Secondary health conditions in long-term spinal cord injury

Jacinthe Adriaansen

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Secondary health conditions in long-term spinal cord injury

Secundaire gezondheidsproblemen bij een dwarslaesie op de lange termijn

(met een samenvatting in het Nederlands)

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Contents

Chapter 1

General introduction

In this general introduction, an overview is given of the context of this thesis. The health condition spinal cord injury and its accompanying health complications are described. The current care of aging spinal cord injured people living in the Netherlands is outlined. Further, the research context of this thesis is described, and finally the main aims and the outline of this thesis are specified.

Spinal cord injury

Spinal cord injury (SCI) is an insult to the spinal cord resulting in a change, either temporary or permanent, in the cord's normal motor, sensory, or autonomic function.[1] People with SCI usually have permanent and often devastating neurologic deficits and disability. The neurological level and completeness of the injury determine the degree of impairment. The SCI level is roughly divided into tetraplegia and paraplegia. Tetraplegia refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord.[2] Tetraplegia results in impairment of function in all four extremities, the trunk, and pelvic organs. Paraplegia refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral segments of the spinal cord.[2] With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved.

The American Spinal Injury Association (ASIA) Impairment Scale (AIS) classifies SCI into five categories of severity, labelled A through E, based on the degree of motor and sensory loss (Table 1.1).[2] A complete injury is defined as an injury in which there is a lack of any sensory or motor function in the lowest sacral segment (S4–S5), i.e. AIS category A. An incomplete

Table 1.1 ASIA Impairment Scale[2]

A = Complete	No motor or sensory function is preserved in the sacral segments S4–S5.
B = Sensory incomplete	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5, AND no motor function is preserved more than three levels below the motor level on either side of the body.
C = Motor incomplete	Motor function is preserved below the neurological level, and more than half of the key muscles below that neurological level have a muscle grade less than 3.
D = Motor incomplete	Motor function is preserved below the neurological level, and at least half of the key muscles below that neurological level have a muscle grade of 3 or more.
E = Normal	Motor and sensory function are normal.

injury is defined as an injury in which there is at least partial sensory or motor function in the lowest sacral segment (S4–S5). AIS categories B through E designate incomplete injuries.

Epidemiology

It is unclear how many people are currently living with SCI in the world, but the international incidence data of 40 to 80 new cases per million population per year suggest that every year between 250 000 and 500 000 people become spinal cord injured.[3] The majority of these cases are traumatic spinal cord injuries, the leading causes of which are road traffic injuries, falls and violence.[4] Recent studies show an increase in the age of SCI onset and a gradual increase in the proportion of non-traumatic SCI cases, partly attributable to the world's aging population.[3] In a previous research among 11 Dutch and Flemish rehabilitation centres with a specialty in SCI rehabilitation, 55% of admitted patients with SCI had a non-traumatic lesion.[4] Non-traumatic causes were vascular diseases (28%), spinal degeneration (26%), inflammation (17%), malignant tumour (17%), benign tumour (11%), and other causes (1%).[4]

With an estimated incidence of traumatic spinal cord injuries surviving the acute phase of 11.7 per million citizens per year, the Netherlands have a relatively low incidence of spinal cord injuries.[5] Hospital-based data showed that 75% of the people who suffer traumatic SCI were male with a median age at onset of 62 years. Almost 70% had a tetraplegia and 62% had a motor incomplete lesion. The leading causes of traumatic spinal cord injuries were falls (53%), traffic (22%) and sports incidents (14%).[5]

In the developed countries, life expectancy of people with SCI has increased since the 1950s due to improvements in clinical care and rehabilitation medicine. However, according to the Spinal Cord Injury Model Systems, life expectancies for people with traumatic SCI have not improved since the 1980s.[6] People with SCI still die earlier than people without SCI. Overall, studies have indicated that people with SCI are 2 to 5 times more likely to die prematurely than people without SCI in which the mortality risk depends on the level and severity of the injury.[3]

Secondary health conditions (SHCs)

An SCI leaves people with autonomic and somatic nervous system dysfunction, which results in lasting impairment of many organ systems. Hence, people with SCI are likely to

experience serious health problems associated with their injury. These so-called secondary health conditions (SHCs) are defined as "physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment".[7] Lots of different SHCs are related to SCI (Table 1.2).[7]

Table 1.2 A list of secondary health conditions related to SCI[8]

Secondary health condition
Cardiovascular disease
Chronic pain
Constipation
Contractures
Deep vein thrombosis/pulmonary embolism
Depression
Fractures
Heterotopic ossification
Immobilisation hypercalcemia
Insomnia/sleep difficulties
Kidney stones
Neurogenic bladder
Neurogenic bowel
Non-urinary tract infections
Obesity
Osteoporosis/bone density loss
Pressure sores
Restrictive lung disease
Septicaemia
Sexual dysfunction
Sleep apnea
Spasticity
Urinary tract infection

A number of reports have described an increasing prevalence of SHCs associated with aging in people with SCI.[8-10] There have also been several reviews summarising the impact of aging with SCI by organ system.[11-13] People with SCI report more health problems, and they do so at a younger age, than non-disabled individuals.[14]

Aging with SCI

The aging process in people with SCI may be accelerated by years of cumulative stresses due to limited mobility, inactivity, nervous system dysfunction, and increased inflammatory response.[12,15] An individual with SCI may age more quickly because of these added stresses that push some physical systems beyond their ability to repair themselves, and thus, become symptomatic. This may be seen first in tissues that undergo unusual use, such as the shoulders and the urinary tract.[11]

Taking the genitourinary system as an example, the function of the lower urinary tract has been noted to decline with age in terms of bladder capacity, the ability to postpone voiding, urethral and bladder compliance, and an increase in involuntary bladder contractions. In the individual with SCI, these lower urinary tract changes may be aggravated or accelerated by such things as years of trauma to the urethra through catheterization, bladder hypertrophy due to chronic sphincter-detrusor dyssynergia and chronic urinary tract infections.[11]

The impact of health-related changes on quality of life (QoL) in people aging with SCI is complex.[16] QoL is a multidimensional and dynamic construct that is influenced by many physical, psychosocial and environmental factors.

A consistent finding from several studies included in a review on the influence of aging with SCI on QoL was that, regardless of chronological age, people with a SCI ≤5 years post-injury have the potential to improve their overall QoL and/or various QoL domains.[17] In studies among people with a SCI of ≥6 years post-injury, overall QoL was consistently reported as good or excellent over time, but with variation in different QoL domains (e.g. employment, social life, sex life, general health).[17]

Complexities of aging and SCI in research

The complexities of aging and SCI in research are in part caused by the interaction and overlap of various age-related factors. There are four key age-related factors that are related to SCI outcomes: (1) current age, (2) age at injury, (3) time since injury (TSI) and (4) generation cohort-effects.[16,18]

These four age-related variables can have independent effects on an outcome or health condition and interact with each other to affect an outcome. Considering current age: because organ system functions decline as people age, the older a person is, the greater the

risk for health conditions such as diabetes, heart disease and osteoporosis. Age at injury is important when one considers the fact that younger adults are generally healthier and have greater physiologic "reserve capacity" than do older people. TSI can have both negative effects, such as a longer sedentary lifestyle, and positive effects, such as the experience in coping with one's SCI and greater self-efficacy.

Cohort effects can be divided into birth cohort effects (chronological age; related to year of birth) and in onset cohort effects (treatment era; related to year of injury). It reflects the social, economic and medical circumstances around a person with SCI. Medical advances in treating both SCI and related SHCs and socio-political factors such as a general increase in disability awareness are examples of environmental changes that have occurred over the past decades. Birth-cohort effects or onset-cohort effects are prone to be reflected as aging processes and may be interpreted as morbidity related to aging with SCI versus morbidity associated with treatment history.

A major issue in aging research is the so called "survivor effect". Survivor effect is a form of bias in cross-sectional and longitudinal cohort studies caused by selective dropout, meaning that participants represent only the survivors, or, more generally, those healthy enough to participate in the study.[18] Positive correlations between increasing age and outcome variables, or higher mean scores on outcome variables at later test occasions can thereby lead to an inaccurate conclusion that individuals actually improve as they age.[18]

Care for (aging) spinal cord injured people in the Netherlands

In the Netherlands there are 11 hospitals with trauma centres that are equipped for the acute care of trauma victims with SCI. Mean duration of hospital stay for traumatic SCI in the Netherlands is 24.7 days.[5] When patients are clinically stable, rehabilitation continues in a rehabilitation centre.[19] Due to the low incidence of spinal cord injuries in the Netherlands, rehabilitation is concentrated in a limited amount of rehabilitation centres so that sufficient knowledge and experience can be build and maintained. The Netherlands have eight rehabilitation centres with a specialisation in SCI. A decade ago, the mean length of stay at the rehabilitation centre was 183.3 days.[4] Length of stay was longer for people with traumatic SCI, motor complete and cervical lesions.[4]

There is a lack of national guidelines for long-term SCI care and most people with SCI are not followed life-long by a rehabilitation specialist. People with long-term SCI are more

likely to visit their general practitioner (58%) than a rehabilitation specialist (25%) in case of SHCs.[20] This might be a less desirable situation. Because of the low incidence of SCI it is unlikely that general practitioners have the expertise to manage all problems encountered in the complex care of people aging with SCI. Therefore, there is a need for more knowledge on the health status and functioning of people aging with SCI living in the Netherlands in order to be able to formulate requirements and guidelines for lifespan covering SCI care.

Research programme ALLRISC

The multicentre research programme Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC) is embedded in the Dutch SCI rehabilitation clinical research network (www.scionn.nl).[21] This well-organised network is a multicentre and multi-disciplinary collaboration among the eight Dutch rehabilitation centres with a specialised SCI unit, academic research groups, the Dutch Flemish Spinal Cord Society (DUFSCoS) and the Dutch SCI patient organisation (Dwarslaesie Organisatie Nederland (DON)). It started with The Umbrella project "Restoration of mobility in spinal cord injury rehabilitation", a prospective cohort study that mainly focused on the clinical rehabilitation phase and up to five years after discharge from inpatient rehabilitation.[22] Building upon the outcomes and experience of this previous clinical research programme, ALLRISC focused on the long-term impact of SCI on active lifestyle, fitness, health, participation and QoL, and on interventions to improve these facets in the context of lifelong rehabilitation follow-up care.[23]

The main objectives of ALLRISC are:[23]

1. To obtain a better understanding of the importance and requirements of regular rehabilitation care in the context of long-term preservation of an active lifestyle and fitness, to prevent SHCs, and to increase activities, participation, health and QoL in people aging with long-term SCI;

2. To develop evidence-based components and guidelines for an adequate SCI rehabilitation aftercare system in The Netherlands.

To meet the objectives, four studies, one cross-sectional study and three randomised controlled trials (RCTs), were conducted within this multidisciplinary multicentre collaboration of all eight Dutch rehabilitation centres with a specialty in SCI rehabilitation and four research groups (Figure 1.1). The RCTs aimed to investigate the effects of 1) a 16-week

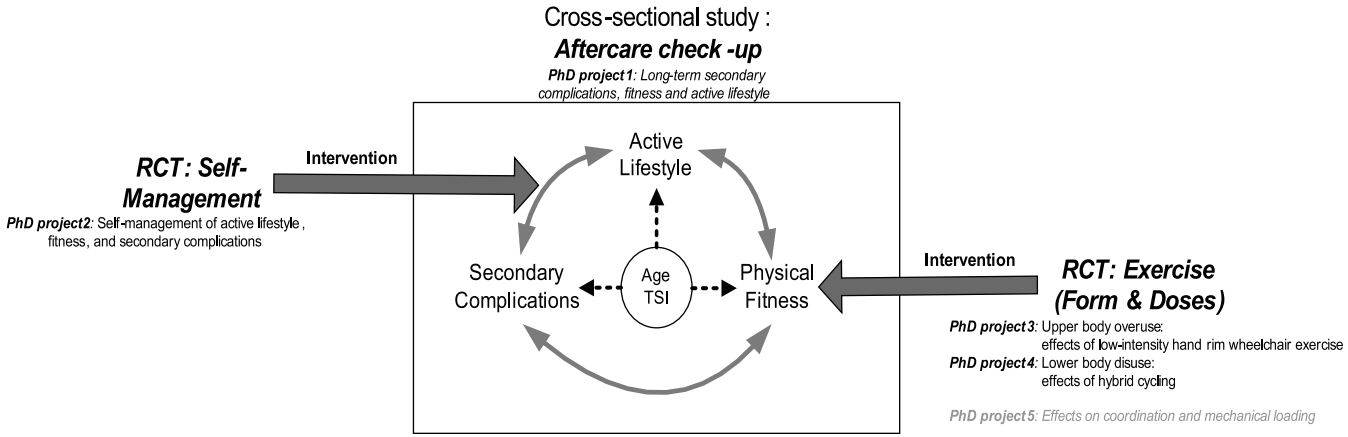

Figure 1.1 The ALLRISC programme with its four studies focusing on the assumed associations among active lifestyle, physical fitness, SHCs, age, and TSI as described for people with SCI by Van der Woude et al.[23]

self-management intervention, 2) a low-intensity wheelchair exercise intervention, and 3) a hybrid cycle exercise intervention on the programme-wide and project-specific outcome measures. The self-management intervention, performed in four of the eight Dutch rehabilitation centres with a specialty in SCI rehabilitation, focused on problem-solving ability, proactive coping, education and self-efficacy.[24] The experimental group (N=40) received individual and group teaching with counselling sessions, while the control group (N=40) only received oral and written information. The low intensity wheelchair exercise trial was performed in two other rehabilitation centres and focused on the upper-body overuse paradigm.[25] To avoid overuse of the upper-body musculoskeletal system, the intensity of exercise should not be too high in people with SCI. Therefore, a low intensity (30–40% heart rate reserve) wheelchair exercise intervention group (N=20) was evaluated and compared with a non-trained control group (N=20).[25] The third RCT, focused on the lower-body disuse paradigm with the main aim to evaluate the integrated effects of hybrid cycling (N=20) versus hand cycling (N=20) on fitness, physical activity and health related parameters (i.e. cardiovascular disease risk factors, lower-body soft tissue composition, and proximal tibia and distal femur bone mineral density) in physically inactive people with long-term SCI.[26] This study was also performed in two of the eight participating rehabilitation centres. The cross-sectional study is more extensively described in the next section.

The cross-sectional study on secondary health conditions, fitness, participation and well-being in long-term spinal cord injury

The ALLRISC cross-sectional study was a TSI-stratified study among people with long-term SCI living in the Netherlands. The design of this study will be more extensively described in Chapter 2. The study mainly focused on the prevalence and impact of several SHCs. People were included if they had a traumatic or non-traumatic SCI with a TSI of at least 10 years, an age at injury between 18 and 35 years, a current age between 28 and 65 years, and they had to be wheelchair-dependent (hand-rim propelled or electric), at least for longer distances (>500 m). People were excluded if they had insufficient mastery of the Dutch language to respond to an oral interview. Eligible people were identified through databases from all eight participating Dutch rehabilitation centres specialised in SCI rehabilitation. Since it was aimed to include 30–35 persons per centre and a response rate of around 50% was expected, 62 persons per centre were invited for the study. If the number of eligible people allowed it, a random sample per centre was drawn. If the response was less than 30–35 persons per centre an additional sample was drawn at that centre.

Participants were invited for a one-day visit to the rehabilitation centre for a check-up including an extensive medical assessment and physical examination performed by a rehabilitation physician and an oral interview and several physical tests performed by a research assistant. Two weeks before the visit to the rehabilitation centre, participants were asked to complete a self-report questionnaire.

An overview of the different concepts of outcomes of this cross-sectional study is illustrated in Chapter 2.

Aims and outline of the present thesis

The general aim of the present thesis was to describe the prevalence and impact of secondary health conditions (SHCs) in people with long-term SCI and to examine possible determinants of the presence of these SHCs. The main hypothesis was that a longer duration of injury would be associated with a higher prevalence of SHCs.

Chapter 2 of this thesis is a detailed description of the design of this multicentre cross-sectional study. **Chapter 3** describes the occurrence of different SHCs and their potential risk factors in people with SCI from 1 to 5 years post-discharge from initial inpatient rehabilitation. For this study, data from the prospective cohort study called "Restoration of mobility in spinal cord injury rehabilitation" was used.[22] **Chapter 4** describes long-term bowel management, neurogenic bowel dysfunction and associations between bowel management and experienced bowel dysfunction and satisfaction in people with long-term SCI. **Chapter 5** describes the use of different bladder-emptying methods and aims to determine differences herein for different time since injury (TSI) periods, gender, lesion level and completeness in people with long-term SCI. Furthermore, the relationship between bladder-emptying methods and the impact of neurogenic lower urinary tract dysfunction on quality of life is assessed. In **Chapter 6**, the current urological surveillance in people with long-term SCI is described and compared to the recommendations of national and international guidelines on urological surveillance. Second, this chapter aimed to describe the outcomes of urologic ultrasonography and to explore whether demographic and injury-related characteristics, type of bladder-emptying method and having routine urological checkups are associated with the outcome of urologic ultrasonography. **Chapter 7** aims to describe the prevalence of the diagnosis of hypertension and associated risk factors. Furthermore, to compare the prevalence of single-measured high blood pressure and/or the use of antihypertensive

drugs with the prevalence in the Dutch general population. A description of the prevalence of several SHCs among people with long-term SCI, stratified for three different TSI periods (10–19, 20–29, and ≥30 years) is given in **Chapter 8**. In this chapter the relationship between these SHCs and quality of life is also explored, while controlling for confounders. Finally, in **Chapter 9**, the main findings of this thesis are summarised and discussed. Implications for clinical practice and recommendations for future research are provided.

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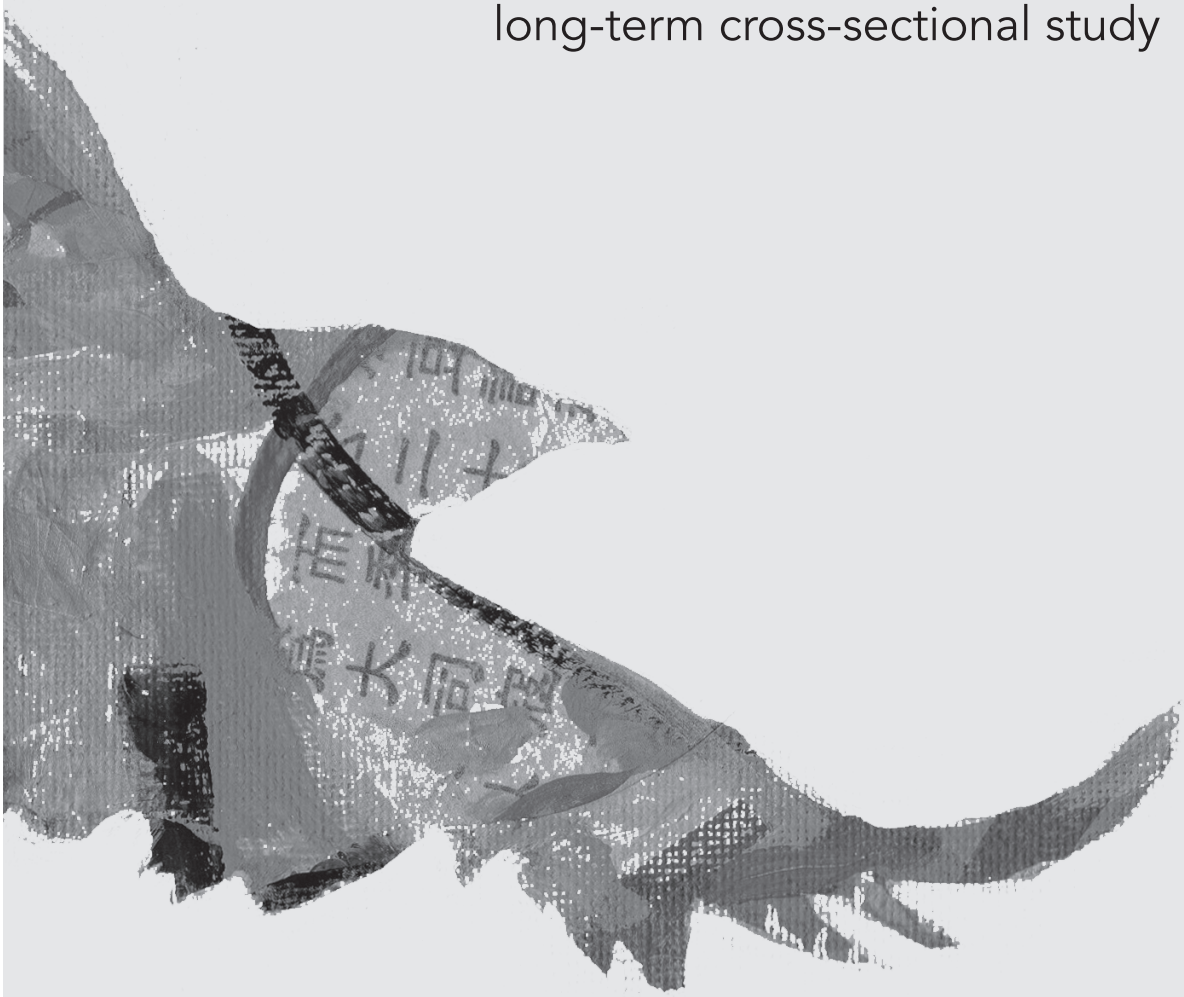
Chapter 2

Secondary health conditions in persons with a spinal cord injury for at least ten years: design of a comprehensive long-term cross-sectional study



Secondary health conditions in persons with a spinal cord injury for at least ten years: design of a comprehensive long-term cross-sectional study

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Abstract

Purpose To describe the prevalence of secondary health conditions (SHCs) (urinary tract and bowel problems, pressure ulcers, spasticity, musculoskeletal and neuropathic pain, sexual dysfunction, respiratory and cardiovascular disorders) in persons with long-term spinal cord injury (SCI), and to explore the impact of SHCs on fitness, active lifestyle, participation and well-being.

Methods A time since injury (TSI)-stratified cross-sectional study among 300 persons between 28- and 65-year-old with a SCI for at least 10 years. Strata of TSI are 10–19, 20–29, and 30 or more years. All eight Dutch rehabilitation centres with a SCI unit will participate. Participants will be invited for a one-day visit to the rehabilitation centre for an aftercare check-up by the local SCI rehabilitation physician (neurological impairment, SHCs and management), physical tests by a trained research assistant (lung function, wheelchair skills, physical capacity), and they will be asked to complete a self-report questionnaire in advance.

Results Not applicable.

Conclusion This study will provide knowledge on the health status and functioning of persons aging with SCI living in the Netherlands. This knowledge will help us to develop predictive models for the occurrence of SHCs and to formulate guidelines to improve health care for persons with long-term SCI.

Background

With increasing age and time since injury (TSI), more serious health problems may arise in persons with a spinal cord injury (SCI).[1] These "secondary health conditions (SHCs)" have been defined as: physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment.[2] Examples of SHCs are bladder- and bowel disorders, pressure ulcers, spasticity, upper-extremity pain, obesity and cardiovascular and respiratory problems. These SHCs hamper an active lifestyle and quality of life on top of the primary motor and sensory impairments due to the SCI.[3]

Numerous studies reported on the prevalence of SHCs in persons with long-term SCI. The most frequently reported SHCs in these studies were spasticity,[4-7] pressure ulcers,[5-9] pain,[5-7] and urinary tract infections.[4,7,8]

Several studies explored relationships between aging, i.e. increasing age and increasing TSI, and SHCs.[10-13] Krause,[13] for instance, reported a significantly greater odds of kidney stones, non-urinary related infections, and various musculoskeletal conditions among participants who were 20–29 years post-injury and 30 or more years post-injury compared to participants who were less than 10 years post-injury. The odds of heart problems and bowel obstructions were higher with a higher age at onset, whereas the odds of kidney stones were lower with increasing age at injury onset. Hitzig et al.[12] showed that, from a longitudinal perspective, the odds of reporting spasticity, kidney problems, high blood pressure and chronic pain increased over time for the cohort, irrespective of TSI or current age. The risk of cardiac problems increased with age and with time. The risk of bladder infections decreased with age, whereas the risk of respiratory complications increased. Finally, the risk of having a pressure ulcer increased with TSI. In an evidence-based review, Hitzig et al.[14] found evidence for an increasing incidence of shoulder pain over time in persons with SCI, with strong evidence that upper-limb pain in men with complete paraplegia who use manual wheelchairs may be attributed to longer TSI and not to chronological age.

Pressure ulcers are one of the most common SHCs. In their systematic review, Gélis et al.[15] described several pressure ulcer risk factors for persons with long-term SCI, including socio-demographic, medical, neurological, cutaneous or behavioural characteristics. Young age at the time of injury and an increasing TSI were found to be pressure ulcer risk factors.

Regarding the common urinary tract problems, Drake et al.[16] evaluated aging-related complications of various bladder management methods in a population with a SCI for at

least 20 years. Both age and TSI were significantly associated with rising complications rates regardless of bladder management methods. Renal function decreased significantly with increasing age and TSI. No significant effect of aging on urinary tract infections was found.

So far, only one study conducted in The Netherlands has described the prevalence of SHCs in relationship with TSI on a long-term.[17] The prevalence of problems regarding sexuality decreased significantly with TSI. The prevalence of pressure ulcers and contractures showed a significant non-linear relationship with TSI. Unfortunately no distinction was made between age and TSI, so it is unclear which of these factors contributed to these SHCs. In a study based on the same data,[18] 72% of all participants indicated a need for additional care in general, and participants indicated that 34% of all most-important SHCs were perceived as preventable by themselves.

In The Netherlands, there is a lack of coordination of the complex care required for persons aging with SCI. Often, persons with SCI stay out sight of specialised care, unless they take the initiative to visit a specialised rehabilitation centre in case of health problems.[18] Persons with long-term SCI were in case of SHCs more likely to visit their general practitioner (58%) than a rehabilitation specialist (25%).[18] However, general practitioners generally lack the expertise on SHCs in persons with SCI. Therefore, it is likely that there is an under-diagnosis and under-treatment of long-term health problems in persons with SCI in The Netherlands.[17]

Internationally, it has recently been recommended that more research on this field is necessary, and that it should focus on the physiology of aging in persons with SCI, the effects of aging, and the efficacy of interventions and possible preventive measures that might be used to reduce the prevalence of SHCs.[19]

In response to this lack of knowledge, a cross-sectional study has been developed within the research programme "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury" (ALLRISC) in the Netherlands.[1] This cross-sectional study will address SHCs and care needs in a large sample of persons with long-term SCI in the Netherlands. The ultimate aim is to develop predictive models for the occurrence of SHCs, in particular TSI-effects, and to develop guidelines to improve long-term health care for this group.

The first aim is to study the prevalence of the main SHCs (urinary tract and bowel problems, pressure ulcers, spasticity, musculoskeletal and neuropathic pain, sexual dysfunction and respiratory and cardiovascular disorders) in persons with long-term SCI. It is hypothesized that longer duration of injury is associated with a higher prevalence of SHCs. In addition,

current medical management, unmet needs and risk factors of these SHCs will be examined.

The second aim is to explore the impact of SHCs on fitness, active lifestyle, participation, and overall well-being in persons with long-term SCI. It is hypothesized that people with more, or more severe SHCs, will show a less active lifestyle, a lower fitness level and lower levels of participation and well-being.

Methods

Design

This will be a TSI-stratified cross-sectional study among 300 persons with long-term SCI in the Netherlands. Strata of TSI will be 10–19, 20–29 and 30 years or more after SCI and it is aimed to include 100 persons with SCI in each stratum.

The primary outcome is the prevalence of SHCs, in particular: urinary tract and bowel problems, pressure ulcers, spasticity, musculoskeletal and neuropathic pain, sexual dysfunction and respiratory and cardiovascular disorders.

Secondary outcomes are fitness, active lifestyle, participation and overall well-being.

Participants

The inclusion criteria are: SCI; age at injury between 18 and 35 years; time since injury at least 10 years; current age between 28 and 65 years; wheelchair dependent (hand-rim propelled wheelchair or electric wheelchair), at least for longer distances (>500 m). The overall exclusion criterion is: Insufficient mastery of the Dutch language to respond to an oral interview or to understand the test instructions.

Power calculation

With α=0.05 and power=0.80, the prevalence of a certain SHC of 0.2 can be estimated with a margin of error of ±4.6%. A prevalence difference of 0.2 (0.3 vs. 0.5) between two TSI strata of 100 participants each will be statistically significant with the same alpha and power. For the exploratory regression analysis, this number of 300 participants allows inclusion of 19

independent variables in the analysis, using the rule of thumb of 15 participants/variable. This will be sufficient to analyse associations between SHCs and participation and quality of life, accounting for the influence of demographic and type of SCI variables.

Procedure

Eligible persons will be identified from all eight rehabilitation centres with a specialty in SCI rehabilitation in the Netherlands. A major effort will be made to trace persons without a valid address in the databases, if necessary supported by the membership database of the Dutch SCI Patient Organization. TSI-stratified random samples will be drawn per centre.

Participants will be invited for a one-day visit to the rehabilitation centre, including an aftercare check-up by the local SCI rehabilitation physician, physical tests by a trained research assistant (physical or occupational therapist), and they will be asked to complete a self-report questionnaire in advance. Part of the protocol is a maximum exercise test, but this test is presented as voluntary, i.e. participants do not need to perform this test in order to take part in the study, to avoid under-representation of people in worse health condition. The questionnaire can be completed either in digital or in paper and pencil form. The total length of the aftercare check-up will be around 4.5 h.

This study protocol has been approved by the Medical Ethics Committee of the University Medical Center Utrecht.

Instruments

An overview of the concepts of outcomes of the study, according to the domains of the ICF-model, is presented in Figure 2.1.

Measurements include:

1. *Blood sampling*: Fasting blood samples will be taken to determine the lipoprotein profile, glucose level, HbA1c level, creatinine level and urea level.

2. *Electrocardiogram*: The electrocardiogram will be carried out to examine abnormalities in the electrical activity of the heart, both to describe the prevalence of these abnormalities as part of the study aims, and to check

the participant's eligibility to participate in the maximal exercise test, in accordance with the guidelines of the American College of Sports Medicine.[20]

3. *Ultrasound of bladder and kidneys*: The presence of potential dilatation of the urinary tract, and kidney or bladder stones will be observed.

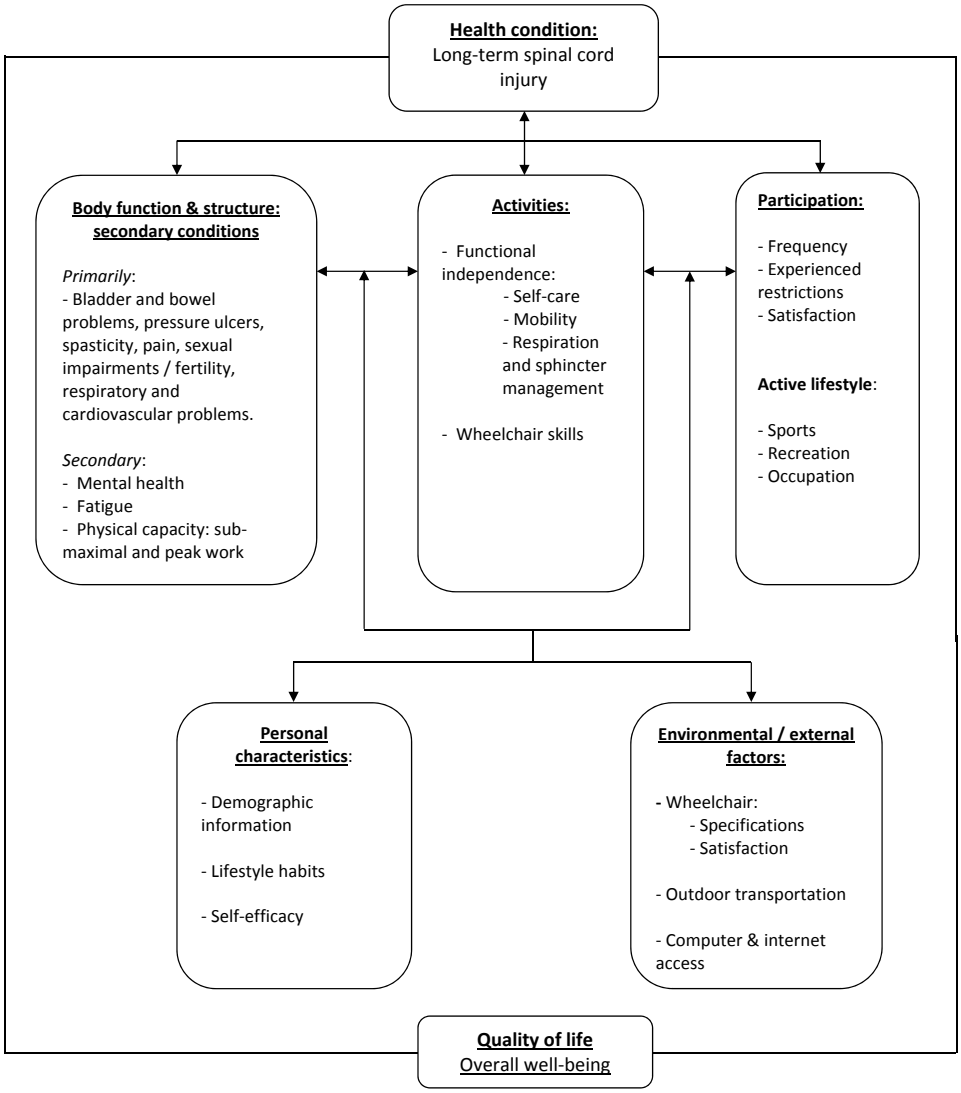

Figure 2.1 The outcomes split into the domains of the ICF-model, including body function and structure, activities, participation, personal and environmental factors.

4. *Consultation with the physician*:
   a) Structured interview on the medical history, co-morbidity, lifestyle habits like smoking, alcohol and drugs use, and medication use.
   b) Structured interview on the presence, severity and the past and present management of SHCs.
   c) Examination of blood pressure, heart rate, auscultation of heart and lungs, body mass and height.
   d) Neurological examination of the SCI according to the ASIA-classification.[21]
   e) Examination of spasticity of the knee extensors/flexors and elbow extensors/flexors with the Modified Ashworth Scale.[22] Furthermore, the elbow, wrist and ankle will be tested for the attendance of a clonus.

5. *Oral interview and tests by the research assistant*:
   a) *Functional independence* by administering the Spinal Cord Independence Measure III (SCIM-III) as an oral interview.[23]
   b) A *wheelchair check*. Specific attention will be paid to the adjustments and the functionality of the wheelchair.
   c) *Respiratory function* using spirometry.[24] The forced vital capacity (FVC), forced inspiratory flow per second (FIV1), and forced expiratory flow per second (FEV1) will be expressed as a percentage of what the participant was expected to score based on age, sex, and height.
   d) *Wheelchair skills* using the Wheelchair Circuit, a test of manual wheelchair skill performance.[25,26] It consists of eight standardised tasks that will be performed in a fixed sequence on a floor surface and on a motor-driven treadmill. The eight tasks are (1) figure-of-8 shape, (2) crossing a doorstep (height, 0.04 m), (3) mounting a platform (height, 0.10 m), (4) 15-m sprint, (5) 3% slope, (6) 6% slope, (7) 3-minute wheelchair propulsion, and (8) transfer. All participants will use their own wheelchair. Test parameters are the ability to perform the test items and the total time of performance of the 8-shape and 15-m sprint.
   e) *Physical capacity* using a maximal exercise test on a motor-driven treadmill to determine endurance capacity, peak power output (PO_{peak}) and peak oxygen uptake (VO_{2peak}) according to the protocol by Dallmeijer et al.[27] First, a drag test will be performed to determine rolling resistance

of the individual wheelchair-user combination on the treadmill (F_{drag}) as described by van der Woude et al.[28] These force measurements will be used for calculating the PO for each angle of inclination on the treadmill: PO (W) = F_{drag} (N) x belt velocity (m/s). The belt velocity is chosen depending on the lesion level and ability of the participant, and will be held constant during the entire test.

