



Original Article

Sexual dysfunction and sexual concerns among persons with disability due to myelopathy: A cross-sectional study

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ABSTRACT

Objectives: We have very little information about sexual activity and concerns of patients with myelopathy from India. The objectives of this study were to assess the sexual dysfunction and sexual concerns among patients with myelopathy due to spinal cord lesion (SCL).

Materials and Methods: This study was a single-center, cross-sectional, and hospital-based study among male and female patients in the age-group 18–50 years, with disability due to myelopathy due to SCL. The data were collected using a self-designed, pretested, and semi-structured questionnaire by face-to-face interview.

Results: Eighty participants were recruited in the study, of which 62 (77.5%) were men. The mean standard deviation (SD) age of the participants was 33.7 (8.6) years, and mean (SD) age at time of illness was 31.4 (8.6) years with median duration of 17 months. Among 62 males, psychogenic erection was impaired in 77.2%, reflex erection was impaired in 78.9%, and ejaculation was affected in 70.7%. Orgasm was absent or reduced in 66.1% males. Among 18 female participants, psychogenic genital arousal was reduced in 66.5%, reflex genital arousal was impaired in 55.5%, and orgasm was absent in 38.8% subjects. Sexual desire in these patients was unchanged in 41 (51.2%) and decreased or absent in 39 (48.8%). Sexual activity involvement was there in 46 (57.5%) and 34 (42.5%) had not involved in any kind of sexual activity after injury/illness. The main reasons of non-involvement in sexual activity were bladder and bowel accidents, spasticity, and difficulty in positioning.

Conclusion: Comprehensive neurological rehabilitation should address sexual function of affected individual to allow them highest level of function and quality of life.

Keywords: Myelopathy, Sexual concerns, Sexual dysfunction, Sexual rehabilitation

INTRODUCTION

The holistic rehabilitation of patients with spinal cord lesions (SCLs) should address sexual function of the affected individuals to enable them highest function and quality of life.

Only few studies have explored the issue of sexual function in patients with myelopathy in India.

There is a negative concept in the community that disabled people are asexual or they do not have interests or concerns regarding sexuality as other abled people.^[1] However, there is evidence that persons with disability, due to myelopathy, are indeed sexually active. Even though the people with myelopathy have sexual dysfunction, they continue to retain need for sexual intimacy.^[2] Sexual rehabilitation is essential

to promote sexual health, encourage positive sex experiences, and relationships for patients with myelopathy.^[2] The purpose of this study was to assess sexual dysfunction and sexual concerns among persons with disability due to myelopathy attending neurological rehabilitation department of a tertiary care Institute in India.

MATERIALS AND METHODS

This was a single-center, cross-sectional, and hospital-based study among male and female patients in the age-group 18–50 years, representing persons with disability due to myelopathy due to SCL, carried out from June 2015 to June 2017. Sampling frame comprised eligible patients attending the inpatient and outpatient clinics of the department of neurological rehabilitation of a tertiary care institute.

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A potential participant was recruited in the study if he had myelopathy operationally defined as lesions of the spinal cord, conus medullaris, and/or cauda equina due to trauma or non-traumatic etiology with at least 3 months since injury or illness and was willing to provide written informed consent for the study. A person with myelopathy with spinal shock, or major cognitive disorder, or sexual dysfunction that occurred before injury or illness was excluded from the study.

The data were collected using a self-designed, pretested, and semi-structured questionnaire by gender specific investigators, by face-to-face interviews.

All the patients were screened for symptoms of anxiety of depression using hospital anxiety and depression scale (HADS). As part of routine care, all the patients received counseling sessions if they had symptoms of depression and/or anxiety. Spinal Cord Independence Measure (SCIM) scores were filled for all the participants. A written informed consent was sought from the participants. The investigators responsible for data collection were trained in administering the study tool, emphasizing on the need for rapport building to elicit intimate questions. The study was approved by the Institute Ethics Committee.

