

ORIGINAL REPORT

SEXUALITY AND SEXUAL LIFE IN WOMEN WITH SPINAL CORD INJURY: A CONTROLLED STUDY

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Objective: To describe sexual life in women with spinal cord injury.

Design: Controlled cross-sectional, questionnaire.

Participants and methods: Women, 18–65 years, treated at spinal cord centres in Sweden, Denmark, Norway, Finland and Iceland. 545 women (57%) completed the questionnaires. The age-matched control group consisted of 507 women. The 104-item Spinal Cord Injury Women Questionnaire, was designed to assess different dimensions of sexuality.

Results: 80% of the women with spinal cord injury had engaged in sex after the injury. Reasons for not wanting or not having the courage to be intimate and sexual were physical problems, low sexual desire, low self-esteem and feelings of being unattractive. The motivations of both the women with spinal cord injury and controls to engage in sexual activity were intimacy-based rather than primarily sexual. Being in the right mood both before and during sex to become receptive to sexual stimulation was important.

Conclusion: For women who are able to overcome the physical restrictions and mental obstacles due to injury, it is possible to regain an active and positive sexual life together with a partner. Sexual information and counselling should be available both during initial rehabilitation and later when the women have returned to their homes.

Key words: spinal cord injuries, women, sexuality, partner relationship, control group, questionnaire.

J Rehabil Med 2008; 40: 61–69

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Submitted February 7, 2007; accepted August 29, 2007.

INTRODUCTION

Comparatively little research on sexuality in the spinal cord injury (SCI) population has focused specifically on sexual concerns of women. However, in the last 20 years there has been

a growing acknowledgement of the sexual concerns of women with SCI. Despite this, the conveyance of this knowledge to the women with SCI appears to be insufficient (1–4).

Studies have shown that most of the women investigated (65–80%) continue to be sexually active after the injury, but to a much lesser extent than before injury (1, 4–8). Also, satisfaction with sexual life is diminished in approximately 25% of the women (5, 9). Few studies have compared sexuality and sexual functioning in women with SCI with that of able-bodied women. One such study showed that women with SCI report significantly lower satisfaction with sexual life and lower sexual desire (10). A recent study found that sexual activity was lower among women with SCI, but the desire did not differ from controls (8). A Swedish study found that the importance of sexuality had decreased among women with tetraplegia, but not among those with paraplegia. The greatest physical obstacles for sexual activity were urinary leakage, problems with positioning and spasticity (11).

Dissatisfaction with the quality and quantity of sexuality-related rehabilitation services has been pointed out (1, 3, 4, 12). Nosek et al. (2) found that women with disabilities received sexual information more seldom than did men.

Multiple laboratory-based trials have yielded better understanding of the impact of SCI on the female sexual response (13–16). In a study with 62 women with SCI and 21 able-bodied controls, 44% of the SCI participants were orgasmic in the laboratory trial and 52% of them reported the ability to achieve orgasm, compared with 100% of the able-bodied controls (16).

Positive self-image and self-esteem and feelings of being attractive to self and others are fundamental issues in sexual relations (9, 17–18). Publications addressing these aspects of sexuality in women with SCI are limited (1, 6, 19).

The purpose of this study was to describe physical, psychological and social aspects of sexual life in women with SCI.

Four research questions were formulated:

- What experiences of sexuality and intimate relationships do the women with SCI have?
- How do women with SCI perceive their sexual interest, desire, arousal, behaviour and satisfaction with sexual life compared with before injury and compared with age-matched women from the general population?

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- What experiences do the women have of sexual information and counselling?
- What factors are important to the women to enhance sexuality and sexual life after the injury?

MATERIAL AND METHODS

Study groups

All women with traumatic SCI treated at spinal cord centres in the Nordic countries (Sweden, Denmark, Norway, Finland and Iceland) comprised the pool of potential participants for this cross-sectional study. Exclusion criteria were: known recovery (Frankel grade E/ASIA Impairment Scale E) (20–21), injured less than 2 years, known brain injuries and psychiatric diseases, and inability to understand the Nordic language. The inclusion criterion was age between 18 and 70 years.

Names and addresses of a total of 1011 women with SCI were provided from the spinal cord centres in the 5 Nordic countries: Sweden ($n = 375$), Denmark ($n = 163$), Norway ($n = 215$), Finland ($n = 236$) and Iceland ($n = 22$). Questionnaires with a letter describing the rationale for the study were posted to the potential participants. They were guaranteed complete confidentiality of their responses and were offered the option of returning the questionnaires anonymously. The women were asked to return their completed questionnaires either in a postage-paid, pre-addressed envelope or by filling in an electronic version. The Swedish and Danish women were also offered the opportunity to respond via telephone interview; 8 Swedish women with SCI chose this alternative. Two repeat postings were sent.

Out of the 1011 women, 52 were excluded: 4 due to death, 7 were recovered, 3 with language difficulties, 8 had congenital injuries, 3 due to psychiatric disease, 18 due to other severe illness and 9 because they could not be located. The total eligible sample thus comprised 959 women.

