

## People with Spinal Cord Injury in Poland

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### 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 Epidemiologic data are mainly derived from hospital-based studies and different time points and may be outdated.<sup>1</sup> 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.<sup>2,3</sup> Currently, there are no studies investigating the prevalence of SCI in Poland.<sup>1</sup>

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.<sup>1,4-7</sup> 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.<sup>2,4,7</sup> Males were affected 2.8 to 6 times more frequently compared with females.<sup>2,8</sup> A systematic review revealed that there are no studies concerning the epidemiology of SCI that resulted from conditions other than trauma.<sup>1</sup>

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<sup>2,5,9,10</sup> 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.<sup>7,9,10</sup> 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%).<sup>10</sup>

### 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).<sup>1</sup> 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.<sup>1</sup>

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

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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.<sup>11</sup> 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.<sup>12</sup> 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.<sup>13</sup> 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.<sup>13</sup>

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.<sup>14</sup> 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.<sup>15</sup>

## 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.<sup>12,16</sup> 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.<sup>16,17</sup>

Financial shortages, inadequate allocation mechanisms for real health needs and lack of standards result in relatively high out-of-pocket expenditures (22%) for households.<sup>12</sup> According to 2010 data, the average health care expenditure per capita accounted for 4.8% of the household budget, nearly doubled for retirees.<sup>18</sup>

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.<sup>16</sup> 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.<sup>19</sup>

## 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,<sup>19–22</sup> 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.<sup>1</sup> 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.<sup>1</sup> 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<sup>13,14,23</sup> 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.<sup>24</sup> 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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