A Multidisciplinary Approach to Sexual and Fertility Rehabilitation: The Sexual Rehabilitation Framework

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Many studies have identified improvement in sexual function as a priority for persons with spinal cord injury (SCI). Due to the various secondary sensory, motor, and autonomic consequences following SCI and due to the complexity of sexuality per se, this area can be overwhelming to many health care professionals. The literature indicate that sexual and fertility rehabilitation must be addressed in a biopsychosocial manner and include various disciplines. The multidisciplinary utilization of a Sexual Rehabilitation Framework (SRF) allows the medical and/or psychosocial factors that impede or improve sexual and reproductive function to be examined. The SRF is a user-friendly and simplified way to proactively address the major biopsychosocial areas of sexuality and to create a plan of action for the person with SCI. It is an adjunct tool to the full sexual history, and it encourages all disciplines involved in SCI rehabilitation to address the issue of sexual function in the same manner as they would other activities of daily living. Eight areas are included in the SRF: sexual drive/interest, sexual functioning, fertility and contraception, factors associated with the condition, motor and sensory influences, bladder and bowel influences, sexual self-view and self-esteem, and partnership issues. The use of the SRF is encouraged in both inpatient and outpatient settings. Multidisciplinary or interdisciplinary team work is encouraged in sexual and fertility rehabilitation to move clinicians toward providing proactive and comprehensive care for individuals with SCI or other chronic disabilities. **Key words:** fertility, framework, multidisciplinary, rehabilitation, sexual, spinal cord injury, tool

Need for a Comprehensive View of Sexuality After Spinal Cord Injury

There is no doubt that sexuality is of major importance to quality of life (QOL) after spinal cord injury (SCI). Over 30 years ago, the American Occupational Therapy Association recognized sexuality as an activity of daily living, establishing it a rehabilitation priority.

Sex, bladder, and bowel function are ranked amongst the top 5 most important functions for persons with SCI.¹ A large-scale cross-sectional questionnaire inclusive of 350 respondents from 4 European counties identified sexual activity as the area of greatest unmet need for persons with SCI.² In a recent multicenter prospective cohort study in which the objective was to describe and compare the impact of health problems secondary to SCI on functioning during home and social activities at 1 and 5 years after discharge from first

inpatient rehabilitation, sexuality was one of the most frequently mentioned health problems.³ In the study, 681 persons with SCI (25% females, 75% males) were questioned on what functional gain was most important to their QOL (including sexual function, return of sensation, walking, and bladder and bowel function). For the majority of individuals with paraplegia, regaining sexual function was their highest priority; it was the second highest priority (preceded only by regaining hand and arm function) for individuals with quadriplegia.⁴ Furthermore, the vast majority of individuals felt their SCI had altered their sexual sense of self and that improving their sexual function would improve their QOL.⁵ Alternatively, in a study of persons with quadriplegia and paraplegia in the Netherlands and the United Kingdom, improvement in a different function, such as hand function, was found to improve their sexual QOL.⁶

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Patients expect their health care professionals to bring up the topic of sexuality. However, health care professionals are often reluctant to do so because of deficits in knowledge and communication skills, time and reimbursement constraints, unrealistic fear of offending the patient, and discomfort in asking and addressing sexual concerns.⁷ Patients complain of the lack of opportunity to ask questions about their sexual concerns, feel ashamed or embarrassed about the topic of sexuality, do not know which provider is appropriate to answer their questions, and/or they may not feel optimistic about the outcome of such a discussion.⁷

For these reasons, it is important to have a comprehensive view of sexuality in the rehabilitation setting. Acting within their traditional role as physicians (family doctor, treating psychiatrists, urologists, and gynecologists), these professionals cannot manage the entirety of a person's sexuality, but they can offer help within the confines of their own expertise. Because of this, other health care professionals have an equally important part in helping patients with sexual readjustment, including the pursuit of fertility and parenthood. For example, they would initiate a discussion about the various potential types of sexual activity that could be considered after SCI, whereas physicians could address sperm retrieval for fertility.

All members of the rehabilitation team should include sexuality as part of their standard enquiry, just like any other bodily function that is addressed by rehabilitation. By sharing the management of sexual concerns utilizing a team approach, no one provider is expected to be the designated sexual health care expert. However, if there is a dedicated sexual health and/or fertility health care professional in a rehabilitation setting, this is to be commended. It is rare to have a team of comprehensive speciality sexual and fertility SCI rehabilitation experts in any rehabilitation setting, though it would be the ideal.