Data collection and statistical analysis

The data were entered in Epi Info version 7 and exported to Microsoft Excel. Following data quality checks, the analysis was done in Stata v.13 (*Stata Statistical Software: Release 13. College Station, TX: StataCorp LP. StataCorp.*). We did a descriptive analysis to present the profile of the study participants and to explain the perspective of the participants.

RESULTS

A total number of 80 participants were recruited in the study, of which 62 (77.5%) were men. There were no non-responders. The mean (standard deviation [SD]) age of the participants was 33.7 (8.6) years, and mean (SD) age at time of injury was 31.4 (8.6) years.

Duration since injury/illness

The median (Interquartile range [IQR]) duration since onset was 17 (8, 36.5) months. There were 16 (20%) patients within 6 months of SCL, 18 (22.5%) patients within 6 months to 1 year, 12 (15%) patients between 1 and 2 years, and 34 (42.5%) patients with more than 2 years of injury or illness.

Neurological level of injury

There were 26 (32.5%) cervical, 8 (10%) upper thoracic (D1-D6), 19 (23.8%) lower thoracic (D7-D12), and 16 (20%) lumbosacral/cauda equina patients according to neurological level classification. Eleven (13.75%) patients did not fit into

any category since they had shown recovery after treatment. According to ASIA impairment score, there were 11 (13.8%) patients of AIS-A, 7 (8.8%) of AIS-B, 9 (11.3%) of AIS-C, 30 (37.5%) of AIS-D, and 16 (20%) of AIS-E. Seven patients could not be classified in any categories. In the clinical presentation, out of 80 participants, 54 (68.4%) patients had paraplegia, 21 (26.6%) had quadriplegia, and four recovered patients did not fit into either category.

Etiological classification

There were 36 (45%) traumatic and 44 (55%) non-traumatic patients. Among 36 traumatic patients, majority (19 patients) were result of fall from height, 12 due to road traffic accident, two due to assault, and one due to fall of heavy object on back. Among 44 non-traumatic patients, inflammation including transverse myelitis was the leading etiology in 17 patients, followed by infection in 13, PIVD in six, and tumor in three patients.

SCIM scores

Ranged from 14 to 100, with a median (IQR) of 72 (47, 90).

HADS

The proportion of participants scoring HADS anxiety >8 was 22 (28.6%), and HADS depression >8 was 35 (45.6%). The median (IQR) for HADS anxiety and HADS depression scores were 5 (2, 9) and 7 (4, 10), respectively.

The details of bladder and bowel management in all the patients were noted. The patients could give more than one response if they were practicing more than one method of bladder and bowel management.

Bladder management

Majority (49 patients) were on clean intermittent catheterization (CIC) followed by self-voiding with or without CIC (21 patients) and six patients had indwelling catheter for bladder management. Five patients were using Crede's maneuver and one patient was using reflex voiding for bladder management.

Bowel management

Forty four patients were using timed program for evacuation, 22 patients were using digital stimulation, seven patients were using digital evacuation, and three patients were using either enema or suppository for managing bowels.

Secondary conditions

That could affect sexual activity were also elicited. Spasticity of limbs was present in 54 patients, while 31 had spasms of

lower limbs. Neuropathic pain was present in 51 patients and six patients had pressure ulcers.

Male sexual function

Among 62 males, psychogenic erection was reduced in 53.2%, absent in 24%, and normal in 14% participants. Reflex erection was reduced in 56.4%, absent in 22.5%, and normal in 14.5% of participants. Ejaculation was absent in 46.7%, reduced in 24%, and normal in 19% of participants. Orgasm was absent in 38.7%, reduced in 27.4%, and normal in 9.6% of study participants.

Female sexual function

Among 18 female participants, genital sensation was absent in 22.2%. Psychogenic genital arousal was reduced in 61%, absent in 5.5%, and normal in 11% of participants. Reflex genital arousal was reduced in 44.4%, absent in 11.1%, and normal in 11.1% of participants. Orgasm was absent in 22.2%, reduced in 16.6%, and normal in 22.2% of study participants.

