Feature article

Outcomes and reflections on a consensus-building workshop for developing a spinal cord injury-related chronic pain research agenda

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Context/ Objective: Chronic pain following spinal cord injury (SCI) is a prevalent secondary health condition that significantly impacts quality of life (QoL). Although growing, the number of available effective pain management approaches for SCI is limited. Recognizing the need to “kick-start” activity on this topic, a consensus-building workshop on developing a research agenda for SCI-related chronic pain was held in 2006 with an expert panel. The present paper describes the processes of the consensus-workshop and its associated outcomes towards advancing the research agenda for SCI-related pain in Canada. A commentary on the current state of knowledge regarding SCI-related pain is also provided.

Methods: Thirty-nine stakeholders (researchers, clinicians, policy-makers, SCI advocates, and people with SCI) attended the consensus-workshop. A modified Delphi approach was employed to gain consensus on identifying the top five SCI pain research priorities for improving QoL post-SCI. As well, project planning along with infrastructure support opportunities were discussed.

Results: The top five pain research priorities were: 1) pain management and treatment; 2) measurement tools; 3) health services policy and advocacy; 4) knowledge transfer; and 5) mechanisms of pain. Recommendations related to the priorities and related resources were generated, and pilot work was initiated.

Conclusions: The consensus workshop provided an initial roadmap for research on SCI-related chronic pain, and supported five pilot projects on the identified priorities. Reflections on the current research landscape in Canada and abroad suggest increased activity towards addressing pain post-SCI but evidence-based approaches are still lacking.

Keywords: Spinal cord injuries, Pain, Quality of life, Consensus development

Introduction

Despite impressive improvements in addressing other sequelae of spinal cord injury (SCI) over the last 30 years, chronic neuropathic pain post-SCI remains resistant to treatment. Consequently, it can be one of the most challenging problems that individuals with SCI experience.^{1–3}

The presence of pain and difficulties with its management may impede the initial SCI rehabilitation process for an individual and their subsequent re-entry into the community.^{4,5} Chronic pain in people with SCI affects sleeping patterns,³ vocational status,^{6,7} sexuality,⁸ leisure time activities,⁶ activities of daily living,³ and quality of life (QoL) over and above the consequences of their injury.^{9–11} As well, chronic pain after SCI has been noted in some cases to be a contributing factor in suicide.¹²

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In 2003–2004, our research group conducted an evaluation of the long-term outcomes of persons aging with SCI in Canada ($N = 781$), which described pain to be a prevalent condition (58%).¹³ Of the sub-set of participants reporting pain, 81.5% reported it to be moderate or severe, and 56.2% stated it had an impact on some or most of their daily activities.¹⁴ Moreover, the presence of moderate/severe pain significantly impacted on community participation and life satisfaction.¹³ The high frequency of pain reports, along with its negative influence on QoL and community participation, prompted our group to further explore the current state of research related to pain post-SCI.

When the state of the literature was reviewed to inform next steps for our research program (prior to 2005), we found that the general consensus in the field was that research in this area had surprisingly been neglected.^{15,16} The evidence related to understanding the cause of pain, and the effectiveness of various treatments, was limited and mixed. For instance, only a few presumed mechanisms for the causes of chronic pain had been substantiated by pathophysiology at the time^{17,18} while findings related to various factors (e.g. age, level of injury, duration of injury, etc.) contributing to the development and maintenance of pain were contradictory.^{19–25} Despite the recognition of the importance of using a biospsychosocial framework in the study of pain,^{26,27} only a handful of studies were identified that had explored elements of key variables of these models (i.e., catastrophizing, social support, etc.).^{28,29} As well, there were many questions regarding the efficacy of various forms of treatment. The results from pharmacological (e.g. anti-inflammatory drugs, opioids, N-Methyl-D- Aspartate [NMDA] receptor antagonists, anticonvulsants, local anesthetics, etc.), surgical, psychological (e.g. cognitive behavioural therapy), and/or alternative interventions (e.g. acupuncture) were also limited and provided mixed findings.^{10,11,30–34} Further, most SCI consumers reported being dissatisfied with available treatments.³⁵

