ARTICLE

People ageing with spinal cord injury in New Zealand: a hidden population? The need for a spinal cord injury registry

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ABSTRACT

AIMS: To identify and establish a research database of ageing New Zealand people who sustained a traumatic or non-traumatic spinal cord injury (SCI) before 1990.

METHODS: All living New Zealand residents incurring a SCI before 1 January 1990 were eligible. A co-ordinated consultation with apposite New Zealand organisations was undertaken to identify and access existing SCI databases, and remove duplicate or ineligible records.

RESULTS: 1,400 people were identified. Using the national patient information management system to determine eligibility, 1,174 people remained after exclusions; 600 (51.1%) through the Auckland Spinal Rehabilitation Unit and 574 (48.9%) through the Burwood Spinal Unit. Common to both databases were people’s National Health Index number, contact details, basic demographic data, date of injury, and neurological level of SCI.

CONCLUSIONS: An unexpectedly large SCI population was uncovered; a population largely hidden due to the uncoordinated, fragmented and inconsistently collected information held within different organisations. As life expectancy rapidly increases for those with SCI, coupled with an accelerated ageing general population, this hidden SCI population can be expected to grow. A single, well-managed and coordinated national SCI registry is urgently needed in New Zealand for planning and delivery of services, especially for those developing age-related complex interwoven secondary conditions.

A new demographic phenomenon is emerging throughout the world; people with spinal cord injury (SCI) who are living increasingly longer after their injury event. SCI mainly occurs among young and middle-aged people who sustained a traumatic injury, or non-traumatic medical condition resulting in a disability that has life-long major consequences. Approxi-mately 80–130 people are diagnosed with a SCI in New Zealand each year, with an estimated incidence rate ranging from around 30 per million, to 49.1 per million people. Marked gender and ethnic differences exist, with estimated age-standardised incidence rates for males (71.9 per million) significantly higher than for females (26.0 per million), while Māori (46 per million) and Pacific (70 per million) people have significantly higher incidence rates than people of European origin (25 per million). Males aged between 15 and 29 years account for nearly half of all newly acquired SCIs, with motor vehicle accidents (54%), followed by falls (24%), the leading causes of these injuries. However, due to the scarcity of recently published national epidemiological information, it must be noted that some of this cited demographic information is drawn from a study published over 20 years ago, which may be no longer accurate.

Until the mid-twentieth century, the life expectancy of people with SCI was relatively short, with people commonly dying as a result of renal failure and infection. In recent years, however, life expectancy, mortality, and morbidity have changed dramatically for the majority of people with
SCI. With appropriate care and support many can expect to live an ‘almost normal’ lifespan.\textsuperscript{1,6,7} Although many people with SCI enjoy increased longevity, it is recognised and accepted that they live and age in ways that differ from their able-bodied counterparts.\textsuperscript{8-10} Once regarded as a relatively stable condition, SCI is now seen as dynamic and changeable over time. People living and ageing with SCI, depending on the age that the initial injury occurred, seem to have a period of relative stability post injury of 20 or so years before they develop a variety of physical secondary conditions (eg, shoulder pain, stenosis, musculoskeletal deterioration). These secondary conditions are often associated with medical complications which can seriously compromise a person’s lifestyle and even be life threatening.\textsuperscript{1,8,9}

Very little is known on a population level about people living with SCI, their ageing, and their growing importance in health service delivery and society at large within New Zealand. Indeed, the most basic questions such as population size and demographic composition are absent from almost all literature.\textsuperscript{11} Given the growing importance and impact of this population, both for individuals and for society, it is necessary that these issues be better understood. However, fundamental to any population-level understanding is the ability to reliably sample from those eligible members of the population of interest. Increasingly, population registries have been advocated and established as one mechanism for providing clinical support, improving understanding, and facilitating research.\textsuperscript{12}

