

The Tipping Point: Perspectives on SCI Rehabilitation Service Gaps in Canada

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Abstract

Spinal Cord Injury (SCI) is a life-changing event that can have a significant impact on all aspects of a person's life. Changes in sensory, motor and autonomic function often impede the individual's activities of daily living, emotional wellbeing, and quality of life. As a person with SCI ages, they experience multimorbidity that compromises their health and functional abilities, and exacerbates caregiver burden. It is therefore pertinent to revolutionize current SCI rehabilitation and address these issues through health care service and policy reform. The Environmental Scan (E-Scan) Atlas is the product of a translational research project that sought to describe current Canadian tertiary SCI rehabilitation service delivery in order to prescribe necessary changes in knowledge generation, clinical application and policy, to achieve evolution in Canadian rehabilitation service delivery. This manuscript presents perspectives and key national messages derived from the E-Scan scoping review process, in hopes that the content will provoke an international dialogue intended to enhance rehabilitation service delivery in Canada by the year 2020.

Keywords: Spinal cord injury; Rehabilitation; Health services; Health; Wellbeing

Spinal Cord Injury

SCI results in diverse, often devastating motor, sensory, and autonomic impairments, including absence or limitations in one's involuntary ability to breathe, regulate blood pressure and temperature, and voluntary ability to evacuate one's bladder or bowel, dress, bathe, feed oneself, or move about one's home or community. These impairments have lifelong catastrophic implications for the survivor, their long-term health, and wellbeing [1,2]. Although survival and life expectancy after SCI have increased, most individuals 10 years post-SCI report a mean of seven concurrent secondary health conditions [3] with one in four of these patients being hospitalized each year [4,5]. SCI and related secondary health conditions negatively impact health preference. The mean Health Utility Index Score (HUI-III score, which is a measure of health status and health-related quality of life) for the SCI population is 0.27, which is less than, or equal to, the mean HUI-III score reported for other vulnerable populations: 0.58 [6] - 0.68 [7] for stroke; 0.77 [6] - 0.78 [7] for arthritis/rheumatism; 0.57 for multiple sclerosis [8]; 0.42 for Parkinson's disease [9]; and 0.45 [6] - 0.58 [7] for Alzheimer's disease.

The impact of SCI on the individual, his or her family, and the health system in terms of medical complexity, health care utilization, and cost, is greatest during the first two years after injury and the ten years prior to death. SCI costs the Ontario provincial government over \$1.38 billion per year, with the direct mean costs of rehabilitation ranging between \$112,000 - 120,000 CAD per person (2003-2006 CAD) [10]. Recently, the total lifetime economic burden (CAD) associated with SCI in Canada was estimated to be \$3,026,027 for complete tetraplegia, \$2,105,811 for incomplete tetraplegia, \$1,782,698 for complete paraplegia and \$1,471,930 for incomplete paraplegia (CAD) [11]. Describing the current goals and rehabilitation practices associated with managing patients with SCI is an important activity prior to prescribing changes aimed to optimize function and wellbeing, and minimize multimorbidity in an era of fiscal constraint.

In October 2012, a group of Canadian investigators launched the "Rehabilitation Environmental-Scan (E-Scan) Atlas: Capturing Capacity in Canadian Spinal Cord Injury (SCI) Rehabilitation" [12]. The E-Scan project is part of a program of translational research that

aims to describe current Canadian SCI rehabilitation service delivery in tertiary rehabilitation centres in order to drive change in rehabilitation service delivery by 2020. The atlas represents an amalgamation of a national data set describing current rehabilitation resources and service delivery, results of a scoping review, and the expert opinion of 46 co-authors, and 86 collaborators from 15 tertiary SCI rehabilitation centres across the nation regarding the current state of SCI rehabilitation knowledge generation, clinical application, and policy change in Canada. An overall framework for understanding the rehabilitation process is presented in the atlas [13]; summary data from the scoping review is presented throughout the atlas as it relates to specific goals of rehabilitation (i.e., maintaining skin integrity or developing independence in breathing). Intended for use by multiple stakeholders (clinicians, administrators, non-governmental organizations, etc.), the atlas attempts to: facilitate program self-evaluation and service enhancements; articulate future research and health policy agendas; and inform accreditation processes and best practice implementation. Through the scoping review methodology employed by the authors [13], the atlas identified national trends, gaps (regional and/or process disparity) and priorities in SCI rehabilitation service delivery. This article presents key national perspectives derived from the scoping review process that warrant international reflection and dialogue. The content is intended to provoke the reader while highlighting the need for dynamic service paradigms to keep pace with global findings and national initiatives.

