Chapter 8

General discussion
This thesis focuses on the functional outcome following spinal cord injury (SCI). It presents outcomes of a Dutch population with SCI on the level of daily activities and vocational and leisure participation. The study also provides insight in aspects of the process of inpatient multidisciplinary rehabilitation and the process of reintegration into society, as part of the continuum of care for SCI patients in The Netherlands. In all stages the role of the individual patient was emphasised and it turned out to be important in predicting functional outcome.

Knowledge of the functional outcome after SCI, and of characteristics of the process leading to these results, is indispensable to provide accurate prognostic information for the patient and family, to improve rehabilitation and reintegration programmes, and to set out health care policies. Moreover, evaluation of the performance of health care providers has become a topical subject and asks for adequate quality indicators regarding rehabilitation facilities.

In this general discussion we address the principle findings of this thesis and discuss the implications and challenges of our study. Recommendations for further research are provided.

The continuum of care

The first aim of this thesis is to give an overview of the characteristics of the population under study and to describe aspects of their process of rehabilitation, as part of the continuum of care for people with SCI in The Netherlands. The incidence was estimated to be on average 16 new patients with SCI per million per year admitted to the rehabilitation centre. Demographic differences were found between groups with traumatic and non-traumatic lesions. Nearly all patients go home after the discharge from the rehabilitation centre.

Data were analysed of a cohort of patients with spinal cord lesions admitted to the rehabilitation centre. The results of patients with traumatic SCI can be generalised to the whole Dutch population with traumatic SCI, as nearly all these patients follow a rehabilitation programme. The characteristics of patients with non-traumatic lesions are not representative for the total group of patients with non-traumatic lesions, as they are not always transferred to a rehabilitation centre. A reliable nation-wide registration of this group is not available.
Contrary to other Dutch studies we also included patients with malignant tumours with a relatively good prognosis, who were able to finish a rehabilitation programme with short-term goals. This has influenced the average length of stay at the rehabilitation centre.

Globally young males of 20 to 40 years of age are most at risk of having a traumatic SCI. As about half of the rehabilitation population have non-traumatic lesions, a second peak is found in the age group 61 to 70 years and a high number of females. Special programmes for this group are needed based on a short rehabilitation admission with short-term realistic objectives. In The Netherlands patients with acute SCI are admitted at traumatological, neurological, neurosurgical and orthopaedic departments of university and general hospitals. This variation in referring hospitals leads to fragmentation of initial medical care. As soon as the physical condition is stable they are transferred to one of the rehabilitation centres with a specialised department for spinal cord lesion care. In our opinion regional SCI-care systems should be set up in The Netherlands, consisting of close collaboration between specialised SCI departments in an academic or top-referent hospital and the rehabilitation centre. It has already been emphasised in literature that this has several benefits: more experience with the management of SCI, decrease of preventable complications and mortality, shorter lengths of stay and reduction of costs \(^1\)-\(^3\). Rehabilitation medicine should be integrated with the continuum of care of spinal cord lesions from the very first day after injury.

The Dutch National Health Service and the private health insurances cover hospitalisation in a rehabilitation centre on medical grounds. Discharge from the rehabilitation centre is very often delayed by social circumstances. A substantial number of patients have to wait for suitable housing facilities, or for semi-independent institutions with professional help with activities of daily living available on demand. Post et al. already reported low satisfaction with service delivery procedures in The Netherlands and found that the discharge from the rehabilitation centre was delayed by a median time of 15.5 weeks for one third of the respondents \(^4\). This asks for more rapid service delivery procedures. Most services such as domestic adaptations, wheelchairs and modes of outdoor transport are provided by means of the Act on Facilities for the Handicapped (Wet Voorzieningen Gehandicapten (WVG), executed by local councils with medical account given by the Local Health Authority (Gemeentelijke Gezondheidsdienst (GGD). Procedures can be accelerated if the advice regarding required services is formulated by the rehabilitation team and replaces the often bureaucratic and time-consuming assessments by GGD and WVG officials.

Almost all patients go to their homes after their inpatient rehabilitation period. From the start of the rehabilitation programme goals are set to train skills regarding independence and facilitate personal and environmental circumstances which determine the individual’s ability to live independently after discharge. After the inpatient period the patient usually follows an outpatient programme from his home for two or three days a week. This
transitional stage provides an opportunity to try out the new living situation and to evaluate the amount of care, equipment and adaptations. In this phase issues such as return to work and leisure activities become important.

As the SCI leads to chronic disabilities and an increased risk of specific health problems, the continuum of care should be prolonged after the rehabilitation period with a long-term follow-up by the rehabilitation team\textsuperscript{5,6}. In this thesis we were not able to analyse all aspects of the aftercare of the patients, but it certainly revealed unmet needs regarding contacts with the rehabilitation team in later phases after SCI. Further research should explore the benefits regarding efficiency and quality of the entire continuum of care for people with SCI.

