Promoting Physical Activity in Persons with Subacute Spinal Cord Injury

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Promoting Physical Activity in Persons with Subacute Spinal Cord Injury

Het bevorderen van lichamelijke activiteit bij mensen met een subacute dwarslaesie

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Chapter 1

General introduction

Spinal cord injury

Spinal cord injury (SCI) is a disruption of the spinal cord resulting in loss of motor, sensory and autonomic function below the level of lesion. The extent of the SCI is determined by the lesion level and completeness. Lesion level can be roughly divided into paraplegia and tetraplegia. In persons with paraplegia, depending on the exact level of injury, the trunk, legs and pelvic organs may be involved. Tetraplegia is a higher lesion level in which also the arms are involved.[1] With a complete lesion, no function is preserved in the sacral segments, whereas with an incomplete lesion there is some function preserved below the neurological level.[1] Completeness is determined separately for sensory and motor function.

The cause of SCI can either be traumatic or non-traumatic. In traumatic cases the injury is typically a result of a fall, traffic or- sport accident, where non-traumatic causes are e.g. vascular diseases, spinal degeneration, inflammation or tumors. In the Netherlands the incidence of SCI is 14 per million persons per year for traumatic cases[2] and an additional comparable amount for non-traumatic SCI.[3] Worldwide the incidence of traumatic SCI is estimated at 23 cases per million persons[4] and of non-traumatic SCI, depending on the region, between 6 million in Western Europe to 76 per million per year in North America.[5]

In the Netherlands, after several days to weeks in the hospital, most persons with newly acquired SCI are transferred to one of the eight specialized rehabilitation centers for further treatment. Evaluation of rehabilitation programs in three centers showed that during inpatient rehabilitation, persons spend on average 4.5 hours a week in physical therapy, occupational therapy or sports therapy.[6] Between 2002 and 2007, the median length of stay in the inpatient rehabilitation setting in the specialized rehabilitation centers was 156 days (interquartile range: 77–256).[3]

Secondary conditions

Besides muscle paralysis and loss of sensation, persons with SCI often have secondary conditions, such as bladder and bowel dysfunction, sexual dysfunction, musculoskeletal pain, neuropathic pain, spasticity, pressure ulcers and psychological problems.[7] Compared to the general population, persons with SCI are more likely to be overweight[8] and persons with SCI have increased risk of cardiovascular disease and type II Diabetes.[9] Furthermore, more than half of the persons with SCI in the chronic phase report complaints of fatigue.[10-12] Fatigue has been defined as an overwhelming sense of tiredness, lack of energy and often a

feeling of total exhaustion.[13] The prevalence and severity of fatigue in persons with subacute SCI is unknown.

Physical capacity

Rehabilitation of persons with SCI used to focus solely on functional goals, contributing to an acceptable degree of independence, participation and quality of life.[14] However, during the last years it is increasingly recommended to also strive for the highest possible physical capacity.[7, 15] To maximize results in persons with SCI generally known to have low physical capacity,[16] it seems important to start training during inpatient rehabilitation.

Several training modalities for upper-body exercise have demonstrated effectiveness in increasing physical capacity in persons with SCI who are wheelchair-dependent.[17] Handcycling has been suggested as an appropriate training method because handcycling is less strenuous and the risk of upper extremity overuse injury is smaller compared to handrim wheelchair propulsion.[18] Furthermore, handcycling is possible even for persons with tetraplegia during an early phase of rehabilitation.[19] In persons with SCI in the chronic phase, handcycle training has shown to be effective for improving physical capacity.[20, 21] Only one training study has assessed the additional effect of handcycle training to regular rehabilitation in persons with recent SCI.[19] In this study of 14 participants, the increased wheelchair capacity did not differ significantly from that of matched controls participating in regular rehabilitation only. However, power was limited and there was a large range (9 to 39 weeks) in training duration.

Physical capacity can be regarded as a prerequisite for physical activity. A higher physical capacity may allow individuals to perform activities in daily life more proficient, faster, with less difficulty and for longer periods.[22]

Physical activity

Physical activity has been defined as any bodily movement produced by the muscles that results in increased energy expenditure.[23] In the general population, physical activity contributes to the primary and secondary prevention of several chronic diseases and is associated with a reduced risk of premature death.[24] Independent of physical activity, prolonged periods of sedentary behavior, defined as a distinct class of activities that requires low levels of energy expenditure, negatively affect the metabolic and cardiovascular systems.[25]

Consequently, for the general population, besides meeting physical activity guidelines it is also recommended to limit the amount of sedentary day time.[26]

Persons with SCI in inpatient rehabilitation participate in therapies in which they are physically active. However, after discharge from inpatient rehabilitation, daily physical activity levels in persons with SCI are known to decline to a level that is severely low compared to the general population and also low compared to persons with other chronic diseases.[27, 28] Breaking up sedentary behavior in persons with SCI who are wheelchair dependent is difficult since sitting less is not possible. It is unknown for this group what type, intensity and duration of physical activity is necessary to break up sedentary time for health benefits.[29]

Intervention

A higher physical capacity may not automatically lead to more physical activity, a behavioral change has been suggested to be needed.[30] To achieve a change in behavior, behavioral interventions are thought to be necessary. The Transtheoretical Model of Change is often used as a fundamental basis for health-related behavioral interventions.[31] The model describes change of behavior as a process which runs through several stages. These stages are 1) Precontemplation: no intention to change, or denial of the need of change, 2) Contemplation: seriously considering change, 3) Preparation: making small changes, 4) Action: actively engaged in changing behavior, and 5) Maintenance: being able to sustain action for at least six months and working to prevent relapse. A health care practitioner can help by facilitating movement along the stages by using motivational interviewing. Motivational interviewing is defined as a person-centred directive counselling style used to address individual ambivalence about behavior change by placing the emphasis on an individual producing own arguments for change.[32] It has shown to be an effective approach in altering behaviors[33] and support for the clinical utility of this method to increase physical activity in persons with chronic health conditions has been found.[34] Motivational interviewing includes five basic principles to guide practice: express empathy, develop discrepancy, avoid argumentation, roll with resistance, and support self-efficacy. Exercise self-efficacy, the confidence persons have in their ability to exercise,[35] is an important and modifiable predictor of exercise and physical activity behavior.[36] Persons with higher exercise self-efficacy are more likely to be successful at exercise adherence.[37] By helping persons to increase exercise self-efficacy, practitioners may be more successful in achieving higher levels of exercise and physical activity.[37]

Previous studies in persons with SCI tended to show positive effects of behavioral interventions on physical activity.[38-43] However, all those studies were performed in persons with SCI in the chronic phase. During the first months after SCI, persons establish a new routine and therefore this period might be critical to introduce and encourage new habits that incorporate physical activity. Furthermore, only one of the previous studies[40] used objective measures of physical activity and found no significant effect of the intervention. All other studies used self-reported measures, of which outcomes are possibly biased.[44, 45] Moreover, only two of six studies[41, 42] reported on long-term effects, which is a limitation since it seems clinically relevant to evaluate whether the new behavior was maintained after the intervention.

Umbrella project and act-active

Chapter two in this thesis is based on data from a Dutch prospective cohort study named the Umbrella Project. In this project persons with recent SCI performed an extensive measurement protocol at several occasions during and after inpatient rehabilitation. For this thesis we used physical activity, physical fitness and lipid profile data collected at the start of active rehabilitation, after 3 months of active rehabilitation, at discharge from inpatient rehabilitation and at 1 year after discharge.

All other chapters are based on data from a study named Act-Active. The goal of this randomized controlled trial was to evaluate the added value of a behavioral intervention focusing on an active lifestyle after discharge from inpatient rehabilitation, in persons with subacute SCI. Participants were included during inpatient rehabilitation and had to be dependent on a manual wheelchair. All participants received regular rehabilitation and a handcycle training program. Half of participants received a behavioral intervention consisting of 13 individual sessions, between two months before till six months after discharge, with a coach trained in motivational interviewing. Measurements were performed two months before discharge from inpatient rehabilitation, at discharge, six months after discharge and one year after discharge.

Outline of this thesis

The main objective of this thesis was to evaluate the added value of a behavioral intervention, on top of regular rehabilitation and handcycle training, on physical activity in persons

with subacute SCI. Additionally, the intervention effects on secondary outcomes as health, participation and quality of life were studied and working mechanisms of the behavioral intervention evaluated. For further insight on the promotion of physical activity in persons with subacute SCI we additionally explored handcycle training feasibility during inpatient rehabilitation. Furthermore, baseline levels of exercise self-efficacy and fatigue were described and relations with demographic- and lesion characteristics were assessed.

Chapter 2 describes the longitudinal relation between physical activity and physical fitness and health and **chapter 3** focuses on the prevalence and severity of fatigue for persons with subacute SCI. **Chapter 4** describes the psychometric properties of a Dutch questionnaire on exercise self-efficacy, and with this questionnaire exercise self-efficacy was assessed in persons with subacute SCI as described in **chapter 5**. **Chapter 6** describes the feasibility and physical capacity results of handcycle training during inpatient rehabilitation. In chapter 7, 8 and 9 the results of the randomized controlled trial on the added value of a behavioral intervention are described, in **chapter 7** the primary results of the intervention on physical activity, in **chapter 8** the results on health, participation and quality of life, and **chapter 9** describes the working mechanisms of the behavioral intervention. Finally, **chapter 10** contains the general discussion of this thesis including results interpretation and literature perspective, methodological considerations, clinical implications, and recommendations for future research.

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Chapter 2

A more active lifestyle in persons with a recent spinal cord injury benefits physical fitness and health

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Spinal Cord 2012;50:320-323.

Abstract

Study design: A prospective cohort study.

Objective: To study the longitudinal relationship between objectively measured everyday physical activity level, and physical fitness and lipid profile in persons with a recent SCI.

Setting: A rehabilitation center in The Netherlands and the participant's home environment.

Methods: Data of 30 persons with a recent SCI were collected at the start of active rehabilitation, 3 months later, at discharge from inpatient rehabilitation, and 1 year after discharge. Physical activity level (duration of dynamic activities as % of 24-hours) was measured with an accelerometry-based activity monitor. Regarding physical fitness, peak oxygen uptake (VO_2peak) and peak power output (POpeak) were determined with a maximal wheelchair exercise test, and upper extremity muscle strength was measured with a handheld dynamometer. Fasting blood samples were taken to determine the lipid profile.

Results: An increase in physical activity level was significantly related to an increase in VO_2peak and POpeak, and an increase in physical activity level favorably affected the lipid profile. A non-significant relation was found with muscle strength.

Conclusions: Everyday physical activity seems to play an important role in the fitness and health of persons with a recent SCI. An increase in physical activity level was associated with an increase in physical fitness and with a lower risk of cardiovascular disease.

Introduction

Most persons with a spinal cord injury (SCI) have an inactive lifestyle.[1] Van den Berg-Emons et al.[2] studied the course of everyday physical activity level of persons with SCI. During inpatient rehabilitation the levels of physical activity improved. However, shortly after discharge from the rehabilitation center the levels declined sharply. One year after discharge, activity levels had recovered somewhat but were still much lower than those of able-bodied persons and were even lower than those of persons with other chronic diseases.[3]

Besides these low everyday activity levels, it is known that the physical fitness of persons with a SCI is generally low and that they have an enlarged risk of cardiovascular disease.[4] In the able-bodied population it is well-known that physical activity has a positive effect on health. This relation has also been studied in persons with a SCI.[5-11] However, these studies all used questionnaires to determine physical activity level. Although studies have shown that when using questionnaires there is a risk of overestimation and that self-reported activity level is only weakly related to objectively measured activity level.[12] Another shortcoming of previous studies is that most studies had a cross-sectional design.

The purpose of this study was to assess the longitudinal relationship between objectively measured everyday physical activity, and physical fitness and lipid profile in persons with a recent SCI. We used an accelerometry-based activity monitor to determine everyday physical activity. With this monitor we could determine the duration someone was performing dynamic activities (mainly wheelchair driving, handcycling, and walking). This included all everyday physical activities with varying intensities, not only sports. We hypothesized that persons who were more physically active were physically fitter and had a more favorable lipid profile.

Methods

Design

This prospective cohort study was part of the national research program "Physical Strain, Work Capacity and Mechanisms of Restoration of Mobility in the Rehabilitation of Individuals with Spinal Cord Injuries". All data were collected at four test occasions: at the start of active inpatient rehabilitation (t1), 3 months later (t2), at discharge from inpatient rehabilitation (t3), and 1 year after discharge (t4).

Inclusion criteria were: initial inpatient rehabilitation, 18 to 65 years old, (partly) dependent on a manual wheelchair during inpatient rehabilitation, and sufficient comprehension of Dutch. Exclusion criteria were: cardiovascular contraindications for exercise, and progressive disease or psychiatric condition that could interfere with participation. The Medical Ethics Committee of the Rehabilitation Center, Hoensbroek, The Netherlands approved the protocol of the national research program and the Medical Ethics Committee of Erasmus Medical Center, The Netherlands the protocol of this study.

Participants

Participants were recruited during inpatient rehabilitation at Rijndam Rehabilitation Center in Rotterdam from 2001 until 2005. All eligible persons were asked to participate. A total of 42 persons with a SCI agreed to participate. Data on 2 participants were excluded because these persons became completely ambulatory during their inpatient period. Data on an additional 10 participants were excluded because only 1 of the minimum of 2 required physical activity measurements was available. Average time of inpatient rehabilitation of the remaining 30 participants was 7 months (range: 2–15 months).

Physical activity level

Everyday physical activity level was objectively measured for 48 h during 2 consecutive weekdays using an accelerometry-based activity monitor (Vitaport; Temec Instruments, Kerkrade, The Netherlands, and Analog devices Nederland, Breda, The Netherlands).[2] This activity monitor has shown to be reliable,[13] and valid for persons with SCI.[14] Per participant, one accelerometer was attached to each thigh and wrist, and two accelerometers to the sternum. All accelerometers were connected to a data recorder, which participants wore in a padded bag around the waist. Data were collected on a memory card and downloaded on a computer for analysis with Vitagraph software (Temec Instruments). To avoid measurement bias, principles of the activity monitor were not explained to the participants until all measurements had been completed. Participants were instructed to continue their ordinary daily activities (including therapy and sports), but were not allowed to swim or take a bath or shower during the 2 test days. Data from the activity monitor were analyzed per day, and since there were no significant differences in physical activity between the 2 days, averaged over 2 days. We determined the duration per day a person was performing dynamic activities, including manual wheelchair driving, handcycling, walking, and general non-cyclic movement. All activities on varying intensities

were included. The total duration of dynamic activities was expressed as a percentage of 24 h.

On the 4 test occasions for the 30 participants, a total of 89 measurements of physical activity level were performed. The baseline data on 1 participant could not be measured because the person was wearing a corset during that particular measurement period. The t2-measurement was not performed on eight participants because the two test occasions (t2 and t3) were too close to one another. The t3-measurement of four participants was missing for personal reasons or technical problems with the activity monitor. Three other participants dropped out at t3: two died and one had personal reasons. Data at t4 were missing for further 12 participants mainly because of personal reasons, and in some cases due to technical problems.

Physical fitness

Aerobic capacity

The peak oxygen uptake (VO_2peak in $L \cdot min^{-1}$) measured with an Oxycon Delta (Jaeger, Germany) and the peak power output (POpeak in W) were determined during a graded maximal wheelchair exercise test on a treadmill (Lode BV, Groningen, The Netherlands). A detailed description of the procedure was given previously.[15]

Upper extremity muscle strength

Isometric muscle strength was measured with a handheld dynamometer (Biometrics Europe BV, Almere, The Netherlands) using the 'break' testing procedure.[16] The strength (in kN) of 5 muscle groups (elbow flexors-extensors, shoulder flexors, external rotators and abductors) was assessed on both sides. A sum muscle strength score was calculated by totalling the values of the muscle groups of both sides.

Risk of cardiovascular disease

Lipid profile was measured to get an indication of the risk of cardiovascular disease. Therefore, fasting blood samples were taken. Total cholesterol (TC in $mmol \cdot l^{-1}$) and triglycerides (TG in $mmol \cdot l^{-1}$) were determined using standardized enzymatic procedures. For determining the high-density lipoprotein (HDL in $mmol \cdot l^{-1}$), the very low-density lipoprotein and low-density lipoprotein (LDL) were selectively precipitated. The Friedewald equation was used to compute the LDL concentration (in $mmol \cdot l^{-1}$). Ratios for TC/HDL and LDL/HDL were calculated.

Possible confounding variables

Age (in years), gender, and lesion characteristics were recorded at t1. Tetraplegia was defined as a lesion at or above the Th1 segment, and paraplegia as a lesion below Th1. A complete lesion was defined as motor complete, ASIA grade A or B, an incomplete lesion as ASIA grade C or D. In addition, height was determined (in cm) at t1 and body mass (in kg) was measured on all four test occasions. These measures were used to calculate body mass index (BMI in $kg \cdot m^{-2}$).

Statistics

For the statistical analysis, physical activity data of a minimum of two test occasions were required. Multilevel regression analysis was used to determine the longitudinal relationship between physical activity level and the different physical fitness and lipid profile parameters (MLwiN version 2.02, Centre for multilevel modeling, Bristol).[17] The dependent variables were the physical fitness (VO_2peak, POpeak, muscle strength) and lipid profile parameters (TC, HDL, LDL, TG, TC/HDL, LDL/HDL). First, nine models were made for the course of these different physical fitness and lipid profile parameters. Time was included as three dummy variables, with t3 as the reference test occasion: t1t3, t2t3, and t4t3. Next, models for the individual relationship with physical activity level were made by adding physical activity level to the nine models. Age, gender, lesion level, completeness, and BMI were added separately to the models, to study their possible confounding effects on the relationships. If after adding one of these factors, the β of physical activity level changed by >10%, this factor was marked as a confounder and was added to the final regression models. A t-test was performed to test for differences in activity level at t1 between the persons who dropped out (n=15) and who had not dropped out at t4 (n=14). Significance was set at $p \leq 0.05$.

Results

Participants

At t1, the mean age of the participants was 42 ± 15 years, 72% were men, 53% had a tetraplegia, and 72% a motor complete SCI. The mean BMI at the four test occasions varied between 24.1 ± 4.7 and 24.6 ± 4.2 $kg \cdot m^{-2}$. The t-test, used to test for differences in activity level at t1 between the persons who dropped out (mean=3.55%, SD=2.29) and who had not dropped out at t4 (mean=2.84%, SD=1.92), showed no significant difference (t=-0.89, p=0.38). The descriptive statistics are presented in Table 2.1.

Table 2.1 Group sizes, means and SD of physical activity level and the physical fitness and lipid profile parameters at the four test occasions

	t1 start		t2 3 months later		t3 discharge		t4 year after discharge	
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)
Activity level (%)	29	3.21 (2.11)	22	4.98 (2.27)	23	5.00 (2.33)	15	3.51 (3.40)
VO_2peak ($L \cdot min^{-1}$)	20	1.01 (0.37)	19	1.02 (0.47)	25	1.15 (0.45)	15	1.17 (0.47)
POpeak (W)	20	29.17 (16.93)	19	34.40 (22.12)	25	35.25 (21.22)	15	39.34 (21.91)
Muscle strength (kN)	19	1.65 (0.54)	19	1.90 (0.57)	22	2.03 (0.54)	11	1.96 (0.61)
TC ($mmol \cdot l^{-1}$)	28	4.83 (1.08)	26	4.71 (0.96)	29	4.70 (1.03)	17	5.01 (0.98)
HDL ($mmol \cdot l^{-1}$)	28	0.99 (0.30)	26	1.15 (0.31)	29	1.20 (0.38)	18	1.17 (0.41)
LDL ($mmol \cdot l^{-1}$)	28	3.01 (1.12)	26	3.03 (0.95)	29	2.99 (1.01)	18	3.46 (0.96)
TG ($mmol \cdot l^{-1}$)	28	1.57 (0.57)	26	1.50 (0.72)	29	1.36 (0.62)	17	1.61 (0.98)
TC/HDL	28	5.17 (1.45)	26	4.37 (1.31)	29	4.24 (1.46)	17	4.77 (1.61)
LDL/HDL	28	3.25 (1.36)	26	2.86 (1.20)	29	2.72 (1.19)	18	3.32 (1.53)

Activity level: duration of dynamic activities, as a percentage of 24 h. An activity level of 3.21% corresponds with performing dynamic activities for 46 minutes/day.
Physical fitness: VO_2peak, peak oxygen uptake in $L \cdot min^{-1}$; POpeak, peak power output in W; Muscle strength of the upper extremities in kN.
Lipid profile: in $mmol \cdot l^{-1}$; TC, total cholesterol; HDL, high-density lipoprotein; LDL, low-density lipoprotein; TG, triglycerides; and the ratios TC/HDL and LDL/HDL.

Relations

Table 2.2 shows the relations between physical activity level, and the physical fitness and lipid profile parameters. After correction for confounders, physical activity level was significantly correlated to VO_2peak and POpeak ($p<0.01$). An increase in physical activity level was associated with an increase in aerobic capacity. Corrected for confounders, we found a nonsignificant correlation between activity level and muscle strength ($p=0.09$). With regard to lipid profile, an increase in activity level was correlated to a decrease in concentration of TG ($p<0.01$) and to a decrease in TC/HDL ratio ($p<0.05$).

The coefficients from the models presented in Table 2.2 can be used to get an indication of the strength of the relations. In this example we used the actual average increase in physical activity level from t1 to t3. At t1 activity level was 3.21%. This level increased with 1.79% to 5.00% at t3. This increase of 1.79% corresponds with 26 minutes/day. For the relation between activity level and VO_2peak, $\beta=0.059$. This means that corrected for confounders and time, an increase in physical activity level of 26 minutes/day was associated with an increase of 0.11 $L \cdot min^{-1}$ ($\beta=0.059 * 1.79\%$) in VO_2peak. The same of 26 minutes/day was,

Table 2.2 Multivariate regression models for the relation between physical activity level, and the physical fitness and lipid profile parameters

	Activity level			Constant		t3t1		t3t2		t3t4		Confounders		
	β	s.e.	p	β	s.e.	β	s.e.	β	s.e.	β	s.e.	Confounder	β	s.e.
VO_2peak (L·min $^{-1}$)	.059	.019	.002	.842	.311	-.141	.092	-.171	.098	.059	.113	Gender Lesion level Completeness BMI	-.415 .072 -.703 .017	.088 .366 .088 .009
POpeak (W)	2.27	.758	.003	43.69	6.42	-8.05	3.97	-3.13	4.20	2.28	4.78	Gender Lesion level	-21.13 18.01	3.34 3.04
Muscle strength (kN)	.277	.165	.093	19.78	3.47	-2.50	.968	-1.01	.981	.163	1.28	Age Gender Lesion level Completeness BMI	-.035 -8.93 3.18 3.46 .296	.027 .934 .817 .956 .093
TC	-.060	.045	.184	5.30	0.36	-.147	.282	-.178	.291	-.235	.347	Lesion level Completeness	.072 -.219	.219 .243
HDL	-.017	.016	.289	1.15	.109	-.208	.103	-.035	.106	-.019	.124	Lesion level	.015	.079
LDL	-.054	.045	.230	3.43	.310	-.237	.292	-.172	.302	.026	.351	Lesion level	-.021	.225
TG	-.076	.025	.002	.212	.388	.091	.016	.033	.165	.287	.197	Lesion level BMI	.344 .073	.124 .014
TC/HDL	-.127	.061	.038	5.01	.421	.575	.404	-.242	.413	.040	.495			
LDL/HDL	-.098	.057	.087	3.34	.390	.227	.375	-.166	.384	.170	.450			

Abbreviations: VO_2peak, peak oxygen uptake; POpeak, peak power output; TC, total cholesterol; HDL, high-density lipoprotein; LDL, low-density lipoprotein; TG, triglycerides; BMI, body mass index.
β indicates the regression coefficient, and s.e. the standard error.
t3t1, t3t2, t3t4 indicate time as 3 dummy variables, with t3 as reference test occasion.
Definition of confounders: Gender, male = 0 and female = 1; Lesion level, tetraplegia = 0 and paraplegia = 1; Completeness, incomplete = 0, complete = 1.

corrected for confounders and time, for power associated with an increase of 4.06 W (β=2.27 * 1.79%), for TG with a decrease of 0.14 mmol·l^{-1} (β=-0.076 * 1.79%) and for TC/HDL ratio with a decrease of 0.23 (β=-0.127 * 1.79%).

Discussion

In this longitudinal study of persons with a recent SCI, an increase in objectively measured everyday physical activity level related to a higher physical fitness and to a more favorable lipid profile in persons with a recent SCI. More specifically, an increase in everyday physical activity level was significantly correlated with an increase in aerobic capacity (VO_2peak and POpeak). Furthermore, an increase in physical activity level favorably affected two of the six lipid profile parameters (TG and TC/HDL), indicating reduced risk of cardiovascular disease.

Our results confirm the findings of three previous studies,[5, 6, 10] which correlated activity level to aerobic capacity in persons with SCI. These three studies, in which questionnaires were used to ascertain physical activity level, found low-to-moderate correlations. In our study, an increase in activity level of 26 minutes/day was associated with an increase in VO_2peak of 0.11 L·min^{-1}. This increase seems clinically relevant, since the average VO_2peak at discharge was only 1.15 L·min^{-1} (10% increase). Not all previous studies that have objectively measured physical activity in persons with other physical disabilities have found this correlation with aerobic capacity. No relation was found in a study of ambulatory persons with cerebral palsy,[18] and in another study, on persons with myelomeningocele, a correlation was only found in the non-ambulatory group.[19] It seems that activity level is correlated with aerobic capacity only in persons with a very low aerobic capacity, that is, wheelchair users who are subject to a sedentary lifestyle.

We found a non-significant relation between activity level and muscle strength. To our knowledge, only one previous study has assessed this relation in persons with a recent SCI.[10] In that study, in which a questionnaire was used to ascertain activity level, a weak correlation was found. More research is necessary to elucidate this relationship.

The correlation between activity level and lipid profile suggests that persons with a SCI who are more physically active have less risk of cardiovascular disease. Of the 30 participants, 5 had elevated TG levels (>2.00 mmol·l^{-1}) at the start of the study, compared to 2 at discharge from the rehabilitation center. At the start of the study, 15 persons had elevated TC/HDL ratios (>5.00) compared with 11 at discharge. Our results strengthen and expand the findings of three previous studies, which assessed the relation between self-reported activity level

and lipid profile. One study found that mobility activities correlated with a more favorable lipid profile.[11] Another study found that only a high level of physical activity was associated with a more favorable lipid profile.[8] In a third study, activity level was only found to be correlated with HDL.[9]

Currently, there is only little attention for everyday physical activity level in most rehabilitation centers. Given the health-related benefits of a higher everyday physical activity level found in our study, we suggest that more attention should be paid to physical activity level during rehabilitation, with the goal of promoting an active lifestyle after discharge from the rehabilitation center. Everyday physical activity may be promoted by means of behavior-oriented interventions. There is preliminary evidence for this type of intervention for persons with chronic SCI,[20] but more research is required.

Our study, the first longitudinal study to relate objectively measured physical activity level to physical fitness and lipid profile, in persons with SCI has some limitations. First, the sample size was rather limited, which may influence the ability to generalize our findings. Another consequence is that the number of variables, which could be added to each model was limited. Therefore, we choose to sum the scores of five muscle groups. However, by summing the scores, information about specific muscle groups may be lost. Also, a handheld dynamometer does not cover all the lower ranges of strength. Furthermore, power was limited because of a large number of missing values. Therefore, we were unable to determine possible interaction effects. Unfortunately, in this type of study, missing values are an insurmountable problem. Besides, we looked for a large number of possible correlations, thereby increasing the probability that one of the correlations was significant because of chance. Also, our activity monitor data was limited to 48 h. However, it is suggested that, for measurements with the activity monitor, this is an adequate duration to reliably record activities.[3] Finally, lipid profile can be affected by diet, but we do not have data on the diet of the participants. Besides, there are other risk factors than lipid profile, which might contribute to the risk of cardiovascular disease. However, most of these factors, for example, blood pressure and BMI, are complex in people with SCI because these factors should be interpreted differently compared to the able-bodied population.

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Chapter 3

Fatigue in persons with subacute spinal cord injury who are dependent on a manual wheelchair

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Abstract

Objectives: To determine the prevalence and severity of fatigue in persons with subacute spinal cord injury (SCI), assess whether demographic and lesion characteristics are related to fatigue, and determine the relationship with physical fitness and physical behavior.

Design: Cross-sectional.

Setting: Measurements were performed two months prior to discharge from inpatient rehabilitation.

Methods: Thirty-six persons with subacute SCI, dependent on a manual wheelchair, mean age 43 ± 15 and 83% men, completed the Fatigue Severity Scale (FSS). FSS scores >4 indicated fatigue. We recorded age and lesion characteristics, measured BMI, measured peak power output and peak oxygen uptake during a maximal handcycling test and determined physical behavior using an accelerometer-based activity monitor. T-tests were used to test for differences in fatigue between subgroups based on age- and lesion characteristics, and regression analyses to assess the relationship with physical fitness and physical behavior.

