residents, physical therapists, occupational therapists, rehabilitation nurses, a social worker, and an orthotist. Common short- and long-term goals, whether intensive or less intensive rehabilitation management should be used, and a tentative discharge date are all established based on the patient's medical conditions and rehabilitation problems, expectation and needs as well as features of their living situation and other environmental factors. Patient education and caregiver training are always included in the process so that the patient's health will be looked after. For those with high lesion with severe disability, one family member is trained to become a primary caregiver.

From the Department of Rehabilitation Medicine, Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand.

All correspondence and requests for reprints should be addressed to: Apichana Kovindha, MD, Department of Rehabilitation Medicine, Faculty of Medicine, Chiang Mai University, Chiang Mai 50200, Thailand.

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Generally, the postacute rehabilitation phase usually lasts approximately 3 to 4 weeks if there is no associated injury or complication. The length of stay (LOS) of the initial postacute rehabilitation has been decreasing over the past 2 decades. This is partly because Thailand is using the disease-related group (DRG) approach, and the average LOS for in-patient rehabilitation of neurological cases has been established to be 23 days. Owing to this, the hospital management prefers a short LOS so that the hospital charge is not more than the payment.

A study on payment on subacute and nonacute in-patient care predicted that more than 30% of patients never received any rehabilitation service.⁸ Owing to the limitation in providing in-patient rehabilitation services, recently, the National Health Security Office and the Ministry of Public Health agreed to start a pilot project of in-patient rehabilitation services at mid-level hospitals with stroke patients. If this project shows cost-effectiveness, there is hope that such services will be expanded to patients with SCI.

When goals are reached, patients are discharged home or referred back to their local hospital for continuous medical care. One to 3 months after discharge, they are reassessed at an outpatient clinic. If there is a potential for improvement or a complication, they will be re-admitted for further rehabilitation or treatment of complication.

As many SCI individuals still need continuous medical care, they are visited by a nurse or a health volunteer from a community hospital. According to a recent study on patient quality of life, nearly 70% of individuals with chronic SCI living in the community rated their overall quality of life as fair and nearly 30% rated it as good.⁹ Females made up 75% of primary caregivers, and 34% were spouses.¹⁰ Approximately 84% primary caregivers worked outside the home as well.¹⁰ Based on the 36-item short form health survey (SF-36), the quality of life scores were not different between those taking care of patients with paraplegia and those taking care of patients with tetraplegia. However, the scores were lower in 2 domains: role limitations due to physical and emotional problems; but when compared with the scores of the general Thai population, the caregivers of persons with SCI had lower scores of all domains except for social functioning.¹⁰

LIVING WITH SCI

Owing to limitation of in-patient rehabilitation services, after acute management, many SCI patients are discharged home and a caregiver is advised how to continue physical therapy at home, whereas some are referred/transferred to a tertiary-level or advanced hospital for postacute rehabilitation. According to our recent unpublished data of 66 newly admitted patients with SCI for rehabilitation (2015), at discharge, 51.5% of the patients were AIS-D according to the American Spinal Injury Association Impairment Scale (AIS) and approximately 60% were rated as independent (no or minimal difficulties) in eating and drinking, followed by dressing (45.5%), washing oneself (40.9%), caring for body parts (39.45%), and toileting (33.3%). These data showed that the other half of the patients were still dependent after postacute rehabilitation, probably due to too short postacute rehabilitation admission (average LOS for AIS-A, B, C: 31–55 days and AIS-D: 18–44 days).

According to the Rehabilitation for Persons with Disability (PWD) Act enacted in 1991 and the Promotion and Development

of Quality of Life of Persons with Disability enacted in 2007, people with disabilities have a right to be voluntarily registered. Before discharge from the hospital, those with disabilities are informed about the benefits of a registration as a person with a disability. These benefits are free medical services, necessary medications and assistive devices from public hospitals; appropriate education; vocational training and social supports, for example, a monthly allowance of 800 baht or a loan up to 60,000 baht with 5 years interest-free for starting up a self-employment.

