# Life satisfaction and wheelchair exercise capacity in the first years after spinal cord injury

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# Life satisfaction and wheelchair exercise capacity in the first years after spinal cord injury

## Welbevinden en rolstoel uithoudingsvermogen in de eerste jaren na een dwarslaesie

(met een samenvatting in het Nederlands)

## Proefschrift

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door


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geboren op 16 mei 1970
te Arnhem

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# 1

# Introduction

In this general introduction, an overview will be given of the context of this thesis. The health condition spinal cord injury and its accompanying health complications will be described. The International Classification of Functioning, Disability and Health will be introduced with respect to a spinal cord injury. The consequences of a spinal cord injury on wheelchair exercise capacity and life satisfaction will be discussed. Further, the research context of this thesis will be described and finally the main aims and the outline of this thesis will be specified.

## Spinal cord injury

The spinal cord is the major bundle of nerves that carry nerve impulses to and from the brain to the lower parts of the body. The spinal cord is divided into 31 different segments (Figure 1.1). A spinal cord lesion, also referred to as spinal cord injury (SCI), is an interruption of these neural pathways directly resulting in muscle weakness, loss of sensation and autonomic dysfunction below the level of the lesion.[1,2] Dependent on the level and completeness of the lesion, loss of motor function leads to problems with hand and arm functions, stability of the trunk (in lesions above T10) and mobility of the lower limbs, varying from light disturbances to complete paralysis.[2,3] Loss of sensory functions in the abdomen is followed by disturbance of bladder, bowel and sexual functions.[2,3] Completeness of lesion is defined by the loss of sensation in the lowest sacral segments, S4 and S5.[4]

The level of the lesion divides the SCI population roughly in a) persons with tetraplegic lesions (lesions at or above the level of T1), with impairment of sensory and/or motor functions of the upper (and lower) extremities and trunk and b) persons with paraplegic lesions (lesions under T1), leaving the upper extremities intact, yet involving lower extremities and trunk. The control for the primary muscle for inspiration, i.e. the diaphragm, is located in the higher areas of the cervical spinal cord, i.e. at or above C4 and disturbance of the function of the diaphragm leads to lower lung capacity. Further, restrictive lung functions caused by lesion dependent paralysis of respiratory supportive muscles, might lead even more to reduced lung capacity.[2,3] Many persons with a lesion in this area will be in some way dependent on ventilator support during the day.[2,3]

The autonomic nervous system is divided into the parasympathetic and the sympathetic system. Below the level of injury the autonomic nerves are preserved, however, they are without central supraspinal control, depending on the completeness of injury. With regard to loss of autonomic control, the cranial parasympathetic nervous system will not be affected by SCI whereas the sacral part of this nervous system is almost always included in the lesion. A cervical lesion may result in a total sympathetic block, and for lesions below L3 the sympathetic system will be unaffected

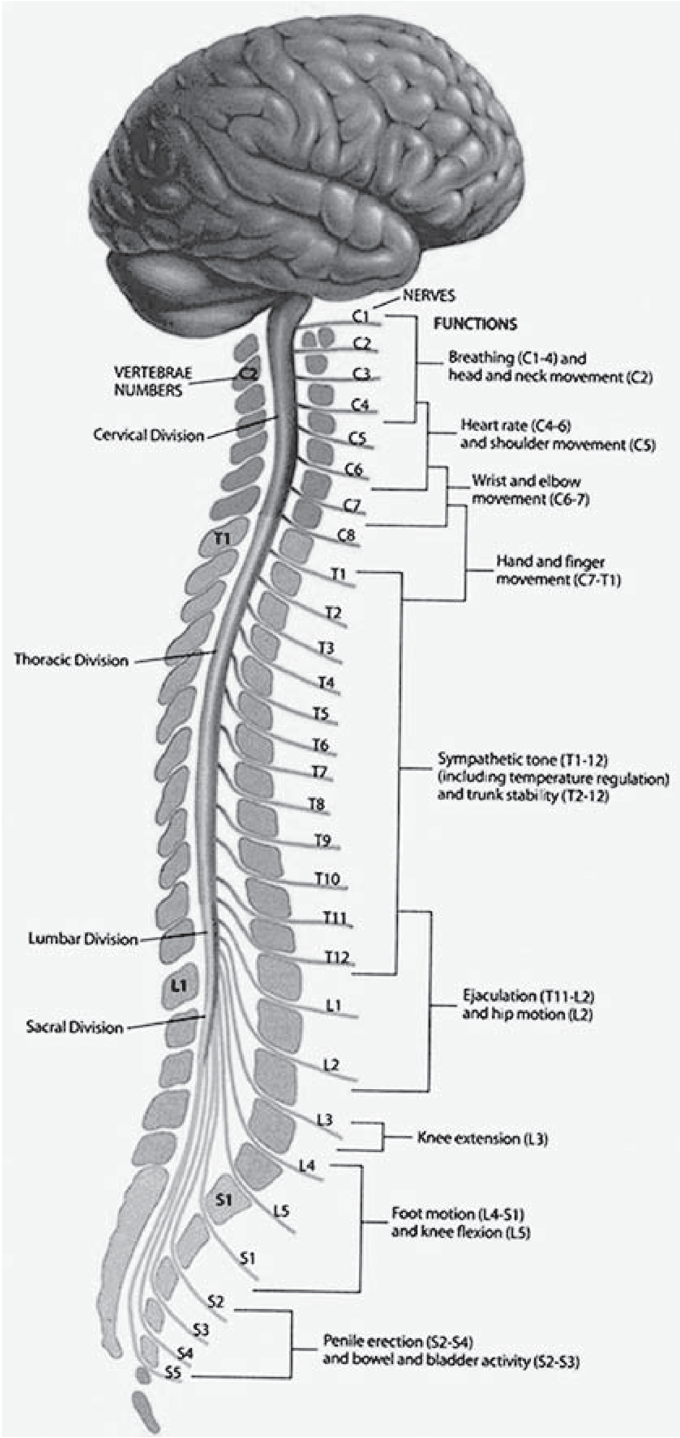


**Figure 1.1** Spinal cord: motor, sensory and autonomic innervations.

(Figure 1.1). Persons with lesions between T1 and T5 may have disturbed cardiac sympathetic innervations. The parasympathetic innervations of the heart (N. Vagus) will be intact, which may lead to a dominating disbalance resulting in a limitation of the normal exercise-induced heartbeat acceleration and myocardial contractility. In people with lesions below T6, cardiac sympathetic innervations will not be affected, suggesting a basically normal regulation of the cardiac function. However, they lack the innervations of the abdomen, pelvis and legs, important for an appropriate redistribution of blood during exercise. In practice, there is a considerable and individual variable overlap in neuronal outflow of the autonomic nervous system.[5]

In persons with SCI secondary complications are common on the short or long-term, including pressure sores, urinary tract infections, pulmonary infections, neurogenic heterotopic ossification, oedema, hypotension, autonomic dysregulation, spasticity and pain.[2,3]

As a consequence of the paralyses of the muscles, the restrictive lung function, the autonomic disturbances, and the secondary complications, exercise capacity of persons with SCI is diminished. This altogether has an enormous impact on daily life activities, participation in society and overall quality of life of the person involved,[1,6] both early after onset as well as in the chronic phase. Although SCI is studied extensively, there still is no cure for this condition.

About 300–400 persons are admitted yearly to a rehabilitation centre in the Netherlands as a consequence of a new traumatic or non-traumatic SCI. The incidence of traumatic SCI in the Netherlands is estimated at 10.4/million every year, comparable to some European countries, but lower than the USA and some other European countries.[2,7] In the Netherlands traumatic lesions are mainly caused by traffic, sports or leisure accidents. More than 70% of the persons who suffer traumatic SCI is male with a mean age at onset of 43 years.[7,8] A growing cause of SCI in the elderly population is minor trauma in combination with pre-existing cervical spondylarthropathy. Among persons with traumatic SCI an estimated 50% has a tetraplegia and over 50% a motor complete lesion.[7,8]

The incidence of non-traumatic SCI is most certainly under-registered, especially for SCI caused by spinal tumours of malignant origin. Common non-traumatic causes of SCI are tumours, metastasis, infection (myelitis transversis), and haemorrhage or infarction of the spinal blood vessels.[7,8] In the rehabilitation centres in the Netherlands the proportion of persons with SCI of non-traumatic origin has grown a majority of 55% in the last decade. Mean age of onset of non-traumatic SCI is 57 years and over 60% is male.[2,8] Within this group of persons with non-traumatic lesions 24% has a tetraplegic lesion and 26% has a motor complete lesion.[8]

Because of improvements in medical care, the average life expectancy of persons with a SCI has considerably increased in the last decades coming close to the life expectancy of the general population, except for persons with complete high tetraplegia.[9] Optimizing social participation, maximizing wellbeing of persons with SCI and minimizing stress of relatives has become a main outcome of the rehabilitation program.[10]

## Organisation of medical care

In the Netherlands 11 trauma centres are equipped for the acute care of trauma victims with SCI. After stabilisation of vital functions (ventilation, blood circulation) on the intensive care with eventually surgical stabilisation of the spinal column, people are transported to a specialized spinal cord unit in a rehabilitation centre. The length of hospital stay, with a current median of 31 days in the Netherlands, depends on the patient's physical state and the opportunities for admission to a rehabilitation centre.[18] About 70–80% of patients with SCI are admitted to a rehabilitation centre.[7] In the Netherlands eight rehabilitation centres are specialised in SCI rehabilitation care and the involved professionals collaborate in the Dutch Flemish Spinal Cord Society, which holds regular meetings for all professional disciplines (medical doctors, nurses, occupational therapist, physiotherapist, psychologists, and sports instructors; www.nvdg.org)). In the Netherlands the length of stay in inpatient rehabilitation varies considerably, with an average of about nine months for a person with a tetraplegia and four months for a person with a paraplegia.[11] The rehabilitation period consists mostly of an inpatient and an outpatient period. Over 90% of the patients are discharged home and others are discharged to guided living facilities or nursing homes. For patients with non-traumatic SCI, the medical route is similar, but for some specific categories like spinal tumours of malignant origin the route is more dependent on the individual needs of hospitalised care and life expectancy. Not all patients enter the rehabilitation circuit.

The expenses involved in life time care of those with SCI are of growing importance. In a Canadian study the total costs in the first year were estimated at $121,600 for patients with a complete SCI, and $42,100 for patients with an incomplete injury. In the subsequent five years, annual costs were $5,400 and $2,800 for patients with complete and incomplete SCI, respectively.[12] No comparable data are present for the situation in the Netherlands, but we assume it will be similar.

## Impact of SCI

As described above, a SCI affects many domains of life which is best described in the World Health Organization (WHO) model of International Classification of Functioning, Disability and Health.[13]

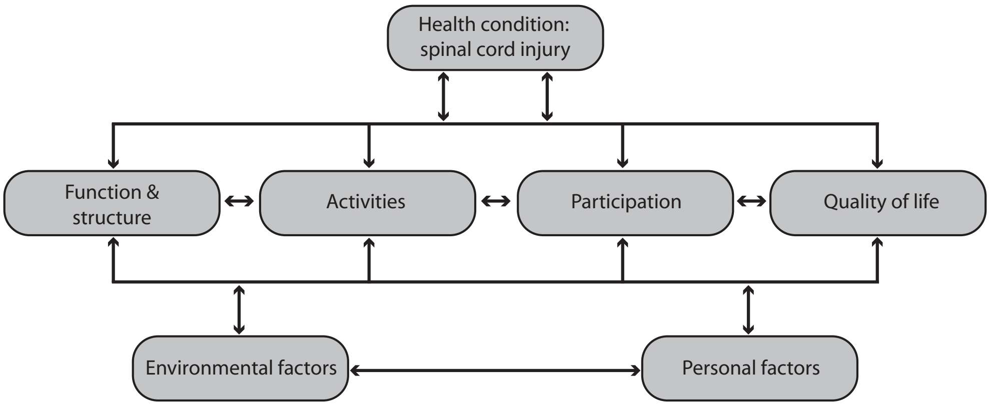


**Figure 1.2** The WHO ICF model with the added domain of Quality of life.[14]

## The International Classification of Functioning, Disability and Health (ICF)

The ICF, developed by the World Health Organization,[13] is a worldwide used conceptual framework to classify the functional consequences of a disease or other health condition. The ICF describes the effects of the health condition in relation to three levels of human functioning: body structures and functioning, activities and participation. These levels are influenced by personal factors such as age, gender, history and psychological characteristics, and by environmental factors such as social support, religion or financial and economic resources. All these aspects interact with each other. For example, a SCI (health condition) can lead to low exercise capacity (function), which leads to mobility problems (activities) and as a result a person has problems with finding work, being active in sports or visiting friends and family (participation). These consequences can lead to a lower quality of life of the person involved. Quality of life is not incorporated in the ICF model, but can be considered the ultimate dependent variable of elements in the ICF model and depicted as a separate domain (Figure 1.2).[14] Given the numerous impairments and disabilities that may exist after SCI, the ICF framework has been recommended to describe or investigate SCI-related disability.[15]

## Wheelchair exercise capacity

The majority of persons with SCI remain wheelchair users and are dependent on arm work for mobility and activities during daily life.[16] In our cohort study we focus on the restoration of mobility of wheelchair dependent persons with SCI and consequently we define exercise capacity in this study as wheelchair exercise capacity. Wheelchair exercise capacity is the combined ability of the cardiovascular, respiratory and neuro-musculoskeletal systems to attain a certain level of wheelchair activity.[17]

Wheelchair exercise capacity in persons with SCI is diminished because of muscle weakness, loss of autonomic control below the level of injury and changes in metabolic and vascular function. The impact of the lesion on wheelchair exercise capacity depends on the level and on the completeness of the injury. Arm exercise results in a lower exercise capacity in comparison to leg exercise, due to the lower number and size of muscles that can be effectively applied.[17] Due to their sedentary lifestyle, wheelchair-bound subjects with SCI have an increased risk of cardiovascular and cardiopulmonary diseases, which in itself may result in an even more sedentary lifestyle, leading to a potential debilitative circle.[18]

Altogether, wheelchair exercise capacity is an important determinant of long-term health status of persons with SCI,[19] because low wheelchair exercise capacity exposes them to an increased risk of complications, diabetes, metabolic syndrome, cardiovascular problems and upper body overuse injuries.[20,21] Low wheelchair exercise capacity is also related to reduced levels of activities, participation and quality of life.[22-25] Wheelchair exercise capacity is influenced by personal and lesion-related factors, exercise mode, expertise and training.[22-27]

Increasing exercise capacity by increasing physical activity is likely to increase the general health of a person with SCI. In fact, exercise is so beneficial for humans, that it should be considered as medicine (www.exerciseismedicine.org), with evidence in the general population for prescribing exercise in the primary and secondary prevention of pulmonary and cardio-vascular diseases, metabolic disorders, muscle-, bone- and joint diseases, forms of cancer and depression.[28] In addition to the physical benefits of exercise, many positive effects on quality of life have been recorded in the general population.[29] Benefits of exercise to quality of life are assigned to the direct neuro-hormonal effects of endorphin and oxytocin-production during and after exercise[30,31] or the indirect improvement of social status and self-esteem, as was also found for people with disabilities.[6,32]

Most of the medical conditions mentioned above are related to the chronic phase of spinal cord injury,[33,34] therefore, exercise capacity is considered as an important determinant of long-term health status of persons with SCI[19] and a potential determinant of quality of life.[6]

In this thesis we measure wheelchair exercise capacity with a standardised incremental peak exercise test in a hand rim wheelchair on a motor driven treadmill. Wheelchair exercise capacity comprises both the peak oxygen uptake ($VO_{2\,peak}$) and peak aerobic power output ($PO_{peak}$), outcomes of this peak exercise test. The $VO_{2\,peak}$ is directly measured through breath by breath gas exchange analyses, whereas the $PO_{peak}$ is indirectly determined and is the product of the velocity of the wheelchair and the drag force of the person and the wheelchair during the peak stage of the test on the treadmill. The peak power output is therefore determined by a combination of peak oxygen uptake, anaerobic power, wheelchair skills and the interface characteristics of the wheelchair and the user (Figure 1.3).

In SCI research most studies on (wheelchair) exercise capacity are cross-sectional, including healthy, young and active male persons with a long time since injury (>6 years).[23,25,26] In the one longitudinal study that included persons with SCI during initial inpatient rehabilitation, recovery of wheelchair exercise capacity was found during inpatient rehabilitation up to one year after discharge, and this recovery was positively associated with lower age, male gender, low level and incompleteness of the lesion.[17] Similar determinants were found in cross-sectional studies on determinants of exercise capacity.[35] Until now prospective data on the course of wheelchair exercise capacity in persons with SCI in the first five years after discharge and the interactions with complications, functioning or life satisfaction have not been described. A (small) decline in exercise capacity might be expected because of ageing,[36,37] inactivity and other lifestyle changes in life after discharge of inpatient rehabilitation,[17] although a recently published small longitudinal study with 20 years follow up revealed a stable exercise capacity.[38] Moreover, clinical observations suggest a certain amount of heterogeneity in the course of exercise capacity in the first few years after onset of SCI.

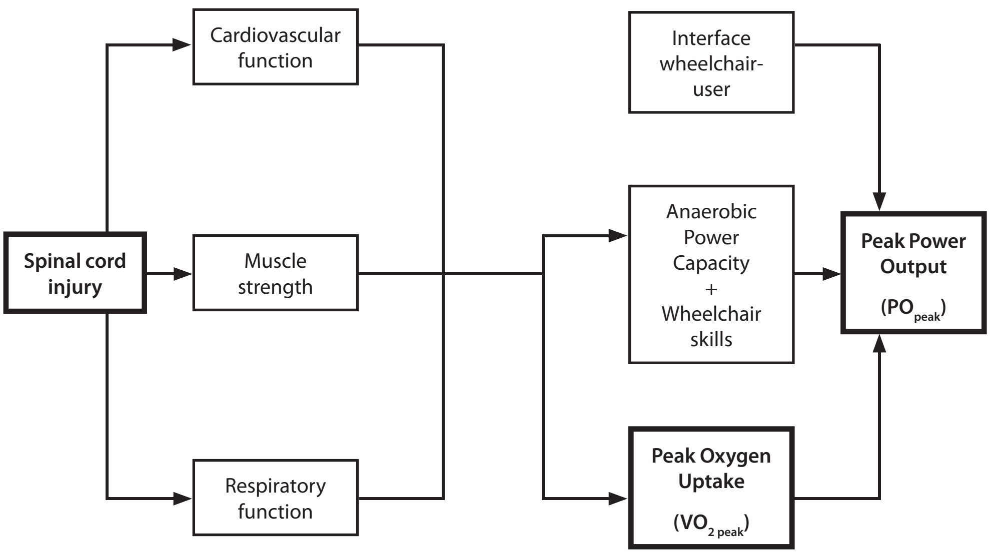


**Figure 1.3** Interaction between components of physical capacity and interface factors in respect of wheelchair exercise capacity based on van der Woude.[39]

## Life satisfaction

### *The concept of quality of life*

In rehabilitation medicine research on the concept of quality of life has been introduced at the end of the last century and since then many definitions of quality of life have been suggested and a diversity of measures have been published.[1] The debate on the optimal definition of quality of life is ongoing. Quality of life has been equated with health status, physical functioning, perceived health status, subjective health, health perceptions, symptoms, need satisfaction, individual cognition, functional disability, psychiatric disturbance, well-being and, often, several of these at the same time.[40]

A broad review[1] revealed three broad approaches to the operationalization of quality of life: quality of life (1) as *utility*, (2) as *achievements*, and (3) as *well-being*.[1]

The concept of well-being can be further sub-divided into objective well-being and subjective well-being. Objective well-being concerns, for example, housing, access to clean drinking water and having sufficient financial resources. Subjective well-being, concerns the subjective experience of quality of life and has a *cognitive* component (a cognitive evaluation of one's life), which refers to life satisfaction and is equivalent to terms like happiness or global well-being[1] (see Figure 1.4), and an *emotional* component, i.e. mental health.[41] In this thesis we focused on life satisfaction, which is considered a more stable factor than mental health, and further less exclusively determined by psychological factors than mental health.[21] Life satisfaction can be reliably measured in SCI populations.[42]

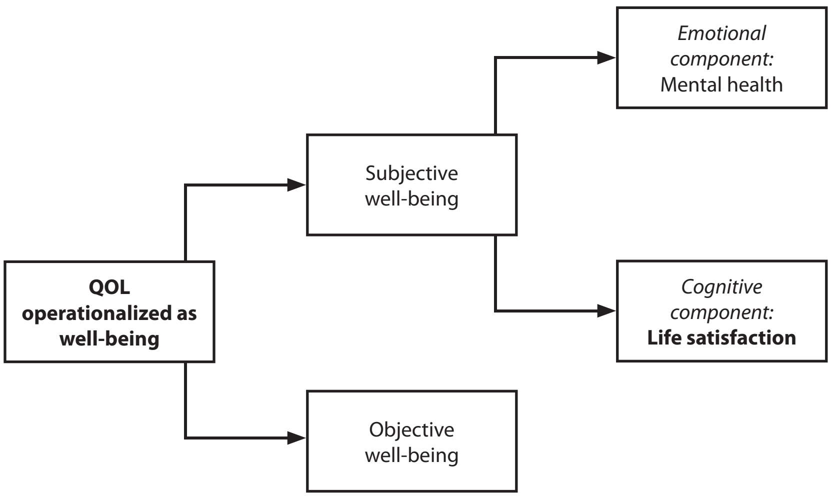


**Figure 1.4** Operationalization of quality of life based on Post and van Leeuwen.[41]

A remarkable finding is that life satisfaction in persons with SCI, as rated by care professionals like nurses and doctors, is substantially lower than the self-ratings of life satisfaction by the persons with SCI involved.[43] This is most probably caused by application of coping strategies to deal with the changed world of a person with a SCI, resulting in internal and external changes of one's expectations and goals in life, the so called response shift.[44] Coping styles vary between persons, and so two persons with identical limitations in functioning can evaluate their life satisfaction completely different.

Literature on life satisfaction in SCI population shows a wide variation in design, inclusion criteria, setting, and measures of life satisfaction. Most studies used a cross-sectional design and measured life satisfaction many years after SCI. One cross-sectional study including persons 1–7 years after onset of SCI revealed that modest recovery of life satisfaction might be expected in the first years after SCI.[45]

Longitudinal studies on life satisfaction in the early phase of SCI are sparse. Only one small-scale study (n = 29) collected life satisfaction data from subjects with SCI in initial inpatient rehabilitation. The mean over-all life satisfaction score of this group was lower than that of a non-injured control group, but was still "rather happy".[46] In another study,[40] over-all quality of life ratings of most subjects improved between 6 months and 1 year after SCI, and remained more or less stable after the first year. Kennedy et al.[47] found no differences in life satisfaction between 1 and 6 months after discharge from inpatient rehabilitation. A stable course of life satisfaction was detected in a large longitudinal study (n = 207) with measurements from one up to five years after SCI.[48]

A review showed that physical disability was a consistent, but weak determinant of life satisfaction after SCI.[49] However, literature about determinants of life satisfaction early after injury is limited. One available study showed significant relationships between gender, employment status, self-perceived health, mobility and social integration one year after SCI and life satisfaction two years after SCI, but after inclusion of life satisfaction at one year after SCI in the regression analysis, only mobility and self-perceived health remained significant determinants.[50]

### ***Relationship between exercise capacity and life satisfaction***

Exercise capacity and quality of life are influenced by the SCI, but literature on the direct or indirect relationships between exercise capacity and quality of life is limited,[6] especially when searches are restricted to studies on the narrower definitions of wheelchair exercise capacity and life satisfaction.

Several positive relationships between the broader constructs physical activity and quality of life of persons with spinal cord injury have been published,[51-56] although some others found indifferent results.[57,58] However, most of these studies were cross-sectional, including healthy, young and active male persons with a long time since injury. To our knowledge, no papers on the longitudinal association between wheelchair exercise capacity and life satisfaction, within the strict definitions, in a general spinal cord injury cohort have been published.

In summary, little is known about the course and determinants of wheelchair exercise capacity and life satisfaction and their mutual relationship during initial inpatient rehabilitation and the first years after discharge. Persons with SCI go through a process of physical and mental adaptation to the new life situation in the first few years after SCI onset[1] and they have to deal with many threats to and barriers for maintaining an adequate wheelchair exercise capacity and life satisfaction, once they have reintegrated in society.[14,50] Knowledge on the course of wheelchair exercise capacity and life satisfaction and its relationships in the first few years after onset of SCI may help to improve the understanding of physical and mental adaptation to (the consequences of) a SCI over time and thus may help to improve goal setting and intervention programs in in- and outpatient rehabilitation and follow-up care. It was therefore the Umbrella Project and its sequel (the SPIQUE Project) were introduced in the Netherlands.

## Context of research: the Umbrella Project

The Umbrella project "Restoration of mobility in spinal cord injury rehabilitation" is a Dutch prospective cohort study that is part of the Dutch research program "Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of persons with spinal cord injury".[59] The main purpose of the prospective cohort study was to investigate the course of restoration of mobility on the levels of body functions, activities and participation during and after SCI rehabilitation, and to study possible determinants of this course. Persons were included in 8 rehabilitation centers with specialized SCI units in the Netherlands between August 2000 and July 2003. Participants were eligible to enter the project if they had an acute SCI, were between 18 and 65 years of age, were classified as A, B, C or D on the American Spinal Injury Association Impairment Scale (AIS), did not have a progressive disease or psychiatric problems, and had sufficient understanding of the Dutch language to understand the purpose of the study and the testing methods. Since most people with SCI use a hand rim wheelchair for mobility, only persons who were expected to remain, at least partly, hand rim wheelchair dependent were included. An extensive measurement protocol was administered, including measures of lesion characteristics, co-morbidity, physical capacity, basic skills, daily functioning, quality of life, demographics and psychosocial factors (Figure 1.5). One measurement took a maximum of eight hours to complete, divided over two consecutive days. Four measurements were performed: The first when a person was able to sit in a wheelchair for 3–4 hours at a time (start); the second three months later (3M), the third at discharge from inpatient rehabilitation (discharge) and the fourth one year after discharge (1Y).[60,61] A fifth measurement was performed two years after discharge, but this was a restricted measurement, only consisting of telephone interviews and performed in a selection of the participating rehabilitation centres.

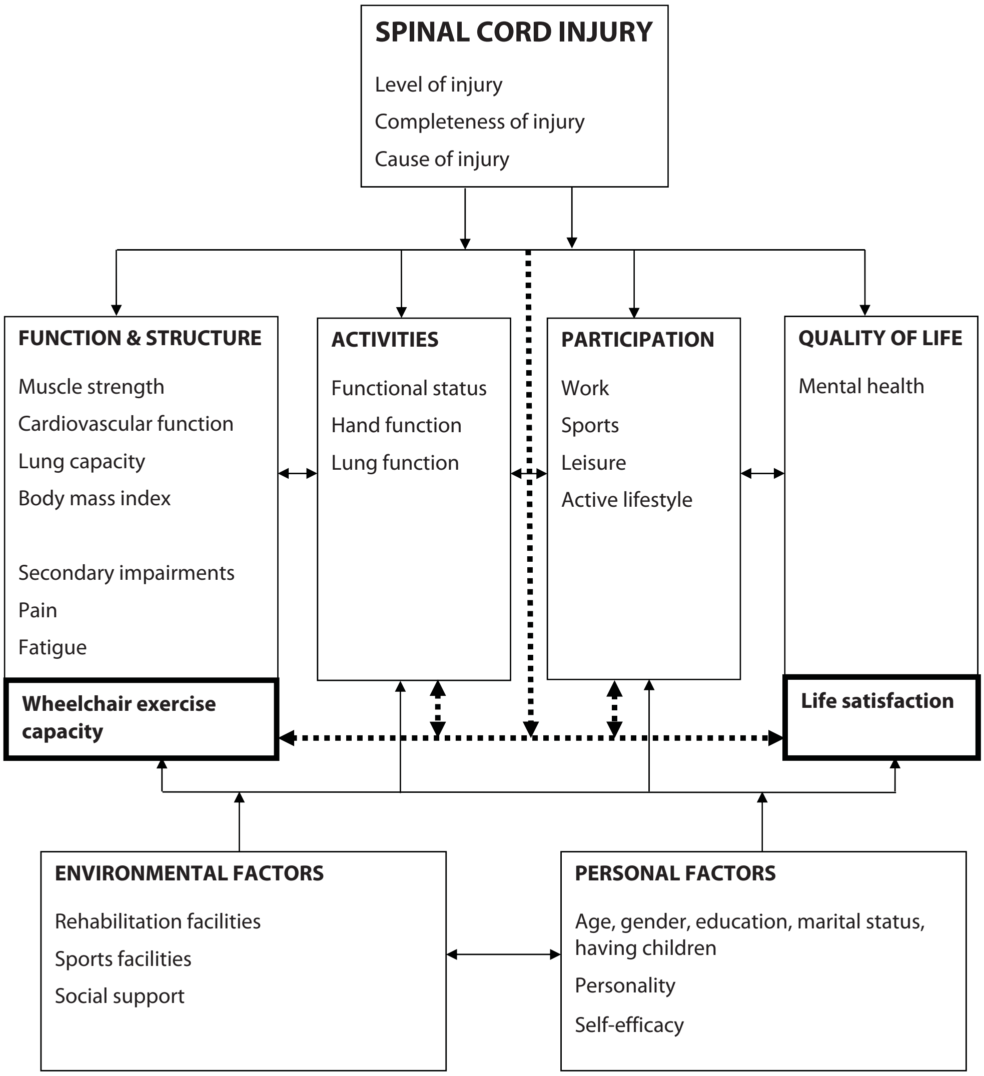


**Figure 1.5** Spinal cord injury and impact on one's life based on the WHO ICF model, modulated by Post and Noreau.[21] Relevant variables to describe the functioning, disability and health of persons with SCI, and selected measures are displayed. Dashed lines are the relationships between the different components studied in this thesis.

**Table 1.1** Theses utilizing data from the Umbrella Project "Restoration of mobility in spinal cord injury rehabilitation" (www.scionn.nl)

| Topic | PhD student | Year |
|---|---|---|
| Wheelchair skills | Kilkens O. | 2004 |
| Health problems | Bloemen J. | 2006 |
| Upper-extremity load | van Drongelen S. | 2008 |
| Physical capacity | Haisma J. | 2008 |
| Respiratory adaptations | Müller G. | 2008 |
| Hand cycling | Valent L. | 2009 |
| Upper-extremity task performance | Spooren A. | 2010 |
| Quality of life | van Leeuwen C. | 2011 |
| Wheelchair skills | Douer-Fliess O. | 2012 |

The outcomes of the Umbrella project were published in over 90 peer-reviewed papers and 9 Theses, the topics of which are shown in Table 1.1.