Results: Mean FSS was 3.3 ± 1.3. Fatigue, including severe fatigue, was prevalent in 31% (95% CI: 16–46) of participants compared to 18% of persons in the general population. Furthermore, mean fatigue was significantly higher in persons with incomplete compared to complete lesions (t=2.22, p=0.03). Mean scores between other subgroups did not differ significantly. Of the physical fitness and physical behavior measures, only peak oxygen uptake tended to be related to more fatigue (B=-1.47, p=0.05).

Conclusion: Fatigue was prevalent and is of concern in persons with subacute SCI. Those with incomplete lesions seem to be at higher risk. Because fatigue is known to persist among persons with SCI, interventions to reduce fatigue seem necessary.

Introduction

Spinal cord injury (SCI) is a chronic condition that causes paralysis and leads to multiple associated symptoms, including fatigue. Fatigue has been defined as an overwhelming sense of tiredness, lack of energy and often a feeling of total exhaustion.[1] Fatigue is known to negatively impact quality of life.[2] In persons with SCI in the chronic phase, at least one year post-injury, fatigue has been reported in more than half of the persons and has been found to interfere with daily functioning[3-5] To our knowledge, the prevalence and severity of fatigue in persons with subacute SCI is unknown.

The first step in preventing fatigue is to identify persons at risk. If demographic and lesion characteristics related to fatigue are known, subgroups at higher risk can be identified. Furthermore, fatigue has been suggested to be related to low daily physical activity and physical fitness levels within a cycle of deconditioning.[6] Because both daily physical activity and physical fitness levels are known to be low in persons with SCI,[7, 8] these factors may influence fatigue development. Besides physical activity, amount of sedentary day time is another independent aspect of physical behavior[9] that might impact fatigue. Assessing the impact of physical behavior and physical fitness on fatigue may help optimize interventions.

Fatigue is thought to be a multifactorial problem. In persons with SCI in the chronic phase, fatigue has been shown to relate to age[10] and lesion characteristics.[4] With regard to physical factors, being overweight has been found to negatively impact fatigue,[11] and physical activity that requires a lot of physical effort[12] is related to less fatigue in persons with SCI in the chronic phase.

Knowledge of fatigue in (subgroups of) persons with subacute SCI may help prevent chronic-phase fatigue. It is unknown whether fatigue onset immediately follows SCI or develops over time. Furthermore, it is unknown which physical factors are associated with fatigue development in persons with subacute SCI. Therefore, the goal of this study was to determine the prevalence and severity of fatigue in persons with subacute SCI who are wheelchair-dependent and assess if demographic and lesion characteristics are related to fatigue. Demographic and lesion characteristics studied include: age, sex, lesion level and lesion completeness. Second, we determined the relationship of physical fitness and physical behavior to fatigue.

Materials and methods

Design

This study is part of Act-Active, a longitudinal multi-center randomized controlled trial which includes a behaviorally-focused intervention on physical behavior in persons with subacute SCI, registered at the Dutch trial register: NTR2424. Persons were recruited from four Dutch rehabilitation centers and target sample size was 60 participants. The current study, in which we analyzed baseline data-from Act-Active, has a cross-sectional design.

Participants

Inclusion criteria were: 1) SCI, both traumatic or non-traumatic, 2) participation in initial inpatient rehabilitation, 3) dependence on a manual wheelchair, 4) age 18 to 65 years, and 5) sufficient comprehension of Dutch Language. Exclusion criteria were psychiatric conditions or progressive diseases that could interfere with participation as determined by a rehabilitation physician. The study was approved by the Medical Ethics Committee of the Erasmus Medical Center Rotterdam and all participants provided written informed consent. A rehabilitation physician screened participants for contraindications to maximal exercise including recent cardiovascular events and a diastolic blood pressure >90 mmHg or systolic blood pressure >180 mmHg at rest. Furthermore, all participants completed the Physical Activity Readiness Questionnaire.[13] Data were collected two months before discharge from inpatient rehabilitation, prior to the start of the Act-Active interventions. This measurement point was determined based on the discharge date set by the rehabilitation physician. At this standardized time in rehabilitation, all participants, regardless of lesion level and completeness, were expected to be engaged in active inpatient rehabilitation.

Outcome measures

Fatigue was measured using the Fatigue Severity scale (FSS), a validated questionnaire assessing the perceived impact of fatigue on an individual's daily functioning.[14] The range of answer possibilities is 1 to 7, and the total FSS score is the mean of nine questions. The mean Dutch general population score is 2.9 ± 1.1.[15] "Severe fatigue" was defined as a score on the FSS of more than 2 standard deviations above the mean score in the general population (FSS≥5.1).[15] "Fatigue" was defined as a score on the FSS of more than 1 standard deviation above the mean score in healthy individuals (FSS>4.0).[15] The prevalence of fatigue in our

sample was compared to the prevalence of fatigue in the general population (fatigue in 18% and severe fatigue in 4%).[16]

Participant sex and age were recorded. We defined persons 50 years or older as an older person and grouped participants into two age groups, <50 years and ≥50 years. A rehabilitation physician assessed lesion level and motor completeness. Paraplegia was defined as a lesion below Thoracic 1 (T1) and tetraplegia as a lesion at or above the T1 segment. Motor completeness included the AIS (American Spinal Injury Association Impairment Scale) categories A and B and motor incompleteness included AIS C and D.

Body mass index (BMI in $kg \cdot m^{-2}$) was calculated from height and body mass. Physical capacity was determined by performing a maximal hand cycle test on a Tacx Flow ergotrainer (Tacx, Wassenaar, The Netherlands and Double Performance, Gouda, The Netherlands). During the test, the participants were seated in an add-on hand cycle provided by the rehabilitation center. The test started after a three-minute warm-up period with minimal resistance. Resistance was increased every minute by 2 to 10 Watts, depending on lesion characteristics. During the test, persons were instructed to keep cycling at a rate of 60 rpm. The test ended when the participant indicated to be too exhausted to continue despite verbal encouragements of the research assistant or when failed to keep cycling at the rate of 60 rpm. Oxygen uptake (VO_2) was measured with an Oxycon Delta (Jaeger, Germany). VO_2peak, in milliliters per minute (mL/min), was determined and defined as the highest mean oxygen uptake during 30 seconds. Furthermore, power was measured continuously with an ergotrainer. When using correction equations, the Tacx Flow ergotrainer was found to be a reliable and valid instrument for power estimation. Peak power output (POpeak), in Watts, was defined as the highest power output sustained for a minimum of 30 seconds.

Physical behavior was measured objectively using the VitaMove activity monitor (2M Engineering, Veldhoven, The Netherlands) (Figure 3.1), an ambulatory monitoring system with body-fixed accelerometers (Freescale MMA7260Q, Denver, USA).[17, 18] The system consists of three recorders which are wirelessly connected and synchronized every 10 seconds. One recorder was attached to the sternum and one recorder to each wrist using specially developed belts. The activity monitor was worn continuously for 96 hours on four weekdays, except during swimming, bathing and sleeping. Due to logistic and technical reasons, the measurement duration goal of 96 hours was not always met; the minimum required duration was 24 hours for inclusion in analysis. To avoid measurement bias, participants were instructed to continue their ordinary daily life, including therapies. The principles of the activity monitor were explained only after participants completed the randomized

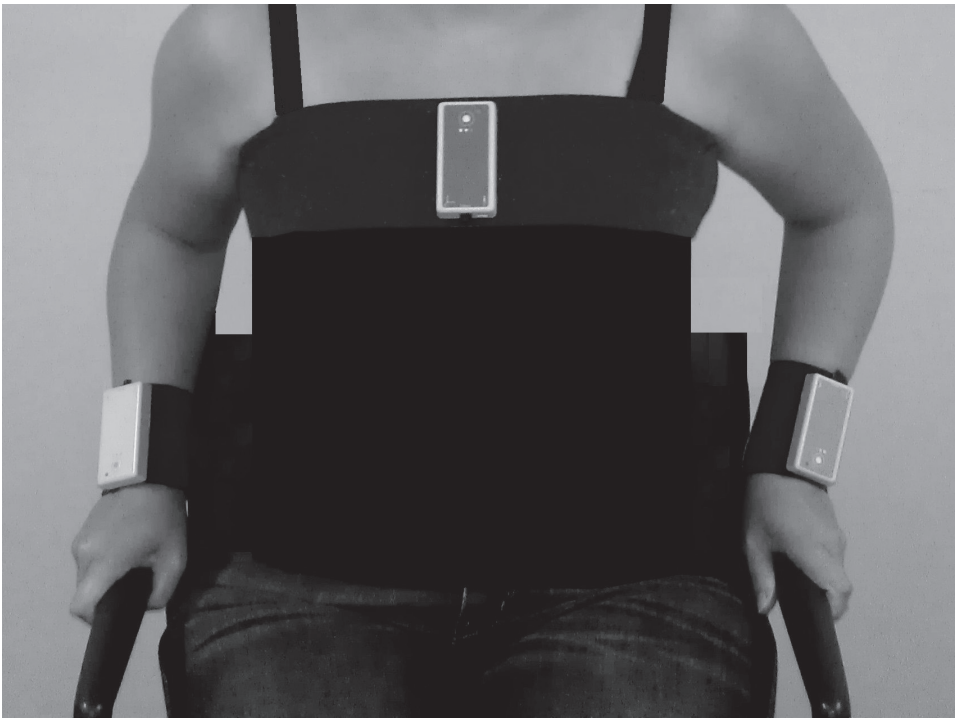

Figure 3.1 VitaMove activity monitor.

controlled trial. Measurements were uploaded to a computer for kinematic analysis using VitaScore Software (VitaScore BV, Gemert, The Netherlands). A detailed description of this configuration and analysis has been described elsewhere.[18]

Every second of the measurement was assigned to one of the four categories: sitting, lying, wheelchair propulsion and handcycling. The following outcome measures were determined as a mean of available measurement days:

a. Duration of wheeled physical activity, including wheelchair propulsion and hand cycling, in hours per 24-hour period.

b. Sedentary day time, including sitting and lying, in hours per 24-hour period.

c. Motility, mean variability of the trunk and arm signals independent of the assigned category, a measure of intensity and duration of all physical behavior, in g*100 (gravitational forces), per 24-hour period.

Data analysis

Descriptive statistics were used to summarize participant characteristics and describe the prevalence and severity of fatigue. Parametric tests were used because the Shapiro-Wilk test showed that fatigue data was normally distributed ($W(36)=0.95$, $p=0.09$). Independent t-tests were used to test for mean differences between subgroups. Secondary, separate regression models with fatigue as a dependent variable were made for the physical fitness (BMI, VO_2peak and POpeak) and physical behavior (physical activity duration, sedentary day time and motility) measures. Assumptions for normality and collinearity for regression analysis were met. In the regression models, possible confounding effects of demographic and lesion characteristics were assessed. Demographic and lesion characteristics were added one by one to the regression models of the physical fitness and physical behavior measures. At first, the characteristic causing the largest change in B (unstandardized regression coefficient) of the independent variable, with a minimum change of 10%, was added to the model as a confounding variable. This procedure was repeated for the remaining characteristics and ended when none of the characteristics caused a change in B of >10%. Because of the limited sample size, a maximum of two confounders were added to each regression model. We reported B, standard errors, 95% confidence intervals, ß and p-values for the regression analyses. The statistical significance level was set at $p<0.05$ (SPSS Inc, Chicago, IL).

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Results

Between January 2011 and August 2013 45 persons with SCI agreed to participate in the randomized controlled trial Act-Active. FSS data were not available for nine persons; therefore, the present study included data for 36 participants. In these 36 participants there were data missing for physical fitness and physical behavior. BMI was not available in two persons. Furthermore, eight participants were unable to perform maximal hand cycle testing due to contraindications to maximal exercise. VO_2 data were not available for an additional three participants, two because of technical problems and one because of a bacterial infection. Physical behavior data were missing for three participants due to logistical reasons.

Table 3.1 shows participant characteristics. Mean FSS was 3.1 (SD±0.5) for women and 3.3 (SD±1.4) for men. Our sample included only five women, and all 5 had complete paraplegia. None of the women had scores indicating fatigue and 36% of men had scores indicating

fatigue or severe fatigue. Because the group of women was small and uniform in lesion characteristics, sex was not statistically assessed in relation to fatigue.

Table 3.2 shows the prevalence and severity of fatigue for the entire group and for subgroups based on lesion characteristics and age. The mean score for our sample was 3.3 (SD±1.3).

Table 3.1 Participant characteristics (n=36)

Age, years, mean (SD)	43 (15)
Sex, %	
Men	86
Women	14
Lesion level, %	
Paraplegia	67
Tetraplegia	33
AIS score, %	
A	47
B	17
C	17
D	19
Time since injury in months mean (SD)	4.7 (2.4)
Time in rehabilitation in months, mean (SD)	3.4 (2.0)
Cause of lesion, %	
Traumatic	74
Non-traumatic	26

AIS, American Spinal Injury Association Impairment Scale.

Table 3.2 Prevalence of fatigue

		Age		Lesion level		Completeness	
	All n=36	<50 yrs n=24	≥50 yrs n=12	Paraplegia n=24	Tetraplegia n=12	Incomplete n=13	Complete n=23
Mean (SD)	3.3 (1.3)	3.2 (1.4)	3.6 (1.2)	3.0 (1.1)	3.9 (1.5)	3.9 (1.4)	3.0 (1.1)
T-test results		t=-0.85, p=0.40		t=-1.83, p=0.08		t=2.22, p=0.03*	
Fatigued† (%) (95% CI)	31[1] (16–46)	25	41	21	50	46	21
Severely fatigued‡ (%) (95% CI)	11[1] (1–21)	13	8	8	17	15	9

* indicates significant difference between subgroups;
[1] General population: fatigue in 18% and severe fatigue in 4%;[16]
† (FSS>4); FSS, fatigue severity scale;
‡ (FSS≥5.1);
CI, confidence interval.

Persons with motor incomplete lesions had significantly higher FSS scores compared to those with complete lesions (t=2.22, p=0.03).

Table 3.3 shows the regression models assessing the relationship between fatigue and physical fitness and physical behavior. The mean BMI was 25.0 (SD±5.0), mean POpeak was 49.1 (SD±31.4) Watts and mean VO_2peak was 1304.0 (SD±484.6) mL/min. The relationship between fatigue and VO_2peak bordered on statistical significance (B=-1.47, p=0.051). Persons with lower VO_2peak tended to be more fatigued. BMI and POpeak were not significantly related to fatigue. On average, participants were physically active for 1.2 (SD±0.5) hours per 24-hour period, sedentary for 10.5 (SD±1.2) hours during waking hours and mean motility was 16.5 (SD±4.2) g. No significant relationships were found between any physical behavior measures and fatigue.

Table 3.3 Regression models with fatigue as the dependent variable and physical fitness and physical behavior measures as independent variables

	FSS				
Independent variable*	B†	SE°	95% CI*	ß°	p
BMI, n=34	-0.004	0.05	-0.10–0.09	-0.02	0.93
Age	0.02	0.02	-0.02–0.05	0.19	0.28
Completeness	-0.96	0.46	-1.90–-0.03	-0.35	0.04
VO_2peak‡, n=25	-1.47	0.71	-2.94–0.00	-0.48	0.05
Lesion level	-0.26	0.91	-2.15–1.63	-0.09	0.78
Completeness	-1.23	0.73	-2.75–0.29	-0.41	0.11
POpeak§, n=28	-0.01	0.01	-0.04–0.01	-0.27	0.27
Lesion level	0.54	0.68	-0.87–1.95	0.19	0.44
Physical activity, n= 33	0.18	0.51	-0.87–1.23	0.07	0.73
Age	0.02	0.02	-0.02–0.06	0.22	0.25
Lesion level	0.82	0.48	-0.17–1.81	0.31	0.10
Sedentary day time, n=33	-0.17	0.20	-0.56–0.23	-0.16	0.41
Age	0.02	0.02	-0.02–0.05	0.17	0.36
Completeness	-0.72	0.48	-1.70–0.25	-0.27	0.14
Motility, n=33	-0.03	0.06	-0.17–0.10	-0.11	0.61
Age	0.01	0.02	-0.03–0.04	0.06	0.77
Completeness	-0.88	0.47	-1.85– 0.09	-0.33	0.07

* Each determinant was analyzed in a separate regression model;
† B, unstandardized regression coefficient;
° SE, standard error;
* CI, confidence interval;
º ß, standardized regression coefficient;
‡ VO_2peak, peak oxygen uptake;
§ POpeak, peak power output.

Discussion

Fatigue was prevalent and is of concern in persons with subacute SCI. Persons with incomplete lesions seem to be at higher risk. Rehabilitation professionals should recognize fatigue complaints and the possible impacts of fatigue. Because fatigue is known to persist among persons with SCI,[3-5] intervention to reduce fatigue is necessary.

Our sample seems representative for the Dutch population, as demographic and lesion characteristics are comparable to those reported in a previous large Dutch cohort study.[19]

Previous studies in persons with SCI in the chronic phase included relatively larger proportions of participants with incomplete lesions or tetraplegia.[3-5] This might partly explain that the prevalence of fatigue in our participants with subacute SCI was lower compared to the 52% to 57% prevalence previously reported for persons with SCI in the chronic phase.[3-5] Prospective studies assessing the course of fatigue are needed.

The finding that persons with incomplete lesions are more fatigued compared to persons with complete lesions was also described by Fawkes-Kirby et al. (2008)[4] in a study of persons with SCI in the chronic phase. Those authors proposed that persons with incomplete lesions attempt to complete more activities and rely less on assistive devices or care attendants; therefore, their total daily energy expenditure and the physiological energy cost of specific activities would be larger.[6] In this study, we did not find any relationship between fatigue and total duration of physical activity or activity intensity (motility). Physical activity duration was similar between subgroups based on SCI completeness (1.2 (SD±0.5) hours for both groups), and motility was also comparable (16.9 (SD±5.1) g for those with incomplete lesions and 16.2 (SD±3.7) g for those with complete lesions). However, we only applied the activity monitor to measure postures, wheeled activities and motility of the trunk and arms. Although all study participants were wheelchair-dependent, persons with incomplete lesions may use their legs to reposition in the chair or make transfers. We suggest that these types of activities may cause more fatigue in persons with incomplete lesions.

Persons 50 years or older had a fatigue prevalence of 41% versus 28% for persons younger than 50. However, we found a relatively high prevalence (13%, n=3) of severe fatigue among persons younger than 50. Of these three severely fatigued participants, two had incomplete tetraplegia and all were 40 years or older. These characteristics may partly explain this unexpected high prevalence of severe fatigue in the subgroup younger than 50. In a previous study, older age was associated with more fatigue.[10] Further studies with larger samples are necessary.

Our finding that aerobic capacity tended to relate to fatigue indicates that there may be a physical origin of fatigue in persons with subacute SCI. This finding underscores the importance of aerobic capacity training in the early rehabilitation phase.[20] Our finding is consistent with that of a previous study that showed that less exercise was related to more fatigue[5] and heavy intensity activity was related to lower fatigue in persons with chronic SCI.[12] However, we found no relationship between fatigue and physical behavior in our study. Therefore, we could not confirm the fatigue, physical fitness and physical behavior cycle hypothesis proposed by Durstine et al. (2000).[6] However, our physical behavior measurement was limited to outcomes on postures, wheeled physical activity and mean motility of trunk and arms. We did not specifically assess the amount and type of therapy of the participants. Moreover, for this group, daily self-care is already time-consuming and a straining every day activity.[21] Unfortunately, physical strain was not assessed in the present study. Future research should assess duration and type of therapy in relation to fatigue and should study the relation between physical strain and fatigue in persons with subacute SCI.

Furthermore, previous studies show that fatigue is a multifactorial problem and that other factors such as pain, depression, sleep-related problems as sleep apnea, and medication[3, 5, 22] contribute to fatigue development. Further research should address the effects of these parameters on fatigue development in persons with subacute SCI.

Because fatigue is known to persist in persons with chronic SCI, intervention seems necessary. To our knowledge, fatigue interventions in persons with SCI have not been studied previously. In other patient groups, a self-management program[23] and an exercise training program have been shown to reduce fatigue.[24] Further research on interventions in persons with SCI is necessary.

Study limitations

Our study is limited by its cross-sectional design and we cannot, therefore, infer causality from the results. Sample size calculation was performed based on the randomized controlled trial and the sample was limited to 36 participants. We could not assess sex as a determinant because our sample included only five women. Furthermore, due to multiple testing and the number of variables in the regression models, one should be careful to draw strong conclusions from individual results. Also, physical behavior was limited to weekday measurements. Longitudinal studies are needed to evaluate the course of fatigue and its determinants in persons with subacute SCI. Furthermore, our study was limited to persons who are dependent on a manual wheelchair and were younger than 65 years. Therefore,

future research should assess fatigue in ambulatory persons, persons dependent on power wheelchairs and persons older than 65 years.

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Chapter 4

Exercise self-efficacy in persons with spinal cord injury: psychometric properties of the Dutch translation of the Exercise Self-Efficacy Scale (ESES)

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Abstract

Objective: To assess the reliability and validity of the Dutch version of the Exercise Self-Efficacy Scale (ESES) in persons with spinal cord injury. This is the first independent study of ESES psychometric properties, and the first report on ESES test–retest reliability.

Subjects/patients: A total of 53 Dutch persons with spinal cord injury.

Methods: Subjects completed the Dutch ESES twice, with 2 weeks between (ESES_1 and ESES_2). Subjects also completed the General Self-Efficacy scale (GSE), and a questionnaire regarding demographic characteristics and lesion characteristics. Psychometric properties of the Dutch translation of the ESES were assessed and compared with those of the original English-language version.

Results: The Dutch ESES was found to have good internal consistency (Cronbach's α for ESES_1=0.90, ESES_2=0.88). Test–retest reliability was adequate (intraclass correlation coefficient=0.81, 95% confidence interval 0.70–0.89). For validity, a moderate, statistically significant correlation was found between ESES and the GSE (Spearman's ρ ESES_1=0.52, ESES_2=0.66, $p<0.01$). Furthermore, the psychometric properties of the Dutch ESES were found to be similar to those of the original English version.

Conclusions: The results of this study support the use of the ESES as a reliable and valid measure of exercise self-efficacy.

Introduction

A spinal cord injury (SCI) is characterized by muscle paralysis and loss of sensation below the level of the lesion. Persons with SCI often have secondary conditions, such as bladder and bowel dysfunction, sexual dysfunction, neuropathic pain, spasticity, pressure ulcers and psychological problems.[1] There is preliminary evidence that a physically active lifestyle can prevent or reduce some of these secondary conditions.[2] Moreover, studies show that physical activity in persons with SCI benefits several health aspects, including physical fitness, risk of cardiovascular disease, and quality of life.[2, 3]

Despite these known benefits, physical activity levels in persons with SCI are generally very low.[4-6] Therefore, it is important to promote physical activity among persons with SCI. Several interventions are available;[7] however, the most effective way to promote physical activity in this group remains unknown. Finding the optimal intervention to achieve and maintain higher activity levels in persons with SCI requires identification of modifiable factors that correlate with changes in physical activity. Multiple factors are linked to exercise participation.[8] Self-efficacy is one modifiable factor that has proven to be the most consistent correlate of physical activity behavior in non-disabled adults.[9] Self-efficacy is defined as "beliefs in one's capabilities to organize and execute the courses of action required for producing given attainments".[10] In persons with SCI, self-efficacy has been shown to be related to increased exercise, and self-efficacy is a predictor of exercise outcomes.[11] Moreover, other studies suggest that self-efficacy could be a key mediating factor in the promotion of physical activity in persons with SCI.[12-16]

To assess self-efficacy specific for exercise and physical activity in persons with SCI, Kroll et al.[17] developed the Exercise Self-Efficacy Scale (ESES). This scale was found by its developers to be a valid and internally consistent measure.[17] To be able to use this questionnaire in Dutch persons with SCI, we translated the ESES into Dutch. The purpose of the current study was to assess the reliability and validity of the Dutch version of the ESES in persons with SCI and to compare its psychometric properties with those of the original English-language version. This is the first independent study of the psychometric properties of the ESES, and the first to report ESES test–retest reliability, which has never been assessed for the English version.

Methods

Participants

A convenience sample of 53 persons with SCI participated in this study between March 2011 and January 2012. Inclusion criteria were: aged 18–80 years with sufficient comprehension of Dutch to complete questionnaires. Participants were recruited from the inpatient (n=14) and outpatient (n=23) departments of Rijndam Rehabilitation Center in Rotterdam and from the Dutch Spinal Cord Injury Association (n=16). This study was approved by the medical ethics committee of Erasmus Medical Center Rotterdam, The Netherlands.

Instruments

The ESES consists of 10 items about level of self-confidence with regard to performing regular physical activities and exercise.[17] A sample item is: "I am confident that I can overcome barriers and challenges with regard to physical activity and exercise if I try hard enough". Respondents answer using a 4-point scale: not at all true, rarely true, sometimes true, and always true. The minimum score is 10 and the maximum score 40. A higher score indicates higher exercise self-efficacy. Two Dutch persons with expertise in rehabilitation medicine independently translated the ESES from English to Dutch. These two translations were synthesized into a final document using consensus between the two translators and an expert committee. A professional translator then back-translated the Dutch version into English. The English translation was compared with the original English version; in consultation with the expert committee and the developers of the English questionnaire, a final Dutch version was created. To assess validity, participants completed the Dutch version of the General Self-Efficacy Scale (GSE).[18] The GSE is commonly used to measure self-efficacy in general situations. For example: "I can always manage to solve difficult problems if I try hard enough." This scale is also a 10-item scale with 4 response categories: not at all true, hardly true, moderately true and exactly true. The minimum score is 10 and the maximum score 40. A higher score indicates higher general self-efficacy. Participants also answered a question about sports participation: whether they currently participated in sports, and if so, which sport and for how many hours per week. Participants completed an additional questionnaire regarding demographic and spinal cord lesion characteristics. Demographic characteristics included: age, gender, country of birth, educational level and marital status. Educational categories were: low (prevocational practical education or less), medium (prevocational theoretical education and secondary education) or high (higher

vocational education and university). Lesion characteristics included lesion level, motor completeness, time since injury, and cause of lesion. Tetraplegia was defined as a lesion at or above the Th1 segment, and paraplegia as a lesion below Th1.

Procedure and data analysis

Participants initially completed the ESES (ESES_1), the GSE, and the demographic and lesion characteristic questionnaire. All participants completed the ESES again (ESES_2) 2 weeks later, as recommended by Terwee et al.[19] Score distribution was assessed by calculating the mean (standard deviation; SD), median (interquartile range; IQR), skewness, and floor and ceiling effects. Skewness was present if values exceeded the range of -1 to 1.[20] Floor and ceiling effects were present if 15% or more of the participants scored either the lowest score or highest score on a scale.[19] Because data were not normally distributed, non-parametric tests were used where possible. To assess reliability, internal consistency and test–retest reliability were determined. Internal consistency was determined by assessing Cronbach's α. An α of 0.70 was considered adequate.[21] For test–retest reliability, the intra-class correlation coefficient (ICC) between ESES_1 and ESES_2 was determined. An ICC >0.75 was considered sufficient.[21] Construct validity was assessed by correlating the ESES with the GSE. A moderate Spearman's ρ (0.30–0.70)[22] was expected because the two questionnaires measure related, but different, constructs of self-efficacy. In addition, discriminant validity was tested by comparing exercise self-efficacy scores of regular exercisers and non-exercisers. Based on the question about sports participation, participants were classified as regular exercisers (persons participating in sports at least once per week) or non-exercisers (all others). The 14 participants recruited from inpatient rehabilitation did not answer this sports participation question because all participated in daily therapy with several types of exercise. Therefore, these participants were treated as a separate group in this analysis. It was hypothesized that regular exercisers would score higher on the ESES compared with non-exercisers. A Kruskal-Wallis test was used to test for differences in exercise self-efficacy between regular exercisers, non-exercisers and participants in inpatient rehabilitation. For a Kruskal-Wallis test showing significance, *post hoc* analyses were performed using Mann-Whitney tests with Bonferroni correction (p-value 0.05/3=0.017). Statistical analysis was performed using SPSS version 17.0.

Results

Score distribution

Participants characteristics are shown in Table 4.1. Descriptive statistics for ESES and GSE are shown in Table 4.2. Both the ESES_1 and ESES_2 scores were negatively skewed. No floor or ceiling effects were noted.

