

A Primary Care Provider's Guide to Sexual Health for Individuals With Spinal Cord Injury

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Abstract: The collaboration with individuals regarding their sexual health is an important component of patient-centered health care. However, talking about sexual health in primary care settings is an area not fully addressed as a result of time limitations, medical task prioritization, awareness or knowledge deficit, and discomfort with the topic of sexuality. A critical shift in professional focus from disease and medical illness to the promotion of health and wellness is a prerequisite to address sexual health in the primary care setting. This article provides guidance for practitioners in primary care settings who are caring for persons with spinal cord injury. Clinicians should seize the opportunity during the encounter to reframe the experience of disability as a social construct status, moving away from the narrow view of medical condition and “find it, fix it” to a broader understanding that provides increased access to care for sexual health and sexual pleasure. **Key words:** primary care, sexual health, sexuality, spinal cord injury

Health Maintenance Checklist

Open the door for communication:

- Start a conversation by saying, “Many people with spinal cord injuries have concerns related to sexuality, and it can be an important part of your quality of life. What questions or concerns do you have related to sexuality, intimacy, relationships, or sexual functioning? I’d be happy to discuss them with you.”

Ask, listen, and follow-up:

- How is your sexual health?
- Have you experienced any difficulty in the areas of [e.g., sexual desire, erection, orgasm, lubrication, pain during sexual activity]?
- Do you or your partner have any concerns or questions that have not been addressed?

Episodic Care Key Points

Listen to concerns, validate, and provide information:

1. PleasureABLE: Sexual device manual for persons with disabilities, <https://sci-bc-database.ca/wp-content/uploads/PleasureABLE-Sexual-Device-Manual-for-PWD.pdf>, is one self-empowering resource that may increase opportunity and perspective on potential options that can be a part of sexual practices.

Explore multiple etiologies and factors related to identified issue:

1. Consider pharmacological and psychosocial factors as potential causes, as well as solutions. Make referrals as clinically indicated.

Case Reports

Case 1

Christine, an active 42-year-old female, sustained a spinal cord injury (SCI), C6-7 American Spinal Injury Association Impairment Scale (AIS) B in a motor vehicle accident 6 months ago. She completed rehabilitation at an SCI center 4 hours away from home. She reports that the sexuality class she attended was geared toward males. She has a supportive and committed partner and feels ready to explore sexuality. She would like help with the following issues: feeling unattractive due to body changes and weight gain since her SCI, feelings of inadequacy related to physical functioning, and experiences of high blood pressure of 210/165 mm Hg with intense clitoral stimulation but no other symptoms of autonomic dysreflexia (AD). She is wondering if the high blood pressure is still considered AD, even though she does not have the pounding headache, sweating, and red flushing on her face and neck that she typically experiences with AD. Her primary care physician (PCP) provides education on silent AD, prescribes 2% topical nitroglycerin ointment (Nitro-BID), and tells her to apply an inch. The PCP refers Christine to a nutritionist to help her reduce calorie intake and a behavioral medicine specialist to help her develop coping strategies to feel sexier and improve her sexual esteem, including cognitive reframing of thoughts such as “I can’t do what I use to do or look like I used to, so it’s not satisfying.” Christine returns for follow-up in 4 weeks and is feeling better about herself. However, even with an inch of Nitro-BID, her blood pressure is still 190/150 mm Hg, although it returns to her baseline level of 90/60 mm Hg when sexual activity stops. Her PCP researches the issue and realizes that 34% of patients with SCI need 2 inches of nitro paste to resolve AD.¹ She advises Christine to try 2 inches of nitro paste. In her next follow-up, Christine reports that using 2 inches of nitro paste only lowers her blood pressure to 172/140 mm Hg. The PCP prescribes 10 mg of nifedipine. Christine needs to plan ahead in dosing with this medication, but it lowers her blood pressure to safe levels during clitoral stimulation.

