Spinal Cord Injury: Progress in Care & Outcomes In the Last 25 Years

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Prepared For
The Rick Hansen Institute

By

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Table of Contents

TABLE OF CONTENTS .................................................................................................................................2
ACKNOWLEDGMENTS .................................................................................................................................4
EXECUTIVE SUMMARY ...............................................................................................................................5
INTRODUCTION: MARKING A MILESTONE IN SCI LEADERSHIP ............................................................10
  BRIEF OVERVIEW OF SPINAL CORD INJURY .........................................................................................12
    Classification of Injury and its Effects ....................................................................................................12
    Etiology ...............................................................................................................................................13
    Burden ...............................................................................................................................................14
  TRACKING PROGRESS ............................................................................................................................15
ENVIRONMENTAL PROGRESS ..................................................................................................................17
  ORGANIZATIONAL INFRASTRUCTURE ....................................................................................................18
  LEGISLATIVE AND POLICY FRAMEWORKS ..........................................................................................20
    Disability Legislation ..........................................................................................................................20
    Legislation Concerning Research .........................................................................................................22
  SPORT ORGANIZATIONS AND EVENTS ..................................................................................................23
  PUBLIC PERCEPTIONS AND ATTITUDES ...............................................................................................24
  PREFERENCES IN THE SCI COMMUNITY .................................................................................................26
RESEARCH PRODUCTION ..........................................................................................................................28
  PUBLICATION VOLUME .........................................................................................................................28
  BASIC INVESTIGATION OF POTENTIAL CURES ......................................................................................29
  EVOLUTION OF RESEARCH FOCUS: DURATION AND QUALITY OF LIFE ..............................................31
    Pre-Hospital Care ..................................................................................................................................32
    Acute Management ..............................................................................................................................33
      Surgical Treatment ............................................................................................................................33
      Pharmacological Treatment ...............................................................................................................34
    Rehabilitation .......................................................................................................................................35
    Secondary Complications ....................................................................................................................36
      Urinary Tract Infections .......................................................................................................................37
      Chronic Pain .....................................................................................................................................39
      Pressure Ulcers ...............................................................................................................................41
  INTERVENTION EFFECTIVENESS ...........................................................................................................43
TRANSLATION TO APPLICATION ...............................................................................................................47
  PUBLIC HEALTH PRACTICE AND PRIMARY PREVENTION ..................................................................47
    Legislation ..........................................................................................................................................48
    Education ..........................................................................................................................................48
      ThinkFirst Canada ..........................................................................................................................48
    SMARTRISK .......................................................................................................................................50
  GUIDELINES FOR BEST CLINICAL PRACTICES ....................................................................................50
  DEVELOPMENT AND TRACKING OF OUTCOME MEASURES ...............................................................52
PROGRESS IN POPULATION-LEVEL OUTCOMES .......................................................................................56
  SURVIVAL/LIFE EXPECTANCY IN TRAUMATIC SCI .............................................................................56
  OTHER PATIENT OUTCOMES ..................................................................................................................59
  PARTICIPATION IN WORK AND PHYSICAL ACTIVITY ..........................................................................60
  ACCESS TO PUBLIC FACILITIES AND TRANSPORTATION .................................................................63
    Removal of Architectural Barriers .......................................................................................................63

March 2011  Page 2
Mobility Technology.................................................................................................................................64
Health Care Efficiency..................................................................................................................................65
Length of Stay................................................................................................................................................65
Intervention Cost-Effectiveness.....................................................................................................................67

CONCLUSION: MAKING PROGRESS IN THE PAST, PRESENT, AND FUTURE .................................69

Environmental Progress.................................................................................................................................70
Research Production.........................................................................................................................................71
Translation to Application.................................................................................................................................72
Population-Level Outcomes............................................................................................................................72
The Next 25 Years...........................................................................................................................................73
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Spinal Cord Injury: Progress in Care & Outcomes in the Last 25 Years

Executive Summary

To reduce the overall burden of neurotrauma demands actions which extend from the political to basic patient care.¹

This report was commissioned by the Rick Hansen Institute to review the gains made in spinal cord injury (SCI) care and outcomes over the last 25 years, and in this way help to commemorate the historic Man in Motion World Tour that was launched by Mr. Hansen in 1985.

Spinal cord injuries have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. The physical effects include loss of sensation and/or paralysis, which often causes long-term disability; further, there are many complications and co-morbidities associated with SCI that can significantly affect quality of life and even be life-threatening. The associated economic burden of SCIs is substantial, due not only to direct health care costs, but also to high rates of physical morbidity and premature mortality that have an impact on productivity at a societal level.

The substantial challenges related to SCI certainly call for concerted leadership. A serious response among health care providers and other leaders has developed in various phases over the previous century, with associated progress that has benefited individuals with SCI. By the 1970s, for instance, the Model Systems network for treatment of SCI was being established in various parts of the U.S. to translate into the civilian sector the many advances that had been gained in the context of caring for disabled veterans. This period also saw the creation of what is still the largest registry of SCI patient information, a valuable source for tracking trends, notwithstanding the unique features of the U.S health care system that may affect the interpretation of any observed patterns.

Understanding the progress related to SCI over the last 25 years may be accomplished in a comprehensive manner by tracking the story across a simplified model of influences and impacts. As indicated in the following diagram, there are four key domains where progress may be identified:

1. Environment: the evolving social context within which individuals with SCI live and operate

2. Research: the priorities and output related to investigating questions generated by SCI, from basic research (“bench”) to intervention effectiveness (“bedside”)

3. *Application:* how (and how much) any insights have been translated into clinical practice and public health

4. *Outcomes:* the actual changes experienced by individuals with SCI, from survival to quality of life, as measured at a population level, as well as effects in the health system in terms of efficiency

As indicated, there were a number of themes or sub-domains that emerged under each domain; each was examined by means of a search in the biomedical literature and pertinent grey literature documents. The aim was to provide selected information on each topic that would demonstrate the degree of progress that has been achieved in recent decades.

A high-level summary of the results found for the four overarching domains of progress is provided below, followed by a table that serves as a compressed “snapshot” of advances made in each of the more specific areas.

**Environmental Progress**

The review herein focused on the larger scale of environmental spheres, that is, society as a whole rather than the context defined by the home, workplace, etc. of a particular individual with SCI. Several of the environmental sub-domains have demonstrated remarkable progress in the last 25 years, especially the dramatic increase in networks, foundations, associations, and institutes dedicated to supporting and expanding SCI-related research and care. The fact that
disability legislation has come to fruition in the last two decades is another encouraging
development, as is the public profile of individuals from around the world with SCI and other
disabilities being involved with sports, including the Paralympic Games. Other environmental
sub-domains are at an earlier stage of development, but a platform at least has been built upon
which further gains may be made. Thus, the SCI community is being consulted more than ever
about its concerns and needs, but this path could be followed further—especially regarding
experience of people with such serious disabilities with stereotypes, prejudice, and similar
negative attitudes.

Research Production

Quantitatively, there has been a steady increase in scientific publishing related to SCI, partly
reflecting the launch of new specialty journals in the last 25 years. Even more encouraging is
the large increase in clinical trials being published, as this represents the fountainhead of all
translation and implementation work that eventually brings improvements in the medical care
and everyday life of individuals with SCI. The sub-domain of basic research into cures remains
a mixed affair, evoking both a degree of disappointment and continuing optimism. There is no
doubt that great strides in scientific insight have occurred, so that cure/reversal in the near
future seems all the more probable. At the same time, current scientific insights about the spinal
cord, both damaged and whole, are being translated into therapies that will help preserve
function and even see improved function without full organic repair. While the “quest for a
cure” has become protracted, one consequence has been a recent expansion of research interest
in other areas of care, including pre-hospital, rehabilitation, and preventing/treating secondary
complications.

Translation to Application

The work of fostering improvements in SCI care is ongoing. For instance, it is certainly a
concern that some 20% of trauma sufferers with SCI still die before being admitted to hospital.
Even when basic insights and potential interventions emerge for this and other areas of need, it
is just the beginning of the process. The various stages of “translating” the expanding research
results into application in the real world starts with sifting the existing body of evidence in
systematic ways, developing and testing practice guidelines, and then tracking the ultimate
results in terms of patient and other outcomes. Progress has been made on all of these fronts,
especially in terms of identifying and developing protocols for applying best practices; the Rick
Hansen Foundation has liberally supported this cause by funding systematic reviews of
published evidence on clinical and other interventions. One major advance in the realm of
practical application has been the development of many more outcome measures specific to
SCI; while many of these metrics are still being validated, they do hold out promise for better
tracking of SCI outcomes in the future—especially in light of the commitment of the Rick
Hansen Institute and other groups to expand and strengthen national and international registries
of SCI patients.

Population-Level Outcomes

The intention to develop more robust SCI registries is welcome news, given how important
such a tool is to tracking patient outcomes at a population level. Several encouraging results
can already be identified, especially through the data set at the National Spinal Cord Injury
Statistical Center (NSCISC) in the U.S., the largest and longest-running SCI database,
capturing data since 1973. In that context, there has been:

- A 40% reduction in mortality in the first two years post-injury over the last three
decades
A gain in neurologic improvement during inpatient care, combined with lower frequencies of complications

A long-term improvement in global measures of community integration, although understanding the positive aspect of work participation rates in particular requires a more nuanced assessment

In addition, a number of encouraging trends were identified in the report that extend beyond the individual to society as a whole, including broader compliance with building codes requiring accommodations to permit access to individuals dealing with disabilities such as SCI. The following table offers a brief view of this and other gains over the last quarter century.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Then: 25 Years Ago</th>
<th>Now: Circa 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organizational Infrastructure</td>
<td>Limited number of organizations</td>
<td>Major expansion of organizations around the world</td>
</tr>
<tr>
<td>Legislative &amp; Policy Frameworks</td>
<td>Major legislation still being developed</td>
<td>Model legislation established in key countries</td>
</tr>
<tr>
<td>Sports Organizations &amp; Events</td>
<td>Disabled sports well-established but still limited exposure</td>
<td>Paralympics a major global phenomenon</td>
</tr>
<tr>
<td>Public Perceptions &amp; Attitudes</td>
<td>SCI and other disabilities not well understood</td>
<td>Measurable improvement in attitudes in some countries</td>
</tr>
<tr>
<td>Preferences in the SCI Community</td>
<td>SCI community consulted about priorities</td>
<td>Individuals with SCI at the centre of decision-making</td>
</tr>
<tr>
<td>Research Production</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Publication Volume</td>
<td>Less than 100 scientific articles per year, by title</td>
<td>Almost 450 publications per year related directly to SCI</td>
</tr>
<tr>
<td>Investigation of Potential Cures</td>
<td>Focus on the quest for a cure</td>
<td>Focus expanded to other biological aspects of recovery</td>
</tr>
<tr>
<td>Evolution of Research Focus</td>
<td>Less focus on rehabilitation and chronic care</td>
<td>Expanded focus on long-term care, including secondary complications</td>
</tr>
<tr>
<td>Intervention Effectiveness</td>
<td>Limited analyses of a limited evidence base</td>
<td>Multiple systematic reviews across many interventions</td>
</tr>
<tr>
<td>Translation to Application</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Prevention</td>
<td>Limited attention on major causes of SCI</td>
<td>Substantial legislative and educational programs launched</td>
</tr>
<tr>
<td>Best Clinical Practices</td>
<td>Few clinical guidelines published</td>
<td>Guidelines published in multiple arenas</td>
</tr>
<tr>
<td>Outcome Measures</td>
<td>Small number of measures (mostly not specific to SCI) developed and in use</td>
<td>Majority of SCI-specific measures developed since 1985</td>
</tr>
<tr>
<td>Population-level Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survival/Life Expectancy</td>
<td>Enjoying gains in life expectancy across recent decades</td>
<td>Ongoing gains in short-term survival; possible flattening of improvements in long-term survival</td>
</tr>
<tr>
<td>Other Patient Outcomes</td>
<td><strong>One U.S. example:</strong> 8.8% of complete injuries converted to incomplete (1973-81)</td>
<td>15.1% converted to incomplete (2002-6); certain other outcomes also improved</td>
</tr>
<tr>
<td>Community Participation</td>
<td>About 40% employment rate among individuals with SCI (1976-91)</td>
<td>Similar employment rate maintained in a much larger pool survivors (1992-2005)</td>
</tr>
<tr>
<td>Access to Facilities</td>
<td>Limited legislation and assistive technology</td>
<td>Major breakthroughs in building codes, compliance, and equipment</td>
</tr>
<tr>
<td>Health Care Efficiency</td>
<td><strong>One U.S. example:</strong> mean length of inpatient stay over 130 days (1973-81)</td>
<td>Length of stay about 60 days (2002-6)</td>
</tr>
</tbody>
</table>
The Next 25 Years

Driven by the enormous personal disaster and societal burden that SCI represents, it is clear that even more progress is needed on every front. The last 25 years of positive developments, as summarized in the table above and the preceding commentary, may be attributed to people known and unknown—leaders with high profile such as Rick Hansen and countless other stakeholders, from researchers to health care providers to fund-raisers and volunteers, and most importantly the entire community of individuals dealing with SCI. A similar army will be required to continue to advance the cause over the next 25 years and realize Rick Hansen’s original vision from 1985: *A world without paralysis after spinal cord injury.*
Introduction: Marking a Milestone in SCI Leadership

Today, the opportunity to live fully and completely with the disability is a very reasonable possibility for most, but this has added many dimensions to the problem of SCI for the person, the health care providers, and society at large.²

The spinal cord is a long, tube-shaped bundle of nerves that carries impulses between the brain and the rest of the body. It is surrounded by rings of bone called vertebra, which together constitute the spinal column or back bone. Spinal cord injury (SCI) is defined as damage to the spinal cord that results in a change, either temporary or permanent, to its normal motor, sensory, or autonomic functions.

Spinal cord injuries have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. The physical effects include loss of sensation and/or paralysis, which often causes long-term disability; further, there are many complications and co-morbidities associated with SCI that can significantly affect quality of life and even be life-threatening. The associated economic burden of SCIs is substantial, due not only to direct health care costs, but also to high rates of physical morbidity and premature mortality that has an impact on productivity at a societal level. And the preceding commentary does not even begin to address the profound psychosocial obstacles that face individuals with SCI.

The substantial challenges related to SCI call for concerted leadership. A serious response among health care providers and other leaders has developed in various phases over the previous century, with associated progress that has benefited individuals with SCI. For example, prior to the early 1940s the majority of people experiencing traumatic SCI died within weeks, most often due to infection.³ The advent of antibiotics and other medicines improved the survival rate dramatically, but those who did survive still “lived fairly restricted lives, and few achieved full reintegration into the normal activities of their family and society.”⁴ Clearly, further leadership was needed, and several physicians in the United Kingdom and the United States in fact stepped up to advocate (and organize) for a more comprehensive response to the problems and needs related to SCI.

For some whose lives were touched by spinal cord injury, advocacy became a significant focus. In 1974, Kent Waldrep, a star running back for Texas Christian University, received a spinal cord injury in a football game and became a quadriplegic. Post-injury, Waldrep raised the awareness of spinal cord injuries; just five years after he was paralyzed, he formed what became the American Paralysis Foundation. He was appointed to the National Council on Disability by President Reagan and helped to draft the Americans with Disabilities Act.

Marc Buoniconti is another football player who experienced a spinal cord injury in a college football game. At the age of 19 years – in 1985 – he was rendered a quadriplegic. His father, Nick, a Hall of Fame former NFL linebacker, leveraged his fame and connections to help Marc establish the Miami Project to Cure Paralysis. The Project is an interdisciplinary research center

dedicated to research in the field of paralysis and spinal cord injury; it has raised over $350 million to support paralysis research over its first 25 years.

Henry G. Stifel III, Vice Chairman of the Board of Directors of the Christopher and Dana Reeve Foundation, has a personal connection to the SCI community. In 1982, during his junior year of high school, Mr. Stifel was involved in a car accident that shattered his C4 and C5 vertebrae, leaving him paralyzed from the chest down. Later that year, with the goal of changing attitudes in the medical field, Mr. Stifel's family created the Stifel Paralysis Research Foundation. In 1985, the Foundation became the American Paralysis Association, and in 1998, it merged with the Christopher Reeve Foundation (now named the Christopher & Dana Reeve Foundation, CDRF). Mr. Stifel is very active in the Foundation's advocacy efforts. With a goal of increasing awareness and federal dollars for spinal cord injury, he has lobbied members of Congress on behalf of the Christopher Reeve Paralysis Act, which, if passed, will advance collaborative research in paralysis and improve the quality of life today for people living with paralysis and mobility impairments. In addition, Mr. Stifel serves as an ambassador within the spinal cord injured community, helping to keep the CDRF connected with the concerns of those who live with SCI every day.

Another influential figure based in the U.S. is Sam Maddox. He is a journalist with broad experience in news and feature writing who focused his reporting specialty on clinical medicine and neuroscience research related to spinal cord dysfunction. He authored *Spinal Network* in 1988, a critically acclaimed seminal resource for spinal cord dysfunction. Additionally, Mr. Maddox published *Quest for Cure* in 1994, a historical overview of research to restore function after spinal cord injury. He is currently a Member of the Board of Directors of the Foundation for Spinal Cord Injury Prevention, Care & Cure, and is the Knowledge Manager for the CDRF.