## The SPIQUE project

The last measurement at one year after discharge of rehabilitation in the Umbrella project was probably too early to reflect a more or less stable situation.[45,49,62] The life situation of a person with SCI might change during the first few years after SCI[1] and therefore a longer follow-up period was desirable. The SPIQUE project consists of an extra follow-up measurement five years after discharge of all persons with SCI who participated in the Umbrella project. Most of the outcome measures that were assessed in the Umbrella project were also included in the SPIQUE project, but condensed because of logistics and concerns of overloading the participants. It took the participants a maximum of four hours to complete the SPIQUE measurement. Table 1.2 shows the main measures utilized in this thesis.

During the data collection of the SPIQUE project we analysed unpublished life satisfaction data from the Umbrella Project (chapters 2 and 3). After completion of this data collection, we used Umbrella and SPIQUE data up to five years after discharge to study the course of wheelchair exercise capacity and relationships between wheelchair exercise capacity and life satisfaction. The SPIQUE data on the course and determinants of life satisfaction have been reported earlier, by Van Leeuwen in her thesis "Quality of life in the first years after spinal cord injury" (2011)[63] and are therefore not part of this thesis.

**Table 1.2** Life satisfaction measures, wheelchair peak exercise tests and other questionnaires in the Umbrella and SPIQUE project

| Variable | Instrument | Umbrella | | | | SPIQUE |
|---|---|---|---|---|---|---|
| | | Start | 3M | Discharge | 1Y | 5Y |
| Life satisfaction | 2-item questionnaire | X | X | X | X | X |
| LiSat-9 | 9-item questionnaire | X | | | X | X |
| Wheelchair exercise capacity | Peak wheelchair exercise test | X | X | X | X | X |
| Functional status | FIM | X | X | X | X | X |
| Pain | 22-item questionnaire | X | X | X | X | X |
| Secondary impairments | 7-item questionnaire | X | X | X | X | X |
| Participation | UAL | | | | X | X |
| Participation | PASIPD | | | | X | X |

LiSat-9 = Life Satisfaction Questionnaire-9, at Start measured in retrospection for situation before SCI; FIM = Functional Impairment Measurement; UAL = Utrecht Activity List; PASIPD = Physical Activity Scales for Individuals with Physical Disabilities. Start = Start of active rehabilitation; 3M = three months after start; Discharge = At discharge from inpatient rehabilitation; 1Y = one year after discharge from inpatient rehabilitation; 5Y = five years after discharge from inpatient rehabilitation.

## Aims and outline of the present thesis

The general aim of the present thesis is to describe the course, determinants and the relationship of wheelchair exercise capacity and life satisfaction during inpatient rehabilitation and the first years after discharge in persons with SCI.

Hence, the following research questions will be studied within the ICF framework (Figure 1.6):

1. How do persons with SCI rate their life satisfaction at one year after discharge, and how can we interpret this in relation to general population figures and to their life satisfaction before SCI? How is (the change of) life satisfaction influenced by personal and lesion characteristics and secondary impairments?
2. What is the course of life satisfaction of persons with SCI during and after initial rehabilitation up to one year after discharge and how can we interpret changes in life satisfaction? How is (the change of) life satisfaction influenced by personal, lesion, physical and functional characteristics?
3. What is the course of wheelchair exercise capacity of persons with SCI up to five year after discharge? How is (the change of) wheelchair exercise capacity

during and after initial rehabilitation up to five year after discharge influenced by personal and lesion characteristics?

4. Can we identify heterogeneity in the course of wheelchair exercise capacity in SCI population up to five years after discharge and can we identify determinants of this heterogeneity in wheelchair exercise capacity?

5. What is the association between wheelchair exercise capacity and life satisfaction in persons with SCI in a cohort up to five years after discharge of inpatient rehabilitation?

The answers to these research questions are given in the following six chapters:

The aim of **chapter 2** is to determine life satisfaction of persons with a SCI one year after discharge of inpatient rehabilitation, to compare life satisfaction before and after SCI and to study the influence of personal and lesion characteristics and secondary impairments on life satisfaction and the change in life satisfaction after SCI. **Chapter 3** reports the course of life satisfaction from start of active inpatient rehabilitation up to one year after discharge of inpatient rehabilitation and identifies the personal, physical and functional characteristics related to life satisfaction in persons with SCI.

**Chapter 4** aims to study the course of wheelchair exercise capacity up to five years after discharge and to identify the predictive personal en lesion characteristics. Second aim is to describe the loss to follow up in the wheelchair exercise test up to five years after discharge.

**Chapter 5** focuses on the identification of distinct trajectories in the course of wheelchair exercise capacity in the period between the start of active SCI rehabilitation and five years after discharge. Secondly, this chapter aims to explore the distinctive value of personal and lesion characteristics, functional status, secondary impairments and participation between the different trajectories. **Chapter 6** examines the relationship between wheelchair exercise capacity and life satisfaction in persons with SCI, after correcting for possible confounders.

Finally, **chapter 7** summarizes the main findings and discusses the general aim of this thesis. What can we conclude with respect to the course of life satisfaction and wheelchair exercise capacity in persons with SCI? Which physical factors are related to life satisfaction and wheelchair exercise capacity and how are these determinants, others predictors and life satisfaction itself related to wheelchair exercise capacity? Finally, this chapter discusses theoretical and methodological considerations of the Umbrella and SPIQUE projects and describes directions for future research and clinical practice.

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2

# Changes and determinants of life satisfaction after spinal cord injury: a cohort study in the Netherlands

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## ABSTRACT

**Objective:** To determine the impact of spinal cord injury (SCI) on life satisfaction of persons with SCI one year after discharge of inpatient rehabilitation.

**Design:** Cohort study. Life satisfaction before SCI was retrospectively measured at the start of active rehabilitation. One year after discharge from inpatient rehabilitation, current life satisfaction was measured.

**Setting:** The Netherlands.

**Participants:** 147 persons, aged 18–65, wheelchair-dependent at least for long distances.

**Main outcome measure:** Life Satisfaction Questionnaire (LiSat-9).

**Results:** Mean satisfaction with Life as a whole was 5.3 (SD 1.0) before SCI and 4.3 (SD 1.3) one year after inpatient rehabilitation. Sexual life, Self care and Vocational situation showed largest impact of SCI, whereas the social relationships domains appeared least affected. Decrease of life satisfaction after SCI was larger using the retrospective ratings than using general population scores. Significant determinants of life satisfaction after SCI were high lesion level (0.31 lower score), pain (0.19 lower score) and secondary impairments (0.22 lower score).

**Conclusion:** Life satisfaction decreased in persons with SCI. Level of lesion and suffering secondary impairments or pain were associated with low life satisfaction one year after discharge from inpatient rehabilitation.

## INTRODUCTION

Because of improvements in medical care, the average life expectancy of persons with Spinal Cord Injury (SCI) has considerably increased in the last decades.[1] Most persons with SCI may now expect to live for many years. Nevertheless, SCI is a major life event that leads to serious physical disability and secondary medical problems, and seriously impacts life satisfaction of persons involved.[2,3]

Life satisfaction is studied widely in SCI population. However, there is a wide variation in the design of these studies regards design, inclusion criteria, setting, and measures of life satisfaction. At least three different types of measures have been used: (1) single item rating scales;[4-7] (2) multiple item rating scales focused on general life satisfaction, as the SWLS[2,8] the Life Situation Questionnaire[9,10] or the Life Satisfaction Index-A[11-13] and (3) multiple item rating scale including domain-specific life satisfaction, as the Life Satisfaction Questionnaire,[14-18] or the Flanagan QOLS.[19,20] Most studies into life satisfaction of persons with SCI used a cross-sectional design and measured life satisfaction many years after SCI.[2,4,6,7,9,11-18,20] Only two longitudinal studies were found: one compared life satisfaction one and two years after discharge of initial rehabilitation and showed a slight progression in life satisfaction over time[8] and the other studied long-term changes in life satisfaction and showed stability of life satisfaction.[10] Several studies compared life satisfaction of persons with SCI to figures of healthy peers or the general population to quantify the impact of SCI on life satisfaction.[3] The assumption underlying this comparison, that persons with SCI would have showed the same scores as the reference group, if they would not have had the SCI, is however challenged.[21] Only one study[22] compared life satisfaction before SCI with life satisfaction after SCI directly by asking persons with SCI to rate their life satisfaction before injury.

In SCI research, gender and race were largely unrelated to life satisfaction. The relationships between life satisfaction and age, marital status, time since injury, level of injury, impairment and disability were inconsistent: some studies showed a significant relationship, whereas others failed to find an effect.[23,24]

The purpose of this study was to determine life satisfaction of persons with a SCI one year after discharge of inpatient rehabilitation, to compare life satisfaction before and after SCI and to study the influence of personal and lesion characteristics and secondary conditions on life satisfaction and the change in life satisfaction after SCI.

# METHODS

## Subjects

This study is part of the Dutch research program "Physical strain, work capacity, and mechanisms of restoration of mobility in the rehabilitation of persons with a SCI". Eight rehabilitation centres with a specialty in SCI rehabilitation participated in the study. Subjects were eligible to enter the project if they had an acute SCI; were between 18 and 65 years of age; were classified as A, B, C, or D on the American Spinal Injury Association Impairment Scale; and were expected to remain wheelchair-dependent (at least for long distances). Exclusion criteria were: SCI due to malignant tumour, progressive disease, known cardiovascular disease or psychiatric problems and insufficient command of the Dutch language to understand the goal of the study and the testing methods. All subjects gave informed consent, and the Medical Ethics Committee of the SRL/iRv Hoensbroek approved all tests and protocols

## Procedure

Two measurements from the research program were relevant for this study. The first was performed at the start of active rehabilitation (the moment that a person could sit for 3 to 4 hours) and the second one year after discharge of inpatient rehabilitation. Both measurements comprised, amongst others, a medical anamnesis and physical examination by a rehabilitation physician, an oral interview by a trained research assistant and a self-report questionnaire. At the first measurement, participants were asked to rate their life satisfaction before the SCI as part of the oral interview. At the second measurement one year after discharge, participants were asked to rate their current life satisfaction.

## Instruments

*Life satisfaction* was measured with the Life Satisfaction Questionnaire (LiSat-9).[25] The LiSat-9 consists of nine questions about satisfaction with life as a whole and about satisfaction with eight life domains: Self-care ability, Leisure time, Vocational situation, Financial situation, Sexual life, Partnership relations, Family life, and Contact with friends. Each question was scored on a 6-point scale: very unsatisfied, unsatisfied, rather unsatisfied, rather satisfied, satisfied and very satisfied. The LiSat-9 is a valid measure of life satisfaction and has been used often in SCI research.[14,16-18]

*Demographic* characteristics collected at the second measurement were age, gender, educational level, marital status (married or living together, single or living at parental home) and having children.

*Lesion characteristics* were assessed according to the International Standards for Neurological Classification of Spinal Cord Injury.[26] The ASIA impairment scale classifications A and B were considered motor complete and the classifications C and D were considered motor incomplete. Neurological lesion level was defined as the highest motor level. Neurological levels below T1 were defined as paraplegia and neurological lesion levels at or above T1 were defined as tetraplegia.

*Secondary conditions* were grouped into two categories: (1) eight items about pain and other abnormal sensations as itching and dull feelings that were scored as "absent" or "present", and (2) eight items about other secondary conditions, including pressure sores, urinary tract infections, airway infections, neurogenic heterotopic ossification and circulation disturbances. These items were also scored as "absent" or "present".

## Statistical analyses

A non-response analysis was performed, comparing person and lesion characteristics of persons who completed both measurements with those of persons who did not complete the second measurement. Chi square tests were used to test (in-) dependency between participant characteristics and drop-out.

A total LiSat-9 score was computed as the average of all item scores, so that the total score also has a range from 1 up to 6. The Cronbach's α of this score was good (0.8). Two methods to describe LiSat-9 results were used. First, mean item and total scores and mean change scores were described and differences between mean scores of both measurements were tested for statistical significance using paired t-tests. Effect sizes (ES) were used to interpret changes in mean life satisfaction scores and were computed as the difference between the first and last measurement, divided by the mean standard deviation of both measurements. Effect Sizes were described as small (0.20>ES<0.50), medium (0.50>ES<0.80) or large (ES>0.80).[27] Pearson correlations between LiSat-9 scores before and after SCI were calculated to examine stability of life satisfaction. The interpretation of correlation coefficients was: <0.30 weak; 0.3–0.5 moderate; >0.5 strong.[27] Secondly, LiSat-9 item scores were dichotomised according to Fugl-Meyer[25] in Dissatisfied (scores 1–4) and Satisfied (scores 5 or 6). Percentages of persons being satisfied and dissatisfied were reported and the changes of satisfaction before and after SCI were analysed using the McNemar test. Persons perceiving a substantial decrease of life satisfaction after SCI were compared to persons who did not perceive a substantial decrease of life satisfaction using dichotomised scores. Substantial decrease was defined as change from satisfied before SCI into dissatisfied after SCI in more than two life domains.

The impact of personal characteristics (gender, age, education), lesion characteristics (level, completeness, cause of lesion), pain and other secondary impairments on life satisfaction was analysed using regression analyses. Linear regression analyses were performed with the LiSat-9 total score after SCI and with the change in LiSat-9 total score as dependent variables. A logistic regression analysis was performed with the dichotomous variable representing deterioration or no deterioration of life satisfaction as the dependent variable. All determinants were dichotomised. Based on score distributions, the score for pain and abnormal feelings was dichotomised into a group with 0 to 4 complaints and a group with 5 to 8 complaints. The score for other secondary impairments was dichotomised into a group with 0 or 1 complaint and a group with 2–8 complaints. Finally, the results of this study were compared to those of other studies using the LiSat-9 in persons with SCI and to a reference population. Mean scores were presented and, if necessary, obtained by personal communication with the authors. For all statistic procedures the SPSS 15.0 statistical program was used. The level of significance was set at $p<0.05$.

## RESULTS

### Respondent characteristics

Of the initial study group of 222 persons, 147 completed the measurements one year after discharge of inpatient rehabilitation. Drop-out had different causes: 9 persons died, 12 persons were excluded from the study because they regained ability to walk for longer distances and 19 refused to collaborate. Some other persons had moved, had developed a psychiatric condition after the first measurement, or could not be contacted at all.[28] A comparison between participants and non-participants showed no differences regarding gender, age and completeness of injury, but more non-participants (50%) than participants (30%) had tetraplegia ($p<0.05$). Characteristics of the study group are displayed in Table 2.1.

The study group consisted for nearly three quarters of males. Mean age one year after discharge was 41.6 years (SD 14.5). Time since injury ranged from 16.0 months up to 45.2 months with a mean of 25.3 months (SD 6.1). Cause of injury was for three quarters traumatic; in one third a traffic accident, more than 15% as the result of falls and nearly 10% due to sports. Non-traumatic causes contributed for almost one fourth, most were myelum vessel problems.

**Table 2.1** Characteristics of respondents (n = 147)

| | n | % |
|---|---|---|
| Gender | | |
| Man | 107 | 72.8 |
| Woman | 40 | 27.2 |
| Age | | |
| 18–25 | 22 | 15.1 |
| 25–35 | 37 | 25.3 |
| 35–45 | 24 | 16.4 |
| 45–55 | 27 | 18.5 |
| 55–65 | 36 | 24.7 |
| Cause of injury | | |
| Traumatic | 111 | 75.5 |
| Non-traumatic | 36 | 24.5 |
| Type of injury | | |
| Complete tetraplegia | 35 | 23.8 |
| Incomplete tetraplegia | 14 | 9.5 |
| Complete paraplegia | 70 | 47.6 |
| Incomplete paraplegia | 28 | 19.0 |
| Home situation before injury | | |
| Married/together | 82 | 55.8 |
| Living at parental home | 26 | 17.7 |
| Single | 39 | 26.6 |
| Children | | |
| Yes | 72 | 49.0 |
| No | 75 | 51.0 |
| Education | | |
| High | 75 | 50.7 |
| Low | 71 | 48.0 |

Most persons suffered a complete paraplegia, followed by complete tetraplegia (together 71.4%). The majority of the participants lived together or were married, and more than half of the persons had one or more children. Half of the population had a degree in higher secondary education.

## Life satisfaction of persons with a SCI before and after SCI

Table 2.2 shows LiSat-9 scores before and after SCI, change scores and correlations between scores before and after SCI.

**Table 2.2** Life satisfaction scores (LiSat-9) before and one year after spinal cord injury (n = 147)

| LiSat-9 | n | Before SCI | | After SCI | | Difference between scores before and after SCI | | | | Correlations between scores before and after SCI |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Mean | SD | Mean | SD | Mean | SD | t-value | ES | Pearson's r |
| Life as a whole | 147 | 5.3 | 1.0 | 4.3 | 1.3 | 1.0 | 1.6 | 7.37$^{\dagger}$ | 0.8 | 0.08 |
| Self care ability | 147 | 5.7 | 0.9 | 4.2 | 1.6 | 1.5 | 1.9 | 9.40$^{\dagger}$ | 1.2 | 0.08 |
| Leisure situation | 147 | 5.1 | 1.0 | 4.6 | 1.2 | 0.5 | 1.7 | 4.37$^{\dagger}$ | 0.5 | 0.03 |
| Vocational situation | 99 | 5.1 | 1.1 | 4.1 | 1.4 | 1.1 | 1.2 | 6.60$^{\dagger}$ | 0.9 | 0.12 |
| Financial situation | 147 | 4.8 | 1.2 | 4.4 | 1.4 | 0.4 | 1.6 | 3.48$^{\dagger}$ | 0.3 | 0.27$^{\dagger}$ |
| Sexual life | 144 | 4.9 | 1.1 | 3.3 | 1.7 | 1.6 | 1.9 | 10.06$^{\dagger}$ | 1.1 | 0.19* |
| Partner relationship | 109 | 5.5 | 0.9 | 5.1 | 1.2 | 0.4 | 1.2 | 3.11* | 0.4 | 0.35$^{\dagger}$ |
| Family life | 144 | 5.4 | 0.8 | 5.1 | 1.0 | 0.3 | 1.1 | 3.39† | 0.3 | 0.24$^{\dagger}$ |
| Contact friends | 147 | 5.3 | 0.9 | 5.2 | 1.0 | 0.1 | 1.2 | 1.44 | 0.1 | 0.15 |
| LiSat Total | 147 | 5.2 | 0.7 | 4.5 | 0.8 | 0.8 | 1.0 | 9.35$^{\dagger}$ | 1.0 | 0.16 |

t-value = Student t-test; ES = Effect size: (Mean before - Mean after) / ((SD before + SD after)/2). * $p<0.05$; $^{\dagger}$ $p<0.01$.

LiSat-9 scores were significantly lower after SCI compared to before SCI, except for the domain Contact with friends. Larg Effect Sizes were seen for deterioration of satisfaction with Life as a whole, Self care ability, Vocational situation, Sexual life and the LiSat Total score. Small effect sizes were seen for decrease of Financial situation, Family relations and Contacts with friends and acquaintances. Correlations between life satisfaction scores before and after SCI were weak and for the most part non-significant. Only for Partner relations a moderately strong correlation was found.

Life satisfaction scores showed also a marked decrease after SCI if expressed as percentages satisfied participants (Table 2.3).

The proportion of satisfied people decreased strongest for satisfaction with Life as a whole and for the domains Self care, Vocational situation and Sexual life. The domains Financial situation, Partner relations, Family life and Contact with friends and acquaintances appeared least significantly affected by SCI (Table 2.3). Remarkably, most of the participants who were dissatisfied with Life as a whole, Self-care, Leisure time, Family Life and Contacts with friends before SCI, were satisfied with their functioning in these domains one year after SCI. A total of 49.2% participants perceived a change from satisfaction into dissatisfaction for more than two domains.

**Table 2.3** Percentage Satisfied / Dissatisfied and Change of Life satisfaction domains Before and After onset of SCI (n = 147)

| Domains | Satisfied before SCI | Satisfied after SCI | If dissatisfied before SCI: After SCI | | If satisfied before SCI: After SCI | |
|---|---|---|---|---|---|---|
| | n (%) | n (%) | Dissatisfied (n) | Satisfied (n) | Dissatisfied (n) | Satisfied (n) |
| Life as a whole | 129 (88) | 83 (57)[†] | 6 | 12 | 58 | 71 |
| Selfcare | 134 (91) | 89 (61)[†] | 4 | 9 | 54 | 80 |
| Leisure | 125 (85) | 96 (65)[†] | 7 | 15 | 44 | 81 |
| Vocational | 84 (86) | 51 (52)[†] | 7 | 7 | 40 | 44 |
| Financial | 109 (74) | 95 (65) | 20 | 18 | 32 | 77 |
| Sex life | 102 (73) | 47 (34)[†] | 32 | 6 | 61 | 41 |
| Partner relationship | 92 (92) | 83 (83)[†] | 4 | 4 | 13 | 79 |
| Family life | 128 (91) | 118 (83) | 4 | 9 | 19 | 109 |
| Contact friends | 130 (88) | 129 (88) | 2 | 15 | 16 | 114 |

Dissatisfied: LiSat-9 scores 1–4 ; Satisfied: LiSat-9 scores 5–6. [†] Mc Nemar test for measuring significance of change scores before and after SCI. $p<0.01$.

## Determinants of life satisfaction and of change in life satisfaction after SCI

Hierarchic regression analyses were performed to examine the independent influence of lesion characteristics and secondary impairments on life satisfaction and change in life satisfaction after SCI (Table 2.4).

Three regression analyses were performed with different dependent variables: firstly the total LiSat-9 score after SCI, secondly the change in LiSat-9 score between the measurements before and after SCI, and finally a dichotomous variable comparing the group of persons satisfied before SCI and dissatisfied after SCI to the other participants. The results of these three analyses were more or less the same. Gender, age and educational level showed little relationship with life satisfaction scores. Lesion level was a significant predictor in all three analyses, whereas completeness of lesion was only associated with the change in total LiSat-9 scores. Pain was associated with the total LiSat-9 score after SCI and the dichotomous change score, and having other secondary impairments was associated with decreased life satisfaction in all analyses. The amounts of explained variance were limited to 17–23%.

**Table 2.4** Hierarchic regression of the influence of personal factors, lesion characteristics and secondary conditions on Life satisfaction (n = 147)

| Determinant | Life satisfaction after SCI | | Change in life satisfaction before and after SCI | | Deterioration of life satisfaction after SCI‡ | |
|---|---|---|---|---|---|---|
| | Beta value | p-value | Beta value | p-value | Odds ratio | p-value |
| Personal factors | | | | | | |
| Gender | -0.21 | 0.021* | -0.12 | 0.203 | 0.41 | 0.070 |
| Age | 0.09 | 0.366 | 0.11 | 0.262 | 1.31 | 0.535 |
| Education level | 0.02 | 0.366 | -0.06 | 0.484 | 0.49 | 0.083 |
| $R^2$ Change | 3.0% | 0.350 | 2.0% | 0.556 | 3.0% | 0.350 |
| Lesion factors | | | | | | |
| Cause of injury | 0.07 | 0.677 | -0.04 | 0.721 | 1.23 | 0.702 |
| Completeness | 0.12 | 0.789 | 0.23 | 0.026* | 1.97 | 0.188 |
| Lesion level | 0.31 | 0.001† | 0.28 | 0.002† | 4.02 | 0.003† |
| $R^2$ Change | 9.0% | 0.022* | 10.0% | 0.027* | 10.0% | 0.022* |
| Consequences | | | | | | |
| Total pain | 0.19 | 0.032* | 0.13 | 0.160 | 2.89 | 0.017* |
| Total sec impairments | 0.22 | 0.014* | 0.22 | 0.015* | 2.66 | 0.023* |
| $R^2$ Change | 8.0% | 0.001† | 6.0% | 0.004† | 10.0% | 0.004† |
| Total explained variance | 19.0% | | 17.0% | | 23.0% | |

* $p<0.05$. † $p<0.01$. ‡ Logistic hierarchic regression with Nagelkerke $R^2$.

# DISCUSSION

The results of this study show a marked decrease in life satisfaction of persons with SCI at one year after discharge from inpatient rehabilitation, compared to their life satisfaction before SCI, retrospectively reported early in inpatient rehabilitation. Decrease of life satisfaction was strongest for the domains Sexual life, Self care and Vocational situation. Partner relations, Family life and Contacts with friends and acquaintances appeared the least affected life domains. Age, gender and education had little influence on life satisfaction after SCI and change of life satisfaction. High level of lesion, suffering from secondary impairments and from pain, were associated with decrease of life satisfaction and with low life satisfaction one year after discharge.

## Comparison of life satisfaction before and after SCI

Only one earlier study compared life satisfaction after SCI with a retrospective rating of life satisfaction before SCI, both measured during initial inpatient rehabiliation.[22] The levels of satisfaction with life as a whole before and after SCI (4.4 and 3.0 on a 0–5 scale) were similar to the scores of 5.3 and 4.3 on a 1–6 scale found in this study. Regarding other diagnostic groups, Fugl-Meyer and co-workers asked persons three years after multiple trauma[29] and 4–6 years after stroke[30] to rate their current life satisfaction and their life satisfaction before trauma with the LiSat-9. They also found a significant decrease of satisfaction with Life as a whole and with most life domains, and found the social relationships domains to be least affected. Of the stroke patients, 82% were satisfied with life as a whole before the event and 58% after the event. Of the trauma patients, 75% were satisfied with life as a whole before and 41% after the event.[29,30] The figures of this study (88% satisfied before and 57% satisfied after SCI) show a similar decrease and show percentages similar to the stroke group, but somewhat higher percentages than in the trauma group.

## Satisfaction after SCI compared to population figures

Satisfaction with Life as a whole after SCI in the current study (4.3; 57% satisfied) was significantly, but only moderately lower than in the general population (4.7; 66.8% satisfied) as described by Post et al.[16] Comparison of LiSat-9 Life as a whole scores of Swedish SCI and population studies showed a similar difference.[14,31] Dijkers[3] reviewed comparative studies and found lower levels of life satisfaction in persons with SCI than in reference groups in 14 out of 15 studies. Effect sizes were between 0.3 and 1.5, indicating that the difference in satisfaction with life as a whole found in this study was relatively small. However, the use of different life satisfaction measures hampers comparisons with these other studies.

Regarding separate life domains, Sexual life showed the largest difference between SCI and population (0.8 points, Effect Size 0.48). Other differences were less pronounced. Three domains, Financial situation, Family life and Contacts with friends and acquaintances were even rated higher by persons with SCI than by the reference group. Post[16] found in comparison with the same control group lower ratings in the SCI population for Self care, Sexual life, Leisure an Vocational situation and higher ratings for Family life.

## Retrospective ratings

Interestingly, the retrospective ratings by persons with SCI of life satisfaction before SCI were much higher than ratings of current life satisfaction in the reference population.[16] As a result, decrease in life satisfaction after SCI was larger compared to the retrospective rating of the persons themselves, than compared to population data.

One possible explanation for the extraordinary high ratings of life before SCI is memory bias, but the mean time between injury and the retrospective measurement was only three months. An alternative explanation for the high retrospective ratings is idealization of life before injury,[22,29] suggesting that these ratings are unrealistic and possibly even harmful for current life satisfaction.[22] A better explanation for both the high ratings of life satisfaction before SCI and the relatively small differences between post-injury scores and population figures is provided by response shift theory.[32] This theory suggests a psychological adaptation to life after SCI through changes in internal standards, values and conceptualisations. Because of this adaptation, comparisons of life satisfaction ratings of persons with SCI to those of reference groups, as is usually recommended,[3] might result in underestimations of the true changes induced by the SCI. Comparison of current life satisfaction to a retrospective rating of life satisfaction before SCI, a so-called thentest, might better reflect the impact of SCI on life satisfaction.[33] In this study, life satisfaction before injury was included in the first measurement only and not in the measurement one year after discharge simultaneously with the rating of current life satisfaction. This limits comparability of both measurements. On the other hand, such a later retrospective rating might more strongly suffer from memory bias. Further research is necessary to reveal the most useful approach.

## Comparison with other LiSat-9 studies in SCI populations

The mean score for satisfaction with Life as a whole in this study (4.3) was in the range of mean scores (4.2–4.6) reported in other SCI studies using the LiSat-9 (Table 2.5).[14,16-18]

**Table 2.5** Comparison of LiSat-9 scores after spinal cord injury in different studies

| LiSat | This study (n = 147) | | Netherlands Schonherr[17] (n = 57) | | Netherlands Post[16] (n = 318) | | Sweden Budh[14] (n = 192) | | UK Tasiemski[18] (n = 985) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | Mean | SD | Mean | SD |
| Life as a whole | 4.3 | 1.3 | 4.6* | 1.0 | 4.4 | 1.2 | 4.2 | 1.2 | 4.2 | 1.3 |
| Self care ability | 4.2 | 1.6 | 4.4 | 1.4 | 4.3 | 1.6 | 4.0 | 1,3 | 4.0 | 1.7 |
| Leisure situation | 4.6 | 1.2 | 4.7 | 1.3 | 4.4† | 1.3 | 4.2† | 1.3 | 3.9† | 1.4 |
| Vocational situation | 4.1 | 1.4 | 4.3 | 1.6 | 3.8 | 1.7 | 4.1 | 1.3 | 3.7* | 1.5 |
| Financial situation | 4.4 | 1.4 | 4.3 | 1.2 | 4.1* | 1.4 | 4.6 | 1.2 | 3.8† | 1.4 |
| Sexual life | 3.3 | 1.7 | 3.3 | 1.6 | 3.1 | 1.6 | 3.0* | 1.7 | 2.7† | 1.8 |
| Partner relationships | 5.1 | 1.2 | 4.7† | 1.6 | 4.9 | 1.5 | 4.1† | 1.7 | 4.0† | 2.0 |
| Family life | 5.1 | 1.0 | 5.1 | 1.1 | 4.8† | 1.2 | 4.7† | 1.3 | 4.8† | 1.4 |
| Contact friends | 5.2 | 1.0 | 5.0† | 1.3 | 4.7† | 1.0 | 4.6† | 1.4 | 4.5† | 1.4 |

One Sample t-test between means of the LiSat-9 after SCI in the current study and the other studies. * $p<0.05$, † $p<0.01$.

The overall-pattern of higher and lower rated life domains was similar for all studies: satisfaction with Sexual life was lowest, Vocational situation also obtained relatively low scores, and social relationships (Family, Friends) were rated highest. Sexual dysfunction is common after SCI, either caused directly by sexual dysfunctions due to the disease or its treatment, or indirectly by adjustment problems and reactions of others.[34]

Satisfaction scores for Self-care ability, Vocational situation and Financial situation in this study were more or less similar to those of the two other Dutch studies[16,17] and the Swedish study.[14] Because of the short time after injury in this study, lower satisfaction scores with Vocational and Financial situation might have been expected since vocational reintegration after SCI often takes several years.[10,35-37] An explanation might be the current social security system in the Netherlands, in which continuation of job and income are guaranteed during two years of sick-leave and therefore still applying to many participants.

The UK study[18] showed generally lower life satisfaction scores than the other studies. The reason for this is not clear. Semantic differences might be present, although an English version was provided by the author.[25] Cultural differences might also be present, but cannot be explored as LiSat-9 reference values for the British population are not available.

