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Improving your care of patients with spinal cord injury/disease

Ninety percent of patients with spinal cord injury/disease identify FPs as their “regular doctors.” So what can you do to keep them healthy and out of the hospital?

PRACTICE RECOMMENDATIONS

- › *Have a high index of suspicion for the leading causes of hospitalization among patients with spinal cord injury and disease (SCI/D). These include respiratory infections, urinary tract infections, and pressure ulcers.* **(A)**
- › *Treat respiratory infections early and aggressively in patients with SCI/D; strongly consider inpatient management because of the high risk of respiratory failure.* **(C)**
- › *Be alert to atypical signs and symptoms of urinary tract infection in patients with SCI/D, such as fever, chills, spasm, autonomic dysfunction, nausea and vomiting, abdominal discomfort, and fatigue.* **(C)**

Strength of recommendation (SOR)

- (A)** Good-quality patient-oriented evidence
- (B)** Inconsistent or limited-quality patient-oriented evidence
- (C)** Consensus, usual practice, opinion, disease-oriented evidence, case series

More than 5 million Americans are living with paralysis, and for nearly one in 4 of them the cause is spinal cord injury or disease (SCI/D).¹ More common than multiple sclerosis (17%) as a cause for the loss of movement, SCI/D is second only to stroke (29%).¹

The percentage of people living with paralysis due to SCI/D is increasing, partly because the population is aging and partly because management of infections has improved. Prior to the 1970s, life expectancy for people with SCI/D was significantly shortened, largely because of urologic and respiratory infections. But improved bladder management, in particular, has increased life expectancy—especially for the least severely injured.² Respiratory diseases and septicemia remain the leading causes of death, but with increased longevity, other causes, such as endocrine, metabolic and nutritional diseases, accidents, nervous system diseases, and musculoskeletal disorders, are becoming increasingly common.^{2,3}

Primary care’s pivotal role. Given the size of the population affected by SCI/D and the increase in life expectancy, family physicians (FPs) are more likely than ever before to care for these patients, most of whom have highly specific needs. However, little information about the primary care of patients with SCI/D exists. This patient population tends to consume a relatively large share of practices’ resources because of high case complexity.⁴

A recent Canadian report confirms our clinical experience that FPs report knowledge gaps in the area of SCI/D care, yet the same report found that 90% of people with SCI/D identify FPs as their “regular doctors.”⁵ Although a large number of patients with SCI/D identify their physiatrist as their primary care physician (PCP), one study reported that fewer than half of physiatrists are willing to assume that role.⁶ And while more than half of all patients with SCI/D have both specialists and PCPs involved in their care,⁵ communication breakdowns are a concern for patients receiving medical and rehabilita-

tive direction from multiple health care professionals.

Below we take a closer look at the distinct patient populations affected by SCI/D, summarize several clinical conditions that contribute to hospitalization, and provide clinical management recommendations (TABLE⁷⁻²⁶).

2 patient populations, one diagnosis

Paralysis due to spinal trauma occurs predominantly in non-Hispanic white and black males because of vehicular accidents, falls, violence, and sports.² The mean age of injury has increased from 29 years during the 1970s to 42 years since 2010.² However, this calculated average is misleading because there is an emerging bimodal distribution of people injured during early adulthood and a new increase in older adults injured primarily because of falls.²⁷ In addition to those injured traumatically, a broader cohort of approximately 1 million patients represents a largely undefined group of people with paralysis due to diseases such as spinal stenosis, cancer, infection, multiple sclerosis, or other non-traumatic causes.

As a result, the population with SCI/D is comprised primarily of young adult males who have relatively few chronic medical conditions at the time of their injury and age with SCI/D, and older patients who are more likely to have already developed chronic medical conditions by the time of their SCI/D. Approximately 60% of SCI/Ds result in tetraplegia (ie, 4 limbs affected), although approximately two-thirds are incomplete, meaning that patients have some residual motor or sensory function below the level of injury.² Not surprisingly, the level and severity of SCI/D impact life expectancy inversely and lifetime financial costs directly.

■ **High health care utilization.** Morbidity data largely parallel mortality data, often resulting in high health care utilization and cost among SCI/D patients.²⁸ In a recent prospective observational study of nearly 1000 people with new traumatic SCI, 36.2% were rehospitalized at least once and 12.5% were rehospitalized at least twice during the 12-month period after discharge following injury.²⁹

Rehospitalization, an outcome often quoted as a proxy for inadequate primary care, remains unacceptably high (36%-50%) for people with SCI/D.^{29,30} The leading causes of rehospitalization—pneumonia, urinary tract infection (UTI), and pressure ulcers²⁹—have not changed over the years and persist over the lifetime of individuals with SCI/D.³⁰

