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Sexuality and Women with Spinal Cord Injury

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Women with spinal cord injury (SCI) have unique concerns and problems related to their sexuality. The purpose of this study is to assess sexual issues in women with SCI, for better management and rehabilitation of such patients. Consequently, 40 such women were interviewed based on a standardized questionnaire. Evaluation of sexual activity, medical problems most significantly interfering with sexual activity, menstruation, pregnancy, child bearing and relationships was done. Interest in sex and importance of sex in lives did not change significantly after SCI. The key concerns after SCI were sexual, bladder and bowel dysfunctions, bed sores, pain, spasticity and satisfaction of partner and cultural taboos. Only, 30% women had received information on sexual matters, that too to isolated problems. There is a distinctive need for clinical attention, education, research and development around gynaecological/reproductive, sexual and urogenital issues unique to women with SCI in India.

KEY WORDS: spinal cord injury; sexuality; women; relationships; sexual concerns.

INTRODUCTION

Sexuality is an important aspect of a person's life. When an individual sustains a spinal cord injury (SCI) there is an immediate impact on the emotional and physical aspect of their sexuality (1). Roughly 80% of spinal cord injuries are sustained by men. As a result, research has historically rarely focused specifically on the needs and issues of the remaining 20% of persons with SCI, who are women (2). Consequently, too few

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women are available in some study samples to warrant separate statistical analysis of their data (3). Alternatively women are excluded purposely from some studies. Spinal cord injury has markedly different effects on the sexuality of men and women. Dramatic changes in men after SCI, particularly erectile dysfunctions and infertility, has merited more attention in the literature (4,5). Because a women's ability to become pregnant, carry and deliver a child is largely unaffected following SCI, it is assumed that her sexuality is similarly unaffected (6–8).

In the recent past, interest in the topic has generated and few systematic studies have been reported (1,2,9–11). These studies have focused on physiological parameters, sexual activities, concerns, interests and impact of aging in women with SCI. Most of these studies have been carried out in western world. Asian countries differ a lot socio-culturally from western countries. Primarily sexual attitudes and values from parents and other that "sex is dirty", punishable for masturbation and double standard's of behaviour for men and women, religious beliefs that sex is only for reproduction and not for pleasure, are the socio-cultural factors affecting sexual functions (12). The ideal for a Hindu women to remain loyal to her husband under all circumstances—Patibrata—has mostly retained a social force in contemporary India (13). So, the findings of these studies from western world cannot be taken as trends in women with SCI in countries like India.

The present study was undertaken to assess sexual issues in women with SCI to enable us in better management and rehabilitation of such patients.

MATERIALS AND METHODS

Participants with acquired traumatic SCI were sought for this study. To be included in the study, an individual had to have a traumatic SCI sustained as least 1 year before the study and be at least 18 years old. Those fulfilling the criteria received written information about the study. About 223 female patients with SCI were treated or followed up at Department of Orthopaedics and Rehabilitation of our institute between January 1999 and December 2003. One hundred and seventeen patients fitted into the inclusion criteria, but only 40 women with SCI showed willingness to participate in the study. Age, etiology, level of injury and socioeconomic status of the sample were comparable to the 117 women with SCI who fitted the inclusion criteria, indicating that this sample is representative of population surveyed.

In order to assess sexuality a questionnaire was developed on the basis of the clinical experience of authors and review of relevant

literature (3,9,10,14). The items of the questionnaire were selected keeping in mind the complex culture and principles of our society. Questions related to social, medical and sexual activity, menstruation, pregnancy and child bearing were included in this. Information on the counseling and/or information on sexual matters was also obtained. Written consent was obtained from all the participants before the interviews and questionnaires were administered. They were assured of the complete confidentiality of their responses. The questionnaire was read to the patient by one of the authors in the presence of female staff.