Table 4.1 Participants characteristics (n=53)

Age in years, mean (SD)	51.5 (12.3)
Gender, n (%)	
Men	44 (83)
Women	9 (17)
Country of birth, n (%)	
The Netherlands	48 (91)
Other	5 (9)
Education, n (%)	
Low	14 (26)
Medium	25 (47)
High	14 (26)
Current marital status, n (%)	
Married / living together	31 (58)
Other	22 (42)
Lesion level, n (%)	
Paraplegic	33 (62)
Tetraplegic	20 (38)
Completeness, n (%)	
Complete	34 (64)
Incomplete	19 (36)
Time since injury, mean in months (SD), [range]	107.2 (122.3), [2–513]
Cause of lesion, n (%)	
Traumatic	40 (75)
Non-traumatic	13 (25)

SD, standard deviation.

Table 4.2 Descriptive statistics of the ESES and GSE (n=53)

	Mean (SD)	Median (IQR)	Skewness	Floor (%) score=10	Ceiling (%) score=40
ESES_1	33.1 (5.6)	34.0 (30.5–37.0)	-1.64	1.9	9.4
ESES_2	33.6 (5.0)	35.0 (31.0–37.0)	-1.38	0	11.3
GSE	33.7 (4.4)	34.0 (30.5–37.0)	- 0.46	0	7.5

ESES_1, first completion; ESES_2, second completion, two weeks later; SD, standard deviation; IQR, interquartile range.

Reliability

Cronbach's α was 0.90 for ESES_1 and 0.88 for ESES_2, indicating good internal consistency. Furthermore, the ICC between ESES_1 and ESES_2 was 0.81 (95% CI 0.70–0.89), indicating adequate test–retest reliability.

Validity

With respect to construct validity, a correlation of ρ=0.52 ($p<0.01$) was found between ESES_1 and GSE, and ρ=0.66 ($p<0.01$) between ESES_2 and GSE. Validity was also tested by comparing exercise self-efficacy of regular exercisers, nonexercisers, and participants in inpatient rehabilitation. Median ESES and GSE scores for the 3 groups are shown in Table 4.3. The Kruskal-Wallis test showed a significant group effect for ESES_1 (χ^2=6.68, p=0.035). *Post hoc* analysis showed a significant difference between the participants in inpatient rehabilitation and non-exercisers (U=61.00, p=0.013). A nonsignificant difference was found between regular exercisers and non-exercisers (U=119.50, p=0.050). Regular exercisers and participants in inpatient rehabilitation had comparable scores (U=135.50, p=0.697). The Kruskal-Wallis test showed no significant group effect for ESES_2 (χ^2=1.89, p=0.389) or GSE (χ^2=0.22, p=0.898).

Table 4.3 Median ESES and GSE scores for regular exercisers, non-exercisers and participants in inpatient rehabilitation

	Median (IQR)		
	Regular exerciser (n=21)	Non-exerciser (n=18)	Inpatient rehabilitation (n=14)
ESES_1*	35.0 (31.0–38.0)	30.5 (27.5–35.0)	35.0 (34.0–36.25)
ESES_2	35.0 (31.0–37.0)	32.0 (28.0–37.25)	35.0 (31.0–38.0)
GSE	34.0 (30.5–37.0)	33.5 (29.0–38.0)	33.0 (31.0–38.25)

IQR, interquartile range.
* ESES_1 showed a significant group effect (p=0.035), with a significant difference between non-exercisers and participants in inpatient rehabilitation (p=0.013). There was a non-significant difference between regular exercisers and non-exercisers (p=0.05).

Discussion

This study shows that the Dutch translation of the ESES is a valid and reliable measure of exercise self-efficacy in persons with SCI. This is the first study to assess ESES test–retest reliability, which was found to be adequate. Also, internal consistency was good and comparable to that reported by Kroll et al.[17] (Cronbach's α=0.87).

The moderate correlation between the ESES and GSE implies that both questionnaires measure related, but different, constructs of self-efficacy. The correlation between ESES and GSE (ρ=0.52 for ESES_1 and 0.66 for ESES_2) found in the current study was higher than the correlation (ρ=0.32) found by Kroll et al.[17] for the English-language version, who also used the GSE as a reference measure. We do not have an explanation for this difference in validity found between the Dutch and English versions.

The inpatient rehabilitation participants in our study had significantly higher exercise self-efficacy compared with nonexercisers. Exercise self-efficacy of inpatient rehabilitation participants was comparable to the exercise self-efficacy of regular exercisers. This implies that persons in inpatient rehabilitation are as confident about physical activity and exercise as regular exercisers. Because persons enrolled in inpatient rehabilitation programmes are engaged in daily therapy including a relatively large amount of exercise and physical activity, they can be considered regular exercisers. That persons in inpatient rehabilitation are relatively physically active is supported by a study by van den Berg-Emons et al.,[5] which showed that physical activity levels during inpatient rehabilitation are low, but significantly higher compared with physical activity levels following discharge.

Regular exercisers showed higher median ESES scores (35 for ESES_1 and 35 for ESES_2) compared with non-exercisers (30.5 for ESES_1 and 32 for ESES_2). However, this difference in exercise self-efficacy between regular exercisers and non-exercisers was not statistically significant. This not statistically significant difference could be explained by the relatively large range in the group of regular exercisers compared with the smaller range among participants in inpatient rehabilitation, for whom we did find a significant difference with the non-exercise group. Although the regular exerciser group was larger (n=21) than the inpatient rehabilitation group (n=14), all study groups were small and it is likely that low power accounted for the lack of significant difference. Both Kroll et al.[17] and Stroud et al.[23] reported that regular exercisers scored significantly higher on the ESES compared with non-exercisers.

No ceiling effects were found for the ESES, but scores were negatively skewed, indicating that participants frequently had high scores. Our mean scores (33.1 for ESES_1 and 33.6

for ESES_2) were higher compared with mean ESES scores reported in previous studies. Kroll et al.[17] reported a mean score of 31.8 (SD±8.8) in persons with SCI and Stroud et al.[23] reported a mean score of 28.8 (SD±5) in persons with multiple sclerosis. Our higher mean score could have resulted from our recruitment venues: inpatient rehabilitation, outpatient rehabilitation, and via the Dutch Spinal Cord Injury Association. Approximately half of the participants recruited from outpatient rehabilitation and via the Dutch Spinal Cord Injury Association were regular exercisers with high ESES scores. The participants in inpatient rehabilitation also scored high on ESES. Therefore, we had a relatively large number of participants with high scores, leading to a negative skew. It is important when interpreting ESES to consider the high scores of persons with SCI in inpatient rehabilitation. Furthermore, our results imply that a focus on exercise self-efficacy may be of little value during inpatient rehabilitation. However, it may be of added value to focus on expectations about exercise self-efficacy after discharge from the rehabilitation center. Longitudinal studies are needed to verify these hypotheses.

In addition to participant recruitment, participant characteristics could also affect scores. Although sample characteristics were comparable to those reported in previous Dutch studies,[24] our sample consisted of more males (83% vs 60% and 18%) compared with two other studies using the ESES.[17, 23] Whereas a previous study showed that boys had significantly higher self-efficacy compared with girls,[5] we found no such difference in exercise self-efficacy between men and women (U=167, p=0.46).

Although this study met criteria for psychometric studies[19] there are some limitations. First, group sizes to compare scores of regular exercisers, non-exercisers and participants in inpatient rehabilitation were small. Nevertheless, we found some significant between-group differences. Furthermore, allocation to the group of regular exercisers or non-exercisers was based on only one question about sports participation. In addition, non-participation in sports does not mean that someone is physically inactive.

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Chapter 5

Exercise self-efficacy and the relation with physical behavior and physical capacity in persons with subacute spinal cord injury

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Submitted.

Abstract

Background: Since physical activity and exercise levels are known to be generally low in persons with spinal cord injury (SCI), there seems to be a need for intervention. Exercise self-efficacy (ESE), the confidence persons have in their ability to be physically active and exercise, is an important and modifiable predictor of physical behavior. The goal of this study was to 1) describe ESE in persons with subacute SCI, 2) to assess ESE in subgroups based on demographic and lesion characteristics, and 3) to explore the relation between ESE and physical behavior and physical capacity.

Methods: Thirthy-seven persons with subacute SCI who are wheelchair dependent participated. Participants completed the Exercise Self-Efficacy Scale. We recorded age and lesion characteristics, measured physical behavior (physical activity, motility and sedentary day time) with an accelerometer-based activity monitor and measured physical capacity (peak power output and peak oxygen uptake) during a maximal hand-cycling test. Measurements were performed two months prior to discharge from inpatient rehabilitation. Mann-Whitney tests were used to test for differences between subgroups based on age and lesion characteristics and spearman correlations were used to assess the relation between ESE and physical activity and physical capacity.

Results: Persons with tetraplegia had lower ESE compared to persons with paraplegia ($Z=-1.93$, $p=0.05$). No differences in ESE were found between subgroups based on age and lesion completeness. In persons with paraplegia, ESE was positively related to peak power output ($\rho=0.58$, $p=0.02$). The correlation of ESE with wheeled physical activity was $\rho=0.36$, $p=0.09$.

Conclusions: Lesion level seemed to affect ESE while age and lesion completeness were not related to ESE. Persons with tetraplegia were found to have lower confidence with regard to physical activity and exercise indicating that this subgroup can benefit from extra attention in the promotion of physical activity and exercise. In persons with paraplegia, ESE seemed to be lower in persons with less peak power output and less daily physical activity.

Introduction

Daily physical activity and exercise are known to reduce the risk of cardiovascular disease, prevent or reduce secondary conditions, and improve quality of life for persons with spinal cord injury (SCI).[1-5] However, physical activity and exercise levels are known to be generally low in persons with SCI in the chronic phase.[6, 7] In addition to maintaining sufficient physical activity, interposing of breaks in sedentary day time is another independent aspect of physical behavior that is thought to be important for optimal health.[8, 9] More physical activity and exercise is known to reduce the risk of cardiovascular disease, prevent or reduce secondary conditions, and improve physical fitness and quality of life in persons with SCI.[2, 3] Thus, it seems important to promote an active lifestyle in persons with SCI.

Exercise self-efficacy (ESE), the confidence persons have in their ability to exercise,[10] is an important and modifiable predictor of physical activity and exercise behavior.[11] Persons with higher ESE are more likely to be physically active and to exercise.[12] During the first months after SCI, persons establish a new routine and therefore this period might be critical to introduce and encourage new habits that incorporate physical activity and exercise and limit sedentary day time. By helping persons to increase ESE, practitioners may be more successful in achieving higher levels of physical activity and exercise.[12] A previous study showed that a behavioral intervention targeting ESE was effective in increasing the frequency of physical activity and exercise among persons with SCI in the chronic phase.[13] However, to our knowledge this has not been studied in persons with subacute SCI. Furthermore, it is unknown what determines ESE in persons with subacute SCI. Among able-bodied adolescents[14] and older adults,[15] men show higher ESE compared to women. Among persons with coronary heart disease, age is inversely associated with ESE.[16] Furthermore, ESE has been related to aerobic capacity among middle-aged adults.[17]

The goal of this study was to 1) describe ESE in persons with subacute SCI, 2) to assess ESE in subgroups based on demographic and lesion characteristics, and 3) to explore the relation between ESE and physical behavior and physical capacity. We hypothesized that ESE was lower among females, older persons, persons with higher lesion levels and among those with complete lesions. Furthermore, we expected ESE to be lower among persons with lower daily physical activity levels, with more sedentary time, and with lower physical capacity. This study may assist in identifying subgroups of persons with lower ESE who could benefit from more attention. Furthermore, this study is important to optimize interventions targeting ESE.

Methods

This study is part of a multi-center randomized controlled trial, Act-Active, that evaluates the added value of a behaviorally focused intervention on physical activity, physical fitness and health among persons with subacute SCI. Persons aged 18 to 65 years with subacute SCI were recruited from four Dutch rehabilitation centers: Rijndam in Rotterdam, Adelante in Hoensbroek, Heliomare in Wijk aan Zee and De Hoogstraat in Utrecht. To meet inclusion criteria, persons had to be involved in initial inpatient rehabilitation following SCI, use a manual wheelchair, and sufficiently comprehend the Dutch language. Persons were excluded for progressive disease or severe psychiatric condition that could interfere with participation. All participants provided written informed consent. The study was approved by the Medical Ethics Committee of the Erasmus Medical Center in Rotterdam and local approval was granted by the four participating centers. Participants were screened for contraindications to exercise by a rehabilitation physician and all participants completed the Physical Activity Readiness Questionnaire.[18]

Data were collected between January 2011 and August 2013 at the four centers using consistent testing protocols. In the current study, baseline data of the longitudinal study that were collected previous to the start of the interventions of Act-Active, two months before discharge from inpatient rehabilitation, were analysed. At this time point, all persons with SCI meeting the inclusion criteria were participating in active inpatient rehabilitation.

ESE was assessed using the Dutch Exercise Self-Efficacy Scale (ESES).[19] The ESES consists of 10 items about self-confidence level with respect to performing exercise and daily physical activities. The ESES has demonstrated reliability and validity for use in persons with SCI.[19, 20] The ESES minimum score is 10 and the maximum score is 40, with higher scores indicating higher ESE.

Gender and age of the participants were recorded and lesion level and motor completeness were determined by a rehabilitation physician using international standards.[21] Subgroups of age were <50 years and ≥50 years old. Tetraplegia was defined as a lesion at or above the Th1 segment, and paraplegia as a lesion below Th1. Motor completeness included American Spinal Injury Association Impairment Scale categories A and B, whereas motor incompleteness included categories C and D.

Physical behavior was objectively measured using the VitaMove activity monitor (2M Engineering, Veldhoven, The Netherlands) (Figure 5.1), an ambulatory monitoring system with body-fixed accelerometers (Freescale MMA7260Q, Denver, USA).[22-24] The system

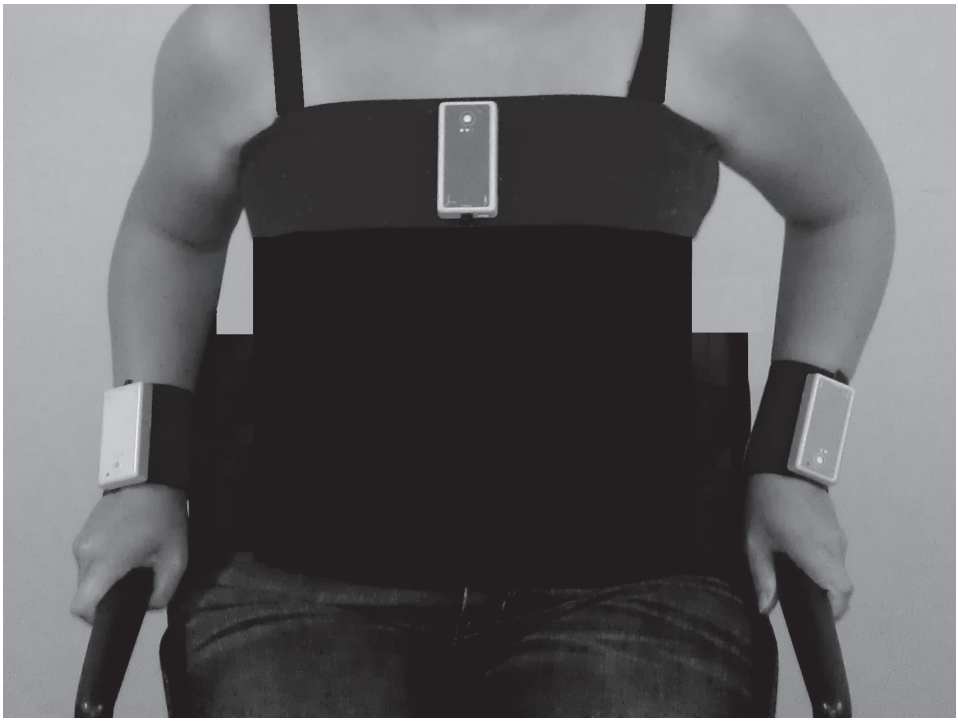

Figure 5.1 VitaMove activity monitor.

consists of three recorders which are wirelessly connected and synchronized every 10 seconds. One recorder was attached to the sternum and one recorder to each wrist using specially developed belts. The activity monitor was worn continuously for 96 hours on four weekdays, except during swimming, bathing and sleeping. Due to logistic and technical reasons, the measurement duration goal of 96 hours was not always met; the minimum required duration was 24 hours for inclusion in analysis. To avoid measurement bias, participants were instructed to continue their ordinary daily routine, including therapies. The principles of the activity monitor were explained only after participants completed the randomized controlled trial. Measurements were uploaded to a computer for kinematic analysis using VitaScore Software (VitaScore BV, Gemert, The Netherlands). A detailed description of this configuration and analysis has been described elsewhere.[23, 24] Every second of the measurement was assigned to one of the four categories: sitting, lying, wheelchair propulsion and handcycling. The following outcome measures were determined as a mean of available measurement days:

a. Duration of wheeled physical activity, including wheelchair propulsion and hand cycling, in hours per 24-hour period.

b. Duration of sedentary daytime bouts longer than 30 minutes, including sitting and lying without interruption by physical activity for a minimum of 5 seconds, in hours, per 24-hour period.

c. Mean motility per 24-hour period. Motility is based on the variability of the accelerometer signal of the trunk and arm recorders and is a measure of intensity and duration of all movement, expressed in gravitational force (g).

Physical capacity was determined during a maximal handcycle test using a Tacx Flow ergotrainer (Tacx, The Netherlands and Double Performance, The Netherlands). The test was performed in an add-on handcycle, often used by the participant during rehabilitation and provided by the rehabilitation center. The test started with a warm-up period of three minutes during which the participants cycled on the resistance equal to the resistance of the first minute of the handcycle test. The resistance was estimated based on lesion characteristics and the warm-up period was used to check if the estimation seemed to be correct such that duration of the test would be between 8–12 minutes. After this warm-up period there was sufficient time to rest. During the test, the resistance was increased every minute by 2 to 10 Watts, depending on lesion characteristics. Throughout the test, participants cycled at a cadence of 60 rpm. The test ended when the participant stopped voluntarily due to exhaustion, or when the participant was unable to maintain the target cadence. During the test, oxygen uptake (VO_2) was measured using an Oxycon (Jaeger, Germany). VO_2peak was defined as the highest mean oxygen uptake during 30 seconds and expressed in liters per minute (L/min). Furthermore, power was measured continuously with the Tacx Flow ergotrainer. When using correction equations, this ergotrainer has been found reliable and valid in estimating power.[25] Peak power output (POpeak, in Watt) was defined as the highest power output sustained for a minimum of 30 seconds.

Statistical analyses

Shapiro-Wilk test showed that ESE data were not normally distributed ($W(37)=0.90$, $p<0.01$). Differences in ESE between subgroups based on gender, age (<50 years and ≥50 years), lesion level (tetraplegia and paraplegia), and lesion completeness (motor complete and motor incomplete) were assessed with Mann-Whitney tests. Spearman correlations were used to assess the relation between ESE and wheeled physical activity, sedentary daytime bouts longer than 30 minutes, motility, POpeak and VO_2peak in the total group. If statistical level was $p<0.10$, spearman correlations were determined per lesion level and showed in scatter plots. The statistical significance level was set at $p\leq0.05$. Statistical analyses were performed using SPSS 20 (SPSS Inc, Chicago, IL, USA).

Results

A total of 45 persons with SCI agreed to participate. ESE data were not available for eight participants, thus the present study included ESE data of 37 participants. Data of the activity monitor were missing for two persons because these measurements did not meet the minimum required duration. Nine participants were unable to perform the maximal handcycle test due to contraindications for maximal exercise. Of an additional four participants, who did have POpeak data available, VO_2 data were unavailable: two because of technical problems and two because of bacterial infections. Table 5.1 shows participant characteristics.

Table 5.1 Participant characteristics (n=37)

Age, median (IQR)	44 (30–56)
Men, n (%)	32 (86)
Lesion level, n (%)	
Tetraplegia	12 (32)
Paraplegia	25 (68)
AIS, n (%)	
Motor incomplete	13 (35)
Motor complete	24 (65)
Time since injury, median days (IQR)	124 (89–160)
Time in rehabilitation, median days (IQR)	83 (57–125)
Cause of injury, n (%)	
Traumatic	26 (70)
Non-traumatic	9 (24)
Unknown	2 (5)
Wheeled physical activity (in hours/24-hour period), median (IQR)	1.12 (0.80–1.58)
Sedentary day time >30 min. (in hours/24-hour period), median (IQR)	1.55 (0.90–3.14)
Motility (in g), median (IQR)	16.20 (13.00–20.05)
VO_2peak (in L/min), median (IQR)	1.15 (0.92–1.62)
POpeak (in Watt), median (IQR)	50.37 (27.14–69.24)

IQR, interquartile range.

Median ESE was 38.0 (IQR=32.0–38.5) for women and 36.0 (IQR=34.0–39.0) for men. Our sample included only five women, all of whom had complete paraplegia. Because the number of women was small and lesions were uniform, we did not assess ESE in subgroups based on gender.

Table 5.2 shows median values on ESE for the total group and for subgroups based on age and lesion characteristics. Persons with tetraplegia seemed to have lower ESE compared to persons with paraplegia (Z=-1.93, p=0.054).

Table 5.2 Exercise self-efficacy for the total group and for subgroups

		ESE Median (IQR)	Subgroup analysis
All, n=37		37.0 (34.0–39.0)	
Age			
	<50 yrs, n=25	37.0 (34.0–39.0)	Z=-0.10, p=0.92
	≥50 yrs, n=12	36.5 (32.5–39.0)	
Lesion level			
	Tetraplegia, n=12	35.0 (31.8–37.0)	Z=-1.93, p=0.05
	Paraplegia, n=25	38.0 (34.5–39.5)	
Completeness			
	Incomplete, n=13	35.0 (32.5–38.5)	Z=-0.91, p=0.36
	Complete, n=24	37.0 (34.0–39.0)	

In Table 5.3 the correlations between ESE and physical behavior and physical capacity. For the total group ESE was positively related to VO_2peak (ρ=0.45, p=0.03) and POpeak (ρ=0.52, p<0.01). The correlation of ESE with physical activity was ρ=0.31, p=0.07. Figure 5.2 describes the correlations separately for persons with paraplegia and tetraplegia for physical activity, VO_2peak and POpeak. No significant correlations were found for persons with tetraplegia. In persons with paraplegia a significant correlation was found for ESE with POpeak (ρ=0.58, p=0.02). Furthermore, the correlation of ESE with physical activity for persons with paraplegia was ρ=0.36, p=0.09.

Table 5.3 Correlations between ESE and physical activity and physical capacity

		ESE	
	n	ρ	p
Physical activity (in hours/24-hour period)	35	0.31	0.07†
Sedentary day time >30 min (in hours/24-hour period)	35	-0.06	0.73
Motility (in g)	35	0.12	0.51
VO_2peak (in L/min)	24	0.45	0.03†
POpeak (in Watt)	28	0.52	<0.01†

ρ, Spearmans' Rho.
† p<0.10.

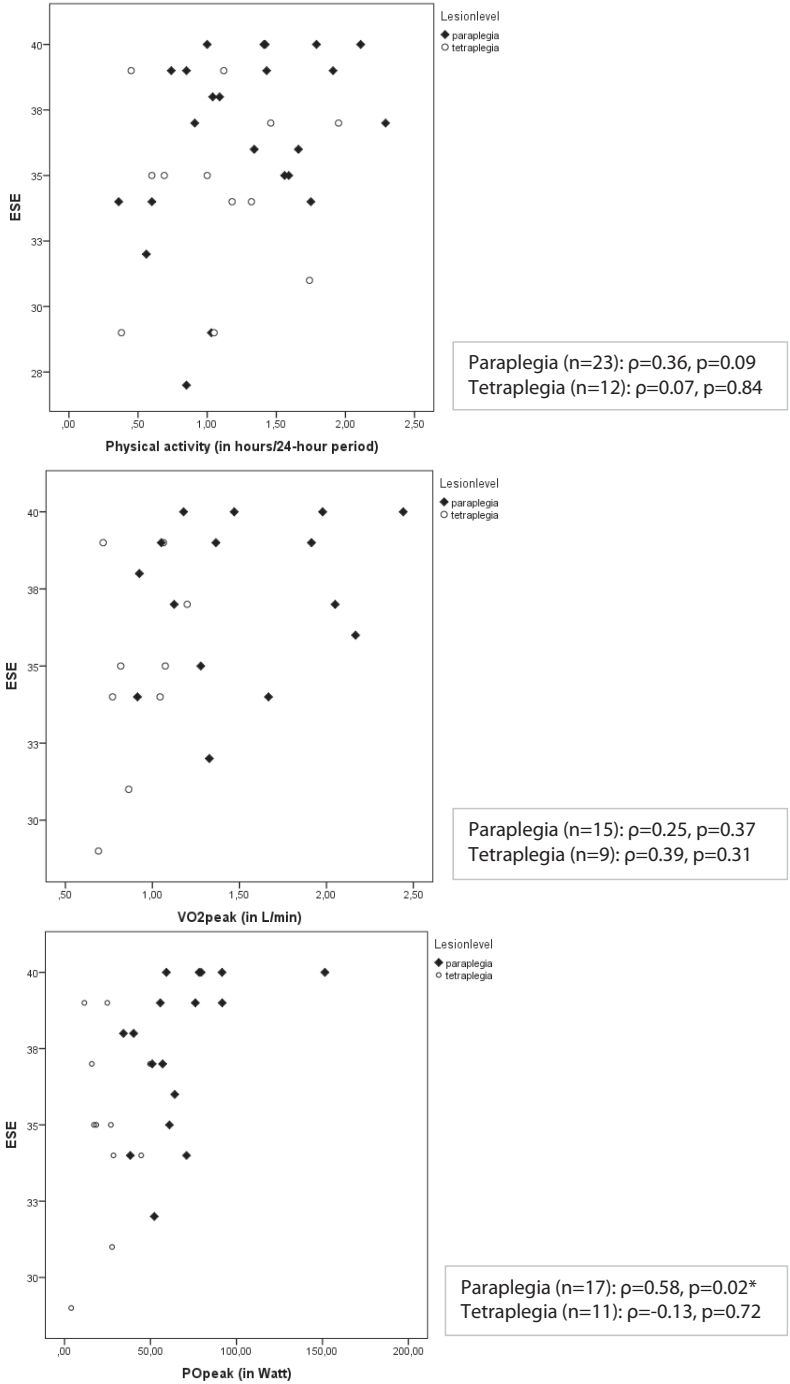

Figure 5.2 Correlations between ESE and physical activity and physical capacity in subgroups based on lesion characteristics.

* indicates significant correlation.

Discussion

This study assessed ESE in persons with subacute SCI. Lesion level seemed to affect ESE while age and lesion completeness were not related to ESE. Persons with tetraplegia were found to have lower confidence with regard to physical activity and exercise. Relations of ESE with physical activity and physical capacity (peak power output) were found for persons with paraplegia but not for persons with tetraplegia.

Generally, ESE seemed relatively high in our group of persons with subacute SCI, median ESE was 37 with a maximum score of 40. However, previous studies using the ESES in other patient groups also found relatively high median scores.[26, 27] Nevertheless, the range in ESE (27 to 40) was large enough to test for differences between subgroups in ESE and to assess correlations with physical behavior and physical capacity.

Lower ESE in persons with tetraplegia indicates that that this subgroup can benefit from extra attention in the promotion of physical activity and exercise, e.g. by offering them extra sessions in behavioral interventions targeting ESE. This result is in line with previous findings that persons with tetraplegia are less physically active and have less physical capacity in the year following discharge than persons with paraplegia.[28, 29] However, a previous study on ESE in persons with subacute SCI did not find significant differences in ESE between persons with subacute tetraplegia and paraplegia.[30] This is possibly explained by the use of a different questionnaire for exercise self-efficacy assessing more specific constructs, e.g. confidence to engage in moderate and heavy intensity aerobic and strengthening activity for 10, 20, 30, 45 and 60 minutes without stopping. Further studies on ESE constructs are necessary.

To our knowledge this is the first study assessing relations of ESE with objectively measured physical behavior and physical capacity. The relation of ESE with POpeak in persons with paraplegia indicates that ESE is lower when persons have lower POpeak. Furthermore, although not significant, there seemed to be a relation of ESE with physical activity in persons with paraplegia, indicating that ESE is lower in persons with lower daily physical activity levels. This indicates that for ESE it is both important what one actually does (physical activity) and what one is capable of (peak power output). However, these results were not supported by the non-significant correlation of ESE with sedentary time and motility and with VO_2peak in the subgroups based on lesion level. Further longitudinal studies are necessary.

Lesion completeness and age were not related to ESE. However, ambulatory persons were excluded from the current study and our sample was relatively young with only 12 persons

older than 50 and a maximum age of 65 years. Although sample characteristics were similar to those reported in previous Dutch studies,[31] our conclusions are limited to persons who are wheelchair dependent, within the age range of 18 to 65 years. Further study in ambulatory persons and those aged above 65 years is necessary.