## Determinants of life satisfaction

The relationships found between level of lesion and life satisfaction were in concordance with the study by Clayton and Chubon[38] but were in contrast with results of other studies[5,8,11,34,36,39,40] in which no relationships with level of lesion were found. Dijkers[3] suggested in his meta analysis that the impairment itself (correlation of -0.05) barely affected life satisfaction, but that the impact of the impairment on activities ($r = -0.21$) and participation ($-0.17 < r > -0.48$) affected life satisfaction.[3]

Pain was a determinant for life satisfaction in our study. Pain in the SCI population has been studied widely.[41] In his one to two years post-injury follow-up study Putzke[8] found a decrease in life satisfaction of people who developed pain and an increase in life satisfaction in people who resolved their pain. Recent cross-sectional studies revealed a decreased life satisfaction in SCI population with pain.[14,42-45]

As expected, we found negative associations between secondary impairments and life satisfaction. These results are in accordance with the findings of Ville[44] (urinary tract problems) and Post,[40] who found a negative association between life satisfaction and the secondary complications pressure sores, spasticity, respiratory problems and pain.

## Limitations

The relatively high drop out of persons with tetraplegia might have resulted in an overestimation of life satisfaction after SCI. Another limitation is the lack of a prospective rating of life satisfaction before SCI, but in most rehabilitation research, retrospective ratings will be unavoidable as SCI is a rare condition. For more common disabilities, the use of large longitudinal population cohort studies might provide useful comparisons of the impact of disability on life satisfaction.[21,46]

## Strengths

This is one of the few studies in which life satisfaction was studied in persons with SCI in the first years of the injury and in which a retrospective rating of life satisfaction before injury enlarged insights in the impact of SCI on life satisfaction as perceived by the persons themselves. The large number of participants allowed for valid estimations of life satisfaction and for multivariate analyses. The use of the LiSat-9 provided descriptions of both satisfaction with Life as a whole and satisfaction with important life domains and facilitated comparisons with five other studies of life satisfaction in SCI using the same instrument.

## Clinical implications

Life satisfaction at one year after discharge was negatively influenced by pain and other secondary impairments and these conditions should therefore be treated adequately in multidisciplinary setting in outpatient rehabilitation. Sexual life must be questioned in follow-up situations for potentially intervention, because of the clearly low satisfaction with sexual life after SCI.[34]

The weak correlations between pre-injury and post-injury life satisfaction suggest that life satisfaction is not a stable personal characteristic, so it might be positively influenced by psychological interventions directed at strategies to cope with the SCI.[15,47-49]

## Research

Measurement of life satisfaction one year after discharge might be too early to reflect a more or less stable situation.[8] A long-term follow-up is necessary to identify determinants that influence life satisfaction.[2,16,35,50] The use of the LiSat-9 facilitated comparisons with other studies and is recommended for further study. Addition of the Satisfaction With Life Scale (SWLS) that is used commonly in the US would further improve comparability of study results.[51] In the current study, person and lesion characteristics allowed only for a minor amount of explained variance of life satisfaction. Future studies need to focus on the influence of environmental factors like social support[37,52] and personal factors like coping style, self efficacy and personality.[15,19,43,45,49]

## Conclusion

One year after discharge of inpatient rehabilitation life satisfaction of individuals with a spinal cord injury was moderately lower than the general Dutch population but strongly lower than life before SCI in retrospect. Life satisfaction after SCI and decrease of life satisfaction after SCI were associated with level of lesion, pain and secondary impairments.


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# 3

# Recovery of life satisfaction of persons with spinal cord injury during inpatient rehabilitation

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## ABSTRACT

**Objective:** To determine the course of life satisfaction of persons with spinal cord injury (SCI) and its determinants during inpatient rehabilitation and up to one year after discharge.

**Design:** Prospective cohort study of 222 persons with SCI. Measurements at the start of active rehabilitation, after three months, at discharge and one year after discharge. Questions about current life satisfaction and current life satisfaction compared with life satisfaction before SCI were asked and analysed, and the sum score Life Satisfaction Total (LS Total) of these questions were analysed using multilevel regression analysis. Person and injury characteristics and secondary impairments at each measurement were analysed as possible determinants of the LS total score.

**Results:** Estimated LS Total scores improved from 5.3 (SE 0.16) at the start of active rehabilitation up to 6.5 (0.17) at discharge and remained stable (6.5; 0.16) during the first year after discharge. Significant determinants of a positive course of life satisfaction were less pain, fewer secondary impairments and better functional status.

**Conclusions:** Life satisfaction already improves during inpatient rehabilitation. Functional status, pain and secondary impairments must be treated adequately in multidisciplinary rehabilitation.

# INTRODUCTION

Spinal cord injury (SCI) is a major life event that leads to serious physical disability and secondary medical problems, and impacts life satisfaction of persons involved.[1,2] Life satisfaction is studied widely in the SCI population. However, most studies on life satisfaction of persons with SCI used a cross-sectional design and measured life satisfaction many years after SCI.[3-15] Life satisfaction measurements in the early phase of SCI are however sparse. Only one small-scale study (n = 29) collected life satisfaction data from subjects with SCI in initial inpatient rehabilitation.[16] The mean over-all life satisfaction score of this group was lower than that of a non-injured control group, but was still above "rather satisfied".[16] A cross-sectional study including persons 1–7 years after onset of SCI revealed that modest recovery of life satisfaction might be expected in the first years after SCI.[13,17] Only three longitudinal studies of life satisfaction in the first years after SCI were found. Stensman[18] followed a small group of 17 patients from six months up to five years after SCI. Most (14/17) subjects reported the first seven months after SCI to be the most difficult time. Over-all quality of life ratings of most subjects improved between six months and one year after SCI, and remained more or less stable after the first year.[18] Kennedy et al.[19] found no differences in satisfaction in a small group of 24 persons with SCI between 1 and 6 months after discharge from inpatient rehabilitation. A large longitudinal study (n = 207) with measurements from one up to five years after SCI[20] showed a stable course of life satisfaction over this period.

Studies into determinants of life satisfaction in SCI showed that age, gender, marital status, time since injury and level of injury were weak and inconsistent determinants.[2,21] Physical disability was a consistent, but weak determinant of life satisfaction.[2] Little is known however about determinants of life satisfaction early after injury. One available study showed significant relationships between gender, employment status, self-perceived health, mobility and social integration one year after SCI and life satisfaction two years after SCI, but after inclusion of life satisfaction at one year after SCI in the regression analysis, only mobility and self-perceived health remained significant determinants.[21]

In summary, little is known about the course and determinants of life satisfaction in the early inpatient and post-discharge period. The current study aims to answer the following research questions: 1) what is the course of life satisfaction in a cohort of Dutch persons with a SCI during initial inpatient rehabilitation until one year after discharge, and 2) what are the associations of personal and lesion characteristics, functionality and secondary impairments and the course of life satisfaction.

# METHODS

## Subjects

This study is part of the Dutch research program "Physical strain, work capacity, and mechanisms of restoration of mobility in the rehabilitation of persons with a SCI". Eight rehabilitation centres specialized in SCI participated in the project. Subjects were eligible to enter the project if they had an acute SCI; were between 18 and 65 years of age; were classified as A, B, C, or D on the American Spinal Injury Association Impairment Scale and were expected to remain wheelchair-dependent, at least for long distances. Exclusion criteria were: SCI due to malignancies, progressive disease, known cardiovascular disease or psychiatric problems; insufficient command of the Dutch language to understand the goal of the study and the testing methods. The Medical Ethics Committee of the Stichting Revalidatie Limburg / Institute for Rehabilitation Research in Hoensbroek and all local Medical Ethics Committees approved the research protocol and all subjects gave written informed consent.

## Procedure

Measurements were performed at the start of active rehabilitation (Start, defined as the moment that a person could sit for 3 to 4 hours), three months after Start (3M), at discharge from inpatient rehabilitation (Discharge) and one year after discharge (1Y). The 3M measurement was performed only if active rehabilitation took longer than three months. These four measurements comprised amongst others a medical examination by a rehabilitation physician, an oral interview with a trained research assistant and a self-report questionnaire.

## Instruments

*Measurement of life satisfaction* was part of the oral interview. We used two questions to measure life satisfaction:

1. *Life Satisfaction Now (LS Now)* was phrased: People can be more or less satisfied with their life as a whole, their so called "quality of life". What is your quality of life at the moment? Response categories were: very unsatisfying (1), unsatisfying (2), rather unsatisfying (3), rather satisfying (4), satisfying (5) and very satisfying (6).

2. *Life Satisfaction Comparison (LS Comparison)* was phrased: When you compare your life now with your life shortly before the SCI; is your quality

of life now worse, equal or better than before the SCI? Response categories were: much worse (1), worse (2), somewhat worse (3), about the same (4), somewhat better (5), better (6) and much better (7).

Supported by correlations (Pearson's r = 0.5–0.6) between both scores at all measurements, a sum score of both questions, *Life Satisfaction Total (LS Total)*, was computed. This LS total score was normally distributed at each measurement (Skewness 0.0–0.5).

*Demographic characteristics* collected at the first measurement were age, gender, educational level, marital status (married or living together; single; living at parental home) and having a paid job.

*Lesion characteristics* were assessed according to the International Standards for Neurological Classification of Spinal Cord Injury.[22] The ASIA impairment scale classifications A and B were considered motor complete and the classifications C and D were considered motor incomplete. Neurological lesion level was defined as the highest intact motor level. Neurological levels below T1 were defined as paraplegia and neurological lesion levels at or above T1 were defined as tetraplegia. Cause of injury was dichotomised in traumatic versus non-traumatic, the latter group including causes like spinal cord infarction or benign tumours.

*Functional independence* was measured using the motor score of the Functional Independence Measure (FIM)[23,24] The motor score consists of 13 items about self care, mobility, transfers and bladder/bowel function and the total score is between 13 and 91.

*Secondary impairments* were grouped into two categories:

1. *Pain*: 8 items about pain and other abnormal sensations as numbness, tingling, burning, phantom, hot or cold feelings, itching and dull feelings. All were scored as "absent" or "present" A total pain score was calculated as the sum score of all items and the total scores were dichotomised into one group with 0 or 4 complaint (score = 1) and one group with 4 or more complaints (score = 0).

2. *Other secondary impairments*: 7 items including pressure sores, urinary tract infections, pulmonary infections, neurogenic heterotopic ossification, oedema, hypotension and autonomic dysreflexia. Each impairment was scored as "absent" or "present". A total score was computed as the sum score of all items and the total scores were dichotomised into one group with 0 to 1 impairment (score = 1) and one group with 2 or more impairments (score = 0). The cut-off points of both variables were chosen to create more or less even numbers of persons reporting few and reporting many secondary impairments.

## Statistics

*Descriptive statistics* (means and standard deviations) of personal and lesion characteristics and of life satisfaction were calculated.

*Random coefficient analysis* (MlwiN version 1.1; Centre for Multilevel Modelling, Institute of Education, London, UK), also known as mixed effects model analysis, was used to study the course of life satisfaction and its determinants. One main advantage of multilevel analysis in longitudinal studies is that cases with missing values can be included in the analyses. Therefore, all available assessments are taken into account in the analyses in contrast to repeated measurement analysis of variance.[25,26]

The course of LS Now, LS Comparison and LS Total was studied with multilevel linear regression models with time as the only determinant, entered in the model as a set of three dummy variables. The assessment of life satisfaction at discharge (Discharge) was chosen as the reference measurement. The differences between life satisfaction at discharge and at the other measurement times were estimated by the coefficients for these measurement times. Estimates of life satisfaction at the other measurement times were obtained by adding these coefficients to the intercept.

Possible determinants of the course of life satisfaction (LS Total score) were examined in a multilevel regression model with LS Total at Start, Discharge and 1Y as the dependent variable. The LS total score is an ordinal variable, but because of its normal distribution and the large number of subjects, the use of linear regression is nevertheless acceptable.

Time was included in a basic model as a set of 2 dummy variables, representing the period during (Start–Discharge) and after inpatient rehabilitation (Discharge–1Y). Independent variables, measured at Start, Discharge and 1Y, were: FIM-scores, Pain (few pain = 1, much pain = 0), Secondary impairments (few impairments = 1, much impairments = 0), Cause of SCI (traumatic = 1, non-traumatic = 0), Level of SCI (tetraplegia = 1; paraplegia = 0) and Completeness of SCI (motor complete = 1; motor incomplete = 0) and the interaction between lesion level and completeness were added one by one to the basic model to study their individual relationship with the LS Total scores. Pain and other Secondary impairments were digitomized, because their score distributions were skewed and therefore did not fit the assumptions of linear regression.

For each individual independent variable, the possible confounding effect of age, gender, and education level on the relationship between the independent variable and the LS Total score was investigated. Age, gender and education level were considered a confounder if the Beta of the independent variable changed more than 10% after adding one of these variables to the model. Finally, all independent variables that were significantly ($p<0.10$) related to the LS Total score and, if applicable, their confounders and the interaction terms between confounders and independent variables were simultaneously entered in the multivariate multilevel regression model using the Backward elimination method, leading to a final model including only significant ($p<0.05$) determinants.

# RESULTS

## Respondent characteristics

Two hundred and twenty two persons with a SCI were included and their characteristics are displayed in Table 3.1. Mean age at discharge was 40.7 (SD 14.5) and mean time since injury at discharge was 10.4 (SD 5.2) months.

## Non-response analysis

Of the initial study group of 222 persons at Start, 149 attended 3M, 186 attended Discharge and 146 attended the measurement one year after discharge (1Y). The lower number of subjects at 3M occurred because 3M was omitted if patients were discharged within three months after the start of inpatient rehabilitation. Drop-out over time had different causes: 9 persons died, 12 persons were excluded because they regained ability to walk for longer distances and 19 persons refused to collaborate. Some others had moved abroad, had developed a psychiatric condition after the first measurement, or could not be contacted at all. A comparison between participants and non-participants showed no differences regarding gender, age and completeness of injury, but more non-participants (50%) than participants (30%) had tetraplegia ($p<0.05$).

## Level of life satisfaction, impairment and function

Descriptives of life satisfaction and its predictors at all measurements are displayed in Table 3.2. The proportion of persons unsatisfied with their life as a whole decreased from 74.6% at Start to 49.3% at 1Y. The proportion of persons experiencing deterioration of quality of life after SCI however only decreased from 85.8% at Start down to 75.3% at 1Y. The correlations (Pearson's r) between life satisfaction scores at the first and last measurements were 0.41 ($p<0.001$) for LS Now and 0.60 ($p<0.001$) for LS Comparison. The proportion of persons experiencing pain increased during inpatient rehabilitation, but decreased after discharge. The proportion of persons experiencing many secondary conditions increased from 37% at discharge up to 50.3% one year after (Table 3.2). FIM motor-scores increased during and after inpatient rehabilitation.

## Course of life satisfaction

Estimated scores of LS Now, LS Comparison and LS Total all increased during the first three months of active rehabilitation (Start–3M) using the basic regression model (Figure 3.1). Between three months after the start of active rehabilitation and discharge (3M–Discharge),

**Table 3.1** Characteristics of respondents (n = 222) at start of active rehabilitation

| | n | % |
|---|---|---|
| Gender | | |
| Man | 165 | 74.3 |
| Woman | 57 | 25.7 |
| Age | | |
| 18–25 | 45 | 20.6 |
| 25–35 | 45 | 20.6 |
| 35–45 | 40 | 18.2 |
| 45–55 | 40 | 18.2 |
| 55–65 | 49 | 22.4 |
| Cause of injury | | |
| Traumatic | 153 | 67.1 |
| Non-traumatic | 53 | 32.9 |
| ASIA Impairment Scale grade | | |
| A | 99 | 43.8 |
| B | 51 | 22.6 |
| C | 47 | 20.8 |
| D | 22 | 9.7 |
| Type of injury | | |
| Motor completeness | | |
| Complete tetraplegia | 54 | 24.7 |
| Incomplete tetraplegia | 31 | 14.2 |
| Complete paraplegia | 96 | 43.8 |
| Incomplete paraplegia | 38 | 17.4 |
| Home situation before injury | | |
| Married/together | 123 | 56.3 |
| Living at parental home | 38 | 17.4 |
| Single | 54 | 24.7 |
| Group | 4 | 1.8 |
| Education | | |
| High | 108 | 49.5 |
| Low | 110 | 50.5 |
| Vocational status before injury | | |
| Yes | 186 | 83.8 |
| No | 36 | 16.2 |

Missing data are ignored.

the increase of life satisfaction scores was smaller and was only significant for the LS Now score. During the first year after discharge, mean life satisfaction scores remained stable. The time variables showed a significant increase of the mean LS Total score of 0.69 points between the start of active rehabilitation and discharge, and a stable score between discharge and one year after discharge.

Figure 3.2 shows the course of being satisfied/unsatisfied with life as a whole on Start, Discharge and 1Y. Of 138 persons with data on these three measurements, 43 (31.2%) were unsatisfied at all measurements, 28 (20.3%) were satisfied at all measurements and the others shifted between both conditions. From Start to Discharge, 37 persons experienced a positive change, from unsatisfied to satisfied, and 8 a negative change. From Discharge to 1Y, 21 persons

**Table 3.2** Descriptives of life satisfaction (LS) and pain, secondary impairments and functional outcome

| | Start (n = 212) | 3M (n = 149) | Discharge (n = 186) | 1Y (n = 146) |
|---|---|---|---|---|
| LS Now | | | | |
| Very unsatisfying | 10.4 | 7.4 | 5.4 | 4.8 |
| Unsatisfying | 25.9 | 18.1 | 10.2 | 6.2 |
| Rather unsatisfying | 16.0 | 14.1 | 10.2 | 11.6 |
| Rather satisfying | 21.2 | 24.2 | 28.0 | 26.7 |
| Satisfying | 21.7 | 31.5 | 40.3 | 45.9 |
| Very satisfying | 4.7 | 4.7 | 5.9 | 4.8 |
| LS Comp | | | | |
| Much worse | 45.3 | 38.9 | 30.1 | 28.1 |
| Worse | 27.4 | 28.9 | 28.5 | 24.7 |
| Somewhat worse | 13.2 | 10.7 | 21.5 | 22.6 |
| Equal | 9.9 | 10.7 | 12.4 | 15.8 |
| Somewhat better | 3.3 | 4.0 | 2.2 | 4.8 |
| Better | 0.9 | 4.7 | 3.2 | 2.7 |
| Much better | 0 | 2.0 | 2.2 | 1.4 |
| LS Now; correlation with first measurement | NA | 0.49 | 0.46 | 0.41 |
| LS Comp; correlation with first measurement | NA | 0.54 | 0.63 | 0.60 |
| Pain | | | | |
| ≥ 2 pain conditions | 30.8 | 61.4 | 52.6 | 36.7 |
| 0–1 pain conditions | 69.6 | 38.6 | 47.4 | 63.3 |
| Secondary impairments | | | | |
| ≥ 4 impairments | 44.9 | 54.7 | 37.0 | 50.3 |
| 0–3 impairments | 55.1 | 45.3 | 63.0 | 49.7 |
| FIM (mean; SD) | 40.9 (19.1) | 52.8 (22.6) | 63.4 (21.7) | 67.1 (21.6) |

All figures are percentages unless otherwise indicated. FIM = Functional Independence Measure.

experienced a positive change and 20 a negative change. The predictive value of satisfaction with life as a whole on Start for satisfaction with life as a whole at 1Y was high: 60.2% of all persons unsatisfied at Start were unsatisfied at 1Y and 77.5% of al persons satisfied at Start were satisfied at 1Y (Odds ratio = 5.16; 95% CI = 2.29–11.65; p<0.001).

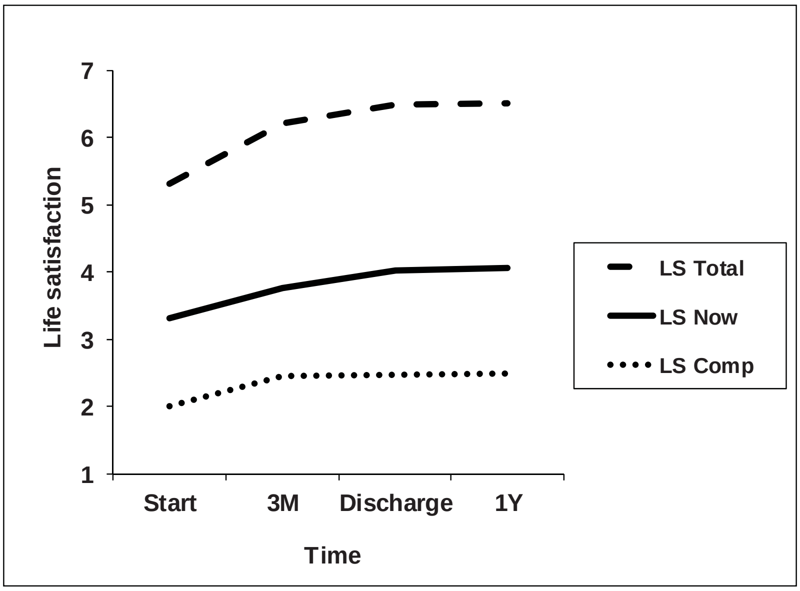


**Figure 3.1** Course of Life Satisfaction 'Now', Life Satisfaction 'In comparison with life before SCI' and Life Satisfaction Total as estimated by multilevel analyses. Start = start active rehabilitation; 3M = 3 months after start; Discharge = at discharge; 1Y = one year after discharge; LS Now = Life satisfaction at the moment of measurement; LS Comp = Life satisfaction in comparison with life before spinal cord injury; LS Total = sum scores of LS Now and LS Comp. LS Now: 1 = very unsatisfying; 2 = unsatisfying; 3 = rather unsatisfying; 4 = rather satisfying; 5 = satisfying; 6 = very satisfying. LS Comp: 1 = much worse; 2 = worse; 3 = somewhat worse; 4 = equal; 5 = somewhat better; 6 = better; 7 = much better.

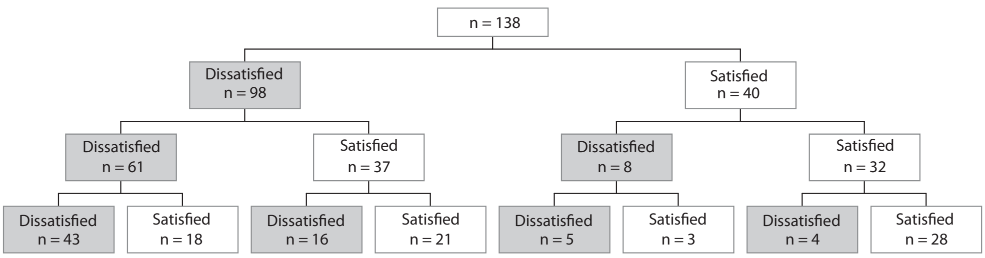


**Figure 3.2** Course of being satisfied/unsatisfied with life as a whole on Start, Discharge and 1Y.

**Table 3.3** Life satisfaction in multilevel association with time interval and characteristics

| Variable | Life satisfaction | SE | p-value |
|---|---|---|---|
| Constant | 3.80 | 0.55 | |
| | Regression coefficient | | |
| Time interval | | | |
| Start–Discharge* | -0.69 | 0.21 | 0.001 |
| Discharge–1Y** | 0.05 | 0.16 | 0.75 |
| Characteristics | | | |
| Level | n.s. | | |
| Completeness | n.s. | | |
| Cause | n.s. | | |
| FIM | 0.02 | 0.005 | 0.0001 |
| Pain | 0.33 | 0.16 | 0.04 |
| Sec impairment | 0.41 | 0.16 | 0.01 |

All results are regression coefficients (ß) of the final stepwise backward multiple linear regression analysis for Life Satisfaction Total. Regression coefficient indicates the increase of life satisfaction with an increase of the variable with 1 unit.
* The differences in life satisfaction between the start of active rehabilitation and discharge of rehabilitation.
** The differences in life satisfaction between discharge of rehabilitation and one year after discharge of rehabilitation.
Start–Discharge = time interval between start and discharge of inpatient rehabilitation; Discharge–1Y = time interval between discharge and one year after discharge of inpatient rehabilitation; n.s. = non significant.

### Determinants

All determinants were univariately related to the course of LS Total and were entered in the backward multilevel regression analysis. Age, gender and level of education were not confounders for one or more of these determinants. The final regression model is shown in Table 3.3. Significant determinants of the course of higher LS Total were a high FIM score, having few pain sensations and having few secondary impairments (Table 3.3). Lesion level, completeness or their interaction did not show a relationship with LS Total in this analysis.

## DISCUSSION

The results of this study showed that life satisfaction improved during inpatient rehabilitation, especially during the first three months of active rehabilitation, and remained stable during the first year after discharge. Having few pain sensations and a low number of other secondary impairments, and having a better functional status were predictors of a more favourable course of life satisfaction early after SCI.

## Course of life satisfaction

Our results showed that recovery of life satisfaction after SCI starts early after injury and reaches a plateau at discharge. The mean LS Now score at 3M, 3.76 on a 1–6 scale, was similar to the life satisfaction score of 2.96 on a 0–5 scale found in the only other study measuring life satisfaction during inpatient rehabilitation.[16] In that, cross-sectional, study no significant relationship between time after injury (one month to one year after SCI) and life satisfaction was found, but our larger study with a longitudinal design was better suited to examine the course of life satisfaction over time. Our first measurement was at the start of inpatient rehabilitation, about two months after SCI, so that the LS Now score at Start is probably not the all-time low. Literature suggests that well-being after SCI reaches a plateau at the end of the adjustment period, which has been estimated to last from two to five years.[2] The stability of well-being scores between discharge and one year after discharge found in our study suggests an earlier plateau, namely at the time of discharge from the rehabilitation. This was at a mean time of 10.4 months after injury, so that our results might be consistent with those of other studies finding little or no change in life satisfaction after the first year post-SCI.[18,20,21] However, the mean LS Now score we found at one year after discharge is lower than life satisfaction scores found in earlier long-term studies in the Netherlands,[13,14] suggesting that further improvement of life satisfaction scores longer after SCI might be possible.

Several explanations for the positive course of life satisfaction found in this study are possible. First of all, recovery of life satisfaction in our study group might be a reflection of improved functional independence, physical capacity, wheelchair mobility, etcetera, as described in various other publications based on this cohort.[27-29] A second, psychological explanation is post-traumatic growth.[30] This phenomenon is described as a process in which individuals adopt an approach towards traumatic events which allows them to perceive benefits such as positive personality change, positive relationships with new persons and a changed notion about what is really important in life.[18] Thirdly, the positive course of LS Now might be explained by response shift theory.[31] This theory suggests the presence of a change in internal standards, values and conceptualisations of life, resulting in adaptation to the new situation and improved levels of life satisfaction. Our finding of improving LS Now scores but more or less stable LS Comparison scores supports this response shift theory. One year after discharge, more than three-quarters of our study group was at least "somewhat satisfied" with their lives, but three-quarters nevertheless experienced deterioration of quality of life. Elsewhere, we described retrospective ratings of life satisfaction before SCI in this patient group, ratings that were substantially higher than those of the reference population suggesting idealization of life before SCI.[32] This idealization indicates probably a change of internal standards due to adaptation to the injury.

## Determinants

Having pain, other secondary impairments and lower levels of functional independence were determinants of the course of LS Total scores. Pain, with a prevalence of 27 to 77%[33] in SCI patients, has a strong impact on quality of life,[34] as was confirmed in our study. In a one to two years post-injury follow-up study[35] a decrease in life satisfaction of people who developed pain and an increase in life satisfaction in people whose pain resolved, was found. Cross-sectional studies also revealed decreased life satisfaction in SCI-populations with pain.[33,36-40]

Having many secondary impairments was also related to a smaller change in life satisfaction. These results are in accordance with the findings of other studies,[41,42] in which also a negative association between life satisfaction and secondary complications was found.

The FIM-score was a determinant of change in life satisfaction in this study, an increase of 25 points in FIM-scores corresponded to an increase of 0.5 points on the LS Total score. Level and completeness of SCI were however not related to changes in LS Total in this regression analysis. FIM-scores are strongly related to lesion characteristics.[24] Other studies also showed that life satisfaction was more strongly related with activity limitations than with impairments.[1,43] This is in agreement with the suggestion that not the lesion itself relates to lower life satisfaction, but its influence on activities (functional status) and participation.[2]

## Limitations of this study

The relatively high drop out of persons with tetraplegia during the study might have resulted in an overestimation of life satisfaction after SCI. However our multilevel analysis ensured that that every participant and all available data were used. Another limitation is the lack of a prospective rating of life satisfaction before SCI and of life satisfaction ratings immediately after SCI. Pre-injury ratings are however not easily available as SCI is a rare condition. For more common disabilities, the use of large longitudinal population cohort studies might provide both pre-disability and post-disability data and thereby allow assessment of the impact of disability on life satisfaction.[44] To obtain over-all life satisfaction ratings in the acute care hospital may be experienced by persons with SCI as an odd question or as irrelevant in that phase of recovery.

## Clinical implications

Our study showed substantial improvement of life satisfaction scores in the early phase of SCI. We found however, like other authors,[45-47] also moderate to strong associations between life satisfaction scores on the first and the last measurements, suggesting long-lasting consequences of low life satisfaction early after SCI. Therefore we recommend assessment of psychological functioning early in rehabilitation and, if applicable, psychological intervention targeted on, for example, dysfunctional coping strategies to improve psychological functioning and well-being.[35,46,47] Pain and secondary impairments have a negative impact on life satisfaction, therefore these impairments must be treated adequately in multidisciplinary setting in in- and outpatient rehabilitation. The influence of functional status on life satisfaction prompts the relevance of training people to the highest possible level of functioning.

### Research recommendations

The life situation of a person with SCI develops during the first few years after SCI, and the final measurement at one year after discharge of our study is therefore too early to reflect a more or less stable situation.[21] Moreover, a longer follow-up period is further necessary to identify determinants that influence life satisfaction on the long term.[1,13,21,34,35] A sequel on this cohort with a focus on long-term life satisfaction has started recently. The influence of pain, secondary impairments and activity limitations has been confirmed in this study. Further research on the course of life satisfaction in SCI needs to focus on other domains of the ICF-model, especially the influence of environmental factors like social support and personal factors like coping style, self efficacy and personality.

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# 4

# Wheelchair exercise capacity in spinal cord injury up to five years after discharge of inpatient rehabilitation

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## ABSTRACT

**Objective:** 1) determining course and determinants of wheelchair exercise capacity in spinal cord injury (SCI) up to five years after discharge of inpatient rehabilitation, and 2) describing loss to follow-up.

**Design:** Prospective cohort study. Measurement of peak aerobic power output ($PO_{peak}$) and peak oxygen uptake ($VO_{2\,peak}$) at Start and Discharge of inpatient rehabilitation, one year (1Y) and five years after discharge (5Y).

**Subjects:** 128 persons with SCI, aged at onset 18–65 years, and wheelchair-dependent.

**Setting:** Eight rehabilitation centres.

**Results:** Significant change for both $VO_{2\,peak}$ and $PO_{peak}$ in interval Start–5Y and for $VO_{2\,peak}$ in Discharge–5Y interval. No significant changes of $VO_{2\,peak}$ and $PO_{peak}$ for 1Y–5Y interval. Age, sex, level and completeness of lesion were determinants for level of $VO_{2\,peak}$ and level of lesion and sex for level of $PO_{peak}$. No significant determinants for course of wheelchair exercise. The loss to follow-up group was older and included more persons with tetraplegia, this might have been an overestimation.

