The Cross-Cultural Societal Response to SCI

Health and Related Systems

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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 on 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.

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 recommendations[4] and WHO's six building blocks of the health system[14] 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.
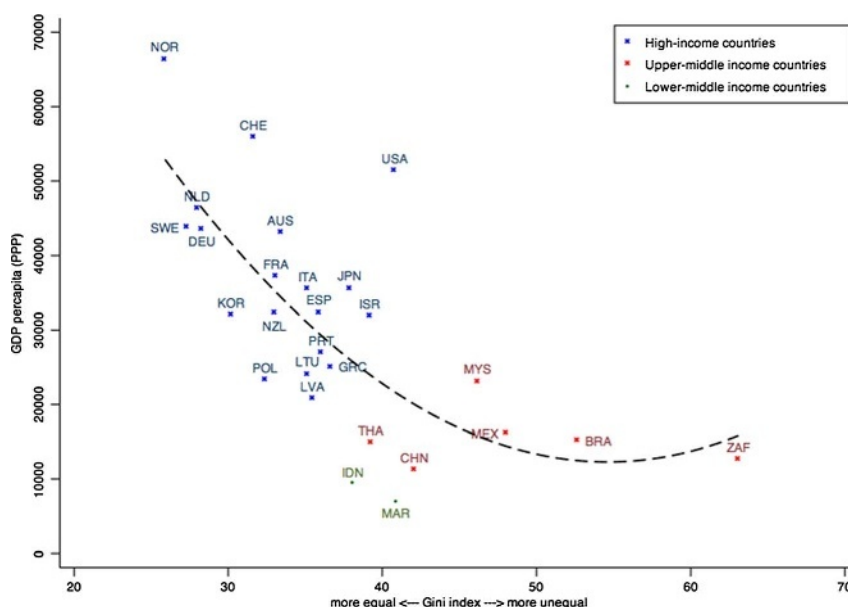
Country Characteristics (Macroeconomic Perspective)

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
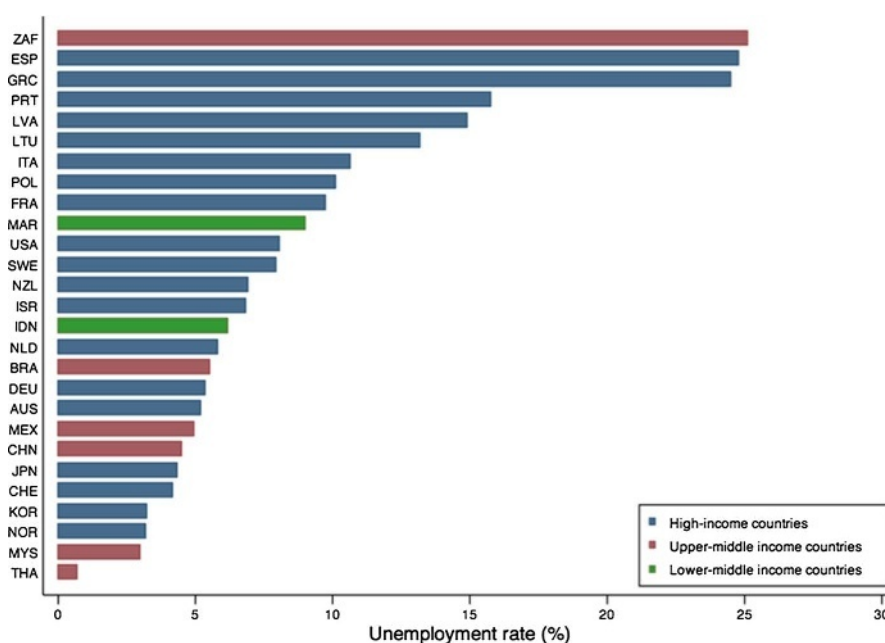

