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The role of physical exercise as a stress-coping resource for persons with functionally incomplete spinal cord injury

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List of papers

Paper I

Lannem, A. M., Sørensen, M., Froslie, K. F., & Hjeltnes, N. (2009). Incomplete spinal cord injury, exercise and life satisfaction. *Spinal Cord, 47*(4), 295-300.

Paper II

Lannem, A. M., Sørensen, M., Lidal, I. B., & Hjeltnes, N. (2010). Perceptions of exercise mastery in persons with complete and incomplete spinal cord injury. *Spinal Cord, 48*(5), 388-392.

Paper III

Lannem, A. M., & Sørensen, M. The role of physical exercise, perceived exercise mastery, and stress in persons with incomplete spinal cord injury (SCI). Submitted to Journal of Rehabilitation Medicine.

Paper IV

Lannem, A.M. Physical exercise, stress, coping, burnout and fatigue in persons with incomplete spinal cord injury (SCI). Accepted with minor revisions, October 9th 2011, European Journal of Adapted Physical Activity.

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Abbreviations

ADL	Activity of Daily Living
ASIA	American Spinal Injury Association
AIS	ASIA Impairment Scale
AIS A-E	ASIA Impairment Scale grade A-E
FSS	Fatigue Severity Scale
CATS	Cognitive Activation Theory of Stress
CI	Confidence Interval
LiSat	Life Satisfaction Scale
n	Numbers/sample size
n.s.	Not significant
PA	Physical Activity
PASW	Predictive Analytics SoftWare
PBM	Pines Burnout Measure
PBS	Pines Burnout Scale
PE	Physical exercise
PEM	Perceived Exercise Mastery
PDSS	Physical Disability Stress Scale
QoL	Quality of Life
RCT	Randomised Controlled Trial
SCI	Spinal cord injury
SD	Standard deviation
SPSS	Statistical Package of the Social Sciences
SWB	Subjective well-being
VAS	Visual Analogue Scale
VO_2	Ventilatory Oxygen-uptake
WHO	World Health Organization

Abstract

A spinal cord injury (SCI) changes a person's life in many ways. Physical exercise has traditionally been used in SCI-rehabilitation to maximise the possibilities for a better life by increasing physical capacity, physical function and psychological well-being. In general, research supports that physical exercise is associated with improved physical fitness, health and psychological well-being in persons with SCI. Even so, the level of physical activity is still low in this population, and there is limited knowledge regarding benefits from physical exercise particularly in persons with functionally incomplete SCI.

The main aim of this dissertation was to examine the role of physical exercise on positive and negative health outcomes for persons with incomplete SCI. Using the Cognitive Activation Theory of Stress (CATS) as a framework, the objectives were to investigate how self-perceptions of exercise and coping with disability-stress influenced the association between stress caused by disability and the health outcome.

The overall design of the dissertation comprises a triangulation of methods including the collection of both quantitative and qualitative data. The mixed method approach was carried out across the four coordinated studies, starting with one cross-sectional mailed survey (study1).

The results in study 1 (Paper I), demonstrated that those who performed physical exercise regularly perceived a significantly higher life satisfaction than those who did not exercise. To experience oneself as physically fit, was the only variable which contributed significantly to improved life satisfaction (Paper I). Perceived fitness mediated the association between physical exercise and life satisfaction (new analysis with data from study 1). Study 1 also revealed some puzzling results where more physical exercise was related to lower perceptions of exercise mastery. These results prompted study 2 which was performed in order to compare exercise related self-perceptions in persons with complete and persons with incomplete SCI. The cross-sectional study included both clinical examinations and a questionnaire. Exercise mastery was perceived differently in persons with motor complete and functionally incomplete SCI (Paper II). More in-depth knowledge was needed regarding exercise perceptions and persons with incomplete SCI, and therefore, a qualitative interview-study was performed (study 3). The in-depth exploration indicated that perceived exercise mastery was associated with unrealistic expectations concerning the extent that physical exercise could contribute to regaining or maintaining physical function (Paper III). Increased fatigue was associated with less use of adapted aids. Further, if the total physical demands in life increased above the total resources available, physical exercise seemed to turn into an extra stressor (Paper III). In order to establish the prevalence of the qualitative findings, and learn more about the relationship between the variables studied, a cross-sectional mailed survey, was performed. Physical exercise and the degree of coping with disability-stress mediated the relationship between stress perceived from the disability and both burnout and fatigue (Paper IV).

The main results demonstrated that the role of physical exercise in the health-stress relationship was a double-edged sword for persons with incomplete SCI. On the one hand it played a positive role in this association in that those who exercised experienced higher life satisfaction than those who were physically inactive (study 1). Physical exercise mediated the association between disability-stress and burnout and fatigue (study 4). On the other hand, physical exercise turned into a stressor when the total physical demands in everyday life exceeded the functional capacity (study 3). This is supported both by CATS and other reported research. Perceived fitness mediated the positive relationship between exercise and life satisfaction (study 1), whereas perceived exercise mastery contributed both negatively (study 1) and positively (study 4) to health outcomes. The higher the individuals rated their coping with stress caused by their disability, the lower they scored on both burnout and fatigue.

Keywords: Incomplete spinal cord injury, physical exercise, self-perceptions in exercise, coping with disability-stress, life satisfaction, burnout and fatigue.

1. Background

> "Find a way of training that you enjoy, preferably something which is more than just the usual physiotherapy.
>
> Accept your disability, the fact that you won't necessarily be completely cured, but make the most of what you've got. Sooner or later you'll get used to it anyway.
>
> Just about all forms of physical exercise can be adapted to suit handicapped people. I think it's especially important for people with a disability like mine to keep in good shape, as the ability to cope with everyday life often depends on narrow margins."
>
> (Female, 24 years old, with spinal cord injury since 2000.
> A comment written on one of the questionnaires in study 4)

A spinal cord injury (SCI) changes a person's life in many ways. This dissertation investigated the consequences of a SCI and how physical exercise possibly may enhance the abilities of coping with the demands of everyday life for those living with incomplete SCI. The following sub-sections present information about SCI, recommendations for physical exercise, and a review of the literature on the effects of physical exercise and SCI.

1.1. SCI

The neurological disturbance and the functional impairment due to a SCI depend on the injury level, and whether the injury of the spinal cord is complete or incomplete. The severity of the injury is classified in accordance with the American Spinal Injury Association (ASIA) Impairment Scale (AIS A-E) (Marino et al., 2003; Maynard et al., 1997). This classification system is modified from the five category system to classify completeness, introduced by Frankel and co-workers (Frankel et al., 1969), see Figure 1 and Table 1. In this dissertation, the wording incomplete SCI or functionally incomplete SCI are used synonymously with SCI AIS-D, and the wording complete SCI or motor complete SCI is used synonymously with SCI AIS A-B.

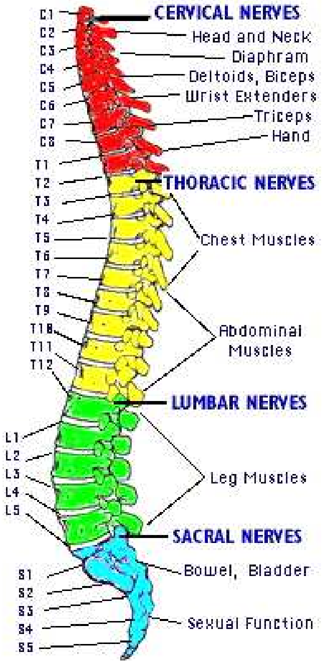


Figure 1.
Illustration of the spinal cord including references to muscle innervations. (http://www.spinalinjury.net)

The term tetraplegia is used when the SCI is located in the cervical part of the spine (coloured red in Figure 1). Tetraplegia results in impairments in all extremities, in addition to central parts of the body. The term paraplegia refers to SCI below the cervical level, i.e. the thoracic, lumbar or sacral levels. Persons with paraplegia have paresis and paralyses in the lower extremities, in addition to parts of the stomach and back muscles, depending on the level of injury, se Figure 1. A cauda equine lesion damages only spinal roots and not the spinal cord itself. A cauda equine lesion is defined as an injury in the lumbo-sacral nerve roots within the neural canal. The results may be a so-called areflexic bladder, bowel- and lower limb paresis/paralysis. Injuries involving the conus medullaris or the cauda equine are usually included into the paraplegia group (Marino et al., 2003).

Table 1.

Classification of injury severity; previous system (Frankel A – E), and current system (AIS A – E).

Frankel (Frankel et al., 1969)		AIS (Marino et al., 2003)	
Frankel A	No Function	*AIS A - Complete*	No sensory or motor function is preserved in the sacral (S) segments S4 - S5.
Frankel B	Only sensory function	*AIS B - Incomplete*	Sensory, but not motor function is preserved below the neurological level and includes the sacral segments S4 - S5.
Frankel C	Some sensory and motor preservation	*AIS C - Incomplete*	Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3 (Grades 0 – 2) (3= Movements against gravity but not against resistance).
Frankel D	Useful motor function	*AIS D - Incomplete*	Motor function is preserved below the neurological level, and at least half of the key muscles below the neurological level have a muscle grade of 3 or more.
Frankel E	Normal function below injury level	*AIS E - Normal*	Sensory and motor functions are normal

There is a distinction between traumatic and non-traumatic injury. A traumatic SCI is an injury caused by an external trauma such as direct or indirect damage to the spinal cord. In Norway, the most common causes of traumatic SCI are traffic accidents, falls or sports injuries (Hjeltnes, 2008). A non-traumatic SCI is a non-progressive damage to the spinal cord, for example caused by infection, circulatory disturbance or a tumor (benign or malignant), or caused by medical or surgical treatment. In addition, a non-traumatic injury can be congenital (hereditary or acquired during pregnancy or childbirth) (Hjeltnes, 2004).

Both the number of people with incomplete injuries and the long-term survival of persons with SCI have increased (DeVivo & Chen, 2011; Hartkopp, Brønnum-Hansen, Seidenschnur, & Biering-Sørensen, 1997). Persons living with SCI are confronted with various health problems related to associated conditions or to secondary conditions, even many years post injury (Bloemen-Vrencken, de Witte, Post, & van den Heuvel, 2007; Dunn, Love, & Ravesloot, 2000; Hitzig, Campbell, McGillivray, Boschen, & Craven, 2010; Hitzig, Eng, Miller, & Sakakibara, 2011; Krahn, Suzuki, & Horner-Johnson, 2009; Middleton, Lim, Taylor, Soden, & Rutkowski, 2004). Included in these health-risks is also physical inactivity. Physical exercise is of particular importance in order to prevent cardiovascular diseases in the population of persons with SCI (Wahman, Nash, Lewis, Seiger, & Levi, 2010; Wahman et al., 2010). In the following, findings related to physical exercise and SCI will be presented.

1.2. Physical exercise for persons with SCI

"*The World Health Report 2002 - Reducing Risks, Promoting Healthy Life*", published by WHO, focuses on health risks. Physical exercise was introduced as a health promoter. Among the most serious risk factors, are those predominating in wealthy societies, i.e. high blood pressure and high blood cholesterol level, tobacco and alcohol consumption, obesity and *physical inactivity* (WHO, 2002). Physical inactivity has been identified as the fourth leading risk factor for global mortality, and therefore WHO has focused on physical activity for health (WHO 2010). For health benefits, adults (aged 18-64 years) should perform at least 300 minutes of moderate-intensity aerobic physical activity per week (WHO 2010). In Norway, the Norwegian Directorate of Health has proposed similar recommendations with a minimum of 30 minutes brisk walking daily (Jansson & Anderssen, 2008).

Haskel, Blair and Hill (2009) reported that persons with physical disabilities are among the least active populations, and that they have more to gain from increasing the level of physical activity than the general population.

The positive connection between exercise and health-condition in persons with SCI was established in a clinical context by Sir Ludwig Guttmann more than sixty years ago (Guttmann, 1976; Scruton, 1998). He found that sport activities positively influenced physiological, psychological and social SCI-rehabilitation, and Guttmann therefore integrated sport activities in the rehabilitation programme for patients at Stoke Mandeville Hospital, UK. Even so, previous studies of physical activity and physical exercise have reported low levels of physical activity and physical capacity in persons with SCI (Buchholz, McGillivray, & Pencharz, 2003; Haisma et al., 2006; Hjeltnes & Wallberg-Henriksson, 1998; Janssen, Dallmeijer, Veeger, & van der Woude, 2002; Martin Ginis et al., 2010b; Saebu & Sorensen, 2010). Martin Ginis et al. (2010b) reported that those using a wheelchair for ambulation were more active than those using walking aids for ambulation.

1.3. Review of literature on physical exercise and SCI

In 2007, a review of the literature was performed by searching BibsysAsk, Medline, PubMed, and Google Scholar in order to identify appropriate literature on physical exercise and SCI. The purpose of the searches was to get an updated base of literature when performing the studies on SCI and outcomes of exercise. The focus was on literature published from 2000 – 2007 including the key words: spinal cord injury, health, exercise, physical activity, quality of life, life satisfaction, and combinations of these.

In order to identify the most recent literature, a new search with the same keywords was performed in May 2011. The search was limited to include review articles from 2006-2011. An overview of recent review-articles presenting the effects of physical activity, exercise and physiotherapy interventions on SCI is given in Table 2. The overview also includes one meta-analysis. The quality of each article was assessed using the Grading of Recommendations Assessment Development and Evaluation (GRADE) guidelines and presented in Table 2 (Balshem et al., 2011; Guyatt et al., 2011a; Guyatt et al., 2011b; Guyatt, Oxman, Schunemann, Tugwell, & Knottnerus, 2011c; Guyatt et al., 2011d). It should be noted that the assessment was made by one person only (the author of this dissertation). Review-articles that included research on persons with complete SCI exclusively were not included.

The search in 2007 revealed a considerable amount of literature. Quantitative measurements have been used to report physiological and functional improvements from physical exercise, i.e. oxygen consumption, metabolic changes, walking distance or other measures of activities in everyday life (Janssen et al., 2002; Nash, 2005; Zoeller, Jr. et al., 2005). Also changes in psychological parameters such as quality of life (QoL) and well-being related to a physically active life-style has been reported (Devillard, Rimaud, Roche, & Calmels, 2007; Latimer, Martin Ginis, & Hicks, 2005; Manns & May, 2007; Post, de Witte, van Asbeck, van Dijk, & Schrijvers, 1998; Tasiemski, Kennedy, Gardner, & Taylor, 2005). Even with the great number of articles, the literature was limited regarding persons with incomplete injuries and physical exercise exclusively.

The result of the search in 2011 (presented in Table 2) was based on review articles and one meta-analysis. The qualities of the articles were assessed to be of moderate and high quality according to the GRADE guidelines (Balshem et al., 2011; Guyatt et al., 2011c). The result verified that early initiation of rehabilitation was recommended (Labruyere, Agarwala, & Curt, 2010). There was some initial evidence of the effect of exercise regarding fitness, strength and function, however all the authors point out methodological weaknesses due to small sample sizes and lack of

Table 2. Summary of recent review-articles (2006-2011) on physical exercise in persons with SCI.

Author(s); year; Quality of review (GRADE)	Identified abstracts; Included papers	Type of participants	Objective	Results. Weaknesses
Swinnen et al. 2010 High quality	722 papers identified, 37 papers selected, 6 studies included	SCI AIS C-D	To assess the effects of walking-related function.	There is insufficient evidence to draw conclusions that robot-assisted gait training improves function more than other locomotor training strategies. Small sample sizes, methodological flaws and heterogeneous training procedures are common.
Labruyère et al. 2010 High quality	508 identified, 3 papers selected	Traumatic SCI, adults.	Among the objectives were to assess the optimal timing for initiating active rehabilitation following acute SCI.	A strong recommendation for early initiation of rehabilitation.
Martin Ginis et al. 2010 Meta-analysis Moderate quality	21 studies included	SCI, paraplegia and tetraplegia. AIS score not specified.	To determine if there is an association between PA and SWB among people with SCI.	There is small to medium-sized positive relationship between PA and SWB in persons with SCI.
Harvey et al. 2009 Australia High quality	4543 abstracts, 65 full papers reviewed, 31 RCT included	At least 75% SCI; No restriction on time post-injury, type of injury or age.	To assess physical intervention typically provided by health-care professionals.	The review provided initial evidence of the effectiveness of fitness training, strength training, gait training and acupuncture. Also low-quality trials with inherent biases are included.

Table 2. Summary of recent review-articles (2006-2011) on physical exercise in persons with SCI, cont.

Author(s); year; country; Quality of review (GRADE)	Identified abstracts; Included papers	Type of participants	Objective	Results. Weaknesses
Spooren et al, 2009 High quality	316 articles identified, 12 studies included.	SCI, Cervical lesions, Complete and incomplete	To assess intervention studies on outcome of motor training on arm and hand functions.	Motor training programmes may improve arm and hand functioning at function and/or activity level in cervical spinal injured patients. No general conclusion based on a meta-analysis can be drawn due to the wide variety of approaches.
Kloosterman et al, 2009 High quality	447 articles identified, 8 studies included	SCI, Cervical lesions, Complete and incomplete	To investigate the effect of exercise therapy on the upper extremity motor control and functional ability.	Most of the studies reported a positive effect of exercise training. Small number of clinical and randomised controlled trials. The authors recommended more specific research.
Hettinga et al, 2008 High quality	53 articles identified 35 studies included	SCI, AIS score not specified	To identify what levels of VO_{2peak} or $VO_{2sub\text{-}peak}$ can be achieved during FES-exercise in SCI.	VO_2 during FES-rowing or FES-hybrid exercise is considerably higher than during FES-cycling.
Mehrholz et al, 2008 High quality	33 studies identified 4 studies included	SCI, all levels, AIS B, C or D	To assess the effects and acceptability of locomotor training, defined as the repetitive practice of complex gait cycles, i.e. treadmill-based walking.	There is insufficient evidence that any 1 approach to locomotor training is more effective than any other for improving the walking function for people with SCI. Small number of trials and small sample sizes.

Table 2. Summary of recent review-articles (2006-2011) on physical exercise in persons with SCI, cont.

Author(s); year; Quality of review (GRADE)	Identified abstracts; Included papers	Type of participants	Objective	Results. Weaknesses
Valent et al. 2007 High quality	1309 papers identified, 40 paper selected, 25 papers included	SCI, all levels, AIS A-E	To assess the effect of different modes of upper body training on physical capacity and power output, on people with paraplegia and tetraplegia.	Regular exercise for people with SCI seems beneficial for overall fitness. Due to the low number of studies and the overall low quality it is not possible to derive definitive evidence-based conclusions.
Devillard et al, 2007 Moderate quality	185 studies identified, 62 references reviewed, 30 studies included	SCI, AIS score not specified	Address recent results of training, i.e. the effects on all physiological systems, on function, psychological state or well-being.	Reconditioning training programme after SCI has a direct impact on function and QoL, participation in physical activities in addition to daily living activities in subjects with SCI.
Haisma et. al, 2006 Moderate quality	1105 studies, 67 studies assessed, 52 studies included	Wheelchair-dependent persons with complete and incomplete SCI.	To assess the level of physical capacity in wheelchair-dependent persons with SCI.	The level of physical capacity is reduced and varies in persons with SCI. The variation between results is caused by population and methodological differences.

Quality of evidence across studies for the GRADE of outcome (Balshem et al., 2011).
High GRADE = We are confident that the true effect lies close to that of the estimate of the effect.
Moderate GRADE = The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low GRADE = The true effect may be substantially different from the estimate of the effect.
Very low GRADE = Any estimate of effect is very uncertain.

Abbreviations: AIS = ASIA Impairment Scale; FES = Functional Electrical Stimulation; RCT = Randomised Clinical trial; SCI = Spinal Cord Injury; VO_{2peak} = Peak Ventilatory Oxygen-uptake.

controls in many of the studies (Devillard et al., 2007; Harvey, Lin, Glinsky, & De, 2009; Kloosterman, Snoek, & Jannink, 2009; Spooren, Janssen-Potten, Kerckhofs, & Seelen, 2009; Valent, Dallmeijer, Houdijk, Talsma, & van der, 2007). Gait training of various types seemed effective regardless of type of intervention, i.e. treadmill therapy with or without body weight support, over ground walking or with robot assistance (Swinnen, Duerinck, Baeyens, Meeusen, & Kerckhofs, 2010; Mehrholz, Kugler, & Pohl, 2008).

Martin Ginis, Jetha, Mack and Hetz (2010a) concluded in their meta-analysis of cross-sectional, quasi-experimental and experimental studies, that there was a small to medium-sized relationship between physical activity and subjective well-being in persons with SCI.

In conclusion, physical exercise seems to be effective in order to increase and maintain health regarding functional improvement and psychological well-being both during rehabilitation and later. Even so, the level of physical activity is still low in the population. The literature is mostly on physiological and general psychological effects, and less is known about psychological processes and mechanisms related to physical exercise and persons with incomplete SCI. There is a need for a theoretical framework to inform these processes, and in the following chapter the search for this framework will be presented.

2. Theoretical Framework

We need to better understand psychological processes and mechanisms related to physical exercise for this group. A theoretical framework is a necessary tool in such an endeavour. Living with a SCI creates problems in everyday life and may be considered a stressor. Various theories have been used in order to explain the relationship between stress, coping and health (Coleman & Iso-Ahola, 1993; Israel, Baker, Goldenhar, Heaney, & Schurman, 1996; Iwasaki & Mannell, 2000; Lazarus, 1999; Lazarus, 2000; Ursin & Eriksen, 2004; Ursin & Eriksen, 2010). The cognitive stress and coping theory developed by Lazarus (1999) comprises that the balance in a stress-coping relationship is an interaction between the demands an individual are faced with and the individual's resources to cope with these demands. Lazarus (1999) definition of coping includes both positive and negative outcome result. Israel et al. (1996) presented a conceptual framework of the health-stress process. The model includes stressors as harmful, threatening, or bothersome (Israel et al., 1996). Further, the effects of the stressors are not necessarily negative. Factors such as social support, personality and genetic factors, coping abilities, health status, exercise and other behavioural habits may buffer the relationship between perceived stress and short term response to stress which in turn influence the long-term health outcome. Coleman and Iso-Ahloa (1993) presented a theoretical model of the relationship between stress, health and leisure activities. Iso-Ahola and Park (1996) followed up with a cross-sectional study that demonstrated that leisure activities (i.e. things done with friends) buffered the effects of stress on physical and mental health. Based on the relationship between stress and health described by Coleman and Iso-Ahloa, Iwasaki and Mannell (2000) introduced an even more elaborated model with several hierarchical dimensions.

Within the Cognitive Activation Theory of Stress (CATS) it is possible to predict health consequences, and expectancies and coping are central concepts (Ursin & Eriksen, 2004; Ursin & Eriksen, 2010). The role of expectations based on learning is seen as essential for coping. In relation to this dissertation, CATS, therefore, seemed to cover the relevant aspects of SCI perceived as a stressor in everyday life, the appraisals of the stressors leading to different ways of coping with the stressors as well as the long term health outcome. CATS will be explained in greater detail in the next sub-section.

2.1. The Cognitive Activation Theory of Stress (CATS)

CATS` focuses on total health resources (physiological, psychological and social). The theory considers how the overall health resources respond to stressors of everyday life. It examines how stressors are perceived and coped with. Four different aspects are defined and operationalized: stress stimulus (stressor), stress experience (perceptions), an unspecific, general stress response and the personal experience that form the expectancies of the stress response (Ursin & Eriksen, 2004; Ursin & Eriksen, 2010). The general non-specific stress response can be viewed as an alarm to raise neuro-physiological activation to a higher level. The alarm is activated when something is missing or unexpected and which triggers physical reactions in the body. Whether the stressor is edifying or frightening, depends upon the individual's assessment of the situation. The level of alarm depends on the outcome expectations and the resources available for coping. The stress response is a necessary physiological response, and this response is not dangerous in itself. It is only when this response is maintained long-term that it can lead to negative health consequences. The alarm also facilitates behaviour to cope with the situation. According to CATS "coping is defined as "positive response outcome expectancy" (Ursin & Eriksen, 2010). In other words, the person has established the belief that he or she will cope with the stressor in a positive way. Previous experience, education and learning will also improve the expectation of how to cope with different types of stimuli. If there is either no relationship or a negative relationship between the individual's attempts to manage and the outcome, helplessness or hopelessness may develop. Helplessness occurs when there is no relationship between anything the person does and the outcome. Hopelessness is more directly the opposite of coping with negative response outcome expectancy. Both helplessness and hopelessness may lead to sustained arousal, which, in turn, may lead to illnesses or poor health outcome such as burnout or fatigue. In this way, CATS highlight the coping attempts and learning process which in turn lead to the final outcome (i.e. physiological and psychological health or disease/distress).

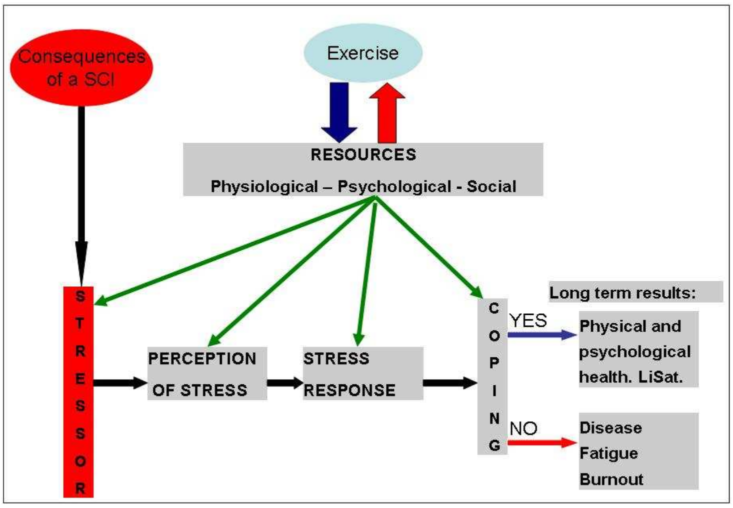


Figure 2.
Illustration of CATS in relation to persons with SCI and physical exercise. The stressor is represented by the consequences of a SCI. The resources in all fields will influence how the stressor(s) are perceived in different situations, reaction to the stressor(s), as well as how the perceived stressor(s) are coped with.

A SCI affects a person’s life in several ways, and all obstacles perceived in daily living due to restrictions or consequences of the SCI can be explained as a stressor according to CATS. Figure 2 illustrates that physical exercise may create resources in different areas. We know that exercise can be a positive resource against illness in the general population (Kobasa, Maddi, Puccetti, & Zola, 1985; Haskell et al., 2009). Persons with SCI may likewise develop protective health resources through physical exercise in physiological, psychological and social fields. When a person with SCI performs physical exercises, physiological components such as muscle strength and endurance capacity may increase (Harvey et al., 2009; Valent, Dallmeijer, Houdijk, Talsma, & van der Woude, 2007). Exercise may also influence various psychological parameters such as coping skills, self-perceptions and well-being (Fernhall, Heffernan, Jae, & Hedrick, 2008; Latimer, Ginis, Hicks, & McCartney, 2004; Latimer et al., 2005). In addition, exercise may lead to social resources as part of a network and an arena for social support (Anneken, Hanssen-Doose, Hirschfeld, Scheuer, & Thietje, 2010).

Based on the CATS framework the present knowledge about SCI and physical exercise demonstrates the possible importance of exercise for building and/or maintaining a person’s health resources and coping with the stressors of everyday life, and thereby the long term health consequences. Before an introduction of how CATS was used to inform the studies of this dissertation the central concepts in the dissertation will be presented.

3. Central Concepts in the dissertation

This dissertation is not an attempt to test the CATS theory as such; however relevant aspects from CATS related to SCI and exercise are examined. These are: the disability experienced as a stressor in everyday life, coping with the stressor(s) and positive or negative outcomes, i.e. positive health measured by life satisfaction or reduced health measured by burnout and fatigue.

The following sub-sections (3.1 – 3.5.3) define stress, physical activity and physical exercise, perceived exercise mastery, coping with stress, health and life satisfaction, burnout and fatigue as the central concepts in the dissertation.

3.1. Stress

Historically, the concept of stress can be traced back to the 13th century England, when used in conjunction with the concept of wear (strain) (Ursin & Eriksen, 2004). Stress is a term often heard in everyday speech: we rush to catch something, we experience stress in relation to requirements in everyday life. We are supposed to do everything in a limited timeframe. For scientific use, the term "stress" needs a clearer definition. Hans Selby introduced the concept of stress and stressor in his research 60 to 70 years ago (Ursin & Eriksen, 2004). However, there has been much confusion about the concept, and the term is used both as a stimulus, process and reaction. What we experience as stress, how much and how we react to stress, and how long we let it bother us is individual. Levine refers to several stress definitions and emphasizes that all are problematic in that this is a multidimensional concept, and the different components interact (Levine, 2005).

With the cognitive activation theory of stress (CATS), Ursin and Eriksen (2004) defined four different aspects of stress as the load which is evaluated by each individual. In this dissertation the 4 aspects of stress are examined in relation to the possible stressor(s) caused by the SCI evaluated by the individual.

