

People with Spinal Cord Injury in Greece

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN GREECE

There are no reliable epidemiological data regarding the incidence, prevalence, and mortality rate after spinal cord injury (SCI) in Greece.¹ The only evidence available comes from studies that cover only a small part of the total Greek population.^{2,3} The larger study available reports an annual incidence rate of 33.6 per million, and transportation accidents are reported as the leading causes of injury. (The study refers to the greater Thessaloniki region, consisting of Central and Western Macedonia. The reported data correspond to the years 2006–2007, where the population of this region was approximately 2 million inhabitants. In the same years, the Greek population was 11.16 million inhabitants.) The percentage of injured males was significantly higher than that of the females.²

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

There are emergency medical services available to all citizens in Greece, regardless of their financial or insurance status. The National Centre of Emergency Health Care (EKAB) was founded in 1985 (according to the law, no. 1579/1985) and is a public entity supervised by the Ministry of Health, responsible for coordinated first aid and emergency medical care to citizens and their transfer in health care units.⁴ Highly skilled health personnel trained in emergency services reach the place of injury by ambulance or helicopter depending on the geomorphology. Services of the EKAB services are established and operating in 12 regions all over Greece as stand-alone branches. Each EKAB branch is responsible for a particular geographical region.⁵ The geomorphology of Greece (several remote islands and mountains) has significant effect on mean transfer delay at hospital.⁶ In the areas the EKAB services can reach the injured person, acute care starts even before the patient reaches the emergency department, with spinal immobilization principles, which are well established in Greece, and are followed to prevent secondary injury to the cord (data provided by the EKAB medical service).

In Greece, given the absence of specialized centers for SCI, patients with acute SCI are admitted to orthopedic,

neurosurgery, or specialized spine surgery departments of general hospitals.

Rehabilitation services should begin in the intensive care setting.⁷ However, most of the times, owing to lack of rehabilitation teams providing health care in the acute SCI stage, initial rehabilitation management is limited to physiotherapy. After the acute phase, usually during the first month after injury, patients are transferred to public or private rehabilitation departments, where the interdisciplinary approach of the rehabilitation team is provided. According to Hellenic unpublished data, the average initial hospitalization in Rehabilitation Departments is 7 months.⁸

The prevalence of patients with SCI of traumatic and nontraumatic origin represents 5.7% of the total number of rehabilitation beds. Patients with SCI of traumatic or nontraumatic origin are dispersed in several rehabilitation centers, and the average number of patients with SCI is 3 patients per center.⁹ During inpatient rehabilitation, persons with SCI and their family members or significant ones receive information and training regarding bladder and bowel management and skills such as transferring, wheelchair skills, and assistance for activities of everyday living. Information concerning sexual function, fertility issues, and psychological burden is poorly addressed, however.¹⁰

Entering the chronic phase, a large percentage of Greeks with SCI have follow-up services provided by physical and rehabilitation medicine (PRM) physicians in rehabilitation departments. However, individuals with SCI (25.4%) seem to lose their initially gained independence with activities of daily living (ADL) during follow-up.⁸ In case of an emergency, these patients visit the emergency department of a general hospital, where physicians of specialties other than PRM treat them.¹¹

In addition, geographical region seems to affect the follow-up services. Distance from health facilities, lack of access to means of transportation, and unavailability of adequate infrastructure and human resources are reported as the main reasons.¹²

In general, Greeks with SCI are not adequately prepared for the transition to live in the community. There are no policies to facilitate housing modifications and return to work. Furthermore, in the current period of economic crisis, even basic issues like assistive devices are not considered priorities. Consequently, individuals with SCI use inappropriate equipment resulting in complications, many of which could have been prevented.^{13,14}

LIVING WITH SCI

A young person with SCI faces many obstacles to return to school. It is difficult to overcome feelings of low self-esteem, and there is not always organized counseling available, or other

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preparatory supports. In addition, the lack of teachers trained in the needs of children with SCI, as well as bullying by other students can have a negative impact on their decision to return to school. Finally, exclusion of the educational system is often due to physical environmental barriers. Greece needs to prepare a practical education policy, strategies for making school buildings accessible, as well as to provide educators trained in the needs of children with SCI.

The State is making promising steps toward vocational reintegration, but it must be noted that vocational counselors do not participate in the rehabilitation team. As far as employment is concerned, obtaining a job or returning to a preinjury employment is also a challenge. Lack of vocational rehabilitation, counseling and preparation, and inappropriate work adjustments and accommodations exclude people with SCI from most jobs.¹

THE HEALTH AND REHABILITATION SYSTEM

A public-private combination of both funding and service delivery characterizes the Greek health care system. The National Health System provides universal coverage to everyone and operates according to the principles of equal access to health services for all. Insurance coverage of hospitalization costs in public rehabilitation centers is 100% in contrast to private rehabilitation centers, where only 50% or less is covered.

Greece has one of the highest rates of physicians (6.2 per 1000 population), and one of the lower rates of nurses (3.3 per 1000 population).¹⁵ Unfortunately, very few of them are trained in SCI rehabilitation issues.