A number of methodological factors may have contributed to the contradictory research findings and equivocal treatment outcomes.³⁶ These factors include (1) different definitions of pain after SCI, both with regard to specific pain types and recognition of abnormal sensations as pain; (2) low response rates from survey studies and inadequate sampling techniques; (3) variable time between injury and pain assessment; (4) heterogeneous classification schemes of pain after SCI; and (5) lack of demonstrated ability to discriminate between types of pain (e.g. nociceptive vs. neuropathic).^{15,36,37} Overall, the increasing number of studies on SCI-related pain, along with the noted

methodological issues in its study, indicated that SCI-related pain was an emerging topic of importance to many stakeholders in the field of SCI in the mid 2000s.

Recognizing that pain in SCI is a highly complex clinical phenomena that required collaboration and coordination across disciplines studying this topic,^{15,38} a collaborative process was initiated in 2006 to organize efforts in Canada to better address this serious SCI secondary health condition. This involved identifying the top research SCI-related pain priorities in order to improve QoL post-SCI, which involved hosting a consensus-building workshop using a modified Delphi approach with an expert panel comprised of researchers, clinicians, community advocates, policy-makers and people with SCI. Recent involvement by members of our team in the development of the upcoming Canadian clinical guidelines for the management of SCI-related neuropathic pain³⁹ prompted us to re-visit this initiative to determine whether or not progress has been made on the identified priority areas. Thus, the present article provides an overview of the consensus-building workshop to develop a research agenda on SCI-related chronic pain, and then provides a reflection of the current SCI-related pain landscape in Canada (and internationally) as a benchmark on progress in the field. Doing so will highlight where gaps in knowledge still exist, and where efforts are needed for advancing knowledge on this serious secondary health condition.

Methods

Guiding framework

The processes guiding the workshop structure were based on the Delphi method.⁴⁰ Delphi is “a structured group communication method for soliciting expert opinion about complex problems or novel ideas, through a series of questionnaires and controlled feedback.”⁴¹ The selection of the Delphi expert panel is the most critical step in the process since it has a direct bearing on the quality of the results generated,⁴² and it is highly recommended that participants be competent and highly trained within the specialized area of knowledge related to the issue at hand.⁴⁴ Thus to ensure a broad perspective on the topic, a heterogeneous group of stakeholders working in the field of SCI was selected to participate who had relevant expertise on SCI-related pain at the research, clinical, policy, and/or personal level.

With regards to the number of rounds for achieving consensus on the research priorities, a total of two sequential rounds⁴³ were used via a pen-and-paper approach at a face-to-face meeting of the entire panel. The first round used a divergent, exploratory process to establish a broad list of potential research priority

areas and an accompanying list of research headings under which to categorize the research topics. The second round used a two-step convergent process to agree on a list of five headings.

Identification of workshop participants

For the SCI pain consensus-workshop, a heterogeneous set of participants were targeted for invitation. Similar to other Delphi studies, this was accomplished by reviewing authors of relevant publications in the literature,⁴⁴ by making contacts with those who had firsthand relationships with the issue at hand,⁴⁵ and by contacting members of our existing network who met the listed criteria above (e.g. persons from the SCI rehabilitation and/or pain field, etc.). The use of our existing network was particularly important for identifying clinicians with relevant expertise and people with SCI-related chronic pain to provide a “person-with-pain”

perspective; thereby ensuring that identified pain priorities would be deemed relevant towards improving QoL.

