Hand function in patients with Dupuytren's disease

Assessment, results & patients' perspectives

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Cover art:
Illustration of the most common words in the thesis.
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"It's really good that you follow up on this because it's very important, to improve health care, that you get the stories back. If you don't get them back, then you're just left in the dark and you don't see things you should see, so it's really good."

— Participant in the interview study

CONTENTS

ABSTRACT

Background: Dupuytren's Disease (DD) is a soft tissue disorder that leads to finger joint contractures affecting hand function. DD can be treated with surgery or injection and hand therapy to improve finger joint extension and thereby improve hand function. However, this does not cure the disease and recurrence is common. Previous research on DD has shown improvement in finger joint extension and in self-reported disability of the upper extremity after surgery and hand therapy for DD. However, this provides only a limited perspective on hand function, and multiple dimensions of changes in hand function (i.e. physical, psychosocial aspects and including the patients' views of results) have not been reported as a whole.

Aim: The overall aim of the thesis was to explore hand function before and after surgery and hand therapy in patients with DD, including assessment, results and patients' perspectives.

Methods: The thesis comprises three studies: Study A was a methodological study of interrater reliability in goniometry of the finger joints. Study B was a prospective cohort study with a repeated measures design. Study C was a qualitative interview study, using the model of Patient Evaluation Process and content analysis.

Results: Interrater reliability was high or very high for goniometer measurement of finger joint range of motion (ROM) in patients with DD when experienced raters follow our standardized guidelines developed for the study. Changes in hand function consisted of improvement of finger joint extension while active finger flexion was significantly impaired during the first year after surgery and hand therapy. No patient reached a normal ROM, but the majority reached a functional ROM. Sensibility remained unaffected. Patients with surgery on multiple fingers had worse scar pliability than patients with surgery on a single finger. Most patients had their expectations met and were pleased or delighted with their hand function at 12 months after surgery and hand therapy. Safety issues of hand function were of greater concern than social issues. Patients reported less disability and improved health-related quality of life after surgery and hand therapy. The three variables "need to take special precautions", "avoid using the hand in social context", and health-related quality of life had significant importance for patients' rating of functional recovery. Together, these variables explained 62% of the variance in functional recovery. Patients' perspectives of undergoing a surgical intervention process were described through five categories. Previous experiences of care influenced participants' expectations of results and the care they were about to receive. Previous experiences and expectations were used as references for appraisal of results, which concerned perceived changes in hand

function, the care process, competency, and organization. Appraisal of results could also vary in relation to patient character. Appraisal of results of the intervention process influenced participants' expectations of future hand function, health and care.

Conclusions: Surgery and hand therapy for DD improve hand function and patients regain a functional ROM needed for performance of common daily activities. Despite the negative effect on finger flexion present during the first year after surgery, patients' regards their hand function as recovered six to eight months after surgery and hand therapy. Measuring digital ROM in the finger joints with a goniometer is a reliable assessment method. However, from the patient's perspective, it is not enough to evaluate results only in terms of digital extension or ROM. From their view, results of treatment concern consequences on daily use of the hand, what happens during the care process in terms of interaction between patient and health care provider, as well as their view of the competence and logistics of the organization providing the care.

LIST OF PAPERS

I. Christina Engstrand, Barbro Krevers, Joanna Kvist.
Interrater reliability in finger joint goniometer measurement in Dupuytrens disease. American journal of Occupational Therapy 2012:66,98-103.

II. Christina Engstrand, Barbro Krevers, Göran Nylander, Joanna Kvist.
Hand function and quality of life before and after fasciectomy for Dupuytren disease. Journal of Hand Surgery Am. 2014:39,1333-1343.

III. Christina Engstrand, Barbro Krevers, Joanna Kvist.
Factors affecting functional recovery after surgery and hand therapy in patients with Dupuytren's disease. Journal of Hand Therapy. 2015:28,255-260.

IV. Christina Engstrand, Joanna Kvist, Barbro Krevers.
Patients' perspective on surgical intervention for Dupuytren's disease – experiences, expectations and appraisal of results. Published online 12 February 2016, in Disability and Rehabilitation.

ABBREVIATIONS

ANOVA   Analysis of variance
DASH   Disabilities of the arm, shoulder and hand questionnaire
DD   Dupuytren's disease
DIP   Distal interphalangeal joint
EQ-5D   Euroqol five dimensions
EQ VAS   Euroqol visual analogue scale
ICC   Intra class correlation
MCP   Metacarpophalangeal joint
PIP   Proximal interphalangeal joint
ROM   Range of motion
SD   Standard deviation
SEM   Standard error of the mean
SWM   Semmes-Weinstein monofilament
TAE   Total active extension
TAF   Total active flexion
VSS   Vancouver scar scale

INTRODUCTION

This thesis is about changes in hand function after surgery and hand therapy for patients with Dupuytren's disease (DD), and about how results and care are valued and measured. The studies in the thesis are based on a pragmatic approach with focus on effectiveness, i.e. the aim was to determine benefits of treatment in a specific population in a clinical setting (1). Evaluating results in clinical practice is increasingly important to determine the impact of treatment in general practice, to provide accurate information to patients about expected outcomes, and to identify areas for improvement in health care services (2).

The research questions emanate from my own clinical work as an occupational therapist at a hand surgery unit. In this context, therapists meet patients before and in the early phase of rehabilitation after surgery. Hand therapy after surgical intervention is often directed towards issues on a structural or functional level, although the overall aim of hand therapy is to increase the patients' ability to use the hand in daily activities (3, 4). The assignment for the hand therapist is to build cooperation between therapist and patient, to share information and guide the patient towards recovery. Patient education is crucial in all stages and is a collaborative process where the patient's engagement and understanding is needed (5).

Hand function refers in a broad sense to the ability to use the hand in everyday activities (6). Our hands are used in a variety of situations, for performance of fine-motor skills or heavy work, and for interaction and communication with others. Therefore, disorders of the hand can influence our well-being. Hand function can be affected in many different ways depending on the injury or disease. Patients with DD are the study population in this thesis as they constitute a large group of patients with a similar impairment in hand function and who often need repeated treatment sessions. Thus, this group of patients gave me the opportunity to study changes in hand function, and patients' perspectives on outcome and care in a relatively homogenous sample.

Evaluation of results in hand therapy has often taken the view of the health care provider and has focused on physical function and aspects such as ROM, sensibility or strength. However, in order to evaluate results after treatment in a way that is meaningful for the patients, it is crucial to include their perspective. Furthermore, judgments about results are seldom formed in isolation but rather in connection to a context. Thus, in this thesis, changes in hand function after surgery and hand therapy are explored from the patients' perspective with self-reported outcomes and interviews, and this is complemented by measurements of physical aspects of hand function.

BACKGROUND

Dupuytren's disease

Clinical presentation

DD is a soft tissue disorder that has been recognized for approximately 400 years (7) and descriptions of permanent finger contractures can be found in the Icelandic sagas from around 1200. DD was named after the French surgeon Guillaume Dupuytren who described the disease in the Lancet in 1834 (8), but it is believed that the genetic origin of the disease dates back to the time of the Vikings (9).

The etiology of DD is still unknown but risk factors are genetics, ethnicity, sex and age. DD has also been associated with environmental risk factors, such as smoking, alcohol, trauma or exposure to vibration, and other diseases, mainly diabetes, though the evidence is conflicting (10). DD is more common among men than women, and the incidence of DD increase with age (11). The prevalence of DD varies in different geographical locations but the mean world prevalence among men and women aged 65-74 has been estimated to be 33 and 18% respectively (12). In Western populations aged 65, a mean prevalence of 21% has been reported among men and 5% among women (13). The prevalence in a Swedish population aged 55 has been estimated to be 10% in men and 2% in women (14). It is unclear whether these differences in prevalence are due to genetic or environmental factors, or both (12).

It has been shown that patients in the Nordic region more commonly have a family history of DD, and a majority of the patients (70%) have a more severe disease (contracture >45°) when receiving the diagnosis compared to patients in the rest of Europe. Research has shown that most patients (90%, N=3357) treated for DD in Europe were 50 years of age or older, and although there were large intraregional variations, the patients in the Swedish cohort were the oldest in the region (15).

The diseased tissue in DD is commonly described as nodules and cords. Nodules are palpable subcutaneous lumps that can be fixed to the skin and palmar fascia, while cords are organized collagen structures arranged in parallel that might resemble flexor tendons (9). Clinical signs in the early phase consist of thickening of the palmar skin and palmar nodules. The nodules can progress to cords and contractures which usually cross the metacarpophalangeal (MCP) and proximal interphalangeal (PIP) joints (8). However, not all nodules change into cords and contractures (9), and the short-term course of DD vary (16). It has been estimated that 50% of patients with nodules develop cords (9), and as the disease

progresses, the fingers increasingly bend into a flexed position into the palm (8) (figure 1A-C).

Figure 1A-C. In A-B: Dupuytren's disease affecting one or multiple fingers. In C: Two weeks after surgery on one finger.

DD also commonly causes reduced space between digits, especially between the ring and little fingers (9). The disease is progressive and the finger joint contractures usually develop over several months or years (17). Although DD can appear in all fingers, it predominantly affects the ulnar side of the hand and especially the ring and little fingers but also a triple combination of the middle, ring and little fingers. The radial side of the hand and particularly the index finger is more rarely affected (18). The severity of DD can be described by the degree of contractures, or by using grading systems such as Tubiana (19).

Treatment

For patients with DD, the inability to extend the finger joints leads to restrictions in hand function that affect performance of activities of daily living and quality of life (20). Treatment for DD aims to improve finger joint extension, though treatment does not cure the disease (8). Recurrence or disease extension is common, i.e. the disease returns to the original surgical site or develops in previously not affected fingers (21).

Surgery has been the main treatment method (7, 10) although non-surgical treatment strategies also exist with injection of collagenase clostridium histolyticum (10, 22). Surgery for DD consists of several procedures, which are more or less invasive, where the diseased tissue is removed to different extents (22). Less invasive procedures consist of fasciotomy or needle aponeurotomy, while more invasive procedures consist of fasciectomy (limited/partial) or dermofasciectomy (10, 22).

In general, patients with severe DD require more complex measures to be taken for correction of the contractures, as there is greater tissue involvement (23). They are also more likely to have surgery on several fingers (24). The surgeons' decision on which procedure to use is influenced by patients' age, lifestyle factors and preferences, the severity of contracture, disease recurrence and

speed of disease progression over time (25). Critical factors for choosing the more invasive procedures are having MCP or PIP joint contractures >45°, high speed of disease progression, recurrent contracture and high expectations for success (15). A survey investigating surgeons' experiences with different surgical procedures has shown that, according to the surgeons, all surgical procedures restore finger extension. Though more invasive procedures result in a longer time to recurrence, the patient burden is higher in terms of recovery of hand function and frequency of complications (25).

Complications after surgery

Fasciectomy is the most commonly used surgical procedure for DD in Europe and is the surgical procedure that has the highest rate of complications (26). Commonly reported complications during and after fasciectomy are nerve, arterial or volar plate injuries, hematoma, delayed healing, pain, loss of sensibility, stiffness, scar hypertrophy and scar contractures (21, 23, 26). These can be experienced by as many as 24-34% of the patients (21, 26). Further, extensive fasciectomy of the palm and fingers is a potential cause of permanent impairment of finger flexion (27).

Previous research has reported varying recurrence rates (20-44%), and time to recurrence (17-48 months) depending on surgical procedure (21, 25). Factors associated with a more aggressive disease and thus higher risk for recurrence are having a family history of DD (one or more affected siblings/parents), bilateral disease, Garrod's pads (knuckle pads to the dorsal of the PIP joints), male sex and age at onset of DD younger than 50 years. Having all of these factors together increases the risk of recurrence by 71% compared to not having any of them (28).

Postoperative hand therapy for DD

Hand therapy practice is a specialty emerging from occupational and physiotherapy as a response to improved surgical techniques and medical management of upper extremity injuries and diseases. The aims of hand therapy are to prevent, restore and reverse progression of upper limb pathologies in order to enhance the individuals' ability to execute tasks and participate in life situations (3, 4). The hand therapist's task is to address issues of hand function that can occur after injury or surgery and to guide the patient towards recovery (5). Teamwork between patient, hand therapist and surgeon has been considered the best approach for ensuring good results (5, 29).

Hand therapists commonly use multiple treatment modalities and many of these are used regardless of the patients' diagnosis. Postoperative hand therapy for DD commonly includes night-time splinting, active exercises, edema control, scar management, and patient education. The goal is to maintain the achieved gains in finger extension and to minimize the negative effects of surgery (10, 27).

However, another goal in clinical practice is to help patients to be actively involved in the postoperative rehabilitation, as many of the modalities used in hand therapy rely on patients performing exercises or using splints as recommended. Postoperative hand therapy after surgery for DD is recommended by most surgeons (30), and a review of common practice among surgeons in Europe has shown that patients undergoing more invasive surgical procedures may need a longer period of hand therapy and splinting (24, 25).

Hand function

Definition of hand function

The hand is important for connecting us with the environment. Hand function can be affected in different ways depending on the injury or disease, but also depending on the person and the context (31-33). Therefore, to understand limitations in hand function it is important to consider the consequences of those limitations in connection to a context (34).

Physical components such as ROM, sensibility, grip strength, coordination and dexterity form the basis for hand function and make it possible for us to use the hands as tools (35). Impairment in these physical components of hand function can lead to difficulties with gripping and handling objects. However, there can also be psychosocial consequences due to impairment, e.g. performance of activities may take longer, which can lead to stressful events. There can also be concerns about appearance of the hand, or fear and worry about coping with daily life and activities. Additionally, loss of independence in everyday life and work can affect relationships (family, intimacy), and/or leisure activities (36-38).

In the present thesis, hand function is defined as the ability to use the hand in everyday activities (6), thus including physical, psychological and social aspects of functioning. Functional recovery is used as a concept describing patients' partial or complete regaining of hand function.

