Dupuytren's disease: more than extension deficit

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Dupuytren's Disease: More Than Extension Deficit

Ziekte van Dupuytren: meer dan extensiebeperking

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Voor Pap en Mam

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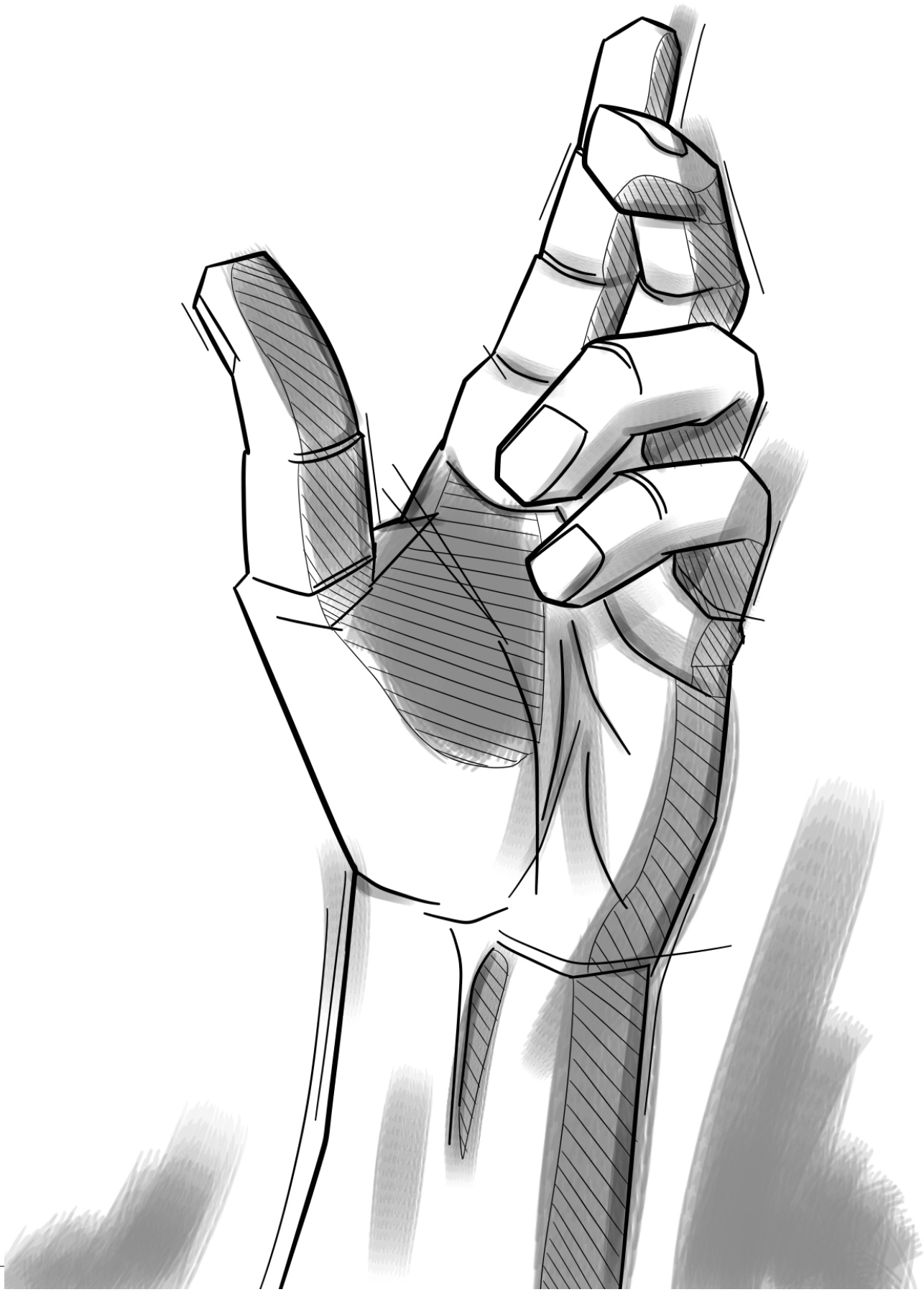

Chapter 1

General Introduction

GENERAL OVERVIEW OF DUPUYTREN'S DISEASE

Dupuytren's disease is a chronic progressive fibroproliferative disorder of the palmar fascia characterized by flexion contractures of the fingers.[1] It is named after Baron Guillaume Dupuytren, who described the disorder in 1831. However, it was earlier described by Felix Platter (1680), Henry Cline (1808) and Sir Astley Cooper (1818).[2]

Classically, the first sign of Dupuytren's disease is the formation of palmar nodules. These nodules are the result of myofibroblast proliferation and extracellular matrix synthesis.[3] When the disease progresses, these nodules develop into fibrotic cords, which lead to digital contractures.[4] Finally, these contractures can lead to the loss of hand function and diminished quality-of-life in patients with Dupuytren's disease.[5] Dupuytren's disease is more prevalent in Caucasian, older males. Prevalence rates vary from 0.2% to 56% depending on the population studied.[6] A recent study in the Netherlands reported an overall incidence of 22.1%.[7]

Various risk factors have been linked to Dupuytren's disease of which familial predisposition is one of the strongest.[8] Genetic abnormalities and pathways for Dupuytren's disease have been described.[9,10] Other risk factors include smoking, alcohol consumption, excessive vibrations, manual labor, hand trauma and diabetes.[7,11-13] The precise role of these risk factors in the pathogenesis remains unclear. Overall, Dupuytren's disease is likely to be a multifactorial and polygenic condition.[14]

CLINICAL PRESENTATION AND TREATMENT OPTIONS

The clinical presentation of Dupuytren's disease varies greatly depending on the location and severity of the contractures. Contractures are most commonly seen in the metacarpophalangeal (MCP) and proximal interphalangeal (PIP) joints of the fourth and fifth digit of the hand. However, other fingers can be affected as well as interdigital web spaces.[15] The severity of the disease is determined by the underlying biology of the disease, known as the Dupuytren's diathesis. Factors that influence the Dupuytren's diathesis are bilateral hand involvement, ectopic disease, a positive family history for Dupuytren's disease, male gender and an early onset of the disease. A more severe diathesis will result in a higher prevalence of recurrence.[16]

A variety of treatment options exist for Dupuytren's disease depending on the location of the contracture(s) and the severity of the disease. Surgery has been the mainstay of treatment, as it provides long-lasting correction.[17] How-

ever, factors such as complication rates and return-to-work, also play a role in treatment choice.[18] Most common treatment options, increasing in invasiveness, are: collagenase injections, percutaneous needle fasciotomy, limited fasciectomy and dermofasciectomy.

Collagenase injections are gaining in popularity as they are minimal-invasive and do not require formal surgery.[19] Collagenase can be injected at one to several points along the fibrotic cord. The collagenase enzymes cleave the collagen, which results in weakening of the cord. One to four days later the cord can be broken by straightening the finger.[20] Results in terms of straightness of the finger after treatment are good and major complications are low. However, minor complication rates, such as hematomas and skin tears, are high.[21,22] Collagenase injections are relatively new, but the first studies show a high recurrence rate at follow-up (3-year: 35%, 5-year: 47%).[23] The use of collagenase in the Netherlands is limited as healthcare insurances do not reimburse the use of collagenase injections.

Percutaneous needle fasciotomy (PNF) is a minimal-invasive technique in which the cord is transected percutaneously.[24,25] It is commonly used for contractures in the MCP joint, where a clear cord is palpable. It has a low complication rate and quick recovery.[26,27] The disadvantage is the high percentage of recurrence (3-year: 58%, 5-year: 85%).[17,26]

Limited fasciectomy (LF) is the most commonly used treatment for Dupuytren's disease. An incision is made over the affected fascia after which the pathological fascia is removed. Care must be taken not to damage the neurovascular bundles or the flexor tendons. Recurrence rates are lower compared to PNF (5-year: 20.9%).[17] However, the complication rates are higher then for PNF and recovery after surgery takes considerably longer.[28]

Dermofasciectomy involves the removal of the skin together with the affected fascia and a full thickness graft is used to close the skin. It is reserved for patients with severe diathesis and recurrent cases. Recurrence under a skin graft is rare.[29,30]

OUTCOME MEASUREMENTS

In Dupuytren's disease it is generally assumed that improvement of the hand function is an important goal for patients seeking treatment. Therefore, hand function is, alongside complication- and recurrence rates, an important outcome measurement in determining the success of treatment. This hand

function can be measured in various ways. Performance-based measures such as the improvement in range of motion are widely used and provide an objective measurement of hand function. Additionally, so-called patient-reported outcome measures (PROMs) are used. These questionnaires reflect the patient' perspective on the impact of the disease and its treatment on hand function.

The treatment of Dupuytren's disease is aimed at improving the range of motion of a finger or fingers (that is, reduce the digital contracture(s)), which should lead to improvement in hand function. However, several studies have shown that an increase in range of motion is poorly correlated with an improvement in patient-reported hand function.[31,32] Comparative studies between various treatments have shown that, despite similar contracture reduction, differences exist in patient-assessed hand function and satisfaction with hand function.[33,34] These results demonstrate that improvement of the patient-reported hand function is not simply achieved by correcting the extension deficit of patients.

AIMS OF THIS THESIS

This discrepancy between performance-based outcome measures and patient-reported outcome measures in Dupuytren's disease is remarkable and not fully understood. In order to improve outcome of Dupuytren's disease a good understanding of its underlying pathophysiology is needed. However, especially in patient-centered care, measuring and understanding what is important for a patient is fundamental to understanding the burden of disease and the success of treatment.[35]

The overall aim of this thesis was to explore the various outcome measures in Dupuytren's disease and how these outcome measures are influenced by patient- and disease characteristics and treatment. To do so, this thesis has been divided in four parts. In the first part we introduce the Hand and Wrist Cohort, which forms the basis of this study. In the second part we explore psychologically orientated factors in patients with chronic hand- and wrist disorders and how these factors influence the (perceived) hand function. In the third part, we study the advantages and pitfalls of various outcome measures for Dupuytren's disease and determine which measurements are most beneficial for recording outcome in Dupuytren's disease. In the final part, we examine to which extent pre-operative patient- and disease characteristics can reliably predict outcome in Dupuytren's disease.

OUTLINE OF THIS THESIS

To study the questions asked in this thesis an open, prospectively maintained cohort of patients with hand and wrist disorders, including Dupuytren's disease, is introduced in **Chapter 2**.

As there are many psychologically orientated factors which potentially have a role in perceived hand function, this thesis focuses on two of those factors. First, we studied the perception of illness in patients with chronic hand and wrist disorders, including Dupuytren's disease (**Chapter 3**). Second, we examine the relationship between experience with healthcare delivery and outcome measures in Dupuytren's disease (**Chapter 4**).

The current standard to measure patient-reported hand function is with standardized, pre-defined questionnaires. These questionnaires are widely used and well validated for various hand- and wrist disorders. Nonetheless, they might be less applicable for patients with Dupuytren's disease, as the pre-defined nature might not capture all functional problems.[36] In **Chapter 5**

we evaluate the use of the Patient Specific Functional Scale (PSFS), a so-called individualized PROM, in patients with Dupuytren's disease.

It is generally accepted that hand function is the main outcome parameter in Dupuytren's disease, either as a performance-based or as a patient-reported outcome measure. However, there is evidence from other hand disorders that other outcome parameters, such as hand appearance, are of importance to patients.[37,38] Therefore, in **Chapter 6**, we evaluate what other outcome parameters might be of importance to patients with Dupuytren's disease.

Although a disease which mainly affects the older population, half of the patients with Dupuytren's disease is working at the moment they seek treatment. For these patients, return to work might be an important (additional) outcome measurement. However, very little is known about return to work after treatment for Dupuytren's disease. In **Chapter 7** we aim to fill this void.

The progressive character of Dupuytren's disease results in recurrence of digital contractures after initial treatment in numerous patients. In **Chapter 8** the hand function of patients after repeated treatment is compared to that of the same patients after initial treatment.

As shared decision making becomes more and more important, so does the need for reliable information about post-operative results. In **Chapter 9** we explore to which extent pre-operative patient- and disease characteristics can reliably predict a complete finger extension after surgery.

Finally, in **Chapter 10**, we discuss the main findings from this thesis and implications for future research.

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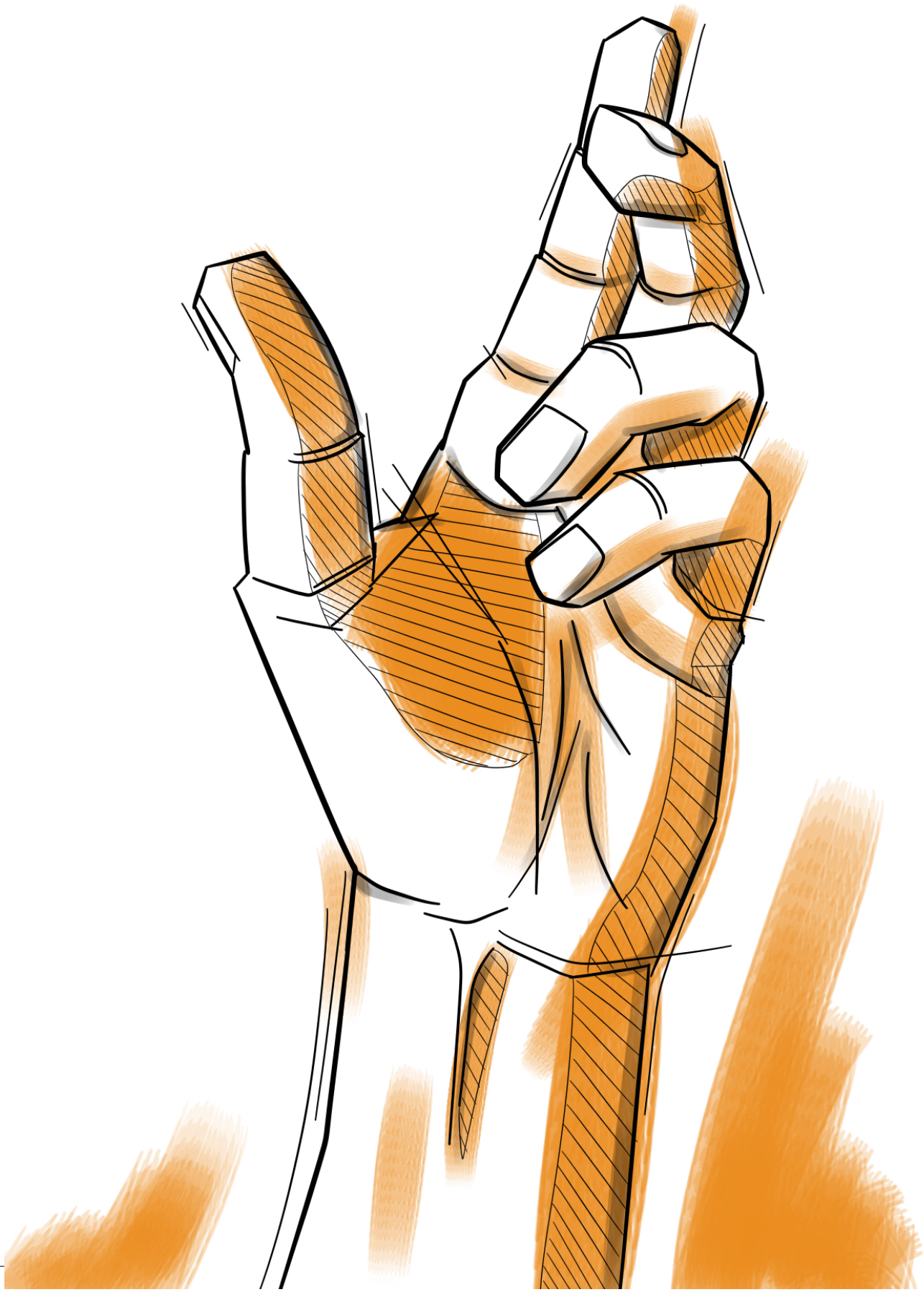
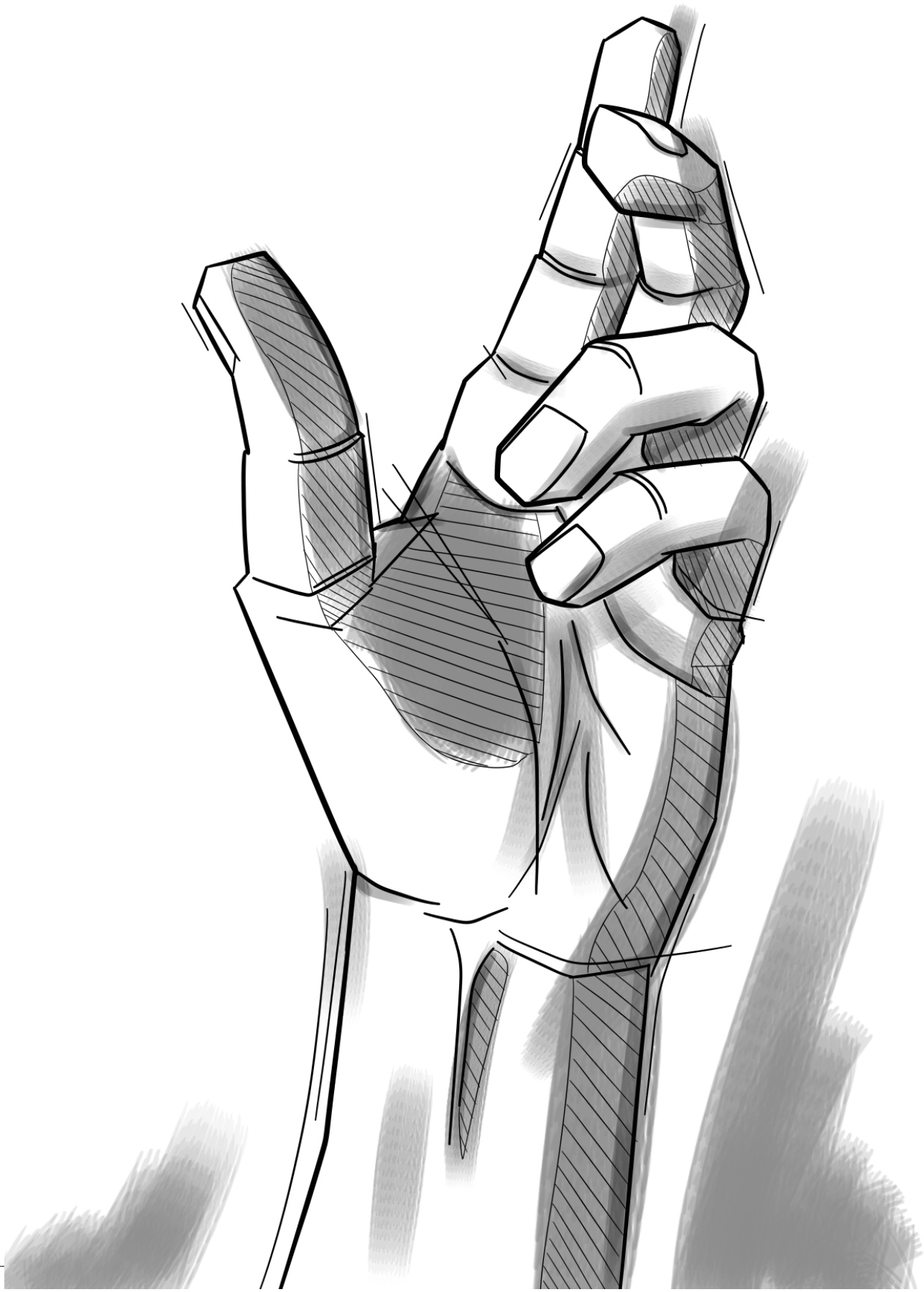


Part I

The Hand and Wrist Cohort



Chapter 2

Routine health outcome measurement: development, design and implementation of the Hand and Wrist Cohort.

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ABSTRACT

Routine measurement of outcome of clinical care is increasingly considered important, but implementation in practice is challenging. This paper describes how 1) we created and implemented a routine outcome measurement cohort of patients with hand and wrist conditions, and 2) these data are used to improve the quality of care and facilitate scientific research. Starting in 2011, routine outcome measurement was implemented at all practice sites (currently 22) of a specialized treatment center for hand and wrist conditions across the Netherlands. We developed five 'measurement tracks', including measurements administered at predetermined time points covering all hand and wrist disorders and treatments. An online system automatically distributes measurements amongst patients, which can be accessed by healthcare professionals. Using this system, the total number of yearly assigned tracks increased up to over 16.500 in 2018, adding up to 85.000 tracks in 52.000 patients in total. All surgeons, therapists, and other staff have direct access to individual patient data and patients have access to their treatment information using a secure patient portal. The data serves as a basis for studies on, amongst others, comparative effectiveness, prediction modeling, and clinimetric analyses. In conclusion, we present the design and successful implementation of a routine outcome measurement system that was made feasible using a highly automated data collection infrastructure, tightly linked to the patient journey and the workflow of healthcare professionals. The system not only serves as a tool to improve care but also as a basis for scientific research studies.

INTRODUCTION

Routine measurement of the outcome of clinical care is increasingly considered important in healthcare. It is a key aspect of value-based healthcare, patient-centered care, and other quality of care initiatives.[1] For example, the Dutch government strives to have objective outcome data on 50% of all healthcare in 2022,[2] while in Sweden outcome measurements have been part of a national registry for years.[3]

The goals of routine outcome measurement are multitude, including improving communication and treatment guidance at patient level, as well as benchmarking of outcome at the level of individual clinicians or treatment centers. This benchmark information may help to establish priorities in resource allocation, and provide clinicians and managers with valuable feedback on performance. Furthermore, routine outcome measurement systems generate large datasets that can be used in scientific research. This so-called 'big data' can help provide knowledge on, for example, comparative effectiveness, predictive factors of outcome, and psychometric properties of measurement instruments.

While routine outcome measurement has been advocated for years, implementation in clinical practice is limited due to several challenges. These include lack of 1) consensus on which outcome measurements to be collected; 2) appropriate IT infrastructure for data collection; 3) time and financial resources for data collection; 4) compliance of both patients and healthcare providers in data collection; 5) analysis and visualization tools and; 6) knowledge to improve clinical care by using the data.

In 2009, Xpert Clinic, Handtherapie Nederland and Erasmus MC - University Medical Center Rotterdam started an initiative to collect routine outcome data in all patients with hand and wrist disorders undergoing surgical or non-surgical treatment in their centers. This paper provides an overview of this routine outcome measurement cohort by describing its design, development, and implementation. Furthermore, we describe how the accumulated data are used to improve the quality of healthcare and facilitate ongoing scientific research. By sharing our lessons learned, we hope to help others overcome the hurdles to implement routine outcome measurement.

1. Wrist extended	2. Thumb extended	3. Finger extended	4. Dupuytren's Disease	5. Compression neuropathy	6. Wrist regular	7. Thumb regular	8. Finger regular
- Corrective osteotomy distal radius - Ulna shortening - Brunelli / 3 LT - LT reconstruction - Proximal row carpectomy - LCTH-fusion / four corner - Total wrist arthrodesis - Wrist prosthesis - TFCC reinsertion - Dorsal capsulodesis wrist (possibly combined with dorsal ganglion excision) - Pisiformectomy - Tenorrhaphy flexors wrist	- Trapeziectomy with Burton-Pellegrini - Trapeziectomy without LRTI - Hemitrapeziectomy without LRTI - CMC-1 denervation - CMC-1 arthrodesis - CMC-1 revision arthroplasty - STT excision - CMC-1 instability surgery - UCL reinsertion MCP-1 - VP reinsertion MCP-1 - VP reconstruction MCP-1 - MCP-1 arthrodesis - IP-1 arthrodesis - Tenolysis tendons of the thumb - Fracture thumb treated surgically	- MCP/PIP/DIP arthrodesis - MCP/PIPDIP prosthesis - Tenolysis flexors finger - Tenolysis extensors finger - Neurorhaphy finger - VP reinsertion MCP - VP reinsertion PIP - VP release PIP - UCL/RCL reinsertion/reconstruction MCP - Sagittal band reinsertion - Corrective osteotomy P1 P2 - Fracture finger treated surgically - Fracture finger treated non-surgically - Amputation	- Limited fasciectomy - Limited fasciectomy with skin graft - Percutaneous needle aponeurotomy (possibly with lipofilling) - Collagenase clostridium histolyticum (Xiapex)	- Carpal tunnel release - Guyon tunnel release - Cubital tunnel release - Radial tunnel release - Carpal tunnel syndrome treated non-surgically - Pronator syndrome treated non-surgically - Cubital tunnel syndrome treated non-surgically - Radial tunnel syndrome treated non-surgically	- Release 1st extensor compartment - Reconstruction 1st extensor compartment - Wrist arthroscopy (diagnostic) - Carpal boss wig excision - GCD excision - Removal of osteosynthesis material wrist - Denervation wrist - Midcarpal instability/laxity treated non-surgically - Wrist OA treated non-surgically - STT OA treated non-surgically - Tendinitis/ tendovaginitis wrist treated non-surgically - Wrist synovectomy	- Trigger thumb release - Mallet surgery thumb - Mucoid cyst thumb excision - Excision glomus tumor - Nail bed surgery - Trigger thumb treated non-surgically - Mallet thumb treated non-surgically - CMC-1 OA treated non-surgically - CMC-1 instability treated non-surgically	- Trigger finger release - Mallet surgery finger - Excision glomus tumor - Nail bed surgery - Removal of osteosynthesis material finger - Trigger finger treated non-surgically - Mallet finger treated non-surgically - MCP/PIP/DIP OA treated non-surgically - UCL/RCL/VP injury MCP/ PIP/DIP treated non-surgically

METHODS

Treatment locations and patient population

Routine outcome measurement was implemented in 2011 at all practice sites (currently 22) of Xpert Clinic and Handtherapie Nederland across the Netherlands. Presently, 23 European Board certified (FESSH) hand surgeons, multiple hand surgery fellows, and >150 hand therapists are employed within these organizations. The organizations provide non-surgical and surgical treatment for acute and non-acute hand and wrist disorders, excluding emergency care. Patients are referred by either their general practitioner or another medical specialist. Surgical treatment is only performed in patients with an American Society of Anesthesiologists score (ASA) of 1-2. Table 1 shows an overview of the most common disorders and treatments.

Prior to any measurement or treatment, all patients are digitally asked for permission to use their data anonymously for scientific research. If a patient does not provide informed consent, the data will only be used for direct healthcare purposes but not for scientific analysis. Patients can always withdraw their consent. Access to all questionnaires, including the one on informed consent, is restricted through the use of a unique secret identifier provided to the individual patient by email. Approval from local medical ethical review board is obtained for each scientific study that uses the data.

Measurements

In 2010, a working group consisting of hand surgeons, hand therapists and researchers from Xpert Clinic, Handtherapie Nederland and Erasmus MC developed a measurement set based on existing guidelines.[7] Instruments were considered if they were of direct use for clinical care, quality assessment, or treatment outcome evaluation and had proper psychometric properties.[7]

Table 1 (opposite page). Overview of how the primary interventions performed on patients in this study and how they are organized into the measurement tracks. Grouping is based on similar outcome domains and follow-up periods needed to capture the health status of the patient after and intervention. If a patient receives multiple treatments, only one track is assigned based on a priority rule. The tracks are ordered from left to right based on this priority. Hence, for example, when Dupuytren surgery (Dupuytren track) and a trigger finger release (Finger Regular track) are performed at the same time, only the Dupuytren track is assigned because it has a higher priority. Moreover, when a treatment is started with a higher track priority (e.g., trapeziectomy with the Thumb Extended track) then the earlier assigned track (e.g., non-surgical treatment for thumb osteoarthitis with Thumb Regular track), the earlier track is stopped and the new track is assigned.

Table 2. Overview of the predefined tracks, their measurements and time points. This table shows the measurements performed in all tracks and the additional measurements performed in each specific track. For each type of treatment, it was decided whether patients would be assigned a regular track with a short follow-up of maximally three months or an extended track with a 12-month follow-up and more extensive measurements. Measurements performed only in the extended tracks for a specific time points are denoted by an asterix (*).

Track	Baseline	6 weeks	3 months	6 months	12 months
	Regular & Entended	Regular & Entended	Regular & Entended	Regular & Entended	Regular & Entended
All tracks	VAS: pain, function, satisfaction PSFS	VAS: pain, function, satisfaction PSFS Return to Work Satisfaction treatment result	VAS: pain, function, satisfaction PSFS Return to Work Satisfaction treatment result PREM	VAS: pain, function, satisfaction* PSFS* Return to Work* Satisfaction treatment result*	VAS: pain, function, satisfaction PSFS Return to Work Satisfaction treatment result
Thumb	MHQ Thumb ROM* Grip & Pinch strength*		MHQ Thumb ROM* Grip & Pinch strength*		MHQ Thumb ROM* Grip & Pinch strength*
Finger	MHQ Finger ROM* Grip strength*		MHQ Finger ROM* Grip strength*		MHQ Finger ROM* Grip strength*
Wrist	PRWHE Wrist ROM* Grip strength*		PRWHE Wrist ROM* Grip strength*		PRWHE Wrist ROM* Grip strength*
Compression neuropathy	BCTQ		BCTQ	BCTQ	
Dupuytren	MHQ Finger and/or Thumb ROM		MHQ Finger and/or Thumb ROM		MHQ Finger and/or Thumb ROM

MHQ, Michigan Hand Outcome Questionnaire; VAS, Visual Analog Scale; VAS Function, Visual Analogue Scale for hand function; PREM, Patient Reported Experience Measure; PRWHE, Patient Rated Wrist-Hand Evaluation; BCTQ, Boston Carpal Tunnel Questionnaire; ROM, range of motion; Satisfaction, satisfaction with the outcome of treatment; PSFS, patient specific function scale.

Measurements only relevant for scientific research or analyses of underlying pathology (e.g., radiographic imaging or electromyography) were excluded from routine registration. All measurements were kept to a minimum to reduce the burden and optimize compliance.

