

A Primary Care Provider's Guide to Clinical Needs of Women With Spinal Cord Injury

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Abstract: Women are a growing proportion of individuals with SCI and have distinctive health needs spanning the life course that demand deliberate consideration and clinical expertise. Practitioners caring for women with SCI must incorporate broad medical knowledge of SCI physiology and health promotion for women, including differences in complication rates following SCI, and work collaboratively with rehabilitation, medical, and surgical specialists to optimize function and health for women with SCI. Clinical researchers must continue to perform population-based studies to best characterize the evolving needs of women with SCI and evaluate treatment efficacy and care delivery models to best serve this population. **Key words:** reproductive health, spinal cord injury, women's health

Health Maintenance Checklist

1. Cancer screenings (breast, cervical, colorectal, other) according to authoritative guidelines.
2. Immunizations according to authoritative guidelines. Consider influenza vaccine for most women with SCI; pneumococcal and shingles vaccines for women 60 years of age and older; and papillomavirus vaccine for girls and young women.

Episodic Care Key Points

1. Reproductive health counseling for women with SCI should take into account relevant secondary medical complications of SCI, including neurogenic bladder, neurogenic bowel, and autonomic dysreflexia.
2. Women with SCI may be at increased risk of developing SCI-related bone loss and/or cardiometabolic disease due to impaired mobility and should receive individualized health maintenance counseling and diagnostic screening.
3. Routine preventive screenings for women with SCI should be performed in accordance with existing best practices for the general population with special consideration by providers for any specific physical accessibility needs when ordering diagnostic tests (e.g., mammography, colonoscopy).

Case Report

L. S. is a 43-year-old woman with a history of T6 American Spinal Injury Association Impairment Scale (AIS) A paraplegia due to a remote traumatic spinal cord injury (SCI) with associated medical complications including neurogenic bowel, neurogenic bladder, impaired sensation, and mobility impairment who presents for an annual wellness visit. She informs you that her 56-year-old sister-in-law was just diagnosed with breast cancer, and she is worried about her own risk of breast cancer. She states that she does not have a family history of breast cancer and smokes a half-pack of cigarettes per day. She has never had a mammogram performed and does not perform regular breast self-examinations. She asks for your advice regarding breast cancer screening.

Introduction

Women represent approximately 20% of the traumatic SCI population and are a growing proportion of individuals with SCI in terms of both incidence and prevalence.¹ According to national estimates, approximately 40,000 to 45,000 women with SCI are living in the United States.¹ The most recent data from the National Spinal Cord Injury Statistical Center (NSCISC) suggest that 19% of all new SCIs are in women, and historical data show that each year women have sustained proportionally more SCIs than in prior years. As such, it is imperative that clinicians

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and clinical investigators — in spinal cord injury medicine and primary care alike — work together to understand best practices in medical management and priorities for future research to deliver and advance the highest quality of care for women with SCI.

Demographics

The most common cause of SCI in women is motor vehicle collisions (MVCs), followed by falls and sports injuries. The increasing proportion of women parallels larger shifts in the SCI population and trends that include a decrease in the number of injuries due to violence and a progressive increase in the mean age at injury.^{1,2} Longitudinal studies of SCI have shown that injury severity is consistently associated with mortality and reduced life expectancy,³⁻⁵ especially as related to cause-specific mortality from respiratory illness and infectious conditions.^{4,5} Education, socioeconomic status, and medical complications including pressure ulcers have all been associated with long-term mortality and morbidity following SCI.⁵ While there is some evidence to suggest that the etiology of SCI may be protective for those with sports-related injuries,⁶ overall long-term survival for individuals with SCI has not changed significantly over the past three decades.⁷

Reproductive Health and Sexuality

Significant differences have been observed in numerous studies of women's sexual response before and after SCI. SCI has been associated with lowered sexual desire, impaired lubrication, and changes in orgasm for women with SCI as well as changes to erogenous zones.⁸⁻¹¹ Medical complications of SCI such as neurogenic bowel, neurogenic bladder, muscle spasms, and mobility impairment may also have secondary effects on sexual activity that affect the quality of intimate relationships.¹²⁻¹⁴ Studies relying on interviews suggest low satisfaction among individuals with SCI who receive counseling and education regarding sexuality, despite the fact that sexuality remains an important and valued aspect of individuals' identities following

