

Original Article

Spinal cord injury influences psychogenic as well as physical components of female sexual ability

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Study design: Secure, web-based survey.

Objectives: Elicit specific information about sexual function from women with spinal cord injuries (SCI).

Setting: World-wide web.

Methods: Individuals 18 years or older living with SCI obtained a pass code to enter a secure website and then answered survey questions.

Results: Bladder and/or bowel incontinence during sexual activity and/or sexual intercourse were significant concerns and prevented some women from seeking sexual activity. Autonomic dysreflexia (AD) during sexual activity was interpreted negatively by many and was found to interfere with sexual activity. Most subjects reported difficulty becoming psychologically aroused as well as physically aroused, which were both correlated with feeling that their SCI had altered their sexual sense of self. An inverse relationship existed between developing new areas of arousal above the level of lesion and not having sensation or movement below the lesion. The most commonly reported sexual stimulation leading to the best arousal involved stimulation of the head/neck and torso areas. The majority of subjects reported having experienced intercourse postinjury. Most participants reported difficulty with positioning during foreplay and intercourse, vaginal lubrication, and spasticity during intercourse. Almost half reported experiencing orgasm postinjury and this was positively associated with the presence of genital sensation.

Conclusion: SCI significantly impairs psychological and physical aspects of female sexual arousal. In addition, bladder and bowel incontinence as well as AD negatively impact sexual activity and intercourse.

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Introduction

Women living with spinal cord injury (SCI) are a minority of minorities. First, there are only an estimated 250 000 persons in the United States (US) living with SCI. Of those, only 20% are females. Worldwide, the total number of people living with SCI and the proportion of females is not known. Historically, the majority of research regarding SCI has focused on

males, most likely due to sheer numbers. In recent years, however, research regarding gender-related differences has become more prevalent. Although acute neurologic outcome is not influenced by gender,^{1–4} there is some evidence that females are more prone to developing depression as well as deep venous thrombosis acutely after injury.⁴ At later times postinjury, after discharge from acute rehabilitation, there is evidence from a retrospective study that females experience more spontaneous natural recovery than males.³ The effects of aging in females with SCI are only beginning to be studied. A recent study revealed that the most pressing

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issues of women with SCI as they age were physical changes, such as gynecological and sexual problems, deterioration in bladder and bowel function, increased musculoskeletal pain and fatigue, and decreased skin integrity plus increased weight gain.⁵ Other issues associated with aging regarded as important were social and emotional changes, finding adequate female health-care and resources, increasing financial worries, and increasing dependency and isolation. With increasing time postinjury, women with SCI are at a higher risk of experiencing depression than men.^{6–8} A small multinational study revealed that females felt that SCI accelerated their aging process and they reported more problems with pain, fatigue, skin integrity, and transportation than males.⁹ These issues warrant extensive investigation, especially with the knowledge that women (nondisabled) live on average 7.5 years longer than men.¹⁰

The impact of SCI on female sexual function has been particularly less well studied in comparison to males. The state of our current knowledge suggests that the neuroanatomy and neurophysiology of sexual function in females is similar to males.¹¹ Afferent sensory information from the genitalia to the spinal cord is relayed via the pudendal nerves (S2–S4). Parasympathetic input to the genitalia is via the pelvic nerves (S2–S4) and sympathetic input to the genitalia is via the hypogastric nerves (T10–L2). Parasympathetic input causes engorgement and swelling of the labia and clitoris as well as vaginal lubrication. Sympathetic input causes rhythmic contractions of the uterus, fallopian tubes, paraurethral glands, and pelvic floor musculature. In regard to how SCI affects the physiology of female sexual function, there are a small number of studies addressing different topics and most of the studies involve a small number of research subjects (for a more detailed review, see Sipski and Arenas¹²). In 1995, Sipski *et al*¹³ demonstrated that, in women with complete SCI above T6, psychogenic arousal can occur in the absence of genital arousal (genital vasocongestion). In addition, direct genital stimulation can induce genital vasocongestion in the absence of subjective arousal. Later studies indicated that preservation of sensory input to the T11–L2 dermatomes was associated with the ability to experience psychogenic genital vasocongestion.^{14,15} It is thought that approximately 50% of women with SCI have the ability to experience orgasm postinjury,^{14,16,17} although there is a longer latency to reach orgasm.¹⁴ One important component, however, appears to be sparing of the sacral reflex arc. A complete lower motor neuron lesion affecting S2–S5 greatly reduces the likelihood of experiencing orgasm.¹⁴

Although laboratory-based studies are essential for evaluating and quantitating physiologic sexual responses, they involve invasive, intravaginal measurements. Many women with SCI may choose not to participate in such studies owing to shyness, embarrassment, or inhibitions (self-imposed, social, or cultural). SCI can negatively influence self-esteem and body image, which can further deter participation in laboratory-based sexual research. Additionally, women who

require physical assistance, as would be associated with the majority of cervical lesions, may have difficulty participating in studies involving self-stimulation. Thus, in order to determine what women in the general SCI community are experiencing in the privacy of their own homes, we conducted this secure, internet-based survey. Here, we present detailed information regarding both psychological and physical aspects of sexual stimulation and arousal in women. We also present a comprehensive analysis of difficulties associated with vaginal intercourse, deterrents of anal intercourse, prevalence of orgasm, and methods of birth control.

Methods

Survey design

A general questionnaire covering a wide variety of sexual components was developed to acquire more detailed information related to sexual function and SCI. This questionnaire was not designed to be used as a sexual function outcome measure. Rather, it was designed to query the general SCI population beyond those individuals who actively seek out laboratory research studies or fertility clinics.