3.2. Physical activity (PA) and physical exercise (PE)

Caspersen, Powel and Christenson (1985) defined physical activity (PA) as “any bodily movement produced by skeletal muscles that result in energy expenditure” (p. 126). Physical activity is positively associated with physical fitness. Physical activity in everyday life is a broad term including activities related to work, leisure time activities including sports, housework etc. Caspersen et al. (1985) defined physical exercise (PE) as a subgroup of physical activity, which is “planned, structured, repetitive, and purposive in the sense that improvement or maintenance of one or more components of physical fitness is an objective”, see Table 3.

Table 3
Elements included in physical activity and exercise (Caspersen, Powell, & Christenson, 1985).

Elements of physical activity and physical exercise	
Physical Activity	Physical Exercise
1. Bodily movement via skeletal muscles. 2. Results in energy expenditures. 3. Energy expenditure (kilo-calories) varies continuously from low to high values. 4. Positively correlated with physical fitness.	1. Bodily movement via skeletal muscles. 1. Results in energy expenditures. 2. Energy expenditure (kilo-calories) varies continuously from low to high. 3. Very positively correlated with physical fitness. 4. Planned, structured, and repetitive bodily movement. 5. An objective is to improve or maintain physical fitness component(s).

In this dissertation, we differentiated between physical activity and physical exercise and thus followed the definitions used by Caspersen et al. (1985).

3.3. Perceived exercise mastery (PEM)

During the rehabilitation process, persons with SCI learn to use physical exercise to improve and maintain physical function and health. Physical exercise is recommended as a part of a lifelong protective routine in order to reduce complications and positively enhance fitness and well-being. In order to continue using routine exercise, it is important to experience mastery of exercise (McAuley & Blissmer, 2000). In this dissertation, Perceived exercise mastery (PEM) is defined according to Sorensen (1997) as "perceived competence when performing physical exercise".

3.4. Coping

Lazarus and Folkman in their research on stress and coping discriminated between active, problem-solving coping strategy and, a passive or emotional coping strategy (Folkman, 1984; Lazarus, 1999). The problem solving strategies focus on reducing the source of stress, and passive coping strategies aim at adapting to the stress. Lazarus (2000) emphasized that coping is the psychological analogue of action tendencies. Laux and Weber (1991, as cited in Lazarus 2000) argued that coping is a way of dealing with the changed, hence newly motivated, person-environment relationship.

CATS views coping in a positive way, and defines it as "positive response outcome expectancy", as opposed to helplessness and hopelessness (Ursin & Eriksen, 2004). This means that if an individual expect to handle the stressor in a positive way, the arousal will be short and no harmful health consequences will occur. If, however, the individual expects to be unable to handle the stressor, the arousal will persist, and may result in hopelessness. CATS also emphasises the learning aspects in coping. The arousal will also persist if there is no relationship between the coping attempt and the outcome, i.e. helplessness, see page 20. In this dissertation, coping with stress related to the disability is therefore defined as “either fulfilment of expectations of physical function or successful adjustment of expectations to actual physical function”.

3.5. Health

Health can be viewed from different perspectives, and throughout the ages, various theorists have tried to define the concept of health. World Health Organization (WHO) defined health in 1948, and the definition has remained unaltered (WHO, 2011): “Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.” Health is a contingent on total assets and total loads including physical, psychological and social dimensions, each characterised on a continuum with positive and negative values. In this dissertation positive and negative health is defined according to Bouchard and Shepard (1993). They stated that positive health is associated with a capacity to enjoy life and to cope with challenges, as opposed to negative health which is associated with illness. Further, Bouchard and Shephard (1993, p. 19) defined wellness “as a holistic concept, describing a state of positive health in the individual, and comprising physical, social and psychological well-being”. On this basis, the positive health outcome is measured as a subjective component of well-being, and the negative health outcome is measured by both burnout and fatigue as described in the three following sub-sections.

3.5.1. Life satisfaction

Life satisfaction is a measure of one positive aspect of health, namely of an individual’s level of well-being and happiness; a subjective component of quality of life (QoL). Dijkers (2005) concluded that persons with SCI reported lower level of QoL than persons without SCI, regardless of definition of the concept of QoL used. Life satisfaction is understood within a personal and subjective reference frame. The underlying concept is that measuring a person’s level of satisfaction is best done by measuring his contentment with life as a whole and within different domains. If there is harmony between the personal goals that have been set and the goals that have been reached, the experience of being satisfied with life as a whole or with one or more of the different life domains will be greater. Alternatively, the person will feel dissatisfied if the gap between the goal and the possibility of reaching the goal is too wide. A person's experience of life satisfaction reflects the extent to which the person achieves his vital goals (Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991). In this dissertation, the definition of life satisfaction is "one aspect of positive health, the individual's level of satisfaction with domains of life" as measured by the LiSat-9 scale.

3.5.2. Burnout

The term burnout comes originally from studies on work-related stress. Work-related burnout is defined as "a psychological syndrome of emotional exhaustion, depersonalisation, and reduced personal accomplishment that can occur among individuals who work with other people in some capacity" (Maslach, 1993, p. 20). Further, the reduced personal sense of accomplishment refers to: "a decline in one's feelings of competence and successful achievement in work" (Maslach, 1993, p. 21). Based on this concept, Raedeke (1997) and Raedeke and Smith (2001) described athlete burnout as a multidimensional syndrome involving emotional and physical exhaustion, reduced sense of accomplishment in sport and devaluation of participation in sport. In a sporting context, Lemyre, Hall and Roberts (2008) argued that long-lasting physical exhaustion may contribute to the development of burnout. (Lemyre, Hall, & Roberts, 2008) In this dissertation the term burnout is defined as "a multidimensional syndrome involving emotional and physical exhaustion, reduced sense of accomplishment in physical activity in everyday life, and devaluation of participation in physical activities in everyday life." In this dissertation burnout is measured by Pines burnout measure (PBM) which is considered a context-free measure of burnout.

3.5.3. Fatigue

The term fatigue can be defined as an overwhelming sense of tiredness, lack of energy and, often, a feeling of total exhaustion (Herlofson & Larsen, 2002). While burnout is more strongly linked to psychological factors, prolonged fatigue is more related to physical problems (Leone, Huibers, Knottnerus, & Kant, 2009; Leone, Wessely, Huibers, Knottnerus, & Kant, 2010). In this study, the term fatigue is used as a symptom, and not as the diagnosis Chronic Fatigue Syndrome (CFS) (Wessely, 2001; Huibers et al., 2003). Furthermore, Leone et al. (2010) argued that CFS and burnout are different concepts, but that the relationship between them should be examined further. Fatigue is a frequently reported symptom in a large number of neurological disorders and, is characterized by a feeling of constant exhaustion, including both a sense of physical exhaustion and an important cognitive component, a sense of mental fatigue (Chaudhuri & Behan, 2004). Fatigue is also reported as an extra symptom for persons living with SCI (Anton, Miller, & Townson, 2008; Fawkes-Kirby et al., 2008; Jensen, Kuehn, Amtmann, & Cardenas, 2007; McColl et al., 2003). In this dissertation, fatigue is defined according to Herlofsen and Larsen (2002) as “an overwhelming sense of tiredness, lack of energy and, often, a feeling of total exhaustion”, as measured by Fatigue Severity Scale (FSS).

4. Aims of the dissertation

The relevant literature indicated that among persons with SCI exercise is associated with improved physical fitness, health and subjective well-being (Devillard et al., 2007; Harvey et al., 2009; Hettinga & Andrews, 2008; Kloosterman et al., 2009; Labruyere et al., 2010; Martin Ginis et al., 2010a; Mehrholz et al., 2008; Spooren et al., 2009; Valent et al., 2007). Consequently, physical exercise has been recommended as a key component of health interventions for persons with SCI (Bouchard, Shephard, & Stephens, 1993; Jacobs & Nash, 2004; Nash, 2005; Rimmer, 1999).

The existing knowledge is based mostly on studies not differentiating between persons with complete and incomplete SCI, or on studies with complete injuries. Very little is known about activity levels, exercise and health consequences exclusively for persons with incomplete SCI.

The main aim of this dissertation was therefore:

"*to examine the role of physical exercise on positive and negative health outcomes for persons with incomplete SCI, and to investigate how self-perceptions in exercise and coping with disability-stress influences the relation between stress caused by the disability and the health outcome*".

In order to fulfil this aim, the cognitive activation theory of stress (CATS) was used as a framework, and the following four research questions were formulated:

1. Is physical exercise associated with positive health outcome measured by life satisfaction in persons with SCI, and what are the roles of perceived exercise mastery and perceived fitness in this association?
2. Do persons with motor complete and persons with incomplete SCI experience similar self-perceptions in exercise, and which factors explain the variance in perceived exercise mastery?

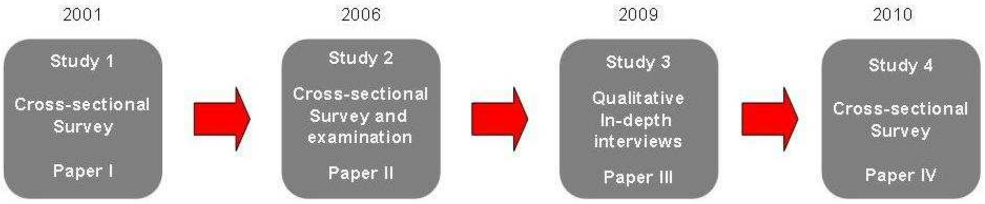
3. Why or in what situations do persons with incomplete SCI experience high or low perception of exercise mastery, and how is this associated with stress, coping, fatigue or burnout?
4. What is the prevalence of burnout and fatigue in a Norwegian population of persons living with incomplete SCI, and what are the roles of physical exercise and the degree of coping with disability-stress in the association between stress caused by the disability and burnout or fatigue?

5. Methods

5.1. Overall project design

The overall design of the dissertation comprises a triangulation of methods including both quantitative and qualitative data collections (Greene, 2008; Patton, 2002). The mixed method approach was carried out across four coordinated studies, starting with two cross-sectional studies leading into one qualitative study with in-depth interviews, and followed up by another cross-sectional survey, see Figure 3.

Figure 3. Overall project design



In cooperation with an epidemiological study performed at Sunnaas Rehabilitation Hospital, 2001 – 2006, the two first data-collections within this dissertation, were made possible (Lidal, 2010). These data-collections resulted in Paper I, and Paper II. The results from the first two studies revealed some questions that needed further investigation and a qualitative study with in-depth interviews was performed in 2009. Based on the qualitative findings a new cross-sectional survey was carried out in 2010.

In order to minimize bias from general changes due to aging in the four studies, persons above 60 years at the time of injury were excluded, as well as persons who were unable to respond to the questionnaire.

5.2. Study 1 (Paper I): Study design, participants, data collection and statistical analyses

The design of the study was a cross-sectional survey. Included in the study were persons with traumatic SCI rehabilitated at Sunnaas Rehabilitation Hospital before 1992. About 50 % of the total population of persons with need of rehabilitation after a SCI in Norway is rehabilitated at this particular Hospital (catchment area south-eastern Norway).

From Lidal's (2010) epidemiological study, a total of 67 persons with SCI (D) were identified. This was a rather small sample, and we decided to include 10 more years of data from the hospital's register. In total, 579 persons (AIS A-E, or Frankel A-E) injured before 1992 were identified and still alive. To be included in the study, the injury had to be classified as incomplete according to Frankel D (Frankel et al., 1969; Maynard et al., 1997; Marino et al., 2003). Owing to the incomplete data available in old medical records, Frankel classification was used. In total, 100 persons fulfilled the inclusion criteria and received the questionnaires used in this study. After two reminders, 72 respondents (72 %) returned the questionnaire. Two returned questionnaires were excluded due to wrong diagnoses, and one respondent was excluded because of dementia senilis. The final sample consisted of 69 participants. In accordance with ethical regulations, it is not possible to compare with the non-respondents.

Demographic and injury related data were extracted from the medical records, and exercise habits, exercise hours per week, self-reported walking distance, self-perception in exercise and life satisfaction were combined in a mailed questionnaire (Appendix III).

Statistical analyses were conducted by using SPSS 15.0 for Windows. Descriptive statistics were used to characterize the sample. Data were summarised by mean values and standard deviations (SD) or median and range when appropriate. Comparisons of data on life satisfaction, perception of exercise mastery and perception of fitness for the active and non-active groups were made by using two-sample t-tests and Pearson's chi-square tests. Comparisons of physical exercise in the study population and the general population were done by confidence intervals (one-sample t-tests) due to the large difference in sample sizes. Comparisons of life satisfaction in the study population and the Swedish reference population were done by z-tests for comparison of two proportions. An open factor analysis with direct oblique rotation was used on the Life Satisfaction Scale to establish subscales because some correlations between the subscales could be expected. Linear regression analysis was used to study the relationship between life satisfaction and a set of covariates, including gender, age, time since injury, injury level, physically active or physically inactive, exercise hours per week, perceived exercise mastery and perceived fitness. In order to test the internal consistency of the scales for perceived exercise mastery and perceived fitness, they were tested with Chronbach alpha coefficients.

In the course of writing this dissertation, a new analysis was performed with the data from study 1. In order to test for a possible role of perceived fitness as a mediator in the path between physical exercise and life satisfaction, the following three linear regression equations were estimated in each model: first, regression of the mediator (perceived fitness) on the independent variable (physical exercise); second, regression of the dependent variable (life satisfaction) on the independent variable (physical exercise); and third, regression of the dependent variable (life satisfaction) on both the independent variable (physical exercise) and the mediator (perceived fitness) (Baron & Kenny, 1986). Separate coefficients for each equation were estimated and tested using standard linear regression procedure (Pallant, 2010).

5.3. Study 2 (Paper II): Study design, participants, data collection and statistical analyses

The design of the study was cross-sectional. Invitations to participate were sent to 49 persons with motor complete SCI, and 100 persons with incomplete SCI. The first group (persons with motor complete SCI) was recruited from an epidemiological study at Sunnaas Rehabilitation Hospital (Lidal, 2010; Lidal, Veenstra, Hjeltnes, & Biering-Sorensen, 2008). Of the 49 invited persons, 2 persons refused to participate.

The final sample in the first group consisted of 47 persons with motor complete SCI. They were assessed in the same order they were admitted to the hospital for follow-up. The data were compared with the sample used in study 1, which consisted of 69 persons with incomplete SCI, rehabilitated at Sunnaas Rehabilitation Hospital before 1992.

Demographic and injury related data were extracted from the medical records in Sunnaas Rehabilitation Hospital. A clinical examination was performed in order to assess the persons AIS scores. Aerobic work-capacity was tested on an arm ergo-meter in participants with motor complete SCI. In the total samples (SCI AIS A-B and AIS D) data on exercise habits exercise hours per week, self-reported walking distance, exercise-related self-perceptions were collected by questionnaires (Appendix III).

Statistical analyses were conducted by using SPSS 15.0 for Windows. Descriptive statistics were used to characterize the samples. Independent sample t-tests and Pearson’s Chi-Squared tests were used where appropriate. First, we compared data in order to expose differences between the subgroups, i.e. time since injury (for persons with incomplete SCI), on age, gender, injury level, exercise hours per week, exercise-status, mean scores on perceived exercise mastery and perceived fitness. We compared data on perceived exercise mastery and perceived fitness for exercisers and non-exercisers. Associations between exercise hours and physiological parameters were studied by using the Spearman’s correlation test. Linear regression analysis was used to study the relationship between perceived exercise mastery and a set of covariates. The covariates included gender, age, time since injury, injury level, exercise-status, exercise hours per week, and perceived fitness.

5.4. Study 3 (Paper III): Study design, participants and data collection

In order to explore the role of physical exercise, perceived exercise mastery, stress and coping more closely, a qualitative study with in-depth interviews was chosen (Patton, 2002). Because the group of persons with incomplete SCI is extremely heterogeneous, a set of inclusion criteria as well as a purposeful and critical case sampling procedure were used in order to attain a wide range of information from persons with possibly varying perceptions of exercise mastery (Patton, 2002). We wanted a sample which represented different levels of functional ability, both genders, and people with differing ages and times since injury. ASIA impairment scale was used to classify the participants (Marino et al., 2003). In order to eliminate those who could still have a spontaneous recovery, the time since injury was set to be at least two years (Burns & Ditunno, 2001). Only persons classified as AIS D were included in the study. Six persons with incomplete SCI, admitted to Sunnaas Rehabilitation Hospital for follow-up during the spring 2009 were asked to be interviewed, and all accepted to participate in the study.

Data was collected from semi-structured interviews. An interview-guide was developed according to guidelines for qualitative interviews (Patton, 2002). The guide was based on CATS, clinical experience and previous research (studies 1 and 2). Open-ended questions were asked about the following: the influence of SCI on their lives, the perception of stress owing to mobility restrictions in daily life, their exercise habits both before and after injury up to the present day, their feelings towards exercise, their perception of exercise and exercise mastery, their motivation for exercise, their perception of overtraining and burnout. The interview-guide is added in Appendix IV. The interviews were tape-recorded in full, and within the first month after the interviews, the tapes were transcribed verbatim (Patton, 2002).

5.5. Study 4 (Paper IV): Study design, participants, data collection and statistical analyses

The design of the study was cross-sectional. Included in the study were persons rehabilitated at Sunnaas Rehabilitation Hospital between 1962 and 2008. Invitations were sent to 316 persons classified as AIS D or with a cauda equine injury. Data was collected from a mailed questionnaire that measured perceived stress due to the disability, leisure time physical activity, perceived exercise mastery, coping, burnout and fatigue (Appendix V). Background information was gathered from medical records. The AIS score D was used as the main inclusion criteria (Marino et al., 2003).

All statistical analyses were conducted using PASW statistics 18.0 for Windows. Descriptive statistics were used to characterise the sample. Data was summarised by mean values and standard deviations (SD) or median values and range, when appropriate. Independent sample t-tests were used to compare mean values of dependent and independent variables in tetraplegia versus paraplegia. The Spearman correlation test was used to measure the correlation between leisure time physical activity and the International Physical Activity Questionnaire. In order to test the mediations, the following three linear regression equations were estimated in each model: first, regression of the mediator on the independent variable; second, regression of the dependent variable on the independent variable; and third, regression of the dependent variable on both the independent variable and the mediator (Baron & Kenny, 1986). Separate coefficients for each equation were estimated and tested using standard linear regression procedure (Pallant, 2010). Pearson’s correlation coefficient was used for correlation between variables in the mediation analyses.

5.6. Scales and measurements used in the surveys (studies 1, 2 and 4)

In the following subsections, descriptions of relevant variables and specific measurement instruments which were used will be presented. An overview of variables and questionnaires used in the studies are presented in Table 4.

5.6.1. Demographics and diagnostic items

The variables are listed in Table 4. In all the studies, demographic and injury related data were extracted from the medical records. However, there is need for some

Table 4. Overview of scales and measurements used in studies 1-4

Variables	Study 1	Study 2	Study 3	Study 4
Socio-demographic variables				
* Age at injury	x	x	x	x
* Age at time of survey	x	x	x	x
* Date of injury (and time since injury)	x	x	x	x
* Gender	x	x	x	x
Specific SCI characteristics				
* Frankel score D	x			
¤ AIS scores A-B		x		
¤ AIS score D		x	x	x
* Tetraplegia	x	x	x	x
* Paraplegia	x	x	x	x
* Traumatic injury	x	x	x	x
* Non-traumatic injury				x
Aerobic work capacity				
¤ Peak VO_2 max ml/kg/min		x		
¤ Max work load		x		
Questionnaires				
† LiSat-9	x			
† Exercise hours per week	x	x		
† Type of exercise	x	x		
† Walking distance	x	x		
† IPAQ				x
† LTPA				x
† SPEQ (Perveived exercise mastery)	x	x		x
† SPEQ (Perveived fitness)	x	x		x
† PDSS				x
† PEM (VAS)				x
† Degree of coping				x
† PBM				x
† FSS				x

* Data collected from the medical records.

¤ Data collected from clinical examination.

† Data collected from questionnaires.

AIS: Asia Impairment Scale; FSS: Fatigue severity scale; IPAQ: International physical activity questionnaire; LiSat-9: Life Satisfaction Scale-9; LTPA: Leisure time physical activity; PDSS: Physical Disability Stress scale; PEM: Perceived exercise mastery; PBM: Pines Burnout measure; SPEQ: Self Perception in Exercise questionnaire; VAS:Visual analogue scale.

additional information. For some of the analytical purposes, we grouped variables into categories as follows:

Demographic variables:

1) For persons with incomplete injury time since injury was divided into injured before 1982, and those injured between 1982 and 1992 (Paper II).

Specific SCI characteristics:

1) Neurological levels of injury: tetraplegia and paraplegia (Paper I-IV).

2) AIS classes were separated into AIS A-B and AIS D to reflect motor complete SCI and functionally incomplete SCI respectively (Paper II).

Aerobic work capacity

Peak aerobic capacity (VO_2max ml kg^{-1} min^{-1}) and max work load (Watt) was measured by arm-cranking. The participants, sitting in their own wheelchair, used an adapted ergometer for arm cycling (Ergometrics 800, Ergoline, Germany). They performed a stepwise, graded exercise test until exhaustion. Expiratory volume and gas concentrations were measured continuously. Minute ventilation and oxygen uptake (VO_2) were calculated every 15 seconds (Sensor Medics Vmax 229) (study 2).

5.6.2. Physical activity and physical exercise (studies 1, 2 and 4)

There are different methods to assess amounts of physical activity and energy expenditure. It is important to keep in mind that physical activity and energy expenditure are different terms; physical activity is a behaviour that results in energy expenditure (Lamonte & Ainsworth, 2001). Self-reported questionnaires are the most frequently used method in large-scale epidemiological studies of health related outcomes.

Physical activity and physical exercise, studies 1 and 2.

The participants reported the number of exercise hours per week. In addition, they reported frequency of exercise in 19 defined exercise activities. Those who exercised less than once a week were classified as non-exercisers, and those exercising once a week or more as exercisers (exercise-status). In order to check the accuracy of the self-reported exercise-status, a correlation test between self-reported exercise-status and the physiological data (Peak VO_2 max ml/kg/min) was performed, see page 48. We used the data from the participants with motor complete paraplegia (n=34), because it is well documented that exercise is associated with higher VO_2 in this group (Hjeltnes & Wallberg-Henriksson, 1998; Janssen et al., 2002; Valent et al., 2007). Aerobic work-capacity was measured by arm-cranking. The participants, sitting in their own wheel-chair, using an adapted ergometer for arm cycling (Ergometrics 800, Ergoline, Germany) performed a stepwise, graded exercise test until exhaustion. Expiratory volume and gas concentrations were measured continuously. Minute ventilation and oxygen uptake (VO_2) were calculated every 15 seconds (Sensor Medics Vmax 229).

Physical activity and physical exercise, study 4:

The International Physical Activity Questionnaire (IPAQ) short version

IPAQ short version was developed for use with adults (18-69 years) (Craig et al., 2003). It is used to collect information from the last 7 days, on time spent walking, doing moderate and vigorous-intensity activities and, also, time spent sitting. The instrument has shown acceptable reliability and validity (Craig et al., 2003). A Norwegian translation was available and had been used both for persons with and without a physical impairment (Saebu & Sorensen, 2010; Wilhelmsen, 2009).

Leisure Time Physical Activity (LTPA).

A four-item scale, developed in the 1960s and widely used in Norwegian health surveys, was used to measure leisure time physical activity (LTPA) (Graff-Iversen, Anderssen, Holme, Jenum, & Raastad, 2008; Saltin & Grimby, 1968). To select the amount of exercise performed, the respondents were asked to rate their weekly average

LTPA on a 4 item scale; 1) Reading, watching TV or other sedentary activities, 2) Walking, cycling, using a wheelchair or moving about in some other way at least 4 hours per week – including commuting to work and Sunday walks. 3) Taking part in physical exercise or sports, heavy gardening work etc. - at least 4 hours a week. 4) Exercising hard or taking part in competitive sports regularly several days a week. Both Wilhelmsen et al. (1976), Aires, Selmer and Thelle (2003) and Graff-Iversen et al. (2008) reported stable construct validity.

In order to check the accuracy of LTPA in the study population, a correlation test was performed between LTPA and the IPAQ, short version, see page 52.

5.6.3. Life-Satisfaction Scale (LiSat-9) (study 1)

In study 1, the questionnaire constructed by Fugl-Meyer and his co-workers was used to measure overall and domain specific life satisfaction (LiSat-9). The questionnaire consists of one global question which measures satisfaction with life as a whole, and of eight domain specific questions; Activity of Daily Living (ADL), Leisure, Vocational situation, Financial situation, Sexual life, Partnership relations, Family life and Contacts (Fugl-Meyer et al., 1991). The responses were recorded using a 6-point scale ranging from 1 (very dissatisfied) to 6 (very satisfied). The scale scores can be dichotomised into dissatisfied/unhappy (1-4) versus satisfied/happy (5-6). The questionnaire has demonstrated reliability and validity in previous research (Bränholm, Eklund, Fugl-Meyer, & Fugl-Meyer, 1991). Reliability was demonstrated by obtaining similar results when using different data-collection methods (mailed questionnaire (n = 126) vs. telephone interview (n = 53)) (Bränholm et al., 1991). In order to establish the construct validity of the instrument, factor analyses were performed for different populations (Bränholm et al., 1991; Bränholm, 1992; Fugl-Meyer et al., 1991; Viitanen M, Fugl-Meyer KS, Bernspang B, & Fugl-Meyer AR, 1988). Level of happiness in life as a whole was correctly classified by an identical three-factor construct which contained all eight domain-specific domains in the different studies, and thus supported the construct validity.

LiSat-9 is one of the measures evaluated by a group of clinical and rehabilitation psychologists for measuring one of the domains in Health related QoL (HRQOL) in research on SCI (Alexander et al., 2009). The group defined QoL as a multi-dimensional construct that includes physical functioning, functional ability and satisfaction with life. LiSat was judged as one of four scales that met the criteria for measuring SWB and examining only one domain within the HRQOL framework.

Fugl-Meyer and co-workers recommend not summing up the scores for clinical purposes. They argued that in a rehabilitation setting where therapeutic goal setting is crucial, a summed score can conceal domains that are clinically relevant (Fugl-Meyer, Melin, & Fugl-Meyer, 2002). In a broader setting, as in this study where we want a general expression of life satisfaction in a wide perspective, it makes sense to sum up the scores and use a total sum score.

The LiSat has been used in several studies in Sweden and Norway (Anke & Fugl-Meyer, 2003; Blaasvær & Stanghelle, 1999; Fugl-Meyer AR, Eklund M, & Fugl-Meyer KS, 1991; Fugl-Meyer et al., 2002; Fugl-Meyer et al., 1991). Fugl-Meyer et al. (1992) have published normative values from the general population (northern Swedes), in addition to data on persons with SCI (n=82) (Fugl-Meyer, Bränholm, & Fugl-Meyer, 1992). The results indicated that 69% of the northern Swedes were satisfied with their lifes as a whole, as were 49% of persons with SCI. Both populations are used as references in the study 1 because the living conditions in Scandinavia are similar.

5.6.4. Perceived Exercise Mastery (PEM) (studies 1, 2 and 4)

Self-Perception in Exercise Questionnaire (SPEQ) (studies 1, 2 and 4)

Sørensen (1997) constructed a scale to measure self-concept variables that are exercise specific, the Self-Perception in Exercise Questionnaire (SPEQ). The scale consists of four subscales, and in this study two of these subscales were used; perceived exercise mastery, and perceived fitness. Each of the items of the subscales (eight items for perceived exercise mastery and four items for perceived fitness) was scored on a 4-point scale (1- 4), and a mean score for each subscale was computed. Higher scores indicate a more positive self-perception. Sorensen reported internal reliability for the subscales by Chronbach alpha coefficients: .81 for the exercise mastery scale and .62 for the perceived fitness scale. Construct validity was demonstrated with moderate correlations with a relatively similar scale (Harter adult self-perception profile) for exercise mastery and athletic abilities (r = .54).

For persons with a physical disability, however, some of the items were not suitable and were removed. The internal reliability for the applied scales (five items for perceived exercise mastery and three items for perceived fitness) by Chronbach alpha coefficients demonstrated .75 for the exercise mastery and .83 for the perceived fitness scale. In addition, included as a test of the construct validity for perceived fitness in this study, the participants self-reported how satisfied they were with their physical fitness on an ordinal scale ranging from 1(dissatisfied) to 5 (satisfied). The correlation was statistically significant (r = .74, p< .001).

Perceived exercise mastery measured on a Visual Analogue Scale (VAS) (study 4)

In the mailed questionnaire perceived exercise mastery (PEM) was defined as: “perceived competence when performing physical exercise”. The respondents were asked to rate their perceived exercise mastery at present on a VAS scale ranging from 0 – 10 (0 = I never perceive any competence when performing physical exercise, 10 = I always perceive competence when performing physical exercise). In order to test the construct validity of the VAS scale for perceived exercise mastery, a correlation test with perceived exercise mastery was performed. The correlation was statistically significant (r = .34, p< 0.001).

