Summary

Patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits as well as bladder, bowel and sexual dysfunction, which lead to a fundamental change of life. Because of the extensive medical, emotional and social consequences of the SCI, multidisciplinary management is essential. All over the world rehabilitation programmes have been developed in order to enhance the functional outcome after SCI. Important goals of rehabilitation are maximising the independence in daily activities and providing optimal reintegration in society. This thesis focuses on the functional outcome after a spinal cord injury.

The functional outcome can be described according to the three levels of the International Classification of Functioning, Disability and Health (ICF), namely 1) functions and anatomical structures, 2) activities and 3) participation. Several frameworks were developed for considering subjective rehabilitation outcomes and interventions based on the ICF. They are an important source of inspiration for this thesis.

Knowledge of the functional outcome is indispensable to provide accurate prognostic information for the patient and family soon after the SCI. Moreover, it is essential to improve acute medical treatment and rehabilitation, to set out health care policies for the SCI disabled, and to evaluate the quality of care. Extensive research has been done on the outcomes of rehabilitation after SCI. Most studies have focused on incidence rates and general characteristics of people with SCI. Objective predictors and outcomes of self-care and work have been comprehensively analysed.

At the outset of our study little was known about the characteristics of patients with spinal cord lesions in The Netherlands. More knowledge was needed about the actual outcomes of activities and participation, and particularly of the results of vocational reintegration, as this largely takes place beyond the scope of the rehabilitation team. In literature the information on the process of rehabilitation and reintegration into society after SCI is limited. Our attention is drawn to the role of the individual patient during the rehabilitation process, and the personal experiences and satisfaction of people with SCI after the reintegration in society.
The main objectives of this thesis are:

1. To give an epidemiological overview of the characteristics of a cohort of patients with spinal cord lesions and their process of rehabilitation;
2. To describe the outcome of independence in daily activities of patients with spinal cord injuries at discharge from the rehabilitation centre, in relation to the early expectations of the rehabilitation team and the individual patient at admission;
3. To describe the outcomes of vocational and leisure participation several years after the spinal cord injury, in relation to the early expectations, reintegration interventions, the current experiences, satisfaction and unmet needs.

In the first part of this thesis an introduction on the subject is given (chapter 1), followed by an epidemiological description of the population with SCI (chapter 2).

Chapter 1 is the introduction and includes a review of the literature and the aims of this thesis. In chapter 2 an overview is given of the characteristics of a cohort of patients with spinal cord lesions. It presents the occurrence of SCI in The Netherlands, the general characteristics and rehabilitation routing of this patient group. Data are gathered of 293 patients who followed a comprehensive inpatient rehabilitation programme.

In The Netherlands on average sixteen new cases per million per year were admitted to the rehabilitation centre, and this is comparable with the rates found in other European studies. Patients with non-traumatic lesions formed half of the rehabilitation population and are distinguished by age and sex. As it concerns on average older people this subgroup benefits from special programmes with realistic objectives.

Acute medical care is fragmented as patients come from many different hospitals and departments. Aiming at optimal rehabilitation management a regional SCI care system is recommended, based on close collaboration between a special SCI department in an academic or top-referent hospital and the rehabilitation centre. Nearly all patients go home after discharge. Attention paid to independent living programmes, appropriate housing facilities and more rapid procedures, can reduce the length of stay in the rehabilitation centre and enhance discharge to the patient’s environment.

The second part of this thesis evaluates the functional outcome regarding daily activities in relation to the expectations. The objectives were to provide a more accurate prognosis of independence in daily activities for each type of SCI, and to enlarge the role of the patient in setting realistic rehabilitation goals. Results of independence in activities of daily living at discharge after inpatient rehabilitation were compared to the expected functional outcome based on theoretical models (chapter 3), and to the early expectations of the professionals.
In chapter 5 the vocational reintegration process after SCI was studied. Of the 49 respondents who were employed at the moment of the SCI, 45% expected to resume work. Positive expectations were associated with higher education. Two-thirds returned to work, which was more than expected from literature. The chance to reintegrate successfully is significantly better for those patients who expect to return to their jobs. In this study several personal and injury-related variables proved not to be associated with success. A description is given of the reintegration interventions, including vocational re-training, changes in job type or working hours, and adaptations of the workplace. In view of the experiences and unmet needs, focus on the reintegration process should start during the rehabilitation period. A reintegration plan is advocated, drawn up by the rehabilitation team, in which all necessary steps and responsibilities of the patient, employer and reintegration professionals are recorded.

