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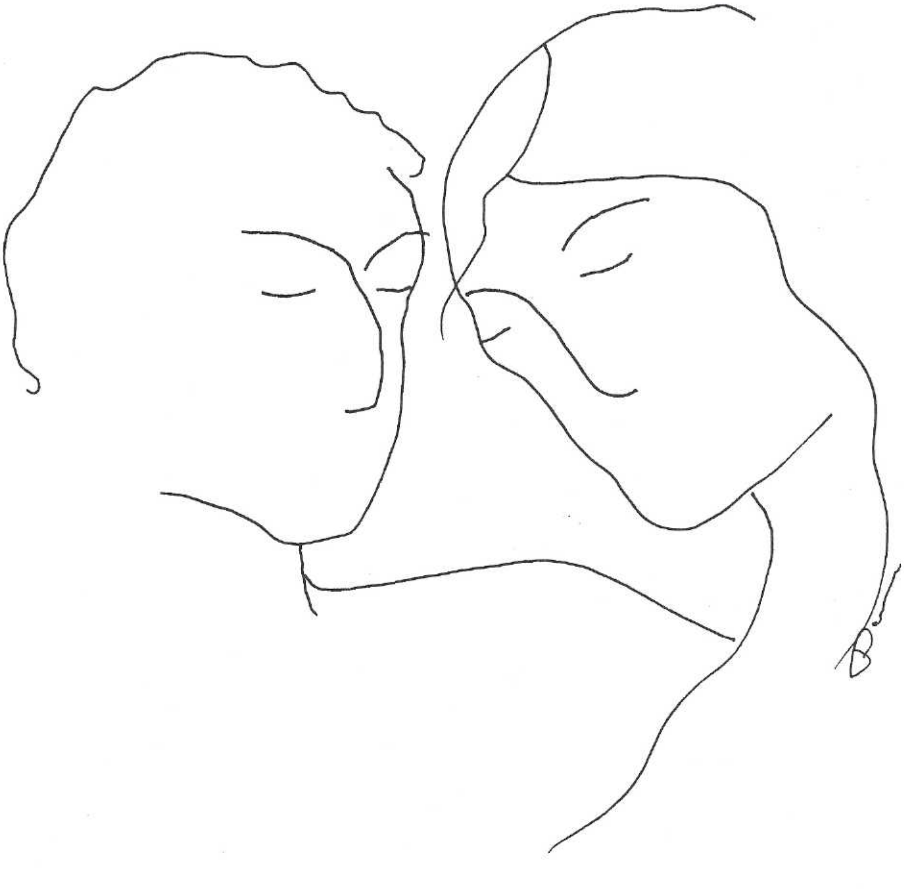
Partner Relationships, Sexuality and Quality of Life

in persons with spinal cord injury and traumatic brain injury



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PARTNER RELATIONSHIPS, SEXUALITY AND QUALITY OF LIFE
in persons with spinal cord injury and traumatic brain injury

AKADEMISK AVHANDLING

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Sexual adjustment and emotional quality of relationships in spinal paraplegia: A controlled study.
Arch Phys Med Rehabil (1996) 77, 541-548.

II. Margareta Kreuter, Marianne Sullivan and Agneta Siösteen.
Sexual adjustment after spinal cord injury (SCI) focusing on partner experiences.
Paraplegia (1994) 32, 225-235.

III. Margareta Kreuter, Marianne Sullivan and Agneta Siösteen.
Sexual adjustment after spinal cord injury - comparison of partner experiences in pre- and postinjury relationships.
Paraplegia (1994) 32, 759-770.

IV. Margareta Kreuter, Ann-Gret Dahllöf, Geir Gudjonsson, Marianne Sullivan and Agneta Siösteen.
Sexual adjustment and its predictors after traumatic brain injury.
Submitted for publication, 1996.

V. Margareta Kreuter, Marianne Sullivan, Ann-Gret Dahllöf and Agneta Siösteen.
Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury.
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PARTNER RELATIONSHIPS, SEXUALITY AND QUALITY OF LIFE in Persons with Spinal Cord Injury and Traumatic Brain Injury

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ABSTRACT

The perception of partner relationships, sexuality and quality of life was investigated in 167 persons with Spinal Cord Injury (SCI) and 92 persons with Traumatic Brain Injury (TBI). The SCI person's partner and a control group consisting of 264 persons were part of the study design. The SCI persons were treated at a spinal unit and the TBI persons were rehabilitated at a rehabilitation department. In addition to medical characteristics, data were collected using well-established general self-assessment instruments and study-specific questionnaires. The main research question concerned sexual adjustment and perceived quality of life, their components and determinants.

Most SCI persons enjoyed their sexual relationship, although it was a common perception that sex life had been better before injury. Significantly more SCI persons experienced lower personal satisfaction with their sex life and also lower self-perceived sexual attractiveness compared with the controls. A varied repertoire of sexual expressions and the perception that the partner enjoyed the sexual part of the relationship and was satisfied with the quality of the couple's sexual relationship played the most important role in sexual fulfilment after SCI, in accordance with results from people in the general population.

Most partners of SCI persons experienced satisfaction in their sexual relationships, affectionate expressions and overall relationship parameters. From the partners' perspective, trust, emotional closeness, mutual concerns and willingness to engage in a variety of sexual activities seem more important for positive sexual adjustment than the physiological aspects of sexuality.

A traumatic brain injury commonly alters sexual functioning as well as desire and sexual dysfunctions increase with the severity of injury. A high degree of physical independence and maintained sexual ability were the most important determinants of the TBI persons' sexual adjustment.

Being in good spirits, i.e. lack of depressive symptoms, and being employed or engaged in studies had a profound positive impact on the perception of global quality of life in both SCI and TBI as well as control persons.

Both SCI and TBI appear to affect partner relationships, functioning, mood and global quality of life negatively. The number of sustained relationships and the number of relationships contracted after injury among both SCI and TBI persons indicate, however, that the impact of these injuries on relationships is not as great as sometimes postulated.

KEY WORDS: Spinal cord injury, traumatic brain injury, quality of life, partner relationships, sexuality, functioning, mood.
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Partner Relationships, Sexuality and Quality of Life

in persons with spinal cord injury and traumatic brain injury

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Göteborg 1997 Sweden

From the Institute of Clinical Neuroscience, Department of Neurosurgery and
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To

Annica, Jessica and Tobias

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CONTENTS

APPENDIX A AND B

PAPERS I - V

ABBREVIATIONS

ADL	Activities of Daily Living
EQR	Emotional Quality of the Relationship
FAM	Functional Assessment Measure
FIM	Functional Independence Measure
GOS	Glasgow Outcome Scale
HAD	Hospital Anxiety and Depression
KSP	Karolinska Scales of Personality
PTA	Post-Traumatic Amnesia
QL	Quality of Life
SAS	Sexual Activity and Satisfaction
SB	Sexual Behaviour
SIAS	Sexual Interest, Activity and Satisfaction
SCI	Spinal Cord Injury
SIP	Sickness Impact Profile
SIS	Sexual Interest and Satisfaction
TBI	Traumatic Brain Injury
VAS	Visual Analogue Scale

INTRODUCTION

Spinal cord injury (SCI) and traumatic brain injury (TBI) are two sudden and unexpected events that cause dramatic changes in life. They occur primarily to young people, previously in full health, who are just beginning to map out a life for themselves.[156] The majority of persons with these two disabilities are young males. The disabilities are caused by sudden damage to the central nervous system, are irreversible and require lengthy hospitalisation. The injuries are sustained from a variety of causes including automobile, motorcycle, sports, fall and diving accidents. The median age of persons sustaining spinal cord injury is about 25 years, with four times as many males as females suffering injury. About 120 new spinal cord injuries occur annually in Sweden.[43] The estimated annual incidence of traumatic brain injuries in Sweden exceeds 5 cases per 1000 inhabitants.[22,143] Most brain injuries occur in the 15-25 year group and with three to four times as many males as females suffering injury.

Both severe SCI and TBI require numerous personal life-style changes. The instant nature of a spinal cord or traumatic brain injury and the consequences of the injuries alter the balance in life and require an adjustment to be made, physically, socially, vocationally and sexually. In spite of the above-mentioned similarities, there is, however, a fundamental difference between these two disabilities. In SCI, the implications are mostly physical, whereas in TBI changes in personality and behaviour are common in addition to the physical limitations.

Adjustment to disability means learning to live by coping with limitations.[156] The adjustment of brain-injured persons does not always follow the process found in other physical disabilities.[58] The theoretical models that deal with loss and adjustment to a disability stress the importance of the continuity between the past and the present in the life of the person.[6,58,99] The process of coping with a disability is based on the assumption that at the acceptance stage a balance between the past and the present is achieved. Clinical experience has shown that in TBI persons, owing to the nature of this condition, the continuity has been disrupted. This disruption in continuity may have a profound impact on the adjustment of the TBI individual.[6,92,99]

The quality of life (QL) in persons with disabilities is influenced by a variety of psychological, social and environmental conditions.[156] The negative sequelae of a spinal cord or traumatic brain injury may mean that the QL for individuals with these disabilities will necessarily be reduced. In order to adapt to the new situation, the person with a disability has to make internal and external changes. It is believed that people need a certain amount of time after injury to adjust to the problems imposed by a SCI and TBI.[19,85,97] One of the differences between a person with SCI and a person with TBI concerns not only the changes themselves, but also the relationship between the changes and the resources that are available to the person in order to adapt to the new reality. Persons with TBI are exposed to prolonged distress, which appears to be related more to the daily coping with the disability than to the severity of the initial injury.[58] SCI does not necessarily negatively influence the internal resources for adaptation,[156] whereas in TBI persons the resources themselves are affected by the disability.[6,58] While persons with SCI can realistically integrate the injury in their life continuum, persons with TBI may encounter major difficulties in this task.[16,121] When the brain is the organ affected, the persisting disability usually comprises both mental and physical impairments which can seriously impair the QL.

Improvements in medical management have ensured long life expectancies in persons with SCI and TBI[49,165] and dealing with the sexual function of these persons is or should be an integral part of these patients' rehabilitation. Sex, as Trieschmann[156] describes it, is one of four primary drives, along with thirst, hunger and avoidance of pain. It is a natural and healthy part of living. Bogle et al[12] define sexuality as *"the integration of physical, emotional, intellectual and social aspects of an individual's personality which express maleness or femaleness"*. All individuals are sexual and express their sexuality in different ways throughout the life cycle. Acquired physical and mental disability may significantly alter, yet do not eliminate, basic drives or human needs for affection, intimacy and a healthy and positive self-concept.[106] SCI has implications for the sexual functioning depending on the neurological level and the completeness of the lesion, whereas in TBI persons there are mainly cognitive, emotional and behavioural deficits, in addition to physical problems.

The present series of studies is the result of a comprehensive investigation of persons with spinal cord injuries and traumatic brain injuries. The SCI patients were treated at the Gothenburg Spinal Injuries Unit. The unit provides comprehensive medical care, transdisciplinary team care and life-long follow-up. The rehabilitation programmes are patient focused and individually designed in order to meet each patient's needs. We emphasise the learning process.[156] Each member of the team functions as a teacher and the patient is an active participant in the rehabilitation process.

The TBI persons were treated at a neurological or neurosurgical department during the acute phase, and rehabilitation took place at the Department of Rehabilitation Medicine or the Department of Neurological Rehabilitation, Sahlgrenska University Hospital, Gothenburg. These rehabilitation departments offer comprehensive interdisciplinary team care to patients with various diagnoses.

Sexuality and Partner Relationships

A definition of sexuality that is wider than genital and motor functioning is particularly important for people with disabilities whose opportunities to engage in some activities may be limited. The sexual expression of people with disabilities is affected not only by their particular medical condition but also by the attitudes of society toward the disability. Research on attitudes towards persons with disabilities has shown that people tend to reject close and intimate relationships with persons who are disabled.[133] As Cole[26] notes, *"society is still struggling with the negative concept that disabled people are asexual and could not possibly have concerns or problems regarding sexuality in the same way as able-bodied people"*. Other general types of prevailing attitudes toward sexuality and disability have been described by Comfort:[33] *"The individual is because of the handicap unable to engage in sexual activity"* and *"Since the handicap causes the individual to be abnormal in some way, sex with this individual must also be abnormal"*. These attitudinal preconceptions must be overcome so as not to limit sexual opportunities for people with disabilities.

Sexuality always involves an interplay between physiological and psychological processes. Changes occur throughout our lives which are influenced not only by functional independence, but also social, psychological, economic and political factors.[162] Sexual dysfunction occurs at one time or another in at least 50% of the general population and Masters and Johnson[101] point out that most sexual dysfunctions result from psychological causes or are exacerbated by psychological reaction to organic pathology.

For people with and without disabilities, having a satisfactory sex life has a positive effect on all aspects of human function.[156] A satisfactory sex life results, however, from the interaction of many factors in our lives ordinarily, and some of these factors will be directly influenced by a spinal cord or traumatic brain injury. Psychosocial problems such as impaired body image, lowered self-esteem and feelings of inadequacy may pose barriers to intimate relationships.

Feelings of sexual inadequacy may be reinforced by negative attitudes and prejudices of other people and by the injured person's own view of physical deviance and sexuality in persons with disabilities. Emotional distress and depression after injury, lowered self-confidence and feelings of being physically unattractive may lead to withdrawal from social and sexual relations or deterioration of the emotional climate in an existing relationship. Furthermore, both SCI and TBI cause numerous lifestyle changes that affect the marital relationship. The many changes involved in acquiring a disability can place relationships under considerable strain. There is much despair to be expected in both partners when a severe injury occurs and this despair may lead to marital discord and even break-up. The partner mourns these same losses, although from a different vantage point. Sexual life with a partner is a two-person system; the feelings and attitudes of the partner are as crucial in determining the couple's sexual fate as are those of the injured person.

Trieschmann[156] has noted that the term *sexuality* involves three components: sex drive, sex acts, and the broader concept of sexuality. Each of these components has physiological and emotional aspects. Behaviours that involve the genitals and erogenous zones are considered sexual acts. The combination of sex drive, sex acts and the psychosocial aspects of emotions, attitudes and relationships are learned communications and form the essence of sexuality. Thus, sexuality is an expression of ourselves, all our maleness or femaleness. It involves the way we relate to each other as men and women, the tenderness, the desire to give as well as take, the reciprocal concerns, the forms of communication that both include and go beyond words.[156]

In this study, sexuality is viewed as a process based on developmental learning experiences, with psychological, social and behavioural components that interact with each other.[8] The psychological component includes sexual interest and satisfaction, as well as the person's perceived quality of life, self-esteem and feelings of interpersonal attractiveness. The social component characterises the nature of the intimate relationship and the behavioural component comprises the repertoire of sexual expressions used. The conceptual framework of this study is built on literature reviews and results from earlier studies[8,135,156] in combination with clinical experience (Fig. 1 and 2).

Sexual activity is in this study defined as touching, kissing, or any form of genital stimulation as well as stimulation of other erogenous zones together with a partner. A stable partner relationship is defined as being married, cohabiting or having a steady partner relationship without living together.

SEXUALITY AFTER INJURY: A CONCEPTUAL FRAMEWORK

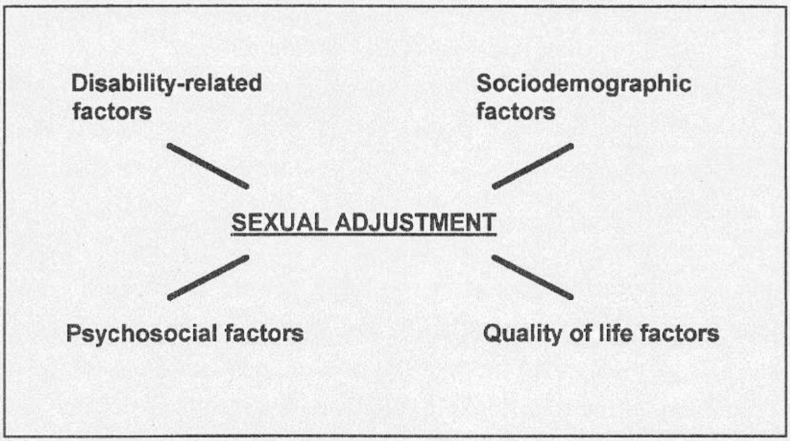

Figure 1.

