Functional outcome after spinal cord injury
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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2003

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):
Chapter 2

Rehabilitation of spinal cord lesions in The Netherlands: an epidemiological study

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Spinal Cord 1996;34:679-683

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Abstract

Very little is known about the occurrence of spinal cord lesions and results of rehabilitation in The Netherlands. This study was conducted to describe the process of rehabilitation treatment in the Dutch situation, to assess the incidence of spinal cord lesions in a regional rehabilitation centre and to characterise differences between traumatic and non-traumatic spinal cord lesions regarding age, level and extent of lesion.

In this study 293 patients were included who were admitted to the rehabilitation centre between 1982 and 1993. Sixty-six per cent of this group came from the university hospital. The mean length of stay in the rehabilitation centre was 154 days. After completing the rehabilitation programme 94% of patients went home. Sixteen new SCI patients per million per year were admitted to the rehabilitation centre. Of our group 52% had a non-traumatic lesion, which concerned older patients with more incomplete lesions.

In our opinion close collaboration between the university hospital and the rehabilitation centre is needed for optimal rehabilitation treatment. Attention to independent living programmes and appropriate housing facilities can shorten the length of stay and increase the number of discharges of patients to the own environment. For patients with non-traumatic spinal cord lesions special programmes should be made available.
Introduction

Spinal cord injury (SCI) leads to a fundamental change of life of the injured. It has many medical, emotional and social consequences for the patient, so multidisciplinary management is essential. SCI regional care systems have been established in a few countries\(^1\,^2\,^3\). In The Netherlands patients with acute SCI are admitted to traumatological, orthopedic, neurological and neurosurgical departments of university and general hospitals. As soon as the physical condition is stable they are transferred to one of the rehabilitation centres with a specialised department for spinal cord lesion care. If possible, patients go home after their inpatient rehabilitation period. In this study we investigated the leading role of the university hospital in taking care of SCI patients as a co-ordinating centre for a specific region. Length of stay in the rehabilitation centre was examined. Especially, we wanted to know the number of patients actually going to their home situation as being a goal of rehabilitation.

Many epidemiological studies present the incidence of SCI and analyse characteristics of the patients. Over the world the incidence of SCI varies from 9 to 53 per million inhabitants per year\(^4\). We will assess the incidence and characteristics of patients with SCI in the Dutch situation. International literature focuses on traumatic SCI. However, in European studies non-traumatic lesions form 25 to 39 per cent of all spinal cord lesions\(^5\,^6\,^7\). Characteristics of patients with non-traumatic spinal cord lesions differ from those with traumatic lesions. Analysis of these groups is also a subject of this study.

Methods

This retrospective study is based on data of 293 patients with spinal cord lesions admitted to the rehabilitation centre Beatrixoord in the period from 1982 to 1993. The SCI department accepts patients with acute and prolonged spinal cord lesions, who are suitable and motivated for a rehabilitation programme. A spinal cord lesion was defined as an acquired transverse lesion of the spinal cord and cauda equina, resulting in loss of motor and sensory function below the level of lesion and dysfunction of bladder and bowel\(^8\,^9\). Patients with systemic, demyelinating or degenerative diseases of the central nervous system, such as multiple sclerosis, and congenital diseases of the spinal cord, such as spina bifida, were excluded in this study. Patients with prolonged spinal cord lesions who had their first rehabilitation admission before 1982 or in another rehabilitation centre were also excluded. The data we obtained from the medical records include age, sex, neurological level and extent of the lesion, causes of SCI, hospital of origin, duration of hospitalisation of first admission and destination after discharge.

Revisions of the standards for neurological classification of spinal cord injured patients are made regularly by the American Spinal Injury
According to these standards we defined the neurological level of lesion as the most caudal intact segment of the spinal cord. The extent of the lesion was measured at the time of discharge. A complete lesion was defined as a SCI with no preserved motor or sensory function below the level of injury; an incomplete lesion as an injury with some motor and/or sensory function below the level of lesion. As collection of data started in 1982 we based our definitions on those of the American Spinal Injury Association of 1982.