Findings

Demographics

The mean age of participants was 29.2 years (range 18–54 years). The mean age at the onset of injury was 24.4 years (range 15–37 years). The mean duration of injury was 6.2 years. The mean length of marriage was 7.4 years. Only 12.5% of the participants were postgraduates/professionals. Table 1 contains the detailed socio-demographic information of the sample.

Ten women had quadriplegia and 30 had paraplegia. Seventy percent of the women had incomplete neurological lesions. Ten percent of the women had evidence of mental illness/drug addiction. Table 2 shows detailed injury characteristics and medical information of the sample.

Sexual Activity

A substantial portion of the participants indicated that they had interest in sex (72.5%) and understood the importance of sex in life (87.5%) after injury. Sixty-five percent of the women indicated decrease in the desire for sex and 30% of the women had never indulged in sexual activity after injury. Physical relationship in the form of genital intercourse was practiced by most of the women (60%). Fifty-eight percent of the women who had partner-related sexual activity had problems of bladder and bowel during intercourse. Overall, 55% of the women were satisfied with their post-injury sexual experiences (Table 3).

Although a substantial portion of women felt that their partners had adjusted well to disability related issues, 15 women reported that their partners were never satisfied with sexual activity after injury. Nineteen women rated their current sexual life worse than pre-injury. In addition to the indifferent attitude of partner and medical problems, lack of privacy,

Table 1. Sample Socio-demographic Characteristics (n = 40)

Age in years	
Mean	29.2
Range	18–54
Age of onset of injury in years	
Mean	24.4
Range	15–37
Time since injury in years	
Mean	6.2
Range	1–17
Educational status	
Uneducated	22
Matric	10
Graduate	3
Postgraduate	3
Professional	2
Family type	
Nuclear	12
Joint	28
Length of marriage/relationship	
<1 year	3
1–5 years	12
5–10 years	18
>10 years	7
Marital status	
At the time of injury	
Married	33
Unmarried	7
At the time of study	
Married	30
Unmarried	4
Widower	3
Divorced	3

cultural taboos, presence of attendant and preparations prior to partner related sexual activity were the reasons cited for less satisfaction and worsening of sexual life after injury.

Relationship with Partner

Overall relationship with the partner was cordial in 29 women. Twenty-three women reported that sexual aspect of this relationship was either more cordial or no change. Sixty-four percent of the women reported that they get active cooperation during partner-related sexual activity. In the group of seven unmarried women at the time of injury, 3 got married and reported partner-related sexual activity. Although 86% of these 7 unmarried women wanted to marry. Nine percent of the married women separated/divorced after injury (Table 4).

Table 2. Injury Characteristics and Medical Information

Level of injury	
Cervical	10
Thoracic	18
Lumbar	12
Extent of injury	
Incomplete	28
Complete	12
Evidence of any chronic medical illness	
Yes	6
No	34
Evidence of mental illness or drug addiction	
Yes	4
No	36
Bladder functions	
Indwelling catheter	17
Partially controlled	14
Controlled	9
Flexor spasm	
Present	13
Absent	27
Back pain	
Present	30
Absent	10
Bed sores	
Present	14
Absent	26
Urinary tract infection	
Present	16
Absent	24

Menstrual and Female Hygiene History

Two women were in post-menopausal period and two had undergone hysterectomies prior to their SCI. Two women were pregnant at the time of injury. Of the remaining 34, 39% reported no interruption of their menses following SCI. Out of 22 women reporting amenorrhea; 20 had return of normal menses; the median time until return of menses was 6.6 months. Two women had not resumed menses since injury. No major change in regularity, duration and intensity was observed after injury by majority of women. However, heavier, longer and less regular periods were reported by 28%, 17% and 14% of the women, respectively.

