

A Cross Sectional Study Assessing Sexual Dysfunction in Women with Traumatic Spinal Cord Injury and its Impact on Quality of Life: An Observational Study

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Abstract

Aim: The aim of the present study was to describe sexual life in women with spinal cord injury

Material & Methods: A cross sectional study included all women with traumatic spinal cord injury treated at spinal cord centres at hospital. Out of the 300 women, 100 were excluded: 8 due to death, 14 were recovered, 6 with language difficulties, 16 had congenital injuries, 6 due to psychiatric disease, 18 due to other severe illness and 18 because they could not be located. The total eligible sample thus comprised 200 women.

Results: Mean age of the women was 44 years and the average time since injury was 12 years. Almost two-thirds were married or in a committed relationship. 56 women were tetraplegics and 96 women had paraplegics. For single women, both SCI and controls, wanting a partner, the most common reason reported for being single was that they had not met the “right” partner. Other reasons reported by the women with SCI were feelings of inadequacy, fewer opportunities to find new contacts, low self-esteem, and feelings of being unattractive, doubts about sexual abilities and fear of bladder and/or bowel leakage. Hugging, kissing and caresses were listed as important by approximately three-quarters of the women with SCI both before and after the injury, and the control women. Almost half of the women with SCI considered it important to be caressed, even on body parts with no sensation, in order to become sexually aroused.

Conclusion: For women who are able to overcome the physical restrictions and mental obstacles due to injury, it is possible to regain an active and positive sexual life together with a partner. Sexual information and counselling should be available both during initial rehabilitation and later when the women have returned to their homes.

Keywords: Spinal Cord Injury, Women, Sexuality And Disability, Sexual Rehabilitation, India.

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Introduction

Every year, around 250,000–500,000 people acquire a Spinal Cord Injury (SCI) worldwide. [1] SCI can be traumatic (following road accidents, falls, sports injuries, violence) or non-traumatic (involving an underlying pathology, such as infectious diseases, tumours or congenital problems). Road traffic injuries, falls and violence are the most common causes of SCI. Around 80% of these injuries are sustained by men. [2] SCI is a complex condition involving complete or incomplete damage of one or more levels of spinal cord and/or the nerve roots in the spinal canal that affect the connection between the brain and other parts of the body. Depending on the level of injury, the SCI can cause varying degrees of loss of motor (the ability to control body movements), sensory

(the ability to sense touch, temperature, pain) and autonomic functions (including breathing, heart rate, blood pressure, temperature control, bowel and bladder control, lubrication, orgasms, etc.) in an individual. [1] According to the WHO, [3] health impacts quality of life beyond the absence of illness or disease, and rather encompasses an interaction between biological and psychological factors, and the social environments in which one lives. Sexual health also has multiple dimensions (e.g., biological, psychological, cultural, relational) and is important to be included in rehabilitation efforts. Attending to the sexual health and sexual function of women living with SCI supports whole-person care for these women, which will improve clinical outcomes and decrease health care costs.

Few studies have compared sexuality and sexual functioning in women with SCI with that of able-bodied women. One such study showed that women with SCI report significantly lower satisfaction with sexual life and lower sexual desire. [4] A recent study found that sexual activity was lower among women with SCI, but the desire did not differ from controls. [5] A Swedish study found that the importance of sexuality had decreased among women with tetraplegia, but not among those with paraplegia. The greatest physical obstacles for sexual activity were urinary leakage, problems with positioning and spasticity. [6] Typically, the traditional approaches to sexual health and SCI have been rooted in the conventional medical model, including both men and women or a collective of chronic conditions, which does not observe sexual health within the lived psychosocial experiences that encompasses women's emotional needs, interpersonal relationships, body image, and cultural beliefs and values as well as their experience with their disability. Some studies tackle this multifaceted phenomenon and have identified women's sexual health as a combination of understanding of the human body, experiencing satisfaction (alone or with consenting others) while maintaining autonomy, minimizing exposure to infection, and preserving safety. [7,8] Others characterize women's sexual health including sexual satisfaction, sexual function, cognitive flexibility, sexual health/risk, attitudes and outlook, positive emotions, sexual self-esteem, and mutual and synchronous experiences. [9,10]

The purpose of this study was to describe physical, psychological and social aspects of sexual life in women with SCI.