The drag test will be followed by the submaximal exercise test which consists of two 3-min exercise blocks with a 2-min rest in between. Participants will perform the first 3-min exercise block with the treadmill belt in a horizontal position and the second 3-min block at a 0.36° incline. After a 2-min rest, the workload will be increased every minute by increasing the slope of the belt by 0.36°. The test will be terminated when the participant can no longer maintain the position on the belt as a consequence of exhaustion, or when the participant indicates that he or she wants to stop.

Two weeks before the aftercare check-up in the rehabilitation centre, the questionnaire will be sent (preferably by email) to the participants. Participants are asked to complete the questionnaire before the aftercare check-up. The total time required to fill out the questionnaire is estimated 1 hour.

The questionnaire consists of:

1. *Perceived severity of secondary conditions*. The following standardised questionnaires are administered:
   a) The Qualiveen-Short Form is developed for patients with neurogenic bladder problems.[29] It consists of 8 items distributed in four domains including bother with limitations (2 items), frequency of limitations (2 items), fears (2 items) and feelings (2 items). Participants are asked to respond to each question on a 5-point scale.
   b) The Neurogenic Bowel Dysfunction Score (NBD-score) is a symptom-based score for neurogenic bowel dysfunction (NBD) in SCI patients.[30] It covers both constipation and faecal incontinence and it consists of 10 items. The maximum total NBD score is 47 points. A NBD score of 14 or more indicates severe bowel dysfunction.

c) The questionnaire on spasticity focuses on the individual perception and description of spasticity in the lower limbs.[31] Four manifestations of spasticity are predefined in the questionnaire of which patients can choose one or more when applicable. Participants can also provide a description in their own words as well. The perceived degree of spasticity will be assessed using a visual analogue score (VAS), a 10-point scale with "no spasticity" and "most spasticity imaginable" at the extremes.[32] Finally, participants are asked to list activities during which they experience little or high degree of spasticity.[31]

2. *Active lifestyle* will be measured with the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD).[33] The PASIPD requests the number of days a week and hours daily of participation in recreational, household, and occupational activities over the past 7 days.

3. *Participation* will be measured with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P).[34-36] It assesses three aspects of participation: frequency of social activities (11 items), experienced restrictions (11 items), and satisfaction with participation (10 items).

4. *Fatigue* will be measured with the Fatigue Severity Scale (FSS).[37,38] The FSS is a brief self-report of fatigue severity that consists of 9 items.

5. *Mental health* will be measured with the Mental Health Inventory-5 (MHI-5).[39] The MHI-5 consists of 5 questions on mood over the last 4 weeks.

6. *Life satisfaction* will be measured by the International SCI Quality of Life Basic Data Set from the International Spinal Cord Society[40] and by a 2-item life satisfaction measure.[41]

7. *Overall well-being* will be measured with 5 satisfaction items from the abbreviated World Health Organization Quality of Life measure (WHOQOL-BREF).[42] The 5 items cover overall quality of life, and satisfaction with health, daily activities, relationships, and living conditions.

8. *Personal characteristics* included are:
   a) Demographic: age, gender, marital status, ethnicity, having children, education, work, and living situation.

b) Exercise self-efficacy: SCI Exercise Self-Efficacy Scale (SCI-ESES).[43] The SCI-ESES is a survey on exercise behaviour in people with SCI. The answers indicate how confident a person is with regard to carrying out regular physical activities and exercise.
c) Disability Management Self-Efficacy Scale – Short Form (DMSES).[44] The DMSES is a 6-item scale developed for persons with SCI. It asks the person to rate his/her confidence regarding the handling of potential negative effects of the SCI.

9. *Assistive devices and support*:
   a) Participants are asked to answer 12 specifically designed questions regarding their posture in their wheelchair.
   b) Questions about outdoor transportation, computer and internet accessibility and use, and utilizing assistive devices during computer use.

Statistical analysis

Main research question

To answer our primary research question on the prevalence of SHCs, the proportion of persons experiencing a certain SHC in the previous 3 months will be computed. Additionally, data from the medical consultation will be used to describe characteristics (e.g., type of respiratory problems), current management (e.g. use of suppositories), and consequences (e.g. days of bed rest) of these problems.

The hypothesized association between longer time since SCI and prevalence of SHCs will be tested by comparing the prevalence of various SHCs between the three TSI cohorts (10–19 years; 20–29 years; ≥30 years) with Chi-square tests. To correct for demographic characteristics and SCI characteristics, a series of eight logistic regression analyses will be performed, each with one health condition as the dependent variable and the TSI categories as predictors (dummy variables), controlling for demographic and SCI characteristics as appropriate.

Secondary research question

Associations between the severity of SHCs and the secondary outcomes will be explored using correlation and regression analysis. Demographic characteristics and SCI characteristics will be considered potential confounders and will be controlled for in the regression analyses if they are related to the main outcomes ($P<0.10$).

With Structural Equation Modelling, a path model will be constructed to analyse the influence of SHCs on the main secondary outcomes (participation, well-being). With this analysis the hypothesis that SHCs have an independent influence on well-being, both directly and indirectly through the variables activities and participation can be tested.

Discussion

With this study, we expect to gain more knowledge on the prevalence and risk factors of important SHCs (urinary tract and bowel problems, pressure ulcers, spasticity, musculoskeletal and neuropathic pain, sexual dysfunction and respiratory and cardiovascular disorders) in persons with long-term SCI. We aim to answer questions like:

1. Which of these SHCs play a role in limiting participation, activity level and well-being?
2. What kind of persons aging with SCI are more likely to develop certain SHCs?
3. What are the most effective strategies, from a health services perspective, for helping these persons aging with SCI to prevent or delay the onset of the SHCs?

This will be the first study conducted in the Netherlands which will specifically address aging-related changes in SHCs in persons with long-term SCI.

Although several international projects like the Spinal Cord Injury Model Care Systems in the United States, have been contributing in gaining a better understanding of the medical complications that can result from long-term SCI, as well as their risk factors and trends in time, there still is a need for continuing data collection to develop SHC-prevention strategies.[17,19]

Several aspects of the design of this study will contribute to its strength. In contrast to studies measuring only self-reported SHCs using questionnaires or telephone interviews,[4,6,11-13] this study will consist of an extensive aftercare check-up day in the rehabilitation centre with a medical consultation and additional examinations. This way of reporting SHCs will reveal better figures on the prevalence of SHCs. Furthermore, the large study sample and the restriction to persons aged 18–35 at onset of SCI will minimize the confounding effect of age at injury. Finally, by taking a stratified random sample we will ensure sufficient numbers of participants in all three TSI groups.

One of the limitations of this study will be that we will not be able to report on aging with SCI in persons who were older than 35 years at the time of injury. Since more older people are being injured, the mean age of SCI onset increases.[19] However, by restricting our study to people who suffered from SCI at a relatively young age, and mostly without any co-morbidity at the onset of SCI, we expect to be better able to study long-term consequences of the SCI itself.

Probably, we also won't be able to distinguish well between age and TSI effects because we will have little variation in age at injury. However, the advantage will be that biological aging will not be an important confounder, since we will mainly examine persons under the age of 60 years. Further, we can address this problem by comparing study outcomes, for example fitness and participation, with age-matched control groups to examine the impact of SCI.

It is also questionable to what extent our results can be generalised to other countries. Differences in health care systems might play an important role. To take a first step towards an international comparison we use some measurement instruments also used in the current community study in Switzerland.[45]

Conclusion

This study, together with the other projects of the ALLRISC programme, will provide knowledge on the health status and functioning of persons aging with SCI living in the Netherlands and it will help us to formulate requirements and guidelines for a lifespan covering rehabilitation aftercare system.

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Chapter 3

Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge

Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge

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Abstract

Objective To assess the occurrence of secondary health conditions and their potential risk factors in persons with spinal cord injury from 1 to 5 years after discharge from initial inpatient rehabilitation.

Design Multicentre longitudinal study.

Subjects A total of 139 wheelchair-dependent persons with spinal cord injury.

Methods The occurrence of secondary health conditions and their potential risk factors were assessed in a clinical interview with a rehabilitation physician at 1 and 5 years after discharge from inpatient rehabilitation and by a telephone interview 2 years after discharge. Self-report questionnaires were used for the assessment of musculoskeletal and neuropathic pain.

Results Neuropathic pain (83.7–92.1%), musculoskeletal pain (62.3–87.1%) and urinary tract infection (56.5–58.9%) were the most frequently reported secondary health conditions. The occurrence of several secondary health conditions was higher among women and individuals with a complete lesion, tetraplegia, and with a higher body mass index.

Conclusion Secondary health conditions are common in the first years post-discharge following spinal cord injury and their course seems to be relatively stable. These results emphasize the number of health issues that must be considered during post-injury care of persons with spinal cord injury living in the community, and the importance of a well-coordinated interdisciplinary approach from specialised rehabilitation centres.

Introduction

Persons with spinal cord injury (SCI) often face serious health problems, such as bladder and bowel disorders, pressure ulcers and neuropathic pain. These secondary health conditions (SHCs) have been defined as: physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment.[1] SHCs hamper an active lifestyle and quality of life on top of the primary motor and sensory impairments due to the SCI.[2] They are a frequent cause of mortality and rehospitalisations.[3-6]

Few prospective studies have provided a longitudinal perspective on the occurrence of SHCs in persons with SCI.[7-9] Other studies have compared the occurrence of SHCs between groups with different time since injury (TSI), but in a cross-sectional design.[10-14]

One study is available in which persons with SCI participated in telephone interviews on SHCs at their first, third and fifth year post-injury.[7] The most frequently reported SHCs were problematic spasticity (34%, 31% and 28%, respectively) and musculoskeletal pain (28%, 29% and 36%, respectively). However, assessment of SHCs by self-report was a limitation of this study.

Some other studies collected their data through objective assessments.[8,9,11,12] Two of these studies utilised the National Spinal Cord Injuries Statistical Center (NSCISC).[8,11] The NSCISC collects data through a combination of annual medical history interviews and physical examinations. The two studies reported on different SHCs. In the longitudinal study,[8] with a TSI of 5 years, the most frequently reported SHCs were constipation (40.0%), bowel accidents (35.3%) and upper-extremity pain (34.1%). With an occurrence of 15.2% at the first year, 17.8% at the second year, and 19.9% at the fifth year post-injury, pressure ulcers were the most frequently reported SHC in the retrospective study.[11]

Risk factors for SHCs in the first years post-injury, in particular SCI-related, have been investigated by previous studies. Not surprisingly, persons with a complete lesion and tetraplegia are most at risk for many SHCs.[8-13,15,16] Higher age,[9,11,16] female gender,[9,12,13] male gender,[9,11,12] a higher body mass index (BMI),[9] traumatic injury[9] and smoking[9] are other identified risk factors.

Although differing in design and used methods these studies emphasize the number of health issues that must be considered during the post-injury care.

The Dutch research programme on the restoration of mobility, "The Umbrella Project", a prospective cohort study,[17] provided the first objective information on the occurrence, course and risk factors of SHCs in the Netherlands, from the start of inpatient rehabilitation until 1 year after discharge from inpatient rehabilitation.[9] During that follow-up period most participants experienced neuropathic and musculoskeletal pain, or spasticity. Increased age, higher BMI, traumatic lesion, tetraplegia and complete lesion were identified as risk factors for SHCs. Knowledge on the course of SHCs during a longer follow-up period is, however, needed to develop preventive strategies and to improve treatment programmes for SHCs.

The present study assesses the occurrence of SHCs using data from The Umbrella Project at 1, 2 and 5 years after discharge from inpatient rehabilitation. Research questions were:

- What is the occurrence of SHCs (pressure ulcers, heterotopic ossification, urinary tract infection (UTI), pulmonary infection, autonomic dysreflexia (AD), hypotension, oedema, problematic spasticity, neuropathic pain, musculoskeletal pain and cardiovascular disorders) in persons with SCI 1, 2 and 5 years after discharge from inpatient rehabilitation?
- Are demographic (age, gender), lifestyle (smoking, BMI), or SCI-related (aetiology, level, completeness) variables risk factors for these SHCs?

Methods

Details on The Umbrella Project are provided elsewhere.[17] In short: persons were recruited in all eight rehabilitation centres with specialised SCI units in the Netherlands between August 2000 and July 2003. Inclusion criteria were: 1) recently acquired SCI; 2) age between 18 and 65 years; 3) grade A, B, C, or D on the American Spinal Injury Association (ASIA) Impairment Scale (AIS); 4) sufficient understanding of the Dutch language; and 5) expected to remain wheelchair-dependent, at least for longer distances. This choice was made because the Umbrella Project was focused on restoration of wheeled mobility, and the core physical tests were to be performed in a wheelchair. Exclusion criteria were: 1) a SCI caused by a progressive disease (e.g. malignant tumour, multiple sclerosis); 2) a progressive disease (e.g. Parkinson's disease, progressive neuromuscular disorder); and 3) psychiatric problems.

Approval of the research protocol was obtained from the Medical Ethics Committee of the SRL/iRv Hoensbroeck and the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent prior to participation.

Procedure

Data from three measurement occasions were used for the present study: 1 year (T1), 2 years (T2) and 5 years (T3) after discharge from inpatient rehabilitation.

The measurements relevant for this study comprised a consultation by a SCI rehabilitation physician, including a physical examination at T1 and T3, a structured telephone interview by a trained research assistant at T2, and a self-report questionnaire for the assessment of neuropathic pain and lifestyle habits at all three measurement occasions. A self-report questionnaire on musculoskeletal pain was only included at T1 and T3. Assessment of the occurrence of SHCs was part of the consultation at T1 and T3 and part of the telephone interview at T2.

Secondary health conditions (SHCs)

The occurrence of a SHC was assessed over the last 12 months and reported as 0 = no occurrence over the last 12 months, or 1 = currently present or has occurred in the last 12 months. The SHCs assessed this way were: pressure ulcers, problematic spasticity, UTIs, pulmonary infections, heterotopic ossification, oedema, hypotension, AD, musculoskeletal and neuropathic pain. Cardiovascular disorders were grouped and included conditions such as myocardial infarction or aortic valve stenosis.

When a participant indicated that he or she had a pressure ulcer in the past 12 months, the rehabilitation physician asked further questions on the location and the severity of the ulcer according to the classification of the European Pressure Ulcer Advisory Panel (EPUAP): grade I, II, III or IV.[18] All pressure ulcers, irrespective of grade, were included.

The occurrence of problematic spasticity during certain activities was assessed for: sleeping, the execution of a transfer, washing oneself and clothing, wheelchair propulsion, and other daily activities. Answers were registered as follows: 0 = no discomfort caused by spasticity, 1 = some discomfort caused by spasticity, and 2 = much discomfort caused by spasticity. Problematic spasticity was registered when a participant scored much discomfort caused by spasticity for at least one activity.

UTI was operationalised as a symptomatic UTI (e.g. fever, malaise, incontinence, increased spasms of legs, abdomen or bladder, gritty particles or mucus in the urine or cloudy urine, foul-smelling urine) which was treated with antibiotics. Pulmonary infections were also only included when they were treated with antibiotics.

Heterotopic ossification was defined as the presence of bone in soft tissue surrounding paralysed joints confirmed by radiological examination.

Oedema was scored when the participant had received treatment (e.g. compression stockings, bandages, tubigrip, diuretic medication).

The occurrence of hypotension was checked by the assessment of symptoms (e.g. light-headedness or dizziness, fainting).

AD was defined as a sudden reaction of the autonomic nervous system triggered by a stimulus below the level of the lesion (e.g. bladder distension, UTI) which caused an increase in blood pressure associated with symptoms such as: 1) below the level of the lesion: piloerection, pallor, cool extremities, profuse sweating; 2) above the level of the lesion: severe headaches, nasal congestion, flushing of the skin and bradycardia. When the occurrence of AD was checked, a description of AD with the most common associated symptoms, as described above, was given.

Standardised questions on the nature of pain were completed when the participant reported having pain. Musculoskeletal pain was defined as nociceptive pain originating from bone, joint or muscle trauma or overuse.[19] Thirteen locations on the upper and lower limbs, back and neck were scored with a 5-point scale (ranging from 1: "not severe" to 5: "very severe"). A sum score was made by adding up the scores for the 13 locations. Sum scores ranged from 1 to 65. The occurrence of musculoskeletal pain was only registered at T1 and T3. Severe musculoskeletal pain was defined as having scored severe pain or very severe pain in at least one location.

Neuropathic pain was defined as at-level or below-level pain originating from syringomyelia, spinal cord ischaemia or trauma.[19] The presence (yes/no) and severity of eight neuropathic pain characteristics (other pain than musculoskeletal pain, numbness, itching, tingling, cold, warm, girdle zone pain and phantom feeling) were assessed using a 5-point scale (ranging from 1: "not severe" to 5: "very severe"). A sum score was made by adding up the scores of all eight neuropathic pain characteristics. Sum scores ranged from 1 to 40. Severe neuropathic pain was defined as having scored at least one characteristic as severe or very severe.

Potential risk factors

We selected potential risk factors based on Haisma et al.[9]: age, gender, smoking status (smoker vs non-smoker), BMI, aetiology (traumatic vs non-traumatic), level of the lesion (paraplegia vs tetraplegia) and completeness of the lesion (complete vs incomplete). Tetraplegia was defined as a lesion at or above the first thoracic segment, and paraplegia as a lesion below the first thoracic segment. A complete lesion was diagnosed in the absence of motor and sensory function in the sacral segments, i.e. ASIA Impairment Scale grade A. AIS grades B, C, and D were considered incomplete.[20] The assessments of BMI, level and completeness of the lesion were all part of the physical examination performed by the rehabilitation physician at T1 and T3. Since a physical examination was not possible at T2, the data of level and completeness of the lesion were adopted from T1. At T2, height was also adopted from T1, and body weight was asked for by the research assistant to determine the person's BMI.

Statistics

Only persons who completed at least two measurement occasions were included in the analyses. A non-response analysis was performed by comparing data at the start of active rehabilitation between persons who completed the measurement 5 years after discharge with persons who did not, using Chi-square and *t*-tests.

Descriptive statistics of participants' demographic and SCI characteristics were calculated for each measurement. Random coefficient analyses (MlwiN version 2.02) were used to estimate the occurrence of the SHCs and the association with the potential risk factors.

Analysis of secondary health conditions

A logistic random coefficient model was made for the occurrence of each SHC. Time was included as a set of two dummy variables with T2 as reference. The occurrence of a SHC at T2 was estimated by the intercept: 1 / {1 + exp [- (intercept)]}. The occurrence of a SHC at the other two measurement occasions was estimated as: 1 / {1 + exp [- (intercept + regression coefficient)]}.[21] Significance was set at a *P*-value less than 0.05.

The severity scores for neuropathic pain were estimated with a linear regression model. Again, time was modelled as two dummy variables and the score at T2 was estimated by the intercept. The sum scores at the other measurements were calculated by adding the intercept to the regression coefficient of the dummy variable.

Analysis of potential risk factors

All risk factors were simultaneously added to the previous described models. With these multivariate models, the contribution of each risk factor was corrected for. Odds ratios (ORs) for the risk factors were calculated as: OR = exp[regression coefficient]. The corresponding 95% confidence intervals were calculated as: exp[regression coefficient ± (standard error x 1.96)].

Results

Participants

At the start of active rehabilitation, 224 persons with SCI were included in the study. A total of 156 persons participated 1 year after discharge from the rehabilitation centre (the present study's first time of assessment), 99 persons 2 years and 146 persons 5 years after discharge. Because two rehabilitation centres did not participate 2 years after discharge, a lower number of participants appeared in this measurement. A total of 139 persons completed at least two of the three measurements and were included in the analyses. Participants were lost to follow-up for several reasons: 27 persons died, 18 refused to collaborate, 5 moved, 11 could not be contacted, and the rest had other reasons for dropping out of the study.

Table 3.1 gives the descriptive characteristics at the start of active rehabilitation of the participants and the non-participants in the measurement occasion 5 years after discharge. No significant differences between both groups were seen, except that the non-participants were somewhat older than the participants, and less often had a complete lesion.

Table 3.1 Descriptive characteristics at the start of active rehabilitation of the participants and non-participants 5 years after discharge

	Participants	Non-participants	*P*-value
Participants (N)	139	85	
Age (years), mean (SD)	39 (14)	43 (14)	0.048
Gender (% male)	72	79	0.232
Body mass index (kg/m^2), mean (SD)	22.8 (3.9)	22.9 (3.7)	0.869
Smoker (% smoker)	24	25	0.793
Cause (% traumatic)	77	67	0.109
Level (% tetraplegia)	36	48	0.070
Completeness (% complete)	57	38	0.006

SD: standard deviation.

Table 3.2 gives the descriptive characteristics of the participants at all measurement occasions. Approximately one-third of the participants had a lesion at or above the first thoracic segment, and approximately half of the lesions were complete. More than three-quarters of the lesions were of traumatic origin.

Table 3.2 Descriptive characteristics of the 139 participants who completed at least 2 of the 3 measurements and who were included in the analyses

	1 year after discharge	2 years after discharge	5 years after discharge
Participants (N)	139	98	121
Age (years), mean (SD)	40 (14)	41 (14)	44 (13)
Gender (% male)	72	75	73
Body mass index (kg/m^2), mean (SD)	24.4 (4.5)	24.4 (4.8)	25.6 (4.8)
Smoker (% smoker)	35	32	24
Cause (% traumatic)	77	81	78
Level (% tetraplegia)	33	31	34
Completeness (% complete)	53	54	58

SD: standard deviation.

Secondary health conditions

Figure 3.1 shows the estimated occurrence of a SHC at each time point. The most frequently reported SHCs were neuropathic pain (83.7–92.1%) and UTIs (56.5–58.9%). Musculoskeletal pain was reported by 62.3% at T1 and 87.1% at T3. There was a significant decrease in the occurrence of problematic spasticity and the occurrence of neuropathic pain between 1 and 2 years after discharge.

The mean severity score for neuropathic pain at T1, T2 and T3 was, respectively, 7.1, 7.6 and 9.3 points. The differences of 2.2 points between T1 and T3 and 1.7 points between T2 and T3 were significant.

Neuropathic pain was severe for 41.7% of the participants at T1, 39.8% at T2 and 44.4% at T3.

The mean severity score for musculoskeletal pain at T1 and T3 was, respectively, 7.1 and 10.1 points. This was a significant difference. Musculoskeletal pain was severe for 22.3% of the participants at T1 and 34.7% at T3.

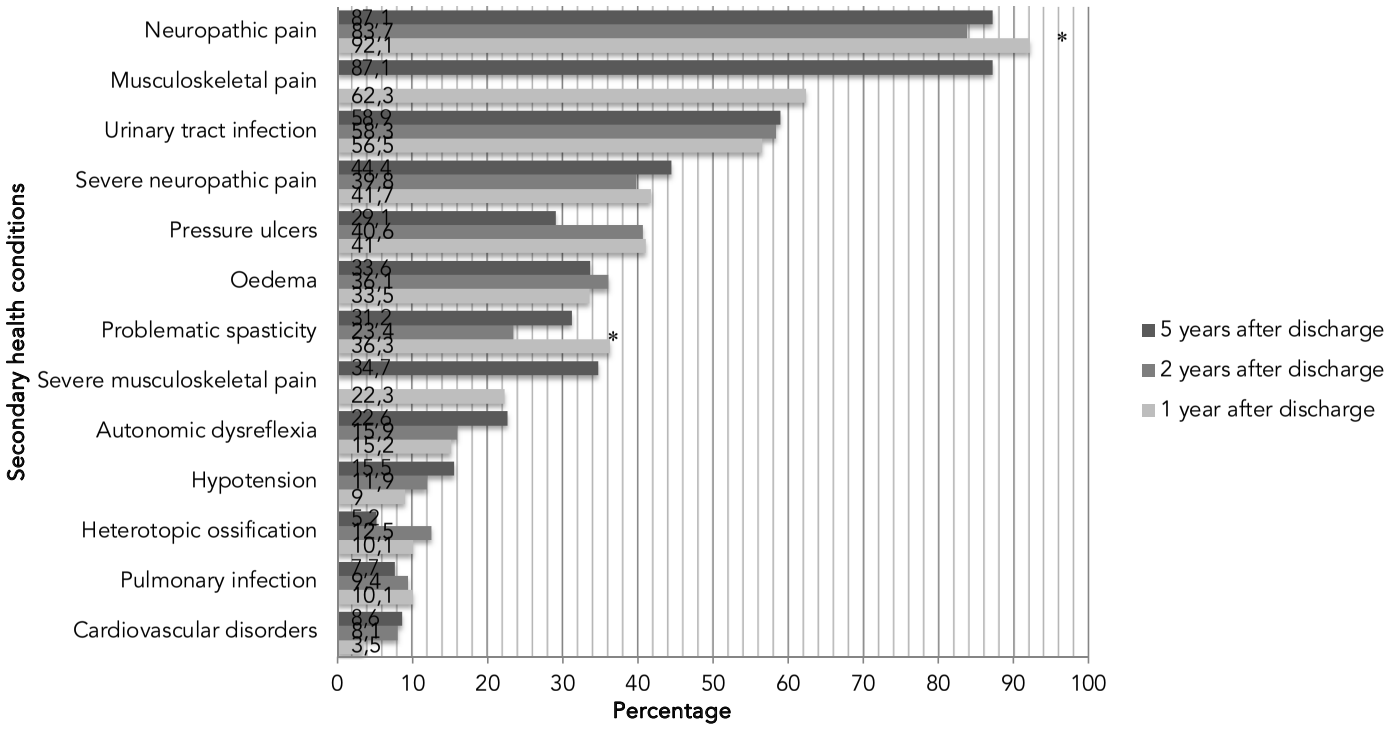

Figure 3.1 The estimated occurrence of the secondary health conditions at each time of assessment: random coefficient modelling.
* Significant difference ($P \leq 0.05$) between the estimated occurrence of neuropathic pain and of problematic spasticity at 1 and 2 years after discharge from inpatient rehabilitation.

Table 3.3 Odds ratios (and 95% confidence intervals (95%CI)) for the association between secondary health conditions (SHCs) and potential risk factors: multivariate logistic random coefficient modelling. Regression coefficients (and 95% CI) for the association between the severity score of neuropathic pain and potential risk factors: multivariate random coefficient modelling.

	Age (years) OR (95% CI)	Gender[a] OR (95% CI)	Smoking[a] OR (95% CI)	BMI (kg/m^2) OR (95% CI)	Cause[a] OR (95% CI)	Level[a] OR (95% CI)	Completeness[a] OR (95% CI)
Cardiovascular disorders	1.01 (0.96–1.06)	2.90 (0.95–8.86)	1.66 (0.45–6.09)	**1.17** (1.04–1.32)	0.66 (0.16–2.68)	2.29 (0.57–9.25)	0.70 (0.22–2.29)
Pulmonary infection	1.03 (0.99–1.07)	**2.73** (1.09–6.81)	0.96 (0.33–2.86)	**1.10** (1.00–1.22)	0.63 (0.18–2.22)	**0.18**[b] (0.06–0.52)	1.86 (0.65–5.34)
Heterotopic ossification	0.98 (0.95–1.02)	0.30 (0.09–1.04)	0.55 (0.21–1.42)	0.94 (0.86–1.04)	0.70 (0.17–2.82)	0.87 (0.35–2.15)	1.56 (0.62–3.88)
Hypotension	0.99 (0.95–1.03)	**2.78** (1.16–6.66)	1.04 (0.41–2.60)	0.99 (0.91–1.08)	1.24 (0.34–4.54)	**0.09** (0.03–0.23)	1.31 (0.52–3.33)
Autonomic dysreflexia	0.99 (0.96–1.01)	0.94 (0.45–1.96)	0.64 (0.29–1.40)	**1.09** (1.02–1.16)	1.23 (0.47–3.19)	**0.20** (0.10–0.42)	**3.09** (1.43–6.67)
Oedema	**1.03** (1.01–1.06)	**2.14** (1.19–3.85)	0.70 (0.38–1.28)	**1.10** (1.03–1.16)	1.35 (0.66–2.77)	**0.49** (0.27–0.90)	**3.14** (1.71–5.78)
Pressure ulcers	1.01 (0.99–1.03)	1.48 (0.76–2.56)	0.82 (0.47–1.43)	1.03 (0.97–1.09)	1.42 (0.72–2.82)	0.70 (0.40–1.23)	**3.34**[b] (1.92–5.83)

Urinary tract infection	1.00 (0.98–1.02)	1.58 (0.91–2.73)	0.83 (0.49–1.40)	1.01 (0.96–1.07)	1.06 (0.55–2.01)	0.69 (0.41–1.19)	**2.84** (1.70–4.75)
Problematic spasticity	0.99 (0.97–1.02)	1.06 (0.60–1.87)	1.06 (0.60–1.87)	1.00 (0.94–1.06)	1.62 (0.82–3.22)	**0.53** (0.30–0.93)	1.14 (0.66–1.98)
Neuropathic pain	**1.04** (1.00–1.07)	1.59 (0.60–4.20)	0.86 (0.37–2.00)	0.98 (0.90–1.07)	3.60 (0.76–17.10)	**0.34** (0.13–0.89)	1.22 (0.54–2.74)
Musculoskeletal pain	0.99 (0.97–1.02)	1.86 (0.91–3.83)	0.90 (0.64–1.28)	**1.11** (1.03–1.20)	0.83 (0.37–1.88)	0.98 (0.49–1.94)	0.76 (0.40–1.47)
Neuropathic pain severity score[c]	**0.06** (0.00–0.11)	**1.65**[d] (0.21–3.09)	-1.28 (-2.73–0.17)	0.10 (-0.05–0.25)	-1.39 (-3.14–0.35)	-0.89 (-2.31–0.53)	-0.35 (-1.73–1.04)
Musculoskeletal pain severity score[c]	-0.03 (-0.12–0.06)	**2.67** (0.33–5.01)	-0.838 (-3.33–1.66)	0.07 (-0.18–-.32)	2.51 (-0.26–5.28)	-1.12 (-3.53–1.30)	-2.28 (-4.64–0.08)

Significant associations ($P \leq 0.05$) are printed in **bold**.

[a] Gender: men = 0, women = 1; Smoking: non-smoker = 0, smoker = 1; Cause: traumatic = 0; non-traumatic = 1; Level: tetraplegia = 0, paraplegia = 1; Completeness: incomplete = 0, complete = 1.

[b] As an example is given that persons with a complete lesion were 3.3 times more at risk of a pressure ulcer, than those with an incomplete lesion; persons with a paraplegia were 5.6 times less at risk of a pulmonary infection, than those with a tetraplegia.

[c] Regression coefficients (and 95% CI) are given.

[d] As an example is given that women scored their degree of neuropathic pain 1.7 points higher than men.

Risk factors

Table 3.3 gives the ORs for the associations between the potential risk factors and the occurrence of a SHC. The most frequently observed significant risk factors were female gender, an increase in BMI, having a tetraplegia and having a complete lesion.

Persons with a complete lesion were at increased risk for pressure ulcers, UTIs, AD and oedema. Females had, compared with males, an increased risk for the occurrence of a pulmonary infection, hypotension and oedema. Persons with paraplegia were significantly less susceptible for pulmonary infections, AD, hypotension, oedema, problematic spasticity and neuropathic pain compared with persons with tetraplegia. A higher BMI was significantly associated with an increased risk for pulmonary infection, AD, oedema, musculoskeletal pain and cardiovascular disorders.

Table 3.3 also gives the regression coefficients for the association between potential risk factors and the severity score of neuropathic and musculoskeletal pain. An increase in age was associated with an increase in severity score of neuropathic pain (0.6 points per 10 years of age). Females scored their severity of neuropathic pain and musculoskeletal pain respectively 1.7 points and 2.7 points higher compared to males.

Discussion

Secondary health conditions

Our study shows that at 1, 2 and 5 years after discharge from inpatient rehabilitation neuropathic pain and UTIs were most often reported by the participants. Musculoskeletal pain had a high prevalence at 1 and 5 years after discharge. However, when we took only severe complaints of neuropathic and musculoskeletal pain into consideration the rates were considerably lower. Furthermore, we found that the prevalence of SHCs was relatively stable in this period.

The present study was a sequel to the study by Haisma et al. who studied the occurrence of the same SHCs during inpatient rehabilitation until 1 year after discharge.[9] As in our study, neuropathic pain was the most frequently reported SHC, with a stable occurrence of 89–91% across measurement occasions. We also noted some differences in the occurrence of SHCs with regard to the results of Haisma et al. We observed a slight increase in the occurrence

of AD, a decrease in the occurrence of heterotopic ossification and a slight increase in the occurrence of cardiovascular disorders.

Differences with other studies that assessed the occurrence of several SHCs among persons with SCI in the first years post-injury might be attributed to the use of various study designs and data collection methods; e.g. physical examinations,[12] in-person interviews,[11,12] self-report questionnaires[10,16] and telephone interviews.[7,11] Furthermore, none of these studies explored exactly the same SHCs as we did and there were differences in the selection procedure of the study population. We included relatively severely spinal cord injured persons, since they all had to be dependent on a wheelchair, at least for longer distances. Also, the period covered by our study (the previous 12 months) is likely to increase the prevalence of SHCs compared to studies using a shorter time-frame (e.g. at the time of medical examination, or in the previous 4 weeks).

Since neuropathic pain, musculoskeletal pain and UTIs were the most frequently reported SHCs we will discuss these three SHCs separately.

Neuropathic pain

In a longitudinal cohort study at-level neuropathic pain and below-level neuropathic pain were present in, respectively, 41% and 34% of persons with traumatic SCI in the first 5 years post-injury.[22] The latest review on the occurrence and chronicity of neuropathic pain reported a prevalence of 40%.[23] Our percentages are much higher (84–92%), which might be explained by not making a distinction between at- or below-level neuropathic pain. We also included a wider range of characteristics in our definition of neuropathic pain. When only severe neuropathic pain is addressed, our numbers of occurrence (40–44%) are more in accordance with the literature. Furthermore, our results are consistent with the literature, in that those with neuropathic pain early following their injury are likely to continue to experience ongoing pain.[22-24]

Musculoskeletal pain

In a study using a similar follow-up period,[22] musculoskeletal pain was present in 40% of the participants at 6 months following SCI (compared with 62.3% at our first follow-up year) and in 59% of the participants 5 years after SCI (compared with 87.1% in our study). They also found that, at 5 years following SCI, 25% reported their musculoskeletal pain as severe.

We found a slightly higher percentage of 34.7%. What corresponded was the increase in musculoskeletal pain during the 5-year follow-up period, which can be explained by the physiological age-related decline in the musculoskeletal system and the chronic overuse of the upper extremities due to their wheelchair-dependent life.[25]

Urinary tract infections

In the present study we found an occurrence of UTIs at 1, 2 and 5 years following SCI of, respectively, 56.5%, 58.3% and 58.9%. These results are similar to earlier findings of Levi et al.[12] and Noreau et al.,[10] who noted an occurrence that varied between 55% and 77% (TSI 0–7 years).

Course of secondary health conditions

Only the changes in reported neuropathic pain and problematic spasticity 2 years after discharge from inpatient rehabilitation compared with 1 year after discharge were found to be significant. This might be explained by the rather short post-injury period that was used for the follow-up measurements. Continuation of the follow-up is necessary to establish the long-term course of SHCs in this cohort.

Risk factors

We found that the occurrence of several SHCs was higher among women and persons with a complete lesion and particularly among those with tetraplegia and a higher BMI. For some SHCs this was not surprising, since there is a pathophysiological explanation for it.

