

## Original Article

# Life situation of spinal cord-injured persons in Central Finland

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**Study design:** Individual interview and questionnaire of a regional spinal cord-injured (SCI) population.

**Objective:** Local health care centres are mainly responsible for the SCI patients health care and rehabilitation after initial hospitalization in Finland. The purpose of the present study was to study aspects of the SCI patients life situation and their opinion of the health care services after 1 year since the injury.

**Setting:** Regional study in Central Finland.

**Methods:** Subjects were individually interviewed in their homes using a semi-structured questionnaire, the Functional Independence Measure (FIM) and the Beck Depression Inventory (BDI).

**Results:** The female/male ratio was 1:4. The mean age at the time of injury was 34 years in female and 40 in male. Traffic accidents accounted for 46% of the injuries. In all, 48 subjects (63%) used electrical or manual wheelchair or both. Most subjects regarded their living conditions as good having enough personal assistance in their everyday life. Only 10% of the subjects were employed. Half of the subjects had had out-patient physiotherapy, but no other therapies after 1 year since the injury. More than half of the subjects were dissatisfied with the current health care services. Many had experienced complications after the initial hospitalization, especially urinary tract infections, decubitus ulcers and neurogenic-type pain. FIM classified well according to the disability groups. The motor complete tetraplegic group had the lowest mean scores (63) and the recovered group the highest ones (122). There was no association between the FIM and the BDI results. There was a correlation between the BDI and the subject's age at the time of the injury and the year of the injury. The older the subjects were when injured, the higher were the BDI scores, that is, they had more depressive symptoms. Those injured in the 1990s had the highest BDI scores. Nearly one-third of the subjects had mild, moderate or severe depression.

**Conclusions:** The reported medical complications, depression and dissatisfaction with the health care services support a life-long care for SCI patients in Jyväskylä Central hospital, not in the local health care centres. The psychological services, for example, prevention and treatment of depression, in particular, require more attention.

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**Keywords:** spinal cord injury; life situation; medical complications; functional independence; depression; health care

## Introduction

Although the incidence of spinal cord injury (SCI) is relatively low, the estimated aggregate costs to society are high. Few injuries result in more profound and long-term disability than SCI. The injury means not only loss of mobility but also changes in the vital functions as well. The disturbances of bladder and bowel or sexual

functions may restrict the social life and cause psychological distress.

There are epidemiological surveys of SCI all over the world.<sup>1–5</sup> There are also some studies of SCI in Finland,<sup>6–12</sup> but the exact number of the SCI patients in this country is not known. It has been estimated that there are approximately 2000 traumatic SCI patients in Finland.<sup>8</sup> The annual incidence rate of SCI is about 11 per million population,<sup>7</sup> which is less than it has been reported in other countries.<sup>1,2,4,5</sup>

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The main causes of SCI have been reported to be events involving motor vehicles and falls.<sup>1-7</sup> The SCI occurs more frequently among males than females.<sup>1-7</sup> The mean age of the SCI patients at the time of the injury is over 40 years,<sup>1,5</sup> but SCI occurs more frequently among those between the ages of 15 and 30 years.<sup>2,3</sup> Psychological distress is not an inevitable consequence of SCI. If anxiety and depression exist, they are maintained over time and the intensity does not decrease.<sup>13-16</sup> But it has also been suggested that depression is most common in the acute phase of the injury and during the months after discharge.<sup>17</sup> Persons with incomplete SCI might have more distress than those who have complete SCI, possibly due to expectations of full recovery.<sup>18</sup> However, it is also supposed that depression is independent on the level of injury.<sup>19</sup>

Finland is divided into 20 health care districts, which have central hospitals of their own. These are responsible for the acute and the operative care of SCI. The initial rehabilitation usually takes place in Käpylä rehabilitation centre in Helsinki, where some 55 new traumatic SCI patients have their rehabilitation every year. Later on, local health care centres and central hospitals are responsible for the life time care of SCI patients.

The population of the province of Central Finland is about 260 000, that is, 5% of that in Finland. All the SCI patients within this catchment area are initially treated in Jyväskylä Central Hospital. There are 12 local health care centres for the basic health care in the area.

Most SCI patients live in their own homes and the local health care centres are responsible for the health care and rehabilitation. Usually, the staff does not have enough know-how on SCI problems in the health care centres. The purpose of the present study was to study aspects of the SCI patients' life situation, depression and their opinion on health care and to clarify the exact number of the SCI patients living in Central Finland.

