

Sexual Dysfunction Following Spinal Cord Injury: the Experiences of Malaysian Women

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Abstract The aim of the study is to assess the changes in sexual life and sexual function in women after spinal cord injury using the validated Malay Version of Female Sexual Function Index. Thirty-three women with spinal cord injury from the Spinal Rehabilitation Unit of a tertiary hospital in Malaysia participated in this study. A comparison was made between this group of women and a control group comprising 34 women matched for age and marital status. The findings showed that 40% of the women continued to have sexual activity after injury. Frequency of sexual activity and desire was lower among women with spinal cord injury, but the ability to achieve arousal, lubrication, orgasm and overall sexual satisfaction did not differ from those of the control group. These findings imply that it is possible for women with spinal cord injury to have an active, satisfying sexual life in spite of changes in sexuality caused by the injury.

Keywords Sexual function · Female · Physical disability · Rehabilitation · Malaysia

Introduction

A spinal cord injury (SCI) is a life changing event. It can affect the body functions in many ways, including changes to sexuality. Sexuality is very intricate; it involves a complex interaction between physical, emotional, intellectual and social aspects [1]. Sexual dysfunction in people with SCI may have both physiological and psychological elements that affect self-esteem and intimate relationship. This can be distressing, leading to social withdrawal and deterioration in existing relationships [2, 3].

Compared to literature on male sexuality following SCI, that on female sexuality is scarce. One reason for this is the male dominance of traumatic SCI, making problems related to females insignificant. However, over the last 20 years, there has been a growing acknowledgement in the SCI literature on aspects of women and their sexual concerns. Numerous

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observational studies have found that women with SCI have lower frequency of sexual activity [2, 4, 5] but only very few studies have compared sexual functioning in women with SCI with able-bodied women. Black [6] and Matzaroglou et al. [7] found that compared to able-bodied persons, married women with SCI are as sexually satisfied as their able-bodied counterparts, whereas Kreuter et al. [8] found women with SCI have lower sexual satisfaction compared to able-bodied persons. It was also found that the motivation for subjects with SCI as well as the control groups to engage in sexual activity were intimacy-based rather than sexual [8].

There is still limited understanding with regards to sexual behavior of women with SCI, particularly in the Asian context, where sexuality is still considered a taboo. A study involving Indian women with SCI reported that despite having near normal sexual functions, there were high frequency of sexual problems, and unique concerns linked to living with disability [9]. Chinese women with SCI were inclined to have negative attitude towards, and unpleasant feelings about their sexuality [10].

In Malaysia, issues related to sexual dysfunction in men and women with disability are largely unexplored. A number of local studies conducted at a government primary health care clinic found that the prevalence of female sexual dysfunction among normal married Malaysian women ranged from 25.8 to 29.6%. The risk factors for female sexual dysfunction were old age, prevalence of medical illness, menopause and low frequency of sexual intercourse [11, 12]. In Malaysian culture, issues related to sex are not discussed openly. Sexual issues are often only disclosed to traditional healers or discussed between spouses in the privacy of the bedroom [13]. Women with SCI differ from able-bodied persons, both in physical and psychological aspects, which have negative impact on sexual functioning. Therefore, there is an urgent need to understand sexual problems in women with disability as it would help physicians to deal with such issues that are part of the former's everyday life. Hence, the objective of this study is to assess the changes in sexual life and sexual response in women after SCI, as to enable us to develop better management and rehabilitation intervention for such patients.

Methodology

Study Design

This was a case–control study conducted at the Spinal Rehabilitation Clinic and Primary Care Clinic, University Malaya Medical Centre (UMMC).

Study Population

The study group comprised women with traumatic spinal cord injury who attended the Spinal Rehabilitation Clinic, UMMC. All women who attended scheduled check-ups, over a period of 12 months (June 2009 to May 2010), and who met the inclusion criteria were included. The inclusion criteria for this study were that participants had to be aged above 18 years, had spinal injury of traumatic etiology, were part of a community and had completed the process of rehabilitation. Exclusion criteria were known recovery and concurrent traumatic brain injury or known psychiatric illness.