The questionnaire was divided into three sections. The first section was answered by males and females and those results are presented in the accompanying paper.¹⁸ The second section was answered only by males and those data are presented in an additional accompanying paper.¹⁹ The third section was completed by females only. This section contained specific and detailed questions about female arousal, orgasm, intercourse, and birth control/fertility. Analyses were then performed (see Statistics below) to identify how SCI alters female sexual function and the factors that influence sexual response over time. Those data are presented in this paper. Wherever possible, a list of answers was provided for each question to assist in standardization of responses. Few questions required descriptive answers.

The study was approved by the University of California Irvine Institutional Review Board. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Attached to the survey was an introductory statement explaining the purpose of the survey, directions for participating, the right to privacy, what the results were to be used for, and that three of the five investigators conducting the survey also had spinal cord injuries. This information served as the informed consent statement, as required by the Institutional Review Board.

Participant recruitment

The eligibility requirements for the survey were simply that an individual be 18 years of age or older and be living with permanent spinal paralysis. Advertisements were placed on multiple SCI websites, online support

groups, SCI bulletin boards, etc (including the National Spinal Cord Injury Association, Project Walk, Reeve-Irvine Research Center, NeuroFitness Foundation, SCI Zone, 360mag, Paralysis Resource Center, Mobile Women, Paralysis Project of America, United Spinal/Orbit magazine, Florida SCI Resource Center, Miami Project E-News, and Canadian Paraplegic Association). Print advertisements were also placed in *Paraplegia News*, *New Mobility*, and the California Paralyzed Veterans Association monthly newsletter.

Eligible subjects who were willing to participate received a randomly generated pass code in order to enter the secure website. Upon completion of the survey, the pass code used by an individual to enter the website was not linked to his/her answers, thereby preserving anonymity. Individuals interested in participating who did not have access to the internet could receive a paper version of the questionnaire in the mail and then send it back to the lead investigator, who then entered the information into the secure database. The study was open for enrollment for a 6-month time period.

Statistical analyses

Statistical assessments were performed using the JMP 6.0.0 Statistical Discovery™ software package from SAS, with guidance from the UCI Center for Statistical Consulting. Descriptive analyses of the data were performed first. After which, a series of bivariate analyses were performed to determine whether any of the following variables (*X*) influenced any of the following responses (*Y*):

X factor

1. Current age group (under 30, 30–50, over 50)
2. Years post-injury group (0-5, 6–10, > 10)
3. Injury group (cervical, upper thoracic, lower thoracic, lumbosacral)
4. Can you feel touch in the anal area? (yes/no)
5. Can you lift your legs against gravity? (yes/no)
6. Reported Pain (yes/no)
7. Reported Depression (yes/no)
8. Reported Spasticity (yes/no)
9. Using spasticity medication (yes/no)
10. Using pain medication (yes/no)
11. Using bladder medication (yes/no)
12. Using recreational drugs (yes/no)
13. Current bladder management (controlled voiding, manual crede or spontaneous voiding, indwelling catheter, intermittent catheterization, condom catheter, suprapubic catheter, other)
14. Current bowel management (voluntary control, digital stimulation alone, enema ± digital stimulation, suppository ± digital stimulation, other)
15. Do you experience AD during bladder care? (yes/no/sometimes)
16. Do you experience AD during bowel care? (yes/no/sometimes)

17. Are you concerned about bladder incontinence during sexual activity? (not concerned, undecided, concerned)
18. Are you concerned about bowel incontinence during sexual activity? (not concerned, undecided, concerned)
19. Do bladder and bowel issues prevent you from seeking sexual activity with partners? (yes/no/sometimes)
20. Do you have any genital sensation? (yes/no)
21. Were you ever involved in any type of sexual relationship pre-injury? (yes/no)
22. Have you ever been involved in any type of sexual relationship post-injury? (yes/no)
23. Are you currently involved in any type of sexual relationship? (yes/no)
24. Do you experience AD during any type of sexual activity (alone or with a partner)? (yes/no)
25. How much does AD interfere with your sexual activity? (none/some)
26. Do you experience the symptoms of AD as pleasurable/arousing? (yes/no/not applicable)
27. Pain during sexual activity (yes/no)
28. Headache during sexual activity (yes/no)
29. Tingling sensations during sexual activity (yes/no)
30. Spasms during sexual activity (yes/no)
31. Shortness of breath during sexual activity (yes/no)
32. What is the primary reason you are interested in pursuing sexual activity? (sexual need, intimacy need, self-esteem, fertility, to keep my partner, other)
33. Do you agree that your injury has altered your sexual sense of self? (disagree, undecided, agree)
34. Is improving your sexual function important to improving your quality of life? (yes/no)

Y response

1. Do you feel a build up of sexual tension in your body during sexual stimulation? (yes/no)
2. Do you feel a build up of sexual tension in your head during sexual stimulation? (yes/no)
3. Do you feel your mental arousal translates to your genitals in physical sensation? (disagree, undecided, agree)
4. Do you think you lubricate adequately with sexual stimulation? (yes, no, not sure)
5. Difficulty with becoming psychologically aroused (none/some)
6. Difficulty with becoming physically aroused (none/some)
7. Are you aroused by sensual light stroking of nearby non-genital skin (ex. perineum, inner thigh, etc.)? (yes/no)
8. Have you developed new areas of arousal above the level of your lesion? (yes/no)
9. Have you developed new areas of arousal at the level of your lesion? (yes/no)
10. Aroused by head/neck stimulation (yes/no)

