Ingrid Bjørgen

Physical Activity, Stress, Coping and Life-Satisfaction among persons with Motor Complete Spinal Cord Injury

Erasmus Mundus Master of Adapted Physical Activity
Department of Coaching and Psychology
Norwegian School of Sport Sciences, 2013

Acknowledgements

This thesis is the final part of my European Master Degree in Adapted Physical Activity, completed at Katholieke Universiteit, Leuven and the Norwegian School of Sport Sciences. It started out as a vague idea during the first year in Belgium and has developed into the final product that I am proud to have completed today.

I would like to thank all the respondents for taking part in this study; dedicating their time to complete the questionnaire- I am very grateful for your participation.

I would also like to thank my supervisors Anne Lannem, Phd, Sunnaas Rehabilitation Hospital and Professor Marit Sørensen, Phd, Norwegian School of Sport Sciences. Marit was the one who suggested this subject for me and made the connection to Sunnaas Rehabilitation Hospital and Anne. I have learned a lot about the research process and about spinal cord injuries from both of them and I am very thankful for their support and guidance.

Thank you to physical therapist at Sunnaas Rehabilitation Hospital, Karin Breistein and my brother Håvard for helping me control the data and to my father Joar for reading through my work and bringing constructive criticism. Markus Koch deserves big thanks for being a statistics expert and helping me find my way through this complicated field.

Thank you also to the Norwegian Physical Therapy Association for financial support and most of all thank you to my dear family and friends for being supportive, understanding and encouraging through a long period of hard work. To all of my international friends in the Erasmus Mundus Adapted Physical Activity program, I want to say thank you for the good times we shared these two years in Belgium and Norway, it would not have been the same without you.

Oslo, May 2013
Ingrid Bjørgen

Abstract

Background: Being physically active is associated with improved physical fitness, health and psychological well being in persons with spinal cord injury (SCI). Even so, the level of physical activity is still low in this population. There is a limited amount of research investigating the levels of physical activity and how physical activity relates to aspects of health among persons with motor complete spinal cord injury in Norway.

Aim: The purpose of this study was to get an overview of the level of physical activity among individuals with motor complete SCI in Norway and examine the correlation between the amount of physical activity performed and the levels of stress experienced. The study also looks at the factors that can influence the participants coping with disability related stress.

Method: The cognitive activation theory of stress (CATS) was used as the theoretical framework in order to demonstrate how disability related stress affects persons with motor complete spinal cord injury. A cross-sectional survey methodology was employed with a sample of 185 persons with motor complete spinal cord injury (AIS A or B). Participants responded to a posted questionnaire consisting of the International Physical Activity Questionnaire (IPAQ), a scale measuring leisure time physical activity (LTPA), the Physical Disability Stress Scale (PDSS) and a VAS-rating of their coping and a measure of life satisfaction (LiSat-9).

Results and conclusion: The results from the present study show that persons with motor complete SCI have in general low levels of physical activity with large variations between the least active and the most active. The participants were less physically active than the general population. A small positive correlation was found between physical activity and life satisfaction. No correlation was found between physical activity and stress. The results from the present thesis cannot be generalized to apply to the entire Norwegian population of persons with motor complete SCI as the study group is small and the participants have not been located randomly.

Keywords: Physical activity, spinal cord injury, stress, life satisfaction, coping

Abbreviations

ADL	Activity of Daily Living
AIS	ASIA Impairment Scale
ASIA	The American Spinal Injury Association
CATS	Cognitive Activation Theory of Stress
ICF	International Classification of Functioning, Disability and Health
IPAQ	International Physical Activity Questionnaire
LiSat	Life Satisfaction Scale
LTPA	Leisure time physical activity
MET	Metabolic equivalent
n	Numbers/ sample size
PASW	Predictive Analysis Software
PDSS	Physical Disability Stress Scale
PWB	Perceived well being
QOL	Quality of Life
SD	Standard deviation
SCI	Spinal cord injury
SWB	Subjective well being
VAS	Visual Analogue Scale
WHO	World Health Organization

Tables

Table 1: *International Standards for Neurological and Functional Classification of Spinal Cord Injury*... 15

Table 2: *Sample and injury characteristics of participants*…………………………... 37

Table 3: *Employment situation of participants*……………………………………….. 38

Table 4*: Description of work among participants*……………………………………. 38

Table 5: *Participants responded to whether or not they participate in organized physical activity?*.. 39

Table 6: *Participants indicated how often they go to physical therapy* ……………… 39

Table 7: *If you go to physical therapy, what kind of therapy?*.. 40

Table 8: *Do you exercise regularly besides physical therapy?*...................................... 40

Table 9: *Overview of the participants mean physical activity levels per week as measured by the IPAQ*.. 42

Table 10: *LTPA data from a Norwegian survey*……………………………............. 44

Table 11: *Correlation between LTPA and IPAQ*………………………………………. 44

Table 12: *Median scores LiSat-9, present study and comparing studies*………………. 46

Table 13: *Physical Disability Stress Scale, all items*………………………………….. 48

Table 14: *Correlations between LTPA, IPAQ, LiSat-9 and PDSS*…………………….. 49

Figures

Figure 1: *Illustration of the spinal cord (http://www.scitcs.org)……………………....* 14

Figure 2: *The ICF model, interactions between the components* (WHO, 2004)………. 17

Figure 3: *CATS in relation to persons with SCI and physical exercise (Lannem, 2011)……………………………………………………………………………..……..………* 26

Figure 4: *Leisure Time Physical Activity, 4 levels……………………………………..* 43

Figure 5: *Participants coping with the consequences of having a motor complete SCI…………………………………………………………………….......................* 45

Appendices

Appendix I	Questionnaire
Appendix II	Cover letter with letter of consent
Appendix III	Approval from the Regional Committee for Medical and Health Research Ethics (31.01.12)

Table of contents

Acknowledgements……………………………………………………………………... 3
Abstract………………………………………………………………………….. 4
Abbreviations……………………………………………………………………. 5
Tables…………………………………………………………………………….. 6
Figures…………………………………………………………………………… 7
Appendices……………………………………………………………………….. 8
Table of contents………………………………………………………………. 9

1.0 Introduction…………………………………………………….……………… 11
1.1 Structure of the thesis………………………………………………… 12

2.0 Background……………………………………………………………….. 13
2.1 Spinal cord injury…………………………………………………… 13
2.2 Classification of injury severity……………..……………………… 14
2.3 Prevalence…………………………………………………………... 15
2.4 Spinal cord injuries in Norway……………………………………… 16
2.5 ICF………………………………………………………………….. 16
2.6 Rehabilitation after spinal cord injury………………………………. 18
2.7 Physical activity and health…………………………………………. 19
2.8 Physical activity in Norway…………………………………………. 19
2.9 Physical activity and spinal cord injury…………………..…………. 20
2.10 Barriers to being physically active………………………………… 22

3.0 Theoretical framework and central concepts……………………………….. 24
3.1 The Cognitive Activation Theory of Stress (CATS)…………………… 24
3.2 Stress……….……………………………………………………….... 27
3.3 Stress and SCI…………………….. 27
3.4 Physical activity (PA) and physical exercise (PE)……………………… 28
3.5 Life satisfaction……………………………………………………….. 28
3.6 Research questions……………………………………………………. 30

4.0 Method…………………………………………………………………….. 31
4.1 Research design……………………………………………………….. 31
4.2 Sample population…………………………………………………….. 31
4.3 Practical concerns……………………………………………………... 32
4.4 The Questionnaire……………………………………………………... 32
4.4.1 Measures……………………………………………………... 33
4.4.2 Demographic information……………………………………… 33

4.4.3 Physical Disability Stress Scale (PDSS)………………………… 33
4.4.4 Injury level and severity of the injury…………………………… 33
4.4.5 Physical activity………………………………………………. 33
4.4.6 International Physical Activity Questionnaire (IPAQ)…………… 34
4.4.7 Leisure Time Physical Activity (LTPA)………………………… 34
4.4.8 Degree of coping………………………………………………. 34
4.4.9 Life satisfaction………………………………………………… 35

4.5 Validity and reliability……………………………………………… 35
4.6 Statistical Analysis………………………………………………… 35
4.7 Ethical considerations……………………………………………… 36
4.8 Data collection……………………………………………………… 36

5.0 Results……………………………………………………………….. 37
5.1 Participants…………………………………………………………… 37
5.2 Employment situation……………………………………………… 38
5.3 Physical Activity……………………………………………………… 39
5.4 Physical activity measured by the IPAQ…………………………… 40
5.5 Leisure time physical activity measured by the LTPA……………… 43
5.6 Comparison of LTPA and the IPAQ…………………………………... 44
5.7 Coping……………………………………………………………… 45
5.8 Life Satisfaction…………………………………………………….. 46
5.9 Disability related stress……………………………………………... 47
5.10 Correlations between LTPA, IPAQ, LiSat-9 and PDSS……………… 49

6.0 Discussion……………………………………………………………..... 50
6.1 Discussion of the results regarding research question 1…………….. 50
6.2 Discussion of the results regarding research question 2…………….. 54
6.3 Discussion of the results regarding research question 3…………….. 56
6.4 Design of the study………………………………………………….. 57
6.5 Participants………………………………………………………….. 59
6.6 Missing data………………………………………………………… 60
6.7 Recommendations for future research ……………………………… 61

7.0 Conclusion…………………………………………………………….. 62

8.0 References…………………………………………………………….... 63

1.0 Introduction

There is a great focus on physical activity and health in our society today. This focus is mainly directed towards people without disabilities and their opportunities to participate in physical activity. In Norway, only 20 % of the general population meets the recommended levels of 30 minutes of daily physical activity in moderate intensity (Anderssen, 2009). As the level of physical activity in the population decreases, the prevalence of diseases increases. Inactivity is in other words a risk factor leading to higher morbidity and premature mortality rates (Haskell, Bouchard, & Blair, 2007).

Research has shown that physical activity levels are lower among people with disabilities than in than in the rest of the population. (Rimmer, 2005; Saebu & Sorensen, 2010). Previous studies of physical activity and physical exercise have reported low levels of physical activity and physical capacity in persons with spinal cord injury (SCI) (Haisma et al., 2006; Martin Ginis et al., 2010b; Saebu & Sorensen, 2010). Until now little research has been done on investigating if there is a difference between persons with complete and incomplete spinal cord injuries with regards to benefits from being physically active.

Knowledge of the physical activity levels of persons with motor complete SCI and how physical activity can influence disability related stress, coping and life satisfaction is important for health professionals when developing physical activity interventions and guidelines for this population. A recent dissertation by Lannem (2011) examined the role of physical exercise on positive and negative health outcomes for persons with incomplete SCI. The Cognitive Activation Theory of Stress (CATS) was used as a framework. From her studies the main results demonstrated that the role of physical exercise in the health- stress relationship was complex for persons with incomplete SCI. One aspect was that those who exercised experienced higher life satisfaction than those who were physically inactive. The present study aims to take similar approach, now looking at levels of physical activity for persons with motor complete SCI, disability related stress, coping and life satisfaction.

1.1 Structure of the thesis

The present thesis includes an introduction to the topic, background with more detailed information on prevalence of SCI in Norway and how the rehabilitation process is structured for those who are affected. The International Classification of Functioning, Disability and Health (ICF) is presented, in relation to rehabilitation in Norway. In addition literature on physical activity and its influence on health are presented both in the general population and for persons with SCI. Lastly, literature on barriers to participation in physical activity is reviewed.

In the theory chapter the Cognitive Activation Theory of Stress (CATS) is presented in addition to central concepts relevant to the present thesis.

In the method section, an overview is given of the study's design, data collection procedure, how the study was conducted and the measurement tools that were used.

Lastly, the results from the questionnaires are presented and discussed. The study is summarized, recommendations for future research are made and a conclusion is made answering the research questions.

2.0 Background

2.1 Spinal cord injury

A SCI presents with a muscular paralysis of varying degree, loss of sensation and loss of autonomic nervous system functions such as bladder and bowel movements and sexual function. It also affects the regulation of blood pressure and body temperature (Hjeltnes, 2008). Following a SCI one usually differentiates between sequelae, indicating changes that cannot be prevented, and medical complications, which can be prevented. It is also useful to differentiate between conditions arising in the acute (first month after injury) and early phase (first year after injury) (Kostovski, 2012).

The neurological deficits and the functional limitations depend on whether the injury is complete or incomplete. If partial preservation of sensory and/or motor functions is found below the neurological level and includes the lowest sacral segment, the injury is defined as incomplete. Sacral sensation includes sensation at the anal mucocutaneous junction as well as deep anal sensation. The test of motor function is the presence of voluntary contraction of the external anal sphincter upon digital examination. An injury is defined as complete if there is an absence of sensory and motor function in the lowest sacral segment (Gregory, 2003).

According to Kirshblum et al. (2011) the term tetraplegia refers to: " impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as in the trunk, legs and pelvic organs. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal. Paraplegia refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved" (Kirshblum et al, 2011).

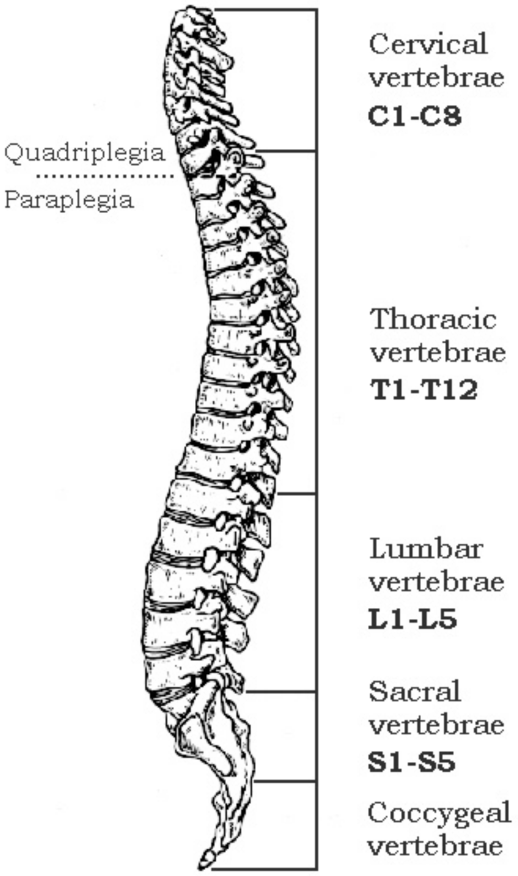

Figure 1: *Illustration of the spinal cord* (http://www.scitcs.org)

2.2 Classification of injury severity

To assess the neural disturbances after a spinal cord injury, the American Spinal Injury Association (ASIA) has published the International Standards for Neurological and Functional classification of Spinal Cord Injury (Marino et al., 2003; Maynard et al., 1997). The classification is based on a precise neurological examination, including sensory, motor and functional tests. It has been modified from the five-category system to classify completeness, introduced by Frankel and co-workers (Frankel et al., 1969). In the present thesis the wording complete SCI or motor complete SCI is used synonymously with SCI AIS A-B and the wording incomplete SCI or functionally incomplete SCI is used synonymously with AIS-D.

Table 1: *International Standards for Neurological and Functional Classification of Spinal Cord Injury (Marino et al., 2003).*

AIS A	Complete: No sensory or motor function is preserved in the sacral segments S4-S5
AIS B	Incomplete: Sensory, but no motor function is preserved below the neurological level and includes the sacral segments S4-S5
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). (Grade 3= Movements against gravity, but not against resistance).
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.
AIS E	Normal: Sensory and motor functions are normal.

