Patients' perceived outcomes of tetraplegia hand surgery

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”At the end of the mind, the body. But at the end of the body, the mind”

Paul
Valéry

Patients' perceived outcomes of tetraplegia hand surgery

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ABSTRACT

Aim: To investigate patients perceived benefits after upper limb surgery in persons with tetraplegia - with a special focus on the participants' perspective and their experiences from regaining lost functions.

Methods: A combined Quantitative and Qualitative design was used. The outcome measures in study I and III was the Canadian Occupational Performance Measure (COPM). It captured patients perceived performance and satisfaction with their prioritized activities. Study II was a correlation study between activity gains and physical factors. Study IV and V used a grounded theory approach to capture patients experiences regarding a) changes in their daily life and b) the transformation process of regained function into daily use. Patients were recruited from National center of Reconstructive hand surgery in tetraplegia, Sahlgrenska University Hospital, Sweden. Patients came from diverse parts of the Nordic countries.

Results: Patients set up goals relevant to the specific surgery, they experience improvements and were satisfied with the performance of their prioritized goals. All types of goals improved after grip reconstruction, especially eating and goals generally regarded as more complex ea domestic life and leisure activities. The satisfaction was similar to the performance improvements. When the patients expressed their experienced after surgery the core theme was "enhanced independence" including both practical and psychological aspects and an increased self-efficacy in their hand control.

No correlation between a single physical factor and perceived improvement in activity was found, suggesting there are also other factors relevant for the transformation process to use regained function in daily life. "Determination for higher independence" was the core concept to transform the function into daily use, described by the participants. Time, training in home environment and social support was other important factors. In the process "belief in ability" and later "confident in ability" were important stages to proceed further into daily use.

Discussion: Reconstructive hand surgery and rehabilitation are shown to have impact in many dimensions in life and it gives reflexions in all domains of the International Classification of Functioning, Disability and Health (ICF) model; body structures and function, activity, participation, personal factors and environmental factors. A carefully informed and highly motivated patient is important to receive a good result, not only in grip strength but also in all the other domains of ICF. No single physical factor known before surgery, e.g. sensibility or age could alone explain improvements in prioritized activities. Traditional limitations with high age and lack of sensibility could not be proven to be a limitation to activity improvement in present study. Therefore, all patients with tetraplegia should have the opportunity to choose to have hand surgery. Neither could grip strength alone demonstrate a correlation with activity improvements. Physical factors have of course an important impact on the capability in activity performance but in agreement with the ICF model, personal and environmental factors also plays an important role in activity and participation improvements after reconstructive hand surgery in tetraplegia. Accordingly, body functions, activity and participation all should receive attention in the rehabilitation after surgery and also the need for evaluations in the diverse dimensions to capture multiple perspectives of changes after surgery.

Conclusion: Reconstructive hand surgery is a useful and valuable intervention for people with tetraplegia. The participants experienced an increased hand control that had impact not only on physical aspects but also in participation, practical and psychological aspects. Together with the physical improvement, high motivation and development of self-efficacy in hand control seems, from the results of these studies, to be important factors to secure activity and participation improvements after surgery.

Keywords: Outcome, tendon transfer, tetraplegia, patient perspective, hand function

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SAMMANFATTNING PÅ SVENSKA

En ryggmärgsskada är en traumatisk upplevelse för den drabbade personen och hans eller hennes anhöriga och vänner. Från att ha levt ett ”normalt liv” är plötsligt de flesta vardagliga uppgifter svåra eller omöjliga att utföra. Dessutom påverkas både individen och omgivningens roller och vanor. Den mest önskade förmågan att återfå efter en halsryggmärgsskada (tetraplegi) är handfunktion. På Sahlgrenska Universitetssjukhuset har sedan 1970-talet handfunktionsförbättrande kirurgi vid tetraplegi utförts på en regelbunden basis. I ett globalt perspektiv finns tusentals personer med halsryggmärgsskada som inte vet om och/eller inte har möjlighet att kunna genomgå kirurgisk rekonstruktion. En av anledningarna kan vara brist på kunskap om nyttan av operationerna. De flesta utvärderingar som är gjorda har fokuserat på kroppsfunktionsnivå och mycket begränsad information finns om individens aktivitet och delaktighet. Därför var syftet med denna avhandling att belysa just dessa aspekter utifrån ett patientperspektiv.

Resultatet av studierna visar att rekonstruktiv handkirurgi kan påverka personen på många plan. Det sammanfattande uttrycket för effekten av de utförda kirurgiska åtgärderna var ”upplevelsen av att vara mer självständig”. Självständigheten inkluderade både praktiska och psykologiska aspekter. Förbättringar kunde ses i alla typer av aktivitetsmål som personerna satte upp före operationen. Störst förändring efter grepprekonstruktion var förmågan att äta självständigt samt att utföra hushållsarbete och fritidsaktiviteter. Efter en tricepsrekonstruktion var det förmågan att skriva och att sträcka ut armen i liggande som visade de största förbättringarna. Inga samband mellan en enskild fysisk faktor och förbättringar i prioriterade aktiviteter kunde påvisas. Rehabiliteringen beskrevs som lång och utmanande. För att omsätta den vunna handfunktionen i sitt dagliga liv var det gemensamma uttrycket bland deltagarna ”att bestämma sig för att uppnå en ökad självständighet”. Viktiga steg i den processen var att våga prova och tro på förbättring, och senare i processen, att ha tilltro till sin förmåga så att handkontrollen verkligen utnyttjades i vardagen.

Rekonstruktiv handkirurgi vid tetraplegi har förutsättningar att förbättra och förenkla livet efter en halsryggmärgsskada. Målmedvetenhet och tilltro till sin förmåga verkar vara viktiga faktorer för att den vunna handkontrollen ska ge optimala vinster i dagligt liv.

LIST OF PAPERS

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

I. Satisfaction and performance in patent selected goals after grip reconstruction in tetraplegia.
Wangdell J, Fridén J.
J Hand Surg Eur. 2010;35:563-568.
http://www.ncbi.nlm.nih.gov/pubmed/20494917

II. Performance of prioritized activities is not correlated with functional factors after grip reconstruction in tetraplegia.
Wangdell J, Fridén J.
J Rehabil Med. 2011;43:626-630.
http://www.ncbi.nlm.nih.gov/pubmed/21584483.

III. Activity gains after reconstructions of elbow extension in patients with tetraplegia
Wangdell J, Fridén J.
J Hand Surg Am. 2012 37(5):1003-1010
http://www.ncbi.nlm.nih.gov/pubmed/22425341

IV. Enhanced independence: experiences after regaining grip function in persons with tetraplegia
Wangdell J, Carlsson G, Fridén J.
Disabil & Rehabil. 2013; Jan 07 [Accepted for publication].

V. From regained function to daily use after grip reconstructive surgery in tetraplegia: Patients' experiences
Wangdell J, Carlsson G, Fridén J.
In manuscript

CONTENT

ABBREVIATIONS

ADL	Activities of daily living
BR	M. Brachioradialis
CMC	Carpometacarpal joint of the thumb
COPM	Canadian Occupational Performance Measure
C-SCI	Cervical Spinal Cord Injury
ECRB	M. Extensor Carpi Radialis Brevis, Wrist extensor muscle
ECRL	M. Extensor Carpi Radialis Longus, Wrist extensor muscle
ECU	M. Extensor Carpi Ulnaris, Wrist extensor muscle
EPL	M. Extensor Pollocis Longus, Thumb extensor muscle
FDP	M. Flexor Digitorium Profundus, Finger flexor muscle
FPL	M. Flexor Pollicis Longus, Thumb flexor muscle
ICF	International Classification of Functioning, Disability and Health (see definitions)
MMT	Manual Muscle Test
ROM	Range of motion
SCI	Spinal Cord Injury
WHO	World Health Organisation

DEFINITIONS IN SHORT

Activity	Refers to ICF definition: the execution of a task or action by an individual. It ranges from basic activities as grasping and moving objects to complex activities like self-care and domestic life. Activity limitations are difficulties an individual may have in executing activities (1).
Environmental factors	Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (1).
Function/ Body function	Refers to ICF definition of body functions as physiological functions of body systems (1).
ICF	International Classification of Function, disability and health (ICF) is WHO's framework for measuring health and disability at both individual and population levels (1).
Occupation	Occupation is everything a person do to occupy them self, including looking after themselves, enjoying life and contributing to the social economical fabric of their communities. Occupations encompass more than one task or activity of everyday life and it gives meaning and value by individuals and a culture (2).
Occupational performance	The ability to choose, organize and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one´s self, enjoying life, and contributing to the social and economic fabric of a community (2).

Performance	Successful engagement in occupation. With three components: affective (feelings), cognitive (thinking) and physical (doing) (2).
Personal factors	Personal factors are the particular background of and individual´s life and living, and comprise features of the individual that are not a part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level (1).
Satisfaction	The experience of pleasure and contentment with one's task performance (3).
Self-efficacy	Confidence in one's ability to perform a task or specific behavior (4).

1 INTRODUCTION

The experience of a cervical spinal cord injury (C-SCI) is a traumatic event for an individual and his or her family and friends. The person experiences limitations in body function, but also limitations related to activity, participation, environmental, and personal factors (5). The injured patient goes from living a "normal life" to experiencing an abrupt change in her or his ability to perform many activities and roles. Situations that were previously dealt with without thinking or were taken for granted suddenly become impossible. The limitations range from essential basic abilities to eat, use the toilet, and regulate body temperature to more complex abilities such as taking care of children, working, or spontaneously visiting a restaurant on the second floor with friends. This kind of condition forces the injured person, relatives, and friends to re-evaluate their obligations, roles and priorities in life, and adapt to the new situation.

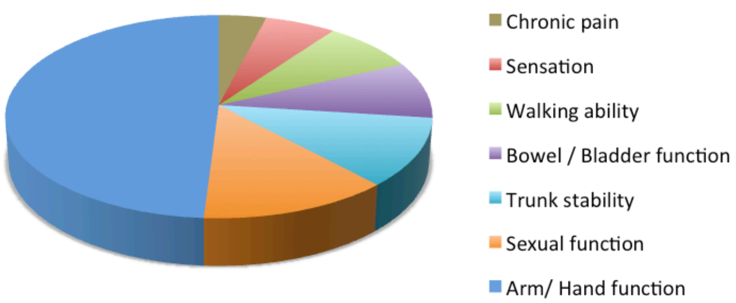


Figure 1. Functions improving quality of life, as prioritized by people with tetraplegia (6).

People with tetraplegia prioritize regaining upper limb function more highly than other lost functions as bowel, bladder, sexual function, or walking ability (Figure 1) (6). In a study of 565 people, 77 percent expected to experience a significant improvement in their quality of life if their hand function improved (7). Reconstructive hand surgery has been developed over decades and has been found to improve elbow extension, pinch, and grip strength in the tetraplegic upper limbs (8-20). However, the treatments are not accessible to everyone with tetraplegia. In countries like Sweden and New Zealand, almost all newly injured people are informed of their possibilities for regaining arm-hand function and almost half of the eligible population has had surgery (21). The corresponding number in the US is approximately 14 percent (22). The reasons for the low rate of surgery performed in many countries are diverse. Even though improvement of the upper limb is known to be a highly desired outcome for people with tetraplegia living in the US (6), 25 percent had not heard about the possibilities to surgically improve hand function. Of those who had, 38 percent said they had had a negative first impression (23). As well as patients' lack of information, other barriers seem to be professionals' limited knowledge about the benefits of surgery and inadequate referral networks between physiatrists and hand surgeons (24). In New Zealand, the most common reasons for declining surgery were the hope for cure or further recovery, alongside an inadequate physical environment or social support. Particularly for women, the temporary loss of independence and increased need for help were identified as reasons to decline surgery (25).

1.1 Cervical spinal cord injury

The incidence of spinal cord injury differs between countries. In Sweden it is 10-15 cases per million inhabitants, compared to 58 in Portugal and 40 in the USA (26) and only 4.5 in Norway (27). The global incident rate in 2007 was estimated at 23 cases per million inhibitions (28). The most common cause of traumatic spinal cord injury in developed countries is road traffic accidents, although causes differ significantly between developed and developing countries (28). Most of those injured are men; the ratio between men and women is 4:1. The average age of injury in the United States between 2005 and 2008 was 40, an increase of 11 years since the mid-1970s (29).

A cervical spinal cord injury leads to impairment in all four extremities, known as a tetraplegia, while a lower injury leads to impairment in the two lower extremities, or paraplegia. About 55 percent of these are cervical spinal cord injuries (26). As seen in figure 2, the deltoid muscle function in the shoulder and the elbow flexion, at cervical level 5 (C5), has the highest innervation in the upper limb. For C6 the most important function is the wrist extension. At C7 the patient also has the elbow extension retained. At C8 the finger and thumb flexion are present. All participants in this thesis have had spinal cord injuries between C4 and C7.