Evaluation of hand function

Evaluating hand function is crucial for determining the extent of functional loss after trauma or disease, but also for follow-up of results after surgery and hand therapy. However, hand function is a latent construct that cannot be measured directly (39). Therefore, hand function is usually measured by its components. There are several objective outcome measures available for the physical components of hand function e.g. ROM, sensibility or grip strength (35, 40). There are also tests of hand function focusing on gripping or dexterity (41). In hand therapy research, ROM measured with a goniometer is the most commonly used outcome measure (42). It is considered an accurate measure (40, 43) and several studies on the accuracy of goniometer measurement have been published. However, only a

few have investigated the reliability of goniometry in the finger joints (44-48), and all of those studies except one (45), were based on people with healthy hands. Still, the reliability of a measure is dependent on the group of people that are being measured (49), and should be investigated for the specific context or sample (50).

In previous research on hand therapy there has been an emphasis on evaluation of physical components of functioning (42, 51), yet this provides only a limited perspective on hand function. Although the physical aspects of functioning are important to evaluate, they cannot be used for drawing conclusions about changes in using the hand in daily activities. To my knowledge, there is only one study investigating ROM needed for performance of common daily activities. The study by Hume et al. (52) concluded that the total active ROM of the finger joints needed for performance of functional tasks was ≥165°. This implies that only part of the normal active ROM of the finger joints (0-290°) is required for common daily activities such as turning a key, holding a fork or a toothbrush, or opening a jar etc.

Patient-reported outcome measures can provide the patients' perspective on functioning, health, or quality of life (53). However, it has been shown that the patient-reported outcomes commonly used in hand therapy only capture parts of functioning aspects that patients with hand disorders consider important. For example, emotional functions such as anxiety about the ability to cope with daily life or to handle occupational demands are often overlooked (36). This highlights the need for qualitative information to provide insights about the impact of treatment for hand disorders beyond what patient-reported outcome measures can provide.

Previous research on hand function for patients with DD

Effect on contractures

DD has been extensively researched with a focus on surgical technique and on determining functional outcomes after treatment (54-57) Change in finger extension has been the most commonly reported clinical outcome measure after surgery for DD (56). Nevertheless, the inconsistent reporting of outcomes and different definitions of disease recurrence, complicate comparison of surgical techniques and results (21, 54, 58, 59).

Short-term postoperative outcomes after surgery for DD (within six months) are usually successful in terms of improving finger joint extension. In general, a mean improvement ranging between 31°-51° across all joints and patients has been reported. The outcomes on finger joint extension reported for correction of the MCP is in general better than for the PIP joint (21). Furthermore, having a severe preoperative deformity in the PIP joint has been shown to predict a worse outcome on joint motion (60, 61).

Some studies have used the Sollerman grip function test (62) to measure hand function, and have concluded that deformity of the MCP and PIP joint restrict hand function and that this is improved by surgery (63, 64). However, it is unclear what the changes in contracture angle mean for the patients' hand function in terms of using the hand in daily activities.

Recovery of hand function

Based on a review of patient charts it has been suggested that a majority of the patients recover hand function three months postoperatively (26), though it is unclear how hand function was defined and measured. Recovery of hand function should also consider the impact surgery might have on finger flexion. Yet, this has been given little attention in previous research and studies have shown contradicting outcomes, e.g. no change in finger flexion (65), finger flexion regained within two weeks (66), flexion deficits present six weeks after surgery (60), or no patient regaining full ROM (67).

Research on other components of importance for hand function in patients with DD, for example sensibility or skin issues, is scarce. Sensibility testing has commonly been used for monitoring complications after surgery and it has been assumed that patients have normal sensibility before treatment. Therefore, few studies have performed sensibility testing before and after surgery (56). To my knowledge, only one previous study has investigated sensibility before and after surgery for DD, using moving two-point discrimination (2PD). The results of the study showed unchanged sensibility after treatment (68), but further studies are needed to verify these findings. Outcome on sensibility testing after surgery for DD using the Semmes-Weinstein Monofilament (SWM) has shown that one third of the patients had diminished protective sensation (32%, n=19) (67). This was assumed to be an effect of multiple surgical procedures but no preoperative data were available for comparison. Skin issues (scar hypertrophy or contracture) can follow surgery for DD (23) and the bumps that can occur surrounding the scar can restrict ROM and be of concern for patients who may see them as an indication of recurrent DD (27). However, change in healing of the scar over time is usually not addressed in studies of results after surgery for DD. Only one previous study monitored scarring and used the Vancouver Scar Scale (VSS) (65), but no data from the VSS was reported in the study results.

Patient-reported outcomes

A recently published review concluded that few studies on surgery for DD have included patient-reported hand function in their evaluation (69). The patient-reported outcome measure most frequently used in previous research on patients with DD has been the Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) (56). The DASH was created as an outcome measure for upper extremity disorders, viewing the upper extremity, i.e. shoulder, elbow and hand, as a

functional unit. The scorings of the items in DASH are combined into a summary score ranging from 0 to 100, where higher scores indicate worse disability (70). Advantages of the DASH are that it is available in many different languages and has shown good construct validity, test-retest reliability and responsiveness to change in both proximal and distal disorders of the upper extremity. However, patients with wrist or hand conditions may demonstrate less disability, as described by the DASH summary score, compared to patients with shoulder conditions (71-73).

When the work presented in this thesis started in 2010, DASH was considered the best available instrument for DD. This was based on the fact that patients with DD also were included in studies of validity and reliability of the DASH (72, 73). Furthermore, the items in DASH cover the three domains of the International Classification on Functioning, Disability and Health (ICF), and thus comprise physical, psychological and social aspects of functioning (74). Since then, the question has been raised of whether DASH is an appropriate instrument to use in patients with DD as there may be problems with ceiling effects, i.e. discriminating higher functioning individuals (75, 76). Review of previous research using the DASH after treatment for DD has shown different levels of improvement of the summary DASH score. The preoperative scores have often been low and close to scores in a general American population (56). Moreover, in a newly published study, the use of the summary DASH score has been questioned as the instrument is not unidimensional but rather represents two different constructs when used on patients with DD, i.e. one reflecting activities involving the upper extremity and one reflecting patients' experience of DD (39). Development of disease-specific patient-reported outcomes for DD is in progress (77-79) but these instruments need to be investigated further. Thus, at the time of writing, DASH is still considered the best available instrument.

Previous research on patients with DD has also sought to explain the level of DASH score by the severity of extension deficits in the finger joints. This is based on the assumption that improving finger joint extension would lead to patients experiencing less disability. However, only weak relationships between DASH score and extension deficit in the finger joints among patients with DD have been found (75, 80-82). This indicates that patients' rating of DASH is not dependent only on the severity of the finger joint contractures (82); however, which other factors contribute to DD patients' rating of DASH is not fully known.

Patients' perspective

Beside the use of DASH, there are studies using different approaches for assessment of functional problems in DD, and these involve the patients' perspective to different degrees. In one study, hand function in work and leisure activities was reported as a major area for improvement (24), though this was investigated

through a review of patient charts and not by patient-reported outcomes or interviews. In another study, patients were asked to rate specific predetermined activities assumed to be difficult for patients with DD, such as shaking hands, placing hands in pockets, or putting on gloves. Putting on gloves was shown to be the most commonly reported functional problem in this study (67). In two studies, patients were allowed to define their own functional problems (80, 83). One of those studies showed that difficulty with washing oneself, picking things up, or fingers hooking on things were the most common types of problem for which patients wanted treatment (83). The other study showed improvement in a range of daily activities three months after surgery, e.g. using a computer, baking, playing an instrument, gardening, doing gymnastics, gripping a bicycle handlebar, or any activity that required the manipulation of objects with both hands (80).

At the time of writing, there are only two qualitative studies available describing DD patients' perspectives. A study by Wilburn et al. (20) stated that quality of life is affected by DD through the disease preventing fulfilment of needs related to confidence, social interaction, intimacy and appearance. Pratt and Byrne (84) showed that patients with DD tend to ignore the disease until it influences the ability to perform activities. Sudden changes with worse finger joint contractures can come as a surprise and are the main reason for seeking medical care. Patients can feel anxiety about the uncertainty of disease progression and may lack information regarding their condition (84).

Despite the possible drawbacks of surgery, several studies have reported high overall patient satisfaction. This has been evaluated by using visual analogue scale (VAS), yes/no or descriptive responses (56, 66, 85, 86). However, no single method for measurement of patient satisfaction has been used consistently, and patient satisfaction has not always been defined, i.e. what patients should report satisfaction about (treatment, outcome, care etc.). Furthermore, satisfaction with the results has not been examined in relation to hand function (56).

Theoretical framework

Two theoretical frameworks have been used in the thesis for providing understanding of evaluation of results, and for guiding data collection and analysis.

Structure, process and outcome

Assessment of quality of care can be described by Donabedian's three-dimensional model consisting of structure, process and outcome (87).

Structure stands for the attributes of the setting in which care occurs and includes material and human resources as well as organizational structure. *Process* concerns what is done in giving and receiving care, and the interpersonal relationship between patient and health care provider (e.g. information, communication, and involvement in decision-making). *Outcome* refers to effects on patients'

health status, which also include improvements in patients' knowledge, useful changes in behavior, and patients' satisfaction with care. In any evaluation of treatment, elements of structure, process and outcome should be included to help interpret findings and to gain a more complete and accurate picture. The nature of the interpersonal exchange between patient and health care provider needs to be better understood to identify and quantify its attributes, and to determine how these contribute to patients' view of the results (87).

The model of the Patient Evaluation Process

Patients' evaluation of treatment is complex and can be influenced by many components, as described in the model of Patient Evaluation Process (figure 2) (88). The model can be used as a starting point for investigating patient-perceived results.
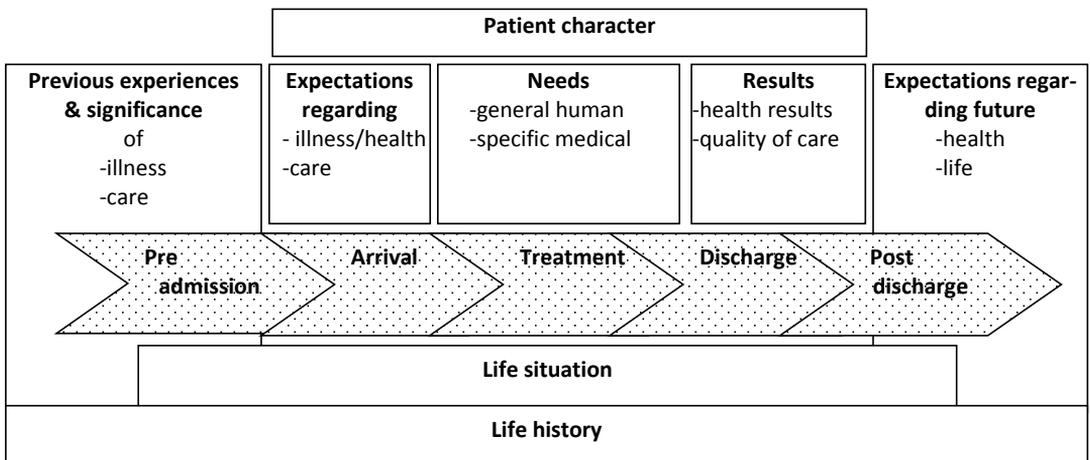
Figure 2. Model of patients' evaluation process, published in Krevers B, Närvänen A-L, Öberg B. Patient evaluation of the care and rehabilitation process in geriatric hospital care. Disability and Rehabilitation. 2002;24(9):482-491. [1]

The model consists of five phases that constitute the patients' care process (preadmission, arrival, treatment, discharge and post discharge). The patients' evaluation of results is described as a flexible procedure and not simply as a linear course. The patients' evaluation of results involves multiple factors such as needs, previous experiences, and present and future expectations. Patients can have previous experiences of illness and care that influence their expectations of the care they are about to receive. Their needs can vary during the care process, and the ways in which these needs are met can influence patients' evaluation of

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results. However, patients' evaluation of results can also be influenced by the patient's life history and life situation, as well as the patient's character. Four patient characters are described in the model: active, passive, tolerant and frustrated. A patient's character is not static and should not be seen as a personality type. Rather, in the model of the Patient Evaluation Process, a patient's character is a product of the patient's own self-description and the situation. In the model, patient character is defined by the patient's description of their involvement in communication and activities of care and rehabilitation (88).

The rationale for the thesis

Despite being the most commonly used outcome measure in hand therapy (42), and after surgery for DD (56), the accuracy of goniometry has seldom been investigated among different patient groups. Therefore, the reliability of goniometer measurement in the finger joints needs to be investigated to determine if the commonly accepted level of measurement error of five degrees for measurement of the finger joints (43) is also true for a specific patient population with DD.

Previous research has shown there are improvements in finger extension, grip function and in self-reported outcome measures such as the DASH after surgery for DD. However, this provides only a limited perspective on hand function. Instead, multiple dimensions of changes in hand function (i.e. physical and psychosocial aspects and including the patients' views of results) need to be reported as a whole. It has been suggested that hand function is recovered three months postoperatively (26, 89). Still, this has not been fully investigated in clinical studies of changes in hand function over time during the first year after surgery and hand therapy.

The indication for treatment of DD is to have extension deficits that cause limitations in hand function. Thus, it would be reasonable to assume that correction of the extension deficits would improve patients' functioning. However, research on the relationship between improved finger extension and functional recovery measured by the DASH has shown only weak associations (75, 80-82). Thus, the factors that explain most of the changes in functional recovery seen after surgery for DD are still unknown (82). The importance of emotional aspects, such as anxiety about the ability to cope with daily life or handle occupational demands, needs to be investigated further. Although these have been shown to be important to patients, such aspects are often overlooked in the most common questionnaires regarding hand function (36). Furthermore, to fully understand how patients value the results after surgery and hand therapy it is crucial to include the patients' perspective. Attention must be given to how interaction between patient and healthcare provider, and factors such as previous experience, needs and expectations can influence patients' views of the results (88, 90). However, this has not been investigated previously among patients with DD. In order to capture patients' experiences and expectations as well as their views of results, it is crucial to investigate their perspective both before and after undergoing treatment.

