Concerns of Falling in Individuals with Spinal Cord Injury who Depend on a Wheelchair

Translation, Cross-Cultural Adaptation and Reliability of the Norwegian Spinal Cord Injury Falls Concern Scale (SCI-FCS)

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Sammendrag

Uberettiget bekymring for å falle er ugunstig i forhold til selvstendighet hos personer med ryggmargsskade da det kan bidra til aktivitetsbegrensninger og delaktighetsinnskrenkninger. Bekymring for å falle er derfor viktig å fokusere på innen rehabilitering. Spinal Cord Injury Falls Concern Scale (SCI-FCS) er et nytt selvrapporteringsskjema som kartlegger bekymring for å falle hos rullestolbrukende personer med ryggmargsskade.

Formål: Oversettelse, tverrkulturell tilpasning og undersøkelse av reliabilitet av den norske versjonen av SCI-FCS.

Teoretisk forankring: Studien er basert på den opprinnelige versjonen av SCI-FCS av Boswell-Ruys og medarbeidere i Australia 2010, samt internasjonal litteratur om fall, fallredsel og ryggmargsskade.

Metode: SCI-FCS ble fram- og tilbakeoversatt og tverrkulturelt tilpasset i tråd med anbefalte retningslinjer. Reliabilitet ble testet i en tverrsnittsstudie med et test-retest design hos 54 deltakere med ryggmargsskade under opphold ved Sunnaas sykehus HF. Deltakerne besvarte SCI-FCS to ganger i løpet av en uke. Reliabiliteten ble evaluert med intraclass korrelasjonskoeffisient ($ICC_{2.1}$), standard målefeil (SEM og SEM%) og minste påvisbare endring (SDC og SDC%). Intern konsistens ble evaluert med Cronbach's alpha.

Resultater: Oversettelsen og den tverrkulturelle tilpasningen av SCI-FCS til norske forhold var vellykket og den norske versjonen ble funnet å være relevant, lett å forstå og enkel å besvare. Test-retest overensstemmelse, var høy ($ICC_{2.1}$ 0.83). Standard målefeil (SEM, SEM%), som representerer den minste forandring som kan indikere en reell (klinisk) endring for en gruppe individer, var liten, 2.6 (12%). Den minste påvisbare endring (SDC, SDC%), som representerer den minste forandring som kan indikere en reell (klinisk) endring for enkeltindivider var noe høyere, 7.1 (32%). Intern konsistens målt med Cronbach´s alpha var høy (0.88).

Konklusjon: Den norske versjonen av SCI-FCS har god test-retest-reliabilitet for å kartlegge bekymring for å falle hos rullestolbrukende individer med ryggmargsskade. SCI-FCS kan være bedre egnet som et screeninginstrument enn et effektmål på individnivå.

Abstract

Unwarranted fear of falling is detrimental to independence in individuals with spinal cord injury, as it limits a person's willingness to move and participate in activities. It is, therefore, important that concerns about falling be addressed in rehabilitation. The Spinal Cord Injury Falls Concern Scale (SCI-FCS) is a newly developed, self-report scale that assesses concerns about falling in people with spinal cord injury using a wheelchair.

Purpose: The translation, cross-cultural adaptation, and evaluation of the reliability of the Norwegian version of the SCI-FCS.

Literature framework: This study is based on the original version of the SCI-FCS by Boswell-Ruys et al., formulated in Australia in 2010. Literature from international sources on falls, fear of falling and spinal cord injuries is also incorporated.

Methods: The SCI-FCS was forward- and back-translated and adapted for cross-cultural use, according to guidelines. Reliability was tested in a cross-sectional study with a test-retest design in 54 participants with SCI during their regular stays at Sunnaas Rehabilitation Hospital. They participants responded to the SCI-FCS twice within a week. Reliability was evaluated with the intraclass correlation coefficient ($ICC_{2.1}$), the standard error of measurement (SEM and SEM%) and the smallest detectable change (SDC and SDC%). Internal consistency was evaluated by Cronbach's alpha.

Results: The SCI-FCS was successfully translated into Norwegian and adapted for cross-cultural use and was found to be relevant, understandable and easy to respond to. Test-retest agreement was high ($ICC_{2.1}$ 0.83). The standard error of measurement (SEM, SEM%), that indicates a real (clinical) change in a group of individuals, was small at 2.6 (12%). The smallest detectable change (SDC, SDC%), that indicates a real (clinical) change for a single individual, was somewhat higher, at 7.1 (32%). Internal consistency (Cronbach's alpha) was high (0.88).

Conclusion: The Norwegian version of the SCI-FCS has good test-retest reliability for assessing concerns about falling in people with spinal cord injury who depend upon a wheelchair. The SCI-FCS might be better suited as a screening instrument than an outcome measure on an individual level.

Preface

This study marks the end of my Master's Degree in Health Science at the University of Oslo. Occasionally, working at Sunnaas Rehabilitation Hospital while studying part-time has been tough. I have appreciated, however, the opportunity to have learnt so much. This thesis is a part of a larger research effort between Sunnaas Rehabilitation Hospital (Norway), Rehab Station Stockholm/Spinalis and Karolinska Institutet (Sweden). My hope is that this study will contribute to research on fall-related psychological issues and falls in people with SCIs in the future.

I want to thank the four translators of the SCI-FCS; my expert group, comprising Vivien Jørgensen (PT/PhD student), Anne Lannem (PT/PhD) and Arve Opheim (PT/PhD); the 14 participants in the pilot study; and the 54 participants in the cross-sectional study. Without you, this study would not have been feasible. I am very grateful to you all!

I also want to thank my supervisors at Sunnaas Rehabilitation Hospital, who have made it possible for me to combine work and study.

Thanks, too, to the PVO4 unit for cooperating while I collected data on all participating patients from September 2012 until February 2013.

Many thanks to my supervisor Kirsti Skavberg Roaldsen (PT/PhD), who has shared her knowledge, been supportive and enthusiastic and had a problem-solving attitude throughout the whole research process.

Thanks also to my family and especially my son, Jonas, with whom I have had interesting discussions on statistics, as he has a Master's degree but in a completely different field.

Last, but not least, I want to thank the following from the University of Oslo: Anne Therese Tveter, Gro Tangen and Ingvild Kjeken for helping me see the light in statistical analyses; and Anne Marit Mengshoel for good advice on different issues throughout my Master's studies.

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Abbreviations

FoF: Fear of Falling

$ICC_{2.1}$: Intraclass coefficient

ICF: International Classification of Functioning, Disability and Health

LoA: Limits of Agreement

OT: Occupational therapist

PT: Physiotherapist

PVO4: Unit for outpatient, assessment and follow-up, team 4, at Sunnaas Rehabilitation Hospital

REK: the Regional Committees for Medical and Health Research Ethics

RMN: Unit for Spinal Cord Injury, Multi-trauma and Neurology at Sunnaas Rehabilitation Hospital, primary rehabilitation unit

SCI: Spinal Cord Injury

SCI-FCS: Spinal Cord Injury Falls Concern Scale

SEM: Standard Error of Measurement

SDC: Smallest Detectable Change

T1: Time 1

T2: Time 2

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1 Introduction

The typical sequelae after spinal cord injury (SCI) are total loss or partial loss of motor function and sensory input below the level of injury, which leads to reduced postural control, increased risk of falls and fall-related injuries, and further disability. Falls, fall-related injuries and the detrimental consequences of falls in the SCI population are growing health concerns. Although most falls do not cause serious injury, the psychological impact is often significant, and may lead to unwarranted fear of falling, low fall-related self-efficacy, self-restriction, activity limitation and participation restriction, resulting in a reduced quality of life and/or increased dependency. It is, therefore, important to address falls and fall-related psychological issues in rehabilitation.

Fall-related psychological issues are often assessed with the Falls Efficacy Scale International (FES-I) (Yardley, Beyer, Hauer, Kempen, Piot-Ziegler & Todd, 2005). Recently, the Spinal Cord Injury Falls Concern Scale (SCI-FCS) for wheelchair users (Boswell-Ruys, Harvey, Delbaere & Lord, 2010b) was developed in Australia based on the FES-I.

The SCI-FCS is a self-report scale addressing concerns about falling during the performance of 16 daily-living activities associated with falling and is specific to people with SCI who depend on wheelchairs. It is found to have excellent internal and test-retest reliability and good construct validity in an Australian population (Boswell-Ruys et al., 2010b). To be used in a Norwegian context, the SCI-FCS need to be translated and cross-cultural adapted and the reliability and validity of the Norwegian version has to be established.

The aim of the present study was, therefore, to translate and adapt the SCI-FCS into Norwegian and to establish test-retest reliability in a Norwegian-speaking sample of individuals with SCI who are dependent on a wheelchair for ambulation. Data upon validation has also been collected (see Appendix 6). Upon recommendation from the Institute of Health and Society, the Department of Health Sciences, the Faculty of Medicine, University of Oslo, the validation process is not presented as part of the Master's study and will be presented elsewhere.

The study was conducted under supervision at Sunnaas Rehabilitation Hospital as part of a larger Swedish-Norwegian research project conducted in 2012-2016 by the Sunnaas Rehabilitation Hospital, Karolinska Institutet and Rehab Station Stockholm/Spinalis.

2 Background

2.1 Spinal cord injury

SCI is a severe condition that results in radical change in the lives of the injured and their families. The morbidity spectra are multifaceted, and the SCI-population is at increased risk for morbidity and premature death (NSCISC, 2014). The typical sequelae after SCI are total loss or partial loss of motor function and sensory input below the level of injury. The injury to the spinal cord may be due to a traumatic or a non-traumatic mechanism of injury and may be complete or incomplete, and the severity and classification of the injury will depend on these conditions.

2.2 Incidence and Prevalence of SCI

The incidence of traumatic SCI is 10-20 injuries per million inhabitants per year in Norway (URT, 2005; LARS, 2012), which equates to approximately 50 to 100 new injuries per year. In the neighboring country of Sweden, the incidence is 10-15 injuries per million inhabitants per year (Holz & Levi, 2010). In 2001, the incidence in the Nordic countries was 16 injuries per million inhabitants (Hjeltnes, 2004). The incidence of SCI is increasing slightly each year, due to falls in the elderly population (Hagen, Eide, Rekand, Gilhus & Gronning, 2010). The incidence of incomplete new injuries has increased at the expense of complete injuries in the last decades (URT, 2005).

The prevalence of non-traumatic and traumatic injuries is more or less the same in Norway, but the number of non-traumatic injuries seems to have increased during the last decade (LARS, 2012). Research on non-traumatic SCI is scarce, probably due to diagnostic difficulties (van den Berg, Castellote, Mahillo-Fernandez, & de Pedro-Cuesta, 2010). An estimated 300 to 500 per million inhabitants of Nordic countries are affected by SCI (URT, 2005) and the number of persons living with an SCI in Norway is estimated to be between 1,500 and 2,500 (LARS, 2012). Worldwide, the reported prevalence of traumatic SCI is insufficient, and incidence data is only comparable between the United States, Australia and Europe (Cripps, Lee, Wing, Weerts, Mackay & Brown, 2011). In the United States the prevalence is 700-900 individuals per million inhabitants, meaning around 250,000 individuals, and in Sweden, around 5,000 individuals (Holz & Levi, 2010). Developed

countries have significantly improved SCI survival rates over the last 40 years, compared to undeveloped countries (Cripps et al., 2011).

In Norway, most SCIs occur between the ages of 18 and 35 and 60-70 (LARS, 2012). Around 50-70% of all patients are younger than 30 years of age when injured (Holz & Levi, 2010). The mean age of injury in Norway is 40 years (URT, 2005). Worldwide, the incidents of traumatic SCI peak at ages 20-29 and 70 or older, while the incidents of non-traumatic SCI peak at ages 75-84 (van den Berg et al., 2010). Europe has one of the highest proportions of older adults in the world (age > 60 years), which will likely contribute to higher fall rates in the future (Cripps et al., 2011). Concerning age, there is already a trend towards increased incidence of SCI in the elderly, due to falls and non-traumatic injuries (van den Berg et al., 2010). In the period 1997-2001, the incidents of traumatic SCI were highest for men in their 70s in Western Norway, but in Estonia, they were highest for men in their 20s (Sabre, Hagen, Rekand, Asser & Kõrv, 2013).

Very few small children get acute traumatic SCI, but the incidents in teenagers are increasing. About 20% of the incidents of traumatic SCI are found in children aged 1-15 years of age (Holz & Levi, 2010). Children below 14 years of age are seldom affected. At Sunnaas Rehabilitation Hospital, there is only one injured child per year or every second year (URT, 2005).

More men than women get traumatic or non-traumatic SCIs and women represent only approximately eight percent of people living with SCI (van den Berg et al., 2010; NSCISC, 2014). Of the traumatic SCIs, 15-20% of the injured are women (Holz & Levi, 2010).

2.3 Causes and pathology of SCI

2.3.1 Causes

An SCI can be caused by a trauma (e.g. a fall or traffic accident) or by such non-traumatic causes as tumor, degeneration, hematoma in the medulla, infection, inflammation of the spinal cord, congenital disease or medical or surgical treatment (Hjeltnes, 2004).

Worldwide, traffic accidents represent 41% of the reported cases of SCI, followed by fall accidents (27%), violence (15%) and sport and leisure activities (8%) (NSCISC, 2014). In

Western Europe, falls are the most-common cause of traumatic SCI (Cripps et al., 2011). In Norway, falls caused 45% of traumatic SCI and traffic accidents caused 40% in 1997-2001 (Sabre et al., 2013).

2.3.2 **Consequences**

Due to medical improvements and the expansion of comprehensive rehabilitation-management systems to include life-long follow-up, acute and long-time survival after SCI has increased (URT, 2005). Still, instant mortality is relatively high for individuals with a traumatic SCI. Mortality depends on other injuries like head injuries, multi-trauma, and/or not being able to breathe because of a high tetraplegic lesion (Holz & Levi, 2010). In the acute hospital-care phase, the mortality is around 3%. The long-term causes of death are cardiovascular diseases, pneumonia, pulmonary embolism and sepsis. Previously, renal failure was a common cause of long-term death, but improved urological care has changed that significantly (Holz & Levi, 2010).

The individuals surviving traumatic or non-traumatic SCI get typical sequelae like partial or total loss of motor function and sensory input (URT, 2005; Bromley, 2006; Harvey, 2008; LARS 2012).

There are three pathophysiological phases in traumatic SCIs: the primary, the secondary and the chronic phase. The primary injury causes direct mechanical damage of nerve tissue and blood vessels and is regarded as irreversible. The secondary injury mechanisms come from several minutes to days after the initial trauma, including vascular mechanisms, biochemical changes, edema, inflammation and apoptosis (programmed cell death). In the chronic phase, which can take days to years, apoptosis continues. Structures are trying to restore their functions, and damaged tissue is transported away. A continued demyelination occurs of the white matter in the central nervous system. The end result can be cyst formation in previously damaged spinal cord tissue, syringomyelia, and/or the spinal cord is tied to the surrounding layer like the arachnoid and dura (Holz & Levi, 2010). See Figure 1 for an illustration of damage to the spinal cord and the surrounding structures and Figure 2 for a cross-section of the structure of the spinal cord (http://www.picsearch.com/Spinal-cord-pictures.html).

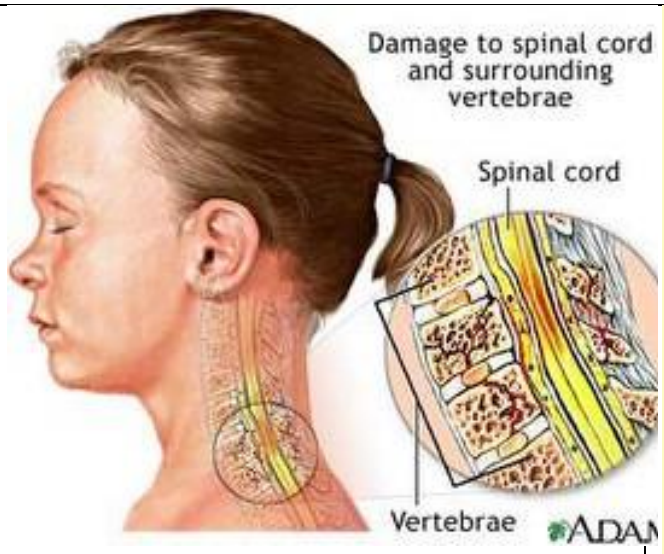


Figure 1. Damage to spinal cord and surrounding structures (http://www.picsearch.com/Spinal-cord-pictures.html).

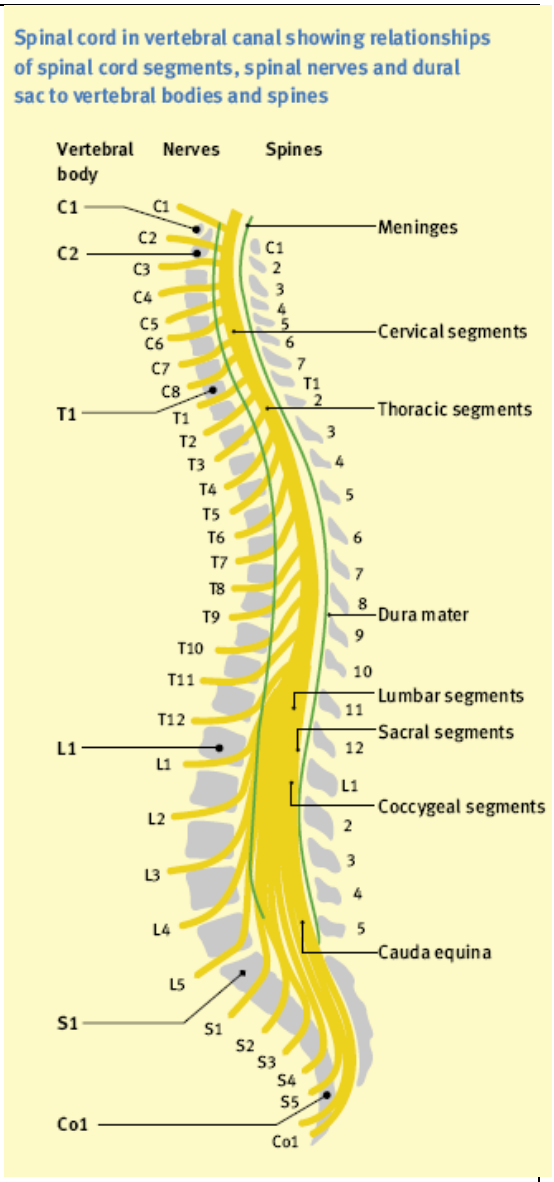


Figure 2. A cross-section of the structure of the spinal cord (http://www.picsearch.com/Spinal-cord-pictures.html).

The extent of an SCI lesion depends on an injury's impact on the spinal cord and which spinal segment or segments are affected. The injury level and the extent of injury can differ, with complete lesions typically being associated with no neurological contact below the injured segment, and incomplete lesions normally being associated with some nerve contact and partial sensibility or motor function below the injured segment (Harvey, 2008; Bromley, 2006). With tetraplegia, the trunk, arms and legs are affected, and the injury is situated in the cervical segments (C1-C8). With paraplegia, the injury is situated below the cervical

segments, arm function is preserved, but the trunk and legs are affected by pareses or paralysis (Harvey, 2008; Bromley, 2006) (Figure 1 and Figure 2).

Respiration may be affected by an SCI, especially with higher lesions where respiratory muscles can become paralyzed to different extents depending on the injury´s severity (Hjeltnes, 2004).

Natural functions may be fully or partially affected by SCIs. Reduced bowel and sphincter functionality can lead to incontinence and obstipation. The urinary tract may also be affected by leakage of urine caused by paresis/paralysis of the sphincter muscle and bladder, a hyperactive bladder, or problems emptying the bladder if the sphincter muscle is unable to relax. The injured might not feel the need to empty bowels and bladder because of the loss of sensation. In both sexes, sexual function may also be affected by loss of sensation. Men may also experience erectile problems (URT, 2005; Bromley, 2006; Harvey, 2008; LARS 2012). Further, SCI may affect the autonomic nervous system, leading to autonomous dysreflexia and problems regulating body temperature, heart and blood pressure (Bromley, 2006; Harvey, 2008).

Most individuals with SCI experience reduced postural control and impaired balance (Harvey, 2008; Bromley, 2006; Boswell-Ruys, Sturnieks, Harvey, Sherrington, Middleton & Lord, 2009; Boswell-Ruys, Harvey, Barker, Ben, Middleton & Lord, 2010a; Boswell-Ruys et al., 2010b). Higher levels of spinal lesions are related to lesser amounts of innervated muscles that help a person maintain balance while sitting, standing, walking or keeping an upright position (Bromley, 2006).

2.3.3 **Complete and incomplete tetra- and paraplegia**

The different kinds of spinal cord injuries are described below based on literature by Hjeltnes (2004), Bromley (2006) and Harvey (2008).

Complete tetraplegia: There will be paralysis or paresis of whole arms and hands or in combination with a partially full function at some cervical segments from the injury level or higher. Depending on the injury level, hand function can be totally or partly affected. For example, a complete C6 lesion will allow the patient to maintain function of wrist extension, but no other wrist motions or finger motions will be possible (Hjeltnes, 2004). The injured

person can learn to transfer in and out of a wheelchair by oneself. With adaptation, orthopedic aids and technical aids, a person with a complete C6 injury will be able to manage most of all daily-living activities by him or herself. One will be able to drive a car and live by oneself but will need help emptying the bowels (Hjeltnes, 2004). Some can learn to catheterize.

Incomplete tetraplegia: One could walk without walking aids and have arm and hand function but with neuropathic pain, reduced coordination or reduced balance. One can also be walking but using a wheelchair for longer distances. Arms, trunk and legs are affected to different degrees. Some could have almost full strength or sensibility all over the body or have a mixture of different kinds of strength or sensibility on different extremities and parts of the trunk. Natural functions work normally or are slightly affected.