Material & Methods

A cross sectional study included all women with traumatic spinal cord injury treated at spinal cord centres at PMCH, Patna, Bihar, India for five years. Out of the 300 women, 100 were excluded: 8 due to death, 14 were recovered, 6 with language difficulties, 16 had congenital injuries, 6 due to psychiatric disease, 18 due to other severe illness and 18 because they could not be located. The total eligible sample thus comprised 200 women.

Exclusion Criteria:

Table 1: Background and clinical characteristics of women with spinal cord injury (SCI) and control women

Background characteristics	SCI N=200	Control N=200
Age (years)		
Mean (SD)	44.2 (12.2)	44.2 (12.2)
Median (range)	45 (18–70)	45 (18–70)
Educational level, n (%)		
Compulsory level	42 (21)	40 (20)
High school	104 (52)	100 (50)

Known recovery (Frankel grade E/ASIA Impairment Scale E) (20–21), injured less than 2 years, known brain injuries and psychiatric diseases.

Inclusion Criteria:

Age between 18 and 70 years.

Methodology

Names and addresses of a total of 300 women with SCI were provided from the spinal cord centres in Bihar region. Questionnaires with a letter describing the rationale for the study were posted to the potential participants. They were guaranteed complete confidentiality of their responses and were offered the option of returning the questionnaires anonymously. The women were asked to return their completed questionnaires either in a postage-paid, pre-addressed envelope or by filling in an electronic version.

Control Group

A control group comprising 200 women was selected randomly from the general population of Bihar to match the SCI study group on individual level by age and rural vs urban residence.

Statistical analysis

For comparison between countries Kruskal-Wallis test was used for continuous variables, χ^2 test for dichotomous variables and Semi-trend test for ordered categorical variables. The Semi-trend test is the equivalent of the Kruskal-Wallis test for singly ordered $R \times C$ contingency tables with ranks replaced with the original values. The χ^2 test was used for testing differences between countries (non-ordinal variables). For testing ordinal variables, the Semi-trend test was used. For comparisons between 2 groups, Fisher's permutation test was used for continuous variables, Fisher's exact test for comparison of proportions (26), and Mantel Haenszel's χ^2 test for ordinal categorical variables. Changes before and after the injury were tested using the Sign test. Due to the multiple comparison problems, a p-value of 0.01 or less was considered significant. All significance tests were two-tailed.

Results

University	54 (27)	60 (30)
Marital status, n (%)		
Married	100 (50)	100 (50)
Stable partner	20 (10)	22 (11)
Single	80 (40)	78 (39)
Disability-related Age at lesion (years)		
Mean (SD)	32.8 (14.2)	
Median (range)	32 (3–68)	
Duration of disability (years)		
Mean (SD)	13.7 (10.1)	
Median (range)	12 (1–54)	
Neurological classification N=150		
Tetraplegia complete	20 (13.34)	
Tetraplegia incomplete	36 (24)	
Paraplegia complete	39 (26)	
Paraplegia incomplete	55 (36.66)	
Genital sensation (n = 100), n (%)		
Normal	15 (15)	
Somewhat decreased	29 (29)	
Much decreased	27 (27)	
None	29 (29)	
Mobility, n (%)		
Wheelchair dependent	140 (70)	
Walking with aids	20 (10)	
Walking without aids	40 (20)	

Mean age of the women was 44 years and the average time since injury was 12 years. Almost two-thirds were married or in a committed relationship. 56 women were tetraplegics and 96 women had paraplegics.

Table 2: Reasons listed for being single (more than one reason could be given)

Reason	SCI n = 200 n (%)	Controls n = 200 n (%)
Have not met the “right” partner yet	110 (55)	170 (85)
Low self-esteem	76 (38)	40 (20)
Feelings of being unattractive	80 (40)	20 (10)
Fewer opportunities to make new contacts	96 (48)	70 (35)
Doubts about sexual ability	70 (35)	10 (5)
Decreased sexual interest	30 (15)	14 (7)
Fear of bladder and/or bowel leakage	64 (32)	0
Feelings of being inadequate when confined to a wheelchair or having a visible disability	108 (54)	–
Feelings of inadequacy	–	24 (12)
Lack of time	12 (6)	34 (17)

For single women, both SCI and controls, wanting a partner, the most common reason reported for being single was that they had not met the “right” partner. Other reasons reported by the women with SCI were feelings of inadequacy, fewer opportunities to find new contacts, low self-esteem, and feelings of being unattractive, doubts about sexual abilities and fear of bladder and/or bowel leakage.

