Evidence-based interventions by hospital social workers for patients with spinal cord injuries

- A literature review -
Evidence-based interventions by hospital social workers for patients with spinal cord injuries
Ruth Kusec Fredriksson

ABSTRACT

Some 120 to 150 people per year, in Sweden, injure their spinal cord in an often traumatic accident. During the initial trimester in a university hospital there are several issues arising for the patients, not only the fact that they suddenly cannot walk. The aim of this undergraduate thesis is to provide a review of selected literature on evidence-based interventions by hospital social workers for spinal cord injured. The method used in the thesis is database searches. Fourteen articles were included in the review. These articles have been divided into the categories: coping and interventions. Research shows that spinal cord injured have an increased risk of anxiety and depression. The most important findings were that spinal cord injured in both Sweden and Finland are dissatisfied with the societal services, that a spinal cord injury does not necessarily lead to anxiety and depression and that there are even positive outcomes of a spinal cord injury. Social and societal services are important in the adjustment process for spinal cord injured. Psychological interventions based on cognitive-behaviour therapy have been proven effective in the care of spinal cord injured.

Keywords: spinal cord injury, social work, interventions, coping, counseling.
## CONTENTS

1. **Introduction** ......................................................................................................................... 5  
   1.1 Introduction .......................................................................................................................... 5  

2. **Background** ............................................................................................................................ 6  
   2.1. Spinal cord injury ..................................................................................................................... 6  
      2.1.1. The spinal cord ..................................................................................................................... 6  
   2.3. Coping and coping strategies ................................................................................................. 7  
   2.4. Interventions ......................................................................................................................... 8  
   2.5. Aim .......................................................................................................................................... 9  

3. **Method** ..................................................................................................................................... 10  
   3.1. The structure of the thesis ...................................................................................................... 10  
   3.2. Perspective ............................................................................................................................ 10  
   3.3. Gathering data ....................................................................................................................... 10  
   3.4. Including and excluding data ............................................................................................... 11  
   3.5. Table 1 – Database search .................................................................................................... 11  
   3.6. Ethical issues ......................................................................................................................... 12  

4. **Findings and discussion** .......................................................................................................... 13  
   4.1. Table 2 - Findings .................................................................................................................. 13  
   4.2. Origin of the articles .............................................................................................................. 18  
   4.3. Categorising the articles ....................................................................................................... 18  
   4.4. Study designs ....................................................................................................................... 19  
   4.5. Findings .................................................................................................................................. 20  
      4.5.1. Coping ............................................................................................................................... 20  
      4.5.2. Interventions ..................................................................................................................... 24  
   4.6. Discussion of method ............................................................................................................ 27  
   4.7. Conclusion ............................................................................................................................ 27  

5. **Glossary** ................................................................................................................................... 29  
   5.1. Locus of control ..................................................................................................................... 29  
   5.2. Positive psychology .............................................................................................................. 29  
   5.3. Post traumatic stress disorder .............................................................................................. 29  
   5.4. Sense of coherence ............................................................................................................... 30  
   5.5. Subjective well-being .......................................................................................................... 30  

6. **References** ............................................................................................................................... 31  

7. **Appendix 1 – List of excluded articles** .................................................................................... 31
1. Introduction

1.1 Introduction

In Sweden some 120 to 150 people per year injure their spinal cord in an often traumatic accident. About 80% of the injured are men, 20% are women. During the initial trimester in a university hospital there are several issues arising for the patient, not only the fact that they suddenly cannot walk. These issues vary from being purely medical to social and economical. As the average age of the spinal cord injured patients is forty-four (males dominate the age group of twenty-one to thirty), most patients also have families (spouse and children) that are directly affected by the injury. (RTP - The Swedish Association of Survivors of Traffic Accidents and Polio, 2005).

Some studies show an elevated risk of alcohol and substance abuse among spinal cord injured. Suicide risk is four to five times higher for a spinal cord injured than for able-bodied persons in the same age and sex group, according to Craig and Hancock (1998, p. 103). Risk of serious illness is much higher in spinal cord injured than the rest of the community. This risk of serious illness can be a consequence of self-neglect (passive behaviour: not taking care of pressure wounds). Self-neglect is often prevalent (generally existing) when depressive illness is involved. Long-term on-going pain is found to be related to both depression and, of course, reduced quality of life. Craig and Hancock (1998, p. 103) write that as pain is found to be a psychological factor, maybe psychological interventions could help spinal cord injured to control their pain. According to Craig and Hancock (1998, p. 104), 30% of spinal cord injured have increased levels of anxiety and depressive mood (compared to the community in general). These increased levels stay the same over a time period up to two years after the injury.

During four months in the summer of 2005 I had the privilege to work with this in-patient category as a temp social worker. The patients I met had all different injuries and social conditions. Initially the spinal cord injured patients did not know what they needed help with. And, I am sorry to say, I had a big knowledge gap. Fortunately, I was part of a team of physicians, nurses, occupational therapists, physiotherapists as well as a psychologist. This team of staff, with their vast experience of spinal cord injured patients, gave me the support I needed to be able to conduct my work in a satisfactory manner.

My lack of knowledge and lack of guidance from colleagues on how to work with spinal cord injured patients inspired me to explore what issues are addressed by researchers in the field of social work during the initial trimester of admission to hospital. Such an exploration is needs the overall concept of a review in order to address the research question.

Two major perspectives emerged from the literature: the coping theory and interventions. Consequently, the literature is categorised into these two subjects. Both coping theory and interventions are described in Background. These perspectives are used in a wider sense in this thesis. The purpose is to facilitate the reading of the thesis.
2. Background

2.1. Spinal cord injury

2.1.1. The spinal cord

The spinal cord is the largest nerve of the body. It extends from the base of the brain to about the waist. The spinal cord is protected by 29 vertebrae and runs through the middle of the vertebral (or spinal) column like a cable. The function of the spinal cord is to send and receive messages back and forth between the brain and the other parts of the body.

The spinal cord can be injured by a traumatic injury (car accident) or acquired as a consequence of an illness (cancer). It can also be congenital (hydrocephalus). In most cases, an injury occurs when the vertebrae pinches the spinal cord which then becomes swollen or bruised. This injury causes a functional loss in nerves and muscles below the point of injury. Any messages sent between the brain and the other parts of the body are not delivered because of the injury.

An injury is defined by its level and type. Level: If the point of injury on the spinal cord is high (close to the brain), the injury is defined as tetraplegia (loss of feeling and/or movement in both arms, both legs and torso). If the point of the injury on the spinal cord is in the lower parts of the body, the injury is defined as paraplegia (loss of feeling and/or movement in both legs and torso). Type: a patient with a complete injury has no feeling or movement below the point of injury. A patient with an incomplete injury has some feeling or movement below the point of injury. (Spinal cord injury information network, 2000)

Consequences of a spinal cord injury:

- Medical consequences: paralysis, spasms, incontinence (bowel and bladder), low blood pressure, pain and skin problems (pressure wounds).
- Psychological consequences: grief, denial, sadness, anxiety, depression and anger.
- Economical consequences: income loss, extra costs for special equipment or clothes that is not refunded by the social security system, architectural re-decorations to fit a wheelchair and other equipment.

