Original Article

Sexual issues in a sample of women with spinal cord injury

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Study design: Semistructured interview.

Objectives: To assess the degree of participation in sexual intercourse of a sample of women with spinal cord injury (SCI) in our community, to establish to what extent their sexual lives have been affected in comparison to before the injury, and to search for those factors that may have a major influence on both aspects.

Setting: Spinal Cord Injuries Unit, A Coruña, Spain.

Participants: A total of 37 women, average age 40 years, time since onset average 10 years.

Results: In all, 62% claimed regular sexual activity after the injury. The women who suffered the injury before reaching the age of 18 years run a higher risk of not having physical relationships than those who were above that age when they incurred the SCI ($P=0.04$, OR 4.75). We discovered a significant drop in the frequency of intercourse ($P=0.003$) and the ability to reach an orgasm ($P=0.008$), after the injury. Of these women, 69% were satisfied with their current sexual activity and 77.4% considered the information they received from their doctors on the changes the SCI would cause in their sexuality to be either insufficient or nonexistent.

Conclusions: There is a noticeable decrease in the frequency of intercourse as well as a significant reduction in the capability of reaching orgasm. Despite these changes and problems that ensue during intercourse as a result, most show satisfaction with their current sexual lives. On the other hand, the occurrence of the injury before the age of 18 years may imply a greater risk of not having an active sex life in adult years. We consider it is essential to provide the appropriate sexual information during the process of rehabilitation, aimed at helping women with SCI to adapt to their new situation.

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Introduction

The literature regarding the sexuality of those with spinal cord injury (SCI) concerns predominantly the male cases.¹ There are few studies which assess the impact that SCIs have on the sexuality of women, and the majority which do so are focused primarily on reproductive aspects.^{2–5} The reasons behind this fact may probably be explained by the much higher incidence of SCI in men than in women,^{5–7} by the belief that female sexual dysfunction is less problematic given their supposed passive role during sexual intercourse,^{5,8} and by the greater objectivity of loss of erection, ejaculation, and male fertility.^{6,7}

Sexuality constitutes a fundamental part of people's lives, integrating physical, emotional, intellectual, and social aspects.⁵ A spinal injury may affect the patient's

sex life not only due to the physical impairments, but also owing to a lower self-esteem and self-image, as well as the attitude that both society and their partners show towards disability.⁹ There is still a tendency in society to regard the disabled as asexual, always dependent on others and unable to have physical relationships on equal terms.¹⁰

Various reports have been published on the characteristics of the women's sexual activity, both before and after suffering a spinal injury. The percentages published of women who are sexually active after having suffered SCI range between 53 and 67%,^{1,7,11,12} indicating a significant decrease in the frequency of sexual activity.^{3,6,12} Jackson and Wadley¹¹ reported that the number of years postinjury and level of injury were predictive of intercourse, while extent of injury was not. Charlifue *et al*⁶ find that those women with a complete tetraplegia have the most sporadic sexual encounters,

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yet without significant differences with regards to paraplegic women or those with incomplete injuries.

The capacity for some women with both complete and incomplete SCI to achieve orgasm was reported in several studies. Jackson and Wadley¹¹ in their report suggest that subjects with incomplete injury were more likely to report orgasm than those with complete injury. Sipski^{3,13} does not find any relationship with neurological levels nor the ASIA grade, although in another study¹⁴ reported that an intact sacral reflex arc is necessary for experiencing orgasm through direct genital stimulation.

The aim of this study is to assess the degree of participation in sexual intercourse of a sample of women with spinal cord injury in our community, to establish to what extent their sexual lives have been affected in comparison to before the injury, and to search for those factors that may have a major influence on both aspects.

Method

The participants in our study are women with SCI in Galicia, an autonomous region located in the northwest of Spain. The patients were recruited in the outpatient clinic of our hospital, whose Spinal Cord Injury Unit (SCIU) serves as a reference for the whole of the studied region. All women who attended scheduled check-ups, over a period of 6 months, and who complied with the criteria for inclusion in the study, were consecutively included. The criteria for inclusion were as follows: spinal injury sequelae of any etiology, aged between 18 and 65 years at the time of the study, living in the community and having completed the process of rehabilitation.