It is an unfortunate reality that major aspects of the progress to date have been generated in the context of caring for veterans in the U.S., a situation created by the high number of SCI cases arising from large-scale wars experienced by that country.\(^5\)\(^6\) However, by the 1970s the Model Systems network for treatment of SCI was being established in various parts of the U.S. to translate the advances into the civilian sector.\(^7\) A “systems concept” of medical management of high-cost disabilities was established, marking an important shift in focus: “It was demonstrated that the cost of SCI could be reduced…by preventing unnecessary medical complications and providing expert rehabilitation in a timely manner as a result, the length of hospitalization could be reduced to three or four months in uncomplicated cases of paraplegia and quadriplegia.”\(^8\)

This advances the storyline to the time period of interest in the present report, namely, the last 25 years. Why this period? The mid-1980s was marked both by recognition of new concerns related to SCI care and by a significant international event. First, the shifts in priority and focus throughout the history of SCI research and care continued to the point where two new dimensions dominated the horizon by 1985: the survival of more people with severe disability (including ventilator-dependency) and the survival of many individuals with SCI into older age. Such outcomes were almost “inconceivable” just 25 years earlier. Survival, and then ageing,

\(^7\) Hosack K. The model spinal cord injury system. *Case Manager.* 1999; 10(2): 51-3.
with SCI are thus tremendous markers of health care progress in themselves, plus a clear challenge. The priorities related to emergency and acute care (that is, life saving) and early rehabilitation are certainly maintained at that time, but the urgency about discovering a biological-organic cure becomes intensified; later, the emerging demands of chronic care and dealing with late complications come increasingly to the forefront.

Second, the era of interest in this report began with the *Man in Motion* World Tour. In 1985, at the age of 27, SCI-survivor Rick Hansen was inspired by the dream of creating a world that cares for and is inclusive of all people. Rick wheeled through 34 countries on four continents, travelling the equivalent of more than two marathons a day (40,000 km in total) before returning home to Vancouver, Canada. The accomplishments of the tour were both intangible and tangible: it raised awareness of the potential of people with disabilities, and it also raised $26 million for work related to SCI. Part of the initial fund seeded the beginning of the Rick Hansen Foundation (RHF), which has raised a further $200 million since the original tour ended in 1987. Rick Hansen’s international journey marked the start of an era where many new organizations were established (see the pertinent section below) and new fund-raising efforts were launched by high-profile figures such as the late Christopher Reeve to further the cause of SCI research and care. Now, 25 years later, it is important to look back at the accomplishments of the last two-and-a-half decades, partly to celebrate and partly to anticipate and plot further progress to come.

**Brief Overview of Spinal Cord Injury**

**Classification of Injury and its Effects**

The spinal cord does not have to be severed for loss of function to occur; in fact, for most people with SCI, the cord remains intact but experiences damage through squeezing, bruising, or swelling, or through a decrease in blood flow. This clarifies the common distinction made between complete and incomplete SCI. A complete SCI means there is no sensory or motor function below the injury site, whereas in an incomplete SCI there is some preservation of sensory or motor function below the level of the injury.

Generally, the higher on the spinal column the injury occurs, the more extensive the dysfunction that a person will experience. SCI is usually classified as tetraplegic (formerly termed quadriplegic) or paraplegic. **Tetraplegia** relates to injury of the spinal cord in the cervical (or neck) region, with associated loss of muscle strength or paralysis in all four extremities. **Paraplegia** relates to an SCI below the cervical region; in such cases, the upper body usually retains motor and sensory functions.

There are various other potential effects of SCI besides loss of sensation or motor functioning. SCI symptoms are dependent on the severity and level of the injury. Complete injury at almost any level will result in bladder and bowel dysfunction, as these are controlled by the sacral nerves that originate near the bottom of the spinal cord. High cervical SCIs result in complete paralysis and loss of breathing control, so that the individual is ventilator-dependent. In individuals with severe or complete SCIs above the mid-thoracic region, **autonomic dysreflexia** may occur. This entails hyperactivity of the autonomic nervous system that may manifest in substantial increases in blood pressure, headaches, elevated heart rate, excessive sweating, nausea, etc. Other effects of SCI can include muscle fatigue, mood disorders, chronic pain, and spasticity, as well as complications that may be considered secondary to care and therefore potentially preventable; the latter include skin ulcers (usually referred to as pressure ulcers) and urinary tract infections.
Etiology

Another common type of classification of SCI involves cause (or etiology). SCIs may be referred to as either traumatic or non-traumatic in origin. Traditionally, the most frequent cause of traumatic SCI worldwide has been motor vehicle accidents, followed by falls.\textsuperscript{9,10} However, more recent reports from some jurisdictions suggest an equalizing of the percentages of SCI due to motor vehicle accidents and falls.\textsuperscript{11} The rates for falls seem to have progressively increased over the last 25 years in developed countries, partly mediated by the reality of an ageing population.\textsuperscript{12} When stratified by age, falls are in fact the most common cause of traumatic SCI in the over 65-year age group.\textsuperscript{13} In young and middle-aged persons, however, motor vehicle accidents remain the most frequent cause of traumatic SCI. In most countries, accidents involving other vehicles, including bicycles and snowmobiles, are the third most common cause, followed by sports-related injuries. Trauma to the spinal cord due to military action and violent crime is a unique causal factor in the U.S. context, as reflected in the following trend chart. Taken together, the shifting etiologic profile of SCI in each jurisdiction should help to set priorities for prevention efforts (see the pertinent section later in the report).

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{chart.png}
\caption{Trends in Traumatic SCI Causation by Time Period, 1973-2009 United States}
\end{figure}

\begin{tabular}{lcccccc}
\hline
\hline
\textbf{Vehicular} & 46.9\% & 45.2\% & 42.2\% & 36.4\% & 40.0\% & 47.5\% & 41.3\% \\
\textbf{Falls} & 16.5\% & 16.9\% & 20.7\% & 20.0\% & 23.3\% & 23.0\% & 27.3\% \\
\textbf{Violence} & 13.3\% & 16.0\% & 18.8\% & 28.9\% & 21.1\% & 13.9\% & 15.0\% \\
\textbf{Sports} & 14.4\% & 14.2\% & 10.2\% & 7.5\% & 7.0\% & 8.8\% & 7.9\% \\
\hline
\end{tabular}

Non-traumatic SCIs have numerous causes, with the most common being cancerous tumours, degeneration of the spinal disks, and multiple sclerosis. Such diseases can create lesions on the spinal cord that may result in paralysis and other neurologic deficits. There is limited information about the epidemiology of non-traumatic SCI. Only one population-based study of the incidence of non-traumatic SCI appears to have been published. According to this Australian report, the age-stratified incidence is very different for traumatic versus non-traumatic SCI. Almost half of traumatic SCI cases occur in individuals aged from 15 to 39 years, producing a peak in the incidence curve for that cohort; by contrast, most of the diseases generating non-traumatic SCI increase steadily with age, so that almost half of the cases ultimately occur in individuals over the age of 65.

Burden

SCI represents one of the relatively unusual medical conditions where there is no inherent primary protection from living in a wealthy country. Indeed, some of the highest incidence rates in the world appear to be in the U.S. and Canada. There is wide variation even among developed countries, however, with North American SCI incidence rates being more than double than those found in Australia and Western Europe.

In Canada, an estimated 1,785 new traumatic SCI cases occurred in 2010, with some 1,500 of these individuals surviving to be hospitalized, and 1,387 surviving their initial hospitalization. Approximately 44,000 individuals are currently living with a traumatic SCI in Canada. The estimated figures for the U.S. are naturally higher in absolute terms, with about 12,000 individuals experiencing a new SCI each year, and 256,000 living with the condition. The prevalence rates, reflecting the pool of individuals surviving SCI beyond the acute phase, generally appears to be higher in Canada and the U.S. compared to most other settings; this would be expected given the higher incidence rate that prevails in those countries and the effective emergency and acute medical care now available. It should be noted that, no matter which country is being considered, adding in SCI cases of non-traumatic origin would obviously increase both the incidence and prevalence figures. A recent report commissioned by the Rick Hansen Institute (RHI) suggested that the prevalence number may almost double in Canada (at 86,000) with the inclusion of non-traumatic SCI.

As already noted, SCI has a devastating impact on an individual, resulting in long-term disability, reduced quality of life, and lower life expectancy. As summed up by researchers in

the U.S. Veterans Affairs system, “SCI is a debilitating and costly condition that compromises the ability to work, engage in social or leisure activities, and pursue many activities usually associated with an independent and productive lifestyle.” 22 SCI is also very expensive in economic terms, placing a significant financial burden on the individual, the health care system, and society as a whole. Combining direct costs (i.e., health care, equipment and modifications, and long-term care) with indirect costs (i.e., morbidity, premature mortality, and unpaid caregiving), the total lifetime cost per individual with SCI in Canada is estimated at $1.6 million for paraplegia and $3.0 million for tetraplegia; this translates into an annual economic burden for all traumatic SCI cases of $3.6 billion. 23 Clearly, fully understanding the cost of SCI can by itself be a driver of improvements in research efforts and actual delivery of care.

Tracking Progress

Understanding the progress related to SCI over the last 25 years may be accomplished in a comprehensive manner by tracking across a simplified model of influences and impacts. As indicated in the following diagram, there are four key domains where progress may be identified:

5. Environment: the evolving social context within which individuals with SCI live and operate

6. Research: the priorities and output related to investigating questions generated by SCI, from basic research (“bench”) to intervention effectiveness (“bedside”)

7. Application: how (and how much) any insights have been translated into clinical practice and public health

8. Outcomes: the actual changes experienced by individuals with SCI, from survival to quality of life, as measured at a population level, as well as effects in the health system in terms of efficiency


As indicated in the diagram, these domains may be characterized in terms of “soft” and “hard” progress. The first three, environment, research, and application of insights all represent the potential for actual progress in outcomes at a population level. Outcomes are the ultimate end-point of the process, and the marker of progress that is of greatest interest.

There are a number of themes under each domain that will be examined by means of a search in the biomedical literature and pertinent grey literature\(^{24}\) documents. The aim is to provide selected information on each topic that will demonstrate the degree of progress that has been achieved in recent decades.

\(^{24}\) The term ‘grey literature’ refers to documents available outside of the formal channels of publication and distribution. Examples include scientific and technical reports, government documents, theses, and so on.
Environmental Progress

All the current environmental taxonomies consistently include physical, attitudinal, and policy factors. They also include factors at all 3 of the environmental levels—the micro (personal), meso (community/services), and macro (societal/systems) levels. Together, the taxonomies show that environmental factors are far more than just physical barriers to mobility; they include all external influences on health and how people live their lives.²⁵

Before turning to the more traditional topics of biomedical research, application, and outcomes, it is important to acknowledge that there is a broader social context in which individuals with SCI must live and operate. In the present report, this context is referred to as the environment. It is arguable that environmental progress has been as valuable for individuals with SCI as the various improvements in other arenas. For example, a 2004 paper noted that acute treatments aimed at neurologic preservation in SCI have been shown to predict outcomes such as mortality, independence in activities of daily living, and certain medical complications.²⁶ However, standard acute treatments are not strong predictors of perceived stress, long-term employment stability, life satisfaction, marital stability, perceived well-being, or quality of life. Instead, “these outcomes are influenced by such diverse factors as family support, adjustment and coping, productivity, self esteem, financial stability, education, and the physical and social environment.” In response to these factors, ones that are not directly related to an injury and its treatment, the perspective on what needs to be addressed in SCI (and disability in general) has steadily broadened in recent years.²⁷ In this regard, certain countries have led the way; for instance, during the 1980-2002 time period, “several advances were made in the United States that articulated the significant role of the environment in the lives of people with disabilities.”²⁸

While recognizing that environmental factors may be found at multiple levels, from the personal to the societal, this section will focus mostly on the larger scale. Other sections of the report will address interventions targeting the individual; here the concern is the role of environmental factors that affect whole populations. The following areas of progress will be discussed in subsequent sections:

- Organizational infrastructure, that is, the growth in the organizations dedicated to SCI-related advocacy, investment, research, etc.
- Legislative and policy frameworks aimed at improving the lives of individuals with SCI, especially with respect to employment
- Sports organizations and events, as one key example of an environmental sub-domain that promotes participation and (it is hoped) enhances life satisfaction
- Public and professional attitudes impacting upon individuals with SCI
- Preferences in the SCI community, in other words, the climate where the opinions of those with SCI are consulted and actually count

Organizational Infrastructure

Research, advocacy, and service delivery in health care are typically undergirded by formal organizations of patients, professionals, and other stakeholders. This is an important component of the “environment” within which a disease or conditions exists—and this is no less true for the sphere of SCI. Associations, foundations, and institutes devoted to the study of SCI and the support of those with the condition have expanded dramatically since the 1940s, when the first such organizations were established to work with and for injured veterans of World War II. The introduction of penicillin in this period meant that SCI patients who would have previously died from infection were now surviving in larger numbers; to help meet their needs, groups such as the Canadian Paraplegic Association and the Paralyzed Veterans of America were organized in 1945 and 1946, respectively. The creation of these groups inspired the formation of similar support groups for civilians, as well as organizations for health care professionals focused on SCI. From these roots, the complement of SCI-related organizations has continued to grow. As noted in the Introduction, the last 25 years has especially been marked by a flood of new organizations around the world that are dedicated to SCI and affected individuals.

The following table provides a selected inventory of recently launched organizations.

<table>
<thead>
<tr>
<th>Name</th>
<th>Location</th>
<th>Founded</th>
<th>Key Activities/Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Networks, Alliances, and Federations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consortium for Spinal Cord Medicine</td>
<td>Washington, DC</td>
<td>1995</td>
<td>Develop, produce, and disseminate evidence-based clinical practice guidelines (CPGs)</td>
</tr>
<tr>
<td>International Campaign for Cures of Spinal Cord Injury Paralysis</td>
<td>Multiple sites</td>
<td>1998</td>
<td>A network of 13 organizations funding research into cures for paralysis caused by spinal cord injury. Co-founded by the Rick Hansen Foundation.</td>
</tr>
<tr>
<td>European Spinal Cord Injury Federation</td>
<td>Office in Nottwil, Switzerland</td>
<td>2005</td>
<td>Collaboration of national organizations from 19 countries</td>
</tr>
<tr>
<td>North American Clinical Trials Network for the Treatment of Spinal Cord Injury</td>
<td>Nine hospitals across North America, including one in Toronto</td>
<td>2006</td>
<td>Connected research centres developing therapies for SCI and performing clinical trials. An initiative of the Christopher &amp; Dana Reeve Foundation supported by the American Department of Defense/Veterans Health Administration</td>
</tr>
<tr>
<td>The Spinal Cord Injury Network</td>
<td>Australia and New Zealand</td>
<td>2008</td>
<td>An alliance of researchers, clinicians and people with spinal cord injuries; the alliance currently consists of more than 35 organizations and 900 individuals</td>
</tr>
<tr>
<td><strong>Foundations and Trusts</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rick Hansen Foundation</td>
<td>Richmond, BC</td>
<td>1988</td>
<td>Funds research into high impact innovations that will accelerate a cure for SCI and improve quality of life for those with SCI</td>
</tr>
<tr>
<td>Spinal Cord Society of New Zealand</td>
<td>Matamata, New Zealand</td>
<td>1988</td>
<td>Established SCI research centre within the Centre for Innovation at the University of Otago, Dunedin, New Zealand</td>
</tr>
<tr>
<td>Mike Uley Foundation</td>
<td>Orlando, WA</td>
<td>1992</td>
<td>Offers financial support to pursue an effective treatment for SCI</td>
</tr>
<tr>
<td>Spinal Cure Australia</td>
<td>East Sydney, NSW, Australia</td>
<td>1994</td>
<td>Aims to end the permanence of SCI through promoting and funding research, fostering cooperation between medical disciplines, and monitoring research progress</td>
</tr>
<tr>
<td>Christopher and Dana Reeve Foundation</td>
<td>Short Hills, NJ</td>
<td>1995</td>
<td>Dedicated to curing spinal cord injury by funding research, and improving the quality of life for people living with paralysis through grants, information, and advocacy. Formerly the American Paralysis Foundation (est. 1982), reinvigorated by the involvement of Christopher Reeve and his supporters</td>
</tr>
<tr>
<td>International Foundation for Research in Paraplegia</td>
<td>Chêne-Bourg, Switzerland</td>
<td>1995</td>
<td>Promotes and funds clinical research related to SCI</td>
</tr>
<tr>
<td>Morton Cure Paralysis Fund</td>
<td>Minneapolis, MN</td>
<td>1995</td>
<td>Funds proof-of-concept data that allows researchers to pursue grants from larger foundations</td>
</tr>
<tr>
<td>Neil Sachse Foundation</td>
<td>Adelaide, South Australia, Australia</td>
<td>1995</td>
<td>Raises funds and lobbies for government funding for SCI treatments and technologies. Established a research centre at the University of Adelaide as a centre-of-excellence.</td>
</tr>
<tr>
<td>Japan Spinal Cord Foundation</td>
<td>Tokyo, Japan</td>
<td>1996</td>
<td>Promotes research into regeneration, rehabilitation, and development of care systems</td>
</tr>
<tr>
<td>Sam Schmidt Paralysis Foundation</td>
<td>Princeton, NJ</td>
<td>2000</td>
<td>Funds research, treatment, rehabilitation and technological advances</td>
</tr>
<tr>
<td>South Carolina Spinal Cord Injury Research Fund</td>
<td>Charleston, SC</td>
<td>2000</td>
<td>Funds the Rehabilitation Research and Training Center on Secondary Conditions in Individuals with SCI (University of South Carolina), as well as other research initiatives</td>
</tr>
<tr>
<td>Craig H. Neilsen Foundation</td>
<td>Encino, CA</td>
<td>2002</td>
<td>Fund programs supporting SCI research, rehabilitation, and training for SCI professionals</td>
</tr>
<tr>
<td>Wings for Life</td>
<td>Salzburg, Austria</td>
<td>2004</td>
<td>Promotes research worldwide in order to expedite scientific and clinical progress towards a cure for SCI paralysis</td>
</tr>
<tr>
<td>CatWalk Spinal Cord Injury Trust</td>
<td>Masterton, New Zealand</td>
<td>2005</td>
<td>Raises funds to support research for a cure for SCI</td>
</tr>
</tbody>
</table>
As the table indicates, four categories of SCI-related organizations may be helpfully identified:

- International networks and federations of organizations that maintain their individual identity while cooperating on one or more key SCI agendas
- Foundations, mainly focused on fund-raising and grant-making
- Advocacy and support organizations driven by (and serving) patients, professionals, or other stakeholders
- Institutes focusing on management of actual research activity

Sometimes new groups have been formed through amalgamation of two or more existing organizations, or through a major reshaping and re-energizing of a group with a long history. At the same time, organizations are collaborating with more regularity, forming networks such as...
the International Campaign for Cures of Spinal Cord Injury Paralysis, as well as establishing
databases and research initiatives that cross provincial and national borders.

