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***published in***

Spinal Cord  
2006

***DOI (link to publisher)***

[10.1038/sj.sc.3101906](https://doi.org/10.1038/sj.sc.3101906)

***document version***

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

***citation for published version (APA)***

de Groot, S., Dallmeijer, A. J., Post, M. W., van Asbeck, F. W., Nene, A. V., Angenot, E. L., & van der Woude, L. H. V. (2006). Demographics of the Dutch multicenter prospective cohort study 'Restoration of mobility in spinal cord injury rehabilitation'. *Spinal Cord*, 44, 668-75. <https://doi.org/10.1038/sj.sc.3101906>

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## Original Article

# Demographics of the Dutch multicenter prospective cohort study 'Restoration of mobility in spinal cord injury rehabilitation'

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**Study design:** A multicenter prospective cohort study.

**Objective:** To compare the demographic data of the included population with other studied spinal cord injury (SCI) populations in the international literature.

**Setting:** Eight Dutch rehabilitation centers with a specialized SCI unit.

**Methods:** A total of 205 individuals with SCI participated in this study. Information about personal, lesion and rehabilitation characteristics were collected at the beginning of active rehabilitation by means of a questionnaire.

**Results:** The research group mainly consisted of men (74%), of individuals with a paraplegia (59%), and had a complete lesion (68%). The SCI was mainly caused by a trauma (75%), principally due to a traffic accident (42%). The length of clinical rehabilitation varied between 2 months and more than a year, which seemed to be dependent on the lesion characteristics and related comorbidity.

**Conclusions:** The personal and lesion characteristics of the subjects of the multi-center study were comparable to data of other studies, although fewer older subjects and subjects with an incomplete lesion were included due to the inclusion criteria 'age' and 'wheelchair-dependent'. The length of stay in rehabilitation centers in The Netherlands was longer compared to Denmark but much longer than in eg Australia and the USA.

*Spinal Cord* (2006) **44**, 668–675. doi:10.1038/sj.sc.3101906; published online 7 February 2006

**Keywords:** spinal cord injury; rehabilitation; demography

## Introduction

The life expectancy of people with a spinal cord injury has improved over the years due to improved medical treatment.<sup>1–3</sup> In the past, research was mainly focused on the prevention and cure of health-threatening complications such as infections of the urinary tract and airways. Today, the focus of research has shifted much more towards restoration of mobility and optimization of the rest capacity of the individual to improve the quality of life.<sup>4,5</sup>

Previous studies<sup>6–9</sup> concentrated on one particular aspect of rehabilitation and/or included only relatively small numbers of subjects. In 1970, the USA started the 'Model Spinal Cord Injury Systems',<sup>10</sup> which in 1999 contained data of about 19 000 individuals with an acute traumatic SCI from different US centers. However, that database does not contain results of physical tests. In contrast the Dutch multicenter project 'Restoration of mobility in SCI rehabilitation' involves a relatively large group of patients with SCI ( $n = 205$ ) who performed an extensive test battery four times during ( $3 \times$ ) and after ( $1 \times$ ) rehabilitation with outcome measures covering the broad framework of the ICF model.<sup>11–19</sup>

We compare the demographic data of the included population with other studied SCI populations in the international literature.

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## Methods

### *Subjects inclusion*

Persons with recent SCI, that is, not readmitted, were recruited from eight rehabilitation centers that specialize in SCI rehabilitation in the Netherlands between August 2000 and July 2003. Subjects were eligible to enter the project if they had an acute SCI and were classified as A, B, C, or D on the American Spinal Injury Association (ASIA)<sup>20</sup> impairment scale. An age range of 18–65 years was chosen to avoid the possible confounding effect at a young (eg development) and older age. People older than 65 were excluded because they are more at risk during the maximal exercise test, which was one of the tests conducted in the multicenter study. Since mobility restoration means wheelchair mobility in most of the people with SCI, only subjects who were at least in part wheelchair-dependent were included. Potential participants with a progressive disease or psychiatric problem and those who did not have enough knowledge of the Dutch language were excluded, as these factors may have a possible confounding effect on testing of the restoration of mobility.