The study was carried out in the form of a semistructured interview, personal and private, always conducted by the same female doctor of the SCIU. The interview was based on a questionnaire with demographic items, regarding the SCI, frequency of sexual intercourse and capacity for experiencing orgasm pre- and postinjury, reasons for absence or decreased frequency of intercourse, problems associated with sexual intercourse, birth control methods, sexual information received and overall sexual satisfaction. Other sexual practices such as masturbation or oral sex have not been taken into consideration.

The patients were previously notified of the purpose of the study, and they were assured confidentiality of the data gathered during the interview.

In all, 54 women were surveyed. Of them, 17 were excluded for the following reasons: under 18 (two) and over 65 (13) years old, and refused to participate (two). The number of patients who participated in the study totaled 37. The average age of the patients at the time of the study was 40 years 6 months, ranging between 18 and 65, and 30 years of age at the time of the injury, including injuries incurred from birth until the age of 62 years. The duration of the injury varied between 10 months and 37 years, with 74% of the cases within a time span of 2–10 years. With reference to the

neurological level, the sample was distributed as follows: cervical 18.9%, dorsal 54.1%, and lumbosacral 27%.

The low percentage of cervical injuries in our sample does not correspond with our epidemiological data, yet there was no deliberate selection of patients nor was there a reduced frequency of tetraplegic women attending check-ups. Possibly the reason behind this low percentage lies in the relatively short 6-month period over which the patients were consecutively surveyed.

With reference to the American Spinal Injury Association/International Medical Society of Paraplegia (ASIA/IMSOP) impairment scale 51.4% correspond to grade A, 10.8% to grade B, 8.1% to grade C, and 29.7% to grade D. As far as independence in daily lives is concerned, 67.6% of the patients were independent, 21.6% were partially dependent, and the remaining 10.8% of the patients were completely dependent. With regard to the management of the neurogenic bladder, 51.4% were on intermittent catheterization, 10.8% had an indwelling urinary catheter, and 37.8% had voluntary control of micturition. At the time of the study, 54% of the women were either married or in a stable relationship. Regarding the different levels of education, 48.6% had primary studies, 21.6% secondary studies, and the remaining 29.5% had higher studies.

In the statistical study of the data, we have used χ^2 -test, Student's *t*-test, exact statistics of Fisher, McNemar and Wilcoxon, considering only those values with $P < 0.05$ as significant.

Results

Of the 37 women interviewed in our study, 62% claimed regular sexual activity after the injury until the moment of the survey. Of those women who did not engage in sexual activity, the vast majority (77%) stated that the principal reason behind this was the lack of a stable partner.

Comparing the group of women who were sexually active after the injury to those who were not, we have observed that variables such as the neurological level, the ASIA grade, the level of independence, or the type of bladder management did not have an influence on physical relationships. As regards the differences according to the duration of the SCI, although there is a higher incidence of sexual activity in those whose injury duration lies between the period of 2–10 years, these differences are not significant.

In all, 10 women suffered the injury before reaching the age of 18 years (ranging from birth to 17 years) with a mean of 18.7 years postinjury (10 months–37 years). In this group, six patients were 12 years or older at the time of injury. Two reported having intercourse before the injury and another two after the injury (only one reported having had regular sexual activity at the time of the interview). The age at the time of the injury was indeed an influential factor on sexual activity after the lesion. The women in our sample who suffered the injury before reaching the age of 18 years run a higher risk of

not having intercourse, than those who were above that age when they incurred the SCI ($P=0.04$, OR 4.75).

We have precisely analyzed the group who engaged in intercourse before the lesion and who, after the injury, continued to have physical relationships ($n=19$), in order to study the changes that SCI had brought about in their sex lives. We discovered a significant drop in the frequency of intercourse after the SCI ($P=0.003$) with an average of 9.9 times per month preinjury as opposed to 4.2 times per month postinjury. We have not observed any relationship between the frequency of sexual activity and age, nor with the characteristics associated with SCI such as neurological level, the ASIA grade, functional independence, the type of bladder management or injury duration. Among the reasons stated to justify the decrease in sexual activity, the most frequently put forward was that of a drop in libido (60%), generally in relation with a loss of sensitivity in the genital region. Other reasons were discomfort (20%), disturbed body image (17.4%), spasticity (10%), no opportunities (8.7%), not important (8.7%) and no partner (4.3%). A total of 70% percent are still with the same partner.