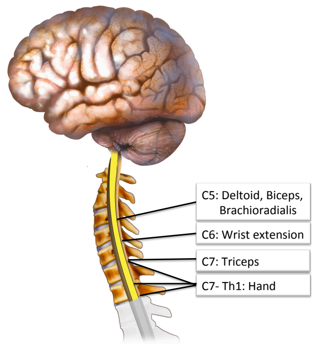


Figure 2. Consequences of injury in various parts of the cervical spinal cord.

Lesion in the spinal cord causes loss of muscle function, sensory dysfunction, impairment in vegetative functions like bowel and bladder, sexual dysfunction, and problems with thermo and blood pressure regulation. The extent of the damage depends on the lesion level and completeness. Common secondary complications to cervical spinal cord injury include pressure source, pulmonary difficulties, and bowel and bladder complications. These changes in body structures and function reduce the injured person's chance of functioning in daily life. Elderly people especially might experience difficulties in translating their remaining functions into daily life (30). However, in Sweden most people with C-SCI are active in society, working and living in their own homes, often with the support of personal assistants.

Today, approximately 5000 people in Sweden live with a spinal cord injury. Given today's rehabilitation techniques, a person with spinal cord injury can be expected to live almost as long as a non-injured person (26). Therefore it is important that these people are well-rehabilitated and as independent as possible, not only for their and their relatives' quality of life but also for the financial costs to society.

1.1.1 Level of injury and classifications

ASIA score

ASIA score is used worldwide to describe the *neurological* level of spinal cord injury. The neurological level defines the injury of the spinal cord and is not always the same as the skeletal injury level. The score was developed by the American Spinal Injury Association (31) and measures both sensory and motor functions. The neurological level of injury is defined as the lowest spinal cord segment with normal sensation *and* motor function. Motor function is measured by the strength of ten key muscles on each side of the body. The key muscles for the upper limb are shown in table 1 and scored on a five-point muscle grading scale as shown in table 2.

Table 1. Key muscles in ASIA scoring system.

Key muscles for upper limb	
C5	Elbow flexors
C6	Wrist extensors
C7	Elbow extensors
C8	Finger flexors
Th1	Finger abductors

Sensory function is measured by light touch and pinprick sensations, one for each dermatome. There are 28 specific sensory locations on each side of the body. The sensory levels are scored on a 0 to 2 scale (Table 2). The neurological level is set at the lowest segment where motor and sensory function is normal on both sides.

Table 2. ASIA scoring system to define neurological level of spinal cord injury.

Muscle strength is graded as	
0	Total paralysis
1	Palpable or visible contraction
2	Active movement, full range of motion, gravity eliminated
3	Active movement, full range of motion, against gravity
4	Active movement, full range of motion, against gravity and provides some resistance
5	Active movement, full range of motion, against gravity and provides normal resistance
Sensibility is graded as	
0	The sensation is absent
1	The sensation is present but impaired
2	The sensation is normal

The neurological injury is not always a complete lesion: nerves can still be intact, despite the injury, to various extents. Therefore, ASIA also contains an impairment scale that describes a person's functional impairment as a result of their spinal cord injury, scoring from A to E (Table 3). The impairment scale grades the completeness of the injury by how much of the motor and sensory functions that are preserved below the injury. The grade of incompleteness presents special considerations in terms of rehabilitation, since it has various impacts on the person's functional impairment and on the disability. In terms of hand surgery, patients with incomplete injuries must pay attention to special considerations to optimize their possibilities of functioning.

Table 3. ASIA impairment scale.

- **A.** **Complete**: No motor or sensory function in the lowest sacral segment (S4-S5)
- **B.** **Incomplete:** Sensory function below neurologic level and in S4-S5, no motor function below neurologic level
- **C.** **Incomplete** Motor function is preserved below neurologic level and more than half of the key muscle groups below neurologic level have a muscle grade less than 3.
- **D.** **Incomplete** Motor function is preserved below neurologic level and at least half of the key muscle groups below neurologic level have a muscle grade >3
- **E.** **Normal** Sensory and motor function is normal

International Classification for Surgery of the Hand in Tetraplegia (ICSHT)

The tetraplegia hand surgery society has another way of classifying the functions that remain after a cervical spinal cord injury. ICSHT categorizes vision, sensibility, and the number of key muscles available for transfer (Table 4). All key muscles with strength of M4 or more are recorded (32).

Table 4. Key muscles as defined by International Classification for Surgery of the Hand in Tetraplegia (ICSHT)(32).

Group	Muscles, grade 4 or more
0	No muscle below the elbow
1	m. Brachioradialis
2	m. Extensor carpi radialis longus
3	m. Extensor carpi radialis brevis
4	m. Pronator teres
5	m. Flexor carpi radialis
6	Finger extensors
7	Thumb extensors
8	Partial finger flexors
9	Lack only of intrinsics
X	Exceptions

Tenodesis grip function

Injuries from C6 and lower have their wrist extensors preserved to various degrees. The wrist extensor is critical for arm-hand skills performance. The active movement of the wrist makes a weak, passive grip and grasp possible: this is the so-called tenodesis grip or functional hand. Tenodesis grip aims for passive opening of the hand when flexing the wrist (actively or by gravity), as seen in the left hand picture in figure 3, and closing the hand and thumb against the index finger when extending the wrist, the right hand picture in Figure 3. With training, this grip offers major opportunities to manage daily activities. The grasp and grip rely entirely on the position of the wrist. Not all people with C-SCI develop a tenodesis grip, and the way to facilitate the optimal tenodesis grip has not yet been fully explained (33). Even though a well-trained tenodesis grip is very useful for a person with tetraplegia, it has its limitations since the force in the hand and key pinch grip is seriously limited. The grip also relies on the position of the wrist, which can be restrictive in many situations in daily life.

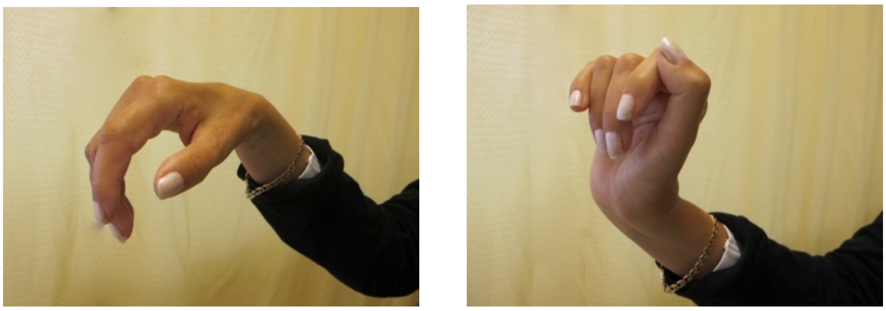


Figure 3. Tenodesis grip. Passive opening of the hand when flexing the wrist (left) and passive flexion of fingers and thumb when extending the wrist (right)

1.2 Tendon transfer in tetraplegic upper limb

Tendon transfer surgery in humans has been described since the late 1800s, and reconstructions of hand function in tetraplegia have been undertaken for more than 60 years, since Bunnell advocated tendon transfer and tenodesis in C6/7 patients (34). Thereafter pioneers like Moberg, Zancolli, McDowell, and House contributed to the establishment of tetraplegic upper limb surgery (8,11,13,14,35-37). In later years, these developments have proceeded with, for example, Lieber and Fridén's studies regarding muscle function and methods in reconstructions, which have provided valuable information and increased knowledge in this field (38-40).

Restoration of upper limb function in tetraplegia involves an advanced combination of tendon transfers, tenodesis, and often arthrodesis. A skilled and experienced surgeon is essential to create a functional balance in the hand, and experienced and dedicated therapists are needed to optimize the recreated functions. The surgeon must be trained to decide on the best combination of operations and surgery techniques to create a balanced hand, all in harmony with the patient's specific requests. The therapist must have an understanding of the surgery performed and the knowledge to confidently guide the patient through the quite extensive functional training, without being disturbed by fear, pain, blood, or oedema. After the initial functional training the therapist must guide the patient to use the regained function in activity and daily life. The patients included in this thesis all underwent their surgery and rehabilitation in a specialized unit with experienced staff, from nurses to rehab personnel and surgeons.

1.2.1 Triceps reconstruction

Lack of triceps function limits the ability to control the arm, reach against gravity, and straighten the elbow. Reaching above shoulder level is a common circumstance in daily life for a person using a wheelchair, who is in a sitting position. Restored elbow extension provides opportunities to straighten the arm and thereby gain an increased personal workspace.

There are two common donor muscles to restore triceps function in tetraplegia, M. Biceps and M. Deltoid. All patients in this thesis have M. Deltoid as the motor in their triceps reconstruction. The posterior portion of the Deltoid muscle is attached to the triceps using a tendon graph (Tibialis anterior) (41), as shown in figure 4. Postoperatively, the attachment has to be protected from over-tensioning. The reconstruction must therefore be protected from flexion in the elbow and adduction and flexion in the shoulder. Alongside splints that restrict elbow flexion, patients require an electric wheelchair with a special armrest to position the arm for the first 10 weeks after surgery.

Figure 4.

The reasons for doing a triceps reconstruction are not only to extend the workspace of the arm. Another argument is that it allows the injured person to gain a better functional use of a future grip reconstruction. Triceps supports the grip function two-ways: firstly they allow the person to position the arm and use the grip in various positions in space, and secondly they work as an antagonist to the elbow flexor, M. Brachioradialis, which is often used as a donor muscle in grip reconstructions. A strong antagonist gives the reconstructed grip a more favorable mechanical condition of functioning in various workspaces in daily life.

1.2.2 Grip reconstruction

Grip reconstructions contain an advanced combination of tendon transfers, tenodesis, and often arthrodesis. A detailed preoperative examination of the hand is essential to decide on the optimal surgical strategies for each individual patient. First, the surgeon needs to have a comprehensive and careful discussion with the patient that should include the patient's specific needs and expectations, and how surgery can meet them. Often, the discussion must be continued over several meetings before decisions can be made to go ahead with the surgery and what that surgery should include (42). Reconstruction of the grip function can range from restoring a passive key pinch to a full alphabet procedure including active thumb flexion, active finger flexion, passive or active extension of the PIP joints, passive opening of thumb, and adjusting for radial deviation in the wrist (16,43). The decision relies on each specific patient's situation in terms of remaining functions, time, motivation, and, most important, requests.

Passive key pinch with active wrist extension

The first established grip reconstruction involved restoring a passive key pinch (44), which is still is a useful technique. When Brachioradialis (BR), an elbow flexor, is the only remaining function below the elbow this surgery can provide the patient with active wrist extension and passive thumb flexion, making a key pinch grip when the wrist is extended. A transfer of BR to M. Extensor Carpi Radialis Brevis (ECRB) provides the patient with an active wrist extension. The passive key pinch is then provided by arthrodesis of CMC1 and tenodesis of Flexor Pollicis Longus (FPL) and Extensor Pollicis Longus (EPL) (45).

The Alphabet procedure

The alphabet procedure stands for Advanced Balanced Combined Digital Extensor Flexor Grip (ABCDEFG). It is comprised of seven operations and combines flexion and extension reconstruction in one procedure (43). BR is transferred into FPL to restore thumb flexion (Figure 5) and Extensor Carpi Radialis Longus (ECRL) to Flexor Digitorium Profundus (FDP) to restore finger flexion. To optimize thumb movement the FPL is split in half and one portion of the tendon is transferred to Extensor Pollicis Longus (EPL). EPL is also tenodesed into the forearm fascia and the base of the thumb (CMC1) is fused. As an adjustment to the power grasp, the Extensor Carpi Ulnaris (ECU) is tenodesed into the ulnar head to avoid radial deviation of the wrist, and a reconstruction of intrinsic with free tendon grafts is performed to allow the patient to open the hand better.

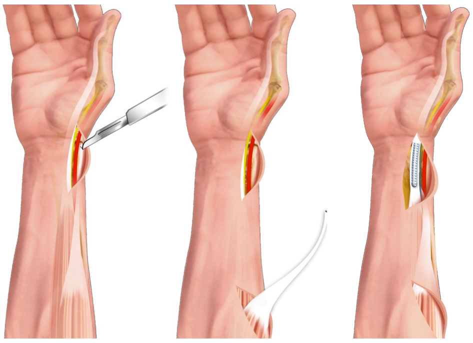


Figure 5. Surgical procedure for tendon transfer of Brachioradialis (BR) to Flexor Pollicis Longus (FPL)

This procedure provides the patient with far better possibilities to function since it combines finger flexion to grip with passive finger extension, enabling the hand to grasp more easily (Figure 6). The advantage is that this facilitates both the closing and the opening of the hand within one surgery and rehabilitation period (43).