**Activities and goal-setting**
The functional outcome of patients with traumatic SCI is described in terms of independence in daily activities at discharge from the rehabilitation centre. The objectives of this study are to provide more accurate prognostic information about the independence in daily activities and to explore the role of the patient in setting realistic goals. The level of independence in daily activities at the end of the inpatient rehabilitation is not as good as expected from literature. Prediction of functional outcome after spinal cord injury is most successful if the expectations of the team and patients are combined.

The study group is a representative cohort of inpatient rehabilitation patients. All patients with traumatic SCI admitted to the rehabilitation centre in the given period were included. In this retrospective study we used the Rehabilitation Information System-Information System for spinal cord injuries (RIS-DIS) as a database, which provided extensive and detailed information on medical and functional progress. It also includes expectations of the rehabilitation team and individual patient, reported 8 weeks after admission. This information system was developed in the 1970s to evaluate the rehabilitation treatment of patients with a spinal cord injury in The Netherlands and to work out a prognostic model for functional outcome. We assessed a basic set of relevant daily activities, but we realised that it was not simply comparable to scales with accepted validity and reliability such as the Barthel Index\textsuperscript{7}. Further research has to be done to examine the clinimetric properties of the RIS-DIS for more extensive scientific purposes.

Early prediction of neurological and functional outcome of SCI is useful in informing the patient and family and making decisions about treatment. Functional prognosis is usually based on the initial level and extent of the lesion. However, the level of independence in daily activities which was achieved in this study was not as good as expected, based on the theoretical models. Other factors such as co-morbidity, spasticity, pain, motivation and coping also seem to play an important role and are subject to change during the rehabilitation process. This is an important issue in giving prognostic information. We assume that expectations of the individual patient are based on prognostic information received from professionals and the progress that is
made so far, and are also influenced by subjective factors, such as understanding and coping. Predicting the functional outcome after SCI is most reliable if the expectations of both the professionals and the patients are taken into account.

Expectations of the individual patient are a complicated construct, but we believe that they should play an important role in goal-setting and involvement of patients in their rehabilitation process. Goal-setting forms the basis of interdisciplinary teamwork, which means that the whole team works towards goals relevant to the patient. The results of rehabilitation interventions depend on the patients’ expectations regarding functional outcome and the goals they want to attain. Especially in later phases of the rehabilitation programme the patient becomes more autonomous and responsible for achieving the goals, with the rehabilitation team acting as a coach. The team gradually loses the more paternalistic professional attitude, which is indispensable at the start of the rehabilitation programme. More research is needed to evaluate the process of interdisciplinary goal-setting and treatment on its effectiveness and efficiency.

The outcomes of independence in bladder and bowel care of our study population were poor. In order to reduce the practical and emotional consequences of incontinence, focus on optimal independence in bladder and bowel care is essential in the rehabilitation programme. An urologist and a nurse specialised in bladder and bowel problems are recommended as a full member of the rehabilitation team and they should also play an important role during long-term follow up.

Reintegration in work
The most important goal of rehabilitation is to enable disabled people to return to independent and satisfying lives in the community. This thesis evaluates the outcomes and process towards participation following SCI, in order to improve information to the patient, to enhance vocational rehabilitation and reintegration programmes and set out policies regarding work disablement. The rate of successful job reintegration was higher than expected from literature and the patient’s expectations regarding future participation turned out to be an important indicator of the vocational outcome. Despite several useful job modifications, the unmet needs regarding reintegration interventions and negative experiences in the current job should not be neglected.

The study group is a representative cohort of patients with traumatic SCI with vocational potential in The Netherlands. All findings in this part of our research are based on the reports of the respondents, which makes them obviously subjective. Most parts of the questionnaire were standardised measures and used in other Dutch studies. We sent the questionnaire at least two years after the SCI, so that the respondents had their first definitive assessment of work disablement according to the Dutch Work Disability Act. The interval between the injury and the current assessment showed
considerable variation, which means that the level of experience with the reintegration process in time also varied within the study population.

From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society. Despite the serious consequences of the SCI we conclude that a fatalistic attitude towards resumption of paid work is unfounded. The vocational outcomes of this study are encouraging. We have to take into account that until recently the economy was booming and the Dutch government stimulated work participation. Unlike several years ago, protection of income by social security is now secondary to being employed. Reintegration in work is a complex process that results from an interaction of many factors. In this study 45% of those who were employed pre-injury had positive expectations regarding work resumption and this was associated with a higher educational level. This study shows that the expectations of the patient are a strong indicator of success of reintegration in work. The role of the patient in predicting the vocational outcome is very important.

Because of physical disabilities as a consequence of SCI, job modifications are often indispensable to resume work. Material adaptations can compensate for reduced functional abilities and ambulation. Immaterial adjustments such as reduction of working hours and personal time management, make it possible to deal with the extra time needed for self-care and transport, and with reduced physical capacity. The majority of the workers undergo extensive changes in working hours. Financial consequences should be at least partially compensated by benefit from the Work Disability Act, which make it attractive to carry on working, both for the employer and for the employee.