11. Aroused by torso stimulation (yes/no)
12. Aroused by touching genitals (yes/no)
13. Aroused by touching (yes/no)
14. Aroused by kissing (yes/no)
15. Aroused by oral sex (yes/no)
16. Aroused by visualization (yes/no)
17. Are you able to have penetrative intercourse? (yes/no)
18. Have you had vaginal penetration since your injury? (yes/no)
19. Have you had anal penetration since your injury? (yes/no)
20. Difficulty with positioning during foreplay, post-injury (some/none)
21. Difficulty with positioning during intercourse, post-injury (some/none)
22. Difficulty with vaginal lubrication, post-injury (some/none)
23. Difficulty with spasms, post-injury (some/none)
24. Difficulty with shortness of breath, post-injury (some/none)
25. Difficulty with vaginal pain during intercourse, post-injury (some/none)
26. Difficulty with musculoskeletal pain during intercourse, post-injury (some/none)
27. Difficulty with urinary incontinence during intercourse, post-injury (some/none)
28. Difficulty with bowel incontinence during intercourse, post-injury (some/none)
29. Difficulty with vaginal discharge after intercourse, post-injury (some/none)
30. Difficulty with urinary tract infections after intercourse, post-injury (some/none)
31. Difficulty with dysreflexia during intercourse, post-injury (some/none)
32. Did you ever experience orgasm PRE-injury? (yes/no)
33. Have you tried to reach orgasm POST-injury? (yes/no)
34. Are you able to reach orgasm post-injury? (yes, no, not yet, n/a)
35. Do you think your injury has negatively altered your fertility? (yes/no)
36. Do you think your injury has negatively altered your chance of being a mother? (yes/no)
37. What type of birth control do you use? (none, chemical {pill, patch, IUD}, diaphragm, condom, tubal ligation, hysterectomy, partner had vasectomy, other)
38. Does your method of birth control affect your willingness/availability to be sexual? (yes/no)
39. Have you given birth since your injury? (yes/no)

The resulting contingency tables were reviewed and factors accounting for <5% of the variability of responses ($r^2 < 0.05$) were discarded. Factors accounting for >5% of the variability of responses are reported in the text along with the r^2 -value. In addition, χ^2 analyses were performed for those factors and the P -values are reported in the text.

Results

Table 1 provides a description of the demographics specific to the female participants ($N = 87$). For data regarding the general study population and the male subpopulation, refer to the accompanying papers.^{18,19}

General sexual activity and associated influences during sexual activity: female subpopulation

The majority of female participants had been involved in a sexual relationship preinjury (88.5%) and also postinjury (94.3%), and were involved in a sexual relationship at the time of study participation (69%). Only 41.4% had genital sensation. In contrast to the male subpopulation, more than half of the females reported being concerned about bladder incontinence during sexual activity (51.7%) and fewer, but still a significant proportion, were concerned about bowel incontinence (41.4%). Additionally, many subjects reported that bladder and/or bowel issues always (19.5%) or sometimes (26.4%) prevented them from seeking sexual activity with a partner. Just under half, 39.1%, experienced AD during any type of sexual activity (alone or with a partner) and 28.1% reported that AD interfered with sexual activity to some extent. Again, those proportions were higher than those reported by the male subpopulation.

The most commonly reported physical sensations experienced during sexual activity were tingling sensations (41.4%) and spasms (37.9%). Similar to males, the primary reason for pursuing sexual activity was intimacy need (69%). In contrast, however, the second most commonly cited reason for pursuing sexual activity was 'to keep my partner' (13.8%). Most women felt that their injury had altered their sexual sense of self (74.7%) and that improving their sexual function was important to improving their quality of life (75.9%).

Altered, and adapted, sexual arousal and stimulation

Relatively little information is known about how SCI alters female sexual arousal and stimulation, both physically and psychologically, thus, several questions were asked regarding this topic. In this survey, arousal was not assigned a specific definition. Rather, it was left to the interpretation of each subject and her perception of arousal.

The majority of female participants reported that they could feel the build up of sexual tension in their body (58.6%) during sexual stimulation as well as in their head (64.4%). Reporting the ability to feel the build up of sexual tension in the body was positively correlated with the presence of genital sensation ($r^2 = 0.14$ ($r = 0.37$); $\chi^2 = 15.46$, $P < 0.0001$). Interestingly, 91.7% of the women who reported that the primary reason they pursued sexual activity was to keep their partner also reported that they did not feel a build up of sexual tension in their body during sexual stimulation ($r^2 = 0.18$ ($r = 0.42$); $\chi^2 = 18.34$, $P = 0.0026$). Additionally, 75% of

