Functional outcome after spinal cord injury
Schonherr, Marleen C.

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

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):

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.
Chapter 6

Vocational outcome after spinal cord injury: experiences, satisfaction and unmet needs

Marleen Schönherr, Johan Groothoff, Dineke Mulder, Willem Eisma.

Submitted
Abstract

Study design: Survey
Objectives: To give insight in the vocational situation several years after a traumatic spinal cord injury (SCI), including the relation with the health status and work-related disabilities, and to give a description of the personal experiences and satisfaction with the current job situation.
Setting: Dutch rehabilitation centre with special department for patients with spinal cord injuries.
Methods: Descriptive analysis of data gathered by a mailed questionnaire, which was returned by 57 individuals (response 83%) with a traumatic SCI, aged 18 to 60 years, admitted to the rehabilitation centre from 1990 to 1998.
Results: An overview is given of the health status, disabilities and satisfaction per type of SCI. The number of work-related disabilities and perceived physical functioning were associated with the extent of the lesion and not with the level of the lesion. There were no differences between the subgroups with different types of SCI as far as being employed or general satisfaction were concerned. At the moment of assessment 60% of the respondents had a paid job which was related to a higher educational level. The respondents who changed to a different employer needed more time to resume work, but seemed more satisfied with the job and lost fewer working hours than those who resumed work at the former employer. In spite of a reasonable to good satisfaction with the current work situation, several negative experiences and unmet needs were reported.
Conclusions: Vocational outcome after a SCI is not associated with SCI-specific factors. As the educational level is an important indicator, educational opportunities for people with SCI should be stimulated. Personal experiences of working people with SCI should not be neglected and regular follow-up of the rehabilitation team is advocated, including attention paid to the job situation.
Introduction

Quality of life after a spinal cord injury (SCI) depends on the way a patient learns to adapt to the fundamental changes in his life and the reintegration into society. Active involvement in activities seems strongly related to health and well-being. Participation includes reintegration in work and school, but also significant involvement in housekeeping and community organisations. From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society. From other studies we know that the chances to resume work are restricted for patients with chronic diseases and disabilities. The aim of this study was to give insight in the vocational situation of SCI disabled in The Netherlands, several years after the SCI.

Several studies reported quantitative results of employment status after a SCI and work rates vary from 31 to 48%. In a Dutch multi-centre study 37% of pre-injury workers were gainfully employed after the SCI. Several authors identified factors related to return to work. Predictors of vocational outcome often mentioned in literature are age, education level, motivation, pre-injury type of job, and disease-specific problems and disabilities. Several subjective factors such as motivation and expectations of the patient regarding return to work will affect the outcome to a great extent.

The Dutch Organisation for Applied Scientific Research (TNO Arbeid) has developed a research programme to evaluate the vocational situation of people with chronic diseases. The main goal of this Vocational Handicap Research Programme was to describe the working conditions and reintegration experiences of chronic disabled with various diagnoses, to create a more positive image of their capabilities and improve reintegration interventions. The studies of TNO Arbeid highlight the aspects of work of people with various diagnoses. Persons with SCI have not been under study yet.

Post et al. performed a nation-wide study on the health status and life-satisfaction of Dutch people with a SCI, which revealed relationships between rehabilitation outcomes of different dimensions. Little is known about the role of SCI-specific factors in vocational outcome. Satisfaction with the vocational situation after a SCI is usually low, which can be explained by change to unrewarding, poor-quality jobs and insufficient income. We assumed that the satisfaction with several aspects of work during and after resumption of work determines if the disabled worker will keep his job or not.

With more knowledge about specific problems due to the SCI that affect the job situation, the rehabilitation team can prepare patients and family and teach them how to cope with these matters. Information about unmet needs after the reintegration can help job professionals to keep people with SCI at work. In this study several aspects of vocational outcome were analysed of
people with SCI, who were currently working after a successful reintegration. We assessed the current health status, disabilities and dependence on help related to work. Several changes regarding the job situation were studied, including changes in working hours, job adjustments and contacts with professionals. We gathered the personal experiences, job satisfaction and unmet needs in the current work situation.