Unfortunately, we were unable to assess the relation of gender with ESE because our sample included only five women. Previous research among able-bodied found a relation between gender and ESE.[14, 15] However, a previous study among persons with SCI showed ESE to be similar between men and women.[19] This seems in line with the current study, although the number of women was limited.

Study limitations

Our study was limited by its cross-sectional design and small sample size. Besides, the measurement with the activity monitor was limited to wheeled physical activity. Other types of physical activity and exercise, such as swimming, were not measured. Further study of the effectiveness of interventions targeting ESE in persons with subacute SCI is also needed.

Conclusion

Lesion level seemed to affect ESE while age and lesion completeness were not related to ESE. Persons with tetraplegia were found to have less confidence with regard to physical activity and exercise indicating that that this subgroup can benefit from extra attention in the promotion of physical activity and exercise, e.g. by offering them extra sessions in behavioral interventions targeting ESE. For persons with paraplegia, ESE seemed to be lower in persons with lower daily physical activity levels and lower peak power output. This might indicate that for ESE it is both important what one actually does (physical activity) and what one is capable of (peak power output). Assessing ESE in the individual might help practitioners in finding the appropriate guidance a person needs for exercise promotion.

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Chapter 6

Feasibility of handcycle training during inpatient rehabilitation in persons with spinal cord injury

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Abstract

Objective: To assess the feasibility of a handcycle training program during inpatient rehabilitation and the changes in physical capacity in persons with subacute SCI.

Design: Before-after trial.

Setting: Four Dutch rehabilitation centers.

Participants: Forty-five persons with subacute SCI in regular rehabilitation.

Interventions: A structured handcycle interval training program during the last eight weeks of inpatient rehabilitation. Training was scheduled 3x/week (24 sessions total) with an intended frequency of ≥2x/week. Intended intensity was Borg score 4 to 7 on a 10-point scale.

Main outcome measures: Feasibility was assessed and participant satisfaction evaluated (n=30). A maximal handcycling test was performed eight weeks prior to discharge and at discharge to determine peak power output (POpeak) and peak oxygen uptake (VO_2peak) (n=23).

Results: 91% of participants completed the handcycle training and no adverse events were reported. Mean training frequency was 1.8x/week (SD=0.5), mean Borg score 6.2 (SD=1.4). Persons with complete lesions demonstrated lower training feasibility. Most participants were satisfied with the handcycle training. POpeak and VO_2peak improved significantly after training period ($p<0.01$), with respectively 36.4 and 9.6%.

Conclusions: Overall, handcycle training during inpatient rehabilitation in persons with SCI was feasible except for the training frequency. Persons with complete lesions likely need extra attention to benefit optimally from handcycling training. Since the improvements in physical capacity were larger than those known to occur in persons with paraplegia receiving regular rehabilitation the results suggest that the addition of handcycle training may result in larger increases in physical capacity compared to regular rehabilitation only.

Introduction

Handcycling has been suggested as an appropriate training method for persons with spinal cord injury (SCI) because handcycling is less strenuous and the risk of upper extremity overuse injury is smaller compared to handrim wheelchair propulsion.[1] Integrating handcycle training into the rehabilitation program of this vulnerable group may be challenging.[2, 3] Feasibility knowledge is important to facilitate successful implementation. The purpose of this study was to assess the feasibility of a handcycle training program during inpatient rehabilitation and the changes in physical capacity in persons with subacute SCI.

Methods

Persons were recruited from four Dutch rehabilitation centers. Inclusion criteria were: initial inpatient rehabilitation, dependence on a manual wheelchair, and 18 to 65 years old. The Medical Ethics Committee of Erasmus Medical Center Rotterdam, The Netherlands, approved the protocol of this study and all participants provided written informed consent.

All participants participated in a structured handcycle training program during the last eight weeks of inpatient rehabilitation. The training, performed on an add-on handcycle, was supervised by a sports therapist and consisted of an interval training protocol tailored to the individual.[4] During the first week of training, the sessions consisted of six repetitions of three minutes of handcycling, each followed by a two-minute interval of active rest during which participants cycled at low resistance. During the eight weeks of handcycle training, the number of repetitions and handcycle time increased, whereas the rest time decreased. Last week of training consisted of seven repetitions of four minutes of handcycling with rest-intervals of 1.5 minutes. Training was performed indoors by placing the handcycle in an ergotrainer or outside. Each training session lasted 45 to 60 minutes including short warming-up and cooling-down periods. Training was scheduled 3x/week (24 sessions total) with an intended frequency of ≥2x/week. Training intensity was controlled by measuring central cardiovascular perceived exertion from 0 to 10 on a Borg Scale after each training session.[5, 6] Intended intensity was a Borg score between 4 and 7.

For feasibility, training details were registered by sports therapists in a handcycle training journal. Furthermore, at the end of the training period, a self-set evaluation form was completed by participants. This included questions on general satisfaction, and satisfaction with training frequency, training intensity, starting time in rehabilitation, and total training program duration with answering possibilities “satisfied” or “not satisfied” for which reason.

Before and after handcycle training participants performed a maximal handcycle test on an add-on handcycle placed in a Tacx Flow ergotrainer.[a] The resistance was increased every minute by 2 to 10 Watts, as estimated based on lesion characteristics and adjusted where necessary such that the duration of the test would be 8–12 minutes. Throughout the test, participants cycled at a cadence of 60 rpm. The test ended when the participant stopped voluntarily due to exhaustion or when the participant was unable to maintain the target cadence. Peak power output[a,7] (in Watt and Watt/kg) was defined as the highest power output sustained for at least 30 seconds. Peak oxygen uptake[b] (VO_2peak in L/min and mL/kg/min) was defined as the highest mean oxygen uptake measured in periods of 30 seconds.

Tetraplegia was defined as a lesion at or above the Thoracic (Th)1 segment and paraplegia as a lesion below Th1. Motor completeness included American Spinal Injury Association Impairment Scale categories A and B, whereas motor incompleteness included categories C and D.

Data analysis

Non-parametric tests were used because Shapiro-Wilk tests showed that not all variables were normally distributed. Mann-Whitney U tests were used to test for differences in training frequency and training intensity between subgroups based on lesion characteristics. Wilcoxon tests were used to test for differences in physical capacity before and after training. Statistical analysis was performed using SPSS version 21 and significance level with Bonferroni correction was $p<0.013$ (0.05/4).

Results

Forty-five persons were included, 44 (IQR=30–56) years old, 87% men, 67% paraplegia and 64% with motor complete lesions. The median time since injury was 128 (IQR=90–173) days, median time in rehabilitation 84 (IQR=59–125) days and the cause of the lesion was traumatic in 68% of participants.

Forty-one participants (91%) completed the training. Training was not completed by four participants due to: severe pressure ulcers and therefore bed rest (n=2), forced discharge before start of training (n=1), and dislike of training (n=1). Three participants who did not complete the training had paraplegia, and all had complete lesions. No adverse events related to handcycle training were reported.

Table 6.1 Training frequency and training intensity

	Training frequency (sessions/a week)	Training intensity (Borg)
Total group, Median(IQR), n=30	1.9 (1.4–2.2)	6.5 (5.1–7.4)
Paraplegia, n=20	1.9 (1.3–2.2)	6.0 (4.4–6.9)
Tetraplegia, n=10	1.9 (1.7–2.2)	7.0 (6.4–7.9)
Mann-Whitney U	U=88.0, p=0.62	U=53.0, p=0.04
Effect size r†	0.1	0.4
Incomplete lesion, n=12	2.1 (1.9–6.8)	7.4 (6.8–8.1)
Complete lesion, n=18	1.7 (1.1–2.0)	5.7 (4.3–6.4)
Mann-Whitney U	U=52.0, p=0.02	U=27.0, p<0.01*
Effect size r†	0.4	0.6

IQR, interquartile range; * indicates significant difference p<0.013; † r=Z/√n.

Of the remaining 41 participants, training journals were available for 30 participants. Training journals were missing because of change in trainers (n=5), inaccuracies of trainer (n=4) or lost by participant (n=2). The maximal handcycle test was performed before and after training by 23 participants. Data were missing due to contraindications for maximal exercise (n=13) or logistic reasons (n=5).

Table 6.1 shows training frequency and intensity for all participants and subgroups. The intended training frequency (≥2x/week) was not met by 50% of the total group, when described in lesion completeness subgroups: 33% of the incomplete and 61% of the complete subgroup. Intensity was as intended or higher than intended in 93% of participants. Evaluation forms showed that 80% of participants enjoyed training. Participants were mostly satisfied with training frequency (88%). Training intensity was rated as good by 74% of participants, too high by 11% and too low by 16%. About half of participants were satisfied with starting training eight weeks before discharge, whereas 44% would have preferred to start training earlier. The total training program duration was rated as good by 63%, with the remaining 37% reporting preference for a longer training period.

Physical capacity results are presented in Table 6.2.

Discussion

Overall feasibility was good except for training frequency. Main reasons for missed training sessions seemed to be logistic reasons such as conflicting therapy, hospital visit or unavailability of trainer. When implementing handcycle training in regular rehabilitation

Table 6.2 Results on physical capacity before and after training, of the total groups and of subgroups based on lesion characteristics, median (IQR)

	n	T1 8 weeks before discharge	T2 At discharge	Wilcoxon	% improvement[1]
POpeak in Watt	23	40.2 (24.9–57.1)	54.8 (36.3–76.1)	T=264.0, p<0.01*	36.4
POpeak in Watt/kg	23	0.6 (0.4–0.8)	0.8 (0.3–1.1)	T=263.0, p<0.01*	27.2
Paraplegia	13	0.8 (0.6–1.0)	1.1 (0.8–1.3)		
Tetraplegia	10	0.4 (0.2–0.5)	0.4 (0.3–0.8)		
Incomplete lesion	9	0.5 (0.2–0.7)	0.8 (0.3–1.1)		
Complete lesion	14	0.7 (0.4–0.9)	0.9 (0.4–1.08)		
VO_2peak in L/min	20	1.1 (0.9–1.4)	1.2 (1.0–1.7)	T=188.0, p<0.01*	9.6
VO_2peak in ml/kg/min	20	16.5 (12.2–22.4)	18.2 (14.1–26.0)	T=178.0, p<0.01*	9.9
Paraplegia	12	18.5 (16.5–25.5)	20.6 (17.1–27.1)		
Tetraplegia	8	12.5 (10.2–15.1)	13.3 (10.4–18.6)		
Incomplete lesion	8	15.0 (11.2–22.9)	17.8 (10.7–28.0)		
Complete lesion	12	17.1 (12.7–22.4)	18.2 (14.5–25.3)		

IQR, interquartile range; * indicates significant difference p<0.013; [1] Percentage improvement based on medians.

it could be considered to reschedule missed sessions or continue training after clinical discharge for optimal benefit of training.

Lower feasibility in persons with complete lesions might be caused by the higher prevalence of secondary complications such as urinary tract infections and pressure ulcers in this subgroup.[8] Persons with complete lesions likely need extra attention to benefit optimally from handcycling training.

Further research is necessary on ratings of perceived exertion in untrained persons. Previous research was performed in athletes with SCI and found, in contrast to the present study, that persons with tetraplegia reported lower ratings of perceived exertion even at moderate-high exercise intensities.[6]

Participants were generally satisfied with the handcycle training but common preferences were to start earlier during inpatient rehabilitation and continue the training period longer. Starting training in an earlier phase needs further study on feasibility. There is initial evidence from a previous study that starting training earlier is safe.[4]

The combination of handcycle training and regular rehabilitation resulted in a larger increase in physical capacity when compared to improvements of around 10% previously reported for persons with paraplegia receiving regular rehabilitation only.[9] Previous handcycling training studies reported gains of 20% in VO_2peak and 36% in POpeak in persons with subacute SCI[4] and 8% in VO_2peak and 20% in POpeak in persons during the chronic phase.[10] Therefore, in consideration of the difficulties in comparing our results to previous studies, our study seems to suggest that handcycle training is effective in improving physical capacity in persons with subacute SCI.

Study limitations

Although we have no reason to believe that feasibility was lower in participants for whom data were missing, we must be careful when interpreting training frequency and training intensity results.

Conclusion

Overall, handcycle training during inpatient rehabilitation in persons with SCI was feasible except for the training frequency. Persons with complete lesions likely need extra attention

to benefit optimally from handcycling training. Since the improvements in physical capacity were larger than those known to occur in persons with paraplegia receiving regular rehabilitation the results suggest that the addition of handcycle training may result in larger increases in physical capacity compared to regular rehabilitation only.

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Suppliers list

[a] Tacx, Wassenaar, The Netherlands and Double Performance, Gouda, The Netherlands.
[b] Jaeger, Hoechberg, Germany.

Chapter 7

A behavioral intervention leads to a more active lifestyle in persons with subacute spinal cord injury: a randomized controlled trial

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Abstract

Background: Physical activity levels are known to decline in persons with spinal cord injury (SCI) after discharge from inpatient rehabilitation.

Objective: To evaluate the effects of a behavioral intervention promoting an active lifestyle after discharge.

Design: Randomized controlled trial.

Setting: Four Dutch rehabilitation centers.

Patients: Thirty-nine persons with subacute SCI (33% tetraplegia, 62% motor complete, 150±74 days post injury), dependent on a manual wheelchair.

Intervention: The intervention and control group both received regular rehabilitation including a handcycle training program. Only the intervention group received a behavioral intervention, involving 13 individual sessions beginning two months before and ending six months after discharge, delivered by a coach trained in motivational interviewing.

Measurements: At baseline, discharge, six and 12 months after discharge from inpatient rehabilitation. Outcome measures were objectively measured physical activity with an accelerometer-based activity monitor and self-reported physical activity.

Results: An overall intervention effect was found for objectively measured wheeled physical activity ($B=0.35$, $p<0.01$). Compared to the control group, the intervention group was 50% more physically active (0.47 more hours of activity per 24-hour period; $p<0.01$) six months after discharge and maintained this higher level 12 months after discharge ($B=0.42$ hours, $p=0.06$). No significant intervention effect was found for sedentary daytime periods longer than 30 minutes ($B=-0.57$, $p=0.29$). Self-reported physical activity showed an overall significant intervention effect ($B=20.26$, $p<0.01$).

Limitations: Missing values and drop-outs.

Conclusion: The behavioral intervention was effective in eliciting a behavioral change toward a more active lifestyle among persons with subacute SCI. Addition of the behavioral intervention resulted in more physical activity half year after discharge from inpatient rehabilitation as well as continuation of the more active lifestyle up to one year after discharge.

Introduction

Persons with spinal cord injury (SCI) in inpatient rehabilitation are physically active during therapy sessions. However, after discharge from inpatient rehabilitation, daily physical activity levels are known to decline to a level that is severely low compared to the general population and also low compared to persons with other chronic diseases.[1, 2] In addition to maintaining sufficient physical activity, interposing of breaks in sedentary time is another independent aspect of physical behavior that is thought to be important for optimal health.[3, 4] More physical activity is known to reduce the risk of cardiovascular disease, prevent or reduce secondary conditions, and improve physical fitness and quality of life in persons with SCI.[5, 6] Thus, it seems important to prevent the decline in physical activity level and promote an active lifestyle in the home situation of persons with subacute SCI.

Physical capacity can be regarded as a prerequisite for an active lifestyle. Higher physical capacity may allow individuals to perform activities in daily life more proficiently, faster, with less difficulty and for longer periods.[7] Nevertheless, persons with SCI often have poor physical capacity.[8] In recent years it has become increasingly recommended to attain the highest possible physical capacity level during inpatient rehabilitation.[5, 9] However, higher physical capacity may not automatically lead to a more active lifestyle; a behavioral change may also be needed.[10]

To achieve a change in behavior, behavioral interventions are thought to be necessary. Previous studies in persons with SCI have tended to show positive effects of behavioral interventions on physical activity.[11-16] However, all those studies were performed in persons with SCI in the chronic phase. Furthermore, only one study[13] used objective measures of physical activity; the others used self-reported measures, which might cause bias.[17] Moreover, only two of six studies[14, 15] reported on long-term effects, which is a limitation since it seems clinically relevant to evaluate whether the new behavior was maintained after the intervention.

The goal of the present study was to evaluate the added value of a behavioral intervention on top of a physical exercise intervention in persons with subacute SCI. The main outcome measure was physical activity both in the short and long term. We hypothesized that physical exercise alone would not automatically lead to a more active lifestyle and that the addition of a behavioral intervention is necessary. The primary outcome measure of this study was objectively measured physical activity using an accelerometer-based activity monitor. Secondarily, the effects on self-reported physical activity were studied. Effects of

the intervention on the secondary outcome measures physical capacity, health, participation, and quality of life, will be presented in a separate publication.

Methods

Design overview

This study, named Act-Active, was a single-blind multi-center randomized controlled trial. Research assistants performing the measurements were blinded for group allocation. This trial was carried out in four Dutch rehabilitation centers with specialized SCI-units: Rijndam Rehabilitation Institute in Rotterdam, Adelante in Hoensbroek, Heliomare in Wijk aan Zee and Hoogstraat in Utrecht. The study was prospectively registered at the Dutch trial register: NTR2424.

Setting and participants

Participants were enrolled during inpatient rehabilitation. Persons were eligible if they met the following inclusion criteria: diagnosed with SCI, initial inpatient rehabilitation, dependent on a manual wheelchair, able to handcycle, and between 18 and 65 years old. Persons were excluded if they did not have sufficient comprehension of the Dutch language to understand the purpose of the study and its testing methods, or in case of a progressive disease or a psychiatric condition that could interfere with participation. Written informed consent was provided by all participants. The Medical Ethics Committee of Erasmus Medical Center Rotterdam, The Netherlands, approved the protocol of this study, and all participating centers granted local approval.

Randomization and intervention

Participants were randomized into two groups: an intervention group and a control group. To obtain equally distributed groups with regard to motor loss, randomization was performed in four strata based on lesion level (tetraplegia–paraplegia) and completeness (motor complete–motor incomplete). Tetraplegia was defined as a lesion at or above the Th1 segment, and paraplegia as a lesion below Th1. A complete lesion was defined as motor complete, AIS grade A or B, and an incomplete lesion as AIS grade C or D, according to international standards.[18] Random group allocation (1:1) was performed for each participating center and within each stratum. Participants were assigned in chronological order of enrolment.

Prior to the inception of Act-Active, rehabilitation programs in the participating rehabilitation centers were not comparable with regard to physical capacity training.[19] Because previous studies have demonstrated a longitudinal relationship between physical activity and physical capacity in persons with subacute SCI,[6, 7] standardization of physical capacity training was thought to be necessary. Therefore, participants of both the control and intervention groups performed a structured handcycle training program during the last eight weeks of inpatient rehabilitation. The training was scheduled 3 times per week and consisted of an interval training protocol[20] on an add-on handcycle provided by the rehabilitation center. Details of the handcycle training and results on physical capacity have been described elsewhere.[21]

Only the intervention group received an additional behavioral intervention. The aim of this intervention was to increase the amount of daily physical activity after inpatient rehabilitation. The intervention consisted of 13 individual sessions with a coach, with a maximum duration of one hour. Sessions were performed face-to-face and in some cases via the telephone (for practical reasons) after discharge from inpatient rehabilitation. Two sessions were planned every month beginning two months prior to discharge until three months after discharge from inpatient rehabilitation, and during the following three months there was one session a month. The coach was a physical therapist or occupational therapist and all coaches were trained in motivational interviewing, as based on the transtheoretical model. Motivational interviewing has been shown to be the most effective approach for altering behavior,[22] and there is evidence to support the clinical utility of this technique to increase physical activity in persons with chronic health conditions.[23] Each session began with the participant composing a program for that session in agreement with the coach. The behavioral intervention consisted of four main components. First, feedback on daily wheelchair activity using bicycle odometers. A bicycle odometer was attached to each participant's wheelchair and registered the amount of kilometers traveled per day. The participant was instructed to keep track of and to set goals to increase the distance traveled. The second component was formulating action plans on how and when to be physically active. In addition, coping strategies were formulated for dealing with barriers that could hinder the actual performance of an action plan.[12] A third component was a home visit by the coach in the first month after discharge from inpatient rehabilitation. During this visit the coach helped to optimize the home environment of the participant for an active lifestyle. Lastly, additional information was provided at the request of the participant about relevant topics related to physical activity such as possible health benefits.

Outcomes and follow-up

Measurements were performed on four occasions: (T1) – two months before discharge from inpatient rehabilitation, which was before the start of the interventions; (T2) – one or two weeks before discharge from inpatient rehabilitation; (T3) – six months after discharge from inpatient rehabilitation, which was after completion of the behavioral intervention; and (T4) – one year after discharge from inpatient rehabilitation.

Objective measurement of physical activity

Physical activity was measured objectively with an ambulatory monitoring system, VitaMove (Figure 7.1) (2M Engineering, Veldhoven, The Netherlands), with body-fixed three-axis accelerometers (Freescale MMA7260Q, Denver, USA). This activity monitor was found to be valid to quantify mobility-associated activities and postures and to detect intergroup differences in physical activity, including in persons with SCI.[24-26] The system consists of three recorders which are wirelessly connected and synchronized every 10 seconds. One recorder was attached to each wrist and a third recorder to the sternum, with specially developed belts. The activity monitor was worn continuously for 96 hours on four consecutive weekdays

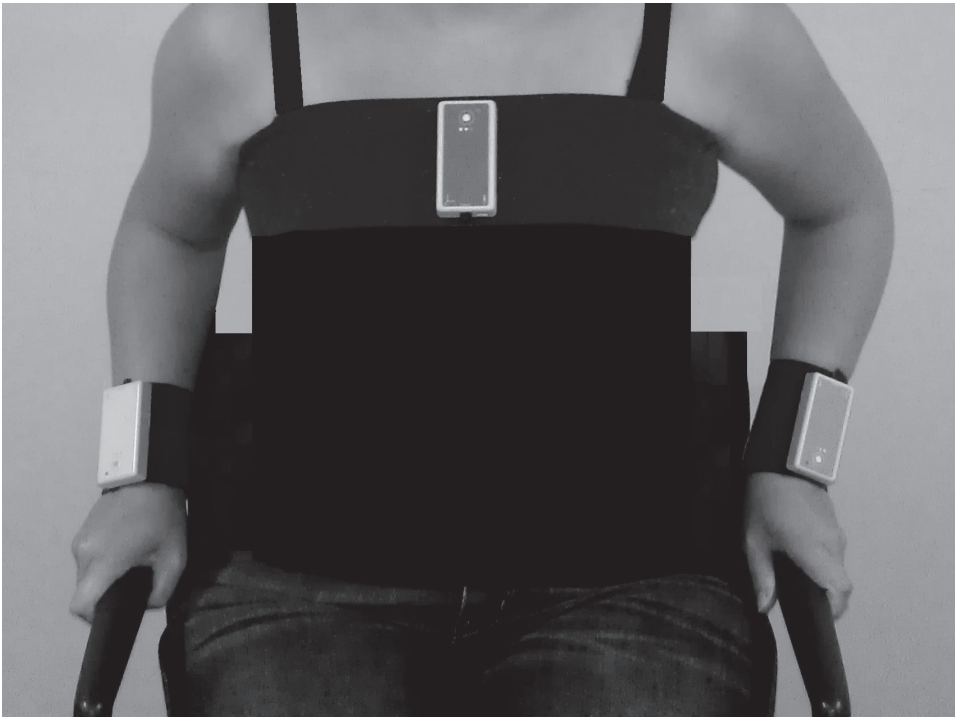

Figure 7.1 VitaMove activity monitor.

during all activities, except swimming, bathing and sleeping. We asked participants to note the time and duration of swimming in a diary such that we could correct these periods manually. To avoid measurement bias, we instructed the participants to continue their ordinary daily life activities and therapy, and the principles of the activity monitor were explained only after finishing the study. Accelerometer signals of each recorder were sampled and stored digitally on a micro Secure Digital memory card. Measurements were uploaded to a computer for kinematic analysis using VitaScore Software (VitaScore BV, Gemert, The Netherlands). Details of the configuration and analysis have been described elsewhere.[25, 26]

The following data were obtained:

1. Total duration of wheeled physical activity, including wheelchair propulsion and handcycling in hours, per 24-hour period.
2. Total duration separately for wheelchair propulsion and handcycling in hours, per 24-hour period.
3. Distribution of wheelchair propulsion bouts (0–10 seconds, 10–60 seconds and 1–10 minutes).
4. Total duration of sedentary daytime bouts longer than 30 minutes, including sitting and lying without interruption by physical activity for a minimum of 5 seconds, in hours, per 24-hour period.
5. Mean motility per 24-hour period. Motility is based on the variability of the accelerometer signal of the trunk and arm recorders and is a measure of intensity and duration of all movement, expressed in gravitational force (g).

Self-reported physical activity level

Self-reported physical activity levels were measured with the Dutch version of the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD), a 13-item, 7-day recall questionnaire developed for people with a physical disability.[27] The scale consists of questions regarding leisure time, household-related and work-related physical activity. The total PASIPD score was calculated by multiplying the average hours per day for each item by a given metabolic equivalent (MET) value associated with the intensity of the activity. Because the questionnaire is not suitable for persons in inpatient rehabilitation, self-reported physical activity was only measured at T3 and T4.

Statistical analysis

Forty-two participants were required to detect a 30-minute per 24-hour period difference in objectively measured wheeled physical activity between the intervention group and the control group, with a power of 0.8 and an alpha of 0.05. We aimed to recruit 60 participants to allow for drop-outs. The power analysis was based on a previous study at our department on the physical activity level of persons with subacute SCI.[1] The power analysis did not consider repeated measurements or missing values. Independent t-tests and Chi-square tests were used to test for differences in personal characteristics, lesion characteristics and baseline physical activity between the drop-outs of both groups.

To determine the additional effects of the behavioral intervention, Generalized Estimating Equation (GEE) analyses with exchangeable correlation structures were performed. First, we made overall models for each outcome variable, including group allocation and baseline values of the particular outcome variable. Then, we assessed the between-group differences for the three follow-up measurements (T2, T3 and T4) by adding time and an interaction variable between group allocation and time to the overall models. We presented the B, p and confidence intervals for the crude models, and the models were adjusted for rehabilitation center, sex and age. The B of the overall model represents the between-group difference over all measurements, and the B at the specified measurement time represents the between-group difference at that measurement. The control group was the reference group for all analyses. In case of missing values at baseline, data of the particular participant from the second measurement were imputed to the baseline measurement of that participant. No baseline measurements were available for self-reported physical activity and therefore baseline corrections were performed using the T1 data of objectively measured physical activity. SPSS version 21 was used for all analyses.

Results

Between January 2011 and August 2013, 45 persons with subacute SCI were included. Figure 7.2 shows the flow diagram of inclusion. Three persons in both the intervention group and the control group dropped out before the second measurement and were therefore excluded from analysis. Baseline personal and lesion characteristics of the remaining 39 participants are presented in Table 7.1. Participants completing the behavioral intervention attended 73% of sessions on average. Drop-outs in the intervention group (n=12) and in the control group (n=11) did not differ significantly in terms of personal or lesion characteristics and physical activity at baseline.

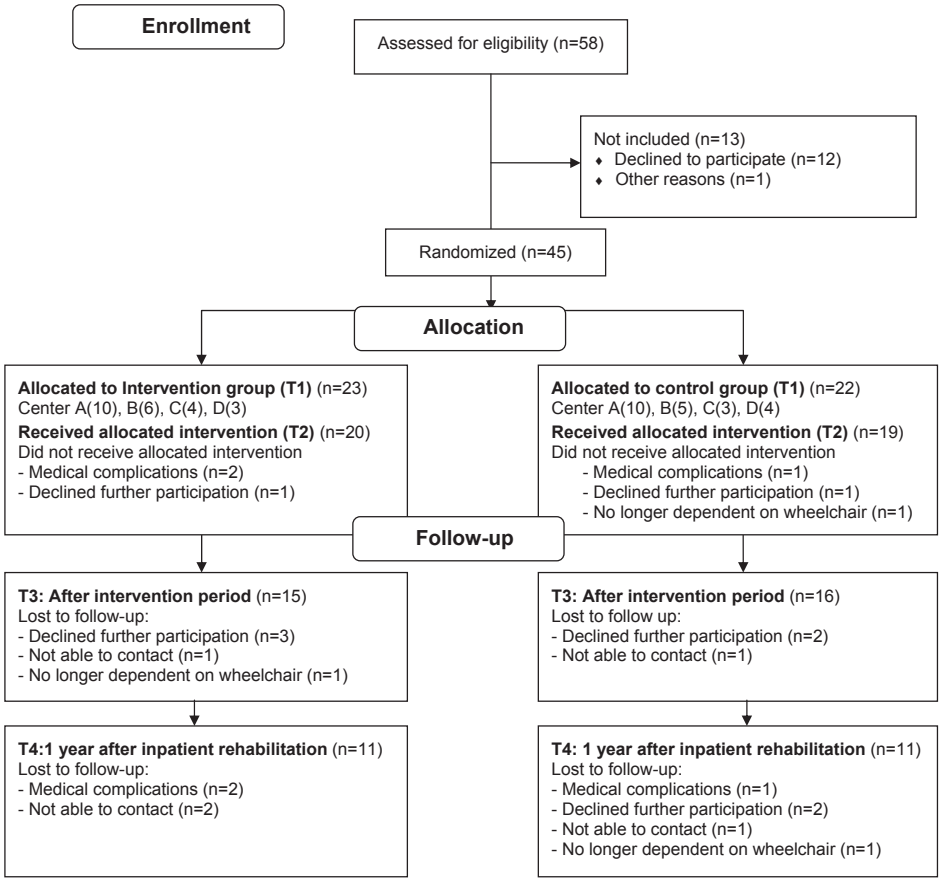

Figure 7.2 CONSORT flow diagram of study participation.

