Original Article

Sexual rehabilitation of women with a spinal cord injury

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Study design: Literature review and a qualitative study.

Objective: This article reviews literature examining the sexual rehabilitation of women following spinal cord injury (SCI). It includes recommendations for improvements in initial clinical rehabilitation efforts and counselling services.

Setting: United Kingdom, Denmark and Sweden.

Methods: Articles concerning sexual rehabilitation following SCI from the last two decades have been reviewed and critiqued. Qualitative results from discussions with women with SCI in Denmark and Sweden are presented.

Results: The literature focuses on the effect of neurological change on women's ability to achieve sexual arousal and orgasm. Urinary and bowel incontinence, spasticity, vaginal lubrication and autonomic dysreflexia are the physical consequences of SCI that appear to have most impact on sexual activity. More recent studies have acknowledged that psychosocial factors such as age and partnership status may also affect the successful sexual rehabilitation. Discussions with women with SCI in Denmark and Sweden on their reactions to information and counselling offered during rehabilitation revealed an overwhelming need for the exchange of information and experience with other women with SCI, and a desire for opportunities for counselling after initial rehabilitation.

Conclusion: Successful sexual rehabilitation of women with SCI demands a holistic approach that considers individual neurological, physical and psychosocial circumstances. Peer-counselling could make a significant contribution to the sexual rehabilitation of women with SCI. *Spinal Cord* (2006) **44**, 234–241. doi:10.1038/sj.sc.3101844; published online 20 September 2005

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Introduction

The rehabilitation of sexual function in women following spinal cord injury (SCI) is aimed at facilitating a form of sexual expression that is both acceptable and satisfying to the women. For many women, the aim is to return to a sexual function that is as similar as possible to that in her life prior to the injury, but the exploration of alternative modes of sexual expression should also be encouraged.^{1,2}

In this article, we attempt to provide a comprehensive review of recent research into the effects of various neurological, physical and psychosocial issues that most commonly affect women's sexual activity following SCI. The medical profession is currently striving to provide a holistic approach to treatment management after SCI and, thus, we draw together information and approaches from a variety of specialisations that are relevant to sexual rehabilitation. We consider both current approaches and SCI women's wishes for the future management of sexual dysfunction.

Effect of neurological changes following SCI on sexual response

Neurophysiological studies of sexual response in women following SCI are divided into those that evaluate sexual arousal and those that assess the ability to achieve orgasm.¹

Sexual arousal

Sexual arousal arises from the synergistic actions of a psychogenic and a reflex pathway,³ resulting in vaginal lubrication. Laboratory-based research into the arousal

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phase of sexual response has focused on the significance and effect of varying degrees and levels of SCI on psychogenic and reflex lubrication.

There is strong evidence to support a sympathetic nervous system component to psychogenic sexual arousal with a critical contribution from the sympathetic outflow at the lower thoracic and upper lumbar spinal cord. A study of 17 women with incomplete SCI at or below T6, demonstrated that perception of light touch and pinprick in the T11–L2 dermatomes was associated with the ability to achieve psychogenic lubrication (P=0.04)⁴ Those who had no sensation in the T11– L2 dermatomes were unable to achieve significant genital lubrication. Furthermore, there was no significant difference in genital responsiveness when women were classified according to the degree of sensory preservation in T6–T9 or S2–S5.⁴ These results are supported by the finding that sympathetic cell bodies regulating vaginal blood flow can be found at T11-L2.⁴ Further, studies involving able-bodied females demonstrated that greater genital lubrication is achieved by increasing sympathetic tone through pharmacological treatment and/or inducing anxiety.³ Additionally, the extra-genital responses displayed during the excitement phase, such as increased blood pressure and increased respiratory rate, are well-known indicators of heightened sympathetic tone.⁵

Reflex lubrication may be a function of a sacral reflex arc. Sipski *et al*⁶ found that when women with complete SCI are asked to arouse themselves manually, all but those patients with complete lower motor neuron (LMN) injuries at S2–S5 choose genital stimulation. Up to 25% of women with complete LMN injuries report achieving psychogenic lubrication but none achieve reflex lubrication.⁶ These findings underline the importance of an intact sacral spinal cord in achieving reflex lubrication.