For people with SCI, a functioning, well-maintained registry would seem both a logical and appropriate vehicle to negate the current paucity of evidence. Indeed, such SCI registries have been established in other countries, such as the Rick Hanson Spinal Cord Injury Registry (RHSCIR) in Canada.\textsuperscript{13} Launched in 2004, the RHSCIR is now a nationwide database of patients with acute traumatic SCI admitted to major trauma centres and rehabilitation centres.\textsuperscript{13} Australia also has a national SCI register, the Australian Spinal Cord Injury Register (ASCIR); first mooted in 1987 and established in 1995.\textsuperscript{14} Managed by the Research Centre for Injury Studies at Flinders University, the ASCIR collates information from six specialised SCI units in Australia. Both the RHSCIR and ASCIR hold information for people living with traumatic SCI, but omit a significant sub-population—namely, people living with non-traumatic SCI. Currently, no SCI registry exists in New Zealand, although good examples of other registries exist, such as the New Zealand Cancer Registry (NZCR).\textsuperscript{15} The NZCR has successfully collected information since 1948, with cancer registration becoming a legal requirement with the passing of the Cancer Registry Act 1993.\textsuperscript{15,16}

Motivated by a programme of epidemiological research aimed at describing and understanding ageing amongst the New Zealand population who sustained a traumatic or non-traumatic spinal cord injury (SCI) before 1990, it quickly became apparent that no reliable national database or comprehensive single knowledge source existed. The purpose of this paper is three-fold: (i) to describe the development of a New Zealand SCI research database of people who sustained SCI prior to 1 January 1990 used for our programme of research; (ii) to quantify and describe the people ageing in New Zealand who incurred a SCI before 1 January 1990; and (iii) to provide evidence and support for the establishment and ongoing maintenance of a SCI registry within New Zealand.

Method

Study design

A retrospective audit and compilation registry of New Zealand people living and ageing with SCI sustained prior to 1 January 1990.

Target population

All people residing in New Zealand with SCI that had occurred before 1 January 1990. People identified as being deceased or residing outside New Zealand were excluded.

Ethics

Multi-region Ethics Committee (MEC) locality assessments were sought and gained from each participating organisation. MEC clearance was obtained for the establishment, secure transmission, and retention of the research database (MEC/09/06/061).
Setting and process

Multiple organisations within New Zealand hold various forms of information about people with SCI. These include the Auckland Spinal Rehabilitation Unit (ASRU), the Burwood Spinal Unit (BSU), the New Zealand Spinal Trust (NZST), and The Association of Spinal Concerns (TASC). In brief, established in 1977, the ASRU is based in South Auckland and administered by the Counties Manukau District Health Board (CMDHB). It is responsible for providing rehabilitation services to people who incur SCI and live north of New Plymouth across to Hastings (see Figure 1). The BSU, established in 1965 initially at Christchurch Hospital and then relocated to Burwood Hospital in 1980, is based in Christchurch and administered by the Canterbury District Health Board (CDHB). The BSU provides services for people with spinal cord impairments caused by accident, illness or congenital abnormalities, and is responsible for providing acute and rehabilitative care for those people who reside under the geographic line shown in Figure 1. Based in the Allan Bean Centre, Burwood Hospital, Christchurch, the NZST is a nationwide, consumer-focused charitable trust that provides a variety of support services for spinal cord impaired people. It works in close association with staff from both spinal units, concentrating on providing post discharge support and assistance—eg, information, vocational advice, peer support. TASC is a consumer-led, non-profit organisation based at the ASRU which concentrates on providing a ‘buddy support’

Figure 1: Admission boundary areas between the Auckland Spinal Rehabilitation Unit (ASRU) and Burwood Spinal Unit (BSU).

Supplied by Liz Oliver, Service Manager, BSU, 2012.
system for those with a spinal cord injury in the Auckland area (http://www.tasc.org.nz/).

