People with Spinal Cord Injury in Thailand

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN THAILAND

There are few epidemiologic studies of people with spinal cord injury (SCI) in Thailand, predominantly coming from the Chiang Mai province, as no national data for the whole country exist. Most studies that have been done come from university hospitals with rehabilitation wards. This report is mainly based on studies done at Maharaj Nakorn Chiang Mai Hospital, a tertiary/advanced level and university hospital with a dedicated rehabilitation ward for SCI. Over the past 30 years, most SCI cases in the northern region were referred to this hospital for treatment and rehabilitation. According to a 5-year study (1977–1981) of patients with spinal injuries admitted, 48% of 577 patients had SCI.[1] During 1985–1991, there were 398 new patients with SCI admitted, and when counting only those living in Chiang Mai, the incidence of SCI was approximately 23 cases per million per year.[2]

According to a 6-month survey of road traffic accidents done by the National Rehabilitation Center in 2006 to study the incidence of disability and impact of these collisions,[3] data were collected from 8 of 28 trauma centers operated by the Ministry of Public Health. When extracting data from this survey, there were 9,737 victims with major injuries. Of these, 82% used a motorcycle, 32% drank alcohol before the collision, and 3.2% became disabled. Among those with disabilities, 10.4% had SCI (tetra-AB, 26%; tetra-CD, 55%; para-AB, 12%; and para-CD, 7%). From these data, 0.3% of major injuries or 3 of 1,000 severely injured road traffic accident victims had SCI. In addition, the economic loss of more than 2.6 million baht per case with disability was reported.[3]

When comparing data between 2 previous studies (1977–1981 and 1985–1991),[1,2] causes of SCI have changed: falling from height, the main cause 30 years ago, declined from 42.8% to 33%, whereas the prevalence of road traffic accidents increased from 28.4% to 47%. Among road traffic accidents, 54% were collisions involving motor cycles. In addition, later data in 2006 indicate that 67.5% of new patients with SCI were caused by road traffic accidents.[4] Two studies from Siriraj Hospital in Bangkok showed that the prevalence of road traffic accidents increased from 50.7% of SCI causes in 1989–1994 to 74.8% in 1997–2000.[5,6] Clearly, road traffic accident–related injury is a major cause of SCI in Bangkok.

Concerning mortality during the acute phase, in the study covering the years 1987–1991, 31 patients (8%) of 398 cases died[2] compared to only one of 91 new SCI cases admitted in 2013.[7] There are no studies on mortality of chronic SCI individuals living in the community.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

During 1985–1991, only 30% were admitted within 6 hours after injury, 57% were admitted within 24 hours, 12% had neurological deterioration before admission, 12% had urinary infection, 11% had pressure ulcers, and 7% had respiratory complication.[2] During the past decade, the prehospital service has been much developed after the National Emergency Medical Service (EMS) Act, enacted in 2009. Most of the injured victims from road traffic accidents are now transferred to a nearby hospital by a hospital ambulance in the EMS system, as this can be accessed by a nationwide phone call: 1669. According to the survey of road traffic accidents in 6 trauma centers in 2006, 92.4% arrived at the hospital within 24 hours.[3]

Based on the SCI model at Maharaj Nakorn Chiang Mai Hospital, one of the trauma centers with facilities for advanced imaging and treatments, new patients with spinal injuries and SCI are admitted to the acute spinal orthopedic ward. Those with associated injuries are admitted to neurosurgical or trauma wards. As surgical instruments had been developed, more cases have been operated on: less than 50% in 1985–1991[2] and more than 75% in 2006.[4] Two or 3 weeks after surgery, when the medical and surgical conditions are stable, patients with SCI are then transferred to a rehabilitation ward. A spinal surgery is performed at the tertiary-/advanced-level hospital where at least one rehabilitation physician/consultant and physical and occupational therapists provide rehabilitation services. However, if there is no rehabilitation ward and the rehabilitation consultant decides that the patients with SCI need further rehabilitation, they will be referred to another hospital, where a dedicated in-patient rehabilitation service for SCI is available.