Complete paraplegia: There will be full arm function but paralysis in the legs from the hips. There will be partial innervation of the trunk depending on which segment is injured. After primary rehabilitation, one will be able to transfer in and out of a wheelchair while sitting, bearing one's weight on both arms and using transfer techniques. One will have the ability to lie down, sit up and change position while lying in bed. The arms and trunk are the resources to move paralyzed legs. Sitting balance depends on the injury level. Natural functions are injured.

Incomplete paraplegia: There is full function in the arms and paresis in the legs from the hips and in the trunk depending on the injury level. Depending on the severity, one could be walking without walking aids, walk using aids, or use wheelchair for longer distances in combination with walking shorter distances or use a wheelchair all the time for moving around. Natural functions operate totally or to a certain extent.

Some kinds of SCI have specific signs as described below (Hjeltnes, 2004):

Brown-Séquard syndrome is an injury on one side of the medulla, where motor function and deep sensibility are reduced or absent below the injury level on one side of the body, and superficial sensibility is reduced or absent on the other side of the body.

Anterior spinalis syndrome is an injury in the area supplied from the Arteria Spinalis Anterior. The consequence is loss or absence of motor function and skin sensibility below the injury level, but deep sensibility like joint and vibration sensibility may be preserved.

Centromedullar syndrome is often caused by contusion in a trauma that leads to centromedullar necrosis in the medulla. An example of this injury is elderly people having a narrow spinal canal.

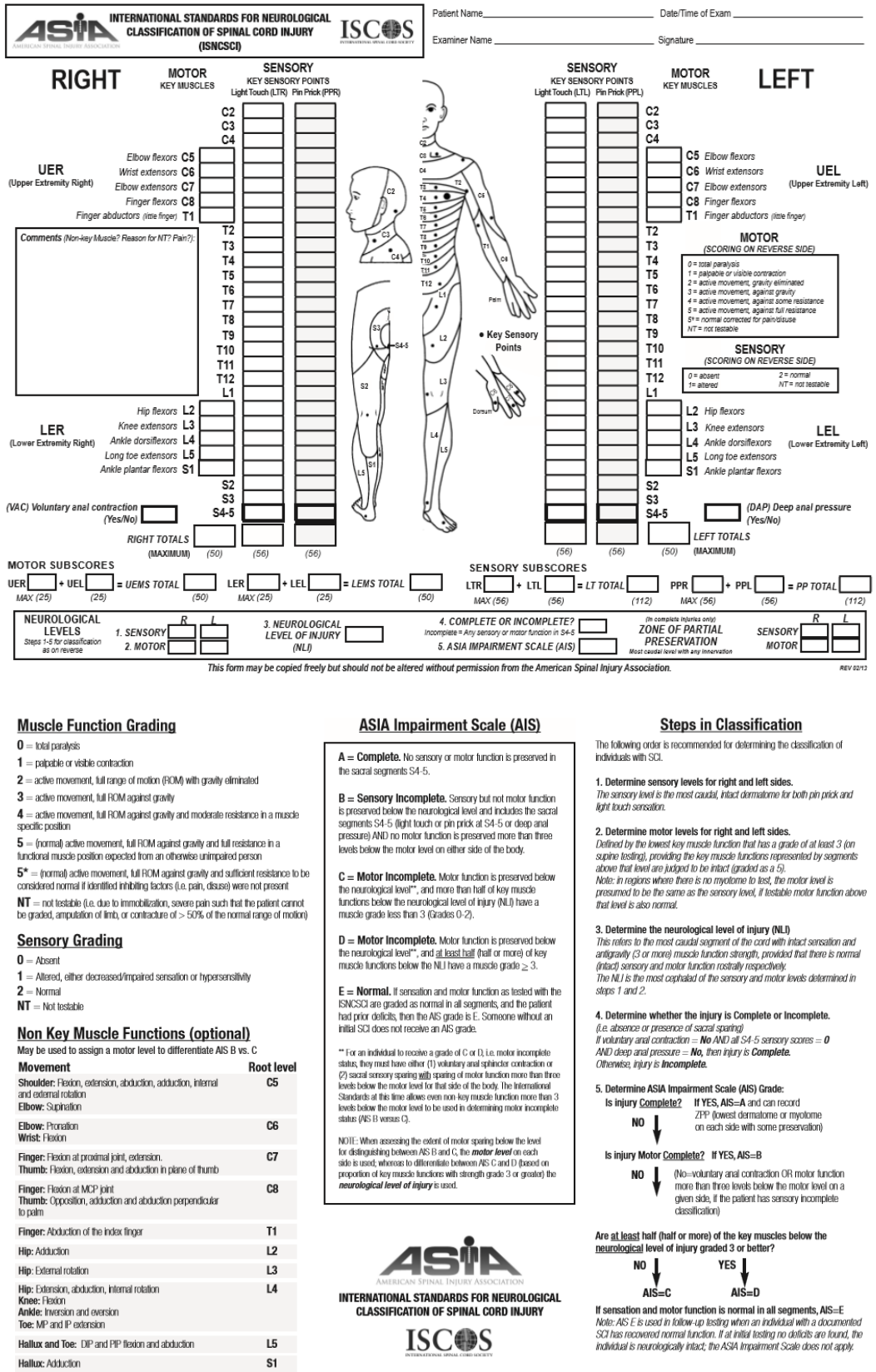
Conus medullaris injury is an injury in the most-caudal part of the medulla, which can lead to a mixture of hypertonia and hypotonia, because it can injure both the central nerves in the spine and peripheral nerves that go out from the spine.

Cauda equina injury affects the nerves that go out from the medulla in the lower part of the spine and leads to hypotonia because the nerves belong to the peripheral nervous system. Often, the bladder and bowels are affected which can lead to "hidden" problems. For example, a person with cauda equina injury could appear to have full motor function and be walking around with no visual affections. However, one might have special regimes while toileting.

2.3.4 **Classification of SCI**

When classifying an SCI, the following must be assessed: Neurological level (the level above the injured segment at which nerves are intact), injury extent (complete versus incomplete), side(s) of the body affected (right and/or left), motor and sensory functioning (ASIA, 2014).

The American Spinal Injury Association (ASIA) classification system, the ASIA Impairment Scale (AIS), is used to categorize the extent of SCIs and the degree of injury from A-E (ASIA, 2014). In Figure 3, the AIS score sheet is shown. Motor and sensory sum scores are used. "A" represents complete injury and "B" connotes no motor functionality but some sensory function. "C" means some motor functionality below the neurological level, but half of the muscles that are included in the AIS classification have a muscle strength of 3 (movement against gravity) or less on a scale from 0 to 5, where 0 is no contraction and 5 is normal strength. "D" means motor functionality is preserved below the neurological level, but half or more of the tested muscles below the neurological level have muscle strength of a 3 or more. "E" signifies normal functionality. One cannot be categorized as an E if one has not had an SCI.



Muscle Function Grading

0 = total paralysis

1 = palpable or visible contraction

2 = active movement, full range of motion (ROM) with gravity eliminated

3 = active movement, full ROM against gravity

4 = active movement, full ROM against gravity and moderate resistance in a muscle specific position

5 = (normal) active movement, full ROM against gravity and full resistance in a functional muscle position expected from an otherwise unimpaired person

5* = (normal) active movement, full ROM against gravity and sufficient resistance to be considered normal if identified inhibiting factors (i.e. pain, disuse) were not present

NT = not testable (i.e. due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of > 50% of the normal range of motion)

Sensory Grading

0 = Absent

1 = Altered, either decreased/impaired sensation or hypersensitivity

2 = Normal

NT = Not testable

Non Key Muscle Functions (optional)

May be used to assign a motor level to differentiate AIS B vs. C

Movement	Root level
Shoulder: Flexion, extension, abduction, adduction, internal and external rotation **Elbow:** Supination	C5
Elbow: Pronation **Wrist:** Flexion	C6
Finger: Flexion at proximal joint, extension. **Thumb:** Flexion, extension and abduction in plane of thumb	C7
Finger: Flexion at MCP joint **Thumb:** Opposition, adduction and abduction perpendicular to palm	C8
Finger: Abduction of the index finger	T1
Hip: Adduction	L2
Hip: External rotation	L3
Hip: Extension, abduction, internal rotation **Knee:** Flexion **Ankle:** Inversion and eversion **Toe:** MP and IP extension	L4
Hallux and Toe: DIP and PIP flexion and abduction	L5
Hallux: Adduction	S1

ASIA Impairment Scale (AIS)

A = Complete. No sensory or motor function is preserved in the sacral segments S4-5.

B = Sensory Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body.

C = Motor Incomplete. Motor function is preserved below the neurological level**, and more than half of key muscle functions below the neurological level of injury (NLI) have a muscle grade less than 3 (Grades 0-2).

D = Motor Incomplete. Motor function is preserved below the neurological level**, and at least half (half or more) of key muscle functions below the NLI have a muscle grade ≥ 3.

E = Normal. If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

** For an individual to receive a grade of C or D, i.e. motor incomplete status, they must have either (1) voluntary anal sphincter contraction or (2) sacral sensory sparing with sparing of motor function more than three levels below the motor level for that side of the body. The International Standards at this time allows even non-key muscle function more than 3 levels below the motor level to be used in determining motor incomplete status (AIS B versus C).

NOTE: When assessing the extent of motor sparing below the level for distinguishing between AIS B and C, the ***motor level*** on each side is used; whereas to differentiate between AIS C and D (based on proportion of key muscle functions with strength grade 3 or greater) the ***neurological level of injury*** is used.

ASIA
AMERICAN SPINAL INJURY ASSOCIATION
INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY
ISCOS
INTERNATIONAL SPINAL CORD SOCIETY

Steps in Classification

The following order is recommended for determining the classification of individuals with SCI.

1. Determine sensory levels for right and left sides.
The sensory level is the most caudal, intact dermatome for both pin prick and light touch sensation.

2. Determine motor levels for right and left sides.
Defined by the lowest key muscle function that has a grade of at least 3 (on supine testing), providing the key muscle functions represented by segments above that level are judged to be intact (graded as a 5).
Note: in regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level, if testable motor function above that level is also normal.

3. Determine the neurological level of injury (NLI)
This refers to the most caudal segment of the cord with intact sensation and antigravity (3 or more) muscle function strength, provided that there is normal (intact) sensory and motor function rostrally respectively.
The NLI is the most cephalad of the sensory and motor levels determined in steps 1 and 2.

4. Determine whether the injury is Complete or Incomplete.
(i.e. absence or presence of sacral sparing)
*If voluntary anal contraction = **No** AND all S4-5 sensory scores = **0** AND deep anal pressure = **No**, then injury is **Complete**.*
*Otherwise, injury is **Incomplete**.*

5. Determine ASIA Impairment Scale (AIS) Grade:

Is injury Complete? If YES, AIS=A and can record ZPP (lowest dermatome or myotome on each side with some preservation)

NO ↓

Is injury Motor Complete? If YES, AIS=B

NO ↓ (No=voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification)

Are at least half (half or more) of the key muscles below the neurological level of injury graded 3 or better?

NO ↓ AIS=C

YES ↓ AIS=D

If sensation and motor function is normal in all segments, AIS=E
Note: AIS E is used in follow-up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact; the ASIA Impairment Scale does not apply.

Figure 3. The American Spinal Injury Association AIS score sheet for classification of neurological level (the level above the injured segment at which nerves are intact), injury extent (complete versus incomplete), side(s) of the body affected (right and/or left), motor and sensory functioning of a spinal cord injury (SCI) (ASIA 2014).

2.4 Rehabilitation, physiotherapy and life-long follow-up

2.4.1 Rehabilitation overview

Approximately 50% of individuals with SCIs in Norway receive their primary rehabilitative and follow-up care at Sunnaas Rehabilitation Hospital (URT, 2005; Sunnaas, 2011a, 2013, 2014a, 2014b).

Sunnaas Rehabilitation Hospital is a highly specialized rehabilitation hospital with both regional and national responsibilities in Norway for patients with SCIs. Specialized rehabilitation is conducted by interdisciplinary teams, using assessments and interventions based on the International Classification of Functioning, Disability and Health (ICF) (WHO, 2014a), evidence-based methods, best clinical practices, clinical experience, documentation and research. The aim of rehabilitation is to enhance patients' participation in society.

Each primary rehabilitation patient is met by an interdisciplinary team comprising a doctor, nurses, auxiliary nurses, a physiotherapist (PT), an occupational therapist (OT), a psychologist, a special teacher, a social worker and a team coordinator. When needed, the following professionals are added to this team: a speech therapist, a sports teacher, a specialist teacher for people with visual impairment, an assistive technology consultant, a driving instructor and a priest.

The ICF is used in goal-setting meetings with the patient and the multidisciplinary team. The long- and short-term goals for each patient are adjusted every fourth week. The overarching goal is to secure optimal participation in daily life, self-care, family life, work, education and leisure activities. Community reintegration is important, and taking short periods (a couple of days) of leave from the hospital when appropriate is an important component of the rehabilitation process (Sunnaas, 2014a, 2014b).

Physical rehabilitation is led by PTs and OTs. The goal of physical rehabilitation is to help the patient regain as much functionality as possible and learn compensating techniques when regaining functionality is not possible. For example, head and arm movements are used to compensate for paresis or paralysis in the trunk to keep one's balance while sitting. Compensatory mechanisms are important for the restoration of postural control/balance and

the strengthening of innervated muscles in the shoulders, shoulder girdle, arms and trunk (Bromley, 2006). The goal is also to find, adjust and apply technical and orthopedic aids. Patients are offered individual physiotherapy and occupational therapy, training groups (e.g., in endurance, strength, wheelchair techniques, cooking) and hydrotherapy with their PTs or (if they are confident to do so) by themselves under supervision. Training is continuous throughout the day and connects to common daily activities, including washing, dressing/undressing, toileting, transfers and eating with tools.

After primary rehabilitation, patients are supervised indefinitely with in-patient stays for control, assessment, problem-solving and exercise. The first control after primary rehabilitation is within one year and is subsequently once per year or upon request. Patients can also make appointments at the out-patient department.

2.4.2 **SCI rehabilitation in a three-phase program**

At Sunnaas Rehabilitation Hospital the primary rehabilitation consists of an SCI program with three phases (Sunnaas, 2011a, 2014b, 2014c), where categories from the ICF (WHO 2014a) are central for each phase. The aim with the phase model is to give the patient the best possible rehabilitation out of several aspects. The phase model has several problem areas and each has goals for the early, middle and the reversal phase. Problem areas may be as follows: reduced lung function, autonomous dysreflexia, reduced circulation, changed bowel function, problems with the urinary tract, nutrition, immobilization, medical complications (e.g., pressure ulcers), pain, insecurity caused by a changed life situation, psychological reactions, imbalance between rest and activities, lack of knowledge related to a new situation, additional injuries, reduced sensibility, reduced physical function, sexuality, reduced ability to perform ADL, the home situation, changed economical situation, changed work or studying situation, permanent need of help and care, and changed socialization because of the SCI. The phases are described below.

Early phase: Body functions and structures in the ICF are central in this phase. The main focus in this phase is to prevent medical and physiological complications that can occur as a consequence of getting an SCI, and to assess the needs for the following phases. Good routines have to be established. Already in this phase, assessment of the home situation should begin.

Middle phase: The main focus in this phase is to regain the highest possible level of functioning according to the SCI level. Activities and participation in the ICF are central.

Reversal phase: Environmental factors in the ICF are central in this phase, even if the other mentioned ICF areas are still important. This phase mainly focuses on consequences related to the home situation, work situation and social network.

2.4.3 **SCI physiotherapy program**

The PTs role in the multidisciplinary team at Sunnaas Rehabilitation Hospital is to assess the patient´s physical function, including balance and risk of falling, and to implement rehabilitative actions accordingly. The main goal for physiotherapy assessment and intervention is to regain the highest possible level of function and independence, based on each patient's potential. The PT contributes significantly to the setting of realistic goals for physical training through challenging and manageable training. From a physiotherapy perspective, it is important to train balance, strength, endurance and functional tasks as transfers to achieve independence; to increase activity and participation and to prevent falls in SCI individuals (Harvey, 2008; Bromley, 2006). Sunnaas Rehabilitation Hospital has specific physiotherapy programs for patients with SCI (Sunnaas, 2011b, 2013). The patients are examined at admission, during the rehabilitation process, and at discharge. When assessing the patients' resources and function, the PT tests muscle strength with the MRC scale (MRC, 1981, 1943; Medical Criteria, 2014) ranging from 0-5, where 5 is normal strength, or the PT uses other functional muscle-strength tests. Information about pain and type of pain is registered. The PT also checks for neurological findings like tonus and sensibility. When required, the PT orders spirometry to examine lung function and performs an endurance test and Cybex muscle-strength test at a clinical physiological laboratory.

After the assessment process or parallel to it, the training with the physiotherapist starts individually in the beginning, and in addition, in a group after a while. Training programs and self-training programs are included and integrated through the day in cooperation with the interdisciplinary team. Training runs continuously throughout the day and connects to common daily activities, including washing, dressing/undressing, toileting, transfers and eating with tools.

The training is divided into basic training (body function and structures), mobility, strength, standing, endurance, balance and functional training (activity and participation), changing positions, training on transfers, wheelchair skills and walking. Basic and functional training can be conducted in parallel. Functional training will consist of both training to optimize function and for compensatory techniques. The amount of training on compensatory techniques depends on the severity of the injury and is adjusted according to the patients' regained function through the different phases of the rehabilitation. For example, head and arm movements are used to compensate for paresis or paralysis in the trunk and keep balance while sitting. Compensatory mechanisms are important to the restoration of postural control/balance and the strengthening of innervated muscles in the shoulders, shoulder girdle, arms and trunk (Bromley, 2006).

Physiotherapy of persons with SCIs also aims to prevent contractures, deal with non-functional and painful spasticity, achieve functional joint mobility, achieve adequate orthostatic function and optimized mobilization routines (involving neck collars and corsets), maintain and increase strength in intact muscles, prevent lung complications, increase lung capacity, achieve optimal endurance, and adapt necessary, functional orthopedic and technical aids (Sunnaas, 2011b; Sunnaas, 2013).

2.5 Falls and fall-related psychological issues

2.5.1 Falls

In the present study, a fall is defined according to the European fall-prevention network (ProFaNE) as an unexpected and unintentional event in which the participant comes to rest on the ground, floor or lower level (ProFaNE, 2014). This includes falling into a chair or bed and falling out of, or tilting, within a wheelchair.

Another definition of a fall is an event whereby an individual comes to rest on the ground or another lower level with or without loss of consciousness (NICE, 2004). According to WHO, a fall is defined as an event which results in a person coming to rest inadvertently on the ground or floor or some other lower level (WHO, 2014b). The last definitions are quite similar to the definition by ProFaNE (2014).

The body of knowledge on falls and consequences of falls is primarily linked to the elderly population. Ambulatory elderly people may fall more often for a variety of reasons like poor balance, poor vision and dementia (Gillespie et al., 2010). The risk of falling depends on several factors including general muscle weakness (especially in the legs), reduced responsiveness, visual impairment and reduced proprioception (the individual's perception of the position of the joints). Fall risk factors may also interact causing a fall and/or a fall injury, and the more factors that interact, the higher the risk of falling (NICE, 2004).

Increased tendency of falling is a huge risk factor for fractures in the elderly, and up to 30% of all elderly fall some time in one year (Gillespie et al., 2010; Bishop, Meuleman, Robinson & Light, 2007). Besides fractures and other injuries, impaired function, reduced quality of life, fear of falling, depression, and other negative consequences and fall-related complications, increase with age (Gillespie et al., 2010).

Primary fall-related injuries are fractures, head injuries and post-fall anxiety. These complications lead to a loss of independence through decreased mobility and increased fear of falling (Bishop et al. 2007; Tinetti, Speechley & Ginter, 1988).

According to WHO (2014), fall prevention strategies should emphasize education, training, creating safer environments, prioritizing fall-related research and establishing effective policies to reduce risk. Several researchers suggest fall prevention programs with physical exercises and information to the elderly (Tinetti, Mendes de Leon, Doucette & Baker, 1994) would be beneficial. By identifying those at highest risk of falling, individuals can be targeted for fall prevention (Friedman, Munoz, West, Rubin & Fried, 2002).

The scarce literature on falls after SCI and falls from a wheelchair is presented in paragraph 2.6.1.

2.5.2 **Fall-related psychological constructs**

Fear of falling and other fall-related psychological constructs

Fall-related psychological constructs as "fear of falling", "fall-related self-efficacy" and "balance confidence" are commonly presented and discussed in the literature on falls. The operationalization of the different constructs will be discussed in the next chapter. In the present chapter, fear of falling (FoF) will be used as a generic term.

FoF is a multi-faceted phenomenon, compiling terms like self-efficacy, confidence, phobia, concern and fear (Legters, 2002). According to Yardley & Smith (2002), the concept of FoF holds not only the actually fear of falling but also the fear of pain and suffering, fear of losing one's independence and fear of embarrassment in front of others.

FoF can be warranted and justified as a protection mechanism, such as to avoid icy and slippery surfaces, but in case the fear is unwarranted, it can be a social dysfunction and lead to activity restrictions (Moore & Ellis, 2008; Legters, 2002).

In the eighties the terms post-fall syndrome (Murphy & Isaacs, 1982) and ptophobia, the phobic reaction to standing and walking because of FoF (Bhala, O'Donnel & Thoppil, 1982), were identified and used. Today, these terms have been substituted by FoF (Legters, 2002). According to Tinetti, Richman & Powell (1990), FoF is an ongoing concern about falling that ultimately limits the performance of daily activities. Often-used definitions of FoF are a patient's loss of confidence in his or her balance abilities (Tinetti et al.,1988; Maki, Holliday & Topper, 1991), a general concept that describes low fall-related efficacy (low confidence at avoiding falls) and being afraid of falling (Cumming, Salkeld & Szonyi, 2000). According to Tinetti et al. (1990), the operationalization of FoF as "low perceived self-efficacy" has advantages as self-efficacy is a concept based on strong theoretical assumptions about the social cognitive processes that underlie emotions (Bandura, 1986). Cognitive processes in turn are emergent brain activities that exert determinative influence, and people construct outcome expectations from observed conditional relations between environmental events in the world around them and the outcomes the given actions produce (Bandura, 1986). According to this social cognitive theory, peoples' beliefs about their capabilities impact how they behave in particular situations, e.g., dealing with fear or anxiety.