## Methods

Permission to establish the research programme was granted by the Ethics Committee of the Central Finland Health Care District and the Ministry of Social Affairs and Health in Finland.

### *Subject identification*

The study group comprised persons 16 years or older with SCI when 1 year or more has passed since the injury and they were living within the catchment area of Jyväskylä Central Hospital. Subjects were selected from the discharge register and from the files of the health care centres. All subjects thus identified were sent a questionnaire where the purpose of the study was explained. After that the researcher contacted the subjects by phone to confirm the participation in the study.

### *Data collection*

The study was conducted by individual sessions in the subjects' homes by the researcher. The semi-structured questionnaire was filled during the visit. The questionnaire used in the present study was a slightly shortened version of the uniform data collection system performed by a Swedish group of specialists in the care of SCI.<sup>20</sup> In this study, the questions were divided into eight sections; motor function/technical aids, living conditions/family, personal assistance, education/occupation, leisure time, rehabilitation/health care, medical problems and pain. The researcher assessed the level of disability by using the Functional Independence Measure (FIM),<sup>21</sup> which includes 18 items grouped into six categories: self-care, sphincter control, mobility, locomotion, communication and social cognition. Each of the 18 items has a 7-point scale, with 1 corresponding to complete dependence and 7 to complete independence. The maximum score of 126 means that the person is totally independent. The subjects completed the Beck Depression Inventory (BDI),<sup>22</sup> which has 21 items dealing with mood. The maximum score is 63. We used the cut-scores according to Kendall *et al*:<sup>23</sup> 0-9 normal, 10-19 mild depression, 20-30 moderate depression, 31-63 severe depression. Data collection were performed between June 1997 and December 1997. The groups were compared with *T*-test and one-way ANOVA. Correlations between variables were calculated according to Spearman.

## Result

Out of the 93 subjects, 76 (82%) participated in the study. In all, 17 persons (18%) either refused or the researcher did not manage to contact them. Overall, 59 subjects (78%) were male and 17 (22%) were female. Age characteristics of the subjects are described in Table 1. The mean age at injury was 40 in male and 34 in female. The incidence of SCI was highest among male and female aged 16-30 years.

The causes of injury are reported in Table 2. Traffic accidents accounted for 46% of the injuries and falls 36%. Traffic accidents included both motor vehicle and bicycle accidents. Falls included falls from a height and falls on a level ground. Table 3 describes the aids for locomotion indoors and outdoors. In total, 48 subjects (63%) used electrical or manual wheelchairs or both.

### *Life situation*

More than half of the subjects were married and had children. Nearly one-third of them had children after the injury. Most subjects (91%) lived either in a one-family house, in a terraced house or in a block of flats. Three dwelled in a service home for disabled, two in a home for the aged and one in a rehabilitation home. Nearly all regarded their living conditions as good despite the functional deficiency. In addition to good accommodation, the suitable aids for daily living and personal assistance made it possible for them to live at home. Personal assistance was mainly arranged by a spouse or

**Table 1** Demographic data of traumatic SCI patients in Central Finland in 1997

<i>Age at contact (years)</i>	<i>Female (n = 17)</i>	<i>%</i>	<i>Male (n = 59)</i>	<i>%</i>
16–30	2	11.8	2	3.4
31–45	6	35.3	20	33.9
46–60	3	17.6	19	32.2
61+	6	35.3	18	30.5
Mean (years)	49 ± 16		51 ± 14	
Range	20–74		24–81	
<i>Age at injury (years)</i>	<i>Female (n = 17)</i>	<i>%</i>	<i>Male (n = 59)</i>	<i>%</i>
0–15	2	11.8		
16–30	7	41.2	23	39.0
31–45	2	11.8	14	23.7
46–60	4	23.4	15	25.4
61+	2	11.8	7	11.9
Mean (years)	34 ± 20		40 ± 15	
Range	5–67		19–74	
<i>Year of injury (decade)</i>	<i>Female (n = 17)</i>	<i>%</i>	<i>Male (n = 59)</i>	<i>%</i>
1950–1959	1	5.8		
1960–1969	2	11.8	4	6.8
1970–1979	2	11.8	10	16.9
1980–1989	5	29.4	16	27.1
1990–1996	7	41.2	29	49.2

**Table 2** Causes of traumatic SCI in Central Finland

<i>Causes</i>	<i>No.</i>	<i>%</i>
Transport accident	35	46.1
Fall	27	35.6
Diving	6	7.9
Falling object	3	3.9
Occupational accident	2	2.6
Sport	1	1.3
Shooting accident	1	1.3
Suicide attempt	1	1.3

another relative, home help or a personal assistant (Table 4). One-third of the wheelchair users had their relatives as the only assistant, but only few of them found their relatives overloaded. The average working time of the personal assistant was 61 h a week for the wheelchair users. Besides a visiting nurse or a home help visited those who lived alone. During the nights they had security telephones. Nearly all subjects found that they had enough personal assistance in their everyday life.