Case 2

Four months ago, William, a healthy 25-year-old male, fell approximately three stories and experienced an SCI C5 AIS A. He was recently engaged and was known to the medical practice prior to his injury. William is doing well overall, but he is dealing with the reality that his SCI is not going to improve. He is very frustrated with his erectile dysfunction (ED) and inability to orgasm. The PCP starts him on sildenafil. He is seen at a follow-up appointment 8 weeks later. He did not have any response to the 50 mg dose. He had some response to the 100 mg dose, but he was not able to maintain erection. Significant spasticity is now requiring high doses of baclofen. He continues to be very frustrated with his ED and inability to orgasm. He is then prescribed caverject. The PCP also recommends that William not take his baclofen when attempting to get an erection. William calls in 4 weeks later to report he is getting good response but has difficulty in maintaining the erection. He read about other injections on an online SCI message board and is requesting a prescription for Tri-mix. This is initially effective, but his spasticity continues to increase. He now has an intrathecal baclofen pump. He has gradually been increasing the Tri-mix with a good response, but he still cannot maintain an erection during intercourse. He now asks about a vacuum erection “pump” device (VED). He tries the Tri-mix with the VED. He reports a good erection, but he is getting a lot of bleeding from the injection sites. He is really upset and feels inadequate. After a couple of years, he sees a different urologist along with being followed by his PCP. The urologist recommends sildenafil with the VED, which works remarkably well. William can maintain a solid erection for as long as necessary. Occasionally, the erection strength will decrease during adaptive equipment² use for sexual intimacy and mutual enjoyment. William is still frustrated but is pleased that he is able to fulfill his wife’s needs.

Sexual Health in the Primary Care Setting

The World Health Organization defines sexual health as a “state of physical, emotional, mental, and social well-being in relation to sexuality...as

well as the possibility of having pleasurable and safe sexual experiences.”³ Sexuality is a core component of personality and a fundamental aspect of the lives of patients and families. For individuals with SCI, sexuality and sexual health is often a central but overlooked aspect of their identities. For medical providers, a shift in focus from disease and medical illness to the promotion of health and wellness through the identification of biopsychosocial factors contributing to sexual well-being is a prerequisite to addressing sexual health in primary care settings.⁴

The Affordable Care Act (ACA) seeks to lower the exploding health care costs in the United States through a pay-for-performance system that incentivizes Centers for Medicare and Medicaid Services (CMS) and hospitals to save money by improving their quality of health care. Under ACA, quality of health care is not just about medical care in the narrowest sense of the word. It also encompasses patient-centered care.⁵ Increasingly, integrated primary care – wherein medical and behavioral health providers (BHPs) partner to provide comprehensive, patient-centered care – has been identified as a means to promote sexual health and well-being.

Patient preferences for provider initiation of sexual health conversations have been documented.^{6,7} However, many medical providers continue to express discomfort about initiating these conversations, citing embarrassment, lack of preparedness, time constraints, and a belief that sexual history is not relevant to the presenting concern as barriers to comprehensive, proactive evaluation.^{8,9} Sexual health for persons with disabilities is often considered a double-barreled taboo, and providers may inappropriately assume a patient’s asexuality by failing to initiate conversations about sexual behaviors even when they otherwise regularly assess for such concerns. Open dialogue about sexual health with patients will uncover their sexual concerns, provide an opportunity to address the presenting problems, and may uncover other primary medical or psychological conditions that will benefit from early detection and treatment and will save money. No general conversation between a physician and patient is complete if it does not

provide at least the opportunity for people to express concerns or raise questions about sexual issues. For providers working in integrated care, collaboration with other specialties and disciplines (e.g., mental health, medical rehabilitation specialties) may promote comprehensive sexual assessment of biopsychosocial factors contributing to sexual health.

Basic sexual health knowledge and beyond

Providers must attend to the prevention and management of primary and secondary conditions following SCI, as well as the biopsychosocial factors influencing sexual health, well-being, and enjoyment.^{10,11} Sexual dysfunction (sexual desire, genital arousal, orgasm, and pain with sex), change in sensation, and AD can be present in both sexes after SCI. AD typically occurs in individuals with an injury at or above T6. Symptoms of AD include elevation in blood pressure (>20-40 mm Hg from baseline), pounding headache, facial flushing, blurred vision, profuse sweating above the lesion and piloerection below the lesion, sense of apprehension or anxiety over an impending physical problem, and bradycardia (or sometimes tachycardia). Any noxious stimuli to skin, bladder, joints, and bones as well as sexual stimulation (particularly orgasm and ejaculation) can precipitate it.

