

**Upper extremity functioning in
individuals with spinal cord injury
- From body functions to
participation**

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UNIVERSITY OF GOTHENBURG

Gothenburg 2023

Cover illustration: 'Hand after spinal cord injury', by M. Lili

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ISBN: 978-91-8069-357-8 (PRINT)
ISBN: 978-91-8069-358-5 (PDF)

Printed in Borås, Sweden 2023
Printed by Stema Specialtryck AB
<http://hdl.handle.net/2077/76811>

to my children, but above all to my parents.

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ABSTRACT

Background: A spinal cord injury (SCI) can lead to a range of impairments in various body functions, including the function of upper extremity, with severity varying from mild to severe. Long-term consequences for functioning and disability are a dynamic result of the injury characteristics and various other factors, requiring further knowledge regarding upper extremity functioning.

The overall **aim** was to enhance the knowledge of upper extremity functioning across various domains of the International Classification of Functioning, Disability, and Health (ICF) in individuals with SCI. The specific aims of the four studies were to determine the altered kinematic measures during a purposeful daily task and to identify the relationships across kinematics, clinical assessments, independence in everyday activities, and self-perceived autonomy in participation.

Methods: For this thesis, 29 individuals with cervical or thoracic complete or incomplete SCI and 54 non-disabled controls recruited. Assessments used were: American Spinal Injury Association (ASIA),

kinematics during the 'drinking task,' grip strength, Action Research Arm Test (ARAT), Sollerman Hand Function Test (SHFT), Box and Block Test (BBT), International SCI Upper Extremity Basic Data Set (ISCI-Hand, ISCI-Shoulder), Spinal Cord Independence Measure (SCIM), and Impact on Autonomy and Participation.

Results: Several kinematic measures (e.g., movement time (MT), smoothness, wrist dorsiflexion) were altered in the upper extremities with limited functioning after SCI. Wrist angle, alongside MT or smoothness, explained 82% and 77% of the variance in ARAT and SHFT, respectively, and explained 91% of the variance in ARAT and SHFT with the addition of hand proprioception. Wrist angle alone explained 59% of ISCI-Hand. MT, smoothness ($r \geq 0.6$), and grip strength ($r \geq 0.5$) correlated with SCIM-self-care, feeding, and dressing, as well as with ARAT, BBT, and ISCI-Hand (r 0.52-0.76). SCIM-mobility items correlated similarly. Independence in respiration management correlated with MT (r -0.53), smoothness (r -0.50), BBT (r -0.56), and toilet use solely with MT (r -0.66). Most participants with SCI (68%–88%) reported restrictions in outdoor, family role, and indoor autonomy in participation. Indoor autonomy correlated (r 0.72) with SCIM-self-care and SCIM-mobility (r 0.60), while problematic work autonomy correlated (r 0.55) with SCIM-respiration/sphincter management.

Conclusions: This thesis emphasises the critical importance of addressing upper extremity functioning within rehabilitation medical practises from various perspectives and highlights certain key aspects within 'functioning and disability' ICF section.

Keywords: activity, autonomy, capacity, functioning, participation, performance, spinal cord injury, upper extremity.

ISBN: 978-91-8069-357-8 (PRINT)

ISBN: 978-91-8069-358-5 (PDF)

<http://hdl.handle.net/2077/76811>

SAMMANFATTNING PÅ SVENSKA

Bakgrund: En skada i ryggmärgen kan leda till funktionsnedsättningar i olika grad, från mild till svår, i exempelvis övre extremitet. Långsiktiga funktionshinder är ett dynamiskt resultat av skadans lokalisation och svårighetsgrad samt av flera olika faktorer. Därav behövs det ytterligare kunskap om olika aspekter av den övre extremitetens funktion.

Det övergripande **syftet** med denna avhandling var att öka kunskapen om övre extremitetens funktion inom olika områden enligt Internationella klassifikationen funktionstillstånd, funktionshinder och hälsa (ICF) hos individer med ryggmärgsskada. De specifika syftena för de fyra studierna var att med en ändamålsenlig vardaglig uppgift fastställa kinematiska rörelsemått för ryggmärgsskada och identifiera samband mellan kinematik, kliniska bedömningar, självständighet i vardagliga aktiviteter samt autonomi och delaktighet.

Metoder: Till studierna rekryterades 29 individer med cervikal eller thorakal, komplett eller inkomplett ryggmärgsskada och 54 icke-funktionshindrade kontroller. Följande bedömningar användes: bedömning enligt Amerikanska Föreningen för Ryggmärgsskada (ASIA), kinematik under "att dricka testet", greppstyrketest, Action Research Arm Test (ARAT), Sollermans Handfunktion Test (SHFT), Box & Block Test (BBT), International Spinal Cord Injury Upper Extremity Basic Data Set, Spinal Cord Independence Measure (SCIM) och Inverkan på delaktighet och självbestämmande (IPA-E).

Resultat: Flera kinematiska rörelsemått (t.ex. rörelsetid, smidighet, handledsvinkel) var förändrade i gruppen med begränsad funktion i övre extremiteter på grund av ryggmärgsskada jämfört med kontrollgruppen. Handledsvinkel, tillsammans med antingen rörelsetid eller smidighet, förklarade 82 % av variansen i ARAT och 77 % av SHFT, och 91 % när det kombinerades med handproprioception. Handledsvinkel ensamt förklarade 59,3 % av ISCI-Hands varians. Rörelsetid och smidighet ($r \geq 0,6$) samt greppstyrka ($r \geq 0,5$) korrelerade med SCIM-subskala för personlig hygien och med moment för matintag och klädsel, liksom med ARAT, BBT och ISCI-Hand (r 0,52–0,76). SCIM-mobilitets moment korrelerade på liknande sätt. Självständighet i skötsel av andningen korrelerade med rörelsetid (r -0,53), smidighet (r -0,50), BBT (r -0,56) och självständighet i toalettbesök korrelerade endast med rörelsetid (r -0,66). De flesta individerna (68%–88%) upplevde begränsningar i autonomi i delaktighet utomhus, i familjerollen och i autonomi i delaktighet inomhus. Autonomi inomhus korrelerade (r 0,72) med SCIM-personlig-hygien och (r 0,60) med SCIM-mobilitet. Problem med arbetsautonomi korrelerade (r 0,55) med SCIM-andning/sfinkter.

Slutsatser: Denna avhandling betonar det kritiska betydelsen inom rehabiliteringsmedicin av att hantera övre extremitetens funktion från olika perspektiv och belyser vissa nyckelaspekter inom ICFs del av funktionshinder och hälsa.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Lili, L., Sunnerhagen, K. S., Rekand, T. & Alt Murphy, M. Quantifying an upper extremity everyday task with 3D kinematic analysis in people with spinal cord injury and non-disabled controls. *Front. Neurol.* 12, 755790. <https://doi.org/10.3389/fneur.2021.755790> (2021).
- II. Lili, L., Sunnerhagen, K. S., Rekand, T. & Alt Murphy, M. Associations between upper extremity functioning and kinematics in people with spinal cord injury. *J. Neuroeng. Rehabil.* 18, 147. <https://doi.org/10.1186/s12984-021-00938-9> (2021).
- III. Lili, L., Sunnerhagen, K. S., Rekand, T. & Alt Murphy, M. Independence and upper extremity functioning after spinal cord injury: a cross-sectional study *Scientific Reports.* (2023) 13:3148. <https://doi.org/10.1038/s41598-023-29986-y> (2023).
- IV. Lili, L., Sunnerhagen, K. S., Rekand, T. & Alt Murphy, M. Self-perceived autonomy in participation related to independence in daily life and upper extremity activity capacity in individuals with spinal cord injury. In manuscript.

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ABBREVIATIONS

ADL	Activities of Daily Living
ARAT	Action Research Arm Test
ASIA	American Spinal Injury Association
AIS	ASIA Impairment Scale
BBT	Box and Block Test
ES	Effect Size
ICF	International Classification of Functioning, Disability, and Health
ISCoS	International Spinal Cord Society
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
ISCI	International Spinal Cord Injury Upper Extremity Basic Data Set
ISCI-Hand	ISCI's section focusing mainly on the hand: 'Basic hand-upper extremity function'
ISCI-Shoulder	ISCI's section focusing mainly on the arm and shoulder 'Shoulder function classification'
IPA	Impact on Autonomy and Participation
MMT	Manual Muscle Test
MT	Movement Time

NMU	Number of Movement Units
SCIM	Spinal Cord Independence Measure
SD	Standard Deviation
SHFT	Sollerman Hand Function Test
UE	Upper Extremity

INTRODUCTION

DEFINITION

A spinal cord injury (SCI) is a lesion in somatic and/or autonomic neural pathways in the spinal cord or nerves at the end of the spinal canal, called the cauda equina. An interruption of these neural pathways that provide communication between the central nervous system (brain and spinal cord) and peripheral nervous system disturbs the control of voluntary and/or involuntary body functions. The consequences of SCI on several functions, such as walking, upper extremity, bladder, bowel, and sexual function, can vary from highly severe consequences to minor changes, depending mainly on the neurological level and the completeness of the injury. ¹ The consequences for life and functioning in the long term will also depend on multiple other internal or external factors, such as those expressed below. ²

AETIOLOGY AND EPIDEMIOLOGY

SCI can arise from a variety of causes. Traumatic injuries are caused by external forces such as road traffic, falls, or sport-related accidents. Non-traumatic spinal cord injuries are caused by underlying pathologies, including acquired conditions (e.g., tumours, ischaemia, infections, degenerative intervertebral disc diseases, spinal stenosis), congenital (e.g., spina bifida), and hereditary factors (e.g., hereditary spastic paraplegia). ^{1, 3-11}

Among traumatic injuries worldwide, falls and traffic accidents are the leading causes of SCI.^{7,9} In high-income countries, such as Sweden or other Nordic countries, falls are the leading cause of SCI.^{7,12,13} These falls are often caused by low-impact accidents at home among the elderly, which, in combination with age-related degenerative changes in spinal structure (e.g., spinal stenosis, osteoporosis), commonly lead to incomplete injuries.^{10,13,14} Simultaneously, severe traffic accidents, often involving relatively younger populations,¹² have become less frequent because of numerous improvements made to vehicle safety, road infrastructure, assessments of driving ability, and driver education.^{7,8} More stringent law enforcement on alcohol consumption, seatbelt usage, and hands-free mobile device usage have also improved traffic safety.⁷ Furthermore, non-traumatic injuries are proportionally increasing because of the ageing population and longer life expectancy following SCI.⁴ Given these changes, a proportional shift has occurred over time in which the prevalence of incomplete SCI and SCI among older adults is increasing.^{7,8,13,15,16}

Although the routines for the diagnosis and management of traumatic SCIs are well-organised within SCI-specialised units, the clinical consensus for non-traumatic injuries, both in acute and long-term care, is much less developed. For example, not all non-traumatic injuries are referred to SCI-specialised units because of different routines or, in some cases, because of comorbidities; therefore, incomplete injuries with minor neurological deficits can be missed. Consequently, non-

traumatic injuries are sometimes excluded from national SCI registries and research. ^{4, 17}

The estimated prevalence of SCI across all causes stood roughly at 0.9 million cases worldwide ¹⁸ in 2019 and 3 million cases in western Europe in 2016. ¹⁶ The incidence rate of traumatic SCI in developed high-income western countries such as Australia, ¹⁹ Canada, ²⁰ and western Europe ¹⁶ has been estimated at 32, 20, and 16 per one million people per year, respectively. Within the Nordic countries, the annual incidence rate of traumatic SCI is also 16 per one million people per year. ⁷ while an incidence rate of 19 per million cases has been reported in Sweden. ^{12, 21} For non-traumatic injuries, the annual incidence rate is evaluated as 6 new cases per million individuals in western Europe ¹⁷ and ranges from 7.7 to 10.4 in Norway. ⁴

