

EMPIRICAL STUDIES

**The experience of being a partner to a spinal cord injured person:
A phenomenological-hermeneutic study**SANNE ANGEL, PhD¹ & NIELS BUUS, PhD²¹*Department of Nursing Science, Institute of Public Health, Aarhus University, Aarhus C, Denmark and* ²*Institute of Public Health, University of Southern Denmark, Odense C, Denmark***Abstract**

This qualitative interview study focuses on the personal experiences of partners to a spinal cord injured person. Using a Ricoeurian phenomenological-hermeneutic approach, we analysed seven partners' narratives 1 and 2 years after their partner's injury. The study revealed how the injury was experienced from the partners' perspective through the aftermath. In the acute phase after the injury, partners also felt harmed, and support was needed in relation to their own daily activities, eating, resting, and managing distress. During the institutionalized rehabilitation, partners felt torn between supporting the injured partner and the demanding tasks of everyday life outside the institution. After discharge, partners struggled for the injured partner to regain a well-functioning everyday life and for reestablishing life as a couple. The partner struggled to manage the overwhelming amount of everyday tasks. Some sought to reestablish their usual functions outside the family, whereas others focused on establishing a new life together. The partners experienced much distress and appreciated the support they got, but felt that they were mainly left to manage the difficult process on their own.

Key words: *Interviews as topic, rehabilitation, narration, social support, spinal cord injuries, spouses*

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This study explores the experiences of partners to persons who had suffered a sudden spinal cord injury. The overwhelming physical and emotional challenges facing a person with a sudden spinal cord injury are well described (see for instance: Angel, Kirkevold, & Pedersen 2009; Laskowski & Morse, 1993; Lohne & Severinsson, 2005). However, not only the injured person is affected by this event but also the whole family (Chan, 2000). The awareness of increased vulnerability and ill-health among partners to sick relatives has increased in recent years, and this study examines the psychosocial processes partners go through while living with a person with a recent, sudden spinal cord injury.

Background

Many ill or injured people benefit physically and emotionally from having a partner (Crewe & Krause, 1988; Holicky & Charlifue, 1999). Having a partner is a strong indicator for a successful adaptation to a

new life situation following a spinal cord injury (Holicky & Charlifue, 1999). In Crewe and Krause (1992)'s long-term follow-up study, 301 persons with a spinal cord injury were surveyed in 1974 and 1985. The study identified a significantly positive effect of marriage on quality of life. The group of separated, divorced, or widowed were significantly worse off than the married couples or singles with regards to level of income, family conflicts, difficulty in making friends, and dependency and lack of transportation (Crewe & Krause, 1992). This indicated that it was important to uphold marriage, and in this context it is worrying that there is an increased incidence of separation and divorce following spinal cord injury. Devivo and Fine (1985) found a significant higher incidence of separations and divorces in the first 3 years after an injury, which indicated that it was very demanding trying to reestablish everyday life and relationship. Kreuter, Sullivan, Dahllof, and Siosteen (1998) studied reasons for divorce after

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a partner had been spinal cord injured. Reasons included: problems of adapting to new physical functions, difficulties in maintaining the relationship, and/or unwillingness to live with a disabled person (Kreuter et al. 1998). The authors emphasized the importance of partners' mutual support and the significance and challenges of retaining a marriage/relationship.

A related issue is the increased physical and psychosocial burden on persons who are primary caregivers for a partner with a spinal cord injury. A study by Post, Bloemen, and de Witte (2005) showed that the burden on caregivers correlated with the level of physical disability, the hours of daily caregiving, and the caregiver's depression. The experience of burden increases with the overall length of caregiving and the caregiver's age. The increased burden can have devastating consequences, including reduced well-being, increased stress, burn-out, fatigue, resentment, depression, and neglect of own health needs and problems (Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997). Blanes, Carmagnani, and Ferreira's (2007) study of long-term caregivers' quality of life reported that many suffered from chronic illness. Compared to the general population, caregivers tended to develop psychological problems rather than physical illness, they visit their general practitioner more, and report poorer health (Blanes et al. 2007). Sheija and Manigandan's (2005) study of the effect of support groups emphasized the primary caregivers' isolation and need for support, education, and opportunity to talk about the burden to other spouses in a similar situation. Weitzenkamp et al. (1997) found that caregivers had lower quality of life scores compared to their injured partners.