SEXUALITY AFTER INJURY: DEFINITIONS OF CONCEPTS

Disability-related
Age at injury
Duration of disability
Severity of disability
Genital function
Medical complications
Medical consequences

Sociodemographic
Age
Sex
Length of relationship
Pre/postinjury relationship
Education
Occupation

SEXUAL ADJUSTMENT
Sexual interest and desire
Sexual activity
Sexual satisfaction

Psychosocial
Self-esteem
Emotional quality of the relationship
Recreational and social activities
Attitudes towards sexuality
Perceived sexual attractiveness
Previous sexual experiences
Repertoire of sexual behaviours
Concerns about the partner's sexual pleasure

Quality of life
Functioning
Mood
Global quality of life

Figure 2.

Quality of life

Quality of life (QL) is the quality of our lives at each point in time between birth and death.[155] It is an ongoing response to life events. QL can be viewed in terms of both handicap and resilience.[114] It is a composite variable that cannot be distinctly defined, because it is a person's own sense of well-being that stems from satisfaction or dissatisfaction with the areas of life and living situation that are important to him or her.[21,61,131] QL is influenced by a variety of factors, including physical, psychological and emotional function, ability to work and to perform leisure activities, and relations to other people and society. Additional factors that may influence perceived QL are sexual function, body image and self-esteem. QL probably has more influence on how patients adapt to their situation than many of the traditional measures of the results of clinical care.[146]

Methodological considerations

Quality of life research technology has developed over a period of more than a decade. There is now consensus on major purposes and basic tools in clinical research areas. Especially when impairments are incurable, the self-evident and realistic goal of care is to provide as comfortable, functional and satisfying lives as possible.[146] The broad QL concept can then be made concrete by measuring a number of health-related components, such as physical and cognitive complaints, functional status, affective responses and social interaction. Many of these components can be adequately assessed by using established generic measures, others may require additional specific measurements, e.g. sexuality in SCI and TBI. The patient is often the only logical expert on the various impacts of an injury or disease. In these studies, we used a battery of generic and specific measures as well as a global QL scale. The advantage of the inclusion of the latter is that with such a scale it is possible to quantify the associations of different components to global QL and to capture aspects of QL that are not defined by other dimensions.

Quality of life in chronic conditions

Studies of chronically ill patient groups have shown that patients can vary greatly, regaining their mental well-being if they are not in pain and do not suffer unpredictable conditions; this has been shown for patients with long-standing rheumatoid arthritis[4] and cancer in remission[147] and for patients who have been long-term candidates for renal transplantation.[68] In some disabled groups it has been found that the more severe the disability, the greater is the likelihood that the individual will be depressed.[57,164] The study of Helgason et al[70] showed that quality of life was decreased in most prostate cancer patients experiencing reduced sexual function.

SCI patients treated and followed in specialised units have an almost normal life expectancy.[49] The increased efficiency of the emergency health care system and refined neurosurgical techniques have greatly improved the survival rate of those who sustain severe brain injury.[165] The increased survival rate is associated with an increase in life-long disability. In both disabilities the person often becomes dependent on others to a lesser or greater extent. Living with a disability is a life-time process and different problems arise at different stages of life.[156] With an increased survival rate and improved life expectancy, quality of life is an even more important outcome to consider and assess using the standardised methodology now available.

Spinal cord injury

Traumatic spinal cord injury (SCI) is an abrupt and unexpected event that causes dramatic changes in functioning. These changes occur in both sensory and motor systems. Depending on the level of lesion of the spinal cord and the extent of neurological damage at that level, varying degrees of disability result. With complete lesions, no motor or sensory functioning is present below the lesion level. In addition to the physical limitations, bowel and bladder function are impaired. In the most severe cases, the injury may result in total paralysis and require a ventilator for respiration.

Spinal cord injury and sexuality

The degree and type of sexual dysfunction after spinal cord injury depends on the victim's sex, the level of the lesion and the completeness of the injury.[30,32,64] For women with spinal cord injury, the motor paralysis may not be a deterrent to participation in any sexual activity, but the lack of sensation may alter the degree of pleasure experienced.[25,32,64] While some report that women with complete injuries do not have orgasms,[113] others describe fantasy orgasms and orgasms emanating from other, unimpaired erogenous zones.[31] A laboratory-based assessment conducted by Sipski et al[139,140] showed that a large percentage of SCI women responded with arousal to genital stimulation and achieved orgasm regardless of the pattern or degree of neurological injury.

Men with SCI experience disruption of sexual function because of the motor paralysis and sensory deficit. The level of injury and completeness of the lesion are the key factors in the ability to have erections.[30] In general, it has been noted that erection is more common among men with incomplete spinal lesions, upper motor neurone lesions and lesions located higher in the cord.[63] Psychogenic erections in response to sexual situations only occur in a minority of SCI men, whereas erections obtained by reflex/external stimulation are typical.[29] The probability of psychogenic erections increases with incomplete injuries. Being capable of reflexogenic erections does not, however, ensure successful coitus. Spontaneous reflexogenic erections may occur at any time but may not be elicited when the partner is available and the time is desirable. Men with complete spinal cord injuries in the lumbar and sacral areas are generally not able to achieve any erection. Ejaculation in complete lesions is usually impaired. However, it is possible for a man to achieve an ejaculation with the aid of a vibrator applied to the penis. With incomplete lesions, ejaculation may not be altered. As with spinal cord-injured women with complete lesions, sensations similar to orgasm are possible. Furthermore, it is possible to have orgasms without any motor or sensory function in the genital organs. With spinal cord lesions there is often a hyperaesthetic area of the body just above or at the segment of the lesion. This may become a strongly erogenous zone of the body. Thus, it is possible for both women and men with SCI to experience an orgasm whilst the hyperaesthetic erogenous zone is being stimulated by the partner. Sexual pleasure, however, is always a result of a combination of physical and psychological factors in all of us, those with disabilities and those without.

Although the disability may have profound effects on sexual functioning as measured by normative standards, it is apparent that persons with SCI do not loose their sexual desires or need for sexual intimacy.[8,116,135,142,144,148,156] The impact of SCI on a person's sexuality will, however, be closely related to the SCI person's view of himself, body-image and self-esteem and will be highly influenced by his or her confidence in interpersonal relationships.[129,135,156]

Spinal cord injury and sexual counselling

Sexual concerns are an important part of the comprehensive rehabilitation. At our spinal unit, sexual education and counselling are routine components of the rehabilitation programme. Both individual and group sessions are available. Most of the SCI participants and their partners have taken part in our sexual information and counselling programme. Furthermore, it is of great importance that all treatment staff has established an atmosphere of openness and readiness to address sexual issues. Therefore, all team members are educated in sexuality issues on a regular basis. Hence, the staff feel comfortable about raising the issue of sexuality with the patient and allowing him or her permission to discuss this topic. The team of staff have enough sexual knowledge to provide accurate information to the patient and to be able to make a judgement as to when to refer the patient for more specific suggestions.

Spinal cord injury and partner relationships

Despite the fact that many clinicians emphasise the importance of the spouse's attitudes and behaviour for the rehabilitation and adaptation process, relatively little research has concentrated on the partner's perception of marital and sexual life with an SCI person.[44,81] It has been assumed that there is no greater test of a marriage than that presented by a physical disability.[137] The injured person must learn an assortment of social skills to help put himself, his partner and others at ease with the disability. Often, the partner must play a dual role as lover and care-giver, which may create deleterious situations and conflicts. Partners may feel reluctant or unable to engage in sexual activity due to overemphasis on their caring role. Thus, the premises in already existing intimate relationships may be totally altered since the injury was something neither partner had considered. This has led some researchers[36,37,50] to believe that marriages occurring after SCI are more likely to succeed, assuming that the couple has a clearer picture of the mutual life-style they are entering. It has also been suggested that spouses in postinjury marriages have unusual qualities or values that contribute to the success of these unions.[37,158] Some studies, however, have shown that the impact of SCI on postinjury marriages is only slightly less than it is on pre-existing marriages.[20,46,47,52,53]

Several studies have shown that SCI has a short term impact on marriage indicated by a rise in divorce rates.[20,46,48] Marriages that do survive are generally viewed as satisfying.[37,50] De Vivo and Fine[46] examined the influence of SCI on the marital status of 276 injured persons in the United States and found significantly more divorces and significantly fewer marriages than the norm. Their study also showed that women with SCI were more likely than men to become divorced after marriages that predated the injury but were less likely than men to become divorced after postinjury marriages. Other studies have shown that the divorce rate of SCI persons is comparable to that of the general population.[52] The level or extent of injury has not been found to be related to divorce.[37]

Being involved in a caring and intimate sexual relationship is an important part of the self-concept of most people. The physical losses of mobility and sensation may, however, limit the SCI person's opportunities to meet and attract a new partner. Most of us working in a spinal unit have frequently had the experience of having a newly injured patient ask, often in despair, *"but what kind of person could possibly find someone like me attractive?"* These patients must be helped to realise that they are still attractive, despite the physical losses.

Spinal cord injury and quality of life

We found in earlier studies[97,136] that the SCI person's mental well-being improved to the extent that it almost corresponded to that of the normal population four years after injury. Perceived QL was, however, on average 25% lower compared with a reference group.[97] QL, assessed by the SCI person through a global rating, was closely related to sexual adjustment.[135] Furthermore, young age, a high level of social activity and gainful employment were closely associated with perceived high QL.[135] Severe pain was the only medical complication that was associated with lower QL scores.[97]

The level or extent of injury was not related to perceived QL,[97] which is consistent with the study of Cushman & Haslett,[42] undertaken 10 and 15 years after the injury. The large British study of Whiteneck and colleagues[162] showed that the level of the lesion predicted neither life satisfaction nor well-being. The results of a meta-analysis study[56] demonstrated that severity of injury is significantly associated with QL, measured in various ways, more severe injuries being related to reduced QL. Approximately five per cent of the variability in QL was found to be attributed to the severity of injury.

The study of Krause and Crewe[85] showed that chronological age and time since injury have distinctive, but different impacts on the quality of life of persons with SCI. Their findings regarding chronological age suggest that older persons are likely to experience a less active and less rewarding life after SCI than younger persons. Whereas chronological age was generally related to a decline in activity level, a greater time since injury was more likely to be associated with enhanced psychological functioning and an increased number of hours spent per week working. Positive relationships with subjective well-being have been reported for satisfaction with the amount and quality of social contacts,[39,45,130] leisure activities,[35] family relations,[5,83] sex life[5,83] and community life.[167]

Self-esteem may be greatly diminished after a spinal cord injury and sexual adjustment can be critical in the total rehabilitation. Judd et al[76] found that sexual relationships were strongly correlated with the SCI persons' overall adjustment. Frankel[59] believes that sex-related anxiety can be transferred to anxieties concerning other body functions, which can have a direct influence on motivation and overall adjustment.

When measuring quality of life in SCI persons, various instruments have been used. Because of poor validity of measurements, it has been suggested that QL research with SCI persons needs to be better designed and include more uniform and valid criteria.[56] In order to determine which parts of a battery of health-related standard questionnaires[7,141,168] could most accurately predict the QL assessments of SCI persons, we followed a new path of analysis.[98] Through a stepwise model, particular areas were identified as being capable of independently predicting SCI persons' QL assessments. Single questions within these areas which substantially influenced the QL assessments could then be identified. We could thereby derive a short SCI-adapted 22-item questionnaire that explained almost two-thirds of the variance of SCI persons' global QL ratings.[96,98,134] This shortened questionnaire was used in the present series of studies.

Traumatic brain injury

Individuals with TBI sometimes have the mobility problems seen in SCI persons, but more often have cognitive and behavioural problems.[74,110,112,119,153,154] It has been found that approximately 55% of persons who incur brain trauma survive with some degree of permanent impairment.[77] TBI may be classified as open (as in damage from a skull fracture or a gunshot wound) or closed (as in damage from a severe impact because of a vehicular accident). Closed head injuries are more common and tend to produce more diffuse and less localised damage than open head injuries.[19]

The most consistent and, in a long-term perspective, the most enduring and disabling consequences of brain injury are not the physical or neurological sequelae per se, but the impairments in cognition, emotions and behaviour that create barriers to successful psychosocial functioning.[17,105,112,160] Researchers have claimed that in brain-injured persons the general functional disruptions are greater than would be expected from the severity of the specific deficits.[51,74] The TBI persons have mostly sustained widespread damage which has more effect on mental than on neurological function. Personality change is the most consistent finding and this can constitute an appreciable deficit even in patients without significant cognitive or physical sequelae.[75]

Traumatic brain injury and sexuality

A psychosocial consequence of TBI that has received scant attention from professionals is that on sexuality. Unlike conditions such as a spinal cord injury, in which sexual concerns may be functional and obvious, the effects of TBI on sexuality are more subtle and prone to be neglected.[58] Neurological disability after TBI may result in sexual dysfunction at both the genital and a nongenital level. Sexual dysfunction is more often the rule than the exception.[11] Kosteljanetz[82] reported that sexual dysfunction was present in 58% of the 19 TBI persons studied. Investigation of 21 male patients showed that the majority of the sample reported negative changes in sexual behaviour, including decreased sex drive, erectile function and frequency of intercourse. Common personality changes included depression, reduced self-esteem and a perceived decline in personal sex appeal.[89] Furthermore, problems associated with TBI often result in low self-esteem, a distorted self-image and social isolation, which adversely affect sexual self-image and the quality of intimate relationships. Thus, while TBI may not always impair physical sexual functioning, the broad range of thoughts, feelings and interactions encompassed by sexuality are often adversely influenced.

Inappropriate sexual behaviours or lack of control over sexual impulses have been found as the result of brain damage.[58] The sexual correlates of damage to the frontal lobe are related to disinhibition, euphoria and lack of tact.[103] Temporal lobe dysfunction is associated with a change in the sexual activation system, which is often associated with a decreased libido and decreased genital and sexual arousal.[28] Damage to central and basal frontal areas is typically accompanied by loss of spontaneity and lack of vitality.[103] Injuries to the basal hypothalamus may lead to total and irreversible loss of libido.[82] It has been noted that the incidence of sexual dysfunction increases with the severity of the injury.[94]

Traumatic brain injury and partner relationships

Several studies have demonstrated that negative changes in behaviour and personality after brain injury are more strongly associated with family disruption than are the negative physical changes associated with the brain injury.[103,104] Difficulties in marriages are reflected by high rates of marital breakdown which is often due to the psychosocial changes and the burden placed on spouses.[121,152] Mental deficits contribute more to the burden reported by caring relatives than does physical impairment.[104] McKinlay et al[104] found in their studies that one year after the injury of the husbands, 48% of the spouses reported changes in their husbands' sexual behaviour. Several studies[73,95,154] have shown that the divorce rate is higher among TBI persons compared to the general population. It has been suggested that the change in marital status may be related to the continuing changes and challenges of living with the disabilities. Rosenbaum and Najenson[121] found that spouses of men with TBI experienced greater role change and distress than the wives of men with SCI. The wives of the men with TBI reported a decrease in leisure time, fewer contacts with friends and greater disruption of their marital relationship.

Traumatic brain injury and quality of life

It has been found that work and leisure activities are the most disrupted aspects of daily life after a TBI. Quality of life was severely reduced for those TBI persons who could not occupy their time.[19,151] Thomsen[152] found that the main problem mentioned by persons with TBI one to six years after severe brain injury was lack of social contacts and little opportunity to make new friends. A study on long-term QL in married and single TBI persons showed that severely injured persons reported more depression, confusion and overall mood disturbance compared to moderately injured TBI persons regardless of marital status. Married TBI persons reported more anxiety, depression, fatigue, confusion and overall mood disturbance than single TBI persons, regardless of age.[107]

AIMS OF THE THESIS

Rationale

Sexuality after SCI has received increased attention in recent years, although there are as yet few studies comparing the sexuality of persons with SCI with that of persons in the general population. Furthermore, most of the literature concerning the various aspects of sexuality after SCI focuses on the injured person. As sexual interaction is a joint responsibility, the impact of disability is more adequately assessed by asking both partners. Comparisons of SCI persons' experiences of the sexual relationship with those of persons from the general population, as well as a better knowledge of sexual adjustment after SCI from the perspective of the SCI person's partner, would improve information and sexual counselling currently available to SCI persons and their partners.

Recently, research has begun to examine psychosocial adjustment after TBI, particularly the effects on the spouse and family. The brain-injured person's own experiences of sexuality, sexual function and adjustment have received sparse attention. A greater understanding of the sexual disturbances after brain injury will identify the areas in which sexual information and counselling are needed.

The literature comparing partner relationships, functioning, mood and perceived global quality of life in persons with disabilities and people from the general population is limited. Better knowledge in these areas will help rehabilitation professionals to understand the nature and extent of barriers that face persons with SCI and TBI and help them to work more effectively with the patients.

