The rehabilitation management of sexuality and fertility issues in people with disabling health conditions

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Abstract

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality. Disabling health conditions can impact sexual function, identity, self-esteem and self-image, fertility and pregnancy. People can experience primary impairments such as a loss of sensibility or erectile dysfunction, but also consequences of secondary impairments like incontinence, pain, fatigue, or spasticity. Moreover, limitations of activities and participation restrictions can impact intimacy, sexuality and reproduction. Therefore, sexual issues should be an integral part of quality rehabilitation care.

Components of a sexual rehabilitation programme are information/education of patient (and partner), practical advice, finding new positions, medication, using assistive devices and aids (like vibrator, sex toys, lubricating gel, massage oil), pelvic floor training, coping strategies and addressing self-image and self-esteem. People should be encouraged to explore their changed bodies and experiment. Sexual rehabilitation requires a personalized biopsychosocial and integrative approach by the entire multiprofessional team, including peer counsellors.

Keywords: Rehabilitation, Disabled Persons, Sexuality, Sexual Health, Fertility, Erectile Dysfunction, Psychosocial Functioning.

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Introduction

Sexuality plays a significant yet often implicit role in individuals' lives. Sexual health is defined by the World Health Organization (WHO) as a state of physical, emotional, mental, and social well-being concerning sexuality and all individuals should have access to comprehensive, good-quality information about sex and sexuality.[1]

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Unfortunately, disabling and chronic health conditions can profoundly affect various aspects of sexuality, including sexual function, identity, self-esteem, self-image, and fertility. Health conditions that are congenital or alter human functioning from childhood like cerebral palsy or muscle dystrophy, shape the sexual experiences that typically occur during adolescence. Disorders acquired in adulthood, change sexual lives in people with a previous sexual history. Sexual dysfunction may occur from a direct structural or neurophysiological problem such as penile, vulvar cancer, spinal cord injury (SCI), or stroke but also indirectly, such as decreased libido due to hormonal issues, mobility problems, illness-related anxiety, side effects of treatments that result in erectile dysfunction, or difficulties in lubrication.

Patients with disabilities often face unique challenges that affect sexual desire and function, as well as satisfaction with sexual life. Therefore, sexual health should be considered not only individually but also from a social and public health perspective - there might be an unawareness of the risks of sexuality such as sexually transmitted diseases, undesirable pregnancies, sexual misconduct, and violence.

In this paper, we aim to outline the key sexual functioning problems in people with disabling health conditions, focusing on SCI as an example. Using the International Classification of Functioning, Disability and Health (ICF) framework,[2] healthcare providers can better understand the multidimensional nature of sexual health challenges in individuals with disabilities and develop comprehensive, person-centred care approaches.

Body functions

One of the most significant alterations in men with SCI is the primary sexual dysfunction regarding erection and ejaculation. Erections are controlled by autonomic and somatic nervous systems. Injuries at or above the T10-L2 level can disrupt sympathetic pathways, which are crucial for psychogenic erections that are initiated by erotic or emotional stimuli. Reflex erections are initiated by direct physical stimulation of the genital area and can be preserved if the sacral segment S2-S4 remains intact (lesions above S2). Ejaculation is controlled by the T10-L2 sympathetic fibers and S2-S4 somatic nerves. Lesions in these areas can affect seminal emission and the ability to

ejaculate. At the peak of sexual arousal, orgasm is the brain's interpretation of the visceral and somatic events happening. While is distinct from ejaculation, they usually occur together. Men with SCI can experience "orgasm" even despite complete lesions, for example by stimulating supralesional erogenous zones that may become hyper-receptive. In women with SCI or other neurological conditions, lubrication and swelling of the small lips can be reduced, and sensory changes can reduce orgasm and pleasure. However, with more time, different kinds of stimulation (clitoral, vaginal, cervical, G-spot, breasts, other erogenous zones, or psychogenic stimulation) and aids such as vibrators, lubricating gel, or massage oils, up to 78% of women with SCI may experience a form of orgasm.[3]

Hormonal changes can occur in both sexes. Women usually present a 3 to 6-month lasting episode of amenorrhea after an acutely acquired SCI or other severe condition. Then, fertility returns to the premorbid status. Pregnancy following SCI may pose additional risks, such as autonomic dysreflexia, preterm delivery, thromboembolic events, increased incontinence and urinary infections, respiratory problems, edema, or even pressure injuries.[4] In men with SCI fertility is often reduced not only due to anejaculation, but also sperm quality is often an issue. Sperm retrieval methods for men with SCI include 1) penile vibratory stimulation, 2) electroejaculation, or 3) surgical sperm retrieval (testicular sperm aspiration or extraction). Due to the often low to very low sperm quality, assisted fertility technologies may be required.

Psychological issues such as stress or anxiety caused by suffering from a disease or loss of function, emotional issues, and challenges with partnerships can lead to a decrease in sexual activity and satisfaction.[4,5] For example, patients who have suffered a stroke, report a higher incidence of loss of libido and significantly less sexual activity.