SPINAL CORD INJURY CARE THEN AND NOW

From ancient Egypt ²² and Greece ²³ to the mid-19th century, an injury to the spinal cord, especially a complete lesion, was considered incurable. ^{22, 24, 25} Due to the lack of curative options, surgical efforts to discover a way to reverse the damage predominated medicine until the turn of the 20th century. After World War II, the first SCI-specialised unit was founded at Stoke-Mandeville Hospital in England. ²⁴⁻²⁷ Sir Ludwig Guttman, the medical director, was the first surgeon to introduce a holistic conservative treatment, demonstrating that several SCI-related consequences are preventable. Guttman also established fundamental guidelines for 'multidisciplinary rehabilitation' after SCI,

which included a team of experienced health professionals led by an experienced physician, as well as services such as occupational therapy, social reintegration, and systematic lifelong follow-up. Guttman's influence on SCI rehabilitation was profound and endures to the present day. Many subsequent SCI-specialised units were directed by physicians trained in SCI medicine under Guttman's supervision at Stoke-Mandeville Hospital, and inpatient SCI-specialised rehabilitation is still advocated internationally.²⁴⁻²⁷

In 1983, Lars Sullivan opened the first comprehensive spinal cord unit in the Nordic countries at Sahlgrenska University Hospital in Gothenburg, Sweden.²⁸ Since April 2023, this SCI-specialised unit has been one of the only two comprehensive SCI-specialised rehabilitation units in Sweden (with integrated both acute and rehabilitation services for all ages and all levels of injuries) for primary inpatient rehabilitation of individuals with acquired non-progressive SCI.²⁷ Similar to Norway,⁴ the Sahlgrenska SCI Unit excludes congenital (e.g., spina bifida) as well as acquired non-traumatic but progressive injuries such as multiple sclerosis-related SCI.²⁹

Following the establishment of the first SCI unit until the 1980s, survival rates and estimated life expectancies initially progressed substantially, plateaued for two decades, and then presented a slight resurgence again since 2010.³⁰ This progress is attributed to enhancements in the healthcare system, including emergency and early response services, trauma transportation and care, SCI-specialised

inpatient rehabilitation, sustained long-term follow-up and rehabilitation, and the provision of welfare system benefits and services (e.g., personal assistance, housing adaptations, and assistive technologies).^{7, 27} These enhancements and benefits, however, substantially increase the economic burden for healthcare and welfare,³¹⁻³³ despite the relatively lower annual incidence of SCI compared with other chronic conditions like stroke or diabetes. Recommendations from the research underscore the significance of engaging in 'focused management of SCI-specific health issues' to ensure an effective standard of care for all people after SCI, regardless of which regions or countries they leave.^{24, 27}

CLASSIFICATION OF THE SPINAL CORD INJURY

Since antiquity,^{22,23} treatment plans have been based on the assessment of impairments and injury location in medical practices.²⁷ Regarding SCI, a rough screening assessment begins directly in the emergency room or during transport by ambulance staff, where injuries are classified into either paralysis of all four extremities (i.e., tetraplegia) or solely of the lower extremities (paraplegia).³⁴ Sir Guttman introduced two pivotal dimensions: the dimension of completeness by classifying injuries as 'complete' or 'incomplete,' and the dimension of functional progression by classifying the functional status as 'improved, unchanged, and deteriorated.'^{26, 27} This simplified classification system was later extended, also in Stoke-Mandeville by Dr. Frankel, into the widely recognised Frankel scale.²⁶

Based on the Frankel scale, the American Spinal Injury Association (ASIA) developed the ASIA classification system in 1973 and the ASIA Impairment Scale (AIS) in 1982.³⁵ ASIA and AIS identify the vertical level, typically termed the neurological level of injury, as well as the horizontal level of injury, termed the grade of completeness, including complete injury (AIS A) or four grades of partially damaged spinal cord (AIS; B, C, D, and E).^{36, 37} Since 2000, the ASIA examination (including the neurological level of injury, grade of completeness (AIS), motor score, and sensory score) has been recommended by the International Spinal Cord Society (ISCoS) as the gold standard for assessment and classification of SCI, also known as the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).^{36,37} The ASIA/ISNCSCI assessment is commonly used as an outcome measure to evaluate the recovery of impairment (without considering compensatory strategies), or the efficacy of applied interventions, as well as to predict the outcome or to early detect deterioration during lifelong follow-up.³⁸⁻⁴¹

FROM CLASSIFICATION TO FUNCTIONAL STATUS

Looking at assessment from a long-term perspective, several factors can compromise a clear identification of the ASIA neurological level of injury. ² For example, pre-injury or post-injury non-SCI comorbidities (e.g., amputation), reconstructive hand surgery, compensatory strategies learned and established over time (e.g., passive tenodesis), and consequences of overuse (e.g., shoulder overuse syndrome, other conditions). ^{2, 42-44} Furthermore, certain spinal cord segments (i.e., upper cervical, thoracic, and sacral) are neglected by the ASIA examination, leaving gaps in the assessment. ⁴⁵ For example, the assessment of trunk function alone or combined with upper extremity function and transfers (mobility) is not covered. In addition, ASIA components, such as motor or sensory score, cannot alone directly indicate a specific functional status. ⁴⁶⁻⁴⁸

The ASIA assessment and its correlations with overall functional status have been extensively researched due to the need to inform both patients and the welfare system about expected functional status and the need for assistance and adaptations. ⁴⁹ In 2000, an ISCoS expert panel summarised the expected functional outcomes for each ASIA segmental neurological level of motor complete injury, while ³⁸ functional status was defined as either requiring or not requiring assistance or other adaptations (dependent or independent, respectively). ^{38, 40}

Furthermore, as each key muscle reflects a certain ASIA motor level of injury, recovery of a certain key muscle indicates the transition between different degrees of expected independence: from great need of

assistance to weak independence (C5-elbow flexors), to near full independence (C7-triceps), or to full independence (T1-finger abductors). This simplified relationship model has considerably impacted SCI research and clinical practise in terms of universal thinking when the outcome of functioning is assumed by the ASIA classification.^{38, 40}

In recent years, it has been increasingly acknowledged that due to the wide variety of clinical manifestations following SCI and, in particular, incomplete SCI resulting in asymmetrical impairments (e.g. differences in function between the right and left sides),³⁸ it is necessary to include individuals with incomplete injuries in research to a greater extent.⁵⁰ That said, the inclusion of such representative diversity would require larger study samples to ensure robust statistical power in subgroup analyses.³⁸ To achieve this, multicenter studies may be the only viable solution, which in turn requires shared, agreed-upon terminology and standardised protocols across centres and regions.^{51, 52} With this imperative in mind, ISCoS^{51, 53} launched the International Data Sets project to overcome the limitations of the ASIA/AIS classification.^{51, 54}

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

Apart from the nature of the injury (ASIA level, motor score, etc.), various contextual factors may impact an individual's functional status.⁵⁵⁻⁵⁷ Therefore, the International Classification of Functioning, Disability, and Health (ICF), developed by the World Health

Organization (WHO) in 2001, consists of two sections: (i) the central section pertains to 'functioning and disability,' and (ii) the complementary ICF section of 'contextual factors.'⁵⁸ To better understand the relationships between different sections of the ICF and domains of functioning after an injury or medical condition, the biopsychosocial model has become a fundamental concept. The health condition (e.g., spinal cord injury) and its consequences for functioning, alongside contextual factors, collectively shape an individual's 'functioning and disability' (*Figure 1*).⁵⁸

The 'contextual factors' section consists of personal and environmental factors.⁵⁸ Environmental factors encompass the effectiveness of acute trauma care, the structure of inpatient rehabilitation, the long-term follow-up and rehabilitation, as well as the social support and welfare benefits (e.g., personal assistance, housing adaptations, assistive technologies, car modifications).^{59, 60} Personal factors include mental and cognitive status,^{61, 62} compliance,⁶³ positive thinking ability, problem-solving skills, and self-perception of the new altered body or functioning.⁶⁴ As life expectancy increases, the role of personal factors becomes more pronounced, especially in areas such as goal-setting during rehabilitation and long-term follow-up. Here, the focus shifts from mere survival to cultivating a meaningful and qualitative life^{61, 62, 65-69} in accordance with the person's perception rather than relying solely on caregiver assessment.^{70, 71, 50}

The 'functioning and disability' section of the ICF consists of three domains: "body structures and function" (e.g., upper extremity function, C5 SCI, AIS C), 'activity' (e.g., ability to drink from a glass), and 'participation' (e.g., fulfilling the parental role). The body structures and functions domain concerns the physiological functions of body systems and the anatomical parts of the body, such as organs, extremities, and their components. The activity domain covers 'capacity' (the ability to perform standardised tasks and activities in a standardised environment), e.g., grasping a drinking glass, ⁷² or combing hair ⁷³ and 'performance' (actual use of the upper extremity in real-life activities), e.g., eating a meal. ⁷⁴ Engagement in life situations is termed 'participation' ^{66, 67, 70, 71, 75, 76} (e.g., meeting friends at a restaurant) and is regarded as the ultimate goal of rehabilitation. ⁵⁶ (*Figure 1*)

The ICF was created to provide a comprehensive theoretical foundation, or, in other words, a common terminology for health, functioning, and disability that could be applied both at individual and population levels. ⁵⁶ The ICF has gained widespread acceptance among researchers as a guide for the selection of appropriate assessment tools and study designs. In clinical practise, it is used to aid goal-setting, treatment selection, and evaluation in rehabilitation. ^{56, 77} (*Figure 1*).

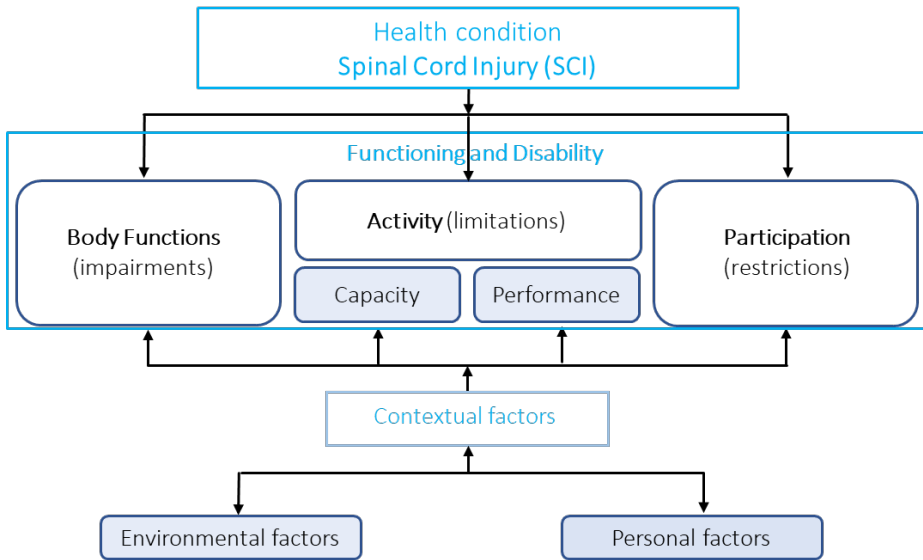


Figure 1. The International Classification of Functioning, Disability, and Health (ICF) consists of two sections: one for Functioning and Disability and one for Contextual factors.

