Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

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“A mind is like a parachute.

It doesn’t work if it is not open”

Frank Zappa
ABSTRACT

Background: The ability to perform everyday life activities is beneficial for one's self-identity and contributes to human well-being. Enhancement of activity performance is therefore central in all forms of rehabilitation. Spasticity is a common secondary complication after injuries to the central nervous system (CNS), which can negatively affect the ability to perform activities. There is conflicting evidence regarding the effectiveness of available spasticity treatments. Surgical treatment for spasticity has been an option for many years, but due to limitations in outcomes and the diversity of techniques, conclusions about the effectiveness cannot be drawn.

Aim: The main aim is to describe and evaluate the feasibility of a treatment algorithm for upper limb (UL) spasticity-correcting surgery with tendon lengthening and comprehensive rehabilitation and its impact on the everyday life of patients with disabling spasticity after CNS injuries. More specifically, the aims were to investigate the feasibility of the treatment algorithm, describe patients' experiences with the treatment, describe prioritized occupational performance problems (POPPs) that patients identify before surgery, and map those problems onto the International Classification of Function, Disability, and Health (ICF). An additional aim was to translate the self-report Arm Activity Measure into Swedish (ArmA-S) and evaluate the psychometric properties of ArmA-S.

Methods: In Study I, 30 consecutive patients who underwent surgery between March 2015 and January 2017 were assessed before and 12 months after
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Methods: In Study I, 30 consecutive patients who underwent surgery between March 2015 and January 2017 were assessed before and 12 months after
surgery. In a retrospective study (Study II), data were extracted from patients who underwent UL surgery between February 2017 and June 2019. In Study II, data from the assessments before and 6 months after surgery were used to evaluate the feasibility and outcome of the treatment algorithm allocating patients to high-, low-, or non-functioning treatment regimens (HFR, LFR, NFR). In a methodological study (Study III), the translated ArmA-S was subjected to psychometric evaluation. In a qualitative study (Study IV), interviews were conducted and analysed using a phenomenographic approach. In Study V, POPPs were identified using the Canadian Occupational Performance Measure (COPM) and mapped onto the ICF.

Results: Twelve months after surgery (Study I), significant improvements were found for UL spasticity graded according to the Modified Ashworth Scale (MAS) (average decrease: 1.4; p < 0.01) and grip strength (average increase: 4.1; p < 0.01). The regimen-specific primary outcome measures for all three groups (HFR, LFR, NFR) were significantly improved six months after surgery (Study II). In the HFR group, the average increase in the Grasp and Release Test (GRT) was 19.6 ± 19 (p < 0.001). In the LFR group, the average median (IQR) decrease for ArmA-S section B was -5 (-1 to -12.5) (p < 0.001). In the NFR group, the average median (IQR) decrease for ArmA-S section B was -12 (-10 to -14) (p < 0.02). Study III demonstrated that ArmA-S could be considered a reliable, valid, and clinically feasible measure of passive (section A) and active (section B) hand function. The interviews (Study IV) revealed the patients’ experiences with surgery in everyday life, such as bodily changes, improved occupational performance, regained control, enhanced interpersonal interactions, and psychological well-being. In Study V, 320 POPPs were translated into prioritized occupational performance goals (POPGs). The POPGs were mapped onto the ICF activity domain, most often relating to self-care (41%), domestic life (21%), and mobility (18%). Diagnosis, gender, and motor function did not influence patients’ preferences. Study V also showed significant increases in COPM scores after surgery, but these improvements were not or only weakly correlated with hand function.

Conclusions: The algorithm for spasticity-correcting surgery that customizes the postoperative treatment regimen to the individual’s degree of residual motor control was shown to be feasible and successful. Patients had improvements in various domains, such as spasticity, pain, hand function, and occupational performance, with sustained effects at long-term follow-up.
ArmA-S is a suitable measure for monitoring changes in patients receiving UL spasticity-correcting surgery. Participants’ improvements experienced in everyday life include activities, body functions, and psychological and social well-being. Yet the treatment-induced significant gains in occupational performance had no clear correlation with gains in grip ability or grip strength. Independently of diagnosis, gender, and residual motor function, it seems to be important for patients to address self-care activities, but also activities relating to domestic life and mobility, in the rehabilitation after spasticity-correcting surgery.

**Keywords:** activities of daily living, central nervous system diseases, muscle spasticity, occupational therapy, patient-reported outcome measures, rehabilitation, spinal cord injuries, stroke, surgery, brain injuries traumatic, upper extremity, motor activity.

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**SAMMANFATTNING PÅ SVENSKA**


**Syfte:** Avhandlingens övergripande syfte var att beskriva och utvärdera genomförbarhet och utfall av en behandlingsalgoritm innehållande spasticitets-korrigerande kirurgi i form av senförlängningar samt efterföljande regimspecifik rehabilitering hos patienter med spasticitetsproblematik i övre extremitet efter CNS skada. Specifika mål var att utforska behandlingsalgoritmens kliniska applicerbarhet, beskriva individers upplevelser av hur behandlingen inverkat på vardagligt liv, beskriva vilka prioriterade aktivitetsbegränsningar individer identifierade inför behandlingen omvandlade till målsättningar, och kartlägga dessa utifrån Internationell klassifikation av funktionstillstånd, funktionshinder och hälsa (ICF). Ytterligare ett syfte var att översätta självskattningsformuläret Arm Activity Measure till svenska (ArmA-S) och utvärdera dess psykometriska egenskaper.

Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

aktivitetsbegränsningar identifierade med Canadian Occupational Performance Measure (COPM) enligt ICF.

**Resultat:** Tolv månader efter kirurgi (Studie I), påvisades signifikanta förbättringar avseende spasticitet i övre extremitet mätt med Modified Ashworth Skalan (MAS) (med en genomsnittlig reduktion på 1.4, p < 0.01), och handstyrka (genomsnittlig förbättring: 4.1 kilo p < 0.01). De primära regimenspecifika utfallsmätten i samtliga tre grupper (HFR, LFR, NFR) påvisade signifikanta förbättringar sex månader efter kirurgi (Studie II). För HFR gruppen var medelförbättringen i Grasp and Release Test (GRT) 19.6±19 (p < 0.001). I LFR gruppen minskade median (IQR) värdena för ArmA-S sektion B med -5 (-1 till -12.5), (p < 0.001). I NFR gruppen minskade median (IQR) värdena för ArmA sektion A med -12 (-10 till -14), (p < 0.02). Studie III påvisade att ArmA-S, är valid, reliabel och klinisk användbart som självskattningsformulär för att mäta passiv (sektion A) och aktiv (sektion B) handfunktion. Under intervjuerna (Studie V) framkom patienternas olika upplevelser av kirurgins inverkan i vardagslivet, såsom kroppsliga förändringar, underställande av aktivitetsutförande, upplevelser av ökad kontroll, positiv inverkan på relationer och ökat psykologiskt välmående. I Studie V identifierades 320 prioriterade aktivitetsproblem vilka transfigurerades till specifika aktivitetsmål. Aktivitetsmålen kartlades enligt ICF aktivitetsdomän, merparten tillhörande personlig vård (41%), hemliv (21%) eller förflyttning (18%). Diagnos, kön eller funktionsnivå påverkade inte patienternas val. Studie V påvisade signifikanta förbättringar i COPM efter kirurgi, men dessa hade ingen eller svag korrelation med handfunktion.

**Konklusion:** Behandlingsalgoritmen för kirurgisk korrigerings spasticitet, vilken anpassar den postoperativa behandlingsregimen till individens kvarstående motoriska funktion visades vara klinisk applikerar med goda resultat. Patienter påvisades ha förbättringar i olika domäner, så som minskad spasticitet, minskad smärta, förbättrad handfunktion, förbättrat aktivitetsutförande och tillfredsställelse med aktivitetsutförandet. Svenska versionen av självskattningssformuläret ArmA-S är ett användbart formulär för att följa förändringar hos personer som genomgår spasticitets-korrigerande kirurgi övre extremitet. Deltagarna upplevde förbättringar inom en rad olika vardagliga situationer, som aktivitetsförändringa, kroppsfunktioner, psykologiskt och socialt välbefinnande. Även om specifika aktivitetsmålsättningar ökade signifikant framkom ingen tydlig korrelation med vare sig handstyrka eller
greppförmåga. Oberoende av diagnos, kön eller motorisk funktion, förefaller det viktigt för patienter att fokusera på personlig vård, men även hemlivsaktiviteter och förflyttningsförmåga i rehabiliteringen efter spasticitetskorrigering.
LIST OF PAPERS

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


Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

**CONTENT**

**ABBREVIATIONS**

**DEFINITIONS IN SHORT**

1. **INTRODUCTION** ................................................................. 1
   Rehabilitation, goal setting and patients’ perspective .................. 1
2. **BACKGROUND** ................................................................. 4
2.1 Central nervous system (CNS) and acute injuries to the CNS ....... 4
   The motor control system ....................................................... 5
   Upper motor neuron syndrome ............................................. 7
2.2 Spasticity ............................................................................ 9
   Definitions of spasticity ........................................................... 9
   Pathophysiology of spasticity .................................................. 11
   Prevalence of spasticity .......................................................... 13
   Consequences of spasticity ...................................................... 13
2.3 The importance of the arm and hand function ......................... 16
   Uni- and bilateral hand function ............................................ 16
2.4 Treatment options for spasticity ............................................ 18
   Decision to treat spasticity ...................................................... 18
   Non-surgical treatment options for spasticity ......................... 19
   Surgical treatment options for spasticity .............................. 24
   Rehabilitation protocols after surgical treatments for spasticity .... 32
2.5 Assessment and outcomes .................................................. 39
2.6 Theoretical framework ...................................................... 41
   International classification of functioning, disability, and health (ICF) . . 41
   The occupational perspective .................................................. 42
   The biomechanical model ....................................................... 42
2.7 Lack of knowledge / research gap ......................................... 44
3. **AIM** .................................................................................. 47
4. **PATIENTS AND METHODS** .............................................. 48
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

Overall study design .......................................................... 48
Study population ................................................................. 50
Methodological quality, registration, and protocol ....................... 52
Context of the study ............................................................. 53
4.1 Data collection ............................................................... 54
Outcome measures used in the studies ........................................ 54
Observer-rated measures ...................................................... 55
Patient-reported outcome measures (PROMs) ............................ 60
4.2 Data analyses ............................................................... 65
4.3 Ethical considerations ................................................... 68
5 RESULTS ........................................................................... 70
5.1 Summary of changes after surgery and regimen-specific rehabilitation... 70
5.2 Changes in body function and structure after surgery and regimen-specific rehabilitation .................................................. 72
5.3 Changes in activity after surgery and regimen-specific rehabilitation .... 77
5.4 Changes in participation after surgery and regimen-specific rehabilitation .......................................................... 80
5.5 Prioritized occupational performance problems classified according to the International Classification of Functioning, Disability, and Health (ICF) ... 83
5.6 Patient demography ........................................................ 86
Treated muscles .................................................................. 86
Assigned regimen and diagnosis .............................................. 88
Complications and feasibility of the regimen ............................... 88
5.7 Translation of the Arm Activity measure (ArmA) and psychometric testing of the Swedish version (ArmA-S): Study III ...................... 90
Translation and cultural adaption of ArmA ................................ 90
Psychometric analyses of ArmA-S .......................................... 92
6 DISCUSSION ................................................................... 94
6.1 Summary ...................................................................... 94
6.2 Treatment regimens ...................................................... 97
6.3 Treatment outcomes on body function and structure ............... 99
Changes in spasticity ................................................................. 99
Changes in pain ................................................................. 100
Changes in range of motion ......................................................... 100
Changes in strength .............................................................. 101
6.4 Treatment outcomes on activity ........................................ 102
Changes in active upper limb activities ........................................ 102
Changes in passive upper limb activities ..................................... 104
Changes in mobility .............................................................. 105
6.5 Treatment outcomes on participation .................................. 106
6.6 Patient demography .......................................................... 108
Timing of surgery and study population ...................................... 110
Complications ................................................................. 110
6.7 Occupational performance goals ........................................ 111
6.8 Outcome measures .......................................................... 113
Observer-rated measures ....................................................... 113
Patient-reported outcome measures .......................................... 116
Minimal clinically important difference .................................. 118
6.9 Methodological considerations ........................................... 121
Quantitative research .......................................................... 121
Qualitative research ............................................................ 123
6.10 Ethics ................................................................. 125
6.11 Generalizability ............................................................. 126
6.12 Limitations ................................................................. 128
7 CONCLUSION .................................................................. 132
8 FUTURE PERSPECTIVES ................................................. 134
ACKNOWLEDGEMENT .......................................................... 136
REFERENCES ................................................................. 139
APPENDICES ........................................................................ 157
### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
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<td>ArmA</td>
<td>Arm Activity measure</td>
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<tr>
<td>ArmA-S</td>
<td>Arm Activity measure Swedish version</td>
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<td>BoNT</td>
<td>Botulinum toxin</td>
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<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
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<tr>
<td>C.A.R.E</td>
<td>Centre of Advanced Reconstruction of Extremities</td>
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<tr>
<td>CNS</td>
<td>Central nervous system</td>
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<td>CI</td>
<td>Confidence interval</td>
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<td>EAR</td>
<td>Early active rehabilitation</td>
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<td>GRT</td>
<td>Grasp and Release Test</td>
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<td>HFR</td>
<td>High-functioning regimen</td>
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<tr>
<td>ICF</td>
<td>International Classification of Function, Disability and Health</td>
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<tr>
<td>IQR</td>
<td>Interquartile range</td>
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<td>LFR</td>
<td>Low-functioning regimen</td>
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<td>MAS</td>
<td>Modified Ashworth Scale</td>
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<tr>
<td>MCID</td>
<td>Minimal clinically important difference</td>
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<tr>
<td>NFR</td>
<td>Non-functioning regimen</td>
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<tr>
<td>PROM</td>
<td>Patient reported outcome measure</td>
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<td>POPP</td>
<td>Prioritized occupational performance problems</td>
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<tr>
<td>POPG</td>
<td>Prioritized occupational performance goals</td>
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<tr>
<td>RS</td>
<td>Spearman’s rank correlation coefficient</td>
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<tr>
<td>ROM</td>
<td>Range of Motion</td>
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<td>SCI</td>
<td>Spinal cord injury</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
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<tr>
<td>TBI</td>
<td>Traumatic brain injury</td>
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<tr>
<td>UL</td>
<td>Upper limb</td>
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<tr>
<td>UMNS</td>
<td>Upper motor neuron syndrome</td>
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<tr>
<td>VAS</td>
<td>Visual Analog Scale</td>
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<td>WHO</td>
<td>World Health Organization</td>
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### DEFINITIONS IN SHORT

<table>
<thead>
<tr>
<th>Definition</th>
<th>Description</th>
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<tr>
<td><strong>Activity</strong></td>
<td>The execution of a task or action by an individual&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Activity limitations</strong></td>
<td>Difficulties an individual may have in executing activities&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Body functions</strong></td>
<td>The physiological functions of body systems (including psychological functions)&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td>An umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and the individual’s contextual factors (environmental and personal factors)&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Environmental factors</strong></td>
<td>The physical, social, and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person’s functioning&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Functioning</strong></td>
<td>An umbrella term for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Impairment</strong></td>
<td>Problems in body function and/or structures such as a significant deviation or loss&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>International Classification of Functioning, Disability, and Health (ICF)</strong></td>
<td>The WHO’s framework for measuring health and disability at both individual and population levels; it provides a standard language&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
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<tr>
<td><strong>Occupation</strong></td>
<td>Occupation is everything a person does to occupy him- or herself. Occupations encompass more than one task or activity of everyday life, and it gives meaning and value to individuals and cultures&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Occupational performance</strong></td>
<td>The ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally and age defined and that are appropriate for looking after oneself, enjoying life, and contributing to the social and economic fabric of a community&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td>Involvement in a life situation&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Participation restrictions</strong></td>
<td>Problems an individual may experience in involvement in life situations&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Performance</strong></td>
<td>What a person does in his or her current environment&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Personal factors</strong></td>
<td>Represent influences on functioning particular to the individual&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Spasticity</strong></td>
<td>Abnormal muscle tightness, increased muscle tone, or stiffness, causing continuous resistance to stretch. The symptom is associated with damage to the brain, spinal cord, or motor nerves&lt;sup&gt;3&lt;/sup&gt;. The definition used in this thesis is, velocity dependent hypertonia or sustained involuntary activation of muscles, the spasticity should hinder body function, activities, and/or participation to be treated with surgery.</td>
</tr>
<tr>
<td><strong>Spasticity-correcting surgery</strong></td>
<td>Refers in this thesis to, tendon lengthening and muscle release to relax the muscle-tendon unit in order to reduce spasticity (to reduce the effect of the spasticity)</td>
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<td>----------------------------------</td>
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<tr>
<td><strong>Rehabilitation</strong></td>
<td>A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment</td>
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Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

Spasticity

Correcting surgery

Refer to tendon lengthening and muscle release to relax the muscle-tendon unit in order to reduce spasticity (to reduce the effect of the spasticity).

Rehabilitation

A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.
INTRODUCTION

REHABILITATION, GOAL SETTING AND PATIENTS’ PERSPECTIVE

Rehabilitation is an educational, problem-solving process that focuses on activity limitations and aims to optimize patients' social participation and well-being and to reduce the stress burden on career and/or family. The rehabilitation process usually involves four stages. Stage 1 identifies the problems experienced by the person and collects information to begin the process. Stage 2 focuses on setting goals, both immediate and long-term goals. In Stage 3, the planned intervention is carried out. In Stage 4, the final stage, an evaluation of the interventional effects is conducted, which considers the patient's individualized goals. The rehabilitation process is a cycle, and if problems remain after an intervention, the process can start again from Stage 1. This four-stage procedure is the core element in the treatment of the study participants in this thesis. The rehabilitation methodology used following surgery is similar to the regimen called early active rehabilitation (EAR). The EAR concept includes two cornerstones: early active mobilization of sutured tendons and surrounding tissues as well as the maintenance of activity of daily living (ADL). EAR was developed to guide the rehabilitation of patients with tetraplegia subjected to surgical tendon transfers to restore function. The benefits of early active mobilization include reduced risk of adhesions, joint stiffness, and swelling. The benefits of an approach that encourages individuals directly after surgery to be as active as possible in their daily life are, that active use of the arms facilitates activation of the muscle pump, which improves circulation and prevents oedema. Additionally, an active daily life helps to sustain general fitness and independence. Worth mentioning, however, is that
1 INTRODUCTION

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Rehabilitation is an educational, problem-solving process that focuses on activity limitations and aims to optimize patients´ social participation and well-being and to reduce the stress burden on career and/or family\(^5\). The rehabilitation process usually involves four stages. Stage 1 identifies the problems experienced by the person and collects information to begin the process. Stage 2 focuses on setting goals, both immediate and long-term goals. In Stage 3, the planned intervention is carried out. In Stage 4, the final stage, an evaluation of the interventional effects is conducted, which considers the patient’s individualized goals. The rehabilitation process is a cycle, and if problems remain after an intervention, the process can start again from Stage 1\(^5\). This four-stage procedure is the core element in the treatment of the study participants in this thesis. The rehabilitation methodology used following surgery is similar to the regimen called early active rehabilitation (EAR)\(^6\). The EAR concept includes two cornerstones: early active mobilization of sutured tendons and surrounding tissues as well as the maintenance of activity of daily living (ADL). EAR was developed to guide the rehabilitation of patients with tetraplegia subjected to surgical tendon transfers to restore function\(^6\). The benefits of early active mobilization include reduced risk of adhesions, joint stiffness, and swelling. The benefits of an approach that encourage individuals directly after surgery to be as active as possible in their daily life are, that active use of the arms facilitates activation of the muscle pump, which improves circulation and prevents oedema. Additionally, an active daily life helps to sustain general fitness and independence. Worth mentioning, however, is that
the population in these doctoral studies is heterogenic, which prompted the need to somewhat adapt the study protocol throughout the thesis work.

Patient participation is central in the EAR protocol and advocated by patient organizations. The World Health Organization (WHO) considers patient participation as a core component of high-quality rehabilitation. Patients’ opportunities to participate are strongly influenced by clinicians but also by patient-related factors, such as motivation, capabilities, and health status. Patient participation is considered essential in the rehabilitation of patients with spinal cord injuries (SCIs) and desired from a patient’s view.

Goal setting is considered an important element for achieving patient participation and a core component in rehabilitation. It is considered to be of value to be able to adapt the treatments to patients’ individual needs. Goal setting can increase the communication between team members as well as between clinicians and patients. Further, it can enhance an individual’s motivation and direct attention to what is important and achievable.

Patient-reported outcomes (PROs) are reported by the patient, with no interpretation from the clinician. The importance of involving the patient’s view in both clinical care and research has been advocated. Patient-reported outcome measures (PROMs) are self-report instruments designed to measure the patients’ perception of their symptoms, functional or activity status, or health-related quality of life. The use of PROMs helps in empowering the patient and in increasing the engagement in treatment planning. Hence, the use of PROMs that capture the patient’s perspective is valuable in both goal setting and increasing patient participation.

The importance of multidisciplinary evaluation, realistic and appropriate goal setting prior to treatment initiation, and subsequent rehabilitative efforts is
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

clearly emphasized in the literature\textsuperscript{15-25}. Enslin et al.\textsuperscript{22} summarize this well, when they point out that surgery forms only a small part of the management of individuals with spasticity. Further, they point out that surgery should be preceded by careful evaluation and followed by rehabilitation and that it is highly important to include the patients and/or the family. The importance and rationale of this thesis are summarized in Figure 1, adapted from Enslin et al.\textsuperscript{22}, highlighting the importance of combining evaluation, surgery, and rehabilitation.

\textbf{Figure 1. The importance of evaluation and rehabilitation in upper limb spasticity management. Adapted from Enslin et al.\textsuperscript{22}.}
2 BACKGROUND

2.1 CENTRAL NERVOUS SYSTEM (CNS) AND ACUTE INJURIES TO THE CNS

The nervous system consists of the central nervous system (CNS) and the peripheral nervous system (PNS). The central nervous system (CNS) includes the spinal cord and the brain. The brain comprises the cerebrum, the corpus callosum, the cerebellum, and the brainstem. The brain interprets information, and the spinal cord works like a highway, where information between the body and the brain is transported. CNS injuries include stroke, traumatic brain injury (TBI), and spinal cord injury (SCI) and have in common that they often cause significant sensorimotor impairments. There are approximately 330 new cases of SCIs yearly in Sweden. For stroke and TBI, the yearly incidence is approximately 25,400 and 282, respectively. Many of these individuals will suffer from permanent impairment of the upper limb (UL), which diminishes their ability to function and reduces their quality of life (QoL). UL recovery is identified as a high-priority goal among affected individuals.