SCI Pain Report and expert speakers

Preparatory effort is a necessary precursor before the start of the rounds in the Delphi approach.⁴³ Although the panel all had expertise relevant to the target issue, an SCI Pain Report was drafted specifically for the workshop by the core investigation team and circulated to all invitees prior to the meeting, which included identified pain priorities from both the literature and pilot data from three stakeholder groups: (1) people with SCI-related pain;⁴⁶ (2) SCI rehabilitation clinicians;⁴⁷ and 3) SCI researchers. The SCI Pain Report compiled 11 priority areas and listed a total of 35 research topics, which were cross-tabulated by source (Table 1). In addition, four expert keynote speakers addressed the entire group of participants before beginning the Delphi rounds. Speakers included researchers who

Table 1 SCI pain research priorities and topics (T) by stakeholder group

Research Priorities	SCI Consumer	Clinician	Research	Literature
1. MECHANISMS OF PAIN				
T1. Need to better identify causes of pain	X	X	X	X
T2. Explore mechanisms of hypersensitivity including both central and peripheral mechanisms of hyperalgesia and allodynia.			X	X
2. EPIDEMIOLOGY OF PAIN				
T3. Require longitudinal studies on SCI-related pain. This may help to identify risk factors and prevention strategies for different types of pain (e.g. shoulder pain).			X	X
T4. Evaluate potential exacerbators of pain such as nicotine, obesity, and physical activity (e.g. transfers).		X	X	
T5. Need to compare SCI-related pain to other chronic pain conditions/populations (e.g. thoracotomies, cancer, etc.).			X	
T6. Evaluate factors associated with development of pain (age, gender, level of injury, etc.)				X
3. BIOPSYCHOSOCIAL FACTORS				
T7. Develop an understanding of psycho-social factors influencing SCI-pain, including family, personality, cultural beliefs, socio-economics, work, pain coping mechanisms and exploring co-morbidities such as anxiety and depression.	X	X	X	X
T8. Research on adaptation to pain and coping mechanisms.		X	X	X
4. ACCESS TO HEALTHCARE SERVICES				
T9. Need for strategies to improve interactions with healthcare professionals for access to a wider variety of treatment modalities.	X			
T10. Lack of adequate pain treatment	X	X	X	X
T11. Other pain treatments are offered but not explained (marijuana, stem cell, research, recreational therapy, psychological).	X			
5. KNOWLEDGE TRANSFER				
T12. Develop education models that foster both a better understanding of SCI-related pain and available treatment options.	X	X	X	
T13. Evaluate knowledge gaps in the community, including family doctors.		X	X	
T14. Involve consumer groups to call for and support more research activities	X			X
T15. Develop resources to improve consumers' knowledge about pain, and to be able to evaluate treatment options.	X			
6. ASSESSMENT				
T16. Develop better pain assessment measures (clinical)		X	X	X
T17. Achieve consensus on pain classification systems.			X	X
T18. Develop measures to evaluate effectiveness		X	X	X
T19. Develop a core set of outcome measures				X

Continued

Table 1 Continued

Research Priorities	SCI Consumer	Clinician	Research	Literature
7. PAIN MANAGEMENT				
T20. Multidisciplinary or self-management approaches should be developed and evaluated (Hospital and Community-based).		X	X	X
T21. Educate consumers regarding prescription medications which may alleviate fears regarding side effects and addiction, and may improve better compliance to a prescribed pain management program.	X	X		
8. TREATMENT				
T22. Evaluate which treatment(s) works in which patient(s).		X	X	X
T23. Develop new treatment(s)	X	X	X	
T24. Test combinations and sequencing of pharmacological, non-pharmacological, and behavioral interventions to manage pain		X	X	X
T25. Determine whether the response to treatment is influenced by the level and cause of the SCI as well as by the duration, distribution, and characteristics of the pain.		X		X
T26. Design and execute relevant clinical trials (e.g. observational studies) to establish best pain management.			X	X
T27. Develop preventative pain interventions.			X	
9. PAIN BELIEFS & MISBELIEFS				
T28. Misbeliefs and misconceptions about addiction and drug-seeking in rehabilitation professionals.	X	X		
T29. Misbeliefs and misconceptions about addiction and drug-seeking in SCI Consumers.		X		
10. IMPACT OF PAIN ON QUALITY OF LIFE				
T30. Document effects of pain on quality of life, activities of daily living, and mood.	X	X	X	X
T31. Elucidate the interactions of pain and sleep, their combined impact on function and illness recovery, and develop interventions that target these interactions.			X	X
T32. Understand relationship of pain and impact on QOL (direct or indirect influences).			X	X
11. PAIN EDUCATION				
T33. Develop education on SCI-related pain to community health providers, such as family physicians, may help improve consumers cope with their pain.	X	X	X	
T34. Patient education in rehabilitation and community.		X		
T35. Elucidate diverse cultural beliefs about and actions taken for pain and its management including self-care and that of lay caregivers.		X	X	X