Sexual desire, activity, and satisfaction

On exploring sexual desire in these patients, importantly, we found that it was unchanged in 41 (51.2%), decreased in 28 (35%), and non-existent in 11 (13.75%) participants. Sexual activity involvement was there in 46 (57.5%) participants and 34 (42.5%) had not involved in any kind of sexual activity after injury/illness. The reasons for not involving in any kind of sexual activity in 34 participants were elicited and we found that medical condition of the patient resulted in no sexual activity in 23 (67.6%) participants. Other reasons were physical limitations (4 participants), no interest, no desire, no partner, lack of opportunity, long-term hospitalization, and fear of injury (one participant each). The sexual concerns of the participants who involved in sexual activity are shown in [Table 1].

DISCUSSION

People with disability receive little information on sexuality in India. They are often regarded as non-sexual. Sexual counseling is yet to become an integral part of rehabilitation. There are only few studies in India that have explored sexual dysfunction and sexual concerns among Indian patients with myelopathy. In one study, authors assessed the physical, psychological, and social aspects of sexuality among patients with spinal cord injury (SCI) through a questionnaire designed to determine different aspects of sexuality. This Indian study observed that complications present in SCI patients, partner dissatisfaction, less partner cooperation, lower self-esteem, and social taboos were main factors resulting in reduced sexual activity. The authors

Table 1: Sexual concerns of participants with SCL who involved in sexual activity after injury/illness.

| Concern | Male (n=62) | Female (n=18) | Total |
|-------------------------------|-------------|---------------|-------|
| Bladder accidents | 12 | 11 | 23 |
| Bowel accidents | 6 | 7 | 13 |
| Spasticity | 11 | 7 | 18 |
| Difficulty in positioning | 26 | 1 | 27 |
| Difficulty in orgasm | 23 | 2 | 25 |
| Fear of infections | 5 | 5 | 10 |
| Fear of injury | 9 | 5 | 14 |
| Less confidence | 34 | 6 | 40 |
| Rejection by partner | 17 | 2 | 19 |
| Satisfaction of partner | 33 | 5 | 38 |
| Absence of genital sensations | 5 | 4 | 9 |
| Neuropathic pain | 7 | 2 | 9 |
| Body feeling less attractive | 26 | 4 | 30 |

suggested that medical complications should be adequately treated, sexual counseling, information, and peer support are intensely required in the country.^[3]

The present study included 80 participants with 62 men with myelopathy, in the age range of 20–56 years. Mean duration of injury was 27 months. Seventy percentages of the participants were married and 55% had children. Even though there was preponderance of cases with cervical injury (32.5%), majority (67.5%) of them had clinical presentation as paraplegia. Non-traumatic etiology (55%) was more common than trauma in present study. The reason may be that the institute is a referral center and more non-traumatic cases are referred to the rehabilitation department.

A person with lesion in spinal cord can experience disruption in number of aspects of sexuality. The disability can cause decreased self-esteem and altered body image. Furthermore, secondary complications such as spasticity and incontinence can interfere with proper positioning, mobility, and pleasure. The dysfunction of erectile function, ejaculation, and ability to reach orgasm is chief complaints in men and decreased vaginal lubrication, genital congestion is major concerns in women with spinal lesions. The sexual rehabilitation should address all the concerns of the patients to allow them to lead an active sexual life and improve their quality of life.^[4]

The SCL causes interruption in the long spinal tracts between cortex and sacral cord and affects erection, ejaculation, and orgasm. Furthermore, the physical disability impedes the ability to embrace, stimulate, and engage in intercourse and maintain urinary and bowel continence during sexual activity.