Anxiety, fear and fall-related psychological issues

Fear and anxiety are closely related primitive emotions originating in evolved mammalian defense systems that function to preserve life and can facilitate action in an effort to maintain safety and wellbeing, but when they become characteristic of an individual or are trait-like, they can turn physically and psychologically destructive (Sylvers, Lilienfeld and La Prairie, 2011; Öhman, 2008). The concepts anxiety and fear are poorly delineated and have been used both separately and interchangeably in research and theories (Sylvers et al., 2011). The concepts anxiety and fear may be similar, but their causes are different. Anxiety is often "pre-

stimulus" (i.e., anticipatory to more or less real threatening stimuli), whereas fear is "post-stimulus" (i.e., elicited by a defined fear stimulus) (Öhman, 2008).

Bandura's (1988) definition of anxiety is a state of anticipatory apprehension over possible deleterious happenings. In the present study's context the possible deleterious happening could be a fall. In social cognitive theory, perceived self-efficacy to exercise control over potential threats plays a central role in anxiety arousal (Bandura, 1988). People who believe they cannot manage threatening events like a possible fall that might occur, experience high levels of anxiety arousal. Anxiety is characterized by a state of apprehension, persistent hyper-vigilance and prolonged hyper-arousal from overestimating a threat in ambiguous situations (Sylvers et al., 2011). According to the American Psychiatric Association (APA, 2000), anxiety denotes "apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension". The behavioral consequences of anxiety may include the avoidance of distressing situations such as those involving fall risks and falls.

Fear is an emotion induced by an external threat and/or the perception of danger (e.g., fall risk or fall) that evokes a change in behavior, leading to confrontation with an intense urge to defend oneself or escape from/avoid the threat (also known as the fight or flight response) which in extreme cases of fear (horror and terror), can be a freeze response or paralysis (Öhman, 2008).

According to the descriptions of anxiety and fear above, both emotional concepts may be involved when experiencing FoF.

Ambulatory elderly and fall-related psychological issues

The target group for research regarding FoF is primarily ambulatory elderly people, where the incidence and prevalence are significant (Lach, 2005; Yardley et al., 2005; Gyllensvärd, 2009). In a longitudinal study of falls on community-dwelling elderly people over 65 years, Lach (2005) found that the prevalence of FoF increased over two years from 23% to 43%, and that the incidence averaged 22,5 % in the follow-up years.

Several of the following factors are found to be closely correlated with FoF in ambulatory elderly including reduced physical and mental function: low level of physical activity; reduced fitness; reduced mobility; reduced balance; poor health status; problems in

conducting all daily living activities; psychological conditions like depression, isolation, anxiety and cognitive impairment; reduced quality of life; medical interventions; previous falls; and increased risk of falling (Lach, 2005; Suzuki, Ohyama, Yamada & Kanamori, 2002; Legters, 2002; Friedman et al., 2002; Kiel, Schmader & Sokol, 2013; Yardley & Smith, 2002; Scheffer, Schuurmans, van Dijk, van der Hooft & de Rooij, 2008; Lachman, Howland, Tennstedt, Jette, Assman & Peterson, 1998).

Risk factors for developing FoF are as follows: having two of more falls, feeling unsteady, reporting fair or poor health status, and being a woman and old (Lach, 2005; Legters, 2002; Scheffer et al., 2008). Females have greater odds of FoF than males (LeBouthillier, Thibodeau & Asmundsen, 2013). Only women who experienced a fracture or head injury had increased odds of FoF, and only women who experienced a head injury had increased odds of restricting activities compared with women who fell without injury (LeBouthillier et al., 2013). The relationship between severe fall-based injuries and activity restriction associated with FoF is unique to women (LeBouthillier et al., 2013). However, Bishop et al. (2007) found that pain was a significant predictor of decrease in balance and mobility outcome scores, though not with FoF in male veterans.

Elderly people with FoF do not need to have fallen earlier to experience FoF. Of community-living elderly people who live independently and do not have a history of previous falls, FoF exists in 12-65 % and is higher in women than in men according to Delbaere, Crombez, Vanderstraeten, Willems and Cambier (2004). Legters (2002) found that 30% of the elderly without a previous history of falls experienced FoF. Of those who had fallen previously, 29-92% experienced FOF (Legters, 2002). Vellas, Wayne, Romero, Baumgartner and Garry (1997) found that about one-third of elderly people develop a FoF after an incident fall, and this issue should be specifically addressed in any rehabilitation programme.

According to Lach (2005), screening and health programs for older adults are recommended. Interventions to decrease FoF should be multidimensional and include the following: education/information, physical activity, and cognitive-behavioral changes (Tennstedt, Howland, Lachman, Peterson, Kasten & Jette, 1998).

Fear-related avoidance of activities due to fear of falling

In falls and FoF, what comes first is not easy to know, but a study on older people by Friedman et al. (2002) showed that falls and FoF share predictors, and that FoF may also cause falls. Figure 4 shows the "Vicious circle of frailty" postulated by Delbaere et al. (2004). The figure describes how FoF may increase risk of falling, leading to avoidance of more activities, which in turn may lead to more difficulties in performing activities of daily living and in exercising their muscular strength and postural control. In turn, that pattern may fuel fear and avoidance and may lead to a further non-use of physical resources and an increased risk of falls.

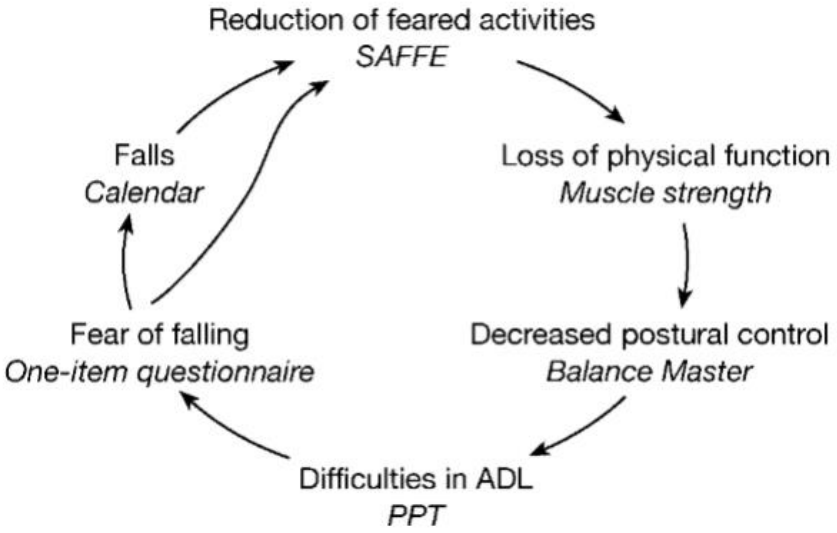


Figure 4. "Vicious circle of frailty" from the article by Delbaere et al. (2004). The"vicious circle of frailty" describes how fear of falling may increase risk of falling, leading to avoidance of more activities, which in turn may lead to more difficulties in performing activities of daily living and exercising their muscular strength and postural control. In turn, that pattern may fuel fear and avoidance and may lead to a further non-use of physical resources and an increased risk of falls. SAFFE =SAFE="Survey of Activities and Fear of Falling in the Elderly Scale". PPT=Physical Performance Test (measuring physical frailty).

Murphy, Williams and Gill (2002) found that older persons with fear-related avoidance of activities due to FoF, were more physically frail and had a higher degree of chronic conditions and depressive symptoms than those with FoF alone. Fear-related avoidance of activities is an independent predictor both for decline in physical function and for future falls among the

elderly (Delbaere et al., 2004; Deshpande, Metter, Lauretani, Bandinelli, Guralnik & Ferruccio, 2008). Fear-related avoidance of activities is therefore an important additional psychological variable in the development of physical frailty in the elderly (Delbaere et al., 2004).

2.5.3 **Operationalization and measurement of fall-related psychological constructs**

There is some confusion regarding the best method of defining and measuring fall-related psychological constructs. The most-common and best-studied, fall-related psychological constructs today are "fear of falling", "fall-related self-efficacy" (also called "falls efficacy") (Tinetti et al., 1990), and "balance confidence" (Powell & Myers, 1995). Each of these constructs is unique, although similar in nature, and should be measured and spoken of as unique, which unfortunately is not the case today (Moore & Ellis, 2008). For example, both "The Falls Efficacy Scale – International" (FES-I) (Yardley et al., 2005), which was designed to measure the construct of falls efficacy, and "The Activities-Specific Balance Confidence Scale" (ABC) (Powell & Myers, 1995), designed to measure the construct of balance confidence, have been used extensively to measure fear of falling.

In addition to the three more-known constructs, several other less-common, fall-related psychological constructs have been identified like "feared consequences of falling" (Yardley & Smith, 2002), "perceived control over falling and perceived ability to manage falls" (Lawrence et al., 1998).

Fear of falling

"Fear of falling", defined as a lasting concern about falling that leads to an individual avoiding activities that he/she remains capable of performing (Tinetti & Powell, 1993) has been operationalized using generic, single-item questions as well as multi-item measures, i.e. "The Survey of Activities and Fear of Falling in Elderly" (SAFE, also called SAFFE) by Lachman and co-workers (1998). In early research, the single question "Are you afraid of falling?" was asked with response alternatives like "yes/no" or "fear/no fear" (Legters, 2002). Single-item questions are still useful in research studies where participants are categorized into "afraid of falling" and "not afraid of falling", as in the present study.

Fall-related self-efficacy

"Fall-related self-efficacy" or "falls efficacy" refers to the confidence in one's ability to perform activities of daily living (ADL) without falling (Tinetti et al., 1990). "The Falls Efficacy Scale" (FES), commonly referred to as the "gold standard" is the most widely used fall-related psychological instrument. There are several modified versions of the FES, and "The Falls Efficacy Scale - International" (FES-I) (Yardley et al., 2005) is a universal adaptation that is suitable for use in a wide range of cultural contexts and languages within the elderly ambulatory population and is recommended by the Prevention of Falls Network Europe (ProFaNE, 2014). Inappropriately, FES-I has been used as a measure of FoF, and FoF has been used as a general term to represent a low fall-related self-efficacy, which has created a widespread confusion about the difference between the constructs (Moore & Ellis, 2008).

The SCI-FCS (Boswell-Ruys et al., 2010b) is based on the FES-I and it is the authors' opinion, though not stated or discussed by the originators, that the SCI-FCS represents the same fall-related psychological construct as FES-I, "fall-related self-efficacy", and does not represent the construct "fear of falling". Thus, in the present study, the fall-related psychological construct of "fall-related self-efficacy" is used and defined as "the degree of confidence that a person has in performing common daily activities without falling" (Tinetti et al., 1994, p. M141). Also, the terms "fear of falling" and "fall-related self-efficacy" are seen as unique constructs and will therefore be used according to their definitions and measurement methods from this point on.

In line with the authors of the SCI-FCS, we use the term "concern about falling" when discussing confidence in performing common daily activities without falling. Concern about falling is also used in the shared wording in the instructions of the FES-I and SCI-FCS: "We would like to ask some questions about how concerned you are about the possibility of falling…" (Yardley et al., 2005; Boswell-Ruys et al., 2010b).

Balance confidence

Balance confidence, defined as the confidence in one's ability to maintain balance and remain steady (Powell and Myers, 1995), is a situational-specific form of "self-efficacy" that relates to perceived balance ability. "The Activities-Specific Balance Confidence Scale" (ABC) measures this concept (Powell and Myers, 1995).

Other fall-related psychological instruments

Other less-common, fall-related psychological instruments are "The Perceived Control over Falling Scale" (PCOF), "The Perceived Ability to Manage Falls Scale" (Lawrence, Tennstedt & Kasten, 1998), "The Consequences of Falling Scale" (COF) (Yardley & Smith, 2002) and "The Nursing Home Falls Efficacy Scale" (Lach, Ball & Birge, 2012).

All the mentioned scales have ambulatory elderly people as a target group. Legters (2002) confirms that there is a need for measures/scales for other populations, e.g., younger people or populations with spinal cord injuries driving a wheelchair. Established scales may also be standardized for other populations than the elderly where that is possible. For populations with spinal cord injury, the Spinal Cord Injury Falls Concern Scale (SCI-FCS) was recently developed by Boswell-Ruys et al. (2010b) based on the FES-I and is the first scale assessing fall-related psychological issues in wheelchair users.

2.6 Falls and fall-related psychological issues in individuals with SCI

2.6.1 Falls after SCI

Managing an aging population with SCI is a new and unique challenge for SCI-units in the Western world, and falls, fall-related injuries and unwarranted fear of falling are growing health concerns.

There are some studies on spinal cord injury, fall and fear of falling but mostly on ambulatory incomplete spinal cord injured individuals (Brotherton, Krause & Nietert, 2007; Phontee, Saengsuwan and Amatachaya, 2013; Amatachaya, Wannapakhe, Arrayawichanon, Siritarathiwat & Wattanapun, 2011). In one study, one-third of the independent ambulatory individuals with SCI experienced falls (John, Cherian & Babu, 2010). The fallers, though, had better functional ability than the non-faller subjects.

Six months after discharge from primary rehabilitation, 55% (n=24) of 44 subjects with complete and incomplete SCI had at least one fall. Of the completely injured, 33% (n= 7) of 21 subjects were wheelchair-bound and fell from a wheelchair, and 74% (n=17) of 23 subjects of the incompletely injured fell while walking or standing (Amatachaya, et. al., 2011). That

indicates a high risk of falling, especially among the incompletely injured who fell from walking and standing.

Falls represent 60-80% of accidents in individuals with SCI (Boswell-Ruys et al., 2010b). The first study to report wheelchair-related falls in SCI individuals followed wheelchair users monthly for over one year (Nelson et al., 2010). A total of 553 fall incidents were reported in 31% (n = 204) of 659 individuals, and 14% were injured by falling. The mean number of falls per person was 0.83, and the mean number of falls causing injury was 2.40 per individual who fell.

Statistics from Sunnaas Rehabilitation Hospital, the unit for Spinal Cord Injuries, Multitrauma and Neurology (RMN), show an incidence of 28 falls in 2009, 27 falls in 2010, 30 falls in 2011 and 19 falls in 2012 (Sunnaas, 2012). The clinical impression is that most falls are represented by ambulating individuals with SCI, and that individuals who depend on wheelchairs fall relatively less often. This phenomenon needs to be studied in Norway and the other Nordic countries.

Nelson et al. (2010) identified six risk factors for falling in wheelchair-bound veterans: 1) pain in previous months, 2) alcohol abuse, 3) greater motor function, 4) history of previous falls, 5) fewer SCI years (more recent onset of SCI) and 6) inaccessible home entrance.

Falls that occur in individuals with SCI who depend on wheelchairs are often caused by wheelchairs tipping or by transfers to or from wheelchairs (Boswell-Ruys, 2010b).

At the Sunnaas Rehabilitation Hospital RMN unit, several causes of falls from wheelchairs were reported in 2012: non-use of an anti-tipper, the threshold between the terrace and the canteen, mistakes made during wheelchair-skill training, and hazards encountered when pushing the wheelchair outdoors in a city environment (Sunnaas, 2012).

In most cases, falls lead to such relatively less-serious injuries such as overstretching and contusions (Boswell-Ruys et al., 2010b). However, falls can also lead to fractures. In a retrospective study of medical journals on SCI individuals, 27 falls resulted in 31 fractures in 24 SCI individuals (Nelson, Ahmed, Harrow, Fitzgerald, Sanchez-Anguiano & Gavin-Dreschnack, 2003). The fractures were in the lower extremities in 97% of cases. Over 80% of fractured individuals were hospitalized for a mean of 66 days.

2.6.2 **Fall-related psychological issues after SCI**

The literature on fall-related psychological issues in individuals with SCI is scarce. The clinical impression, however, is that unwarranted and unmotivated FoF is detrimental to independence, as it limits an individual's activity and participation. It is therefore important for rehabilitation to address the FoF, identifying fall-related concerns and ascertaining whether these are justified. Although most falls do not cause serious injury, their psychological impact may be significant, leading to unwarranted FoF and self-restriction, which in turn may result in a reduced quality of life and/or increased dependency.

Boswell-Ruys et al. (2010b) found that concerns about falling negatively affected independence by restricting willingness to mobilize and participate in activities. Participants who showed high levels of fall-related concern also had higher levels of SCI, (partial or full paralysis of the abdominal muscles), self-reported FoF, poor or fair supported and unsupported sitting ability and dependency in vertical wheelchair transfers. Participants who fell once a year or less had significantly higher concerns about falling than those who fell more than once a year.

The fact that there is a general rise in the number of fall-induced cervical spine injuries among older adults may have fall-related psychological consequences. A fall causing SCI might lead to FoF later on and could thus affect rehabilitation potential (John et al., 2010). Amatachaya et al. (2011) found a decrease in functional ability among individuals with SCI six months after discharge from primary rehabilitation, and this turn can lead to FoF (Amatachaya et al., 2011).

John et al., (2010) found a higher level of FoF in low-level paraplegics using knee-ankel-foot-orthoses (KAFOs) for walking, the better standing stability they had (reduced postural sway on a force platform). The studied population were paraplegics with a complete SCI using KAFOs in combination with elbow crutches, a way to walk that requires a lot of energy (John et al., 2010). To proceed using KAFOs, the user needed a higher level of confidence and self-efficacy in all daily-living activities than individuals who choose a wheelchair (John et al., 2010).

Being a woman and older is a risk factor in ambulatory elderly people for developing FoF (Scheffer et al., 2008). Aging women with SCI have unique concerns and experiences with

daily living compared with men with SCI (Pentland, Walker, Minnes, Tremblay, Bouwer & Gould, 2002). However, there is little research on gender, SCI and FoF.

2.7 Translation and cross-cultural adaptation procedures of self-report scales

When a self-report scale or questionnaire is to be used in a new culture and/or language from where it was developed, it has to be translated and cross-culturally adapted. According to Beaton, Bombardier, Guillemin and Ferraz (2000), the term cross-cultural adaptation includes both translation and cultural adaptation, but both terms are often used in literature. The aim of the process is to produce equivalency between the source and target based on content (Mokkink, Terwee & Patrick, 2010), emphasizing conceptual and cultural rather than literal translation (WHO, 2014c). The translation and cross-cultural adaptation in the present study was done according to guidelines by Beaton et al. (2000) and goes through several stages (see Figure 5).

Stage I: Initial translation is the forward translation from the original language to the target language. Two translations are recommended with two independent bilingual translators with different backgrounds and whose mother tongue is the target language. One translator should be a health professional who is aware of the concepts in the questionnaire. The other translator should be "naive", meaning not having a clinical or medical background.

Stage II: Synthesis of the translations through a consensus of two translations into one with a written report of the process.

Stage III: Back translation with two back-translators with the source language as their mother tongue.

Stage IV: Expert Committee which comprises health professionals, methodologists, language professionals and translators that are involved until this stage. The expert committee consolidates all the versions of the questionnaire and develops the pre-final version.

Stage V: Test of the pre-final version. A pilot has to be conducted to ensure that the adapted version is still retaining its equivalence in an applied situation. Pilot participants from the target group respond to the questionnaire.

Stage VI: Submission of documentation to the developers or coordinating committee for appraisal of the adaptation process.

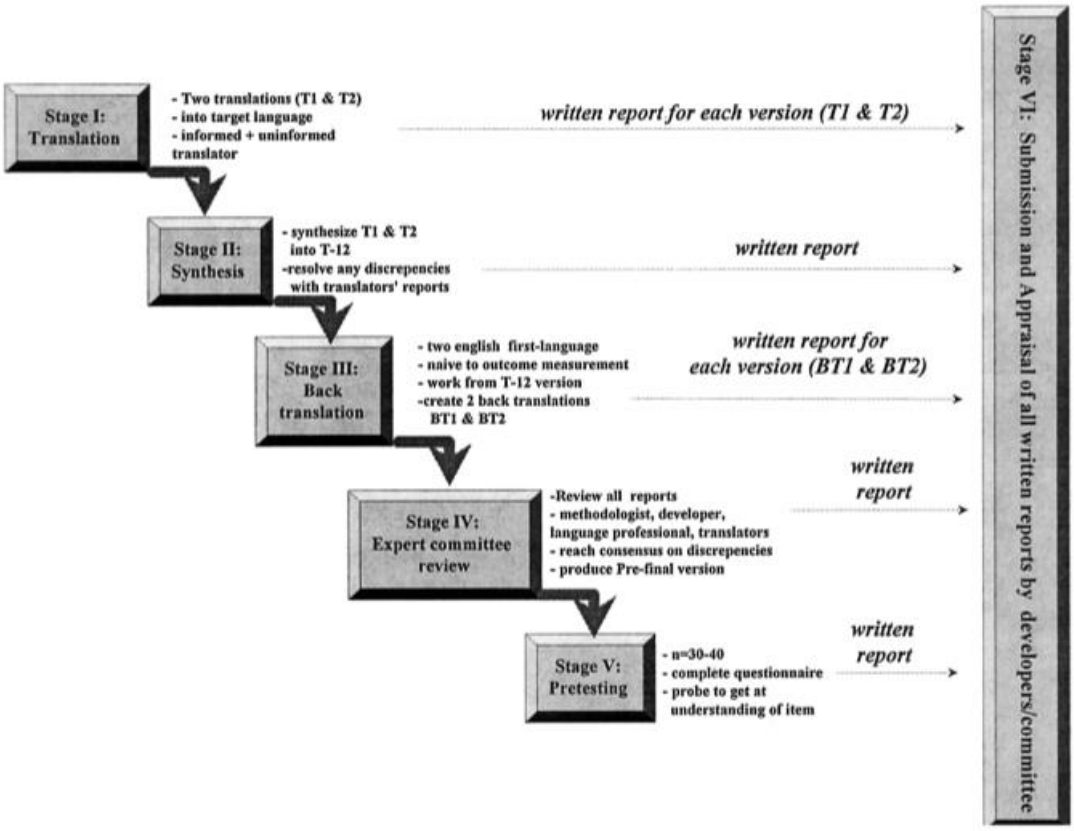


Figure 5. Graphic presentation of the stages of translation and cross-cultural adaptation recommended by Beaton et al. (2000)

2.8 **Reliability**

Reliability is a major criterion for assessing a measurement's quality and adequacy (Polit & Beck, 2008) and is defined as the degree to which the measurement is free from measurement error on repeated measures (Mokkink et al., 2010). Reliability refers to the reproducibility of measurements, which are reliable if they are stable and precise over time and show adequate levels of measurement variability.