According to a recent survey of 100 persons with chronic SCI (more than 2 years after injury), at the time of the survey (2012), 47% were engaged in remunerative employment, which is less than an employment rate of 81% before SCI. Among those who worked, 66% were self-employed, followed by 27.6% of full-time employment and 6.4% of part-time employment; but only 48.9% were satisfied with their income.¹¹ As a result of the low income they received, most of them live with and depend on family members. The ability to drive increases the chance of being employed,¹¹ since public transportation is a barrier for persons with SCI.¹²

THE HEALTH AND REHABILITATION SYSTEM

Most hospitals in Thailand are operated by the Ministry of Public Health. Hospitals are also operated by other government sections and foundations, such as the military, universities, and the Red Cross. In 2010, there were 1,002 public hospitals and 316 registered private hospitals. Hospitals operated by the Ministry of Public Health are classified into 5 levels: (1) the primary health care level (small-size community hospitals), (2) the first level (medium-size community hospitals), (3) the mid-level (large community hospitals and general hospitals), (4) the standard level, and (5) the advanced level. Both the standard level and the advanced-level hospitals provide specialized care for complicated cases, but the latter has more high technology and more subspecialists. At present, few advanced hospitals in the public health sectors and some university hospitals provide an in-patient rehabilitation program for patients with SCI. There are only 13 hospitals with 260 beds in total for in-patient medical rehabilitation. Among rehabilitation admissions, 42% comprised patients with SCI, including both new and chronic cases.¹³

All Thais are eligible for one of the 3 main health insurance schemes: the universal health coverage, the civil servant health benefit scheme, and the social security scheme. The universal health coverage scheme covers 80% of the population, and the rest are covered by either the civic servant health benefit scheme or the social security scheme. All have the right to receive sufficient basic health services free of charge. The benefits are different depending on which health insurance scheme they are under, and they have to pay for medications and equipment not in the essential drug list or not in the health service packages.

WHAT IS THE STATE OF SPECIALIZED CARE?

The Royal College of Physicians of Thailand started training rehabilitation specialists in 1982. For more than 30 years, more than 500 physiatrists (rehabilitation specialists) have graduated and are practicing all over the country. Some universities provide educational programs for other rehabilitation

professionals, such as BSc, MSc, and PhD degrees in physical therapy, occupational therapy, and clinical psychology. However, only one university provides a BSc in prosthetics-orthotics and another provides vocational certificate in prosthetics-orthotics. There is no advanced training in assistive technology generally.

Based on the latest data of rehabilitation specialists (2015), most (40%) works at Ministry of Public Health hospitals, followed by 21% at private hospitals, 19% at university hospitals, 5% at military hospitals, 4% at Bangkok metropolitan health centers, and the rest in other government sectors and nonprofit foundations. If only those hospitals operated by the Ministry are considered, all regional hospitals and 60% of general hospitals have rehabilitation specialists, physical therapists, occupational therapists, and prosthetics-orthotics technicians. The latter are responsible for assistive technology.

These data suggest that there are not enough rehabilitation professionals working in the rural or remote areas of the country. As a result, individuals with chronic SCI have difficulty accessing to rehabilitation professionals. Although community hospitals play a role in providing an outreach and home-visiting services such as nursing care and physical therapy for bed-bound or home-bound individuals, they do not have enough expertise in SCI. When a secondary condition or complication occurs, they generally go to a nearby community hospital to get diagnosis and a proper treatment such as antibiotics for urinary tract infection. For major complications, they are referred to secondary- or tertiary-level hospital for proper management.

Pressure ulcers are still prevalent among individuals with chronic SCI, causing increased burden to caregivers, requiring high hospital expenditures for long LOS and preventing individuals with SCI from social reintegration.¹⁴ Over the past 2 decades, 80% of patients with SCI had an ulcer at least once in their life, but recently, the prevalence has decreased to 54.3% (26.4% had an ulcer or more at the time of the study and 27.9% had healed ulcers).¹⁵ This was most likely due to better pre-hospital acute and postacute management, patient and caregiver education, and better wheelchairs and cushions.