Studies have shown that level and completeness of injury determine the extent to which erectile and ejaculatory capacity is affected. There are spinal reflex and psychogenic

pathways for erection. After a high lesion, psychogenic erections that are mediated by T12-L2 thoracolumbar sympathetic pathway are lost, but reflex erections remain intact. Low lesions, especially in cauda equina, reduce reflex erectile capacity.^[5]

The erotic sensation spinal pathway is close to spinothalamic tract.^[6] However, one study showed that 38% of patients with complete lesion still retained the ability to experience orgasm.^[7]

The observation from an Indian study revealed that 64% of males with SCI experienced useful erections and 60% had significant ejaculation. They also stated that erections were almost equally present at all levels of SCI, except for those in lumbar region where it slightly higher.^[3] In comparison, another Indian study found that 55% of patients with SCI had normal erectile functions and ejaculation functions were normal or near normal in 40% of total 36 male patients.^[8] In contrast, sexual excitability and orgasm have been rated much lower levels after SCI as compared to before injury.^[9]

However, in the present study, we found psychogenic erection and reflex erection normal in only 14% subjects.

A study indicated that after complete lesions of spinal cord only 4% of men with high lesions and 18% of men with conus or cauda lesions are able to ejaculate.^[5] In our study, we found ejaculation was absent in 46.7%, reduced in 24%, and normal in 19% of subjects. Orgasm was normal in 9.6% of study subjects.

Ejaculation is of concern to patients for fertility issues, those who wish to have children. Poor sperm quality is also one of the concerns in these patients. Various methods such as vibrostimulation or electroejaculation from transrectal stimulation of prostatic nerve plexus allow sperm retrieval for assistive reproductive techniques.^[10]

Sexual desire, activity, and concerns

The SCI causes physiological, psychological, and emotional consequences that complicate sexuality in these individuals.^[11,12] On the subscales general health and social function of quality of life, scores are lower for persons with SCI. As compared to controls, sexual activity and satisfaction are low in the patients after SCI.^[7,13] A study suggested that sexual self-acceptance is essential for development of positive self-esteem.^[14] The sexual satisfaction in patients with SCI has a direct influence on the confidence of these patients.^[15] A study showed that the patient with SCI should be conscious of and use his sexuality as there is a positive correlation between patient's conscious avoidance of his sexuality and realistic acceptance of physical disability.^[16] One Indian study showed that interest in sex after injury was present in 93% males and 65% of female participants with SCI and majority patients acknowledged the importance of sex in life.^[3] In the present

study, among study participants, sexual desire was unchanged in 51%, decreased in 35%, and non-existent in 10%.

Sexual activity and concerns

About frequency of engagement in sexual activity, Kreuter *et al.* reported that about half of the patients in study had sexual activity once a week or more. Out of 286 subjects in the study, majority admitted that SCI had altered their sexual sense and their quality of life would increase on improving their sexual functioning. Intimacy and not fertility are recognized as the primary reason for pursuing sexual activity. They found that bladder and bowel accidents during sexual activity did not deter the subjects from pursuing sexual activity.^[13] However, another study pointed out that bladder and/or bowel incontinence during sexual activity prevented many women from seeking sexual activity and were major concerns.^[3] The feeling that the SCI had altered their sexual sense of self was directly correlated with difficulty in physical and psychological arousal.^[3] The results for involvement in sexual activity from the present study showed that 57% had involved in sexual activity after injury. Those who had not involved in sexual activity after injury, medical condition, were given as the main reason for non-involvement in 67% cases. The present study explored about the sexual concerns from a list of factors commonly studied in other research studies. The most common sexual concerns included fear of bladder accidents, bowel accidents, spasticity and spasms, difficulty in positioning, neuropathic pain, fear of aggravating spinal injury, and less confidence in sexual activity.

Studies have suggested that engagement in sexual activity after injury has a positive impact on quality of life and interpersonal relations for spinal cord injured patients. More attention must be given to sexuality of patients with myelopathy.^[17] The present study too corroborates the same findings.

CONCLUSION

The study concludes that patients with myelopathy have sexual desire and are involved in sexual activity. The comprehensive rehabilitation of patients with myelopathy should include sexual rehabilitation that commences with initiating the topic of sexual function by health-care professionals with these patients, exploring the sexual desire and concerns of the patients, discussion about the problems faced during sexual activity, and problems of fertility. The understanding of sexual issues by patients will promote sexual health and allow highest level of function and quality of life.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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