One of the top 10 research questions for SCI found by British researchers was "Does the provision of specialist rehabilitation services, which includes multidisciplinary team planning, improve health and wellbeing?"^{8(p344)} The biopsychosocial approach to sexual and fertility rehabilitation *requires*

a team approach and, as such, the concepts of multidisciplinary versus interdisciplinary care are important. In multidisciplinary care, team members use their expertise and perspective based on their discipline to develop individual goals for the client. These are then joined together and shared, with or without the patient, to form a cohesive team care plan in a case conference. In interdisciplinary care, the team members conduct their assessment with the patient together, so their disciplines are merged instead of being siloed. A more holistic, patient-centered approach is emphasized in interdisciplinary care, with learning available for all.⁹ The reality of the rehabilitation centers models of care and funding will often dictate whether the multidisciplinary or interdisciplinary approach will be used. Furthermore, because of the sensitivity of the subject of sexuality, some patients may prefer to have limited, individual multidisciplinary appointments versus team assessments.

Sexual Rehabilitation Framework

Because sexuality must be addressed through a biopsychosocial approach, it can feel overwhelming to many health care providers. A simplified, user-friendly, clinical framework to address the basics of sexuality is therefore needed. The Consortium for SCI Medicine supports the clinical benefit of addressing these issues.¹⁰ Sexual rehabilitation must occur within the context of the life of the person with SCI. The multidisciplinary utilization of a Sexual Rehabilitation Framework¹¹ (SRF) allows the medical and/or psychosocial factors that impede or improve sexual and reproductive function to be examined. The suggestions in the structural template of the SRF are applicable to any acute or chronic illness/condition/surgery or disability.

To assess and manage sexual issues, single or multiple disciplines can be recruited to suit the needs each individual client. Health care providers can include physicians, nurses, occupational therapists, physiotherapists, recreational therapists, psychologists, and social workers. Peer experience around sexuality can also be invaluable, but will depend on the availability of peer programs or counselors. Basic training in sexual health care is important,

as many damaging myths and misconceptions can be promoted by well-intentioned but untrained health care professionals or peers. Health care professionals must also be aware of their own attitudes so they can remain nonjudgmental and respectful toward the clients.

The SRF consists of 8 sexual areas. Some areas are not applicable to some conditions or stages of life. Taking a sexual history and thinking beyond sexual (genital) function to the factors that influence sexuality within the practicality of a table helps reduce the intimidating task of addressing the complexity of sexuality. This framework can be helpful in chronic conditions even if a specific sexual complaint is not yet voiced, since it will identify expected changes to sexuality that the health care professional might be able to preempt. The framework can also delineate the contributing factors to the sexual concern, allowing for proactive solutions.

It is important to understand that the framework, being primarily medically based, is not a substitute for a full sexual history, but rather it is an adjunct tool to utilize in the context of chronic illness and disability. For example, it does not fully account for the past psychosocial history of the client, as would be obtained in the full sexual history. Rather it incorporates these factors in a “here-and-now” approach, while recognizing that these issues of the past are embedded in the present experience. General sexual and SCI-related knowledge should be assessed. The framework is best utilized for identifying sexual areas that need attention and for categorizing the severity of the sexual issues according to the priorities of the person with the disability or chronic illness. It also allows the clinician to see what can be done immediately and what will require further investigation or referral.

In its simplest form, the SRF can be utilized as a checklist that covers the sexual areas and notes how one area can affect another area. For example, a client’s urinary continence may have to be dealt with before the client is willing to investigate his or her sexual function potential.

The SRF presented here can help identify the main sexual issues for the person with SCI and outline a plan for how these can be addressed and with whom. Specific sexual issues of the person with SCI, and even of their partner, can then best be served by the health care provider or service

with the appropriate expertise. For example, for someone who has difficulty with sexual positioning due to loss of motor function and new onset spasticity, a physician may aid in medication use; a physical therapist may instruct the patient about stretching, transferring, and reducing spasm; a nurse may assist with optimizing bladder and bowel continence and managing the emotional reaction to these issues; and an occupational therapist may assist with adaptive positioning aids or cushions in the bedroom setting. Having only one discipline address all these issues is ultimately less productive than using a multidisciplinary approach.