At the rehabilitation ward, patients receive a comprehensive medical rehabilitation program provided by rehabilitation team consisting of rehabilitation consultants (physiatrists), in-training rehabilitation residents, physical therapists, occupational therapists, rehabilitation nurses, a social worker, and an orthotist. Common short- and long-term goals, whether intensive or less intensive rehabilitation management should be used, and a tentative discharge date are all established based on the patient's medical conditions and rehabilitation problems, expectation and needs as well as features of their living situation and other environmental factors. Patient education and caregiver training are always included in the process so that the patient's health will be looked after. For those with high lesion with severe disability, one family member is trained to become a primary caregiver.

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Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article.

ISSN: 0894-9115
DOI: 10.1097/PHM.0000000000000585

Generally, the postacute rehabilitation phase usually lasts approximately 3 to 4 weeks if there is no associated injury or complication. The length of stay (LOS) of the initial postacute rehabilitation has been decreasing over the past 2 decades. This is partly because Thailand is using the disease-related group (DRG) approach, and the average LOS for in-patient rehabilitation of neurological cases has been established to be 23 days. Owing to this, the hospital management prefers a short LOS so that the hospital charge is not more than the payment.

A study on payment on subacute and nonacute in-patient care predicted that more than 30% of patients never received any rehabilitation service.[8] Owing to the limitation in providing in-patient rehabilitation services, recently, the National Health Security Office and the Ministry of Public Health agreed to start a pilot project of in-patient rehabilitation services at mid-level hospitals with stroke patients. If this project shows cost-effectiveness, there is hope that such services will be expanded to patients with SCI.

When goals are reached, patients are discharged home or referred back to their local hospital for continuous medical care. One to 3 months after discharge, they are reassessed at an outpatient clinic. If there is a potential for improvement or a complication, they will be re-admitted for further rehabilitation or treatment of complication.

As many SCI individuals still need continuous medical care, they are visited by a nurse or a health volunteer from a community hospital. According to a recent study on patient quality of life, nearly 70% of individuals with chronic SCI living in the community rated their overall quality of life as fair and nearly 30% rated it as good.[9] Females made up 75% of primary caregivers, and 34% were spouses.[10] Approximately 84% primary caregivers worked outside the home as well.[10] Based on the 36-item short form health survey (SF-36), the quality of life scores were not different between those taking care of patients with paraplegia and those taking care of patients with tetraplegia. However, the scores were lower in 2 domains: role limitations due to physical and emotional problems; but when compared with the scores of the general Thai population, the caregivers of persons with SCI had lower scores of all domains except for social functioning.[10]

LIVING WITH SCI

Owing to limitation of in-patient rehabilitation services, after acute management, many SCI patients are discharged home and a caregiver is advised how to continue physical therapy at home, whereas some are referred/transferred to a tertiary-level or advanced hospital for postacute rehabilitation. According to our recent unpublished data of 66 newly admitted patients with SCI for rehabilitation (2015), at discharge, 51.5% of the patients were AIS-D according to the American Spinal Injury Association Impairment Scale (AIS) and approximately 60% were rated as independent (no or minimal difficulties) in eating and drinking, followed by dressing (45.5%), washing oneself (40.9%), caring for body parts (39.45%), and toileting (33.3%). These data showed that the other half of the patients were still dependent after postacute rehabilitation, probably due to too short postacute rehabilitation admission (average LOS for AIS-A, B, C: 31–55 days and AIS-D: 18–44 days).

According to the Rehabilitation for Persons with Disability (PWD) Act enacted in 1991 and the Promotion and Development of Quality of Life of Persons with Disability enacted in 2007, people with disabilities have a right to be voluntarily registered. Before discharge from the hospital, those with disabilities are informed about the benefits of a registration as a person with a disability. These benefits are free medical services, necessary medications and assistive devices from public hospitals; appropriate education; vocational training and social supports, for example, a monthly allowance of 800 baht or a loan up to 60,000 baht with 5 years interest-free for starting up a self-employment.