Etiology of SCI was divided into traumatic and non-traumatic causes. Patients were transferred from university or general hospitals, mainly from the three northern provinces. Mean length of stay of 261 patients who completed the rehabilitation programme was determined. After discharge they went home or were transferred to a nursing home or to a semi-independent living situation.

Data analysis was done by SPSS/PC programme, descriptive statistics were used to characterise the study sample.

Results

Rehabilitation routing of SCI patients

Of 293 patients admitted to the rehabilitation centre after the acute phase 66% were referred from the Groningen University Hospital (GUH). The others came from smaller general hospitals in the northern provinces (26%) or other hospitals in the Netherlands (8%). From 1982 to 1993 there was no noticeable change in the number of GUH patients.

The characteristics of 193 patients from the university hospital were compared with those of 75 patients from the northern general hospitals. Patients from the GUH were on average younger with a mean age of 41.6 years as opposed to 56.2 years of patients from general hospitals. Patients younger than 40 years ($n=117$) had their acute phase of management after SCI in the university hospital in 89% of the cases, while 59% of patients older than 40 ($n=151$) were transferred from the GUH. The GUH group consisted of slightly more complete lesions (26% versus 19%). Patients with cervical lesions ($n=108$) came from the GUH in 69% of the cases, patients with lower lesions ($n=160$) in 74%. Patients with traumatic SCI ($n=129$) came from the GUH in 86% of the cases, patients with tumour ($n=49$) in 57%, with vascular causes ($n=36$) in 47% and with spinal degenerative causes ($n=44$) in 70% of the cases.

The length of first admission in the rehabilitation centre Beatrixoord after the onset of the spinal cord lesion varied from 1 day to 648 days. To determine the mean length of stay of the completed inpatient rehabilitation periods we excluded three patients who died, 11 patients who were admitted shorter than 8 days and 18 patients who were transferred to hospitals or other rehabilitation centres. Of the remaining 261 patients the mean length of stay was 154 days. There was a tendency that younger people stayed longer than
the older patients. Regarding sex there was no difference in length of stay. Complete cervical lesions led to the longest mean rehabilitation period of 296 days. The mean length of stay of patients with complete lesions was 244 days as opposed to 122 days for patients with incomplete lesions. Traumatic SCI led to an average admission of 205 days, while patients with myelopathies caused by tumour or degenerative changes of the spine stayed about 85 days. Six patients who went to semi-independent living situation stayed on average 312 days. There was no difference between patients who went home or who went to nursing homes (150 days).

In this period 261 patients completed their rehabilitation in our centre. Of this group 244 patients (94%) went home after the inpatient rehabilitation period. Eleven patients (4%) did not become independent enough to go home despite the intensive programme and went to nursing homes; three of them were younger than 40 years, two between 41 and 60 years of age and eight patients had cervical lesions. For six patients a place was found in a semi-independent living situation.

Figure 1. Distribution over age groups of patients with traumatic and non-traumatic spinal cord lesions ($n = 293$)
General characteristics
During twelve years 293 new cases of SCI were admitted to the rehabilitation centre. This means 16 new cases per million per year for a population of 1.5 million inhabitants. The male-female ratio was 2.2 : 1. The mean age at admission to the rehabilitation centre is 45.1 years. Most patients were in age groups 21 to 40 and 61 to 70 years (Figure 1). Regarding the level and extent of lesion 41% had a cervical lesion, 9% a complete cervical lesion. There was no noticeable trend in the number of cervical lesions during these 12 years.

Table 1. Characteristics of patients with non-traumatic spinal cord lesions as opposed to patients with traumatic lesions (n=293).