SCI.^{15,16} Recommendations for rehabilitation professionals and primary care providers include encouragement of self-exploration, education on techniques for optimizing bowel and bladder continence in preparation for and during sexual activity, and support and education for individuals with SCI and partners following acute injury. Use of the extended PLISSIT model clinical and educational framework may help support health care providers to meet women's sexuality needs during rehabilitation following SCI and in subsequent clinical encounters.¹⁷

SCI does not typically affect women's fertility or desire to bear children, although some population and database studies suggest that pregnancy rates among women with SCI are lower than general population controls.^{18,19} Although multiple studies document overall favorable pregnancy outcomes for women after SCI,²⁰⁻²³ these women may face barriers to appropriate care during pregnancy and childbirth due to physical accessibility of health care environments, lack of specialty providers, and challenges related to communication, information, and attitudes that may affect health care delivery. Health risks and secondary complications during pregnancy and childbirth for women with SCI include urologic compromise leading to hydronephrosis and/or impaired renal function, urinary tract infections (UTIs), intestinal obstruction, constipation, musculoskeletal pain, hypertension, preeclampsia, pressure injury, preterm delivery, and higher rates of cesarean deliveries.²⁴

Reproductive health of women with SCI is often challenged by a secondary condition that is unfamiliar to most medical professionals — autonomic dysreflexia (AD). AD is a potentially life-threatening medical emergency that affects people with SCI at the T6 level or higher; it is caused by disruption to the autonomic nervous system. AD may manifest as a headache, flushing, and malaise or it may be clinically silent, but it is always accompanied by a systolic blood pressure that is 20 mm Hg or more above an individual's baseline. Although rare, some people with T7 and T8 injuries can also develop AD; if untreated, AD can lead to significant morbidity and even mortality. When appropriately identified, AD can

be easily treated as well as prevented by knowing potential noxious triggers and an individual's typical AD symptoms. During a pelvic exam, AD can even be triggered by a cold speculum or other procedural situations. Thus, it is important for women with SCI to have their blood pressure taken before and after the exam, noting any significant changes.²⁵

Endocrine and Bone Health

The monitoring and prevention of bone loss in people with SCI is critical to prevent osteoporosis and fractures that can lead to significant complications and mortality. Following SCI, individuals can lose up to 1% of their bone mineral density per week — a faster rate than seen in other forms of immobilization and in postmenopausal women.²⁶ Individuals with complete SCI are twice as likely to develop fractures compared to people without SCI.²⁷ While some studies have found there is a greater risk for fracture in women with SCI compared with men, overall there is a lack of information about bone health specifically in women with SCI. SCI-related bone loss is thought to occur in two phases: an acute phase characterized by calciuria and hypercalcemia with rapid bone mineral loss followed by a stabilization of bone mineral density by 1 to 2 years post injury leading to a chronic phase.^{28,29}

There is no consensus on screening and treatment guidelines for SCI-related osteoporosis.²⁸ Biologic screening for diagnosis and prevention may be helpful in the first year.²⁹ Dual-energy x-ray absorptiometry (DXA) is considered the gold standard for diagnosis and is recommended after a fracture occurs. The efficacy of either pharmacologic or mechanical interventions to prevent and treat SCI osteoporosis is not well established. Bisphosphonates are traditionally considered the preferred treatment. Studies suggest that when started within 12 months of the injury they can be effective in preventing bone loss; however, their efficacy in the chronic phase may be limited.^{28,29} Nonpharmacological interventions, including MES (muscular electrical stimulation), ultrasound, and FES (functional electrical stimulation), may increase or maintain

bone mineral density in the acute phase, especially if high volume, but the effects do not seem to be lasting.²⁹