Table 1 Female demographics

Variable	Response	Response	Response	Response
Mean age at time of injury	26.4 ± 12.14 years	< 30 years 64.4%	30–50 years 31%	> 50 years 4.6%
Mean current age at time of study participation	41.5 ± 9.2 years	18–29 years 10.3%	30–50 years 73.6%	> 50 years 16.1%
Mean number of years postinjury	15.1 ± 12.3 years	0–5 years 25.3%	6–10 years 20.7%	> 10 years 54%
Injury level		Cervical 36.8%	Thoracic 52.9%	Lumbosacral 10.3%
Cause of injury	Vehicular 46%	Sports 9.2%	Falls 10.3%	Violence 3.4%
Feel touch below level of lesion	Yes 49.4%	No 50.6%		
Feel touch in anal area	Yes 37.9%	No 62.1%		
Tell difference between sharp and dull	Yes 31%	No 69%		
Voluntarily tighten anal sphincter	Yes 26.4%	No 73.6%		
Walk without assistance	Yes 12.6%	No 87.4%		
Reported chronic pain	Yes 39.1%	No 60.9%		
Reported severe spasticity	Yes 28.7%	No 71.3%		
Reported depression	Yes 25.3%	No 74.7%		
Reported autonomic dysreflexia (AD)	Yes 27.6%	No 72.4%		
Use bladder maintenance medication	Yes 62.1%	No 37.9%		
Use pain management medication	Yes 47.1%	No 52.9%		
Use spasticity medication	Yes 24.1%	No 75.9%		
Use recreational drugs	Yes 11.5%	No 88.5%		
Bladder management	IC 49.4%	Indwelling cath. 13.8%	Suprapubic catheter 8%	Voluntary control 8%
Number of bladder accidents/month	0 (37.9%)	1–5 (32.2%)	6–10 (12.6%)	> 10 (17.2%)
Number of UTIs/year	0 (29.9%)	1–5 (58.6%)	6–10 (4.6%)	> 10 (5.7%)
Bowel management	DS 36.8%	Suppository ± DS 29.9%	Enema ± DS 6.9%	Voluntary control 14.9%
AD during bladder care	Yes 12.6%	No 57.5%	Sometimes 29.9%	
AD during bowel care	Yes 10.3%	No 65.5%	Sometimes 24.2%	

DS, digital stimulation; IC, intermittent catheterization; UTI, urinary tract infection

those same women reported not feeling a build up of sexual tension in their head ($r^2=0.12$ ($r=0.35$); $\chi^2=14.16$, $P=0.0146$). For those women who did report the ability to feel the build up of sexual tension in their head, there was a positive association with the presence of AD during sexual activity ($r^2=0.10$ ($r=0.32$); $\chi^2=10.66$, $P=0.0011$), during normal bladder care ($r^2=0.12$ ($r=0.35$); $\chi^2=10.28$, $P=0.0058$), and during normal bowel care ($r^2=0.10$ ($r=0.32$); $\chi^2=9.96$, $P=0.0069$).

Approximately 69% of all the females felt that their mental arousal translated to their genitals as physical sensation (16.1% were undecided on this issue). This was associated with having genital sensation ($r^2=0.06$ ($r=0.24$); $\chi^2=8.54$, $P=0.014$). However, 74.7% of the total group reported difficulty becoming psychologically aroused and 87.4% reported difficulty becoming physically aroused. There was a positive relationship between reporting that their injury had altered their sexual sense of self and reporting difficulty becoming psychologically aroused ($r^2=0.13$ ($r=0.36$); $\chi^2=13.43$, $P=0.0012$), and an even stronger correlation with reporting difficulty becoming physically aroused ($r^2=0.31$ ($r=0.56$); $\chi^2=25.69$, $P<0.0001$). In addition, all of the 25 women who reported that AD interfered with sexual activity also reported having difficulty becoming physically aroused and this relationship was statistically significant ($r^2=0.12$ ($r=0.35$); $\chi^2=5.08$, $P=0.0242$).

Regarding the physiologic aspects of sexual arousal, it is known that vaginal lubrication can be diminished in spinal injured women. In this study, 48.3% felt that they experienced adequate lubrication during sexual stimulation, 27.6% reported that they did not, and 24.1% were not sure.

The majority of subjects reported that they had not developed new areas of arousal AT their level of lesion (70.1%), but almost half (48.3%) reported that they had developed new areas of arousal ABOVE their level of lesion. There were several factors that influenced the development of new areas of arousal ABOVE the level of lesion. There was a positive relationship with the length of time postinjury ($r^2=0.13$ ($r=0.36$); $\chi^2=14.59$, $P=0.0007$) and a negative/inverse relationship with the ability to feel touch in the anal area ($r^2=0.17$ ($r=0.41$); $\chi^2=19.28$, $P<0.0001$) and the ability to lift legs against gravity ($r^2=0.11$ ($r=0.33$); $\chi^2=12.53$, $P=0.0004$).

Figure 1 demonstrates that the primary areas of sexual stimulation leading to the best arousal were the head/neck area and torso area. Both of these were positively associated with longer time postinjury (head/neck stim. $r^2=0.07$ ($r=0.26$); $\chi^2=8.23$, $P=0.0163$; torso stim. $r^2=0.05$ ($r=0.22$); $\chi^2=6.07$, $P=0.0480$) and were negatively/inversely associated with the ability to feel touch in the anal area (head/neck stim. $r^2=0.12$ ($r=0.35$); $\chi^2=14.33$, $P=0.0002$; torso stim. $r^2=0.08$ ($r=0.28$); $\chi^2=8.91$, $P=0.0028$) and the ability to lift

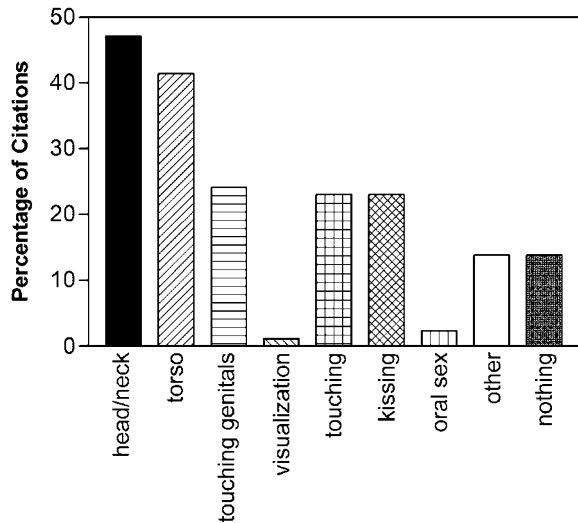


Figure 1 Nature and location of specific sexual stimulation leading to the best arousal

legs against gravity (head/neck stim. $r^2 = 0.13$ ($r = 0.36$); $\chi^2 = 14.99$, $P = 0.0001$; torso stim. $r^2 = 0.10$ ($r = 0.32$); $\chi^2 = 10.33$, $P = 0.0013$).