Stroke can be ischemic or hemorrhagic. Ischemic stroke causes reduced blood flow because of narrowed or blocked blood vessels in the brain. Hemorrhagic stroke occurs when a blood vessel in the brain leaks or ruptures. A stroke can cause temporary or permanent disabilities, depending on which part of the brain becomes affected and how long the brain lacks blood flow. TBI is a sudden damage to the brain caused by closed-head or penetrating injuries and can range from mild concussions to severe permanent brain damage. Recovering from an acquired brain injury, such as stroke or TBI, depends on which parts of the brain are injured, the regeneration and repair of nerve cells, and the brain's plasticity—the ability of undamaged areas to take over functions from damaged areas.
over functions from damaged areas. Complications that can occur after acquired brain injuries are; paralysis or loss of muscle movement; spasticity; pain and other abnormal sensations; speech and swallowing problems; changes in behaviour; memory loss; problems with reasoning, judgments, and understanding concepts; and emotional problems, such as depression and difficulties with controlling emotions. The motor impairment normally affects one side of the body (hemiplegia), the opposite side from the lesion.

An SCI can be complete or incomplete. A complete SCI means a total loss of sensory and motor function below the injury. Both sides of the body are equally affected. In an incomplete SCI, some function remains below the level of the injury. It can affect both sides but to different degrees, one side, both upper and lower limbs, or only the lower limbs (paraplegia). Tetraplegia, also known as quadriplegia, refers to paralysis in both the upper and lower limbs. Complications after an SCI differ depending on the level of injury and can include loss of muscle movement, spasticity, loss of sensation, neuropathic pain, dysfunction of the urinary bladder, bowel and sexual dysfunction, autonomic dysreflexia, reduced lung capacity, and neurogenic heterotopic ossification.

THE MOTOR CONTROL SYSTEM

The motor control system contains four main components: (1) the cerebral cortex, (2) the subcortical structures, (3) the brainstem and cerebellum, and (4) the spinal cord. See Figure 2 for a schematic overview. The cerebral cortex is essential for directing signals for the preparation and execution of movements, such as programming and planning voluntary movements and controlling the execution of movements. The subcortical structures, including the basal ganglia, are necessary for movement coordination and sustaining tone. The brainstem has a central role in stretch reflexes, posture,
and repetitive movements. The spinal cord is the pathway for messages sent by the brain to the body and from the body to the brain\textsuperscript{35}. At the spinal level, motor function is controlled by three elements: afferent input from sensory receptors, interneurons, and reflex activity\textsuperscript{35}.

Figure 2. Schematic of the nervous system responsible for motor control.
UPPER MOTOR NEURON SYNDROME

Upper motor neuron syndrome (UMNS) is a collective term referring to different motor behaviours that can affect individuals with lesions in the descending corticospinal system. The lesions can occur at the level of the cortex, internal capsule, brainstem, or spinal cord. The UMNS is manifested in two ways, positive and negative signs. Positive signs are characterized by muscle overactivity, and negative signs by what is lost\textsuperscript{3,36,37}; see Table 1 for details. The positive signs can be divided into three main areas. (I) Spinal reflexes: abnormal processing of the spinal reflexes is believed to be behind most of the positive UMNS features. These reflexes are afferent dependent and need sensory feedback, such as pain, muscle stretch, and cutaneous simulation, from the peripheral system. (II) Efferent drive: this consists of continuous muscle contractions that are not dependent on peripheral feedback, so they occur in the absence of sensory feedback. (III) Disordered control of movement: this occurs in co-contraction when the contraction of agonist and antagonist muscle groups are present at the same time. For example, if a person is asked to open the hand, he or she tends to close it even more, because of a strong tendency to activate finger flexors and extensors simultaneously\textsuperscript{37}.

<table>
<thead>
<tr>
<th>Negative signs</th>
<th>Positive signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>Spasticity</td>
</tr>
<tr>
<td>Impaired coordination</td>
<td>Athetosis</td>
</tr>
<tr>
<td>Impaired motor control</td>
<td>Clonus</td>
</tr>
<tr>
<td>Impaired motor planning</td>
<td>Dystonia</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>Primitive reflexes/cutaneous reflexes (Babinski signs)</td>
</tr>
<tr>
<td>Loss of dexterity</td>
<td>Rigidity</td>
</tr>
<tr>
<td></td>
<td>Co-contraction</td>
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<td></td>
<td>Hyperactive reflexes</td>
</tr>
</tbody>
</table>
The positive and negative consequences, as well as the different positive and negative signs, appear, evolve, and interact with each other, causing a dynamic clinical presentation\textsuperscript{37-39}. For example, weakness can lead to muscle immobilization in a shorted position; this can lead to biomechanical changes, which in turn could lead to stiffness and contractures\textsuperscript{37}. Positive and negative signs can interact and lead to impaired function (Figure 3).

\textbf{Figure 3.} An overview of upper motor neuron features and how the positive and negative signs integrate. Adapted from Sheean\textsuperscript{37}. Abbreviations: UMN = upper motor neuron; ROM = Range of Motion.
2.2 SPASTICITY

Spasticity is a condition in which there is an abnormal muscle tightness. The symptom is associated with damage to the CNS.

DEFINITIONS OF SPASTICITY

In the medical literature, there are several different definitions of spasticity together with countless similar concepts, and the co-existence of these makes the clinical definition of spasticity a challenge. See Table 2 for the definitions of similar concepts. One of the most commonly used definitions was proposed by Lance. It states that “spasticity is a motor disorder characterized by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks, resulting from hyperexcitability of the stretch reflex as one component of the UMN syndrome”. This definition implies that stretch reflex hyperactivity is the sole cause of spasticity and has been criticized for being too narrow. A wider and frequently referred definition was published by Pandyan et al., explaining that there is not enough evidence to indicate that spasticity results only from stretch reflex hyperexcitability. They suggested that the supraspinal systems and afferent pathways may play a role as well and published the following definition: “disordered sensorimotor control, resulting from an upper motor neuron lesion, presenting as intermittent or sustained involuntary activation of muscles”. Ward advised that a universal definition was not possible since spasticity was not a “single entity” and that there were considerably different clinical manifestations among patients. Burns et al. have recommended a definition concentrating on the effect and suggested “spasticity which is perceived by the affected individual or caregivers as hindering body function, activities, and/or participation”. In a recent systematic review on physiotherapy interventions for spasticity treatment, Barbosa et al. used the term spasticity to reflect the many different
presentations of involuntary muscle contractions (intermittent or sustained) that are associated with UMN lesions. The rationale for this was stated as follows: “physiotherapy interventions are advocated and used for the management of spasticity without consideration of its various manifestations”. A summary of the different definitions is presented in Figure 4. Throughout this thesis, a broader definition of spasticity, similar to that proposed by Barbosa et al.\textsuperscript{45}, is used. The definition used in this thesis is, velocity dependent hypertonia or sustained involuntary activation of muscles. In the study population, alike to what proposed by Burn et al.\textsuperscript{44}, the spasticity should hinder body function, activities, and/or participation to be treated with surgery.

Figure 4. Summary of the different definitions of spasticity presented in the literature\textsuperscript{44}. Abbreviations: UMN= upper motor neuron.
PATHOPHYSIOLOGY OF SPASTICITY

The pathophysiology of spasticity remains somewhat unclear. It is proposed that it is of supraspinal origin and that it results from an imbalance between descending inhibitory pathways and facilitatory regulation of the spinal stretch reflexes. The excitability of the healthy spinal stretch reflex arc is maintained by a balanced descending regulation from inhibitory dorsal reticulospinal tracts (RSTs) and facilitatory medial RSTs and vestibulospinal tracts (VSTs), as well as intraspinal processing. Hyperexcitability of the stretch reflex might be mediated by abnormal regulation and/or abnormal intraspinal processing. The great variation in clinical syndromes depends also on the fact that inhibitory and excitatory fibres run in different areas of the spinal cord. Hence, lesions can affect one fibre tract and not another. After a lesion to the CNS, there is a delay from the time of injury until spasticity develops, which implies that CNS plasticity might be involved in spasticity development. Sprouting of afferent axons and changes in receptor sensitivity are possible explanations. Hypertonia is suggested to be divided into two components: hypertonia facilitated by the stretch reflex (spasticity) and hypertonia due to muscle...
contracture referred to as nonreflex hypertonia or intrinsic hypertonia. In the clinic, it is often difficult to differentiate these two components. Fibre segments from individuals with spasticity had significantly shorter sarcomere lengths than fibre segments from individuals without spasticity\(^{48}\).

Two subtypes of spasticity have been proposed: spasticity of cerebral origin and spasticity of spinal origin; the clinical differences are supposed to depend on the level of the UMN lesion\(^{49}\). Different CNS-induced spasticity models (rodent) have revealed differences in the time course of development, pattern, and severity of spasticity. In the rodent models, TBI produces more severe spasticity than SCI\(^{50}\). In humans, the opposite occurs: a lesion in the cortex of the corticobulbar fibres or the internal capsule leads to a decline in cortical facilitation of the inhibitory pathway\(^{47}\). This leads to a mildly reduced inhibitory drive and net excitation of spinal cord activity and, consequently, a less severe positive UMN feature than a lesion of the dorsal reticulospinal pathway. This is proposed to explain why stroke and other supraspinal lesions lead to some spasticity, hyperreflexia, and clonus but not as much as is seen after a spinal cord lesion. A spinal cord lesion can result in a complete or a partial lesion. A partial lesion that destroys the inhibitory pathway but not the excitatory fibres leads to a strong excitatory drive to the spinal reflexes. This would cause marked spasticity, hyperreflexia, and flexor and extensor spasm. A complete spinal cord lesion that affects both inhibitory and excitatory pathways leads to lost supraspinal control over spinal reflexes. The lost control can lead to hyperactivity of these reflexes\(^{47}\). In summary, the clinical pattern of spasticity is determined by the location of the lesion; however, the impact it has on the individual depends largely on the coexistence of other UMN symptoms. The study participants in this thesis include individuals suffering from spasticity with a cerebral or spinal origin.
PREVALENCE OF SPASTICITY

The prevalence data is insufficient, and the definitions and measurement tools of spasticity vary, so the patients that are included in the different prevalence reports also vary. Spasticity following stroke occurs in 10% to almost 50% of stroke survivors but is commonly reported in 30% of patients. The majority (80%) of patients with SCI develop spasticity, especially those with cervical lesions and/or incomplete injuries. For TBI, the data is more sparse, but approximately 60% of patients report having spasticity. Up until recently, clinicians and researchers relied on clinical measures such as the Modified Ashworth Scale (MAS) to measure spasticity. Studies indicate that this measurement tool is not sensitive enough to detect spasticity. Malhotra et al. evaluated wrist spasticity by using the MAS and electrophysiological measures on individuals with post-stroke symptoms; the two measurements indicated spasticity in 44% and 87% of cases, respectively. This implies that the prevalence of spasticity could be underestimated when only clinical measurements are used.

CONSEQUENCES OF SPASTICITY

The severity of spasticity can vary greatly depending on the cause (e.g., stroke, SCI, or TBI). Whether the spasticity is uni- or bilateral and the existence and severity of concomitant CNS syndromes may further add to the severity. Consequently, it is difficult to isolate the disability related to spasticity from the disabling effect of other symptoms. Some consider spasticity to be a significant contributor to activity limitations; others consider weakness to be a more vital factor, particularly in limiting the performance of UL tasks. Factors such as posture, stress, cold, skin breakdown, bowel and bladder infections, circadian rhythm, pregnancy, menstrual cycle, and tight clothes can affect the amount of spasticity. In addition, spasticity can also be beneficial.
Nevertheless, if disabling spasticity is left untreated, it might cause contractures, deformity, pain, and involuntary movements, which further compromise the functional capacity (e.g., reduced mobility, self-care, and dressing)\textsuperscript{54, 63-65}. It may also cause medical complications (e.g., skin maceration and pressure sores), negative self-image, and disturbed sleep. All these factors affect the patients’ quality of life\textsuperscript{66}; in Figure 5, commonly reported negative consequences are merged and structured according to the International Classification of Functioning, Disability, and Health (ICF). Persons with SCI have clearly indicated that spasticity has a negative impact on their daily life performance and quality of life, and persons with tetraplegia perceive the impact higher than persons with paraplegia\textsuperscript{67}. Further, they reported that stiffness had a greater negative impact than clonus and spasm in daily activities\textsuperscript{67}. In an international survey, 72\% of the respondents reported that the spasticity had a negative impact on their QoL, 44\% reported a negative effect on independence, and 44\% reported depression and mood alternations as a result of spasticity\textsuperscript{68}. In another survey, 52\% of participants answered that they lost their self-confidence, 46\% that they experienced depression, and 41\% that they suffered from lack of sleep due to spasticity problems\textsuperscript{69}. The negative impacts of spasticity also make the burden heavier for the caregiver, and reducing spasticity has been shown to ease caregiver burden\textsuperscript{70, 71}. Spasticity has been reported by individuals with disabilities as one of the leading negative secondary conditions\textsuperscript{72}. Spasticity also has an economic impact, by increasing costs of care and treatment\textsuperscript{73}. 
Nevertheless, if disabling spasticity is left untreated, it might cause contractures, deformity, pain, and involuntary movements, which further compromise the functional capacity (e.g., reduced mobility, self-care, and dressing)\textsuperscript{54,63-65}. It may also cause medical complications (e.g., skin maceration and pressure sores), negative self-image, and disturbed sleep. All these factors affect the patients' quality of life\textsuperscript{66}; in Figure 5, commonly reported negative consequences are merged and structured according to the International Classification of Function, Disability, and Health (ICF). Persons with SCI have clearly indicated that spasticity has a negative impact on their daily life performance and quality of life, and persons with tetraplegia perceive the impact higher than persons with paraplegia\textsuperscript{67}. Further, they reported that stiffness had a greater negative impact than clonus and spasm in daily activities\textsuperscript{67}. In an international survey, 72\% of the respondents reported that the spasticity had a negative impact on their QoL, 44\% reported a negative effect on independence, and 44\% reported depression and mood alternations as a result of spasticity\textsuperscript{68}. In another survey, 52\% of participants answered that they lost their self-confidence, 46\% that they experienced depression, and 41\% that they suffered from lack of sleep due to spasticity problems\textsuperscript{69}. The negative impacts of spasticity also make the burden heavier for the caregiver, and reducing spasticity has been shown to ease caregiver burden\textsuperscript{70,71}. Spasticity has been reported by individuals with disabilities as one of the leading negative secondary conditions\textsuperscript{72}. Spasticity also has an economic impact, by increasing costs of care and treatment\textsuperscript{73}.

\textbf{Figure 5.} Common negative consequences of spasticity\textsuperscript{54,63-69} structured by the International Classification of Functioning, Disability, and Health (ICF).
2.3 THE IMPORTANCE OF THE ARM AND HAND FUNCTION

The hand is an important work tool and a sensory organ. It is involved in the ability to perform work, leisure activities, self-care, and social interaction, as well as communication and expression. The function of the hand is multifaceted, which necessitates a large area of the cortex (see Figure 6) to handle the interaction between movements, cognition, perception, and emotions that occurs in daily activities. In day-to-day performance, the hand acts as a grasping tool, a sensory organ, and a communication device, and the arm plays an essential role in moving the hand to an object. Improvement in UL function is reported to be one of the functions that individuals with cervical SCIs identify as most important for improving the quality of life. Impaired hand function is proposed to contribute to the disability following stroke, and poorer health-related QoL has been associated with reduced UL function in a population of stroke survivors.

UNI- AND BILATERAL HAND FUNCTION

In daily life, we perform bimanual tasks, requiring the use of both arms, and unilateral tasks, which are done with one arm. In bimanual activities, the hands are sometimes used symmetrically, but they usually have different tasks. One hand might stabilize, and the other hand might perform a manipulation task. Therefore, while performing activities, we may need to coordinate different forces, as when one hand needs the power to stabilize and the other needs the skills to manipulate objects. Bimanual activities are reported to be performed more frequently in daily life than unilateral activities. Although bimanual activities are more frequent in daily life, many daily tasks can be accomplished with one hand. This non-use of the affected UL makes rehabilitation outside therapy sessions a challenge as compared with the rehabilitation of lower limb.
disorders since walking requires the use of both legs\textsuperscript{80}. The use of the affected UL can be effortful and frustrating, which is why the use of the other arm is more common\textsuperscript{80}.

Being active is considered to be the foundation of all living beings, and participation in activities is a necessary component of human physical and mental well-being\textsuperscript{81}. Given that hand function is central in all periods of life, a person affected by disability in the UL can experience physical, mental, and social consequences\textsuperscript{75}. Therefore, spasticity of the hand can be particularly debilitating because it prevents prehension and grasp, which are critical for the ability to independently perform ADLs\textsuperscript{82}. The degree of the impact of spasticity on daily life activities depends on whether the spasticity is uni- or bilateral, with bilateral spasticity increasing the overall disability.

\begin{figure}[h]
    \centering
    \includegraphics[width=\textwidth]{figure6.png}
    \caption{Cortical representation in the primary motor cortex (M1) and the primary sensory cortex (S1), where the hand has a large representational area.}
\end{figure}
2.4 TREATMENT OPTIONS FOR SPASTICITY

The main goal of any spasticity intervention is to improve function, although the treatment potential depends greatly on the motor recovery stage of the UL\textsuperscript{83}. Motor recovery requires trained motor capability, which is based on muscle synergies, and the ability to use those movements in various combinations when performing activities\textsuperscript{84}.

**DECISION TO TREAT SPASTICITY**

Some individuals with spasticity use key trigger strategies to beneficially apply the spasticity in daily life. It is therefore important to consider whether the spasticity is useful (facilitating an active grasp) or harmful for the patient before planning an intervention. A holistic team-based approach is needed that considers the complexity of the disorder to make a proper judgement. The decisions about whether and how to treat a patient’s spasticity are to be made on an individual basis following assessment by the treating team\textsuperscript{85,86}. Factors to consider include the chronicity, severity, and distribution of spasticity; the degree of weakness; the presence of contractures; the development of compensatory strategies; the severity of comorbidities; and the availability of support and treatment goals\textsuperscript{85,86}. Patients with spasticity may be treated if improvement in activity or participation (such as gait, independence in transfers, hygiene, dressing ability) or reduction in impairments (such as pain or contracture) can be realistically expected\textsuperscript{85,86}. Spasticity management should be goal directed, and goals should address function. In some cases, inappropriate treatment of spasticity may lead to loss of function, particularly when spasticity is counterbalancing the effects of paresis. On the other hand, spasticity may hinder the return of selective movement in a paretic limb, and relief of spasticity may facilitate the return of active movement in these cases. However, this cannot be guaranteed because of underlying persistent
weakness, which limits functional gains\textsuperscript{85,86}. Different algorithms for spasticity management have been published\textsuperscript{3,85,87,88}, with the common theme of determining whether the spasticity is useful and recommendations of non-pharmacologic treatment as a first line of treatment.

**NON-SURGICAL TREATMENT OPTIONS FOR SPASTICITY**

Non-surgical treatment for UL spasticity should always precede surgical treatment. Non-surgical treatments are often divided into non-pharmacological and pharmacological treatments.

**NON-PHARMACOLOGIC TREATMENT OPTIONS FOR SPASTICITY**

Rehabilitation goals for the management of UL spasticity include (1) restoring active function if there is reappearance of motor control or (2) improving passive function to facilitate care of the UL if no or little reappearance of motor control is achievable\textsuperscript{89,90}. Rehabilitation is described as the basic treatment for all patients with disabling spasticity\textsuperscript{91}. In isolation, rehabilitation might help to reduce increased muscle tone for a short period, but it is essential to help patients adapt to changes after other treatments, such as drugs or surgery.

There is a variety of available non-pharmacologic treatments for spasticity, and a combination is often used in clinical practice\textsuperscript{91-95}. Therapeutic interventions are typically divided into active and passive movement therapies\textsuperscript{81,96}.
ACTIVE INTERVENTIONS

The therapeutic modalities that fit in the active movement category include muscle strength training, repetitive task training, constraint-induced movement therapy (CIMT), neurodevelopmental therapy (NDT), mirror therapy, functional neuromuscular electrical stimulation (NMES), sensory-level stimulation (TENS), and robotic therapy. The aim of the active movement modalities is to diminish muscle spasticity and weakness. Active stretching of spastic muscles through reaching, grasping, and releasing tasks may also improve motor learning. CIMT and modified CIMT have been shown to be more effective than other upper limb (UL) therapies, but there is little quality evidence that they reduce UL spasticity. Three different reviews evaluating electrical stimulation as an adjunct to botulinum toxin (BoNT) found positive spasticity-reducing effects for patients with SCI, but not for patients with stroke, and insufficient support for TENS in isolation. A systematic review and meta-analysis showed that NMES combined with other treatment modalities, such as stretching, reduced spasticity and increased the range of motion (ROM) after stroke. Muscle training to increase the strength in the antagonist muscles has been a source of conflict, because a theory that resistive muscle strengthening increases tone, a theory promoted by Bobath, remains unsupported. A previous systematic review concluded that there is no evidence that strength training increases spasticity. Instead, the review demonstrated that there is preliminary evidence that progressive resistance training reduces musculoskeletal impairment after stroke. Progressive resistance training is a widely used approach in spasticity management today, but it remains unknown whether strengthening enhances the performance of functional activities or participation in societal roles.
PASSIVE INTERVENTIONS

The passive movement category includes prolonged muscle stretching, muscle cooling/heating, splinting, serial casting, kinesiotaping, vibration, traction, acupuncture, and neurodynamic mobilization. The common aim of passive treatments is to decrease abnormal muscle tone, prevent the shortening of soft tissue, maintain joint movement, decrease pain, and possibly improve function. Stretching is probably the most commonly used non-pharmacologic therapy; the study results are, however, inclusive. A systematic review indicated positive effects of stretching but also that the results were inconclusive and that further studies are needed. The evidence for treatment with orthosis is also inclusive. There is no evidence that wearing a splint all night has an additional effect on reducing spasticity over the usual therapy. Case reports suggest improvement in passive ROM (P-ROM) after serial casting, and a recent review found that static splinting reduced spasticity and improved hand function. The same review found that stretching devices, such as a hand splint fitted with adjustable components, reduce spasticity; the long-term effect is, however, still unknown. Shock wave therapy on flexor hypertonic muscles of the forearm and interosseous muscles of the hand in patients with stroke showed a significant reduction in muscle tone lasting up to three months. Cryotherapy, using cold packs, is promising as preparatory management in therapeutic treatment, providing greater functional independence, but future studies are needed to confirm the effect. Acupuncture has in some studies proven to yield positive effects on spasticity, whereas other findings indicate a lack of effectiveness. Neurodynamic mobilization of the median nerve has been shown to reduce spasticity, improve ROM and UL function, and alter electrical signals of spastic muscles.
To sum up, previous studies investigating the effectiveness of therapeutic interventions have yielded varying outcomes and have demonstrated variable degrees of effectiveness\textsuperscript{45,124}. The main purpose of many of the aforementioned treatments is to maintain ROM and prevent secondary complications rather than decrease the spasticity. This can answer some of the varying results. A small sample size, heterogenous patients, and several simultaneously provided interventions (cofounders) can also have impacted the results, thus making the interpretations of the study findings challenging\textsuperscript{45,125}. In an international survey, 75\% of the respondents reported receiving physiotherapy/physical therapy, 43\% massage, 41\% active and passive stretching and exercise, and 38\% splinting\textsuperscript{68}. Important in rehabilitation protocols for spasticity is self-rehabilitation, such as stretching posture, splints, and active exercises, taught to the patients or caregivers\textsuperscript{126}. One such programme consists of self-rehabilitation contracts for spasticity, developed by Garcias\textsuperscript{127}.