2.3 Prevalence

There are relatively few studies of prevalence of SCI done worldwide. A recent Norwegian study by Hagen, Rekand, Gilhus & Grønning (2012) looked at studies regarding prevalence of SCI across the world. The authors found that India had one of the lowest, with only 236 cases per million (Razdan et al., 1994). USA was found to have a high prevalence with 1800 cases per million inhabitants (Kurtzke, 1977). Since there have not been any overall incidence studies of SCI in the U.S. since the 1970's it is not known if the prevalence has changed in recent years. In Europe, only a few studies of prevalence were identified, among those one by Dahlberg, Kotila & Leppänen (2005) who found a prevalence of 280 per million in Finland in 1999.

The National Spinal Cord Injury Statistical Center (USA) reports that the average age at point of injury in USA was 29 years in 1970 and 37 years in 2005. A recent review by De Vivo (2012) states that “ the average age of both newly injured persons and persons currently alive with SCI is expected to increase slowly. The percentage of new injuries occurring among persons over 60 years of age will increase, but the percentage of the overall SCI population over 60 years of age will increase more slowly because of high mortality rates among older persons with SCI ”. De Vivo also states that the percentage of higher-level injuries will increase among new injuries, but remain stable in the overall SCI population.

2.4 Spinal Cord Injuries in Norway

In the Nordic countries each year between 10 and 20 persons per million inhabitants suffer a traumatic SCI that causes permanent and severe disability. There are no Norwegian prevalence studies, but studies from outside Norway show a prevalence of between 200 and 1000 per 1 million inhabitants. According to these numbers an estimated 1000-5000 persons in Norway have a permanent disability due to spinal cord injury. There are also an increasing number of people with non-traumatic injuries (Hjeltnes, 2008).

Every year approximately 60-80 people suffer from SCI in Norway and the percentage of women affected is between 20 and 25. In Norway the most common causes of traumatic SCI are traffic accidents, falls or sports injuries (Hjeltnes, 2008). The non-traumatic injuries are damage to the spinal cord caused by for example infection, circulatory disturbance, tumors or by medical or surgical treatment. It can be congenital, either hereditary or acquired during pregnancy or childbirth (Hjeltnes, 2004).

2.5 ICF

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors (World Health Organization [WHO], 2001).

The ICF is a conceptual framework designed not only to describe limitations medically, but also to capture the individuals functioning. Rimmer (2006) recommended the use of the ICF as a framework for identifying factors that may impact physical activity among people with disabilities. The ICF is based on the integration of a medical model of understanding disability and a social model. In the medical model disability is viewed as a problem of the individual, caused by disease or trauma whereas the social model of disability sees the issue as a problem created by our society. Theoretically the ICF is building a bridge between these two models. The result is a "bio- psycho-social" approach including the perspectives of health from a biological, individual and a social perspective. A spinal cord injury is a condition that influences a person's level of functioning. The ICF can help visualize how a condition, like SCI, affects functioning, and how the aspects of functioning interact with one another.

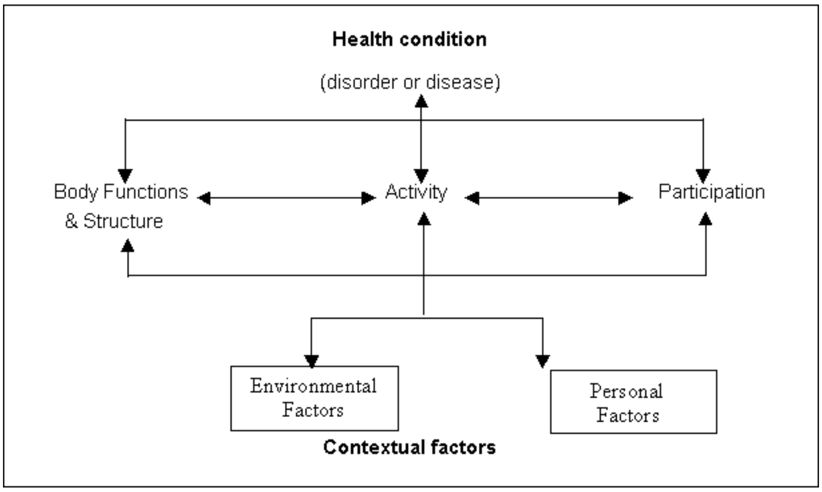

Figure 2: *ICF model, interactions between the components* (WHO, 2004 s. 12)

By implementing the ICF model in SCI rehabilitation in Norway, the focus will be changed from cause to effect. The purpose of the model is to place all disabilities on a common scale in order to see the person's functional abilities in relation to the surroundings the person is living in. This may be participation in work life, daily activities or social activities (Ude & Sommerfelt, 2009). The Norwegian Directorate of Health has the responsibility of implementing ICF in rehabilitation in Norway. The goal is to use ICF as a standardized system for a common terminology for clinical practice, statistics, education and international communication (Kompetansesenter for IT i helse- og sosialsektoren [KITH], 2010).

2.6 Rehabilitation after spinal cord injury

The definition of rehabilitation in Norway states:

" *Habilitering og rehabilitering er tidsavgrensa, planlagde prosessar med klare mål og virkemiddel, der fleire aktørar samarbeider om å gi nødvendig assistanse til brukarens eigen innsats for å oppnå best mogleg funksjons- og meistringsevne, sjølvstende og deltaking sosialt og i samfunnet."* (St.meld.nr.21 (1998- 99), 1998)

Translated from Norwegian to English this definition states that rehabilitation and habilitation is a "Planned and time limited process with distinct goals and methods. Professional multidisciplinary cooperation is required in order to give the necessary assistance to enable people to reach their highest level of functioning, coping, independence and social participation in society".

Physical activity and exercise after a spinal cord injury is a central part of the rehabilitation. The sort of activity or exercise program used will depend on the same factors as with the non-injured population such as age, gender and physical condition. The most important consideration is the level of the spinal injury, the extent of injury and the time passed since the injury. All patients need to be mobilized as soon as it is medically possible. In the beginning the activities will be passive and conducted by a therapist. Methods such as stretching of musculature, passive movements, mobilization of joints and respiratory techniques will be used. Later active exercise is encouraged in order to improve physical capacity, muscle strength, coordination and balance. The guidelines for exercise will be based on the same principals as for persons without injury, but with a different intensity and amount, considering individual adjustments (Hjeltnes, 2008).

In Norway there are three spinal units, St. Olavs hospital in Trondheim, Haukeland hospital in Bergen and Sunnaas Rehabilitation Hospital in cooperation with Oslo University hospital. These units have the responsibility for life-long follow up of the patients with SCI. There are also rehabilitation possibilities at Beitostølen helsesportsenter, Catosenteret and Nord-Norges kurbad in Tromsø. According to Lannem (2011) the goal of the rehabilitation process is to prevent complications and increase the individual's abilities for independent living on the basis of their abilities. The physical rehabilitation consists of a personally adapted exercise program where ordinary exercise principles in strength and endurance training are used (Gjerset, 1992).

2.7 Physical activity and health

The benefits of physical activity for physical health have been well documented and are a major deterrent for morbidity and mortality rates (Richardson et al, 2005). Research has shown that people who are physically active have a decreased risk of developing diabetes, heart disease and high blood pressure (Hillsdon & Thorogood, 1996). Physical activity is not only beneficial for an individual's physiological development, but can also promote psychological wellbeing. Participation in exercise noticeably improved the well-being of people suffering from chronic health conditions (Graham, Kremer & Wheeler, 2008), and factors of well-being, such as coping, fortitude and stress management have all been shown to significantly improve when associated with regular exercise habits (Edwards, 2006). It has also been found that regular exercisers see themselves as being more autonomous, having more personal growth, purpose in life and positive relations with others than non-exercisers (Edwards, Ngcobo, Edwards & Palavar, 2005).

"The *World Health Report 2002 - Reducing Risks, Promoting Healthy Life",* published by the World Health Organization, focuses on health risks. Physical exercise has been introduced as a health promoter. Among the most serious risk factors of decreased health levels, are those predominating in wealthy societies, i.e. high blood pressure, high blood cholesterol level, tobacco and alcohol consumption, obesity and physical inactivity (WHO, 2002). 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 of a minimum of 30 minutes brisk walking daily (Jansson & Anderssen, 2008).

2.8 Physical activity in Norway

Physical activity is an area of research that has not been thoroughly examined in Norway. (Søgaard et al., 2000). Several studies have pointed out that people with disabilities are one of the most understudied groups when it comes to physical activity (Søgaard, Bø, Klungland & Jacobsen, 2000; Ingebrigtsen & Aspvik, 2010; Saebu & Sorensen, 2010). Norway is one of the few countries in the world to have results from a national survey investigating the level of physical activity of the population by using accelerometers. In 2008 and 2009 a nation wide survey was done to investigate the physical activity levels among adults and elderly in Norway (Stokke, 2010). A selection of Norwegian women and men aged 20-85 years were included in the study. The researchers used an objective measurement tool (accelerometer) to examine the physical activity. In relation to the recommendations for physical activity, only 20 % of the participants met the demands of these. There were significantly more women (22%) than men (18%) who met the recommended levels (Anderssen, 2009).

2.9 Physical activity and spinal cord injury

It is well known that regular physical activity performed by people with mobility impairments, such as those due to a SCI has beneficial effects on both stamina and strength, as well as on the ability to manage daily life activities and psychological well being. Rimmer (1999) suggests that health promotion for those with disabilities, including those with SCI, has historically been directed at primary prevention of disability rather than prevention of secondary conditions; however, the benefits of exercise in improving outcomes after SCI are increasingly recognized. Still, the leading causes of death in the SCI population are diseases linked to a physically inactive lifestyle: cardiovascular and respiratory disease (Wahman et al. 2010). Having a SCI has been referred to as a model of premature aging, specifically from a cardiovascular and endocrinological perspective (Hitzig, Campbell, McGillivray, Boschen & Craven, 2011).

According to Garshick et al. (2005) the increased mortality in chronic SCI is related to factors that may potentially be improved. Recognition and treatment of cardiovascular disease, diabetes and lung disease, as well as cessation of smoking may significantly reduce mortality in persons with SCI. In a Norwegian study by Lidal, Snekkevik, Aamodt & Hjeltnes (2007), researchers looked at mortality, cause of death and risk indicators for death in Norwegian patients with SCI. The main causes of death were pneumonia/influenza (16%), ischemic heart diseases (13%) and urogenital diseases (13%). Standardized mortality ratio was 1.8 for men and 4.9 for women. Some of the risk indicators for death were: higher ages at injury, tetraplegia, functionally complete SCI, pre-injury cardiovascular disease, alcohol or substance abuse and psychiatric diagnosis (Lidal et al., 2007).

Furthermore, it has been estimated that only a small minority of healthy young persons with SCI have the minimal level of fitness needed to maintain independent living (Noreau &

Shephard, 1995). According to Lannem (2011), “ Haskel, Blair & 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 ”. Ditor et al. (2003) reported greater perceived quality of life and less stress and pain in individuals with SCI who participated in supervised exercise training two times a week than in a non-exercising cohort. These results were seen after a 9-month randomized control trial of exercise training. At the end of the training program, the authors emphasized the importance of continuing to adhere to exercise in order to maintain the exercise-related increases in psychological well-being among individuals with SCI. Exercise training has been shown to reduce pain and depression among people with SCI (Hicks, Martin & Ditor, 2003). A study by Martin Ginis et al. (2003) showed that after exercising two times a week for 3 months, people with SCI reported lower levels of stress, pain, and depression and better physical self-concept and overall quality of life (QOL) than those who did not exercise. These findings indicate that alterations in pain and stress may mediate changes in QOL and perceived well-being (PWB). From a therapeutic perspective, these findings highlight the potential value of exercise for improving PWB and QOL among persons with SCI (Martin Ginis et al., 2003). With regard to the risk of chronic disease, there is preliminary evidence that among persons with SCI, physical activity is associated with positive changes in disease risk factors such as triglyceride levels (Nash, Jacobs, Mendez & Goldberg, 2001), body fat (Olle, Pivarnik, Klish & Morrow, 1993) and insulin resistance (Mohr et al., 2001).

Physical activity guidelines for adults with SCI in Canada recommend 20 minutes of moderate to vigorous intensity aerobic activity two times a week. In addition strength training should be done two times a week, exercising each major muscle group. This combination should ensure the achievement of important health benefits. (Martin Ginis, 2011). Until now little research has been done on investigating if there is a difference between complete and incomplete spinal cord injuries with regards to benefits from physical activity. There are some Norwegian guidelines made by the directory for Social services and health (Sosial og Helsedirektoratet) in 2004 (Sköld & Sternhag, 2004) and the directory of health (Helsedirektoratet) in 2008. These are not very detailed and contain no recommendations about how to adapt and adjust exercises or how the different groups experience exercise. At Sunnaas Rehabilitation Hospital studies on experiences with physical exercise from 2-40 years after injury has been done among people with incomplete injuries (Lannem & Sorensen, 2007; Lannem, Sorensen, Froslie, & Hjeltnes, 2009; Lannem, Sorensen, Lidal & Hjeltnes, 2010; Lannem, 2011). According to Lannem (2011) the literature on SCI and physical activity is mostly centred around 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 reason to think that the literature on motor complete SCI is also lacking in these areas.

2.10 Barriers to being physically active

Health care professionals have generally recommended that persons with SCI take part in physical activities as part of a healthy lifestyle, to the extent that their disability allows. The question of *how* they should do so, however, has yet to be concluded in research. Unlike persons without disability for whom exercise is easily accomplished, exercise possibilities for those with SCI are more limited. Depending on level of injury the physiological responses to acute exercise may also be less robust than for able-bodied people, the magnitude of training benefits diminished, and risks of ill-considered activity both greater and possibly irreversible. This makes an understanding of exercise opportunities and risks important if exercise undertaken by those with SCI will ultimately promote benefit and not harm (Nash, 2005).

Achieving a physically active lifestyle can be very difficult for people with disabilities. Several barriers to exercise have been identified in past studies, including pain, accessibility, financial issues, psychological barriers, a lack of motivation and energy and logistical hindrances (Kala, Hanley, Watson, Hicks & McCartney, 2002; Zemper et al, 2003; Vissers, Sluis, Bergen, Stam & Bussmann, 2008). In spite of all such potential barriers, there are indeed people with SCI who adopt a physically active lifestyle. Motivating factors include the whole spectrum from enjoyment, fitness, competition, and maintaining mental and physical health, to social values (Henderson & Bedini, 1995; Wu & Williams, 2001; Maher, Kinne & Patrik, 1999).

Prior studies have shown that getting started with physical activity is difficult for people with disabilities (Saebu & Sorensen, 2010). With an acquired injury or disability one needs to be very resourceful in order to find motivation and energy to establish a physically active lifestyle; especially if the person was inactive pre-injury (Saebu & Sorensen, 2010). According to Saebu (2011) personal factors explain more of the variance in total physical activity than environmental factors and factors relating to functioning and disability. Personal factors such as identity as a physically active person and intrinsic motivation seemed to be important factors for involvement in physical activity for those with a disability. Wu and Williams (2001) concluded in their study that there is lack of research identifying the difficulties and reasons why people with SCI do not participate in sport activities and how they can be encouraged to participate in those activities. A challenge for persons with SCI is to learn to identify, manage and overcome the many barriers to participation in physical activity and sports. Although only a few studies have tested strategies to tackle these barriers and facilitators in persons with SCI, positive effects have been observed for interventions that feature elements such as action planning, goal setting, and self-monitoring (Wolfe et al., 2008).

According to Elnan (2010) a lack of information may be a factor causing people with disabilities to be less active. This applies for information on physical activity in general and information concerning the opportunities for participation in adapted sports. Public advise and recommendations that are made regarding physical activity, such as walking stairs instead of using elevators, walking or biking to work, or reaching 10000 steps every day are useful for encouraging able bodied people to increase their levels of activity. For people with disabilities these advices may be harder to follow, especially when walking is not a possibility. Rimmer (2005) recommends exercising the upper body, by for example arm ergometers or swimming. By choosing these types of activities one may reach health benefits equal to 10000 steps a day.