Touching the genital area was also important for inducing the best arousal, but was positively correlated with the ability to feel touch in the anal area ($r^2 = 0.29$ ($r = 0.54$); $\chi^2 = 26.85$, $P < 0.0001$), the ability to lift legs against gravity ($r^2 = 0.07$ ($r = 0.26$); $\chi^2 = 6.69$, $P = 0.0097$), and the presence of genital sensation ($r^2 = 0.24$ ($r = 0.49$); $\chi^2 = 22.43$, $P < 0.0001$). Interestingly, 21 of the 22 subjects who reported being depressed also reported not being aroused by touching the genital area. Of those 22 subjects, eight could feel touch in the anal area (six of those eight had genital sensation) and 14 could not (one of those 14 had genital sensation). A total of 42.5% of subjects reported being aroused by sensual light stroking of nearby nongenital skin. However, this was strongly contingent upon the presence of genital sensation ($r^2 = 0.28$ ($r = 0.53$); $\chi^2 = 31.22$, $P < 0.0001$) and somewhat upon the ability to feel touch in the anal area ($r^2 = 0.17$ ($r = 0.41$); $\chi^2 = 19.84$, $P < 0.0001$).

Difficulties related to sexual intercourse

The next category of questions in the survey was in regard to intercourse. When asked if they were able to have penetrative intercourse, 96.9% of the subjects reported yes. A total of 92% had experienced vaginal penetration postinjury and 28.7% had experienced anal penetration postinjury. There were 8% of the subjects who reported not having experienced vaginal or anal penetration. When taking the survey, any participant who reported no to both of those two questions was directed to the next section of the survey. Thus, they have been excluded from the remainder of this section regarding intercourse. Of note, however, all of those

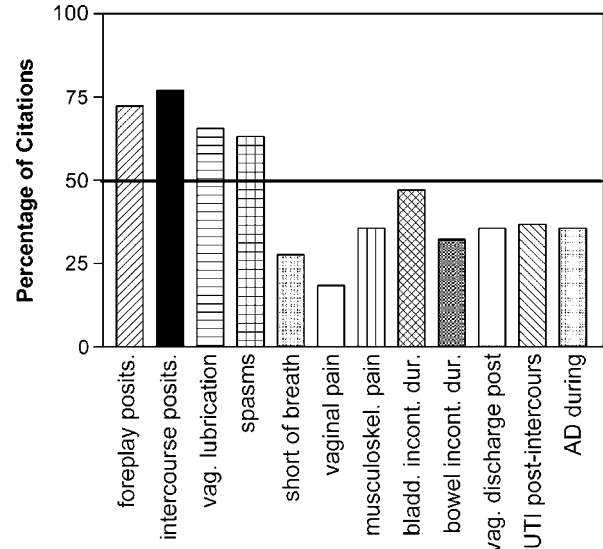


Figure 2 Difficulties related to sexual intercourse

excluded subjects ($n = 7$) reported having been involved in a sexual relationship preinjury, four of the seven had been involved in a sexual relationship postinjury, and one of the seven was currently involved in a sexual relationship. All of the seven subjects reported experiencing continuous chronic pain and this significantly influenced the reporting of not having had vaginal penetration postinjury ($r^2 = 0.29$ ($r = 0.54$); $\chi^2 = 11.87$, $P = 0.0006$). Also of note, having been involved in a sexual relationship was not synonymous with having had penetrative intercourse.

Several questions were asked about the difficulties women experienced before, during, or after vaginal intercourse. Figure 2 shows that the top four problems reported by females were positioning during foreplay (72.4%), positioning during intercourse (77.0%), vaginal lubrication (65.5%), and spasticity (63.2%). The least commonly reported problem was vaginal pain during intercourse (18.4%). Table 2 reports the statistical significance of factors that positively correlated with different difficulties experienced related to intercourse. The most predominant factors leading to the likelihood of experiencing difficulties related to intercourse were injury level (greater difficulties for cervical injuries), having severe spasticity (during typical daily life), having pain, spasticity, or AD during any type of sexual activity, and reporting that AD interferes with sexual activity.