Take steps to prevent pneumonia, other respiratory complications

Many people with SCI/D are at high risk for respiratory complications because of their weakened respiratory muscles. This is particularly true for individuals who have injuries occurring above T10; those with injuries that are high on the spinal cord have the highest complication risk.^{7,8} In fact, pneumonia, atelectasis, and other respiratory complications are the leading causes of mortality in patients with tetraplegia, occurring in 40% to 70% of these patients.⁷

The diaphragm, innervated by the phrenic nerve (C3-C5), is the primary muscle of inspiration. Accessory muscles of inspiration include the scalenes (C5-C8), sternocleidomastoid and trapezius (C1-C4), and intercostals (T1-T11); whereas forced exhalation (cough) occurs with contraction of the abdominals (T5-T12).⁹ Diminished inspiration in individuals with higher level lesions can lead to microatelectasis, dyspnea with exertion, and even respiratory insufficiency.

In SCI/D above T8, weakened expiration can severely decrease cough effectiveness and secretion clearance, increasing susceptibility to lower respiratory tract infections. In addition, experts have described asthma-like disorders of airway function, particularly in those with higher lesions, due to unopposed parasympathetic innervation of respiratory smooth muscle.¹⁰

Management of this neurogenic pulmonary dysfunction after SCI/D relies on extensive preventive measures, including positioning and postural changes, breathing techniques, coughing (assisted for patients with tetraplegia), postural drainage, chest compression and percussion, and suctioning to avoid atelectasis, aspiration, and pneumonia. Ensure that patients receive in-



Rehospitalization, an outcome often quoted as a proxy for inadequate primary care, remains unacceptably high—up to 50%—for people with spinal cord injury/disease.

>
Use general population guidelines to target antibiotic therapy, as guidelines validated for use in the spinal cord injury/disease population don't exist.

TABLE

Ways to optimize management of patients with SCI/D*

<p>Respiratory⁷⁻¹³</p> <ul style="list-style-type: none"> • Monitor respiratory function (eg, respiratory rate, oximetry, and spirometry) at every visit. • Strive to reduce secretions, aspiration, and atelectasis via interventions such as positioning, suctioning, breathing techniques, voluntary or assisted cough, mechanical insufflation-exsufflation, chest physiotherapy, abdominal binder, and pulmonary hygiene. • Treat respiratory infections aggressively and early. • Have a lower threshold for obtaining x-rays and referring for hospital admission. • Provide immunizations (eg, influenza and pneumococcal). • Urge and assist with smoking cessation. • Use bronchodilators, steroids, anticholinergics, methylxanthines, mucolytics, and/or hydrating agents when indicated. • Consider ordering polysomnography for sleep-disordered breathing.
<p>Neurogenic bladder¹⁴⁻¹⁸</p> <ul style="list-style-type: none"> • Maintain a high level of suspicion for a UTI because symptoms are often non-specific and may include: fever, rigors, chills, nausea and vomiting, abdominal discomfort, sweating, muscular spasms, fatigue, and autonomic dysreflexia. Classic symptoms, such as dysuria, frequency, and urgency, are often absent. • Do not order routine screening urinalysis or urine culture. • Avoid antibiotic prophylaxis. • Avoid antimicrobial treatment in asymptomatic patients. • Refer patient to a urologist annually for an evaluation. An ultrasound may be required every 1-2 years, and urodynamic studies are recommended every 5 years or upon clinical changes. Perform yearly urologic follow-up evaluations. • Refer individuals with indwelling catheters for a cystoscopy annually after 5-10 years of use. • Avoid prophylaxis in the form of cranberry tablets or mannose; neither has been well studied in this population.
<p>Neurogenic bowel^{19,20}</p> <ul style="list-style-type: none"> • Recommend bowel emptying every day or every other day. • Recommend adequate fiber in the diet, intake of fluids, stool softeners, bulk-forming agents, contact irritants (eg, bisacodyl), and prokinetic agents to achieve optimal bowel care.
<p>Pressure ulcers²¹⁻²⁶</p> <ul style="list-style-type: none"> • Perform risk assessment of patients using a valid scale (such as the SCIPUS-A, available at: https://www.scireproject.com/outcome-measures-new/spinal-cord-injury-pressure-ulcer-scale-acute-scipus) to determine risk for pressure ulcer formation. The optimum frequency for this assessment has not been determined. • Assess patients for risk factors for pressure ulcers (eg, poor nutrition, smoking, engagement in little to no activity) and for feasibility of self-assessment; modify risk factors as appropriate.

See footnotes on facing page.

fluenza and pneumococcal vaccinations, and encourage smoking cessation. Obtain a chest x-ray if the patient demonstrates a decrease in respiratory function, deteriorating vital signs, reduced vital capacity, an increase in subjective dyspnea, or a change in sputum

quantity. Treat respiratory infections early and aggressively,⁷⁻¹⁰ and strongly consider in-patient management because of the high risk of respiratory failure.

