People with Spinal Cord Injury in New Zealand

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN NEW ZEALAND

New Zealand (NZ) has an estimated population of just over than 4.5 million people. Currently, there exists no national registry for spinal cord injury (SCI) in NZ. As a result, the incidence of SCI is difficult to ascertain accurately, and the incidence of nontraumatic SCI is even more difficult to determine.[1] However, information collated up to 2012 from various sources suggests that approximately 100 to 170 persons each year had a diagnosis of some form of SCI in NZ, giving an estimated annual incidence of 30 to 40 SCI cases per million population.[2] More recent estimates put this figure closer to 45 per million.[3] Data from the Derrett longitudinal study found the incidence to be 29 per million for European, 46 per million for Maori, 70 per million for Pacific Islands people, and 16 per million for other ethnicities.[2]

Spinal cord injury rates are very low in children (single digits per year). The average age at time of injury for traumatic SCI is 34 years. Cervical SCI is the most common level in NZ,[4] with males between 15 and 29 years being most frequently affected, reflecting international trends.[5] Traumatic SCI grading in New Zealand follows the International Standards for Neurological Classification of SCI (ISNCSCI), which assigns AIS (American Spinal Injuries Association Impairment Scale) categories A through E to paraplegia and tetraplegia. Reviewed SCI data from one SCI unit between 2005 and 2010 reveal 30% complete SCI, counting both tetraplegia and paraplegia (American Spinal Injury Association Impairment Scale), 36.2% incomplete tetraplegia (AIS B-D), and 33.8% incomplete paraplegia (AIS B-D).[6] Motor vehicle accidents remain the leading cause of SCI in NZ, followed by falls, reflecting trends reported internationally. Sporting accidents (e.g., rugby football, horseback riding, skiing, mountain biking, diving) constitute the third most common cause. Recent data suggest a decrease in sports-related causes of tetraplegia, and a rapid increase in SCI from falls.[7] Of note, there has been a 2,000% increase in the post-onset life expectancy of people with a SCI over the past 50 years.[8]

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

Patients with isolated SCI without hemodynamic instability are air-lifted directly from the scene of injury to one of the two specialized regional SCI centers: Christchurch (facilities include Christchurch Public Hospital and Burwood Spinal Unit) or Auckland (facilities include Middlemore Hospital and Auckland Spinal Rehabilitation Unit). Children with acute SCI without hemodynamic instability from the South Island are air-lifted to Christchurch Public Hospital and from the North Island to Starship Hospital for acute management followed by rehabilitation at Wilson Centre in Auckland. This streamlined fast tracking of their management is in keeping with established international standards and is believed to constitute "best practice," whereby early admission not only saves lives but also reduces secondary complications common to this cohort of patients and therefore reduces total hospital length of stay. This has seen a dramatic reduction in injury-to-decompression/reduction times for acute spinal injuries. Patients presenting acutely with symptoms and signs consistent with SCI may make first contact with their general practitioner, and are then referred to secondary or tertiary services depending on their assessment, i.e., either to the nearest general hospital emergency department or to specialist orthopedic surgery or neurosurgery. For those presenting to emergency departments, spinal injury assessment and triage by the attending doctors is followed by rapid referral and transfer directly to a tertiary spinal trauma unit if indicated.

For patients with suspected/confirmed traumatic SCI and multitrauma who are transferred immediately to the nearest regional trauma center, assessment and initial management will involve early consultation with an orthopedic surgeon or spinal physician based in one of the two specialized regional SCI centers (see above). Admission to the intensive care unit or orthopedic unit usually comes next, followed by spinal team assessment and early surgical intervention if judged appropriate.

As soon as the patient is considered medically stable, with no further need of intensive medical or surgical care, he or she is transferred to the relevant specialist spinal rehabilitation unit. Nontraumatic SCI and neurological syndromes with similar presentation, such as epidural abscess, or transverse myelitis, will follow one or other of these pathways of assessment and triage as appropriate for their acuity of presentation, followed by a period of specialist management in a tertiary neurological, orthopedic, or neurosurgical unit as appropriate. If specialist inpatient rehabilitation is indicated for remaining neurological impairment, admission to a specialist SCI rehabilitation service or other neurorehabilitation service will follow.

Later, the patient receives ongoing services from one of various national outreach services and specialist home and community support services, where long-term rehabilitation can continue in a step-down model (if and when appropriate) either after a period of inpatient rehabilitation or directly after specialist orthopedic or neurological or neurosurgical treatment.

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Community rehabilitation teams in NZ usually consist of occupational therapists, speech-language therapists, assistive technology consultants, psychologists and counsellors, social workers, vocational rehabilitation specialists, orthotists, and physiotherapists.

Generally, postacute inpatient rehabilitation for a person with incomplete tetraplegia may extend to 5 to 6 months, and with paraplegia to approximately 3 months. Thereafter, individuals remain under the care of the spinal team for the duration of their lives; commencing with a comprehensive 3-day reassessment 6 months after discharge from their initial postacute rehabilitation, followed approximately 12 months later (and again 12 months after that) by further reassessments. Thereafter, reassessment appointments with their spinal team occur at three-yearly intervals. Reassessments are made more frequently if clinically indicated. Readmission for periods of rehabilitation (even years after SCI onset) is often offered when changes, caused either by aging, SCI-related complications or new pathology, cause functional deterioration.