Please note that the above mentioned consequences are only examples, all patients have different experiences. (Spinal cord injury information network, 2004).

As mentioned above, spinal cord injured have an increased risk of depression, alcohol and substance abuse. They also have a increased risk of acquiring a serious illness due to self-neglect. Divorce, substance abuse and alcohol abuse are some of the possible consequences of a spinal cord injury. Maybe the most important consequence to focus on is self-neglect as the lack of self-care can become a threat to the patients’ lives. Neglect of skin care or bladder care can lead to septicaemia.

The average age of a spinal cord injured in Sweden is forty-four and males dominate the population. Many spinal cord injured have families and, without turning to research, it is clear that the family play an integral part in the
care of a spinal cord injured. The impact of the spinal cord injury on the family has not been properly researched. Studies have found that family members report chronic health problems, frustration, isolation, guilt as well as resentment towards the spinal cord injured.

2.3. Coping and coping strategies

In this literature review I have divided the articles found into two categories: coping and interventions. The purpose of the division is to facilitate the reading of the thesis. When searching for literature relating to this thesis it soon became evident that coping with spinal cord injury was a major issue among researchers. Likewise, quite a few articles were about interventions for this group of patients. In Findings, the division into coping and interventions is continued.

The coping theory was developed by Lazarus and is a transactional theory (person, environment and time interact dynamically) of stress and coping. In Lazarus theory, a stressor is defined as a situation in which the individual’s demands or demands from the environment or both exceeds the capacity of the individual to meet the demands. A spinal cord injury is an example of a stressor: it is life-threatening (in the acute phase) and the injured does not have previous experience of such an injury. Coping is a conscious act to solve a situation that is perceived e.g. as a threat.

Lazarus and Folkman (1984, p. 141) define coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” To elaborate this, coping is a process in the sense that there is a focus on what a person actually does in a specific situation rather than how the person usually reacts to a stressor. The conclusion is that coping is related to thoughts and actions that are applied in a certain situation. Coping is, thus, also context dependent. Coping is a dynamic process in which a person uses different types of coping strategies (see below) depending on the stressor experienced by the person.

Coping strategies are conscious efforts to manage the stress by thoughts or actions. For example: when you are angry at someone you might count to ten to calm down and not to yell. Or you could also refrain from counting and start yelling. That is also a coping strategy. It is not very efficient, but still a coping strategy. Coping strategies are not to be confused with the outcomes of coping. Efforts to manage a situation might have various consequences. (Elfström, 2003, p. 11).

Lazarus and Folkman (1984, p. 148) explain that coping is much more that problem solving. According to them, coping services multiple functions. They caution us not to confuse functions with outcomes. “A coping function refers to the purpose a strategy serves; outcome refers to the effect a strategy has.” (Lazarus & Folkman, 1984, p. 149).

Coping is also divided into emotion-focused forms of coping and problem-focused forms of coping. Emotion-focused coping could include decreasing emotional distress, increasing emotional distress or cognitive reappraisals. Problem-focused forms of coping are more directed at defining the problem, finding alternatives, weighting alternatives into cost and benefits, choosing an alternative and then put it into action. The two forms of coping can help each other in the coping process but they can also collide with each other. An example: if you are going to hold a public speech you might be very nervous. Giving yourself encouraging words and time to take a deep breath (decreasing emotional distress) might make it easier for you to focus on your task and deliver your speech (problem-focussing). Yet another example: you need to make a difficult decision. This decision
causes you great emotional distress. In order to reduce the emotional distress you might make a premature decision which is not based on sufficient consideration. (Lazarus & Folkman, 1984, p. 150-154).

2.4. Interventions

As mentioned above, one of the issues addressed by researchers was interventions. Primarily, my focus was to find evidence-based interventions by hospital social workers for spinal cord injured patients during the initial trimester at a rehabilitation ward. I would like to begin with explaining the meaning and etymology of the term and then to give examples of what interventions hospital social workers might perform.

Intervene is defined as follows by Merriam-Webster’s on-line dictionary (2005):

Etymology: Latin *intervenire* to come between, from *inter-* + *venire* to come. 1: to occur, fall, or come between points of time or events, 2: to enter or appear as an irrelevant or extraneous feature or circumstance, 3: to come in or between by way of hindrance or modification <intervene to stop a fight>, 4: to occur or lie between two things, 5 a : to become a third party to a legal proceeding begun by others for the protection of an alleged interest b: to interfere usually by force or threat of force in another nation's internal affairs especially to compel or prevent an action.

The use of intervention in this thesis is in the sense of helping patients to overcome the obstacles following a spinal cord injury whether they are of practical, psychological, vocational or other nature. That is, to come in or to occur between two things: the spinal cord injured and the issues he/she has due to the injury.

An example of a psychological intervention is cognitive behaviour therapy which is a kind of psychotherapy used to treat, for example, depression, anxiety disorders and phobias. It involves recognising distorted thinking and learning to replace it with more realistic substitute ideas. Its practitioners hold that much (though not all) clinical depression is associated with (although not necessarily caused by) irrational thoughts. With thoughts stipulated as being the cause of emotions rather than vice-versa, cognitive therapists reverse the causal order more generally used by psychotherapists. The therapy is essentially, therefore, to identify those irrational or maladaptive thoughts that lead to negative emotion and identify what it is about them that is irrational or just not helpful; this is done in an effort to reject the distorted thoughts and replace them with more realistic alternative thoughts. (Wikipedia – The Free Encyclopedia, 2005a).

The role of the hospital social worker has been defined in a small study by Davis, Baldry, Milosevic and Walsh (2004, p. 346-358). They found in their study that social workers were involved in wide range of activities related to patients and their families. The study is small (N=19) and conducted in Australia. Still it has similarities to my own experiences as a hospital social worker. According to Davis et al (2004, s. 356) hospital social workers made assessments of patients, counseling, discharge planning, education (e.g. educating patients in what kind of societal services are available to them), information, liaison (with authorities), bereavement interventions and crisis interventions, family interviews or spouse interviews, individual interviews, telephone consultations, written communication (e.g. authorities). Davis et al (2004, p. 346) also divide the social work into direct treatment and indirect treatment of patients. The direct treatment is e.g. counseling, the indirect treatment is e.g. departmental meetings regarding patients treatment. This is also consistent with my own experience of working as a hospital social worker at many different departments at a university hospital.
2.5. Aim

The aim of this undergraduate thesis is to explore what evidence there is on helping traumatic spinal cord injured patients as a hospital social worker during the initial trimester at a hospital ward. The thesis will be presented in the form of a literature review. More specifically, the aim is to investigate what issues regarding spinal cord injured patients are addressed by researchers.
3. Method

3.1. The structure of the thesis

In chapter 1, I tried to give a brief introduction to the thesis. The background as well as aim was presented in chapter 2 including a description of the spinal cord and explanation of a spinal cord injury. This chapter primarily focuses on the data collection. Chapter 4 opens with a table presenting the findings. The table is then followed by details of the findings. In chapter 5 the reader finds a glossary of terminology specific to psychology. Finally, there is a list of references as well as an appendix with a list of excluded articles.