Figure *6. Ability to grasp and grip the pushrim on the wheelchair after an Alphabet procedure.*

1.2.3 Rehabilitation after surgery

Grip reconstruction

Early activation of the new functions is essential for several reasons. First, maintaining tendon sliding prevents adhesions and oedema, which are common obstacles after surgery. Early activation also maintains muscle capability and neuromotor activation, while immobilization leads to muscle atrophy, decreased muscle force, and, to some extent, muscle stiffness (46). Neurological input is also known to decrease during immobilization (47). A prerequisite for using the early activation concept is a reliable suture technique. The surgeries included in this thesis all used the side-to-side technique (39), which is known to be strong enough to securely permit early activation (40). Early activation means that the patient starts active training of the restored functions within 24 hours after surgery, and is taught to take control over and play an active part in the training, which happens four times a day. The aim is to activate the restored functions with a large range of motion (ROM) and in as isolated and smooth a manner as possible. There is no strength training at this point. An experienced and enthusiastic therapist is critical to guide the patient through this quite aggressive and demanding training. In between sessions the hand is protected in a splint, also designed to prevent oedema.

The rehabilitation staff needs to pay attention to more than training the transferred muscles. The patient has done a hard job of becoming as strong and independent as possible during the initial rehabilitation after the spinal cord injury. It is mentally important to most patients to maintain this independence, and losing general fitness means months of hard work to get it back. Therefore, encouragements and adjustments to remain as active in daily activities as possible. during restriction period are essential, for example regarding the ability to drive manual wheelchair (Figure 7). Patients who feel secure and are educated to **be active** use their arms more, which increases blood flow, prevents postoperative oedema, and supports healing. There are therefore both physical and psychological reasons to make it possible to maintain as normal a life as possible during the initial restriction time after surgery. Being active also prevents complications like pressure sores and pulmonary infections.

Figure 7. Driving wheelchair with splint applied on the hand at the first postoperative day.

The first four weeks of rehabilitation focus on ***neuro-motor training*** in order to find and activate the new functions, and to prevent oedema. In the fourth week after surgery the focus changes to **activity-skills training,** even as training of the function continues. The functional training is now more concentrated on activation with the arm in different positions, moderate strength, and isolated movements. Activity-skills training initially focuses on transforming the function into useful activities (Figure 8). Step two in activity training focuses on movement patterns in the upper limb. The increased hand control offers opportunities to position the arm more efficiently, for example letting it rest on the table instead of working with the shoulder abducted or active grasping in the push rims (Figure 6). Training in real environment is here essential (48-50). The last step in activity training is the demanding challenge of re-examining the patient's habits and fully integrating the new possibilities into everyday life.

Figure 8. Examples of activities trained four weeks after grip reconstructive surgery.

Triceps reconstruction

Rehabilitation is slightly different after triceps reconstruction. The neuromotor training starts the day after surgery, but activation of the new function is performed in the splint during the first four weeks. Thereafter active elbow extension training is performed, with gradually increasing flexion of the elbow in a dynamic splint. The training focuses on the full active extension of the elbow. Full flexion is usually allowed after 10 to 12 weeks. In order to protect the tendon-to-tendon attachments from lengthening, flexion in the elbow and adduction and flexion in the shoulder are restricted. Therefore, adjustments to electric wheelchairs with special armrests and no manual transfers are required during the first 10–12 weeks after surgery. Thereafter, the patient must undertake activity, skills, and strength training. Even though the patient may be seriously restricted during the first 12 weeks, it is important to facilitate possibilities to remain as active as possible in daily life.

1.3 Theoretical framework

This thesis has its basis in a combined hand surgery, neurological, and occupational therapy perspective.

1.3.1 Occupational performance

Occupation is here defined as everything a person does to occupy him or herself, including looking after him or herself, enjoying life, and contributing to the socio-economical fabric of his or her community. This definition comes from the Canadian model of occupational performance (CMOP), which has been used in occupational therapy for the last 30 years. Occupations encompass more than one task or activity in everyday life and are given meaning and value by individuals and a culture (2). A client-centered rehabilitation after upper limb surgery in tetraplegia should focus on *enabling occupation*, collaborating with patients to choose, organize, and perform occupations that they find useful or meaningful in a given environment. Occupational performance is a dynamic interaction between person, occupation, and environment (Figure 9). Changes in any of these areas will influence a person's performance in, and satisfaction with, their occupational performance. In the current studies, the occupational therapists use the CMOP as their theoretical framework, taking a client-centered approach with a focus on enabling occupation during the rehabilitation after surgery.

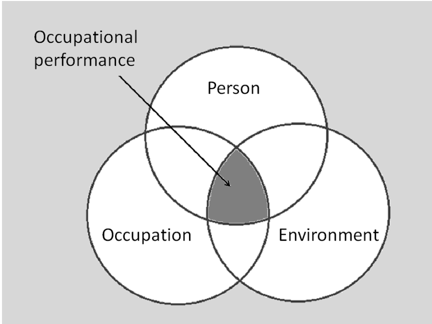


Figure *9. Occupational performance.*

The CMOP inspired the development of a semi-structured evaluation tool called the Canadian occupational performance measure (COPM). COPM is an individualized, client-centered measure designed to detect changes in a client's self-perception of occupational performance over time (51). For further details regarding the COPM please see the methods section 3.3.1.

Reconstructive upper limb surgery in tetraplegia aims to regain body function, which facilitates potentials for improvements in occupational performance. The Canadian occupational performance measure is a useful tool for detecting the individual's desired occupations and a structured way of evaluating changes in occupational performance, including satisfaction with that performance. Evaluations of reconstructive upper limb surgery in tetraplegia have not previously focused on this perspective of possible changes after the intervention.

1.3.2 International Classification of Function, Disability and Health (ICF)

The ICF is the World Health Organization's (WHO) framework for measuring health and disability at both individual and population levels (1). In 2001, all WHO member states sanctioned the ICF (resolution WHA 54.21) and endorsed it as the international standard to describe and measure health and disability. The ICF puts the notions of "health" and "disability" in a new light, shifting the focus from cause to impact and not seeing disability as a solely "medical" or "biological" dysfunction. Furthermore, the ICF takes into account the social aspects of disability and the impact of environment on the person's functioning (Figure 10).

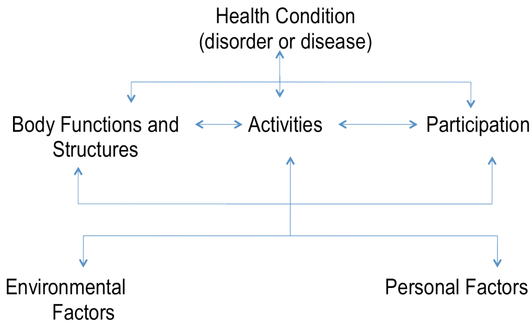


Figure 10. ICF model (1).

The ICF is recommended and used in the management of SCI in order to categorize and highlight different aspects of the consequences associated with the condition (52). All patients in this thesis had suffered a spinal cord injury, a health condition that has a major impact on the person's whole life. The SCI influences the body structure, function, activities, and participation. Changes in those areas also affect personal and environmental aspects of life (53).

Both the ICF and CMOP emphasize awareness of activity, participation, and personal and environmental factors to reduce disability and improve occupational performance. Reconstructive arm-hand surgery affects body structure in order to regain body function, for example finger flexion or elbow extension (9,15,18-20). Positive results have also been shown in activity and, to some extent, participation (54-56). I believe that the goal of surgery is not only improvements in body function but also to better the person's everyday life, decrease disability, and improve occupational performance. Therefore, the aim of this thesis was to investigate the relationship between body function advancements and activity and participation improvements. Moreover, the CMOP and ICF framework addresses environmental and personal factors that impact on body structure, body functions, activity, and participation. Therefore, environmental and personal factors are also taken into account in this thesis.

2 AIMS

The general aim of this thesis was to investigate and gain a better understanding of patients' perceived outcomes after upper limb surgery for people with tetraplegia, with a special focus on the participants' perspectives on activity, participation, and personal and environmental factors.

Specific aims

1. To evaluate and analyze patients' individual activity goals related to grip reconstruction. Study design included (A) analysis of particular activity areas that the individuals prioritized as important to improve and (B) measurements of subjective functional changes and satisfaction with the performance in these prioritized activity goals (Study I)

2. To investigate (A) the relationship between perceived performance in prioritized activities and physical conditions pertinent to grip reconstruction and (B) whether functional factors known before surgery can predict post-operative activity improvement (Study II).

3. To evaluate and analyze patients' individual activity goals related to triceps reconstruction. Study design included (A) analysis of the particular activity areas the individuals prioritized as important to improve and (B) measurements of subjective functional changes and satisfaction with the performance in these prioritized activity goals (Study III).

4. To investigate and better understand the consequences that the participants experienced after grip reconstructive surgery and rehabilitation (Study IV).

5. To explore and better understand the participants' experiences of the relearning process, from gained body function to activity and participation benefits, after grip reconstruction (Study V).

3 PATIENTS AND METHODS

3.1 Study group

All participants underwent their surgery at Sahlgrenska University Hospital, Göteborg, Sweden. They lived in diverse parts of the Nordic countries. Study I includes 22 grip reconstructions performed on 20 people, and analyzed the 106 goals these patients prioritized. Study II extended the number of participants to 46 grip reconstructions on 41 people. Nineteen triceps reconstructions performed on 14 people were included in Study III. Studies IV and V interviewed 11 people (Table 5).

Table 5. Demographics.

	Number of surgeries included	Man/ Women	Age (yrs)	Time since Injury (yrs)
Study I	22	16/4	44 (20-74)	7.3 (1-34)
Study II	46	36/11	40 (20-74)	8.0 (1-34)
Study III	19	15/4	30 (18-63)	7.0 (2-16)
Study IV	11	10/1	39 (22-73)	3.0 (2-6)
Study V	11	10/1	39 (22-73)	3.0 (2-6)

3.2 Study context

Sahlgrenska University Hospital has a long tradition of upper limb surgery in tetraplegia. Erik Moberg began in the 1970s and since then over 800 surgeries have been performed at the clinic. The center for reconstructive hand surgery in tetraplegia has a specialized team of two surgeons, two occupational therapists, two physiotherapists, and a neurologist trained in spinal cord injury. The patients come from diverse parts of the Nordic countries. They stay in the clinic for three days after surgery to initiate the rehabilitation and then come back after four weeks for five days of follow-up and progression in the rehabilitation process.

3.3 Data collection and analysis methods

This thesis uses a combined qualitative and quantitative research approach that captures the diversity of the individuals' experiences of changes in their lives after reconstructive hand surgery. Since the nature of the research must guide the choice of approach (57), this combined methodology benefits from the strengths of different methods and therefore offers a deeper understanding about the phenomenon studied (58).

General test batteries are, in contrast with individualized outcome measures, often not designed to detect specific changes that may be important to the patient (59). An item score can suggest maintenance of the status quo, but the patient may still experience improvement. The patient may improve on only particular components of the skill being analyzed, which would not be visible in the score of a generic skill test battery (60). In contrast, an individualized outcome measurement provides information that is important to patients and, in the end, the main goal of intervention is improving patient experienced gains, not capturing a change with the outcome measurement. Because of this knowledge, the methods in this thesis are based on the individuals' perceived outcomes after surgery and rehabilitation. Its main advantage is its sensitivity to changes in individual experience, while its disadvantage is a possible loss of objectivity and generalizability.

Studies included in this thesis highlight diverse aspects in the ICF framework (Figure 11). The first three focused on activity improvement and its relation to body function. Study 4 aimed to learn more about gains in a broader perspective, including questions regarding personal and environmental aspects alongside activity and participation. The last study (Study 5) investigated patients' perspectives on the transformation process, from improved body function to activity improvements. Together, the studies cover outcomes after tetraplegia hand surgery in all aspects of the ICF framework, except for the Health condition aspect, where the C-SCI represents the major impact.

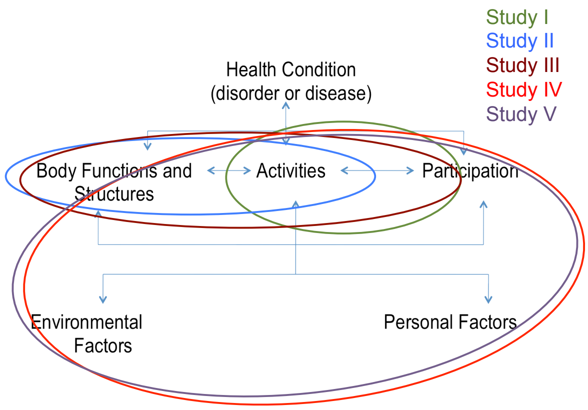


Figure 11. Evaluation focus on the studies included in the thesis, from an ICF perspective.

3.3.1 Canadian Occupational Performance Measure (COPM)

The Canadian Occupational Performance Measure (COPM) is an individualized, client-centered measure designed to detect changes in a client's self-perception of occupational performance over time (61,62). The instrument was designed for use as an outcome measure and has been developed to apply the Canadian Model of Occupational Performance (see Introduction, 1:3:1). The COPM is a standardized instrument in that there are specific instructions and methods for administering and scoring the test. It has a semi-structured interview format and structured scoring method and was designed for use with clients with a variety of disabilities and across all developmental stages (61,62).

