

People with Spinal Cord Injury in Malaysia

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN MALAYSIA

Very little is published on the demographics or epidemiological patterns of spinal cord injury (SCI) in Malaysia. Available studies show that most persons with SCI were males, aged younger than 40 years, and had paraplegia.¹⁻³ A related study showed a bimodal distribution of age, with peaks of incidence in the 25 to 34 and 55 to 64 age groups.² The most common cause of injury was caused by motor vehicle accident followed by fall from height.¹⁻³ Tumor-related cases made up 40% of nontraumatic causes of SCI.¹ No data are available on the mortality and life expectancy of persons with SCI in the Malaysian population.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

People with SCI receive prehospital care, acute care, inpatient rehabilitation, outpatient rehabilitation, and community care. Upon injury, first aid is usually provided either by bystanders, the police, or paramedics. Whereas paramedics are usually trained to be aware of the possibility of SCI and use spinal boards to transport people, the public is usually not so prepared. Emergency treatments are given at the nearest hospital and are accessible to everybody regardless of insurance status. A person suspected or diagnosed to have an SCI will be referred to the nearest general hospital with the necessary facilities and specialists. There is no specialized SCI center or unit in Malaysia; these cases are usually managed in the orthopedic or neurosurgical wards of general hospitals. Staffs in these wards generally have limited skills, expertise, and support to manage patients with SCI. To date, there is no clear pathway of transition from acute to rehabilitation care for patients with SCI.

General rehabilitation services are available mainly in the government hospitals: there are 16 state hospitals, 3 teaching hospitals, and a rehabilitation hospital throughout the country, with a total population of 29,714,700. Although all hospitals are equipped to deliver spinal rehabilitation care, not all of them have inpatient rehabilitation beds. In some, rehabilitation service is provided in the orthopedic ward; only the

rehabilitation hospital has a dedicated spinal ward with 25 beds. Owing to limited beds and opportunity for prolonged admission, most patients complete a basic inpatient spinal rehabilitation program that is followed by outpatient rehabilitation. The duration of inpatient rehabilitation varies widely between hospitals, ranging from 6 weeks to 6 months.

Most patients are discharged home directly from the hospital. Assistance to manage daily activities at home are usually given by family members or paid attendants. After discharge, patients continue their rehabilitation process by attending outpatient rehabilitation therapy at the admitting hospital. Patients are also followed up at the rehabilitation clinic to monitor progress and for any secondary complications. Readmission is possible for further rehabilitation or for management of complications. There is no community care available specifically for those with SCI; however, the health care system does provide home-nursing services that may be used by people with SCI.

LIVING WITH SCI

There is not much published information on how well people with SCI do in the community. Based on the authors' own experience, there is limited support available in the community and people living with SCI face various obstacles to re-integrate with the society. Access to wheelchairs and other rehabilitation equipment for home and work also varies. Those who are under the social security scheme will receive funding, and those who are registered with the Department of Social Welfare may receive support from the government. Most private insurance policies do not cover for such rehabilitation aids and technologies. There are significant variations on how return-to-work program is implemented throughout Malaysia. Some are carried out by individual hospitals, whereas some collaborate with the Social Security Organization (SOCO). Ramakrishnan et al.⁴ found a 57% employment rate in an urban sample, which is comparatively high to other available data.

THE HEALTH AND REHABILITATION SYSTEM

The Malaysian health care system consists of tax-funded and government-run universal services and is centrally administered by the Ministry of Health (MOH). Malaysian society places high importance on the expansion and development of health care, putting 5% of the government social sector development budget into public health care.⁵ The MOH offers a comprehensive range of services, including health promotion, disease prevention, and curative and rehabilitative care delivered through clinics and hospitals, whereas special institutions provide long-term care. The government hospitals have the country's best health care equipment and facilities apart from having specialists in the field. Most Malaysians rely on

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government hospitals; they only need to pay very small fee. People with disabilities who are registered with the social welfare department received free inpatient and outpatient medical treatment and most of the medications. Malaysia generally has an efficient and widespread system of health care, and people generally have good physical access to health facilities, as 92% of the urban population and 69% of the rural population live within 3 km of a health facility.⁶ There is still, however, a significant shortage in the medical workforce, especially of highly trained specialists; thus, certain medical care and treatment is available only in large cities.

WHAT IS THE STATE OF SPECIALIZED CARE?

With regard to specialized care for people with SCI, Malaysia has spinal surgeons and neurosurgeons, rehabilitation physicians, and the technology to diagnose and manage SCI. All rehabilitation physicians received a 6-month clinical training to manage people with SCI during their residency, but there are few nurses trained in spine rehabilitation. A similar trend is seen with physiotherapists and occupational therapists: most become experts through the years spent treating people with SCI but not through formal training. There is no formal peer counseling support provided by the hospitals, but it is common for physicians to ask patients who are far beyond the rehabilitation stage to counsel the newly injured patients.