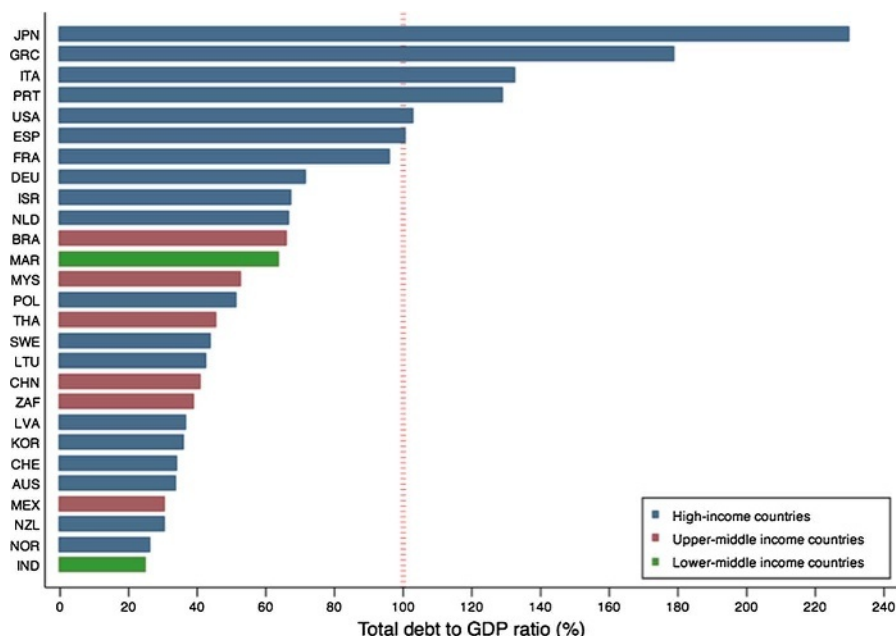**FIGURE 2.** Unemployment rate (source: OECD statistics, 2012).

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
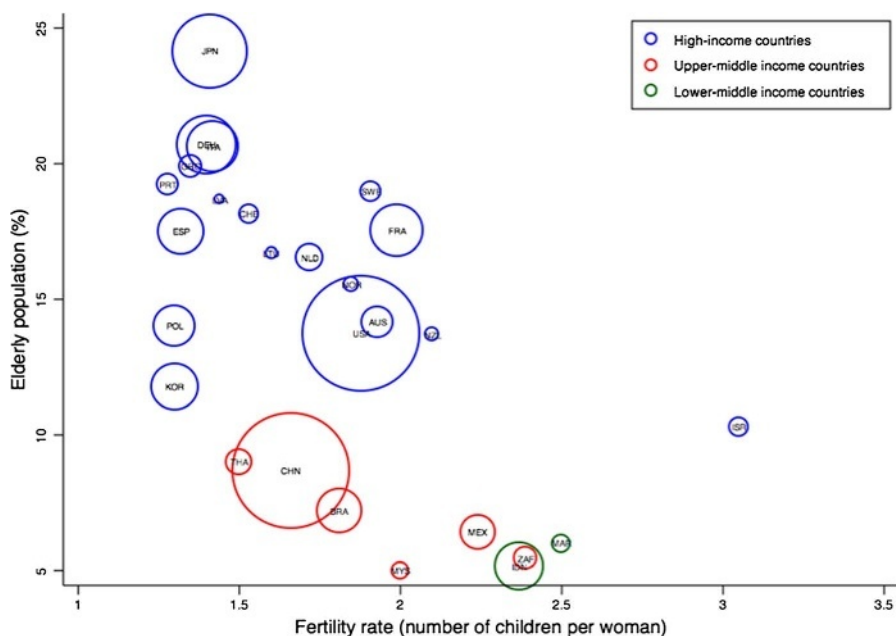

FIGURE 4. Sociodemographic composition (source: OECD statistics, 2012). The size of the circles correspond to the population size in each country.
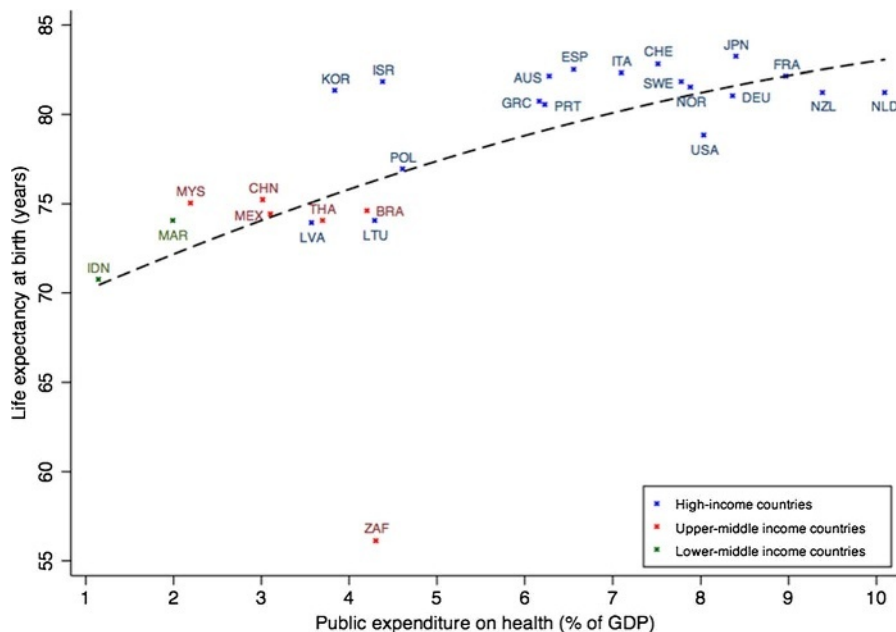
FIGURE 5. Life expectancy and public expenditure on health (source: OECD statistics, 2013. World Bank for Malaysia and Thailand).