A total of 545 women returned the questionnaires. Thirteen women did not return usable questionnaires and were thus excluded. The sample thus consisted of 532 participants: 257 from Sweden (257/352, response rate 73%), 91 from Denmark (91/155, 60%), 73 from Norway (73/195, 37%), 102 from Finland (102/235, 43%) and 9 from Iceland (9/22, 41%). Background and clinical characteristics for women with SCI and controls are given in Table I. Mean age of the women was 45 years and the average time since injury was 13 years. Almost two-thirds were married or in a committed relationship. Thirty-five percent of the women were tetraplegics and 65% paraplegics. Table II describes background and clinical characteristics of the participants by country. The educational level was low in the Finnish and Danish SCI populations in particular, while the Swedish and Finnish populations were more likely to be living in big cities. The participants from the 5 Nordic countries were generally treated as a single group in the analyses, except for the variables showing significant differences between countries.

Control group

A control group comprising 1000 women was selected randomly from the Swedish general population by the Swedish Person- and Address Registry (SPAR) to match the SCI study group on individual level by age and rural vs urban residence. Of a total of 564 respondents, 42 declined to participate and 15 were excluded due to: dementia [7], severe illness [6], and staying abroad [2]. The control group thus comprised 507 participants (507/985, response rate 51%). The basic socio-demographic characteristics of the respondents are shown in Table I. More of the control group had university education and were married than the women with SCI.

Ethical considerations

The local ethics committees in the 5 Nordic countries approved the study. The ethics committees in Norway and Iceland approved the study on condition that the questionnaires were to be returned anonymously.

Table I. Background and clinical characteristics of women with spinal cord injury (SCI) and control women.

Background characteristic	SCI women ($n = 532$)	Control group ($n = 507$)
<i>Sociodemographic</i>		
Age (years)		
Mean (SD)	45.1 (13.1)	44 (13.4)
Median (range)	45 (18–70)	44 (18–68)
Educational level*, n (%)		
Compulsory level	105 (20)	53 (10)
High school	265 (50)	252 (50)
University	162 (30)	202 (40)
Marital status†, n (%)		
Married	267 (50)	337 (66)
Stable partner	65 (12)	51 (10)
Single	200 (38)	119 (23)
Place of residence, n (%)		
Countryside	172 (32)	160 (32)
Town < 100,000	174 (33)	180 (35)
Big-city > 100,000	186 (35)	167 (33)
<i>Disability-related</i>		
Age at lesion (years)		
Mean (SD)	31.7 (14.2)	
Median (range)	29 (3–68)	
Duration of disability (years)		
Mean (SD)	13.3 (10.1)	
Median (range)	11 (1–54)	
Neurological classification ($n = 518$), n (%)		
Tetraplegia complete	63 (12)	
Tetraplegia incomplete	119 (23)	
Paraplegia complete	129 (25)	
Paraplegia incomplete	207 (40)	
Genital sensation ($n = 498$), n (%)		
Normal	68 (14)	
Somewhat decreased	138 (28)	
Much decreased	141 (28)	
None	151 (30)	
Mobility, n (%)		
Wheelchair dependent	371 (70)	
Walking with aids	55 (10)	
Walking without aids	106 (20)	

* $\chi^2 = 16.43$ (d.f. 2), $p = 0.0003$; † $\chi^2 = 29.79$ (d.f. 2), $p < 0.0001$.

SD: standard deviation.

mously. The ethics committees in Sweden, Denmark or Finland did not make this requirement; however, the women in these 3 countries were also given the option to return the questionnaires anonymously. Fifty-eight women with SCI (29 Swedish, 13 Danish and 16 Finnish) and 30 of the controls chose to respond anonymously. The Swedish women were offered 100 Swedish Crowns (approximately 13 US dollars) for their participation. The ethics committees in the other countries did not approve of this type of compensation. The study was initiated by kNORR¹.

Measurements

Sexuality and sexual life. The Spinal Cord Injury Women Questionnaire (SCIWQ), comprising 104 items, was designed by the first 2 authors

¹kNORR (kvinnor i Nordiska RyggmargsskadeRådet) was formed in 2001 to draw attention to the particular problems confronting women with SCI. The members of kNORR are all women with SCI.

Table II. Background and clinical characteristics of the women with spinal cord injury ($n = 532$), divided by country