SOCIETAL RESPONSE

Social services for people with SCI are very limited, other than those generally available to all people with disabilities. No social service is automatically provided to people after an SCI. People who are employed by the government and their dependents, and those with social security coverage are entitled to medical rehabilitation and equipment support. Support ranges from inpatient and outpatient public health care needs, funding of equipment, disability pensions, caregiver allowance, return-to-work program, purchases of medicine and continence needs. The Department of Social Welfare in Malaysia also provides these services depending on the patient's economic status. The government policy states that 1% of employment positions are officially reserved for persons with disability, but this has never been achieved even in the government sector. Accessibility of public places for people with disabilities is spelled out under the Uniform Building By-Laws Act 133 amended in 2006 and the Persons with Disabilities Act 2008.⁷

There is also access to funding from nongovernmental organizations such as The Rotary Club, Lion's Club, and various religious associations. Nevertheless, none of this funding is specifically dedicated for people with SCI. Various disability-related advocacy groups have been active in raising awareness about disability and the need for an accessible environment, affordable health care, and equipment as well equal opportunities to education and employment.

The Malaysian government response to SCI prevention has been limited to the provision of folic acid to expecting mothers and the implementation of seat belts for the driver and front passenger. The 10th National health strategy does not have specific health agenda related to people with SCI. Malaysia has strict road traffic rules and regulation, but

implementation has been inconsistent. Motorcycles are popular in Malaysia, and this has contributed to the high incidence of road traffic accidents.⁸

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

The InSCI study aims to describe the lived experience of persons with SCI in the participating countries including Malaysia, in particular, to collect comprehensive data on functioning, health, and well-being of people living with SCI in the community. Participating in the InSCI study gives us the opportunity to greatly increase our insight into the lived experience of people with SCI in Malaysia and will be used to raise some policy recommendations. This is a cross-sectional study that will be implemented in 9 state hospitals that provide SCI rehabilitation services in Malaysia.

The National Study Protocol

Each health facility will include all eligible participants from their hospital in-patient and outpatient registry. In addition, participants will be recruited from SCI associations throughout the country such as Malaysian Spinal Cord Injury Association, Sibul Spinal Cord Injury Association, Kuching Spinal Injury Association, and Persatuan Spinal Pantai Timur. This is in line with the recommended method of recruitment by the Coordinating Institute to ensure an unbiased sample. The eligible participants are people with SCI older than 18 years at the time of study, who have traumatic or nontraumatic SCI, who have lived with SCI in the community for at least a year after initial hospital discharge, reside in Malaysia and are able to answer the survey questionnaire (available in English and Bahasa Malaysia). We will exclude those with progressive disease (malignant/neuropalliative disease), congenital cases, or cognitive impairment. Every eligible participant will be getting a unique ID.

The sample size calculation performed by the Coordinating Institute stated a minimum number of 400 participants, considering that there would be 50% nonresponse rate. An invitation letter together with a study information leaflet will be sent to all participants who fulfill the inclusion/exclusion criteria. They are required to indicate their preferred method of participation in the survey: the choice of online data entry, pen and pencil, or face-to-face interview. Persons who prefer the online method will receive a package consisting of a log in ID, the consent form, and a return envelope. Persons who prefer to participate using a pen and pencil will receive the study package consisting of the consent form, the questionnaire, and a return envelope. Persons who prefer interviewer-administered survey will be contacted for appointments.

Once the invitations are sent out, an electronic reminder will be sent out 30 days later if there is no response. A second reminder will be done via telephone call 30 days after the first reminder. A maximum effort of 10 calls are planned to reach potential participants. Within the second stage after the participants have agreed to participate and have received the questionnaire, if the tracking tool does not see a response or have

not received the returned questionnaire within 30 days, an electronic message will remind the participants. In the same way, a second reminder will be done via telephone call 30 days later of nonreceipt of completed questionnaire.

At the country level, we will collect epidemiologic and preventive data on SCI, which will address the epidemiologic gap in the country, especially related to prevalence of SCI, the demographics of persons with SCI, and the characteristics of SCI and cause of SCI in Malaysia. These data are essential to define the magnitude and trend of SCI and to explore effective preventive strategies. We will use dual approach for data collection: (1) by means of a retrospective review of hospital records on all admissions due to SCI who were treated by the rehabilitation team; and (2) by a prospective study on patients admitted due to SCI. In relation to the existing InSCI modules, the proposed national module will take place during the initial hospital registry screening. All patients who are referred for SCI rehabilitation will be included in this epidemiologic data survey. The only exclusion criteria will be patients who do not have neurological deficits on initial assessment. Three data collection forms will be implemented for this exercise: (1) international SCI core data sets; (2) international SCI nontraumatic SCI data sets; and (3) minimum injury/safety data set.

CONCLUSION

The societal response to health and social needs of persons with SCI remains deficient in Malaysia, although the breadth and depth of services available for these patients have significantly improved over the past decade. Improved epidemiologic

data from the InSCI study will enable us to fill this gap and quantify the magnitude of SCI, information that will be essential for policymaking. In general, there is in Malaysia a need to create awareness among the general public of the importance of SCI prevention and the society requirement to respond to the unmet needs of people with SCI.

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