COPM has demonstrated sufficient test-retest reliability and validity across several populations, treatment sessions, and countries (64,65), and is sensitive to changes in the SCI population (66)**.** COPM is a recommended measurement tool in research in this field. One of the strengths of using a client-centered approach is that it focuses on activities that are important to the patient's individual situation and on goals relevant for her or his (67). The VIII International meeting on upper limb in tetraplegia in 2004 agreed on COPM as its recommended evaluation tool in tetraplegia upper limb surgery (68).

As the COPM interviews were orientated towards the planned surgeries, the individuals described problems experienced in their daily lives caused by arm/hand function. Each person chose up to five problems from these occupational limitations, which described her or his activity goals with grip reconstruction. Finally the patient rated the chosen goals for current level of performance respectively satisfaction with the performance on scales, from 1 to 10 (1 = not able to do it, not satisfied at all and 10 = able to do extremely well, extremely satisfied). The semi-structured interviews were undertaken on three occasions; prior to surgery then six and 12 months postoperatively. Three therapists performed all the interviews, the first therapist performed approximately 80 percent of them.

In study I and III each goal categorized according to the ICF classification of activity and participation (69). This method facilitated an ability to analyze changes in of types of goals instead of changes per person.

3.3.2 Correlation analysis

In study II, Spearman's rank correlation coefficient was used to test the possible relationship between physical data and activity change. Functional characteristics and performance data were collected retrospectively from our database and from medical records.

Physical factors

Physical factors known before surgery included:

- Age at surgery, in years
- Time since injury, in years
- Severity of injury, according to ICSHT (32)
- Sensibility, measured by two-point discrimination. More than 10 mm on the thumb was considered "no sensibility"
- Hand dominance at time of surgery

Physical factors examined at the one year follow-up were:

- Ability to close the hand. Reflected by:
    - Grip strength (kg) (Jamar hand dynamometer, North Coast Medical, Gilroy, USA)
    - Key pinch strength (kg) (Preston Pinch Gauge, North Coast Medical, Gilroy, USA)
    - Finger pulp-to-palm distance (cm)
- Ability to open the hand. Reflected by:
    - Maximal distance between thumb and index (cm)
    - Range of motion of wrist flexion
    - Muscle strength of wrist flexion (MMT)

Activity performance

The research used the prioritized goals from COPM to evaluate the changes in activity performance after surgery and analyze the difference between the preoperative and postoperative COPM ratings for each patient.

In order to perform a group analysis of the activity change, activity performance differences were divided into three groups:

- Unsure improvement (-0.7 – 2.0 points)
- Improvement (2.1 – 4.0 points)
- Major improvement (4.1 – 9.0 points)

The authors of COPM claims a scale difference of 2 as a "clinically important change" (64). Therefore the "unsure improvement" group included patients with ≤ 2 points improvement.

3.3.3 Qualitative analysis, grounded theory

Studies IV and V used grounded theory, mostly inspired by the Glaser tradition (70-72). Grounded theory is a qualitative approach that aims to create a theory confidently grounded in collected data, rather than reflecting predetermined hypotheses. Since minimal qualitative research has been previously done in this field and our area of research was more one of exploring nature than testing a predefined hypothesis, grounded theory was a useful method. Accordingly, we conducted semi-structured interviews held between seven and 17 months after surgery. The timeframe of the interviews was adjusted through the interactive process of data collection and analysis. During analysis of the first interviews, which occurred at least 12 months after surgery, results indicated that some information had been lost because of the long perspective. In accordance with grounded theory methodology, the timeframe was therefore adjusted (71) to include interviews that took place earlier than 12 months after surgery.

The interviews included two main topics. The first explored the participant's perception of the major effects of surgery and associated changes on his or her life, with questions regarding the psychological, social, and cosmetic effects, degree of assistance needed, disadvantages of the surgery, and the participant's general level of satisfaction (Study IV). The second explored important stages and feelings when integrating a new function in daily life, with questions covering success factors, obstacles in the process, patients' and others' contributions, and timeframes in the relearning process (Study V). In order to strengthen the studies' theoretical sensitivity, the first author conducted all the interviews. The interviews occurred at the participants' home clinics, in spinal cord injury units throughout Sweden. The interviewer has extensive experience with spinal cord injury and the specific hand surgery intervention received by these participants. Most of the participants had previously met the interviewer during the five-day rehabilitation periods that occur immediately following surgery, and during another five days of rehabilitation four weeks after surgery. In some cases, they also met briefly after three or six months. All interviews were audio recorded and transcribed verbatim. Theoretical memos were written throughout the entire process.

The first step of analysis was the “open coding,” in which data was broken down into meaning units and codes were identified. To maintain trustworthiness, the two authors performed open coding separately. These codes were compared and thereafter condensed into categories. The authors discussed disagreements until they reached a consensus. This condensed process was a result of their awareness of the participants’ context and the authors’ varying theoretical frameworks and levels of prior knowledge. First and last authors have extensive experience in this field and with this patient population, but have different professional backgrounds. Author 2 had minimal preconceptions because she has no prior experience with this patient group; her expertise lies in qualitative methods. The authors performed comparisons between data, codes, categories, and theoretical memos throughout the whole analytical process. Since functionality and relevance are important in a well-made model (72), the model was presented to two experienced therapists: one from the center in which the study was conducted, and one therapist and researcher from New Zealand. Both therapists stated that the model was understandable and relevant to their field (although some linguistic adjustments were necessary to maintain the correct meanings of words when translating them into English).

3.4 Ethical considerations

The Regional Ethics Committee of Research Involving Humans in Gothenburg, Sweden, approved the studies (Dnr. 010-09 for study I-III and 080-10 for study IV-V).

Except for the interviews, all outcome measurements are a part of the clinical assessments. COPM in particular is clinically important and not primarily a research instrument. It emphasizes patients’ expectations and important activities. This information is critical during the rehabilitation after surgery so that it can be focused on activities that are relevant to the patient. Therefore, outcome measures are a part of our regular clinical follow-up.

The interview studies required one extra hour at follow-up. Since these kinds of patients are often the objects of research interest, the participants were carefully informed of the voluntariness of taking part in the study.

4 RESULTS AND DISCUSSION

This thesis demonstrates that upper limb surgery in tetraplegia can affect all ICF domains: body function, activity, participation, personal and environmental. The improvements were not just seen in basic ADL activities such as eating. There were major improvements in activities generally regarded as more complex to perform, such as domestic life and leisure activities (Studies I and III).

The patients summarized their gains as *enhanced independence.* In this context, independence meant autonomy, freedom from control, self-reliance, and acting for oneself. Enhanced independence contained both practical and personal changes. It was not just described in terms of enhanced ability to more easily and efficiently perform activities. It was also described in terms of ability to participate more actively and in added situations. Psychological aspects included feelings of greater management in daily life, less dependence on people and environment, but also increased self-efficacy in hand control. One patient described the most important change as: *"I have an entirely changed sense of freedom regarding my left hand. I can use it in a totally different way, compared to previously."* Another said: *"A feeling of being more complete, in a way"* (study IV). The results of this thesis agree with the single case study performed in New Zealand, suggesting hand surgery affects all ICF dimensions (73).

Physical function is important for the activity performance, but one function alone could not explain activity change (Study II). The patients defined *determination for higher independence* as the most important factor to transform body function into activity and participation improvements. Belief in improved ability and confidence in the new ability were critical to proceed into daily use (Study V).

4.1 Body function and structure changes

Body functions and structure evaluations after upper limb surgery have been evaluated previously (9,15,18-20). The general conclusion is that hand surgery in tetraplegia can give substantial functional improvement. Therefore, evaluations of this section in the ICF model were not the main focus of this thesis. However, some general data on body functions and structure were collected and assessed.

Grip reconstruction

Results from 12-month follow up of 47 grip reconstructions demonstrated a mean grip strength of 5.6 kg, ranging from 2 kg to 20 kg. Pinch strength after 12 months was 2.1 kg (0.2 kg to 5.6 kg). Maximum distance between thumb and index finger when opening the hand was 5.0 cm (range 0 cm to 14.5 cm). When flexing the fingers, the gap between fingertips and palm was less than 1 cm (Table 6). In conclusion, and in concert with previous studies, the changed body structure following surgery improved body function (9,15, 18-20).

Table 6. Body functions improvement one year after grip reconstruction (N=47) and triceps reconstruction (N=19).
**= Maximum distance between thumb and index finger in cm when opening the hand.*

Body function outcome 12 months postoperatively

		Mean	Range
GRIP	Pinch strength (kg)	2.1	0.2 - 5.6
	Grip strength (kg)	5.6	2.0 – 20.0
	Max opening (cm)*	5.0	0.0 - 14.5
TRICEPS	MMT 5	1 arm	
	MMT 4	9 arms	
	MMT 3	7 arms	
	MMT 2	2 arms	
	MMT 1	0 arms	

Triceps reconstruction

Body function improvements from triceps reconstructions have been described previously (9,15,19,20). The observed improvements in this thesis were based on 19 deltoid-to-triceps reconstructions. Graded muscle strength after 12 months ranged between 2 and 5 as follows: MMT 5, one arm (a rugby player); MMT 4, nine arms; MMT 3, seven arms; and MMT 2, two arms (figure 6). Eleven arms had preoperative extension deficits, ranging from 10 to 25 degrees. The deficits were decreased or absent after 12 months in six of these 11 cases. The maximum extension deficit at 12 months was 20 degrees (in one arm). In conclusion, 17 of 19 arms had the strength to reach against gravity, and six of 11 decreased their extension deficit after deltoid-to-triceps reconstruction (Study III). Extension and stabilization of the elbow for people with tetraplegia is known to be strongly correlated to transfer abilities in C-SCI (74) and independence in self-care (75). Therefore, this procedure seemed to reliably increase the important triceps function and functional conditions for greater independence for C-SCI patients.

4.2 Activities and participation changes

Two studies in this thesis, one for grip reconstruction and one for triceps reconstruction, evaluated performance changes in prioritized activities and satisfaction with that performance. The studies used the COPM as the outcome measurement (Studies I and III). The results from these studies are presented in Chapters 4.2.1–4.2.4.

4.2.1 Patients reached their prioritized activity goals

General and significant improvements were observed for both performance and satisfaction when comparing the preoperative results with those at six and 12 months postoperatively. Improvements were seen after both grip reconstructions and triceps reconstructions. As a parameter of performance, it is likely that satisfaction interacted with an individual's willingness to engage in a task and participate (76). Therefore, it is important that both performance and satisfaction improves after an intervention. Average performance and satisfaction for grip reconstructions improved by approximately 3.5 points at both six and 12 months postoperatively (Figure 12A). The mean improvement in performance was 2.5 points after 12 months for triceps reconstruction (Figure 12B). No single goal was rated lower at 12-month follow up than before surgery, independent of surgery type. These improvements are similar to the results in a previous study where six of eight patients achieved improvements in all five goals after hand surgery (77).

A

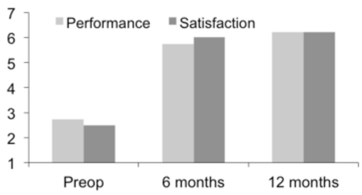


Figure 12 A: Grip reconstructions general improvements in prioritized activities. Statistically significant differences between all test occasions were observed (P < 0.05).

B

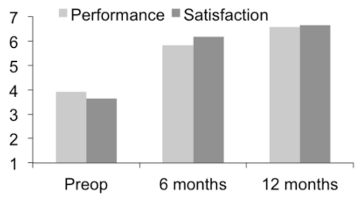


Figure 12 B: Triceps reconstructions general improvements in prioritized activities. Statistically significant differences between all test occasions were observed (P < 0.05).

Previous evaluations of triceps reconstructions in children with spinal cord injury reported slightly higher improvements by three and four points, respectively (78,79). Comparative studies using the same evaluation tool after grip reconstruction are missing. In comparison to primary rehabilitation of spinal cord injury, the increased level of performance was 4.6 points (66). It might not be correct to compare improvements between primary rehabilitation and, for example, grip reconstruction, since the type of goals might differ. Important is however that grip reconstruction can improve activity, although not as much as the whole primary rehabilitation. Comparisons between different areas using the COPM as an evaluation tool must generally be handled conservatively, since the evaluation might cover entirely diverse activities. Examples comparing type of goals between grip and triceps reconstructions are shown elsewhere (p 28). However, when asking patients about their experiences after grip reconstruction, they all claimed to have achieved a greater independence, which was their overall goal with surgery. One participant said: *"When you don't have to ask for help with certain things, you can manage by yourself. Then, it feels more like it was before [the injury], really. …You want them to be friends, not helpers."* In conclusion, patients mainly reached their prioritized activity goals and were satisfied with their new performance.