Table 3: Sexual expressions listed to be of importance for becoming sexually aroused

Preferred type of sensory stimulation for becoming sexually aroused	Before injury	After injury	p-value
Visual	70 (35)	72 (36)	0.981
Hearing	32 (16)	40 (20)	0.0022
Taste	20 (10)	26 (13)	0.2102
Smell	46 (23)	52 (26)	0.3920
Sexual fantasies	54 (27)	76 (38)	< 0.001
Hugging, kisses, caresses	144 (72)	146 (73)	0.7432
Caresses of the breast with hands	96 (48)	106 (53)	0.7036
Caresses of the breast with mouth	92 (46)	100 (50)	1
Caresses of the genitals with hands	108 (54)	82 (41)	< 0.001

Caresses of the genitals with mouth	84 (42)	52 (26)	< 0.001
Vibrator stimulation of clitoris	20 (10)	18 (9)	0.4050
Vibrator stimulation with artificial penis	12 (6)	14 (7)	1
Stimulation of vagina and clitoris	56 (28)	40 (20)	< 0.001
Sexual intercourse	102 (56)	82 (41)	< 0.001
Caressing of body parts at the level of injury	n.a.	20 (10)	-

Hugging, kissing and caresses were listed as important by approximately three-quarters of the women with SCI both before and after the injury, and the control women. Almost half of the women with SCI considered it important to be caressed, even on body parts with no sensation, in order to become sexually aroused.

Discussion

This study showed that it is possible for women with SCI to have an active and satisfying sexual life in spite of the many changes in sexual life engendered by the injury. Most aspects of sexuality were negatively affected by the injury. Many of these impacts were of a physical or medical nature, but psychological factors, such as desire, subjective arousal, body image, self-esteem and self-confidence, were also affected by the injury. For many women, the importance of sex had declined after injury and sexual desire, arousal, activity and satisfaction were lower than before injury and compared with controls. For the single women in our study who wished to have a partner, one of the frequently mentioned obstacles was to find dating opportunities. Also, many of the women with SCI felt that they would be an unattractive prospect for any partner and thus avoided intimate relationships. A new relationship may be more influenced by sexual attractiveness and sexual capacity than a long-term relationship.

Mean age of the women was 44 years and the average time since injury was 12 years. Almost two-thirds were married or in a committed relationship. 56 women were tetraplegics and 96 women had paraplegics. For single women, both SCI and controls, wanting a partner, the most common reason reported for being single was that they had not met the "right" partner. Other reasons reported by the women with SCI were feelings of inadequacy, fewer opportunities to find new contacts, low self-esteem, and feelings of being unattractive, doubts about sexual abilities and fear of bladder and/or bowel leakage. Hugging, kissing and caresses were listed as important by approximately three-quarters of the women with SCI both before and after the injury, and the control women. Almost half of the women with SCI considered it important to be caressed, even on body parts with no sensation, in order to become sexually aroused. Prior studies involving women have identified rare positive experiences of sexual desire, body image, emotional closeness, and the

ability to communicate sexual needs while living with an SCI. [11] However, it is unclear how women explain the lived experience of living with SCI and what psychosocial dimensions drive their clinical outcomes associated with sexual function. [12] Additionally, it is unclear how this impacts their intimate partner's sexual health. Nevertheless, only minimal sexual health education occurs during medical school or during the allied health professions trainings, leading to the importance of better understanding these concepts from the women's voice to improve rehabilitation practices that lead to a greater quality of life. [13]