Background characteristic	Sweden ($n = 257$)	Denmark ($n = 91$)	Finland ($n = 102$)	Norway ($n = 73$)	Iceland ($n = 9$)	p -value
Age (years)						0.488*
Mean (SD)	45 (12.9)	45 (11.2)	46 (14–2)	43 (14.6)	(29–58)	
Median (range)	45 (18–70)	45 (23–70)	48 (18–70)	41 (18–70)		
Age at lesion (years)						0.037*
Mean (SD)	33 (14.6)	29 (12)	29 (12.5)	34 (16.6)	n.a.	
Median (range)	31 (3–67)	25 (12–61)	28 (5–65)	33 (6–68)		
Duration of disability (years)						0.038*
Mean (SD)	11.9 (9.6)	16 (9.7)	17.4 (10.6)	9.6 (9.4)	n.a.	
Median (range)	8 (1–49)	15 (1–38)	16 (1–40)	6 (1–54)		
Neurological classification, n (%)	($n = 249$)	($n = 88$)	($n = 101$)	($n = 71$)		0.531†
Tetraplegia complete	35 (14)	10 (11)	10 (10)	7 (10)	1 (11)	
Tetraplegia incomplete	55 (22)	23 (26)	23 (23)	18 (25)	0	
Paraplegia complete	53 (21)	21 (24)	34 (34)	18 (25)	3 (33)	
Paraplegia incomplete	106 (43)	34 (39)	34 (34)	28 (39)	5 (56)	
Mobility, n (%)						0.048†
Wheelchair dependent	167 (65)	73 (80)	79 (77)	46 (63)	6 (67)	
Walking with aids	27 (10)	7 (8)	11 (11)	8 (11)	2 (22)	
Walking without aids	63 (25)	11 (12)	12 (12)	19 (26)	1 (11)	
Educational level, n (%)						0.0002†
Compulsory level	37 (14)	29 (32)	33 (32)	5 (7)	1 (11)	
High school	127 (49)	40 (44)	52 (51)	41 (56)	5 (55)	
University	93 (36)	22 (24)	17 (17)	27 (37)	3 (33)	
Place of residence, n (%) ^a						
Countryside	82 (32)	32 (36)	26 (26)	26 (36)	4 (44)	0.002†
Town < 100 000 inhabitants	64 (25)	34 (39)	43 (43)	26 (36)	5 (56)	
Big city > 100 000 inhabitants	111 (43)	22 (25)	32 (32)	21 (29)		
Marital status, n (%)						0.93†
Married	129 (50)	47 (52)	52 (51)	34 (47)	5 (55)	
Stable partner	27 (10)	11 (12)	15 (15)	11 (15)	1 (11)	
Single	101 (39)	33 (36)	35 (34)	28 (38)	3 (33)	
Marital status when injured, n (%)						0.455†
Stable partner	176 (69)	61 (67)	73 (72)	43 (59)	6 (67)	
Single	80 (31)	30 (33)	29 (28)	30 (41)	3 (33)	
Separated after injury, n (%)	86 (49)	36 (59)	48 (67)	21 (49)	2 (33)	0.399†
Separation caused by the injury	34 (39)	10 (28)	22 (46)	8 (38)	1 (50)	
Unknown reason	17 (20)	6 (17)	9 (9)	3 (14)	0	
Sexual experience after the injury, n (%) ^a						0.001†
With partner	187 (76)	74 (88)	82 (86)	52 (75)	7 (78)	
Without partner	8 (3)	0	1 (1)	2 (3)	2 (22)	
No experience	52 (21)	10 (12)	12 (13)	15 (22)	0	
Significance of sex, n (%) ^a						0.01†
Decreased	125 (52)	26 (32)	59 (63)	33 (48)	7 (78)	
Unchanged	98 (41)	45 (56)	25 (27)	29 (43)	1 (11)	
Increased	15 (6)	9 (11)	10 (11)	6 (9)	1 (11)	

*Kruskal-Wallis test, † χ^2 test, ^a there are missing values in some of the groups.
SD: standard deviation; n.a.: not available.

to assess different dimensions of sexuality: sexual experience, sexual interest, desire, arousal and satisfaction with sexual life, sexual self-confidence, sexual activity and behaviour, consequences and changes in sexual life after injury, sexual information and counselling, and relationship issues. Reviews of the literature, instruments used in earlier studies (17, 18, 22, 23), and our clinical experiences guided us in developing the SCIWQ. In addition, the group of women with SCI from kNORR, made suggestions about questions they considered relevant and wanted to be answered. The questionnaires were pilot-tested in 3 women with SCI. A similar questionnaire excluding SCI specific questions was designed for the women in the control group.

The SCIWQ was divided into 3 sections: SCIWQ-1 (34 questions) to be answered by all women, irrespective of being sexually active or not after injury; SCIWQ-2 (30 questions) to be answered only by

those who had been sexually active after injury; and women who were married/living with partner or had a stable partner relationship lasting for more than 6 months were also requested to complete SCIWQ-3 (40 questions), including 19 questions from the Female Sexual Function Index (24), and 11 questions from the SCI Relationship Questionnaire (22).

The questionnaires were translated from Swedish into the different languages following standard procedures adopted by the International Quality of Life Assessment Project (25). For each language, 2 bilingual translators performed forward translations independently. The translators jointly resolved the discrepancies between their translations. Bilingual translators performed backward translations. One of the authors (MK) compared the backward translations with the original wording and resolved discrepancies.

Sociodemographic and disability-related variables. Age, age at injury, time after injury, level and completeness of spinal cord lesion, marital status, mobility ability, residential area, and educational level were self-report items in the questionnaire (Tables I and II). The controls' questionnaire contained the same questions except for the SCI specific questions (Table I).