highlighted the current state of the field and their perceived areas of importance, and a person with an SCI who provided a firsthand account of her experience dealing with chronic pain on a daily basis. These preparatory materials and presentations were to ensure that all the participants were properly oriented to the workshop's goals and to highlight the relevant key issues to the various stakeholder groups.

Results

Meeting participants and workshop structure

Sixty-one potential participants were identified for the meeting in March 2006. Of those 61, 39 attended the consensus-workshop. The majority of participants were from the province of Ontario (Canada; 82%), with some experts coming from other provinces (8%), and the rest from abroad (13%). See Table 2 for a breakdown of the professional backgrounds and domains of expertise of the expert panel.

Table 2 Delphi expert panel characteristics (N = 39)

Stakeholder Category / Expertise	Percentage %
Clinical / Research Professional	
Medical Doctor	26%
Nurse	5%
Physical Therapist / Occupational Therapist	18%
Psychology / Social Work	18%
Researcher	33%
Other	15%
Consumer / Community / Policy	
SCI Consumer	10%
SCI Advocacy	5%
Grant Funder	3%
Other	3%
Domains of Expertise	
Pain Clinical Practice	8%
Pain Research	18%
SCI	82%
Quality of Life	23%
Health Outcomes / Measurement	18%
Epidemiology	5%
Health Policy	15%

SCI = Spinal Cord Injury

Some categories of expertise / professional practice encompassed more than one domain in some cases.

The meeting was led by a professional facilitator and the 39 participants were pre-assigned to one of seven table groups, each comprised of approximately 5–7 persons representing clinical, research, and consumer perspectives. Each group was provided with a table facilitator and student note-taker for the small-group breakout sessions. Fig. 1 provides an overview of the processes undertaken for developing research topics and headings, and for generating the top five research priorities.

Round one—developing research priority areas

The participants' first task was to individually review the previously identified research topics and the priority research areas (Table 1) and assign one or more topic to the most appropriate research heading. The participants were then invited to generate additional research topics,

which were either assigned to a previously identified priority research area(s) or assigned to a “Miscellaneous” category if it could not be subsumed under an existing heading. The participants then reviewed the headings, held small group discussions, and then modified or expanded the headings. This step completed the expansion of potential research priority areas and the divergent phase of the workshop.

Round two—prioritizing research areas

Following structured time for small group discussions, the participants then voted independently for the research headings they deemed to be of highest priority. The top ten research headings, from highest to lowest priority, were: (1) Pain management and treatment; (2) Knowledge transfer; (3) Mechanisms of pain; (4) Impact of pain; (5) Measurement tools; (6) Health

Figure 1 Consensus meeting structure and processes for generating the top five pain research priorities.