Personality changes following a spinal cord injury also add to the burden on couples. Buchanan and Elias's (1999) study identified challenging changes in personality and behaviour. They interviewed nine couples who reported major negative personality and behavioral changes after a spinal cord injury (Buchanan & Elias, 1999). This was supported by Chan's (2000) finding that it was very challenging coping with a partner's depressed mood and pessimism. Chan (2000) suggested that good communication was central in order to reach an understanding of each other's expectations when they adjusted to new roles.

Most studies of the burden of having a partner with a spinal cord injury were quantitative surveys, and the limited number of qualitative studies did not specifically focus on investigating the period immediately after an injury. Therefore, this qualitative study was focused on the personal experiences

of having a partner with a traumatic spinal cord injury during the first 2 years after the injury.

Method

This paper reports the findings of a prospective study of life during rehabilitation after a traumatic spinal cord injury. Using a narrative approach based on Ricoeur's phenomenological-hermeneutic understanding (Ricoeur, 1983, 1985, 1988), we explored the personal experiences of being partner to a person who had suffered a sudden spinal cord injury. The empirical material consisted of two times seven interviews performed 1 and 2 years after the injury. From the partners' narratives, we got insight about how they interpreted their situation and how their concerns developed over time. In the following, we will refer to the spinal cord-injured partner as "the injured partner," and to the noninjured as "the partner."

Setting

In Denmark, where this study took place, there are two central rehabilitation units for patients with spinal cord injuries. Patients are admitted to these rehabilitation units for 2–12 months after an injury. All patients in this study returned to their own homes, and some experienced a lot of difficulty, as they could not function properly in their home environment.

Participants

Partners were defined as cohabitant couples at the time of the injury. There were seven partners (see Table I), four men (three in their 60s and one in his 40s) and three women (three in their 30s). All the relationships had lasted for more than 5 years before the injury. One man and three women had children living at home. Most managed to continue living in the same house, which in most cases had to be converted. None of the partners were able to go back to a working life as before, despite four of the partners keeping their previous employment.

The interviews

Interviews were conducted from a phenomenological-hermeneutic perspective using a narrative approach (Ricoeur, 1976, 2008). This approach is founded on the understanding of narratives as the way humans interpret themselves and their world (Polkinghorne, 1988; Ricoeur, 1986, 1991).

The partners were interviewed by the first author in their home 1 and 2 years after their partners'

Table I. Demographic description and functional abilities

Name	Age at the time of injury	Employment	Name	Accident	Spinal Cord Injury	Dysfunction of bowel, bladder/dysfunction of hands 2 years after the injury	Home-living children	Mobility 2 years after the injury
Ben	60–70	Skilled worker	Married to Belinda:	Fall	Incomplete C5	+/+	–	Walk with sticks, wheelchair
Charles	60–70	Skilled worker	Married to Cindy:	Road trauma	Incomplete C5	–/+	–	Walk, wheelchair
Frida	30–40	Middle-range training	Married to Frank:	Industrial accident	Severe incomplete L1	+/-	+	Wheelchair, walk with sticks
Geogina	30–40	Middle-range training	Married to Georg:	Industrial accident	Complete Th4 + Th5	+/+	+	Wheelchair
Ib	40–50	Skilled worker	Married to Isabel:	Fall	Incomplete C7 + Th1	–/+	–	Walk, walk with sticks, wheelchair
Kent	40–50	Middle-range training	Married to Kate:	Road trauma	Severe incomplete C7 + Th1	+/+	+	Wheelchair
Laura	30–40	Unskilled worker	Married to Larry:	Road trauma	Complete Th4	+/-	+	Wheelchair

spinal cord injury. They had all experienced everyday life with their injured partner. The interviews sought to encourage a narrative approach by inviting the person to reflect and talk openly about his/her situation (Angel, Kirkevold, & Pedersen 2009; Cicourel, 1988; Kvale, 1998). In accordance with narrative methodology (Polkinghorne, 1988), the partners were posed open questions like “How has the rehabilitation affected you?” “What did it mean to you and your life?” The interviewer’s first-hand knowledge of the couples’ rehabilitation process was used to facilitate trust and conversational depth. The interviews were conducted in the participants’ private homes.