**Conclusion:** Wheelchair exercise capacity of persons with SCI stabilizes between one year after discharge up to five years after discharge. The participating group appears to be a positive selection of the total study group.

# INTRODUCTION

A spinal cord injury (SCI) is one of the greatest physical calamities that one can overcome,[1] and dramatically impacts exercise capacity and activity level of persons involved.[2-6] The majority of persons with SCI are wheelchair users and dependent on arm work for mobility and activities during daily life. Wheelchair exercise capacity is the combined ability of the cardiovascular, respiratory and musculoskeletal systems to attain a certain level of wheelchair activity.[7] The different components of wheelchair exercise capacity are influenced by personal and lesion-related factors, exercise mode, expertise and training.[3,7-9] Wheelchair exercise capacity is diminished in many persons with SCI because of muscle weakness, loss of autonomic control below the level of injury and subsequent changes in metabolic and vascular function. Wheelchair exercise capacity is an important determinant of health status of SCI subjects especially on the long term,[10] because a low wheelchair exercise capacity exposes them to increased risk of developing medical conditions like metabolic syndrome and cardiovascular disease,[11] and is related to a reduced level of functioning, a reduced level of activities and participation and quality of life.[11-14]

Most studies on exercise capacity in the SCI population are cross-sectional, including healthy, young and active male persons with a long time since injury (>6 years).[15-16] A recent longitudinal study with 20 years follow-up (n = 7 persons with SCI) revealed a stable exercise capacity.[17] In our own SCI cohort, on which the present study is based, recovery of wheelchair exercise capacity during inpatient rehabilitation up to one year after discharge was positively associated with lower age, male gender, low level and incompleteness of the lesion,[7] as was found in other cross-sectional studies on determinants and the level of exercise capacity.[2,11] No other longitudinal studies on this topic were found.

Persons with SCI endure a process of adaptation to the new life situation in the first few years after SCI onset[18] and they have to deal with many threats to and barriers for maintaining an adequate exercise capacity, once they have reintegrated in society.[10] Therefore, it is important to study the course of exercise capacity at mid and long term and to identify determinants that influence the exercise capacity over a longer follow-up period. Based on the limited longitudinal literature on this subject we hypothesized that the exercise capacity will remain stable up to five years (5Y) after discharge.[3,7,17,19,20]

In a longitudinal study amongst others comprising a voluntary and physically demanding peak wheelchair exercise test, loss to follow-up is an inevitable selection bias. As literature reveals, loss to follow-up is clearly related to age and disability and perceived benefit of the test.[21,22] Even more, in the long-term follow-up, the ability to trace and contact subjects is hard and accounts also for a higher loss to follow-up, as already described in our study population.[23] Therefore, we expected the loss to follow-up to be higher at 5Y for the older persons and for those with a more severe spinal cord lesion. In order to control for effects of loss to follow-up in the best possible way, we used random coefficient analyses, which allows to include also those participants who (temporarily) dropped out at some point during the longitudinal study.[24]

The current study aims are 1) to determine the course of wheelchair exercise capacity of persons with spinal cord injury (SCI) and its determinants up to five years after discharge of inpatient rehabilitation, and 2) to describe the loss to follow-up.

# METHODS

## Subjects

This study is part of the research program "Restoration of mobility in the rehabilitation of persons with a SCI".[25] Eight rehabilitation centres specialized in SCI participated in the project. Subjects were eligible to enter the project if they had an acute SCI; were between 18 and 65 years of age; were classified as A, B, C, or D on the American Spinal Injury Association Impairment Scale[26] and were expected to remain wheelchair-dependent, at least for community use. Exclusion criteria were: SCI due to malignancies, progressive disease, known cardiovascular disease or psychiatric problems; insufficient command of the Dutch language to understand the goal of the study and the testing methods. The Medical Ethics Committee of the Stichting Revalidatie Limburg / Institute for Rehabilitation Research in Hoensbroek approved the research protocol in 1999 and The Medical Ethics Committee of the University Hospital of Utrecht approved for the follow-up research protocol in 2006. All subjects gave written informed consent.

## Procedure

Measurements were performed at the start of active inpatient rehabilitation (Start, defined as the moment that a person could sit for 3 to 4 hours), at discharge from inpatient rehabilitation (Discharge), one year after discharge (1Y) and five years after discharge (5Y). These four occasions comprised amongst others a medical history and physical examination by a rehabilitation physician and a wheelchair peak exercise test.[9,32]

## Instruments

In this study we defined exercise capacity as wheelchair exercise capacity, being the peak results of the *peak exercise wheelchair test* in external power output ($PO_{peak}$ (W)) and oxygen uptake ($VO_{2\ peak}$ ($l.min^{-1}$)). To determine $PO_{peak}$ and $VO_{2\ peak}$, subjects performed a graded maximal wheelchair exercise test on a motor-driven treadmill. The testing protocol and equipment have previously been described by Kilkens et al.[27] and Haisma et al.[7] Before testing, subjects were asked to eat a light meal only, to refrain from smoking and drinking coffee or alcohol before testing, and to void their bladder. For each subject, and at every occasion, a drag test was used to determine the drag force and concomitant external power output for the wheelchair-user system on the treadmill at increasing inclinations and the actual testing speed.[28] Subjects performed two blocks of submaximal exercise of three minutes each, separated by a 2-minute rest. The treadmill incline was horizontal during the first block and then set at 0.36° during the second block. Treadmill velocity was set at 0.55 $m.s^{-1}$ for subjects with tetraplegia and at 1.1 $m.s^{-1}$ for subjects with paraplegia. In some subjects with a low cervical lesion, we used a protocol with a velocity of 0.89 $m.s^{-1}$. After two minutes of rest, the peak exercise test followed at the same constant velocity, and the inclination was increased 0.36° every minute. The test was terminated when the subject was exhausted or could no longer keep pace with the speed of the treadmill. Individual testing protocol was identical for each of the testing occasions.

The $VO_{2\ peak}$ was defined as the highest value of oxygen consumption recorded during 30 seconds. The $PO_{peak}$ was defined as the power output at the highest inclination that the subject could maintain for at least 30 seconds. The participants were tested at consistent time setting for every measurement.

*Demographic characteristics* collected at the first test occasion were age, gender, body weight and height. At each subsequent test occasion body mass (kg) was measured by the trained research assistant. Body Mass Index (BMI) was calculated in $kg.m^{-2}$.

*Lesion characteristics* were assessed according to the International Standards for Neurological Classification of Spinal Cord Injury.[26] The ASIA Impairment Scale classifications A and B were considered motor complete and the classifications C and D were considered motor incomplete. Neurological lesion level was defined as the highest motor level. We clustered the cervical, thoracic and lumbar lesions for presentation. Neurological levels below T1 were defined as paraplegia and neurological lesion levels at or above T1 were defined as tetraplegia. Cause of injury was dichotomised in traumatic versus non-traumatic (e.g. spinal cord infarction, benign tumours, infections). Time since injury was counted in years.

## Statistics

Descriptive statistics (means and standard deviations) of personal and lesion characteristics and ) at all test occasions were calculated with SPSS 16.0.

Random coefficient analysis (MlwiN version 1.1; Centre for Multilevel Modelling, Institute of Education, London, UK) was used to study the course of wheelchair exercise capacity up to five years after inpatient rehabilitation and its determinants.[24] The benefits of this method are 1) that it accounts for the dependency of repeated measures within the same person, 2) that it accounts for the hierarchical nature of the longitudinal data of the present study (Three levels of hierarchy are present: the repeated measurements are nested within the participants and the participants are nested with rehabilitation centers.), and 3) that, in contrast to traditional methods of longitudinal data analysis (i.e. MANOVA for repeated measures), the number of observations per individual may vary, so repeated measures as well as cases with missing values can be included in this multiple regression analyses. Therefore, we included the persons who performed two or more peak exercise tests during the test period (STUDY), which allows us to evaluate the course over time as well as the role of different determinants.[24] We divided STUDY into the group with tetraplegic lesions and a group with paraplegic lesions and studied the course of exercise capacity for these groups separately.

Possible determinants of the course of wheelchair exercise capacity were examined in a random coefficient regression model with $PO_{peak}$ and $VO_{2\ peak}$ at Start, Discharge, 1Y and 5Y as the dependent variables. Time was included in the basic model as a set of three dummy variables, representing the long-term period after start of active inpatient rehabilitation (Start–5Y), the period after inpatient rehabilitation (Discharge–5Y) and the period from one year up to five years after discharge (1Y–5Y). The 5Y occasion was chosen as the reference and was estimated by the intercept. The independent variables selected for further analysis were personal: age (years), gender (woman = 1, man = 0); and lesion characteristics: level of SCI (tetraplegia = 0; paraplegia = 1) and completeness of SCI (complete = 1; incomplete = 0). These were added one by one to the basic model to study their individual relationship with the wheelchair exercise capacity scores. Finally, all independent variables that were significantly ($p<0.10$) related to the $PO_{peak}$ or $VO_{2\ peak}$ score were simultaneously entered in the multivariate random coefficient regression model using the backward elimination method, leading to a final model for $PO_{peak}$ and $VO_{2\ peak}$ ($p<0.05$).

Furthermore, the interaction of the personal and lesion characteristics with time was studied by adding them to the basic model.

In the total study group of 225 persons, we identified two subgroups: the study group that performed two or more peak exercise tests during follow-up (STUDY), whose data were used in the random coefficient regression model. The group that performed one or no peak exercise test (EXCLUDED), were NOT used in the model. In order to describe possible consequences of loss to follow-up on STUDY outcomes, we performed t-tests and Chi-square tests for STUDY versus EXCLUDED on available personal and lesion characteristics at Start and 5Y and on available $PO_{peak}$ and $VO_{2\,peak}$ scores at Start and Discharge ($p<0.05$). To study the effect of loss to follow-up on the course of $PO_{peak}$ and $VO_{2\,peak}$, we entered a variable yes/*no 5Y-test* in the multivariate random coefficient regression model for the STUDY group.

Further, we identified a subgroup of STUDY that attended all the peak exercise tests (ALLTESTS) and studied their personal and lesion characteristics and their $PO_{peak}$ and $VO_{2\,peak}$ scores at all occasions. We performed t-tests and on available $PO_{peak}$ and $VO_{2\,peak}$ scores at all measurements ($p<0.05$) for ALLTESTS and STUDY.

# RESULTS

## Respondent characteristics

In total 225 persons were included in the study. Of the four occasions, 128 persons performed two or more peak exercise tests, representing our study group in the random coefficient analyses (STUDY). The remaining group with less than two occasions (n = 97) were treated as loss to follow-up (EXCLUDED). The characteristics of STUDY and EXCLUDED are given in Table 4.1.

Only 31 persons attended the peak exercise tests at all occasions (ALLTESTS). The characteristics of this group are presented in Table 4.1.

We found no significant differences in the outcomes of the wheelchair exercise test for the STUDY and ALLTESTS.

## Course of wheelchair exercise capacity in STUDY

We found a significant improvement of $PO_{peak}$ and $VO_{2\,peak}$ in the interval Start–5Y and an improvement of $VO_{2\,peak}$ for the interval Discharge–5Y. In addition, we found no change in the course of $PO_{peak}$ between 1Y (50.8 W) and 5Y (53.8 W), nor in the course of $VO_{2\,peak}$ between 1Y (1.31 l/min) and 5Y (1.41 l/min).

Figures 4.1 and 4.2 show the course of wheelchair exercise capacity over time as estimated with the basic regression model.

**Table 4.1** Personal and lesion characteristics at start and outcomes of wheelchair exercise test at different measures of the participants (STUDY) and non participants (EXCLUDED) and participants that attended all four peak exercise tests (ALLTESTS) in means and standard deviations (SD) or percentage.

| Characteristic | | ALLTESTS n = 31 | | STUDY n = 128 | | EXCLUDED n = 97 | | p-value |
|---|---|---|---|---|---|---|---|---|
| Age (years) | Mean (SD) | 38.0 | | 38.1 | (13.8) | 44.1 | (13.9) | 0.00* |
| Gender | Male % | 70 | | 76 | | 74 | | 0.67 |
| BMI (kg.m$^{-2}$) | Mean (SD) | 23.7 | (3.6) | 22.9 | (3.4) | 23.1 | (3.9) | 0.58 |
| AIS Impairment Scale % | A | 69 | | 57 | | 38 | | 0.00* |
| | B | 8 | | 14 | | 31 | | |
| | C | 14 | | 11 | | 15 | | |
| | D | 9 | | 18 | | 16 | | |
| Type of lesion % | Cervical | 10 | | 24 | | 58 | | 0.00* |
| | Thoracic | 81 | | 64 | | 34 | | |
| | Lumbar | 9 | | 12 | | 8 | | |
| Cause of injury | Trauma % | 87 | | 76 | | 69 | | 0.30 |
| | Non trauma % | 13 | | 24 | | 31 | | |
| Time since injury at 5Y | (years) | 6.6 | (0.7) | 6.4 | (2.3) | 6.6 | (0.9) | 0.14 |
| Mean $PO_{peak}$ Start (W) | Mean (SD) | 35.2 | (16.3) | 34.0 | (19.1) | 24.5 | (21.3) (n = 13) | 0.01* |
| Mean $PO_{peak}$ Discharge | Mean (SD) | 51.5 | (20.2) | 46.4 | (23.5) | 31.9 | (20.5) (n = 20) | 0.01* |
| Mean $PO_{peak}$ 1Y | Mean (SD) | 54.9 | (23.0) | 50.7 | (27.0) | NA | | NA |
| Mean $PO_{peak}$ 5 Y | Mean (SD) | 56.3 | (22.2) | 53.8 | (24.4) | 39.3 | (12.0) (n = 4) | NA |
| Mean $VO_{2\,peak}$ Start (L/min) | Mean (SD) | 1.00 | (0.3) | 1.05 | (0.4) | 0.86 | (0.2) (n = 13) | 0.01* |
| Mean $VO_{2\,peak}$ Discharge | Mean (SD) | 1.24 | (0.4) | 1.25 | (0.4) | 1.05 | (0.4) (n = 20) | 0.01* |
| Mean $VO_{2\,peak}$ 1Y | Mean (SD) | 1.31 | (0.4) | 1.31 | (0.4) | NA | | NA |
| Mean $VO_{2\,peak}$ 5Y | Mean (SD) | 1.38 | (0.5) | 1.41 | (0.4) | 0.80 | (0.2) (n = 4) | NA |

Personal and lesion characteristics were counted at start of inpatient rehabilitation. ALLTESTS = persons that attended all four peak exercise tests; STUDY = persons that attended two or more out of four peak exercise tests; EXCLUDED = persons that attended one or less peak exercise test; BMI = Body Mass Index; PO = peak Power Output; $VO_2$ = peak maximal oxygen intake; Start = Start of active rehabilitation; Discharge = discharge of inpatient rehabilitation; 1Y = test occasion at 1 year after discharge of inpatient rehabilitation; 5Y = test occasion at 5 years after discharge of inpatient rehabilitation; NA = not applicable.
* Significance set at $p<0.05$ for t-test and Chi square tests between STUDY and EXCLUDED.

Model outcomes for those with paraplegia and tetraplegia are presented separately in Figures 4.1 and 4.2. The figures show an improvement during inpatient rehabilitation and a stabilization after discharge up to 5Y. There are no differences in the course of $PO_{peak}$ and $VO_{2\,peak}$ for persons with a tetraplegia or a paraplegia up to five years after discharge of inpatient rehabilitation. We found no significant difference for the level and course of $PO_{peak}$ and $VO_{2\,peak}$ from Start up to 5Y between the subgroup of STUDY that attended the 5Y measurement and the subgroup that did not attend the 5Y measurement.

## Determinants

Table 4.2 presents the outcomes of the random coefficient analysis on the association between the wheelchair exercise capacity ($PO_{peak}$ and $VO_{2\,peak}$ ) and the time intervals (basic regression model) and the association between wheelchair exercise capacity, the determinants personal and lesion characteristics and the time intervals (final backward regression model).

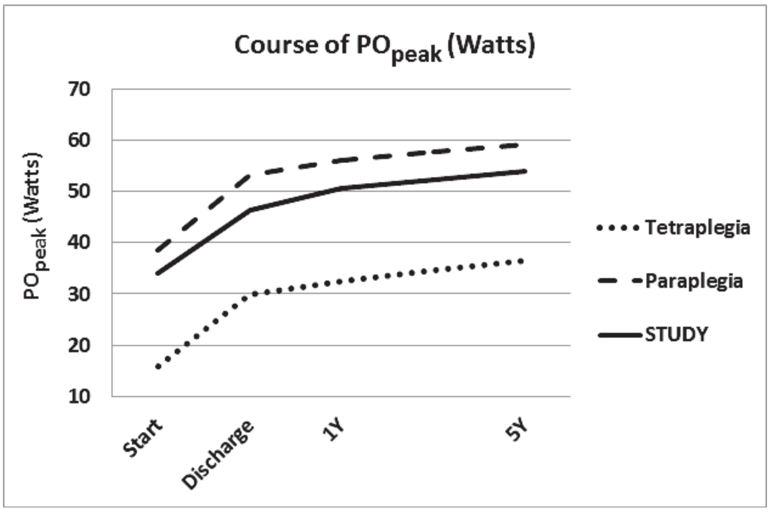


**Figure 4.1** Course of $PO_{peak}$ (Watts) as calculated from the regression model with lesion level added. The course of wheelchair exercise capacity for STUDY was estimated with the basic regression model (constant + 3 time dummies). The course of wheelchair exercise capacity for Tetraplegia and Paraplegia figures was estimated with regression model including level of lesion as determinant (constant + time dummies + lesion level + interaction term lesion level * time dummies). * The improvement in intervals Start–5Y and Discharge–5Y were significant for STUDY, Tetraplegia and Paraplegia. $PO_{peak}$ = peak Power Output; Start = start of clinical rehabilitation; Discharge = discharge of clinical rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge; SCI = Spinal Cord Injury; STUDY = total group (tetraplegia and paraplegia) models.
* $p<0.05$

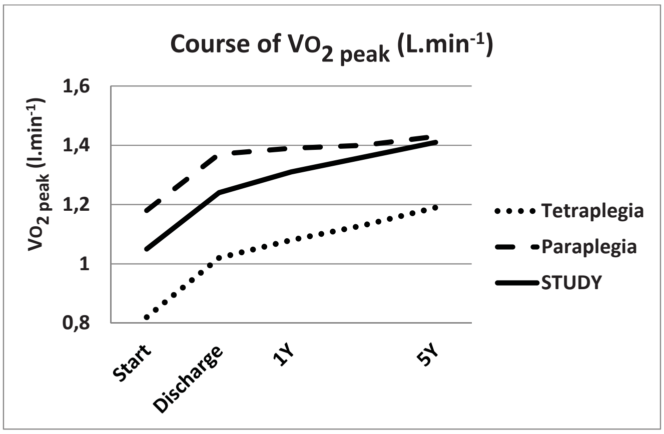


**Figure 4.2** Course of $VO_{2\ peak}$ (L.min$^{-1}$) as calculated from the regression model with lesion level added. The course of wheelchair exercise capacity for STUDY was estimated with the basic regression model (constant + 3 time dummies). The course of wheelchair exercise capacity for Tetraplegia and Paraplegia figures was estimated with regression model including level of lesion as determinant (constant + time dummies + lesion level + interaction term lesion level * time dummies). * The improvement in intervals Start–5Y and Discharge–5Y were significant for STUDY, Tetraplegia and Paraplegia. $PO_{peak}$ = peak Power Output; Start = start of clinical rehabilitation; Discharge = discharge of clinical rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge; SCI = Spinal Cord Injury; STUDY = total group (tetraplegia and paraplegia) models.
* $p<0.05$

The regression coefficients represent the change in $PO_{peak}$ and $VO_{2\ peak}$ with an increase of the independent variable of one unit. Level of lesion and gender were significantly related to $PO_{peak}$. Paraplegia was associated with a higher $PO_{peak}$ (+22.5 W) than tetraplegia. Men had a significantly higher $PO_{peak}$ (+17.7 W) than women. Age, gender, completeness and level of lesion were significantly related to $VO_{2\ peak}$. Paraplegia was associated with a higher $VO_{2\ peak}$ (+0.36 L/min ) than tetraplegia. Men had a significantly higher $VO_{2\ peak}$ (+0.33 L/min) than women. An increase of ten years in age was associated with an decrease of 0.06 L/min in $VO_{2\ peak}$. Subjects with complete lesions had 0.15 L/min lower $VO_{2\ peak}$ than persons with incomplete lesions.

We found no significant differences in the course of wheelchair exercise capacity between persons with different personal or lesion characteristics (interaction terms of personal or lesion characteristics with time) and these outcomes are therefore not presented.

**Table 4.2** Data on the longitudinal relation between subject and lesion characteristics and the (change in) physical capacity in STUDY. Basic model and final backward regression model presented.

| Independent variable | $PO_{peak}$ (W) | | | $VO_{2\,peak}$ (L/min) | | |
|---|---|---|---|---|---|---|
| | Beta | SE | P | Beta | SE | P |
| **Basic model** | | | | | | |
| Constant (reference 5Y) | 53.77 | 4.95 | | 1.41 | 0.08 | |
| Δ 5Y–Start | -19.44 | 3.59 | 0.00* | -0.35 | 0.07 | 0.00* |
| Δ 5Y–Discharge | -7.05 | 3.75 | 0.06 | -0.15 | 0.08 | 0.04* |
| Δ 5Y–1Y | -3.21 | 3.21 | 0.42 | -0.09 | 0.08 | 0.26 |
| **Final model** | | | | | | |
| Constant (reference 5Y) | 59.12 | 4.81 | | 1.95 | 0.12 | |
| Δ 5Y–Start | -20.77 | 3.07 | 0.00* | -0.44 | 0.07 | 0.00* |
| Δ 5Y–Discharge | -6.68 | 3.24 | 0.04* | -0.21 | 0.07 | 0.03* |
| Δ 5Y–1Y | -4.05 | 3.40 | 0.23 | -0.16 | 0.07 | 0.03* |
| Gender[a] | -17.68 | 2.32 | 0.00* | -0.33 | 0.05 | 0.00* |
| Age ( 10 years) | - | - | | - 0.06 | 0.02 | 0.00* |
| Level[b] | -22.47 | 2.51 | 0.00* | -0.36 | 0.05 | 0.00* |
| Complete[c] | - | - | | -0.15 | 0.05 | 0.00* |

All results are regression coefficients (β) and Standard Errors (SE) for the regression model (constant + time dummie + determinant). The regression coefficients represent the change in outcome associated with an increase in the independent variable of one unit. [a]0 = men; 1 = women; [b]0 = paraplegia; 1 = tetraplegia; [c]0 = incomplete; 1= complete. 1Y and 5Y = test occasion, respectively one and five years after discharge of inpatient rehabilitation; PO = peak Power Output; $VO_2$ = peak maximal oxygen intake; * significant with $p<0.05$.
For the peak power output the interaction term 5Y–Start, for example, indicates the difference between 5Y and Start was -19.44W, i.e. power output improved from start up to five years after discharge 19.44 W.

## Determinants of loss to follow-up

In comparison to the STUDY group, the EXCLUDED group was older and included relatively more persons with a tetraplegia. The attendance of EXCLUDED in the peak exercise test was low, especially at 1Y and 5Y with respectively two and four participants. The $PO_{peak}$ and $VO_{2\,peak}$ of STUDY and EXCLUDED at Start and Discharge are presented in Table 4.1. Both the $PO_{peak}$ and $VO_{2\,peak}$ scores were significantly lower in EXCLUDED compared to STUDY (Table 4.1).

# DISCUSSION

## Course of wheelchair exercise capacity

Random coefficient analysis revealed a significant change for both $VO_{2\,peak}$ and $PO_{peak}$ in the interval Start–5Y and for $VO_{2\,peak}$ in the Discharge–5Y interval. No significant changes of $VO_{2\,peak}$

and $PO_{peak}$ were found for the 1Y–5Y interval. Age, sex, level and completeness of lesion were determinants for $VO_{2\,peak}$ scores and level of lesion and sex for $PO_{peak}$ scores. No significant determinants for the course of wheelchair exercise capacity in the 1Y–5Y interval were detected. The loss to follow-up group was older and included more persons with tetraplegia, probably leading to an overestimation of the model outcome for wheelchair exercise capacity.

Our study is the first published longitudinal study of wheelchair exercise capacity in a general cohort of SCI patients with measurements both during inpatient rehabilitation and at follow-up to five years after discharge. We included only those patients for the multilevel regression analyses with two or more wheelchair exercise tests from the start of active inpatient rehabilitation, which gives us the important advantage to include more subjects with missing values during follow-up, which improves the power of our analyses.[24]

In our previous study[7] the mean wheelchair exercise capacity, expressed in $PO_{peak}$ and $VO_{2\,peak}$, improved during inpatient rehabilitation and $VO_{2\,peak}$ improved even further up to one year after discharge. In the current study we underlined these findings by showing that $PO_{peak}$ and $VO_{2\,peak}$ did improve from Start up to 5Y and $VO_{2\,peak}$ from Discharge up to 5Y. We did not find significant changes for $PO_{peak}$ and $VO_{2\,peak}$ between one year and five years after discharge. This is in line with our hypothesis, based on our previous study[7] and with other small prospective studies, all performed with a shorter follow-up period after onset.[3,17,19] Our findings are in contrast with the conclusions of Hoffman's review,[20] which however deals with older study material from a possibly different clinical area. Overall, it seems that persons with SCI in the Netherlands with a mean time since injury of 6.4 years, might be able to maintain a stable wheelchair exercise capacity over time.

The mean wheelchair exercise capacity in our study group did not change during the 4-year interval from 1Y to 5Y, despite the observations by many authors that the aerobic capacity declines with aging in able-bodied population,[29] as well as in SCI population.[30] Nevertheless, in accordance with our study, Janssen et al.[19] found no decline in a 3-year follow-up of a group of SCI patients and Shiba et al.[17] recently demonstrated almost no change in $VO_{2\,peak}$ in approximately 20 years follow-up in a group of seven subjects with SCI. The mean time after injury of 6.4 years in our study population might be too short to really reflect an aging decline effect and the (increased) level of activity of the participants might have balanced the age-related decline in $VO_{2\,peak}$. Another explanation might be that the participants were allowed to use their own wheelchair, which might suggest to contribute to a higher wheelchair exercise efficiency.

## Determinants

Gender and level of lesion were related to the level of $PO_{peak}$ and $VO_{2\ peak}$. Men show higher scores of wheelchair exercise capacity than women and persons with paraplegia show higher scores than persons with tetraplegia; both findings conform with previous literature.[3,4,7,11] In addition, as literature reveals, lower scores of $VO_{2\ peak}$ for persons with complete lesions and for older persons were found.[3,4,11] In our previous study up to one year after discharge, completeness of lesion and age were not found as determinants of $VO_{2\ peak}$,[7] which might have partially been caused by the lost to follow-up of older persons with SCI.

None of the personal and lesion characteristics were related to the course of wheelchair exercise capacity up to five years after discharge, which is partially in contrast with our previous study up to one year after discharge, in which sex and age were found to be determinants of the course of $PO_{peak}$ and level of lesion was a determinant of the course of $VO_{2\ peak}$.[7] Perhaps on the long term the beneficial circumstances, the personality and coping strategies of the persons involved may be responsible for the maintenance of an active lifestyle[31] and indirectly to the maintenance of wheelchair exercise capacity, irrespective of the influences of age, gender and level of lesion.[32]

## Loss to follow-up

In contrast to STUDY, EXCLUDED had only 13% and 20% of the subjects performing a peak wheelchair exercise test at Start, respectively Discharge. The EXCLUDED group contained older people and more subjects with a tetraplegia. Both determinants ageing and severity of spinal cord lesion, reduce functional outcome and give more secondary impairments,[33,34] reducing the chance of active involvement wheelchair exercise capacity (testing) as well, which in turn may lead to a lower general participation and finally leading to loss to follow-up.[35-37] The $PO_{peak}$ and limited numbers of $VO_{2\ peak}$ tests conducted provided $VO_{2\ peak}$ scores in EXCLUDED at Discharge that were relatively low, especially for the persons with paraplegia (not presented). The loss to follow-up of the less fit persons with paraplegia and the loss to follow-up of relatively more persons with a tetraplegia might have contributed to an overestimation at 1Y and 5Y of the level of the mean wheelchair exercise capacity in STUDY. It might be postulated that persons who died during the follow-up, were not able or willing to attend, or who performed only one peak exercise test in total follow-up, had a low physical fitness in the first place in comparison with the group that attended at least two of the four tests.

## Limitations and clinical implications of this study

Unfortunately, we had a large drop out in the peak exercise test follow-up. The relatively large drop out of old persons and of persons with a tetraplegia, who are prone to have lower physical fitness, might have resulted in an overestimation of wheelchair exercise capacity after SCI. However, our use of random coefficient analysis generated the best possible estimation of the course of exercise capacity during inpatient rehabilitation and the first five years after discharge.

In published data from our cohort a pattern of lower physical activity scales in the older and tetraplegic persons with a SCI was found.[5] In order to prevent negative side effects of a low exercise capacity on the long-term, it might be suggested to give persons with tetraplegia and the older persons at onset of injury, an intense and long medical supervision, as well as a structural follow-up rehabilitation opportunity in combination with exercise recommendations, such as low intensity wheelchair training.[38]

In random coefficient analysis, dichotomous variables add a significant degree of uncertainty to the outcomes compared to continuous variables. In our analysis only the variables age and change in peak exercise test are continuous variables, which forms a limitation to this study.[24]

## Research recommendations

To unravel the complex long-term physical adaptation process of persons with SCI, the relations of wheelchair exercise capacity with the International Classification of Functioning domains activity level, participation, social support, general health and life satisfaction[39] need to be studied in more detail, longitudinal, in the early phase of rehabilitation and on the long term after discharge. Especially the influence of physical activity and suffering from the SCI-related secondary impairments as potential determinants of wheelchair exercise capacity, need to be studied in more detail in this cohort. In order to improve the attendance at the measurements it might be suggested to fit in a less physically demanding submaximal exercise test although the maximal wheelchair exercise test is the golden standard.

## Conclusion

The mean wheelchair exercise capacity performance of persons with SCI seems to stabilize between one year after discharge up to five years after discharge. However, because of the loss of the older persons and of persons with more severe lesions, the participating group appears to be a positive selection of the total study group.

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# 5

# Trajectories in wheelchair exercise capacity after spinal cord injury

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## ABSTRACT

**Objective:** 1) to identify different trajectories in the course of exercise capacity in the period between the start of active spinal cord injury (SCI) rehabilitation and five years after discharge; 2) to examine determinants of the trajectories in the course of exercise capacity.

**Design:** Prospective cohort study. Measurements at the start of active inpatient rehabilitation (Start), three months later (3M), at discharge of inpatient rehabilitation (Discharge), one year (1Y), and five years after discharge (5Y).