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
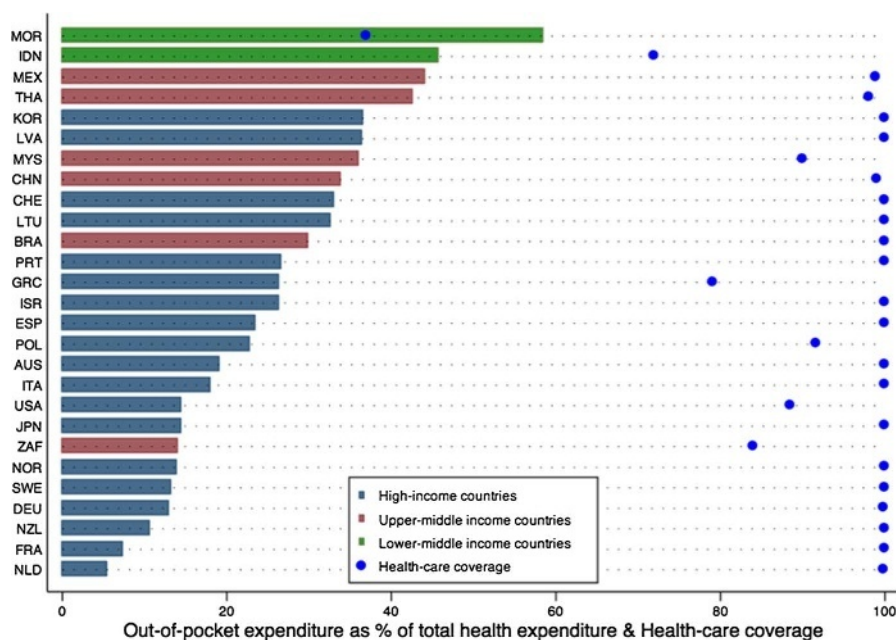

FIGURE 6. Out-of-pocket expenditures and healthcare coverage (source: OECD statistics, 2013).