<table>
<thead>
<tr>
<th></th>
<th>Non-traumatic</th>
<th>Traumatic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=151</td>
<td>n=142</td>
</tr>
<tr>
<td>Sex: Males</td>
<td>93</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>61.6%</td>
<td>76.8%</td>
</tr>
<tr>
<td>Females</td>
<td>58</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>38.4%</td>
<td>23.2%</td>
</tr>
<tr>
<td>Extent / level:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>20</td>
<td>58</td>
</tr>
<tr>
<td>- cervical</td>
<td>3</td>
<td>24</td>
</tr>
<tr>
<td>- thoracic</td>
<td>16</td>
<td>29</td>
</tr>
<tr>
<td>- lumbar/conus-cauda</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>13.2%</td>
<td>40.8%</td>
</tr>
<tr>
<td></td>
<td>2.0%</td>
<td>16.9%</td>
</tr>
<tr>
<td></td>
<td>10.5%</td>
<td>20.4%</td>
</tr>
<tr>
<td></td>
<td>0.7%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Incomplete</td>
<td>131</td>
<td>84</td>
</tr>
<tr>
<td>- cervical</td>
<td>52</td>
<td>42</td>
</tr>
<tr>
<td>- thoracic</td>
<td>54</td>
<td>16</td>
</tr>
<tr>
<td>- lumbar/conus-cauda</td>
<td>25</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>86.8%</td>
<td>59.2%</td>
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<td></td>
<td>34.4%</td>
<td>29.6%</td>
</tr>
<tr>
<td></td>
<td>35.8%</td>
<td>11.2%</td>
</tr>
<tr>
<td></td>
<td>16.6%</td>
<td>18.4%</td>
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<tr>
<td>Discharge:</td>
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<td></td>
</tr>
<tr>
<td>Premature</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>12.6%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>5.3%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Semi-independent</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>2.6%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Home</td>
<td>119</td>
<td>125</td>
</tr>
<tr>
<td></td>
<td>78.8%</td>
<td>88.0%</td>
</tr>
</tbody>
</table>

Traumatic versus non-traumatic spinal cord lesions
In our rehabilitation centre more than half of the population had a non-traumatic cause for the spinal cord lesion (52%). Of patients older than 40 years 74% had a non-traumatic cause and older than 60 years 81%. The non-traumatic group was on average older than the group with traumatic SCI with a mean age of 54.6 years as opposed to 35.0 years. The distribution over the age groups is shown in Figure 1. The male-female ratio was about 3 : 2 in the non-traumatic group as opposed to 3 : 1 in the traumatic group (Table 1). The non-traumatic group consisted of more patients with
incomplete lesions, 87% versus 59% in the traumatic group. Many of these patients with an incomplete non-traumatic lesion were in lower level groups, particularly mid-thoracic and low-thoracic lesions. The group with complete non-traumatic lesions was small (13%). Premature discharge to hospitals or nursing homes happened in 18% of those with non-traumatic lesions, especially when it concerned patients with tumours, and in 9% of traumatic lesions. Seventy-nine per cent of patients with non-traumatic lesions went home as opposed to 88% of the traumatic group.

Discussion

The concept of the comprehensive treatment of patients with spinal cord lesions is based on the concept that multidisciplinary treatment is essential for successful rehabilitation and the reintegration of the patient into society. Rehabilitation should not be separated from the initial treatment of SCI patients. In the USA a network of regional SCI care systems was established during the 1970s. In recent years it became clear that one of the benefits of regionalised centres is that they gain experience with the management of SCI. Moreover, it leads to shorter lengths of stay, decrease of preventable complications and mortality, and reduction of costs. In The Netherlands rehabilitation of spinal cord lesions is centralised in special departments of rehabilitation centres. Patients who are transferred to these departments come from different hospitals, as was found in this study. Of all patients admitted for the first time 66% came from the Groningen University Hospital. In our opinion regionalised SCI care systems should be set up in The Netherlands, consisting of a close collaboration between one hospital and a SCI rehabilitation centre. University hospitals should ideally treat patients in the acute phase, as they are already regional specialised trauma centres and cancer centres. Rehabilitation medicine should be integrated with the treatment of patients with spinal cord lesions from the start.