Regained activities

Before grip reconstruction, patients rated 35 percent of the goals as impossible to perform (1 on the rating scale). After surgery, patients rated 78 percent of those goals as possible to perform, 11 percent were rated "able to perform extremely well" (10 on the rating scale). These activities included "writing," "sewing," holding a fishing pole," and "buttoning clothing." These findings reflect two interesting aspects. First, the surgery substantially improved the ability, even though these patients had high expectations from surgery since they stated goals that were not possible to perform preoperatively. High expectations is known to have a positive effect on results from rehabilitation (80). Second, since 78 percent of the goals that were impossible to perform before surgery were possible after surgery and rehabilitation, patients were well-informed and could set high but reasonable goals before surgery. This patient information can be provided by fellow patients, surgeons, and other personnel with knowledge about expected outcomes.

4.2.2 Activity improvement over time

Both grip and triceps reconstructions improved activity performance during the first 12 months. Patients who underwent grip reconstructions made major improvements during the first six months, and then showed a smaller, but still improvement between six and 12 months (Figure 12A and14). Patients who underwent triceps reconstructions had slower initial improvement, but showed significant improvement between six and 12 months (Figure 12 B and 15). This finding might reflect the fact that rehabilitation after triceps reconstruction was more conservative and restricted the patient and the regain of functions for the first 10 to 12 weeks. Patients who underwent grip reconstruction were allowed and encouraged to use the hand in daily activities after four weeks.

4.2.3 Activity goals differ between type of surgery

Substantial differences were found when analyzing type of prioritized activities in triceps and grip reconstructions (Figure 13). It makes sense, since a well-informed patient can set goals relevant to the type of surgery they underwent. Goals associated with triceps reconstructions were the ability to move the body ("changing body position" and "walking and moving"), which represented 46 percent of the goals. It represented 11 percent of the prioritized activities related to grip reconstruction. In grip reconstruction, the typical goal was activities related to self-care for 36 percent to 46 percent of patients. In comparison, this was a stated goal for 19 percent of patients who underwent triceps reconstructions.

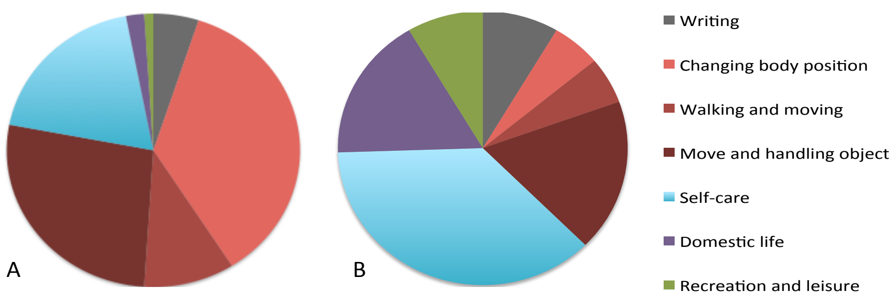


Figure 13. Activity goals prioritized in reconstructions of (A) triceps and (B) grip.

However, differences in goals between surgery types might also be explained by the fact that patients who needed triceps reconstruction generally had a higher level of C-SCI. This might also affect activity performance.

4.2.4 Improvements related to type of activities

After analyzing general improvements and prioritized activities, the next step merged these results to investigate changes in specific activity areas, using the ICF to classify the goals.

Grip reconstruction

The largest improvement in grip reconstructions was observed in the basic activity of eating, which was in line with previous studies (54) (Figure 14). Significant improvement was also noted in activities generally regarded as complex, namely housework and taking part in leisure activities. There was greater than four points of improvement in these areas after six and 12 months, for both performance and satisfaction. Satisfaction with writing and meal preparation activities also improved by more than four points. The greatest improvements in satisfaction occurred with leisure activities, demonstrating an increase of six points after 12 months. The activities of dressing and personal care showed the smallest improvement of only two points for performance (Figure 14).

The greatest improvements were observed not only in the basic activity of eating, but in activities that were generally regarded as complex and not measured in standard ADL measurements such as leisure and domestic life. Reflecting that surgery and rehabilitation made a difference in the activities most important in the individual's situation and in activities important for community living, with responsibilities more than just self-care.

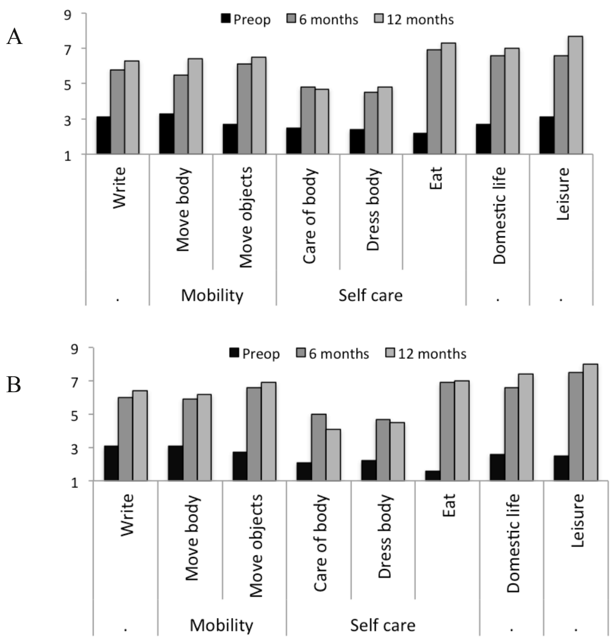
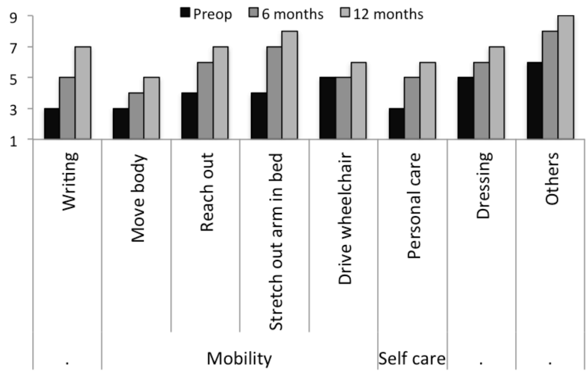


Figure 14. Activity changes in prioritized activities after grip reconstruction. (A) Performance, (B) Satisfaction with the performance.

Triceps reconstruction

For triceps reconstructions, activities with the highest performance improvements were writing and the ability to stretch out the arm when laying down, with four points for each (Figure 15A). The ability to stretch out the arm when lying down also showed the greatest improvement in satisfaction, with a mean of five points (Figure 15B). The other activity group with five points of improvement in satisfaction was goals related to the ability to reach out. Although driving a wheelchair and transfers represent common goals (20 percent), the smallest improvements were reported in these areas for both performance and satisfaction after 12 months.

A



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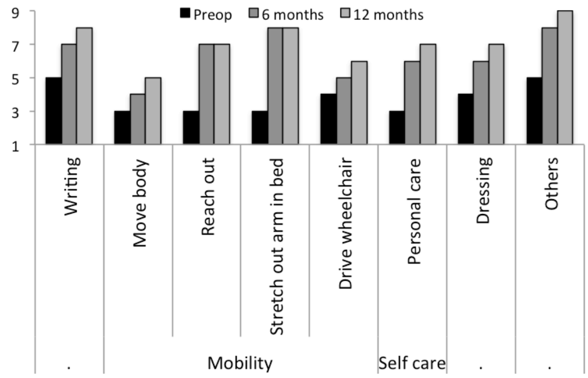


Figure *15. Activity changes in prioritized activities after triceps reconstruction. (A) Performance, (B) Satisfaction with the performance.*

The developer of COPM reported that changes greater than two points represent “a clinically important change” (64). This two-point change is frequently mentioned in studies, but its foundation is unclear. However, all activity groups in the grip reconstructive study, and all activities except driving a wheelchair in the triceps reconstructive study, improved by at least two points. Nevertheless, improvements in wheelchair maneuverability after reconstructive upper-limb surgery have been demonstrated in another study (81). In studies of newly injured SCI patients, triceps was critical for activities such as self-care (74,75). The presence of triceps allowed other techniques such as transfers and wheelchair driving. The patients in this study did not receive specific technique and skills training in these activities after surgery. It has yet to be determined if specific technique training could improve abilities in these areas.

4.2.5 Patients' perspective of activity change

A limitation in the results reported previous in this chapter, using the COPM as main method (study I and III), are that it only evaluates activity goals predicted before surgery. This information gives important knowledge of how the surgery meet patients' expectations of gains in daily live. As a compliment to this results a study focusing on what the patients experiences were one year after surgery were conducted. The study aimed to discover what the gains from surgery looked like and in which areas in life the changes occurred. It was designed to capture patient experiences regarding perceived activity, participation changes but also the impact from a personal and environmental perspective. A qualitative approach to capture these questions was chosen.

From the result of this study (study IV) the patients defined several aspects of activity improvements, but also personal- and environmental changes were described. The core concept describing the overall experience after grip reconstructive surgery was found to be **enhanced independence** (Figure 16). In this context, independence means autonomy, freedom from control, self-reliance and acting for oneself. Therefore, not only activity and participation improvements were described but also changes in patients' personal and environmental perspectives. The enhanced independence model, developed in study IV, was found to contain two main categories; "practical aspects of independence" and "psychological aspects of independence". In each main category five subcategories were identified which describe diverse aspects of the main categories. Subcategories of "practical aspects of independence" included; "perform more activities", "smoother everyday life", "renewed ability to participate in social activities", "less dependence on assistance" and "less restricted by physical environment". "Psychological aspects of independence" included; "regained privacy", "increased manageability", "regained identity", "recapture a part of the body" and "share positive experiences with relatives and friends" (Figure 16).

Figure 16. Experiences of changes in daily life after grip reconstruction in SCI

Encompassing all categories, a specific element was found; "self-efficacy in hand control." This element was seen as a result included in the enhanced independency core but also as an important factor for the development of the categories. Therefore, self-efficacy in hand control was considered within the enhanced independency core as a result but more than a subcategory. It was seen as result from the intervention but also an important element for subcategories to develop. Therefore, self-efficacy in hand control is considered within the enhanced independence core but also surrounding and in connection with all subcategories (Figure 16). The subcategories interacted and developed in concert with self-efficacy in hand control within the core category of enhanced independence. However, the importance of specific subcategories differed for each individual, depending on their situation in life. One person described it like this: *"The thing is that I can decide for myself. ... It is I who decides how good [the hand] gets… I can be finished now but I can also get better"*. The opportunity to regain something that has been lost and is deeply missed affects a person on many levels. One participant described the most important change as: "*I have an entirely changed sense of freedom regarding my left hand; I can use it in a totally different way, compared to previously"*. Another said: *"You get more independent, you can do more thing…. It feels good"*.

In the following pages experiences related to activity and participation changes are described. The other categories in the model are described in the chapter "Personal factor changes" and "Environmental factor changes", respectively.

Perform more activities

Improved hand control offered direct benefits on the ability to perform new activities. All participants gave examples of activities they were able to complete after surgery that were impossible before surgery, such as making breakfast, self-catheterization, locking the door, picking up objects an d playing cards. Although the functional improvements from surgery were limited to hand function, this had far-reaching effects, including increased ability to perform activities with the whole body, such as improved ability to walk due to improved ability to grasp walking aids Ability to maintain an active hold on dumbbells opened new possibilities in the gym. Overall, the increased activity level led to an increased overall strength, yielding opportunities to perform new skills and activities. Several people reported an increased level of participation in outdoor activities and also appreciated the opportunity to be out of the house more. *"I'm out of [the house] more nowadays - before, I thought it was boring to go out."*

Smoother everyday life

Following spinal cord injury, many tasks become more complicated and time consuming. Hand surgery does not eliminate this additional level of complication or time consumption, but some tasks become a little easier. For example, prior to surgery, eating or writing was typically accomplished through use of a strap, usually attached to the hand by someone else, and then passively hold the fork/pen. This is a stark contrast to the ability to grasp any fork available, as experienced after surgery (Figure 18 and 20). Secondly, the participants were able to perform tasks more quickly due to improved ability to use their dominant hand or to execute bimanual activities, such as grabbing a glass with one hand and medication with the other. Likewise, their work life was similarly affected: *"I can work easier and more efficiently at work. Not more [hours], just more efficiently."* Finally, people living with tetraplegia learn a number of compensatory skills to manage their everyday lives. One such skill is the use of their mouth to compensate for a loss of grip function: *"Before, if I tried to grab something… I always had to compensate with my mouth."* After surgical reconstruction, participants had to rely on these compensatory skills much less frequently.

