

People with Spinal Cord Injury in Indonesia

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN INDONESIA

The epidemiological data of spinal cord injury (SCI) in Indonesia are now currently being collected. In 2014, 104 SCI cases were registered at the Fatmawati General Hospital whereat 37 had traumatic and 67 had non-traumatic SCI as origin. The most common etiologies of traumatic SCI were car accidents and falls from heights, whereas the major causes for nontraumatic SCI were infection and neoplasm.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

After an accident-related SCI occurred, the patients are referred to emergency services by the rescue team, where they are treated as cervical trauma cases. The patients are transported to the nearest hospital by ambulance, which is the major transportation of choice, or by helicopter, which is available only in the private sector. Upon arrival at the emergency room, the patients are received by the frontline staff who are certified physicians in Advanced Trauma and Cardiac Life Support—standard requirements for physicians working in hospitals in Indonesia. If the injury requires surgery and intensive care, the patients are assigned to a neurosurgeon or orthopedic surgeon to obtain further medical intervention. Afterward, they will be transferred to the intensive care unit (ICU) for stabilization. Every hospital has an ICU in Indonesia, but the units do not have special standard care for patients with SCI. Patients in stable condition are transferred to the acute care and usually need an average length of stay from 1 to 2 weeks. After discharge, patients are trained to continue with the rehabilitation program and to have regular medical consultation in a hospital every 3 months.¹

There are only 2 hospitals in Indonesia that have special units for SCI services, which are the Fatmawati General Hospital in Jakarta and Prof. Dr. R. Soeharso Orthopedic Hospital in Solo. Other hospitals that have qualified staff and facilities for neurosurgeons, vascular surgeons, cardiothoracic surgeons, orthopedics, intensive care, anesthesiology, and rehabilitation are also

allowed to provide medical services for SCI patients. Currently, Indonesia has 163 neurosurgeons, 65 cardiothoracic surgeons, and 19 vascular surgeons. Rehabilitation units are available in all types of hospitals, but still have limited human resources with specific SCI rehabilitation skills. Most of these hospitals provide only general medical rehabilitation services. When patients become outpatients, they are suggested to have regular medical evaluations (usually every 3 months) in a hospital.¹

Rehabilitation services in Indonesia have some limitations. Most SCI patients use health insurance provided by the Social Security Administrators (Badan Penyelenggara Jaminan Sosial [BPJS]) to cover for rehabilitation services. Nevertheless, BPJS covers only for limited types of orthosis, prosthesis, or assistive devices for patients. Rehabilitation facilities such as specialized rehabilitation wards are also limited. The numbers of medical staff with specialization in SCI medical care are limited, and they are not evenly distributed among hospitals in the country.

Patients with SCI face many problems in the society. They have problems with accessibility to travel from home to the outpatient care in assigned hospitals because of lack of facility, money, or caregiver. They also have problems with the availability of a qualified caregiver once they are discharged from hospital. Caregivers, who are usually a family member, do not have sufficient training or capabilities to care for the patient at home. In most cases, patients end up being treated at community care centers, which are still limited in Indonesia.

LIVING WITH SCI

Special education for people with disabilities is limited in Indonesia. Schools that accept students with disabilities are rare.² Indonesia has laws and regulations to facilitate return to work for the disabled. Law No. 4/1997 and Government Regulation No. 43/1998 detail specific efforts to improve social welfare of people with disabilities, including the obligation quota of 1% in public and private institutions with a minimum of 100 employees, support for rehabilitation, and job placement for workers with disabilities in the private sector (Circular Letter of the MOMT 2002).^{3,4}

There are some vocational rehabilitation premises available in Indonesia where many supporting facilities are provided and produced. For example, the Great Hall of Vocational Rehabilitation for Disabled by the Ministry of Social Affairs Republic of Indonesia (annual capacity: 140 people) in Cibinong, West Java, and the Great Hall of Social Rehabilitation for Disabled Prof. Dr. R. Soeharso, with a capacity of 300 people, in Solo, Central Java.

Despite the governmental regulations, nearly 70% of people with disabilities in Indonesia are unemployed. Contributing

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factors to this situation are the lack of understanding and awareness of the potential and capabilities of people with disabilities, lack of opportunity to participate in education and training, and lack of confidence.⁵ The occupational profile of persons with SCI is not yet available, but there is an impression that the majority of people with SCI do not work as an employee, but they rather open independent handicraft business. In Indonesia, the majority of people with SCI have access to wheelchairs, but approximately 10% of the 24 million persons with disabilities who require assistive devices cannot afford them. These people must crawl, be carried, or simply stay at home. Many individuals with SCI who are fortunate to access mobility devices receive support from the United Cerebral Palsy Wheels for Humanity (UCP–Roda Untuk Kemanusiaan [UCPRUK]).⁵ UCPRUK focuses on providing appropriately designed, low-cost wheelchairs (standard, pediatric, rough terrain, and sport) and other mobility devices throughout the country with an emphasis on quality service and long-term sustainability. Their products enable children to go to school and to socialize, help adults to earn an income and participate in their communities, and help families to care for their loved ones. Manufactured in Jakarta, the wheelchairs are approved by ISO (International Organization for Standardization) and exported to the United States and Europe.

