

## People with Spinal Cord Injury in Lithuania

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### EPIDEMIOLOGY OF SPINAL CORD INJURY IN LITHUANIA

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 In another unpublished study, it was noticed that there has been since the early 1990s an increasing incidence rate of nontraumatic SCI (39%) among older persons with corresponding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

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

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

### THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

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

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

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

### LIVING WITH SCI

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

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

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

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

## THE HEALTH AND REHABILITATION SYSTEM

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

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

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

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

## WHAT IS THE STATE OF SPECIALIZED CARE?

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

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

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

### THE SOCIAL RESPONSE TO SCI

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

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

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

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

## THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

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

### THE NATIONAL STUDY PROTOCOL

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

### CONCLUSION

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

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

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