Table 3 Key research recommendations

Priority	Research Recommendations
Pain Management & Treatment	<ol style="list-style-type: none"> 1. Early aggressive treatment of neuropathic pain – medications. 2. Alternative therapies for SCI pain, including marijuana, massage, and meditation. 3. Acupuncture for neuropathic pain. 4. Participation in physical activities twice a week for 1–2 hours (reported to alleviate pain – multi-faceted approach).
Measurement Tools	<ol style="list-style-type: none"> 1. Validate assessment tools for the SCI population. 2. Determine which tools are optimal in SCI. 3. Assess the impact of the measurement tool administrator on the results and report the reliability between different administrators (e.g. nurse, research assistant, medical doctor). 4. Determine the sensitivity to treatment and reliability of the application of a given measurement tool or scale.
Health Services Policy & Advocacy	<ol style="list-style-type: none"> 1. Identify access issues such as system-related barriers, availability of drugs and procedures, barriers associated with providers, consumer-identified needs, and consumer/professional biases. 2. Identify caretaker burden associated with a lack of support systems and the current provision of social services to families. 3. Perform SCI pain and QoL needs assessments from the consumers' point of view.
Knowledge Transfer	<ol style="list-style-type: none"> 1. Partner with provincial and federal funding agencies to "piggy-back" on other initiatives, paying particular attention to the unique needs of geographical regions and their knowledge transfer priorities. 2. A knowledge broker is needed to spearhead this initiative. If the broker is a clinician, they will need support to organize their caseload so they have adequate time to devote to this project. This role would require strong project management/organizational skills. The initiative would involve the exchange of both information and resources. 3. Partner with a SCI advocacy group to disseminate information to SCI consumers regarding accessible services for proper pain management. 4. Rehabilitation centres could be used to pilot a project that would raise the Ambassador Strategy. 5. Team communication and team-building strategies could be implemented. 6. A project grant could be obtained to link and connect healthcare professionals using media such as electronic transfer, audio, video, etc. to share documents among healthcare professionals.
Mechanisms of Pain	<ol style="list-style-type: none"> 1. Validate a core set of measures of pain, including measures of neuropathic pain, and clinically relevant outcome measures. 2. Determine individual differences in function at the molecular, cellular, genetic, psychophysical, and psychosocial level with respect to: a) each individual's clinical pain characteristics, and b) responders vs. non-responders to specific pain management strategies. 3. Compare measures of neural function in humans with specific pain symptoms to findings in relevant animal models. 4. Evaluate the influence of cognitive and affective stressors on biophysical measures of pain.

policy; (7) Multi-disciplinary and multi-faceted; (8) Alternative therapy; (9) Access and disparities; and (10) Pain education. The newly-selected research headings replaced the initial research priority areas, and the participants re-assigned their expanded potential research priority areas to these new headings. This concluded the first item reduction step in Round 2.

The next step aimed to further reduce the number of headings from ten to five for a potential research plan for future teams through consensus rather than by voting. The results were tallied based on the mode and rank for each nominated research heading (the convergent phase of the Delphi process). The resulting list of top research priorities based on the process of tabulation was as follows: (1) Pain management and treatment; (2) Measurement tools; (3) Health services policy and advocacy; (4) Knowledge transfer; (5) and Mechanisms of pain. Dedicated time was spent by the participants in small groups for each priority to develop a roadmap

for moving these areas forward (i.e., project planning; Table 3).

Discussion

The present article describes the processes and outcomes of a consensus-building workshop for developing a research agenda addressing SCI-related pain for improving QoL. From an expert panel comprised of key stakeholders, the outcomes of the workshop identified five research priorities, which were: (1) pain management and treatment; (2) measurement tools; (3) health services policy and advocacy; (4) knowledge transfer; and (5) mechanisms of pain. Thus the workshop objectives were achieved, and led to the initiation of five pilot studies to advance work on some of the identified priorities.⁴⁸ With regard to the pain management and treatment priority, three studies emerged: (1) an evaluation of the feasibility and efficacy of a group cognitive behavior therapy intervention; (2) a multi-centre study

examining an acupuncture protocol (<http://clinicaltrials.gov/show/NCT00523016>); and (3) a secondary data analysis on an existing pain management program for potential application in SCI, which led to a prospective cohort trial evaluating the effectiveness of an interdisciplinary program for pain in persons with chronic SCI (N = 22).⁴⁹ With regard to mechanisms of pain, work was funded to develop and conduct the preliminary validation of a questionnaire that collects pain phenotypes in individuals with SCI. Similarly, work was done examining biopsychosocial factors that contributed to the maintenance and development of pain post-SCI. Overall, the consensus-workshop served as an initial catalyst for raising awareness and facilitating work on pain in SCI in Canada.

