A Primary Care Provider’s Guide to Pain After Spinal Cord Injury: Screening and Management

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Abstract: Individuals with spinal cord injury (SCI) often experience chronic pain as a secondary complication. It can significantly impair mental health, sleep, mood, and overall quality of life. It is important for providers within a primary care setting to recognize the different types of pain such as nociceptive and neuropathic. Various assessment tools are available to guide proper classification and subsequent management. Providers need to have a good knowledge base, structure, and patient focus when managing care. Nonpharmacological interventions are just as important and should be explored prior to or along with pharmacological interventions. Treatment modalities such as physical therapy, exercise, acupuncture, and cognitive behavioral therapy should be tailored to the individual to the greatest extent possible. Gabapentin, pregabalin, and amitriptyline have been studied extensively and are the first-line pharmacological agents for neuropathic pain. It is important to involve patients as equal stakeholders in any pain intervention with adequate lifelong follow-up. The aim of this article is to offer an overview of pain assessment, information, patient interaction, and treatment options available. Although chronic pain has remained difficult to treat successfully, primary care providers can play an integral role in delivering evidence-based and patient-centered care for managing chronic pain among individuals with SCI. Key words: chronic pain, neuropathic pain, primary care, spinal cord injury

Health Maintenance Checklist

1. Consider at least yearly assessment of pain or assessment with any changes and its interference on quality of life.
2. Assess for type of pain (neuropathic, nociceptive), interference in life, function, and management.
4. Monitor effectiveness of pain management and side effects.

Episodic Key Care Points

1. Pharmacological treatment
   - For nociceptive pain, consider symptomatic management with acetaminophen and nonsteroidal anti-inflammatory drugs.
   - For neuropathic pain, consider gabapentin, pregabalin, or amitriptyline as first-line medication management.
2. Nonpharmacological interventions such as exercise therapy and cognitive behavioral therapy should be offered in conjunction with pharmacological interventions.
3. Consider referral to physiotherapy/occupational therapy for further evaluation and management of pain.
4. Consider referral to specialist for refractory pain despite treatment, complex pain, or complications (e.g., autonomic dysreflexia).

Case Report

Peter is a 35-year-old individual with paraplegia as a result of a complete spinal cord injury at T5 secondary to a motor vehicle accident 5 years ago. He presents to your primary care clinic for assistance with pain. For the past 3 months he has had a dull aching pain in his right shoulder. Pain is worse with transferring from bed to wheelchair, propelling his wheelchair, and reaching and lifting. He also reports burning pain with tingling into both legs that has been present since shortly after...
injury and is unchanged but is very bothersome, affecting sleep and his mood. He previously used oxycodone and amitriptyline for the leg pain but found the side effects (dry mouth, constipation, sedation) unfavorable. What would you do for Peter?

Introduction

Pain is one of the most frequently described symptoms that impairs quality of life among individuals with spinal cord injury (SCI). A recent prospective study showed an 80% prevalence of chronic pain after SCI among adults. It negatively affects sleep, mood, anxiety, and other activities of daily living. One study reported that individuals with SCI felt frustrated with their primary care providers’ (PCPs) lack of interest, lack of time, and limited knowledge in managing pain care visits. Similar frustrations and displeasure were reported by the PCPs themselves. The unique characteristics of pain associated with SCI may cause PCPs to have uncertainty in evaluating and managing these pain conditions.

Types of Pain Encountered by PCPs

The International Spinal Cord Injury Pain Basic Data Set (ISCIPBDS) and the International Spinal Cord Injury Pain (ISCIP) classification include the most common pain types (both injury and noninjury related) that may occur among individuals post SCI. Both the ISCIPBDS and ISCIP were created to incorporate updated SCI taxonomy and facilitate consistency in collection and reporting of SCI pain by health care professionals. Pain is divided into four main pain categories: nociceptive, neuropathic, other, and unknown.

Nociceptive pain

Nociceptive pain reflects activity in the neural pathways related to tissue or organ damage. It is generally divided into musculoskeletal, visceral, and other types of pain.