Statistical analysis. For comparison between countries Kruskal-Wallis test was used for continuous variables, χ^2 test for dichotomous variables and Semi-trend test for ordered categorical variables. The Semi-trend test is the equivalent of the Kruskal-Wallis test for singly ordered R \times C contingency tables with ranks replaced with the original values. The χ^2 test was used for testing differences between countries (non-ordinal variables). For testing ordinal variables, the Semi-trend test was used. For comparisons between 2 groups, Fisher's permutation test was used for continuous variables, Fisher's exact test for comparison of proportions (26), and Mantel Haenszel's χ^2 test for ordinal categorical variables. Changes before and after the injury were tested using the Sign test. Due to the multiple comparison problems, a p -value of 0.01 or less was considered significant. All significance tests were two-tailed.

RESULTS

Sexual experience

Eighty percent of the women with SCI reported that they had engaged in sex together with a partner, with or without sexual intercourse, after the injury. Significantly ($p < 0.001$) more of the women with complete tetraplegia (37%) had not engaged in sex after injury compared with women with incomplete tetraplegia (21%), complete paraplegia (15%) and incomplete paraplegia (11%).

Forty-six percent of the SCI women who had engaged in sexual activity after injury, with or without sexual intercourse, had done so within 6 months after the injury, 39% between 6 months and 2 years, and the remaining 16% more than 2 years after injury. Among the women who had been sexually active within 6 months after injury more than half (53%, $p < 0.001$) had an incomplete paraplegia, 20% a complete paraplegia, 21% an incomplete tetraplegia and 5% a complete tetraplegia.

Relationships

At the time of injury, two-thirds were married and/or cohabiting. More than half (54%) had subsequently divorced or separated and 39% of these women blamed the injury (Table II). At the time of the investigation half of the SCI women and 67% of the controls were married or cohabiting ($p < 0.001$). The majority of the women, both with SCI and the controls considered the quality of the overall relationship as very or rather good (85%-63%). Ninety-six (18%) of the women with SCI had given birth to a child after injury.

Of those who were single, half (51%) of the women with SCI and 69% of the controls wanted to have a stable partner and the others were satisfied being single.

For single women, both SCI and controls, wanting a partner, the most common reason reported for being single was that they had not met the "right" partner. Other reasons reported by the women with SCI were feelings of inadequacy, fewer opportunities to find new contacts, low self-esteem, and feelings of being unattractive, doubts about sexual abilities and fear of

Table III. Reasons listed for being single (more than one reason could be given)

Reason	SCI	Controls
	<i>n</i> = 102 <i>n</i> (%)	<i>n</i> = 82 <i>n</i> (%)
Have not met the "right" partner yet	55 (54)	70 (85)
Low self-esteem	36 (35)	16 (20)
Feelings of being unattractive	39 (38)	9 (11)
Fewer opportunities to make new contacts	49 (48)	28 (34)
Doubts about sexual ability	34 (33)	4 (5)
Decreased sexual interest	14 (14)	6 (7)
Fear of bladder and/or bowel leakage	32 (31)	0
Feelings of being inadequate when confined to a wheelchair or having a visible disability	54 (53)	–
Feelings of inadequacy	–	11 (13)
Lack of time	6 (6)	15 (18)

SCI: spinal cord injury.

bladder and/or bowel leakage. These reasons were given by the controls to a much lesser extent, and the last reason not at all (Table III).

Sexual self-confidence

Sixty-two percent of the controls considered themselves to be very or rather attractive as women compared with 41% of the SCI women after injury ($p < 0.001$) and 74% before injury ($p < 0.001$). Among women with complete injury, more than one-third (37%) felt that they were not at all attractive as women, compared with 21% of women with incomplete injury ($p = 0.01$). Approximately one-third of the women with SCI felt that other people considered them to be less attractive as women. The majority of the controls (91%) and the women before the injury (93%) reported that they had been able to sexually please a partner, compared with 66% ($p < 0.001$) after injury.

Sexual interest

Half (51%) of the women who had been sexually active before injury reported that the importance of sex had decreased after injury, 40% reported that its importance was unchanged, whereas 8% mentioned that the importance of sex had increased. Women with preserved genital sensation rated sex more important than women with absent or much decreased genital sensation ($p < 0.001$).

Women with complete spinal cord lesions (tetraplegia 63%, paraplegia 61%) more often reported that sex had become less important than did those with incomplete lesions (tetraplegia 31%, paraplegia 33%). The perception that sex was less important after injury was significantly ($p < 0.01$) more common among women living in pre-injury relationships (65%) than among those who had met the partner post-injury (44%).

Sexual desire

Significantly more of the controls reported having a rather or very great sexual desire than did the SCI women (54% vs 38% $p < 0.001$). Many women with SCI experienced a major decline in sexual desire. Three-quarters (75%) reported that they had

had a rather or very great sexual desire before the injury, i.e. significantly ($p < 0.001$) more than after the injury. Perceived sexual desire was significantly ($p = 0.01$) related to level and completeness of SCI and genital sensation. The reasons listed by the women themselves for reduced sexual desire were sensory loss, impaired bladder and bowel control, decreased mobility, paralysis, inability to reach an orgasm, pain, feelings of being ashamed of the body, feelings of not being attractive, medication, lack of partner, tiredness, depressed mood, too many preliminaries before the sex act, low self-esteem, too many worries, etc. Ten percent of the controls and 18% of the SCI women used antidepressants such as citalopram, sertraline, etc. Sixty-eight percent of the SCI women and half of the controls who used antidepressants reported very or rather low sexual desire.