5.6.5. Physical disability-stress (study 4)

Furlong and Connor (2007) constructed a scale to measure disability related stress in persons with physical disability. The Physical Disability Stress Scale (PDSS) was originally validated for adults with an acquired physical disability and who required the use of a wheelchair as their main source of mobility (Furlong & Connor, 2007). The scale was translated into Norwegian using a double Translation – Back – translation technique. The total scale (22 items) consists of 4 subscales, namely Access (four items), Physical (five items), Social (seven items) and Burden of care (six items). As the population in this study was more heterogeneous than the original population, we tested the internal consistency of the total scale in the studied population. The Chronbach Alfa coefficient was .93. Therefore we used the total score.

5.6.6. Coping with stress (study 4)

In this dissertation coping is defined as "either fulfilment of expectations of physical function or successful adjustment of expectations to actual physical function", see page 26. The respondents were asked to rate how they coped with the total physical demands in everyday life as experienced due to the SCI, on a VAS scale rating from 0 – 10 (0 = no coping, 10 = optimal coping).

5.6.7. Burnout (study 4)

The 21 items Pines burnout measure (PBM) express exhaustion and are scored on a 7-point rating scale from 1 = never to 7 = always (Schaufeli, Enzmann, & Girault, 1993). The scores can be recoded into a burnout score (PBS). Scores higher than 4 indicates a perceived burnout that needs consideration of changes in life (Pines & Aronson, 1988). The instrument has been tested for reliability and validity and is considered a reliable and valid research instrument. (Pines & Aronson, 1988; Schaufeli et al., 1993). The scale was translated to Norwegian using a double Translation – Back Translation technique.

5.6.8. Fatigue (study 4)

To measure fatigue, FSS was used (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). The FSS consists of nine items, each scored on a Likert scale from 1 = "strong disagreement” to 7 = “strong agreement”. Reliability and validity for FSS has been reported to be good in different populations with person with different impairments and normal healthy adults (Anton et al., 2008; Fawkes-Kirby et al., 2008; Krupp et al., 1989). Cut-off score over 4 was set as indicative for fatigue by Krupp et.al. (1989). FSS has previous been used in similar Norwegian populations (Rand-Hendriksen, Sorensen, Holmstrom, Andersson, & Finset, 2007; Schanke & Stanghelle, 2001).

5.7. Ethical aspects

All four studies have been approved by the Regional Medical and Health Research Ethics Committee, Eastern Norway (Appendix I). In addition, supporting documents were submitted three times:

1) Concerning an extra written informed consent for clarification in study 2;
2) Concerning clarifications and new written consent in study 3;
3) Concerning clarifications and new written consent in study 4.

The fundamental principles of medical ethics were taken into account when planning the studies, including respect for the respondent’s autonomy, a minimum of burden to the respondent, and balancing the risks, costs and benefits of action.

All respondents gave their written informed consent, and they were informed that they could withdraw from participation at any time during the study (Appendix II). Study participation did not imply any harm to the respondent except for possible psychological strain in answering the questionnaires.

The Data Inspectorate accepted the methods used for conducting the study. The Privacy Protection Supervisors, Oslo University Hospital, advised on the application processes including storing the data and the content in the information letters.

6. Results (main findings and summary)

The main results of the present dissertation are presented in Papers I-IV. However, some results from study 1, which is not presented in any of the papers are relevant for the research questions, and thus presented in this section. In the following, the main findings in each study are presented followed by a summary.

6.1. Study 1

Incomplete spinal cord injury, exercise and life satisfaction.
Lannem, A. M., Sorensen, M., Froslie, K. F., & Hjeltnes, N.

The main purpose of Study 1 was to investigate the role of physical exercise and self-perceptions in relation to subjective health measured by life satisfaction in persons with SCI AIS D. The final sample in the statistical analyses consisted of 69 persons, 56 men and 13 women. Mean age was 48 years (SD = 13.7 years), and time since injury was 18 years (SD = 8.1 years). Of the respondents, 34 persons (49%) were able to walk more than 500 metres without getting tired, and 13 persons (19%) could walk less than 50 metres. For the total sample, median exercise hours per week were 1.5 with a range from 0 to 12 hours. No statistical significant difference was shown within the subgroups tetraplegia/paraplegia regarding walking distance or exercise parameters.

Results showed that those who exercised scored significantly higher than those who did not exercise on the overall measurements relating to life satisfaction. The exercisers in the study scored significantly higher than the non-exercisers on perceived fitness ($p < .01$), and significantly lower on perceived exercise mastery ($p < .05$).

A regression analysis with LiSat-9 as the dependent variable and gender, age, time since injury, injury level, exercise versus non-exercise, exercise hours pr. week, perceived exercise mastery and perceived physical fitness, as independent variables, was performed. Perceived physical fitness and time since injury were the only variables that contributed significantly to the LiSat-9 in this sample (p<.05). Together they explained 23% of the variance in LiSat-9.

In the submitted paper we did not test for mediation. It can, however be tested according to the criteria for mediation as suggested by Baron and Kenny (1986), see Figure 4 and Table 5.

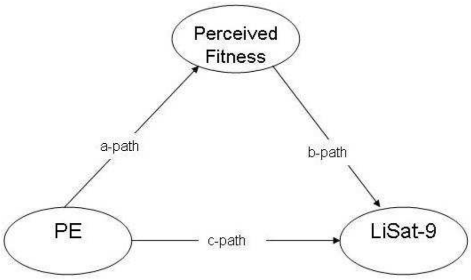


Figure 4

Conceptual model used for mediation analyses in the path between physical exercise (PE) and LiSat-9.

Table 5

Linear Models testing: PE → Perceived fitness → LiSat-9

Variables and paths	ΔR^2	*β*	*t*	*p*
Model 1: PE → Perceived fitness → LiSat-9				
Perceived fitness as mediator of LiSat-9				
Path a, PE → Perceived fitness	.08	.299	2.508	.015
Path b, perceived fitness → LiSat-9	.17	.422	3.753	.000
Path c, PE → LiSat-9	.07	.295	2.524	.014
Path c + path b	.18			
PE		.163	1.400	n.s.
Perceived fitness		.375	3.214	.002

In total, all the paths tested in the model were significant; see Table 5 and Figure 4. The models were tested separately for mediation with three simple regression equations. In Figure 4, the regression of the mediator (perceived fitness, path a) demonstrated a significant effect on the independent variable (physical exercise)

(R^2adj = .08, F = 6.291, $p < .02$). Second, the dependent variable (LiSat-9, path c) significantly affected the independent variable (physical exercise), (R^2adj = .07, F = 6.371, $p < .02$). Finally, the mediator (perceived fitness) significantly affected the dependent variable (LiSat-9) in a regression model with both perceived fitness and physical exercise as predictors. In this equation, physical exercise affected LiSat-9 less than in the equation in path c. See Table 5 for details. The result of these analyses supported the role of perceived fitness as a mediator in the relation between physical exercise and LiSat-9.

The results regarding self-perception in exercise were unexpected concerning the measured perceived exercise mastery. The lower measured perceived exercise mastery for those with incomplete SCI who exercised was different from previous research on able-bodied persons (Sørensen, Anderssen, Hjerman, Holme, & Ursin, 1997). In order to investigate whether this phenomenon was particular to those with incomplete SCI, a new study was performed to include also persons with motor complete SCI.

6.2. Study 2

Perceptions of exercise mastery in persons with complete and incomplete spinal cord injury.
Lannem, A. M., Sorensen, M., Lidal, I. B., & Hjeltnes, N.

The purpose of study 2 was to compare the exercise-related self-perceptions between persons with motor complete and motor incomplete SCI, and to explore which factors that explained the variance in perceived exercise mastery. This cross-sectional study included 116 persons with SCI, 47 persons with motor complete SCI, and 69 persons with motor incomplete SCI. Of this sample 97 were men and 19 were women, and there were 48 persons with tetraplegia and 68 persons with paraplegia. Mean age was 48 years (SD = 11.7), and mean time since injury in the total sample was 23 years (SD = 8.8). For persons with motor complete SCI, mean time since injury was 29 years (SD 5.3) versus 18 years (SD 8.1) for persons with incomplete SCI. However, we found no significant differences related to time post injury in persons with incomplete SCI concerning age, gender, injury level, exercise-hours per week, exercisers versus non-exercisers, mean perceived exercise mastery scores, or on perceived exercise fitness in either of the analyses. There were no differences in gender distribution, injury level or age between the exercisers and non-exercisers in the samples.

The average number of exercise hours per week for persons with motor complete SCI was 2 hours ranging from 0 to 15 hours, and for persons with incomplete SCI the exercise hours per week was 1.5 hours ranging from 0 to 12 hours.

Regarding the accuracy of the self-reported exercise status in exercisers with motor complete paraplegia, there was a statistically high, and significant correlation (r_s= .605, p<.01) between their self-reported exercise-status and the measured Peak VO_2 max. Also the association between exercise hours per week and Peak VO_2 max ml/kg/min demonstrated a statistically significant correlation (r_s = .773, p < .01).

Exercisers with motor complete and exercisers with motor incomplete SCI demonstrated significant differences in perceived exercise mastery compared to their non-exercising peers (p = .002 and p = .012 respectively). Exercisers with motor complete lesions reported more positive perceived exercise mastery, and persons with motor incomplete lesions reported more negative perceived exercise mastery than their non-exercising peers.

Perceived fitness scores were significantly higher for exercisers versus non-exercisers in both samples; (p = .016 and p = .004 for motor complete and motor incomplete SCI respectively).

In order to identify factors that explained the variance in perceived exercise mastery for the two samples, linear regressions were performed separately. The dependent variable was perceived exercise mastery, and the independent variables were age, gender, time since injury, exercise-status, exercise-hours per week and perceived fitness. For persons with motor complete SCI the regression model was significant (R^2adj = .26, F = 16.102, p < .001). However, exercise-status was the only variable that contributed significantly to the equation (p< .001).

For persons with motor incomplete SCI, the same regression model did not reach statistical significance. In this group, a regression model with perceived exercise mastery as the dependent variable, exercise hours per week and exercise-status as independent variables, was significant ($R^2adj = .07$, $F = 3,527$, $p < .01$). For the group with motor incomplete SCI, both the variable exercisers versus non-exercisers as well as hours per week contributed to the variance in perceived exercise mastery ($p = .007$ for exercise hours per week and $p = .04$ for exercise-status), but the association was negative. That means that if they exercised, or the more hours per week they exercised, the less mastery of exercise was perceived.

In summary, the most important finding in study 1 was the difference in perceived exercise mastery between exercisers with motor complete and motor incomplete SCI. For persons with motor complete lesions, the exercise-status (exercisers versus non-exercisers) was the variable most clearly associated with perceived exercise mastery. This association was positive, which means that if they exercised, they reported higher perceived exercise mastery. For persons with incomplete lesions, both exercise hours per week and exercise-status contributed significantly to the variance in perceived exercise mastery. However, this relation was negative. Persons who exercised regularly or for more hours per week reported lower scores on the perceived exercise mastery scale.

The knowledge we attained from studies 1 and 2 were that exercise was positively associated with life satisfaction in people with incomplete injuries SCI. The same positive association has been reported in persons with motor complete SCI (Lannem & Sørensen, 2007). In addition, perceived fitness was an important factor in explaining the variance in life satisfaction.

In study 2, persons with incomplete SCI experienced lower perceived exercise mastery when exercising in contrast to those with motor complete SCI. In terms of CATS, coping is to have positive outcome expectancies. According to these data, it seemed as if outcome expectancies may also be too high if these expectancies never can be fulfilled. In order to explore this negative association more in depth, a qualitative study was performed.

6.3. Study 3

The role of physical exercise, perceived exercise mastery, and stress in persons with incomplete Spinal Cord Injury (SCI).
Lannem, A. M., & Sorensen, M.

The purpose of study 3 was to explore why or in what situations persons with incomplete SCI experience high or low perception of exercise mastery, and how this is associated with stress, coping, fatigue or burnout. In this qualitative study, four men and two women with motor incomplete SCI participated. Their ages ranged from 39 to 62 years, and the number of years post-injury ranged from four to 40. Among them, four persons were walkers and two persons combined walking with the use of wheelchair for mobility. Two of the persons received disability pensions, one was on 50% sick leave from a full time job, two worked full time, and one had a 50% disability pension combined with 50% employment.

Before injury, four of the participants were physically active with different sports including jogging, skiing, and hiking in the mountains. One participant competed at a national level in an endurance sport. Two of the participants had never been involved in any kind of sports or physical activity. During rehabilitation all respondents followed the standard programme for SCI which includes exercise in both in acute care phase and subsequent rehabilitation phase. All respondents continued with exercise supervised by a physiotherapist after discharge from the rehabilitation hospital. At the time of the interviews, three of the six respondents did not follow any planned exercise programme.

There were individual differences related to factors which contributed to the perception of stress, overload and personal coping strategies. Exercise mastery was perceived when the respondents perceived improvement or maintenance of physical function. According to CATS, this may be interpreted as fulfilment of expectancies of physical function as a result of physical exercise. For some of the participants this could only be achieved by adjustment of other factors in life, i.e. reducing working hours, periods with sick leave or use of adaptive aids. Physical exercise became a stressor for the individual when the physical progression stagnated in spite of exercise, or fatigue and overload developed. Similar processes have been described in other areas, e.g. long-lasting physical exhaustion or reduced sense of accomplishment in sports leading to burnout (Lemyre et al., 2008).

The individual’s potential to recover physical function is difficult to predict for persons with a motor incomplete SCI, compared with those with motor complete SCI (Burns & Ditunno, 2001; Whiteneck et al., 1999). Persons with incomplete SCI are therefore likely to have higher expectations of recovery when exercising than is realistic. When these high expectations are not met, the result will be helplessness or, in terms of CATS, with no correlation between the attempts to manage and the outcome, which again may lead to sustained arousal. In this way, physical exercise might turn into a stressor.

6.4. Study 4

Physical exercise, stress, coping, burnout and fatigue in persons with incomplete spinal cord injury (SCI).
Lannem, A.M.

The purpose the study was both to determine the prevalence of burnout and fatigue in a Norwegian sample of persons with incomplete SCI; and to examine the role of physical exercise and the degree of coping with disability-stress in the association between disability-stress and burnout or fatigue. The final sample in study 4 included 186 persons with incomplete SCI (AIS D) or with cauda equine injury. Of this sample, there were 142 men and 44 women, of which 85 persons with tetraplegia and 101 persons with paraplegia. The mean age was 48 years ranging from 18 to 87 years, and mean duration of injury was 15 years, ranging from two to 55 years.

The mean PBS was 2.8 (SD = 1.2), and 26 persons, 15% of those who completed the PBM, scored above 4, the cut-off point for burnout. Mean FSS was 4.4

(SD =1.5), which means borderline fatigue, and 63 % of the sample scored 4 or above, whereas 43% scored 5 or above.

All tested variables demonstrated statistically significant correlations between them. The correlation was negative between leisure time physical activity (LTPA) and the physical disability stress scale (PDSS), the Pines burnout score (PBS) and the fatigue severity scale (FSS). The perceived exercise mastery correlated negatively with the same variables. Degree of coping correlated positively with LTPA, but negatively with the PDSS, the PBS and the FSS, see Table 2 in Paper IV for details.

Regarding the accuracy of self-reported LTPA, the measure was compared with another self-report with IPAQ short version. The correlation between LTPA and IPAQ, short version was reasonably high ($r_s = .55$, p < .001). However, all the IPAQ measures were highly skewed towards zero and LTPA had a normal distribution. It seems as though, in a less active population such as persons with incomplete SCI, LTPA captures more of the variance in the lower part of the scale, and was therefore used in the final analyses.

In order to test the conceptual models used for the mediation analyses, the criteria for mediation as suggested by Baron and Kenny (1986) was used. In total, all the paths tested in the three models were significant; see Table 3 and Figure 1 in Paper IV for details. The models were tested separately for mediation with three simple regression equations. The results of the mediation analyses demonstrated that PDSS was indirectly linked to perceived exercise mastery through LTPA ($R^2_{adj} = .28$, F = 31.839, p < .001) and, that perceived exercise mastery was indirectly linked to burnout through degree of coping ($R^2_{adj} = .51$, F = 82.777, p < .001), and lastly that perceived exercise mastery was indirectly linked to FSS through degree of coping ($R^2_{adj} = .36$, F = 45.808, p < .001).

Study 4 demonstrated that the sample of persons with incomplete SCI experienced burnout and fatigue more frequently than the general population. Physical exercise and degree of coping with disability-stress seemed to mediate the association between disability-stress and both burnout and fatigue. In the terms of CATS, no coping may end with helplessness and hopelessness, which again may facilitate sustained arousal and as a long-term, disease may develop.

6.5. Summary of results

The most important achievement in this dissertation is the identification of the potential positive or negative role of physical exercise in the health-stress process for persons with functionally incomplete SCI. The positive contribution is measured by life satisfaction, and the negative is measured by both burnout and fatigue. However, the relationships are not direct, as illustrated by CATS. Those who performed physical exercise regularly perceived a significantly higher life satisfaction than those who did not exercise (Paper I). Among the variables measured, perceived fitness was the only variable which contributed significantly to the higher life satisfaction (Paper I). Perceived fitness also mediated the association between physical exercise and life satisfaction (new analysis with data from study 1). Perceived exercise mastery was experienced differently in persons with motor complete and functionally incomplete SCI (Paper II). An in-depth exploration indicated that the total physical and psychological demands of everyday life related to functional capacity, influenced how exercise mastery was perceived. Low exercise mastery was experienced and overload or fatigue developed when the physical progression stagnated, and if physical function declined. This may also be associated with unrealistic expectations about to what extent physical exercise could help regaining or maintaining physical function (Paper III). On the one hand, as long as the outcome of physical exercise is positive, i.e. the physiological parameters and/or the perception of well-being and other positive psychological components such as perceived exercise mastery, perceived fitness and degree of coping, increase, the exercise helps building resources to counteract negative effects of the stressors. On the other hand, if the physical demands in everyday life are higher than the person's physical capacity, the resources are likely to be overloaded in the long run. In such a situation, physical exercise might turn into an extra stressor (Paper III and Paper IV). Physical exercise mediated the relation between stress experienced from the disability and perceived exercise mastery. Degree of coping with the disability-stress mediated the relation between perceived exercise mastery and both burnout and fatigue (Paper IV). It seems important to take into consideration the total physical load in life when designing individual exercise programmes for persons with functionally incomplete SCI.

7. Discussion

In this chapter, the main findings of the individual research questions will be discussed within the CATS framework in the same order as the studies, followed by a general discussion.

7.1. Research question 1 (study 1)

Is physical exercise associated with positive health outcome measured by life satisfaction in persons with SCI, and what are the roles of perceived exercise mastery and perceived fitness in this association?

Study 1 investigated the role of physical exercise and self-perceptions in exercise in life satisfaction. The result demonstrated that persons with incomplete SCI who performed physical exercise regularly scored significantly higher on LiSat-9 than those who were physically inactive. This result is in agreement with previous studies that have reported a positive relationship between physical exercise and subjective well-being (SWB) in persons with SCI (Martin Ginis et al., 2010a). However, the causality in this association is not yet fully established for persons with SCI as discussed by Martin Ginis et al. (2010a) in their meta-analysis. Study 1 could not demonstrate any causality due to the cross-sectional design, but the relationship between variables was examined. A regression analysis demonstrated that perceived fitness was the only psychological variable that contributed significantly to the variance in life satisfaction. In the published paper (Paper I) mediation analysis was not reported. However, a test according to the criteria for mediation suggested by Baron and Kenny (1986), supported that perceived fitness mediated the relationship between physical exercise and LiSat-9. For details, see Figure 4 and Table 5, page 46. This mediation is consistent with CATS in that physical exercise may enhance the perception of fitness which is a psychological resource that may reduce the perceived disability-stress and enhance the positive outcome expectancies (coping).

An unexpected result was that perceived exercise mastery was negatively associated with physical exercise, in contrast to previous research on an able-bodied population (Sørensen et al., 1997). One explanation may be that it is more difficult to perform different types of physical exercise for persons with physical limitations, as in persons with incomplete SCI. Thus, the exercisers may challenge themselves more physically and, therefore, be more aware of their physical limitations. Consequently, they might perceive a lower level of exercise mastery. Another possible explanation may be related to expectations. Persons with incomplete SCI may have higher expectancies as to what and how much they can do, and to what extent physical exercise may restore physical function than is realistic. In terms of CATS, the mismatch between expectancies and reality can lead to sustained arousal. See also discussion of research question 2.

Several limitations can be argued in this study. Even with the relatively high response rate, the sample is small compared with the total SCI population in the world today. In addition, the cross-sectional study design limits the possibility for causality. The scales for perceived fitness and perceived exercise mastery were not developed for persons with physical disabilities, and some adaptations were therefore made. In order to test the reliability of this version, factor analysis and calculations of Chronbach alpha coefficients were performed. The internal consistency of the adapted scales was demonstrated by high Chronbach alpha coefficients. Self-reports in physical exercise have also been debated, and a limitation of the study might be that social desirability may result in over-reporting of physical exercise (Sallis & Saelens, 2000).

The answer to research question 1 is that it is likely that physical exercise is associated with life satisfaction. The association in this sample, however, was mediated by perceived exercise fitness. Perceived exercise mastery was negatively associated with physical exercise, which is counter intuitive. Further research was needed to investigate if this was a general phenomenon in persons with both incomplete and complete SCI.

7.2. Research question 2 (study 2)

Do persons with motor complete and persons with incomplete SCI experience similar self-perceptions in exercise, and which factors explain the variance in perceived exercise mastery?

In study 2, the most important observation was that there was a difference in perceived exercise mastery in exercisers with motor complete SCI and persons with functionally incomplete SCI. Perceived fitness was positively associated with physical exercise in the whole study population. Perceived exercise mastery was negatively associated with physical exercise in persons with incomplete SCI, and positively associated with physical exercise in persons with motor complete SCI. As discussed in Paper II, it is likely that persons with incomplete SCI try harder to function as "normal" as possible in everyday life and, therefore, also make less use of needed adapted aids. However, this warrants further research.

In terms of CATS, coping is positive outcome expectancies, but the question is whether these results indicate that such expectancies also can become too high. Fulfilment of outcome expectancies in order to restore function through physical exercise after the SCI, may have failed because they were too high. According to CATS the result may be the same as if the expectancies were negative, meaning this ends up as helplessness or hopelessness which both facilitate sustained arousal. In the long-term, this can affect health negatively. This might explain the low perceived exercise mastery in the study participants with incomplete SCI who exercised.

Another possible explanation of these results may be the low level of physical activity in persons with incomplete SCI. Among those who exercised, the median time of physical exercise was 21 minutes per day for those with incomplete SCI versus 32 minutes per day for those with motor complete SCI. The amount of physical exercise for persons with incomplete SCI is far below both the international and Norwegian recommendations for physical activity and exercise (Jansson & Anderssen, 2008; WHO, 2010). Study participants with motor complete SCI exercised more. Similar results on amount of physical exercise are reported in a Canadian sample (Martin

Ginis et al., 2010b). The authors reported less physical exercise per day for those who used walking aids compared to those who used wheelchair for ambulation. Therefore, it can be questioned if those with incomplete SCI are physically active enough to be able to experience perceived exercise mastery. However, it is a paradox that the persons who exercised most, had the most negative perceived exercise mastery. This is difficult to explain. One explanation may be that both exercisers and non-exercisers perceived low exercise mastery, and the more they exercised, the more they were confronted with their physical limitations and, therefore, perceived even lower exercise mastery. This needs further investigation.

Self-reports on physical exercise may result in incorrect data about the real amount of exercise as discussed above as a limitation in study 1. In order to support the reported amount of exercise, the data on persons with motor complete paraplegia were compared with available data on peak VO_2 max. The results demonstrated satisfactory correlation. There was a difference in time since injury in the two populations with complete and incomplete SCI. However, analyses demonstrated that this difference had little impact on the results in the incomplete group, most likely because they all had lived with their SCI for a long time.

In summary, the answer to research question 2 indicated that perceived fitness was positively associated with exercise for both persons with complete and incomplete SCI in the study. However, persons with complete and persons with incomplete SCI perceived exercise mastery differently. Those who sustained an incomplete SCI were less physically active, and the exercisers experienced lower perceived exercise mastery the more they exercised. Physical exercise contributed positively in association with perceived exercise mastery for persons with motor complete SCI. The phenomenon of lowered perceived exercise mastery in exercisers with incomplete SCI facilitated the next two studies in this dissertation.

7.3. Research question 3 (study 3)

Why or in what situations do persons with incomplete SCI experience high or low perception of exercise mastery, and how is this associated with stress, coping, fatigue or burnout?

In study 3, high perceived exercise mastery was experienced when the exercise was perceived as building or maintaining physical resources. Low perceived exercise mastery was experienced when the physical progression stagnated, if overload or fatigue developed or if physical function declined. Various stages or transitions in life after injury contributed to a change in perceived exercise mastery. The specific transitions that emerged were mostly related to social roles and total physical resources. Stress often increased in connection with work. Going back to the same job as before the injury, can be difficult. In order to cope, changing the work situation or going through some kind of re-education, were coping strategies used by some of the respondents. This is supported by previous research where the results have indicated low employment rate for persons with longstanding SCI (AIS A-E) (Lidal, Huynh, & Biering-Sorensen, 2007; Lidal, Hjeltnes, Roislien, Stanghelle, & Biering-Sorensen, 2009).

The natural decrease in physiological capacity due to age changes also played a role (Astrand, 1960; Gulsvik, 1979). Such changes will complicate the ability to benefit from exercise even more when the physiological capacity is already reduced. The consequences of ageing were illustrated by Evan’s case (see Paper III), describing the dilemma when his physical function declined because of ageing. In spite of exercising he may have lost so much physiological work capacity over the years that his activities overloaded his already reduced capacity. This is supported by literature on premature ageing and SCI regarding cardiovascular, musculoskeletal and immune systems (Hitzig et al., 2010; Hitzig et al., 2011).

The results of the interviews indicated that for some, a gap existed between the physical capacity of the individual and the personal expectations of how much normal function can be restored as a result of physical exercise. Such expectations are also held by others. However, for persons with incomplete SCI, the individual’s potential to recover function is difficult to predict (Burns & Ditunno, 2001). Therefore, they may experience stressful uncertainty and, as a result, have too high expectations about their future physical function. On the one hand, unrealistically high expectations may result in sustained arousal but, on the other hand, high expectations may give positive motivation to reach demanding goals as expressed by Ted in Paper III (see also discussions in previous research questions regarding expectancies).

In order to cope with the differences between the total physical demands and functional capabilities of the individual, it seemed to be very important to make choices in order to balance the total physical demands of everyday life, i.e. reducing working hours, getting help in the home, using adaptive aids, hiring a personal assistant to take care of the daily strain etc. This is supported by CATS in showing how physical and psychological resources are challenged when living with the consequences of an incomplete SCI. This is also in accordance with recent literature on coping after SCI (Chevalier, Kennedy, & Sherlock, 2009; Elfstrom, Kennedy, Lude, & Taylor, 2007; Galvin & Godfrey, 2001; Kennedy et al., 2010; Kennedy, Lude, Elfstrom, & Smithson, 2011; Pollard & Kennedy, 2007).

A critical question could be that when physical overload occurs, why not stop exercising as a coping strategy in order to restrict the use of physical resources? Therapists are often faced with the argument that activities of daily living (ADL) entail enough physical activities for persons with SCI in order to keep fit. Although this may be the case sometimes, whenever possible exercise and activity alternatives are recommended to ensure a balanced use of all active movements including those not necessarily used in ADL. Because of reduced muscle mass in some of the persons with incomplete SCI, variation in the exercise programme is necessary to avoid overuse problems and in order to stimulate supporting muscles (Nash, 2005). We find support in the literature concerning the effectiveness of systematic exercise or therapy both for physical and psychological benefits (Fernhall et al., 2008; Harvey et al., 2009). Regular physical exercise is important as a lifelong coping strategy to achieve optimal health and function. In order to impact positively in the health-stress relationship, it is important that the exercise programme take into consideration the individual's available physical and psychological resources. In sports, attention is given to the process for configuration and handling of the total stress load in everyday life (Genttä & Hassmén, 2002). A balance in the intensity of activity and periods of restitution or relaxation is necessary for coping. Persons with incomplete SCI can take advantage of a similar approach to coping with their own combination of challenges that can affect their perceived exercise mastery. In order to remain physically active, it seemed important to the respondents to be able to find an enjoyable and adapted exercise strategy; whether it was physical therapy, specific sports or outdoor life activities. Loss of motivation for exercise is the distinction between overtraining and burnout in a sporting context (Gould, 1996; Lemyre, Treasure, & Roberts, 2006). One of the respondents described an experience of burnout with no motivation for exercise, similar to sport burnout. This can also be explained in terms of CATS through lowered exercise mastery.

It may be a limitation of this study that six respondents represented only a limited selection of the heterogeneity of the population with incomplete SCI, even with a purposeful and critical case sample procedure. Given that a SCI is a physical injury, the focus of this study has been more on the physical and the perception of physical capabilities and functional resources, than on psychological and social resources. The strength of the study was the in-depth knowledge we gained through the interviews. This was important when designing study 4.

In summary, the answer to research question 3 was that the method of coping with the total sum of physical demands of everyday life including work, family responsibilities, leisure-time activities, low physical capacity or ageing, was important for whether the respondents perceived high or low exercise mastery. The coping strategy influenced if exercise was perceived as positive and edifying, or if exercise caused wear and tear on their physical and psychological resources. Keeping up motivation for exercise through enjoyable physical activities was important for remaining physically active, and thereby experience of higher exercise mastery. Increased fatigue was associated with less use of adapted aids, and one of the respondents experienced burnout.