For comparison, a control group comprising 34 women was recruited from patients who attended primary care clinic to match the SCI group on individual level by age and marital status. Exclusion criteria include patient suffering from chronic and serious medical and psychiatric illness.

Measurement

The study was carried out in a form of a one-to-one interview, in private, by the same female doctor who is part of the rehabilitation unit. The interview was based on a questionnaire which consisted of two parts. The first part was designed to obtain respondents' socio-demographic and clinical characteristics information, including age, educational level, monthly family income and marital status at time of injury and at time of study. Clinical data included data on age at injury, time after injury, level and completeness of injury, and other co-morbid illnesses.

The second part enquired about sexual activity and changes in sexual function after injury. The researchers used the validated Malay Version of the Female Sexual Functional Index (MVFSFI) to assess different dimension of sexuality [14]. The original Female Sexual Function Index (FSFI) was developed by Dr. Raymond Rosen [15]. It is 19-item questionnaire and covers six basic domains of female sexual functioning: desire, arousal, lubrication, orgasm, satisfaction and pain. The questionnaire assessed sexual functioning or problems faced by the participants during the past 4 weeks. The scoring ranged from 0 (lowest score) to 5 (highest score); the lower the score, the higher the probability of having sexual dysfunction. The MVFSFI was used since it had been validated for Malaysian women who are known to be sexually conservative [14]. Based on a validity study of MVFSFI, the cut-off score had been established as ≤ 9 for sexual arousal disorder, ≤ 10 for disorder of lubrication, ≤ 4 for orgasmic disorder, and ≤ 11 for sexual dissatisfaction. We used the same questionnaire for the women in the control group. Each respondent was required to indicate her sexual function during the 4 weeks prior to the day the questionnaire was administered.

Ethical Consideration

Approval to conduct the study was obtained from the UMMC research ethics committee. In addition, all respondents who fulfilled the inclusion criteria were given explanations about the study and consent was obtained from them. They were assured regarding their anonymity and the confidentiality of the data obtained.

Statistical Analysis

Descriptive statistics were used to summarize the socio-demographic characteristics and medical background of the respondents. Means and standard deviations were calculated for continuous variables. For further analyses, continuous variables were recorded as categorical variables. Proportions in terms of percentages were used in the case of categorical variables. To test the association between socio-demographics and the domain of sexual function variables between the study and control groups, chi-square tests were utilized, and where relevant, Fisher's exact test was used. Analysis of the data was done using SPSS 17 for Windows. For all tests, $p < 0.05$ was deemed statistically significant.

Results

Over the study period, a total of 34 women with SCI met the study criteria. One woman refused to participate, thereby reducing the response rate to 97%. The mean age of the women at the time of interview was 37 years (range 20–68 years). The mean age of the

women at time of injury was 26 years (range 12–63 years). The mean duration of disability was 11 years, ranging between 24 months and 41 years. The socio-demographic data of women with SCI and control are given in Table 1. There was no significant difference in demographic characteristics between the SCI respondents' and the control group's age, marital status and educational levels. With reference to the neurological level, 21% of women had cervical injuries, 46% thoracic and 33% lumbar or sacral injuries. Based on the American Spinal Injury Association (ASIA) Impairment Scale (AIS), 46% corresponded to AIS A, 12% were AIS B, 21% were AIS C and 21% were AIS D. The characteristics of the injury are presented in Table 2.

Twelve respondents with SCI (36%) were single. The top three reasons for staying single included not having met the right person (58%), decreased sexual interest (33%) and fear of bowel or bladder incontinence (17%). Two married couples and one with a stable partner separated after the injury. Two of them claimed that the disability had led to the separation. At the time of the study, 40 percent of the women with SCI (13/33) reported that they were currently involved in sexual relationships and had engaged in sex after the injury. Of the 40%, 62% were married and the remaining 38% had stable partners. Of those who had sex, 38% had done so within 6 months after injury, 15% between 6 months and 2 years and 47% more than 2 years after injury. Significantly more of the SCI women (72%) reported low level of desire compared to the control group ($p < 0.05$). There was no significant difference between level of desire with variables such as age, duration of injury, neurological level and completeness of injury.

