People with Spinal Cord Injury in Portugal

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN PORTUGAL

In Portugal, there are no national data about spinal cord injury (SCI) or about most other health conditions that may cause disabilities. Since the last census (2011), there are general questions about "activity of daily living" (ADL) disabilities related to *vision*, *hearing*, *mobility*, *memory/concentration, hygiene and personal arrangement*, and *to be understood and to understand others.*[1] Eighteen percent of the population aged 5 or older mentioned having difficulty performing 1 of these 6 activities; in the population aged 65 or older, this number exceeded 50%. Portugal has no central registry of SCI cases nor has there been a national epidemiologic study on SCI.

In 1998, Martins et al.[2] (1998) claimed that the epidemiology of SCI in Portugal's central region was not representative of the country overall SCI population. They identified 398 cases, with a predominance of males (3.4–1 ratio) and a bimodal age distribution in 2 peaks (15–24 and 55–74 years). The major causes of the injury were traffic accidents (57.3%) and falls (37.4%). The annual incidence rate was estimated at 57.8 per million inhabitants, and the annual survival rate was 25.4 per million inhabitants. We are not aware of new publications regarding the subject.

There are some single-center studies on their own SCI population, but they are not representative.[3–5] One study[3] evaluated 178 paraplegic patients followed for neurogenic sexual dysfunction and found a predominance of males (87.1%) aged between18 and 81 years; traumatic etiology was the main cause of SCI (79.2%), with a similar number of complete (n = 90) and incomplete lesions (n = 88). Another study[4] analyzed demographic data of patients with nontraumatic SCI admitted for rehabilitation between 2007 and 2009, and 69 patients were included; there was a small predominance of males (55.1%), with a mean age of 58 years; 79.9% were paraplegic and 89.9% had incomplete lesions. One small retrospective study[5] included 16 patients with iatrogenic SCI admitted for rehabilitation between 2004 and 2009; 9 women and 7 men, with a mean age of 58.3 years.

Nowadays, based on our experience, we think that the survival rate significantly improved, and there is a decrease in traffic accidents and a trend to increase in falls and nontraumatic cases. In parallel, the SCI population is aging along with the overall Portuguese population and is experiencing better survival rates. Although we have no data, we believe that patients with SCI are living longer, with a live expectancy close to the general Portuguese population (except for those with high-level, complete injuries).

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Since 1981, every injured person was rescued by an emergency specialized team. All emergency team members have the skills to deal with major trauma and advanced life support. The emergency system may use rescue helicopters, or the patient will be driven to the nearest hospital with neurosurgery or orthopedic acute care and intensive care. After clinical stability, the patient is transferred to the ward (neurosurgery or orthopedics, depending on the hospital and clinical condition). Rehabilitation care starts as soon as the medical condition allows it.

After the acute phase, most patients with SCI are transferred to a rehabilitation center for a comprehensive rehabilitation program conducted by a physical and rehabilitation medicine physician, supplemented with physical therapy, occupational therapy, rehabilitation nursing, psychological support, social service counseling and assistive devices prescription and adaptation, and adapted sports. Most of the patients with SCI return to their homes after discharge.

As outpatients, they have access to physiotherapy treatments in local rehabilitation clinics (financed by the national health system, NHS, or insurance companies), and maintain follow-up appointments on the rehabilitation center or rehabilitation unit. For those who are able and wishing to work after the injury, there are 2 institutions in Portugal dedicated to vocational rehabilitation (www.cmra.pt and www.crpg.pt). Other institutions are dependent on fund raising to provide this service.

Overall, the rescue and acute care are in a very high standard quality, whereas access to comprehensive rehabilitation care has improved over the years by increasing the number of beds for inpatient rehabilitation. Portugal has 4 major rehabilitation centers covering the entire country. However, the number of rehabilitation beds remains low, approximately a total of 450 beds. Another gap is in the area of social integration and the availability of vocational rehabilitation and professional (re)integration.

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LIVING WITH SCI

Portugal has legislation concerning accessibility to public buildings and transportation, although these laws are not yet widely applied. Outside major cities, sidewalks, public transportation, and many public buildings are not wheelchair accessible, but the picture is improving.

For students with SCI, it is easy to return to school. Usually, the school tries to eliminate barriers to accessibility. On the other hand, it remains difficult for a person with SCI to return to work or to get a paid job; the unemployment rate for people with disabilities is estimated to be 2.5 times as much as the general unemployment rate.[6] Portugal signed and ratified the Convention on the Rights of Persons with Disabilities. The "Initial report of Portugal on the implementation of the Convention on the Rights of Persons with Disabilities, August 2012" describes the work that has been done. In the report, Portugal commits itself to guarantee that employers and insurance companies will help to adapt the working place and provide needed vocational rehabilitation up to 36 months. In fact, most people with disabilities are unemployed in Portugal because of their low educational level and the lack of work adaptations. Specific legislation is still missing to oblige employers to hire a percentage of workers with disabilities, or to apply penalties for employers that refuse to adapt the workplace or prepare the employee with disabilities for shifting to alternative jobs after injury. If the SCI was suffered as a result of an accident at work, however, there is legislation that provides for both professional rehabilitation and reintegration.

Although there are no data concerning divorce rates for SCI persons, we feel that they have a higher percentage than the general population. Yet, they generally have good family support and a caregiver and are socially integrated with a good social network.