Male sexual health

Access

Access for socialization can be a challenge for many men and women in terms of internal (e.g., self-worth, self-confidence, comfort level relating to others) and external (e.g., attitudinal barriers from the environment, limited community travel access) factors. The experience of microaggressions, mobility limitations, and fear of bladder and bowel complications can negatively impact the experience of sexuality. Persons with disabilities are also at increased risk for sexual abuse from both males and females compared to persons who do not have disabilities, so abuse reporting and effective intervention are important for individuals with disabilities.³

Erectile dysfunction

Physicians should be aware of medications that can contribute to sexual dysfunction, such as antispasmodics (i.e., baclofen), antidepressants, and antihypertensives. First-line treatment includes phosphodiesterase type 5 inhibitors (PDE5i) such as sildenafil, vardenafil, tadalafil (longer duration), and avanafil. All have similar efficacy. Lower level injuries, flaccidity, and cauda equina syndrome have poorer responses to PDE5i than higher, more complete SCIs. PDE5i should be avoided in patients with retinitis pigmentosa and concomitant use of nitrates and alpha blockers. Any decrease in libido or sexual dysfunction should be investigated further for testosterone deficiency.

Second-line therapies can include:

1. Intracavernosal injections (ICI)^{12,13}: Papataverine, phentolamine, prostaglandin E1, or a combination of these agents (often referred to as bi-, tri- or quad-mix) are used. Patients should be counseled for possible hematoma and priapism. If an erection lasts for more than 4 hours, seek medical attention. Self-administration will be difficult with poor hand function.
2. Vacuum erection devices (VED)^{12,13}: They can produce sustained erections and can be used separately or together with tension rings. These tension rings should not be left on for longer than 30 minutes to reduce the risk for tissue ischemia or gangrene. Petechiae and premature loss of erection (venous leak) have also been reported.
3. Urethral suppository^{12,13}: MUSE (medicated urethral system for erection) uses prostaglandin E1 (alprostadil) absorption through the urethral lumen. Effectiveness is variable, especially among patients who use intermittent catheterization. This intervention can be considered in patients with intact sensation and incomplete injuries but is often less effective in patients with complete SCI.
4. Surgical therapies^{12,13}: Infection, extruded rods, erosion, and pain are possible side effects of penile prosthesis (PP). PP removal damages the cavernosal bodies so ICI or PDE5i are not usually effective. Complications

are less common with newer, inflatable PP.¹⁴ Additional devices such as sacral anterior root stimulators, dorsal rhizotomy, and neuromodulation have mixed results.

Ejaculatory dysfunction

Patients with ejaculatory dysfunction^{13,15} are better managed at specialty clinics. About 16% of men with SCI are able to ejaculate through sexual stimulation.¹⁶ Many, however, require some form of assistive device. It is also important for PCPs to take a good history and ensure that alcohol and antispasticity agents (such as baclofen and diazepam) do not interfere with impaired reflex erection, ejaculation, and orgasms.¹⁷ The first-line treatment for anejaculation of neurogenic origin in those with complete SCI above T10 is penile vibratory stimulation (PVS). The FertiCare (Multicept, Denmark) and the Viberec (Reflexonic, USA) have been approved by the US Food and Drug Administration due to their higher vibratory amplitude and frequency. PCPs need to consider pre-procedural precautions with sublingual nifedipine or topical nitroglycerin paste for patients at risk for AD. A trial of midodrine, pseudoephedrine, and ephedrine can also facilitate ejaculation in those unresponsive to PVS and with low risk for AD.^{18,19} Electroejaculation (EEJ) is another technique, and it is often attempted in patients with poor response to PVS, injury below T10, and poor predictive reflexes.²⁰ While both PVS and EEJ are often used for sperm retrieval, they can be used to stimulate ejaculation itself. Precautions to reduce the risk of AD need to be followed.