Methods

Patients
In this study we focused on patients with acute traumatic spinal cord injury, aged 18 to 60 years, who were consecutively admitted to the Centre for Rehabilitation Beatrixoord from 1990 to 1998. Of 89 eligible candidates 16 patients were excluded: four patients deceased, three had serious psychiatric problems, one was discharged to a nursing home, two finished their rehabilitation programme in another rehabilitation centre and six were foreigners with difficulties with the Dutch language. Of four patients the addresses were not found and they were lost for follow up. To 69 patients a questionnaire was sent. The questionnaire was filled in and returned by 57 patients, which means a response of 83%.

Questionnaire
Data on the current vocational situation and several factors that might be associated with this outcome were gathered from a questionnaire, which was developed for this study. This questionnaire largely consisted of selected items of a questionnaire developed as part of the Vocational Handicap Research Programme of TNO Arbeid (Dutch Organisation for Applied Scientific Research). TNO Arbeid validated their questionnaire in several research projects\(^2\,^6\). Data became available on the employment situation of this study group both pre-injury and after the reintegration. Respondents were asked to report their income, educational level (grades 1-8), vocational re-training, changes in job or employer, changes in working hours, adaptations of the workplace, contacts with professionals, and their opinion on the working conditions and social atmosphere. Satisfaction with the job ranged from not satisfied to satisfied (grades 1 to 4). The TNO assessment also includes several injury-related scales regarding work-related disabilities (TNO score 0-54) and dependence on help (TNO weighted score 0-42) (appendix).

The type of SCI was defined according to the standards for neurological and functional classification by the American Spinal Injury Association. The study group was divided into four subgroups: (1) complete tetraplegia; (2) incomplete paraplegia; (3) complete paraplegia; (4) incomplete paraplegia. We used a validated scale with eight health problems related to SCI experienced in the last four weeks before assessment\(^18\): respiratory problems, pain, spasms, contractures, excessive sweating, oedema, pressure sores, urinary tract
infections (score 0-8). We asked an estimation of the time in minutes used for self-care pre- and post-injury and calculated the extra time currently needed. The ability to walk and the level of continence for urine were both assessed on a three-point scale.

The impact of the health status was assessed by the RAND 36 (Dutch version). The RAND 36 is a short version of the RAND Health Insurance Study Questionnaire and is similar to the MOS SF-36. It measures health perception on nine multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health and health change. A lower score is indicative of a worse health experience.

For information on life satisfaction we used the Fugl-Meijer Life Satisfaction Questionnaire (LSQ). The questionnaire was translated in Dutch and validated by Post et al. The LSQ measures general life satisfaction and satisfaction on eight life domains, including satisfaction with self-care ability, the leisure situation, the vocational situation, the financial situation, sexual life, partnership relation, family life and contacts with friends. LSQ item scores range from grade 1 (very dissatisfying) to grade 6 (very satisfying).

Analysis
We defined having paid work as being able to work gainfully for at least eight hours a week. Descriptive statistics were performed using the Statistical Product and Service Solutions (SPSS). Analyses of variance and multiple comparisons of the groups were used to compare the subgroups with different types of SCI regarding health status, disabilities and satisfaction. Differences in the indicators between groups of patients with and without a paid job were tested using univariate logistic regression analyses. Odds ratios were presented as they are a useful indicator of the strength of the relationship, and the significance level was chosen as $p < 0.05$.

Results
The study group of 57 respondents consisted of 52 males (91%) and 5 females. Their age at the moment of the SCI ranged from 18 to 59 years with a mean of 33 years. The time since injury varied from 29 to 140 months with a mean of 84 months. Forty percent of the injuries were caused by traffic accidents, 23% by industrial accidents, 37% by sports and private accidents. Six patients had complete tetraplegia, 17 patients incomplete tetraplegia, 20 patients complete paraplegia and 14 incomplete paraplegia.

The group of patients who returned the questionnaire was compared to the group who gave no response (Table 1). The most remarkable difference between the group of respondents and non-respondents is the percentage of patients who worked at the moment of the SCI. In the group of respondents 86% worked pre-injury versus 42% in the group of non-responders. The time
elapsed since the SCI was on average longer for the group of non-responders than for the group of responders. The differences regarding age, gender and type of SCI were not significant.

