

People with Spinal Cord Injury in Korea

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN KOREA

Korea performs a national disability survey every 3 years, and epidemiological data concerning 15 official disability categories set by the government are provided in open access. It is estimated that 91.7% of the population of persons with disabilities are registered in the National Disability Registry system.¹ The most recent results of the National Disability Survey (2014) estimates the disability prevalence in Korea to be 5.59% (2,726,910 persons).

There is no national spinal cord injury (SCI) registry in Korea. However, the Korean government officially categorizes spinal cord injury–related paralysis into the paralysis section of “physical disability.” Physical disability is further divided into amputation, joint contracture, and deformities, but epidemiological data specific to spinal cord injury are lacking, and thus only an estimation of SCI persons in Korea is possible: According to the 2014 National Disability Survey, estimated persons with physical disability was 1,373,737 with a prevalence of 2.82%.¹ Among the diagnoses that make up Physical disability, the percentage of SCI (cervical, thoracic, lumbar) and myelitis add up to 4.9%, and thus a figure of 67,313 (excluding nonresponders) is a rough estimate of spinal cord injury persons. According to the Statistics Korea (KOSTAT), the total population in Korea is 50,617,000, and thus SCI persons would make up approximately 0.1% of the total Korean population.² (Because very mild SCI persons (ASIA impairment scale D, E) may not be included in these statistics, this figure is only an extremely rough estimate.)

There is no national demographic data specific to SCI. In 1999, Park et al. analyzed demographics of 590 SCI patients.³ Men accounted for 79.6% and the peak age group were those in their twenties (32.5%). Etiologically, 91.2% were traumatic in origin. The National Rehabilitation Center analyzed 3076 SCI patients admitted to the National Rehabilitation Center

between 1994 and 2014 to obtain a rough demographic picture of SCI persons. Among the patients analyzed, 72.9% were men and 27.1% were women. Etiological analysis showed that 80.9% (n = 2488) were of traumatic origin with the most frequent cause being traffic accidents (55.3%) followed by falls (32.1%), sports-related accidents (6.1%), and violence (0.9%). Among the 19.1% of nontraumatic origin, tumor (19.6%) was the most common etiology followed by myelitis (19.2%), spinal stenosis and herniated disc (15.3%), infection (12.9%), and arteriovenous malformation (4.2%).⁴

The National Rehabilitation Center performed an interval analysis of the data to investigate for etiological changes in traumatic SCI between years 1994–2000 and 2008–2014. Results showed that the most common cause of traumatic SCI was traffic accidents, but the percentage had fallen from 64% to 45% in 1994–2000 and 2008–2014, respectively. In contrast, falls, which was the second most common cause of traumatic SCI, had risen from 23% to 43% during the same time intervals implying a change in trends regarding etiology of SCI among SCI patients of traumatic cause. Furthermore, the percentage of incomplete injuries between the two time frames had risen from 70.5% to 82.6%, respectively.⁴

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

After an SCI, emergency services are available regardless of insurance schemes and trained personnel, who follow basic protocols for spinal cord protection, would take SCI patients to tertiary hospitals for acute care. Some tertiary hospitals have specialized SCI units, but the number of those that do is not known, although most tertiary hospitals have the capability to treat SCI in the acute stage with intensive care units and specialized spinal teams.

Most tertiary hospitals also have rehabilitation departments, and thus a transition to the subacute phase would typically include rehabilitation. After or during the subacute phase, patients would be transferred to rehabilitation departments in other tertiary, secondary, or rehabilitation-specific hospitals.

LIVING WITH SCI

The impact of SCI on an individual is multifaceted. However, with adequate health care and fulfillment of rehabilitation needs, the impact can be cushioned and minimized. Unfortunately, due to the lack of epidemiological and socioeconomic data regarding SCI, little is known about the lived experience. In 2012, the Korea Spinal Cord Injury Association (KSCIA), a nonprofit organization by SCI persons, conducted

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a self-report survey with a randomized sampling of its members. Out of the 307 respondents, 303 were obtained and analyzed. According to the survey results, 69.6% responded that they were employed before SCI. These rates dropped to 13.0% after experiencing SCI.⁵ However, due to the scarcity of sampling, it is extremely difficult to say that these results reflect the whole SCI population in Korea.