Table 7.1 Characteristics of participants at baseline

	Intervention group	Control group
	n=20	n=19
Personal characteristics		
Age in years, mean±SD	44±15	44±15
Sex, n (%) men	17 (85)	16 (84)
Lesion characteristics		
Lesion level, n (%) tetraplegia	7 (35)	6 (32)
Completeness, n (%) motor complete	13 (65)	11 (58)
Days since injury, mean±SD	139±67	161±81
Days since admission, mean±SD	104±64	108±60
Cause, n (%) traumatic	14 (70)	12 (63)

Average measurement duration with the activity monitor was 65±26 hours. Due to logistic and technical reasons, the intended measurement duration of 96 hours was not always met. Minimum duration of a measurement was 24 hours.[28] A total of 112 activity monitor measurements were available (35 at T1, 30 at T2, 27 at T3 and 20 at T4). Two measurements at T1 were missing due to logistic problems, five measurements at T2 were missing due to unexpected early discharge from inpatient rehabilitation, two T2 measurements and one T3 measurement were not available due to technical problems and 10 measurements (2 at T1, 3 at T2, 3 at T3, and 2 at T4) were not available because the participant did not wear the activity monitor for at least 24 hours.

Intervention effects

Figure 7.3 graphically presents the observed data of objectively measured wheeled physical activity, sedentary daytime bouts longer than 30 minutes, motility, and self-reported physical activity. The modeled data are presented in Table 7.2. Overall intervention effects were found for wheeled physical activity, wheelchair propulsion, handcycling and self-reported physical activity. Compared to the control group, the intervention group was 28 minutes (B=0.47 hours, p<0.01) more physically active per 24-hours directly after the intervention (T3) and 25 minutes per 24-hours (B=0.42 hours, p=0.06) more physically active one year after discharge (T4). For wheelchair propulsion the intervention effect was largest at T3 (B=0.33, p<0.01) and for handcycling at T4 (B=0.27, p=0.07). Analyses of wheelchair propulsion bouts showed that the largest overall intervention effect was for bouts of 10-60 seconds (B=0.14 hours, p<0.01).

In the intervention group, none of the participants had a physical activity level lower than 0.50 hours per 24-hours at T3, whereas in the control group there were seven participants (50%) with an activity level lower than 0.50 hours per 24-hour period. At T4 there was one person (10%) in the intervention group and four (40%) persons in the control group with activity levels lower than 0.50 hours per 24 hours (data not shown).

Discussion

To our knowledge this was the first study to assess the added value of a behavioral intervention on objectively measured physical activity in persons with subacute SCI. The addition of a behavioral intervention was successful in preventing the decline in physical activity level after discharge[1] and resulted in 50% more wheeled physical activity. Moreover, the more active lifestyle was maintained for one year after discharge from inpatient rehabilitation.

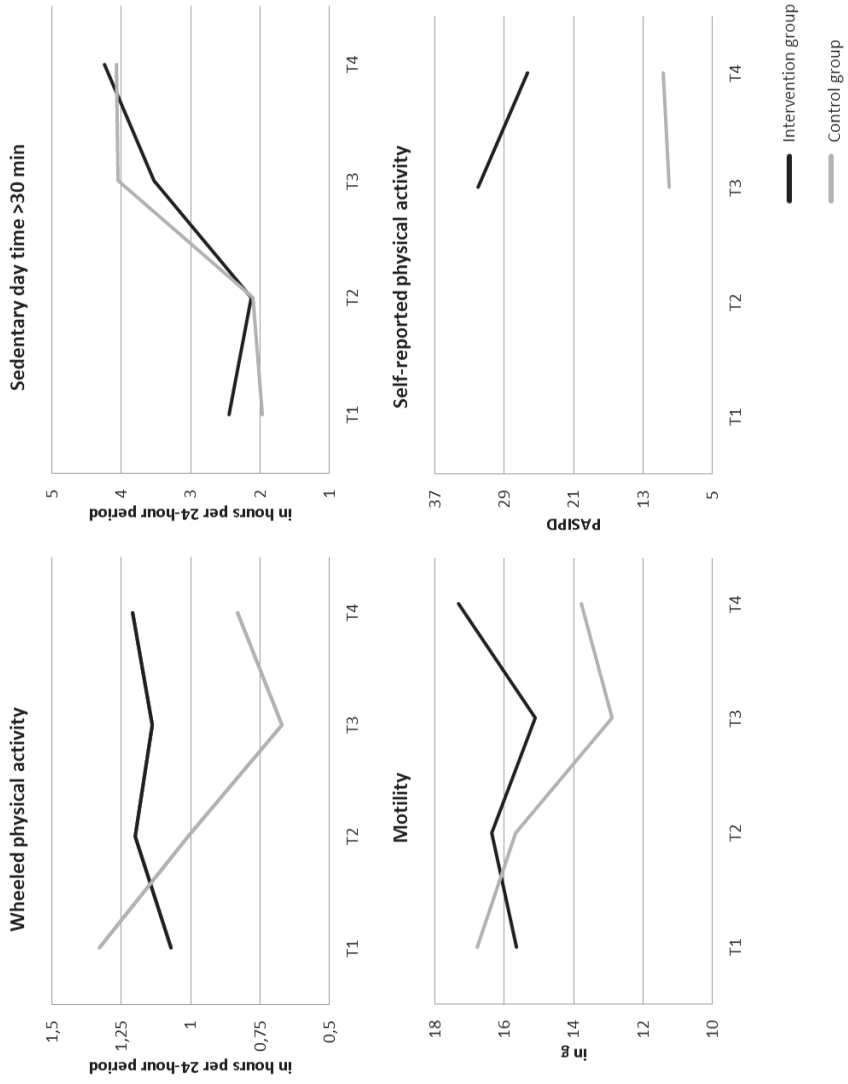

Figure 7.3 Observed data for objectively measured physical activity, sedentary daytime bouts longer than 30 minutes, motility and self-reported physical activity.

Table 7.2 GEE models for objectively measured and self-reported physical activity

			Crude				Adjusted†			
			B	p	95% CI		B	p	95% CI	
Wheeled physical activity (in hours per 24-hour period)		Overall	0.36	<0.01*	0.10	0.62	0.35	<0.01*	0.13	0.58
		T2	0.17	0.07	-0.13	0.35	0.17	0.05*	0.00	0.33
		T3	0.48	<0.01*	0.12	0.84	0.47	<0.01*	0.14	0.80
		T4	0.43	0.07	-0.04	0.90	0.42	0.06	0.01	0.84
Wheelchair propulsion (in hours per 24-hour period)		Overall	0.22	<0.01*	0.06	0.39	0.22	<0.01*	0.06	0.38
		T2	0.15	0.05*	0.00	0.31	0.15	0.04*	0.01	0.30
		T3	0.33	<0.01*	0.09	0.58	0.33	<0.01*	0.09	0.57
		T4	0.13	0.40	-0.17	0.42	0.13	0.38	-0.15	0.40
	0–10 sec	Overall	0.04	0.02*	0.01	0.06	0.03	0.02*	0.01	0.06
		T2	0.02	0.08	-0.00	0.05	0.03	0.08	-0.00	0.05
		T3	0.08	0.02*	0.02	0.14	0.08	0.01*	0.02	0.13
		T4	0.00	0.93	-0.05	0.05	0.00	0.87	-0.05	0.05
	10–60 sec	Overall	0.14	0.01*	0.03	0.24	0.14	<0.01*	0.04	0.24
		T2	0.08	0.07	-0.01	0.17	0.09	0.07	-0.01	0.19
		T3	0.22	<0.01*	0.06	0.38	0.23	<0.01*	0.08	0.38
		T4	0.07	0.46	-0.12	0.26	0.07	0.42	-0.11	0.25
	1–10 min	Overall	0.05	0.05*	0.00	0.09	0.04	0.06	-0.00	0.08
		T2	0.05	0.26	-0.04	0.13	0.04	0.24	-0.03	0.11
		T3	0.05	0.10	-0.01	0.11	0.04	0.22	-0.02	0.09
		T4	0.03	0.39	-0.04	0.11	0.03	0.45	-0.05	0.10

Handcycling (in hours per 24-hour period)	Overall	0.13	0.08	-0.02	0.28	0.14	0.02*	0.02	0.25
	T2	-0.01	0.93	-0.13	0.12	0.02	0.79	-0.12	0.16
	T3	0.16	0.18	-0.07	0.39	0.15	0.16	-0.06	0.36
	T4	0.28	0.10	-0.05	0.61	0.27	0.07	-0.02	0.57
Sedentary >30 min (in hours per 24-hour period)	Overall	-0.66	0.28	-1.84	0.53	-0.57	0.29	-1.61	0.48
	T2	-0.36	0.36	-1.15	0.42	-0.24	0.61	-1.15	0.67
	T3	-0.94	0.25	-2.54	0.66	-0.84	0.24	-2.23	0.55
	T4	-0.34	0.71	-2.12	1.43	-0.35	0.67	-1.98	1.28
Motility (in g)	Overall	1.74	0.11	-0.42	3.90	1.24	0.10	-0.25	2.73
	T2	0.32	0.72	-1.43	2.07	0.06	0.96	-2.15	2.27
	T3	2.05	0.25	-1.43	5.54	1.75	0.21	-1.01	4.52
	T4	3.17	0.09	-0.50	6.85	1.98	0.14	-0.65	4.61
Self-reported physical activity (PASIPD)	Overall	19.78	<0.01*	6.60	32.97	20.26	<0.01*	7.61	32.92
	T2	-	-	-	-	-	-	-	-
	T3	21.78	0.02*	4.12	39.44	21.45	0.01*	5.17	37.73
	T4	17.04	<0.01*	6.42	27.66	18.51	<0.01*	7.35	29.66

† Adjusted for rehabilitation center, sex, and age.
T2 at discharge, T3 6 months after discharge and T4 1 year after discharge from inpatient rehabilitation.

Although the behavioral intervention resulted in more wheeled physical activity, the mean activity level in the intervention group was still only 1 hour and 13 minutes per 24-hours. It seems that the behavioral intervention had the effect of preventing persons with subacute SCI from attaining a very inactive lifestyle. Compared to the general population, the mean physical activity level of our intervention group was still only 50% of that of the general population.[2] Possibly, physical strain is higher in persons with SCI. Furthermore, for this group, daily self-care is already time-consuming and a strenuous everyday activity,[29] leaving less time and energy for dynamic activities. Unfortunately, physical strain was not assessed in the present study. Future research on behavioral interventions should study physical strain and its relationship with physical fitness and health in persons with subacute SCI.

The behavioral intervention had little focus on sedentary time during the day. This might explain the relatively small between-group differences on this outcome measure. Focusing more on breaking up long periods of sedentary daytime might optimize the intervention. However, breaking up sedentary time in persons who are wheelchair-dependent is difficult because sitting less is not possible. It is unknown for this group what type, intensity and duration of activity are necessary to break up sedentary time for health benefits.[4] Future studies should focus more on sedentary time in relationship to health benefits in persons who are wheelchair-dependent.

Of the previous studies performed in persons with SCI in the chronic phase, only one study used an objective measure of physical activity and found no significant effect of the intervention.[13] When comparing our objective and self-reported between-group effects, the effect on the self-reported measure confirmed our objective results but was relatively much larger (100% vs 50% of the mean). This confirms previous findings, that self-reported measures overestimate changes in physical activity level.[17] Therefore, especially in intervention studies where self-reported outcomes could be biased by socially desirable answers, one should be careful to draw strong conclusions from questionnaires on physical activity. Several previous studies on behavioral interventions based on motivational interviewing in other groups of persons with a physical disability (non-SCI) and using objective outcome measures reported no long-term significant effects of a behavioral intervention on physical activity.[30-33]

Limitations

This study on the effects of a behavioral intervention assessed physical activity objectively at four time points in a vulnerable group of persons with subacute SCI. The main limitations

in our study were the small sample size, missing values and drop-outs. However, despite these limitations, we found significant between-group differences in our primary outcome measure. Based on inclusion rates in a previous cohort study, we expected to be able to enrol more participants.[34] Possibly it is more difficult to include persons in a randomized controlled trial. Furthermore, lesion characteristics and age have changed over the last 15 years.[35, 36] Relatively more persons have incomplete lesions now and are therefore less likely to be wheelchair-dependent. In addition, relatively more persons were older than 65 years, and therefore did not meet our inclusion criteria.

Measuring physical activity objectively with the VitaMove activity monitor has limitations. First, due to technological challenges or user errors, the intended measurement period of four days was not always achieved. Secondly, for logistic reasons and to facilitate comparison of the measurements during inpatient rehabilitation and after discharge, we choose to take measurements on weekdays only. Therefore, it is unknown what effect our intervention had on weekend physical activity. Furthermore, the season of the year is known to influence the level of physical activity;[37] however, our study spanned 2.5 years over all four seasons and the participants were randomly allocated 1:1 to the intervention and control groups, so no effects of season on between-group differences were expected.

Conclusion

A behavioral intervention consisting of 13 individual sessions with a coach was effective in eliciting a behavioral change toward a more active lifestyle among persons with subacute SCI. Addition of a behavioral intervention to regular rehabilitation and handcycle training resulted in 50% more wheeled physical activity. In order to promote an active lifestyle in this population generally known to be inactive and at risk for health complications, we advise to add a behavioral intervention to the regular care of persons with subacute SCI.

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Chapter 8

A behavioral intervention promoting physical activity in persons with subacute spinal cord injury: secondary effects on health, participation and quality of life

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Abstract

Question: To evaluate the effects of a behavioral intervention promoting physical activity in people with subacute spinal cord injury (SCI) on secondary outcomes health, participation and quality of life.

Design: Randomized controlled trial.

Participants: Thirty-nine participants analysed (45 included), with subacute SCI in inpatient rehabilitation, dependent on a manual wheelchair (33% tetraplegia, 62% motor complete, 150±74 days post injury).

Intervention: All participants received regular rehabilitation which included a handcycle training program. Only the intervention group received a behavioral intervention promoting an active lifestyle after discharge. This intervention involved 13 individual sessions delivered by a coach trained in motivational interviewing, beginning two months before and ending six months after discharge from inpatient rehabilitation.

Outcome measures: Health-related outcomes were: physical capacity as determined during a maximal exercise test, body mass index (BMI), blood pressure and fasting lipid profile. Furthermore, participation and quality of life were determined using questionnaires. Measurements were performed two months before discharge, at discharge, and six and 12 months after discharge from inpatient rehabilitation. B represents the between-group difference.

Results: Twelve months after discharge, significant intervention effects were found for diastolic blood pressure (B=-11.35 mmHg, p=0.01, 95%CI=-19.98–-2.71), total cholesterol (B=-0.89 mmol/L, p=0.01, 95%CI=-1.59–-0.20), LDL (low-density lipoprotein cholesterol; B=-0.63 mmol/L, p=0.05, 95%CI=-1.25–-0.00) and participation (B=9.91, p<0.01, 3.34–16.48).

Conclusion: A behavioral intervention promoting an active lifestyle seems to improve health and participation in people with subacute SCI. Therefore, we advise to add a behavioral intervention to regular care.

Introduction

Spinal cord injury (SCI) is a chronic condition that causes paralysis and leads to multiple secondary complications.[1] Compared to the general population, people with SCI are more likely to be overweight[2] and have an increased risk of cardiovascular disease and type II diabetes.[3] Physical capacity is defined as the ability to perform activities of daily living and leisure, determined by the capacities of the physiological system and the neuromuscular system.[4] Higher physical capacity is related to less secondary complications.[5] Over the last years, it has been increasingly recommended that people with SCI attain the highest possible physical capacity during rehabilitation.[1]

To stay physically fit, maintaining an active lifestyle after discharge from inpatient rehabilitation seems important for people with SCI.[6] However, physical activity levels are known to be generally low in this group and therefore interventions seem necessary.[7] Although exercise interventions may increase physical capacity and allow to perform activities in daily life easier and faster for longer periods, such efforts may not automatically lead to a more active lifestyle.[8] The addition of behavioral interventions is thought to be needed. During the first months after SCI (subacute phase), people establish a new routine and therefore this period might be critical to introduce and encourage new habits that incorporate physical activity.

The addition of a behavioral intervention to regular care, including handcycle training, was found to be effective in eliciting a behavioral change towards a more physically active lifestyle in persons with subacute SCI. Addition of the behavioral intervention resulted in 50% more physical activity half year after discharge from inpatient rehabilitation as well as continuation of the more active lifestyle up to one year after discharge. More details on the effect of the intervention on physical activity (primary outcome) are presented in a separate publication.[9] Effects of a behavioral intervention on health-related outcomes in persons with subacute SCI are unknown. Furthermore, no previous study has assessed the effects of a behavioral intervention promoting physical activity on participation and quality of life in people with SCI. The clinical relevance of the intervention effect is increased when accompanied by evidence on these outcomes.[10]

Two previous randomized controlled trials in people with SCI in the chronic phase and in inactive wheelchair users assessed the effects of a behavioral intervention on health-related outcomes.[11,12] One randomized controlled trial in 128 inactive wheelchair users including 59 persons with SCI, comparing a self-guided and a staff-supported group, found no effects on

physical capacity and body weight.[11] Another randomized controlled trial in 43 adults with SCI, in which the intervention group attended wellness workshops, also found no significant effects on body mass index (BMI), physical capacity and total cholesterol.[12]

The goal of the present study was to evaluate in people with subacute SCI, the added value of a behavioral intervention promoting physical activity, on top of regular rehabilitation including handcycle training, on the secondary outcomes health, participation and quality of life. Health-related outcomes were: physical capacity, BMI, blood pressure and lipid profile. Both short- and long-term effects were assessed. We hypothesized that the addition of a behavioral intervention is necessary to achieve and maintain improved health, participation and quality of life.

Methods

Study design

A single-blind, multi-center, randomized controlled trial (RCT) named Act-Active. Research assistants who performed the measurements were blinded for group allocation. The RCT was prospectively registered at the Dutch trial register: NTR2424.

Participants, therapists, centers

Four Dutch rehabilitation centers with specialized SCI-units were involved: Rijndam Rehabilitation Institute in Rotterdam, Adelante in Hoensbroek, Heliomare in Wijk aan Zee, and Hoogstraat in Utrecht. Participants were enrolled during inpatient rehabilitation by research assistants at the rehabilitation centers. Inclusion criteria were: diagnosed with SCI, initial inpatient rehabilitation, dependent on a manual wheelchair, able to handcycle, and between 18 and 65 years old. Exclusion criteria were: not sufficient comprehension of the Dutch language to understand the purpose of the study and its testing methods, and progressive disease or a psychiatric condition that could interfere with participation. All participants provided written informed consent. The Medical Ethics Committee of Erasmus Medical Center Rotterdam, The Netherlands, approved the protocol of this study, and all participating centers granted local approval.

Participants were randomized to an intervention or control group by the first author of this manuscript by a concealed allocation procedure. Randomization was stratified by level of injury (tetraplegia-paraplegia) and completeness of injury (motor complete-motor

incomplete). A lesion between C5 and T1 segment was defined as tetraplegia, and a lesion below T1 as paraplegia. A motor complete lesion was defined as AIS grade A or B, a motor incomplete lesion as AIS grade C or D.[13] Block randomization was by a computer generated random number list prepared by an investigator with no clinical involvement in the trial. Random group allocation (1:1) was performed for each rehabilitation center and within each stratum. Participants were assigned in chronological order of enrolment.

Intervention

All participants of the control and intervention groups performed a structured handcycle training program during the last eight weeks of inpatient rehabilitation. This handcycle training was scheduled three times per week and consisted of an interval training protocol on an add-on handcycle. Details of this handcycle training program and effects on physical capacity have been described elsewhere.[14]

Only participants in the intervention group received an additional behavioral intervention. This intervention aimed at increasing the amount of everyday physical activity after discharge from inpatient rehabilitation. Thirteen individual face-to-face sessions with a coach were planned, each session having a maximum duration of one hour. For practical reasons, some sessions after discharge were conducted via the telephone. Two sessions were scheduled per month beginning two months before discharge and ending three months after discharge; thereafter, in the following three months there was one session per month. The coach was an occupational therapist or physical therapist trained in motivational interviewing, as based on the transtheoretical model. Motivational interviewing has been shown to be an effective method for altering behaviors, and there is evidence to support the clinical utility of this technique to increase physical activity in people with chronic health conditions.[15] Each session began with the participant proposing a program for that session. The four main components of the behavioral intervention were: (1) feedback on daily wheelchair activity using bicycle odometers. A bicycle odometer was attached to the wheelchair and registered the distance traveled per day. The participant was instructed to keep track and to set goals toward increasing the traveled distance. (2) Formulating action plans on how and when to be physically active and formulating coping strategies for dealing with barriers that could hinder the actual performance of an action plan. (3) A home visit by the coach in the first month after discharge during which the coach helped to optimize the home and the environment of the participant for an active lifestyle. (4) Providing additional information at the request of the participant on relevant topics related to physical activity such as possible health benefits.

Outcomes measures

Measurements were performed at four time points: T1, before the start of the interventions at two months before discharge from inpatient rehabilitation; T2, before discharge from inpatient rehabilitation (<2 weeks before); T3, after completion of the behavioral intervention at six months after discharge from inpatient rehabilitation; and T4, one year after discharge from inpatient rehabilitation. Start of the study was determined based on the discharge date as estimated by the rehabilitation physician.

Health-related outcomes

Participants performed a maximal handcycle test on a Tacx Flow ergotrainer (Tacx, The Netherlands and Double Performance, The Netherlands). The test was performed using the same add-on handcycle as used during training. After a warm-up period of three minutes with minimal resistance, the resistance was increased every minute by 2 to 10 Watts, depending on lesion level. Throughout the test, participants cycled at a cadence of 60 rpm. The test ended when the participant stopped voluntarily due to exhaustion, or when the participant was unable to maintain the target cadence. During the test, oxygen uptake (VO_2) was measured using an Oxycon (Jaeger, Germany). VO_2peak was defined as the highest mean oxygen uptake during 30 seconds and expressed in liters per minute (L/min). Furthermore, power output was measured continuously with the Tacx Flow ergotrainer. After applying correction equations, this ergotrainer is reliable and valid in estimating power.[16] Peak power output (POpeak, in Watts) was defined as the highest power output sustained for a minimum of 30 seconds. Before the start of each handcycle test, a rehabilitation physician screened each participant for contraindications to exercise, including recent cardiovascular events and a diastolic blood pressure >90 mmHg or systolic blood pressure >180 mmHg at rest. Furthermore, all participants completed a screening tool: the Physical Activity Readiness Questionnaire.[17]

Body mass index (BMI in $kg \cdot m^{-2}$) was calculated from height and body mass. Diastolic and systolic blood pressure (in mmHg) were measured by a rehabilitation physician while the participants were sitting at rest. Lipid profile was measured to get an indication of the risk of cardiovascular disease and type 2 diabetes. Therefore, fasting blood samples were taken. Total cholesterol (TC), high density lipoprotein cholesterol (HDL), low density lipoprotein cholesterol (LDL), triglycerides and glucose levels were determined.

Participation

IMPACT-S is the screener part of the ICF Measure of Participation and ACTivities questionnaire. IMPACT-S consists of 33 items in 9 scales, reflecting the 9 activity and participation chapters of the International Classification of Functioning, Disability and Health (ICF).[18] Higher scores reflect better participation. We assessed the effects on the total participation score consisting of scales on knowledge, general tasks, communication, mobility, self-care, domestic life, interpersonal, major life areas and community life.

Quality of life

The 36-item Short Form Health Survey questionnaire (SF-36)19 was used to measure three domains of health-related quality of life: general health perceptions, mental health and vitality. Higher scores reflect better health-related quality of life.

Data analysis

As this study is part of Act-Active, the power analysis was performed based on objectively measured physical activity because this was the primary outcome of the RCT. Forty-two participants were required to detect a 30-minute per 24-hour period difference in objectively measured wheeled physical activity between the intervention group and the control group, with a standard deviation of 35 minutes,[7] a power of 0.8 and an alpha of 0.05. We aimed to recruit 60 participants to allow for drop-outs. Generalized Estimating Equation (GEE) analyses with exchangeable correlation structures were performed to determine the intervention effects of the behavioral intervention. First, we made an overall model for each of the 14 secondary outcome measures, including group allocation and baseline values of the particular outcome measure. Secondly, we added time and an interaction variable between group allocation and time to the overall models to assess the between-group differences for the three follow-up measurements (T2, T3 and T4). B, p and confidence intervals for the crude models and for the models adjusted for rehabilitation center, sex and age are presented. The B of the overall model represents the between-group difference over all measurements, and B at the specified measurement represents the between-group difference at that time point. In all analyses, the control group was the reference group. When values were missing at baseline, data of the particular participant from the second measurement were imputed to the baseline measurement of the participant. SPSS version 21 was used for all analyses.

Results

Flow of participants, therapists, and centers through the study

In total, 45 participants were included between January 2011 and August 2013. In August 2013 we stopped recruiting participants since this study concerned a PhD project and we were restricted to a certain time frame and budget. Figure 8.1 presents the flow diagram of inclusion. Three participants in both groups (n=6) dropped out before the second measurement and were therefore excluded from analysis. Baseline characteristics of the remaining 39 participants are shown in Table 8.1. On average, participants completed 73% of the sessions of the behavioral intervention. Drop-outs in the intervention group (n=12) and control group (n=11) did not differ significantly in personal characteristics and lesion characteristics.

Due to contraindications for maximal exercise and logistic reasons, there were missing data in the results of the maximal handcycle test: at T1, data for ten participants with contraindications and two because of logistic reasons; at T2, data for six participants with contraindications and two because of logistic reasons; at T3, data for five participants with contraindications; and at T4, three participants with contraindications. Furthermore, blood samples were missing because participants did not give consent for blood samples or due to logistic problems: at T1, data were missing for three, at T2 in 11, at T3 in 14, and at T4 in three participants.

Intervention effects

Table 8.2 presents the observed data for all outcome measures. Modeled data are presented in Table 8.3. An overall significant intervention effect was found for diastolic blood pressure. Furthermore, significant intervention effects at T4 were found for TC, LDL and participation. Total cholesterol one year after discharge from inpatient rehabilitation was 0.89 mmol/L lower in the intervention group compared to the control group. There seemed to be a clinically relevant between-group difference for POpeak, BMI and general health perceptions; however, the differences between the groups were not statistically significant. POpeak was 10.89 Watts (p=0.28) higher in the intervention group one year after discharge. The observed mean BMI in the intervention group was stable over time. The between-group difference in BMI increased over time, and one year after discharge the BMI of the intervention group was 0.72 $kg \cdot m^{-2}$ (p=0.36) lower compared to the control group. Of the three health-related quality-of-life subscales, only general health perceptions seemed to show a clinically relevant between-group difference at T4 (B=-7.48, p=0.28).

