

# People with Spinal Cord Injury in Spain

*Merce Avellanet, MD, PhD, and Miguel Angel Gonzalez-Viejo, MD, PhD*

## EPIDEMIOLOGY OF SPINAL CORD INJURY IN SPAIN

The incidence of traumatic spinal cord injury (SCI) has increased from 8 cases per million population (1984–1985) to 23.5 cases per million population (2000–2009) in Spain.<sup>1</sup> Currently, it is estimated that 38,000 persons live with SCI in Spain.<sup>2</sup>

According to data from the Spanish Ministry of Health (Ministerio de Sanidad, Servicios Sociales e Igualdad, 2014), hospital mortality rate from first admission is 1.4%.<sup>3</sup> Mortality rate after hospital discharge is not available. Among traumatic SCI, 39% are due to road accidents, 55% are a result of falls during sporting or leisure activities, 1% are caused by violence, and 5% result from other miscellaneous reasons mainly attributed to accidents at the workplace. Traffic accidents are represented as follows: 40%, car; 40%, motorbike accidents; and 20%, pedestrian-related incidents.<sup>3,4</sup> Other important data on SCI epidemiology are missing. Currently, a National Register System on epidemiological data does not exist, although it is expected that one will be operative in the future.

Over the last decades, the assistance to road traffic accidents and the acute care of SCI have improved notably in Spain. Moreover, after a specific report of the situation in 2005, the Ministry of Health implemented a national protocol in 2010.<sup>5</sup> That is why a lesser number of complete injuries and a longer life expectancy have been observed.<sup>2,4</sup> Similar to other countries, there is also a progressive increase in the mean age of patients with SCI. This is most likely caused by a shift from traumatic to nontraumatic cases. Moreover, improvement in acute and subacute care implies that people with SCI are living longer.<sup>1</sup>

## THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Emergency care is provided 24 hours a day, both within and outside health care centers, including home emergency care, “in situ” care, and emergency transportation. It involves medical and nurse resources, as well as other professionals. Coordination across different emergency resources and mobilization according to need is centralized in emergency call centers.<sup>6</sup>

Once an injury has occurred, emergency services can be contacted by dialing 112. This call is free and initiates an immediate rescue process based on the information provided. The Emergency Medical System (EMS) coordinates a specialized medical rescue team. Medicalized ambulances as well as helicopters are available. Because the EMS covers all Spanish geographical areas, the average response time is usually fast. Depending on the information given to the EMS, trained and specialized technicians and/or physicians will attend the injured patients. If firefighters are required, they are trained to deal with SCI, too. The time between calling and the arrival of the medical team depends on the location of the accident, but generally it is no longer than 30 minutes.<sup>5</sup>

There are more than 200 intensive care units (ICUs) located in general hospitals throughout Spain.<sup>7</sup> Only hospitals designated by the National Health System at the upper level (level III), which provide advanced care, can offer all surgical techniques such as neurosurgery, spine surgery, general surgery, thoracic surgery, cardiac surgery, and pediatric surgery. Most patients are initially admitted to an SCI specialized acute care unit within a level III hospital. If the person who contacted the emergency services mentions the possibility of an SCI, the patient is taken directly to the specialized hospital with ICU and SCI unit. If the information provided is not accurate, the injured patient would be initially taken to a level III hospital without SCI or even a general hospital. Once physicians are aware of an SCI, the patient is immediately transferred to a specialized SCI unit. This may mean a delay of a few hours, less than 24 hours. In total, there are 11 hospitals throughout the country with both ICU and SCI units; these cover 11 of the 17 autonomous communities. Terrestrial ambulances are usually used for transportation; however, when the journey is expected to take longer than 30 minutes, a helicopter is used. Regarding the therapeutic approach of physiatrists who take care of acute SCI, the Spanish Paraplegia Society<sup>8</sup> recommends that they follow the clinical guidelines published in the 2013 Neurosurgery issue.<sup>9</sup> Moreover, the Spanish Paraplegia Society has recently published an evidence-based review guideline on the use of corticosteroids.<sup>10</sup> High-dose therapy is not recommended in acute traumatic SCI as part of a routine therapeutic approach.

All of the 11 specialized SCI centers have rehabilitation units, and there are also 2 SCI rehabilitation hospitals. All of these centers provide medical and psychological rehabilitations; however, vocational rehabilitation is currently not sufficiently covered.<sup>2</sup> The length of stay will depend on the neurological level and the American Spinal Injury Association classification. For persons with paraplegia, the length of stay is 120 days; that for persons with tetraplegia is 189 days, including the period of acute ICU admission.<sup>11</sup> Rehabilitation services include physiotherapy, occupational therapy, pain management, spastic treatment, and the use of technical aids.

From the PMR Department, Hospital Nostra Senyora de Meritxell, Andorra (MA); and SCI Unit, Hospital Universitari Vall d'Hebron, Barcelona, Spain (MAG-V). All correspondence and requests for reprints should be addressed to: Merce Avellanet, MD, PhD, PMR Department, Hospital Nostra Senyora de Meritxell, Fiter i Rossell 1-13, Escaldes-Engordany AD700, Andorra.