Pneumococcus is the most common cause of respiratory infections, although up to 21% of

TABLE

Ways to optimize management of patients with SCI/D* (cont'd)

Pressure ulcers²¹⁻²⁶ (cont'd)

- Recommend that patients use pressure redistribution surfaces for beds and wheelchairs and avoid donut cushions because they create pressure around the hole.
- Advise patients or caregivers to inspect the skin daily for the development of pressure ulcers.
- Recommend that patients with SCI/D turn themselves or be turned by a caregiver every 2 hours in the acute and early rehabilitation period while in bed, and perform pressure reliefs every 15-30 minutes for at least 15-30 seconds while seated in a wheelchair.
- Promote any kind of exercise or movement to help maintain skin integrity and avoid contractures.
- Educate patients and caregivers on the prevention of pressure ulcers by referring them to vetted sources of consumer information, such as the Spinal Cord Injury Model Systems Knowledge Translation Center (<http://www.msktc.org/sci/factsheets>).
- Ensure that treatment for pressure ulcers is started immediately and that the stage of the ulcer is documented.

SCIPUS-A, Spinal Cord Injury Pressure Ulcer Scale-Acute; SCI/D, spinal cord injury and disease; UTI, urinary tract infection.

*The strength of all of the recommendations in this Table is a C (based on consensus, usual practice, opinion, disease-oriented evidence, or case series for studies of diagnosis, treatment, prevention, or screening).

cases of community-acquired pneumonia in patients with SCI/D are caused by *Pseudomonas*.¹¹⁻¹³ Avoid the use of antibiotics in patients who do not have signs or symptoms of a respiratory infection to minimize the development of resistant organisms. Target antibiotic therapy as per general population guidelines, as guidelines validated for use in the population with SCI/D do not currently exist.^{7,11}

Be alert for UTIs—typical signs, symptoms don't apply

The bladder receives innervation from S2 to S4 via the hypogastric, pudendal, and pelvic nerves. As such, the vast majority—70% to 84%—of patients with SCI/D report some degree of bladder dysfunction.¹⁴ Generally, SCI/D contributes to a combination of a failure to empty the bladder and a failure to store urine. The former is more frequent and the latter occurs more often in people with bladder outlet flaccidity, which usually occurs with low injury, such as that of the lumbar spine.¹⁴

The majority of people with SCI/D who are unable to empty their bladder require the use of some type of bladder catheter, either intermittent, indwelling (urethral or suprapubic), or condom. The choice of bladder management technique depends on gender,

hand function, body habitus, caregiver assistance, and medical comorbidities. People with SCI/D are at greater risk for bladder and renal stones, UTI, vesicoureteral reflux, and bladder cancer.^{15,16} That said, the risk of bladder and renal stones declines somewhat after the first 6 months following an injury due to an immobility-induced loss of calcium.

Patients with SCI/D are often found to have bacteruria and even pyuria, and although they are at high risk for recurrent UTIs, these can be difficult to diagnose because signs and symptoms may differ from those seen in people with neurologically intact bladders. Symptomatic UTIs may present with fever, hematuria, abdominal discomfort, and/or increased spasticity, among other symptoms. They may cause increased bouts of autonomic dysreflexia, malaise, or a change in functional status. One cannot rely on the typical symptoms of dysuria and increased urinary frequency in this patient population. Further, the Infectious Diseases Society of America (IDSA) states that cloudy or foul-smelling urine in adults with catheters is not a symptom or sign mandating treatment.¹⁷

Because there is a lack of consensus as to what constitutes UTI symptoms in patients with SCI/D, PCPs need to be aware of changes from baseline in patients; these, combined



One can't rely on the typical UTI symptoms of dysuria and increased urinary frequency in this patient population.

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Fertility is often unaffected in women with spinal cord injury/disease, so routine discussions about contraception in those who are sexually active are imperative.

with urine dip and culture results, should guide initiation of treatment.¹⁶

Prophylactic antibiotics have no role in the prevention of UTIs in patients with SCI/D. The minimal benefits associated with prophylaxis are outweighed by the risks of increased bacterial resistance to antibiotics. Research shows no significant benefit associated with the use of non-antibiotic prophylaxis, including the use of cranberry products and mannose, but further studies are needed in this patient population.¹⁸

Focus on bowel function; it correlates with quality of life

Bowel dysfunction is nearly universal in patients with SCI/D. The enteric nervous system is modulated via the sympathetic, parasympathetic, and somatic systems, and intrinsic control occurs via the myenteric and submucosal plexi. The loss of volitional control of defecation can result in prolonged transit time, reduced colonic motility, fecal incontinence, and difficulty with evacuation.