The knowledge provided by this thesis can increase our understanding of how patients value results after treatment. This knowledge can be used for guiding evaluation or improvement of health care services.

AIM

Overall aim

The overall aim of the thesis was to explore hand function before and after surgery and hand therapy in patients with DD, including assessment, results and patients' perspectives.

Specific aims

- To assess the interrater reliability of goniometer measurement of the finger joints in people with DD (study A).

- To describe clinical and patient-reported outcomes on hand function and quality of life before and after surgery and hand therapy for DD, and to explore factors related to functional recovery in patients with DD (study B).

- To explore patients' perspectives on surgical intervention for DD, focusing on patients' appraisal of results, involving previous experiences, expectations, and patient characters (study C).

METHODS

Study design

This thesis is based on three studies performed between 2010 and 2013. The results are presented in four papers.

Study A: A methodological study with a repeated measures design, investigating interrater reliability in finger joint ROM in people with DD when using standardized guidelines (paper I).

Study B: A prospective cohort study with a repeated measures design, investigating hand function and quality of life before and after surgery for DD. The study consisted of data from four measurement points: before surgery, and three, six and 12 months postoperative (paper II). Longitudinal data from before surgery to three months were used for secondary analysis of factors most important for functional recovery (paper III).

Study C: A qualitative interview study of patients' perspectives on a surgical and hand therapy intervention process. Interviews were performed at two time points: pre- and post-surgical intervention (paper IV).

An overview of the studies and papers are presented in table 1.

Table 1. Overview of the studies and papers in the thesis.

	Study A	**Study B**		**Study C**
Papers	Paper I	Paper II	Paper III	Paper IV
Participants	13 individuals with DD and 8 occupational therapists working with hand therapy	90 patients with DD and an extension deficit of 60 degrees or more in one or several of digit II-V	81 patients with DD drawn from the cohort study sample, with complete measurement before and three months after surgery	21 patients with DD undergoing surgical intervention
Methods	Clinical measures of finger joint ROM.	Clinical measures and questionnaires performed before and three, six and 12 months after surgery and hand therapy	Secondary analysis of change in clinical outcome measures and patient-reported outcomes from before and three months after surgery and hand therapy	Interviews, performed based on an interview guide, before and six-eight months after surgery. The model of Patient Evaluation Process used as a theoretical framework.
Analysis	Standard error of the mean (SEM), intra class correlation (ICC), two-way repeated measures analysis of variance (ANOVA)	Parametric and nonparametric statistics for changes over time and differences between subgroups, risk ratio	Bivariate and multivariable analyses	Problem-driven content analysis performed deductively with inductive elements. Analysis of typologies

Participants and recruitment

Study A: The sample in the methodological study consisted of individuals previously treated, but currently not in treatment for DD, at a department of hand surgery in southeast Sweden. Individuals living within 70 km from the hospital were recruited for the study. Of 19 eligible individuals, 13 gave informed consent to participate and were included in the study. They had different severity of finger joint contractures. Eight occupational therapists (OT), experienced in hand therapy, were included in the study as raters. They were recruited from different hospitals in the southeast region of Sweden via the regional network for hand rehabilitation and had different experience of working with hand injuries. Data collection was performed in April 2010.

Study B: For the cohort study, patients were recruited consecutively from a department of hand surgery in southeast Sweden during autumn 2010 and spring 2011. We estimated the necessary sample size to 58 patients based on a change of 15° in extension deficit with an SD of 30° and a power of 90%. Inclusion criteria for the study were having DD with a total finger extension deficit of 60° or more in an isolated joint or totally in one finger of digit II-V. Exclusion criteria were not speaking Swedish, having other surgical intervention for DD i.e. arthrodesis, or simultaneous surgery for other hand condition. Of 123 eligible patients, 19 did not meet the inclusion criteria and ten declined to participate. Ninety-four patients gave written informed consent but four had incomplete measurements and were excluded. Finally, 90 patients with a mean age of 68 (SD 9) years were included in the study (table 2). There were some dropouts at the follow-ups, and of the 90 patients included in the study 77 attended all four follow-up occasions. Of these 77 patients, 57 had surgery in one finger while 20 had surgery in two or three fingers. Patients were divided into subgroups based on number of treated fingers in order to handle multiple observations and the possibility that outcome could differ between them.

Table 2. Background information on the sample in study B, presented as number of patients and proportions (%) for the whole group and for subgroups.

		The whole group, n=90 n (%)	Patients with surgery on one fin-ger, n=70, n (%)	Patients with surgery on multiple fingers, n=20, n (%)
Sex	male	77 (85)	61 (87)	16 (80)
Disease duration[1]	0-5 years	22 (24)	19 (27)	3 (15)
	6-10 years	32 (36	28 (40)	4 (20)
	11-15 years	17 (19)	12 (17)	5 (25)
	> 15 years	19 (21)	11 (16)	8 (40)
DD[1]	bilateral	64 (71)	46 (66)	18 (90)
Previous surgery for DD		n=85	n=65	n=20
	No	54 (64)	46 (71)	8 (40)
	Other hand	19 (22)	11 (17)	8 (40)
	Same hand, other finger	3 (3)	2 (3)	1 (5)
	Same hand & finger	9 (11)	6 (9)	3 (15)

[1]Significant difference between subgroups $p<0.05$.

Study C: Participants in the interview study were recruited from a department of hand surgery in south Sweden during 2012. Patients planned for DD surgery were invited by mail to participate in the study. They were selected via a rele-vance (i.e. purposeful) sampling strategy (91) based on age, working or retired, extent of the disease (recurrence, uni- or bilateral disease), and experience of having had surgery previously or not. Only men were invited to the study, as DD is rare among women. A written invitation letter about the study was sent to 7-10 patients at a time, adapted to the flow of patients due for surgery. The invitation letter to the study was followed up one week later by phone. An appointment for the pre-treatment interview was made with those who gave oral informed consent to participate in the study. The intention before the study started was to include 15-20 patients, as this was considered appropriate in order to capture unique var-iations and common patterns within a group of patients with DD. Inclusion of participants was performed parallel to the pre-surgery interviews and was stopped after inclusion of 21 participants when interviews was deemed rendering no new information. The 21 men included in the study had a mean age of 66 years (range 46-83 years). They had experiences from private and public health care providers, from the primary health care level to specialist clinics. Their pre-vious experience of treatment for DD varied from not having any hand surgery before to having surgery more than 15 times (table 3).

Table 3. Background information on participants of study C (n=21), presented as number of patients.

Background data	No of patients
Working	9
Retired	12
Married	16
Living alone	5
Family history of DD	12
DD in both hands	15
Previous experience of treatment for DD:	
Previous treatment of same hand and finger	2
Previous treatment in other hand or finger	7
No previous treatment for DD	12

Clinical intervention and study context

Study B and C contained clinical interventions provided at two different departments of hand surgery in Sweden.

Study B:

The patients in the cohort study underwent surgery and hand therapy treatment at a department of hand surgery in southeast Sweden. The surgical intervention followed a standard protocol of fasciectomy with straight-line incisions, removal of the pathological tissue, and closure with z-plasties. If there was a shortage of skin or bad skin quality, the surgeon used an open palm technique (n=8). If there was a residual extension deficit of 25° to 30° left in the PIP joint after the fasciectomy, the surgeon removed the volar plate of the PIP joint (n=9). Table 4 shows surgical interventions and complications during and after surgery.

Table 4. Surgical interventions and complications during and after surgery in study B, presented as number of patients and proportions (%) for the whole group (n=90) and for subgroups (n=70 and n=20).

	The whole group, n=90 n (%)	Patients with surgery on one finger, n=70 n (%)	Patients with surgery on multiple fingers, n=20, n (%)
Type of surgery			
Fasciectomy	73 (81)	60 (85)	13 (65)
+ Open palm	8 (9)	4 (6)	4 (20)
+ Volar release	9 (10)	6 (9)	3 (15)
Complications during surgery			
Nerve injury	4 (4)	3 (4)	1 (5)
Blood vessel injury	1 (1)	0	1 (5)
Complications after surgery			
CRPS[1]	4 (4)	3 (4)	1 (5)
Infection	6 (7)	6 (9)	0
Surgery in dominant hand	49 (54)	40 (57)	9 (45)
Operated fingers	*n=114*	*n=70*	*n=44*
Index	1 (1)	0 (0)	1 (2)
Long	9 (8)	1 (1)	8 (18)
Ring	34 (30)	15 (21)	19 (43)
Small	70 (61)	54 (77)	16 (36)

[1]CRPS=Complex regional pain syndrome

After surgery, the hand was casted. Postoperative hand therapy was given according to a standard protocol regardless of the extent of surgery.

- One week after surgery, the cast was removed and all patients started active exercises four times/day with isolated joint motions of the MCP, PIP and the distal interphalangeal (DIP) joints as well as composite flexion and extension. All patients received a volar splint to use day and night and only remove when performing exercises. Position of the splint was with the wrist in 10° to 20° extension, the MCP joint in 10° to 20° flexion, and the interphalangeal joints in maximum extension without stressing the wounds.

- Two weeks after surgery, the patients removed the splint during the day and were allowed to start using the hand in light activities. They continued performing exercises and using their splint at night. The splint was used for three to six months or as long as the finger had the tendency to loose extension during the day.

- Follow-up and treatment of swelling, ROM, pain and skin issues, and the ability to use the hand in activities continued during the first three months after surgery, depending on the patients' needs.

Ninety-eight percent of the patients reported using their splint at three months after surgery and 37% were still using it at six months. Some patients needed further postoperative hand therapy directed towards ROM, swelling, pain or scar issues (table 5).

Table 5. Postoperative intervention in study B directed towards ROM, swelling, pain or scarring given to patients attending 3 months follow-up (n=86). Data is presented as type of problem and intervention in hand therapy, n (%).

Postoperative intervention	n (%)
ROM	
Dynamic extension splint	2 (2)
Dynamic flexion splint	4 (5)
Swelling	
Compression glove or finger wrapping	26 (30)
Pain	
Transcutaneous nerve stimulation (TENS) or acupuncture	5 (6)
Pain medication (diclofenac, paracetamol)	13 (15)
Scarring	
Zinc tape, occlusive materials	10 (12)

Study C:

Participants in study C underwent an outpatient surgical intervention process at a department of hand surgery in south Sweden. They had surgery and went home the same day, returning to the clinic some days later for wound care and follow-ups. Most of them were provided postoperative hand therapy, except those with less severe DD who were given instructions about exercise directly from their surgeon. Hand therapy consisted for example of exercises, splinting or treatment of swelling or scar issues.

Data collection

Study A:

In the methodological study, ROM in the finger joints of digit II-V was measured with a plastic finger goniometer graded in intervals of 2° according to study guidelines created by the research group. The guidelines were based on review of the literature and clinical experience, and included goniometer placement, measurement position, and instructions to the patient. Goniometer placement was dorsal midline over the metacarpals or phalanges.

Starting position for flexion:

- Elbow placed on table, forearm in neutral position, wrist in 30° extension. MCP and PIP joint flexion were measured in full fist position (figure 3A-B)
- Elbow placed on table, forearm and wrist in neutral position. DIP joint flexion was measured with the MCP joint in as much extension as possible, and the PIP and DIP joints in flexion, attempting to make a hook fist (figure 3C)
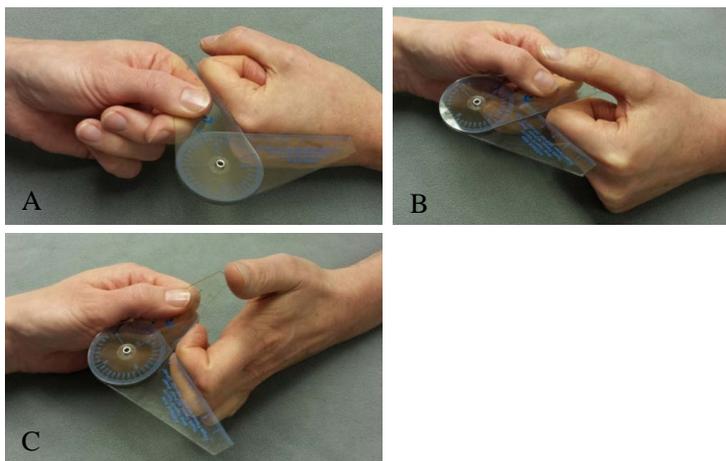
Figure 3A-C. Goniometer measurement of active MCP (A), PIP (B) and DIP (C) joint flexion.

Starting position for extension:

- Elbow placed on table and forearm in neutral position, wrist in neutral position (0°), and fingers in full extension

Instructions to the patients were:

- "make a fist"
- "straighten your knuckles and keep your finger joints in flexion"
- "straighten the fingers all the way"

The OTs participating as raters received the guidelines one month before the day of assessments, and the guidelines were reviewed at a meeting with the opportunity of practice and discussion. The eight raters performed one trial of measurement of all 13 individuals with DD. Measurements of flexion and extension of the MCP, PIP, and DIP joints in one affected finger for each individual were performed, giving 104 measurements of joints and motions. The results are presented in paper I.

Study B:

In the cohort study, data were collected before surgery and at three, six and 12 months after surgery and hand therapy. The results of changes in hand function over time are presented in paper II. Data from the cohort study was also used for secondary analysis to explore factors most related to functional recovery. For this analysis, data from before surgery and the three months follow-up was collected. The time point three months after surgery and hand therapy was chosen as it represents a common time point for clinical evaluation of the short-term outcome. The results from the secondary analysis are presented in paper III.