The aims of the studies were to clarify:

- determinants of the SCI persons' sexual adjustment and quality of the relationship compared with persons in the general population;
- how partners of a sample of SCI persons experience the sexual and emotional aspects of their intimate relationships;
- whether there are sexual and emotional differences between lasting spinal cord preinjury and postinjury relationships from the partner's point of view;
- if the personality profile differs between partners in lasting spinal cord preinjury and postinjury relationships or from that in a reference group;
- the impact of traumatic brain injury on sexual ability, activity and satisfaction and how the findings relate to physical, social, emotional and cognitive function;
- if SCI and TBI persons differ from persons in the general population concerning partner relationships, perceived quality of life and mental well-being.

STUDY POPULATIONS

Descriptive characteristics of respondents in Studies I-V are presented in Table I.

Study I

Sexual adjustment and quality of the relationships in spinal paraplegia. A controlled study

This study was part of an investigation of a consecutive series of 252 persons with traumatic SCI who were admitted to the Gothenburg Spinal Injuries Unit between November 1982 and July 1991. At the time of the study, 36 had died and 37 had recovered from their injury (Frankel class E).[60] Four persons were excluded because they were below the age of 18 years at the time of the study, five could not be located, two had language difficulties and one had a psychiatric illness. Of the remaining 167 persons with SCI, 85 (51%) had a stable partner relationship (i.e. were married, cohabiting or had a permanent partner relationship without living together) and they formed the basis of the research sample reported in this study. Seventyfive persons (88%) completed and returned the questionnaires.

The respondents' median age was 33 years, ranging from 19 to 76 years. Age when injury occurred ranged from 14 to 69 years (median 29 years). Time since injury ranged from one to nine years (median five years). Thirtyeight per cent had tetraplegia (cervical lesion of the spinal cord) Frankel classes A, B or C, indicating that there was no useful motor function below the level of injury, 12% had tetraplegia Frankel class D, indicating some useful motor function below the level of injury; 32% had paraplegia Frankel A, B or C, 18% had paraplegia Frankel D. Wheelchairs were used by 76% and the remainder walked with or without aids.

No significant demographic or clinical differences were found between the participants and non-participants.

An age and sex-matched control group was randomly selected from the general population by the Gothenburg City Registry. Of the 264 respondents, 155 (59%) had a stable partner relationship and formed the control group.

Table I. *Descriptive characteristics of participants in Studies I-V*

Background variables	**Study I**		**Study II**	**Study III**		**Study IV**	**Study V**		
	SCI persons n=75	Controls n=155	SCI partners n=49	Preinjury partners n=26	Postinjury partners n=23	TBI persons n=92	SCI n=167	TBI n=92	Controls n=264
Sex									
Men	64 (85%)	119 (77%)	10 (20%)	7 (27%)	3 (13%)	65 (70%)	136 (81%)	65 (70%)	203 (77%)
Women	11 (15%)	36 (23%)	39 (80%)	19 (73%)	20 (87%)	27 (30%)	31 (19%)	27 (30%)	61 (23%)
Age (years)									
Median (range)	33 (19-76)	30 (19-79)	34 (18-79)	51 (21-79)	28 (18-45)	40 (20-70)	33 (19-79)	40 (20-70)	31 (19-79)
Age at injury (years)									
Median (range)	29 (14-69)	n.a.	n.a.	n.a.	n.a.	32 (16-56)	28 (14-76)	32 (16-56)	n.a.
Time since injury (years)									
Median (range)	5 (1-9)	n.a.	n.a.	n.a.	n.a.	9 (1-20)	5 (1-9)	9 (1-20)	n.a.
Marital status									
Married/cohabiting	57 (76%)	128 (83%)	49 (100%)	26 (100%)	23 (100%)	39 (42%)	63 (38%)	39 (42%)	128 (48%)
Steady relationship	18 (24%)	27 (17%)				14 (15%)	22 (13%)	14 (15%)	27 (10%)
Single						39 (42%)	82 (49%)	39 (42%)	109 (41%)
Working/studying	45 (64%)	119 (81%)				45 (52%)	99 (66%)	45 (52%)	195 (79%)
Tetraplegia									
Frankel A,B and C	29 (38%)	n.a.	18 (37%)[a]	8 (31%)[a]	10 (43%)[a]	n.a.	65 (39%)	n.a.	n.a.
Tetraplegia Frankel D	9 (12%)	n.a.	7 (14%)[a]	4 (15%)[a]	3 (13%)[a]	n.a.	20 (12%)	n.a.	n.a.
Paraplegia									
Frankel A,B and C	24 (32%)	n.a.	14 (29%)[a]	9 (35%)[a]	5 (22%)[a]	n.a.	49 (29%)	n.a.	n.a.
Paraplegia Frankel D	13 (18%)	n.a.	10 (20%)[a]	5 (19%)[a]	5 (22%)[a]	n.a.	33 (20%)	n.a.	n.a.
GOS	n.a.	n.a.	n.a.	n.a.	n.a.		n.a.	n.a.	n.a.
3 [b]						2 (2%)		2 (2%)	
4 [b]						8 (9%)		8 (9%)	
5 [b]						35 (38%)		35 (38%)	
6 [b]						26 (28%)		26 (28%)	
7 [b]						18 (20%)		18 (20%)	
8 [b]						3 (3%)		3 (3%)	

n.a. = not applicable, [a] SCI persons, [b] For definitions, see page 33.

Study II

Sexual adjustment after spinal cord injury (SCI) focusing on partner experiences

In this study, the intimate relationship as experienced by the SCI person's partner was evaluated. Partners who at the time of the investigation were living in a stable partner relationship with a person with SCI were included. The injured person was to have been living outside the hospital for a minimum of one year. Partners of SCI persons who were recovered (Frankel class E) were excluded. Sixty-three SCI persons were married or living in a permanent relationship and their partners formed the basis of the research sample. Fortynine couples (78%) completed and returned the questionnaires. Some partners who chose not to participate did so because they found the questions "too personal".

The participating partners' ages ranged from 18 to 79 years (median 34 years). Thirtynine partners were women and ten partners were men. The couples had been married or cohabiting for between one and 51 years (median six years). All couples were living in their own homes. No significant demographic or clinical differences were found between the SCI participants and non-participants.

Study III

Sexual adjustment after spinal cord injury – comparison of partner experiences in pre and postinjury relationships

This study comprises the same study group as in Study II. Two groups of SCI partner relationships were investigated from the partners' perspective: those that were established before the injury (26 relationships) and those that began post injury (23 relationships). At the time of the investigation, the length of preinjury relationships ranged from 3.5 to 51 years (median 24 years). The duration of postinjury relationships ranged from one to eight years (median two years). In the preinjury group, 19 were female and seven were male partners, and in the postinjury group 20 were female and three were male partners. Among preinjury partners, age ranged between 21 and 79 years (median 51 years) and postinjury partners ranged in age from 18 to 45 years (median 28 years). The SCI persons in preinjury relationships were equivalent to the postinjury group in terms of level and completeness of the lesion.

Study IV

Sexual adjustment and its predictors after traumatic brain injury

The population of this study comprised 152 traumatic brain-injured persons treated at the Department of Rehabilitation Medicine or the Department of Neurological Rehabilitation at Sahlgrenska Hospital, Gothenburg, during the years 1971-1990. TBI persons were ineligible if their injury was diagnosed as commotio cerebri or they were younger than 16 years or older than 60 years at the time of the injury or older than 70 years at the time of the study.

When the records were studied we found that 14 had died, 9 persons had moved abroad, two had no known address, eight were too severely injured to participate and five had heavy abuse problems and where thus excluded. Of the 116 eligible TBI persons, 92 (79%) agreed to participate. The sample included 65 men and 27 women, ranging in age from 20 to 70 years (median 40 years). Median age at injury was 32 years, ranging from 16 to 56 years. Elapsed time since injury ranged from one to 20 years (median nine years). Thirtynine of the participants (42%) were married or cohabiting at the time of the study and a further fourteen persons had a partner relationship without living together. Twentyfour relationships were established before the injury and 29 after.

As a measure of the severity of the brain damage, the post-traumatic amnesia (PTA) was used. PTA is a retrospective assessment of the period from time of injury to full awareness and the ability to retain a stable record of events.[122] In most studies the boundary between minor and major injury is a PTA of 24 hours.[103] In this group, the average PTA was four weeks.

Study V

Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury

In this study on partner relationships, perceived quality of life and mental well-being, 167 persons with SCI (136 men and 31 women), 92 persons with TBI (65 men and 27 women) and 264 controls (203 men and 61 women) were compared. At the time of the investigation the median age of the SCI persons was 33 years (ranging from 19 to 79), the TBI persons' median age was 40 years (ranging from 20 to 71) and the controls' median age was 31 years (ranging from 19 to 79).

METHODS

Design

The initial contact with the spinal cord-injured persons and their partners was made by telephone with an explanation of the study aims. Basic sociodemographic and clinical data were collected at this time. Questionnaires with letters further describing the objectives of the study were mailed to the subjects and they were assured of the complete confidentiality of their responses. The questionnaires were sent separately to the SCI person and his or her partner and the couples were asked not to discuss the questions with each other before answering.

An age and sex-matched control group (Studies I and V) was randomly selected from the general population by the Gothenburg City Registry. The questionnaires were mailed together with a letter that explained the purpose of the study. Persons in the control group were offered 150 Swedish Crowns (≈ 20 US$) for their participation and a guarantee of the complete confidentiality of their responses. They could also choose to return the questionnaires anonymously.

The TBI persons were investigated at the Department of Neurological Rehabilitation at Sahlgrenska Hospital. The investigation comprised a neurological examination, self-assessment of general health status, functioning and mood and collection of data on social conditions, and various aspects of sexuality. Sexuality was assessed by means of a study-specific questionnaire. This questionnaire was completed by personal interview with one investigator present (M.K.). Thus, misunderstandings and omission of answers were avoided.

Before giving their informed consent to inclusion in the study, the participants had received both written and verbal information on the studies.

Clinical data

All clinical information collected in the telephone interviews on the SCI persons was checked by reference inquiries using the medical records. The neurological examination of the TBI persons was performed according to a fixed protocol by two neurologists working independently.

Social and demographic data

Age, age at injury, time since injury, marital status, education and occupation were recorded using questionnaires.

Generic questionnaires

The generic and study-specific instruments used in each study are shown in Table II.

Sickness Impact Profile

General health status was self-assessed by means of the Sickness Impact Prifile (SIP),[7] translated and extensively validated for Swedish conditions.[97,145] The questionnaire has been thoroughly validated for persons with mild brain injury[149,150] and in SCI persons at our hospital.[97] The SIP consists of 136 items, describing the functional limitations within twelve well-defined areas of daily living, and allows for summarising of the results into a physical, a psychosocial and a total index. Each item is presented as a statement of an aspect of health-related dysfunction and respondents check all items that apply to them at the time of examination. A predetermined weighting system quantitates the dysfunction, expressed as a percentage of maximum dysfunction (score-range 0-100).

Hospital Anxiety and Depression scale

The Hospital Anxiety and Depression (HAD) scale consists of 14 items measuring the level of anxiety and depression in two separate subscales. Each item has 4 response categories, reflecting a continuum of increasing level of emotional distress in the somatically ill. Scale scores range from 0 (no symptoms) to 21 (maximum of distress) for both depression and anxiety. This is a self-assessment scale which can reliably detect the presence of depression and anxiety, and the subscales it yields have been shown to be valid measures of the severity of emotional disorder, possible clinical cases (8-10 points) and probable clinical cases (> 10 points).[168] Adaptation to Swedish conditions is documented earlier.[97]

Functional Independence Measure and Functional Assessment Measure

The Functional Assessment Measure (FAM) was developed as an adjunct to the Functional Independence Measure (FIM) to address the major functional areas that are less emphasised in the FIM. The FAM adds 12 items on cognitive, behavioural, communication and community function to the FIM. They total 30 items, each assessed on 7 levels which, when summed, may be used to estimate a person's need for assistance (burden of care). The lower the score, the severer the indicated dysfunction. The 18 FIM items concerning self-care, bladder and bowel control, mobility and locomotion are indicators of motor disability. The 12 FAM items covering comprehension, expression, social interaction, emotional state, adaptation to limitations, ability to work, problem solving, memory, powers of concentration and ability to form an opinion on safety are indicators of communication and psychosocial and cognitive functioning.[62,65,80] Prior research indicates that the FIM has good validity and inter-rater reliability.[65,66,93] Data on the reliability of the FAM have not been published.

Glasgow Outcome Scale

The Glasgow Outcome Scale (GOS) is a functional assessment tool for use in head-injured individuals. The assessment technique has been widely adopted as the preferred tool for describing outcome after head injury in large-scale neurosurgical studies. The developers of the GOS found inter-rater reliability rates as high as 95%.[75] The GOS is a one-to-eight-point measure with the following categories: 1 = dead, 2 = vegetative state, 3 = dependent for daily living more than half the time, 4 = dependent for daily living less than half the time, 5 = not able to go back to previous work and social activities, 6 = able to go back to previous work or social activities but not with full ability, 7 = able to live a normal life but some symptom after the brain damage, and 8 = no symptom after the brain injury.

Global quality of life

Perception of global quality of life (QL) was recorded on a visual analogue scale (VAS)[23] and endpoints were labelled "very low" and "very high". For SCI persons and controls, a 0-to-100 scale was applied, while the TBI persons were examined with the aid of an earlier 7-point scale linearly transformed to match the current scale.[97] The participants were asked to make a mark on the line at the point considered to best represent their current quality of life. The QL VAS was used as the dependent variable in the analyses of QL in Study V.

Karolinska Scales of Personality

The Karolinska Scales of Personality inventory, KSP,[2,123,127,128] self-assessment of personality traits, was used to determine the personality characteristics of the partners. The KSP inventory has been used in a large number of studies both on healthy subjects and on patients with various psychiatric and psychosomatic disorders. It has been proved reliable and valid to measure biologically based personality traits or temperament dimensions that can be regarded as markers for different kinds of vulnerability.[123-128] The questionnaire includes 136 items organised into 15 scales, ten of which are grouped into the following three main areas:[2,127]

1. Anxiety Proneness Scales (Psychic anxiety, Somatic anxiety and Muscular tension).
2. Extraversion-related Scales (Impulsiveness and Monotony avoidance).
3. Aggression-Hostility Scales (Indirect aggression, Irritability, Verbal aggression, Suspicion and Guilt).

The remaining scales are: Psychasthenia, Detachment, Inhibition of Aggression, Social Desirability and Socialization. The items are statements with a 4-point response format, ranging from strongly disagree to strongly agree. Except for the Socialization (20 items) and Aggression scales (15 items), most scales consist of ten items, with higher scores indicating a higher degree of the trait measured. Raw scores are transformed into T-scores (mean 50, SD 10) to allow comparisons across scales.[127]

Study-specific measures

Quality of life SCI-23

To further explore QL from the perspective of the SCI and TBI persons, a brief function and mood self-assessment questionnaire, containing 22 items derived by Lundqvist et al[98] from an extensive battery of questionnaires, was used. (Appendix A). This brief version contains ten items from the Sickness Impact Profile (SIP)[7] covering functional limitations in mobility, body care, movement and social interaction, and six items from the Hospital Anxiety and Depression (HAD) scale[168] measuring different aspects of depressed mood. In addition, the SCI persons completed six items from the SCI Problem scale defining the SCI person's perception of loss of independence.[98] The procedure and metric properties of this quality-of-life measure have earlier been described.[98] The controls completed the six items reflecting Depression from the HAD scale.[168]

The Relationship Questionnaire

The questionnaire, comprising 80 items, was developed to assess different dimensions of sexuality (sexual function, desire and activity, sexual behaviour and satisfaction with sex life), and the emotional quality of the relationship (feelings of affection and intimacy, ability to solve problems within the relationship, ability to communicate about sex with the partner, recreational activities engaged in alone and together with the partner, satisfaction with these areas of the relationship and satisfaction with the relationship in general). Additional data were collected to determine perceived sexual attractiveness, concern about the partner's sexual pleasure and the individual's perception of the partner's sexual enjoyment and satisfaction.