**PHARMACOLOGIC TREATMENT OPTIONS FOR SPASTICITY**

Pharmacologic approaches to spasticity management include oral medication, intrathecal pumps, and intramuscular injections, with the common aim to decrease the amount of spasticity\textsuperscript{21,93,128,129}. The potential downsides of such therapies are general weakness and fatigue\textsuperscript{93,128,129}. Intrathecal baclofen therapy may be considered a neurosurgical treatment. In an international survey, 57\% of respondents reported that they were prescribed oral medication and 4\% intrathecal baclofen therapy for spasticity\textsuperscript{68}. Evidence regarding the most effective treatment modality for reducing spasticity is conflicting, and in general, no single treatment modality can successfully manage the broad spectrum of spasticity\textsuperscript{63,93,128,129}.

BoNT is considered to be the gold standard pharmacologic treatment for focal spasticity\textsuperscript{130}, and in a previous survey\textsuperscript{68}, 73\% of participants with spasticity had
been treated with BoNT. There is promising evidence that BoNT injections plus rehabilitation may have sustainable effects on spasticity reduction and functional UL improvement, which could have a carry-over effect. A recent systematic review concluded that BoNT injections can reduce muscle tone and improve passive function, such as hand hygiene and caregiver burden. However, the effect of BoNT injections on active function remains unclear. The effects last commonly up to three months, and the peak effect is usually around 4–6 weeks after the injection. Reducing spasticity alone, without addressing other negative components of a UMN syndrome, limits meaningful recovery. Thus, a combination of treatment techniques is required to optimize functional improvements.
SURGICAL TREATMENT OPTIONS FOR SPASTICITY

Surgical treatment has been a treatment option for many years and can be classified into orthopedic and neurosurgical procedures\textsuperscript{133,134}. The orthopedic procedures address the consequences of spasticity rather than the movement disorder and consist mainly of tendon lengthening, tendon release, and tendon transfer\textsuperscript{16,17,71,82,135,136}. These procedures affect not only the velocity-dependent spasticity but also soft-tissue tightness. With surgery, the muscle force can be adapted by redirecting, eliminating, or decreasing the muscle force\textsuperscript{137}. Surgery cannot increase the strength or recreate volitional control of spastic muscles. Rather, by decreasing or eliminating the force of a spastic muscle, the muscle’s antagonists could more easily be trained, thereby regaining volitional motor control\textsuperscript{137}. Further, it can also target the biomechanical alterations in joints and soft tissues. However, if the muscle has no underlying motor control, surgery cannot increase the force that a muscle generates or create volitional control, but sometimes it can unmask motor control in a muscle that may not have been observed initially because of spasticity. Neurosurgical procedures include neurectomy and selective dorsal rhizotomy\textsuperscript{25,133}. Due to limitations in outcome assessment and different types of surgical procedures, conclusions with respect to treatment effectiveness cannot be drawn yet\textsuperscript{16,25,71,82,138-142}.

SURGICAL PROCEDURES USED IN THIS THESIS

The surgical procedures used in this study population were primarily tendon lengthening and muscle releases, so-called tenotomies. Lengthening a tendon or releasing a muscle from its insertion relaxes the whole muscle-tendon unit. Hence, the spasticity is alleviated but not eliminated. After the intervention, the spasticity is not gone but reduced in strength. If a targeted muscle is still innervated despite the neurological injury, the muscle can be actively trained after surgery. The wrist and the fingers are set in a normal resting position. The
tendon lengthening procedure involved a stair-step incision and reattachment in the lengthened position with a side-to-side suture, running cross-stitches$^{143,144}$. With a 5cm overlap each tendon can be loaded with 20 kg$^{145}$, which is far more than necessary in daily life tasks. The suture material used is non-resorbable 3-0 Ti-Cron. Resorbable sutures are not recommended because of the long healing time in tendons. Safe sutures allow for early mobilization on the first postoperative day and prevent the build-up of adhesions and excessive scarring. Side-to-side sutures are flat and less bulky than Pulvertaft attachments, allowing for a better cosmetic result and smoother tendon sliding.

Tenotomy is often carried out on the tendons of the pronator teres (PT), the adductor pollicis (ADP), the palmaris longus (PL) and the superficial flexor digitorum muscle (FDS) to the 5th finger. The tendons to the PT and FDS are thin and sometimes absent. Tenotomy is performed at the insertion site of the pronator teres (PT) and the adductor pollicis (ADP) instead of at the origin site, which requires a deeper dissection and larger surgery. At tenotomy, the muscle pulls back 2–3 cm (PT) or 1 cm (ADP) and probably stays there to adhere to its surroundings, and a new resting position is found. The muscle still works after surgery but may be weaker, at least initially. Fractional muscle release is chosen for the brachialis and biceps brachii muscles (e.g., because of its tendon anatomy). Fractional lengthening cannot be controlled in the same way and usually gives less length. The finger flexors often need 3 cm lengthening, and fractional muscle lengthening adds a maximum of 2 cm and requires larger surgery. All the tendons are easily available under a semicircular flap at the volar distal forearm. Common knowledge among hand surgeons is that tendons in the forearm can be lengthened up to 3 cm without affecting the muscle’s (sarcomere’s) ability to contract. The pronator teres may be released or lengthened. The description of the procedures is presented in Figure 7A–C.
Figure 7A–C. Description of the surgical procedures used at CARE. A) Description of the procedure of tendon lengthening. The tendons are divided by a longitudinal Z-incision, and the spasticity-induced flexion deformity is reduced passively, aiming for a normal resting length of the finger flexors. The distal and proximal parts of the tendons are reattached in a lengthened position using a side-to-side, cross-stitch technique, which enables immediate loading postoperatively. B) Schematic figure of the side-to-side suture technique. C) Description of the surgical procedure of muscle release at the adductor, pronator, and pectoralis.
Figure 7A–C. Description of the surgical procedures used at CARE. A) Description of the procedure of tendon lengthening. The tendons are divided by a longitudinal Z-incision, and the spasticity-induced flexion deformity is reduced passively, aiming for a normal resting length of the finger flexors. The distal and proximal parts of the tendons are reattached in a lengthened position using a side-to-side, cross-stitch technique, which enables immediate loading postoperatively. B) Schematic figure of the side-to-side suture technique. C) Description of the surgical procedure of muscle release at the adductor, pronator, and pectoralis.
OTHER TYPES OF SURGICAL INTERVENTIONS

Other types of surgical options used are muscle lengthening, tendon transfers and neurotomies.

**Muscle lengthening** procedures are usually fractional lengthening or Z-lengthening\(^{16,135,142-144,146-149}\). Intramuscular fractional lengthening is described in palmar interossei, biceps, brachialis, and brachioradialis muscles\(^{135,150}\). A technique described for multiple tendon release is the so-called Page-Scaglletti surgical technique\(^{15}\).

**Tendon transfer** is another surgical option that can be used in case of flexion deformity of the wrist secondary to spasticity when the flexor carpi ulnaris (FCU) is transferred to the extensor carpi radialis brevis (ECRB). The primary goal of the FCU-to-ECRB transfer is to improve the wrist position to a neutral or slightly extended posture and to provide active wrist extension\(^{151,152}\). In this procedure, the surgeon needs to carefully consider the achieved new balance of the hand if spasticity exists in the transferred muscle (FCU). Spasticity should be dealt with before the transfer in order to set the right tension in the transfer. Other surgical options described to stabilize a flexed wrist are wrist extensor tenodesis\(^{146}\) and wrist arthrodesis\(^{153}\). Superficialis-to-profundus tendon transfer is another type of procedure\(^{140,151}\) used in the nonfunctional UL to improve passive function in patients with clenched fists.

**Neurectomy** (complete sectioning of a nerve trunk) is a procedure that may be indicated in patients with a nonfunctional UL\(^{154}\). Hyperselective or partial neurectomy (the division of selected fascicles of a major motor nerve) is reported to be an option also in patients with some existing hand function\(^{154}\). Outcomes and descriptions of the techniques are presented in previous studies\(^{25,155}\). However, as compared with the reversible tendon lengthening procedure, these approaches are not reversible since the muscle loses the nerve connection and thereby its function after surgery\(^{154-156}\). Neurectomy irreversibly paralyses the muscle completely or partially depending on how many branches of the nerve are targeted during surgery. The procedure has gained popularity in recent years. Neurectomy of the motor branch of the ulnaris nerve may be an option when all intrinsic muscles are spastic. Releasing all muscles is a much bigger procedure than a well-aimed neurectomy. Distal ulnar intrinsic release is a small but often appreciated procedure for intrinsic spasticity or tightness. The assessment includes the Bunnell test, which can be used to evaluate sufficient release preoperatively. This procedure is recommended when the intrinsic muscles are partially spastic\(^{157}\). The selection of surgical strategies and the type of postoperative rehabilitation depends on the patient's ability to perform active and passive joint movements, as well as the cognitive capacity of the patient. The treatment aims at improving active or passive function and/or the use of the UL in daily life. For individuals with cognitive impairment and limited voluntary hand control, the primary indications for surgery are to improve hygiene aspects (a clenched fist is prone to candida infections and wounds) and to decrease spasticity-induced pain and joint deformities. The look of a clenched fist is also a stigma that many patients like to diminish\(^7,158\). Gatin et al.\(^{23}\) concluded in a state-of-the-art article that results in the UL are better for hygienic, positioning, and analgesic objectives.

Surgical treatment of the UL is usually not a single procedure, and combined techniques might be used. Additional surgery may be necessary in case muscle imbalance arises after surgery due to disorders that were masked preoperatively, such as spasticity of the intrinsic muscles in the hand. It can also be difficult to differentiate between spasticity and contractures preoperatively, which might be why some lengthening procedures may not
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

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have the anticipated effects. Spasticity evolves over time, and scarring in the UMN may cause cysts (syrinx), which might require neurosurgery of the spinal cord (when SCI is the origin of the spasticity). Other diseases, pain, stress, injuries, etc. affect the spasticity and can change it.

**TIMING OF SURGERY**

There is no upper time frame for surgical interventions, although in a study, it was shown that six months after stroke, 50% of individuals with spasticity develop contractures\(^{159}\). Animal studies have shown that when a muscle has a shortened length (flexed) for four weeks, some pathological changes occur in the muscle tissues, decreasing the number of sarcomeres and replacing them with connective tissue\(^{160}\). As described previously, a paralysed muscle held in a shortened position loses sarcomeres after some time, resulting in stiff muscle fibres\(^{48}\). Therefore, the time since injury can affect the result in cases where time has caused secondary complications to occur. Among adult patients with acquired CNS injuries, surgical procedures should wait until recovery has plateaued. This waiting period was proposed to be at least 6 months after stroke, 18 months after TBI, and 12 months after SCI\(^{18}\). Genete et al. however, proposed that reconstructive surgery should be performed as soon as possible to allow early and intensive rehabilitation in order to optimize recovery. Also, Freeman et al. proposed earlier referral for the assessment of surgery management to avoid contractures and other secondary complications to spasticity. Independently of the surgical technique applied, the surgery should always be preceded by non-surgical treatment, as shown in Figure 8 (the proposed treatment algorithm for spasticity-correcting surgery in this thesis). BoNT injections cause cascades of growth factors and other substances, which might make the muscles increasingly stiff and transform them into more fibrous tissue, according to Lieber\(^{162}\). Repeated BoNT injections might be harmful to the elasticity of the muscle; hence, surgery should be considered.
When non-surgical treatment is not sufficient and the patient is motivated, contact with a surgeon is recommended to assess surgical options. A good preoperative dialogue with the patient and/or close partners or family is essential for expectations and postoperative rehabilitation. The importance of a highly standardized diagnostic strategy is highlighted by Gatin et al.\textsuperscript{23}. 

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{image.png}
\caption{The proposed treatment algorithm for spasticity-correcting surgery in this thesis.}
\end{figure}
Rehabilitation protocols for the surgical management of the spastic UL vary around the world\textsuperscript{14,155,163,164}. The variation is the result of various surgical techniques, which require different postoperative restrictions. Most treatment protocols include splints to protect the surgical wound, oedema control, scar management, P-ROM and active ROM (A-ROM) exercises, activity training, and self-training\textsuperscript{135,163,164}. Rehabilitation protocols after tendon lengthening procedures often advocate the use of a splint or cast after surgery for 24 hours a day for 3 to 4 weeks, after which an exercise regimen is commenced\textsuperscript{142,146,149}. Rehabilitation after tenotomies commonly follows the same regimen as after tendon lengthening, with splints or casts followed by exercise starting the day after surgery or 3 to 4 weeks after surgery\textsuperscript{16,17,163,165}. After neurectomy, therapy is to be initiated on the second postoperative day to avoid oedema and to gently mobilize the muscles involved\textsuperscript{155,156}. Occupational therapy and physiotherapy are to be continued for 6 weeks; the amount and the content are not well described in the literature\textsuperscript{154-156}. Rehabilitation after tendon transfers normally includes splint use for 24 hours a day for 2 to 5 weeks, after which A-ROM and P-ROM are initiated\textsuperscript{164}.

**REGIMEN-SPECIFIC REHABILITATION PROTOCOL**

The regimen-specific rehabilitation protocol used in the thesis is a concept developed at the Centre for Advanced Reconstruction of Extremities (CARE), Sahlgrenska University Hospital, Mölndal, Sweden. The concept is inspired by the EAR protocol, which was developed for patients with SCI undergoing tendon transfer\textsuperscript{6}. The current concept for spasticity-correcting surgery was initially described in 2016\textsuperscript{163}. Preliminary findings demonstrate significant
gains for patients with SCI after surgery\textsuperscript{163}. The goal of surgery is to maximize UL function, which is why regimen-specific rehabilitation is critical after surgery. The rehabilitation concept used in this thesis stratifies patients into three different regimens depending on their degree of residual motor function (non, low, or high), without taking into account the specific diagnosis or muscles affected by spasticity. The rationale for this is that the choice of intervention should be based on whether or not beneficial gains could be expected after surgery. Rather than dividing patients into functional and non-functional groups as reported previously\textsuperscript{166}, we chose to differentiate between high- and low-functioning patients and tailor the rehabilitation accordingly, taking into account any cognitive problems that may affect the treatment.

**Before surgery**
Prior to surgery, all patients are carefully assessed by the team and assigned to one of the three regimens. The regimen-specific inclusion and exclusion criteria are described in Table 3, along with the regimen-specific goals. Some patients are recommended non-surgical management, such as BoNT injection, strength training of the antagonists, orthosis, or other stretching exercises of the spastic muscles/tendons, before surgical management is considered.

**One day to 3 weeks after surgery**
All patients have an in-patient stay varying in length between 3 and 5 days in the surgery week. In case the expectations are not met regarding the patient’s immediate gains from surgery, a change of regimen can take place. Independently of the regimen, the post-surgical rehabilitation is person centred to promote participation in everyday activities that are possible and meaningful for each individual. The initial rehabilitation aims to protect the sutured structures and maximize motor function. The rehabilitation activities in this thesis work were part of standard care. All regimen protocols include splinting
for 24 hours a day for 3 weeks (see Figure 9 for the commonly used splint design). During passive and active ROM exercises, which are initiated the day after surgery, the splint is removed. Training is allowed to the maximum ROM without any restrictions on lengthened muscles or their antagonists. Which ROM exercises can be performed depends on the target muscles. How many times the exercises can be performed and whether A-ROM or P-ROM or both can be done depend on the patient’s degree of volitional motor control.

Figure 9A–C. Splints commonly used after spasticity-correcting surgery at CARE, Sahlgrenska University Hospital. A) Standard splint. B) Splint commonly used to increase the stretch in supinated position. C) Bandage commonly used to increase the stretch in supinated position.
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
<th>Rehabilitation goals</th>
<th>Transfers of gains into daily life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe and mild cognitive impairments</td>
<td>Increased voluntary motor control and A-ROM in the affected UL and minimized compensation with the other hand</td>
<td>Increased ability to use the spastic UL in unimanual and bimanual ADL.</td>
</tr>
<tr>
<td>Severe contractures that hinders surgical benefits**</td>
<td>Increased P-ROM and possible increased voluntary motor control in the affected UL, though reduced compensation with the other hand is unlikely</td>
<td>Increased capacity to use the affected UL in bimanual ADLs.</td>
</tr>
<tr>
<td>Severe contractures that hinders surgical benefits**</td>
<td>Increased P-ROM</td>
<td>Facilitation of hygiene, caregiving, rest positioning and amelioration of spasticity-induced UL pain</td>
</tr>
</tbody>
</table>

BoNT= Botulinum toxin; A-ROM= Active Range of Motion; P-ROM= Passive Range of Motion; LFR= low-functioning regimen; NFR= non-functioning regimen.

Three weeks post- surgery

Three weeks after surgery, all patients are scheduled for a follow-up visit. The length of the stay varies depending on the regimen. From now on, the splint is used only at night-time. The exercises gradually turn into activity-based training for patients who are expected to increase their ability to use the UL in daily life. The therapy content for each regimen is presented in detail in Paper II (Table 2) and summarized below. For patients in the high-functioning regimen (HFR), the 5-day follow-up visit means four daily training sessions from Monday to Friday. The training includes functional tasks, such as grasping and release exercises, and activity-based training. Many patients have come to adopt unfavourable movement strategies to compensate for functional loss. In such cases, some time is devoted to exercises to normalize movement patterns. Exercises for increased ROM, strength, and endurance are to be continued to transfer reestablished active UL function to active use in daily activities. Reduced grip strength is commonly experienced in the initial phase due to lengthened flexor muscles. It is therefore important to prepare the patients for eventual prolonged weakness to avoid anxiety after surgery and to tell them that strengthening the antagonist muscles is still the priority. The
activities that the patient wishes to accomplish after surgery are commonly the ones that are trained at this stage. Upon discharge, the goal is for the patient to be familiarized with tailored exercises to continue training at home with or without assistance. The patients in the low-functioning regimen (LFR), normally have 3–4 daily training sessions for 4–5 days. The training for these low-functioning patients is focused on retrieving appropriate movement patterns (i.e., minimizing compensational movements) rather than pure muscle training. The individualized activity training focuses on activities in which the treated UL is used as a support in bimanual activities. Functional resting positions between training sessions are important in order to prevent the development of stiffness and contractures. As for high-functioning patients, the focus is still on strengthening the antagonist muscles. The weakened lengthened muscles will in most cases regain their strength in due time. Training these muscles too soon after surgery tends to increase the risk that spasticity problems re-occur. Upon discharge, patients become familiarized with individually tailored home training programmes that are to be performed with or without assistance in order to maintain or increase the gains achieved from surgery. For patients in the non-functioning regimen (NFR), the follow-up commonly entails a single outpatient visit. The rehabilitation in this regimen focuses on P-ROM exercises and functional resting positions to maintain improvements and prevent stiffness and contractures. See Figure 10 for examples of common activity training and goals in each regimen.

Three months post-surgery

Three months after surgery, all patients are scheduled for a follow-up outpatient visit. An assessment similar to the baseline assessment is performed to measure the outcome of surgery. Adjustments may be needed, such as modifications in the self-managed training programme, counselling, or similar adaptations. For high-functioning patients, the achieved level of occupational
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

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Three months post-surgery

Three months after surgery, all patients are scheduled for a follow-up outpatient visit. An assessment similar to the baseline assessment is performed to measure the outcome of surgery. Adjustments may be needed, such as modifications in the self-managed training programme, counselling, or similar adaptations. For high-functioning patients, the achieved level of occupational performance determines whether the training is to be continued. A therapist makes a careful assessment of the patient’s functional status and his/her ability to use the UL in daily activities. Most often, the overnight splint usage is terminated; some exceptions may, however, remain, such as the need to improve the balance of the hand to prevent the re-emergence of stiffness, contractures, and deformities. For low-functioning patients, the continued regimen is similar to the HFR, but with the distinction that the patient’s ability to use the UL in daily activities is more limited. Therefore, continued splinting and exercise are often required to better maintain the surgical benefits. For patients with no volitional motor function treated according to the NFR, there is usually a need for continued P-ROM exercises, splints, and functional resting positions to maintain the gains from surgery and prevent relapses.
Six months post-surgery

Six months after surgery, patients are scheduled for an outpatient visit at which a renewed assessment of the surgery results is made. If any changes were made at the three-month follow-up, this occasion provides an opportunity to check the patients’ status. If relevant, recommendations are given about continued or new exercises, as well as other activities, to maintain surgical benefits.

Twelve months post-surgery

At twelve months, the last follow-up takes place with a final evaluation of the surgical outcome. Self-managed preventive activities are recommended if relevant, and in case there is a need for further or complementary surgical procedures, planning for such procedures may take place at this point. For details of the post-surgery protocol, see Figure 11.

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**Figure 11. Description of the post-surgery rehabilitation protocols for the different regimens.**

Abbreviations: HFR= high-functioning regimen; LFR= low-functioning regimen; NFR= non-functioning regimen.
2.5 ASSESSMENT AND OUTCOMES

Measuring spasticity is challenging, for several reasons. The degree of spasticity can vary throughout the day, impacted by changes in body positioning and the amount of stress; it is also increased by noxious stimuli, such as urinary tract infection, pressure, or constipation. Muscle tone can also depend on the temperature and whether the muscle is active or at rest. The heterogeneity of patients with spasticity due to CNS injuries further complicates the assessments and the interpretations.