This reality of an extensive organizational infrastructure has generated both direct and indirect
benefits for people dealing with SCI either personally or professionally as health care
providers. The indirect effects relate to the sheer presence of the SCI theme in the public,
academic, and health care spheres, and the encouragement and hope this engenders for those
impacted by SCI. Notably, the profile of SCI has been enhanced through efforts such as Rick
Hansen’s Man in Motion World Tour in the early 1980s and his subsequent organizational
efforts, as well as the advocacy and fund-raising work of Christopher Reeve after his high-
profile injury in 1995.

Legislative and Policy Frameworks

Nations worldwide in the last generation have introduced legislative measures on the human
rights and social needs of persons with disabilities.29

The general goal of legislation is to create a healthy and balanced society. This is achieved
through a variety of means, including allowing, mandating, or restricting certain actions. Legal
and policy frameworks constitute an important part of the environment in which SCI exists.
Although very little legislation is related to SCI per se, a number of broader legal frameworks
have been established in different parts of the world that influence the way in which individuals
with SCI interact with their local community and wider society. Progress related to two
categories of legislation and policy will be briefly reviewed here; another closely related arena,
legislation to prevent injuries such as SCI, will be addressed in a later section of the report.

Disability Legislation

Progress on disability rights in recent decades has been marked by substantial growth,
developing from a “nascent movement” in the mid-1970s to an agenda with mixed results and
an uncertain future in the 1980s and finally to breakthrough legislation in a number of
industrialized countries starting in the 1990s.30,31 Selected laws, listed in order of their
enactment, are indicated below:

- 1990—Americans with Disabilities Act (ADA)
- 1992—Disability Discrimination Act of Australia
- 2001—Ontarians with Disabilities Act
- 2005—Accessibility for Ontarians with Disabilities Act
- 2008—ADA amended
- 2008—UN Convention on the Rights of Persons with Disabilities32

At each stage of policy-setting, a complex discourse has prevailed around the meaning of and
approaches to disability.33,34,35,36 The laws that have been developed seek to provide people

29 Prince MJ. What about a Disability Rights Act for Canada?: Practices and lessons from America, Australia, and
30 Scotch RK. Politics and policy in the history of the disability rights movement. Milbank Quarterly. 1989; 67 Suppl
2 Pt 2: 380-400.
with disabilities more options and opportunities with respect to employment, access to facilities, access to services (including health care), transportation, and appropriate shelter. Physical access is often important for “opening the door” in more than one way, such as being able to attend classes in order to enhance marketable skills and employability. The issue of particular importance for those with SCI is, of course, wheelchair accessibility. This theme will be revisited in a later section of the report.

It is notable that the legislative milestones have all occurred in the last two decades. The SCI community, as part of the broader disability arena, played its part in setting the pace for this impressive record. It began with the Americans with Disabilities Act (ADA), which “established full participation as the societal goal for all people with disabilities, and ensured their right to reasonable accommodation to achieve that goal.”

In most cases, the various national laws have built upon previously laid legal foundations related to civil rights, and are worded accordingly. The ADA, for example, defines failure to make services or employment opportunities accessible for those with disabilities as a form of discrimination. While this sort of framing does facilitate legal recourse for those with disabilities, it also has the unfortunate result of defining the societal agenda of individuals with conditions such as SCI in negative terms—in other words, the mandate to support persons with disabilities is shaped by unacceptable behaviours rather than positive initiatives. The latter approach could include the requirement for affirmative action in education, employment etc., as well as provision of resources to accommodate and promote involvement by disabled persons. In short, a prohibition against discrimination is generally not enough to improve the quality of life for individuals with SCI and other disabilities. This is why concerns have sometimes been expressed about laws such as the ADA, as well as the Disability Discrimination Act of the UK. The critiques levelled have been partly motivated by the static nature of employment levels among the disabled in general and individuals with SCI in particular (see the pertinent section on this sub-domain later in the report).

For these reasons, some national organizations have expressed caution about adopting disability legislation along the lines of the U.S. and UK models. An article published by the Council of Canadians with Disabilities expresses the opinion that existing human rights and employment equity laws should already apply to everyone—including the disabled—thus making additional

legislation unnecessary. At the same time, others consider the ADA a success, and would like to see it reflected in a similar Canadian law.43 A recent analysis has suggested that this would be a complex endeavour, with success depending on bringing a distinct Canadian perspective to bear; this includes a “positive action” framework that is aimed at an agenda of actual investments rather than stating principles (i.e., related to discrimination) that tend to generate law suits and court rulings more than population-level improvements.44

Certainly, the need to add a policy implementation plan, including resources, to basic laws is well-recognized in Canada. Since 1997, the Canadian government has provided $30 million annually to help people with disabilities achieve their employment goals, via the Opportunities Fund for Persons with Disabilities.45 In 2003, the federal government and the provinces went further, developing Labour Market Agreements for Persons with Disabilities (LMAPDs); these are bilateral, cost-shared agreements designed to generate funding for programs and services that improve the employment situation for Canadians with disabilities, including SCI. The Government of Canada transfers $218 million annually to the provinces for the LMAPDs.46 This overall effort is consistent with the ongoing commitment in other jurisdictions to offer training, job placement, and workplace support services to persons with disabilities.47,48

Legislation Concerning Research

Another area where legislation more directly affects those with SCI is in the field of basic research. For example, between 2001 and 2009, investigation in the promising area of stem cells was limited in the United States by a presidential order because of the controversial nature of a key source of such cells, that is, human embryos. While President Obama signed a more liberal policy related to human embryo stem cells in March 2009, the issue continues to be an apt reminder that politics and policy have the potential to affect those with SCI in important ways.49,50

45 Refer to http://www.hrsdc.gc.ca/eng/disability_issues/funding_programs/opportunities_fund/background.shtml
Sport Organizations and Events

Sports participation with adaptations is expanding and includes a larger variety of organizations and leagues.\(^{51}\)

Sport has the ability to challenge individuals and change societal perceptions—factors of particular importance for individuals with disabilities such as SCI. While it is true that sporting infrastructure (regulatory bodies, federations, funding, etc.) are closely related to the theme of participation in recreation and organized sports (see pertinent section below), it deserves its own consideration as part of the environment in which individuals with SCI “live and move and have their being.” Because of mounting public events with (increasingly) good media coverage, the value of sporting infrastructure extends beyond the impact of physical fitness in the direct participants. As a visible reversal of stereotypes, sports can decrease stigma, accelerate an agenda of inclusion, and emphasize achievement rather than impairment—in addition to the function of role models that encourage individuals with a disability such as SCI to take up physical activity as much as possible.\(^{52}\) While it is not appropriate to isolate SCI in this context, given that infrastructure and events typically cover a number of disabilities, it does represent an important subset of participants. Indeed, SCI, along with other wheelchair-dependent conditions, has been a driving force throughout the history of disabled sports.

The history is longer than just the past 25 years. Following the Second World War, Dr. Ludwig Guttman introduced sport in the UK context as a component of rehabilitation for individuals who had suffered SCI in the context of battle. Thus, from the start, sport represented more than a leisure activity; it was seen as a way to improve physical fitness, and endurance, combat fatigue, restore pleasure in life, and aid in social reintegration. In 1948, a sports festival was held on the lawns of the Stoke Mandeville Hospital, the home of the National Spinal Injuries Centre. Competitions continued in following years, ultimately acting as a direct antecedent to the modern Paralympic Games.\(^{53}\)

The Paralympic Games are the pinnacle of disabled sport—though only representing the tip of a much larger framework that supports many other activities and sports events between the official Olympic years. The Paralympics still offers the best proxy measure of growth, organization, and professionalism in disabled sport, as it brings together many of the sport-specific federations and regulatory bodies; indeed, the organizing committee actually acts as the international federation for 13 of the 25 official Paralympic sports.

Recent growth in the Paralympics has been remarkable. Some of the most notable achievements of the last 25 years include:

- 1988: first Paralympics since 1964 that were held in same city as the Olympics
- 1988: first time the term ‘Paralympic’ came into official use
- 1989: establishment of the International Paralympic Committee (IPC)
- 1996: first mass-media sponsorship of the Paralympic Games
- 2008: full integration of the Olympic and Paralympic organizing committees


Over this same time period, the number of nations participating in the Winter Paralympics doubled from 22 to 44, with the Summer Paralympics seeing even greater growth (involvement rising from 61 to 146 participating nations).  

As suggested above, sport has the ability to change attitudes and foster the agenda of inclusion; nowhere is this accomplishment more apparent than in the Paralympic story. When China was invited to the Games in 1960, the official response was that there were no disabled people in China! Since that time, the country has made significant changes. In 1983, the Chinese Sports Association for Disabled Athletes was established and, by 2004, China won the most Paralympic medals. Hosting the Olympics and Paralympics in the summer games of 2008 marked further progress. For instance, the Beijing Municipal People’s Congress adopted the country’s first local legislation relating to barrier-free access at public facilities. This continues to demonstrate the power of sport in particular and physical activity in general to move a society beyond stigmatization and towards acceptance and inclusion.

The profile of SCI in the context of sport advanced dramatically with the involvement of Rick Hansen in the opening ceremonies of the Olympic and Paralympic winter games hosted by Vancouver in 2010—Metro Vancouver of course being the headquarters of the organizations founded by Mr. Hansen.

Progress continues apace as London has affirmed 8 commitments for the Paralympics in 2012, including maximizing media coverage and training all Games staff in the principles of inclusion. However, challenges do remain. Media coverage tends to focus on the courage of Paralympic athletes rather than their physical accomplishments. So, while it is true that sporting infrastructure and events have helped to advance the agenda of inclusion for individuals with SCI and other disabling conditions, other hurdles involving public perception still need to be overcome.

**Public Perceptions and Attitudes**

The term “attitude” may be defined as a learned evaluative response, either positive or negative, directed at an object or person. Attitudes may be beliefs or feelings held toward ideas, objects, or people that predispose a person to behave a certain way. In studies of societal attitudes, there is little information specific to individuals with SCI; more commonly, it is attitudes toward disabled people as a whole that have been evaluated. The term “disabled” encompasses deficits in physical function (including those experienced by individuals with SCI), sensory impairments, and chronic illness, as well as emotional, mental, and behavioural problems.

A generally positive attitude towards people with disabilities is critical for fostering an inclusive society— that is, a social context in which disabled people have the same opportunities as other citizens to participate in the economic, cultural, political, and spiritual life of the community.

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It is important to note that equity of opportunity involves more than intangibles like perceptions and attitudes. For example, reducing physical barriers is another component of creating an inclusive community; initiatives in this area include modifications to buildings and public transport systems to improve wheelchair accessibility. This topic will be explored further in a later section of the report.

Not surprisingly, measuring and then reducing attitudinal barriers tends to be more challenging than the related tasks with physical barriers. As discussed in the previous section, in the past 25 years, disabled people have campaigned for a “human rights” approach to disability, resulting in pertinent legislation in the U.S., the UK, and various other countries. This has increased the sense that stereotypes, disability-related discrimination, and generally negative attitudes are no longer socially acceptable. Other, more direct “public relations” efforts have also had a positive effect. Rick Hansen’s *Man in Motion World Tour* was instrumental in changing attitudes toward disabled people, as described in Mr. Hansen’s words.60

*Looking back, the greatest impact of the Tour was and always will be the human side of the mission, which was to inspire people as to the potential of people with disabilities—to cause people to think differently about what was possible for anyone when barriers are removed, attitudinal or physical.*

There is some evidence that attitudes to disability in general (and SCI in particular) are improving. In the 2004 Canadian Attitudes Towards Disability Issues survey, there was broad agreement among people with and without disabilities that Canadian society has made progress in becoming more inclusive toward people with disabilities. Respondents did indicate, however, that people with disabilities still face a number of barriers, including negative attitudes. Similarly, in the UK 2002 Attitudes Towards Disability Study, most of the 2064 respondents (of whom 47% themselves had a disability) believed that there had been improvement in the position of disabled people in society, but that structural and attitudinal barriers still remained.61 Results from Ireland’s National Disability Authority 2006 Survey of Attitudes to Disability suggested that attitudes had become more enlightened in that country since the equivalent 2001 survey.62

Some of the key strategies for further countering negative attitudes include expanding education about disability, improving media representation of people with disabilities, and increasing integration of disabled and non-disabled people in public activities and events.63 While some progress has been made in the area of perceptions in the past 25 years, there is still much work to be done in removing attitudinal (and other) barriers to inclusion.

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60 Refer to http://www.rickhansen.com/code/navigate.aspx?Id=48


Preferences in the SCI Community

Nowadays, health researchers, funding agencies, governments, and patient organizations are beginning to acknowledge that the passive role of patients in health research is no longer satisfactory.64

Attitudes found in the environment occupied by the SCI community have been gradually changing in a very specific way: How actively and respectfully the opinion of those with SCI is being pursued in shaping priorities for further investigation. In fact, there are a variety of means that could be used to establish priorities for research and the development of clinical guidelines. These include consulting with those directly or indirectly affected by a condition like SCI (e.g., through surveys, advisory groups, etc.), building a consensus of professional opinion, and/or some sort of objective evaluation based on incidence of a complication, its health outcome, the related economic burden, etc. For a variety of reasons, professional consensus has often been a dominant voice in this regard.65 As noted by Abma, “traditionally, patients are rarely seen as partners in health research; their influence on priority setting, research design, the undertaking of research, and interpretation and dissemination of findings has often been marginal at best.”66

In order to evaluate the relative importance of research into functional recovery for SCI, Kim Anderson conducted a survey of 681 individuals with SCI.67 Subjects were asked “What gain of function would dramatically improve your life?” and then asked to rank seven functional recoveries in order of importance; for each function, the percentage of individuals with paraplegia and quadriplegia who ranked it highest is shown in the following chart:

![Graph showing areas of functional recovery ranked as highest priority for individuals with quadriplegia and paraplegia](chart.png)


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The area of functional recovery ranked highest by individuals with quadriplegia was arm/hand function, whereas among individuals with paraplegia sexual function was given the highest priority. Note that the main purpose of this study was to ascertain what functions are most important to the SCI population in regard to enhancing quality of life.

In 2009, the Rick Hansen Institute initiated a study which involved a literature review, a web-based poll of almost 300 people with SCI or who worked with patients, and an electronic survey of 9 Canadian physiatrists specializing in the management of patients with SCI. There was good agreement among these sources of information on the major concerns facing patients with SCI and the health care system. The results (shown below) for one of the questions from the web-based poll (posed to persons with SCI only) illustrate the overall pattern.

Bladder function/UTIs, pain management, pressure ulcers, and bowel complications were at the top of the priority list, with the next choice(s) then being more equivocal.

The web-based survey conducted by RHI differed from the work by Anderson in that it focused on secondary complications of SCI; thus, categories such as arm/hand function, trunk stability and walking movement were not available responses in the RHI survey, as these are not considered secondary complications.

These types of exercises illustrate the potential role for those with SCI in shaping the research and care agenda for the next 25 years.

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Research Production

Developing strategies and infrastructure for emergency and early acute care delivery in SCI dominated most of the last century. The basic target was ensuring that people with SCI survived beyond the first few days after the presenting trauma. It was not until the 1980s that a broader research agenda became a primary focus of SCI-related organizations; as seen in the Environmental Progress section of this report, many research centres were in fact launched in the last 25 years. Largely considered a “severe and irreversible” condition before that time, experimental results began to generate hope that the effects of SCI could be mitigated, and the condition even cured. Existing organizations expanded their focus, and many foundations were initiated to provide support for ongoing studies—notably dedicated to the effort to find a cure. In more recent years, additional foundations and research institutes have started all over the world, sometimes reflecting new and unique goals; although the pursuit of a cure is still a key driver of SCI research, more work is now being supported on quality of life issues, aging with SCI, etc.

Publication Volume

The first fact to notice is that the volume of scientific publishing has expanded dramatically. Simple citation analysis in the biomedical literature demonstrates that the number of studies related to SCI appears to have steadily climbed over the last quarter century (see the diagram below), increasing by 500%; the number of clinical trials expanded by an even higher factor.

It is important to not over-interpret this picture; the publication of more articles is partly an artefact of founding of new SCI-related journals. It is true that the last 25 years has seen a number of important journals launched, as shown in the following table.