Musculoskeletal pain is independent of the level of injury and generally occurs where there is preserved sensation. Fifty-nine percent of individuals with SCI encounter this type of pain. It is often described as dull in nature, worse with movement, and often tender on palpation. Examples of this type of pain include shoulder overuse syndromes, muscle spasms, spinal fractures, or muscular injuries. Shoulder overuse syndromes are frequently seen among individuals who use upper extremities for mobility and transfers. Specific shoulder injuries include rotator cuff injuries such as tendinitis, tendinosis, and partial and full thickness tears. Heterotopic ossification is an abnormal growth of bone in nonskeletal tissues and is a significant source of pain below the level of injury among individuals with SCI. It is mostly present at the hips but can be found in other joints. Fever, swelling, limited range of motion, and pain are the typical symptoms. Bone scans and x-rays can help detect and determine management appropriately.

Fractures can be common occult sources of pain. Persons with SCI are susceptible to sublesional osteoporosis (bone loss below the level of injury) commonly affecting the long bones and pelvis (distal femur and proximal tibia). Signs and symptoms of fractures can be atypical due to lack of sensation and may present with altered pain, erythema, edema, spasticity, and autonomic dysreflexia (AD).

Visceral pain is likely to originate from visceral structures (thorax, abdomen, and pelvis). Secondary complications (e.g., urinary tract infections, nephrolithiasis, constipation) in SCI may present with visceral pain. However, due to sensory deficits, these symptoms may be atypical resulting in altered pain experience, increased spasticity, or autonomic dysreflexia.

Other nociceptive pain refers to pain unrelated to musculoskeletal and visceral. Pain from pathologies such as skin ulcerations and headaches falls into this category. Treatment aims to address the underlying pathology.

Neuropathic pain

About half of the SCI population suffers from neuropathic pain with typical onset up to 1 year after SCI injury. Neuropathic pain is often described as hot/cold, burning, tingling, pins/needles, electric, pricking, and shooting. Sensory changes (e.g., allodynia, hyperalgesia, hypoesthesia) can occur in the painful area.
At-level SCI pain presents at the neurological level of the injury (NLI) and up to three dermatomes below. It can be either unilateral or bilateral. Symptoms may present within days to weeks post injury.

Below-level SCI pain is usually located more than three dermatomes below the NLI or alternatively located in an area including the injury level and extending three or more dermatomes below the NLI. It typically has a late onset, months to 1 year post injury.

PCPs should be aware of syringomyelia (fluid-filled cavity or cyst that can develop within the spinal cord causing compression of neural tissue) as a rare condition that may cause new signs and symptoms (increased neuropathic pain, change in neurologic status, increased spasticity, and AD).

Other types of neuropathic pain are typically unrelated to SCI and can be in any location. Examples include carpal tunnel syndrome (prevalence of 21%-66% among individuals with SCI), postherpetic neuralgia, painful diabetic neuropathy, and central poststroke pain.

Additional pain classifications include other and unknown pain. Other pain is unrelated to SCI and without an identifiable stimulus (e.g., fibromyalgia, Complex Regional Pain Syndrome type I, interstitial cystitis, irritable bowel syndrome). Unknown pain has an unknown etiology and does not fit the other pain classifications.

Screening Tools and Assessment

Early detection of pain and management can lead to significant improvement in physical and psychological morbidity among individuals living with SCI (refer to Appendix A). Advanced age at SCI, SCI secondary to gunshot injuries, early onset of pain post SCI, early sensory hypersensitivity, and concomitant secondary complications (pressure injuries, neurogenic bowel, infection) have been identified as risk factors that lead to the progression of neuropathic pain.