The Sexual Activity and Satisfaction scale

Three items from the questionnaire, covering 1/sexual activity, 2/sexual enjoyment from sex acts and 3/satisfaction with the sexual relationship, were treated as one composite variable, the Sexual Activity and Satisfaction (SAS) scale.[88] Internal consistency, determined by Cronbach´s alpha,[40] was 0.87 (SCI persons) and 0.82 (controls), and a principal component analysis[109] confirmed the uni-dimensionality of the scale. Factor loadings on the principal factor ranged between 0.56 and 0.60 (SCI persons) and 0.52 and 0.62 (controls). Based on the method of summated ratings, we assumed that responses to items in the scale could be summed without standardisation or weights. The sum of raw scores on the SAS scale ranged from 3 to 16. Higher scores indicated better sexual adjustment. The SAS scale was subsequently used as the dependent variable in the analyses of sexual adjustment in Study I.

The Sexual Interest, Activity and Satisfaction scale

Six items covering sexual interest, activity and satisfaction were designed to be treated as one composite variable, i.e. to meet the criteria of a multi-item scale, the Sexual Interest, Activity and Satisfaction (SIAS) scale.[86,87] Internal consistency, determined by Cronbach´s alpha, was 0.86 and a principal component analysis confirmed the uni-dimensionality of the scale. Factor loadings on the principal factor, which accounted for 62% of the variance, ranged between 0.61 and 0.88. Based on the method of summated ratings, we assumed that responses to items in the scale could be summed without standardisation or weights. The sum of raw sores ranged from 6 to 28. Higher scores indicated better sexual adjustment. The SIAS scale was used in studies II and III.

The Emotional Quality of the Relationship scale and the Sexual Behaviour scale

Seven items relating to emotional intimacy, affection and communication were aggregated to a composite variable, the Emotional Quality of the Relationship (EQR) scale.[86,87] An additional seven items covering sexual expressions – touching, kissing, manual and oral stimulation of the genitals and other erogenous zones and sexual intercourse – formed a scale with confirmed consistency, the Sexual Behaviour (SB) scale.[86,87] Standard methodology to ensure construct validation of these two scales included calculation of Cronbach's alpha and principal components analyses. Factor loading on the principal factor ranged between 0.65 and 0.85 (the EQR scale), and 0.74 - 0.96 (the SB scale). The sum of raw scores on the EQR scale and that for the SB scale ranged from 7 to 28 and 7 to 49, respectively. With each scale, the higher the scores the better. The EQR scale was used as the dependent variable in the analyses of the emotional quality of the relationship in Study I and as an independent variable in Studies II and III. The SB scale was used as an independent variable in Studies I, II and III.

The Sexual Adjustment Questionnaire

A study-specific questionnaire, adapted from the SCI questionnaire[134,135] was designed to explore different aspects of sexuality before and after the brain injury. The perceived impact of TBI on the following sexual areas was recorded:

- Sexual desire and interest
- Frequency of erection, ejaculation, orgasm and intercourse
- Self-perceived personal satisfaction
- Self-rated ability to give partner satisfaction
- Sexual communication and experimentation

A 4-point response scale was used: increased, unchanged, decreased, and absent.

Reasons for decreased sexual satisfaction were recorded. These items covered physical limitations and complications due to injury, sexual habits, communication problems and low self-esteem.

The Sexual Interest and Satisfaction scale

Five items from the questionnaire with psychological content – interest in sexuality and sexual satisfaction – were treated as one composite variable, the modified version of the Sexual Interest and Satisfaction (SIS) scale for spinal cord-injured persons.[135] The internal consistency, determined by Cronbach's alpha, was 0.90 and a principal component analysis confirmed the unidimensionality of the scale. Factor loadings on the principal factor ranged between 0.69 and 0.87. Sixtytwo per cent of the variance was then explained.

Based on the method of summated ratings, we assumed that responses to items in the scale could be summed without standardisation or weights. The sum of raw score ranged from 0 to 15. Higher scores indicated better sexual adjustment.

The SIS-scale was used as the dependent variable in the analyses of the TBI person's sexual adjustment in Study IV.

The Swedish version of the questionnaires (items included in the scales) is shown in Appendix B.

Table II Data collection instruments used in Studies I, II, III, IV and V.

Instruments	**Studies**				
	I	**II**	**III**	**IV**	**V**
Quality of Life VAS scale	X	X	X	X	X
Quality of Life SCI-23	X	X	X		X
Sickness Impact Profile (SIP)				X	
Hospital Anxiety and Depression scale (HAD)				X	
Karolinska Scales of Personality (KSP)			X		
Functional Independence Meaure (FIM) and Functional Assessment Measure (FAM)				X	
Glasgow Outcome Scale (GOS)				X	X
The Relationship questionnaire	X	X	X		
The Sexual Adjustment questionnaire				X	

Psychometrics

All scales used in these studies were constructed in accordance with traditional psychometric theory.[1] We developed multi-item scales, i.e. several questions assumed to measure the same concept were aggregated in order to strengthen reliability. As shown in Table III, the psychometric procedures included tests of internal consistency (Cronbach's alpha) and uni-dimensionality (principal component analysis).[40,109]

Statistical methods

Various non-parametric statistical tests were applied across the series of studies (Table III). Fisher's permutation test was used for comparison between groups and Fisher's exact test for comparison of proportions.[14] For overall comparison between three groups, Kruskal-Wallis one-way analysis of variance (ANOVA) of mean ranks[132] was used. The chi-square test was used for overall comparison of proportions between three groups. Correlations including physical, sociodemographic and psychosocial data were evaluated using Pitman's non-parametric permutation test.[14] Pearson's correlation coefficients were only used for descriptive purposes.

A step-by-step model of consecutive analyses[98] included bivariate correlation (Pitman's permutation test),[14] partial non-parametric correlation (Mantel's test)[100] and multiple correlation procedures to identify the ultimate determinants of the respectively dependent variables from a selection of potentially important independent variables (Figure 3). The last step in the model describes the level of explained variance of each of the dependent variables from the combination of powerful independent variables in the particular data sets using a multiple regression analysis.

In the comparison of pre and postinjury relationships, age was analysed as a confounder and therefore statistically controlled by a non-parametric partial correlation procedure (Mantel´s technique of pooling).[100] A one-way factorial ANOVA was performed on the scores of each KSP subscale.

Table III Data analysis methods used in each study

Methods			**Studies**		
	I	**II**	**III**	**IV**	**V**
Non-parametric					
Fisher's exact test	X	X	X	X	X
Fisher's permutation test	X	X	X	X	X
Pitman's permutation test	X	X	X	X	X
Mantel's test (partial correlation analysis)	X	X	X	X	X
Chi-square test					X
Kruskal-Wallis ANOVA			X		X
Parametric					
Cronbach's alpha	X	X	X	X	
Principal component analysis	X	X	X	X	
ANOVA			X		
Multiple correlation analysis	X	X		X	X

STEP-BY-STEP ANALYSIS MODEL FOR PREDICTION OF A DEPENDENT (OUTCOME) VARIABLE

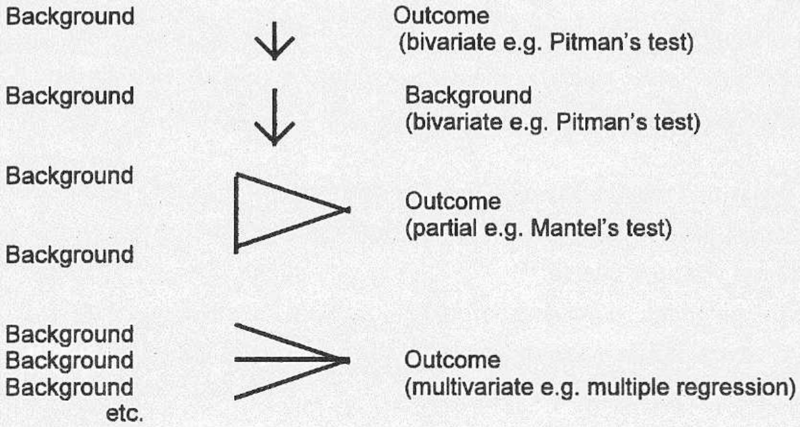

Figure 3.

RESULTS

Summaries of analyses of study-specific scales, global quality-of-life ratings and mood are shown in Tables IV and V.

Study I

Sexual adjustment and quality of relationships in spinal paraplegia: A controlled study

Two main questions were addressed in this study:

1/ How do sexual desire, activity, behaviours and satisfaction with sex life in SCI persons compare with the controls?

2/ What are the physical, psychosocial, behavioural and socio-demographic predictors of sexual adjustment and the emotional quality of the relationship in the SCI persons and controls, respectively?

Items relating to sexual activity and satisfaction were treated as one composite variable, the Sexual Activity and Satisfaction (SAS) scale, and this scale was used as the dependent variable in the analyses of sexual adjustment. Items relating to emotional intimacy, affection and communication were aggregated to a second composite variable, the Emotional Quality of the Relationship (EQR) scale. This scale was used as the dependent variable in the analyses of the emotional quality of the relationship.

Sexual function, desire and activity

Only two SCI persons reported that their genital sensation was totally unaltered after injury and six men reported unaltered ability to achieve and maintain an erection sufficient for coitus. Significantly more persons with SCI (67%) than controls (6%) seldom or never experienced orgasm. Some injured males reported that stimulation of body areas with preserved sensibility combined with enjoyment from the perception of the partner's sexual arousal and pleasure gave them a feeling of excitement similar to that of an orgasm.

The majority of SCI respondents and controls considered sex an important part of their lives. However, perceived sexual desire differed significantly between the two groups, 22% of the SCI respondents reporting low sexual desire, compared with 6% of the controls.

Persons with SCI and controls differed significantly concerning the frequency of sexual activity, 56% of the SCI persons and 73% of the controls engaging in sexual activity at least once a week. One-third of the SCI persons and 10% of the controls reported infrequent or no sexual activity of any kind. About half of the SCI respondents (47%) and the controls (51%) reported being content with the frequency of sexual activity. However, almost the same proportion in each group (45% of persons with SCI and 48% of the controls) expressed a wish to engage in sexual activity more often.

Sixtytwo per cent of the SCI respondents reported a decline in the frequency of sexual activity compared with before the injury. Of the controls, 73% reported decreased sexual activity due to different circumstances. The most common reasons for the decline mentioned by the SCI persons were physical limitations (51%) and decreased sexual ability (21%). Tiredness and lack of time due to too much work were the most commonly mentioned reasons for decreased sexual activity among the controls (51%). Decreased sexual desire was listed by 16% in each group, and the partner's decreased sexual desire was considered the reason for diminished sexual activity by 15% of the SCI persons and by 21% of the controls. Lowered self-esteem was listed by 8% of the SCI persons and by 4% of the controls. Decreased sexual activity due to ageing was reported by 6% of the SCI persons and by 4% of the controls.

Sexual behaviour

Hugging, kissing, and manual stimulation of the genitals and other erogenous zones were common in the sexual repertoire of more than half of the persons with SCI and most controls. About half of the SCI and control individuals reported engaging in orogenital stimulation almost every time they had sexual contact. Considerably fewer of the SCI respondents (39%) than the controls (83%) engaged in intercourse most of the times they had sexual contact.

Satisfaction with sexual life

Significantly fewer of the injured persons (64%) than the controls (86%) reported that they had the perception that their partner was satisfied with the respondent's sexual adequacy and an almost similar proportion among SCI persons (67%) and controls (85%) had the perception that their partner enjoyed their sexual interactions. Although a greater proportion of the controls (88%) than persons with SCI (71%) reported enjoyment from their sexual activities, the difference was not significant. However, a significant difference between the two groups was disclosed with regard to personal satisfaction with sex life, 61% of persons with SCI and 86% of controls reporting being satisfied with the quality of their current sex life. Many SCI respondents (76%) considered their sex life now to be less satisfying than before injury, while 16 SCI respondents (21%) considered their current sex life to be as good as or better than their previous sex life. Two young men could not compare because of lack of any previous sexual experience. A larger proportion of the controls (66%) than the SCI persons (36%) considered themselves sexually attractive.

Open communication and mutual honesty were the most commonly listed factors in both groups for maintaining a positive and satisfying sexual relationship. The use of sexual fantasy and experimentation with a variety of sexual expressions were also listed by many persons in both groups as important for keeping sexuality alive.

The emotional quality of the relationship

No significant differences were found concerning the different aspects of the emotional quality of the relationships between the two groups. The majority of the SCI respondents (87%) and controls (93%) considered their overall relationship to be satisfactory. Most of the SCI persons (76%) and controls (80%) indicated that they frequently expressed their feelings of affection for their partner, verbally and non-verbally. Many of the persons with SCI (57%) and the controls (69%) reported that they had the perception that their partner was satisfied with the way they expressed their affectionate feelings.

The persons with SCI scored significantly lower than the controls on the Sexual Activity and Satisfaction scale ($p<0.001$), the Sexual Behaviour scale ($p<0.001$) and the Quality-of-Life rating ($p<0.001$) and higher on the Depression scale ($p<0.001$). Only the Emotional Quality of the Relationship scale scores showed no significant differences between the two groups.

Sexual adjustment in relation to physical, sociodemographic and psychosocial variables

In both SCI persons and controls, an active and satisfying sex life, as measured by the SAS scale, was positively correlated to a good emotional quality of the relationship, perceived partner sexual enjoyment and satisfaction, partner perception of the respondent's sexual adequacy, experimentation with different sexual expressions, personal experience of orgasm, ratings of sexuality as an important part of life, perceived high quality of life and lack of depressive symptoms. The duration of the relationship was negatively correlated to the sexual activity and satisfaction in both groups. Althoug young age, previous sexual experience and the use of technical aids to enhance sexual pleasure were positively correlated to the SCI persons' sexual adjustment, these correlates were not found in the control group. The level of leisure activities undertaken alone correlated significantly with the SCI person's sexual activity and satisfaction, whereas the level of recreational activities outside the home together with the partner correlated significantly with the control's sexual activity and satisfaction. Sex, level of education and employment were not correlated to sexual adjustment in either group.

Concerning the SCI persons, physical variables such as the level and completeness of the lesion were not significantly correlated to sexual adjustment, whereas the ability to achieve an erection and the preservation of genital sensation were positively correlated to sexual activity and satisfaction.

Determinants of sexual adjustment

Partial and multiple correlations were used to identify which of the measured independent variables were the most powerful determinants of sexual adjustment. Among SCI persons, 91% of the variance was explained by three variables: a varied repertoire of sexual behaviours (the greater the variety of sex acts the better), perceived partner sexual enjoyment and satisfaction (the greater the better) and perceived partner satisfaction with the respondent's sexual adequacy (the greater the better).

In the control group, 82% of the variance was explained by six variables: experimentation with different sexual expressions, the use of a varied repertoire of sexual behaviours, perceived partner sexual enjoyment and satisfaction, perceived partner satisfaction with the respondent's sexual adequacy, feelings of being sexually attractive and a good emotional quality of the relationship.

Determinants of emotional quality of the relationship

Perceived partner satisfaction with the manner in which SCI persons expressed their feelings of caring and affection (the greater the better) and partner perception of the respondent's sexual adequacy (the greater the better) were the most important determinants of a good emotional quality of the SCI persons' relationship. Fortynine per cent of the variance was thereby explained.

In the controls, four variables explained 55% of the variance: perceived partner satisfaction with the manner in which the respondents expressed affectionate feelings, an active and satisfactory sex life, a varied repertoire of sexual expressions and perceived high quality of life.

Study II

Sexual adjustment after spinal cord injury (SCI) focusing on partner experiences

The main questions were:

1/ How do partners of SCI persons experience the sexual and emotional aspects of their intimate relationship?

2/ What are the psychosocial, behavioural, physical and socio-demographic determinants of sexual adjustment from the partner's perspective?

Items covering sexual interest, activity and satisfaction were treated as one composite variable, the Sexual Interest, Activity and Satisfaction (SIAS) scale. This scale was used as the dependent variable in the analyses of the partner's sexual adjustment.

SCI partner experiences of the emotional quality of the relationship

Most partners (84%) considered their relationship overall to be satisfying and all but one respondent felt substantial affection for their partner. Most of the respondents (78%) indicated that they frequently expressed this affection verbally and non-verbally. Eightyfour per cent of the partners reported being satisfied with the manner in which the SCI person demonstrated affection for them. Fortytwo partners (86%) were also satisfied with the manner in which relationship problems were solved by the couple. Only six partners had considered divorce or separation. Three-quarters of the partners thought they were able to have open and honest communication about sex within the relationship.