Data analysis

The analysis was based on Ricoeur’s (2008) theory of interpretation that entails three interpretative steps. First, the *naïve interpretation*, where the transcribed interviews were read several times and interpreted one by one and as a whole (Ricoeur, 2008). The aim was to develop a preliminary overall understanding of the interviews. The naïve interpretation emphasized how the terrifying experience of the beloved person’s injury took all their attention and pushed their own life into the background. Second, the aim was to substantiate initial naïve interpretation through the *structure analysis*. We examined if—and to what extent—the texts really said what we revealed in the naïve interpretation (Ricoeur, 2008). This provided us with many aspects of the partners’ experience. The software program NVivo 8 was used as a supplementary tool to systematically identify themes and their relationships and importance. In the third step, the *critical interpretation*, the initial interpretation was challenged by themes and questions from the structure analysis. From the similarities and variations in the data, we elicited the partners’ trajectory through rehabilitation by drawing conceptual maps, discussions, writing, and rewriting in order to develop a deep interpretation leading from subjective experiences to a more general knowledge. A general understanding of the harmful effects the spinal cord injury had on the partners emerged from the individual narratives. As the critical interpretation was conducted, we continually verified our interpretations by relating them to the partners’ stories and continued until the interpretation of the partners’ experience seemed to be the most significant among possible interpretations, and provided coherent and nuanced illumination of the partner’s experiences (Ricoeur, 1976).

Both authors conceptualized the study, analysed data, and wrote up the analysis; the first

author performed the interviews and transcribed the recordings.

Ethics and inclusion procedure

In line with Danish legislation, the interview study was notified to the Regional Scientific Ethics Committee and to the Danish Data Protection Agency; neither institution had any objections toward the study. The participants' injured partners were already enrolled in a parallel qualitative study of the rehabilitation process, and the injured partners were asked for permission to invite their partners. Two partners refused to participate. All participants gave their informed consent to participate based on written and spoken information. Interview responses were handled with full confidentiality.

Findings

The narratives confirmed that they had a tremendous impact on a person when his/her partner had a spinal cord injury. The partner had to cope with the shock, support the injured partner during the institutionalized rehabilitation, and struggle to make their relationship and life together function again. The partners' experiences could be understood as a trajectory with three distinct successive phases: (1) To be harmed by the partner's injury. (2) To find oneself on the outside of their partner's life. (3) To struggle for the injured partner and reestablishing life as a couple. These three phases were related to the injured partner's trajectory through rehabilitation. The first phase was during the acute stage and the period after the spinal cord injury. The second phase took place when survival was secured and the injured partner was institutionalized and followed a rehabilitation program. The third phase was after the partner had returned home. Thus, the rehabilitation process was decisive in relation to the demands on the partner, and the impact on the partner's life and psychosocial well-being.

Phase 1: To be harmed by the partner's injury. The injury meant that everything suddenly revolved around the injured partner. The situation necessitated a lot of attention and effort to minimize and treat the injury. Care was provided by professionals and was crucial for survival. The partners watched from the sideline without being able to do much; they were entirely focused on their injured partner. They were struck by the brutal fact that their partner had been seriously injured and their own needs faded into the background. The injured partner required care and support from the

professionals, and it was of great significance how the professionals involved the relatives in the caring process.