Sexual arousal and sexual behaviour

More than half (53%) of the women who had been sexually active after injury reported that their possibilities to become sexually aroused were less compared with before the injury, whereas 29% reported no change. Approximately half of the women with incomplete tetraplegia (51%) and 45% with incomplete paraplegia reported no change in their ability to become sexually aroused compared with 22% with complete tetraplegia and 15% with complete paraplegia. Nine percent of the women with SCI and 5% of the controls claimed that they never became sexually aroused.

The preferred means for getting sexually aroused are listed in Table IV. Hugging, kissing and caresses were listed as important by approximately three-quarters of the women with SCI both before and after the injury, and the control women. Almost half of the women with SCI considered it important to be caressed, even on body parts with no sensation, in order to become sexually aroused.

Sexual fantasies ($p < 0.001$) and hearing impressions ($p < 0.001$) were significantly more important for the SCI

women than for controls, while genital caressing with hands and mouth were significantly ($p < 0.001$) less important for the injured women. Sexual intercourse was not as important after injury as before injury ($p < 0.001$). However, the after injury frequency for sexual intercourse was of the same magnitude as for controls. Otherwise the reported frequencies of preferred sexual expressions are very similar for before injury in SCI women and the control women.

Many of the SCI women reported that they tried to compensate for decreased or absent sensation by fantasizing and thinking about how sex had been before the injury, as well as by using all their senses and their erogenous zones of the body. Several of the women pointed out that more powerful and longer stimulation was important to enhance sexual pleasure. Nearly a quarter of the SCI women (21%) reported that their sexual repertoire was more varied after injury, whilst 37% reported no change and 42% reported that it had decreased.

Being in the right mood to be *willing to have sex* had been very important before injury for 30% of the women compared with 48% after injury ($p < 0.01$). Being in the right mood to be able to *experience pleasure during* sexual activity was significantly ($p < 0.01$) more important after injury (56%) than before (30%). Of the controls 39% considered it to be very important to be in the right mood to be *willing to have sex* and 49% thought it was very important to be in the right mood to be able to *experience pleasure during* sexual activity.

More than a quarter (27%) of both the SCI women and the controls mentioned that they would like to engage in sex more often than they actually did. The women with SCI listed several reasons for not engaging in sexual activity as often as they wished. The most frequently mentioned reasons were sensory loss or decreased sensation (44%), followed by reduced sexual desire (31%), pain (29%), and decreased mobility (29%). Other frequently mentioned reasons were fear of leakage from the bladder (25%), not being able to have sex spontaneously (25%), problems with positioning (21%), fear

Table IV. Sexual expressions listed to be of importance for becoming sexually aroused

Preferred type of sensory stimulation for becoming sexually aroused	Before injury <i>n</i> = 415 <i>n</i> (%)	After injury <i>n</i> = 415 <i>n</i> (%)	Before vs after injury <i>p</i> -value	Controls <i>n</i> = 502 <i>n</i> (%)	Before injury vs controls <i>p</i> -value	After injury vs controls <i>p</i> -value
Visual	137 (33)	147 (35)	1	131 (26)	0.027	0.0028
Hearing	65 (16)	88 (21)	0.0021	58 (12)	0.086	< 0.001
Taste	45 (11)	55 (13)	0.2101	53 (11)	0.97	0.25
Smell	97 (23)	113 (27)	0.3915	147 (29)	0.052	0.54
Sexual fantasies	114 (27)	156 (38)	< 0.001	125 (25)	0.42	< 0.001
Hugging, kisses, caresses	297 (72)	304 (73)	0.7428	372 (74)	0.43	0.83
Caresses of the breast with hands	198 (48)	220 (53)	0.7035	232 (46)	0.70	0.047
Caresses of the breast with mouth	192 (46)	209 (50)	1	257 (51)	0.16	0.85
Caresses of the genitals with hands	226 (54)	171 (41)	< 0.001	307 (61)	0.048	< 0.001
Caresses of the genitals with mouth	173 (42)	109 (26)	< 0.001	198 (39)	0.53	< 0.001
Vibrator stimulation of clitoris	38 (9)	37 (9)	0.4050	45 (9)	1	1
Vibrator stimulation with artificial penis	26 (6)	30 (7)	1	20 (4)	0.16	0.045
Stimulation of vagina and clitoris	112 (27)	84 (20)	< 0.001	123 (24)	0.43	0.14
Sexual intercourse	231 (56)	171 (41)	< 0.001	211 (42)	< 0.001	0.85
Caressing of body parts at the level of injury	n.a.	41 (10)		n.a.	n.a.	n.a.

p-values for Fisher's exact test.

n.a.: not applicable

of leakage from bowel (20%), feelings of being unattractive (20%), being ashamed of the body (17%), fear of failing (17%) and lack of self-confidence (15%).