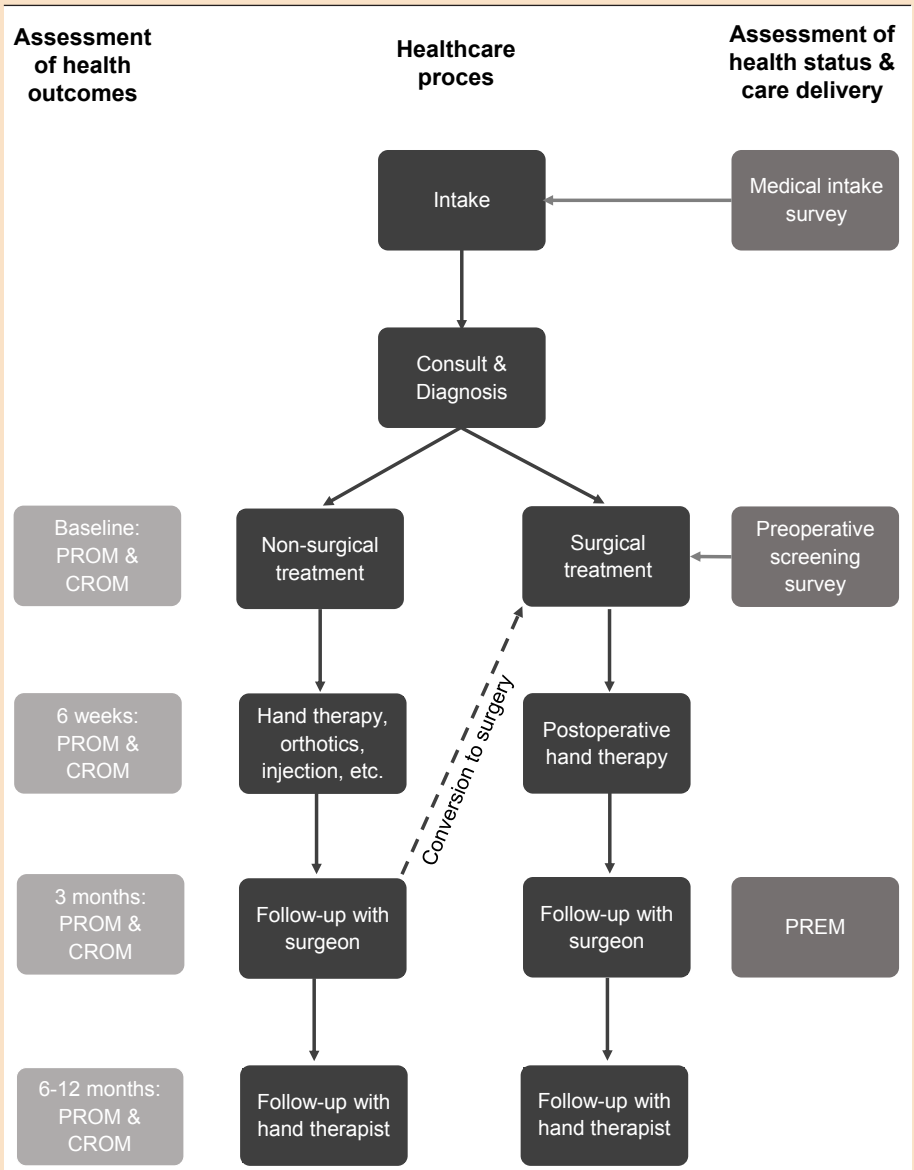
The Clinician Reported Outcome Measurements (CROMs) include grip & pinch strength and range of motion, while Patient Reported Outcome Measurements (PROMs) include pain, hand function, aesthetics, return to work/daily activities, and satisfaction with the outcome. Furthermore, a Dutch Patient Reported Experience Measure (PREM) is used.[8]

Next, we created 'measurement tracks' comprising a specific set of measurements administered at predetermined time points for each treatment or condition. We aimed to create as few measurement tracks as possible, based on similarity in the relevance of outcome domains and time points needed to capture the patients' health status. Eventually, five main measurement tracks were developed: 1) thumb disorders; 2) wrist disorders; 3) finger disorders; 4) Dupuytren's disease; and 5) compression neuropathy. The thumb, wrist, and finger tracks were further divided into a 'regular' track (including shorter follow-up and fewer measurements, e.g., for trigger finger) and an 'extended' track (including longer follow-up and more measurements, e.g., for thumb base surgery). For all measurement tracks, selected time points were baseline and combinations of six weeks, three, six, and twelve months post-treatment (see Table 2). Table 2 shows the content of each measurement track, which is reviewed and updated every two years. If a patient receives multiple concurrent treatments, only one track is assigned at treatment onset by the hand therapist in collaboration with the hand surgeon. To select this single track, we developed a priority rule based on the treatment that we expected, on average, to have the most impact (see Table 1). Although only a single track is assigned in these cases, all concurrent treatments are registered. The same priority rule is applied when a new treatment starts during an already active measurement track, e.g. three months postoperatively to determine if a new track needs to be assigned.

Measurement logistics and data collection

For efficient implementation of routine outcome measurement, measurement time points were aligned with the sequence of care events of typical patients (see Figure 1). For example, when a first consultation is registered in the electronic patient record, this initiates the distribution of baseline questionnaires assessing risk factors (e.g., smoking, comorbidity, and medical history)

Figure 1. Flowchart of measurement timing relative to common care paths of patients. Since the measurement system is coupled to electronic patient records with care information, measurements, and questionnaires emailed to patients, it can be fully automated as soon as non-surgical or surgical treatment is entered into the system.



and patient expectations of the consultation and treatment. Then, during the first consultation, a hand surgeon registers the diagnosis and decides together with the patient to start either non-surgical or surgical treatment. Based on this information, a hand therapist assigns a specific measurement track. At the same visit, the hand therapist records patients demographics (e.g., hand dominance) and CROMs and informs the patient on the treatment and future measurements. Subsequently, PROMs are e-mailed to the patient. The start of non-surgical treatment or the date of surgery determines the timing of future questionnaires or assessments. To guarantee the validity and reliability of our data, all therapists received specific training on performing the measurements.

All data are collected digitally in an online system named Pulse, which was developed using GemsTracker electronic data capture tools.[9] GemsTracker is a secure, open-source, web-based application for distribution of questionnaires and forms for clinical research and quality registration. GemsTracker uses the open-source software LimeSurvey[10] for building and storing questionnaires. To ensure data safety, measurements are administered using methods similar to those in electronic patient records, including annual audits and tests, two-way authentication login, and logging and monitoring of all activity.

Since Pulse is linked to our electronic patient records, it automatically sends invitational emails to patients for completing questionnaires as soon as a diagnosis and treatment onset are assigned to a patient in the electronic patient record. Also, healthcare providers can access Pulse and see which measurements they need to complete for a specific patient.

Pulse directly calculates scores of PROMs and displays an overview of answered, open, and missed measures. When the same measure is administered multiple times within a track, score development over time is displayed. In the case PROM data are missing, the surgeon or therapist can request the patient to complete the missing questionnaires, but treatment can also continue without this information.

RESULTS

Collected data

Figure 2 shows the number of tracks assigned to patients over the years. The total number of yearly assigned tracks increased up to over 16.300 in 2018, adding up to a total of 85.000 tracks in 52.000 patients. The increase

Figure 2. The number of yearly activated measurement tracks. Dashed lines indicate the regular tracks, solid lines the extended tracks. Note that more than one measurement track can be assigned to a patient, for example when a new treatment track (e.g., surgery) is initiated after an initial treatment track failed to obtain sufficient relief of symptoms (e.g., an injection or hand therapy). The decrease in track assignment in 2015 and 2016 was due to organizational problems leading to a significant number of patients where a measurement track was not assigned at the start of treatment. However, as can be seen below, this improved by 2017.

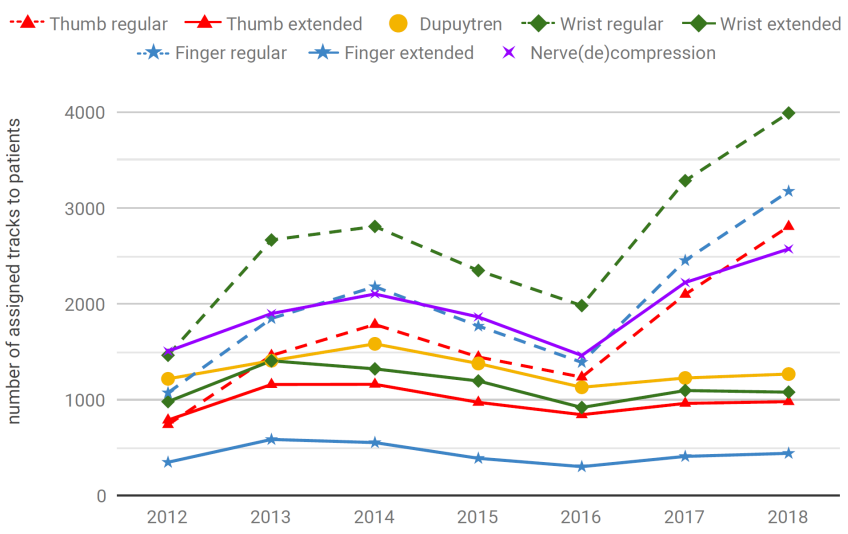


Table 3. The total number of patient questionnaires (across all tracks) and the median time to complete the questionnaires is shown for the period 2011-2018.

Questionnaire	Number of completed questionnaires	Median time to complete
MHQ	49925	4:15 min
PRWHE	28784	3:43 min
BCTQ	17680	1:54 min
Return to Work	40998	0:39 min
Satisfaction with Result	81534	0:14 min
VAS pain and function	135074	0:33 min
PREM	25407	4:17 min

MHQ,: Michigan Hand Outcome Questionnaire; PRWHE, Patient Rated Wrist-Hand Evaluation; BCTQ, Boston Carpal Tunnel Questionnaire; VAS, Visual Analog Scale; PREM, Patient Reported Experience Measure.

in the track numbers reflects the growth in treatment volume and the opening of new centers. The regular tracks, which include non-surgical treatments (e.g., orthotics, exercise therapy, injections) and minor surgical interventions (e.g., trigger finger release), were more often assigned than extended tracks, which include more invasive surgery. Table 3 shows that the Michigan Hand outcomes Questionnaire (MHQ), Patient-Rated Wrist/Hand Evaluation (PRWHE) and our PREM are the most time-consuming measures, with a median of 3-4 minutes to complete. These completion times are lower than initially reported; for example, the MHQ is reported to take ±15 minutes to complete according to its developers.[11]

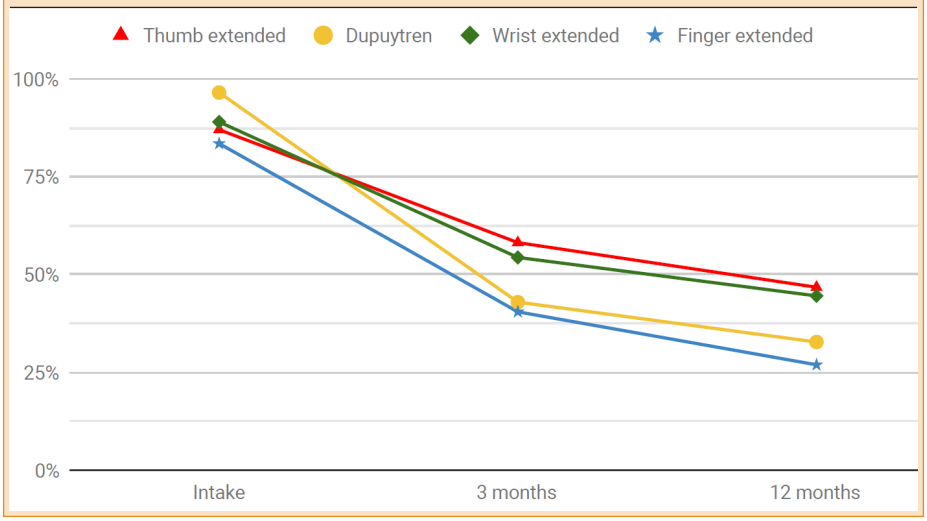
Patient compliance for completing questionnaires was highest at baseline. For example, for pain, hand function, and satisfaction questionnaires, compliance was 73% at baseline and decreased to 62% at 12 months (see Figure 3a). Compliance in extended tracks was 8% higher at baseline and 14% higher at three months compared to regular tracks. Compliance also decreased at follow-up for CROMs (Figure 3b); at baseline, 90% of measurement forms were completed, while at 3 and 12 months these numbers decreased to 50% and 38% respectively.

Using outcome data in clinical practice

From the start in 2011, all surgeons, therapists, and staff had direct access to all scores of individual patients and their development over time. Hence, for example, hand therapists use the measurements to evaluate treatment progress and set new treatment goals. Also, we introduced an integrated secure patient portal (Figure 4) to allow patients to access their treatment information. Within this portal, patients can complete their questionnaires and see their progress over time. Based on the assigned treatment, patient-specific treatment information is provided, e.g., disease-specific instructional videos on postoperative exercises. In 2018, approximately 3100 patients logged into their patient portal each month.

From 2017 onwards, we show individual patient outcomes relative to the average outcome from previous patients. For example, patients can see their pain score over time relative to mean scores of previous patients undergoing the same treatment (Figure 5). Moreover, we introduced a physician dashboard, where physician-specific outcomes for >100 treatments are compared to the average of all other physicians.

Figure 3a. Compliance of patients completing the patient-reported outcome measurements, illustrated using the compliance on the Visual Analogue Scale for pain, hand function, and satisfaction. There are differences in compliance between measurement tracks, but the most important factor is the duration of the follow-up.



Figuere 3b. Compliance of hand therapists filling in the clinician-reported outcome measurements, such as goniometry and grip strength.

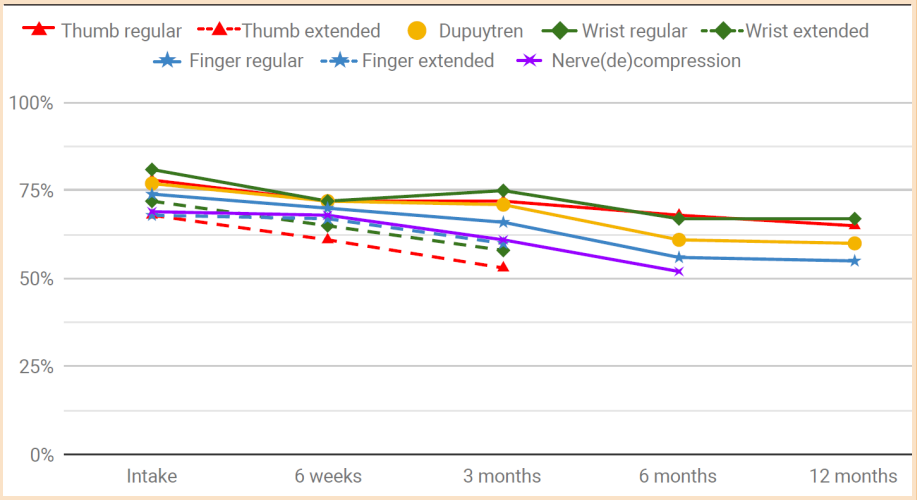
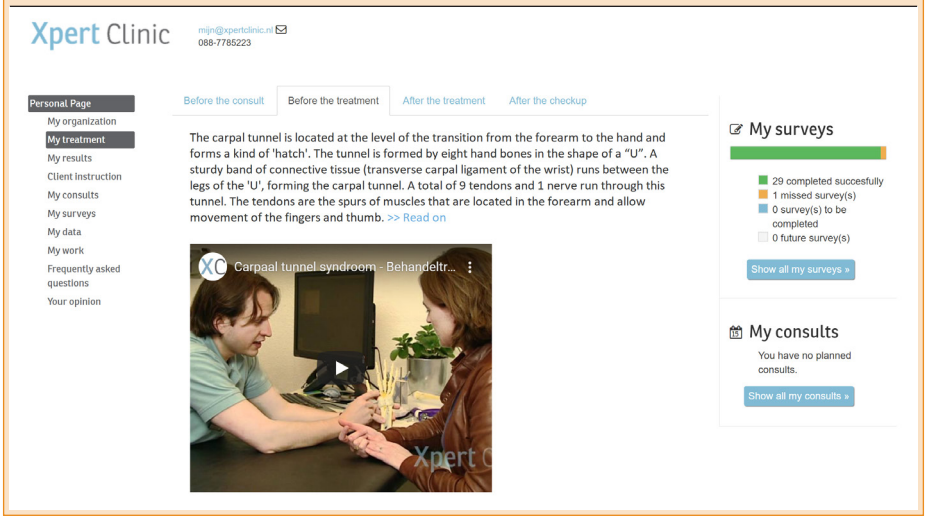


Figure 4. Screenshot of the personalized patient portal, where patients can learn about the treatment, healthcare process, expected outcomes, exercises and can also complete the required questionnaires. As soon as a measurement track is assigned to a patient, disease-specific information is provided.



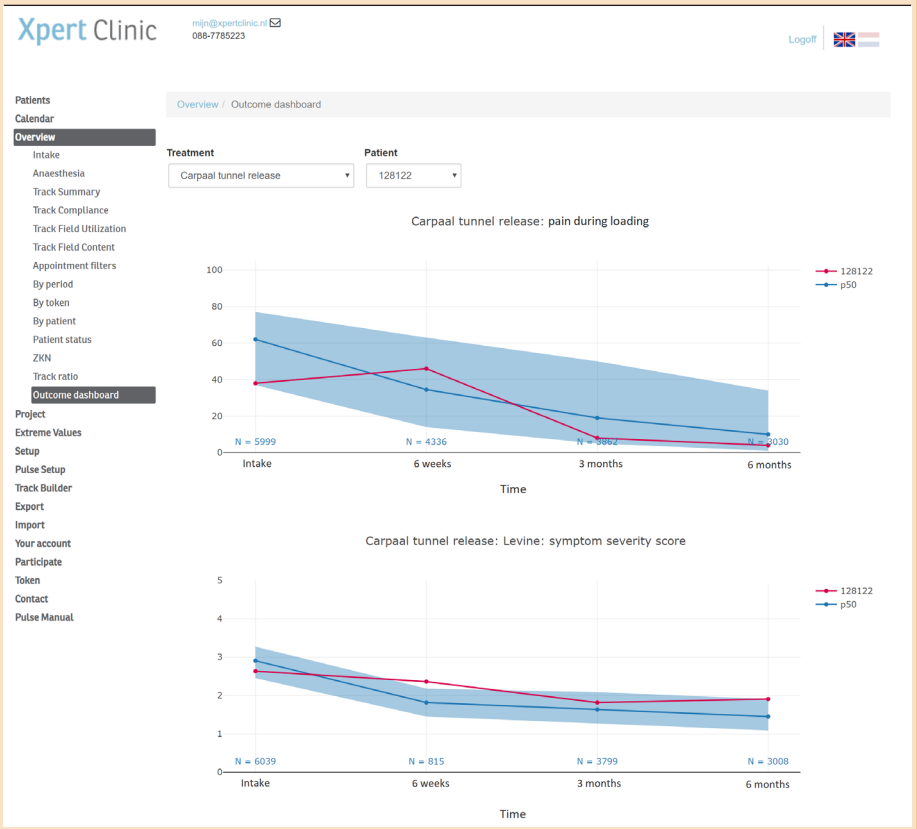
Scientific research with the collected data

While our data collection system was primarily designed to improve and monitor the quality of healthcare of our patients, the system also constitutes a cohort of high-quality data suitable for scientific research: the Hand-Wrist Study Group Cohort.

Comparative effectiveness and prediction modeling

Our first published studies[12-16] focused on comparative effectiveness. In these studies, variation in daily clinical practice is used to compare different treatments, for example, when different surgeons prefer different treatments in the same patient population. To correct for baseline differences between treatment groups, we use propensity score matching and mixed models. For example, we showed that collagenase clostridium histolyticum in Dupuytren's disease was not significantly different from limited fasciectomy in reducing metacarpophalangeal joint contractures in short term outcome, whereas proximal interphalangeal joint contractures showed slightly better reduction following limited fasciectomy.[17] Furthermore, we demonstrated that exercise therapy in addition to an orthosis reduces pain more compared to an orthosis

Figure 5. Screenshot of a physician dashboard, showing the individual patient's outcome (magenta line) compared to the 'average patients' outcomes (blue line, p50 and blue area, p25-p75) after a carpal tunnel release. The data shown can be modified by the user who can select a treatment, a treatment location, and a surgeon. These outcomes will then be plotted over the outcomes of all surgeons, treatment locations for each treatment.



only in patients with thumb base osteoarthritis[16] and that, following a thumb carpometacarpal resection arthroplasty, shorter immobilization is non-inferior compared to more prolonged immobilization.[13]

In addition to comparative effectiveness, we use our data to develop and validate prognostic and clinical prediction models that allow outcome prediction of individual patients, for example on the outcome of non-surgical for thumb base osteoarthritis,[16,18-20] surgical treatment of primary or recurrent carpal tunnel syndrome[21-23,] and surgery in Dupuytren's contracture.[24,25]

Healthcare context and treatment outcomes

We also study how outcomes are not only influenced by treatment but also by the process of care delivery and patient experiences. More specifically, we consistently found positive associations between patient experiences on care delivery and improvement in PROMs following surgical treatments.[8,26,27] The strongest associations were found for positive experiences with the communication of the surgeon and providing treatment information, which is in line with other studies.[8,26,27]

Clinimetric studies

The collected data also allows evaluating the psychometric measurement properties. For example, in patients with Dupuytren's contracture, we reported that the Patient-Specific Functional Scale (PSFS) is more responsive than the more generic and standardized MHQ, despite being much shorter to fill in.[28] Additionally, we developed decision tree-based versions of the PRWHE[29] and the Boston Carpal Tunnel Questionnaire[30] to reduce the number of items needed to calculate the total score from 15 and 18 to 6 for both PROMs, without loss of information (see http://handquestionnaires.org).

DISCUSSION

We introduce the design, development, and implementation of a routine outcome measurement system in hand and wrist care, describing how our data are collected and used for improving clinical care and performing scientific research. The system was feasible by using a highly automated data collection infrastructure, tightly linked to the patient journey and the workflow of healthcare professionals. With this paper, we intend to share our experiences in designing such a system, our lessons learned, and describe the remaining challenges.

The design and implementation of our routine outcome measurement system were facilitated by the specific expertise of the collaborating parties. The Erasmus MC, as a large academic center, contributes scientific knowledge and Xpert Clinic, as a highly specialized hand and wrist clinic, can quickly innovate and integrate the measurements in their workflow. By developing dedicated software,[9] we could customize the data collection to our specific needs and implement changes efficiently.

Ensuring high compliance of both patients and clinicians remains a challenge, as in all outcome measurement systems[31]. We took several measures to optimize compliance. A first step was to minimize the measurement bur-

den and allow direct measurement feedback to both patients and clinicians. A second step was to improve data integration during consults and therapy. For instance, instead of asking for limitations in daily life during a patient's first visit, clinicians can now see this information beforehand and can discuss these issues directly. As a third step, we visualize individual outcomes relative to other patients, which provides a reference for both patient and clinician to discuss treatment outcomes. At present, we present outcomes as group means plus confidence intervals at the level of specific treatments (e.g., a trapeziectomy) but this can be further personalized to individuals, e.g., a 70-year old female a baseline MHQ score of 50. Hence, in the future, we plan to extend this and present individualized outcome predictions based on existing data.

Although clinicians value outcome information, more research is needed on how to efficiently use outcome data to improve quality of care, while maintaining practical feasibility. Presently, it remains challenging for clinicians to actually use the data in daily practice, due to a variety of reasons such as lack of time or inexperience in how to use the data in daily clinical practice. Another concern is that a multitude of factors can influence expected outcomes for an individual patient which need to be taken into account when discussing the expected outcome with a patient. Therefore, we are presently developing models that can predict outcome of individual patients. Our current efforts are focused on the implementation of these models in daily clinical practice so that they can be used in real-time during consultation. In addition, in the future, we plan to link outcome data with the cost of treatment as recorded in the electronic healthcare record, providing insight into the quality of care from a value-based healthcare perspective.

We found that efficient data acquisition software allows outcome recording with a relatively small time investment per patient. Further, at present, the main costs include software development and maintenance (approximately 2-3 fte throughout the last years for all participating treatment centers) and the efforts of staff, management and researchers to design the system. By making the Gemstracker software open-source and describing our procedures in detail, we intend to lower the costs for new centers to develop a similar system. However, despite our successful implementation, reimbursement by healthcare insurance companies for outcome measurement remains unusual, despite the wish of insurance companies and the government to collect outcome data. Hence, further collaboration between healthcare providers,

scientists, insurance companies, and governments is needed, since these investments are currently being made by healthcare organizations themselves.

When comparing the Hand-Wrist Study Group cohort with other large cohorts and related initiatives, there are significant similarities and differences. For example, registries such as the Swedish hand registry[32] have larger patient numbers but less detailed information. Other commonly-used cohorts consist of administrative or claim data on hospital, regional, or national level (e.g.,[33-36]). To our knowledge, the present cohort is unique within the field of hand and wrist disorders since it contains a large number of patients with relatively patients detail of data, covering both outcomes, treatment information, and patient characteristics. A limitation, however, is that this cohort is not representative of all hand and wrist patients in the Netherlands, for example, because complex trauma patients and patients with more severe comorbidities may be treated more often elsewhere. Also, if patients seek treatment elsewhere, no follow-up is available.

For all clinical (e.g., quality evaluation and benchmarking) and scientific analysis, missing data are always an important issue. In several of our research papers, we have performed extensive missing data analysis and have consistently found that our data can be qualified as missing completely at random.[37-40] In literature, many statistical analyses and simulation papers have indicated that either multiple imputation techniques or analyses that account for missing data are superior to complete case analyses.[37-41] However, we noticed that such techniques are counter-intuitive to many readers. Consequently, we have frequently been asked by journal reviewers to report complete cases, despite that there is literature advising otherwise.

Since measuring outcomes is central in value-based healthcare,[1] it would be of great value if more healthcare providers in hand and wrist care would routinely measure outcomes. Although there have been several consensus initiatives on outcome sets,[42-46] none has led to widespread implementation. We hope that our example of routine outcome measurement implementation and the development of the hand and wrist standard set by the International Consortium for Health Outcome Measurement[47] will lead to a common ground for more widespread comparisons of outcomes.

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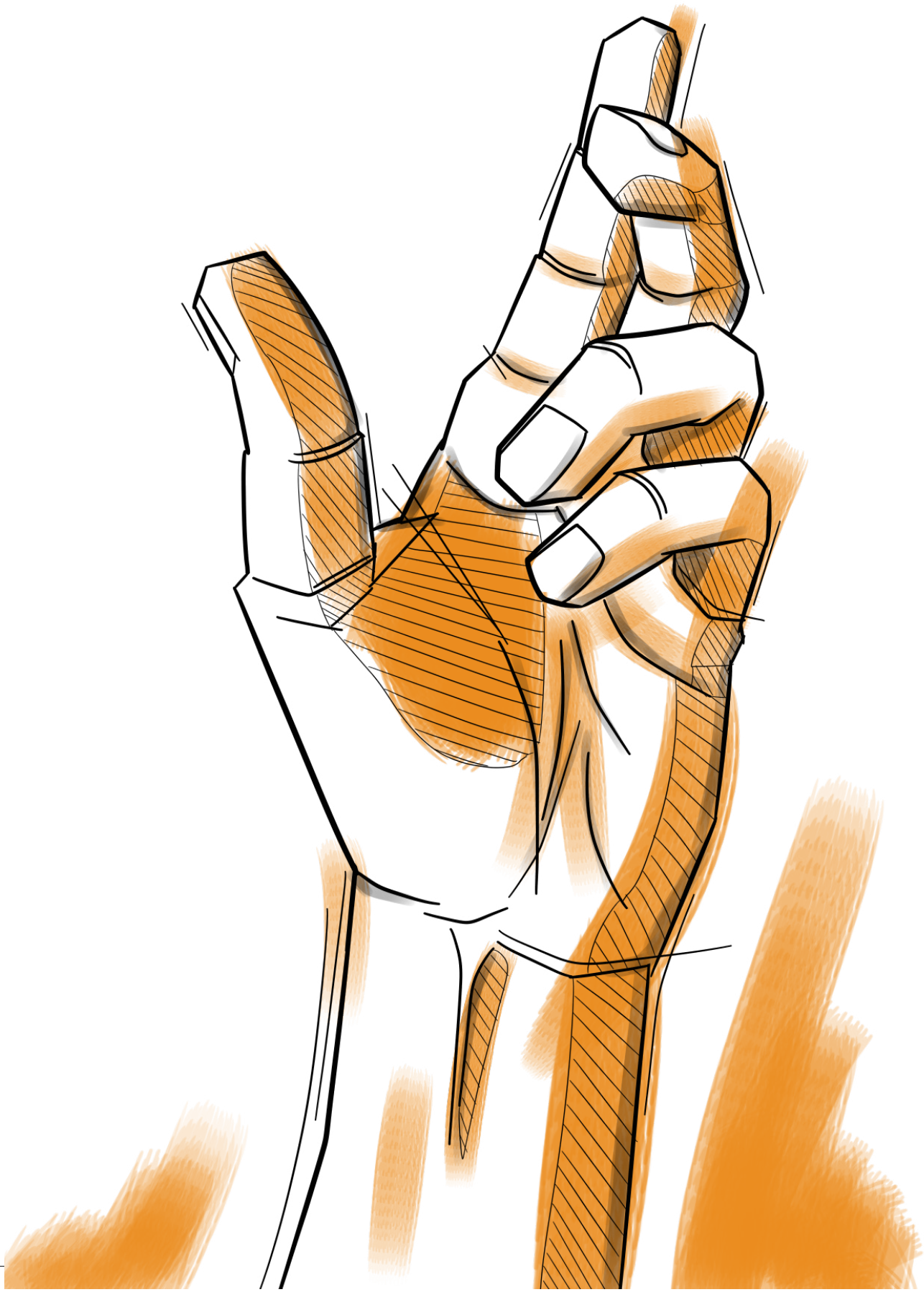
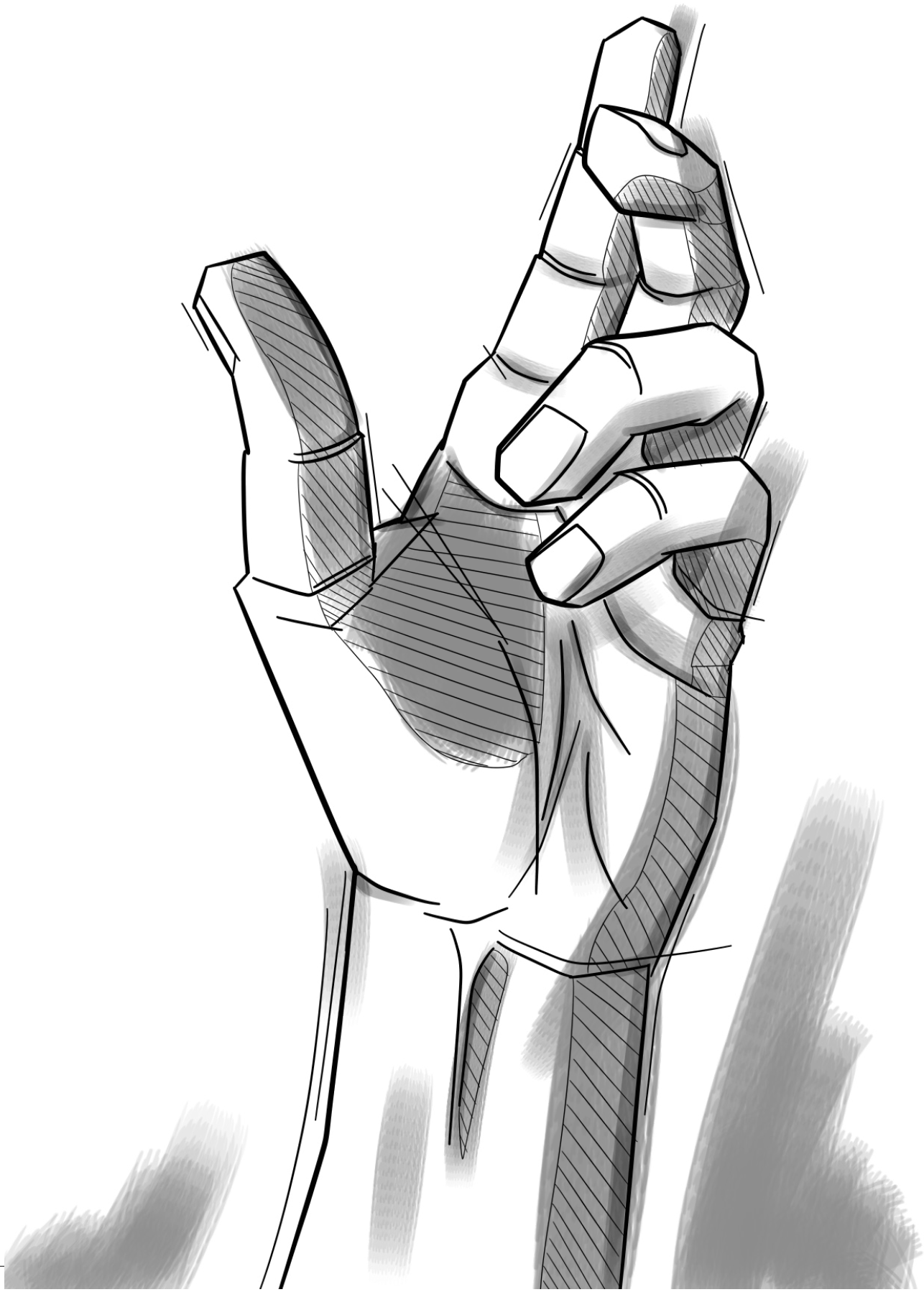


Part II

Psychology and Context



Chapter 3

Illness perceptions of patients with first carpometacarpal osteoarthritis, carpal tunnel syndrome, Dupuytren contracture, or trigger finger.