In terms of our method for achieving consensus on SCI pain priorities, the adoption of a Delphi approach was appropriate since it is useful for situations in which there is a lack of empirical evidence or when there are strong differences of opinion. However, using a Delphi process for achieving consensus does not imply that the “right” answer has been found⁵⁰ nor that a correct answer exists. The achieved consensus simply reflects an expert group’s opinion and should be interpreted as such.⁵¹ Therefore, the resulting priorities are reflective of but may not be generalizable to the larger SCI-related pain field. Regardless, our initiative successfully engaged the participation of persons with research, clinical and policy expertise in the area of SCI and/or pain as well as persons living with SCI-related pain. Thus, we feel that we had a well-balanced expert panel with relevant perspectives for generating the targeted priorities, and who could work to advance these priorities across domains (e.g. policy, advocacy, education, etc.).

When re-visiting the present state of research within the SCI-related pain field, there has been a great degree of progress addressing pain post-SCI,⁵² suggesting that the topic is emerging from its infancy. Yet, when examined against the current landscape (both in Canada and abroad), the priorities generated a decade ago remain relevant. This highlights the complexity of pain post-SCI but also suggests that there may be other factors that need to be addressed in order to elevate the state of the field.

With regard to the priorities of “Measurement Tools,” there has been substantial advancements in this priority area. For instance, the advent of the International SCI pain data set has helped to provide some cohesion to the field by facilitating the synthesis of research in pain and SCI.⁵³ As well, recent updates to the data set have increased its clinical utility,⁵⁴ and

there is growing psychometric evidence for its validity and reliability.^{55,56} Further, the number of available screening measures for identifying neuropathic pain post-SCI has increased (e.g. Leeds Assessment of Neuropathic Symptoms and Signs [LANSS],⁵⁷ Douleur Neuropathique 4 [DN4],⁵⁸ the PainDETECT Questionnaire [PD-Q],⁵⁹ Neuropathic Pain Questionnaire [NPQ]⁶⁰). Despite these gains, efforts are required to prompt adoption of the International pain data set, along with available validated tools for pain assessment, and to develop strategies for circumventing barriers to its implementation within clinical settings (e.g. lack of time, resources for pain assessment, etc.). Within Canada, there are several available pain assessment approaches and current guidelines in use across rehabilitation centres, but none are explicitly referencing the International SCI pain data set and less than half of major sites use validated outcome tools.⁶¹ Thus, existing platforms for improving research on the topic are now available (e.g. taxonomy) but more efforts are needed for effective translation into clinical practice.

With regard to the “Pain Mechanisms” priority, progress achieved in this domain has been uneven. Similar to a decade ago, the underlying mechanisms of neuropathic pain are multiple and remain incompletely understood.⁶² Although there have been some gains in knowledge from experimental studies (see Finnerup & Baastrup⁶³ for a full review), the advances in these areas have not been as dramatic as those seen examining psycho-social mechanisms contributing to the development and maintenance of SCI-related pain. Since the time of the consensus-workshop there have been several studies examining the role of coping strategies,^{42,64–68} pain cognitions, such as pain acceptance,^{69,70} catastrophizing,^{42,65,66,68,71} and other psycho-social variables such as self-efficacy⁷¹ and social support.^{66,68} Although some of the work has promoted psychosocial pain profiles post-SCI, the work in this domain has taken a somewhat piecemeal approach and has not been grounded in a firm theoretical model of pain, which may have relevance for explaining the interrelationship among factors contributing to pain post-SCI (e.g. diathesis-stress model⁷²). Overall, the number of studies and constructs examined within biopsychosocial approaches is promising but further work is needed to better understand vulnerabilities to factors that contribute to the development and maintenance of SCI-related chronic pain.