Pharmacological attempts to assist SCI women with sexual dysfunction have so far not yielded statistically significant results. Only one study has, as yet, been conducted on the effect of *Sildenafil citrate* on sexual response in SCI women. Results did not indicate a significant improvement in vaginal pulse amplitude (P < 0.07), or subjective parameters as compared to placebo.⁷ The effects of Sildenafil have also been studied on women with multiple sclerosis. This did not generate an improvement in orgasm, though a statistically significant increase in lubrication was noted (P = 0.03).⁸ Trials on Sildenafil in women have since been terminated.⁹

Orgasm

Women with complete SCI between C4 and T9 in a controlled laboratory setting report experiencing orgasms that are indistinguishable in description and similar in physiological autonomic response (increased heart rate and blood pressure) to those of able-bodied women.²⁰ Women with SCI are, however, significantly less likely to achieve orgasm than able-bodied women (P=0.001),¹⁰ and take considerably longer to achieve orgasm than their able-bodied counterparts (P=0.049).⁶

Sipski *et al*¹¹ hypothesised that orgasm is a sacral reflex function that can be augmented or inhibited by supraspinal innervation in noninjured individuals and that this is accompanied by a sensory perception. It is assumed that the sacral reflex arc will remain intact in suprasacral injuries and, further, that the neurological potential for orgasm should remain at all other levels and degrees of SCI. This is supported by laboratory-based research on 25 SCI women with complete upper motor neuron (UMN) injury at and above T6, where 52% achieved orgasm following genital stimulation. In contrast, women with complete LMN lesion at S2–S5 were found to be significantly less likely to achieve orgasm (P < 0.05).^{6,12}

Recent studies provide compelling evidence for the involvement of the vagus nerve in the sensory component of orgasm. Komisaruk *et al*^{13,14} hypothesised that the nucleus tractus solitarii in the medulla oblangata to which the vagus nerves project, is activated during orgasm. Support for this theory is derived from animal studies¹³ and functional magnetic resonance imaging on women with complete SCI at or above T10 (n=4),¹⁴ which demonstrated activation of the inferior region of the nucleus tractus solitarii on vaginal–cervical self-stimulation.

However, it has also been shown that patients with cervical SCI are less likely to achieve orgasm than patients with thoracic and lumbosacral lesions (37.3, 40.5 and 51.5%, respectively).¹⁵ This clearly contradicts the current understanding of the neurological basis of orgasm. Further research is required to clarify whether this discrepancy is due to an inaccurate current understanding of the issue or whether a non-neurological cause should be sought.

Physical factors influencing sexual activity

Physical factors associated with SCI such as urinary and bowel incontinence, spasticity, lack of vaginal lubrication and autonomic dysreflexia may significantly compromise both the woman's social life and her sexual activity. Achieving good control of these problems is essential in order to improve overall quality of life. Certain practical measures may be used, when sexual activity is anticipated, in order to avoid 'accidents' during the sexual encounter.

Urinary incontinence

Urinary incontinence is a manageable, but greatly distressing, condition for SCI women, especially when this occurs in conjunction with sexual activity. It is cited by 16.5% of a sample female SCI population (n = 315) as a major physical problem associated with sexual activity.¹⁵ It has a negative impact on the self-image of SCI women¹⁶ and this is associated with poor sexual adjustment post injury.¹⁷

The chosen mode of control of urinary incontinence is, in part, dependent on the type of neurogenic bladder dysfunction - especially when pharmacological or surgical options are considered.

Intermittent catheterisation is the most commonly used method to improve bladder emptying and may provide good control with a low risk of complica-tions.^{18,19} It should be considered for paraplegic and quadraplegic women who have retained sufficient manual dexterity to be taught the appropriate technique. Another option for bladder management is the use of indwelling catheters. These are now used primarily in situations where other forms of bladder management are impracticable (for example, during the later stages of pregnancy²⁰ as they are associated with complications such as recurrent urinary tract infections, and a 5% risk of developing urethral squamous cell carcinoma after 10 years.²¹ Furthermore, they have been cited by up to 10% of SCI women^{21,22} as a source of interference with sexual activity.