In chapter 6 the experience with the current job situation is presented. It starts with an overview of the health status, disabilities and satisfaction per type of SCI. The number of work-related disabilities and perceived physical functioning are associated with the extent and not with the level of the lesion. There were no differences between subgroups with different types of SCI as far as being employed or general satisfaction were concerned. Of the respondents 60% were currently employed, which was related to a higher level of education. Persons who changed to a different employer needed more time to resume work than those who returned to their former jobs and employer, but they experienced less loss of working hours, less benefit from the Work Disability Act, and more job satisfaction. Despite the high level of job satisfaction of the workers, the reported negative job experiences and absence of work due to the SCI should not be neglected. This asks for long-term counselling of the SCI disabled during and after the reintegration period with more attention paid to their personal experiences and needs.

In chapter 7 attention is paid to the changes in vocational and leisure participation and current satisfaction of people with SCI after reintegration in society. The number of hours spent on participation activities have changed to a great extent. This is mainly explained by a large reduction of working hours of more than 50%. Substantial variation is found in the degree of loss of participation. Part of the study group without paid work compensated the loss of work with domestic and leisure activities. The level of change in participation is not significantly associated with the number of work-related disabilities and SCI-specific health problems. As in many other studies concerning chronically disabled people, most persons with SCI are satisfied with the quality of their lives. The level of satisfaction is not significantly related to SCI-specific and participation-related variables. Reduced perceived quality of life is particularly associated with a unsatisfactory vocational and leisure situation and more unmet needs regarding reintegration interventions. Focus on work and leisure during
follow-up of the rehabilitation team several years after the SCI, might enhance a satisfactory participation.

In the general discussion the most important findings and weaknesses of this study are addressed, as well as the consequences and challenges for the rehabilitation medicine. Recommendations for further research are given. The results of this study emphasise the need for a regional SCI-care system. Rehabilitation activities are integrated with this care system from the first day after the injury until the phase of long-term follow-up after reintegration into society. In this whole process personal experiences and unmet needs of people with SCI are at the centre. The level of independence in daily activities after SCI is often lower than indicated by theoretical models. In the process of goal-setting regarding future functioning, the assessment of expectations of the individual patient and the rehabilitation team should play an important role. This enhances functional prognosis and increases the involvement of the patient in the rehabilitation process.

People with SCI are able to achieve satisfactory participation levels. A majority of them reintegrate in paid work. Focus on the reintegration process should start during the inpatient rehabilitation period. An active role of the rehabilitation team is recommended in drawing up a reintegration plan in close collaboration with the patient and employer. Long-term follow-up by the rehabilitation team, in which attention is paid to vocational and leisure issues, completes the continuum of care for people with SCI.
and the individual patient at admission (chapter 4). Data on expectations of the patient and rehabilitation team and functional progress were gathered from the database of the Rehabilitation Information System - Information System for patients with spinal cord injury (RIS-DIS). This information system was developed in the 1970s to evaluate the rehabilitation treatment of patients with SCI in The Netherlands and to work out a prognostic model for functional outcome. Data were obtained of 55 patients with traumatic SCI who followed a comprehensive inpatient rehabilitation programme.

In chapter 3 the recovery of functional improvement during the inpatient rehabilitation period is evaluated and compared with information from other studies. Nearly all patients with complete spinal cord lesions at admission kept complete motor and sensory loss. Significant progress in independence was made in self-care, ambulation, and incontinence care. Differences in the extent of functional improvement were found between subgroups with different types of SCI. The level of independence after inpatient rehabilitation was not as good as expected, based on the theoretical models. This is an important issue in giving prognostic information. Particularly as far as bladder and bowel care are concerned, poor results were found. Attention paid to urological management regarding incontinence and optimal independence in incontinence care, was recommended as an important part of the rehabilitation programme.

In chapter 4 the early expectations of the rehabilitation team and patients regarding functional outcome were explored and related to the results of independence after the inpatient rehabilitation programme. Prediction of functional outcome soon after the SCI is most successful if the expectations of the rehabilitation team and patients are combined. Prognosis of independence in self-care of patients with paraplegia and mobility potential of patients with a complete SCI, is usually clear at admission. However, early prediction of the outcome concerning self-care of patients with tetraplegia and mobility of patients with incomplete lesions is far more complicated. Gradual adjustment of objectives during the rehabilitation process is needed, in close collaboration between the professionals and the individual patient.

Although a satisfactory participation is one of the ultimate goals of rehabilitation, the process of reintegration in society takes largely place outside the scope of the rehabilitation centre. The third part of this thesis is about participation and reintegration in society. The aim of this part is to provide topical information about the outcomes of vocational and leisure participation following SCI as well as the reintegration interventions. Both the process of reintegration in work (chapter 5) and the experiences with the current job situation (chapter 6) were studied, and changes in participation after SCI were related to life satisfaction (chapter 7). Data are gathered from a mailed questionnaire about work and leisure activities, which was developed for this study. The questionnaire was returned by 57 persons with traumatic SCI (response 83%), aged 18 to 60 years, who earlier followed a rehabilitation programme.