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Female Sexuality After Spinal Cord Injury

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A questionnaire investigating women's perception of sexuality and sexual behavior after spinal cord injury was mailed to all 74 women followed by the Central Pennsylvania Spinal Cord Injury Program. 37% responded. (After spinal cord injury, women rated sex as being 26% less important to them, but also felt 23% less satisfied with their sexual lives.) 52% were able to achieve an orgasm after their injury, but half of the women who experienced orgasm felt it was different after spinal cord injury. The biggest perceived change after spinal cord injury was perceived attractiveness of their bodies. Women rated their bodies as being only half as attractive after their injury as before. Female sexuality remains a vastly underresearched area in spinal cord injury, and much more data is needed to counsel women about sex after their injury. All members of the rehabilitation team need to be comfortable addressing issues of sexuality with their patients.

KEY WORDS: spinal cord injury; orgasm; female sexuality.

Remarkably little has been written about female sexuality after spinal cord injury. While male sexuality is more often discussed, with extensive research on erectile aids for men available, female sexuality has been largely ignored. The reasons for this are not entirely clear. Since only one in five spinal cord injuries occurs in a woman, this lack of information may reflect a lack of knowledge in a specialized area in a less affected population. However, medicine has

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ignored sexuality and especially female sexuality far too often, and the lack of data concerning female sexuality may simply reflect this overall trend in medicine. We decided to study sexuality in our female patient population to provide more complete care for them in the years of follow-up that ensue after a spinal cord injury.

Sexuality, of course, remains an important part of life after spinal cord injury and discussion and education about sexuality must be an integral part of the rehabilitation process. Weiss and Diamond's classic work showed the percentage of women involved in sexual activities actually increases slightly after spinal cord injury[1]. If the goal of rehabilitation is to return the injured person as fully as possible to their premorbid level of functioning, this must apply to sexuality as well. In rehabilitation, sexual adjustment seems to follow one's overall adjustment to injury[2] and it makes sense as well that better sexual adjustment may aid overall adjustment to spinal cord injury.

Discussions of female sexuality after spinal cord injury have often focused on issues concerning pregnancy after injury, marital adjustment, and the possible presence of orgasm in injured patients. Berard reviews in great detail female sexual response and aspects of pregnancy and delivery in women with spinal cord injuries[3]. Francois and Maury (1987) and others present similar material in less detail[4].

Several articles studied the quality of marital relationships in spinal cord injured populations focusing on divorce rate as a measure. 25 years of study have not reached a definitive conclusion about the stability of marriages in the spinal cord injured compared to their able-bodied counterparts. However, most studies show that post-injury marriages are more stable and more successful than marriages began before a spinal cord injury affects one member of the couple.

In his early study, Guttman showed the divorce rate for women married at the time of their injury (7.3%) is not different from the divorce rate for women married after their injury (7.0%)[5]. These rates were slightly higher than general divorce rates in Great Britain at the time of the study. In a carefully designed study of marriages using both local and national spinal cord injury data, DeVivo and Fine show spinal cord injured victims are less likely to marry in the three years after a spinal cord injury than the general population, and are more likely to be divorced in the same period[6]. This study, however, did not separate out female patients, presenting data for both sexes.

However, other work shows the divorce rates in spinal cord injured patients as a whole to be lower than rates in the general U.S. population. Studying only male patients, El Ghatit and Hanson found divorce rates for spinal cord injured patients are slightly below U.S. rates, and divorce rates for those married at the time of injury and those married after their injury were almost identical[7]. Looking at spinal cord injured women, Weiss and Diamond found

no change in the proportion of husbands who were accepting of their wives' attitudes toward sex before and after their spinal cord injury[1]. However, Crewe, Athelstan and Krumberger while showing the overall divorce rates in spinal cord injured of both sexes are a bit lower than the U.S. population found that divorce rates were lower in those married after injury than marriages existing when one spouse became spinal cord injured[8]. Moreover, they found that post injury marriages seemed happier and featured a better sex life for its members. A follow-up study again found that post injury marriages were socially, sexually and emotionally happier than marriages begun before a spinal cord injury affected a spouse[9].