**Setting:** Eight rehabilitation centres.

**Participants:** 130 persons with SCI, aged 18–65, and wheelchair-dependent at least for long distances.

**Interventions:** Not applicable.

**Main outcome measures:** Wheelchair exercise capacity: Peak Oxygen Uptake ($VO_{2\ peak}$ ($L.min^{-1}$)), Peak Power Output ($PO_{peak}$ (W)).

**Results:** We found four different trajectories in the course of $PO_{peak}$: (1) HIGH–PRO (33%): high progressive scores (Start: 49 W–5Y: 77 W), (2) DETER (12%): progressive scores during inpatient rehabilitation with deteriorating figures after discharge (29–60–39 W), (3) LOW–PRO (52%): low progressive scores (20–33 W), and (4) LOW–RISE (3%): low inpatient scores with strong progressive scores after discharge (29–82 W). $VO_{2\ peak}$ showed similar trajectories. Logistic regression of factors that might be distinctive between HIGH–PRO and LOW–PRO trajectory revealed that older age, female gender, tetraplegic lesion and low functional status were associated with LOW–PRO trajectory.

**Conclusion:** Wheelchair exercise capacity after SCI shows a positive trend and can be described in distinct trajectories dependent on personal, lesion and functional characteristics. Conducting a peak wheelchair exercise test in SCI follow-up care might help to identify persons at risk for a debilitative cycle of exercise capacity with long-term health consequences.

# INTRODUCTION

A spinal cord injury (SCI) is a devastating medical condition that highly affects exercise capacity of persons involved as a result of muscle weakness, loss of autonomic control below the level of injury and subsequent changes in metabolic and vascular function.[1-5] Most people with an SCI have a sedentary lifestyle and maintenance of an adequate exercise capacity is under pressure by medical problems, social barriers, low activity levels and low participation.[1,3,4,6-8] This potentially leads to a debilitative cycle of exercise capacity and exposes them to an increased risk of developing medical conditions like metabolic syndrome and cardiovascular disease, nowadays the leading cause of death in persons with SCI.[9]

Longitudinal research on the course of exercise capacity is scarce.[10] Earlier, we showed recovery of exercise capacity up to one year after discharge of inpatient rehabilitation[11] and subsequent stabilisation up to five years after discharge.[12] Most previous research on exercise capacity in SCI had a cross-sectional design, and the results of these studies were influenced by an over-representation of active and young paraplegic patients.[13-15] Variable-centred statistical approaches revealed age, sex, and level and completeness of the lesion to be longitudinal[11,12] and cross sectional[13-15] related to exercise capacity. Other determinants of exercise capacity were secondary impairments, pain and activity levels.[16-18] However, clinical observations suggest a certain amount of heterogeneity in the course of exercise capacity after SCI. A person-centred statistical method, as Late Class Growth Mixture Modelling,[19-21] is an appropriate method to unravel this heterogeneity, which may help to understand how individuals differ in their physical adaptation to an SCI. By identifying different trajectories and the characteristics of persons at risk for persistent low levels or deterioration of exercise capacity, follow-up rehabilitation care of persons with SCI can be improved.

The aims of the present study are: 1) to identify different trajectories in the course of wheelchair exercise capacity in the period between the start of active SCI rehabilitation and five years after discharge; 2) to examine determinants of these different trajectories of exercise capacity. We hypothesised that a high age, a tetraplegia, low functional independency, suffering from secondary impairments, having pain and low activity level can be identified as determinants of low figures of exercise capacity.

# METHODS

## Participants

This study is part of the research program "Restoration of mobility in spinal cord injury rehabilitation".[22] Eight rehabilitation centres specialized in SCI participated in the project. Participants were eligible to enter the project if they had an acute SCI; were between 18 and 65 years of age; were classified as A–D on the American Spinal Injury Association Impairment Scale and were expected to remain wheelchair-dependent, at least for long distances. Exclusion criteria were: SCI due to malignancies, progressive disease, known cardiovascular disease or psychiatric problems; insufficient command of the language to understand the goal of the study and the testing methods. The Medical Ethics Committee of the Stichting Revalidatie / Institute for Rehabilitation Research and all local Medical Ethics Committees approved the research-protocol in 1999 and The Medical Ethics Committee of the University Medical Center approved the sequel research protocol in 2006. All participants gave written informed consent.

## Procedure

Measurements were performed at the start of active rehabilitation (Start, defined as the moment that a person could sit for 3 to 4 hours), three months after start (3 M), at discharge from inpatient rehabilitation (Discharge), one year after discharge (1Y) and five years after discharge (5Y). These five measurements comprised amongst others a medical history and physical examination by a rehabilitation physician, an oral interview with a trained research assistant, a self-report questionnaire and a peak wheelchair exercise test. For persons with a short inpatient rehabilitation the three months measurement was replaced by the measurement at discharge.

## Instruments

### *$PO_{peak}$ and $VO_{2\,peak}$*

Wheelchair exercise capacity, expressed as peak external power output ($PO_{peak}$ (W)) and peak oxygen uptake ($VO_{2\,peak}$ (l.min$^{-1}$) was determined in a *peak wheelchair exercise test* on a motor-driven treadmill. The testing protocol and equipment have previously been described.[11,23,24] Participants performed two blocks of submaximal exercise of three minutes each, separated by a 2-minute rest. After two minutes of rest, the peak exercise test followed at the same constant velocity, and the inclination was increased 0.36° every minute. The test was terminated when the subject was exhausted or could no longer keep pace with the speed of the treadmill. The individual testing protocol was identical for each of the testing occasions. $VO_{2\,peak}$ was defined as the highest value of oxygen consumption recorded during 30 seconds. $PO_{peak}$ was defined as the power output at the highest inclination that the subject could maintain for at least 30 seconds.

***Personal and lesion characteristics***

*Demographic characteristics* collected at the first test occasion were age, gender, body mass and height. At each subsequent test occasion body mass (kg) was measured by the trained research assistant. Body Mass Index (BMI) was calculated in $kg.m^{-2}$.

*Lesion characteristics* were assessed according to the International Standards for Neurological Classification of Spinal Cord Injury.[25] The American Spinal Injury Association Impairment Scale (AIS) classifications A and B were considered motor complete and the classifications C and D were considered motor incomplete. Neurological lesion level was defined as the highest motor level. Neurological levels below T1 were defined as paraplegia and neurological lesion levels at or above T1 were defined as tetraplegia. Cause of injury was dichotomised in traumatic versus non-traumatic. Length of rehabilitation was defined as the number of days between admission to and discharge of inpatient rehabilitation.

*Functional independence* was measured with the motor score of the Functional Independence Measure (FIM), consisting of 13 items about self care, mobility, transfers, and toileting.[26]

*Secondary impairments* were grouped into three categories:

*Musculoskeletal pain:* 13 locations about musculoskeletal pain were asked. All were scored as “absent = 0” or “present = 1” during the last 12 months. A total Musculoskeletal Pain score was computed as the sum score of all items (range: 0–13).

*Neuropathic pain:* one item about pain other than musculoskeletal pain and eight other abnormal sensations as numbness, tingling, burning, phantom, hot or cold feelings, itching and dull feelings. All were scored as “absent = 0” or “present = 1” during the last 12 months. A total Neuropathic Pain score was calculated as the sum score of all items (range: 0–9).

*Other secondary impairments:* seven items including pressure sores, urinary tract infections, pulmonary infections, neurogenic heterotopic ossification, oedema, hypotension and autonomic dysreflexia were scored as “absent = 0” or “present = 1” during the last 12 months. A total score was computed (range: 0–7).

*Physical Activity Scale for Individuals with Physical Disabilities:* Information on level of physical activity (leisure, household and occupational activity) was collected using the Physical Activity

Scale for Individuals with Physical Disabilities (PASIPD).[27] The PASIPD was developed to assess the self-reported physical activity level of individuals with a disability, expressed in MET hr.day$^{-1}$ (maximum score is 182.3 MET hr.day$^{-1}$). One MET is defined as the amount of oxygen required per minute under quiet resting conditions. The PASIPD was evaluated in people with disabilities and in people with SCI for construct validity, reliability and criterion validity.[27-29]

The Utrecht Activities List sports activities (Sports participation) was used to assess the time spent in hours sports per week.[30] This questionnaire is a Dutch adaptation of part of the Craig Handicap Assessment Rating Technique.[31]

## Statistics

*Descriptive statistics* (means and standard deviations) were calculated with SPSS version 18.0 at all test occasions.

Only persons who performed at least two out of five wheelchair exercise tests were included in the analyses. We used Chi-square tests and t-tests to compare data between the participants (STUDY) and the loss to follow-up group (EXCLUDED) at the start of active rehabilitation.

### *Latent Class Growth Mixture Modelling*

Trajectories of exercise capacity ($PO_{peak}$ and $VO_{2\,peak}$) were determined by fitting a latent class growth mixture model (LCGMM) to the data,[20] using the Mplus 6.1 software program.[32] LCGMM is a contemporary longitudinal technique based on structural equation modelling, incorporating both continuous and categorical latent (unobserved) variables. The aim is to capture heterogeneity in the course of exercise capacity in an optimal number of subgroups, each with a unique trajectory. Each subgroup has its own growth parameters (intercept, slope, quadratic slope). The optimal model is a model where individuals within a subgroup are most similar to each other and most different to individuals in other subgroups. To determine the optimal number of trajectories, a "forward" approach was started with a model with one developmental pattern, implying that all individuals in the study had the same course of $PO_{peak}$ and $VO_{2\,peak}$. Subsequently, one trajectory at a time was added, and the model fit was assessed. To determine the optimal number of trajectories the Bayesian Information Criterion (BIC) and the Bootstrapped Likelihood Ratio Test (BLRT) were used. Lower values of the BIC and a significant p-value of the BLRT indicate a better model fit.[20] Participants were assigned to the trajectory to which they had the highest probability of belonging to, by the use of posterior probabilities.

Because of the strong correlation between $PO_{peak}$ and $VO_{2\ peak}$ in SCI,[11] we chose $PO_{peak}$ as mean outcome to study the differences between trajectories in $PO_{peak}$. We performed logistic regression analyses to determine which independent variables could discriminate between the trajectories. First, bivariate logistic regression analyses were performed, to select independent variables for the multivariate model by using the selection criteria of $p<0.10$. Second, a backward elimination method was used for the multivariate model, leading to a final model including only significant predictors ($p<0.05$). SPSS version 18.0 was used for the regression analyses.

# RESULTS

## Respondent characteristics

At the start of active rehabilitation, 225 persons with SCI were included in the cohort study.[22] Participation in the peak exercise test was 109/225 persons at Start, 95/155 at 3M, 137/198 at Discharge, 91/156 at 1Y, and 73/149 at 5Y. 130 Persons performed at least two peak exercise tests and were included in the analyses of the current article. Participants' characteristics are displayed in Table 5.1 (column STUDY). Mean age at the start of inpatient rehabilitation was 38.7 (SD 14.5) years, 74.6% was male and 72.1% had a paraplegic lesion.

A comparison in personal and lesion characteristics between STUDY (n = 130) and EXCLUDED (Table 5.1, column EXCLUDED, n = 95) showed that EXCLUDED had a higher lesion level and were older of age.

## Exercise capacity trajectories

Table 5.2 shows that a model with four exercise capacity trajectories for $PO_{peak}$ represented the data best, i.e. having the lowest BIC number and a significant p-value of BLRT. Because $VO_{2\ peak}$ is strongly correlated to $PO_{peak}$,[11] we chose the four exercise capacity trajectories model for $VO_{2\ peak}$, although the BIC number was higher than a model with three trajectories and the BLRT was not significant (Table 5.3).

For $PO_{peak}$, the first trajectory (HIGH–PRO) consisted of 43 participants with relatively initial high levels of exercise capacity and strong increments during inpatient rehabilitation and the first year after discharge, more or less stabilizing between one and five years after discharge (Figure 5.1). The second trajectory (DETER) contained 15 participants showing improvement in exercise capacity during inpatient rehabilitation but deterioration after discharge. The third

**Table 5.1** Participant and lesion characteristics between trajectories of distinct patterns of Wheelchair Exercise Capacity ($PO_{peak}$) (n = 130)

| Characteristics | STUDY n = 130 | EXCLUDED n = 95 | HIGH–PRO n = 43 | DETER n = 15 | LOW–PRO n = 69 | LOW–RISE n = 3 |
|---|---|---|---|---|---|---|
| Male gender (%) | 74.6 | 74.2 | 95.3 | 93.3 | 56.5 | 100 |
| Age at start (yrs) (SD) | 38.7 (13.7) | 44.1 (13.9)* | 36.4 (13.0) | 32.9 (10.4) | 41.5 (14.5) | 37.8 (5.8) |
| Paraplegic lesion (%) | 72.1 | 42.3* | 97.7 | 92.9 | 52.2 | 100 |
| Completeness start (%) | 68.5 | 69.3 | 69.8 | 66.7 | 68.1 | 100 |
| Completeness 5Y (%) | 70.7 | - | 72.1 | 86.7 | 65.2 | 100 |
| Traumatic cause of injury (%) | 76.0 | 69.0 | 81.4 | 92.9 | 68.1 | 100 |
| Length of rehab (days) | 248.1 (132.3) | 265.1 (150.8) | 203.8 (92.8) | 240.2 (67.6) | 282.3 (152.1) | 118.3 (10.6) |

Missing data are ignored. Data represent mean (SD) and proportions; Start = start of active rehabilitation; 5Y = five years after discharge. STUDY = total study group with two or more exercise measurements during follow-up; EXCLUDED = loss to follow-up in peak wheelchair exercise test during follow-up; HIGH–PRO = trajectory with high and progressive scores; DETER = trajectory of improvement during, and deterioration after inpatient rehabilitation; LOW–PRO = trajectory with low and only slightly progressive scores; LOW–RISE = trajectory with low scores during inpatient rehabilitation and a sharp rise after discharge. * significant difference with $p<0.05$ between STUDY and EXCLUDED.

trajectory (LOW–PRO), (n = 69) showed low levels of exercise capacity at start with a relatively strong improvement over time. The fourth trajectory (LOW–RISE) consisted of only three persons with low levels during inpatient rehabilitation and a relatively sharp performance rise from discharge up to five years after discharge. The $VO_{2\,peak}$ trajectories followed approximately the same pattern as the trajectories of $PO_{peak}$ (Figure 5.2).

**Table 5.2** Model fit indices for the selection of the number of trajectories for $PO_{peak}$

| | Bayesian information criterion | Bootstrapped likelihood ratio test | Average posterior probabilities | n = 130* |
|---|---|---|---|---|
| K = 1 | 3683.078 | N/A | 1 | 130 |
| K = 2 | 3671.695 | p<0.001 | 0.955 | 59/71 |
| K = 3 | 3673.948 | p=0.0128 | 0.963 | 3/68/59 |
| K = 4 | 3670.725 | p<0.001 | 0.924 | 3/43/69/15 |
| K = 5 | 3682.838 | p=0.667 | 0.916 | 15/65/3/4/43 |

N/A = not applicable. * Numbers are total amount of persons included in the different numbers of distinct trajectories.

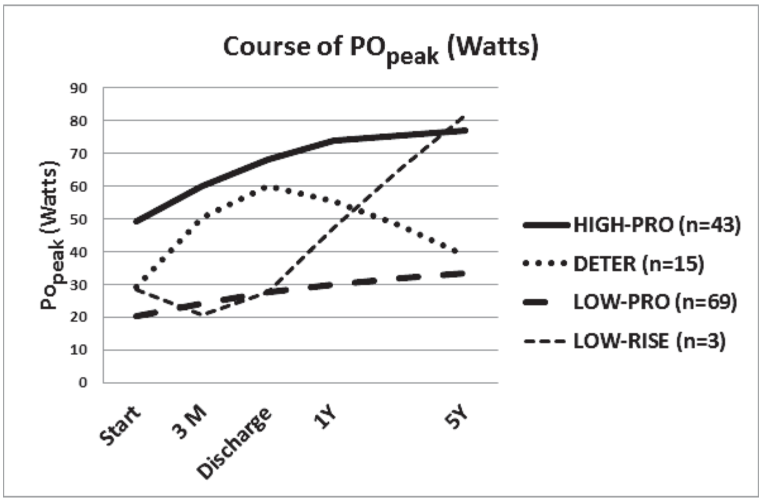


**Figure 5.1** Distinct trajectories in the course of $PO_{peak}$ (Watts) up to five years after discharge of inpatient rehabilitation. Start = start of active rehabilitation; 3M = three months after start; Discharge = discharge of inpatient rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge; HIGH–PRO = trajectory with high and progressive scores; DETER = trajectory of improvement during, and deterioration after inpatient rehabilitation; LOW–PRO = trajectory with low and only slightly progressive scores; LOW–RISE = trajectory with low scores during inpatient rehabilitation and a sharp rise after discharge.

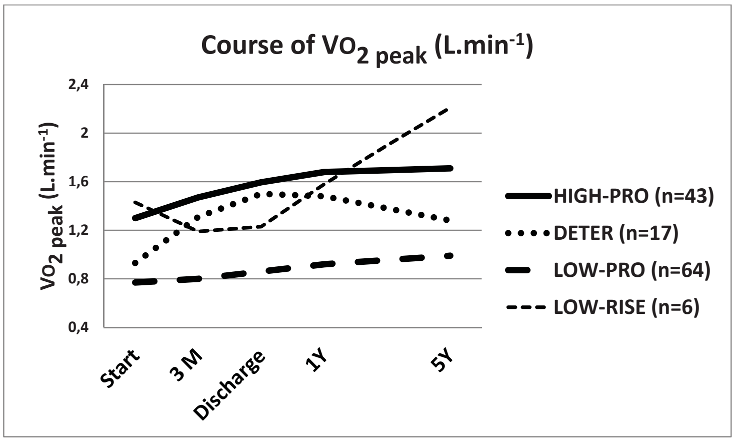


**Figure 5.2** Distinct trajectories in the course of $PO_{peak}$ (Watts) up to five years after discharge of inpatient rehabilitation. Start = start of active rehabilitation; 3M = three months after start; Discharge = discharge of inpatient rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge; HIGH–PRO = trajectory with high and progressive scores; DETER = trajectory of improvement during, and deterioration after inpatient rehabilitation; LOW–PRO = trajectory with low and only slightly progressive scores; LOW–RISE = trajectory with low scores during inpatient rehabilitation and a sharp rise after discharge.

## Determinants of trajectory membership

All characteristics per $PO_{peak}$ trajectory are displayed in Tables 5.1 and 5.4 (columns HIGH–PRO, DETER, LOW–PRO, LOW–RISE). The LOW–RISE trajectory contained three men with complete paraplegic lesions who had a relatively short length of rehabilitation and both low functional status and low wheelchair exercise capacity at discharge. Because of the small numbers, the LOW–RISE trajectory (n = 3) was not taken into account in the remaining analyses of the determinants The DETER trajectory consisted of mostly males, young of age with a paraplegic lesion of traumatic origin. The DETER trajectory showed more neuropathic and musculoskeletal pain and was less active in sports than HIGH–PRO (Table 5.4).

## HIGH–PRO versus LOW–PRO

Regression analyses were performed between the HIGH–PRO and LOW–PRO trajectories only. Persons in the HIGH–PRO trajectory, compared to persons in the LOW–PRO trajectory were more often the young men with paraplegic lesions, having a short length of rehabilitation, a high functional status, less musculoskeletal and neuropathic pain (bivariatic analyses, Table 5.5).

**Table 5.3** Model fit indices for the selection of the number of trajectories $VO_{2\,peak}$

| | Bayesian information criterion | Bootstrapped likelihood ratio test | Average posterior probabilities | n = 130* |
|---|---|---|---|---|
| K = 1 | 159.538 | N/A | 1 | 130 |
| K = 2 | 159.782 | p<0.001 | 0.928 | 72/58 |
| K = 3 | 159.589 | 0.0128 | 0.923 | 57/6/67 |
| K = 4 | 164.662 | 0.118 | 0.879 | 43/17/6/64 |

N/A = not applicable. * Numbers are total amount of persons included in the different numbers of distinct trajectories.

**Table 5.4** Variables related to Wheelchair Exercise Capacity ($PO_{peak}$) (n = 127) of persons with SCI between trajectories of distinct patterns

| Characteristics | | HIGH–PRO n = 43 | DETER n = 15 | LOW–PRO n = 69 |
|---|---|---|---|---|
| BMI | Start | 23.1 (3.2) | 22.7 (3.3) | 22.7 (4.1) |
| | 5Y | 25.4 (4.0) | 25.2 (4.1) | 25.4 (5.5) |
| FIM (13–91) | Start | 54.3 (16.7) | 47.6 (13.5) | 42.2 (18.2) |
| | 5Y | 77.3 (6.9) | 76.8 (7.9) | 59.4 (21.0) |
| Secondary impairments | Start | 1.3 (1.0) | 1.4 (1.1) | 1.4 (1.3) |
| | 5Y | 1.7 (1.4) | 1.3 (0.8) | 1.3 (0.8) |
| Neuropathic pain | Start | 2.6 (1.8) | 3.6 (1.6) | 3.1 (1.7) |
| | 5Y | 2.4 (1.6) | 4.1 (2.6)) | 3.3. (2.1) |
| Musculoskeletal pain | Start | 1.5 (1.5) | 2.0 (2.0) | 2.2 (2.2) |
| | 5Y | 2.0 (2.4) | 2.9 (2.4) | 3.3 (3.1) |
| PASIPD | 1Y | 23.5 (15.8) | 18.5 (20.5) | 16.0 (18.6) |
| | 5Y | 24.8 (18.0) | 18.8 (15.4) | 18.1 (18.6) |
| Sports participation | 1Y | 3.5 (4.5) | 1.6 (2.1) | 1.9 (3.7) |
| | 5Y | 4.7 (5.4) | 1.0 (1.7) | 3.8 (6.6) |

Missing data are ignored. Data represent mean (SD) and proportions. 1Y = one year after discharge; 5Y = five years after discharge. HIGH–PRO = trajectory with high and progressive scores; DETER = trajectory of improvement during, and deterioration after inpatient rehabilitation; LOW–PRO = trajectory with low and only slightly progressive scores; BMI = Body Mass Index; FIM = Functional Independence Measure; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; Sports participation = Utrecht Activity List Sport.

Multivariate analysis detected four determinants of high power output in the wheelchair exercise test: the odds for being a member of the HIGH–PRO trajectory for female persons was 1/50, for persons with a tetraplegia 1/33, for being older 0.93 and for a higher functional status 1.09 (Table 5.6), together explaining a large proportion of the variance (Nagelkerke pseudo R-square 0.70). Having neuropathic pain was just not significant.

**Table 5.5** Bivariatic logistic regression analyses to distinguish between HIGH–PRO (n = 43) and LOW–PRO (n = 69) trajectory of Wheelchair Exercise Capacity ($PO_{peak}$) in SCI

| Variables | Odds ratio | 95% CI | | p |
|---|---|---|---|---|
| Age (higher) | 0.97 | 0.95 | 1.00 | 0.065* |
| Gender (female) | 0.06 | 0.01 | 0.28 | 0.000* |
| Lesion level (tetraplegic) | 0.03 | 0.04 | 0.21 | 0.000* |
| Complete Lesion | 1.38 | 0.60 | 3.16 | 0.449 |
| Cause of lesion (traumatic) | 1.99 | 0.70 | 5.59 | 0.127 |
| Length of rehabilitation (Longer) | 0.99 | 0.99 | 0.99 | 0.087* |
| BMI Start (higher) | 1.02 | 0.92 | 1.13 | 0.671 |
| BMI 5Y (higher) | 1.00 | 0.91 | 1.10 | 0.997 |
| FIM.Start (higher) | 1.04 | 1.01 | 1.10 | 0.001* |
| FIM.5Y (higher) | 1.09 | 1.04 | 1.15 | 0.000* |
| Secondary impairments (more) | 0.84 | 0.60 | 1.17 | 0.571 |
| Musculoskeletal pain (more) | 0.83 | 0.69 | 0.99 | 0.043* |
| Neuropathic pain (more) | 0.74 | 0.58 | 0.94 | 0.012* |
| PASIPD (higher) | 1.02 | 0.99 | 1.05 | 0.137 |
| Sports participation (higher) | 0.98 | 0.91 | 1.05 | 0.493 |

95% CI = 95% confidence interval. Start = start of active rehabilitation; 5Y = five years after discharge. HIGH–PRO = trajectory with high and progressive scores; LOW–PRO = trajectory with low and only slightly progressive scores; BMI = Body Mass Index; FIM = Functional Independence Measure; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; Sports participation = Utrecht Activity List Sports.

**Table 5.6** Outcome of backward multivariate logistic regression analyses to distinguish between HIGH–PRO (n = 34) and LOW–PRO (n = 47) trajectory of Wheelchair Exercise Capacity ($PO_{peak}$) in SCI at 5Y

| Variables | Odds ratio | 95% CI | | p |
|---|---|---|---|---|
| Age (higher) | 0.93 | 0.87 | 1.00 | 0.048 |
| Gender (female) | 0.02 | 0.00 | 0.02 | 0.000 |
| Lesion level (tetraplegic) | 0.03 | 0.00 | 0.39 | 0.034 |
| FIM.5Y (higher) | 1.09 | 1.00 | 1.18 | 0.042 |
| Pain neuropathic 5Y (more) | NS | | | |
| Length of rehabilitation | NS | | | |
| Pain musculoskeletal | NS | | | |
| R-square Nagelkerke | 0.708 | | | |
| Predicted percentage correct | 83.3% | | | |

CI = confidence interval; p = significance; 5Y = measurement at five years after discharge. HIGH–PRO = trajectory with high and progressive scores; LOW–PRO = trajectory with low and only slightly progressive scores; FIM = Functional Independence Measure; NS = not significant.

# DISCUSSION

Our hypothesis that exercise capacity in our Dutch cohort of persons with SCI follows distinct trajectories from the start of active rehabilitation up to five years after discharge was confirmed, we found four different trajectories.

For the vast majority (LOW–PRO, LOW–RISE and HIGH–PRO, total 88%) of the study population, exercise capacity improved up to five years after discharge. A minority (DETER, 12%) showed a clear deteriorating trend after discharge. The second hypothesis was only partially confirmed: older of age, female gender, tetraplegic lesion and low functional status were associated with low progressive trajectory of $PO_{peak}$. These results underlined the findings of variable-centred studies.[11-15] In contrast to literature, we could not confirm an association with secondary impairments, pain and activity level.[14-18]

As far as we know, LCGMM has never been applied to longitudinal data of wheelchair exercise capacity in SCI. In comparison to the variable-centred analyses on the course[11,12] or status[13-15] of exercise capacity, the person-centred LCGMM revealed different recovery patterns and identified characteristics of persons with low or deteriorating levels.

## Trajectories and characteristics of wheelchair exercise trajectory membership

The HIGH–PRO trajectory showed high progressive levels of exercise capacity over time, which might be due to the high amount of male persons with paraplegia (97.7%, Table 5.1) with resulting high functional independence[11] and relative short length of rehabilitation.[33]

The LOW–PRO trajectory contained almost all the persons with a tetraplegia (94%) of the total study group. Persons with tetraplegia have few available functional muscles and less sympathetic control of the cardiovascular system to cope with the exercise demands, resulting in reduced oxygen uptake and power output and low improvement potential.[2,10] This partly explains the relatively low figures in this trajectory. The LOW–PRO trajectory also comprised most of the women (95%), who have lower oxygen uptake in general, mostly due to their lower mean body masses.[16] Nevertheless, the LOW–PRO trajectory showed a progression over 50% (from 20.1 W to 31.2W) for $PO_{peak}$ from start of active rehabilitation up to 5Y (Figure 5.1). This improvement might protect persons with SCI from musculoskeletal overload injuries in daily life activities[34] and might promote participation in work, sport and other leisure activities.[35] The lower improvement in $VO_{2\ peak}$ (25%) as compared with $PO_{peak}$ indicates that simultaneous improvements of anaerobic exercise capacity and wheelchair skills and technique, resulting in a better wheelchair propulsion efficiency,[11] do take place in the course of time.

The DETER trajectory has the highest potential of recovery of exercise capacity in our study population, because it has the youngest participants (32.9 yrs) and consists mostly of men with a complete paraplegia.[16] Nevertheless, the DETER trajectory showed more neuropathic and musculoskeletal pain and was less active in sports than HIGH–PRO (Table 5.4), a possible explanation for the deterioration of exercise capacity after discharge.[17,18]

In contradiction to literature[14,15,17] sports participation was not a distinctive determinant for $PO_{peak}$ between HIGH–PRO and LOW–PRO, which might have been caused by the relatively high sports participation in both trajectories (resp 4.6 and 3.8 $hrs.wk^{-1}$ (Table 5.4)). Our activity figures might have been overestimated due to the loss to follow-up of the older persons with more severe lesions, who are prone to have lower activity levels.

The LOW–RISE showed relatively short length of rehabilitation, low functional status and low wheelchair exercise capacity at discharge. In view of the remarkable recovery after discharge, *outpatient* rehabilitation seems to have been sufficient for these persons.

## Limitations and implications

The relatively high drop out of persons with tetraplegia and of older age who are prone to have lower physical fitness, might have resulted in an overestimation of the exercise capacity after SCI. However, the Latent Class Growth Mixture Modelling allows the number of observations per person to vary, so repeated measures as well as cases with missing values can be included in these analyses.

The distinct trajectories give professionals insight into how persons differ in their physical adaptation to an SCI up to five years after discharge. Monitoring wheelchair exercise capacity in SCI follow-up care might help to identify persons at risk for a debilitative cycle of exercise capacity with long-term health consequences.

## Conclusions

We identified four different trajectories in recovery of wheelchair exercise capacity after SCI up to five years after discharge, that expressed a positive trend in the vast majority (88%) of subjects. A minority (12%) showed a clear deteriorating trend. Higher age, female gender, a tetraplegia and low functional status were associated with a low progressive trajectory. The identified trajectory with a deteriorating wheelchair exercise capacity consisted of men with a paraplegia, mostly of traumatic cause, with relatively high pain levels and low sports activity levels. Conducting a peak wheelchair exercise test in SCI follow-up care might help to identify persons at risk for a debilitative cycle of exercise capacity with long-term health consequences.

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# 6

# The longitudinal relationship between wheelchair exercise capacity and life satisfaction after spinal cord injury: a cohort study in the Netherlands

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## ABSTRACT

**Objective:** To examine the relationship between wheelchair exercise capacity and life satisfaction in persons with spinal cord injury from the start of active rehabilitation up to five years after discharge.

**Design:** Prospective cohort study.

**Subjects:** 225 persons with SCI, aged 18–65, and wheelchair-dependent at least for long distances.

**Method:** Measurements at the start of active rehabilitation, after three months, at discharge from inpatient rehabilitation, and one year and five years after discharge. A peak wheelchair exercise test on a treadmill was performed to record peak oxygen uptake ($VO_{2\,peak}$) and peak power output ($PO_{peak}$). Life satisfaction was measured with one question on current life satisfaction and one question on current life satisfaction compared with life satisfaction before spinal cord injury. Relationships between (changes in) exercise capacity and (changes in) life satisfaction were analysed using multilevel regression analysis, corrected for possible confounders (age, gender, level of lesion, functional status, secondary impairments, pain and sports activity) if necessary.