Focus on the injured partner's situation and rehabilitation. Experiencing the injured partner was terrible. The injury was a shock to them, suddenly their world stood still, and their focus was entirely on their injured partner. Being aware that they could have lost their partner, they mourned their partner's loss:

Charles: But why her? She didn't deserve it. At first, when she was lying there, I often thought, "if only it had been me"

Although the focus was on the injured person, the spinal cord injury was also a significant misfortune for the partner. Because of their interwoven lives, the partners felt that the injured body was their body as well, and the pain and loss of the injured partner was their pain and loss too. The powerlessness was hard to deal with and left only little, and often symbolic, opportunities for action:

Laura: You more or less get a shock. And I was pregnant I had just stopped smoking And I couldn't stop thinking about that for God's sake, Laura, don't start thinking about cigarettes I didn't want to give him more bad news that I had started smoking again. He was so happy that I had stopped.

The professionals were in charge of care, and the partner was transformed from being the primary person in the injured partner's life and placed in an uncertain and painful waiting position. The feeling of being struck was more than a bodily experience. The partner was also affected existentially. Every effort was made to minimize the consequences of the injury, and because it was unknown how the injury would influence on their future life, they could do nothing but focus at the present situation and wait.

To forget oneself needing care and guidance. The acute period was characterized by a tremendous shock, so the partner almost forgot her/himself and her/his basic needs. This meant that the concern expressed by the professionals in regard to these needs was highly appreciated. In the period just after the accident, the partner needed support for managing and prioritizing daily tasks in order to take care of him/herself in this difficult situation:

Ib: I just couldn't go into work. I drove by, but I didn't get anything done and I couldn't do it. They [the nurses] told me that I should go home and eat some good food and drink a glass of wine and make sure to have enough energy to get through the next day. So I did, and it was good. It was really good advice for me.

This concern was of great significance for the partners. Not just because this supported them in being there for their injured partner but also as an act of human kindness, understanding, and support in the situation they now were faced with. This provided an important feeling of being included.

Different needs for participation. There was a need for support in relation to being included in care and treatment of the injured partner. The narratives show different levels of need for inclusion. In Ib's situation, the professional managed to meet his wishes: "I was allowed to stay as much as I wanted to. I believe this was the right thing for me."

Some partners visited their injured partner without engaging in the physical rehabilitation and said nothing about a need for being included. Still, they measured distress that maybe could have been met in contrast to more positive experiences measured by those who had participated.

Relatives as an important support and for some a burden. The shock of the injury influenced families and social networks. Relatives, friends, and even neighbors were affected and tried to give contribution in different ways. This could make an important difference to the partner's situation. The need for support was also very concrete because the partner spent so much time in hospital. This could include help with cleaning, the laundry, caring for animals, or preparing food. Especially, if the partner also had children to take care of, friends and relatives could be a significant resource:

Frida: The kids stayed with my brother and his wife. She came and collected me. I just couldn't drive home at that point. And then she collected me and came with me. My other brother and his wife also came with me. We tried contacting Frank's [the injured partner's] sister... to find out if I could stay the night. She took 3 days off work to stay with me all the time

In some cases, the relatives were so affected that they instead of supporting the partner themselves

reached out for support from the partner. This could be experienced as an additional burden.

Whether family, friends, or neighbors were perceived as a resource or a burden depended on whether they were able to be supportive without being intrusive.

Consequently, the shock of the accident had a profound impact on the partner and provided a feeling of vulnerability. The painful experience embedded itself in their body. This pain was reactivated time and time again when they faced their partner's struggle and had to repeat the story in different social situations.

Phase 2: To find oneself on the outside of their partner's life

The injury was the beginning of a long period of separation between the partners. Everyday life had to continue somehow, even though nothing was the same. The partner was torn between the demands of everyday life and the needs and obligations to support their injured partner.

The need to be a part of the rehabilitation. During the institutionalized period of the rehabilitation process, the injured partner struggled toward recovery with assistance from the professionals. The days were tied up with training activities. The struggle to regain function was a struggle to reclaim life and was totally absorbing. This was also very important for the partner. However, despite the partner's engagement in the rehabilitation, it was still predominantly a matter for the injured partner and the professionals. Taking part in care on the rehabilitation ward was a valuable preparation for the period after discharge. This may have avoided the misunderstandings and disappointment that Hank's wife experienced:

Hank: My wife thought: "well, I am sure Hank will be able to manage things when he comes home" . . . but I ran into a lot of problems when we got home. All I had learnt on the rehabilitation ward did not work at home and I had to start from the beginning all over again.

