



Scientific Review

Spinal cord injury and partner relationships

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Introduction: Among the many issues confronting a newly spinal cord injured (SCI) person are apprehension about the potential impact of the acquired disability on present or future intimate relationships.

Objective: To summarize the research regarding partner relationships and SCI.

Method: Medline, Psychlit and Cinahl database researches were undertaken.

Results: Several studies have focused on the issue of marital status before and after the onset of the injury. The results of the studies carried out on the prevalence of divorce are conflicting. Divorce rates have been reported to be anywhere from 8% to 48%. It appears that divorce rates tend to decline to the normal rate for the general population after the initial high risk period. Some studies have shown that marital status is a powerful predictor of independent-living outcome variables. Thus, marital stability is a concern in SCI care. The study investigating why able-bodied women might choose to marry men with a permanent physical disability, such as a SCI, showed a substantial overlap with existing models of courtship. It was also shown that a SCI person who strives to minimise the impact of the disability on a potential partner makes a more attractive candidate for a long-term relationship than an individual who has come to rely on others.

Conclusion: Partner relationships seem to be affected by a SCI, although not as much as is widely believed. There are, however, problems interpreting the varying results of the studies due to culture differences, changes in family life in society in general and the different methodologies used. Systematic research that puts the patients' and partners' problems into perspective is necessary. Uniformity in measurement instruments would facilitate comparisons of studies.

Spinal Cord (2000) **38**, 2–6

Keywords: spinal cord injury; partner relationships; divorce; marriage

Introduction

Among the many issues confronting a newly spinal cord injured person are apprehension about the potential impact of the acquired disability on present or future relationships. The spouse of an acute spinal cord injured patient is also a victim of events beyond his or her control. The adaptive changes required of the partner are in many ways equal in magnitude to the changes required of the patient. Given the trauma and the high level of dependence that often results from a SCI, it is not surprising that couples are under extreme pressure to adapt and cope following the injury. Often, the partner must play a dual role as lover and caregiver, which may create deleterious situations and conflicts. Furthermore, caregiving often changes the

balance of power in the marriage and the family's dynamics, potentially placing the relationship at risk. Couples who are unable to maintain equality within their relationships may have greater difficulty maintaining them.

It is also important to note that for spinal cord injured people who are not involved in an intimate relationship at the time of the injury, opportunities for developing intimate relationships may be hampered by lack of peer acceptance in the community as well as lack of self-confidence.

This review comprises the following aspects of partner relationships and spinal cord injury: divorce, the emotional quality of the SCI person's relationship, comparisons of relationships existing when the injury occurred and relationships established after the injury, the able-bodied partner's personality characteristics, and single SCI persons' possibilities to find and attract a partner.

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Divorce

Several studies have focused on the issue of marital status before and after the onset of the injury. The results of the studies carried out on the prevalence of divorce are conflicting. Divorce rates have been reported to be anywhere from 8% to 48%.^{1–11}

Some studies have shown that the divorce rates differ from the general population, whereas others have not. El Ghatit and Hanson³ studied the outcome of 333 marriages which were intact at the time of the husband's injury. They found that 27% of these marriages ended in divorce. This divorce rate did not differ from that of the general population in the entire United States. DeVivo and Fine⁷ examined the influence of a SCI on the marital status of 276 injured persons in the US for a period of 3 years after injury. They found that their sample had more divorces during that period than would be predicted by population base rates. These findings were confirmed by analysing a 3-year follow-up data on 1531 persons with SCI. They also found that women with SCI are more likely to be divorced than men. In a later study, DeVivo and Richards⁹ found that among persons who were married at the time of their injury, 81% were still married 5 years later, compared to an expected 89%. They concluded that the following characteristics carry a high risk for divorce among SCI persons: being young, being female, being black, being nonambulatory, having no children, having a prior divorce, and having been injured less than 3 years. The study by my colleagues and myself¹¹ showed that the divorce rate did not differ between a sample of 167 SCI persons and an age- and sexmatched control group consisted of people from the Swedish general population. Van Asbeck *et al*¹⁰ found that 82% of the SCI persons who were married or living with a partner prior to the injury had remained together 5–12 years after the injury. Their study comprised of 117 injured persons. Craig *et al*¹² also found similar low rates of separation.

Results from the studies carried out on the prevalence of divorce are difficult to compare as the time frame after injury for divorce and separation differ, as does the definition of marriage. For example, in some studies only married people are included, whereas in others, people who are cohabiting without being married are included and sometimes even those who have a stable partner relationship without living together. In general, the injury seems to have only a short-term impact on the divorce rate. After an initial high risk period, divorce rates tend to decline to the normal rate for the general population.

The emotional quality of the relationships

Couples managing SCI have to make difficult ongoing adjustments in their lives and it can be assumed that there is no greater test of a marriage than that presented by a spinal cord injury. Given the fact that communication and problem solving are critical to

marriage stability among able-bodied couples,¹³ these relationship factors may be even more important for couples managing spinal cord injury.