Although a greater proportion of the women in the control group (31%) compared to persons with SCI (15%) reported engaging in sexual activity at least once a week, the difference was not significant ($p > 0.05$). It is clear that the frequency of sexual activity was affected after the injury (Fig. 1). There was significant decline in the frequency of sexual intercourse with only 15% of the SCI women engaging in sexual intercourse more than once a week as compared to 62% before the injury ($p < 0.05$), with sexual intercourse at 4.6 times per month pre-injury, as opposed to 1.5 times per month post-injury.

We further analyzed the responses of the respondents who continued to have sexual activity following the injury ($n = 13$) so as to study the changes in sexual function after the injury. Only 8 women with SCI had sexual activity within 4 weeks of the study. The respondents were questioned about their ability to become sexually aroused, their lubrication levels and ability to achieve orgasm. There was no statistical difference on these between the study group and the control group. Results are depicted in Table 3.

After the injury, more than half (63%) of the women with SCI who had been sexually active reported the possibility of them becoming sexually aroused with high levels of arousal during sex compared to nearly all (92%) of the women in the control group. Only one out of the eight respondents with SCI (13%) and none of the control claimed that they had never become sexually aroused. Similarly in the domain of lubrication, only one SCI respondent reported the inability to lubricate, while none of the women in the control group was unable to become lubricated. Of those seven SCI women who did report the ability to lubricate, four (50%) claimed it was not difficult to maintain the lubrication until the end of sexual activity as compared to eight (62%) of the control group. The ability to achieve orgasm was reported by five of eight SCI women (63%) compared with nine out of the thirteen women (70%) from the control group. All women with SCI reported a high satisfactory level with their sexual life compared to 85% from the control group.

Table 1 Socio-demographic characteristics of women with spinal cord injury and control

	SCI women (n = 33)	Control (n = 34)	<i>p</i> -value
Age (at time of study)			
Mean (SD)	37 (12)	37 (12)	NS
Median (range)	35 (20–68)	35 (20–67)	
Race, n (%)			
Malay	10 (31)	20 (58)	NS
Chinese	14 (42)	4 (12)	
Indian	6 (18)	7 (21)	
Others	3 (9)	3 (9)	
Educational level, n (%)			
Primary school	5 (15)	1 (2)	NS
Secondary school	16 (49)	17 (50)	
College	6 (18)	8 (24)	
University	6 (18)	8 (24)	
Monthly family income, n (%)			
<RM1000	9 (27)	6 (18)	NS
RM1000-1999	13 (39)	9 (27)	
RM2000-2999	4 (13)	8 (23)	
> RM3000	7 (21)	11 (32)	
Marital status at time of study, n (%)			
Single	12 (36)	12 (35)	NS
Married	12 (36)	14 (41)	
Steady relationship	6 (18)	4 (12)	
Separated/divorced	3 (10)	4 (12)	
Marital status at time of injury, n (%)			
Single	20 (61)		NS
Married	10 (30)		
Stable partner	3 (9)		
Menopause, n (%)			
Yes	4 (12)	4 (12)	NS
No	29 (88)	30 (88)	

NS not significant, SD standard deviation: $p < 0.05$

Discussion

In our study, forty percent of the women with SCI had engaged in sexual activity after the injury. This percentage was lower compared to existing studies [4, 8, 16–18]. We are not sure whether this lower figure is peculiar to the Asian population as literature related to Asians is scarce. Even though a study involving Indian subjects showed that 70% of women had sexual activity after SCI, only 40 out of 117 eligible participants volunteered for the study [9]. Socio-demographic background, cultural factors and belief systems could explain the differences of our findings compared to the studies carried out in western countries. In SCI, lower level of injury and longer duration after injury have been identified as significant predictors of sexual intercourse [16].