So, while the data remain quite controversial, one cannot with confidence state that marriages among the spinal cord injured more often lead to divorce. Post injury marriages, where both partners know ahead of time exactly what "for better or worse" means seem to be happier and more stable.

Some work has also been done investigating the possibility of orgasm in women after spinal cord injury. Early work seemed to ignore reports from patients, stating that orgasms cannot occur with a complete lesion but also simultaneously report subjective orgasm in women with complete spinal cord injuries[10]. The concept of "phantom orgasm" was introduced to explain the presence of subjective orgasm in women whose genitals were insensate[11]. However, it seems clear that some women, even with complete injuries can experience the psychological and even physical sensations of orgasm. In their series of 31 women, Bregman and Hadley found that 3 women experienced the same orgasm after their injury as before. Of those who did not experience the same orgasm, 4 women experienced intense psychological pleasure and 22 experienced intense physical pleasure during sex after spinal cord injury[12]. Because the senorgasm is a complex event involving not only neurologic but also psychologic and interpersonal input it follows that even if one source of input in the sexual response were removed, the others could still be present and enjoyed. Moreover, in an interesting study, Axel found that in her sample of 36 women, 56% experienced the same discomfort with their menstrual period as before their spinal cord injury. 22% had less discomfort, and 22% had more discomfort[13]. So this "sexual" experience was often experienced to be the same after spinal cord injury as well. After spinal cord injury then, women can often experience orgasm although the appreciated sensation may be different.

Even with this information, however, large gaps of information concerning female sexuality remain. Because rehabilitation is aimed to return the individual as much as possible to her premorbid level of functioning, we sought to compare sexual attitudes and behavior after spinal cord injury to before injury. This comparison would be practically useful in a rehab setting to ready the patient for her new life after injury. With more information about what to expect in her new life, she would be better able to manage problems with her

new sexuality. We sought information on social and sexual practices after spinal cord injury as well as subjective measures of how enjoyable that new life was, socially and sexually, compared to life before spinal cord injury

METHODS

A questionnaire addressing changes in sexuality after spinal cord injury was mailed to all 74 women followed by the Central Pennsylvania Spinal Cord Injury Program and the Penn State University Rehabilitation Center. The questionnaire was anonymous. A repeat mailing was sent to all patients who did not return the original questionnaire to maximize the number of responses. 27 women, or 37% of the total returned usable data.

The questionnaire was designed to compare sexual attitudes and practice assessed subjectivity by the patient. Questions were rated by respondents on a five point scale rating each issue as they experienced it before and after spinal cord injury. The mean of the rating for each question before injury is compared to the mean of the rating after injury. The perceived change experienced by the patients after injury is then presented and discussed.

74% listed their level of injury and of those, half sustained paraplegia, and half sustained quadriplegia. 78% commented on whether their injury was complete, and of these, 62% suffered an incomplete injury, and 38% suffered a complete spinal cord injury. Only 17, or 63% of the respondents identified both the level of injury and whether it was complete on the questionnaire. Despite reassurances that any individual response would be anonymous, many patients did not want to identify the exact nature of their injury presumably because they feared they would then be more readily individually identified. While this is understandable, this smaller number made interpretation of the data according to level of injury very difficult. Of the seventeen who identified the exact nature of their injury, four suffered a complete paraplegia, four sustained an incomplete paraplegia, four sustained a complete quadriplegia, and five sustained an incomplete quadriplegia. Because the numbers of each type of injury are so small, for the most part the data will be analyzed and addressed as a whole. Where possible, differences between types of injury will be presented and analyzed using an ANOVA, one way analysis of variance. Level of significance was selected to be 0.05. Participants in the survey were more open about other questions that did not identify them and completed the rest of the survey.

89% of those surveyed were living with family members at the time of the survey. 67% were married, 22% were single, and 11% were divorced or widowed. 52% of the sample had children. The mean age of the respondents was 40, and the median age was 33.

56% of the sample had finished high school, and 37% had finished college. 67% were unemployed at the time of the survey.