The mainstay of pharmacological treatment is anticholinergic therapy. Pharmacological alternatives/ additions to catheterisation include anticholinergic medication to reduce detrusor overactivity.¹⁸ Treatment with localised injection of botulinum toxin is still unlicensed but has been shown to be highly effective in the treatment of severe detrusor overactivity which is refractory to oral anticholinergics.²² A recent randomised placebo controlled trial of 59 patients (53 of whom were spinal cord injured) demonstrated a high level of efficacy and safety following this treatment.²³

Several surgical treatment methods exist but careful selection of patients, depending on severity of symptoms and suitability for the procedure, is required before embarking on surgical treatment. There is very little research into the effect of different surgical procedures on SCI women's sexual satisfaction. However, one group of investigators has published a case report on female tetraplegic patients $(n=3)^{24}$ indicating that urinary diversions with umbilical stomas can increase sexual satisfaction and body image among SCI women.

Careful pre-coital preparation is required to avoid urinary incontinence during sexual activity. Women with neurogenic detrusor overactivity benefit from the use of anticholinergics. Fluid restriction prior to sexual activity is recommended in order to decrease leakage accidents. However, common side effects of anti-cholinergics include dry mouth and constipation¹⁷ and, thus, they may not be conducive to attempts to restrict intake of fluids prior to sexual activity. Women who use intermittent catheterisation should, naturally, remember to empty the bladder before intercourse.

Bowel incontinence

Bowel incontinence is a cause of great anxiety for SCI women who resume sexual activity.²⁵ In one study (n=40) bowel incontinence ranked second only to urinary accidents as an area of concern following injury.²⁶ Methods of bowel control depend on many

factors including level and completeness of injury, previous bowel habit, medication regimen and temperament of the SCI woman.²⁴

One study (n = 424) indicated that digital stimulation of the anal canal or digital evacuation of the rectum is used regularly by 65% of SCI patients.²⁷ Several other methods exist to control bowel incontinence and the choice of treatment may largely depend on whether the SCI patient has an UMN 'reflex' bowel or an LMN atonic bowel.¹⁸ Management options include rectal and oral laxatives, retrograde colonic washout and surgical treatment - most often involving the creation of a stoma.¹⁸

To our knowledge, no evidence-based recommendations currently exist for bowel management in relation to sexual activity. Bowel regimens are generally adjusted over time to achieve regular evacuation and, thus, sexual activity should preferably be planned at a time which is compatible with the bowel regimen.¹

Spasticity

Spasticity was found to interfere with sexual activity in up to 26% of SCI women.¹⁵ It especially affects those women who have incomplete injuries.²⁵ Severe spasticity can have a profound adverse effect on the patient's ability to cope with everyday activities and, thus, on the quality of life.²⁸ It can be treated with oral medication (such as baclofen, tizanidine, clonidine), injection of botulinum toxin for localised spasms or intrathecal administration of baclofen or clonidine.²⁹ However, there is still insufficient evidence to support treatment with oral spasmolytics. Localised spasticity may be treated with botulinum toxin which is effective for 3 months after injection, reducing spasms and improving function. Treatment of nonlocalised spasticity by use of intrathecal baclofen has proven effective in relieving symptoms,²⁹ although it is clear that patients frequently suffer complications.³⁰ Intrathecal baclofen may also improve neurogenic bowel³¹ and increase functional bladder capacity and compliance.^{21,31} These effects may act synergistically and improve quality of life²⁸ and sexual function. However, one clinical trial (n=9) has shown evidence to the contrary effect in men.³¹ It indicates a reversible deleterious effect of intrathecal baclofen on erection and ejaculation. A similar effect on women has not yet been investigated although anecdotal evidence suggests that women may also experience greater difficulties in achieving orgasm.

Vaginal lubrication

Inadequate vaginal lubrication was considered to interfere with sexual activity by 23.2% of SCI women²⁵ and can be solved by the use of water-based lubricating jelly. However, this requires knowledge and awareness of vaginal lubrication requirements for intercourse, and as at least those SCI women with complete transection of the spinal cord have no sensory preservation, this may not reflect the true extent of the problem.^{6,2}