All data in study B were collected by two OTs, one of them was me, who were not involved in the postoperative treatment. The same OT followed each patient with the exception of five patients living further away from the hospital, where local OTs specially trained for the study performed the follow-up measurements. The OTs also systematically collected information about postoperative hand therapy given for swelling, pain, ROM, splinting and scars.

Overview of data collection

Data collection in study B consisted of:

- Clinical outcome measures of physical aspects of hand function
  - finger joint ROM
  - sensibility
  - scar pliability
- Patient-reported outcome measures
  - DASH
  - Expectations, recovery and satisfaction with hand function
  - Safety and social issues of using the hand
  - Health-related quality of life

   The clinical measures of physical aspects of hand function were chosen based on their significance for DD, and the patient-reported outcomes were chosen to capture multiple perspectives on hand function and quality of life.

Clinical outcome measures of physical aspects of hand function

Finger joint ROM

ROM of individual finger joints was measured according to guidelines developed and tested in study A. In study B, finger joint ROM consisted of:

- Active extension deficit in isolated finger joints (MCP, PIP, DIP) in the operated finger/fingers
- Maximum active finger flexion in isolated finger joints (MCP, PIP, DIP) in the operated finger/fingers

If hyperextension was present in the DIP joint, it was recorded as 0 degrees in order not to underestimate the extension deficit.

Sensibility

Sensibility can, on the simplest level, be divided into protective or discriminative sensibility (92). Protective sensibility pertains to the sensation of potentially harmful stimuli on the skin, e.g. heat, cold, or superficial pain (93). Discriminative sensibility refers to functional sensibility enabling the individual to identify shape or texture (92). In study B, sensibility was measured on the radial and ulnar part of the fingertip of the operated finger with the Semmes-Weinstein Monofilament (SWM). The SWM is a standardized instrument of touch threshold measuring at which force a person can detect a stimuli to the skin (94). The SWM is well documented regarding validity and reliability for sensory recovery after nerve repair (92). The SWM consist of filaments representing different amount of pressure that is applied to the skin. Each filament has a descriptor that translates the different thresholds into functional levels e.g. "normal sensibility", "diminished light touch" or "diminished protective sensation" (94). Five filaments were used in study B ranging from 0.07 g pressure equaling normal sensibility to 450 g equaling deep pressure only. Testing started with application of the 0.07 filament and progressed to less pliant filaments applying greater pressure according to guidelines.

Scar pliability

Scar pliability refers to the functional mobility and the elastic texture of the scar and are rated by comparison of manipulation of normal skin (40). In study B, scar pliability was assessed at tree, six and 12 months after surgery and hand therapy using a subscale from the Vancouver Scar Scale (VSS) (95). The pliability sub scale of the VSS was chosen as it was considered most applicable for assessment of scar tissue after surgery for DD.

The pliability subscale of the VSS consists of six scale steps: 1=normal skin, 2=supple (flexible scar with minimal resistance), 3=yielding (scar giving away to pressure), 4=firm (scar inflexible, not easily moved, and resistant to manual pres-

sure), 5=ropes (rope like tissue that blanches with extension of scar), 6=contracture (permanent shortening of scar producing deformity/distortion) (95). The VSS can be used for different types of scars, although it is commonly used for rating of burn scars (96). Limitations of the VSS are that it is dependent on the raters' experience and observations skills (40, 96, 97). In study B, this was addressed by using short statements describing each level of the rating scale and OTs with long experience of treating patients with DD as raters. The rating scale was also discussed among the OTs responsible for assessments before the study started.

Patient-reported outcome measures

DASH

The Swedish version of the DASH was used to assess general disability in the upper extremity (72, 73). The DASH consists of a 30-item disability/symptoms scale where the items are rated on a five point scale ranging from "no problem" to "unable to do". Based on the 30 items a total DASH score can be calculated ranging from 0=no disability to 100=severest disability. Normal values of the DASH of 10.1 score points (SD 14.68) has been reported among a general American population (98). A change of 15 score points has been proposed as representing both the minimal detectable change and an important clinical change (71, 99).

In study B, patients rated the 30-item disability/symptoms scale before treatment and at each follow-up. For secondary analysis, the change in DASH score from before surgery to three months postoperative was used as a measure of functional recovery.

Expectations, recovery and satisfaction with hand function

Before surgery, patients were asked to rate their *expectations* of their future hand function, and at the follow-ups they were asked to rate their *recovery* of hand function. Response options for expectations and recovery of hand function were: "fully recovered" , "much better", "somewhat better", "unchanged", "uncertain", "somewhat worse ", "much worse". At each time point, patients were also asked about satisfaction with their current hand function. Response options were: "delighted", "pleased", "mostly satisfied", "mixed feelings", "mostly dissatisfied", "dissatisfied", and "terrible".

The rating scales for expectations/recovery and satisfaction was originally developed for patients with incontinence (100) and for low back pain (101). However, the questions about expectations/recovery and satisfaction were not regarded as disease-specific as both are one-question global rating scales. A global rating scale can capture patients' perception of improvement in a construct of interest and is useful to get an overall appraisal of a complex phenomenon

(53). Thus, the questions were slightly adapted to apply to the study context of expectations/recovery and satisfaction with hand function.

Safety and social issues of using the hand

At each follow-up, patients were asked five questions about safety and social issues of using the hand (table 6). These questions were developed by the research group with inspiration from Mohtadi (1998) (102), in order to capture emotional functions (103) and aspects shown previously to be important for patients with DD (84). Thus, the questions were based on clinical experience and theoretical knowledge. The questions regarding safety issues have been validated in a health-related quality of life questionnaire from another area (102), but not specific for patients with DD. In order to achieve face and content validity of the five questions a consensus discussion was carried out with experts and clinicians with experience of patients with DD. Face validity was also achieved by asking patients with DD about the questions and they were deemed as easy to understand and rate, and as relevant to their condition.

Table 6. Questions regarding safety and social issues of hand function used in study B.

Question	Rating scale
Safety issues	
"Do you worry about not trusting in your hand function, for example when gripping an object?"	1=extremely worried 10=not worried at all
"Do you need to take special precaution due to your hand function (for example when lifting/carrying or handling objects) at work or at home?"	1=takes great precautions 10=takes no precautions at all
"Are you afraid to hurt the hand due to your hand function (for example getting stuck with the finger)?"	1=extremely afraid 10=not afraid at all
Social issues	
"Are you concerned about the appearance of your hand?"	1=extremely concerned 10=not concerned at all
"Do you avoid using your hand in social contexts (for example shake hands)?"	1=avoid to a great extent 10=do not avoid at all

Health-related quality of life

Health-related quality of life was measured with the Swedish version of the Euroqol five dimensions (EQ-5D). The Euroqol consist of two parts:

- EQ-5D index, which is a descriptive profile of five areas which is converted into an index (range 1=full health to -0.594=worst imaginable health state)
- EQ VAS which is a vertical visual analogue scale on which overall health is rated (100="best imaginable health state" and 0="worst imaginable health state") (104).

The Euroqol was developed by the EuroQol Group as a generic standardized instrument for evaluating health-related quality of life (104). It can be used as a measure of health outcome and are available in different languages (105). A change in 0.07 in the EQ-5D index has been proposed as a minimal important difference, i.e. the smallest difference in score that patients perceive as beneficial (106).

Study C:

In the interview study, each participant was interviewed twice: pre-surgery (i.e. two to four weeks before surgery) and post-surgery (i.e. six to eight months after surgery). Two participants were only interviewed before surgery as one of them was not available for the follow-up interview and the other had his surgery postponed due to other health reasons.

The researchers of study C had no connection to the clinic providing the care. The interviews were performed by me, a doctoral student and hand therapist with long experience of clinical practice with patients with DD. I introduced myself as a doctoral student performing a research project and the participants were not informed about my clinical expertise. This "under cover" act was chosen in order to receive rich descriptions from the participants.

All interviews were performed by phone except the pre-surgery interview with the first participant, which was performed at the clinic providing the care. An interview guide in two parts was created with inspiration from the model of Patient Evaluation Process (88). The interview guide followed the phases of the care process, i.e. the past, present and future. The first interview covered *previous experience* of care regarding DD and other health issues, *present life situation, needs* and *expectations* of the results. The second interview covered *results, impact on hand function*, and *expectations* of the future. The interview guide was tested at the pre-surgery interview with the first participant and no changes were made.

All interviews started with the same questions: *"Why did you seek medical care for your hand condition?"* (first interview), and *"what do you think about the treatment you have received?"* (second interview). Depending on the respondents, the following questions could be asked in different order. The interviews were conducted in an open style with adapted probing in order to create a dialogue that would be as respondent-oriented as possible. Follow-up questions were asked with respect to the aim of the study and what the participant was willing to talk about. The two interviews with each participant lasted approximately 20-45 minutes each (median 23 minutes). They were recorded digitally, and field notes about the interview were written down immediately after it was finished. The interviews were transcribed verbatim by me.

Data analysis

Statistical analyses were performed in study A and B, while qualitative content analysis and analysis of typologies was performed in study C.

Study A:

Statistical analyses were performed on isolated finger joint motions, and on total active extension (TAE) and total active flexion (TAF). TAE and TAF were calculated as the sum of the scores for extension and flexion in the MCP, PIP and DIP joints. The following analyses were performed:

- Descriptive statistics were calculated for each patient's ROM as measured by the eight raters, to illustrate the patient's level of severity of DD. Descriptive statistics for each rater, joint and motion were also calculated.

- Differences between the rater with the highest and the lowest mean scores were calculated for each joint and motion.

- The standard error of the mean (SEM) was calculated for each joint and motion as an indication of the precision in measurements. Calculation of SEM was performed as described by Altman & Bland, i.e $SEM = SD/\sqrt{(\text{sample size})}$ (107).

- A two-way repeated measures analysis of variance (ANOVA) for each ROM measure was performed to determine whether there were differences in means between raters.

- Relative interrater reliability was assessed with the Intra Class Correlation (ICC) two-way mixed model and an absolute agreement definition (108). This model of ICC treats raters as a fixed effect and patients as random effects. Absolute agreement definition were chosen since systematic variability among raters was relevant to the analysis. The strength of ICC was interpreted using a classification in which 0–0.25 = little if any, 0.26–0.49 = low, 0.50–0.69 = moderate, 0.70–0.89 = high, and 0.9–1.0 = very high correlation (109).

Study B:

Statistical analyses of changes over time in hand function (paper II):

- Descriptive statistics were used for demographic data and sample characteristics, and Fisher exact and t-tests for identifying differences between subgroups regarding sample characteristics.

- Rating of safety issues (questions 1-3) and social issues (questions 4-5) before surgery was summed and averaged, and compared with Wilcoxon signed rank test.

- TAE was calculated by the sum of extension deficit in isolated finger joints and TAF was calculated by the maximum flexion in isolated finger joints.

- Total ROM in the operated finger was calculated as the total active finger flexion minus the total active extension deficit. The participants' ROM was compared to 165° ROM. This represented the minimum level of functional ROM needed for performance of 11 common daily activities (52).

- To handle multiple observations in the analysis, patients were divided into two subgroups consisting of patients with surgery on one finger and surgery on multiple (two or three) fingers. For patients with surgery on multiple fingers, an average for ROM and sensibility outcomes were calculated. The analysis was performed on the whole group and on subgroups.

- For ROM, DASH, and EQ-5D, a 1-way full factorial repeated measures ANOVA was used with surgery on one or multiple fingers as a between-subjects factor. In addition, a single-contrast analysis was performed using the preoperative measure as a reference.

- For nonparametric variables, the Friedman test and Wilcoxon signed rank test with Bonferroni correction were used for identifying differences between follow-up occasions. The Kruskal Wallis Test was used for analysis of differences between subgroups.

- The scar pliability scale was dichotomized based on whether the scar tissue affected functional use of the hand or not. It was deemed that the three first rating categories, i.e. normal, supple or yielding scar tissue, would not affect functional use of the hand. Then the relative risk (risk ratio) for having scar pliability rated as firm, ropes, or contracture depending on the number of operated fingers was calculated.

A p-value of .05 or less was considered as significant.

Statistical analyses of factors most related to functional recovery (paper III):

The analysis were based on longitudinal data from the cohort study i.e. change scores from before treatment to three months after surgery and hand therapy.

- Descriptive statistics were applied to show the characteristics of the study population. The extent of the disease was represented by the variables having one or multiple affected fingers, and unilateral versus bilateral disease. The variables sex, one/multiple affected fingers, unilateral/bilateral disease was explored with the Student's t-test to investigate if there were any differences in functional recovery.

- Associations between functional recovery measured with DASH and the other outcome variables were explored with bivariate and multivariable analyses. Bivariate analysis involved the Pearson's correlation coefficient for interval scales (ROM, DASH, EQ-5D index, EQ VAS) and Spearman's rank correlation coefficient for ordinal/categorical scales.

- From the bivariate analysis, variables with an alpha level of < 0.1 were chosen to create a regression model that best explained functional recovery measured with DASH. A multivariable regression analysis, of the linear backwards type, was applied with an alpha level of 0.06 as a limit for removal of variables and with DASH change score as the dependent variable. Nine independent variables were included in the initial regression analysis: TAE, TAF, worry about not trusting in hand function, need to take special precautions due to hand function, fear of hurting the hand, avoid using the hand in social context, EQ VAS, EQ-5D index and sex. Alpha level was set to 0.05 for significance. The final model presented in the study included three variables giving a sample size of 22 cases per variable. In the EQ-5D index, 0.1 point represented one scale step of change in the regression analysis.