Table 1. Representativeness of the response group (mean (SD) and percentages).

<table>
<thead>
<tr>
<th></th>
<th>Respondents n = 57 (83%)</th>
<th>Non-respondents n = 12 (17%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at SCI (years): mean(SD)</td>
<td>33 (11)</td>
<td>34 (14)</td>
</tr>
<tr>
<td>Gender: Male (%)</td>
<td>52 (91%)</td>
<td>12 (100%)</td>
</tr>
<tr>
<td></td>
<td>5 (9%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Time since SCI (months): mean (SD)</td>
<td>84 (29)</td>
<td>99 (30)</td>
</tr>
<tr>
<td>Type of SCI: ComplTetra (%)</td>
<td>6 (10%)</td>
<td>2 (17%)</td>
</tr>
<tr>
<td></td>
<td>IncompTetra (%)</td>
<td>17 (30%)</td>
</tr>
<tr>
<td></td>
<td>ComplPara (%)</td>
<td>20 (35%)</td>
</tr>
<tr>
<td></td>
<td>IncompPara (%)</td>
<td>14 (25%)</td>
</tr>
<tr>
<td>Job situation at SCI: Work (%)</td>
<td>49 (86%)</td>
<td>5 (42%)</td>
</tr>
<tr>
<td></td>
<td>School (%)</td>
<td>5 (9%)</td>
</tr>
<tr>
<td></td>
<td>Other (%)</td>
<td>3 (5%)</td>
</tr>
</tbody>
</table>

Health status and work-related disabilities

Several aspects of the health status, the work-related disabilities and dependence on help were analysed in the four subgroups with different types of SCI, and the results are shown in Tables 2a and 2b. Health problems were experienced by 83% of the 57 respondents in the last four weeks before the assessment with a mean of two problems per individual. More than half of the study population reported pain (56%) and spasms (61%). Pain and spasms were not significantly related to the type of SCI. Oedema (23%), urinary infections (21%), excessive sweating (18%) and pressure sores (9%) were reported less frequently. Most of the respondents with incomplete lesions were able to walk with or without difficulty and all persons with complete lesions were fully wheelchair-bound. About one-quarter of the people with tetraplegic lesions had problems with continence for urine, versus two-thirds of the persons with paraplegic lesions.

The analyses of variance showed differences between the subgroups regarding work-related disabilities, dependence on help, extra time for self-
care, satisfaction with self-care abilities (LSQ) and perceived physical functioning (RAND36). None of the other dimensions of health experience (RAND36) and domains of life satisfaction (LSQ) were related to the level and extent of the lesion. Multiple comparison of the groups showed that persons with complete tetraplegia needed significantly more help with self-care, and also with transport and domestic activities, and were least satisfied with their self-care abilities. Complete lesions were associated with a significantly higher number of work-related disabilities, more extra time for self-care and lower perceived physical functioning in the RAND36.

Table 2a. Comparison of subgroups with different types of SCI (n= 57) regarding health problems, walking, continence for urine, dependence on help and having a paid job (%).
Vocational outcome
Of 57 respondents 49 patients (86%) had a job at the moment of the SCI. Five males with a mean age of 21 years went to school. Three males were out of work for a long time. Of the group of 49 respondents who were employed pre-injury 33 patients returned to work and 16 patients failed. Return to a paid job took place after an interval of 3 to 108 months (median 12 months). Four of them stopped working in the meantime after on average 67 months (range 50-90 months) after the SCI and were not working anymore at the moment of assessment. Two persons were made redundant after a successful reintegration including vocational training, not related to the SCI. One is now full-time responsible for the housekeeping. Two self-employed responders initially carried on with their company after rehabilitation, but stopped after about four years working for reasons related to the SCI, like progressive physical restrictions and mobility problems.

Table 2b. Comparison of subgroups with different types of SCI (n = 57) regarding health status, disabilities and aspects of self-care (mean (SD)) using analyses of variance.