Pain can also be triggered by factors related to other impairments caused by the SCI. Therefore, a thorough evaluation of constipation, distended bladder, muscle spasms, prolonged sitting, and other potential triggering factors are important for optimal pain management. Due to the altered sensation, some signs and symptoms in SCI may be difficult to interpret. For example, individuals with SCI may present with venous thromboembolism without obvious calf pain, kidney stones without flank pain, or myocardial infarction without any chest pain. Moreover, several psychosocial factors can negatively influence the pain experience. For example, depression and anxiety are commonly associated with severe SCI-related pain. The ISCI-PBDS contains three questions that evaluate interference with sleep, activities, and mood. Any other factors that aggravate pain should be addressed during the clinical consultation.

A thorough assessment is essential to determine the type of pain, intensity, and interference with daily functioning (e.g., activities, sleep, mood). Detailed history should include:

- Onset
- Quality/characteristics
- Location
- Severity
- Daily course
- Exacerbating and alleviating factors
- Functional effect (sleep, mood, activities)
- Changes in baseline condition or neurological status
- Concerning features (fever, limb deformity, autonomic dysreflexia)
Physical examination should be guided by the history and may involve neurological, musculoskeletal, and skin examinations. Physical examination may include:

- Vital signs
- Inspection of areas (in areas lacking sensation full inspection is important)
- Palpation
- Range of motion (including passive range of motion to inspect for tone/spasticity and contractures)
- Strength testing
- Sensation
- Gait (if ambulatory)
- Wheelchair, seating, transfer (or refer to occupational or physiotherapy)
- Other: abdominal, pelvic, respiratory

The ISCIPBDS v2.0 (Appendix A) can be used as a standardized tool for assessing and documenting pain during visits. It can be used along with the American Spinal Injury Association Impairment Scale (AIS) and the International SCI Core Data Set. It is concise, reliable, and valid and has clinically relevant data to evaluate SCI-related pain. PCPs should use neuropathic pain screening tools that are quick and that have been designed for use in specialized SCI pain settings. The two simplest screening tools appropriate for SCI are a simple yes/no algorithm to screen for pain during inpatient and outpatient visits, developed by the CanPain SCI working group, and the SCI Pain Instrument (SCIPI), another similar yes/no validated tool (Appendix B and Figure 1).

Investigations and diagnostic tests should be guided by history and physical findings. Other secondary complications that affect pain should be appropriately investigated. X-rays and MRIs of the spine should be performed based on suspicion and changes in neurological findings (e.g., syringomyelia). Primary abdominal pain may require abdominal ultrasound, x-rays, or computed tomography (CT). Chest x-ray may be indicated for suspected respiratory pathology whereas CT angiogram or ventilation/perfusion lung scan may be indicated for suspected pulmonary embolism.

Approach to Management

It is important for PCPs to recognize that no one modality of treatment is consistently effective. Pharmacological and nonpharmacological interventions should be used to improve and prolong successful outcomes among individuals with SCI.

Structure

Structured and multidisciplinary treatment approaches are not uniformly offered in primary care. Limited knowledge, lack of interest, and lack of resources are some barriers to providing more comprehensive care and lead to dependence on pharmacological methods. Individuals with SCI are often concerned about unwanted side effects, and they are reluctant to use pain medication long term, whereas others have reported being afraid of being labeled as “drug seekers.” It is no surprise that they have unmet needs and perceive that they receive poor quality of care. PCPs should also aim to establish connections with local pain clinics and rehabilitation centers for specialty support.