Each of these organisations generates and utilises various in-house databases. The ASRU and BSU both hold detailed records of people with SCI admitted to their units. However, they do not as yet provide systematic follow-up of all people, once discharged. Consequently, some records may become inaccurate or obsolete over time as individual circumstances change, or as people relocate, opt out, or die. The NZST has a national database, known as ‘Kaleidoscope’, which is used by its vocational assessment team. Developed in 2003, it built on a pre-existing database established and was funded by a New Zealand Racing Board grant. Unfortunately, the contract for this pre-existing database concluded in 2000, and no funding was secured in the interim, leaving a gap in records between 2000 and 2003. The original database was designed to include records of all BSU and ASRU admissions, obtained from their Patient Information Management Systems (PIMS). From 2003, data were only held for inpatients who enrolled in Kaleidoscope’s vocational programmes (ie, a relatively small subset of the total number of actual inpatients during that time). TASC has developed an in-house, Auckland-focused database of people with SCI. While supportive of the proposed research and indicating a willingness to assist the researcher (RS) in contacting people in the Auckland area, direct access to the TASC database was not permitted.

Extensive consultation with key stakeholders, including senior administrative and clinical personnel, at the ASRU, BSU, NZST, TASC, and the Accident Compensation Corporation (ACC) was undertaken to identify the coverage, completeness, format, and reliability of the information contained on their databases. It was decided that a minimum dataset should include a person’s name, contact details, National Health Index (NHI) number, date and type of injury, gender, age (or date of birth), and neurological level of injury. It was accepted that there would be some information overlap from the different sources which would need to be addressed. The organisations were also consulted on ways to contact people outside these four databases (eg, prior to the establishment of the ASRU or BSU, a person could incur a SCI and be treated and discharged from a local general hospital). Suggestions included making contact through word-of-mouth, and organisational network magazines. TASC also worked with the ASRU to supply additional names of people not identified on the CMDHB’s PIMS.

As the focus of this research was those ageing with a SCI, in October 2009 the NZST Kaleidoscope database was reviewed, with the assistance of the Trust’s Chief Executive Officer (CEO). Over 1,400 people were identified as having incurred a SCI before 1 January 1990. Due to the large population identified, it was decided that subsequent efforts should concentrate on refining this database, although there were known gaps in its coverage, and questions about both the scope and its quality. This strategy was considered advantageous as the database clearly identified which spinal unit a person had been admitted to, and therefore enabled further checking and verification.

As part of the MEC approved locality assessment, RS was given temporary approval to work with DHB staff and patient information for the duration of the project. In the first instance, the NZST Kaleidoscope database was partitioned into two, based on spinal unit admission (henceforth referred to as the BSU and ASRU databases). Each component was then considered by the appropriate unit.

At the BSU, a temporary clerk, supervised by the Unit’s Research Nurse, employed the following process:

1. After referring to the unit’s ‘deaths book’, deceased individuals were removed from the BSU database. (The ‘deaths book’ was handwritten, and in use since the mid-1960s, recording details of individuals known to have died). In recent years, the book had ceased to be used, replaced by the CDHB’s PIMS.

2. Individuals’ details were then checked on the CDHB’s PIMS. Potentially eligible individuals not on the initial BSU database were added; those people recorded as being deceased or residing overseas were removed. Contact details were updated using the most recent...
3. As a further check, individuals’ contact details were then compared to Telecom’s “White Pages” address and phone listings. (Note: Now rebranded as Spark New Zealand, New Zealand’s largest telecommunications company).

At the ASRU, its Administration Coordinator was contracted to undertake the following process:

1. Individuals identified as being deceased on the ASRU’s ‘R’ drive patient folders were removed from the ASRU database. (The ‘R’ drive was an old computer record database no longer used for basic patient details).

2. Patient admissions from the ASRU log-book dated from 1987 to 1989 were collated, and any duplicated information or people identified as being deceased were deleted.

3. Individuals’ details were then checked on the CMDHB’s PIMS. Potentially eligible individuals not on the ASRU database were added; those people recorded as being deceased or residing overseas were removed. Contact details were updated using the most recent PIMS information. Some individuals’ contact details were missing or invalid.

The two spinal units then independently contacted people on their list to request consent for the unit to pass their contact details onto RS. Given the time delay between establishing the original list and conducting the survey, due to the Christchurch earthquake sequence,17 patients’ contact details were re-confirmed using the DHB’s PIMS prior to conducting the survey. Consistent with MEC approval, the individual BSU and ASRU databases were retained and held by the relevant spinal unit, not the research team.