3.2. Perspective

The perspective is the social worker’s. I am primarily interested in how a social worker should work with spinal cord injured patients. But the patients experience of their impairment and their way of coping is important information on what interventions might be helpful. This information will be found in the referred research articles.

3.3. Gathering data

According to Taylor & Procter (2005) a literature review is an account of what has been published on a topic by accredited scholars and researchers. The literature to be used in the review is the data that is going to be analysed according to Taylor & Procter’s (2005) suggestions and which I have revised to be applicable to my thesis.

I have conducted systematic internet searches for literature. I have used descriptors that I have come up with myself or that I have found in articles. I also received help from the university librarians at Stockholm University as well as Uppsala University to find other descriptors or other ways of searching for relevant literature. All searches have been documented according to date, database, descriptor/keyword, number of hits. I have read the abstract of each text found, I have analysed the texts and finally categorised them into either to be included in the thesis or not. There have been several levels of analysis. First of all the analysis of the data, then the analysis of the contents and focal points, then an overall analysis of data as well as a summary of the findings. Hence, it will be the texts found in connection to the research question that will determine the content of the thesis.

I have used the reference lists of the found data to find new articles or books. I have made a conscious effort to find articles from different professions and countries to expand my horizon and to find new angles on the research questions. I am certain that I have omitted articles that could have been interesting for the thesis. That is the backside of subjectivity. I have also made an effort to include articles by researchers that are often quoted by peers.

The basis of the thesis are peer-reviewed articles and doctoral theses (Elfström, 2003; Grundén, 2005). The literature review is expected to give an overview and answers to my research question. I have included books (Levi & Herlofsson, 1997; Fortsättning följer, 1999) directed at a popular readership in the thesis in order to give the spinal cord injured a voice. These books are obviously not included in the review.
3.4. Including and excluding data

I have searched data to match my research question. Logically I have excluded data that I found neither interesting nor relevant for the thesis, e.g. articles with a purely medical content. Sixty-two articles were selected from the database searches. Out of these, thirty-two were discarded, the majority (twenty-three) due to inaccessibility. Please see Appendix 1 for a detailed list of discarded literature as well as stated reason for exclusion. I have searched for literature at the library of Karolinska Institutet in Stockholm, Stockholm University library and Uppsala University library.

The inclusion criteria were:

- Articles/books with evidence-based interventions by hospital social workers for spinal cord injured.
- Articles/books with evidence-based interventions (non-medical) for spinal cord injured.
- Articles/books published in Swedish or English.
- Adults (> 18 years) studied.

Sixty-two articles/books were selected from the database searches. Twenty-two articles/books related to spinal cord injuries were included in the first filtering. In a second filtering, eight articles were discarded. That leaves a final fourteen articles/books included in the review. Several articles appeared in different databases hence the sum of thirty articles/books in the column Included in the review below. Please see Appendix 1 for a list of excluded articles/books as well as stated reason for exclusion.

3.5. Table 1 – Database search

Database search, keywords, hits and selection. Only the first twenty hits of every database search were reviewed.

<table>
<thead>
<tr>
<th>Database</th>
<th>Keywords</th>
<th>Hits</th>
<th>Selection</th>
<th>Included in the review</th>
</tr>
</thead>
<tbody>
<tr>
<td>IBSS</td>
<td>Spinal cord</td>
<td>24</td>
<td>2</td>
<td>2</td>
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<tr>
<td>ASE-EBSCO</td>
<td>Spinal cord</td>
<td>4854</td>
<td>0*</td>
<td>0*</td>
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<tr>
<td>ASE-EBSCO</td>
<td>Spinal cord injuries</td>
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<td>4</td>
<td>2</td>
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<tr>
<td>ASE-EBSCO</td>
<td>Spinal cord injuries and social</td>
<td>95</td>
<td>10</td>
<td>2</td>
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<tr>
<td>ASE-EBSCO</td>
<td>Spinal cord injuries and counseling</td>
<td>33</td>
<td>3</td>
<td>2</td>
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<tr>
<td>Medline Pubmed</td>
<td>Spinal cord injuries and social work</td>
<td>14</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Medline Pubmed</td>
<td>Spinal cord injuries and trauma coping</td>
<td>307</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Medline Pubmed</td>
<td>Spinal cord injuries and psychosocial care</td>
<td>45</td>
<td>5</td>
<td>1</td>
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</tbody>
</table>
3.6. Ethical issues

The biggest ethical issue is that there are no interviews with patients or social workers in the thesis. As the data is secondary, I had be conscientious when analysing it. Even so, there is always a risk of making mistakes. The exclusion of data (as mentioned above) could have been an ethical issue if I did not present what was excluded. Consequently as mentioned above, a list of excluded data is presented in Appendix 1.

The philosophical stand of the writer is also an ethical issue. My values permeate the thesis no matter how objective I have tried to be. I confess to the humanistic perspective of life. The humanistic perspective emphasises free will, innate tendencies toward growth, and the attempt to find ultimate meaning in ones existence. (Passer & Smith, 2003, p. 11). The next natural step is positive psychology which emphasises the study of human strengths, fulfilment and optimal living. (Passer & Smith, 2003, p. 12).

There is always a risk of confirmation bias, meaning that the author tends to seek information and evidence that will support her views rather than looking for opposing evidence. I have done my best to avoid confirmation bias by presenting different stands. Overconfidence is another obstacle which implies that the author is overestimating her being correct in knowledge, facts, decisions, etc. If I am guilty of such arrogance is for the reader to decide. I can only hope, that I am not. Passer & Smith (2003, p. 298) urges us: "The best thing we can do to test our ideas is to seek evidence that will disconfirm them, rather than look for evidence that supports them."
## 4. Findings and discussion