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,
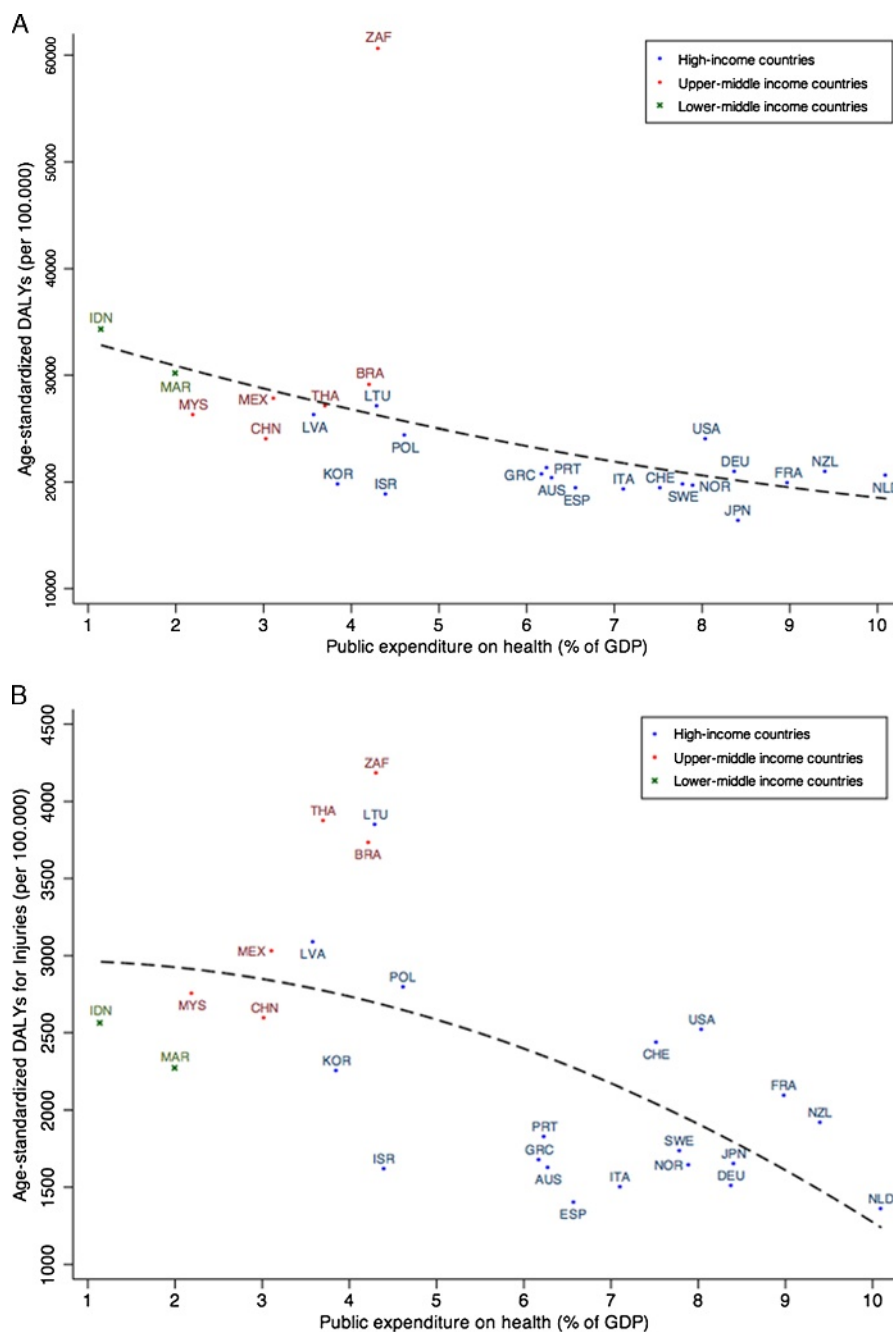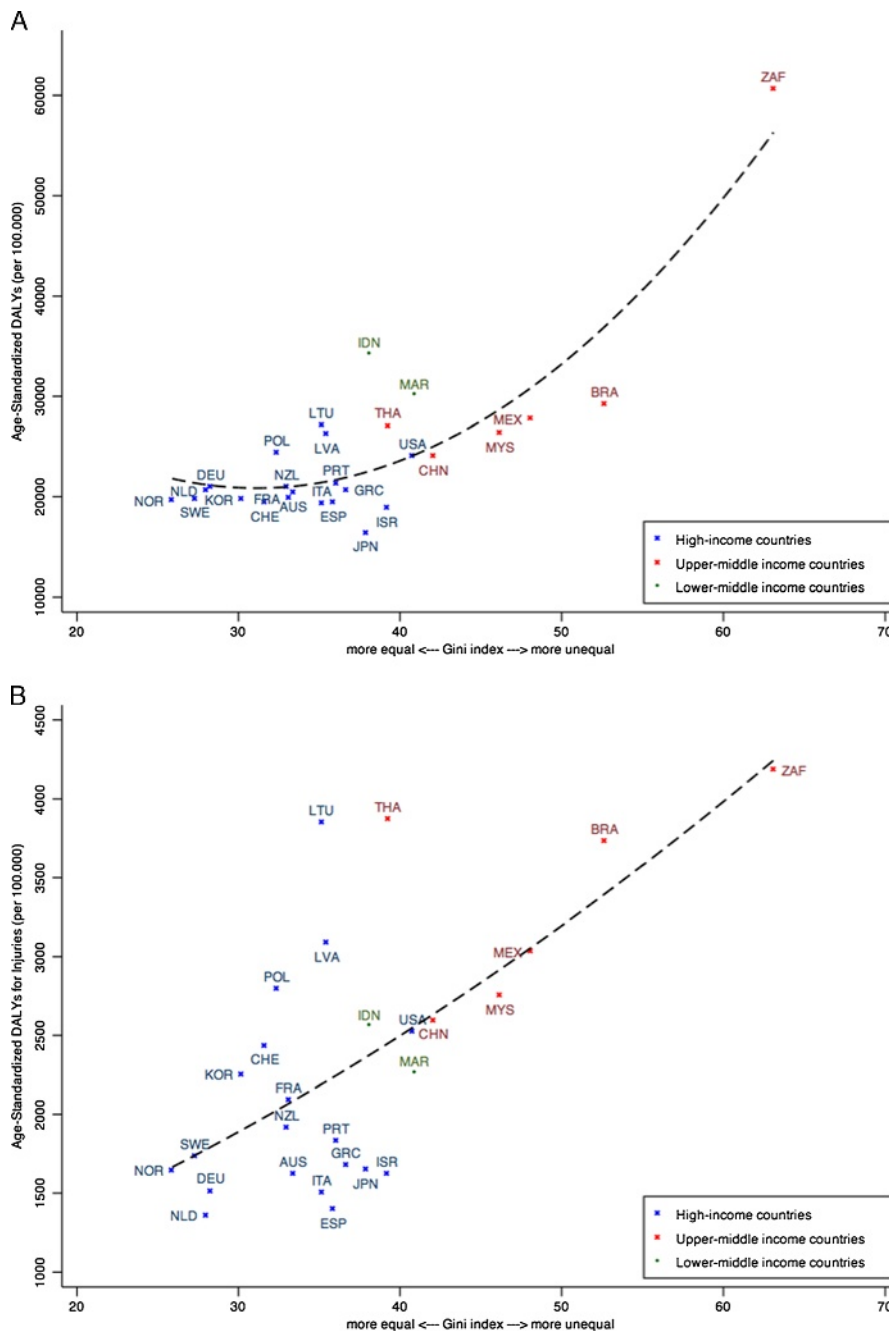