Urey and Henggeler¹⁴ examined the communication patterns of 20 couples. Ten couples were judged to be coping successfully with SCI, and ten couples were not. The findings indicated that the couples who avoided conflicts and had an unclear or vague communication style coped less successfully.

The majority of women in the study by Kester *et al*,¹⁵ felt that their partner's injury had resulted in some positive changes. The women reported that they felt closer as a family because of increased communication with their SCI partners and the amount of time their partners spent with their children. Most couples in our studies^{16,17} thought they were able to have open and honest communication and they were satisfied with the manner in which they solved relationship problems. Another study by Kreuter *et al*¹⁸ showed that the emotional quality of the relationships do not differ from an age- and sexmatched able-bodied control group. A similar finding was reported by Yim *et al*¹⁹ in their study of marital life among Korean SCI patients.

It has been shown that positive rehabilitation outcomes are related, in part, to the strength and quality of the patient's marital relationship. Several studies^{3,7,20} have shown that marital status is a powerful predictor of independent-living outcome variables. Thus, marital stability is a concern in SCI care.

Our study of 49 spouses and partners of SCI persons shows that caregiving has a negative impact on the couple's relationship.¹⁶ Weitzenkamp *et al*²¹ conducted a longitudinal study of 124 spouses of SCI persons. Their results show that spouses in a caregiving role report more symptoms of stress, fatigue and depression than their own partners with SCI and other spouses who are not caregivers. Shackelford *et al*²² found that SCI women are more likely to have paid an attendant as a caregiver while SCI men are more likely to have their spouse assist.

Comparisons of pre- and postinjury relationships

The premises in already existing relationships may be totally altered since the injury was something neither partner had considered. As the disability is known from the beginning in relationships established after injury, there may be a better chance of success. Consequently, some studies have identified fewer problems and higher levels of marital satisfaction among persons whose marriages began after their injuries than among persons who were married at the time of injury. Simmons and Ball²³ showed that both husbands and wives in postinjury relationships are more inner-directed and have better marital adjustment compared with those married before the injury. Crewe *et al*⁴ interviewed 55 injured persons and their spouses regarding marital adjustment factors. In comparing

preinjury with postinjury marriages, they found postinjury marriages to be more stable than preinjury ones. Furthermore, life satisfaction was higher in the postinjury marriages. Crewe and Krause²⁴ conducted a questionnaire follow-up study on married SCI individuals to determine whether this pattern of better adjustment in postinjury marriages persisted over time. The investigators increased the sample size to 300 and statistically controlled for age, a factor that may have influenced the findings in their earlier study.⁴ Again, findings indicate better adjustment in postinjury marriages, even when the effects of age were controlled for. The authors concluded that relatives of the able-bodied partner shouldn't be concerned about the prospects for happiness, as the responses across a decade are emphatically positive.²⁴

Our study¹⁷ showed that there are no differences between lasting preinjury and postinjury relationships in terms of emotional attachment and satisfaction with the relationship as a whole. Age seems to be a more important factor for sexual adjustment than whether the relationship is established before or after injury. DeVivo *et al*²⁵ showed that the impact of the injury on postinjury marriages is only slightly less than on preinjury marriages. The study included 622 persons who married after the injury.

Single SCI persons' possibilities to find and attract a partner

The physical losses of mobility may limit a spinal cord injured 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?'

Crewe and Krause²⁶ suggest that spouses in postinjury marriages might have unusual qualities or values that contribute to the success of these unions. Neumann²⁷ found it impossible to believe that a SCI man can be attractive to a woman and he suggested that women dating SCI men are inexperienced and therefore do not know better or can not do better. Unfortunately, such attitudes are still present in some health care professionals as well as in the general population. DeLoach and Greer²⁸ described individuals attracted to disabled people as 'the walking wounded' (persons so deeply hurt before that they seek a relationship with someone unlikely to emotionally harm them), 'would-be dictators' (very insecure individuals who need to dominate others), 'unsolicited missionaries' (those who seek to save partners with a disability), and 'gallant gesturers' (individuals who consider marrying a partner with a disability to do him or her a favour, providing an opportunity for self-congratulation). However, no data was given in support of these descriptors.

Our study¹⁷ showed that the personality characteristics of partners in postinjury relationships were similar to a reference population group on most

scales. We used the Karolinska Scales of Personality Inventory to determine the personality characteristics of 49 partners. The questionnaire included 136 items organised into 15 scales. The differences found indicate that the partners in our study respond less according to rules and conventions; and that they are able to speak up and assert themselves in social situations. Their special personality traits imply that they might be somewhat more courageous and confident than the average person might. I therefore agree with Crewe and Krause²⁶ who suggest that partners in postinjury marriages 'may have the independence necessary to look beyond society's stereotypes concerning intimate involvement with a disabled person.'