Finally, while it is true that similar expansion in publishing (as a proxy for research activity) would be observed for other medical fields, it is encouraging that leaders, funders, and investigators in the SCI sphere have at least kept pace with the drive to make scientific progress in a number of critical areas affecting individuals with this devastating condition.

**Basic Investigation of Potential Cures**

*The central nervous system has limited capacity of regenerating lost tissue in slowly progressive, degenerative neurological conditions such as Parkinson's disease, Alzheimer's disease or Huntington's disease, or in acute injuries resulting in rapid cell loss for example, in cerebrovascular damage (for example, stroke) or spinal cord injury.*

The most extensive feature of a nerve cell or neuron is the long nerve fibre known as the axon that conducts signals away from the cell body, as illustrated in the adjoining diagram. The biological impediment creating the greatest challenge in SCI research is the fact that central nervous system (CNS) axons of mammals essentially do not regenerate after an injury. It seems that the environment within the CNS, especially following trauma, effectively inhibits the repair of myelin and neurons. A further challenge involves the degeneration after axons are first damaged by SCI, as described in a 2009 review in *Neuroscientist*.

...a direct impact to the spinal cord initiates an injury response that unfolds as a series of cellular and molecular events in the

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subsequent hours, days, and weeks. Primary injury involves direct cell death and bleeding that is caused by the initial mechanical damage sustained. However, within hours, further tissue damage begins to occur around the injury core. This secondary damage involves a cascade of vascular, biochemical, and cellular events.

A final phenomenon of interest is the property known as neuroplasticity, that is, “the capacity of the nervous system to modify its organization…as a consequence of many events, including the normal development and maturation of the organism, the acquisition of new skills ('learning') in immature and mature organisms, after damage to the nervous system and as a result of sensory deprivation.”76 While still not well understood, neuroplasticity is thought to be an important mechanism in potential rehabilitation after SCI, whether accomplished by physical training, drugs, or other intervention.77,78,79,80,81,82

The three biological phenomena introduced above provide a map to the main pathways of basic SCI research, as follows:

- Preventing further neurological damage (such as neuronal death) after SCI (sometimes referred to as neuroprotection)
- Restoring neurological (and thus motor/sensory) function without full organic repair (or neurorehabilitation)
- Restoring neurological (and thus motor/sensory) function with actual reversal of organic damage (i.e., a repair or cure)

Tremendous effort has been exerted in all three arenas over the last 25 years, with major breakthroughs, at least in terms of basic science. For instance, “multiple mechanisms limiting central nervous system regeneration have been identified.”83 Nonetheless, there is perhaps no other section of this report that raises more questions about how to define true “progress.” When basic science insights have been moved into the realm of clinical investigation in humans, observed results have been negative or, at best, modest.84,85 On the other hand, the ongoing quest for the “holy grail” of a full cure still continues to generate promising insights, some of which have begun to influence other areas of management.86

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appears to have progressed furthest in this regard. The exploitation of neuroplasticity using a functional training program is now well established; in recent years, this has included the application of robotic devices to allow for longer training sessions, feedback information systems, etc. A current hope is that some form of combination therapy will be effective in SCI, specifically where regeneration stimulation and rehabilitation regimens are brought together.

Above all, optimism in this area of research is sustained by the remarkable fact that experimental SCI in model animals is no longer incurable, as well as by the advances seen in potential stem cell therapies and the development of imaging tools critical to monitoring any axonal re-growth. A more cautious assessment arises from the relatively slow pace of investigating clinical applications of experimental breakthroughs, and the mixed results from the few human trials that have been pursued. Most authorities and advocates agree that a positive attitude should prevail. The latter is important for maintaining hope in those living with SCI and for making sure that research resources continue to be made available. It would be unfortunate to not continue exploring the promising avenues and building upon the many basic scientific gains that have already been achieved.

**Evolution of Research Focus: Duration and Quality of Life**

*Stem cell research is just one of the many avenues being explored by SCI researchers. Addressing the needs of individuals with SCI means looking beyond the cellular level. There are many active areas of multidisciplinary research in engineering, medicine, surgery, psychology, pharmacology, nursing, technology and outcomes.*

There have been pendulum swings in SCI-related research priorities. Prior to the 1980s, there was reportedly a shift away from longer-term rehabilitation and chronic care themes to acute interventions, and especially exploration of strategies to reverse SCI at an organic level (see the preceding section). While the most fundamental investigations of reducing or reversing SCI-related paralysis will likely continue apace into the future, the last 25 years has been marked by a rise in research goals related to increasing both survival rates and quality of life of those afflicted with SCI. These two goals are connected in a very important way. Thus, as survival has improved and more individuals with SCI are living longer (see the specific section below on this theme), the need to effectively address secondary complications has intensified. Responding to the various *chronic* aspects of SCI is especially integral to the quality of life enjoyed by individuals now living with SCI into their 60s and beyond.

Basic research is vital to informing clinical trials that ultimately lead to evidence-based protocols along the entire continuum of care for individuals with SCI. The latter includes:

- Pre-hospital care by emergency medical services
- Acute management limiting damage and initial complications in traumatic SCI
- Rehabilitation aimed at restoration of function to enable better social reintegration
- Long-term management of secondary complications of SCI

Progress in the first two spheres has enabled a decrease in early mortality, whereas progress in the latter two areas has allowed for increased productivity and enjoyment over life-spans that are now measured in multiple decades rather than months or years. Some of the basic research agendas in these areas will be outlined below.

**Pre-Hospital Care**

Basic aspects of pre-hospital (and emergency room) care in SCI are well-accepted, including the ABCs of initial assessment and resuscitation: airway, breathing, and circulation. However, other specific therapies preceding transport to the hospital remain unproven or at least controversial.95

A potential cause of secondary injury in cases of spinal trauma, especially in the context of pre-hospital care, involves the "inadvertent manipulation of the spinal cord in the setting of an unstable spinal column injury."96 As a result of this concern, specific practices have emerged. For example, over the course of the 1980s and 1990s manual in-line stabilization became the standard of care for airway management (both pre-hospital and in the emergency room) for patients experiencing a trauma to the upper spinal cord.97

As well, spinal immobilization through the best available means is very commonly applied, even though only a small percentage of trauma patients actually sustain SCI. This reality has been reinforced in countless media reports, movies, etc. featuring the iconic image of trauma victim strapped to a rigid board, usually wearing a neck collar. A 2010 review of this area examined the pertinent scientific literature from 1966 to 2008.98 Notably, all of the research located on the topic dated from 1987 and later, in other words reflecting the period of interest to this report. Two overarching issues were the focus of the reviewers:

- Whether pre-hospital care providers could be trained to reliably assess whether a trauma sufferer had experienced an actual SCI
- The optimal type and duration of spinal immobilization in the instance of SCI

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There was modest evidence available on the first question, suggesting that further research is needed, especially to identify a standard triage algorithm.\(^99\) The experimental work informing the second question was more voluminous, with 25 pertinent studies identified. Various configurations of equipment producing vertebral column immobilization can be effective. Information about optimal duration is scarcer, suggesting that there is more room for basic and clinical research in this area. The issue at hand is the tendency for lying on a rigid board to increase pressures at the occipital and sacral points, leading to ulcers; other problems may also develop, including swallowing and breathing. This makes it all the more important to move beyond basic research to clinical investigation. In fact, it may not be ethical to conduct a trial pitting immobilization against non-immobilization; this is similar to the ethical and other obstacles to pursuing controlled trials of whether or not manual in-line stabilization should be applied during airway management.\(^100\) However, it is at least feasible to compare different methods of immobilization following suspected SCI. Since a 2007 Cochrane review suggested that no such trials of different immobilization strategies had yet been conducted,\(^101\) the potential for making more progress in this area of research is clear.

**Acute Management**

Individuals who sustain an SCI and reach the hospital may experience multiple early complications as a result of the injury, and are therefore at high risk of mortality. While the proximal injury mechanism—usually rapid spinal cord compression caused by a fracture—is irreversible, the secondary injury mechanisms are preventable and may be reversible. These secondary mechanisms lead to tissue destruction within the first few hours after injury. Research around strategies for acute management of SCI, which tend to be neuroprotective in nature, fall into two main categories: surgical and pharmacological.

**Surgical Treatment**

There are two goals related to surgery for SCI: realignment/stabilization of the spinal column (sometimes known as fixation) and decompression. While extensive research has occurred with respect to spinal fixation,\(^102\) investigations related to decompression have been more limited. The aim of decompression surgery is to increase blood flow (and thus oxygen) to the damaged area, potentially leading to a better neurological outcome. The evidence for benefit to the patient is mixed, however, with compelling outcomes from animal studies but less substantive results from human clinical trials.\(^103\) The timing of surgery is also the subject of some debate, with clinical benefits being weighed against potential risk of aggravating secondary injury when surgery is conducted less than 24 hours post-injury.\(^104\) An RHI-funded review of the pertinent studies ultimately suggested that early surgical decompression (< 24 hr) can reduce the overall length of hospitalization, decrease the length of stay in the intensive care unit,


improve neurological outcomes, and reduce the number of secondary complications following injury.\textsuperscript{105}

The continuing debate about timing of surgical interventions inspired a new investigation, entitled Surgical Treatment for Acute Spinal Cord Injury Study (STASCIS); the aim was to see whether the consensus developing in the literature could be confirmed. This multicentre trial is ongoing, but early results have been encouraging; 24.2\% of patients who underwent surgery within 24 hours of injury improved two steps on the American Spinal Injury Association (ASIA) Impairment Scale, while only 9.6\% of those treated more than 24 hours post-injury achieved the same result.\textsuperscript{106} Additionally, those treated within the first 24 hours post-injury appear to have 20\% fewer complications than those treated afterwards.\textsuperscript{107} Final results from STASCIS will be used to inform best practices in the area of spinal decompression surgery. The expectation is that the trial will lead to significant improvements in acute care for individuals experiencing traumatic SCI, while reducing health care costs.

\textbf{Pharmacological Treatment}

Pharmacotherapy in the acute stages of SCI is aimed at limiting secondary injury via various mechanisms, including modulating the immune/inflammatory response, apoptosis, excitotoxicity, or lipid peroxidation. Methylprednisolone was the first pharmacotherapy proven to affect neurologic outcome after SCI in randomized human trials; however, the studies have been highly criticized, with concerns being raised regarding methodology and data quality, as well as increased risks of infections and other complications.\textsuperscript{108}

While steroids such as methylprednisolone are now standard in acute SCI care,\textsuperscript{109} antibiotics have begun to be introduced as an alternate pharmacotherapy. Minocycline is a tetracycline derivative that shows enhanced uptake into the cerebrospinal fluid and a longer half-life compared with first-generation tetracyclines. In addition to its antimicrobial activities, minocycline has demonstrated neuroprotective effects in a number of animal models of neurologic disorders, including SCI. Various positive impacts have been associated with minocycline, including reduced neuronal cell death and decreased inflammation; related physical benefits include smaller lesion size and sparing of spinal cord tissue.\textsuperscript{110,111,112}

Building on this knowledge, RHI funded a single-centre, double-blind, placebo-controlled pilot study evaluating the effectiveness of intravenous minocycline in acute treatment of SCI (< 12 hours after injury). Promising preliminary evidence from this study indicates that treatment


with minocycline results in enhanced motor recovery and improvements in other functional outcomes; results have been received very positively by the research community, with a number of experts acknowledging the clinical potential of the project. The trial is currently being expanded to include multiple participating centers.  

There are various other pharmacotherapies currently being researched for possible use in the acute management of SCI; some that have entered human clinical trials include riluzole, a sodium channel-blocking agent that is reported to have neuroprotective properties, and Rho antagonists, which show promise in promoting axonal sprouting and regeneration.  

Rehabilitation

In the past quarter-century, there have been significant advances in rehabilitation therapies for individuals with SCI. Research in this area is mainly focused on improving functional outcomes; key areas of SCI rehabilitation research include functional electric stimulation (FES), brain-based command signals, and locomotor training.  

The use of electrical stimulation devices to overcome functional limitations in people with SCI has become commonplace over the last 25 years. FES works by generating muscle contractions through stimulation of peripheral nerves by electrodes. Electrodes can either be placed on the surface of the skin or implanted subcutaneously; although implantation is more invasive, it has the advantage of precise stimulation of target muscles. Functional improvements in upper- and lower-extremity use, bladder control, respiration, and cardiovascular and tissue health have been demonstrated through the use of FES systems. To date, various types of neuroprostheses based on this technology have been commercialized, while others are at the clinical testing stage. However, commercial success for such systems has been limited due to the high cost of the equipment and various technological shortcomings. Currently, researchers are making use of advances in design (such as decreasing the physical size and costs of devices) and methodology (such as implantation techniques that lower the risk of infection) in order to develop a “totally implantable, easily manufactured, modular FES system that can be used for all purposes.”

The cutting edge of rehabilitation engineering research includes the use of brain-based command signals for controlling assistive technology. Similar to FES, the approach involves electrodes that are either placed on the surface or implanted at various levels between the surface of the brain and the scalp; this enables the collecting and processing of brain signals. Such an “awareness” system has the ability to integrate and reflect “functional activities, context, previous experience, human and social behaviours, physiology, physical capacity, and

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cognition.” While no clinical product is yet available, trends indicate that this type of adaptive technology presents the future of SCI rehabilitation.

Understandably, the restoration of walking function is a high priority for individuals with SCI. There have been a number of interventions introduced in the past decade that have improved the ambulatory function of those with incomplete SCI. These include task-specific functional training performed by physiotherapists, in combination with manual or robotic assisted bodyweight-supported treadmill training.

As evidenced in this section, technology has and will continue to play a vital role in ongoing research related to the SCI continuum of care. This appears to be especially true of the rehabilitation phase, as researchers have successfully translated technological advances into functional gains for individuals with SCI—with a number of additional gains within reach. Techniques such as FES, which today is used to address individual functional limitations, is on the cusp of being able to provide multiple benefits simultaneously. The fact that even more advanced approaches using brain signals are now considered feasible is a testament to the vigour with which researchers approach this area of SCI care.

Secondary Complications

As summarized by an international study team in 2006, “injury to the cervical and upper dorsal spinal cord produces a variety of changes in the physiological function of different body systems.” Thus, while loss of function is one of the most immediate and serious consequences of SCI, many other conditions related to the injury also require medical management. In recent years, for example, chronic or recurring secondary complications have occupied a higher position on the research priority list. While only occasionally life-threatening in a direct way, these conditions certainly represent erosion in quality of life. The psychological consequences thus may be as serious as the physical effects of any complications; in the most extreme cases, this may actually contribute to an increase in SCI-related mortality, specifically through suicide.

A number of secondary complications of SCI have been identified as priorities in recent years, including:

- Urinary tract infection
- Chronic pain
- Pressure ulcers

This list could be expanded (e.g., impaired sexual function, bowel incontinence, etc.), but as indicated in an earlier section of the report, these conditions do represent critical areas often

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identified by the SCI community itself. Each of these three conditions will be briefly introduced here in terms of research and clinical progress over the last two decades. It should be noted that none of these complications are restricted to SCI; they occur as serious concerns in various other disorders, especially those involving the nervous system and/or some form of limitation to mobility. However, just as individuals with SCI have generated insights and interventions of use to other areas of medicine, disorders and disabilities unrelated to SCI per se have offered benefits within that specific community.

**Urinary Tract Infections**

The urinary system, and especially the bladder, is one part of the body that is particularly affected as a result of SCI. The bladder has two main functions, the storage of urine under low pressure, and the “periodic release of urine in a controlled coordinated manner during an acceptable time to void.”125 Logically, this suggests two major dysfunctions: uncontrolled voiding (leakage or incontinence) and failure to void.126 A so-called neurogenic bladder refers to dysfunction of lower urinary tract control mechanisms due to disease or injury to neural pathways; the most common cause of such dysfunction is in fact SCI. Both incontinence and failure to void are common occurrences in SCI, with the latter problem arguably being the more critical medical issue.

As will be seen below, the list of concerns related to bladder management in SCI is often dominated by infection. Historically, infection was (literally) a grave matter in SCI. Before the advent of antibiotics, many individuals experiencing SCI died early from some sort of infection. While urinary tract and other infections continue to cause a certain proportion of deaths in the SCI population, many more such cases are now routinely treated. This may be considered a form of progress in SCI care, albeit one that was developed through a broader avenue of medical research (i.e., the introduction of penicillin).

Notwithstanding the discomfort of UTIs, the change in the deadliness of classic infections in SCI is why the dominant cause of mortality has now shifted to respiratory diseases. Another consequence is that the goals of bladder management research and practice have been able to multiply in new directions, which again can be considered a form of progress. According to authorities Samson and Cardenas, the aims of urinary system/bladder management that move beyond basic UTI prevention and treatment are as follows:127

- Ensuring social continence to facilitate reintegration into the community
- Allowing low-pressure storage of urine and efficient bladder emptying
- Preventing urinary tract complications from high pressures in the bladder
- Avoiding stretch injury from repeated over-distension of the bladder wall

Despite progress in prevention and control, infection in the urinary system of individuals with SCI continues to be a morbidity concern, especially recurring episodes that erode quality of life and generate expense for the health care system. Some investigators have theorized that the risk of UTIs is elevated as a direct, chronic complication of the neurogenic bladder, but most


Clinicians implicate the phenomenon of infection as a by-product (i.e., a so-called iatrogenic effect) of the routine management of bladder dysfunction. Specifically, the main culprit appears to be the catheterization that is routinely used to drain urine from the bladder of most SCI patients.