All subjects completed an informed consent form after they were given information about the study, which was approved by the local Medical Ethics Committee of rehabilitation center Hoensbroek.

### *Demographics*

Personal and lesion characteristics, the cause of the spinal cord injury, the age and gender of the patients were collected at the start of active rehabilitation (when the patient was able to sit in a wheelchair for 3–4 h) by means of a questionnaire, which was administered by eight local research assistants. To determine the lesion characteristics (tetraplegia, paraplegia and complete or incomplete lesion) the ASIA form<sup>21</sup> was used.

### *Patient selection*

To evaluate possible consequences of patient selection bias, the registration of people with SCI between 18–65 years who did not enroll into the study was conducted in seven centers. Unfortunately, in one center the registration was not conducted sufficiently systematic.

### *Statistics*

In addition to descriptive statistics, cross tables were used to describe personal characteristics. Differences between the participants of the multicenter project and those who did not participate due to exclusion criteria were tested with a  $\chi^2$  test (gender, lesion level and completeness) and an independent *t*-test (age) ( $P < 0.05$ ).

## Results

### *Subjects included*

During the 3-year period 205 patients were included in the Dutch multicenter study. The personal characteristics of the participants at the start of active rehabilitation are presented in Table 1. Most of the participants were male (74%). The patients were reasonably spread over the age groups (Figure 1, Table 1), and had a mean age of  $40.8 \pm 14.1$  years.

Of the total group, 68% had a complete lesion and 59% were treated for paraplegia (Figure 2, Table 1). For 75% of the patients the cause of the spinal cord injury was a trauma. The main cause of the traumatic lesion was a traffic accident (42%), thereafter a fall (23%) and a sports accident (15%) (Table 1). The nontraumatic lesions were mainly caused by various other reasons not mentioned in the questionnaire (Table 1), namely spondylodiscitis, astrocytoma, tuberculous process, empyema, hernia nucleus pulposus, arthrosis, syringomyelia, echinococcus infection, osteoporosis.

### *Subjects excluded*

A total of 163 patients were excluded or did not enroll while 189 patients were included in those seven centers. Of the excluded group, 67% were male, 72% had a paraplegia, 20% had a complete lesion and the average age was  $43.8 \pm 13.1$  years. The excluded group contained significantly more patients with an incomplete lesion or paraplegia. Reasons for not participating in the study varied: refusal, would not remain wheelchair dependent, had a progressive disease or psychiatric problem, or did not have enough knowledge of the Dutch language (Figure 3).

### *Demographics*

The time between the occurrence of the lesion and the start of active rehabilitation varied between 0 and 2 months and more than a year (Figure 4). Some patients performed the tests more than 8 months after incurrance of their injury. This was due to several secondary complications, such as decubitus, that led to bed rest (range: 20–240 days), which made it impossible to perform the tests earlier.

The clinical rehabilitation took longer than a year for 50% of the 39 patients with a complete tetraplegia (average:  $387 \pm 174$  days) (Figure 5). The average length of clinical rehabilitation varied between persons with an incomplete tetraplegia ( $243 \pm 138$  days), incomplete paraplegia ( $221 \pm 145$  days) and complete paraplegia ( $212 \pm 90$  days).