### 4.1. Table 2 - Findings

<table>
<thead>
<tr>
<th>Authors &amp; Country</th>
<th>Title &amp; Publishing date</th>
<th>Contents</th>
<th>Data collection</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elfström Sweden</td>
<td>Coping strategies and health-related quality of life in persons with traumatic spinal cord lesion, 2003</td>
<td>Doctoral thesis based on four articles with the objective of investigating coping strategies of spinal cord injured and the relationship between coping strategies and health related quality of life.</td>
<td>Questionnaire. Spinal cord injured admitted between 1982 and 1998. Sample of paper 1: 274 participants. Out of these 274, 255 participants were the main sample in paper 2 and 256 in paper 3. Finally, in paper 4 181 participants were the main sample (from 274 participants originally).</td>
<td>Spinal cord injury related coping strategies are distinct correlates of health related quality of life. Reevaluation of life values is associated with better health related quality of life. Unconditional reliance on other people is associated with unsatisfying health related quality of life.</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Description</td>
<td>Participants</td>
<td>Methods</td>
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<tr>
<td>Grundén</td>
<td>Reclaiming the body. A study of life after a spinal cord injury, 2005</td>
<td>A doctoral thesis to gain understanding of how the relationship between the body and its environment is rebuilt after a spinal cord injury and how patients learn to live with a newly altered body.</td>
<td>17 participants</td>
<td>Interviews, field studies and participant observation.</td>
</tr>
<tr>
<td>Hampton</td>
<td>Subjective well-being among people with spinal cord injuries: the role of self-efficacy, perceived social support, and perceived health, 2004</td>
<td>A study to explore the joint contributions of demographic variables, perceived health, self-efficacy beliefs, and perceived social support to subjective well-being in people with spinal cord injuries. Interventions are proposed.</td>
<td>127 participants</td>
<td>Different measurement rating tools were used (participant rating) and a demographic questionnaire.</td>
</tr>
<tr>
<td>King &amp; Kennedy</td>
<td>Coping effectiveness training for people with spinal cord injury: preliminary results of a controlled trial, 1999</td>
<td>The objective was to develop and evaluate a brief group-based psychological intervention for improving psychological adjustment and enhancing adaptive coping following spinal cord injury.</td>
<td>19 intervention group participants and 19 matched controls.</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Lohne &amp; Severinsson</td>
<td>Hope during the first months after acute spinal cord injury, 2003</td>
<td>An exploration into patients’ experience of hope following a spinal cord injury.</td>
<td>Patients hoped for recovery and every improvement stimulated hope. The process of hope was future-oriented, characterised by dichotomies.</td>
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<td>Personal interviews with 10 patients at a rehabilitation clinic.</td>
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<tr>
<td>Lude, Kennedy, Evans, Lude, Beedie</td>
<td>Post traumatic distress symptoms following spinal cord injury: a comparative review of European samples, 2005</td>
<td>The objective was to highlight any cross-cultural differences in the prevalence of post traumatic stress disorder and the type of coping strategies implemented following spinal cord injury.</td>
<td>No cross-cultural differences in the level of post traumatic stress disorder seemed apparent between the UK and the CH/DE populations.</td>
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<tr>
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<td>Questionnaire. 85 UK participants and 71 from Switzerland and Germany.</td>
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<tr>
<td>Lustig</td>
<td>The adjustment process for individuals with spinal cord injury: the effect of perceived premorbid sense of coherence, 2005</td>
<td>Investigation of the relationship between perceived changes in the sense of coherence from pre- to post-injury and adjustment for a group of spinal cord injured. Implications for rehabilitation counselors are discussed.</td>
<td>Approximately one third (38 %) of the participants perceived strengthened sense of coherence post-injury, and two thirds (62 %) perceived weakened sense of coherence post-injury. Perceived weakened sense of coherence was associated with problematic adjustment post-injury, whereas perceived strengthened sense of coherence was associated with adaptive adjustment.</td>
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<td>48 participants with spinal cord injury. Different measurement rating tools were used (participant rating) and a demographic questionnaire.</td>
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<tr>
<td>McColl, Lei &amp; Skinner</td>
<td>Structural relationships between social support and coping, 1995</td>
<td>Relationships between social support and coping were examined over a one-year period in a sample of 120 participants exposed to the stressor spinal cord injury.</td>
<td>The results shows that social support has a significant and direct effect on coping at future points in time, and that social support and coping are both predictive of future social support and coping respectively.</td>
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<td>Questionnaire. 120 participants. Assessment was made one, four and twelve months post-discharge.</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Findings/Summary</td>
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<td>-----------------------------------------------------------------------</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
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<tr>
<td>McMillen &amp; Loveland Cook</td>
<td>The positive by-products of spinal cord injury and their correlates, 2003</td>
<td>To assess positive by-products from the struggles with traumatic spinal cord injury and to explore their contents.</td>
<td>Interviews with 42 spinal cord injured and one person close to each injured (who had known the spinal cord injured before the injury). Increased compassion and family closeness and decreased alcohol consumption were commonly reported following injury. Positive by-products are different from other types of outcomes, but because loved ones do not necessarily notice these benefits, their validity remains in doubt.</td>
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<tr>
<td>Nordgren, Levi, Ljunggren &amp; Seiger</td>
<td>Societal services after traumatic spinal cord injury in Sweden, 2003</td>
<td>Societal services after traumatic spinal cord injury were investigated, including self-rated levels of satisfaction with the application process and resource allocation.</td>
<td>Questionnaire and interviews with 34 participants. Insufficient information and co-ordination of the societal services are reported as weaknesses. The spinal cord injured patient’s efforts to acquire knowledge of how the system works takes time which could be better used for rehabilitation and full integration into the community.</td>
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<tr>
<td>Saikkonen, Karppi, Huusko, Dahlberg, Mäkinen &amp; Uutela</td>
<td>Life situation of spinal cord injured persons in Central Finland, 2004</td>
<td>The objective was to study aspects of the spinal cord injured patients life situation and their opinion of the health care services one year after the injury.</td>
<td>Individual interview and semi-structured questionnaire with 76 participants. More than half of the participants were dissatisfied with the current health services (provided in local health care centres).</td>
<td></td>
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<tr>
<td>Scivoletto, Petrelli, Di Luce &amp; Castellano</td>
<td>Psychological investigation of spinal cord injury patients, 1997</td>
<td>The objective of the study was to assess the degree of anxiety and depression in spinal cord injured patients, and to study factors contributing to their origin.</td>
<td>Questionnaire. 100 participants. Psychological distress is limited to 20 % of the patients. Anxiety and depression are maintained over time and do not decrease. Psychological services should be available to spinal cord injured patients during hospitalisation and after discharge.</td>
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</tr>
<tr>
<td>Siösteen, Kreuter, Lampic &amp; Persson</td>
<td>Patient-staff agreement in the perception of spinal cord lesioned patients’ problems, emotional well-being, and coping pattern, 2005</td>
<td>To investigate spinal cord injury rehabilitation staff perceptions of spinal cord injured patients problems, coping efforts, and well being, and to compare these evaluations with patient self-reports of the same aspects.</td>
<td>Matched patient/staff study including 29 patients with spinal cord injury and the 24 persons in the staff caring for these patients. Questionnaires were used.</td>
<td>Relatively high agreement between patients and staff. Staff systematically overestimated patients’ emotional problems and underestimated patients’ coping abilities.</td>
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</table>
4.2. Origin of the articles/books

Fourteen articles/books were included in the review. Four of the articles/books originated in Sweden (Elfström, 2003; Grundén, 2005; Nordgren, Levi, Ljunggren and Seiger, 2003; Siösteen, Kreuter, Lampic and Persson, 2005).

Three of the articles originated in the USA (Hampton, 2004; Lustig, 2005; McMillen & Loveland Cook, 2003).

Two of the articles originated in the UK (King & Kennedy, 1999; Lude, Kennedy, Evans, Lude & Beedie, 2005).

Two of the articles originated in Canada (Donnelly, Eng, Hall, Alford, Giachino, Norton and Kerr, 2004; McColl, Lei & Skinner, 1995).

Finland (Saikkonen, Karppi, Huusko, Dahlberg, Mäkinen & Uutela, 2004), Italy (Scivoletto, Petrelli, Di Lucente & Castellano, 1997), and Norway (Lohne, & Severinsson, 2003) are each represented by one article/book.

The articles were published between 1995 and 2005.