First, AD can only occur in spinal cord injured persons with a lesion at or above T6.[26,27] Therefore, it is rational that persons with paraplegia are less susceptible. It has also been described as being less frequent and less severe in incomplete lesions.[26,28] Secondly, persons with tetraplegia are more at risk for pulmonary complications, such as pulmonary infection, because these are associated with respiratory muscle paralysis, which causes, for example, impaired cough, difficulty mobilizing secretions and microatelectasis.[29] Thirdly, it is known that the likelihood of experiencing (orthostatic) hypotension is higher amongst persons with higher spinal cord lesions. Sympathetic nervous system dysfunction below the level of injury (due to loss of supraspinal control) and the loss of reflex vasoconstriction are two

major causes for hypotension following SCI.[30,31] The extent to which this sympathic control is disrupted is directly related to the level of the lesion.[30,32]

The observed significant associations between female gender and pulmonary infections, hypotension, oedema and the severity of musculoskeletal and neuropathic pain are difficult to explain. As far as we know this also has not been described in previous studies. Our observed significant association between female gender and the severity of neuropathic pain is in contradiction with the literature on pain in persons with SCI. Cardenas et al.,[33] for instance, reported no differences between gender and pain severity scores in persons with SCI. In addition, a retrospective study on neuropathic pain after traumatic SCI found no correlations with gender.[15]

We found no significant differences between traumatic and non-traumatic SCI. This indicated that, adjusted for differences between age, gender, level and completeness of SCI, the occurrence of SHCs did not differ between persons with traumatic and persons with non-traumatic SCI.

Limitations

Our study was limited by the fact that only Dutch persons with a SCI between 18 and 65 years old who were wheelchair-dependent (at least for longer distances) were included. This may influence the degree to which the results can be generalised to the whole population of persons with a SCI. Furthermore, the period of observation is too short to make any statement on the course of different SHCs in the long-term.

It should also be taken into account that, at T2, the results were based on a telephone interview by a trained research assistant. This is in contrast to the more objective manner of data collection by the consultation and physical examination by the rehabilitation physician at T1 and T3.

Unfortunately, we could not report data on co-morbid conditions or extra-spinal injuries, since these data were not systematically registered.

Finally, we did not correct for medication use in the logistic random coefficient models, since we had too much missing data on medication use at T3. This is unfortunate, since medication use could have had an effect on the reported SHCs, in particular for problematic spasticity and neuropathic pain.

Conclusion

These results emphasize the importance of a well-coordinated interdisciplinary approach during the follow-up care of persons with SCI living in the community. Since this kind of approach is feasible only at specialised rehabilitation centres, persons with SCI should be encouraged to contact these centres, instead of their general practitioner, in case of SCI-related health problems.

Follow-up care should consist of structured consultations with a rehabilitation physician at set times. In addition to offering adequate treatment in case of SHCs, follow-up care should also be aimed at, for example, an early identification of spinal cord injured persons at risk for certain SHCs and continued patient education on SHCs.

To be able to observe possible changing trajectory patterns of SHCs in persons ageing with SCI, studies such as these need to be conducted for more than 5 years. Future research should also be aimed at exploring which of these SHCs play a role in limiting participation, activity level and quality of life.

The new research project "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury" (ALLRISC) aims at providing us with more knowledge on the health status and functioning of persons aging with SCI living in the Netherlands and it will help us to formulate requirements and guidelines for a lifespan covering rehabilitation aftercare system.[34]

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Chapter 4

Outcomes of neurogenic bowel management in individuals living with a spinal cord injury for at least ten years

Outcomes of neurogenic bowel management in individuals living with a spinal cord injury for at least ten years

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Abstract

Objective To describe bowel management and its outcomes in individuals living with a spinal cord injury (SCI) for at least ten years.

Design Cross-sectional multicentre study.

Setting Dutch community.

Participants Individuals (N=258; age range 28–65y) who acquired their SCI between 18 and 35 years of age, who were at least 10 years post-SCI, and who used a wheelchair for their daily mobility.

Interventions Not applicable.

Main outcome measures The International SCI Bowel Function Basic Data Set, the Neurogenic Bowel Dysfunction (NBD) score, and a single item on satisfaction with bowel management.

Results Mean time since injury (TSI) was 24±9 years. Seventy-four percent used ≥1 conservative bowel management method, specifically digital evacuation (35%) and mini enemas (31%). Transanal irrigation (TAI) and surgical interventions were used by 11% and 8%, respectively. Perianal problems were reported by 45% of the participants. Severe NBD was present in 36% of all participants and in 40% of those using a conservative method. However, only 14% were (very) dissatisfied with their current bowel management. Dissatisfaction with bowel management was significantly associated with constipation and severe NBD. With increasing TSI, there was a non-significant trend observed towards a decline in dissatisfaction with bowel management and a significant decline in severe NBD.

Conclusions Although satisfaction rates were high, more than a third of the participants reported severe NBD and perianal problems. Apart from severe NBD, there were no significant associations between bowel problems and TSI. Conservative methods were most often used, but some of these methods were also significantly associated with the presence of severe NBD. Longitudinal research is necessary to provide more knowledge concerning the course of NBD with increasing TSI.

Introduction

In patients with spinal cord injury (SCI), neurogenic bowel dysfunction (NBD) causes colonic and anorectal dysfunction, resulting in constipation and fecal incontinence. NBD is one of the main secondary health conditions (SHCs) resulting from SCI that hampers an active lifestyle and impacts negatively on quality of life.[1-5] In a Dutch survey, for instance, bowel problems were rated by 42% of 454 participants with SCI as one of the most important SHCs they experienced.[5] Coggrave et al.[6] assessed NBD with a postal questionnaire among 1334 persons who had suffered an SCI at least 1 year ago. The most commonly reported problems were constipation (39.0%), hemorrhoids (36.0%) and abdominal distension (31.0%). In another study, no less than 39.4% of 142 individuals with SCI reported severe NBD according to their NBD score.[7] To date, only one study of NBD after SCI with a longitudinal design has been performed. Faaborg et al.[8] assessed NBD 10 years apart, with a mean time since injury (TSI) of 14 years at the first assessment. The proportion of participants defecating less than every second day increased significantly from 11% to 16% over time, whereas the number of participants reporting fecal incontinence at least once a month decreased significantly from 22% to 17%. The mean NBD score did not change.

Although NBD is common in persons living with SCI, studies have shown that satisfaction with bowel management appears high (80–85%).[6,9] In both studies, satisfaction was significantly associated with the duration and frequency of bowel care.

Bowel management is an individualised bowel routine aimed at a predictable and regular evacuation of the feces, continence and prevention of constipation and perianal problems. It has a stepwise hierarchical approach, beginning with conservative methods such as digital ano-rectal stimulation, digital evacuation and/or the use of rectal laxatives (e.g. suppositories, mini enema). If this does not lead to a satisfactory situation, the next step is transanal irrigation (TAI).[10-12] Finally, surgical interventions such as sacral anterior root stimulation (SARS) and ostomy surgery provide an option when other methods have failed.[13,14]

Several studies, mostly cross-sectional in design and with a mean TSI ranging between 3 and 29 years, have described bowel management and its associations with demographic characteristics, injury-related characteristics and bowel problems in groups of individuals with SCI living in the community.[2-4, 6, 9, 15-19] However, most studies used self-constructed questionnaires so that their results are difficult to compare,[2,4,6,9,17,19] had small sample sizes (N≤100) and therefore lacked precision,[3, 17-19] or only described the use of the conservative approaches.[9,15,16,19]

The aim of the current study was therefore to describe long-term bowel management and NBD in individuals who have been living with an SCI for at least 10 years in the Netherlands. This study is part of the Dutch multicentre research programme called "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury".[20] Research questions of the current study were as follows: First, which bowel management methods are currently used by individuals with long-term SCI? For this purpose, bowel management was divided into four categories: no intervention, conservative bowel management, TAI and surgical bowel management. Second, what is the prevalence of perianal problems, constipation, fecal incontinence, severe NBD, and dissatisfaction with current bowel management? Finally, what are the associations between demographic and injury-related characteristics and bowel management, severe NBD, and satisfaction with bowel management?

Methods

Design

This study was a TSI-stratified cross-sectional study among individuals with long-term SCI living in the Netherlands. TSI strata were 10–19, 20–29, and ≥30 years after SCI. It was aimed to include 100 individuals per stratum.

Participants

Inclusion criteria were as follows: (1) traumatic or non-traumatic SCI with a TSI of at least 10 years; (2) age at injury between 18 and 35 years; (3) current age between 28 and 65 years; and (4) using a wheelchair (hand-rim propelled or electric), at least for longer distances (>500 m). Persons were excluded if they had insufficient mastery of the Dutch language to respond to an oral interview.

Procedure

Eligible individuals were identified through databases from all eight Dutch rehabilitation centres specialising in SCI rehabilitation. In the first round, 62 individuals per centre were invited for the study. If the number of eligible individuals allowed it, a random sample per centre was drawn. If the response was less than 30–35 individuals per centre, an additional sample was drawn at that centre.

The study consisted of a one-day visit to the rehabilitation centre for a check-up including an extensive medical assessment and physical examination performed by a rehabilitation physician and an oral interview and several physical tests performed by a research assistant.[21] Two weeks before the visit to the rehabilitation centre, participants were asked to complete a self-report questionnaire.[21]

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Data on medication use was extracted from consultation with the physician and medical file.

Bowel management and bowel problems were described using the International SCI Bowel Function Basic Data Set, a standardised 12-item assessment of bowel function.[22] Digital evacuation was defined as the need to dig out stools from the bowel with a finger. Digital ano-rectal stimulation was defined as digital (manual) triggering of rectal contractions and anal relaxation to cause rectal emptying. In contrast with the Data Set, we did not differentiate between main and supplementary defecation methods. For the categorisation of the four bowel management strategies (no intervention, conservative, TAI, surgical), we only reported the use of the most invasive defecation method. For instance, if a participant used a combination of TAI and digital evacuation, he/she was included in the TAI category and not in the conservative category. Furthermore, we used a time frame of 3 months instead of 4 weeks to avoid short-term fluctuations in the chronic situation.

In addition to this Data Set, constipation during the last 3 months was recorded according to the Rome III criteria;[23] 2 items regarding the participant's ability to perform bowel management were included from the Spinal Cord Independence Measure, version III;[24] and 1 question was asked about the participant's satisfaction with current bowel management on a 5-point scale from very satisfied to very dissatisfied.

The International Standards for Neurological Classification of Spinal Cord Injury were used to assess lesion characteristics.[25] Tetraplegia was defined as a lesion at or above the first thoracic segment, and paraplegia was defined as a lesion below the first thoracic segment. A complete lesion was diagnosed in the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A. AIS grades B, C, and D were considered to represent an incomplete lesion.

The NBD score is a 10-item symptom-based score for NBD in individuals with SCI.[26] It covers both constipation and fecal incontinence. The maximum total NBD score is 47 points. The interpretation of the total NBD score is very minor NBD (0–6), minor NBD (7–9), moderate NBD (10–13), and severe NBD (≥14).

Statistics

Descriptive analyses were used to describe participants' demographic and injury-related characteristics, bowel management, frequency of reported bowel problems, and satisfaction with bowel management.

The Chi-square test was used to explore associations between the categorical variables. Because age and total NBD score were normally distributed, the independent samples *t*-test was used to compare two independent groups regarding these continuous measures. TSI was not normally distributed; therefore, the Mann-Whitney *U* test was used to test for differences between two independent groups regarding this continuous measure.

Chi-square tests were used to test associations between different categorical variables and the four bowel management categories. Significant differences in mean age between the bowel management categories were tested using one-way between-group analysis of variance, whereas the Kruskal-Wallis test was used for the same purpose for the TSI variable. In case of a significant association, we explored the association further by comparing each bowel management category with each of the other three, leading to six comparisons.

Associations between modes of bowel management and other variables were assessed one by one, each comparing the subgroup of participants using a particular bowel management method with all other participants. This was chosen because of the relatively large number and mostly small size of the bowel management subgroups.

We controlled for type I errors by applying a Bonferroni correction for a number of analyses. First, this was done for the associations between bowel management categories and demographic and injury-related characteristics (significance set at $P<0.0083$). Second, it was applied for the associations of bowel management with bowel problems and satisfaction with bowel management (significance set at $P<0.00625$). Third, it was applied for the associations between satisfaction with bowel management and bowel problems (significance set at $P<0.01$).

Finally, variables showing a significant bivariate association with severe NBD and with satisfaction with bowel management were included in a multiple logistic regression analysis.

All analyses were performed using the SPSS statistical software program (SPSS version 21.0 for windows; IBM corp.; Armonk, New York).

Results

Participant characteristics

Between November 2011 and February 2014, a total of 282 individuals participated in the check-up, 258 (91.5%) of whom also completed the self-reported questionnaire and were included in the current study. The characteristics of this sample are described in Table 4.1. Completeness of the lesion and age were the only demographic- or injury-related characteristics significantly associated with TSI. There was a significant increase in age ($P<0.001$) and a significant decrease in complete motor and sensory lesions ($P=0.009$) with increasing TSI.

Bowel management

Table 4.2 summarises the bowel management results. The most commonly used defecation methods (as main or supplementary method) were digital evacuation (35%) and mini enemas (31%).

Relations between demographic characteristics and the four bowel management categories are displayed in Table 4.1. Participants using surgical bowel management were significantly older ($P=0.008$) and had a significantly longer TSI ($P=0.002$) than those using TAI. They also had a significantly longer TSI than those using a conservative bowel management method ($P=0.002$). The no intervention group included significantly fewer participants with complete SCI than the other bowel management groups ($P<0.001$ for all three comparisons).

Bowel problems

Reported perianal problems are also shown in Table 4.2. Forty-five percent of the participants had experienced ≥1 perianal problem over the last 3 months. Hemorrhoids (39%) and constipation (25%) were the most frequently reported problems.

Table 4.1 Participant characteristics (N=258)

	Total (N=258)	No inter-vention (N=19)	Conservative bowel management (N=190)	Transanal irrigation (N=29)	Surgical bowel man-agement (N=20)	Sig.
Age (years) mean (range)	48 (29–65)	52 (34–65)	48 (29–65)	45 (29–64)	54* (43–65)	**0.003**
Gender (% male)	73	55	75	77	52	0.088
Cause (% traumatic)	90	75	88	100	95	0.085
Level (% tetraplegia)	40	32	41	41	40	0.890
ASIA Impairment Scale (AIS), (%)						
A	70	20§	71	80	80	**<0.001**
B	12	10	13	10	10	
C	9	15	10	3	10	
D	9	55	6	7	0	
Time since injury (years) mean (range)	24 (10–47)	29 (10–47)	24 (10–47)	22 (10–46)	29† (14–42)	**<0.001**
Time since injury strata (%)						
10–19 years	36	21	38	55	5	
20–29 years	35	21	37	24	40	
≥30 years	29	58	25	21	55	

Significant associations (*P*<0.0083) are printed in **bold**.
* Participants using surgical bowel management were significantly older than those using transanal irrigation (*P*=0.008).
§ The no intervention group included significantly fewer participants with complete SCI than the other three bowel management groups (*P*<0.001 for all three comparisons).
† Participants using surgical bowel management had a significantly longer TSI than participants with conservative bowel management (*P*=0.002) and those using transanal irrigation (*P*=0.002).

Figure 4.1 shows the proportion of participants reporting bowel problems in each of the three TSI groups. Table 4.3 shows the proportion of participants reporting bowel problems for each defecation method. Significant associations are also displayed.

NBD score

Overall, 36% percent of the participants suffered from severe NBD. The proportion of participants with severe NBD decreased over time from 44% to 26% (Figure 4.1), and an increase in TSI was significantly correlated with a decrease in the total NBD score (ρ=-0.183, *P*=0.003). Experiencing severe NBD was associated with the use of suppositories and digital

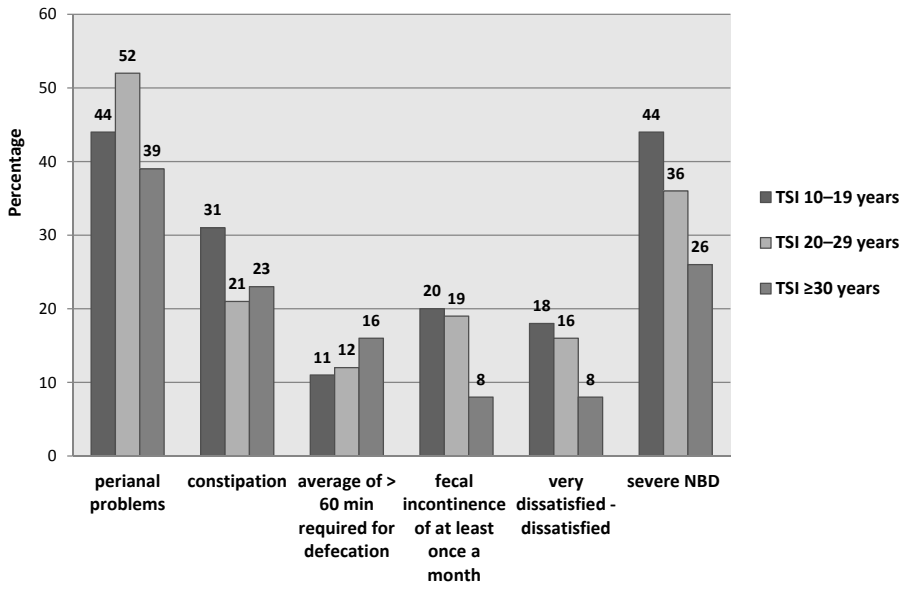

Figure 4.1 Proportion of participants reporting bowel problems by TSI group.

Table 4.2 Description of bowel function according to the International Bowel Function Basic Data Set (Version 1.1)

Item	N (%)
Gastrointestinal or anal sphincter dysfunction unrelated to the spinal cord lesion	
No	245 (95.0)
Yes	12 (4.7)
Unknown	1 (0.4)
Surgical procedures on the gastrointestinal tract	
No	177 (68.6)
Appendicectomy	18 (7.0)
Cholecystectomy	18 (7.0)
Colostomy	7 (2.7)
Ileostomy	6 (2.3)
Other	31 (12.0)
Hemorrhoidectomy	12 (4.7)
SARS implantation	19 (7.4)
Prolaps surgery	3 (1.2)
Closure of intestinal perforation	3 (1.2)
Closure of gastric perforation	2 (0.8)
Other	14 (5.4)
Unknown	0 (0.0)
Awareness of the need to defecate	
Normal	43 (16.7)
Indirect	116 (45.0)
None	99 (38.4)
Unknown	0 (0.0)

Table 4.2 ***Continued***

Item	N (%)
Defecation method and bowel care procedures	
Normal defecation	19 (7.4)
Straining/bearing down to empty	31 (12.0)
Digital ano-rectal stimulation	40 (15.5)
Suppositories	47 (18.2)
Digital evacuation	89 (34.5)
Mini enema (clysma ≤150 mL)	80 (31.0)
Enema (>150 mL)	6 (2.3)
Colostomy	7 (2.7)
Sacral anterior root stimulation	8 (3.1)
Other method, specify:	
Ileostomy	5 (1.9)
Transanal irrigation	29 (11.2)
Tapping / abdominal massage	4 (1.6)
Average time required for defecation	
0–5 minutes	45 (17.4)
6–10 minutes	41 (15.9)
11–20 minutes	29 (11.2)
21–30 minutes	40 (15.5)
31–60 minutes	55 (21.3)
More than 60 minutes	33 (12.8)
Unknown	3 (1.2)
Not applicable (stomas)	12 (4.7)
Frequency of defecation	
Three times or more per day	6 (2.3)
Twice daily	13 (5.0)
Once daily	81 (31.4)
Not daily but more than twice every week	123 (47.7)
Twice every week	26 (10.1)
Once every week	2 (0.8)
Less than once every week, but at least once within the last four weeks	1 (0.4)
No defecation the last four weeks	0 (0.0)
Unknown	6 (2.3)
Frequency of fecal incontinence	
Two or more episodes per day	2 (0.8)
One episode per day	0 (0.0)
Not every day but at least once per week	13 (5.0)
Not every week but more than once per month	10 (3.9)
Once every month	17 (6.6)
Less than once per month	73 (28.3)
Never	137 (53.1)
Unknown	6 (2.3)
Need to wear pad or plug	
Daily use	27 (10.5)
Not every day but at least once per week	3 (1.2)
Not every week but at least once per month	4 (1.6)
Less than once per month	4 (1.6)
Never	212 (82.2)
Unknown	8 (3.1)

Table 4.2 ***Continued***

Item	N (%)
Medication affecting bowel function / constipating agents	
No	160 (62.0)
Yes, anticholinergics	55 (21.3)
Yes, narcotics	10 (3.9)
Yes, other, specify	
NSAIDs	18 (7.0)
Antiepileptic drugs	22 (8.6)
Bisfosfonates	10 (3.9)
Calcium carbonate	9 (3.5)
Calcium antagonists	6 (2.5)
SSRIs	7 (2.7)
Oral laxatives	
No	154 (59.7)
Yes, osmotic laxatives	65 (25.2)
Yes, bulking laxatives	48 (18.6)
Yes, irritant laxatives	28 (10.9)
Yes, prokinetics	0 (0.0)
Yes, other, specify:	0 (0.0)
Unknown	2 (0.8)
Perianal problems	
None	142 (55.0)
Haemorrhoids	101 (39.1)
Perianal sores	6 (2.3)
Fissures	10 (3.9)
Rectal prolapse	10 (3.9)
Other, specify	
Rectal bleeding	4 (1.6)
Perianal abscess	1 (0.4)
Unknown	0 (0.0)

evacuation (Table 4.3). Severe NBD was also positively associated with completeness of the lesion (P=0.010) and was negatively associated with increasing age (P=0.038).

A multiple logistic regression analysis with severe NBD as the dependent variable showed that completeness of the lesion (odds ratio [OR]=1.98, P=0.046), use of suppositories (OR=4.02, P<0.001), and digital evacuation (OR=2.40, P=0.003) were significant predictors of severe NBD.

Satisfaction with bowel management

Fourteen percent of the participants (N=37) were dissatisfied or very dissatisfied with their bowel management. Participants who used digital ano-rectal stimulation were most likely

Table 4.3 Proportion of participants reporting bowel problems, severe NBD, and dissatisfaction by defecation method

	Perianal problems (%)	Constipation (%)	An average of >60 minutes required for defecation (%)	Fecal incontinence of at least once a month (%)	Severe NBD (%)	(very) Dissatisfied (%)
Total (N=258)	45.0	25.2	12.8	16.3	36.1	14.3
No intervention (N=19)	26.3	31.6	0.0	10.5	**5.3** ***P*=0.002** **OR=0.09**	0.0
Conservative bowel management						
Straining / bearing down to empty (N=31)	45.2	29.0	0.0	19.4	22.6	19.4
Digital ano-rectal stimulation (N=40)	57.5	**45.0** ***P*=0.003** **OR=2.98**	12.5	15.0	55.0	25.0
Suppositories (N=47)	48.9	25.5	**38.3** ***P*<0.001** **OR=8.11**	17.0	**57.8** ***P*=0.002** **OR=2.99**	19.1
Digital evacuation (N=89)	51.7	20.2	15.7	13.5	**51.1** ***P*<0.001** **OR=2.67**	16.9
Mini enema (clysma ≤150 mL) (N=80)	56.3	27.5	5.0	13.8	41.3	13.8
Transanal irrigation (N=29)	41.4	27.6	24.1	34.5	41.4	17.2
Surgical bowel management (SARS, colostomy/ileostomy) (N=20)	20.0	10.0	10.0*	10.0	21.1	10.0§

Significant associations are printed in **bold**.
Only significant associations ($P<0.00625$) are shown.
* Not applicable for colostomy / ileostomy.
§ All of these participants were SARS users.

to be dissatisfied with their bowel management (Table 4.3). No association between bowel management methods and satisfaction with bowel management was found, however (Table 4.3). Dissatisfaction with bowel management was associated with having perianal problems (P=0.005), constipation (P=0.001), and severe NBD (P<0.001). Twenty-six percent of the participants with severe NBD were dissatisfied or very dissatisfied, compared with 8.0% of those without severe NBD.

No associations were found between satisfaction with bowel management and demographic (age, gender) or lesion characteristics (TSI, completeness, tetraplegia/paraplegia, traumatic/non-traumatic). The need for help with defecation was not associated with satisfaction with bowel management either.

A multiple logistic regression analysis with satisfaction with bowel management as the dependent variable showed that constipation (OR=3.16, P=0.003) and severe NBD (OR=3.53, P=0.001) were significant predictors of dissatisfaction with bowel management.

Discussion

The present study is one of the few studies addressing bowel management and NBD in individuals with long-term SCI. Conservative defecation methods were the most frequently used across all three TSI strata. We did not find indications for a decrease in bowel function over time: longer TSIs were associated with less severe NBD, and TSI was unrelated to satisfaction with bowel management.

Two previous studies also reported digital evacuation to be the most commonly used intervention.[2,6] The reported use of suppositories (18%) is in the lower range of previously reported percentages (15%–54%).[2,4,6,16] The use of mini enemas (31%) was higher than the 6% to 11% use of enemas described elsewhere.[2,4,6,16] In the Netherlands, suppositories for suprasacral lesions are generally prescribed when bowel management is done in a supine position, and mini enemas are prescribed when this is done in a sitting position.

TAI was used by only 11% of the participants, and even fewer participants (8%) had undergone a surgical intervention as part of their bowel management. Three percent reported having had a colostomy, 3.5% reported having SARS, and 1.9% reported having an ileostomy. Coggrave et al.[6] reported a similar percentage for colostomies (2.4%) but a lower percentage for SARS (0.5%). These small percentages illustrate the hierarchical

stepwise approach in the treatment of NBD and suggest possible reluctance to advise surgical interventions for bowel management.[14]

The proportion of participants with perianal problems was relatively large (45%). Twenty-five percent reported having complaints of constipation, which is lower than the percentages that have been described in previous studies (39–58%).[3,6,15,17] Severe NBD was present in 36% of all participants. A notable finding was that 41% of the participants using TAI reported severe NBD, which was nearly double the percentage reported by participants using a surgical defecation method. This incidence of severe NBD is similar to the 39% reported by Liu et al.[7] However, in contrast with our findings, Liu et al.[7] reported longer duration of injury (TSI ≥10 years) to be a risk factor for severe NBD. One possible explanation for these diverging results is that we did not include individuals with a TSI <10 years. Alternatively, because NBD also reflects the severity of the SCI, the significantly lower percentage of participants with complete motor and sensory lesions in the longest TSI group might partially explain the decline in severe NBD. Furthermore, Krause et al.[27] suggested that individuals who survive the longest after SCI are those with better adjustment patterns. It therefore seems plausible that individuals who have survived the first 3 decades after SCI are those who are less prone to SHCs like severe NBD.

The levels of satisfaction with bowel management we found were relatively high and contrasted with the prevalence of perianal problems and severe NBD. This might be explained by some kind of acceptance of the situation regarding bowel problems which has grown over the years. Furthermore, the bowel problems may have been worse and more unsatisfactory in the past. Similar levels of satisfaction were found in previous studies.[6,9] Fifty-seven percent of the participants dissatisfied with severe NBD used a combination of conservative defecation methods, which means that it is especially this group of patients who needs our attention during follow-up care.

We observed a trend towards greater satisfaction with bowel management with increasing TSI. This may be correlated with the observed decline in severe NBD over time or it might illustrate increased acceptance with the current situation concerning bowel function and bowel management. Longitudinal research is necessary to clarify this matter.

Implications

Our study shows that conservative bowel management methods were most often used; however, some of these conservative methods were associated with severe NBD. Our results emphasize that during follow-up, clinicians must continuously evaluate whether the current bowel management methods are still satisfactory or whether interventions (e.g. TAI or surgical procedures) should be considered. Our results show that TAI was not successful in all participants using this method. However, we may assume that they used TAI because their previous bowel management was even less satisfactory. If TAI does not result in a satisfactory situation, surgical procedures can be the next step.[14] A systematic review of the outcomes in patients with SCI and gastrointestinal symptoms managed by conservative interventions versus colostomy or ileostomy showed that a significant proportion of the patients who underwent ostomy surgery were satisfied with their surgery, and in retrospect, 86 to 92% of them would have liked to be counselled about this option earlier.[28] This is in accordance with our study results because none of the participants who underwent ostomy surgery were dissatisfied with their bowel management. In view of these data and the current literature, these surgical procedures may provide a solution for individuals who use conservative methods but experience severe NBD and dissatisfaction with their bowel management.

Longitudinal research focusing on the effects of aging with SCI in general and the impact on the gastrointestinal tract in particular is necessary to provide more knowledge concerning the course of NBD with increasing TSI. Moreover, there is a need for more knowledge about the long-term effects of TAI and surgical interventions for NBD, so that patients and clinicians can make a considered decision about switching from a conservative intervention.

Study limitations

The cross-sectional design of this study limits the possibilities to interpret associations with TSI caused by a possible (onset) cohort effect. The inclusion criteria also meant that our study sample consisted of a selected group, predominantly including participants with a traumatic and complete SCI who had acquired their SCI at a relatively young age. This does not correspond with the general SCI population.[29] Furthermore, our analyses were exploratory and hampered by the limited number of participants in several bowel management groups.

Conclusion

Over one-third of the participants in this study reported severe NBD and perianal problems. Satisfaction with bowel management was nevertheless high and there was, in contrast with our expectations, a decline in severe NBD with increasing TSI and a trend towards a decline in dissatisfaction with bowel management. Conservative bowel management methods were most often used, but the results of this study suggest that therapeutic interventions like TAI and surgical procedures might be considered more often in case of severe NBD and dissatisfaction with bowel management.

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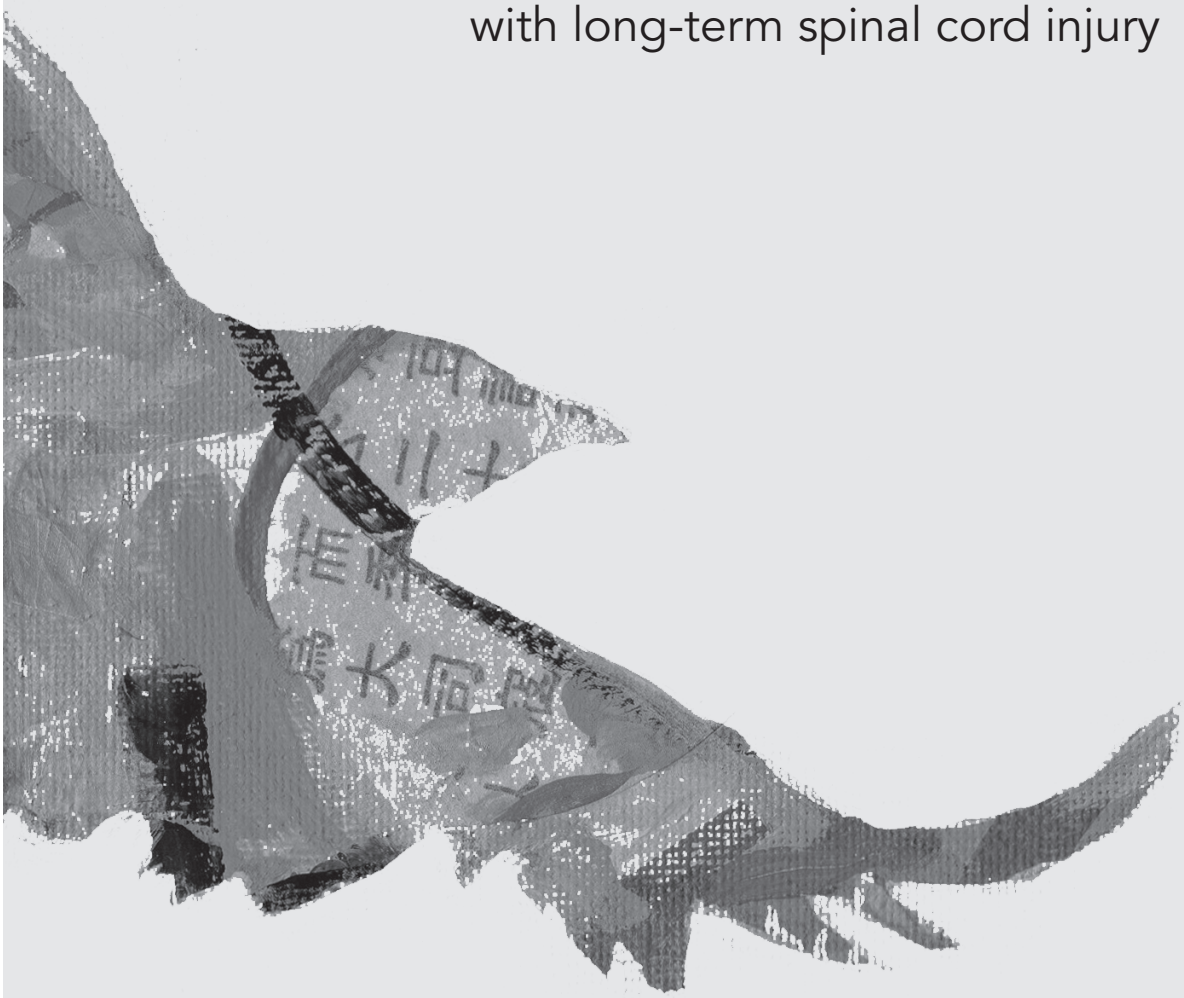
Chapter 5

Bladder-emptying methods, neurogenic lower urinary tract dysfunction and impact on quality of life in people with long-term spinal cord injury



Bladder-emptying methods, neurogenic lower urinary tract dysfunction and impact on quality of life in people with long-term spinal cord injury

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Abstract

Objectives To describe bladder-emptying methods used by people with long-term spinal cord injury (SCI) and to determine usage differences in relation to time since injury, gender, lesion level and completeness of lesion. Furthermore, to evaluate the relationship between bladder-emptying methods and the impact of neurogenic lower urinary tract dysfunction (NLUTD) on quality of life (QoL).

Design Cross-sectional multicentre study.

Setting Dutch community.

Participants Persons dependent on wheelchairs (N=282) with traumatic or non-traumatic SCI for ≥10 years and age at injury of 18–35 years.

Interventions Not applicable.

Outcome measures The International Lower Urinary Tract Function Basic SCI Data Set and the Short-Form Qualiveen (SF-Qualiveen).

Results Median time since injury was 22.0 years (IQR: 16.8–30.3). Clean intermittent catheterisation (CIC) was most commonly used (42.6%). Longer time since injury was associated with fewer continent urinary diversions and more transurethral catheter use. Transurethral catheter use and continent urinary diversions were more prevalent among women. Participants with tetraplegia were more likely to use reflex voiding or a suprapubic catheter, and participants with paraplegia were more likely to use CIC. Transurethral catheter users reported the highest impact of NLUTD on QoL (SF-Qualiveen score: 1.9; SD=0.8). Participants with a continent urinary diversion reported the lowest impact (SF-Qualiveen score: 0.9; SD=0.6). Higher age and indwelling catheter use versus CIC were associated with a higher impact of NLUTD on QoL.

Conclusions CIC is the most common bladder-emptying method in Dutch people with long-term SCI. Clinicians should be aware of the impact of NLUTD on QoL, especially for those using an indwelling catheter.

Introduction

A spinal cord injury (SCI) may interrupt the communication between the pontine micturition centre and the spinal cord, causing neurogenic lower urinary tract dysfunction (NLUTD) which can include detrusor overactivity, detrusor sphincter dyssynergia, hypocontractile detrusor, sphincter insufficiency and impaired bladder compliance. NLUTD may give rise to incontinence and bladder-emptying difficulties and may result in urological complications such as urinary tract infections (UTIs), vesico-ureteral reflux, hydronephrosis, urolithiasis and ultimately renal failure.

Proper bladder management is an important element of SCI rehabilitation. Its goal is to maintain continence, to prevent urological complications, to preserve upper and lower urinary tract function and to make bladder management compatible with the person's lifestyle and environment. Conservative bladder-emptying methods include: bladder reflex triggering, bladder expression, clean intermittent catheterisation (CIC), or the use of an indwelling transurethral catheter. A more invasive method is a suprapubic catheter. Surgical bladder-emptying methods include: sacral anterior root stimulation (SARS), incontinent urinary diversions (ileal conduit, colon conduit) and continent urinary diversions (catheterisable pouches like the Indiana pouch or catheterisable channels like the Mitrofanoff procedure).