Forty-one percent of the menstruating women used external sanitary pads and 59% used ordinary clothes during menstruation. Bladder and bowel changes were associated with menstrual periods in 55% of the women. They indicated that menses often creates symptoms of bladder infection and diarrhoea/constipation. Diarrhoea frequently associated with

Table 3. Information about Sexuality after injury

1. Do you have any interest in sex (n = 40)	
Yes	29(72.5%)
No	9(22.5%)
Do not know	2(5%)
2. Do you understand the importance of sex in life (n = 40)	
Yes	35(87.5%)
No	4(10%)
Do not know	1(2.5%)
3. Do you find any change in desire for sex in your life (n = 40)	
Increase	2(5%)
No change	10(25%)
Decrease	26(65%)
Do not know	2(5%)
4. Do you have intercourse (n = 40)	
Yes	24(60%)
No	16(40%)
5. How many times do you indulge in sexual activity (n = 40)	
Daily	2(5%)
Every 3rd or 4th day	5(12.5%)
Weekly	8(20%)
Occasionally	13(32.5%)
Never	12(30%)
6. Do you feel satisfied with sexual activity (n = 40)	
Usually	13(32.5%)
Sometimes	9(22.5%)
Never	18(45%)
7. Does your partner feel satisfied with sexual activity (n=36)	
Usually	12(33.3%)
Sometimes	9(25%)
Never	15(41.6%)
8. How does your current sex life compare your sex life before injury (n=40)	
Better	7(17.5%)
No change	14(35%)
Worst	19(47.5%)
9. Do you face any problem of bladder bowel dysfunctions of flexor spasms or any other problem during intercourse (n=24)	
Yes	14(58%)
No	10(42%)

n = Number of women with SCI.

menstrual periods lead to bowel "accidents" and in turn to bladder and vaginal infections.

Contraception

At the time of study 25% of the women reported using contraception. The intrauterine devices (IUD) were used by 70%, condom 30% and contraceptive pills 10% of these women. Of those not using contraceptives, 40% were not sexually active, 6.6% were amenorrheic and, 6.6% out of

Table 4. Relationship with the Partner

1. Overall relationship with partner (n = 36)	
Cordial	29(80.6%)
Uncordial	7(19.4%)
2. Have you noticed any change in sexual relation with your partner in life (n = 36)	
More cordial	6(16.6%)
No change	17(47.2%)
More uncordial	13(36.1%)
3. Do you feel your partner cooperates with you during coitus (n = 36)	
Usually	16(44.4%)
Sometimes	7(19.4%)
Never	13(36.1%)
4. Do you want divorce/break relation with partner you are (n = 33)	
Yes	3(9%)
No	30(91%)
5. Do you desire for marriage in unmarried (n = 7)	
Yes	6(85.7%)
No	1(14.3%)

ignorance. Finally, 14 women (46%) of those not using contraceptives had tubal ligations or hysterectomies (10 tubal ligations + 4 hysterectomies).

Pregnancy and Child Bearing

Total eight pregnancies in 7 women were reported, including two in women who were pregnant when injured. Medical termination of the pregnancy was done in one female who was pregnant at the time of injury due to severe autonomic dysreflexia and uraemia, and other delivered a normal child. The remaining six pregnancies resulted in five live births and one miscarriage.

Of these 8 pregnant women, 4 reported increase in or appearance of bed sores, episodes of UTI and vaginal infections. Other medical problems like back pain, spasticity and hyperreflexia also increased. There were two unassisted vaginal deliveries and forceps had to be used in two. Two patients had caesarian section. The average birth weight of the infants of these spinal cord injured women was 2.4 kg. The smallest baby was 1.2 kg and the largest was 3.4 kg. Only, one baby had problem of cord prolapse during delivery and emergency caesarian section was done in this. All the babies had normal development, thereafter.

Sexual Information

Of the 40 women surveyed in this study, only 12 stated that they had received some information on sexual and psycho-social matters during

rehabilitation or subsequent follow-ups. Although 75% of those received information reported it had been useful, but majority of reported that it was fragmented. None of the women had received a comprehensive counseling at any stage.