Besides pressure ulcer, neurogenic bladder and bowel dysfunctions are impairments, which need specialized care and management. Only one third had normal or nearly normal control of urination.¹⁶ According to our recent data, 19% of those using clean intermittent self-catheterization with a reusable catheter reported having at least one treatment of urinary tract infection during the past year, and on the day of hospital visit for urodynamic study, 47% had bacteriuria, but only 15% had significant bacteriuria with pyuria, indicating urinary tract infection. In addition, 28% reported urinary incontinence.¹⁷ More than half (53%) of individuals with chronic SCI living in community had moderate to severe neurogenic bowel dysfunction. Most of them (44%) needed mini-enema as a main bowel care, 23% reported fecal incontinence, and 15% had hemorrhoid.¹⁸

THE SOCIAL RESPONSE TO SCI

After 26 years of implementing the Rehabilitation for Persons with Disability Act, medical, educational, vocational, and social rehabilitation services have all been developed. Nonetheless, societal attitudes and other barriers persist. At present, all 28 regional hospitals have at least one rehabilitation specialist

(physiatrist) and also physical therapists and occupational therapists working, providing treatments and therapy for patients with SCI.

In 2007, the Thai government enacted the promotion and development of quality of life of persons with disability, aiming at protecting the rights of people with disabilities and promoting equality of opportunities and social inclusiveness. Moreover, Thailand had successfully ratified the Convention on the Rights of Persons with Disabilities (CRPD) as a tool for promoting and protecting the fundamental rights and freedoms of persons with disabilities. More recently (2012), Thailand, as a member of the United Nations Economic and Social Commission for Asia and the Pacific, adopted the Incheon Strategy¹⁹ (2012) aimed at making societies barrier-free.

Following the Act and ministerial regulations, persons with disabilities have more opportunity to receive educational and vocational training suitable to their disabilities and their goals and interests. Moreover, the government and private sectors have to accept registered people with disabilities for employment, previously at a ratio of 1:200 and now at a ratio of 1:100. We found that 47% of individuals with SCI (more than 2 years after the injury), are mostly self-employed and can drive a car, which gives them more chance to work.¹¹ The main remaining barriers are buildings and transportation systems that are not wheelchair accessible. Although the ministerial regulations promote universal design, only some public agencies and the private sector, such as hospitals, have ramps, elevators, and toilets for persons with disabilities and elderly people.

To prevent injuries, a campaign to prevent driving when drinking has been instituted. In addition, the government has approved a ministerial regulation to use part of the money from car license plates to support expensive but necessary assistive devices for those becoming disabled as a result of a road traffic accident. Many persons with tetraplegia have received an electric wheelchair, and those with paraplegia have received a sport or active wheelchair under this program. This gives them more opportunities for social activities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

At present, there is no rehabilitation center dedicated to providing comprehensive rehabilitation for patients with SCI. We therefore hope that participating in the InSCI study will produce information relevant to the Thai situation that can be used to make an argument to the National Health Security Office to agree with the view that a dedicated rehabilitation center would greatly improve the quality of life of persons with SCI, as it does in other countries that are more developed.

THE NATIONAL STUDY PROTOCOL

Owing to lack of the national data, in 2015, we started a national SCI registry project and used the International Spinal Cord Injury data sets by ISCOS core sets and some categories of the WHO's International Classification of Functioning, Disability and Health (ICF) core sets for SCI for data gathering.

Four standard- and advanced-level hospitals with a rehabilitation ward have joined this project. The inclusion criteria for participation are that they be traumatic or nontraumatic patients, postacute or chronic, and who give consent to participate in the study. The exclusion criteria are those who cannot communicate or complete the questionnaire.

OPTIONAL NATIONAL MODULE

We may also add other module(s):

1. To compare present and past conditions, and in particular to collect data on whether the conditions for persons with SCI at the time of the interview present is worse, the same or better than the conditions at discharge or before injury or disease.
2. To assess the attitudes, needs, and expectations of persons with SCI toward specific environmental factors (barriers and facilitators) and to ask them to prioritize these factors that have the most impact on their lives.

CONCLUSION

According to the law and policy aimed at improving the quality of life of persons with disabilities in Thailand over the past 25 years, and in particular, because they are covered by the universal health coverage scheme, persons with SCI have a better and longer life, with fewer complications, more appropriate assistive devices, more social reintegration, and less anxiety about health care expenses. The challenge now is to ensure that comprehensive rehabilitation services are equally accessible to all persons with SCI. There are encouraging signs that this is happening, such as the fact that there are more rehabilitation professionals working in the country and public policy is now aimed at empowering people with disabilities.

If the output of the InSCI project gives us valid and relevant comparison data between those using more dedicated hospitals for SCI and those using other facilities, then we can go to the National Health Security Office to try convincing them to increase the LOS for postacute rehabilitation for patients with SCI, and to establish dedicated rehabilitation hospitals for SCI in all regions of the country so that all patients with SCI will have equal opportunity to access standard rehabilitation services.