THE HEALTH AND REHABILITATION SYSTEM

Korea does not have a single health care and rehabilitation policy regarding SCI. However, Korea is making enormous efforts to improve health care provision for persons with disabilities through reforms in policy and legislation, financing and affordability, service delivery, and human resources. Every 5 years, the Ministry of Health and Welfare reviews its legislation and policy in light of social welfare guidelines that help to raise awareness to the need for appropriate legislation to improve healthcare service delivery for persons with disabilities.⁶

Korea has universal health coverage managed by the National Health Insurance Corporation. Thus, all Korean citizens are enrolled in the National Health Insurance (NHI) of Korea. Moreover, 5–20% of inpatient and 30–60% of outpatient medical costs are paid out of pocket, and the remaining costs are reimbursed by the NHI, depending on the type and level of medical institution visited by the beneficiary.⁷ For those with the lowest income, both NHI insurance fees and out-of-pocket medical fees are exempt and covered by the government. Currently, about 17.1% of the population of people with disabilities and 12.4% of those registered as having physical disability (which includes SCI) are within this lowest income population and so qualified for exemption of these fees, compared with 3% of the general population.⁶

Most treatments after SCI including acute care, specialized treatment, and rehabilitation are reimbursed through the National Health Insurance. However, traffic accident insurances cover medical costs related to traffic accidents, and worker's compensation insurances reimburse for medical fees involving work-related accidents. The NHI also reimburses for assistive devices and 80% of the upper limit of standard costs defined by the NHI Corporation is reimbursed by the NHI.⁷

WHAT IS THE STATE OF SPECIALIZED CARE?

Korea has made efforts to improve service delivery in the subacute phase by evenly redistributing rehabilitation services in Korea. Currently, there is one National Rehabilitation Center (NRC) in Seoul that provides subacute rehabilitation services and research data regarding disability care. The NRC coordinates and guides rehabilitation services in the 6 provincial rehabilitation centers, 17 community rehabilitation hospitals, and 113 regional public health centers in Korea. There is also a university-affiliated hospital, Yonsei University Severance Rehabilitation Hospital, which provides coordinated rehabilitation services in various fields from the acute phase of rehabilitation and onward. The National Traffic Injury Rehabilitation Hospital is a hospital affiliated with the Ministry of Land, Infrastructure and Transport and is specialized in rehabilitation associated with traffic accident-related injuries. Korea has 82

training hospitals with rehabilitation departments that run comprehensive residency programs.

Korea has continually strived to increase the specialized pool related to rehabilitation. The Ministry of Health and Welfare currently certifies physicians specialized in rehabilitation through board examinations since 1983. Currently, there are 1855 certified specialists and 514 doctors in rehabilitation training residency programs. The certification process has been expanded to include physiotherapists, occupational therapists, orthotists and prosthetists, and speech-language therapists.

THE SOCIAL RESPONSE TO SCI

In light of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), Korea has strengthened health care service provision, including provision of assistive health products, ensuring barrier-free hospitals, providing caregiver support, and facilitating transportation. The significance of capturing the "lived experience" of people with disabilities within nations has been emphasized in Article 31 of the CRPD, according to which data collection relevant to the lives of persons with disabilities is no longer an option but a basic human right that must be undertaken by its member states.⁸ For Korea, the collection of data on persons with disabilities has been ongoing since 1980. Article 31 of the Korean Act on Welfare for Persons with Disabilities mandates a national disability survey where problems are identified and policies are formulated on the basis of such data to give effect on the identified shortcomings of the realities of persons with disabilities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

The Korean team (KoSCI team) has been organized to lead The Korean Spinal Cord Injury Cohort Study (KoSCI) through the International Spinal Cord Injury (InSCI) study. The KoSCI team aims to develop a Korean protocol that will ultimately use the InSCI survey as a basis to formulate a Korean SCI database that will have common questions with the InSCI but also a set of questions specific and important to SCI persons in Korea.

Only community-dwelling SCI persons will be included in the initial Korean study protocol. The source population will be based on the approximately 3000 NRC SCI patient database, 2500 KSCIA member database, and the 2000 Korea Society for Industrial Disaster Victim member database. However, eliminating redundancy within the source population will be important. Hospital pools often overlap and the KSCIA pool will also have duplicate participants. Ways to overcome this may be to use the largest pool as the main source and carefully eliminate duplicates using name and birthdates.

Modes of data collection will be done through a combination of electronic survey and paper and pencil. All those who agree to be surveyed will receive both electronic and paper and pencil surveys via Email or postage. For those who respond

that they are unable to perform the surveys due to lack of caregiver or poor hand control, a face-to-face or telephone interview by educated interviewers will be performed. The KoSCI team will manage all data input using a central database coordinated by Swiss Paraplegic Research in Nottwil, Switzerland. Korea's data will be authorized by the Data Usage Committee within the KoSCI team.

CONCLUSION

International data encompassing all disabilities is important. However, for identification of concrete problems and formulation of realistic policies, there is also a need for condition-specific data. Collaborative efforts, such as the InSCI survey, must be initiated so that in the future this may act as an example for data formulation in other disability conditions. The Korean Team hopes to work in synergy with the international community to capture the lived experience of persons with SCI and ultimately contribute to bettering the lives of persons with SCI not just in Korea, but globally.

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