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PERSPECTIVES IN REHABILITATION: DEVELOPING ROBUST RESEARCH DESIGNS

Secondary health conditions in persons with a spinal cord injury for at least 10 years: design of a comprehensive long-term cross-sectional study

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***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 1-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.**

Keywords: Aging, health, long-term care, spinal cord injuries

Implications for Rehabilitation

- Persons with long-term spinal cord injury may be susceptible to many types of secondary health conditions (i.e. pressure ulcers, urinary tract infections, pain and spasticity).
- Coordinated long-term health care is required for this population but this is currently not operational in all specialized rehabilitation centres in the Netherlands.
- This study aims to develop predictive models for the occurrence of secondary health conditions and to develop guidelines to improve long-term health care for persons living with a spinal cord injury in the Netherlands.

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].

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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 specialized care, unless they take the initiative to visit a specialized 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 a 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 program "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 $\alpha = 0.05$ 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 analyze 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 Centre Utrecht.

Instruments

Measurements include

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

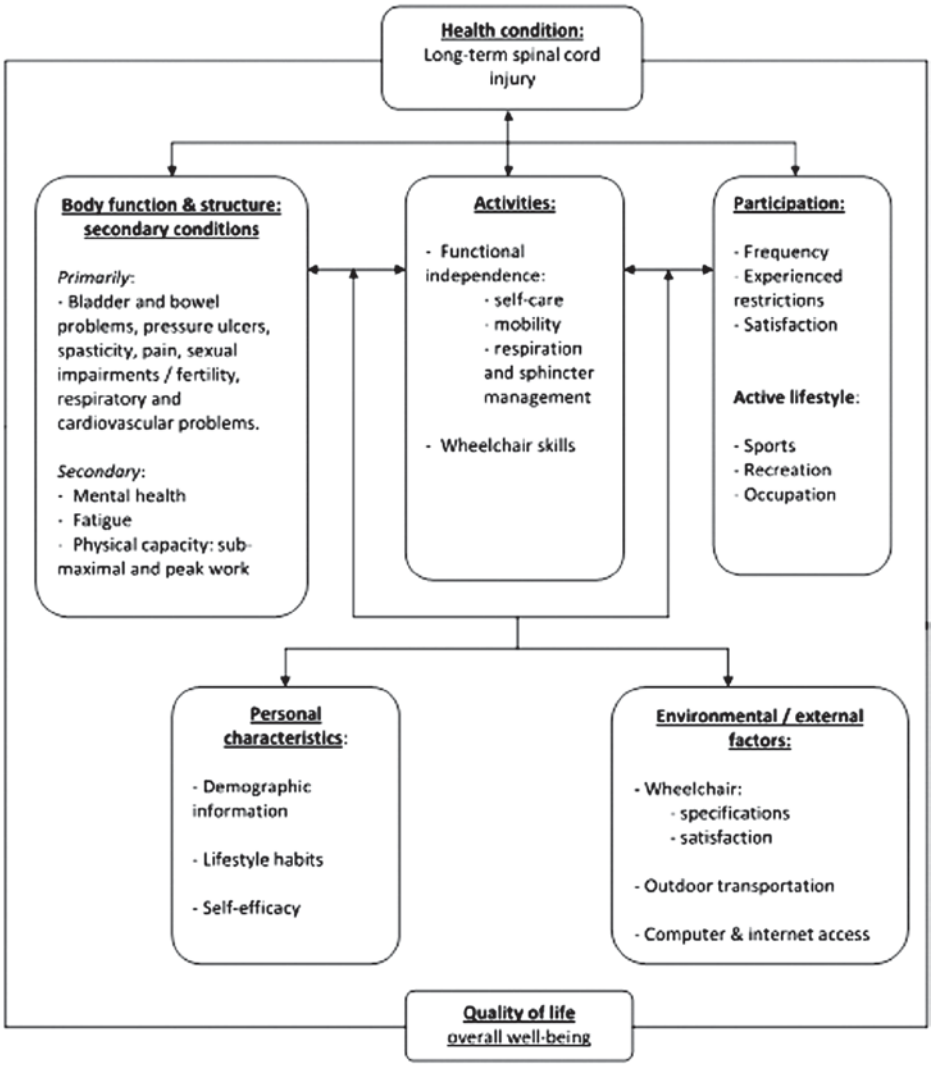

Figure 1. The outcomes split into the domains of the ICF-models, including body function and structure, activites, participation, personal and environmenal factors.

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.
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) [23] as an oral interview.
   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 standardized 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-min 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) × 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 one hour.

The questionnaire consists of:

1. Perceived severity of secondary conditions. The following standardized questionnaires are administered:
   a) The Qualiveen-Short Form is developed for patients with neurogenic bladder problems [29]. It consists of eight items distributed in four domains including bother with limitations (two items), frequency of limitations (two items), fears (two items) and feelings (two 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 nine items.

5. Mental health will be measured with the Mental Health Inventory-5 (MHI-5) [39]. The MHI-5 consists of five questions on mood over the last 4 weeks.
6. Life satisfaction will be measured by the Quality of Life international data sets from the International Spinal Cord Society [40] and by a 2-item life satisfaction measure [41].
7. Overall well-being will be measured with five 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 twelve 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 three 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; 20–29; ≥30 years) with Chi-square tests. To correct for demographic characteristics, and SCI characteristics, a series of 8 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 ($p < 0.20$).

With Structural Equation Modelling, a path model will be constructed to analyze 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 generalized 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 program, 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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