According to a recent survey of 100 persons with chronic SCI (more than 2 years after injury), at the time of the survey (2012), 47% were engaged in remunerative employment, which is less than an employment rate of 81% before SCI. Among those who worked, 66% were self-employed, followed by 27.6% of full-time employment and 6.4% of part-time employment; but only 48.9% were satisfied with their income.[11] As a result of the low income they received, most of them live with and depend on family members. The ability to drive increases the chance of being employed,[11] since public transportation is a barrier for persons with SCI.[12]

THE HEALTH AND REHABILITATION SYSTEM

Most hospitals in Thailand are operated by the Ministry of Public Health. Hospitals are also operated by other government sections and foundations, such as the military, universities, and the Red Cross. In 2010, there were 1,002 public hospitals and 316 registered private hospitals. Hospitals operated by the Ministry of Public Health are classified into 5 levels: (1) the primary health care level (small-size community hospitals), (2) the first level (medium-size community hospitals), (3) the mid-level (large community hospitals and general hospitals), (4) the standard level, and (5) the advanced level. Both the standard level and the advanced-level hospitals provide specialized care for complicated cases, but the latter has more high technology and more subspecialists. At present, few advanced hospitals in the public health sectors and some university hospitals provide an in-patient rehabilitation program for patients with SCI. There are only 13 hospitals with 260 beds in total for in-patient medical rehabilitation. Among rehabilitation admissions, 42% comprised patients with SCI, including both new and chronic cases.[13]

All Thais are eligible for one of the 3 main health insurance schemes: the universal health coverage, the civil servant health benefit scheme, and the social security scheme. The universal health coverage scheme covers 80% of the population, and the rest are covered by either the civic servant health benefit scheme or the social security scheme. All have the right to receive sufficient basic health services free of charge. The benefits are different depending on which health insurance scheme they are under, and they have to pay for medications and equipment not in the essential drug list or not in the health service packages.

WHAT IS THE STATE OF SPECIALIZED CARE?

The Royal College of Physiatrists of Thailand started training rehabilitation specialists in 1982. For more than 30 years, more than 500 physiatrists (rehabilitation specialists) have graduated and are practicing all over the country. Some universities provide educational programs for other rehabilitation

professionals, such as BSc, MSc, and PhD degrees in physical therapy, occupational therapy, and clinical psychology. However, only one university provides a BSc in prosthetics-orthotics and another provides vocational certificate in prosthetics-orthotics. There is no advanced training in assistive technology generally.

Based on the latest data of rehabilitation specialists (2015), most (40%) works at Ministry of Public Health hospitals, followed by 21% at private hospitals, 19% at university hospitals, 5% at military hospitals, 4% at Bangkok metropolitan health centers, and the rest in other government sectors and nonprofit foundations. If only those hospitals operated by the Ministry are considered, all regional hospitals and 60% of general hospitals have rehabilitation specialists, physical therapists, occupational therapists, and prosthetics-orthotics technicians. The latter are responsible for assistive technology.

These data suggest that there are not enough rehabilitation professionals working in the rural or remote areas of the country. As a result, individuals with chronic SCI have difficulty accessing to rehabilitation professionals. Although community hospitals play a role in providing an outreach and home-visiting services such as nursing care and physical therapy for bed-bound or home-bound individuals, they do not have enough expertise in SCI. When a secondary condition or complication occurs, they generally go to a nearby community hospital to get diagnosis and a proper treatment such as antibiotics for urinary tract infection. For major complications, they are referred to secondary- or tertiary-level hospital for proper management.

Pressure ulcers are still prevalent among individuals with chronic SCI, causing increased burden to caregivers, requiring high hospital expenditures for long LOS and preventing individuals with SCI from social reintegration.[14] Over the past 2 decades, 80% of patients with SCI had an ulcer at least once in their life, but recently, the prevalence has decreased to 54.3% (26.4% had an ulcer or more at the time of the study and 27.9% had healed ulcers).[15] This was most likely due to better prehospital acute and postacute management, patient and caregiver education, and better wheelchairs and cushions.

Besides pressure ulcer, neurogenic bladder and bowel dysfunctions are impairments, which need specialized care and management. Only one third had normal or nearly normal control of urination.[16] According to our recent data, 19% of those using clean intermittent self-catheterization with a reusable catheter reported having at least one treatment of urinary tract infection during the past year, and on the day of hospital visit for urodynamic study, 47% had bacteriuria, but only 15% had significant bacteriuria with pyuria, indicating urinary tract infection. In addition, 28% reported urinary incontinence.[17] More than half (53%) of individuals with chronic SCI living in community had moderate to severe neurogenic bowel dysfunction. Most of them (44%) needed mini-enema as a main bowel care, 23% reported fecal incontinence, and 15% had hemorrhoid.[18]

THE SOCIAL RESPONSE TO SCI

After 26 years of implementing the Rehabilitation for Persons with Disability Act, medical, educational, vocational, and social rehabilitation services have all been developed. Nonetheless, societal attitudes and other barriers persist. At present, all 28 regional hospitals have at least one rehabilitation specialist (physiatrist) and also physical therapists and occupational therapists working, providing treatments and therapy for patients with SCI.