Because bowel care and function are highly correlated with quality of life,¹⁹ recommend bowel emptying every day or every other day, as well as adequate fiber in the diet, intake of fluids, stool softeners, bulk forming agents, contact irritants (eg, bisacodyl), and prokinetic agents to achieve optimal bowel care.

Prevent and treat pressure ulcers whenever possible

Accompanying the paralysis associated with SCI/D is often some degree of sensory loss of pain, light touch, temperature, and/or proprioception. The combination of insensate skin, immobility, and sarcopenia with resultant body composition changes places individuals with SCI/D at high risk for skin breakdown.^{21,22} Blood flow and oxygen tension at the skin surface are also decreased in patients with SCI/D compared to those without, further contributing to the problem.^{21,23} Increased latency from the time of injury correlates with increased likelihood of pressure ulcer development.^{21,22,24}

External risk factors for pressure ulcers include prolonged pressure exposure, or intense pressure over a short period, shear forces, poor

nutrition, smoking, moisture, and immobility. The incidence of pressure ulcers in patients with SCI/D is 25% to 66%, compared with 0.38% in the general population.^{21,22} Research indicates that US hospitals spend \$11 billion annually on the treatment of the condition.²²

To minimize pressure ulcers in this population, perform a risk assessment, using, for example, the Spinal Cord Injury Pressure Ulcer Scale-Acute (SCIPUS-A) available at <https://www.scireproject.com/outcome-measures-new/spinal-cord-injury-pressure-ulcer-scale-acute-scipus>. In addition, recommend that patients use pressure redistribution surfaces for beds and wheelchairs, turn while in bed, perform frequent (approximately every 15-30 minutes) pressure reliefs, exercise or move regularly, and that they or a caregiver inspect the skin daily. If pressure ulcers do occur, start treatment immediately and document the stage of the ulcer.

Ensure that screening efforts go beyond what's standard

Preventive care for patients with SCI/D is similar in many ways to that recommended for the general population. Screening for colorectal cancer,³¹ cervical cancer, and breast cancer³² should follow the same evidence-based intervals and age ranges suggested by groups such as the US Preventive Services Task Force (USPSTF). The only difference is to give special consideration to patients' physical limitations and the set-up of exam rooms when scheduling and conducting procedures, such as Pap smears, colonoscopies, and mammograms.^{33,34}

■ **Bladder cancer.** Because of the high risk for bladder cancer (ie, squamous cell carcinoma, as opposed to the more common transitional cell carcinoma) in this population, experts recommend annual cystoscopy for bladder cancer surveillance in patients who have had indwelling catheters for more than 5 to 10 years.³⁵

■ **Osteoporosis.** Screening for osteoporosis is another preventive health area in which recommendations differ from those addressing the general population. Paralysis contributes to a decrease in mechanical stress on bone and to accelerated bone loss, and, thus, to osteoporosis.³⁶

CONTINUED

➤ Male fertility is usually profoundly affected by spinal cord injury/disease; patients and their partners who are interested in having children will require specialized interventions.

In patients with SCI/D, osteoporosis affects primarily weight-bearing areas below the injured lesion, such as the distal femur and proximal tibia. Fractures in patients with SCI/D may occur during minor trauma (eg, during transfers from wheelchair to bed). Although screening and treatment guidelines for osteoporosis in patients with SCI/D are not established, most experts recommend early screening and early and aggressive treatment.³⁶

■ **Depression** reportedly occurs more frequently in individuals with SCI/D than in the general population,^{37,38} affecting adjustment, quality of life, and social, behavioral, and physical functioning. In light of this, it's advisable to use screening tools, such as The Patient Health Questionnaire (PHQ)-9, routinely.³⁹

■ **Sexuality and sexual function** are often adversely affected in both men and women with SCI/D. Loss of sensation in the sexual organs, combined with difficulty with positioning and mobility and bowel and bladder dysfunction, contribute not only to sexual dysfunction, but to lower self-esteem and altered body image.⁴⁰

It is important to remember that fertility is often unaffected in women, so routine

discussions about contraception with women who have SCI/D and who are sexually active are imperative. At the same time, male fertility is usually profoundly affected by SCI/D; patients and their partners who are interested in having children will require specialized interventions. Address sexuality and fertility during primary care visits and refer patients to counseling or specialists as necessary.⁴¹⁻⁴³

SCI/D requires a whole-person approach

The care of individuals with SCI/D requires a holistic approach that takes into consideration physical, psychological, environmental, and interpersonal factors^{44,45} and involves ongoing support from a variety of specialists. FPs, with their whole-person orientation, can be instrumental in ensuring the successful rehabilitation of patients affected by SCI/D, and in helping individuals attain, preserve, and enhance their health and well-being. **JFP**

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