However, despite all rehabilitation efforts and advances in surgical treatment options, NLUTD remains one of the most frequently reported health issues among people with SCI.[1,2] In a Dutch survey, problems with bladder regulation were reported by 71% of 454 participants with SCI, and 52% rated these as one of their most important health issues.[1] In addition, urological complications such as UTIs have been described as the leading cause of rehospitalisations after traumatic SCI.[3,4]

Previous studies have shown that NLUTD is associated with lower quality of life (QoL) in people with SCI.[5,6] However, conflicting results have been published regarding the relationship between different bladder-emptying methods and QoL. While two studies found that QoL seemed most affected in people using CIC by an attendant[7,8] and in those with an indwelling catheter,[7] another study found no differences in QoL with regard to bladder-emptying method.[9] This discrepancy might be caused by the use of different generic health-related QoL (HRQoL) instruments.[7-9] Furthermore, generic measures may be less sensitive to condition-specific problems such as NLUTD. To date, only two studies are available in which a domain-specific QoL instrument, the Qualiveen,[10] was used to measure

the impact of NLUTD in people with SCI.[6,11] However, both studies focused on just one specific bladder-emptying method.

Few studies have described long-term use of bladder-emptying methods in relation to time since injury (TSI).[2,12-16] Conflicting results have been published concerning the use of CIC over time.[2,12,13] One study reported an increase in CIC use from 11% at initial discharge to 36% at a mean TSI of 24 (10–45) years.[13] Another study reported a decrease in CIC use from 46% at discharge to 14% at 30 years after injury.[12] This study also showed an increase in indwelling catheter use from 23% to 45% in the same period and a decrease in the use of condom catheters, with 35% of individuals continuing to use condom catheters at 30 years after injury.[12]

People with SCI may change their bladder-emptying method even long after the onset of SCI. A longitudinal study among people who had had an SCI for at least 20 years found that no less than 29% of the participants had changed their bladder-emptying method during the 6-year follow-up period.[14]

Not enough is known about the distribution of bladder-emptying methods among people with long-term SCI and about the relationship between different bladder-emptying methods and the impact of NLUTD on QoL. This has led to the following research questions:

- Which bladder-emptying methods are currently being used by people with long-term SCI living in the Netherlands?
- Are there differences in the use of bladder-emptying methods in relation to different TSI periods (10–19 years, 20–29 years and ≥30 years), gender, spinal cord lesion level and completeness of the injury?
- Which demographic or injury-related characteristics and types of bladder-emptying methods are associated with a greater impact of NLUTD on QoL?

Methods

This study is part of the Dutch multicentre research programme 'Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)',[17] a TSI-stratified cross-sectional study among people with long-term SCI living in the Netherlands. TSI strata were 10–19, 20–29 and 30 years or more after SCI. We aimed to include 100 persons per stratum.

Participants

Inclusion criteria were: (1) traumatic or non-traumatic SCI with a TSI of ≥10 years, (2) age at injury between 18 and 35 years, (3) current age between 28 and 65 years, (4) using a wheelchair (hand-rim propelled or electric wheelchair), at least for longer distances (>500 m). We choose the restriction to persons aged 18–35 years at onset of SCI in order to minimize the confounding effect of age at injury. By restricting our study to persons who suffered from SCI at a relatively young age, and mostly without any co-morbidity at the onset of SCI, we expected to be better able to study long-term consequences of the SCI itself. The exclusion criterion was insufficient mastery of the Dutch language.

Since the ALLRISC research programme aims to analyse associations between secondary health conditions and participation and QoL, accounting for the influence of demographic and injury-related variables, we performed the following power calculation. With alpha = 0.05 and power = 0.80, a prevalence of a particular secondary health condition of 0.2 can be estimated with a margin of error of ±4.6%. A prevalence difference of 0.2 (0.3 versus 0.5) between two TSI strata with 100 participants each would be statistically significant with the same alpha and power. For the exploratory regression analysis, this number of 300 participants allows inclusion of 19 independent variables in the analysis, using the rule of thumb of 15 participants per variable.

Procedure

Eligible persons were identified in databases from all eight Dutch rehabilitation centres specialising in SCI rehabilitation. Since we aimed to include 30–35 persons per centre, and expected a response rate of around 50%, 62 persons per centre were invited for the study. If the number of eligible persons allowed it, a random sample was drawn at each centre. If the response was less than 30–35 persons per centre, an additional sample was drawn at that centre.

The study consisted of a one-day visit to the rehabilitation centre for a check-up, including an extensive medical assessment and physical examination, performed by an SCI rehabilitation physician, and an oral interview and several physical tests, performed by a research assistant.[17] Two weeks before the visit to the rehabilitation centre, participants were asked to complete a self-report questionnaire.[17]

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Personal characteristics: The self-report questionnaire included questions concerning age, nationality, relationship status, educational level, and employment.

Medication use and urological medical history were addressed in the consultation with the rehabilitation physician, and further data was retrieved from the medical file if applicable.

Lesion characteristics: The International Standards for Neurological Classification of Spinal Cord Injury were used by the rehabilitation physician to assess lesion characteristics.[18] Tetraplegia was defined as a lesion at or above the first thoracic segment, and paraplegia as a lesion below the first thoracic segment. Complete lesion was defined as the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A. AIS grades B, C, and D were classified as an incomplete lesion.

Date of onset of SCI, age at injury and cause of the injury were asked for in the self-report questionnaire.

Bladder-emptying methods: The International Lower Urinary Tract Function Basic SCI Data Set was used by all physicians for the standardised assessment of bladder management.[19] This data set includes items on urinary tract impairment unrelated to spinal cord lesion, awareness of the need to empty the bladder, main and supplementary bladder-emptying methods, frequency of incontinence over the last 3 months, use of collecting appliances for urinary incontinence, any medication use for the urinary tract, surgical procedures on the urinary tract and any change in urinary symptoms (changes in presentation of UTI, in frequency, urgency, incontinence, hesitancy) during the previous year.[19] The distinction between main and supplementary bladder-emptying methods was made by determining which method was used most frequently (the main method) and which method(s) was used in a supplemental manner with a lesser frequency.

The only adaptation we made was that we recorded the use of a condom catheter separately, instead of classifying it as involuntary bladder reflex triggering.

Incontinence: Incontinence was operationalised as any involuntary leakage of urine. No involuntary urine leakage implied no leakage of urine outside the urinary tract or a closed urinary collection system.[19]

Urinary tract infections: Participants were asked about UTIs within the last 3 months. UTI was defined as a symptomatic infection of the urinary tract, treated with antibiotics. Symptoms had to include one or more of the following: onset of urinary incontinence, increased spasticity, malaise, autonomic dysreflexia, discomfort or pain during urination, gritty particles or mucus in the urine or cloudy urine with increased odor.

Urinary specific QoL: The self-report questionnaire included the Short-Form Qualiveen (SF-Qualiveen).[20] This is an 8-item instrument developed for people with neurogenic bladder problems. The 8 items are distributed over four domains, including 'bother with limitations', 'frequency of limitations', 'fears' and 'feelings'. A total SF-Qualiveen score (range 0–4) is calculated as the average of the item scores. The lower the score, the lower the impact of NLUTD on QoL.

Statistics

Descriptive statistics were used to describe participants' demographic and injury-related characteristics, bladder-emptying methods and SF-Qualiveen scores.

There were some missing values for some variables (nationality, relationship status, level of education, employment and SF-Qualiveen score) since not all participants completed the self-report questionnaire. These missing data were not included in the descriptive analyses. There were no missing data on the participants' bladder-emptying method.

The Chi-square test was used to explore associations between TSI groups and categorical variables, such as gender and level of SCI.

Associations between bladder-emptying methods and other variables were assessed one by one using the Chi-square test, each time comparing the subgroup of participants using a particular bladder-emptying method with all other participants. This was done because of the relatively large number and mostly small size of the bladder-emptying subgroups.

Since age and the SF-Qualiveen score were normally distributed, the independent samples *t*-test was used to compare two independent groups regarding these continuous measures.

One-way ANOVA was used to test for differences in age for the three TSI groups. Age at injury was not normally distributed, so the Mann Whitney *U* test was used to assess differences between two independent groups regarding this continuous measure. The Kruskal-Wallis Test was used to assess differences in age at injury between the three TSI groups.

Bivariate regression analysis was used to study the relationships between demographic and injury-related characteristics and bladder-emptying methods with the SF-Qualiveen score. We first calculated the predictive value of each independent variable separately, and then used multiple regression analysis to explore how much of the variance of the SF-Qualiveen score was explained by a set of independent variables. Bladder-emptying method was included as a set of six dummy variables with CIC as the reference category, since CIC has been described as the gold standard for bladder-emptying.[21]

We dealt with missing data by using pairwise deletion of cases with missing values.

All analyses were performed using the SPSS statistical software (SPSS 21.0 for Windows; IBM corp; Armonk, NY, USA).

Results

Participant characteristics

Between November 2011 and February 2014 a total of 566 persons were invited to participate in the study, 292 of whom were ultimately included. The main reasons for non-participation were a large travel distance, unwillingness, too busy with daily life, and health issues. After the inclusion procedure there were 10 participants who in retrospect did not meet all the inclusion criteria and were therefore excluded from the analyses. A total of 266 participants (94.3%) completed the self-report questionnaire. The characteristics of the participants (N=282) are described in Table 5.1. We were not able to perform a non-response analysis since not all of the participating rehabilitation centres could provide us with the required information concerning the non-respondents.

Table 5.2 presents the scores on the items of the International Lower Urinary Tract Function Basic SCI Data Set, including the reported bladder-emptying methods. Twenty-seven percent of the participants reported being incontinent at least once a month, 58.5% used a collecting appliance for urinary incontinence, 22.7% used bladder relaxant drugs and 19.1%

Table 5.1 Participant characteristics, N=282

	Total (N=282)	TSI 10–19 years (N=107)	TSI 20–29 years (N=96)	TSI ≥30 years (N=79)	Sig.
Age (years), mean (SD)	48.3 (8.9)	40.8 (5.4)	48.5 (5.7)	58.3 (5.2)	<0.001
Age at injury (years), median (IQR)	23.4 (20.6–27.8)	25.3 (21.6–29.2)	23.5 (20.9–28.5)	21.3 (19.4–24.3)	<0.001
Gender (% male)	74	72	80	70	0.229
Nationality (% Dutch)*	96	94	98	97	0.315
Cause (% traumatic)	91	94	92	87	0.231
Level (% tetraplegia)	41	42	43	39	0.896
Cervical (%)	41	42	43	39	0.398
Thoracal (%)	53	49	54	56	
Lumbal (%)	6	9	3	5	
Relationship (% married/stable relationship)*	61	57	64	62	0.586
Level of education (% college/university)*	44	45	48	40	0.549
Employment (% having paid work ≥1 hour/week)*	39	48	39	28	0.023
ASIA Impairment Scale (AIS), (%)					0.170
A	69	74	70	59	
B	14	11	10	20	
C	10	10	10	8	
D	8	5	8	13	
Time since injury (years), median (IQR)	22.0 (16.8–30.3)	-	-	-	-

* Data extracted from the self-report questionnaire: N=268.

Table 5.2 International Lower Urinary Tract Function Basic Spinal Cord Injury Data Set (N=282)

Item	N (%)	
Urinary tract impairment unrelated to spinal cord lesion		
No	274 (97.2)	
Yes	8 (2.8)	
Unknown	0 (0.0)	
Awareness of the need to empty the bladder		
No	77 (27.3)	
Yes	43 (15.2)	
Indirectly (i.e. by spasms, unpleasant sensations, abdominal cramps, headache, sweating)	158 (56.0)	
Unknown	4 (1.5)	
Bladder-emptying	*Main:*	*Supplementary:*
Normal voiding	21 (7.4)	1 (0.4)
Bladder reflex triggering:		
Voluntary (tapping, scratching, anal stretch, etc.)		
Independently	27 (9.6)	16 (5.7)
By attendant	4 (1.4)	3 (1.1)
Bladder expression:		
Straining (abdominal straining, Valsalva's manoeuvre)	6 (2.1)	1 (0.4)
External compression (Credé manoeuvre)	0 (0.0)	2 (0.7)
Intermittent catheterisation:		
Self-catheterisation (*excluding catheterisation of a continent urinary diversion*)	113 (40.1)	14 (5.0)
Catheterisation by attendant	7 (2.5)	7 (2.5)
Indwelling catheter:		
Transurethral	9 (3.2)	0 (0.0)
Suprapubic	32 (11.3)	0 (0.0)
Sacral anterior root stimulation	15 (5.3)	0 (0.0)
Incontinent urinary diversion / ostomy	8 (2.8)	0 (0.0)
Other method, specify:		
Collection of urine in condom catheter	32 (11.3)	65 (23.0)
Continent urinary diversion	8 (2.8)	0 (0.0)
Unknown	0 (0.0)	0 (0.0)
Any involuntary urine leakage (incontinence) within the last 3 months		
No	164 (58.2)	
Yes, average daily	27 (9.6)	
Yes, average weekly	28 (9.9)	
Yes, average monthly	21 (7.4)	
Yes, less than once per month	40 (14.2)	
Not applicable	0 (0.0)	
Unknown	2 (0.7)	
Collecting appliances for urinary incontinence		
No	117 (41.5)	
Yes, condom catheter / sheath	104 (36.9)	
Yes, absorbing appliances: diaper / pad / panty liner	64 (22.7)	
Yes, ostomy bag	7 (2.5)	

Table 5.2 continues on next page

Table 5.2 ***Continued***

Item	N (%)
Any drugs for the urinary tract	
No	155 (55.4)
Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressants, etc.)	64 (22.7)
Yes, sphincter / bladder neck relaxant drugs (alpha adrenergic blockers etc.)	13 (4.6)
Yes, antibiotics / antiseptics:	
For treatment of urinary tract infection	1 (0.4)
For prophylactic reasons	54 (19.1)
Yes, other, specify:	
Reflux (methenamine)	12 (4.3)
For prophylactic reasons:	
Cranberry tablets	54 (19.1)
Cranberry juice	18 (6.4)
D-mannose	4 (1.4)
Vitamin C	16 (5.7)
Surgical procedures on the urinary tract	
No	146 (51.8)
Supra-pubic catheter insertion	43 (15.2)
Bladder stone removal	26 (9.2)
Upper urinary tract stone removal	17 (6.0)
Bladder augmentation	7 (2.5)
Sphincterotomy / urethral stent	20 (7.1)
Botulinum toxin injection	26 (9.2)
Artificial sphincter	1 (0.4)
Ileovesicostomy	1 (0.4)
Ileoureterostomy (Bricker conduit)	7 (2.5)
Continent catheterisable stoma	8 (2.8)
Sacral anterior root stimulator	21 (7.4)
Yes, other	27 (9.6)
Any change in urinary symptoms within the last year	
No	214 (75.9)
Yes	62 (22.0)
Not applicable	1 (0.4)
Unknown	5 (1.8)
At least one symptomatic urinary tract infection during the last 3 months	94 (33.3)

used prophylactic antibiotics. In addition, 48.2% of the participants reported to have had at least one surgical procedure on the urinary tract.

Bladder-emptying methods and association with TSI

CIC was most commonly used as the main bladder-emptying method (42.6%, excluding the catheterisable pouches and channels), followed by condom catheter drainage (11.3%),

indwelling suprapubic catheterisation (11.3%) and voluntary bladder reflex triggering (11.0%).

The continent urinary diversions included the Indiana pouch (N=5), the Mitrofanoff procedure (N=2), and the Monti procedure (N=1). The incontinent urinary diversions included ileal conduit (Bricker procedure; N=7) and an ileo-vesicostomy (N=1).

Table 5.3 presents the distribution of the main bladder-emptying methods for each of the three TSI groups. There were more participants with a continent urinary diversion in the TSI 10–19 years group compared to the other two TSI groups. More participants in the TSI ≥30 years group had a transurethral catheter than in the other two TSI groups. No further significant associations were found between bladder-emptying methods and TSI.

Bladder-emptying methods and associations with gender, lesion level, and completeness

Table 5.3 also presents the different bladder-emptying methods by gender, lesion level (tetraplegia versus paraplegia) and completeness of the lesion. Transurethral catheter use and continent urinary diversions were more prevalent among women. While voluntary bladder reflex triggering and suprapubic catheter use were more often reported by participants with tetraplegia than by participants with paraplegia, more participants with paraplegia used CIC.

Among participants with complete lesions there were more who used CIC than among those with an incomplete lesion. There were no participants with a complete lesion who voided normally, and none of the participants with an incomplete lesion used SARS.

SF-Qualiveen score

The mean SF-Qualiveen score for all participants was 1.33 (SD 0.72) (Table 5.4). Participants with a transurethral catheter reported the highest impact of NLUTD on QoL, while participants with a continent urinary diversion reported the lowest impact. As regards SF-Qualiveen domain scores, participants who needed an attendant for bladder reflex triggering or CIC and those with SARS reported the highest scores for the 'bother with limitations' domain. Participants with a transurethral catheter had the highest scores on the 'frequency of limitations', 'fears' and 'feelings' domains. Participants with an incontinent or continent urinary diversion reported the lowest scores on all four domains.

Table 5.3 The different bladder-emptying methods reported by TSI group, gender, lesion level (tetraplegia versus paraplegia) and completeness of the injury

	TSI 10–19 years (N=107)	TSI 20–29 years (N=96)	TSI ≥30 years (N=79)	Sig.	Male (N=209)	Female (N=73)	Sig.	Tetraplegia (N=116)	Paraplegia (N=165)	Sig.	Complete (N=193)	Incomplete (N=89)	Sig.
Normal voiding* (N=21)	7 (6.5%)	8 (8.3%)	6 (7.6%)	0.887	13 (6.2%)	8 (11.0%)	0.199	11 (9.5%)	9 (5.5%)	0.240	0 (0.0%)	21 (23.6%)	**<0.001**
Bladder expression* (N=6)	0 (0.0%)	3 (3.1%)	3 (3.8%)	0.146	3 (1.4%)	3 (4.1%)	0.182	1 (0.9%)	5 (3.0%)	0.406	5 (2.6%)	1 (1.1%)	0.669
Bladder reflex triggering (voluntary)* (N=31)	9 (8.4%)	13 (13.5%)	9 (11.4%)	0.502	26 (12.4%)	5 (6.8%)	0.276	22 (19.0%)	9 (5.5%)	**0.001**	19 (9.8%)	12 (13.5%)	0.482
Condom catheter* (N=32)	11 (10.3%)	15 (15.6%)	6 (7.6%)	0.226	32 (15.3%)	NA	NA	16 (13.8%)	16 (9.7%)	0.382	22 (11.4%)	10 (11.2%)	1.000
CIC* (N=120)	51 (47.7%)	36 (37.5%)	33 (41.8%)	0.339	90 (43.1%)	30 (41.1%)	0.877	21 (18.1%)	99 (60.0%)	**<0.001**	93 (48.2%)	27 (30.3%)	**0.007**
SARS* (N=15)	2 (1.9%)	9 (9.4%)	4 (5.1%)	0.059	11 (5.3%)	4 (5.5%)	1.000	9 (7.8%)	6 (3.6%)	0.177	15 (7.8%)	0 (0.0%)	**0.004**
Indwelling catheter (N=41)	18 (16.8%)	8 (8.3%)	15 (19.0%)	0.096	28 (13.4%)	13 (17.8%)	0.467	29 (25.0%)	12 (7.3%)	**<0.001**	27 (14.0%)	14 (15.7%)	0.839
Transurethral catheter (N=9)	2 (1.9%)	1 (1.0%)	6 (7.6%)	**0.030**	3 (1.4%)	6 (8.2%)	**0.011**	5 (4.3%)	4 (2.4%)	0.495	6 (3.1%)	3 (3.4%)	1.000
Suprapubic catheter (N=32)	16 (15.0%)	7 (7.3%)	9 (11.4%)	0.228	25 (12.0%)	7 (9.6%)	0.673	24 (20.7%)	8 (4.8%)	**<0.001**	21 (10.9%)	11 (12.4%)	0.871
Urinary diversion (N=16)	9 (8.4%)	4 (4.2%)	3 (3.8%)	0.297	6 (2.9%)	10 (13.7%)	**0.002**	7 (6.0%)	9 (5.5%)	1.000	12 (6.2%)	4 (4.5%)	0.783
Continent urinary diversion (N=8)	7 (6.5%)	1 (1.0%)	0 (0.0%)	**0.013**	0 (0.0%)	8 (11.0%)	**<0.001**	3 (2.6%)	5 (3.0%)	1.000	7 (3.6%)	1 (1.1%)	0.442
Incontinent urinary diversion (N=8)	2 (1.9%)	3 (3.1%)	3 (3.8%)	0.720	6 (2.9%)	2 (2.7%)	1.000	4 (3.4%)	4 (2.4%)	0.721	5 (2.6%)	3 (3.4%)	0.710

* Only the use of main bladder-emptying methods is reported.
NB: associations are displayed in **bold**. CIC = clean intermittent catheterisation; NA = Not Applicable; SARS = sacral anterior root stimulation; TSI = time since injury.

In order to perform the regression analyses with the lowest possible number of groups using different bladder-emptying methods, we merged the transurethral and suprapubic catheter groups to form one indwelling catheter group, and the continent and incontinent urinary diversions groups to form one urinary diversion group. This was justifiable since no significant differences in mean total SF-Qualiveen scores were observed between these groups (Table 5.4).

Table 5.4 Mean SF-Qualiveen score for the different main bladder-emptying methods

	SF-Qualiveen score Mean (SD)
Total (N=266)	1.33 (0.72)
Normal voiding (N=18)	0.93 (0.71)
Bladder expression (N=6)	1.27 (0.45)
Bladder reflex triggering (voluntary) (N=29)	1.50 (0.75)
Independently (N=26)	1.51 (0.72)
By attendant (N=3)	1.42 (1.21)
Condom catheter (N=30)	1.32 (0.67)
CIC (N=113)	1.30 (0.67)
Independently (N=106)	1.29 (0.65)
By attendant (N=7)	1.48 (0.91)
SARS (N=15)	1.64 (0.88)
Indwelling catheter (N=39)*	1.54 (0.79)
Transurethral catheter (N=9)	1.86 (0.82)
Suprapubic catheter (N=30)	1.44 (0.76)
Urinary diversion (N=16)†	0.90 (0.65)
Continent urinary diversion (N=8)	0.89 (0.58)
Incontinent urinary diversion(N=8)	0.91 (0.75)

NB: CIC = clean intermittent catheterisation; SARS = sacral anterior root stimulation.
* No significant difference in total SF-Qualiveen score between transurethral catheter use and suprapubic catheter use (*P*=0.159).
† No significant difference in total SF-Qualiveen score between continent and incontinent urinary diversions (*P*=0.963).

In the series of bivariate regression analyses, complete SCI, incontinence at least once a month, the use of a collecting appliance for urinary incontinence, and the need for an attendant to assist with bladder-emptying were all associated with a higher impact of NLUTD on QoL (Table 5.5). Normal voiding versus CIC and urinary diversion versus CIC were associated with a lower impact of NLUTD on QoL (Table 5.5).

Table 5.5 Bivariate and multiple regression analysis for the association between potential predictors and the overall quality of life score of the SF-Qualiveen

	Bivariate regression			Standard multiple regression		
Variables entered	B (SE)	beta	Sig.	B (SE)	beta	Sig.
Age	0.009 (0.005)	0.105	0.089	0.021 (0.010)	0.253	**0.036**
TSI	0.005 (0.005)	0.062	0.314	-0.013 (0.009)	-0.164	0.170
Gender (man = 1)	0.092 (0.101)	0.056	0.364	0.048 (0.112)	0.029	0.664
Completeness of SCI (motor and sensory complete = 1)	0.237 (0.095)	0.152	**0.013**	0.148 (0.112)	0.095	0.188
Level of SCI (paraplegia = 1)	0.067 (0.091)	0.046	0.457	0.088 (0.111)	0.060	0.428
Cause of injury (traumatic = 1)	-0.209 (0.154)	-0.083	0.178	-0.142 (0.160)	-0.056	0.375
Education (college / university = 1)	-0.020 (0.089)	-0.014	0.826	0.006 (0.089)	0.004	0.944
Main bladder-emptying method						
Constant*	1.299 (0.067)					
Dum_M1 (normal voiding vs. CIC)	-0.368 (0.181)	-0.128	0.043	-0.252 (0.193)	-0.092	0.192
Dum_M2 (voluntary bladder reflex triggering vs. CIC)	0.201 (0.148)	0.087	0.175	0.128 (0.158)	0.056	0.417
Dum_M3 (condom catheter vs. CIC)	0.018 (0.146)	0.008	0.902	-0.035 (0.153)	-0.016	0.818
Dum_M5 (SARS vs. CIC)	0.343 (0.196)	0.110	0.081	0.344 (0.203)	0.108	0.092
Dum_M6 (Indwelling catheter vs. CIC)	0.237 (0.132)	0.116	0.075	0.353 (0.143)	0.174	**0.014**
Dum_M7 (Urinary diversion vs. CIC)	-0.400 (0.190)	-0.132	**0.036**	-0.358 (0.197)	-0.116	0.070
Incontinence of at least once a month	0.265 (0.099)	0.162	**0.008**	0.161 (0.107)	0.099	0.134
Use of collecting appliances for urinary incontinence	0.243 (0.089)	0.165	**0.007**	0.181 (0.101)	0.123	0.076
Bladder-emptying by attendant	0.382 (0.163)	0.142	**0.020**	0.355 (0.171)	0.124	0.052
At least one symptomatic UTI during the last 3 months	0.224 (0.093)	0.146	**0.017**	0.161 (0.092)	0.105	0.082
				R	**R square**	
				0.420	0.176	

* The reference category was clean intermittent catheterisation.
NB: CIC = clean intermittent catheterisation; SARS = sacral anterior root stimulation; TSI = time since injury; UTI = urinary tract infection.

The multiple regression model revealed that higher age and indwelling catheter use versus CIC were the only independent variables associated with a higher impact of NLUTD on QoL, explaining 18% of the variance (Table 5.5).

Discussion

This study on bladder-emptying methods used by Dutch persons with long-term SCI showed that CIC was the most commonly used bladder-emptying method. A decrease in continent urinary diversions and an increase in transurethral catheter use were observed with increasing TSI. Transurethral catheter use and continent urinary diversions were more prevalent among women. Furthermore, participants with tetraplegia were more likely to use reflex voiding or a suprapubic catheter, and participants with paraplegia were more likely to use CIC.

Transurethral catheter users reported the highest impact of NLUTD on QoL, while participants with a continent urinary diversion reported the lowest impact. A higher age and indwelling catheter use were independently associated with a higher impact of NLUTD on QoL, but explained only a small proportion of the variance.

Bladder emptying methods

Overall, most participants used CIC (43%) as their main bladder-emptying method, and this percentage remained fairly stable over time. A previous study reported CIC use by 44% of the participants with a TSI of 10–20 years and by 29% and 30% of those with a TSI of 20–30 years and 30–45 years, respectively.[13] Other studies also described a decline in CIC use over time, mostly due to a switch to indwelling catheter use.[12,22] The main reasons for this switch were dependence on caregivers and unacceptable incontinence. However, another study found that CIC use remained relatively constant over time, with a prevalence of 30% for the 11–20 years TSI group, 45% for the 21–25 years TSI group and 32% for the 26–30 years TSI group.[16] The stability of CIC use over time in our study is encouraging, since CIC has been established as the safest bladder-emptying method in individuals with SCI, in terms of urological complications.[21]

Regarding gender differences, more women than men used transurethral catheters, which can possibly be explained by the fact that the option of external condom drainage is

not available to women. Furthermore, women were more likely to have continent urinary diversions, which can be a valuable alternative, especially for wheelchair-bound women who suffer from bladder-emptying problems and have difficulty performing CIC.[23,24] Continent urinary diversions enable them to self-catheterise without having to make a transfer, thereby avoiding the use of indwelling catheterisation.

There were more participants with continent urinary diversions in the 10–19 years TSI group than in the other two TSI groups. This probably illustrates the growing familiarity and greater experience with these procedures during the past years.

SF-Qualiveen score

Relatively low mean SF-Qualiveen scores were reported, indicating a slight to moderate impact of NLUTD on QoL. Participants using a transurethral catheter (1.86) and those treated with SARS (1.64) reported the highest impact of NLUTD on QoL. Since there have been no similar studies using the SF-Qualiveen in people with SCI, we cannot compare our results with other data.

Two studies have used the King's Health Questionnaire to assess the effects of different bladder-emptying methods on QoL in people with SCI.[7,8] Both studies described that participants who voided normally reported the highest QoL and those with CIC performed by an attendant reported the lowest QoL. We found similar results in our sample, although in our study participants using an indwelling catheter also reported a relatively high impact of NLUTD on QoL.

Implications

Overall, our results show a moderate impact of NLUTD on QoL. The lack of an association with TSI is encouraging, since one might expect worsening of NLUTD and thereby of the impact of NLUTD on QoL over time. Almost all participants experienced at least some impact of NLUTD on QoL, with substantial differences in impact scores within and between bladder-emptying methods. This underlines the need to optimise bladder management across the life span of people with SCI. Our findings suggest underuse of continent urinary diversions in individuals with long-term SCI, which is unfortunate since these procedures can be a valuable alternative, especially for a selected group of people with paraplegia and women needing CIC. We found the highest impact of NLUTD on QoL among participants using

transurethral catheters and those needing an attendant. Clinicians can use this information when discussing treatment options with people with SCI.

However, the choice for a specific bladder-emptying method needs to be tailored to the individual patient, since it depends on a number of different factors, including spinal cord lesion level (suprasacral versus sacral), manual abilities, convenience, and risk of complications. The most disabled individuals living with SCI, who are likely to experience the highest impact of their disabilities on QoL, are also most likely to be assigned to indwelling catheter use or to bladder- emptying by an attendant.

Our multiple regression model only explained 18% of the variance of the total SF-Qualiveen score. NLUTD-related QoL is probably influenced by many more factors than we have included, such as psychological factors (i.e. self-efficacy, coping, self-esteem), social support, and financial circumstances.[25] This implies that future studies on the association between bladder-emptying methods and QoL should also focus on these other psychosocial and environmental factors.

Limitations

Due to the cross-sectional design of the study, our analyses of associations with TSI are limited and possibly biased. In addition, it was not possible to reliably reconstruct the use of bladder-emptying methods over periods of sometimes more than 30 years from the available medical records. Hence, we were not able to provide information regarding previous use of bladder-emptying methods, nor did we know for how many years participants had been using their current method(s). Finally, the inclusion criteria we used resulted in a study sample that predominantly consisted of participants with a traumatic and complete SCI who had acquired their SCI at a relatively young age. This does not correspond to the general profile of the SCI population in the Netherlands.[26] The advantage, however, is that the impact of normal aging of our sample will be limited, so that NLUTD can be ascribed to the SCI.

Conclusions

This study shows that CIC is the most common main bladder-emptying method among people with long-term SCI living in the Netherlands. People with long-term SCI who use a transurethral catheter as their main bladder-emptying method experience the highest

impact of NLUTD on QoL, while people with a continent urinary diversion experience the lowest impact. Increasing age and the use of an indwelling catheter are both independently associated with a higher impact of NLUTD on QoL. This indicates that clinicians should be aware of the impact of bladder-emptying methods on the QoL of people with long-term SCI, especially for those using indwelling catheters.

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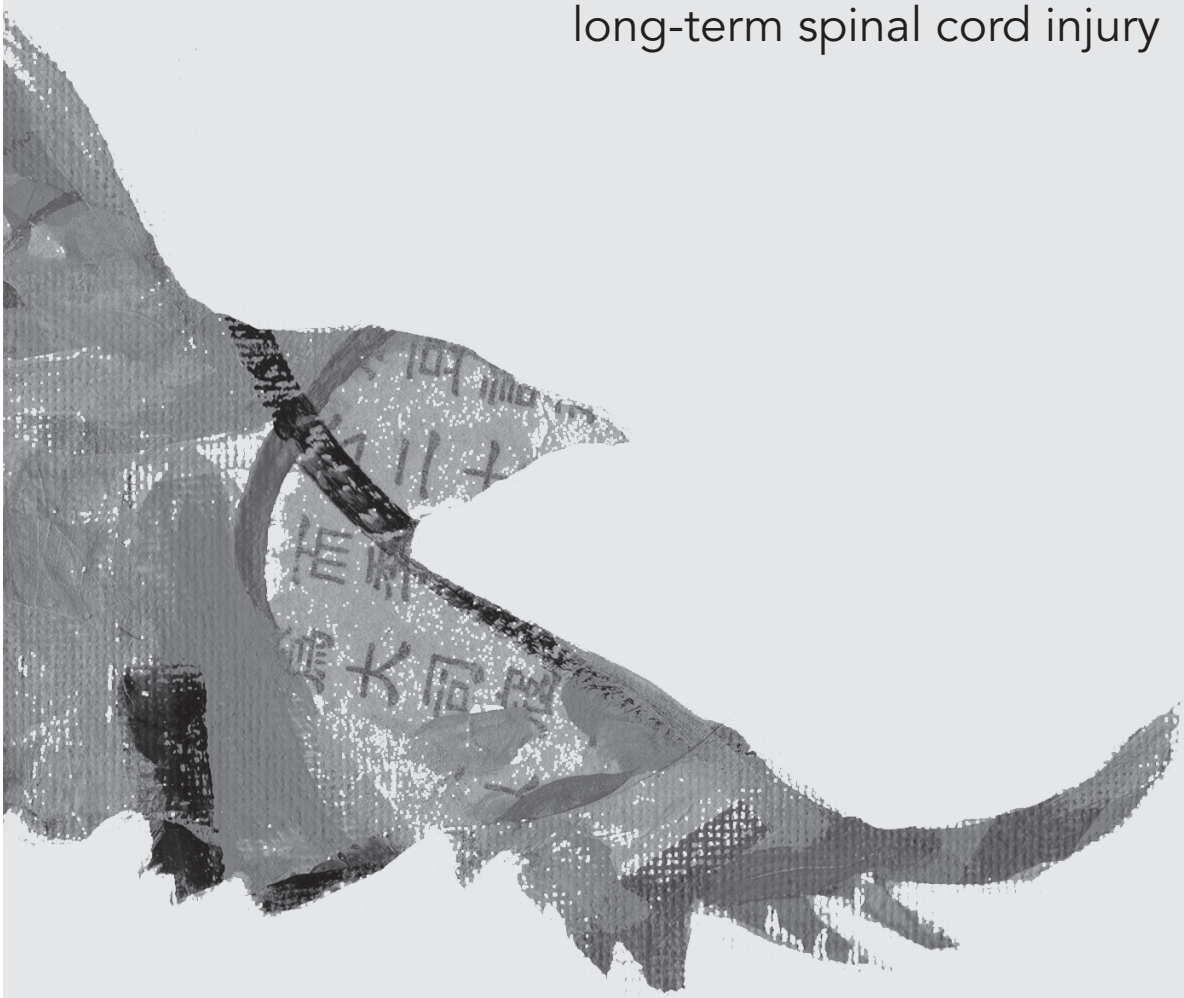
Chapter 6

A description of urological surveillance and urologic ultrasonography outcomes in a cohort of individuals with long-term spinal cord injury



A description of urological surveillance and urologic ultrasonography outcomes in a cohort of individuals with long-term spinal cord injury

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Abstract

Background Individuals with spinal cord injury (SCI) have an increased risk of developing urological complications. Therefore, long-term routine urological surveillance is recommended.

Objective To describe urological surveillance in individuals with long-term SCI and to determine factors associated with urologic ultrasonography (UU) outcome.

Methods Wheelchair dependent individuals with a SCI for ≥10 years were included. A medical assessment was done in eight participating rehabilitation centres. The International Lower Urinary Tract Function Basic SCI Data Set was used to assess bladder-emptying methods and previous surgical procedures on the urinary tract. We studied urological surveillance: whether participants had routine urological check-ups (including UU) and when latest urodynamic study was performed. Latest UU (performed <1 year ago) was retrieved or, when lacking, yet performed.

Results Median time since injury (TSI) was 22.0 years. Overall, 39% of the 282 participants did not have routine urological check-ups and 33% never had a urodynamic study performed. UU data (N=243) revealed dilatation of the upper urinary tract (UUT) in 4.5% of the participants and urinary stones in 5.7%. Abnormal UU outcome was associated with increasing TSI, non-traumatic SCI and previous surgical bladder or UUT stone removal. UU outcome was not associated with routine urological check-ups or type of bladder-emptying method.