In many cases, the topic of sexual health is presented when women may not be ready to discuss sexual health and are still adjusting to their newly acquired injury or diagnosis. According to our preliminary work, sexual health is typically not addressed again during follow-up care unless the patient seeks out specific information from a health care provider or engages in independent internet-based research. Of special note, our prior research indicated that women also desire having the information on sexual health be endorsed by a rehabilitation hospital or an institution of education, so they are assured the information is accurate and evidence based. [14,15] Sexual function and psychosocial dimensions are important, regardless of whether there is a SCI present or not. The conversation becomes even more important when adjusting to a body that looks, feels, and moves differently. Understanding sexual function and the psychosocial dimensions of sexual health among women living with SCI is critical toward developing clinical and educational interventions to support these women's sexual health, relationships, and overall quality of life. [16]

Conclusion

For women who are able to overcome the physical restrictions and mental obstacles due to injury, it is possible to regain an active and positive sexual life together with a partner. Sexual information and counselling should be available both during initial rehabilitation and later when the women have returned to their homes.

References

1. WHO. International perspectives on spinal cord injury. Geneva: World Health Organization; 2013.

2. Consortium for Spinal Cord Medicine. Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for health-care providers. Washington, DC: Paralyzed Veterans of America; 2010.
3. Rosenbaum P, Stewart D. The World Health Organization International Classification of Functioning, Disability, and Health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. In *Seminars in pediatric neurology* 2004 Mar 1;11(1): 5-10. WB Saunders.
4. Black K, Sipski ML, Strauss SS. Sexual satisfaction and sexual drive in spinal cord injured women. *The journal of spinal cord medicine*. 1998 Jan 1;21(3):240-4.
5. Matzaroglou C, Assimakopoulos K, Panagiotopoulos E, Kasimatis G, Dimakopoulos P, Lambiris E. Sexual function in females with severe cervical spinal cord injuries: a controlled study with the Female Sexual Function Index. *International Journal of Rehabilitation Research*. 2005 Dec 1;28(4): 375-7.
6. Westgren N, Hultling C, Levi R, Seiger A, Westgren M. Sexuality in women with traumatic spinal cord injury. *Acta Obstetrica et gynecologica Scandinavica*. 1997 Jan 1;76(10): 977-83.
7. Daugherty TK, Julian HM, Lynch NM, Chen SJ, Whipple TL, Ginsburg AF. Beyond the absence of disease or infirmity: the case for sexual wellness. *College Student Journal*. 2017 Sep 1;50(3):404-8.
8. Dundon CM, Rellini AH. More than sexual function: Predictors of sexual satisfaction in a sample of women age 40–70. *The journal of sexual medicine*. 2010 Feb;7(2_Part_2):896-904.
9. Syme ML, Cohn TJ, Stoffregen S, Kaempfe H, Schippers D. “At my age...”: Defining sexual wellness in mid-and later life. *The Journal of Sex Research*. 2019 Sep 2;56(7):832-42.
10. Santos-Iglesias P, Byers ES, Moglia R. Sexual well-being of older men and women. *The Canadian Journal of Human Sexuality*. 2016 Aug;25(2):86-98.
11. Reitz A, Tobe V, Knapp PA, Schurch B. Impact of spinal cord injury on sexual health and quality of life. *International journal of impotence research*. 2004 Apr;16(2):167-74.
12. Makivić I, Kersnik J, Klemenc-Ketiš Z. The role of the psychosocial dimension in the improvement of quality of care: a systematic review. *Slovenian Journal of Public Health*. 2016 Mar;55(1):86-95.
13. Criniti S, Andelloux M, Woodland MB, Montgomery OC, Hartmann SU. The state of sexual health education in US medicine. *American Journal of Sexuality Education*. 2014 Jan 2;9(1):65-80.
14. Piatt JA, Knee E, Eldridge L, Herbenick D. Women with spinal cord injury and sexual health: The role of the recreational therapist. *American Journal of Recreation Therapy*. 2018 Jul 1;17(3):25-35.
15. Piatt JA, Simic Stanojevic I, Stanojevic C, Zahl ML, Richmond MA, Herbenick D. Sexual health and women living with spinal cord injury: the unheard voice. *Frontiers in Rehabilitation Sciences*. 2022 May 6; 3:853647.
16. Amjadi MA, Simbar M, Hosseini SA, Zayeri F. The sexual health needs of women with spinal cord injury: a qualitative study. *Sexuality and Disability*. 2017 Sep; 35:313-30.