Most of the working respondents changed to other jobs, especially if physically demanding jobs were concerned. As a consequence of legislation, employers are obliged to adjust the job or offer an alternative more suitable job. In view of tremendous changes in the first years following the SCI, it seems most comfortable for the person involved to return to the job and be spared the life-event of a new job. However, persons who changed to other jobs in this study are on average more satisfied with the job, experience less reduction of working hours, and are less dependent on benefits from the Work Disability Act. It confirms the assumption that new jobs are less physically demanding and match better with the disabilities. As persons who change to a different employer receive more vocational re-training and need more time to return to work, long-term counselling of this group is essential. Further prospective research is needed to find out in which situations the reintegration in a new job finally has more advantages.

In spite of several measures that should stimulate employers to keep disabled people employed, we know that the chances to resume work are restricted for patients with chronic diseases and disabilities. Those who are motivated to resume work will find obstacles on their way. In this study both those who failed and those who succeeded in reintegrating, mentioned
several unmet needs. Negative experiences of persons with a paid job several years after the SCI, should not be neglected. To make reintegration in work successful on the long run, several interventions that fit personal requirements are indispensable. The rehabilitation team should play an important role.

Firstly, this study supports the importance of early interventions aiming at optimal participation, integrated in the rehabilitation process. The chance to have a paid job several years after the SCI is best for higher-educated people and for those who expect to return to their former jobs. Educational opportunities should be explored extensively for those who are motivated and potential candidates for vocational training should be indicated. Detailed information on these issues must be available. Besides, we advocate that the rehabilitation team plays an active role in drawing up a reintegration plan before discharge from the rehabilitation centre, supported by the patient, employer and all professionals involved in the reintegration process. This plan includes a description of the physical and mental abilities of the individual patient and inventory of required adaptations, set down by the rehabilitation team. The employer and the physician on occupational health give an indication of the requirements the job should meet. The employer is responsible for creating opportunities to resume work by adjusting the job or providing another job with less physical workload. The patient plays a central role and his expectations, wishes and needs regarding the reintegration are of great importance. A personal reintegration budget should be offered to overcome financial barriers. In recent years the concept of a vocational reintegration plan is laid down by law in the Wet Verbetering Poortwachter, an act that stimulates the employee and employer to start reintegration activities within six weeks. The effects of this act will become clear in the near future. We hope that the advantages of these tailor-made reintegration plans will prevail over the disadvantages of bureaucratic and lingering procedures.

Secondly, the support and interventions during the complex reintegration process should take place within the scope of the rehabilitation team. Coaching through the forest of rules and legislation is necessary to facilitate the process and keep the patient closely associated with his own reintegration process. A case manager who links the rehabilitation team and the work professionals and provides up-to-date information, can play an important role in this complex process of vocational reintegration.

Thirdly, during and also after the reintegration process the subjective experience of workers should not be neglected, especially when extensive changes in the job take place. The current experience and satisfaction of the working respondents in our study group were on average positive. Nevertheless, the negative experience associated with work, absence due to illness, and unmet needs regarding adjustments and support, are important signals that people with SCI are at risk of losing their jobs. This favours long-term follow-up by professionals, including those from the rehabilitation...
team if necessary. It must be considered a challenge to complete the continuum of care for people with SCI with adequate vocational rehabilitation facilities.

In terms of future research, prospective studies are needed regarding the process of reintegration in society. Identification of subgroups of individuals who need special services or who experience problems in the reintegration process following SCI, might enhance the quality of individual counselling and effective interventions. Effect studies on the result of vocational reintegration programmes are an important next step.

**Participation and satisfaction**
Finally we discuss the outcomes of vocational and leisure participation in relation to life satisfaction, several years after the spinal cord injury. It is an important finding that a substantial number of people with SCI are able to retain a satisfying productive life in terms of paid work, or find other roles and activities to compensate for their lost jobs. The level of change in participation is not associated with the type and consequences of the SCI. As we expected, a lot more time is spent on self-care. Moreover, we think that the extra time that is needed for all inconveniences outdoors is usually underestimated.

Most respondents of our study are satisfied with their lives, which is often found in studies on the quality of life among persons with chronic diseases. After an intensive process of adjustment, a lot of people with serious disabilities are able to cope with their handicaps. The life satisfaction does not seem to be associated with being employed in the long run. It illustrates that most of the work-disabled people with a SCI gradually adjust to a situation without paid work. Persons who were not satisfied with their lives are particularly dissatisfied with their work and leisure situation, and report more unmet needs regarding support from professionals.

Participation issues deserve more priority during follow-up of the multidisciplinary rehabilitation team. For some patients it is too premature to focus on resumption of work and leisure during the rehabilitation period, due to a delayed or postponed coping and acceptance process. Also for those who fail to reintegrate in work a renewed attempt in creating leisure opportunities should be made, even if it is made several years after the initial rehabilitation period. In-depth interviews with all persons involved can reveal which interventions are best to promote satisfactory participation, and in which phase they are most effective.

**Conclusions**

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.
References