UPPER EXTREMITY FUNCTIONING

According to previous studies performed in various countries, individuals with upper extremity impairments (referred to often as tetraplegia) can represent more than 50% of the SCI population.¹⁸ Recent studies have shown a noticeable trend towards an increasing proportion of tetraplegia as well as a trend towards more incomplete injuries.⁷ These tendencies have mainly been noticed in highly developed countries such as Australia, the USA, Western Europe, and Nordic countries such as Finland.^{7, 16, 17, 78}

The upper extremity plays a fundamental role in activities of daily living (ADL).^{38, 79} Not surprisingly, individuals with tetraplegia have ranked upper extremity functioning as their top priority for recovery, surpassing other functions such as walking, sexual function, bowel function, and bladder function.⁸⁰⁻⁸⁴

ASSESSMENT OF BODY FUNCTION (IMPAIRMENT)

Assessment of upper extremity impairments after SCI comprises assessment of both sensory and motor functions. Muscle strength can be assessed using the manual muscle test (MMT) or hand-held dynamometers. The MMT score is determined in comparison to the resistance exerted by the assessor. MMT in key muscles is also integrated into the ASIA Upper Extremity Motor Score.³⁶ Grip strength can be quantified using a hand-held dynamometer, resulting in a more objective measurement.^{27, 85} Sensory assessment of light touch

and pain on a 3-level ordinal scale is also integrated into the ASIA/ISNCSCI assessment. ³⁶

Other biomechanical parameters of the upper extremity can be objectively measured using techniques such as 3D motion capture systems. These systems can offer detailed quantitative analyses of movement kinematics measured in space and time, including linear and angular displacements of body parts and segments, velocity, and acceleration, regardless of the forces involved. Kinematic analysis has been used for several decades to measure movements in both healthy individuals and those with various neurological conditions. ^{72, 73, 86-89}

In contrast to, for example, a stereotypical gait pattern, quantifying the movements of the upper extremities is challenging because they can possess multiple degrees of freedom and perform various types of tasks. ⁴³ The execution of upper extremity movements is specific to the goal, context, and constraints of the task. This implies that the tasks selected for measurements should be ecologically valid to reflect an individual's functioning in ADL. ⁹⁰ While the kinematic properties of simple tasks such as pointing and reaching have been evaluated in several studies, the quantification of complex series of tasks with a certain purpose that incorporate grasping ⁸⁷ and manipulating objects (e.g., grasping and drinking from a glass), ^{72, 87, 91} or a series of tasks such as eating a meal, is sparse.

A recommended task for kinematic analysis of upper extremity movement is the 'drinking task,'⁸⁶ since the standardised protocol of this task has demonstrated good test-retest reliability in people with stroke.^{90,92} This task has also been used in studies concerning individuals with complete SCI.⁹¹ The complete movement sequence of the drinking task consists of five movement phases: (i) the reaching phase, in which the glass is reached for, grasped, and lifted from the table; (ii) the forward transport phase, in which the glass handle is secured and the glass is transported to the mouth; (iii) the drinking phase, in which a sip is taken; (iv) the backward transport phase, in which the glass is placed back on the table and the handle is released; (v) and the return phase, in which the hand is returned to the starting position on the table's edge.^{90,93} Various kinematic variables, including time, smoothness, velocities, joint angles, interjoint coordination, and trunk displacement, can be calculated.^{90,93}

ASSESSMENT OF ACTIVITY CAPACITY (LIMITATION)

During the acute phase of SCI, the primary focus of care is on impairments of body functions, whereas during the chronic phase of SCI (more than 12 months after injury), the focus is redirected towards assessing activity and participation.^{70,71,94,95} In this phase, the ASIA assessment may not fully capture all significant aspects of functional status.⁴⁶ A plethora of clinical assessments, such as the Action Research Arm Test (ARAT), Box and Block Test (BBT), Purdue Pegboard Test, Jebsen Test of Hand Function, and Nine-Hole Peg Test, can be used to assess upper extremity activity capacity in clinical settings.⁹⁶

Furthermore, disease-specific clinical assessments, including the Sollerman Hand Function Test (SHFT), Grasp and Release Test, and Capabilities of Upper Extremity, can be employed.⁹⁶ Given the absence of consensus for a single optimal clinical assessment,⁹⁶ ISCoS has developed and endorsed the use of the International Upper Extremity Data Set, version 1.1.^{97, 98} This Data Set consists of two sections, one addressing the hand ('Basic hand-upper extremity function,' ISCI-Hand), and the other targeting the arm and shoulder ('Shoulder function classification,' ISCI-Shoulder).^{97, 98}

However, regardless of the specific clinical assessment used, the psychometric properties of these assessments are not fully established for individuals with SCI.⁹⁶ Furthermore, the precision and sensitivity of these scales are considered comparatively lower than those accepted as objective measurements, such as camera-based kinematic movement analysis or grip strength measurement.^{72, 85, 99-101} Therefore, when it comes to assessing and describing upper extremity activity capacity, clinical assessments should preferably be combined with other, more objective assessment methods.^{85, 86}

ASSESSMENT OF ACTIVITY PERFORMANCE (LIMITATION)

Alongside the ability to perform standardised tasks and activities (activity capacity), the ICF domain of activity also encompasses the actual use of the upper extremity in real-life activities (activity performance), such as feeding, bathing, dressing, and mobility.⁵³

(*Figure 1*) General tools, such as the Functional Independence Measurement,³⁵ Barthel Index, and disease-specific tools, such as the Spinal Cord Independence Measure (SCIM)^{74, 102-104} can be used to assess activity performance. These assessments focus on “what a patient actually does in their daily life and not what he or she might be able to do.”⁴⁸ Among these, the SCIM^{74, 102-104} is widely recognised as a reliable and valid measure,¹⁰⁵ particularly for chronic SCI.⁴⁸ The SCIM is designed to assess an individual’s actual performance in their daily activities (sometimes referred to as independence), offering valuable insights into their real-life functioning.

The relationships between SCIM subscales and upper extremity functioning have previously been investigated, and the SCIM-self-care subscale has been found to be correlated with the assessment of upper extremity functioning.¹⁰⁶ Furthermore, the SCIM-self-care subscale has widely been used as a reference to validate other upper extremity assessments¹⁰⁷ and to evaluate the effects of interventions involving upper extremities.¹⁰⁸⁻¹¹¹ The total score of SCIM has shown a correlation with the kinematic measure of movement smoothness during reach-to-grasp,¹¹² whereas specific items, such as feeding, transfer from bed to wheelchair, and management of the bowel and bladder, have been used separately in research and clinical practise.^{113, 114}

ASSESSMENT OF PARTICIPATION (RESTRICTION)

Participation is defined by the ICF as involvement in life situations, ⁵⁸ “which includes being autonomous to some extent or being able to control your own life, even if one is not actually doing things themselves.” ¹¹⁵ Participation can be assessed by several generic scales, such as the Craig Handicap Assessment and Reporting Technique, ¹¹⁶ the Participation Scale ¹¹⁷, the Participation Survey/Mobility, ¹¹⁸ the Perceived Handicap Questionnaire, ¹¹⁹ the London Handicap Scale, and the World Health Organization Disability Assessment Schedule II. ¹²⁰ However, most of these scales address everything from the execution of tasks to autonomy and engagement, and some of them incorporate comparisons with able-bodied people or peers. ^{115, 121}

Individuals with disabilities clearly claim, however, that performance and participation are distinct concepts, as self-perceived and professional-reported participation also are. ^{122, 123} Self-perceived participation is a complex result of the dynamic transaction between personal preferences and societal standards, reflecting the involvement in life situations that each individual with disabilities perceives as satisfying and meaningful (personal perspective). ¹²²⁻¹²⁴ Participation, when observed and assessed by professionals, only provides an outsider perspective according to societal norms. ^{122, 123} When participation is only assessed “objectively,” the individual’s free will is ignored, and the core value of person- or patient-centeredness in rehabilitation fails to be incorporated. Cardol et al. pointed out the need to assess self-perceived participation alongside free will in participation, which is referred to as

'autonomy.'⁷¹ For this reason, a self-administered questionnaire called Impact on Participation and Autonomy (IPA) was developed.⁷¹

RATIONALE FOR THIS THESIS

Upper extremity impairments (ICF body functions domain) caused by a health condition such as SCI can result in activity limitations (ICF activity domain) and restrictions on participation (ICF participation domain). The relationships between various ICF domains are intricate rather than straightforward and streamlined since they are also influenced by contextual (environmental or personal) factors, such as the usage of adapted tools (e.g., special utensils for eating) or hand orthoses, admission to SCI-specialised units with skilled and professional health care or hand surgery units for hand reconstruction, use of compensatory strategies (e.g., passive tenodesis grasp), social and family support, and coping ability.^{87, 125}

Impairments of the upper extremity after SCI have shown a correlation with upper extremity activity capacity,¹²⁶ performance,^{110, 127-129} independence in self-care,¹²⁸ and participation.^{76, 130} Specifically, limitations in upper extremity activity performance in terms of independence are associated with weakness in grip strength,¹³¹ recovery, therapy response, rehabilitation outcome, and consequently, patient satisfaction, and overall quality of life.^{80, 82, 132-134} Independence has shown a correlation with the kinematic measure of movement smoothness during reach-to-grasp.¹¹² Independence in self-care has widely been used as a reference to validate other upper extremity assessments^{110, 127, 135} and to evaluate the effects of interventions involving upper extremities.^{48, 108, 111, 136} Independence in certain series of tasks, such as feeding, transfer from bed to wheelchair, and

management of the bowel and bladder, have been selected to be used separately in research and clinical practise as outcome measures, ^{114, 137, 138} even though more detailed knowledge of the relationships between independence in certain series of tasks separately and upper extremity functioning is limited. ^{114, 137, 138}

Nevertheless, previous research to a great extent targeted homogeneous samples by recruiting individuals with complete injuries at specific segmental neurological levels of injury and excluding those with incomplete SCI. ^{87, 91} These uniform samples are not representative of the entire SCI population, which decreases the generalizability of their findings. Besides, the goal of homogeneity, together with the relatively low prevalence of SCI and the diversity of injuries, led to several studies with small samples (4 to 20 participants) and limited statistical power. ⁸⁷ On the other hand, therapist-rated clinical assessments based on ordinal ratings are considered less accurate than measurements of kinematics or kinetics (using techniques like 3D motion capture systems and handheld dynamometers). ^{79, 90, 139}

Thus, additional research is warranted to reveal even further how objective assessments, clinical observational measures, and patient-reported questionnaires relate to each other across several ICF domains of functioning (e.g., activity, independence, and autonomy) in a study population that should be more representative. ⁷⁹ This additional knowledge would enrich rehabilitation practises, support clinical decision-making, facilitate goal-setting, and refine outcome

measurement, including the aforementioned aspects of activity, independence, and autonomy in participation.^{50, 125}

AIM

The overall aim of this project was to enhance our comprehension of upper extremity functioning across the various domains of ICF in individuals with established cervical or thoracic SCI, whether complete or incomplete.

Specific aims of each study:

1. To determine the altered kinematic variables of upper extremity movement in individuals with cervical or thoracic SCI, as measured during a purposeful daily task, in comparison with able-bodied controls.
2. To determine the associations between kinematic variables and clinical assessments of upper extremity functioning in individuals with cervical or thoracic SCI.
3. To determine the extent to which different aspects of independence in ADL correlate with upper extremity functioning in individuals with cervical or thoracic SCI.
4. To determine the extent to which self-perceived autonomy in participation after cervical or thoracic SCI correlates with activity performance in terms of independence in everyday life activities and upper extremity activity capacity.

METHODS

PARTICIPANTS AND DESIGN

All four studies adopted a cross-sectional study design. Adults with SCI who had been in contact with the outpatient rehabilitation clinic at Sahlgrenska University Hospital between 2006 and 2016 were screened for inclusion. For Study I, a convenient sample of able-bodied individuals was also recruited.

The neurological level of injury as defined by the ASIA/ISNCSCI examination and classification system was used to categorise the type of SCI (i.e., cervical, thoracic, or lumbar). Individuals with lumbar SCI were excluded from the project. This information was extracted from participants' medical records or assessed on the day of the appointment using the ASIA/ISNCSCI examination.^{36,37} The grade of completeness of injury (AIS; A-E) was also derived from medical records and used to classify injuries as AIS A, B, C, D, or E. Individuals with AIS E (complete recovery) were excluded from studies II, III, and IV. This approach ensure consistent inclusion and relevant categorisation in subsequent analyses.