<table>
<thead>
<tr>
<th></th>
<th>Complete Tetra n = 6</th>
<th>Incomplete Tetra n = 17</th>
<th>Complete Para n = 20</th>
<th>Incomplete Para n = 14</th>
<th>Total n = 57</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health probl (0-8)</td>
<td>2.5 (1.5)</td>
<td>1.7 (1.3)</td>
<td>2.4 (1.46)</td>
<td>1.5 (1.2)</td>
<td>2.0 (1.4)</td>
</tr>
<tr>
<td>Disabilities* (0-54)</td>
<td>26.7 (2.8)</td>
<td>13.5 (4.5)</td>
<td>22.9 (2.7)</td>
<td>13.9 (4.7)</td>
<td>18.3 (6.4)</td>
</tr>
<tr>
<td>Dependence* (0-42)</td>
<td>33.0 (11.2)</td>
<td>7.1 (10.4)</td>
<td>10.0 (9.0)</td>
<td>2.9 (4.1)</td>
<td>9.8 (12.1)</td>
</tr>
<tr>
<td>Extra time * for self-care</td>
<td>68.3 (22.3)</td>
<td>19.7 (41.3)</td>
<td>60.0 (41.1)</td>
<td>28.9 (31.3)</td>
<td>40.9 (41.3)</td>
</tr>
<tr>
<td>Perc. phys.* funct (0-100)</td>
<td>10.0 (13.4)</td>
<td>45.6 (27.2)</td>
<td>17.1 (10.6)</td>
<td>46.1 (24.0)</td>
<td>32.2 (25.3)</td>
</tr>
<tr>
<td>Satisfaction* self-care(1-6)</td>
<td>2.0 (1.1)</td>
<td>4.6 (1.5)</td>
<td>4.7 (0.8)</td>
<td>4.8 (1.0)</td>
<td>4.4 (1.4)</td>
</tr>
<tr>
<td>Satisfaction general (1-6)</td>
<td>4.2 (1.2)</td>
<td>4.4 (1.2)</td>
<td>5.0 (0.8)</td>
<td>4.5 (1.0)</td>
<td>4.6 (1.0)</td>
</tr>
</tbody>
</table>

* p<0.05
At the moment of assessment 34 persons (60%) had paid work, including 29 pre-injury workers and 5 students who graduated in the meantime. It concerned 50% of persons with complete tetraplegia, 53% of persons with incomplete tetraplegia, 60% of persons with complete paraplegia and 71% of persons with incomplete paraplegia. Table 3 shows that a higher educational level is a significant indicator of being employed after a SCI. Neither age, health problems, work-related disabilities nor the dimensions of health experience (RAND36) and life satisfaction (LSQ) were significantly related to the current work situation.

Table 3. Comparison of subgroups with or without a paid job regarding personal and SCI-related variables and satisfaction (mean (SD)) using univariate logistic regression analyses (odds ratios (OR)).

<table>
<thead>
<tr>
<th></th>
<th>Paid job (n = 34 (60%))</th>
<th>No paid job (n = 23 (40%))</th>
<th>OR</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age now (yrs)</td>
<td>38.4 (9.4)</td>
<td>42.8 (11.9)</td>
<td>1.0</td>
<td>0.122</td>
</tr>
<tr>
<td>Educational level * (1-8)</td>
<td>4.7 (1.8)</td>
<td>3.5 (1.4)</td>
<td>1.6</td>
<td>0.019</td>
</tr>
<tr>
<td>Time since SCI (mths)</td>
<td>89.4 (31.5)</td>
<td>76.7 (24.2)</td>
<td>1.0</td>
<td>0.109</td>
</tr>
<tr>
<td>Health problems (0-8)</td>
<td>2.2 (1.3)</td>
<td>1.7 (1.5)</td>
<td>1.3</td>
<td>0.256</td>
</tr>
<tr>
<td>Disabilities (0-54)</td>
<td>15.8 (7.1)</td>
<td>17.3 (5.2)</td>
<td>1.0</td>
<td>0.369</td>
</tr>
<tr>
<td>Dependence (0-42)</td>
<td>8.1 (9.9)</td>
<td>12.4 (14.6)</td>
<td>1.0</td>
<td>0.197</td>
</tr>
<tr>
<td>Extra time self-care (min)</td>
<td>36.1 (35.6)</td>
<td>47.8 (48.4)</td>
<td>1.0</td>
<td>0.297</td>
</tr>
<tr>
<td>Perceived phys func(0-100)</td>
<td>37.0 (28.4)</td>
<td>25.4 (18.6)</td>
<td>1.0</td>
<td>0.099</td>
</tr>
<tr>
<td>Satisfaction self-care (1-6)</td>
<td>4.6 (1.2)</td>
<td>4.1 (1.6)</td>
<td>1.3</td>
<td>0.246</td>
</tr>
<tr>
<td>Satisfaction general (1-6)</td>
<td>4.6 (1.1)</td>
<td>4.6 (0.9)</td>
<td>1.0</td>
<td>0.832</td>
</tr>
</tbody>
</table>