Figure *18. Smoother writing ability four weeks after surgery (right), compared to preoperatively (left).*

4.2.6 Summary of activity and participation changes

Patients experienced performance improvements in their prioritized activities and satisfaction with the performance. No single goal was rated lower 12 months after grip or triceps reconstruction surgery. Patients were also able to perform more activities. Seventy-eight percent of the goals rated as impossible to perform were possible at follow up. After grip reconstruction, eating activities showed the greatest improvement, more complex domestic and leisure activities also improved. After triceps reconstruction, the greatest improvements were seen in writing ability and stretching out the arm when lying down. The core concept found that explained the participants experience after a grip reconstruction was *enhanced independence*. Activity and participation changes related to this enhanced independence included the ability to perform more activities, less dependence on assistance, and a generally smoother everyday life.

4.3 Personal factor changes

Patients described several aspects of improvements after grip reconstruction related to personal factors. Self-efficacy was a key improvement. Gains after grip reconstruction were also described in terms of changes in the person's self-image.

4.3.1 Self-efficacy in hand control

Self-efficacy, defined as confidence in one's ability to succeed in specific situations (4), was a critical element in enhancing independence. Having confidence in grasping and gripping for common tasks when having a hand worth trusting, generated an important practical and psychological change in hand control. One participant described: *"I feel more secure now because before, even if I could do it, I thought– what if I drop it? However, now it* *feels much safer; it is, yes, easier."* Effects of increased self-efficacy in hand control were far-reaching and inspired participants toward additional improvements and even greater self-efficacy. *"I manage so many things that I never thought I would. Through doing that, I found motivation to try new things."* Therefore, self-efficacy in hand control was not only a result of surgery but also an important catalyst for other gains.

4.3.2 Enhanced self-image

Regained privacy

Surgery allowed several participants to be left alone for longer periods of time, which was described as a relief. The physical benefits of this change are further described in the section 4.4.2, "less dependence on assistance." However, this benefit was not limited to functional gains. Patients said it was a relief to be able to be alone, without constantly being surrounded by people: *"It feels good to be able to be by myself now."*

Another aspect of regained privacy was the ability to perform personal or intimate activities independently, such as catheterization or dressing. Beyond personal self-care, there were other private activities that patients could perform, such as typing and sending a text message. The psychological benefits of being able to perform personal and private activities without needing assistance were evident. *"I no longer need the assistants to write my messages online or to send texts or to hold the phone while I'm talking. I manage all that by myself now and I can drive away if there is something I do not want the assistants to hear. It has given me a lot. It has affected me a great deal."*

Regained identity

Increased ability to participate in different life situations generated a changed identity. One aspect of regained identity was a sense of equality. The equality was for example seen in the identity as an employee, as they could perform more efficient and equal at their jobs. One person described increased hand control as critical for him to believe in the possibility of returning to work. Secondly, regained identity was demonstrated in the appreciation of the ability to take a larger part in domestic chores such as drying dishes or playing with the children (Figure 19). Taking an active role in caring for the home and kids decreased the sentiment of being a burden to other family members. The ability to participate more equally promoted psychological benefits in terms of regained identity and a re-established role in both the family and the community. One participant described it as following; "*I am back to where I was."*

Figure 19. Ability to hold the toothbrush helps a patient to regain the role of an active parent.

Increased manageability

Participants described a renewed sense of manageability, cascading from their increased ability to perform tasks effectively and independently to increased capacity for an active lifestyle. Descriptions included not only a confidence in their ability but also a feeling of more control of their own life. They saw them self as a person who could actively direct their own actions, having the skills necessary to handle more situations in life. The feeling of becoming a person with increased ability to manage tasks gave psychological benefits. *"Because of all I have learned, my self-confidence and self-esteem have become better. They've been affected since I manage better by myself".* Some also reported that the increase in manageability led to a decrease in psychologically "bad days".

Recapture a part of the body

Following surgery, the hand became a source of pride, something special and useful. Positive feelings were associated with others seeing the hand in use: *"Others see that I can use my hand, previously I could only sit there ... I had no movement whatsoever. Now I have increased movement….and it, it is visible."* Participants also described feeling as if they had reclaimed a part of their body, a part they had lost and missed: *"I still have not comprehended that I have lost everything…. This is very confusing because at the same time that I lost control of my body, I suddenly got a part back - so it's a bit strange, but very satisfying."*

4.3.3 Summary of Personal changes

Regained functions integrated in daily life provided benefits not just in improved participation. It also directly affected the person. Patients described gains in terms of increased privacy, manageability, and identities. The impact of grip reconstructive hand surgery on personal changes has not been specifically studied, but there have been indications that patients perceive improved quality of life and increased self-confident after surgery (73,82). Self-efficacy in hand control was both an important gain from improved hand function and critical to developing and translating regained function into daily use. The impact of self-efficacy is further discussed in paragraphs 4.7.3.

4.4 Environmental factor changes

According to ICF, environmental factors were includes both technological and relationships aspects. Changes in both this aspects were reported as a consequence from grip reconstructive surgery.

4.4.1 Enhancement related to products and technology

Less restricted by the physical environment

As a consequent of improved hand control, several patients described a less need for special arrangement and specific aids and ability to use standard equipment and environment instead. The typical example were the gained ability to grasp and hold a fork in contrast to the preoperatively passive attachment of the fork to the hand, which in many cases had to be put on by an assistance (Figure 20).

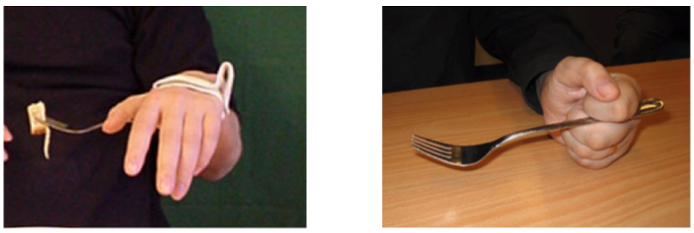


Figure 20. Ability to hold a fork, before (left) and after (right) a grip reconstruction.

Moreover, improved hand control also contributed to an ability to participate in an environment not specifically adapted for patients' needs: *"I can* *participate in events even if they are not planned."* There was also a decreased need for specific arrangements in order for patients to participate in an event. Previously, a small change in the environment presented major difficulties: *"It is not as important to have it exactly as it was before. Now I can have my sink a bit messy and I can still manage. There is a difference. 'Cause, if the smallest thing was moved, then # # #, I could not perform."*

On the contrary, the increased ability forced new arrangements in the physical environment since new activities were now possible. For example, the kitchen might have to be rearranged after surgery since it was possible for patients to make breakfast by themselves.

4.4.2 Enhancements related to support and relationships

Relationship with family and others

In the enhanced independence model in study IV, there were two sub-categories supporting changes in social relationships after grip reconstruction, namely "renewed ability to participate in social activities" and "share positive experiences with relatives".

Renewed ability to participate in social activities had impact on the relationships with family members and others, The participants associated themselves with multiple role changes that had impact on their relationships - from "an independent person" and "an active father" to "a friend among peers." One young woman described the changed relationship thusly: *"When you don't have to ask for help with certain things, ′cause you can manage by yourself - then, it feels more like it was before, really. ... You want them [your friends] to be friends, not merely helpers".* The increased ability to perform social activities also promoted relationships through simplifying social interactions. Several social interactions were described as important gains and strengthened the individuals' sense of identity. Examples of simplified social interactions were; shaking hands, eating together and drinking a beer or coffee with friends without assistance. *"Being able to grab a beer is mainly a social thing…and it has helped me a great deal. It is easier to socialize with people if they don't need to help me with things".* The patients' ability to participate in social activities had improved in various ways and it is previous known that participation in social activities is strongly related to life satisfaction in the SCI population (83). The participants enjoyed the enhanced independence.

Share positive experiences with relatives were described by several participants. After SCI, participants and his or her friends and family underwent many very challenging experiences. Some participants expressed they were feeling "like a burden" and felt responsible for causing sorrow and complications for their entire family. The improved hand control and regained abilities allowed participants to share new hope and positive experiences with relatives and loved ones. This opportunity filled participants with feelings of happiness. "*This has given everybody hope... Since all this hell started... this is the first movement in a positive direction. It has pushed the whole family forward. Because when they suddenly see that I can grasp a glass with my left hand, which I haven't moved in 22 years, at a family dinner, then they react and it is a wonderful feeling."* The participants' concerns about their relatives were described from various perspectives in the interviews. The primary feeling expressed by the participants regarding their family was joys in being able contribute further to domestic life and responsibilities. The functional improvements also provided the participant and his or her family an inspiring point of focus, in contrast to the other, mostly negative, effects from the spinal cord injury. Family members were not interviewed about their experiences during this study, but it is reasonable to expect that they also found benefit in the results of the intervention.

Less dependent on personal assistance

Several participants found that the results of the surgery decreased their need for external, government funded, assistance since they become self-sufficient for longer periods of time. Some assistance reductions exceeded 40%. The assistances helped in fewer situations and to some extent in other situations after the surgery. The assistances become more in the background. People living by themselves enjoyed an increased ability to act on their own rather than having to wait multiple hours for help. One participant relates a specific experience detailing this benefit of increased independence; *"If something started itching at night, and [the assistants] started at 8, then I'd just have to wait until someone came. Now I can scratch myself."*

4.4.3 Summary of environmental changes

Increased ability in activities and participation had impact on both the physical and social environment. The physical environment was characterized by less need for a planned and adapted physical environment. Social changes were characterized by renewed ability to participate in social events an, share positive events with relatives and less dependence on personal assistance. While the benefits on body function and activity dimension are well described, the implications of these gains for society and more specific for the individual are yet to be described.

4.5 Negative experiences

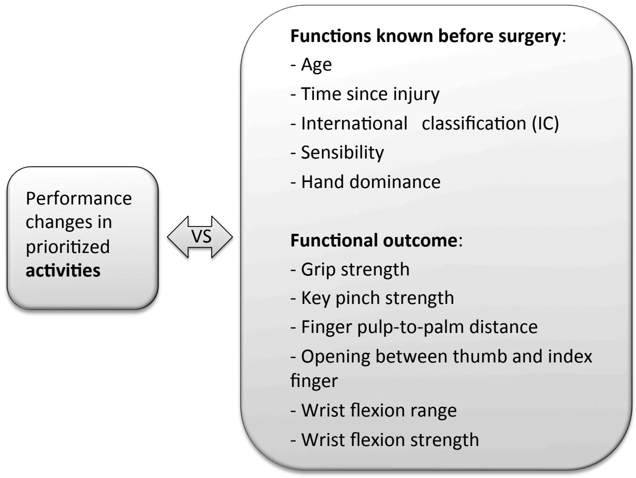
Participants were specifically asked about negative experiences associated with the grip reconstructive surgery and rehabilitation. They were also asked about their surgical scars. Aside from some initial pain, patients had no negative experiences from a body structure perspective. Nobody thought that the scars were any problem. In activity perspective the improvements were so dominant that it was worth it. Some participants were even proud of their scars and claimed it proved that they were a person with experiences. There were some complaints (related to the fusion of the CMC1 joint) regarding difficulties grabbing large objects. From a personal perspective, the participants said it was a long and demanding rehabilitation process. *"It is after three months it really starts and that is truly the difficult part. The time before were just peanuts."* In conclusion, even though there were some negative issues, all participants clearly stated that the gains from surgery were much more prominent and that they unquestionably were satisfied with the surgery.

4.6 Relationship between body functions and activity improvement

We learned from previous studies that grip strength was expected to be between 2 kg and 20 kg after grip reconstruction surgery and that patients experienced improvements in their prioritized activities by an average of three-scale steps. To investigate the relationship between body functions and activity improvements, a correlation study was performed. The physical factors were: age at surgery, time since injury, International Classification for Surgery of the Hand in Tetraplegia (ICSHT), sensation, and hand dominance. Physical outcome factors included: grip strength, key pinch strength, finger pulp-to-palm distance, opening between index and thumb, ROM wrist flexion, and wrist flexion strength (Table 7).

Although there were improvements in both physical factors and prioritized activity performance, there was no correlation between performance change and any of the physical functions (Figure 21 and 22). The correlation coefficient never exceeded 0.2, and there were no relevant significances.

Table 7. Matrix of factors analyzed in correlation with performance change in prioritized activities after grip reconstruction.



Preoperative factors

None of the analyzed factors known before surgery showed noteworthy correlations with performance improvements in prioritized activities. Absence or presence of sensibility did not discriminate performance improvement between the groups. Patients without sensibility displayed similar performance improvement in their prioritized goals as those with sensibility (Figure 21 a). Neither age nor hand dominance predicted the outcome in performance improvements. The nondominant hand showed similar improvements to the dominant hand (Figure 21 b). Old and young patients also showed similar improvements.

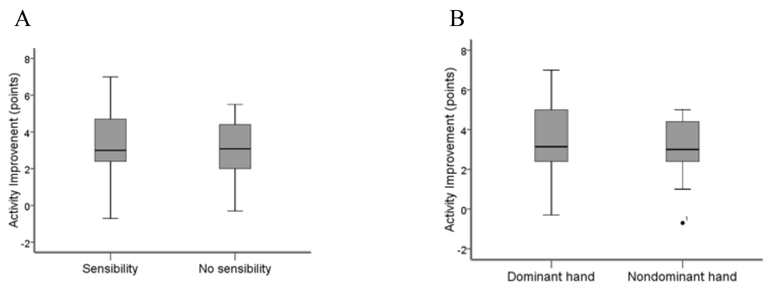


Figure 21. Magnitude of the improvement of activity performance measured as difference between pre- and postoperative assessments, relative to (A) sensibility and (B) hand dominance.