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Autonomic dysreflexia

Autonomic dysreflexia occurs in individuals with SCI lesions primarily above T6 and is a neurological response to noxious stimuli below the level of the lesion.³² It is characterised by severe hypertension, pounding occipital headache, shivering, anxiety and feelings of impending doom. It can be a life-threatening condition as it may lead to cerebral haemorrhage. Autonomic dysreflexia occurs as a result of the lack of inhibition of the sympathetic outflow causing overactivity.² Frequently, it is a response to a full bladder or blocked catheter but may also occur in response to sexual activity or labour.^{2,32} In a sample group of SCI women (n = 315), 11.4% were troubled by autonomic dysreflexia during sexual activity.²⁵ If the patient experiences autonomic dysreflexia, she must discontinue sexual activity, sit upright and loosen any tight clothing. Unfortunately, the condition cannot be pharmacologically pre-empted, but can often be resolved on administration of sublingual nifedipine.²

Psychosocial factors influencing sexual rehabilitation

Age

Age carries one of the strongest negative correlations with subjective and objective satisfactory sexual rehabi-litation.^{16,33-35} It has been suggested that poor sexual satisfaction (regardless of form of sexual activity) of SCI women over the age of 30 years can be traced to a 'natural' physiological decline in sexual interest.¹¹ This is inconsistent with findings in able-bodied women, which show that satisfaction with sexual life increases with age.^{11,36} It is not known why this is the case.³⁶ However, disabled women are often stereotyped as not being interested in sexual interaction,^{37,38} which may be reflected in the information offered to them during rehabilitation. This may especially apply to older SCI women, who may not be offered the same degree of sexual counselling as younger women since they are perceived to be less interested in sexual activity.³⁴ It has been suggested that older women require particular attention to sensitive issues, such as the acceptability of masturbation,⁶ in the pursuit of a satisfactory sex life. A lack of post-injury positive sexual self-esteem^{39,40} and unwillingness among the older population to pursue more experimental aspects of sexual activity³³ have also been proposed as barriers to rehabilitation of older women. Rehabilitation issues for older women with SCI may be further exacerbated by symptoms related to the menopause such as genital atrophy.³

Special attention must be given to women who suffer an SCI before the age of 18 years. A study of 37 women indicated that these women are less likely to enter into a sexual relationship than any other group of SCI women (P=0.04).⁴¹

Relationships

Controversy exists over the importance of relationship status in rehabilitation to a satisfactory sexual life. Lack of partner availability is cited by 16.4% of a sample of SCI women as the cause of being sexually inactive (P < 0.01).¹⁵ It may also be more difficult for SCI women to find sexual partners than able-bodied women.³⁵

One study in Sweden revealed that women with regular partners are less likely to receive sexual counselling during their rehabilitation than single women and, therefore, subsequently experience a decline in sexual activity and satisfaction post injury.³⁴ This may have detrimental effects on the woman's overall quality of life, as we may assume that a healthy sexual life is important in sustaining a marriage.⁴⁵ However, another study, comparing SCI women to able-bodied women, found that married SCI women are as sexually satisfied as their able-bodied counterparts.⁴²

Following a SCI, the SCI partner frequently becomes more dependent on the non-injured partner, who must often take on responsibility as the main carer.³⁵ Care giving may change the balance of power in a relationship^{35,38} and can be detrimental to sexual adjustment.⁴⁶ However, for lasting relationships, there appears to be no difference between satisfaction in pre-injury and post-injury relationships.¹⁶

Relationships where the non-injured partner has a greater understanding of his partner's sexual needs are more successful in sexual adjustment.⁴³ This is in keeping with the finding that the preferred type of sexual activity changes post injury. Before injury, penis–vagina intercourse is considered the preferred type of sexual activity, whereas kissing is the preferred type of sexual activity in 76% of SCI women after injury.²⁶

Number of years passed since injury

Time elapsed post-injury affects sexual function. Jackson *et al*¹⁵ found that only 18% of women were able to achieve orgasm 1 year post-injury, whereas 49.7% had experienced orgasm after 11 years. This is in keeping with the finding that the more time that has passed since the injury, the higher the correlation with satisfaction with sexual life.^{40,42} According to the Derogatis Sexual Functioning Inventory (DFSI), several factors determine the risk of sexual dysfunction. These risk factors are significantly decreased as time passes post-injury: women acquire more liberal attitudes to sex (P < 0.02), develop an understanding of more integrated gender roles (P < 0.01) and engage in more sexual fantasies (P < 0.01) than women who have recently been injured.⁴²