Only 10% of the subjects were employed. The most common reasons for retirement were severity of the

**Table 3** Technical aids for locomotion indoors and outdoors of traumatic SCI patients in Central Finland

<i>Inside</i>	<i>No.</i>	<i>%</i>
Wheelchair	42	55.3
Electrical wheelchair	9	11.8
Crutches	5	6.6
Four-wheeled walker	3	3.9
Walking stick	3	3.9
Lower extremity braces	2	2.6
Other	2	2.6
<i>Outside</i>		
Wheelchair	39	51.3
Electrical wheelchair	12	15.8
Crutches	6	7.9
Walking stick	2	2.6
Four-wheeled walker	1	1.3
Lower extremity braces	1	1.3
Other	9	11.8

**Table 4** Personal assistance of traumatic SCI in Central Finland

<i>Assistance</i>	<i>No.</i>	<i>%</i>
Relatives	41	61.2
Home help	17	25.4
Personal assistant	16	23.9
Visiting nurse	13	19.4
Friends	11	16.4
Staff of the service house	4	6.0
Other	11	16.4

injury, lack of professional education or old age. Despite the retirement nearly half of the subjects regarded their own economy as good.

#### Rehabilitation

Rehabilitation after 1 year since the injury had consisted of institutional rehabilitation for 2–4 weeks and outpatient physiotherapy by the time of the study contact. None of the subjects had had domiciliary occupational or psychological therapies. Half of the subjects had one or two physiotherapy sessions weekly and less than one-third had institutional rehabilitation annually or every other year. One-third of the subjects thought that they should have more physical rehabilitation.

#### Health care services

Two-thirds of the subjects had met a physician at least once during the last year because of the SCI. Totally, 15% had visited a doctor more often than five times. Only 39% had an urologist's follow-up annually or every other year. More than half of the subjects regarded the

physicians' and nurses' know-how on SCI problems as poor. The percentage was even higher among wheelchair users (70%). Nearly 80% of the subjects found that a specialized spinal cord unit with all the modern information should be needed. It should take place at Jyväskylä Central Hospital, that is, the place of the initial hospitalization.

#### Medical problems

Table 5 shows the incidence of medical problems at the time of the study contact and the causes of medication. Nearly half of the subjects reported to have neurogenic pain nearly every day, but only one-fourth of the subjects had longer-standing muscle pain in the upper limbs nearly every day. Neurogenic pain harmed their lives more than muscle pain. However, the incidence of pain problems was 37%. Those who used wheelchair had skin problems. More than half of them (60%) had had decubitus ulcers after the injury. Overall, 23% of the wheelchair users had decubitus ulcer that needed medical treatment at the time of the contact, but most of the wheelchair users told the dermatological symptoms did not harm their lives much. Three-fourths of the

**Table 5** Incidence of medical problems and causes of medication at contact

Problem	No.	%
Loss of mobility	46	64.8
Bladder	33	46.5
Pain	26	36.6
Bowel	25	35.2
Sexual function	18	25.7
Skin	12	16.9
Spasticity	11	15.5
Other	21	29.6
<i>Medication</i>		
Urinary tract infection prophylactic	38	50.0
Pain	27	35.5
Spasticity	20	26.3
Insomnia	21	27.6
Depression	11	14.5
Other	42	55.3

subjects had experienced an urinary tract infection after the initial discharge. Half of the subjects had suffered from at least one urinary infection during the last year. More than half of the subjects said that bladder problems disturbed their lives. The most often used medication was a urinary tract infection prophylactic. Sexual problems were mostly experienced by young men. Beside the sexual organ dysfunction, lack of tactile sensation, physical disability and bladder and bowel dysfunction caused problems in sexual life. The main problem was the loss of locomotion. Most subjects were dependent on technology aids and personal assistance in their everyday lives. However, 67% of the subjects exercised regularly and went outdoors almost every day. The most popular exercises were wheelchair jogging, swimming, body building, cycling and walking for those who could walk.

