

## Paraplegia

# Sexual Ability, Activity, Attitudes and Satisfaction as Part of Adjustment in Spinal Cord-Injured Subjects

A. Siösteen, BA,<sup>1</sup> C. Lundqvist, MD,<sup>2</sup> C. Blomstrand, MD, PhD,<sup>2</sup> L. Sullivan, MD, PhD,<sup>1</sup> M. Sullivan, PhD<sup>3</sup>

<sup>1</sup>Spinal Injuries Unit, Department of Neurosurgery, <sup>2</sup>Department of Neurology, <sup>3</sup>Department of Medicine I Health Care Research Unit, Gothenburg University and Sahlgrenska University Hospital, Gothenburg, Sweden.

### Summary

*Changes in different aspects of sexuality were investigated and related to overall quality of life and physical, psychological and social adjustment in 73 SCI subjects, who were sexually active both before and after injury. Items on sexual interest and satisfaction were treated as one composite variable, the SIS scale, measuring sexual adjustment after injury.*

*Despite severe genital dysfunction, more than half of the subjects (57%) rated their sexual relations after injury as satisfying or at least rather satisfying. The majority continued having intercourse, although many of them more seldom than before, and about half experienced orgasm.*

*Sexual adjustment after injury was closely and positively correlated to frequency of intercourse, willingness to experiment with alternative sexual expressions and young age at injury. Physical and social independence and a high mood level were further positive determinants of sexual adaptation after injury, whereas the neurological level and completeness of injury showed no significant correlation with sexuality.*

*It is suggested that sexual information and counselling should be integrated in the total care of the SCI patient to reduce the negative effects on sexuality, caused by the injury.*

**Key words:** *Spinal cord injuries; Sexual adjustment; Function; Mood; Sexual interest and Satisfaction scale.*

Spinal cord injury often severely affects both genital and sexual functioning. Early studies described in detail genital dysfunctions related to the level of injury and sexual function was defined in terms of erection, intercourse and fertility (e.g. Bors and Comarr, 1960; Griffith *et al.*, 1973). In later studies, psychological aspects of sexuality were explored, showing that sexual interest and need for emotional, sexual expressions often remain intact after SCI (Hohmann, 1972; Phelps *et al.*,

1983; Sjögren and Egberg, 1983). Little has been published to document the relationship between sexuality in these patients and their adjustment after injury (Berkman *et al.*, 1978).

In this study three interacting aspects of sexuality were examined: the physical aspect, comprising genital function, motor and sensory loss, and medical complications; the psychological aspect, including self-esteem, feelings of attractiveness as a partner, and satisfaction with sex life; and the social aspect characterising the subject's relationship with his or her partner. A spinal cord injury will often affect all these aspects of sexuality.

The aim of this investigation was to study the impact of SCI on sexual ability, activity, attitudes and satisfaction and to relate the findings to neurological status, function and mental well-being. The study is part of a comprehensive follow-up of SCI subjects treated at the Spinal Unit in Gothenburg.

### **Material and methods**

Out of a series of 98 consecutive subjects with SCI, treated or followed up at the Spinal Unit, 73 who reported sexual experience both before and after the injury were included in the study. There were 60 males and 13 females. The subjects' ages varied between 16 and 72 years, median 34 years. The age at injury ranged between 15 and 67 years, median 27 years. No participant had been injured less than 1 year. A neurological examination was performed by two neurologists independently, who, in cases of disagreement, re-examined the subjects together. The neurological lesion level ranged from C4 to L4. There were 17 (23% of all) complete tetraplegics and 19 (26%) incomplete. Seven (10%) of the paraplegics were complete and 30 (41%) were incomplete. Forty eight (66%) of the subjects were married or lived with a permanent partner, 25 (34%) were living alone.

All subjects recruited to the study had participated in a series of information and counselling sessions on sexual problems and options in spinal cord injuries. All thus had earlier experience of the investigator, personally and professionally. Before giving their informed consent to take part in the study, the subjects had read written information on the study. Both in the latter and by oral appeal, the subjects were urged only to agree to items that they were certain applied to them. Not until then did the subjects sign a 'study contract' for informed consent.