Psychological factors

SCI women who are more independent of their ablebodied partners, and do not rely on them for care giving, are more likely to adjust successfully to sexual life postinjury.^{40,43} The level of dependence will to a certain extent depend on the level of injury but, more importantly, will depend on the availability of other carers.⁴² Other factors that are indirectly related to sexual satisfaction by correlating positively with partner availability, are outgoing personalities, a high level of

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social and vocational activity and acceptance of the disability.⁴⁴ Previous sexual difficulties persist and are often exacerbated post injury. Westgren *et al*³⁴ found an unexpectedly high level of SCI caused by self-destructive lifestyles among women. It is suggested that this indirectly affects sexual rehabilitation, as these women are likely to have many other psychosocial issues that may interfere with, or deprioritise, sexual rehabilitation.

Sexual rehabilitation: response and demands from women with a spinal cord injury

In the autumn of 2003, kNORR (kNORR was an ad hoc working group of the Nordic Council for Spinal Cord Injuries – an umbrella organisation of SCI organisations in the Nordic countries and its members are all women with SCIs. kNORR was formed in 2001 to draw attention to the particular problems confronting women with SCI. In addition to the seminars mentioned in this article, kNORR has been responsible for initiating a research project into women with SCI.) arranged a number of 1-day seminars for women with SCI and for personnel from the SCI rehabilitation centres in Denmark and Sweden. Approximately 130 people participated in the seminars – of these around 70 were women with SCI. In workshop sessions, the women with SCI were asked to share their experiences of sexual counselling at the rehabilitation centres and to consider how counselling could be improved in order to facilitate sexual rehabilitation. The workshop leaders were women with SCI who used a topic checklist to guide the discussion. The discussions were informal and no attempt was made to quantify the results. The points emerging from the discussions were remarkably similar from group to group and country to country.

More information during initial rehabilitation

In keeping with findings by Richards *et al*³⁹ the majority admitted that sex and sexual rehabilitation had not been a primary concern during the initial rehabilitation. There were simply too many other issues and problems to consider. There was, however, widespread agreement that counselling should be offered and that this should be initiated by the personnel. Many felt that, at this stage, the key was information – designed to enable women to understand the consequences of a spinal cord injury – rather than individual counselling. For whatever reason, all expressed dissatisfaction with the amount and quality of the information they received during the initial rehabilitation.

These attitudes conform to those identified in earlier scientific studies where approximately half of all women with SCI would have liked more sexual counselling during rehabilitation.^{25,34,39} It seems clear that women who are more knowledgeable are more successful in achieving a satisfying sex life post injury.^{3,25}

A Norwegian study⁴⁵ revealed that patients expect clinicians to initiate discussions about sex and sexuality, whereas clinical personnel expect the patients to make the first move. Likewise, findings in an American study revealed SCI patients have a perception of a 'don't ask don't tell' attitude among health professionals.⁴⁰ Similar discussions arose during the kNORR workshops. Some women blamed themselves for their lack of information (they had not actively sought information or advice). Others defended their apparent lack of interest by arguing that it is impossible to ask meaningful questions without prior information. Most felt very strongly that it was the responsibility of the rehabilitation centre personnel to inform the patients and suggested that clinicians chose to ignore this area because it was 'embarrassing' to talk about.

At both rehabilitation centres in Denmark all patients are expected to attend a course dealing with the consequences of spinal cord lesions. Sexuality and fertility are topics discussed on the course. In addition, both centres have a group (comprising members from different personnel groups within the clinics) that has received special training in sexual counselling. One specific criticism expressed by Danish women at the workshops and by women in a recent American study⁴⁰ was that the information offered tended to be oriented towards male patients.

Many women at the kNORR seminars recounted difficulties in adjusting to their 'new' bodies and most felt that they had become less attractive since suffering the spinal cord lesion. This seemed to be a general problem, independent of age or whether or not the women had a partner, and is echoed in an early study by Richards *et al.*³⁹ Several reported that they had discussed this with a psychologist at the rehabilitation centre and had found this help invaluable. Unfortunately, not all rehabilitation centres offer the services of an 'in-house' psychologist.

Continued opportunity for sexual counselling

The vast majority of women claimed that they first became truly aware of problems relating to their sexual life when they returned home. Thus, they felt that some form of post-rehabilitation counselling would be extremely helpful.

