

People with Spinal Cord Injury in Switzerland

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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

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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 psychiatrists) 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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