#### *Study-specific questionnaire*

A structured questionnaire was designed to explore different aspects of sexuality before and after the injury. The questionnaire was completed with the same investigator present (A.S.) and the answers were checked by personal interview. Thus, misunderstandings and omission of answers were avoided.

The first five questions were used to determine the subjects' social status and, if they had a permanent sexual partner, whether they were sexually active, i.e. carrying on intimate sexual activity with or without intercourse. The next two questions were constructed to assess general satisfaction with sex life before and after injury, using a visual analogue scale (VAS). A frequently used VAS is the horizontal line, 10 cm long. In order to reduce the need for abstract thinking (Carlsson, 1983), this study applied a modification, a 6 cm long line with the

numbers 1 to 7 as reference. One end represented very dissatisfying sexual relations, the other very satisfying. The subjects were asked to make a mark on the line at the point best considered to represent their satisfaction. A change of score between post- and pre-injury values was calculated for each subject.

The subjects' perception of the impact of the SCI on sexuality and on a series of sexual functions, performance and desire was explored in six items. A four-point response scale was used: increased, unchanged, decreased, and absent.

The subjects were asked to check every item relating to reasons for their reported decrease of personal sexual pleasure and reduction of their possibilities of giving such pleasure to their partner. Items included covered physical limitations and disabilities in spinal injuries: decreased motility, loss or decrease of sensibility, erectile and orgasmic problems, spasticity, bladder leakage, dysreflexic rise of blood pressure, and fatigue. Additional items concerned routine sexual habits after injury, difficulties in communicating about sexuality with the partner, and low self-esteem. Two items were designed to explore the subjects' ability to communicate with their partners about sexuality and their willingness to experiment with various sexual options. Supplementary open answers were also recorded.

#### *Construction of the Sexual Interest and Satisfaction (SIS) scale*

Items with psychological content—interest in sexuality and sexual satisfaction—were treated as one composite variable, the SIS scale. Areas covered, questions, scale points, and scores are shown in Table I. Internal consistency, determined by Cronbach's alpha, was 0.96, and a principal component analysis confirmed the unidimensionality of the scale. Factor loadings on the principal factor ranged between 0.72 and 0.82. Sixty per cent of the variance was then explained. The range of SIS scale scores was 0–16, mean  $8.52 \pm 4.16$  (median value 9).

#### *Selected questions from other parts of the follow-up study*

Quality of life (QL) was recorded, using the VAS technique. Ten items were developed to elucidate SCI subjects' perception of loss of independence (not being able to walk or move freely, being in need of help with many things, not being able to do things when wanted), complications (urinary, intestinal, dermatological including pressure sores, pain, sexual) and social stigma (untoward reactions from others, not being able to hide oneself in a crowd). The response format was a four-point scale from very difficult to not at all difficult. The scores of the items were added to form the SCI problem scale. The procedure and metric properties of this scale will be described elsewhere (Lundqvist *et al.*, 1989, to be published). In this study, the two most prominent questions for the description of SCI subjects' QL were applied (Table II).

#### *Generic questionnaires*

Health status was recorded according to the Sickness Impact Profile (SIP) (Bergner *et al.*, 1981), a widely used behaviour-based measure. It has been proved valid and reliable, sensitive to clinical changes, and comprehensive in assessing a wide range of dysfunctions.