The reporting of having participated in anal sexual intercourse postinjury was negatively/inversely influenced by multiple factors. Factors influencing the likelihood of NOT having experienced anal sexual intercourse postinjury were: (1) having spasticity severe enough to require medication ($r^2 = 0.05$ ($r = 0.22$); $\chi^2 = 4.80$, $P = 0.0285$), (2) having continuous chronic pain ($r^2 = 0.05$ ($r = 0.22$); $\chi^2 = 5.36$, $P = 0.0206$), (3) using pain medication ($r^2 = 0.08$ ($r = 0.28$); $\chi^2 = 7.53$,

Table 2 Factors influencing difficulty with intercourse

<i>Difficulty</i>	<i>Injury group</i>	<i>Daily spasticity</i>	<i>Pain during SA</i>	<i>Spasms during SA</i>	<i>AD during SA</i>	<i>AD interferes with SA</i>	<i>Concern of bladder incont. during SA</i>	<i>Concern of bowel incont. during SA</i>	<i>Altered sexual sense of self</i>
Positioning during foreplay									<i>r</i> = 0.28, <i>P</i> < 0.03
Positioning during intercourse									
Vaginal lubrication									
Spasms during intercourse	<i>r</i> = 0.36, <i>P</i> < 0.01 ^a	<i>r</i> = 0.36, <i>P</i> < 0.01	<i>r</i> = 0.24, <i>P</i> < 0.03	<i>r</i> = 0.57, <i>P</i> < 0.01	<i>r</i> = 0.26, <i>P</i> < 0.02	<i>r</i> = 0.35, <i>P</i> < 0.01			
Shortness of breath					<i>r</i> = 0.26, <i>P</i> < 0.01				
Vaginal pain during intercourse			<i>r</i> = 0.30, <i>P</i> < 0.01	<i>r</i> = 0.24, <i>P</i> < 0.03		<i>r</i> = 0.26, <i>P</i> < 0.02			
Musculoskeletal pain during intercourse			<i>r</i> = 0.41, <i>P</i> < 0.01						
Urinary incontinence during intercourse	<i>r</i> = 0.36, <i>P</i> < 0.01 ^b						<i>r</i> = 0.46, <i>P</i> < 0.01		
Bowel incontinence during intercourse								<i>r</i> = 0.35, <i>P</i> < 0.01	
Vaginal discharge after intercourse									
UTI after intercourse									
AD during intercourse	<i>r</i> = 0.42, <i>P</i> < 0.01 ^a			<i>r</i> = 0.36, <i>P</i> < 0.01	<i>r</i> = 0.92, <i>P</i> < 0.01	<i>r</i> = 0.62, <i>P</i> < 0.01			

AD, autonomic dysreflexia; incont., incontinence; SA, sexual activity

^aGreatest for cervical injuries

^bGreatest for lower thoracic and lumbosacral/conus/cauda equine injuries

$P=0.0061$), (4) experiencing AD during typical bladder care ($r^2=0.08$ ($r=0.28$); $\chi^2=7.43$, $P=0.0243$), (5) experiencing AD during typical bowel care ($r^2=0.11$ ($r=0.33$); $\chi^2=8.48$, $P=0.0144$), and (6) experiencing AD during any type of sexual activity ($r^2=0.08$ ($r=0.28$); $\chi^2=7.85$, $P=0.0051$). Interestingly, concern about bowel incontinence during sexual activity did not influence the likelihood of experiencing anal sexual intercourse.

Orgasm

A number of questions were asked about how SCI affects orgasm. A detailed description of those data will be presented in a separate paper regarding orgasm in both women and men living with SCI. Briefly, however, 82.8% of participants had experienced orgasm preinjury and 93.1% had attempted to reach orgasm postinjury. Not surprisingly, having experienced orgasm preinjury was strongly correlated with having been involved in a sexual relationship preinjury ($r^2=0.54$ ($r=0.73$); $\chi^2=54.23$, $P<0.0001$) and attempting to reach orgasm postinjury was influenced by having been involved in a sexual relationship postinjury ($r^2=0.11$ ($r=0.33$); $\chi^2=9.05$, $P=0.0026$). In contrast to the majority of subjects having attempted to reach orgasm postinjury, only 46% of the subjects reported having successfully achieved orgasm postinjury (the 6.9% who had not attempted to reach orgasm postinjury were excluded from this question). There was a positive correlation between the presence of genital sensation and ability to achieve orgasm ($r^2=0.11$ ($r=0.33$); $\chi^2=11.98$, $P=0.0005$). Additionally, reporting spasticity during sexual activity was associated with reporting having achieved orgasm ($r^2=0.08$ ($r=0.28$); $\chi^2=9.19$, $P=0.0024$). Finally, there was a relationship between having an altered sexual sense of self and orgasm ($r^2=0.11$ ($r=0.33$); $\chi^2=11.71$, $P=0.0029$). Of the 59 subjects who felt that their SCI had altered their sexual sense of self, 35 had not yet experienced orgasm postinjury. Of the 16 subjects who felt that their SCI had not altered their sexual sense of self, 14 had achieved orgasm postinjury. Of the six subjects who were undecided about whether or not the SCI had altered their sexual sense of self, only two had reached orgasm postinjury.

Birth control and fertility

The final set of questions dealt with fertility and birth control. A total of 14.9% of the participants thought that their injury had negatively altered their fertility and 21.8% thought that their injury had negatively altered their chances of being a mother. Figure 3 demonstrates that the most common method of birth control used by participants was by chemical/hormonal means (pill, patch, or IUD). Interestingly, 41.4% of the subjects did not use any type of birth control. No underlying commonalities as to possible confounding factors or reasons for not using birth control could be identified in