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Key National Messages for SCI Rehabilitation

Multimorbidity challenges the single disease framework

Multimorbidity may be more important than initial impairment in driving health service needs as one ages with SCI. Individuals with SCI develop complex health states, or multimorbidity, which disrupts their state of wellbeing and impacts negatively on health outcomes. Multimorbidity is defined as any combination of chronic disease with at least one other disease (acute or chronic) or biopsychosocial factor, including the social network, the burden of diseases, health care consumption, and individual coping style [14]. Current health care delivery in Canada is in large part conducted in silos, with diagnosis and management of disease or health complications often addressed independently from one another (e.g. cancer care, heart disease, renal failure). This leads to inefficiencies and repetitiveness in care processes, which stem from the lack of an infrastructure to coordinate and integrate multiple services for persons with multimorbidity and comorbid SCI-related impairments [15]. SCI therefore challenges the single disease framework within the Canadian health care system at all levels - locally, provincially and nationally, creating a pressing need to create an organized multi-system of care that facilitates efficient management of complex patients with multimorbidity.

In particular, current chronic disease management models and access to diagnostic services are often barriers to service integration. The chronic disease management movement is predicated upon the assumption that self management strategies can change the clinical course of disease or health complications. This assumption requires rigorous investigation to develop a body of supporting evidence, and formal evaluation of its effectiveness, prior to implementation within the SCI community. Specifically, there is a need for biomedical discovery and health service innovation to ensure provision of integrated care that promotes health and wellbeing, considering the myriad of demands dictated by multimorbidity, while minimizing the burden of rehabilitation service delivery.

Non-traumatic SCI and traumatic SCI do not equate

The incidence of non-traumatic spinal cord injury (NTSCI) is on the rise, with persons with NTSCI now comprising the majority admitted for SCI rehabilitation in Canada. This, coupled with the aging demographic, is creating an anticipated tsunami of NTSCI incidence and prevalence that will shortly overwhelm current system resources. Persons with NTSCI tend to be older, and have a greater number of concurrent medical conditions and incomplete injuries, with unique recovery profiles after surgery. These individuals with NTSCI require substantial medical and rehabilitative resources and often a greater rehabilitation length of stay to achieve similar outcomes to their traumatic SCI counterparts. It is therefore incumbent on all tertiary rehabilitation service organizations and health care professionals to develop service models designed specifically to accommodate the influx of NTSCI patients.

Unfortunately, current SCI surveillance strategies in Canada have limited ability to identify or track the incidence, prevalence, resource requirements, and outcomes of persons with NTSCI prior to rehabilitation admission. This challenge is, in part, attributable to difficulties with case finding, due to a lack of consensus regarding how to best use current ICD-10 codes to identify patients with NTSCI. Resolution of these coding issues and addition of NTSCI data fields, service interruptions, and relevant measures of medical co-morbidity to the national Rick Hansen Spinal Cord Injury Registry (RHSCIR)

would substantially enhance our understanding of the incidence, prevalence and rehabilitation resource utilization, as well as future resource requirements of this population.

Compounding these issues, a high proportion of individuals with NTSCI are receiving inpatient rehabilitation services outside of tertiary academic sites, potentially compromising their access to the appropriate specificity, timing and intensity of rehabilitation services. It is evident that a cross-continuum system of care is needed to identify patients with NTSCI and route them to the most appropriate rehabilitation service in a timely manner. A strategy must be put forth to eliminate current mismanagement of these individuals (e.g., high rates of late or missed diagnoses, long diagnostic and surgical consultation waiting times, with urgent or emergent consultation waiting until paralysis or a neurogenic bladder occurs). Specifically, care must be customized to the individual, the underlying course of disease or pathology, and their co-morbid medical conditions. In an ideal model of NTSCI care, there should be opportunities for pre-rehabilitation – interprofessional assessment and monitoring of individuals prior to, or at the time of, initial onset of sensorimotor or autonomic deficits, prior to surgical intervention. Such a system of NTSCI care would recognize the value of appropriate and timely care, as well as access to appropriate rehabilitation services and lifetime management of concurrent/related health conditions.