PIMS information. Some individuals’ contact details were missing or invalid.

Figure 2: Participant recruitment flow diagram.
Table 1: Demographic and injury characteristic profile of survey participants (n=284).

<table>
<thead>
<tr>
<th>Demographics and injury characteristics</th>
<th>Mean</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>57.2</td>
<td>(10.0)</td>
</tr>
<tr>
<td>Age at injury (years)</td>
<td>25.7</td>
<td>(9.8)</td>
</tr>
<tr>
<td>Time since injury (years)</td>
<td>31.6</td>
<td>(7.5)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>225</td>
<td>(79.2)</td>
</tr>
<tr>
<td>Female</td>
<td>59</td>
<td>(20.8)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>European/Pākehā</td>
<td>233</td>
<td>(84.4)</td>
</tr>
<tr>
<td>Māori</td>
<td>33</td>
<td>(12.0)</td>
</tr>
<tr>
<td>Chinese</td>
<td>5</td>
<td>(1.8)</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>(1.8)</td>
</tr>
<tr>
<td>Marital status</td>
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<td></td>
</tr>
<tr>
<td>Married/de facto or civil union</td>
<td>169</td>
<td>(61.2)</td>
</tr>
<tr>
<td>Never married</td>
<td>51</td>
<td>(18.5)</td>
</tr>
<tr>
<td>Separated</td>
<td>48</td>
<td>(17.4)</td>
</tr>
<tr>
<td>Widowed</td>
<td>8</td>
<td>(2.9)</td>
</tr>
<tr>
<td>SCP</td>
<td></td>
<td></td>
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<tr>
<td>Tetraplegic</td>
<td>98</td>
<td>(34.6)</td>
</tr>
<tr>
<td>Paraplegic</td>
<td>112</td>
<td>(39.4)</td>
</tr>
<tr>
<td>Walking</td>
<td>72</td>
<td>(25.4)</td>
</tr>
<tr>
<td>Neurological level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C1-C7 Complete</td>
<td>93</td>
<td>(35.4)</td>
</tr>
<tr>
<td>C1-C7 Incomplete</td>
<td>29</td>
<td>(11.0)</td>
</tr>
<tr>
<td>T1-T12 Complete</td>
<td>85</td>
<td>(32.3)</td>
</tr>
<tr>
<td>T1-T12 Incomplete</td>
<td>19</td>
<td>(7.2)</td>
</tr>
<tr>
<td>L1-L5 Complete</td>
<td>22</td>
<td>(8.4)</td>
</tr>
<tr>
<td>L1-L5 Incomplete</td>
<td>11</td>
<td>(4.2)</td>
</tr>
<tr>
<td>S1 Complete</td>
<td>1</td>
<td>(0.4)</td>
</tr>
<tr>
<td>S1 Incomplete</td>
<td>3</td>
<td>(1.2)</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor-vehicle</td>
<td>103</td>
<td>(37.6)</td>
</tr>
<tr>
<td>Motorbike</td>
<td>34</td>
<td>(12.4)</td>
</tr>
<tr>
<td>Sport</td>
<td>38</td>
<td>(13.9)</td>
</tr>
<tr>
<td>Fall</td>
<td>23</td>
<td>(8.4)</td>
</tr>
<tr>
<td>Diving</td>
<td>19</td>
<td>(6.9)</td>
</tr>
<tr>
<td>Falling object</td>
<td>11</td>
<td>(4.0)</td>
</tr>
<tr>
<td>Medical misadventure</td>
<td>11</td>
<td>(4.0)</td>
</tr>
<tr>
<td>Medical condition</td>
<td>11</td>
<td>(4.0)</td>
</tr>
<tr>
<td>Work injury</td>
<td>10</td>
<td>(3.6)</td>
</tr>
<tr>
<td>Aviation</td>
<td>9</td>
<td>(3.3)</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>(3.6)</td>
</tr>
</tbody>
</table>

*8 (2.8%) values missing; *2 (0.7%) values missing; *21 (7.4%) values missing; *10 (3.5%) values missing.