Just being in the ward contributed to an experience of being a part of the injured partner's life. Then, it was easier for the couple to share experiences and feelings and thereby avoid frustrations to mount up. Most partners appreciated the possibility of being present in the rehabilitation ward, during training activities and being engaged in drawing up plans for the rehabilitation process. However, various issues, such as obligations in everyday life and the distance

between home and rehabilitation ward, determined the extent to which this was possible.

Coping with two worlds. The desire and need to take part in the rehabilitation process on the ward stemmed from both the partners' personal motives and the injured partner's need for support. But everyday life had to go on and many had to manage a double job. In some cases, it was coping with both the household tasks and managing the injured partner as well, which the injured partner's well-being depended on: "Someone has to be there to watch over everything" (Gina.). It was both mentally and physically demanding to substitute for the injured partner. The attempt to overcome everything was extremely strenuous for some.

Becoming an outsider. Being an active partner in the rehabilitation process and handling the necessary everyday tasks were sometimes in conflict, and in some cases, the professionals' practice made it more difficult. Despite the joint understanding that the focus was on the rehabilitation of the injured partner, there was no consensus about the partner's role. This caused frustration and had consequences for the well-being of the partner:

Frida: They didn't think about asking me to take part in the conferences You weren't involved in anything. I just had to go out and ask every time: Why, how and what and when? All the time. In the evening they told Frank that there was a conference the following day at 11 am. Well, I just got so angry. I think it is appalling. We had told them time and time again that we both wanted to be there, in particular at the beginning. There was nothing wrong with Frank's head, but the accident was so overpowering, and it affected his memory.

Getting the chance to be supportive toward their injured partner was very significant, and feeling like an outsider could affect their social life and cause loneliness:

Gina: I would have liked an evening with the other relatives You don't go anywhere when your husband is in hospital. And you don't say, "let's drive into town" and well, you could do, but you don't anyway. I asked once, if we could meet up one night [patients and partners at the ward] because we could talk to each other about other things than what had happened and how it was going. It was sometimes annoying, sitting at home and maybe something had

happened that day, and you felt very sad. And you just sit at home with your thoughts. Then you ring up only to hear that George is enjoying himself with the others and you are just sitting there while the kids are sleeping, alone with your sad thoughts and the TV as your only companion.

Thus, the partners experienced a difficult situation during the institutionalized rehabilitation both with regard to overcoming own expectations to the amount of support given to the injured partner and gaining an acceptable level of well-being. This had consequences for the partner's process and strength.

Phase 3. To struggle for the injured partner and to reestablish life as a couple

The discharge was something everyone looked forward to. However, it was also a situation full of difficulties, which took most by surprise, and took focus away from reestablishing their relationship. The impact of the injured partners' needs on the partner's life was profound and caused feelings of being on standby and of the loss of one's life.

To lose one's life because the partner lost his/hers. As the rehabilitation proceeded, the permanent alienations and loss became manifest. A picture of the future life began to emerge. The injured partner's loss affected both. Being partners meant that the one's loss was the other's loss as well:

Ken: It makes me unhappy if she is distressed That is the worst thing for me Your thoughts keep revolving around other things and, well, you think "we will probably never dance together again" and so on.

The partner would do anything to support any sort of progress that would ease the injured partner's life. If that would lead to reduced dependency, it would mean an improved life quality for both because the dependency meant reduced opportunities for both; the injured partner was limited by the disability, and the partner felt the limitation through the needs of the injured partner, a need which the partner wanted to fulfill, but which limited the partner's opportunities for personal activities and self-realization:

Ken: I don't think much about it [how life is], really. My day just passes so quickly if I didn't have a job, I think I would go bananas As long as I can get away and concentrate on something else.

Thus, this lack of time for oneself may be concrete, but there is also the mental aspect in leaving the injured partner alone at home going out and enjoying oneself. This experience was harder for some than for others. The partners need to maintain doing things on their own varied somewhat. For some, it helped to keep some kind of normality and gain strength to be supportive toward their injured partner:

Ben: Well, there is no reason for sacrificing two lives. I didn't want to change my life to such an extent where I would be unhappy. Then both of us would be unhappy.