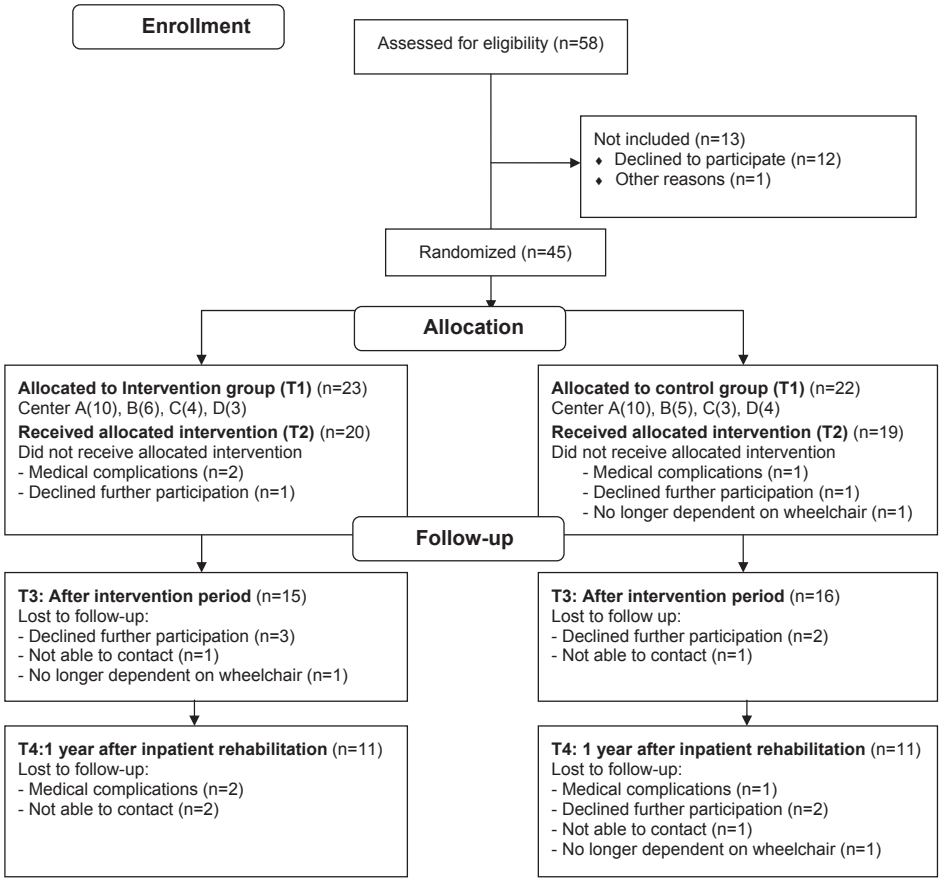

Figure 8.1 CONSORT flow diagram of study participation.

Table 8.1 Baseline participant characteristics

	Intervention group	Control group
	n=20	n=19
Personal characteristics		
Age in years, mean±SD	44±15	44±15
Sex, n (%) men	17 (85)	16 (84)
Lesion characteristics		
Lesion level, n (%) tetraplegia	7 (35)	6 (32)
Completeness, n (%) motor complete	13 (65)	11 (58)
Days since injury, mean±SD	139±67	161±81
Days since admission, mean±SD	104±64	108±60
Cause, n (%) traumatic	14 (70)	12 (63)

Table 8.2 Observed data over time, specified per allocated group. Reported as mean (SD)

	Intervention group				Control group			
	T1	T2	T3	T4	T1	T2	T3	T4
Physical capacity								
POpeak in Watts	44.41 (23.37)	62.99 (40.91)	72.20 (41.24)	80.19 (49.27)	47.15 (25.40)	54.14 (29.91)	65.22 (41.74)	72.85 (48.08)
VO_2peak in L/min	1.20 (0.43)	1.38 (0.54)	1.48 (0.65)	1.52 (0.60)	1.19 (0.40)	1.29 (0.45)	1.36 (0.51)	1.48 (0.62)
BMI in $kg \cdot m^{-2}$	25.43 (5.23)	25.60 (5.56)	25.66 (5.53)	25.36 (5.59)	23.90 (4.68)	24.60 (5.18)	26.00 (5.53)	27.13 (5.20)
Blood pressure in mmHg								
Systolic	123 (19)	120 (15)	128 (28)	125 (19)	127 (21)	124 (14)	132 (14)	130 (18)
Diastolic	72 (9)	73 (9)	74 (13)	74 (12)	77 (13)	77 (8)	84 (11)	83 (18)
Lipid profile in mmol/L								
Total cholesterol	4.47 (0.84)	4.47 (0.92)	4.63 (0.85)	4.17 (0.51)	4.96 (1.19)	5.17 (1.00)	5.55 (1.29)	5.21 (0.83)
HDL	1.37 (1.21)	1.02 (0.31)	1.08 (0.48)	1.04 (0.31)	1.23 (1.02)	1.01 (0.15)	0.97 (0.15)	1.09 (0.31)
LDL	2.76 (0.85)	2.63 (0.73)	2.95 (0.54)	2.46 (0.75)	3.22 (0.91)	3.39 (0.86)	3.46 (1.10)	3.13 (0.63)
Triglycerides	1.40 (0.76)	1.50 (0.97)	1.80 (1.71)	1.12 (0.65)	1.84 (0.93)	1.93 (0.93)	2.24 (1.23)	2.37 (1.38)
Glucose	4.97 (0.69)	5.16 (1.28)	5.00 (0.57)	5.66 (1.93)	5.52 (2.20)	6.61 (3.02)	6.25 (1.27)	7.13 (3.55)
Participation (0–100)	63.14 (11.33)	65.04 (13.37)	66.67 (11.37)	71.02 (15.14)	71.32 (17.08)	73.96 (13.56)	67.63 (15.60)	66.25 (13.04)
Quality of life								
General health (0–100)	60.00 (21.34)	54.12 (21.38)	55.00 (23.86)	53.50 (25.83)	58.46 (23.66)	54.58 (20.05)	53.85 (15.70)	54.50 (21.66)
Mental health (0–100)	72.42 (16.43)	75.33 (18.88)	73.14 (23.03)	73.45 (23.14)	64.92 (19.26)	69.33 (19.32)	62.77 (21.06)	68.80 (16.31)
Vitality (0–100)	67.11 (15.30)	67.22 (18.80)	67.14 (18.99)	67.27 (18.22)	61.92 (16.14)	69.17 (13.79)	60.38 (15.47)	65.50 (15.71)

T1, two months before discharge; T2, at discharge; T3, 6 months after discharge; T4, 1 year after discharge.

Table 8.3 GEE models – health-related outcomes, participation and quality of life

			Crude				Adjusted†			
			B	p	95% CI		B	p	95% CI	
Physical capacity										
	POpeak (n=68)	Overall	3.19	0.63	-9.92	16.29	3.29	0.60	-9.08	15.65
		T2	2.66	0.65	-8.73	14.06	2.88	0.59	-7.58	13.34
		T3	-0.88	0.92	-17.24	15.49	-0.83	0.91	-15.87	14.21
		T4	10.93	0.27	-8.62	30.47	10.89	0.28	-8.91	30.68
	VO_2peak (n=61)	Overall	0.07	0.38	-0.08	0.22	0.02	0.76	-0.13	0.17
		T2	0.04	0.59	-0.10	0.17	0.00	0.99	-0.16	0.16
		T3	0.06	0.52	-0.13	0.26	0.02	0.81	-0.17	0.22
		T4	0.11	0.53	-0.23	0.45	0.06	0.70	-0.26	0.39
BMI (n=85)		Overall	-0.64	0.24	-1.69	0.42	-0.54	0.29	-1.53	0.45
		T2	-0.39	0.24	-1.03	0.25	-0.22	0.56	-0.98	0.54
		T3	-0.71	0.40	-2.36	0.94	-0.65	0.41	-2.20	0.90
		T4	-0.75	0.38	-2.41	0.91	-0.72	0.36	-2.27	0.83
Blood pressure										
	Systolic (n=81)	Overall	-3.41	0.51	-13.57	6.76	-3.49	0.46	-12.71	5.74
		T2	-1.96	0.68	-11.28	7.37	-1.40	0.75	-9.94	7.15
		T3	-3.85	0.63	-19.41	11.71	-3.91	0.62	-19.46	11.64
		T4	-5.00	0.49	-19.04	9.05	-5.92	0.36	-18.58	6.75
	Diastolic (n=81)	Overall	-6.40	0.03*	-12.11	-0.69	-6.54	0.02*	-11.93	-1.15
		T2	-1.61	0.52	-6.46	3.24	-1.48	0.52	-6.00	3.03
		T3	-8.26	0.05*	-16.34	-0.17	-8.55	0.04*	-16.68	-0.41
		T4	-11.29	0.02*	-20.54	-2.04	-11.35	0.01*	-19.98	-2.71

Table 8.3 continues on next page.

Table 8.3 *Continued*

		Crude				Adjusted†			
		B	p	95% CI		B	p	95% CI	
Lipid profile									
TC (n=60)	Overall	-0.53	0.07	-1.12	0.05	-0.55	0.06	-1.10	0.01
	T2	-0.28	0.39	-0.92	0.36	-0.28	0.39	-0.91	0.36
	T3	-0.54	0.21	-1.40	0.31	-0.58	0.17	-1.41	0.25
	T4	-0.87	0.01*	-1.55	-0.19	-0.89	0.01*	-1.59	-0.20
HDL (n=60)	Overall	-0.01	0.91	-0.18	0.16	-0.05	0.62	-0.24	0.14
	T2	-0.01	0.95	-0.18	0.17	-0.05	0.61	-0.24	0.14
	T3	0.08	0.57	-0.20	0.37	0.04	0.80	-0.26	0.33
	T4	-0.07	0.46	-0.27	0.12	-0.12	0.23	-0.30	0.07
LDL (n=58)	Overall	-0.38	0.08	-0.82	0.05	-0.38	0.08	-0.81	0.05
	T2	-0.28	0.29	-0.81	0.24	-0.26	0.34	-0.78	0.27
	T3	-0.25	0.46	-0.90	0.41	-0.26	0.40	-0.87	0.35
	T4	-0.61	0.05*	-1.20	-0.01	-0.63	0.05*	-1.25	-0.00
Triglycerides (n=60)	Overall	0.05	0.86	-0.46	0.55	0.10	0.71	-0.42	0.61
	T2	0.05	0.80	-0.36	0.47	0.07	0.71	-0.32	0.46
	T3	0.70	0.20	-0.36	1.77	0.75	0.17	-0.32	1.81
	T4	-0.38	0.31	-1.11	0.35	-0.34	0.36	-1.07	0.39
Glucose (n=60)	Overall	-0.35	0.36	-1.09	0.40	-0.70	0.05	-1.40	0.00
	T2	-0.73	0.19	-1.83	0.37	-1.16	0.06	-2.33	0.03
	T3	-0.06	0.91	-1.12	0.99	-0.32	0.58	-1.42	0.79
	T4	-0.12	0.86	-1.48	1.24	-0.48	0.38	-1.57	0.60
Participation (0–100) (n=73)	Overall	3.59	0.14	-1.19	8.36	3.56	0.09	-0.50	7.62
	T2	-1.87	0.58	-8.39	4.65	-2.20	0.48	-8.29	3.90
	T3	4.75	0.11	-1.06	10.56	4.47	0.05*	0.07	8.87
	T4	9.88	<0.01*	3.22	16.53	9.91	<0.01*	3.34	16.48

Quality of life										
General health (0–100) (n=73)	Overall	-1.00	0.84	-10.55	8.54	-1.57	0.74	-10.86	7.72
	T2	1.53	0.79	-9.83	12.90	0.82	0.89	-10.68	12.32
	T3	-0.82	0.90	-12.94	11.30	-1.04	0.86	-12.63	10.55
	T4	-6.79	0.33	-20.57	6.99	-7.48	0.27	-20.84	5.87
Mental health (0–100) (n=77)	Overall	5.34	0.27	-4.09	14.77	5.44	0.23	-3.52	14.39
	T2	3.17	0.49	-5.80	12.15	3.41	0.45	-5.47	12.29
	T3	8.31	0.16	-3.14	19.77	8.26	0.14	-2.76	19.28
	T4	3.36	0.62	-9.92	16.63	3.49	0.59	-9.17	16.16
Vitality (0–100) (n=77)	Overall	0.66	0.88	-8.09	9.41	0.58	0.90	-8.06	9.22
	T2	-3.26	0.51	-13.04	6.51	-3.43	0.49	-13.23	6.37
	T3	4.52	0.41	-6.25	15.30	4.38	0.44	-6.61	15.36
	T4	-0.63	0.91	-11.72	10.47	-0.74	0.89	-11.20	9.73

† Adjusted for rehabilitation center, sex, and age.
T2 at discharge, T3 6 months after discharge, and T4 1 year after discharge.
N, amount of data points in analysis.

Discussion

To our knowledge this is the first study to assess the effects on health, participation and quality of life of a behavioral intervention promoting an active lifestyle in adults with subacute SCI. The addition of a behavioral intervention resulted in lower TC and LDL, lower diastolic blood pressure and higher participation one year after discharge from inpatient rehabilitation. Furthermore, there seemed to be a clinically relevant, although non-significant, between-group difference on POpeak and BMI. Perceived general health seemed to be lower in the intervention group one year after discharge from inpatient rehabilitation, while no effects on mental health and vitality were found.

The behavioral intervention resulted in a lower diastolic blood pressure. From previous studies it is known that, generally, people with SCI show an increase in diastolic blood pressure after discharge,[20] as was seen in our control group. In the intervention group, diastolic blood pressure remained fairly stable. However, the mean values were relatively low, considering that, for the general population, diastolic blood pressure greater than 90 mmHg is defined as hypertension. The group means included values from people with low blood pressure due to damaged descending spinal sympathetic pathways to the heart and vasculature.[21] It is unknown what would be favorable blood pressure values in relationship to cardiovascular disease for people with cardiovascular dysfunction after SCI. Further research is necessary.

The behavioral intervention was effective in increasing participation. A descriptive analysis on outcomes for the different scale scores of the participation questionnaire showed that higher participation was reflected in mobility, self-care, domestic life, major life areas, and community life. It can be concluded that not only did the intervention impact health-related aspects, but higher participation scores imply also positive influence on social functioning.[22]

Physical capacity seemed to show a clinically relevant, although non-significant, improvement due to the intervention, with a between-group difference in POpeak of more than 10% of the mean. No effect was found on VO_2peak. Attaining higher physical capacity is important in this group generally known to have a low physical capacity.[23] Previous research has shown that higher physical capacity makes it easier to perform activities of daily living[24] and is associated with more functional independence in people with SCI.[25] Further study is necessary.

Although the difference between groups was not significant, BMI seemed to remain rather stable in the intervention group, whereas it increased in the control group. High BMI is a known risk factor for coronary heart disease and for overuse injuries of the upper extremities

in people with SCI.[2, 26] Newly injured people commonly experience weight loss, which is explained as a shock response of the body to the trauma manifested as faster metabolism.[27] Over time, the metabolism slows down as a consequence of the new lifestyle in a wheelchair and loss of muscle mass.[28] It was previously reported that BMI gradually increases during and after inpatient rehabilitation, with a significant increase in the first year after discharge from inpatient rehabilitation,[2] resulting in 70% of this population being overweight or obese, based on adopted cut-off points. Additional nutritional counseling might help in preventing overweight.[29] Further study on preventing overweight in people with SCI is necessary.

Perceptions of general health seemed to be lower (not significant) after the intervention. Possibly, due to the intervention, people became more critical or more aware of their own health, as reflected in questions such as "I seem to get sick a little easier than other people" and "I expect my health to get worse". Other domains of health-related quality of life did not seem to be affected by the behavioral intervention.

Limitations

Although our power analysis was not based on the outcomes presented in the present study, we were able to find significant between-group differences for blood pressure, lipid profile and participation. The most important limitations of this study were the missing data for the maximal handcycle test and lipid profile. The maximal handcycle test could not be performed by a considerable number of participants due to contraindications for maximal exercise. Despite the random group allocation, people with contraindications were not equally distributed between the two groups. Of the 15 participants with contraindications on one or more measurements, ten participants were allocated to the control group and five to the intervention group. Therefore, results on physical capacity have to be interpreted with caution. Data on lipid profile were missing mainly because of organizational problems. Collecting fasting blood samples after discharge, on top of a visit to the rehabilitation center for the physical measurements, was difficult to organize. Since we expected the largest effect on lipid profile to be one year after discharge, we concentrated time and effort on gathering blood samples at the last measurement. This resulted in missing data for only three participants at T4. Furthermore, one should be careful to draw strong conclusions from single significant findings, due to multiple testing in the present study. Besides, we did not control our analyses for diet and medications.

Clinical implications

A behavioral intervention focusing on an active lifestyle after discharge from inpatient rehabilitation seems to improve health and participation among people with subacute SCI. Due to the behavioral intervention, consisting of 13 individual sessions with a coach, the risk for cardiovascular disease seems to be reduced and social functioning seems to be improved. Therefore, we advise to add a behavioral intervention to the regular care of people with subacute SCI.

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Chapter 9

Working mechanisms of a behavioral intervention promoting physical activity in persons with subacute spinal cord injury

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Abstract

Objective: In order to unravel the working mechanisms that underlie the effectiveness of a behavioral intervention on physical activity in persons with subacute spinal cord injury (SCI) , the goal of the current study was to assess the mediating effects of physical and psychosocial factors on the intervention effect on physical activity.

Design: Randomized controlled trial.

Setting: Four rehabilitation centers in The Netherlands.

Subjects: Thirty-nine persons with subacute SCI.

Intervention: Behavioral intervention promoting an active lifestyle, based on motivational interviewing. The intervention involved a total of 13 individual sessions beginning 2 months before and ending 6 months after discharge from initial inpatient rehabilitation.

Main measures: Potential mediating effects of fatigue, pain, depression, illness cognition, exercise self-efficacy, coping and social support on the effect of the behavioral intervention on objectively measured physical activity ($B=0.35$ hours, $p<0.01$) were studied. Measurements were performed at baseline, discharge, six months and one year after discharge.

Results: No single factor was found which strongly mediated the effect of the behavioral intervention on physical activity; however, multiple factors could partly explain the effect. Mediating effects of greater than 10% were found for proactive coping (17.6%), exercise self-efficacy (15.9%), pain disability (15.3%), and helplessness (12.5%).

Interpretation: Proactive coping (the ability to anticipate and deal with potential threats before they occur), exercise self-efficacy (self-confidence with respect to performing exercise and daily physical activities), pain disability (interference by pain of daily activities) and helplessness (emphasizing the aversive meaning of the disease) are important concepts in interventions promoting physical activity in persons with subacute SCI.

Introduction

After discharge from inpatient rehabilitation, physical activity levels of persons with spinal cord injury (SCI) are known to decline to a level that is severely low compared to the general population and also low compared to persons with other chronic diseases.[1, 2] These low physical activity levels are associated with more secondary health problems in persons with SCI.[3] Physical factors such as fatigue and pain,[4] and psychosocial factors such as depression, illness cognition, exercise self-efficacy, coping and social support have all been linked to (changes in) physical activity.[5, 6]

In a previous study, the addition of a behavioral intervention to regular care, including handcycle training, was found to be effective in promoting a more physically active lifestyle in persons with subacute SCI, resulting in 50% more physical activity half a year after discharge from inpatient rehabilitation as well as continuation of the more active lifestyle up to one year after discharge. Details of that randomized controlled trial are presented in a separate publication.[7]

It is important to understand the working mechanisms that underlie the effectiveness of behavioral intervention on physical activity in persons with subacute SCI. Therefore, the goal of the current study was to assess the mediating effects of both physical and psychosocial factors on the intervention effect on physical activity. The physical factors we assessed were fatigue and pain. The psychosocial factors were depression, illness cognition, exercise self-efficacy, coping and social support. These factors were expected to be influenced by the behavioral intervention but not as a direct intervention effect, leading to significant between-group differences. We hypothesized that these factors would be mediating on the intervention effect on physical activity and thus partly explain the effect of the intervention on physical activity.

Methods

Study design

This study is part of Act-Active, a single-blind multi-center randomized controlled trial (RCT). Research assistants performing the measurements were blinded for group allocation. Participating rehabilitation centers were: Rijndam Rehabilitation Institute in Rotterdam, Adelante in Hoensbroek, Heliomare in Wijk aan Zee, and Hoogstraat Rehabilitation in

Utrecht, all in The Netherlands. The RCT was prospectively registered at the Dutch trial register: NTR2424.

Participants

Participants were included during inpatient rehabilitation if they satisfied the following criteria: diagnosed with SCI, initial inpatient rehabilitation, dependent on a manual wheelchair for their daily mobility, able to handcycle, and between 18 and 65 years old. Persons were excluded when they had insufficient comprehension of the Dutch language to understand the purpose of the study and its testing methods, or a psychiatric condition, or a progressive disease that could interfere with participation. The Medical Ethics Committee of Erasmus Medical Center Rotterdam, The Netherlands, approved the protocol of this study, and all participating centers granted local approval. All participants provided written informed consent.

Randomization and intervention

Randomization into the intervention or control group was performed in four strata based on lesion level (tetraplegia-paraplegia) and completeness (motor complete-motor incomplete). A lesion at or above the Th1 segment was defined as tetraplegia, and a lesion below Th1 as paraplegia. A motor complete lesion was defined as American Spinal Injury Association Impairment Scale (AIS) grade A or B, a motor incomplete lesion as AIS grade C or D.[8] Random group allocation was performed for each rehabilitation center and within each stratum.

Before the start of Act-Active, rehabilitation programs in the participating rehabilitation centers were not comparable with regard to physical capacity training,[9] and this training was therefore standardized. All participants of both the control and intervention groups performed a structured handcycle training program during the last two months of inpatient rehabilitation. This handcycle training consisted of an interval training protocol and was scheduled three times per week.[10] Additional details of this handcycle training program have been reported.[11]

Only persons in the intervention group participated in a behavioral intervention. The aim of this intervention was to promote a more physically active lifestyle after discharge from inpatient rehabilitation. Thirteen individual face-to-face sessions with a coach were planned, each with a maximum duration of one hour. For practical reasons, a few sessions after

discharge were performed via the telephone. From two months before until three months after discharge, two sessions were planned every month, and in the following three months there was one session a month. The coach was a physical therapist or occupational therapist. The Transtheoretical Model of Change was used as a basis for the behavioral intervention.[12] This model describes the change of behavior as a process which runs through several stages. The coach helped to facilitate movement along the stages by using motivational interviewing. Motivational interviewing has been shown to be an effective approach for altering behavior,[13] and there is evidence to support the clinical utility of this method to increase physical activity in persons with chronic health conditions.[14] Each session began with the participant setting the agenda. Both physical and psychosocial factors were included in the intervention. The four main components of the intervention were: (1) Feedback on daily wheelchair activity using bicycle odometers. The participant was instructed to keep track of the distance traveled per day with the wheelchair and to set increasing distance goals. (2) Setting action plans on how and when to be physically active and on coping strategies for dealing with barriers that could hinder the performance of an action plan.[15] (3) Home visit by the coach in the first month after discharge to help optimize the home and environment of the participant to undertake physical activity. (4) Providing additional information on request by the participant on relevant topics related to physical activity, e.g. possible health benefits.

Outcomes and follow up

Four measurements were performed: T1, prior to the start of the interventions at two months before discharge from inpatient rehabilitation; T2, before discharge from inpatient rehabilitation (<2 weeks before); T3, after completion of the behavioral intervention at six months after discharge from inpatient rehabilitation; and T4, one year after discharge from inpatient rehabilitation.

Physical factors

Fatigue was measured using the Fatigue Severity scale (FSS), a questionnaire assessing the severity of fatigue and the perceived impact of fatigue on an individual's daily functioning.[16, 17] Pain was measured with The Chronic Pain Grade questionnaire.[18, 19] The *Pain intensity* score was used to determine the severity of pain.[19] At the two measurements after discharge (T3 and T4), participants also completed items of the Chronic Pain Grade questionnaire on *pain disability*, including the interference of pain, and change in daily work/housework, and recreational/social activities due to pain.

Psychosocial factors

The Center for Epidemiological Studies-Depression scale (CES-D)[20] was used to measure symptoms of *depression*, a higher score indicates more symptoms of depression. The scale consists of 4 domains: somatic-retarded activity, depressed affect, positive affect and interpersonal affect.

Illness cognition was assessed with the Illness cognition questionnaire,[21] to get an indication of both unfavorable and favorable ways of adjusting to an uncontrollable long-term stressor, in this case the SCI. The questionnaire assesses three domains: *helplessness, acceptance and disease benefits*. Helplessness refers to emphasizing the aversive meaning of the disease, acceptance to diminishing the aversive meaning, and perceived benefits to adding a positive meaning to the disease.

Exercise self-efficacy was assessed using the Exercise Self-Efficacy Scale.[22, 23] Self-efficacy is defined as the beliefs in one's capabilities to organize and execute the courses of action required for producing given attainments.[24] The exercise self-efficacy scale contains items about self-confidence with respect to performing exercise and daily physical activities.

Proactive coping was measured with the Utrecht Proactive Coping Competence Scale.[25, 26] Proactive coping is the ability to anticipate and deal with potential threats before they occur. This scale assesses the individual's competency with regard to the various skills associated with proactive coping.

Social Support was measured with the Social Support for Exercise Behavior Scale.[27] We reported on the domains of *family support* (participation and involvement) and *friends support* (exercising together). All questionnaires used in the current study were validated.[16-23, 25-27]

Statistical analyses

Generalized Estimating Equation (GEE) analyses with exchangeable correlation structures were used for the analyses. To assess the mediating effects of the physical and psychosocial factors, these were added separately to the overall model for the effect of the behavioral intervention on objectively measured wheeled physical activity (primary outcome measure of the RCT). This overall model on physical activity showed a significant intervention effect of B=0.35 hours per 24-hour period, $p<0.01$ (confidence interval: 0.13–0.58).[7] B represents the overall between-group difference, adjusted for baseline levels, rehabilitation center, sex and age. Thus, overall the intervention group was 0.35 hours (=21 minutes) per 24-hour period more physically active compared to the control group. Mediation was expressed as

the percentage of change of the overall between-group difference after adding each of the potential mediators separately to the model on physical activity. For pain disability the mediating effect was assessed in a model without the T2 measurement (B=0.47 hours). Furthermore, we made overall models, correcting for baseline values, age, gender and rehabilitation center, for each outcome variable to assess the direct intervention effects.

Independent t-tests and Chi-square tests were used to test for differences in personal characteristics, lesion characteristics and baseline physical activity between the drop-outs of both groups. SPSS version 21 was used for all analyses.

Results

A flow diagram of inclusion is presented in Figure 9.1. A total of 45 participants were included between January 2011 and August 2013. Three persons in each group (n=6) were excluded from further analyses because they dropped out of the study before the second measurement. Table 9.1 shows baseline characteristics of the remaining 39 participants. Participants completed an average of 73% of the behavioral intervention sessions. Drop-outs at T3 or T4 in the intervention group (n=12) and control group (n=11) were not significantly different in terms of personal characteristic and lesion characteristics. Table 9.2 shows observed data for the physical and psychosocial factors. None of the outcome measures showed a direct significant intervention effect: Fatigue: B=0.03, p=0.93; Pain intensity: B=3.71, p=0.57; Pain disability: B=0.43, p=0.24; Depression: B=0.96, p=0.72; Helplessness: B=-0.11, p=0.57; Acceptance: B=0.04, p=0.81; Disease benefits: B=-0.09, p=0.55; Exercise self-efficacy: B=-0.30, p=0.81; Proactive coping: B=-0.10, p=0.34; Social support family: B=-0.55, p=0.71; Social support Friends: B=0.07, p=0.94). Results on mediating effects are shown in Table 9.3. The intervention effect on physical activity was mediated separately by >10% by pain disability, helplessness, exercise self-efficacy and proactive coping.

Discussion

To our knowledge this is the first longitudinal study assessing the working mechanisms of a behavioral intervention intended to promote an active lifestyle in adults with subacute SCI. No single factor strongly mediated the observed positive effect of the behavioral intervention on physical activity, but multiple factors can partly explain the effect. The strongest mediating effects were found for proactive coping, exercise self-efficacy, pain disability, and helplessness.

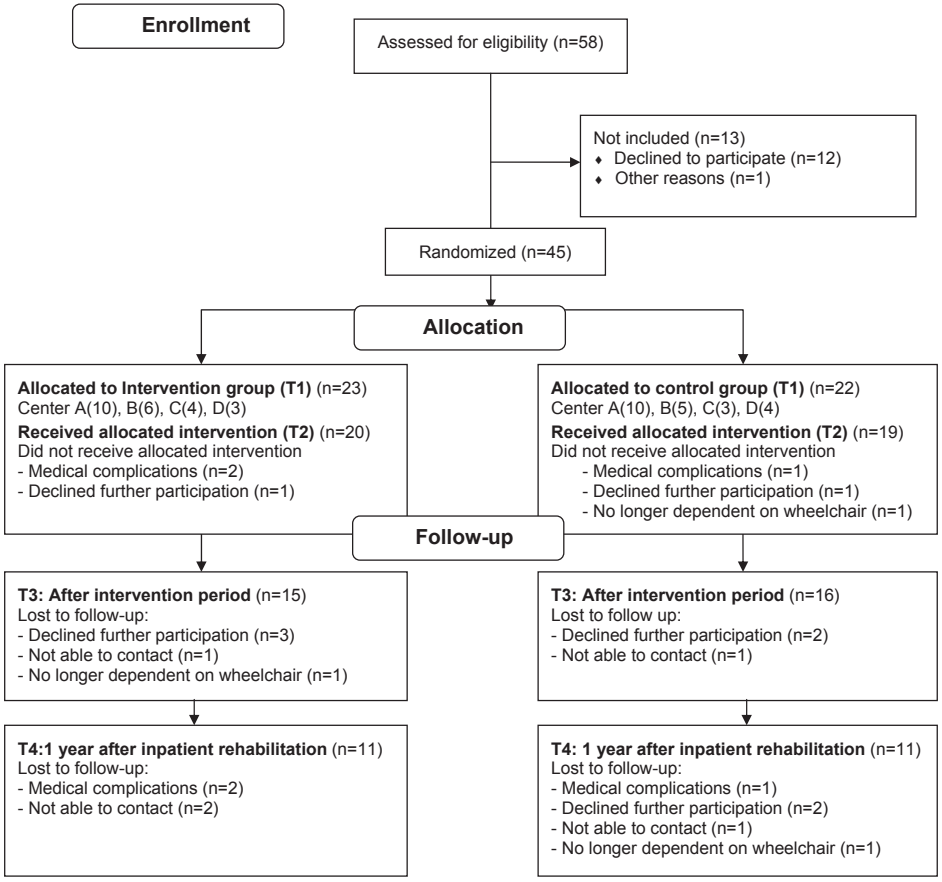

Figure 9.1 CONSORT flow diagram of study participation.