Conclusions Contrary to (inter)national guidelines, over one-third of Dutch individuals with long-term SCI did not receive routine urological surveillance. UU outcome was not associated with routine urological check-ups or type of bladder-emptying method. Further research on the indication and frequency of urological surveillance is recommended.

Introduction

Urological surveillance and improved medical management have contributed to greatly reduced rates of mortality due to urological complications in spinal cord injury (SCI).[1] However, individuals with SCI remain at risk of developing urological complications which are still the leading cause of rehospitalisation after traumatic SCI.[2] The increased risk of developing urological complications, such as renal stones and upper tract dilatation, is coupled with an often atypical clinical presentation.[3] Therefore, long-term routine urological surveillance is recommended.

The European Association of Urology (EAU) published an extensive guideline on Neurogenic Lower Urinary Tract Dysfunction (NLUTD) in 2008.[4] Based on expert opinion, a follow-up scheme is recommended in which urologic ultrasonography (UU) should be performed every 6 months. Urodynamic study is recommended every 2 years and yearly in patients with detrusor overactivity and/or low bladder compliance.

Less rigorous recommendations concerning urological surveillance have been published by the Paralyzed Veterans of America,[5] the Spinal Cord Injury Think Tank from the United Kingdom[6] and the Dutch Urological Association.[7] This last guideline states that the urological surveillance interval can vary dependent on the neurological pathology and the type of neurogenic bladder dysfunction.[7] For patients with high bladder pressures, urological surveillance, including UU and urodynamic studies, should be performed every 1 to 2 years. In case of low bladder pressures and little post-void residual no routine urodynamic studies would be necessary.

The only component of urological surveillance which is recommended in all guidelines is routine UU to detect upper urinary tract (UUT) abnormalities. UU is non-invasive, cost-effective and easy to perform making it an established component of urological surveillance to date.[8]

Few studies explored outcomes of UU and influencing factors in individuals with long-term SCI. One study found renal stones to be present in 9.7% of the participants and dilatation of the UUT in 17.3%.[9] Increasing age and TSI were associated with renal scarring, but not with renal stones and UUT dilatation. Another study retrospectively reviewing renal ultrasonography outcomes in individuals with long-term SCI, found moderate or severe dilatation of the UUT, renal scarring or a renal size <8 cm in 26.3% of the participants.[10] A higher incidence of UUT abnormalities was associated with the use of a suprapubic

indwelling catheter in this study[10] but with transurethral catheter use in another long-term follow-up study.[11]

Since previous studies in other countries have reported a variable adherence to the available urological surveillance guidelines,[12-15] and, since just few studies have explored UU outcomes in individuals with long-term SCI we conducted this study with the following aims:

1. To describe current urological surveillance in a cohort of Dutch individuals with long-term SCI.
2. To explore whether demographic and injury-related factors, type of bladder-emptying method and having routine urological check-ups are associated with the outcome of UU.

Methods

Design

The current study is part of the Dutch multicentre research programme "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)".[16] This is a TSI-stratified cross-sectional study among individuals with long-term SCI living in the Netherlands. TSI-strata were 10–19, 20–29 and ≥30 years after SCI.

Participants

Inclusion criteria were: 1) traumatic or non-traumatic SCI with a TSI of ≥10 years, 2) age at injury 18-35 years, 3) current age 28–65 years, 4) wheelchair-dependency (hand-rim propelled or electric wheelchair), at least for longer distances (>500 m). Exclusion criterion was: insufficient mastery of the Dutch language.

Basis for the power analysis was the aim to detect differences in the prevalence of secondary health conditions between TSI strata. With alpha = 0.05 and power = 0.80, a prevalence of 0.2 can be estimated with a margin of error of ±4.6%. A prevalence difference of 0.2 (0.3 versus 0.5) between two TSI strata with 100 participants each would be statistically significant with the same alpha and power. For regression analysis, this number of 300 participants would allow inclusion of 19 independent variables in the analysis using the rule of thumb of 15 participants per variable. Therefore, it was aimed to include 100 participants per stratum.

Procedure

Eligible individuals were identified through databases from all eight Dutch rehabilitation centres with a specialty in SCI rehabilitation. The study consisted of a one-day visit to the rehabilitation centre for a check-up including an extensive medical assessment and physical examination performed by a SCI rehabilitation physician and an oral interview and several physical tests performed by a research assistant.[16] Two weeks before the visit to the rehabilitation centre participants were asked to complete a self-report questionnaire.[16] The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Personal characteristics: Questions concerning age, nationality, relationship status, educational level, and employment were addressed in the self-report questionnaire.

Urological surveillance: Routine urological check-ups were defined as routine check-ups with a urologist and/or by routine UU in a hospital or specialised rehabilitation centre. It was asked to the participants and checked in the medical file whether the participants had had a UU of the bladder and the UUT within the 12 months prior to the visit and in which year the latest urodynamic study was performed.

Urologic ultrasonography: When UU was performed >1 year ago, a new UU of the bladder and UUT was requested. The results of UUs performed <1 year prior to the visit were reclaimed with approval of the participants. All UUs were evaluated by a radiologist and classified as abnormal in case of dilatation of the UUT, renal and/or bladder stone(s).

Bladder management: The International Lower Urinary Tract Function Basic Spinal Cord Injury Data Set was used to assess bladder-emptying methods and previous surgical procedures on the urinary tract.[17] If participants used more than one type of bladder-emptying method, only the main (most frequently used) bladder-emptying method was reported.

Urinary tract infections: One question on UTIs within the last 3 months was asked. UTI was defined as a symptomatic infection of the urinary tract, treated with antibiotics. Symptoms had to include one or more of the following: onset of urinary incontinence, increased spasticity, malaise, autonomic dysreflexia, discomfort or pain during urination, gritty particles or mucus in the urine or cloudy or smelly urine.

Injury-related characteristics: The International Standards for Neurological Classification of Spinal Cord Injury were used to assess the level and completeness of the injury.[18] Tetraplegia was defined as a lesion at or above the first thoracic segment, and paraplegia as a lesion below the first thoracic segment. A complete lesion was diagnosed in the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A. AIS grades B, C, and D were considered incomplete.

Date of the origin of the SCI, age at injury and cause of the injury were asked for in the self-report questionnaire.

Statistics

Descriptive analyses were performed. Data was partly missing because some participants did not complete the self-report questionnaire (N=266). Furthermore, UU outcomes lacked in 39 participants due to lack of willingness (N=8), no appointment for UU (N=5), no referral for UU (N=5), health issues (N=3), UU performed too late (N=2), deceased (N=2) and unknown (N=14). The actual N of each analysis is reported in the Results section.

The Chi-square test and Fisher's Exact test were used to explore associations between the categorical variables. Since age was normally distributed, the independent samples t-test was used to compare two independent groups on this continuous measure. TSI was not normally distributed so the Mann Whitney U test was used to test for differences between two independent groups on this continuous measure. The level of significance was set at $P<0.05$. All analyses were performed by using the SPSS statistical software program (SPSS 21.0 for windows; IBM corp; Armonk, New York).

Results

Participant characteristics

Between November 2011 and February 2014 a total of 566 individuals were invited to participate in the study of whom ultimately 292 participated. Main reasons for non-participation were a large travel distance, no willingness, being too busy and having health issues. Afterwards, 10 participants who did not meet all eligibility criteria were excluded from the analyses. The characteristics of the 282 participants are described in Table 6.1.

Table 6.1 Participant characteristics, N=282

Age (years), mean (SD)	48.3 (8.9)
Age at SCI (years), median (IQR)	23.4 (20.6–27.7)
Time since injury (years), median (IQR)	22.0 (17.0–30.5)
Time since injury strata, (%):	
10–19 years	38
20–29 years	34
≥30 years	28
Gender (% male)	74
Nationality (% Dutch)[a]	96
Relationship (% married/stable relationship)[a]	61
Level of education (% college/university)[a]	44
Employment (% having paid work ≥1 hour/week)[a]	39
Cause (% traumatic)	91
Level (% tetraplegia)	41
ASIA Impairment Scale (AIS), (%):	
A	69
B	14
C	10
D	8
Previous surgical procedures of the urinary tract, (%):	
Bladder stone removal	9
UUT stone removal	6
Cystectomy	1
Nefrectomy	1

[a] Data extracted from the self-report questionnaire: N=268.
ASIA = American Spinal Injury Association; SCI = spinal cord injury; UUT = upper urinary tract.

A non-response analysis was not possible, since not all participating rehabilitation centres could provide us with the required information concerning the non-respondents.

Urological surveillance

Overall, 39% of the participants had no routine urological check-ups (Table 6.2). This percentage was not significantly different between the three TSI groups. In about half of the participants no UU was performed in the past year. Urodynamic study was done 0–5 years prior to the check-up in 29% of the participants, 6–10 years prior in 9% and in 20% >10 years prior to the check-up. For 10% of the participants this was not known and one-third of the participants never had had a urodynamic assessment after the onset of their injury. More participants in the TSI ≥30 years group never had a urodynamic study performed compared to those in the TSI 10–19 years and 20–29 years groups.

Table 6.2 Distribution of routine urological check-ups and urinary tract evaluation by ultrasonography and urodynamic study for the three TSI-groups and for the total group of participants

	TSI 10–19 years (N=107)	TSI 20–29 years (N=96)	TSI ≥30 years (N=79)	Sig.	Total (N=282)
No routine urological check-ups	38 (35.5%)	40 (41.7%)	33 (41.8%)	0.586	111 (39.4%)
No urologic ultrasonography in the past year	54 (50.5%)	44 (45.8%)	35 (44.3%)	0.672	133 (47.2%)
No urodynamic study after injury	29 (27.1%)	28 (29.2%)	35 (44.3%)	0.032	92 (32.6%)

Sig = significance; TSI = time since injury.

A comparison between participants with and without routine urological check-ups is given in Table 6.3. Significant differences in the severity of the lesion and the type of main bladder-emptying method were observed.

Urological surveillance and bladder-emptying methods

The proportion of participants without routine urological check-ups for the different main bladder-emptying methods was as follows: normal voiding: 86%; voluntary bladder reflex triggering: 42%; condom catheter drainage: 41%; bladder expression: 67%; clean intermittent catheterization (CIC): 32%; sacral anterior root stimulation (SARS): 27%; indwelling catheter (transurethral or suprapubic catheter): 44%; and urinary diversion: 25%.

Urologic ultrasonography

A total of 243 UU studies were analysed. Fewer participants without UU data had routine urological check-ups (33%) compared to participants with UU data (63%) (P=0.003). No other differences between both groups were observed.

Urologic ultrasonography outcomes

Ninety percent of the 243 UUs were classified as normal (Table 6.4). Dilatation of the UUT was observed in 4.5% of the participants and renal and bladder stones in 4.5% and 1.2%,

Table 6.3 Comparison of demographic and injury-related characteristics and type of main bladder-emptying methods for participants with and without routine urological check-ups

	Routine urological check-ups		
	Yes	No	Sig.
Age (years), mean (SD)	47.9 (8.9)	49.1 (8.8)	0.268
Time since injury (years), median (IQR)	21.0 (16.0–30.0)	24.0 (17.0–31.0)	0.291
Time since injury strata (%)			0.586
10–19 years	40.4	34.2	
20–29 years	32.7	36.0	
≥30 years	26.9	29.7	
Cause (%)			0.619
Traumatic	91.8	90.1	
Non-traumatic	8.2	9.9	
Level (%)			0.693
Tetraplegia	40.4	42.7	
Paraplegia	59.6	57.3	
ASIA Impairment Scale (%)			**0.002**
A	73.1	61.8	
B	12.3	15.5	
C	11.1	7.3	
D	3.5	15.5	
Gender (%)			0.363
Men	76.0	71.2	
Women	24.0	28.8	
Relationship (%)			0.868
Married/stable relationship	61.2	60.2	
Single	38.8	39.8	
Education: college/university (%)			0.281
Yes	41.8	48.5	
No	58.2	51.5	
Employment (%)			0.868
Having paid work (≥1 hour/week)	38.8	39.8	
Not having paid work	61.2	60.2	
Main bladder-emptying method (%)			**<0.001**
Normal voiding	16.2	1.8	
Bladder reflex triggering (voluntary)	11.7	10.5	
Condom catheter drainage	11.7	11.1	
Bladder expression	3.6	1.2	
CIC	33.3	48.5	
SARS	3.6	6.4	
Indwelling catheter	16.2	13.5	
Urinary diversion	3.6	7.0	

ASIA = American Spinal Injury Association; CIC = clean intermittent catheterization; IQR = interquartile rang; SARS = sacral anterior root stimulation; SD = standard deviation; Sig. = significance; TSI = time since injury.

Table 6.4 Results of the urologic ultrasonography outcomes for the total group (N=243) and for the three TSI-groups

	TSI: 10–19 years (N=90) N (%)	TSI: 20–29 years (N=83) N (%)	TSI: ≥30 years (N=70) N (%)	Sig.	Total (N=243) N (%)
Normal (no dilatation or renal / bladder stones)	86 (95.6)	74 (89.2)	58 (82.9)	**0.031**	218 (89.7)
Dilatation in UUT	3 (3.3)	3 (3.6)	5 (7.1)	0.457	11 (4.5)
Renal stone(s)	2 (2.2)	5 (6.0)	4 (5.7)	0.414	11 (4.5)
Bladder stone(s)	0 (0.0)	1 (1.2)	2 (2.9)	0.262	3 (1.2)

Sig = significance; TSI = time since injury; UUT = upper urinary tract.

respectively. A significant decrease in the proportion of normal UU outcomes with increasing TSI was observed.

Increasing TSI, having a non-traumatic SCI and previous surgical bladder or UUT stone(s) removal were the only variables associated with an abnormal UU outcome (Table 6.5). Previous surgical bladder or UUT stone(s) removal was, however, only associated with bladder and/or renal stones and not with dilatation of the UUT (data not shown). There were no significant differences in UU outcome for the different bladder-emptying methods nor for the participants with and without routine urological check-ups.

Discussion

This study is one of the few addressing urological surveillance and UU outcomes in individuals with long-term SCI. The results show that over one-third of our participants did not receive routine urological check-ups and that one-third of the participants never had any urodynamic study performed. Meanwhile, the frequency of abnormal UU outcomes was relatively low and not associated with receiving routine urological check-ups.

Urological surveillance

A total of 39% of the participants did not receive routine urological check-ups, including no routine lower and UUT imaging studies. This observation is in contrast with the recommendations of all guidelines on NLUTD. Studies on urological surveillance in individuals with SCI in other countries also demonstrated inadequate adherence to the respective

Table 6.5 Bivariate analyses for the association between potential predictors and an abnormal urologic ultrasonography outcome

	Normal urologic ultrasonography outcome (%) (N=218)	Abnormal urologic ultrasonography outcome (%) (N=25)	Sig.
Age (years), mean (SD)	48.1 (8.9)	50.7 (8.5)	0.179
TSI (years), median (IQR)	21.0 (17.0–30.0)	29.0 (21.0–37.0)	**0.017**
Gender			0.097
Male (N=179)	72.0	88.0	
Female (N=64)	28.0	12.0	
Education			0.313
Low (N=149)	54.5	43.5	
High (college/university) (N=119)	45.5	56.5	
Completeness of SCI			0.822
Complete: AIS A (N=167)	68.3	72.0	
Incomplete: AIS B, C, or D (N=76)	31.7	28.0	
Level of SCI			0.672
Paraplegia (N=144)	58.7	64.0	
Tetraplegia (N=99)	41.3	36.0	
Cause of SCI			**0.019**
Traumatic (N=220)	92.2	76.0	
Non-traumatic (N=23)	7.8	24.0	
Main bladder emptying method			0.745
Normal voiding (N=17)	6.9	8.0	
Bladder reflex triggering (voluntary) (N=27)	11.5	8.0	
Condom catheter drainage (N=26)	11.0	8.0	
Bladder expression (N=5)	2.3	0.0	
CIC (N=109)	44.0	52.0	
Indwelling catheter (N=32)	13.3	12.0	
SARS (N=12)	5.5	0.0	
Urinary diversion (N=15)	5.5	12.0	
Urologic ultrasonography in the past year			0.794
Yes (N=142)	58.7	56.0	
No (N=101)	41.3	44.0	
Routine urological check-ups			0.092
Yes (N=154)	65.1	48.0	
No (N=89)	34.9	52.0	
UTI(s) in the past 3 months			0.275
Yes (N=84)	35.8	24.0	
No (N=159)	64.2	76.0	
Surgical bladder stone(s) or UUT stone(s) removal in the past			**0.008**
Yes (N=32)	11.0	32.0	
No (N=211)	89.0	68.0	

AIS = ASIA Impairment Scale; CIC = clean intermittent catheterization; SARS = sacral anterior root stimulation; TSI = time since injury; UTI = urinary tract infection; UUT = upper urinary tract.

guidelines.[12,14,15] For instance, a recent study from the United States reported that only 35.7% of a large cohort of individuals with SCI visited a urologist in a 2-year period.[12]

A higher proportion of participants receiving routine urological check-ups was expected based on a survey among Dutch urologists.[19] In this survey 84% of the urologists claimed to perform routine follow-up in patients with NLUTD every 6 or 12 months.[19] Possible explanations for this apparent discrepancy are that some participants might not have been referred to a urologist at all, or that some participants have been non-compliant with scheduled follow-up contacts. Factors identified as being associated with non-compliance are costs, distance, transportation, time and the belief that follow-up was not necessary.[20]

In 53% of the participants UU was performed within 1 year prior to participation in this study. This does not correspond with the recommended 6 or 12 monthly assessment of the UUT with UU according to the available guidelines on NLUTD. Unfortunately, however, there is no evidence regarding the optimal follow-up intervals of UU with respect to long-term UUT outcomes.

Disappointingly, many participants never had had a urodynamic study after their injury (33%), especially since all published guidelines on NLUTD recommend to perform urodynamics at least once after SCI to determine lower urinary tract function and risk of UUT impairment.[4-7] However, recall bias may have played a role, as well as loss of information in medical records of a period of up to 47 years. That participants with a shorter TSI had a urodynamic study performed more often may also be explained by the increasing recognition of the value of urodynamic studies in more recent decades.

Urologic ultrasonography outcomes

UU showed no dilation of the UUT nor signs of renal and/or bladder stones in a high proportion of participants (90%). Few studies exploring UU outcomes in individuals with long-term SCI are available.[9,21] In one study evaluating urinary tract complications over a 6-year period (mean TSI: 33 years), renal stones were present in 9.7%, and UUT dilatation in 17.3%.[9] These numbers are higher compared to our findings, but that study used a longer observation period with three assessments instead of one. Vaidyanathan et al. performed UU in 87 individuals with SCI without urinary symptoms (e.g. recurrent UTIs, passing blood in urine or purulent urine), and in 21 individuals with urinary symptoms.[21] Some abnormalities were detected in 24 of the 87 individuals without

urinary symptoms (e.g. mild hydronephrosis in one and renal stones in five individuals), but according to the authors no specific surgical or medical intervention was needed.

Increasing TSI, having a non-traumatic SCI and previous surgical bladder or UUT stone(s) removal were the only characteristics that were associated with an abnormal UU outcome in our study. To our knowledge, only two previous studies have investigated potential risk factors for abnormal UU outcomes in individuals with long-term SCI.[9,11] The first study observed no significant associations between both renal stones and upper tract deterioration with age, TSI, completeness of the lesion, level of injury, and type of bladder-emptying method.[11] The second study also found no associations between age and TSI with the presence of renal stones or dilatation of UUT.[9]

It has been demonstrated that the prevalence of recurrent renal stone disease is high in individuals with SCI with reported frequencies of 34–64%.[22,23] Also, bladder stone recurrence appeared to be 23%.[24] These data supports our observation of an increased risk of finding urological stones with UU in individuals with a history of surgically removed bladder and/or renal stone(s).

Furthermore, we noticed that despite the amount of individuals with (in)voluntary reflex voiding not receiving routine urological surveillance (41%), the frequency of abnormal UUs in these groups of participants was relatively low (7.4–8.0%) and did not significantly differ from the frequency of abnormal UUs in the CIC group (11.9%). However, the subgroups in our study were too small to draw conclusions from this observation.

Limitations

There were some limitations concerning this study. First, its cross-sectional design limits the possibilities to interpret associations with TSI due to possible cohort-effects. Second, as high bladder pressure is supposed to increase the risk of UUT dilatation, stratification based on urodynamic outcome would be recommendable. Unfortunately, in our study population, too few urodynamic parameters were available to calculate risk for UUT dilatation based on bladder pressure. Third, we lacked information on the reason why participants not received routine urological surveillance. Fourth, we were not able to perform logistic regression analysis due to the small number of participants with abnormal UU outcomes. Hence, these study results should be regarded as descriptive and exploratory. Fifth, individuals with UUT deterioration may have died prematurely and were thus not evaluated, causing selection

bias. Finally, due to the inclusion criteria, our study sample predominantly consisted of participants with a traumatic and complete SCI who obtained their SCI at a relatively young age, not corresponding with the general Dutch SCI population.[25]

Implications for future research

The fact that guidelines on the management of NLUTD in SCI are available does not necessarily mean that all individuals with SCI receive care accordingly. Individuals with long-term SCI may not be aware of the importance of urological surveillance that might be explained by a lack of education. More research on factors that may cause individuals with SCI not to receive urological surveillance is needed. Furthermore, the fact that all available guidelines on urological surveillance are mainly based on expert opinion emphasizes the need for further research concerning the content, indication, and frequency of urological surveillance.

Taking into account the low percentage of abnormal UU outcomes, the recommended frequency of UU needs to be critically evaluated. Identification of risk factors for UUT deterioration or stones, including the risks associated with the use of different type of bladder-emptying methods, is of utmost importance.

Conclusion

In contrast to existing guidelines, 39% of our participants with long-term SCI did not receive routine urological check-ups and 33% never had had a urodynamic study. However, UU outcome was not associated with routine urological check-ups or with type of bladder-emptying method. The low frequency of abnormal UU outcomes found advocates identification of risk factors, and emphasizes the need for further research on the indication and frequency of urological surveillance.

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Chapter 7

Prevalence of hypertension and associated risk factors in people with long-term spinal cord injury living in the Netherlands

Prevalence of hypertension and associated risk factors in people with long-term spinal cord injury living in the Netherlands

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Abstract

Purpose To describe the prevalence of hypertension and associated risk factors in people with long-term spinal cord injury (SCI) and to compare the prevalence of high blood pressure and/or the use of antihypertensive drugs with the prevalence in the Dutch general population.

Method Multicentre cross-sectional study (N=282). Hypertension was defined as a systolic blood pressure (SBP) of ≥140 mmHg and/or a diastolic blood pressure (DBP) of ≥90 mmHg after ≥2 blood pressure measurements during ≥2 doctor visits. High blood pressure was defined as a single measurement of a SBP of ≥140 mmHg and/or a DBP of ≥90 mmHg.

Results The prevalence of hypertension was 21.5%. Significant predictors were: lesion level below C8 (T1–T6: OR=6.4, T7–L5: OR=10.1), history of hypercholesterolemia (OR=4.8), longer time since injury (OR=1.1), higher age (OR=1.1). The prevalence of high blood pressure and/or the use of antihypertensive drugs was higher in men (T1–T6 lesion: 48%; T7–L5 lesion: 57%) and women (T1–T6 lesion: 48%; T7–L5 lesion: 25%) with a SCI below C8 compared to Dutch able-bodied men (31%) and women (18%).

Conclusion High blood pressure is common in people with SCI. Screening for hypertension during annual check-ups is recommended, especially in those with a SCI below C8.

Introduction

Cardiovascular disease (CVD) includes diseases of the heart, vascular diseases of the brain and diseases of blood vessels and has become the leading cause of mortality in people with long-term spinal cord injury (SCI).[1]

Hypertension is one of the most important risk factors for premature death due to CVD worldwide.[2] The diagnosis of hypertension is made in case of a systolic blood pressure (SBP) of ≥140 mmHg or a diastolic blood pressure (DBP) of ≥90 mmHg based on the mean of ≥2 properly measured seated blood pressure readings on each of ≥2 office visits.[3,4] The prevalence of hypertension increases with age[5] and is influenced by many modifiable lifestyle factors such as high salt intake, physical inactivity, obesity and smoking.[3,4,6]

Blood pressure regulation is altered in people with SCI due to sympathetic nervous system dysfunction. Below the level of the injury there is decentralized vascular control and, depending on lesion level, this may cause cardiovascular disturbances with low resting blood pressure, orthostatic hypotension and autonomic dysreflexia.[7] As a result, clinicians might not consider hypertension to have a high prevalence among people with SCI. However, people with SCI are not excluded from the development of hypertension,[7] since risk factors for hypertension, such as physical inactivity[8,9] and obesity,[8,10,11] are common due to a sedentary lifestyle.

Studies on the prevalence of hypertension in people with SCI for more than 10 years showed figures ranging between 14% and 61%.[10,12-19] This wide range might, firstly, be attributed to the use of different outcome parameters. Some studies reported previously diagnosed hypertension[10,14,18,19] and/or the use of antihypertensive drugs.[10,18] Other studies reported hypertension based on one blood pressure measurement and/or the use of antihypertensive drugs[12,15] or on multiple blood pressure measurements during one doctor visit.[13] Secondly, differences between studies in participant characteristics, such as age and spinal cord lesion level, might also have contributed to the reported wide range in prevalence.

The most commonly reported determinants of hypertension in people with SCI are a lower level of injury[10,12,13,15-17,19-21] and an increased age.[10,13,19,22] Other factors that have been reported are a body mass index (BMI) ≥25 kg/m^2,[13] African-American[13,18] and Hispanic[13] race, being male,[16,18] being married,[18] a non-traumatic injury,[18] a history of smoking in persons with tetraplegia[18] and having comorbidities.[18]

To our knowledge, no previous studies have investigated the association between hypertension and other established CVD risk factors such as diabetes, hypercholesterolemia and being physically inactive in people with SCI. Since these are potentially treatable factors, it is important to study whether these factors are also determinants of hypertension in this diagnostic group.

Summarising, knowledge on the prevalence of hypertension and its associated risk factors in people with long-term SCI is scarce. Therefore, it can be questioned whether hypertension is accurately diagnosed and treated in this population. For these reasons, we conducted this study with the following aims:

1. To determine the prevalence of hypertension in Dutch persons with a SCI for at least 10 years.
2. To evaluate the association between hypertension and demographic characteristics, injury-related characteristics, BMI, physical activity level, a history of diagnosed hypercholesterolemia, current LDL- and HDL-cholesterol values, diabetes mellitus, family history of CVD and smoking status.
3. To compare the prevalence of high blood pressure and/or the use of antihypertensive drugs in the study population with the prevalence in the Dutch general population

Methods

Design

This study is part of the Dutch multicentre research programme "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)".[23] It was a time since injury (TSI)-stratified cross-sectional study among people with long-term SCI living in the Netherlands. TSI-strata were 10–19, 20–29 and 30 years or more after SCI. We aimed to include 100 persons per stratum.

Participants

Inclusion criteria were: (1) traumatic or non-traumatic SCI with a TSI of ≥10 years, (2) age at injury between 18 and 35 years, (3) current age between 28 and 65 years, (4) using a wheelchair (hand-rim propelled or electric wheelchair), at least for longer distances (>500 m). Exclusion criterion was: insufficient mastery of the Dutch language.

Procedure

Eligible persons were identified through databases from all eight Dutch rehabilitation centres specialising in SCI rehabilitation. The study consisted of a one-day visit to the rehabilitation centre for a check-up including an extensive medical assessment and physical examination performed by a SCI rehabilitation physician and an oral interview and several physical tests performed by a research assistant.[23] Two weeks before the visit to the rehabilitation centre participants were asked to complete a self-report questionnaire.[23]

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Hypertension was defined according to the European Society of Hypertension (ESH) and the European Society of Cardiology (ESC) guidelines for blood pressure classification: a SBP of ≥140 mmHg and/or a DBP of ≥90 mmHg based on the mean of ≥2 properly measured seated blood pressure readings on each of ≥2 office visits.[4] Since blood pressure was only measured during one visit in the ALLRISC study, these values were not used to determine the diagnosis of hypertension. Instead, we classified our participants as having hypertension when they had a history of diagnosed hypertension with the current use of antihypertensive drugs or when they were newly diagnosed with hypertension and started antihypertensive treatment after referral to a cardiologist or general practitioner (GP) based on the results of our check-up.

Blood pressure was measured during the physical examination of the check-up. The physician recorded the blood pressure using a digital sphygmomanometer while participants were seated in their wheelchair. When any abnormality in blood pressure was observed, participants were referred to their GP or cardiologist for a further assessment of the

blood pressure. Outcomes of the referral were obtained by correspondence of the GP or cardiologist or by a phone call to the participants.

High blood pressure was defined as a single measurement of a SBP of ≥140 mmHg and/or a DBP of ≥90 mmHg during the physical examination.

Demographic characteristics like age, gender, nationality, relationship status and level of education were extracted from the self-report questionnaire. Relationship was dichotomised in 'married/stable relationship' and 'not having a partner'. Level of education was subdivided in 'low level of education' and 'high level of education', in which 'high' meant completed college/university education.

Lesion characteristics: The International Standards for Neurological Classification of Spinal Cord Injury were used to assess lesion characteristics.[24] Complete lesion was defined as the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A. AIS grades B, C, and D were classified as an incomplete lesion. Neurological levels of SCI were subdivided in three groups to avoid the potential confounding effect of grouping individuals with intact and non-intact autonomic control of the heart and vasculature:[25] C1–C8 levels were defined as cervical (C), T1–T6 levels as high-thoracic (HT) and SCI levels at T7 or below as low-thoracic and lumbar (LTL).

Date of onset of SCI, age at injury and cause of the injury were asked for in the self-report questionnaire.

Medication with possible hypertensive side-effects included non-steroidal anti-inflammatory drugs (NSAIDs), acetylsalicylic acid and sympathicomimetics.[3,26] Anti-hypotensive drugs included glucocorticoids and mineralocorticoids (Fludrocortisone), ergot alkaloids (Dihydergot) and Midodrine which is a selective alpha1-adrenergic agonist.[27] Data on medication use were retrieved from the consultation with the physician and the medical file.

Family history of CVD: Participants were considered to have a positive family-history if a first-degree family member had had a cardiovascular event before the age of 60 years.

History of CVD, diagnosed hypercholesterolemia and diabetes mellitus were addressed in the consultation with the physician and retrieved from the medical file. History of CVD included stroke and myocardial infarction.

Body mass index (BMI) was calculated as: body mass (kg) / height (m^2). Participants, wearing no shoes and light clothing, were weighed in their wheelchair on a weigh bridge. The weight of the wheelchair was subtracted from the total weight. Weight was measured to the nearest kg. Participants reported their height.

Blood samples were taken in the morning in fasting state at the rehabilitation centre or in a hospital in which levels of HDL- and LDL-cholesterol were assessed. LDL-cholesterol was considered in good range if ≤2.5 mmol/L and HDL-cholesterol was considered in good range for men if ≥0.9 mmol/L and for women if ≥1.1 mmol/L.[26] Standardised laboratory techniques were used.

Smoking status was addressed in the consultation with the physician and was dichotomised as 'current smoker' and 'non-smoker'.

Physical activity level was measured with the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD).[28] The PASIPD measures the number of days a week and hours daily of participation in recreational, household, and occupational activities over the past 7 days. In this study, a customised version for the Dutch population was used, which contains 11 questions.[29] Outcome is the total physical activity score, which is expressed in metabolic equivalent (MET) in hours per day with a maximum of 182.3 MET h/day.

Dutch general population

NL de Maat Genomen (NLdeMaat) was a Dutch study in the general population aged between 18–70 years.[30] Approximately 4,500 persons were included between 2009–2010. Participants visited a research centre for a physical examination in which a digital sphygmomanometer was used for the blood pressure measurement. High blood pressure was defined as a single measurement of a SBP ≥140 mmHg and/or a DBP ≥90 mmHg and/or the use of antihypertensive medication.

Statistics

Descriptive analyses were performed to describe demographic and lesion characteristics, health conditions, and activity levels for the total group.

Since BMI and TSI were not normally distributed, non-parametric statistics (Mann-Whitney *U* and Kruskall-Wallis tests) were used for all analyses with the continuous variables (age, BMI, TSI).

The Chi-square test was used to determine significant differences between categorical variables.

If groups were too small (N ≤10), they were excluded from further analyses.

With the use of boxplots, we checked for cases with outliers for the single measured blood pressures (SBP and DBP) in order to explore if there were blood pressure measurements suggestive for autonomic dysreflexia. Using these boxplots, we explored the distribution of SBP and DBP for all different lesion levels. Ultimately, we observed one outlier (194/104 mmHg) which was most likely a reflection of autonomic dysreflexia, based on the lesion level and medical record. When we checked the medical record, we found out that this person had had a second blood pressure measurement during the study visit which revealed a much lower blood pressure, 94/50 mmHg. Therefore, we changed the values of the systolic and diastolic blood pressure into 94 and 50, respectively.

Logistic regression analysis was performed to assess the impact of a number of factors on the likelihood that participants were diagnosed with hypertension. Only the variables that showed an association with hypertension at a significance level of ≤0.10 in the bivariate analyses were included in the multivariate logistic regression analysis. Lesion level was included as a set of two dummy variables, once with the C lesion group as the reference category and once with the LTL lesion group as the reference category. Before performing logistic regression, variables were checked for multicollinearity with Pearson's correlation. When two variables were highly intercorrelated (r≥0.7) we removed one of the highly intercorrelating variables from the model.

All analyses were performed using the SPSS statistical software programme (SPSS 21.0 for windows, IBM Corp., Armonk, NY). The level of significance was set at $P<0.05$.

Results

A total of 282 participants were included in the study. Of them, 268 completed the self-report questionnaire. Blood samples were available for 250 participants. The other 32 participants either did not give consent or the venipuncture was not successful. LDL-cholesterol could not be measured in a further four participants due to high triglycerides values. Participant characteristics are described in Table 7.1.

Table 7.1 Participant characteristics, N=282

	All (N=282)
Age (years), median (IQR)	47.8 (41.6–55.0)
Time since injury (years), median (IQR)	22.0 (16.8–30.3)
Gender (% male)	74.1
Relationship (% married/stable relationship)*	60.8
Level of education (% college/university)*	44.4
Cause (% traumatic)	91.1
Level	
Cervical (C1–C8) (%)	43.8
High-thoracic (T1–T6) (%)	33.8
Low-thoracic and lumbar (T7 and below) (%)	22.4
ASIA Impairment Scale (AIS), (%)	
A	68.7
B	13.5
C	9.6
D	8.2
BMI (kg/m^2), median (IQR)	24.8 (22.2–28.4)
BMI strata§ (%)	
Recommended (<22 kg/m^2)	22.9
Overweight (≤22–<25kg/m^2)	30.1
Obesity (≥25 kg/m^2)	47.0
Diabetes mellitus (%)	7.1
History of diagnosed hypertension (%)	19.2
Stroke (%)	1.1
Myocardial infarction (%)	1.1
History of diagnosed hypercholesterolemia (%)	9.9
Family history of CVD (%)	31.2
Use of anti-hypertensive drugs (%)	16.7
Use of anti-hypotensive drugs (%)	0.7
Use of medication with possible hypertensive side-effects (%)	12.4
PASIPD, median (IQR)*	12.8 (5.7–26.4)
HDL-cholesterol (% men <0.9 mmol/l or women <1.1 mmol/l)**	19.6
LDL-cholesterol (% >2.5 mmol/l)***	72.0
Smoking (% current smoker)	22.1

ASIA = American Spinal Injury Association; BMI = body mass index; CVD = cardiovascular disease; HDL = high-density lipoprotein; IQR = inter quartile range; LDL = low-density lipoprotein; PASIPD = physical activity scale for individuals with physical disabilities; SD = standard deviation.
* N=268, data extracted from self-report questionnaire; ** N=250, participants with available blood sample; *** N=246, participants with available blood sample in which LDL-cholesterol values could be measured. § The prevalence of being overweight and obese was calculated with the adjusted cut-off points for people with SCI.[41]

Blood pressure and referral outcomes

Table 7.2 shows the outcomes of the blood pressure measurements. Blood pressure was measured in 279 participants. High blood pressure was observed in 31.3% of the participants. Whether a participant was referred for further examination of their blood pressure was known in 272 participants. A total of 8.1% of these participants were referred to a cardiologist or GP and this led to a change in therapy or new diagnosis of hypertension in 3.3% of all participants. Together with the participants with previously diagnosed hypertension a total of 60 patients (21.5%) had hypertension.