In Study I, the sample included 54 non-disabled individuals (referred to as controls) and 29 individuals with cervical or thoracic SCI of different grades of completeness (AIS A, B, C, D, or E) and motor neurological levels (from C5 to T12). The kinematic data from each upper extremity of the participants with SCI (57 upper extremities in total) were divided

into two groups: the limited upper extremity functioning group (ARAT < 57 points) (n = 30 upper extremities) and the full functioning group (ARAT = 57 points) (n = 27 upper extremities). Regarding nine participants with SCI, the kinematic data from their upper extremities were classified into different functioning groups because of the asymmetric impact of incomplete SCI on each upper extremity. These two functioning groups were then compared with the data from the 54 non-dominant upper extremities of able-bodied age- and sex-matched controls. The decision to use the non-dominant upper extremity of the controls as a reference rather than the dominant extremity was made to mitigate any disparities between able-bodied participants and those with SCI, thus ensuring a more equitable basis for comparison. ¹⁴⁰

In Studies II, III, and IV, a sample of 25 individuals with cervical or thoracic SCI, either complete or incomplete (AIS C, D), was included. For the analyses in these studies, clinical and kinematic data from a single upper extremity, referred to as the 'tested arm,' were used. The tested arm was the more affected upper extremity, as determined on the basis of the clinical assessment of ARAT. ¹²⁶ Among the 29 participants initially included in Study I, four were excluded from Studies II, III, and IV. This exclusion was either due to having a lumbar motor level of injury on the side of the more affected upper extremity (one participant) or because they had an AIS E grade of completeness.

In studies III and IV, the same participants with cervical or thoracic SCI and limited independence (SCIM-total score < 100) from study II were

included, although the inclusion criteria varied slightly between studies III and IV.

The inclusion process for individuals with SCI in all four studies is shown in *Figure 2*. The inclusion and exclusion criteria are presented in Table 1.

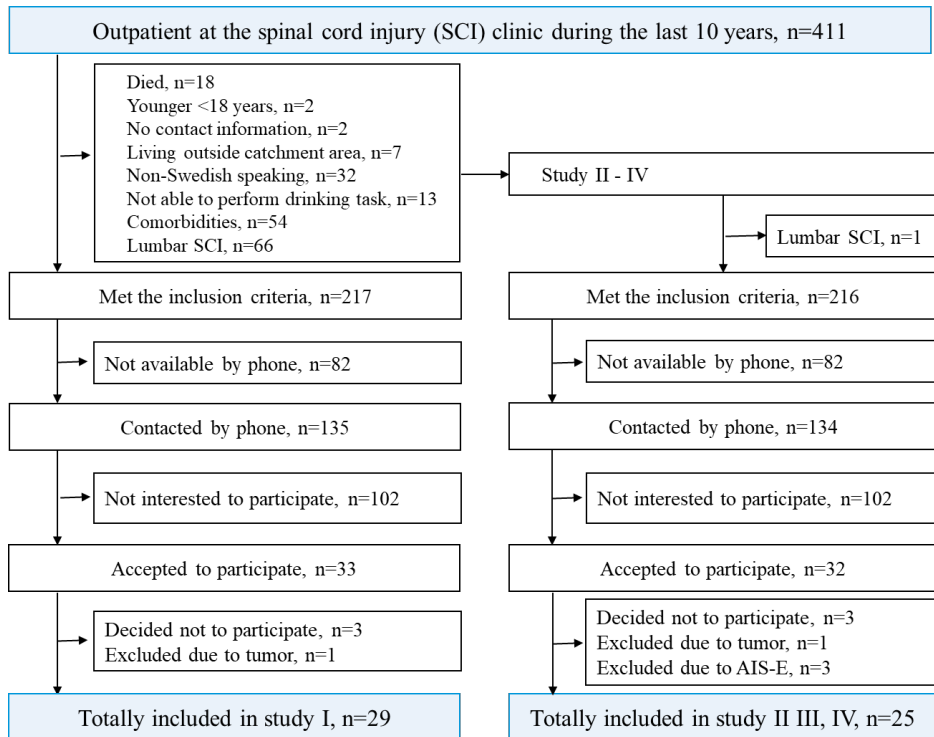


Figure 2. Inclusion process for individuals with spinal cord injury (SCI) in all four studies.

AIS, American spinal injury association Impairment Scale.

Table 1. Inclusion and exclusion criteria for the four studies in this thesis.

Inclusion criteria Study I	Inclusion criteria Study II	Inclusion criteria Study III, IV	Exclusion criteria
Complete or incomplete spinal cord injury at the cervical or thoracic level	Complete or incomplete (AIS A, B, C, D) spinal cord injury at the cervical or thoracic level		Not Swedish speaking
Impaired upper extremity	Limited upper extremity functioning (ARAT < 57 or SHFT < 80)	Limited independence (SCIM < 100)	
Able to perform the 'drinking task' at least with one arm			Other neurological conditions that could limit the ability to participate
>1 year after injury			
Age >18			
Living in hospital's geographical catchment area			Psychological (e.g., major depression, psychosis, or other mental disorders) that could limit the ability to participate
			Musculoskeletal conditions that could limit the ability to participate

AIS, American spinal injury association Impairment Scale; ARAT, Action Research Arm Test; SHFT, Sollerman Hand Function Test; SCIM, Spinal Cord Independence Measure.

ASSESSMENTS USED IN THE THESIS

The ICF framework was used as a guide for the selection of assessments used in this thesis (see *Figure 3*). Assessments from all three ICF domains—body function, activity, and participation—were included.

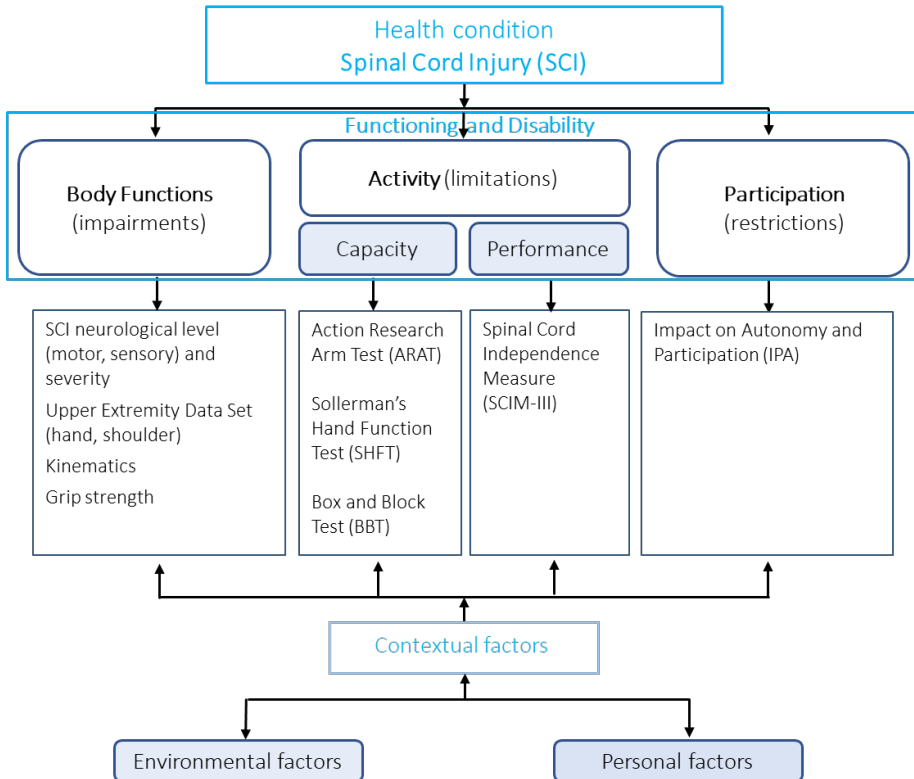


Figure 3. International Classification of Functioning, Disability, and Health (ICF) with all the assessments used in this thesis.

ASSESSMENTS OF BODY FUNCTION

The assessment performed at the body function level included a set of clinical assessments of motor and sensory functions (Table 2) as well as kinematic movement analysis of the drinking task.

Table 2. Clinical assessments at the body function level used in the thesis.

Name	Purpose	Description
ASIA Impairment Scale (AIS)	Grade of completeness	Derived from the participants' medical records.
ASIA Upper Extremity Motor Score	Strength of the key muscles	Rated from 0 to 5 using manual muscle testing, maximum score of 25 points for each upper extremity. ^{36,37}
Grip Strength Test	Grip strength	Measured using a hydraulic hand-held dynamometer (Jamar); performed in a sitting position, elbow flexed at 90 degrees, wrist dorsiflexed (at 0–30 degrees); dynamometer's weight was supported by the tester or table; an average of 3 trials was calculated. ¹⁴¹
ASIA Upper Extremity Sensory Score	Sensation in the key points	Rated from 0 to 2, maximum score of 32 points for each upper extremity. ^{36,37}
Passive joint position detection and	Proprioception of the hand	Every finger was grasped laterally and moved up/down with participant's eyes closed. Impaired

motion discrimination (Study II)	proprioception=wrong answer about finger's position and direction at least one finger. ¹⁴²
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ASIA, American Spinal Injury Association

KINEMATIC ANALYSIS OF THE DRINKING TASK

In both Studies I and II, kinematic analysis was employed to measure upper extremity movements during the drinking task. ⁹³ The optoelectronic Pro Reflex Motion Capture System (MCU240 Hz, Qualisys AB, Gothenburg, Sweden) was used. This system comprised five cameras emitting infrared light signals and tracking the movement of reflective markers. ⁹³ The captured 3D kinematic data were then filtered using a 6 Hz second-order Butterworth filter in both forward and reverse directions and analysed offline using custom-made MATLAB (The Math Works Inc.) software. ^{90, 93}

Throughout the analysis process, efforts were made to adhere closely to the previously published standardised drinking task protocol. ¹⁴³ Nine reflective markers were placed at specific anatomical landmarks on the upper extremities, face, body, and glass. ¹⁴³ Participants with motor-complete SCI performed the task while seated in their own chair, whereas able-bodied controls and individuals with incomplete SCI performed the task seated in a height adjustable chair. Participants sat in front of a height adjustable table. The sitting position was standardised according to the protocol described in previous studies. (see *Figure 4*).

92, 143



Figure 4. Initial sitting position and marker placements on the body for the kinematic drinking task in a participant with complete spinal cord injury (SCI) (the markers on the right shoulder and the right elbow are not visible). (Illustration by M. Lili.)

During the drinking task, participants were instructed to perform the task unimanually, repeating it 8-10 times at a self-paced and comfortable speed. The statistical calculations were based on the mean of all successful trials.⁷² Data collected throughout the entire movement of the drinking task, as well as from different phases of the movement, were used for statistical calculations in Study I. In Studies II and III, only the total movement time (Movement Time, MT) and smoothness (Number of Movement Units, NMU) during the entire movement were calculated.⁷²

KINEMATIC VARIABLES

The kinematic variables that were calculated were: movement smoothness during the entire movement except for the drinking phase; movement times (i.e., total time, time taken for each separate phase except for the drinking phase); time to peak velocity; joint angles; and interjoint coordination.⁷² The start and end of the entire movement were defined by the hand marker velocity cut-off of 2% of maximum velocity.