**Table I** Sexual Interest and Satisfaction (SIS) scale: Areas and underlying questions.

Area	Question	Scale point	Score								
Sexual desire	How is your sexual desire now compared to before injury?	Increased, unchanged, decreased, non-existent	3-0								
Importance of sexuality	How important is sexuality to you now compared to before injury?	Increased, unchanged, decreased, non-existent	3-0								
General satisfaction with sex life before injury	How was your relationship, most of the time, with your sexual partner before injury?	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%;"></td> <td style="width: 25%; text-align: center;">1 2 3 4 5 6 7</td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> </tr> <tr> <td style="text-align: left;">Very dissatisfying</td> <td></td> <td style="text-align: right;">Very satisfying</td> <td></td> </tr> </table>		1 2 3 4 5 6 7			Very dissatisfying		Very satisfying		7-1*
	1 2 3 4 5 6 7										
Very dissatisfying		Very satisfying									
General satisfaction with sex life after injury	How is your relationship, most of the time, with your sexual partner after injury?	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%;"></td> <td style="width: 25%; text-align: center;">1 2 3 4 5 6 7</td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> </tr> <tr> <td style="text-align: left;">Very dissatisfying</td> <td></td> <td style="text-align: right;">Very satisfying</td> <td></td> </tr> </table>		1 2 3 4 5 6 7			Very dissatisfying		Very satisfying		7-1*
	1 2 3 4 5 6 7										
Very dissatisfying		Very satisfying									
General satisfaction after injury compared with before injury	-----	Difference between post- and pre-injury values on VAS	Change score**								
Self-perceived personal satisfaction	How are your possibilities and your ability to enjoy sexuality <i>yourself</i> , compared to before injury?	Increased, unchanged, decreased, non-existent	3-0								
Self-rated ability to give partner satisfaction	How are your possibilities and your ability to give <i>your partner</i> sexual fulfilment, compared to before injury?	Increased, unchanged, decreased, non-existent	3-0								
SIS Scale	Composite of questions	Summary of scale points	18-0								

\* Rescaled to fit the composite score: 1.0 = 0; 1.1 - 3.0 = 1; 3.1 - 5.5 = 2; >5.5 = 3

\*\* Rescaled to fit the composite score: <-2.0 = 0; -2.0 - <0 = 1; 0 = 2; >0 = 3

**Table II** Brief Quality of Life QL questionnaire for SCI subjects\*

Items in scale	Composite variable (range of score)	Correlation with total QL rating r
1. I am doing fewer social activities with groups of people		
2. I get dressed only with someone's help	Dysfunction-SIP (0-100)	-0.61
3. I am getting around only within one building		
4. My sexual activity is decreased		
1. I look forward with enjoyment to things		
2. I can laugh and see the funny side of things	Depression-HAD (0-9)	-0.69
3. I have lost interest in my appearance		
1. How difficult is it not being able to walk or move freely?	Problem-SCI (0-6)	-0.60
2. How difficult is it being in need of help with many things?		

\* Scale construction described elsewhere (Lundqvist C *et al.*, 1989, to be published)

r = Pearson's correlation coefficient

Affective responses were measured using the Mood Adjective Check List (MACL) (Sjöberg *et al.*, 1979). The instrument offers a quantitative, composite measure of mental well-being. Being a measure of feelings, it represents a complement to the SIP, which is a dysfunction measure. For this study, the three main MACL dimensions were considered satisfactory.

In addition, the Hospital Anxiety and Depression Scale (HAD) (Zigmond and Snaith, 1983) was applied. It measures emotional distress not directly related to immediate symptoms and experiences but rather reflects the emotional background linked to dysfunction or prognosis. A recently completed multicentre study in cancer patients has given further evidence of the validity of the scale in screening for psychiatric morbidity (Hopwood *et al.*, 1989, to be published).

In a model of consecutive statistical analyses, a very brief QL questionnaire was derived for routine clinical use in SCI patients (Lundqvist C *et al.*, 1989 to be published). The predominant questions included four SIP items and three HAD items (Table II). The composite variables seen in the table were used in this study.

### Statistical methods

All data were analysed by means of the Statistical Analysis System (SAS). Standard methodology was applied for construct validation of scaling procedures including the calculation of Cronbach's alpha and principal components (Nunnally, 1978).

Fischer's non-parametric permutation test was used for the significance testing of differences between groups (Bradley, 1968).

The relationship between the SIS scale and sociodemographics, neurological, functional, and mental status and total QL was explored by means of Pitman's permutation test.

A four-step model of consecutive analyses including bivariate, partial and multiple correlations was applied for prediction of SIS scale scores from a selection of potentially influential variables.