There was accordingly a disconnection between some of the factors traditionally judged as appropriate indicators of successful grip reconstructions in tetraplegia (84-86). The results from this study cannot support these statements. It seems that the nondominant hand can achieve activity goals to the some extent as the dominant hand. Sensibility did not predict perceived activity improvement after grip reconstructive surgery and rehabilitation. These patients learned strategies to compensate for their limited sensation, such as vision. After grip reconstruction, the hand still lacked sensation. Still, a hand with no sensibility was more useful with some hand control than without grip ability. Our conclusion is that with the right expectations and training, patients could reach their activity goals, independent of sensibility, age, or hand dominance. Therefore, we recommend surgeons consider older patients with lack of sensibility as surgery candidates, even on the nondominant hand.

Physical outcomes

Since both closing and opening the hand are important factors in grasp and grip ability, physical factors facilitating both opening and closing of the hand were analyzed. Ability to close the hand was reflected by grip strength, key pinch strength, and finger pulp-to-palm distance. The following items were included for the ability to open the hand: maximum distance between thumb and index finger, ROM, and muscle strength of wrist flexion. There was no consequential difference between the three performance improvement groups and any of the physical outcome factors (Fig 22).

A B C

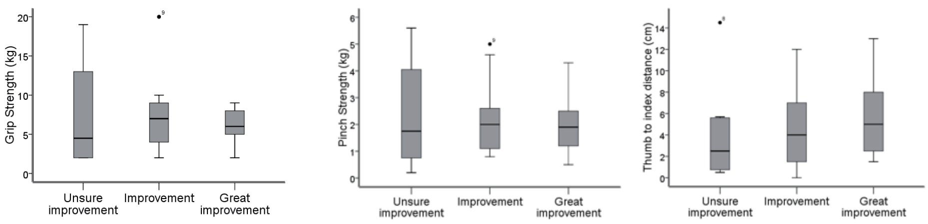


Figure 22. Functional characteristics measured as (A) grip strength, (B) key pinch strength, and (C) opening of the hand (maximum distance between thumb and index finger) for different levels of improvement in prioritized performance. The magnitudes were essentially the same across different improvement groups.

Body functions such as grip strength were important to perform various tasks. However, the weak correlations between physical factors and activity performance indicated a need for both physical and activity training to ensure optimal results from rehabilitation after grip reconstructions. Improvement in the activity dimension was a complex process that relied on many factors, including body function. Specific activity training is necessary to transform the improved functions into activities to develop new skills and ensure that the new function is integrated optimally in daily living (48,49). Except for learning new motor programs, personal factors (determination, self-assurance, habits, and willingness to relearn), as well as physical environment and social support, influence activity results. It is important to be aware of these resources and/or barriers to the rehabilitation process to gain desired improvements in activity and attain new function in daily living. The next chapter describes patients' relearning process. The patients there depict important phases in the process, including both internal and external factors.

4.7 Patients' perspective of transforming functional improvements into activity and participation gains

When patients were asked to describe their relearning process from regained function to improvements in daily life the main them was "determination to reach a greater level of independence." It was critical to maintain a determination to reach greater independence throughout the entire process. This was defined as motivation to develop activity and participation improvements from regained functions. One person described it thusly: *"The thing is that I can decide for myself. It is I who decides how good [the hand] gets. I can be finished now but I can also get better."*

4.7.1 Stepwise development

Three phases were identified: initiate activity training; establish hand control in daily activities; and challenge dependence. In each phase, both internal and external factors were described (Figure 23). There was a mental stage before patients proceeded to the next phase in the model. Initiating activity training resulted in a belief in improved ability. Confidence in ability and hand control appeared before challenging dependence (Figure 23). Two factors were critical before starting the process of integrating the new function into daily life. The first factor was an ability to activate the new functions and complete a movement. Restored grip function had to be developed so that active use of the grip was possible. The second factor was determination for greater independence. This was seen during the whole process, until greater independence was achieved.

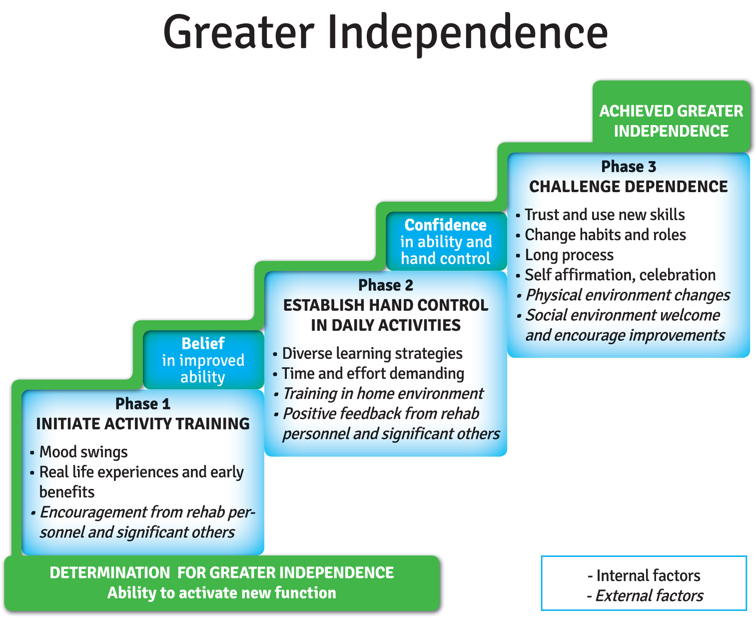


Figure 23. The transformation process from gained function to everyday use.

Phase 1: Initiating activity training

The first phase contained aspects about overcoming the unfamiliar feeling of using the regained functions in practice. There were mental, practical, and social themes included in the initial activity-training phase.

Mood swings The mental factor in the initial activity-training phase was mood swings. Patients described both positive and negative moods. Patients initially commonly felt pain and feared damaging the results from the grip reconstruction when starting activity training. The changes in the hand made it unfamiliar and scary to start using: *"It was super scary because then you did not know how it would, and should, be. It hurts, and they just told me to go for it and that it was safe. Otherwise, I was afraid that the hand would be damaged – a lot of that stuff."* Participants also described curiosity, fascination with the new functions, and eagerness to see expected improvements: *"I was curious what I would be able to do with the hand. On the other hand, I understood that it would take time." "I was not afraid, I was very fascinated, surprised."* Moods shifted between fear and curiosity during the initial activity-training phase.

Real life experiences and early benefits Therapists encouraged and instructed participants to use the hand in practice. Previous strategies might not work, new skills had to be developed, and it felt unfamiliar and confusing to use the hand: *"First I had no hand function, and then I had the surgery, and thereafter, I was supposed to do things that I did not know how to perform. It was difficult to get started, to start using in reality."* When this resulted in a positive experience, it decreased fear of using the hand. Participants were inspired to try other tasks. Therefore, gaining benefits early was important to keep participants motivated. It inspired them to try other tasks: *"I imagine you feel better when experiencing the strength coming at once. It is mentally better than if you starts thinking this was no good. Then you lose the inspiration."*

Encouragement from rehab personnel and significant others External encouragement was critical for participants to overcome initial fear and start using the hand. There was encouragement from professionals, but also from relatives, assistants, and well-wishers: *"The fact that people around me have encouraged me as much as I did myself has been important."*

Belief in improved ability

At the end of the initial activity-training phase, participants believed they had improved ability. They experienced real-life improvements and some early benefits from surgery. It made the participants confident enough to try new activities: *"We tried to do dishes and stuff already then, so I was never afraid to try things and I think that is good, being positive." "I was never afraid of trying things. It worked actually quite well."*

Phase 2: Establish hand control in daily life

After initial practical use of the hand and believing in improved ability, participants moved into the next phase of integrating hand control into their daily activities. There were several internal factors.

Diverse learning strategies The participants used diverse learning strategies. Some used trial and error, while others carefully planned before trying a new activity. However, there were some similar learning strategies: First, there were intensive efforts to find new techniques and ways of using the grip. *"It was very intensive in the beginning. I was squeezing on everything just to know I found it."* Participants were examining every task from various perspectives until they found a workable strategy: *"I was trying from all different angles to finally make it doable. If it does not work the first time, it might work the second or third. At last it worked. I just had to find the right techniques."* Second, participants focused on one task at a time and did not try everything at once. This was a uniting theme. Prioritizing one activity at a time gave a structure in the relearning process so that it did not get too overwhelming: *"You start with one thing and then go on to the next one. If you take everything at the same time, you would have died. I take it gradually and look at it as long-term goals."* "*I focused on doing one thing well first before jumping into the next."*

It was more challenging to establish hand control on the nondominant hand in daily life. It was more difficult to remember to use that hand. Participants described a tendency to use the dominant hand too much. The nondominant hand needed more attention than the dominant hand to establish daily use.

Time- and effort-demanding Participants thought motivation and investing time were important. Some described relearning in daily life as much more time- and effort-demanding than finding the function itself: *"[It was important] to have time and patience. Then new abilities arise the whole time. So you do not need to discover everything directly. It takes time. They sad it would take three months but it was not really true. At least six months, I would say. It is after three months it really starts. It is then you really convert or then you can actually use it in reality, and that is truly the difficult part. The time before was just peanuts."*

Training in home environments Participants frequently mentioned the importance of training in home environments as much and as early as possible: *"The best training is that you understand fast as the rhythm of everyday life, to get hold of that as soon as possible. You can never do that inside these walls. You can never simulate everyday life at a hospital, even if you try."* The literature says that knowledge of a specific activity is created in the context of where it will be applied and practiced (87,88). Accordingly, training in the proper environment as soon as possible must be an effective way of transforming the gained function into real life.

A home environment naturally encouraged using the hand for personal daily activities. The participants did not feel the need for in-clinic professional help and guidance in this phase. None of the participants wanted an intensive rehabilitation period in the clinic. They believed in their improved ability and felt secure enough to manage in their homes: *"It is quite nice to figure it out oneself. It is fine not having anyone looking over your shoulder."*

Positive feedback Although participants wanted to do skills training by themselves in their home environments, they said that support and encouragement from the rehab personnel and significant others was essential to keep motivated and working. Demonstrating their improvements for others was an important motivator. Therefore, regular follow ups were important to keep developing improvement: *"Just knowing that I am going here [the clinic] again has been motivating, to keep on fighting and be able to come* *here and show off."* The ability to reach therapists over the phone, between clinic visits, was useful. Knowing there was backup if something happened, or for encouragement to keep the process going, made participants confident. Encouragement from significant others was also important to keep relearning and improving: *"They [the assistants] were impressed."*

Confidence in ability and hand control

Self-efficacy or confidence in ability and hand control occurred when performance of everyday activities was established. Participants could perform specific tasks and needed to proceed into regularly using the new skills in daily life. It was critical for participants to trust and feel confident in their ability to take this next step. Without confidence in their ability, patients only learned the skill, but never used it in life. One participant described this as: *"You use it more if you feel you can trust the hand."* Another described the process of gaining confidence in hand control in a more philosophic way: "*To see is one thing, to understand is a difference. Then, to understand the consequences of what you see is also a distinction. So even if I knew I had much more movement, it took time to really understand it."*

Phase 3: Challenging dependence

After participants developed confidence in their abilities, they could challenge their dependency. The confidence in abilities challenged hand control not only in specific, practiced daily activities, but also provided conditions to integrate gained activities into daily use and new routines. When trusting a new ability, assistance and environmental constraints were changed, and new habits and roles developed.

Trusting and using new skills Confidence in the ability must reach a level high enough to proceed to the final step of challenging dependence. After practicing daily activities, confidence in the ability provided conditions for improvements in daily life and trusting new skills: *"I made it [making coffee] for the first time yesterday, on my own then. Because I have trained some before, but then I have always had someone just in case it would go to hell. But yesterday, I made it on my own."* Trusting the grip can be particularly challenging, since lack of sensitivity and trunk stability are other factors that interfere with performance for people with C-SCI: *"I do not have any sensation in my hand, so I do not feel if I have a good grip or not, but actually I know I have a good grip. I just have to trust it."*

Change habits and roles Changing habits was not just a question of ability or daily activities. It was a long process of awareness in all situations of daily life, including small ones. This was not just about gaining confidence in specific daily activities and occasionally performing them. The next step was to change daily life into new habits and routines that could also include changes of roles. Therefore, the participants saw determination to achieve greater independence and confidence in ability as key factors in challenging habits and roles: *"It took a while until it became a habit, before I remembered that I had it somehow, so I could use it too."* Confidence in abilities and new habits worked together in positive reinforcement. One activity improvement encouraged other activity improvements: *"I have noticed I use it more and more."* Improved ability also led to reformed social roles. Some young participants said they went out with friends more after surgery. The father could play more with his children, and the old men could again play cards with their wives and friends.