**Results:** Of 225 persons included, only 130 persons attended two or more peak exercise tests during follow-up. Mean age at start was 39 yrs, 75% were male, 72% had paraplegia, and 76% had a traumatic lesion. An increase of $PO_{peak}$ with 10 W was associated with a 0.3 point increase of life satisfaction ($p=0.01$). An increase of $VO_{2\,peak}$ with 0.1 $L.min^{-1}$ was associated with a 0.1 point increase of life satisfaction ($p=0.049$).

**Conclusion:** High(er) wheelchair exercise capacity is related to high(er) life satisfaction in spinal cord injury patients.

# INTRODUCTION

Spinal cord injury (SCI) is a catastrophic, life-threatening condition resulting in abrupt physical disability, loss of independence, and many secondary conditions, altogether affecting exercise capacity and life satisfaction.[1-15]

Low exercise capacity is an important determinant of the health status of persons with SCI functioning and quality of life.[10,12] Exercise capacity in SCI is under pressure because of loss of motor control and sympathetic influence below the lesion, while arm work by definition is lower than leg work.[12,13] The level of exercise capacity in SCI is largely determined by a combination of genetic predisposition, co-morbidity, functional outcome of SCI and the degree of conditioning. Only the latter two can be (partly) influenced by training.[16,17] Literature on the course of wheelchair exercise capacity (WEC) after SCI is scarce, but WEC in our SCI cohort improved from the start of active rehabilitation up to one year after discharge, and stabilized after that up to five years after discharge.[14] Further analysis showed four different trajectories in the course of WEC with different starting values and slopes. For the vast majority of the study group an improvement up to five years and for a small proportion a decrease after discharge.[18] Female gender, high age, having tetraplegia and low functional status were negatively associated with the course and level of WEC, which is a confirmation earlier SCI research.[10-12,19-21]

Life satisfaction (LS) is defined as the *cognitive component of subjective wellbeing*[22] and is studied widely in SCI.[1-10] In previous studies[2-4] we found lower LS scores in persons with SCI than in the general population, but an increase of LS scores in subsequent measurements from the start of inpatient rehabilitation up to five years after discharge. Negatively associated with LS were physical factors as having pain, having many secondary impairments and low functional status,[2,22] and psychosocial factors including low social support and low self efficacy.[4] This is similar to what has been found in other studies.[1-3,5-10]

Sir Guttmann was the first to introduce a sports and exercise program as part of rehabilitation following SCI as early as the 40s of the last century,[23] and initiated research on physical exercise in persons with SCI focused primarily on the physiological changes and benefits.

Several studies on the relationship between physical activity and aspects of quality of life (QOL) of persons with SCI have been published,[24-32] for the most part showing associations between exercise and QOL,[25-31] although some indifferent results were published.[31,32] Overall, higher fitness levels seems to be associated with higher QOL, but most studies were cross-sectional, including healthy, young and active male persons with a long time since injury. To our knowledge, no papers on the longitudinal association between WEC and LS, within the strict definitions, in SCI have been published.

Therefore, it is important to study the relationship between WEC and LS in a SCI cohort from the start of active rehabilitation up to several years after discharge. This might help to improve the understanding of physical and mental adaptation to an SCI over time in order to improve goal settings and intervention programs in in- and outpatient rehabilitation and follow up care.

The aim of our study was to investigate the longitudinal relationship between WEC and LS in a prospective cohort in the Netherlands from the start of inpatient SCI rehabilitation up to five years after discharge. Our hypothesis was: *Persons with SCI who are (more) fit, are (more) satisfied with their life*.

# METHODS

## Participants

This study is part of the Dutch research program "Restoration of mobility in the rehabilitation of persons with an SCI".[33] Eight rehabilitation Centers specialized in SCI participated in the project. Subjects were eligible to enter the project if they had an acute SCI; were between 18 and 65 years of age; were classified as A, B, C, or D on the American Spinal Injury Association Impairment Scale[34] and were expected to remain wheelchair-dependent, at least for long distances. Exclusion criteria were: SCI due to malignancies, progressive disease, known cardiovascular disease or psychiatric problems; insufficient command of the Dutch language to understand the goal of the study and the testing methods. The Medical Ethics Committee of the Stichting Revalidatie Limburg / Institute for Rehabilitation Research in Hoensbroek and all local Medical Ethics Committees approved the research protocol in 1999 and The Medical Ethics Committee of the University Medical Center of Utrecht approved the sequel research-protocol in 2006. All subjects gave written informed consent.

## Procedure

Measurements were performed at the start of active rehabilitation (start, defined as the moment that a person could sit for 3 to 4 hours), three months after start (3M), at discharge from inpatient rehabilitation (discharge), one year after discharge (1Y) and five years after discharge (5Y). The 3M measurement was performed only if active rehabilitation took longer than three months. These five measurement occasions comprised a medical anamnesis and physical examination by a rehabilitation physician, an oral interview with a trained research assistant, a self-report questionnaire, and physical tests amongst which a peak wheelchair exercise test.

## Instruments

### *Outcome measure*

Measurement of *life satisfaction* was part of the oral interview. A total score (LS Total) was used that is the sum of two items on current life satisfaction and on life satisfaction now compared to life satisfaction before the SCI (range of 2–13). Its internal consistency is supported by strong correlations (Pearson's r = 0.5–0.6) on all test occasions[22] and its validity is supported by strong correlations (0.59–0.60) with the Life Satisfaction Questionnaire and the Satisfaction With Life Scale.[35] This LS total score was sufficiently normally distributed at each measurement (Skewness 0.0–0.5).

### *Determinant*

#### Wheelchair exercise capacity

Subjects performed a peak maximal wheelchair exercise test on a motor-driven treadmill. The testing protocol and equipment have been described elsewhere.[11,36] Before testing, subjects were asked to eat a light meal only, to refrain from smoking and drinking coffee or alcohol two hours before testing, and to void their bladder. For each subject, and at every occasion, a drag test was used to determine the drag force and concomitant external power output for the wheelchair-user system on the treadmill at increasing inclinations and the actual testing speed.[37] Subjects performed two blocks of submaximal exercise of three minutes each, separated by a 2-minute rest. The treadmill incline was horizontal during the first block and then set at 0.36° during the second block. Treadmill velocity was set at 0.55 $m.s^{-1}$ for subjects with tetraplegia and at 1.1 $m.s^{-1}$ for subjects with paraplegia. In some subjects with a low cervical lesion or high thoracic lesion, we used a protocol with a velocity of 0.89 $m.s^{-1}$. After two minutes of rest, the peak exercise test followed at the same constant velocity, and the inclination was increased 0.36° every minute. The test was terminated when the subject was exhausted or could no longer keep pace with the speed of the treadmill. Individual testing protocol was identical for each of the testing occasions.

$VO_{2\,peak}$ was defined as the highest value of oxygen consumption recorded during 30 seconds. $PO_{peak}$ was defined as the power output at the highest inclination that the subject could maintain for at least 30 seconds.

### *Potential confounders*

*Demographic characteristics* were collected at the first measurement and included age and gender.

*Lesion characteristics* were assessed according to the International Standards for Neurological Classification of Spinal Cord Injury.[34] The ASIA Impairment Scale classifications A and B were considered motor complete and the classifications C and D were considered motor incomplete. Neurological lesion level was defined as the highest motor level. Neurological levels below T1 were defined as paraplegia and neurological lesion levels at or above T1 were defined as tetraplegia. Cause of injury was dichotomised in traumatic versus non-traumatic.

*Functional independence* was measured with the motor score of the Functional Independence Measure (FIM), consisting of 13 items about self care, mobility, transfers, and toileting.[38] We dichotomised into a group with low scores, 0–74 points (score = 0) and a group with high scores 75–91 points (score = 1). The cut-off point was chosen to create more or less even numbers of persons with low and with high functional status.

*Secondary impairments* were grouped into three categories:

1. *Musculoskeletal pain:* 13 locations about musculoskeletal pain were asked. All were scored as “absent = 0” or “present = 1” during the last 12 months. A total Musculoskeletal Pain score was computed as the sum score of all items (range: 0–13) and the scores were dichotomized into one group with 0 to 1 complaints (score = 1) and one group with two or more complaints (score = 0). The cut-off point was chosen to create more or less even numbers of persons reporting few and reporting many complaints.
2. *Neuropathic pain:* one item about pain other than musculoskeletal pain and eight other abnormal sensations as numbness, tingling, burning, phantom, hot or cold feelings, itching and dull feelings. All were scored as “absent = 0” or “present = 1” during the last 12 months. A total Neuropathic Pain score was calculated as the sum score of all items (range: 0–9) and the scores were dichotomized into one group with 0 to 2 complaints (score = 1) and one group with 3 or more complaints (score = 0). The cut-off point was chosen to create more or less even numbers of persons reporting few and reporting many complaints.
3. *Other secondary impairments:* seven items including pressure sores, urinary tract infections, pulmonary infections, neurogenic heterotopic ossification, oedema, hypotension and autonomic dysreflexia were scored as “absent = 0” or “present = 1” during the last 12 months. A total score was computed as the sum score of all items (range: 0–7) and the total scores were dichotomised into one group with 0 to 1 impairments (score = 1) and one group with two or more impairments (score = 0). The cut-off point was chosen to create more or less even numbers of persons reporting few and reporting many secondary impairments.

*Sports participation:* the time spent on sports activities (UAL Sport) was recorded in hours per week at the measurement occasions 1Y and 5Y. This item is part of the Utrecht Activities List.[39] This score was dichotomised into a group with 0–1 hours sports per week (score = 0) and a group with more than 1 hour (range 1.1–40) sports per week (score = 1). The cut-off point was chosen to create more or less even numbers of persons reporting low and high sports participation.

## Statistics

*Descriptive statistics* (means and standard deviations) were calculated with SPSS version 18.0.

*Random coefficient analysis*, also known as mixed effects model analysis, was used to study the course of life satisfaction and its relationship with the independent variables $PO_{peak}$ and $VO_{2\,peak}$.[40] We performed analyses for $PO_{peak}$ and $VO_{2\,peak}$ separately because of the strong inter-correlation between both variables. Included in these analyses were subjects who performed two or more out of five peak exercise tests during the test period (STUDY). In order to describe possible consequences of this selection on the study outcomes, we compared the included and excluded subjects (EXCLUDED) on available personal and lesion characteristics and on life satisfaction at all occasions using t-tests and Chi-square tests ($p<0.05$).

Two different multilevel linear regression models were computed: a standard model based on values at each test occasion (standard model) and a model based on change scores (change model). This latter model was added, because in the standard model, the regression coefficients reflect a combination of the within-subject variance (longitudinal relationship) and the between-subjects variance (cross-sectional relationship) between wheelchair exercise capacity and life satisfaction, whereas the regression coefficients in the change model only reflect the within-subjects variance. If the results of the standard model and the change model show similar relationships, the association between determinant and life satisfaction is mainly based on within-subject variance. If not, the association is mainly based on between-subjects variance.

In the standard model, LS total was used as the dependent variable. Time was included in the basic model as a set of four dummy variables, representing active inpatient rehabilitation (Start–Discharge), the last part of active inpatient rehabilitation (3M–Discharge), the short-term period after inpatient rehabilitation (Discharge–1Y) and the long-term period after discharge of inpatient rehabilitation (Discharge–5Y). The assessment of life satisfaction at discharge was chosen as the reference measurement and was estimated by the intercept. Estimates of life satisfaction at the other measurement times were obtained by adding the regression coefficients of the time dummies to the intercept. The independent variables $PO_{peak}$ and $VO_{2\,peak}$ and their interactions with time were added separately to the basic model to study their individual relationship with the LS Total scores.

The possible confounding effect of the variables age, gender, level of lesion, completeness of lesion, functional status (FIM), secondary impairments, musculoskeletal pain, neuropathic pain, and sports activity at 5Y on the relationship between the independent variables $PO_{peak}$ and $VO_{2\ peak}$ and the LS Total score were studied. The possible confounders were added one by one to the basic model. A variable was considered a confounder if the Beta of the independent variable $PO_{peak}$ and $VO_{2\ peak}$ changed more than 10% after adding one of these variables to the model. Ultimately, by entering all time interaction terms, adding $PO_{peak}$ and $VO_{2\ peak}$ and their time interaction terms separately and including the significant confounders, two final multivariate multilevel regression models were built to determine the course of wheelchair exercise capacity in relation to life satisfaction.

In the change model, a change in LS Total for every time interval between the successive measurements was used as the dependent variable. Change scores for the independent variables $PO_{peak}$ and $VO_{2\ peak}$ were added, to study their bivariate relationship with the change in LS Total. The possible confounders were added one by one again to the model, in the same way as the standard model. Separate models for $PO_{peak}$ and $VO_{2\ peak}$ were built.

## RESULTS

### Respondent characteristics

At the start of active rehabilitation, 225 persons with SCI were included in the cohort study, while 146 participants attended the 5Y measurement. Descriptives for STUDY and EXCLUDED are displayed in Table 6.1. Included patients were on average younger and had more often paraplegia than excluded patients. Life satisfaction scores were significantly lower for EXCLUDED patients at all occasions (only start and 5Y figures presented).

Descriptive data of life satisfaction, wheelchair exercise capacity ($PO_{peak}$ and $VO_{2\ peak}$) and possible time-dependent confounders are presented in Table 6.2.

### Relations between Wheelchair Exercise Capacity and Life Satisfaction

Both $PO_{peak}$ and $VO_{2\ peak}$ were significantly associated with LS Total in both the basic models and the models after correction for confounders (Table 6.3, Table 6.4). There were no significant interactions of $PO_{peak}$ and $VO_{2\ peak}$ with time. Confounders were gender, level of lesion, FIM and UAL Sport. Neuropathic pain was a confounder only for $PO_{peak}$ and completeness of injury only for $VO_{2\,peak}$ in relation to LS Total. The regression coefficients in the table represent the change in outcome associated with an increase in the independent variable $PO_{peak}$ or $VO_{2\,peak}$ of 1 unit. After correction for confounders, a 10 W higher $PO_{peak}$ score was associated with

**Table 6.1** Participant and lesion characteristics and Life Satisfaction scores for participants (STUDY) and non-participants (EXCLUDED)

| Characteristics | STUDY<br>n = 130 | EXCLUDED<br>n = 95 |
|---|---|---|
| Male gender (%) | 74.6 | 74.2 |
| Age at start (yrs) (SD) | 38.7 (13.7) | 44.1 (13.9)* |
| Paraplegic lesion (%) | 72.1 | 42.3* |
| Completeness start (%) | 68.5 | 69.3 |
| Traumatic cause of injury (%) | 76.0 | 69.0 |
| Length of rehab (days) | 248.1 (132.3) | 265.1 (150.8) |
| Life satisfaction start | 5.7 (2.2) | 4.9 (2.3)* |
| Life satisfaction 5Y | 7.8 (2.4) (n = 100) | 6.7 (2.6)* (n = 41) |

Data represent mean (SD) and proportions; Start = start of active rehabilitation; 3M = three months after Start; Discharge = discharge of active rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge. STUDY = total study group with two or more exercise measurements during follow up; EXCLUDED = loss to follow up in peak wheelchair exercise test during follow up; * significant difference with $p<0.05$ between STUDY and EXCLUDED.

**Table 6.2** Descriptive data of life satisfaction, wheelchair exercise capacity ($PO_{peak}$ and $VO_{2\,peak}$) and time-dependent confounders (mean, SD) in STUDY (n = 130)

| | Maximum range | Start<br>n = 129 | 3M<br>n = 92 | Discharge<br>n = 126 | 1Y<br>n = 107 | 5Y<br>n = 100 |
|---|---|---|---|---|---|---|
| Life satisfaction | 2–13 | 5.7 (2.2) | 6.3 (2.4) | 6.8 (2.3) | 6.9 (2.1) | 7.8 (2.4) |
| $PO_{peak}$ (W) | 3.4–134.4 | 32.9 (17.0) | 41.6 (20.8) | 44.6 (22.0) | 50.2 (26.1) | 55.9 (27.2) |
| $VO_{2\,peak}$ ($L.min^{-1}$) | 0.33–2.96 | 1.02 (0.3) | 1.14 (0.4) | 1.21 (0.4) | 1.27 (0.4) | 1.38 (0.5) |
| FIM | 13–91 | 46.8 (17.8) | 61.6 (20.4) | 72.8 (15.7) | 67.2 (16.5) | 68.6 (17.9) |
| Secondary impairments | 0–7 | 1.3 (1.2) | 1.6 (1.1) | 1.1 (1.1) | 1.5 (1.3) | 1.7 (1.4) |
| Musculoskeletal pain | 0–13 | 2.1 (2.0) | 1.7 (1.5) | 1.4 (1.5) | 1.5 (1.9) | 2.8 (2.8) |
| Neuropathic pain | 0–9 | 3.0 (1.8) | 4.0 (1.6) | 2.4 (1.6) | 2.6 (1.6) | 2.9 (2.2) |
| Sports participation (hours) | 0–40 | 3.9 (5.6)* | - | - | 2.4 (3.8) | 3.9 (6.0) |

Data represent means (SD); STUDY = total study group with two or more exercise measurements during follow-up; Start = start of active rehabilitation; 3M = three months after Start; Discharge = discharge of active rehabilitation; 1Y = one year after discharge; 5Y = five years after discharge. FIM = Functional Independence Measurement; $PO_{peak}$ = peak Power Output; $VO_{2\,peak}$ = peak maximal oxygen intake; * Sports participation before onset of SCI.

**Table 6.3** The longitudinal relation between wheelchair exercise capacity ($PO_{peak}$ and $VO_{2\ peak}$) and life satisfaction: basic multilevel linear regression model

| Independent variable | Model 1 with $PO_{peak}$ as determinant | | | Model 2 with $VO_{2\ peak}$ as determinant | | |
|---|---|---|---|---|---|---|
| | Beta | SE | p | Beta | SE | p |
| Constant (reference Discharge) | 6.019 | 0.300 | | 5.925 | 0.383 | |
| Δ Discharge–Start | -1.042 | 0.311 | 0.001* | -1.211 | 0.313 | 0.000* |
| Δ Discharge–3M | -0.538 | 0.326 | 0.099 | -0.634 | 0.326 | 0.052 |
| Δ Discharge–1Y | 0.076 | 0.319 | 0.812 | 0.057 | 0.320 | 0.859 |
| Δ Discharge–5Y | 0.894 | 0.358 | 0.013* | 0.811 | 0.363 | 0.026* |
| $PO_{peak}$ (W) | 0.019 | 0.005 | 0.000* | NE | NE | |
| $VO_{2\ peak}$ (l/min) | NE | NE | | 0.863 | 0.363 | 0.018* |

All results are regression coefficients (β) and Standard Errors (SE) for the regression model (constant + time dummy + determinant). The regression coefficients represent the change in outcome associated with an increase in the independent variable of one unit; Start = start of active inpatient rehabilitation; 3M = three months after start; discharge = discharge of inpatient rehabilitation; 1Y and 5Y = respectively one and five years after discharge of inpatient rehabilitation; $PO_{peak}$ = peak Power Output; $VO_{2\ peak}$ = peak maximal oxygen intake; * significant with $p<0.05$. NE = not entered.

a 0.34 higher LS Total score. A higher score of 0.1 $L.min^{-1}$ $VO_{2\ peak}$ was associated with a 0.12 higher LS Total score (Table 6.4).

The change model (Table 6.5) showed a significant association between change of WEC and LS Total. An improvement of 10 Watts in $PO_{peak}$ was associated with an improvement of 0.28 in LS Total scores. A progression of 0.1 $L.min^{-1}$ $VO_{2\ peak}$ was associated with a progression of 0.1 in LS Total scores. Age was a confounder in the relation between the change in $PO_{peak}$ and the change in LS Total and Sports participation was a confounder for both the change scores in $PO_{peak}$ and $VO_{2\ peak}$ and the change score in LS Total.

## DISCUSSION

Our hypothesis "Persons with SCI who are (more) fit, are (more) satisfied in life" was confirmed. Moreover, change in exercise capacity was positively related to change in life satisfaction. The change in both models was nearly identical, and therefore we conclude that the relationship between exercise capacity and life satisfaction was mainly based on the within-subject variance instead of between-subject variance. This implicates that persons who are able to improve their physical fitness, might expect an improvement of their life satisfaction.

**Table 6.4** The longitudinal relation between wheelchair exercise capacity ($PO_{peak}$ and $VO_{2\,peak}$) and life satisfaction: final regression model

| Independent variable | Model with $PO_{peak}$ as determinant | | | Model with $VO_{2\,peak}$ as determinant | | |
|---|---|---|---|---|---|---|
| | Beta | SE | p | Beta | SE | p |
| Constant (reference Discharge) | 5.985 | 0.414 | | 5.411 | 0.509 | |
| Δ Discharge–Start | -0.499 | 0.378 | 0.187 | -0.810 | 0.400 | 0.043 |
| Δ Discharge–3M | -0.900 | 0.589 | 0.114 | -0.381 | 0.376 | 0.312 |
| Δ Discharge–1Y | 0.249 | 0.355 | 0.484 | 0.200 | 0.370 | 0.589 |
| Δ Discharge–5Y | 0.910 | 0.376 | 0.016 | 0.885 | 0.392 | 0.024 |
| $PO_{peak}$ (W) | 0.034 | 0.008 | 0.000* | NE | NE | |
| $VO_{2\,peak}$ (l/min) | NE | NE | | 1.174 | 0.403 | 0.000* |
| **Confounders** | | | | | | |
| Gender[§] | -0.990 | 0.313 | 0.002 | -0.826 | 0.313 | 0.008 |
| Level of lesion[‖] | -0.851 | 0.363 | 0.019 | -0.044 | 0.341 | 0.897 |
| NP Pain[#] | 0.458 | 0.254 | 0.072 | - | | |
| Complete[¶] | - | | | 0.515 | 0.311 | 0.097 |
| FIM[†] | 0.332 | 0.299 | 0.271 | 0.301 | 0.251 | 0.230 |
| Sport participation[‡] (hours) | 0.297 | 0.253 | 0.241 | 0.261 | 0.300 | 0.384 |

All results are regression coefficients (β) and Standard Errors (SE) for the final regression model (constant (B) + time dummie + determinant + confounders) The regression coefficients represent the change in outcome associated with an increase in the independent variable $PO_{peak}$ or $VO_{2\,peak}$ of one unit. [§] 0 = women; 1 = men; [‖] 0 = tetraplegia; 1 = paraplegia; [¶] 0 = incomplete; 1 = complete. [#] 0 = much pain; 1 = low pain; [†] 0 = low functional status; 1 = high functional status; [‡] 0 = low sports participation; 1 = high sports participation. Start = start of active rehabilitation; 3M = three months after start; discharge = discharge of inpatient rehabilitation; 1Y and 5Y = respectively one and five years after discharge of inpatient rehabilitation. $PO_{peak}$ = peak Power Output; $VO_{2\,peak}$ = peak maximal oxygen uptake; NP Pain = total score of neuropathic pain; Complete = complete lesion; FIM = functional status; Sport participation = hours per week sports; * significant with $p<0.05$. NE = not entered. A confounder is significant when the constant (B) changes with more than 10% when the confounder is entered in the regression model.

## Exercise (Capacity) and QOL in SCI

To our knowledge no similar studies on the longitudinal relationship *between wheelchair exercise capacity* and *life satisfaction* in SCI have been published. Our results lend additional support to the positive relations between (sport) exercise participation and QOL-related entities like symptoms of depression,[28] mood state,[27] self perception,[41] perception of capacities[42] and life satisfaction[29] that were reported in SCI research. Specific benefits of exercise to QOL are attributed to the direct neuro-hormonal effects of endorphin and oxytocin-production during

**Table 6.5** Data on the longitudinal relation between the change in wheelchair exercise capacity ($\Delta PO_{peak}$ and $\Delta VO_{2\,peak}$) and the change in life satisfaction: final regression model

| Independent variable | Model with $PO_{peak}$ as determinant | | | Model with $VO_{2\,peak}$ as determinant | | |
|---|---|---|---|---|---|---|
| | Beta | SE | p | Beta | SE | p |
| Constant Δ Life Satisfaction | 0.462 | 0.470 | | 0.336 | 0.209 | |
| $\Delta PO_{peak}$ (W) | 0.028 | 0.011 | 0.011* | NE | NE | |
| $\Delta VO_{2\,peak}$ (l/min) | NE | NE | | 0.981 | 0.497 | 0.049* |
| **Confounder** | | | | | | |
| Age§ (years) | -0.004 | 0.010 | 0.689 | - | - | - |
| Sport participation‡ (hours) | -0.006 | 0.271 | 0.982 | -0.076 | 0.269 | 0.779 |

All results are regression coefficients (β) and Standard Errors (SE) for the regression model (constant + time dummy + determinant). Final regression model (constant + determinant + confounders). The regression coefficients represent the change in outcome associated with a change in the independent variable $\Delta PO_{peak}$ and $\Delta VO_{2\,peak}$ of one unit. $PO_{peak}$ = peak Power Output; $VO_{2\,peak}$ = peak maximal oxygen uptake; Sport participation = hours per week sports; $\Delta PO_{peak}$ = change in $PO_{peak}$; $\Delta VO_2$ = change in $VO_{2\,peak}$; * significant with $p<0.05$. NE = not entered. § 0 = older than 40 yrs; 1 = younger than 40 yrs; ‡ 0 = low sports participation; 1 = high sports participation. A confounder is significant when the constant (B) changes with more than 10% when the confounder is entered in the regression model.

and after exercise[43] or the indirect improvement of social status and self-esteem by being a member of a group, or by identification as being a sportsmen or athlete, as was also found for people with disabilities.[29,44] We were also able to establish a relationship between change in WEC and change in LS and found sports participation to be a confounder in this relation. In comparison, one study[30] found a positive effect of a 10 week fitness training program on subjective wellbeing in SCI subjects. A Canadian study on a 9-months training program in a small case-control study in SCI revealed that people who exercised twice per week reported less stress, pain and depression, and better physical self concept, health-related QOL and overall subjective wellbeing than the control group during the program.[15,25,26,45] However, a Dutch study revealed no associations between exercise capacity and health related QOL in tetraplegic patients in a handcycle training,[31] while no relationship was found between physical activity, fitness and subjective quality of life in SCI in a cross-sectional study.[32] The design of the studies and the small group sizes might play a role in these deviating results.

Altogether, the findings in literature support our results of a positive relationship between (change in) WEC and (change in) LS.

## Clinical relevance

An improvement in $PO_{peak}$ with 10W, that implies an Effect Size (ES) of (10/17=) 0.59, leads to an improvement of (0.2/2.2=) 0.14 ES in LS, which might not seem clinically relevant. However, life satisfaction is a multidirectional influenced entity and dependent also on genetic influences[46-48] and environmental factors as financial resources, economically and politically stability.[46,48] Furthermore, SCI-related physical factors as pain, secondary impairments and low functional status,[1,2,7,9] and psychosocial factors as personality, appraisals, social support and self efficacy[1,3-5] are all predictors of LS. In this context it is encouraging that a significant relationship between WEC and LS was found. Up to 20% improvement in peak oxygen uptake and peak power can be achieved in persons with SCI by correct training regimes,[31,49] and the amount of consequential improvement in LS is comparable to a positive major life event like marriage.[46] Hence, in the perspective of life satisfaction being an important outcome in rehabilitation,[50] our results might eventually be considered as clinically relevant.

## Limitations of this study

In a longitudinal study with a physically demanding peak wheelchair exercise test, loss to follow up is inevitable, and only 58% of the patients had two or more WEC measurements and could be included in our analyses. This figure could have been higher if we would have included all persons with one or more out of five WEC measurements, but this seemed too speculative, although the analytical strategy we used allows it.[40] Most reasons for not attending the peak exercise test were health related, e.g. having pain or suffering from infections. Life satisfactions scores of EXCLUDED were significantly lower than STUDY at all measurement, which is in line with our previous finding that LS is related to health conditions like secondary impairments and pain.[2]

The EXCLUDED group was of older age and consisted of more persons with tetraplegia. Both entities were determinants of low WEC[18] and of drop-out.[51] Moreover, level of lesion was a confounder in the relation between the wheelchair exercise capacity and life satisfaction, therefore most probably the loss of the older persons with tetraplegic lesions has influenced our results, although we find it too speculative to report a direction.

Our study had a longitudinal observational design; therefore no causal relations can be drawn between life satisfaction and exercise capacity.

The LS Total score is not commonly used worldwide to measure life satisfaction in SCI, but in comparison to other life satisfaction instruments it shows similar psychometric properties.[9]

## Clinical implications and research recommendations

Our study revealed that most persons with SCI in the Netherlands showed recovery of wheelchair exercise capacity[11,14] and life satisfaction[2,3] from start up to five years after discharge. Nevertheless, we want to emphasize that both figures are lower than general population[9,14] and in our studies on different trajectories in WEC[18] and LS,[3] classes with deterioration were found. In long-term SCI rehabilitation practice, a clinician needs to detect the "*persons at risk*" for poor health, including risk for low WEC and low LS because these might have long-term physical health consequences. Hence, to our opinion, conducting a wheelchair exercise test and measuring life satisfaction during inpatient rehabilitation and in follow up care is desirable.

There is a need for cohort studies in other countries with sufficient sample size in the early phase after onset to compare our results with, in order to identify people at risk of poor mental and physical adaptation.

## Conclusion

Wheelchair exercise capacity and life satisfaction are longitudinally associated up to five years after discharge of inpatient rehabilitation in our SCI cohort: an improvement in exercise capacity is associated with an improvement in life satisfaction. To our opinion, altogether there are many convincing arguments to proclaim the message of adopting habitual exercise as part of a healthy lifestyle.

# CLINICAL MESSAGE

- Wheelchair exercise capacity and life satisfaction recover from start of active rehabilitation up to five years after discharge in SCI population.
- Wheelchair exercise capacity and life satisfaction are longitudinally related: persons who are more fit, are more satisfied in life.
- A positive change in wheelchair exercise capacity leads to a positive change in life satisfaction, this means that persons who are able to improve their physical fitness, might expect an improvement of their life satisfaction.

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# 7

# Discussion

This chapter starts with an overview of the main findings of our study. Subsequently, theoretical and methodological considerations associated with our study design are discussed. Finally, directions for future research and recommendations for clinical practice are presented.

# MAIN FINDINGS

## Life satisfaction

*How do persons with SCI rate their life satisfaction at one year after discharge, and how can we interpret this in relation to general population figures and to their life satisfaction before SCI? How is (the change of) life satisfaction influenced by personal and lesion characteristics and secondary impairments?*

The results of **chapter 2** showed a marked decrease in life satisfaction of persons with SCI at one year after discharge from inpatient rehabilitation compared to general population figures and compared to their life satisfaction before SCI. The latter was retrospectively reported early in inpatient rehabilitation. Decrease of life satisfaction was strongest for the domains Sexual life, Self care and Vocational situation. Partner relations, Family life and Contacts with friends and acquaintances appeared the least affected life domains. Age, gender and education had little relationship with life satisfaction and the change of life satisfaction after SCI. Having a tetraplegia, suffering from pain and suffering from secondary impairments were associated with low life satisfaction and with a decrease of life satisfaction one year after discharge.