Results

By the end of December 2009, after exhaustive checking and verification, the initial 1,400 people identified on the NZST's Kaleidoscope database had been refined to 1,174 people; 600 through the ASRU, and 574 through the BSU. Checking the contact details of those on the BSU database against their “White Pages” address and phone listings yielded only 159 (28%) concordant matches. This relatively low concordance generated considerable discussion with senior personnel at the two spinal units. One suggestion to redress this was to seek MEC approval to run the two datasets through the national PIMS, held by Ministry of Health, as a way of ensuring currency. However, following extensive methodological consideration and ethical discussion, and given people's increasing reliance of different technologies and telecommunication companies outside of Telecom, the most appropriate agreed way forward was to use the DHB PIMS contact details. The “White Pages” matching was therefore not undertaken for the ASRU database.

Of the 574 people initially identified on the BSU database, by June 2011 (the time of the survey) a further 20 had died, 6 were living overseas, and 1 (RS) was excluded, leaving 547. Similarly for the 600 identified on the ASRU database, by July 2011 (the time of the survey), 55 had died, 5 were living overseas, and 52 were not found on the CMDHB PIMS (suggesting relocation), leaving 495 people. Of the combined sample of 1,042 people, 284 (27.3%) completed the questionnaire; Figure 2 presents the participant recruitment flow diagram. Most respondents were male (79.2%), the mean age was 57.2 years (range: 28–83 years), the mean age when injured was 25.7 years (range: 2–57 years), and so the mean time that people had lived with their injury was 31.6 years (range: 21–59 years). Table 1 summarises the key demographic characteristics of the participants.

Discussion

Primary results

Aim (i) was to describe the development of a New Zealand SCI research database of people who sustained their SCI prior to 1
January 1990. Despite significant support from key stakeholders, including the NZST, BSU, and ASRU, this development was a complex, technical, time-consuming task. Most sources reviewed were no longer in use, were ad hoc, or had incomplete population coverage and information. Therefore, eligible people may have been missed, introducing important non-sampling biases and threats to external validity.\(^\text{18}\) Without any reference or registry population, the magnitude and direction of these biases is unknown.\(^\text{12,18}\) Essential information, such as identifying the number of people who had died since the onset of their SCI and the reasons for their death, was not reliably available. Moreover, without continuous oversight and updating, this database immediately becomes obsolete, and future researchers are required to repeat the preliminary work of establishing a reliable sampling frame.

Aim (ii) was to quantify and describe the people ageing in New Zealand who incurred a SCI before 1 January 1990. The number of people ageing with SCI in New Zealand was unknown to spinal specialists, DHBs, ACC, researchers, and the Ministry of Health. This was the first time that a comprehensive national database of people ageing with SCI had been compiled. Initially 1,400 people were identified, then reduced to 1,174 after exhaustive checking and verification. This number exceeded the expectations of everyone involved, leading to the discovery of a ‘hidden population’,\(^\text{11}\) similar to that which has been made elsewhere.\(^\text{19}\)

Lastly, aim (iii) was to provide evidence and support for the establishment and ongoing maintenance of a SCI registry within New Zealand. With many more people found than anticipated, it does raise questions as to why these people were not readily identified and part of a PIMS whereby people ageing with SCI were monitored and periodically medically reassessed. Without a reliable registry, a population is potentially marginalised or worse, hidden from policy makers and health managers;\(^\text{18}\) the scale of conditions and related issues are also likely to be underestimated, and potentially misunderstood and neglected.\(^\text{12}\) Furthermore, it may denigrate the patient experience, and increase costs.\(^\text{12}\) This lack of reliable information severely limits effective economic evaluation of the long-term impact people with SCI have on health and social support services in New Zealand.\(^\text{12,20}\) A high priority has been placed on establishing mutual agreement among the key stakeholders (eg, spinal specialists, ACC, Ministry of Health, DHBs, health researchers, and policy makers) to develop a national registry of people with SCI.\(^\text{3}\)

Limitations of study

Establishing a complete sampling frame \textit{de novo} is fraught with challenges and limitations, which may threaten the internal and external validity of any database. Patient coverage and inclusion, retention or known exit, accurate, complete and current information collection are all pivotal.\(^\text{18}\) Yet, each of these domains in our database development encountered difficulties. Ultimately, those we omitted or excluded due to missing or erroneous information cannot be determined and may further still undercount those enumerated here.