Currently, no single test exists that is superior for measuring spasticity and functional outcomes following interventions. Rather, a battery of tests may be required. Most of the outcome measures used in the clinic and research evaluate the consequences of spasticity. The most frequently and routinely used outcome measures in the clinical assessment of spasticity are ROM and the MAS, followed by the Tardieu Scale\textsuperscript{167}. The outcome measures used in clinical work and research should have sufficient evidence of reliability, validity, and responsiveness. If the evidence is insufficient, there is a substantial risk of receiving imprecise or biased results in the evaluation of an intervention\textsuperscript{168,169}. It is preferable that assessments are time- and cost-efficient and cover the different ICF domains. Further, PROMs and goal setting should be included\textsuperscript{170,171}. When measuring spasticity-associated problems according to the ICF, a potential change can be demonstrated not only at the level of impairment but also at the functional level\textsuperscript{42,171}. Functional outcome measures, including goal achievement, seem to be sparsely used in clinical practice, in which assessing the effectiveness of spasticity treatment occurs mainly at the impairment level\textsuperscript{167}. PROMs are designed to measure the patients’ view of their health rather than the clinicians’, which gives an indication of how the patients perceive their health\textsuperscript{172}. This can help identify problems that otherwise would
have gone unnoticed\textsuperscript{173}. PROMs are also time-efficient and do not involve advanced instruments or administration costs and can be sent home to patients\textsuperscript{169}. PROMs are not suitable for individuals with impaired cognitive skills, as they may be too challenging to be completed correctly. To ease the implementation of PROMs in clinical work and research, certain modifications may be justified\textsuperscript{174}.
2.6 THEORETICAL FRAMEWORK

This thesis includes both quantitative and qualitative studies and different theoretical perspectives have been used.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF)

The ICF was developed by the WHO\(^1\). ICF is a classification system, for which the overall goal was to create a unified and standardized language and structure for describing health and health-related conditions. The ICF classifies body function/structure, activity, participation, and environmental and personal factors (Figure 12)\(^1\). The ICF is a useful framework for describing the impact of diseases and the benefits of treatments. UL spasticity can cause problems in any of the ICF domains. Understanding the impact of a disease on a person at different levels facilitates the planning of individualized, goal-directed, and functionally orientated rehabilitation programmes. The evaluation in the present studies aims at describing the UL spasticity problems with respect to several levels of functional ability and impairment according to the ICF.

![Figure 12. International Classification of Functioning, Disability, and Health\(^1\).](image-url)
THE OCCUPATIONAL PERSPECTIVE

The occupational perspective is an approach to viewing and thinking about human occupation\textsuperscript{175}. The perspective is based on the assumption that humans are active, that occupation is important for the development of a person, and that humans are social beings that perform activities in interaction with others\textsuperscript{2}. In occupational therapy intervention, occupational performance is a useful and commonly used tool\textsuperscript{176}. Occupations are conducted in a dynamic interaction between the person, the activity, and the environment, and the result is influenced by the interaction between these components\textsuperscript{177}. Occupational patterns are different for each individual and are created on the basis of the individual's interests, volition, and values; people are involved in occupations because they want and need to\textsuperscript{178}. The challenge for individuals with CNS spasticity is to deal with their performance capacity and manage activities occurring in different contexts. This is important for the ability to perform activities that the individual needs, wants, and is expected to perform in daily life. In this thesis work, each individual’s needs and most wanted gains are carefully assessed in order to plan the treatment.

THE BIOMECHANICAL MODEL

The occupational therapy biomechanical model assumes that movements form the foundation of human activity and that all meaningful activities are built on the ability to move the body\textsuperscript{179,180}. The model can be applied in the rehabilitation of patients whose activity limitations are due to problems in the musculoskeletal system and in the rehabilitation of patients with limitations in ROM, muscle strength, coordination, endurance, or sensibility\textsuperscript{180}. The biomechanical features during the performance of an activity include, for example, the size, force, and location of objects. The goal is to focus on
assessment and treatment in order to facilitate the performance of specific activities, by maintaining existing and/or regaining ROM and compensating for the loss of it\textsuperscript{179,180}. In the present thesis work, many outcome measures and treatments focus on improvements in domains such as ROM, strength, coordination, and muscle tone (spasticity). This model fits well in the treatment of UL spasticity.
2.7 LACK OF KNOWLEDGE / RESEARCH GAP

Spasticity is described as one of the prominent secondary conditions in individuals with various disabilities. Numerous reviews and previous studies have highlighted that future research should focus on improving spasticity management. Surgery management in the adult patient has been described as the last option when noninvasive management has failed or in the most severe cases or has not even been mentioned as an option. In a recent review of management options for focal spasticity, surgery in the adult population was recommended in four of the thirteen papers reviewed. The underutilization of UL surgery has been questioned by several surgeons who consider it to be a missed opportunity. The underutilization of surgical management may be explained by a lack of knowledge about surgery options, a wide variety of available procedures without a clear algorithm, limited outcome evidence or consensus, unfavourable earlier experiences, lack of access to surgery as a treatment for spasticity, and lack of close collaboration between surgeons and rehabilitation therapists. It has been anticipated that 10% of patients with spasticity would benefit from surgery. Some surgeons advise surgery to be regarded as a possibility for every patient with troublesome spasticity. It has been reported that less than 1% of patients who suffered TBI or stroke with residual spasticity were managed with surgery.

After any spasticity management, guidelines promote a multidisciplinary rehabilitation approach based on expert opinions and goal-directed and person-centred care. The significance of structured treatment regimens for improving the outcomes after spasticity treatments is highlighted. Nevertheless, the guidelines lack details of the content of such treatment regimens. A recent review of preferred options and evidence for UL surgery
emphasized that future studies should focus on postoperative outcomes to develop consistent surgical algorithms\textsuperscript{187}. A literature review on surgery targeting spasticity in the UL of adult individuals concluded that efficacy cannot be proven due to the heterogeneity of patients and procedures\textsuperscript{188}. A recent systematic review found that 15 of 16 studies demonstrated significant benefits postoperatively\textsuperscript{186}. However, the quality of the included studies was low, and the authors suggested that future work should focus on high-quality studies, developing consensus regarding outcome measures, and including and validating PROMs, along with the assessment of patients’ functionality and quality of life\textsuperscript{186}. Evaluating the overall effectiveness of an intervention is crucial for guiding patients, healthcare teams, and decision makers. In an international survey, only 67\% of the respondents had discussed treatment expectations with the treatment team\textsuperscript{68}. Since spasticity is generally a lifelong disorder, realistic expectations are central for patients to be satisfied with their treatments.

Evidently, there is a lack of well-defined surgical and rehabilitation regimens for adults with disabling UL spasticity and a lack of appropriate PROMs in Swedish. Moreover, little is known about patients’ experience of the treatment results. This thesis work intended to fill some of the knowledge gaps and identify key areas for future research. The findings could be used to inform patients about the surgical procedure and subsequent treatment regimen. The increased knowledge may also enhance the understanding of what to expect from surgery and how the benefits can translate into gains in daily life activities. Potentially, this work will help individuals to prepare for surgery and subsequent rehabilitation. It could also help in the discussion of realistic expectations and occupational goal setting. Eventually, it may raise awareness of the current treatment concept, as a means to efficiently manage and treat UL spasticity. This may in turn increase the number of referrals and thereby
increase the number of patients that achieve long-lasting functional and activity-based gains despite a chronic disorder.
3 AIM

The overall aim of the thesis was to describe and evaluate the impact of a treatment algorithm on spasticity-correcting UL surgery and comprehensive rehabilitation for patients with CNS injuries.

SPECIFIC AIMS

**STUDY I:** To investigate how UL spasticity-correcting surgery followed by the EAR concept impacts the daily life of patients with spasticity of cerebral and spinal origin.

**STUDY II:** To describe and evaluate whether the current treatment algorithm for spasticity-correcting surgery is feasible for patients with disabling UL spasticity of cerebral and spinal origin.

**STUDY III:** To translate the Arm Activity measure (ArmA) into Swedish and evaluate the psychometric properties of the Swedish version (ArmA-S).

**STUDY IV:** To explore how treatment gains translate into everyday life as experienced by individuals who underwent spasticity-correcting surgery and comprehensive rehabilitation.

**STUDY V:** To describe the prioritized occupational performance problems identified by individuals with UL spasticity who underwent spasticity-correcting surgery and to map these problems onto the ICF.
4 PATIENTS AND METHODS

OVERALL STUDY DESIGN

The number of participants included in the different studies varies, as does the distribution of the diagnoses and regimens, the study design, data collection and the data analysis. In table 4 an overview of the aims and methodological approaches are presented. The clinical characteristics of the participants are presented in Table 5. The patients included in Study I (n = 30) were consecutively admitted to CARE, Sahlgrenska University Hospital, from March 2015 to January 2017. In Study II, a retrospective study, all patients older than 18 years who underwent surgery between February 2017 and June 2019 were included (n = 58). In Study III, data from 66 cases were included. Eight patients were included in Study IV, and 71 cases in Study V. Different inclusion and exclusion criteria were applied in the studies (Table 3). Common to all studies were the inclusion criteria age above 18 years and problematic UL spasticity due to CNS injuries.
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### Table 4. Overview of the studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Data Collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To investigate how UL spasticity-correcting surgery followed by the EAR concept impact the daily life of patients with spasticity of cerebral and spinal origin.</td>
<td>Quantitative prospective observational study</td>
<td>Longitudinal</td>
<td>Wilcoxon signed rank test</td>
</tr>
<tr>
<td>II</td>
<td>To describe and evaluate whether the current treatment algorithm for spasticity-correcting surgery is feasible for patients with disabling UL spasticity of cerebral and spinal origin.</td>
<td>Quantitative retrospective observational study</td>
<td>Longitudinal</td>
<td>T-test, Wilcoxon signed rank test</td>
</tr>
<tr>
<td>III</td>
<td>To translate the Arm Activity Measure (ArmA) into Swedish and evaluate the psychometric properties of the Swedish version (ArmA-S).</td>
<td>Quantitative translation and psychometric evaluation of a PROM</td>
<td>Longitudinal</td>
<td>Cronbach’s alpha, Quadratic weighted Kappa, Spearman’s rank correlation coefficient, Wilcoxon signed rank test, Distribution-based method and Criterion-based method for MIC calculation</td>
</tr>
<tr>
<td>IV</td>
<td>To explore how treatment gains translate into everyday life as experienced by individuals who underwent spasticity-correcting surgery and comprehensive rehabilitation.</td>
<td>Qualitative interpretive</td>
<td>Individual semi-structured interviews</td>
<td>Phenomenographic approach</td>
</tr>
<tr>
<td>V</td>
<td>To describe the prioritized occupational performance problems identified by individuals with UL spasticity who underwent spasticity-correcting surgery and to map these problems onto the ICF.</td>
<td>Quantitative, retrospective mapping study</td>
<td>Longitudinal</td>
<td>Wilcoxon signed rank test, Mann-whitney U test, Spearman correlation</td>
</tr>
</tbody>
</table>

Abbreviations: EAR = early active rehabilitation; UL = upper limb; PROM = patient reported outcomes, MIC = minimal important change; POP = prioritised occupational performance problems; ICF = International Classification of Function, Disability and Health.
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

STUDY POPULATIONS

The characteristics of the study participants are presented in table 5, including age, gender, regimen, diagnosis, treated arm, time since the injury/event, and the primary method of ambulation (walking/wheelchair).

<table>
<thead>
<tr>
<th>Study</th>
<th>Patients</th>
<th>Regimen</th>
<th>Age mean (min–max)</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Time (years) between injury and surgery mean (min–max)</th>
<th>Operated arm right/left</th>
<th>Transfers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>30</td>
<td>HFR 15(50)</td>
<td>57(28–85)</td>
<td>Women 7(23)</td>
<td>SCI 9(36)</td>
<td>14.3(1–57)</td>
<td>12(40)</td>
<td>Wheelchair 17(57)</td>
</tr>
<tr>
<td>Study II</td>
<td>58</td>
<td>LFR 3(10)</td>
<td>57(19–79)</td>
<td>Men 23(77)</td>
<td>Stroke 13(43)</td>
<td>8.6(0–31)</td>
<td>29(50)</td>
<td>17(57)</td>
</tr>
<tr>
<td>Study III</td>
<td>66</td>
<td>NFR 12(40)</td>
<td>57(19–79)</td>
<td></td>
<td>TBI 5(17)</td>
<td>8.1(1–26)</td>
<td>29(50)</td>
<td>34(59)</td>
</tr>
<tr>
<td>Study IV</td>
<td>8</td>
<td></td>
<td>62(49–78)</td>
<td></td>
<td>Other* 3(10)</td>
<td>8(1–18)</td>
<td>37(56)</td>
<td>35(53)</td>
</tr>
<tr>
<td>Study V</td>
<td>71</td>
<td></td>
<td>57(24–79)</td>
<td></td>
<td></td>
<td>8(1–35)</td>
<td>3(56)/29(44)</td>
<td>3(56)/29(44)</td>
</tr>
</tbody>
</table>

Data is reported as number(%) unless indicated otherwise. Other diagnosis: multiple sclerosis, cerebral paralysis, spina bifida, Wilson disease. Abbreviations: Min = minimum; Max = maximum; SCI = spinal cord injury; TBI = traumatic brain injury; HFR = high-functioning regimen; LFR = low-functioning regimen; NFR = non-functioning regimen; m = missing.
Some of the patients were included in more than one of the studies.

**Study I:** no patients were included in previous studies.

**Study II:** 3 out of 58 patients were also included in Study I when they underwent surgery on the other arm.

**Study III:** 56 of 66 protocols came from individuals included in two or more studies (Study I, n = 2; Study II, n = 46; Study IV, n = 8).

**Study IV:** all participants were included in two or more studies (Study II, n = 6; Study III, n = 8; Study V, n = 6).

**Study V:** 71 COPM forms, all from patients included in two or more studies (Study I, n = 15; Study II, n = 48; Study IV, n = 6; an ongoing study, n = 8).

**DROP-OUTS**

In Study I, two patients dropped out: one patient died before the 12-month follow-up, and the other declined to take part in the 12-month follow-up. Due to the retrospective design of Study II, there were some missing data. Data from the six-month follow-up was available for 17 patients in the HFR group (94%), 24 patients in the LFR group (89%), and 9 patients (69%) in the NFR group. In Study III, because of missing answers, 3 questionnaires were excluded from analyses of test-retest reliability. In Study IV, all invited patients consented to participate, and all interviews were used in the analyses. In Study V, 11 COPM forms on performance outcomes and 12 forms on satisfaction outcomes were missing due to missing follow-ups.
METHODOLOGICAL QUALITY, REGISTRATION, AND PROTOCOL

Study I was an observational study including a consecutive case series of patients with disabling spasticity who received tendon lengthening and/or muscle releases accompanied by the EAR concept. The assessments were made the day before surgery and 12 months after surgery. The main outcome measure was the MAS.

Study II was a descriptive feasibility study of a treatment algorithm for spasticity-correcting surgery in patients with disabling UL spasticity of cerebral and spinal origin. The study had a retrospective observational design. Data were extracted from medical records of patients who underwent spasticity-correcting surgery, primarily tendon lengthening. Depending on residual UL function prior to surgery, patients obtained treatment according to HFR, LFR, or NFR. The analyses were based on measurements and data acquisition applied as part of routine care. Assessments were made before and six months after surgery, involving measures of body function and activities. The primary outcome measure depended on treatment regimen, but common to all groups was the measurement of spasticity with MAS. The primary outcome measures for each of the three regimens were GRT for HFR, ArmA-S section B for LFR, and ArmA-S section A for NFR.

Study III was a methodological study describing the translation and adaptation of the original version of the Arm Activity Measure (ArmA) into Swedish (ArmA-S). Further, the study evaluated the reliability, validity, and responsiveness of ArmA-S in a sample of Swedish-speaking patients with problematic UL spasticity due to CNS injuries.
Study IV was a qualitative study exploring the experiences of patients who had undergone UL spasticity-correcting surgery with respect to their everyday life.

Study V was a retrospective mapping study that reviewed individualized occupational performance problems and perceived performance and satisfaction, among patients with disabling spasticity who underwent spasticity-correcting surgery.

Studies I and II, the observational studies, as well as Study V, were conducted and reported following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statements\textsuperscript{189}. The translation of ArmA (Study III) followed the Beaton guidelines for the translation of self-report health questionnaires\textsuperscript{190}, and the psychometric analyses followed the Consensus-based Standards for Health Status Measurement Instruments (COSMIN)\textsuperscript{191}. The interviews were semi-structured and influenced by the recommendations from Kvale\textsuperscript{192} for a phenomenographic analytic approach\textsuperscript{193} and were reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ)\textsuperscript{194}.

**CONTEXT OF THE STUDY**

CARE, Sahlgrenska University Hospital, Sweden, is an internationally recognized specialized multidisciplinary unit. The CARE team is specialized in UL disorders resulting from neurological injuries, and the clinicians combine clinical work with research. At CARE, patients with UL spasticity due to different CNS injuries are treated. Patients with SCI are referred from all over Sweden, and a few patients are referred from abroad. Patients with disability resulting from other CNS injuries are mainly referred from within the region of Västra Götaland.
4.2 DATA COLLECTION

The non-hierarchical framework of the ICF can be applied when appropriate measurements need to be selected in the planning, goal setting, and evaluation of treatments. Since the different domains in ICF represent different aspects of functioning, assessments on each domain are recommended in order to fully understand the impact of disability.

OUTCOME MEASURES USED IN THE STUDIES

A variety of outcome measures were used in this thesis to enable the detection of improvements across a range of domains, such as function, satisfaction, and caregiver burden. Another reason for the rather broad assessment was to tailor the outcome assessment for each of the three regimens. All measures used to collect data in the studies are applied to the ICF constructs\(^1\).

An overview of the outcome measures used in this thesis, classified according to the ICF model, is given in Table 6. Table 7 presents a summarized description of the outcome measures used in this thesis. The knowledge of what could be considered minimal clinically important differences (MCIDs) for the outcome measurements is limited. There are good reasons for specifying the MCID for outcome measures before the start of a study\(^{195}\). To not rely exclusively on p-values when reporting and discussing treatment effects is critical since statistical significance may not be clinically meaningful, as well as the other way around\(^{196}\). In this thesis, an *a priori* approach was used for outcome measures without established MCIDs\(^{195,197}\). In the *a priori* approach used by Harvey et al., 10% of the range of the scale, or a 10% change in score from baseline was applied\(^{45,197}\). The author of this thesis arranged discussions with colleagues in the field to estimate how much the patients on average would improve with treatment to justify all costs, resources, and
efforts associated with it. The group discussions continued until a consensus was reached about what could be considered appropriate MCIDs. Study I started before these discussions were finished, whereas all analyses took place after the MCIDs were defined.

**OBSERVER-RATED MEASURES**

Observer-rated measures predominantly assess impairments or functional capacity, in this thesis fulfilled by the clinicians.

**SPASTICITY**

The MAS\textsuperscript{57} was used as a clinical measure of muscle tone during passive joint movement. The MAS is a modified version of the Ashworth Scale (AS). AS was developed to estimate the efficacy of antispastic drugs in persons with multiple sclerosis\textsuperscript{198}. The AS is a 5-point scale, with scores ranging from 0 to 4. To increase the sensitivity and facilitate scoring, Bohannon and Smith\textsuperscript{57} added the grade 1+ and proposed slight changes in the definitions, resulting in the 6-point MAS. For analysis purposes in the present thesis, the MAS scores of the treated muscles were summed to provide a “composite spasticity score”. The MAS has shown good inter- and intra-rater reliability for use in the UL over time\textsuperscript{199}. However, essential to point out is that the psychometric properties of the MAS have been questioned\textsuperscript{200,201}. The MCID of the MAS in UL assessments is reported to be 0.48 (effect size set at 0.5) and 0.76 (effect size set at 0.8) with respect to improvement from baseline scores in individuals suffering from stroke\textsuperscript{202}. With the 10% range of the scale approach, a 0.5 change in MAS scores would be considered an appropriate MCID\textsuperscript{45}. In this thesis work, a change of 1 was defined as the MCID.
RANGE OF MOTION (ROM)

ROM is a measurement of the distance and direction a joint can move. ICF identifies joint mobility as an essential component of health and so a potential component of impairment. Spasticity can cause reduced active and passive joint mobility. The extent of movement is generally measured in degrees, with a goniometer. Different types of goniometers exist, such as simple universal mechanical devices, gyroscope-based tools, electromechanical systems with sensors integrated into fabrics, and goniometer apps. Age, gender, injuries, and diseases can affect ROM. Inter-rater reliability has been shown to improve with practice. In this thesis, active and passive ROM in target joints were measured by experienced therapists with a hand-held goniometer in a sitting position following standard procedures. ROM measurement could be applied to any joint of the body independently of diagnosis. Generally accepted normative reference values are published by the American Academy of Orthopaedic Surgeons. Normative values and reference values stratified by age and gender have been published previously. In patients with Dupuytren’s contracture, the MCID of ROM measurement was found to be 13.5 degrees. The common error for both intra- and inter-rater testing is reported to be $5^\circ - 10^\circ$. The accuracy of using a manual goniometer has been shown to be within $8^\circ$. In the present thesis, the MCID was set to 15 degrees. Goniometric measurements of finger ROM are of questionable accuracy. In this thesis, the ability to accomplish a passive and active opening of the hand was rated using a 5-point grading system ranging from 0 to 4 ($0 = \text{closed hand}; 1 = \frac{1}{4} \text{ opened hand}; 2 = \frac{1}{2} \text{ opened hand}; 3 = \frac{3}{4} \text{ opened hand}; 4 = \text{a fully opened hand}$), as reported in a previous study on individuals with UL spasticity due to stroke. This measure is referred to as the hand-opening scale. This 5-point scale was also used to grade the resting position of the hand. The MCID for the
hand-opening scale has not yet been determined, but for the purpose of the present thesis, it is defined as a minimum change of 1 point.

MUSCLE STRENGTH

Grip strength is frequently used to measure overall muscle strength. In this thesis, maximum handgrip strength was measured with a hydraulic hand dynamometer (JAMAR® 5030J1, Sammons Preston Rolyan, USA)\textsuperscript{211}. Maximum pinch grip strength was measured with a Preston Pinch Gauge (European Bissel Healthcare Ltd, Winchester, England)\textsuperscript{211}. Both grip and pinch strength were measured in a standard position, with the maximum value of three attempts being used for analyses. Reference values are available\textsuperscript{212}, the reliability is well established\textsuperscript{213}, but the MCID is not fully established\textsuperscript{214}. A change of 19.5% is proposed to be an MCID\textsuperscript{215}. Since the intervention in this thesis work was not aimed at improving grip strength but rather hand opening, a decrease in grip strength of $\leq 20\%$ (due to tendon lengthening) was considered acceptable and not seen as a clinical deterioration.

GRASP AND GRIP

Grasp and release ability is frequently used to measure hand function. The Grasp and Release Test (GRT) is a measure that assesses the ability to grasp, move, and release six different objects of various textures, weights, and forms\textsuperscript{216}; the objects in the GRT are presented in Figure 13. In this thesis, we use GRT to measure the participants’ grasp and release capacity. The GRT is developed for assessing hand neuroprostheses in patients with cervical SCIs. Neuroprostheses are surgically implanted systems that apply controlled electrical stimulation to paralysed nerves and muscles. GRT is frequently used to evaluate reconstructive tetraplegic hand surgery\textsuperscript{217}. The test-retest reliability is shown to be good and therefore the possibility of detecting changes\textsuperscript{218}. To the best of my knowledge, the MCID value for GRT is yet unknown. We
estimated that a smaller treatment effect would be clinically beneficial in patients with poor UL function prior to surgery (LFR) compared with those with some retained active UL function (HFR). Hence, we expect the MCID in the HFR to be 12 repetitions and that in the LFR to be 6 repetitions.