Body structures

Some conditions can directly affect sexual organs, such as burns, penile, vulvar or breast cancer, or Peyronie´s disease. New treatment strategies for oncological diseases are more conservative towards preserving the structure, but patients may have both physical and emotional consequences that may impair their sexual life. Pelvic floor disorders, which occur when normal anatomy is disrupted (e.g. pelvic organ prolapse) can cause various types of urinary and faecal incontinence and impact sexual relationships. Rheumatologic diseases impair sexual functioning due to reduced joint mobility, muscle weakness, and pain, requiring adapted positions. This is also the case for people with amputation of limbs.

Activities and participation

Diseases accompanied by sexual dysfunction not only compromise physical health but impact an individuals' emotional well-being and social interactions. People with the above- mentioned problems can have feelings of embarrassment or inadequacy for relationships. This may result in lifestyle changes, including avoidance of intimate relationships or alterations in sexual activities, particularly in cases of ED or incontinence. Furthermore, societal norms and personal beliefs regarding sexuality, influenced by factors like social, cultural and religious norms, can exacerbate problems with self-image and self-esteem, create feelings of shame, and hinder open communication about sexual concerns. These challenges can strain intimate relationships, affecting their quality and significance. Consequently, individuals may withdraw from meaningful connections, impacting their overall well-being and participation in various aspects of life.

Environmental factors

Effective sexual health management in rehabilitation settings is hindered by different barriers. Patients report that during rehabilitation and consultations inquiry on sexual health is often lacking but also, and many health professionals seem to be scared to talk about it.[6,7] Most barriers seem linked to sociocultural attitudes and taboos, but also lack of knowledge and skills. To overcome these obstacles there is a need for specialized education and training in sexual healthcare for health professionals. Another issue is that many health services present physical or other barriers to access for people with disabilities, impeding for example screening programmes for this population. Facilitators enhancing these efforts include the development of interdisciplinary sexual rehabilitation programmes to treat people post-injury, post-illness, and particularly when the onset of the condition is before adolescence, during different phases of life. The Sexual Rehabilitation Framework (SRF) developed for persons with SCI is such a model and can be applied to similar disabling conditions.[8-10]

Sexual rehabilitation management

In this context, managing sexual dysfunction implies a holistic, integrative, and tailored approach, emphasizing the unique needs of individuals with disabilities. One of the most accepted general models is the PLISSIT model or extended version "EX-PLISSIT".[11,12] These frameworks support and provide sexual information and discuss sexual changes at four levels: P (Permission), LI (Limited Information), SS (Specific Suggestions), and IT (Intensive Therapy). In the EX-PLISSIT model feedback is essential to increase self-awareness. While counselling is linear in the PLISSIT model, it is feedback-oriented in EX-PLISSIT. In the case of sudden loss of functioning like in SCI or stroke,

rehabilitation professionals should advise both patients and partners in developing coping strategies for dealing not only with motor and cognitive problems but also sexual health. Information, education, and counselling on drugs, assistive devices, and other therapeutic options should be offered from the acute phase as a part of the rehabilitation approach.[5,13] The SRF covers eight areas: 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. All members of the rehabilitation team should include sexuality as part of their standard inquiry, just like any other bodily function that is addressed by rehabilitation, and ensure that rehabilitation is person-centered and patients feel informed and supported in their sexual health.[14] Information for both patients and their partners should include practical adjustments like exploring new sexual positions and using assistive devices such as vibrators, lubricants, or (adapted) sex toys. Pelvic floor training can be of great help in some indications. Each rehabilitation professional can assist patients according to their expertise. For example, the physiotherapist can train new positions, the nurse can help in grooming or bladder and bowel management, the occupational therapist may adapt sexual aids and the home environment, and the psychologist can work on self-image and self-esteem (learning new body maps, breathing, visualization methods, mindfulness exercises). Peer counsellors can offer helpful tips on how to maximize sexual satisfaction and are much appreciated by patients, especially by women with disabilities. Physicians can tackle hindering medical factors such as pain or spasticity, and adjust medication schemes. Treatment for erectile dysfunction includes phosphodiesterase-5 (PDE-5) inhibitors, intra-cavernous injections of alprostadil or Prostaglandin E, vacuum devices, vibro-stimulation, as well as neo-phalloplasty, penile prosthesis or penile lengthening. In particular, for those who have difficulties in finding partners due to the disability itself, there have been some initiatives to provide professional assistance to help them experience physical intimacy through the role of sexual workers. This service not only aids in fulfilling people's sexual needs but also has an educational role, teaching them about safe and consensual sexual interactions.

Conclusions

Effective management of sexual dysfunction in individuals with disabling conditions requires a holistic approach. Following the SRF principles it should include: 1) maximizing the remaining capacities of the total body before relying on medications or aids 2) adapting to residual limitations by utilizing specialized therapies, and 3) staying open to rehabilitative efforts and new forms of sexual stimulation, with an optimistic outlook. This paper advocates integrating sexual health into broader health and rehabilitation frameworks to improve quality of life and ensure inclusive care.

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