Semen abnormalities and fertility

Men with an SCI have been shown to have adequate numbers of spermatozoa but abnormally low sperm motility and viability.^{12,15} Due to the risks of AD, any assistive techniques require referral to specialty clinics. Various fertility techniques have been mentioned in the literature. For men who respond to PVS, intravaginal insemination is inexpensive and can be attempted by couples in a private setting, using only a specimen cup and small syringe. Fertility monitors can be purchased to

target ovulation timing. Intrauterine insemination (IUI) also requires sperm preparation. There have been good success rates in SCI. In vitro fertilization (IVF) or intracytoplasmic spermatozoa injection (ICSI) are additional procedures to consider, with costs exceeding \$13,000 per cycle.

Female sexual health

Access

Women with disabilities often report limited access to sexual partners,²¹ and 39% of women with disabilities will experience intimate partner violence – defined as physical or sexual abuse or refusal to provide essential personal assistance resources – in their lifetime.²² In addition, securing accessible ob-gyn services is difficult, especially for women who live in rural areas and do not have access to transportation. Sexual concerns among women and men with SCI can range from psychosocial concerns such as satisfaction with one's partner and feelings of body dissatisfaction to physical concerns such as bowel and bladder accidents and the physical–emotional experience of orgasm or low sexual drive. Age at onset of disability or injury is related to sexual functioning, particularly pertaining to reproductive function, which remains intact after menses have resumed.²³

Many women with SCI are successful with pregnancy despite often experiencing barriers to receiving reproductive health care due to provider concerns of complications during pregnancy and delivery, such as increased risk of urinary tract infections (UTIs), AD, biomechanical issues, and respiratory difficulties, and misconceptions regarding a woman's ability to parent with a disability.²⁴ PCPs need to advocate and appropriately combat microaggressions and barriers faced by women with SCI as they pertain to accessing appropriate reproductive health care, provide adequate resources, and offer consultation with specialists when appropriate. PCPs should attend to medical particulars such as initial amenorrhea, reduced lubrication, pericare, and perineal hygiene requirements along with hand function capability, and they should refer the patient to reproductive specialists when necessary.

Initial amenorrhea/menstrual cycle

Amenorrhea that lasts between 3 and 24 months has been reported among women post SCI.²⁵ A cross-sectional study of 128 women with SCI found that 41% experienced postinjury amenorrhea, but there was no difference in duration of amenorrhea between those who became pregnant and those who did not.²⁶ Exacerbated premenstrual and menstrual symptoms such as dysmenorrhea, cramps, spasms, and autonomic changes such as increased sweating, headaches, and flushing have also been reported. Naproxen, ibuprofen, and other anti-inflammatory agents can reduce these symptoms.²⁷ Following the initial amenorrhea, any change in menstrual length or alterations in the cycle should be investigated further by PCPs. Resources about feminine hygiene products, counseling, and instructions to caregivers are often overlooked by PCPs.

Lack of lubrication

Decreased vaginal lubrication has been reported in up to one in four women with SCI.²⁵ Non-petroleum and fragrance-free hydrophilic lubrication gels along with frequent checks for skin breakdown are important as patients may not feel the discomfort. Women are also encouraged to behaviorally explore sexual positions and stimulation that can promote sexual pleasure in the presence of reduced lubrication.

Contraception

The PCP's recommendation for contraception will consider the status of circulation in legs, history of clots, genital sensation, manual dexterity, and menstrual hygiene. Before deciding on the agent of contraception, the PCP should provide education regarding the effectiveness of each method of contraception. Oral contraceptive pills and hormonal preparations need to be avoided in women within 1 year of injury, those who smoke, and those who have a history of cardiovascular issues. Outside these limitations, the overall risks of oral contraceptive use among individuals with SCI are no greater than the

general population.^{25,27} Progesterone preparations usually have a lower risk of thrombosis. Options such as depot-medroxyprogesterone acetate (DMPA) and intrauterine devices (increased risk of pelvic inflammatory diseases, UTIs) are generally not recommended. DMPA can cause side effects such as weight gain, depression, hair loss, and hypoestrogenism. Hypoestrogenism can in turn lead to osteopenia. Thus, in patients with SCI who are chronically immobilized, such progestin-only agents can compound existing bone fragility. Diaphragms, cervical caps, and vaginal sponges may not be ideal in patients with poor hand dexterity and may increase the chance of vaginal wall breakdown.