SCI partner experiences of the sexual part of the relationship

Five men and thirteen women (37%) thought that their interest in sex had decreased because of their partner's spinal cord injury. Sixtyone per cent of the partners (5 men and 25 women) appreciated the quality of their current sex life. Half of the partners reported sexual interaction, with or without intercourse, once a week or more. Manual and oral stimulation of secondary erogenous zones were an important and pleasurable part of the sexual repertoire of many couples, as reported by the partner. Almost two-thirds of the partners said that their injured partner showed considerable concern about the partner's sexual pleasure and satisfaction and three-quarters of the partners thought that their injured partner enjoyed their sexual relationship. Emotional factors such as honesty, trust, closeness, mutual respect, communication, caring and appreciation were reported to be important in maintaining a positive and satisfying sexual relationship, as were the use of sensuality and sexual fantasy. A quarter of the partners reported that the couple experimented with different sexual expressions more often since their partner's injury or with non-SCI partners.

Slightly more than half of the partners (5 men and 22 women) reported being content with the frequency of sexual activity. However, more than one-third (4 men and 15 women) expressed a wish to engage in sexual activities more often. Several partners reported that the injury had caused some positive changes in their sex life such as increased playfulness, prolonged foreplay and feelings of sexual equality. The injured person's inability to achieve orgasm was perceived as interfering negatively with the sexual satisfaction of some of the partners.

Of the 44 couples who were sexually active, two-thirds of the partners (66%) and one-third of the injured persons (34%) experienced orgasm on most occasions during sexual activity, as reported by the partners.

No significant sex differences were found concerning the various sexual and emotional aspects of the relationships.

Sexual adjustment in relation to physical, sociodemographic and psychosocial variables

Partner sexual adjustment as measured by the SIAS scale was significantly correlated to high partner perceived overall quality of life as well as the SCI person's physical and psychosocial well-being and perception of high quality of life.

The emotional quality of the relationship and mutual concerns about the sexual pleasure of the partner were positively correlated to active and satisfying sexual fulfilment.

A varied repertoire of sexual behaviours and willingness to experiment with different sexual expressions were significantly correlated to higher SIAS scores. Furthermore, the SCI person's ability to maintain erections and to engage in intercourse was positively correlated to the partner's sexual satisfaction, as was the frequency of experienced orgasm.

Youth and injury at young age were significantly correlated to high scores on the SIAS scale. The level and completeness of the SCI person's lesion showed no significant correlation with the partner's sexuality, although there was a significant correlation between the injured person's preserved genital sensibility and the partner's perceived sexuality.

Determinants of the SCI partners' sexual adjustment

A multivariate analysis was used to identify which of the independent variables were the most important determinants of sexual adjustment. High general satisfaction with life, a varied repertoire of sexual expressions, including intercourse, concern about the able-bodied partner's sexual pleasure and the preservation of genital sensation in the SCI person were positive determinants of an active and fulfilling sexual relationship. Sixtytwo per cent of the variance was thereby explained.

Study III

Sexual adjustment after spinal cord injury – comparison of partner experiences in pre- and postinjury relationships

The main questions were:

1/ Are there any sexual and emotional differences between lasting preinjury and postinjury relationships from the partner's point of view?

2/ Do the personality profiles differ between partners in preinjury and postinjury relationships or from those in a reference group?

Pre and postinjury partners' experiences of the emotional quality of the relationship

Most of the partners in both preinjury (88%) and postinjury (86%) relationships considered their overall relationship to be satisfactory. Most of the partners in both groups were also satisfied with the manner in which problems within the relationship were solved. Many partners in the preinjury group (40%) thought that sex was a difficult subject to talk about, whereas 86% of the postinjury partners reported that they could easily discuss sex with their injured partner. One-third of the preinjury partners and nearly half of the postinjury partners were engaged in out-of-home activities alone as well as together with their injured partner at least once weekly. A larger proportion of SCI persons in preinjury relationships received regular assistance with personal care from their partner (54% compared with 17%).

The partners in postinjury relationships scored significantly higher than partners in preinjury relationships on the QL scale ($p<0.001$).

Pre and postinjury partners' experiences of the sexual part of the relationship

All but three preinjury partners considered sex an important part of their lives. However, almost half of preinjury partners reported decreased sexual interest after their partner's injury and a quarter of postinjury partners reported that their sexual interest was decreased due to their partner's disability.

Less than half of the preinjury partners (46%) but most postinjury partners (78%) were satisfied with their current sex life. Three-quarters of the preinjury partners considered their sex life now to be less satisfying compared with the situation before their partner's injury. No-one in the preinjury group thought it was better. Compared with their previous sex life with a non-injured person, current sex life was considered better by half of the partners in postinjury relationships. Four partners in the postinjury group could not compare because of no previous sexual experience.

In the preinjury group, about a quarter of the respondents (27%) reported sexual activity once a week or more, whereas infrequent or no sexual activity of any kind was reported by almost half (46%) of the partners in this group. All couples in the postinjury group were sexually active. Nearly three-quarters (74%) of the partners in this group reported sexual interaction once a week or more.

Intercourse and manual and oral stimulation of the genitals were commonly part of about a quarter (23%) of the preinjury couples' sexual repertoire, whereas the remainder of this group seldom or never used these sexual expressions. Almost two-thirds (62%) of the partners in postinjury relationships reported that they engaged in intercourse every or almost every time they had sex, and manual and oral genital stimulation also became a common part of their sexual repertoire. Manual and oral caressing of other erogenous zones were an important part of the sexual repertoire in most postinjury relationships (87%) and nearly half of the preinjury relationships (43%).

Almost half (46%) of the partners in preinjury relationships were satisfied with the frequency of sexual activity, and 42% expressed a wish to engage in sexual activity more often. In the postinjury group, approximately two-thirds of the partners (65%) reported being content with the frequency of sexual activity. The remainder in this group expressed a wish to engage in sexual activities more frequently.

The SCI person's physical limitations and decreased sexual ability were listed as reasons for decreased or diminished sexual activity by nearly two-thirds (60%) of partners in preinjury relationships. The same reasons were given by one-third (32%) of partners in the postinjury group. Eight preinjury and one postinjury partner claimed that their own decreased sexual desire and unwillingness to engage in sex contributed to diminished sexual interactions.

Age-adjusted differences

Due to the large differences in age between partners in preinjury and postinjury relationships, statistical analysis with age as a covariate was used. The influence of age was responsible for most of the differences between the two groups, whereas some significant differences remained.

The frequency of sexual activity and the use of various sexual expressions were significantly lower in preinjury relationships. Furthermore, perceived deterioration of sex life due to the disability was significantly more common among preinjury partners. In contrast, sexual adjustment as measured by the SIAS scale showed no significant differences when age was statistically controlled. All other variables addressing sexual and emotional aspects of the relationship were also found to be primarily related to the age discrepancy between the two groups. Furthermore, the partners' perception of their overall quality of life showed no significant difference between the two groups when the influence of age was controlled.

Personality characteristics

The partners' personality characteristics differed only slightly from those of a sex and age-matched reference group and not at all between partners in pre and postinjury relationships. The partners of the SCI persons had somewhat lower scores on the Socialization scale and the Inhibition of aggression scale, whereas they had higher scores on the Monotony avoidance scale.

Study IV

Sexual adjustment and its predictors after traumatic brain injury

The study attempted to answer two main questions:

1/ What characterises the sexual ability, activity and satisfaction with sex life in the traumatic brain-injured persons?

2/ What are the physical, psychosocial, behavioural and socio-demographic predictors of sexual adjustment in the TBI persons?

Items relating to sexual interest and satisfaction were treated as one composite variable, the Sexual Interest and Satisfaction (SIS) scale, measuring sexual adjustment after injury.

Sexual ability and activity

Many of the 84 respondents who had been sexually active together with a partner before the injury reported that substantial changes in sexual function had taken place after the injury. Thirty per cent of the men reported decreased or absent ability to achieve an erection and decreased frequency of ejaculation, 40% mentioned that their ability to experience orgasm was decreased or non-existent, 24% reported decreased and 23% non-existing frequency of intercourse.

More than half of the 92 TBI respondents (56%) reported dissatisfaction with the frequency of sexual activity and almost one-third (31%) reported lack of a close partner as the main reason. A further 15 persons (16%) mentioned that low sexual interest contributed to decreased sexual activity. Poor self-esteem was listed by 14 (15%) of the participants. Eleven per cent of those who had a partner relationship postulated that their partner's unwillingness to engage in sex was the main reason for limited sexual activity. Six respondents believed that their physical unattractiveness and decreased sexual ability were reasons for ceased sexual activity.

Sexual desire and satisfaction with sexual life

Fiftyeight per cent of the participants thought that sexuality was as important to them as before injury, whereas 42% regarded sex as a trivial part of their lives. Forty per cent of the respondents reported diminished sexual desire after injury. Almost all (89%) of the 53 TBI persons who had a partner relationship at the time of the investigation were satisfied with the sexual part of the relationship and three-quarters (75%) were also satisfied with the frequency of sexual activity. Sixtyone per cent had the perception that they were able to give their partner sexual pleasure and enjoyment. Sixtyfour per cent of the 92 respondents reported that they enjoyed their sex life, together with a partner or by self-masturbation.

None of the respondents had received information or counselling about sexuality after the injury.

Functional status, mood and global quality of life

Fortythree per cent of the TBI person exceeded 10% in the SIP physical dimension and 63% exceeded 10% in the SIP psychosocial dimension, thus indicating clinically significant levels. Eleven per cent were classified as having severe disability and 66% moderate disability, whereas 23% had achieved a level of "good recovery", according to the Glasgow Outcome Scale (GOS).

Thirty per cent of the TBI persons fulfilled HAD criteria for anxiety (borderline 18% and morbid 12%) and 26% met HAD criteria for clinical depression (borderline 16% and morbid 10%).

Global quality of life ratings are shown in Table V.

Sexuality related to functioning and well-being

Analyses including those 84 respondents who were sexually active before the injury showed that occurrence of sexual intercourse, ability to achieve an erection, ability to ejaculate, experience of orgasm and satisfaction with the frequency of sexual activity were positively correlated to a satisfactory sexual life as measured by the SIS scale. High scores on the SIS scale were also significantly correlated to injury at an early age. Perceived quality of life showed no significant correlation to sexuality, whereas depressed feelings as measured by the HAD scale showed a negative correlation to sexuality. Negative correlations were found between sexuality and SIP physical dysfunction, SIP psychosocial dysfunction and the severity of the disability as measured by the GOS, whereas a negative but nonsignificant correlation was found between PTA and sexual adjustment. No significant correlations were found between the physical or the cognitive dimensions of the FIM and FAM and sexuality.

Determinants of the TBI persons' sexual adjustment

A multivariate analysis was performed to identify which of the measured independent variables were the most important determinants of sexual adjustment. In the 84 respondents who had been sexually active before the injury, 79% of the variance was explained by three variables in combination: occurrence of sexual intercourse, the ability to experience orgasm and a high degree of physical independence (SIP physical dimension).

Analyses including only the 53 TBI persons with a sexual partner at the time of the investigation showed that occurrence of sexual intercourse, the ability to experience orgasm and satisfaction with the overall relationship were the strongest determinants of sexual adjustment, together explaining 76% of the variance.

Study V

Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury

The main question was:

Are there any differences between SCI and TBI persons and people from the general population concerning partner relationships, mood and perceived quality of life?

Partner relationships

Significantly fewer of the SCI persons (51%) than TBI persons (58%) and controls (59%) had a partner relationship at the time of the investigation. More than one-third of the SCI and more than half of the TBI relationships (38% and 55% respectively) were established after injury. Significantly more of the persons with SCI (48%) and TBI (56%) were divorced or separated compared with the controls (39%). The most commonly mentioned reasons for the separation among the SCI persons were either difficulties in attaining new physical functioning and maintaining a partner relation at the same time (20%), or the partner's unwillingness to live with a disabled persons (25%).

Of those who were single at the time of the investigation, approximately half of the persons with SCI (45%) and TBI (54%) had not engaged in sexual activity after injury. The remainder reported sexual experience with between one and eight partners. Almost one-third (31%) of the single controls had no experience at all of sexual activity together with a partner. The remainder of the single controls reported sexual experience with between two and 30 partners.

Of those who were single at the time of the investigation, 25% of the SCI persons, 2% of the TBI persons and 9% of the controls mentioned that they had neither the time nor interest in having sexual relationships. Fifteen per cent of the SCI persons reported poor self-esteem in combination with decreased sexual ability as the main reason for being single. Poor self-esteem was listed by 15% of the TBI persons and by 14% of the controls. Ten per cent of the SCI persons reported that they had difficulties in meeting and attracting a new partner when disabled and in a wheelchair.

Functioning, mood and global quality of life

Both SCI and TBI persons showed significantly more depressive feelings according to the HAD Depression scale compared with the controls. Twentytwo per cent of the SCI persons and 30% of the TBI persons fulfilled HAD criteria for clinical depression, compared with 5% of the controls. Perceived quality of life was lower in both the SCI and TBI groups compared with the controls, although the TBI persons' and controls' perception of quality of life did not differ significantly.

SCI and TBI persons did not differ significantly in level of education, physical and social functioning as measured by the SIP, mood as measured by the HAD Depression scale and perceived quality of life.

Significantly more of the SCI persons (66%) were employed or studying compared with the TBI persons (51%). Compared with the controls, however, significantly fewer persons in both the SCI and TBI group were employed or engaged in studies.

In all three groups, perceived QL was significantly lower among persons who were single compared with those in a relationship. Furthermore, physical and social functioning (SIP) were significantly lower in the single SCI and TBI groups compared with those who had a partner relationship. Whereas mood (HAD Depression) was significantly lower among persons who were single in the SCI group, there was no significant difference in mood between those who were single and those in a relationship in the TBI and control groups. Perceived loss of independence (SCI Problem) showed no significant difference between SCI persons who were single and those that had a partner relationship.

Quality of life in relation to physical, sociodemographic and psychosocial variables

Marital status correlated significantly with the SCI person's perceived QL, whereas no correlation to sex could be found. Young age and young age at injury were associated with high QL scores, whereas elapsed time since injury was not significantly correlated to perceived quality of life. The level of engagement in employment or studies correlated significantly to the SCI person's global QL, whereas level of education showed no association with perceived QL. The level and completeness of the lesion showed a slight but nonsignificant correlation to overall QL. The respondents who reported pain severe enough to interfere with daily function showed lower QL perceptions, whereas spasticity problems showed no significant correlation to perceived overall QL.

Mood (HAD Depression), physical and social functioning (SIP) and perceived loss of independence (SCI Problem) were significantly correlated to the SCI persons' global QL.

The TBI person's sex, age, age at injury, marital status and level of education were not significantly correlated to their global QL. Time since injury, the level of engagement in work or studies, mood (HAD Depression), physical and social functioning (SIP) and the severity of the disability (GOS) were, however, significantly correlated to the TBI person's global quality of life.

Sex, age and level of education showed no significant correlation with the controls' global QL, whereas marital status, the level of engagement in work or studies and mood (HAD Depression) correlated significantly with their QL perception.

Determinants of global quality-of-life perception

Partial and multiple correlations were used to determine which of the independent variables were the most powerful determinants of global QL.

Concerning SCI persons, 57% of the variance was explained by three variables in combination: the SCI person's mood, physical and social functioning and perceived loss of independence.

The most important determinants of the TBI persons' global QL were mood, physical and social functioning, severity of disability and time since injury. Fortysix per cent of the variance was explained by these variables.

Concerning the controls, the most important determinants of global QL were mood, time spent in work or studies and marital status, explaining 50% of the variance.

Table IV. Summary of main results of study-specific scales in Studies I, II, III and V. Mean values and standard deviations (SD) are given

Study groups	SAS-scale	SIAS-scale	SIS-scale	EQR-scale	SB-scale
SCI persons *(n=75)*	**65.3** (31.1)			**22.1** (4.0)	**30.5** (14.2)
Controls *(n=155)*	**77.9** (22.3)			**23.4** (3.6)	**37.4** (8.7)
SCI Partner *(n=49)*		**17.6** (7.0)		**22.5** (4.8)	**30.7** (13.5)
Preinjury partners *(n=26)*		**13.8** (6.7)		**21.6** (5.0)	**22.8** (11.9)
Postinjury partners *(n=23)*		**22.4** (3.7)		**23.9** (3.9)	**40.0** (7.3)
TBI persons *(n=92)*			**57.3** (5.2)		

SAS-scale = The Sexual Activity and Satisfaction scale. Used in Study I. Range of scale 0-100.
SIAS-scale = The Sexual Interest, Activity and Satisfaction scale. Used in Studies II and III. Range of score 6-28.
SIS-scale = The Sexual Interest and Satisfaction scale. Used in Study IV. Range of scale 0-100.
EQR-scale = The Emotional Quality of the Relationship scale. Used in Studies I, II and III. Range of score 7-28.
SB-scale = The Sexual Behaviour scale. Used in Studies I, II and III. Range of score 7-49.