SCI rehabilitation is forever

The importance of long-term follow up for individuals with SCI over the course of their lifetime cannot be overstated. Long-term follow up is essential to address new rehabilitation goals as they emerge, maintain functional abilities over time, monitor for changes in neurologic impairment, prevent SCI-related secondary health conditions, enable access to new therapies and technologies, assist with accommodation to aging with a disability, and living with multimorbidity after SCI. Interprofessional care in a variety of settings, and a system of care that is not merely reactive to adverse events, but is able to incorporate preventive approaches, and which enables re-entry to inpatient and outpatient rehabilitation services over a person's lifetime, is required.

For example, an individual with SCI may develop an episode of acute shoulder pain, which makes wheeling difficult. Their untreated shoulder injury may contribute to reduced mobility, deteriorating transfers, and development of a pressure sore on the ischia, followed by months of bed rest to enable healing of the pressure sore. This bed rest, in turn, contributes to a first episode of depression due to social isolation and results in bed rest-induced global deconditioning. This aforementioned cascade of events and the associated health care costs could have been prevented with eight to ten weeks of care in an interprofessional outpatient rehabilitation environment.

Triaged access to community rehabilitation service providers should self-limit the course of events and prevent similar cascades of secondary health conditions that plague individuals with SCI and multimorbidity living in the community. The vast majority of current outpatient service models in Canada are not interprofessional due to inadequate funding models or inadequate complement of skill mix.

Development of an interprofessional model to support lifetime care is a key priority in Canadian SCI rehabilitation. In particular, the ability of the system to provide timely assessment and interprofessional management when acute or severe changes in health and function occur, and to disrupt the typical cascades of health complications, is of paramount importance. Such a model would likely result in substantial

system savings longitudinally through reductions in inappropriate emergency department use and physician visits, particularly in the chronic SCI population.

Change service models with the evidence

It is becoming increasingly apparent that the volume and intensity of rehabilitation services determine the extent and nature of an individual's functional outcomes (e.g., the ability of individuals with AIS C and D impairment to return to walking) [16]. Despite evolving evidence that the volume of training matters, there are currently unprecedented system pressures to reduce both rehabilitation onset days (date of injury to date of rehabilitation admission) and length of inpatient rehabilitation stay. These reductions necessitate that the health care system provide structures and processes and develop services that support optimal rehabilitation outcomes, and facilitate access to the right type and intensity of tertiary outpatient rehabilitation (Body Weight Support Treadmill Training, Advanced Wheelchair Skills, etc.). Health system providers should now focus efforts on ensuring a seamless transition from inpatient rehabilitation to community living, while ensuring delivery of an adequate volume and intensity of therapy services.

Emotional wellbeing a key to success

Current staff-to-patient ratios of patient educators, psychologists, psychiatrists, social workers, and recreation therapists for outpatients with SCI, are inadequate. Dramatic increases are needed in the availability of resources to support the biopsychological care of individuals with SCI living in the community. There is need for a dramatic paradigm shift in service delivery, acknowledging the value of pre-emptive models of care, versus current models, in which provincially funded services only become available once an individual has a wellbeing crisis.

Friends and family count

Individuals with SCI have smaller social networks, with more intense bonds, than those with chronic disease [17]. Family members, neighbours, and friends play significant roles in assisting the individual with SCI to remain independent in the community. Despite this, services to support and train these crucial, unpaid members of the care team are absent in the current health care system, which is particularly problematic given that support providers may not be part of the social circle of every individual with SCI. It is essential that the health care system support community living by providing respite care, including short-term access to increased attendant care resources in the event of illness or absence of a key member of a patient's social network, and emotional and logistical support services for informal care providers.

Make employment a reality

The recently imposed reductions in rehabilitation length of stay and the erosion of the infrastructure that supports inpatient rehabilitation have led to an overemphasis on self-care activities, and a de-emphasis on employment as an outcome of importance. In addition, there are systemic and financial disincentives for individuals to return to employment. These actions have led to the existence of "career disability" and low employment rates among persons with SCI, which have profound personal, economic, and health consequences for the individual over their lifetime. Advances in technology, accessible transit, and growing flexibility in the work environment are means by which persons with SCI may sustain employment after injury. Vocational training, currently not funded as part of a model of care for SCI, needs to be addressed.