Given its invasive nature, it is understandable that catheterization would be suspected as a culprit in infection. In fact, the two major approaches to catheterization (i.e., permanent or indwelling catheters and intermittent catheters) both increase the risk of symptomatic lower tract infection. Nonetheless, there still has been a shift towards using some type of intermittent catheterization, engendering a shift away from the once dominant method of indwelling catheterization.

The choice between the two major categories of catheterization has ultimately been driven less by UTIs per se and more by other types of primary and secondary complications that are elevated with the use indwelling catheters. For example, multiple retrospective studies have shown that squamous cell cancer of the bladder, although still rare, is elevated in patients using indwelling as opposed to intermittent catheters over a longer period of time. This sort of variation in the conditions following different types of catheterization may account for the decreased mortality rate for SCI patients in an earlier era that coincides with the increased use of intermittent catheterization (i.e., since the early 1970s).

Finally, there has been one infection-related difference demonstrated between the two catheterization methods: patients using indwelling catheters appear to be at elevated risk for recurrent symptomatic UTIs. Despite this result, it must be admitted that the present evidence base related specifically to UTIs for distinguishing the two types of catheterization is quite modest.

In fact, the pertinent Cochrane Library review group has focused on three types of catheterization used in medicine: “permanent urethral catheters (in the tube draining the bladder), suprapubic catheters (via the abdomen) or intermittent catheters (when a catheter is inserted via the urethra several times a day).” They noted that, as of August 2008, there were no eligible trials comparing these different methods. They further concluded that there was “weak evidence that using antibiotics all the time reduced the chance of having a urinary tract infection while using intermittent catheters, but there was not enough information about side effects.” A different review group focusing on catheterization strategies with neurogenic bladder found a similar lack of conclusive data in the scientific literature.

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why the Cochrane Library, for instance, indicated in 2007 that there is not enough evidence yet to choose between different types of indwelling catheter technologies.\textsuperscript{134}

In summary, while progress has been made in the treatment of infections and therefore their worse sequelae, it is clear that further research is warranted in order to reduce UTI-related morbidity in the context of essential bladder management approaches in individuals with SCI.

**Chronic Pain**

The management of pain is in fact common in all phases of SCI care—initial hospitalization, early rehabilitation, and long-term support. SCI-related chronic pain, which is the focus of most research, is typically categorized as nociceptive pain (i.e., due to non-neurogenic tissue damage) or the neuropathic pain related to damage in central and/or peripheral nervous tissue. The second category, neuropathic pain (also known as neurologic or central pain), usually includes frank pain and other unpleasant sensations (known as dysaesthesia) directly arising from sensory abnormality; it tends to be the predominant focus for SCI patients and researchers.

In the simplest terms, then, there is pain resulting from damage to the spinal cord itself, and pain that arises due to collateral damage, medical complications, and the lifestyle restrictions imposed by the neurological lesion. Beyond these basic distinctions, the experience of pain in SCI patients is heterogeneous and complex; as a consequence, classification schemes for pain following SCI have become more elaborate and numerous over the years.\textsuperscript{135,136} Fortunately, a consensus has begun to emerge.\textsuperscript{137} It appears that two schemes introduced a decade ago now dominate the field.\textsuperscript{138,139}

A common feature of the two classification approaches is the general localization of pain in the body in terms of being above, at, or below the level of the injury to the spinal cord. This basic pattern was identified in reference to neuropathic pain as early as World War I.\textsuperscript{140} Neuropathic pain at the level of the injury tends to have an early onset (days or weeks), while pain below the level of the injury can take months or years to emerge. There is an ongoing effort to rationalize the location of neuropathic pain in terms of chronic pain syndromes afflicting SCI patients; this includes increasing the understanding of underlying both the pathophysiological mechanisms and the psychosocial influences related to chronic pain.\textsuperscript{141}

\footnotesize
It is fair to say that the optimum approach to screening, diagnosis, and evaluation of pain after SCI is still a “work in progress.” According to a research team sponsored by RHI, “no adequate measure for the symptomatic assessment of SCI-related neuropathic pain has been developed to date.”\textsuperscript{142} It continues to be a very important quest. There is value in devising well-accepted assessment tools (and possibly even classification schemes), both to guide clinical interventions and to create consistency in outcomes research.\textsuperscript{143}

Identifying effective interventions for pain management can be a complex and even elusive process no matter what underlying disease mechanism or injury, and this is no less true for the specific phenomenon of SCI-related pain. Despite the challenges involved with classification, knowing the source and cause of pain is the typical starting point with any treatment approach. The various types of nociceptive pain require heterogeneous approaches. For example, overuse pain may be addressed by physical therapy, non-steroidal anti-inflammatories, and opioids. Muscle spasms are usually treated with antispasticity medications. Pain related to spine instability may be alleviated by immobilization and surgery—including spinal fusion procedures. Visceral pain management usually tries to target the source, from UTIs and urinary obstructions to bowel impaction.\textsuperscript{144}

Neuropathic pain is generally more challenging to control. First-line treatments involve anti-convulsants; some authorities suggest that these may be more effective if administered with tricyclic antidepressants. Opioids are also commonly used for both acute and chronic neuropathic pain. There are problems with most approaches, as summarized in a brief review by Charles Booker of the Pain Management Research Institute in Australia:\textsuperscript{145}

\begin{quote}
Pharmacological management is difficult and is fraught with ineffective drugs and difficulties coping with side effects. For example constipation and weight gain from trycyclics are a particular issue for SCI patients. Opioids have concerns due to the lifelong issues with pain and tolerance problems.
\end{quote}

Electrical nerve stimulation or spinal cord stimulation have offered relief of pain at the level of injury; applying this modality to the brain itself remains controversial, albeit controlled trials have produced some positive results for SCI pain. It has long been recognized that psychological factors play a substantial role in the experience and consequence of SCI-related pain.\textsuperscript{146} Thus, cognitive-behavioural approaches continue to be recommended as part of an interdisciplinary response to pain following SCI—despite the fact that controlled trials have not been conducted and the acceptance of this approach by SCI patients remains limited.\textsuperscript{147} Finally, interpersonal support, even in the face of severe pain, has been shown to increase life control and decrease life interference.\textsuperscript{148,149}

As has already been suggested, the “holy grail” in managing SCI pain is to match interventions to identified mechanisms. This leads back to the theoretical issue of SCI pain classification, and onward to the practical issue of relevant and consistent assessment methods. Both of these areas continue to be active fields of investigation and debate. Additional clinical examinations appear to be warranted for certain types of pain, to confirm an initial diagnosis. However, there continue to be substantial knowledge gaps in all aspects of pain identification and characterization in SCI, creating many opportunities for further research and analysis.

Beyond the important objectives of assessment and classification, leaders in this area have begun to agree that SCI pain treatments (especially for pain of the neuropathic type) will have to be multimodal and interdisciplinary in order to maximize effectiveness. In particular, a comprehensive approach must pay attention to educational, cognitive, and behavioural components, as well as taking into account the contribution of social and other environmental factors. These are relatively easy directions to affirm concerning conservative interventions; the more challenging questions continue to be centred on the effective medical therapies for SCI-related pain.

**Pressure Ulcers**

Despite the investment of tremendous research and care resources over many years, pressure ulcers remain a dominant health problem for persons with SCI. In fact, it may be the most common secondary complication, although probably exceeded by UTIs in terms of hospital readmissions.

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A pressure ulcer (also known as a pressure sore) is a lesion of the skin and underlying tissues; although multifactorial in nature, it appears to be primarily caused (as the name indicates) by prolonged, uninterrupted pressure localized on those tissues by the weight of the body.

The literature on this topic is vast, especially if one considers information that may be gleaned from the full range of conditions and situations where pressure ulcers are prevalent. These include diseases marked by impairment of mobility, sensation, skin integrity, and/or psychological responsiveness; included in the list are relatively common conditions such as diabetes mellitus and Alzheimer’s disease.161,162

It is important to note that, contrary to the popular notion that equates pressure ulcers with being “bedridden” in a hospital, the lesions also occur in people at home and/or in ambulatory care. On the other hand, it is true that a large proportion of pressure ulcers arise during hospital stays or long term care. A 2004 study examined the prevalence of pressure ulcers in a variety of health care settings across Canada; it found that 25% of patients in acute care settings and 30% in non-acute settings experienced one or more pressure ulcers.163 Alarming nonetheless, is evidence that the prevalence of pressure ulcers is actually increasing in some countries.164,165 Since the usual assumption is that a certain proportion of hospital-acquired cases may be traced to inadequate care, the phenomenon remains a great concern of health care planners.166 In particular, there is intensive focus on any medical context involving bed care or prolonged sitting, including critical illness or injury requiring intensive care and chronic conditions requiring long-term care.

The classic example of such care is of course the acute and early rehabilitation phases following SCI, as well as any re-hospitalization occasioned by later complications. It is important to reiterate that community-dwelling individuals with SCI are also very susceptible to pressure ulcers, underlining the importance of risk reduction by self-management, the support of well-coached caregivers at home, and the provision of professional assistance and specialized equipment.167 To this end, while biomechanical explanations of pressure ulcers understandably dominate the discussion in SCI care, the role of behavioural components in pressure ulcer development is a growing area of interest.168

**Intervention Effectiveness**

Evidence-based medicine (EBM) as a discipline has been developed since the 1970s, before gaining widespread acceptance in the early 1990s.\(^{169}\) EBM is defined as “a systemic approach to analyze published research as the basis of clinical decision making.”\(^{170}\) A commitment to scientific evidence was developed in part due to Archibald Cochrane’s suggestion that “many of the treatments, interventions, tests and procedures used in medicine had no evidence to demonstrate their effectiveness, and may in fact be doing more harm than good.”\(^{171}\) Of course, the famous and influential Cochrane evidence review program was launched due to these concerns.

According to Bigby, EBM is comprised of four fundamental steps:\(^{172}\)

1. Formulating well-built clinical questions
2. Finding the best evidence to answer the questions
3. Critically appraising the evidence
4. Applying the evidence to specific patients

Assessing intervention effectiveness is a subset of the entire EBM program, specifically answering questions about the effectiveness of an intervention of interest by analyzing available scientific literature; in this process, it plays an important role in bridging the gap between research and clinical practice.

Not surprisingly, evidence review publications related to SCI have grown exponentially over the years.\(^{173}\) This sort of volume expansion is also observed in related areas such as outcome measures (covered later in the report). A scan of systematic reviews specific to SCI acute care, rehabilitation, and chronic care revealed a substantial number of publications (see following table).

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### Systematic Reviews in Medline Supporting Evidenced-Based SCI Care

<table>
<thead>
<tr>
<th>Issue/Intervention</th>
<th>Year</th>
<th>Lead Author</th>
<th>Review Group</th>
<th>Lead Country</th>
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<tbody>
<tr>
<td><strong>Acute Care</strong></td>
<td></td>
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<td>Acute respiratory management</td>
<td>2011</td>
<td>Berney</td>
<td>Austin Hospital</td>
<td>Australia</td>
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<td>Vasopressor support in acute SCI</td>
<td>2010</td>
<td>Ploumis</td>
<td>University of Ioannina</td>
<td>Greece</td>
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<tr>
<td>Electromagnetic therapy for the treatment of pressure sores</td>
<td>2010</td>
<td>Aziz</td>
<td>Cochrane</td>
<td>Malaysia</td>
</tr>
<tr>
<td>Methylprednisolone in acute SCI</td>
<td>2009</td>
<td>Botelho</td>
<td>IAMSPE</td>
<td>Brazil</td>
</tr>
<tr>
<td>Therapeutic interventions for pressure ulcers</td>
<td>2009</td>
<td>Regan</td>
<td>SCIRE</td>
<td>Canada</td>
</tr>
<tr>
<td>Gangliosides for acute SCI</td>
<td>2009</td>
<td>Chinnock</td>
<td>Cochrane</td>
<td>U.K.</td>
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<td>Steroids for acute SCI</td>
<td>2008</td>
<td>Jones</td>
<td>Cochrane</td>
<td>U.K.</td>
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<td>Spinal injuries centers for acute traumatic SCI</td>
<td>2008</td>
<td>Bagnall</td>
<td>Cochrane</td>
<td>U.K.</td>
</tr>
<tr>
<td>Review of treatment trials in SCI</td>
<td>2006</td>
<td>Tator</td>
<td>Toronto Western Hospital</td>
<td>Canada</td>
</tr>
<tr>
<td>Effectiveness and cost-effectiveness of acute hospital-based services</td>
<td>2003</td>
<td>Bagnall</td>
<td>NHS Centre for Reviews &amp; Dissemination</td>
<td>U.K.</td>
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<tr>
<td>Spinal immobilization for trauma patients</td>
<td>2001</td>
<td>Kwan</td>
<td>Cochrane</td>
<td>U.K.</td>
</tr>
<tr>
<td><strong>Rehabilitation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>Robot-assisted gait training</td>
<td>2010</td>
<td>Swinnen</td>
<td>Vrije Universiteit</td>
<td>Belgium</td>
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<td>Gait-training for walking with incomplete SCI</td>
<td>2010</td>
<td>Wessels</td>
<td>Vrije Universiteit</td>
<td>The Netherlands</td>
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<td>Acupuncture for SCI in the Chinese literature</td>
<td>2009</td>
<td>Shin</td>
<td>Pusan National University</td>
<td>South Korea</td>
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<td>Effectiveness of physical interventions</td>
<td>2009</td>
<td>Harvey</td>
<td>University of Sydney</td>
<td>Australia</td>
</tr>
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<td>Clinical relevance of gait research</td>
<td>2009</td>
<td>Ditunno</td>
<td>Thomas Jefferson University</td>
<td>U.S.</td>
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<td>Locomotor training for walking after SCI</td>
<td>2008</td>
<td>Mehrohloz</td>
<td>Cochrane</td>
<td>Germany</td>
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<td>Respiratory muscle training</td>
<td>2006</td>
<td>Van Houtte</td>
<td>Katholieke Universiteit Leuven</td>
<td>Belgium</td>
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<td>Walking after spinal cord injury: evaluation</td>
<td>1999</td>
<td>Barbeau</td>
<td>McGill University</td>
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<td>2010</td>
<td>Reid</td>
<td>University of British Columbia</td>
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<td>SCIRE</td>
<td>Canada</td>
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<td>2010</td>
<td>Opperman</td>
<td>University of Guelph</td>
<td>Canada</td>
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<td>Pharmacological treatment of pain</td>
<td>2010</td>
<td>Teasell</td>
<td>SCIRE</td>
<td>Canada</td>
</tr>
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<td>The management of orthostatic hypotension</td>
<td>2009</td>
<td>Krassioukov</td>
<td>SCIRE</td>
<td>Canada</td>
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<td>Phosphodiesterase type 5 inhibitors</td>
<td>2009</td>
<td>Lombardi</td>
<td>Careggi University Hospital</td>
<td>Italy</td>
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<tr>
<td>Effect of exercise on disorders of carbohydrate and lipid metabolism</td>
<td>2009</td>
<td>Carlson</td>
<td>VA Medical Center</td>
<td>U.S.</td>
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<tr>
<td>Pharmacological interventions for spasticity</td>
<td>2009</td>
<td>Tarico</td>
<td>Cochrane</td>
<td>Italy</td>
</tr>
<tr>
<td>Pregabalin and gabapentin for neuropathic pain</td>
<td>2008</td>
<td>Tziolios</td>
<td>Aristotle University of Thessaloniki</td>
<td>Greece</td>
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<tr>
<td>Neurotoxin treatment for urinary incontinence</td>
<td>2008</td>
<td>MacDonald</td>
<td>Veterans Affairs Medical Center</td>
<td>U.S.A.</td>
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<tr>
<td>Oxygen consumption during FES-assisted exercise</td>
<td>2008</td>
<td>Hettinga</td>
<td>Brunel University</td>
<td>U.K.</td>
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<tr>
<td>Botulinum toxin for treatment of urinary incontinence</td>
<td>2007</td>
<td>MacDonald</td>
<td>Veterans Affairs Medical Center</td>
<td>U.S.</td>
</tr>
<tr>
<td>Male erectile dysfunction</td>
<td>2006</td>
<td>Deforge</td>
<td>Ottawa Hospital</td>
<td>Canada</td>
</tr>
<tr>
<td>Algorithm for the management of pain</td>
<td>2006</td>
<td>Siddall</td>
<td>University of Sydney</td>
<td>Australia</td>
</tr>
<tr>
<td>Follow-up care in the community</td>
<td>2005</td>
<td>Bloemen-Vrenken</td>
<td>Rehabilitation Centre Hoensbroeck</td>
<td>The Netherlands</td>
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<tr>
<td>Dorsal root entry zone lesioning to treat central neuropathic pain</td>
<td>2002</td>
<td>Denkers</td>
<td>McMaster University</td>
<td>Canada</td>
</tr>
<tr>
<td>Effectiveness of vibratory stimulation in anejaculatory men</td>
<td>1993</td>
<td>Beckerman</td>
<td>Free University Hospital</td>
<td>The Netherlands</td>
</tr>
</tbody>
</table>

SCI = Spinal cord injury  
IAMSPE = Institute for Medical Assistance to Civil Servants (translated from Portuguese)  
SCIRE = Spinal Cord Injury Rehabilitation Evidence  
UTI = Urinary tract infection  
FES = Functional electrical stimulation

Several key observations can be made related to this table.