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## LIVING WITH SCI

One of the most important gaps in the SCI care process is preparing patients to return to work. There are many difficulties facing a person with SCI. Apart from the disability itself, employment prospects are very low and are additionally hindered by the general high unemployment rate in the Spanish population (25%).<sup>12</sup> Moreover, patients usually receive a monthly payment from the government, which may deter persons with SCI from searching employment.

Community resources to improve the lives of persons with SCI depend on the geographical location, which shows a great variability within different autonomous communities. The availability of techniques or devices required for support in daily life activities for disabled people is subject to the existence of specific bilateral agreements between central and regional administrations.<sup>6</sup> There are numerous factors influencing these differences, many of which are beyond the scope of this report. For example, like in other European countries, the Spanish population has a high life expectancy, with an increasing ratio of people older than 60 years old with SCI.<sup>13</sup> Community reintegration in this subset of patients is therefore very difficult, which explains the fact that 30% of people with SCI patients are institutionalized.<sup>2</sup>

All patients have regular checkups in SCI units at least once a year to monitor functional and urological conditions, neurogenic bowel dysfunction, pain, spasticity, and accompanying morbidities, such as bedsores and syringomyelia. A percentage of patients following discharge are likely to be readmitted to an SCI unit because of a variety of conditions, most of them because of infections, bedsores, autonomic dysreflexia, or acute respiratory disease. In primary care, access to medical and psychological services is the same as that for the general population. There are no special support services for people with SCI in Spain.

Very few studies are available that focus on the quality of life in the Spanish SCI population. A prospective and observational study of 91 SCI patients leaving in Catalonia concluded that in men sexual function was the main concern of most patients, followed by bowel dysfunction, urinary incontinence, and ambulation or gait problems, whereas in women the main concerns were urinary incontinence, bowel dysfunction, and ambulation or gait.<sup>14</sup>

Returning to community life is still a challenge for most people with SCI. In most cases, continuing with school or university courses is possible, and there are programs for students with disabilities in different universities all over the country. For instance, the Universitat Autònoma de Barcelona developed in 2011 an action plan composed of 32 measures to foster the inclusion of students with disabilities. However, as mentioned earlier, employment is a different matter. Even though it is not uncommon to see people with SCI active within the community, there are still many barriers, both physical and psychological, to achieve complete integration.<sup>15,16</sup> Limited access to health technologies such as innovation or assistive devices provides a paradigmatic example of those barriers. Furthermore, not all disability needs are financially covered by the Spanish National Health System. Regarding assistive devices and technologies, the common benefits basket includes, for example, wheelchairs, cushions, and orthoses, but

do not include vehicle adaptation. Vocational rehabilitation remains largely underdeveloped. Accessibility to the workplace itself is often not available, and there is often little or no assistance given to SCI patients when trying to adapt back into their previous roles. Generally speaking, employers still believe that persons with physical disabilities are considerably less capable in their role than an able-bodied employee. In addition, the monthly compensation provided by the government has proved to be another barrier to return to work because it is attached to the household income. If the household income surpasses a specific limit, the disabled person stops receiving the money.<sup>17</sup>

## THE HEALTH AND REHABILITATION SYSTEM

Spain is a devolved country, with 17 decentralized regions, known as autonomous communities. Local communities currently administer health management policy decisions. Consequently, within each community, there may be different criteria regarding health decisions. Since 1989, the National Health System has been publicly financed, and universal coverage is offered as a constitutionally guaranteed right.<sup>6</sup> Patients do complain, however, about long delays for an appointment with medical specialists.<sup>18</sup> Recent data from the Ministry of Health state a 65-day delay for external consultation and 38% of patients waiting for more than 60 days, data for all patients in first consultation, and basic medical specialties.<sup>19</sup> Although the private health system does not play any relevant role in Spain, the number of people opting for private health care varies significantly between different autonomous communities (in Catalonia 20%–30% of patients seek private care, whereas in Andalucía only 10% do).

Regarding specialized care, well-trained specialists are available for everyone with SCI. There are 1313 physical medicine and rehabilitation physicians and 50 SCI expertise fellows. The number of physical medicine and rehabilitation physicians is sufficient, but they are not evenly spread over the autonomous communities.<sup>20</sup> Both specialized nurses and allied health professionals develop their work in the SCI centers.

## WHAT IS THE STATE OF SPECIALIZED CARE?

There are a total of 11 SCI units across the country. These units together with the 2 SCI rehabilitation hospitals (Hospital Nacional de Paraplégicos de Toledo and Institut Guttmann) provide a wide range of medical and psychological rehabilitation from physiotherapy and occupational therapy to pain management, spasticity treatment, and use of technical aids.