Still, he struggled with thoughts about whether he had done everything he should have done. The support could also become the partner's whole life for a period, like Ib, who chose to reduce his workload and let his wife's life and function be his first priority, taking all his time:

Ib: She has to go to the Physio on Wednesdays, and it is usually at noon. On Thursdays, she goes to the PTU [a training center] for a couple of hours, and then she is driven to the Physio, where I collect her. So work, well, it is not often I get any done. It has not amounted to much over the past two years, but I do miss going in and doing some work. I do. But I will. I will suddenly get started again.

The changed life was incontrovertible and adapting to it could be approached in different ways, such as holding on to some elements from the previous life or redefining the values in life at least for the time being.

To get the injured partner settled before seeking a new life. The focus on the injured partner continued after discharge; how to get on with life; functioning at home, eventually a job/reeducation, find a way to reestablish social activities. This was based on compassion and loving feeling for the other partner, and although, it could reduce the partner opportunities it was experienced as the way forward to reestablishing a life together:

Laura: I have to say "this [his work] is his one and all". He feels that he makes a difference and he does too! This is our top priority at home, and it is hard sometimes, being left here to look after things at home.

The conditions for their new life together were simply that the injured partner could not exist as

independently as before and take on as many tasks in the everyday household as before. This meant that things had to be redefined. For some this came naturally:

Frida: I have never fussed about Frank. The first time he was home on a visit, I asked him to go to the bathroom and help Maureen (their youngest daughter) who was in the bath while I made dinner. "She can climb up on your lap and you can dry her". I got him organized the first weekend he was home.

Despite attempts to find a way to cohabit that would satisfy both, this meant that the partner had to take over more obligations and engage more in their life together. This did not receive much understanding and recognition from the health and social system.

To do two people's job without much help and recognition. The amount of tasks could be overwhelming. It included housekeeping with extra laundry caused by occasional or frequent involuntary discharge of urine, helping the injured partner with all kinds of tasks, driving the injured partner, and shopping. Doing everything they could to help the partner was often surprisingly overlooked with no help or recognition from the community, which caused a lot of frustration:

Gina: At one point they said (to Gina's husband) "your wife is healthy and she can manage", so I said, what about when I have to go to work and everything. I do get some support. They come and help with the cleaning. But that is only one hour every two weeks. It isn't enough.

Despite the necessity and importance, the tasks were time consuming and fatiguing. Some things simply had to be skipped or done sparsely, which created a feeling of insufficiency. Along with fatigue came the experience of vulnerability as a reaction to the injury, for some this culminated in a depression.

Reestablishment of coexistence after one partner's spinal cord injury was a long and troublesome process that the couples had to manage by themselves. Two people, both in a deep existential crisis, were supposed to overcome challenges in their relationship, which could be more than couples living a normal life could handle.

Discussion

The partners were so shocked by the injured partners' situation that they were forced to focus

their energy, which could be the reason for the professionals' misinterpretation of the partners' well-being and ability to cope. The partners maintained their focus until things settled into a regular everyday life. Thus, the partners' crisis began when the injured persons' situation stabilized, and it was surprising for some that they felt distressed just as things seemed to turn out acceptable. All of the participants' stories contributed to this general pattern. Our findings show that the spinal cord injured patient's rehabilitation process significantly increased the healthy partner's burden of psychosocial stress—even though they were not the primary carers. The injured partner's loss, pain, recovery, and rehabilitation processes were overwhelming for the healthy partner. This study reports the distress and difficulties experienced by the healthy partner in the first phase after the accident and the long-term impact of the injury.