In the kinematic analysis, the tangential velocity profile was used to count the NMU. This involved identifying the local minimum and the next maximum velocity value that surpassed an amplitude threshold of 20 mm/s, with a minimum time of 150 ms between two consecutive peaks.⁷² This calculation enabled the quantification of repeated accelerations and decelerations within the movement, ultimately measuring the smoothness of the movement. The minimum NMU value for the drinking task was four, representing one unit for each movement phase. Notably, a higher NMU value is indicative of less smooth or more fragmented movement during the task.⁷²

Joint angles were calculated for maximal elbow extension during the reaching phase, maximal wrist angle during the reaching and forward transport phases, and maximal arm abduction during the reaching and drinking phases. During the reaching phase, the inter-joint correlation between shoulder flexion and elbow extension joint angles was computed and referred to as interjoint coordination, as was trunk

displacement by the maximal forward displacement of the trunk in the sagittal plane.⁷²

ASSESSMENTS OF ACTIVITY CAPACITY

To assess upper extremity activity capacity, the Sollerman Hand Function Test (SHFT)¹⁴⁴ was employed in Studies I and II. Originally designed to evaluate hand function in individuals with chronic tetraplegia after hand reconstruction,¹⁴⁵ the SHFT has excellent reliability and validity.¹⁴⁵ It comprises 20 ADL tasks that require seven distinct hand grips. Each task is scored between 0 and 5, considering both time taken and movement quality. Among these tasks, 17 are unimanual, and three are bimanual.¹⁴⁴ The administration of the SHFT typically takes approximately 20–25 minutes,⁹⁶ though times as high as 60–90 minutes have been reported.¹⁴⁶ The summative score of SHFT, ranging from 0 to 80 points, indicates the level of performance, with higher scores denoting better hand activity capacity.¹⁴⁴

The Action Research Arm Test (ARAT) was utilised in all four studies included in this thesis to assess upper extremity activity capacity.¹²⁶ ARAT can reliably assess the unimanual gross and fine movements of the tested upper extremity.¹²⁶ It consists of 19 items, hierarchically grouped into four subscales: grasp, grip, pinch, and gross movement, with scores ranging from 0 to 3.¹²⁶ Each task is scored based on observed time and movement quality (e.g., grip configuration, transfer of an object, and trunk stability). The total ARAT score is the sum of the separate task scores, with a maximum of 57 points. Objects of

varying shapes and sizes are grasped and transferred to different vertical or horizontal locations. A full score of three points per task is awarded if the movement adheres to specified criteria, including the grasped object being transferred within a time limit of five seconds and the quality of the movement matching that of the movement in able-bodied individuals. ARAT has been used in SCI populations ^{147, 148} and has displayed correlation with kinematic variables obtained during a purposeful task. ⁹²

Gross manual dexterity was quantified using the Box and Block Test (BBT), which evaluates the efficiency of unimanual movement by measuring the number of 2.5-cm wooden blocks transferred from one compartment to another within one minute. The reliability and simplicity of the test make it a valuable tool for assessing movement efficiency, regardless of compensatory strategies. ¹⁴⁹⁻¹⁵²

The International Spinal Cord Injury (ISCI) Upper Extremity Basic Data Set, which consisted of two sections: ISCI-Hand and ISCI-Shoulder, was also used in this study. ISCI-Hand assesses common arm and hand movements such as reaching, grasping, manipulation, and arm positioning. It employs a 5-level scoring system based on the voluntary motor innervation of the upper extremity muscles activated. Each score reflects the quality of the movement, aligning with how closely it mirrors the specified "correct" movement. ^{97, 98} Similarly, ISCI-Shoulder employs a 4-level scoring system, assessing observed shoulder and upper extremity function during arm positioning. ^{97, 98} The ISCI Upper

Extremity Basic Data Set Form has been tested and has shown strong inter-rater reliability in individuals with cervical SCI¹⁵³. ISCI-Hand also demonstrated a moderate correlation with the kinematic measure of wrist angle¹⁵⁴, further establishing its clinical relevance.

ASSESSMENTS OF ACTIVITY PERFORMANCE

To assess upper extremity activity performance, particularly the extent of assistance needed for ADL in individuals with SCI, the third version of the disease-specific Spinal Cord Injury Independence Measure (SCIM) was used.^{102, 103, 155} The SCIM-III comprises nineteen items grouped into three subscales: (i) self-care (SCIM-self-care), (ii) respiration and sphincter management (SCIM-respiration/sphincter), and (iii) mobility (SCIM-mobility). A total score of 100 indicates that the individual is totally independent across all domains and does not need any assistance.^{102, 103}

Within the SCIM-self-care subscale, with a maximum score of 20, six items assess various series of tasks, including feeding, upper and lower body bathing, upper and lower body dressing, and grooming. This subscale has shown the strongest correlations with upper extremity activity capacity in individuals with SCI compared with the other SCIM subscales.^{106, 110, 127, 156, 157}

The SCIM-respiration/sphincter and SCIM-mobility subscales consist of nine items each and share a maximum score of 40 points. The SCIM-respiration/sphincter subscale encompasses a series of tasks related to

respiration, sphincter management (bladder and bowel care), and toilet use. Similarly, the SCIM-mobility subscale assesses a series of tasks related to bed mobility, transfers, indoors, and outdoors.

ASSESSMENTS OF PARTICIPATION

In the current thesis, the self-administered questionnaire Impact on Participation and Autonomy (IPA), created by Cardol et al., was used.¹²⁴ IPA emphasises personal perspective in fulfilling roles over the normative perspective of another person (e.g., a clinician).^{94, 95} The English version of the IPA (IPA-E)^{95, 158-163}, translated into Swedish, was used to assess self-perceived autonomy in participation. IPA has been tested in adults with various conditions, including SCI.^{158, 160-163}

The IPA-E questionnaire is divided into nine sections that address various aspects of life, including mobility, self-care, household activities, looking after money, leisure, social life and relationships, helping others, paid or voluntary work, and education and training. Aside from these nine questions, IPA-E includes a general question (question 10) about the impact on life in general ("My chances of living life the way I want to are"). The questions are phrased as "my chances of doing the activity, either by myself or others as I want are" with response options ranging from excellent to very poor (0 to 4). The responses are categorised for the analyses into five different 'impact areas' of life: indoors, family role, outdoors, social life and relationships, and work and education. A median value was calculated for each impact

area, with a higher score representing lower self-perceived autonomy. The answer to question 10 is loaded into outdoor autonomy.

An additional question within each of the nine sections asks the respondent to indicate the extent to which this injury-related self-perceived impact on autonomy is experienced as problematic (0 = no problems, 1 = minor problems, 2 = major problems).¹⁵⁸ Initially, the identified 'problematic life aspects' were intended for clinical decision-making.⁹⁵ It should be noted that the 'problematic life aspects' do not directly correspond to the five 'impact areas.'

The IPA-E questionnaire also includes two optional open-ended questions. First, the respondent was asked to list the top three injury-related problems among the problematic life aspects listed in the IPA-E questionnaire. Finally, the respondent is asked to add other aspects important for autonomy and participation ("Are there any other aspects you want to mention that we have not asked you about?").

DATA ANALYSES AND STATISTICAL METHODS

Statistical data analyses were performed using IBM SPSS (Statistical Package for Social Sciences) version 24. A significance level (alpha value) of 0.05 was used in all statistical analyses, and the Bonferroni correction method was applied whenever multiple comparisons were performed. Descriptive statistical methods were used to describe the groups of participants in terms of demographic and clinical characteristics, kinematic variables, and scores from self-reported

questionnaires. Numerical ratio values are presented as mean and standard deviation (SD). Categorical ordinal variables are presented as medians and quartiles. Statistical analyses conducted in the different studies are shown in Table 3.

In Study I, the independent t-test was used for comparisons between the limited upper extremity functioning group or the full functioning group against the able-bodied control group.

For all significant differences, the strength of the difference between the groups was determined using the eta squared (η^2) effect size (ES) estimates. The eta squared ranges from 0 to 1 and represents the proportion of variance in the kinematic variable explained by the group variable. Cohen's guidelines were followed to interpret the effect size, with 0.01–0.05 indicating a small effect, 0.06–0.13 indicating a moderate effect, and ≥ 0.14 a large effect size.¹⁶⁴

In Studies II, III, and IV, data from only the more-affected arm (i.e., with a lower total ARAT score) or the non-dominant arm were used. Spearman correlation analysis was used in studies II, III, and IV to analyse correlations because the majority of variables were not normally distributed. The strength of correlation was interpreted as 0.00–0.25 (very low), 0.26–0.49 (low), 0.50–0.69 (moderate), 0.70–0.89 (high), and 0.90–1.00 (very high).¹⁶⁵

In Study II, a stepwise backward regression was used to construct multiple regression models. The kinematic variables that showed a statistically significant correlation with clinical assessment scales (dependent variables) were selected as independent variables and included in the regression analysis.

Table 3. Statistical methods used in the studies of this thesis.

Analytical statistical methods	I	II	III, IV
Analyses of difference between groups			
Wilcoxon signed rank test	√		
Kruskal-Wallis one-way analysis of variance	√		
Mann–Whitney U test	√		
Eta squared (η^2) effect size (ES)	√		
Analyses of relationships			
Spearman rank-order correlation		√	√
Univariate and multiple linear regression		√	

ETHICAL CONSIDERATIONS

In relation to potential health risks, no significant adverse effects were observed before, during, or after the assessment process. Moreover, there were no financial or other incentives for participating in these studies. Participants were afforded the opportunity to engage in discussions and pose questions to the lead researcher, thereby facilitating increased awareness of their challenges and activity limitations throughout the assessment process.

In terms of clinical assessments, careful consideration was given to the time commitment required for all assessments when preparing each assessment session and scheduling appointments at our laboratory. Consequently, not all examinations were conducted on-site; the self-reported IPA-E questionnaire was dispatched by mail one week prior to the appointment. Additionally, certain data (e.g., ASIA, AIS) were obtained from medical records after obtaining participants' consent and securing approval from the head of the department at Sahlgrenska University Hospital. Our laboratory also provided a suitable environment with a treatment bed in case participants experienced mental fatigue or physical exhaustion.

The self-reported IPA-E questionnaire primarily addressed autonomy in participation within everyday life contexts (e.g., social interactions, financial matters, family roles). As such, some questions may have posed emotional challenges or caused distress. Verbal complaints regarding the administration time and comprehension of various

concepts within the IPA-E arose from some participants. Therefore, sufficient time was allocated after the assessment session to discuss and clarify these questions with participants. While no specific cognitive, speech, or psychological screenings were conducted, individuals with SCI exhibiting concomitant severe neurological or psychological conditions were excluded based on our criteria during the review of eligible participants' medical records. Moreover, adhering to principles of inclusivity, both in research and in society at large, we aimed to recruit individuals irrespective of nationality or origin, as long as they possessed sufficient proficiency in spoken and written Swedish to engage in communication during the assessment session and respond to questions, including those in the IPA questionnaire.

Participants with severely limited functioning occasionally experienced emotional frustration due to their inability to complete certain tasks, particularly during the SHFT test. Conversely, many participants with moderate or high functioning regarded the entire assessment process as a form of training or enjoyable competition, particularly during the BBT test. To the best of our knowledge, none of the participants required immediate professional assistance for emotional reactions, possibly due to their extensive experience and understanding of their long-standing injuries. Notably, one inclusion criterion mandated that the injury had occurred at least one year prior, with an average duration of over 15 years. This potential risk was taken into account in the study's design, and as such, expertise in SCI and clinical experience were prerequisites for researchers involved in these studies. In addition, the research group

comprised individuals with extensive clinical experience in various fields, including psychology, and they were readily available for support.

During kinematic analysis, markers were affixed to the skin using double-sided tape, which may contain rosin, a potential allergen. Participants were thoroughly questioned about known allergies, and they were informed of this potential risk prior to the study. To the best of our knowledge, none of the participants experienced allergic reactions following the assessment process.

The project received ethical approval from the Regional Ethical Review Board in Gothenburg, Sweden (408-17) and adhered to the ethical principles for medical research involving human subjects outlined in the WMA Declaration of Helsinki. All participants received comprehensive information about the project before they provided verbal and written consent. In addition, details regarding confidentiality and data handling in accordance with the data protection law were provided before participants commenced their participation. The participants were also informed of their right to withdraw from participation without the need for justification.

RESULTS

An overview of the study designs, samples, and methods of the studies included in the thesis is displayed in *Figure 5*.