4.3. Categorising the articles/books

The fourteen articles have been divided into two main categories: coping and interventions. Seven articles are related to coping (quality of life, post traumatic stress syndrome, hope, positive by-products of a spinal cord injury, negative consequences of a spinal cord injury). Four articles are categorised as interventions (positive psychology, cognitive behaviour therapy, teaching coping skills, assessment tools). Four of the articles are both related to coping and interventions.

Coping:


**Interventions:**


**Both coping and interventions:**


### 4.4. Study designs

Eight of the studies were of quantitative design (questionnaires were most frequently used):


Four of the studies were qualitative (interviews mostly):


Two of the studies used both quantitative and qualitative design:


4.5. Findings

4.5.1. Coping

Lohne and Severinsson (2003, p. 283) have made a study on spinal cord injured patient’s hopes. Apparently patients’ hopes are about returning to their earlier states of health and everyday life as it was pre-injury. The patients in Lohne and Severinsson’s (2003, p. 283) study also reported that the process of hoping was a movement between dichotomies: helplessness and independence; courage and uncertainty, ups and downs, etc.

Hope could be influencing the way spinal cord injured experience their body. It is possible that the more hope of full recovery a patient has, the more difficult it is to accept an altered body. Grundén (2005, p. 40) studied how the altered body after a spinal cord injury is experienced and integrated into the lived body. The participants in
the study initially did not want to acknowledge the paralysed parts of their body. Later on they developed a positive attitude towards the body. Knowing that there is no other choice than to learn to use the altered body in order to live, the participants also learnt to recognise the new signals from the injured part of the body. Thus the injured part of the body became integrated with the rest of the body. Thus the result of this study is that spinal cord injured can reclaim their bodies and their lives with full dignity and that disability does not exclude a good life.

It would be interesting to compare Grundén’s study to the participants’ own views of how they experience their altered body. Studies like Grundén’s (2005, p. 40) and Lohne and Severinsson’s (2003, p. 279-286) are necessary in order to understand how the spinal cord injured are affected by their impairment. The understanding is helpful for the social worker when suggesting different interventions early on (e.g. personal assistant, rebuilding the house to meet the new needs of the spinal cord injured). However as these studies are small, they can not be generalised. North (1999, p. 371) also discusses the distorted body image in a review and concludes that such a change in body image might cause significant psychological trauma which would require psychological interventions. It is not evident whether spinal cord injured have voiced such psychological trauma or if it is health professionals reporting it in North’s (1999, p. 371) article.

Lustig’s (2005, p. 151) results show that about one third of the participants perceived a strengthened sense of coherence post-injury and two thirds perceived weakened sense of coherence. Apparently perceived weakened sense of coherence was associated with problematic adjustment post-injury whereas perceived strengthened sense of coherence was associated with adaptive adjustment (Lustig, 2005, p. 153). The study provides support for the hypothesis that a person with a spinal cord injury who perceived a weakened sense of coherence post-injury also may experience negative psychosocial reactions to the disability (e.g. shock, anger, depression).

The result of the Hampton (2004, p. 35) study is that persons with spinal cord injuries have, logically, different levels of subjective well-being. The difference might be due to the patient’s general self-efficacy beliefs, perceived social support, perceived health and also age at injury. Age at injury is a variable that also Saikkonen, Karppi, Huusko, Dahlberg, Mäkinen and Uutela (2004, p. 459) found to be important. They studied the life situation of spinal cord injured in Central Finland and found that the older the subjects were when injured, the more depressive symptoms they had. They also found that the participants in the study were rather dissatisfied with the health care services provided by local health care centres.

Lude, Kennedy, Evans, Lude and Beedie (2005, p. 102) used different recognised measurement tools to measure levels of post traumatic stress, depression, coping strategies and well being up to six months post injury. They examined if the prevalence of post traumatic stress disorder (PTSD) in spinal cord injured patients differ in three countries. Findings showed no cross-cultural differences between the UK and Swiss/German population regarding the prevalence of post traumatic stress disorder. The incidence (occurrence) of PTSD following a spinal cord injury requires further research according to a scientific review of the subject by Kennedy and Duff (2001, p. 4). Exposure to a traumatic event, e.g. road traffic accident, is not sufficient to develop PTSD. Although research indicates prevalence of PTSD from 10 % to 40 % in spinal cord injured persons, no one really knows if PTSD is a consequence of the experienced trauma, the spinal cord injury or both alternatives, according to the findings of Kennedy and Duff (2001, p. 8). North (1999, p. 672) also discusses the incidence of PTSD in spinal cord injured persons. As PTSD is related to traumatic events like road traffic accidents, North (1999, p. 672) writes: “one might assume that PTSD following spinal cord injury would be a significant problem.” North (1999, p. 672) claims that further research is necessary as small studies indicate PTSD being a significant problem for spinal cord injured. If that is true, then my conclusion is that a very small population of spinal cord injured are affected. This conclusion is based on research (see below Scivoletto, Petrelli, Di Lucente and
Castellano, 1997, p. 516) findings that some 20% report anxiety and depression. Not all 20% will develop a PTSD. I find that North (1999, p. 672) is drawing conclusions that are inconsistent with both Lude et al’s (2005, p. 102) and Kennedy and Duff’s (2001, p. 4) findings. The latter studies are more recent and differ in design from North’s study.

Elfström (2003, p. 41) found in his study a strong correlation between coping strategies and health-related quality of life. He found that the coping strategy acceptance lead to an increased emotional well-being. He also found that the more spinal cord injured had to rely on other people the more dissatisfied they were. These findings are supported in Grundén’s (2005, p. 82) study. The participants in that study stressed the importance of being responsible of their own lives. They also mentioned the importance of coping on their own and not being dependant on other people. The conclusion is that independence and freedom are considered to be the most important issues for the spinal cord injured. Lohne and Severinsson (2004, p. 282) also reported that the participants in their study expressed a sadly missed ability to live independently of help from others.

There seems to be a common and frequent thought among researchers that persons with spinal cord injury have to reassess and reconstruct their identity with the result of a more positive view of themselves (Elfström, 2003, p. 51). This view is supported by some of the nine interviewed Swedish spinal cord injured in a book (Fortsättning följer, 1999) published by RTP - The Swedish Association of Survivors of Traffic Accidents and Polio. The interviewees talk about changing their views of themselves, shaping their own new identity and finding new goals in life. The same was found in Grundén’s (2005, p. 40) study. These findings are logical as the impact of a spinal cord injury is vast and turns a patient’s whole life around. Generalising is not possible due to the size of the study.

Detecting mood disorders in in-patients has been extremely low. One of the theories to account for this is the assumption among health care professionals that anxiety and depression are normal in spinal cord injured patients. This normalisation has lead to absence of interventions, according to North (1999, p. 672). Scivoletto, Petrelli, Di Lucente and Castellano (1997, p. 516) found that twenty patients out of a hundred suffer from anxiety or depression. North (1999, p. 672) reviewed the literature on psychological effects of spinal cord injury and found studies showing that spinal cord injured persons have a substantially higher risk of suffering from anxiety and depression than control groups. Anxiety and depression have been considered inevitable consequences of a spinal cord injury. McMillen and Loveland Cook’s (2003, p. 80) research shows that anxiety and depression are not inevitable consequences of spinal cord injury.