* p < 0.05

**Job modifications**

Of the 29 respondents working pre-injury eight (28%) were able to reintegrate in the same job. Nine changed to a different job at the same employer (31%) and twelve (41%) found a new job at a different employer. At the moment of the SCI the persons with a paid job worked on average 48.7 hours a week, while present job hours averaged 29.3 hours a week.
(range 4 to 70 hours). Eighteen persons (62%) worked less hours than before the SCI: five reported a reduction of 75-90%, ten a reduction of 25-74% and three reduced their working hours to less than 25%. Thirteen of the 34 working respondents (38%) had a paid job without any supplementary benefit and 62% worked with benefit from the Work Disability Act.

In 25 of the 34 present work situations (74%) job adjustments had been made. The majority of respondents (80%) received one or more material job adaptations such as personal aids (38%) and adapted furniture or toilet facilities (44%). Adapted transport was available for 24% of the workers. Nine percent received help with self-care. Immaterial adjustments were arranged for 88% of the workers. Personal time management (planning your own working day) was mentioned by 50% of the workers, and they also reported flexible working hours, less tasks and a slower work tempo. One-quarter were able to work at home.

Table 4. Changes to a different job or employer of respondents currently working (n=34) related to reintegration aspects and current experiences.

<table>
<thead>
<tr>
<th></th>
<th>Same employer, same job n=8</th>
<th>Same employer, other job n=9</th>
<th>Other employer n=12</th>
<th>No job pre-injury n=5</th>
<th>Total n=34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reintegration aspects:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Months not working: median (range)</td>
<td>9 (3-12)</td>
<td>9 (6-18)</td>
<td>20 (8-108)</td>
<td>-</td>
<td>12 (3-108)</td>
</tr>
<tr>
<td>-Vocational retraining: %</td>
<td>13%</td>
<td>22%</td>
<td>58%</td>
<td>-</td>
<td>34%</td>
</tr>
<tr>
<td>-Change job hours: %</td>
<td>63%</td>
<td>89%</td>
<td>42%</td>
<td>-</td>
<td>62%</td>
</tr>
<tr>
<td>-Adaptation of workplace: %</td>
<td>75%</td>
<td>89%</td>
<td>75%</td>
<td>40%</td>
<td>74%</td>
</tr>
<tr>
<td>Current experiences:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Benefit from WDA: %</td>
<td>63%</td>
<td>100%</td>
<td>50%</td>
<td>20%</td>
<td>62%</td>
</tr>
<tr>
<td>-Contacts with professionals: %</td>
<td>63%</td>
<td>67%</td>
<td>33%</td>
<td>40%</td>
<td>50%</td>
</tr>
<tr>
<td>-Wish (more) adaptations: %</td>
<td>25%</td>
<td>44%</td>
<td>8%</td>
<td>0%</td>
<td>21%</td>
</tr>
<tr>
<td>-Good job satisfaction: %</td>
<td>75%</td>
<td>44%</td>
<td>75%</td>
<td>60%</td>
<td>65%</td>
</tr>
</tbody>
</table>
In Table 4 we related the changes to a different job or employer to several aspects of the job reintegration. Respondents who changed to a different job at the same employer (31%) experienced the most changes in working hours (89%) and job adjustments (89%). They were all working with full or partial benefit from the Work Disability Act (WDA). The majority of those who changed to a different employer (41%) followed vocational re-training (58%) and needed the longest time to return to work. This subgroup showed the least change of working hours, the least benefits from the WDA, the least current contacts with work professionals, and the least need for more adaptations. The majority of them were satisfied with the job.