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ABSTRACT

Purpose

Previous studies indicate that patients with a more negative perception of their illness tend to respond less favorably to treatment, but little is known about whether illness perceptions differ based on the type of hand or wrist conditions. Therefore, we compared illness perceptions between patients scheduled to undergo surgery for four major illnesses in hand surgery: carpometacarpal osteoarthritis, Dupuytren's disease, carpal tunnel syndrome, and trigger finger syndrome. We hypothesized there would be differences in illness perception between these patient groups.

Methods

Pre-operatively, patients were asked to complete the Brief Illness Perception Questionnaire (Brief-IPQ) as part of routine outcome measurement in a specialized hand and wrist surgery clinic. The Brief-IPQ is a validated questionnaire to rapidly assess the cognitive and emotional representation of illness. Differences in illness perception between the four diagnostic groups, corrected for age and sex, hand dominance and work type, were examined. Cohen's D effect sizes were calculated for the between group differences.

Results

We included 514 patients in the analyses: 87 with carpometacarpal osteoarthritis, 146 with Dupuytren's disease, 129 with carpal tunnel syndrome and 152 with a trigger finger. On a scale ranging from zero (most positive perception) to 80 (most negative perception) the Brief-IPQ sum scores for these subgroups were 42.0, 28.2, 38.8 and 33.3, respectively. Corrected for age, sex, hand dominance and work type, patients with Dupuytren`s disease had a more positive perception of their illness than patients with carpometacarpal osteoarthritis and carpal tunnel syndrome. Compared to carpometacarpal osteoarthritis patients the effect size for Dupuytren, carpal tunnel syndrome, and trigger finger syndrome patients was respectively 1.28, 0.32 and 0.81.

Conclusions

In these patients with various hand/wrist disorders, small to very large differences were found in their preoperative perceptions of illness. These differences need to be considered during preoperative medical consultations and/or when investigating surgical outcomes. Interventions that directly target negative illness perceptions might improve treatment outcomes for carpometacarpal osteoarthritis and carpal tunnel syndrome.

INTRODUCTION

Understanding how patients perceive their illness is important to improve treatment outcomes. A negative illness perceptions is associated with decreased hand function in patients suffering from chronic osteoarthritis of the hand.[1] Psychosocial interventions can improve illness perceptions and are associated with both better treatment outcomes[2,3] and increased self-efficacy.[4] Illness perceptions before treatment have shown to be important independent predictors of treatment outcome in other medical areas. It is important to investigate potential differences in illness perceptions before treatment of patients with various hand pathologies. There is only one study that investigated illness perception in chronic osteoarthritis patients, but a comparison across different hand or wrist conditions has not been made. Increasing knowledge about differences in illness perceptions between hand surgery patients is important to understand which illness perceptions need to be addressed in which patient group to ultimately improve outcomes in hand surgery. Interventions to modify patients' illness perceptions may be particularly relevant for those patient groups presenting with more negative illness perceptions.

The common sense model of self-regulation describes how patients perceive their illness and how it relates to patients' experience of symptoms.[5,6] This model describes a feedback loop in which patients respond to their condition and symptoms by the formation of illness perceptions, which influence coping mechanisms and health behaviors (e.g., treatment initiation, treatment adherence). These coping mechanisms and health behaviors will then again influence symptom severity. Based on the common sense model, the Illness Perceptions Questionnaire (IPQ) was developed to measure patients` perception of their illness.[7] This questionnaire captures eight domains of illness perception: 1) 'consequences' describes the expected outcome/effects of the illness, 2) 'timeline' describes how long the patient believes the illness will last, 3) 'personal control' evaluates beliefs as to how much the patient can control the illness, 4) 'treatment control' how much the treatment can control the illness, 5) the domain 'identity' describes the extent to which patients view experienced symptoms as part of their illness, 6) the 'concern' domain describes how concerned patients are about their illness, 7) 'illness comprehensibility' describes how well the patient understands their disease, and 8) the 'emotional representation' domain is the extent of emotional complaints the patient experiences due to the illness.

The aim of this study was to determine whether patients scheduled for surgery for one of four common hand illnesses (First Carpometacarpal Osteoarthritis (CMC-1), Carpal Tunnel Syndrome (CTS), Trigger Finger Syndrome (TFS) and Dupuytren's contracture) differ in their overall and domain specific illness perceptions. We hypothesized there would be differences in illness perceptions between these groups, even when taking into account possible demographic differences between the diagnostic groups.

MATERIALS AND METHODS

Study design

Between September 2017 and November 2017 patients were included for this study at our clinic. Our clinic is a specialized center for treatment of hand and wrist problems and has 18 different locations, 18 European Board certified (FESSH) hand surgeons, and over 150 hand therapists. We included all patients who were scheduled to undergo surgery for either: 1) carpometacarpal osteoarthritis (CMC-1 OA), 2) carpal tunnel syndrome (CTS), 3) a trigger finger, or 4) Dupuytren's disease, who gave written informed consent and who completed the illness perception questionnaire, as part of routine outcome measurements. A clinical diagnosis was made by a certified hand surgeon; when considered necessary, a radiograph was taken or electrodiagnostic studies were performed to confirm the diagnosis. The study was approved by the local institutional review board.

MEASUREMENT

Participants completed the Dutch version of the Brief-IPQ[8,9] as part of their clinical care between the first consultation and one day before surgery. A brief demographic questionnaire was completed with a hand therapist after the first consultation. Patients received an invitation to complete the IPQ in an email. Up to three reminders were sent. The Brief-IPQ is a reliable and validated measuring tool based on the original and the revised IPQ.[7,10]

The Brief-IPQ consists of eight questions to quantify how patients perceive their illness across eight different illness perception domains. Patients are asked on 10-point scales "how much does your illness affect your life?" (0 = no affect at all, 10 = severely affects my life; Consequences domain), "How long do you think your illness will continue?" (0 = a very short time, 10 = forever; Timeline domain), "How much control do you feel you have over your illness?" (0 = absolutely no control, 10 = extreme amount of control; Personal

control domain), "how do you think your treatment can help your illness?" (0 = not at all, 10 = extremely helpful; Treatment control domain), "how much do you experience symptoms from your illness?" (0 = no symptoms at all, 10 = many severe symptoms; Identity domain), "how concerned are you about your illness?" (0 = not at all concerned, 10 = extremely concerned; Concern domain), "how well do you feel you understand your illness? (0 = don't understand at all, 10 = understand very clearly; Illness comprehensibility domain)" and "how much does your illness affect you emotionally?" (0 = not at all affected, 10 = extremely affected; Emotional consequences domain). The authors of the Brief-IPQ advise to replace the term 'illness' in these questions with the illness being studied in a particular setting.[9] We changed the term 'illness' to 'hand or wrist illness' to cover the large variety of patients that are treated for different hand or wrist conditions in our clinic. As an indication of patient's overall illness perception, we calculated a sum score after reverse scoring the treatment control, personal control and illness comprehensibility items, as proposed by the questionnaire developers. The Cronbach's Alpha in our sample was 0.7 indicating an acceptable internal consistency.[11] Higher scores reflect a more negative perception of illness.

Baseline demographics

To correct for potential confounding, demographic characteristics of all patients (including age, sex, work type and hand dominance) were collected before initiating treatment.

Statistical analysis

An ANOVA was performed to assess differences between the four diagnostic groups. If the data was not normally distributed, a Kruskal-Wallis test was performed. ANCOVA was performed to investigate confounding of potential differences in the ANOVA analysis by patient characteristics. A post-hoc analysis of the ANCOVA using Tukey's test was performed to compare the illness perceptions of the four groups. We performed a post-hoc sensitivity analysis to determine the effect size we could detect with our sample. Given a numerator degree of freedom of 18, a power of 0.8 and an alpha of 0.05, we would be able to detect an effect size of 0.15 or larger in the ANOVA and an effect size of 0.2 or larger in the ANCOVA. For all tests, a p-value ≤ 0.05 was considered statistically significant. Cohen's D effect sizes were calculated as the differences between the two groups divided by the pooled standard deviation. An effect size between 0.2 and 0.5 was deemed small, between 0.5 and 0.8 medium, between 0.8 and 1.2 large and bigger than 1.2 as very large.[12]

RESULTS

Of 1059 eligible patients, 514 (48%) completed the Brief-IPQ as part of routine outcome measurements. There were no significant differences in baseline characteristics age, sex, hand dominance and work type between patients that did complete the questionnaires and those who did not. Of the 514 patients who completed the questionnaire, 87 had CMC-1 OA, 146 Dupuytren's disease, 152 CTS, and 129 had a trigger finger. Table 1 presents the patients demographics of the entire group and each diagnostic group separately. The CTS group had a significantly lower age and more patients with CTS were employed in jobs with average physical intensity of work. There were no significant between-group differences on other clinical and demographic variables.

There was a significant difference between groups in overall IPQ scores ($p<0.05$). After adjusting for age, sex, workload and whether the dominant hand was operated, ANCOVA still showed a significant difference between the overall IPQ scores of the four groups ($F(3.351) = 20.48$, $p<0.05$. CMC-1 patients had the most negative illness perception followed by Dupuytren, CTS, and TFS patients (see Table 1). Compared to carpometacarpal osteoarthritis patients the effect size for Dupuytren, CTS, and TFS patients was respectively 1.28, 0.32 and 0.81.

All patients had a similar strong positive belief in the treatment, as well as low personal control (see Figure 1). On the consequences, timeline, identity, concern, illness comprehensibility and emotional representation scales there were significant differences between the groups (Table 1). These differences remained significant after adjusting for age, gender, workload and whether the dominant hand was operated. The general pattern for these subscales was that patients with CMC-1 OA had the worst illness perception, followed by CTS and TFS. An exception was the timeline domain, where patients with Dupuytren's disease and CMC-1 OA had worst perception of timeline, see Figure 1.

Table 2 presents the post-hoc analysis of the ANOVA of the differences in IPQ subscale scores between the groups. The largest significant differences were found between CMC-1 OA and Dupuytren's disease on the consequences and identity scales, i.e. patients with CMC-1 OA scored 3.9 and 3.2 points higher (i.e. less favorable perception), respectively, compared to patients with Dupuytren's disease. Moreover, the only significant difference between the CMC-1 OA and CTS groups was on the timeline scale and the sum score, i.e.

Table 1. Baseline patient characteristics and Illness Perception Questionnaire (IPQ) domains for all patients and for the diagnostic groups separately. Higher values of the illness perception domains correspond with a more negative illness perception.

	All patients	CMC-1 group	Dupuytren group	CTS group	Trigger finger group
	N = 514	N = 87	N = 146	N = 152	N = 129
Age in years, mean (sd)	58.6 (12.4)*	60.0 (8.5)	62.5 (9.1)	54.24 (14.8)	58.5 (12.9)
Sex (% female)	53 †	76	23	73	62
Dominant hand treated (%)	57 †	46	49	64	64
Work type (%)					
No work	42 †	49	49	32	40
Light work	23 †	13	22	35	24
Average work	26 †	23	15	38	27
Heavy work	9	15	7	9	9
Brief IPQ-subscale, mean (sd)					
Consequences[1]	5.8 (2.8)*	7.5 (1.6)	3.5 (2.7)	6.8 (2.3)	6.1 (2.6)
Timeline[1]	5.6 (2.9)*	6.7 (2.3)	6.1 (3.4)	5.5 (2.6)	4.2 (2.6)
Personal control[2]	4.0 (2.8)	4.2 (2.5)	3.8 (3.2)	4.1 (2.6)	4.2 (2.7)
Treatment control[2]	8.4 (1.4)	8.3 (1.2)	8.3 (1.4)	8.5 (1.4)	8.6 (1.5)
Identity[1]	5.6 (2.8)*	6.9 (2.2)	3.7 (2.7)	6.6 (2.4)	5.6 (2.7)
Concern[1]	5.1 (2.9)*	6.5 (2.5)	3.5 (2.6)	5.8 (2.8)	4.8 (2.9)
Illness comprehensibility[2]	8.3 (2.0)*	8.4 (1.9)	8.6 (1.6)	8.0 (2.0)	8.2 (2.3)
Emotions[1]	3.7 (3.0)*	5.2 (2.8)	2.1 (2.5)	4.5 (3.0)	3.4 (2.8)
Sum score (range: 0-80)	34.9 (12.1)*	42.0 (9.6)	28.2 (11.8)	38.8 (10.1)	33.3 (11.7)

CTS, carpal tunnel syndrome; CMC-1 OA, carpometacarpal osteoarthritis; sd, standard deviation

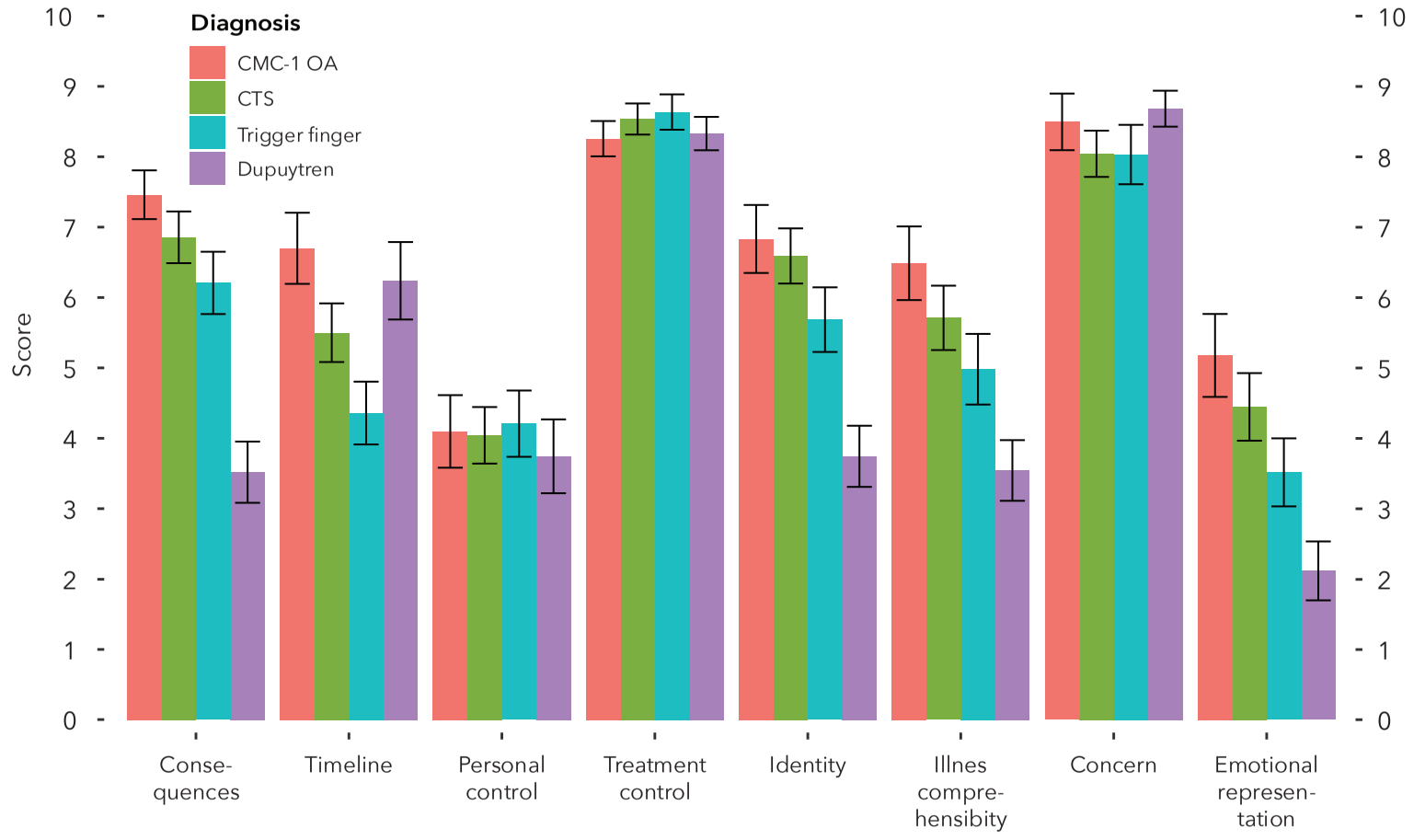
* indicates $p < 0.05$ using an ANOVA

† indicates $p < 0.05$ using a chi-squared test

[1] indicates a range from 0 to 10, where a higher value corresponds with a more negative illness perception

[2] indicates a range from 0 to 10, where a higher value corresponds with a more positive illness perception

Figure 1. Mean IPQ subscale scores for each diagnostic group. The error bars represent the 95% confidence intervals for the mean score in a specific diagnostic group.



CTS, carpal tunnel syndrome; CMC-1 OA, carpometacarpal osteoarthritis

Table 2. Post-hoc analysis of the ANOVA: differences between the individual subgroups. This table indicates the mean difference of a subscale of the IPQ in the upper row between the pairs of illnesses in the left column. The first stated illness is the reference value.

	Conse-quences	Timeline	Personal control	Treatment control	Identity	Concern	Illness compre-hensibility	Emotional represen-tation	IPQ sumscore
CTS - CMC	-0.6	-1.2*	-0.1	0.2	-0.3	-0.7	-0.4	-0.7	-3.7*
Trigger finger - CMC	-1.3*	-2.5*	0.0	0.2	-1.3*	-1.7*	-0.2	-1.8*	-8.5*
Dupuytren - CMC	-3.9*	-0.6	-0.4	0.0	-3.2*	-3.0*	0.3	-3.1*	-13.9*
Trigger finger - CTS	-0.8*	-1.3*	0.1	0.1	-1.0*	-1.0*	0.2	-1.1*	-4.8*
Dupuytren - CTS	-3.4*	0.6	-0.3	-0.2	-3.0*	-2.3*	0.7*	-2.4*	-10.1*
Dupuytren - Trigger finger	-2.6*	1.9*	-0.4	-0.2	-1.9*	-1.3*	0.5	-1.3*	-5.3*

CTS, carpal tunnel syndrome; CMC, carpometacarpal osteoarthritis

* *p*-value < 0.05

Table 3. Post-hoc analysis of the ANCOVA: differences between the subgroups after correcting for age, sex, workload and hand dominance. This table indicates the mean difference of a subscale of the IPQ in the upper row between the pairs of illnesses in the left column. The first stated illness is the reference value.

	Conse-quences	Timeline	Personal control	Treatment control	Identity	Concern	Illness compre-hensibility	Emotional represen-tation	IPQ sumscore
CTS - CMC	-0.5	-1.1*	-0.1	-0.2	-0.4	-0.7	0.6	-1.1*	-3.4
Trigger finger - CMC	0.3	-1.5	-0.1	-0.4	0.5	-0.7	-0.7	-2.1	-4.7
Dupuytren - CMC	-3.4*	-0.4	0.2	0.0	-2.9*	-2.8*	-0.2	-3.2*	-12.7*
Trigger finger - CTS	-0.9	-0.4	-0.1	-0.2	0.9	0.0	-1.4	-1.0	-1.2
Dupuytren - CTS	-2.9*	0.7	0.2	0.2	-2.5*	-2.1*	-0.8*	-2.1*	-9.3*
Dupuytren - Trigger finger	-3.8*	1.1	0.3	0.4	-3.4*	-2.1	0.5	-1.1	-8.0

CTS, carpal tunnel syndrome; CMC, carpometacarpal osteoarthritis

* *p*-value < 0.05

patients with CMC-1 OA scored 1.2 and 3.7 points higher, respectively, than patients with CTS.

Furthermore, post-hoc analysis of the ANCOVA (Table 3) showed that only patients with Dupuytren's disease had a significantly more positive illness perception than the other three groups. The only other significant differences were between CMC-1 OA and CTS on the emotional representation and timeline scale, i.e. patients with CMC-1 OA scored 1.1 and 1.1 points higher, respectively, than patients with CTS.

DISCUSSION

This study compared preoperative illness perceptions in patients scheduled for surgery for CMC-1 OA, Dupuytren's disease, CTS or TFS. Patients with CMC-1 OA have a more negative perception of their illness, whereas patients with Dupuytren's disease have a more positive perception of their illness. This difference was mainly driven by: i) consequences patients experienced from the disease, ii) to what extent patient viewed the experienced symptoms as part of their illness, iii) their concern about the illness, and iv) emotional consequence of the illness.

These findings suggest that preoperative interventions focused on changing illness perceptions may not be necessary for patients with Dupuytren's, but may be helpful for patients with CMC-1 and CTS. A meta-analysis of illness perception[13] has shown that individuals with various medical illnesses and similar illness perceptions to patients with CMC-1 and CTS have impaired physical functioning, psychological wellbeing and social functioning.[14-17] Research also shows that psychosocial interventions can change illness perception and thus improve treatment outcomes across a variety of medical conditions.[18,19] Such psychosocial interventions focus on patients' perceptions of the consequences of their disease and the manner in which they label and interpret their symptoms and disease. For example, in patients with coronary heart disease, interventions that i) educated patients about their illness, ii) changed nonadaptive or incorrect perceptions, or iii) taught patients how to cope with their illness, were effective to change patients illness perceptions.[20] This is in line with the current opinion about the added value of psychosocial interventions on outcomes in hand surgery.[21]

We also found between group similarities regarding the amount of perceived control over the illness. Although patients in these four groups may have different underlying pathologies, they all had similarly low levels of per-

sonal and high levels of treatment control, as well as similarly high levels of perceived understanding of their illness. This pattern is similar to what has been reported for patients undergoing total hip or knee replacement surgery.[22] Such patterns of low perceived personal control on the one hand, and high treatment control and understanding of the disease on the other hand, might be typical for patients scheduled for elective surgery.

Especially low personal control could have a negative influence on the outcome and might therefore be a viable target for intervention. Low personal control has been shown to be associated with worse adherence to treatment[23,24] and worse outcomes.[25,26] For example, Hsiao et al showed that patients with positive illness perceptions adhered better to anti-hypertension medication than patients with negative illness perceptions. If this association of adherence also extends to post-operative rehabilitation, this represents an opportunity for educational or psychosocial interventions. This could be achieved by helping patients understand that, after surgery, the outcome of their recovery is co-dependent on their motivation and adherence to post-operative rehabilitation protocols.[27] By helping patients to reconsider their perceived lack of personal control, we may improve treatment outcome.

A limitation of our study is the non-responder rate. Of all patients who were scheduled for surgery during the study period, 52% did not complete the Brief-IPQ. However, non-response was not dependent on any of the baseline characteristic (age, sex, hand dominance and work type; data not shown). Thus, we believe that these factors did not influence the conclusions of this study.

Several factors may have influenced the results acquired via the Brief-IPQ. First, all questionnaires were collected after patients had received their diagnosis during initial consultation and were scheduled for surgery; this may have had an impact on how they perceived their illness. Consulting with a surgeon can influence the perception of the illness. Any misconception the patient had before the consultation might be addressed by the surgeon during the consultation. Second, for most patients this was the first time that their illness was labeled as 'something to be treated' and the need for surgery itself might make the illness seem more threatening; both these aspects may have influenced the patient's perception of illness. Third, differences between treatment locations may result in different illness perception. However, post hoc analyses revealed that there was little variance in illness perceptions that could be explained by location (ICC = 0.03; not further reported). Fourth, we

know that patients with Dupuytren's disease have no pre-operative pain[28,29] and that CMC-1 OA is characterized by pain.[30] While we could not test this in the present study, it is possible that pain influences illness perceptions of hand surgery patients, and this should be assessed in future studies. Fifth, differences in other psychosocial factors such as anxiety and depression, as described by Beleckas et al. could influence patients perception of illness.[31] Finally, patients referred to a highly specialized hand clinic, such as our clinic, might perceive their illness as being more severe as compared to patients referred to a less specialized clinic. All these factors exist in daily practice and will likely influence, to some extent, illness perception in daily practice. Therefore, our findings can only be generalized to situations where illness perceptions are evaluated under similar circumstances.

The results of this study have important clinical implications by drawing attention to the differences in illness perception among individuals who undergo four common hand and wrist conditions. By being aware of an individual's illness perception along with the type of surgery they will receive, surgeons can directly target the particular aspects of illness perception through educational information and the language they use (i.e. avoiding language that may amplify negative illness perceptions). In some cases, in which illness perception is negative, psychosocial interventions focused on increasing resiliency may be helpful. Given that the four surgical procedures are elective, undergoing skills training to improve illness perception may be feasible, particularly when recommended by surgeons, along with educational information about optimized recovery and outcome of surgery.

Future studies should focus on how illness perceptions of patients scheduled for hand surgery relate to treatment outcomes, how illness perceptions relate to specific types of coping, and how interventions on illness perceptions affect outcomes. For example, in patients suffering from CMC-1 OA, evaluating the association between illness perception and outcome might provide more preoperative information on the expected outcome and enable surgeons to better inform patients about their expected outcome. Furthermore, evaluating how these patients cope with pain may provide more insight into the role of illness perceptions in coping with the outcomes of disease, which can provide a framework to guide patients during treatment and optimize their outcome.

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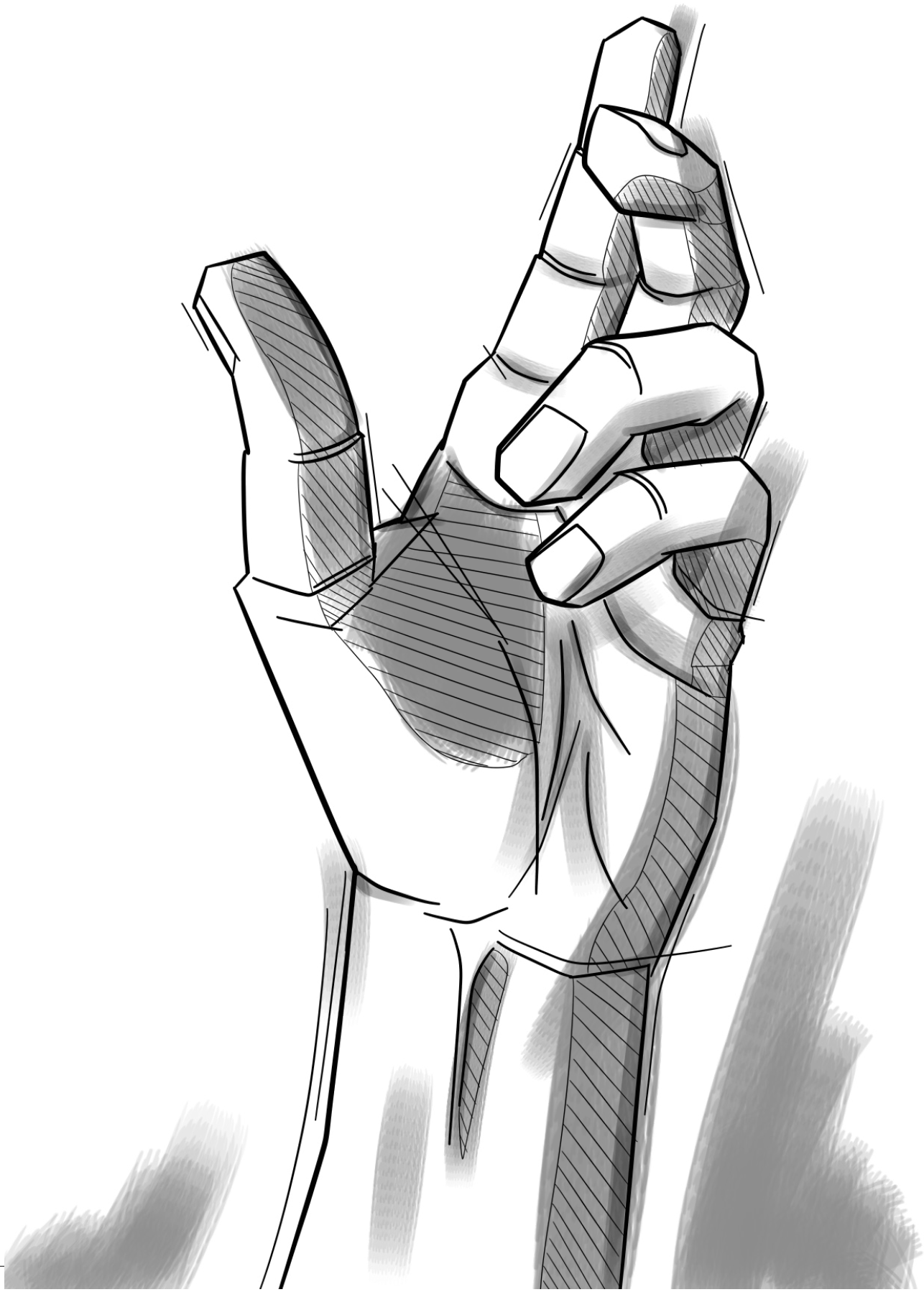

Chapter 4

Better patients' treatment experiences are associated with better postoperative results in Dupuytren's disease.

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ABSTRACT

This prospective study investigates the extent to which a better experience with healthcare delivery is associated with better postoperative treatment outcomes after surgery for Dupuytren's contracture. Patients undergoing limited fasciectomy or percutaneous needle fasciotomy for Dupuytren's contractures completed the Michigan Hand Outcomes Questionnaire before and 3 months after surgery, together with a patient reported experience measure, while hand therapists assessed the straightness of the finger with a goniometer. Regression analyses were used to examine associations. We found that a better experience with healthcare delivery was associated with better patient-reported outcomes, while association with residual extension deficit was minimal. Strongest associations were seen with communication of the physician, postoperative care and information about the treatment. Experience with the treatment explained up to 12% of the variance in treatment outcome. These findings suggest that patient reported treatment outcomes in Dupuytren's disease can be improved by improving the treatment context.