#### Functional independence

The subjects were divided into five groups using our own classification:

Group 1: Motor complete tetraplegic, Group 2: Motor complete paraplegic, Group 3: Motor incomplete tetraplegic (motor useful), Group 4: Motor incomplete paraplegic (motor useful), Group 5: Recovered. Table 6 shows the FIM scores in these groups. There were statistically significant differences between the groups. The motor complete tetraplegic group had the lowest scores and the recovered group the highest ones.

#### Depression

There were 11 subjects (14%) who could not or did not want to complete the BDI. The BDI scores varied between 0 and 37. There were four (19%) women and 16 (24%) men who had more than nine points, but there were no significant differences between the sexes. One person scored over 30 and two had over 20. When the subjects were divided according to the classification of the disability, there was a significant difference in the BDI between the motor incomplete paraplegic group and the recovered group ( $P < 0.05$ ) (Table 6). There was no association between the BDI and the FIM scores. However, there was an association between the BDI and the subject's age at the time of the injury ( $r = 0.35$ ,

**Table 6** Mean scores of the Functional Independence Measure (FIM) and the Beck Depression Inventory (BDI) in different groups according to the classification of the disability

Index	1 = Motor complete tetraplegia (n = 21-17)	2 = Motor complete paraplegia (n = 19-18)	3 = Motor incomplete tetraplegia (n = 11)	4 = Motor incomplete paraplegia (n = 15-12)	5 = Recovered (n = 10-7)
FIM scale 0-126	63.0 (*2,3,4,5)	107.3 (*4,5)	112.4	118.6	122.0
BDI scale 0-63	6.6	7.4	9.1	11.3 (*5)	4.4

\* $P < 0.05$  and the group number compared are in parentheses

$P < 0.01$ ) and the year of the injury ( $r = 0.52$ ,  $P < 0.01$ ). The older the subject was when injured, the higher were the scores. Among those injured between the age of 46 and 60 years, the mean BDI score was 11.6 and among the injured when over 60 years 9.4. Those who had been injured in the 1990s had higher BDI scores than those who had injured during the earlier years ( $P < 0.001$ ). There were also an association between the BDI and physical exercise activity ( $r = -0.24$ ,  $P < 0.05$ ). Those who were active had less-depressive symptoms than the inactive subjects.

## Discussion

The register used in the present study was a computerized data bank which contains registration of all-cause total intraregional inpatient treatment in Jyväskylä Central Hospital since 1980. The health care centres had no computerized data bank and only few SCI subjects were found from the files of the physiotherapists and visiting nurses. Because of these restricted registers some SCI subjects might be missed in our study.

It has been estimated that there are approximately 2000 traumatic SCI patients in Finland.<sup>9</sup> Thus, there should be about 100 traumatic SCI patients living within the catchment area of Jyväskylä Central Hospital. The number of SCI subjects was 93 according to the registers available. There was a drop-out of 17 subjects (18%) in this study. Nevertheless, the total number of the subjects in this study can be regarded as a representative sample of all the SCI patients in the catchment area.

The level of disability was evaluated by using our own classification based loosely on the Frankel classification system.<sup>24</sup> Motor functions were evaluated below the lesion. Those who had useful motor functions below the lesion were classified into incomplete tetraplegic or paraplegic groups, and those who had useless motor functions were categorized into the complete tetraplegic or paraplegic groups. Those who had no neurological problems left were regarded as recovered. The American Spinal Injuries Association (ASIA) has a similar grading system, but they have also developed a scoring system using key muscle groups and dermatome sensory testing. This system was not used in our hospital and therefore not used in the present study, either.

The FIM has been developed for rehabilitation patients with varying disabilities. It has been reported that the increase in the FIM scores is greatest between hospital admission and discharge and slower improvement continues 1 year after the SCI.<sup>25,26</sup> Later, there are rarely any changes in the scores.<sup>25</sup> Beside the ASIA motor score the FIM has been shown to be useful in functional assessment of patients with an SCI.<sup>25</sup> The level of functional independence was evaluated 1 year or more after the injury in the subject's home in the present study. At that time, most subjects should have reached the plateau scores, but there were significant differences between the disability groups. The testing situation

was different at home than it would have been in the rehabilitation centre or in the hospital. However, FIM classified the disability groups well and it is a useful tool to evaluate the functional independence even at home.