Health Maintenance and Preventive Care

Ninety percent of people with SCI consider their primary care doctor to be their regular doctor; however, there are significant gaps in access to primary care, largely surrounding lack of expertise in disability-specific issues among providers, physical barriers, and health care costs.^{30,31} Primary care for women with SCI encompasses the same preventive measures as those for the general population, but there are specific needs that should be addressed. Many patients with SCI have bowel and bladder dysfunction. Women with SCI who have neurogenic bladder should receive referral to a urologist for urodynamic studies to assess for intravesical pressures; they may require cystoscopy and/or additional diagnostic studies to rule out bladder or kidney stones as potential causes of recurrent urinary tract infections (UTIs). It is important to maintain a high level of suspicion for UTIs for women with SCI, since those with higher level injuries may not be able to report classic symptoms such as dysuria or discomfort and may present with new incontinence or nonspecific complaints. Women with SCI who report hematuria should be evaluated for kidney and bladder stones and considered for cystoscopy, given reportedly increased rates of bladder cancer in persons with SCI who are long-term indwelling catheter users. Neurogenic bowel is also a common medical complication of SCI, and women with SCI should be encouraged to maintain adequate fiber intake, hydration, and a bowel regimen, including stool softeners, laxatives, suppository use, digital stimulation, and/or manual disimpaction as needed.³² Women with persistent constipation, diarrhea, hemorrhoids, or rectal bleeding may benefit from tailored assessment by a gastroenterology, colorectal surgery, or intestinal motility specialist. Individuals with SCI are at high risk for respiratory complications, and providers should emphasize preventive immunizations and smoking cessation and should have a low threshold for infectious work-up.³² Patients with

SCI should also be routinely assessed for risk factors for pressure ulcers, given that disease of the genitourinary and integumentary systems are the most likely reasons for hospitalizations in individuals with SCI in any given year post injury.

There are many opportunities to improve preventive care in women with SCI, including performing annual exams, providing recommended immunizations, and screening for cancer. Screening for breast, cervical, and colorectal cancer follows the same guidelines as for the general population.³³⁻³⁶ Unfortunately, longitudinal studies show that women with SCI are less likely to have received the recommended exams.³⁷ Primary care physicians who treat women with SCI may consider exploring local resources, including women's health providers and imaging centers, to advocate for proper accessibility for women with mobility impairments and identify potential barriers to age-appropriate cancer screening. As noted earlier, individuals who have had indwelling catheters for more than 5 to 10 years should have annual cystoscopy for bladder cancer screening.³² Although some urologists recommend performing annual cystoscopy studies, cystoscopy is not currently recommended as a general screening test in persons with SCI, and clinical urology practice in the United States varies widely in population-based studies.

Obesity, hypertension, and insulin resistance are highly prevalent among individuals with SCI. A survey of health maintenance behavior in women with and without disability found that practices were similar, with one large exception being exercise. Only 46% of women with disabilities got regular exercise compared to 73% of women without disabilities.²⁷ A comprehensive lifestyle approach emphasizing exercise and nutrition aimed at decreasing cardiometabolic disease should not be overlooked in individuals with SCI. Women with disabilities may be at increased risk of interpersonal violence, making it important to screen for a trauma history in addition to other social determinants of health. Offer appropriate referrals, including for appropriate counseling and support services, based upon the specific needs of

women with SCI as part of routine primary care practice. Primary care offers the opportunity to provide holistic, multidisciplinary care for women with SCI.

Case Resolution

Given her negative family history and age, L. S. should be offered smoking cessation resources to support overall health maintenance and should be offered screening mammography as part of a shared decision-making process that includes a discussion of the benefits and harms of annual and biennial screening and incorporates her individual values and preferences. Several screening paradigms exist that recommend either annual or biennial screening mammography until at least age 74 years for women of average risk of breast cancer.³³⁻³⁵

Conclusion

Women are a growing proportion of individuals with SCI and have distinctive health needs spanning the life course that demand deliberate consideration and clinical expertise. Practitioners caring for women with SCI must incorporate broad medical knowledge of SCI physiology and health promotion for women, including differences in complication rates following SCI, and work collaboratively with rehabilitation, medical, and surgical specialists to optimize function and health for these women. Clinical researchers must continue to perform population-based studies to best characterize the evolving needs of women with SCI and evaluate treatment efficacy and care delivery models to best serve this population.

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