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People with Spinal Cord Injury in the United States

Christine Richards, Neil MacKenzie, Shawn Roberts, and Reuben Escorpizo, DPT, MSc, PT

EPIDEMIOLOGY OF SPINAL CORD INJURY IN THE UNITED STATES

The incidence of traumatic spinal cord injury (SCI) in the United States is estimated to be 40.1 cases per million,¹ indicating approximately 12,500 new SCI occur each year.² The prevalence of SCI is estimated to be 906 cases per million, or 276,000 individuals.^{1,2} Males are more likely to experience an SCI than females at a ratio of 2.25:1 and are estimated to account for 80% of all traumatic SCI cases. Between 1993 and 2012, there was an estimated decrease in incidence of SCI from 144 to 87 cases per million in younger males aged 16 to 24 years.³

Vehicular accidents are the leading cause of SCI in the United States, accounting for approximately 39.08% of all SCIs between 2005 and 2015. Unintentional falls (29.54%) ranked second, followed by acts of violence (14.41%; 13.01% from gunshot wounds) and sports/recreational activities (8.39%).⁴

The average life expectancy for an individual with SCI has not changed since the 1980s and is significantly lower than an individual without SCI.² The leading cause of mortality in SCI individuals is disease of the respiratory system, such as pneumonia, accounting for 21.6% of all deaths.⁵ Between 1997 and 2012, there was a significant increase in the incidence of acute traumatic SCIs as a result from unintentional falls.³ Incidence and prevalence of SCI in individuals older than 60 years have increased, with prevalence increasing at a slower rate because of higher mortality rates in this age group.⁶

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Milestones and expected outcomes are highly dependent on the neurological level of injury as well as whether the injury is complete or incomplete.⁵ The prevalence of neurologically complete injuries has decreased, potentially indicating that the immediate postinjury care and surgical response has improved.⁶ Between 1973 and 1979, the median number of days spent in an acute care unit was 24.0. That number decreased to 11.0 from 2010 to 2014.

Nine-four percent of patients go directly to an inpatient rehabilitation center.⁷ The median stay in inpatient rehabilitation

has decreased from 98.0 days in 1973 to 1979 to 36.0 days from 2010 to 2014.⁵ Average stay is longer for those using a wheelchair versus those who are able to walk.⁷ During this phase of rehabilitation, it is important to have medical specialists nearby if complications arise. People with SCI are at high risk of pneumonia, deep vein thrombosis, and pressure ulcers, as well as gastrointestinal, respiratory, urogenital, and cardiovascular problems.⁸ Following inpatient rehabilitation, nearly 3 quarters of patients are discharged back into the community.⁷ A 2004 study by Cardenas et al.⁹ found a post-SCI rehospitalization rate of 55% within the first year. Low motor Functional Independence Measure scores at time of discharge from acute care public health insurance coverage correlated with higher rates of rehospitalization.⁹

LIVING WITH SCI

According to the National Spinal Cord Injury Statistical Center, 91% of people with SCI live in a private residence 1 year after injury, and 4% live in a skilled nursing facility. At 20 years after injury, 97% live in a private residence, and less than 1% live in a skilled nursing facility.⁵ Functional Independence Measure scores upon discharge from initial rehabilitation average 55/126, with scores being lower for those with complete (28/126) and incomplete (50/126) tetraplegia and higher for those with complete (65/126) and incomplete (70/126) paraplegia.⁵ The largest gains in function are made in the first year after injury as evidenced by an increase in Functional Independence Measure scores from discharge to 1 year after injury, followed by a leveling off of average scores throughout the lifespan.

Societal participation for people with SCI is essential. Using the Craig Handicap Assessment and Reporting Technique, the physical independence subscale scores ranged from 71/100 on year after injury to 88/100 at 35 years after injury. Mobility subscale scores ranged from 73/100 at 1 year after injury to 79/100 at 15 to 25 years after injury. Finally, the social integration subscale mean scores were 86/100 1 year after injury and remained consistent throughout life.⁵ These data indicate that people with SCI in the United States are generally independent and are participating in society.