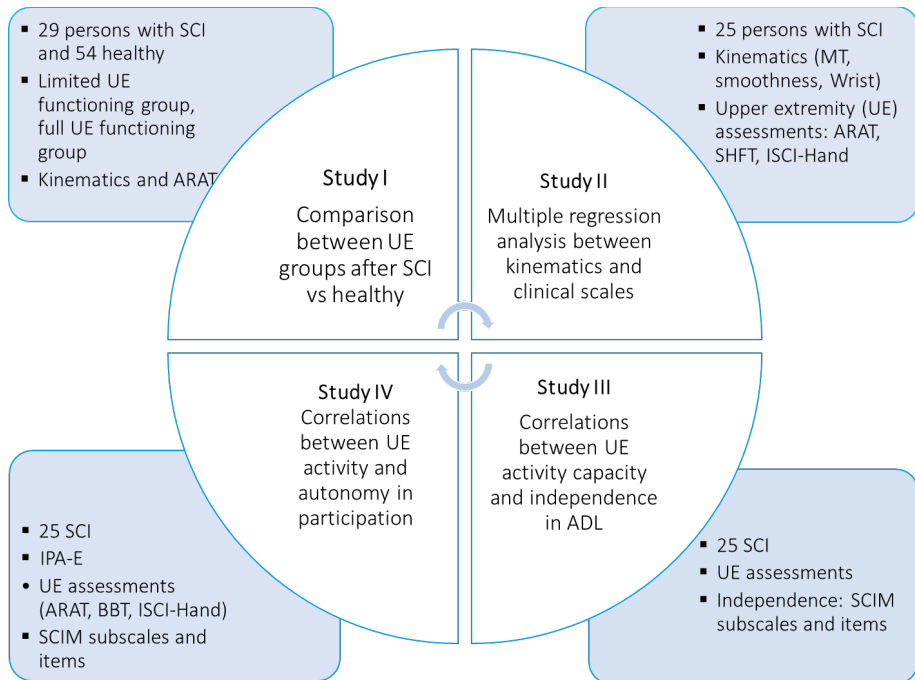


Figure 5. An overview of the four studies included in this thesis.

ADL, Activities of Daily Living; ARAT, Action Research Arm Test; BBT, Box and Block Test; IPA-E, Impact on Autonomy and Participation; ICF, International Classification of Functioning, Disability and Health; ISCI, International Spinal Cord Injury Upper Extremity Basic Data Set Form; ISCI-Hand, basic Hand variable, ISCI-Shoulder, Shoulder variable; SCI, Spinal Cord Injury; SCIM, Spinal Cord Independence Measure; SHFT, Sollerman Hand Function Test; UE, Upper Extremity.

PARTICIPANTS

A flowchart of participant inclusion with reasons for exclusion is shown in *Figure 2* (Methods section). The main reasons for declining participation in the project were lack of time or energy, age, other complications, or booked time for an operation. The majority of individuals who declined to participate were defined as having tetraplegia or using a wheelchair for transportation.

The baseline characteristics of the sample of 29 participants with SCI and of the control group of able-bodied individuals included in Study I are shown in Table 4.

Table 4. Baseline demographics of able-bodied controls and participants with spinal cord injury (SCI).

	Participants with SCI n=29		Able-bodied controls, n=54	
	Mean or n	SD or %	Mean or n	SD or %
Age, years	59.5	13.4	59	26–81
Female	9	31 %	15	28%
Male	20	69 %	39	72%
Height, cm	176	9	176	7.8
Weight, kg	76	15	71	17.2

SCI, Spinal Cord Injury.

Four of the 29 participants with SCI were excluded from studies II, III, and IV because they had a lumbar motor level of injury on the side of the tested (i.e., more severely affected) upper extremity or because they

had an AIS E grade of completeness. The demographics and clinical characteristics of the participants included in these studies are described in the respective studies (publication or manuscript).

STUDY I

The total MT, movement times during several phases, total number of movement units (NMU) (referred to as smoothness) during the entire drinking task, wrist joint (dorsal flexion) during reaching and forward transport phase, and trunk displacement were significantly larger in the limited functioning group (large effect size between 0.14 and 0.17) than in the control group. The arm abduction angle during the drinking phase (p -value 0.002, moderate effect size 0.12) and inter-joint coordination (between the elbow extension and shoulder flexion) during reaching (p -value 0.038, moderate effect size 0.06) in the limited functioning group were statistically significant compared with the control group of upper extremities.

Between the full functioning group and the control group, only the arm abduction angle in the upper extremities of the participants with SCI was significantly (p -value 0.031, moderate effect size 0.06) greater. No differences in velocity variables or other joint angles were found either between the limited functioning group and the control group or between the full functioning group and the control group.

STUDY II

The kinematic variables of movement time and smoothness, as well as movement pattern measures of the trunk, shoulder, elbow, and wrist joint, showed statistically significant correlations with all three clinical assessments (ARAT, SHFT, and ISCI-Hand). Because of the multicollinearity between all movement times and NMU measures, these variables were separately added to the multiple regression models.

A large majority of the total variance in ARAT (82–83%) and SHFT (77–79%) was explained by the wrist angle and one of the variables of movement time or smoothness. The wrist angle uniquely explained the largest amount of variance (19%–28%) in all four models. The wrist angle was the only significant variable, explaining 59% of the total ISCI-Hand variance. Among the confounding variables, only the proprioception of the hand improved the explanatory power of the final models for ARAT and SHFT by up to 90%–91%.

STUDY III

Movement time and smoothness ($r \geq 0.6$) as well as grip strength ($r \geq 0.5$) were strongly or moderately correlated with the SCIM-self-care subscore and the subscale's items on feeding and dressing (upper and lower body). The clinical assessments ARAT, BBT, and ISCI-Hand also correlated moderately (r 0.52-0.76) with the SCIM-self-care subscale and items of feeding and dressing (upper and lower body) (r 0.57-0.74). The feeding and upper body dressing items correlated with the Upper Extremity Motor Score and ISCI-Hand but moderately. The upper body

dressing item correlated (r 0.51-0.76) with all upper extremity functioning assessments applied in the current study.

The SCIM-mobility subscore had significant but weak (r 0.3-0.5) correlations with grip strength and ISCI-Hand. The items on mobility in bed and wheelchair correlated moderately (r 0.51-0.61) with the kinematic measure of movement time. The bed mobility item alone correlated moderately or strongly with the kinematic measures of movement smoothness (r -0.59), grip strength (r -0.61), ARAT (r 0.57), BBT (r 0.52), and ISCI-Hand (r 0.51). The item on ground wheelchair mobility correlated moderately with ISCI-hand (r 0.50) and movement time (r 0.58).

All assessments presented a non-significant and weak or very weak correlation with the SCIM-respiration/sphincter subscore. The only items from the SCIM-respiration/sphincter subscale with moderate correlations with the assessments were the respiration and the toilet use items. The respiration item correlated with the kinematic measures of movement time (r -0.53) and smoothness (r -0.50), as well as with BBT (r -0.56). The item of toilet use correlated with movement time (r -0.66).

An **overview** of the relationships with $r \geq 0.5$ between assessments used in Study III (i.e., assessments of body function, activity capacity, activity performance) at the subscale and item levels is displayed in *Figure 6*.

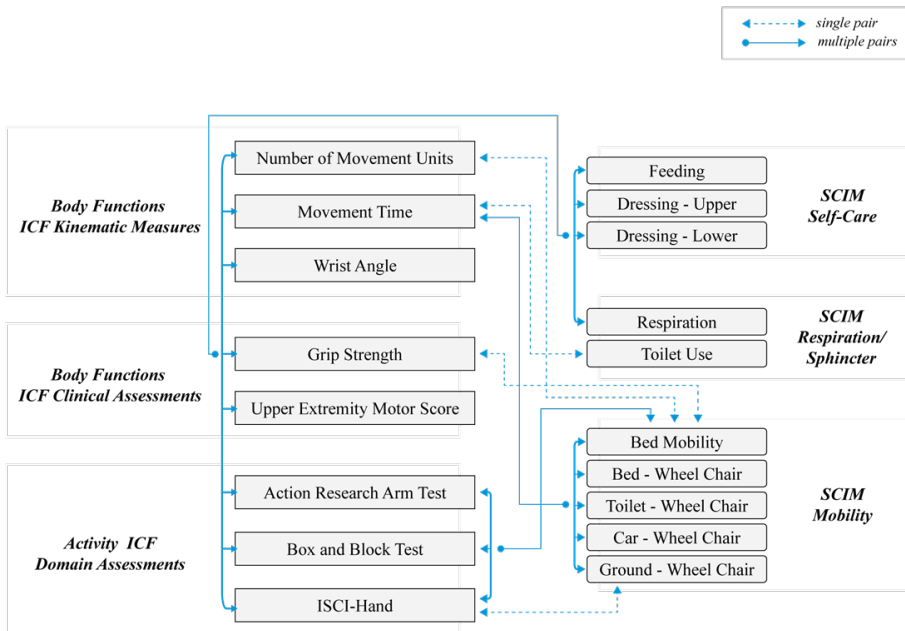


Figure 6. An overview of the relationships with $r \geq 0.5$ between assessments used in the Study III at the subscale and item level.

ICF, International Classification of Functioning, Disability, and Health; ISCI, International Spinal Cord Injury Upper Extremity Basic Data Set Form; ISCI-Hand basic Hand variable; SCIM, Spinal Cord Independence Measure; A dotted line indicates a 1-to-1 variable correlation with $r > 0.5$; A dashed line indicates that the variable(s) correlate with each and every variable inside the bracket with a correlation with coefficient $r > 0.5$.

STUDY IV

The majority of participants perceived injury-related restrictions on outdoor (88%), family role (80%), and indoor (72%) autonomy in participation as well as autonomy in participation in life in general (i.e., the chances of living life the way they wanted to (72%). These restrictions on autonomy were, however, experienced as problematic only in the aspects of mobility (88%), self-care (81%), leisure (76%), household and social life (68%). Restricted autonomy in the life aspect of work and education was also reported as problematic by the majority of the participants, who thought this aspect was relevant for them.

Self-perceived autonomy indoors was strongly ($r = 0.72$) correlated with SCIM self-care and moderately ($r = 0.60$) correlated with SCIM-mobility. Social autonomy correlated moderately with SCIM self-care ($r = -0.50$). Problematically restricted autonomy in paid or voluntary work correlated ($r = 0.55$) with SCIM-respiration/sphincter. The correlations observed between SCIM self-care and problematic restriction of autonomy in leisure and self-care were weak ($r = -0.49$, $r = -0.40$), as was the correlation found between autonomy in social life and performance during mobility activities (i.e., SCIM-mobility) ($r = -0.41$). Self-perceived autonomy in participation after SCI did not show any significant correlation with upper extremity activity capacity.

Indoor and outdoor autonomy were the most frequently rated areas of autonomy restricted due to SCI, according to the participants' top three rankings. This injury-related restriction on mobility autonomy was

experienced and ranked as the most problematic, followed by self-care autonomy. Among the aspects of life in which injury-related restrictions on autonomy were perceived as problematic by the majority of participants, mobility was in first place, followed by self-care and aspects of social life. Finally, nine participants responded and mentioned the following aspects as issues not addressed in the IPA-E: relationships, acceptance, human values, medical issues, environmental factors, and factors related to the healthcare system. Only one participant mentioned relationships as an issue not addressed in IPA-E.

A **summary** of the relationships (with $r \geq 0.5$) between assessments of body function (kinematic measures), activity capacity, activity performance, and participation is displayed in *Figure 7*.