INTRODUCTION

In modern practice both physical treatment outcomes and patient-reported outcome measures (PROMs) are used to evaluate health outcomes after treatment. Most recently, patient-reported experience measures (PREMs) were added to this evaluation.[1,2] Patient-reported experience measures focus on aspects such as respect and dignity, communication by physicians and cleanliness or hygiene of facilities, and can be used to routinely measure and quantify different aspects of treatment context or experience with healthcare delivery.[3] Besides being useful in the evaluation of treatment, PREMs can be useful in clarifying the relation between experiences with healthcare delivery and treatment outcomes. Several observational studies have shown that a better experience with healthcare delivery is associated with better patient reported outcomes.[4] Although these observational studies do not provide causal evidence for this relationship, recent meta-analyses of randomized clinical trials have shown that influencing the context, for instance by improving the communication between patient and clinician, directly improves the patient-reported health status.[5,6]

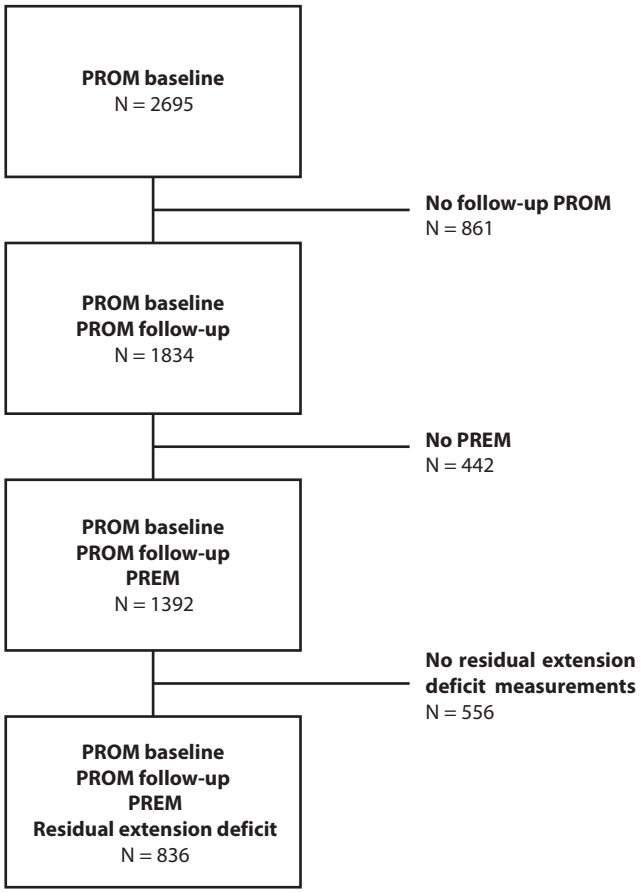
Despite being deemed important[7], these relationships have not yet been studied in Dupuytren's disease nor in hand surgery all together. Therefore, the objective of this prospective study was to investigate the extent to which a better experience with healthcare delivery is associated with better post-operative treatment outcomes after surgery for Dupuytren's contracture, as assessed by both a patient-reported outcome measurement as well as remaining extension deficit in the finger recorded by a therapist.

METHODS

Study design

Patients who underwent either limited fasciectomy (LF) or percutaneous needle fasciotomy for Dupuytren's contractures between February 2011 and December 2016 at a consortium of 16 hand surgery practice sites in the Netherlands were selected from a prospectively maintained database that was designed for clinical and research purposes. Patients who had completed a post-operative PROM and PREM and had finger goniometry recorded were included in the final analysis (Figure 1). All patients provided written informed consent for the use of their data. As part of routine outcome measurement, patients were invited to complete a PROM questionnaire prior to surgery and both a PROM and PREM questionnaire three months afterwards.

Figure 1. Flowchart of subject inclusion.



PROM, Patient reported outcome measures; PREM, Patient reported experience measures

Two reminders were mailed to non-responders. Patient and disease-specific characteristics derived from this database were age, sex, occupational status, comorbidities, current tobacco and alcohol use, family history of Dupuytren's disease, hand dominance and post-operative degree of contracture.

PROM

Patients completed the Michigan Hand Outcomes Questionnaire (MHQ).[8] This rigorously developed, hand-specific PROM assesses six domains of hand function: overall hand function, activities of daily living, work performance,

pain, aesthetics and patient satisfaction with hand function. All questions are answered by means of a five-point Likert scale. Domain- and total scores, ranging from 0 (poorest function) to 100 (best function), were calculated according to the questionnaire developer's instructions.[8] As most of the patients in our population were either unemployed or retired, the domain on work performance was not included in this study. Only the scores pertaining to the treated side were used. As a measure of treatment effectiveness, the change between the pre- and post-operative PROM for each patient was calculated.

PREM

Patients completed a widely used PREM questionnaire in private practice clinics in The Netherlands. This questionnaire aims at measuring the patient's experience with the clinic, marketing position of the clinic and logistics within a clinic. For the current analysis, 25 items concerning the patient's experience were used. With help of an exploratory factor analysis six subscales were identified: physician communication and competence (six items); peri-operative care (four items); post-operative care (four items); general information (two items); treatment information (three items); quality of facilities (six items) (See appendix, Online Supplementary Material, which contains the questions used in the PREM questionnaire). The subscale regarding peri-operative care was reduced to two items for patients undergoing needle fasciotomy, dropping the items concerning the anaesthetist, as this procedure is done under local anesthesia administered by the hand surgeon.

Each item pertaining to one of the six domains of healthcare delivery, was graded by the patient according to the Dutch academic grading system consisting of a ten point scale where one represents a very poor result, and ten an excellent result. When a question did not apply to a patient, for example, if they did not use the website, there was a possibility to answer so. Scores on different subscales were determined as the mean of the items on that subscale.

Internal consistency in our sample, assessed using Cronbach's α, was: physician communication and competence 0.95; peri-operative care 0.83 (for needle fasciotomy patients 0.62); post-operative care 0.89; general information 0.84; treatment information 0.87; quality of facilities 0.87.

Residual extension deficit

The degree of total residual contracture was assessed by certified hand therapists during visits occurring between six and twelve weeks after treat-

ment by calculating the sum of the degree of active extension deficit at the metacarpophalangeal, proximal interphalangeal, and distal interphalangeal joint levels. Any hyperextension was converted to 0 degrees at an individual joint level to prevent underestimation of the total degree of extension deficit. When multiple digits were affected, we used the measurements pertaining to the most severely contracted digit at follow-up.

Missing data

Diabetes, smoking- and alcohol status was unknown in 18% of the patients. In the PREM questionnaire there was missing data in the 'post-operative care', 'general information' and 'peri-operative care' subscales of, respectively, 17%, 21% and 29%. In the three remaining PREM-subscales the missing data was less than one percent. Subscales with missing data were not calculated, as most of the missing data was accounted for by patients answering that a question did not apply to them.

Statistical Analyses

Significance testing was done by means of a Student's t test for normally distributed data, a Wilcoxon rank-sum test for non-normally distributed data and a chi-squared test for categorical data. Distribution of the data was evaluated with histograms and QQ norm plots. To assess the potential of selection bias, we compared baseline patient characteristics between patients who met the inclusion criteria and those who did not.

To assess the relationship between PREM scores and PROM change scores and residual extension deficit, linear regression analyses were used. Beta-coefficients were used to determine the effect size of each PREM-subscale. As the measurement error for goniometry is commonly accepted to be roughly three to five degrees per joint[9], an effect size of smaller than ten degrees for the residual extension deficit (all joints summed up) was regarded as not clinically relevant. To determine to what extent the variation in treatment outcome between patients could be explained by the experience with healthcare delivery, all six PREM-subscales were introduced simultaneously in the same model as independent variables. Multivariable regression models were used to adjust for potential confounders. The significance threshold was set at 0.05.

RESULTS

A total of 836 patients met the inclusion criteria. Patients who met the inclusion criteria underwent more limited fasciectomies and had a slightly better patient reported outcome compared to those who did not meet the inclusion criteria. Patient and disease-specific characteristics that were derived from the database are shown in table 1. The change between pre- and post-operative PROM scores was significant across all subscales (Table 2). The different PREM-subscores and residual extension deficit are shown in table 2.

For the univariate relation between the PREM score and the PROM score, we found significant positive associations between patients' PREM score and the change in their PROM score on all subscales, with the exception of the association between the quality of the facilities and the aesthetics subscale of the MHQ (Table 3). For example, an improvement of one point in the physician 1-10 PREM-scale was associated with an increase of 3.7 points of the total 0-100 PROM-score. The strongest associations with a better PROM change score were seen in 'physician communication and competence', 'post-operative care' and 'treatment information', which can be determined from the standardized associations. PREM-subscales explained 3-12% of the variation in MHQ-subscales (bottom row Table 3).

Similarly, for the univariate relation between the PREM score and residual contraction, we found positive associations between all PREM-subscores and straightness of the finger (i.e. a lower residual extension deficit), with only the association between the quality of the facilities and residual contraction not being significant (Table 3). For example, an increase of one point in the physician PREM-scale was associated with a decrease of 2.1 degrees in residual extension deficit. However, none of the effect sizes for the residual extension deficit was larger than ten degrees and were therefore not clinically relevant.

Adjusting for potential confounders had little effect on the size of the associations, with only two associations being no longer significant, both of which had borderline significance before adjusting for potential confounders (Table 4). Most notably, recurrent disease and the type of surgery had no influence on the associations. Addition of these patient- and disease characteristics added an additional 4-8% to the explained variance (bottom row Table 4).

Table 1. Baseline characteristics of included vs. not included patients.

	Included	Not included	p-value
	N = 836	N = 1859	
Age in years, mean (sd)	63.4 (8.4)	62.4 (9.6)	0.01
Sex (% male)	74.8	73.9	0.69
Smoking (%)	13.2*	17.0	0.03
Alcohol (%)	81.5*	79.6	0.34
Diabetes (%)	8.8*	10.4	0.31
Positive family history (%)	48.9	49.2	0.92
Occupational intensity (%)			0.03
Unemployed/retired	56.2	50.8	
Light (e.g. office work)	27.4	30.1	
Medium (e.g. cleaning)	11.7	12.3	
Heavy (e.g. construction work)	4.7	6.8	
Surgery on dominant hand (%)	51.7	53.5	0.40
Type of surgery (%)			<0.01
Limited fasciectomy	82.5	74.9	
Needle fasciotomy	17.5	25.1	
MHQ – baseline, mean (sd)			
General hand function	67 (16)	67 (17)	0.79
ADL	90 (14)	88 (16)	0.19
Pain	77(20)	74 (22)	0.003
Aesthetics	71 (20)	70 (21)	0.77
Satisfaction	67 (24)	65 (25)	0.19
Total	76 (14)	75 (16)	0.046

MHQ, Michigan Hand Outcome Questionnaire; ADL, Activities of Daily Life
* N = 688

DISCUSSION

In this study, we found that patients with Dupuytren's contractures who reported more positive experiences with the way their care was delivered, also showed more positive treatment outcomes. Confounding factors including

Table 2. Outcome measurements of included patients (N = 836)

	Pre-operative	Post-operative
PREM - scores, median (IQR)		
Physician: communication & competence		8.2 (7.8-9.0)
Peri-operative care (N = 595)		8.5 (8.0-9.0)
Post-operative care (N = 696)		8.3 (8.0-9.0)
General information (N = 660)		8.0 (8.0-9.0)
Treatment information		8.0 (7.7-9.0)
Quality of facilities		8.3 (7.8-9.0)
MHQ - scores, mean (sd)		
General hand function	67 (16)	73 (16)*
ADL	90 (14)	92 (12)*
Pain	77 (20)	80 (19)*
Aesthetics	71 (20)	84 (19)*
Satisfaction	67 (24)	82 (20)*
Total	76 (14)	83 (13)*
Residual extension deficit – degrees, median (IQR)		16 (6.8-27.3)

MHQ, Michigan Hand Outcome Questionnaire; PREM, Patient Reported Experience Measure; ADL Activities of Daily Life; IQR, InterQuartile Range; sd, standard deviation

* difference pre- and post-operative with $p<0.01$

patient- and disease-specific characteristics, most notably, recurrent disease, had a limited effect. Thus previous experience with surgery for Dupuytren's disease, and the type of surgery did not influence the associations. While treatment context had a relatively large effect on patient-reported outcomes, the association with physical treatment outcomes was very small and may not be considered clinically relevant. These findings imply that the context of a surgical treatment for Dupuytren's disease has a greater effect on the patient's perceived outcomes than on physical treatment outcome measurements.

In general, the domains of 'physician communication and competence', 'post-operative care' and 'treatment information' had the strongest association with a more positive treatment outcome. This finding is in line with previous studies which reported that patient experience with the physician's communication is the most important factor in the relationship with treatment

Table 3. Unadjusted beta-coefficients of change score in PROM-subscale and residual extension deficit associated with 1 point difference in PREM score

	Change score in PROM subscales (95% CI)						Degrees (95% CI)
PREM - Difference of 1 point in:	**General Hand Function**	**ADL**	**Pain**	**Aesthetics**	**Satisfaction**	**Total**	**Residual extension deficit**
Physician communication & competence	2.8 (1.7-4.0)	2.5 (1.6-3.4)	5.3 (3.9-6.6)	3.5 (1.9-5.0)	6.3 (4.6-8.0)	3.7 (2.8-4.6)	-2.1 (-3.5--0.7)
Peri-operative care	2.4 (0.9-3.9)	2.0 (0.8-3.2)	3.3 (1.6-5.1)	2.3 (0.2-4.4)	4.0 (1.8-6.2)	2.5 (1.4-3.7)	-1.9 (-3.7--0.2)
Post-operative care	3.7 (2.4-5.1)	2.4 (1.4-3.5)	5.5 (4.0-7.0)	2.8 (1.0-4.6)	5.7 (3.7-7.6)	3.6 (2.5-4.6)	-2.1 (-3.6--0.6)
General information	2.3 (0.9-3.7)	2.1 (1.0-3.3)	3.6 (1.9-5.2)	2.1 (0.2-4.0)	5.1 (3.0-7.1)	2.9 (1.8-4.0)	-1.8 (-3.4--0.2)
Treatment information	3.8 (2.6-5.0)	3.0 (2.1-4.0)	5.7 (4.3-7.0)	4.1 (2.5-5.7)	6.9 (5.1-8.6)	4.3 (3.4-5.2)	-2.2 (-3.6--0.8)
Quality of facilities	2.5 (1.1-3.9)	2.2 (1.0-3.3)	4.2 (2.6-5.9)	1.6 (-0.4-3.5)*	3.0 (0.9-5.1)	2.6 (1.5-3.7)	-0.6 (-2.3-1.1)*
Explained Variance (%)**	3.2	4.7	8.6	4.7	11	12	6.0

PROM, Patient Reported Outcome Measure; PREM, Patient Reported Experience Measure; ADL, Activities of Daily Life

* $p>0.05$, all others $p<0.05$

** all six PREM-subscales as independent variables simultaneously to predict either the PROM subscales or residual extension deficit.

Table 4. Adjusted[$] beta-coefficients of change score in PROM-subscale and residual extension deficit associated with 1 point difference in PREM score

	Change score in PROM subscales (95% CI)						Degrees (95% CI)
PREM - Difference of 1 point in:	**General Hand Function**	**ADL**	**Pain**	**Aesthetics**	**Satisfaction**	**Total**	**Residual extension deficit**
Physician: communication & competence	3.0 (1.7 -4.2)	2.6 (1.6-3.5)	5.4 (4.0-6.9)	3.1 (1.3-4.8)	6.5 (4.7-8.3)	3.7 (2.8-4.7)	-1.8 (-3.2--0.4)
Peri-operative care	2.6 (0.9-4.3)	1.8 (0.4-3.2)	3.4 (1.4-5.4)	2.2 (-0.3-4.6)*	3.7 (1.2-6.2)	2.5 (1.2-3.8)	-1.9 (-3.9--0.09)
Post-operative care	4.3 (2.8-5.8)	2.5 (1.3-3.6)	5.8 (4.0-7.5)	2.4 (0.3-4.4)	5.9 (3.7-8.1)	3.7 (2.5-4.8)	-1.8 (-3.4--0.08)
General information	2.3 (0.8-3.9)	1.8 (0.6-3.1)	3.7 (1.9-5.5)	1.9 (-0.2-4.0)*	5.0 (2.8-7.3)	2.8 (1.6-4.0)	-2.1 (-3.9--0.6)
Therapy information	3.9 (2.6-5.2)	3.0 (1.9-4.0)	5.8 (4.3 -7.4)	3.6 (1.8-5.4)	6.8 (4.9-8.7)	4.3 (3.3-5.3)	-2.1 (-3.6--0.6)
Quality of facility	2.4 (0.8-3.9)	2.0 (0.8-3.3)	4.4 (2.5-6.2)	1.1 (-1.0-3.3)*	3.1 (0.8-5.4)	2.5 (1.3-3.7)	-0.5 (-2.3-1.2)*
Explained Variance (%)**	9.4	9.4	13	9.3	17	16	14

PROM, Patient Reported Outcome Measure; PREM, Patient Reported Experience Measure; ADL Activities of Daily Life

[$] adjusted for age, sex, diabetes, alcohol, smoking, positive family history, occupational intensity, surgery on dominant hand, recurrent disease and type of surgery

* $p>0.05$, all others $p<0.05$

** all six PREM-subscales as independent variables simultaneously to predict either the PROM subscales or residual extension deficit with correction for potential confounders[$]

outcome.[4,10,11] In addition, our results show that a good experience with the treatment information provided was also strongly associated with patient-reported treatment effectiveness. Overall, treatment context explained 11.6% of the variation of the total MHQ-score. Addition of patient- and disease characteristics as well as surgery type only added an additional 4% to the explained variance of the total MHQ-score. These results suggest that treatment context, rather than patient- and disease characteristics or the type of surgery, played a large role in predicting patient-reported outcomes in Dupuytren's.

A possible explanation for these results could be that good communication and good treatment information results in better or more realistic expectations of the outcome.

Expectations are seen as a crucial ingredient of placebo-like effects.[12] It has been shown that expectation can be modulated by using an empathetic interaction style[13] or by discussing patient's treatment believes[14], which in turn can have a beneficial effect on treatment.[15,16]

Besides the role of optimized expectations, a more positive evaluation of the physician might also reflect a more trustful physician-patient relationship.[17] In turn, this might lead to better treatment adherence and arguably better treatment outcomes.[18,19] However, it is also possible that patients with a better outcome will report a better experience, as they may be more inclined to accept shortcomings in their experience with the given care. In the absence of an interventional study, a definitive conclusion about the direction of this association between treatment context and health outcome cannot be made.

The main strengths of this study are the use of both patient-reported and physical outcome parameters, prospective collection of the data and the large sample size collected across the Netherlands. The relative large loss to follow-up (69%) is a limitation of this study, which may have led to under- or overestimation of the identified associations. However, our analyses did not show clinically relevant differences in baseline characteristics between patients who were included or excluded, reducing the likelihood of biased results. It is uncertain if the results are generalizable to other hand disorders. In Dupuytren's disease, pain is not as prominent as in, for example, arthrosis. This might result in different associations, as patients with pain have different reasons to seek medical help and therefore different expectations from their treatment.[20] With regard to the patient-reported experience, the questionnaire used in this study is not as thoroughly developed and tested as some of the other experience questionnaires.[21] Nevertheless, the subscales showed

good internal consistency.

In conclusion, this study shows that a better experience with healthcare delivery is associated with a better treatment outcome in the treatment of Dupuytren's disease. Optimizing experience with health care delivery may provide a new and relatively unexplored pathway for improving healthcare outcomes in hand surgery.

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Online Supplementary Material 1. PREM-questionnaire. Questions translated from original, Dutch questionnaire

Physician communication & competence	
What do you think of personal contact with the doctor?	**1 2 3 4 5 6 7 8 9 10**
How well did the doctor listen to your input?	**1 2 3 4 5 6 7 8 9 10**
How good was the doctor's treatment towards you (politeness, etc.)?	**1 2 3 4 5 6 7 8 9 10**
What do you think of the time the doctor has taken for you?	**1 2 3 4 5 6 7 8 9 10**
Did the doctor explain things in an understandable way?	**1 2 3 4 5 6 7 8 9 10**
What do you think of the medical expertise of the doctor?	**1 2 3 4 5 6 7 8 9 10**
Peri-operative care	
What do you think of the medical expertise of the anesthesiologist?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the guidance during the operation by the anesthesiologist/ anesthesia employee?	**1 2 3 4 5 6 7 8 9 10 NA**
How do you feel about the type of anesthesia used?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the guidance/care provided by the nursing staff?	**1 2 3 4 5 6 7 8 9 10 NA**
Post-operative care	
What do you think of the hand therapist's guidance before and after treatment?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the information that the hand therapist has given you?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the alignment in communication between the hand therapist and doctor?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the aftercare provided by the clinic (recovery period, controls, medication, emergency)?	**1 2 3 4 5 6 7 8 9 10 NA**

General information

What do you think about the quality of the information brochure?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of the information on the website?	**1 2 3 4 5 6 7 8 9 10 NA**

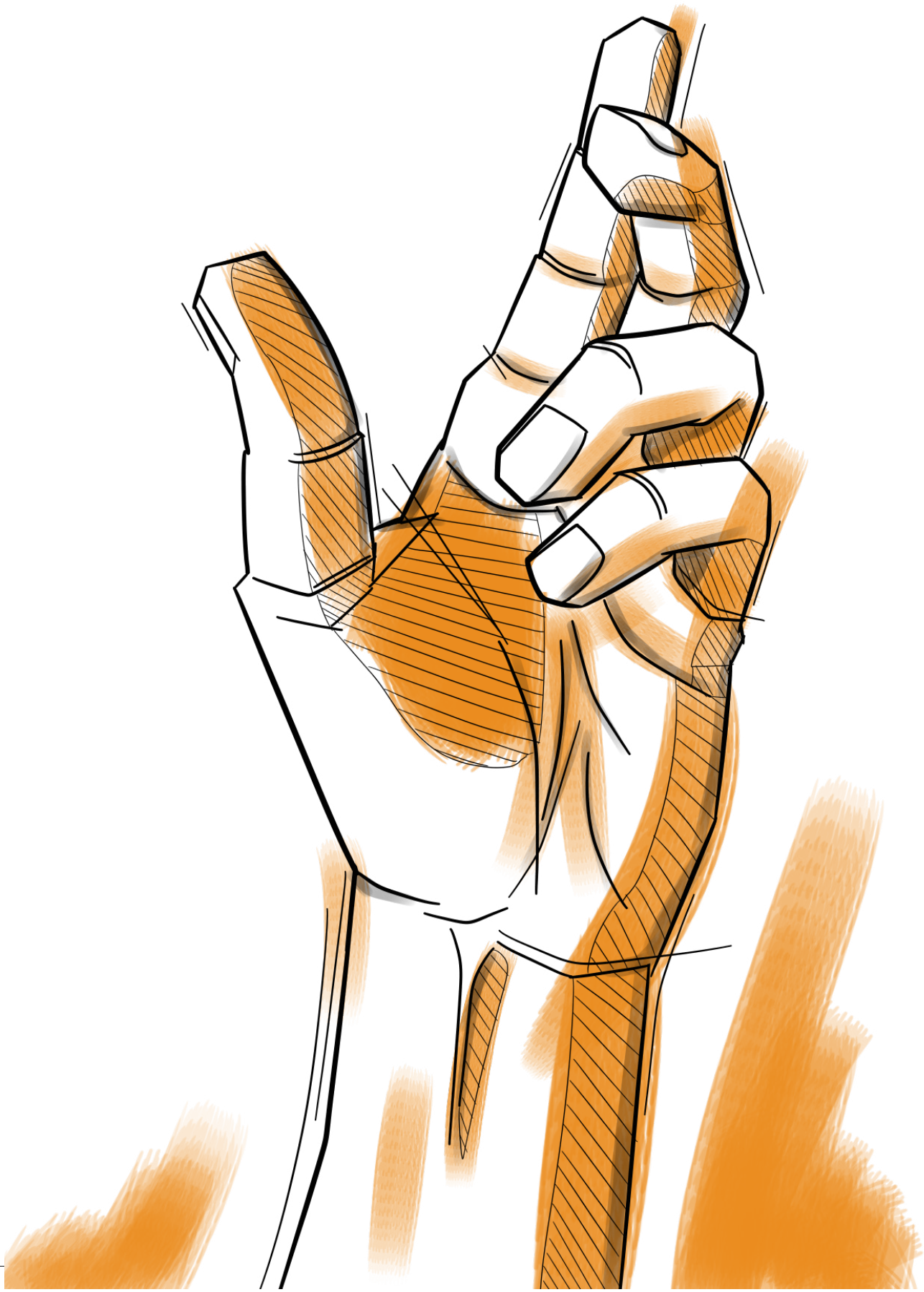
Treatment information

How well did you find the information prior to your treatment?	**1 2 3 4 5 6 7 8 9 10 NA**
Are you well informed about the results, alternatives and risks of treatment?	**1 2 3 4 5 6 7 8 9 10 NA**
What do you think of information about the aftercare (checks, emergencies, etc.) after your treatment?	**1 2 3 4 5 6 7 8 9 10 NA**

Quality of facility

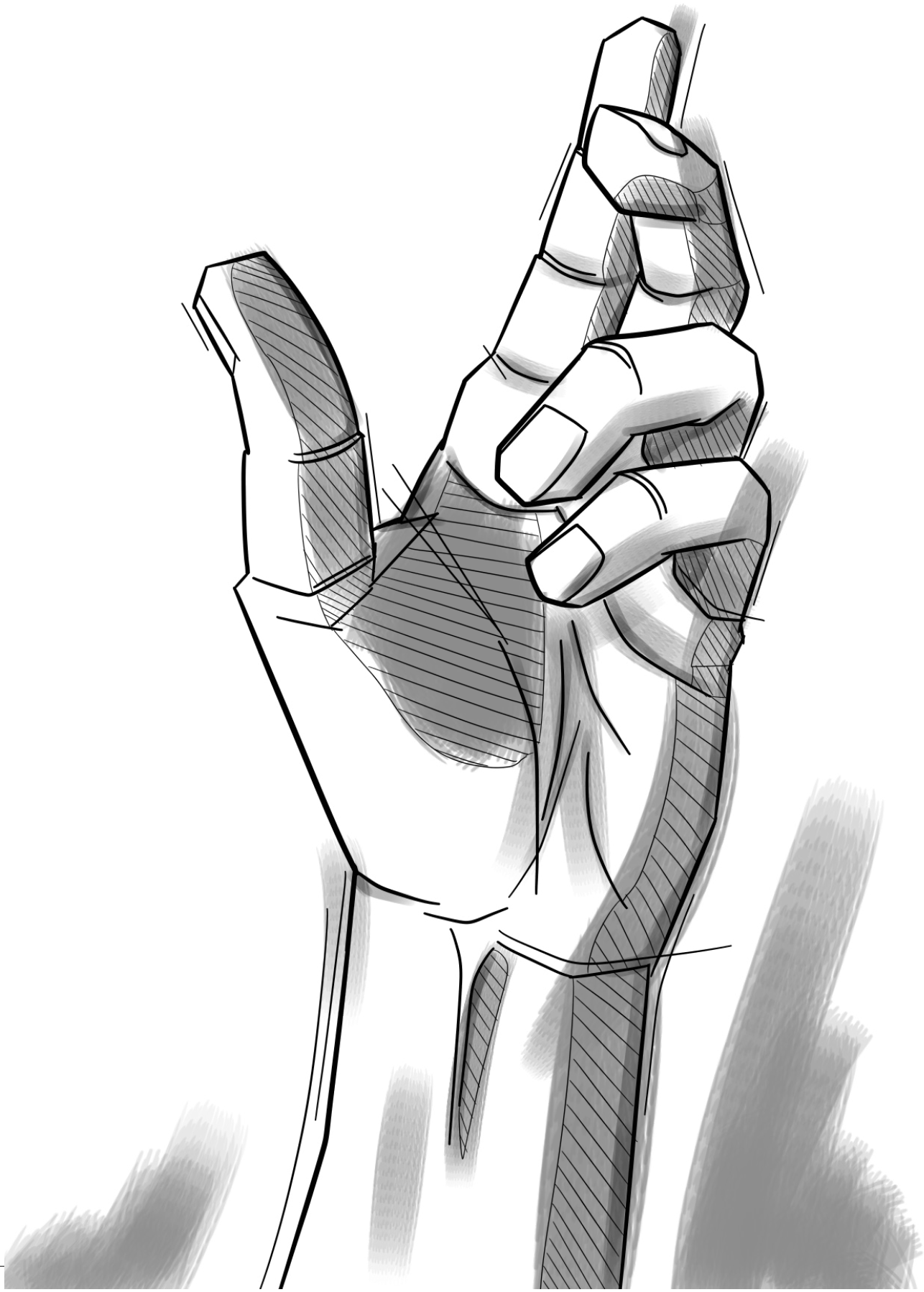
What do you think of the telephone accessibility of the clinic?	**1 2 3 4 5 6 7 8 9 10**
How well were you assisted via telephone?	**1 2 3 4 5 6 7 8 9 10**
What do you think of the hygiene in the clinic?	**1 2 3 4 5 6 7 8 9 10**
What do you think of the clinic's accessibility and parking?	**1 2 3 4 5 6 7 8 9 10**
Has your Xpert Clinic performed your treatment safely?	**1 2 3 4 5 6 7 8 9 10 NA**
How were you received at the clinic (hospitable, friendly, etc.)?	**1 2 3 4 5 6 7 8 9 10**

NA: not applicable, did not apply to patient



Part III

Treatment and Outcome



Chapter 5

Content validity and responsiveness of the Patient Specific Functional Scale in patients with Dupuytren's disease.

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ABSTRACT

Background

Patient reported outcome measures have become the standard tool for reflecting the patient's perspective on their functioning and treatment outcome for a wide variety of hand conditions. One such measure, the Patient-Specific Functional Scale (PSFS), is an individualized questionnaire that enables patients to specify those activities with which they have difficulty in daily life.

Purpose

This study aims to determine the content validity and responsiveness of the PSFS compared with the Michigan Hand Questionnaire in patients with Dupuytren's disease.

Methods

Patients with Dupuytren's disease being treated with percutaneous needle aponeurotomy, limited fasciectomy or skin graft were selected from a database with routine outcome measurements. These measurements were performed as part of usual care prior to and three months after treatment. In order to assess content validity of the PSFS, the activities specified by patients were classified into the International Classification of Function core set for hand conditions. The Standardized Response Mean is calculated for the pre-, post change scores of the PSFS to evaluate responsiveness.

Results

308 patients were analysed prior and three months after treatment. Content validity of the PSFS was appropriate since 95% of all items could be classified into the International Classification of Function activities and participation domain. The Standardized Response Mean of the PSFS was 1.0 (95% confidence interval 0.86-1.2), which was substantially larger than the Standardized Response Mean of the Michigan Hand Questionnaire score 0.58 (95% confidence interval 0.42-0.74).

Conclusions

Our results indicate that the PSFS scale is a content-valid questionnaire which may be more responsive to change than a fixed-item instrument like the Michigan Hand Questionnaire in patients with Dupuytren's disease, making it a valuable additional instrument to highlight therapy goals and evaluate the progress over time in a patient with Dupuytren's disease.

INTRODUCTION

Patient-centred care is the practice of caring for patients in ways that are meaningful and valuable to the individual patient.[1] In recent years patient reported outcomes measures have become the standard measurement for reflecting the patient's perspective for a wide variety of hand conditions.