The ability to reach an orgasm also decreased, from 95 to 53%, after the injury ($P=0.008$). Of those women who were able to reach an orgasm, 72% claimed that it was less pleasurable and more difficult to reach than before the injury. We have not found any relationship between these facts and characteristics of the injury, such as neurological level, ASIA grade, or the injury duration.

We have researched the problems experienced during intercourse by the women who were sexually active after the injury ($n=23$), with urinary incontinence and positioning difficulties being the most common (Table 1). Our findings show that 69% of these women were satisfied with their current sexual activity. Within this group of women, we detected that 47.6% do not use any method of contraception or simply use natural methods, such as *coitus interruptus* or the Ogino method, relating this fact to the lower level of education ($P=0.0006$). The most commonly used birth control method was the condom, present in 38% of the cases.

Of all the women surveyed, 77.4% considered the information they received from their doctors on the

changes the SCI would cause in their sexuality to be either insufficient or nonexistent.

Discussion

Although the percentage of sexually active women with SCI in our sample is to be found within the range published in other studies,^{1,7,11,12} we have objectified that the occurrence of the injury before the age of 18 years presents a greater risk of women not having a physical relationship in adulthood. Nosek *et al*¹⁵ adopt the same hypothesis as the starting point in their study, but conclude that differences do not exist according to the age at the time of the injury. In this study, women with physical disabilities of several etiologies (not only SCI) are included, therefore other variables related to the disability type could be influencing the result. On the other hand, Westgren *et al*⁷ and White *et al*¹ find a greater participation in intercourse in younger women and in those who had suffered SCI at earlier ages. In White's report, the mean age was 21.8 years in women who had had intercourse after the injury, compared to the mean age of 35.1 years who had not, but he does not provide specific information for different age groups, as such, we are not able to compare there data to that of our study. Cultural and political education could explain the differences of our results compared to the study carried out in Stockholm by Westgren *et al*.⁷ Sweden is a country that has a long tradition of sexual education, both in schools and the community in general, with an open attitude towards sexual issues, which, we consider, helps women with SCI to keep an active sexual life.

Parents do not usually speak with their disabled daughters on the topic of sexuality, and this conveys, for them, the message that disabled women are not able to be sexually desirable,¹⁶ which is often reinforced by the deterioration of their self-esteem and self-image.^{9,17} The overprotective family environment can deprive these children of their privacy and independence, hindering the acquisition of sexual knowledge. All these factors could imply a more limited social life, thus reducing the possibilities of encountering a partner. The principal reason given by those women who did not have intercourse after the injury was the fact that they did not have a stable partner, a fact that seems to confirm the above mentioned. Although some authors find an advantage in the young age of these patients, owing to the fact that they have not yet established any sexual habits and there is a greater flexibility redefining their sexual aims and expectations,¹⁸ we consider that these patients are candidates for a specific therapeutic program that helps them to achieve an active and satisfactory sexual life in the future.

To discover to what extent the sexual lives of women change after a SCI, we have individually analyzed the group of women who were sexually active before the injury and who continue to remain so afterwards. A noticeable drop in the average number of sexual encounters per month clearly stands out, diminishing

Table 1 Problems associated with sexual intercourse

	Preinjury (%)	Postinjury (%)
Pain	5.3	16.7
Lack of vaginal lubrication	0	21.7
Vaginal bleeding	0	8.7
Difficulty with positioning		30.4
Increased spasticity		17.4
Bladder incontinence		30.4
Autonomic dysreflexia		0
Problems with indwelling catheter		5.26

from an average of 9.9–4.2. Other authors^{3,6,12} have discovered decreases in the frequency of intercourse of women with SCI in comparison to before the injury. This decrease in the frequency of sexual activity, which affected most participants in the study group, derived in some cases to the point where sexual activity came to a complete halt. The fact that no relationship was found between the decrease in the frequency of intercourse and the characteristics of the injury leads us to believe that there are variables not contemplated in this study, most probably of emotional and psychosocial nature, and which have an influence on sexual behavior. Nosek *et al*¹⁵ highlight the importance of these psychological and social factors in the sexuality of disabled women as one of the principal findings of their study.