Components of the SRF

Sexual drive or sexual interest

Sexual drive (libido) has a biological component (the urge to seek out sexual activity and/or to be sexually satisfied) and a motivational component (the psychological recognition of the physical or emotional sexual payoff of being sexual). A third component, called the wish component, incorporates the cultural ideals, values, and rules that person lives in socially.¹² Identifying the main source or etiology of the sexual dissatisfaction within the components of biological drive, motivation, and wish can help direct the patient to the appropriate resource.

Sexual functioning abilities

Sexual functioning abilities include genital arousal (vaginal lubrication and accommodation in women, erection in men), ability to attain and experience orgasm, ejaculation potential in men (most men with SCI have anejaculation or ejaculatory difficulty), ejaculate direction (antegrade or retrograde or absent), and freedom from genital pain related to sexual acts (dyspareunia). Problems in these areas are called *sexual dysfunctions*.

Fertility and contraception concerns

Issues about fertility (conception) potential include the ability to enter into the act of vaginal sexual intercourse with adequate erection and/or

to ejaculate with sexual activity, having a normal hormonal milieu in both sexes, and the ability to carry a pregnancy to term and/or undergo labor and delivery with any expected complications. For men with SCI, fertility is affected by erection and ejaculatory concerns, as well as poor semen quality secondary to toxic changes in the seminal fluid.¹³ For women with SCI, fertility is unaffected; considerations for birth control include limited mobility and clotting risk, poor hand function with barrier methods, lack of sensation to pain from extruded intrauterine devices, or medication contraindications. It is important for health care professionals to preserve the rights of persons with SCI to become biological parents while addressing the requirements of physical accessibility and the demands on emotional energy.

Factors associated with the condition

This area includes overall medical status, prescribed and over-the-counter medications, and ongoing treatment effects. Medication or other iatrogenic treatments can directly affect sexual function. The secondary medical consequences of SCI (eg, chronic pain, fear of autonomic dysreflexia [AD], spasm, general malaise, fatigue, depression, and temperature dysregulation) can impair sexual response and the willingness to be sexual. The clients' ability to be independent in personal and hygienic care can also affect their sexuality and sexual self-view. Comorbid conditions or conditions such as diabetes that existed before the SCI can cause or exacerbate any sexual problem.

AD deserves special mention in the SCI population. AD interfered with the motivation to be sexual in 28% of women and 16% of men in a recent survey.¹⁴ It can be triggered with arousal as well as orgasm. The occurrence of AD during typical bladder or bowel care was a significant variable predicting the occurrence and distress of similar symptoms during sexual activity.⁵ AD is most often provoked at ejaculation and is probably more severe with the intensity of the stimulation (such as penile vibratory stimulation [PVS]). Cardiovascular responses are very different following SCI as compared to the able-bodied population, especially during sperm retrieval procedures.¹⁵

Motor and sensory influences

Motor function includes the ability to undress independently; to get into a bed or other sexual environment; to reposition oneself or one's partner; and to touch, caress, and hold a partner. The clients' ability to transfer or turn independently in bed should be assessed. Spasm and other motor problems can limit the options for sexual activity or participation in the use of sexual aids. Assistive devices to hold sexual aids can be made by therapists. Loss of mobility and dependency on wheelchairs or mobility aids can also limit access to certain social venues and opportunities.

Appreciation of sexual touch and build-up of arousal will be affected by any loss of sensation in the genital area or other erogenous areas. Hypersensitivity along the zone of injury for some persons with SCI can be sexually unpleasant or a source of arousal. Chronic pain is counterintuitive to relaxation, and pain (and the medications used to treat it) can be a serious sexual deterrent for the affected patient and their partner. Anxiety around sexual avoidance can exacerbate the pain or lead to sexual performance anxiety.

Bowel and bladder issues

One of the most often reported and distressing issues around sexuality post SCI is bladder and bowel continence and bladder management. If these issues are significant enough, the learning trajectory of sexuality can be delayed in young people (ie, spina bifida population) and individuals with secondary incontinence will withdraw from sexual activity or social activities. Fortunately, a survey of persons with SCI noted that their concerns about bladder and bowel function during sexual activity were not strong enough to deter the majority of the population from engaging in sexual activity. However, in the subset of individuals concerned about bladder and/or bowel incontinence during sexual activity, this was a highly significant issue.⁵

Sexual self-view and self-esteem

The secondary consequences of having an SCI can adversely affect a person's sense of sex appeal and femininity/masculinity or gender expression.