Standardized patient reported outcomes measures such as the Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH), Michigan Hand Questionnaire (MHQ) and Patient Rated Wrist and Hand Evaluation (PRWHE) use predefined questions to assess hand function. These fixed-item questionnaires allow comparing patient groups and treatment methods and support the development of evidence-based practice. However, the predefined nature of these fixed-item patient reported outcomes measures may limit the capability to capture the unique needs and difficulties of each individual patient, especially for those conditions where patients experience a wide variety of problems[2]. Individualized patient reported outcomes measures enable patients to specify activities with which they have difficulty in their daily life. Such patient specific questionnaires may provide a valuable addition to fixed-item patient reported outcomes measures to capture individual functional problems encountered by patients with Dupuytren's disease.[3-6] As each activity is self-generated by the patient, the scale is patient-specific and thus fits well with the current emphasis on the patient being the focus of healthcare. In addition, a patient-specific questionnaire may be more responsive to change than standardized fixed-item patient reported outcomes measures.[2]

Several individualized patient reported outcomes measures exist, such as the Measure Yourself Medical Outcome Profile (MYMOP)[7], Canadian Occupational Performance Measure (COPM)[8] and the Patient-Specific Functional Scale (PSFS).[10] In the field of hand therapy, the PSFS is the most commonly used individualized patient reported outcomes measure.[10] The COPM is based on a semi-structured interview and although previous studies have shown the potential benefit of the COPM in patients with Dupuytren's disease[4], it is time-consuming to administer the COPM in clinical practice. In contrast, the PSFS is an easy and relative quick tool where patients identify and score up to five activities affected by their condition. The PSFS was reported valid, reliable and responsive in conditions such as knee dysfunction, cervical radiculopathy and acute low back pain.[11] While the individualized aspect and ease of the PSFS may be promising, its use in patients with Dupuytren's disease has not yet been studied. Therefore, the aim of this study is to establish

the content validity of the PSFS in our sample and determine which of the most frequently-mentioned functional problems in the PSFS are evaluated in the fixed-item patient reported outcomes measures (DASH, MHQ, PRWHE and URAM). Moreover, the responsiveness of the PSFS in patients with Dupuytren's disease, i.e. its ability to detect change, is assessed and compared with the MHQ.

METHODS

Study design

This multicentre inception cohort includes all patients being treated for Dupuytren's disease with percutaneous needle aponeurotomy, limited fasciectomy or skin graft between October 2014 and September 2015 in seven hand surgery practice sites. Patients were selected from a database which contained routine outcome measurements.[12] Measurements were performed as part of usual care prior to and three months after treatment. We restricted our analyses in this study to patients with available preoperative data on the PSFS questionnaire and we did not exclude patients based on patient characteristics, clinical success or failure. All patients provided written informed consent for the use of their data. The study protocol was approved by the institutional review board of the Erasmus Medical Centre. Patient characteristics derived from this database included age, sex, diabetes, smoking, employment, recurrent disease and family history.

Outcome Measurements

Patient Specific Outcome Scale (PSFS)

In the PSFS, patients identify and score three to five important activities that they are unable to perform or have difficulty with as a result of their condition[9]. More specifically, before treatment, a hand therapist asked the patient: "I am going to ask you to identify up to five important activities that you are unable to do or are having difficulty with as a result of your hand problem. Are there any activities that you are unable to do or having difficulty with because of your hand problem?" Activities were scored on an 11-point scale with '0' representing 'unable to perform' and '10' representing 'able to perform at prior-disease level'. At follow-up, the patients are presented with the same activities again and ask to rate the ability for each activity. The total PSFS score is the average score of all activities produced by the patient.

Michigan Hand Outcome Questionnaire (MHQ)

The MHQ is a hand-specific questionnaire with six domains: 'hand function', 'activities of daily living' (ADL), 'work performance', 'pain', 'aesthetics' and 'patient satisfaction with hand function'. All questions are answered on a five-point Likert scale. Domain and total scores, all ranging from 0 to 100, were calculated according to the instructions.[13] Higher scores indicate better hand performance. The MHQ is a valid and reliable measurement instrument for several hand problems.[13] The Dutch Language Version of the MHQ is used in this study.[15]

Total Active Extension Deficit (TAED)

The TAED of the affected fingers was assessed by hand therapists prior to treatment and 6 to 12 weeks after treatment by calculating the sum of the degree of active extension deficit at the metacarpophalangeal, proximal interphalangeal, and distal interphalangeal joint levels. Any hyperextension was converted to 0 degrees at an individual joint level to prevent underestimation of the total degree of extension deficit. Patients are asked to active extend the finger as much as possible and the range of motion in measured with a goniometer on the dorsal aspect of the finger. The dorsal measurement method with good alignment of the goniometer has been reported to be a reliable measurement method to assess active range of motion of the finger.[16] Measurements were recorded to an accuracy of one degree. When multiple fingers were affected, we used the measurements of the most severely contracted finger at baseline.

Content validation

The PSFS aims to evaluate patient-specific problems in the 'activities and participation' component of the International Classification of Function (ICF) scale. Activity limitations are defined as difficulties an individual may have in executing activities in daily life. Participation restrictions are problems that an individual may experience in involvement in life situations.[17] Appropriate content validity is reached if 90% of all reported items on the PSFS can be classified in the 'activities or participation' domain of the ICF scale.[18,19] To analyse which functional problems patients with Dupuytren's disease were mentioned in the PSFS, we used the Comprehensive ICF Core Set for Hand Conditions as a framework. This framework is developed as a basis for studying content validity of already existing instruments.[20] Two authors (Yvk and KG) independently classified all problems as reported by patients on the PSFS within

the Comprehensive Core Set for Hand Conditions. Items that were differently classified by the two authors were discussed until consensus was reached. Thereafter, we evaluated to what extent the ten most frequently-mentioned functional problems in the PSFS are present in the Unité Rhumatologique des Affections de la Main (URAM), DASH, PRHWE and MHQ questionnaires.

Responsiveness to change

Patients with pre- and post-operative measurements were compared using a paired t-test for normally distributed data and the Wilcoxon signed-rank test for non-normally distributed data. Data distribution was analysed using histograms and QQ norm plots. Sensitivity analyses were performed to compare baseline characteristics of patients who completed both the PSFS and MHQ at follow-up and those patients who did not. Significance thresholds were set at $p \leq 0.05$. To compare the responsiveness to change of the PSFS and MHQ the Standardized Response Mean (SRM) for paired data with 95% bias-corrected bootstrap confidence intervals were calculated. The SRM is calculated as the mean change score divided by the standard deviation of the change score and were considered significantly different if confidence intervals did not overlap. SRM smaller than 0.20 was considered small, up to 0.50 moderate and SRM higher than 0.80 was considered large.[21] Based on the fact that the MHQ may miss items that are important for the individual patient, we hypothesized that there would be greater improvement 3 months after surgery in the scores of the PSFS (SRM> 0.80) compared with the functional scales 'Hand Function' and 'ADL' of the MHQ and the total MHQ score (SRM< 0.50). Floor- and ceiling effects were defined as at least 15% of the patients achieving the best or worst level of the questionnaire score.[22]

RESULTS

325 patients with Dupuytren's disease were eligible for this study. One patient was excluded because the PSFS items were accidentally changed during the post-operative evaluation. Sixteen patients could not mention a single functional problem. These patients were included for the content validation, but not for the analysis of responsiveness to change. The mean age was 63 (SD 9) years and 76% underwent a limited fasciectomy (Table 1).

A total of 943 items in 42 different dimensions of the Comprehensive Core Set for Hand Conditions were mentioned in the PSFS. Almost all (95%) of these items could be classified in the 'activities and participation' domain of the ICF. The remaining five percent were classified in the ICF 'function' do-

Table 1. Patient characteristics (N = 308)

Age in years, mean (sd)	63 (9)
Sex (% male)	71
Surgery on dominant hand (%)	49
Positive family history (%)	46
Occupational situation (%)	
Unemployed/retired	53
Light (e.g. office work)	27
Medium (e.g. cleaning)	14
Heavy (e.g. construction work)	6
Type of surgery (%)	
Limited fasciectomy	76
Needle fasciotomy	20
Limited fasciectomy & skin graft	3
Needle fasciotomy & lipofilling	<1
Recurrent disease (%)	29
Duration of disease in months, median (IQR)	24 (12-48)

sd, standard deviation; IQR, interquartile range

main, including items such as 'stiffness' and 'strength'. The majority of the functional problems could be classified in the 'recreation and leisure' domain (Table 2), including, sports, playing a music instrument and gardening. The second most commonly mentioned items were functional problems like 'pushing yourself up' or 'lean on your hand'. Furthermore, the PSFS identified very specific problems such as 'to put on a glove', 'hand in pocket', or 'computer use'; activities that are not evaluated on the DASH, PRWHE, MHQ or URAM questionnaire.

197 patients completed both the PSFS and MHQ at baseline and follow-up. Sensitivity analyses showed no baseline differences between patients who completed both questionnaires and those who did not (Table 3). The mean PSFS score improved significantly from 5.0 (SD 2.2) at baseline to 7.7 (SD 2.1) at follow-up. Similarly, all MHQ subscales, except the 'work'-subscale, showed significant improvement (Table 4). The TAED improved from 67 degrees prior to surgery to 20 degrees after surgery. The SRM of the PSFS was 1.0 (95% con-

Table 2. The top 10 most mentioned functional activities of the PSFS compared to fixed-items questionnaires. The first row indicates that 14.4% of the items mentioned by the patients in the PSFS could be classified as recreation and leisure activities on the ICF set for hand conditions. The last column represents whether these activities are evaluated by the DASH, PRWHE, MHQ or URAM.

ICF items (N = 943)	% of total number of items	Items represented in de following questionnaires
D920 Recreation and leisure Eg. sports, music instrument, gardening	14.4	DASH, PRWHE
D410 Changing basic body position Eg. pushing yourself up, lean on hand	7.3	PRWHE, URAM
D230 Carrying out daily routine Eg. hand in pocket, opening a door	6.9	DASH, PRWHE, MHQ
D540 Dressing Eg. putting on gloves, button a shirt	6.4	PRWHE, MHQ
D430 Lifting and carrying objects Eg. carrying a shopping bag	6.3	DASH, PRWHE, MHQ, URAM
D650 Using household objects Eg. opening a jar	5.5	DASH, MHQ
D360 Using communication devices Eg. typing, computer use	5.5	None
D7 Interpersonal interactions Eg. shaking hands, clap hands	5.2	URAM
D520 Caring for body parts Eg. wash your face or hair, to smear lotion	4.4	DASH, PRWHE, MHQ, URAM
D4458 Hand and arm use Eg. using tools	4.2	DASH, PRWHE

ICF, International Classification of Function; PSFS, Patient Specific Functional Scale; DASH, Disabilities of the Arm, Shoulder and Hand Questionnaire; PRWHE, Patient Rated Wrist and Hand Evaluation; MHQ, Michigan Hand Questionnaire; URAM, Unité Rhumatologique des Affections de la Main

fidence interval 0.86-1.2), whereas the SRM of the total MHQ score was 0.58 (0.42-0.74). The SRM of the MHQ subscales varied from 0.28 to 0.73 (Figure 1). Ceiling effects were observed in the 'ADL'- and 'work'- subscales of the MHQ, whereas no floor or ceiling effects were observed in the PSFS (Table 4).

DISCUSSION

In this study we found that the PSFS has appropriate content validity for

Table 3. Sensitivity analyses. Comparison of the baseline characteristics of patients who completed both the PSFS and MHQ at follow-up and those who did not.

	Complete follow-up (N = 197)	No or incomplete follow-up (N = 111)	*p*-value
Mean age (years (sd))	63 (8)	64 (10)	0.29
Sex (% male)	71	72	0.96
Surgery on dominant hand (%)	50	48	0.76
Positive family history (%)	47	46	0.99
Diabetes (%)	7	3	0.35
Smoking (%)	14	15	0.84
Occupational situation (%)			0.23
Unemployed/retired	53	51	
Light (e.g. office work)	28	25	
Medium (e.g. cleaning)	14	14	
Heavy (e.g. construction work)	4	10	
Type of surgery (%)			0.51
Limited fasciectomy	78	74	
Needle fasciotomy	20	22	
Limited fasciectomy & skingraft	2	5	
Needle fasciotomy & lipofilling	<1	0	
Recurrent disease (%)	28	30	0.84
Duration of disease in months (median (IQR))	24 (12-48)	24 (12-48)	0.63

sd, standard deviation; IQR, interquartile range

patients with Dupuytren's disease. In particular, patients mentioned problems in the 'activities and participation' domain of the ICF. Furthermore, the SRM of the PSFS was larger compared to the SRM of the total MHQ score, indicating better responsiveness to change of the PSFS.

In line with previous studies, we found a wide variety of functional problems in patients with Dupuytren's disease, of which the majority is not covered by fixed-item patient reported outcomes measures like the MHQ.[3,6,19,23] Most notably, none of the fixed-item questionnaires assess the use of communication

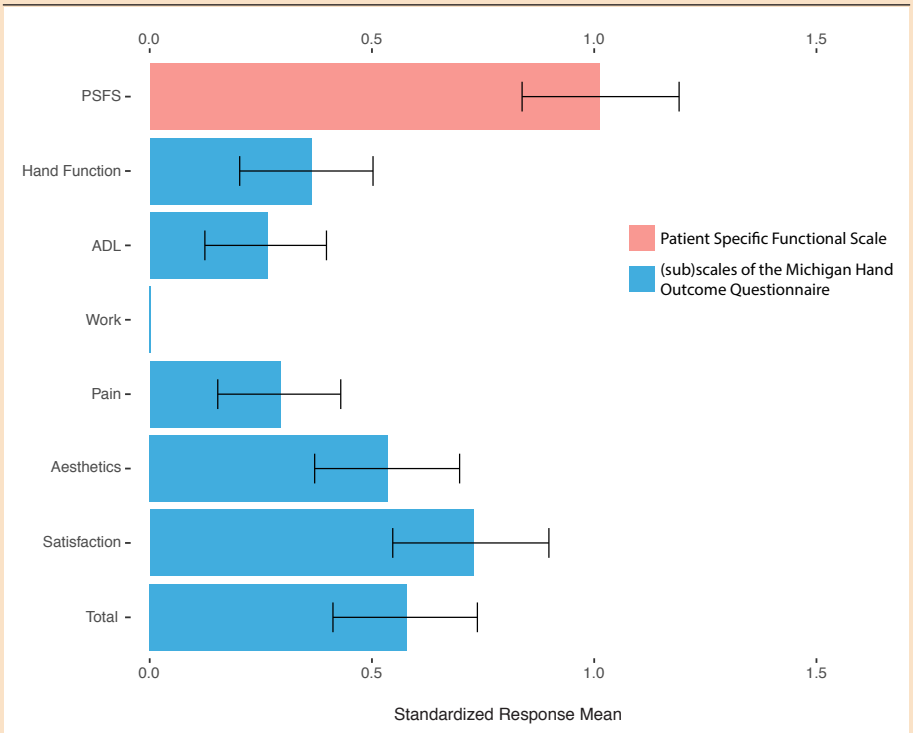
Table 4. Outcome measurements collected as baseline and at 3 months post-operatively. The p-value indicates the significance of the change from baseline to follow-up. The last column indicates the number of patients with the highest score on intake, indicating potential ceiling effects in the measures.

	Intake - scores (mean (sd))	3 months - scores (mean (sd))	*p*-value	% of patients with highest score on intake
PSFS				
Number completed	*308*	*208*		
Mean score	5.0 (2.2)	7.7 (2.1)	<0.001	2.3
MHQ scores				
Number completed	*282*	*202*		
Hand function	64 (18)	71 (17)	<0.001	6.4
ADL	85 (18)	89 (17)	<0.001	22*
Work	83 (23)	83 (25)	0.90	44*
Pain	71 (22)	76 (21)	<0.001	13
Aesthetics	70 (19)	82 (21)	<0.001	9.2
Satisfaction	60 (25)	79 (22)	<0.001	4.2
Total	72 (15)	80 (15)	<0.001	0
Goniometry				
Number completed	*287*	*120*		
TAED (degrees)	67 (42)	20 (20)	<0.001	

sd, standard deviation; TAED, total active extension deficit.
*indicate a ceiling effect

devices, despite the increasing use of such devices in modern day society. With several hundred separate functional problems mentioned by patients with Dupuytren's disease, it is impossible to assess all patient specific problems with predefined questions. Therefore, the advantage of the PSFS is that it gains insight into the most important personal problems of the patient, making it a valuable additional instrument to plan therapy goals and to evaluate the progress over time in a patient with Dupuytren's disease. Remarkably, not all patients with Dupuytren's disease experience functional problems, as indicated by the small group of patients (4,9%) who could not mention a functional problem in the PSFS. These patients apparently seek medical treatment

Figure 1. Standardized Response Mean of the PSFS and MHQ. Error bars represent the 95% confidence intervals.



PSFS, Patient Specific Functional Scal; ADL, Activities of Daily Life

for other reasons. Therefore, it is important to evaluate the complete aspect of the ICF, including body function (e.g., pain and range of motion), activities, participation, environmental- and personal factors. Although not explored in this study, previous studies have shown that problems such as pain and cosmetic concerns prompt patients to seek medical treatment and therefore should be considered when treating patients with Dupuytren's disease.[5]

Fixed-item patient reported outcomes measures are widely used in healthcare to support better and more patient centred care, amongst other to assess and compare the quality of providers and to provide data for evaluating practices.[24] However, the present study clearly underlines the potential added value of individual patient reported outcomes measures like the PSFS, in particular to investigate patient specific change over time. However, due to the lack of item standardization, the PSFS may not be as useful for benchmarking purposes across clinics and different countries.[25]

The main strength of this study is the use of the PSFS alongside the MHQ, which enables direct comparison of the PSFS with a fixed-item patient reported outcomes measures. Furthermore, this study has been conducted in a relatively large population of patients with Dupuytren's disease; measurements were performed as part of usual care in consecutive patients. Data therefore are likely to reflect all patients with Dupuytren's disease, as compared to, for example, populations in many randomized controlled trials which have restricted selection criteria. However, a drawback of the routine outcome measurement setting is that patients may be less inclined to return for follow-up measurements and to fill out questionnaires. This could introduce missing values and therefore some potential bias. Despite this potential flaw, in fact our sensitivity analyses showed no differences in baseline characteristics between responders and non-responders in this study. A further limitation concerns the lack of a gold standard to evaluate the responsiveness of both questionnaires. The SRM is frequently used as responsiveness parameter.[26] However, the higher SRM of the PSFS may also be caused by factors unrelated to the ability of the instrument to detect changes in functional limitations (e.g. regression to the mean).[25]

In conclusion, this study demonstrates an appropriate content validity and good responsiveness of the PSFS. Self-generated items and the measurement of such items allow reflecting the needs and problems of the individual patient and these characteristics make the PSFS a valuable additional tool to measure outcome in Dupuytren's disease, which fits perfectly the ethos of patient-centred healthcare.

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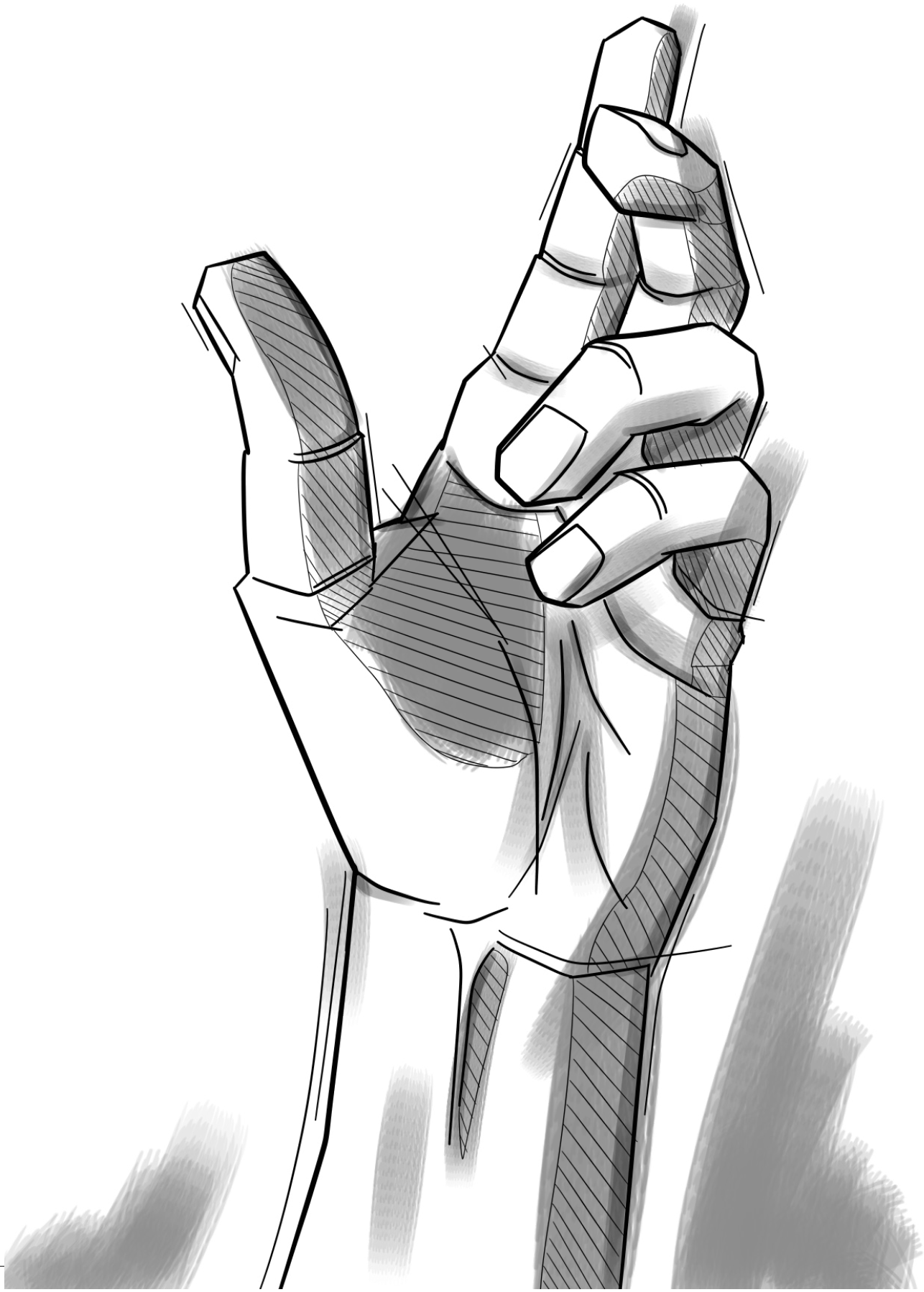

Chapter 6

Patient's satisfaction beyond hand function in Dupuytren's disease: analysis of 1106 patients.

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ABSTRACT

This study investigates the effect of the treatment of Dupuytren's disease on the different domains of patient-reported hand function, such as hand appearance and satisfaction with hand function, and how these changes are associated with contracture reduction. Patients undergoing limited fasciectomy or percutaneous needle fasciotomy completed the Michigan Hand Outcomes Questionnaire before and three months after surgery and straightness of the finger was assessed with a goniometer. Change scores for the various outcome parameters were calculated and linear regression analyses were used to examine associations between the change in extension deficit and change in MHQ-(sub)scores. The largest effects of surgery were seen in the change in extension deficit, the appearance of the hand and the satisfaction with the hand function. All associations remained weak with relatively low explained variances. This study underlines the importance of assessing other domains than hand function in Dupuytren's disease.

INTRODUCTION

Hand surgical treatment options are focused on restoring the function of the upper extremity. Performance-based measures such as the improvement in range of motion or hand strength are widely used. They provide an objective measurement of the hand function at the function level of the International Classification of Function (ICF) model.[1] Additionally, so-called patient-reported outcome measures (PROMs) are used to assess hand function at activity and participation level of the ICF, reflecting the patient' perspective of the impact of disease treatment on hand function.

In Dupuytren's disease it is generally assumed that improvement of the hand function is an important goal for patients, with the aim to improve the range of motion of a finger or fingers (that is to reduce the contracture(s)). However, several studies have shown that an increase in range of motion is poorly correlated with an improvement in patient-reported hand function.[2,3] Comparative studies between various treatments have shown that, despite similar contracture reduction, differences exist in patient-assessed hand function and satisfaction with hand function.[4,5] Thus improvement of patient-reported hand function is not simply achieved by correcting the extension deficit of patients.

While most Dupuytren studies focus on contracture correction and self-reported hand function, several studies regarding rheumatoid arthritis have shown that post-operative hand appearance was an important determinant of post-operative satisfaction.[6,7] Zhou et al.[8] demonstrated that hand appearance is an important predictor for patient satisfaction in Dupuytren's disease. Kan et al.[9] examined patients' preferences for treatment and found that complete contracture reduction was the most important attribute, but that patients were willing to trade up to almost 5% increase in recurrence rate and four degrees of residual contracture deficit for an excellent aesthetic result compared to a moderate result. This suggests, that other issues besides hand function are of importance to patients with Dupuytren's disease.

Experienced clinicians may already recognize that aspects such as aesthetics play an important role, most PROMs in hand surgery solely assess hand function.[10] For example, the Disability of the Arm, Shoulder and Hand questionnaire (DASH), does not assess hand appearance or satisfaction. The same is true for the only Dupuytren-specific PROM available, the Unité Rhumatologique des Affections de la Main (URAM).[11] Other PROMs have a single question, e.g. the Patient Evaluation Measure,[12] on the appearance of the

hand, but these are included in a total score, making separate assessment of various issues impossible. However, the Michigan Hand Outcome Questionnaire (MHQ) has separate domains on hand appearance and satisfaction,[13] which make it possible to assess different domains of patient-reported hand function separately.

We assess the effect of Dupuytren treatment on the different domains of patient-reported hand function as measured with the MHQ, and to assess to what extent change in the different domains of the MHQ is associated with the change in contracture correction.

METHODS

Study design

Patients who underwent either limited fasciectomy (LF) or percutaneous needle fasciotomy (PNF) for Dupuytren's contractures between February 2011 and June 2017 at a consortium of sixteen hand surgery practice sites in the Netherlands were selected from a prospectively maintained database designed for clinical and research purposes. Following the definition of Tang and Giddins, all surgeons can be considered specialists (dedicated hand surgeons with between two and twenty years of experience), including one expert in the field of Dupuytren's disease.[14] Total extension deficit of the affected fingers was assessed prior to surgery and three months after surgery. Patients with baseline finger goniometry and a completed MHQ at baseline were eligible for this study. Patients with an affected thumb at baseline were not eligible, as problems with the thumb affect hand function very differently compared to other fingers. Patients with both, finger goniometry and a completed MHQ at follow-up were included in the final analyses. Patient- and disease-specific characteristics derived from this database were age, sex, occupational status, family history of Dupuytren's disease, hand dominance, whether surgery was for primary or recurrent disease and type of surgery.

PROMs

As part of routine outcome measurement, patients were invited to complete the Michigan Hand Outcome Questionnaire (MHQ) prior to surgery and three months afterwards.[15] This thoroughly developed, hand-specific PROM assesses six domains of hand function: overall hand function, activities of daily living (ADL), work performance, pain, aesthetics and patient satisfaction with hand function. All questions were answered by means of a five-point

Likert scale. Domain- and total scores, ranging from 0 (poorest function) to 100 (best function), were calculated according to the questionnaire developer's instructions.[15] Two reminders were mailed to non-responders. Only the scores pertaining to the treated side were used. As a measure of treatment effectiveness, the change between the pre- and post-operative PROM for each patient was calculated.

Total active extension deficit

The degree of total active extension deficit (TAED) was assessed by hand therapists during visits prior to surgery and 3 months after surgery by summing up the degree of active extension deficit at the metacarpophalangeal, proximal interphalangeal, and distal interphalangeal joint levels. Assessment prior to and after surgery could be done by either the same or a different hand therapist. Any hyperextension was converted to 0 degrees at an individual joint level to prevent underestimation of the total degree of extension deficit. As a measure of treatment effectiveness, the change between the pre- and post-operative extension deficit for each patient was calculated. When multiple digits were affected, we used the measurements pertaining to the most severely contracted digit at baseline.

Statistical analyses

Cohen's D effect sizes for paired data were calculated to facilitate comparison between the various outcome parameters. This standardized measure of effect describes the magnitude of change and can be interpreted as follows: 0.20, small; 0.50, medium; 0.80, large effect size.[16]

The relationship between the change in finger goniometry and change in different (sub)scores of the MHQ was assessed using linear regression analyses. For each MHQ-(sub)score, two separate models were used. In the first model, the change in the various MHQ-(sub)scores were introduced as the dependent variable and the change in extension deficit as the independent variable, along with the extension deficit at baseline prior to surgery to correct for baseline differences. In the second model, the above-mentioned patient- and disease parameters were added as independent variables to the first model to correct for potential confounding of the association studied in the first model. The explained variance was calculated of both models to assess to which extent the independent variables could explain the variance in MHQ-(sub)scores.

A power analyses for the multivariable linear regression models determined

Table 1. Patient characteristics (N = 1106)

Age in years, mean (sd)	63 (9)
Sex (% male)	75
Positive family history (%)	50
Occupational intensity (%)	
Unemployed/retired	55
Light (e.g. office work)	28
Medium (e.g. cleaning)	13
Heavy (e.g. construction work)	5
Duration of disease in months, median (IQR)	24 (12-24)
Recurrence (%)	21
Surgery on dominant hand (%)	53
Type of surgery (%)	
Limited fasciectomy	79
Needle fasciotomy	21
Number of affected fingers (%)	
1	54
2	35
3 or more	11
Most affected finger (%)	
Index finger	1.5
Middle finger	11
Ring finger	28
Pink	60

sd, standard deviation; IQR, interquartile range

that a sample size of 394 patient would provide a power of 80% with 20 independent variables (to account for dummy variables) in the model, given a significance threshold of 0.05 and an expected explained variance of 5%.

RESULTS

At baseline, 2758 patients were eligible for this study. A total of 1106 patients completed both finger goniometry and the MHQ at follow-up and were included in this study. Patients had a mean age of 63 years (SD 9 years), 55% were retired or unemployed and 79% underwent limited fasciectomy (Table 1). Post-operative finger goniometry of the most affected finger at baseline was not available in 110 patients (10%). These patients did return for follow up, but the treated finger was not entered in the database, possibly due to wrong labelling of the measurements.

The change in the different outcome measurements from baseline to follow-up can be seen in Table 2. The mean TAED improved from 60 degrees prior to surgery to 20 degrees after surgery, which corresponds with a large effect size of 1.3. In the MHQ, the 'aesthetics'- and 'satisfaction'-subscales showed the largest improvements, with medium effect sizes of 0.54 and 0.61, respectively, while the changes in the more function-related subscales 'general hand function' and 'ADL' were small with effect sizes of 0.29 and 0.12, respectively. The 'work'-subscale showed no significant treatment effect at all.

Table 2. Outcome measurements at baseline and 3 months after surgery (N = 1106)

	Baseline	3 months	Effect Size	*p*-value
TAED in degrees, mean (sd)*	62 (36)	20 (22)	1.3	<0.0001
MHQ-subscales, mean (sd)				
General hand function	68 (16)	72 (16)	0.29	<0.0001
ADL	90 (14)	91 (12)	0.12	<0.0001
Work	85 (21)	86 (21)	0.00	0.94
Pain	76 (20)	80 (19)	0.17	<0.0001
Aesthetics	71 (20)	83 (19)	0.54	<0.0001
Satisfaction	66 (24)	81 (21)	0.61	<0.0001
Total	76 (14)	82 (14)	0.46	<0.0001

TAED, Total Active Extension Deficit; sd, standard deviation; MHQ, Michigan Hand Outcome Questionnaire
* N = 996

Table 3. Beta-coefficients for the change in MHQ-(sub)scales adjusted for baseline extension deficit (N = 996).