Approximately 15% of women in both groups wanted longer foreplay and more frankness when talking about sex with the partner. Approximately 30% of women with SCI and controls, wished to have more intimacy, emotional closeness and greater sexual desire. Forty percent of the women with SCI and 65% of the controls reported that they sometimes masturbated to give themselves sexual pleasure ($p < 0.001$). Approximately one-third of these women in both groups used sexual aids, such as a vibrator, artificial penis and hand-shower, to enhance sexual pleasure. Masturbation was more commonly used by SCI women with preserved or partly reduced genital sensation than by women with no or much decreased genital sensation ($p < 0.001$).

Approximately two-thirds of the women with SCI reported problems with leakage from the bladder and/or bowel during sexual activity. The majority emptied the bladder (80%) and/or the bowel (28%) before engaging in sexual activity, 15% put a towel on the bed, 15% reduced their liquid intake and 10% took medication against leakage. Two-thirds of the women used some kind of contraceptives, mainly contraceptive pills, condoms or intra-uterine contraceptive device.

Sexual satisfaction

Among the 210 women with SCI (married, cohabiting or with a stable partner relationship) who had been sexually active during the past 4 weeks, 23% had always or almost always achieved an orgasm, compared with 42% of the controls ($p < 0.001$). Significantly ($p < 0.001$) fewer women (51%) were very or rather satisfied with their sex life after injury compared with before injury (83%) and compared with the controls (62%). It should be noted that nearly twice as many women with SCI as controls (44% vs 24% $p < 0.001$) reported that they were very satisfied before injury. The respondents' perceptions of their sex life in general are shown in Fig. 1. Women with preserved genital sensation enjoyed their sex life more than women with absent or much decreased genital sensation ($p < 0.001$).

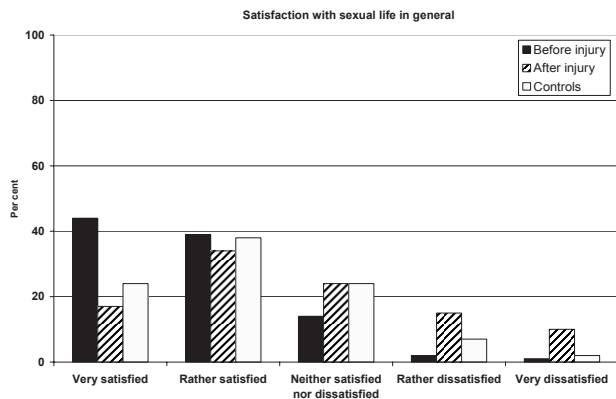


Fig. 1. Satisfaction with sexual life in general in women with spinal cord injury before and after injury and in controls.

Information and sexual counselling

Sixty-one percent of the women had not received any information about sexuality after the injury. At the time of the investigation, 40% expressed a wish to receive information. Furthermore, only 7% of the women with a partner at the time of the injury reported that their partner had received any information about sex after the injury. There were, however, no differences found in any of the measured variables between those who had received information about sexuality after the injury and those who had not.

Many women pointed out the importance of being offered the opportunity to talk to someone with good knowledge about the impact of a SCI on sexuality and sexual life. Many of the women also mentioned that it was important that the information not be given too early after the injury, but that they should be informed whom they could talk to when the need arose. It was also pointed out that talking to someone with personal experience of a similar situation was of great help. Among the recommendations, given by the participants to recently injured women were; ‘Don’t give up, give yourself time, learn about yourself and your body, experiment with positions and don’t be afraid of using sexual aids. Be open and honest to your partner, accept your sexuality and respect yourself’.

DISCUSSION

This study shows that it is possible for women with SCI to have an active and satisfying sexual life in spite of the many changes in sexual life engendered by the injury. Most aspects of sexuality were negatively affected by the injury. Many of these impacts were of a physical or medical nature, but psychological factors, such as desire, subjective arousal, body image, self-esteem and self-confidence, were also affected by the injury. For many women, the importance of sex had declined after injury and sexual desire, arousal, activity and satisfaction were lower than before injury and compared with controls.

It is interesting to note that a significantly higher proportion of the women with SCI than controls reported high levels of pre-injury desire, satisfaction and attractiveness. This may be a memory bias or a glorification of the time before injury. The finding is of importance when interpreting results from non-controlled studies because retrospective reports may well exaggerate the effects of injury on sexual functioning.

SCI was shown to impact on marital relationships. Considerably more of the women with SCI than controls were single at the time of investigation. Furthermore, more than half of the relationships existing at the time of injury had terminated, which is higher than the Swedish national average. The proportion of divorced or separated women in this study was also slightly higher than in an earlier, predominantly male study (27). For the single women in our study who wished to have a partner, one of the frequently mentioned obstacles was to find dating opportunities. Also, many of the women with SCI felt that they would be an unattractive prospect for any partner and thus avoided intimate relationships. A new relationship may be

more influenced by sexual attractiveness and sexual capacity than a long-term relationship.

Consistent with results from other studies (1, 4–8) more than three-quarters of the women in our study had been sexually active after the injury, and many within a relatively short time after the injury, i.e. less than 6 months. In this study and Jackson & Wadley's study (7) women with a complete tetraplegia were over-represented among those without any sexual experiences after injury. This indicates that women with severe injuries have greater difficulties in establishing or maintaining sexual relationships. The question as to whether this is due to these women avoiding intimate relationships or to able-bodied persons avoiding women with severe functional limitations was not elucidated.