- **The field is rapidly expanding**, as the great majority of publications have occurred in the last decade.
- **Research and related reviews comprehensively cover the SCI continuum of care**, though it appears that rehabilitation may be lagging as a focus and/or in terms of volume of scientific papers to analyze.
- **SCI research is truly a global effort**, with review groups from a variety of institutions representing all continents except Africa (and Antarctica).
As well, **Canadian investment in the EBM program is well represented**, especially through the work of the Spinal Cord Injury Rehabilitation Evidence (SCIRE) project. It represents a synthesis of the research evidence underlying different rehabilitation interventions to improve the health of people living with SCI.\textsuperscript{174} SCIRE is secondary research collaboration between scientists, clinicians, and consumers drawn from Vancouver, BC and London, ON health centres, research institutions, and universities. The full report covers more topics than have been published in Medline to date, including upper and lower limb rehabilitation, respiratory management, bone health, sexual health, neurogenic bowel, pressure ulcers, and bladder health and function.\textsuperscript{175}

The basic fact that all of these reviews have been funded, completed, and reported is already a testament to the level of progress made in applying EBM principles to SCI. Given the short time frame during which most of these systematic reviews have been published (over 70% since 2008), it is generally not possible to perform a content analysis of how one topic has evolved over a long period. However, focusing on one specific area over the past decade offers a snapshot of the progress than may be anticipated for the entire SCI field in years to come.

Barbeau et al. (1999)\textsuperscript{176} and Wessels et al. (2010)\textsuperscript{177} published reviews on walking after spinal cord injury just over a decade apart. Despite this relatively short time frame, dramatic changes were observed that have important clinical implications. The most obvious difference is between the scope of each review; the more recent publication has a more refined focus, evaluating body-weight supported training rather than the general topic of post-injury walking. The more recent publication included a full\textsuperscript{17} studies, with all but one published since the earlier review. The pertinent section of the earlier review focused on the technological advances made to that point, such as the pulley, spring, pneumatic, and robotic systems necessary to perform body weight-assisted training. Building on this introductory research, researchers are now at a stage where they can conduct trials informing clinical direction on specific types of body weight-assisted training, such as over-ground and treadmill methods.

This example helps to illustrate how quickly primary research that is prioritized and funded can answer clinically relevant questions and then be systematically incorporated into a developing evidence picture. As highlighted in the table above, the potential progress in building and analyzing a body of evidence is not isolated to one intervention; however, all areas are not yet showing the same promise. For instance, Bloemen-Vrencken et al. have examined studies of follow-up care in the community; although they located 24 relevant publications, they also found that “in general the quality of studies was low.” As a result, the reviewers concluded that “there is a need for the development, the publication and the well-designed evaluation of follow-up care programmes for persons with SCI.”\textsuperscript{178}

In areas where clinical questions have been well answered, ensuring that effective interventions are incorporated into best practice guidelines and that these guidelines see widespread

distribution, implementation, and validation becomes the next step; this topic will be covered in
greater detail later in the report.
Translation to Application

Basic epidemiological and biological research needs to be taken from the realm of theory or laboratory insight to clinical trials then to actual practice in the real world. This movement from “bench to bedside” is customarily referred to as “translation.”

The preceding section already suggested that there is substantial opportunity for scientific research extending the evidence base that compares SCI interventions and their respective indications; there is also a great deal of room for further translational research to maximize the adoption of the best practice for various areas of care, calibrated to the relevant subgroups of SCI patients. For example, it is clear that there continues to be great challenges in managing the secondary complications of SCI, and therefore good reason to invest in basic, clinical, and translational research.

The fact that more progress is required should not take away from the positive developments that have occurred over the last quarter century. This section of the report will examine three important areas of translation and application work related to SCI where substantial investment and encouraging movement has occurred, as follows:

1. Primary prevention
2. Guidelines for best clinical practices
3. Development of outcome measures

Public Health Practice and Primary Prevention

Clearly, the most effective means of reducing the rate, severity, and mortality from craniospinal trauma is through prevention.

The most common cause of traumatic SCI is motor vehicle crashes (including motorcycles), followed by falls and sport activities. As noted in the Introduction to the report, falls may be overtaking traffic accidents as the dominant cause of SCI. This finding, and the fact that the number of fall-induced injuries increases steadily with age, may suggest a new prevention target. As noted by Couris et al., “further work is needed to understand this trend in age and gender and the causes of falls to develop effective fall prevention strategies.”

Because the consequences of SCI are so devastating, it is of paramount importance to prevent the injury from occurring in the first place. Primary prevention of SCI seeks to reduce susceptibility, eliminating or minimizing behaviours and environmental factors that increase the risk of injury. The two main approaches to injury prevention are legislation and education. Progress has been made on both fronts in recent decades, as detailed below. Unfortunately, given the difficulty in tracking accurate statistics for traumatic SCI incidence in most jurisdictions, it is not clear how the various initiatives may have reduced actual cases at the

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population level. However, based on substantial reductions in the rate of head injuries in the U.S., the SCI incidence rate is now also probably lower.\(^{182}\)

**Legislation**

Legislation has been developed to modify human behaviour (e.g., reduction in legal blood alcohol concentrations when driving), change environmental factors (e.g., better highways, anti-locking brake systems), and decrease access to hazards (e.g., increasing the cost of alcohol, prohibiting use of handheld devices). There are also laws that are aimed at limiting injury during a traffic accident, such as mandatory usage of motorcycle helmets, bicycle helmets, and seat-belts.\(^{183}\) In fact, since 1990, all new cars manufactured in the U.S. have been equipped with automatic seat belts and/or a driver’s side airbag.\(^{184}\) While there is research showing increased usage of helmets or seat-belts and reductions in acute mortality rates,\(^{185,186,187}\) there are no studies available confirming the long-term incidence effect specific to SCI. Overall, the greatest promise of reduction in injury rates is associated with legislation that is perceived by the public to be strictly enforced.

**Education**

Educational approaches to reducing traumatic SCI are usually integrated into injury prevention programs. For example, there are two major organizations devoted to injury prevention in Canada: ThinkFirst and SMARTRISK.

**ThinkFirst Canada**

ThinkFirst Canada is a national non-profit organization founded in 1992 that is dedicated to the prevention of brain and spinal cord injuries; it has 19 local chapters across the country. The goal of ThinkFirst Canada is to achieve a measurable reduction in traumatic brain and spinal cord injuries through the creation, dissemination, and evaluation of educational activities; by public advocacy activities; and by providing kids with the tools and information they need to “use their minds to protect their bodies.”\(^{188}\) Some of the various ThinkFirst programs are outlined below:

- *TD ThinkFirst for Kids:* School-based curriculum program for children in grades K-8. Designed as a teacher’s resource, the program teaches children how to think first and play safely to prevent brain and spinal cord injuries. It is available free of charge to all Canadian schools and public health agencies; more than 12,000 curriculum sets are in use across Canada.

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\(^{183}\) Reid-Arndt SA, Frank RG, Hagglund KJ. Brain injury and health policy: twenty-five years of progress. *Journal of Head Trauma and Rehabilitation.* 2010; 25(2): 137-44.


• **Give-A-Kid-A-Helmet:** A program created in 2003 that provides children with a helmet when costs are prohibitive for their family; over 35,000 children have been supplied with vital protective gear in this manner.

• **Concussion Road Show:** A traveling information clinic that presents information about the science of concussion, including risk factors, prevention techniques, and concussion management guidelines.

• **Smart Hockey:** An entertaining and educational DVD in which hockey stars share tips and demonstrate how to avoid causing and sustaining hockey injuries. This is part of the Sport Smart series, which also includes programs on diving, equestrian, soccer, and skiing safety.

Almost all scientific evaluations of ThinkFirst programs have concluded that these programs improve knowledge and reduce risk-related behaviour. Tator et al. have recently published a study specific to spinal injuries in ice hockey; examining incidence trends over the long term, the authors concluded that there has been a reduction in such injuries in Canada, and attributed this reduction to the development and dissemination of targeted injury prevention programs.189 The following chart illustrates the findings, including the improvements since the early 1990s.

![Spinal Injuries in Canadian Ice Hockey](chart.png)

*Severe injury defined as a permanent neurological injury due to the cord injury


SMARTRISK

A second pertinent charitable organization in Canada is SMARTRISK, dedicated to preventing injuries and saving lives. Similar to ThinkFirst, the main focus is youth safety; the five messages of the organization are Buckle up, Look First, Wear the Gear, Get Trained, and Drive Sober. Some of their programs and services are as follows:

- **SMARTRISK No Regrets**: A high school program that trains students and teachers to help young people learn to take smart risks. Once trained, they choose and plan activities, events, and campaigns throughout the school year that promote the five key messages (as noted above). No Regrets was created in 2003; by the end of 2009 over 100 schools in 9 provinces and one territory in Canada were equipped to run the program.

- **SMARTRISK Heroes**: A one-hour presentation hosted by an injury survivor who describes how he or she got hurt, and explains how youth can choose smart risks to avoid injury.

- **Ontario Injury Prevention Resource Centre**: Aids in developing injury prevention initiatives across Ontario, including: Canadian Falls Prevention Curriculum, Canadian Injury Prevention Curriculum, and Ontario Injury Compass.

SMARTRISK has evaluated the No Regrets program each year since the program was created. A recent study found students reported 17% fewer injuries requiring medical care following a single year of exposure to the organization’s key messages.

SMARTRISK also offers a program designed for seniors and their caregivers that focuses on falls prevention. Falls are the most common cause of SCI in the over 65 age group. The Smart Moves toolkit focuses on four categories key to fall prevention in the elderly—bone health, exercise, medication management, and home modifications.

It is clear that there has been encouraging progress in the prevention initiatives in Canada and other jurisdictions. To better assess the impact of these efforts at the population level, it is important to improve the tracking of SCI statistics through population-based registries—an initiative that is still at an early stage of development in most jurisdictions.

**Guidelines for Best Clinical Practices**

The development of best practices and their incorporation into practice guidelines for SCI care appears to be a steadily expanding enterprise. For example, an extensive set of guidelines has been published by the Consortium for Spinal Cord Medicine, funded and administered by the Paralyzed Veterans of America. The Consortium—a group of 22 health care professional, payer, and consumer organizations—was initiated in 1995 to develop, produce, and disseminate evidence-based clinical practice guidelines (CPGs) for the SCI clinical and consumer communities. The CPGs are recommendations to health care providers based on current research findings that experts have graded for their scientific strength and validity. There is a clear connection between the present topic of best practices/CPGs and the primary investigations of intervention effectiveness that are then summarized and analyzed in a systematic review of the current body of evidence (see the pertinent section earlier in the

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report); the main difference between the two efforts is that practice guidelines build on the evidence summary to make clear recommendations about a set of standard practices that should be adopted.

The 11 CPGs currently available through the Consortium are as follows:193

- Bladder Management for Adults with SCI
- Respiratory Management following SCI
- Neurogenic Bowel Management in Adults with SCI
- Acute Management of Autonomic Dysreflexia
- Prevention of Thromboembolism in SCI
- Early Acute Management in Adults with SCI
- Preservation of Upper Limb Function following SCI
- Depression following SCI
- Outcomes following Traumatic SCI
- Pressure Ulcer Prevention and Treatment Following SCI
- Sexuality and Reproductive Health in Adults with SCI

In addition, the American Dietetic Association has published evidence-based practice guidelines for registered dietitians on nutrition care for patients with SCI.194 The American Association of Neurological Surgeons has also developed a set of guidelines for the management of acute cervical spine and cervical spinal cord injuries; these guidelines are for the most part related to specific surgical techniques.195

Several other researchers and organizations worldwide are working towards the goal of establishing guidelines for best practice in SCI care.196 The European Spinal Cord Injury Federation, founded in 2005, is engaged in a guideline development project as part of its vision to improve the quality of life of individuals living with SCI. In Canada, the Rick Hansen Institute is funding a translational research project with the ultimate goal of creating a national standard of care for acute SCI; the project will build on systematic reviews of many areas of SCI care in order to create a consensus on best practice recommendations.197

These commitments are laudable; however, guidelines are only as good as the evidence reviews upon which they are built. Clearly, more work is required at the level of basic and clinical research in order to provide the evidence base for guideline development. One example of the gaps in evidence was provided by McMaster University’s Evidence-based Practice Centre report from 10 years ago on the management of chronic neuropathic pain following SCI.198 The reviewers concluded that weak methods (e.g., small samples) had been used in the few studies

of pain after SCI that had been published, making it difficult to develop recommendations based on intervention evidence. In fact, a traditional clinical practice guideline for pain management in SCI has not been published; this may be a reflection of the currently weak evidence base. According to a more recent review, progress has continued to be slow in this area, with the controlled trials being “surprisingly rare given the high prevalence and impact of pain in this population.” The conclusion as late as 2007 was that there were still no routinely effective treatments for SCI pain. Nonetheless, efforts at improving this situation continue to be pursued. For instance, two different study groups, from Denmark and Australia, did devise an algorithm for pain treatment following SCI that synthesized the available evidence 4-5 years ago; a French organization followed up with an algorithm in 2009. This sort of algorithm development represents the state-of-the-art that is a likely direction for future CPG work in chronic pain management and other areas of care. Reflecting the incomplete knowledge base, a leading authority recently acknowledged that all pain treatment modalities need further exploration to refine the management algorithm.

Another example of gaps in SCI protocol development is offered by pressure ulcers. Despite the amount being invested in dealing with SCI-related pressure ulcers, the research on effective therapy is still limited, as is the evidence to guide improvements in care. As a consequence, pressure ulcers remain a complex and often chronic problem for which “no gold standard for prevention or treatment has yet been established.” Again, the opportunities to expand research into the management of pressure ulcers appear to be substantial, including ways to encourage consistent implementation of best practices, which represents the next step in any translation program. Poor adherence to clinical guidelines is a problem facing people with SCI and others who suffer from pressure ulcers. A well-known study in the Netherlands highlighted this issue through a survey of over 16,000 patients in 89 health care centres on one day; no more than a third of the patients at risk for pressure ulcers were found to be receiving recommended interventions.

Development and Tracking of Outcome Measures

Although some measures approach a century in origin, it is important for the next generation of researchers to appreciate how the past has shaped our current concepts so that they may project their future role in SCI care and cure.

There are in excess of a hundred and fifty measures which have been developed for use with individuals with SCI. The oldest measures of neurological impairment trace their origins back to 1912; indeed, certain ones were incorporated into the American Spinal Injury

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Association (ASIA) measurement instrument, the current clinical gold standard for assessing and reporting the severity of SCI.\textsuperscript{206} Given the fast-paced evolution of outcome measures in SCI, tracking the development and clinical usage of specific measures is challenging. Furthermore, quantity is not the same thing as quality; most SCI metrics still need to be tested in real world application. Johnston and Graves explained that “the scarcity of fully validated outcome measures can be particularly problematic in many low-frequency conditions, including the different levels and types of spinal cord injury.”\textsuperscript{207} While the research community is unanimous in calling for further validation studies, it is still important to acknowledge the progress has been made over the last 100 years.\textsuperscript{208}

Initially, objective outcome measures served a critical purpose in classifying the severity of neurological impairment following spinal cord injury.\textsuperscript{209} Over time these measures were modified in order to evaluate therapeutic treatments in the acute and rehabilitation phase. In recent years, topics such as overall quality of life, sexual health, psychological functioning, and community participation have gained increased attention from researchers, resulting in the development of a variety of new measures.\textsuperscript{210,211,212,213}

The table below provides a comprehensive but not exhaustive list of outcome measures related to SCI.