Table V. Summary of perceived global quality-of-life ratings and mood in Studies I, II, III, IV and V. Mean (SD)

Study groups	QL-VAS	HAD Depression
All SCI persons *(n=167)*	**57.2** (28.1)	**4.7** (4.0)
All TBI persons *(n=92)*	**63.3** (24.2)	**4.7** (3.8)
All Controls *(n=264)*	**69.8** (21.3)	**2.7** (2.6)
SCI with partner *(n=75)*	**64.1** (25.6)	**3.9** (3.1)
Controls with partner *(n=155)*	**74.3** (19.5)	**2.3** (2.2)
TBI with partner *(n=53)*	**66.9** (23.5)	**4.6** (4.1)
Single SCI persons *(n=82)*	**50.2** (28.9)	**5.6** (4.3)
Single TBI persons *(n=39)*	**58.8** (24.6)	**5.0** (3.8)
Single controls *(n=109)*	**62.3** (21.3)	**3.1** (3.0)
SCI partners *(n=49)*	**63.2** (31.5)	n.a.
Preinjury partners *(n=26)*	**52.5** (34.3)	n.a.
Postinjury partners *(n=23)*	**79.4** (16.1)	n.a.

QL-Vas = Quality of Life Visual Analogue Scale. Range of scale 0-100.
HAD Depr. = Hospital Anxiety and Depression scale. Range of scale 0-18.
SCI = Spinal cord-injured persons
TBI = Traumatic brain-injured persons
n.a. = not applicable

GENERAL DISCUSSION

Methodological aspects

All studies in this dissertation are cross-sectional. The cross-sectional design has its strengths and limitations. It helps to describe the relationships between the measured variables at a given point in time, but it does not indicate changes over time.

The Relationship Questionnaire used in Studies I, II and III was developed specifically for these studies as there was no standardised instrument that could capture the range of variables needed to adequately assess the emotional aspects of intimate relationships and the different facets of sexual adjustment after SCI. Given the lack of standardised instruments for persons with SCI and the lack of appropriate measures from the non-disabled population, the most viable option was to develop an instrument for this study.

Although the study is unique in that it compared the sexuality of persons with SCI to that of persons from the general population, it has some obvious limitations. The study relies on volunteers and self-report methodology. Furthermore, only those SCI relationships that had the strength to survive the changes imposed by the injury or developed after the injury are represented.

There are limitations in questionnaire studies. A questionnaire study, by definition, can only investigate what people <u>say</u> they do, rather than <u>what</u> they do. Furthermore, there are still limits to the questions that can be asked about sex that are completely without ambiguity and the possibility of misinterpretation, especially if the wording is not to become insensitive or absurd. On sensitive and confidential matters, individuals may give false accounts or reply in a way that they consider socially desirable. The conditions required for people to answer honestly and adequately are that they see a good reason to reveal the information and that they can trust the recipient to treat the information with respect and confidentiality. By the nature of the present studies, one would expect the participants not to answer if this was not the case. Furthermore, we applied the technique of strict operationalisation with several specific questions to cover each domain, thus avoiding global ratings. Some of the limits were overcome by including the partners of the SCI persons as part of the study design. Both partners completed the same questionnaires and the information given by the SCI respondents closely agreed with the answers given by their partners. (Figure 4). There is admittedly no guarantee that respondents answered separately, but several measures were taken to ensure independent answers. Furthermore, most of the SCI persons and their partners had taken part in our sexual information and counselling programme, which may have contributed to the high response rates to the straightforward questions on this private and sensitive subject. The information gathered in this thesis could therefore be regarded as reliable and valid and, due to the high response rates, it could also be considered representative.

There is little research evidence to identify which information is best obtained by questionnaire and which by interview. There are problems with both questionnaires and interviews, particularly for surveys of sexuality. Although interviews may appear to offer higher validity for obtaining such information, much depends on the level of rapport or trust that can be established by the interviewer and the knowledge of potential interviewer-induced bias. Questionnaires allow more economical use of the researcher's time and ensure that questions are standardised, they do not, however, ensure that the questions have been understood and seriously addressed. The combined questionnaire-interview technique was chosen to collect information from the persons with TBI. Any difficulty with the questions could then be explained and straightened out in the personal interview. Very few of the TBI persons, however, needed supplementary explanations.

Researchers have relied primarily on the impressions of TBI persons' spouses and relatives because of the presumed loss of insight that accompanies cognitive disability after TBI.[166] However, the high level of agreement and the clear description of problems and coping strategies among TBI persons and their family members found in some studies,[54,163] indicate that they have greater insight into their problems than previously reported and the authors suggest that TBI persons' opinions and perspectives should be included in TBI research.

The strength of the present investigations is that the number of respondents is quite large with a high response rate, thus giving sufficient variation of responses to allow a series of analyses to better describe sexual adjustment and quality of life, and their possible determinants.

It may seem surprising that no significant differences were found between the sexes concerning the variables measured in these studies. It has been suggested in the literature that disabled women are disadvantaged in the area of sexuality and partner relationships compared to disabled men. However, our results should be interpreted cautiously as the number of SCI and TBI women was small.

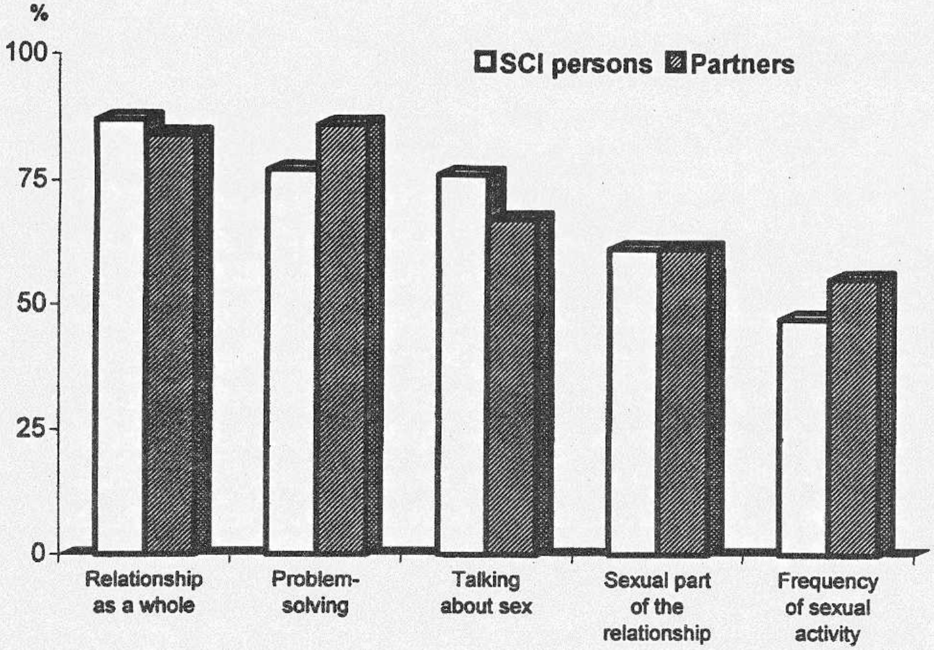

Figure 4. Relative frequency of SCI persons' and partners' satisfaction with different areas of the relationship. The information given by the SCI persons closely agreed with the answers given by their partners.

Statistical issues

In the behavioural sciences one has to be selective in the choice of statistical methods. The more cautious non-parametric technique is preferred when hypotheses are tested in small study samples and with questionnaire data, not quite fulfilling the underlying assumptions for parametric statistics. The permutation tests used in these studies are the most powerful non-parametric statistics available. The extended step-by-step methodology is an elegant, straightforward method of testing relationships without overestimating results and without overlooking important associations. The partial correlation step is the core of the model and parametric statistics are only used for illustration. A regression analysis would be too powerful for our data set as one might run the risk of capitalising on chance findings.

Testing psychometric properties of questionnaires is a highly specialised area of behavioural statistics. Only parts of the basic techniques were used in this thesis to support the internal consistency reliability of each scale.

Sexuality after spinal cord injury

Low sexual desire was reported by almost a quarter of the SCI group and by only a few of the controls. However, nearly all persons in both groups considered sex an important part of their lives, a finding consistent with other studies of persons with SCI[3,72,116,135,138,142,148,156] showing that interest in sexual activity remains alive, at least in the presence of a close partner. *"I can't control or feel my body, but sex is still important to me", "I enjoy our sexual relationship as much as I did before the injury"* and *"I'm still considered sexually attractive by my partner and that means a lot to me",* as some of the SCI respondents put it.

Many in the SCI group were sexually active despite altered genital function. More than half engaged in sexual activity once a week, although this was significantly less than the controls. One-third of the SCI persons and only a few of the controls reported infrequent or no sexual activity of any kind. Several authors have reported continued but decreased sexual activity after SCI,[3,15,138] which was confirmed in this study.

Some of the sexual problems reported by the SCI persons were similar to those of the controls whilst other problems were related to being unable to function sexually in a mobile way, or being unable to experience sensation. *"I miss being able to be the active one during the sexual act"* and *"The problem is that I get sexually aroused, but can't reach the climax",* were comments from some injured men. It has been suggested that the absence of sexual activity in some cases may be a form of successful adjustment. Hohmann[71] reported that some SCI men may find it easier to reduce or eliminate sexual activity from their lives as a means of coping rather than to get sexually aroused without reaching the fulfilment they would like.

The main reasons for decreased sexual activity reported by the controls were relationship problems, tiredness and lack of time due to too much work. This confirms the notion that sexuality may be burdened by many things besides a disability. The majority of the SCI persons, however, enjoyed their sexual relationship and found their current sex life satisfying, although it was a common perception that sex life had been better before injury than it was now. The study showed that previous sexual experience is important for sexual adjustment by the person with SCI. It is assumed that memories and fantasies from previous sexual contacts will increase the sexual desire and enjoyment after injury.

Many SCI persons and controls frequently used other sexual expressions besides intercourse and also reported great enjoyment from these. Even if there are frustrating inequities in a relationship, such as a physical disability, sexual continuity can be maintained if both partners develop innovative approaches to heir previously established sexual patterning. The broader and more flexible a ouple's lovemaking repertoire, the less vulnerable they will be to disruption rom psychological or physical forces. Touching, kissing and manual and oral timulation of the genitals as well as of other erogenous zones are all means of eing intimate, sensual and sexual.

The effect that acquired disability can have on sexuality may depend on ircumstances before the injury. A person who has preinjury experience of omfort and delight in his or her body can often recover these good feelings, lthough the way in which loss is experienced and the kind of initial care given re very important for this process.

Although young age played a positive role in sexual adjustment by the person with SCI, age was not correlated to the control persons' sexual activity and atisfaction. Concerning the SCI persons, this is in agreement with findings from other studies[9,135] and may reflect the greater ability of young people to redefine sexual goals and expectations. The duration of the relationship, however, played an important role in both groups, in that people with a relationship of shorter duration were more sexually active and used a wider range of sexual expressions. This is not surprising considering that couples in recently established relationships may have a greater sexual desire and curiosity than couples in relationships that have lasted for many years. Sexual routine habits may be detrimental to the pleasure of sexual interaction in any long-standing relationship.

A good emotional quality of the relationship, willingness to engage in a variety of sexual activities and the perception that the partner enjoyed the sexual part of the relationship and was satisfied with the respondent's sexual adequacy seemed to play the most important role in sexual fulfilment after SCI and among people in the general population.

Even though sexual activity and satisfaction was lower among persons with SCI compared with controls, the emotional quality of the relationship did not differ. The duration of the relationship was not found to determine the emotional quality of the relationship in either group. This confirms the opinion that there may be other values that are as important as sexual activity in all relationships – short or long.

Interestingly, an active and positive sex life and the use of a varied repertoire of sexual expressions seemed more important correlates of the overall quality of the relationship in the controls than in the SCI group. The perception that the partner was satisfied with the manner in which feelings of caring and affection were shown, however, was equally important for a good emotional quality of the relationship.

Sexuality is an important ingredient of both emotional health and life satisfaction. As Trieschmann[156] states: *"Having a satisfactory sex life has a positive effect on all aspects of human function. It makes us want to take care of ourselves physically, it improves our ability to relate to others harmoniously and it increases our productivity"*. Successful sexual adjustment obviously requires expanding one's personal definition of sexuality. Spinal cord-injured persons may need to develop a more positive body image and to focus more on the sexual functions they have retained rather than on their losses in order to achieve sexual satisfaction. The physical losses can be compensated for by intimacy and togetherness.[121,159] This is supported by comments from some of the SCI persons: *"Sex is even more important now and my sexual fulfilment greater when I have learnt to use all my senses"* and *"Both my partner and I appreciate our sexual interactions more now that both foreplay and the sex act are longer"*. Cole[27] states that the ability to communicate wants and feelings with the partner, the mutual willingness to experiment with sexual activities which are pleasing and not exploitive, an emphasis on fantasy, and the knowledge that more sexuality lies within the head than between the thighs will all help to set the stage for restoration of an active and satisfactory sex life. If intercourse is the ultimate goal of someone's sexuality, however, it is not an appropriate therapeutic approach to try to persuade that person that this is not essential.

SCI Partner experiences

These studies are unique in that they focused on the impact of a spinal cord injury on the sexual and emotional aspects of intimate relationships from the perspective of the injured person's partner.

The majority of SCI partners considered their relationship with an SCI person to be satisfying overall, with considerable mutual affection. Mutual endearments are key ingredients to a satisfying sexual relationship and the partners reported that there were acts of physical intimacy, emotional tenderness, casual caresses and expressed affection pleasing to both individuals. If respect, caring and enjoyment are lacking, sexual satisfaction will decline in most relationships.

Many of the partners mentioned that they could easily talk about sexual matters with their injured partner. Open communication tends to dispel misconceptions which may be even more important in relationships where one of the partners has a physical disability. Open and honest communication is essential to a satisfactory sexual relationship and in a close relationship both partners have the responsibility to communicate their views as honestly and accurately as possible. Talking about sex is, however, taboo among older people, which was confirmed in this study. Decreased sexual activity or disinterest in sex may at least partly stem from a lack of open and honest communication about sexual issues. Considering that frank and open communication between sexual partners is positively related to the quality of their sexual relationship,[13,41,135] couples should be encouraged to use frequent verbal as well as non-verbal feedback about sexual concerns.

Current sexual fulfilment was reduced for nearly one-third of the partners. *"I miss the feeling of making love on the same conditions", "His handicap and sexual inability is a source of frustration"*, and *"I become sexually satisfied, but can't satisfy my partner – that's why my sexual desire is decreased"*, were comments from some of the partners. In addition, reduced sexual satisfaction or diminished levels of sexual activity might be due to the stressful situation and emotional reactions engendered by the injury rather than the physical consequences of the injury itself. The SCI person's lowered self-esteem, performance anxiety and negative body image might also explain the diminished sexual activity.

Only 9% of the couples who were sexually active reported having sexual intercourse every time they initiated sexual contact. Approximately half of the couples used orogenital sex or manual stimulation as their most frequent form of sexual activity. Since the majority of partners experienced orgasm most of the times during sexual interactions and expressed satisfaction with their current sex life, it is clear that coitus is not always the most important source of sexual satisfaction. Thus, sexuality should be considered in its full sense and not confined to sexual intercourse. Studies investigating the female sexual response have shown that manual and oral sexual stimulation are effective ways for women to experience orgasm.[78,101]

The partner's sexual satisfaction was not correlated to the level or completeness of the SCI person's lesion. However, the preservation of genital sensation was shown to be an important factor. Given that the genital area is a primary focus of sexual excitement, it is understandable that preserved genital sensation in the SCI person is important to enhance mutual sexual pleasure.

The injured person's concern about the sexual pleasure and enjoyment of their partner was one of the most important factors for the partner's sexual fulfilment. As sexuality extends beyond the person's physiological capacity for intercourse and covers an expanded sexual repertoire, focusing on sensuality rather than on achievement may lead to positive developments in a couple's relationship and increased feelings of sexual equality for both partners. Furthermore, it is hypothesised that the high level of participation in the information and counselling at our spinal unit may have contributed to positive sexual attitudes and an interest in experimenting with various sexual options.