In 2007, the Thai government enacted the promotion and development of quality of life of persons with disability, aiming at protecting the rights of people with disabilities and promoting equality of opportunities and social inclusiveness. Moreover, Thailand had successfully ratified the Convention on the Rights of Persons with Disabilities (CRPD) as a tool for promoting and protecting the fundamental rights and freedoms of persons with disabilities. More recently (2012), Thailand, as a member of the United Nations Economic and Social Commission for Asia and the Pacific, adopted the Incheon Strategy[19] (2012) aimed at making societies barrier-free.

Following the Act and ministerial regulations, persons with disabilities have more opportunity to receive educational and vocational training suitable to their disabilities and their goals and interests. Moreover, the government and private sectors have to accept registered people with disabilities for employment, previously at a ratio of 1:200 and now at a ratio of 1:100. We found that 47% of individuals with SCI (more than 2 years after the injury), are mostly self-employed and can drive a car, which gives them more chance to work.[11] The main remaining barriers are buildings and transportation systems that are not wheelchair accessible. Although the ministerial regulations promote universal design, only some public agencies and the private sector, such as hospitals, have ramps, elevators, and toilets for persons with disabilities and elderly people.

To prevent injuries, a campaign to prevent driving when drinking has been instituted. In addition, the government has approved a ministerial regulation to use part of the money from car license plates to support expensive but necessary assistive devices for those becoming disabled as a result of a road traffic accident. Many persons with tetraplegia have received an electric wheelchair, and those with paraplegia have received a sport or active wheelchair under this program. This gives them more opportunities for social activities.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

At present, there is no rehabilitation center dedicated to providing comprehensive rehabilitation for patients with SCI. We therefore hope that participating in the InSCI study will produce information relevant to the Thai situation that can be used to make an argument to the National Health Security Office to agree with the view that a dedicated rehabilitation center would greatly improve the quality of life of persons with SCI, as it does in other countries that are more developed.

THE NATIONAL STUDY PROTOCOL

Owing to lack of the national data, in 2015, we started a national SCI registry project and used the International Spinal Cord Injury data sets by ISCOS core sets and some categories of the WHO's International Classification of Functioning, Disability and Health (ICF) core sets for SCI for data gathering.

Four standard- and advanced-level hospitals with a rehabilitation ward have joined this project. The inclusion criteria for participation are that they be traumatic or nontraumatic patients, postacute or chronic, and who give consent to participate in the study. The exclusion criteria are those who cannot communicate or complete the questionnaire.

OPTIONAL NATIONAL MODULE

We may also add other module(s):

1. To compare present and past conditions, and in particular to collect data on whether the conditions for persons with SCI at the time of the interview present is worse, the same or better than the conditions at discharge or before injury or disease.
2. To assess the attitudes, needs, and expectations of persons with SCI toward specific environmental factors (barriers and facilitators) and to ask them to prioritize these factors that have the most impact on their lives.

CONCLUSION

According to the law and policy aimed at improving the quality of life of persons with disabilities in Thailand over the past 25 years, and in particular, because they are covered by the universal health coverage scheme, persons with SCI have a better and longer life, with fewer complications, more appropriate assistive devices, more social reintegration, and less anxiety about health care expenses. The challenge now is to ensure that comprehensive rehabilitation services are equally accessible to all persons with SCI. There are encouraging signs that this is happening, such as the fact that there are more rehabilitation professionals working in the country and public policy is now aimed at empowering people with disabilities.

If the output of the InSCI project gives us valid and relevant comparison data between those using more dedicated hospitals for SCI and those using other facilities, then we can go to the National Health Security Office to try convincing them to increase the LOS for postacute rehabilitation for patients with SCI, and to establish dedicated rehabilitation hospitals for SCI in all regions of the country so that all patients with SCI will have equal opportunity to access standard rehabilitation services.

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