*What is the course of life satisfaction of persons with SCI during and after initial rehabilitation up to one year after discharge and how can we interpret changes in life satisfaction? How is (the change of) life satisfaction influenced by physical and functional characteristics?*

The results of **chapter 3** showed that the total life satisfaction score (current and in comparison with life before SCI) improved during inpatient rehabilitation, especially during the first three months of active rehabilitation, and remained stable during the first year after discharge.

It was shown that demographics and SCI characteristics could not explain the variance in life satisfaction very well. However, a better functional status, less pain, and fewer secondary impairments were associated with higher life satisfaction during the early phase after SCI.

## Wheelchair exercise capacity

*What is the course of wheelchair exercise capacity of persons with SCI during and after initial rehabilitation up to five year after discharge? How is (the change of) wheelchair exercise capacity during and after initial rehabilitation up to five year after discharge influenced by personal and lesion characteristics?*

Our results in **chapter 4** showed an improvement of wheelchair exercise capacity during inpatient rehabilitation, but no significant change of mean wheelchair exercise capacity scores between discharge and five years later. Age, gender and level of lesion were found to be significant determinants for wheelchair exercise capacity.

*Can we identify heterogeneity in the course of wheelchair exercise capacity in SCI population up to five years after discharge and can we identify determinants of this heterogeneity in wheelchair exercise capacity?*

The results presented in **chapter 5** confirmed that different wheelchair exercise capacity trajectories could be distinguished after SCI. We found four different trajectories in the course of $PO_{peak}$: 1) high progressive scores (n = 43); 2) deteriorating scores: progressive scores during inpatient rehabilitation with deteriorating figures after discharge (n = 15); 3) low progressive scores: low scores at the start of rehabilitation with relative strong progressive scores after discharge (n = 69); and 4) low inpatient scores with very strong progressive scores after discharge (n = 3). The $VO_{2\,peak}$ scores showed the same trend in trajectories. Older of age, female gender, tetraplegic lesion and low functional status were associated with the low progressive trajectory of $PO_{peak}$. These results suggest that physical adaptation to a severe disability like SCI is a multi-faceted process that varies between subgroups.

## Relationships between wheelchair exercise capacity and life satisfaction

*What is the association between wheelchair exercise capacity and life satisfaction in persons with SCI in a cohort up to five years after discharge of inpatient rehabilitation?*

In **chapter 6** we found that wheelchair exercise capacity and life satisfaction in a SCI population were longitudinally associated up to five years after discharge of inpatient rehabilitation: an improvement in exercise capacity with 10 Watt was associated with an improvement in life satisfaction with 0.3. Moreover, the change scores of life satisfaction and wheelchair exercise capacity were strongly correlated with each other. This implies that persons, who are able to improve their wheelchair exercise capacity, might expect a small improvement of their life satisfaction.

After having summarized the main findings of this thesis, I would like to link these findings with scientific issues on the mechanisms of mental and physical adaptation to the SCI. I will present an anecdote, which connects the findings of this thesis with my daily experience as a SCI rehabilitation physician: How is it possible that most individuals with SCI adapt physically and mentally so well tot this devastating condition?

## REFLECTIONS AND CONSIDERATIONS

### Reflection on levels of life satisfaction

Quality of life as an outcome of treatment is described more and more often in the medical literature. However, there is a wide variation in concepts, definitions and measurements. We chose in this thesis for a *subjective* quality of life measure of life satisfaction, because literature revealed that *objective* measures overestimate the effect of a trauma as perceived by the person involved.[1] Nurses, therapists and medical doctors tend to underreport the patient's life satisfaction in comparison to the judgement of the person involved.[2] Based on his medical condition, I would have underestimated the life satisfaction of our anecdotal patient (Box 7.1).

Brickman et al.[3] found that lottery winners were not happier than non-winners after a while, and that people with SCI were not as unhappy as one might expect. They suggested that people's life satisfaction levels are influenced by good and bad events, but return to a neutral set-point over time. Since the release of this paper in the seventies of the last century, researchers have referred to this phenomenon as the so-called "hedonic treadmill": people's life satisfaction might fluctuate under positive or negative influences, but always returns to a steady reference point ("set point"[4]). However, to our opinion the classic publication by Brickman et al.[3] has generally been wrongly interpreted and cited.[5] In our study in **chapter 2** we compared Brickman's figures with our own and found remarkably similar figures, with a significant and clinically relevant difference between life satisfaction shortly after SCI compared to a retrospective rating of life satisfaction before SCI. As a recently published review of my colleagues Post and van Leeuwen[6] showed, many studies have been conducted to compare life satisfaction in SCI with life satisfaction in the general population. This review supports our conclusion (**chapter 2**) that figures of life satisfaction in SCI population are substantially lower than in the general population. This is in line with the "revised theory of hedonic treadmill"

**Box 7.1** An anecdotal patient

One of the participants in our cohort study, a man 27 years of age, with a complete paraplegic spinal cord injury after a snowboard accident, rated himself the maximal score on the life satisfaction scales and moreover, he achieved one of the highest scores of all patients in the peak wheelchair exercise test. I dared asking him the "secret of success", because honestly, I did not understand how he managed to be happier and more fit than I was at that moment, while I was able to do my work as a doctor without physical boundaries, to walk out the door, play a game of soccer, travel around the world, visit cities and meet persons, without worrying about the appropriate use of medication, annoying spasms, availability of catheters or unexpected incontinence during daily activities or sexual intercourse.

He told me that first of all he was happy and grateful to be alive after surviving his accident (A), second he was proud of himself that he endured the whole hospital and rehabilitation period by keeping up a good spirit and faith in the future (B). He was thankful that the caretakers and his immediate family and friends did the same (C). Taking his life in consideration, a few years after the onset of his SCI, he valued his life after SCI more meaningful (D). He valued his friends and family, who supported him in rough times, more than he did before his SCI (E). Next to this he felt blessed, because he performed his favourite sport on daily basis, had become one of the best in the world in this field and he was able to make a living out of it (F). Being a sportsman gave him a push in self-confidence and in self-esteem, he told me (G). Further, being physically active almost every day, he felt fit and healthy, even in the perspective of being disabled (H). Moreover he was convinced that his fitness could protect him against all the problems he had sustained during inpatient rehabilitation, such as pressure sores, urinary tract infections and overuse injuries of his back and shoulders (I). Being active in sports gave him the distraction of his neuropathic pain, which he considered as an unchangeable complication of his SCI: "Doctor, we both know I am in the untreatable group here, so I better learn to deal with it." (J). Finally, being a Paralympian gave him the opportunity to travel around the world, meet interesting people, and use his reputation to be active in charity committees and foundations (K). Besides all that, his girlfriend (who he just had met at the moment of the accident), had supported him all the way through the rehabilitation period and she made him happier than all the women in his life before, and as icing on the cake his girlfriend was even pregnant (L)!

by Diener and Lucas, which acknowledges that major life events might change set points of life satisfaction: while some individuals change their set-point, others return to their original set-point.[7] Van Leeuwen[8] indeed showed, using additional data of our Dutch SCI cohort, that some persons maintained high life satisfaction even early after SCI and that others were able to enhance their life satisfaction after an initial low early after SCI. In contrast, a group was found with stable low life satisfaction figures that seem to be unable to mentally adapt to their condition. Diener and Lucas' theory is in accordance with the results of a large international study on twins,[9] in which the genetic role in life satisfaction and mood was estimated to be over 40%, and is also in line with Lyubomirsky et al.,[10] who estimated that 50% of a person's happiness is determined by genetics (i.e. unchanging personality and temperament), 10% is determined by circumstantial factors, and 40% is determined by intentional activity, i.e. by what people do in order to maintain or enhance their happiness. The mid- and long-term figures on life satisfaction in our cohort (**chapter 3**)[11] showed an improvement up to five years after discharge, with a stabilisation of the figures of the current life satisfaction in combination with an improvement of the figures of the comparison question. It seems that persons tend to appreciate their current live satisfaction higher when compared to life before SCI, when time since injury increases. One might state that a retrospective measurement is speculative at any case and biased by potential glorification of one's life before SCI. Nevertheless, to my opinion a combination of the current life satisfaction with the comparison question gives more insight in the real values of life satisfaction and the combination questionnaire is thereby better capable of measuring adaptation than questions on current life satisfaction alone.[12]

Overall, this insight in the different individual courses of life satisfaction after SCI, offers rehabilitation teams possibilities for intervention in a person's grieving and adaptation process to the new world after SCI.

The anecdotal patient (Box 7.1) shows the individual adaptation process to the new life situation after a dramatic and life changing condition as a SCI. There is a body of literature suggesting that people exposed to even the most traumatic events may perceive at least some good emerging from their struggle with such tragedies, and experience so called posttraumatic growth.[13] This might offer us an explanation of the remarkable high life satisfaction experienced by this patient after sustaining SCI. Our patient survived a major trauma, he "reinvented himself" in the new 'personal' world and, after the situation has stabilised and the dust-clouds have disappeared, he first of all appreciates being alive and he appreciates his internal strength and resilience, that has been tested during the strenuous and challenging rehabilitation (A, B). This altogether might give him a stable foundation for acceptable figures of life satisfaction.

A more explanatory model is the *response shift theory*.[14] Response shift refers to a change of internal standards (recalibrations) (D), values (reprioritization) (E) and definition of life satisfaction (reconceptualization) resulting in a changed appreciation of life. Whereas our patient before the SCI was focussed on leisure activities like having fun with his friends in the pub and skiing, he now sports as a professional (F), appreciates his partner (L) and family bonds more (C, E) and the pregnancy of his girlfriend puts his life in another perspective (D, L). He changed his internal standards, values and definition of life satisfaction, altogether improving his general satisfaction in life.

## Relationship between wheelchair exercise capacity and life satisfaction

Another contribution to his remarkable high figures of life satisfaction and exercise capacity might be his elite sportsmanship (F), considering the positive relationship we found between wheelchair exercise capacity and life satisfaction in **chapter 6** of this thesis, comparable to the positive relation between exercise capacity and quality of life found in the healthy population.[15] Due to the paralysis and wheelchair dependency, most persons with SCI are prone to be inactive and lead a sedentary life,[16] but our patient leads a very active life, being a professional sportsman. Increase of exercise capacity by training and/or increasing physical daily activity is likely to increase the general health of a person with SCI.[16-19] In fact, exercise is so beneficial for humans, that it should be considered as medicine, as the American College of Sports Medicine proclaims, with evidence in the general population for prescribing exercise in the primary and secondary prevention of pulmonary and cardio-vascular diseases, metabolic disorders, muscle-, bone- and joint diseases, cancer, pain and depression (H, I, J).[20] In addition to the physical benefits of exercise, many positive effects on life satisfaction have been recorded in the general population.[15] In a large longitudinal international twins study[9] a positive relation between physical fitness and life satisfaction was detected. Direct benefits of exercise for life satisfaction are assigned to the neuro-hormonal effects of endorphin and oxytocin-production during and after exercise.[21] Indirect improvement of life satisfaction might be due to the effect of a good exercise capacity on social status and self-esteem, like our patient told me, by being a member of a group, or by identification as being a sportsmen or athlete, which can be of great importance in the building of adequate levels of life satisfaction (F, G).[22,23]

In **chapter 6** we found that the change scores of wheelchair exercise capacity and life satisfaction were associated with each other. This implies that persons who are able to improve their wheelchair exercise capacity, might expect an improvement of their life satisfaction. This improvement is in spite of all other factors associated with life satisfaction, including SCI-related physical factors addressed in **chapters 2 and 3** such as pain, secondary impairments and low functional status,[24-26] genetic influences,[7,9,10] environmental factors such as financial resources, economic and political stability,[7,10] and psychosocial factors such as personality, appraisals, social support and self-efficacy.[6,10,11,24]

In this context it is encouraging that a significant relationship between wheelchair exercise capacity and life satisfaction was found. Up to 20% improvement in peak oxygen uptake and peak power can be achieved in persons with SCI by correct training regimes[19,27] and the amount of consequential improvement in life satisfaction is comparable to a positive major life event like marriage.[7] Hence, in the perspective of life satisfaction being an important outcome in rehabilitation,[28] our results seem clinically relevant.

Our patient was convinced that his fitness could protect him against the problems he sustained during inpatient rehabilitation, such as pressure sores, urinary tract infections and overuse injuries of his back and shoulders (I). Although having secondary impairments was not a significant determinant to distinguish between a high progressive or low progressive trajectory in the course of $PO_{peak}$ (**chapter 5**), we found more neuropathic and musculoskeletal pain in the group with deteriorating figures of $PO_{peak}$ in comparison with the trajectory of high progressive scores, in which these persons should have been clustered based on their personal and lesion characteristics. These findings are in line with the negative relation of pain and exercise capacity found in the general population[29,30] and in SCI population.[31]

Our anecdotal patient showed high levels of wheelchair exercise capacity and life satisfaction, but we want to emphasize that the mean scores of our cohort are lower than figures in the general population[6,25] (**chapter 4**) and in our studies on different trajectories in the course of wheelchair exercise capacity (**chapter 5**) and life satisfaction,[8] trajectories with deteriorating figures after discharge of inpatient rehabilitation were detected. Therefore, with all the benefits of exercise for life with SCI in mind, it might even be suggested, that rehabilitation professionals pro-actively should try to stimulate persons with SCI to exercise-related hobbies.[23] Exercise capacity seems to be a small but nevertheless trainable and therefore fairly influential brick in the construction of the life satisfaction-house.

Like our anecdotic patient, most persons with SCI in the Netherlands are capable of leading a 'sporty'-lifestyle, regarding the remarkable high figures of sports participation in both the high progressive trajectory (4.7 $hr.week^{-1}$) and the low progressive trajectory (3.8 $hrs.week^{-1}$) at five years after discharge (**chapter 5**). This is in contradiction with the findings of a Dutch study of van den Bergh et al, who found very low activity levels for persons with in comparison with other disabilities, measured with the more objective accelometer.[32] Moreover, it is important to acknowledge that our cohort represents a selection of the total SCI population. We most surely have overestimated the sports participation, due to the age related inclusion criteria of the SPIQUE project and due to the loss to follow-up of the older persons and persons with more severe lesions, who are prone to lead more sedentary lifestyles.

## Interpretation of outcome of the peak wheelchair exercise test: who is fit and who is not?

We defined physical fitness as wheelchair exercise capacity in this thesis. Wheelchair exercise capacity is the combined ability of the cardiovascular, the respiratory and musculoskeletal systems to cope with a certain level of activity.[16] In our study we measured wheelchair exercise capacity with a peak wheelchair exercise test. By using an oxymeter and measuring the peak oxygen uptake ($VO_{2\ peak}$) we were able to interpret one's general endurance capacity, and computing the peak power output ($PO_{peak}$) gave us insight in the outcome of a combination of wheelchair skills, endurance capacity, anaerobic power and the wheelchair-user interface (Figure 1.4).[33]

An earlier publication utilizing data of the Umbrella project, on which the present thesis is also based, showed that mean scores of wheelchair exercise capacity improved during inpatient rehabilitation, especially during the first three months of active rehabilitation, and remained for peak oxygen uptake progressive during the first year after discharge.[16]

Our results in **chapter 4** were based on a longer follow-up period, up to five years after discharge, and showed an improvement of wheelchair exercise capacity during inpatient rehabilitation, but no significant change of mean wheelchair exercise capacity scores between discharge and five years later. This stabilisation of wheelchair exercise capacity is in contrast with literature and the expectations that $VO_{2\ peak}$ will diminish over time. The latter because of ageing and of insufficient daily life activity levels of persons with SCI to maintain adequate levels of wheelchair exercise capacity.[17] We think that our follow-up might be too short to reflect an aging effect. Age, gender and level of lesion were found to be significant determinants for wheelchair exercise capacity, which was in accordance with the literature.[16-18]

As we have seen in **chapter 5**, the lower improvement in $VO_{2\ peak}$ (25%) as compared with the improvement in $PO_{peak}$ (50%) for both the low and the high progressive classes, indicates that simultaneous improvements of anaerobic exercise capacity and wheelchair skills and technique, resulting in a better wheelchair propulsion efficiency,[16] might take place in the course of time (Figure 1.4).

For a wheelchair-dependent population the peak wheelchair exercise test seemed for us the most relevant and functional test. It is important to recognize that for some persons with high levels of tetraplegia and even some persons with a paraplegia, the peak wheelchair exercise test is too strenuous to accomplish. Conducting an arm-cranck test might seem a good alternative, because due to the continuous movement with less coordination problems it is easier to accomplish. Still, this test is to our opinion less functional than a peak wheelchair exercise test conducted in a population with use of a hand rim wheelchair on daily basis.

The outcome of the peak exercise test, $PO_{peak}$, is the combined product of genetics, functional outcome of the SCI and the degree of training of the individual. In the general population one can compare a certain fitness level, tested with a peak graded exercise test on a bike or treadmill (the golden standard), with normative values, related to gender, body mass and age. However, SCI leads to a diversity of functional muscular outcomes due to the variety in lesion characteristics, and a comparison to general normative values is not of any value. First, the spinal cord injury is divided into 31 segmental levels with two sides that can be affected. Second, distinction between complete lesions with no motor function below the level of lesion and incomplete lesions needs to be considered. Third, a complete lesion can be accompanied by a zone of motor preservation, leading to involvement of muscles under the lesion level. Fourth, the impact of the potentially impaired autonomic nerve system on the cardiac output and thus on wheelchair exercise capacity is difficult to assess accurately for every individual.[33] Fifth, the outcome of a peak exercise test in a wheelchair on a treadmill is influenced by coordinative skills, test motivation and the interplay between user, wheelchair and treadmill. Altogether, individual results of a wheelchair peak exercise capacity test are rather difficult to interpret. For example, a person with a tetraplegia with a low wheelchair exercise capacity score might be relatively well-trained and 'fit', whereas a person with a paraplegia with a higher wheelchair exercise capacity score might be deconditioned because he does not meet his 'fitness potential'. The results of wheelchair exercise capacity tests in the SCI literature should, therefore, be interpreted with care, even if these are compared to normative values for persons with SCI.[16,18,19]

Nevertheless, with all the benefits of high levels of exercise capacity for persons with SCI in mind, we want to emphasize that we advise to monitor the wheelchair exercise capacity in a peak exercise test during and after inpatient rehabilitation and compare the outcomes of individuals and of groups with these normative values, corrected for SCI characteristics. Moreover, the individual score can be compared to the previous results of the person involved. At discharge of inpatient rehabilitation people are supposed to have the highest fitness levels during rehabilitation and the discharge score seems therefore a good reference point for comparison in follow-up care.

We were able to detect different trajectories in the course of wheelchair exercise test in **chapter 5**. We found predictors similar to **chapter 4** and literature[16-18,35] to distinguish between high (progressive) scores and low (progressive) scores: tetraplegia, female gender, older age and low functional status were associated with the trajectory with low progressive scores. Persons with tetraplegia have few functional muscle groups available and less sympathetic control of the cardiovascular system to cope with the exercise demands.[34,36,37] The low progressive trajectory also comprised most of the women, who have, due to their lower lean body masses, lower oxygen uptake and therefore exercise capacity in general.[38] It is a general fact of life that exercise capacity declines over time and, therefore, age is a persistent determinant of exercise capacity.[39] Nevertheless all in consideration, the trajectory with low progressive scores still contained many persons with potentially higher exercise capacity, based on gender and type of lesion.

The trajectory with the deteriorating figures after discharge is in clinical perspective the most interesting, but it was too small to statistically compare with the other classes. However, the descriptive figures showed that the persons in the deterioration trajectory could have been clustered in the high progressive trajectory based on their gender, age and level of lesion. However, they showed relative high levels of both musculoskeletal and neuropathic pain and a decline in the already low sports participation from one year to five years after discharge (decline from 1.6 hrs.week$^{-1}$ to 1.0 hrs.week$^{-1}$). In comparison, the high progressive trajectory showed a progress in activities, especially in sports with much higher absolute values from 3.5 hrs.week$^{-1}$ at one year after discharge to 4.7 hrs.week$^{-1}$ at five years after discharge (**chapter 5**). It is speculative, but the inactivity of the deteriorating class might have led to a declination of the exercise capacity, followed by an overload of the musculoskeletal system in daily activities as self-care, transfers and mobilisation, resulting in pain and potentially in a debilitative vicious circle of *inactivity-pain-inactivity-deterioration of exercise capacity*.[32,40]

## METHODOLOGICAL CONSIDERATIONS OF THE STUDY

In the Umbrella and SPIQUE studies some important methodological choices were made that have consequences for the interpretation of our results. In this section, I try to explain the ratio behind the choices that have been made and discuss its consequences.

### Study population

In the Umbrella and SPIQUE studies only Dutch persons with SCI between 18 and 65 years of age with expected permanent wheelchair dependency admitted to a rehabilitation centre were included. This influenced the representativeness of the population and thereby the degree to which the results of our study can be generalized to the whole population of persons with SCI. A consequence of the inclusion criteria was that relatively young and old people and persons with an incomplete AIS D lesion or a cauda equina lesion did not participate and therefore, the results of the present study can only be generalized to wheelchair-dependent adults with SCI. This might be the reason that completeness of injury was not a determinant for wheelchair exercise capacity, in contrast with other studies,[17,18] as a result of the exclusion of persons with relatively less severe lesions.

## Study design

The measurement moments were split up in three measurements during inpatient rehabilitation and two measurements after discharge from inpatient rehabilitation. Time was therefore in our analyses not measured as a continuous entity, which makes it somewhat hard to generalize our results or compare with studies from other countries, because duration of inpatient rehabilitation differs between countries.[41] The second measurement was performed three months after the first measurement. For some persons the second measurement was converted in the third measurement, because there was an overlap with the planned measurement at discharge, due to their relative short length of stay in inpatient rehabilitation. Between the first and second measurement both wheelchair exercise capacity and life satisfaction improved, but we cannot claim that three months is the time in which most improvement takes place. To identify the mean duration of improvement more measurements, for example monthly after the start of active rehabilitation, should have been performed.

## Multicentre research

The contribution of eight rehabilitation centres to this study provides information on a relatively large cohort, but one needs to consider whether the results can be generalised. Differences between observers or instruments may affect the reliability of the data, but we tried to minimize these influences. The researcher assistant in each centre were all rehabilitation professionals who were trained together prior to and during the whole program. They followed a strict protocol that was evaluated in organised training sessions and structured meetings. During every test day, the instruments for the peak exercise test were calibrated and the calculations were standardized. In an investigation of the drag test we used, we found the velocity of the treadmill highly reproducible but lower than the assumed velocity. This forced us to recalculate the power output using the measured velocities.[42] The data were noted in identical measurement books, and finally collected in one database. In the multilevel random coefficient analyses, we used multilevel analysis in which we considered the dependency of more assessments by one observer at each rehabilitation centre and corrected for differences between centres.[43]

## Life satisfaction instrument

In **chapter 2**, the LiSAT-9 was used to study life satisfaction at one year after discharge, in comparison with life before SCI and in comparison with the general population for the several domains of life. The LiSAT-9 is suitable to gain information on satisfaction with life domains, in particular in community settings, and is considered the best combination of efficiency, coverage, and psychometric evidence of all domain-specific life satisfaction measures used in persons with SCI.[11] In addition, a brief new life satisfaction scale (life satisfaction now and in comparison with life before SCI) was used to study the course of life satisfaction. A sum score was calculated and ranged between 2 (very low life satisfaction) and 13 (very high life satisfaction). The reason why we used this latter scale instead of the LiSAT-9 questionnaire to describe the course of life satisfaction during inpatient rehabilitation up to one year after discharge, was that several items of the LiSAT-9, for example work or leisure time, are not relevant during inpatient rehabilitation. The two-item questionnaire, the Life Satisfaction questions, was developed in an attempt to measure recovery of life satisfaction as efficiently as possible and is recommended to study adaptation early after SCI, because this instrument is the shortest, feasible to administer in inpatient rehabilitation, and might reveal response shift effects.[11] A recently published comparison of the measure scales with other measures like LiSAT-9 and Satisfaction With Life Scale, confirmed the satisfying psychometric properties of this life satisfaction scale.[12]

## Recall bias

Another important methodological issue is that our results on life satisfaction might be affected by recall bias. Recall bias refers to the phenomenon that it becomes more difficult to remember certain facts over time. One and five years after discharge it might be difficult for persons to remember how their life satisfaction was before the SCI, as we asked them to do in the comparison question. As a result, recall of level of life satisfaction before SCI might have become unreliable and influenced by later events.

However, in our study the correlations between the 'comparison question' at the measurement at discharge and at later measurements remained more or less the same (Spearman correlation = 0.68, 0.57 and 0.62) (**chapter 3**). This means that answers on the 'comparison' questions are more or less consistent over time, which seems to indicate that persons with SCI are able to recall their life satisfaction from several years before.

## Loss to follow-up

In a longitudinal study, loss to follow-up is inevitable. With regard to the life satisfaction scores, our loss to follow-up at five years discharge was 28%. This is fairly within the acceptable range of loss to follow-up: (20–50%).[44] Loss to follow-up is expected to be higher in a physically demanding peak wheelchair exercise test. Only 58% of the patients had two or more wheelchair exercise capacity measurements and were included in the analyses of **chapters 4, 5 and 6**, implicating a loss to follow-up of 42%, which is still acceptable.[44] Determinants of loss to follow-up found in literature are older age, lower income, poorer health, the nature of the test, perceived benefit of the test, degree of inconvenience of the test and ability to trace and contact subjects.[44,45] During our follow-up until five years after discharge, 30 persons died, 17 refused to collaborate, 5 moved, 10 were untraceable and 20 had other or unknown reasons for not participating. For not attending the peak exercise test by persons who did collaborate in the other measures at the testing day, we registered a wide variety of reasons, most of them were health related, like suffering from pain or acute or recently sustained infections. My impression is that for some persons performing a peak exercise test just might be a very 'annoying thing to do', but others might have feared a possibly disappointing outcome with expressed restrictions due to their disability.

The relatively high drop out of the older persons with tetraplegia during the study, and especially in the peak exercise test, might have resulted in an overestimation of the figures of life satisfaction and wheelchair exercise capacity after SCI. Age and severity of injury often are predictors of lower physical fitness and of drop-out.[30] We however used the statistical techniques that are recommended in this situation.[43] Random coefficient analysis[43] was used to study the course of life satisfaction and wheelchair exercise capacity. The most important advantage of this technique is that the number of observations per person and the temporal spacing of these observations can vary, so that the maximum possible number of respondents can be used in the analyses. Moreover, this method considers dependency of repeated measures within the same person and corrects for possible differences between rehabilitation centres. The latent class growth mixture model[46] has in addition the advantage of capturing heterogeneity in the course of wheelchair exercise capacity by defining subgroups with a unique trajectory.

One could argue that in using these techniques we could have included persons with only one life satisfaction or wheelchair exercise capacity score during follow-up, but this seemed too speculative to us. We found our approach to be valid, because unpublished analyses revealed no differences for the course of wheelchair exercise capacity and life satisfaction between an analysis including the group with one or more peak exercise tests during follow-up and the analysis including the group with two or more tests.

Because of the advantages mentioned above, the multilevel analyses and latent class growth mixture modelling gave us a more differentiated look on our data. There are sufficient articles available which clearly show that modern techniques lead to more reliable results[43,46] and we therefore should embrace these analyses.

## CONSIDERATIONS FOR FUTURE RESEARCH

Literature on quality of life in SCI revealed a great diversity in measures of quality of life and study designs (**chapter 2**), and illustrates that future research on this topic should be critical of and precise in its terminology and use of the measure instruments.[6,12]

The large majority of published studies on the course of wheelchair exercise capacity and life satisfaction are from the United States and Europe and we recommend performing comparable longitudinal studies in countries elsewhere in the world. These longitudinal studies should incorporate large samples and start preferably shortly after onset of SCI, because little knowledge exist on the situation and possible changes early after SCI.

Because in our study only wheelchair-dependent persons with SCI were included, we recommend a longitudinal study including SCI patients with walking abilities, to complete our view on the total SCI population.

Comparisons with follow-up studies in other neurological conditions should be performed, to better understand similarities and differences between trajectories in the course of (wheelchair) exercise capacity and life satisfaction.

We want to emphasise that a peak exercise test is the golden standard in measuring exercise capacity in a wheelchair dependent population and we plead for international standardisation of the wheelchair exercise test protocols.

Due to the enormous diversity in functional outcome and therefore in aerobic potential in persons with SCI, the results of a peak wheelchair exercise test are hard to interpret. Hence, we recommend an update of Valent's systematic review and meta-analysis[47] on all available internationally published figures on wheelchair exercise capacity to provide normative values for all levels and types of spinal cord lesions, disaggregated by age and sex.

For persons with SCI, physical training studies with the highest methodological quality are requested, preferable randomized controlled trials in the early recovery phase and after discharge of inpatient rehabilitation in order to balance the benefits of improved exercise capacity with the adverse effects of training, like overuse injuries.

The effects of these interventions on the short- and long-term need to be studied in terms of the ICF classification and quality of life. It is encouraging that recently a new research program in the Netherlands, ALLRISC (www.scionn.nl), has started that focuses on inactive lifestyles, de-conditioning, secondary complications and quality of life in people aging with SCI.

# CLINICAL IMPLICATIONS

## Life-long patient monitoring

Our study results imply that persons with a SCI in the Netherlands have acceptable figures of wheelchair exercise capacity and life satisfaction (**chapters 2-6**) and that these two entities are positively related. These findings are encouraging, but nevertheless we want to emphasize that both figures are lower than those in the general population[25] (**chapter 5**) and in our studies on different trajectories in wheelchair exercise capacity (**chapter 5**) and life satisfaction,[8] classes with low and deteriorating figures of both entities were identified.

To my opinion our study emphasised the need for lifelong medical follow-up of persons with SCI, a devastating condition with lifelong consequences on the ICF domains Function, Activities, Participation and Life Satisfaction (Figure 7.1). People need to be monitored during inpatient rehabilitation in order to accurately measure the different components of physical and mental recovery and match the results with the individual rehabilitation goals.

Outside the safe and well-organised rehabilitation settings patients may find the environment not adapted to their needs, which could eventually influence their overall functioning. Low exercise capacity and low life satisfaction might lead to a noticeable decline in functioning and an increase in morbidity, hospital or rehabilitation admissions, and costs attributable to health care or loss of productivity.[24,48] Rehabilitation professionals need to be aware of these cumulative effects over time and, in anticipation of potential decline persons with SCI should be life-long monitored.

All persons should be screened on wheelchair exercise capacity and life satisfaction *during inpatient rehabilitation*. Life satisfaction questionnaires can be used as a direct psychological instrument during and after rehabilitation, but the results can also give direction in goal setting in rehabilitation and life after rehabilitation. People with low or declining life satisfaction scores during (and after inpatient rehabilitation), should be protected for ongoing deterioration with appropriate psychological counselling.