Three markers of progress observable in the table that are specific to the last 25 years include:

1. **Increasing rate of emergence** of new outcome measures
2. **Growing range of categories**—as noted above, the focus on research has expanded in recent years to include areas such as quality of life and sexual health
3. **The growing number of SCI-specific measures** (indicated by the shading)

Generally speaking, development and validation efforts have focused on the following aims:

- Refining current outcome measures or developing and validating new measures
- Combining metrics to create more inclusive “global measures”

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### Selected Outcome Measures Applied to SCI

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Date 1st Published</th>
<th>Outcome Measure</th>
<th>Date 1st Published</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body Function/Structure</strong></td>
<td></td>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>Beck Depression Inventory</td>
<td>1961</td>
<td>Jebsen Hand Function Test</td>
<td>1969</td>
</tr>
<tr>
<td>Ashworth and Modified Ashworth</td>
<td>1964</td>
<td>Hand-Held Myometer</td>
<td>1992</td>
</tr>
<tr>
<td>Gosnall Measure</td>
<td>1973</td>
<td>Functional Standing Test</td>
<td>1994</td>
</tr>
<tr>
<td>Center for Epidemiological Studies Depression Scale</td>
<td>1977</td>
<td>Sollerman Hand Function Test</td>
<td>1995</td>
</tr>
<tr>
<td>Sexual Attitude and Information Questionnaire</td>
<td>1978</td>
<td>Tool for assessing mobility in wheelchair-dependent paraplegics</td>
<td>1998</td>
</tr>
<tr>
<td>Donovan SCI Pain Classification System</td>
<td>1982</td>
<td>Capabilities of Upper Extremity Instrument</td>
<td>1998</td>
</tr>
<tr>
<td>Brief Symptom Inventory</td>
<td>1983</td>
<td>Walking Index for Spinal Cord Injury</td>
<td>2000</td>
</tr>
<tr>
<td>Tunk’s Classification Scheme</td>
<td>1986</td>
<td>The Grasp and Release Test</td>
<td>2001</td>
</tr>
<tr>
<td>Braden Scale</td>
<td>1987</td>
<td>The Spinal Cord Injury Functional Ambulation Inventory</td>
<td>2001</td>
</tr>
<tr>
<td>Sexual Interest and Satisfaction Scale</td>
<td>1990</td>
<td>Wheelchair Skills Test</td>
<td>2002</td>
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<tr>
<td>Emotional Quality of the Relationship Scale</td>
<td>1994</td>
<td>Clinical Outcome Variables Scale</td>
<td>2003</td>
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<td>Depression Anxiety Stress Scale</td>
<td>1995</td>
<td>Tetraplegia Hand Activity Questionnaire</td>
<td>2004</td>
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<td>Wheelchair Users Shoulder Pain Index</td>
<td>1995</td>
<td>Timed Motor Test</td>
<td>2004</td>
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<tr>
<td>Spinal Cord Injury Pressure Ulcer Scale Measure</td>
<td>1996</td>
<td>10 Meter Walking Test</td>
<td>2005</td>
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<td>Sexual Activity and Satisfaction Scale</td>
<td>1996</td>
<td>The Voris Liebshut Test Short Version</td>
<td>2006</td>
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<td>Sexual Behaviour Scale</td>
<td>1996</td>
<td><strong>Self-Care</strong></td>
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<td>Knowledge, Comfort, Approach and Attitude Toward Sexuality Scale</td>
<td>2003</td>
<td>The Barthel Index</td>
<td>1965</td>
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<tr>
<td>Spinal Cord Injury Pressure Ulcer Scale – Acute</td>
<td>1999</td>
<td>Quadriplegia Index of Function</td>
<td>1980</td>
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<td>Surface Electromyography</td>
<td>2000</td>
<td>Frenchay Activities Index</td>
<td>1983</td>
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<td>Classification System for Chronic Pain in SCI</td>
<td>2002</td>
<td>Functional Independence Measure (FIM)*</td>
<td>1990</td>
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<td>Moorong Self-Efficacy Scale</td>
<td>2003</td>
<td>Self Care Assessment Tool</td>
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<td>Patient Health Questionnaire (PHQ-9)*</td>
<td>2004</td>
<td>The Spinal Cord Independence Measure</td>
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<td>Penn Spasm Frequency Scale</td>
<td>2005</td>
<td>Spinal Cord Injury Lifestyle Scale</td>
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<tr>
<td>The Multidimensional Pain Inventory – SCI version</td>
<td>2006</td>
<td>Quadriplegia Index of Function</td>
<td>1999</td>
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<tr>
<td>Spinal Cord Assessment Tool for Spastic Reflexes</td>
<td>2007</td>
<td>Physical Activity Scale for Individuals with Physical Disabilities</td>
<td>2002</td>
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<tr>
<td>The Spinal Cord Injury Spasticity Evaluation Tool</td>
<td>2007</td>
<td><strong>Participation</strong></td>
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</tr>
<tr>
<td>SCI Exercise Self-Efficacy Scale</td>
<td>2007</td>
<td>The Craig Handicap Assessment &amp; Reporting Technique (CHART)*</td>
<td>1980</td>
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<td>Six-Minute Arm Test</td>
<td>2007</td>
<td>The Community Integration Questionnaire</td>
<td>1994</td>
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<tr>
<td>Multidimensional Pain Readiness to Change Questionnaire</td>
<td>2008</td>
<td>Reintegration to Normal Living Index</td>
<td>2002</td>
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<tr>
<td>Spinal Cord Lesion Emotional Wellbeing Questionnaire</td>
<td>2008</td>
<td>Physical Activity Recall Assessment for People with SCI</td>
<td>2005</td>
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<tr>
<td>Quantitative Sensory Testing</td>
<td>2009</td>
<td><strong>Quality of Life</strong></td>
<td></td>
</tr>
<tr>
<td>The Appraisals of Disability: Primary and Secondary Scale</td>
<td>2009</td>
<td>The Sickness Impact Profile 68</td>
<td>1981</td>
</tr>
<tr>
<td><strong>= Measure specific to SCI</strong></td>
<td></td>
<td>Satisfaction with Life Scale</td>
<td>1985</td>
</tr>
<tr>
<td>*= Tracked in U.S. National Spinal Cord Injury Database</td>
<td></td>
<td>Life Satisfaction Questionnaire</td>
<td>1991</td>
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<td></td>
<td></td>
<td>The Short Form 36</td>
<td>1992</td>
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<td></td>
<td></td>
<td>Quality of Life Profile for Adults with Physical Disabilities</td>
<td>1996</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quebec User Evaluation of Satisfaction with Assistive Technology</td>
<td>2002</td>
</tr>
</tbody>
</table>

• Standardizing measures for use in databases to allow easier comparison between jurisdictions

An example of these aims in operation is offered by the International Spinal Cord Injury Data Set.\textsuperscript{214} The core data set that has been proposed consists of 24 variables, including basic demographic characteristics, cause of injury, hospitalization data, place of discharge, measures of neurological condition (such as ASIA score), and ventilator status. The plan is for this standardized data set, if accepted and adopted, to be used to accurately describe and compare patient populations around the world.

While the SCI Data Set project is ongoing, there are already a number of registries that have been developed at a national level. The most long-standing example is the Spinal Cord Injury Database in the U.S. This registry has been collecting data since 1973; its annual reports now cover four outcome measures:\textsuperscript{215}

• ASIA motor and sensory scores
• Functional Independence Measure (FIM)
• Patient Health Questionnaire (PHQ-9)
• Craig Handicap Assessment & Reporting Technique (CHART)

Two of these four measures (FIM and PHQ-9) have been developed in the time period of interest to this report, and the PHQ-9 as recently as 2004. It is encouraging that new, validated measures are being integrated into clinical and public health practice. However, neither of these measures are SCI-specific, which poses some limitations. For instance, researchers have noted that the FIM might not accurately reflect functional recovery after SCI. In response, there have been SCI-specific measures developed, such as the Spinal Cord Independence Measure (SCIM), to provide an update to the FIM.\textsuperscript{216} These newer measures have not yet seen widespread adoption by registries or centralized databases. Moving forward, this will be one of the greatest challenges facing the SCI research community: ensuring standardization and adoption of measures that will allow better tracking progress in population-level outcomes—the topic to which this report will now turn.

Progress in Population-level Outcomes

Historically, clinical outcomes following spinal cord injury have been dismal. Over the past 20 years, the... long-term outcome of patients with spinal cord injury [has] improved with advances in both medical and surgical treatment.217

Outcomes are critical to evaluating progress in all areas of health care, including the high-burden condition of SCI. As covered in the previous section, there are many outcome measurements of interest in SCI research and care. The critical aspect to note is that the focus of this section is population-level outcomes rather than those generated in patient series and other types of studies. The main aim is to see where actual improvements have occurred in the personal and social experience of individuals with SCI. As well, there are outcomes relevant to society as a whole, including the area of health care efficiency. In a time of financial constraint and in the face of growing costs for ageing SCI survivors, issues of cost-effectiveness become all the more important. In a previous section of the report, what little is known about reduced incidence of SCI following prevention efforts was introduced. As will be made clear below, this outcome tracking suffers from the same limitation that affects other aspects of SCI care, namely, the dearth of national registries and clear trend information.

Five outcome areas will be addressed in this final part of the report:

- Survival/Life Expectancy
- Other Patient Outcomes
- Participation in Work and Physical Activity
- Access to Public Facilities and Transportation
- Health Care Efficiency

Survival/Life Expectancy in Traumatic SCI

Changes in life expectancy following SCI are a direct and strong reflection of the quality of care received across the continuum, including acute care, rehabilitation, and the ongoing management of chronic conditions. Tracking changes in life expectancy is challenging, as it requires a large data set that is tracked over a long period of time. The data set at the National Spinal Cord Injury Statistical Center (NSCISC) in the U.S. is substantially larger than those in other countries, and thus is the best source of data on this subject. For the present analysis, a number of published studies from other jurisdictions were also evaluated for comparison purposes. While changes in life expectancy are often reported in terms of the entire life course, changes in mortality (or, conversely, survival) are often reported for the first year, or the first two years, post-injury.

Trends indicating an overall decrease in mortality following a traumatic SCI have been consistently reported in the literature from various countries.218 For example, a study from Canada estimated that there had been a 5-year increase in life expectancy post-SCI between 1980 and 1990;219 in Denmark the 10-year probability of survival following SCI improved from 78.7% to 86.8% for men, and 72.1% to 86.9% for women between the periods 1953-1971

and 1972-1990.\textsuperscript{220} In the UK, Frankel et al. observed a reduction in mortality of 70-80% between 1943 and 1990.\textsuperscript{221} More recent research in Australia found a 36% reduction in death at two months post-injury, and a 27% reduction in death at one year post-injury between 1986-1991 and 1992-1997. However, all of these studies are restricted in that they are based on small sample sizes. For example, the Canadian and Danish studies included only 142 and 139 deaths, respectively.

Using the NSCISC database, DeVivo et al. assessed survival trends between 1973 and 1998 in a sample of 28,239 individuals with SCI.\textsuperscript{222} They found that the odds of dying during the first year post-injury were reduced by 67% for persons injured between 1993 and 1998 compared to persons injured between 1973 and 1977. For those who survived at least one year, however, “mortality rates...which had been declining from 1973 to 1992, increased by 33% between 1993 and 1998 relative to persons injured between 1988 and 1992.”

In a 2006 follow-up study by the same research group, trends in mortality during and after the first two years post-SCI were assessed.\textsuperscript{223} In the first two years post-injury they observed a 40% reduction in mortality over the last three decades. For individuals with an SCI who survived at least two years, they observed a non-significant 17% reduction in mortality between 1970 and 1980, but no decline at all over the 25-year period from 1980 to 2004.

Data from the NSCISC between 1992 and 2009 confirm this lack of improvement in life expectancy, especially over the last decade. While the life expectancy of the average 20-year-old U.S. resident has increased consistently during this time period, there has not been a similar increase over time for individuals with an SCI (see following chart). This lack of an increase in life expectancy for an individual with an SCI is consistent for injuries occurring at 20, 40, or 60 years of age.

As outlined above, some substantial gains in life expectancy for persons with SCI have been realized over the past half-century. Short-term survival gains are particularly compelling; data from the NSCISC indicates a 40% improvement in 2-year survival post-injury over the past three decades, but no significant increase in long-term survival between 1980 and 2004. The most recent review drew the following conclusions:224

The absence of a substantial decline in mortality after the first 2 years post-injury is contrary to widely held impressions. Nevertheless, the finding is based on a large database and sensitive analytic methods and is consistent with previous research. Improvements in critical care medicine after spinal cord injury may explain the marked decline in short-term mortality. In contrast, although there have no doubt been improvements in rehabilitative care, their effect in enhancing the life span of persons with SCI appears to have been overstated.

One possible explanation for the discrepancy in mortality improvements is that health care is privately funded in the U.S. for a large proportion of the population, and individuals with SCI may experience difficulties in paying for treatment, rehabilitation, and other management of their condition. These challenges may result in decreased life expectancies, and may explain why other jurisdictions with universal public funding of health care are still reporting increases in long-term survival for persons with SCI.

Other Patient Outcomes

Improving patient outcomes naturally represents the pinnacle of the “progress pyramid.” It is the ultimate goal sought by SCI advocacy groups, researchers, and clinicians. However, tracking outcomes at a population level is currently very challenging. It requires a large, standardized dataset that has been sustained over a considerable period of time; at least ten years of comparable data are required in order to draw meaningful conclusions about any positive trends (i.e., progress). The largest dataset in the world that meets these requirements is derived from the SCI model systems program in the U.S., introduced earlier in this report. The program involves institutions providing comprehensive, multi-disciplinary care; it currently comprising SCI centres from 13 states. National, standardized data collection, including medical and psychosocial outcomes, has been conducted by the model systems program since 1973. The database is currently housed at the National Spinal Cord Injury Statistical Center (NSCISC), located at the University of Alabama.

In order to evaluate the effectiveness of the model systems program, DeVivo conducted a comprehensive review of the NSCISC database, comparing the experiences of persons registered in its early stages (from 1973) with those derived from a similar cohort treated in more recent years (up to 2006). Some of the population-level improvements in outcomes noted in the past 30 years were as follows:

- **Gains in neurologic improvement during acute care.** For the 2002-2006 period, among injuries that were initially neurologically complete, 15.1% became incomplete by discharge; by comparison, from 1973 to 1981 only 8.8% of neurologically complete injuries became incomplete.

- **Lower frequencies of in-patient (i.e., early) complications.** The risk of pneumonia and deep vein thrombosis were reduced by 64% and 51%, respectively, during initial hospitalization in 2002-2006 relative to 1992-1996.

- **Long-term improvements in measures of community integration.** The Craig Handicap Assessment and Reporting Technique (CHART) scores measured at 5 years post-injury increased for physical independence, occupational independence, social integration, and economic self-sufficiency from the 1992-1996 period to the 2002-2006 period.

It has been suggested that some of these improvements in outcomes may be traced to patient transfer from the emergency department or regular wards to specialized SCI units at the earliest opportunity; delay in such a transfer appears to cause further medical complications and prolonged rehabilitation. Others have attributed the progress to the utilization of evidence-based treatment guidelines (discussed earlier in the report) and improved intensive care monitoring capabilities.

Although gains have been made in some SCI outcomes, progress in other areas has proved more challenging. According to DeVivo, at 5 years post-injury there recently have been increased odds of medical complications such as renal stones, pulmonary emboli, and pneumonia compared with past decades; depression and pain levels also showed small

225 It is worth noting that some states in the U.S. (e.g., South Carolina) have developed state-of-the-art SCI care programs and data collection systems but are not part of the model system of care.


increases. Also, at 5 years post-injury there have been no significant improvements in self-reported health or life satisfaction—which likely relates to the aforementioned increased odds of medical complications and secondary conditions. The reasons for these discouraging results in the SCI population of the U.S. are still being elucidated, but one explanation may coincide with how the recent lack of improvement in life expectancy can be understood (see the preceding section of the report); in short, the negative effects on any ageing SCI patients dealing with the combination of constrained financial resources and private health care delivery in the U.S. may be coming into play, simultaneously increasing exposure to late complications and mortality. Whatever the causes, it appears that, after gains achieved earlier in history with respect to critical care, survival, and early rehabilitation, it is the long-term, post-acute rehabilitative phase of SCI care where some of the greater health challenges now lie and where important inroads have yet to be made.

**Participation in Work and Physical Activity**

The increasing life expectancy after spinal cord injury has given social participation a new recognition as one of the ultimate goals of a comprehensive rehabilitation process.

Community participation/integration was brought into special focus for health service providers with the 1980 publication *Health for All by the Year 2000* by the World Health Organization. Despite concerted efforts by the research community, defining and measuring the concept of participation and the closely related theme of community integration has proven to be complex and challenging. One SCI-specific definition of community integration is as follows: “resuming age, gender, and culturally appropriate roles/statuses/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multivariad relationships with family, friends, and others in natural community settings.”

Based on this definition, the connection between a broad view of health and well-being among individuals with SCI and their level of community integration becomes very evident. Two of the most studied aspects of community integration, employment and sports and recreation participation, have been shown to decrease significantly following SCI. Combating such trends is important. Being employed is positively correlated with measures of health, both

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subjective (e.g., life satisfaction) and objective (e.g., fewer medical treatments). Similarly, recreation and sport participation has been correlated with higher indices of community integration and integration with “normal living,” better psychological status (e.g., reduced depression, life satisfaction), physiological measures (e.g., reduced pain and fatigue), and even increased life expectancy among individuals with SCIs. It is well known that individuals with SCI have among the lowest levels of physical activity participation, higher rates of cardiovascular disease risk factors (such as hypertension), and early onset of chronic diseases in general; while there is some evidence that exercise is an important avenue of prevention in this regard, more study is needed concerning the specific impact of physical activity in reversing chronic disease risk patterns in the SCI population.

The benefits of resuming appropriate roles enters into the equation with athletes who had been active pre-SCI; according to one study of such athletes, the social aspects of sports participation, such as fun and competition, were at least as important as fitness and health effects. Exercise cannot be limited to athletes, however. The regular involvement of all persons with SCI in some form of leisure-time physical activity is a good way to maintain and extend the benefits of the targeted training programs that are the centrepiece of rehabilitation following the initial injury. The importance of this area was summed up well in a 2004 review: “As the daily lifestyle of the average person with SCI is without adequate stress for conditioning purposes, structured exercise activities must be added to the regular schedule if the individual is to reduce the likelihood of secondary complications and/or to enhance their physical capacity.”

Attempts to track trends over the decades have been more apparent with employment than with sports or exercise. A recent review covering research from 1992-2005 showed that the

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employment rate of individuals with SCI has remained at approximately 40%,250 about the same level determined in an earlier study of the 15 prior years (1976-1991).251 Despite what appears to be a static situation, maintaining employment levels can be seen as highly positive given the steadily increasing pool of SCI survivors;252 furthermore, a “steady state” in terms of work involvement needs to be evaluated against the backdrop of declining employment rates among all disabled individuals in the U.S. in the last 25 years.253 Finally, there is reason for encouragement with respect to the apparent growing interest in the vocational arena of community integration; the more recent review identified 48 pertinent studies over the 13 year period, compared to only 17 studies over a similar period located by the earlier research group. Currently there is no population-based tracking of sports or recreation participation within the SCI community. However, as seen in the earlier section of this report that focused on sports infrastructure and events, it is clear that there is a growing interest and support for such activities at the elite level; there have been dramatic increases over the last 25 years in the number of nations, athletes, and sporting events in the Paralympic Games (see the table below).

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† First time games took place in same city as Olympic Games (since 64). First time Paralympic was used.
‡ First Paralympics to get mass media sponsorship.

