Chapter 1

Introduction
Patients with spinal cord injuries (SCI) are confronted with motor and sensory deficits and dysfunction of bladder and bowel, leading to a fundamental change of life. Until the Second World War the majority of patients with SCI died due to complications, often leading to fatal infections. At first the research of outcomes after a SCI was focused on survival rates and medical consequences in the acute phase. In the last decades there has been a shift of interest to the impact of the SCI, illustrated by the physical and psychosocial consequences for the patient. According to the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF) the functional outcome can be described in three dimensions, namely functions and anatomical structures, activities and participation.

Knowledge of the functional outcome is indispensable to provide accurate prognostic information for the patient and family. Moreover, it is essential to improve acute medical treatment and rehabilitation, to evaluate the quality of care and to set out health-care policies for SCI disabled. Because of the extensive medical, emotional and social consequences of SCI, multidisciplinary management is essential. All over the world rehabilitation programmes have been developed in order to enhance the functional outcome after a SCI. Important goals of rehabilitation are to maximise the independence in daily activities and to provide optimal reintegration in society.

The aim of this thesis was to increase our knowledge of the functional outcome after a SCI on the level of activities and participation. The study provides insight in several aspects of the process of rehabilitation, from admission to the rehabilitation centre until several years after reintegration, and explores the role of the individual patient and professionals in the rehabilitation and reintegration process. Recommendations regarding the whole continuum of care will be given in order to improve the rehabilitation programmes for patients with spinal cord lesions based on realistic goals.
Research on outcome after SCI

Since Guttman started to focus attention on the rehabilitation aspects of patients with SCI after World War II\(^2\), many studies addressed the outcomes following SCI in different regions all over the world. Epidemiological studies from several countries presented the incidence of SCI. A reliable assessment of the incidence in The Netherlands was not yet available. Globally the incidence varies from 9 to 53 spinal cord lesions per million inhabitants per year. In Europe the incidence is generally low (9 to 16 / million/ year)\(^3-6\). Assessments in 1990 estimated a rate of 30 to 32 new traumatic SCI per million in the USA and 39.4 per million in Japan\(^7,8\). Apart from sociological and demographic differences the variance is explained by the definition of SCI used in different studies. Most studies concentrate on patients with traumatic SCI. In European studies 25 to 39% of the spinal cord lesions was non-traumatic and characteristics of these patients differ from those with traumatic lesions\(^3-5\). Peaks are found in the younger age groups for traumatic injuries and in the older age groups for non-traumatic lesions. The majority of patients with traumatic injuries are male, whereas non-traumatic lesions are more equally divided over both sexes.

Activities
Impairments such as motor and sensory loss and impairments of bladder, bowel and sexual function are the most important physical consequences of a SCI, leading to extensive disabilities in activities of daily life. Health problems that often develop secondary to the SCI are pain, spasms, pressure sores, urinary problems, bowel problems, respiratory failure, oedema and excessive sweating\(^9\). In several studies by Waters \emph{et al.} the motor and sensory recovery following traumatic SCI was quantified, using the initial level of injury\(^10-12\). Most of the neurological recovery occurs within the first six months after injury\(^10\).

The degree of functional improvement, which is more relevant in predicting rehabilitation outcome, depends on the level and extent of lesion. Various theoretical models have been developed and studied to predict potential physical abilities based on spared motor and sensory functions\(^1,16\). Many articles focus on self-care of patients with tetraplegia\(^1-19\). C6 and C7 are critical levels for achieving independence in daily activities. Most authors agree that patients with paraplegia can achieve independence in self-care skills\(^14,19\). Ambulation is the subject of several studies with a diversity of results\(^20-24\). Nene \emph{et al.} presented a review of reports concerning locomotion\(^23\). There is considerable difference in opinion regarding a patient's ability to walk and the use of orthoses. Most authors generally accept that patients with complete lesions above T10 are incapable of functional locomotion. The outcome of bladder and bowel care after SCI is comparatively unknown. Advances in urological pharmacology and sacral root stimulators have led to better urological outcome.
The functional performance of those patients also depends on other factors, such as age, co-morbidity, health problems, motivation and coping\textsuperscript{15,16}. Studies that actually evaluate the functional prognosis as predicted by professionals are rare\textsuperscript{12} and the expectations of the individual patient regarding his functional outcome were never examined.