### *Loss to follow-up*

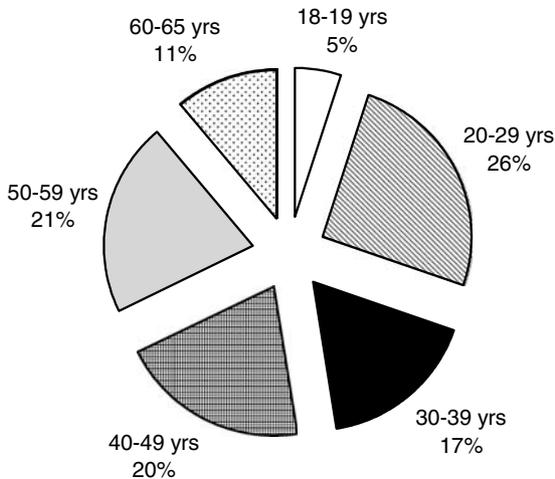
In all, 52 of the 205 included patients at the start of active rehabilitation dropped out during the project. There were different reasons for dropping out: some

**Table 1** Review of epidemiological studies regarding spinal cord injury rehabilitation

Variable	<i>Dutch multicenter study</i>	<i>Schönherr et al<sup>23</sup></i>	<i>Van Asbeek et al<sup>22</sup></i>	<i>Raadsen and Van Asbeek<sup>24</sup></i>	<i>Post et al<sup>33</sup></i>	<i>Model System<sup>32</sup></i>	<i>Garcia et al<sup>28</sup></i>	<i>Martins et al<sup>31</sup></i>	<i>Maharaj<sup>30</sup></i>	<i>Silberstein and Rabinovich<sup>34</sup></i>	<i>Biering-Sorensen et al<sup>25</sup></i>	<i>Campos et al<sup>26</sup></i>	<i>Hart and Williams<sup>29</sup></i>	<i>Soopramanien<sup>35</sup></i>	<i>Celani et al<sup>27</sup></i>
Country	The Netherlands	The Netherlands	The Netherlands	The Netherlands	The Netherlands	USA	Spain	Portugal	Fiji	Russia	Denmark	Brazil	South Africa	Romania	Italy
N	205	293	113	117	315	25,054	261	398	140	196	360	108 trauma	616	412	859
Specification	Selection, Inclusion period: 2000–2003 eight rehabilitation centers	Inclusion period: 1982–1993 one rehabilitation center	Chronic SCI In 1993	Patients between 1980 and 1985 one rehabilitation center	Patients between 1986 and 1992 eight rehabilitation centers	Inclusion period: 1973–1998 24 centers	Inclusion period: 1984–1985 13 hospitals	Inclusion period: 1989–1992 two hospitals only traumatic	Inclusion period: 1985–1994 one rehabilitation unit also readmission	Inclusion period: 1989–1994 one hospital	Inclusion: 1975–1984 two rehabilitation centers	36 hospitals	Inclusion period: 1988–1994 one rehabilitation unit	Inclusion period: 1992–1993 one hospital	Inclusion period: 1989–1995 seven rehabilitation centers