	Change score in MHQ-subscales (95% CI)					
	General hand function	**ADL**	**Pain**	**Aesthetics**	**Satisfaction**	**Total**
Extension gain (per degree)	0.12 (0.07-0.18)	0.085 (0.04-0.13)	0.17 (0.11-0.23)	0.22 (0.15-0.29)	0.20 (0.13-0.28)	0.14 (0.10-0.18)
Explained variance (%)	*2.1*	*2.0*	*5.0*	*6.4*	*2.7*	*4.3*

MHQ, Michigan Hand Outcome Questionnaire; ADL, Activities of Daily Life; CI, Confidence Intervals

Table 4. Beta-coefficients[$] for the change score in MHQ-(sub)scales (N = 996)

	Change score in MHQ-subscales (95% CI)					
	General hand function	**ADL**	**Pain**	**Aesthetics**	**Satisfaction**	**Total**
Extension gain (per degree)	0.11 (0.05-0.16)	0.07 (0.02-0.12)	0.15 (0.09-0.22)	0.21 (0.14-0.29)	0.19 (0.11-0.27)	0.12 (0.08-0.17)
Explained variance (%)	*6.3*	*6.1*	*7.4*	*9.2*	*6.7*	*8.5*

MHQ, Michigan Hand Outcome Questionnaire; ADL, Activities of Daily Life; CI, Confidence Intervals

[$] adjusted for: baseline extension deficit, most affected finger, most affected joint, number of affected fingers, age, sex, positive family history, occupational intensity, surgery on dominant hand, recurrent disease and type of surgery

Linear regression (n = 996) showed a significant positive association between the change in extension deficit and the change subscales of the MHQ, as well as the total score of the MHQ, when corrected for the extension deficit at baseline (Table 3). However, the magnitude of this association was different for the different subscales. A reduction of the extension deficit with 40 degrees was associated with an increase of only 4 points in hand function-subscale but 10 points in the aesthetics-subscale. Expressed as explained variance, we found that change in extension deficit explained less than 5% of the variance in each MHQ-(sub)scale, with the exception of the aesthetics-subscale (6.5%) (Table 3: bottom row).

Adjusting for potential confounders had limited effect on any of the beta-coefficients in the association between change in extension deficit and change in MHQ-(sub)scores, suggesting no confounding of these variables on the associations (Table 4). In other words, there is no effect of other variables on the relation between the between change in extension deficit and change in MHQ-(sub)scores. The explained variance was between 6.1% and 9.2% for all subscales (Table 4: bottom row).

DISCUSSION

We found that the effect size of surgery on goniometry was more than double that of the patient-reported outcome measurements. Within the patient-reported outcome measurements, we found that a decrease in extension deficit mainly improved the appearance of the hand and the satisfaction with the hand function. General hand function and ADL subscales of the MHQ also improved, but less than subscales hand appearance and satisfaction with hand function and these effects may not be clinically relevant. All of the improvements in patient reported outcomes had a positive but weak association with the improvement in extension deficit. Confounding by patient- and disease-specific characteristics was limited across most subscales. Most notably, recurrent disease, the type of treatment and the number of affected fingers did not confound the associations between the improvements in the various subscales of the MHQ and the improvement in extension deficit. The association between the improvement in extension deficit and the improvement in the 'aesthetics'-subscale is the strongest association with the highest explained variance.

These results show that the appearance of the hand might be important to patients with Dupuytren's disease, as is suggested by the large improve-

ment in the 'aesthetics'-subscale and the relative strong association with the improvement of finger goniometry compared to the more function-related subscales. This is in line with findings in patients with degenerative and inflammatory joint diseases or with traumatic injuries, which showed that despite a clear loss in function, patients have concerns about hand appearance and disfigurements.[17,18] For example, in rheumatoid arthritis, patients reported larger improvements in appearance than function or pain relief after metacarpophalangeal joint arthroplasty.[19] Since patients with Dupuytren's disease develop contractures resulting in highly visible hand deformities, similarly to patients with hand osteoarthritis, this aesthetic discomfort in Dupuytren's disease might be associated with depressive symptoms and poor health-related quality of life.[20] The discrepancy between the improvement in the 'general hand function'-subscale and 'satisfaction with hand function'-subscale is remarkable. This discrepancy suggests that patients separately assess their hand function and how satisfied they are with this function. A possible explanation is that satisfaction is determined by multiple factors including the expectations and experience of a treatment, as well as psychological and emotional factors of a patient.[21-23]

The very small effect in the 'ADL'-subscale, indicating a lack of sensitivity for evaluating the treatment effect in Dupuytren's disease, may be related to the specific, predefined tasks included in the relatively generic hand function measure. Patients with Dupuytren's disease experience a broad range of functional problems, which are not covered by the items of the ADL subscale of the MHQ. The specific tasks included in the MHQ might not be those tasks which are problematic in patients with Dupuytren's disease and patients already score near the maximum score prior to treatment. The same problems occur in other questionnaires, like the DASH and URAM.[24,25] A possible solution would be to use patient-specific PROMs, such as the Patient-Specific Functional Scale[26] or the Canadian Occupational Performance Measure,[27] which allow patients to specify tasks with which they have difficulty and score their progress. Relating the improvement in these scores to the improvement in extension deficit may give a more accurate estimate to what extent the improvement in extension deficit really does improve the performance of tasks patients seek help for.

The large loss to follow-up (60%) is a limitation of this study. This may have led to under- or overestimation of the identified associations, as it is unknown if these patients represent a group with good or poor results. However, sen-

sitivity analyses found no significant or clinically relevant differences in baseline between patients included in this study (with both goniometry and MHQ at follow-up) and patients not included in this study (Supplementary Table S1). Similarly, no significant differences were seen in goniometry and minor differences (2 points or less) in MHQ scores between included patients and patients with partial follow-up measurements (with MHQ at follow-up, but no goniometry (n = 667) and vice versa (n = 225)) (Supplementary Table S2). A second limitation in this study is the possible lack of sensitivity in the various function related subscales. Lastly, three months might be too early to notice full functional recovery following fasciectomy. However, in patients with Dupuytren's disease the time to follow-up remains a trade-off between the time to full hand function recovery and the recurrence of Dupuytren's disease, which could be as early as three months after surgery.[28]

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Supplementary Table S1. Sensitivity analyses of baseline characteristics and measurements

	Included (N = 1106)	Excluded (N = 1652)	*p*-values
Age in years, mean (sd)	63 (9)	63 (10)	0.11
Sex (% male)	75	74	0.43
Positive family history (%)	50	51	0.66
Occupational intensity (%)			0.10
Unemployed/retired	55	51	
Light (e.g. office work)	28	30	
Medium (e.g. cleaning)	13	13	
Heavy (e.g. construction work)	5	7	
Duration of disease in months, median (IQR)	24 (12-24)	18 (10-36)	0.01
Recurrence (%)	21	22	0.82
Surgery on dominant hand (%)	53	53	0.78
Type of surgery (%)			0.07
Limited fasciectomy	79	76	
Needle fasciotomy	21	24	
Number of affected fingers (%)			0.01
1	54	60	
2	35	31	
3 or more	11	9	
Most affected finger (%)			0.31
Index finger	1.5	2.1	
Middle finger	11	9.8	
Ring finger	28	31	
Pink	60	56	
TAED in degrees, mean (sd)	62 (36)	60 (39)	0.12
MHQ, mean (sd)			
General hand function	68 (16)	68 (17)	0.80
ADL	90 (14)	89 (14)	0.13
Work	85 (21)	84 (23)	0.05
Pain	76 (20)	75 (22)	0.08
Aesthetics	71 (20)	70 (21)	0.41
Satisfaction	66 (24)	66 (24)	0.96
Total	76 (14)	75 (15)	0.19

sd, standard deviation; IQR, interquartile range; TAED, Total Active Extension Deficit; MHQ, Michigan Hand Outcome Questionnaire

Supplementary Table S2. Sensitivity analyses of the follow measurements of patients with partial follow-up (either goniometry or MHQ)

	Included	Excluded	*p*-value
TAED in degrees, mean (sd)	20 (22)[1]	21 (19)[2]	0.49
MHQ-subscales, mean (sd)	[3]	[4]	
General hand function	72 (16)	71 (18)	0.21
ADL	91 (12)	89 (15)	0.01
Work	86 (21)	84 (23)	0.08
Pain	80 (19)	77 (22)	0.03
Aesthetics	83 (19)	81 (20)	0.02
Satisfaction	81 (21)	79 (23)	0.07
Total	82 (14)	81 (16)	0.01

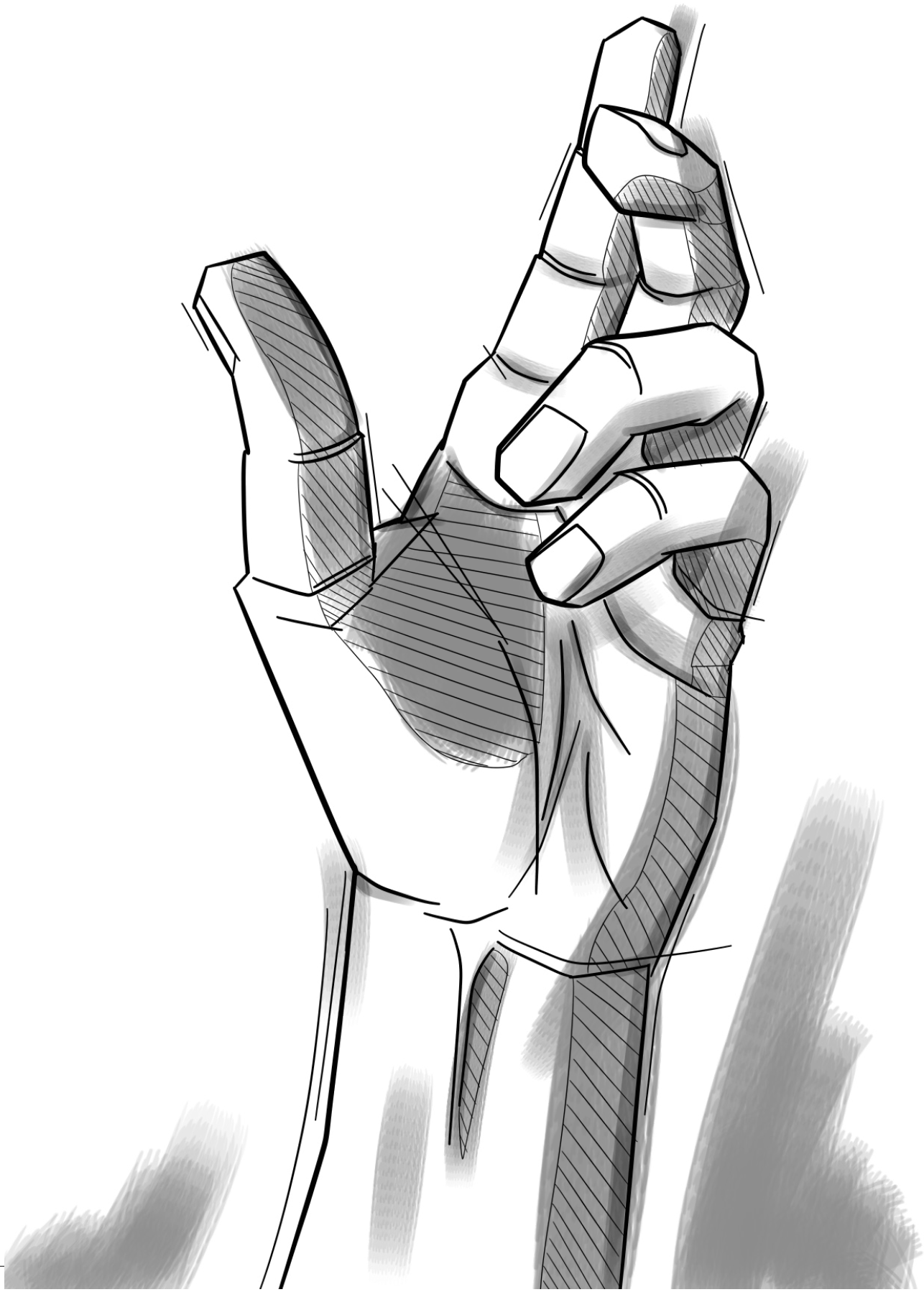
TAED, Total Active Extension Deficit; sd, standard deviation; MHQ, Michigan Hand Outcome Questionnaire

[1] N = 996

[2] N = 252, excluded: no MHQ

[3] N = 1106

[4] N = 667, excluded: no goniometry



Chapter 7

Return to work and associated costs after treatment for Dupuytren's disease.

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ABSTRACT

Background

Return to work is potentially an important factor in assessing the success of treatment. However, little is known about the return to work after treatment for Dupuytren's contracture. Therefore, the primary aim of this study is to assess return to work after limited fasciectomy and percutaneous needle fasciotomy.

Methods

Patients who underwent either a limited fasciectomy or percutaneous needle fasciotomy were invited to complete a 'return to work'-questionnaire at six weeks, three months, six months, and twelve months post-operatively. Median time to return to work was assessed using inverted Kaplan-Meier curves and hazard ratios were calculated with Cox regression models. Finally, a cost analysis was carried out in using the human capital method in order to determine indirect costs due to loss of productivity.

Results

We included 2.698 patients in the study, of which 53% were employed at intake and included in the follow-up. After one year of follow-up, 90% of the patients returned to work. Median time to return to work was two weeks after limited fasciectomy and within days after percutaneous needle fasciotomy. Furthermore, physically strenuous work, female sex, and higher age were associated with a longer time to return to work. Lost productivity per patient was estimated at €2614,43.

Conclusion

The majority of patients returned to work after treatment for Dupuytren's disease. Return to work is much faster after percutaneous needle fasciotomy compared to limited fasciectomy. These findings can be used for more evidence-based preoperative counseling with patients with Dupuytren's disease.

INTRODUCTION

In Western countries, the prevalence of Dupuytren's disease in the general population ranges between 1 and 32%,[1] with an estimated prevalence in the Netherlands of approximately 22% in those above 50 years of age.[2] Often affected patients seek medical advice due to impaired hand function caused by advanced contractures, which make it increasingly difficult to complete everyday activities.[3] Treatment, either surgical or non-surgical, is focused on restoring hand function by reducing digital contractures.

Even though Dupuytren's disease commonly affects patients at an elderly age, more than half of the patients with Dupuytren's disease are employed at the time of treatment.[4] Furthermore, Bainbridge et al. reported that 57% of patients with Dupuytren's disease report functional limitations affecting their work activities.[5] Patient-reported outcome measures, such as the Disability of the Arm, Shoulder and Hand questionnaire (DASH) and the Michigan Hand Outcome Questionnaire (MHQ) can be used to assess disability and work performance from a patient's perspective.[6,7]

Besides work performance, return to work after treatment for Dupuytren's contracture is an important factor in assessing the success of a treatment. Studies in different patient groups have demonstrated that return to work is positively associated with quality of life.[8] Opsteegh et al. reported an overall return to work rate of 49% in a very small population. More insight into the return to work after treatment for Dupuytren's disease would be beneficial when estimating the socio-economic burden of Dupuytren's disease, as well as provide helpful information for shared decision-making. Therefore, the aim of this study is to evaluate time to return to work in patients with Dupuytren's disease after undergoing a limited fasciectomy or percutaneous needle fasciotomy to study factors associated with differences in the return to work time and to calculate the indirect costs associated with absence from work.

METHODS

Study design

Patients treated for Dupuytren's disease between November 2011 and August 2017 were selected from a database maintained by Xpert Clinic, a consortium of 16 hand clinics in the Netherlands. This database and its design have previously been described.[9] In short, this database has the structure of an open inception cohort. The data is collected in a prospective matter and

analyzed retrospectively. Follow-up lasted until patients returned to work with a maximum follow-up of one year. Patients undergoing a limited fasciectomy or percutaneous needle fasciotomy (without fat grafting) were included in this study. All patients provided written informed consent for the use of their data.

As part of the general intake procedure, patients were asked if they had paid employment. Furthermore, patients who had paid employment were asked to specify how strenuous their work was (light, medium or heavy; see Table 1 for examples given to patients). Finally, patients who had paid employment were invited to complete a 'return to work'-questionnaire after treatment. Patient characteristics derived from this database were: age, sex, hand dominance, family history of Dupuytren's disease, whether surgery was for primary or recurrent disease, which joints were affected, and the number of affected fingers.

'Return to work' - questionnaire

As part of routine outcome measurements, patients with paid employment were invited to complete a 'return to work'-questionnaire at 6 weeks, 3 months, 6 months, and 12 months after treatment. Patients were asked if they returned to work and were given the following answer options: 1. Yes; 2. No, because of the hand/wrist problem I am currently being treated for; 3. No, because of something else.

If answered with 'Yes', patients were asked the following questions:

- How many hours per week do you usually work (per employment contract)?
- How many hours per week are you currently working?
- How many weeks after starting your treatment did you return to your work?
- Are you currently doing your regular work or are (temporary) adjustments made to your work?
- How many weeks after starting your treatment did you return to your regular work?

If patients answered the initial question with 'No, …' (option 2 and 3), no further questions were asked. As this study focused on return to work after treatment for Dupuytren's disease, we used answer options 1 and 2 for the analysis. This made for a more intuitive analysis. Moreover, "no, because of

something else" was the final answer in the follow-up in only a few cases, these patients were treated as lost to follow-up and therefore censored.

Cost analysis

In order to assess (indirect) costs associated with the absence of work after treatment for Dupuytren's disease, a productivity cost analysis was carried out using the human capital method. In this method, every hour not worked due to illness and treatment is considered a lost hour of work. Loss of productivity is the product of lost work hours and average productivity costs per work hour.[10] The total hours lost was calculated by multiplying the median time to return to work by the average working hours per week. In the Netherlands the cost of productivity per hour is € 32 for women and € 38 for men.[11] The cost of productivity per hour was calculated using the weighted mean of productivity costs per hour. This translated to an average of € 37.01 per hour (83.5% males, 16.5% females) for the study population.

Human capital method = total lost hours x loss of productivity costs per hour

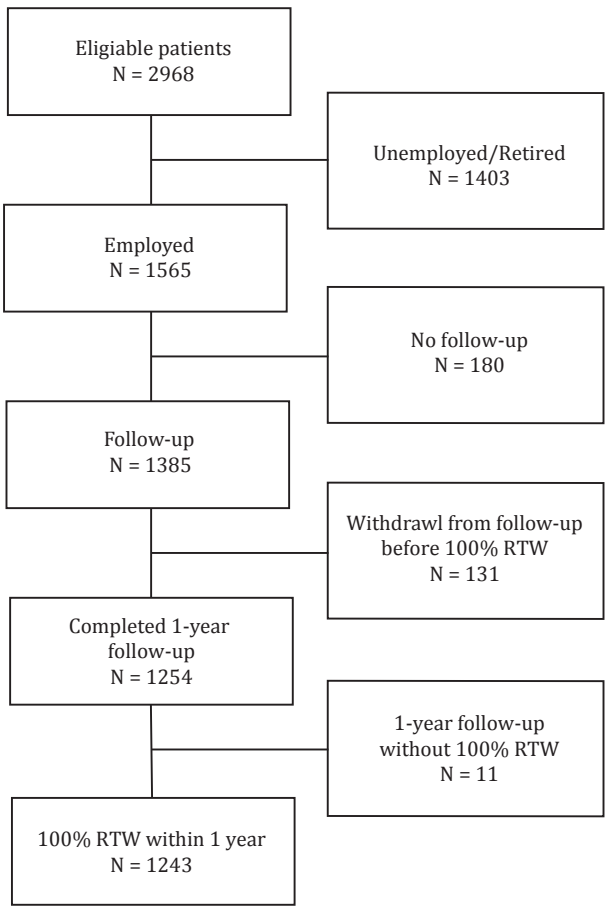
(Median time to return to work in weeks x average working hours per week) x loss of productivity costs per hour

Statistical analysis

Return to work was defined as working 100% of the contractual hours while performing regular work tasks. Time was defined as the self-reported number of weeks it took for patients to return to work. Inverted Kaplan-Meier curves were computed to determine the time to return to work overall and subgroups. Patients who withdrew or were lost from follow-up before return to work were censored when they completed their last follow-up.

In order to calculate hazard ratios, Cox regression models were created. Univariate and multivariable models were performed, including the following factors: treatment, occupational intensity, age, sex, family history, dominant hand, recurrent disease, the affected joints, and the number of affected fingers. A bivariate Cox model was computed for occupational intensity and type of surgery. The proportional hazard assumptions were checked for all Cox models with the Schoenfeld residual tests. If the proportional hazard assumption was not satisfied, time-dependent variables were created by splitting these variables into three groups: 0 - 1 week, 1 - 8 weeks, and 8 - 52 weeks. Cox regression models were stratified by these time-dependent variables. Effect plots were computed to illustrate the impact of different factors

Figure 1. Flowchart. 2968 patients underwent a limited fasciectomy or percutaneous needle fasciotomy of which 1565 (53%) patients had paid employment at intake. Of these, 1385patients completed the return to work (RTW) questionnaire. 131 patient were censored due to withdrawal from follow-up before they returned to work.



on the time to return to work. All models and curves were computed using R statistical programming (version 3.8.1).

RESULTS

We included 2968 patients in the study, of which 1565 (53%) patients were gainfully employed at intake. Of these, 1385 patients responded to the return to work questionnaire (Figure 1).

The mean age of the employed population was 57 years, most patients did light physical work (61%), and the majority of the population underwent a limited fasciectomy (79%) (Table 1). Overall, 50% of the patients returned to work by the two-week mark, 75% returned to work at four weeks, and 90% returned to work at 10 weeks. 90% of the initial 1385 patients returned to work within 12 months. No additional patients returned to work after 30 weeks. During follow-up, 131 patients (119 limited fasciectomy, 12 percutaneous needle fasciotomy) were censored due to withdrawal or lost from follow-up before they returned to work. Eleven patients (nine limited fasciectomy, two percutaneous needle fasciotomy) did not return to work within one year of follow-up. The median return to work for patients who underwent a limited fasciectomy was two weeks (IQR 1-5 weeks), compared to a median return to work of zero weeks (IQR 0-1 weeks) for patients who underwent a percutaneous needle fasciotomy (Figure 2). The 'zero weeks' is due to a lack of precision in the answering options; patients were not able to answer the question with more precision than zero or one week. The 'zero weeks' therefore reflects a return to work within days after percutaneous needle fasciotomy. The overall median return to work based on occupational intensity was one week (IQR 0-2 weeks), three weeks (IQR 1-6 weeks), and five weeks (IQR 2-16 weeks) for light, medium, and heavy physical work, respectively. Figures 3a and 3b illustrate the return to work based on occupational intensity for patients undergoing a limited fasciectomy and needle fasciotomy, respectively.

The overall cost of loss of productivity per patient was € 2614.43, based on the time they were not able to attend work. For the patients who underwent limited fasciectomy, the cost of loss of productivity per patient was € 2638.64; for percutaneous needle fasciotomy, this number was €180.93. Based on occupational intensity, the cost of loss of productivity was € 1323.02 for light work, € 3697.85 for medium work, and € 6966.57 for heavy work.

The hazard ratios extracted from the Cox models, indicating the probability of one group returning to work, varied little between univariate and multi-

Table 1. Patient characteristics (N = 1385)

Age in years, mean (sd)	57 (7)
Sex (male)	1156 (84%)
Type of surgery	
Limited fasciectomy	1087 (79%)
Needle fasciotomy	298 (21%)
Occupational Intensity	
Light (e.g. office work)	841 (61%)
Medium (e.g. cleaning)	371 (27%)
Heavy (e.g. construction work)	173 (12%)
Surgery on dominant hand	733 (53%)
Recurrent disease	328 (24%)
Positive Family history	748 (54%)
Number of affected fingers	
1	738 (53%)
2	421 (30%)
3 or more	116 (8.4%)
Missing	110 (7.9%)
Affected joints	
MCP	255 (18%)
PIP	351 (46%)
MCP and MCP	630 (25%)
Missing	149 (11%)

sd, standard deviation

variable models, indicating little confounding. Males returned to work sooner than females and younger patients returned to work sooner than their older counterparts (Table 2). Patients who had three or more fingers affected took longer to return to work. PIP involvement was not associated with a longer time to return to work. Time-dependent variables were calculated for 'type of treatment' and 'occupational intensity', as the proportional hazard assumption was not met for these two variables (Table 3). The hazard ratio between the type of treatment in time period 1 (0-1 week) was 3.18 (95% CI: 2.72- 3.74), indicating that the probability of a patient who underwent a percutaneous needle fasciotomy to return to work in the first week after the surgery was 3.18 times as high as a patient who underwent a limited fasciectomy. However, this effect was not observed in time period 3 (>8 weeks), meaning that after eight weeks, the type of treatment no longer influences the probability of returning to work. Similar results were observed for the occupational intensity, where in the first eight weeks (time period 1 and 2), patients who did more physically strenuous work had a lower probability of returning to work in comparison to patients who did less physically strenuous work. Effect plots illustrate the effect of 'type of surgery' and 'occupational intensity' on the return to work (Supplementary Figure 1 and 2).

DISCUSSION

The aim of this study was to evaluate time to return to work after surgical treatment for Dupuytren's contracture and the associated, indirect costs. We found that the median return to work after percutaneous needle fasciotomy and limited fasciectomy was within days and two weeks, respectively. In addition, physically strenuous work, female sex, older age, and three or more affected fingers are associated with a longer return to work times. The cost of loss of productivity per patient was €2614.43; the costs were lower in patients who underwent percutaneous needle fasciotomy compared to those who underwent limited fasciectomy and increasing costs were observed in patients with more strenuous work.

Our findings on return to work in Dupuytren's disease are in line with other, although limited, findings in literature. In a mixed population of hand patients, Opsteegh et al. reported an overall return to work of 49%, where the very small population of patients with Dupuytren's contractures included in this study had a return to work of 100%.[12] In our population, 90% of the patients returned to work. However, the patients not returning to work were mainly those who did not complete the follow-up and were censored accord-

Figure 2. Inverted Kaplan-Meier curve for percutaneous needle fasciotomy (PNF) and limited fasciectomy (LF). Complete follow-up is 52 weeks. No additional patients returned to work after 30 weeks. Number at risk implies the patients who could potentially return to work at a given time. Median return to work was within days and 2 weeks for PNF and LF, respectively. 25% returned to work 0 week and 1 weeks after PNF and LF, respectively. 75% returned to work 1 week and 5 weeks after PNF and LF, respectively. 90% returned to work 4 weeks and 14 weeks after PNF and LF, respectively.

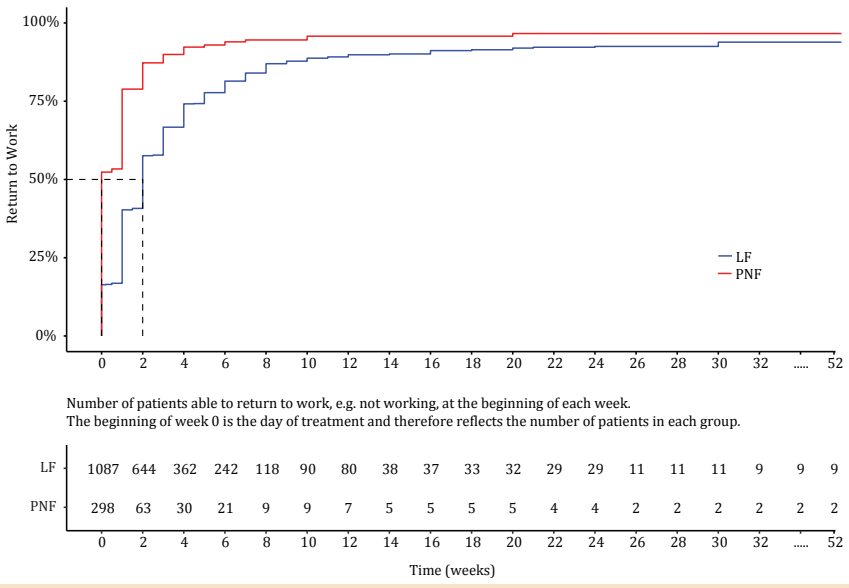
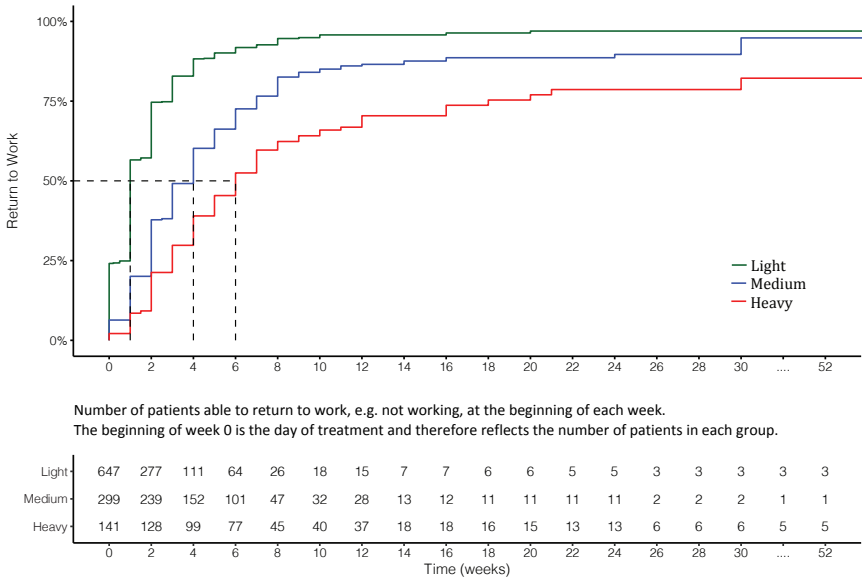


Figure 3a. Inverted Kaplan-Meier curve for patients undergoing limited fasciectomy. Complete follow-up is 52 weeks. No additional patients returned to work after 30 weeks. Number at risk implies the patients who could potentially return to work at a given time. Median return to work for light, medium and heavy work was one week, four weeks and six weeks, respectively (dashed lines). Interquartile ranges for light, medium and heavy work were 1-3 weeks, 2-7 weeks, 3-18 weeks, respectively.

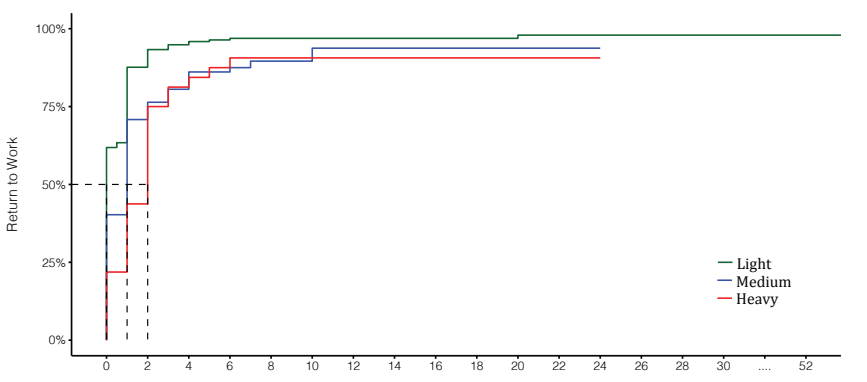


Number of patients able to return to work, e.g. not working, at the beginning of each week.
The beginning of week 0 is the day of treatment and therefore reflects the number of patients in each group.