## Results

### *Sexual function and activity*

**Table III** Sexual function and performance after injury (n=73 SCI subjects)

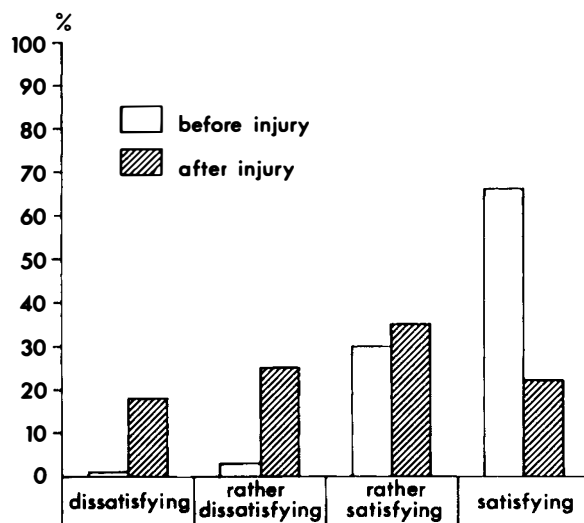
Frequency of	Increased %	Unaltered %	Decreased %	Absent %
Erection sufficient for coitus (n=60 males)	3	40	40	17
Ejaculation (n=60 males)	0	23	29	48
Orgasm				
males (n=60)	1	23	23	53
females (n=13)	0	33	25	42
Intercourse				
males (n=60)	2	30	32	36
females (n=13)	0	50	33	17

As shown in Table III, most of the subjects reported that considerable changes in

sexual function had taken place after the injury. Thus, 83% of the males claimed that they had erections sufficient for coitus although 40% of them less often than before injury. Twenty three per cent reported unaltered frequency of ejaculation. Nearly half of the males and slightly more than half of the females experienced orgasm but many of them not as often as before injury. Sixty four per cent of the males and 83% of the females reported having intercourse, although half of them more seldom than before.

### *Sexual interest and satisfaction*

No significant gender difference was found in the following aspects of sexuality and the results will therefore refer to all the subjects. Sixty three per cent of the respondents reported unchanged sexual desire and 70% thought that sexuality was as important to them as before injury.



**Figure** Distribution of subjects' reports on general satisfaction with sexual relations before and after injury (n=73 SCI subjects).

The figure shows general satisfaction with sexual relations before and after injury. Nearly all of the respondents (96%) rated their sexual relations as satisfying or rather satisfying before injury while 57% said they were satisfied or rather satisfied after injury. One per cent reported their sexual relations as dissatisfying before injury, as opposed to 18% after injury. Overall, the pre-injury reports display a continuously greater number of respondents with increasing levels of satisfaction, whereas after injury the highest number of respondents reported their sexual relations to be rather satisfying and fewer scored in the most satisfied group.

Fifty seven per cent of the respondents reported unchanged ability to satisfy their partners after injury but only 33% rated their ability to feel personal satisfaction from sexuality unchanged.

Twenty five per cent of the spinal cord injured said they had developed their ability to communicate with their partners about sexuality and 19% reported that

**Table IV** Sexual communication and experimentation after injury, compared to before injury (n=73 SCI subjects)

	Ability to communicate with partner about sex %	Ability to experiment with new sexual expressions %
Better now	25	19
Same	62	50
Better before	13	31

they had expanded their range of sexual expressions after injury (Table IV). Both those who reported improved ability to communicate and those who experimented with new sexual options expressed more satisfaction with the existing sexuality ( $p = <0.001$ ) and less deterioration of their sex lives after injury ( $p = <0.001$ ).