Different kinds of reliability are presented as follows:

Internal consistency: Can be measured in a number of ways. The most commonly used statistic is Cronbach's alpha. It provides an indication of the average correlation among all of the items that make up the scale. Cronbach's alpha is usually used as an index of internal consistency to estimate the extent to which different subparts of an instrument (i.e., items) are reliably measuring the critical attribute (Polit & Beck, 2008). Values range from 0 to 1, with higher values indicating greater reliability.

Intra-rater reliability: Reliability where one compares what the same person/examiner measures the first and second time. The intra-rater reliability can depend on the person that measures, the measurement, and the individual that is measured. It is often difficult to separate if the result depends on the examiner or the subject (see intra-subject reliability below) that is studied (Carter, Lubinsky & Domholdt, 2011).

Inter-rater reliability: The inter-rater reliability is determined when two or more raters judge the performance of one group of subjects at the same point in time (Carter et al., 2011). It measures reproducibility in the method.

Intra-subject reliability: This is associated with actual changes from time to time in subject performance. When test-retest reliability is calculated for a measurement method, like a self-report scale, intra-subject reliability could interfere on test-retest reliability, together with instrument errors and tester errors (Carter et al., 2011).

Test-retest reliability: The stability of an instrument like a self-report scale, observational or physiologic measure is the extent to which similar results are obtained on two separate occasions with the same people; this is called test-retest reliability (Polit & Beck, 2008). The reliability coefficient for test-retest estimates is the correlation coefficient between the two sets of scores. The correlation coefficient is a tool for quantitatively describing the magnitude and direction of a relationship between two variables. The correlation coefficient can theoretically change between -1.00 and +1.00. In practice reliability coefficients normally range between .00-1.00 (de Vet, Terwee, Mokkink & Knol, 2011). If the measurement error is small in comparison with the variability between patients, the reliability parameter approaches 1. High test-retest correlations indicate a more reliable scale.

Test-retest reliability is quantified in two ways: *relative and absolute reliability* (Carter et al., 2011).

Relative reliability: Relative reliability examines the relationship between two or more sets of repeated measures (Carter et al., 2011). Relative reliability is measured with some form of a correlation coefficient. A correlation coefficient of 1.0 indicates a perfect association with repeated measures. The intraclass correlation coefficient, $ICC_{2.1}$, is the measure method's ability to distinguish among the individuals in the studied population. After two or more sets of repeated measures, one compares the variation among individuals with the variation in an individual. The $ICC_{2.1}$ is high if the variation in the same individual is small.

Nowadays, the $ICC_{2.1}$ is the preferred test-retest correlation coefficient. "Pearson's r" may be used on normally distributed continuous data and may be illustrated in a scatter plot with a regression line. The non-parametric "Spearman's rho" correlation coefficient and the less-often used "Kendall's tau" are alternative tests when data are not normally distributed (Polit & Beck, 2008).

Absolute reliability: Absolute reliability examines the variability of the scores from measurement to measurement. It indicates the extent to which a score varies on repeated measurements (Carter et al., 2011). Absolute reliability is measured with a "Standard Error of Measurement", SEM and SEM%, "Smallest Detectable Change", SDC and SDC%, and they contribute to the assessment of clinically important changes in a group of subjects and within a single subject.

SEM and SEM% is used to evaluate clinical changes in groups of subjects in comparison to changes that might be expected solely from measurement error. SEM and SEM% denotes the smallest change that indicates a real difference for a group of subjects following, for example, an intervention. In other words, a measurement following an intervention should be outside the range of measurement error to indicate a real improvement or deterioration for a group.

The SDC, also called "Smallest Real Change" (SRC) or "Smallest Real Difference" (SRD), is one way to evaluate clinically important changes and represents the smallest change that indicates a real improvement or change for a single subject (Lexell & Downham, 2005). The SDC is algebraically similar to the "limits of agreement", LoA, proposed by Bland and Altman (1999; Altman, 1999).

Cross-sectional study and test-retest reliability: A cross-sectional study is necessary when one tests an instrument for test-retest reliability with absolute and relative reliability (Polit &

Beck, 2008; De Vet et al., 2011; Aalen, Frigessi, Moger, Scheel, Skovlund & Veierød, 2006). The cross-sectional design is based on the measurement of each participant at one time, even if this one time includes a measurement taken twice within a few days, which is special for test-retest reliability. An observational cross-sectional design involves the collection of data once, at a single point in time, for each participant in a target population during one period of data collection (Polit & Beck, 2008; Carter et al., 2011). In this case, "the one time" or "single point in time" means the short period of one up to a maximum of seven days when each participant was measured a first and second time, responding to the translated SCI-FCS twice. Using a cross-sectional design is also relatively economical (Polit & Beck, 2008). In the present study, each participant is responding to the Norwegian version of the SCI-FCS twice with a maximum of seven days apart. Cross-sectional studies are non-experimental and observational and don't focus on the cause or effect of an intervention like case-control studies and longitudinal cohort studies (Carter et al., 2011).

2.9 The Spinal Cord Injury Falls Concern Scale

The Spinal Cord Injury Falls Concern Scale (SCI-FCS), launched in Australia in 2010, is a self-report scale addressing concerns about falling during 16 daily living activities associated with falling and specific to people with SCI who depend on wheelchairs (Boswell-Ruys et al., 2010b). SCI-FCS refers to the confidence in an individual's ability to perform the given activities without falling, i.e., falls-related self-efficacy or falls efficacy. The scale was influenced by "The Falls Efficacy Scale-International" (FES-I) (Yardley et al., 2005), which is considered the gold standard for assessing fall-related psychological issues within the elderly ambulatory population. SCI-FCS is the first scale to measure fall-related psychological issues in individuals with SCI. The original SCI-FCS is presented in Figure 6 (also see Appendix 8).

Spinal Cord Injury-Falls Concern Scale (SCI-FCS)

We would like to ask some questions about how concerned you are about the possibility of falling. For each of the following activities, please circle the opinion closest to your own to show how concerned you are that you might fall if you did this activity. Please reply thinking about how you usually do the activity. If you currently do not do the activity (for example if someone does your shopping for you), please answer to show whether you think you would be concerned about falling IF you did the activity.

		Not at all concerned 1	*Somewhat concerned 2*	*Fairly concerned 3*	*Very concerned 4*
1	Getting dressed or undressed	1	2	3	4
2	Moving around the bed (including sitting up)	1	2	3	4
3	Inserting enema or toileting	1	2	3	4
4	Washing or showering self	1	2	3	4
5	Transferring on/off a commode or toilet	1	2	3	4
6	Transferring in/out of bed	1	2	3	4
7	Transferring in/out of a car	1	2	3	4
8	Reaching for high objects (e.g. pressing button on a lift, reaching to a high shelf)	1	2	3	4
9	Picking objects up from the floor (e.g. clothes, pet bowl, pen)	1	2	3	4
10	Cooking or food preparation (e.g. making a sandwich, stirring food on the stove)	1	2	3	4
11	Pushing wheelchair on flat ground	1	2	3	4
12	Pushing wheelchair on an uneven surface (e.g. rocky ground, irregular pavement)	1	2	3	4
13	Pushing wheelchair up/down gutters or curbs	1	2	3	4
14	Pushing wheelchair up/down a slope	1	2	3	4
15	Shopping	1	2	3	4
16	Lifting heavy objects across body (e.g. shopping bags, wheelchair into the car)	1	2	3	4

Figure 6. The Spinal Cord Injury Falls Concern Scale (SCI-FCS) (Boswell-Ruys et al., 2010b)

The SCI-FCS is a self-report scale, and the questionnaire can be administered by the respondent him- or herself or by health professionals as the basis of a standardized interview.

The psychometric properties of the scale have been judged to be good to excellent in Australia (Boswell-Ruys, 2010b; Terwee et al., 2007; Polit & Beck, 2008; de Vet et al., 2011). Internal reliability is excellent (Cronbachs $\alpha = 0.92$), as is test-retest reliability (intraclass correlation coefficient, $ICC_{2.1} = 0.93$). The SCI-FCS may be used as a screening tool for fall concerns in SCI people, both in research and in clinical practice (Boswell-Ruys, 2010b).

To be used in a Norwegian context, the SCI-FCS has to be translated, adapted for cross-cultural use and tested for reliability in a Norwegian context, which is the aim of the present Master's study. To our knowledge, this is the first translation of the SCI-FCS. A Swedish translation and cross-cultural adaptation is underway.

3 Aims

The aim of the present study was two-fold. Firstly, the aim was to translate and cross-culturally adapt the SCI-FCS into Norwegian. Secondly, the aim was to investigate the test-retest reliability of the SCI-FCS within a Norwegian-speaking sample of individuals with SCI who are dependent on wheelchairs for ambulation.

Research questions:

i) How is the relative test-retest reliability of the Norwegian version of SCI-FCS?

ii) How is the absolute test-retest reliability of the Norwegian version of SCI-FCS?

iii) How is the internal consistency of the Norwegian version of SCI-FCS?

4 Methods and patients

4.1 Design

The present master study was conducted in two steps. Firstly, the original version of the SCI-FCS was translated and cross-culturally adapted into Norwegian according to guidelines (Beaton et al., 2000). Secondly, the test-retest reliability of the SCI-FCS was studied in a cross-sectional study with a test-retest design.

4.2 Step 1: Translation and cultural adaptation of the SCI-FCS

The SCI-FCS was translated and back-translated, according to guidelines, for the cross-cultural adaptation of self-report instruments (Beaton et al., 2000). See Figure 5.

Initially, a professional translator and a bilingual physiotherapist familiar with the terminology separately translated the SCI-FCS from English to Norwegian. The translators signed a consent form prior to the translation work (see Appendix 1). The translation was conceptual and cultural, rather than letter-by-letter. Ahead of the translation, a form was established with all expressions in the original Australian version, together with space in a table to fill in the Norwegian translation sentence by sentence, expression by expression. Each of the two translators received one copy to fill in by themselves (see Appendix 2).

Both translators were Norwegian, had spent periods of time in Australia and had Australians in their near families. Their Australian connections were considered to be beneficial, as the original version of the SCI-FCS is Australian.

The translated versions produced by each translator were synthesized into the first Norwegian version by the two translators and the Master's degree student. Consensus on the first translated Norwegian version was reached in a meeting with the two translators and the Master's degree student. A report was written on what was difficult, what was clear, and each translator's opinions and questions to bring back to the expert group. The two translations were compared and decisions were made in synthesizing the translations into one translation

in another ready-made form, which contained each translator's translated expression and the synthesized expression on each sentence and each item.

Thereafter, an expert panel, comprising three physiotherapists with expert competence in SCI and the Master's student, met to discuss the first synthesized Norwegian version of the SCI-FCS. Issues with the synthesized translation were identified and resolved and a report was written, before the first Norwegian version was ready for back-translation.

Two independent translators whose mother tongue was English and who had good knowledge of Norwegian performed the Norwegian-English back-translation. One was a linguistics professional, and the other was a physiotherapist. A form was made in advance of the back-translation and was filled in by the back-translators (see Appendix 3). The form contained the Norwegian expressions and space for each sentence and expression to fill in the back-translated English expressions. The back-translators had no knowledge of the original English version. They were asked to consider cultural differences that would require adjustments to the survey during back-translation. The two back-translations were synthesized into one back-translated English version in a meeting with both back-translators and the Master's student. A form was made for this purpose in advance, which contained each back-translator's expression on each item and sentence, including space underneath to fill in the synthesized back-translated expression on each sentence and item after consensus was reached.

A new form was made, consisting of the first Norwegian version, the back-translated version, the original version and space in which to write the final Norwegian translation. The form was used during the last meeting in the expert group, where the linguistic and cultural differences between the versions were compared, and interpretations, modifications and discrepancies were discussed until consensus was reached on the first Norwegian version. The expert group found issues that needed an answer by the author of the original version of the SCI-FCS, Claire Boswell-Ruys, who was contacted by email. Conversation with Boswell-Ruys was incorporated into the expert group's discussions. Changes were made to address translation and cultural concerns. The second Norwegian version of the SCI-FCS was then tested in a patient pilot study at Sunnaas Rehabilitation Hospital (Figure 7).

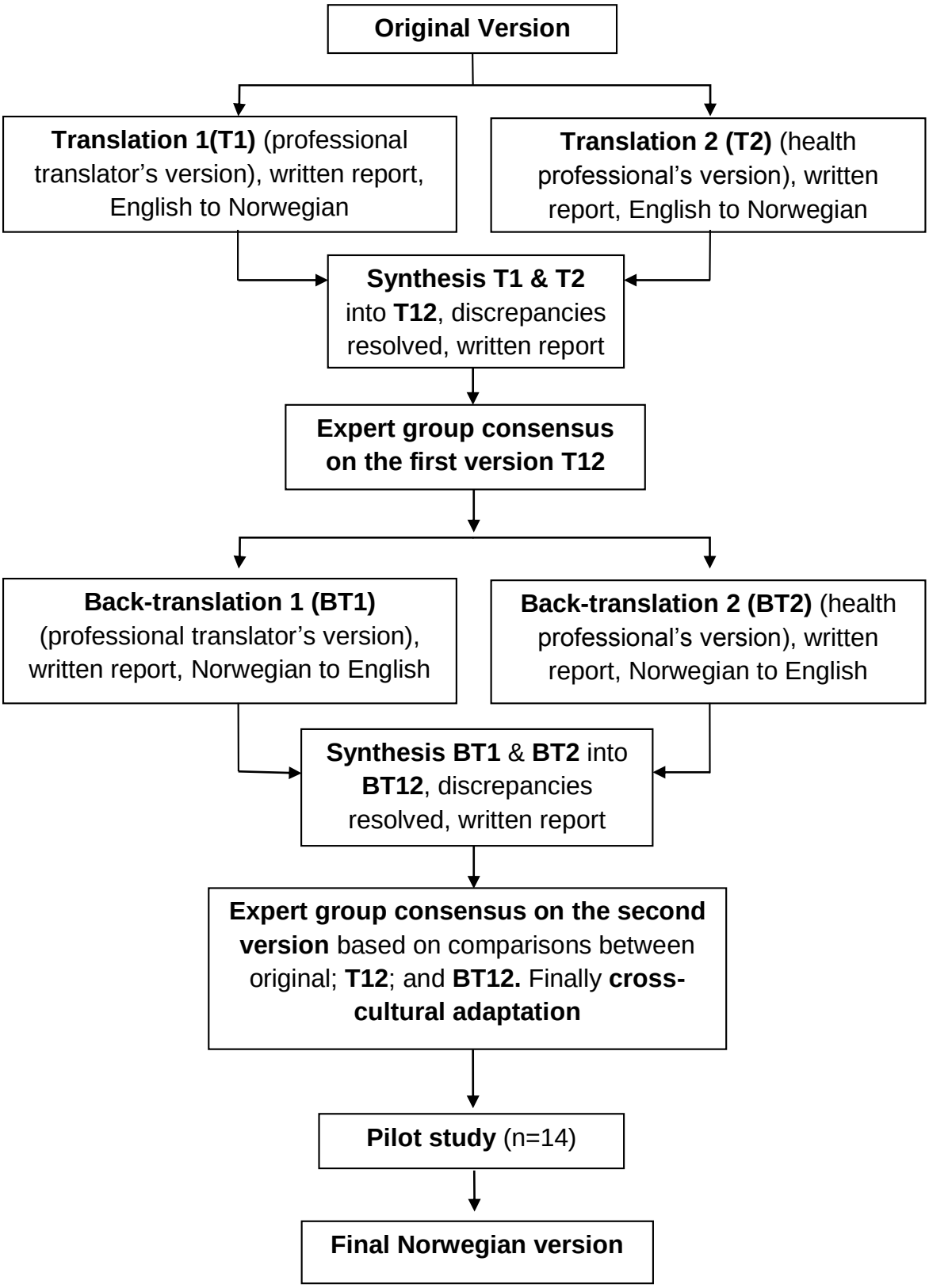


Figure 7. The translation and cross-cultural adaption of the Norwegian version of SCI-FCS.

In the pilot study, a convenience sample of 14 patients (one woman and 13 men aged 24-84 years, mean 55 years), responded once to the Norwegian SCI-FCS in the presence of a PT (the Master's student), after having signed a consent form to participate in the pilot study (see Appendix 4). All but one had been injured for more than one year, had complete or incomplete SCI, and was paraplegic or tetraplegic. The Master's student was present to answer potential questions and register response patterns, hesitations or uncertainties. After filling in the questionnaire, the participants were asked if anything was unclear or difficult, and regarding the participants' perception, they were asked about what they thought was meant by each item and about the chosen response, to ensure that the adapted version still retained its equivalence in an applied situation (Beaton et al., 2000). The expert group analyzed the results of the pilot study and concluded that the first version of the Norwegian SCI-FCS was relevant, understandable and easy to answer, bearing in mind that responders had to focus on how they usually performed the activities in question. On this basis, no changes were made to the first Norwegian version, and consensus was reached to call this version the final version. The final version of the Norwegian SCI-FCS is shown in Figure 8 (paragraph 5.1.).

4.3 Step 2: Reliability study

4.3.1 Patients and design

To assess the test-retest reliability, the final Norwegian version of the SCI-FCS was administered to a sample of individuals with SCI using a wheelchair, consecutively recruited from indwelling patients with SCI from Sunnaas Rehabilitation Hospital, PVO4 team (unit for outpatient, assessment and follow-up, team 4) in the PVO unit. The patients were staying at the hospital during a control stay, assessment stay, problem-solving stay or follow-up rehabilitation stay, with different lengths of stay. The Master's student contacted and recruited all participants when staying at the hospital in the period from September 2012 until the end of January 2013. Patients were included if they fulfilled the inclusion criteria, as follows:

- 18 years of age or older
- Have a complete and incomplete SCI for one year or more

- Use a wheelchair for transportation at least 75% of the time
- Have the ability to collaborate and have good understanding of the Norwegian language in speech and writing

Patients dependent on a ventilator during the day were excluded from the study.

Medical background data were taken from the participants' medical journals. Background data were also collected in interviews with the participants using a background data form (see Appendix 6). Background data used in this study were: age; gender; time since injury; complete or incomplete SCI; and level of injury, AIS motor score, AIS classification, education, fall history last year and a single-item question "In general, are you afraid of falling over?" More background data were collected but will be used in a later validity study of the Norwegian SCI-FCS (see Appendix 6).

Demographic, diagnosis-specific data and fall history for the 54 participants are presented in Table 1. There were 45 men and 9 women, with a mean age of 49 years (min-max: 20-92). Thirty-one of 54 participants (57%) had complete SCIs. The median motor sum score was 50 points (min-max: 2-91), showing a wide range of severity of injury in the group. A few of the participants were able to walk for short distances with walking aids but used wheelchairs more than 75% of the time. Two-thirds of the participants (65%) reported that they were afraid of falling. Three quarters (76%) of the participants had fallen within the last year, and of these, 70% had fallen more than once.

Table 1. Demographic and SCI-related characteristics for the 54 participants in the reliability study.

Characteristics/variable	**N=54**
Age in years: mean (SD)(min-max)	49 (17) (20-92)
Gender, n (%)	
Men	45 (83)
Women	9 (17)
Time since injury (years): median (min-max)	13 (1-59)
Complete or incomplete SCI: n (%):	
Complete SCI	30 (56)
Incomplete SCI	24 (44)
Level of injury, n (%):	
Tetraplegia	21 (39)
Paraplegia	28 (52)
Cauda equina injury	5 (9)
AIS motorscore: median (min-max)	50 (2-91)
AIS classification (n/%):	
A	31 (57)
B	6 (11)
C	9 (17)
D	8 (15)
Education, n (%):	
No secondary school	3 (6)
Secondary school	6 (11)
High school	24 (44)
College/ University	21 (39)
Falls last year, n (%):	
Yes	41 (76)
No	13 (24)
Number of falls last year, n (%):	
0	13 (24)
1	16 (30)
>1	25 (46)
A single-item question: "In general, are you afraid of falling over?", n (%):	
Yes	35 (65)
No	19 (35)

Completeness of SCI classified according to AIS (ASIA Impairment Scale) classification.
AIS motorscore: Scale with a sum score of 0-100 for muscle strength, where each item is scored from 0-5, with 0 indicating paralysis and 5 indicating normal strength. AIS (ASIA Impairment Scale) classification: A = No motor or sensory function is preserved in the sacral segments S4-S5; paralysis below injury level. B = Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5. C = Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade of less than 3. D = Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more. E = Motor and sensory function are normal (not relevant here).

4.3.2 **The Spinal Cord Injury Falls Concern Scale (SCI-FCS)**

The SCI-FCS (Figure 6, paragraph 2.9) evaluates concern about falling during performance of 16 daily-living activities. For each of the 16 activities, participants are asked to circle the opinion closest to their own to show how concerned they are *that* they might fall if they performed the activity. When responding, they are asked to think about how they usually engage in the activity and if they currently do not engage in the activity (e.g., if someone does their shopping for them). They are asked to consider whether they think they would be concerned about falling if they did the activity.

The 16 items are as follows: getting dressed or undressed, moving around the bed, toileting, washing or showering oneself, transferring in and out of a wheelchair in different situations, reaching for high objects, picking objects up from the floor, cooking, pushing a wheelchair in different situations, shopping and lifting heavy objects across one's body. The items in the SCI-FCS may be classified according to activities in the ICF (WHO, 2014a) (Boswell-Ruys et al., 2010b). Each item is scored on a four-category ordinal scale: 1) not at all concerned, 2) somewhat concerned, 3) fairly concerned and 4) very concerned (Figure 6, paragraph 2.9.).