Patient focus

Involving patients as equal care partners leads to better adherence and management of pain. In one study, semi-structured interviews among individuals with SCI were conducted to determine their preferred methods of obtaining information about their chronic pain. They were often dissatisfied with the level of knowledge and primary care involvement. Interestingly, they also preferred to have information available on an as-needed basis. As such, having frequent patient visits to discuss broad themes related to care can be beneficial. These themes can involve the cause of pain and their expectations, pain management (pharmacological intervention including their side effects and nonpharmacological methods), resources for more information (internet sources, multimedia, pamphlets, or magazines),
and communication and involvement with other SCI organizations and rehabilitation centers, as well as other individuals with SCI. Any assessments, treatment plans, or other stakeholder involvement need to be regularly followed up and reevaluated lifelong. Spending extra time during visits, accommodating requests, ensuring regular follow-ups, and providing good education either by the PCPs or staff can lead to good patient-centered care. PCPs can also inquire about local peer support programs. They have often been credited as an important component in assisting with education of injury, social support, strengthening of self-efficacy beliefs, and community reintegration.\(^{19}\) Frequent monitoring and rates of secondary complications including neuropathic pain were reduced for up to 1 year post SCI, when peer support programs were involved.\(^{4}\) The grounded theory of acceptance emphasizes and acknowledges the chronic nature of pain.\(^{20}\) This acceptance leads patients to find ways to adapt and thereby inadvertently reduce the suffering caused by pain. Various institutions use the multimodal rehabilitation approach in which an interdisciplinary team coordinates physical therapy, cognitive behavioral therapy, and workplace accommodations to manage patients’ pain, leading to improved quality of life.\(^{21}\) Connecting with local rehabilitation centers that follow this framework should be part of the treatment strategy.

Treatment

Pharmacological strategies

Nociceptive pain

Musculoskeletal pain can often be relieved by analgesics such as acetaminophen. Second-line therapy can include nonsteroidal anti-inflammatory drugs. These strategies can be supplemented with physiotherapy and exercise programs. A trial of weak opioids can be reserved as a last resort for patients unresponsive to these treatments. Careful initiation, titration, and monitoring should be exercised. PCPs should also be able to promptly discontinue opioids if function and reduction of pain is not adequately achieved. If patients have underlying substance use disorders, opioids should be discouraged. Due to safety concerns, it is recommended that PCPs collaborate with pain management specialists if they are starting opioids in complex patients.

Neuropathic pain

Although various guidelines exist for the management of neuropathic pain, the CanPain SCI working group practice guidelines are specific to individuals with SCI (Table 1).

An important consideration for pharmacology in individuals with SCI is the potential for side effects that can worsen other secondary conditions (e.g., bowel and bladder function, respiratory function).

Nonpharmacological strategies

Because pain after SCI can be challenging to manage, complementary treatments should be discussed in conjunction with other modes of treatment. Treatment plans should be individualized. Barriers to nonpharmacological therapies are common and may include cost or lack of health care coverage, lack of availability of services, lack of SCI-specific expertise, and physical inaccessibility.

- Cognitive behavioral therapy (CBT) has been shown to be effective in treating several domains of chronic pain (intensity, interference, coping) in several populations.
- PCPs should involve physiotherapists to manage pain, especially those with nociceptive etiologies. Having a graded and supervised exercise program can lead to functional improvements and better long-term pain management.
- Thermotherapy (heat applied to the affected region) and in some cases exercise in a warm-water pool have shown mixed results. This may have benefit for nociceptive pain. Caution should be exercised to avoid applying heat in areas with impaired or no sensation to reduce the risk of burns.
- Massage therapy has been reported by some SCI patients as being beneficial to managing pain. PCPs should be open to offering referrals as needed.
- Observational studies have shown that acupuncture therapy has some benefit with SCI pain. An improvement was noted if the pain was bilateral, symmetric, burning, and constant. Acupuncture has been shown to be effective in managing chronic musculoskeletal shoulder pain in individuals with SCI.
- Other treatment modalities that have low quality evidence and are mentioned in the literature include spinal cord stimulation, osteopathy, and transcranial magnetic stimulation.

Referral to SCI health care professionals and/or pain specialists is recommended:

- If the etiology of chronic pain in unknown and further assessment is required.
- If the current treatment is not helping and/or pain causes significant psychosocial and functional impairments in individuals with SCI.
- If individuals currently managed with chronic pain develop SCI-related secondary complications (autonomic dysreflexia, spasticity) or other complications (syringomyelia, fracture).
- If the severity of neuropathic pain increases after 1 year from the onset of initial SCI.
- If the PCP feels uncomfortable in continuing a treatment plan with individuals with SCI.