Study C:

A problem-driven approach to content analysis (91), was used for the analysis of the interviews. Problem-driven content analysis uses predefined coding categories based on specific research questions to make inferences from a body of text, in relation to a specific context. The analysis was performed deductively with inductive elements (91). The coding process was performed using the QSR NVivo 10. The analysis consisted of two parts to capture the components of the model of Patient Evaluation Process: content analysis of data based on predetermined coding categories and analysis of typologies (110). The two interviews with each participant were analyzed as a whole as they represented the patients' care process.

Analysis based on predetermined coding categories:

This part of the analysis was performed on all 21 interviews. The predetermined coding categories were based on components in the model of Patient Evaluation Process: previous experiences, expectations before surgery, needs, appraisal of results, life history, life situation, expectations of future, and patient character. One category was labelled "other" to allow for openness to data not matching the predetermined categories.

The analysis started with deductive coding of text based on the coding categories, and continued with inductive creation of subcategories based on their content. The analysis preceded with continuous moving back and forth between categories, subcategories and text until all 21 interviews were analyzed. Although the analysis started with deductive coding, it was performed with a conscious reflection of different ways of organizing data and whether the meaning bearing units were representative of the categories.

Analysis of typologies:

Analysis of typologies (110) was used to identify patient characters in study C. This part of the analysis was performed on the 19 complete pre- and post-treatment interviews and was complemented by the interviewer's field notes. Each interview was analyzed based on: participants' descriptions of themselves, their initiatives, interaction with the staff, and their involvement in decisions during the care process, and appraisal of results. This was summarized together with the interviewer's field notes, and gave a description of each participant. Each description of the participants was then given a label inspired by patient characters identified in the model of Patient Evaluation Process.

Work process of the qualitative analysis

Initially, I independently performed the coding based on the predetermined categories, and analysis of typologies. My experience of qualitative research methods consisted of completed doctoral courses. However, the coding was, in a collaborative work process, continuously discussed with the third author of paper IV (BK), who was familiar with the theoretical framework and experienced in qualitative analysis and research. The preliminary analysis was presented to the second author of paper IV (JK), an experienced researcher, and was discussed by all three authors of paper IV (CE, JK, and BK). If there were disagreements during the analysis, the authors revisited the data in order to reach consensus.

Not all of the predetermined categories were presented in paper IV. Based on the aim of study C focusing on the intervention process, data from five categories were presented in paper IV: previous experiences, expectations before surgery and of the future, appraisal of the results, and patient characters. These categories represent selected components of the model of Patient Evaluation Process, with some minor adjustments of labels' adapted to the study context.

Ethical considerations

All studies in this thesis were performed in accordance with the declaration of Helsinki ethical principles for medical research. The participants in study A and C provided informed consent to participate by responding to the written and oral information given to them about the studies. In study B, the participants provided informed consent by signing an agreement form to participate in the clinical follow-ups. All participants were informed about the purpose of the studies and the possibility to withdraw from them without giving explanations and that this would not affect their intervention.

Data from study A and B was anonymized and stored in a secure locker at the University Hospital. The digital recordings and the anonymized transcribed material from study C were stored in a locker only accessible to the researchers.

During the analysis of all three studies, the researchers only discussed anony-mized and coded data.

The three studies aimed to improve health care services and were designed not to harm any patient. In study A, the participants were granted with a lottery ticket and the participants in study B received extra follow-ups beyond usual clinical practice. The participants in study C were given the opportunity to freely express their view of the results to someone outside the department providing their care. In study C, participants were not informed about my clinical experi-ence of hand therapy and meeting patients with DD. This decision was taken with respect to whether it could harm the participants or not, and the opportunity to receive a fuller description from the participants.

The regional ethical review board in Linköping, Sweden, approved the studies (Ref no 2010/118-31, 2011/472-32).

RESULTS

Interrater reliability of goniometer measurement (study A)

The results showed that interrater reliability was high or very high (ICC .832 to .973) when using a goniometer to measure ROM in the finger joints of people with DD. The ICC values for measuring digital extension were higher than for flexion. Measurement of PIP joint extension showed the highest ICC value (.973) while measurement of MCP joint flexion showed the lowest (ICC .832). There were larger differences between raters with the highest and the lowest mean score when measuring isolated joint flexion (4°-11°) than isolated joint extension (3°-7°). The SEM across all joints and motions ranged between 1° and 3° (table 7).

Table 7. Measures of all raters across all joints and motions. Data is presented as difference between raters with the highest and lowest mean scores, standard error of the mean (SEM), intra class correlation coefficient (ICC) and 95% confidence intervals (CI).

Joint and motion	Diff between raters	SEM	ICC	CI (95%)
Extension				
MCP	3°	2°	.952	.904–.982
PIP	7°	2°	.973	.944–.991
DIP	3°	2°	.960	.919–.985
TAE	8°	3°	.949	.898–.981
Flexion				
MCP	4°	1°	.832	.696–.934
PIP	4°	1°	.920	.844–.970
DIP	11°	1°	.909	.809–.967
TAF	18°	2°	.898	.873–.976

Changes over time in hand function (study B)

ROM, sensibility and scar pliability

Study B showed that the TAE deficit was significantly reduced at three months after surgery and hand therapy, and remained stable during the first year (figure 4A). The TAF was significantly impaired at three months compared to before surgery, but recovered over time (figure 4B). At 12 months, flexion of the MCP joint had recovered while flexion of the PIP joint still was slightly impaired compared to before surgery.
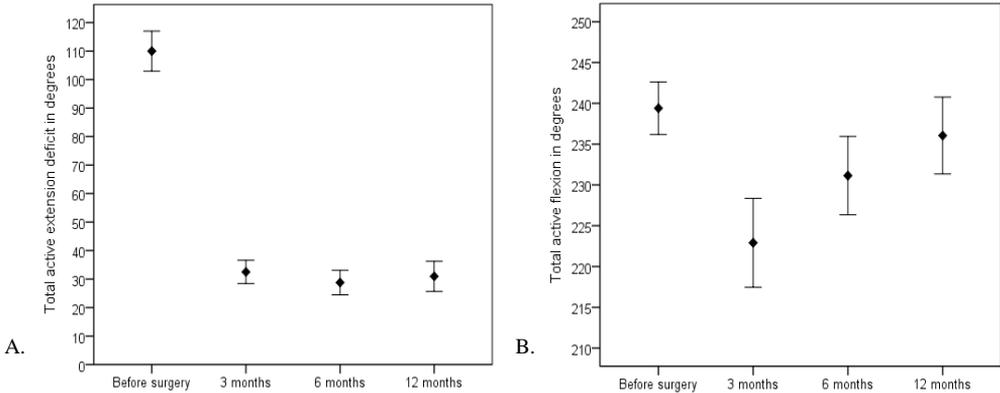
Figure 4A-B. Total active extension deficit (TAE) and total active flexion (TAF) in the whole finger before surgery (n=90), 3 months (n=86), 6 months (n=84) and 12 months after surgery (n=82). Data is presented as mean degrees and 95% confidence intervals (CI).

There was no interaction effect between ROM outcome and having surgery on one or multiple fingers, i.e. subgroups did not differ in ROM and the course of change was similar for both subgroups. The proportion of patients reaching a functional ROM of 165° increased from 20% before surgery to 87% at 12 months. No patient reached a normal total ROM of 290° after surgery (figure 5).
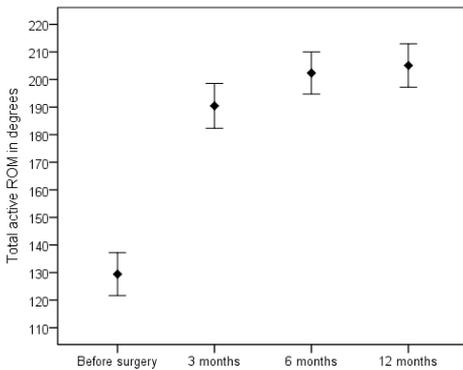
Figure 5: Total active ROM in the whole finger at different time points. Number of patients at each time point: before surgery (n=90), 3 months (n=86), 6 months (n=84), and 12 months after surgery (n=82). Data presented as mean degrees and 95% CI.

Sensibility was unaffected by surgery and did not differ between patients with surgery on a single or multiple fingers. The majority (93%) had normal sensation or diminished sensation for light touch both before and 12 months after surgery.

Scar pliability was in general worse among patients with surgery on multiple fingers. At 12 months, 25% of these patients had a scar pliability rated as firm, ropes or contracture compared to 5% of the patients with a single operated finger (table 8).

Table 8. Outcome on rating of scar pliability as firm, ropes or contracture for patients attending all follow-ups (n=77). Data is presented as proportions (%) and risk ratio and 95% CI.

Scar pliability rated as firm, ropes or contractures	3 months	6 months	12 months
One operated finger (n=57), %	28	18	5
Multiple operated fingers (n=20), %	50	40	25
Risk Ratio (95% CI)	1.78 (0.97-3.26)	2.28[1] (1.05-4.96)	4.75[1] (1.25-18.1)

[1]Significant increased risk of worse scar pliability for patients with surgery on several fingers, P < .05.

Disability measured with DASH

DASH score improved over time for all patients, from mean 20 (95% CI, 17-23) score points to mean seven (95% CI, 5-8) (p<0.05), meaning that patients had less disability after treatment. At all follow-up occasions, patients with multiple operated fingers had significantly higher DASH score compared to patients with surgery on a single finger (p<0.05) (figure 6). There was no interaction effect between number of operated fingers and DASH score.
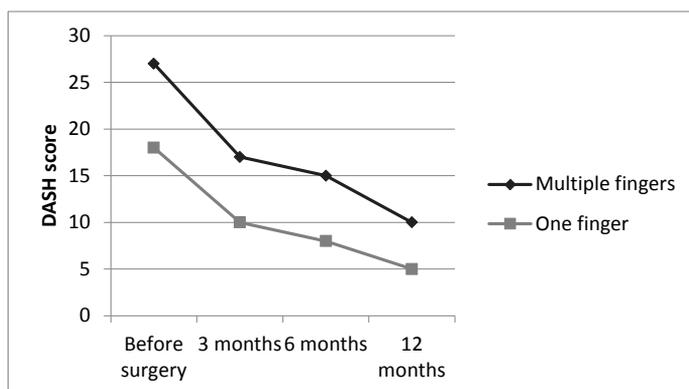

Figure 6. Mean DASH score for subgroups consisting of patients with one operated finger (n=53) and multiple operated fingers (n=17). Rating scale: DASH score 0=no disability 100=severest disability.

Expectations, recovery and satisfaction with hand function

Preoperative expectations regarding future hand function were fulfilled for a ma-
jority of the patients, as there was no difference between preoperative expecta-
tions and self-reported recovery at 12 months (p=0.077) (table 9). Self-reported
recovery of hand function improved until 6 months (p<0.001) and no further
changes were seen at 12 months. There were no differences between patients
with surgery on one or multiple fingers regarding preoperative expectations, self-
reported recovery or satisfaction with hand function.

Table 9. Self-reported outcome on expectations, recovery and satisfaction with
hand function for patients attending all follow-ups (n=77). Data is presented as
proportions (%).

	Before surgery %	3 months %	6 months %	12 months %
Expectations before surgery, (n=74):				
Hand function will be "fully recovered"	43			
Hand function will be "much better"	51			
Self-reported recovery of hand function, (n=74):				
Hand function "fully recovered"		18	32	37
Hand function "much better"		60	60	50
Satisfaction with present hand function, (n=75):				
"Delighted"/"pleased" with current hand function	4	65[1]	73[2]	81

[1] Significant difference compared to before surgery, p≤0.05
[2] Significant difference compared to 3-month follow-up p<0.05

Safety and social issues of hand function

Before surgery, patients rating of safety and social issues showed that safety is-
sues of hand function were a larger problem than the social issues (p<0.001).
However, over time, all five questions were rated as improved (p<0.001) (figure
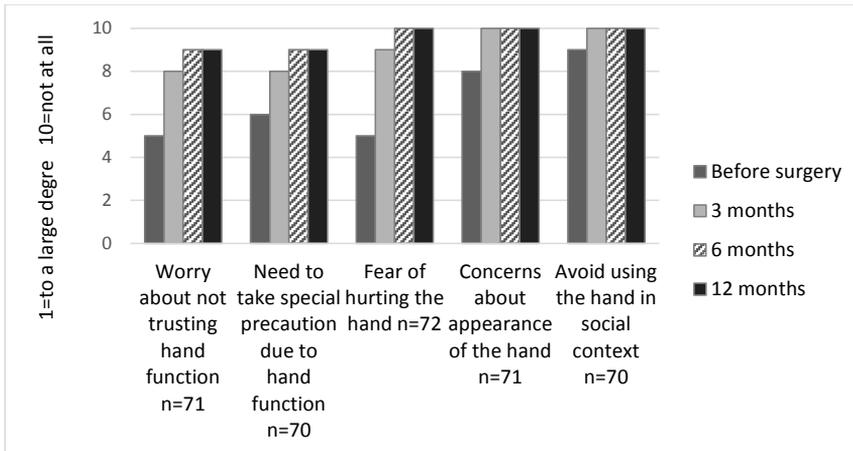7).

Figure 7. Outcome on safety and social issues of hand function for patients attending all follow-ups. Data is presented as median scores for the whole group. Rating scale: 1=to a large degree; 10=not at all. Safety issues: worry about not trusting in hand function, need to take special precautions due to hand function and fear of hurting the hand. Social issues: concerns about appearance of the hand, avoid using the hand in social context.

There were differences between patients with surgery on one or multiple fingers concerning "need to take special precautions due to hand function" and "fear of hurting the hand". Before surgery, patients with surgery on multiple fingers had significantly worse scores on those questions ($p<0.05$) and at 12 months they still had worse scores on "need to take special precautions due to hand function" ($p=0.028$).

Health-related quality of life
Health-related quality of life measured with the EQ VAS improved for all patients over time ($p<0.05$). The EQ-5D index for the whole group increased over time but the change was not statistical significant ($p=0.071$). There was an interaction effect between number of operated fingers and EQ-5D index ($p=0.046$), and patients with surgery on multiple fingers showed temporarily lower scores at three and six months follow-up while patients with surgery on a single finger had higher scores over time (table 10).