High general satisfaction with life, a varied repertoire of rewarding sexual expressions and concern about the able-bodied partner's sexual pleasure were the most powerful determinants of an active and fulfilling sexual relationship from the partners' perspective. Thus, feelings of emotional closeness, mutual concerns and willingness to engage in a variety of sexual activities seemed to be more important for the partner's sexual fulfilment than the physiological aspects of sexuality.

Comparison of pre and postinjury relationships

Although sexual activity had decreased, or even ceased, in many preinjury relationships, there was no difference between the preinjury and postinjury groups in terms of emotional attachment within the couples and satisfaction with the relationship as a whole. Sexuality is an important factor in intimate relationships, yet many authors have reported that the sexual relationship is not a necessary factor for a satisfying partner relationship.[69,115] Satisfaction in a relationship relates to a constellation of activities, sexuality being only one. This holds true for people in general as well as for the person whose sex life is affected by a physical disability.[69,115,156] The depth and stability that may exist in a relationship of long duration may be of greater importance than is sexual activity. This is supported by written comments from some of the respondents: *"At our age and with his disability, we consider sex of less importance"*, *"There are other values in life than sex in a long-lasting relationship"*, and *"Since my husband became totally paralysed, we appreciate and enjoy other things in life than sex"*.

Most of the partners in postinjury relationships were satisfied with their current sex life. Half of them even considered it to be better than their previous sex life with an able-bodied partner. None of the partners in preinjury relationships gave such a response. This could be explained by the postinjury couples' use of a wider range of sexual expressions, which may be a source of greater sexual satisfaction. That some preinjury partners reported deterioration of their sex life after their partner's injury could also be referred to the fact that many of them frequently assisted their injured partner with their personal care.

Partners acting as care-givers might be troubled by the dual role of care-giver and lover. More efforts have to be made to encourage partners not to act as care-givers for their injured partner.

Several partners reported that the injury had caused some positive changes in their sex life such as increased playfulness, prolonged foreplay and feelings of sexual equality. On the other hand, some partners in both groups reported that certain aspects of the injury had a somewhat negative influence on their sexual pleasure, such as catheter routines, the need to plan the sex act and their injured partner's inability to achieve an orgasm.

Most differences revealed between the pre and postinjury relationships studied were age-related. Sexual adjustment, as measured by the SIAS scale, showed that once the influence of age was controlled, there was no significant difference between partners in pre- and postinjury relationships. However, some significant differences remained. The frequency of sexual activity and the use of various sexual expressions were lower in preinjury relationships. Furthermore, perceived deterioration of sex life due to the partner's disability was more common among preinjury partners. Those couples who had totally ceased sexual activity were all older and married before the injury. The study of Nikas et al[108] showed that 40 years after the SCI nearly all had ceased sexual activity. It is possible that in some of these cases the decline in sexuality is due to the normal ageing process. However, several of the preinjury partners mentioned that the decrease in sexual activity was due to the injured partner's disability. Thus, it seems that younger people may be more flexible and able to identify new sexual roles leading to a rewarding sex life. This is not surprising considering that younger people have grown up in a time of sexual liberation. Many of society's former taboos concerning sexuality may withhold older people from some acts of sexual expression. The findings support the conclusion that age seems to be a somewhat more important factor for sexual adjustment after spinal cord injury than whether the relationship is established before or after the injury.

Personality characteristics

It has been suggested that partners of SCI persons might have unusual qualities that contribute to the success of postinjury relationships.[37,158] However, our investigation shows that there were no significant differences between pre and postinjury partners' personality characteristics, as measured by the Karolinska Scales of Personality inventory. Furthermore, the partners' personality traits differed only partly from those of a reference group. The somewhat higher scores on the Monotony avoidance scale indicate a need for change and action and difficulty withstanding boredom and routine. This quality might be valuable considering the flexibility demanded by the disability. The lower scores on the Socialization scales indicate that the partners in this study behave less according to rules and conventions. As suggested by Crewe and Krause,[37] they may have *"the independence necessary to look beyond society's stereotypes concerning intimate involvement with a disabled person"*, and a greater acceptance of sexual variety. Finally, the lower scores on the Inhibition of aggression scale indicate that the partners are able to speak up and assert themselves in social situations. These special personality traits imply that partners in both pre- and postinjury relationships in this study might be somewhat more courageous and confident than the average person.

However, as the personality characteristics of the partners in this study differed only slightly from those of a reference group and not at all between partners in pre and postinjury relationships, we can dismiss the assumption that the partners' unusual qualities or values are the primary explanation for a spinal cord-injured person's satisfactory marriage or relationship.

Sexuality after traumatic brain injury

To our knowledge, this is the first study to report the long-term impact on sexuality from the brain-injured persons' perspective, and to elucidate sexuality from both the physical and psychosocial aspects. This study shows that a brain injury commonly alters sexual functioning as well as desire. Furthermore, sexual dysfunctions increased with the severity of disability, a finding consistent with other studies.[89,94] Nearly all were sexually active at the time they sustained their injury but over a quarter had no experience of sexuality together with a partner after injury. Many of the TBI persons in our study reported decreased sexual desire, decreased ability to achieve an erection, decreased ability to experience orgasm and diminished frequency of intercourse. Almost half of the respondents even considered sexuality to be a trivial part of their lives. Loss of ability to achieve an erection can have a devastating, demasculating effect on a man and can reverse his sexual role into a more passive one. Decreased sexual ability and desire may be due to the location of the brain injury. However, there is no clear-cut relationship between the locus of the injury and sexual function.[121] Sexual difficulties may be related to the TBI person's mood level or deterioration in the intimate relationship. Many of the TBI persons studied met the criteria for clinical depression. Feelings of depression and insufficient personal satisfaction may be detrimental to anyone's sex drive and this study shows that there were clear correlations with sexual adjustment and the brain injured-person's psychosocial status as measured by the SIP and the mental state as measured by the HAD. This is in agreement with the findings of Rosenbaum and Najensson.[121] They investigated the relationship between mood disturbance and level of sexual activity among wives of both SCI persons and TBI persons as well as among that of non-injured controls. An analysis revealed that the greater the mood disturbance, the more diminished was the sexual activity. Furthermore, their study showed that negative attitudes towards perceived sexual changes were associated with a lower mood level. Thus, sexual inadequacy affecting basic psychosocial needs can markedly impede overall adjustment and vice versa.

The high correlation between young age at injury and better sexual adjustment is consistent with findings about spinal cord-injured persons' sexual adjustment.[86,88,135] This confirms the assumption that people injured at an earlier phase in life may be more flexible and able to maintain or restore a satisfying sex life.

Half of the TBI persons were dissatisfied with the frequency of sexual activity. A frequently reported reason for the decreased sexual activity was lack of a close partner. Cognitive and behavioural alterations can interfere with an individual's capacity for social and sexual relationships. Based on a literature review, Lezak[92] suggest that many brain-injured individuals lost their capacity to relate sensitively to their partners, thus being less able to satisfy their partners sexually. Spouses may feel disinterest in sex due to the changes that have occurred in the TBI person, as reported in many studies.[89,102,103,111] However, in this study, only six respondents mentioned that their partner's unwillingness to engage in sex was the main reason for decreased sexual activity. Part of the problem with the decreased sexual interest and activity may be due to the failure of the rehabilitation programme to focus on the sexual needs of the TBI patients. The present work shows that the TBI participants were particularly disadvantaged in this respect. None of the TBI persons studied had received sexual information or counselling after injury. Considering that maintained ability to engage in sexual intercourse and experience of orgasm correlated positively with the injured person's sexual adjustment, one may assume that counselling and information about sexual options, including available technical aids, would have been helpful for many TBI persons.

In many studies, the length of post-traumatic amnesia (PTA) has been regarded as the most consistent indicator of global outcome after a traumatic brain injury,[90,103] whereas other studies have shown a very weak and ambiguous relationship between PTA and, for example, the extent of personality changes.[18] In this study, a less severe disability as measured by the GOS and a high degree of physical independence as measured by the SIP were more important for sexual adjustment than the degree of organic damage as measured by the PTA.

Partner Relationships functioning, mood and quality of life

Both a spinal cord injury and a traumatic brain injury appear to affect partner relationships, overall quality of life and mental wellbeing negatively. However, the number of sustained relationships and the number of relationships contracted after injury among both SCI and TBI persons indicate that the impact of these injuries on relationships is not as substantial as has sometimes been assumed.

Among those who were single at the time of the investigation, approximately half of both SCI and TBI persons had no experience of sexual activity together with a partner after the injury. The remainder reported sexual experience with between one and eight partners. Almost one-third of the single controls had no experience at all of sexual activity together with a partner, whilst the remainder of the single controls reported sexual experience with between two and 30 partners. Obviously, some continue to seek sexual interactions with multiple partners, maybe in order to test their sexual adequacy. They may not, however, constitute the majority of SCI and TBI persons.

The proportion of single SCI and TBI persons was somewhat higher compared with the control group. Some of those who remained single had made this choice for the same reasons as single people among the general population, i.e. they had neither the time nor interest in having sexual relationships. The disabled person, as well as the able-bodied individual, has the right to determine whether or not to express himself sexually, as discussed by Comarr and Vigue.[32] Decreased sexual ability contributed to not having a partner relationship among a few of the injured persons. Furthermore, some persons with SCI mentioned that they had difficulties in meeting and attracting a partner when disabled and in a wheelchair, stating *"you can't flirt in a wheelchair", and "no-one wants a cripple"*. This indicates that individual attitudes toward people with disabilities and the injured person's own prejudices of physical deviance may in some cases make it difficult to develop new relationships or re-establish old ones. It is, however, beyond the scope of this study to assess the extent to which physical and cognitive limitations in fact preclude SCI and TBI persons from establishing intimate relationships. It has been suggested that only individuals who are especially likeable, active and well-adjusted succeed in attracting partners and establishing close relationships after an SCI.[38] About the same number in all three groups considered low self-esteem to be a barrier to establishing close partner relationships. Thus, lack of peer acceptance as well as lack of self confidence may be a hindrance in initiating a relationship.

Because of the sudden onset and severity of a spinal cord or traumatic brain injury, they pose the most extreme psychological insults of all forms of trauma. Individuals with these disabilities must face considerable adjustment in their lives as they cope with the long-term consequences of their injuries. Learning to live with a disability such as a spinal cord or traumatic brain injury is a frustrating and possibly life-long process. It has been suggested that the key to this learning process is to perceive the disability as part of the picture in one's life.[120] The continuity of one's self and the reconciliation of the changes resulting from the injury into the concept of self is considered to be essential to assimilate the disability into the context of life.[24]

Self-perceived quality of life varies in these two groups, as it does in persons from the general population. The analyses of response patterns showed close associations between perceived overall quality of life, mood level, sexuality and the emotional quality of the relationship in both the SCI and control group. Furthermore, the SCI partner's sexual adjustment was closely related to his or her perceived overall quality of life as well as to the SCI person's physical and psychosocial well-being and quality of life perception. Thus, sexual adjustment seems to follow overall adjustment to injury. Having a close and caring partner and an active and fulfilling sex life has a positive effect on many aspects of living and improves quality of life. On the other hand, a high quality of life will also have a positive influence on an individual's sex life. Insufficient personal life satisfaction may be very detrimental to sexual activity and satisfaction and to the emotional quality of the relationship. Overall quality of life may be influenced by sexual inadequacy because it affects basic psychological and social needs. A positive relationship between sexuality and the SCI person's overall adjustment after injury has been described earlier.[9,38,76,135] It has also been shown in the literature that anxiety and depression are associated with diminished levels of sexual activity. [79,91,117,118,121]

Many SCI and TBI individuals reported relatively high levels of life satisfaction and psychological well-being, which is in agreement with other studies.[24,34,136,162] Most of the major influences on QL are social and psychological in nature,[24] thus indicating that social and psychological adjustment or assimilation is made by many persons with spinal cord and traumatic brain injuries. In this study, about half of the total variance of global QL was explained by these components in all three groups, which illustrates the multidimensional nature of the QL concept. Despite the high level of explained variance in global quality of life, the amount of unexplained variance offers a challenge for future research.

The SCI persons' perception of a high quality of life was significantly correlated to youth and injury at a young age, which indicates that older people are more resentful of the changes imposed on their lives by the injury than are younger people. This is also supported by the fact that the perceived lower satisfaction with life among SCI persons' preinjury partners was primarily related to the age discrepancy. Youth, may therefore be an important resource in adjusting to a disability. Older individuals may be less able to develop new coping strategies and ways of maintaining self-esteem. It could also be that older people are less well provided for in both vocational, social and leisure activities.

The level and completeness of the SCI person's lesion did not influence perceived quality of life, whereas the TBI person's quality of life perception was strongly correlated to the severity of the disability. This might be explained by the TBI person's prolonged distress to the daily living with both cognitive and physical impairments. A meta-analytical review of studies[56] indicated that at most 5% of the variance in quality of life scores is due to the severity or level of the SCI. The TBI person's QL perception was significantly correlated to duration of disability, which indicates that persons with TBI need a certain amount of time after injury to adjust to the problems imposed by the brain injury. With increasing time since injury, people are likely to learn different adaptive strategies to cope with the problems presented by the brain injury. The SCI person's perceived QL was not significantly correlated to time since injury, which is inconsistent with findings in our earlier studies.[97,98] The true nature of the relationship of time since injury and perceived QL remains open to question.

A high level of physical and social independence was positively correlated to the SCI and TBI person's perception of a high quality of life, which is in agreement with an earlier study carried out on SCI persons.[97,136] The limitations imposed by an SCI or TBI are likely to place the greatest restraints on the oldest individuals, particularly as regards activities.[85] Being employed or engaged in studies was closely correlated to the injured person's as well as the control person's perception of a high QL. A study carried out on SCI persons showed that employment is associated with superior adjustment.[84] A crucial element in this relationship may be that social relationships are developed and maintained in work and educational environments, which may be as important as the occupation itself.[84] A relatively high unemployment rate in society in general might impair the chances of a disabled individual's getting a job. However, the majority of SCI and TBI persons are able to return to work or studies and this must be facilitated by vocational rehabilitation and further formal education. It is important to help SCI and TBI persons overcome feelings of worthlessness and despair by showing them that they still have some control over their lives and that life after injury can be meaningful and rewarding.

Lack of, or changes in, self-esteem may contribute to feelings of inadequacy and result in increased levels of anxiety and depression. It appears from the present data that single persons – whether disabled or not – tend to experience a lower overall quality of life and more depressive feelings compared to those who have a close partner relationship. However, persons with depressed mood may have problems sustaining or establishing meaningful relationships with others. Thus, it is not clear which causes the other. Some researchers[55,76,120] have identified a positive influence of supportive interpersonal relationships upon adjustment to SCI as well as on life satisfaction and well-being after SCI. Therefore, one cannot ignore a possible relationship between mood, perceived quality of life and being in a partner relationship. Crewe and Krause[38] found that SCI persons who are married are less likely to be troubled by loneliness and boredom. They suggest that SCI persons who get married after injury are a selected group and that the experience of marriage will further strengthen their satisfaction with life and with their own adjustment.

Sexual counselling

Life after a spinal cord injury or traumatic brain injury goes on and rehabilitation should prepare the patients to participate in a wide range of activities that are a natural part of life. It is important to understand rehabilitation as a learning process.[156] The comprehensive rehabilitation has to provide programmes that are responsive to individual needs. Sexual loss most certainly is an important concern of spinal cord and traumatic brain injured individuals. As shown in this study, sexual adjustment is dependent on physical, social and psychological factors. (Figure 5). Since sexuality is a primary component of normal functioning, addressing sexual concerns in rehabilitation is essential. SCI and TBI persons and their partners need counselling and support to develop realistic goals and expectations and to adapt to sexual limitations regarding functional problems such as decreased sensation and mobility, and problems with erection, lubrication and orgasm. Couples can be encouraged to act and guide each other in the erotic exploration of genital as well as of intact physical sensation in unaffected body parts. The non-injured partner can assume a more active role in finding comfortable sexual positions. Manual genital stimulation, orogenital sex and the use of vibrators can provide alternative methods of sexual satisfaction. Injured persons who do not have a regular sexual partner should be counselled about the treatment options available and encouraged to meet and establish friendships with potential partners as if they had no injuries. Every person with SCI or TBI should have the opportunity to learn how to relate sexually to a partner if he or she chooses to do so.

However, it should always be remembered that sex is not an issue for everyone. It is important when counselling patients to provide a private atmosphere, obtain information about all areas of need, not just sexual ones, be honest yet empathetic and use nondirective techniques when possible. Approaches that focus on counselling, education and information about sexual possibilities and limitations at an early stage after injury may dispel some of the doubts about sexual attractiveness and encourage engagement in sexual activity. It is essential, however, not to imply that sex is an all-important experience and never to put the patient or couple in conflict with their moral or ethical views. It is important to keep in mind when dealing with this subject that sexuality is a sensitive and private issue.