7.4. Research question 4 (study 4)

What is the prevalence of burnout and fatigue in a Norwegian population of persons living with incomplete SCI, and what are the roles of physical exercise and the degree of coping with disability-stress in the association between stress caused by the disability and burnout or fatigue?

In study 4 we observed a markedly higher prevalence of both burnout and fatigue in persons with incomplete SCI compared with the able-bodied population (Hallsten, Bellagh, & Gustafsson, 2002; Krupp et al., 1989). As observed and supported by CATS, it is likely that persons with physical impairments struggle more in activities of everyday life and are, therefore, more exposed to experience a state of burnout than the general population.The prevalence of the symptom of fatigue is more common among persons with incomplete SCI than in the general population, and much more common than burnout. This result is supported by other studies, both for persons with SCI and other neurological diseases (Anton et al., 2008; Fawkes-Kirby et al., 2008; Herlofson & Larsen, 2002; Krupp et al., 1989; Lerdal, Wahl, Rustoen, Hanestad, & Moum, 2005; Schanke & Stanghelle, 2001). It is argued that an overloading process triggers the onset of both chronic fatigue syndrome and burnout, and that fatigue is one of the symptoms in both concepts (Leone et al., 2010). In a sporting context, Lemyre, Hall and Roberts (2008) argued that long-lasting physical exhaustion may contribute to the development of burnout. In this study, we can speculate whether fatigue, as a symptom, is a precursor of burnout, and that a person with a high level of fatigue may be particularly at risk of developing burnout. Persons with incomplete SCI have a relatively unpredictable potential for recovery and, thereby, end up with unrealistic expectations of their own physical capacity. Consequently, they use less adaptive aids than needed in everyday life, as discussed under the previous research questions. Fawkes-Kirby et al. (2008) argued that lack of use of adaptive aids by persons with SCI was one of the reasons for fatigue. In addition, they registered that persons with incomplete SCI reported more severe fatigue than those with complete lesions. Within the terms of CATS, Wyller, Eriksen and Malterud (2009) argued for a causal link between sustained arousal and the experience of fatigue within the disease Chronic Fatigue Syndrome. The results in the present study supported that those who experienced burnout, also experienced fatigue, and that the symptom of fatigue seemed to be a precursor for burnout. This is also consistant within the terms of CATS. For persons with reduced physical capacity, like those with incomplete SCI, it is ,therefore, especially important to be aware of the consequences of neglecting the symptom of fatigue.

In the present study, physical exercise was associated with higher perceived exercise mastery regardless of the questionnaire used (the visual analogue scale or the self-perception in exercise questionnaire). This result is in accordance with previous research on both an able-bodied population, as demonstrated by Sørensen et al. (1997) and on persons with complete SCI (study 2 in this dissertation). However, this is in contrast to the findings in study 1 which initiated the process of the additional studies in this dissertation. In order to explain the difference of the results in studies 1 and 4, time since injury may play an important role. In study 1, all respondents had lived with the a long period of time; mean time was 18 years, ranging from eight to 38 years. In study 4, mean time since injury was 15 years, ranging from two to 55 years. The results in study 4, showed a lower score on perceived exercise mastery the more years since injury. This difference, however, was not statistically significant. Even so, it can be argued that the length of time since injury is clinically relevant. In terms of CATS, decline in physical function, due to age-changes, may influence the total available resources, including the psychological resources, i.e. perceived exercise mastery.

Coping with disability-stress seemed to mediate the negative health outcome. This is in accordance with previous research on the role of coping after SCI, and supported by CATS as discussed in research question 3.

A limitation in the study may be the cross-sectional reports and self reports, as discussed before under research questions 1 and 2. In order to control for the reported amount of exercise, two different measures were used. It is a strength that in the final analysis, we used the questionnaire which captured most of the variance within the studied population. Another limitation was the sample size, and that we know nothing about the 37 % that did not respond to the survey, which limits generalisation. There is a possibility that persons with more complications or more severe impairment, are less likely to participate in surveys like this. The comments from the seven respondents who refused to participate indicated either severe complications or functional limitations.

In summary, the answer to research question 4 is that the sample of persons with incomplete SCI experienced burnout and fatigue more frequently than the general population, and fatigue seemed to be a precursor of burnout. Physical exercise and the degree of coping with disability-stress seemed to mediate the association between disability-stress and both burnout and fatigue. In the terms of CATS, not being able to cope may end with helplessness and hopelessness, which again may facilitate sustained arousal and, as a long-term outcome, disease may develop.

7.5. General discussion and methodological consideration

The main aim of this dissertation was to examine the role of physical exercise on positive and negative health outcomes for persons with incomplete SCI, and to investigate how self-perceptions in connection with exercise and coping with disability-stress influences the relationship between stress caused by the disability and final health outcome. In order to do so, four studies were performed and CATS was used as the theoretical framework. It is important to remember that this dissertation did not test the CATS theory as such, however, relevant aspects from CATS were examined related to SCI and exercise.

The answer to the main aim of this dissertation is that the results demonstrated that the role of physical exercise in the health-stress relationship was a double edged sword for persons with incomplete SCI. On the one hand it played a positive role in that those who exercised experienced higher life satisfaction than those who were physically inactive (study 1), and physical exercise mediated the association between disability-stress and burnout and fatigue (study 4). On the other hand, physical exercise turned into a stressor when the total physical load in everyday life exceeded the functional capacity (study 3). This is supported both by CATS and other reported research. Perceived fitness mediated the positive relationship between exercise and life satisfaction (study1), whereas perceived exercise mastery contributed both negatively (study 1) and positively (study 4) to health outcomes. The higher the individuals rated their ability to cope with stress caused by the disability, the lower they scored on both burnout and fatigue. The details were discussed in relation to research questions 1- 4 above.

Study design

We chose to make cross-sectional studies with the inclusion of retrospective data collected from medical records at Sunnaas Rehabilitation Hospital. Three of the studies were surveys with questionnaires, one of them in combination with clinical examination. The remaining study was qualitative with in-depth interviews. With cross-sectional design, it was possible to gather a relatively large amount of information with moderate resources. The main strength in the overall design of the studies in this dissertation is the triangulation of methods including both quantitative and qualitative studies. In order to investigate the surprising result on perceived exercise mastery between persons with motor complete SCI and persons with functionally incomplete SCI, revealed in the first two studies, the in-depth knowledge gathered in the third study added valuable information as a basis for study 4. An additional strength is the use of theory (CATS) as a basis for the studies. In general, there is a lack of theory based studies on physical exercise and persons with disabilities, and this dissertation will make a contribution in that aspect (Kosma, Cardinal, & McCubbin, 2003).

The access to retrospective data from medical records made it possible to identify those with incomplete SCI exclusively. It is important to be aware of the possible inaccuracy of retrospective data as a source of bias (Altman, 1991). In our data, there was incomplete data in the medical records regarding AIS classification, and in the first study, Frankel classification had to be used.

The limitations of the qualitative in-depth interviews include possible misunderstandings or lack of awareness due to personal bias, both during the interview, and with the interpretation of the data (Patton, 2002). In order to limit these errors, an interview-guide was used, see Appendix V. In order to increase the credibility and authenticity of the study, both authors conducted the analyses, first separately, then together. The different quotes, the context in which they were used, analyses and conclusions were approved by the respective respondents.

Cross-sectional design limits the possibility to study causal associations (Altman, 1991). For example, in Paper I, it is impossible to conclude that a high level of physical exercise causes higher life satisfaction, since the fact may be that a low life satisfaction may lead to depression and a lower level of all kinds of activities, including physical exercise.

Questionnaires and self-reporting limitations.

Self-reporting, such as answering mailed questionnaires, is a practical method for collecting and assessing data from many persons in a short time due to their relatively low costs of administration. The method has limitations which may reduce the validity and the reliability of the results. *Reliability of a scale* refers to how free it is from random errors (Pallant, 2010). Reliable scales will therefore produce similar results. In order to strengthen the results in this dissertation we tested some of the scales used for reliability and with satisfactory result. Reliability is necessary, but not sufficient for a measurement to be valid (Sutton & French, 2004). *The validity of a scale* refers to the degree to which it measures what it is supposed to measure (Pallant, 2010). Valid measures are relatively free from systematic errors. There is no a clear-cut indicator for validity of a scale.

Even with self-reporting as the most common method to measure physical activity and exercise, the method has limitations which may influence the results (Baranowski & De, 2000; Booth, 2000; Sallis & Saelens, 2000). In order to strengthen the results, the questionnaires on physical exercise used in the studies 1, 2 and 4, were tested with satisfactory results.

8. Conclusion and implications

The results demonstrated that the role of physical exercise in the health-stress relationship was a double edged sword for persons with incomplete SCI. On the one hand it played a positive role in this association in that those who exercised experienced higher life satisfaction than those who were physically inactive (study 1), and physical exercise mediated the association between disability-stress and burnout and fatigue (study 4). On the other hand, physical exercise turned into a stressor when the total physical load in everyday life exceeded the functional capacity (study 3). This is supported both by CATS and other reported research. Perceived fitness mediated the positive relationship between exercise and life satisfaction (study1), whereas perceived exercise mastery contributed both negatively (study 1) and positively (study 4) to health outcomes. The higher the individuals rated their ability to cope with stress caused by their disabilities, the lower they scored on both burnout and fatigue.

The present dissertation highlights the complexity of the relationship between physical exercise and health for persons with incomplete SCI. The findings are very important in a clinical context, both during the rehabilitation process and later. It is likely that persons with incomplete injuries need lifelong follow-up programmes for several reasons. The findings demonstrate the importance of individual monitoring of changes/reductions in physical function. These potential changes will have consequences for realistic expectations for coping with stress caused by the SCI, which again will have implications for the future. For some, adjusted goals and the adaptation of needed aids will be necessary, and it is important to continue to perform physical exercise. In order to achieve a positive result in the health-stress relationship, any exercise programme, however, needs to be individually designed. It is important to strengthen muscles that stabilise and support the movements used in everyday life, and to prevent overuse problems. The physical exercise programme has to take into consideration the individual’s available resources, the motivation for physical exercise, individual goals and the total physical demands in life. As a clinical physiotherapist, I realise that these results have practical implications for rehabilitation professionals working with persons with incomplete SCI. The findings help us to understand the possible positive or negative effects of physical exercise. The end of the quotation by the young woman at the beginning of this dissertation (page 9) was illustrative for the importance of physical exercise: “I think it’s especially important for people with a disability like mine to keep in good shape, as the ability to cope with everyday life often depends on narrow margins”.

The dissertation has indicated that further research is needed. We need more data on the physiological variation in persons with incomplete SCI. We also need to know how the association between physiological and psychological factors may influence the degree of coping. In order to further investigate the relationship between a stressor and positive health-outcome in CATS, both randomised controlled trials (RCT) and longitudinal studies will be needed.

9. References

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Paper 1

Lannem, A. M., Sørensen, M., Froslie, K. F., & Hjeltnes, N. (2009). Incomplete spinal cord injury, exercise and life satisfaction. *Spinal Cord*, *47*(4), 295-300.

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Paper 2

Lannem, A. M., Sørensen, M., Lidal, I. B., & Hjeltnes, N. (2010). Perceptions of exercise mastery in persons with complete and incomplete spinal cord injury. *Spinal Cord, 48*(5), 388-392.

Lannem, A. M., Sørensen, M., Lidal, I. B., & Hjeltnes, N.
(2010). Perceptions of exercise mastery in persons with complete
and incomplete spinal cord injury. *Spinal Cord, 48*(5), 388-392.

Paper 3

Lannem, A. M., & Sørensen, M. The role of physical exercise, perceived exercise mastery, and stress in persons with incomplete spinal cord injury (SCI). Submitted to Journal of Rehabilitation Medicine.

The Role of Physical Exercise, Perceived Exercise Mastery, and Stress in Persons with Incomplete Spinal Cord Injury (SCI).

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Abstract

The aim of this study was to explore the experiences of persons with incomplete Spinal Cord Injury (SCI) with physical exercise, perceived exercise mastery (PEM) and stress. A phenomenologically orientated qualitative study with in-depth interviews was performed. Six persons, 2 females and 4 males, ages between 39 to 62 years, participated. Years post-injury ranged from 4 to 40. The main finding was that the total physical and psychological demands of everyday life related to functional capacities, influenced how exercise mastery was perceived. High PEM occurred when exercise was perceived as building or maintaining physical resources. Reduced PEM occurred when physical progression stagnated, physical resources were overloaded, and fatigue developed. Personal differences contributed to stress-accumulation and individual coping strategies were needed.

Keywords: Incomplete spinal cord injury, exercise, stress, coping.

The Role of Physical Exercise, Perceived Exercise Mastery, and Stress in Persons with Incomplete Spinal Cord Injury.

After a Spinal Cord Injury (SCI), most individuals have reduced possibilities to regain normal muscle strength in affected parts of the body. The neurological deficits and the functional limitations depend on where in the spinal cord the disruption occurs, and whether the injury is complete or incomplete (Marino et al., 2003). The physical limitations the individual with an incomplete SCI faces in everyday life, can be perceived as the case of stressful situations. According to the Cognitive Activation Theory of Stress (CATS), each stress experience may trigger a stress response (Ursin & Eriksen, 2004). The level of the stress response depends on the individuals appraisal of the situation, which is based on previous experience and learning. If the stressor is perceived as possible to overcome, or coped with, the stress response will be less severe and short-lived, with no negative health consequences. According to CATS, “coping is positive outcome expectancy.” (Ursin & Eriksen, 2004). However, if the stressor is perceived as impossible to overcome, no coping will occur, and the stress may lead to negative health consequences. Physical activity and exercise is defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (p.126), and “Exercise is a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness” (Caspersen, Powell, & Christenson, 1985). We know that exercise can be a positive resource against illness in the general population (Haskell, Blair, & Hill, 2009). Persons with SCI may likewise build protective health resources through physical exercise in physical, psychological and social fields. When a person with SCI exercises, physical components such as muscle strength and endurance capacity increases (Harvey, Lin, Glinsky, & De, 2009; Valent, Dallmeijer, Houdijk, Talsma, & van der Woude, 2007). Exercise may also influence different psychological parameters such as coping skills and well-being (Fernhall, Heffernan, Jae, & Hedrick, 2008; Lannem, Sorensen, Froslie, & Hjeltnes, 2009; Lannem, Sorensen, Lidal, & Hjeltnes, 2010; Latimer, Ginis, Hicks, & McCartney, 2004; Latimer, Martin Ginis, & Hicks, 2005). In addition, exercise may build social resources such as networks and be an arena for social support (Anneken, Hanssen-Doose, Hirschfeld, Scheuer, & Thietje, 2010). Physical exercise is used as a protective resource both during rehabilitation after the acute SCI and, is afterwards recommended as a part of a lifelong routine in order to reduce complications and positively enhance fitness and well-being (Fernhall et al., 2008; Lannem et al., 2009; Manns, McCubbin, & Williams, 2005; Nash, 2005; Tasiemski, Kennedy, Gardner, & Taylor, 2005; Valent et al., 2007). During the rehabilitation process, the patients learn to use exercise to improve and maintain function and health. To feel mastery of exercise is, therefore, important in order to continue exercise behaviour (McAuley & Blissmer, 2000), and to cope with the stressors and overcome the stress response (Eriksen, Murison, Pensgaard, & Ursin, 2005). Perceived exercise mastery (PEM) is defined as a perception of competence when performing physical exercise (Sorensen, 1997).

The level of physical activity in the population living with SCI is still low (Buchholz, McGillivray, & Pencharz, 2003; Martin Ginis et al., 2010a; Martin Ginis et al., 2010b; Saebu & Sorensen, 2010; Wahman, Biguet, & Levi, 2006). An individual with incomplete SCI who perceives physical limitations in everyday life, may perceive the same physical limitations and reduced sense of accomplishment when performing physical exercise if the exercise program is not adapted to his physical capacity and functional abilities. Without adaptations, he will expect not to be able to cope, and exercise may turn into an additional stressor.

Earlier research has demonstrated that exercise mastery was perceived differently in persons with complete and incomplete SCI. Those with incomplete SCI perceived less exercise mastery the more hours they exercised per week (Lannem et al., 2010). This is different for persons with a complete injury and for the general population (Lannem et al., 2010; Sorensen, Anderssen, Hjerman, Holme, & Ursin, 1997). The results are in contrast to the logical assumption that because those with incomplete SCI have more physical function intact, they should be able cope better with the physical demands of exercise and everyday life. For persons with incomplete SCI the prognosis for recovery is more uncertain compared to persons with complete lesions (Burns & Ditunno, 2001). This may give more unrealistic expectations than the person can tolerate owing to weakness and lack of muscle mass. In addition, there is some evidence that long term living with a SCI may speed up the normal ageing process regarding the cardiovascular system, musculoskeletal system and the immune system (Hitzig, Eng, Miller, & Sakakibara, 2010). Chiodo et al. (2007) recommended lifelong follow-up programme for individuals with SCI, and underlined that it is important to focus on the combination of ageing and living with a chronic disability.

PEM should be expected as long as the outcome of physical exercise is positive, i.e. the physiological parameters and/or the perception of well-being and other positive psychological components increase, the exercise help building protective resources to counteract negative effects of stressors. On the other hand, if the physical demands in everyday life are higher than the person’s capacity, low PEM and exercise perceived as stress might be expected instead. Such a situation may result in the similar concepts as overtraining and burnout as found in sports (Lemyre, Treasure, & Roberts, 2006).

To explore the role of physical exercise, PEM, stress and coping, a qualitative study was performed. The focus of the in-depth interviews was on why or in what situation persons with incomplete SCI tend to perceive high and low exercise mastery, and how this is associated with stress, coping, exercise motivation, fatigue or burnout.

Method

Participants

In order to investigate these phenomena more closely, a qualitative study with a phenomenological approach and in-depth interviews was chosen (Patton, 1990). Because the group of persons with incomplete SCI is extremely heterogeneous, a purposeful and critical case sampling procedure was used in order to attain a wide range of information from persons with possibly different perceptions of exercise mastery (Patton, 1990). We wanted different levels of functional ability represented in the sample as well as both genders and people with differing ages and times since injury. AIS (ASIA Impairment Scale) was used to classify the participants (Marino et al., 2003). In order to eliminate those who could still have a spontaneous recovery, the time since injury was set to be at least 2 years (Burns & Ditunno, 2001). Only persons classified as AIS D were included in the study. AIS D is defined as "when motor function is preserved below the neurological level, and at least half of the key muscles below the neurological level have a muscle grade of 3 or more (3= Movements against gravity but not against resistance)". (Marino et al., 2003).

Six persons with incomplete SCI AIS D, admitted to a rehabilitation hospital for follow-up during the spring 2009 were asked to be interviewed, and all accepted to participate in the study. Demographics are given in Table 1.

Data collection and interviews

Data was collected by semi-structured interviews conducted by the first author. The interviews were tape-recorded in full, and within the first month after the interviews, the tapes were transcribed verbatim (Patton, 1990). An interview-guide was developed according to guidelines for qualitative interviews (Patton, 1990). The guide was based on CATS, clinical experience and previous research (Lannem et al., 2009; Lannem et al., 2010). Open-ended questions were asked about the following: the influence of SCI on their lives, the perception of stress owing to mobility restrictions in daily life, their exercise habits both before and after injury to present day, their feelings towards exercise, their perception of exercise and exercise mastery, their motivation for exercise, their perception of overtraining and burnout.

Additional definitions in the interview

All definitions in the interviews were given both orally and in writing. The definitions were for physical activity and exercise, PEM, coping, overtraining and burnout. The overtraining syndrome is comprised of a large numbers of symptoms including psychological, physiological, biomechanical and immunological factors that lead to a feeling of psychological and physical exhaustion (Kenttä & Hassmén, 2002). Overtraining was defined as "An accumulation of training and non-training stress resulting in long-term decrement in performance capacity with or without related physiological and psychological signs and symptoms of overtraining in which restoration of performance capacity may take weeks or months." (Kreider, Fry, & O´Toole, 1998). Burnout was defined as: "A multidimensional syndrome depicted by emotional and physical exhaustion, devaluation of physical exercise participation, and a reduced sense of accomplishment" (Lemyre et al., 2006; Raedeke, 1997; Raedeke & Smith, 2001). Overtraining and burnout share symptoms, except that in burnout loss of motivation for further exercise is present (Gould, 1996; Lemyre et al., 2006).

Procedure

All interviews were conducted in a face to face setting at the rehabilitation hospital. On average, the interviews lasted one hour. The study was approved by the Regional Medical Research Ethics Committee. The respondents gave their written consent to participate in the study. The transcripts were confirmed as correct by the respondents. In order to increase the credibility and authenticity of the study, both authors conducted the analyses, first separately, then together. The different quotes, the context in which they were used, analyses and conclusions were approved by the respective respondents after their amendments were taken into consideration.

Data analyses

The data was analysed using MaxQda (MAXQDA, 2007). The analyses were conducted in different steps according to the guidelines (Kvale, 2006; Patton, 1990). First, the transcripts of the interviews were read through in order to gain a general picture of the texts. Second, the case story of each respondent was written chronologically from the time of injury to present day, with special attention given to situations that challenged the experience of PEM. Third, cross-case analyses were conducted. The texts were coded by the thematic units used in the interviews, and the information was examined to discover cross-case patterns related to overtraining, burnout and total physical demands. We compared the patterns with exercise habits and total life situations before injury, the years after injury and at the time of the interview. We also examined the respondents' expectations as to how much exercise could help with regaining physical function after the injury, and to what extent their initial expectations about recovery post-injury had been fulfilled.

Results

Descriptives of the sample

Six persons, 2 females and 4 males with incomplete SCI (AIS D) participated in the study. Their ages ranged from 39 to 62 years, and the number of years post-injury ranged from 4 to 40. Among them, 4 persons were walkers, and 2 persons combined walking and the use of wheelchairs for mobility. Two of the persons received disability pensions, one was on 50 % sick leave from a full time job, 2 worked full time, and one had a 50 % disability pension combined with 50% employment.

Before injury, 4 of the participants were physically active with different sports including jogging, skiing, and hiking in the mountains. One participant competed at a national level in an endurance sport. Two of the participants had never been involved in any kind of sports or physical activity. In the rehabilitation phase, all respondents followed the standard programme for SCI including exercise, both in acute care and, later, in rehabilitation. All respondents continued with exercise supervised by a physiotherapist after discharge from the rehabilitation hospital. At the time of the interviews, 3 of the 6 respondents did not follow any planned exercise program. Exercise habits, work and family relations are presented in Table 2 and Table 3. PEM and coping are presented in table 4.

Table 1, 2, 3 and 4 in near here.

Cross-case analyses

The most important observation was that the PEM was dependent on whether exercise was perceived as building or maintaining resources, an extra burden or as a stressor. There were individual differences as to what contributed to the perception of stress and overload, and how they coped. Exercise was perceived as a resource building tool when they perceived improvement or maintenance of physical function or if they had sufficient time and capacity to exercise. For some of the participants this could only be obtained when being on sick leave or by reducing working hours. Ann said: “I have felt that after I had children, the time for physical exercise is limited. The period with sick leave, a few years ago, gave me back some of that time, and my energy level increased remarkably.” Ted perceived that his exercise program gave him both physical and some psychological energy. To enhance the psychological part even more, he used mental training by imaging the movements of different tasks before he performed them. Ted was familiar with this technique from his active sport career before injury. Until a few years ago, Evan performed physical exercise in order to be able to do the things that persons without SCI do automatically. He said:

> I have lived a rich life, a very fulfilling life, maybe more so than some healthy people, too. From that perspective I think I have benefited a lot (from exercise) in terms of self-perception, self-esteem and psychological and physical well-being.

Exercise was perceived as an extra burden or stressor in connection with life transitions, for instance, after being discharged from the hospital following initial rehabilitation. Caroline divulged:

> And then, when you leave the hospital, you have to do multiple tasks, and I think, then everything comes to a stop. It is not because I don't like to exercise any more, I simply cannot find the energy to do it. It is hopeless. It takes so much energy to perform daily activities, and it takes even more energy to exercise.

Discharge from the rehabilitation hospital seemed to be a difficult time, also due to invisible impairments. David told us:

> During hospital rehabilitation, you experience huge improvements in the main components of function. Then, when you go home, you expect the same rate of recovery. Instead, you come to a standstill. The worst thing was to have no bladder and bowel control. That was what took so long to learn to cope with. The weakness in my leg was nothing compared with that. That was what bothered me most.

Physical exercise was perceived as an extra stressor in connection with work, and with family life with small children. Caroline was always tired, slept a lot and had no energy to do any physical exercise. She said:

> I have experienced some fatigue all the time since injury. It is only that now with work and family life, I have less time to recover. In everyday life, all the things needed to be managed require so much, and I have no energy left to do exercise in addition to work and family.

A consequence of reduced physical capacity may also be over-use of the physical resources used in everyday life. This may be compared to the concept of overtraining with reduced sense of accomplishment as found in sports. Ted used his knowledge and personal experiences about exercise and overtraining from his former sport career. In general, he felt that his exercise program built resources, both physically and mentally. He also experienced that the spasticity was more bothersome the days he was not training. Even so, he feared overtraining. Therefore he kept two days per week without training. He took an extra day off training if his performances were poor. He said:

> It may be easier, I think, to get over-trained when you have a SCI, especially in the initial phase when your muscle volume is remarkable reduced, and due to the limited physical abilities. You may not feel the physical strain or the over-use due to the reduced or changed sensibility in your body. So, my concern still is that you have to take special care and be more aware when you have a SCI. Due to the changes in sensibility, you might not feel the same way as before the injury when you get tired and normally would have taken a rest. I have also experienced that after a stop of training for some days, when I start again, I perform better.

Most of the respondents had experienced problems with fatigue, with sleep disturbances, pain and physical overload at one or more points in time. Both Evan and Caroline experienced extreme pain that used up a great deal of energy. Of the respondents, only Evan had experienced burnout. He was advised by health workers to take it easy when his physical function declined because of ageing. He feared that when he was resting and using more adaptive aids, that he would lose his physical abilities to be independent and admitted:

> At the same time as I take it easy and rest, I lose functions because I am not engaged in exercise as I should! So it is a double-edged sword, or a circle that is

> difficult to break. I am more exhausted than over-trained. I have used my body more than most people. What other people call the activities of daily living have been as exercise for me. As a result, I have been physically burned-out and physically exhausted for having pushed my body too far. I have pain, I have disregarded pain and disregarded weakening muscles. I have depended on my willpower for many years. I have had expectations for myself, and I have met expectations from others. I have overexerted myself for many years in relation to my physical resources. I still would not have done otherwise.

The wish to appear healthy and fit without any weakness was exemplified in this study by Ann’s and Caroline’s barriers to using adaptive aids. The time, when Ann`s children were in a stroller, she described as a good time:

> When our first child was born, I noticed how fantastic it was to go for a walk with the stroller. It was a perfect walking aid just like a walking frame with wheels. I could walk much longer distances without getting tired and I noticed much more balance problems when walking without it.

Those who experienced high PEM at the time of the interview had made active choices to reduce stressors in everyday life in different ways. According to CATS` definition of coping as positive outcome expectancy, reducing the stressors in everyday life will enhance the possibilities for a successful coping. Ted stopped working in order to have time for physical exercise. He clearly emphasised the importance of building up his physical and psychological resources by performing physical exercise. Experiencing a total change in life after an injury demands time for adaptation, both physical and psychological. In order to reduce the demands in everyday life, Caroline never worked fulltime due to her physical impairment, but even this did not seem to be enough. Bill both planned to undergo a re-training in order to reduce the physical load at work, and had changed his exercise strategy from physical therapy to an active outdoor-life. David re-trained to a less physically demanding job. In addition, he maintained that it was necessary to adjust the expectations about what exercise could do for recovery after injury. He told:

> I think that those who exercise a lot, if they experience a dramatic injury, such as a SCI, probably expect that the recovery depends on how much they exercise, and that they can regain what they have lost by training. I think they get a mental crash much bigger than those of us who do not have the same interest in exercise. We do not expect so much, and we set less ambitious goals or take smaller steps on our way back.

Both one's own expectations and the expectations of health professionals or family can influence how PEM are perceived. Adjustment of the expectations and acceptance of physical limitations seemed to be necessary to achieve coping in everyday life. In addition, use of adaptive aids could be of help.

Discussion

The purpose of the study was to explore in depth why or in what situation persons with incomplete SCI tend to perceive high and low exercise mastery, and how this perception is associated with stress, coping, exercise motivation, fatigue or burnout. The most important observation was that PEM was experienced as long as the exercise was perceived as building or maintaining physical resources or physical function (strength, endurance, flexibility, movement capacity etc.). The sum total of physical demands of everyday life including work, family responsibilities, leisure-time activities, reduced physical capacity or ageing, and how they were coped with, was important for whether the respondents perceived exercise mastery. When the physical progression stagnated, or fatigue and overload developed, low exercise mastery was experienced. Physical exercise turned into a stressor for the individual. CATS illustrate how challenges to the physical resources are perceived as stressors, and may result in low perceived exercise mastery.