RESULTS

After suffering a spinal cord injury, women are socially and sexually less active. The women we surveyed felt they went out socially 23% less, and enjoyed their social time 25% less after their injury. Sexual activity was 19% less frequent, and was 26% less important after their injury. Even though sex was less important, it was also less satisfying. In fact, our patients felt sex was 23% less satisfying for them compared to before their injury. They also felt 15% less satisfied with the frequency of sex after their injury.

Physical difficulties interfered with sex 57% more after their injury than before their injury. Despite these difficulties, the women surveyed felt they satisfied their sexual partners on average, 93% as well as before their injury. Only 15% felt their injury led to the break-up of a relationship, and only half of that small number felt sexual difficulties contributed to the break-up of that relationship.

As might be expected, complete quadriplegics felt they experienced a much bigger difference in their social and sexual lives after their injury than incomplete paras or quads, or complete paraplegics. After their spinal cord injury, women suffering from a complete quadriplegia said they enjoyed their social life significantly less than women with an incomplete paraplegia ($p < 0.05$) with complete paras and incomplete quads rating their social lives in between the two groups. These differences were not significant. Accordingly, women with complete quadriplegias said sex was much less important to them than women with incomplete paraplegia ($p < 0.05$), and that they were less satisfied with their sex lives ($p < 0.05$) than incomplete paraplegics. As before, complete paraplegics, and incomplete quadriplegics had non-significant differences in rating their sexual lives with the groups. Women with complete quadriplegia also rated the frequency of sexual activity as much less than other levels of injury but this difference did not reach statistical significance.

After spinal cord injury, sexual practice does not seem to change as much as sexual frequency. Generally the same types of sexual activity are pursued after injury as before. Intercourse remains the most pleasurable sexual act for the women surveyed both before and after spinal cord injury. However, more women rate kissing and caressing as being most pleasurable act after their injury than before (see Table 1). 24 of the 27 women surveyed responded to questions about oral sex and they showed no clear change in frequency of oral sex. Ten never engaged in oral sex and of the remainder, 5 patients engaged in oral sex less after their injury than before, 3 the same, and 6 engaged in oral sex more often after their injury than before. Only one woman engaged in anal sex after her injury. In general, there was a decrease in masturbation after spinal cord injury. 24 of 27 women responded to questions about masturbation, and of this number, 17 did not masturbate after their injury. Five women said

Table 1. Most Pleasurable Sexual Act

	Before Injury	After Injury
Intercourse	52%	41%
Kissing and Caressing	19%	30%
Masturbation	11%	11%
Oral Sex	7%	7%
Other	11%	11%

they masturbated less often after their injury, one said she masturbated the same amount, and one masturbated more often after her injury than before.

Having a spinal cord injury does not necessarily prevent a woman from being orgasmic. 52% (14 of 27) of the women surveyed were still able to have an orgasm after their injury. However, half of the group (7) said their orgasm was very different than what they experienced before their injury. Three women said their orgasm was exactly the same and two said their orgasm was similar after their injury. Two of the women who remained orgasmic did not comment on the quality of their orgasm.

Looking at the 17 women who identified their spinal level and completeness of injury provides intriguing data on the question of orgasm after spinal cord injury. Only one of four complete paraplegics, and only one of four complete quadriplegics were able to experience an orgasm after their injury. Two of five incomplete quadriplegics, and all four incomplete paraplegics were able to experience post-injury orgasms. Thus, as expected, full sexual sensation and enjoyment was best in those with incomplete injuries, especially in incomplete paraplegias, and worst in those with complete injuries.

The biggest change noted by the survey was not the frequency or quality of sex or of their social lives. Instead, the largest difference was the worsening of their body image after spinal cord injury. After injury, women felt their bodies were only 52% as attractive as before. This is a truly remarkable change considering that while physical function had decreased, overall physical appearance had not changed markedly. Since body image, or perceived attractiveness is certainly an important factor in sexuality, this change in body image and resultant reduction in perceived personal attractiveness may play a role in both a reduction of sexual activity and enjoyment.

DISCUSSION

Some caution must be used in generalizing our data to the entire female spinal cord injury population. All patients studied were followed by one center—and this may entail some selection bias since all live in the same locale.