Decreased or absent genital sensation seems to significantly affect sexual life after SCI. Sensory loss or decreased sensation was a common reason for reduced sexual desire and activity. Furthermore, women with preserved genital sensation appreciated their sex life more than women with absent or much decreased genital sensation. Masturbation was likewise more commonly used by women with SCI with preserved or partly reduced genital sensation than by women with no or decreased genital sensation, which may explain the lower frequency of masturbation among women with SCI compared with control women. Finally, caressing of genitals with hands or mouth was reportedly of less importance after injury, which may well correspond to decreased or absent sensation in the genitals.

Our observations are in accordance with recent findings of an inverse relationship between developing new areas of arousal above the level of lesion and lack of sensation or movement below the lesion. Likewise, orgasm post-injury was positively associated with the presence of genital sensation (28).

Many facets of women's sexual functioning have been shown to be different from the linear and rather genitally focused model of human sexual response by Masters & Johnson (29) and Kaplan (30). To better understand the complexity of the circumstances affecting sexuality after SCI we have adopted an expanded conceptual framework (Fig. 2) that combines

interpersonal, contextual, psychological and biological factors (31). This model takes into account the many reasons why women agree to or refrain from sexual activity and underlines the importance of subjective sexual arousal.

According to the women with SCI, emotional closeness, the desire to express and receive love and to share physical pleasure were most important for having an active and satisfying sexual life. Thus, the motivations of the women with SCI to engage in sexual activity were intimacy-based rather than primarily sexual. Fulfilment of spontaneous or initial desire *per se* was not often mentioned as the primary reason for sexual activities. Our results concerning the controls as well as those of several other studies have shown that this is also true for many women without physical impairments, especially those in long-term relationships (32–34).

Many of the women in our study, both women with SCI and controls, wanted to engage in sex more often; however, for the women with SCI the obstacles to this were multiple and complex. Besides physical problems (sensory loss, bladder and bowel incontinence, problems with positioning), psychological (poor self-image, low desire, distress) and interpersonal problems (lack of emotional closeness with partner, no current partner) were common. Unfortunately, we did not ask the controls about their reasons for not engaging in sex as often as they wished.

According to Basson's model (Fig. 2), a requisite for a woman to become sexually aroused is that she be positively motivated for sexual activity; however, sexual stimuli *per se* do not necessarily lead to subjective arousal. The sexual stimulation and its context must be mentally exciting and pleasurable for the women (31). Approximately half of the women with SCI reported that their possibilities to become sexually aroused had decreased after injury. Due to decreased or absent sensation below the level of injury, women with SCI may be unable to respond to the same sexual stimuli that were pleasurable before injury and the physical stimuli generating subjective arousal may be insufficient. Therefore it is not surprising that longer foreplay and more powerful stimulation were often required to enhance sexual arousal and pleasure. However, genital arousal in women was very weakly correlated to subjective arousal in women with no damage of the autonomic nervous system (35). The use of antidepressant medication reported by 18% of the women with SCI may also contribute to declines in sexual arousal (36).

Exploring "new" erogenous zones and using all possible input from other senses were considered more important than before injury (28). Most of the women thought that hugging, kissing and caressing (also of body parts with no sensation) were essential and pleasurable ingredients of the sexual experience.

Positive emotional feedback from the sexual experience, such as feelings of enjoyment and self-confirmation, will enhance subjective arousal. In contrast, negative psychological factors, such as distractions of daily living, low sexual self-confidence and lack of emotional intimacy with the partner may inhibit the mental processing of the sexual stimuli, thus further reducing the women's arousal (31). Many women in our study pointed

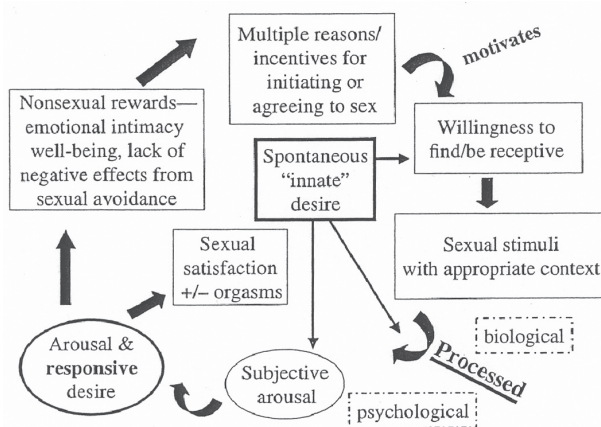


Fig. 2. Women's circular sexual response cycle of overlapping phases of variable order. Adapted from Basson et al. (31). By permission from Blackwell Publishing.

out the importance of being in the right mood both before and during sex to become receptive to sexual stimulation. Sexual fantasies were used more frequently than before injury. This might be a deliberate means to avoid distractions and to focus on the sexual stimulation (31). When asked how subjective arousal could be improved, one-third of the women wished to have more intimacy and emotional closeness. When physical sexual stimulation becomes less "effective" due to sensory loss or decreased sensation, the context of the sexual experience and the emotional intimacy between partners may become even more important to enhance subjective, mental arousal.