Eighty-nine per cent of the study group completed the multidisciplinary rehabilitation programme in our centre. The mean length of stay of 154 days is comparable with the data from rehabilitation centres in Denmark and Japan. The length of hospitalisation in the USA is much shorter with a mean duration below 100 days. In contrast to the USA the Dutch National Health Service and private health insurances cover hospitalisation in a rehabilitation centre for an indefinite period. The average length of stay of patients with an incomplete SCI was shorter than of patients with complete SCI, despite the theory that patients who regain muscle strength usually require more intensive training to convert this improvements into functional abilities. Discharge from the rehabilitation centre is very often delayed by social circumstances. A substantial number have to wait for suitable housing facilities, nursing homes and semi-independent institutions.

The aim of rehabilitation is to teach disabled persons to live with their disabilities in their own environment. In our population a high percentage of
patients (94%) went home after completing the programme. Only a few patients were transferred to nursing homes, because not enough care was provided in their home situation. In two American studies 95% of the patients were discharged to their own homes, in an other study 7% ended up in a nursing home. Discharge to a nursing home often seems to fail for young SCI adults because of medical and psychosocial discongruences. This should be an extra stimulus to provide training programmes concentrating on medical, personal and environmental factors, which determine the individual’s ability to live independently after discharge.

Attention should be paid to appropriate housing, transportation, vocational aspects and leisure activities. Moreover, institutions for semi-independent living are needed with professional help in activities of daily living available on demand.

A reliable assessment of the incidence of spinal cord lesions in The Netherlands has not yet been done. In European studies the incidence appears to be low (9 to 16/million/year). Most studies concentrate on traumatic SCI. In the USA the annual rate was estimated to be between 30.0 and 32.1 new traumatic SCI patients per million persons in 1990. The incidence of traumatic SCI is 39.4 per million per annum in Japan. Variation in the incidence is explained by the definition of SCI and by sociological and demographic characteristics. In our study we have taken into account that we based our figures on patients being admitted to the rehabilitation centre. We assume that nearly all patients with traumatic SCI are transferred to our centre and are registered. However, reliable registration of the group with non-traumatic lesions is not available, thus we can only give an estimation of the incidence (16 per million per year). This problem was also mentioned in another study.

All over the world young people of 20 to 40 years of age are most at risk of having a SCI. Vehicle accidents are the most important cause. The percentage of females is 20 to 28% of the total SCI population, regardless of aetiology. The mean age and the distribution of age of our patients is comparable with those found in other studies. The large number of females being admitted to the rehabilitation centre (31%) is remarkable. In comparison with male-female ratios in other studies this can be partly explained by the high number of non-traumatic lesions. Social, economic and cultural dissimilarity also leads to variation in sex ratios. The percentage of cervical lesions (41%) is similar to the percentage in other European countries, which varies from about 38% to 74%.

A large number of patients with non-traumatic spinal cord lesions was admitted to the SCI department of our rehabilitation centre. In studies regarding traumatic lesions, peaks are found in the younger age groups. Most patients with non-traumatic lesions, on the other hand, are 50 to 60 years of age. The male-female ratio is about 4 : 1 for traumatic causes and 3 : 2 for the non-traumatic lesions. Our results are consistent with those reported in other studies. Special programmes for these groups are needed based on
short inpatient rehabilitation treatment with realistic objectives. An assessment of the prognosis of functional outcome is necessary to prevent the disappointment of not completing the rehabilitation or not becoming independent enough to go home.

**Conclusions**

The purpose of this study was to give a epidemiological description of the process of rehabilitation, and the characteristics of a group of spinal cord lesion patients who were admitted to a Dutch rehabilitation centre. In our opinion the university hospital should ideally treat patients with spinal cord lesions in close collaboration with the rehabilitation centre. In this study 66% of the population came from the university hospital. The average length of stay in our centre was 154 days and 94% of the patients went home after discharge. It is important to focus our attention on independent living programmes and appropriate housing facilities to shorten length of stay and discharge even more patients to their own environment. Patients with non-traumatic lesions form half of the rehabilitation population and are distinguished by sex and age. We assume that special programmes with realistic objectives can provide better rehabilitation outcomes for those patients.
References

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