POWERFUL DETERMINANTS OF SEXUAL ADJUSTMENT

Disability related
Severity of disability [4]
Genital function [3,4]

Sociodemographic

SEXUAL ADJUSTMENT
Sexual interest and desire
Sexual activity
Sexual satisfaction

Psychosocial
Repertoire of sexual behaviours [1,2,3]
Perceived partner sexual enjoyment and satisfaction [1,2]
Partner perception of the respondent's sexual adequacy [1,2]
Concern about the partner's sexual pleasure [3]
Perceived sexual attractiveness [2]
Attitudes towards sexuality [2]
Emotional quality of the relationship [2,4]

Quality of life
Global quality of life [3]
Physical and social functioning [4]

Figure 5. *SCI persons [1], Controls [2], SCI partners [3] and TBI persons [4].*
Cf. Figures 1 and 2

CONCLUSIONS

- Despite severely altered genital function, many SCI persons were sexually active. Most SCI persons enjoyed their sexual relationship, although it was a common perception that sex life had been better before injury. Significantly more SCI persons experienced lower personal satisfaction with their sex life and also lower self-perceived sexual attractiveness compared with the controls.
- A varied repertoire of sexual behaviours and the perception that the partner enjoyed the sexual part of the relationship and also was satisfied with the quality of the couple's sexual relationship seemed to play the most important role in sexual fulfilment after SCI, in accordance with results from people in the general population.
- Willingness to engage in a variety of sexual activities is important for sexual fulfilment among SCI persons as well as among persons from the general population. With increased acceptance of sexual variety and information about sexuality, an increased repertoire of sexual behaviours is indicative of a satisfying sexual relationship after injury. The more sexual behaviours used, the more satisfied the individual is with the sexual relationship. The greater the range of sexual behaviours used, the greater the probability of more frequent sexual interactions.

- Many partners of SCI persons experience satisfaction in their sexual relationships, affectionate expressions and overall relationship parameters, even though many partners would prefer to engage in sexual activities more frequently.
- From the partners' perspective, trust, emotional closeness, mutual concerns and willingness to engage in a variety of sexual activities seem to be more important correlates for positive sexual adjustment than the physiological aspects of sexuality.
- Sexual activity had decreased or even ceased in many preinjury relationships. There were, however, no differences between preinjury and postinjury relationships in terms of emotional attachment within the couples and satisfaction with the relationship as a whole.
- As the personality characteristics of the partners in this study differed only slightly from those of a reference group and not at all between partners in pre and postinjury relationships, we can dismiss the assumption that the partners' unusual qualities or values are the primary explanation for a spinal cord-injured person's satisfactory marriage or relationship.

- A traumatic brain injury commonly alters sexual functioning as well as desire and sexual dysfunctions increase with the severity of injury.
- A high degree of physical independence and maintained sexual ability are important for the brain-injured person's sexual adjustment.

- Both SCI and TBI appear to affect partner relationships, quality of life and mental well-being in a negative fashion. The number of sustained relationships and the number of relationships contracted after injury among both SCI and TBI persons indicate, however, that the impact of these injuries on relationships is not as substantial as has sometimes been postulated.
- Being in good spirits, i.e. lack of depressive symptoms, has a profound positive impact on the perception of quality of life in both SCI, TBI and persons from the general population.
- Being employed or engaged in studies is important for the quality of life of persons with SCI and TBI as well as people from the general population.
- A high level of physical and social independence is positively related to both the SCI and TBI person's perception of a high quality of life.
- Persons who are single – whether disabled or not – tend to experience a lower quality of life compared to those having a close partner relationship.
- The younger the age at injury, the greater the opportunity to adjust in the area of sexuality and life satisfaction.

IMPLICATIONS

To help reduce the psychological disruption experienced by some SCI and TBI persons, psychological rehabilitation programmes could be developed. These programmes could be implemented to cover areas of need. Such interventions could consist of providing skills to cope with depression and anxiety, feelings of helplessness, poor social communication, lack of assertion and sexual problems. Intervention to counsel SCI and TBI persons and support partners and relatives may lead to long-term benefits by reducing the burden and providing hope for a meaningful future. The rehabilitation programmes should therefore emphasise support in all activities that contribute to a sense of usefulness and life satisfaction, including a person's participation in gainful employment, educational programmes, community services and active leisure.

If the goal of rehabilitation is to restore the injured person as fully as possible to their premorbid level of functioning, this must apply to sexuality as well. Rehabilitation professionals must recognise the importance of assessing ways in which a person's sexuality – in its broadest sense – has been affected by a spinal cord or brain injury and the ways in which education, counselling, and medical intervention are indicated. It is just as important to address all components of sexuality as it is to address aspects of mobility, self-care and vocational re-entry. Organised programmes of sexuality education should be an integral component of TBI rehabilitation, as they ar in most spinal units. TBI sexual counselling interventions must be concrete, structured and repetitive.[106] Therapy might focus on counselling, increasing positive reciprocity, decreasing the frequency of negative behaviours, reducing reactivity to negative events, enhancing communication and improving relationship and intimacy skills.[10]

Spouses and partners of SCI and TBI persons should be included early in sexual counselling and particular attention needs to be given to older couples. Counselling and information about sexual functioning and the opportunity to understand the sexual acts within the context of a caring relationship can be helpful to those with conservative attitudes toward sexual variety in their lives.[156] Furthermore, booster sessions should be available repeatedly since sexually related needs and concerns might change over time.

Patients with sexual concerns typically approach those among the staff with whom they feel most comfortable. Thus, it is important that the professionals feel comfortable raising the issue of sexuality with the patient to allow him or her permission to discuss this topic. Although the staff must be comfortable with their own sexuality before discussing this topic with others, it is just as essential not to "threaten" the patient or couple with one's own sexuality.

There is a need for spinal units and rehabilitation centres to develop a philosophy of care which not only encourages open exploration, but also ensures the provision of an adequately trained team of staff who can provide specialist support. The staff must have enough sexual knowledge to provide limited, accurate information to the patient and to be able to make a judgement as to when to refer the patient for more specific suggestions and intensive therapy. The management and attitude of the staff will influence the patient's physical as well as mental health. Through the process of rehabilitation and counselling, perceptions of the injured person's body should be reworked and reclaimed so that positive regard can be re-established. Recent research suggests that the way in which people view themselves is predictive of how they adjust to physical disability.[67,157,161] The physical management and contact as well as positive attitudes from the staff will confirm to the patient that he or she is accepted and respected. This may be conducive to the patient's positive body image and identity of being an adequate person regardless of the physical or cognitive disability.

Future research

To better understand the complexity of sexuality, partner relationships and quality of life after spinal cord injury and traumatic brain injury, both qualitative and quantitative studies need to be undertaken. Burning topics might include the following themes:

- Further studies are needed to elucidate the influence of the participation of the injured persons' significant others in the process of rehabilitation and adjustment.
- The adjustment process after spinal cord and traumatic brain injury needs to be better understood and requires further research into coping strategies.
- Future studies evaluating the adjustment process and quality of life after SCI and TBI need to address the impact of rehabilitative care.
- To get a deeper understanding of the strategies used to maintain and develop a rewarding sex life after injury a qualitative study needs to be undertaken.
- Despite the high level of explained variance in global quality of life, the amount of unexplained variance offers a challenge for further research.
- Research that combines a cross-sectional and longitudinal design needs to be undertaken. This research should use participants with a wide range of ages and times since injury.

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APPENDIX A.

LIVSKVALITET VID RYGGMÄRGSSKADA

1. Personer med ryggmärgsskada säger ibland att de har följande problem. Har Ditt sätt att leva förändrats? Läs varje påstående. Svara endast på de påståenden som Du är säker på passar in på Dig i dagens läge och har med Din hälsa/skada att göra. (Om Du instämmer, sätt ett kryss i rutan under "Stämmer".)

	Stämmer
a. Jag ägnar mig mindre åt förenings- och sällskapsliv.	
b. Jag får på mig kläderna endast om någon hjälper mig.	
c. Jag rör mig bara inomhus.	
d. Min sexuella aktivitet har minskat.	
e. Jag går inte ut så ofta och hälsar på bekanta.	
f. Jag tar mig inte själv i eller ur en säng eller stol. Jag behöver hjälp av någon annan eller använda något hjälpmedel.	
g. Jag stannar mestadels hemma.	
h. Jag ligger i sängen mer.	
i. Jag umgås kortare tid i taget med mina vänner.	
j. Jag får hjälp med svåra förflyttningar, t ex i och ur bil eller badkar.	

2. Hur har Du känt Dig under veckan som gått? Välj det svarsalternativ som passar bäst in på Dig för varje delfråga.

a. Jag ser fram emot saker och ting med glädje:

(Sätt en ring runt en siffra)

Lika mycket som förut.........................1

Något mindre än jag brukade.................2

Klart mindre än jag brukade..................3

Nästan inte alls....................................4

b. Jag kan skratta och se saker från den humoristiska sidan:

(Sätt en ring runt en siffra)

Lika mycket som jag alltid kunnat...........1

Inte riktigt lika mycket nu......................2

Absolut inte så mycket nu.....................3

Inte alls...4

c. Jag har tappat intresset för mitt utseende:

(Sätt en ring runt en siffra)

Absolut..1

Jag bryr mig inte om det så mycket
som jag borde.......................................2

Jag kanske inte bryr mig om det
riktigt så mycket...................................3

Jag bryr mig precis lika mycket om
det som förut..4

d. Jag känner mig glad:

(Sätt en ring runt en siffra)

Inte alls...1

Inte ofta...2

Ibland..3

För det mesta.......................................4

e. Jag uppskattar fortfarande samma saker som förut:

(Sätt en ring runt en siffra)

Precis lika mycket................................1

Inte riktigt lika mycket..........................2

Bara lite...3

Knappast alls.......................................4

f. Jag känner mig som om jag gick på "lågt varv":

(Sätt en ring runt en siffra)

Nästan jämt..1

Mycket ofta..2

Ibland...3

Inte alls...4

3. Hur upplever Du följande situationer? Välj det svarsalternativ som passar bäst in på Dig för varje delfråga. Om Du inte har några problem ringar Du in 4 = Inte alls svårt.

(Sätt en ring runt en siffra på varje rad)

Hur svårt är det:	**Mycket svårt**	**Svårt**	**Inte särskilt svårt**	**Inte alls svårt**
a. att inte kunna gå, röra sig fritt?.	1	2	3	4
b. att Du behöver hjälp med många saker?	1	2	3	4
c. att inte kunna göra det Du vill - när Du vill?	1	2	3	4
d. att inte kunna gömma sig i mängden?	1	2	3	4
e. att ha problem med tarmarna, t ex lös mage, trög mage, hålla tätt?	1	2	3	4
f. att besväras av smärta?	1	2	3	4

4. Bedöm hur du tycker att Din livskvalitet är i dagens läge.

(Markera Ditt svar med ett kryss på linjen nedan)

____

0 Livs- kvaliteten låg	100 Livs- kvaliteten hög

APPENDIX B.

Multi-items scales from THE RELATIONSHIP QUESTIONNAIRE

Sexuell anpassning – SAS-scale (Study I)

1. Uppskattar Du den sexuella delen av Ert förhållande?

Mycket	☐	4
Ganska mycket	☐	3
Ganska litet	☐	2
Inte alls	☐	1

2. Hur tycker Du – för det mesta – att det sexuella samlivet med Din partner fungerar?

Fungerar mycket bra	☐	4
Fungerar ganska bra	☐	3
Fungerar ganska dåligt	☐	2
Fungerar mycket dåligt	☐	1

3. Hur ofta har Du i genomsnitt sex (sexuell samvaro med eller utan samlag) tillsammans med Din partner?

Var eller varannan dag	☐	8
2-3 gånger i veckan	☐	7
1 gång i veckan	☐	6
1-2 gånger i månaden	☐	5
1-2 gånger var tredje månad	☐	4
1-2 gånger/halvår	☐	3
1-2 gånger om året	☐	2
Mer sällan än 1 gång om året	☐	1

Sexuell anpassning – SIAS-scale (Studies II and III)

1. Händer det att Din sexuella lust är nedsatt?

Mycket ofta	☐	4
Ofta	☐	3
Då och då	☐	2
Aldrig	☐	1

2. Uppskattar Du den sexuella delen av Ert förhållande?

Mycket	☐	4
Ganska mycket	☐	3
Ganska litet	☐	2
Inte alls	☐	1

3. Tror Du att Din partner uppskattar den sexuella delen av Ert förhållande?

Mycket	☐	4
Ganska mycket	☐	3
Ganska litet	☐	2
Inte alls	☐	1

4. Hur ofta har Du i genomsnitt sex (sexuell samvaro med eller utan samlag) tillsammans med Din partner?

Var eller varannan dag	☐	8
2-3 gånger i veckan	☐	7
1 gång i veckan	☐	6
1-2 gånger i månaden	☐	5
1-2 gånger var tredje månad	☐	4
1-2 gånger/halvår	☐	3
1-2 gånger om året	☐	2
Mer sällan än 1 gång om året	☐	1

5. Hur ofta skulle Du vilja ha sex tillsammans med Din partner om Du skulle tänka på Dig själv och Dina sexuella behov?

Oftare än vad Du har nu ☐ 3
Samma som nu ☐ 2
Mera sällan än vad Du har nu ☐ 1

6. Om Du jämför med Ditt/Dina sexuella förhållanden med andra partners, eller med samma partner som Du har nu men innan han/hon fick sin ryggmärgsskada, anser Du då att Ditt nuvarande sexuella samliv är

Mycket bättre än tidigare ☐ 5
Bättre än tidigare ☐ 4
Ungefär lika som tidigare ☐ 3
Sämre än tidigare ☐ 2
Mycket sämre än tidigare ☐ 1

Förhållandets känslomässiga kvalitet – EQR-scale (Studies I, II and III)

1. Är Din tillgivenhet för Din partner

Mycket stor ☐ 4
Stor ☐ 3
Liten ☐ 2
Mycket liten ☐ 1

2. Säger Du till Din partner att Du tycker om henne/honom?

Mycket ofta ☐ 4
Ofta ☐ 3
Sällan ☐ 2
Aldrig ☐ 1

3. Är Du nöjd med Din partners sätt att uttrycka sin tillgivenhet för Dig?

Ja, mycket ☐ 4
Ja, ganska nöjd ☐ 3
Nej, inte speciellt ☐ 2
Nej, inte alls ☐ 1

4. Hur tycker Du att Du och Din partner kan handskas med Era problem/svårigheter?

På ett mycket bra sätt ☐ 4
Ganska bra ☐ 3
Ganska dåligt ☐ 2
Klarar av det mycket dåligt ☐ 1

5. Har Du, eller har Du haft, tankar på att separera eller att skiljas?

Mycket ofta ☐ 1
Ofta ☐ 2
Sällan ☐ 3
Aldrig ☐ 4

6. Tycker Du att Du och Din partner kan tala om sex och samlevnad på ett öppet och ärligt sätt?

Har mycket lätt för att tala om sex ☐ 4
Har ganska lätt för att tala om sex ☐ 3
Har ganska svårt för att tala om sex- ☐ 2
Har mycket svårt för att tala om sex ☐ 1

7. Hur tycker Du att Ert äktenskap/förhållande för det mesta är?

Mycket bra ☐ 4
Ganska bra ☐ 3
Ganska dåligt ☐ 2
Mycket dåligt ☐ 1

Multi-item scale from TBI SEXUAL ADJUSTMENT QUESTIONNAIRE

Sexuell anpassning SIS-scale (Studie IV)

1. Hur har följande sexuella funktioner påverkats av skadan?	Ökad 4	Oförändrad 3	Minskad 2	Obefintlig 1
a) Sexuell lust	☐	☐	☐	☐
b) Betydelsen,vikten av sexuell samvaro	☐	☐	☐	☐
c) Förekomst av samlag	☐	☐	☐	☐

2. Hur är Dina möjligheter och Din förmåga att själv njuta fysiskt av sexuell samvaro?

Mycket bra	☐	4
Ganska bra	☐	3
Ganska dålig	☐	2
Mycket dålig	☐	1

3. Hur är Dina möjligheter och Din förmåga att ge Din partner sexuell njutning?

Mycket bra	☐	4
Ganska bra	☐	3
Ganska dålig	☐	2
Mycket dålig	☐	1