THE HEALTH AND REHABILITATION SYSTEM

Public and private health insurance companies are available in Indonesia. In the public sector, there are 2 insurance arrangements, *Jasa Raharja* and the universal health coverage provided by the newly created BPJS. The latter allows patients with SCI to be referred to advanced level of health services, including outpatient services (for medical examination, consultation, procedures, drugs, diagnostic tools, and rehabilitation) and inpatient services (for non-ICU and ICUs). Private insurances include Allianz Indonesia, Prudential Indonesia, Zurich Insurance Group in Indonesia, AXA General Insurance Indonesia, Panin Dai-ichi Life, and ANZ Indonesia. Primary care facilities are easy to access in the country, with nearly 9600 clinics scattered throughout the country.⁶ Nearly all primary health care services are covered by insurance. Currently, there are more than 561 psychiatrists (data collected in July 2015), 3646 physiotherapists, 288 occupational therapists, 244 speech therapists, and 93 orthotics and prosthetics practitioners.⁷ The number of health workers nationwide is adequate, but their distribution is uneven.

WHAT IS THE STATE OF SPECIALIZED CARE

Several hospitals have SCI-related treatments in intensive care, surgery, and anesthesiology. They employ neurosurgeons, vascular surgeons, and orthopedic, for example. SCI rehabilitation services are provided in the Fatmawati General Hospital in Jakarta and Prof. Dr. R. Soeharso Orthopedic Hospital in Solo.¹

In Indonesia, rehabilitation services for people with SCI are provided by well-trained health professionals such as psychiatrists, nurses, and allied health professionals, including physiotherapists, occupational therapists, speech therapists, social workers, orthosis-prosthesis practitioners, nutritionists, and psychologists.

Community care support for reintegration of patients with SCI is available in Indonesia, at, for example, the Prof. Suyoto Hospital–Rehabilitation Centre of the Ministry of Defense Indonesia, nongovernment organization: Cheshire, Sasana Bina Daksa Budi Bhakti Pondok Bambu, and YAKKUM Rehabilitation Center Yogyakarta.⁸ Even though there is a current good coordination with nongovernment organizations specializing in SCI, the amount and quality of cooperation should be further improved.

Spinal cord injury–relevant assistive devices available in Indonesia are sets for canes and crutches, standard walkers, reciprocal walkers, rolling/gliding walkers, reverse walkers, manual wheelchairs, electric wheelchairs, and spinal orthotics. The majority of people with SCI, like most others with disabilities, have limited access to assistive technology.⁵ However, there are some nonprofit organizations that facilitate the availability of wheelchair and other mobilization and ambulation aids to people in need.

THE SOCIAL RESPONSE TO SCI

Indonesia has social protection laws to reduce poverty and social isolation of persons with disabilities, such as Law No. 13/2011 about poverty management and Law No. 11: 4-6/2009 about social welfare. The Occupational Injuries Benefits Program (*Jaminan Kecelakaan Kerja* [JKK]) is expected to become a social protection law, which is designed to improve the independence of persons with disabilities.⁹ Participants of JKK with occupational injuries or diseases are entitled to receive JKK benefits in the form of health services according to medical needs and financial compensation. Financial compensation includes reimbursement for transportation cost to the hospital and/or work and first aid fees. Temporary compensation is also available for participants who are unable to work until they receive confirmation to be cured or impairment reduced based on a medical certificate.