Table 7.2 Descriptives of blood pressure and referral outcomes, N=279*

Measured systolic blood pressure, mean (SD)	125.8 (24.8)
Cervical lesions	111.9 (23.5)
High-thoracic lesions	136.0 (21.5)
Low-thoracic and lumbar lesions	137.0 (18.1)
Measured diastolic blood pressure, mean (SD)	76.5 (14.9)
Cervical lesions	69.1 (14.8)
High-thoracic lesions	81.7 (13.2)
Low-thoracic and lumbar lesions	82.8 (10.9)
High blood pressure (SBP ≥140 mmHg and/or DBP ≥90 mmHg) (%)	31.3
Referred participants (%)**	
Total	8.1
With a history of hypertension	2.6
Without a history of hypertension	5.5
Referred to (%):**	
General practitioner	5.5
Cardiologist	2.6
Referral led to change in therapy or new diagnosis of hypertension (%)**	3.3
Newly diagnosed hypertension after referral (%)**	2.2
Hypertension (previously diagnosed hypertension or newly diagnosed) (%)	21.5
Men	21.7
Women	20.8
Cervical lesions	9.0
High-thoracic lesions	28.7
Low-thoracic and lumbar lesions	35.5

DBP = diastolic blood pressure; SBP = systolic blood pressure; SD = standard deviation.
* Number of participants whose blood pressure was measured.
** N=272, participants of who was known whether they were referred.

Antihypertensive treatment

Seventeen percent of the participants used antihypertensive drugs: angiotensin-converting-enzyme inhibitors (N=19), beta-blockers (N=18), thiazide diuretics (N=10), angiotensin-receptor blockers (N=9), calcium channel blockers (N=6), angiotensin-receptor blocker + thiazide diureticum (N=6) and loop diuretics (N=2).

Blood pressure according to lesion level, age and TSI

Figure 7.1 shows the distribution of systolic and diastolic blood pressures (measured during the physical examination) for all lesion levels, both complete and incomplete. T1 was found to be the highest neurological level of SCI in which a median SBP of ≥140 mmHg was reported.

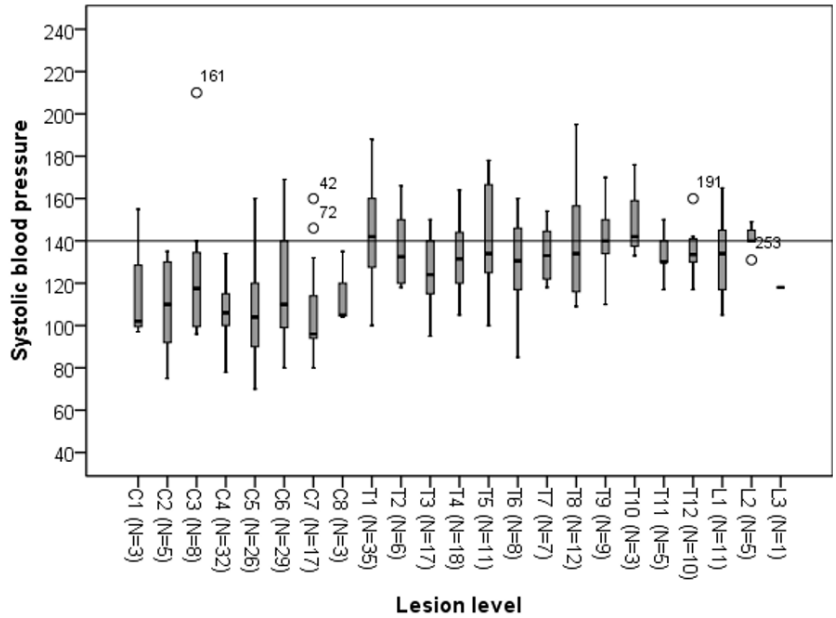
A median SBP of ≥140 mmHg was reported for both HT and LTL lesions from the age of 46–50 years (Figure 7.2). Furthermore, a median SBP of ≥140 mmHg was observed in the participants with a HT lesion and a TSI of 21–45 years and in those with a LTL lesion and a TSI of 16–20 years and 26–40 years (Figure 7.3).

Prevalence of high blood pressure compared to the Dutch general population

The proportion of persons aged 30–59 years with high blood pressure and/or using antihypertensive drugs in the NLdeMaat study was 30.6% in men, and 17.9% in women. In men and women aged 30–59 years with a HT lesion or a LTL lesion in our study, the prevalence of high blood pressure and/or the use of antihypertensive drugs was higher, namely 48.1% in both men and women with a HT lesion and 56.8% in men with a LTL lesion and 25.0% in women with a LTL lesion. Only the men and women with a C lesion showed a lower prevalence of high blood pressure and/or the use of antihypertensive drugs compared with the Dutch general population (respectively, 18.2% and 10.0%) (Table 7.3).

Factors associated with hypertension

The subgroups of participants using anti-hypotensive drugs (N=2), with a history of stroke (N=3) and a history of myocardial infarction (N=3) were very small and were therefore excluded from further analyses.



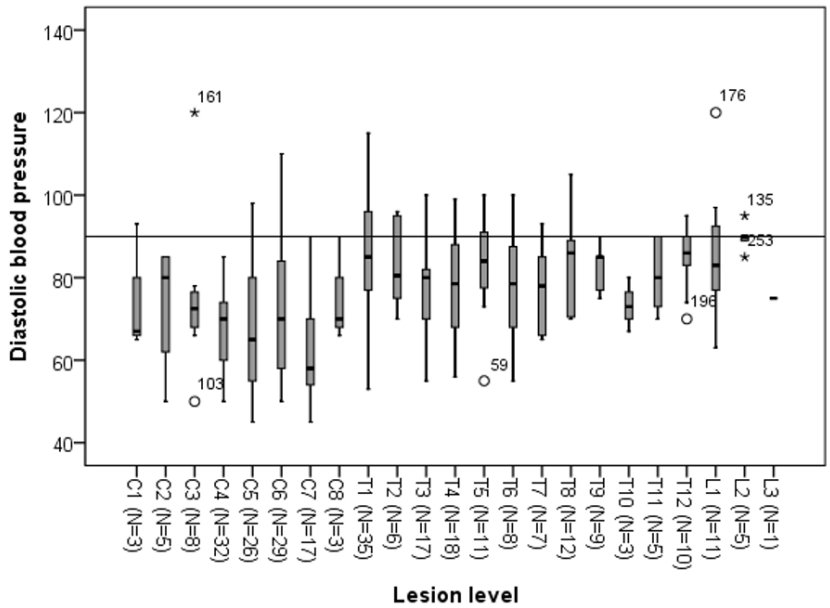


Figure 7.1 The distribution of systolic and diastolic blood pressure for all neurological spinal cord injury levels.

* 161: motor and sensory incomplete SCI right T1, left C3, AIS D. Blood pressure measurement revealed a blood pressure of 210/120 mmHg. The participant was referred to a general practitioner and was diagnosed with hypertension and started antihypertensive treatment.

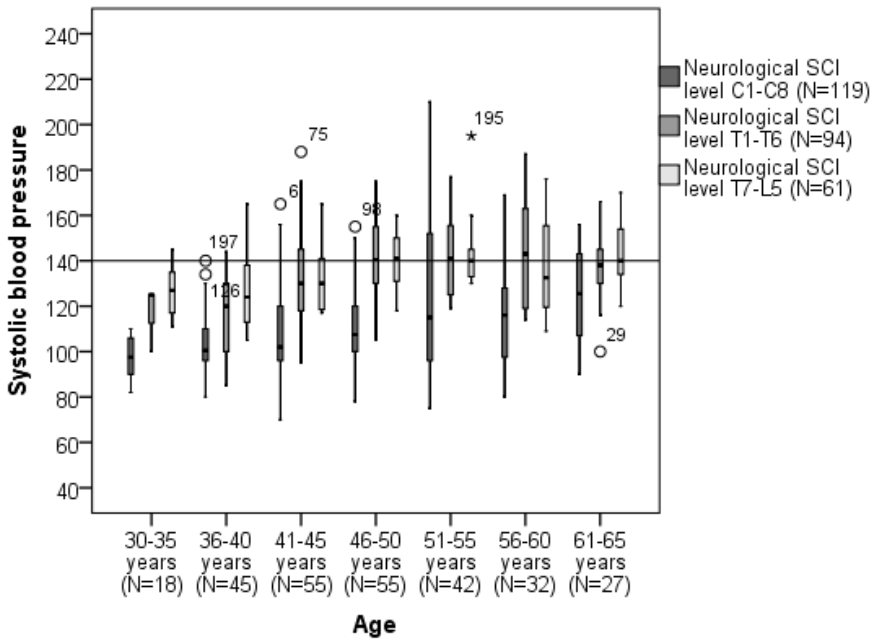


Figure 7.2 The distribution of systolic blood pressure for different age groups for cervical, high-thoracic and low-thoracic/lumbar lesions.

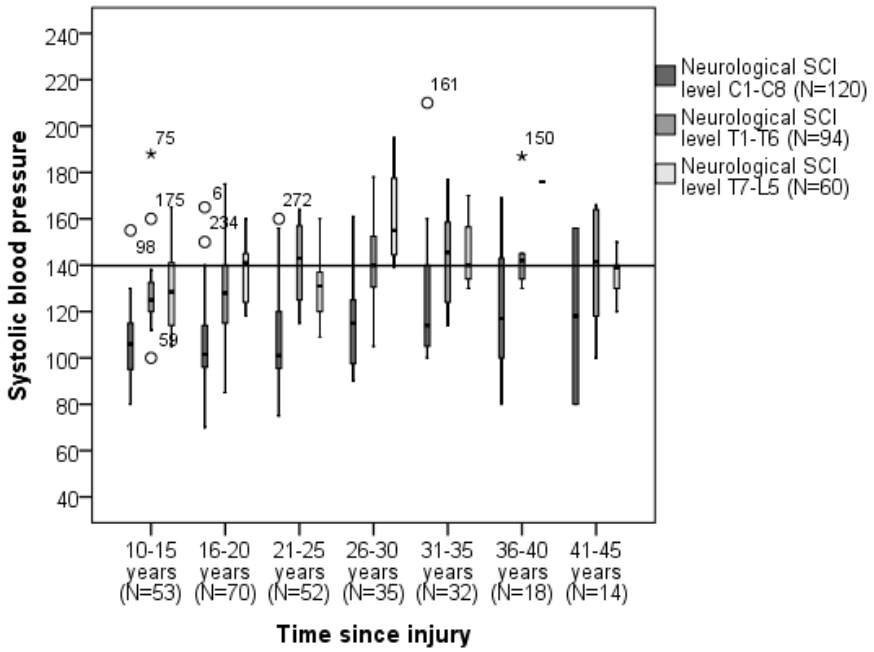


Figure 7.3 The distribution of systolic blood pressure for different time since injury groups for cervical, high-thoracic and low-thoracic/lumbar lesions.

Table 7.3 The proportion of participants in this study with high blood pressure and/or the use of antihypertensive drugs in comparison with the proportion participants with high blood pressure and/or the use of antihypertensive drugs in a Dutch population-based study (NLdeMaat)

	Men				Women			
	NLdeMaat		ALLRISC		NLdeMaat		ALLRISC	
Age (years)	N	High blood pressure and/or use of antihypertensive drugs (%)	N	High blood pressure and/or use of antihypertensive drugs (%)	N	High blood pressure and/or use of antihypertensive drugs (%)	N	High blood pressure and/or use of antihypertensive drugs (%)
30–39	288	16.7	39	15.4	358	7.5	15	0.0
40–49	410	27.8	85	30.6	518	14.7	28	28.6
50–59	513	47.4	55	54.5	552	31.5	17	58.8
60–70	591	61.8	22	63.6	608	55.3	13	69.2
30–59	1,802	30.6	179	34.6	2,036	17.9	59	30.0
C lesions 30–59			88	17.0			20	10.0
HT lesions 30–59			54	48.1			27	48.1
LTL lesions 30–59			37	56.8			12	25.0

ALLRISC = Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury; C = cervical; HT = high-thoracic; LTL = low-thoracic / lumbar; N = number.

Table 7.4 Bivariate analyses and logistic regression analyses with hypertension as the dependent variable

	Bivariate analyses			Logistic regression analysis (N=258)[¥*]					
				Hypertension as the dependent variable					
	Hypertension			Including TSI			Including age		
					95% CI for Odds ratio			95% CI for Odds ratio	
Independent variables	No	Yes	Sig.	Odds ratio[§]	Lower	Upper	Odds ratio[§]	Lower	Upper
Age, median (years)	45.5	55.9	**<0.001**	-	-	-	**1.14**	1.08	1.19
TSI, median (years)	22.0	30.7	**<0.001**	**1.13**	1.08	1.18	-	-	-
Gender (% male)	74.0	75.0	0.872	-	-	-	-	-	-
Cause (% traumatic)	92.7	86.7	0.140	-	-	-	-	-	-
Lesion level (cervical is reference)			**<0.001**						
Cervical (C1–C8) (%)	50.9	18.3							
High-thoracic (T1–T6) (%)	30.7	45.0		**6.38**	2.47	16.48	**5.70**	2.24	14.52
Low-thoracic and lumbar (≤ T7) (%)	18.3	36.7		**10.08**	3.50	29.03	**8.16**	2.94	22.69
Completeness (% complete)	68.8	68.3	0.944	-	-	-	-	-	-
Relationship (% married/stable relationship)	59.9	62.1	0.766	-	-	-	-	-	-
Level of education (% college/university)	74.4	62.1	**0.065**	1.34	0.58	3.13	1.36	0.60	3.09

BMI (kg/m^2), median	25.23	26.53	**0.038**	1.05	0.97	1.14	1.04	0.96	1.12
Smoking (% current smoker)	23.9	16.7	0.236	-	-	-	-	-	-
Diabetes mellitus (%)	4.6	15.0	**0.005**	2.37	0.59	9.44	2.60	0.69	9.82
Family history of CVD (%)	29.5	39.0	0.164	-	-	-	-	-	-
Previously diagnosed hypercholesterolemia (%)	6.4	23.3	**<0.001**	**4.75**	1.54	14.67	**3.93**	1.30	11.87
HDL-cholesterol (% men <0.9 mmol/l or women <1.1 mmol/l) **	21.9	12.7	0.134	-	-	-	-	-	-
LDL-cholesterol (% >2.5 mmol/l) ***	72.0	70.4	0.820	-	-	-	-	-	-
Use of medication with possible hypertensive side-effects (%)	9.2	23.3	**0.003**	2.20	0.84	5.77	2.24	0.86	5.86
PASIPD score, median	12.6	13.3	0.532	-	-	-	-	-	-

BMI = body mass index; CI = confidence interval; CVD = cardiovascular disease; HDL = high-density lipoprotein; LDL = low-density lipoprotein; PASIPD = physical activity scale for individuals with physical disabilities; Sig. = significance level; TSI = time since injury.
§ Odds ratios printed in **bold** are significant at $P<0.05$.
* Due to a high correlation between age and TSI ($r=0.864$), we could not include both age and TSI in the same logistic regression analysis. ** N=250, participants with available HDL-cholesterol values; *** N=246, participants with available LDL-cholesterol values.
¥ = only the variables that showed a significance level of ≤0.100 in the bivariate analyses were included in the logistic regression analysis.

The variables that showed a significance level of ≤0.10 in the bivariate analyses were age, TSI, lesion level, level of education, BMI, diabetes mellitus, previously diagnosed hypercholesterolemia and the use of medication with possible hypertensive side-effects (Table 7.4). Due to a high correlation between age and TSI (r=0.9), we could not enter both variables in the same analysis and therefore performed the logistic regression analysis twice, once with TSI and once with age as a predictor of hypertension. No other high intercorrelations among the predictor (independent) variables were observed.

The outcomes of the logistic regression analyses are shown in Table 7.4. Four independent variables made a statistically significant contribution to the model: (1) TSI, (2) age, (3) lesion level: HT lesion compared to C lesion, LTL lesion compared to C lesion, and (4) history of diagnosed hypercholesterolemia. When lesion level was included with the LTL lesion group as reference category, no significant difference was observed between the HT and the LTL lesion groups. The full model with TSI was statistically significant, χ^2 (N=258) = 83.19, $P<0.001$, indicating that the model was able to distinguish between participants with and without hypertension. The model as a whole explained 42.3% (Nagelkerke R^2) of the variance in hypertension, and correctly classified 86.0% of cases.

The strongest predictor of hypertension was a LTL lesion, indicating that participants with a LTL lesion were ten times more likely to have hypertension than those with a C lesion, controlling for all other factors in the model.

The logistic regression model containing age instead of TSI was also statistically significant (χ^2 (N=258) = 81.45, $P<0.001$), explained 41.5% of the variance in hypertension, and yielded the same variables that made a statistically significant contribution to the model. In this model, age recorded an OR of 1.14.

Discussion

This study on the prevalence of hypertension yielded a prevalence of 21.5%. Independent predictors were a lesion level below C8, higher age, longer TSI and a history of diagnosed hypercholesterolemia. Furthermore, this study reported a higher prevalence of high blood pressure and/or the use of antihypertensive drugs in both men and women aged between 30–59 years with a HT or LTL spinal cord lesion level, compared with the age-matched Dutch general population.

Prevalence of hypertension

One previous study used a similar method to identify participants with hypertension. In the Stockholm SCI study, 14.1% of the participants with a mean age of 47.8 years and a mean TSI of 18.4 years had hypertension.[10] Also, blood pressure was measured once, leading to a prevalence of high blood pressure of 39%. These values are close to our values of 19.2% and 31.7%, respectively. Other studies on this topic have reported a large range of the prevalence of hypertension, between 14% and 61%. This may be due to different outcome parameters used. Two studies in participants with a mean age above 60 years used the International Classification of Diseases, Ninth Revision (ICD-9) code for hypertension to identify participants with hypertension.[17,18] They reported a much higher prevalence of hypertension of 44.9% and 61.3%.[17,18] Other studies described the prevalence of self-reported hypertension (28.7%)[19] or used one (39.3%[15] and 45.2%[12]) or multiple blood pressure measurements to identify hypertension (22.0%).[13]

Compared to the Dutch population-based study, both men and women with a HT or LTL lesion, showed a higher prevalence of high blood pressure and/or the use of antihypertensive drugs. This suggests that the possible protective effect of the SCI on the presence of hypertension only applies to people with a C lesion.

Lesion level

Having a LTL lesion compared to a C lesion yielded the highest OR for the risk of hypertension. Also, having a HT lesion compared to a C lesion was associated with a higher risk. This observation reflects the decentralisation of autonomic cardiovascular control in people with SCI which depends on the level of SCI.[25] The higher the level of SCI, the greater the degree of cardiovascular dysfunction, causing lower systolic and diastolic blood pressures.

Few previous studies have related levels of blood pressure to the same categories of lesion level. Those who did, observed similar differences per lesion level in SBP, with persons having a C lesion showing the lowest SBP.[17,22,25,31] The fact that the mean SBP and DBP did not differ between HT and LTL lesions in our study was surprising since HT lesions will have partial sympathetic preservation of cardiac innervation and vascular control of the upper body while the LTL lesions will have full sympathetic preservation. However, this phenomenon of similar SBP and DBP in HT and LTL lesions was also reported in an earlier

meta-analysis of cardiovascular outcomes in SCI.[25] It deserves a further investigation since we could not find a possible explanation of this finding in the literature.

Age and TSI

Based on previous research in the general population, an association between increasing age and hypertension was expected.[30] An association between TSI and hypertension was also expected since a longer TSI means a longer exposure to a sedentary lifestyle. Furthermore, previous studies have demonstrated a higher prevalence and greater degree of coronary artery calcification and increased arterial stiffness in people with SCI compared to a matched able-bodied population.[32,33] A remarkable observation in the present study was that the median SBP decreased in those participants injured longer than 41 years, especially in those with a lesion below T6. Unfortunately, we have no clear explanation for this outcome, except the fact that this was a very small group of six participants. Also, a possible explanation is the so-called "survivor-effect", meaning that those with better health outcomes are more likely to survive and live longer with their injury.[34]

One previous study on the prevalence of self-reported hypertension in people with a similar mean age of 48.4 years and mean TSI of 16.9 years also observed a bivariate association with age and TSI.[19] In contrast to the present study, they included both age and TSI in a logistic regression model in which only age made a significant contribution with an OR of 1.06.

In two other studies hypertension was also related to being older in people with long-term SCI.[13,18] These studies did not assess an association with TSI.

In the present study, every additional year of TSI recorded an OR of 1.13 for hypertension. One other study also found a significant association between TSI and hypertension with an OR of 1.05, which is in line with our result.[10] However, that study considered participants as having hypertension when they had ongoing drug treatment for hypertension and/or when a high blood pressure was recorded once in rest.

Since this is a cross-sectional study, it is impossible to clarify the role of TSI in the development of hypertension. Longitudinal studies are required to further assess this matter.

Hypercholesterolemia

In this study, an association between a history of diagnosed hypercholesterolemia and hypertension was found. None of the studies in the SCI-literature we examined, found this association. According to data from the Framingham Heart Study, 80% of persons with hypertension have other CVD risk factors.[35] Population-based studies have reported that hypercholesterolemia is one of these risk factors that is common in people with hypertension. In the United States, prevalence estimates for concomitant hypertension and hypercholesterolemia range from 15% to 31%.[36-38] This association may reflect the casual co-existence of two widely distributed CVD risk factors, or may be explained by the same metabolic abnormalities that are thought to underlie both conditions.[39]

Clinical implications

Extra attention for blood pressure is needed in people with a spinal cord lesion level below C8 and especially below T6, with a longer TSI, a higher age, and for those with a history of hypercholesterolemia. Based on the study results, one could recommend screening for hypertension during annual checkups, especially in those with a higher risk for developing hypertension, e.g. those with a lesion level below C8 and an age of ≥45 years or a TSI of ≥20 years. When a high blood pressure is measured, these persons should receive a further assessment of the blood pressure according to the available guidelines for the general population, including ambulatory 24-h blood pressure monitoring.

Study limitations

There were some limitations concerning this study. Firstly, the cross-sectional design limits the possibilities to interpret associations with TSI. Furthermore, since we observed a high correlation between age and TSI, we could not enter both variables in the same logistic regression analysis. Therefore, we were not able to test both TSI and age in one block to assess their predictive ability while controlling for the effects of each other.

Secondly, referral of the participants to the GP or cardiologist depended on the clinical judgement of the physician. Thirdly, other factors known to have an association with hypertension in the general population such as diet, excessive alcohol use and psychosocial stress, were not measured in the present study. Fourthly, when interpreting the results concerning the prevalence of high blood pressure and/or the use of antihypertensive

drugs one has to bear in mind that these might represent overestimations of the actual prevalence of hypertension. Both in the present study and in the Dutch population-based study no multiple blood pressure measurements were taken during several visits. Therefore, within-person variability in blood pressure was not taken into account. Finally, due to the inclusion criteria, our study sample predominantly consisted of participants with a traumatic and complete SCI who obtained their SCI at a relatively young age, not corresponding with the general Dutch SCI population.[40]

Conclusion

This study reported a prevalence of hypertension in Dutch people with long-term SCI of 21.5%. Hypertension was associated with a lesion level below C8, a longer TSI, a higher age and a history of diagnosed hypercholesterolemia. Furthermore, it appeared that the prevalence of high blood pressure and/or the use of antihypertensive drugs was higher in both men and women aged between 30–59 years with a HT or a LTL injury level compared with the Dutch age-matched general population. Therefore, screening for hypertension during annual check-ups in this group of men and women with a lesion level below C8 is suggested. Moreover, further studies are required to clarify the exact role of potential SCI-related risk factors for hypertension, such as TSI.

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Chapter 8

Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years

Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years

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Abstract

Objective To describe (1) the prevalence of secondary health conditions (SHCs) among persons with long-term spinal cord injury (SCI) and (2) the relationship between these SHCs and quality of life (QoL).

Design Multicentre cross-sectional study.

Subjects Individuals (N=282) with traumatic or non-traumatic SCI for ≥10 years, age at injury 18–35 years, current age 28–65 years, and using a wheelchair.

Methods The occurrence of 13 SHCs was assessed during a consultation with a rehabilitation physician. QoL was measured with the International SCI QoL Basic Data Set.

Results Median time since injury (TSI) was 22.0 years. The median number of SHCs was 4. The most prevalent SHCs were musculoskeletal pain (63.5%), oedema (38.7%), neuropathic pain (34.1%) and urinary tract infections (33.3%). Only oedema showed a significant association with increasing TSI. The median total QoL Basic Data Set score was 7. Musculoskeletal pain, pressure ulcers, problematic spasticity and constipation showed an independent association with QoL in the multiple regression analysis, but in general, these associations were weak.

Conclusion SHCs are common among persons with long-term SCI and several SHCs were independently associated with lower QoL. Minimizing the impact of SHCs should be a priority in the long-term care for persons with SCI.

Introduction

Persons with SCI are likely to experience serious health problems associated with this condition. These secondary health conditions (SHCs) have been defined as "physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment".[1] Examples of SHCs associated with SCI are bladder- and bowel disorders, pressure ulcers, spasticity, upper-extremity pain, and cardiovascular and respiratory problems.[1] In persons with SCI, the presence of SHCs is associated with a lower life-expectancy which still remains below the life expectancy of the general population.[2] Therefore, it is essential to gain more knowledge on the long-term consequences of SCI on the health of persons living with SCI.

In a Dutch survey among 454 persons with SCI and a mean time since injury (TSI) of 13.3 years in 2002, an average of 4.6 SHCs were reported.[3] Problems with bladder (71%) and bowel regulation (61%), spasms (57%), and pain (55%) were the most frequently reported SHCs.[3] Two studies reporting on persons living with SCI for at least 20[4] and 25 years,[5] found the same SHCs to be highly prevalent and additionally found pressure ulcers (39% and 56%, respectively) to be a frequent problem. Although exact figures varied between studies, other studies in persons with long-term SCI confirm the frequent occurrence of the aforementioned SHCs.[6,7]

Several demographic and injury-related characteristics have been associated with the prevalence of SHCs.[6,8-10] A previous review found contractures to be more frequent with longer TSI and that cardiovascular disease, diabetes, and respiratory complications were more prevalent in older persons.[8]

Quality of life (QoL) reflects an individual's overall perception of, and satisfaction with, how things are in his/her life.[11] The average QoL in persons with SCI is below the average of the general population.[12] The presence of SHCs may contribute to the explanation of this lower QoL in persons with SCI. However, the literature on this topic shows diverging results. In two studies, an association was found between an increasing number of SHCs with lower QoL,[13,14] but two other studies did not find such an association.[15,16] We were not able to find earlier studies on relationships between specific SHCs and QoL in persons with long-term SCI (mean TSI of ≥10 years), despite the fact that such knowledge may be helpful in improving long-term care and identifying research priorities.

Therefore, the aims of this study were:

1. To investigate the prevalence of 13 SHCs during the previous 3 months among persons with long-term SCI, stratified for three different TSI periods (10–19, 20–29, and ≥30 years).
2. To explore the relationships between these SHCs, TSI and QoL.

Methods

Design

This study is part of the Dutch multicentre research programme "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)", a TSI-stratified cross-sectional study among persons with long-term SCI living in the Netherlands.[17] TSI strata were 10–19, 20–29 and ≥30 years after SCI. We aimed to include 100 persons per stratum.[17]

Participants

The inclusion criteria were 1) traumatic or non-traumatic SCI with a TSI of ≥10 years, 2) age at injury between 18 and 35 years, 3) current age between 28 and 65 years, and 4) using a wheelchair (hand-rim propelled or electric wheelchair), at least for longer distances (>500 m).

These age and age at onset inclusion criteria were applied to limit the confounding effects of age-related co-morbidities and thereby to be better able to study the long-term consequences of SCI. The exclusion criterion was an insufficient mastery of the Dutch language to respond to an oral interview or to understand test instructions.

Basis for the power analysis was the aim to detect differences in the prevalence of SHCs between TSI strata. With alpha=0.05 and power=0.80, a prevalence of 0.2 can be estimated with a margin of error of ±4.6%. A prevalence difference of 0.2 (0.3 versus 0.5) between two TSI strata with 100 participants each would be statistically significant with the same alpha and power. For regression analysis, this number of 300 participants would allow inclusion of 19 independent variables in the analysis using the rule of thumb of 15 participants per variable. Therefore, it was aimed to include 100 participants per stratum.

Procedure

Eligible persons were identified in databases from all eight Dutch rehabilitation centres specialising in SCI rehabilitation. Since we aimed to include 30–35 persons per centre, and expected a response rate of around 50%, 62 persons per centre were invited for the study. If the number of eligible persons allowed it, a random sample was drawn at each centre. If the response was less than 30–35 persons per centre, an additional sample was drawn at that centre.

The study consisted of a one-day visit to the rehabilitation centre for a check-up, including an extensive medical assessment and physical examination performed by an SCI rehabilitation physician, and an oral interview and physical tests performed by a research assistant. Two weeks before the visit to the rehabilitation centre, participants were asked to complete a self-report questionnaire.

The research protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht. All participants gave written informed consent.

Instruments

Secondary health conditions

The occurrence of 13 SHCs was reported as 0 = no occurrence over the past 3 months or 1 = currently present or has occurred over the past 3 months. Standardised questions on the type of pain were completed in case the participant reported having pain.

Neuropathic pain was defined as at-level or below-level pain, originating from syringomyelia, spinal cord ischemia or trauma.[18] It was further objectified by using the Douleur Neuropathique en 4 Questions (DN4).[19] The DN4 questionnaire consists of seven items related to symptoms and three items related to a clinical examination. A total score of 4 or higher out of 10 suggests neuropathic pain. It has shown good test-retest reliability (κ=0.75) and a high sensitivity of 93% and specificity of 75% in persons with SCI.[20]

Musculoskeletal pain was defined as nociceptive pain originating from bone, joint, or muscle trauma or overuse.[18]

Pressure ulcers were defined according to the classification of the European Pressure Ulcer Advisory Panel (EPUAP): category I, II, III or IV.[21] When a participant indicated that

he/she had had a pressure ulcer in the past 3 months, the rehabilitation physician asked further questions on the location and severity of the ulcer. All pressure ulcers, irrespective of category, were included.

Problematic spasticity was scored when a participant indicated that spasticity was present and that it interfered moderately or extensively with activities in daily life.

Autonomic dysreflexia (AD) was defined as a sudden reaction of the autonomic nervous system triggered by a stimulus below the level of the lesion (e.g. bladder distension, UTI), causing an increase in blood pressure in association with other symptoms such as 1) below the level of the lesion: piloerection, pallor, cold extremities, profuse sweating and 2) above the level of the lesion: severe headaches, nasal congestion, flushing of the skin and bradycardia.

Hypotension was checked for by the assessment of symptoms (e.g. light-headedness or fainting).

Oedema was scored when the participant had received relevant treatment (e.g. compression stockings, bandages or diuretic drugs).

Neurogenic heterotopic ossification (NHO) was defined as the presence of bone in soft tissue surrounding paralysed joints, confirmed by radiological examination.

Pneumonia was defined as a lower respiratory tract infection that was treated with antibiotics.

Urinary tract infection (UTI) was defined as a symptomatic infection of the urinary tract, treated with antibiotics. Symptoms had to include one or more of the following: onset of urinary incontinence, increased spasticity, malaise, AD, discomfort or pain during urination, gritty particles or mucus in the urine or cloudy urine with increased odor.

Urinary incontinence was operationalised as any involuntary urine leakage, occurring at least once a month. No involuntary urine leakage implied no leakage of urine outside the urinary tract or a closed urinary collection system.

Fecal incontinence was defined as involuntary loss of faeces occurring at least once a month.

Constipation was scored according to the Rome III criteria for functional constipation.[22]

Quality of life

The International SCI QoL Basic Data Set was used for the assessment of QoL.[11] It contains three items: satisfaction with life as a whole, satisfaction with physical health and satisfaction with psychological health. All three items are self-rated on a 0–10 scale with a time frame of the past 4 weeks, with 0 = completely dissatisfied and 10 = completely satisfied.[11] The total QoL Basic Data Set score (total QoL score) is the mean of the three item scores.

Details on the validity of the International SCI QoL Basic Data Set items are reported elsewhere.[23] The three items showed generally strong inter-correlations and the total QoL score showed good internal consistency (Cronbach's alpha = 0.81). The three items and the total score were strongly correlated with scores on reference measures.[23]

Potential confounders (demographic and injury-related characteristics)

Potential confounders in the relationship between SHCs and QoL were identified from previous studies.[13,16,24,25]

Demographic variables were part of the self-report questionnaire and included age, gender, nationality (Dutch, other), married/stable relationship (yes, no), having children (yes, no), level of education (high/low was defined as with/without college or university degree) and employment (paid work for at least 1 hour per week).

The International Standards for Neurological Classification of SCI were used to assess lesion characteristics.[26] Tetraplegia was defined as a lesion at or above the first thoracic segment and paraplegia as a lesion below the first thoracic segment. A complete lesion was diagnosed in the absence of motor and sensory function in the sacral segments, i.e. American Spinal Injury Association (ASIA) Impairment Scale (AIS) A. Grades B, C and D on the scale were considered to represent an incomplete lesion.[26] TSI and aetiology (traumatic versus non-traumatic) were also recorded.

The Spinal Cord Independence Measure III (SCIM-III) was used to assess functional independence. The total score range is 0 to 100 and higher scores indicate higher levels of independence in daily activities.[27]

Statistics

Descriptive analyses were performed to describe demographic and injury-related characteristics, frequency of SHCs, and QoL scores.

Chi-square Tests were used to explore differences in the proportions of participants suffering from certain SHCs between the three TSI strata. When a statistically significant effect ($P<0.05$) was found, post-hoc tests were performed to explore between which of the three TSI strata the difference existed. To decrease the risk of committing a Type I error in these post-hoc analyses, a Bonferroni correction ($P=0.05/3=0.017$) was applied.

Continuous variables were assessed for normality. Two of the four QoL scores (satisfaction with life as a whole and satisfaction with psychological health), TSI and functional independence scores showed skewed score distributions. Therefore, the Kruskal-Wallis Test was used to analyse differences between the three different TSI groups on the continuous variables. The Mann-Whitney *U* Test was used to test for differences between two independent groups (the SHCs as dichotomous variables) on TSI as a continuous variable and on the QoL scores. Effect sizes were calculated from the Mann-Whitney *U* Test statistics as follows: r = Z-value / square root of N (N = total number of cases). Effect sizes were interpreted using Cohen criteria: .10–.29 small effect; .30–.49 medium effect; .50–1.0 large effect.

Bivariate linear regression was performed to explore the association between a single possible determinant on the total QoL score. Standard multiple linear regression was used to assess independent associations between SHCs and the total QoL score, corrected for the potential confounding effect of demographic and injury-related characteristics. Preliminary analyses were performed to ensure the assumptions for multiple regression (normality, linearity, homoscedasticity and multicollinearity) were not violated. For the multiple regression analysis the rule of thumb of 15 participants per determinant was used, allowing the use of 17 determinants. Therefore, only variables with a *P*-value below 0.10 in the bivariate regression were entered in the multiple regression analysis.

We dealt with the missing data by using pairwise deletion of cases with missing values.

All analyses were performed using the SPSS statistical software (SPSS 21.0 for Windows; IBM corp.; Armonk, New York).