44

Table 10. Outcome on health-related quality of life measured with EQ-5D index and EQ VAS for patients attending all follow-ups. Data is presented as mean (95% CI).

	Before surgery	3 months	6 months	12 months
EQ-5D index, (n=68)	0.82 (0.79-0.85)	0.88 (0.84-0.91)	0.87 (0.84-0.90)	0.91 (0.88-0.95)
One operated finger (n=52)	0.81 (0.78-0.85)	0.89 (0.85-0.94)	0.89 (0.85-0.92)	0.93 (0.89-0.97)[1]
Multiple operated fingers (n=16)	0.85 (0.79-0.91)	0.82 (0.75-0.90)	0.82 (0.76-0.88)	0.85 (0.78-0.92)
EQ VAS, (n=67)	80 (76-83)	80 (76-84)	83 (79-87)	84 (80-88)[2]

[1]Significant difference between subgroups, p<0.05. Rating scales: EQ-5D index 1=full health, -0.594=worst imaginable health state. EQ VAS 100=best imaginable health state 0=worst imaginable health state. [2]Significant difference compared to before surgery p<0.05.

Factors important for functional recovery (study B)

Functional recovery measured as change in DASH score from before to three months after treatment differed between men and women. The relatively few women participating in study B had a greater improvement in DASH score (mean change 18, SD 18) compared to the men (mean change 8, SD 13) (p=0.036). Otherwise, there were no differences in functional recovery between patients with one or multiple operated fingers or patients with uni- or bilateral DD.

Bivariate analysis showed that functional recovery was positively associated with improvement of TAE, TAF, four questions regarding safety and social issues, and quality of life (table 11).

Table 11. Associations between functional recovery (improvement on DASH from before surgery to three months) and other variables. The data is presented as Pearson's (r) or Spearman's (rho).

Variables	n	r	rho	p
Age	81	.085		.449
TAE improved	81	.256		**.021**
TAF improved	81	.302		**.006**
Worry about hand function improved	77		.693	**.000**
Need to take special precautions due to hand function improved	76		.700	**.000**
Fear of hurting the hand improved	78		.497	**.000**
Concerned about the appearance of the hand improved	78		.110	.337
Avoid using the hand in social context	78		.283	**.012**
EQ VAS improved	74	.275		**.018**
EQ-5D index improved	77	.525		**.000**

Nine variables were entered into the multivariable regression analysis: sex and eight variables from the bivariate analysis. During the backwards procedure, six of the variables were excluded, giving three variables in the final model that best explained the variation in DASH; "need to take special precautions due to hand function," "avoid using the hand in social context," and health-related quality of life measured with the EQ-5D index (Table 12).

The standardized coefficients (*β*) showed that an improvement in "need to take special precautions due to hand function" had the greatest relative effect of the individual variables in the final model. The unstandardized coefficient (B) showed that an improvement of one score point in this variable was associated with an improvement in DASH with 2.55 score points. The overall model fit showed that improvements in the three variables in the final model explained 62% of the variance in DASH scores.

Table 12. Analysis of independent variables best explaining functional recovery measured with DASH. Data for the final model presented as the unstandardized coefficient (B) with 95% confidence intervals, the standardized coefficient (β) for the independent variables, and adjusted coefficient of determination (adj r^2) for overall model fit.

Independent variables	n	*B*	95% CI Lower	Upper	β	p-value	Adj r^2
Need to take special pre-cautions due to hand function improved	68	2.55	1.85	3.24	0.577	.000	
Avoid using the hand in social context improved	68	0.73	0.002	1.45	0.156	.049	
EQ-5D index improved 0.1	68	2.42	1.30	3.54	0.340	.000	
Overall model fit							.621

Patients' perspective on surgical intervention (study C)

Patients' perspective on surgical intervention was described as five main categories: previous experiences; expectations before surgery; appraisal of results; expectations of the future; and patient characters (figure 8).
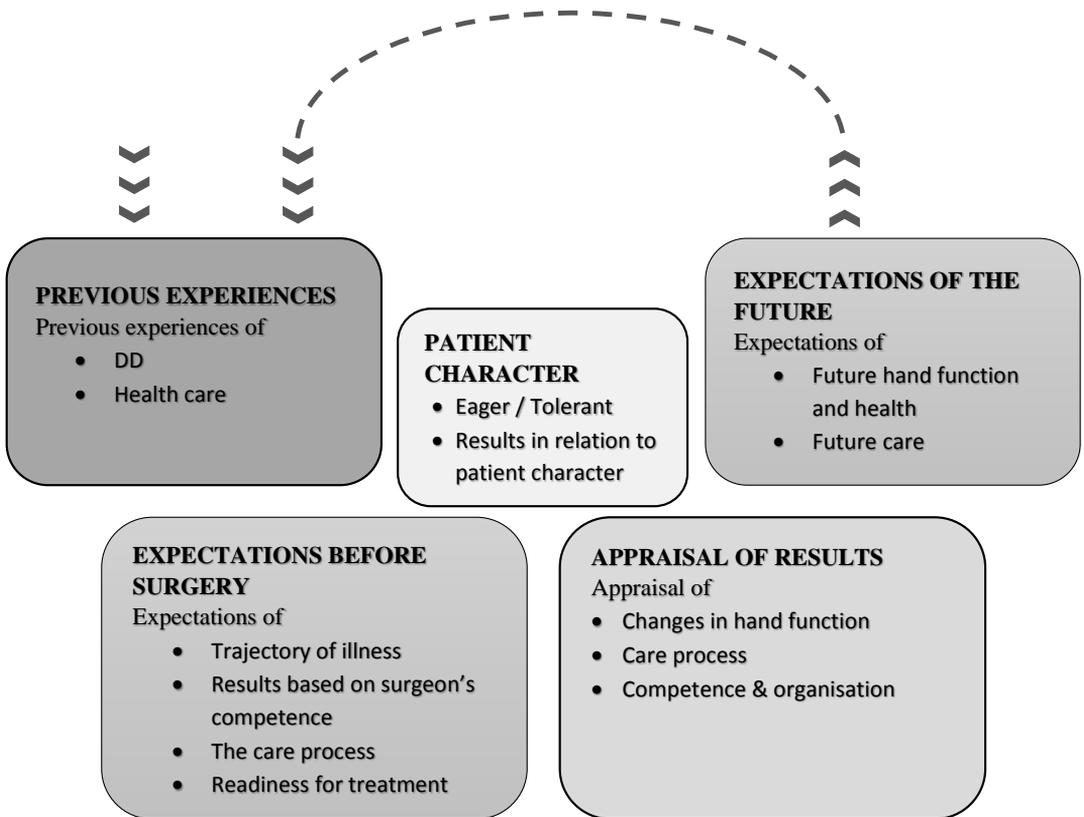
Figure 8.The main interconnected categories and their content, based on selected components of the model of Patient Evaluation Process. Previous experiences influenced patients' expectations before surgery. Patients' appraisal of results involved previous experiences, expectations, patient character, and concerned changes in hand function, care process and organizational matters. Expectations regarding the future were influenced by appraisal of results. The three pointers placed before the category 'Previous experiences' and after the category 'Expectations of the future' indicate the entry and exit of the care process the patient went through. The dotted line illustrates how experience from one care process can form the basis for evaluation of future care processes.

Previous experiences

Participants described their *previous experiences of DD* as the disease causing a range of problems with hand function and activity limitations. It could be difficulties with gripping, holding and carrying objects. They also described positive and negative *previous experiences of health care*, their own or friends and relatives experiences. Positive previous experiences could be having an improved ROM or being able to extend the fingers fully, not having pain during or after surgery, being involved in decision-making, or having a rational and smooth care process. Negative experiences were for example recurrence of contractures, scar problems or impaired sensation, having a lot of pain, seeing many different doctors, being sent back and forth between health care providers, having surgery postponed with short notice or not getting enough information.

Expectations before surgery

Expectations before surgery consisted of expectations of trajectory of illness; on the results based on the surgeon's competence; on the care process; and readiness for treatment. A common feature of these subcategories was how previous experiences colored the participants' expectations.

Four different expectations of *trajectory of illness* were identified, i.e. participants could expect hand function to be improved, or to be stable, or they could be uncertain or feel resignation about their coming hand function. Regardless of having previous experience of hand surgery or not, there was an emphasis on expecting an improved hand function. The trajectory of illness "resignation" was new compared to those identified in the original model.

Participants' expectations regarding results were influenced of their view of *the surgeon's competence and skills*. This was the participants' non-professional view of competence rather than an expression of the surgeons' formal qualifications. They spoke of the surgeons' competence in relation to their own previous experiences of treatment, or that they had trust and confidence in the hand surgeon being a specialist.

Participants with previous experience of surgery expressed expectations of the coming *care process* in relation to their previous experiences. Nevertheless, regardless of having previous experiences or not participants could be uncertain about the content of the coming care process. There were concerns about events during and after surgery, e.g. about the anesthetic procedure, extent of surgery, if there would be time delays, if they would have pain, receive a cast or a splint, about rehabilitation and their own ability to influence the outcome, and about time needed for recovery of hand function.

Participants described *readiness for treatment* as either reluctance towards treatment or as feeling happy and confident. This could be expressed as fear of pain, worry, or having unpleasant thoughts about surgery and anesthetic, or as feeling safe and informed about what was going to happen.

Appraisal of results

Participants' appraisal of results was described through three subcategories: changes in hand function; care process; and competency and organization.

When speaking about the results, participants used several aspects to value the *changes in hand function*. They used previous experiences of surgery for comparison, they reflected on whether their expectations of hand function had been met, if previous activity limitations or problems were improved, how the healing process had progressed, their present issues with hand function, and they put their hand function in relation to quality of life or general health. Changes in hand function could also be seen in relation to the participants' view of a normal hand, i.e. how a hand is supposed to look and function.

Appraisal of results also involved the *care process* as a whole. The participants compared the care process they had gone through with their previous information/knowledge and expectations from before surgery. Based on this, there were wishes for further information about content of the care process but also comments about information being exaggerated. Important matters for how participants looked upon the care process was connected to its progression and to response from the staff, e.g. that everything was going as planned and on time, if staff had given enough support and let the participants share their knowledge and expertise.

Participants' appraisal of results also concerned *competence and organization.* They could connect having a good result with the surgeon's skill and competence, and that it felt safe to be treated at an institution with long and wide experience.

Expectations of the future

Expectations of the future were described through future hand function, health and care.

Expectations of *future hand function and health* were influenced by the participants' appraisal of the results. Expectations of future hand function and health were dominated by hope for stability, although there could also be uncertainty, fear of recurrence and awareness that changes in hand function were not permanent. Participants spoke of how to avoid recurrence by being more careful with their hands and yet remain active. They also had thoughts about the risk of their children having DD due to the strong heredity of the disease.

Expectations of *future care* were expressed as hope for new treatment methods. Depending on their appraisal of results, they spoke of being more or less prepared for a new care process. The need for further treatment could also be considered unlikely based on their age.

Patient characters

Two different patient characters were identified: the *eager* and the *tolerant* patient character. The eager patient character was new compared to those presented in the original model. The two patient characters in the present study could vary in an active-passive continuum, depending on the situation and the opportunities given to them to participate in care.

The *eager* patient character described how they asked questions, sought information and made active choices about their treatment. They spoke of the importance of being fully informed and highly involved in the decisions about treatment, wanting to influence their care. In contrast, the *tolerant* patient character described how they waited and watched to see what was going to happen. They described being partly involved in decisions, putting their trust in the surgeon's expertise or transferred control to the surgeon/staff to a large degree.

The participants' views of the results varied depending on the patient character. The *eager* patient characters generally described the results as positive. Although there could be experiences of negative events during the care process, this did not influence their view of the results. The *tolerant* patient characters had diverse views of the results and could be positive, hesitant or negative about it. Those who were hesitant about the results could have remaining issues with hand function or did not have their expectations met. Still, they could regard the care process as positive in general. It could also be the other way around. Those with a negative view of the results expressed it mainly as not having their expectations met.

Regardless of the view of the results, those with the *tolerant* patient character wished for more information before treatment compared to the *eager* patient character. It could be information about time for recovery, the care process as a whole, and the anesthetic procedure. They also spoke of the importance of seeing the surgeon after surgery, and of wanting further follow-up on exercise.

DISCUSSION

Discussion of main findings

Reliability of goniometry

Study A, shows that finger joint goniometry is a reliable clinical tool to use in hand therapy among patients with DD. According to the study findings, the commonly accepted level of measurement error of five degrees (43) is true also for a specific patient population with DD, regardless of joint and motion.

Several factors can complicate ROM measurement of the fingers, i.e. the large number of joints in a small area, short segments, complex movement patterns, and difficulty to control forces affecting the joint (46). Further, reliability is also affected by measurement position, the use of anatomical landmarks, goniometer placement (111), the group of people that are being measured, the situation and the instrument (49). One key aspect of the methodological study is the use of standardized measurement guidelines and the training of the raters. Training of the raters and standardization of procedure are strategies known to improve reliability of a measurement (53).

Only active motion was investigated in the study A, as the focus of the forthcoming study B was on hand function, i.e. the ability to use the hand in everyday activities. Thus, investigating reliability in goniometer measurement was a prerequisite to test the measurement guidelines, and to define the size of the measurement error in order to draw reasonable conclusions about changes in ROM in study B.