**Job satisfaction, personal experiences and unmet needs**

The assessment of satisfaction with the job on the TNO questionnaire showed that one person (3%) was “not satisfied” (grade 1), one person (3%) was “little satisfied”, ten persons (29%) were “reasonably satisfied” (grade 3) and 22 persons (65%) were “satisfied” with their jobs (grade 4). According to the results of the Life Satisfaction Questionnaire this group showed a median score of 5 (satisfying) regarding their vocational situation and for life as a whole.

Regarding the experiences in the present work situation 43% of workers reported physical strain, 68% reported mental strain and 46% were working under time pressure. A quarter found their work tiring, 36% mentioned they should calm down in their work and 16% that their health was influenced negatively by their work. Most of these workers judged the accessibility positively (88%) and none of them had transport problems. In 44% of the work situations the respondents were dependent on their colleagues and 21% experienced insufficient consideration of their colleagues. A fifth of the employees did not experience enough consideration of their boss. Significant relations between these experiences and the degree of satisfaction with work were not found. Seven (21%) of the present workers wished (more) job modifications, especially more personal time management, the opportunity to work at home, or (more) adaptations of the workplace.

Absence due to illness at present was reported by 17% of the respondents; ten per cent were absent because of factors related to the SCI. Half of the working respondents recently had contacts with work professionals regarding their health at work. Three of them still received support from the rehabilitation team. Six (18%) wished more contacts with work professionals, and half of them was in need of more support from the rehabilitation team. This subgroup with unmet needs also seemed less satisfied with the job, but the differences were not significant. Two persons were looking for a different job with better working conditions, flexible working hours or better salary.
Discussion

Return to work is regarded as one of the most important long-term rehabilitation goals\textsuperscript{4,5}. In this study we found that a large number of people with SCI are able to work, which was not associated with SCI-specific factors. The educational level was a significant indicator of vocational outcome. The personal experiences and unmet needs of the workers reveal that long-term support is indispensable to keep them at work.

The group of patients under study completed a standard multidisciplinary rehabilitation programme including education, training and counselling. The study group was a representative cohort of patients with traumatic SCI with vocational potential. As Dutch patients with traumatic SCI usually are admitted to the rehabilitation centre and have equal rehabilitation and reintegration opportunities, generalisation of the results is possible to the whole population with traumatic SCI in The Netherlands.

As the majority of patients with a traumatic spinal cord injury are relatively young, attention to social and vocational reintegration is of particular importance, not just to the patients themselves but also from a wider social point of view\textsuperscript{9}. Despite the serious consequences of the SCI regarding ambulation, functional independence and social continence, this should never be a reason to exclude people with SCI from the labour market without exploring vocational possibilities. Participation in the employment process of chronically disabled has been an important point of political interest in The Netherlands for the last decade and equal opportunities for persons with a chronic disease are laid down by law. Individual job counselling and vocational services are formally available for all persons with vocational handicaps. However, many studies have shown that the chronically disabled still experience problems and are often insufficiently enabled to participate in the employment process\textsuperscript{2,6,7}.

An outline is given of the health status, work-related abilities and dependence on help, to reveal factors which play a role in reintegration in work in four different SCI groups. Regarding the number of work-related disabilities, the extra time needed for self-care, and the degree of perceived physical functioning, the completeness of the lesion differentiated better than the level of the lesion. In view of these outcomes, the impact on the level of activities is larger for people with complete SCI. The high dependence score and dissatisfaction with self-care abilities of persons with complete tetraplegia illustrate the dependence on others with several daily activities. The results on the other perceived health items and life satisfaction domains were not associated with the type of SCI. And what is important for this study: also the vocational outcome did not show significant difference between the subgroups.