Various stages or transitions in life after injury contributed to a change in PEM. The specific transitions that emerged were mostly related to social roles and resources. Coming back to everyday life on new and very different terms that required an adaptation, and in addition having to handle a certain bureaucracy related to the situation was challenging. Stress continued to accumulate in connection to work, either going back to the same job as before the injury, having to change the work situation or going through some kind of re-education. This is supported by previous research where return to work and barriers to employment have been investigated, and the results have indicated low employment rate for persons with longstanding SCI (AIS A-E) (Lidal, Hjeltnes, Roislien, Stanghelle, & Biering-Sorensen, 2009). A literature review confirmed these findings (Lidal, Huynh, & Biering-Sorensen, 2007).

A normal active family life can also challenge the physical and psychological capacity for a person with SCI and, this may be difficult for family members to accept and understand. The time spent with small children may demand more planning for those with reduced physical capacity. Family members may have to take more responsibilities to help balance the logistics in daily life. Previous research has indicated that a substantial proportion of the partners of persons with sequelae after SCI, experience a serious increase in caregiver burdens, especially during the initial phase after an injury, a severe impairment or in conjunction with ageing (Post, Bloemen, & de Witte, 2005). It is important to be realistic about the total demands in everyday life for the whole family and make choices that contribute to a positive energy balance. All transitions demand adjustments.

As demonstrated by Evan’s case, another factor, potentially important for whether exercise will function as a resource building activity or not, is the natural decrease in physiological capacity due to age changes in both lung function and aerobic capacity. The normal decrease in both is estimated to be about 1% reduction per year (Astrand, 1960; Gulsvik, 1979; Loeppky & Luft, 1989). These changes will complicate the ability to benefit from exercise even more when the physiological capacity is already reduced. Evans reduced physiological capacity was probably a combination of the consequences of his SCI and the normal ageing process. He had lived 40 years with an incomplete SCI and severe mobility restrictions. In spite of exercising he may have lost so much physiological work capacity during all these years that his activities started to overload his already reduced capacity. He admitted that he had overexerted himself for many years in relation to his physical capacity. However, for Evan, it may have been a dilemma but it was conscious choice.

The results of the interviews indicate that a gap may exist between the physical capacity of the individual and the personal expectations of how much exercise can restore normal function. Such expectations are also held by others. However, the individual's potential to recover function is difficult to predict. In the literature, predictions of future functional outcome are much better documented for persons with complete SCI than for those with incomplete lesions (Burns & Ditunno, 2001; Whiteneck et al., 1999). This represents another dilemma. Persons with an incomplete SCI may experience more uncertainty and, as a result, have more unrealistically high expectations about their future, resulting in a lower degree of PEM. On the one hand, unrealistically high expectations may result in disappointment, low PEM, and potentially fatigue or burnout. On the other hand, high expectations may give positive motivation to reach demanding goals. Ted still gained function 4 years post-injury. He talked about the expectations of the health professionals regarding his recovery during his initial period of rehabilitation. At the time of the interview, Ted had become much more mobile than they had predicted. He described how some therapists had told him that a task was impossible to perform and stopped him from trying to do it. Sometimes the health professionals were simply mistaken. Ted's experience was that, most of the time, when he had tried new tasks that he, himself, believed he could perform, he could do more than the therapists had expected. For Ted, challenging his physical limits was a way of motivating himself during rehabilitation and, it still was, in connection with his exercise programme. In contrast during her initial rehabilitation, Caroline experienced that the rehabilitation professionals were sure she would gain much more strength and physical function than she actually did. As a result, she did not receive as many assistive devices from the health care system as she needed. This caused her a great deal of stress, for some years, demonstrating that the need for adjustment of expectations, whether they be one's own or others, can be necessary when they prove to be inaccurate.

Barriers to using aids have also been reported and discussed in previous research (Fawkes-Kirby et al., 2008; Kemp & Thompson, 2002). Fawkes-Kirby et al. (2008) reported that persons with complete SCI experienced less fatigue than those with incomplete injuries. They argued that less use of adaptive aids by persons with incomplete injuries was one of the reasons causing fatigue. Lannem et al. (2010) argued that realistic goal-setting was important to adjust expectations. In addition, as a basis for realistic goal-setting, persons with incomplete SCI must both accept the physical limitations experienced as a result of their injuries and, use aids in connection to everyday life activities. Bill, with his invisible impairment, met with little empathy from others` (family, friends and colleagues) in connection with the consequences of his injury. Their misconceived expectations believing that he was totally recovered were extremely stressful for him. He felt that he was expected to do everything as he had done before. Unrealistic expectations about what exercise can do to help recovery, both one's own and that of others, may be affected by little or no acceptance for reduced capacity. The gap between understanding the consequences of the injury, hope for recovery and the reality of the situation may be too wide. The disappointment of unfulfilled or only partially fulfilled goals can influence life in a negative way. In the present study, David's reflections about how high expectations for recovery connected to amount of exercise, supports the importance of the acceptance of, whatever reduced function one has after injury, as a basis for realistic goal-setting.

In this study, PEM was related to coping by reducing the physical demands in everyday life. A critical question could be that when physical overload occurs, why not stop exercising in order to restrict the use of physical resources? Therapists are often faced with an argument that activities of daily living (ADL) are enough physical activity for persons with SCI to keep fit. Although this may be the case sometimes, whenever possible exercise and activity alternatives are recommended to ensure a balanced use of all active movements not necessary used in ADL. Because of reduced muscle mass in some of the persons with incomplete SCI, variation in the exercise program is necessary to avoid overuse problems and, to stimulate supporting muscles (Nash, 2005). By following a systematic and individually designed exercise program, a person with SCI could also strengthen muscles that stabilise and support the movements used during ADL. We find support in the literature concerning the effectiveness of systematic exercise or therapy both for physical and psychological benefits (Fernhall et al., 2008; Harvey et al., 2009; Lannem et al., 2009; Latimer et al., 2004; Latimer et al., 2005; Valent et al., 2007).

Loss of motivation for exercise, as previously mentioned, is the distinction between overtraining and burnout (Gould, 1996; Lemyre et al., 2006). Of the respondents only Evan reported no motivation for exercise and, thus, was the only one to experience burnout. The others were motivated for physical activity, either in the form of systematic exercise or in the form of an active outdoor life. But, all of them had experienced different degrees of overtraining, overload or reduced sense of accomplishment. In sports attention is given to the process for configuration and handling the total stress load in everyday life (Kenttä &

Hassmén, 2002). A balance in the intensity of activity and periods of restitution or relaxation is necessary for coping. Persons with incomplete SCI could take advantage of a similar approach to coping with their own combination of challenges that can affect their PEM. In this study, each of the participants coped differently with the stressors in their everyday life. The coping strategy will influence whether exercise is perceived as positive and edifying, or if exercise causes wear and tear on their physical and psychological resources. Acceptance of decreased physical function, even when it is not visible to others, may help to reduce the perceived stress in everyday life. When one is realistic about one's own abilities, coping strategies will be more specific, as for those who had undergone retraining to have less physically demanding work. As mentioned before, regular physical exercise is important as a lifelong coping strategy to achieve the main goal of optimal health and function (Fernhall et al., 2008; Harvey et al., 2009; Lannem et al., 2009; Latimer et al., 2004; Latimer et al., 2005; Nash, 2005; Valent et al., 2007). To remain physically active it seemed important to the respondents to be able to find an enjoyable adapted exercise strategy whether it was physical therapy, specific sports or, as exemplified by Bill and David, outdoor life activities. To cope with the differences between the total physical demands and functional capabilities of the individual, it seems to be very important for the injured person to make choices to balance the total physical demands of everyday life, i.e. reducing working hours, getting help in the home, using adaptive aids, hiring a personal assistant to take care of the daily strain etc. Hopefully, this will prevent a future physical overload resulting in burnout. This is also supported by CATS in showing how physical and psychological resources are challenged when living with the consequences of an incomplete SCI.

It may be a limitation of this study that six respondents only represent a limited extent of the heterogeneity of the population with incomplete SCI, even with a purposeful and critical case sample procedure. Given that a SCI is a physical injury, the focus of this study has been more on the physical and the perception of physical capabilities and functional resources, than on psychological and social resources. In addition, the study has been made in a country with a well-functioning governmental health-care system and easy access to hospital care and adaptive aids.

Conclusion

This study explored the experiences persons with incomplete SCI had with physical exercise. The main finding was that the total physical and psychological demands of everyday life related to functional capacity, influenced how exercise mastery was perceived. High PEM was experienced when the exercise was perceived as building or maintaining physical resources. Low PEM was experienced when the physical progression stagnated, and if function declined, overload or fatigue developed. Similar processes have been described in other areas, e.g. a reduced sense of accomplishment in sport leading to burnout. Further research is needed. We need more knowledge about the physiological variations found among those with incomplete SCI. We also need to know the incidence of overload, fatigue and burnout in the population with incomplete SCI. Such knowledge could serve as a basis for individualised exercise guidelines for persons with incomplete SCI.

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To be added.

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Table 1 Description of the participants

	Age	Year post injury	Injury level	Spasticity	Walking Aids	Main mobility
Evan	62	40	C6	Yes	AFO one cain	Manual wheelchair and walking
Ann	46	27	T11-T12	No	AFO	Walking
Caroline	39	13	C5-C6	Yes	AFO	Walking
Bill	41	4	C6	No	No	Walking
Ted	53	4	C4-C5 and L1-L2	Yes	Crutches	Power wheelchair and walking
David	50	27	L3	No	AFO	Walking

Abbreviations: AFO: ankle-foot orthotis

Table 2 Physical exercise habits

	Evan	Ann	Caroline	Bill	Ted	David
PE pre injury	No	Active in sports	Very active with running and skiing	Heavy manual labour and active outdoor life	National level endurance sport	No
PE during rehabilitation	Yes	Yes	Yes	Yes	Yes	Yes
PE after rehabilitation	PT with PE program twice a week till three years ago	PT with PE program.	PT with PE program the first years post injury	PT with PE programme. After a while he got tired of all kinds of PT	He looked on PE as his work. PE with an assistant 5 days a week.	The first year post-injury PT with PE programme.
PE at present	No	When on 50% sick leave she has energy to do PE.	No	Active outdoor life summer and winter.	Same programme, supervised by a therapist 3 days a week.	No

Abbreviations: PE: Physical exercise; PT: Physical therapy

Table 3 Work and family life

	Evan	Ann	Caroline	Bill	Ted	David
Work at injury	Student	Student	Student	Manual labour	Office work	Manual labour
Change in work status	Changed study and worked full time for 22 years	Continued same study	Continued same study	Planning to start retraining	Stopped working to be able to do PE	Retrained to less physical job
Employment at the time of interview	Disability pension began 8 years ago	50% sick-leave	50%	100%	0%	100%
Family status at injury	Single	Single	Single	Divorced with teenagers	Spouse and teenagers	Single
Family status	Divorced with grown up children	Family with small children	Family with small children	Grown up children	Spouse and grown up children	Divorced with teenagers

Table 4

Name	PEM and coping
Evan	He experienced high PEM until a few years ago. From the moment exercise was of no more help for maintenance of physical function, he lost his motivation for exercise, and his level of PEM decreased. He perceived physical exercise as a resource until this happened. During all the years post-injury he disregarded pain. At the time of the interview, Evan felt exhausted and was experiencing burnout. All the same, he did not regret the regular exercise and active life of his earlier years.
Ann	With full time work and an active family life, she had no energy reserves left. She was physically overloaded and experienced very low PEM. Exercise had become a stressor. During periods with sick leave or maternity leave, she felt she got her energy resources increased and experienced higher PEM. She found she had sufficient energy to do exercise again. At the time of the interview, she realised she had to make some choices in order to balance the total physical demands in her life.
Caroline	Until 2 years ago, she experienced high PEM because exercise built up her resources. At the time of the interview, she was overloaded by the physical demands in her life and PEM was low. Exercise had turned into a stressor, and in one way or the other, she needed to make some choices to reduce the demands of everyday life in order to save the energy to exercise and re-build her resources. She found this difficult.

Bill	He experienced high PEM until his recovery came to a halt. At that time, when he experienced that exercise drained him for energy, he was overtrained. In addition, the total demands in his life with the heavy manual labour were too much. To cope with the situation, he both changed his exercise strategy and decided to undergo vocational re-training to a less physically demanding job.
Ted	At the time of the interview, he still experienced improvement in his physical capabilities, and had high PEM. Because of his exercise knowledge pre-injury, he was especially aware of the dangers of overtraining and overload. In order to cope with the situation and continue his active family lifestyle, and have enough energy continue to exercise without overtraining, he had decided to stop working.
David	He coped with his working situation after vocational re-training to a less physically demanding job. He experienced high PEM owing his realistic expectations as to how much exercise could help his recovery.

Paper IV

Lannem, A.M. Physical exercise, stress, coping, burnout and fatigue in persons with incomplete spinal cord injury (SCI), European Journal of Adapted Physical Activity. (Accepted for publication with minor revisions, October 9th 2011)

Physical exercise, stress, coping, burnout and fatigue in persons with incomplete spinal cord injury (SCI).

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Incomplete SCI, Exercise, Burnout, fatigue.

Abstract

The aim of this study was first to examine the prevalence of burnout and fatigue in a sample of persons with incomplete Spinal Cord Injury (SCI). The second aim was to analyse the role of physical exercise and degree of coping in the association between stress caused by the disability and burnout or fatigue. A mailed survey was performed. A total of 186 persons, 142 males and 44 females, ages between 18 – 87 years, were included in the study. Years post-injury ranged from 2 to 55. The main findings were that 15 % experienced burnout and 63% perceived fatigue or borderline fatigue. Physical exercise and degree of coping buffered the associations between stress caused by the disability and both fatigue and burnout.

Keywords: Incomplete spinal cord injury, exercise, stress, coping, burnout, fatigue.

Physical Exercise, Stress, Coping, burnout and fatigue in Persons with Incomplete Spinal Cord Injury (SCI).

The level of physical activity is reported to be generally low in the population with spinal cord injury (SCI) (Buchholz, McGillivray, & Pencharz, 2003). Consistent with the general population, physical exercise is recommended to prevent lifestyle diseases and enhance the quality of life and well-being for persons living with SCI (Harvey, Lin, Glinsky, & De, 2009; Hicks et al., 2003; Martin Ginis et al., 2003). However, a person with an incomplete SCI may be confronted with reduced physical function in many daily life situations and also when exercising. In this study, the cognitive activation theory of stress (CATS) was used as a theoretical framework (Ursin & Eriksen, 2004). The physical consequences of the SCI may be explained as stressors according to CATS. According to the theory, a homeostatic imbalance between the expected outcome and the factual outcome of a situation activates a neurophysiological stress alarm. The total health consequences of the stress alarm are determined by the way one reacts to the activation of the stress alarm. According to CATS, coping is defined as “positive outcome expectancy” (Ursin & Eriksen, 2004). If the individual expects to be able to handle the stressful situation, i.e. has learned to cope effectively, the stress response or arousal level is reduced, and there are no further negative health consequences. If the imbalance persists, negative health effects such as burnout, fatigue or illness may occur. The consequences of an incomplete SCI may act as a persistent stressor. If, for example, a person with spasticity and limited walking abilities is always afraid of stumbling or falling, all obstacles, such as curbstones, uneven or slippery ground, a street with fast following traffic etc., can be perceived as stressors. The person’s own low expectations to manage the situation may result in stumbling or falling. There are different possibilities to overcome such a stressor. Acceptance of reduced walking abilities is necessary for finding the best individual coping solution for outdoor mobility. One possible strategy is to increase strength, balance and walking ability with exercise and thereby prepare the person for outdoor ambulation. Another option is use of adaptive aids such as wheelchair or walking aids. Even if a person is able to cope with some of the stressors during the day, all together they may prove to be too much to handle. Coping with the stressors will be influenced by previous experiences and learning (Eriksen, Murison, Pensgaard, & Ursin, 2005). The total rehabilitation process post-injury aims at preparing the persons with SCI to cope with such obstacles in everyday life by building protective levels of resources within physical, psychological and social fields. Acceptance of the consequences of the injury and realistic goal-setting is crucial for coping with the stressors due to the SCI (Kennedy, Evans, Berry, & Mullin 2003; Roberts & Kristiansen, in press).

Realistic goal-setting should also include adjustment of expectations of recovery from being too high. This is a double edged sword as discussed by Lannem and Sørensen (in review). On the one hand, high expectations may enhance positive motivation to reach demanding goals. On the other hand, too high expectations may lead to defeat and increase the stress. Both too high and too low expectations from others, i.e. health professionals, may lead to frustration. Finally, while low expectation may simply reduce the stress, it may be that the person will not exploit his/her potential opportunities for maximum function.

In general, the rehabilitation process will influence both how stress is perceived in different situations, and how to cope with it. Lannem and Sørensen (in review) discussed how persons living with an incomplete SCI have to make active adjustments in order to reduce the physical demands in everyday life and cope better with the consequences of their disability. As long as the level of physical, psychological and social resources are high enough and, the person believes that he/she can cope with the stressors, the resources may counteract the negative stress effects. If the physical demands in everyday life, however, are more than the person’s total physical capacity, these resources may be overloaded. In the long run, they are likely to be reduced. Physical exercise in such a situation may be difficult to perceive as positive and instead turn into an extra stressor (Lannem & Sorensen, in review). A long term outcome may result in overtraining and burnout, similar to what may happen to athletes in a sport context (Lemyre, Hall & Roberts, 2008). Compared to an able-bodied person, it will be even more difficult to predict how much physical demands a person with SCI can tolerate before overtraining or burnout occur as a result of muscle weakness, lack of muscle control, weakened sensory input and autonomic reflexes resulting in reduced physical capacity.

The term and phenomenon burnout comes originally from studies on work-related stress. Work-related burnout is characterised as a psychological syndrome, including emotional exhaustion, depersonalisation, and reduced personal accomplishment (Maslach, 1993). Further, the reduced personal sense of accomplishment refers to: “a decline in one’s feelings of competence and successful achievement in work” (p 21, Maslach, 1993). Based on this concept, Raedeke (1997) and Raedeke and Smith (2001) described athlete burnout as a multidimensional syndrome involving emotional and physical exhaustion, reduced sense of accomplishment in sport and devaluation of participation in sport. Lannem and colleagues argued that persons living with incomplete SCI may experience overload and burnout in relation to exercise (Lannem et al., 2010; Lannem & Sorensen, in review). In addition, non-acceptance of technical aids, even if they need it, may increase overload of physical resources.

For persons with incomplete SCI, the prognosis for recovery is more uncertain than for those with complete SCI (Burns & Ditunno, 2001). This may result in unrealistic expectations of future physical function for those with incomplete lesion. For some, the expectations of recovery are fulfilled to a certain extent during the first years post injury, in particular if they exercise. The functional improvements diminish over the years, and a decline in daily function may occur because of complications, possible overload, or normal aging. They will probably perceive a reduced sense of accomplishment, even if they exercise, which is considered a causal factor both in work-related and athlete burnout.

The role of physical exercise for the perception of stress and coping with stress was explored in persons with incomplete SCI in a qualitative study (Lannem & Sorensen, in review). The main finding was that the total physical and psychological demands of everyday life influenced how exercise mastery was perceived. High exercise mastery was experienced when the exercise was perceived as building or maintaining physical resources. Low exercise mastery was experienced when the physical improvement stagnated, and when overload or fatigue developed.

The term fatigue can be defined as an overwhelming sense of tiredness, lack of energy and, often, a feeling of total exhaustion (Herlofson & Larsen, 2002). While burnout has a stronger psychological background, prolonged fatigue is more related to a physical problem (Leone et al., 2010). In this study, the term fatigue is used as a symptom, and not as the diagnosis of Chronic Fatigue Syndrome (CFS) (Wessely, 2001). Fatigue is a frequently reported symptom in a large number of neurological disorders and is characterized by a feeling of constant exhaustion, including both a sense of physical exhaustion and an important cognitive component, a sense of mental fatigue (Chaudhuri & Behan, 2004). Fatigue is also reported as an extra symptom for persons living with SCI (Anton, Miller & Townson, 2008; Fawkes-Kirby et al., 2008).

According to CATS stress factors may accumulate and lead to burnout, fatigue, and chronic illness because of the physical disabilities of persons with incomplete SCI, unless the challenges are coped with. Coping strategies may be physical exercise or the use of adaptive aids as mentioned above. Therefore, the purpose of the present study was: First, to determine the prevalence of burnout and fatigue in a Norwegian population of persons living with incomplete SCI; and second, we wanted to analyse the role of physical exercise in the association between stress caused by the disability and burnout or fatigue. We hypothesized that the stress caused by the disability was indirectly linked to both burnout and fatigue, and that physical exercise and degree of coping with the perceived stress would buffer its negative effects.

Methods

The design of the study was cross-sectional. Data was collected by a mailed questionnaire that measured perceived stress of the disability, leisure time physical activity, exercise mastery, coping, burnout and fatigue. Background information was gathered from medical records. The AIS (ASIA impairment Scale) score D was used as the main inclusion criteria (Marino et al., 2003).

Participants

Included in the study were persons rehabilitated at Sunnaas Rehabilitation Hospital between 1962 and 2008. Invitations were sent to 316 persons classified as AIS D or with a cauda equina injury. In order to minimize bias from general age changes, persons above 60 years at the time of the injury were excluded, as well as persons who were unable to respond to the questionnaire.

Measures:

Physical Disability Stress Scale (PDSS): Furlong and Connor (2007) constructed a scale to measure disability-related stress in persons with physical disability. The PDSS was originally validated for adults with an acquired physical disability and who required the use of a wheelchair as their main source of mobility (Furlong & Connor, 2007). The scale was translated into Norwegian using a double Translation – Back Translation technique. The total scale (22 items) may be used with 4 subscales, namely Access (4 items), Physical (5 items), Social (7 items) and Burden of care (6 items), or as a total scale score. The range of scores for the total scale is 0-110.

Injury level and severity of the injury were assessed as recommended by the American Spinal Injury Association (ASIA) and divided into tetraplegia and paraplegia (Marino et al., 2003). Tetraplegia describes those with impairments in all extremities, in addition to central parts of the body. Paraplegia refers to those with paralyses in the legs, in addition to parts of the stomach and back muscles, depending on the level of injury.

Exercise: Physical activity and physical exercise were measured by the International Physical Activity Questionnaire (IPAQ) and a 4-item rating of leisure time physical activity (LTPA).

LTPA: A one-item scale, developed in the 1960s and widely used in Norwegian health surveys, was used to measure leisure time physical activity (LTPA) (Graff-Iversen et al., 2008; Saltin & Grimby, 1968). The respondents were asked to rate their weekly average LTPA: 1) Reading, watching TV or other sedentary activities; 2) Walking, cycling, using a wheelchair or moving about in some other way at least 4 hours per week – including commuting to work and Sunday walks; 3) Taking part in physical exercise or sports, heavy gardening work etc. - at least 4 hours a week; and 4) Exercising hard or taking part in competitive sports regularly several days a week. Wilhelmsen et al. (1968), Aires et al. (2003) and Graff-Iversen et al. (2008) have reported stable construct validity.

IPAQ: The IPAQ short version was developed for use with adults (18-69 years) (Craig et al., 2003). It collects information from the last 7 days, on time spent walking, doing moderate and vigorous-intensity activities and, also, time spent sitting. The instrument has shown acceptable reliability and validity (Craig et al., 2003). A Norwegian translation was available and had been used both for persons with and without a physical impairment (Saebu & Sorensen, 2010; Wilhelmsen, 2009).

Perceived exercise mastery (PEM): In the mailed questionnaire PEM was defined as "a perception of competence when performing physical exercise" (Sorensen, 1997). The respondents were asked to rate their PEM at present on a visual analogue scale (VAS) ranging from 0 – 10 (0 = I perceive no competence when performing physical exercise, 10 = I perceive optimal competence when performing physical exercise). Aitken (1969) demonstrated that a VAS captures slight differences in personal perceptions better than a categorical scale.

Degree of Coping: Coping was defined according to CATS as "positive outcome expectancy" (Ursin & Eriksen, 2004). The respondents were asked to rate how they coped with the total physical demands in everyday life as experienced due to the SCI, on a VAS rating from 0 – 10 (0 = no coping, 10 = optimal coping).

Pines Burnout Measure (PBM): The 21 items in the PBM are scored on a 7-point Likert scale ranging from 1 =never to 7=always (Schaufeli et al., 1993). The scores can be recoded into a total burnout score (PBS). Scores higher than 4 indicate burnout to the extent that mandatory changes in everyday life are necessary (Pines & Aronson, 1988). The instrument has been tested and is considered a reliable and valid research instrument (Pines & Aronson, 1988; Schaufeli, Enzmann, & Girault, 1993). The PBM has been used as a measure for context-free burnout, and a Swedish national survey was used as comparable normative data (Hallsten, Bellagh, & Gustafsson, 2002). The scale was translated to Norwegian using a double Translation – Back Translation technique.

Fatigue Severity Scale (FSS): To measure fatigue, the FSS was used (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). It consists of nine items, each scored on a Likert scale ranging from 1 = "strong disagreement" to 7 = "strong agreement". Reliability and validity of the FSS has been reported to be good in populations of persons with different impairments and normal healthy adults (Anton et al., 2008; Fawkes-Kirby et al., 2008; Krupp et al., 1989; Lerdal, Rustoen, Hanestad, & Moum, 2005; Schanke & Stanghelle, 2001). The cut-off score of over 4, as indicative of fatigue, was originally set by Krupp et.al. (1989). In a Norwegian translation of the instrument and test of the psychometric properties, the investigators suggested that the threshold for defining severe fatigue should be a FSS score of 5 as opposed to the original score of 4 (Lerdal et al., 2005). Furthermore, they suggested that scores between 4 and 5 indicate borderline fatigue.

Procedure: The study was approved by the Regional Medical Research Ethics Committee, Eastern Norway. Respondents gave their written consent to participate. Background information regarding injury level and severity, as well as additional injuries and complications, was collected by reviewing medical records. Two letters were sent prompting replies.

Statistical analyses: All analyses were conducted using PASW statistics 18.0 for Windows. Descriptive statistics were used to characterise the sample. Data was summarised by mean values and standard deviations (SD) or median values and range, when appropriate. Independent sample t-tests were used to compare mean values of dependent and independent variables in tetraplegia versus paraplegia. The Spearman correlation test was used to measure the correlation between LTPA and the IPAQ. To test the mediations in Figure 1, the following three linear regression equations were estimated in each model: First, regression of the mediator on the independent variable; second, regression of the dependent variable on the independent variable; and third, regression of the dependent variable on both the independent variable and the mediator (Baron & Kenny, 1986). Separate coefficients for each equation were estimated and tested using standard linear regression procedure. Pearson’s correlation coefficient was used for correlations between variables in the mediation analyses.

Results

Participants

A total of 316 persons fulfilled the inclusion criteria and received a mailed questionnaire. After two reminders, 199 persons (63 %) responded, either by returning the questionnaires or by a telephone interview. Seven persons refused to participate, and 4 persons were not able to answer due to pre-senile dementia. In addition, 2 persons turned out to be classified as AIS C and were consequently excluded from the analysis. The final sample consisted of 186 respondents. Because of ethical regulations, it is not possible to compare the respondents with the non-respondents. The characteristics of the sample are given in Table 1. No differences were found between the subgroups tetraplegia versus paraplegia, for any of the dependent or independent variables.

Table 1 in near here.

PDSS

As the population in this study was more heterogeneous than the original population, we tested the internal consistency of the total scale in the studied population. The Chronbach Alfa coefficient was 0.93. Therefore we used the total score.

Comparison of LTPA and the IPAQ

To compare the measures LTPA and IPAQ in the study population, a correlation test was performed between LTPA and IPAQ, short version. The correlation was reasonably high (r_s = .55, $p < .001$). However, all the IPAQ measures were highly skewed towards zero and LTPA had a normal distribution. It seems as though, in a less active population such as persons with incomplete SCI, LTPA captures more of the variance in the lower part of the scale, and was therefore used in the final analyses.

Burnout and fatigue

PBM. Of the respondents, 173 persons (93%) completed the PBM. The mean PBS was 2.8 (SD = 1.2), and 26 persons, 15% of those who completed the PBM, scored above 4, the cut-off point for burnout, which is higher compared with 7.1% in the Swedish national survey (Hallsten et al., 2002).

FSS. Of the respondents, 176 persons (95%) completed the FSS, and 63 % of those scored 4 or above, whereas 43% scored above 5. Mean score was 4.4 (SD =1.5), which means borderline fatigue, compared with 4.0 (SD = 1.3) in a Norwegian normal sample of Lerdal et al. (2005). In a Canadian sample of persons with SCI this was 4.5 (SD =1.8) (Fawkes-Kirby et al., 2008), and in Norwegian sample of polio-survivors this was 5.2 (SD = 1.5) (Schanke & Stanghelle, 2001).

Correlations between independent variables, mediators and dependent variables

All tested variables demonstrated statistically significant correlations with each other. The correlation was negative between LTPA and the PDSS, the PBS and the FSS. The PEM correlated negatively with the same variables. Degree of coping correlated positively with LTPA, but negatively with the PDSS, the PBS and the FSS (see Table 2 for details).