HAND OPENING

The ability to actively and/or passively open the hand and grasp and release a cylindrical object was measured using a specially designed measure called the Cylinder Test. The Cylinder Test was developed by the author of this thesis together with her supervisors for individuals with UL spasticity due to CNS injuries. The Cylinder Test was developed to capture meaningful changes in patients’ palmar grasp capacity, not only active one-handed capacities but also bilateral grasp capacities, with a focus on the opening of the hand. Therefore, the test is separated into four subtests, which are processed in the following order: normal one-handed cylinder grip, adapted one-handed cylinder grip, two-handed cylinder grip, and adapted two-handed cylinder grip (Figure 14). The assessment battery comprises 15 plastic cylinders ranging in diameter from 10 mm to 150 mm and in weight from 15 g to 377 g (Figure 14).
ongoing study, the Cylinder Test is subjected to psychometric evaluations. In this thesis work, the MCID was set to 20 mm.

COGNITIVE FUNCTION

Cognition is not formally assessed in this thesis but is deemed relevant for the purpose of treatment. The cognitive abilities that are considered relevant for the intervention are the capacity to follow instructions for training and splint treatment and the ability to take responsibility for the home training. During the different assessment procedures, the clinicians pay attention to how the patients process and use information, possible spatial problems, and other cognitive impairments that can negatively impact the rehabilitation.
PATIENT-REPORTED OUTCOME MEASURES (PROMS)

PROMs are measures completed by the patients and are designed to measure the patients’ perception of their symptoms.

VISUAL ANALOG SCALE (VAS)

VAS is often used to measure subjective aspects on a 100 mm line. The ends are defined as the extreme limits of the parameter that is measured, oriented from left (worst) to right (best). In this thesis, self-rated pain intensity, UL spasticity, arm and hand function (usefulness), and appearance (cosmesis) were measured with a VAS. VAS has been used in various symptoms and diagnoses to measure the intensity or frequency of different experiences, particularly pain\textsuperscript{219}. Difficulties in interpreting and responding accurately to the VAS scale, as compared with other self-rated scales, have been shown in patients with cognitive and perceptual deficits\textsuperscript{220}. MCID values for self-rated pain vary between 4 and 40 mm or between 15\% and 50\% at a group level\textsuperscript{221}. When it comes to postoperative pain, the following cut-points have been recommended: no pain (0–4 mm), mild pain (5–44 mm), moderate pain (45–74 mm), and severe pain (75–100 mm)\textsuperscript{222}. A reduction of 18\% has been proposed to represent the MCID in self-measuring spasticity\textsuperscript{223}. In this thesis, we expect a change of 20 mm to be the MCID in all four VAS measurements.

THE ARM ACTIVITY MEASURE (ARMA)

The ArmA is a self-reported (by a patient or a caregiver) measure of the difficulties experienced in passive and active arm function\textsuperscript{224,225}. The English ArmA version (available for download) comprises an 8-item passive function subscale and a 13-item active function subscale. Each item is measured on a
PATIENT-REPORTED OUTCOME MEASURES (PROMS)

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CANADIAN OCCUPATIONAL PERFORMANCE MEASURE (COPM).

In COPM, patients are asked to identify occupational performance problems in daily life. The prioritized problems are rated on a 10-point scale, the performance ranging from 1 = not able to do it at all to 10 = able to do it extremely well and satisfaction ranging from not satisfied at all to extremely satisfied with regard to each of the prioritized problems. In this way, COPM enables patients to identify and prioritize problems in everyday life and provides a basis for goal setting. These goals can be used for treatment planning. In this thesis, COPM was used to describe prioritized occupational performance problems (POPPs), map these onto the ICF, and measure occupational performance goal achievements in those prioritized problems.
For analysis purposes, a mean COPM score was calculated for each individual (scores were added and divided by the number of activities, a maximum of 5 per person). COPM was developed to be used by occupational therapists to guide a client-centred approach, by measuring a client’s self-perception of performance in everyday life over time after an intervention, regardless of age or diagnosis. Today, it is adopted by other health professionals to guide client-centred individualized care. A 2-point change in score is considered a clinically important change with regard to both performance and satisfaction. The test-retest reliability of both COPM performance and COPM satisfaction is shown to be good in a population of patients with stroke.

DISABILITIES OF THE ARM, SHOULDER, AND HAND (DASH)

DASH is a questionnaire used to evaluate self-rated upper extremity disability symptoms for any person with upper extremity musculoskeletal disorders. The DASH consists of a 30-item disability/symptom scale, with a score ranging from 0 (no difficulty) to 5 (extreme difficulty). The DASH comprises two optimal, four-item modules focused on high-performance functions. In this thesis, the first 21 items of DASH were used to evaluate the construct validity of ArmA-S; this was the same strategy as in the initial evaluation of ArmA, in which a total score was calculated for the summated active function items (items 1 to 21). The MCID is 10.83–15.

INTERVIEWS

Interviews are commonly used to collect information from respondents. The primary goal of interviews is often to hear what respondents think is important and to hear it in their own words. If the researcher has a particular topic about which to collect information, semi-structured interviews are commonly used. In this thesis, semi-structured interviews were used to learn more about...
the different ways persons experience the treatment effects, with a focus on the effect on everyday life.

| Table 6. Measures used in the thesis classified according to the International Classification of Functioning, Disability and Health. |
|---|---|---|---|---|---|---|
| ICF Component | Outcome measure | Study |
| BF | A | P | EF | PF | I | II | III | IV | V |
| v | v | v | v | v | MAS |
| v | v | v | v | v | Goniometer A-ROM |
| v | v | v | v | v | Goniometer P-ROM |
| v | v | v | v | v | Hand opening scale |
| v | v | v | v | v | Jamar grip strength |
| v | v | v | v | v | Pinch gauge pinch strength |
| v | v | v | v | v | VAS spasticity |
| v | v | v | v | v | VAS pain intensity |
| v | v | v | v | v | Cylinder Test (subtest 1-4) |
| v | v | v | v | v | GRT |
| v | v | v | v | v | VAS appearance |
| v | v | v | v | v | VAS arm-hand function |
| v | v | v | v | v | COPM P/S |
| v | v | v | v | v | ArmA-S A passive |
| v (v) | v | v | v | v | ArmA-S B active |
| v | v | v | v | v | Qualitative interviews |

Abbreviations: BF = body function; A= activity; P = participation; EF = environmental factors; PF = personal factors; MAS = Modified Ashworth Scale; P-ROM = Passive Range of Motion; A-ROM = Active Range of Motion; VAS = Visual Analog scale; GRT = Grasp and Release Test; COPM = Canadian Occupational Performance Measure Performance; COPM S = Canadian Occupational Performance Measure Satisfaction; ArmA-S = Arm Activity measure Swedish version; ArmA A = passive subscale; ArmA B = active subscale; DASH = Disability of the Arm Shoulder and Hand.
### Table 7. Description of the outcome measures used in the thesis.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Subjective or objective</th>
<th>Developed for</th>
<th>Scale level</th>
<th>Range sum score</th>
<th>MCID applied in thesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>MAS</td>
<td>Subjective</td>
<td>Condition-specific (Velocity-dependent stretch reflex)</td>
<td>Ordinal</td>
<td>0-4 extra point allocated at 1+ 0-5</td>
<td>1</td>
</tr>
<tr>
<td>Goniometer</td>
<td>Objective</td>
<td>Generic, used to assess the ROM a joint can be moved active or passive. Any joints and any diagnosis</td>
<td>Interval</td>
<td>0-360 degrees</td>
<td>+15</td>
</tr>
<tr>
<td>Hand opening scale</td>
<td>Subjective</td>
<td>Condition-specific, spasticity treatment (BoNT) in the hand</td>
<td>Ordinal</td>
<td>0-5</td>
<td>1 step</td>
</tr>
<tr>
<td>Jamar</td>
<td>Objective</td>
<td>Generic isometric muscular strength of hand and forearm</td>
<td>Interval</td>
<td>0-90 kilograms</td>
<td>-20%</td>
</tr>
<tr>
<td>Pinch gauge</td>
<td>Objective</td>
<td>Generic isometric muscular strength of the pinch-grasp</td>
<td>Interval</td>
<td>0-28 kilograms</td>
<td>-20%</td>
</tr>
<tr>
<td>VAS spasticity</td>
<td>Subjective</td>
<td>VAS generic</td>
<td>Ordinal</td>
<td>0-10 (0-100mm)</td>
<td>20mm</td>
</tr>
<tr>
<td>VAS pain intensity</td>
<td>Subjective</td>
<td>Generic</td>
<td>Ordinal</td>
<td>0-10 (0-100mm)</td>
<td>20mm</td>
</tr>
<tr>
<td>Cylinder Test</td>
<td>Objective</td>
<td>Uni and bilateral hand function after CNS injuries</td>
<td>Interval</td>
<td>0-150mm</td>
<td>20mm</td>
</tr>
<tr>
<td>GRT</td>
<td>Objective</td>
<td>Unilateral hand function after tendon transfer and FES of individuals with tetraplegi</td>
<td>Interval</td>
<td>0- points, as many times as possible in 30sec/ object</td>
<td>HFR 12p, LFR 6p</td>
</tr>
<tr>
<td>VAS appearance</td>
<td>Subjective</td>
<td>Generic</td>
<td>Ordinal</td>
<td>0-10 (0-100mm)</td>
<td>20mm</td>
</tr>
<tr>
<td>COPM</td>
<td>Subjective</td>
<td>Generic, assesses an individual’s perceived occupational performance</td>
<td>Ordinal</td>
<td>1-10</td>
<td>+2</td>
</tr>
<tr>
<td>ArmA-S</td>
<td>Subjective</td>
<td>Condition-specific, UL spasticity</td>
<td>Ordinal</td>
<td>0-4</td>
<td>Section A 3; B 2</td>
</tr>
<tr>
<td>DASH</td>
<td>Subjective</td>
<td>Generic, any disorder of the UL</td>
<td>Ordinal</td>
<td>0-5</td>
<td>NA</td>
</tr>
</tbody>
</table>

Abbreviations: MAS= Modified Ashworth Scale; Min= minimal; Max= maximum; ROM= Range of Motion; BoNT= Botulinum toxin; VAS= Visual Analog Scale; mm= millimetre; GRT= Grasp and Release Test; FES= Functional electrical stimulation; HFR= High-functioning regimen; LFR= Low-functioning regimen; COPM= Canadian Occupational Performance Measure; ArmA-S= Arm Activity measure Swedish version; UL= upper limb; DASH= Disability of the Arm, Shoulder and Hand; NA= not applicable.
4.3 DATA ANALYSES

The statistical analyses in all papers were performed using the Statistical Package for Social Science (SPSS©), Version 27, SPCC Inc., Chicago, IL, USA. All the tests were two-tailed, and a significance level of 0.05 was applied. The correlation coefficients (Spearman’s rho) were interpreted according to an often-quoted rule of thumb for interpreting the size of a correlation: 0.90–1.00, very high; 0.70–0.90, high; 0.50–0.70, moderate; 0.30–0.50, low; and 0.00–0.30, little or none. A Cronbach’s alpha >0.80 was considered good, 0.80–0.70 was considered moderate, and <0.70 was considered low. Kappa ≥0.70 was considered to indicate good reproducibility. For analyses of normality, graphical methods and Shapiro-Wilk normality test were used.

The statistical tests used in this thesis are presented in Table 8. Descriptive statistics were used to describe the clinical characteristics and demographic data of the study population. They were presented with the mean, standard deviation, and range for continuous variables and as a percentage for categorical variables. Changes over time within groups were analysed in Studies I, II, and V by means of the post hoc Wilcoxon signed rank test and the paired t-test. To analyse differences between groups (Study V) with continuous variables, the Mann-Whitney U test was used. To analyse correlations between different outcome measures (Study V), Spearman’s rank correlation coefficient ($r_s$) was used.

In Study III, reliability was assessed by analysing the internal consistency reliability with Cronbach’s alpha, and test-retest reliability was assessed with the quadratic weighted kappa. Different aspects of validity were assessed. Construct validity was assessed by using Spearman’s rank correlation.
coefficient (rs) to test several predefined hypotheses concerning the relationship between ArmA-S and other baseline measurements. Face and content validity (the relevance and adequacy of items for the intended use) were assessed by letting a group of clinical experts in spasticity induced by CNS injury and patients with UL spasticity review the pre-final and final versions of ArmA-S. The acceptability of the questionnaire’s response rate was assessed by computing the percentage of missing responses to survey questions and the distribution of scores for ceiling and floor effects. Responsiveness, referred to as longitudinal validity, was assessed by calculating the change in outcome scores. Interpretability was judged from estimates of MCID. MCID was calculated in the same two ways as in the psychometric analyses of ArmA, using a distribution-based method and half-the-baseline standard deviation for sections A and B as an estimation of MCID.

In Study IV, a qualitative analysis was used. The data from the interviews were analysed according to the phenomenographic approach and inspired by Alexandersson’s four steps. In Step 1, to obtain an overall impression of the material, the verbatim-transcribed interviews were read several times systematically. In Step 2, the similarities and differences in the material were noted. According to the phenomenographic approach, saturation is achieved in the analytic process when no new interpretations are found in the material. In Step 3, similarities and differences were classified in order to generate an initial set of categories. These categories are called the outcome space in the phenomenographic approach. In Step 4, the categories were reflected upon to identify themes describing the participants’ experiences of how the treatment affected their daily life.
### Table 8. Statistical methods used in the studies

<table>
<thead>
<tr>
<th>Statistical method</th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
<th>Study V</th>
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Abbreviations: SD = Standard deviation; IQR = Inter Quartile Range.
4.4 ETHICAL CONSIDERATIONS

The Regional Ethics Review Board in Sweden approved all studies. Patients who met the inclusion criteria in the studies were informed orally and in writing and signed a consent form if they chose to participate. Hence, in Study I, the local ethics committee declared that this study was considered part of a clinical quality assurance, which did not require their ethical approval (letter 407-16; 23 June 2016). Studies II and V are retrospective studies; Study II was approved by the ethics review board (Dnr 2019-05162), but informed consent form was not needed. Studies III and IV were approved by the ethics review board (Dnr 535-18). In Study V, data is gathered from Studies I and II or from an ongoing study, all with ethical approvals (Dnr 999-18 for the ongoing study). The patient information contained information about the overall plan for the studies as well as the aim of each study. Also included was information that participation was voluntary and could be interrupted at any time without the patient having to state why and without affecting his/her continued treatment and rehabilitation. Further, the patients were informed about the person responsible for the research and that treatment did not depend on whether they chose to participate in the studies.

Personal data is processed in accordance with the General Data Protection Regulation (GDPR). The results are reported at the group level, so no persons can be identified in the completed studies. Patients are covered by customary patient insurance, and no compensation was paid for participation in the studies.

Approval decision letter 407-16 for Study I
Approval decision Dnr 2019-05162 for Study II
Approval decision Dnr 535-18 for Studies III–IV
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Personal data is processed in accordance with the General Data Protection Regulation (GDPR). The results are reported at the group level, so no persons can be identified in the completed studies. Patients are covered by customary patient insurance, and no compensation was paid for participation in the studies.

Approval decision Dnr 999-18, 407-16, and 2019-05162 and letter 407-16 for Study V, in which secondary analyses were performed from data collected from one of these studies.
5 RESULTS

5.1 SUMMARY OF CHANGES AFTER SURGERY AND REGIMEN-SPECIFIC REHABILITATION

Presented here is a synthesis of the results from Studies I, II, and IV. Parts of the results from Study V are presented in the synthesis, and some results are presented separately. The results from Study III are presented separately. Detailed results from the studies are presented in the respective papers. The characteristics of the participants in the five studies are presented in Table 5.

The improvements experienced in daily life by the participants in Study IV cover various ICF domains. The effects of the treatments presented in Studies I and II also span various ICF domains. Improvements in body functions, such as an increased range of motion and decreased muscle tone and pain, were shown in both the qualitative and quantitative findings. Improvements in activities, such as grasp ability, self-care, and occupational performance, were also frequently reported. In addition, the qualitative study (Study IV) showed that the benefits from the treatment go beyond what can be measured with quantitative outcome measures. Important experiences that the participants mentioned during the interviews were increased participation in leisure activities and community life, enhanced self-confidence, and a sense of bodily ease and bodily control. A synthesis of the positive effects that were found in Studies I, II, and IV is presented in Figure 15.
RESULTS

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Figure 15. Synthesis of the results from the studies on positive treatment effects presented according to the International Classification of Functioning, Disability, and Health. Abbreviations: SCI = spinal cord injury; TBI = traumatic brain injury; CNS = central nervous system.
5.2 CHANGES IN BODY FUNCTION AND STRUCTURE AFTER SURGERY AND REGIMEN-SPECIFIC REHABILITATION

The effects on body function and structure are measured with different outcome measures, as presented in Table 6. The effect on body function, including physical and psychological aspects, was highlighted by all the participants during the interviews (Study IV).

In both Study I and Study II, the primary outcome measure was spasticity measured with MAS. Individual MAS results are presented in Figure 16. Spasticity measured with MAS was significantly decreased, from a median (range) value of 3 (3–5) to 2 (1–4) (p < 0.01) at the one-year follow-up (Study I). Six months after the surgery, the spasticity had decreased independently of residual function (regimen). The mean change in the target muscle in the whole study population ranged from 3.2 (±0.9) to 1.1 (±1.1) (p < 0.001), in the HFR group from 3.4 (±0.8) to 1.2 (±1.2) (p < 0.001), in the LFR group from 2.9 (±1.0) to 1.0 (±1.1) (p < 0.001), and in the NFR group from 3.6 (±0.6) to 1.4 (±0.9) (p < 0.001) (Study II).

Perceived pain measured with VAS was significantly decreased at the one-year follow-up, from a median (range) value of 2.3(0–10) to 0 (0–7) (p < 0.05) (Study I). Six months after the surgery, the decrease in perceived pain intensity was significant in the LFR group, from a mean value of 1.8 (±2.8) to 0.4 (±0.9) (p = 0.011). During the interviews (Study IV), improvements in spasticity-induced pain were brought up. The increased muscle tone was experienced by many patients as painful and was ameliorated after surgery. In Figure 17, the changes in perceived pain, hand function, spasticity, and appearance, as measured with VAS, are presented.
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Figure 16A–B. Individual; (-) Study I; (-), Study II HFR;(-), LFR; (-); NFR;(-) and group (-- mean changes in mean composite MAS scores from baseline to follow-up presented for participants in A) Study I (n=30) (12-month follow-up) and B) Study II (HFR n=17; LFR n=20; NFR n=7) (6-month follow-up). Abbreviations: MAS=modified Ashworth scale; HFR= high-functioning regimen; LFR= low-functioning regimen; NFR= non-functioning regimen.
Figure 17A–C. Changes in mean VAS scores in Studies I and II from baseline to follow-up. Changes in A) perceived pain (Study I; n= 30; Study II HFR; n= 15, LFR; n= 23, NFR; 5) B) perceived hand function (Study I; n=30; Study II HFR; n=14, LFR; n= 20), and C) perceived appearance/ spasticity (Study II HFR; n=11 /4, LFR; n= 16 /5). Results from Study II are presented separately in the regimens. In Study I, the follow-up occurred 12 months after surgery. For the participants in Study II, the follow-up occurred 6 months after surgery. Abbreviations: VAS= visual analogue scale; HFR= high-functioning regimen; LFR= low-functioning regimen; NFR= non-functioning regimen.
At the 6-month follow-up of the participants in Study II, the mean grip strength measured with Jamar was significantly decreased, in the HFR group from 14.4 (±8.6) to 10.5 kg (±5.4) (p = 0.009) and in the LFR group from 7.1 (±4.0) to 5.0 kg (±3.2) (p = 0.045) (Study II). At the one-year follow-up of the participants in Study I, the median (range) grip strength measured with Jamar was improved from 4 (1–21) to 8.5 kg (2–25) (p < 0.01) (Study I).

Furthermore, patients described an increased endurance, positive mood changes, and a better control of their own body (Study V). Figure 18 shows the opening ability of the hand before and after the surgery for patients allocated to HFR and LFR. Figure 19 shows the resting position before and after the surgery for patients allocated to LFR and NFR. For a more detailed summary, see Papers I and II.

![Before surgery](image1.png) ![After surgery](image2.png)

Figure 18A–B. Opening ability of the hand before and after surgery: A) patient allocated to high-functioning regimen, and B) patient allocated to low-functioning regimen.
5.3 CHANGES IN ACTIVITY AFTER SURGERY AND REGIMENT-SPECIFIC REHABILITATION

The interventional effects on activity level are measured with the different outcome measures presented in Table 6. In Study IV, all participants experienced positive changes in their activity level, such as a regained capacity to hold a glass or a smoother or easier performance of certain tasks. The ability to grasp, move, and release different objects was measured with GRT. The median (range) GRT score was significantly increased at the one-year follow-up (Study I), from 34 (2–149) to 71 (20–193) repetitions (p < 0.01). When analysing the results in the different regimen groups in Study II at the 6-month follow-up, we found that the GRT mean score was significantly increased in the two active groups: the HFR group had an increase from 101 (±39) to 121 (±49) repetitions (p < 0.001), and the LFR group had an increase from 25 (±24) to 34 (±29) repetitions (p = 0.014). GRT was not applicable in the NFR group due to a lack of active UL functions. In Figure 20, the GRT results are presented. For a more detailed description of the results, see Manuscripts I and II.

Perceived hand function measured with VAS was significantly increased one year after surgery. In Study I, the median (range) VAS score increased from 2 (0–8) to 4.5 (0.5–8) (p < 0.01). At the 6-month follow-up, perceived hand function was significantly increased in the HFR and LFR groups, with the mean VAS score increasing from 3 (±1.6) to 5 (±1.7) (p = 0.002) and from 2 (±1.6) to 4 (±1.9) (p = 0.000), respectively. Perceived hand function measured with VAS was not applicable in NFR due to a lack of active UL functions.
5.3 CHANGES IN ACTIVITY AFTER SURGERY AND REGIMEN-SPECIFIC REHABILITATION

The interventional effects on activity level are measured with the different outcome measures presented in Table 6. In Study IV, all participants experienced positive changes in their activity level, such as a regained capacity to hold a glass or a smoother or easier performance of certain tasks.