Results

Participant characteristics

Between November 2011 and February 2014 a total of 566 persons were invited to participate in the study, 292 of whom were ultimately included. The main reasons for non-participation were a large travel distance, unwillingness, too busy with daily life, and health issues. After the inclusion procedure there were 10 participants who in retrospect did not meet all the inclusion criteria and were therefore excluded from the analyses. A total of 261 participants (92.6%) completed all QoL questions. The characteristics of the participants (N=282) are described in Table 8.1. We were not able to perform a non-response analysis, since not all of the participating rehabilitation centres could provide us with the required information concerning the non-respondents.

Secondary health conditions

A median number of four (IQR: 2–5) SHCs were reported over the previous 3 months. Furthermore, 98.5% of the participants had suffered from at least one SHC.

The prevalence of SHCs in each TSI stratum is displayed in Table 8.2. In general, the hypothesis that the prevalence of SHCs would increase with increasing TSI could not be confirmed. Musculoskeletal pain was the most frequently reported SHC and was more common in the TSI ≥30 years group, compared to the TSI 20–29 years group. Oedema was more common in the TSI ≥30 years group, compared to the TSI 10–19 years group. AD was less common in the TSI 20–29 years and ≥30 years group, compared to the TSI 10–19 years group. Pneumonia was also less common in the longer TSI groups, however, this was not statistically significant after the Bonferroni correction.

Quality of life

Table 8.3 shows the QoL scores stratified for TSI. No significant differences in QoL scores between TSI strata were observed.

Table 8.4 displays the effect sizes for the differences in QoL scores for the different SHCs, tested with the Mann-Whitney *U* Test. In general, the effect sizes were small.

Table 8.1 Participant characteristics, N=282

	Total (N=282)	TSI 10–19 years (N=107)	TSI 20–29 years (N=96)	TSI ≥30 years (N=79)	Sig.
Age (years), median (IQR)	47.8 (41.6–55.0)	40.3 (36.6–44.5)	48.0 (44.0–52.3)	59.0 (53.9–63.1)	**<0.001**
Time since injury (years), median (IQR)	22.0 (16.8–30.3)	-	-	-	-
Gender (% male)	74	72	80	70	0.229
Nationality (% Dutch)*	96	94	98	97	0.315
Cause (% traumatic)	91	94	92	87	0.231
Level (% tetraplegia)	41	42	43	39	0.896
ASIA Impairment Scale (AIS) (%)					0.170
A	69	74	70	59	
B	14	11	10	20	
C	10	10	10	8	
D	8	5	8	13	
Functional independence (SCIM-III score), median (IQR)**	64.0 (43.0–69.0)	66 (44.5–68.0)	64.5 (36.5–69.25)	62.5 (45.75–68.0)	0.627
Relationship (% married/stable relationship)*	61	57	64	62	0.586
Children (% with ≥1 child)	47	43	48	53	0.445
Level of education (% college/university)*	44	45	48	40	0.549
Employment (% having paid work ≥1 hour/week)*	39	48	39	28	**0.023**

AIS = American Spinal Injury Association Impairment Scale; IQR = interquartile range; SCIM-III = Spinal Cord Independence Measure III; Sig. = significance; TSI = time since injury.
* N=268 participants who completed the self-report questionnaire.
** N=277 participants who completed the SCIM-III questionnaire.

Table 8.2 Prevalence of secondary health conditions (SHCs) with 95% confidence intervals

SHCs	Overall group (%) (N=282)	TSI 10–19 years (%) (N=107)	TSI 20–29 years (%) (N=96)	TSI ≥30 years (%) (N=79)	*P* for between group difference	*P* for TSI as a continuous variable
Neuropathic pain	34.1 (0.27–0.38)	35.5 (0.26–0.44)	34.0 (0.23–0.41)	32.1 (0.21–0.41)	0.887	0.660
Musculoskeletal pain	63.5 (0.58–0.69)	65.4 (0.56–0.74)	51.0 (0.41–0.61)	75.9 (0.66–0.85)	**0.003** [c]	0.197
Pressure ulcers	29.4 (0.24–0.35)	27.1 (0.19–0.36)	30.2 (0.21–0.39)	31.6 (0.21–0.42)	0.781	0.369
Problematic spasticity	23.8 (0.19–0.29)	28.0 (0.19–0.37)	26.0 (0.17–0.35)	15.2 (0.07–0.23)	0.102	0.036
Autonomic dysreflexia	19.1 (0.15–0.24)	30.8 (0.22–0.40)	12.5 (0.06–0.19)	11.4 (0.04–0.18)	**0.000** [a,b]	**0.001**
Hypotension	20.6 (0.16–0.25)	24.3 (0.16–0.32)	22.9 (0.14–0.31)	12.7 (0.05–0.20)	0.119	0.089
Oedema	38.7 (0.33–0.44)	29.0 (0.20–0.38)	41.7 (0.32–0.52)	48.1 (0.37–0.59)	**0.023** [b]	**0.001**
NHO	24.1 (0.19–0.29)	20.6 (0.13–0.28)	29.2 (0.20–0.38)	22.8 (0.14–0.32)	0.341	0.469
Pneumonia*	5.1 (0.03–0.08)	9.4 (0.04–0.15)	2.2 (0.00–0.05)	2.7 (0.00–0.06)	**0.036** [d]	0.035
Urinary tract infection	33.3 (0.28–0.39)	30.8 (0.22–0.40)	36.5 (0.27–0.46)	32.9 (0.23–0.43)	0.695	0.825
Urinary incontinence	27.0 (0.22–0.32)	26.2 (0.18–0.35)	27.1 (0.18–0.36)	27.8 (0.18–0.38)	0.967	0.778
Faecal incontinence**	16.0 (0.12–0.20)	17.8 (0.11–0.25)	18.9 (0.11–0.27)	10.1 (0.03–0.17)	0.236	0.489
Constipation	25.2 (0.20–0.30)	31.8 (0.23–0.41)	19.8 (0.12–0.28)	22.8 (0.14–0.32)	0.123	0.115

NHO = neurogenic heterotopic ossification; SHCs = secondary health conditions; TSI = time since injury; * total of one missing in 20–29 years group; ** total of nine missings: one in 10–19 years group, three in 20–29 years group, five in ≥30 years group; [a] Statistically significant difference between TSI 10–19 years and 20-29 years groups; [b] Statistically significant difference between TSI 10–19 years and ≥30 years groups; [c] Statistically significant difference between TSI 20–29 years and ≥30 years groups; [d] No statically significant difference between groups after Bonferroni correction ($P>0.017$).

Table 8.3 Quality of life scores, median (IQR)

Quality of life scores	Overall group	TSI 10–19 years	TSI 20–29 years	TSI ≥30 years	Sig.
Satisfaction with life as a whole (N=263)	7 (6–8)	7 (6–8)	7 (6–8)	7 (6–8)	0.910
Satisfaction with physical health (N=264)	6 (4–7)	6 (4–7.5)	6 (4–7)	6 (5–7)	0.508
Satisfaction with psychological health (N=262)	7 (6–8)	7 (6–8)	8 (7–9)	7 (6–8)	0.256
Total QoL Basic Data Set score (N=261)	7.0 (5.7–7.7)	7.0 (5.3–7.7)	7.0 (5.7–7.7)	6.7 (5.7–8.0)	0.981

IQR = interquartile range; QoL = quality of life; TSI = time since injury; Scores for all four quality of life variables range from 0 to 10, with 0 = completely dissatisfied and 10 = completely satisfied.

Bivariate regression

Results of all regression analyses are summarised in Table 8.5. SHCs that were negatively associated ($P<0.05$) with the total QoL score were musculoskeletal pain, pressure ulcers, problematic spasticity, hypotension, UTI and constipation. AD showed a negative association with QoL at $P<0.10$. Participant characteristics that were found to have a positive bivariate association ($P<0.05$) with the total QoL score were employment, having a stable relationship and higher functional independence.

Standard multiple regression

Four out of seven included SHCs showed a unique association with lower QoL (Table 8.5). These were musculoskeletal pain, pressure ulcers, problematic spasticity and constipation. Participant characteristics that had an association with higher QoL were having a stable relationship and employment. The multiple regression model explained 23.0% of the variance in total QoL scores (Table 8.5) of which 12.6% was explained by the included SHCs and 10.4% was explained by the included participant characteristics.

Discussion

This study shows that SHCs are common among persons with long-term SCI. Only one SHC showed a significant association with increasing TSI. Four SHCs (musculoskeletal pain,

Table 8.4 The effect sizes[a] for the differences in quality of life scores for the different secondary health conditions tested with the Mann-Whitney *U* Test

Secondary health conditions	Satisfaction with life as a whole (N=263)	Satisfaction with physical health (N=264)	Satisfaction with psychological health (N=262)	Total QoL Basic Data Set score (N=261)
Neuropathic pain	.07	.00	.00	.03
Musculoskeletal pain	.08	**.12***	**.14***	**.13***
Pressure ulcer	**.15***	**.16***	**.14***	**.17****
Problematic spasticity	**.16***	**.19****	**.13***	**.20****
Autonomic dysreflexia	.10	.09	.03	.07
Hypotension	**.13***	**.14***	.10	**.14***
Oedema	.03	.04	.06	.03
NHO	.03	.01	.00	.00
Pneumonia	.04	.02	.06	.05
Urinary tract infection	.09	**.20****	.03	.12
Urinary incontinence	.07	.04	.05	.07
Faecal incontinence	.03	**.14***	.02	.08
Constipation	**.13***	**.15***	**.17****	**.17****

[a] The calculation of the effect size of Mann-Whitney's *U* test: r = Z-value / square root of N.
NHO = neurogenic heterotopic ossification; QoL = quality of life.
* Significance level <0.05; ** Significance level <0.01.

pressure ulcers, problematic spasticity and constipation) appeared to have an independent association with QoL, but in general, these associations were weak.

Prevalence of secondary health conditions

The number of SHCs experienced by the participants was comparable to findings of other studies. A previous study found that only 4.4% of persons with a SCI for at least 10 years were free from SHCs at the time of routine physical examination.[28] Another study with a mean TSI of 19 years found an average of 4.1 SHCs over the past year.[6]

The expected increase in prevalence of SHCs with longer TSI was observed only for oedema. A possible explanation for the absence of this association for other SHCs is the so-called "survivor effect", meaning that those with better outcomes are more likely to survive and participate in a study.[29]

Table 8.5 Regression analyses, total QoL Basic Data Set score (N=261)

	Bivariate regression			Standard multiple regression		
				Constant (SE): 6.390 (.384)		
Variables entered	B* (SE)	beta*	Sig.	B (SE)	beta	Sig.
Age (*continuous*)	-.006 (.012)	-.029	0.643			
Gender, male	.371 (.241)	.095	0.124			
TSI (*continuous*)	.007 (.012)	.035	0.572			
Cause, traumatic	.103 (.373)	.017	0.782			
Level, tetraplegia	-.153 (.215)	-.044	0.479			
Complete lesion	.135 (.229)	.037	0.555			
Functional independence (*continuous*)	.018 (.006)	.196	**0.002**	.010 (.005)	.112	0.061
Stable relationship	.564 (.214)	.161	**0.009**	.566 (.199)	.162	**0.005**
Children	-.033 (.212)	-.010	0.878			
Education, high	.276 (.213)	.080	0.196			
Employment	.855 (.210)	.245	**0.000**	.664 (.202)	.190	**0.001**
Neuropathic pain	.084 (.223)	.023	0.707			
Musculoskeletal pain	-.468 (.218)	-.132	**0.033**	-.488 (.200)	-.138	**0.016**
Pressure ulcer	-.708 (.228)	-.189	**0.002**	-.687 (.215)	-.184	**0.002**
Problematic spasticity	-.744 (.245)	-.186	**0.003**	-.788 (.232)	-.197	**0.001**
Autonomic dysreflexia	-.475 (.268)	-.110	**0.077**	-.050 (.265)	-.012	0.850
Hypotension	-.747 (.258)	-.177	**0.004**	-.363 (.254)	-.086	0.155
Oedema	-.010 (.218)	-.003	0.964			
NHO	-.067 (0.248)	-.017	0.787			
Pneumonia	.310 (.489)	.04	0.526			
Urinary tract infection	-.470 (.223)	-.130	**0.036**	-.248 (.213)	-.069	0.246
Urinary incontinence	.199 (.239)	.052	0.404			
Faecal incontinence	-.416 (.288)	-.089	0.150			
Constipation	-.627 (.241)	-.159	**0.010**	-.514 (.225)	-.131	**0.023**
				R	**R square**	
				.480	.230	

NHO = neurogenic heterotopic ossification; QoL = quality of life; TSI = time since injury; * Positive B and beta values signify an increase in total QoL Basic Data Set score, negative values a decrease.

Comparing frequencies of specific SHCs across studies is complicated, as study populations and definitions of SHCs differ. Musculoskeletal pain showed to be highly prevalent. The overall prevalence of 63.5% is somewhat higher than the 50.5% found by Wollaars et al.[30]

This difference might be explained by their shorter mean TSI of 11.8 years and the fact that only chronic pain (>6 months duration) was measured. A previous review also reported the prevalence of only chronic musculoskeletal pain (≥3 months duration) in persons with SCI (TSI range 3–51 years) and found prevalence ranges of 28.4%–59.0% which is still lower compared to our overall prevalence.[31]

The observed prevalence of neuropathic pain was low compared to the literature. Previous studies in persons with a mean TSI of at least 10 years, showed percentages ranging from 56% to 65%.[7,30] The highest prevalence was found in a study in which neuropathic pain was assessed over the past year.[7] Wollaars et al.[30] also measured chronic neuropathic pain (>6 months duration), potentially partially explaining the differences with our study. Another possible explanation is that there seems to be a positive correlation between an advanced age at injury and the onset of neuropathic pain. Compared to previous studies on neuropathic pain, our participants were relatively young at the time of injury, between 18 and 35 years old, potentially explaining our lower observed prevalence. Furthermore, none of these previous studies have used a screening tool that has been validated for screening neuropathic pain in persons with SCI, while in our study the DN4 questionnaire was used which has been described as the most suitable screening tool for neuropathic pain in persons with SCI.[20]

The prevalence of pressure ulcers was comparable to previous studies in long-term SCI. Prevalences between 23.3% (TSI 10 years) and 29.4% (TSI 20 years) at the time of evaluation,[32] and 38.7% (TSI >20 years) over the past 3 years[4] have been reported. The prevalence in our study might be an underestimation. Since bed rest is a common treatment for pressure ulcers, persons with pressure ulcers might have been prohibited from study participation, which required travelling to the rehabilitation centre. The increasing prevalence with longer TSI in some,[28,33] but not all previous studies,[8] was not seen in the current study.

Secondary health conditions and quality of life

Study participants scored their QoL as rather satisfying. This is in accordance with previous studies.[12,34] Overall, the associations between SHCs and QoL were surprisingly weak. There might be two explanations. First, with a median of four SHCs over the past 3 months, it is reasonable to assume that participants have experienced SHCs regularly over the previous years, have accommodated to their presence, and that SHCs thereby no longer substantially

influence self-evaluations of QoL. In the literature this process of adaptation in persons with a chronic disease is known as "response shift".[35] Second, it could well be that SHCs that occurred and have been overcome early in the 3 month period, no longer influenced QoL, which was measured over the previous 4 weeks.

Notwithstanding this, four SHCs did relate with lower QoL. A number of previous articles did show a negative association between pain and QoL after SCI.[24,30,36] As expected, musculoskeletal pain was negatively associated with QoL in this study. Surprisingly, neuropathic pain was not. It might be that this is due to the definition, which did not include a severity nor a frequency criterion. Perhaps we would have found an association with QoL if we had also measured the severity of the neuropathic pain. Problematic spasticity influenced QoL negatively. Two previous studies found an association between spasticity and lower QoL in persons with SCI,[24,37] while one other did not.[38] Only one of these studies included interference with daily life in the definition of spasticity.[37] It is known that spasticity can be experienced as negative (e.g. hampering daily activities) and positive (e.g. facilitating transfers) and that context is important in this difference. Having added "problematic" to the definition might be the reason an association was found in this study, but not in all others.

The negative effect of pressure ulcers on QoL is in accordance with some,[24] but not all previous studies.[39] Treatment for pressure ulcers in the Netherlands includes fully bed rest and sometimes surgical interventions and is most likely to impact QoL.

Constipation was negatively associated with QoL in this study. As far as we know, this relationship has not been studied in the SCI-population before. A recent study among persons with SCI did show that constipation is associated with an increased risk of not participating in many daily activities.[40] The authors suggested that this might be because constipation management can be time-consuming and subsequently have a disruptive effect on daily schedules.[40] Participation restriction might be one explanatory link between constipation and lower QoL in persons with SCI.

Strengths

To the best of our knowledge, this is one of the few studies specifically addressing SHCs in persons with long-term SCI (≥10 years) and the first international study to relate SHCs with QoL in this population. Further, unlike other studies that measured self-reported SHCs using questionnaires[3,7,10,30] or telephone interviews,[4,6] SHCs were assessed in a more

objective manner by a consultation with a rehabilitation physician in this study. Lastly, the restriction to persons aged 18–35 years at SCI onset and current age below 65 minimized the confounding effect of age at injury and current age, respectively.

Limitations

There are also some limitations concerning this study. First, the cross-sectional design limits the possibilities to interpret associations with TSI and age. As a consequence of its design, causal conclusions on the association with QoL cannot be drawn either. Second, we have not been able to reach the inclusion target of 100 persons with a SCI for at least 30 years. Third, recall errors might have taken place, although the restriction of the time frame of the occurrence of SHCs to the previous 3 months probably limits the extent of this problem. As mentioned before, the prevalence of pressure ulcers might be an underestimation of the true extent. Fourth, as this is an explorative study we have chosen not to adjust the *P*-value for multiple comparisons concerning our analyses with the 13 SHCs. Therefore, the risk of finding a false positive result by chance cannot be ruled out. Fifth, we did not report on concomitant diseases, although these might also impact the presence of certain SHCs and QoL. Finally, due to the inclusion criteria, our study sample predominantly consisted of participants with a traumatic and complete SCI who obtained their SCI at a relatively young age. This should be kept in mind when interpreting the study results, since some SHCs, such as pneumonia and AD, are more common in certain SCI patient groups. Another limitation concerning the representativeness of the study sample was the fact that we had no information regarding the comparability between participants and non-participants, nor for the total group, nor for the three TSI groups.

Clinical implications

It is important that professional caregivers and health care policy makers are aware of the high prevalence of SHCs among persons with long-term SCI. Since most SHCs are at least partially preventable, patient education and adequate self-management should become a focus point. For unpreventable conditions, such as neuropathic pain, adequate treatment plans should be made together with the patient. Since musculoskeletal pain, pressure ulcers, problematic spasticity and constipation are associated with lower QoL, special attention should be paid to these in terms of prevention, early diagnosis and treatment.

In the Netherlands, a substantial part of the complex care for persons with long-term SCI is provided by general practitioners. Centralising care for persons with long-term SCI in specialised rehabilitation centres and the development of national guidelines for systematic follow-up are possible strategies to enhance the quality of long-term care for persons with SCI that need to be evaluated for their ability to decrease the occurrence of SHCs.

In conclusion, SHCs are highly frequent among persons with long-term SCI. Four SHCs showed independent weak associations with QoL, these being musculoskeletal pain, pressure ulcers, problematic spasticity and constipation.

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Chapter 9

General discussion

This chapter discusses the main findings of our study, as well as its strengths and limitations. It also discusses implications with respect to a follow-up health care programme for people with SCI. Finally, suggestions are made for future research.

Main findings

In summary:

- Secondary health conditions are common in people with a SCI living in the Netherlands, both in the first years post-discharge as in the decades thereafter.
- In the first 5 years post-injury, the most prevalent secondary health conditions were neuropathic pain (84%–92%), musculoskeletal pain (62%–87%) and urinary tract infections (57%–59%). In people with a SCI for at least 10 years, the most prevalent secondary health conditions were musculoskeletal pain (64%), oedema (39%), neuropathic pain (34%) and urinary tract infections (33%).
- In general, the hypothesis that the prevalence of secondary health conditions would increase with increasing time since injury could not be confirmed.
- For both bladder- and bowel-emptying methods, the prevalence of non-conservative treatment options such as urinary diversions, transanal irrigation and colostomies was low, while several of their outcomes were more favourable compared to the different conservative methods.
- Hypertension is not a rare condition in people with long-term SCI (overall prevalence: 22%), especially not in those with a lesion level below C8, a history of hypercholesterolemia, a higher age and a longer time since injury.
- In accordance with previous studies, participants scored their quality of life as rather satisfying, and in general the associations between secondary health conditions and quality of life were weak.
- It is not common practice that people with a SCI for at least ten years, living in the Netherlands, participate in a structured follow-up health care system.

Discussion of main findings

This part of the General discussion reflects on our main findings concerning 1) secondary health conditions (SHCs) in general, 2) neurogenic bowel dysfunction and bowel management, 3) neurogenic lower urinary tract dysfunction and bladder management, and 4) blood pressure.

These specific SHCs are only few of the many SHCs associated with SCI. In this Thesis, we specifically addressed bowel and bladder dysfunction since these affect most people with SCI. In a previous study among 454 members of the Dutch Association of Spinal Cord Injured Patients, bladder and bowel regulation problems were the most frequently reported SHCs (71% and 61%, respectively) and rated as the most important SHCs they encountered in their life (52% and 42%, respectively).[1] In contrast, blood pressure became a specific topic of interest during the data acquisition phase, since several involved clinicians observed unexpected high blood pressures in our study participants.

Secondary health conditions (SHCs) in general

In **chapter 3**, we assessed the occurrence of several SHCs in people with a SCI at 1, 2 and 5 years after discharge from inpatient rehabilitation. It is one of the few studies providing a longitudinal perspective on the occurrence of SHCs in people with SCI. Neuropathic pain (84%–92%), musculoskeletal pain (62%–87%), and urinary tract infections (57%–59%) turned out to be the most frequently reported SHCs in this period of time post-injury. Comparison with other studies that assessed the occurrence of several SHCs among people with SCI in the first years post-injury was difficult due to the use of various study designs, selection procedures and data collection methods; e.g. physical examinations,[2,3] in-person interviews,[2-4] self-report questionnaires,[5-7] and telephone interviews.[4,8]

In **chapter 8** we assessed the prevalence of SHCs in people who were injured between 10 and 47 years prior to their participation in the study. When we compare the results of this study with the results of our study described in **chapter 3**, we observed that, although the incidences were lower in **chapter 8**, musculoskeletal pain (64%), neuropathic pain (34%) and urinary tract infections (33%) remained the most frequently reported SHCs over time.

A striking difference between both studies is the occurrence of neuropathic pain. In **chapter 8** we observed that only 34% of the participants reported neuropathic pain, against

84%–92% in **chapter 3**. When we compare this with the amount of participants who scored their neuropathic pain as severe in **chapter 3** (40%–44%), this difference becomes less pronounced, but does not disappear. However, in **chapter 8**, the presence of neuropathic pain was rated irrespective of its severity. On the other hand, we did use a more restrictive definition of neuropathic pain using the Douleur Neuropathique en 4 Questions criteria in **chapter 8**.[9] Another possible explanation is based on the difference in mean age at injury between both studies, of 39 years in **chapter 3**, compared to 24 years in **chapter 8**. A positive correlation has been described between an advanced age at the time of the injury and the onset of neuropathic pain.[2,10,11] For example, one of these studies reported that neuropathic pain was less than half as frequent (26%) in their group participants aged less than 20 years at the time of injury as in the group participants who were at least 50 years old at the time of injury (58%).[10]

We found that a median number of four SHCs were reported by people living with a SCI for at least 10 years and that only 1.5% were free from SHCs. This number of SHCs experienced by our participants was comparable to other studies.[7,12,13] This implies that SHCs are frequently encountered by people with long-term SCI.

In contrast to our expectations, an increase in prevalence of SHCs with longer TSI was only observed for oedema. This may suggest that the impact of increasing TSI on the prevalence of most SHCs is less explicit than expected. It may also be that the negative effects of TSI on the prevalence of SHCs are mainly present at a later stage in the aging process, e.g. beyond the age of 65 years. Also, our participants were relatively young at the time of injury (between 18 and 35 years old). TSI may have a more marked impact on the prevalence of SHCs in people who obtain their SCI at an older age. Younger adults are generally healthier and have greater physiologic "reserve capacity" than do older people. As a result, with the same severity of SCI, older people might be more susceptible to suffer from SHCs with increasing TSI. A previous study on the effect of age on disability in people with SCI observed that those who sustained an SCI at an older age showed a different course of disability than those who were younger at the time of injury.[14] The older participants were at the time of injury, the more rapidly their disability increased over time.

Another important possible explanation for the absence of an association between TSI and SHCs is the so-called "survivor effect", meaning that those with better health outcomes are more likely to survive (and outlive their chronological peers) and participate in a study.[15]

Despite the frequent reported SHCs, our study participants scored, on average, their quality of life (QoL) as rather satisfying which is consistent with the literature.[16,17] A previous review on the influence of aging with SCI on subjective QoL concluded that among people with advanced years post-injury overall QoL is consistently reported as good or excellent over time.[16] The authors of this review described the Response Shift theory by Sprangers and Schwartz[18] and the Life Span Development theory by Baltes[19] which may explain how people are able to maintain their QoL after life-altering disabilities such as SCI. According to the Response Shift theory, to accommodate changes in health and/or physical functioning, people inherently undergo simultaneous changes in their internal standards, values and conceptualizations of QoL. The Life Span Development theory postulates that human development occurs throughout the life course and is observed by the way people continuously adapt to changing external demands. The authors of the review suggested, that based on these two theories, it would be plausible that people with SCI are able to separate their compromised physical functioning from positive psychological well-being due to response shift.[16] Furthermore, as these people age, and perhaps other health conditions arise, but are perhaps expected, compensatory actions may lead people to engage in fewer, yet more life-enriching activities.[16]

Bowel problems and bowel management

Neurogenic bowel dysfunction (NBD) is one of the main SHCs resulting from SCI that hampers an active lifestyle and impacts negatively on QoL.[1,2,20-22] Bowel management in people with SCI is an individualised routine aimed at a predictable and regular evacuation of the faeces and the prevention of the negative effects of NBD such as constipation and incontinence. In **chapter 4**, we presented one of the few international studies addressing bowel management and NBD in people with long-term SCI. Conservative defecation methods were used most frequently. Transanal irrigation (TAI) was used by only 11% of the participants, and even fewer participants (8%) had undergone a surgical intervention as part of their bowel management. Furthermore, we observed that 36% of our participants reported severe NBD and 45% reported ≥1 perianal problem such as haemorrhoids, indicating that these bowel problems are not rare issues in people with long-term SCI.

Despite this, satisfaction with bowel management was relatively high. Only 14% of the participants were (very) dissatisfied with their bowel management which was consistent with levels of satisfaction found in previous studies.[23,24] Dissatisfaction was associated with

having perianal problems, constipation and severe NBD, but not with demographic or lesion characteristics.

The low frequency of TAI and surgical interventions merits exploration as it is possible that these are currently underused. A systematic review on neurogenic bowel management after SCI stated that conservative or pharmacological management of NBD is only successful in 67% of the SCI population and that, despite this, surgical interventions such as colostomy, supported by lower levels of evidence (pre-post studies) in reducing bowel related complications and in improving QoL, are not routinely used.[25]

Once again, we did not find indications for a decrease in bowel function over time: longer TSI was associated with less severe NBD and TSI was unrelated to satisfaction with bowel management. Because NBD also reflects the severity of the SCI, the significantly lower percentage participants with complete motor and sensory lesions in the longest TSI group might partially explain the decline in severe NBD with longer TSI. Furthermore, it may be that people with a longer TSI have suffered from more severe NBD in the past, but have eventually switched to another, perhaps less conservative, defecation method with a positive effect on the degree of NBD.

Bladder management

In **chapter 5**, we showed that clean intermittent catheterisation (CIC) was the most commonly used bladder-emptying method. This is in line with previous studies on bladder management[26-28] and is encouraging, since CIC lessens the frequency of long-term complications such as hydronephrosis, bladder and kidney stones.[29] However, CIC is not the ideal solution for all people with SCI. A previous study reported that 52% of people with SCI on CIC eventually revert to indwelling catheter use for reasons including dependence on caregivers, spasticity rendering catheterisation difficulties, incontinence, and female gender.[30] In our study, participants with tetraplegia were more likely to use reflex voiding or a suprapubic catheter, probably because of lack of manual dexterity and the reluctance of being dependent on a caregiver for CIC.

Further, 14.5% reported indwelling catheter use, despite this being associated with a higher impact of neurogenic lower urinary tract dysfunction (NLUTD) on QoL in our study and not being a preferred long-term management option due to the frequency of complications such as bladder cancer.[31] It would have been very interesting to know why these people

have chosen to manage their bladder with an indwelling catheter and when in the course of their treatment this decision was made, as this had the highest negative impact on QoL.

Perhaps, some would be able to catheterise a cutaneous stoma. The introduction of the continent urinary diversions (catheterisable pouches like the Indiana pouch or catheterisable channels like the Mitrofanoff procedure) into SCI urological practice has opened up the use of CIC to a wider population including paraplegic people who struggle with urethral self-catheterisation through limitations of mobility or problems with urethral sensitivity (in some incomplete SCI patients) and a small group of carefully selected tetraplegic patients. Perrouin-Verbe et al. studied the long-term complications of continent urinary diversions in adult SCI patients.[32] The overall complication rate was 44.8% with a reoperation rate of 24.1%. However, at last follow-up, 100% of patients had a catheterisable continent stoma and urethral continence was achieved in 96%. An improvement of QoL was reported by 90% of patients.[32]

Alternatives for people with SCI who desire independent bladder management and cannot perform CIC of urethra or stoma are, besides an external sphincterotomy in men, the construction of an incontinent urinary diversion like the ileal conduit or an ileovesicostomy.[33] However, both are not without complications, and many clinicians will suggest these procedures only after more conservative options have failed.[33] In our study, only 2.8% of the participants had underwent the construction of an incontinent urinary diversion which illustrates the fact that this is the last resort for a group of carefully selected patients.

As the person with SCI ages, physiologic and anatomical changes (e.g. prostatic enlargement, years of trauma to the urethra through catheterisation, bladder hypertrophy due to chronic sphincter-detrusor dyssynergia and chronic infections) may necessitate reassessment and modification of a previous adequate bladder management strategy.[34] Changes in overall endurance, such as in women who must transfer in and out their wheelchair to perform CIC, or changes in reliable access to caregivers, may require reassessment and alteration of a previous effective bladder-emptying method.

There is general agreement that urological surveillance is of utmost importance in people with SCI. Despite the improved medical management over the past decades, people with SCI remain at risk of developing urological complications which are still the leading cause of rehospitalisations after traumatic SCI.[35] In order to explore current urological surveillance in people with long-term SCI living in the Netherlands, we conducted a study of which the

results are described in **chapter 6**. It turned out that 39% of our participants had no routine follow-up of their urinary system, indicating no check-ups with a urologist and/or no routine ultrasonographies of the urinary tract.

Although there is no evidence regarding the optimal follow-up intervals of urologic ultrasonography (UU) with respect to long-term upper urinary tract (UUT) outcomes, all international and national guidelines recommend to perform urological surveillance routinely.[36-39] Also, a disappointingly large amount of participants (33%) reported that they had never had a urodynamic assessment after their injury. Although recall bias might have played a role, this percentage is still high and again does not correspond to the recommendations of published guidelines on NLUTD.

In **chapter 6** we also described UU outcomes. Unexpectedly, our data revealed dilatation of the UUT in only 4.5% of the participants and urinary stones in only 5.7%. This seems good news, but we have to keep in mind that these results are based on data of "survivors" and not on those who may have died prematurely due to UUT deterioration, although urinary disorders, including renal failure, account for only a small portion of the underlying causes of death among people with SCI.[35,40] Abnormal UU outcome was associated with increasing TSI, having a non-traumatic SCI and previous surgical bladder or UUT stone removal. The ultrasonography outcome was not associated with routine urological check-ups or type of bladder-emptying method. Based on these UU results one can argue about the recommended frequency of the performance of UU once a year. Further research concerning the content, indication and frequency of urological surveillance is needed.

Blood pressure

Cardiovascular disease (CVD) has become the leading cause of mortality in people with long-term SCI.[41] Hypertension is one of the most important risk factor for premature death due to CVD worldwide. Knowledge on the prevalence of hypertension and its associated risk factors in people with long-term SCI is scarce. In **chapter 7** we explored the occurrence of hypertension and its associated risk factors, and observed a prevalence of hypertension of 21.5%. To our surprise, the prevalence of single-measured high blood pressure and/or the use of antihypertensive drugs was higher in men (T1–T6 lesion: 48%; T7–L5 lesion: 57%) and women (T1–T6 lesion: 48%; T7–L5 lesion: 25%) with a SCI below C8 compared to Dutch able-bodied men (31%) and women (18%) in the same age range.

Interestingly, the mean systolic blood pressure (SBP) and diastolic blood pressure (DBP) did not differ between high-thoracic (HT) (T1–T6) and low-thoracic and lumbar (LTL) (T7–L5) lesions. Since HT lesions will have partial sympathetic preservation of cardiac innervation and vascular control of the upper body, while the LTL lesions will have full sympathetic preservation, we hypothesized a significant difference in the prevalence of hypertension between HT and LTL lesions, which was non-existent. This phenomenon of similar SBP and DBP values in HT and LTL spinal cord lesions was also reported in an earlier meta-analysis of cardiovascular outcomes in SCI.[42] It is a very interesting phenomenon which deserves a further investigation.

Methodological considerations

The aim of the present study was to explore the prevalence and impact of several SHCs among people with long-term SCI living in the Netherlands. We used a cross-sectional design, which fitted this aim and allowed us to include a large group within a limited age at injury range. It was a multicentre study, in which all eight Dutch rehabilitation centres with a specialty in SCI rehabilitation took part. We used an extensive set of measurements to gather data in different domains of the International Classification of Functioning, Disability and Health (ICF), including physical examination, in-person interviews and questionnaires. Since the present study used, if available, standardised measures like the International Spinal Cord Injury Data Sets,[43] it had important added value relative to earlier studies, which often included smaller numbers of participants, used only data from medical records or telephone interviews and/or did not use standardised measurements. The combination of examination by a physician and self-reported impact of SHCs added to the strength of the present study.

Despite the strengths of this study there are also limitations. First, a cross-sectional design allows only for the identification of associations between variables without causal conclusions. Second, due to the inclusion criteria the study sample predominantly consisted of participants with a traumatic SCI who obtained their injury at a relatively young age, which represents only a minor part of the general Dutch SCI population.[44] Nowadays, a substantial part of the Dutch population with SCI consists of people with non-traumatic SCI and people injured at an older age.[44] Third, this study might have suffered from the so called "survivor effect".[15] Survivor effect is a form of bias in cross-sectional and longitudinal cohort studies caused by selective dropout, meaning that participants represent only the survivors, or, more generally, those healthy enough to participate in the study.[15] The

resulting positive associations between increasing age and outcome variables can lead to an inaccurate conclusion that people actually improve as they age.[45,46] We have tried to limit this bias as much as possible by trying to include those who could not take part due to health problems again later in time. Nevertheless, since we had no information about non-participants our observations may be too optimistic, especially for the TSI group which included participants with a SCI for at least 30 years.

Fourth, cohort effects may have been present.[47] Cohort effects, also called treatment era effects, result from situations where those who are more recently injured may differ from their predecessors because of differences in for instance rehabilitation, medical care, and emergency services. Cohort effects are prone to be reflected as aging processes and may be interpreted as morbidity related to aging with SCI versus morbidity associated with treatment history.[45] This also indicates that, due to rapid advances in SCI care, survivor effects (as mentioned above) can be expected in SCI aging research.[45] On the other hand, mortality rates after the first 2 years post-injury have not changed since the early 1980s, so the influence of the treatment era effects may have been limited.[48]

One other problem we encountered was collinearity between age and TSI. Collinearity occurs when independent variables are so highly correlated that it becomes difficult or impossible to distinguish their individual influences on an outcome variable. This problem resulted from our choice to include only people who were injured as young adults (18–35 years) and were below 65 years at the time of the study. This choice was made to be able to study long-term consequences of SCI while limiting the confounding effect of biological aging as much as possible. This worked well for most SHCs, but not for blood pressure since the presence of high blood pressure is strongly age-dependent and manifests itself at a relatively young age. We addressed this problem, as much as possible, by comparing study outcomes with age-matched able-bodied control groups to examine the impact of the SCI, and also by studying the effect of TSI and age separately.