3.0 Theoretical framework and central concepts

This section presents the theory behind the thesis. In order to improve the understanding of the psychological processes and mechanisms related to physical activity among people with SCI a theoretical framework is needed. Living with a SCI creates obstacles in everyday life and can be considered a stressor (Lannem, 2011). In the present thesis the Cognitive Activation Theory of Stress (CATS) has been used as a framework as this theory covers the relevant aspects of stress, coping and health outcomes.

Central concepts relevant to the topic are also presented including stress, physical activity and exercise and life satisfaction. Lastly the research questions are presented.

3.1 Cognitive activation theory of stress (CATS)

CATS is a theory presented by Holger Ursin focusing on total health resources including physiological, psychological and social aspects (Ursin & Eriksen, 2004; Ursin & Eriksen, 2010). The theory considers how the overall health resources respond to the stressors we encounter in everyday life. It assumes that the stress response depends on acquired expectancies of the outcomes of stimuli and available responses. It also examines how these stressors are perceived and coped with. Four different aspects are defined and operationalized:

1. Stress stimulus (stressor)
2. Stress experience (perceptions)
3. An unspecific, general stress response
4. The personal experience that form the expectancies of the stress response

The general non-specific stress response can be viewed as an alarm to raise the neurophysiological activation to a higher level. The alarm is activated when something is missing or unexpected and which triggers a 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 individual’s expectations of the outcome and the resources that are available for coping. This stress response is a necessary physiological response, and the response is not harmful in itself. It is only when this response is maintained for a long period of time that it can lead to negative health consequences. The alarm also facilitates behaviour to cope with the situation. (Ursin & Eriksen, 2004).

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 (Lannem, 2011). 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.

Ursin (1998) stated that although the term *coping* has been used for the strategy selected or actions taken when confronting a stressful situation (e.g., Folkman & Lazarus, 1985; Lazarus & Folkman, 1984), it is only when it is used for the expected results from these strategies that coping is predictive of health. One example of how the expectation of being able to perform may decrease stress levels, is found in research by Ursin, Baade & Levine (1978). A sample of parachutists were tested for fear and endocrine responses after their first training session- prior to their performance reaching an acceptable level. The tests showed a general reduction of both variables, meaning that neither successful performance nor feedback from actually parachuting reduced the arousal. The expectation of being able to perform was what decreased their stress response.

When looking at coping strategies undertaken by individuals with SCI it seems that individuals who use engagement-type coping strategies, which include problem-solving, seeking social support and other active measures generally have demonstrated healthier psychosocial adaptation. In contrast, individuals with SCI who use disengagement-type coping strategies, such as passive, avoidant-type behaviors that include drug and alcohol use, denial, fantasy, or blaming self and others, generally have displayed inferior psychosocial outcomes (Livneh, 2000). Kennedy et al. (2010) also emphasizes the importance of social participation for improved physical and psychological well being for people with SCI. The use of maladaptive coping strategies such as avoidance and withdrawal can potentially have a negative effect on social participation and hence hinder positive rehabilitation outcomes.

According to Lannem (2011) the consequences of a spinal cord injury may be seen as stressors according to CATS. The theory explains that a homeostatic imbalance between the expected outcome and the factual outcome of a situation activates a neurophysiological stress alarm. The total consequences of the stress alarm are determined by the way the individual reacts to the activation of it. If for example, a person with motor complete SCI in a wheelchair is worried about accessibility in the environment around him, all obstacles and hindrances can be seen as stressors. The person´s own low expectations to manage the situation to manage the situation may lead to reluctance to leave the house. Strategies to help overcome these hindrances could be to increase strength, balance and wheelchair skills and thereby prepare the person for independent ambulation.

If, for a person with SCI the future is unpredictable or if an individual does not have the necessary resources to handle the demands placed by the injury, the stress alarm is activated. There may also be instances such as avoidant coping or learned helplessness when individuals do not possess the necessary resources to handle the situation and remove themselves from it. This will engage a passive response that provokes a *positive* outcome expectation, reducing stress activation.

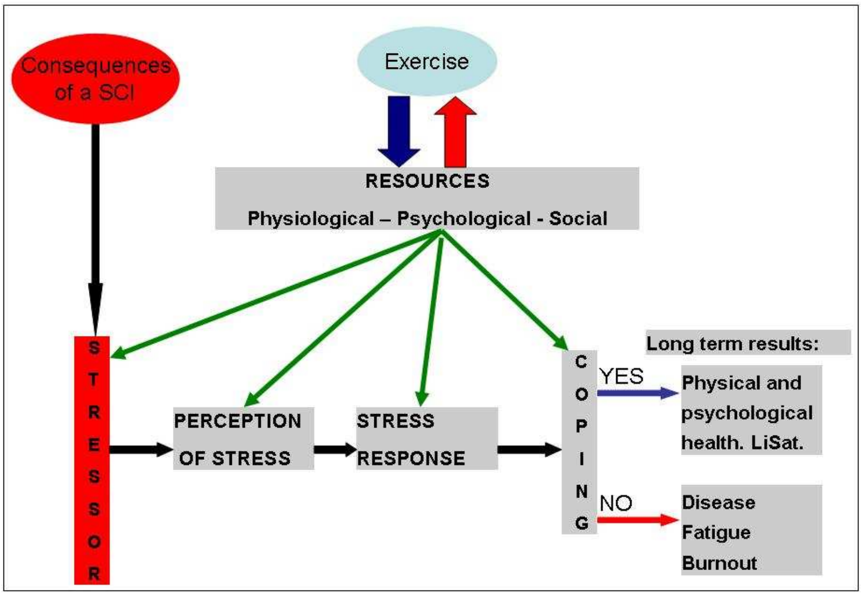

Figure 3: *Illustration of CATS in relation to persons with SCI and physical exercise. The stressor is represented by the consequences of a SCI. The resources in all fields will influence how the stressor(s) are perceived in different situations, reaction to the stressor(s), as well as how the perceived stressor(s) are coped with* (Lannem, 2011).

3.2 Stress

Stress is an old term, in English used for pressure or distress at least from the 13th century, and related to sources of strain. Hans Selye is frequently said to be the “father” of the stress concept (Ursin & Eriksen, 2004). According to Ursin & Eriksen (2004) in the earliest work by Selye the actual word *stress* is not used, but the terms stress and stressors develop in his later work. From 1949 or 1950 ‘stress’ was his main theme (Selye, 1950). Since he used the term stress on the response rather than the more proper word strain, he had to invent a word for the load or stimulus that triggered this response. This is the origin of the term ‘stressor’.

According to Ursin & Eriksen (2004) “ later research (Mason, 1968) pointed out that the most potent stimuli for pituitary–adrenocortical activity were psychological factors. Although Mason avoided the use of the term stress, the realization of the importance of psychological factors for neuroendocrine regulation (‘the Mason principle’) has been an important part of later stress theory (Ursin, 1998).” It has also been recognized that ‘stress’ is not essentially a negative factor that should be avoided, Selye expressed this by making a clear division between the terms ‘eustress’ and ‘distress’ (Selye, 1974). One commonly adopted view of stress considers it to be “*the experienced condition or feeling when individuals perceive that the demands of a situation exceed their perceived resources and endanger well-being”* (Lazarus, 1966, 1999; Lazarus & Folkman, 1984).

3.3 Stress and SCI

A large amount of research data suggest that people tend to adapt well after sustaining a SCI, a finding attributed to the high frequency of adaptive coping strategies reported in this population (Kennedy, Lude & Taylor, 2006). However, inconsistency in adjustment does exist in this population and some individuals remain vulnerable to experiencing psychological difficulties. Raised levels of anxiety have been reported in 23–35% of the SCI population and elevated levels of depression in 35–38% (Kennedy, Duff, Evans & Beedie, 2003).

Rintala, Hart & Fuhrer (1996) studied global perceived stress in community-residing persons with SCI. The findings were that persons with SCI had greater perceived stress than persons in the general population and that higher perceived stress was associated with more symptoms of depression, lower life satisfaction, and poorer self-assessed health (Rintala et al., 1996). Gerhart, Weitzenkamp, Kennedy, Glass & Charlifue (1999) found greater perceived stress to be related to more depressive symptoms, less life satisfaction, and poorer perceived well being among British individuals who had lived with SCI for at least 20 years.

3.4 Physical activity and physical exercise

Physical activity is defined as "any bodily movement produced by skeletal muscles that result in energy expenditure" (p.126). The energy expenditure can be measured in kilocalories. Physical activity in daily life can be categorized into occupational, sports, conditioning, household, or other activities. Caspersen, Powell & Christenson, (1985) defined physical exercise as " 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". In the present study physical activity was defined as activity during work or at home, transportation from place to place, leisure time activity, recreation, and exercise or sport participation. The physical activity was assessed in metabolic equivalent (MET minutes per week) as measured by the International Physical Activity Questionnaire- IPAQ (Craig et al., 2003) or rated on a level from 1-4 by the LTPA.

3.5 Life Satisfaction

Mental and social satisfaction with life is included in the health concept used by the World Health Organization. Life Satisfaction is one component of subjective well being (SWB). SWB refers to how individuals evaluate their lives. People experience SWB when they feel many pleasant and few unpleasant emotions, when they are engaged in interesting activities, when experiencing many pleasures and few pains, and when they are satisfied with their lives (Diener, 2000). Shin & Johnson (1978) defined life satisfaction as "*a global assessment of a person's quality of life according to his chosen criteria*" (p. 478). Life satisfaction has also been defined as "*an attitude or a summary evaluation of objects along a dimension ranging from positive to negative* " (Petty, Wegener, & Fabrigar, 1997, p. 611). Life satisfaction can be seen as a person´s subjective well-being with cognitive judgments that life and life circumstances are satisfactory.

In general, persons with SCI seem to demonstrate less satisfaction with life compared to the normal population. In a study on persons with incomplete SCI, exercise and life satisfaction one of the findings was that those who exercised scored higher on the summed life satisfaction than the non-exercisers (Lannem et al., 2009). This result is in agreement with previous studies that have reported a positive relationship between physical exercise and 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).

A study by Jørgensen, Lexell, Iwarsson & Mårtensson (2002) found that older Swedish men and women more than ten years post-SCI experience a reduced life satisfaction compared to an able- bodied population. The results also indicated that life satisfaction in people with SCI is neither dependent on injury-related factors nor age, but influenced by their marital status. The study emphasized the need to implement appropriate rehabilitation interventions to enhance life satisfaction in older persons living with SCI. A study by Tasiemski, Kennedy, Gardner & Taylor (2005) revealed that higher satisfaction with life in general was demonstrated in respondents with SCI who were involved in sports or physical recreation compared to those who did not participate in physical activity.

A recent study by van Leeuwen et al. (2012) described the development of life satisfaction in the period between discharge from inpatient rehabilitation and 5 years after discharge in a cohort of Dutch persons with SCI. The researchers found no changes in mean life satisfaction between discharge and 2 years after discharge; however, there were small increases in life satisfaction between 2 years and 5 years after discharge. Social support, self-efficacy, functional independence, and pain were related to life satisfaction after discharge. Secondary impairments, on the other hand, were not related to life satisfaction after discharge. An increase in everyday social support and an increase in self-efficacy were associated with an increase in life satisfaction.

3.6 Research Questions

The level of physical activity has been reported to be generally low in the population with SCI (Buchholz, McGillivray & Pencharz, 2003). Based on this knowledge, the first research question is a descriptive question about the level of physical activity in this population:

1. *What are the levels of physical activity among people with motor complete spinal cord injury (AIS A or B)?*

According to Lannem (2011) the consequences of a spinal cord injury may be seen as stressors according to CATS. The second research question concerns physical activity in relation to the participants' experiences with disability related stress:

2. *Is there a correlation between the amount of physical activity performed and the levels of disability related stress experienced?*

The third question aims to look at the factors that can influence how persons with motor complete SCI cope with disability related stress:

3. *Which factors are associated with coping with disability-related stress among persons with motor complete SCI?*

4.0 Method

In 2011 a study on physical exercise, stress, coping, burnout and fatigue in persons with incomplete SCI was carried out (Lannem, in press). In this cross sectional study the data was collected through a mailed questionnaire, gathering the data from the experts themselves- the persons with incomplete SCI. Knowledge can come from persons working in health care services or relatives to persons with SCI but most importantly from persons with SCI themselves. The same philosophy has been applied in the present study, and a choice was made to collect data by a mailed questionnaire posted to persons with motor complete SCI.

4.1 Research design

The design of the present study is a cross-sectional survey. The most practical method, when considering time consumption and financial matters was a survey questionnaire administered by posted mail. The journal system at Sunnaas Rehabilitation Hospital was made available to search for eligible participants. The present master thesis has been carried out as a minor part of a larger project led by Professor Marit Sørensen and Doctor Anne Lannem. The questionnaire (Appendix I) includes only the items that were reviewed in the present study. The complete questionnaire received by the participants also included other items that have not been reviewed and are therefor not presented in the present study.

Locating the participants and finding contact information was done through searching the electronic journal system at Sunnaas Rehabilitation Hospital as well as looking through the written archive with older journals. The AIS score A or B was used as the main inclusion criteria (Marino et al., 2003). For more information on AIS scores, see chapter 2.2.

4.2 Sample population

Sunnaas Rehabilitation Hospital is the largest specialized unit within rehabilitation and physical medicine in Norway and treats approximately 2800 persons a year. The hospital covers the health regions east and south – altogether 2,5 million inhabitants. Sunnaas Rehabilitation Hospital is the institution in Norway with the primary responsibility for the rehabilitation of the majority of persons with SCI, both children and adults. The population included in this study includes persons with a complete spinal cord injury (AIS A or B) admitted at Sunnaas Hospital up until January 2010. The selection was made from the patient journal register at Sunnaas Rehabilitation Hospital and questionnaires were sent to all patients registered with a date of injury between 1958 and 31.12.2009.

To avoid the effect of general age-related changes, people older than 60 years when injured were excluded. A choice was also made to exclude participants under the age of 18 from participation. The reason for this is that children often present a different pattern of physical activity than adults and also that the parts of the questionnaires concerning stress and life satisfaction were not applicable for use with children. After limiting the population according to age requirements contact with the National Birth Register was made. This was done in order to ensure that the persons were still alive and with residence at a known address in Norway.

4.3 Practical concerns

The questionnaires were sent to the home address of the potential participants. Those who were able to answer and return the information by mail did so by mailing their filled-in questionnaires back to Sunnaas Rehabilitation Hospital. Those unable to answer by writing had the opportunity to contact the researchers by telephone to make arrangements for answering the questionnaire verbally.

4.4 The Questionnaire

In a questionnaire both open-ended and closed questions can be included. An open-ended question allows the respondent to give the answer in his own words and to add personal remarks. Open-ended questions are more time-consuming to answer, and they are also more time-consuming for the researcher to analyze. The closed question, which is preferred in the present study, requires a specific response. With a few exceptions the questions in the present study are closed.

4.4.1 Measures

The questionnaire used in the present study included questions concerning demographic information, injury level, physical activity, disability-related stress, coping and life satisfaction.

4.4.2 Demographic information

The first section of the survey concerned general demographic information such as age, gender, marital status, level of education and level of SCI. Most of these questions are closed with multiple response alternatives. Some questions had open possibilities for answering with numbers, such as " How old were you at the time of injury? ".