**Participation and reintegration in work**

Most people with SCI are able to live in their community after the rehabilitation process. A significant number of them achieves independence in daily activities. Reintegration in work, leisure activities and sports is considered to be a subsequent important goal of rehabilitation. Active involvement in activities and roles is strongly related to health and well-being\textsuperscript{25} and a high level of social activities leads to a better quality of life\textsuperscript{26,27}. According to the ICF participation in society includes reintegration in work and school, but also significant involvement in housekeeping and community organisations\textsuperscript{1}.

In literature many reports were published on the quantitative outcomes of employment after the SCI, mainly expressed as work rates. The variation in study groups makes it difficult to compare the results of different studies. American studies in the eighties showed poor rates up to a maximum of 25% of persons being employed after SCI\textsuperscript{14,28-30}. In more recent American, Australian and European studies the percentages of persons gainfully working improved and ranged from 31 to 48%\textsuperscript{27,31-33}. In a Dutch multi-centre study Tomassen et al. reported that 37% of pre-injury workers were gainfully employed after SCI\textsuperscript{34}. Returning to work is a complex process that results from an interaction of impairment and personal and environmental factors\textsuperscript{25}. Predictors of successful job reintegration are subject of a lot of research on vocational outcome of persons with SCI\textsuperscript{14,27,31-38}. Several studies focused on demographic and injury-related factors, such as age, type of lesion, Barthel Index and time elapsed since injury. Work-related factors were studied, including educational level, pre-injury employment status, vocational re-training, social security system, financial disincentives (losing benefits when becoming gainfully employed) and work place discrimination. Also environmental factors such as transportation and architectural barriers apparently played a role. Only few studies focused on the role of subjective indicators such as work interests and values, educational and vocational plans and societal attitudes\textsuperscript{28,32}. Expectations of the individual patient regarding work, were scarcely studied in relation to vocational outcome.

For those persons who were not able to reintegrate in work, participation in non-vocational activities must also be considered as a successful rehabilitation outcome. Only few studies have described the outcomes of participation other than traditional employment\textsuperscript{25,27,35,37}. The assessment of these non-vocational outcomes is more difficult, since those activities are
more complex to quantify in everyday life. A major shift in time use occurred from time spent on social activities to personal care activities.

**Quality of life**
Attaining an acceptable quality of life can be seen as the ultimate goal of rehabilitation. Satisfaction with the quality of life after a SCI depends on the way a patient learns to adapt to fundamental changes in his life. Various objective and subjective determinants of quality of life after a SCI were studied in literature. More subjective approaches focus on the person's satisfaction with those aspects of his life situation thought to be affected by the particular disability under study\textsuperscript{26,39}. Some authors found that life satisfaction among persons with SCI is relatively good and in a few studies even better than their peers\textsuperscript{40,41}. Other findings indicate that people with SCI who live in the community report a lower level of satisfaction with life\textsuperscript{42}. Post et al. also found a lower general life satisfaction than in the Dutch population group, but some differences disappeared after adjustment for age and marital status\textsuperscript{43}. Satisfaction with the vocational situation is usually low\textsuperscript{9,42}. For those persons who returned to work after the SCI this can be explained by unrewarding, poor-quality jobs and insufficient income\textsuperscript{26}. Information about the satisfaction with non-vocational participation in other activities is scarce\textsuperscript{25,27}.

**Dutch research on outcome after SCI and outcome measures**
In the last decades several interesting studies have been done in The Netherlands. Their results were of great importance to the rehabilitation medicine in The Netherlands in general, and the rehabilitation of people with SCI in particular. Van Asbeck performed a descriptive study regarding the functional outcome of persons with paraplegia in the Netherlands in his thesis of 1987\textsuperscript{44}. De Witte analysed the outcomes of patients with SCI and other diagnoses after the rehabilitation centre\textsuperscript{45}. Van Bennekom and Jelles presented the ICIDH as a framework for assessment in rehabilitation medicine in their dissertation of 1995\textsuperscript{46}.

In Post’s thesis of 1997 a large-scale nation-wide study was performed regarding the health status and life satisfaction of people with SCI, including non-traumatic lesions\textsuperscript{47}. It revealed various relationships between rehabilitation outcomes of different dimensions. He developed a conceptual framework for rehabilitation outcomes, which is an extension of the International Classification of Impairments, Disabilities and Handicap (ICIDH)\textsuperscript{48}. In this model he added a subjective axis linked to the original objective outcome levels. “Somatic sensation, perceived health and life satisfaction” were indicated as subjective counterparts of respectively “impairment, disability and handicap”. Besides, the concept of happiness was given a separate place in the framework.