	0	2	4	6	8	10	12	14	16	18	20	22	24	26	28	30	....	52
Light	647	277	111	64	26	18	15	7	7	6	6	5	5	3	3	3	3	3
Medium	299	239	152	101	47	32	28	13	12	11	11	11	11	2	2	2	1	1
Heavy	141	128	99	77	45	40	37	18	18	16	15	13	13	6	6	6	5	5

Time (weeks)

Figure 3b. Inverted Kaplan-Meier curve for patients undergoing needle fasciotomy. Complete follow-up is 52 weeks. No additional patients returned to work after 30 weeks. Number at risk implies the patients who could potentially return to work at a given time. Median return to work for light, medium and heavy work was zero weeks, one week and two weeks, respectively (dashed lines). Interquartile ranges for light, medium and heavy work were 0-1 week, 0-2 weeks, 1-2 weeks, respectively. Last patients able to return to work were censored at six months (or 26 weeks) before returning to work.



Number of patients able to return to work, e.g. not working, at the beginning of each week.
The beginning of week 0 is the day of treatment and therefore reflects the number of patients in each group.

	0	2	4	6	8	10	12	14	16	18	20	22	24	26	28	30	....	52
Light	194	24	10	7	3	3	3	3	3	3	3	2	2	2	2	2	2	2
Medium	72	21	14	10	5	5	3	1	1	1	1	1	1	0	0	0	0	0
Heavy	32	18	6	4	1	1	1	1	1	1	1	1	1	0	0	0	0	0

Time (weeks)

Table 2. Hazard ratios of the non-time dependent variables with 95% confidence intervals (CI) in the univariate and multivariable models. The multivariable model included all mentioned variables, as well as the time dependent variables 'type of treatment' and 'occupational intensity' (see Table3).

Variables	Univariate Hazard ratio (95% CI)	Multivariable Hazard ratio (95% CI)
Age	1.0 (1.00- 1.01)	0.99 (0.98- 1.00)*
Female sex	0.80 (0.68- 0.94)*	0.74 (0.62- 0.88)*
Surgery on dominant hand	1.04 (0.93- 1.16)	0.96 (0.85- 1.08)
Recurrent disease	0.98 (0.87- 1.12)	1.04 (0.90- 1.20)
Family history	0.97 (0.87- 1.08)	0.98 (0.87- 1.10)
Number of affected fingers		
1	REF	REF
2	0.85 (0.75-0.97)*	0.88 (0.78-1.01)
3 or more	0.71 (0.57-0.88)*	0.72 (0.58-0.89)*
Affected joints		
MCP	REF	REF
PIP	0.81 (0.68-0.96)*	1.11 (0.93-1.34)
MCP and PIP	0.82 (0.70-0.95)*	1.02 (0.87-1.19)

*p<0,05

Table 3. Hazard ratios of the time dependent variables with 95% confidence intervals (CI) for the univariate, bivariate and multivariable models. The bivariate model included the time dependent variables 'type of treatment' and 'occupational intensity'. The multivariable model included the variables mentioned in Table 2, as well as the time dependent variables 'type of treatment' and 'occupational intensity'.

	Univariate model Hazard ratios (95% CI)			**Bivariate model Hazard ratios (95% CI)**			**Multivariable model Hazard ratios (95% CI)**		
Occupational intensity	0-1w	1-8w	8-52w	0-1w	1-8w	8-52w	0-1w	1-8w	8-52w
Light	REF	REF	REF	REF	REF	REF	REF	REF	REF
Medium	0.16 (0.11-0.24)*	0.42 (0.34-0.55)*	1.12 (0.46-2.77)	0.36 (0.29-0.44)*	0.61 (0.50-0.73)*	1.29 (0.51-3.26)	0.36 (0.29-0.46)*	0.64 (0.52-0.78)*	1.31 (0.51-3.40)
Heavy	0.35 (0.29-0.43)*	0.61 (0.50-0.73)*	1.31 (0.53-3.29)	0.16 (0.11-0.23)*	0.43 (0.34-0.55)*	1.09 (0.43-2.73)	0.16 (0.10-0.24)*	0.43 (0.33-0.56)*	0.98 (0.38-2.57)
Type of surgery									
Limited fasciectomy	REF	REF	REF	REF	REF	REF	REF	REF	REF
Needle Fasciotomy	3.18 (2.71- 3.74)*	1.09 (0.81- 1.48)	0.81 (0.25- 2.65)	3.19 (2.72- 3.75)*	1.07 (0.79- 1.45)	0.81 (0.25- 2.79)	3.42 (2.85- 4.10)*	1.11 (0.77- 1.56)	0.66 (0.15- 2.91)

*p<0.0001

ingly. In contrast, those patients who did complete the follow-up almost all returned to work. The 90% of patients returning to work is, therefore, likely an underestimation of the total of patients returning to work. No patients returning to work after 30 weeks highlights what has been previously found in work-related studies; the chance of returning to work decreases as time on sick leave increases.[13,14] Percutaneous needle fasciotomy is less invasive and has a shorter recovery time than limited fasciectomy.[15,16] Rodrigo et al. described a recovery time of 21-58 days for limited fasciectomy, defined as the time from operation to return to work, without further therapy.[17] Patients who undergo percutaneous needle fasciotomy can use their hands optimally one week after surgery.[18] Since 1976, when the study of Rodrigo et al. was published, the operation and postoperative practices have improved. Hovius et al. reported a return to work time of 2-4 weeks in patients with Dupuytren's disease, similar to our findings.[19] Other return to work research focuses on different patient populations: for example, Bruyns et al. found a mean time off work of 31 weeks in patients who had median or ulnar nerve damage. Pain is associated with a prolonged return to work but is not a typical symptom of Dupuytren's disease,[20] which may explain the relatively short return to work time in patients with Dupuytren's disease compared to patients other hand problems.[12,21,22]

In general, patients who have work which predominantly involves manual labor have longer periods off work compared to patients who predominantly work behind a desk[21,23] after treatment for hand conditions or injuries, which is also reflected by the differences between the occupational intensity categories in the current study and can probably be explained by the different physical demands of the job.[12,24] In our study, patients who had three or more affected fingers took longer to return to work. Although data on the extent of the surgery is not available, the involvement of more fingers arguably leads to a more extensive surgery, which leads to a longer recovery and postponed return to work. Interestingly, PIP involvement is not associated with a longer time to return to work. The effect on return to work is explained by other variables such as the type of treatment, as can been seen by the change in coefficients between the univariate and multivariable model. Patients with significant PIP involvement are probably more likely to undergo a limited fasciectomy which explains the longer return to work. Hovius et al. reported that males return to work sooner than females, supporting our findings.[19] In the Netherlands men are more commonly the primary earner within the household,[25] making their need to go back to work more pronounced. Increasing age is associated with

long-term sick leave.[14,20] Getting older comes with many physical changes that can influence the return to work time; older patients often have more comorbidities, decreased physical function, and delayed recovery in comparison to younger individuals.[26]

Macaulay et al. reported risk-adjusted indirect costs of €2492,46 for patients with Dupuytren's disease,[27] a number comparable to our estimation. When compared to other common hand disorders, such as rheumatoid arthritis and carpometacarpal arthritis, the costs associated with loss of productivity are much less in Dupuytren's disease.[28,29] Costs of loss of productivity for those who underwent percutaneous needle fasciotomy were much lower than for those who underwent limited fasciectomy, which can be expected given the difference in median return to work time. However, recurrent contractures are more frequent after percutaneous needle fasciotomy,[30] making the need for additional procedures and, thus, additional costs more likely. How this affects long-term costs is currently unknown and cannot be determined using his study, as follow-up is limited to one year.

The current study indicates a shorter median time to return to work after a percutaneous needle fasciotomy compared to a limited fasciectomy. Although this could be an important consideration for patients, return to work is not the only consideration in the decision for a certain treatment. Other important considerations could be complication rates, expected severity of complications, and recurrence rates. Furthermore, percutaneous needle fasciotomy and limited fasciectomy have their own indications depending on the severity of the disease. Nonetheless, insight into the estimated time to return to work can be helpful in shared decision making for both patients and physicians.

The main strengths of this study are the large sample size, the longitudinal nature of the data, and low loss to follow-up. However, this study does have some limitations. Absenteeism is most likely dependent on local legislation and guidelines. Sick leave is tightly regulated in The Netherlands. Most notably, employers are obliged to pay a minimum of 70% of the employee's monthly wage in the first two years of sickness or work disability. Moreover, many employers agreed to diverge from this rule and pay 100% of the wages during the first year of absence. However, strict rules are enforced to avoid abuse of these compensations, including obligatory visits to independent occupational physicians determining the employee's ability to work and, if possible, reintegration to work by doing alternative tasks at work. In counties

where sick leave is regulated differently, other incentives to return to work might arise, such as pressure from employers to return to work or financial incentives, which might limit the generalizability of the current study. On the other hand, the effect of factors such as the type of surgery and type of work that we found in our study may still be similar across countries. Furthermore, information on whether patients were self-employed was not available. If a patient is self-employed, they do not benefit to the same extent from Dutch legislation and guidelines. These patients might have financial incentives to return to work earlier, unless they have insurance covering their sick leave, further complicating matters. However, we assume that the potential influence of these rules and laws is limited as the current estimates for return to work showed a rapid return to work. Finally, the disease severity and the extent of the surgery could influence the return to work. To account for this, which joints are affected and the number of affected fingers are taken into account in the analysis. Although these factors do not completely correlate with disease severity and extent of surgery, they most likely represent a significant portion of the extent of the surgery.

In conclusion, this study demonstrates that return to work after treatment for Dupuytren's contractures is high and relatively short for both needle fasciotomy and limited fasciectomy, although much shorter after needle fasciotomy. In addition to the type of treatment, patients with physically demanding employment take longer to return to work. Furthermore, the cost of loss of productivity for Dupuytren's disease seems to be lower than for other illnesses. These results can be helpful in informing patients about treatment options during preoperative counseling.

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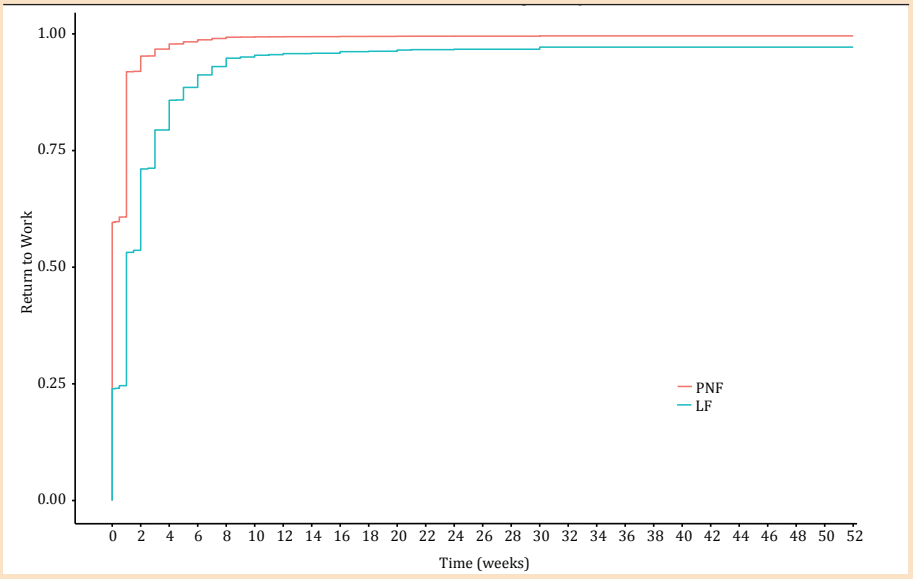
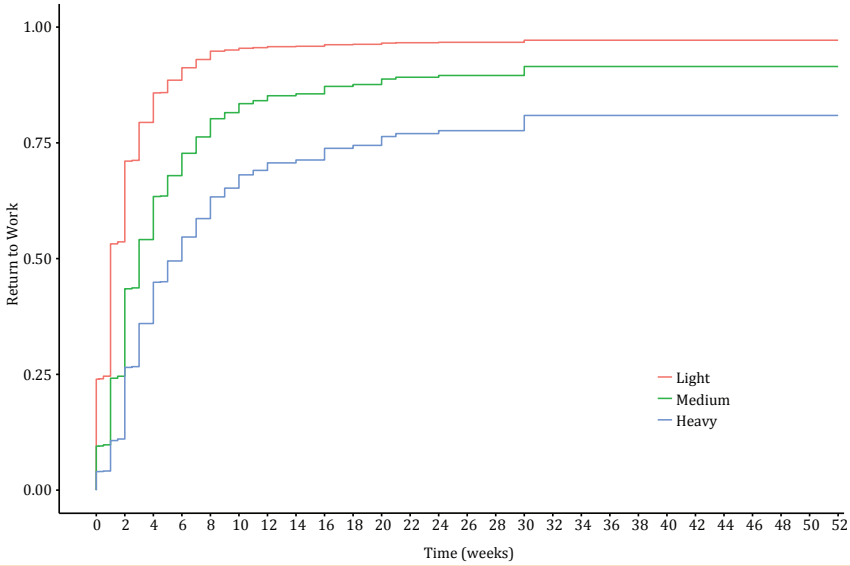
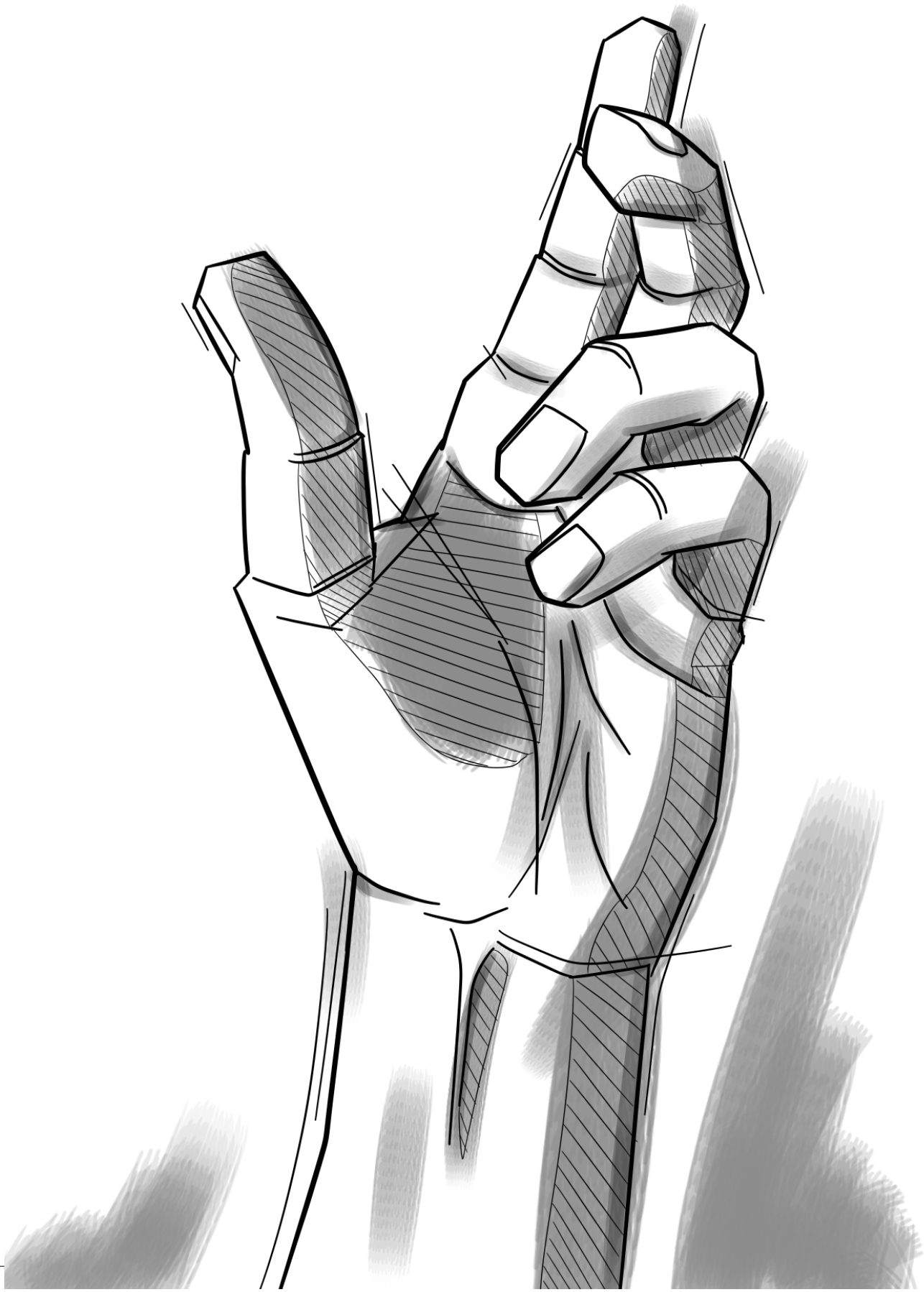
Supplementary Figure 1. Probabilities of returning to work by a given point in time based on the multivariable model. To illustrate the effect of treatment, all other variables are kept constant. Here, the probability of returning to work by a given point in time of a 60-year old, male patient with primary disease of the dominant hand, light occupational intensity and positive family history is illustrated. The probability of this specific patient for returning to work after 52 weeks is 0.972 and 0.996 for LF and PNF, respectively.



Supplementary Figure 2. Probabilities of returning to work by a given point in time based on the multivariable model. To illustrate the effect of occupational intensity, all other variables are kept constant. Here, the probability of returning to work by a given point in time of a 60-year old , male patient with primary disease of the dominant hand and a positive family history undergoing a limited fasciectomy is illustrated. The probability of this specific patient for returning to work after 52 weeks is 0.972, 0.915 and 0.809 for light, medium and heavy work, respectively.





Chapter 8

Outcome of recurrent surgery in Dupuytren's disease; comparison with initial treatment.

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ABSTRACT

Background

There are multiple studies about the effectiveness of primary treatment in Dupuytren's disease. However, such studies concerning treatment effectiveness of recurrent disease are scarce. Therefore, the primary aim of this study is to compare treatment effectiveness of initial and repeated surgery in patients with Dupuytren's disease.

Methods

Patients who underwent both initial and repeated treatment were selected from a prospectively maintained database. Outcome measurements consisted of finger goniometry, the Michigan Hand Outcomes Questionnaire (MHQ) and complications. Treatment effectiveness was defined as improvement in extension deficit and patient-reported hand function. In addition, measurements at intake of both treatments were compared. Subgroup analysis were done to evaluate influence of type of surgery of initial treatment on outcomes of repeated treatment.

Results

114 Patients were included in the final analyses. Improvement in extension deficit and MHQ outcomes was equal for initial and repeated treatments. Extension deficit and MHQ were worse at intake of repeated treatment compared to these outcomes at intake of initial treatment. In addition, patients who initially underwent needle fasciotomy achieved a better contracture reduction after repeated treatment.

Conclusion

This study demonstrates that treatment of recurrent Dupuytren's disease is as effective as initial treatment, despite larger extension deficit and worse self-assessed hand function before undergoing repeated treatment. Complication rates were similar for initial and repeated treatments. Furthermore, needle fasciotomy for initial treatment results in better outcomes of repeated treatment compared to patients who initially underwent limited fasciectomy. These findings can be used for a more evidence-based preoperative counseling with patients with recurrent Dupuytren's disease.

INTRODUCTION

Dupuytren's disease is a progressive disease of the hand involving fibrotic strands in the palmar fascia, which leads to formation of cords, nodules and contractures of the affected fingers and eventually loss of hand function.[1,2] Depending on various factors, such as the chosen operation and the aggressiveness of the disease, recurrence of contracture formation occurs over time, subsequently leading to deterioration of the hand function and the need for new treatment.[3]

Although there is increasing evidence of primary treatment efficacy,[4-6] little is known about the success of treatment of recurrent disease, i.e. to what extent the same reduction in contracture can be achieved. Two earlier studies on this topic showed that when percutaneous needle fasciotomy is used for repeated treatment it is just as effective as when it is used for initial treatment.[7,8] Other studies did subgroup analyses for different treatments in recurrent Dupuytren's disease to evaluate whether they were equally effective, however these studies did not compare the effectiveness between initial and repeated treatment.[4,9] Increasing this knowledge would benefit the preoperative counseling of patients with recurrent Dupuytren disease, as patients require well-balanced, preferably evidence-based, information to opt for a certain treatment. Furthermore, it is unknown how the contracture degree at intake compares to the degree of contracture on repeated treatment; knowledge on this may indicate whether patients are inclined to elect surgery with a larger or smaller contracture at the second treatment. Also, it is unknown to what extent the success of repeated treatment is influenced by the treatment choice at initial treatment. For example, it has been argued that needle fasciotomy has a relatively high recurrence rate but that recurrent surgery can be successfully performed after initial fasciotomy.[7] However, a comparison of the success of recurrent surgery after different initial treatments has not been reported.

The primary aim of this study is to compare differences in treatment effectiveness of initial and repeated surgery in patients with Dupuytren's disease. In addition, we will compare contracture rate and hand function at intake of initial and repeated treatment in the same patients, to determine if patients undergo surgery at different levels of contracture rates and hand function levels. Furthermore, we will evaluate if the treatment effect of the repeated treatment was different for patients that initially underwent limited fasciectomy or needle fasciotomy.

METHODS

Patient population

Patients were selected from a database with outcome data from a consortium of 16 hand surgery practice sites in the Netherlands. This database with routine outcome measurement is designed for both clinical and research purposes. Outcome measurements consisted of finger goniometry prior to treatment and 3 months afterwards. Furthermore, patients were invited to complete a PROM questionnaire prior to surgery and three months afterwards. Two reminders were mailed to non-responders.

We selected all patients who underwent initial treatment for Dupuytren's contractures and repeated treatment for the recurrence of Dupuytren's contractures on the same finger(s) between 2011 and 2017 and with goniometry measurements on baseline of both treatments. No further exclusion criteria were applied.

Patient- and disease-specific characteristics were derived from this database including age, sex, occupational status, current tobacco and alcohol use, family history of Dupuytren's disease and hand dominance. Complications for each treatment were documented and grouped in categories. The local institutional review board approved the study and all patients provided written informed consent.

Treatment

Treatments were performed by certified hand surgeons, all with multiple years of experience in hand surgery. The timing and type of treatment was based on shared decision-making; the participating practice sites did not have specific guidelines concerning the timing and type of treatment. However, the Dutch guidelines do suggest limited fasciectomy as standard treatment, where needle fasciotomy can be used in cases with a palpable cord and if patients accept the higher probability of a recurrence.[10] The various treatments, being collagenase, needle fasciotomy, limited fasciectomy without or with skin graft, were performed according to standardized protocols. A more extensive description of these treatments has been reported earlier in three comparative studies.[4,9,11] All treatments were covered by healthcare insurances, except collagenase, which was for a short period temporarily provided by the manufacturer, leading to a short period that collagenase was administered to eligible patients.

Measurements

Certified hand therapists assessed the degree of total residual contracture. The degree of extension of isolated finger joints in the affected finger(s) was measured with a goniometer. The total residual contracture was calculated per finger as the sum of the deficit of the metacarpophalangeal, proximal interphalangeal and distal interphalangeal joint (Total Active Extension deficit, TAED). Any measured hyperextension was converted to 0 degrees to prevent underestimation of the total active extension deficit. When multiple digits were affected, we only used the measurements pertaining to the most severely contracted digit at intake. As a measure of treatment effectiveness, the change between the pre- and post-operative TAED was calculated for each patient.

Patients completed the Michigan Hand Outcomes Questionnaire (MHQ) to assess the hand function from a patient perspective. This hand-specific PROM contains six domains of hand function: overall hand function, activities of daily living, work performance, pain, aesthetics and patient satisfaction with hand function. The questions are answered by means of a five-point Likert scale which is converted to a scale from 0 (poorest function) to 100 (best function) according to the questionnaire's developer's instructions.[12] Only the scores pertaining to the treated side were used. As a measure of treatment effectiveness, the change between the pre- and post-operative MHQ-(sub)scores was calculated for each patient.

Statistical analyses

For the primary analysis, to compare differences in treatment effectiveness of initial and repeated surgery, we compared the change in scores in goniometry and MHQ scores of both interventions using a student's T-test for normally distributed data and a Wilcoxon signed rank test for non-normally distributed data. Distribution of the data was evaluated with histograms and QQ norm plots.

As a secondary analysis, we compared contracture rate and hand function at intake of initial and repeated treatment, to determine if patients undergo surgery at different contracture rates and hand function levels. As above, we used the student's T-test and Wilcoxon signed rank test, depending on whether or not the data is normally distributed, to determine any significant difference. Finally, we evaluated if the treatment effect of the repeated treatment was dif-

ferent for patients that initially underwent fasciectomy or needle fasciotomy using either an unpaired t-test or Wilcoxon rang sum test, again depending on whether or not the data is normally distributed. The significance threshold for all tests was set at 0.05.

A power analyses was performed to calculate the necessary sample size for the primary analysis (comparison of treatment effectiveness). A sample size of 34 patients would provide a power of 80%, given a significance threshold of 0.05 and an expected effect size of 0.5 for the change in goniometry.

RESULTS

A total of 114 patients, 77 men and 37 women with a mean age of 59,5 ± 12 years, were included in the final analysis (Table 1). The mean time between the two successive operations was 114 ± 57 weeks. In the majority of the patients, the initial treatment was a needle fasciotomy (45%) or limited fasciectomy (40%), whereas most patients (79%) underwent a limited fasciectomy for their recurrent contracture (Figure 1). No Boutonniere deformities

Table. 1 Patient characteristics at baseline of initial and repeated treatment (N = 114)

	Initial treatment	Repeated treatment
Age (mean (sd))	60 years (12)	62 years (12)
Sex (male)	66%	66%
Positive family history	57%	57%
Occupational intensity		
Unemployed/retired	33%	47%
Light (e.g. office work)	40%	36%
Medium (e.g. cleaning)	17%	11%
Heavy (e.g. construction work)	10%	6%
Surgery on dominant hand	58%	58%
Little finger most affected*		
Limited fasciectomy	30 out of 47 (64%)	59 out of 92 (64%)
Needle fasciotomy	27 out of 53 (51%)	7 out of 16 (44%)
Collagenase	8 out of 12 (67%)	1 out of 1 (100%)
Dermatofasciectomy	2 out of 2 (100%)	4 out of 5 (80%)

*numbers reflect the number of cases where the little finger was most affected finger *out of* the total number of cases done with this procedure.

or other abnormalities potentially confounding the data were seen. Various patients did not return for follow-up goniometry and/or did not complete the MHQ. Follow-up measurements for the goniometry were available in 57 and 48 patients in the initial and repeated treatment, respectively. The MHQ was completed in 94 and 86 patients at the intake of the initial and repeated treatment, respectively, and in 66 and 57 patients at follow-up.

After the initial treatment eight complications (7% of all initial treatments) were documented and after repeated treatment 16 complications (14% of all repeated treatments) were documented. When separating complications based on the type of treatment, limited fasciectomy and needle fasciotomy

Figure 1. Distribution of the combination of initial and repeated treatments in percentages. The x-axis indicates the initial treatments, the y-axis the repeated treatments. The numbers below the x-as indicate the distribution at initial treatment; the numbers left of the y-axis the distribution of the repeated treatment. This shows, for example, that 41% of the patients underwent a limited fasciectomy for their initial therapy and 80% limited fasciectomy for the repeated treatment. The numbers within the graph indicate the distributions of all possible combinations. This, for example, shows that the majority of patients (39%) underwent limited fasciectomy as both initial and repeated treatment and that 36% of the patients had needle fasciotomy as an initial treatment and limited fasciectomy for the repeated treatment.

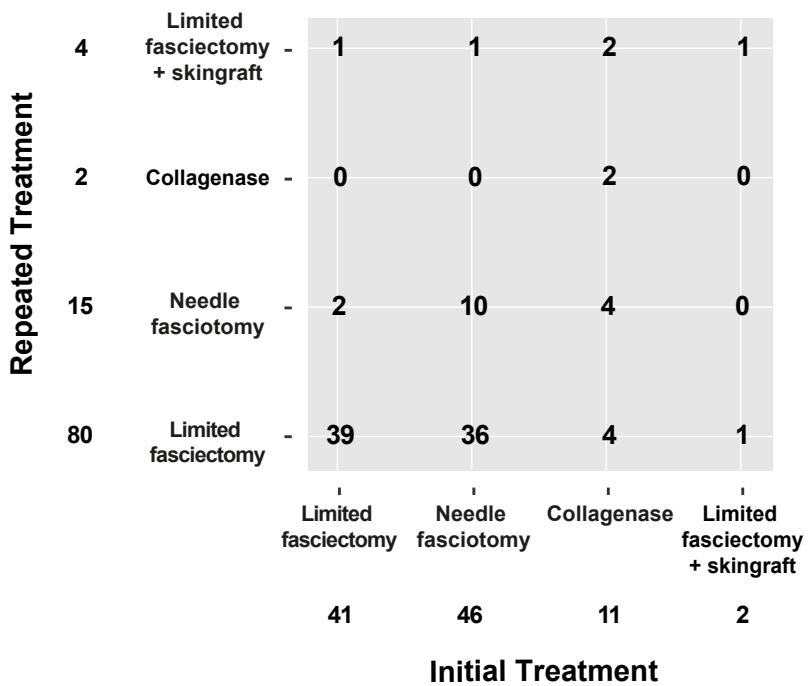

Table 2. Number of complications grouped by timing and type of treatment. Other treatments included one collagenase injection (sensibility) and two dermofasciectomies. For the initial treatment this group is not shown as no complications were seen in this group.

	Initial treatment		Repeated treatment		
Complication	**LF (n = 47)**	**PNF (n = 53)**	**LF (n = 91)**	**PNF (n = 17)**	**Other (n = 6)**
Sensibility[1]	1	2	4	1	2
Scars/Adhesions[2]	3	0	3	0	0
Infection/Inflammation[3]	1	1	3	0	0
Other	0	0	2[4]	0	1[5]
Total	5 (11%)	3 (5.6%)	12 (13%)	1 (6.6%)	

LF, Limited fasciectomy; PNF, percutaneous needle fasciotomy

[1] Includes numbness, burning and tingling sensation, pain

[2] Includes scar contractions, hypertrophic scar tissue adhesions of tendons

[3] Includes infection (with antibiotic treatment and/or surgical treatment) and prolonged inflammation

[4] one transient winging of scapula (due to plexus block), one Swanneck deformity after surgery.

[5] one transient winging of scapula (due to plexus block)

Table 3. Pre- and postoperative extension deficits for the initial and repeated treatment. Total extension deficit is the sum of the deficit of the metacarpophalangeal, proximal interphalangeal and distal interphalangeal joint. For significance levels see Table 4.

	Initial treatment		Repeated treatment	
Extension deficit in degrees (mean(sd))	**Intake**	**3 months post-op**	**Intake**	**3 months post-op**
MCP	22.6 (22.2)	3.0 (5.0)	22.1 (21.0)	4.5 (8.1)
PIP	27.8 (26.5)	18.4 (16.7)	34.9 (24.6)	19.0 (16.5)
Total	53.8 (29.7)	22.8 (17.2)	60.3 (28.2)	24.8 (18.7)

MCP, metacarpophalangeal joint; PIP, proximal interphalangeal joint

had similar complication rates (Table 2) although no formal statistics were used to compare these groups as the number of complications is low. For example, one more complication in the initial limited fasciectomy group would result in a complication rate of 13%, similar to the repeated limited fasciotomy group.