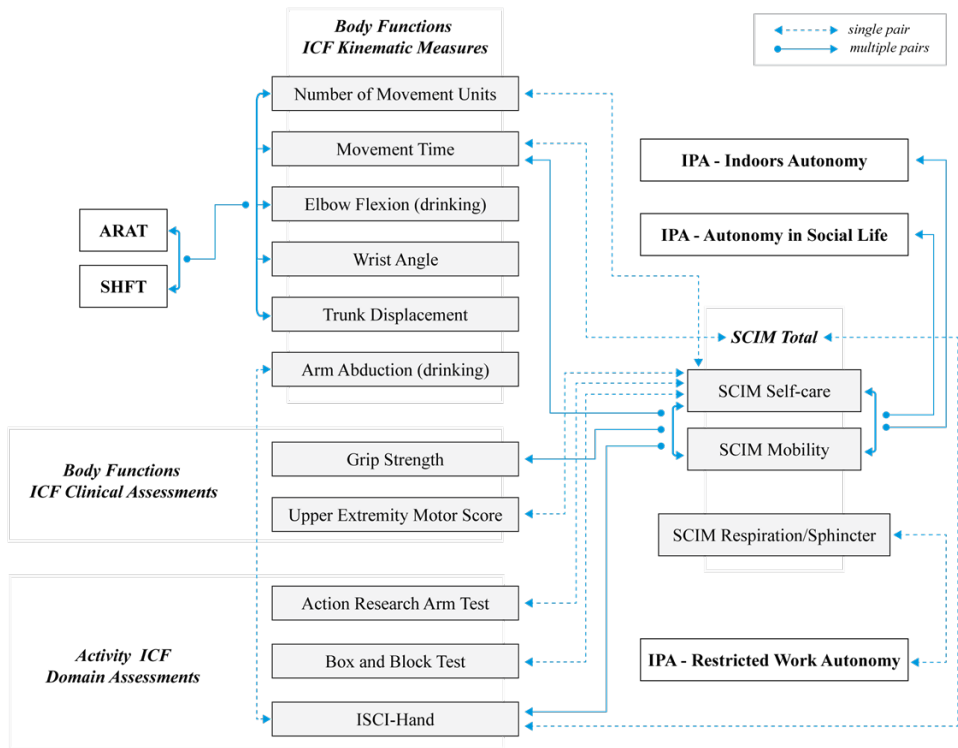


Figure 7. A summary of the relationships between the assessments used in the studies included in this thesis.

ARAT, Action Research Arm Test; IPA, Impact on Autonomy and Participation; ICF, International Classification of Functioning, Disability and Health; ISCI, International Spinal Cord Injury Upper Extremity Basic Data Set Form; ISCI-Hand basic Hand variable, ISCI-Shoulder Shoulder variable; SCIM, Spinal Cord Independence Measure; SHFT, Sollerman Hand Function Test; Only items with significant correlations are presented; Single pairs and a dotted line indicate a 1-to-1 variable correlation with $r > 0.5$; Multiple pairs and a dashed line indicate that the variable(s) correlate with each and every variable inside the bracket with $r > 0.5$.

DISCUSSION

This thesis sheds new light on the assessment of the upper extremities and provides a deeper understanding of the relationships between different ICF domains in the context of upper extremity functioning in individuals with established complete or incomplete cervical or thoracic SCI. The selection of assessment methods was guided by the ICF framework to provide a comprehensive perspective on the different aspects of functioning. The altered functioning due to SCI in individuals is a combined result of upper extremity impairment (ICF body functions domain), activity limitation (ICF activity domain), and participation restriction (ICF participation domain). The relationships between a particular injury and its 'expected functional independence outcome,'³⁸ and the different ICF domains are not streamlined because every level of injury and ICF domain is also dynamically influenced by contextual factors. As such, further knowledge about the relationships between various assessment tools of the upper extremity from all three aforementioned ICF domains is still needed.

MAIN FINDINGS

The first study found that movement time, smoothness, and most of the pattern-related kinematic variables, but not the velocity-related variables, were able to discriminate the movement performance of upper extremities with limited functioning after SCI from the movement performance of able-bodied controls. Movement performance of the upper extremities with full functioning (full score on the ARAT

assessment) after SCI was close to normal compared to the movement of the upper extremities of able-bodied participants.

The second study showed that movement time and smoothness were the kinematic variables that best correlated with clinical assessments of upper extremity activity capacity (ARAT, SHFT, and ISCI-Hand) and that they, along with wrist dorsiflexion angle, could explain the most variance in the clinical assessments, i.e., 82% of the total variance in ARAT and 77% in SHFT. This explanatory power was increased to 90%–91% by the addition of the hand proprioception variable in the model. Approximately 60% of the variance in the ISCI-Hand score was explained merely by the wrist angle.

In the third study, movement time, movement smoothness, and grip strength, as well as the clinical assessments of activity capacity (ARAT, BBT, and ISCI-Hand), were found to be correlated with activity performance (termed independence) during self-care activities, in particular the sub-scale items of feeding and of dressing. Independence in mobility activities (classified as a set of several tasks) was only weakly correlated with grip strength and ISCI-Hand. At the individual task level, however, independence in wheelchair mobility was correlated with movement time, while independence in bed mobility was correlated with movement time, smoothness, grip strength, ARAT, and BBT. ISCI-Hand showed a correlation with independence in ground wheelchair mobility. Across the tasks related to respiration and sphincter management, independence during respiration management

and toilet use were correlated with clinical assessments of upper extremity activity capacity. Independence in respiration was also correlated with movement time, smoothness, and BBT. Furthermore, independence during toilet use was correlated with movement time.

The fourth study showed that the majority of participants experienced restricted autonomy both outdoors and indoors, as well as in the area of family role after SCI. Indoor autonomy was rated as one of the three most restricted domains by most participants, followed by outdoor autonomy. The restricted autonomy was perceived as problematic in mobility, self-care, leisure, household, and social life. Activity performance assessed as independence during self-care activities correlated with participants' perceived restrictions for indoor and social autonomy, as well as with perceived problems related to leisure and self-care autonomy. Perceived restrictions on indoor autonomy correlated with mobility independence. Independence during respiration and sphincter management correlated with perceived problems related to work autonomy. Aside from indoor autonomy, outdoor autonomy and social life autonomy were ranked as the top three restricted areas. Mobility, self-care, and activities in and around the house were ranked as the top three problematic life aspects.

In summary, the movements of the upper extremities with decreased functioning due to SCI were less smooth, and the completion of tasks took longer. The shoulder and wrist joint movements, along with trunk movements, were altered, whereas the measures of maximum velocity

were comparable with those of normal movement execution. In addition, movement time and smoothness, together with wrist dorsiflexion angle, explained almost the entire variance in clinical assessments of the upper extremity (ARAT, SHFT). These findings indicate that movement smoothness, task completion time, and wrist angle during the drinking task are key kinematic measures to identify movement deficits in people with SCI. The wrist dorsiflexion angle used in the drinking task was strongly associated with ISCI-Hand, which in turn correlated with independence during transfer from the ground. These relationships highlight the importance of wrist dorsiflexion when performing common daily tasks, such as drinking or getting up from the ground. ARAT, SHFT, and ISCI-Hand also correlated with independence in the tasks of dressing, feeding, and other self-care activities.

An interesting finding was that upper extremity functioning (as assessed by kinematics and clinical scales) was associated with independence in respiration management and toilet use. Regarding perceived autonomy, independence in respiration and sphincter management correlated with perceived autonomy in work life. These findings highlight the need to consider upper extremity functioning and how it influences independence and a person's life.

METHODOLOGICAL CONSIDERATIONS

CONSIDERATIONS REGARDING SAMPLE AND INCLUSION PROCESS

The inclusion criteria for this thesis were broad enough to enable a representative sample of participants with cervical and thoracic SCI while maintaining a focus on upper extremity functioning and general functioning in activities of daily living rather than the neurological level of the injury. All eligible individuals with SCI were contacted and informed about the study both verbally on the telephone and via written information on paper or electronically. Thus, the final sample consisted of participants with various neurological levels of cervical or thoracic injury, including almost all grades of completeness and all types of handedness, with or without a reconstructed hand. Individuals with high cervical SCI were excluded since they were unable to drink from a glass with at least one hand, and individuals with lumbar SCI were excluded because they had full upper extremity functioning according to clinical assessments. The majority of the eligible individuals with SCI who refused to participate were initially positive about participating but lacked time or energy.

The clinical presentation of SCI has progressively transformed from severe impairments caused by a complete neurological injury to diverse minor impairments depending on the localisation and grade of the injuries. ⁷ Incomplete injuries, affecting both sides of the body in different ways, along with a higher proportion of cervical injuries (affecting all extremities), cause variations in functioning not only at the

group level for each individual ^{166, 167} but also for each impaired extremity. Because the majority of individuals with SCI lack a non-impaired (healthy) side, comparisons cannot be made between impaired and non-impaired extremities. Similarly, no assumptions can be derived from assessing only the dominant side, and a detailed assessment of both sides separately is required. ⁵⁰ Some individuals with incomplete injuries have changed their hand use and use the better functioning hand as their dominant hand after SCI, whereas others opt for an ambidextrous approach. Thus, in contrast to previous studies assessing the dominant hand at specific segmental neurological levels after complete cervical injuries, ⁸⁷ the current thesis considered the unimanual functioning of both upper extremities in everyday tasks as the main criteria for inclusion and as the basis of data analysis.

In the past, when the SCI population consisted mainly of younger individuals with complete injuries and few concomitant conditions, ³⁸ ¹⁶⁸ the 'expected functional independence outcome' ³⁸ was predicted depending on the neurological ASIA level in terms of two alternatives (i.e., independent versus dependent or requiring assistance). ^{38-41,143} Even though this classification was practical and relevant in the past, a more differentiated assessment is now required, especially in the chronic phase of SCI (more than 12 months after injury). ^{7, 13, 46, 102-104} In the chronic phase, the functioning level does not always reflect the expected neurological ASIA level because most patients have learned to use compensatory strategies, and some patients have undergone upper extremity surgery or suffer from other conditions that could impact the upper extremity. ^{38, 40, 49, 50, 108, 169} Hence, functioning depends not only

on anatomical impairments but also on a variety of contextual factors (both environmental and personal) such as accessibility, older age at injury time, ageing with SCI, time since injury, concomitant conditions, long-term consequences, compensatory strategies, and surgical interventions in the upper extremities (e.g., tendon and nerve transfers).

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Before and after surgical interventions, such as hand reconstruction, standardised assessments according to the International Classification for Surgery of the Hand in Tetraplegia ¹⁷¹ and ASIA are used. ¹⁷² However, knowledge about how these assessments correlate with upper extremity functioning in daily living after SCI is limited. In addition, the majority of the studies performed after hand surgery included almost exclusively participants with complete cervical injuries. ^{171, 172} Therefore, this thesis was intended to study a wider representative sample by including individuals with incomplete SCI as well.

CONSIDERATIONS REGARDING CLINICAL ASSESSMENTS

While ARAT, as an assessment tool, is more standardised and easier to score, the assessment of SHFT was perceived by the participants as more natural and functional. On the other hand, some participants with high cervical injuries and low upper extremity functioning experienced some frustration at their inability to perform several tasks in the SHFT. The hierarchical construction of the ARAT minimises this type of frustration because all assessment items between the easiest and most difficult

items can be scored automatically and do not need to be performed. This also significantly reduces the assessment administration time. Even the shorter administration time of BBT and the simplicity of the test make it particularly useful in clinical settings. However, the BBT score, i.e., the number of blocks moved for one minute, does not provide any information on how or what kind of compensatory movements are used during task performance. The clinical scales of ARAT and SHFT both take altered movement into account in the scoring; therefore, a full score is only achieved when no compensation is used.

To obtain a better understanding and quantification of movement compensations, however, more detailed analysis, such as kinematic movement analysis, is necessary. Even when the use of a 3D motion capture system is relatively easy when the protocols and analysis for a specific task are established, not every research or clinical setting has access to this equipment. A battery of assessments, for example those used in this thesis, including the advanced 3D kinematic analysis of the drinking task, provides a unique opportunity to gather richer information on upper extremity functioning in people with SCI.

According to the verbal feedback of many participants after the assessment session, the SHFT was experienced by the participants with full upper extremity functioning as more natural and meaningful than the ARAT, whereas those with high cervical injuries and low functioning experienced frustration because of their inability to perform numerous tasks on the SHFT. On the other hand, BBT was simpler and

easier to both understand and perform, regardless of the level and severity of the injury.

STRENGTHS AND LIMITATIONS

The sample in the current thesis was heterogeneous, including patients with several neurological levels of cervical or thoracic injury, almost all grades of injury completeness, and all types of handedness. Given this heterogeneity of the sample and the limited number of eligible participants, it was not possible to draw specific conclusions about individuals in any particular subgroup (e.g., right-handed patients, patients with incomplete cervical SCI), although such results were reported where possible (e.g., Study 1).