Table 9.1 Baseline participant characteristics

	Intervention group	Control group
	n=20	n=19
Personal characteristics		
Age in years, mean±SD	44±15	44±15
Sex, n (%) men	17 (85)	16 (84)
Lesion characteristics		
Lesion level, n (%) tetraplegia	7 (35)	6 (32)
Completeness, n (%) motor complete	13 (65)	11 (58)
Days since injury, mean±SD	139±67	161±81
Days since admission, mean±SD	104±64	108±60
Cause, n (%) traumatic	14 (70)	12 (63)

Table 9.2 Observed data over time, specified per allocated group. Reported as mean±SD

	Intervention group				Control group			
	T1	T2	T3	T4	T1	T2	T3	T4
Fatigue (1–7)	3.05±1.31	3.24±1.51	2.79±1.30	3.39±1.58	3.71±1.41	3.35±1.37	3.86±1.37	3.46±1.59
Pain								
Pain intensity (0–100)	52.46±18.39	50.74±25.32	50.72±24.98	45.76±32.25	54.62±21.84	47.78±30.69	49.49±29.72	49.67±26.36
Disability score (0–6)	-	-	0.86±1.46	1.55±1.57	-	-	0.92±1.66	0.40±0.70
Depression (0–60)	11.61±8.71	14.94±10.28	15.93±14.36	11.91±12.16	13.00±9.17	12.00±7.30	16.62±9.73	13.30±8.60
Illness cognition								
Helplessness (1–4)	2.73±0.64	2.71±0.67	2.62±0.68	2.21±0.98	2.83±0.63	2.60±0.77	2.79±0.82	2.60±0.68
Acceptance (1–4)	2.26±0.64	2.37±0.79	2.39±0.85	2.52±0.91	2.45±0.82	2.53±0.94	2.46±0.87	2.60±0.74
Disease benefits (1–4)	2.40±0.86	2.41±0.82	2.52±0.84	2.70±0.93	2.15±0.57	2.64±0.71	2.28±0.64	2.55±0.45
Exercise self-efficacy (10–40)	35.56±3.73	34.94±4.99	34.50±5.00	34.27±5.57	35.87±3.66	36.17±3.56	32.69±5.42	34.30±4.03
Proactive coping (1–4)	3.18±0.36	3.21±0.49	3.04±0.78	3.12±0.58	2.96±0.35	3.04±0.32	2.97±0.53	2.92±0.44
Social support								
Family (0–40)	20.67±9.57	19.83±7.38	21.21±10.66	19.64±12.09	20.85±9.77	22.67±9.37	22.85±7.98	22.00±10.93
Friends (0–20)	11.50±6.85	9.78±5.88	10.79±5.31	9.36±5.30	8.69±5.81	8.42±3.48	9.38±4.50	9.50±5.56

T1, two months before discharge; T2, at discharge; T3, 6 months after discharge; T4, 1 year after discharge.

Table 9.3 Mediating effects on the intervention effect on physical activity

		n[1]	B	Mediating effect (%)
Overall model physical activity		*75*	*0.352*	
Fatigue		69	0.322	8.5
Pain				
	Pain intensity	69	0.332	5.7
	Pain disability	44[2]	*	15.3
Depression		69	0.335	4.8
Illness cognition				
	Helplessness	69	0.308	12.5
	Acceptance	69	0.345	2.0
	Disease benefits	69	0.328	6.8
Exercise self-efficacy		68	0.296	15.9
Proactive coping		69	0.290	17.6
Social support				
	Family	69	0.326	7.4
	Friends	69	0.370	-

[1] Number of measurements in analysis.
[2] No T2 measurement available.
* Physical activity model without T2 measurement changed from B=0.470 to B=0.398.

This study unraveled different concepts that support the benefits of the behavioral intervention. Firstly, proactive coping, which assumes that persons not only react to presently threatening situations, but can also anticipate and respond to situations that may threaten or influence their goals in the future[25, 28] Secondly, helplessness, which refers to emphasizing the aversive meaning of the disease, and is strongly related to the concept of control. Helplessness has been proposed to be an important mediator between condition and well-being.[29] Thirdly, self-efficacy, suggesting that confidence in one's ability to perform a certain behavior is strongly related to one's ability to perform that behavior. Higher exercise self-efficacy has previously been linked to more physical activity.[30] Although exercise self-efficacy levels were found to be rather high in persons with subacute SCI,[23] the current study confirms that it is an important concept within physical activity promotion. Furthermore, pain disability, wherein pain interferes with daily activities, seems an important factor when promoting an active lifestyle in persons with subacute SCI. The observed data (Table 9.2) indicate that, at one year after discharge, pain disability increased in the intervention group while it seemed to have decreased in the control group. Unfortunately, we did not assess the locations of pain in the current study. In the behavioral intervention, there was no explicit

focus on pain. Possibly the behavioral intervention can be optimized when coaches are more aware of pain disability with regard to physical activity and incorporate this in the intervention. Pain is one of the most common secondary conditions in persons with SCI.[31] While there is increased understanding of the underlying mechanisms of pain in persons with SCI, treatment is still unsatisfactory and there is an unmet need to improve pain relief.[32]

Fatigue was not a strong mediator on the intervention effect on physical activity, and no direct intervention effect on fatigue was found. This is in line with our previously published results, that fatigue is not related to physical activity in persons with subacute SCI.[33] However, fatigue is an important issue in persons with SCI because it is prevalent in both persons with subacute SCI and persons with SCI in the chronic phase[34] and is known to interfere with daily functioning.[35] Since fatigue is a multifactorial problem, a specific fatigue management program might be necessary to reduce fatigue.[36] Further study on fatigue, and the physical component of fatigue, in persons with SCI is necessary.

Depression and family support for exercise behavior only explained a small part of the intervention effect on physical activity. In previous studies, mental health problems have been identified as an important barrier to and social support as an important facilitator of physical activity in persons with SCI.[37, 38] Further research is necessary to clarify the roles of depression and social support within the promotion of physical activity in persons with subacute SCI.

Limitations

Although the sample size of 45 is relatively large considering the incidence of SCI and the vulnerability of this group, the absolute number is still small. Furthermore, power was limited because of missing values and drop-outs.

Clinical messages

- Proactive coping (the ability to anticipate and deal with potential threats before they occur), exercise self-efficacy (self-confidence with respect to performing exercise and daily physical activities), pain disability (interference with daily activities by pain) and helplessness (emphasizing the aversive meaning of the disease) are important concepts in an intervention intended to promote physical activity in persons with subacute SCI.
- No single factor strongly mediated the effect of the behavioral intervention on physical activity, but multiple physical and psychosocial factors could partly explain the effect.

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Chapter 10

General discussion

The primary aim of this thesis was to evaluate the added value of a behavioral intervention, on top of regular rehabilitation and handcycle training, on physical activity in persons with subacute SCI. Additionally, the intervention effects on secondary outcomes as health, participation and quality of life were studied and working mechanisms of the behavioral intervention evaluated. We hypothesized that physical exercise alone would not automatically lead to a more active lifestyle and that the addition of a behavioral intervention would be necessary to achieve and maintain a higher physical activity level, and to improve health, participation and quality of life. For further insight on the promotion of physical activity in persons with subacute SCI, we additionally explored handcycle training feasibility during inpatient rehabilitation. Furthermore, baseline levels of exercise self-efficacy and fatigue were described and relations with demographic- and lesion characteristics assessed. Figure 10.1 shows a schematic representation of the studied relations and effects in this thesis. The present chapter concerns the study results interpretation and discussion within the context of the published literature. Methodological considerations, clinical implications and recommendations for future research are described.

Results interpretation and literature perspective

The behavioral intervention, consisting of 13 individual sessions with a coach, was effective in eliciting a behavioral change toward a more active lifestyle among persons with subacute SCI. Addition of the behavioral intervention to regular rehabilitation and handcycle training resulted in 50% more wheeled physical activity after discharge from inpatient rehabilitation (chapter 7). Furthermore, the addition of a behavioral intervention resulted in a more favorable lipid profile, lower diastolic blood pressure and higher participation one year after discharge from inpatient rehabilitation. In addition, there seemed to be clinically relevant between-group differences on peak power output, BMI and general health perceptions (chapter 8).

Physical activity

It seemed that the behavioral intervention especially prevented persons with SCI from attaining a very inactive lifestyle (<1/2 hour per 24-hours) after discharge from inpatient rehabilitation (mean physical activity level of total sample was 1 hour per 24-hours). A clinically relevant finding because the most inactive group, is the group at highest risk for secondary conditions.[1] When comparing to the general population, the mean physical

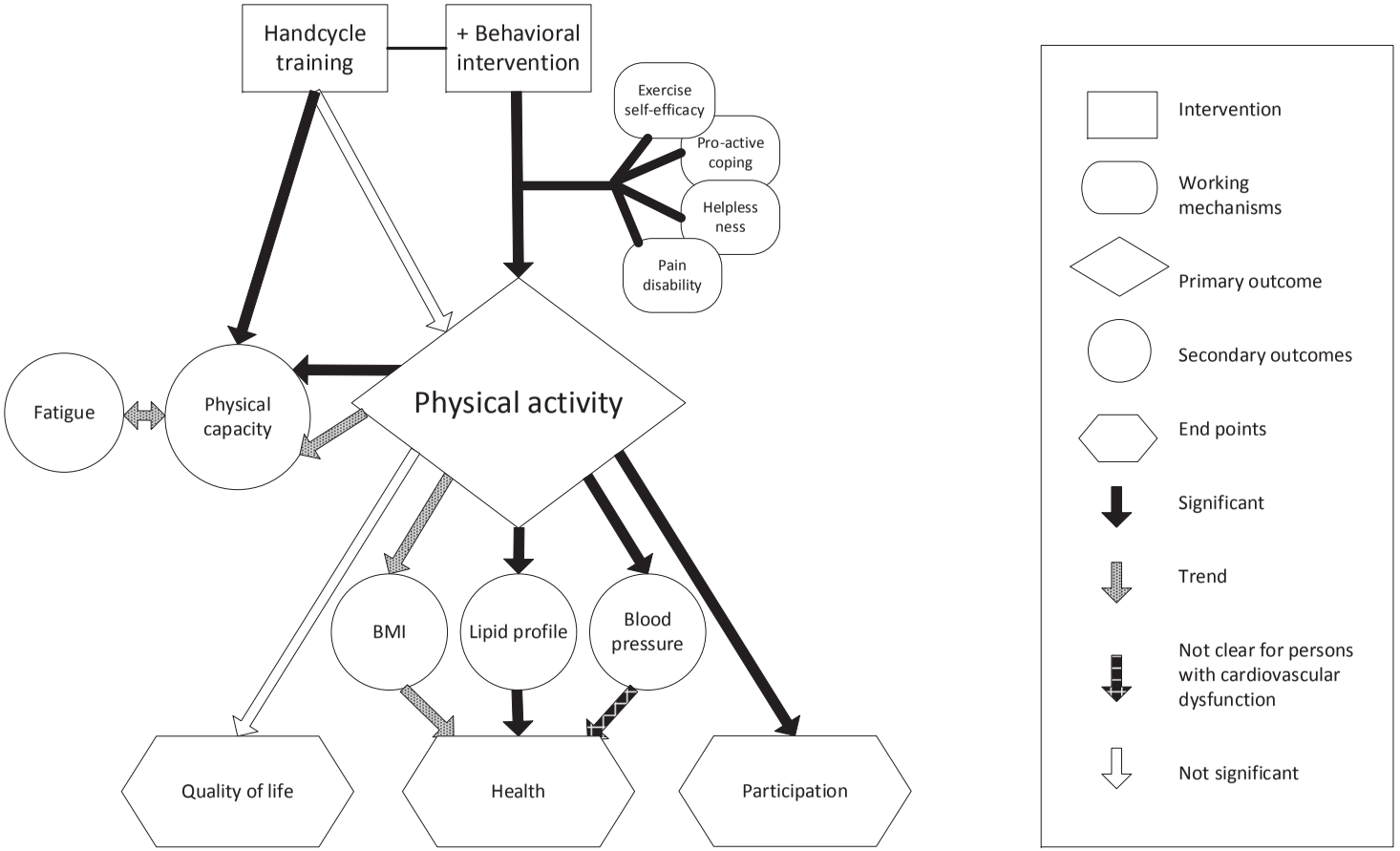

Figure 10.1 Schematic representation of the studied relations and effects in this thesis.

activity level of persons with subacute SCI receiving the behavioral intervention was still only 50%.[2] However, possibly it cannot be expected for persons with SCI who are wheelchair dependent to be as physically active as the general population. For this group, daily self-care is already time-consuming and a straining every day activity[3] leaving less time and energy for dynamic activities. Furthermore, multiple impossible or hard to overcome barriers for physical activity for this group have been described.[4]

In the promotion of physical activity for persons with subacute SCI it is essential that they have their own custom-fitted wheelchair and handcycle as fast as possible. When persons with SCI go home after discharge from inpatient rehabilitation in the Netherlands, they often do not have their own handcycle yet. It seems that this period at home waiting for their own handcycle was compensated by being more active by propelling their wheelchair. Since handcycling is known to be less strenuous for the shoulder joint,[5] it is a desirable development that one year after discharge participants were more physically active in their handcycle.

The behavioral intervention had little focus on sedentary day time. This might explain that the intervention was not effective in reducing sedentary day time periods longer than 30 minutes. Focusing more on breaking up long periods of sedentary day time might optimize the intervention. However, breaking up sedentary time in persons who are wheelchair dependent is difficult since sitting less is not possible. It is unknown for this group what type, intensity and duration of activity is necessary to break up sedentary time for health benefits.[6]

Previous studies in persons with SCI in the chronic phase tended to show positive effects of behavioral interventions on physical activity.[7-12] Only one of these previous studies reported on outcomes on objective measures of physical activity and found no significant effect of the intervention.[9] Three studies, using self-reported outcome measures and without a follow-up period, indicated positive effects of a behavioral intervention on physical activity.[7, 8, 12] Telephone counseling was reported to be a suitable option.[7, 12] Furthermore, combining action and coping planning was found to be more effective than action planning only.[8] Two studies on a combined exercise and behavioral intervention with a follow-up period reported an increase in self-reported physical activity of respectively 15 min per week[10] and 39 minutes per week.[11]

In other groups of persons with a physical disability, several studies on behavioral interventions based on motivational interviewing and using objective outcome measures reported no long-term effects on physical activity.[13-16] A possible explanation for the discrepancy with results of our study could be that we did not attempt to change long-term inactive behavior in persons with a chronic condition but our group of persons with subacute SCI just started

new physical activity behavior from a wheelchair. Furthermore, our population consisted mainly of young adults. Possibly the impact of a life-event also plays a role. Moreover, since persons with SCI are known to be among one of the most inactive groups, even compared to persons with other chronic diseases, there was much room for improvement.[2] Since behavioral interventions in previous studies were different in content and design it is also possible that the behavioral intervention in our study was simply more effective.

Secondary effects: health-related outcomes

Cardiovascular disease risk is known to be high in persons with SCI, with cardiovascular diseases reported in 30–35% of persons with SCI in the chronic phase.[17] Outcomes on health-related aspects indicate that the behavioral intervention resulted in a lower risk for cardiovascular disease. First, an intervention effect was found for lipid profile. Both total cholesterol and LDL showed significantly more favorable values as a result of the behavioral intervention. No significant intervention effect was found for glucose. This indicates that the intervention did not decrease the risk for Diabetes. Diabetes has a prevalence of 5–22% in persons with SCI.[17]

Secondly, the behavioral intervention resulted in a lower diastolic blood pressure. From previous studies it is known that, generally, persons with SCI show an increase in diastolic blood pressure after discharge.[18] As a result of the behavioral intervention, diastolic blood pressure remained lower. Mean values were relatively low compared to norm values, but included persons with low blood pressure due to damaged descending spinal sympathetic pathways to the heart and blood vessels.[19] It is unknown what blood pressure is favorable for persons with cardiovascular dysfunction after SCI. Therefore, it remains uncertain whether the lower diastolic blood pressure in our participants with cardiovascular dysfunction can be considered a favorable outcome. We analyzed data separately for persons expected to have no cardiovascular dysfunction, as based on lesion characteristics and peak heart rate results. This analysis indicates that in this subgroup blood pressure also remained lower and is thus a favorable intervention effect.

Furthermore, due to the behavioral intervention, BMI seemed to stay rather stable. BMI is a known risk factor for coronary heart disease and for overuse injuries of the upper extremities in persons with SCI.[20, 21] Newly injured persons commonly experience weight loss, which is explained by the body being in shock due to the trauma resulting in a faster metabolism.[22] Over time, the metabolism slows down due to the new lifestyle in a wheelchair and a decrease in muscle mass.[23] BMI has previously been reported to gradually increase during and after inpatient rehabilitation, with a significant increase in the first year after

discharge from inpatient rehabilitation,[20] resulting in 70% of this population being overweight or obese when using adapted cut-off points. More physical activity is possibly not enough to prevent overweight in this group restricted to physical activity from a wheelchair and with an altered metabolism.[23] Additional nutritional counseling might be necessary for preventing overweight.[24] There is initial evidence that a carefully planned program with restricted dietary intake and lifestyle modification could be effective to reduce the body mass in obese persons with SCI without compromising total lean body mass and overall health.[25] However, currently there are no SCI-specific guidelines for prevention and management of overweight.[26] Lack of guidelines makes it difficult to offer the appropriate treatment.[26]

Lastly, physical capacity, in terms of peak power output, seemed to show a clinically relevant benefit due to the behavioral intervention. No effect was found on peak oxygen uptake. This is in line with previous studies in persons with subacute SCI showing larger effects on peak power output than on peak oxygen uptake.[27, 28] In our observational study (chapter 2) it was found that an increase in physical activity of 30 minutes per day was related to 0.11 L/min higher peak oxygen uptake and 4 Watt higher peak power output. Possibly, the increased physical activity level due to the addition of the behavioral intervention was straining enough to lead to more peripheral (muscle) training effects, whereas more straining activity is necessary to acquire additional central effects.

From previous studies on physical capacity and health in persons with SCI in the chronic phase, one study also reported no significant effect of a behavioral intervention on peak oxygen uptake.[10] Another study, using total work expressed in kilopond-meters as an outcome measure, also reported no significant effect of a behavior intervention.[29] A study in adolescents with mobility impairment due to spinal cord dysfunction, without a control group, found significant increases in peak power output but not in peak oxygen uptake.[30] Furthermore, in this latter study, significant effects on body composition were found but not on lipid profile.[30]

Secondary effects: participation and quality of life

It can be concluded that the behavioral intervention did not only impact health-related aspects but also the individuals' social perspective of functioning.[31] The behavioral intervention was effective for increasing participation. This was not only reflected in the domain of mobility, but also in the domains of self-care, domestic life, major life areas, and community life.

General health perceptions seemed to be lower after the intervention. Possibly, due to the intervention persons became more critical or more aware of their own health. Other domains of health-related quality of life did not seem to be affected by the behavioral intervention. Previously, physical activity has been related to quality of life in persons with SCI.[32] However, quality of life is known to be explained by multiple factors such as neuroticism and general self-efficacy, which might predominate quality of life in the subacute phase after SCI.[33]

Working mechanisms of the behavioral intervention

There was not one factor that strongly mediated, but multiple physical and psychosocial factors explained the effect of the behavioral intervention on physical activity. Pro-active coping, exercise self-efficacy, pain disability and helplessness seem important concepts in interventions promoting physical activity in persons with subacute SCI (chapter 9).

Our results confirm different concepts that support the benefits of the behavioral intervention. Firstly, proactive coping, which assumes that persons do not only react on threatening situations, but can also anticipate on situations that may threat or influence their goals in the future.[34, 35] Secondly, helplessness, which refers to emphasizing the aversive meaning of the disease, and is strongly related to the concept of control.[36] Helplessness has been proposed to be an important mediator between condition and well-being.[37] Thirdly, self-efficacy, suggesting that confidence in one's ability to perform certain behavior is strongly related to one's ability to perform that behavior. Higher exercise self-efficacy has previously been linked to more physical activity.[38] Exercise self-efficacy levels were found to be rather high in persons with subacute SCI (chapters 4 and 5). Another study in persons with subacute SCI using a different questionnaire also found high exercise self-efficacy.[39] Despite the high scores, results on exercise self-efficacy confirm previous research proposing that exercise self-efficacy is an important factor in physical activity promotion. The lower exercise self-efficacy found in persons with subacute tetraplegia is in line with previous findings that persons with tetraplegia are less physically active in the year following discharge than persons with paraplegia.[40] The lower confidence with regard to physical activity might indicate that persons with tetraplegia can benefit from extra attention in the promotion of physical activity, e.g. by offering them more sessions in the behavioral intervention. A previous study on exercise self-efficacy in persons with subacute SCI did not find significant differences in exercise self-efficacy between persons with subacute tetraplegia and paraplegia.[39] This is possibly explained by the use of a different questionnaire for exercise self-efficacy assessing more specific constructs, e.g. confidence to engage in moderate and

heavy intensity aerobic and strengthening activity for 10, 20, 30, 45 and 60 minutes without stopping.[39]

Furthermore, pain disability, which refers to the interference of pain on daily activities, seems an important factor when promoting an active lifestyle in persons with subacute SCI. One year after discharge pain disability seemed to increase in the intervention group, referring to more interference of pain on daily activities, while there seemed to be a decrease in the control group. Unfortunately, we did not assess the locations of pain in the current study. In the behavioral intervention, there was no explicit focus on pain. Possibly the behavioral intervention can be optimized when coaches are more aware of pain disability with regard to physical activity and incorporate this in the intervention. Pain is one of the most common secondary conditions in persons with SCI.[17] While there is increased understanding of underlying mechanisms of pain in persons with SCI, treatment is still unsatisfactory and there is an unmet need to improve pain relief.[41]

Social support for exercise behavior and depression only explained a small part of the intervention effect on physical activity. This is not in line with previous studies in which social support has been indicated to be an important facilitator and mental health problems an important barrier for physical activity in persons with SCI.[42, 43]

Fatigue was no strong mediator on the intervention effect on physical activity. This is in line with our baseline results showing no relation between fatigue and physical activity level measured with the activity monitor (chapter 3). Baseline results further show that fatigue, including severe fatigue, was prevalent in 31% of the participants with subacute SCI compared to 18% of persons in the general population. Previous research indicates that fatigue persists in persons with SCI in the chronic phase.[44] Persons with incomplete lesions reported more complaints of fatigue. This was also reported in persons with SCI in the chronic phase.[45] It was proposed that persons with incomplete lesions attempt to complete more activities and rely less on assistive devices or care attendants; therefore, their total daily energy expenditure and the physiological energy cost of specific activities would be larger.[46] The finding that aerobic capacity tended to relate to fatigue indicates that there may be a physical origin of fatigue in persons with subacute SCI. Our finding is consistent with a previous study that showed that less self-reported exercise was related to more fatigue[47] and self-reported heavy intensity activity was related to lower fatigue in persons with SCI in the chronic phase.[48] Fatigue is known to be a multifactorial problem, at least the physical aspect of fatigue might be important to consider in physical activity promotion. Our behavioral intervention was not effective in reducing fatigue. A specific fatigue management program might possibly be more effective.[49]

Handcycle training

Our hypothesis that handcycle training only is not enough for achieving higher levels of physical activity after discharge seems to be supported by our results. Although the control group received handcycle training in addition to regular rehabilitation, they still showed a large decline in physical activity level after discharge. A previous study of van den Berg-Emons et al. 2008[21] reported on the course of physical activity level in participants receiving regular rehabilitation only, as part of the Umbrella project. When we compare these data to our control group receiving handcycle training in addition to regular rehabilitation, the groups show comparable courses in physical activity level after discharge from inpatient rehabilitation as shown in Figure 10.2. In both groups there is a large decline in physical activity after discharge (T3 and T4). It must be noted that the first and third measurement were defined differently in Act-Active and in the study of van den Berg-Emons et al. Overall, the physical activity level in the study of van den Berg-Emons et al. was found to be slightly higher compared to our control group, which might be explained by the general trend that

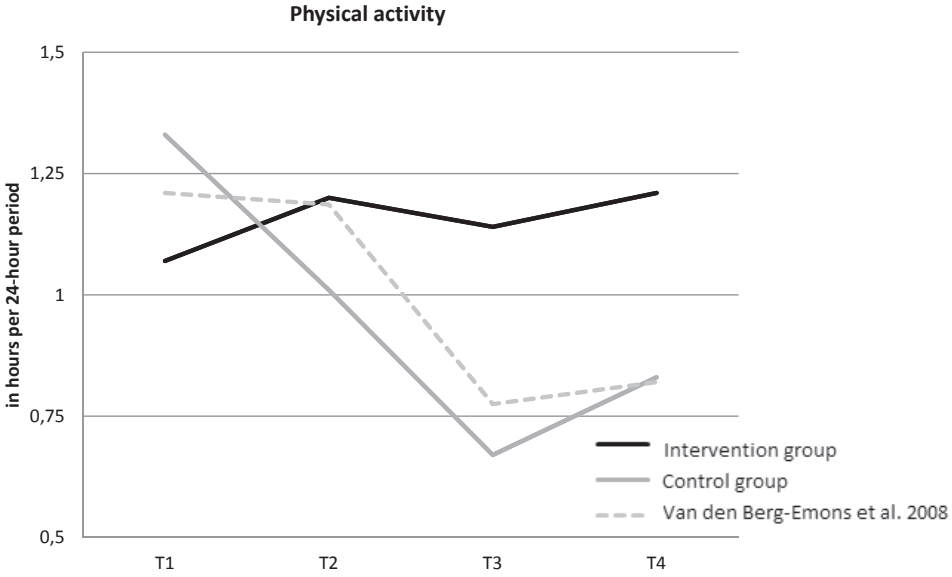

Figure 10.2 Physical activity results of Act-Active and of previous study with regular rehabilitation only (observed data).
T1: Act-Active: 2 months before discharge from inpatient rehabilitation, van den Berg-Emons: after 3 months of active rehabilitation;
T2: At discharge from inpatient rehabilitation (both studies);
T3: Act-Active: 6 months after discharge from inpatient rehabilitation, van den Berg-Emons et al. 2 months after discharge;
T4: 1 year after discharge from inpatient rehabilitation (both studies).

persons have become more inactive during the last 10 years. However, it might also be caused by the new wireless version of the activity monitor that was used in Act-Active, compared to the predecessor with slightly different analysis software as used by van den Berg-Emons et al.

Physical capacity can be regarded as a prerequisite for an active lifestyle. Nevertheless, persons with SCI often have poor physical capacity.[50] Thus, attaining the highest possible capacity during rehabilitation seems important for the success of the behavioral intervention. The results on physical capacity of the participants of Act-Active support previous research that handcycle training is effective in increasing physical capacity in persons with subacute SCI (chapter 6).[27, 51] Overall feasibility of the handcycle training program was good. Training frequency was less than intended. This is commonly reported in training studies in persons with subacute SCI[52] and a portion of this non-attendance is unavoidable in this vulnerable group. More focus on training logistics could improve training frequency and is an important consideration when implementing handcycle training during inpatient rehabilitation. Furthermore, feasibility of the handcycle training seemed lower in persons with complete lesions. This may be partly explained by the higher risk of secondary complications such as urinary tract infections and pressure ulcers in this subgroup.[53, 54] When handcycle training is added to rehabilitation programs for persons with subacute SCI, extra attention for rescheduling missed training sessions or continuing training after clinical discharge might help participants with complete lesions optimally benefit from training.

Methodological considerations

Study design

The design of Act-Active was a single-blind multi-center randomized controlled trial. Research assistants performing the measurements were blinded for group allocation. It was not always possible to keep research assistants blinded for group allocation since they were working as a therapist in the same clinical environment as the participants and coaches of the behavioral intervention. However, for the primary outcome measure, physical activity as measured with the activity monitor, no bias is expected. Principles of the activity monitor were only explained to the participants after the last measurement and data analysis was performed while blinded for group allocation.