Enjoyable sexual arousal is an important component of the female sexual response cycle in that it helps to trigger sexual desire (Fig. 2). Even when initially absent, desire may be triggered during the sexual experience once the women has been subjectively aroused (responsive desire) (31). Low sexual desire was frequently reported both by the women with SCI (62 %) and the controls (46 %). However, the lack of initial (spontaneous) desire does not preclude the experience of sexual desire that is subsequent to or coincides with subjective arousal. In addition to the woman's original intimacy-based motivation, she may achieve a desire to continue the experience for sexual reasons (31).

Sexual satisfaction may occur with or without orgasms (Fig. 2). Consistent with results from another study (11), approximately half of the SCI women never (32%) or seldom (21%) reached an orgasm. Even if physiological orgasm is not possible, rewarding or pleasant, the sexual experience can be completed by psychological satisfaction. If the sexual experience has been emotionally and physically rewarding (Fig. 2) it will enhance the couple's emotional intimacy, thereby increasing the motivation for subsequent sexual activity. Many of the women with SCI were satisfied with the sexual part of their relationships. A warm and close relationship and deep feelings of affection for the partner may compensate for not reaching an orgasm during sexual activity.

This study clearly shows the complexity of factors influencing sexuality in women with SCI. Successful sexual rehabilitation therefore requires a holistic approach, taking into account physical, psychological and interpersonal circumstances. Low self-esteem and feelings of unattractiveness were common reasons for not wanting or not having the courage to be intimate and sexual. Regaining self-worth and the sense of being feminine takes time. The process of mourning the losses imposed by the injury requires psychological support (11) and sometimes interventions. The women with SCI emphasized that it is very important to have the opportunity to talk to other women, who have learned to cope with the consequences of a SCI, both during initial rehabilitation and after coming home. Besides serving as role models, the women could also serve as a source of much useful and practical advice and knowledge concerning everyday life, including sexuality, that they have gained from experiencing first hand a similar situation. In a recent study the importance of peer counselling was stressed by women with SCI (37).

The majority of the women with SCI expressed dissatisfaction with the quality and quantity of sexuality-related rehabilitation services. Involvement of the partner in sexual

rehabilitation programmes was very rare. The time considered as best suited for information on sexual matters after injury appeared to be highly individual, but most of the women agreed that information should be given during initial rehabilitation, be initiated by the staff, and be on an individual basis. Films, books and other written information should be easily available at the spinal unit. As sexual needs and concerns may not become evident until after returning home to the partner or when trying to find a new partner, it was also considered important to have continued opportunities for further discussions and counselling after discharge. At this point, the women's individual experiences, expectations and attitudes can be focused on. Specific and concrete solutions can be discussed concerning how to optimize sexual stimulation (physical and mental) to enhance sexual pleasure and satisfaction for the women – and their partners. Give it time, explore your "new" body to become aware of new signs and reactions, and experiment with a variety of sexual options and positions were some of the pieces of advice that the women with SCI considered important to give to women who had recently sustained a SCI.

Limitations of the present study include the cross-sectional design, which precludes us from knowing the direction of the relationship between the variables. Another weakness is that many of the women with SCI and controls chose not to participate in the study, which is not surprising given the subject of the study. On the other hand, the response rate among the Swedish women with SCI was high and satisfying (73%), and actually represent more than 50% of all participants. The economic compensation offered to the Swedish women may have contributed to their willingness to respond.

Although our SCI sample was heterogeneous, encompassing a wide range of ages, length of times since injury, neurological status, and marital status, we do not know if the participants differed from non-responders in any appreciable way. It may be speculated that women with a generally poor and unsatisfying sexual life on average feel less motivated to answer questions about their sexual life than those who have an active and satisfying one. Despite our low response rates, we believe that we have gleaned enough knowledge from our data to be able to draw some conclusions that are relevant for many women with SCI.

In conclusion, this study shows that women who are able to overcome the physical restrictions and mental obstacles due to injury can regain an active and positive sexual life together with a partner.

Sexual information and counselling should be available both during initial rehabilitation and later when the women have returned to their homes. An awareness and understanding of the expanded conceptual model of sexual arousal and response, elucidating the role of psychological and interpersonal circumstances on sexuality, may help these women to recognize, appreciate and address the potential consequences of the SCI.

ACKNOWLEDGEMENTS

This article has been fully handled by one of the Associate Editors, who has made the decision for acceptance.

We thank the heads of the spinal cord centres in the Nordic countries for providing the names and addresses of the women with SCI. For statistical consultation and analyses we thank Nils-Gunnar Pehrsson and Aldina Pivodic. Above all else, we express our sincere thanks to all the women who participated in the study and to the women in kNORR for initiating this study and for their input in developing the questionnaire. This work was supported by grants from the Swedish National Associations of People Disabled by Road Accidents and Polio (RTP), Landsforeningen af Polio-, Trafik- og Ulykkesskadede (PTU), Denmark, the Association of Cancer and Road Accident Victims (CTRF), Sweden and the Norrbacka-Eugenia Foundation, Sweden.

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