All 16 item scores are summed to obtain a single sum score varying from 16 to 64 points, with lower scores indicating low levels of concern about falling. The questionnaire takes 5-20 minutes to complete. In this master study the participants fill out the form by themselves if they are able but participants who are incapable of filling out the questionnaire by themselves (e.g., whose arms and hands are paralyzed) get help from the Master's student.

4.3.3 **Fear of falling**

Fear of falling was assessed by asking the patients the single-item question "In general, are you afraid of falling over?" (Yardley & Smith, 2002). Answering alternatives were "very much", "quite a bit", "a little" or "not at all". Answers were dichotomized into YES ("afraid of falling") and NO ("not afraid of falling"). Patients answering "not at all" were categorized into the "not afraid of falling" group.

4.3.4 **Data collection procedure**

From September 2012 until the end of January 2013, all in-patients that fulfilled the inclusion criteria were contacted by the Master's student at arrival at Sunnaas Rehabilitation Hospital,

at the PVO unit, team 4. This unit has a responsibility for the life-long follow up of patients with SCI after primary rehabilitation and is the most likely unit to recruit patients one or more years post-injury. The patients in the PVO4 unit are considered to be stable concerning function, disability and health, meaning that there is a great possibility that particpants' responses to the Norwegian SCI-FCS the first and second time were not affected by changes of those conditions. The stays for the PVO4 patients may be a three-day control stay, a five-day assessment stay or problem-solving stays for even more than five days. A few patients also get a secondary rehabilitation period according to their issue.

The PVO4 unit receives follow-up patients continuously each week and it was therefore easy to get access to the patients by asking them to participate at admission. It is also less time-consuming and easier to follow up face-to-face regarding the cross-sectional study than using mail, e-mail or telephone calls.

Before asking the patients to participate, the Master's student had read each patient's medical journal to check if they filled the inclusion criteria for participating, in order to avoid participants that didn't fill the inclusion criteria. The patients that filled the inclusion criteria were asked to participate at admission, and all were willing to participate. The participants gave their informed consent (see Appendix 5) prior to the participation, and they recieved verbal and written information about the study. The information included background of the study, what the study meant to the participant, possible advantages and disadvantages, what was going to happen with the information about each participant, and that the participation was voluntary. A total of 56 patients were first included in the study. Two patients were excluded later, one due to missing data (as the participant left the hospital before responding to the Norwegian SCI-FCS a second time) and the other due to being injured for less than one year. Thus, a total of 54 participants were finally involved in the study (see Table 1). Prior to the data-collection period, the multidisciplinary team at the PVO4 unit that worked with the patients participating in the study were informed about the study by e-mail and by an information meeting. In addition, the health professionals were continuously updated verbally through the data collection period. Nurses were willing to contribute to the data-collection procedure by weighing the patients, and physicians contributed by conducting the AIS screening test and obtaining the AIS motor scores.

To conduct the data collection, the Master's student had to book appointments in the participants' weekly hospital schedule. All patients at Sunnaas Rehabilitation Hospital who

stay for several days receive a weekly schedule that is printed out for them, so that their day and week is predictable. The weekly schedule is made the week before it is valid. The health professionals in the multidisciplinary team fill in all their activities in advance of the coming week and check that the activities don't collide. At least two appointments were booked for each patient within a maximum of seven days between. The first appointment took longer (about one hour) because of interviewing the participant concerning background data and conducting some physical tests for later validation after this Master's study. The patient's room or another chosen room was used when filling out the Norwegian SCI-FCS and conducting the interview for background data. The first and second time that the patient filled out the Norwegian SCI-FCS, the same room was used, with a few exceptions where that was not possible. The aim of using the same room the first and second time was to reduce the possibility that participants might be affected by different surroundings when completing the questionnaire. The participants responded twice to the Norwegian version of the SCI-FCS, with one to seven days (median three days) between the two occasions. With few exceptions, the Master's student was present helping the participants in case of questions or practical problems. Some of the participants needed help filling out the form due to lack of ability to hold and steer a pen.

Background data and data related to the testing of reliability and validity were collected by the Master's student through the use of structured interviews and established clinical tests, based on a questionnaire and a study protocol developed for the study (see Appendix 6) The SCI-FCS was administered in connection with the data collection or separately, depending on what was possible in light of the participants' and the master student's daily schedules. Interviews and clinical testing were conducted in the same way for each participant. For the present reliability study, the following data were collected: socio-demographic data, diagnosis-specific data, fall history and fear of falling (see Table1).

Validity data was collected in parallel to data on reliability, but as the scope is beyond the present study, details will be presented elsewhere. The validity data concerned the use of medicines and alcohol, spasticity, anxiety, fall risk, functional independence and some physical tests.

4.4 Statistical analysis

All statistical analyses were performed using IBM-SPSS Statistics, versions 18.0 and 20.0 (SPSS Inc., Chicago, IL, USA), as well as manual calculations. Parametric statistical methods were used, except for data not normally distributed that required non-parametric methods. Categorical data are presented as frequencies, percents and ranges (min-max) for each item scored. Numeric data are presented as means/medians and standard deviations (SDs) or ranges.

The Wilcoxon Signed Rank test for non-parametric data and the One Sample t-test for parametric data were used to test for any systematic differences between the groups (Polit & Beck, 2008). The sum scores at Time 1 (T1) and Time 2 (T2) are not normally distributed; therefore the Wilcoxon Signed Rank test was chosen. The difference between T2 and T1 is normally distributed, therefore the One Sample t-test was used with a confidence interval (CI) of 95% (see Table 3).

In order to analyze the reliability, the sum scores of T1 and T2, the mean sum scores for T1 and T2, and the difference between T2 and T1 were calculated for all participants.

A significance level greater than 0.05 represented non-significance, meaning that the probability of falsely detecting a correlation when in fact there was none, was 5%.

4.4.1 Relative test-retest reliability

To establish relative reliability, the $ICC_{2.1}$ was used. A one-way, repeated-measure analysis of variance (ANOVA) was used to calculate $ICC_{2.1}$ values. Strength of agreement for $ICC_{2.1}$ values was classified according to Bland and Altman (1999): poor = < 0.20, fair = 0.21-0.40, moderate = 0.41-0.60, good = 0.61-0.80, very good = 0.81-1.00.

4.4.2 Absolute test-retest reliability

Absolute reliability was analyzed using the SEM and SEM% and the SDC and SDC%. SEM denotes the smallest change that indicates a real difference for a group of subjects, while SDC represents the smallest change that indicates a real difference on an individual level (Bland & Altman, 1999). The SEM and SDC may indicate clinical changes.

The standard deviation of the difference between the sum scores at T2 and T1, "diffT2T1" was calculated in SPSS to be used to assess the SEM and SDC according to the formulas below.

The formula for SEM = Standard deviation (SD) of the difference between T2 and T1 sum scores divided on the square root of 2 = SDdiff/ $\sqrt{2}$

The SEM%, the within-subject standard deviation as a percentage of the mean, was defined by: SEM% = (SEM/mean) x 100 where mean is the mean for all observations from tests 1 and 2. The SEM% represents the limit for the smallest change that indicates a real (clinical) improvement or change for a group of individuals, such as an intervention.

The formula for SDC = SEM x 1.96 x $\sqrt{2}$

The SDC can be expressed as a percentage value, SDC% [SDC% = (SDC/mean) x 100] to allow the SDC to be independent of the units of measurement and thereby be used to determine a relative difference after an intervention or detect a relative deterioration over time.

A visualization of the SDC is made in a Bland Altman plot with upper and lower limits of agreement (LoA). These limits are calculated manually with the following formulas, where the difference between T2 and T1 in sum scores is named "diffmeanT2T1":

Upper LoA = diffmeanT2T1 + (1.96 x SDdiff)

Lower LoA = diffmeanT2T1 - (1.96 x SDdiff)

A scatter plot is made in SPSS with diffT2T1 on the y-axis and the mean of T1 and T2 sum scores (meanT1T2) on the x-axis. Then, the upper LoA and the lower LoA are plotted as two horizontal lines, illustrating how much the individual sum scores have to change from T1 to T2. The confidence interval is between the two lines of upper and lower LoA.

4.4.3 **Internal consistency**

Internal consistency was measured using Cronbach's alpha, which was interpreted as follows on the group level: excellent = > 0.9, good = > 0.8, acceptable = > 0.7, questionable = > 0.6, poor = > 0.5, unacceptable = < 0.5 (George & Mallery, 2003).

4.5 Ethical perspectives

The study protocol was approved by the Regional Committee for Medical Research Ethics in southeast Norway in May 2012 (2012/531) and the Ombudsmann for Privacy in Research at the Norwegian Social Science Data Services in June 2012. All participants gave their written informed consent before participation.

All translators, pilot participants and participants in the cross-sectional study signed an informed consent form (see Appendices 1,4 and 5). Information was given to the participants on the study's purpose and benefits and disadvantages. Participants were also informed that their participation was anonymous and voluntary and that they were free to withdraw at any time. Each participant was identified by a number in the pilot and cross-sectional study. In the cross-sectional study, each participant's number was registered in the SPSS statistical program. The paper documents (on which the participants' names were written and connected with specific numbers) were stored in locked cabinets.

The participants were also informed that there would be no consequences to their present or future hospital stays if they decided not to participate in the study. Secure copies of the data will be saved on the research server, according to Sunnaas Rehabilitation Hospital's guidelines for storage of research information, until destruction in 2016.

The translators were treated anonymously and not presented with names, to protect their privacy. For that reason, no documents with their translations are presented in the Appendix section. Only the consensus of the final Norwegian version and elements that were discussed in the translation process are presented. The discussions in the Results section are presented in a way that it should not be possible to discover which of the translators expressed or meant what.

The participants in the pilot and cross-sectional study were informed that participating in this study would probably not lead to any personal concrete benefits in the first run but maybe for future studies or interventions with the aim of preventing falls in populations in Norway with SCI. However, the participants might consider it worthwhile to contribute to the research, knowing that it might become beneficial for people with SCI in Norway in the future.

A disadvantage for the participants in the pilot and especially in the cross-sectional study is that they spent some time filling out the questionnaire form, being interviewed on background

data and conducting some clinical tests in the cross-sectional study. As the in-patients have a weekly schedule for all days of the week, this extra activity for participating in this study might cause a stressful situation for them, especially if they participated in other studies at the same time. However, the participants' weekly schedules were checked continuously in an attempt to avoid too many activities in one day, and extra considerations were taken for participants that were extra vulnerable and needed lengthy personal-care time.

The process of participating in the pilot and cross-sectional study could also be both beneficial or a disadvantage, because the participants have to reflect on fall-related psychological issues, their own FoF, transfers, and wheelchair skills while doing the clinical tests. Some might become strengthened in their own mastering, but some might be even more aware of how little they have mastered and become even more concerned about falling.

The advantage in the long run, if the psychometric properties are satisfying in the Norwegian SCI-FCS, would be further use of this study in research and in clinics to guide tailored interventions for addressing warranted and unwarranted concerns about falling for people with SCI who are using wheelchairs in Norway. Thus, health professionals could help in maximizing mobility and independence to enable greater community participation for this target group.

5 Results

5.1 Step 1: Translation and cultural adaptation

The SCI-FCS was translated into Norwegian and cross-culturally adapted for use in the Norwegian context. It was found to be relevant, understandable and easy to answer by individuals with SCI who depend on wheelchairs. The finalized Norwegian version of the SCI-FCS is presented in Figure 8.

Spinal Cord Injury Falls Concern Scale (SCI-FCS) - Norsk versjon

Vi ønsker å stille noen spørsmål om hvor bekymret du er for å falle. For hver av aktivitetene nedenfor skal du sette et kryss under det utsagnet som best beskriver din opplevelse av hvor bekymret du er for å falle når du utfører den aktuelle aktiviteten.
Når du svarer, tenk på hvordan du vanligvis utfører aktiviteten. Hvis du for tiden ikke utfører denne aktiviteten (for eksempel hvis noen handler for deg), svar likevel for å vise om du tror du ville vært bekymret for å falle HVIS du utførte aktiviteten.

		Ikke bekymret i det hele tatt 1	Litt bekymret 2	Ganske Bekymret 3	Svært bekymret 4
1	Kle på deg eller kle av deg				
2	Bevege deg i sengen (inkludert å sette deg opp)				
3	Ordne deg på toalettet inkludert sette klyster				
4	Vaske deg eller dusje				
5	Forflytte deg over på/av toalettstol eller toalett				
6	Forflytte deg inn i /ut av seng				
7	Forflytte deg inn i/ut av bil				
8	Strekke deg etter noe som er høyt oppe (f.eks. trykke på en heisknapp, nå opp til en hylle)				
9	Plukke opp ting fra gulvet (f.eks. klær, penn, matskål til kjæledyr)				
10	Lage mat (f.eks. smøre en brødskive, røre i mat på komfyren)				
11	Kjøre/bli kjørt i rullestol på flatt underlag				
12	Kjøre/bli kjørt i rullestol på ujevnt eller glatt/snødekket underlag (for eksempel grusvei, ujevnt/ dårlig vedlikeholdt fortau, brosten)				
13	Kjøre/bli kjørt i rullestol opp/ned fortauskant, eller over rennestein				
14	Kjøre/bli kjørt i rullestol opp/ned en bakke				
15	Handle				
16	Løfte tunge gjenstander fra en side av kroppen til den andre (f. eks. handleposer)				

Figure 8. The Norwegian version of SCI-FCS

The translation and cross-culturally adapted Norwegian version was considered to be equivalent to the original Australian version, as the process was thorough using the guidelines from Beaton et al. (2000), and all stages were followed with written reports for each stage. The final translated and cross-cultural Norwegian version was therefore considered to be ready to be tested for psychometric properties, which is necessary, as the new version might have altered the statistical or psychometric properties of the original instrument.

Below is an overview of the difficulties in translation and the cross-cultural adaptation process as well as the solutions for each expression and item. The expert group discussions revealed the difficulty of interpreting two expressions and 10 items connected to cultural and climatic differences between Australia and Norway. Questions were adapted to the habits of Norwegian individuals with SCI and reworded to facilitate interpretation:

- The word "concerned": The Norwegian language has more than one translation for the word "concerned". The Norwegian word bekymret was chosen. The expression "possibility of falling" could not be translated directly into Norwegian. The closest translation is mulighet, which does not fit in the context and the phrase hvor bekymret er du for å falle was chosen.

- Item 2: *Moving around the bed (including sitting up).* According to Boswell-Ruys, this includes all kinds of movements in and transfers into and out of bed. This was unclear to Norwegians and had to be clarified via email.

- Item 3: *Inserting enema or toileting*. When translating, the word "toileting" was discussed. The conclusion was that it included all actions performed while sitting on the toilet.

- Item 9: *Picking up objects from the floor (e.g., clothes, pet bowl, pen).* The word "pet bowl" was used as an example in the original. Finally, an equivalent Norwegian word was chosen after discussion of whether other items would be more relevant as examples in the Norwegian version.

- Item 10: *Cooking or food preparation (e.g., making a sandwich, stirring food on the stove).* In Norwegian, one word can be used to cover the preparation of hot or cold foods.

- Items 11-14: Pushing a wheelchair under different conditions. Item 11: *Pushing wheelchair on flat ground*; Item 12: *Pushing wheelchair on an uneven surface (e.g., rocky ground, irregular pavement)*; Item 13: *Pushing wheelchair up/down gutters or curbs*; Item 14: *Pushing wheelchair up/down a slope*. Australians use "push" in reference to both pushing oneself and being pushed by others. The clinical experience of the expert group was that individuals with SCI are more concerned about falling when they are being pushed by others, compared to when they control their wheelchairs themselves. We therefore chose to specify this by including the Norwegian expressions for pushing oneself and being pushed by others.

- Item 12: *Pushing wheelchair on an uneven surface (e.g., rocky ground, irregular pavement)*; In the Norwegian version, "slippery surface" and "snow-covered surface" were added.

- Item 13: *Pushing wheelchair up/down gutters or curbs.* The word "gutters" was discussed because several translators wondered if Norway has many gutters or if there is even a Norwegian word for "gutter". It was decided to include the Norwegian word for "gutter".

- Item 15: *Shopping*. The Norwegian word for "shopping" could also mean "to act" or "to take action". The context, though, was reckoned to be understandable, such that one Norwegian word was chosen.

5.2 Step 2: Reliability

5.2.1 Item scores at Time 1 and Time 2

Participants´ responses to each of the 16 items at Time 1 (T1) and Time 2 (T2) are presented in Table 2. From the table, we see that the patients' responses cover virtually the entire range of the scale from one to four for most of the items, both at T1 and T2.

Table 2. Item scores at T1 and T2 (test-retest) in the Norwegian version of the SCI-FCS presented as median and min-max for T1and T2. Possible scores for each item are 1, 2, 3 and 4.

Nr	Aktivitet	Median T1	Min-max T1	Median T2	Min-max T2
1	Kle på deg eller kle av deg	1	1-4	1	1-4
2	Bevege deg i sengen (inkludert å sette deg opp)	1	1-2	1	1-4
3	Ordne deg på toalettet inkludert sette klyster	1	1-4	1	1-4
4	Vaske deg eller dusje	1	1-4	1	1-4
5	Forflytte deg over på/av toalettstol eller toalett	1	1-4	1	1-4
6	Forflytte deg inn i /ut av seng	1	1-4	1	1-4
7	Forflytte deg inn i/ut av bil	1	1-3	1	1-4
8	Strekke deg etter noe som er høyt oppe (f.eks. trykke på en heisknapp, nå opp til en hylle)	1	1-4	1	1-4
9	Plukke opp ting fra gulvet (f.eks. klær, penn, matskål til kjæledyr)	1	1-4	1	1-4
10	Lage mat (f.eks. smøre en brødskive, røre i mat på komfyren)	1	1-4	1	1-4
11	Kjøre/bli kjørt i rullestol på flatt underlag	1	1-3	1	1-2
12	Kjøre/bli kjørt i rullestol på ujevnt eller glatt/snødekket underlag (f. eks. grusvei, ujevnt/dårlig vedlikeholdt fortau, brosten)	2	1-4	2	1-4
13	Kjøre/bli kjørt i rullestol opp/ned fortauskant, eller over rennestein	2	1-4	2	1-3
14	Kjøre/bli kjørt i rullestol opp/ned en bakke	1	1-3	1	1-4
15	Handle	1	1-3	1	1-3
16	Løfte tunge gjenstander fra en side av kroppen til den andre (f. eks. handleposer)	1	1-4	1	1-4

The median score was 1, meaning that at least 50% of the participants scored 1, which is "not at all concerned" about falling at both T1 and T2 for 14 out of the 16 items. The exceptions

were Item 12 “Wheel or drive your wheelchair on an uneven surface” and Item 13 “Pushing wheelchair up/down gutters or curbs”, for which the median was 2, “somewhat concerned” about falling.

5.2.2 **Time 1 and Time 2 sum scores**

The mean difference between T2 and T1 sum scores was -1.1 (Table 3). The median of the sum score for the SCI-FCS was 21 (range 16-46) for the first time (T1) and 20 for the second (T2) (range 16-44) (p=0.02).

There was a significant difference between T2 and T1 (DiffT2T1) with the One Sample t-test (p= 0.04) (95% confidence interval (CI) -2.07,-0.08).

Wilcoxon’s Signed Rank test for non-parametric data was also used and showed the same result, a significant difference between T2 and T1 sum scores (p= 0.02).

5.2.3 **Relative and absolute test-retest reliability and internal consistency**

The relative test-retest reliability of the Norwegian SCI-FCS proved to be very good, as indicated by the intraclass coefficient $ICC_{2.1}$ value of 0.83 (see Table 3).

The absolute reliability, i.e., the measurement error or the smallest change, SEM, was 2.6, representing a real improvement/change at the group level [SEM = SD diff/$\sqrt{2}$ = 3.64/1.414 = 2.57] (see Table 3). The SEM % was 11.7%.

At the individual level, the smallest detectable change, SDC, was 7.1 [SDC= SEM x 1.96 x $\sqrt{2}$ = 2.57 x 1.96 x 1.414 = 7.12] (see Table 3). The SDC% was 31.9%.

Table 3. Mean value, standard deviation (SD), min-max for T1 and T2 (test-retest), mean difference between T2 and T1 (95% confidence interval, CI), intraclass correlation coefficient ($ICC_{2.1}$), standard error of measurement (SEM), variation of measurement error (SEM%), smallest detectable change (SDC), SDC%, limits of agreement (LoA) and internal consistency (Cronbach´s alpha) for the Norwegian version of the Spinal Cord Injury Falls Concern Scale (SCI FCS) for 54 included participants in the reliability study.

	Time 1	Time 2								
n=54	Mean (SD) (min-max)	Mean (SD) (min-max)	Mean Difference (95% CI)	$ICC_{2.1}$	SEM	SEM%	SDC	SDC%	LoA	Cronbach´s alpha
SCI-FCS	22.8 (6.7) (16-46)	21.7 (6.3) (16-44)	-1.1 (-2.1,-0.1)	0.83	2.6	11.7	7.1	31.9	6.1, -8.2	0.88

Significant difference in sum score between T2 and T1 (p = 0.04).

A scatterplot defined as a Bland and Altman Plot (Bland & Altman, 1999; de Vet et al., 2011) is presented in Figure 9 and illustrates the difference between T2 and T1 plotted against the mean of T1 and T2. Each dot represents one or more participants. It is an illustration of the SDC with upper and lower limits of agreement (LoA).

As illustrated in Figure 9, the Bland and Altman Plot shows a concentration of low scores in the group, i.e., low concern about falling. In total, 48/54 participants (89%) scored 16 to 28 points (MeanT1T2 sum score). Six participants scored 32 to 42 and are spread across the middle part of the plot.

Some outliers were evident, and a tendency toward systematic change could be seen in the larger variation of the mean in individuals with higher mean scores on the SCI-FCS, compared to those with lower scores.