Kind of research	Prospective	Retrospective	Retrospective	Retrospective	Retrospective	Prospective	1x questionnaire	1x looked at files of new patients	Retrospective	1x questionnaire	Retrospective	1x questionnaire between March and September	Retrospective	Prospective	Retrospective
Measurements	a,b,c,d,e	a,b	a,b	a,b,c,d	a,b,c,d	a,b,c,d	a,b	a,b	a,b,c	a,b	a,b	a,b,c	a,b,c	a,b,c	a,b,c
Male	74%	69%	77%	73%	75%	82%	72%	77%	80%	78%	73%	81%	80%	77%	73%
Female	26%	31%	23%	27%	25%	18%	28%	23%	20%	22%	27%	19%	20%	23%	27%
Age (mean ± SD)	40.8 ± 14.1	45.1			39.4 ± 12.5	32.3 ± 15.8	41.8 ± 1.2	50	37.8	33.5		30.3 ± 1.1			37.9
<20 years	5%	12%	13%	13%	18–25: 16%	0–15: 4%	12%		0–15: 6%	6%	20%				10%
20–29 years	26%	18%	25%	34%	26–35: 28%	16–30: 54%	22%		16–30: 35%	38%	24%				15%
30–39 years	17%	12%	14%	26%	36–45: 22%	31–45: 23%	14%		31–45: 24%	34%	16%				17%
40–49 years	20%	16%	11%	9%	46–55: 20%	46–60: 10%	13%		46–60: 22%	13%	14%				16%
50–59 years	21%	13%	7%	10%	56–65: 14%	61–75: 6%	23%			6%	14%				21%
>60 years	11%	29%	30%	8%		76+: 2%	16%		61+: 13%	3%	12%				21%
Paraplegia	59%	59%	43%	56%	59%	46%	62%	51%	69%	51%	Trauma: 49%	65%	75%	40%	68%
Tetraplegia	41%	41%	57%	44%	41%	54%	38%	49%	31%	49%	51%	35%	25%	60%	32%
Complete	68%	27%	49%	67%	51%	49%		56%	52%	44%	Trauma: 48%	87%	66%	40%	58%
Incomplete	32%	73%	51%	33%	49%	50%		44%	48%	56%	52%	13%	34%	60%	42%
Traumatic	75%	48%	All				61%	All	54%	All	74%	68% of total	89%	All	75%
Traffic accident	42%		31%		35%	35%	52%	57%	25%	25%	47%	42%	28%	13%	58%
Industrial accident	11%		4%		13%				11%					15%	
Fall	23%		49%		9%	16%	27%	37%	39%	19%	26%	15%	3%	59%	5%
Sport accident	15%		9%		15%	6%	3%		32%	33%	11%	9%	7%	8%	
Violence	4%				9%	14%	3%			2%	2%	1%	62%	3%	
Other	5%		7%		18%	12%	14%	5.3%	4%	10%	14%	27%	7%	21%	10%
Nontraumatic	25%	52%				2%	39%		46%		26%		11%		25%
Myeluminfarct/bleeding	21%						16%								25%
Myelitis	12%						19%		32%						14%
(Benign) tumor	10%						44%		9%						
Iatrogenic	14%														
Other	43						16%		58%						61%