Get policy smart

Although Canadian rehabilitation service providers are knowledgeable of the best available therapies for specific health conditions [18], lack of funding often precludes optimal therapy delivery for individuals with SCI. The development of a national body (akin to the Ontario SCI Solutions Alliance and its member organizations) to routinely lobby and advocate for changes in health policy are essential to the future of rehabilitation services enhancements. There are many inequities and challenges associated with bringing about policy change for individuals with a relatively rare disease, such as SCI, compared to individuals with larger scale, common diseases (e.g., diabetes, cancer) [19]. One example of the challenges associated with generating policy change for persons with SCI is the difficulty of conducting clinical trials, health policy analysis, and economic evaluations with a population that has low incidence, but high prevalence and cost, to inform enhancements in provincial and or national services. It is essential that health care researchers move to align their efforts and choice of outcomes in order to secure a sufficient volume of data to move the field from generating evidence to generating evidence-informed policies, which reflect the complex longitudinal and resource intense nature of living with a SCI.

Telemedicine for all Canadians

Two-way videoconferencing has been the most popular mode of telecommunication among Canadians for health purposes for over 25 years [20]. Recent technological advancements offer an opportunity to enhance health care delivery by: (1) Efficiently using cell phone and or tablet technology to ensure timely and accurate communication between patients and providers, facilitate monitoring of a patient's health status (blood pressure, bladder volumes, peak cough flow, etc.) and therapy adherence, and educate/maintain provider competence through provision of decision support tools and evidence-based information; (2) Using the current strength in Canadian telemedicine expertise to facilitate transitions in care (e.g. from rehab to community; acute care to rehabilitation), assessment of patients living in remote areas, access to care in non-peak hours for those who are employed, providing timely education for patients living in the community when they are prepared and motivated to learn (e.g., sexual health and addressing erectile dysfunction once a person has a new partner or resumes sexual relations with a former partner following injury, upgrading skin care and nutrition education concurrent with the onset of a pressure sore, supportive counselling during times of extreme personal stress, such as divorce, caregiver illness or death of a spouse), and providing access to psychological services when a person is too depressed or anxious to attend appointments; and (3) Facilitating interprofessional care across disease providers and regions [21-25].

Early adoption and leveraging of these communication technologies is vital, given the typical time frame involved in the implementation of novel therapies and rehabilitation devices (17 years for drug therapies, and even longer for rehabilitation devices). A national implementation strategy focusing on universal and effective use of mobile devices is essential. This strategy should also address barriers to the implementation, including obtaining regulatory approvals, and establishing funding mechanisms (billing codes, etc.) to sustain the use of the technology.

Extend the knowledge base for success

In concert with the current move toward increasing the volume

of patients served, while simultaneously reducing costs, various types of “extenders” have been introduced (physician, nursing, physical therapy and occupational therapy assistants) into newer models of care. It is of critical importance that these “extenders” be provided with the appropriate knowledge, skills, and training, to manage the complexity of patients with SCI. This will be particularly important as the number of persons requiring services expands over time. Providing “extenders” with the necessary education can be achieved through strategic partnerships with local colleges and universities offering related certification and training programs (e.g., the physician assistant training program recently established in Ontario and Alberta, and the sexual health rehabilitation courses for rehabilitation professionals at University of British Columbia [26] and SCI-U [27]).

Get on the Global Enhancement Train

The enclosed perspectives discussed were derived from conduct of a scoping review and a related service audit completed in 2011, with data validation throughout 2012. Many of the challenges discussed are not unique to rehabilitation service delivery in Canada, and likely apply in other settings. Thus, these challenges are worthy of international discussion and global solutions. The authors hope that we have hit a critical “tipping point” in Canadian SCI Rehabilitation, “...that magic moment when an idea, trend or behaviour crosses a threshold, tips and spreads like wildfire” [28]. Rehabilitation policy makers, administrators, and service providers must implement innovative solutions in order to serve the needs of a diverse, complex, and growing population of persons with SCI over their lifetime. Imminent strategic planning for the field must systematically address the identified service gaps through funding of discovery in rehabilitation, development and broad implementation of evidence-informed care paradigms, creation and dissemination of international training and accreditation standards for health care providers and institutions, developing a national “rehabilitation is forever” marketing campaign, establishing an inclusive registry, and launching a lobby of SCI stakeholders to address health policy inequity. These processes will require the community to harness the global passion, expertise, and ingenuity of rehabilitation professionals to work collaboratively with one another and individuals with SCI and their families to achieve exponential changes in Canadian rehabilitation outcomes by the year 2020.

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