In terms of the “Pain Management and Treatment” priority, the number of interventions aimed at addressing pain have increased, which are providing more options for people with SCI-related pain. Nevertheless,

a recent review⁴ indicates that since 2006, there have been only 23 non-pharmacological pain intervention studies (2 from Canada,^{49,73} and 16 pharmacological studies (none from Canada). The general consensus is that tricyclic antidepressants and pregabalin are first line treatments,⁶³ and that non-pharmacological interventions are not as effective as pharmacological ones.⁶¹ However, it is recognized that an inter-professional multi-modal approach is viewed as the best option for maximizing pain management options,⁶¹ and further work examining combinations of therapies should continue to be explored. Despite these advancements, the recent environmental scan of pain practices across rehabilitation centres in Canada found that only 3 centres of 12 followed any kind of clinical practice guidelines,⁶¹ which suggests that not all options are being fully explored for this population.

Arguably, the priorities of “Health Services Policy and Advocacy (HSPA)” and “Knowledge Transfer” priorities are highly relevant in today’s landscape, and there is a need for more work in these domains at the research, clinical and policy level. With regard to HSPA, there have only been a few studies to-date examining SCI-related pain and health utilization,^{74–76} and the lack of work detailing the costs of pain post-SCI is somewhat surprising, given its high prevalence and chronicity.⁷⁷ When examined in the larger context of the general pain field, however, it appears the SCI field is on par. In the US, the cost of chronic pain in adults, including direct costs and lost productivity, is approximately \$560–\$630 billion annually.⁷⁸ Based on these data, it is estimated that the annual cost of chronic pain in Canada is at least \$56–60 billion dollars.⁷⁹ Despite this high burden, pain research is grossly under-funded in Canada with less than 1% of total funding from Canadian Institutes of Health Research, Canada’s federal health research funder, and only 0.25% of total funding for health research going to pain related studies.⁸⁰

Further work on the “Knowledge Transfer” priority might be key for stimulating better research, clinical practice and education on SCI-related pain. In Canada, progress in this area includes recent investments by the Canadian Federal and Provincial branches of Government to the Rick Hansen Institute’s “Care Program”⁸¹ that has funded a number of research and knowledge translation activities with clear linkages at the research, clinical, and policy levels.^{82–85} These resources elevates the SCI research field’s ability to easily access information and/or tools to better address pain, which may be of use to help inform the wide range of information needs of people with SCI

and their family members and caregivers. In general, there has been a clear gain in the number of research studies in the area of pain, but the ability to generalize findings into clinical practice remains problematic. Although funding opportunities have improved somewhat, it is imperative that knowledge transfer efforts are continued to ensure the sustainability of these resources, which will require on-going advocacy to demonstrate the burden of pain post-SCI.⁶¹ This includes taking into account the perspectives of people with SCI related to what they feel is important on the management of their pain.^{86–88} Given that persons with SCI still report being dissatisfied with the level of knowledge regarding their pain by family physicians,⁸⁶ there is a need for ways to improve communication pathways between clinicians and patients regarding pain treatment algorithms and patient expectations regarding the outcomes of various pain management approaches.⁸⁷ The upcoming SCI neuropathic pain clinical guidelines³⁹ may serve to address this issue but the fact that people with SCI are still grossly dissatisfied with their pain management options is the biggest red flag that the field needs to do better.

Conclusions

When framed against the current body of SCI-related pain research, the priorities identified at our 2006 consensus-workshop remain highly relevant. Despite the progress in some areas, the ability to effectively translate research findings into clinical practice remains highly problematic. Continued efforts are needed to build upon the momentum of coordinated initiatives currently being undertaken to address chronic pain following SCI, which may lead to improved QoL.

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