Milligan and Neufeldt²⁹ examined why able-bodied women might choose to marry men with a permanent physical disability. This was an exploratory study which employed a grounded theory methodology to examine the courtship experiences of eight able-bodied women who made postinjury marital commitments to spinal cord injured men. Contrary to what the authors expected to find, their findings suggest a substantial overlap with existing models of courtship. Some relationships developed quickly and were characterised by strong attraction and immediate connection. For others, a romantic relationship evolved over time, sometimes beginning as a platonic friendship. Overall, the women reported satisfaction in their relationships with their partners. They describe their SCI partner as positively adjusted to their disability and as demonstrating autonomous attitudes which, along with personality factors, were considered important elements of attraction. Their research indicates that specific qualities in able-bodied partners such as maturity, autonomy, resistance to social negativity and conventions, and flexibility in role performance are important to courtship in the context of disability. Furthermore, their study shows that a SCI person who strives to minimise the impact of his or her disability on a potential partner makes a more attractive candidate for a long-term relationship than an individual who has come to rely, perhaps to excess, on others. They conclude that love and attachment, relationship satisfaction, interdependence and commitment, compatibility and similarity, and investment in the relationship appear to carry the most significant influences in the decision to marry (as in the general population).

Some spinal cord injured people mention that they have difficulties in meeting and attracting a new partner when disabled and in a wheelchair because 'you cannot flirt in a wheelchair,' or 'no-one wants a cripple.' This indicates that individual attitudes toward people with disabilities and the injured person's own prejudices against physical deviance may make it difficult to develop a new relationship. Thus, a spinal cord injury may be handicapping not because it imposes actual physical limitations but because it interferes with social relations or is in conflict with the individual's value system.

In a semi-structured interview study, Yoshida³⁰ investigated the concerns and experiences of 27 men with SCI regarding intimate relationships and marriage. While some men reported worries about their level of attractiveness and had difficulty meeting interested women, others learned that they could be attractive again and they did not experience obstacles to dating.

Berkman *et al*³¹ asked the 145 male veterans in their sample whether they experienced problems finding dates or partners. Only 9% replied that they had any difficulty. De Vivo and Richards⁹ found that 12% get married within 5 years, whereas 35% would be expected to get married based on rates for the general population. Out of 18 spinal cord injured women in the study by Westgren and Levi,³² 15 had met their spouse after the injury. Craig *et al*³³ found that almost 50% had a new stable partner following the injury. Although the proportion of single SCI persons in our study¹¹ was somewhat higher compared with an age- and sexmatched control group, the difference was not significant.

Crewe and Krause²⁶ found that only individuals who are especially likeable, active and well adjusted succeed in attracting partners and establishing close relationships after a spinal cord injury. The authors found in a later study³⁴ that SCI persons who get married after injury are 'more active both socially and vocationally during their single days compared to those who remained single.' Furthermore, Crewe and Krause²⁶ found that injured persons who are married are less likely to be troubled by loneliness and boredom. They concluded that the individuals who marry after a spinal cord injury are a selected group with some special characteristics and that the experience of marriage will further strengthen their satisfaction with life and with their own adjustment.

In the literature,^{1,2,4-7,10,11,32,35} the percentage of marriages among SCI persons occurring after the injury, varies from 6% to 80%.

Conclusion

Partner relationships seem to be impacted by a spinal cord injury, although not as much as is widely believed. However, there are problems interpreting the varying results of the studies due to cultural differences, changes in family life in society in general and the different methodologies used. Systematic research that puts the patients' and partners' problems into perspective is necessary. Uniformity in measurement instruments would facilitate comparisons of studies.

Implications for future research

Future research should focus on identifying predictors of divorce and reasons for divorce after SCI so that appropriate interventions to reduce the divorce rate can be developed. Furthermore, research is needed to

determine whether single persons with SCI remain single indefinitely or not. The impact of SCI on partner relationships, self-esteem and self-confidence, coping strategies and quality of life needs to be further studied. The research needs to be longitudinal in nature, it should have a large enough sample to represent the heterogeneity of spinal cord injured persons and a control group of age- and sex-matched able-bodied people.

Clinical implications

Well-designed interventions are needed to decrease marital distress resulting from SCI and to promote conditions for improving rehabilitation outcomes. Communication skills training for couples living with SCI could be a useful approach for improving relationship skills and helping couples to adapt to the ongoing demands of SCI. Counselling SCI persons and supporting partners may produce long-term benefits by reducing burdens and providing hope for a meaningful future. Finally, the way in which people view themselves is predictive of how they adjust to physical disability. Thus, through the process of rehabilitation, perceptions of the injured person's body should be reworked and regained so that positive self-esteem can be re-established. The physical management and contact as well as positive attitudes from the staff will confirm for the patient that he or she is accepted and respected. This may be conducive to the patient's positive body image and identity as being an adequate person regardless of the physical disability.

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