THE HEALTH AND REHABILITATION SYSTEM

The Portuguese National Health System, financed by the state budget, is a hierarchized system, and the facilities have levels of responsibility and capabilities, from the local hospital to the regional and central hospitals (named group 2 and 3).[7] Access to required health service is generally easy but depends on geographic and bureaucratic issues of the NHS and insurance companies. All the patients with disabilities have priority in the access to primary care. The number of physicians, nurses, rehabilitation therapists, and other health professionals are generally enough to fulfill the demands. The country's 13 hospitals have the equipment and staff, including a rehabilitation department, with the abilities to manage patients with SCI in the acute phase. Many patients with SCI are financed by insurance companies (mainly for traffic and work accidents) and have easy access to health care and assistive technology. For patients assisted through the NHS, access may be delayed, but medical appointments, treatments, and assisting technology are available across the country, nearly free of charge. The removal of architectural barriers in the person's house is generally on their own expenses (except for those assisted through insurance companies).

WHAT IS THE STATE OF SPECIALIZED CARE?

Portugal has 4 rehabilitation centers covering the entire country, and 5 physical and rehabilitation medicine departments inside acute care hospitals that provide comprehensive and intensive rehabilitation, with the complete technological equipment needed to screen and treat patients with SCI. All the group 2 and group 3 hospitals have rehabilitation departments for acute SCI rehabilitation and follow-up appointments. Some treatments, such as medically assisted procreation, are only available in specialized centers resulting in that not all the patients have access to it. Local outpatient clinics have a physiatrist who may or may not be specialized in SCI. There are a few centers where individuals with SCI have free access to assistive devices. Although the access is unequal across the country, generally all patients with SCI have at least a wheelchair and assistive devices for activities of daily living. In Portugal, there are qualified professionals to fit and repair the assistive devices.

THE SOCIAL RESPONSE TO SCI

There is no national health strategy specifically designed for SCI, although most of the health coverage is public (the rest is covered by work or traffic insurance). There are no national organized campaigns designed to reduce stigma against disability, but there are campaigns during the summer to prevent SCI diving accidents. There are national campaigns to prevent car accidents, and the Portuguese law remains very strict concerning safety equipment (in particular, seat belts), speed limits, and alcohol consumption.

Portugal has laws that state tax benefits for the employers of disabled workers, but most of the persons with SCI do not work, so the national government provides pensions for all the persons with disabilities with at least 60% of disability, which is much lower than the country's minimum salary. There are patients' associations for persons disabled by motor accidents, and some of these provide very limited and scarce funds to people with SCI. Social attitudes toward persons with SCI are very positive, with special parking places, supermarket queue priority, and public institutions' preferential attendance for persons with motor disabilities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

As noted, in Portugal, there are no national data about SCI, so we are extremely hopeful that the InSCI in Portugal will be the first step to closing that important epidemiological gap. We intend to use the national survey data we get from the study to assisting in raising awareness in Portugal about persons with disabilities in general and persons with SCI in particular and to use that momentum to try to influence politicians and the opinion and decision makers.

THE NATIONAL STUDY PROTOCOL

As patient's associations are not very active, nor do they focus on SCI in particular; our sampling frame will rely on multicenter hospital databases, based on *International Classification of Diseases* codes, to contact patients from the 4 rehabilitation centers and 5 physical and rehabilitation medicine departments that provide specific care for inpatients with

SCI. We will also recruit through social media. We acknowledge that this approach may underrepresent those with less disability who do not attend regular medical appointments. The inclusion criteria are the following: adult patients with traumatic SCI and nontraumatic nonprogressive etiologies, living in a community in Portugal, able to respond in Portuguese, with the informed consent given any time since injury. The exclusion criteria are the following: progressive etiologies such as inflammatory and autoimmune diseases, malignant tumors, toxic agents, radiation, and congenital SCI. First contact will be conducted by their physiatrist to obtain consent; the patient will receive by post the invitation letter, the informed consent, and the paper-and-pencil questionnaire; an online response will be given as an option. There will be 2 reminders for nonresponders at the 30th and the 90th days and the possibility of a telephone interview.

A local database will be established and hosted by *Rovisco Pais*, with username and password protection and limited access. The contact details and personal data database will be matched for repeated patients. The survey data will be hosted by the Swiss Paraplegic Research in Nottwil.

OPTIONAL NATIONAL MODULE

The National module will address issues concerning patient's accessibility to rehabilitation health care, namely, access to assistive devices, urinary catheters, physiotherapy treatments, specific appointments for SCI, and adapted sports. It is presumed that the access to rehabilitation health care and physical activity, as well as for the entire Portuguese population, is very unequal across the country, but there are no reliable data. The national module may allow the national authorities to update health policies.

CONCLUSION

Generally, the societal and health response to persons with SCI is good and universal. The exception is mechanisms for returning to work or getting a paid employment for the first time. Portuguese legislation is fairly advanced in the area of human rights and anticipates a proactive social response to remedy discrimination. For some reason, however, the rules and regulations that put these laws into practice are still missing. The same is happening with the legislation about architectural barriers in public and private buildings. As a people, the Portuguese have a positive and inclusive attitude toward people with motor disabilities, in particular, toward the persons with SCI.

The discouraging signs for the future concern the national, and European, economic crisis. Unemployment and poverty are growing among the Portuguese population and may become even worse for disabled persons. Although Portugal has a good public health system, the basic needs depend on the country's economy. The lack of national data avoids comparison of these variables for the SCI population. Additionally, the absence of a powerful and active association of patients with SCI makes even more difficult for the patients to claim their rights and to get attention from the health authorities.

The most encouraging signs are the positive cultural and social attitude toward those with disabilities, the respect to those that are "different" and needing special social support, mainly due to the tremendous growth of the educational level of the Portuguese population. We aim that this survey will allow the promotion of an active and representative organization of patients with SCI.

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