Moreover, since only 37% of the patients responded to the questionnaire, this data cannot with certainty be applied to the entire group. In addition, this examination of social and sexual lives is retrospective. After an injury, patients may view their pre-injury lives as being better or easier than they, in fact, were. The present hardships of life with their injury may cloud their perceptions. Finally, all responses to all questions were entirely subjective reports of a subjective experience—sexuality. However, since so much of sexual life is entirely subjective, this is not inappropriate. With these cautions in mind, however, much can be learned from the data.

To being, the disability and extra work of a spinal cord injury decreases available time that can be used socially and sexually. Our patients were less socially and sexually involved than before their injury, and were dissatisfied with this difference. Although they were less satisfied with their sexual life, they felt they satisfied their partners almost as well and only 15% felt their injury led to the break-up of a relationship. This data would tend to agree with data presented in the introduction showing marriages in the spinal cord injured were not more likely to end in divorce. More research work, however, is clearly needed to clarify this issue.

Complete quadriplegics are more disabled physically, and more disabled sexually. Among the different groups of injuries—complete and incomplete paraplegics and complete and incomplete quadriplegics, those suffering from a complete quadriplegia clearly experienced the biggest change in their social and sexual lives. Thus, sexuality joins a long list of other normal functions affected and changed by a complete spinal cord injury. Sex, and even orgasm remain possible and enjoyable, but are more difficult, and occur less frequently.

Since half of the women surveyed experience orgasm, a full sexual response remains a possibility for those injured. So, education about how to further stimulate areas where sensation remain, experimentation with different coital positions, and work on how to psychologically enhance one's sexual response may lead to a more full sexual life. One of the pieces of good news with this study is another affirmation that orgasm can occur even occasionally in those with complete injuries. This orgasm is not "phantom," but an appreciation of the physical, psychological and interpersonal experience that sex presents even if physical perception is diminished.

The women surveyed did not expand their repertoire of sexual behavior after injury. Rather, they continued to express themselves sexually as they always had. So, sexual counseling should be oriented to having women achieve a sexual life as close as possible to what was previously experienced. It is unlikely an individual will change personal sexual preferences because of physical changes. However, open communication and sexual experimentation with an understanding partner is essential. Rehabilitation staff should be prepared to offer suggestions about different coital positions, use of a vibrator, or stimulat-

ing areas where sensation remains or is heightened. Managing bladder problems during sex needs to be addressed. Finally, enhancing psychological aspects of sexuality will enhance sexual expression and enjoyment.

The biggest and most remarkable change after spinal cord injury in our study was the worsening in body image. This was far greater than any change in ratings of sexual practice or enjoyment. Altered sensory input caused by the spinal cord injury may contribute to this worsening in body image. However, given that these women were not physically disfigured this great change remains remarkable. Rehabilitation should focus on strengths the individual continues to possess, including physically attractive features that remain after spinal cord injury. This work appreciating self perception may improve sexual and even interpersonal confidence.

Finally, a remarkable 78% of our sample is not using any form of birth control. While some of the women surely were post-menopausal, others clearly were not using adequate birth control. Berard (1989) also found that only 47% of his survey of 15 patients were using contraception. So, education about the continued possibility of pregnancy and the necessity for birth control must be part of sexual education in rehabilitation.

Finally, it seems clear that post injury relationships that foster open communication fare best. Clinical relationships with our patients must also have this same openness about sexuality. All members of the treatment team must be comfortable in addressing and educating the patient about sexuality after spinal cord injury. As Goddard emphasizes, spinal cord injured patients will rarely spontaneously discuss sexuality, and so staff must take the initiative to address that aspect of post injury life at different points in the rehabilitation process[14].

The most important lessons in female sexuality after spinal cord injury come, of course, from our patients. Two of them comment, "The most important thing is to learn to be open and creative. Just because you can't move certain parts of your body doesn't mean you can't be exciting. A lot of orgasms come from the excitement of the act of intercourse, not just the physical feeling." "I believe that sex is so different and you really have to try different ways until (you find) what satisfies you. Every person has their own sexuality and they will have to learn what they need."

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