Measurements: (a) Demographic; (b) Lesion characteristics; (c) Secondary complications; (d) Medical-psychological questionnaires; (e) Physical testing

subjects were diseased, others moved away or refused to collaborate further, could not be reached, could walk again, were mistakenly included, or got psychological problems (Figure 3).

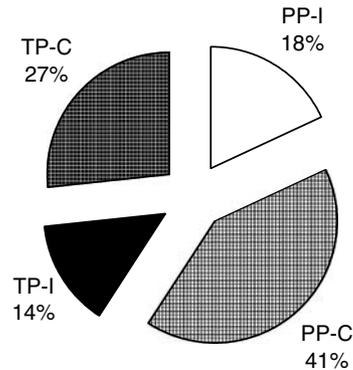


**Figure 1** Age distribution of the 205 participants of the Dutch multicenter study

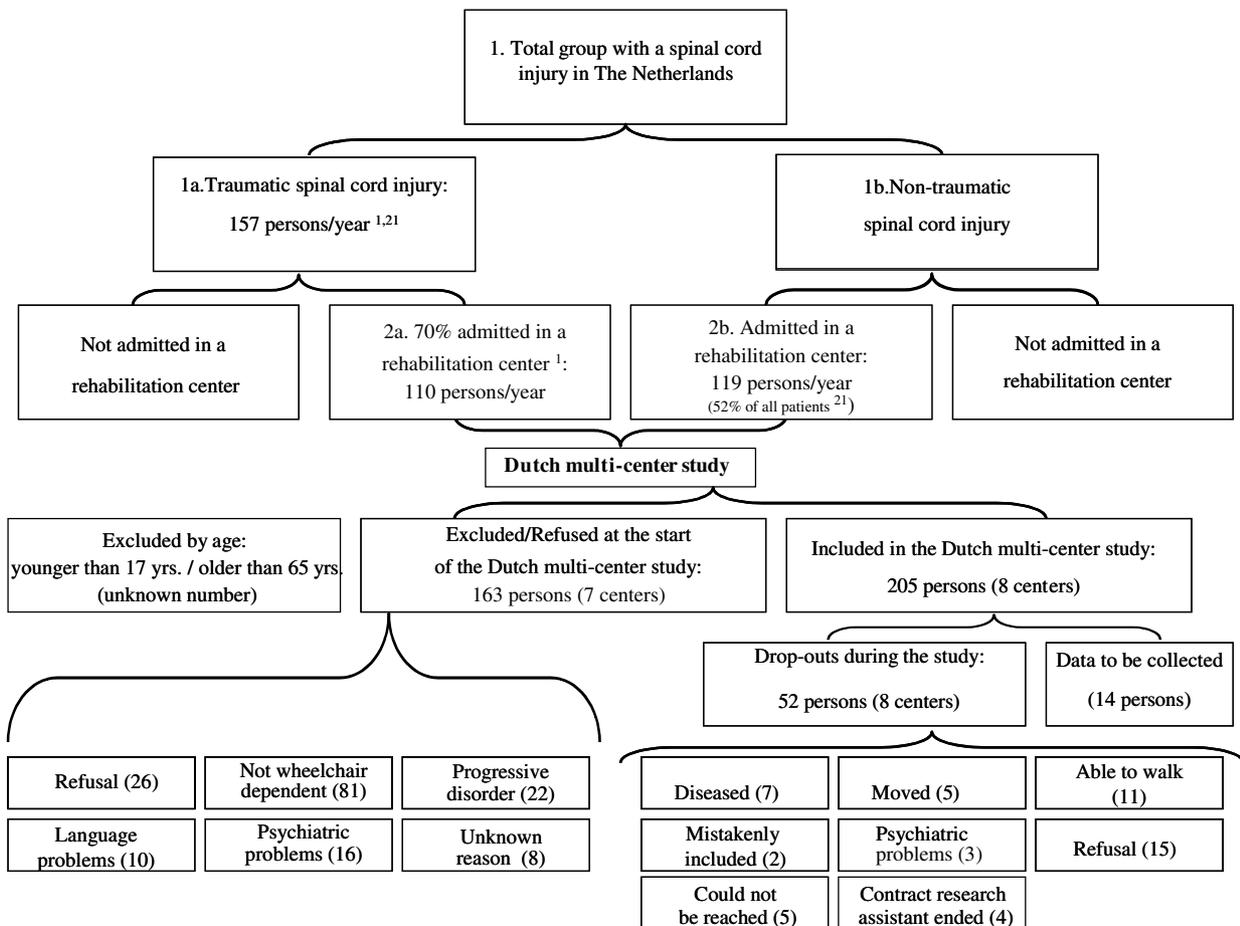
**Discussion**

*Subjects included*

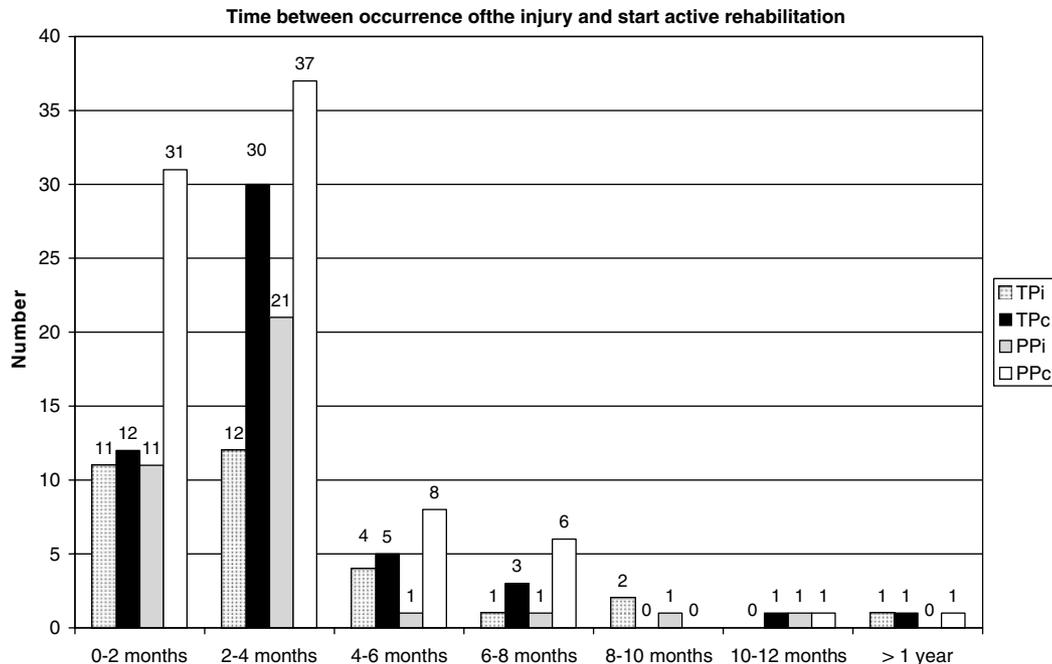
In a study of Van Asbeck *et al.*<sup>22</sup> the incidence of a traumatic lesion in The Netherlands was estimated to be 10.4 per million inhabitants per year. With 15.1 million inhabitants, that means an estimated 157 new indivi-



**Figure 2** Distribution of lesion level (paraplegia (PP) and tetraplegia (TP)) and completeness (complete (C) and incomplete (I)) of the 205 participants of the Dutch multicenter study



**Figure 3** Flow chart of the total group of people with a spinal cord injury that were admitted in a rehabilitation center and the group that participated in the Dutch multicenter study



**Figure 4** Time between the occurrence of the injury and the start of active rehabilitation, subdivided in persons with a complete (c) or incomplete (i) tetraplegia (TP) and paraplegia (PP)

duals with a traumatic lesion per year from which 70% (110 people) will be admitted in a rehabilitation center<sup>22</sup> (Figure 3). This is 48% (only traumatic) of the total number of patients with a SCI,<sup>23</sup> that subsequently can be estimated on 229 patients per year. That means that during the inclusion period of the multicenter project (3 years) 687 potential subjects would have been available, with the assumption that almost everybody will be admitted to one of the eight rehabilitation centers. These numbers suggest that an estimated 30% ( $N=205$ ) of the potential subjects satisfied the inclusion criteria and enrolled.

A total of 85% of the patients, who satisfied the inclusion criteria (189 patients plus those who refused and did not participate for unknown reasons), were included. This percentage is higher than the response on questionnaire studies among ex-patients of a Dutch rehabilitation center, respectively 60%<sup>20</sup> and 67% response.<sup>24</sup> The participants of the multicenter project are representative for the whole group of clinical patients regarding age and gender but the Dutch multi-center study included more persons with a tetraplegia and complete lesion compared to the group with excluded patients and drop-outs at the start of the project. Furthermore, it should be kept in mind that there were 52 drop-outs during the study, which might have led to a positive selection of subjects at the last test occasion.