How individuals view themselves in society and their consequential ability to form relationships and/or become parents are dependent on sexual self-view. Loss of confidence or former abilities at work or athletics, role reversal between partners, and the lack of support or loyalty of friends, family, and employers can further drain self-esteem. Body image and sense of attractiveness can be threatened by altered body composition, loss of hair or skin changes, weight loss or gain, obvious bladder and bowel management devices, medication side effects, or use of motor aids or wheelchairs. In a relationship, gender roles can be undermined if there is role change or reversal or loss of independence in daily living, which indirectly affects sexual self-view. Other important variables include the living conditions and number of family members in the house or in the community, the availability and loyalty of friends and other supports, the ability to work, financial status, and future prospects.

Partnership issues

Partnership issues include the status of sexual partnerships, whether the person with SCI is single or in a partnered relationship, that pre- or post-date the injury. Sexual gender orientation(s) as well as gender identity and expression should be identified. Issues related to the loss of attractiveness and accessibility to social situations and whether the sexual partner also looks after the basic physical or hygienic needs of persons with SCI (the “caregiver-lover” syndrome) need to be identified. The ways that people meet other people after SCI need to be explored, including barriers to and optimizing access. The extensive use of social media and the potential for abuse for all vulnerable populations also should be discussed.

Value of Different Disciplines in Sexual and Fertility Rehabilitation After SCI

In both inpatient and outpatient settings, the team works together to fulfill the biopsychosocial sexual health and reproductive needs of the person with SCI as identified in the SRF. Emotional readiness of the client can be assessed by any discipline.

Medical doctors: Physicians are often team leaders, but they depend on delegation, collaboration, and referral to other disciplines to maximize clinical care. Physicians must be familiar with changes to sexual physiology after SCI and take direct responsibility for inquiring about sexual issues during routine assessments with the SRF in mind. They can address the role of medications and medication sexual side effects and assess the client’s physical and mental health.

Nurses: As a discipline, nursing assists clients and their families in many ways, from providing acute medical care to teaching clients how to care for themselves. Nurses are involved in the day-to-day needs of clients. They have the opportunity to teach clients about sexual health during daily routines of bladder, bowel, skin, hygiene, and transfers. Nurses can address issues directly, normalize and validate a client’s concerns, collaborate with other disciplines, and refer clients to other team members depending on the specific concern or area of difficulty.

Sexual Health Clinicians/Sex Therapists (SHC/ST): The role of sexual health clinicians (usually nurses) specially trained in sexuality and chronic illness/disability and those of community sexual therapists (often psychologists) goes beyond providing permission to discuss the area of sexuality and normalizing and validating client’s concerns. SHC/ST are trained to take full sexual histories and to provide more specific information related to a client’s particular concern. With or without other disciplines, they can intervene with therapeutic options (ie, looking at erection enhancement options, fertility procedures, techniques to address anejaculation and/or premature ejaculation, ways to experience pleasure in the context of limited or decreased sensation, mindfulness work). Specialized training and knowledge in sexuality and disability are required in this role.

Occupational therapists (OTs): OTs assist clients in managing activities of daily living and educate clients in self-care activities, including bathing, dressing, toileting, and attending to personal hygiene. They prepare individuals to have the social/sexual confidence to participate in the community. OTs are in an excellent position to normalize sexual health as part of rehabilitation and

assist in specifics for sexual activity, such as adaptive sexual devices, environmental controls, and adapted clothing.

Physiotherapists (PTs): PTs assist clients in optimizing their physical (sensory and motor) function by educating them about managing mobility, range of motion, transferring, repositioning, balance, spasticity, and maintaining skin integrity, all of which directly or indirectly help individuals prepare to reintegrate sexuality into their lives. Improved mobility, strength, stamina, and range of motion may secondarily improve body image and confidence. A PT is often the first clinician that clients see in community, and he or she can be very effective in opening the conversation, normalizing sexual health rehabilitation as part of overall rehabilitation, and connecting individuals to necessary supports.

Psychologists and counselors: Depression, anxiety, loss and grief, role changes, and relationship discord are common post SCI and can have a significant effect on sexual health (sexual drive, relationships, etc). Behavior modification, challenging negative or limiting beliefs, and treating depression and anxiety through techniques such as cognitive behavioural therapy, mindfulness-based cognitive therapy, interpersonal psychotherapy, and psychoeducation can assist in the process of adjustment. A more stable and positive outlook promotes sexual adaptation to limitations.