Effects on physical aspects of hand function

Impairment in finger joint extension is the main clinical feature of DD that is targeted by surgery. Study B showed how the improvement in total active finger extension remained stable during the first year after surgery. The improvement in active extension in isolated joints was greater for the MCP than the PIP joint, which is consistent with previous research findings of the PIP joint being more difficult to correct (21, 60, 61). The risk of losing finger flexion has been given little attention in previous research, though occasional findings have reported flexion deficits being present after surgery (60). Loss of finger flexion was confirmed in the study B and new findings are the magnitude of impairment in finger flexion, and that it is transient in nature. Recovery of finger flexion continued during the first year after surgery and hand therapy, with the PIP joint requiring the longest time for recovery. No patient reached a normal total ROM, which is consistent with previous findings (67). Despite this, the finger extension im-

proved enough for the majority of patients to reach a functional ROM sufficient for performance of common daily activities (52). Thus, reaching a normal ROM might not be a realistic goal after surgery for DD. Rather, the goal should be to reach an improvement that allows for an acceptable hand function.

Change in sensibility has only been investigated occasionally in previous research on DD (56, 68). Based on the risk of nerve injury as a complication to surgery (21, 23, 26), and previous research findings of reduced sensibility after surgery for DD (67), we assumed there could be a negative effect on sensibility after surgery. However, the results of study B show that sensibility was unaffected by surgery as measured with the SWM. A majority of the patients had diminished sensation for light touch both before and after surgery. It has been shown previously that diminished sensation for light touch may be present among patients with DD and healthy older people (67, 112). One explanation for this can be age (112, 113) or differences between men and women, where women may have better sensibility (112). The functional impact of having diminished sensation for light touch is assumed to be minor and can even be unnoticed by the individual (94).

Having surgery to one or multiple fingers did not affect ROM or sensibility outcomes, but increased the risk for a prolonged healing process of the scar. It has been reported that scar issues can be present in 10% of the patients treated with fasciectomy (23), and in study B, 12% of the patients received additional postoperative treatment directed towards scarring. New findings regarding scar issues were that the proportion of patients having scars rated as firm, ropes or contracture varied between 5-25% depending on the number of treated fingers. The finding of worse scar pliability in multiple treated fingers may not be surprising clinically, as surgery to multiple fingers usually involves a larger area of the skin of the hand. Nevertheless, this has not been described in earlier research on DD. Future studies need to investigate the effect of zinc tape and occlusive dressings used in hand therapy to treat scar issues in DD.

Functional recovery

Disability measured with DASH decreased over time. An interesting finding is the parallel decrease in DASH score over time, between patients with surgery on one or multiple fingers. For patients with surgery on multiple fingers the improvement in DASH score exceeded 15 score points and thus were large enough to be considered a clinically important change (71, 99). It has been suggested that the functional impact of DD might be underestimated in the DASH as the activities rated in the questionnaire primary involve grips between the three radial digits, while DD most commonly affects the ulnar digits (75). Perhaps this contributed to the different level of DASH score based on the number of operated fingers. The low baseline scores on DASH for patients with surgery on a single finger were in line with normal values (98). Still, these patients improved over time although the improvement did not reach the level of an important change due to a

ceiling effect. Given a starting point of 18 in DASH score among patients with surgery on a single finger, a reduction of 13 score points equals an average reduction of disability with 72%, which must be seen as quite substantial. The finding of a parallel decrease in DASH score can also be seen as an illustration of DASH being able to describe a range of experiences without reaching the bottom of the scale (99).

Change in DASH score was also used as a measure of functional recovery. The underlying assumption for the regression analysis was that other factors than reduction in extension deficit in the finger joints may contribute to the change in how patients rate their functional ability according to DASH. This was based on earlier studies showing inconsistent evidence of the relationship between reduced digital extension and improved functional recovery (6, 75, 80-82, 114). The results of the regression analysis confirmed this assumption and new findings were the associations between functional recovery measured by DASH and four of the five questions regarding safety and social issues created for the study. For the safety issues the associations with functional recovery were moderate to strong. This confirms previous findings of emotional functions being highly important for patients with hand disorders (36). The two questions "need to take special precautions due to hand function" and "avoid using the hand in a social context" also touch on themes found in previous research on the patients' perspective on DD (20, 84). Quality of life measured with the EQ-5D index was the third variable in the regression analysis best explaining functional recovery. DASH score has been shown to correlate with depression (115-118), and as anxiety/depression is one of the dimensions in the EQ-5D index this may have contributed to the findings. Still, the great impact the three variables from the regression analysis had on patients' rating of DASH is an important finding.

Health-related quality of life

There has been increasing interest in investigating health-related quality of life among patients with DD (20, 57, 119). Using instruments such as the Euroqol has also been recommended as an important part of prospective hand surgery studies (120). The baseline and follow-up levels of the EQ-5D index and EQ VAS were consistently high in study B, and in line with the general Swedish population (121). However, although both scales improved over time in the whole group, only the improvement in EQ VAS was statistically significant. The EQ-5D index showed no significant improvement despite an increase for the whole group at 12 months exceeding the proposed level of a minimally important difference (0.07) (106). This finding may be due to the interaction effect that occurred between the EQ-5D index and numbers of operated fingers, where patients with one or multiple operated fingers had a different course of change over time.

During the interviews, participants also touched on health-related quality of life, although the study did not focus on this matter. When participants were speaking freely about their appraisal of the results they reflected on how changes

in hand function had led to a higher quality of life. However, they also spoke of the DD as only a minor part of their life. This dualism shows that health-related quality of life is a highly individual and complex phenomenon.

Expectations, recovery and satisfaction with hand function

In study B, comparison of patient-reported expectations of future hand function, and self-reported recovery at 12 months revealed that most patients had their pre-operative expectations fulfilled. The majority of the patients were also satisfied with their hand function at that time point. Patient satisfaction has been shown to be associated with fulfilment of expectations (122, 123), thus expectations can be used as a frame of reference for the patient for making comparative judgments (122). However, previous research has not fully explained how having preoperative expectations met can influence patient satisfaction (124). Therefore, it cannot be concluded that the majority of the patients in the study B were satisfied with their hand function only due to having their expectations met.

In study C, expectations were investigated further, and the study confirms that unfulfilled expectations can be one reason for a negative view of the results. The study also shows that participants had expectations not only on the treatment effect (trajectory of illness), but also on the surgeon's competence, the care process and its content. This confirms previous findings of the multifaceted nature of expectations, and how they represent what patients hope for and what they think is likely to happen (125). Before surgery, expectations were influenced by the patients' previous experiences of treatment for DD or other health issues. Furthermore, expectations of the trajectory of illness changed over time, from emphasis on improvement of hand function before surgery, to hope for stability or uncertainty about future hand function after surgery. This change in expectations regarding the trajectory of illness was connected to the new experience the participants had gained after undergoing surgery. This supports previous findings of the close connection between experiences and expectations (88, 125) and of how expectations can evolve and change over time (88).

Patients' view of results

To facilitate positive clinical outcomes, health care providers must consider different types of knowledge in order to meet the philosophy of a client-centered approach. This knowledge should not be confined to diagnosis or physical findings but should also include the patients' experiences, preferences and needs (126-128). The results of the interview study add knowledge about the complexity of how patients evaluate changes in hand function after surgery for DD. Fulfilment of expectations was only one of many aspects that influenced the participants' views of the results. They also reflected on whether treatment solved their previous activity limitations; how the healing process progressed; present issues with hand function; how a normal hand should function and how quality of life or general health was affected. This shows that a positive view of the results is

not only about the degree of correction of contractures or about other objective aspects of hand function that we may focus on as health care providers. Rather, having a positive view of the changes in hand function seems to be connected to whether the hand can be lived with and used in most contexts (129). This is a key finding to be aware of in future evaluation of results.

Previous research about DD has mainly focused on evaluation of functional outcomes after treatment (54-56) while little or no attention has been given to structure and process aspects of care and how these may influence patients' appraisal of results. The interviews revealed that patients' evaluation of the surgical intervention involved not only effects on health status but also structure and process aspects of care. This means that patients' appraisal of results also involved their non-professional opinion of the surgeon's competence, the organization in general, response from the staff in terms of support and shared knowledge, and whether there were issues of lack of information or a need for further follow-up. These matters influenced the participants' appraisal of results either positively or negatively. Patient satisfaction is a highly desired result of care (87). However, it is also a multidimensional concept that can be difficult to capture (90, 123, 129-131). Expression of satisfaction/dissatisfaction represents the patients' judgment on all aspects of treatment, but concerns particularly the interpersonal process (87, 90, 132-134). It has been concluded that patients evaluate their health care providers' intervention, their knowledge and skills, and the interaction between them (135). Thus, improvement in the interpersonal relationship between patient and health care provider is most likely to positively increase patients' overall evaluation of care (90).

Patient characters further illustrate the multidimensionality of patients' appraisal of results. The patient characters found in the interview study were a product of the participants' own descriptions of themselves and the situation interaction. The 'eager' patient character was new compared to those identified in the original model of the Patient Evaluation Process (88). The 'eager' patient character was in general more positive towards results compared to the 'tolerant' patient character, and perhaps this was due to their active participation and information gathering before surgery. It has been shown in previous research that patients who are more engaged in their health care have better results (136-138). Though there were 'tolerant' patient characters that certainly could take the initiative in some situations, some of them still expressed a wish for further information, or said that expectations had not been met. One explanation may be that highly active patients to a greater extent prepare questions and find out what they need from their health care provider (138). So, the diverse views on the results among the 'tolerant' patient characters may be because they did not inform themselves about what was going to happen as much as the 'eager' patient characters did. Therefore, the 'eager' patient characters might have been more aware of what to expect. However, regardless of patient character, it must be in the health

care providers' interest to make sure that all patients are fully informed and given the opportunity to participate actively in their care.

Methodological considerations

Study A

In study A, we did not investigate intra-rater reliability as previous research has shown larger differences between than within raters (44, 48, 139). A universal type of finger goniometer with short levers was used but still, measuring DIP joint flexion was difficult to perform in a full fist position. Therefore, assessment was performed in an attempted hook fist position. In theory this would not matter as differences in DIP joint flexion are more likely to occur when the PIP joint is positioned in extension (43).

There may be several sources of error that can affect the result of goniometer measurement e.g. the amount of pressure applied against the phalanges, effects of repeating the same motion several times, motivation or fatigue (48, 139, 140). This was dealt with by a practice session with the participating raters, and having them performing the measurement of the individuals in a random order.

Strength of study A is that both the ICC and SEM are reported. The SEM was chosen as an absolute index of reliability because it quantifies the precision of individual scores and indicates how much difference in a measurement is needed for that difference to be considered a true change. The SEM is expressed in the same units as the measurement of interest, which enhances interpretation. The SEM is also an important complement to the ICC values, as sample heterogeneity affects the ICC values (141).

Study B

Study design

Study B was a prospective cohort study, tracking patients forward in time. This is an observational study design that is analytical in nature and can be useful for several purposes, e.g. measuring events in temporal sequence, examining the progress of a disease, the trajectory of recovery after treatment, or investigating associations between multiple factors (142, 143). It can be used for examination of the outcomes of a disease or health condition in the context of clinical practice (2), and can generate information that can be used to advise patients (144). It can provide answers about benefits of treatment and what aspects of function or quality of life are targeted by intervention (145). Furthermore, data can describe characteristics to identify patients that differ in outcomes or recovery rate (146). Findings from a cohort study might also generate hypotheses for future studies (147). A weakness of this design is that it cannot be used to identify treatment effect modifiers (146, 148). Thus, conclusions cannot be drawn about how hand

therapy specifically contributed to the results in study B. Other shortcomings of observational studies are confounding and bias (149). This was addressed in study B for example by consecutive recruitment of patients. There were few who declined to participate, and those who did, were not different in background characteristics from those included in the study. All data in the study were collected in a systematic way. To handle multiple observations, i.e. having surgery on two or three fingers, the sample was divided into subgroups depending on the number of operated fingers. However, the sample could have consisted of other subgroups of patients that may be associated with different outcomes or recovery rate depending on factors such as severity or location of the preoperative contracture, or having surgery that included volar plate release. These aspects were not taken into consideration in the analysis due to power reasons.

Outcome measures

Patient-reported outcomes are important but understudied. Taking a holistic view emphasizes patients' experiences while diagnosis implies a focus on a single organ system or pathology. Using a patient-focused approach may yield unexpected outcomes about what matters most to patients (2).

The outcome measures included in the study B were aimed at capturing multiple dimensions of hand function based on the definition used in the thesis. Thus, passive ROM in the finger joints was not measured although this could have provided information for distinguishing between contracture and motion lag. However, the measurement of active ROM reflects the actual deficits patients experience when using the hand (150), and from the patients' view, the compromised function is what matters, regardless of its cause (151).

Another concern is the lack of grip strength measurement. Few studies have measured grip strength before and after surgery for DD, and the findings of these studies are diverse, with grip strength either being unaffected by surgery (68, 81) or being temporarily worse at three months postoperative and recovered at 14 months (65). Grip strength was not included in the cohort study due to difficulties with baseline measurements associated with severe contractures, but could have been measured at the follow-ups to provide a more complete picture of the patients' hand function. However, participants in the interview study did not mention problems with grip strength when talking about their experience of DD but rather spoke of other consequences related to the limited ROM (unpublished data).

Pain has not commonly been associated with DD, and therefore assessment of pain was not included in study B. However, recent findings by Rodrigues et al. 2014 (83) showed that 15% of the patients with DD (n=110) experienced pain as a functional problem. In study C, participants also spoke of pain as an issue, e.g. when fingers were hooking onto things, but also pain at rest during the evening or night (unpublished data). Pain can also be related to the surgical treatment

(39) and the results of study B show that 21% of the patients received treatment for postoperative pain (TENS, acupuncture or pain medication). Therefore, it is recommended that assessment of pain is included in future evaluation of hand function for DD.