On questioning the women about their impressions on the cause of the lower frequency of sexual activity with respect to before the injury, most claimed a drop in libido in relation to a loss of sensitivity in the genital region. We believe that this is a relatively important aspect of sexuality that we should address during the period of hospitalization. There is a certain social tendency to situate one's sexual pleasure in the genital region, and to consider intercourse as being the sole aspect of sexual activity. This tendency may cause frustration or at least a decrease in the quality of the sexual activity in those people who are not able to perceive any sensation in that region. A woman with SCI must learn to explore and investigate the erotic possibilities that lie in the rest of her body¹⁷ and to understand sexuality in a wider sense, not only limited to intercourse.⁹

Similarly, the ability to achieve an orgasm also diminishes considerably after the injury. The majority of women who reached an orgasm claimed to do so less frequently, with greater difficulty, and they described it as less pleasurable than before the injury. Sipski^{3,13,14} publishes similar percentages in several of her studies, and congruent to our findings, does not find any relationship with neurological levels nor the ASIA grade. In one of their studies, Sipski *et al*¹⁴ found that women with SCI require more time and more intense stimulation to reach orgasm than the women in the control group, yet the subjective characteristics of the orgasm did not vary between the two groups nor with respect to their previous experiences. Charlifue *et al*⁶ obtain a similar percentage, and also comments that the women required more stimulation time, they reached orgasm less frequently, and that they experienced less intense orgasms than previously. Furthermore, they find that paraplegic women are able to reach orgasm with more ease than tetraplegic women. In our study, we have not encountered any differences according to the different levels or ASIA grade. Jackson and Wadley¹¹ find a drop in the ability to reach orgasm, decreasing from 79.1% preinjury to 37.3% postinjury, with significant differences according to level, scope, and duration of the injury.

On the basis of investigations that have identified phosphodiesterase type 5 in human clitoral tissue¹⁹ and

the excellent results obtained with sildenafil and the treatment of sexual dysfunction in men with SCI,²⁰ studies have been undertaken to establish if this drug is able to increase sexual arousal in women with SCI.^{8,21} The first controlled study was carried out by Sipski *et al*²¹ and revealed a partial improvement in the arousal and orgasmic phases of sexual response with the sildenafil. Other studies have been carried out in women without SCI with positive results, but for the moment its use has not been approved by the Food and Drug Administration (FDA) for female sexual dysfunction.²²

Women with SCI are faced with numerous problems during intercourse, urinary leakage and difficulties with positioning are the most commonly encountered in our study. Nonetheless, as the women themselves stated, these problems were never a reason for a decrease in sexual activity, as easy solutions were found, such as maintaining positions that required minimum effort or emptying the bladder prior to intercourse. Another problem that commonly arises is that of vaginal dryness, which can be solved with a lubricant preferably on the acid side of the pH-scale so as not to damage the natural vaginal environment.¹⁵ The problems these women suffer during intercourse do not differ from those mentioned in other studies,^{7,11} the absence of episodes of autonomic dysreflexia caused by intercourse being the sole difference to highlight in our study.

With respect to satisfaction with their postinjury sexuality, 69% of the women claimed to be satisfied with their sexual lives. This percentage is similar to that found by Charlifue *et al*⁶ and greater than the 48% found by Sipski and Alexander.³ In other studies⁴ reference is made to a lesser degree of sexual satisfaction in women with SCI as opposed to able-bodied women.

The majority of women in our sample classified the information they received as insufficient or nonexistent. Many of the published studies on the subject with women with SCI do not address the sexual aspect of this condition,^{1,6,7,12,23} which highlights the fact that those professionals who provide care and/or rehabilitation for women with these lesions are usually not involved in the important process of sexual readaptation. It is our belief that it is more difficult to adapt without help, and consequently we are in favor of a structured plan of information and integration of women with SCI in their new sexual lives. We also consider that a plan of joint information for stable couples would be effective, dispelling many doubts and fears that may worry the partner of a woman with SCI.

We acknowledge certain limitations of our research, namely the small sample used and the absence of a life quality scale, as well as the possible bias in results due to the low percentage of tetraplegic women.

Conclusions

More than half of the women included in our sample have an active sexual life after the SCI, although there is a noticeable decrease in the frequency of intercourse

as well as a significant reduction in the capability of reaching orgasm. Despite these changes and problems that ensue during intercourse as a result, most women show satisfaction with their current sexual lives.

On the other hand, the occurrence of the injury before the age of 18 years may imply a greater risk of not having an active sex life in adult years.

We consider that it is essential to provide the appropriate sexual information during the process of rehabilitation, aimed at helping women with SCI to adapt to their new situation.

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