Being a partner to a spinal cord injured person meant being hurt without a physical injury. The emotional distress caused by mourning their injured partner's and their own situation, the workload, and the insecurity about the future affected the partner's well-being. Life as it used to be disappeared in a split second. In the foreground was the beloved person's bad fortune, and in the background the partner's personal loss in relation to this. To understand the depth of these experiences, this discontinuity in life can according to the Austrian, existential psychologist Frankl be compared with loss of meaning. In Frankl's (1970) theory of meaning, the meaning of life is lost when the coherence between past, present, and future is ruptured. Meaning can be reached by letting the values of the past guide actions in the present leading toward a meaningful future. In light of this theory, the central value in this acute situation was the compassion for and devotion to the injured partner. Despite everything was uncertain, the partners' lack of meaning was related to the tragic event more than life in general. Meaning came from the purpose of getting the best out of what was left by being supportive to the injured partner. This implied an overwhelming amount of tasks that some managed better than others. It seemed to be an issue whether the partner had any influence on the type of tasks and to which extent they could take on the task or object without negative reaction from the injured partner. The increased amount of tasks, where some were new, was more easily handled if they were perceived as meaningful and corresponded to the values of the healthy partner. Thus, it felt like a more acceptable burden if their priority was to spend time together with the injured partner. Then, the tasks were experienced as meaningful in contrast to tasks out

of line with their skills or taking time from things that were more important to them. This corresponds to Frankl's (1970) theory of meaning where the troublesome present can be handled when past values are recognized as important in a valuable future. These values happen to be the clue in an otherwise confused present. This may explain why for some partners it was essential to maintain some of the old routines to regenerate the energy and not allow the spinal cord injury to take over completely, whereas others could manage that their "own life" was on hold.

The role of the healthy partner is really important—in both a good and a distressing way. Karp (2000) described the difficult role of a partner as being both encumbered with and compassionate toward the injured partner. This feeling of compassion is so deep seated that it often can completely deactivate the healthy partner's sense of self-awareness and can severely affect their concern for their own well-being. Despite how well the partner handled that the injured partner's rehabilitation was the focal point of—it had consequences for the healthy partner's own life. The couple had a shared goal for the injured partner to find a kind of satisfactory way of functioning and stability in everyday life. Some partners did not begin to consider their own needs before this was achieved. Others maintained some of the old routines; often their job, and justified this as necessary for the generation of well-being and energy to support their injured partner and the forthcoming efforts for their future life together. How they dealt with their action depended on the spinal cord-injured partner's reaction, and their own expectations toward being a supportive partner. This opens up for a deep ethical concern about being a good partner and a good person, how to know what the best thing to do is, and overcome doing it in a situation with many external demands and personal strength and needs. This is seen in a retrospective perspective in Beauregard and Noreau's (2010) study that underlines the importance of maintaining meaningful activities to sustain the partner's strength. One partner believed that the sacrifice of his hobby was expected by his spinal cord injured partner. Years later, this misunderstanding came out in the open. This emphasizes the significance of communication in altered life situations. Even though this could seem obvious, it indicates how important it is to acknowledge that communication may become even more difficult in such a vulnerable situation. This is also central with regard to the importance of partners' mutual support and the difficulties in retaining a relationship, which Kreuter et al.'s (1998 study points to

as a reason for divorce. In situations where even mentioning the feeling of being encumbered could be experienced as unethical, sustaining compassion will be challenged by lack of recognition and personal free space.

Our study demonstrated that the healthy partner's severe situation could be alleviated by professional support, but that this help was not always available. Particularly, in the acute period because of the overwhelming incident, the partner was at risk of forgetting entirely about her/his own needs. The professionals play a principal role in the spinal cord injured partner's physical and existential survival. The healthy partner's lack of self-awareness gave the nurses another role than traditionally recognized with respect to relatives (Benzein, Johansson, Arestedt, & Saveman, 2008). Intensive care units (ICU) are well known for providing care for relatives as well, but the focus is primarily on how much care the relatives can provide for the patient (Aagaard & Terkildsen, 2009). In our study, the healthy partner's needs were similar to that of a patient, albeit without the injury and benefit from the professionals' awareness of and reaction to her/his agony. This meant providing comfort and acknowledgment of the distress and assisting with basic requirements such as food and rest. The experiences of the healthy partners in our study with respect to not always feeling cared for were very diverse. Their experiences during the whole rehabilitation period indicate an attitude more in line with how nurses' perception of relatives differs from being a resource in relation to caring for the patient, and sometimes as a burden they wished to avoid (Benzein et al. 2008). This could explain how some partners met commendable care, whereas others suffer from the lack of it. These unmet needs made coping even more difficult (Isaksson et al. 2008). Isaksson et al.'s study (2008) of four male partners' retrospective experiences also emphasized the long-term consequences. One husband spoke about how he later declined emotional support from the professionals because he found recalling the experience too painful (Isaksson et al. 2008). The missing initial support for healthy partners was later related to the professionals' avoiding contact with them and stresses the necessity for professional support during the acute phase. A way to ensure care for the partner could be a reinterpretation of what it means to be a partner and examining what is on offer for the healthy partner from the professional. Perhaps if the healthy partner in these severe situations instead was classified as a patient or a potential patient, it might optimize the professional care for all the partners to spinal cord injured patients.