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The limitation in active and passive real-life arm function as measured with the self-report questionnaire ArmA-S showed a significant decrease in the consequences of the spasticity 6 months after surgery. The passive aspects (ArmA-S A) decreased in median score from 12 to 9, from 10 to 3, and from 17 to 5 in HFR, LFR, and NFR, respectively. The active aspects (ArmA-S B) decreased in HFR and LFR from 35 to 26 and from 45 to 38, respectively. ArmA-S section B was not applicable in NFR (Study II). Figure 21 presents the ArmA-S results in Study II.
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Figure 20. Mean changes in grasp ability measured with the Grasp and Release Test (GRT) from baseline to follow-up in Studies I (n= 9) and II (high regimen n= 16- and low-functioning regimen groups n= 20). In Study I, the follow-up occurred 12 months after surgery. For the participants in Study II, the follow-up occurred 6 months after surgery. Abbreviations: HFR= high-functioning regimen; LFR= low-functioning regimen.

Figure 21A–B. Median changes in ArmA-S from baseline to the 6-month follow-up presented for participants in Study II: A) ArmA-S section A (whole population; n= 41, HFR; n= 13, LFR; n= 21, NFR; n= 7), and ArmA-S section B (whole population; n= 33, HFR; n= 12, LFR; n= 21) Abbreviations: ArmA-S= Arm Activity measure Swedish version; HFR= high-functioning regimen; LFR= low-functioning regimen; NFR= non-functioning regimen; * indicates significantly difference below 0.005; ** indicates significantly difference below 0.001; error bars indicate standard error means.
5.4 CHANGES IN PARTICIPATION AFTER SURGERY AND REGIMEN-SPECIFIC REHABILITATION

The results from Study IV showed that the participants experienced increased participation. They mentioned that the gains in physical abilities and enhanced mood (e.g., happier, less frustrated) enabled increased participation in social activities. They mentioned that the attitude and behaviours of the surroundings had changed after improvements in the UL appearance and that this made them more comfortable participating in social interactions.

In Studies I, II, and V, individual prioritized occupational problems were identified and measured with COPM. See Figure 22 for details. All studies demonstrated significant COPM improvements that reached or exceeded the predefined MCIDs. In Study I, the median (range) COPM performance and satisfaction scores increased from 1.7 (1–3.8) to 5.5 (2–9.4) (p < 0.01) and from 2 (1–3.8) to 6 (1.8–10) (p < 0.01), respectively. In Study II, the corresponding mean COPM performance scores for the HFR and LFR groups increased from 2.9 (±1.2) to 5.1 (±2.1) (p = 0.001) and from 2.1 (±1.0) to 4.4 (±1.7) (p = 0.000), respectively. The corresponding COPM satisfaction scores improved from 2.5 (±1.4) to 4.8 (±2.2) (p = 0.001) and from 1.7 (±0.8) to 4.5 (±1.6) (p < 0.000) for the HFR and LFR groups, respectively. In Study V, when the outcomes were analysed for the respective diagnosis groups, the corresponding numbers were a mean increase of 2.4 and 2.5 in COPM performance scores and 2.4 and 3.0 in COPM satisfaction scores in the SCI and stroke groups, respectively. There was no significant difference between stratified groups (diagnosis, sex, regimen) with respect to mean changes in performance or satisfaction scores. In Study V, three out of 60 individuals had a negative or no change in COPM performance score. Six out of 59 individuals
had a negative or no change in COPM satisfaction score. There was no significant correlation between treatment-induced changes in COPM scores and grasp or grip strength improvements.
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

Figure 22A–C. Mean changes in COPM P and S from baseline to follow-up in A) Study I (n= 13), B) Study II (whole population; n= 37, HFR; n= 17, LFR; n= 20), and C) Study V (n= 60/59). In Studies I and V, the follow-up occurred 12 months after surgery. For the participants in Study II, the follow-up occurred 6 months after surgery. Abbreviations: COPM-P= Canadian Occupational Performance Measure performance; COPM-S= Canadian Occupational Performance Measure satisfaction; HFR= high-functioning regimen; LFR= low-functioning regimen; * indicates significantly difference below 0.005; ** indicates significantly difference below 0.001; error bars indicate standard error means.
5.5 PRIORITIZED OCCUPATIONAL PERFORMANCE PROBLEMS CLASSIFIED ACCORDING TO THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF)

The prioritized occupational performance problems (POPPs) identified preoperatively with COPM were transformed into prioritized occupational performance goals (POPGs) in the subsequent rehabilitation. Figure 24 shows pictures on POPG before and after the surgery. The COPM is used as an outcome measure in Studies I and II. In Study V, POPPs reported by patients were identified and thoroughly analysed. In Study V, 71 COPM forms were included in the analyses. The 71 COPM forms generated 320 POPPs, which were transformed into POPGs and mapped onto ICF. On average, the patients had listed 4.5 goals each. Common goals that were identified by patients in the different studies were writing on paper, using a computer or phone, carrying objects, improving the position of the UL when walking, propelling a wheelchair, opening doors, grasping glasses, handling cutlery, dressing, UL hygiene, washing up the dishes, preparing meals, playing guitar, and handling different objects in the gym. Most of the goals were mapped onto the self-care domain (46%, 38%, and 41% in Studies I, II, and V, respectively). For details, see Figure 23. When the goals were stratified based on diagnosis, gender, and treatment regimen in Study V, self-care remained the most common goal. Hence, the goals were spread over different ICF domains, such as communication, mobility, self-care, domestic life, community, social and civic life, and major life areas; for details, see Manuscript V. In the preoperative assessment, 134 of the 320 goals were rated as impossible to perform (score 1); 44.8% of these were mapped onto self-care. Out of the 134 goals, 89 were rated as possible to perform at follow-up, and 45 had a score of 5 or higher.
ICF chapter whole group

- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationship
- Major life areas
- Community, social and civic life

Figure 23. The occupational performance goals in study I and II (n= 281) reported by patients by means of COPM, divided into the ICF domains. Abbreviations: ICF= International Classification of Functioning, Disability, and Health; COPM= Canadian Occupational Performance Measure.
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

Figure 24A–C. Prioritized occupational performance problems before and after surgery: A) patient allocated to high-functioning regimen, B) patient allocated to low-functioning regimen, and C) patient allocated to non-functioning regimen.
5.6 PATIENT DEMOGRAPHY

The number of patients included in the different studies range from eight to 71. The clinical characteristics of the patients are presented in table 5.

TREATED MUSCLES

In total, 131 muscles were targeted for surgical procedures in Study I, and 273 in Study II. The eight participants included in the qualitative study (Study IV) had spasticity-correcting procedures performed on a total of 35 muscles. The anatomic distribution of muscles subjected to surgery is presented in Table 9. The study populations in Studies III and V are included in other studies and therefore not presented separately.
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Table 9. The anatomic distribution of the target muscles

<table>
<thead>
<tr>
<th>Muscle</th>
<th>Study I (n=30)</th>
<th>Study II (n=58)</th>
<th>Study IV (n=8)</th>
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<td>35</td>
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<tr>
<td>Pectoralis</td>
<td>1(3)</td>
<td>5(9)</td>
<td>3(37)</td>
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<td><strong>Elbow</strong></td>
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<tr>
<td>Triceps</td>
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<td>2(3)</td>
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<tr>
<td>Biceps</td>
<td>8(27)</td>
<td>10(17)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Brachioradialis</td>
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<td>0(0)</td>
</tr>
<tr>
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<tr>
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<td>5(62)</td>
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<tr>
<td><strong>Wrist</strong></td>
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<tr>
<td>Flexor carpi ulnaris</td>
<td>11(37)</td>
<td>19(33)</td>
<td>3(37)</td>
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<td>Flexor carpi radialis</td>
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<td>Palmaris longus</td>
<td>14(47)</td>
<td>29(50)</td>
<td>1(12)</td>
</tr>
<tr>
<td><strong>Fingers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexor digitorum superficialis</td>
<td>18(60)</td>
<td>44(76)</td>
<td>7(87)</td>
</tr>
<tr>
<td>Flexor digitorium profundus</td>
<td>18(60)</td>
<td>33(57)</td>
<td>6(75)</td>
</tr>
<tr>
<td>Extensor digitorum</td>
<td>1(3)</td>
<td>5(9)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Intrinsic</td>
<td>5(17)</td>
<td>19(33)</td>
<td>2(25)</td>
</tr>
<tr>
<td><strong>Thumb</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexor pollicis longus</td>
<td>11(37)</td>
<td>26(45)</td>
<td>2(25)</td>
</tr>
<tr>
<td>Flexor pollicis brevis</td>
<td>1(3)</td>
<td>9(15)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Adductor pollicis</td>
<td>2(7)</td>
<td>5(9)</td>
<td>1(12)</td>
</tr>
<tr>
<td>Abductor pollicis</td>
<td>1(3)</td>
<td>1(2)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Extensor Pollicis Brevis</td>
<td>0(0)</td>
<td>0(0)</td>
<td>1(12)</td>
</tr>
</tbody>
</table>

Presented as total number and percentage of the individual that target the special muscle for surgery.
ASSIGNED REGIMEN AND DIAGNOSIS

In Study I, 15 patients were assigned to the HFR group, three to the LFR group, and 12 to the NFR group. The corresponding numbers in Study II were 18, 27, and 13, respectively. Figure 25 describes how the patients were divided into regimens and diagnosis groups.

![Figure 25. Patients included in the two observational studies (Studies I and II) divided into regimens and diagnosis groups. Abbreviations: HFR= high-functioning regimen; LFR= low-functioning regimen; NFR= non-functioning regimen; SCI= spinal cord injury; TBI= traumatic brain injury.]

COMPLICATIONS AND FEASIBILITY OF THE REGIMEN

In the observational studies (Studies I and II), the feasibility was assessed as well as complications. The number of complications was 7 (8%). Out of 88 patients, 80 (91%) completed the assigned treatment regimen. Since some patients changed regimens once included in the study, the completion rate of the assigned treatment regimens was 87% and 93% in Studies I and II, respectively. In Study I, the reasons for a change of regimen were more volitional motor control than expected after surgery, which resulted in two patients switching to a more intense regimen; two patients switched to a less intense regimen due to cognitive impairment that affected the possibility of...
adhering to treatment. In Study II, four patients switched to a less intense regimen after treatment was initiated, two patients switched because of less volitional motor control than expected after surgery, and two patients switched because of cognitive impairment that affected treatment adherence. In Study I, 90% of the patients (n = 27) complied with the assigned treatment regimen. In Study II, 88% of the patients (n = 51) complied with the treatment. Patients who did not adhere to the treatment used the orthoses less frequently than ordered or did not perform the exercises according to the instructions given. Two patients (6.7%) reported complications in Study I: one patient reported bleeding (NFR group), and one patient had postoperative pain that negatively affected the postoperative rehabilitation (LFR). The number of complications in Study II was five (8.6%): none in the HFR group, three superficial wound infections in the LFR group, and one major oedema and one bleeding complication in the NFR group.
5.7 TRANSLATION OF THE ARM ACTIVITY MEASURE (ARMA) AND PSYCHOMETRIC TESTING OF THE SWEDISH VERSION (ARMA-S): STUDY III

TRANSLATION AND CULTURAL ADAPTION OF ARMA

In Study III, a back-translation procedure was used. The translation of the guide and the questionnaire items in ArmA was first done. Item 10 in section B, handle a home telephone, was replaced by handle your phone, because nowadays home telephones are infrequently used in Sweden. In the demographic part of ArmA-S, some adjustments were made: SCI was added as a neurological condition, detailed information about the caregiver was provided, and ArmA-S was extended to include information about hours and type of assistance (caregiver or professional). Information about the age and gender of the caregiver was removed in ArmA-S. The term affected arm in the ArmA-S was rephrased as the arm that will be or is treated. This rephrasing was done to facilitate the completion of the questionnaire by patients with bilateral UL motor impairment. The most substantial change in ArmA-S was done to decrease the risk of faulty/misleading responses when a certain activity was never done by patients. Misunderstanding could have led to false-negative results if the patient thought that the activity was never done before surgery (which according to the original manual would be graded with score 0, no difficulty), even though the hindering factor was the severely impaired UL, and the score achieved after surgery is 1 (no difficulty) to 4 (maximum difficulty). Thus, while the patient improved after treatment, the scoring implies the contrary. To help patients select more appropriate answers, the response
alternative "never done" (score 0) was included, resulting in a six-point Likert scoring system. See Figure 26 for the change/development of the scale.

Figure 26. Likert scale modifications of ArmA-S. Abbreviation: ArmA= Arm Activity measure; ArmA-S= Arm Activity measure Swedish version.
PSYCHOMETRIC ANALYSES OF ARMA-S

Patients with UL spasticity and clinicians working with the patient group evaluated the content and face validity of the final version of ArmA-S. Based on the results, the final version was considered to be understandable, clear, and easy to complete. All patients said that the questions were moderately to very relevant, and all but one patient found the final version easy or moderately easy to complete. All clinicians reported that the questionnaire would be suitable in clinical settings for both patients with hemiplegia and patients with bilateral spasticity problems. See Figure 27 for detailed responses. Internal consistency was high and consistent with ArmA (Cronbach’s alpha coefficients: ArmA-S section A = 0.94 and ArmA-S section B = 0.93). Test-retest reliability was good (Kappa values: ArmA-S section A = 0.86 and ArmA-S section B = 0.83) when analysed in a subgroup of 48 participants. Two subanalyses of test-retest reliability were made, in which the scores were transformed and analysed as follows. If the presurgical score was 0 (never done) and the postsurgical score was 0 (no problem) or between 1 and 4 (various degrees of difficulty), the presurgical score was considered an error and was changed into score 4 (unable to do). This transformation required that the functional status before surgery clearly indicates that the patient was unable to do the specific activity. In total, 40% of the patients made this error and were included in the subanalysis. The results from this analysis considerably lowered the confidence interval (CI), resulting in a quadratic weighted kappa coefficient of 0.91 (95% CI: 0.85–0.97) for section A and 0.96 (95% CI: 0.93–0.99) for section B. In the second subanalysis, the participants were divided based on diagnosis into two subcohorts (SCI n = 18 and stroke n = 20). For section A, these additional analyses resulted in a quadratic weighted Cohen’s kappa coefficient of 0.92 (95% CI: 0.85–0.99) in the SCI group and 0.79 (95% CI: 0.62–0.97) in the stroke group. For section B, the quadratic weighted Cohen’s kappa coefficient
in the SCI and stroke groups was 0.79 (95% CI: 0.51–1.07) and 0.82 (95% CI: 0.67–1.0), respectively.

Figure 27. The results of questions assessing the content validity of the final version of ArmA-S as reported by patients (SCI n=10; stroke n=10) and clinicians (n=8). Abbreviation: ArmA-S= Arm Activity measure Swedish version; SCI= spinal cord injury; ArmA A=section A passive subscale; ArmA B= section B active subscale.
6 DISCUSSION

6.1 SUMMARY

This thesis describes the outcome of spasticity-correcting surgery and comprehensive rehabilitation. As expected, the outcomes vary, mainly depending on residual muscle control. The most prominent improvements were gains in bodily function: decreased spasticity as measured with MAS and increased P-ROM. These gains were achieved independently of the degree of residual muscle control and regimen. How these improvements in bodily function were transformed into activity gains was most likely dependent on various factors, such as the degree of residual muscle control, whether the injury caused uni- or bilateral spasticity, cognitive impairment, and previous habits and roles.

The results of the studies demonstrate that individuals with remaining muscle control increase their capacity to use their affected arm in unilateral as well as bilateral activities. For individuals with little residual muscle control, the treatment serves as a means to increase the capacity to use the affected hand/arm as a supportive limb in bilateral activities. In case of unilateral spasticity problems, the affected arm most likely remains the less dominant but supportive arm. For individuals with no or minimal residual muscle control, gains in passive activities, such as caring for the affected limb (cleaning the palm, elbow, or armpit) or dressing, facilitate daily life. Gains in passive activities are achieved for patients independently of the remaining muscle function, although not all patients have problems with hygiene and other passive activity aspects prior to surgery. To be able to transform the gains from surgery into occupational performance gains, rehabilitation is of the foremost importance. The detailed description of treatment regimens presented in the
thesis can be helpful for this by transforming POPPs into treatment goals. The importance of rehabilitation after an intervention is often highlighted, as is the importance of having realistic aims with a treatment. The feasibility of the current treatment algorithm was shown to be good, which emphasizes the clinical utility of the treatment concept. Individuals with unrealistic goals will most likely be disappointed with the treatment outcome. It is critical to make a thorough assessment prior to treatment in order to understand the problems experienced by the individual as well as to plan the treatment and to estimate potential gains of surgery. The present thesis demonstrates what occupational problems patients experience, which supports the use of PROMs and qualitative research methodology. An interesting finding from this thesis is the calmness and bodily control experienced by some patients and the positive effect this had on them. This can be difficult to measure with standardized outcome measures, which further points to the value of interview studies. Patients with no measurable treatment gains but who still expressed satisfaction with the results could have experienced less bodily hassle after surgery. There were also patients who improved according to the outcome measures used but who were not satisfied with the outcome. These patients might have had expectations beyond what was achievable. The presurgical assessment is important for the planning of appropriate treatment. Muscles targeted for surgery must be selected, as well as existing spasticity in the antagonist muscles since this could cause new imbalance problems after surgery. Communication between the treating team and patients is of the foremost importance. Patient participation is advocated today and is further supported by the outcome measures and results presented in this thesis. By focusing on the patients’ individual needs, treatment could be appropriately tailored by using PROMs and facilitating goals prioritized by the individual.
The results of this thesis support the use of the current surgical concept not only for individuals with severe spasticity problems. Nevertheless, surgery may not be suitable for all patients with UL spasticity. A multidisciplinary team should conduct follow-up appointments to evaluate the long-term results. To prevent recurrence after surgery, some patients may need lifelong stretching and splint treatment, especially patients who are not able to use the hand, typically in the non-functional regimen. This thesis may be used as a guide to aid in the evaluation of the suitability of patients for spasticity-correcting surgery and the subsequent rehabilitation content.
6.2 TREATMENT REGIMENS

Patients were allocated to three different treatment regimens. The results presented in this thesis support the feasibility of the current treatment algorithm. The selected regimen is not dependent on diagnosis but on the degree of residual motor function. In rehabilitation and medical care, regimens and groups are often built on diagnosis. In a recent synthesis of the clinical guidelines and reviews for the management of focal spasticity, 19 of the 25 papers included focused on a specific diagnosis, and only 6 targeted focal spasticity of any origin\textsuperscript{184}. This tradition can be rational in many situations, but in some cases it might be better to focus on the needs, functions, and aims independently of the diagnosis or treated muscle groups. If we had followed the common way and treated patients depending on diagnosis, some of the patients would most likely have received a more intensive regimen and some would have had a less intensive regimen. Whether and how this would have affected the result of these studies cannot be answered.

Previous reports of surgical management have divided patients into two groups: patients with functional and nonfunctional extremities\textsuperscript{82,166}. Other studies have divided patients into three groups depending on the aim and function: aesthetic, hygienic, and analgesic groups\textsuperscript{134}. Our empirical knowledge is that in the group of patients with volitional motor function, there is a vast variety of gains that we judge could be achieved by surgery. The importance of having realistic treatment aims is highlighted by many authors\textsuperscript{15,19,20,23,24}. We therefore believe that it is preferable to divide this group into two. In our opinion, this approach helps the clinicians to plan an appropriate treatment and helps the patients to formulate realistic aims. The results from Study II confirm that a treatment algorithm for spasticity-
correcting surgery that considers the degree of functional impairment is feasible for patients with disabling spasticity resulting from CNS injuries. All patients—high-, low-, and non-functioning—achieved significant gains in the predefined primary and secondary outcomes. These findings agree with Francis et al.’s statement124: “to enable patients to take advantage of lessened spasticity, they should be given access to standardized regimens of rehabilitation soon after the start of treatment”. The heterogeneity in the patient group makes the anticipation of a treatment outcome a challenge, which further underscores the need to divide the group into subgroups. By doing that, the clinicians can easier estimate the perceived gains and plan a suitable treatment level. It can also be helpful in discussing expectations and can therefore provide patients with realistic expectations of the treatment. Another gain is that the intensity of the treatment can better match the perceived outcome. Chung234 has investigated the implications of stratifying patients to better recognize possible outcomes and to plan treatment and length of stay in the hospital. The way we stratified patients into different regimens with the help of predefined inclusion criteria was shown to be successful, with 87% and 93% of the patients in Studies I and II completing the appointed regimen, respectively. The qualification to assign patients to a certain regimen preoperatively requires clinical experience, but this could be simplified by the use of distinct inclusion criteria. Since 2015, when Study I was initiated, the clinicians involved in this work have gained a broader experience and clinical skills to determine appropriate regimens for patients. This may have resulted in the higher percentage of patients allocated to the “right” regimen preoperatively in Study II (93%). Nonetheless, the corresponding percentage in Study I (87%) speaks in favour of allocating patients in regimens with the help of the current algorithm.
6.3 TREATMENT OUTCOMES ON BODY FUNCTION AND STRUCTURE

The results from Studies I and II indicate long-lasting effects after surgery. This contrasts with today’s gold standard treatment with BoNT injections, which is a method known to have a limited lasting effect\textsuperscript{132}, so the comparison is difficult.

CHANGES IN SPASTICITY

In all studies presented in this thesis, the degree of spasticity in the treated muscle measured with MAS was significantly reduced. The mean reduction was \(-1.4\) after 12 months and \(-2.0\) after six months in Studies I and II, respectively. When a separate analysis was performed for each regimen in Study II, the reduction was \(-2.2\) in the HFR group, \(-1.9\) in the LFR group, and \(-2.1\) in the NFR group. The absence of equivalent studies hinders comparisons with previous findings. When the results were compared with BoNT injection in the UL after stroke or TBI, the results at the 12-month follow-up were similar to the results achieved four weeks after injection (decreases of 1.2 or 1.4, depending on dose)\textsuperscript{235}. However, 12 weeks after injection, the improvements in MAS scores had diminished to 0.6 and 0.7, respectively\textsuperscript{235}. Comparing the results achieved six months post-surgery with the results achieved four weeks post-BoNT injection speaks in favour of surgery. Patients with SCI who received BoNT injection had similar results: a reduction in the mean MAS score of 1.3 one month after injection\textsuperscript{236}. The long-lasting effect of spasticity-correcting surgery enables relearning of movement patterns and facilitates changes in habits and behaviour in daily life. In Study IV, the participants described that they experienced less hassle, that the treated arm bothered them less, and that they felt calmer. As presented in a previous study\textsuperscript{237}, individuals with spasticity use different expressions to describe what clinicians call
spasticity. Spasticity has been associated with a higher negative impact in everyday life and lower satisfaction with physical health in a population suffering from SCI\textsuperscript{238}, which emphasizes the importance of improving spasticity treatments. The experience of less hassle reported by patients may be interpreted as reduced spasticity.