In the meantime the ICIDH changed into a concept of “functions and anatomical structures, activities and participation”, which means a positive
approach of rehabilitation outcomes (ICIDH-2). Personal and environmental factors recently have been incorporated in the model in 2001, leading to the renewed International Classification of Functioning, Disability and Health (ICF)\(^1\).

**Research on the process of rehabilitation**

Following the definitions of the World Health Organisation of 1980 the philosophy of rehabilitation is to reduce disabilities and handicaps resulting from impairments caused by trauma or disease\(^48\). Wade described the core features of rehabilitation as follows: co-ordinated, multidisciplinary teamwork, by a team interested in disability, who actively involves the patient and family in the process, which is set in an explicitly recognised framework encompassing all aspects of illness\(^49\). Several studies were found in which aspects of the process of rehabilitation after SCI were explored.

Research on the process of interdisciplinary rehabilitation treatment following SCI is limited. In a framework for considering rehabilitation interventions Wade suggested evaluation of treatment on the levels of the ICIDH\(^50\). Rehabilitation interventions on the level of activities intend to alter the behaviour of the patient and family by teaching adequate skills and strategies, and alter the physical environment by providing appropriate equipment, adaptations and trained caregivers. Interventions at the level of participation ideally maximise the behavioural repertoire of the patient and provide suitable opportunities for social interaction, like educational and employment services. Participation outcomes are largely influenced by factors outside the influence of most health-care systems. Well-being is reduced if there is a discrepancy between a patient’s behaviour and social-role functioning and too high expectations. Pain and anxiety are also important factors influencing well-being. Rehabilitation interventions on the level of well-being should focus on reduction of high expectations and treatment of distress.

The process of goal planning has received considerable attention in studies regarding interdisciplinary rehabilitation treatment\(^51\). The role of the individual patient in the process of rehabilitation seems very important. Fuhrer et al. mentioned that the subjective experiences of those involved are usually not represented in the outcome measures and generally neglected\(^42\). It is assumed that motivation and expectations of the patient regarding reintegration in society will affect the outcome to a great extent. In his editorial on evidence relating to goal planning Wade stated that goals are central to the process of rehabilitation\(^51\). Rehabilitation involves altering the behaviour of people and this can only be achieved if the patient wishes to attain a goal in agreement with the rehabilitation team. There was no evidence on the most appropriate method to undertake goal planning and this should be a challenge for further investigation on the impact of goals and expectations.
In the last decade the evaluation of the quality of health care has become an important topic. Health-care providers are stimulated to assess their performances in order to compare the health services regarding quality and efficiency. Various indicators of performance are selected that reflect the quality of care. It is essential that also in rehabilitation medicine attention is given to the settlement of adequate and validated quality indicators of rehabilitation facilities. Choices have to be made regarding the value of several outcome measurements as part of our conceptual framework of rehabilitation outcomes, which go beyond complications and survival. The outcomes of specific diagnosis groups should be clear to explain differences in performance of specialised rehabilitation departments.

**Research on the process of reintegration in work**

The Dutch legislation regarding work disability is complex and different from that of most other countries. Because of a large number of work-disabled people in The Netherlands several changes in legislation have been made in the last decade aiming at the increase of reintegration in work. In the first year of absence from work due to illness or injury, the employee receives full compensation of his salary based on the principles of the Sickness Benefit Act. During the first two years of absence from work due to illness or injury, both the employer and the employee are responsible for reintegration in work. The employer is obliged to support resumption of work or to offer an alternative job. At the end of the second year a decision of disablement can take place, either leading to continuation of employment with or without supplementary benefit from the Work Disability Act, or to termination of the employment. Benefit from the Work Dependent Act depends on the loss of earning capacity regarding employment that the employee can manage. Supplementary benefit from the Work Disability Act for the employee and a bonus for the number of disabled workers in the company for the employer, should make it more attractive for employers to keep disabled people employed.

Participation in the employment process of chronically disabled people has been an important point of political interest in The Netherlands in the last decade. However, many studies have shown that the chronically disabled still experience problems and are often insufficiently enabled to work. TNO Arbeid (Dutch Organisation for Applied Scientific Research) 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 experiences of chronically disabled people with various diagnoses, to create a more positive image of their capabilities and to improve reintegration care. People with SCI have not been involved in the programme yet. Recommendations to improve vocational outcome of disabled people found in international literature, were tailor-made educational and vocational
counselling, contact with peer groups, changing employer perceptions, improving transport and equal access, and reducing financial disincentives to working\textsuperscript{33}. Most of these proceedings usually take place beyond the scope of the rehabilitation team. In her thesis, Schoppen emphasised the benefits of job modifications, specialised vocational rehabilitation programmes, and cooperation between all professionals involved in the process of reintegration of people with a leg amputation\textsuperscript{57}.