Social Workers (SW): Social work is a profession concerned with helping individuals, families, groups, and communities to improve their individual and collective well being. In the context of sexual rehabilitation, the social work lens provides an in-depth view of the social and emotional aspects of sexuality, pregnancy, and parenting after an injury and the impact that societal norms, lack of information/awareness, and support system gaps can have on this population group. The SW is then able to work with the client or group to seek out individual resources as well as sources of support and resources in the community that can be creatively pieced together to support clients to attain their goals and to achieve a positive outcome.

Recreational therapists (RTs): Recreation therapy re-integrates a person into the community by teaching them new or adaptive ways of expressing themselves through activities such as sports, art, exercise, and dance. A sense of confidence and self-esteem can be restored, re-establishing a sense of purpose and positive sense of self for a person. This is an important aspect of a person's sense of his or her sexual self in the world and how he or she is seen as a sexual person by others.

Vocational Rehabilitation Therapists: Loss of employment following an injury can be devastating to a person's sense of self. As a result, confidence and self-esteem, including sexual self-esteem, can be negatively impacted. Supporting a person to return to previous employment, train for a new occupation, or assume a volunteer role is important for re-establishing a sense of purpose, accomplishment, and wholeness to a person's life.

The SRF can be utilized easily as a simple table. For those interested in a more specific tool that can be used in a clinical setting, a modified SRF inclusive of potential health care professionals is included in **Table 1** showing how the different disciplines could be involved in specific areas of the SRF.

Conclusion

SRF can be used in both inpatient and outpatient settings. It can be attached to a patient chart or used as a tool by any health care professional to ensure that sexual and fertility rehabilitation has been initiated and followed through.

The SRF is contextualized within the 3 principles of sexual rehabilitation¹⁶:

- Maximize the remaining capacities of the total body before relying on medications or aids (learning new body maps, breathing, visualization methods, mindfulness exercises),
- Adapt to residual limitations by utilizing specialized therapies (use of vibrators, mobility devices, training aids, phosphodiesterase type 5 inhibitors, vacuum device aids), and
- Stay open to rehabilitative efforts and new forms of sexual stimulation, with a positive and optimistic outlook.

Table 1. Sexual Rehabilitation Framework multidisciplinary working sheet example

Patient identifier: 26-year-old C6 complete SCI male; 1 year post injury; current meds: baclofen									
Sexual area	Sexual concern	Referral							
		MD	RN	PT	OT	Psych	SW	RT	Other
Sexual drive/interest	Decreased secondary to ED and depression?	X				X			
Sexual functioning abilities	ED, anejaculation, anorgasmia	X ED meds	X		X Adapt vibrator				Sexual health clinician/therapist
Fertility & contraception	Curious	X Urologist	X						Sperm retrieval assessment
Factors associated with the condition: fatigue, pain, AD, depression, medications, cultural / religious, other	AD	X BP; medication adjustment?							
Motor & sensory influences	Spasm, transfers, hypersensitivity at area of injury	X Medications?	X	X	X				Skin care needs improving
Bladder & bowel influences	Catheter use with sex ?		X						
Sexual self-view & self-esteem	“Lost manhood,” difficult adjustment to WC living, substance abuse, poor social supports					X	X		Peer counseling, vocational rehab
Partnership issues	Single, gay (preinjury partner left)					X		X	Wants to find a partner
Specific concerns:									

Note: AD = autonomic dysreflexia; ED = erectile dysfunction; MD = physician; RN = nurse; OT = occupational therapist; Psych = psychologist and counselor; PT = physical therapist; RT = vocational rehabilitation therapist; SW = social worker; WC = wheelchair.

The key to successful rehabilitation is the willingness to address sexual issues. Various disciplines should be engaged to start the conversation and include sexual and fertility issues as an essential part of rehabilitation. All disciplines can have a role in introducing the topic and giving permission to the person with SCI to discuss the issue. Clients should be assured that the appropriate health care professional will handle their questions and issues. There is no excuse for ignoring or sidestepping this important part of life after SCI, as has been the practice in the past. Improvement in sexual function and dealing with issues that interfere with sexual abilities have been

shown to improve the QOL for persons with SCI.⁵ Research on this important area of sexuality and fertility after SCI must continue to be actively pursued.

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