In an article by Gill (1999), a social worker at Allegheny General Hospital in Pittsburgh, Pennsylvania, USA, depression is discussed as a necessary process in order to work toward successful adaptation of a spinal cord injury. Gill (1999) even suggests that the absence of depressive symptoms could be an obstacle to recovery. But the author also comes to the conclusion that many spinal cord injured patients being diagnosed as depressed actually are in a period of adjustment. When Scivoletto et al (1997, p. 519) investigated the evolution of the two syndromes (anxiety and depression) over time, there were no significant changes of their (the newly injured) affective status over time. The psychological effects of a spinal cord injury is dependant on the degree of autonomy and the possibility to have “normal” lifestyle. Spinal cord injury is often compared to other psychological distress like mourning. The mourning process usually decreases over time and follows certain stages like denial, depression, anger and acceptance. But the participants in the above mentioned study did not show any decrease or change in anxiety or depression over time. The variables in Scivoletto’s et al (1997, p. 519) study that were most related to anxiety and depression were those influencing social and vocational life. Finally, Scivoletto et al (1997, p. 519) conclude
that adjustment to a spinal cord injury is very much dependant of the individual due to the interaction of several factors: medical, personality, capacity to manage stress and family support and socio-economic status.

McMillen and Loveland Cook’s (2003, p. 80) study focussed on positive outcomes of a spinal cord injury and found e.g. increased compassion. Joseph and Linley (2005, p. 262) have developed a theory called the organismic valuing theory of growth through adversity. The theory assumes that people are naturally inclined and motivated towards growth. They define growth as when a) people report enhanced relationships, b) people report changes in their view of themselves, and c) people report changes in life philosophy. One of the examples of triggers of growth is spinal cord injury. According to Joseph and Linley’s theory (2005, p. 273) positive changes in the psychological well-being of the person will take place through positive accommodation of new trauma-related information, if the social environment is able to provide the support needed for the positive accommodation process. In other words: a spinal cord injured will have an increased psychological (and as a consequence of that increased subjective well-being) well-being if he/she look at their new situation positively (appreciative of relationships, re-evaluating life philosophy) and receives sufficient support from the social environment (health professionals, relatives, society). Gill (1999) writes:

“It is important for persons with SCI to continue to have relationships outside the family system to facilitate feelings of independence and better psychological adjustment.” (Gill, 1999, p.3)

Siösteen, Kreuter, Lampic and Persson (2005, p. 180) came to the conclusion that there is a tendency of staff overestimating the patient’s emotional and social problems. Staff underestimating the patient’s use of coping activities was also found in the study. Staff were accurate in assessing the physical symptoms or functional limits and role problems. If the staff has misconceptions about the psychological state of the patient it might “create a climate in which the person with SCI (spinal cord injury) realises that everyone considers him to be very unfortunate” (Trieschmann quoted in Siösteen et al, 2005, p. 180).

Although spinal cord injured have an increased risk of developing negative consequences after their injury, they are not inevitable consequences. Actually, there are even positive outcomes reported. People who have survived natural disasters, war and other adversities report that good has come out of their harsh experiences. Alcohol abuse and substance abuse is usually considered to be a risk factor for spinal cord injury, but McMillen and Loveland Cook (2003, p. 80) found a decreased alcohol consumption in their study. The participants of the study reported increased family closeness and compassion. The study found it reasonable to question the validity of positive outcomes because loved ones do not necessarily notice the perceived outcomes. Several patients in Grundén’s study (2005, p. 119) claim to have changed because of the injury. Thoughts and values are said to have changed. Feelings are expressed more often. The patients’ also claim to have more patience.

Obviously, a spinal cord injury has an immense impact on the psyche as well as the daily life of the patient and next of kin. The studies above should make social workers more aware of different psychological reactions to such an injury and not take certain reactions for granted. Also, during the first trimester, the medical care as well as physiotherapy and occupational therapy are prioritised. Studies suggest that psychological care is as vital as the medical care. It can be questioned if psychological care is a task for social workers. Especially as a psychologist is a part of the multi-professional team treating spinal cord injured in Sweden. But nevertheless, it is important for a social worker (and all team members) to be aware of the different psychological outcomes of a spinal cord injury. Being aware of the psychological consequences and how they can be expressed could be helpful when intervening. It is also important to be aware of the fact that there might be a discrepancy between the perceived problems of staff and spinal cord injured. A discrepancy might lead to interventions that are unhelpful for the patient. Scivoletto et al (1997, p. 519) found in their study that anxiety and depression did not decrease over time. This result is very interesting as social workers in Sweden are taught that a crisis follows a
certain pattern with four phases. The final phase is characterised by the crisis event being a scar on the soul but where life goes on as the scar fades. Spinal cord injured live with their crisis everyday and are reminded of their trauma in everything they do. Their scars are never allowed to fade. It would certainly be very interesting to see if a Swedish study would come to the same conclusions as Scivoletto et al (1997, p. 519).

How are we supposed to help spinal cord injured patients? Livneh and Antonak (2005, p. 17) propose psychodynamic therapy in the early stages of a spinal cord injury. In the later stages they propose cognitive-behavioural based therapies.

“Assessment of clients’ levels of psychosocial adaptation to their condition should pave the way to appropriate selection of intervention strategies” (Livneh and Antonak, 2005, p. 18). Without an assessment of the problem areas, an intervention could be harmful and counterproductive. Livneh and Antonak (2005, p. 12) have made an overview of three different areas of psychosocial adaptation to chronic illness and disability:

1. the process of the adaptation,
2. assessment of adaptation and finally,
3. intervention strategies.

Livneh and Antonak (2005, p. 16) give an example of an assessment tool related to social work: the Psychosocial Questionnaire for Spinal Cord Injured Persons by Bodenhamer, Achterberg-Lawlis, Kevorkian, Belanus and Cofer. Livneh and Antonak (2005, p. 12) are found in the reference lists of several of the studies in included in this review. One can assume that their suggestions are well worth trying in a clinical setting.

4.5.2. Interventions

Several studies in North’s (1999, p. 674) review showed the importance of social support. (North [1999, p. 674] does not define social support. I assume that social support is an overall term including societal support.) Without social support there is a major risk of not recovering from a mood disorder, experiencing health problems, problems adjusting to spinal cord injury and more frequent hospital re-admissions (than for spinal cord injured persons with social support). The more recent studies of Nordgren, Levi, Ljunggren and Seiger (2003, p. 126) and Saikkonen et al (2004, p. 463) show that there has been little done in improving societal services in Sweden and Finland.

Nordgren et al (2003, p. 126) advocate a holistic approach to rehabilitation to include the whole process of returning to independent living. They found that such an approach requires a structural change of interventions by authorities. The participants in the study were dissatisfied with the support from social services. The conclusion is that involvement from different authorities need to be co-ordinated in order to be successful and effective for the spinal cord injured.