4.4.3 Physical Disability Stress Scale (PDSS)

This scale by Furlong & Connor (2007) was composed to measure disability-related stress in persons with physical disability. The PDSS has originally been validated for adults with an acquired physical disability who require 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 by Lannem, and used in a similar study as the present for people with incomplete SCI (Lannem, in press). The total scale (22 items) can be used with 4 subscales, being Access (4 items), Physical (5 items), Social (7 items) and Burden of care (6 items), or as a total score. The range of scores for the total scale is 0-110.

4.4.4 Injury level and severity of the injury

This was assessed as recommended by the American Spinal Injury Association (ASIA) (Marino et al., 2003). The ASIA recommendations for assessment can be found in Chapter 2.

4.4.5 Physical activity

Physical activity and physical exercise were measured by the International Physical Activity Questionnaire (IPAQ) and in addition a 4-item rating of leisure time physical activity (LTPA). These two questionnaires are both measures of physical activity, but do not measure within the same time frame or using the same measuring units. Both questionnaires are used to get an overall more detailed picture of the participants' physical activity levels.

4.4.6 International Physical Activity Questionnaire (IPAQ)

The IPAQ short version has been developed for use with adults (18-69 years) (Craig et al., 2003). It collects information from the past 7 days, on time spent walking, doing moderate and vigorous-intensity activities. It also includes information on time spent sitting. The instrument has shown acceptable reliability and validity (Craig et al., 2003). A Norwegian translation was available and had been used for both persons with and without a physical impairment (Saebu & Sorensen, 2010; Wilhelmsen, 2009; Lannem, in press). In this questionnaire the respondents indicated how many days and hours they were physically active at intensive and moderate intensity over the past seven days. They also indicated how much time they spent rolling in the wheelchair for more that ten minutes continuously and how much time they spent seated in the past seven days.

4.4.7 Leisure Time Physical Activity (LTPA)

The LTPA is a one-item scale developed in the 1960s and is commonly used in Norwegian health surveys (Graff-Iversen et al., 2008; Saltin & Grimby, 1968, Stokke, 2010). 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 and 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. Stable construct validity has been reported by Aires, Selmer & Thelle (2003) and Graff-Iversen, Anderssen, Holme, Jenum & Raastad (2008).

4.4.8 Degree of coping

Coping was described 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) (Lannem, 2011).

4.4.9 Life satisfaction

The LiSat-9 is a domain specific measure of life satisfaction. It consists of one question about satisfaction with life as a whole and eight questions about satisfaction with different life domains: self-care ability, leisure time, vocational situation, financial situation, sexual life, partnership relations, family life, and contact with friends. Each question is scored on a 6-point scale (1, very unsatisfied; 6, very satisfied) (Fugl-Meyer, Eklund & Fugl-Meyer, 1991). The questionnaire is suitable to gain information on satisfaction with life domains, in particular in community settings, and has showed the best combination of efficiency, coverage, and psychometric evidence of all domain-specific life satisfaction measures used in persons with SCI (Post et al., 2010). If the scale should be used in a clinical setting, summing up the scores would not be recommended, as this might not uncover which domains are clinically relevant (Fugl-Meyer et al., 2002). In a research setting a more general idea of the life satisfaction is desired, and the total score can therefore be used. The LiSat-9 was used on a population with incomplete SCI by Lannem et al. (2009) and has demonstrated reliability and validity in resent research (Post, van Leeuwen, van Koppenhagen & de Groot, 2012).

4.5 Validity and reliability

The validity of the present study is determined by two factors. First, the validity is the degree to which the questionnaire measures what it aims to measure (Thomas & Nelson, 1996). Secondly, the validity of the study is also set by the reliability of the data that has been collected. The reliability depends on how accurately the procedure of measurement and registrations of the data are done (Hellevik, 2000). Testing the reliability can be done in different ways. The most relevant test for the questionnaire of the present study would have been a re-test, an identical questionnaire answered by the same respondents at a later time. Due to several practical reasons, this was not done- but the same type of questionnaire was recently used on a population with incomplete SCI in 2011 (Lannem, in press).

4.6 Statistical Analysis

All analyses were made using PASW statistics 18.0 for Windows. The author and an assistant checked the raw data for correctness and outliers. Descriptive statistics were used to characterise the sample. The tables have been made using Microsoft Word and the figures using Microsoft Excel and PASW. The descriptive data are presented as number (N), percent (%), mean (M), and standard deviation (SD), median and range. Different groups were compared with independent samples t-tests. Kendall´s tau correlation test was used to measure the correlation between LTPA, IPAQ, PDSS and LiSat-9. The strength of the correlations was assessed according to Pallant (2010) where the following guidelines were suggested: small correlation (r=. 10 to .29), medium correlation (r=. 30 to. 49) and large correlation(r=. 50 to 1.0).

4.7 Ethical considerations

The questionnaires contain sensitive information and the documents have been made available only for the research group in an anonymous form using number codes instead of names. Data has been published in a non-identifiable design. Participants were asked about participation in the study and signed a form of consent, which was posted together with the questionnaire. This letter also contained information concerning the questionnaire. In this letter the participants were informed about the purpose of the study, what it will be used for and how spinal cord injury rehabilitation in Norway could benefit from the given information. In addition it was underlined that participation was voluntary and participants could at any time during the process chose to end their cooperation or decide not to answer particular questions. The study has been approved by the Regional Medical and Health Research Ethics Committee, Eastern Norway (Appendix III).

4.8 Data collection

The questionnaire was posted together with the introductory letter and the form of consent (Appendix II). The questionnaires were sent to the 330 recipients in March 2012. A reminder was sent in April 2012 and a second reminder in June 2012.

5.0 Results

In this chapter, the relevant analyses of the collected data will be presented. Descriptive data are presented first, to give an overview of the participant characteristics. Secondly the levels of reported physical activity are presented. The results from the responses on stress level, life satisfaction and coping are then presented, followed by a correlation analysis.

5.1 Participants

A total of 330 persons fulfilled the inclusion criteria and received a mailed questionnaire. After two reminders, 190 persons responded, either by returning the questionnaire or by a telephone interview. 4 persons refused to participate, and 1 person was not able to answer due to language barriers. The final sample consisted of n=185 respondents (56% response rate). Because of ethical regulations, it is not possible to compare respondents with non-respondents, so this will not be done in the present study.

In Table 2 the key figures of the sample characteristics of sex, age, age at injury and injury level are given:

Table 2: *Sample and injury characteristics of participants (n=185)*

	Mean (SD)	**Range**	
Age (years)	50,7 (11,7)	19-75	
Age at injury (years)	25,9 (11,9)	0,5-60	
		n	**%**
Gender			
Male		147	79,5
Female		38	20,5
Injury level			
Tetraplegia		62	33,5
Paraplegia		122	66
Missing injury level		1	0,5

The distribution of gender, current age, age at the time of injury and injury level in the study group was compared to a similar study done by Lannem (in press) on persons with incomplete SCI. In her study from 2011 the sample consisted of 186 participants. The mean age in her study was 48 years and the mean age at injury was 33 years. The sample consisted of 142 men (76%) and 44 women (24%). 85 (46%) of the participants were tetraplegics and 101 (54%) were paraplegics. The distribution of gender and age of the present study correspond with the study by Lannem, but the present study has a higher percentage of paraplegics and a lower percentage of tetraplegics.

5.2 Employment situation

Table 3: *Employment situation of participants (n=185)*

	n	%
Working	109	58,9
Not working	76	41,1
Total	185	100

Table 3 shows that the majority of the participants took part in working life, this includes both part-time and full-time work. Taking the average age of the respondents into consideration, the fact that over 40 % of the study group were not working demonstrates a higher percentage of persons that are not working in this group compared to the general population. A report from Statistics Norway from 2012, on the work situation of persons with disabilities in Norway, found that 41 % of persons with disabilities are in paid employment, whereas 2,6 % were unemployed. Summarized this means that 43,6 % of the persons with disabilities were a part of the work force as apposed to 77,3 % of the general population between the age of 15-66 years. This report included persons with all kinds of disabilities, including both physical and psychological conditions causing limitations in daily life (SSB, 2012).

Table 4: *Description of work among participants (n=83)*

	n	%
Sitting while working	64,0	34,6
Work that demands a lot of walking	12,0	6,5
Walking, rolling, lifting a lot while working	7,0	3,8
Total	83,0	44,9
Missing	102,0	55,1

The participants were asked to indicate what type of work they have considering physical activity at work. The majority of the participants had a job where they were sitting while working. Only a few participants indicated walking, rolling or lifting a lot while working. Being physically inactive at work is not unusual among the general population either. A report by Ommundsen & Aadland (2009) looking at physical inactivity in Norway found that a larger percentage of the general population have work of mainly inactive character now compared to the previous years. 41 % of the population reported that they have jobs where they are mostly sitting down. 32 % of the population reported to have jobs including walking, lifting, carrying or heavy physical labour.

5.3 Physical Activity

Table 5: *Participants responded to whether or not they participate in organized PA? (n= 184)*

	n	%
No	143	77,3
Yes, one activity	16	8,6
Yes, several activities	11	5,9
I have, but have quit	14	7,6
Total	184	99,5
Missing	1	0,5

The majority of the respondents answered that they did not take part in organized physical activity. Data from a report on inactivity in the general Norwegian population by Ommundsen & Aadland (2009) show that 22 % of the respondents reported that they are members of an organized sports club, 24 % have never been a member. 32 % quit participating in their childhood/ youth and 23 % quit as adults.

Table 6: *Participants indicated how often they go to physical therapy? (n=183)*

	n	%
Rarely or never	79	42,7
Not on a regular basis	27	14,6
1 time a week	44	23,8
2-3 times a week	33	17,8
Total	183	98,9
Missing	2	1,1

Table 6 shows that the majority of the participants in the present study do not go regularly to physical therapy. Still, more than 40 % of the respondents go to physical therapy at least 1 time a week. A report from 2010 describing the health and livelihood of persons with disabilities in Norway showed that persons with disabilities are more likely to go to physical therapy than the general population. 32 % of persons with disabilities had been to physical therapy the past year, compared to 17 % of the general population (SSB, 2010).

Table 7: *If you go to physical therapy, what kind of therapy? (n=167)*

	n	%
No physical therapy	87	47
Active exercises	17	9,2
Stretching/massage	42	22,7
Active exercises and stretching/massage	21	11,4
Total	167	90,3
Missing	18	9,7

Almost half of the respondents answered that they did not have physical therapy. Of those going to physical therapy, the majority of them receive passive treatments such as stretching and massage.

Table 8: *Do you exercise regularly besides physical therapy? (n=182)*

	n	%
Yes	54	29,2
I am active, but not regularly	74	40
No	54	29,2
Total	182	98,4
Missing	3	1,6

The majority of the participants state that they either exercised regularly or were active, but not regularly besides physical therapy.

5.4. Physical activity measured by the IPAQ

The respondents reported a mean time of 150, 51 minutes of total physical activity per week with a standard deviation of 271 minutes. In MET minutes the mean is 2274,88 with a standard deviation of 2819. 33 respondents (17,8%) reported 0 minutes of total physical activity. Some of the respondents did not answer all items; therefore the number of respondents (n) varies in table 9.

T-test for independent groups showed a significant difference between genders with regard to the levels of PA (t= -3.305, p=. 003). Men were on average more active than women. A significant difference was found between those who were working and those who were not (t=2.057, p= .042). Those who were not working had higher average levels of physical activity compared to those who were working. There was no significant difference found between the physical activity levels of tetraplegics and paraplegics (t= -.672, p=. 504).

In comparison to a study by Saebu & Sorensen (2010) examining the total physical activity among young adults with a disability, the participants of the present study reported higher levels of physical activity. Saebu and Sorensen found that the average weekly physical activity as measured by the IPAQ was 1595 MET minutes (SD = 1985) per week for both genders in their study group of 327 young adults. Looking at IPAQ numbers from the general population, the participants of the present study reported lower levels of physical activity. Anderssen & Andersen (2004) found that looking physical activity levels, the total MET measured in hours per week was 89,9 for men and 59,5 for women. This equals 5389 MET minutes and 3569 MET minutes per week.

Table 9: *Overview of the participants mean physical activity levels per week as measured by the IPAQ. Presented in moderate activity (minutes, MET-minutes and days), vigorous activity (minutes, MET-minutes and days), walking/rolling (days and MET-minutes) and total physical activity (minutes and MET-minutes)*

	n	**Mean**	**SD**
Moderate (min)	125	93,36	124,61
Moderate (MET-min)	173	836,88	2161,6
Moderate (days)	178	2,17	2,44
Vigorous (min)	183	35,75	69,98
Vigorous (MET-min)	180	877,78	2727,3
Vigorous (days)	181	0,97	1,75
Walking/rolling (days)	180	2,1	2,66
Walking/rolling (MET-min)	171	985,85	2978,9
Sum of moderate phys. act. , vigorous act. and walking (min)	174	150,51	271
Sum of moderate phys. act. , vigorous act. and walking (MET-min)	108	2274,88	2819

5.5 Leisure time physical activity measured by the LTPA

The leisure time physical activity scale (LTPA) was used to measure leisure time physical activity. The respondents were asked to rate their weekly average LTPA on a level from 1-4.

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.

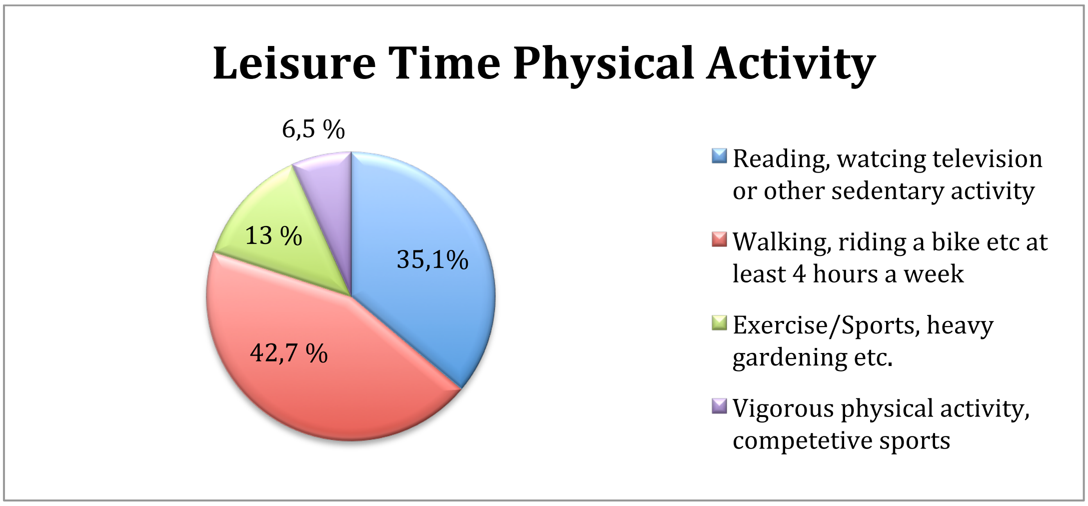

Figure 4: *Leisure Time Physical Activity, 4 levels*

Figure 4 shows that the majority of the participants reported either an inactive or a moderately active leisure time. T-test for independent groups showed no significant difference between genders with regard to the levels of physical activity as measured by the LTPA. (t=-.583, p= .562) A significant difference was found between physical activity levels of tetraplegics and paraplegics, where paraplegics had a higher average level of physical activity compared to tetraplegics (t=-3.042, p= .003). No significant difference was found between those who were working and those who were not working (t= -1.05, p =. 296). Data from a national survey (Stokke, 2010) on physical activity in 2008-2009 among a representative selection of Norwegian adults show a different pattern of LTPA than in the present study. In the general population 17% of the women and 20% of the men reported having a sedentary activity level in their leisure time as opposed to 35,1 % of the persons with motor complete SCI in the present study (Stokke, 2010).