The percentage of 60% who were currently being employed in the present study was higher than expected. The variation in study samples in terms of demographic and injury-related characteristics, makes it difficult to compare results of different studies. In a Dutch multi-centre study\textsuperscript{12} Thomassen et al.
reported that 37% of pre-injury workers were gainfully employed after the SCI, which was lower than the outcome in this study. The recruitment of participants was comparable. Persons in our study group were slightly younger with little more incomplete lesions and the time since injury was on average longer. Other factors such as socio-economic and cultural circumstances were assumed to play a role, but were not analysed in this study. We were not able to identify significant SCI-specific indicators of vocational outcome several years after the SCI. The educational level turned out to be an important factor. This asks for an extensive evaluation of opportunities for education and vocational re-training during the vocational rehabilitation.

In this study two-thirds of persons at work underwent on average extensive changes in working hours. Employees reduced their average working hours to two-thirds and self-employed workers even to half of their former hours. Financial consequences were often at least partially compensated by benefits from the Work Disability Act, which makes it attractive to carry on working. Job adjustments are often indispensable to return successfully to former and new jobs. Despite small numbers of patients, several differences in the interventions and experiences can be found between persons who kept working at the same employer and those who changed to a different employer. The first group re-integrated relatively fast with various adjustments and loss of working hours. The employer is obliged to support all measures needed to re-integrate in work. Persons who had to find a different employer received more vocational re-training and needed more time to return to work, so long-term counseling of this group is essential. However, it seems that working hours are less often reduced, people are less dependent on the Work Disability Act, and more satisfied with their job, which confirms the assumption that new jobs are less physically demanding and match better with the disabilities. In view of these findings we assume that persons who change to a different employer have better chances to keep at work in the long run. Prospective studies are necessary to test this hypothesis.

The main goal of the Vocational Handicap Research Programme which was developed by TNO Arbeid (Dutch Organisation for Applied Scientific Research), was to describe the working conditions and experiences of chronic disabled people with various diagnoses, to create a more positive image of their capabilities and improve interventions. The personal experiences of working respondents in our study were reasonably positive. Most of them were fairly satisfied or satisfied with their jobs and that is comparable to the experiences of other disabled workers. Nevertheless, the number of negative experiences associated with work such as mental strain, working under pressure, insufficient consideration of colleagues and bosses, and absence due to illness, are relatively high and should not be underestimated. As in other studies of the research programme of TNO Arbeid a substantial number of workers wished more adjustments and contacts with professionals. Employees are less satisfied if they feel a need...
for further adaptations in the workplace and experience negative social effects due to their disorder. The group of ageing SCI disabled is even more at risk of not sustaining employment, because of early reduction of physical condition. This asks for ongoing efforts of professionals to keep this group with SCI at work, with interventions that fit personal requirements. More freedom in personal time management and the opportunity to work at home seem preferable.

In-depth interviews are needed to gain more insight in the personal experience of those who returned to work following a SCI, to enhance the quality of individual counselling and effective interventions. Vocational guidance should not be restricted to the rehabilitation and following reintegration period, but to be continued in the long run to keep the people with SCI at work.

Appendix

Questionnaire for workers as part of the Vocational Handicap Research Programme of TNO Arbeid (items not used in this study are in italics):

1. Disease-specific items:
   - Disabilities regarding work-related activities
   - Dependence on help with self-care, domestic activities, transport
   - Complaints / symptoms

2. Health: assessment of health perception on 9 dimensions (RAND 36)

3. Income

4. Educational level

5. Pre-injury employment situation: type of job, job contract, working hours

6. Current employment situation: type of job, job contract, working hours

7. Job modifications:
   - Change of job or employer
   - Material and immaterial adaptations of the job

8. Opinions about the current working conditions and social atmosphere:
   - Job satisfaction
   - Personal experiences regarding the job
   - Accessibility and transport
   - Relationship with colleagues and boss
   - Possibilities for promotion
   - Influence of job on health
   - Wish for (more) job modifications
   - Absence due to illness
   - Contacts with work professionals
   - Wish for (more) contacts with work professionals
   - Looking for another job

9. Situation of those who stopped working
References