Table 2 in near here.

The role of exercise in burnout and fatigue

Figure 1 in near here.

Figure 1 illustrates the conceptual models used for the mediation analyses. First, we tested the relationship between PDSS and PEM. This relationship was mediated by LTPA (model 1). Then, we tested the relationship between PEM and burnout, which was mediated by degree of coping (model 2). Finally, we tested the relationship between PEM and fatigue, which was mediated by degree of coping (model 3). The criteria for mediation as suggested by Baron & Kenny (1986) was used. In total, all the paths tested in the 3 models were significant; see Table 3 and Figure 1. The models were tested separately for mediation with three simple regression equations. In model 1, the regression of the mediator (LTPA, path a) demonstrated a significant effect on the independent variable (PDSS) ($R^2_{\mathrm{adj}} = .09$, F = 17.614, $p < 0.001$). Second, the dependent variable (PEM, path c) significantly affected the independent variable (PDSS), ($R^2_{\mathrm{adj}} = .11$, $F = 21.474$, $p < 0.001$). Finally, the mediator significantly affected the dependent variable (PEM) in a regression model with both LTPA and PDSS as predictors. In this equation, PDSS affected PEM less than in the third equation. See Table 3 for details. Model 2 and model 3 were tested in the same order, for details, see Table 3. The results of the mediation analyses demonstrated that PDSS was indirectly linked to PEM through LTPA ($R^2_{adj} = .28$, F = 31.839, p < .001), that PEM was indirectly linked to burnout through degree of coping ($R^2_{adj} = .51$, F = 82.777, p < .001), and lastly, that PEM was indirectly linked to FSS through degree of coping $R^2_{adj} = .36$, F = 45.808, p < .001).

Table 3 in near here.

Discussion

In this study we examined the prevalence of burnout and fatigue within a sample of persons living with incomplete SCI. We observed a markedly higher prevalence of both burnout and fatigue compared to able-bodied populations (Hallsten et al., 2002; Krupp et al., 1989). In addition, we analysed the role of physical exercise in the association between stress caused by the disability and burnout or fatigue. We hypothesised that the PDSS was indirectly linked to PEM through LTPA, and that PEM was indirectly linked to burnout and fatigue through the individual's degree of coping with their everyday situation. All the findings in the mediator tests were consistent with this hypothesis.

In the literature, it is difficult to find information about the prevalence of burnout in the general population. In a Swedish national survey of the general adult population, the prevalence of burnout measured by the PBM was lower compared with the present study (7.1

% versus 15 % respectively) even if the PBM mean score did not differ (Hallsten et al., 2002). The comparable mean score could partly be explained by the difference in sample sizes and that the distribution of the PBS in our sample was slightly skewed (range 5.7 and skewness 1.12 to the lower value). As observed, it is, however, likely that persons struggling in their everyday life to overcome their physical impairments in order to function as independently as possible are more likely to experience a state of burnout than the general population.

The prevalence of the symptom of fatigue, as measured by the FSS in the present study, indicated that fatigue is much more common than burnout. This result is supported by other studies, both for persons with SCI and other neurological impairments (Anton et al., 2008; Fawkes-Kirby et al., 2008; Herlofson & Larsen, 2002; Krupp et al., 1989; Schanke & Stanghelle, 2001). For the general population, Lerdal et al. (2005) reported data from the FSS that revealed that scores were higher for persons with chronic illness (lasting 6 months or more). To avoid over-diagnosing high fatigue levels, they suggested that the threshold for high fatigue probably should be 5 on the FSS, instead of 4, as had been suggested originally. In the present study, as many as 43% scored above 5 on the FSS, compared with 23% in the general population as reported by Lerdal et al (2005). In addition, 20 % in the present study, scored between 4 and 5 on the FSS, indicating a borderline state of fatigue. It is argued that an overloading process is triggering the onset of both chronic fatigue syndrome (CFS) and burnout, and that fatigue is one of the symptoms in both concepts (Leone et al., 2010). The present findings emphasised how vulnerable persons with incomplete SCI are for both burnout and fatigue compared with the general population.

Furthermore, Leone et al. (2010) argued that CFS and burnout are different concepts, but that the relationship between them should be examined further. In a sport context, Lemyre et al. (2008) argued long-lasting physical exhaustion may contribute to the development of burnout. In this study, we can speculate whether fatigue, as a symptom, is a precursor of burnout, and that a person with a high level of fatigue may be at particularly risk of developing burnout. For persons with reduced physical capacity, like those with incomplete SCI, it is especially important to be aware of the consequences of neglecting the symptom of fatigue. Persons with incomplete SCI have a relatively unpredictable potential for recovery (Burns & Ditunno, 2001). This may result in unrealistic expectations of their own physical capacity, and, consequently, they use less adaptive aids than needed in everyday life. Fawkes-Kirby et al. (2008) argued that lack of use of adaptive aids of persons with incomplete SCI was one of the reasons for fatigue. In addition, they registered that persons with incomplete SCI reported more severe fatigue than those with complete lesions. The results in the present study supported that those who experienced burnout, also experienced fatigue, and that the symptom of fatigue seemed to be a precursor for burnout.

Following the pathways in Figure 1, the mediating effects of both LTPA and the degree of coping seemed to buffer the negative effects due to stress. This is consistent with earlier research. Martin Ginis et al. (2003) demonstrated that changes in pain and stress improved well-beeing, and Latimer et al. (2005) found preliminary support for exercise in buffering the effects of stress on well-beeing.

Gerhart, Weitzenkamp, Kennedy, Glass and Charliefue (1999) reported various correlates of stress in long-term SCI from a longitudinal study, and Quale, Skanke, Froslie and Roise (2009) reported from a cohort study on posttraumatic stress symptoms in severely injured patients but neither of the studies found a relationship between stress and severity of disability. This finding is consistent with the present study where no differences in PDSS were found between the subgroups tetraplegia versus paraplegia.

In the present study, 2 pathways demonstrated an indirect association between stress and fatigue. First, PDSS and LTPA explained 27% of the variance in PEM, and secondly, PEM and the degree of coping explained as much as 37 % of the variance in FSS. A stronger association was found between PEM and PBS where PEM and degree of coping explained 51 % of the variance in PBS. This means that the associations between the variables in the study are stronger for PBS than for fatigue. This may be explained by the fact that the measure of burnout relies on psychological processes but the measure of fatigue is of a more physical nature.

In order to control for the reported amount of exercise, two different measures were used. A limitation in the use of IPAQ in this population was demonstrated. The IPAQ measures were highly skewed towards zero, and as a result did not capture the variation in the responses in the relative low physically active population. The response alternatives in LTPA included 2 responses for less active persons, either sedentary activities, or low intensity at least 4 hours per week. This seemed to be enough to statistically achieve a normal distribution, and thereby capture more of the variance in the low physical active population.

A limitation of this study may be the cross-sectional design and use of self-reports. Also, social desirability may result in over-reporting of exercise (Sallis & Saelens, 2000). Another limitation was the sample size, and that we do not know anything about the 37% that did not respond to the survey, which limits the generalisation. Due to ethical regulations, we could not gather details (gender, age, severity of injury and complications) from medical records of the non-respondents. There is a possibility that persons with more complications or a more severe impairment, even if this is a very inactive population, are less likely to participate in a survey like this. The comments from the seven respondents who refused to participate indicated severe complications or functional limitations.

Perspective

This study examined the prevalence of burnout and fatigue within a sample of persons with incomplete SCI. In addition, we analysed the role of physical exercise and degree of coping in the association between stress caused by the disability and burnout or fatigue. This sample of persons with incomplete SCI perceived burnout and fatigue more frequently than the general population. Physical exercise and degree of coping buffered the associations between stress caused by the disability and both fatigue and burnout. Further research is needed. We need more knowledge about the physiological variations found among those with incomplete SCI. We also need to know more about the association between the physiological and psychological variables and how this association may influence degree of coping.

Acknowledgements

To be added

Incomplete SCI, Exercise, Burnout, fatigue.

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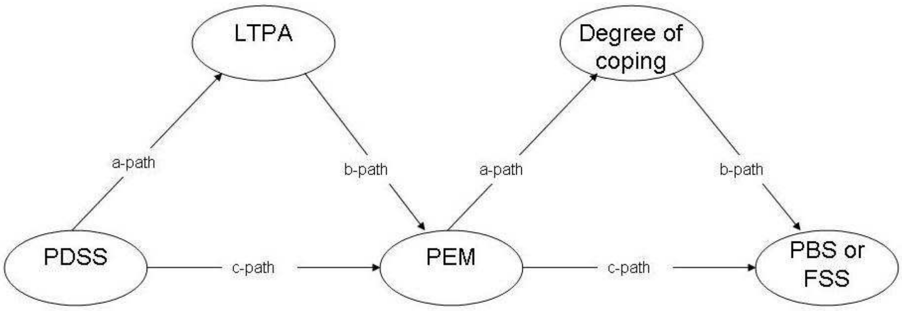
Figuere1. Conceptual models used for the mediation analyses.



Abbreviations: PDSS: physical disability stress scale; LTPA: Leisure time physical activity; PEM: Perceived exercise mastery; PBS: Pines burnout score; FSS: fatigue severity scale.

Table 1 Sample and injury characteristics (n= 186)

	Mean (s.d.)	Range
Age (years)	48 (14)	18 - 87
Age at injury (years)	33 (14)	5 - 60
Duration of injury (years)	15 (13)	2 - 55
	n	%
Sex		
Male	142	76
Female	44	24
Injury level		
Tetraplegia	85	46
Paraplegia	101	54
Additional illness/ injury	80	43

Table 2. Mean scores and Pearson's correlations among variables

Variables	Mean	SD	1.	2.	3.	4.	5.	6.
1. PDSS	38.6	23.1	-					
2. LTPA	2.3	.9	-.304**	-				
3. PEM	6.1	2.7	-.343**	.516**	-			
4. Coping	6.6	2.3	-.469**	.268**	.530**	-		
5. PBS	2.8	1.2	.564**	-.319**	-.489**	-.705**	-	
6. FSS	4.4	1.5	.431**	-.312**	-.464**	-.554**	.628**	-

**. Correlation is significant at the 0.01 level (2-tailed). Abbreviations: PDSS: physical disability stress scale; LTPA: Leisure time physical activity; PEM: Perceived exercise mastery; PBS: Pines burnout score; FSS: Fatigue severity scale

Table 3. Linear Models testing: PDSS → LTPA → PEM → Coping → PBS or FSS

Variables and paths	ΔR^2	β	t	p
Model 1: PDSS → LTPA → PME				
LTPA as mediator of PEM				
Path a, PDSS → LTPA	.09	-.304	-4.197	.000
Path b, LTPA → PEM	.26	.516	7.775	.000
Path c, PDSS → PEM	.11	-.343	-4.634	.000
Path c + path b	.27			
PDSS		-.197	-2.779	.006
LTPA		.434	6.112	.000
Model 2: PEM → Coping → PBS				
Coping as mediator of PBS				
Path a, PEM → Coping	.28	.530	7.933	.000
Path b, Coping → PBS	.49	-.705	-12.705	.000
Path c, PEM → PBS	.23	-.448	-7.092	.000
Path c + path b	.51			
PEM		-.161	-2.444	.016
Coping		-.624	-9.479	.000
Model 3: PEM → Coping → FSS				
Coping as mediator of FSS				
Path a, PEM → Coping	.28	.530	7.933	.000
Path b, Coping → FSS	.30	-.554	-8.662	.000
Path c, PEM → FSS	.21	-.464	-6.704	.000
Path c + path b	.36			
PEM		-.268	-3.606	.000
Coping		-.418	-5.621	.000

Abbreviations: PDSS: physical disability stress scale; LTPA: Leisure time physical activity; PEM: Perceived exercise mastery; PBS: Pines burnout score; FSS: fatigue severity scale.

Appendix I

Approval letters from

the Regional Committee for Medical and Health Research Ethics

REGIONAL KOMITÉ FOR MEDISINSK FORSKNINGSETIKK
HELSEREGION 1

Gaustadalléen 21, 0349 Oslo. Telefon 22 95 87 98

Oslo, 27. mai 1999

Hovedfagsstud. Anne Marie Lannem
Sunnaas sykehus
1450 Nesoddtangen

Vår ref.: 184/99-99075

Sammenhengen mellom aktivitetsvaner hos personer med inkomplett ryggmargskade mer enn 15 år etter skaden og deres selvopplevde helse. En retrospektiv undersøkelse av personer med inkomplett ryggmargskade, klassifisert som Frankel D, skadet mellom 1962 og 1982

Regional komite for medisinsk forskningsetikk, helseregion I, vurderte prosjektet på sitt møte 20.05.99.

Komiteen har ingen innvendinger mot at prosjektet blir gjennomført.

Komiteen går ut fra at prosjektlederen vil søke Helsetilsynet om fritak fra taushetsplikten, slik hun skriver i punkt 5 i komiteens vurderingsskjema, og at det således skyldes en glipp at det under punkt 10 med spørsmål om dette, er krysset av for "er ikke aktuelt". Komiteen forutsetter videre at prosjektlederen undersøker i Folkeregisteret om pasientene fortsatt er i live før hun sender ut spørreskjemaene.

Vennlig hilsen

Sten Sander
Sten Sander
professor dr.med.
formann

Ida Nyquist
Ida Nyquist
sekretær

Norsk samfunnsvitenskapelig datatjeneste
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Hans Holmboesgt. 22
N-5007 Bergen
Norway
Tel: +47/ 55 58 21 17
Fax: +47/ 55 58 96 50
E-mail: nsd@nsd.uib.no
http://www.uib.no/nsd

Anne Marie Lannem
Tolia 21

1453 BJØRNEMYR

Dato: 23.06.99 Vår ref: 9900555 RØ/BHB Deres dato: 21.03.99 Deres ref:

SØKNAD OM KONSESJON FOR STUDENTREGISTER

Vi viser til søknad om tillatelse til å opprette personregister mottatt 25.03.99. Søknaden gjelder prosjektet: 6543 - Sammenhengen mellom aktivitetsvaner hos personer med inkomplett ryggmargskade mer enn 15 år etter skaden og deres selvopplevde helse..

Etter en gjennomgang av søknaden finner Datafaglig sekretariat at prosjektet ikke utløser konsesjonsplikt etter personregisterlovens § 9. Det personregister som opprettes vil falle inn under personregisterlovens forskrifter Kapittel 2 Unntak for konsesjonsplikt § 2-17 Forskningsregistre. Vilkår for konsesjonsfritak etter § 2-17 er at det er frivillig å delta, at førstegangskontakten opprettes gjennom faglig ansvarlig person ved den institusjonen respondenten er registrert, at respondentenes skriftlige samtykke for alle deler av undersøkelsen innhentes, at materialet slettes eller anonymiseres ved prosjektavslutning, og at prosjektet ikke varer mer enn fem år.

Prosjektet synes å oppfylle disse vilkårene, men dersom prosjektet endres i forhold til oversendt melde-skjema, kan det utløse konsesjonsplikt og bør vurderes på nytt.

Fritak for konsesjonsplikt medfører samtidig at virksomhetens leder pålegges registeransvar og ansvar for kontroll, sikring mm., jfr. forskriftenes kap. 3. Med registeransvaret følger bl.a. at man plikter å føre oversikt over hvilke personregistre som til enhver tid finnes ved institusjonen. Universitetsrådet og Høgskolerådet har delegert til NSD deler av de administrative plikter som følger av forskriftenes kap. 3. Institusjonene beholder det formelle registeransvar, mens NSD registrerer hvilke prosjekter som er fritatt for konsesjonsplikt, for at institusjonene skal kunne ivareta sine kontrolloppgaver.
Datafaglig sekretariat vil ved prosjektets avslutning rette en henvendelse om arkivering av innsamlet datamateriale. Dette både for å sikre at data ikke blir unødvendig slettet, samt for å bistå dersom det allikevel oppstår behov for konsesjonsbehandling i forbindelse med lagringen av materialet.

Dersom du har spørsmål i forbindelse med tolkningen av de ulike vilkårene eller andre forhold, ta gjerne kontakt med Datafaglig sekretariat.

Vennlig hilsen
Datafaglig sekretariat

Bjørn Henrichsen

Reidar Øygard
Reidar Øygard

Kontaktperson: Reidar Øygard, tlf: 55 58 35 42
Vedlegg

REGIONAL KOMITE FOR MEDISINSK FORSKNINGSETIKK

Øst-Norge (REK I)

Konst. Sjeffysioterapeut Anne Marie Lannem
Sunnaas sykehus
1450 Nesoddtangen

Deres ref.: Vår ref.: 54-04023 Dato: 30. januar 2004

Sammenligning av selvrapportert og målt fysisk form hos personer som har levd lenge med ryggmargsskade

Regional komite for medisinsk forskningsetikk, Øst-Norge, vurderte prosjektet på sitt møte 27.01.04.

Komiteen har ingen innvendinger mot at studien blir gjennomført.

Med vennlig hilsen

Knut Engedal
professor dr.med.
leder

Ida Nyquist
sekretær

REGIONAL KOMITE FOR MEDISINSK FORSKNINGSETIKK

Øst-Norge (REK I)

Klinisk stipendiat Anne M. Lannem
Sunnaas sykehus HF
1450 Nesoddtangen

Deres ref.: Vår ref.: 700-06-04023 Dato: 08. november 2006

Sammenligning av selvrapportert og målt fysisk form hos personer som har levd lenge med ryggmargsskade

Vi viser til brev av 26.10.06 fra prosjektlederen med revidert informasjonsskriv og kopi av mail fra Personvernombudet vedlagt. I brevet opplyses det at det er foretatt en endring i samtykkeerklæringen til ovennevnte prosjekt, samt at prosjektet er noe forsinket.

Komiteen tar brevet med vedlegg til orientering, og har ingen merknader.

Med vennlig hilsen

Ida Nyquist

Ida Nyquist
sekretær

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Stipendiat Anne Marie Lannem
Sunnaas sykehus HF
Bjørnemyrveien 11
1450 Nesoddtangen

Regional komité for medisinsk og helsefaglig forskningsetikk Sør-Øst D (REK Sør-Øst D)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 85 05 93
Telefaks: 22 85 05 90
E-post: i.m.middelthon@medisin.uio.no
Nettadresse: www.etikkom.no

Dato: 17.09.08
Deres ref.:
Vår ref.: S-08566d, 2008/14039

Fysisk trening og personer med inkomplett ryggmargsskade; opplevelser i forhold til treningsmestring og mulig overtreningsproblematikk

Komiteen behandlet søknaden 04.09.2008. Prosjektet er vurdert etter lov om behandling av etikk og redelighet i forskning av 30. juni 2006, jfr. Kunnskapsdepartementets forskrift av 8. juni 2007 og retningslinjer av 27. juni 2007 for de regionale komiteer for medisinsk og helsefaglig forskningsetikk.

Forskningsetisk vurdering:
Det er noe uklart hvordan rekrutteringen til prosjektet skjer. Komiteen understreker at henvendelsen til de aktuelle studiedeltakerne må gå fra sykehuset og ikke fra prosjektleder.

Komiteen har følgende merknader til informasjonsskrivet:
Informasjonsskrivet bør være mer utfyllende, spesielt med hensyn til hva intervjuet skal gå ut på og hvordan det skal gjennomføres.

Vedtak:
Prosjektet godkjennes under forutsetning av at merknadene som er anført ovenfor blir innarbeidet før prosjektet settes i gang.

Vedtaket var enstemmig

Komiteenes vedtak etter Forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes REK Sør-Øst D(jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29).

Med vennlig hilsen

Stein A. Evensen (sign.)
Professor dr.med.
Leder

Ingrid Middelthon
Komitésekretær

Kopi:
- Professor Marit Sørensen, Norges Idrettshøgskole, Sognsveien 220, 0806 Oslo

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Dr.gradsstipendiat Anne Marie Lannem
Sunnaas sykehus HF
Bjørnemyrveien 11
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Regional komité for medisinsk og helsefaglig forskningsetikk Sør-Øst B (REK Sør-Øst B)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 85 06 70
Telefaks: 22 85 05 90
E-post: juliannk@medisin.uio.no
Nettadresse: www.etikkom.no

Dato: 26.6.2009
Deres ref.:
Vår ref.: 2009/149b

2009/149b Ryggmargsskade og symptomer på overbelastning

Vi viser til søknad mottatt til fristen 25.mai 2009.

Komiteen behandlet søknaden i sitt møte den 17.juni 2009. Prosjektet er vurdert etter lov om behandling av etikk og redelighet i forskning av 30. juni 2006, jfr. Kunnskapsdepartementets forskrift av 8. juni 2007 og retningslinjer av 27. juni 2007 for de regionale komiteer for medisinsk og helsefaglig forskningsetikk.

Saksframstilling

Dette er en doktorgradsstudie som fokuserer forekomst av overbelastningssymptomer og tretthet hos personer med inkomplett ryggmargsskade (RMS). Som en følge av bedret akuttbehandling av ryggmargskadede har andelen personer med inkomplett RMS økt. Internasjonale studier kan tyde på at personer med inkomplett skade kan være spesielt utsatt for overbelastning og utmattelse. En av grunnene kan være for mye trening i forhold til ressurser og for lite hvile mellom treningsdosene som kan føre til overbelastning. En tidligere kvalitativ studie fra 2008 kan tyde på lav opplevelse av treningsmestring og tegn på utmattelse. I studien det nå søkes om godkjenning av vil forskerne kvantitativt undersøke hvilke spesielle forhold som må ivaretas m.h.t. trening for personer med inkomplett RMS. Det er en tverrsnittsundersøkelse med spørreskjema som skal kartlegge overbelastnings- og feilbelastningsproblematikk, utmattelsessymptomer, tretthet og treningsmestring.

Forskningsetisk vurdering

Komiteen har ingen forskningsetiske bemerkninger til prosjektet.

Informasjonsskriv/samtykkeerklæring

1. Komiteen har forstått at de innsamlede opplysningene vil lagres avidentifisert. I informasjonsskrivet veksles det mellom "anonymisering" og "avidentifisering" i omtalen av hvordan data skal behandles. Det bes om at man rydder opp i begrepsbruken.
2. Det må antydes hvor lang tid deltakelse vil ta.
3. Henvisningen til "funn fra tidligere studier" gjelder slik komiteen har forstått det funn fra egne studier. Komiteen anbefaler at henvisningen enten utgår eller spesifiseres.

Vedtak

Prosjektet godkjennes under forutsetning av at informasjonsskrivet revideres i tråd med komiteens anbefalinger. Revidert informasjonsskriv sendes komiteen *til orientering.*

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages (jfr. Forvaltningslovens § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes til REK Sør-Øst B (jfr. Forvaltingslovens § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. Forvaltningslovens § 29). Det bes presisert hvilke vedtak/vilkår som påklages og den eller de endringer som ønskes. Se informasjon om klageadgang og partsinnsynsrett på http://www.etikkom.no/REK klage

REK har gått over til elektronisk saksbehandling og fått ny saksportal:
http://helseforskning.etikkom.no
Vi ber om at alle henvendelser sendes inn via denne portalen eller på e-post til:
post@helseforskning.etikkom.no
Vennligst oppgi vårt saksnummer/referansenummer i korrespondansen.

Med vennlig hilsen

Tor Norseth (sign.)
Leder

Julianne Krohn-Hansen
Komitésekretær

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Dr.gradsstipendiat Anne Marie Lannem
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Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst B (REK Sør-Øst B)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 85 06 70

E-post: juliannk@medisin.uio.no
Nettadresse: www.etikkom.no

Dato: 10.05.2010
Deres ref.:
Vår ref.: 2009/149b

2009/149b Ryggmargsskade og symptomer på overbelastning

Vi viser til skjema for endringsmelding innsendt i SPREK 27.04.2010. Vedlagt fulgte også revidert sprørreskjema (27.04.2010) og ny forespørsel om deltakelse (27.04.2010).

Prosjektleder er Anne Lannem.

Det forutsettes at forskningsansvarlig er Sunnaas sykehus. Komiteen gjør oppmerksom på at forskningsansvarlig etter helseforskningsloven § 4 er institusjon eller annen juridisk eller fysisk person som har det overordnede ansvaret for forskningsprosjektet, og som har de nødvendige forutsetninger for å kunne oppfylle den forskningsansvarliges plikter etter denne loven.

Endringene innebærer at samtykkeskjema er endret i henhold til vilkår for godkjenning fra REK sør-øst.

Komiteen har ingen innvendinger, og tar endringsmeldingen med vedlegg til orientering.

Med vennlig hilsen

Stein Opjordsmoen Ilner (sign.)
leder

Olaug Twedt Myhre
Olaug Twedt Myhre
førstekonsulent

Kopi: Sunnaas sykehus HF, v/ klinikksjef Sveinung Tornås, Bjørnemyrveien 11, 1450 Nesoddtangen

Appendix II

Informed consents studies 1 - 4

Oslo kommune
Sunnaas sykehus
Avd. for nevromuskulære skader

Dato 20.01.2000

Deres ref:
Vår ref (saksnr):
Saksbeh: Anne Lannem, 95101005
Arkivkode:

Informasjonsbrev til deltakere i prosjektet

Sammenhengen mellom aktivitetsvaner hos personer med inkomplett ryggmargskade og selvopplevd helse - En retrospektiv undersøkelse av personer med inkomplett ryggmargskade, klassifisert som Frankel D.

Som fagkonsulent i fysioterapi ved Ryggmargskadeseksjonen, Sunnaas sykehus har jeg i mange år vært opptatt av trening og dens innvirkning på helse og trivsel hos personer med ryggmargskade. For tiden har jeg studiepermisjon fra min stilling, og i forbindelse med min hovedfagsoppgave ved Norges Idrettshøgskole skal jeg gjennomføre en spørreundersøkelse om aktivitetsvaner hos personer med inkomplett ryggmargskade.
Tidligere er de fysiske og fysiologiske fordelene med fysisk aktivitet/trening hos personer med komplett skade beskrevet i mange undersøkelser. Langtidseffektene av regelmessig tilpasset fysisk trening for personer med inkomplett skade er imidlertid ikke utfyllende beskrevet i litteraturen. Sammenhengen mellom regelmessig fysisk trening over lang tid og helse/livstilfredshet er det jeg nå ønsker å se nærmere på.

p:\word2\infoskriv.doc

Sunnaas sykehus
RMS-seksjonen
Avd. for nevromuskulære skader

Postadresse:
1450 Nesoddtangen
Besøksadresse:

Bjørnemyrveien 11, Bygning D

Telefon: 66 96 90 00
Telefaks: 66 91 25 76

Giro: 0823 03 06428
Foretaksnr.: 975 911 756

Aktuelle problemstillinger i undersøkelsen er:

- Er det en forskjell i selvopplevd helse og tilfredshet med livet mellom personer med inkomplett ryggmargskade som trener regelmessig og de som ikke trener regelmessig?
- Er det en forskjell i sosial aktivitet mellom personer med inkomplett ryggmargskade som trener regelmessig og de som ikke trener regelmessig?
- Er det forandring i behovet for/bruken av tekniske og/eller ortopediske hjelpemidler siden skaden? Er det sammenheng mellom treningsmengde og behovet for/bruken av hjelpemidler?

I tillegg til spørreundersøkelsen vil det bli hentet ut opplysninger fra din journal ved Sunnaas sykehus.
Resultatene vil gi nyttig informasjon om betydningen av trening /tilpasset fysisk aktivitet for selvopplevd helsetilstand hos personer med inkomplett ryggmargskade. Den vil kunne bidra til bedre planlegging og gjennomføring av treningstilbud for denne pasientgruppen i fremtiden.

Undersøkelsen vil gjennomføres i nært samarbeide med seksjonsoverlege Nils Hjeltnes, ryggmargskadeseksjonen Sunnaas sykehus og lege Hildegunn Snekkevik, Prosjektleder for prosjektet "Senfølger etter ryggmargskade", Sunnaas sykehus.

Prosjektleder er underlagt taushetsplikt, og de innsamlede opplysninger vil bli behandlet konfidensielt. Publikasjoner fra prosjektet vil ikke inneholde opplysninger som kan knyttes til enkeltpersoner.

Deltakelse i prosjektet er selvfølgelig frivillig, og forsøkspersonene står fritt til å trekke seg fra undersøkelsen eller la være å svare på enkeltspørsmål.

Spørreskjemaet kan virke langt og omfattende. For å lette utfyllingsarbeidet står det beskrevet underveis hvordan hver del skal utfylles.

Spørreskjemaet sammen med underskrevet samtykkeerklæring bes returnert i vedlagte svarkonvolutt helst så snart som mulig.

Hvis du lurer på noe, kan du gjerne ta kontakt på telefon 66969000 eller 95101005.

På forhånd takk for hjelpen!

Vennlig hilsen

Anne M. Lannem
Fagkonsulent fysioterapi /Prosjektleder

Samtykkeerklæring:

Ja, jeg har lest ovenstående informasjon og er villig til å delta i undersøkelsen. Deltakelse i undersøkelsen innebærer at jeg deltar i en spørreskjema-undersøkelse, samt at det hentes ut opplysninger om meg fra min journal ved Sunnaas sykehus.

Sted:................ Dato:........... ....