Ninety-five percent of the participants are inside the upper and lower limits of agreement (LoA) (6.1 to -8.2) (Table 3, Figure 9). The phenomenon is stable but, nevertheless, somewhat spread out.

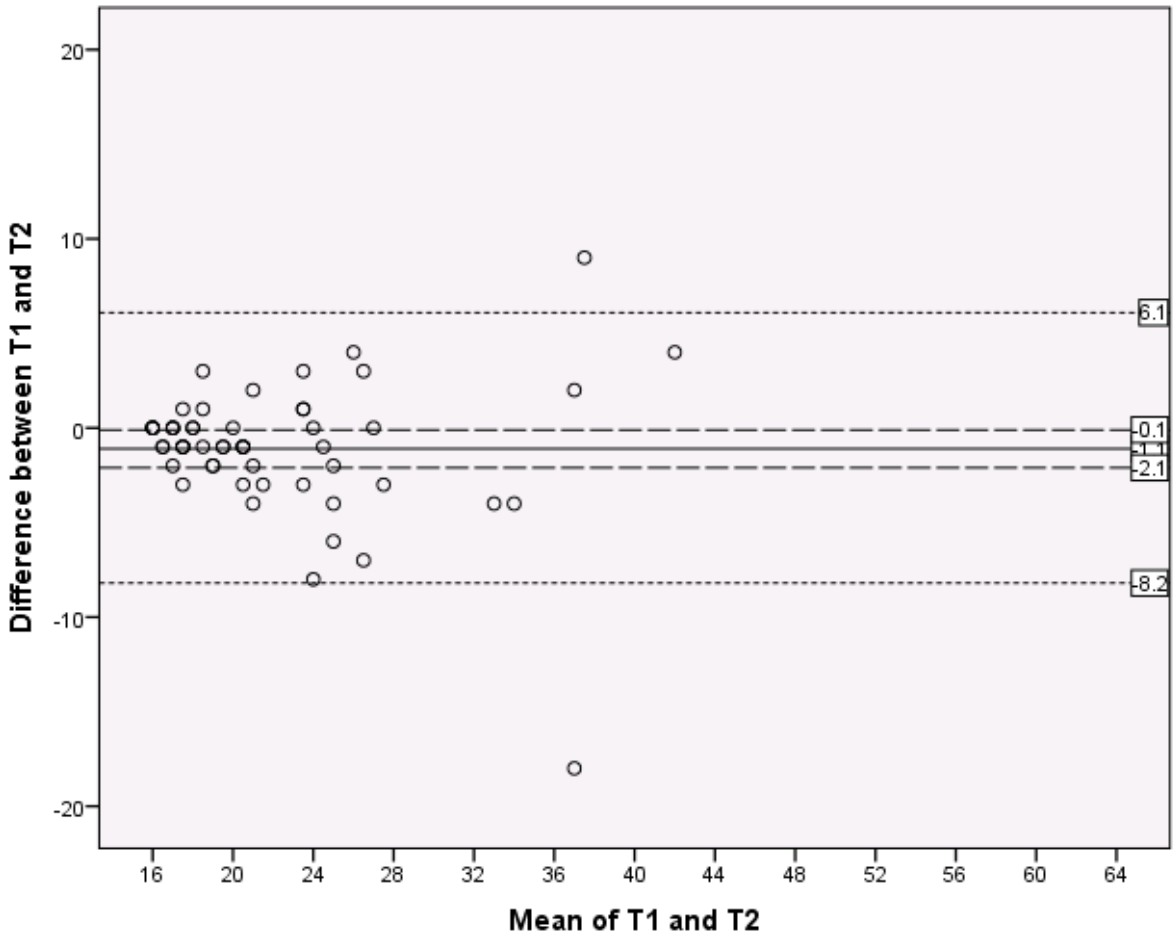


Figure 9. Bland and Altman Plot presenting the test-retest results from the Norwegian version of the Spinal Cord Injury Falls Concern Scale (SCI-FCS). The difference between the two tests, T1 and T2, is plotted against the mean of the two tests. The solid line represents the mean difference between the two tests; the dashed lines, the 95% confidence interval (95% CI) of the mean difference; and the dotted lines, limits of agreement (LoA).

The internal consistency measured by Cronbach's alpha was good (0.88) (see Table 3).

6 Discussion

6.1 Introduction to discussion

The SCI-FCS was successfully translated into Norwegian, adapted for cross-cultural use and was found to be relevant, understandable and easy to answer. Test-retest agreement was high ($ICC_{2.1}$ 0.83). The standard error of measure (SEM, SEM%) representing the smallest change that indicates a real (clinical) difference in a group of individuals was small, 2.6 (12%). The smallest detectable change (SDC, SDC%) representing the smallest change that indicates a real (clinical) difference for a single individual was somewhat higher, 7.1 (32%). Internal consistency (Cronbach's alpha) was high (0.88).

6.2 Methods discussion

6.2.1 Translation and cross-cultural adaptation

The translation and cross-cultural adaptation followed a certain procedure to secure accuracy and thoroughness (Beaton et al., 2000). These guidelines are based on a review of cross-cultural adaptation in medical, sociological and psychological literature (Beaton et al., 2000). Even though all stages have been followed in the process, the present study has some limitations. First, for convenience reasons, the pilot study was conducted after the last expert-group discussion and cross-cultural adaptation and synthesis of the first Norwegian version of the SCI-FCS, as the final stage of the process. By contrast, Abizanda and co-workers (Abizanda, Lóopez-Jiménez, López-Torres, Atienzar-Núñez, Naranjo & McAuley, 2011) chose to perform their pilot study earlier in the research process, so as to include the results of the pilot study in the last round of expert-group discussions. This was not possible in the present study and may not be a weakness, since the pilot study did not change the contents of the Norwegian version. However, failure to include the pilot study's results in expert-group conclusions might have reduced external validity. Abizanda et al. (2011) used the guidelines by Argimón and Jiménez (2000). The guidelines used in the present study by Beaton et al. (2000) are similar for the translation and cross-cultural adaptation of a self-report instrument except for where the pilot study is situated in the process.

It is positive that the pilot study used a population with SCI similar to the target population in the cross-sectional study. All pilot participants except for one, who was injured less than one year ago, would have filled all the inclusion criteria for participating in the cross-sectional study. The final version was approved by the pilot participants, and that created the best premises for further use in the cross-sectional study, because the pilot participants were similar to the participants in the cross-sectional study (even if they were not the same individuals). Using pilot participants without SCI would not be appropriate, as they would not be able to give feedback or have the perspective of an SCI participant.

The translation and cross-cultural adaptation went through several stages, involving several purposefully selected translators, back-translators, expert group and pilot participants and the Master's student. Several stages with written documentation for each stage were conducted with thoroughness. This thorough process is needed to secure an excellent translation and cross-cultural adaptation from the English language and Australian conditions into the Norwegian language and Norwegian conditions. In contrast, if only one Norwegian individual with a good knowledge of the English language just translated the original SCI-FCS into Norwegian and went through the cross-cultural adaptation alone, there would not be any other individual's perspective giving input to the translation and cross-cultural adaptation. Other perspectives and reflections from others, such as purposefully selected translators, back-translators, an expert group, and pilot participants with SCI would have been lacking. It is in meetings and discussions with several individuals that are specifically chosen for the task that a consensus is reached for the most optimal results. If the translation and cross-cultural adaptation process were poor, a Norwegian instrument might have resulted that is not equivalent to the Australian original and was limited in its comparability (Beaton et al., 2000).

It is a strength that the pilot participants were all Norwegians living in Norway and were thereby influenced by the Norwegian culture, which is the culture to which the questionnaire was adapted. There might have been a different situation if several of the pilot participants were immigrants and brought with them their own culture.

6.2.2 **Reliability study**

Material

The sample size in the reliability study was calculated to ensure accuracy in test-retest calculations. According to Terwee et al. (2007) and de Vet et al. (2011), at least 50 participants are required to test the psychometric properties in reliability studies. Thus, the present study fulfills the criteria with the inclusion of a total of 54 participants.

In accordance with the criterion presented by de Vet et al. (2011) and Carter et al. (2011), the present reliability study was performed in a sample of those patients in which the measurement instrument is to be applied in the future. Furthermore, the study population was recruited from individuals who routinely stayed at Sunnaas Rehabilitation Hospital and may not have been representative of the whole SCI-population in Norway. The mean age in the present study (49 years), was somewhat higher than that of the general SCI-population (40 years) (URT,2005). The fact that a few participants were in their eighties or nineties contributes to a higher mean age. However, a wide variation in severity of injury, motor and sensory affection and level of injury, as well as completeness of injury, indicate that the present study population is adequate for testing the reliability of the Norwegian version of the SCI-FCS. The Australian study used a convenience sample of participants from the community and local hospitals specializing in SCI. The inclusion criteria were similar to those of the present study. However, the Australian study included patients with both acute (less than one year since injury) and chronic (one year or more since injury) injuries. In the Norwegian study, patients were included only if they had had an SCI for one year or more, so as to fit the target group in the Swedish-Norwegian longitudinal study. The results of this Master's study are limited to the population that participated, a population that was considered representative of people with SCI who depend upon wheelchairs in the southeastern health region of Norway (URT, 2005; LARS, 2012). It is possible that results from testing individuals with acute SCI would have given a higher level of falls concern. This must be studied further.

When other fall-related psychological measures have been developed and used, they have recruited participants from institutions as in the present study. When using the FES, participants have been recruited from in-hospital patients (Cumming et al., 2000), community-living elderly people (Delbaere et al., 2004; Tinetti et al., 1994) and a geriatric balance and gait clinic in a period of time (Bishop et al., 2007). When using the Nursing Home Falls Self-Efficacy Scale, 14 nursing homes were used when recruiting participants (Lach et al., 2012). When developing the FES (Tinetti et al., 1990), a convenience sample of

elderly community-living people was used, in addition to elderly people living in intermediate-care facilities, senior centers and an elderly housing unit. People from several public senior house developments were used when developing the SAFFE (Lachman et al., 1998). All these examples show that participants for developing or using self-report scales concerning fall-related psychological issues are recruited from the actual target group where it is practically possible to get in touch with participants.

More than half of the participants had a complete SCI, regardless of injury level. Slightly more than half were paraplegics, 39% were tetraplegics, and 15% had cauda equina injuries. The median AIS motor scores (Table 1) were 50 out of a possible maximum of 100 points, meaning that complete paraplegics reached their possible maximum of 50 points for upper-body function and nothing for lower-body function. An incomplete tetraplegic might score the same as a complete paraplegic when having pareses in arms, trunk and legs, but the points are spread out over all possible chosen muscles in the AIS, legs and arms. Thus, the study population consists of both incomplete and completely injured, as in the general SCI-population.

Concerning gender, 45 men (83%), and only 9 women (17%) participated in the present study. This distribution is not alarming, as statistics on incidents show that more men than women get an SCI (see paragraph 2.2). However, it would have been interesting to find out if the research results would have been affected if the gender distribution were more equal or if more women than men had participated. Studies on women with SCI have shown that women are more vulnerable, feel isolated, and sense that many of their key concerns are ignored or dismissed by health care and service providers, and as they age, they are worried about declining health, increasing dependency and financial stresses (Pentland et al., 2002; Samuel, Moses, North, Smith & Thorne, 2007). Therefore, the most striking difference between men and women with SCI are that women have a more profound sense of isolation and perceptions that health care and service providers are unprepared or unwilling to address the unique issues they face as women (Pentland et al., 2002).

As many as 76% had experienced one or more falls last year, 30% had experienced one fall, and 46% had experienced more than one fall. This illustrates that issues about falls and falling are common among people with SCI, as confirmed by the studies of Nelson et al. (2010) and Boswell-Ruys et al. (2010b).

Studies among ambulatory elderly people show a higher frequency of falls according to a person's age. We don't know if this is also the case also in the SCI-population, but the question is relevant and interesting in the present study, as the age range is 20 to 92 years.

Data collection

In the present study, the participants self-reported the Norwegian version of the SCI-FCS, which means that they read the questions on a written form and gave their answers in writing themselves. The self-report method is strong in directness and versatility (Polit & Beck, 2008). If we want to know what people think, feel, or believe, they have to be asked about it (Polit & Beck, 2008). According to Boynton, Wood and Gleenhalgh (2004), questionnaire research can never be completely objective, as researchers and participants are all human beings with psychological, emotional and social needs, and the questionnaire can mean different things to participants and researchers.

The fact that participants responded to the Norwegian version of the SCI-FCS by themselves may be a limitation of the data-collecting process. Using trained data-collectors and interviewer-administered tests, rather than self-administered tests, would have been another alternative to ensure that questions are understood and adequately answered. However, in the present study, a physiotherapist (the Master's student) with a thorough knowledge of the SCI-FCS and the study population was present, giving the informants the ability to discuss the most-appropriate scores and thus minimizing possible sources of error. In addition, a few of the participants got help filling in the questionnaire with a pen due to a lack of function in their upper extremities.

When testing a self-report scale with test-retest reliability, there are some disadvantages in terms of traits like attitudes, behaviors, knowledge, physical condition, etc. that can be modified by experiences between the two test situations (Polit & Beck, 2008). The second test may be influenced by the participant's memory from the first test or a learning effect from the first test. The participants may change as a result of the first testing and may have another attitude about their concern about falling in the second test. They may not be as careful to use the same instrument a second time if they find the test boring, or if they may fill in the questionnaire rapidly. Also, the participants' general condition may vary from day to day. All these aspects may affect how they respond the first and second time, even if the researcher tries her or his best to make the two test situations as similar as possible. Another aspect is

that the results from the clinical tests were conducted in the interval between the first and second situation, and filling in the questionnaire may affect patients' level of falls concern. If the clinical tests showed good results, the participant could gain greater self-esteem and a lower level of falls concern, and the opposite might be true if the results of the clinical tests were not satisfying. In the present study, the participants were stable on all controllable aspects in the interim period on the construct to be measured. However, there seems to be learning effects from the first to the second test, as concerns about falling are lower the second time.

It is important that the situation for a reliability study resembles the situation in which the measurement instrument is going to be used (de Vet et al., 2011). In this case, the measurement instrument is planned to be used in rehabilitation and on individuals with SCI, which is similar to the situation when the test-retest reliability study was conducted. The first and second tests were administered in the same room, the patient's room or another chosen room, so that participants' responses should not be affected by changes in their surroundings. When testing the test-retest reliability, the researcher's ambition was to create a similar situation the first and second time the questionnaire was completed. Surroundings is one factor; the Master's student being present is another factor. In in this study, these factors were stable except for a very few exceptions where they were not possible for practical reasons.

The collection of background data (see Appendix 6) was conducted in connection with the participant filling in the questionnaire for the first time, with few exceptions when it was conducted separately for practical reasons. The Master's student interviewed each participant face-to-face with the background data scheme and interview guide and filled in the answers. The clinical tests were conducted in physiotherapy rooms, adapted for the purpose, and led and instructed by the Master's student. The same procedure for collecting background data and conducting the clinical tests was followed in order to give the participants the same premises, to secure accuracy in the testing of test-retest reliability by using a cross-sectional study.

The appropriate time interval between the two tests when testing the test-retest reliability has to be decided. If the characteristic, falls concern (fall-related psychological issues), changes rapidly, the time between the two tests should be as short as possible. If the characteristic is stable, a longer time interval can be allowed (de Vet et al., 2011). There are no standard rules, but an indication from de Vet et al. (2011) is a time interval of two weeks. In the present

study, a minimum of one day and a maximum of seven days were used between the two tests. The reason for the choice of a shorter period than two weeks was that many of the participants had a shorter stay at the hospital than two weeks, and a short interval between the tests would ensure that the characteristic, falls concern, would be stable enough in that period of time.

Statistical analysis

Of the background data that were collected, only an extract that was considered of value for this Master's study is presented. The rest of the collected data will be used in a validation study later on. The determination of what was going to be included in this study and the next validation study was not totally clear, but it was considered that demographic data, data on falls frequency, and the question "Generally, are you afraid of falling over?" were important to include in the present study. Different statistical analyses have been conducted in the present study using the data collected from the participants, in order to discern test-retest reliability.

One aim of the present study is to investigate the test-retest reliability within a Norwegian-speaking sample of individuals with SCI who are dependent on wheelchairs for ambulation. The statistical analysis for this is measuring relative reliability with the $ICC_{2.1}$ (intra-class correlation coefficient) and absolute reliability with the SEM, SEM% and SDC, SDC%. Also, internal consistency measured with Cronbach's alpha was used. The present study is strong in that absolute reliability for the SCI-FCS was addressed for the first time, providing a conceptual framework for the interpretation of clinically relevant differences in the group and individuals' concern of falling. Other statistical analyses could have been used to shed light on the test-retest reliability like Spearman's rho correlation coefficient. As there are several aspects concerning test-retest reliability, it was necessary to conduct several statistical analyses, both relative and absolute reliability, to strengthen the total impression of the test-retest reliability.

A variety of statistical methods have been used to establish relative test-retest reliability in other fall-related psychological instruments. The authors of SAFFE (Lachman et al., 1998) did not measure test-retest reliability, the modified SAFFE (mSAFFE) used Pearson's rank correlation coefficient (Yardley and Smith, 2002), and Tinetti et al. (1990) used Pearson's r correlation coefficient to assess the test-retest reliability on the first FES (Moore and Ellis, 2008). From 1994, the $ICC_{2.1}$ was used for test-retest reliability by Tinetti et al. (1994) in the

rFES (revised FES). In 1996, it was used by Hill, Schwarz, Kalogeropoulos and Gibson in the mFES (modified FES), and in 2005 by Yardley et al. (1995) in the FES-I (FES-International). Test-retest reliability for the ABC (Activities-specific Balance Confidence Scale) was measured with Pearson's r correlation coefficient in 1995, but the ABC-6 (six item ABC) from 2006 was measured with the $ICC_{2.1}$ (Moore and Ellis, 2008). It seems like there is a trend that the $ICC_{2.1}$ is more frequently used nowadays when measuring relative test-retest reliability and that Pearson's correlation coefficient and other correlation coefficients were used more frequently in the nineties. The $ICC_{2.1}$ is considered to be a more stringent test-retest correlation coefficient than Pearson's r (de Vet et al., 2011), which is less critical.

Concerning the internal consistency, the Cronbach's alpha has been used in most measurement instruments on fall-related psychological issues since 1990 (Moore & Ellis, 2008), which also is the case in the present study.

In the present study, the $ICC_{2.1}$ was used to establish the relative test-retest reliability. To strengthen the test-retest reliability, internal consistency, which is another reliability coefficient, was measured with Cronbach's alpha. In addition the absolute reliability is measured with the SEM, SEM% and the SDC, SDC%, which is not common in other studies on measurement instruments concerning fall-related psychological issues and is considered to strengthen the test-retest reliability results (Moore & Ellis, 2008). Thus, several measurement instruments have been used to establish reliability in the present study, including the absolute test-retest reliability, which is a strength in the study.

6.3 Results discussion

6.3.1 Translation and cultural adaptation

The SCI-FCS was successfully translated and cross-culturally adapted to the Norwegian context and was found to be relevant, understandable and easy to answer by individuals with SCI using a wheelchair. A relevant and understandable questionnaire is important for securing trustworthy responses from participants in a test-retest study. We have no knowledge about other translations and cross-cultural adaptations of the instrument SCI-FCS, except for a parallel ongoing validity study in Sweden. Therefore, there were no other countries'

translations or cross-cultural adaptations to compare to the final Norwegian version, other than the Australian original.

In the Norwegian version of the SCI-FCS, items 11-14 were adapted to Norwegian conditions. This was necessary because surfaces outdoors in Norway are slippery and snowy for long periods each year all over the country, which is challenging for wheelchair users, as their wheels often are thin and easily get stuck in the snow or slush or lose their grip if it is rainy or icy. The cross-sectional study was conducted from September 2012 until February 2013, thus beginning in autumn and ending in winter. This means that the conditions of outdoor surfaces changed during the study. The experience of the researcher was that concerns of falling were not affected by season, as participants had generally low scores through the whole test period. This observation has to be further investigated.

Built on clinical experience, the Norwegian expert group wanted to distinguish between concerns about falling when being pushed, compared to when the individuals were driving the wheelchairs by themselves. This resulted in the inclusion of a greater specification in items 11-14 in the Norwegian version. This was done to encourage respondents to disclose whether they usually were pushed or drove themselves. The changes were approved by the originator, Boswell-Ruys et al. (2010b) who confirmed that both aspects should be emphasized.

The final version of the Norwegian SCI-FCS was the setter for the cross-sectional study, where test-retest reliability was established. We do not know if further changes in the translation and adaptation, the use of another study population or changes to the setting in which the scale was administered would have interfered with the results of the reliability study.

6.3.2 **Relative and absolute test-retest reliability**

In accordance with the original Australian version of the SCI-FCS (Boswell-Ruys et al., 2010b) ($ICC_{2.1}$ 0.93), we found very good test-retest reliability for the Norwegian version of the SCI-FCS ($ICC_{2.1}$ 0.83). One explanation for our slightly lower value may be that the Australian study used telephone and face-to-face-interviews, while we used self-assessments. So far, there are no other studies on psychometric properties in fall-related psychological instruments related to the SCI population.

The present study addresses absolute reliability of the SCI-FCS for the first time. The low SEM and SEM% in the present study reveal that a reasonably small change in sum scores from one test to the next test is enough to detect changes in a group of individuals showing that the Norwegian version of the SCI-FCS is sensitive to change over time. This is important for detecting clinical changes from one test to another using the same self-report scale (Lexell and Downham, 2005). However, in the present study, this applies primarily for subjects with low to moderate concerns about falling. The fact that we found a tendency toward greater variation in the sum score among subjects with greater concern of falling may indicate that the SEM and SDC may be even larger in groups or individuals with greater concerns of falling. It is important to take this into consideration when evaluating the outcomes of the SCI-FCS.