*Sexuality related to physical status and to quality of life*

**Table V** Relationships of sexual adjustment to clinical variables, total Quality of Life (QL) and health status (n=73 SCI subjects)

Characteristic or variable	Sexual Interest and Satisfaction—SIS scale	
	r	p-level
Level of injury	0.06	n.s.
Frankel class	0.07	n.s.
Age at injury	0.63	***
Partnership status	0.16	n.s.
Total QL rating	0.52	***
Dysfunction <sup>†</sup>	-0.61	***
Depression <sup>†</sup>	-0.45	***
Loss or independence <sup>†</sup>	-0.49	***

<sup>†</sup> = Composite variables, see Table II

r = Pearson's correlation coefficient

\*\*\* =  $p < 0.001$ , Pitman's permutation test

n.s. = non-significant

As shown in Table V, scores on the SIS scale were significantly correlated with ratings of total QL ( $p = <0.001$ ) and also with the scores of the three composite variables of the very brief QL questionnaire ( $p = <0.001$ ). High scores on the SIS scale were significantly related to young age ( $p = <0.001$ ) and injury at an earlier age ( $p = <0.001$ ). The level of lesion and completeness of lesion showed no significant correlation with sexuality, neither did partnership permanence or marital status.

The results from the stepwise regression procedure, used for prediction of sexual adaptation, defined by the SIS scale, are shown in Table VI. Seventy seven per cent of the total variance of the SIS scale scores could be explained by four

**Table VI** Prediction of sexual adjustment in SCI subjects by means of stepwise multiple regression (n=68)

	Sexual Interest and Satisfaction—SIS scale	
	r <sup>2</sup>	p-level
1. Frequency of intercourse	0.56	***
2. Experimentation with new sexual expressions	0.13	***
3. Age	0.05	***
4. Loss of independence <sup>+</sup>	0.02	*
	-----	
multiple correlation coefficient =	0.77	
	-----	
	0.88	

<sup>+</sup> = Composite variable, see Table II

r<sup>2</sup> = Fraction of explained total variance

\*\*\* = p < 0.001

\* = p < 0.05 F-test

variables: 56% by frequency of intercourse (the less decrease after injury the better) and an additional 13% by experimentation with new sexual expressions. A small but significant contribution was given by age (the younger the better) and the questions on loss of independence (the less difficulty perceived the better) respectively. Validation testing, using generic health status measures, confirmed that sexual adjustment was not dependent on psychosocial functioning, e.g. emotional control and mental alertness, but it was strongly dependent on limitations of physical function, e.g. primary activities of daily living and mobility (SIP). Also, sexual adjustment correlated strongly to absence of depression (HAD) and of fatigue (MACL).

## Discussion

The study population was mainly selected from SCI subjects with a rather short time elapsed after injury, median 2 years, and only those who had been sexually active both before and after injury were included. That as many as three quarters of the consecutive series, 73 out of 98, were included may relate to the fact that the majority had attended information sessions on sexual possibilities and options after SCI. The group of 25 abstainers comprised four who had not been sexually active before injury, 10 who discontinued the activity after injury and a further 11 who were in a two early phase after injury. We found no consistent reason for ending sexual life in the group of abstainers.

We were aware of the risk of bias due to memory adjustment and the response set factor of retrospective patients' reports when this study was designed. However, as there was no other way of retrieving the pre-injury data needed, a retrospective collection of information was decided upon and various precautions were taken to ensure optimal quality of the data. Thus, the combined questionnaire-interview technique was chosen to collect information about various aspects of sexuality before and after injury. All peculiarities and omission of answers in the questionnaire were then explained to the investigator in personal interviews. In order to obtain



the subjects' co-operation for data accuracy, the form of consent to participation in the study, signed by the subjects, was partly used as a contract urging the subjects to give correct and carefully considered answers. Lastly, the interviewer was well known to all subjects.

It is quite possible that the high sexual activity after injury found in our material is not representative for other SCI populations. Factors that would limit the generalisability are the imbalance between the number of complete and incomplete paraplegics, the subjects' relative youth (median 35 years), normally related to high sexual activity, and the comparatively short time elapsed after injury (median 2 years), thus not allowing advanced deterioration of the genital organs and tract and impairment of hormone balance. Moreover there is no doubt that the frequent participation in a sexual information and counselling programme such as ours has induced a positive attitude and interest towards sexual activity.

Despite severe loss of genital function and often decreased sensibility and motility, the majority of the subjects claimed that sexuality was still an important part of their lives and that their sexual desire was unaltered after injury. This is largely in agreement with reports by Berkman *et al.* (1978) and Sjögren and Egberg (1983).