#### Demographics compared

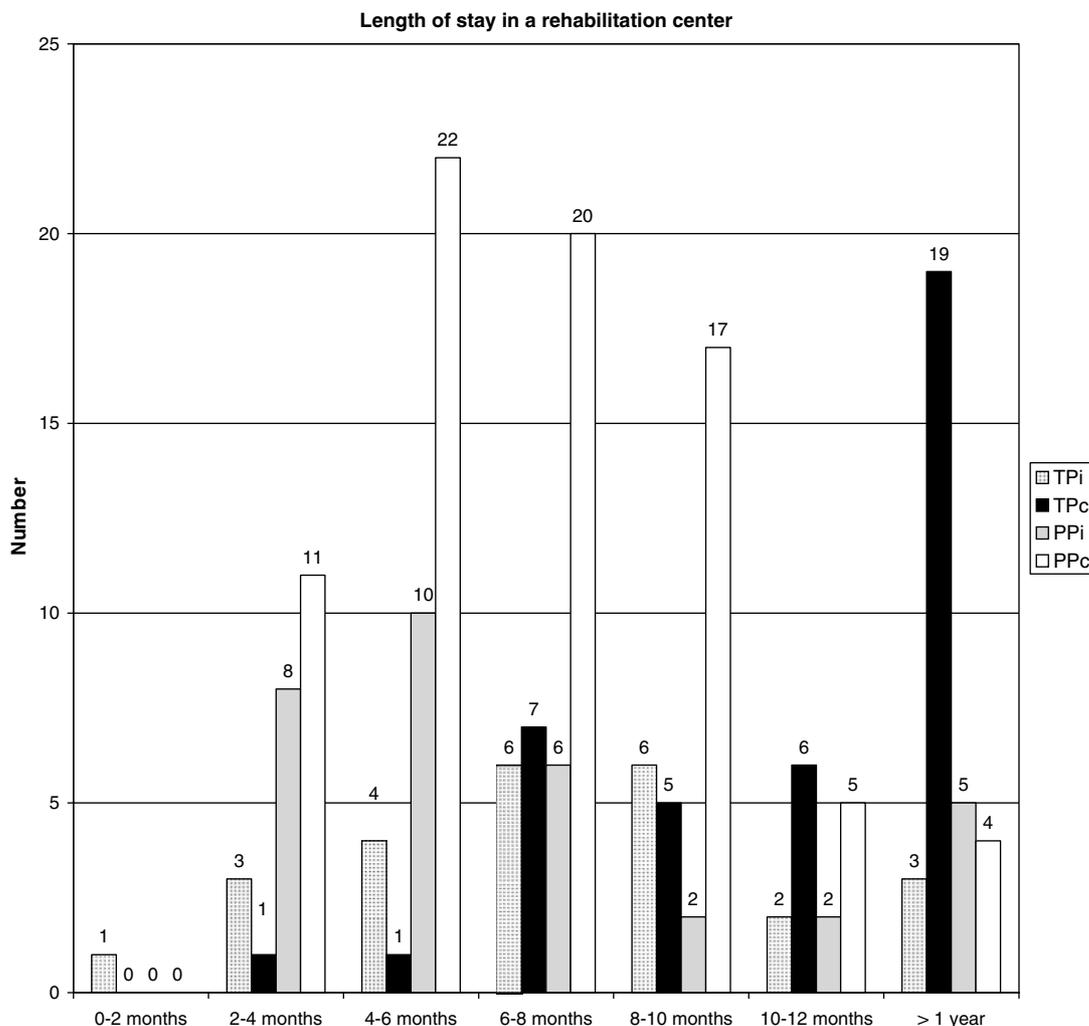
Although the results of the Dutch multicenter study project can be compared with epidemiological literature,

which describe populations with a SCI in- and outside Europe,<sup>22-35</sup> objectives among these studies and their tests do differ. The percentage male subjects (74%) in the multicenter project was in the range of percentages found in other studies (69-82%).<sup>22-35</sup>

The average age in the studies (Table 1) varied between 30-50 years.<sup>23,26-28,30-32,34</sup> The mean age of the subjects of the multicenter project (40.8 years) lies in this range. A quarter of the patients were between 20 and 30 years. This group was also quite large in other studies.<sup>22,24,25,27,28,30,32-34</sup> In the Netherlands younger people are more at risk for a SCI, mainly due to traffic accidents.<sup>23</sup> People older than 65 years were excluded from the multi-center project. Therefore, the percentage subjects in the 60 years and older group of the multicenter project will give an underestimation.<sup>22,23,35</sup> It is important to realize that the older patient group is a special group with other demands on the rehabilitation program.