During hospitalization and after discharge, the healthy partner's situation was characterized by an amount of tasks that could be overwhelming. This happened despite that they were not burdened with the primary caring, which is well described in studies of partners with these responsibilities (Dickson et al. 2010). In our study, the tasks were related to the spinal cord injured partner's individual needs, the healthy partner's own needs, and their future life together. The initial challenge was, as Isaksson et al. (2008) also pointed out, the importance of being prepared for an altered life after discharge, and knowing how to help the spinal cord injured partner. Our study indicated that this could be promoted through the partner's participation during the institutionalized rehabilitation period. This was still not a routine professional proposal but occurred as the result of a particular situation. It also proved supportive in relation to being prepared to take on the role of personal assistant, if something failed after discharge. More formal training would be helpful when complying with this well-known and often problematic issue among healthy partners. We found that this was apparent even when the spinal cord injured partner did not need personal assistance; the loss of capacity that followed the physical impairment meant that there were still a lot of things that the healthy partner had to take on. The couples struggled to maintain their lifestyle prior to the injury, and this agitated the situation with regard to essential tasks. The couples had expected help from the municipality and the Danish social security system. This resulted in frustration as they received much less help than they needed to maintain their previous lifestyle. The health authorities expected that the healthy partner would provide the necessary help that they would have provided, had the injured individual been single—placing this on the healthy partner in a situation where she/he often were in need of help themselves. This emphasizes the devastating impact of the event on the partner's life situation (Weitzenkamp et al. 1997).

This study describes the healthy partner's life situation and the tasks involved on top of the emotional impact. This may limit the retrospective perspective of the partners' experience 1 or 2 years after the accident. Also, none of these couples got divorced within the first 3 years, which Devivo and Fine (1985) reported as being the highest risk. This could mean that the healthy partners are more heavily encumbered than this study reports. To be able to learn more about what matters to the partner during rehabilitation requires a study where the experiences of the healthy partner

are closely followed to unveil important details and guide subsequent professional intervention.

Implications for practice

The knowledge of the partner's delayed distress and prolonged vulnerable situation raises implications for practice, both in the acute state and in the long term. Although the patient is the professional's primary responsibility, this study highlights the partners' need for professional care. Initially, the partner needs emotional support and concrete assistance. Professionals may be active in mobilizing psychosocial and material resources in social networks and thereby initiate an important long-term support. In the long term, nurses could be more active in counseling partners about delayed distress eventually through outreach programs.

Conclusion

When one's partner suffers a spinal cord injury, the world is no longer the same. The event causes a major psychosocial and existential crisis for the injured party, their partners, and families, where the help and support of others is necessary to facilitate a successful transition. The help is crucial in the effort to reestablish a life with the injured partner; continuing life during the institutionalized rehabilitation, supporting the injured partner in getting on with their new life, and finding their own way in the cohabitation. This was not only important to the injured partner, because of the healthy partner's key role in the rehabilitation process, but it was significant for them both and if they had children, naturally, the whole family. To relieve the partner's experience of distress, and being left to manage the difficult process on their own, requires a more focused and outreaching support from the professionals that could make a positive difference to these couples.

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