Reduction in frequency of sexual activity seen in our study is consistent with other studies [5, 17]. Only a small percentage (15%) of the SCI women was very active sexually,

Table 2 Clinical characteristics of the women with spinal cord injury

Clinical characteristics	
Age at lesion (years)	
Mean (SD)	26 (11)
Range	12–63
Duration of disability (years)	
Mean (SD)	11 (8)
Range	2–41
Cause of injury, n (%)	
Motor vehicle accident	26 (79)
Fall	6 (18)
Gunshot	1 (13)
Neurological classification, n (%)	
Cervical	7 (21)
Thoracic	15 (46)
Lumbosacral	11 (33)
ASIA impairment scale (AIS), n (%)	
AIS A	15 (46)
AIS B	4 (12)
AIS C	7 (21)
AIS D	7 (21)
Genital sensation, n (%)	
Normal	6 (18)
Less sensation	10 (30)
No sensation	17 (52)

AIS American Spinal Injury Association (ASIA) Impairment Scale

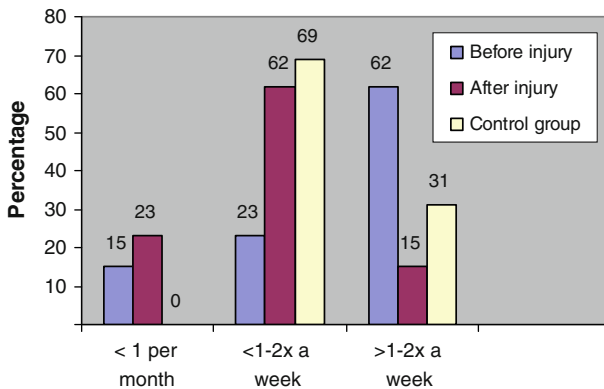


Fig. 1 Sexual intercourse before and after injury in women with spinal cord injury and controls

having sexual activity $\geq 1-2$ times per week as compared to 62% before the injury. Local research shows that almost half of the married women were sexually active and had sexual intercourse at least once a week [12]. The drop in frequency of sexual activity observed in our study is substantial as it has been shown that married couples in Malaysia have sexual intercourse 2.6 times per week compared to only 1.5 times per month in our women with

Table 3 Domains of sexual functioning among women with SCI and control group

Sexual functioning profile	SCI group	Control group	χ^2	p
Sexual desire domain, n (%) ^a				
Women with low desire	24 (72)	16 (47)	4.58	0.03*
Women with high desire	9 (28)	18 (53)		
Sexual arousal domain, n (%) ^b				
Women with low arousal	3 (37)	1 (8)	2.8	0.2
Women with high arousal	5 (63)	12 (92)		
Lubrication domain, n (%) ^b				
Unable to lubricate	1 (13)	0 (0)	1.7	0.3
Able to lubricate	7 (87)	13 (100)		
Orgasmic domain, n (%) ^b				
Women without orgasm	3 (38)	4 (30)	0.1	0.7
Women with orgasm	5 (62)	9 (70)		
Sexual satisfaction domain, n (%) ^b				
Women with dissatisfaction	0 (0)	2 (15)	0.5	0.3
Women with satisfaction	8 (100)	11 (85)		

* Statistically significant, $p < 0.05$

^a $n = 33$ SCI; $n = 34$ control

^b $n = 8$ SCI; $n = 13$ control

SCI [12]. We believe that there are variables which were not investigated in this study such as physical, emotional and psychological make-ups which could have influenced sexual behavior, contributing to the reduced frequency of sexual activity.

Compared to a recent study by Kreuter et al. [8] where more than three-quarters of their sample had sex within 6 months post injury, nearly half of our sample had their first sexual experience 2 years after the injury. This indicates that our women with functional limitation have greater difficulties in establishing, resuming or maintaining sexual relationship within a relatively short time after injury. Whether this is due to these women avoiding intimate relationships or able-bodied persons avoiding women with severe functional limitations was not elucidated. Other possible reasons for such delay could be due to issues in intrapersonal relationships, communication difficulties or both partners feeling insecure and not taking the initiative to involve in sexual activity.