Patients with severe complete injuries receive comparatively more attention and priority in inpatient settings than individuals with low-grade incomplete (i.e., AIS D) non-traumatic injuries. These less severe injuries “may not have been initially diagnosed,”¹⁵ or they are not considered severe enough to be treated in inpatient settings and to be followed up life-long in a specialised unit for SCI. Therefore, patients with discrete SCI could have been missed from the recruitment process for this thesis, even though those injuries might have caused problems that affected their daily lives, independence, and participation in society.

The greater proportion of participants with high functioning according to ASIA in our sample (52% of the sample in the first study had motor incomplete injuries) can be considered a limitation. However, even

individuals with discrete upper extremity impairments due to incomplete injuries could experience problems because of overuse and energy-ineffective movement patterns.

In the current thesis, thoracic injuries were included as long as they had some measured limitations in upper extremity functioning (less than a full score on ARAT) or reported limitations in ADL (less than a full score on SCIM). Traditionally (per the definition of tetra- and paraplegia), a thoracic SCI is not considered to impact upper extremity functioning. This dichotomisation of injuries in tetra- and paraplegia is an oversimplification that is easily ignored. The results of this thesis showed that, indeed, in several cases, upper extremity functioning as measured by kinematics, or ARAT, was limited to some degree in participants with thoracic injuries as well. This result was not surprising, given the essential role of stabilising shoulder and trunk muscles in the performance of upper extremity tasks. The problems with trunk stability in this project were reflected in increased trunk displacement and decreased smoothness during task execution. Some participants also used their other arm on the table or the armrests of the wheelchair to stabilise the body during reaching and when stabilising the glass while performing the drinking task.

CLINICAL IMPLICATIONS

- Time to complete the drinking task and smoothness of movement, as well as wrist dorsal flexion, are key kinematic measures characterising movement deficits in people with SCI.
- All three clinical assessments (ARAT, BBT, and ISCI-Hand) showed moderate-to-strong correlations with kinematics; however, considering the standardisation and administration time, ARAT and BBT can be a more practical choices for evaluations. These clinical assessments could also be used to identify those who would benefit from a more detailed analysis of their movements using more objective kinematic analysis. This could be particularly useful in clinical decision-making before reconstruction surgery or spasticity treatment and as an outcome measure.
- Prolonged and altered task execution, weakness in grip, and limited activity capacity (ARAT, BBT, and ISCI-Hand) correlated with independence in self-care activities, in particular during feeding and dressing. Therefore, these assessments can be used as proxies for understanding functioning and independence in daily life activities.

- Upper extremity functioning (as assessed by kinematics and clinical scales) is associated with independence in respiration management and toilet use, which in turn correlates with problems in work autonomy. Thus, when the goal is work autonomy, special attention should be paid to upper extremity functioning and independence in respiration management and toilet use.
- Outdoor, indoor, and family role autonomy are perceived to be restricted, and this restriction is experienced as problematic in mobility, self-care, leisure, household, and social life. Thus, these life areas and aspects should be considered crucial for the individualisation of the rehabilitation process and the selection of appropriate outcome measures.

CONCLUSIONS

Based on a holistic approach, this thesis, focusing mainly on assessment, provides new insights into the role of the upper extremities after an established cervical or thoracic SCI across several domains of functioning and disability (e.g., upper extremity function, upper extremity activity capacity, independence in daily living, and self-perceived autonomy in participation). This thesis also adds to the knowledge of upper extremity movement in individuals with SCI, regardless of the grade of completeness of the injury. These new insights and knowledge may aid in the individualisation of rehabilitation, prevention of long-term complications, and design of appropriate follow-up for these individuals.

Regarding assessment at the body function level, our findings advocate that kinematic analysis of upper extremity movement during the drinking task, and in particular several kinematic variables (e.g., during the entire drinking task, smoothness and time of movement, and trunk displacement; during reaching and grasping, wrist dorsiflexion; during the drinking phase, shoulder abduction), alter after SCI, even though others, such as velocity-related ones, remain comparable to the movement of an unimpaired upper extremity.

Certain kinematic measures, such as smoothness or time of movement, along with wrist dorsiflexion angle, especially when combined with hand proprioception, are comparable with clinical assessments (i.e.,

ARAT, SHFT, or ISCI-Hand). Certain clinical assessments (ARAT, BBT, grip strength, and ISCI-Hand) correlate with self-care independence, in particular dressing independence and feeding independence. The association of wrist dorsiflexion angle during grasping with ISCI-Hand, which in turn correlates with independence when getting up from the ground, highlights the key role of the wrist when performing several common daily tasks.

Self-care independence correlates with indoor and social autonomy, alongside experienced problems in leisure and self-care autonomy. Indoor autonomy also correlates with mobility independence. Outdoor and indoor autonomy, as well as autonomy in social life, are perceived by individuals with SCI as the three most restricted areas of life. These restrictions cause problems in mobility, self-care, leisure, household, and social life.

Interestingly, given the relationships between upper extremity functioning, independence in respiration management and toilet use, and problems in work autonomy, special attention should be paid to the assessment of upper extremity functioning and performance during respiration management and toilet use when the goal is work autonomy.

FUTURE CONSIDERATIONS

- Given the recent changes in the clinical manifestations of SCI, further research including patients with incomplete injuries is required. Especially in the chronic phase, these injuries have diverse clinical consequences (e.g., muscular fatigue, overuse of the stronger parts of the body) comparable to those of other neurological conditions such as post-polio syndrome. Previous clinical and research expertise from other neurological rehabilitation fields could add valuable insights to the debate about the efficiency of SCI-specialised or non-specific, general SCI care and rehabilitation. Furthermore, research analysing how compensatory strategies influence movements and functioning, as well as research assessing bimanual task execution, would add a more realistic perspective to the interaction and significance of hand dominance and use in people with SCI.
- Adding other factors, such as detailed measurement of trunk movement, in studies with several subsamples of individuals with different thoracic levels (particularly high thoracic) and different grades of completeness (i.e., AIS A, AIS B, AIS C, and AIS D), would provide a more detailed understanding of how thoracic SCI affects trunk and upper extremity functioning. A similar study design

may also determine the 'cut-off' point in the thoracic part of the spinal cord, above which upper extremity movement may be affected.

- More quantitative objective data on upper extremity movements through longitudinal studies (even many years after the injury) utilising kinematic analysis may provide further insights into upper extremity recovery after SCI and could provide additional evidence for the use of kinematics as an outcome measure when evaluating different upper extremity interventions, such as hand reconstruction, antispastic treatment, electrical stimulation, and specific training.
- An even more holistic approach to SCI research, involving both individuals with SCI and healthcare professionals, such as physicians specialising in acute care or rehabilitation, hand surgeons, occupational therapists, and physical therapists, would yield a more comprehensive study design. This, in turn, could result in more accurate and meaningful outcome measurements.

Socrates: "εν οίδα ὅτι οὐδέν οἶδα"

ACKNOWLEDGEMENTS

What a journey!

When writing this thesis, I find myself reflecting on my experience working on my Ph.D. project with only three words: "What a journey!" much like the sentiments the Greek poet Cavafis conveys in "Ithaka":

As you set out for Ithaka

hope your road is a long one,

full of adventure, full of discovery.

.....

Keep Ithaka always in your mind.

Arriving there is what you're destined for.

But don't hurry the journey at all.

Better if it lasts for years,

so you're old by the time you reach the island,

wealthy with all you've gained on the way,

not expecting Ithaka to make you rich.

Ithaka gave you the marvellous journey.

Without her you wouldn't have set out.

She has nothing left to give you now.

And if you find her poor, Ithaka won't have fooled you.

Wise as you will have become, so full of experience,

you'll have understood by then what these Ithaka's mean.

C.P. Cavafy: Collected Poems, Translated by Edmund Keeley and Philip Sherrard.

Having grown “wiser” and older through this marvellous journey, I wish to extend my profound gratitude to everyone who contributed to the completion of this thesis.

First and foremost, I want to acknowledge the individuals who participated in the studies. Both healthy participants and those with spinal cord injuries demonstrated incredible generosity by dedicating their time and effort to our studies. To each of you, my deepest thanks. I also want to acknowledge those with spinal cord injuries who, although unable to participate for practical reasons, expressed genuine interest in our research and held hope for its positive impact on care and people's lives. Even those who chose not to participate contributed to my personal growth, challenging me to improve my Swedish language skills and sharpen my ability to convey vital information quickly and persuasively. Beyond the realm of statistical data, our interactions enriched me with invaluable insights—knowledge that transcends numbers and statistics.

My deepest thanks go to my main supervisor and co-author, Associate Professor Margit Alt Murphy. Your unwavering guidance and support throughout all these years were invaluable. Your extraordinary, structured way of thinking and exceptional ability to balance meticulous attention to detail with a broader perspective steered me through the countless challenges encountered on this journey. Your patience, dedication, and consistent encouragement have made this thesis a reality.

I also extend my heartfelt thanks to my co-supervisor, co-author, and leader of the research group in rehabilitation medicine, Professor Katharina Stibrant Sunnerhagen. First, thank you for granting me the opportunity to work as a PhD. student in this research group. Thank you also for the untiring support you provided throughout these years, especially during periods of struggles with work-related matters or personal concerns. Above all, thank you for sharing your extensive experience and knowledge in the field of rehabilitation medicine, encompassing both clinical expertise and research insights.

My gratitude extends to my co-supervisor and co-author, Professor Tiina Rekand, who contributed her expertise as a physician working clinically in the spinal cord department in Norway and as a reputable researcher in this field. Your valuable and essential insights were a constant presence throughout this journey. Despite the geographical distance, your kindness, accessibility, and encouragement has been a great source of strength.

I am also grateful to Richard La Bontee, Language and Writing Supervisor at the Unit for Academic Language, University of Gothenburg, for awakening my interest in the English language and offering valuable insights on pedagogy and linguistics, along with editing assistance.

I am deeply indebted to all my colleagues in the research group, including docents and students: Tamar Abzhandadze, Sofi Andersson, Linda Ashman, Elisabeth Brodin, Dongni Johansson Buvarp, Netha

Hussain, Ulrica Jonsson, Charlotte Josefson, Emma Kjörk, David Krabbe, Maria Munoz, Carina Persson, Lena Rafsten, Malin Reinholdsson, Annie Palstam, Helena Selander, Adam Viktorisson, Emma Westerlind, and Elisabeth Åkerlund, your contributions created a nurturing, encouraging, and inspiring environment. For the first time in Sweden, I felt a deep sense of belonging to this group. Your support and companionship have been more than essential for my mental well-being, reinforcing my self-worth and reminding me that kindness and love are deserved by all.

A special note of gratitude is reserved for Åsa Lundgren Nilsson, who provided me with the opportunity to work clinically at Sahlgrenska University Hospital, particularly in the spinal cord injury rehabilitation unit. This experience was vital for my financial stability and accelerated my growth as a clinician.

My appreciation is extended to everyone at the institution who supported me throughout my journey as a PhD student and contributed in various ways to the successful completion of this thesis.

To my extended family and friends, I express my gratitude for your assistance in countless forms. Your curiosity, interest, and pride in my research work, care, and trust has been deeply touching.

I am enormously thankful to my close family, especially my children, whose very existence has motivated me to persevere and complete this journey. They have inspired me to show through my life example that

regardless of the circumstances, we should keep fighting, never surrender, pursue dreams, uphold decency, and fulfil our responsibilities.

Last but not least, I owe an immense debt of gratitude to my parents, whose influence has been foundational in shaping my character and guiding my life journey. From a very young age, they instilled in me the values of hard work, discipline, and humility. My father's lessons on commitment, perseverance, and ethics continue to shape my path. My parents' unconditional love and support have been my anchor throughout the years, substantially contributing to my personal and professional development.

This work was supported by the Swedish Society for Medical Research, the Swedish state under an agreement between the Swedish government and the county councils, the ALF agreement, Promobilia, Norrbacka-Eugeniastiftelsen, the local Research and Development Board for Gothenburg and Södra Bohuslän, and Sahlgrenska University Hospital Research Foundation.

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