Nearly one-third of the subjects who completed the BDI had mild, moderate or severe depression, but only one-sixth of the subjects used antidepressive medication. Those who were injured in the 1990s had the highest scores in BDI. The BDI scores associated significantly with the subject's age at the time of the injury. The older the subject was when injured, the higher were the scores. The age group between 46 and 60 had the highest scores and perhaps had more difficulties in adapting to disability. There were no correlation between the BDI and FIM scores. It has been reported that the level of lesion or the completeness of lesion is not related to long-term depression in SCI patients.<sup>27</sup> It was the same in the present study. The only exception was that the motor incomplete paraplegic group differed significantly from the recovered group. However, both the motor incomplete tetraplegic and paraplegic groups had mean scores over nine in the BDI. They possibly had expectations of full recovery and the failure of that led to depression. Our findings support the hypothesis that the neurologically incomplete SCI patients are more distressed than the complete SCI patients.<sup>18</sup>

It has been reported that higher frequency of sports activity in SCI patients reflects better psychological status, especially reduction of depression.<sup>28</sup> In the present study, those who exercised three times a week or more had lower scores in BDI than those who exercised less frequently. Sports activity and physical exercise may reduce depression.

The psychological needs are often neglected. The staff pays more attention to the medical and physical deficits in the hospitals. Our study justifies the provision of psychological services for all SCI patients in the acute phase of the injury as well as later.

Most subjects lived in their own homes. They had suitable technical aids for daily living and enough personal assistance. It was surprising that there were so few who lived in service homes or in homes for the aged and no one was placed in any hospital. It is common in Finland that seriously disabled persons live in their own homes. The local municipality and hospital are responsible for the suitable aids and assisting staff. Our study showed that the SCI patients in Central Finland were satisfied with the current living conditions, personal assistance and technical aids.

It has been reported that the paraplegic patients in Finland are more seldom at work than in other countries.<sup>12</sup> Only 10% of the SCI subjects were at work in the present study. The most common reason for retirement was the severity of the injury. One of the best predictors of returning to work is educational attainment.<sup>12,29</sup> Nearly half of the subjects in the present study had no professional education. Most of the retired subjects were not even interested in returning to work.

The social security in Finland is relatively good, which might partly explain the low motivation to return to work. However, patients need time to adapt themselves before they are ready for vocational rehabilitation. It is not realistic to expect active vocational planning to occur during the initial hospitalization or rehabilitation. It has been estimated that vocational development begins to plateau after 18 months, generally falling below the level before injury.<sup>29</sup> Strengthening of vocational counselling services should be considered at this time.<sup>29</sup>

Urinary tract infections and decubitus ulcers are common complications among SCI patients<sup>30</sup> and are the two main reasons for hospital readmissions.<sup>31</sup> Nearly all the subjects who used wheelchair in this study had had urinary tract infection, even though three-fourths of them used an infection prophylactic. More than one-third of them used intermittent self-catheterization, which has been found to increase the risk of bacteriuria.<sup>32</sup> In the present study, only 39% of the subjects had follow-up annually or every other year by an urologist.

There are plenty of risk factors for pressure ulcers.<sup>33</sup> It has been estimated that as many as 85% of SCI patients develop a pressure ulcer at some point during their lifetimes.<sup>34</sup> Their annual incidence among SCI patients is about 23%.<sup>30</sup> In the present study, 23% of the wheelchair users had a pressure ulcer, which needed medical treatment.

More than half of the SCI subjects in the present study were dissatisfied with the physicians' and nurses' know-how on SCI problems. In Central Finland, the health care centres are responsible for the treatment of SCI patients when 1 year has passed after the injury. Usually, there are only few SCI patients living in the same area and the health care centres do not have enough information on treatment of the SCI patients. Most subjects in this study found that a specialized spinal cord unit with all the modern information should be needed. It might take place in Jyväskylä Central Hospital. Thus, it would be possible to have a regular physical examination and evaluation for every SCI patient. A specialist unit could offer physical, psychological and social support 'under one roof'.

## Conclusions

The SCI patients in Central Finland were satisfied with the current living conditions, personal assistance and technical aids. Their economy was rather good although most of them were retired after the injury. They had had enough rehabilitation after the initial hospitalization. Urinary tract infections and pressure ulcers were common.

Most SCI patients were dissatisfied with the fact that the health care centres are responsible for the treatment of SCI patients after 1 year has passed since the injury. They would prefer a specialized spinal cord unit in Jyväskylä Central Hospital.

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