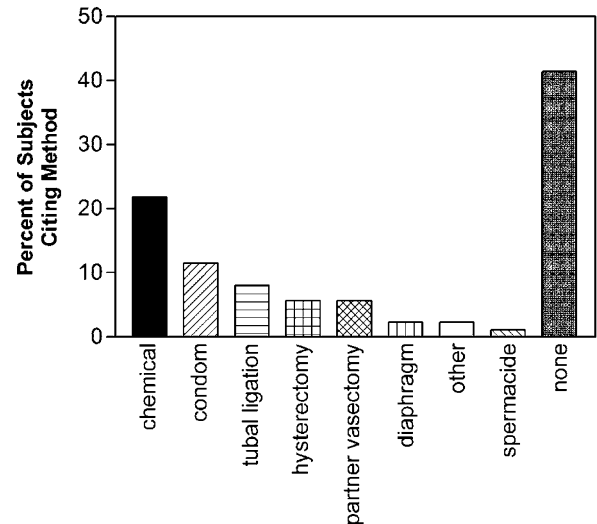


Figure 3 Methods of birth control used

those subjects. However, only 11.5% of all subjects reported that their method of birth control affected their willingness or availability to be sexual. A total of 19.5% of the participants had given birth postinjury. Of the women who had given birth, 82.4% were greater than 10 years postinjury at the time of participating in the survey ($r^2=0.09$ ($r=0.30$); $\chi^2=6.91$, $P=0.0317$).

Conclusions

Here we have presented the data from the female portion of the survey questionnaire for which the general results were presented in an accompanying paper.¹⁸ Bladder and/or bowel incontinence during sexual activity and/or sexual intercourse was a significant issue for females, which prevented some from seeking sexual activity with a partner. In addition, experiencing autonomic dysreflexia (AD) during sexual activity was interpreted negatively by many subjects and was found to interfere with sexual activity. The primary reason for pursuing sexual activity was for intimacy need; however, the second most commonly cited reason was to keep a partner. The majority of women reported difficulty becoming psychologically aroused as well as physically aroused, which were both correlated with the feeling that their SCI had altered their sexual sense of self. There was an inverse relationship between developing new areas of arousal above the level of lesion and not having anal sensation or the ability to lift legs against gravity. The most commonly reported sexual stimulation leading to the best arousal involved stimulation of the head/neck and torso areas, which were also inversely related to the absence of sensory or motor function below the level of injury. The majority of subjects reported having experienced vaginal intercourse postinjury, whereas less than one-third had experienced anal intercourse. More than half of the participants reported difficulty with positioning during foreplay and intercourse, vaginal lubrication, and spasticity during

intercourse. Almost half reported having experienced orgasm postinjury and this was positively associated with the presence of genital sensation. Slightly less than half of the subjects reported not using any type of birth control.

Bladder and bowel dysfunction and AD negatively impact female sexual function

The finding that bladder and/or bowel incontinence during sexual activity is a significant concern for women living with SCI is supported by previous studies.^{17,20–23} Our study further revealed that these concerns are severe enough to prevent a considerable number of women from seeking sexual activity with a partner. It is possible that the fear of incontinence may contribute to psychological aspects of arousal as well. Owing to the positioning of female anatomy, with the vagina being flanked in front by the bladder and in back by the rectum, it is inevitable that vaginal intercourse will stimulate the bladder and bowel. Without the ability to voluntarily control either external sphincter, there is a high risk of incontinence. Certainly precautions can be taken before engaging in intercourse, such as emptying the bladder and bowel, but this is not always enough to prevent incontinence. Further, it negatively impacts the spontaneity often associated with sexual activity. An alternative for women who normally empty their bladder by intermittent catheterization would be to use an indwelling catheter during sexual activities, to try preventing bladder incontinence. However, many women and their partners may view an indwelling catheter as undesirable and as something that would get in the way when engaged in sexual acts. A pad can be used in the event of bowel incontinence, but this too could be undesirable and limit spontaneity. Thus, an important avenue of research to target would be toward reestablishing voluntary control of the external urethral sphincter and external anal sphincter. Additionally, our results indicate that AD negatively impacts female sexual activity and intercourse. This is in line with our findings that AD negatively influences other aspects of sexual function¹⁸ and further supports pursuing research to ameliorate AD. More females reported experiencing AD during sexual activity than males (39 *versus* 29%) and that AD interfered with sexual activity than males (28 *versus* 16%). This raises the question of whether females are more in tune with their bodies than males and, thus, more aware of AD symptoms. Or are women more susceptible to developing severe AD in general or specifically in response to sexual stimulation. These are questions that need to be addressed and can be addressed with current research models.

SCI alters physical and psychological components of sexual arousal

SCI significantly affects the emotional aspects of sexuality and sexual function in women. Societal and cultural ‘rules’ can make it difficult for women to

establish relationships, especially when facing the underlying view that it is taboo to have sex with a woman with a disability or that women with disabilities are asexual. Indeed, the marriage rate for women with SCI is lower than that for men with SCI or for the general population.⁵ Sexual ability can be impacted even further in women with cervical spine injuries that result in reduced arm and hand function, inability to transfer in/out of a wheelchair, and increased dependence on other people. In that regard, such women would also have difficulty sexually satisfying themselves by masturbation. Only 37% of the female participants in our study had cervical SCI. The exact reasons for that are unknown, but one possibility could be that it is more difficult for women with cervical SCI to participate in sexual activities (alone or with a partner). It is possible that a higher percentage of women with cervical SCI were aware of our study, but chose not to participate if they had little or no sexual experience postinjury. If that is true, it provides an even stronger reason for further research toward improving female sexual function.