Table 10: *LTPA data from a Norwegian survey*

	%		
	Male	Female	Total
Reading, watching television or other sedentary activity	20	17	18
Walking, riding a bike etc. at least 4 hours a week	50	68	59
Exercise/Sports, heavy gardening etc.	23	12	18
Vigorous physical activity, competitive sports	7	4	5

When comparing the mean LTPA score from the present study to a study on persons with incomplete SCI (Lannem, in press) the mean score found among the persons with incomplete SCI was 2,3 (SD = 0,9) as opposed to a score of 1,9 (SD = 0,87) in the present study.

5.6 Comparison of LTPA and the IPAQ

The distribution of both the LTPA and the IPAQ were not normal. The IPAQ measures were skewed towards zero, it seems that in a less active population such as persons with motor complete SCI, IPAQ does not capture the variance in the lower part of the scale. To compare the measures LTPA and IPAQ in the study population, a correlation test (Kendall's tau) was performed between LTPA and IPAQ. The correlation was of medium strength according to how to determine the strength of a relationship (Pallant, p.134, 2010).

Table 11: *Correlation between LTPA and IPAQ*

		LTPA	IPAQ MET sum
LTPA	Correlation Coefficient	1.000	.422**
	Sig. (2-tailed)	.	.000
	N	180	158
IPAQ MET sum	Correlation Coefficient	.422**	1.000
	Sig. (2-tailed)	.000	.
	N	158	163

**. Correlation is significant at the 0.01 level (2-tailed).

5.7 Coping

The respondents were asked to indicate how well they coped with the most difficult consequences of their SCI on a Visual Analogue Scale (VAS) from 0-10. Figure 4 shows the mean indicated coping at a score of 6,72 (SD = 2,4) with a range from 0-10.

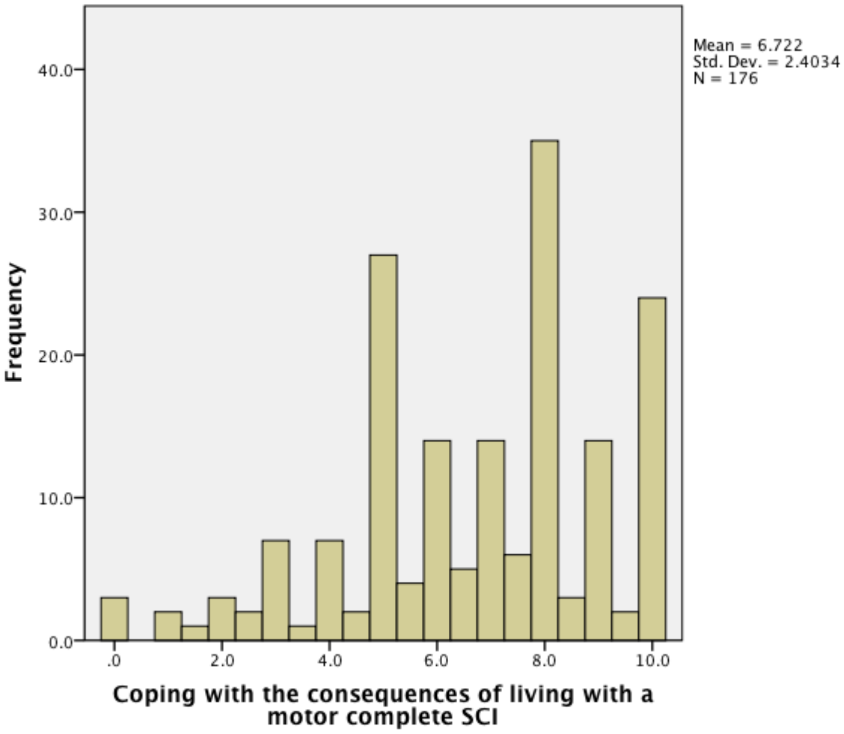

Figure 5: *Coping with the consequences of living with a motor complete SCI*

The scores on coping from the present study correspond with the scores from a study on persons with incomplete SCI by Lannem (in press) where the mean coping score was 6,6 (SD = 2,3). When comparing the mean scores no statistical difference was found between males and females with regard to coping with the consequences of a SCI (t= -1.876, p= .066). A significant difference was found between injury levels with regard to coping (t= 1.997,p= .048) where paraplegics had a lower mean-VAS score. No significant difference was found between those who were working and those who were not working (t =-.943, p =. 347). A significant difference was found between those who indicate experiencing bodily pain and those who did not. (t =2.91, p =.005) where those who indicated experiencing bodily pain had a lower mean VAS-score.

5.8 Life Satisfaction

The LiSat-9 scale was used to measure global and domain specific life satisfaction in the respondents regarding life as a whole (1 question) and in 8 domains of life (8 questions). The questions had to be answered using a 6 grade ordinal scale (1-6). T-test for independent groups showed no significant difference between genders with regard to the mean total score of the LiSat-9 (t=. 262, p=. 794). There was also no significant difference found between tetraplegics and paraplegics (t =-1.218,p =. 225). A significant difference was found between those who were working and those who were not working (t=-3.349, p= .001) where those who were not working had a lower total mean score. A significant difference was also found between those indicating that they experience bodily pain and those who did not (t=3.249, p= .001) where those who experienced bodily pain had a lower total mean score.

The LiSat-9 scores from the present study were compared to the scores from a study by Fugl-Meyer et al. (2002). Fugl-Meyers study included a cross- section of a general population from Sweden. The cross- section was representative of a Swedish population and included 2533 adults between 18 and 64 years of age. The scores of the present study were also compared to a Swedish study by Norrbrink &Osteråker (2007), using the LiSat-9 scale as a measurement tool of life satisfaction. In their study 191 patients with SCI were sent questionnaires about pain, quality of sleep and life satisfaction.

Table 12: *Median scores Lisat-9, present study and comparing studies*

	Study group	Norrbrink & Osterraker	Fugl-Meyer et al.
Life as a whole	5	4	5
Vocational situation	5	4	5
Financial situation	5	4	4
Leisure situation	4	4	5
Contact friends	5	5	5
Sexual life	3	3	5
Ability to maintain self-care	5	5	6
Family life	5	5	5
Partnership relation	5	5	5

A study by Lannem et al. (2009) measuring life satisfaction, self-rated physical exercise and self-perceptions of 69 persons with incomplete SCI also employed the LiSat-9 scale. In this study the total sample of persons with incomplete SCI (n=69) had a mean score of 4,6 (SD = 0.7). Participants defined as exercisers (n = 47) had a mean score of 4.8 (SD = 0.7) and participants defined as non-exercisers (n = 21) had a mean score of 4.2 (SD = 0.7).

5.9 Disability related stress

The Physical Disability Stress Scale was used to measure disability- related stress. The design of the questionnaire required the respondents to think about the disability-specific situations mentioned in the items and to indicate how stressful these situations generally are for them on a scale of 1–5 (where 1 = Not at All, 2 = Slightly, 3 = Moderately, 4 = Considerably, and 5 = Highly) (Furlong, 2007). The total score is the sum of all items and is between 0 and 110. The mean score of the PDSS was 59,69 (SD =19,25). In comparison a study by Lannem (in press) using the PDSS to measure disability related stress among persons with incomplete SCI reported a mean PDSS score of 38,6 (SD = 23,1) among participants.

T-test for independent groups showed no significant difference between genders with regard to the total score on the PDSS (t= .932, p= .355). There was also no significant difference found between tetraplegics and paraplegics (t= -.779, p= .437) or between those who were working and those who were not (t= 1.105, p=. 271). A significant difference was found between those who indicated experiencing bodily pain and those who did not (t =-2.985, p=. 004) where those who experienced bodily pain had a higher total mean score of the PDSS.

Table 13 shows all the items from the PDSS with mean total values and standard deviations. The items rated the most stressful were items concerning physically helping others when they need it, arriving at a place that should be accessible but was not and arriving at a place that has stairs, but has no ramps or elevators. Situations such as using a taxi service, having private issues made public by others or not being recognised for their sexual identity or sexual desires were the lowest rated items of the PDSS.

Table 13: *Physical Disability Stress Scale, all items*

	n	Min	Max	Mean	SD
When you have been unable to travel independently due to inaccessible places	183	0	5	2,78	1,66
When you have not been invited to social activities as much as you used to be	180	0	5	2,01	1,64
When you have been carried up or down stairs	183	0	5	2,74	1,56
When people have tried to help, but have made things more difficult	183	0	5	2,65	1,48
When private issues have been made public to doctors, nurses, family, friends	182	0	5	1,86	1,70
When you have used a taxi service	181	0	5	1,91	1,37
When your disability has affected your relationships/friendships	181	0	5	2,49	1,43
When you have had to deal with carers or helpers	182	0	5	2,28	1,55
When you have not been able to do some activities you used to enjoy	182	0	6	3,19	1,52
When others have not recognised your sexual identity or sexual desires	178	0	5	1,93	1,73
When you have had to rely on others for help	182	0	5	2,48	1,34
When your disability affected the development of intimate or sexual relationships	179	0	5	2,26	1,85
When you have had to manage a number of health care needs	181	0	5	2,74	1,65
When you have arrived at a place that has stairs, but has no ramps or elevators	182	0	5	3,43	1,45
When you have been unable to physically help with manual jobs	178	0	5	3,11	1,40
When others have seen you as a person in a wheelchair before they have seen the person you really are	180	0	5	2,75	1,49
When you have been unable to physically move the way you used to move	180	0	5	3,11	1,49
When your health care needs have required time and energy	178	0	5	3,07	1,45
When you felt there was nothing you could do to change things	179	0	6	3,03	1,58
When others have not considered your needs or abilities	180	0	6	2,70	1,32
When you have been unable to physically help others when they need it	179	0	5	3,51	1,41
When you have been told a place is accessible, but it is not	179	0	5	3,50	1,58
Total score	173	0	101	59,69	19,49

5.10 Correlations between LTPA, IPAQ, LiSat-9 and PDSS

There was no significant correlation found between physical activity and disability related stress levels. A small positive correlation was found between physical activity and life satisfaction and a medium negative correlation was seen between disability related stress levels and life satisfaction. As mentioned in Chapter 5.6, a medium correlation was found between the IPAQ and the LTPA.

Table 14: Correlations between LTPA, IPAQ, LiSat-9 and PDSS

Variables	**Mean**	**SD**	**1**	**2**	**3**	**4**
1. PDSS	59,7	19,5	-			
2. LTPA	1,9	0,9	-0,049	-		
3. IPAQ	150,5	271	0,036	0,422**	-	
4. LiSat-9	2,3	0,91	-0,343	0,147*	0,032*	-

*Correlation is significant at the 0.05 level (2-tailed)
**Correlation is significant at the 0.01 level (2-tailed)

The correlations are interpreted by the guidelines presented by Pallant (2010), see Chapter 4.5.

6.0 Discussion

The aim of the present study was, first, to explore the levels of physical activity in a sample of persons with motor complete SCI. Secondly to investigate the correlation between the amounts of physical activity performed and the levels of disability related stress experienced by the participants. The third aim was to investigate the factors that could influence how persons with motor complete SCI cope with the disability related stress experienced. The discussion includes a discussion of the method and of the results, focusing on the research questions in the perspective of the theoretical foundation. Significant and non-significant differences, with clinical relevance are addressed.

The primary finding of the present study was that persons with motor complete SCI reported low levels of physical activity. The participants reported lower levels of physical activity than persons in the general population. The secondary finding of the study was that a small positive correlation was found between physical activity and life satisfaction. No significant correlation was found between physical activity and disability related stress.

As for which factors are associated with coping with disability related stress a significant difference was found between tetraplegics and paraplegics, where paraplegics had a lower mean-VAS score. A significant difference was also found between those who indicated experiencing bodily pain and those who did not, where those who indicated experiencing bodily pain had a lower mean VAS-score.

6.1 Discussion of the results regarding research question 1

What are the levels of physical activity among people with motor complete spinal cord injury (ASIA A or B)?

The IPAQ results in Table 4 shows that the mean physical activity level of the participants is 150,51 minutes of total PA per week with a standard deviation of 271 minutes. In MET-minutes this equals 2275, with a SD of 2819. The LTPA showed that 35,1 % of the respondents can be considered to have an inactive lifestyle. Both these questionnaires revealed the level of physical activity among persons with motor complete SCI to be low compared to the general population. The correlation between the IPAQ and the LTPA was of medium strength (. 422, p= .001) according to guidelines how to determine the strength of a relationship by Pallant (2010, p. 134). Considering the fact that the IPAQ and the LTPA both measure physical activity subjectively, but do not measure physical activity within the same timeframe and do not use the same measuring units- a strong correlation is not necessarily expected. The IPAQ required the participants to report physical activity measured in minutes, hours or days during the past seven days, not defining if the physical activity took place during work or leisure time. The LTPA asks for physical activity during the participant's leisure time, asking the participants to consider a mean value during the past year.

Anderssen & Andersen (2004) found that looking at the general population, the total MET measured in hours per week was 89,9 for men and 59,5 for women. This equals 5389 MET minutes and 3569 MET minutes per week. In comparison with the present study the participants in Anderssen & Andersen's study were more physically active. In a mapping of physical activity and fitness in the adult population in Norway (Stokke, 2010) participants answered the LTPA questionnaire and 17 % of the women and 20 % of the men report an inactive lifestyle on their leisure time as opposed to 35,1 % of the participants in the present study. The findings of the present study are not unexpected considering the physical, psychological and environmental barriers to being physically active experienced by persons with SCI. The low levels of PA reported also correspond with previous studies that report low levels of physical activity and physical capacity in persons with SCI (Haisma et al., 2006; Martin Ginis et al., 2010b; Saebu & Sorensen, 2010).

In the study by Saebu and Sorensen (2010) it was found that the average weekly physical activity as measured by the IPAQ was 1595 MET minutes per week for both genders. In comparison with their study the participants in the present study are more active, with a mean of 2275 MET minutes per week. Saebu & Sorensens population was larger than in the present study, included other types of disabilities besides SCI and the average age of the participants was younger. A study on persons with incomplete SCI (Lannem, in press) also measured physical activity level of the participants by the IPAQ, but since the IPAQ numbers were highly skewed towards zero, these were not used in the final analysis. The physical activity scores measured by the IPAQ of the present study were also strongly skewed towards zero, and standard deviations (SD) were in some cases more than double of the mean scores. This means that the assumptions of statistical tests conducted may have been violated. When comparing the mean LTPA score from the present study to a study on persons with incomplete SCI (Lannem, in press) the mean score found among the persons with incomplete SCI was 2,3 (SD= 0,9) as opposed to a score of 1,9 (SD= 0,87) in the present study.

Even though data from the present study indicate that persons with motor complete SCI are less physically active than persons without disabilities this does not mean that they are inactive in their lifestyle. If their level of function is low, as might be the case with a high cervical SCI they may not consider activities they do as physical activity because they see it more as ADL than actual exercise (Lannem et al., 2009). 58,9 % of the respondents in the present study are currently working and travelling to and from work or school, all activities during a working day and the sum of all ADL would for some, give enough exercise to maintain a healthy life.

Traditionally people with disabilities have been encouraged to be physically active with the goal of rehabilitation as a focus. Sports and especially competitive sports have been seen as an arena that is not suitable for people with disabilities (Wickman, 2008). In the present study only 6,5 % of the participants indicated that they take part in competitive sports or vigorous physical activity. Adapted physical activity is today recognized as an important part of the rehabilitation after SCI and is necessary not only the first period after injury, but also in the years to come. Looking at the physical activity patterns of Norwegians, walking is the most popular activity. More than two out of three Norwegians list walking as an activity they perform. Other popular activities are biking, skiing, swimming, jogging and strength exercises (SSB, 2009). Persons with SCI may have difficulties participating in several of these activities, especially during wintertime. Activities such as biking and skiing require adapted equipment and possibly expertise from adapted physical activity specialists or other health professionals.