The Canadian Occupational Performance Measure (COPM) is an individualised, client-centred measure designed for use by occupational therapists to detect change in a client's self-perception of occupational performance over time. Full rehabilitation of a spinal cord injured might take as long as 4 years. In this light it is important that patients are proactive in their own care and health. One of the ways to facilitate this is to involve patients in their therapeutic process. Research show that patient have voiced the will to be in charge of their own care and to become experts in their capabilities (Donnelly, Eng, Hall, Alford, Giachino, Norton and Kerr, 2004,
p. 302). Using the COPM, the patient identifies areas that he/she finds difficult (e.g. grooming, leisure activities, household activities). The study found that COPM could facilitate active involvement of spinal cord injured patients in their rehabilitation process (Donnelly et al., 2004, p. 306). As the COPM also identifies psychosocial issues it could be used by social workers to identify issues and to check whether interventions have been efficient and useful to the patients or not. No study was found that investigated the usefulness of the COPM for hospital social workers.

Gill (1999) divides interventions into short term and long term. Short term interventions could be crisis intervention while long term could be enhancing self-esteem. Gill (1999) focuses on the importance of the social worker to act as liaison between the patient/patient’s family and the hospital staff. The role of the social worker is to provide both parties with necessary information. Gill (1999) also explicitly notes the importance of active listening, portraying empathy, caring and personal traits like showing warmth. Emphasis on independence in spinal cord injured patients has a direct effect on self worth and self-esteem. Gill (1999) is an advocate for cognitive behavioral therapy to restructure thoughts and to find new active and positive coping styles in spinal cord injured.

In a clinical trial comparing patients receiving Coping Effectiveness Training (CET) to matched controls, King and Kennedy (1999, p. 11) report significantly greater reduction in levels of depression. King and Kennedy describe CET as follows:

“Coping Effectiveness Training is a brief group-based intervention aimed at teaching appraisal skills and a range of standard cognitive-behavioural coping skills, together with a meta-strategy derived from the cognitive theory of stress to flexibly guide the choice of coping strategies and their application.” (1999, p. 7).

Coping effectiveness training improved the levels of depression and anxiety in an in-patient group of spinal cord injured. But contrary to prediction there was no evidence of greater use of adaptive coping strategies or reduction in the use of maladaptive coping strategies in the intervention group. The study also concluded that peer support was important in the CET-trial.

Peer contact is an important part of rehabilitation according to Grundén’s (2005, p. 128) patients. Meeting with other spinal cord injured usually inspires newly injured patients into trying out moves or other things. Peer contact can provide the newly injured patients with an insight of how other patients have coped with their injuries. These newly spinal cord injured patients also form a new group with whom they can relate to.

Hundred and twenty spinal cord injured participants were assessed at one, four and twelve months post-injury in order to examine structural relationships between social support and coping (McColl, Lei and Skinner, 1995, p. 395). Two issues were evaluated: patterns of social support and coping over time, and the direction of the effects of coping on social support or vice versa. The study came to the result that social support can be viewed as a coping assistance and that social support and coping are related to one another in systematic ways. The results also suggest that the relationship between social support and coping is time-dependant. While perceptions of social support have positive effects on the number and frequency of coping strategies used shortly after injury, high levels of perceived support may have negative impact on the extent of coping efforts. Either the spinal cord injured becomes more efficient in using coping efforts or high levels of social support is preventing the spinal cord injured to use his/hers coping efforts.

When investigating how spinal cord injured rate the societal services in Sweden, the researchers found that the social workers were supplying the patients with information about available services (Nordgren, Levi, Ljunggren and Seiger, 2003, p. 121). When still at hospital, the patients’ applications to different authorities were
administered by social workers who were in charge of the whole application process. Nordgren et al (2003, p. 121) came to the conclusion that insufficient information and lack of co-ordination are weaknesses of societal interventions. Also Saikkonen et al (2004, p. 463) reported that more than half of the participants were dissatisfied with the current health services provided in local health care centres in Central Finland.

One would expect rich countries like Sweden and Finland to offer societal services that are helpful to this group of patients. Probably many of them experience a secondary trauma when being met with ignorance or lack of understanding. There is a point in having a system of interventions that is helpful to spinal cord injured. Not only because it would be cost-efficient but also because it would allow spinal cord injured patients to focus on their rehabilitation and possibly re-integration into work. As there is no formal or structured information supplied to the spinal cord injured, they have to rely in social workers as they typically arrange help for spinal cord injured. However, this is highly vulnerable. The spinal cord injured is dependant of the social worker to be conscientious and well informed of societal services, dedicated to keep up with new legislation, and encouraging as well as helpful.

There are many different civil servants at several different authorities involved in the societal care of spinal cord injured. Maybe it would be wise to have one single authority focussing on disabled or impaired persons. Such an authority would rather quickly build a knowledge base useful for both individuals and society. For a social worker it would also be helpful with a single authority focussing on disabled or impaired persons. As a hospital social worker I have experienced the frustrations of communicating with authorities. There is a lack of understanding and compassion from both my side as well as from authorities. As to interventions there seems to be a common understanding in the articles included in this review that cognitive behaviour therapy is the most efficient therapy for spinal cord injured. Again, one can question if this is an intervention that social workers should offer or supply. With the presence of psychologists in the treatment teams, I suggest it is not. Social workers are primarily educated in the societal services offered to citizens but that does not exempt the use of talks (not therapy) based on cognitive behaviour therapy. Considering the primary focus of the education of social workers, I have not found any guidelines or standards on how social workers should work with spinal cord injured regarding societal services. It is remarkable as there are many interventions that a social worker could undertake during the initial trimester in the hospital. Considering the sometimes long handling of cases at different societal authorities much valuable time could be saved if social workers knew what to do.

The American Association of Spinal Cord Injury Psychologists and Social Workers (AASCIPSW) has published their standards on Internet. The purpose of the standards is to promote better outcomes for persons with spinal cord injury through “providing the highest quality of psychosocial care”. The standards of AASCIPSW give directives on code of conduct, education levels, and interventions among others. A social worker is defined as “a professional who has a degree of Master of Social Work from an institution accredited by the Council of Social Work Education and meets applicable legal requirements.” (AASCIPSW, 2005, p. 8). AASCIPSW suggest a comprehensive spinal cord injury rehabilitation program where the patient is included in creating the treatment plan. The basic components of psychosocial programs should consist of the following items: 1) orientation, 2) assessment, 3) treatment plan, 4) interventions, 5) discharge, 6) monitoring and follow-up. The information provided in the standards is comprehensive and detailed as on how a social worker should help spinal cord injured. The information is not based on evidence but on experience and surveys among organisations for spinal cord injured as well as spinal cord injured. This does not in any way diminish its importance as a guideline. Such guidelines could be outlined and adapted also for the Nordic countries.

As a final note, I would like to add my interest in the outcomes of spinal cord injured children. Research shows that age is an important factor for a positive outcome of spinal cord injury. Consequently, I would be very much
interested in information on children’s experience of a spinal cord injury, psychological outcomes and coping strategies and societal services provided for these children.

4.6. Discussion of method

My ability to find relevant articles is limiting as I have no previous experience in research. Another limit is the number of articles and books included this thesis.