The percentage patients with a paraplegia (59%) in the multicenter study was in the range of values found in the literature (40-75%)(Table 1).<sup>22-35</sup> The percentage people with a complete lesion varied considerably among studies (27-87%).<sup>22-27,29-35</sup> The number of subjects with an incomplete lesion was relatively low in the multicenter project because the subjects had to be wheelchair-dependent.

A traffic accident was the most frequent cause of a traumatic lesion. Local factors appear to affect the cause of the SCI. Violence is for example the main cause (62%) of traumatic lesions in South Africa.<sup>29</sup> The qualification of nontraumatic lesions was more difficult because studies used different group divisions. Table 1



**Figure 5** Time between the start of active rehabilitation and discharge of inpatient rehabilitation, subdivided in persons with a complete (c) or incomplete (i) tetraplegia (TP) and paraplegia (PP)

indicates that the percentage patients with a traumatic lesion (75%) was relatively high compared to some other studies.<sup>23,28,30</sup> According to the results of Schönher *et al*,<sup>23</sup> who studied 293 patients admitted to one Dutch rehabilitation center, the group with a nontraumatic lesion is larger (52%) in the general population with a SCI. Not all studies included both participants with a traumatic and non-traumatic lesion.<sup>22,24,31,33-35</sup> The studies that included both groups varied in the percentage nontraumatic lesions, ranging from 11 to 46%.<sup>25,27-30,36</sup> The relatively low number of participants with a nontraumatic lesion in the present study might be explained by two reasons. Firstly, most patients with nontraumatic lesions are older (50-60 years of age)<sup>23,25,28</sup> and might, due to the exclusion criteria 'age', be excluded from the study. Secondly, nontraumatic lesions might be caused by progressive diseases<sup>36</sup> and these individuals were also excluded.

The time between the occurrence of the lesion and the first measurement varied enormously in the multicenter

project. For some subjects the time since injury was <2 months at the start of active rehabilitation, for others longer than a year due to all kind of secondary complications.

On average per lesion group the length of stay in the rehabilitation center was 212-387 days in the multicenter study. This was higher than for example in Denmark (149-285 days)<sup>25</sup> or Israel (239 days for patients with traumatic lesions and 106 days for patients with nontraumatic lesions).<sup>36</sup> The length of stay in Australia is considerably shorter (43-206 days).<sup>37</sup> In the USA the average length of stay between 1973 and 1977 was 145 days but 15 years later this was decreased to 78 days.<sup>38</sup> In the Netherlands the length of stay is primarily determined in the successful attainment of the rehabilitation goals (optimal level of functional independence and daily functioning). However, it also happens that patients stay in the rehabilitation center longer than necessary because they have to wait for appropriate housing.

## Conclusion

The results of the participant characteristics of the Dutch multicenter study 'Restoration of mobility in SCI rehabilitation' were in the range of what was found in other studies concerning age, gender and lesion level. However, due to the selection criteria (such as 18–65 years and wheelchair dependent) fewer elderly people and more patients with a complete and traumatic lesion were included in the project, which limits the generalization of some of the results. Outcome of restoration of mobility may – to a large extent – be viewed representative for the age group 18–65 years, and those who are (partly) wheelchair-dependent.

## Acknowledgements

We thank the eight participating rehabilitation centers and especially the research assistants for collecting all the data: Sacha van Langeveld (De Hoogstraat, Utrecht), Annelieke Niezen/Peter Luthart (Rehabilitation Center Amsterdam), Marijke Schuitemaker (Het Roessingh, Enschede), Karin Postma (Rijndam Revalidatiecentrum, Rotterdam), Jos Bloemen (Hoensbroeck Revalidatiecentrum, Hoensbroek), Hennie Rijken (Sint Maartenskliniek, Nijmegen), Ferry Woldring (Beatrixoord, Haren), and Linda Valent (Heliomare, Wijk aan Zee). This study was supported by the Dutch Health Research and Development Council, ZON-MW Rehabilitation program, Grant no. 1435.0003.

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