It is not certain whether the reported time spent doing physical activity in the present study is actually correct. The participants may have a desire to be more active than they actually are and may over report their levels when answering the items of the questionnaires. The results from the present study show that is important to make sure that persons with SCI receive adequate information on sports and opportunities to engage in physical activity whilst in hospital and following discharge through outpatient clinics and community settings. In the present study only 14,5 % of the participants take part in organized physical activity.

In the present study it has been found that 41,6 % persons with motor complete SCI reported having physical therapy. Of those going to physical therapy only 38 % do active exercises or a combination of active exercises and other treatments. Physical therapy may be an opportunity to be physically active for persons with difficulties getting involved in organized physical activities. It is surprising that so few of the participants have physical therapy, but seeing as the average age at time of injury is 25,9 years and average age of the participants now is 50,7 years, it may suggest that the participants no longer are in a rehabilitation-setting and may have decreased or ended their physical therapy.

Looking at physical activity for persons with motor complete SCI, it may be discussed at all levels of the ICF model- body function and structures, activities and participation. The ICF definition of participation contains the concept of "involvement," which can mean to take part, be included or engaged in an area of life, being accepted, or having access to needed resources (WHO, 2001). The impact of personal aspects, such as individual interests and lifestyle, are recognized but not classified. To be able to participate in family and community life, taking part in normal roles and responsibilities, and being an active member of society as a whole is important for everyone (WHO, 2001). When starting the rehabilitation phase after a SCI, physical activity and exercise are used from a medical point of view to help rebuild the body. The physical activity helps the person with SCI to regain function and this creates possibilities for activity and increase participation. According to Lannem et al., (2010) the physical reserve capacity for persons with incomplete SCI may be insufficient for exercise activities, in addition to the physical demands of their everyday life. When adding exercise to their activities this may lead to a feeling of exhaustion and a loss of motivation for further exercise. The findings from the present study considering physical activity levels, participation in organized sports and frequency of physical therapy may suggest that also persons with complete injuries meet these same obstacles when trying to make room for physical activity in their everyday lives.

The most important finding considering physical activity in the present thesis was that physical activity had a small positive correlation to life satisfaction. This was demonstrated through a positive correlation between both the IPAQ and the LTPA, and the LiSat-9 scale. This result is supported by earlier findings showing increased life satisfaction for persons with incomplete SCI who exercise (Lannem et al., 2009). Physical activity can through its correlation to life satisfaction be seen as a positive resource for persons with SCI. Looking back to CATS, life satisfaction can be identified as one of the long-term outcomes that result from a person´s ability to cope with the stressors of life with a SCI. CATS explains how physical activity is one way of enhancing a person´s resources. Through being physically active a person with SCI can restore or maintain physical function, improve psychological variables and build social resources. When building these resources, there is a possibility of coping or not managing to cope with the situation. If coping is achieved this may lead to a better physical and psychological health.

6.2 Discussion of the results regarding research question 2

Is there a correlation between the amount of physical activity performed and the levels of disability related stress experienced?

The present study did not show any significant correlation between levels of disability related stress and the amount of physical activity performed. It may seem, as the respondents are quite homogenous group when it comes to their answers on disability related stress. This means that their opinions of which situations they experience as stressful are similar. On the other hand their physical activity levels are less homogenous, there is a great gap between the least and the most active respondent. No significant difference in PDSS was found between the subgroups tetraplegics and paraplegics. This finding is consistent with a study on persons with functionally incomplete SCI by Lannem (in press). Contrary to the present study, Lannem found a correlation between LTPA and stress where the mediating effects of both LTPA and the degree of coping seemed to buffer the negative effects due to stress.

In the present study no significant difference was found between genders with regard to disability related stress levels. A significant difference was found between those who indicated experiencing bodily pain and those who did not, where those who experienced bodily pain had a higher mean PDSS score. Considering that persistent pain is one of the consequences of SCI that has frequently been shown to significantly decrease perceived quality of life and to interfere with cognitive, emotional, and physical health and functioning (Murray et al., 2007) it is not surprising that stress levels are higher among participants who experience bodily pain. Looking back to CATS the finding that persons who experience bodily pain have higher stress levels can be explained both by how pain affects the individual´s opportunities to take part in exercise and how pain itself can cause a physical reaction in the body, causing more stress and thereby negative consequences for the long term health outcome.

Comparing the mean PDSS score of the present study to a study by Lannem (in press) on persons with incomplete SCI, the mean score of the participants in the present study was higher. Lannem et al. reported a mean PDSS score of 38,6 (SD= 23,1) among participants as opposed to a mean score of 59,69 (SD=19,25) among the participants of the present study. It is possible that the persons with motor complete SCI indicate experience more disability related stress because they have not been able to adjust factors in life such as working hours or adaptive aids to their situation. The restrictions and obstacles perceived in daily living for persons with motor complete SCI might be larger than for those with incomplete injuries who need less adaptive aids and be more mobile. Another factor that may influence this difference is the number of years the person has lived with the SCI. In the present study the mean duration of injury was 25 years as opposed to 15 years among the persons with incomplete SCI. When having lived with a SCI for many years, the physical tear on the body may start to have a negative health effect and cause a higher level of disability related stress.

According to Elnan (2010), Rimmer (2005) and Sørensen & Kahrs (2006) environmental factors can be seen as limiting for physical activity among people with disabilities. Especially facilities that are not accessible can be experienced as barriers. In the present study this was confirmed, as one of the items rated most stressful for the participants by the PDSS was an item regarding accessibility. Looking back to the ICF model presented in Chapter 2.5 and the persons functional abilities in relation to the surroundings they are living in, it is clear that a lack of accessibility in the physical surroundings can affect functional abilities and hence also the general health. Participants in the present study also rated “not been able to do activities you used to enjoy” and “ being unable to physically help others when they need it” as two of the most stressful items which can be seen in relation to the social participation.

6.3 Discussion of the results regarding research question 3

Which factors influence the individuals coping with disability-related stress?

When comparing the mean scores of self indicated level of coping a significant difference was found between injury levels with regard to coping, where paraplegics had a lower mean-VAS score. A significant difference was also found between those who indicate experiencing bodily pain and those who did not, where those who indicated experiencing bodily pain had a lower mean VAS-score.

Looking at the mean scores of coping of persons with incomplete SCI (Lannem, in press) in comparison to the mean coping scores of the present study, the results are similar. Persons with motor complete SCI probably have lower expectations concerning recovery of function in comparison to those with incomplete injuries. It is acknowledged that the neurologic prognosis for the individual who sustains a complete traumatic SCI is poor, with limited expectations for motor or sensory recovery (Fisher, 2005). Knowing that the prognosis are low for being able to walk again may affect the outcome expectancies of physical activity for the participants and hence how they cope with this consequence. In terms of CATS, coping is "positive outcome expectancies". For persons with motor complete SCI the outcome expectancies to restore function through physical exercise, may fail if the expectancies are too high or unrealistic. According to CATS the result may be the same if the expectancies were negative, meaning this ends up as helplessness or hopelessness. This could affect the health negatively.

According to Lannem & Sørensen (in review) persons living with an incomplete SCI need to make choices in order to balance the physical demands of everyday life and improve coping with the consequences of their disability. These choices may be reducing work hours, using adaptive aids, receiving help at home or other practical adjustments. According to Lannem & Sørensen, 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. On the other hand if the physical demands in everyday life are more than the person's total physical capacity, these resources may be overloaded. Considering the fact that paraplegics had a lower mean-VAS score of coping compared to tetraplegics in the present study, it is possible that the paraplegics indicate poorer coping due to physical demands of everyday life being higher. With a lower injury, there are more opportunities for being physically active and working, which may cause an overload for the person. It is also possible that persons with higher injuries have accepted their situation to a larger degree than those with low injuries. This acceptance may lead to a better strategy of coping.

Ursin (1998) argued that the most significant reason for a decrease in the stress response is that the person has learned something about the situation, because acquiring expectancies necessitates learning (Ursin & Eriksen, 2010). In other words, individual differences in outcome expectancies are conceptualized as originating from differences in learning experiences (Ursin & Eriksen, 2004). Learning may provide a reduction in insecurity and expectations for future outcomes of stressful encounters, whether they are positive expectancies of coping or negative expectancies. It may be that having lived with their SCI for many years, the participants of the present study have learned to handle the consequences of a SCI and have improved their coping skills. As shown by CATS, when persons develop an effective way of coping with stress, their psychological and physiological reactions tend to involve only short-term arousal. Whereas, when persons engage in psychological defense or have an inability to cope with stressors, their activation levels are sustained, and the impact of the stressful situation is prolonged (Ursin, 2000). Since a complete SCI is a definite diagnosis it may be that the participants have managed to develop acceptance and good coping techniques and strategies for living with their SCI.

Looking back to the ICF model, research question 3 can be seen in connection with all levels in Figure 2, page 17. In any health problems, all levels are involved and the level of participation is in focus with regard to social activity and participation in society. With time, most individuals with motor complete SCI seem to adapt to their new body and the lifestyle it inflicts. The effect of this adaptation can influence the perception of burden and coping perspectives. Through the years after the injury, most persons with SCI face extra challenges that require new adaptations for coping.

6.4 Design of the study

In order to find answers to the research questions in Chapter 1, a questionnaire administered via post was chosen. Self-reporting, such as responding to mailed questionnaires is one of the most applied research methods for measuring physical activity (Sallis & Saelens, 2000).

There are strengths and weaknesses to this method that need to be considered. Through questionnaires one can collect and assess data from many persons in short time due to the relatively low costs of administration. It is possible to investigate multiple dimensions to physical activity through combinations of different questionnaires; this was done in the present study and was considered important when trying to get an overview of the whole picture.

One may consider whether a survey was the best way of answering the research questions presented in Chapter 1. The present survey could have been followed by a structured interview or a clinical examination of a group of participants, to verify some of the self-reported findings. The questionnaires used in the present study could possibly have been administered via e-mail instead. For persons with SCI who have access to a computer, possibly with assistive devices, answering a questionnaire online could be a better solution. This could also have decreased the number of non-respondents. A study by Goldner (2006) showed that people with disabilities or chronic illness were more likely to use the internet to access health information and contact their physician through e-mail than respondents who reported themselves as being in excellent or good health. This may indicate that there could also be a possibility of collecting information from participants through the Internet, as long as patient confidentiality is kept. For the present study the option of collecting information through the Internet was denied by the Regional Committee for Medical and Health Research Ethics in Norway.

In the present study subjective measurement tools were used to assess the levels of physical activity among the participants. If an objective measurement tool had been chosen instead this may have given more precise results on physical activity levels. Objective measurement tools measuring physical activity do not have the same limitations one can find in self-reported methods. By using objective tools researchers can get a more standardized description of behaviours, frequency, intensity and duration (Matthews, 2005). One way of measuring physical activity objectively could be the use of an accelerometer. Recent reports indicating that objective measures provide greater precision in comparison to self-report suggests that accelerometers have the potential to substantially reduce sample sizes in physical activity studies while retaining statistical power (Matthews et al., 2002).

6.5 Participants

The participants were located through a journal search at Sunnaas rehabilitation hospital and were found to meet the inclusion criteria. In addition to this they reported details on injury level, age and age at injury when filling out the questionnaire. If details from the questionnaire did not match the information from the journal this was discovered and corrected. As described in chapter 4, an upper limit for the age at injury was set at 60 years in order to minimize bias from normal health changes with increasing age. The age of the included respondents ranged from 19-75 with a mean age of 50,7 years. The distribution between tetraplegia and paraplegia in the study group was 66 % paraplegics and 33,5 % tetraplegics.

When using questionnaires, there is always a risk that the questions are misunderstood or interpreted differently by different respondents. The researchers and respondents need to have a mutual understanding of the concepts described in the questionnaires. It is possible that the persons who decided to take part in the present study are more interested in and more knowledgeable about physical activity than those who chose not to participate. One can therefore question whether the participants are more physically active than the non-respondents. One aspect that also needs to be considered is that some of the participants needed assistance in filling out the questionnaire. When having to answer questions on for example life satisfaction it may influence the response if the participant knows that a family member or friend will know his or her feelings.

It is possible that social desirability or in general a desire to be seen as more physically active than in reality, could lead to participants over reporting their activity levels. Response bias is possible with any self-reported behaviours, especially when individuals are reporting personal information. In this study participants were guaranteed anonymity and confidentiality, which was intended to decrease bias and increase response validity. Another issue affecting the results could be the participant’s ability to remember past activity. It can be challenging for adults or elderly to remember how physically active they were in their childhood and adolescence. This was also indicated by some of the participants by adding comments to their questionnaires. Some participants who were injured in their childhood chose not to answer questions about activity prior to their injury.

Another limitation is the number of respondents, the 44 % of recipients that did not reply to the questionnaire are unknown, and this may limit the generalisation. The non-respondents could not be described due to ethical regulations. There is a possibility that those with a more severe impairment or more complications are less likely to participate in such a study especially when the topic of the questionnaire is physical activity. To minimize the dropout rate of the respondents, two written reminders were sent out, and the response rate of the present study (56%) was satisfactory.

It is possible that some participants may have misunderstood certain items of the IPAQ. The question about how many minutes spent rolling from one place to another in a manual wheelchair per day gave some registrations that were unusually high. One example of this is the highest reported number of minutes being 960. This would mean 16 hours of rolling the wheelchair on a normal day. There were also some missing data in the IPAQ. Some of the participants would indicate how many days a week they were active, but not how many minutes on average they were active these days. Some participants also ticked the box for being active, not indicating with a number how many days a week they were active. With less missing data, the numbers may have been different concerning the levels of physical activity.

Overall the responses to the questionnaire given by the participants were positive. Those responding by phone could add comments to their answers verbally and those answering in writing could add comments at the end of the questionnaire. Some participants expressed that certain questions were too personal and not relevant for the purpose of the present study. One participant added an extra letter with information about living with a SCI.

6.6 Missing data

Not all participants answered all questions and some questions in the IPAQ were answered with a tick of a box, instead of a number of minutes. Some participants answered how many days they were active, but not how many minutes. When data is missing the participants activity level was recorded as “missing” and when calculating the total physical activity these participants was not taken into consideration. The reasons for missing data may vary; it is possible that some participants misunderstood how to report their numbers. Some may have deliberately chosen not to answer certain questions or not answered because they were not active at all.

6.7 Recommendations for future research

For future research it might be useful to use objective measurement tools for physical activity among persons with motor complete spinal cord injury. The questionnaires used in the present study seemed not to capture the variance of physical activity due to a great number of participants being more or less inactive. Alternately a questionnaire more appropriate and adapted for people with disabilities could be used in a similar study setting. It would be interesting to look closer to what reasons persons with motor complete SCI have for not being active and which barriers exist for participation. It could be recommended to conduct an in depth interview about stress, coping and life satisfaction in order to capture nuances and opinions not surfacing through the use of questionnaires.

7.0 Conclusion

The present thesis highlights the complexity of the relationship between physical activity, disability related stress, coping and life satisfaction for persons with motor complete SCI. The findings are important in a clinical context, both during the process of rehabilitation and later in life. The findings from the present study were that persons with motor complete SCI have in general low levels of physical activity with large variations between the least active and the most active. The participants in the present study were less physically active than the general population. No correlation was found between disability related stress and physical activity, but a small positive correlation was found between life satisfaction and physical activity. In a health-stress perspective persons with SCI would have a lot to gain from being physically active as physical activity plays a positive role in life satisfaction.