DISCUSSION

Women with disabilities have been shown to be more likely than disabled men to be denied access to culturally and age appropriate roles in families, education and employment, to have more difficulty accessing health rehabilitation and financial assistance and to be unmarried, stigmatized, devalued, and treated less humanity (15,16). Society may still prefer to see woman as weaker and more passive and disability support this image (17). Thus they are "doubly disadvantaged" (women plus disabled) (2). Increased demands of aging (adapting physically, psychologically, economically etc.) could put extra burden on the coping resources of these women. In other words, women + disabled + elderly – "triple jeopardy" (2). The most often neglected aspect of their problems is sexuality, which is often believed to be an isolated entity and is an unfortunate thinking.

Women's sexuality is multifaceted, involving relationship, sharing feelings, attractiveness, self confidence and self worth, as well as pregnancy and child rearing (18). Turk and Turk write that modesty, discretion and uneasiness make it difficult to talk about the sexual concerns of women who have spinal cord injuries (19). This study is an attempt to understand this multifaceted sexuality in women with spinal cord injury.

Sexuality

A decrease in sexuality was reported by 65% of the women with SCI, still 70% reported being sexually active after SCI. In 65% of women in series reported by White et al. (11) and 53% women in Zwerner (7) sample of women with SCI, reported being sexually active at the time of study. This clearly relegate that people with disabilities either subjugate their sexual selves (18), or become totally asexual (20).

Twenty-nine (72.5%) women had interest in sex, 35 (87.5%) women understood the importance of sex in their lives, it clearly signifies the utmost desire such women have for resuming sexual activity. Fifty-five percent of the women were satisfied with sexual activity in the present study. Charlifue et al. (9) found that 69% of the women with SCI expressed satisfaction with their post-injury sexual experiences. Compared with other areas of life, sex ranked 10th of 12 areas in series reported by White et al. (11).

A majority of the women (60%) had genital intercourse after injury. We agree with Siosteen et al. (3) that sexual intercourse is a very important factor for individual's general interest in sexuality and willingness to lead a sexually active life. It might also increase interest in sexuality and encourage sexual activity. There were lots of concerns about partner related activity. Fifty-eight percent of the women had problems of bladder and bowel dysfunctions during sexual activity. Bed sores, spasticity and back pain also interfered with sexual activity in these women. These medical conditions can be improved and/or cured with adequate management (11).

Partner Satisfaction and Relationship with the Partner

Forty-two percent of the 36 having partner related sexual activity reported that their partners were never satisfied with the sexual activity and thirteen (36%) reported uncordial sexual relationship after SCI. Reasons cited were either partners not willing to continue sexual contacts or experiment with wide range of sexual expression. Cultural taboos like, it is against norms to have sex with an ill/disabled female also contributed to the sexual dissatisfaction in partners. In other words, women with SCI in India has "quadruple jeopardy" (women + disabled + aging + cultural taboos). Majority of the women (80.6%) had cord cordial relationships with their partners and 64% of the women reported that their partners cooperated with them during sexual activity. These findings further substantiate the views that SCI is not a hindrance to a happy married life (21, 22).

Marriages and Divorce

Marital status has been used as an indicator of adjustment in several studies (23–26) and it has been demonstrated that SCI related disability exert a greater impact on marital status of women than in men. De Vivo and Richards (27) concluded in their study that the following characteristic carry a high risk for divorce among SCI persons: being young, being female, being non-ambulatory, having no children, having a prior divorce and having been injured less than 3 years. Thus, marital stability is a concern in SCI care (28). In the present study on 9% of the women with SCI divorced after injury, while Charlifue et al. (9) reported 22% divorce/separation rate post-injury as compared to 12% pre-injury. Westgren et al. (10) reported separation most common among women under 30 years of age (13/19). The low separation rate in our series could be due

to well integrated society, strongly knit family system and cultural heritage in this part of the world.

Although 86% of the unmarried women wanted to marry, but only 3 (43%) could find partners to marry. These three women were from high socio-economic strata, had higher education standards and adjusted well to their disabilities. A person who strives to minimize the impact of his or her disability on a potential partner makes a more attractive candidate for a long-term relationship than an individual who has come to rely, perhaps to excess, on others (29). Since marriage rate for women with SCI are substantially lower than for general population or men, it is likely that a larger portion of women than men with SCI will face aging process alone (2).