The occupational subscale scores of the Craig Handicap Assessment and Reporting Technique ranged from 49/100 at 1 year after injury to 67/100 at 25 years after injury in 2014⁵; 58.1% of individuals with SCI were employed at the time of their injury; 12.2% were employed 1 year after injury; and 34.4% were employed 20 years after injury.² Race, age, sex, education, and other factors were significantly related to employment outcomes after SCI. Race and sex were also found to play a significant role in employment earnings¹⁰; 15.3% of individuals with SCI were students at the time of injury; 16.1% of individuals attained student status a year after injury,

From the Departments of Rehabilitation and Movement Sciences (CR, NM, RE) and Nutrition and Food Sciences (SR), University of Vermont, Burlington, Vermont; and Swiss Paraplegic Research, Nottwil, Switzerland (RE).

All correspondence and requests for reprints should be addressed to: Reuben Escorpizo, DPT, MSc, PT, Department of Rehabilitation and Movement Science, The University of Vermont, 106 Carrigan Dr, Rowell 310, Burlington, VT 05405.

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whereas only 2.7% were considered students 20 years after injury.² Individuals who had completed at least 16 years of education were associated with a \$21,751 increase in conditional earnings.¹⁰ The average yearly cost of SCI ranged from \$42,206 for American Spinal Injury Association (ASIA) level D to \$184,891 for high tetraplegia. Indirect costs (e.g., lost wages) averaged \$71,961.²

Rates of marriage and divorce were both found to increase in the years after injury. At the time of the injury, approximately 51.6% of patients were single and had never married. By 40 years after injury, that number was reduced to 14.3%, suggesting that individuals experiencing SCI continue to marry.²

Overall satisfaction with life for people with SCI increases throughout the lifespan, ranging from 19/35 at 1 year after injury to 25/35 at 40 years after injury.⁵

THE HEALTH AND REHABILITATION SYSTEM

Health care in the United States is a combination of private and public, with a bias toward the private sector. In 2014, 63.6% of individuals younger than 65 years were covered by private health insurance, whereas 13.3% were not covered at all; 17.7% of adults between the ages of 18 and 64 were covered through public plans such as Medicaid.¹¹ All individuals older than 65 years receive public coverage through Medicare, although as of 2013, nearly 1 in 4 of these paid for private supplementary coverage.¹²

Insurance acceptance by health care providers is another problem in the United States. While 90% of general physicians accept new patients with private insurance, only 75% are willing to accept public coverage such as Medicare or Medicaid.¹³ In 2012, 2.9% of individuals were told that their health insurance was not accepted; this number jumps to 8.3% for adults aged 18 to 64 years with public coverage.¹³

Persons with SCI require the care of a multidisciplinary team including (but not limited to) physicians, specialists, nurses, physical and occupational therapists, and speech and language pathologists.⁸ There are roughly 209,000 physicians, 56,000 nurse practitioners, and 30,000 physician assistants serving in primary care in the United States.¹⁴ A large percentage of primary care professionals practice in urban areas, closely approximating the general population distribution. In some cases, this can create difficulty in finding accessible care for rural populations. The problem becomes much more acute when seeking the care of a specialist: only 11% of specialist physicians practice in rural areas, compared with 22.5% of general practitioners.¹⁴ Numbers are similar for rehabilitation professionals. There are 11,781 physical medicine and rehabilitation physicians (or physiatrists),¹⁵ 204,200 physical therapists, 121,400 physical therapist assistants and aides, 113,200 occupational therapists, and 134,100 speech-language pathologists in the United States.¹⁶ The shortage of health care professionals is concerning for the population with SCI, particularly for those living outside urban centers.

WHAT IS THE STATE OF SPECIALIZED CARE?

There are currently 14 SCI model systems and 5 form II centers responsible for admitting and advancing the treatment of individuals with SCI.⁵ In 2003, Beatty et al.¹⁷ found that

57% of individuals surveyed with SCIs need the assistance of an SCI specialist, but 25% of them indicated that this need had not been met. As of 2014, there were only 635 physiatrists specializing in SCI medicine in the United States.¹⁵

A wheelchair is by far the most common piece of assistive technology used by people with SCI; figures range from 58% to 80% of this population using a wheelchair at 1 and 30 years after injury, respectively.⁵ Selection of a wheelchair is of utmost importance in the mobility of people with SCI. There are many types of chairs available, ranging from lightweight manual models to power wheelchairs and scooters, with several options for customization. Criteria for wheelchair coverage vary widely based on one's insurance plan.¹⁸ There are currently 4180 certified assistive technology practitioners in the United States who are skilled in assessing the needs of people with disabilities and ensuring that they procure the optimal assistive technology.¹⁹ In most cases, the wheelchair evaluation and prescription is done by a physiatrist, physical therapist, or occupational therapist.²⁰