## THE SOCIAL RESPONSE TO SCI

Welfare coverage is available for all patients with SCI. Those patients injured through road traffic accidents or accidents at work may also be covered by private insurances. People with SCI have limited access to assistive technology such as wheelchairs, equipment for the home, and communication systems, because the public health service contributes only to part of that economic burden. Within the legal framework,<sup>21</sup> autonomous communities are free to approve their respective health benefits baskets, supplementing the common benefits

package of the Sistema Nacional de Salud. Both common and regional benefits baskets are updated on a regular base. Consequently, family support and social support are still essential for people with an SCI. Eighty percent of them receive help or support for their daily lives, mainly provided by people living in the same house.<sup>2</sup>

Advocacy groups for persons with SCI are important. There are several national and local SCI patient groups and associations (e.g., Asociación nacional de Lesionados Medulares y Grandes Discapacitados Físicos). One of 4 SCI persons belongs to a disability association.<sup>2</sup> Some of these associations also act as foundations that support research in SCI, such as the Step by Step Foundation in Barcelona, Catalonia (<http://www.fundacionstepbystep.com/>).

Although laws and regulations aim to reduce discrimination against people with disabilities, a recent survey noted 25% of people with SCI had complained of discrimination at least once in the last year.<sup>2</sup> The main problems cited were related to difficulties in transportation or when trying to participate in cultural or leisure activities.

Progress in providing social care is far behind the improvement in the quality of medical care. In 2006, the role of “carer” was recognized by law for promoting personal autonomy and attention to dependant persons (Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las personas en Situación de dependencia y el Sistema para la Autonomía y Atención a la Dependencia).<sup>21</sup> However, the implementation by the law has been difficult because of the economic crisis.<sup>22,23</sup> Therefore, taking into account the aging population, the government has now to cope with an increasing number of elderly patients with SCI and should plan and allocate resources accordingly.<sup>24,25</sup>

The National Health Strategy includes general health recommendations.<sup>26</sup> In order to reduce accident rates and following a cross-sectoral collaboration, some preventive measures have been implemented to reduce both traffic accidents and accidents in the workplace, for instance, the inclusion of security professionals in companies or labor inspectors monitoring periodically.<sup>27</sup> However, these strategies do not focus on SCI. The government has promoted accident prevention programs, such as the use of seatbelts when driving, as well as regulations and advice for sporting activities.

On April 7, 2014, the latest amendment to the Law on Traffic, Motor Vehicle Traffic, and Road Safety, was released.<sup>28</sup> The Spanish traffic laws are very strict on speed limits by means of radar control, alcohol and drug use, the wearing of seatbelts, placement and use of child seats, and yearly technical evaluation of any traffic vehicle. Generally, roads are well maintained in Spain, although there are some notable differences to be found between urban and rural areas. Rural roads are often narrower than the former but still reasonably well maintained.

Social attitudes toward persons with SCI are generally positive in Spain. A few public and private campaigns have promoted social inclusion of people with disabilities. A good illustration of this was a recent TV series in which the main character had suffered a complete SCI (<http://www.ccma.cat/tv3/ventdelpla/>). The program centered on her life following the accident and detailed her rehabilitation progress, which took place at a specialized SCI center.

Existing regulations encourage employers to employ people with disabilities by offering tax benefits. Overall, Spanish society is quite sympathetic to people with disabilities.<sup>29,30</sup>

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

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

We recognize the importance of having accurate information about SCI characteristics, patients' environment, their emotional wellbeing, how active they are, and how much they are able to participate in everyday life. We believe it to be highly beneficial to participate in this study as it will provide an accurate assessment of the situation in Spain regarding all aspects of the patient's life.

### The National Study Protocol

There are 4 SCI units taking part in the study: Hospital Universitari Vall d'Hebron (Barcelona), Hospital Universitario Virgen del Rocío (Sevilla), Hospital Universitario Insular Materno-Infantil de Gran Canaria (Canarias), and Complejo Hospitalario Universitario A Coruña (La Coruña). With these 4 units located in Western, Eastern, and Southern Spain and the Canary islands, a large and representative part of the country is covered, including both urban and rural areas. All admitted patients in these SCI units will be invited to participate in the InSCI community survey. These patients will be interviewed sequentially starting with those patients admitted in 2008. The Minimum Basic Data Set of Hospital Discharge and the database of each SCI unit will provide the information. Patients will be contacted by telephone and will attend the interview in person.

We will seek approval from the local ethical committee ensuring that the criteria on the Spanish Data Protection Act are met. The following drawbacks are anticipated: transportation of patients because the interview is a face-to-face procedure and financial assistance as the development of the study will be time consuming.

## CONCLUSION

Generally speaking, the health needs of persons with SCI are adequately met throughout Spain including acute care, the rehabilitation process, and other comorbidities, which occur during a patient's life. The lack of a national SCI register prevents us from having a better knowledge of the epidemiological characteristics of these patients, including life expectancy.

It is expected that a significant increase in older people having an SCI will be seen over the next 2 decades. This fact has to be considered by the administration, not only in terms of economic expenses, but also as a social burden. Specific measures to cope with this burden need to be implemented now. Although the social feeling is sympathetic to people with SCI, the social needs are far from met, mainly because of the lack of economic resources and the effects of the economic crisis. Finally, the economic recovery together with the political would help to implement the existing laws with regard to social care. More resources are needed to reintegrate people with SCI to the fullest.

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