Our findings that the majority of women in this study had difficulty becoming psychologically aroused could be influenced by multiple factors. Two obvious factors would be depression and/or having a low body image. Other factors could include pain or other secondary conditions, although the only correlation we found was with having reported that SCI had altered one’s sexual sense of self. This further illuminates the fact that SCI alters more than just physical sexual function. Interestingly, the second most commonly cited reason for pursuing sexual activity was ‘to keep a partner’ (whereas for the male participants it was ‘sexual need’¹⁹). Of the women who cited that reason, all of them felt that their injury had altered their sexual sense of self and that improving their sexual function would improve their quality of life. In addition, all reported difficulty becoming physically aroused and all but one reported difficulty becoming psychologically aroused. They were of varying ages, injury levels and completeness, years postinjury, and relationship status. All had experienced vaginal intercourse postinjury and all but one reported difficulty with positioning during foreplay and intercourse. This subset of women appears to not be enjoying sexual activity emotionally or physically and the underlying reasons for that are difficult to discern.

Many women, however, did report having developed new areas of arousal above the level of their injury. As was discovered with the male subjects,¹⁹ this was inversely related to the loss of sensation and motor function in the lower body and positively influenced by increasing time postinjury. This is suggestive of neuroplasticity and the employment of adaptive strategies to enhance sexual arousal and response (for detailed discussion¹⁹). Interestingly, most women felt that their injury had altered their sexual sense of self (74.7%) and that improving their sexual function was important to improving their quality of life (75.9%), but these percentages were about 10% lower than those reported by the male participants.¹⁹

SCI impacts multiple aspects of intercourse

It is important to remember that sexual intercourse is not synonymous with sexual activity, but just a component of sexual activity. Sexual intercourse can include vaginal or anal penetration. The majority of women in our study had experienced vaginal intercourse postinjury (92%), whereas only 29% had experienced anal intercourse postinjury. Other studies indicate that anywhere from 23 to 51% of nondisabled women have experienced anal intercourse at some time in their lives.²⁴⁻²⁶ This is associated with higher sexual risk-taking behaviors. The incidence of women with SCI in our study having participated in anal intercourse falls in the lower end of this range, but is still unexpectedly high. It could be that the women in our study are more willing to sexually experiment to compensate for sensory and motor impairments. Experiencing AD, having chronic pain or severe spasticity, and using pain medication were all associated with not having experienced anal intercourse. That does not necessarily mean that those factors were reasons for not participating in anal intercourse, but admittedly there are secondary conditions associated with SCI that could be negatively influenced by anal intercourse.

The main difficulties that more than half of the women reported during vaginal intercourse were with positioning during foreplay and intercourse, vaginal lubrication, and spasticity during intercourse. Almost half of the women reported some degree of difficulty with bladder incontinence during intercourse. Vaginal pain during intercourse does not appear to be a significant concern. These findings are in support of the only large study published addressing women's health issues.¹⁷ We also found that injury level and different symptoms reported to occur during sexual activity had significant correlations with different difficulties during intercourse.

Orgasm after SCI

The finding that 46% of the participants had successfully achieved orgasm postinjury is strongly supportive of the few other studies examining orgasm in women with SCI.^{14,16,17} The presence of genital sensation, indicative of sparing of the sacral reflex arc, significantly influences the likelihood of achieving orgasm. As mentioned previously, a more detailed analysis of orgasm in our study population will be presented and discussed in a forthcoming paper.

Birth control use after SCI

The reported use of birth control in women with SCI is variable. In one study from Spain, 48% of the female subjects reported not using birth control.²¹ A study from India found that 75% of the women with SCI did not use birth control.²² In the US, one study found that 30% of women with SCI did not use birth control¹⁷ and in our study 41% did not use birth control. In our participants, there were no underlying commonalities

in the women not using birth control. However, one limitation of our study, and other studies, is that information regarding frequency of sexual intercourse has not been collected. Another point that must be considered is that before the advent of low-dose oral contraceptives, it was risky for women with SCI to take birth control pills owing to the increased likelihood of developing deep venous thromboses. The extent to which this traditional practice currently impacts the prescription of oral contraceptives to women with SCI is not known. One must also consider whether any of the subjects interpreted using a condom to be their partner's responsibility rather than their responsibility.

SCI alters different aspects of sexual function in women and men

Although gender has not been proven to influence the acute neurologic damage induced by SCI, there are certainly differences in how SCI alters male and female sexual response. First, women are much more concerned about bladder and/or bowel accidents during sexual activity and intercourse. Second, AD induced by sexual stimulation is more negatively perceived by women. Third, emotions have a much more significant and complex influence on arousal in women. For example, on one hand women have more difficulty becoming psychologically aroused compared to men, but on the other hand women are more likely to translate psychological feelings of arousal into physical sensation. Fourth, it is much more difficult for women to become involved in sexual relationships post-SCI. Psychological and social factors strongly influence this problem. Finally, it is much easier for a woman with SCI to conceive a child than for a man with SCI to father a biologic child, but women face many more risks associated with pregnancy and childbirth than men face with sperm retrieval.

One aspect of SCI-altered sexual function that men and women seem to share is the development of new areas of arousal above the level of lesion when the lesion is complete. It is equally likely that the potential neuroplasticity described in the accompanying paper¹⁹ can occur in both men and women. Both genders are also probably equally likely to become more open to sexual experimentation or to adopting adaptive strategies for enhancing arousal. Furthermore, increasing time postinjury will influence all of these factors.

Summary

The findings presented here indicated that a wide range of components of female sexuality and sexual function are significantly altered by SCI. Clearly, more basic science and clinical research needs to be pursued regarding multiple aspects of how SCI impacts women. Additionally, there needs to be an increased effort for outreach and education about sexual function not only to newly injured women, but also to the worldwide population living with chronic paralysis.

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