FIGURE 7. A, Age-standardized DALYs and expenditure on health. B, Age-standardized DALYs and expenditure on health, adjusted for injuries. (Source: Institute for Health Metrics and Evaluation. Global Burden of Disease Study 2013).

A

B

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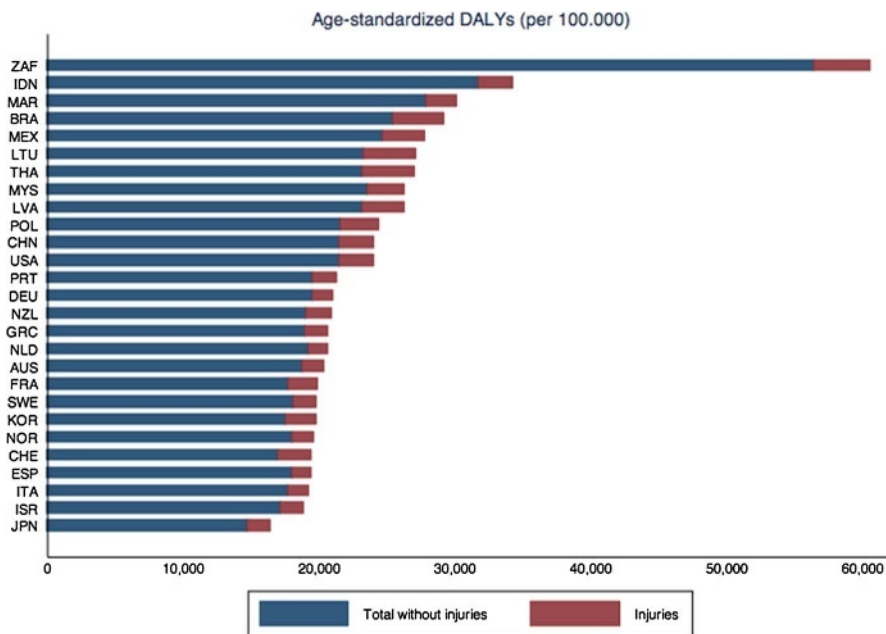
FIGURE 9. Age-standardized DALYs and injuries, global indicator (source: Institute for Health Metrics and Evaluation. Global Burden of Disease Study 2013).

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, incon-
sistent 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 re-
lated 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 experi-
ence and perception of strengths and weaknesses of the health
and related systems of their country.

CONCLUSIONS

Systematic evaluation and comparative analysis of the so-
cietal 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 col-
lected 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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