If chronic pain coexists with depression, anxiety, or other psychological comorbidities, PCPs should consider a referral to behavioral health or psychiatric services.
Table 1. Recommendations based on CanPain SCI practice guidelines\textsuperscript{7,23,28}

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Dosage</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First-line treatment of neuropathic pain</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gabapentin</td>
<td>• 100-300 mg/d</td>
<td>Max dose: 3600 mg/d</td>
</tr>
<tr>
<td></td>
<td>• May be increased by 100-300 mg/d every week</td>
<td>Side effects: peripheral edema, dizziness, drowsiness, weakness, fatigue, nausea, diarrhea, constipation, blurred vision, headache, breast swelling, dry mouth, loss of balance or coordination</td>
</tr>
<tr>
<td>Pregabalin</td>
<td>• 25-150 mg/d</td>
<td>Max dose: 600 mg/d</td>
</tr>
<tr>
<td></td>
<td>• May be increased to 300 mg twice a day within 1 week based on tolerability</td>
<td>Side effects: somnolence, dizziness, peripheral edema, dry mouth, fatigue, blurred vision</td>
</tr>
<tr>
<td></td>
<td>• A dose of 150 mg should be taken as 50 mg three times daily as receiving smaller doses can lead to increased effectiveness and reduced side effects.\textsuperscript{28}</td>
<td></td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>• Initial: 10-25 mg/d at bedtime</td>
<td>Max dose: 150 mg/d</td>
</tr>
<tr>
<td></td>
<td>• May increase as tolerated up to 150 mg/d</td>
<td>Side effects: confusion, paresthesia, headache, constipation, diarrhea, blurred vision, skin rash, angioedema, nausea</td>
</tr>
<tr>
<td><strong>Second-line treatments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tramadol</td>
<td>50 to 100 mg every 4-6 hours</td>
<td>Max dose: 400 mg/d</td>
</tr>
<tr>
<td>Lamotrigine</td>
<td>Starting at 25 mg once daily</td>
<td>Max dose: 400 mg/d</td>
</tr>
<tr>
<td><strong>Third-line treatments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transcranial direct current stimulation (tDCS)</td>
<td>Can be combined with visual illusions that mimic movement of patient’s deafferented or affected limbs</td>
<td></td>
</tr>
<tr>
<td><strong>Fourth-line treatments</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transcutaneous electrical nerve stimulation (TENS)</td>
<td>Side effects: constipation, dry mouth, sedation, nausea, vomiting. Long-term use can result in drug tolerance, hyperalgesia, endocrinopathy, misuse, physical dependence, and fatal overdose.</td>
<td></td>
</tr>
<tr>
<td>Opioid analgesics</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Morphine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Oxycodone</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Fentanyl</td>
<td></td>
</tr>
</tbody>
</table>
|                                  | • Hydromorphone                 | Initiating opioids\textsuperscript{16}:
|                                  | • Start at the lowest dose      |                                                                          |
|                                  | • Opioids should be avoided in patients with active substance abuse |                                                                          |
|                                  | • Caution should be exercised if trial of therapy lasts longer than 3-6 months |                                                                          |
|                                  | • During dosage titration, patients should be advised to avoid driving until no sedation from opioids is established |                                                                          |
|                                  | • Restrict the prescribed dose to less than 50 mg morphine equivalents for patients starting opioid therapy |                                                                          |
|                                  | • Restrict the prescribed dose to less than 90 mg morphine equivalents for patients on long-term opioid therapy |                                                                          |
|                                  | • Withdrawal syndrome can occur within as little as 2-4 weeks while tapering |                                                                          |
Case Resolution

On examination, you find Peter has full range of motion and strength of his right shoulder but pain with resisted abduction. He also has positive impingement tests. You refer him to physical therapy for treatment of his supraspinatus tendonitis and assessment of his transferring technique. You also recommend a trial of acetaminophen and ice as needed for this nociceptive pain. You determine his leg pains are below-level neuropathic pain with no indication of a new etiology. You refer him to occupational therapy as his wheelchair and seating are old. You recommend a trial of gabapentin starting slowly and arrange follow-up to review effectiveness and side effects.