Individuals participating at the elite level represent only a small portion of the overall SCI population; however, growth in the Paralympic movement is likely a good reflection for participation in organized sports, recreational activities, and exercise at all levels. While researchers have been active in constructing and validating instruments to allow more global measurements of community integration and participation for use with the SCI population,

further comparison of the utility of the several candidate instruments is required.\textsuperscript{254,255,256} Ultimately, the cause of SCI care and rehabilitation would be served internationally by “a standardized approach to reporting measures of activities and participation…for purposes of comparing rehabilitation outcomes in settings of differing socio-economic environments.”\textsuperscript{257} In the meantime, the benefits of sport participation, recreation, and leisure-time physical activity, as well as employment, for individuals with SCI are already clear; in fact, a recent study has shown that the employment rate among those with SCI increases with involvement in physical activity.\textsuperscript{258} Thus, these two arenas of participation will continue to offer an important picture of community integration among those affected by SCI. At this juncture, there is solid reason for optimism concerning further progress on both fronts, that is, for the arenas of work and physical play. Maintaining and extending gains will require more research and policy focus on the individual and environmental barriers to participation.\textsuperscript{259,260,261,262}

### Access to Public Facilities and Transportation

A defining feature of SCI is the resulting impairment of function and (usually) mobility. Although there are a variety of functional outcomes that are possible post-SCI, the vast majority of individuals with SCI experiences mobility limitations; very commonly, this results in either permanent or intermittent use of a wheelchair. Individuals so affected are part of a broad and visible population that often faces challenges when attempting to access public spaces, facilities, and transportation services. With the establishment in many parts of the world of legislation to protect the rights of those with disabilities, there is now a strong mandate for improved access to public spaces. Such improvements, in tandem with technological advances in mobility devices, have led to considerable progress in access over the past 25 years.

### Removal of Architectural Barriers

The primary way that wheelchair accessibility is improved is by providing features such as ramps and automatic doors in place of stairs and manual doors. This approach is commonly summed up as the removal of architectural barriers, and is mandated by law for public buildings in many parts of the world.

Measuring actual progress in this area, however, can be difficult. As described in an earlier section of this report, accessibility legislation in various jurisdictions has become more


complete and targeted since 1990. This development has generated obvious benefits, but it has also led to a challenge when evaluating progress. Accessibility is generally assessed in terms of how closely a building or transportation system adheres to legal requirements, rather than the actual reported or measured ability of wheelchair users to navigate to and through public spaces and services.

A review of the academic literature by Welage and Liu highlights the regular method of tracking accessibility. The review examines the findings of 12 separate studies (from 1987-2009) on wheelchair accessibility in the U.S., Mexico, Nigeria, Turkey, the United Arab Emirates, and Zambia; wheelchair accessibility is defined almost exclusively in terms of compliance to regulations rather than actual experience of access. The positive news is that adherence in fact has steadily improved over this time period, from rates below 50% in the 1990s to 90% or higher in more recent years. A primary driver for this change has been new construction; new buildings were shown to comply more fully with accessibility guidelines in every decade since the very earliest disability legislation was enacted.263

There are, of course, barriers to accessibility that are not architectural in nature. A 2002 study by Meyers et al. suggested that the most common environmental barriers are curbs and other structures that fall outside of the usual building codes. The authors also describe other categories, including interpersonal barriers such as prejudice and other forms of incivility expressed by people in society.264 These more intangible impediments can hinder accessibility at least as much as architectural barriers. The present report covered the related topic of public perceptions and attitudes more fully in an earlier section.

Mobility Technology

Given the functional impairment that is typical following SCI, technologies aimed at restoring mobility can have a profound effect on the daily lives of individuals. Examples of such equipment include modified automobiles and, perhaps most notably, wheelchairs.

Surprisingly, depending upon design, wheelchairs themselves are sometimes seen as a barrier; a 2004 study by Chaves et al. found that inadequate wheelchair design that rivalled functional impairments per se or the physical environment in terms of participation.265 Researchers and engineers have taken note, with technological advances in wheelchair design leading to improved, lighter-weight wheelchairs that are easier to manoeuvre, and thus increase functional independence. As well, powered wheelchairs have evolved rapidly over the past two decades, thereby providing previously impossible levels of unassisted mobility.266,267,268 One popular example is the pushrim-activated power-assist wheelchair, which requires less force for propulsion than the standard manual wheelchair; this is particularly important for those with weakness in the upper extremities, for reducing physical strain on all users. Cutting-edge

wheelchairs, termed robotic mobility devices, are being developed that can climb stairs and negotiate curbs.  

What has been very clear in recent decades is that everything must work together to enable full access to the community for individuals with SCI. As Chaves et al. note, “providing a wheelchair that fits well and is simple to operate without addressing environmental access may limit the potential benefits of the equipment. Similarly, an accessible environment is of no benefit if the equipment is difficult for the user to operate.”

In addition, the personal dimension of access cannot be overlooked. As Meyers et al. report, wheelchair users are often only able to access public buildings and services with the assistance of friends, family members, or paid helpers, and must plan their lives accordingly. Overall, the improvements that have been made to date in the area of accessibility have depended on taking many factors into account: physical barriers, assistive technology, public awareness, the availability of personal aides, and skill development. In order to continue the rate of progress, it is important to continue to integrate all of these aspects of the access sphere.

**Health Care Efficiency**

Given the global rise of health care costs, it is not surprising that scientific publications evaluating health care efficiencies have risen dramatically in recent decades. The U.S. Institute of Medicine defines health care efficiency as “avoiding waste, including waste of equipment, supplies, ideas, and energy.” Creating efficiency in the health care system is always a tug-of-war between resources and care, with the ultimate goal of maximizing output from a given amount of input. Efficiencies can be generated by refining current practices and adopting new practices. Generally, any discussion of health care efficiency falls into one of two categories: improvements observed in real-world settings (actual) and improvements that have been measured in controlled settings (potential). In the SCI context, progress has been seen on both these fronts. In the real-world setting, the metric that is most often tracked is length of stay in in-patient care, whether acute or rehabilitation. In terms of potential gains, one of the best indicators is the pursuit of, and positive results from, cost-effectiveness (CE) studies. Each of these areas will be examined below from the perspective of SCI care.

**Length of Stay**

A common measure of actual efficiency improvement is a reduction in the average length of stay in a hospital or in-patient rehabilitation setting. As the chart below shows, the average acute hospital stay in the U.S. in 2002-2006 was less than half it was in 1973-1981.

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This development has positive ramifications for the patient, as they are able to return home or to a community setting more quickly following injury, while at the same time reducing hospital crowding and health care costs. An important factor that must accompany decreasing lengths of stay is the maintenance of outcomes. In fact, this very issue is tracked in the Canadian setting by a combined metric introduced by the National Rehabilitation Reporting System (NRS), namely, Length of Stay Efficiency. The decreases in inpatient rehabilitation length of stay over the last decade have not resulted in any reduction in the average improvement in motor function score (which is based on the FIM instrument introduced earlier in this report).

The dramatic decrease in recovery/rehabilitation time in the U.S., Canada, and other jurisdictions has been credited to various changes in hospital management and specific advances in technology. There is a caveat, however, that must be added to this positive picture; according to DeVivo, daily health care costs and total costs in SCI care have continued to rise. The increase is beyond inflation, perhaps driven (as in other parts of medicine) by the price of emerging drugs and technology. The challenge will be to create even more efficiency gains as the SCI population ages and patients incur greater costs related to managing late complications, both primary and secondary; to this end, various efforts to contain costs being examined in the U.S. managed care context may offer valuable insight.

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274 The NRS data includes demographic, administrative and clinical information on clients from 101 participating facilities in nine provinces; managed by the Canadian Institute for Health Information (CIHI), the NRS has been collecting information on rehabilitation services and outcomes in the country since 2001, and reporting on specific client groups, including spinal cord dysfunction.


Intervention Cost-Effectiveness

A previous section of this report examined the growing attention that has been paid to researching and synthesizing results concerning intervention effectiveness in SCI care. To this body of information must be added the insights derived from cost-effectiveness (CE) studies, an essential tool for evaluating new interventions prior to widespread implementation; as the information derived is related to the controlled environment of scientific studies, it may be fairly characterized as a marker of potential efficiency gains in the real-world setting.

Measuring the potential for progress in efficiency generally involves a comparison of relative efficiency, that is, evaluating two practices against one another in terms of costs and benefits, or one practice against a predetermined threshold.278

To date, CE studies in the SCI field have covered topics such as:

- Treatments for erectile dysfunction279
- Bowel management280
- Detection and treatment of thromboembolic disease281,282,283
- Respiratory pacemakers and mechanical ventilators284
- Drugs and other techniques for the control of muscle spasticity285,286
- Strategies to prevent urinary tract infections287,288

Results of such research can be helpful in selecting interventions to implement and in designing practice guidelines. For instance, Christensen et al. conducted a study comparing bowel management techniques for SCI patients; the authors found that transanal irrigation using a self-administered system, despite higher costs of operation, resulted in reduced symptoms of bowel dysfunction and a lower total cost to society compared with other available methods.289

Despite progress on a number of fronts related to cost-effectiveness, there are still gaps in the research literature. In a 2003 review of spinal injury units (SIUs), Bagnall et al. found no studies that looked at costs and patient outcomes side by side, meaning that cost-effectiveness has yet to be properly examined.\textsuperscript{290} SIUs have the potential to improve efficiency, as prompt admission appears to lead to shorter average length of stay; furthermore, studies have shown that such units actually provide better care for patients.\textsuperscript{291} In theory, these units should be able to act as centres for professional training, public awareness and primary prevention efforts; it remains to be proven if they will also work towards further improving the cost-effectiveness of SCI care.


Conclusion: Making Progress in the Past, Present, and Future

In the past several decades there has been significant progress in improving patient survival and emergency care and in expanding the range of rehabilitative options.\textsuperscript{292}

The statement above was already true before 1985; the aim of this report was to show how much more progress has occurred in the years since. There are many reasons to land on this particular timeline of interest, but one very important one stands out: Twenty-five years ago, SCI-survivor Rick Hansen began his famous \textit{Man in Motion} World Tour, travelling in a wheelchair by manual power through 34 countries over two years. His message was an important one: given its devastating impacts, finding a full cure for spinal cord injury requires serious international attention; in the meantime, the best care needs to be delivered to individuals with SCI, so that they might enjoy the highest function and the fullest life possible.

The immediate benefits of the tour were clear: increased awareness of the needs and potential of individuals who have experienced SCI, many millions of dollars raised, and the first of many influential organizations and programs launched, the Rick Hansen Foundation. However, the effects have also been more long-term; when combined with the efforts of other leaders, such as Christopher and Dana Reeve, and building on societal momentum across many spheres of activity and concern, the accomplishments by and for those with SCI have been remarkable. As Rick Hansen is in the midst of his 25th anniversary tour, it is apt to take a moment to look back and examine the progress and anticipate the ongoing needs for attention. This report has begun this process, categorizing the topics under four domains that move from the “softer” areas of the environment experienced by the SCI community, through the record of research progress and developments in public health and clinical practice related to SCI, and finally to the “harder” results of actual patient and other outcomes—including improvements in the health care system itself.

Notwithstanding the need for focus in the report, the ultimate picture of progress that emerges is both varied and comprehensive. As noted below, other commentators have summed up the momentum and positive results related to specific aspects of SCI—but the compilation of topics assembled for this report tells a uniquely wide-ranging story.

The following table summarizes some highlights from this report covering the last 25 years of progress on SCI care and outcomes. Following the table are subsections offering a summation of the four main domains examined in this project, and some key directions that still need to be pursued.

Environmental Progress

The present report focused on the larger scale of environmental spheres, that is, society as a whole rather than the context defined by the home, workplace, etc. of a particular individual with SCI. Several of the environmental sub-domains have demonstrated remarkable progress in the last 25 years, especially the dramatic increase in networks, foundations, associations, and institutes dedicated to supporting and expanding SCI-related research and care. The fact that disability legislation has come to fruition in the last two decades is another encouraging development, as is the public profile of individuals from around the world with SCI and other disabilities being involved with sports, including the Paralympic Games.
Other environmental sub-domains are at an earlier stage of development, but a platform at least has been built upon which further gains may be made. Thus, the SCI community is being consulted more than ever about its concerns and needs, but this path could be followed further—especially regarding experience of people with such serious disabilities with stereotypes, prejudice, and similar negative attitudes.

**Research Production**

Quantitatively, there has been a steady increase in scientific publishing related to SCI, partly reflecting the launch of new specialty journals in the last 25 years. Even more encouraging is the large increase in clinical trials being published, as this represents the fountainhead of all translation and implementation work that eventually brings improvements in the medical care and everyday life of individuals with SCI. A 2010 review summed up this essential marker of progress as follows:293

*There has been a tremendous increase in the number of basic science and clinical studies on spinal cord injury. Current areas of investigation include early acute management, including early surgical intervention, as well as new pharmacotherapy and cellular transplantation strategies. It is unlikely that a single approach can uniformly address all of the issues associated with spinal cord injury. Thus, a multidisciplinary approach will be needed.*

The sub-domain of basic research into cures—or at least partial organic reversal of SCI (as opposed to “work-arounds” that depend on classic rehabilitation, assistive devices, etc.)—remains a mixed affair, representing both a degree of disappointment and continuing optimism. There is no doubt that great strides in scientific insight have occurred, so that cure/reversal in the near future seems all the more probable. The recent state-of-the-art is aptly summed up in a U.S. Institute of Medicine (IOM) review monograph from 2005:294

*The breadth and depth of neuroscience discoveries relevant to spinal cord injury have widely expanded the horizons of potential therapies. What once was dogma – that the central nervous system cannot regenerate—has been dismissed. This newly discovered potential for central nervous system (CNS) regeneration and repair has opened up numerous therapeutic targets and opportunities.*

On the other hand, the most important current story in this area may be the expansion of focus to see biological insights about the spinal cord, both damaged and whole, translated into therapies that will preserve function and even see improved function without full organic repair. Again, the IOM review of basic research in recent decades sums up this reality very well:

*The new challenge facing researchers is to harness the expanding knowledge to develop effective treatments to protect and repair the spinal cord and improve or restore altered and lost function. To address this challenge, researchers must focus on a set of strategies to prevent further tissue loss, maintain the health of living cells and replace cells that have died through apoptosis or necrosis, grow axons and ensure*


functional connections and re-establish synapses that restore the neural circuits required for functional recovery.

However, despite the need to maintain hope for a full cure or partial reversal of SCI, it is important to be realistic about the timeline. Multiple clinical trials are under way, seeking to advance pertinent insights from the “bench to the bedside.” However, as Kwon et al. noted in 2010, “the task of clinical evaluation…is substantial, and many years will be required before the actual efficacy of the treatments currently in evaluation will be determined.”

While the “quest for a cure” (utilizing the title of a book from 1993 by Sam Maddox) has become protracted, one consequence has been a recent expansion of research interest in other areas of care, including pre-hospital, rehabilitation, and preventing/treating secondary complications. The IOM monograph quoted earlier captures the importance of an expanded research focus as follows:

Spinal cord injury research should focus on preventing the loss of function and on restoring lost functions— including sensory, motor, bowel, bladder, autonomic, and sexual functions—with the elimination of complications, particularly pain, spasticity, pressure sores (decubitus ulcers), and depression, with the ultimate goal of fully restoring to the individual the levels of activity and function that he or she had before injury.

Translation to Application

The work of fostering improvements in SCI care is certainly not completed. For instance, it is certainly a concern that some 20% of trauma sufferers with SCI still die before being admitted to hospital.297 Even when basic insights and potential interventions emerge for this and other areas of need, it is just the beginning. The various stages of “translating” the expanding research results into application in the real world starts with sifting the existing body of evidence in systematic ways, developing and testing practice guidelines, and then tracking the ultimate results in terms of patient and other outcomes. Progress has been made on all of these fronts, especially in terms of identifying and developing protocols for applying best practices; the Rick Hansen Foundation has liberally supported this cause by funding systematic reviews of published intervention evidence. One major advance in the realm of practical application has been the development of many more outcome measures specific to SCI; while many of these metrics are still being validated, they do hold out promise for better tracking of SCI outcomes in the future—especially in light of the commitment of the Rick Hansen Institute and other groups to expand and strengthen national and international registries of SCI patients.

Population-Level Outcomes

The intention to develop more robust SCI registries is welcome news, given how important such a tool is to tracking patient outcomes at a population level. Several encouraging results can already be identified, especially through the largest and longest-running SCI database that captures information from 13 states in U.S. In that context, there has been:

- A 40% reduction in mortality in the first two years post-injury over the last three decades
- A gain in neurologic improvement during inpatient care, combined with lower frequencies of complications
- A long-term improvement in global measures of community integration, although understanding the positive aspect of work participation rates in particular requires a more nuanced assessment

In addition, a number of encouraging trends were identified in the report that extend beyond the individual to society as a whole, including broader compliance with building codes requiring accommodations to permit access to individuals dealing with disabilities such as SCI, and signs of improvements related to health care efficiency (notably, reduced length of stay in costly inpatient care settings).

**The Next 25 Years**

Driven by the enormous personal disaster and societal burden that SCI represents, it is clear that even more progress is needed. The last 25 years of positive developments, as summarized in the earlier table and the preceding commentary, may be attributed to people known and unknown—leaders with high profile such as Rick Hansen and countless other stakeholders, from researchers to health care providers to fund-raisers and volunteers, and most importantly the entire community of individuals dealing with SCI. A similar army will be required to continue to advance the cause over the next 25 years and realize Rick Hansen’s original vision from 1985: *A world without paralysis after spinal cord injury.*