**Aims of this thesis**

Several issues in literature were important sources of inspiration for our research. At the outset of our study, little was known about the occurrence of spinal cord lesions and demographic characteristics of these patients in The Netherlands. Rehabilitation of patients with SCI is restricted to rehabilitation centres with a specialised department for spinal cord injury rehabilitation care. Acute medical care takes place in several hospitals. After the rehabilitation process people with SCI spread to various health care services. First of all, we aimed at an overview of characteristics of the Dutch population with SCI and describe the process of rehabilitation as part of the continuum of care for people with SCI in The Netherlands.

Secondly, more knowledge was needed about the actual outcomes of activities and participation according to the ICF in order to provide accurate prognostic information. This also includes neglected issues with huge social consequences, such as bladder and bowel care. As far as the level of participation is concerned, we lacked insight in the results of reintegration in society, as this largely takes place outside the scope of the rehabilitation team. Vocational reintegration of the chronically disabled is a topical subject and an important issue for people with SCI that should be studied extensively.

Thirdly, our attention was drawn to the role of personal factors of the individual patient and the subjective factors that influence the process of rehabilitation. Expectations of patients regarding functional outcome form an essential basis in the process of goal planning, and might be an important determinant of the rehabilitation outcome. In order to use rehabilitation services efficiently and involve patients in their rehabilitation process, the rehabilitation programmes should be based on realistic goals. Besides, we were interested in personal experiences, satisfaction and unmet needs of people with SCI after the process of rehabilitation and reintegration in society. With more knowledge about the factors interfering with a satisfying participation, the rehabilitation team can prepare patients and family and teach them how to cope with these matters.

Finally, information about external factors such as reintegration interventions and support from professionals was scarce and required attention. Aiming at optimal participation we have to know which
interventions promote adequate skills and strategies and create opportunities for participation.

The following objectives were formulated:

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 injury 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, in relation to the patients’ early expectations, reintegration interventions, current experiences, satisfaction and unmet needs, several years after the spinal cord injury.

Outline of this thesis

The first part includes this introduction on the main thrust of this thesis and an epidemiological overview of characteristics of the population under study. In chapter 2 the incidence and general characteristics of a Dutch population with SCI are presented. Differences between traumatic and non-traumatic spinal cord lesions are indicated. An outline is given of several characteristics of the process of rehabilitation of patients with spinal cord lesions, admitted to a department specialised in SCI care of the rehabilitation centre. We discuss the benefits of regional care systems in the Dutch situation.

The second part focuses on the functional outcome after SCI at the level of activities and the prognosis of independence in daily activities based on early expectations of the individual patient and the rehabilitation team. In chapter 3 a description is given of the neurological recovery and the functional outcome which is achieved during an inpatient rehabilitation period. Subgroups with different levels and extent of lesion are analysed regarding independence in self-care, ambulation and bladder and bowel care. In chapter 4 the predictions of the professionals and the individual patient regarding functional outcome are compared to the number of patients who actually have achieved the expected level of independence at discharge from the rehabilitation centre.

The third part concentrates on aspects at the level of participation following a SCI. The process of reintegration in work is the studied (chapter 5), followed by the current experiences with work (chapter 6). The outcomes of participation and satisfaction with participation are presented (chapter 7). In chapter 5 attention is paid to the role of early expectations the individual person with a SCI regarding return to paid work and other
indicators of success of job reintegration. An overview of the reintegration interventions is presented, including vocational training, job changes and adaptations. The barriers in the process of reintegration of persons who failed to return to work are mentioned. In chapter 6 the vocational situation several years after the SCI is assessed. The results of job participation are related to the current health status and work-related disabilities. A description is given of the personal experiences, job satisfaction and unmet needs of those who are currently working. In chapter 7 the changes in time use and actual reintegration in vocational and leisure activities are analysed several years after onset of the SCI. Results of life satisfaction will be presented, especially regarding the vocational and leisure situation. Reports are given of the support that is received during the reintegration process.

In the general discussion and conclusions the clinical and societal implications of this study are summarised and discussed. Recommendations for further research are given.