Underskrift

Sunnaas sykehus november 2004

Til

Informasjonsbrev : ”Sammenligning av selvrapportert og målt fysisk form hos personer som har levd lenge med ryggmargsskade”

En undersøkelse som skal bidra til økt kunnskap om hvordan fysisk aktivitet påvirker fysisk og psykisk helse hos personer med ryggmargsskade.

Etter at du var med i prosjektet ”Senfølger etter RMS”, ønsker vi å gjennomføre en tilleggsundersøkelse i forhold til fysisk arbeidskapasitet.
Formålet vil være å bidra til økt kunnskap om hvordan fysisk aktivitet påvirker fysisk og psykisk helse hos personer som har levd lenge med en ryggmargsskade. Det har tidligere vært lite fokus på om det er overensstemmelse på selvrapportert og objektivt målt/ faktisk kondisjonsmessig helse.
Vi ønsker at resultatene av undersøkelsen skal brukes som grunnlag for å bedre behandlings- og oppfølgingstilbudet for denne pasientgruppen.

Deltakelse i prosjektet vil innebære at du vil bli testet ved Klinisk fysiologisk laboratorium med arm-/ eller bensykkel, dessuten lungefunksjonsmåling. I tillegg ber vi deg om å svare på spørreskjema.

Alle opplysningene vil bli behandlet konfidensielt. Ved publisering/ offentliggjøring av resultatene fra etterundersøkelsen, vil alle personopplysninger være fjernet, slik at det ikke vil være mulig å identifisere enkeltpersoner.

Det er frivillig å delta, og du kan trekke deg fra hele eller deler av undersøkelsen på ethvert tidspunkt – uten nærmere begrunnelse. For de som ikke ønsker å delta, eller som trekker seg fra undersøkelsen underveis, vil dette ikke få noen konsekvenser for senere kontakt med og behov for tjenester fra helsevesenet.

Dine erfaringer kan øke vår kunnskap og bidra til et bedre behandlings-/oppfølgingstilbud i fremtiden.

Vi håper derfor at du kan tenke deg å delta i undersøkelsen.

Med vennlig hilsen,

Nils Hjeltnes	Anne M. Lannem	Hildegun Snekkevik	Ingeborg Lidal
avd.overlege, dr. med.	Fysio/Prosjektleder	Lege/ Prosjektmedarb.	Lege/ Prosjektmedarb.

☐ JA, jeg har lest ovenstående informasjon og er villig til å delta i undersøkelsen

☐ Nei, jeg ønsker ikke å delta i denne tilleggsundersøkelsen

………………………………………………………………………………………………

Dato underskrift

Sunnaas sykehus oktober 2006

Til

Informasjonsbrev : ”Sammenligning av selvrapportert og målt fysisk form hos personer som har levd lenge med ryggmargsskade”

En undersøkelse som skal bidra til økt kunnskap om hvordan fysisk aktivitet påvirker fysisk og psykisk helse hos personer med ryggmargsskade.

Du har tidligere vært med på og gitt samtykke til denne studien. Det som dessverre ikke kom tydelig frem av informasjonsbrevet og samtykkeerklæringen var at vi i tillegg til data som ble samlet inn har behov for å bruke data samlet inn i studien ”Senfølger etter RMS” og data fra din journal fra tidligere opphold i Sunnaas sykehus.
Formålet vil være å bidra til økt kunnskap om hvordan fysisk aktivitet påvirker fysisk og psykisk helse hos personer som har levd lenge med en ryggmargsskade. Det har tidligere vært lite fokus på om det er overensstemmelse på selvrapportert og objektivt målt/ faktisk kondisjonsmessig helse.
Vi ønsker at resultatene av undersøkelsen skal brukes som grunnlag for å bedre behandlings- og oppfølgingstilbudet for denne pasientgruppen.

Alle opplysningene vil bli behandlet konfidensielt. Ved publisering/ offentliggjøring av resultatene fra etterundersøkelsen, vil alle personopplysninger være fjernet, slik at det ikke vil være mulig å identifisere enkeltpersoner.

Det er frivillig å delta, og du kan trekke deg fra hele eller deler av undersøkelsen på ethvert tidspunkt – uten nærmere begrunnelse. For de som ikke ønsker å delta, eller som trekker seg fra undersøkelsen underveis, vil dette ikke få noen konsekvenser for senere kontakt med og behov for tjenester fra helsevesenet.

Dine erfaringer kan øke vår kunnskap og bidra til et bedre behandlings-/oppfølgingstilbud i fremtiden.

Vi håper derfor at du kan tenke deg å delta i undersøkelsen.

Med vennlig hilsen,

Nils Hjeltnes	Anne M. Lannem	Ingeborg Lidal
avd.overlege, dr. med.	Fysio/Prosjektleder	Lege/ Prosjektmedarb.

☐ JA, jeg har lest ovenstående informasjon og gir samtykke til at data beskrevet over kan brukes i undersøkelsen

☐ Nei, jeg ønsker ikke å delta i denne tilleggsundersøkelsen

……………………………………………………………………………………………

Dato underskrift

Forespørsel om deltakelse i forskningsprosjektet

Fysisk trening og personer med inkomplett ryggmargsskade (RMS); opplevelser i forhold til treningsmestring og mulig overtreningsproblematikk, dybdeintervju.

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å utdype tidligere funn i studier i forhold til opplevelse av trening, treningsmestring og eventuell stressopplevelse og stresshåndtering i forhold til trening. Skaden din er av den typen vi ønsker å undersøke.

Treningsvaner hos personer med ryggmargsskade og opplevelse treningsmestring er kartlagt i tidligere studier fra Sunnaas sykehus HF. Personer med inkomplett skade som trener regelmessig, rapporterer en mindre grad av mestring i forhold til trening enn de som ikke trener. I denne studien forsøker vi å finne mulige forklaringer på dette.

Hva innebærer studien?

Deltakelse i denne studien innebærer at vi gjennomfører et intervju med deg. Intervjuene blir tatt opp på bånd, og du vil bli bedt om å godkjenne utskriftene av det vi snakker om. I tillegg vil det bli hentet ut opplysninger fra din journal ved Sunnaas sykehus HF. Resultatene av intervjuene vil bli lagret og oppbevart utilgjengelig for innsyn. Dataene vil bli publisert i ikke identifiserbar form.

Mulige fordeler og ulemper

Erfaringer fra studien vil senere kunne hjelpe andre med samme diagnose.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer/direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger. Opplysningene blir senest slettet i 2016.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ikke ønsker å delta, trenger du ikke å oppgi noen grunn, og det får ingen konsekvenser for den videre behandlingen du får ved sykehuset.
Dersom du ønsker å delta, undertegner du samtykkeerklæringen på denne siden. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling på sykehuset. Dersom du senere ønsker å trekke deg, kan du kontakte klinisk stipendiat, fysioterapeut Anne M. Lannem, tlf. 66969278 eller 95101005.

Ytterligere informasjon om studien finnes i kapittel *A – utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse

Personer med inkomplett ryggmargsskade (AIS-D) som har levd med skaden i minst 5 år. Utvalget vil bli hentet fra pasientregisteret ved Sunnaas sykehus HF. 4-8 informanter vil bli kontaktet. Utvelgelsen vil skje i samarbeide med den kliniske avdelingen som har ansvar for kontrolloppfølging av personer med RMS.

Bakgrunnsinformasjon om studien

Til nå har det vært gjort lite for å få frem om det er forskjell på komplette og inkomplette skader og hva de får ut av trening. Det som er av retningslinjer i dag er utarbeidet fra Sosial- og Helsedirektoratet i 2004. Det er lite detaljert, og selv om det fremkommer hva de ulike gruppene bør trene med, er det ingen anbefaling om hvordan og hvilken tilrettelegging som kan være nødvendig, eller hvordan de ulike gruppene opplever treningen. Det er behov for mer kunnskap innen dette området.

Funnene fra tidligere studier ved Sunnaas sykehus HF i forhold til opplevelser rundt trening hos personer med RMS er spennende. I en oppfølgingsstudie ønsker vi nå å sette fokus på om det stemmer at personer med inkomplett RMS i mindre grad opplever mestring av fysisk trening. Dette temaet er svært aktuelt, og andre forskningsmiljøer har også satt fokus på beslektede begrep (fatique i Fawkes Kirby et al. 2008).

Ut fra begge disse temaene kan de med inkomplett skade være spesielt i faresonen for overtrening og eventuell utbrenthet. For mye trening i forhold til ressurser og for lite hvile mellom treningsdosene kan føre til en overbelastning.

Alternative prosedyrer eller behandling pasienten får dersom personen velger å ikke delta i studien

Det vil ikke få noen konsekvenser for deg i forhold til behandling eller senere innleggelser ved Sunnaas sykehus HF hvis du ikke ønsker å delta i studien.

Undersøkelse

Det vil bli foretatt dybdeintervju med åpne spørsmål rundt trening og hva det betyr for den enkelte, forholdet til trening, opplevelse av treningsmestring, grad og type motivasjon for trening, eventuell overtrening, stress i forbindelse med trening og håndtering av den eventuelle stressopplevelsen. I tillegg vil det hentes ut opplysninger knyttet til skaden din og rehabiliteringsoppholdet ditt fra journalen ved Sunnaas sykehus HF.

Tidsplan

Intervjuene vil finne sted fra desember 2008 til februar 2009. Intervjuene vil ta ca. en time og finne sted på Sunnaas sykehus HF, Anne Lannem`s kontor ved Norges Idrettshøgskole eller pr. telefon.

Mulige fordeler og ulemper

Erfaringer fra studien vil senere kunne hjelpe andre med samme diagnose.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er det som kommer frem i intervjuet samt medisinske opplysninger om skadeomfang og rehabiliteringsforløp hentet ut fra journalen din ved Sunnaas sykehus HF.

Sunnaas sykehus HF ved administrerende direktør er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre

Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at avidentifiserte opplysninger utleveres til Professor Marit Sørensen og 1.Amanuensis Pierre-Nicolas Lemyre, PhD ved Norges idrettshøgskole.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Studien er finansiert gjennom forskningsmidler fra Sunnaas sykehus HF og Norges Idrettshøgskole. Deltakerne i studien vil få dekket eventuelle reiseutgifter.

Forsikring

Deltakerne i studien er omfattet av pasientskadeerstatningsordningen gjennom Sunnaas sykehus HF.

Informasjon om utfallet av studien

Som deltaker i studien har du rett til informasjon om publisering av resultatene i studien. Dette vil bli sendt deg når det foreligger.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

Anne Lannem

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet ”Forekomst av overbelastningsproblematikk og tretthet hos personer med inkomplett ryggmargsskade, en tverrsnittsstudie”

Bakgrunn og hensikt
Dette er et spørsmål til deg om å delta i en forskningsstudie for å kartlegge hyppigheten av overbelastnings- og feilbelastningsproblematikk, utmattelsessymptomer, tretthet og treningsmestring hos personer med inkomplett ryggmargsskade. Ved en spørreundersøkelse vil vi nå kartlegge dette nærmere som et grunnlag for å kunne utarbeide retningslinjer for trening av personer med inkomplett ryggmargsskade. Sunnaas sykehus HF er ansvarlig for studien.

Hva innebærer studien?
Deltakelse i studien innebærer at du svarer på vedlagte spørreskjema og sender det tilbake i vedlagte svarkonvolutt sammen med samtykkeerklæringen. Deltakelse innebærer ingen prøver eller undersøkelser, du vil bruke ca 30 minutter på å svare på skjemaet.

Mulige fordeler og ulemper
Erfaringer fra studien vil senere kunne hjelpe andre med samme diagnose.

Hva skjer med prøvene og informasjonen om deg?
Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene og prøvene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Navnelisten med koden som knytter deg til dine opplysninger slettes ved avslutning av prosjektet i 2016. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling eller kontakt med Sunnaas sykehus HF. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Anne M. Lannem på 95101005.

Ytterligere informasjon om studien finnes i kapittel *A – utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse
Alle personer med inkomplett ryggmargsskade som har vært til rehabiliteringsopphold ved Sunnaas sykehus HF og var skadet før september 2008 og under 60 år på skadetidspunktet vil forespørres om å delta.

Bakgrunnsinformasjon om studien
Treningsvaner hos personer med ryggmargsskade og opplevd treningsmestring er kartlagt i tidligere studier (Lannem et al. 2005, 2007 og 2009). Resultatet indikerer en forskjell på hvordan personer med komplett og inkomplett ryggmargsskade selvrapporterer treningsmestring. De med inkomplett skade som trener regelmessig, rapporterer at de opplever mindre grad av mestring av fysisk trening enn de som ikke trener. Dette er annerledes enn for personer med komplett skade (Lannem et al. 2007) og for befolkningen generelt (Sørensen 1997). Andre forskningsmiljøer har satt fokus på beslektede begrep som utmattelse (Fawkes-Kirby et al. 2008). I intervjuer våren 2009 med personer med inkomplett skade fikk vi bekreftet at noen sliter med utmattelsessymptomer, overbelastning og opplevelse av lav treningsmestring. Ved en spørreundersøkelse vil vi nå kartlegge dette nærmere som et grunnlag for å kunne gi bedre råd om trening til personer med inkomplett ryggmargsskade.

Undersøkelser og annet den inkluderte må gjennom
Undersøkelsen består i å fylle ut og sende tilbake det tilsendte spørreskjema, eller ta kontakt med prosjektleder for å gjennomføre intervjuet pr. telefon.

Tidsskjema
Spørreskjemaene sendes ut i vår/sommer 2010.

Mulige fordeler
Ved å bli med på undersøkelsen, hjelper du oss med å forbedre rehabiliteringstiltak for personer med inkomplett ryggmargsskade.

Pasientens/studiedeltakerens ansvar
Det pålegges ikke noe ansvar på den enkelte deltaker ut over det å fylle ut og returnere spørreskjemaet.

Kapittel B - Personvern, økonomi og forsikring

Personvern
Opplysninger som registreres om deg er det som kommer frem i spørreskjemaet samt medisinske opplysninger om skadeomfang og rehabiliteringsforløp hentet ut fra journalen din ved Sunnaas sykehus HF.
Formålet er å kontrollere at studieopplysningene stemmer overens med tilsvarende opplysninger i din journal. Alle som får innsyn har taushetsplikt.
Sunnaas sykehus HF er databehandlingsansvarlig.

Utlevering av materiale og opplysninger til andre
Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at Professor Marit Sørensen og 1.Amanuensis Pierre-Nicolas Lemyre, PhD ved Norges idrettshøgskole gis innsyn i dataene som samles inn.

Rett til innsyn og sletting av opplysninger om deg
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du

trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi
Studien er finansiert gjennom forskningsmidler fra stipendiatmidler fra Norges Idrettshøgskole og fra Birgit og Rolf Sunnaas minnefond.

Forsikring
Det er ingen potensiell risiko forbundet med å delta i studien, og det gjelder derfor ingen spesielle forsikringsordninger for studien.

Informasjon om utfallet av studien
Resultatene fra undersøkelsen vil bli publisert i 1-2 artikler i internasjonale tidsskrifter, presentasjoner på nasjonale og internasjonale konferanser og gjennom Landsforeningen for Ryggmargsskadde. Resultatene vil også inngå som en del av doktorgradsavhandlingen til Anne M. Lannem ved Norges Idrettshøgskole.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

Anne M. Lannem, Prosjektleder

Anne Lannem

(Signert, rolle i studien, dato)

Legg samtykkeerklæringen i svarkonvolutten sammen med spørreskjemaet.

Appendix III

Questionnaire studies 1 and 2

NORGES IDRETTSHØGSKOLE

Sunnaas sykehus HF

Spørreskjema om aktivitetsvaner, fysisk form, selvopplevd helse og bruk av hjelpemidler til personer med inkomplett ryggmargskade.

Anne M. Lannem
Fagkonsulent fysioterapi/hovedfagstudent
Sunnaas sykehus/Norges Idrettshøgskole

Skjema nr.:_______

Aktivitetsvaner/Fysisk aktivitet

1. Har du drevet noen form for fysisk aktivitet/trening etter at du fikk din ryggmargskade? (sett ett kryss)

   a: Jeg trener regelmessig ☐
   b: Jeg trener en gang i mellom ☐
   c: Jeg trener sjelden ☐
   d: Jeg trener aldri ☐
   e: Jeg trente de første årene etter skaden ☐ og stoppet for ______ år siden

2. Går du til fysioterapi nå?

   Ja ☐ Nei ☐

   Hvis nei, når sluttet du? (årstall) __________

3. Hvor ofte går du til fysioterapi

   minutter pr. gang
   a: en gang i måneden ☐ varighet________________
   b: en gang hver tredje uke ☐ varighet________________
   c: en gang hver annen uke ☐ varighet________________
   d: en gang i uken ☐ varighet________________
   e: to ganger i uken ☐ varighet________________
   f: tre ganger i uken ☐ varighet________________
   g: eller mer/mindre, hvor mye? ______________________________

4. Hva slags behandling ________________________________
   ____
   ____

5. Har dine trenings/aktivitets-vaner forandret seg de siste årene?

Ja ☐ Nei ☐

6. Hvis trenings/aktivitetsvanene dine har forandret seg, når forandret de seg? (årstall) _____________

7. Hvis trenings/aktivitetsvanene dine har forandret seg, hvordan har de forandret seg?

a: Jeg er mer fysisk aktiv enn før ☐
b: Jeg er mindre fysisk aktiv enn før ☐

8. Hvis ja på 7b, hvorfor er du mindre fysisk aktiv?

a: jeg har for dårlig tid ☐
b: jeg har for dårlig økonomi ☐
c: jeg føler meg for gammel ☐
d: jeg mangler noen å trene med ☐
e: jeg savner instruksjons/treningstilbud ☐
f: jeg får nok mosjon i arbeidet ☐
g: dagliglivets aktiviteter er mer enn nok trening ☐
h: jeg mangler interesse, initiativ/motivasjon ☐
j: kroppen fungerer ikke ☐
i: jeg har for lite ork, er for slapp ☐
k: jeg får smerter/ubehag ☐
l: jeg begrenses av annen sykdom/skade ☐
m: annet, hva?____
____

Hvis du ikke driver noen form for fysisk aktivitet eller går til fysioterapi, gå til spørsmål 15.

Hvis du er fysisk aktiv eller går regelmessig til fysioterapi, fortsett på spørsmål 9.

9. Hvilken type aktivitet(er) driver du med?(sett gjerne flere kryss)

a: turgåing……………………………… ☐
b: jogging/løping/orientering……………….. ☐
c: gymnastikk/dans………………………… ☐
d: styrketrening/vektløfting…………………. ☐
e: badminton/tennis…………………………… ☐
f: bordtennis………………………………….. ☐
g: fri-idrett……………………………………. ☐
h: golf…………………………………………. ☐
i: ridning……………………………………... ☐
k: roing/padling………………………………. ☐
l: seiling………………………………………. ☐
m: svømming…………………………………. ☐
n: sykling…………………………………….. ☐
o: volleyball………………………………….. ☐
p: langrenn…………………………………… ☐
q: alpint………………………………………. ☐
r: kjelkehockey………………………………. ☐
s: fysioterapi…………………………………. ☐
t: annet:……………………………………… ☐ Spesifiser_____________
____

10. Hvilken av aktivitetene i spørsmål 9 driver du mest med om sommeren?

____

11. Hvilke av aktivitetene i spørsmål 9 driver du mest med om vinteren?

____

12. Hvor ofte driver du aktiviteten/e i om sommeren?

			minutter pr. gang
a:	en gang i måneden	☐	varighet________________
b:	en gang hver tredje uke	☐	varighet________________
c:	en gang hver annen uke	☐	varighet________________
d:	en gang i uken	☐	varighet________________
e:	to ganger i uken	☐	varighet________________
f:	tre ganger i uken	☐	varighet________________

g: eller mer, hvor mye?(dager og varighet)_____________________
____

13. Hvor ofte driver du aktiviteten/e om vinteren?

			minutter pr. gang
a:	en gang i måneden	☐	varighet________________
b:	en gang hver tredje uke	☐	varighet________________
c:	en gang hver annen uke	☐	varighet________________
d:	en gang i uken	☐	varighet________________
e:	to ganger i uken	☐	varighet________________
f:	tre ganger i uken	☐	varighet________________

g: eller mer, hvor mye?(dager og varighet)_____________________

14. Dersom du ikke driver fysisk aktivitet, hva er grunnen(e) til det?

a:	jeg har for dårlig tid	☐
b:	jeg har for dårlig økonomi	☐
c:	jeg føler meg for gammel	☐
d:	jeg mangler noen å trene med	☐
e:	jeg savner instruksjons/treningstilbud	☐
f:	jeg får nok mosjon i arbeidet	☐
g:	dagliglivets aktiviteter er mer enn nok trening	☐
h:	jeg mangler interesse, initiativ/motivasjon	☐
i:	kroppen fungerer ikke	☐
j:	jeg har for lite ork, er for slapp	☐
k:	jeg får smerter/ubehag	☐
l:	jeg begrenses av annen sykdom/skade	☐

m: annet, hva?____

15. Går, sykler eller bruker du rullestol til/fra arbeid/skole?

Ja ☐ Nei ☐

16. Hvis du går, sykler eller bruker rullestol til/fra skole/arbeid, hvor ofte?____________

17. Hvis du går, sykler eller bruker rullestol til/fra skole/arbeid, hvor lang tid tar turen hver vei? _____________minutter

Helse og fysisk form

18. Hadde du før du ble skadet noen betydelige helseskader/sykdommer?

Ja ☐ Nei ☐

I såfall hvilke:____

19. Da du ble skadet fikk du noen skader i tillegg til ryggmargskaden? (f.eks. benbrudd, brannskader, hodeskade etc.)

Ja ☐ Nei ☐

Hvis ja, spesifiser:________________________________

20. Har du i ettertid fått noen sykdommer i tillegg til ryggmargskaden? (f.eks. leddgikt, diabetes, hjerte/karlidelser etc.)

Ja ☐ Nei ☐

Hvis ja, spesifiser:________________________________

21. Har du i den senere tid hatt noen av disse helseplagene? (sett ett eller flere kryss)

Trykksår ☐
Urinveislidelser ☐
Problemer med tarmen ☐
Stive ledd ☐
Spasmer ☐
Smerter ☐

Problemer med blodtrykket ☐
Konsentrasjons/hukommelsesvansker ☐
Lungeproblemer ☐
Depresjon ☐
Mangel på tiltakslyst ☐
Ingen helseplager ☐

Hvis annet, spesifiser____

22. Er det andre sider ved din helsetilstand som har forandret seg til det bedre eller dårligere? (vær så snill og spesifiser nærmere)

____

____

____

23. Hvor langt kan du gå uten å bli sliten? (ca. meter) ____________

24. Har du vansker med å gå i trapper?

a: Nei ☐
b: Trenger et rekkverk ☐
c: Trenger mye støtte ☐
d: Kan ikke gå i trapp ☐

25. Har du vansker med å bære 5kg 10 meter?

Ja ☐ Nei ☐

26. Har du vansker med å ta deg fram i boligen din?

Ja ☐ Nei ☐

27. Hvordan tar du deg fram innendørs?

a: Går uten hjelpemiddel ☐
b: Trenger litt støtte ☐
b: Trenger mye støtte ☐
d: Bruker rullestol ☐

28. Har du vansker med å ta deg fram utendørs?

Ja ☐ Nei ☐

29. Hvordan tar du deg fram utendørs?

a: Går uten hjelpemiddel ☐
b: Trenger litt støtte ☐
c: Trenger mye støtte ☐
d: Bruker rullestol ☐

Trivsel med fysisk aktivitet

Sett ett kryss.

30. Jeg har aldri likt noe særlig å drive fysiske aktiviteter

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

31. Jeg er generelt i for dårlig form

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

32. Jeg synes det ofte er spennende å prøve ut hva jeg orker av fysisk aktivitet

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

33. Jeg plages en del av at jeg ikke klarer å holde kroppen i form

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

34. Jeg føler på en måte at jeg får vist hva jeg duger til når jeg driver fysisk aktivitet sammen med andre

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

35. Jeg tror at jeg ikke duger til noe i de fleste fysiske aktiviteter

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

36. Jeg synes fysiske aktiviteter krever for mye innsats i forhold til hva jeg får igjen for slik aktivitet

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

37. Jeg driver med fysisk aktivitet bl.a. fordi det gir en positiv følelse av å få til noe

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

38. Få av de jeg kjenner er i så god form som meg

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

39. Å drive med fysiske aktiviteter er for meg viktig bl.a. fordi jeg da kjenner at jeg virkelig behersker noe

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

40. Jeg tror jeg får til flere typer fysisk aktivitet enn folk flest

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

41. Jeg synes først og fremst fysisk aktivitet er et slit

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

42. Når jeg driver fysisk aktivitet, føler jeg i stor grad at jeg slipper vekk fra hverdagens mas og krav

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

43. Jeg tenker sjelden på at jeg burde være i bedre form

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

44. De fleste jeg kjenner har bedre forutsetninger enn meg for å drive fysisk aktivitet

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

45. Jeg skulle ønske jeg var i atskillig bedre form enn jeg er

Helt enig	Litt enig	Litt uenig	Helt uenig
☐	☐	☐	☐

Hjelpemiddelbehov

Teknisk hjelpemiddel:

Med teknisk hjelpemiddel menes her ganghjelpemidler eller rullestol som du bruker for å klare deg bedre, innendørs, utendørs eller i spesielle situasjoner.

46. Bruker du noe teknisk hjelpemiddel?

Ja ☐ Nei ☐

Hvis ja, hvilken type teknisk hjelpemiddel bruker du? Kryss av for alt du bruker.

a: rullestol ☐
b: rollator ☐
c: krykker ☐
d: stokk ☐
e: annet ☐ hva ……………………………………

47. Når (hvilket år) begynte du med dette hjelpemiddelet/disse hjelpemidlene?………………..

48. Hvor mye bruker du dette hjelpemiddelet/disse hjelpemidlene?________
____
____

Ortopedisk hjelpemiddel:

Med ortopedisk hjelpemiddel menes her hjelpemidler som er tilpasset deg for å styrke eller erstatte funksjon i en kroppsdel som trenger det på grunn av kraftnedsettelse eller smerter.

49. Bruker du noe ortopedisk hjelpemiddel?

Ja ☐ Nei ☐

50. Hvis ja, hvilken type ortopedisk hjelpemiddel bruker du? Kryss av for alt du bruker.

a: korsett Ja ☐ Nei ☐
Hvis ja , hva slags korsett?……………………………..

	Høyre ben	Venstre ben
b: lang skinne med låst kne	☐	☐
c: lang skinne med åpent kne	☐	☐
d: leggskinne i metall	☐	☐
e: leggskinne i plast	☐	☐
f: ortopediske sko	☐	☐

g: annet:……………………………………………………………
……………………………………………………………………

51. Når hvilket år) begynte du med dette hjelpemiddelet/disse hjelpemidlene?…………………

52. Hvor mye bruker du dette hjelpemiddelet/disse hjelpemidlene?

____
____

Sosialt nettverk

53. Hvor mange personer bor det i husstanden din?

a: 1 person ☐
b: 2 personer ☐
c: 3 eller flere ☐

54. Hvis du ikke bor alene, hvem bor du sammen med? (eventuelt flere kryss).

a: Ektefelle ☐
b: Samboer ☐
c: Andre ☐
d: Venn(er) ☐
e: Barn ☐
f: Foreldre/svigerforeldre ☐

55. Omtrent hvor mange nære venner har du – personer du trives sammen med og kan snakke fortrolig med? (Du kan regne med slektninger dersom du ønsker det). (Sett kryss og skriv eventuelt antall nedenfor)

1 Ingen ☐
2 En ☐
3 Flere ☐ Antall………

56. Hvor ofte treffer du venner og slektninger som du ikke bor sammen med, f.eks. på besøk hos hverandre eller for å gå ut sammen? (Sett kryss foran ett alternativ):

a: Flere ganger i uken ☐
b: En gang i uken ☐
c: Minst en gang i måneden ☐
d: Sjeldnere enn hver måned ☐

57. Er det noen av dem som står deg nær , som viser deg oppmerksomhet og som er interessert i det du holder på med?

a: Viser ingen eller lite varme og interesse ☐
b: Ja, viser noe varme og interesse ☐
c: Ja, viser mye varme og interesse ☐

58. Forekommer det at du føler deg ensom?

a: Aldri/Sjelden ☐
b: Av og til ☐
c: Ofte ☐

Tilfredshet med livet

66. Her spør vi om hvor tilfredsstillende ulike sider ved livet er idag.

1= meget utilfredsstillende
2= utilfredsstillende
3= ganske utilfredsstillende
4= ganske tilfredsstillende
5= tilfredsstillende
6= meget tilfredsstillende

Sett ring rundt det tallet som beskriver din situasjon best

Livet er stort sett for meg	1	2	3	4	5	6
Min yrkessituasjon er	1	2	3	4	5	6
Min økonomi er	1	2	3	4	5	6
Min fritidssituasjon er	1	2	3	4	5	6
Mine kontakter med venner og bekjente er	1	2	3	4	5	6
Mitt seksualliv er	1	2	3	4	5	6
Min evne til å klare meg selv (gjelder påkledning, kroppsvask, evne til å gå o.l.) er	1	2	3	4	5	6
Mitt familieliv er	1	2	3	4	5	6
Mitt ekteskap/samboerskap er	1	2	3	4	5	6

Hvilken av de overstående sidene ved livet ditt er viktigst for deg idag?