We recommend assessment of psychological functioning early in rehabilitation and, if applicable, psychological intervention targeted on, for example, dysfunctional coping strategies, to strengthen personal resources and the social network of persons with SCI, all in order to improve psychological functioning and life satisfaction.[26,49,50]

Satisfaction with sexual life after SCI was very low in our cohort, so to our opinion sexual life must be questioned in follow-up situations with respect to potential counselling interventions.[50]

A consulting sexologist should be available to every SCI rehabilitation team during and after inpatient rehabilitation.

Pain and secondary impairments were determinants for low life satisfaction and have negative influence on wheelchair exercise capacity and should be monitored and treated adequately in multidisciplinary setting in in- and outpatient rehabilitation. Promising effects in an intensive

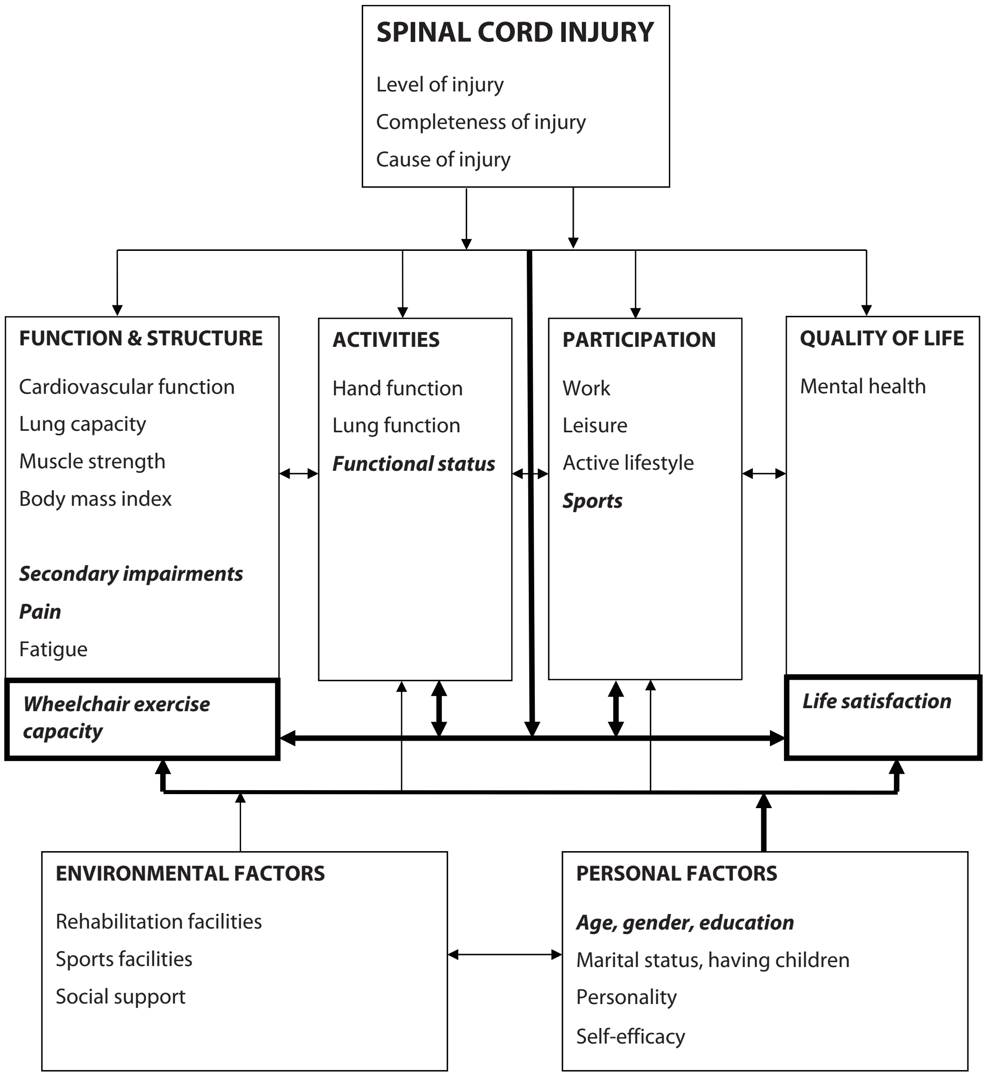


**Figure 7.1** Spinal cord injury and impact on one's life based on the WHO ICF model modulated by Post and Noreau.[60] Relations studied in this thesis are presented in bold arrows. Bold italic characteristics are significant determinants of wheelchair exercise capacity and/or life satisfaction.

exercise program for both musculoskeletal and neuropathic pain were recently published,[31] which might kill two birds with one stone: people decrease their pain levels by improving their wheelchair exercise capacity, and this most probably results in improvement of life satisfaction in two ways.

The influence of functional status on wheelchair exercise capacity and life satisfaction prompts the relevance of training people to the highest possible level of functioning.[52]

Also in *aftercare* in SCI, it is important to detect the *persons at risk* for low figures of wheelchair exercise capacity and life satisfaction. This follow-up should include a peak wheelchair exercise test and a life satisfaction questionnaire, in addition to the regular SCI specific medical history, physical examination and additional assessments as an ultrasound of the urinary tract. For persons who are not capable or willing to attend a peak exercise test, at least their (sports) activities should be monitored. For follow-up care we recommend SCI valid questionnaires like the PASIPD or the UAL.[53,54]

Effective strategies of exercise programs in the non SCI population as supervision, loaning equipment, frequent contact with program staff, inclusion of behavioural component, promotion of moderate intensive activity and maintenance interventions, should be incorporated in stimulation programs in in- and outpatient rehabilitation.[55]

Persons with a SCI need to cope with many social en physical barriers in their life when they reintegrate in society.[56] Sports facilities and exercise practice are scarce for the disabled persons and often in accessible and most people are dependent on others.[57] In a flat country as the Netherlands, handbiking is a relative simple and independent way to cope with logistic and surrounding obstacles. Moreover, it is less stressful for the shoulder in comparison to hand rim wheelchair propulsion and should be suggested to incorporate in daily life activities.[19,58]

As a clinician, I certainly keep in mind the individual patterns of recovery of wheelchair exercise capacity and life satisfaction, whereas statistics show means and conceal individual differences. This unique person in my examination room has his unique functional outcome of SCI with his own unique recovery of wheelchair exercise capacity and life satisfaction, in relation to his unique co-morbidity, his unique personality, education level, work and hobbies and unique social environment, which altogether is influenced by his own unique life circumstances and events and, therefore, this patient will most probably not exactly fit in our mean statistic results (Figure 7.1). However, this thesis provides insight in the expected recovery patterns of wheelchair exercise capacity and life satisfaction and enables us to interpret the level of recovery and potential stretch in recovery possibilities of our individual patient. It gives us the ability to medically intervene on modifiable factors like secondary impairments, pain and activity levels in order to improve recovery of both wheelchair exercise capacity and life satisfaction.

Supported by convincing arguments in current literature, considering the sedentary lifestyle that is more profound in SCI population than in general population and other disabilities[32] and in respect of the potential overload of the shoulder muscles, I strongly recommend rehabilitation professionals to stimulate persons with SCI to adapt an active lifestyle in order to maintain adequate levels of exercise capacity and prevent secondary complications and long-term health consequences of a low exercise capacity. Specifically, in the perspective of the large loss to follow-up of the older persons with tetraplegia in our study, it might be suggested to give these persons an intense and long medical supervision, as well as a structural follow-up rehabilitation opportunity in combination with exercise recommendations.

### Healthy lifestyle

This altogether rises the question how we should interpret the literature and our findings. Should a more intensive training regime be incorporated in inpatient and outpatient rehabilitation and should all efforts to provide adequate sports facilities in society for disabled persons be displayed? Should we propagate to the local and national governments to invest in these objects? Being a sports and rehabilitation physician, working in a system of reactivating all our patients as core business, it is my natural reflex to answer this question with a 'yes we do!' and I fully support the slogan of the ACSM that "exercise is medicine".[17] Nevertheless, I acknowledge that "strenuous exercise in order to obtain a healthy body" is not everybody's adage in life and obtaining a healthy body is not per definition reserved for people engaging in strenuous exercise per se. One might argue that leading a healthy lifestyle means being physically and mentally active during the day, eating and drinking healthy food, sleep well, not smoking and not having any stress, rather than participate in intensive sports training twice a week for 1.5 hours.

As we know many roads lead to Rome, but our propagated "active lifestyle-road" is at least a properly evidence-based and a medically acceptably one. And *when we finally reach Rome, we do as the Romans do* and we will find out whether "mens sana in corpore sano" stated by Juvenalis in the first century AD, still is applicable or is a vanity of human wishes for persons with SCI.[59]

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# Summary

A spinal cord injury is an interruption of the neural pathways from the brains to the lower parts of the body directly resulting in muscle weakness, loss of sensation and autonomic dysfunction below the level of the lesion. The extent of these neurological deficits is determined by both the level and completeness of the lesion. Loss of motor function leads to hand and arm dysfunctions, stability problems of the trunk and mobility changes of the lower limbs, varying from fully paralysed to light walking disturbances. Loss of sensory functions in the abdomen is followed by disruptions in bladder and bowel functions and sexual functions. The impact of the loss of the autonomic regulation for the cardiovascular system, amongst others leading to lower exercise capacity, is most obvious in persons with lesions above the level of thoracal vertebra 6. In addition, secondary complications are common in persons with spinal cord injury, including pressure sores, urinary tract infections, pulmonary infections, neurogenic heterotopic ossification, oedema, hypotension, autonomic dysregulation, spasticity and pain. This altogether has an enormous impact on daily life activities, participation in society and quality of life, central issues in spinal cord injury rehabilitation. Although spinal cord injury is studied extensively, there still is no cure for this condition.

In this thesis findings of the Umbrella study (from start of active rehabilitation up to one year after discharge) and SPIQUE study (SPinal cord Injury QUality of life Evaluation, five years after discharge) are presented. This thesis focuses on the impact of wheelchair exercise capacity, life satisfaction and their mutual relationships over time from the start of active rehabilitation up to five years after discharge of inpatient rehabilitation.

In **chapter 1** an overview was given of the context of this thesis. The health condition spinal cord injury and its accompanying health complications were described. The International Classification of Functioning, Disability and Health was introduced with respect to a spinal cord injury. The consequences of a spinal cord injury on wheelchair exercise capacity and life satisfaction were discussed. Furthermore, the research context of this thesis was described and finally the main aims and the outline of this thesis were specified.

## Life satisfaction

The results of **chapter 2** showed a marked decrease in life satisfaction of persons with spinal cord injury at one year after discharge from inpatient rehabilitation, compared to the general population and compared to their own life satisfaction before spinal cord injury, retrospectively reported early in inpatient rehabilitation. A retrospective measurement is speculative and under pressure of potential glorification of one's life before spinal cord injury, but to our opinion a combination of the current life satisfaction with the comparison question gives more insight in the real values of life satisfaction and is better capable of measuring adaptation.

Decrease of life satisfaction was strongest for the domains Sexual life, Self care and Vocational situation. Partner relations, Family life and Contacts with friends and acquaintances appeared the least affected life domains. Age, gender and education had little influence on life satisfaction after spinal cord injury or change of life satisfaction. High level of lesion, suffering from pain and from secondary impairments were associated with a decrease of life satisfaction and with low life satisfaction one year after discharge.

The results of **chapter 3** showed that life satisfaction improved during inpatient rehabilitation, especially during the first 3 months of active rehabilitation and remained stable during the first year after discharge. Having few pain sensations and a low number of other secondary impairments and having a better functional status were predictors of a more favourable course of life satisfaction early after spinal cord injury. This was a confirmation of cross-sectional and the sparse longitudinal literature on this topic. Pain and secondary impairments should be treated adequately in a multidisciplinary setting in in- and outpatient rehabilitation. The influence of functional status on life satisfaction prompts the relevance of training people to the highest possible level of functioning. We found, like other authors, moderate to strong associations between life satisfaction scores on the first measurement (start of active rehabilitation) and last measurement (one year after discharge of inpatient rehabilitation), suggesting long-lasting consequences of low life satisfaction early after spinal cord injury. Adaptation to a severe disability as spinal cord injury is a multi-faceted process that varies for every person involved.

## Wheelchair exercise capacity

**Chapters 4 and 5** of this thesis described the course of wheelchair exercise between the start of active rehabilitation and 5 years after discharge and explained how changes in wheelchair exercise capacity should be interpreted.

Our results in **chapter 4** were showed that no significant changes in mean wheelchair exercise capacity were found between discharge and five years later. This stabilisation of wheelchair exercise capacity after an increase during inpatient rehabilitation is in contrast with literature and the expectations that the peak oxygen uptake will diminish over time, because of ageing and because of an insufficient daily life activity level of persons with spinal cord injury to maintain adequate levels of wheelchair exercise capacity. No significant determinants for the course of wheelchair exercise capacity in the one to five year interval were detected. Again age, gender, level and completeness of lesion were determinants for peak oxygen uptake and level of lesion and gender for peak power output, a confirmation of other international studies. The loss to follow up-group was older of age and included more persons with tetraplegia, probably leading to a slight overestimation of the model outcome for wheelchair exercise capacity.

Although it is useful to obtain insight in the overall recovery of wheelchair exercise capacity after spinal cord injury for the study group as a whole, this may conceal distinct routes (trajectories) of recovery of wheelchair exercise capacity in smaller subgroups of the population. Insight in these trajectories offers opportunities to understand how persons differ in their physical adaptation to a spinal cord injury, and to find possible risk factors for persistent low or decreasing levels of wheelchair exercise capacity. **Chapter 5** confirmed that different wheelchair exercise capacity trajectories exist after spinal cord injury. A contemporary statistical method, latent class growth mixture modelling, was used to unravel possible trajectories in wheelchair exercise capacity over time. We found four different trajectories in the course of peak power output: 1) high progressive scores; 2) deteriorating scores: progressive scores during inpatient rehabilitation with deteriorating figures after discharge; 3) low progressive scores: low scores at start of rehabilitation with relative strong progressive scores after discharge; and 4) low inpatient scores with very strong progressive scores after discharge. Similar trajectories were found for peak oxygen uptake. Logistic regression of factors that might be distinctive between the two largest trajectory classes, high progressive scores and low progressive scores, revealed that older age, female gender, tetraplegic lesion and low functional status were associated with the class with low progressive scores. Ageing leads to lower peak power output and females have lower peak power output than men, due to their lower lean body masses. Persons with tetraplegia have few functional muscle groups available and less sympathetic control of the cardiovascular system to cope with the exercise demands.

The trajectory with high progressive scores showed the most recovery in exercise capacity, which might be due to a relatively large number of males with a paraplegic lesion with relatively high functional independence. The short length of rehabilitation of this class is related to the lower severity of lesion and the higher functional independence. The class with the deteriorating scores after discharge of inpatient rehabilitation was too small to statistically compare with the larger classes, nevertheless the descriptive figures showed that these persons should have been clustered in the high progressive trajectory based on gender, age and level of lesion. Yet, persons in this deteriorating trajectory showed high levels of pain and low levels of sports activity, potentially explaining the deteriorating figures of wheelchair exercise capacity, possibly caused by a debilitative cycle of inactivity – pain – inactivity – lower exercise capacity – pain – etc. The results of the analyses suggest that physical adaptation to a severe disability like spinal cord injury is a multi-faceted process that varies between subgroups.

## Relationships between wheelchair exercise capacity and life satisfaction

In **chapter 6** we examined the mutual relation between wheelchair exercise capacity and life satisfaction. Wheelchair exercise capacity and life satisfaction in spinal cord injury population are longitudinally associated up to five years after discharge of inpatient rehabilitation: an improvement in exercise capacity with 10 Watt is associated with an improvement in life satisfaction with 0.3 points on a 1-6 scale. Further analyses revealed that the relationship between exercise capacity and life satisfaction was mainly based on the within-subject variance instead of between-subject variance. This suggests that persons who are able to improve their physical fitness might expect an improvement of their life satisfaction.

A moderate improvement in peak power output with 10W, that implies an Effect Size (ES) of (10/17=) 0.59, leads to a small improvement of (0.3/2.2=) 0.14 ES in life satisfaction. This might not seem clinically relevant. However, life satisfaction is a multidirectional influenced entity and dependent also on genetic influences and socio-economic factors as financial resources, economical and political stability. Furthermore, spinal cord injury-related physical factors such as pain, secondary impairments and low functional status, and psychosocial factors as personality, appraisals, social support and self-efficacy are all predictors of life satisfaction. In this context it is encouraging that a significant relationship between wheelchair exercise capacity and life satisfaction was found. Up to 20% improvement in peak oxygen uptake and peak power output can be achieved in persons with spinal cord injury by correct training regimes, and the amount of consequential improvement in life satisfaction is comparable to a positive major life event like marriage. Hence, in the perspective of life satisfaction being an important outcome in rehabilitation, our results might eventually be considered as clinically relevant.

Finally, **chapter 7** summarized the general aim and main findings of this study. Subsequently we addressed theoretical and methodological considerations related to the study design, the outcomes measures and statistical analyses used in this thesis. We aimed to translate the findings of this thesis into research recommendations and clinical implications.

# Samenvatting

Een dwarslaesie is een gehele of gedeeltelijke beschadiging van het ruggenmerg en leidt tot vermindering van spierkracht, sensibiliteit en dysfunctie van het autonome zenuwstelsel. Verlies van spierkracht leidt tot vermindering van de arm-handfunctie, de rompstabiliteit en de loopfunctie. Verlies van de sensibiliteit leidt tot blaas-, darm- en sexualiteitsproblemen. De impact van het verlies in autonome sturing van het cardiovasculaire systeem wordt vooral terug gezien bij mensen met een hoge dwarslaesie boven de $6^{e}$ thoracale wervel, zich uitend in onder andere een verminderde inspanningstolerantie. Daarnaast leidt een dwarslaesie veelal tot secundaire stoornissen, waaronder decubitus, urineweginfecties, bovenste luchtweginfecties, neurogene heterotope ossificaties, oedemen, hypotensie, autonome dysregulatie, spasticiteit en pijn. Dit alles heeft een enorme impact op activiteiten in het dagelijks leven, de zelfredzaamheid, participatie in de maatschappij en de uiteindelijke kwaliteit van leven, oftewel het welbevinden. Ondanks dat er veel onderzoek gedaan is en wordt naar de pathologie van de dwarslaesie is er nog steeds geen remedie gevonden.

In dit proefschrift worden de resultaten van het Koepelproject (van start van actieve revalidatie tot 1 jaar na ontslag) gepresenteerd en van het vervolg daarop, het SPIQUE project (SPinal cord Injury QUality of life Evaluation), tot vijf jaar na ontslag uit de kliniek. Dit proefschrift focust op het beloop van de inspanningscapaciteit in de rolstoel, het welbevinden van mensen met een dwarslaesie en de onderlinge relatie van de inspanningscapaciteit en het welbevinden, van start van actieve revalidatie tot 5 jaar na ontslag uit de kliniek.

In **hoofdstuk 1** werd een overzicht gegeven van de samenhang van dit proefschrift. De gezondheidstoestand 'dwarslaesie' en de consequenties daarvan werden beschreven in het kader van de Internationale Classificatie van Functie, Handicap en Gezondheid van de Wereldgezondheidsorganisatie. De consequenties van de dwarslaesie voor de inspanningscapaciteit in de rolstoel en het welbevinden werden geschetst. Verder werd de onderzoekscontext van dit proefschrift beschreven en werden uiteindelijk de doelstellingen van dit proefschrift gespecificeerd.

## Welbevinden

De resultaten van **hoofdstuk 2** lieten een duidelijke vermindering van het welbevinden van personen met een dwarslaesie zien op 1 jaar na ontslag uit de klinische revalidatie, vergeleken met de algemene bevolking en vergeleken met het leven voor de dwarslaesie, retrospectief gemeten tijdens de actieve klinische revalidatie. Een retrospectieve meting is mogelijk onder invloed van potentiële glorificatie van het leven voor een dwarslaesie. Echter, naar onze mening geeft een combinatie van vragen naar het huidige welbevinden en dat in vergelijking met het leven van voor de dwarslaesie het beste inzicht in het welbevinden en daarmee in de werkelijke adaptatie aan het nieuwe leven met een dwarslaesie.

Vermindering van het welbevinden was het grootst voor de domeinen Seksueel leven, Zelfzorg en Beroepssituatie. Partnerrelaties, Familieleven en Contact met vrienden waren de minst aangedane domeinen. Leeftijd, geslacht en opleidingsniveau hadden een geringe invloed op het welbevinden na een dwarslaesie en op de verandering van het welbevinden. De hoogte van de dwarslaesie, het hebben van pijn en andere secundaire stoornissen waren geassocieerd met een vermindering van het welbevinden en met een laag welbevinden een jaar na ontslag uit de klinische revalidatie.

De resultaten van **hoofdstuk 3** lieten zien dat het welbevinden van onze deelnemers verbeterde tijdens de klinische revalidatie, vooral in de eerste 3 maanden na de start, en stabiel bleef tijdens het eerste jaar na ontslag. Het hebben van weinig pijn en weinig andere secundaire stoornissen en een betere functionele status waren voorspellers van een positiever beloop van het welbevinden in de vroege fase na het ontstaan van een dwarslaesie. Dit was een bevestiging van de cross-sectionele en de schaarse longitudinale literatuur over dit onderwerp. Pijn en secundaire stoornissen moeten daarom adequaat worden behandeld in een multidisciplinaire setting in de klinische en poliklinische revalidatiefase. De invloed van de functionele status op het welbevinden onderstreepte dat het noodzakelijk is mensen op een zo hoog mogelijk niveau van functioneren te trainen. De sterke associaties tussen welbevinden tijdens de eerste en laatste metingen wekten de suggestie dat er al in het begin van de revalidatie aanwijzingen zijn voor langdurende consequenties van de dwarslaesie op het welbevinden. Een psychologische evaluatie vroeg in de revalidatiefase lijkt wenselijk, met indien nodig een psychologische interventie gericht op, bijvoorbeeld, disfunctionele copingstrategieën om het psychologische functioneren en welbevinden te verbeteren.

## Inspanningscapaciteit in de rolstoel

**Hoofdstuk 4 en 5** van dit proefschrift beschreven het beloop van de inspanningscapaciteit in de rolstoel (piek vermogen en piek zuurstofopname) tussen de start van actieve revalidatie en vijf jaar na het ontslag en verklaarden hoe de veranderingen in de inspanningscapaciteit in de rolstoel moeten worden geduid.

Onze resultaten in **hoofdstuk 4** waren gebaseerd op een follow-up tot vijf jaar na ontslag uit de kliniek. Er werden geen significante veranderingen in inspanningscapaciteit in de rolstoel tussen 1 en 5 jaar na ontslag gevonden. Deze stabilisatie van inspanningscapaciteit in de rolstoel is in relatieve contradictie met de literatuur en de verwachting dat de inspanningscapaciteit vermindert over de tijd, vanwege het verouderingsproces en omdat aangenomen wordt dat de dagelijkse bezigheden van iemand in een rolstoel onvoldoende zijn om een adequaat niveau van fitheid te behouden. Er werden geen significante determinanten gevonden voor het beloop van inspanningscapaciteit in de rolstoel tussen 1 en 5 jaar na ontslag uit de kliniek. Wederom waren leeftijd, geslacht, hoogte en compleetheid van de laesie determinanten voor de waarden van de piek zuurstofopname en hoogte van de laesie en geslacht voor de waarden van het piek vermogen, een bevestiging van andere internationale studies. De 'loss to follow-up'-groep was ouder en bevatte meer personen met een tetraplegie, hoogstwaarschijnlijk leidend tot een overschatting van de uitkomst van de inspanningscapaciteit in de rolstoel.

Hoewel het zinvol is om het herstel van de inspanningscapaciteit in de rolstoel voor de hele populatie in kaart te brengen, kan dit verhullen dat er verschillende trajecten van herstel zijn van de inspanningscapaciteit in de rolstoel. Inzicht in deze trajecten kan leiden tot beter inzicht in de fysieke aanpassing van individuen, en beter inzicht in de risicofactoren voor persisterende lage of verslechterende scores van inspanningscapaciteit in de rolstoel. In **hoofdstuk 5** werd een moderne statistische methode, latent class growth mixture modelling, gebruikt om het beloop van inspanningscapaciteit in de rolstoel over de tijd in kaart te brengen. Wij vonden vier verschillende trajecten in het beloop van het piek vermogen: 1) hoge progressieve scores; 2) achteruitgang in scores: verbeterende scores tijdens de klinische revalidatie en achteruitgang na ontslag; 3) lage scores bij de start van actieve revalidatie met relatieve sterke progressie na ontslag; en 4) lage scores tijdens de klinische fase en fors herstel na ontslag. Vergelijkbare trajecten werden gevonden in het beloop van de piek maximale zuurstofopname.

Logistische regressieanalyses van de factoren die mogelijk onderscheidend zijn tussen de twee trajecten met de meeste deelnemers (de hoge en lage progressieve scores), lieten zien dat hogere leeftijd, vrouwelijk geslacht, tetraplegie en lage functionele status geassocieerd werden met het traject met laag-progressieve waarden. De piek zuurstofopname vermindert na het twintigste levensjaar geleidelijk. Vrouwen hebben een lagere piek zuurstofopname dan mannen, ten gevolge van hun kleinere spieromvang. Mensen met een tetraplegie hebben minder functionele spiergroepen en minder orthosympatische controle over het cardiovasculaire systeem om te voldoen aan de inspanningsbehoeften.

Het traject met de verslechterende waarden was te klein om zuiver statistisch te vergelijken met de andere trajecten. Desalniettemin lieten de beschrijvende scores zien dat deze personen op basis van leeftijd, geslacht en ernst van de dwarslaesie eigenlijk in de hoog-progressieve klasse hadden behoren te zijn ingedeeld. Een verklaring voor de achteruitgang van de inspanningscapaciteit ligt mogelijk in het feit dat deze mensen meer (neuropathische) pijn vertoonden en ook veel minder actief in sport waren. Mogelijk is hier sprake van een zogenaamde vicieuze cirkel van inactiviteit – pijn – inactiviteit – lagere inspanningscapaciteit – pijn – etc.

De resultaten van de analyses in hoofdstuk 5 suggereerden dat fysieke adaptatie aan een ernstige aandoening als een dwarslaesie een multidimensioneel beïnvloed proces is dat varieert tussen subgroepen.

## Relatie tussen inspanningscapaciteit in de rolstoel en welbevinden

In **hoofdstuk 6** onderzochten we de wederzijdse relatie tussen inspanningscapaciteit in de rolstoel en welbevinden. Deze twee grootheden zijn longitudinaal geassocieerd tot vijf jaar na ontslag: een verbetering van 10 W in het vermogen hangt samen met een verbetering van 0.3 punten op een schaal van 1-6 in welbevinden. Nadere analyse wees uit dat deze relatie voornamelijk gebaseerd was op de 'binnen-proefpersoon'-variatie in plaats van de 'tussen-proefpersoon'-variatie. Dit suggereert dat personen met een dwarslaesie die in staat zijn hun fitheid te verbeteren, ook een verbetering van het welbevinden kunnen bewerkstelligen.

Een lichte verbetering van het piek vermogen met 10 W impliceert een effect size van 0.59 en leidt tot een geringe verbetering van het welbevinden met 0.3, een effect size van 0.14. Dit laatste lijkt klinisch irrelevant. Echter, het welbevinden is een multifactorieel bepaalde entiteit zoals we weten en afhankelijk van genenpatroon, omgevingsfactoren, financiële bronnen en economische en politieke stabiliteit. Verder zijn aan dwarslaesie gerelateerde factoren als pijn, secondaire stoornissen, lage functionele status en psychosociale factoren als persoonlijkheid, sociale steun, zelfredzaamheid en oordeelvorming, alle determinanten van het welbevinden. In dit licht is het toch bemoedigend dat er een significante relatie bestaat tussen fitheid en welbevinden. We weten dat een verbetering van 20% van de fitheid bewerkstelligd kan worden bij mensen met een dwarslaesie met correcte trainingsregimes. Dit effect op het welbevinden is te vergelijken met dat van het sluiten van een huwelijk. In dit licht bezien en gezien het feit dat het welbevinden een steeds belangrijkere uitkomstmaat is van revalidatieprogramma's, lijken onze bevindingen toch klinisch relevant, en zijn er genoeg argumenten aan te voeren om de boodschap van het aanleren van een actieve levensstijl ten einde de inspanningscapaciteit en het welbevinden positief te beïnvloeden, te blijven verkondigen.

**Hoofdstuk 7** vat de belangrijkste bevindingen samen en theoretische, methodologische overwegingen evenals onderzoeksaanbevelingen en klinische relevantie worden bediscussieerd.

# Dankwoord

Tekst.

# About the author

# CURRICULUM VITAE

Casper van Koppenhagen, was born on May 16 1970 in Arnhem, the Netherlands. He obtained his "VWO" at the Thorbecke Scholengemeenschap Arnhem in 1989. In 1989 he started his study Medicine at Utrecht University, and obtained his Medical Degree in 1997. His first job as a physician was at the Department of Pulmonology of Medisch Spectrum Twente, Enschede. He commenced his specialisation Sports Medicine in 1998, and between 1998 and 2002 he worked as a resident at the Departments of Cardiology, Traumatology and Sports medicine in Weezenlanden Hospital Zwolle, Sophia Hospital Zwolle, Maxima Centre Veldhoven, St Anna Healthcare Geldrop, the Sports medicine Centre of the Dutch Royal Football Association, and professional football clubs V.V.V. Venlo and Vitesse Arnhem. Casper finished his specialization in Sports Medicine in 2002. Thereafter he worked as a sports physician for Physique BV and Rijnstate Hospital Arnhem, Department of Sports Medicine. In 2004 he shifted to Physical Medicine and Rehabilitation and from 2004–2005 he worked as a resident at Rehabilitation Centre Groot Klimmendaal Arnhem, before obtaining a Physical Medicine and Rehabilitation specialisation residency in Rehabilitation Centre De Hoogstraat, Utrecht.

In 2006, Casper started on the SPIQUE project as a PhD student at the Centre of Excellence of De Hoogstraat , with a stipendium of ZonMw. In 2009 he was awarded the Livit Orthopedie Award "Most promising trainee in Rehabilitation Medicine." In 2010, Casper finished his specialisation in Rehabilitation Medicine, and moved to Switzerland to work in the specialized spinal cord rehabilitation hospital "Swiss Paraplegic Centre", Nottwil, Switzerland. Since September 2012 he works as a rehabilitation physiatrist at the spinal cord unit of Rehabilitation Centre De Hoogstraat, Utrecht.

In 1991 Casper and four friends set up the Utrecht Student Soccer Club Odysseus '91. He was the first chairman. In 2006 he authored and published a satirical soccer thriller "Bram Breedveld, Spits van Oranje".

Casper is married to Laura Soudijn-van Koppenhagen. Their two sons Lennard Floris (★2004) and Simon Koen (★2005) both died shortly after birth due to a congenital disorder.

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