Further studies are recommended to investigate the connection between physical activity and aspects of health in persons with motor complete SCI. It would be interesting to look closer at what type, intensity, and amount of physical activity that should be recommended for this population. It would be especially interesting to examine different levels of physical activity and influence on life satisfaction more closely, possibly by carrying out an intervention study. In order to obtain a better understanding of physical activity behavior and activity levels among persons with motor complete SCI studies should be carried out using a combination of objective and subjective measurements of physical activity.

The findings of the present study cannot be generalized to include the entire population of persons with motor complete SCI in Norway as the study group is small and the participants have not been located randomly.

References

Aires, N., Selmer, R., & Thelle, D. (2003). The validity of self-reported leisure time physical activity, and its relationship to serum cholesterol, blood pressure and body mass index. A population based study of 332,182 men and women aged 40-42 years. *European Journal of Epidemiology, 18(6),* 479-485.

Anderssen, S. & Andersen, L. B. (2004). *Fysisk aktivitetsnivå i Norge 2003: data basert på spørreskjemaet "International Physical Activity Questionnaire".* Oslo: Helsedirektoratet.

Anderssen, S. (2009). *Fysisk aktivitet blant voksne og eldre i Norge: resultater fra en kartlegging i 2008 og 2009.* Oslo: Helsedirektoratet.

Buchholz, A. C., McGillivray, C. F., & Pencharz, P. B. (2003). Physical activity levels are low in free-living adults with chronic paraplegia. *Obesity Research, 11(4),* 563-570.

Caspersen, C.J., Powell, K. E., Christenson, G.M. (1985). Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Reports, *100 (2),* 126-131.

Craig, C. L., Marshall, A. L., Sjostrom, M., Bauman, A. E., Booth, M. L., Ainsworth, B. E. et al. (2003). International physical activity questionnaire: 12-country reliability and validity. *Medicine and Science in Sports and Exercise, 35,* 1381-1395.

Dahlberg A., Kotila M., Leppänen P. et al. (2005). Prevalence of spinal cord injury in Helsinki. *Spinal Cord*; *43*: 47–50.

DeVivo M.J. (2012) Epidemiology of traumatic spinal cord injury: trends and future implications. *Spinal Cord*; *50 (5):* 365-72.

Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist, 55*, 34-43.

Ditor D.S, Latimer A.E., Ginis K.A., Arbour K.P., McCartney N., Hicks A.L. (2003). Maintenance of exercise participation in individuals with spinal cord injury: effects on quality of life, stress and pain. *Spinal Cord; 41*: 446–50

Edwards, S., Ngcobo, H., Edwards, D., & Palavar, K. (2005). Exploring the relationship between Physical Activity, Psychological well-being and Physical self-perception in different exercise groups. *South African Journal for Research in Sport, Physical Education & Recreation, 27,* 75-90.

Edwards, S. (2006). Physical Exercise and Psychological well-being. *South African Journal of Psychology, 36,* 357-373. *Motivation and Personality Effects on Exercise/95*

Elnan, I. (2010). Idrett for alle? Studie av funksjonshemmedes idrettdeltakelse og fysisk aktivitet. NTNU Samfunnsforskning AS. Senter for idrettsforskning.

Fisher C.G. (2005). Motor Recovery, Functional Status, and Health-Related Quality of Life in Patients With Complete Spinal Cord Injuries.

Folkman, S., & Lazarus, R. S. (1985) If it changes it must be a process: Study of emotion and coping during three stages of college examination. *Journal of Personality and Social Psychology, 48*: 150-170.

Frankel H.L, Hancock D., Hyslop G., Melzak J., Michaelis L.S., Ungar G.H., Vernon J.D.S., & Walsh J.J. (1969). The value of posteral reduction in the initial management of closed injuries of the spine with paraplegia and tetraplegia. *Paraplegia, 7,* 179-192.

Fugl-Meyer AR., Eklund M., & Fugl-Meyer K.S. (1991). Vocational rehabilitation in northern Sweden. III. Aspects of life satisfaction. *Scandinavian Journal of Rehabilitation Medicine, 23(2),* 83-87.

Fugl-Meyer AR., Melin R., Fugl-Meyer K.S. (2002). Life satisfaction in 18- to 64-year-old Swedes: in relation to gender, age, partner and immigrant status. *J Rehabil Med*; *34:* 23946.

Furlong, M., & Connor, J. P. (2007). The measurement of disability-related stress in wheelchair users. *Archives of Physical Medicine and Rehabilitation, 88(10),* 1260-1267.

Garshick E., Kelley A., Cohen S.A., Garrison A.,Tun C.G.,Gagnon D., Brown R. (2005). A prospective assessment of mortality in chronic spinal cord injury. *Spinal Cord*. July; *43(7):* 408–416.

Gerhart K.A., Weitzenkamp D.A, Kennedy P., Glass C.A., Charlifue S.W. (1999). Correlates of stress in long-term spinal cord injury. *Spinal Cord*; *37(3):* 183–90.

Gjerset A. (1992). *Idrettens treningslære*. Oslo: Universitetsforlaget.

Goldner. M. (2006). Using the Internet and email for health purposes: the impact of health status. *Soc Sci Q*, *87* pp. 690–710.

Graff-Iversen, S., Anderssen, S. A., Holme, I. M., Jenum, A. K., & Raastad, T. (2008). Two short questionnaires on leisure-time physical activity compared with serum lipids, anthropometric measurements and aerobic power in a suburban population from Oslo, Norway. *European Journal of Epidemiology, 23(3),* 167-174.

Graham, R., Kremer, J., & Wheeler, G. (2008). Physical Exercise and Psychological Weil-Being among People with Chronic Illness and Disability: A Grounded Approach. *Journal of Health Psychology, 73*,447-458.

Gregory, C.M. et al. (2003). Human and rat skeletal muscle adaptations to spinal cord injury. Can. J. *Appl.Physiol. 28(3*): p. 491-500.

Hagen E.M., Rekand, T., Gilhus, N.E., Grønning, M. (2012). Traumatiske ryggmargsskader – forekomst, skademekanismer og forløp. *Tidsskr Nor Legeforen* nr. *7*; 132: 831–7.

Haisma J.A., Bussmann J.B., Stam H.J., Sluis T.A., Bergen M.P., Dallmeijer A.J., et al. (2006). Changes in physical capacity during and after inpatient rehabilitation in subjects with a spinal cord injury. *Arch Phys Med Rehabil*; *87:* 741–748.

Haskell, W. L., Bouchard, C., & Blair, S. N. (2007). *Physical activity and health.* Champaign, Ill.: Human Kinetics.

Haskell, W., Blair, S., & Hill, J. (2009). Physical activity: Health outcomes and importance for public health policy. *Preventive Medicine, 49,* 280-282.

Hellevik O. (2000). *Forskningsmetode i sosiologi og statsvitenskap.* (2 ed.) Universitetsforlaget, Oslo.

Henderson K.A., Bedini L.A. (1995). 'I have a soul that dances like Tina Turner, but my body can't': Physical activity and women with mobility impairments. *Research Quarterly for Exercise and Sport*; *66:*151 – 161.

Hicks, A. L., Martin K. A., Ditor D. S. et al. (2003). Long-term exercise training in persons with spinal cord injury: effects on strength, arm ergometry performance and psychological well-being. *Spinal Cord, 41*:34–43.

Hillsdon, M., & Thorogood, M. (1996). A systematic review of physical activity promotion strategies. *British Journal of Sports Medicine*, *30*, 84–89.

Hitzig, S.L., Campbell, K.A., McGillivray, C.F., Boschen, K.A., and Craven, B.C. (2010). Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. *Spinal Cord*, *48(4):* 330–335.

Hjeltnes, N. (2004). Ryggmargsskader. I: Wekre, L.L. & Vardeberg, K. red. *Lærebok i rehabilitering: når livet blir annerledes.* Bergen, Fagbokforlaget, s. 149-166.

Hjeltnes, N. (2008). Ryggmargsskade. In R.Bahr (Ed.), *Aktivitetshåndboken. Fysisk aktivitet i forebygging og behandling* (pp. 537-547). Oslo: Helsedirektoratet.

Ingebrigtsen J. E. og Aspvik N. P. (2010). Barns idrettsdeltagelse i Norge - litteraturstudie av barn i idretten. Trondheim: Senter for Idrettsforskning, NTNU Samfunnsforskning AS.

Jansson, E. & Anderssen, S. (2008). Generelle anbefalinger om fysisk aktivitet. In R.Bahr (Ed.), *Aktivitetshåndboken. Fysisk aktivitet i forebygging og behandling* (pp. 37-45). Oslo: Helsedirektoratet.

Jørgensen S., Lexell, J., Iwarsson, S., Mårtensson L. (2002). Life satisfaction in Swedish men and women aging with a spinal cord injury. Conference abstract. 73rd Annual Assembly of the American Academy of Physical Medicine and Rehabilitation (AAPM&R). Atlanta, USA.

Kala, M. F., C, Hanley H., Watson K., Hicks A.L., McCartney N. (2002). Sustaining exercise motivation and participation among people with spinal cord injuries – Lessons learned from a 9-month intervention. *Palaestra*; *18*:38.

Kennedy P., Duff J., Evans M., Beedie A. (2003). Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *Br J Clin Psychol Med Settings*; *12*: 93–98.

Kennedy P., Lude P., Taylor N. (2006). Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. *Spinal Cord*; 44: 95–105.

Kennedy, P., Smithson, E., McClelland, M., Short, D., Royle, J., & Wilson, C. (2010). Life satisfaction, appraisals and functional outcomes in spinal cord-injured people living in the community. *Spinal Cord, 48(2),* 144-148.

Kirshblum, S.C., Burns, S.P., Biering–Sorensen, F., Donovan, W., Graves, D.E., Jha, A., Johansen, M., Jones, L., Krassioukov, A., Mulcahey, M.J., Schmidt–Read, M., and Waring, W. (2011). International standards for neurological classification of spinal cord injury. J. *Spinal Cord Med. 34,* 535–546.

Kompetansesenter for IT i helse- og sosialsektoren (KITH). (2010). ICF. Retrieved from: http://www.kith.no/templates/kith_WebPage____1897.aspx

Kostovski, E. (2012). Muscle metabolism, diurnal androgenic axis activity and hemostatic regulation of importance to health after cervical spinal cord injuries. Doctoral dissertation. Faculty of Medicine. University of Oslo.

Kurtzke JF. (1977). Epidemiology of spinal cord injury. *Neurol Neurocir Psiquiatr*; *18* (suppl): 157–91.

Lannem, A. M. (2003). *Incomplete spinal cord injuries, exercise habits and aspects of health.* Master thesis. Norwegian School of Sport Sciences, Oslo.

Lannem, A. M., & Sørensen, M. (2007). Spinal cord injury, health and life satisfaction: Associations between aerobic capacity and self-reports. *Program and abstracts. 46th ISCOS annual scientific meeting, 10th NOSCOS congress 27-30 June 2007, Reykjavík, Iceland* (pp. 121).

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

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

Lannem, A.M. (2011). The role of physical exercise as a stress-coping resource for persons with functionally incomplete spinal cord injury. Doctoral dissertation, Norwegian School of Sport Sciences.

Lannem, A.M. (in press). Physical exercise, stress, coping, burnout and fatigue in persons with incomplete spinal cord injury (SCI). *European Journal of Adapted Physical Activity.*

Lannem, A.M., & Sorensen, M. (in review) The role of physical exercise, perceived exercise mastery, and stress in persons with incomplete spinal cord injury (SCI).

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Lidal I.B., Snekkevik H., Aamodt G., Hjeltnes N., et al. (2007). Mortality after spinal cord injury in Norway. *Journal of Rehabilitation Medicine 39*(2):145-51.

Livneh, H. (2000). Psychosocial adaptation to spinal cord injury: The role of coping strategies. *Journal of Applied Rehabilitation Counseling*, *31*(2), 3–10.

Maher E.J., Kinne S., Patrik D.L. (1999). 'Finding a good thing': the use of quantitative and qualitative methods to evaluate an exercise class and promote exercise for adults with mobility impairments. *Disability and Rehabilitation* ;*21*:438 – 447.

Marino, R.J., Barros, T., Biering-Sorensen, F., Burns, S.P., Donovan, W.H., Graves, D.E. et al. (2003). International standards for neurological classification of spinal cord injury. *J Spinal Cord Med*, *26,* Suppl 1, 50-56.

Martin Ginis K.A, Latimer A.E, Hicks A.L, Craven B.C. (2005). Development and evaluation of an activity measure for people with spinal cord injury. *Med Sci Sports Exerc.*;*37 (7):*1099-1111.

Martin Ginis, K. A., Arbour-Nicitopoulos, K. P., Latimer, A. E., Buchholz, A. C., Bray, S. R., Craven, B. C. et al. (2010a). Leisure time physical activity in a population-based sample of people with spinal cord injury part II: activity types, intensities, and durations. *Archives of Physical Medicine and Rehabilitation, 91(5),* 729-733.

Martin Ginis, K. A., Latimer, A. E., Arbour-Nicitopoulos, K. P., Buchholz, A. C., Bray, S. R., Craven, B. C. et al. (2010b). Leisure time physical activity in a population-based sample of people with spinal cord injury part I: demographic and injury-related correlates. *Archives of Physical Medicine and Rehabilitation, 91(5),* 722-728.

Martin Ginis K.A., Hicks A.L, Latimer A.E, Warburton D.E.R, Bourne C., Ditor D.S., Goodwin D.L., Hayes K.C., McCartney N., McIlraith A., Pomerleau P., Smith K., Stone J.A., Wolfe D.L. (2011). The Development of Physical Activity Guidelines for Adults with SCI. *Spinal Cord.* Nov;*49(11):*1088-96.

Mason, J.W., (1968). A review of psychoendocrine research on the pituitary-adrenal cortical system. *Psychosom Med* 30, 576–607.

Matthews, C. E., Ainsworth B. E., Thompson R. W., and Bassett D. J. (2002). Sources of variance in daily physical activity levels as measured by an accelerometer. *Med. Sci. Sports Exerc. 34*:1376– 1381.

Matthews, C. E. (2005). Calibration of accelerometer output for adults. *Med.Sci.Sports Exerc.,* 37, S512-S522.

Mohr, T., Dela, F. Handberg A., Biering-Sorensen, F., Galbo H., and Kjaer M. (2001). Insulin action and long-term electrically induced training in individuals with spinal cord injuries. *Med. Sci. Sports Exerc. 33*:1247–1252.

Murray R.F., Asghari A., Egorov D.D., Rutkowski S.B., Siddall P.J., Soden R.J., Ruff R. (2007). Impact of spinal cord injury on self- perceived pre- and postmorbid cognitive, emotional and physical functioning. *Spinal Cord.* ; *45(6):* 429–36.

Maynard F.M., Bracken M.B., Creasey G., Ditunno J.F., Donovan W.H., Ducker T.B., Garber S.L., Marino R.J., Stover S.L., Tator C.H., Waters R.L., Wilberger J.E., & Young W. (1997). International Standards for Neurological and Functional Classification of Spinal Cord Injury. *Spinal Cord.*, *35*, 266-274.

Nash, M. S., Jacobs P. L., Mendez A. J., and Goldberg R. B. (2001). Circuit resistance training improves the atherogenic lipid profiles of persons with chronic paraplegia. *J. Spinal Cord Med. 24*:2–9.

Nash, M. S. (2005). Exercise as a health-promoting activity following spinal cord injury. *Journal of Neurologic Physical Therapy, 29(2),* 87-103, 106.

National Spinal Cord Injury Center (2011). University of Alabamba at Birmingham, 2010 Annual Statistical Report, March. Retrived from: https://www.nscisc.uab.edu

Noreau L., & Shephard R. (1992). Physical fitness and productive activity of paraplegics. *Sports Med., Training and Rehab*, *3,* 165-181.