Significantly more of the SCI women reported low levels of desire compared to the women in the control group. As seen in the current study, 82% (27/33) of SCI women has less or no genital sensation. Reduced sexual desire and sexual activity has been positively linked to sensory loss or decreased sensation [8]. On the other hand, sexual desire in SCI can also be affected as a result of normal female physiological phenomena such as menstrual cycle and menopause [19]. A local study had identified menopause as a risk factor for female sexual dysfunction [11]. In the current study too, all four SCI and three menopausal women from the control group claimed low sexual desire. It is not known if menopause plays a more important role in determining the level of desire among aging SCI women. Future research could look into this issue as the number of aging SCIs is increasing due to betterment of delivery of medical care.

Statistical analyses show that there are no differences in terms of sexual function in the domain of arousal, lubrication and reaching orgasm between SCI women and women in the

control group. This is contrary to Matzaroglou et al's findings [7], whereby the SCI women in their study have significantly low scores in the components of orgasm and lubrication. We believe a possible explanation could be that the component of the questionnaire related to this aspect requires recall. Taking into account the low frequency of sexual activity, there could be memory bias. There are no specific definition and methods to determine arousal levels. Hence, it is based entirely on the respondents' interpretation and perception. Moreover, the ability to sense lubrication may not be accurate in the presence of impaired genital sensation.

Approximately half of the women in the study reported that they had experienced orgasm since their injuries. This is consistent with other studies [4, 5, 17, 20]. In women with SCI, the time to reach orgasm is significantly increased compared to able-bodied control subjects, and with greater difficulty and less pleasure [4, 5, 17]. A study by Charlifue et al. [4] found that both breast and genital stimulation can lead to orgasm. The ability to achieve orgasm, however, seems unrelated to the pattern or degree of neurological impairment in women with lesions down to T5 level [21]. On the other hand, women with LMN lesions affecting S2 – S5 segments were less likely to achieve orgasm compared with women who had other types of SCI lesion [22]. We were unable to test the relationship between neurological level and orgasm in our study because the number of women involved in sexual activity was very small.

Although there are mixed findings on level of satisfaction of sexual life among women with SCI [4, 8, 17], it is interesting to note that in this study, all the women with SCI reported a high level of satisfaction with their sexual life. This reiterates that even though there are changes in sexual activity and response, women with SCI can lead a satisfactory sexual life [7, 8, 17].

This research has several limitations. Even though the response rate among eligible subjects was satisfying (97%), the sample size is still small. Studying only the women with SCI who are sexually active yielded even smaller numbers and was not adequate for statistical analysis. Thus, the results might not be representative of the true SCI population. Secondly, this study used the Malay validated version of FSFI. The problem in using the FSFI for SCI-related studies is the reliance on data related to sexual activities over the past 1 month. In our sample, 5 subjects did not answer the MVFSFI component as they did not have sexual activity within the 4 weeks prior to the study. Another weakness in this study is memory bias; some women with SCI may have had their last sexual activity 3 to 4 weeks prior to the study. Under such circumstances, the changes reported in sexual responses may not be accurate.

Despite these limitations, this is the first study to assess sexual functioning among women with disability in Malaysia. We believed that we have gleaned some knowledge from our data that is relevant in improving our sexual rehabilitation services for women with SCI. Because of the relatively small number of women with spinal cord injuries and even smaller numbers experiencing the problem described in this report, there is a need to replicate the study with multi-center collaborative effort.

Conclusion

This study has shown that the nearly half of the women in the sample experience active sexual lives after sustaining SCI. Despite having marked reduction in frequency of sexual activity and desire, the ability to become aroused, lubricate and reach orgasm did not

change significantly after SCI. It is still possible for women with SCI to have an active satisfying sexual life in spite of the many changes in sexual life caused by the injury.

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