Clinical Implications

As described in this Thesis, people with long-term SCI are susceptible to many types of SHCs, and based on previous international studies we know that these SHCs contribute to significant morbidity,[35] medical costs,[49] and a high rate of rehospitalisations.[50] The 2015 Annual Statistical Report from the National Spinal Cord Injury Statistical Center[35] describes

that the proportion of people with SCI who reported at least one rehospitalisation in the past 12 months ranged from 26% during year 25 post-injury up to 39% during year 40. Diseases of the genitourinary system were the leading cause of rehospitalisation during most post-injury years.[35] Another study from Canada described that, compared with a matched control group, people with SCI were rehospitalised 2.6 times more often, were 2.7 times more likely to have a physician contact, and required 30 times more hours of home care services.[51]

Further, life expectancies of people with SCI remain substantially below normal, particularly for those with tetraplegia and ventilator-dependency.[35] Even more, since life expectancy in the general population is increasing but life expectancy for people with SCI who have survived the first 2 years after injury has remained relatively constant, the gap in life expectancy between SCI and the general population of comparable age, sex, and race, is increasing.[48]

Standard follow-up programmes in the rehabilitation centre are generally adhered to in the first 1–2 years after discharge from inpatient rehabilitation. Thereafter, the follow-up is dependent on the occurrence of SHCs and/or on the initiative of the person with SCI. People with SCI are encouraged to contact first their general practitioner when health problems occur, but the limited expertise on SCI of the general practitioner has been reported to be a barrier for people with SCI and a cause of unmet needs.[52] Information needs, especially regarding aging with SCI and current research, appear to be particularly poorly met.[53] A number of other issues for which unmet needs have been observed in the primary care are: psychological health, sexual and reproductive health, lifestyle and community functioning.[53]

A previous study on care needs of people with long-term SCI living at home in the Netherlands reported that within a 12 month period 77% of the participants had one or more SCI-related contacts with their general practitioner.[54] Seventy-two percent of the participants indicated a need for additional care in general.[54] They preferred specialised rehabilitation care above community care. Only 43.4% of the participants was satisfied with the expertise of their general practitioner.[54]

In our multicentre study, the check-up has led to a substantial amount of individual policy modifications and/or referrals, particularly in the field of urinary tract and cardiovascular problems (Table 9.1). Policy modifications were mainly changes in treatment methods, such as changes in medication use or in bladder-emptying or defecation method. Referrals could

Table 9.1 Policy modifications and/or referrals based on the results of the check-up (N=272)

	N	%
Total	150	55.1
Urinary tract problems	59	21.7
Cardiovascular problems	47	17.3
Bowel problems	29	10.7
Pain complaints	29	10.7
Pressure sores	22	8.1
Spasticity	16	5.9
Sexual dysfunction	10	3.7
Respiratory problems	4	1.4
Policy modifications based on other problems	26	9.2

be made to other disciplines within the rehabilitation centre, to medical specialists in the hospital, and to primary care (e.g. the general practitioner, physiotherapist or occupational therapist).

In my opinion, coordinated long-term health care is required for this population of people aging with SCI, in order to not only monitor SHCs and self-management strategies, but also to check for problems in daily living (e.g. facilities/equipment, work, leisure time), psychosocial problems and unmet needs in the primary care. A previous review from 2012, regarding primary care of people with SCI, has provided evidence for the importance of regular follow-up by specialised teams of medical and other multidisciplinary providers in people with SCI.[53]

Our study revealed that many people living with long-term SCI in the Netherlands do not meet the recommendations of regular follow-up by specialised teams (Table 9.2 and Table 9.3).

In 2013, the content of a coordinated Dutch health care programme for people with SCI has been defined in the "Zorgstandaard dwarslaesie" drafted by Dwarslaesie Organisatie Nederland in association with the Nederlands-Vlaams Dwarslaesie Genootschap (NVDG) and the Dutch Spine Society (DSS) who have approved this document.[55]

Table 9.2 Amount of years before the study, the participants had no contact with a rehabilitation physician / nurse practitioner / physician assistant

	N	Minimum	Maximum	Mean	SD
Total	265	0	36	3.32	5.44
TSI 10–19 years	100	0	19	3.44	4.48
TSI 20–29 years	92	0	24	2.75	4.74
TSI ≥30 years	73	0	36	3.86	7.22

Table 9.3 Amount of participants who did not have routine consultations with a urologist

	N	%
Total	282	39.4
TSI 10–19 years	107	35.5
TSI 20–29 years	96	41.7
TSI ≥30 years	79	41.8

The main recommendations of the "Zorgstandaard dwarslaesie" concerning follow-up care are as follows:[55]

- The person with a SCI has a consultation with the rehabilitation physician at least once every 2 years.
- The person with a SCI has a consultation with a urologist every year.
- Rehabilitation centres with a specialty in SCI rehabilitation organise "return days" for groups with for example information sessions or demonstrations of new developments.

From my point of view, people with SCI should have:

- Yearly consultations with their general practitioner.
- A consultation with their rehabilitation physician, at least once every 2 years.
- Individualised follow-up consultations with a urologist, preferably at least once every 2 years.

An outline of my vision concerning the allocation of roles of the general practitioner, rehabilitation physician and urologist, as part of a continuum of medical monitoring after discharge from inpatient rehabilitation, is described in the next paragraphs and summarised in Figure 9.1.

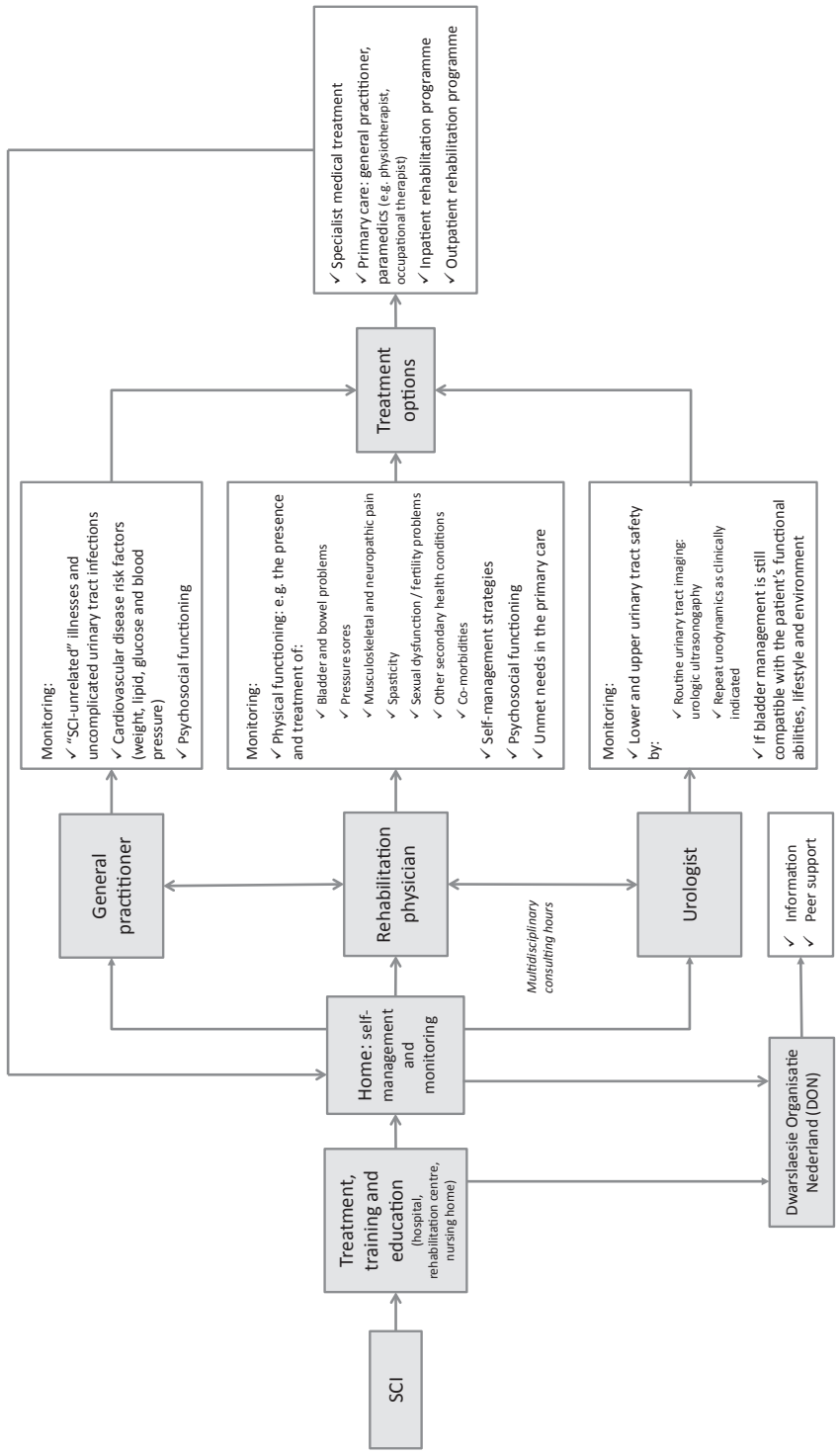

Figure 9.1 Continuum of medical monitoring.

The general practitioner and rehabilitation physician

In a follow-up healthcare system for people with SCI it should be clear what the division of responsibilities is between the general practitioner and the rehabilitation physician.

In my opinion, the general practitioner should be the first consultant in case of "SCI-unrelated" problems (both physical and psychological) and uncomplicated urinary tract infections. If there are signs of SCI-related disorders the general practitioner should always inform the rehabilitation physician.

Further, monitoring of cardiovascular disease (CVD) risk factors may be incorporated in a yearly consultation with the general practitioner.

With CVD becoming a leading cause of mortality in people with SCI,[41] risk factor modification through weight, lipid, glucose and blood pressure control become more important. The injury of the spinal cord is indirectly associated with several risk factors for CVD. The sedentary lifestyle with lack of ambulation, muscle activity and weight bearing contribute to rapid and marked changes in body composition such that muscle mass declines and the amount of adipose tissue increases. Among people with SCI, this adipose tissue tends to be located around the abdomen and there is evidence that abdominal adiposity is an accurate predictor of CVD.[56,57] Both body composition and metabolic profiles seem to change after SCI.[58,59] People with SCI are at high risk of developing glucose intolerance or insulin resistance compared to the able-bodied population due to the associated changes in body composition and lower physical activity levels.[58] They also tend to have increased levels of low-density lipoprotein cholesterol and decreased levels of high-density lipoprotein cholesterol.[58] Furthermore, people with SCI have been shown to be at a greater risk of systemic inflammation with higher CRP levels compared to age and race-matched able-bodied controls,[60] likely because of the heightened fat stores, pressure ulcers and frequent infections.[61,62] Because atherosclerosis has been identified as having an inflammatory basis, this may put people with SCI at an even greater risk of CVD.

Based on the results of **chapter 7** one could recommend to screen for hypertension during annual check-ups with the general practitioner, especially in those with a higher risk of developing hypertension, e.g. people with a lesion below C8 and an age of ≥45 years or a TSI of ≥20 years.

From my point of view, the rehabilitation physician should operate as the coordinator of care for people with SCI. During their routine consultations with the person with a SCI, the rehabilitation physician should monitor physical functioning (e.g. the presence and treatment of SHCs, co-morbidities), self-management strategies, problems in daily living (e.g. facilities/equipment, work, leisure time), psychosocial functioning, and unmet needs in the primary care. Furthermore, it is important that the rehabilitation physician has good working relationships with other medical specialists such as neurologists, urologists and plastic surgeons. Running multidisciplinary consulting hours together with other involved medical specialists would greatly benefit people with SCI.

All discharged people with SCI should be educated to contact their rehabilitation physician in case of certain SHCs. They should contact their rehabilitation physician in case of SCI related problems such as:

- Bladder and bowel problems, such as recurrent urinary tract infections
- Pressure sores
- An increase in spasticity
- Sexual dysfunction / fertility problems
- Musculoskeletal and neuropathic pain complaints
- Sitting problems (including problems with their wheelchair)
- A decline in functioning (e.g. mobility, hand function)

The urologist

People with SCI have an increased risk of developing urological complications which is often coupled with a diverse and atypical clinical presentation.[63] Therefore, accurate lifelong routine urological surveillance is recommended. In the Netherlands, the urological surveillance interval can vary dependent on the neurological pathology and the type of neurogenic bladder dysfunction.

In general, my recommendations for urological surveillance by the urologist are as follows:

- Individualised follow-up consultations, preferably at least once every 2 years, in which the urologist evaluates if bladder management is still compatible with the person's functional abilities, lifestyle and environment. These consultations should also include urinary tract imaging by urologic ultrasonography.

- The performance of a urodynamic study every 1 to 2 years in patients with high bladder pressures (in accordance with the Dutch Urological Association guideline on neurogenic bladder dysfunction[39]).

Self-management and education

Another aspect is that many SHCs can be prevented or lessened through appropriate self-management. In a previous study, 34.1% of all SHCs were perceived as preventive, not the least by the participant's own behaviour.[54] Achieving compliance with preventive strategies through education is a major goal in the prevention of SHCs following SCI. A definition of self-management is given by Barlow et al.[64]:

> "*Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life*".

Self-management revolves around the control the person has dealing with his/her illness or disorder, but it does require the support and facilitation by the professional. Components for this support are, for example, giving specific education concerning SHCs and motivating the person with a SCI so that he/she copes with his/her SCI as well as possible.

The timing of education about prevention of SHCs is challenging. Patients in a rehabilitation setting are only likely to retain information that is provided at a time when they feel ready and when relevance is recognized. This is a very individual process. It is likely that there are many people with SCI who will not be ready to effectively take in information about the prevention of SHCs when they are still admitted in the rehabilitation centre. To address this challenge, rehabilitation programmes may provide strategies to help people receive and utilise information during and after initial inpatient rehabilitation. Examples of such strategies may be to have especially more attention for education during the first year after discharge, to involve an outpatient nurse practitioner (for specific information about for instance bladder and bowel regulation), to refer to good and reliable internet sites that address health after SCI (e.g. www.dwarslaesie.nl), and to arrange periodical contact with a peer counsellor and/or group meetings for educational purposes.

Considerations for future research

Despite the growing literature on SHCs and aging with SCI, many unanswered questions remain. Some of the topics we need more research on are as follows:

- Which age-related health conditions are most likely to emerge at an earlier age in people aging with SCI compared to those people who do not have an SCI?
- What should be the content of a predictive model of aging that provide early identifiers of at-risk people with SCI, so that appropriate intervention can be facilitated timely?
- What are the most effective strategies for helping people with SCI prevent or delay the onset of SHCs and also for lessen the impact of SHCs which cannot be resolved (e.g. neuropathic pain)?
- What type of health care delivery model for people with SCI would be effective in reducing the amount of SHCs and costs of medical care?

Furthermore, we need more knowledge regarding the physiologic changes that occur with aging with SCI. Examples of areas of research include:

- Cardiovascular health. Since CVD has become the leading cause of mortality in people with long-term SCI[41] more focus should be paid to cardiovascular health and related problems including metabolic issues.
- Musculoskeletal decline and overuse, since musculoskeletal pain is one of the most frequent reported SHCs which impacts negatively on functional independence and QoL.
- Genitourinary system. Late structural and physiological changes of the upper and lower urinary tract secondary to SCI and related bladder management interventions, superimposed by the normal aging effects on the urinary tract, are not yet fully understood.

And finally, there is also a need for more research regarding unmet needs for people with SCI living in the Dutch community. Research with a broader scope, focusing on health system factors such as access, availability, satisfaction of service delivery and social networks, since these factors may play a role in the development of SHCs, health care utilization patterns and outcomes. We have now mainly focused on non-modifiable variables such as demographic and injury-related variables as predictors of SHCs. There is a need to examine more process-related factors to better understand the prevention and management of SHCs.

We need ongoing longitudinal studies to continue to identify the natural course of SHCs in SCI. It is essential to strengthen interdisciplinary collaborations among researchers and medical specialists, and both internationally as nationally strive for comparative databases related to aging with SCI. Therefore, standardised international data sets are necessary for the many multicentre trials and investigations that will take place in the years to come. The International Spinal Cord Society (ISCOS) has developed several International SCI Data Sets that should facilitate comparisons regarding spinal cord injuries, SHCs, treatments, and outcomes between patients, centres, and countries.[43] A large part of these International SCI Data Sets have been translated in Dutch and implemented in all eight Dutch rehabilitation centres with a specialty in SCI.

A central electronic database has been developed in which these data of patients with SCI are collected. Currently, these data are only collected during the phase of inpatient clinical rehabilitation. Future perspectives are that these data sets are also incorporated in the outpatient rehabilitation phase which follows our inpatient clinical rehabilitation programme.

I would like to conclude this General discussion with an appropriate quote by Groah et al.[65]:

> "*Through a sustained focus on collaboration, research, coordinated clinical care, and policy making, significant gains can be made toward not only "adding years to life" but also "adding life to years" for those aging with SCI.*"

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Nederlandse samenvatting

Dankzij de verbeterde medische behandeling en revalidatiezorg is de levensverwachting van mensen met een dwarslaesie sinds de jaren 50 aanzienlijk verbeterd. Het is geen uitzondering meer dat mensen na het krijgen van een dwarslaesie nog tientallen jaren doorleven. Wel lijkt het erop dat, met toenemende leeftijd en tijd na ontstaan van de dwarslaesie, er steeds meer problemen optreden op de gebieden van het actief zijn, fitheid en zogenoemde "secundaire gezondheidsproblemen". Voorbeelden van secundaire gezondheidsproblemen zijn: decubitus, spasticiteit, blaas- en darmproblemen zoals incontinentie en obstipatie, musculoskeletale en neuropathische pijn, seksuele functiestoornissen en cardiovasculaire en respiratoire problematiek.

Weinig actief zijn en een slechte fitheid kunnen leiden tot secundaire gezondheidsproblemen, maar een slechte fitheid en secundaire gezondheidsproblemen kunnen op hun beurt ook weer leiden tot inactiviteit, tot beperkingen in de maatschappelijke participatie en tot een slechtere kwaliteit van leven. Het is dan ook belangrijk om te voorkómen dat mensen met een dwarslaesie in een dergelijke negatieve spiraal van toenemende gezondheidsproblemen terecht komen.

Vanwege deze problematiek is een goede, levenslange, nazorg voor mensen met een dwarslaesie van belang. In Nederland bestaat die structurele revalidatienazorg nog niet in alle revalidatiecentra. Het lijkt erop dat veel mensen met een dwarslaesie niet meer geregeld voor controle of behandeling bij een gespecialiseerd revalidatiecentrum komen en voorafgaand aan dit onderzoek was niet bekend hoe het daadwerkelijk met de groep mensen met een langer bestaande dwarslaesie in Nederland gaat. Tevens was er ook nog onvoldoende bekend over hoe de relaties tussen (in-)activiteit, fitheid en secundaire gezondheidsproblemen bij mensen die al langere tijd een dwarslaesie hebben precies in elkaar zitten.

Om deze redenen is het onderzoeksprogramma "Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC)" opgezet. De centrale thematiek van het onderzoeksprogramma was het behoud en de bevordering van een actieve leefstijl, fysieke fitheid en gezondheid bij personen met minimaal 10 jaar een dwarslaesie die ook rolstoelgebruiker zijn. Het programma bestond uit een beschrijvend cross-sectioneel onderzoek en drie interventiestudies.

Dit proefschrift is gebaseerd op de resultaten van de cross-sectionele studie van het ALLRISC onderzoeksproject en focust zich met name op het vóórkomen van secundaire gezondheidsproblemen onder personen met minimaal 10 jaar een dwarslaesie. Met de resultaten

van dit proefschrift hopen we een aanzet te kunnen geven tot een meer systematische en levenslange revalidatienazorg van mensen met een dwarslaesie en daarmee tot de preventie en tevens vermindering van de impact van secundaire gezondheidsproblemen.

Hoofdstuk 2 betreft de opzet van de cross-sectionele studie van het ALLRISC onderzoeksproject. Het doel van deze cross-sectionele studie was het beschrijven van de status van actieve leefstijl, fysieke fitheid en het vóórkomen van secundaire gezondheidsproblemen onder personen met minimaal 10 jaar een dwarslaesie, zowel in relatie tot elkaar, als in het licht van leeftijd en de duur van de dwarslaesie. De centrale hypothese was dat secundaire gezondheidsproblemen toenemen met leeftijd en/of de duur van de dwarslaesie, maar minder aanwezig zijn bij een toenemende fitheid en een actieve leefstijl.

Inclusiecriteria waren: het minimaal 10 jaar hebben van een traumatische of niet-traumatische dwarslaesie; een leeftijd ten tijde van ontstaan van de dwarslaesie van tussen de 18 en 35 jaar; een huidige leeftijd van tussen de 28 en 65 jaar en daarnaast rolstoelafhankelijkheid (met een loopafstand van maximaal 500m). Deelnemers werden uitgenodigd om voor één dag naar één van de acht deelnemende dwarslaesie-revalidatiecentra te komen voor een uitgebreide poliklinische controle, inclusief bloedafname en een aantal fysieke testen. Tevens werden de deelnemers uitgenodigd om 2 weken voorafgaand aan deze onderzoeksdag in het revalidatiecentrum, schriftelijk of digitaal, een uitgebreide vragenlijst in te vullen.

In **hoofdstuk 3** wordt beschreven in welke frequentie bepaalde secundaire gezondheidsproblemen vóórkomen 1, 2 en 5 jaar na ontslag uit het revalidatiecentrum. Tevens is gekeken naar de associatie met een aantal mogelijke demografische en aan leefstijl en dwarslaesie gerelateerde risicofactoren. Deze resultaten zijn afkomstig van het Koepelproject en het SPIQUE project. In het Koepelproject werden 225 mensen met een dwarslaesie gevolgd vanaf de start van klinische revalidatie tot 1 jaar na ontslag. Twee jaar na ontslag volgde bij een deel van de deelnemers nog een laatste meting bestaande uit een telefonisch interview. Het SPIQUE project bestond uit een extra vervolgmeting van deze mensen 5 jaar na ontslag uit het revalidatiecentrum. De studie beschreven in **hoofdstuk 3** is een vervolg op een eerdere studie naar de frequentie van dezelfde secundaire gezondheidsproblemen vanaf de start van klinische revalidatie tot 1 jaar na ontslag uit het revalidatiecentrum (Haïsma et al., 2007).

In totaal werden 139 deelnemers in de analyses geïncludeerd waarbij de meest frequent gerapporteerde gezondheidsproblemen neuropathische pijn (84%–92%), musculoskeletale pijn (62%–87%) en blaasontstekingen (57%–59%) bleken te zijn. Er waren weinig verschillen

over de tijd sinds het optreden van de dwarslaesie. Er werd alleen een significante daling gevonden in het vóórkomen van problematische spasticiteit en neuropathische pijn 2 jaar na ontslag uit het revalidatiecentrum vergeleken met 1 jaar na ontslag.

De meest frequent geobserveerde risicofactoren voor secundaire gezondheidsproblemen bleken het vrouwelijk geslacht, een hogere body mass index (BMI), een tetraplegie en een complete laesie te zijn.

Op basis van de resultaten wordt geconcludeerd dat secundaire gezondheidsproblemen in de eerste jaren na ontslag uit het revalidatiecentrum veel vóórkomen en dat de frequentie daarvan in de eerste 5 jaar relatief stabiel is.

Hoofdstuk 4 geeft een beschrijving van neurogeen darmlijden en associaties tussen defecatiebeleid, ervaren darmproblematiek en tevredenheid met defecatiebeleid bij 258 personen met minimaal 10 jaar een dwarslaesie die deelnamen aan de cross-sectionele ALLRISC studie.

Neurogeen darmlijden is één van de meest voorkomende secundaire gezondheidsproblemen bij mensen met een dwarslaesie met een negatieve invloed op kwaliteit van leven. Adequaat defecatiebeleid is een geïndividualiseerd beleid waarbij men streeft naar een voorspelbare en regelmatige stoelgang zonder het vóórkomen van obstipatie en/of incontinentie. In **hoofdstuk 4** wordt duidelijk dat toucheren (35%) en microlax (31%) het meest werden gebruikt en dat darmspoelen (11%) en chirurgische interventies (8%) veel minder frequent werden toegepast. In totaal rapporteerde 36% van de deelnemers ernstig neurogeen darmlijden en 45% ≥1 perianaal probleem, zoals het hebben van aambeien. Deze resultaten bevestigen dat mensen met een langer bestaande dwarslaesie frequent te maken hebben met darmproblematiek. Desondanks bleek een grote meerderheid van de deelnemers toch tevreden te zijn met het gehanteerde defecatiebeleid. Slechts 14% van de deelnemers was ontevreden tot zeer ontevreden ten aanzien van zijn/haar defecatiebeleid, wat overeenkomt met eerdere studieresultaten uit andere landen. Ontevredenheid was geassocieerd met het hebben van perianale problemen, obstipatie en ernstig neurogeen darmlijden. Er bleek geen associatie te bestaan tussen ontevredenheid met defecatiebeleid en demografische of dwarslaesiekarakteristieken.

In deze studie vonden we geen aanwijzingen voor een achteruitgang in darmfunctie over de tijd. Integendeel, het langer hebben van de dwarslaesie was geassocieerd met minder ernstig neurogeen darmlijden. Tevens bleek tijdsduur sinds ontstaan van de dwarslaesie

geen relatie te hebben met de mate van tevredenheid met het defecatiebeleid. Een mogelijke verklaring hiervoor is dat er in de groep met deelnemers met tenminste 30 jaar een dwarslaesie significant minder motorisch en sensibel complete dwarslaesies waren. Verder zou het kunnen zijn dat de deelnemers met een langer bestaande dwarslaesie in het verleden wel een ernstiger vorm van neurogeen darmlijden hebben gehad, maar dat zij in de loop van de tijd zijn geswitcht naar een andere (mogelijk minder conservatieve) defecatiemethode, met een positief effect op de ernst van het neurogeen darmlijden.

Uit **hoofdstuk 5** blijkt dat intermitterende katheterisatie de meest gebruikte methode is voor het ledigen van de blaas in een groep met 282 personen met minimaal 10 jaar dwarslaesie. Dit is een bemoedigend resultaat aangezien intermitterende katheterisatie internationaal wordt gezien als de "gouden standaard" voor het ledigen van de blaas bij neurogeen blaaslijden. Helaas is intermitterende katheterisatie niet voor alle personen met een dwarslaesie een optie. Zo blijkt uit **hoofdstuk 5** dat deelnemers met een tetraplegie meer gebruik maakten van blaaskloppen of een suprapubische katheter, waarschijnlijk ten gevolge van een verminderde handfunctie en/of het niet afhankelijk willen zijn van een ander voor het ledigen van de blaas. Vrouwen maakten, in vergelijking met mannen, meer gebruik van een transurethrale katheter of een continent urostoma. Vijftien procent van de deelnemers rapporteerde het gebruik van een verblijfskatheter (suprapubische of transurethrale katheter), ondanks dat we vanuit eerdere studies weten dat dit geen ideale blaasledigingsmethode is gezien het risico van urologische complicaties op de lange termijn, zoals blaaskanker. Tevens blijkt uit **hoofdstuk 5** dat het hebben van een verblijfskatheter was geassocieerd met een hogere impact van neurogeen blaaslijden op kwaliteit van leven. De enige andere factor die een significante associatie toonde met een hogere impact van neurogeen blaaslijden op kwaliteit van leven was het hebben van een hogere leeftijd.

Alternatieven voor personen met een dwarslaesie die onafhankelijk willen zijn bij het ledigen van hun blaas, en die niet de mogelijkheid hebben tot het uitvoeren van intermitterende katheterisatie van de urethra of een stoma zijn, naast een externe sphincterotomie bij mannen, de aanleg van een incontinent urostoma zoals de Brickerblaas of een ileovesicostomie. Aangezien dit operatieve ingrepen zijn met de nodige risico's op complicaties, worden deze behandelopties pas gesuggereerd wanneer conservatieve methoden hebben gefaald. In **hoofdstuk 5** wordt ook duidelijk dat deze ingrepen niet frequent worden uitgevoerd bij mensen met een langer bestaande dwarslaesie. Slechts 2,8% van de deelnemers had een incontinent urostoma.

Ondanks dat de laatste decennia de medische zorg sterk is verbeterd blijven personen met een dwarslaesie het risico houden op urologische complicaties die, internationaal gezien, een frequente reden zijn voor heropnames in het ziekenhuis. Vandaar dat er internationaal consensus is ten aanzien van het belang van routinematige urologische controles.

Om meer inzicht te krijgen in de urologische follow-up bij mensen met een langer bestaande dwarslaesie in Nederland, hebben we een studie uitgevoerd waarvan de resultaten zijn beschreven in **hoofdstuk 6**. Uit deze studie blijkt dat 39% van de 282 deelnemers geen routinematige urologische controles hadden, waaronder geen poliklinische controles bij een uroloog en/of routinematige beeldvorming van de urinewegen middels echografie. Verder rapporteerde 33% van de deelnemers nooit eerder een urodynamisch onderzoek gehad te hebben. Hoewel herinneringsbias hierbij een rol kan spelen, blijft dit een hoog percentage wat niet correspondeert met de gepubliceerde aanbevelingen uit (inter)nationale richtlijnen ten aanzien van neurogeen blaaslijden.

In **hoofdstuk 6** worden tevens de uitkomsten van echo-onderzoek van de blaas en nieren beschreven. Slechts 10% van de echo-onderzoeken bleek afwijkend. Er werd bij 4,5% van de deelnemers dilatatie van de hoge urinewegen en bij 5,7% nier- en/of blaasstenen vastgesteld. Een afwijkende echo-uitslag was geassocieerd met een langere tijdsduur sinds ontstaan van de dwarslaesie, het hebben van een niet-traumatische dwarslaesie en operatieve nier- en/of blaassteenverwijdering in het verleden. De echo-uitslag bleek niet geassocieerd te zijn met routinematige urologische controles of met het blaasledigingsbeleid. Op basis van deze resultaten werd geconcludeerd dat men de algemeen aanbevolen jaarlijkse uitvoering van echo-onderzoek van de urinewegen ter discussie kan stellen en dat verder onderzoek ten aanzien van de inhoud, indicatie en frequentie van routinematige urologische controles gewenst is.

Cardiovasculaire aandoeningen zijn tegenwoordig de meest voorkomende doodsoorzaak bij mensen met een langer bestaande dwarslaesie. Hypertensie is één van de meest belangrijke risicofactoren voor overlijden ten gevolge van een cardiovasculaire aandoening. Bij personen met een langer bestaande dwarslaesie is er echter nog weinig bekend over de prevalentie van hypertensie en geassocieerde risicofactoren. **Hoofdstuk 7** beschrijft een studie naar het vóórkomen van hypertensie bij 282 personen met een langer bestaande dwarslaesie, wonend in Nederland. Daarnaast is ook bij deze populatie onderzocht welke factoren geassocieerd zijn met het hebben van hypertensie. In deze studie bleek bij 21,5% van de deelnemers de diagnose hypertensie te zijn gesteld. Significante voorspellers voor

het hebben van hypertensie waren: een dwarslaesie onder niveau C8 (T1–T6: OR=6,4, T7–L5: OR=10,1), een voorgeschiedenis van hypercholesterolemie (OR=4,8), een langere tijd sinds ontstaan van de dwarslaesie (OR=1,1) en een hogere leeftijd (OR=1,1).

Het vóórkomen van een éénmalig gemeten verhoogde bloeddruk (≥140/90 mmHg) en/of het gebruik van antihypertensiva bleek hoger bij mannen (T1–T6 laesie: 48%, T7–L5 laesie: 57%) en vrouwen (T1–T6 laesie: 48%, T7–L5 laesie: 25%) met een dwarslaesie onder niveau C8, vergeleken met mannen (31%) en vrouwen (18%) uit de algemene Nederlandse populatie binnen dezelfde leeftijdsrange.

Een andere interessante bevinding was dat de gemiddelde systolische en diastolische bloeddrukwaarden niet significant verschilden tussen hoog-thoracale (HT) (T1–T6) en laag-thoracale en lumbale (LTL) (T7–L5) laesies. Op voorhand was onze hypothese dat er wel een significant verschil in systolische en diastolische bloeddruk zou zijn, aangezien er bij HT- laesies, in tegenstelling tot bij LTL-laesies, sprake is van een gedeeltelijke sympathische cardiale innervatie en sympathische controle over het vaatbed van de bovenste extremiteit. Deze bevinding van vergelijkbare systolische en diastolische bloeddrukwaardes bij HT- en LTL-laesies is ook beschreven in een meta-analyse over cardiovasculaire uitkomsten bij dwarslaesie. Het is een interessant fenomeen waarvoor verder onderzoek gewenst is.

Hoofdstuk 8 beschrijft het vóórkomen van 13 verschillende secundaire gezondheidsproblemen (neuropathische pijn, musculoskeletale pijn, decubitus, problematische spasticiteit, autonome dysreflexie, hypotensie, oedeem, neurogene heterotope ossificatie, pneumonie, urineweginfectie, urine-incontinentie, fecale incontinentie en obstipatie) bij 282 personen die al 10 tot 47 jaar met een dwarslaesie leefden. Tevens is gekeken naar de relatie tussen deze secundaire gezondheidsproblemen en kwaliteit van leven.

De deelnemers rapporteerden gemiddeld vier secundaire gezondheidsproblemen in de 3 maanden voorafgaand aan het onderzoek. Bij slechts 1,5% van de deelnemers was er in de 3 maanden voorafgaand aan het onderzoek geen sprake geweest van een secundair gezondheidsprobleem. De meest voorkomende secundaire gezondheidsproblemen waren musculoskeletale pijn (63,5%), oedeem (38,7%), neuropathische pijn (34,1%) en urineweginfecties (33,3%). Alleen bij het vóórkomen van oedeem werd een significante associatie met een langere tijdsduur sinds ontstaan van de dwarslaesie waargenomen.

Deelnemers beoordeelden hun tevredenheid met het leven als geheel (kwaliteit van leven) gemiddeld met een 7 (score range van 0–10 waarbij 0=helemaal ontevreden en 10=helemaal

tevreden). In een multipele regressieanalyse bleken musculoskeletale pijn, decubitus, problematische spasticiteit en obstipatie een onafhankelijke, maar zwakke, associatie met kwaliteit van leven te hebben.

Hoofdstuk 9, de algemene discussie, biedt een samenvatting van de belangrijkste bevindingen van dit proefschrift, gevolgd door methodologische overdenkingen waarbij de sterke kanten en beperkingen van de studies in dit proefschrift worden besproken. De resultaten worden verder bediscussieerd in termen van geleerde lessen en implicaties voor de klinische praktijk. Suggesties voor vervolgonderzoek worden gedaan.

Concluderend kan worden gezegd dat de resultaten van dit proefschrift een bijdrage kunnen leveren aan de vorming van een systematisch en levenslang nazorgsysteem voor mensen met een dwarslaesie en daarmee tot de preventie en tevens vermindering van de impact van secundaire gezondheidsproblemen.

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About the author

Curriculum vitae

Jacinthe Adriaansen was born on November 17th, 1985, in Tiel, the Netherlands. In the year 2004 she obtained her "VWO" diploma at the Koningin Wilhelmina College in Culemborg. In 2004 she started the study Medicine at Utrecht University, and obtained her Medical Degree in 2010. Her first job as a physician was at the Neurology Department of Zuwe Hofpoort hospital, Woerden. In 2011 she started her PhD programme within "ALLRISC" (Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury), a Fonds NutsOhra funded, multicentre collaborative clinical rehabilitation research project on health, active lifestyle, fitness and quality of life in the aging person with long-term spinal cord injury. In May 2013 she started her specialisation residency in Physical Medicine and Rehabilitation at De Hoogstraat Rehabilitation Centre, Utrecht.

Jacinthe is married to Rob Rensen. On June 30th, 2016, their daughter Lorèn was born.

Publications

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