This study showed that at the group level, the sum score of SCI-FCS has to change by > 3 points or 12% (SEM = 2.6) to identify a clinical change over time, while on the individual level, the sum score would have to change by > 7 points or 32% (SDC = 7.1). In a study by Halvarsson, Franzén and Ståhle (2012) of elderly people having an increased fall risk, the absolute reliability of the FES-I was similar to the present study. The SEM was 2.9, and the SEM% was 10.6%, whereas the smallest real difference (SRD, identical to SDC) was 7.9, and the SRD% (identical to SDC%) was 29%. The patient groups in the two studies are not comparable other than the common concern about osteoporosis, but one might claim that psychometric properties for the instruments are, as the two instruments FES-I and SCI-FCS are related and built on the same construct.

The SEM and SDC are important when using the SCI-FCS to evaluate changes over time on rehabilitation efforts at the group and/or individual level. However, at the individual level the patients have to improve considerably to exceed the measurement error (32%), which might be unrealistic, as most individuals already have a low concern of falling and thus have a low potential for improvement. Therefore, the SCI-FCS might be better suited as a screening instrument rather than an outcome measure, especially at the individual level. This has to be studied further.

Internal consistency (Cronbach's alpha) in this study (0.88) was good, though slightly lower than the internal consistency of the Australian version, which had excellent internal consistency (0.92). Cronbach's alpha describes the extent to which all the items in the scale measure the same construct (Polit & Beck, 2008). A very high Cronbach's alpha may indicate

overlap between items, and the slightly lower Norwegian values might, therefore, not be a weakness.

The participants in the present study had relatively low concern of falling with a sum score of 16-46 (mean 23) at T1, meaning that they had a relatively good confidence that they could do the 16 activities without falling, i.e., a high falls self-efficacy. Our findings are in accordance with the study of Boswell-Ruys et al. (2010b) who found that the participants had a sum score of 16-35 (mean 23) at T1.

As anticipated, we found higher levels of concern of falling on items 12 and 13, which demand wheelchair skills to maneuver on uneven surfaces (snow, ice, rocky ground, irregular pavement) and up and down gutters or curbs. This is in accordance with the findings of Boswell Ruys et al. (2010b), who concluded that the highest concern of falling addressed activities involving large shifts of the body's centre of mass or movement of the arms and hands that would reduce a person's ability to use the hands to stabilize the body.

Surprisingly, we found that 2/3 (65%) of the participants were afraid of falling when asked the single-item question, "In general, are you afraid of falling over?" This is in contrast to the low percentage of participants (6 out of 54) scoring somewhat higher concerns of falling on the SCI-FCS (32-42 points). The low median scores at T1 and T2 on item scores (Table 2) show that except for items 12-13, the population with SCI in this study mainly "are not at all concerned" and "somewhat concerned" (item 12 and 13) about falling. The discrepancy is probably due to the fact that fear of falling and fall-related self-efficacy represent unique constructs, although similar in nature, and should not be compared but measured and spoken of as unique constructs (Moore & Ellis, 2008). In the study by Boswell-Ruys et al. (2010b), significantly higher levels of concern of falling measured by SCI-FCS were admitted by participants a with self-reported fear of falling. The phenomena will be studied in the coming validity study of the Norwegian SCI-FCS.

Responses to individual activities in our study covered the full range of categories available (1-4) for most items, indicating that the SCI-FCS seems to be relevant to the target group. The total SCI-FCS scores were relatively widespread, from 16 to 46 (mean 23) at T1. This showed that the majority of the participants in our study had a relatively low concern about falling. The relatively low scores in the present study are comparable to the scores in the Australian reliability study, whose range was 16-35 (mean 23 at T1) (Boswell-Ruys et al., 2010b). From

a clinical point of view, the results are interesting and somewhat surprising, as two-thirds had a severe injury classified as A (57%) or B (11%) on the AIS classification and more than half (56%) had a complete SCI. In the study by Boswell-Ruys et al. (2010b), significantly higher levels of concern were reported by participants with paralysis of the abdominal muscles, poor sitting ability and dependence during vertical transfers. Those with an acute injury also tended to have greater fear of falling than participants with chronic injuries. Therefore, it seems important to identify early-on those individuals with a high concern of falling, so as to develop tailored interventions that would address unwarranted concerns and thus optimize rehabilitation.

The tendency towards lower scores at T2 compared to T1 in the present study is probably due to learning effects. The SCI-FCS is a newly-developed instrument, and at T1, the participants had never seen the scale before, nor had they been asked to reflect on its items. By the time of the second test, the participants were familiar with the scale and had the opportunity to test out the different activities mentioned in the test during the intermediate days. When using the SCI-FCS in effect studies, it therefore seems important to familiarize participants with the scale during a pre-test, to pre-empt the learning effect.

At Sunnaas Rehabilitation Hospital, we foresee the use of SCI-FCS in rehabilitation to identify levels of concern about falling in relation to specific activities, such as those related to daily living or wheeling the wheelchair. Furthermore, we hope to develop tailored interventions that address excessive levels of concern about falling and thus maximize mobility, independence and community participation. The SCI-FCS may also be used to set activity goals for patients, to prevent falls in specific situations or to encourage mastery of the activities on the SCI-FCS, as these correspond with some of the most basic and complex skills an individual with SCI has to master to live independently. The study by Tinetti and co-workers (1994) suggests interventions that consist of physical skill training and efficacy training. Personal accomplishment will in turn build efficacy and enable a person to attempt more complicated tasks. In addition to being introduced to other persons with a similar condition, the ability to overcome tasks could build self-efficacy (Tinetti et al., 1994). Using qualitative content analysis, Lundborg & Hartman (2013) studied the perception of fear of falling in male wheelchair rugby players with SCI aged 26-35 years. Wheelchair rugby is a rough sport that causes routine falls from the wheelchair. The more falls they experienced, the lower was these athletes' level of fear of falling. Fear of falling was generally higher in daily

life outside the rugby court, as there always were people present on the court to help them back up into the wheelchair. The players attested that the rugby training gave them useful tools to prevent falls in daily life. It therefore seems that training on falling and getting up in the wheelchair resulted in a reduction of fear of falling and contributed to improved skills.

As most of the individuals with SCI using wheelchairs in the present study scored relatively low on their concern of falling, one might claim that the SCI-FCS is more suitable for epidemiological than effect studies and as a screening instrument rather than an outcome measure, especially on the individual level. Further studies will show if this is the case.

To render the Norwegian version of the SCI-FCS useful in determining the effects of fall-prevention programs, additional study is necessary to establish the scale's validity.

7 Conclusion

The SCI-FCS was satisfactorily translated into Norwegian and cross-culturally adapted for use in the Norwegian context. The Norwegian version of the SCI-FCS is a reliable instrument concerning test-retest reliability for assessing concerns about falling in people with SCI who depend on wheelchairs. The SCI-FCS might be better suited as a screening instrument than as an outcome measure on the individual level.

8 Suggestions for further research

The validity of the Norwegian version of the SCI-FCS has to be tested for further use in Norway. Data on construct validity has already been collected (Appendix 6) with the same population and will be analyzed in 2014. The results will hopefully be presented in a scientific article, together with translation and reliability data.

As this study includes people with SCI that have been injured for more than one year, it would be interesting to investigate a population that has been newly injured and is in primary rehabilitation. There are no data on a newly injured population assessed by the Norwegian SCI-FCS, even if clinical experience indicates that newly injured people with SCI may have higher levels of concern of falling, than the population in the present study.

Coming research in the field of FoF and other fall-related psychological issues (e.g., falls efficacy in individuals with SCI who depend on wheelchairs) will show if there is need for further development of the SCI-FCS. One limitation of the present scale is its failure to address fall concerns related to physical activities, including sports. Situations encountered outside the home, in hotels or when visiting somebody are also not addressed, but they are nevertheless important to investigate, as they are part of an individual's life, including those with SCI who are dependent on a wheelchair.

Future studies will illuminate whether the term "falls concern" includes concern about the consequences of falling. According to the author of the original SCI-FCS, concern about the consequences of falling and concern about falling are part of the same concept, but new qualitative research indicates that these are distinct concepts (Ellis & Moore, 2008). The Consequences of Falling Scale (COF) (Yardley & Smith, 2002) was developed to assess the fear of consequences of falling among the elderly, which was also found to be in strong relationship with the avoidance of activities. In future studies, this should also be considered among populations with SCI who depend on wheelchairs.

Falls concern related to transfer activities (Items 5-7) and wheelchair driving (Items 11-14) can be differently experienced, depending on whether an individual is performing an activity herself or is assisted by someone else. Further research is needed to shed light on this question.

9 Finishing comments

This study has come to an end, but the work with testing the Norwegian SCI-FCS for psychometric properties will continue. More remains to be investigated about the Norwegian SCI-FCS. Data has been collected to test the validity of the Norwegian version for use in a future study. The Norwegian SCI-FCS will hopefully be useful in the larger research project between Norway and Sweden and other future studies.

In addition, it will be necessary to examine the predictive validity of the SCI-FCS and its sensitivity to change following interventions.

Hopefully, the Norwegian version of the SCI-FCS will contribute in the future to research about fall-related psychological issues for people with SCI. Our goal is to implement the Norwegian SCI-FCS at Sunnaas Rehabilitation Hospital. Early identification of individuals with high levels of falls concern may lead to better rehabilitative and preventive interventions and would also likely reduce fall-associated costs for society and increase individual quality of life.

The results of this Master's study will be published in a peer-reviewed journal.

The Master's study has been a learning process with many opportunities and perspectives for development along the way.

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Appendices

Appendix 1. Consent form translators: *Forespørsel om deltakelse som oversetter i forskningsprosjektet "Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS"*

Appendix 2. Translation document: *Skjema for oversettelse av Spinal Cord Injury Falls Concern Scale (SCI-FCS)*

Appendix 3. Back-translation document: *Skjema for oversettelse av Spinal Cord Injury Falls Concern Scale (SCI-FCS). Oversettelse fra norsk tilbake til engelsk: Back-translation (BT)*

Appendix 4. Consent form pilot participants: *Forespørsel om deltakelse i et pilotprosjekt for forskningsprosjektet"Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet Spinal Cord Injury Falls Concern Scale – SCI-FCS"*

Appendix 5. Consent form cross-sectional study participants: *Forespørsel om deltakelse i forskningsprosjektet "Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet Spinal Cord Injury Falls Concern Scale – SCI-FCS samt validering av SCI-FCS"*

Appendix 6. Background data form for the Master's study and validity study: *Tilleggsopplysningsskjema for mastergradsoppgaven: Oversettelse av Spinal Cord Injury Falls Concern Scale, SCI-FCS til norsk og reliabilitetstesting av den norske versjonen*

Appendix 7. Master's study process

Appendix 8. Spinal Cord Injury Falls Concern Scale, SCI-FCS (the original)

Forespørsel om deltakelse som oversetter i forskningsprosjektet "Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS"

Bakgrunn
Dette er et spørsmål til deg om å delta i en forskningsstudie/ mastergradsprosjekt, der hensikten er å oversette og teste selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS" for reliabilitet. SCI-FCS er et spørreskjema for å kartlegge redsel for å falle hos ryggmargsskadde rullestolbrukere og er utviklet i Australia. Forespørselen til deg gjelder rollen som oversetter. Totalt ca 50 pasienter på Sunnaas Sykehus HF som har ryggmargsskade, er over 18 år og har hatt ryggmargsskaden i minst 1 år, vil bli spurt om å delta i en tverrsnittsstudie med bruk av den norske oversatte versjonen av spørreskjemaet. Formålet med studien at SCI-FCS skal kunne tas i bruk i Norge i både forskning og klinikk ut fra norsk kultur og kontekst.
Hva innebærer studien?
Skjemaet skal oversettes av to personer fra engelsk til norsk (translation), og de to oversettelsene syntetiseres. Så oversettes den norske oversettelsen tilbake til engelsk igjen av to personer (back translation) av to personer, og disse to oversettelsene syntetiseres til en. Til slutt vil en ekspertgruppe vurdere den norske og den engelske oversettelsen, og det vil bli enighet om en norsk versjon til slutt. Ditt samtykke gjelder å bidra i oversettelse av selvrapporteringsskjemaet SCI-FCS fra engelsk til norsk.
Den norske oversettelsen skal brukes i en tverrsnittsstudie skal testes for test-retest-reliabilitet, betydende at en og samme deltakende pasient fyller ut spørreskjemaet to ganger med få dagers mellomrom. De to besvarelsene sammenlignes for å se om pasienten svarer likt begge ganger. Det vil bli foretatt statistiske analyser av innsamlende data.
Hva skjer med din oversettelse
Din del av oversettelsesprosedyren består av at du oversetter en vei til/fra norsk/engelsk, samt skriver en rapport om oversettelsen. I rapporten skriver du ned din opplevelse av hvordan oversettelsen har gått, om det var usikkerheter, hva som var vanskelig og/ eller hva som var lett i oversettelsesarbeidet. Andre refleksjoner kan også nevnes i rapporten. Informasjonen som kan knyttes til deg som oversetter, skal kun brukes slik som beskrevet i hensikten med studien, og vil bli slettet senest 2016. Du som oversetter vil ikke ha noen spesielle fordeler av studien, men erfaringer fra studien vil senere kunne hjelpe andre med ryggmargsskade.
Frivillig deltakelse Det er frivillig å delta i oversettelsen av skjemaet. Dersom du ikke ønsker å delta, trenger du ikke å oppgi noen grunn, og det får ingen konsekvenser for det videre arbeidet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på denne siden. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker deg. For spørsmål kan du kontakte Åsa Måøy, tlf. 66969242, eller via e-post: asa.maoy@sunnaas.no.
Samtykke til deltakelse i studien*"Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS"*
Jeg er villig til å delta i oversettelse av selvrapporteringsskjemaet SCI-FCS

(dato, signert av prosjektdeltaker, fødselsnummer)

Jeg bekrefter å ha gitt informasjon om studien

(dato, signert, rolle i studien,)

Skjema for oversettelse av Spinal Cord Injury Falls Concern Scale (SCI-FCS)

Instruksjon: All engelsk tekst nedenfor oversettes til norsk. Den norske oversettelsen føres inn under engelsk tekst hvor det står "Norsk:" som innledning til oversettelsen.

Spinal Cord Injury Falls Concern Scale (SCI-FCS)

We would like to ask some questions about how concerned you are about the possibility of falling. For each of the following activities, please circle the opinion closest to your own to show how concerned you are that you might fall if you did this activity. Please reply thinking about how you usually do the activity. If you currently do not do the activity (for example if someone does your shopping for you), please answer to show whether you think you would be concerned about falling IF you did the activity.

Norsk:

		Not at all concerned, 1	Somewhat concerned, 2	Fairly concerned, 3	Very concerned, 4
		Norsk: ,1	Norsk: ,2	Norsk: ,3	Norsk: ,4
1	Getting dressed or undressed				
1	Norsk:				
2	Moving around the bed (including sitting up)				
2	Norsk:				
3	Inserting enema or toileting				
3	Norsk:				
4	Washing or showering self				
4	Norsk:				
5	Transferring on/off a commode or toilet				
5	Norsk:				

6	Transferring in/out of bed				
6	Norsk:				
7	Transferring in/out of a car				
7	Norsk:				
8	Reaching for high objects (e.g. pressing button on a lift, reaching to a high shelf)				
8	Norsk:				
9	Picking objects up from the floor (e.g. clothes, pet bowl, pen)				
9	Norsk:				
10	Cooking or food preparation (e.g. making a sandwich, stirring food on the stove)				
10	Norsk:				
11	Pushing wheelchair on flat ground				
11	Norsk:				
12	Pushing wheelchair on an uneven surface (e.g. rocky ground, irregular pavement)				
12	Norsk:				
13	Pushing wheelchair up/down gutters or curbs				
13	Norsk:				
14	Pushing wheelchair up/down a slope				
14	Norsk:				
15	Shopping				
15	Norsk:				
16	Lifting heavy objects across body (e.g. shopping bags, wheelchair into the car)				
16	Norsk:				

Skjema for oversettelse av Spinal Cord Injury Falls Concern Scale (SCI-FCS)

Oversettelse fra norsk tilbake til engelsk: Back Translation (BT)

Instruksjon: All norsk tekst nedenfor oversettes til engelsk. Den engelske oversettelsen føres inn under norsk tekst hvor det står "engelsk:" som innledning til oversettelsen.

Fallbekymringsskala for ryggmargsskadde (SCI-FCS)

Vi ønsker å stille noen spørsmål om hvor bekymret du er for å falle. For hver av aktivitetene nedenfor skal du sette et kryss under det utsagnet som best beskriver din opplevelse av hvor bekymret du er for å falle når du utfører den aktuelle aktiviteten.

Når du svarer, tenk på hvordan du vanligvis utfører aktiviteten. Hvis du for tiden ikke utfører denne aktiviteten (for eksempel hvis noen handler for deg), svar likevel for å vise om du tror du ville vært bekymret for å falle HVIS du utførte aktiviteten.

Engelsk:

		Ikke bekymret i det hele tatt	Litt bekymret	Ganske bekymret	Svært bekymret
		Engelsk:	Engelsk:	Engelsk:	Engelsk:
1	Kle på deg eller kle av deg				
1	Engelsk:				
2	Bevege deg i sengen (inkludert å sette deg opp)				
2	Engelsk:				
3	Ordne deg på toalettet inkludert sette klyster				
3	Engelsk:				
4	Vaske deg eller dusje				
4	Engelsk:				
5	Forflytte deg over på/av toalettstol eller toalett				
5	Engelsk:				

6	Forflytte deg inn i /ut av seng				
6	Engelsk:				
7	Forflytte deg inn i/ut av bil				
7	Engelsk:				
8	Strekke deg etter noe som er høyt oppe (f.eks. trykke på en heisknapp, nå opp til en hylle)				
8	Engelsk:				
9	Plukke opp ting fra gulvet (f.eks. klær, penn, matskål til kjæledyr)				
9	Engelsk:				
10	Lage mat (f. eks. smøre en brødskive, røre i mat på komfyren)				
10	Engelsk:				
11	Kjøre rullestol på flatt underlag				
11	Engelsk:				
12	Kjøre rullestol på ujevnt eller vått/ glatt/ snødekket underlag (for eksempel ujevnt/ dårlig vedlikeholdt fortau, brosten, snø/is på gangsti)				
12	Engelsk:				
13	Kjøre rullestol opp/ned fortauskant, eller over rennestein				
13	Engelsk:				
14	Kjøre rullestol opp/ned en bakke				
14	Engelsk:				
15	Handle				
15	Engelsk:				
16	Løfte tunge gjenstander fra en side av kroppen til den andre (f. eks. handleposer)				
16	Engelsk:				

Sunnaas sykehus HF

Appendix 4

Forespørsel om deltakelse i et pilotprosjekt for forskningsprosjektet *"Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS"*

Bakgrunn
Dette er et spørsmål til deg om å delta i en forskningsstudie der hensikten er å oversette og teste selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS" for reliabilitet. Totalt 50 pasienter på Sunnaas Sykehus HF som har ryggmargsskade, er over 18 år og har hatt ryggmargsskaden i minst 1 år, vil bli spurt om å delta i en tverrsnittsstudie etter at spørreskjemaet SCI-FCS er oversatt til norsk. Formålet med studien er å ta selvrapporteringsskjemaet i bruk i Norge i både forskning og klinikk. Skjemaet er et spørreskjema for å kartlegge redsel for å falle.

Hva innebærer studien for deg?
Forespørselen til deg gjelder å delta i et pilotprosjekt for å teste ut den oversatte norske versjonen på noen få deltakere før den større tverrsnittstudien på ca 50 pasienter setter i gang, for å finne ut om skjemaet er forståelig og lett å fylle ut for ryggmargsskadde rullestolbrukere. Pilotprosjektet innebærer at du to ganger med få dagers mellomrom fyller ut et spørreskjema om fallredsel. Det vil ta ca 5-10 min. hver gang du fyller ut skjemaet. En fysioterapeut vil være til stede hver gang du fyller ut for å kunne svare på uklarheter. I etterkant vil du bli intervjuet om dine erfaringer med å fylle ut skjemaet; hva som gikk lett å forstå, hva som var vanskelig å forstå og andre refleksjoner. Du vil ikke ha noen spesielle fordeler av studien, men erfaringer fra studien vil senere kunne hjelpe andre med ryggmargsskade.

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

Frivillig deltakelse
Det er frivillig å delta i studien. Dersom du ikke ønsker å delta, trenger du ikke å oppgi noen grunn, og det får ingen konsekvenser for den videre behandlingen og oppfølgingen du får ved Sunnaas sykehus HF. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på denne siden. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling på sykehuset. Dersom du senere ønsker å trekke deg, eller om du har spørsmål underveis kan du kontakte Åsa Måøy, tlf. 66969242, eller via e-post: asa.maoy@sunnaas.no

Samtykke til deltakelse i studien "Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS"
Jeg er villig til å delta i studien

(dato, signert av prosjektdeltaker, fødselsnummer)

Jeg bekrefter å ha gitt informasjon om studien

(dato, signert, rolle i studien,)

Forespørsel om deltakelse i forskningsprosjektet *"Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS" samt validering av SCI-FCS*

Bakgrunn

Dette er et spørsmål til deg om å delta i en forskningsstudie der hensikten er å oversette og teste selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS" for reliabilitet og validitet. Totalt 50 pasienter på Sunnaas Sykehus HF som har ryggmargsskade, er over 18 år og har hatt ryggmargsskaden i minst 1 år, vil bli spurt om å delta. Formålet med studien er å ta selvrapporteringsskjemaet i bruk i Norge i både forskning og klinikk. Skjemaet er et spørreskjema for å kartlegge bekymring for å falle.

Hva innebærer studien for deg?

Studien innebærer at du to ganger med få dagers mellomrom fyller ut et skjema om fallredsel. Det vil ta ca 5-10 min. hver gang du fyller ut skjemaet. En fysioterapeut vil være til stede hver gang du fyller ut for å kunne svare på uklarheter. I tillegg vil det bli samlet inn bakgrunnsdata, som anonymiseres.

Mulige fordeler og ulemper

Du vil ikke ha noen spesielle fordeler av studien, men erfaringer fra studien vil senere kunne hjelpe andre med ryggmargsskade.