The major strength of our randomized controlled trial was the longitudinal design. The follow-up measurement one year after discharge from inpatient rehabilitation was six months

after the end of the behavioral intervention. This six month period was chosen based upon the transtheoretical model of health behavior change.[55] The last stage in this model is the maintenance phase, defined as "being able to sustain action for at least six months and working to prevent relapse". Thus, when able to maintain the higher physical activity level for six months it can be considered as the new behavior. However, it should be mentioned that in the first year after discharge from inpatient rehabilitation changes in other aspects of daily life for persons with SCI, e.g. returning to work, might influence physical activity.

Based on inclusion rates in the Umbrella project, we expected to be able to include more persons in Act-Active.[56] Possibly it is more difficult to include persons in a randomized controlled trial than in an observational study such as the Umbrella project. Furthermore, lesion characteristics and age have changed over the last 15 years.[57, 58] Relatively more persons have incomplete lesions now and are therefore less likely to be dependent on a wheelchair. In addition, relatively more persons are nowadays older than 65 years, and therefore not meeting the inclusion criteria. Furthermore, in Act-Active there were a considerable amount of drop-outs and missing data. This seems to be an insurmountable problem in this vulnerable group. Despite these limitations, we found significant intervention effects.

Most data were missing for the maximal handcycle test and for lipid profile. The maximal handcycle test could not be performed by a considerable amount of persons due to contra-indications for maximal exercise, such as high blood pressure. Data on lipid profile were mainly missing because of logistic problems. Collecting fasting blood samples after discharge, on top of a visit to the rehabilitation center for the physical measurements, was difficult to organize.

All participants received the handcycle training program. Therefore, no actual control group receiving only regular rehabilitation was available to study the effects of the handcycle training on physical capacity. Results were compared to mean increases in physical capacity as measured during the Umbrella project in which persons only received regular rehabilitation. Initially we proposed a study design with a control group receiving only regular rehabilitation. However, in the rehabilitation centers there was already increasing focus on physical capacity training in regular rehabilitation. In addition, there was initial evidence for the effectiveness of handcycle training on physical capacity.[27] Therefore, one can debate whether it is ethical to withhold handcycle training from persons with subacute SCI.

Outcome measures

The measurements performed with the VitaMove activity monitor were intended to be four-day measurements. Unfortunately, this was not uniformly achieved due to technological challenges such as battery failure or user errors such as wearing the activity monitor a week later than requested and therefore without sufficient battery capacity. Furthermore, the VitaMove activity monitor had to be removed during swimming and we had to make corrections based on a diary. However, possible bias seems limited since only one participant reported swimming in the diary during measurements after discharge. Besides, the season is known to be of influence on physical activity.[59] However, participants were included during 2.5 years over all seasons in a random group allocation procedure and therefore no effects of season on between-group differences were expected. Furthermore, for logistical reasons, to limit the burden during the weekend and for comparison of the measurements during inpatient rehabilitation and after discharge, we choose to only measure with the VitaMove activity monitor on weekdays. Therefore, it is unknown what the effect of the behavioral intervention was on physical activity during the weekend.

When comparing the effects on objectively measured physical activity with self-reported between-group effects, the effect on the self-reported measure confirmed our objective results but was relatively much larger (100% vs 50% of the mean). This confirms previous findings that self-reported measures overestimate changes in physical activity level.[60] Therefore, especially in intervention studies where self-reported outcomes could be biased by social desirable answers or by an increased awareness of physical activity, one should be careful to draw strong conclusions on self-reported physical activity.

Although BMI is a classical method used as a measure of obesity and as a predictor of cardiovascular disease and Diabetes, there are indications that BMI is an inconsistent predictor of coronary heart disease in individuals with SCI due to the altered body composition[61, 62] Therefore, waist circumference was also measured since this is known to be highly correlated with visceral adipose tissue in persons with SCI.[63] Unfortunately, analysis of the waist circumference data showed that these data were not accurately measured. Although we instructed our research assistants carefully, they indicated that the measurement was difficult and time-consuming because waist circumference was measured when lying down and needed an extra transfer.

Clinical implications

The addition of a behavioral intervention, on top of regular rehabilitation and handcycle training, did not only result in an increase in physical activity but also in more favorable health and participation. Therefore, we advise to add the behavioral intervention to the regular rehabilitation of persons with subacute SCI. Without the boundaries of a research project, it might be possible to customize the program more to the individual. One option to consider is to offer persons with tetraplegia more sessions in the behavior intervention than those with paraplegia. Furthermore, the intervention might be optimized by focusing more on breaking up long periods of sedentary day time and adding nutrition and weight management as part of the intervention. Besides, it seems important to instruct the coaches on the possible influence of pain disability.

Handcycle training to increase physical capacity seems also an important part of regular rehabilitation to attain the highest possible physical capacity during rehabilitation. Furthermore, handcycle training is possibility fundamental for the success of the behavioral intervention. As proposed by the participants of Act-Active, training should start earlier in the rehabilitation program and the total duration of the training period should be increased. Valent et al. (2010)[27] started training immediately at the start of active rehabilitation in persons with paraplegia and after three months of active rehabilitation in persons with tetraplegia; their study training periods varied from 9 to 39 weeks. They reported no chronic overuse injuries associated with handcycle training; thus, it is likely safe to start training during the early rehabilitation phase.

Recommendations for future research

The behavioral intervention should be implemented in regular rehabilitation of persons with subacute SCI. To facilitate successful implementation, feasibility knowledge is important. Several factors play a role: secondary complications, therapist schedules, patient schedules, materials availability, other rehabilitation activities, and total rehabilitation duration.[64] Continuing data collection, potentially with a simplified measurement protocol, when implementing the behavioral intervention is important to confirm the effectiveness of the behavioral intervention in a larger sample. Additionally, it would be interesting to study effects at a longer follow-up period, e.g. two years after discharge from inpatient rehabilitation. Furthermore, the cost-effectiveness of the intervention is of interest to study.

Besides, physical strain of everyday life in persons with SCI needs further research. The relation between everyday physical activity and physical strain should be assessed. It should be studied whether the average of 1 hour and 10 minutes as found in our study is the highest physical activity level realistic to achieve or if more is possible and desirable to prevent secondary conditions. Furthermore, it should be further studied whether guidelines for physical activity level should be different based on lesion characteristics.

There is a need for more research on sedentary day time in relation to health benefits in persons who are wheelchair dependent. Knowledge on if and how it is possible to break up longer periods of sedentary day time is necessary for this group for which sitting less is not possible and standing up is difficult.

Our research was limited to persons with SCI who were dependent on a manual wheelchair, aged between 18–65 years and the majority was men. Future research should study physical activity promotion in persons with SCI who are (partly) ambulatory, in children with SCI and the older SCI population and in women. Possible the intervention is also effective for persons who are dependent on a manual wheelchair due to other causes than SCI. Further study is necessary in a broader wheelchair dependent population.

Furthermore, more research is needed on preventing overweight in persons with SCI and on SCI-specific nutrition and weight management guidelines. With proper guidelines it is more likely that the rehabilitation staff will be able to identify persons at risk and offer the appropriate treatment.

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Summary

Persons with spinal cord injury (SCI) in inpatient rehabilitation are physically active during therapy sessions. However, after discharge from inpatient rehabilitation, daily physical activity levels are known to decline to a level that is severely low compared to the general population and also low compared to persons with other chronic diseases. More physical activity in persons with SCI has been found to reduce the risk of cardiovascular disease, prevent or reduce secondary conditions, and improve physical fitness and quality of life. During the first months after SCI, persons establish a new routine and therefore this period might be critical to introduce and encourage new habits that incorporate physical activity. The current thesis focuses on the promotion of physical activity in persons with subacute SCI.

The main objective of this thesis was to evaluate the added value of a behavioral intervention, on top of regular rehabilitation and handcycle training, on physical activity in persons with subacute SCI. Additionally, the intervention effects on secondary outcomes as health, participation and quality of life were studied and working mechanisms of the behavioral intervention evaluated. For further insight on the promotion of physical activity in persons with subacute SCI we additionally explored handcycle training feasibility during inpatient rehabilitation. Furthermore, baseline levels of exercise self-efficacy and fatigue were described and relations with demographic- and lesion characteristics were assessed.

The introductory **chapter 1** describes background information concerning SCI, secondary conditions, physical capacity, physical activity, and interventions to promote physical activity. A short description of Act-Active and the Umbrella project is provided. The chapter concludes with the aims and outline of this thesis.

Chapter 2 describes the longitudinal relation between objectively measured physical activity, and physical fitness and lipid profile in persons with subacute SCI. An increase in physical activity level was significantly related to an increase in physical capacity as measured during a maximal exercise test. Furthermore, an increase in physical activity level favorably impacted lipid profile. The results indicate that a more active lifestyle decreases the risk of cardiovascular disease for persons with subacute SCI.

The study described in **chapter 3** estimates the prevalence of fatigue in persons with subacute SCI. Fatigue was prevalent in 31% of the participants, compared to 18% in the general population. Those with incomplete lesions seem to be at higher risk for fatigue. Furthermore, lower aerobic capacity tended to be related to more fatigue. It was concluded that fatigue is of concern in persons with subacute SCI, and because fatigue is known to persist among persons with SCI, interventions reducing fatigue seem necessary.

Chapter 4 describes the psychometric properties of the Dutch version of the exercise self-efficacy scale. The results support the use of the questionnaire as a reliable and valid measure for exercise self-efficacy. In **chapter 5** this questionnaire was used to describe exercise self-efficacy and to assess subgroup differences in persons with subacute SCI. Persons with tetraplegia were found to have lower exercise self-efficacy, indicating that this subgroup might benefit from extra attention in promoting physical activity.

In **chapter 6** feasibility and physical capacity results of handcycle training during inpatient rehabilitation are described. Overall, handcycle training during inpatient rehabilitation in persons with SCI was feasible except for training frequency. Persons with complete lesions demonstrated lower training feasibility. Most participants were satisfied with the handcycle training. Since the improvements in physical capacity were larger than those known to occur in persons with paraplegia receiving only regular rehabilitation, the results suggest that the addition of handcycle training may result in larger increases in physical capacity compared to regular rehabilitation only.

Chapters 7 to 9 describe the added value of a behavioral intervention promoting an active lifestyle after discharge from inpatient rehabilitation, on top of regular rehabilitation and handcycle training, in persons with subacute SCI. **Chapter 7** describes the primary results on objectively measured physical activity. The behavioral intervention was effective in eliciting a behavioral change toward a more active lifestyle among persons with subacute SCI. Addition of the behavioral intervention resulted in 50% more wheeled physical activity half year after discharge from inpatient rehabilitation as well as continuation of the more active lifestyle up to one year after discharge. In **chapter 8** the added value of the behavioral intervention on health, participation and quality of life is described. The addition of the behavioral intervention resulted in a more favorable lipid profile, lower diastolic blood pressure and higher participation one year after discharge from inpatient rehabilitation. Furthermore, there seemed to be an intervention effect on peak oxygen uptake and BMI. Perceptions of general health seemed to be lower after the intervention, while other domains of health-related quality of life did not seem to be affected by the behavioral intervention. As described in **chapter 9**, there was not one factor found to be a strong mediator but multiple parameters partly explained the effect of the behavioral intervention on physical activity. Pro-active coping, exercise self-efficacy, pain disability and helplessness are important concepts in interventions promoting physical activity in persons with subacute SCI. Based on all results of the randomized controlled trial we advise to add a behavioral intervention, on top of handcycle training, to regular rehabilitation.

Finally, **chapter 10** contains the general discussion of this thesis. This chapter describes the main findings, results interpretation and literature perspective. Methodological considerations are addressed. Furthermore, the chapter describes clinical implications and directions and recommendations for future research.

Samenvatting

Mensen met een dwarslaesie in klinische revalidatie zijn lichamelijk actief tijdens therapie. Uit eerder onderzoek is gebleken dat na ontslag uit klinische revalidatie de dagelijkse lichamelijke activiteit afneemt tot een niveau dat zeer laag is vergeleken met de algemene populatie en bovendien laag is vergeleken met mensen met andere chronische aandoeningen. Meer bewegen bij mensen met een dwarslaesie is geassocieerd met een verminderd risico op hart- en vaatziekten, preventie van secundaire aandoeningen en met een betere lichamelijke fitheid en kwaliteit van leven. Tijdens de eerste maanden na de dwarslaesie ontwikkelen mensen een nieuwe routine en daarom lijkt deze periode belangrijk voor het introduceren van nieuwe gewoontes met betrekking tot lichamelijke activiteit. Het huidige proefschrift richt zich op het bevorderen van lichamelijke activiteit van mensen met een subacute dwarslaesie.

De belangrijkste doelstelling van het onderzoek beschreven in dit proefschrift was het bepalen van de toegevoegde waarde van een beweegstimuleringsprogramma, als aanvulling op reguliere revalidatie en handbiketraining, op lichamelijke activiteit voor mensen met een subacute dwarslaesie. Daarnaast zijn de effecten van het beweegstimuleringsprogramma op de secundaire uitkomsten gezondheid, participatie en kwaliteit van leven bestudeerd en de werkingsmechanismen van het beweegstimuleringsprogramma geëvalueerd. Voor meer inzicht in het bevorderen van lichamelijke activiteit bij mensen met een subacute dwarslaesie hebben wij ook de haalbaarheid van handbiketraining als reguliere revalidatiebehandeling onderzocht. Verder zijn de baselinegegevens van eigen-effectiviteit voor bewegen en van vermoeidheid beschreven en de relatie met persoonlijke en laesiekenmerken onderzocht.

In het inleidende **hoofdstuk 1** worden achtergrondgegevens beschreven over dwarslaesie, secundaire aandoeningen, lichamelijke capaciteit, lichamelijke activiteit en interventies om lichamelijke activiteit te bevorderen. Korte beschrijvingen van Act-Active en het koepelproject worden gegeven. Dit hoofdstuk sluit af met de doelstellingen en een overzicht van de inhoud van dit proefschrift.

Hoofdstuk 2 beschrijft de longitudinale relatie tussen objectief gemeten lichamelijke activiteit en lichamelijke fitheid en het lipidenprofiel bij mensen met een subacute dwarslaesie. Meer lichamelijke activiteit was significant geassocieerd met een hogere lichamelijke capaciteit gemeten met een maximale inspanningstest. Ook werd gevonden dat meer lichamelijke activiteit geassocieerd is met een gezonder lipidenprofiel. Er werd geconcludeerd dat een actievere leefstijl het risico op hart- en vaatziekten lijkt te verminderen bij mensen met een subacute dwarslaesie.

In het onderzoek beschreven in **hoofdstuk 3** wordt de prevalentie van vermoeidheid bij mensen met een subacute dwarslaesie geschat. Vermoeidheidsklachten werden gevonden bij

31% van de deelnemers, in vergelijking met 18% in de algemene populatie. Mensen met een incomplete laesie lijken vaker vermoeidheidsklachten te hebben. Daarnaast werd gevonden dat een lagere lichamelijke capaciteit mogelijk samenhangt met meer vermoeidheid. Er werd geconcludeerd dat vermoeidheidsklachten een zorg zijn bij mensen met een subacute dwarslaesie en omdat bekend is dat vermoeidheid ook bij mensen met een dwarslaesie in de chronische fase aanwezig is, lijken interventies om vermoeidheid te verminderen belangrijk.

Hoofdstuk 4 beschrijft de psychometrische eigenschappen van de Nederlandse versie van de eigen-effectiviteit vragenlijst voor bewegen waarmee het vertrouwen in mogelijkheden om te bewegen kan worden gemeten. De gevonden resultaten op betrouwbaarheid en validiteit ondersteunen het gebruik van deze vragenlijst. In het onderzoek zoals beschreven in **hoofdstuk 5** werd deze vragenlijst gebruikt om de eigen-effectiviteit voor bewegen te beschrijven en subgroepverschillen bij mensen met een subacute dwarslaesie te bepalen. Mensen met een tetraplegie bleken minder eigen-effectiviteit te hebben, wat aangeeft dat deze subgroep zou kunnen profiteren van extra aandacht bij het bevorderen van lichamelijke activiteit.

In **hoofdstuk 6** worden de haalbaarheid en de resultaten op lichamelijke capaciteit van een handbiketraining tijdens klinische revalidatie beschreven. Er werd gevonden dat over het algemeen een handbiketraining tijdens klinische revalidatie bij mensen met een dwarslaesie goed haalbaar is, met uitzondering van het behalen van de geplande trainingsfrequentie. Voor mensen met een complete laesie leek de handbiketraining moeilijker haalbaar. De meeste deelnemers waren tevreden over de handbiketraining. Aangezien de verbeteringen in lichamelijke capaciteit groter waren dan eerder gevonden bij mensen met paraplegie, die alleen reguliere revalidatie hebben gevolgd, lijken de resultaten te impliceren dat door de toevoeging van handbiketraining een grotere toename in lichamelijke capaciteit kan worden behaald dan met alleen reguliere revalidatie.

In de hoofdstukken 7-9 wordt de toegevoegde waarde van een beweegstimuleringsprogramma, als aanvulling op reguliere revalidatie en handbiketraining, beschreven voor mensen met een subacute dwarslaesie. **Hoofdstuk 7** beschrijft de primaire resultaten op objectief gemeten lichamelijke activiteit. Het beweegstimuleringsprogramma was effectief in het bewerkstelligen van een gedragsverandering naar een meer actieve leefstijl bij mensen met een subacute dwarslaesie. Door toevoeging van het beweegstimuleringsprogramma waren mensen 50% meer lichamelijke actief in de rolstoel en handbike een half jaar na ontslag van klinische revalidatie, en dit effect bleef behouden tot een jaar na ontslag. In **hoofdstuk 8** wordt de toegevoegde waarde van het beweegstimuleringsprogramma op

de gezondheid, participatie en kwaliteit van leven beschreven. De toevoeging van het beweegstimuleringsprogramma resulteerde in een gezonder lipidenprofiel, lagere diastolische bloeddruk en hogere participatie een jaar na ontslag uit klinische revalidatie. Bovendien leek er een interventie-effect te zijn op het piekvermogen en op de lichaamssamenstelling (BMI). Perceptie van de eigen gezondheid leek lager te zijn na de interventie, terwijl de andere domeinen van gezondheidsgerelateerde kwaliteit van leven niet leken te worden beïnvloed door het beweegstimuleringsprogramma. Zoals beschreven in **hoofdstuk 9**, was er niet één factor een sterke mediator maar verklaarden meerdere factoren deels het effect van het beweegstimuleringsprogramma op lichamelijke activiteit. Pro-actieve coping, eigen-effectiviteit voor bewegen, invloed van pijn op het dagelijks leven, en hulpeloosheid zijn belangrijke concepten binnen een beweegstimuleringsprogramma voor mensen met een subacute dwarslaesie. Op basis van alle resultaten van de interventiestudie raden wij aan een beweegstimuleringsprogramma, als aanvulling op handbiketraining, toe te voegen aan de reguliere revalidatie van mensen met een subacute dwarslaesie.

Tot slot, **hoofdstuk 10** bevat de algemene discussie van dit proefschrift. Dit hoofdstuk beschrijft de belangrijkste bevindingen en de interpretatie van de resultaten. Daarnaast beschrijven we de sterke en zwakke punten van het onderzoek. In dit hoofdstuk bespreken we tevens de klinische implicaties en aanbevelingen voor toekomstig onderzoek.

Dankwoord

Veel mensen hebben een partij in de uitvoering van deze compositie.

Ik noem niet iedereen bij naam, maar dat maakt mijn waardering niet minder groot. Hopelijk herkennen jullie jezelf in de plaatjes in Act-Active stijl en in de muziek.

Ik wil het accent nog leggen op:

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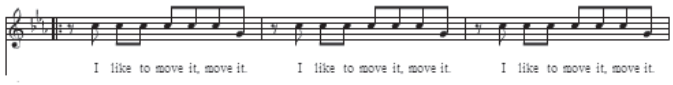
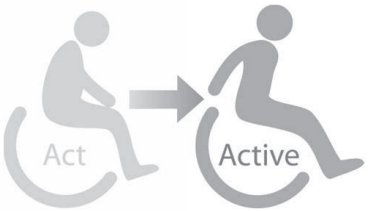
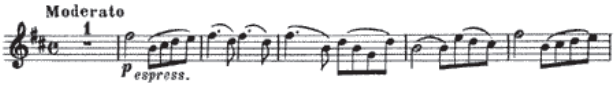
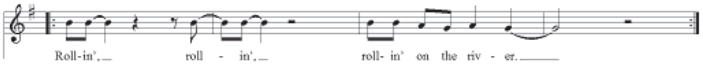
Ik kan niet wachten totdat de pedel het slotakkoord aangeeft en nacht-paranimf Carine het stokje overneemt om samen met jullie allemaal de toegift te laten klinken.









Gemeente Deurne

About the author

Curriculum vitae

Carla Nooijen was born in Deurne on the 23rd of April 1986. She finished high school (VWO) in Deurne in 2004. The same year she started her study Human Movement Sciences at the VU University in Amsterdam. In 2007 she obtained her Bachelor's degree with rehabilitation as a specialization. During her master's study she did an internship at the Miami Project to Cure Paralysis on locomotor training in persons with spinal cord injury. She obtained her master's degree with the predicate cum laude in 2009. In July 2009 Carla started working on the research described in this thesis at the Department of Rehabilitation Medicine of Erasmus MC University Medical Center in Rotterdam. During this period she also worked on other research projects including projects on physical behaviour and physical fitness of adolescents and young adults with cerebral palsy and physical activity of children who are dependent on a wheelchair. Currently, she continues her research work at the Department of Rehabilitation Medicine of Erasmus MC and at Rijndam Rehabilitation Institute. Besides, she is volunteering as an international classifier for para-cycling.

List of publications

Nooijen CF, Stam HJ, Bergen MP, Bongers-Janssen HM, Valent LJ, van Langeveld SA, Twisk JW, van den Berg-Emons RJ, Act-Active Research Group. A behavioral intervention leads to a more active lifestyle in persons with subacute spinal cord injury: a randomized controlled trial. *Submitted*

Nooijen CF, Stam HJ, Sluis TA, Valent LJ, Twisk JW, van den Berg-Emons RJ, Act-Active Research Group. A behavioral intervention promoting physical activity in persons with subacute spinal cord injury: secondary effects on health, participation and quality of life. *Submitted*

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Nooijen CF, Vogels S, Bongers-Janssen HM, Bergen MP, Stam HJ, van den Berg-Emons HJ, Act-Active Research Group. Fatigue in persons with subacute spinal cord injury who are dependent on a manual wheelchair. Spinal Cord. *In press*

Nooijen CF, de Groot JF, Stam HJ, van den Berg-Emons RJ, Bussmann HB, Fit for the Future Consortium. Validation of an activity monitor for children who are partly or completely wheelchair-dependent. J Neuroeng Rehabil. 2015;12:11.

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Houdijk H, ter Hoeve N, **Nooijen CF**, Rijntjes D, Tolsma M, Lamoth C. Energy expenditure of stroke patients during postural control tasks. Gait Posture. 2010;32(3):321-6.

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Nooijen CF, Dubbelman P, ter Horst P, Broeksteeg R, Valent LJ, van den Berg-Emons RJ. The validity and reliability of the power measurement of the Tacx Flow ergotrainer combined with a handcycle. Nederlands Tijdschrift voor Revalidatiegeneeskunde. 2013 december;6:287-92.

PhD portfolio

Summary of PhD training and teaching

Name PhD student: C.F.J. Nooijen
Erasmus MC Department: Rehabilitation medicine
Research School: -

PhD period: 2009–2015
Promotor: Prof.dr. H.J. Stam
Supervisor: Dr. H.J.G. van den Berg-Emons

1. PhD training		
General academic skills		
- CPO course	2010	8 hours
- BROK course	2010	30 hours
- BROK course update	2014	8 hours
- Integrity in research	2010	28 hours
- Biomedical English Writing and Communication	2010	56 hours
Research skills		
- Regression analysis (NIHES)	2010	56 hours
- Longitudinal data analysis (EpidM, VU)	2012	40 hours
In depth courses		
- Motivational interviewing (HAN-VDO)	2009	24 hours
- ECG interpretation	2010	8 hours
- Spinal cord injury (VRA)	2010	8 hours
- Motivational interviewing	2010	24 hours
- Fitness and spinal cord injury	2012	8 hours
- Body Activity Analysis	2012	8 hours
Seminars and workshops		
- VVBN meeting: Van revalidatie naar sport	2009	3 hours
- Minisymposium dwarslaesierevalidatie Rijndam	2009	8 hours
- Congres RCA: 'gedrag in beweging'	2009	8 hours
- PhD school in rehabilitation research, Kopenhagen	2009	50 hours
- Mini symposium Spinal Cord Injury, Enschede	2010	8 hours
- VVBN symposium	2010	8 hours
- Mini symposium Spinal Cord Injury, Rijndam	2010	8 hours
- Mini symposium Spinal Cord Injury, Groningen	2011	8 hours
- NVDG symposium, Groningen	2011	8 hours
- PhD day, Rotterdam	2011	8 hours
- Mini symposium Spinal Cord Injury, Hoensbroek	2011	8 hours
- Mini symposium Spinal Cord Injury, Nijmegen	2013	8 hours
- NVDG symposium, Nijmegen	2013	8 hours
- Mini symposium Spinal Cord Injury, Utrecht	2013	8 hours
- Mini symposium Spinal Cord Injury, Leuven	2015	8 hours
- NVDG symposium, Leuven	2015	8 hours

1. PhD training		
Presentations		
- Oral presentation: VRA Sport en bewegen	2010	8 hours
- Oral presentation: MUSC sports medicine research	2010	8 hours
- Oral presentation: Regionaal refereren Rijndam	2010	8 hours
- Oral presentation: Mini symposium Spinal Cord Injury, Rijndam	2010	8 hours
- Oral presentation: Regionaal refereren Rijndam	2011	8 hours
- Oral presentation: ISCOS/ASIA Washington DC	2011	20 hours
- Oral presentation: PhD day Human Movement Sciences, Erasmus MC	2011	8 hours
- Oral presentation: Wheelchair testing Utrecht	2011	8 hours
- Poster presentation: Groningen sports medicine symposium	2012	8 hours
- Oral presentation: HALYNeD	2012	8 hours
- Oral presentation: Nationale meeting bewegingsagogen	2012	8 hours
- Oral presentation: MoveFoward handbike clinic Rijndam	2013	8 hours
- Oral presentation: MoveFoward handbike clinic Heliomare	2013	8 hours
- Oral presentation: PhD Day Human Movement Sciences, VU	2013	8 hours
- Oral presentation: ISCOS Istanbul	2013	20 hours
- Poster presentation: ISCOS Istanbul	2013	8 hours
- Oral presentation: RehabMove Groningen	2014	20 hours
- Poster presentation: RehabMove Groningen	2014	20 hours
- Oral presentation: ISCOS pre-conference Maastricht	2014	20 hours
- Poster presentation: ISCOS Maastricht	2014	8 hours
- Oral presentation: Heliomare results Act-Active	2014	8 hours
- Oral presentation: Regionaal refereren	2015	8 hours
- Oral presentation: Adelante results Act-Active	2015	8 hours
- Oral presentation: Rijndam results Act-Active	2015	8 hours
- Oral presentation: Mini symposium spinal cord injury, Leuven	2015	8 hours
- Oral presentation: ISCOS/ASIA Montreal	2015	20 hours
- Oral presentation: ICAMPAM Limerick	2015	20 hours
(Inter)national conferences		
- ISCOS/ASIA, Washington DC	2011	28 hours
- Groningen sports medicine symposium	2012	8 hours
- ISCOS, Istanbul	2013	28 hours
- RehabMove, Groningen	2014	28 hours
- ISCOS, Maastricht	2014	28 hours
- ISCOS/ASIA, Montreal	2015	28 hours
- ICAMPAM, Limerick	2015	28 hours
Didactic skills		
- Basic Didactics (RISBO)	2009	32 hours
Other		
- Participating in research meetings department of rehabilitation medicine, Erasmus MC	2009-2015	240 hours
- Organising research meetings department of rehabilitation Medicine, Erasmus MC	2010-2012	50 hours

2. Teaching		
Lecturing		
- Minor rehabilitation medicine for medical students	2010	16 hours
- Medical students in residency: measuring physical activity	2010	16 hours
- Minor rehabilitation medicine for medical students	2011	16 hours
- Minor rehabilitation medicine for medical students	2012	16 hours
- Minor rehabilitation medicine for medical students	2013	16 hours
- Minor rehabilitation medicine for medical students	2014	16 hours
Other		
- Supervising literature review medical students	2010	8 hours
- Supervising student human movement sciences	2012	40 hours
- Supervising literature review medical students	2013	8 hours
- Supervising 2 students human movement technology	2013	30 hours
- Supervising 2 students TU Delft	2013	10 hours
- Supervising research project resident PMR	2013-2015	30 hours
- Supervising literature review medical students	2015	8 hours
- Organising member of the PhD-Day for human movements sciences Rotterdam	2011	12 hours
Total		**1511 hours**