Sixty two per cent engaging in intercourse and half of the subjects being orgasmic seem to be high proportions compared to an early report (Comarr, 1970) but in accord with a recent report from Scandinavia (Sjögren and Egberg, 1983). Our findings may partly be due to the large number of incomplete paraplegics. An external reason may be a change in attitudes in our society towards a more permissive and open view of sexuality and disability, supported and encouraged by patients' organisations and the media.

Nearly all reported satisfactory (almost two thirds) or rather satisfactory (approximately one third) sexual relations before injury. This was not unexpected in this group of mainly young subjects selected for the study partly because they had been sexually active before injury. We have systematically noted that patients with SCI even several months after injury often express severe doubts or even hopelessness concerning their possibilities of having a future active and fulfilling sexual life. It was therefore less expected that more than half of the subjects claimed that their sex life was satisfactory or at least rather satisfactory after injury and only 18% found their sexual relations dissatisfying.

Considerably fewer subjects (33%) reported unchanged personal feelings of pleasure from sexual activity. The most commonly mentioned reasons for perceived decline of personal satisfaction were loss of sensibility and motility, orgasmic problems and lowered self-esteem. This finding demonstrates the importance of encouraging spinal cord injured subjects to carefully explore their patterns of sexual responsiveness and to learn to communicate that knowledge to their partners.

The level of lesion and completeness of lesion were not related to perceived satisfaction with sex life, indicating that sexual adjustment after injury is determined by factors other than the degree of disability.

From the prediction analysis (Table VI), it is clear that maintained ability to engage in sexual intercourse is a very important factor for the individual's general interest in sexuality and willingness to lead a sexually active life. It is not possible, however, to draw any conclusions about the cause and effect relationship. A great interest in sexuality probably stimulates the subject's attempts to engage in

intercourse but ability to have intercourse might also increase interest in sexuality and encourage sexual activity.

It also appeared that the broadening of sexual experience by experimenting with alternative sexual expressions was a valuable asset in sexual adjustment. Open communication and experimentation in sexual activities are helpful in able-bodied sexual relations and perhaps even more so when physical limitations interfere with sexual ability and habits. Sexual arousal and pleasure in the female is often increased by a varied and prolonged foreplay, including manual, oral and skin stimulation (Masters and Johnson, 1966; Kaplan, 1974). Such means of sexual expression are mostly not hindered by the SCI and are also commonly used (Mooney *et al.*, 1975; Phelps *et al.*, 1983). With growing experience, the use of a wider range of sexual expressions might not only become a part of sexual foreplay or a substitute for intercourse, but rather a variation and an extension of sexual experience. Thus, it was not surprising that those subjects who had become more skilful in these respects also expressed more satisfaction with their sex lives.

The high correlation between age at injury and better sexual adjustment after injury suggests that young spinal cord injured subjects were less vulnerable to the changes of sexual life than were the older ones. Younger spinal cord injured subjects, not yet being fully established in sexual gender roles and routine sexual habits, probably have better motivation and flexibility to redefine sexual goals and expectations (Sjögren and Egberg, 1983).

Quality of life, represented by the function and mood measurements in this group of subjects, was found to be closely related to sexual adaptation after injury as measured by the SIS scale. Independence in activities of daily living and a good mental condition, free of anxiety and depression, are likely to increase self-esteem and feelings of attractiveness as a partner, both of which are essential in sexual relations. An active and fulfilling sex life will also improve overall adjustment and quality of life. Thus, alterations in quality of life and sexuality seem to be interwoven and reinforce one another.

In conclusion, this study demonstrates that sexual adjustment after SCI is not solely explained by genital function and degree of physical impairment. General satisfaction with life, high self-esteem and sexual behaviours characterised by mutual openness and experimentation will promote an active and satisfying sex life. We believe that dealing with the sexual concerns of the spinal cord injured subjects should be an integral part of the total routine care. Both general psychological and more specific sexual counselling will help to reduce fear, lack of confidence and self-doubts concerning sexuality after injury, which may have more negative influence on sexual adjustment than genital dysfunction in itself.

### Acknowledgement

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