What potentially makes a good SCI registry?

Population registers have salient advantages, but also challenges.\(^\text{18}\) However, with modern technologies, effective registries have the capability to enhance the patient experience, and serve clinical teams, managers and systems, organisations and funding agencies, and researchers.\(^\text{12}\) Through data matching and integration, predictive analytics for risk stratification, combining predictive modelling with algorithms for financial risk management, identification of care gaps, automated messaging for patient outreach, engaging patients with alerts and educational campaigns, care management tasks, and using analytics to measure performance of organisations and providers are all now possible.

A number of spine and SCI registries have already been established and maintained internationally,\(^\text{13,14,21-23}\) and a body of published best practice for SCI is emerging.\(^\text{24}\) For a successful SCI registry, it is important that all key stakeholders commit to maintaining and using its information. Appropriate governance and project management is essential in ensuring that any SCI registry is safe and well implemented, with appropriate Information Technology Services (ITS) resources to
ensure effective ongoing data collection and review.\textsuperscript{22} Also fundamental is the commitment to adequate ongoing funding. Key stakeholders such as clinicians, policymakers, and researchers need to be identified and agree on dataset inclusion criteria and associated elements.\textsuperscript{18,24} All dataset variables and elements need to be clearly defined.\textsuperscript{21,22,24} Using NHI numbers, the SCI registry should be linked to other key databases, including the Ministry of Health’s PIMS and Mortality Collection (MORT) databases—the latter classifies the underlying cause of death for all deaths registered in New Zealand. Participant consent and privacy issues need to be addressed to ensure appropriate access to the information collected.


In 2014, the New Zealand Spinal Cord Impairment Action Plan 2014–2019 was produced by ACC and the Ministry of Health.\textsuperscript{3} It recognises that “the current model of care for medical interventions and lifelong support is fragmented and needs better coordination”.\textsuperscript{3} Establishing a SCI Registry was seen as one solution (Objective 3). Since the plan’s publication a feasibility pilot study (funded by ACC, CDHB, Canterbury Orthopaedic Services and Medtronic) has been undertaken by a Burwood Academy of Independent Living (BAIL) researcher looking at the Canadian-based RHSCIR and Australian-based SpinalCARE registries.\textsuperscript{1}

The feasibility pilot study, including recommendations, was submitted and considered by the New Zealand Spinal Cord Impairment Action Plan Governance Group in September 2015. This group supported the recommendations, and a business case was subsequently developed which sought sustainable funding for the RHSCIR model. The business case was accepted, and funding established, effective 1 January 2016. A set-up phase is now underway, and the first meeting of the registry governance group was in April 2016.\textsuperscript{25}

It is crucial for the future health and well-being of people with SCI that appropriate resources are devoted to establishing a well-coordinated, contemporaneous SCI registry that can provide accurate information.

**Conclusion**

Due to the fragmented and compartmentalised information sources, an unexpectedly large, hidden population of people ageing with SCI was discovered. A single well-managed and coordinated national SCI registry is urgently needed in New Zealand for planning and delivery of services, especially for those developing age-related complex interwoven secondary conditions. We argue that it is in both patients’ and society’s best interest to firmly support the recommendations of the New Zealand Spinal Cord Impairment Action Plan Governance Group for the establishment of a SCI registry.
Competing interests:
Richard Smaill is on the Board of Trustees, New Zealand Spinal Trust. Pauline Barnett and Richard Smaill are members of the Board of Trustees of the Burwood Academy of Independent Living (BAIL).

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