Each year, a significant proportion of people with SCI have at least 1 emergency room visit. A 2011 study found that 47% of emergency room residents had generally poor knowledge of the 6 categories essential to post-SCI care: autonomic dysreflexia, urinary tract infection, posttraumatic syringomyelia, gastrointestinal system problems, pulmonary disturbances, and cardiac complications.²¹

THE SOCIAL RESPONSE TO SCI

The American with Disabilities Act (ADA) was created in 1990 to protect individuals with disabilities, including SCI, in areas of employment, state and local government programs, public accommodations, commercial facilities, transportation, and telecommunications. It stipulates that parks, transportation, public housing, emergency transport, treatment, and education must be made available to all.²²

Although the ADA requires significant social accommodations for people with disabilities, there remains a gap in implementation of the law. In 2012, there were 60,000 claims related to accessibility in the United States.²³ According to a Bureau of Transportation survey in 2002, 3.5 million people never left their homes. Of these, 1.9 million were persons with disabilities. The homebound in this category were older (average age of 66 years) and had more severe disability than those disabled who left home at least once per week, and many of them had more difficulty accessing transportation (29% as opposed to 11%).²⁴ It can be supposed that access to public transportation could also be more lacking in rural areas than in urban areas.

The Social Security Administration offers two benefit programs for persons with disabilities. Individuals who cannot return to work for at least 1 year are eligible to receive Social Security Disability Insurance and Supplemental Security Income to reduce poverty and social isolation.²⁵ It is unknown how many people with SCI benefit from these services.

Several advocacy and support groups exist for people with SCI. Their purposes span the social, political, educational, and philanthropic spectrum. The largest are the National Spinal Cord Injury Association (ASIA), Paralyzed Veterans of America, and the United Spinal Association.²⁶ Professional groups such as ASIA and the American Paraplegia Society have formed to

pursue educational or scientific goals. The Miami Project, Christopher Reeve Paralysis Foundation, and others have materialized with the goal of finding a cure for SCI or reversing its effects.²⁶ The American Spinal Injury Association, the United Spinal Resource Center, and the American Association of Neurological Surgeons have published materials on prevention of SCI.^{27–29}

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the InSCI Study?

Through participation in the International Spinal Cord Injury Study, we hope to gain insight into the functional ability and quality of life of people with SCI both in the United States and around the world. This valuable information will aid in continued improvement to health care resources, community accessibility, and public policy affecting this population.

The National Study Protocol

The study will encompass traumatic SCI and certain non-traumatic etiologies, including vascular, infection, and benign tumor. Other inclusion criteria are adult age (≥ 18 years) at time of onset, community dwelling (not in first rehabilitation), resident in the participating country, able to respond in one of the available language translations of the survey questionnaire, and having no notable cognitive impairment. Exclusion criteria are progressive etiologies, including other nontraumatic etiologies, such as congenital, inflammatory, and autoimmune diseases; malignant tumors; toxic agents; and radiation. Sample recruitment tactics will include both online and offline strategies such as notices on the Web sites of hospitals and Disabled Persons Organizations (DPOs), social media, national study Web site, DPO newsletters, posters and flyers in hospital waiting areas, and direct contact via phone, e-mail, and social professional networks.

CONCLUSION

Although attitudes toward treatment of and outcomes for SCI have changed drastically in the past 100 years,²⁶ there remains significant work to be done. A general shortage of qualified health care professionals coupled with problems in insurance coverage may create an atmosphere of inferior care for sections of this population. The discrepancy between public and private insurance coverage and the scarcity of health care resources in rural areas have resulted in varying standards of care by region and socioeconomic status. Further improvement of accommodations in public transportation, workplaces, and communities can still occur. Yet despite these shortfalls, enormous strides have been made. The ADA and the disability benefits of the Social Security Administration have gone far in improving quality of life. Advocacy and support for people with SCI, along with research into new treatments and potential cures, are strong. With continued development in these areas, treatment and quality of life for people with SCI will continue to improve in the future.

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