I am aware that a meta-analysis could have been made instead of a literature review. However, that is not the intention with writing the thesis. The purpose is to find some guidelines (literature) on best evidence on how to help spinal cord injured patients. A meta-analysis would demand having knowledge of different methods on helping these patients, finding evaluation research of these methods and then quantifying the results. I do not have such knowledge of methods and that is the point of my thesis: to explore what there is.

4.7. Conclusion

Here are some important findings from the literature review:

- Spinal cord injured have an increased risk of anxiety and depression. Suicide risk is four to five times higher that for able-bodied persons.

- Anxiety and depression are not inevitable consequences of a spinal cord injury. If the patients receive sufficient support from the social environment, there is a good chance of a positive accommodation of the new situation.

- Before offering any interventions (e.g. therapy, architectural changes to the house) an assessment of issues has to be made. Without a thorough assessment of problem areas, an intervention could be harmful and counterproductive.

- Coping strategies can have both positive and negative outcomes for the patient. The coping strategy acceptance leads to increased emotional well-being. The coping strategy self-neglect can lead to pressure wounds.

- Social and societal support is important to spinal cord injured. A supportive social environment decreases the risk of depression and self-neglect. It also increases the subjective well-being. Social support is a form of coping assistance.

- Hospital staff may overestimate the patient’s emotional and social problems. Patient’s are not always depressed or have social problems as a consequence of a spinal cord injury.

- Hospital staff may underestimate the patient’s use of coping activities. The patient’s have a vast array of coping activities that they can and will use when hospital staff is not available.

- Cognitive-behaviour based therapies have been proven effective in treating spinal cord injured. CBT is a tool in helping patients making the right choice of coping strategies and applying them.
Independence and peer support are important to spinal cord injured patients. The more spinal cord injured patient’s have to rely on other people, the more dissatisfied they are. Independence and freedom are very important to spinal cord injured. Peer support is usually inspiring to newly injured patients. The form a new group with whom they can relate to.

Spinal cord injured in Sweden and Finland are not satisfied with societal support. In Sweden, the patients were dissatisfied with the societal lack of support and information provided. Lack of co-ordination between authorities was also a matter of concern. In Finland, the patients were critical of the lack of quality in the health care services provided at local health care centers.
5. Glossary

5.1. Locus of control

The locus of control is a concept in psychology, originally developed by Julian Rotter. People tend to ascribe their chances of future successes or failures either to internal or external causes. Persons with an internal locus of control see themselves as responsible for the outcomes of their own actions. These individuals often believe that they control their destiny, and are often observed to excel in educational or vocational realms. Someone with an external locus of control, on the other hand, sees environmental causes and situational factors as being more important than internal ones. These individuals would be more likely to see luck rather than effort as determining whether they succeed or fail in the future, and are more likely to view themselves as the victim in any given situation. (Wikipedia, 2005b).

5.2. Positive psychology

Positive psychology is a term coined by Abraham Maslow and adopted by psychologist Martin E.P. Seligman. A movement in psychology which emphasises what is right with people rather than what is wrong with them. Psychology tends to be about negative things - anxiety, depression, stress. It is typified by the DSM-IV, a systematic categorisation of mental illnesses. Positive psychology is an attempt to redress the balance, to encourage psychologists to try to contribute to positive aspects of life, not just do something about negative things. Among its aims is to produce an "anti-DSM" of strengths and virtues that are found in the happiest people, but most of all, to enable more people to live lives filled with greater health and well-being as well as the absence of illness and disease, which is a state of "Flourishing" as defined by the sociologist/social psychologist, Corey L. M. Keyes. An important feature of positive psychology is its rejection of moral relativism. (In philosophy, moral relativism is the position that moral or ethical propositions do not reflect absolute and universal moral truths but instead are relative to social, cultural, historical or personal references, and that there is no single standard by which to assess an ethical proposition's truth.) This is based on the observation that certain character traits and ways of acting are considered good by the vast majority of cultures. It is also observed that these traits lead to increased happiness when practised. Another important feature is a distinction between physical pleasure and the gratification of becoming lost in the flow of a task that engages ones abilities (Wikipedia, 2005c).

5.3. Post traumatic stress disorder

Post-traumatic stress disorder is a term for the psychological consequences of exposure to or confrontation with stressful experiences, which involve actual or threatened death, serious physical injury or a threat to physical and/or psychological integrity and which the person found highly traumatic. It is occasionally called post-traumatic stress reaction, to emphasise that it is a fairly normal result of a traumatic experience, rather than a manifestation of a pre-existing psychological weakness on the part of the patient. Symptoms can include re-experiencing phenomena such as nightmares and flashbacks, emotional detachment or numbing of feelings combined with regular hyper-arousal and possibly sleep abnormalities (insomnia), avoidance of reminders and extreme distress when exposed to the reminders ("triggers"), with irritability and excessive startle (Wikipedia, 2005d).
5.4. Sense of coherence

The sense of coherence is the central concept of the Salutogenic Model developed by Aaron Antonovsky. The basis of the model is a focus on health (salutogenesis) rather than illness (pathogenesis). A very simple way of describing it is: “What keeps me healthy?” (salutogenesis) instead of “Why am I ill?” (pathogenesis). Lustig (2005, p. 148) writes that sense of coherence is a meaning-making construct. Sullivan (1993, p. 1773) quotes Antonovsky when defining the sense of coherence:

“global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected”

5.5. Subjective well-being

Subjective well-being (SWB) is an aspect of psychological well-being and is defined as how a person evaluates his/her happiness. The evaluation includes variables such as life satisfaction, marital satisfaction, lack of depression and anxiety, and positive moods and emotions. A person's evaluation of his or her life may be in the form of cognitions (when a person gives conscious evaluative judgements about his or her satisfaction with life as a whole, or evaluative judgements about specific aspects of his or life such as recreation). However, an evaluation of one's life also may be in the form of affect (people experiencing unpleasant or pleasant moods and emotions in reaction to their lives). The cognitive and affective components of SWB are highly interrelated (Diener, 2005).
6. References


## 7. Appendix 1 – Excluded articles/books

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Where to find the article/book</th>
<th>Reason for exclusion</th>
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<tbody>
<tr>
<td>Chan, Lee &amp; Lieh-Mak</td>
<td>The pattern of coping in persons with spinal cord injury</td>
<td>Disability and Rehabilitation, 2000, 20, 22, (11), 201-207</td>
<td>Focus on the particular traits of the Chinese culture.</td>
</tr>
<tr>
<td>Chapin, Miller, Ferrin, Chan &amp; Rubin</td>
<td>Psychometric validation of a subjective well-being measure for people with spinal cord injuries</td>
<td>Disability and Rehabilitation, 2004, 24, (19), 1135-1142</td>
<td>Focus on a psychometric measurement tool.</td>
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<td>Hammell</td>
<td>Quality of life among people with high spinal cord injury living in the community</td>
<td>Spinal Cord 2004, 41, (11), 607-620</td>
<td>Focus on experiences of living in the community as a spinal cord injured.</td>
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<td>Author(s)</td>
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