**CHANGES IN PAIN**

Our findings showed a significant reduction in pain intensity in Studies I and II (LFR group). Moreover, patients in HFR and NFR reported less intense pain at six months, as compared with baseline in Study II. In Study IV, less pain was mentioned by the participants. Pain relief has been reported in patients with post-stroke spasticity treated with BoNT-A\textsuperscript{239}, in patients with SCI\textsuperscript{236}, and in mixed populations\textsuperscript{90,240}. Pain improvements have been reported after different surgical treatments\textsuperscript{187,241}. The coexistence of pain and spasticity has previously been reported\textsuperscript{240,242}. These secondary symptoms have been reported to be the top concerns of people with SCI\textsuperscript{238}. Important to bear in mind is that pain may be multifactorial and that the mechanisms behind the pain in the studies included in this thesis are not defined, so the results of surgery cannot be predicted. Nevertheless, interventions to treat spasticity may have beneficial side effects with respect to pain.

**CHANGES IN RANGE OF MOTION**

Improvement in ROM was mentioned by many of the participants in the qualitative study (Study IV). ROM improvements were also demonstrated in Studies I and II. ROM improvements are well established after BoNT injection treatment\textsuperscript{90} as well as other surgical procedures\textsuperscript{187}. The improvements in ROM were expected results in the present thesis work. How long the improvement after this surgical treatment lasts and whether there are any cut-off values at
which the improvements in ROM lead to improvements in activity are unanswered questions. A previous study reported that patients associated stiffness with spasticity and perceived that stiffness had a greater negative impact on daily activities than clonus\textsuperscript{67}. The improvement in ROM is therefore believed to be of high importance for patients, to be able to transform the improvements into daily activities. Rehabilitation protocols that target this area are of the utmost importance. The ROM required to perform common daily activities has been reported\textsuperscript{243} and can help clinicians to understand how ROM and activity performance are linked.

**CHANGES IN STRENGTH**

After spasticity-correcting surgery, the treated muscles become weakened. Weakening of muscles was reported as a negative impact during the interviews and was shown in Study II. The follow-up time was six months. By then, the mean grip strength across groups had not yet reached the preoperative level, most likely due to the new length-tension properties of the muscles. Study I showed that the patients not only reached the preoperative level of grip strength but also were significantly stronger at twelve months, as compared with baseline. Whether this is also the case in the population in Study II we do not know because the follow-up took place 6 months after surgery. Based on the results from Studies I and II, we can assume that the grip strength reaches the preoperative level between 6 and 12 months postoperatively. How the grip strength and the eventual increase in muscle tone measured with MAS are correlated was not analysed in these studies and thus remains a question to be answered. When planning for surgical treatment, one must take into account the preservation of strength and the correction of eventual resulting imbalances to optimize treatment outcome.
6.4 TREATMENT OUTCOMES ON ACTIVITY

The results from the studies included in this thesis show that the treatment had positive effects on grasp abilities, perceived arm-hand function, and the ability to perform activities. These results contrast with the compiled research on BoNT, confirming the lack of effects of BoNT treatment on arm-hand capacity\textsuperscript{131}. A possible explanation for the sustained arm-hand capacity in this thesis compared with the BoNT results\textsuperscript{131} could be that the surgical procedures did not totally disrupt existing volitional motor function but rather weakened the muscles instead of paralysing them. Moreover, the active rehabilitation and long-lasting treatment effect might improve activity relearning after surgery. Nevertheless, a recent study showed a reduction of -3.2 in ArmA section B for patients treated with BoNT that had active function goals\textsuperscript{90}.

CHANGES IN ACTIVE UPPER LIMB ACTIVITIES

During the interviews, many individuals reported conceptions of how the activity performance had improved. Previous reports regarding surgical outcomes discuss the difficulty of preoperatively foreseeing functional activity-related outcomes compared with hygiene aspects; the latter have been argued to be easier to anticipate\textsuperscript{18,131}. The results of this thesis are considered promising regarding the functional active use of the arm in daily activities. However, included in the study cohort were quite a few patients for whom we did not expect increased activity performance, especially in unilateral tasks. The use of the affected arm as a support arm in bilateral activities is often the main goal for these patients. In order to reach that goal, the hassle to use the arm has to be minimal. Even though patients can make some use of the arm as a support arm in a rehabilitation context, the effort and the time it takes make it unfeasible in daily life. In such cases, it may be better to concentrate on preventing recurrence by focusing on resting positions where the arm is

\textsuperscript{131}BoNT: Botulinum toxin type A

\textsuperscript{18}HFR: High Functioning Regimen

\textsuperscript{131}LFR: Low Functioning Regimen

\textsuperscript{90}ArmA: Assessment of Motor Impairment
stretched in a suitable position or on some specific daily activities where the arm is used to preserve ROM.

The inclusion and exclusion criteria for regimen allocation presented in this thesis can serve as an aid in the prediction of results. The patients fulfilling the criteria of the HFR are expected to achieve functional gains by surgery, and the rehabilitation should strive towards achieving this. The patients to be allocated to LFR have more varying goals. For some patients, functional gains may be expected in bilateral activities with a support hand, whereas for others no such gains are expected. The main gain of this treatment regimen lies within the body function domain. Any improvement in body function, however, can lead to increased daily activity performance and participation. For these individuals, the improvement in the use of the affected arm in daily activities is expected to be small, and it can be difficult to both anticipate and measure the potential benefits. Therefore, individuals matching the inclusion criteria for this regimen are the ones for whom it is most difficult to anticipate the results, which is an important finding to convey to future patients. The results from this thesis can guide the discussions with future patients about what gains to expect. Before treatment, it is important to distinguish individuals who will probably achieve gains in activity performance and those who most likely will not. Therefore, it is important to remember that even if the results in this thesis show that spasticity-correcting surgery enhances activity performance, this is not the case for all patients who underwent treatment. However, for patients assigned to HFR, the improvements in the activity domain are highly promising. For the right patients, spasticity-correcting surgery and comprehensive rehabilitation can greatly improve the use of the affected arm in daily activities.
CHANGES IN PASSIVE UPPER LIMB ACTIVITIES

In this thesis, patients without remaining UL motor function were mainly assigned to the NFR and demonstrated gains in passive activities, as presented in the ArmA section A results. This is in line with previous reports that have shown gains, especially in passive activities, after different UL spasticity treatments\textsuperscript{90,131}. As previously discussed, results in passive activities, such as hygiene and cosmetic aspects, are reported to be easier to predict pre-surgery\textsuperscript{23}. The empirical knowledge and the results in this thesis are in line with this notion. For patients with hygiene problems, regardless of residual motor function, the gain from surgery is predictable and easy to capture with different outcome measures. Appearance is a commonly reported goal in BoNT treatment\textsuperscript{89}. Improved appearance of the UL and the positive effects the changed appearance had were mentioned during the interviews in Study IV. The negative effect that spasticity in the UL has on appearance is something that has previously been reported in qualitative studies\textsuperscript{237,244,245}. For some individuals, the current appearance can hinder participation and can therefore be a reason for treatment. In a study by Louwers et al.\textsuperscript{246}, 22 of 39 patients had a cosmetic goal with the surgical treatment. All patients in Louwers et al.’s study who were pleased with the cosmetic appearance after surgery also showed improvements in the ability to handle objects. Before the surgery, they were embarrassed by the appearance and hid the arm instead of using it. In a study by Tafti et al.\textsuperscript{134}, 15 out of 54 surgeries had aesthetic aspects as the primary aim. In a study by Gatin et. al.\textsuperscript{17}, appearance was the primary goal in 2 out of 70 cases; however, 17 out of 53 patients who chose a second goal in the same study had appearance as the second goal. This shows the importance of discussing how appearance affects the use of the arm.
CHANGES IN MOBILITY

An interesting effect reported by patients in Study IV (which was also mentioned by patients in the other studies but not formally evaluated) was the increased ability to walk and maintain balance. Participants who used walking aids told that they could more easily hold on to the aid, which was perceived as beneficial for their walking capacity. This ameliorating effect has previously been described after UL BoNT treatment and surgery\textsuperscript{247,248}. However, with the conducted studies, we cannot answer whether this is also the case in our population and whether it differs in the population suffering from stroke compared with SCI.
6.5 TREATMENT OUTCOMES ON PARTICIPATION

Results from this thesis show that the positive bodily changes made the participants more inclined to be engaged in their surroundings, both the physical and social environments. In Study IV, one interesting and essential finding expressed by the participants was the sense of regained bodily control and less daily hassle, compared with the situation before surgery. For several of the participants, this sense of increased bodily control led to a better mood, increased self-esteem, and greater participation. They experienced that they now thought less about their arm and that it did not cause the same number of problems as before; for some participants, this led to increased energy levels, increased sleep quality, and a sense of freedom. A rigid flexed position of the UL in the elbow, wrist, and/or fingers caused stigmatic experiences for the participants; this was now changed to a better and more normal position. These bodily changes were appreciated by participants because they were concerned about their own appearance, as well as about how others perceived them. The abnormal limb posture and the negative effects this has on interpersonal interaction have been described previously in a qualitative study. Further, the patients described the psychological distress that the spasticity meant to them, both the impression that they had no control over their body and how this led to anxiety, fear, and social isolation. In another study, the respondents described how spasticity had a negative impact on emotional, economic, and interpersonal domains and how they felt socially stigmatized and that “a lot of people don’t like to touch me”. Decreased self-confidence and depression have previously been reported by individuals with disabling spasticity. The correlation between appearance (cosmetic aspects) and the feeling of shame limiting social participation has been advocated when proposing BoNT. Perceived performance and satisfaction in prioritized
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

occupational performance problems were measured with COPM. All studies showed significant improvements that could be regarded as clinically important according to the predefined MICDs. Previous studies on SCI populations have shown similar results regarding improvements in prioritized occupational performance.\textsuperscript{163,249}
6.6 PATIENT DEMOGRAPHY

The demographics of the patients included in the different studies are similar in terms of wheelchair use, age, and gender distribution. The study population demographics in Study I differ from those in the other studies in a number of ways. Firstly, regarding diagnosis, the number of patients with SCI was lower. Secondly, the allocation of participants in Study I differed from that in the other studies: in Study I, more patients were allocated to NFR and fewer patients to LFR as compared with Studies II–IV. Thirdly, the time since injury was longer in Study I. The difference in diagnosis may be the result of stroke and TBI being new diagnoses at the clinic at the time of inclusion in Study I.

The differences in results between our studies and previous studies could be related to differences in study populations. The demographic data of the study populations in this thesis differs slightly from the data of other studies reporting outcomes after surgical interventions for spasticity. In two previous studies, a larger proportion of participants had suffered a stroke (65%), and the mean age was lower (51 and 47 years, respectively). In a systematic review on UL surgery, the mean age of the participants in the included studies was 49 years (range 27–57). In the review, the male/female ratio was 54%/46%, and the most common cause of spasticity was cerebrovascular accident (49%), followed by SCI (18%) and TBI (16%). The mean age in Studies I and II was 57 years, and the proportion of male participants ranged between 64% and 77%. When the demographic data of the present thesis are compared with those in the latest report from the Upper Limb International Spasticity programme (ULIS), the ULIS cohorts are similar to the ones in Studies I and II with respect to age, treated/affected side, and the time since the injury event (except Study I). The etiology,
However, differs largely, with the proportion of individuals with SCI in our cohort ranging between 30% and 70%, as compared with 1.6% in the ULIS study\textsuperscript{90}.

Another possible explanation for the disparities between the results of this thesis and previously reported results could be the difference in target muscles and whether the patients’ spasticity problems were bilateral or unilateral. In the ULIS study, only 5% of patients were bilaterally affected by spasticity, and whether the spasticity is bimanual or unimanual most likely affects the selection of treatment goals. In this thesis, bilateral or unilateral impairment was noted only in Study IV (37.5% bilateral). The number of patients with spasticity due to SCI is high in all studies (30–75%) and presumably also the number of bilateral impairments. The number of treated muscles in the studies of this thesis (mean 4.4–4.7) is in line with the number of treated muscles in the ULIS study (mean number of injected muscles = 5)\textsuperscript{90}.

The muscles targeted in the surgical interventions in Studies I and II were primarily the pronator (forearm), wrist flexors, and finger flexors. In the ULIS study, the treated muscles were predominately located in the forearm and upper arm, followed by the shoulder and fingers\textsuperscript{90}. In the aforementioned review\textsuperscript{186}, the most commonly treated muscles were located in the fingers, wrist, shoulder, and elbow. In Leclercq et al.\textsuperscript{25}, the target muscles were located in the elbow, forearm, and wrist, and in Gatlin et al.\textsuperscript{17}, the target muscles were mainly located in the fingers, followed by the wrist. It is therefore important to bear in mind the potential differences in target muscles and demographic data when interpreting the results of this thesis in relation to those of other studies.
TIMING OF SURGERY AND STUDY POPULATION

In the different studies, the time passed from the injury event to surgery was on average 14.3, 8.6, 8.1, 8.0, and 8 years (Studies I–V), with a range of 1–57 years. A possible reason for the difference between Study I and the other studies is that during the study period, patients with other CNS injuries than SCI became included. Before, only patients with spasticity due to SCI were offered treatment at the centre. The time elapsed between injury and surgery in our studies is in accordance with a recent review (except Study I) reporting a mean time of 8.6 years (range 0–57)\textsuperscript{186}. A more rapid surgical treatment could perhaps be favourable. Firstly, contractures, as a complication from spasticity, might then be limited or less severe. Secondly, with time, patients develop compensatory movements that can be difficult to unlearn. However, the best timing of surgical treatment for these patients is still unknown. What we do know thanks to previous studies is that a paralysed muscle held in a shortened position loses sarcomeres, resulting in stiff muscle fibres\textsuperscript{48}. Previous studies on BoNT treatments show goals ranging from active function to ease of care when the time since the injury event is longer\textsuperscript{250}. The focus on ease of care for patients with long-term spasticity underscores the development of compensatory movements and the negative effects of non-use on treatment gains. In these studies, we have not taken the time since the injury event into account in the analyses.

COMPLICATIONS

The surgical intervention described in the studies appears to be safe, with a low number of complications (8\%). This is in accordance with a previous study, presenting an overall complication rate of 9.4 for surgical interventions for adult UL spasticity and concluding that UL spasticity surgery appears to be safe\textsuperscript{186}. 

110
6.7 OCCUPATIONAL PERFORMANCE GOALS

The occupational performance goals identified in this thesis were collected by means of the COPM. COPM identifies prioritized occupational performance problems, and these were then transformed into occupational performance goals. The use of COPM in the goal-setting process is common and has previously been described\textsuperscript{251}. The use of COPM in the goal-setting process helps to focus on occupational performance instead of impairments such as pain. It also helps the clinicians to obtain information about what is important to the individual\textsuperscript{251}. Both the Goal Attainment Scale (GAS) and COPM have been recommended in consensus statements and guidelines to identify and evaluate treatment goals\textsuperscript{171,184,252}. GAS and COPM are not comparable. GAS is different in the way that it identifies goals, whereas COPM identifies prioritized occupational problems. Therefore, when using COPM, the occupational problems that are transformed into occupational goals can be better placed into the activity and participation domain of ICF. In Study V, the most common occupational goals were related to self-care (41%), followed by domestic life (21%) and mobility (18%). It is likely that the identified goals are influenced by the outcome measure used. This was shown in the Cusick et al. study\textsuperscript{253}, which compared the use of COPM and GAS in a pediatric population. More goals in the self-care domain were found with COPM than with GAS. Further, COPM was found to be quicker and easier to use, and GAS more flexible. The conclusion from the Cusick et al. study was that the aim and logistic factors should decide which of the two outcome measures is the most appropriate one\textsuperscript{253}.

In this thesis, COPM was not used in the NFR group; the reason for this is that no occupational performance gains are expected for patients in this regimen. Common goals identified with GAS\textsuperscript{89,254} are similar to the treatment
indications/goals in the NFR group. Goal setting with GAS could perhaps be suitable for this regimen. Goals identified with GAS have been divided into ICF domains by Ashford et al.\textsuperscript{89} and Eftekhar et al.\textsuperscript{254}. Ashford et al. found that the most common goals could be divided into two domains, with subdomains. These were symptoms/impairment and activities/function; 46\% and 54\% of the goals were found in these domains, respectively. In the symptoms/impairment domain, reduction of pain, prevention of contractions by improving P-ROMs, and control of unwanted movement were most common. In the activity domain, easier care for the affected arm, using the affected arm in motor tasks such as grasping/holding, and functional tasks such as eating and drinking were common, together with improved mobility\textsuperscript{89}. Eftekhar et al. found a similar division of the goals, with 45\% of the goals linked to the body function domain and 55\% linked to the activity and participation domain\textsuperscript{254}. In a recent systematic review on UL spasticity surgery covering 16 studies, the four most common indications/goals for surgery were improving limb hygiene (n = 9), improving limb function (n = 8), management of pain (n = 4), and improving limb appearance (n = 2)\textsuperscript{186}. The five most common primary goals in the Upper Limb International Spasticity (ULIS) study were passive functions, pain, active functions, ROM, and involuntary movements\textsuperscript{90}. In this thesis, GAS could have been used as an option to identify and evaluate treatment goals. However, both GAS and COPM have been questioned when used in research regarding psychometric properties\textsuperscript{255}. To use GAS goals, such as item banking have been suggested; this allows for an individualized yet generalized approach\textsuperscript{255}. The POPPs that were translated into goals in study V can be used for item banking for future patients. We have recently incorporated VAS ratings of cosmesis and the degree of spasticity in our clinic. Using COPM in clinical and research contexts helps to focus on what is important for the individual, thus helping to achieve a person-centred research approach.
6.8 OUTCOME MEASURES

No gold standard core set of outcome measures is available today. The need for standardization of outcome measurement of surgical interventions in adult UL spasticity has been highlighted in a recent systematic review. Barnham et al. found that 31 unique outcome measures were used across 19 studies. A recent systematic review targeting psychometric properties of UL activity performance in an adult population with and without spasticity concluded that today there is insufficient evidence to recommend one tool over another. Pereira et al. presented a core set of 11 outcome measures relevant for the evaluation of the effectiveness of interventions for spasticity. Pereira et al.’s report serves as a starting point for further discussions and the development of the most appropriate tools for evaluating spasticity interventions. The Ability Network has presented its recommendations on clinical measures and PROMs to be used when evaluating spasticity interventions for persons with spinal cord damage. An international group working on reconstructive hand surgery in tetraplegia has presented recommendations of outcome measures to be used. Recently, recommended outcome measures to be used in post-stroke arm rehabilitation trials have been published. Many of the outcome measures used are consistent with the ones used in the ULIS study. With the use of other outcome measures, the results from the studies could be different. By using outcomes covering different ICF domains, we tried to overcome that some of the outcomes used are unfamiliar to some patient groups.

OBSERVER-RATED MEASURES

Different observer-rated measures were used in this thesis, covering different ICF domains.
SPASTICITY

Spasticity is well known, and it has previously been described that spasticity is difficult to measure\textsuperscript{40}. Moreover, it is difficult to differentiate between the consequences of spasticity and other co-existing consequences of the CNS injury. In two of the studies included in this thesis (Studies I and II), MAS was used as a measurement to evaluate the degree of spasticity. MAS is also used as the primary outcome measure, even though its psychometric properties have been questioned\textsuperscript{200,201}. The reason for this is that MAS still is (even though it is questioned) one of the most used outcome measures in clinical and research work\textsuperscript{167}. In a study conducted in Canada, MAS was used by 75\% of the physio- and occupational therapists, and 91.3\% answered that they were very to somewhat satisfied with MAS\textsuperscript{94}. In a recent review on physiotherapy interventions for spasticity treatments, 15 of the 17 included studies used MAS or the AS\textsuperscript{45}. In order to enable comparisons with other studies, we chose to use MAS as an outcome measure.

RANGE OF MOTION

Measurement with a hand-held goniometer is a common measurement for evaluating spasticity management\textsuperscript{186} and was also used in this thesis. The advantage of goniometer measurements is that they are easy to perform and time-efficient, that no expensive equipment is required, and that a standardized method is available. Disadvantages are errors due to difficulties in maintaining the alignment and a consistent torque at different times and by different raters.

STRENGTH

Strength was measured in the studies of this thesis by means of pinch and grip strength. The grip strength is dependent on the position of the elbow, forearm, and wrist, as well as body posture (sitting/standing). Using a standardized procedure, the assessment of grip strength has been shown to be reliable and
valid in healthy subjects, as well as in populations with various health conditions, including musculoskeletal conditions. To measure grip strength in this way in a population with UL spasticity due to CNS injuries is a challenge. Any deviations from the proposed position were noted in the protocol. It has, however, been shown that measurements of grip strength and ROM correspond at best moderately with the self-perceived ability to perform activities. This was also shown in Study V, in which grasp ability and grip strength had a low correlation with self-perceived ability and satisfaction with activity performance.

GRASP AND GRIP

Grasp ability was measured with GRT. The disadvantage of GRT and many other grasp tests is that they measure unilateral UL skills. For patients with UL spasticity problems this is often not possible. Another disadvantage is that GRT is mainly used for the evaluation of patient with SCI. A global functional test for the UL, such as Action Research Arm Test or the Block and Box Test, could be preferable when comparing our results with the ones from other studies. To compare our current results with our previous results and with results from other similar centres worldwide, the GRT was chosen.