Hva skjer med dine besvarte spørreskjemaer og informasjonen om deg

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

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ikke ønsker å delta, trenger du ikke å oppgi noen grunn, og det får ingen konsekvenser for den videre behandlingen og oppfølgingen du får ved Sunnaas sykehus HF. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på denne siden. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling på sykehuset. Dersom du senere ønsker å trekke deg, eller om du har spørsmål underveis kan du kontakte Åsa Måøy, tlf. 66969242, eller via e-post: asa.maoy@sunnaas.no

Samtykke til deltakelse i studien

Oversettelse og reliabilitetstesting av selvrapporteringsskjemaet "Spinal Cord Injury Falls Concern Scale – SCI-FCS" samt validering av SCI-FCS

Jeg er villig til å delta i studien

(dato, signert av prosjektdeltaker, fødselsnummer)

Jeg bekrefter å ha gitt informasjon om studien

(dato, signert, rolle i studien,)

Tilleggsopplysningsskjema for mastergradsoppgaven og valideringsstudien: Oversettelse av Spinal Cord Injury Falls Concern Scale, SCI-FCS til norsk og reliabilitetstesting av den norske versjonen.

*Skjemaet fylles ut for hver pasient og for hvert test-tilfelle. Sett en **ring** rundt riktige svaralternativer for mann/ kvinne, test1, test 2, samt rundt ja/ nei osv.*

Dato:	
Testleder/ observatør:	
Pasientens seksjon:	
Pasientens navn:	
Kjønn:	mann kvinne
Alder i år:	
Test nr.:	1 2
Utdanning:	
Yrke:	
Antall yrkesaktive timer per uke:	
Diagnose:	
Skadetidspunkt (dato/ år):	
Ryggmargsskade, skadenivå:	
Ryggmargsskade, ASIA impairment scale:	
Ryggmargsskade, ASIA motorscore:	
Relevante tilleggsdiagnoser:	
Vekt i kg:	
Høyde i m:	
BMI (Body mass index, vekt og høydeforhold): $\mathrm{BMI} = \frac{Vekt\ (\mathrm{kg})}{Meter^2(\mathrm{m})}$	
Lengde av overkropp/ truncus målt i cm i sittende fra sitteflaten opp til og med øvre del av skulder:	

Appendix 6

Fall og redsel for å falle:

*Sett en **ring** rundt riktige svaralternativer:" ja" eller "nei", hvis aktuelt "benbrudd","bløtdelsskade" "hjernerystelse", samt litt "redd"/ "ganske redd"/ "veldig redd" .*

1. Har du falt i løpet av det siste året?	Nei	Ja
2. Hvis ja, skadet du deg?	Nei	Ja
3. Hvis ja, hva slags skade fikk du? Sett ring rundt riktig alternativ: benbrudd bløtdelsskade hjernerystelse		
4. Antall fall siste året:		
5. Er du redd for å falle?	Nei	Ja
6. Hvis ja, kryss av for i hvor stor grad du er redd for å falle: 7. litt redd ganske redd veldig redd		
8. Har du endret dine vaner av redsel for å falle?	Nei	Ja
9. Hvis ja, svar kort på hvordan du har endret dine vaner:		
10. Hender det at du kjenner deg svimmel?	Nei	Ja

Spørsmål om bruk av medikamenter og alkohol

1. Medikamenter: Bruker du medikamenter? Hvis ja, svar under for daglig og ukentlig bruk av medikament og mengde.	Nei	Ja
1.1. Daglig:		
1.2. Ukentlig:		
2. Opplever du at medisinene gjør deg sløv, trett eller reduserer konsentrasjonsevnen?		
3. Alkoholvaner: Bruker du alkohol?	Nei	Ja
3.1. Hvis ja, er ditt forbruk mer enn 9 standardenheter for kvinner eller mer enn 14 standardenheter for menn per uke? (en standardenhet=1 flaske øl på 33cl, 1 glass vin 12-15cl eller et glass sterksprit 4cl)  	Nei	Ja
3.2. Hvis ja, har du tilfeller med forbruk på fra 4 standardenheter for kvinner, eller 5 standardenheter for menn eller mer av gangen fra 1 gang per måned eller oftere?	Nei	Ja

Spastisitet. Egenvurdering av spasmer.

1. Hvor ofte har du spasmer?

(sett ring rundt riktig svar)

0	Ingen spasmer
1	Spasmer utløses bare ved stimulering
2	Spontane spasmer som forkommer sjeldnere enn 1 gang pr. time
3	Spontane spasmer som forekommer oftere enn en gang pr. time
4	Spontane spasmer som forekommer oftere enn 10 ganger pr. time

(Priebe et al modifisert fra Penns skala)

2. Hvor sterke vurderer du i tilfelle dine spasmer til å være?

(sett ring rundt riktig svar)

1	Milde
2	Middels
3	Sterke

(Priebe et al modifisert fra Penns skala)

3. Opplever du at spastisiteten påvirker ditt liv?

Nei	I noen grad	Mye

4. Spastisiteten har det siste år

blitt bedre	vært uforandret	blitt verre

Beck's Anxiety Inventory - BAI

INSTRUKSJON: Under er en liste som beskriver visse tilstander folk kan oppleve. Les hvert av punktene nøye. Angi hvor mye du har vært plaget i løpet av siste uke inkludert i dag. Sett en ring rundt riktig tall.

Tilstand	0 = ikke i det hele tatt	1 = litt plaget	2 = ganske plaget	3 = mye plaget
1. Jeg har følt meg svak	0	1	2	3
2. Jeg har følt meg mo i knærne	0	1	2	3
3. Jeg har følt meg svimmel og ør	0	1	2	3
4. Jeg har følt nummenhet eller kribling i kroppen	0	1	2	3
5. Hendene mine har skjelvet	0	1	2	3
6. Jeg har følt meg ustø til bens	0	1	2	3
7. Jeg har følt meg anspent	0	1	2	3
8. Jeg har følt meg nervøs	0	1	2	3
9. Jeg har følt meg skvetten	0	1	2	3
10. Jeg har følt meg skjelven	0	1	2	3
11. Jeg har følt et sterkt ønske om å unngå å være i en situasjon	0	1	2	3
12. Jeg har følt meg ute av stand til å slappe av	0	1	2	3
13. Jeg har vært redd for å miste kontrollen	0	1	2	3
14. Jeg har vært vettskremt	0	1	2	3
15. Jeg har hatt en rar følelse av at ting er uvirkelige	0	1	2	3
16. Jeg har merket at jeg puster hurtig	0	1	2	3
17. Jeg har merket at hjertet mitt hamrer/raser i vei	0	1	2	3
18. Jeg har hatt en følelse av klump i halsen	0	1	2	3
19. Jeg har svettet (skyldes ikke varme)	0	1	2	3
20. Jeg har vært redd for å dø	0	1	2	3
21. Jeg har følelsen av å bli kvalt	0	1	2	3

TOTALSKÅRE: _____

Appendix 6

Downton Fall Risk Index

Tidligere kjente fallulykker	**Skala**
Nei	0
Ja	1

Medisinering	
Ingen	0
Beroligende/ sovemedisin/ neuroleptika	1
Diuretika	1
Antihypertensiva (annet enn diuretika)	1
Antiparkinson legemidler	1
Antidepressiva legemidler	1
Andre legemidler	0

Sensoriske funksjonsnedsettelser	
Ingen	0
Synsnedsettelse	1
Hørselsnedsettelse	1
Redusert motorikk (tegn på lammelse)	1

Kognitiv funksjonsnedsettelse	
Orientert	0
Ikke orientert (kognitiv funksjonsnedsettelse)	1

Gåevne	
Sikker (med eller uten hjelpemiddel)	0
Usikker	1
Mangler	0

Risikofaktorene adderes til en **indexpoeng (0-11)**

3 foreslås å indikere en **høy fallrisiko**. Indexpoeng:_____

Kartleggingen er gjennomført av: _____

Dato: _____

Appendix 6

Kliniske tester
Functional Independence Measure (FIM) (Sunnaasoversettelse) utvalgte items om forflytning *(Sett en ring rundt riktig skåre.)*

Oppgave nr. 9. Forflytning seng, stol, rullestol

Skåre	Funksjonnivå	Independent Performance Scale
7	Helt selvhjulpen	Personen i rullestol nærmer seg seng eller stol, setter på bremsene, svinger til side fothvilere, tar vekk armstøtte om nødvendig, forflytter seg til og fra enten med en stående vridning (høy forflytning) eller med lav sideforflytning begge veier (uten glidebrett). Utføres sikkert
6	Tilnærmet selvhjulpen	Personen trenger hjelpemiddel f.eks. glidebrett, heis, støttehåndtak eller spesialsete eller stol eller skinner eller krykker, bruker mer enn rimelig tid eller må ta sikkerhetshensyn. Protese/ortose regnes her som hjelpemiddel dersom de brukes ved forflytningen.
5	Tilsyn eller tilrettelegging	Personen trenger overoppsyn (f.eks. tilsyn, rettledning eller oppfordring) eller tilrettelegging (plassere glidebrett, svinge til side fothvilere, etc.).
4	Minimal assistanse	Personen utfører 75 % eller mer av oppgavene forbundet med forflytning seng, stol, rullestol.
3	Moderat assistanse	Personen utfører 50 % til 74 % av oppgavene forbundet med forflytning seng, stol, rullestol.
2	Omfattende assistanse	Personen utfører 25 % til 49 % av oppgavene forbundet med forflytning seng, stol, rullestol.
1	Total assistanse	Personen utfører mindre enn 25 % av oppgavene forbundet med forflytning seng, stol, rullestol.

Oppgave 10. Forflytning toalett.

Skåre	Funksjonsnivå	Independent Performance Scale
7	Helt selvhjulpen.	Person i rullestol nærmer seg toalettet, setter på bremsene, svinger til side fothvilere, tar bort armstøtte om nødvendig, forflytter seg til og fra enten med en stående vridning (høy forflytning) eller med lav sideforflytning (uten glidebrett). Utføres sikkert.
6	Tilnærmet selvhjulpen.	Tilnærmet selvhjulpen - Personen trenger hjelpemiddel f.eks. glidebrett, heis, støttehåndtak eller spesialsete, bruker mer enn rimelig tid eller må ta sikkerhetshensyn. Protese/ortose regnes her som hjelpemiddel dersom de brukes ved forflytningen
5	Tilsyn eller tilrettelegging.	Personen trenger overoppsyn (f.eks. tilsyn, rettledning eller oppfordring) eller tilrettelegging (plassere glidebrett, svinge til side fothvilere, etc.).
4	Minimal assistanse.	Personen utfører 75 % eller mer av oppgavene forbundet med forflytning toalett.
3	Moderat assistanse	Personen utfører 50 % til 74 % av oppgavene forbundet med forflytning toalett.
2	Omfattende assistanse.	Personen utfører 25 % til 49 % av oppgaven forbundet med forflytning toalett.
1	Total assistanse.	Personen utfører mindre enn 25 % av oppgavene forbundet med forflytning toalett eller forflytter seg ikke til toalettet.

Oppgave 11. Forflytning badekar/dusj

Score	Funksjonsnivå	Independent Performance Scale
7	Helt selvhjulpen.	Person i rullestol nærmer seg badekar eller dusj, setter på bremsene, svinger til side fothvilere, tar vekk armstøtte om nødvendig, forflytter seg til og fra enten med en stående vridning (høy forflytning) eller med lav sideforflytning (uten glidebrett). Utføres sikkert.
6	Tilpasset selvhjulpen.	Personen trenger hjelpemiddel (inkludert protese eller ortose) som for eksempel glidebrett, heis, støttehåndtak eller spesialsete, bruker mer enn rimelig tid eller må ta sikkerhetshensyn.
5	Tilsyn eller tilrettelegging.	Personen trenger overoppsyn (f.eks. tilsyn, rettledning eller oppfordring) eller tilrettelegging (plassere glidebrett, svinge til side fothvilere, etc.).
4	Minimal assistanse.	Personen utfører 75 % eller mer av oppgavene forbundet med forflytning badekar/dusj.
3	Moderat assistanse.	Personen utfører 50 % - 74 % av oppgavene forbundet med forflytning badekar/dusj.
2	Omfattende assistanse.	Personen utfører 25 % - 49 % av oppgavene forbundet med forflytning badekar/dusj.
1	Total assistanse.	Personen utfører mindre enn 25 % av oppgavene forbundet med forflytning badekar/dusj forflytning eller tar seg ikke opp i og ut av badekar eller dusj.

Oppgave 12. Forflytning gange/rullestol

Skåre	Funksjonsnivå	Independent Performance Scale
7	Helt selvhjulpen.	Personen går minst 50 meter uten hjelpemiddel. Bruker ikke rullestol. Utføres sikkert.
6	Tilnærmet selvhjulpen.	Personen går minst 50 meter men bruker skinne (ortose) eller benprotese, spesialtilpassete sko, stokk, krykker eller rullator, bruker mer enn rimelig tid, eller må ta sikkerhetshensyn. Person i rullestol kjører manuell eller elektrisk rullestol selvstendig minst 50 meter, svinger rundt, manøvrerer rullestolen inntil bord, seng, toalett, klarer en helning på minst 3 %, manøvrerer over tepper og dørterskler.
5	Tilsyn eller tilrettelegging.	Person i rullestol trenger tilsyn, rettledning eller oppfordring for å kjøre rullestol minst 50 meter.
4	Minimal assistanse.	Personen utfører 75 % eller mer av oppgaven å ta seg fram minst 50 meter.
3	Moderat assistanse.	Personen utfører 50 % til 74 % av oppgaven å ta seg fram minst 50 meter.
2	Omfattende assistanse.	Personen utfører 25 % til 49 % av oppgaven å ta seg fram minst 17 meter. Trenger bare hjelp av en person.
1	Total assistanse.	Personen utfører mindre enn 25 % av oppgaven å ta seg fram eller trenger hjelp av to personer eller verken går eller kjører rullestol minst 17 meter.

Kommentar: Hvis pasienten trenger et hjelpemiddel for å forflytte seg: rullestol, protese, rullator, stokk, AFO (ankel/fot ortose), spesialtilpassete sko etc. kan poengene for gange/rullestol aldri bli høyere enn nivå 6. Forflytningsmåten (gange eller rullestol) må være den samme ved innkomst som ved utskriving. Hvis personen endrer forflytningsmåte mellom inn- og utskriving (vanligvis fra rullestol til gange), registreres forflytningsmåten ved innkomst og poengene for den forflytningsmåten som brukes mest ved utskrivning.

T-shirt test:

Instruksjon: Testen måler tiden det tar for deltakeren å ta på seg og ta av seg en t-skjorte. Deltakeren sitter med bøyde ben og hofter (short sitting) og har et bord foran seg med en t-skjorte med framsiden lagt nedover. Bordets nærmeste kant er i linje med deltakerens knær og høyden på bordet er ca som deltakerens bekkenkamm. Størrelsen på t-skjorten skal være en størrelse større enn det deltakeren bruker til vanlig. Deltakeren blir bedt om å ta på seg t-skjorten på tid. Etter en liten pause blir deltakeren bedt om å ta av seg t-skjorten på tid. Testen blir gjennomført to ganger. Gjennomsnittstid beregnes for både å ta av seg og ta på seg t-skjorten, samt total tid. Jo mindre tidsbruk, jo bedre ytelse. Det brukes ikke sele under testen men deltakeren sikres med hensyn til fallfare av en person.

1. Tid (sekunder), å ta på seg t-skjorte:	
2. Tid (sekunder), å ta på seg t-skjorte:	
Gjennomsnittstid, åta på seg t-skjorte:	
3. Tid (sekunder), å ta av seg t-skjorte:	
4. Tid (sekunder), å ta av seg t-skjorte:	
Gjennomsnittstid, å ta av seg t-skjorte:	
Total tid:	

T-shirt test: arbeidsoversettelse sept 2012 ved Åsa Måøy, Sunnaas sykehus HF (asa.maoy@sunnaas.no) med utgangspunkt i Boswell-Ruys 2009 og Chen 2003.

5-AML (Five additional mobility and locomotor items (utvalgte items om rullestolferdigheter, et tillegg til FIM for ryggmargsskadde rullestolbrukere)

Sett en ring rundt riktig skåre.

Oppgave 3: Kjøre rullestol på flatt underlag

Oppgaven innebærer at pasienten kjører en manuell rullestol på flatt underlag. To markeringer, for eksempel kjegler, plasseres 25 m fra hverandre. Pasienten skal kjøre fra ett merke rundt det andre merket og tilbake til det første merket. Tidtakingen starter og slutter når forhjulene er forbi den første markeringen. Total strekning: 50 m.

Score	Level of Independence	Independent Performance Scale
7	Helt selvhjulpen.	Pasienten klarer å kjøre rullestolen selv 200 m under 1,5 min.
6	Tilnærmet selvhjulpen.	Klarer å kjøre selvstendig 200 m under 3 min.
5	Tilsyn eller tilrettelegging.	Klarer å kjøre selv 100 m under 1,5 min.
4	Minimal assistanse.	Pasienten klarer å kjøre 50 m selv under 45 sek.
3	Moderat assistanse.	Pasienten klarer å kjøre 25 m selv under 45 sek.
2	Omfattende assistanse.	Pasienten klarer å kjøre 25 m under 2 min.
1	Total assistanse.	Pasienten klarer ikke å kjøre 25 m under 2 min.

Oppgave 5: Klare å kjøre opp på rampe/fortauskant.

Oppgave innebærer at pasienten kjører opp på en lav (2,5 cm) og en høy (15 cm) rampe/ fortauskant. Oppgaven krever at pasienten starter å kjøre på nivå under rampen/ fortauskanten, kommer opp på den og stopper. Pasienten kan nærme seg rampen/ fortauskanten med fart om nødvendig.

Score	Level of Independence	Independent Performance Scale
7	Helt selvhjulpen.	Pasienten klarer å komme opp på en høy rampe/fortauskant selv.
6	Tilnærmet selvhjulpen.	Pasienten klarer å komme opp på en høy rampe/ fortauskant med tilsyn.
5	Tilsyn eller tilrettelegging.	Pasienten klarer å komme opp på en høy rampe/fortauskant med minimal assistanse.
4	Minimal assistanse.	Pasienten klarer å få forhjulene på rullestolen opp på en høy rampe/ fortauskant og dra seg opp på rampen/fortauskanten med litt hjelp.
3	Moderat assistanse.	Pasienten klarer å få forhjulene på rullestolen opp på en høy rampe/fortauskant.
2	Omfattende assistanse.	Pasienten klarer å kjøre opp på en lav rampe/fortauskant.
1	Total assistanse.	Pasienten klarer ikke å kjøre opp på en lav rampe/fortauskant.

5-AML: arbeidsoversettelse sept 2012 ved Åsa Måøy, Sunnaas sykehus HF (asa.maoy@sunnaas.no) med utgangspunkt i Middleton et al, 2006.

Appendix 7

Master's study process

January 2012: The work with the project plan was finished.

February to March 2012: The project plan for the Master's study was approved the 13th of February 2012 at the University in Oslo. There was held an information meeting about the Master's study for physiotherapist colleagues at the Sunnaas Rehabilitation Hospital the 20th of March 2012. It was applied to "The Regional Committees for Medical and Health Research Ethics" the 27th of March which later on provided approval for this Master's study. The work with translation and cross-cultural adaptation started. The translators were contacted and prepared to participate in the translation work. A consent form was made for the translators and a translation document was made.

April to May 2012: Approval received from "The Regional Committees for Medical and Health Research Ethics" for the Master's study. The translators completed their translations from English to Norwegian, after signing consent forms to participate as translators. The 8th of May a meeting for synthesis of the two translations was held. The 10th of May a consensus on synthesized Norwegian was reached in the expert group. The back-translators were contacted and asked to participate and filled in a consent form. The work with information to colleagues at the Sunnaas Rehabilitation Hospital continued. There were sent information e-mails to colleagues and information was given in physiotherapist meetings and interdisciplinary meetings on the project.

June 2012: The process with the translation and cross-cultural adaptation was finished. A patient pilot study was conducted on 14 patients. All pilot participants filled in a consent form before participating.

August 2012: Documents to use in the cross-sectional study were completed and copied. It was a registration form for background data, the Norwegian SCI-FCS and a consent form to participate in the cross-sectional study. Information was given in e-mails to central leaders about starting up the cross-sectional study.

September 2012 - January 2013: All data was collected for the 54 participants while they had a stay in the PVO unit.

February - April 2013: Statistical analyses were conducted according to examine the test-retest reliability and an analysis course included in the Master's degree program was conducted through February, March and April 2013.

April 2013 - June 2014: Work with writing and finishing the Master's study.

Appendix 8

Spinal Cord Injury Falls Concern Scale (SCI-FCS)

We would like to ask some questions about how concerned you are about the possibility of falling. For each of the following activities, please circle the opinion closest to your own to show how concerned you are that you might fall if you did this activity. Please reply thinking about how you usually do the activity. If you currently do not do the activity (for example if someone does your shopping for you), please answer to show whether you think you would be concerned about falling IF you did the activity.

		Not at all concerned, 1	Somewhat concerned, 2	Fairly concerned, 3	Very concerned, 4
1	Getting dressed or undressed				
2	Moving around the bed (including sitting up)				
3	Inserting enema or toileting				
4	Washing or showering self				
5	Transferring on/off a commode or toilet				
6	Transferring in/out of bed				
7	Transferring in/out of a car				
8	Reaching for high objects (e.g. pressing button on a lift, reaching to a high shelf)				
9	Picking objects up from the floor (e.g. clothes, pet bowl, pen)				
10	Cooking or food preparation (e.g. making a sandwich, stirring food on the stove)				
11	Pushing wheelchair on flat ground				
12	Pushing wheelchair on an uneven surface (e.g. rocky ground, irregular pavement)				
13	Pushing wheelchair up/down gutters or curbs				
14	Pushing wheelchair up/down a slope				
15	Shopping				
16	Lifting heavy objects across body (e.g. shopping bags, wheelchair into the car)				