LIVING WITH SCI

Employment rates after SCI in NZ vary considerably, the average being approximately 35% within the first year after injury.[9] Vocational rehabilitation is strongly supported in NZ, and persons who were employed or studying at the time of their injury are encouraged and assisted to engage with vocational rehabilitation counsellors during their postacute inpatient rehabilitation. Those on Accident Compensation Corporation (ACC) funding (described in detail in the next section) receive further support after discharge through a special scheme designed to help such people develop the skills and functional competence appropriate for their chosen work. A longitudinal study published in 2013 exploring socioeconomic outcomes for 169 participants in NZ 2.5 years after their SCI found that most retained their income and standard of living after sustaining an SCI, and high overall rates of returning to work.[10] The authors attributed these results to the fact that most of the participants in this study were served by the ACC scheme.

Regardless of the funding stream that applies to their healthcare post-injury, all NZ residents have access to assistance to maximize their post-discharge function, which includes aids and equipment (both durable equipment and equipment needing regular renewal), environmental modification, transport options, assistance with personal and household tasks, and assistance with community reintegration once they are discharged into the community.

In 2013, a National SCI Initiative and Implementation Plan, outlining "an integrated and sustainable approach to supporting people with spinal cord impairment in meeting their goals"[11] was developed by the Ministry of Health and ACC in collaboration with a wide range of stakeholders across the health system spectrum including customer groups, professional bodies, expert clinicians, District Health Boards, and researchers, the express aim of which was to improve treatment and rehabilitation outcomes for persons with SCI, and to signalize the achievement of better outcomes after SCI as a national health priority.

THE HEALTH AND REHABILITATION SYSTEM

All New Zealanders have access to free public hospital services; and since 1982, the ACC[12] has provided publicly funded comprehensive, no-fault personal injury insurance cover for all NZ residents (and even for visitors to NZ) who suffer injury through an accident (e.g., a vehicular accident, assault, sporting accident, a fall, etc.) regardless of the legal, social, or personal context of its occurrence. Those whose injury is accepted under the ACC scheme receive a range of benefits: regular weekly payment of 80% of their weekly earnings (if they were employed at the time of their injury); payment of all rehabilitation and hospital care expenses; payment of all expenses relating to equipment and environmental modification needs; payment of all expenses for that portion of their postdischarge health care that relates to their SCI; and, depending on the degree of injury present, a large lump-sum payment that does not affect their other benefits under the scheme. In the case of traumatic SCI, the ACC covers a patient's medical and other ongoing care and function-related needs for life. Many New Zealanders also have private health insurance, and the extent to which this affects (if at all) their entitlement to ACC insurance cover for the same injury is determined by the terms of their private insurance.

Those whose SCI occurred before 1982, or was not the result of an accident, are supported by the general public health system (commonly referred to as "Ministry of Health funding") during and after their hospital treatment. The latter group includes congenital and developmental pathologies, degenerative, ischemic, and inflammatory hemorrhagic, toxic, and neoplastic causes of SCI. These patients outnumber the "accident-generated" group served by the ACC scheme. For individuals under Ministry of Health funding, there is a limit to the funds available that may be spent on facilitating their continuing rehabilitation, functional and care needs after inpatient rehabilitation, and community reintegration. They will also be entitled to a disability allowance if they are unable to return to work, and an unemployment benefit (entitlement to this is means-tested).

In practice, this two-track system fosters potential inequality, and disparities are perceived commonly in the range and quality of resources available through public funding to people with SCI, such as for domestic and personal cares, equipment and transport needs, and environmental modifications. This is a source of considerable dissatisfaction among people in NZ with acquired disabilities.

THE SOCIAL RESPONSE TO SCI

People living with SCI in NZ have the same opportunities available to other New Zealanders to live a full and active life. All public buildings are required by law to be wheelchair accessible, and have accessible toilet facilities. Not-for-profit organizations such as the NZ Spinal Trust (a registered charity formed in 1994) were set up to address unmet needs of the rehabilitation journey for people with SCI, and task themselves with disseminating information, promoting research, providing resources, and providing advocacy and support to people with SCI throughout NZ through initiatives, projects, and programs that directly benefit them. To meet these objectives, the Trust works in collaboration with a number of entities, including government health boards, ACC, and the Ministry of Health.[12]

Independent living and community participation have become central goals in the rehabilitation process in NZ.[13,14]

Therefore, a National Serious Injury Service supported by the ACC was initiated in 2008 that is dedicated to facilitating community participation, independent living, and work reintegration.[13]

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

New Zealand is participating in the InSCI Survey. Maria van den Heuvel is the study coordinator with the backup of Dr XH Xiong, who is national leader. Mr Balraj Singhal, currently the Clinical Director for Adult Rehabilitation in Christchurch (including the Spinal Service), will represent the Australian and New Zealand Spinal Cord Society. Mr Hans Wouters, CEO of NZ Spinal Trust, is the representative for the national SCI consumer organizations. The organization of New Zealand's health care delivery with respect to SCI puts it in a strong position to provide international leadership toward the implementation of International Perspectives on Spinal Cord Injury, and its current collaboration with Canada's Rick Hansen Institute may help improve standards of data collection in New Zealand.

CONCLUSION

New Zealand has established a comprehensive, unique health care system for people with SCI. The incidence of SCI in NZ is very similar to that of Australia and most of the Western world. The most common cause of traumatic SCI in NZ is still motor vehicle accidents, followed by falls and sports-related injuries. New Zealand has two comprehensive SCI services providing comprehensive inpatient rehabilitation, medical and surgical care for patients with spinal cord injuries, and facilitating their transition into the community. Furthermore, they provide for their lifelong follow-up at regular intervals. There exists a national strategy embodied in the NZ Spinal Cord Impairment Action Plan to improve treatment and rehabilitation outcomes to foster well-being, independent living, and community integration for persons with SCI and support their family (commonly referred to as whānau in New Zealand) and caregivers. Progress also is being made toward more comprehensive data collection. With such initiatives assuring continual development of strategies to improve overall standards of care and support for people living with SCI, it is expected that improved survival, lower complication rates, and better quality of life will follow.

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