One significant problem reported in a recent study³⁹ and by a number of women attending the kNORR workshops was related to the reactions of their partners; their husbands/partners were simply unable to achieve an erection. For some women, this was the ultimate proof that they were no longer attractive as women. Others were able to tackle the problem together with their partners or by involving the help of a professional. Those who had overcome the problem related that it seemed to be based on fear: the men were afraid that sexual intercourse would cause further injury.

The type of counselling envisaged post-rehabilitation was rather different to that demanded during the initial rehabilitation period. At this later stage, the women wanted solutions to their individual problems – practical advice rather than medical/physiological information. In fact, it was quite clear that the more sexually

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experienced women found the general approach of the 'experts' somewhat patronising. The sexology groups in the rehabilitation centres tended to emphasise that sex and sexuality were two different things – and the general implication seemed to be that since women with SCI could not experience satisfactory sex (sexual intercourse) then they should concentrate upon the romantic, more sensual aspects of a relationship. Rather than being told (as they perceived it) that they might as well forget the whole idea of a satisfying sex life, many women demanded specific, concrete advice on how to achieve

Peer counselling

and their partners.

The opportunity to talk to other women who had learned to cope with living with SCI was regarded by all kNORR participants as being extremely useful. During the initial rehabilitation, the sight of women who were 'getting on with their lives' provided welcome role models. Later, it was felt that other women with SCI had more to offer in terms of practical advice. Many said that it was less embarrassing to talk about intimate subjects with another woman who had experienced the same problems. However dedicated the personnel, they had not experienced the situation personally and, thus, could not really understand the feelings and anxieties involved. Only by talking to other women with SCI could they learn the all-important coping strategies – as well as a thousand useful tips to use in their everyday (and sexual) lives.

the best possible sexual gratification – for themselves

Not all centres in Scandinavia employ people with SCIs to act as 'mentors' or 'peer-counsellors' and, thus, the need for contact with others in the same situation can, in some regions, only be provided by the user organisations.

Pentland *et al*⁴⁶ commented that the SCI-women in their study displayed an 'overwhelming need' to seek information, ask questions and to share and exchange experiences. Once again, it seems that this need can, at present, best be met by the organisations. In Sweden, the organisation RTP has established a closed 'chat-room' for women on their website. Similarly, the Danish Spinal Cord Injuries Association has set up a Women's Forum on their website that can only be accessed by female members. In addition to providing an easy (and confidential) access to the views and ideas of other women with SCI, it is hoped that this will go some way in preventing the sense of isolation reported by the authors in the above study.

Gynaecological issues

Many participants at the kNORR seminars expressed anxiety about their lack of knowledge and information about the effects of a SCI on other aspects of their physiology. Like the participants in the Canadian study above,⁴⁶ they were particularly concerned with gynaecological and obstetric issues: the long-term effects of childbirth, the possible side-effects of recurring infections of the urinary tract, the problems associated with the menopause – and with such remedies as hormone replacement therapy. Many had scoured the internet to find answers to their questions but had been unable to find many research results from studies of women with SCIs.

Dedicated research in this area is sparse. As such, advice to women with SCIs is based on the advice given to their able-bodied counterparts – even though the physiological differences may be legion.

Conclusion

Response to an SCI depends on both the injury and experiences prior to, during and after rehabilitation. These experiential aspects are likely to be culturally as well as individually determined. It is therefore not possible to produce a list of factors that concisely predicts the extent of sexual rehabilitation that may be achieved or the individual problems that may be encountered. However, identifying predictive factors may be helpful in discovering areas of rehabilitation for patients and clinicians to work on, and may aid future research in improving the quality of life for women with SCI.

Clinicians and therapists involved in sexual rehabilitation could consider the outcome of the discussions described in this paper. There is a need for more information during the initial period of rehabilitation following a SCI. That this information is made available (and attention drawn to it) should be the responsibility of the clinic – not of the individual patient. Sexual counselling should also be available later, when the women have left the rehabilitation centre and returned to their homes – and partners. Peer counselling is regarded as extremely important and useful. Most of the women voiced concerns about the effects of the SCI on gynaecological issues – particularly as they grow older.

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