Nowadays in Greece, inpatient rehabilitation facilities have significantly increased compared to some decades ago.^{1,9} Rehabilitation services for the acute and postacute phases of SCI are provided in general hospitals and rehabilitation centers, in the public and private sectors. Public rehabilitation structures are lacking: there are only 5 public PRM departments in general hospitals and the National Rehabilitation Center, all of which are located in Athens, with a total of 234 beds (data provided by the Hellenic Society of PRM). There are also several regional public rehabilitation departments in Greece, but owing to lack of qualified staff, they are not in use or they function below their capacity. More than 2000 rehabilitation beds have emerged in the private sector during the past decade, located in semi-urban areas and towns in different areas of Greece.⁹

WHAT IS THE STATE OF SPECIALIZED CARE?

No national health strategy for people with SCI has ever been designed in Greece.

The first Rehabilitation Department for people with SCI in Greece was founded by private sponsorship in 2010.¹⁶ It is part of the General University Hospital of Patras, the third largest city of Greece, covering a population of approximately 1 million people. Unfortunately, the foundation of the hospital coincided with the economic crisis in the country. As a result, it remains understaffed, and many inpatient and outpatient services are not fully developed. The lack of resources also affects the outpatient services and the efforts toward the prevention of secondary conditions and complications of SCI. Efforts for creating a proper interrelation between acute medical care, rehabilitation, and community integration are in development.¹⁷

In general, Greek health care system still faces problems related to lack of trained health staff. Very few of Greek rehabilitation therapists work as members of a rehabilitation team.¹⁸ Most work in their own private offices. Even fewer therapists are specialized in SCI rehabilitation. Although there are well-trained PRM physicians in SCI, the lack of specialized spinal cord units has a negative effect in the quality of care. Furthermore, the rehabilitation services provided by the general rehabilitation centers are not reliably assessed.¹⁹

People with SCI have access to assistive technology such as wheelchairs and home equipment. According to the legislation in force since 2012, approximately 50% of the actual cost of these devices is covered, whereas necessary home adaptations are not covered at all.²⁰

THE SOCIAL RESPONSE TO SCI

A telephone survey conducted in November 2013 revealed that persons with mobility impairments (including paraplegia and tetraplegia) face difficulties related to financial issues (51.6%), public services (49.1%), and discrimination and social exclusion (29.0%).²¹ Another recent study on wheelchair users reports significant poor quality of life.²²

Home accessibility represents a major challenge for people with SCI, and public means of transport (buses and trains) are often wheelchair inaccessible. In Athens, most metro stations are wheelchair accessible. Wheelchair-accessible private taxis are available, but their drivers must be informed in advance. Issues of accessibility are addressed in a very popular SCI community site: <http://www.rollout.gr>.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

What Do We Hope to Gain from Participating in the International Spinal Cord Injury Study?

To improve SCI management, it is necessary to better understand rates of occurrence and to have a clear view of the incidence and prevalence of SCI. This knowledge will enable health care providers to estimate both the cost and psychosocial burden of SCI and the resources required for SCI management.

International spinal cord injury (InSCI) survey will help us toward this direction. The Greek translation of the InSCI survey questionnaire will be reviewed and approved by a research ethics committee before the operational phase of the survey. Patients with chronic SCI (≥ 1 year after injury), of sudden onset (traumatic or nontraumatic), age 18 years or older, community dwelling, residents of Greece, capable of answering the survey questionnaire, and without concomitant cognitive impairment will be included. Persons with progressive etiologies of SCI will be excluded. Participants will be informed through letters and telephone calls from member lists of associations of persons with disabilities and SCI and through hospitals' and associations' Web sites. Information will also be provided during their regular reassessment as outpatients in rehabilitation departments. Letters and telephone calls will be used as reminders. Means of contact (first contact and reminders) will be with mixed mode of written invitation letter, e-mail, postal mail, and telephone. Methods of data collection shall include online questionnaire, paper-and-pencil

questionnaire, interviews (possibly computer assisted), face-to-face (eg, hospital, at home), and telephone call. Data will be collected, stored, processed, and strictly protected by members of the Greek InSCI study. Local database should be organized and connected to the international database.

During our national PRM meeting in February 2016, in Athens, the Greek translation of the International Perspectives on SCI and the InSCI survey were presented to the scientific community and authorities. It is expected that successful IPSCI implementation and InSCI survey will give the opportunity to develop national data of people with SCI in Greece and encourage policy makers toward decisions that will improve the situation for persons with SCI in Greece.

CONCLUSION

As a consequence of the absence of specialized SCI units in Greece, patients with SCI are admitted to various rehabilitation centers, where the provision of health care services is often suboptimal with regard to specialization and comprehensive rehabilitation. Current challenges include the following: (1) the identification of the incidence and prevalence of individuals living with an SCI in Greece; (2) the identification of their needs during the chronic phase; (3) the provision of long-term follow-up and maintenance of their functional capacity during aging; (4) the appropriate training of health care professionals not specialized in SCI issues; and (5) the support of public initiatives that challenge negative attitudes to disability.

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