HAND OPENING

The difficulties of unilateral grasp tests, and the fact that a common main goal of the treatment is to increase the opening of the hand, initiated the development of the Cylinder Test. The Cylinder Test includes 4 different grasps (2 unilateral and 2 bilateral grasps) and measures mainly the opening ability of the hand. The establishment and psychometric testing of the Cylinder Test are ongoing.
PATIENT-REPORTED OUTCOME MEASURES

Today, the importance of measuring how the spasticity influences the individual and the interventional effects on different ICF domains has been raised\textsuperscript{170}. The importance of including PROMs or other ways to incorporate patients’ perspectives in evaluation has similarly been raised by several authors\textsuperscript{186,237,265}. Patients’ perception has been proposed as the most important view when deciding on a treatment\textsuperscript{14}. To our knowledge, there were no UL spasticity-specific PROMs in the Swedish language, which initiated the idea of translating ArmA into Swedish and evaluating the psychometric properties of ArmA-S. This specific PROM can help in the communication between clinicians and patients when discussing perceived UL problems related to spasticity. The result from the psychometric evaluation provides support for the use of ArmA-S in research and the clinic to assess active and passive UL function. Further, the psychometric evaluation demonstrated that ArmA-S has good validity, reliability, and responsiveness. Most psychometric properties were in agreement with the original English version of ArmA. We found no floor or ceiling effects, and most of the patients completed ArmA-S in less than 10 minutes, which further supports its implementation ability and clinical feasibility. To be useful in research and the clinic, a PROM’s ability to analyse responsiveness is important. Our results indicate that ArmA-S can detect changes over time. The results further show that ArmA-S can detect significant improvements due to spasticity-correcting surgery and is better than DASH, which did not capture any significant improvements. DASH was developed to assess a wide range of UL problems, not specifically spasticity-related disorders. DASH also assesses higher-level function, which is why floor effects are likely in a neurologically impaired population; the disparity is therefore not surprising. Even though preliminary findings support the use of ArmA-S, it is important to remember that interpreting self-reports of spasticity-related
disability is a challenge, as patients often experience simultaneously clonus, rigidity, and neuropathic pain. Discriminating between symptoms has been shown to be difficult. Outcome measures should be reliable and validated and show good responsiveness, preferably in the investigated patient group. ArmA has previously mainly been evaluated in stroke populations. In Study III, 47% of the participants were suffering from SCIs and thus demonstrated extra usability of ArmA-S. Commonly in PROMs, if a certain task or activity is performed only occasionally, the person is instructed to estimate the degree of difficulty he or she would experience when performing the task. This is perceived as more appropriate than leaving the item blank. The issue of hand dominance is difficult to overcome, but the principle of approximating the difficulty is used, often even in the case of a task that is normally performed with the dominant hand. The use of PROMs to evaluate treatment is a challenge, especially when the score is based on an estimation of performance. This was a problem that occurred during the psychometric analyses of ArmA-S and induced some changes in the recommended version of ArmA-S. Another disadvantage of PROMs is that it is difficult to create a PROM that captures certain tasks and specific activities that might be of value or that are troublesome for the individual to perform. Study IV revealed several aspects of importance, such as increased control and less hassle, that are not measured in ArmA. The COPM can be an alternative to specific PROMs. The advantage of COPM is that the patient chooses to evaluate occupational performance problems of personal importance, which is unique but makes it difficult to compare between individuals. The COPM, however, complements other PROMs and ArmA, as it aims to identify problems in occupational performance that are troublesome for the specific individual. Another proposed advantage of using PROMs is that preoperatively, it can help the clinicians to find patients that are unlikely to improve meaningfully and can help to identify patients that lack awareness of their role in the caring context. In this way,
ArmA can help clinicians to detect individuals with no perceived hygiene problems; if, for example, no active use of the hand exists, the patients are perhaps unlikely to improve meaningfully by the treatment. The use of COPM can help clinicians to understand the patients’ aims with the treatment and from that discuss the likelihood of reaching them with the planned treatment. With the right expectations, satisfaction with any treatment is more likely. In research, the magnitude of change is of interest, and this was calculated in Studies I, II, and V. Language and cognitive skills are needed to be able to complete the ArmA, COPM, and VAS scales; therefore, it was not possible to use these scales for the whole study population. ArmA has the advantage that it is also developed to be completed by a carer.

There are difficulties with both quantifying and objectively measuring spasticity. Including participants’ perceptions is one way of solving this, especially because patients’ perceptions of the treatment effect are most important. However, a problem with PROMs is that because the patients are not blinded, the expectations of treatment benefits can bias the perception. In this thesis, outcome measures covering different ICF domains were used, as well as PROMs and clinician-rated and patient performance measurements.

**MINIMAL CLINICALLY IMPORTANT DIFFERENCE**

MCID is used to interpret whether a change in scores is of importance to the patients, not only whether it is statistically significant. The importance of using MCID and not only p-values when reporting results from studies has been raised, but also the difficulties with defining MCID\textsuperscript{195,197,268}. The accurate determination of MCIDs, however, is important. The MCID should preferably be investigated in the studied population—in this case, persons with UL spasticity due to CNS injuries. The MCID value for the study
population should be higher than the measurement error (minimal detectable difference). Further, the cost and risk of a treatment have to be considered when establishing an MCID; a small improvement can be acceptable for a low-risk and low-cost treatment, as opposed to a high-risk and high-cost treatment\(^{269}\). Consequently, different MCIDs should be applied to patient groups that vary in degree of disability. What is meaningful for one person may not be meaningful for another person, depending on, for instance, injury severity. Furthermore, the spontaneous recovery rate must be considered, so the MCID should differ depending on whether the patient is in an acute or chronic phase. Moreover, to further complicate the calculation of MCIDs, it has been raised that between-group differences and longitudinal changes within an individual would likely provide different MCID values\(^{270}\). In a previous study of gait speed in patients with chronic stroke, Lewek et al.\(^{10}\) suggested that potential changes should be based on baseline values. Thus, for patients with more substantial impairment, one should not expect as large changes as for patients with less substantial impairment. Furthermore, Lewek et al. noted that although the change (in gait speed) is seemingly smaller for slower walkers, it is still a “real change”. Notably, a single MCID is often indiscriminately applied to all study participants to determine success, despite alterations in participants’ potential treatment responses. Like Lewek et al., Harvey et al.\(^{195}\) and Tuszynski et al.\(^{269}\) mentioned that treatment-induced improvements will vary between patients. In UL function, small changes might be more clinically important for patients with more severe functional impairment after neurological injuries. This was also a reason for dividing patients into different regimens, since the expected changes in the different outcomes varied depending on the severity of the impairment. Unfortunately, to our knowledge, there are not many MCIDs for the study population of this thesis, as also found in a clinical review report\(^{271}\). Therefore, before
analysing the outcome, the research group, together with the clinicians working in the field, established MCIDs for outcome measures included in the studies. Although conducting separate studies to establish MCIDs for each outcome measure would be preferable, our approach has been discussed and recommended as an alternative\textsuperscript{195,197}. Previous studies have used 10% of the range of each scale as the MCID, or a 10% change from baseline values\textsuperscript{45,197}. This was brought to our attention after conducting the analyses in Study II, which could have been a more appropriate way of defining MCIDs. If 10% of the scale range had been used instead, the MCIDs would have been slightly different. Readers may choose other MCIDs than the ones used in this thesis, although we found it important to go beyond the tradition of relying on only statistically significant treatment effects. We therefore used our \textit{a priori} defined MCIDs. It would have been favourable to involve patients in the discussion regarding the amount of improvement necessary to justify the surgical treatment.
6.9 METHODOLOGICAL CONSIDERATIONS

In this thesis, different methods were used. Four of the five studies were quantitative, and one was qualitative.

QUANTITATIVE RESEARCH

Research based on quantitative methods focuses on gathering numerical data and generalizing it across groups of people or using it to explain a particular phenomenon. To ensure reliability, it is crucial to follow established routines when the measurements are taken and when PROMs are used. In this thesis, the same clinicians made the measurements before and after the treatment, with few exceptions. In total, five different physio- or occupational therapists collected the data, and agreement on the procedures for the measurements was assured. The advantages and disadvantages of the chosen outcome measures were discussed previously. For the analysis and description of the data, different statistical methods (parametric and non-parametric) and measurements can be used. The sample size, whether the data are normally or not normally distributed, and the data level (nominal, ordinal, interval, ratio) guide the appropriate choice. Central tendencies are commonly reported as mean, mode, or median; the degree of dispersion is commonly reported as range, IQR, or SD. For ordinal data, a small sample size, and/or skewed data, the recommendation is non-parametric statistics and the use of the median for the central tendency. This view has been challenged, and studies report results from, for example, MAS, VAS, and COPM with mean (SD) values. In Study II, we chose to report both mean (SD) and median (IQR) values for comparison reasons. Unfortunately, in Study I, only median (range) values are presented for baseline and follow-up scores and the mean without dispersion, which reduces the possibilities of comparing results.
Rehabilitation and outcomes after spasticity-correcting surgery in the upper limb

Study I was a prospective observational study with assessments conducted before and after the treatment. In this study, the aim was to learn more about the effects of the treatment. This design was considered suitable for this aim. The study population contained only 30 participants and should preferably have been larger, resulting in a more extended data collection period. No power calculation was done with respect to the number of participants needed. At this point, the aim was to explore the effects of the treatment, and therefore a control group was not included. This design is less rigorous than a randomized controlled trial design or a controlled observational study; therefore, the results must be interpreted cautiously.

Study II had a retrospective design. It would be preferable to have a prospective design, but that was not feasible due to missing data, a common weakness in retrospectively designed studies. After the analyses in Study I, some questions about the feasibility of the regimen were raised. In order to answer these questions, a retrospective design was applicable when there were already clinically gathered data to be used. Therefore, the study could be conducted with fewer resources. When it comes to the outcomes of the treatment, the results must be interpreted with caution because of the retrospective design.

The translation and psychometric analyses of ArmA in Study III followed the standard recommendations, although the sample size was rather low. This work was initiated in 2020 when the COVID-19 pandemic made further inclusion of participants in the clinical studies difficult.

Study V was a retrospective mapping study. The occupational performance problems and perceived performance and satisfaction among individuals who underwent spasticity-correcting surgery between 2015 and 2020 were analysed. The main aim of this study was not the outcomes after the treatment but the identification and mapping of the POPPs that individuals with UL
spasticity perceived. During this period, a total of 71 surgeries among patients allocated to the HFR or LFR were performed, which enabled an in-depth analysis of POPPs. A retrospective design was considered suitable for the purpose of the study.

**QUALITATIVE RESEARCH**

Qualitative research aims to obtain an understanding of phenomena, such as experiences of a treatment, and objectivity is neither possible nor an aim. Therefore, the individuals can freely express their experiences, so effects that otherwise might be missed can be captured. Interviews are often used for data gathering. Certain steps are taken to ensure rigor and trustworthiness. To ensure this, a co-researcher tested the results in Study IV, the research group discussed the categories and themes, and an external researcher was asked to assign the quotations to the “correct category”. Citations are often used in qualitative research to show that the interpretation is derived from data and to create dependability and transferability in the analytic process, as in this study. Further, it is essential to describe the settings and the participants included. This information is essential because it gives the reader the opportunity to judge whether the results are transferable to another patient group or setting. There are several qualitative methods and different variants of them. In some methods, the analysis starts directly after the first interview, whereas in other methods it starts after all interviews have been conducted. In grounded theory, as described by Strauss and Corbin, the aim is to build a theory based on the research data, and the analysis starts during the first interview. In phenomenology, the aim is to find the essence. Since the aim of this thesis was not to build a theory, nor to find the essence, but rather to explore different experiences from the persons experiencing them, a phenomenographic analysis method was used and considered appropriate. An alternative to individual interviews could have been focus groups, the advantage of them being the
interaction between the participants, which could perhaps have resulted in more extensive material than the individual interviews. To hear other individuals’ experiences could stimulate the reflection of one’s own experience. The disadvantages may be that participants could be guided by others, and therefore individual conceptions could be lost. Some participants might not feel confident to talk freely in group settings, whereas others can gain confidence in groups. Specific guidelines were followed to improve the quality in the different studies, as presented previously.
6.10 ETHICS

“Primum non nocere” is a Latin expression for “first, do no harm”. This is important to always bear in mind when planning, performing, and reporting research, especially research that involves humans. In research, it is essential to be careful, open, and respectful, but also efficient. Inclusion of more participants than needed should be avoided, but one should neither draw conclusions that do not have enough data to support them nor withhold new knowledge—for example, if the results do not support the aim. When handling personal data, it is important to protect the persons against violations of integrity. In the studies, we have followed the rules and regulations when handling data. In this thesis, all studies have ethical approval or confirmation that ethical approval was not needed. Participants in the studies should be provided with sufficient information about the study to be able to make a decision about participation. Written and oral information about the purpose and procedures, potential risks, benefits, and data handling, as well as the option to withdraw participation at any time without giving any reason, was given to all participants. Informed consent was gathered before the participants were included, and the time between providing the information and the inclusion acceptance was sufficient. The treatment, as well as the follow-up, followed the same protocol regardless of inclusion in studies or not. In Study III, one additional PROM was used, and in the test-retest procedure, one additional assessment was done. In Study IV, the participants were scheduled for an interview that was not part of regular care. The participants could choose to do the interview at the same time as the follow-up or on another occasion and digitally or face to face. In the studies, the clinicians involved in the care were also the researchers. This is not optimal from a patient perspective, since some patients could feel obliged to participate. Because of this, it was stressed that participation was voluntary.
6.11 GENERALIZABILITY

All participants in this thesis were treated in a specialized centre in a university hospital. The participants came from all over Sweden. The context and the surgical treatment algorithm are well described in the thesis and in the papers, which increases the possibility of judging the transferability to other settings. Important to consider is that the participants come from a high-income country and that healthcare is tax-financed and accessible to everyone. This may influence the results and must be considered when generalizing the findings from the studies.

The feasibility and effectiveness of the treatment concept in this thesis have been proven to be good. Surgery for spasticity problems in the adult population, however, is and will probably continue to be questionable and, to some people, controversial. Important to realize is that for many patients, this is an effective treatment option, which could also be an option for a wider population. Surgery for this population could perhaps help many patients enhance the use of the arm in daily life and diminish impairments due to the spasticity—that is, if performed within a multidisciplinary team, with a comprehensive post-surgery treatment plan, and with well-informed and well-prepared patients with realistic expectations. In order to do so, both the surgery and the treatment need to be carefully described, evaluated, and available. Altogether, surgery could be an option for more patients than it is today; however, it is still not an option for everybody. In a large survey, 72% of patients with spasticity due to stroke, TBI, and SCI answered that they would like a treatment regimen with longer-lasting treatment benefits than the effect they received with BoNT\textsuperscript{69}. This could in some cases be achieved with a surgical treatment regimen. Important to bear in mind is that, independently of methodology, surgery for spasticity problems aims at reducing the
consequences of spasticity, while the primary CNS injury causing the spasticity is currently not curable with surgery. The rehabilitation after any spasticity surgical intervention aims at transforming the potential gain from surgery to enhance occupational performance and diminish spasticity-induced impairments.
6.12 LIMITATIONS

This thesis presents encouraging results from five different studies; that said, it has limitations that must be reflected upon. For instance, there is no comparison group to justify whether the outcomes of any kind of intervention are enduring. Notably, in Study II, the amount of missing data was quite high, the data were retrieved from routine clinical care, and some patients were lost to follow-up. Another limitation is that the patients in Studies I and II were evaluated repetitively, which might have caused observer effects, commonly referred to as the Hawthorne effect. Also, important to highlight is that none of the studies had blinded assessors, meaning that for some patients, the rehabilitation was carried out by the same therapist who did the assessments. Preferably, the assessment should have been carried out by independent assessors, not involved in the rehabilitation, to minimize overreporting. Scientifically, this makes the study design weaker. It is, however, clinical research, and the study questions were developed because of the engagement in this group of patients after years of experience in clinical work. This engagement and experience are the background and inspiration of the present work. For determining the implications of research findings for the clinic, this design nevertheless has some advantages.

In this thesis, patients with different CNS diagnoses were included. This influences the heterogeneity of the studied cohorts and might limit the generalizability to clinical practice. On the other hand, the heterogeneity in the studied population reflects the complexity and comorbidity of patients with UL spasticity in general and could therefore increase the generalizability. To our knowledge, no gold standard regarding recommended outcome measurements is available, which is clearly a limitation and makes comparison with other studies difficult. Other outcome measures than the ones used in this thesis work
have been suggested by reviewers, such as Action Research Arm Test, Abilhand, and the Box and Block Test. Some outcome measures are common in stroke rehabilitation, while other measures are common in SCI rehabilitation, which can explain the different suggestions. With the use of reliable and valid measures covering different ICF domains, we tried to reduce this limitation. The use of MAS as a primary outcome measure in Study I and partly in Study II, despite the raised concerns about MAS, is likewise a limitation. The use of ArmA-S as regimen-specific primary outcomes in LFR and NFR (Study II), during the psychometric evaluations of ArmA-S is another limitation. The Cylinder Test used in Study II is not yet psychometrically evaluated, which is another disadvantage. Not only the chosen outcome measures can affect the interpretation of the results (measuring spasticity is difficult), but differences in measurements can also be influenced by factors such as temperature, stress, and fatigue.

The 6-month and 12-month endpoints in Studies II and I, respectively, could be considered too short. It remains to be seen whether the gains are sustained over a longer time. However, a long follow-up time in patient groups with comorbidity is a challenge, as a possible deterioration in the status can be caused by many different factors. No formal cognitive testing was carried out; other preoperative assessments were given priority because cognitive testing can be time-consuming.

The inclusion criteria in the regimen are made by the multidisciplinary team and might be altered in the future. In the studied protocol, the rehabilitation in all three regimens starts the day after surgery, with varying rehabilitation content. Whether starting rehabilitation a few days or weeks later or whether differences in the rehabilitation content might lead to similar outcomes cannot be answered with these studies. Postponing the rehabilitation could reduce the
risk of surgical site bleeding and post-surgery pain; however, the surgical complications in this thesis cohort were considered low.

We cannot compare the outcomes of the different regimens, the main reason being that the indications varied between the different regimens. The lack of power analyses in Studies I–II is a limitation. The sample size may therefore be a limitation.

In Study V, hand dominance was not recorded. Whether the goals differ depending on hand preference can therefore not be answered. Hand dominance after a bilateral disability is also challenging to define since the preferred hand can be the more affected one. COPM targets activity limitation, not body function, which is why the goals identified in Study V are solely in the activity domain.

Some of the patients are included in two or more studies in this thesis. This may have biased the results.

The results in Study IV are based on the perceptions of eight people with UL spasticity due to SCI or stroke, so the generalizability to other populations is unknown and caution should be taken when the results are transferred to a wider population. The intention of qualitative research, however, is to report the conceptions and experiences of participants, not to provide generalizability. However, the results do resonate with clinical experience and the findings of the other studies in this thesis. This supports the transferability of the findings to populations comparable to the current one.

The psychometric evaluation of ArmA-S had some limitations that should be reflected upon. The time span for the test-retest evaluation of 4–10 days might be considered too short and could have resulted in recall bias. An accurate
MCID for different UL spasticity severity levels has not yet been established. To clarify the internal structure, larger sample sizes are needed. Also, no cross-cultural validity was assessed; therefore, comparisons between ArmA and ArmA-S scores are at this time not recommended. Finally, future studies should aim to address these limitations.
7 CONCLUSION

Spasticity-correcting surgery combined with regimen-specific rehabilitation is a management option to reduce muscle over-activity, reduce pain, improve hand function, and improve performance and satisfaction in prioritized occupational performance problems in patients with disabling spasticity, with evidence of effects lasting six months up to one year. The studies of the treatment algorithm provide data in support of its feasibility.

This thesis shows participants’ conceptions of the advantageous effects of surgery on everyday life. Beneficial gains include increased body functions and occupational performance, smoother daily activities, regained roles and interpersonal interactions, and enhanced psychological well-being. Conceptions of the effects were mostly positive. The initial weakness and how it influenced everyday life was a negative experience mentioned by the participants. In this study, the experiences described by all participants were reduced tone and increased active or passive ROM. Still, one of the most interesting findings was the conception regarding perceived increased bodily control. The participants described how the body was perceived as less unpredictable and how this led to increased participation and psychological well-being, even for participants that had not gained much in function or activity level after the treatment. This can help us to understand why some patients are satisfied with their spasticity management, even if the clinicians cannot capture any improvements with the outcome measure used.

The use of PROMs to evaluate treatments and to increase the communication between patients and clinicians has been highlighted. In recommended outcome measure batteries, PROMs are often included. The preliminary evaluation of ArmA-S shows that it is a reliable and valid self-reported
questionnaire to be used in clinical practice and research for assessing both passive and active UL functional improvement after spasticity-correcting surgery. It could help both researchers and clinicians monitor treatment-induced changes in UL function in patients with various degrees of UL spasticity.

The results from the observational studies, the conceptions that emerged in the qualitative study, and the mapping of prioritized occupational problems can be used to facilitate the goal setting based on the individual’s capacity for improvement. The results can be helpful in the discussion between future patients and healthcare professionals, regarding potential complications, the content of the rehabilitation, and the importance of realistic expectations.
8 FUTURE PERSPECTIVES

Study IV focused on the effect, both positive and negative, that the participants experienced in everyday life. Patients’ knowledge of the advantages and disadvantages of the treatment could be of value when refining the current rehabilitation protocol.

The Cylinder Test used in the study, developed by the authors, has not yet been subjected to psychometric evaluations. This is an ongoing project. Initially, the face and content validity of the manual will be evaluated, followed by test-retest reliability, construct validity, and responsiveness.

In these studies, the longest follow-up was 12 months. To learn more about long-lasting effects, further studies should include an extended follow-up period.

Knowledge about long-lasting effects can guide and help to optimize and prioritize the postoperative treatment in order to improve long-term outcomes.

The studies included in this thesis had no control group. Controlled studies are needed. It would be preferable to compare the results of surgery with the results of today’s gold standard treatment, namely BoNT injections. A controlled study that evaluates the outcome between the two groups (BoNT injection vs. spasticity-correcting surgery) is ongoing. The implementation of this study was delayed because of the COVID-19 pandemic from 2020 until 2022.

To learn more about how the outcomes differ after the two treatments (BoNT injection and surgery), a case-controlled study could be conducted.

Cost-benefit and cost-utility analyses are recommended. Spasticity is often a chronic condition, and the economic implications of treatments are important. Comparison of different surgical interventions is difficult to implement. One way of doing this would be to have a gold standard outcome measure protocol. Furthermore, multicentre studies would be needed to achieve such a study design.

How time from injury to surgery affects the outcome and what the optimal timing of the surgical intervention is, need to be investigated in future studies.

The self-report ArmA has been subjected to psychometric evaluations. Further evaluations to establish MCID values and cross-cultural validity are needed.

To my knowledge, there are not many MCIDs for the study population of this thesis. Studies to establish MCIDs for each outcome measure would be welcome.
Cost-benefit and cost-utility analyses are recommended. Spasticity is often a chronic condition, and the economic implications of treatments are important.

Comparison of different surgical interventions is difficult to implement. One way of doing this would be to have a gold standard outcome measure protocol. Furthermore, multicentre studies would be needed to achieve such a study design.

How time from injury to surgery affects the outcome and what the optimal timing of the surgical intervention is, need to be investigated in future studies.

The self-report ArmA-S has been subjected to psychometric evaluations. Further evaluations to establish MCID values and cross-cultural validity are needed.

To my knowledge, there are not many MCIDs for the study population of this thesis. Studies to establish MCIDs for each outcome measure would be welcome.
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“Be yourself; everyone else is already taken” *Oscar Wild*

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REFERENCES

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REFERENCES

17. Gatin L, Schnitzler A, Calé F, Genêt G, Denormandie P, Genêt F. Soft tissue surgery for adults with nonfunctional, spastic hands following central nervous system lesions:


75. Lundborg G. The hand and the brain: from Lucy's thumb to the thought-controlled robotic hand. Springer; 2014.


146


144. Tsaiampa VA, Ignatiadis I, Papalou A, Givissis P, Christodoulou A, Frideres J. Structural and mechanical integrity of tendon-to-tendon attachments used in upper limb tendon


161. Freeman RT, Pickard S, Jarvis S. Orthopaedic surgery can transform the lives of adults with spasticity. *Bmj.* 2014;17(349):5633. doi:10.1136/bmj.g5633


APPENDICES

Paper I

Manuscript (II)

Paper III

Paper IV

Manuscript (V)