Rehabilitation costs include orthosis or prosthesis reimbursement with a certain cost that is applied in the Rehabilitation Centre of Public Hospital plus 40% of the cost. Although the accessibility of wheelchairs distributed in public areas and buildings around urban areas in Indonesia is making progress, there are still many obstacles in other areas. Public spaces are still not taken into account for the ease of movement for persons with assistive devices such as wheelchair or crutches. Special parking spaces for the disabled are not available. Doors to public buildings are not designed to be easily opened and closed, locked, and traversed by people with mobility disabilities, nor are ramps, stairs, and elevators. Accessible toilets are rare; pedestrian paths are impassable and unsafe. Public transportation is equally inaccessible.² Because SCI cases in Indonesia are mostly caused by vehicle accidents, one of the existing prevention regulations is basically on vehicle safety and driver's behavior that are rigorously enforced by the Indonesian National Traffic Police Corps. In addition, with myelitis tuberculosis (TB) as the most common cause of nontraumatic SCI in Indonesia, the government has launched a national TB prevention program, which is part of the National Strategy for Controlling TB in the country in 2010–2014.¹⁰

In addition, approximately 370 organizations are available in Indonesia to support people with disabilities and their

families. Other agencies that provide funds to people with SCI are the Ministry of Social Affairs and JSPACA (Jaminan Sosial Penyandang Cacat Berat)—Cash Transfer for Disabled People.¹¹ There are also international and local private organizations that offer funding to people with SCI such as the Disability Rights Fund, Kick Andy Foundation, Handicap International Indonesia and Timor Leste Program, BILiC (Bandung Independent Living Center), Yayasan Wisma Cheshire (YWC), Kupu-Kupu Foundation, and the Bhakti Luhur Foundation.¹²

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

We expect to identify the response of the health system with respect to mortality, morbidity, and functioning by providing adequate emergency and acute care, and rehabilitation services, opportunities in education, employment, and lifelong support. We also expect to compare and learn from other countries' experiences that have been successful in increasing the quality of functioning and well-being of people living with SCI in relation to health and related systems, policies, services, and care provision.

The National Study Protocol

The Indonesian Physical Medicine and Rehabilitation Association (Perhimpunan Dokter Spesialis Kedokteran Fisik dan Rehabilitasi Indonesia [PERDOSRI]) will coordinate the national study protocol for the InSCI study. They collaborate with the Ministry of Health, Data Collection and Information Center, and 13 branches of PERDOSRI in acquiring the data.

The current research plan is divided into 3 phases. The first phase is creating the SCI profile data in Indonesia. The incidence and prevalence data of SCI in Indonesia have not yet been completed; thus, this research must be performed. The second phase includes the validation study of International Classification of Functioning, Disability and Health core set tabulation in Bahasa by 5 physical medicine and rehabilitation specialist education centers in Indonesia. The third phase is the International Classification of Functioning, Disability and Health core set implementation of measuring SCIs.

There are 510 registered physiatrists distributed in 33 provinces and working in the public and private hospitals. SCI rehabilitation is complicated; thus, physiatrists and a medical rehabilitation team working in types A and B hospitals will manage the treatment. Patients who are hospitalized in types A and B hospitals are selected based on different etiologies of SCI managed by orthopedics, neurosurgeons, and neurologists. Patients in type C hospitals will be referred to type A or B for acute management.

This research will use medical records and the data collection method that should receive ethical approval from the Ethics Committee of Research and Development, Ministry of Health Republic of Indonesia, and the medical committee of each hospital. Physiatrists record the data written on medical records in which the diagnosis was made based on the *International Classification of Diseases, 10th Revision*. Afterward, the data will be

delivered to the secretariat of PERDOSRI to be processed and recapitulated. Indonesia is a large country, and disability has not been a main public health issue. Acquiring the data, such as the mortality rate of SCI, case-fatality rate of traumatic SCI, and life expectancy postinjury data, is very challenging.

OPTIONAL NATIONAL MODULE

We are proposing to construct an additional module for Indonesia that will look at the following considerations:

1. Evaluate the SCI data and the following conditions because most SCI patients ($\pm 50\%$) who were suggested to have outpatient service did not continue the rehabilitation program or control regularly.
2. Determine the factors that prevent return to work and school for people living with SCI because the national number of persons with disabilities who work is estimated to be less than 30% of the total disabled population.

CONCLUSION

Persons with SCI require more attention from the Indonesian Government from the perspective of prevention, health promotion, and rehabilitation. Because the country is located in an archipelago with a tropical climate that shows a high incidence of acute and chronic infections, the government attention is focused on these health problems. Regarding this situation, SCI has not received serious attention, and the patients face different difficulties.

Although there are laws that regulate the protection of the rights of persons with disabilities, the government is committed to ensure that public health services throughout Indonesia incorporate people with SCI. Because of national campaigns, there are improving societal attitudes toward persons with SCI. However, many challenges remain:

1. The number of health professionals specialized in SCI and the number of specialized SCI centers are still limited.
2. Not all of the treatment costs and assistive devices, orthotics, and so on are covered by the BPJS.
3. The number of vocational rehabilitation training halls is limited.
4. The rate of persons with disabilities to return to work is very low.
5. Educational services have not been fully accessible to person with disabilities.
6. Public buildings, public areas, and public transportation are not fully accessible.

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