Clinical Barriers to Addressing Sexual Health Concerns

Clinical barriers to sexual health in primary care settings are well documented, including a belief that a sexual history is not relevant to the presenting concern.^{28,29} Many patients are not comfortable initiating discussions about sexuality and are not sure if it is their place to bring up the subject, but they do have a desire to discuss concerns related to sexual health.²⁸ Furthermore, PCPs are not immune to developing biases fueled by societal stereotypes that people with disabilities are asexual and undesirable.³⁰ A time efficient and easy way to remedy this is for all providers to open the discussion with the patient by saying, “Many people with spinal cord injuries have concerns related to sexuality, and this can be an important part of your quality of life. What questions or concerns do you have regarding sexuality at this time?”

Three Professional Approach Strategies for Primary Care Providers

The PLISSIT model highlights approach, information gathering, therapeutic alliance building, and intervention.³¹

- Permission (P)
 - Who: All individuals working with people with disabilities, including support and clinical staff.

- Focus: Acknowledge that talk about sexual areas is okay. Communicate acceptance and understanding that changes in a person’s sexual life can be an important issue and that the concerns are valid.
- Limited Information (LI)
 - Who: Service providers.
 - Focus: Provide general information related to sexual concerns, dispel sexual myths, and refer the person, when indicated, to someone with more knowledge about the particular area of concern.
- Specific Suggestions (SS)
 - Who: Professionals with specific knowledge/management skills.
 - Focus: Using professional knowledge and skills to provide suggestions to manage a specific concern, including obtaining a sexual problem history; defining the problem, course of the problem, and treatment of the problem; and providing ideas about the causes of the problem and goals of treatment.
- Intensive Therapy (IT)
 - Who: Specialist.
 - Focus: Full sexual history and examination for assessment. Interventions may include medication, surgery, counseling, sex therapy, or a variety of specialized procedures or management techniques.

The Ex-PLISSIT model includes explicit permission-giving as a core feature of each of the other stages, the requirement to review all interactions with patients, and the incorporation of reflection as a means of increasing self-awareness by challenging assumptions.³²

The Sexual Rehabilitation Framework (<https://scisexualhealth.ca>) is a useful guide to conducting a focused sexual health assessment that is inclusive of biopsychosocial aspects of sexuality.²⁹

Components of the framework include:

- Sexual drive or sexual interest
- Sexual functioning abilities
- Fertility and contraception concerns

- Factors associated with the condition
- Motor and sensory influences
- Bowel and bladder issues
- Sexual self-view and self-esteem
- Partnership issues

Future

This article starts the exploration of information and resources around changes to sexuality after SCI and encourages a meaningful discussion of sexual health for individuals with SCI in primary care settings. We hope you will continue to add to your knowledge and skills in service delivery to address this important health care issue.

Recommendations for Primary Care Providers

- Don't wait for the patient to bring up sexuality issues; research shows they are waiting for you!
- Primary care specialization should include a knowledge base of sexual function as well as a psychosocial understanding of sexuality across disability, ability, diversity, preference, age, culture, ethnicity, sex role, anatomy, gender, and sexual orientation.^{33,34} The importance of understanding the intersectionality of these elements for cisgender and LGBTQ+ individuals provides a pathway for optimal holistic health care.
- Provider education should include techniques to increase the comfort level in addressing

sexual concerns and understanding how medical conditions can impact the biopsychosocial functioning of sexuality. Education should dispel myths, such as the belief that a decline of sexual function is just a consequence of ageing and disability.³⁵

- Work collaboratively across specializations and disciplines to comprehensively address biopsychosocial factors influencing sexual health and well-being.³⁶

Key Take Home Points

Relationship factors such as partner satisfaction and relationship quality as well as mood and independence appear to be more important predictors of sexual satisfaction than genital functioning in both men and women with spinal cord injury.

1. Staff and organizational sensitivity training, ethics consultation, and development of appreciation for diversity within the setting may broaden the focus of clinical needs, utilize available resources, and increase comfort level of staff and trainees in provision of information and guidance.
2. You may not know all the answers. However, you can listen, validate the concern, investigate, and provide information.

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