Menstruation and Female Hygiene

Fertility is not significantly altered post-SCI in women of child bearing age. Menses may be altered but, 3–9 months post-SCI, should return to pre-SCI status (9,30). In the present series, the median time while return of menses was 6.6 months. In series of 231 women with SCI reported by Charlifue et al. (9) median time was just over 5 months.

Although menses returned to pre-injury status in majority of the patients in the present study, 28% had heavier, 17% had longer and 14% had less regular menses. Intrauterine devices (IUD) are the most common surgical method used for birth-control in women with SCI. Oral pills are not preferred. Sanitary pads were used only by 41% of the menstruating SCI women and ordinary clothes was used by rest of them. Use of ordinary clothes for sanitary purposes during menses needs to be evaluated, whether it is out of ignorance, due to cultural or economical reasons. Bladder and bowel changes during menses reported by majority of the women with SCI needs special attention. High standards of female hygiene, education and therapeutic interventions may reduce the incidences of such problems.

Pregnancy and Child Bearing

Although few pregnancies occurred in the present series. Fifty percent of these pregnancies were associated with medical complications. Education, treatment and even surgical interventions are required to minimize these medical complications during pregnancy. Pregnancy put an extra burden on the existing resources of the women with SCI. We agree with Charlifue et al. (9) that importance of motherhood to be disabled woman's quality of life need to be acknowledged, and additional physical assistance may need to be offered to make this goal attainable. In India, due to

cultural norms and good family support a pregnant women gets enough assistance and moral support during pregnancy and in rearing the child.

Information and Counseling on Sexual Matters

Only 30% of the women indicated that they have received some information on sexuality since their injury. This information was just like "one shot" approach to isolated problems. Many women indicated that the health care professionals either did not listen to their sexual problems or they themselves were not aware of the solution to these problems. In a series reported by White et al. (11), only 37% of the respondents received information on sexuality since their injury. They stressed that information on sexuality should be integral component of the initial rehabilitation process. Westgren et al. (10) stated that, although the need for such information has long been recognized, health care providers obviously have not yet taken on the responsibility of providing it. Charlifue et al. (9), also reported that sexual information provided to more than half of women with SCI during rehabilitation was inadequate. We are of the opinion that there is a obvious need of a holistic approach to rehabilitation of women with SCI in this part of world.

Limitation of Current Study

Although this unique study is an attempt to understand the sexual aspects and problems of women with SCI, the study relies on information given by women themselves. In India, where, talking of sex in open is considered a taboo, patient may give false accounts, deny aspects of their lives they regard as unacceptable, or reply in a way that they consider socially desirable. However, selecting patients who volunteered to participate in the study and variation of response allowed us to understand possible predictors of sexual adjustment. As there is great heterogeneity in religions, social and cultural norms, in India—multicentre collaborative research might have increased the number of participants and helped in better understanding of cultural bias.

Future Directions

Possible directions for future research include longitudinal designs implemented over longer periods and national level and to more Asian countries, to collect more data on sexuality of women with SCI. Benefits

of this approach would be better understanding of how relationship and satisfaction change over time, looking at differential impact of socio-cultural norms on sexuality, and effect of aging on women with SCI. Further research to decrease the morbidity due to common medical problems faced by women with SCI are required.

CONCLUSION

In conclusion, our study suggests that although women with SCI may have near normal sexual functions, but they have high frequency of sexual problems. They have unique concerns and experience with life with disability. Comprehensive rehabilitation programmes need to be developed in this part of the world, taking into consideration these unique concerns, sexual problems and socio-cultural norms for long-term gains and community reintegration. There is a need of the hour for all service providers to undergo training to recognize and deal with psycho-sexual problems of women with SCI and to provide dynamic attention to these women.

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