A long process At the time of the interview (seven to 17 months post surgery), all participants were still learning new skills. They thought of new situations to use the hand in a different way almost daily for at least the first six to nine moths after surgery. They also said it took time and that it was important to make time for this process to really gain improvements and challenge their dependence.

Celebrations and self-affirmation Most participants used self-affirmations to stay motivated and kept working on the process. Celebration of improvements was important: *"It was hell of a feeling then I managed, then I celebrated!"* Participants saw themselves as people who could manage and succeed, which facilitated further progress. *"I want so much and have managed so much stuff that I never thought I would. It gives me motivation to attempt new stuff."*

Physical environment changes according to new abilities When new activities were introduced,, the physical environment had to change to permit the regained activity to be performed in daily life: *"Making a sandwich and stuff, I did not do that before. So now, I have had to rearrange a bit more at home."* It could also be the other way around. Greater abilities made it possible to perform better, even if the physical environment was not entirely adapted or planned. It made everyday life a little bit smoother, as it provided opportunities to improvise more: *"I manage, even if it is not super planned."*

Social environment welcomed and encouraged improvements It was not just the physical environment that changed. The social environment also had to be re-evaluated. Relatives, friends, and assistants had to let patients use their new skills or these skills would never be used in daily life. The roles of people around participants had to be re-evaluated, and a new balance developed. One participant described their assistant's changed tasks: *"It came quite naturally, actually, because they also wanted it to be as good as* *possible. So it was no problem whatsoever."* Confidence in ability, changed roles, and less need for help led to reduced time for assistance. One participant reduced his time needed for government-payed personal assistance by 41 percent. He also managed to work without personal assistance, trusting his improved ability.

Friends and relatives also motivated participants to practice new activities by more than just encouraging words. They also challenged patients to develop their skills by participating in the community together. For instance, participants trained in specific skills such as manipulating their wheelchairs and eating before going out with others. They pre-trained their skills to be sure of their abilities in front of people.

4.7.2 Long, demanding process

Participants described the whole rehabilitation process as long and demanding, from regained function to fully integrated gains in daily life. Gaining optimal profit from surgery was a much longer process than finding functions. Activating the function was just the first step. All participants were still learning new skills one year after surgery, even though it was not as intensive as the first three to five months. This is important knowledge to communicate to patients before they decide to have surgery. They can then decide if they have sufficient motivation and time for the whole rehabilitation process to optimize daily life following surgery. Participants chose to have the surgery. It is therefore reasonable that most patients were motivated to go through this process. However, if patients don't have the right information and expectations about the rehabilitation, they might lose their determination. Therefore, the results from this thesis can provide clinicians and future patients with information about what might be expected of them during rehabilitation after grip reconstructive surgery to guide their expectations and determination.

4.7.3 Determination and self-efficacy as key factors to success

Determination to reach a greater level of independence was the core concept for transforming regained body function into daily use (Study V). Motivation and interest in learning directly affect adult learning (89), and are important to promote during rehabilitation. Learning processes are performed using various strategies. A strategy that worked for one person does not necessary work that well for another (90). Participants in this study used individual learning strategies, but common themes were that they all were determined to develop new techniques and skills through hard work and investing time.

They also felt a need to concentrate on one skill at the time so that the process did not become overwhelming.

Mezirow noted that adults use transformative learning from prior interpretation to construe future actions (91,92). Participants' previous experience of relearning activity skills might have been such a strong guidance, together with increased self-efficacy in hand control, that they felt confident enough to do this relearning process without continuous professionals or intensive support. These participants also had chosen to have surgery and were not caused by trauma, which was the case in their prior rehabilitation and relearning processes due to their SCI. It might also invigorated their feeling of being able to manage independently, using previous interpretations from rehabilitation. However, managing alone required a strong determination for greater independence, self-efficacy and a belief in improved abilities.

Awareness of, and support in, the development of self-efficacy in hand control seemed to be essential for improved daily use of the hand, increased participation, and indirect psychological benefits. Self-efficacy is a well-known term in psychology (4). In a recent systematic review, self-efficacy was one of four primary concepts that were strongly and consistently related to quality of life for people with spinal-cord injury (93,94). Although self-efficacy was not a specific target of investigation in this study, results support the idea that self-efficacy in hand control is an important characteristic to develop and should receive attention during the rehabilitation process.

High expectations and self-efficacy are important for results from rehabilitation (80). Rehabilitation should therefore include coaching/supporting, rather than just teaching technical skills. It is important that a patient with low self-efficacy in hand control trust the therapist and facilitate positive expectations and confidence to explore their new function. Otherwise, the rehabilitation and relearning process might be interfered. Conversely, therapists and others can have a more non-direct role for a patient with high self-efficacy in hand control (Figure 24).

SELF-EFFICACY — Low Self-efficacy ↕ High Self-efficacy

THERAPIST APPROACH — Directorial ↕ Non directorial

Patient Approach	Patient Feeling	Patient Need	Therapist method
"This is impossible"	Hopeless	See possibilities	Show possibilities/ peptalk/ Motivation
"You know- show me"	Unsecure	Belief in self	Pedagogic and encouraging. "I know you can"
" If I just had…"	Incipient hope	Confirmation	Supportive. "Right, that's the way!"
" No problem- I have already sorted it"	Optimism, Self-efficacy	Maintain independence	Explaining and discussing

Figure 24. An illustration of exemplified approaches and interactions between patients and professionals.

Positive reinforcement can enhance motor learning and performance (48-50). In this context, positive reinforcement was important in terms of strengthening participants' belief, confidence, and expectations. Participants described not only encouragements and feedback from professionals and others, but also celebrating successful performance as important positive reinforcements. After patients started to believe in their improved ability, the therapist's active role progressively decreased. Confident patients who believe in, and control, their abilities, goals, and possibilities, will succeed. From a professional point of view, these factors are particularly important to recognize and support. Therefore, therapists should focus more on trust, motivation, and supporting goal-setting than on teaching technical and compensatory strategies. This approach has previously been highlighted as important when teaching self-care skills to spinal cord injury patients (95).

4.8 Methodological considerations and limitations

Various methods were critical to answer the research questions in the studies. The first three studies used quantitative methods. A qualitative method was suitable to answer the research questions in the last two studies. Together, the studies covered outcome after tetraplegia hand surgery in all aspects of the ICF framework.

4.8.1 Contextual influence on results

All patients were treated in the same specialized clinic. Specialized hand surgeons, physiotherapists, and occupational therapists were on the team. All other personnel were also trained to treat these specific patients. Moreover, patients were aware that they were treated in "the most specialized unit of the country." All of this probably affected the overall results from surgery and rehabilitation. The fact that we evaluated many of our previous patients might also be reflected in the results. In the qualitative studies, an external co-author was included to strengthen the trustworthiness and bring further methodological knowledge to the studies. On the other hand, the advantage of interviewers' knowledge in the field was the possibility to ask detailed follow-up questions to acquire deeper knowledge. However, multicenter studies or similar studies from other settings are needed to confirm these findings. Studies performed entirely by external researchers are also desirable.

Moreover, the goals, or activity limitations identified and analyzed in study I–III are reflected by people with tetraplegia living in the Nordic countries. The social welfare system and other specific country contexts influence a person's possibilities to live and function. It is reasonable to think that the specific country context might influence type of goals. Generalizability must therefore be questioned. Future multicenter studies or studies from other settings might answer that question.

4.8.2 COPM, limitations and methodological considerations

Evaluating patient goals captured not only the outcome from surgery and rehabilitation, but also what patients expected to gain from surgery. Since patients were encouraged to set their goals (activity limitations) before surgery, it is critical that they were well-informed about expected outcomes. Otherwise, they might have unrealistic goals and be dissatisfied with results. Therefore, surgeons and their teams must carefully inform patients before the COPM assessment is done. During the assessment, an experienced therapist with good interview technique and knowledge regarding the surgery and expected outcome is needed to answer additional patient questions.

Slight modifications of COPM were done for this study. Instead of the original encouragement to describe activity limitations in general, patients were encouraged to describe activity limitations related to lack of triceps or grip ability. Since all patients had serious activity limitations, this modification was necessary to evaluate results from the present intervention. Another modification was done during analysis. Our research question was focused on activities that might change after surgery and rehabilitation, rather than on the individual's changes in their prioritized activities. Therefore, the group analyses were not done on the mean values from each patient but instead on mean values of similar type of activity limitations. The ICF was a useful tool in classifying activity limitations.

One could argue that the COPM is too subjective and therefore not suitable for evaluation. However, the instrument offers a true client-centered approach since it provides information about patients' perception of their performance. It does not provide a general, standardized performance but is tailored to performances important in patients' specific life situations. Because of this, the results probably rely more on relevant patient gains than a score on a standardized test. The psychometric properties for the instrument were good (66).

4.8.3 Data limitations

Studies I and III: Each goal in the COPM was classified according to ICF. Due to limited data, some of the ICF groups had to be general, for example "domestic life." Even then, some of the groups were small. With a larger sample size, it would have been possible to analyze more specific ICF groups, and more specific activity changes might have been possible to detect and described.

The types of goals a person prioritizes probably differ, depending on their context and living environment. All patients in this study live in the Nordic countries. These countries have a social system that enables tetraplegic patients to live at home and participate in the community. People living in other contexts might experiences other limitations, and thereby prioritize other goals. Therefore, these types of goals cannot be translated into another context without considering differences in individuals, societies, and environments.

Study II: The correlations study was retrospective. Limitations with this type of study are the uncertainness of standardized measurements. There were also several people involved in assessment. Both of these factors were limitations in Study II. Moreover, with a larger sample size, it might have been possible to detect correlations that could not be found in this limited material.

Studies IV and V: In the interview studies, only one of 11 participants was female. Accordingly, the results might neglect women's' perspectives.

5 SUMMARY

- Patients reached their prioritized activity goals and were satisfied with their performance after surgery. Improvements were seen in all types of activities. (Studies I & III)
- One body function alone cannot predict activity improvement, neither factors known before surgery nor outcome factors. There were improvements in both body function and activity perspectives, but the relationship between them was not straightforward. (Study II)
- Overall, patients experienced enhanced independence after grip reconstruction. This included both practical and psychological aspects. (Study IV)
- Patients described determination for greater independence as the most important factor to transform regained grip function into daily use. It was a long, demanding process and both belief in improved ability and confidence in ability were important stages in the process. (Study V)

6 CONCLUSIONS

A well-implemented upper limb surgery and rehabilitation can provide people with tetraplegia enhanced independence. Improvements occurred in all aspects in the ICF model: body structure, body function, activity, participation, environmental factors, and personal factors.

- Knowledge regarding possible improvements after surgery and rehabilitation provides caregivers with more solid information about patients, provided there are similar context and conditions.
- Prioritized activities showed improvements independent of physical factors such as age, sensation, and hand-dominance. Therefore, these factors should not be considered exclusion criteria for surgery. On the contrary, determination for a higher independence seams to be an important factor to observe during the decision-making process.
- The low correlations between activity change and body functions highlighted the importance of focusing rehabilitation in both these areas. Moreover, evaluations in both body function and activity dimensions were required to reflect the impact of surgery and rehabilitation.
- Determination for greater independence and self-efficacy in hand control were important factors during rehabilitation after surgery.
- Confident patients, who have gained some self-efficacy in hand control, could preferably do their activity and participation training in their home environment.
- Hand-skill development continued for more than a year after surgery, even though the first three to five months represented the most intensive relearning period.

7 FUTURE PERSPECTIVES

These studies were set in one specialized clinic. Future studies should attempt to replicate these findings in other contexts, preferably multicenter studies, to test for generalizability. Larger sample sizes of goals would allow for classifying more specific activities in the ICF and provide information regarding more specific activity changes.

Participants did most of their rehabilitation by themselves in their homes. Participants in the interview studies (Studies IV and V) did not wish to have more in-clinic rehabilitation than the 10 days they were given. However, intensive rehabilitation under supervision might improve surgery results even more. Future research is needed to evaluate different rehabilitation approaches. This is particularly true for rehabilitation after triceps reconstructions, since techniques for transfers and wheelchair skills (including adjustments of the wheelchair) might gain from additional professional guidance.

From the results of the interview studies, self-efficacy seems as critical as enhancements during rehabilitation after surgery. Future studies with specific emphasis on self-efficacy could explore its possible function to predict rehabilitation interventions. Further investigations are needed to learn more, not only regarding self-efficacy, but also what is essential for rehabilitation after hand surgery in tetraplegia. With evidence-based knowledge of what is effective and useful, we might be able to use our time in a more cost-effective manner. However more importantly, we can more confident guide our patients through the stages that lead them further in their progress toward greater independence.

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