DASH was used as a patient-reported outcome measure of functioning in study B, as there was no valid and reliable disease-specific questionnaire for patients with DD available at that time. Today, such questionnaires are the newly developed Southampton Dupuytren scoring scale (77) or the URAM scale (78, 79), although only the latter is available in Swedish (unpublished work). The URAM scale rates the ability to perform nine activities: wash oneself with a flannel keeping the hand flat; wash the face; hold a bottle in one hand; shake someone's hand; stroke something or caress someone; clap the hands; spread out the fingers; lean on the hand; and pick up small objects with thumb and index finger. These are rated on a scale ranging from 0=without difficulty to 5=impossible, giving a total score of 0-45 where higher scores indicate worse disability (78). A criticism of the URAM scale is that despite being developed for patients with DD, the nine activities included in the scale still fail to capture common problems experienced by many patients with DD, e.g. pain, unpleasant appearance of the hand, finger hooking on things, or difficulty putting on gloves (83). Thus, there is a need for further studies of patient-reported outcome measures for patients with DD.

Concerns about the ability to cope with daily life or handle occupational demands have been identified by patients with hand injuries/disorders as important areas for them, but these aspects are seldom captured in patient-reported outcomes (36). In the DASH for example, only two items address capacity and self-confidence in a more general way. Therefore, the five questions regarding safety and social issues were devised to capture emotional aspects of hand function, and were based on clinical experience and theoretical knowledge (84, 102). The questions on safety and social issues of hand function turned out to be more important than expected. The results showed that the safety issues were of greater concern than the social issues of hand function and thus showed greater improvement over time. Given the improvement in the questions regarding safety and social issues and their relative importance in the regression analysis, it can be concluded that these aspects should be considered when evaluating treatment for DD. None of these aspects are captured in the DASH questionnaire.

Study C
Although outcome measures of physical function and patient-reported outcome questionnaires provide useful information from the patients regarding their functioning and health, they may not fully reflect what is most important from the patients' perspective. Therefore, the patients' perspective was further elucidated using interviews and qualitative methods in study C.

Regarding interpretation and analysis, the model of the Patient Evaluation Process was used as a theoretical framework for both data collection and analysis of the interviews. The use of the model contributed to systematizing data collection and analysis, which can increase *credibility* (152). The analysis was performed in a deductive-inductive manner. An alternative way of performing the analysis could have been to start from data and develop categories (inductive reasoning). However, using an available theory or model is a strength in terms of advancing theory and contributing to existing knowledge, as results from different studies may be comparable with each other (91). Furthermore, available theories or models are useful for describing what is known about the phenomenon of interest and can be a way to use previous research to give focus to a study. They can also help to describe the researcher's standpoint during the analysis (91, 153).

The model of the Patient Evaluation Process was developed in a different context (geriatric hospital care) and has not been used previously for evaluation of the patients' perspective on hand surgery or hand therapy. However, the model and its components were useful for elucidating patients' evaluation of care and rehabilitation in a context such as in study C. The results of the interview study contribute some new findings that can develop the original model: a new patient character (eager), variation of patient character on a passive-active behavior continuum; a new trajectory of illness (resignation); and expectations of the future involving fear of recurrence as well as future care.

As patient characters were one component of the original model, study C also involved analysis of typologies (110). This part of the analysis was performed as the last step and involved identifying patterns in data. Thus, analysis of typologies is more interpretive than purely descriptive analysis (110). A strength of performing analysis of typologies is that it can help to draw out underlying dimensions and to map out variation in the results of concern (154, 155). However, it is important to notice that patient characters are not personality types. Rather, they are created by the actions of health care providers during a care process.

With regard to *trustworthiness*, the strengths of the qualitative study are that several researchers performed the analysis in a collaborative work process (156). The participants in study C showed variation in several aspects (e.g. age, previous experience of surgery, working/retired) that contributed to finding both the unique and the common patterns of the patients' perspective on surgical intervention for DD. However, the sample consisted only of men due to DD being more common among them; thus, the result does not reflect differences that might be present based on sex.

To ensure *authenticity* (152), the participants were informed that the interviewer had no association with the clinic providing the care. To eliminate the risk of an interviewer effect the participants were not informed that the interviewer had long experience of clinical practice with patients with DD. Several steps were taken to minimize the potential influence this experience might have on the

analysis and synthesis of findings, i.e. careful selection of the interview guide design, using a conscious interviewer approach, the close analysis collaboration with other researchers not experienced in hand therapy, and the use of the theoretical framework.

Regarding *transferability,* the findings of the qualitative study are connected to its context (91), but the study provides insights about patients' perspectives on hand surgery and hand therapy interventions. Thus, the findings might be transferable and relevant to other health care providers involved in surgical interventions, rehabilitation, or working with patients with recurrent disease patterns or diseases with strong heredity. This information may contribute to improving health care services and better evaluation of outcomes.

Clinical implications

The clinical implications that can be drawn from this thesis are twofold: the importance of timing and content of follow-up, and what to consider for improving health care services.

Based on the results of studies B and C, evaluation of results should take place somewhere between six and 12 months. This would ensure that hand function had recovered enough after surgery. The content of the follow-up should not only address digital extension but should also comprise measurement of other relevant physical aspects of hand function that can be affected by surgery (e.g. finger flexion, strength, skin issues and pain).

Evaluation of results from the patients' perspective should address emotional aspects of hand function, effect on daily life e.g. whether treatment lessened previous activity limitations, whether there are present issues with hand function, and influence on quality of life etc. Patient satisfaction should be assessed by using questions that address the different dimensions of care, i.e. structure, process and outcome. This can be done by using questions about aspects of the organization; patient health care provider communication and interaction; and satisfaction with hand function. This would provide knowledge about why patients have a positive or negative view of the results, which could be useful for future evaluation and improvement of care.

Improvement of health care services means not only providing the best treatment method available but also improving process and structure aspects of care. Patient participation can be enhanced by taking patients' previous experiences and expectations into account and acknowledging different patient characters' needs. Patients should be provided with information about the expected outcome in terms of hand function, time needed for recovery, as well as about the care process. This information is crucial to set realistic expectations of the results, and altogether, play an important part in patients' appraisal of results.

Future research

The findings of this thesis revealed the many aspects patients consider when appraising the results of surgery and hand therapy, and the importance of emotional functions. The influence of previous experiences of care, pre-treatment expectations, aspects related to process and structure of care and emotional functions should be studied further as it can contribute to the development of instruments that capture all aspects of functioning that are important to patients, and thus the development of patient-centered care. Issues brought up by participants as reasons for a negative view of the results included not only unmet expectations, but also lack of information and a wish for further follow-up. These could be expressions of unmet needs during the care process, and in order to understand patients' experiences further, it is important in future research to investigate and describe patients' underlying needs and experiences of DD.

Although developed in another context, the components of the model of the Patient Evaluation Process were suitable for illuminating patients' evaluation of care and rehabilitation in a hand surgery and hand therapy context. Future research should explore the new findings generated in this thesis regarding patient character and trajectories of illness, which could contribute to further development of the model.

CONCLUSIONS

- Surgery and hand therapy treatment for DD improve hand function and patients regain a functional ROM needed for performance of common daily activities.

- Despite the negative effect on finger flexion present during the first year after surgery, patients regard their hand function as recovered six to eight months after surgery and hand therapy. Thus, this is a proper time-point for evaluation of results.

- Measuring digital ROM in the finger joints with a goniometer is a reliable method of evaluation of results when standardized guidelines are followed.

- From the patient's perspective, it is not enough to evaluate results after surgery for DD only in terms of digital extension or ROM. Instead, safety and social issues of hand function and quality of life play an important part in patients' rating of functioning.

- Patients' positive view of hand function after treatment is based on aspects such as whether their previous activity limitations or problems have diminished, and whether the hand can be lived with and used in most contexts.

- Patients' evaluation of results is influenced by their previous experiences of care, their expectations regarding care and outcome, as well as patient character.

- Results of treatment from the patients' perspective concern consequences regarding daily use of the hand, what happens during the care process in terms of interaction between patient and health care provider, and their view of the organization providing the care with respect to competence and logistics.

- Positive experiences of interaction with the staff include feeling informed and supported, and being given the opportunity to share the staffs' knowledge.

- Providing a high quality treatment and care process can influence patients' expectations of future care processes positively.

SAMMANFATTNING PÅ SVENSKA

Bakgrund: Dupuytren's kontraktur är en vanligt förekommande sjukdom som drabbar handens mjukdelar. Sjukdomen leder till oförmåga att sträcka ut i finger-lederna vilket medför en begränsad handfunktion. Kirurgisk behandling för Du-puytren's kontraktur syftar till att avlägsna den sjukliga vävnaden för att räta ut fingrarna och därmed förbättra handfunktionen. Handterapi efter operation syftar till att bibehålla den vinst i sträckning av fingrarna som åstadkommits vid operat-ionen, minimera negativa effekter såsom svullnad, smärta eller rörelseinskränk-ning, och att guida patienten till återhämtning av handfunktionen. Behandlingen botar dock inte sjukdomen och det är vanligt att besvären återkommer. Tidigare forskning om behandling för Dupuytren's kontraktur har fokuserat på val av ki-rurgiska metoder och har visat att förmågan att sträcka ut i fingrarna och generell funktionsförmåga ökar efter behandling. Dock saknas det kunskap om vilka andra aspekter av handfunktionen som påverkas av ingreppet och hur lång tid som krävs för handfunktionen att återhämta sig. Det är också ännu okänt vilka faktorer som har störst betydelse för hur patienter skattar sin funktionsförmåga och vad som har betydelse för hur de ser på behandlingens resultat.

Syfte: Det övergripande syftet med avhandlingen var att undersöka handfunktion före och efter kirurgi och handterapi för patienter med Dupuytren's kontraktur, inklusive bedömning, resultat och patienters perspektiv.

Metoder: I den första studien undersöktes tillförlitligheten vid mätning av led-rörlighet i fingerlederna med goniometer, vilket är en vanligt förekommande mätmetod inom handterapi. I den första studien deltog 13 personer med Du-puytren's kontraktur och åtta arbetsterapeuter verksamma inom handrehabilite-ring. Den andra studien undersökte förändringar i handfunktion under det första året efter operation och handterapi. Studien omfattade fysiska och psykosociala aspekter av handfunktion, som undersöktes med olika kliniska mått och fråge-formulär. I studien deltog 90 patienter som följdes upp vid fyra tillfällen. Den tredje studien undersökte patienters perspektiv på att genomgå en kirurgisk be-handlingsprocess. I studien intervjuades 21 patienter före och efter operation om deras tidigare erfarenheter, förväntningar och syn på resultatet och framtiden.

Resultat: Den första studien visade att tillförlitligheten vid mätning med gonio-meter är hög när erfarna arbetsterapeuter följer standardiserade riktlinjer. Mätfel-et är mindre än fem grader. Den andra studien visade att förmågan att sträcka ut i fingerlederna förbättrades medan förmågan att böja fingrarna temporärt försäm-rades under det första året efter behandlingen. Ingen patient återfick ett normalt rörelseomfång men majoriteten uppnådde däremot ett funktionellt rörelseomfång. Känseln i fingertopparna påverkades inte av den kirurgiska behandlingen. Patien-ter som opererade mer än ett finger hade generellt mer besvär med ärrets töjbar-

het. Majoriteten av patienterna fick sina förväntningar på handfunktionen uppfyllda och ansåg att deras handfunktion var helt återställd eller mycket bättre ett år efter behandlingen. Säkerhetsaspekter, såsom rädsla att skada handen, oro över att inte kunna lita på sin handfunktion eller behov att vidta olika säkerhetsåtgärder, var av större betydelse för patienterna än de sociala aspekterna av att använda handen (handens utseende eller att använda handen i sociala sammanhang). Funktionsförmåga, mätt med ett vanligt frågeformulär för arm och hand (DASH), förbättrades över tid liksom den hälsorelaterade livskvaliteten. Graden av förbättring av sträckning av fingerlederna var dock inte avgörande för hur patienterna skattade förbättring av funktionsförmågan. Tre andra variabler visade sig istället ha störst betydelse för förbättringen av funktionsförmåga: upplevelse av handfunktionen som säkrare; att man inte behövde undvika att använda handen i sociala sammanhang; och förbättrad hälsorelaterad livskvalitet. Dessa tre faktorer förklarade tillsammans 62 % av förbättringen av funktionsförmågan.

Intervjuer med patienter om deras perspektiv på att genomgå behandling, visade att tidigare erfarenheter av vård och av sjukdomen påverkade deras förväntningar på resultat och den kommande behandlingen. Dessa förväntningar och erfarenheter användes sedan för att värdera resultatet av behandlingen, som uttrycktes i termer av upplevda förändringar av handfunktionen, vårdprocessens fortskridande, kompetens och organisation. Två olika patientkaraktärer identifierades som ett resultat av interaktionen mellan patient och vårdgivare. Resultatet av behandlingen värderades olika utifrån dessa olika patientkaraktärer. Hur patienterna såg på sin framtida handfunktion, hälsa och vård präglades av hur de såg på resultatet av behandlingen de gått igenom.

Slutsatser: Kirurgisk behandling och rehabilitering förbättrar handfunktionen hos patienter med Dupuytren's kontraktur. Efter behandlingen uppnår patienterna ett funktionellt rörelseomfång i handen som är nödvändigt för utförande av vardagliga aktiviteter. Trots en negativ påverkan på förmågan att böja i fingrarna under det första året efter behandlingen anser patienterna att hand funktionen är återställd efter sex till åtta månader. Att mäta rörlighet i fingerlederna med goniometer är en tillförlitlig metod för utvärdering, men ur patientens perspektiv är det inte tillräckligt för att beskriva hur de ser på resultatet av behandlingen. Resultat av behandlingen utifrån patientens perspektiv värderas även utifrån de konsekvenser man upplever av att använda handen i vardagen, hur mötet med vårdpersonalen avlöper samt vårdens organisatoriska aspekter. Genom att erbjuda en högkvalitativ behandling och vårdprocess kan patienters förväntningar på framtida vårdprocesser och resultat påverkas positivt.

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Papers

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