Norrbrink Budh, C., & Osteraker, A. L. (2007). Life satisfaction in individuals with a spinal cord injury and pain. *Clinical Rehabilitation, 21(1),* 89-96.

Olle, M. M., Pivarnik J. M., Klish W. J., and Morrow J. R. (1993). Body composition of sedentary and physically active spinal cord injured individuals estimated from total body electrical conductivity. *Arch. Phys. Med. Rehabil. 74*:706–710.

Ommundsen Y., Aadland A.A. (2009). Fysisk inaktive i Norge. Hvem er inaktive - og hva motiverer til økt fysisk aktivitet? Helsedirektoratet. Retrieved from: http://www.helsedirektoratet.no/publikasjoner/fysisk-inaktive-voksne-i-norge-hvem-er-de-og-hva-motiverer-til-okt-fysisk-aktivitet/

Pallant, J. (2010). SPSS survival manual: A step by step guide to data analysis using SPSS (4th ed.). England: Open University Press McGraw-Hill Education.

Petty, W.E., Wegener, D.T., & Fabrigar, L.R. (1997). Attitudes and attitude change. *Annual Review of Psychology,* 48, 609-647.

Post M.W. (2010). Measuring the subjective appraisal of participation with life satisfaction measures: bridging the gap between participation and quality of life measurement. *Top Spinal Cord Inj Rehabil*; *15*: 1-15.

Post M.W., van Leeuwen C.M., van Koppenhagen C.F., de Groot S. (2012). Validity of the Life Satisfaction questions, the Life Satisfaction Questionnaire, and the Satisfaction With Life Scale in persons with spinal cord injury. *Arch Phys Med Rehabil*;93:1832-7.

Razdan S., Kaul R.L., Motta A. et al. (1994). Prevalence and pattern of major neurological disorders in rural Kashmir (India) in 1986. *Neuroepidemiology*; *13*: 113–9.

Richardson, C. R., Faulkner, G., McDevitt, J., Skrinar, G. S., Hutchinson, D. S., & Piette, J. D. (2005). Integrating physical activity into mental health services for persons with serious mental illness. *Psychiatric Services*, *56*(3), 324–331.

Rimmer, J. H., Braddock, D. and Pitetti K. H. (1996). Research on physical activity and disability: an emerging national priority. *Med. Sci. Sports Exerc. 28*:1366–1372.

Rimmer, J. H. (1999). Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Physical Therapy, 79(5),* 495-502.

Rimmer, J. H. (2005). The conspicuous absence of people with disabilities in public fitness and recreation facilities: lack of interest or lack of access? *Am.J.Health.Promot, 19,* 327-9, ii.

Rimmer, J.H. (2006). Use of the ICF in identifying factors that impact participation in physical activity/ rehabilitation among people with disabilities. *Disability & Rehabilitation*, *28 (17),* 1087-1095.

Rintala D.H., Hart K.A., Fuhrer M.J. (1996). Perceived stress in individuals with spinal cord injury. In: Krotoski D, Turk M, Nosek M, editors. Women with physical disabilities: Achieving and maintaining health and well being. Baltimore (MD): Paul H. Brookes; p. 223–42.

Sallis, J. F. & Saelens, B. E. (2000). Assessment of physical activity by self-report: status, limitations, and future directions. *Research Quarterly for Exercise and Sport, 71,* S1-14.

Saltin, B., & Grimby, G. (1968). Physiological analysis of middle-aged and old former athletes. Comparison with still active athletes of the same ages. *Circulation, 38(6),* 1104-1115.

Saebu, M. (2011). Unge voksne med funksjonshemming, fysisk aktivitet og motivasjon. Doctoral dissertation, Norwegian School of Sport Sciences.

Saebu, M. & Sorensen, M. (2010). Factors associated with physical activity among young adults with a disability. *Scandinavian Journal of Medicine and Science in Sports.*

Selye, H., (1950). Stress. Montreal, Acta, Inc.

Selye, H., (1974) Stress Without Distress. Philadelphia, JB Lippincott.

Shin, D.C., & Johnson, D.M. (1978). Avowed happiness as an overall assessment of quality of life. Social Indicators Research, *5*, 475-492.

Sköld C., Sternhag M. (2004). Traumatiske ryggmargsskader. In: Mæhlum S, Heiberg A, Fagerli A, Røe C, Skaug H, Morisbak I, et al., editors. Fysisk aktivitet for mennesker med funksjonsnedsettelser; Anbefalinger. Sosial- og Helsedirektoratet; 2004. p. 105-12.

SSB (2010). På like vilkår? Helse og levekår blant personer med nedsatt funksjonsevne. Retrieved from: http://www.ssb.no/a/publikasjoner/pdf/sa_115/sa_115.pdf

SSB (2009). Mosjon, friluftsliv og kulturaktiviteter. Resultater fra Levekårsundersøkelsene fra 1997 til 2007. Odd Frank Vaage. Retrieved from: http://www.ssb.no/a/publikasjoner/pdf/rapp_200915/rapp_200915.pdf

SSB (2012). Funksjonshemma på arbeidsmarknaden i 2012. Retrieved from: http://www.ssb.no/a/publikasjoner/pdf/rapp_201236/rapp_201236.pdf

Stokke, J. S. (2010). *Korrelater for fysisk aktivitet blant voksne med ulik utdanningsbakgrunn: en delstudie av prosjektet "Kartlegging aktivitet Norge (Kan1)"*. Norges idrettshøgskole, Oslo.

Søgaard, A. J., Bø, K., Klungland, M., & Jacobsen, B. K. (2002). En oversikt over norske studier: hvor mye beveger vi oss i fritiden? In *Fysisk aktivitet og helse: temahefte* Oslo.

Sørensen, M. & Kahrs, N. (2006). Integration of disability sport in the Norwegian sport organizations: lessons learned. *Adapt.Phys.Activ.Q., 23,* 184-202.

St.meld.nr.21 (1998-99) (1998). Ansvar og Meistring. Mot ein heilskapeleg rehabiliteringspolitikk Oslo: Sosial- og helsedepartementet.

Tasiemski, T., Kennedy, P., Gardner, B. P., & Taylor, N. (2005). The association of sports and physical recreation with life satisfaction in a community sample of people with spinal cord injuries. *NeuroRehabilitation., 20(4),* 253-265.

Thomas J.R & Nelson J.K (1996). Research methods in physical activity. (3 ed.) Human Kinetics.

Ude, H. & Sommerfelt, T. (2009). En utprøving av ICF på giktpasienter: en studie på Beitostølen helsesportsenter. UIO, Oslo.

Ursin, H., Baade, E., & Levine, S. (1978). *Psychobiology of stress: A study of coping men.* New York: Academic Press.

Ursin, H., (1998) The psychology in psychoneuroendocrinology. *Psychoneuroendocrinology*. *23*, 555–570.

Ursin, H. (2000) Psychosomatic medicine: State of the art. *Annals of Medicine,* 32: 323-328.

Ursin, H. & Eriksen, H. R. (2004). The cognitive activation theory of stress. *Psychoneuroendocrinology, 29,* 567-592.

Ursin, H. & Eriksen, H. R. (2010). Cognitve activation theory of stress (CATS). Neuroscience and Biobehavioral Reviews, *34*: 877-881.

Van der Ploeg H.P, Streppel K.R, van der Beek A.J., van der Woude L.H., Vollenbroek-Hutten M, van Mechelen W. (2007). The Physical activity scale for individuals with physical disabilities: test-retest reliability and comparison with an accelerometer. J Phys Act Health. ; *4(1):* 96-100.

Van Leeuwen C, Post M., van Asbeck F., Bongers-Janssen H., van der Woude L., Groot S., Lindeman E. (2012). *Disability & Rehabilitation*; *34(1):* 76–83.

Vissers MB-ER, Sluis T, Bergen M, Stam H, Bussmann H (2008). Barriers to and facilitators of everyday physical activity in persons with spinal cord injury after discharge from the rehabilitation centre. *J Rehabil Med*; *40*:461–467.

Wahman, K., Nash, M. S., Westgren, N., Lewis, J. E., Seiger, A., & Levi, R. (2010). Cardiovascular disease risk factors in persons with paraplegia: the Stockholm spinal cord injury study. *Journal of Rehabilitation Medicine, 42(3),* 272-278.

Washburn R.A, Zhu W., McAuley E., Frogley M., Figoni S.F. (2002). The physical activity scale for individuals with physical disabilities: development and evaluation. *Arch Phys Med Rehabil.*;*83(2):*193-200.

Wickman, K. (2008). *Bending Mainstream Definitions of Sport, Gender and Ability – Representations of Wheelchair racers*. Doctoral dissertation, Umeå University.

Wilhelmsen, M. (2009). *Samordnet levekårsundersøkelse 2008. Tverrsnittsundersøkelsen. (Coordinated investigation of living conditions)* (2009/40). Statistics Norway.

Wolfe D.L, Martin Ginis K.A., Latimer A.E., Foulon B., Eng J.J., Hsieh J.T.C. (2008). Physical activity following spinal cord injury. In: Eng J, Teasell R, Miller W, et al, eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 2.0. Chapter 22. Vancouver, BC, Canada: ICORD; p 22-1–22-47.

World Health Organization (WHO) (2001) International classification of functioning, disability and health: ICF. Geneva: WHO.

World Health Organization (WHO) (2002). The World Health Report 2002 - Reducing Risks, Promoting Healthy Life. Retrieved from: http://www.who.int/whr/2002/en/whr02_en.pdf

World Health Organization (WHO) (2010). Global recommendations on physical activity for health. Retrieved from: http://www.who.int/dietphysicalactivity/factsheet_recommendations/en/index.html

Wu, S.K. and Williams, T. (2001). Factors influencing sport participation among athletes with spinal cord injury, *Med Sci Sport Exc 33(2)*, 177–182).

Zemper E.D, Roller S., Forchheimer M., Chiodo A., Nelson V.S., Scelza W. (2003). Assessment of a holistic wellness program for persons with spinal cord injury. *Am J Phys Med Rehabil.* ;*82*:957–968.

NORGES IDRETTSHØGSKOLE

Sunnaas sykehus HF

Skjema nr. _________
Dato for utfylling____________

Opplevelser og erfaringer med fysisk aktivitet og trening for personer med motorisk komplett 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.

---

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.

---

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 Ikke aktuelt. Hvis situasjonen skjer hver dag, men ikke i det hele tatt er stressende eller opprivende, svarer du Ikke i det hele tatt.

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.	☐	☐	☐	☐	☐	☐

	Ikke i det hele tatt	Litt	Moderat	Merkbart	Svært	Ikke aktuelt
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.	☐	☐	☐	☐	☐	☐
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.	☐	☐	☐	☐	☐	☐

59) Her spør vi om hvor tilfredsstillende ulike sider ved livet er i dag.

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

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.

Forespørsel om deltakelse i forskningsprosjektet

”Forekomst av overbelastningsproblematikk og tretthet hos personer med motorisk komplett 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. Skaden din er av den typen vi ønsker å kartlegge. Funnene fra tidligere studier ved Sunnaas sykehus HF i forhold til opplevelser rundt trening hos personer med RMS indikerer en forskjell på hvordan personer med komplett og inkomplett ryggmargsskade rapporterer opplevd treningsmestring. I tidligere studier med personer med inkomplett skade (2007-2011) fikk vi bekreftet at noen sliter med utmattelsessymptomer, overbelastning og opplevelse av lav treningsmestring. Ved en spørreundersøkelse vil vi nå kartlegge dette også for personer med motorisk komplett skade. 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.

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 juli 2007 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, 2009, 2010 og 2011). Resultatet indikerer en forskjell på hvordan personer med komplett og inkomplett ryggmargsskade selvrapporterer treningsmestring. Andre forskningsmiljøer har satt fokus på beslektede begrep som utmattelse (Fawkes-Kirby et al. 2008). I studier i 2009 til 2011 fikk vi bekreftet at noen personer med inkomplett ryggmargskade sliter med utmattelsessymptomer, overbelastning og opplevelse av lav treningsmestring. Ved en spørreundersøkelse vil vi nå kartlegge dette også for personer med komplett skade som et grunnlag for å kunne gi bedre råd om trening i et livsløpsperspektiv.

Undersøkelser og annet den inkluderte må gjennom
Undersøkelsen består i å fylle ut og sende tilbake det tilsendte spørreskjema.

Tidsskjema
Spørreskjemaene sendes ut i januar og februar 2012.

Mulige fordeler
Ved å bli med på undersøkelsen, hjelper du oss med å forbedre rehabiliteringstiltak for personer med 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 fysioterapeut og masterstudent Ingrid Bjørgen 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 Sunnaas sykehus HF og Norges Idrettshøgskole samt fra Stiftelsen Sophies Minde.

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. Noen av resultatene vil inngå i en mastergrad 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

(Signert, rolle i studien, dato)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Gjøril Bergva	22845529	31.01.2012	2011/2175
			Deres dato:	**Deres referanse:**
			11.01.2012	

Anne Lannem
Bjørnemyrveien 11
1450
Nesoddtangen

2011/2175 Forekomst av overbelastningssymptomer og tretthet hos personer med komplett ryggmargsskade, en tverrsnittsstudie

Vi viser til tilbakemelding på komiteens merknader til ovennevnte prosjekt, slik de fremkom i vedtaksbrev av 16.12.2011. Komiteen behandlet prosjektet første gang i møte 01.12.2011, og fattet den gang følgende vedtak: Den foreliggende informasjonen er ikke tilstrekkelig til at komiteen kan fatte en avgjørelse. Komiteen har følgende merknader som må besvares før man kan ta endelig stilling til søknaden:

Merknadene var knyttet til behovet for å etablere en beredskap i prosjektet. Komiteen ba om en beskrivelse av hvordan beredskap kunne ivaretas. I tillegg hadde komiteen en del kommentarer til informasjonsskriv og spørreskjema.

Prosjektleders tilbakemelding ble behandlet i komiteens møte 12.01.2012.

Prosjektleder: Anne Lannem
Forskningsansvarlig: Sunnaas sykehus HF

Prosjektomtale (redigert av REK)
Personer med ryggmargsskade får oftest et endret liv etter skade, og de fysiske ressursene reduseres. Man vet lite om det er forskjell på komplette og inkomplette skader, men det har vært registrert ulike opplevelser i forhold til å mestre trening mellom disse gruppene. Derfor ble det gjort nærmere undersøkelser av erfaringene med fysisk trening fra 2 – til 40 år etter skade hos personer med inkomplette skader, og utbredelsen av disse erfaringene. Formålet med dette prosjektet er å gjøre en tilsvarende undersøkelse av utbredelsen av fysisk overbelastning og tretthet blant personer med komplette ryggmargsskader. Resultatene vil kunne bidra til mer individualisert tilpasset rehabilitering og videre treningsråd for personer med ryggmargsskader. Det skal inkluderes 600 deltakere, og data hentes fra journal og fra spørreskjema. Samtykke innhentes.

Vurdering
Komiteen mener søker har besvart merknadene til prosjektet på en god måte. Det er etablert en beredskap i prosjektet som komiteen finner tilfredsstillende. Informasjonsskriv og spørreskjema er tilpasset studien og revidert i tråd med komiteens kommentarer.

Vedtak
Prosjektet godkjennes med hjemmel i helseforskningsloven.

Prosjektet skal gjennomføres slik det er beskrevet i søknad, protokoll og tilbakemelding fra prosjektleder, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 01.01.2016. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Komiteens avgjørelse var enstemmig.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for *Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen

Arvid Heiberg
professor dr. med.
leder

Gjøril Bergva
rådgiver

Kopi: Sunnaas sykehus HF