Appendix IV

Interview guide study 3

Appendix V

Interview guide to the study:

Incomplete Spinal Cord Injury (SCI), exercise mastery and stress coping.

Exercise habits, perceived exercise fitness and exercise mastery were examined in previous research from this hospital. The results demonstrated that exercise mastery was perceived differently in persons with complete and incomplete SCI. Those with incomplete SCI perceived less exercise mastery the more hours they exercised per week. This is different than for persons with complete injury and for the general population. Therefore this study wanted to explore the experiences with exercise mastery in individuals that had lived for some time with an incomplete SCI. You can help us to find some explanation in this interview.

- Feel free to add anything.
- There is no right or wrong answers; we're just trying to get a "feel" for how you perceive exercise, and how it is for you to live with an incomplete SCI.
- Everything that you say will be kept confidential; when we present any of the data, we will protect your confidentiality.
- Your participation is voluntary, and if for some reason you want to stop the discussion at some point, you can do that. You will have to read the interview and confirm further use before the analyses.

Questions:

General

1. **How did the SCI influence your life? Please, can you first tell about your life situation and changes over time(before injury/ just after injury/ the first years/ and today) in relation to**
    - **Your SCI**
    - **Work situation**
    - **Family**
    - **Leisure time**

   Do you want to add anything?

Exercise and physical activity

We define physical activity and exercise as follows: "Physical activity is defined as any bodily movement produced by skeletal muscles that result in energy expenditure" and "Exercise is a subset of physical activity that is planned, structured, and repetitive and has as a final or an intermediate objective the improvement or maintenance of physical fitness"

2. **Can you describe your level of physical activity / exercise habits before and after you got the SCI?**
    a) **In relation to regularity and amount**
    b) **How you exercise; alone, in a sport club or similar regular activity, with a coach or physiotherapist?**

3. **Can you describe how you perceive or have perceived exercise / physical activity, and how this has developed? Do you perceive exercise as a resource building activity that contributes with joy and coping in everyday life? …. Or is it/ has it been an extra burden in everyday life?**
    a) **Before injury**
    b) **During and just after rehabilitation**
    c) **At present (eventually the latest years)**

Motivation for exercise

4. **Can you describe your motivation for exercise in the different stages and now?**
    a) **Before injury**
    b) **During and just after rehabilitation**
    c) **At present (eventually the latest years)**

5. **Have you experienced beneficial and poor stages regarding exercise? How can you describe the stages and differences?**

6. **What motivates you for exercise /physical activity? And has the motivation changes in relation to**
    a) **Before injury**
    b) **During and just after rehabilitation**
    c) **At present (eventually the latest years)**

7. **What goals do you have for exercise, and how has this been in different stages? I want to know about both general and more specific goals.**
    a) **During and just after rehabilitation**
    b) **At present (eventually the latest years)**
    c) **In eventually beneficial and poor stages**

8. **To what extend to you reach your goals? How do you notice (or have you noticed) if you reach your goals?**
    a) **During and just after rehabilitation**
    b) **At present (eventually the latest years)**
    c) **In eventually beneficial and poor stages**

9. **Have the rehabilitation professionals influenced your goals?**

Exercise Mastery:

Exercise mastery is defined as a perception of competence when executing physical exercise.

10. **How do you perceive exercise mastery? How has it been through the years?**
    a) **During and just after rehabilitation**
    b) **At present (eventually the latest years)**
    c) **In eventually beneficial and poor stages**

Stress in everyday life

11. **How do you perceive stress in everyday life?**
    - a) **During and just after rehabilitation**
    - b) **At present (eventually the latest years)**
    - c) **In eventually beneficial and poor stages**

12. **How do you tolerate stress in everyday life?**
    - a) **During and just after rehabilitation**
    - b) **At present (eventually the latest years)**
    - c) **In eventually beneficial and poor stages**

Perceived overtraining and burnout

Overtraining and Burnout were defined similar to overtraining and burnout in elite athletes. Overtraining was defined as "An accumulation of training and nontraining stress resulting in long-term decrement in performance capacity with or without related physiological and psychological signs and symptoms of overtraining in which restoration of performance capacity may take weeks or month." Burnout was defined as "A multidimensional syndrome depicted by emotional and physical emotion, devaluation of sport participation, and a reduced sense of accomplishment". Overtraining and burnout share symptoms, except that in burnout loss of motivation for further exercise is present.

13. **Have you ever experienced exercise as an extra burden? How and when?**

14. **Have you ever experienced anything like overtraining or burnout?**

15. **When did this happen?**

16. **How did you feel about it?**

17. **How did you cope with it?**

18. **What did it result in?**

19. **What consequences did you experience from it?**

20. **Did it influence your relation to exercise?**

21. **Had you experienced exercise differently if you had a complete SCI?**

22. **What about sleep? Do you have any sleep disturbances? Is it different from before injury?**

23. **What about your general optimism? On a scale 1-10, what is your rating?**

24. **Do you have any additional comments?**

Thank you for your time!

Appendix V

Questionnaire study 4

NORGES IDRETTSHØGSKOLE

Sunnaas sykehus HF

Skjema nr. _________
Dato for utfylling____________

Opplevelser og erfaringer med fysisk aktivitet og trening for personer med inkomplett ryggmargsskade

1) Kjønn

☐ Kvinne ☐ Mann

---

2) Alder?

☐

---

3) Familie. Bor du sammen med noen?

☐ Ja ☐ Nei ☐ Hvis ja, hvor mange _________

---

4) Hvis ja, hvem bor du sammen med?

- ☐ Ektefelle/samboer
- ☐ Andre personer, 18 år og eldre. Antall ______________
- ☐ Personer under 18 år. Antall____________

---

5) Hvor mange års skolegang har du? Angi høyeste grad av utdanning du har.

Mindre enn 7 års grunnskole	☐
Grunnskole 8-10 år	☐
Realskole, yrkesskole, 1-2 års videregående skole	☐
Ex. Artium eller lignende	☐
Høgskole / universitet 5 år eller mindre	☐
Høgskole / universitet mer enn 5 år	☐

6) Arbeids- /trygdesituasjon. Jeg er for tiden

	Ja	Nei	Fulltid	Deltid	
I arbeid	☐	☐	☐	☐	Eventuelt %: _____
Student	☐	☐	☐	☐	Eventuelt %: _____
Sykmeldt	☐	☐	☐	☐	Eventuelt %: _____
Uføretrygdet	☐	☐	☐	☐	Eventuelt %:______
Pensjonist	☐	☐	☐	☐	Eventuelt %:______
Arbeidsløs	☐	☐			
Annet, hva	___________				

---

7) Hvis du er i arbeid, hvordan vil du beskrive ditt arbeid i forhold til fysisk aktivitet (sett bare ett kryss)

- ☐ For det meste stillesittende arbeid (f.eks. skrivebordsarbeid, montering)
- ☐ Arbeid som krever at du går (eller bruker manuell rullestol) mye (f.eks. ekspeditørarb., lett industriarb., undervisning)
- ☐ Arbeid hvor du går (eller bruker manuell rullestol) og løfter mye (f.eks. postbud, pleier, bygningsarb.)
- ☐ Tungt kroppsarbeid (f.eks. skogsarb., tungt bygningsarb.)

---

8) Når fikk du din ryggmargsskade? Skriv skadetidspunkt, (dato-mnd-år)

☐

---

9) Hvor gammel var du da du skadet deg?

☐

10) I hvilket nivå er skaden din? (for eksempel C6, Th5, L1)

☐

11) Har du noen sykdom / skade i tillegg til ryggmargsskaden? Nevn både det som er en følge av ryggmargsskaden og eventuelle andre ting.

○ Ja ○ Nei

12) Hvis ja, når ble dette diagnostisert? Sett inn årstall.

13) Hvis ja, hvilken sykdom /skade?

---

14) Hvor ofte har du hjemmesykepleie, hjemmehjelp eller personlig assistent?

☐ Har ikke hjelp ☐ Hver 14.dag ☐ 1-2 dager per uke ☐ 3-4 dager per uke

☐ 5-6 dager per uke ☐ Hver dag

15) Hvor mange timer per dag har du hjemmesykepleie, hjemmehjelp eller personlig assistent?

☐ Ingen ☐ mindre enn 3 timer ☐ 3-5 timer ☐ 6-9 timer ☐ 10 timer eller mer

16) Hvor mange timer per dag bruker du på personlig stell og påkledning på egenhånd, uten hjelp av andre?

17) Hvilke medisiner bruker du?

☐ Ingen ☐ Smertestillende ☐ Spasmedempende ☐ Muskelavspennende ☐ Beroligende
☐ Sovemedisin ☐ Antidepressiva ☐ Andre, hvilke?_____________________________________

---

18) Er du plaget av smerter i en kroppsdel?

○ Ja ○ Nei

19) Hvis ja, tenk deg siste uke. I forhold til disse smertene, hvor mye smerter har du når du er i hvile, på en skala fra 0 til 10. 0 vil si ingen smerter, 10 er uutholdelige smerter.

0 ____ 10

Ingen smerter Uutholdelige smerter

20) Hvor mye smerter har du når du er i aktivitet (f.eks. når du går, står osv.) på en skala fra 0 til 10. 0 vil si ingen smerter, 10 er uutholdelige smerter. Tenk deg siste uke.

0 ____ 10

Ingen smerter Uutholdelige smerter

21) Hvis du har smerter, hemmer smertene deg i fysisk trening?

○ Ja ○ Nei

22) Hvor ofte går du til fysioterapi?

☐ Sjelden eller aldri

☐ Har ikke fysioterapi regelmessig

☐ 1 gang i uken

☐ 2-3 ganger i uken

☐ 4-5 ganger i uken

Hvis du går til fysioterapi, er det aktiv trening ☐ eller tøyning/ massasje ☐

23) Egentrening utenom fysioterapi. Driver du systematisk fysisk trening?

○ Ja ○ Er aktiv, men trener ikke systematisk ○ Nei

I de følgende spørsmålene bruker vi disse definisjonene om fysisk aktivitet:
<u>Meget anstrengende</u> er fysisk aktivitet som får deg til å <u>puste mye mer enn vanlig</u>.
<u>Middels anstrengende</u> er fysisk aktivitet som får deg til å <u>puste litt mer enn vanlig</u>.

24) Hvor mange dager i løpet av de siste 7 dager har du drevet med <u>meget anstrengende</u> fysiske aktiviteter som tunge løft, gravearbeid, aerobics, sykle fort eller rulle fort med manuell rullestol. Tenk bare på aktiviteter som varte minst 10 minutter i strekk.

☐ Dager per uke ☐ Ingen, gå til spørsmål 26.

25) På en vanlig dag hvor du utførte meget anstrengende aktiviteter, hvor lang tid brukte du da på dette?

_______Timer ________Minutter

26) Hvor mange dager i løpet av de siste 7 dager har du drevet med middels anstrengende fysiske aktiviteter som å bære lette ting, sykle eller rulle med rullestol i moderat tempo. Tenk bare på aktiviteter som varte minst 10 minutter i strekk.

☐ Dager per uke ☐ Ingen, gå til spørsmål 28.

27) På en vanlig dag hvor du utførte middels anstrengende aktiviteter, hvor lang tid brukte du da på dette?

_______Timer ________Minutter

---

28) Hvor mange dager i løpet av de siste 7 dager gikk eller kjørte du aktivt med manuell rullestol minst 10 minutter i strekk for å komme deg fra et sted til et annet? Dette inkluderer gang/rulling på jobb og hjemme, til buss, eller gang /rulling som du gjør på tur.

☐ Dager ☐ Ingen, gå til spørsmål 30.

---

29) På en vanlig dag hvor du gikk eller kjørte aktivt manuell rullestol for å komme deg fra et sted til et annet, hvor lang tid brukte du da på dette (tilsammen på en dag)?

_______Timer ________Minutter

---

30) Dette spørsmålet omfatter all den tid du tilbringer i ro (sittende) på jobb, hjemme, på kurs, på fritiden. Det kan være tiden du sitter ved et arbeidsbord, hos venner, mens du leser eller sitter eller ligger for å se på TV. I løpet av de siste 7 dagene, hvor lang tid brukte du i gjennomsnitt på å sitte i ro på en vanlig hverdag?

_______Timer ________Minutter

---

31) Deltar du i organisert fysisk aktivitet (for eksempel idrettslag, helsesportslag, handicapidrettslag eller lignende).

☐ Nei, ingen ☐ Ja, en aktivitet ☐ Ja, flere aktiviteter ☐ Har deltatt, men har sluttet

---

32) Hvis ja, hvilke(n)?

☐

---

33) Angi bevegelse og kroppslig anstrengelse bare i din fritid. Hvis aktiviteten varierer mye mellom sommer og vinter, så ta et gjennomsnitt. Spørsmålet gjelder bare det siste året.

○ Leser, ser fjernsyn eller annen stillesittende aktivitet

○ Spaserer, sykler, ruller med rullestol eller beveger deg på annen måte minst 4 timer i uka? (Her skal du også regne med gang eller sykling til arbeidssted, søndagsturer m.m.)

○ Driver mosjonsidrett, tyngre hagearbeid eller lignende? (Merk at aktiviteten må vare minst 4 timer i uka).

○ Trener hardt eller driver konkurranseidrett regelmessig flere ganger i uka.

---

34) Hvorfor trener du? Dersom du er regelmessig fysisk aktiv, angi de to viktigste grunnene.

____

____

____

35) Var du fysisk aktiv før du skadet deg?

○ Ja ○ Nei

---

36) Hvis ja, hvor mange timer per uke drev du med fysisk aktivitet tilsvarende de ulike definisjonene under.

Definisjoner: ***<u>Meget anstrengende</u> er fysisk aktivitet får deg til å <u>puste mye mer enn vanlig</u>.***
<u>Middels anstrengende</u> er fysisk aktivitet får deg til å <u>puste litt mer enn vanlig</u>.
<u>Lett fysisk aktivitet</u> er fysisk aktivitet hvor du <u>puster normalt</u>.

☐ Meget anstrengede fysisk aktivitet. Timer pr. uke _______

☐ Middels anstrengende fysisk aktivitet. Timer pr. uke _______

☐ Lett anstrengende fysisk aktivitet. Timer pr. uke ________

---

37) Deltok du i organisert fysisk aktivitet (for eksempel idrettslag eller lignende) før du skadet deg?

○ Nei, ingen ○ Ja, en aktivitet ○ Ja, flere aktiviteter. Hvilke(n)? ___________________________

---

38) Nevn 3 konkrete resultater som du forventet deg som resultat av den fysiske treningen (rehabiliteringen) etter at du skadet deg

○ 1____

○ 2____

○ 3____

---

39) I hvor stor grad har du oppnådd resultat 1 på en skala fra 0-100%

0% ____ 100%

---

40) I hvor stor grad har du oppnådd resultat 2 på en skala fra 0-100%

0% ____ 100%

---

41) I hvor stor grad har du oppnådd resultat 3 på en skala fra 0-100%

0% ____ 100%

I de neste spørsmålene er det snakk om mestring av fysisk trening. Med <u>mestring av fysisk trening</u> menes at <u>treningen virker oppbyggende</u> og <u>vedlikeholder eller øker din funksjonskapasitet.</u>

42) Hvilken grad opplevde du mestring av fysisk trening i rehabiliteringsperioden? Tenk deg en skala fra 0 til 10 der 0 er ingen mestring og 10 er maksimal mestring.

0 ____ 10
Ingen mestring Maksimal mestring

43) Hvilken grad opplever du mestring av fysisk trening idag? Tenk deg en skala fra 0 til 10, der 0 er ingen mestring og 10 er maksimal mestring.

0 ____ 10
Ingen mestring Maksimal mestring

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44) Hvis opplevelsen av mestring av fysisk trening har endret seg, når skjedde dette?

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45) Hvis du har opplevd endring i opplevelsen av mestring av fysisk trening, hva forårsaket endringen?

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46) Har du behov for hjelpemidler (for eksempel rullestol, krykker, arm- eller benskinner).

○ Ja ○ Nei ○ Hvis ja, hvilke(t) ____

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47) Har ditt behov for hjelpemidler forandret seg?

○ Ja
○ Nei
○ Hvis ja, hvordan?____
○ Hvis ja, hvor lenge etter skaden?____

48) Hvordan opplever du bruk av hjelpemidler? Sett gjerne flere kryss.

○ Bedrer funksjonen min
○ Letter hverdagen
○ Forhindrer problemer (senebetennelser, smerter m.m.)
○ Jeg mister funksjon av å bruke dem
○ De er i veien hele tiden
○ De får meg til å virke mer funksjonshemmet
○ Jeg vil helst ikke bruke hjelpemidler
○ Annet, hva____

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49) Sett ett kryss for hver av påstandene under.

	Helt enig	Litt enig	Litt uenig	Helt uenig
Jeg er generelt i for dårlig form	☐	☐	☐	☐
Jeg synes det ofte er spennende å prøve ut hva jeg orker av fysisk aktivitet	☐	☐	☐	☐
Jeg plages en del av at jeg ikke klarer å holde kroppen i form	☐	☐	☐	☐
Jeg driver med fysisk aktivitet bl.a. fordi det gir en positiv følelse av å få til noe	☐	☐	☐	☐
Å drive med fysiske aktiviteter er for meg viktig bl.a. fordi jeg da kjenner at jeg virkelig behersker noe	☐	☐	☐	☐
Jeg tror jeg får til flere typer aktivitet enn andre jeg kan sammenligne meg med	☐	☐	☐	☐
Når jeg driver fysisk aktivitet, føler jeg i stor grad at jeg slipper vekk fra hverdagens mas og krav	☐	☐	☐	☐
Jeg skulle ønske jeg var i atskillig bedre form enn jeg er	☐	☐	☐	☐

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50) Noen spørsmål om tretthet. Velg et tall fra 1 til 7 som angir i hvor stor grad du er enig med hvert enkelt utsag, der en angir at du er helt uenig, og 7 at du er helt enig (sett et kryss for hvert utsagn).

	1	2	3	4	5	6	7
Min motivasjon er lavere når jeg er sliten og uopplagt.	☐	☐	☐	☐	☐	☐	☐
Fysisk aktivitet gjør meg sliten og uopplagt.	☐	☐	☐	☐	☐	☐	☐
Jeg blir fort sliten og uopplagt.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, virker inn på hvordan jeg fungerer fysisk.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, skaper ofte vanskeligheter for meg.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, hindrer meg i å opprettholde min fysiske funksjonsdyktighet over tid.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, virker inn på evnen til å utføre visse oppgaver og plikter.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, er et av de tre symptomene som hemmer meg mest.	☐	☐	☐	☐	☐	☐	☐
Det at jeg er sliten og uopplagt, virker inn på mitt arbeid, mitt familieliv eller min omgang med venner og kjente.	☐	☐	☐	☐	☐	☐	☐

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51) Hvordan sover du? Sett gjerne flere kryss.

☐ Sover normalt
☐ Har problemer nå
☐ Har hatt problemer i perioder
☐ Sover for mye
☐ Sover for lite
☐ Annet, hva?...

52) Å leve med en ryggmargsskade over tid gir ekstrabelastninger i hverdagen. Hvor ofte har du noen av følgende opplevelser? Sett et kryss for hver opplevelse.

	Aldri	Sporadisk	Nå og da	Regelmessig	Ofte	Svært ofte	Daglig
1. Er trøtt	☐	☐	☐	☐	☐	☐	☐
2. Er deprimert	☐	☐	☐	☐	☐	☐	☐
3. Har en fin dag	☐	☐	☐	☐	☐	☐	☐
4. Er fysisk utslitt	☐	☐	☐	☐	☐	☐	☐
5. Er følelsesmessig utslitt	☐	☐	☐	☐	☐	☐	☐
6. Er lykkelig	☐	☐	☐	☐	☐	☐	☐
7. Følelse av å være fullstendig utmattet	☐	☐	☐	☐	☐	☐	☐
8. Følelse av utbrenthet	☐	☐	☐	☐	☐	☐	☐
9. Er ulykkelig	☐	☐	☐	☐	☐	☐	☐
10. Følelse av å være tilsidesatt	☐	☐	☐	☐	☐	☐	☐
11. Følelse av ikke å komme noen vei	☐	☐	☐	☐	☐	☐	☐
12. Følelse av å være verdiløs	☐	☐	☐	☐	☐	☐	☐
13. Er sliten	☐	☐	☐	☐	☐	☐	☐
14. Er bekymret	☐	☐	☐	☐	☐	☐	☐
15. Følelse av å være desillusjonert og uten tro på medmennesker	☐	☐	☐	☐	☐	☐	☐
16. Følelse av svakhet og hjelpeløshet	☐	☐	☐	☐	☐	☐	☐
17. Følelse av håpløshet	☐	☐	☐	☐	☐	☐	☐
18. Følelse av å være avvist	☐	☐	☐	☐	☐	☐	☐
19. Følelse av optimisme	☐	☐	☐	☐	☐	☐	☐
20. Følelse av å være energisk	☐	☐	☐	☐	☐	☐	☐
21. Følelse av å være engstelig	☐	☐	☐	☐	☐	☐	☐

53) Å drive med fysisk trening over tid kan gi både positive og negative konsekvenser i forhold til det å ha en ryggmargsskade. Hvor ofte føler du som angitt i utsagnene nedenfor?

	Nesten aldri	Sjelden	Noen ganger	Ofte	Nesten alltid
Jeg utretter mange verdifulle ting ved å trene.	☐	☐	☐	☐	☐
Jeg føler meg sliten på grunn av treningen min, og jeg har problemer med å finne energi til å gjøre andre ting.	☐	☐	☐	☐	☐
Den innsatsen jeg bruker på trening kunne vært brukt bedre på andre ting.	☐	☐	☐	☐	☐
Jeg føler meg altfor sliten til å delta på trening.	☐	☐	☐	☐	☐
Jeg oppnår ikke mye med trening.	☐	☐	☐	☐	☐
Jeg bekymrer meg ikke på langtnær så mye for mine treningsprestasjoner som jeg gjorde tidligere.	☐	☐	☐	☐	☐
Jeg lever ikke opp til mine egne forventninger i forhold til trening.	☐	☐	☐	☐	☐
Jeg føler meg utslitt av trening.	☐	☐	☐	☐	☐
Jeg er ikke så engasjert i trening som jeg var tidligere.	☐	☐	☐	☐	☐
Jeg føler meg fysisk utslitt av trening.	☐	☐	☐	☐	☐
Jeg føler meg mindre bekymret om å være suksessfull i trening enn det jeg har vært tidligere.	☐	☐	☐	☐	☐
Jeg blir både fysisk og mentalt utmattet av kravene i trening.	☐	☐	☐	☐	☐
Det virker som om, uansett hva jeg gjør, så er ikke prestasjonene mine så gode som de burde være.	☐	☐	☐	☐	☐
Jeg føler at jeg har suksess med trening.	☐	☐	☐	☐	☐
Jeg har negative følelser overfor trening.	☐	☐	☐	☐	☐
Jeg har overskudd til å være sammen med venner og familie i fritiden,	☐	☐	☐	☐	☐

54) Hva opplever du som mest belastende i ditt liv i forhold til det å ha en ryggmargsskade?

____

____

____

55) Hvordan synes du at du håndterer denne belastningen i hverdagen?

0 ____ 10
Svært dårlig Svært godt

56) Nedenfor er det en liste over situasjoner som generelt er funnet å være stressende / opprivende for personer med fysisk funksjonshemming. Vær snill å tenk på hver situasjon og merk av svaret som passer best. OBS! Hvis situasjonen ikke er aktuell for deg, svar <u>Ikke aktuelt</u>. Hvis situasjonen skjer hver dag, men ikke i det hele tatt er stressende eller opprivende, svarer du <u>Ikke i det hele tatt</u>.

Stressopplevelser i forbindelse med å leve med en ryggmargsskade. Hvor stresset/opprørt ble du i situasjoner som er listet opp?

	Ikke i det hele tatt	Litt	Moderat	Merkbart	Svært	Ikke aktuelt
1. Når du ikke har kunnet reise på egenhånd på grunn av mangel på tilgjengelige steder.	☐	☐	☐	☐	☐	☐
2. Når du ikke har blitt invitert til sosiale aktiviteter så mye som du pleide å bli.	☐	☐	☐	☐	☐	☐
3. Når du har blitt båret opp og ned trapper.	☐	☐	☐	☐	☐	☐
4. Når mennesker har prøvd å hjelpe, men har gjort ting mer vanskelig.	☐	☐	☐	☐	☐	☐
5. Når private saker har blitt offentliggjort til helsepersonell, familie og venner.	☐	☐	☐	☐	☐	☐
6. Når du har brukt taxi.	☐	☐	☐	☐	☐	☐
7. Når funksjonsnedsettelsen din har påvirket ditt forhold til andre.	☐	☐	☐	☐	☐	☐
8. Når du har måttet forholde deg til pleiere / hjelpere.	☐	☐	☐	☐	☐	☐
9. Når du ikke har kunnet gjøre aktiviteter du pleide å like og gjøre.	☐	☐	☐	☐	☐	☐
10. Når andre ikke har anerkjent din seksuelle identitet eller seksuelle ønsker.	☐	☐	☐	☐	☐	☐
11. Når du har måttet spørre andre om hjelp.	☐	☐	☐	☐	☐	☐
12. Når funksjonshemmingen din har hindret utviklingen av et intimt eller seksuelt forhold.	☐	☐	☐	☐	☐	☐
13. Når du har måttet ordne opp i behov for flere helsetjenester.	☐	☐	☐	☐	☐	☐
14. Når du har kommet til et sted med trapper og uten rampe eller heis.	☐	☐	☐	☐	☐	☐

	Ikke i det hele tatt	Litt	Moderat	Merkbart	Svært	Ikke aktuelt
15. Når du ikke har kunnet hjelpe til med en fysisk jobb.	☐	☐	☐	☐	☐	☐
16. Når andre har sett på deg som en person i rullestol før de har sett på deg som den personen du virkelig er.	☐	☐	☐	☐	☐	☐
17. Når du ikke fysisk har kunnet bevege deg som du gjorde før.	☐	☐	☐	☐	☐	☐
18. Når dine behov for helsetjenester har trengt tid og energi.	☐	☐	☐	☐	☐	☐
19. Når du har følt at det ikke er noe du kan gjøre for å endre ting.	☐	☐	☐	☐	☐	☐
20. Når andre ikke har tenkt på dine behov eller muligheter.	☐	☐	☐	☐	☐	☐
21. Når du fysisk ikke har kunnet hjelpe andre når de har trengt det.	☐	☐	☐	☐	☐	☐
22. Når du har blitt fortalt at et sted er tilgjengelig, men finner ut at det ikke er tilgjengelig.	☐	☐	☐	☐	☐	☐

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57) Generelt, hvor bra føler du at du håndterer daglige stressituasjoner i forhold til det å ha en fysisk funksjonshemming.

○ Ikke bra ○ Litt bra ○ Moderat bra ○ Ganske bra ○ Veldig bra

58) Har du ett eller flere gode treningsråd å gi til en som er nyskadet med en skade som din?

____

____

____

____

____

____

Takk for at du tok deg tid til å svare. Legg svarskjemaet sammen med samtykkeerklæringen i den frankerte konvolutten og send tilbake så snart som mulig.

ERRATA

The following changes have been made in the text since submission to the doctoral committee:

Page 12, line 20: “In the following physical exercise advices will be presented.” is changed to “In the following, findings related to physical exercise and SCI will be presented.”

Page 14, line 26: “…initiative of rehabilitation were…” is changed to: “…initiation of rehabilitation was…”

Page 19, line 20: “Iso-Ahloah” is changed to: “Iso-Ahloa”.

Page 27, line 27 “…considered context-free…” is changed to “…considered a context-free…”

Page 41, line 19: “…their lifes…” is changed to “…their lives…”

Page 41, line 27: “…Exercise Quesitonnaire…” is changed to “…Exercise Questionnaire…”

Page 43, lines 9-10: “…either fulfilment of expectations of physical function or successful of expectations to actual physical function…” is changed to “…either fulfilment of expectations of physical function or successful adjustment of expectations to actual physical function…”

Page 45, linies 16 - 17: “…34 persons (49%) was able to walk more than 500 metre…” is changed to “…34 persons (49%) were able to walk more than 500 metres…”

Page 53, line 23: “…exercise help…” is changed to “…exercise helps…”

Page 56, line 11: “…can end up with sustained arousal.” is changed to “…can lead to sustained arousal.”

Page 57, line14: “…also use less needed adapted aids.” is changed to “…also make less use of needed adapted aids.”

Page 57, line 21 - 22: “In long-term…” is changed to “In the long-term…”

Page 59, line 13: “Stress often increased in connection to work.” is changed to “Stress often increased in connection with work.”

Page 62, line 19: “…overloading process is triggers…” is changed to “…overloading process triggers…”

Page 64, line 11: “…disease may develope.” is changed to “…disease may develop.”

Page 68, line 8: “…physiological and psychological may influence…” is changed to “…physiological and psychological factors may influence…”