Conclusion

Pain negatively affects the quality of life in individuals with SCI. Therefore, PCPs need to recognize the different types of pain, perform a thorough assessment, and tailor management to each and every individual. Both pharmacological and nonpharmacological treatment approaches should be discussed with the patient as options for managing pain and for improving long-term outcomes. Neuropathic pain conditions are long-lasting, and treatment approaches need to be followed up frequently (at least yearly visits). PCPs should also make referrals to specialists when chronic pain is difficult to manage or when significant psychosocial and functional impairments persist. This article offers some recommendations and insights that will inform practice management for pain among individuals with SCI within a primary care setting.

Acknowledgments

The authors declare no conflicts of interest.

REFERENCES


### APPENDIX A

**International Spinal Cord Injury Pain Basic Data Set**  
**Data Collection Form – Version 2.0**

**Date of data collection:** YYYY/MM/DD  
**Have you had any pain during the last seven days including today?**  
☐ No  ☐ Yes

| Pain locations/sites | R | M | L | Type of pain  
|----------------------|---|---|---|----------------|
| (can be more than one, check all that apply): right (R), midline (M), or left (L) |   |   |   | Intensity and duration of pain  
|                      |   |   |   | Treatment of pain  
| Head                 |   |   |   | Type of pain (check one):  
|                      |   |   |   | Nociceptive  
|                      |   |   |   | Musculoskeletal  
|                      |   |   |   | Visceral  
|                      |   |   |   | Other  
| Neck/shoulders       |   |   |   | Neuropathic  
|                      |   |   |   | At-level SCI  
|                      |   |   |   | Below-level SCI  
|                      |   |   |   | Other  
| Arms/hands           |   |   |   | Unknown  
|                      |   |   |   | Other  
|                      |   |   |   | Intensity and duration of pain:  
|                      |   |   |   | Average pain intensity in the last week:  
|                      |   |   |   | 0 = no pain; 10 = pain as bad as you can imagine  
|                      |   |   |   | 0; 1; 2; 3; 4; 5; 6; 7; 8; 9; 10  
| Frontal torso/genitals |   |   |   | Date of onset: YYYY/MM/DD  
|                      |   |   |   | Are you using or receiving any treatment for your pain problem?  
|                      |   |   |   | No  Yes  
| Buttocks/hips        |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  
| Upper leg/thigh      |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  
| Lower legs/feet      |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  
|                      |   |   |   |  


If yes:

*Please note that the time period during the last week applies to all pain interference questions.*

In general, how much has pain interfered with your day-to-day activities in the last week?

No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8 - □ 9 - □ 10 Extreme interference

In general, how much has pain interfered with your overall mood in the last week?

No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8 - □ 9 - □ 10 Extreme interference

In general, how much has pain interfered with your ability to get a good night’s sleep?

No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8 - □ 9 - □ 10 Extreme interference

How many different pain problems do you have?

□ 1; □ 2; □ 3; □ 4; □ ≥5

Please describe your three worst pain problems or evaluate the pain that the patient considers the worst:


APPENDIX B

The original SCIPI assessment tool consists of seven yes or no items. This has since been reduced to a four-item questionnaire. The selected questions include items 1-3 and 7.¹⁸

<table>
<thead>
<tr>
<th>Pain</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the quality of pain electrical or electric shock-like?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Is the quality of pain like pins and needles or tingling?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Does the skin over the area of pain or inside your body where the pain is located feel hot or burning or cold or freezing?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Does the pain only occur in an area of the body in which you have no feeling on the skin overlying that area?</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

The four questions are given a score of 1 to each positive item and zero for negative score. The total score consists of adding all four items. A score of zero suggests nonneuropathic pain, a score of 1 suggests possible neuropathic pain, a score of 2 or greater suggests probable neuropathic pain.