Comparison of the treatment effectiveness of initial and repeated surgery showed that both treatments equally improved contracture rate (Figure 2A, Table 3 and 4). Similarly, patient-reported hand function improved equal in both treatments in three subscales of the MHQ (Figure 2B and Table 4).

In the secondary analysis, we compared contracture rate and hand function at intake of initial and repeated treatment. Prior to repeated treatment patients had, on average, a worse TAED of 6.5 degrees and worse patient-reported hand function compared to before their initial treatment (Figure 2, Table 3 and 4).

Finally, we evaluated whether the treatment effect of the repeated treatment was different for patients that initially underwent fasciectomy (n = 42) or needle fasciotomy (n = 52). Of the 42 patients who initially underwent a limited fasciectomy, 83% underwent a limited fasciectomy in their repeated treatment again. The 52 patients who underwent a needle fasciotomy 75% underwent a limited fasciectomy for their repeated treatment. Evaluation of the subgroups showed that the contracture reduction in the repeated treatment was significantly better in those patients that initially underwent a needle fasciotomy compared to those that underwent a limited fasciectomy, respectively 40 and 24 degrees (*p*-value = 0.049; see right part of Figure 2A).

DISCUSSION

This study found that the treatment of recurrent Dupuytren's disease is as effective as the initial treatment in reducing contracture correction and improving patient-reported hand function. In addition, we found that patients with recurrent Dupuytren's disease have a larger extension deficit and a worse self-assessed hand function before undergoing repeated treatment compared to the initial treatment. Furthermore, our results suggest that patients who initially underwent needle fasciotomy had a better contracture reduction in their repeated treatment compared to those who initially underwent a limited fasciectomy.

To our knowledge, only two studies did examine post-operative results in

Figure 2. Pre- and postoperative measurements for the initial and repeated treatment. Both graphs indicate mean values at baseline and 3 month follow-up with error bars representing the standard deviation. 2A: goniometry of all treatment combined and for limited fasciectomy (LF) and needle fasciotomy (NF) separate. 2B: MHQ-score (points) and treatment effect (line) for the various subscales. For significance levels see Table 4.

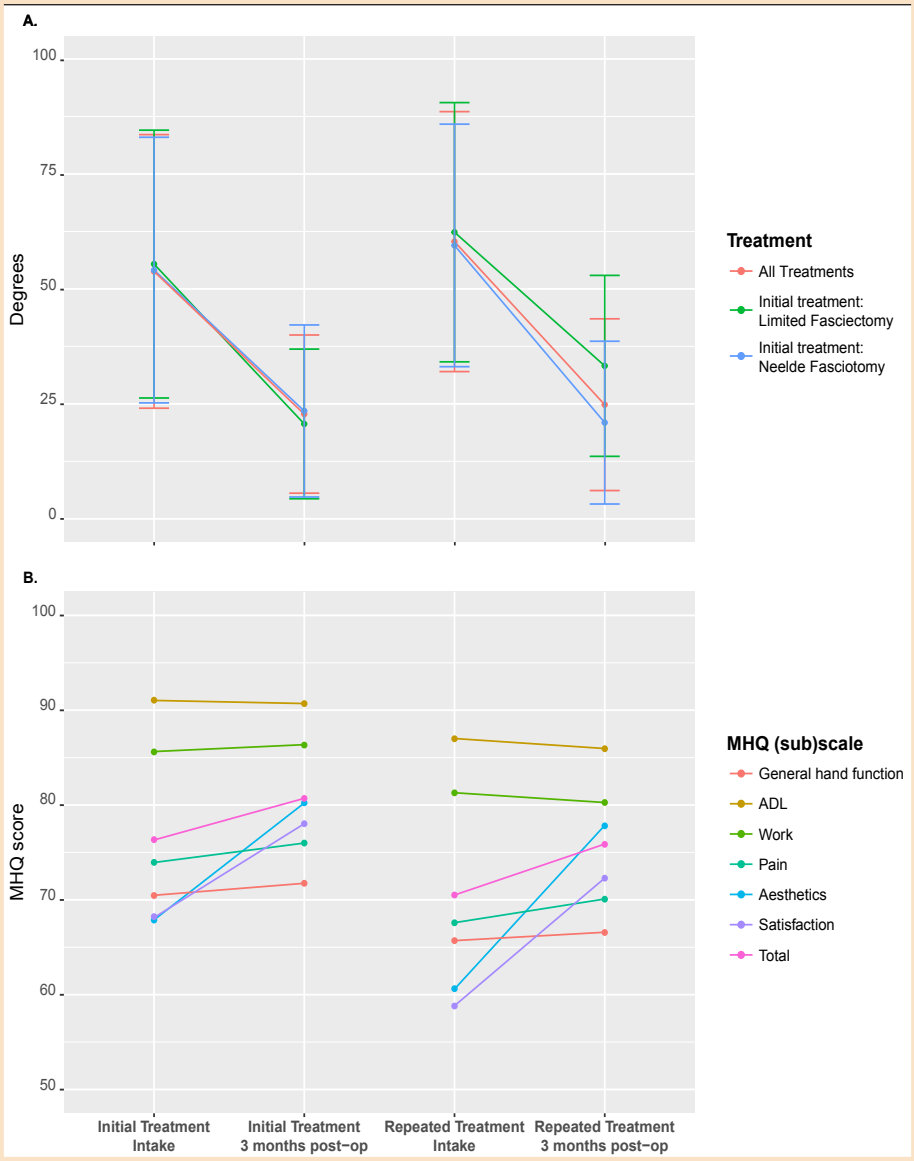

Table 4. P-values for the various differences: between intake and 3 months post-operative (first and second column), between the intake of the initial and repeated treatment (third column; primary analysis) and between the treatment effectiveness of the initial and repeated treatment (fourth column). The difference in treatment effectiveness between patients who underwent either LF or NF as initial treatment was significant (p-value = 0.049). All other differences were not significant (p-value >0.05) (not shown in Table 4).

	***Baseline vs follow-up of* initial treatment**	***Baseline vs follow-up of* repeated treatment**	***Difference in change between both* treatments**	***Difference at* intake between initial and repeated treatment**
TAED	*<0.01*	*<0.01*	*0.13*	*0.01*
MHQ-scores				
General hand function	*0.59*	*0.079*	*0.26*	*<0.01*
ADL	*0.94*	*0.76*	*0.61*	*<0.01*
Pain	*0.49*	*0.76*	*0.56*	*<0.01*
Work	*0.75*	*0.84*	*0.20*	*0.06*
Aesthetics	*<0.01*	*<0.01*	*0.05*	*<0.01*
Satisfaction	*<0.01*	*<0.01*	*0.45*	*<0.01*
Total	*<0.01*	*<0.01*	*0.11*	*<0.01*

TAED, Total Active Extension Deficit; ADL, Activities of Daily Living

patients with recurrent contractures. However, both only focus on needle fasciotomy as repeated treatment, with the conclusion that needle fasciotomy can be applied effectively for recurrent disease.[7,8] Therefore, our study provides new insights in the treatment of recurrent Dupuytren's disease. The equal treatment effectiveness of the repeated surgery compared to the initial treatment shown in our study is important in the preoperative counseling of patients with recurrent Dupuytren's disease.

At first sight, the complication rate appears to be twice as high after repeated treatment compared to initial treatment (14% against 7%). However, twice as much limited fasciectomies were performed as a repeated treatment, a procedure associated with more complications. When comparing complication rates in both limited fasciectomy and needle fasciotomy, they were equal for the initial and repeated treatment. The increase in limited fasciectomies in the repeated treatment might be because of various factors, such as surgeon

or patient preference. Nonetheless, this increase in limited fasciectomies is a likely explanation for the increase in complications and not merely the repeated treatment itself.

When comparing baseline function of the same patients between their initial treatment and repeated treatment, we found that both goniometry and the self-reported hand function was worse at the intake of the repeated treatment. We did not investigate why this is the case and whether or not, for example, disappointment of patients with the initial treatment results or a relatively quick recurrence of the disease play a role. The lack of improvement after surgery in the various subscales of the MHQ might be the result of the lack of sensitivity or relative unimportance of these subscales for patients with Dupuytren's disease.[13] However, there was a clear improvement in satisfaction with hand function.

Patients who initially underwent needle fasciotomy achieved a better contracture reduction after their repeated treatment compared to those who initially underwent limited fasciectomy. Although the observational nature of this study precludes hard conclusions, it has been suggested that the treatment of early recurrent contractures after needle fasciotomy is less complicated because of less scar tissue.[14,15] However, this does not mean that needle fasciotomy should be the primary procedure by default as other factors also play a role, such as that more severely affected patients are better off with more invasive treatments.[14,16] At present, the choice of treatment will remain a trade-off between patient preference, e.g. fast recovery and recurrence rates, and physician preference, e.g. degree of contracture and type of strand.

Strengths of this study are its prospective cohort; the relative large sample size compared to other studies and the use of both physician and patient-reported outcome measurements. Unfortunately, despite the relative large sample size, the current cohort is not large enough to account for differences in treatment effectiveness by severity of disease (e.g., specific digits, joints involved, degree of contracture). This would result in the analyses of very small subgroups. The design of the study limits itself to patients who present themselves at our clinic with recurrence of their Dupuytren's contracture. Although the time to recurrence is relatively quick in this sample, this is in line with what has been previously described by Dias et al.[17] Nonetheless, our population most likely represents an 'early recontracture' group,[17] making it impossible to draw any conclusions about recurrent contractures in Dupuytren's disease as a whole. While a strength of this study is a more natural disease course

compared to patients in a trial setting, a drawback is that patients could be less inclined to return for follow-up measurements and fill out questionnaires. This did introduce missing values and therefore some potential bias. Finally, data on scarring and capsulotomies is not available for our cohort. Furthermore, even if data on scarring was available, would very hard to objectively quantify. This will remain a challenge for further studies, as it might be an important variable.

In conclusion, this study demonstrates that treatment effectiveness is equal in both initial as repeated treatment - at three months follow up after each treatment - since post-operative results after repeated treatment were similar after initial treatment for both finger goniometry and hand function. This equality in effectiveness was achieved despite that patients have a larger finger contracture and a worse self-assessed hand function before undergoing repeated treatment. The complication rates for both limited fasciectomy and needle fasciotomy are equal in the initial and repeated treatments. In addition, our results suggest that patients who initially underwent needle fasciotomy had a better contracture reduction in their repeated treatment compared to those who initially underwent a limited fasciectomy. These findings can be used for a better and more evidence-based preoperative counseling with patients with recurrent Dupuytren's disease.

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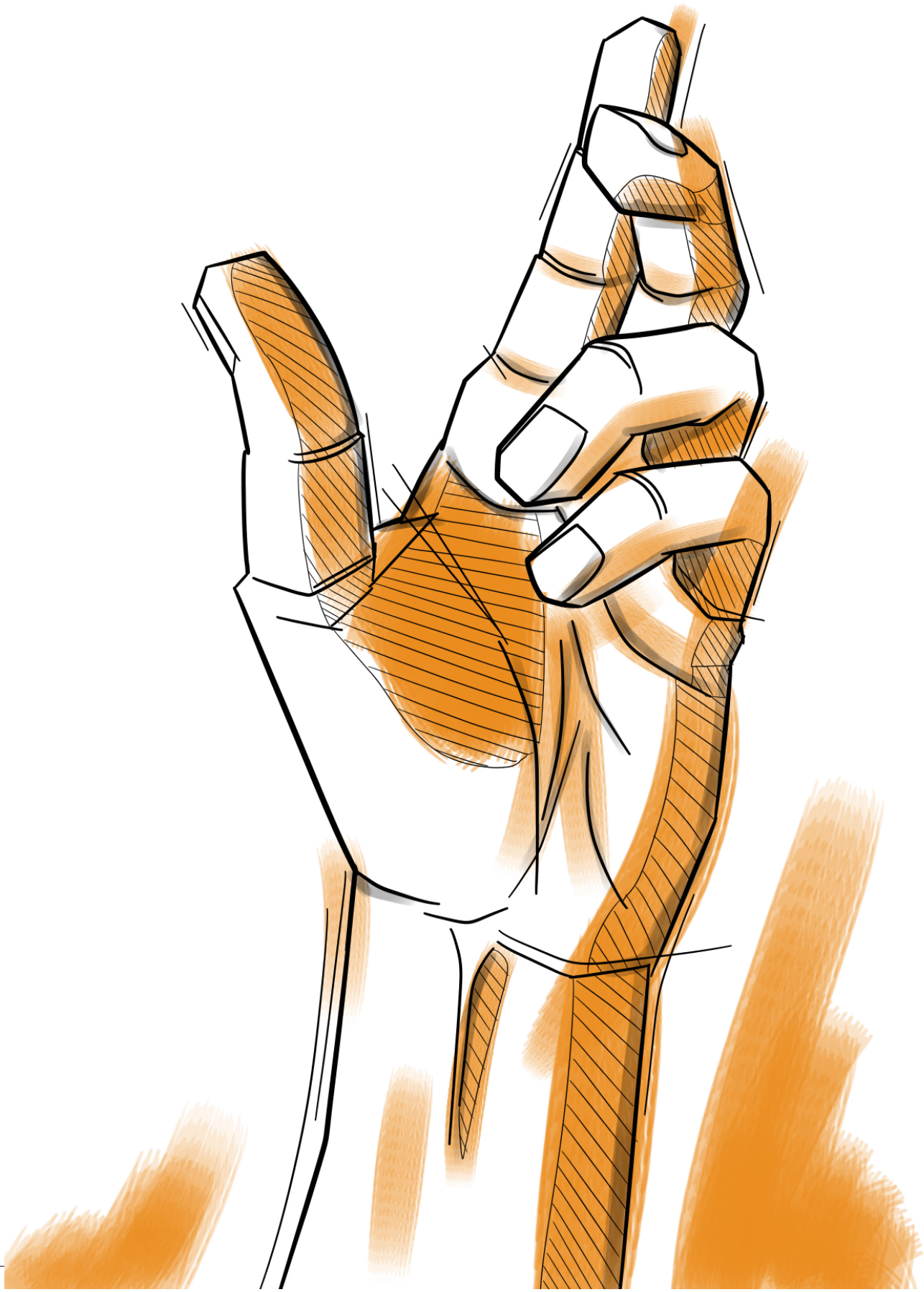
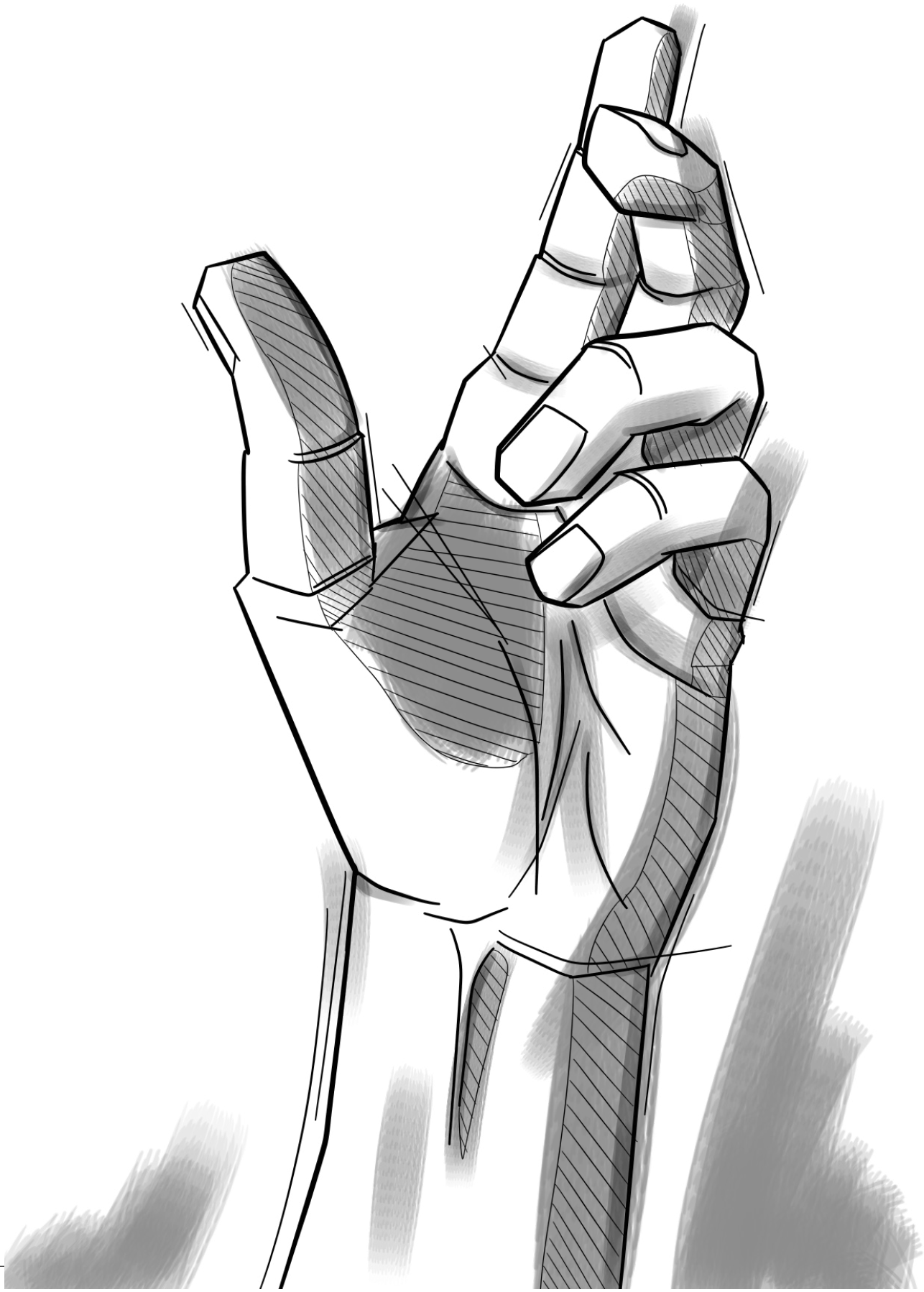


Part IV

Predicting Outcome



Chapter 9

Predicting complete finger extension in Dupuytren's disease.

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Submitted

ABSTRACT

Multiple studies have reported the effectiveness of treatment on contracture reduction in Dupuytren's disease. However, very few studies have attempted to quantify to which extent patient- and disease characteristics influence the chance of achieving a straight finger after surgery. Therefore, the aim of this study is to explore to which extent pre-operative patient- and disease characteristics can reliably predict a straight finger after surgery for Dupuytren's disease. 812 and 281 patients who underwent a limited fasciectomy or needle fasciotomy, respectively, were included in the final analyses. For both treatments, the combination of the extension deficit at baseline; which finger is most affected; which joint is most affected, and the number of affected fingers provided reliable predictions. Classical patient characteristics, such as age and sex, had no additional predictive value. The models presented in this study provide reliable predictions and could be helpful in informing patients and managing their expectations.

INTRODUCTION

Finger contracture in patients with Dupuytren's disease can be treated with a variety of treatments. Although the disease is as yet incurable, each treatment has its own indications depending on the severity of the disease and the preference of the patient.[1-3] In general, more severe cases of Dupuytren's disease achieve a better contracture reduction with a limited fasciectomy, whereas patients who have mild to moderate contractures can be effectively treated with both limited fasciectomy and needle fasciotomy.[4,5] Furthermore, collagenase is a non-surgical treatment option which is gaining popularity worldwide.[6] However, insurance companies in the Netherlands do not reimburse the treatment with collagenase, consequently leading to very limited use of collagenase. Finally, dermofasciectomy is mainly used in patients with recurrent Dupuytren's disease and severe diathesis. Although different indications exist for various treatments, all treatments for Dupuytren's disease share the common aim of improving hand function by straightening the affected finger(s).

Multiple case series and comparative studies have studied the effectiveness of these treatments on contracture reduction.[5,7,8] These studies have demonstrated that contractures in the small finger and the proximal interphalangeal joint are more challenging to correct. However, very few studies have attempted to quantify to which extent these disease factors and factors such as age, sex and family history exactly influence the chances of achieving a straight finger after surgery and how this interacts with the fingers and joints that are affected. This information is of importance as it provides physicians with evidence-based information on what patients can expect from different treatment options.

Therefore, the aim of this study is to explore to which extent pre-operative patient- and disease characteristics can reliably predict a straight finger after surgery for Dupuytren's disease.

METHODS

Study design

Patients who underwent either a limited fasciectomy (LF) or a percutaneous needle fasciotomy (PNF) for Dupuytren's disease between February 2011 and May 2018 at a consortium of 16 hand surgery practice sites in the Netherlands were selected from a prospectively maintained database that was

designed for clinical and research purposes. Treatment protocols were previously described by Zhou *et al.*[4] Total extension deficit of the affected fingers was assessed prior to surgery and three months after surgery. Patient- and disease-specific characteristics derived from this database were age, sex, occupational status, family history of Dupuytren's disease and hand dominance.

Patients were included if the most affected finger (i.e. the most severely contracted finger) was either the ring finger or small finger, as Dupuytren's disease severely affecting other fingers is less frequent. Patients with multiple affected fingers were included if the most affected finger was either the ring finger or small finger. When multiple digits were affected, the most affected finger was included in the analysis. Furthermore, only patients with primary disease and a TAED of more than 20 degrees were included. There were very few patients where the distal interphalangeal joint was the most affected joint and were therefore excluded. Patients treated with collagenase or a dermofasciectomy were not included in this study since use of collagenase is very limited in the Netherlands and since dermofasciectomy is mainly used in patients with recurrent Dupuytren's disease in our patient data.

Total active extension deficit

The degree of total active extension deficit (TAED) was assessed by specialized hand therapists during visits prior to surgery and three months after surgery by summing up the degree of active extension deficit at the metacarpophalangeal (MCP), proximal interphalangeal (PIP), and distal interphalangeal (DIP) joint levels. Any hyperextension was converted to 0 degrees at an individual joint level to prevent underestimation of the total degree of extension deficit.

Statistical analyses

To assess the potential of selection bias, we compared baseline patient characteristics between patients who had a follow-up measurement and those who did not. Significance testing was done by means of a Student's t test for normally distributed data, a Wilcoxon rank-sum test for non-normally distributed data and a chi-squared test for categorical data. Distribution of the data was evaluated with histograms and QQ norm plots.

A logistic modeling framework to model the chances of complete finger extension was chosen over a linear modeling framework to model actual post-operative finger extension. The reason for this approach is the extreme right-screwed distribution of post-operative finger extension, which results

from the aim of the treatment to achieve as little residual extension deficit as possible. This distribution leads to violation of an important assumption (a normal distribution of the residuals) needed for linear models.

Complete finger extension was defined as less than 10 degrees of TAED of the most affected finger (at baseline) after three months of follow-up. Since different indications exist for a limited fasciectomy and a needle fasciotomy, both treatment groups were fitted to separate models and no direct comparisons were made. However, analyses followed the same steps for both groups.

Candidate variables for the models were selected based on clinical experience and divided in two groups: patient characteristics and disease characteristics (see Table 2). Occupational status was dichotomized to 'unemployed/retired' and 'work'. For the PNF-group, patients with three or more affected fingers were excluded from the analysis, as this group consisted of only six patients. In total, 11 candidate variables were selected for the LF-group and 10 candidate variables for the PNF-group. Current recommendations suggest that a minimum of 5-15 event-per-variable should be available.[9] For the LF-group and PNF-group this event-per-variable ratio was 25 and 10, respectively.

For both the LF- and PNF-group, two models were fitted: one model including both patient- and disease characteristics ('patient model') and one model including only disease characteristics ('disease model'). Regression coefficients of the various models were estimated using all available patients. Performance was assessed with the Area Under the Receiver-Operator Curve (AUC). Corrected estimates of this measure were obtained using an internal validation procedure. For this, a 10-fold cross-validation[10] was performed by splitting our data set in ten random subsets, fitting each time the model in nine of the subsets (90% of the data) and calculating the AUC measure in the subset that was excluded (10% of the data). This cross-validation procedure was repeated 10 times. This procedure, known as repeated cross-validation, results in 100 different models and therefore 100 different AUC's. The final AUC is the mean of these AUC's and is the AUC reported in the results. The final AUC's of the 'Patient model' and 'Disease model' were compared to determine the best performing model. When the performance of both models was equal, the model with the least variables (the 'Disease model') was preferred.

Sensitivity analyses were performed to determine the influence of missing data in the smoking- and diabetes status of patients on the model performance. Three separate models were fitted: one model without smoking and

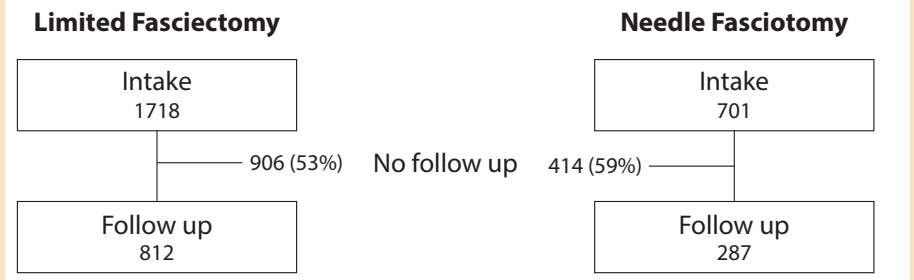
Table 1. Patient- and disease characteristics

	LF (N = 812)	PNF (N = 287)
Patient Characteristics		
Age in years, mean (sd)	64 (9)	66 (9)
Sex (% male)	75	76
Smoking (%)	16*	14**
Diabetes (%)	6*	13**
Occupational intensity (%)		
Unemployed/retired	54	58
Light (e.g. office work)	27	31
Medium(e.g. cleaning)	13	8
Heavy (e.g. construction work)	6	3
Positive family history (%)	48	44
Duration of complaints in months, median (IQR)	24 (12-48)	28 (12-60)
Surgery on dominant hand (%)	51	54
Disease Characteristics		
TAED - baseline, mean (sd)	69 (34)	57 (28)
Most affected finger (%)		
Dig 4	29	40
Dig 5	71	60
Most affected joint (%)		
MCP	44	79
PIP	56	21
Number of affected fingers (%)		
1	52	71
2	35	26
3 or more	12	2
Post operative results		
TAED post-op <10° (number of patients (%))	282 (34.7%)	105 (36.6%)

sd, standard deviation; IQR, Interquartile Range; TAED, Total Active Extension Deficit; MCP, metacarpophalangeal; PIP, proximal interphalangeal

* N = 655
** N = 188

Figure 1. Flowchart



diabetes as a predictive variable; one model with smoking and diabetes as a predictive variable; and one model without smoking and diabetes as a predictive variable, but with patients missing this variable excluded. Performance was assessed again with the procedure described above (repeated cross-validation). When the performance of both models was equal, no significant influence of the missing data was observed.

RESULTS

In total, 812 patients treated with a limited fasciectomy and 287 patients treated with a needle fasciotomy were included in this study (see Figure 1). In the patients that underwent limited fasciectomy and were lost to follow-up, more patients had a single finger affected and more patients had PIP joint involvement (see Supplementary Table S1). Patients undergoing a limited fasciectomy had a mean TAED of 64 degrees and 12% of the patients had 3 or more affected fingers. Complete finger extension was achieved in 35% of the LF-group. Patients undergoing a needle fasciotomy had a mean TAED of 66 degrees and only two percent had 3 or more affected fingers. Complete finger extension was achieved in 37% of the PNF-group (see Table 1).

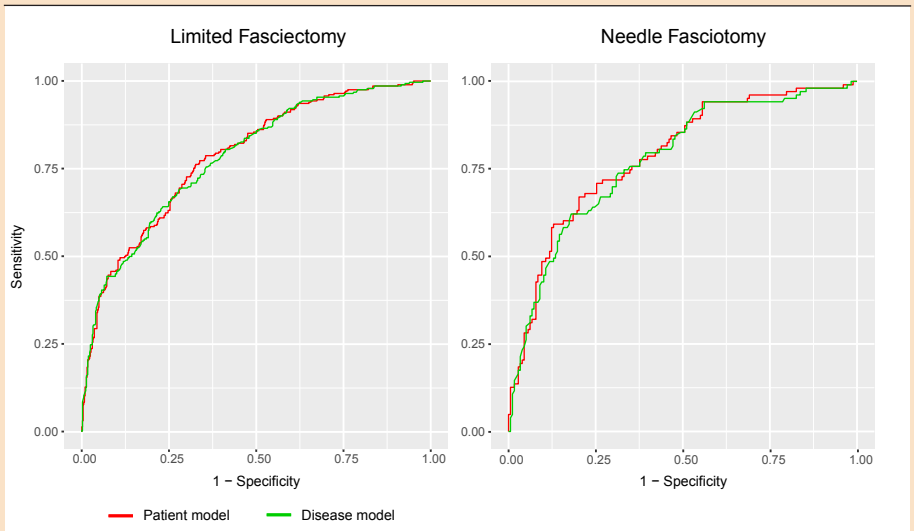
In the LF-group, none of the patient characteristics, such as age and sex, had a significant association with the chances of complete finger extension in the 'Patient model'. In contrast, all disease characteristics, that is, TAED at baseline, most affected finger, most affected joint and the number of affected fingers, had a significant association (see Table 2). No confounding of the disease characteristics by the patient characteristics was observed, i.e. similar regression coefficients were found for the disease characteristics in the two models. Sensitivity analyses showed no significant benefit or influence when including smoking and diabetes status as a variable (see Supplementary Table S2).

Table 2. Regression coefficients (odds ratios) of the various models.

	Limited Fasciectomy		Needle Fasciotomy	
	Patient model	Disease model	Patient model	Disease model
Patient Characteristics (95% CI)				
Age (years)	0.98 (0.95-1.00)	-	0.98 (0.93-1.02)	-
Sex (female = 0, male = 1)	0.73 (0.49-1.09)	-	0.71 (0.36-1.39)	-
Work (no work = 0, work = 1)	0.96 (0.62-1.49)	-	0.96 (0.45-2.04)	-
Positive family history (no = 0, yes = 1)	1.11 (0.79-1.57)	-	1.46 (0.83-2.57)	-
Duration of complaints (months)	1.00 (1.00-1.00)	-	1.00 (1.00-1.01)	-
Surgery on dominant hand (no = 0, yes = 1)	0.95 (0.68-1.33)	-	0.67 (0.38-1.16)	-
Disease Characteristics (95% CI)				
TAED – baseline (degrees)	0.97 (0.97-0.98)	0.97 (0.96-0.98)	0.96 (0.95-0.98)	0.96 (0.95-0.98)
Most affected finger (dig4 = 0, dig5 = 1)	0.40 (0.28-0.58)	0.42 (0.29-0.60)	0.68 (0.38-1.21)	0.68 (0.38-1.20)
Most affected joint (MCP = 0, PIP = 1)	0.44 (0.31-0.63)	0.48 (0.34-0.67)	0.20 (0.08-0.44)	0.22 (0.09-0.46)
Number of affected fingers				
1	REF	REF	REF	REF
2	0.89 (0.62-1.27)	0.89 (0.62-1.27)	1.00 (0.53-1.86)	0.99 (0.53-1.82)
3 or more	0.36 (0.20-0.64)	0.35 (0.19-0.67)	-	-

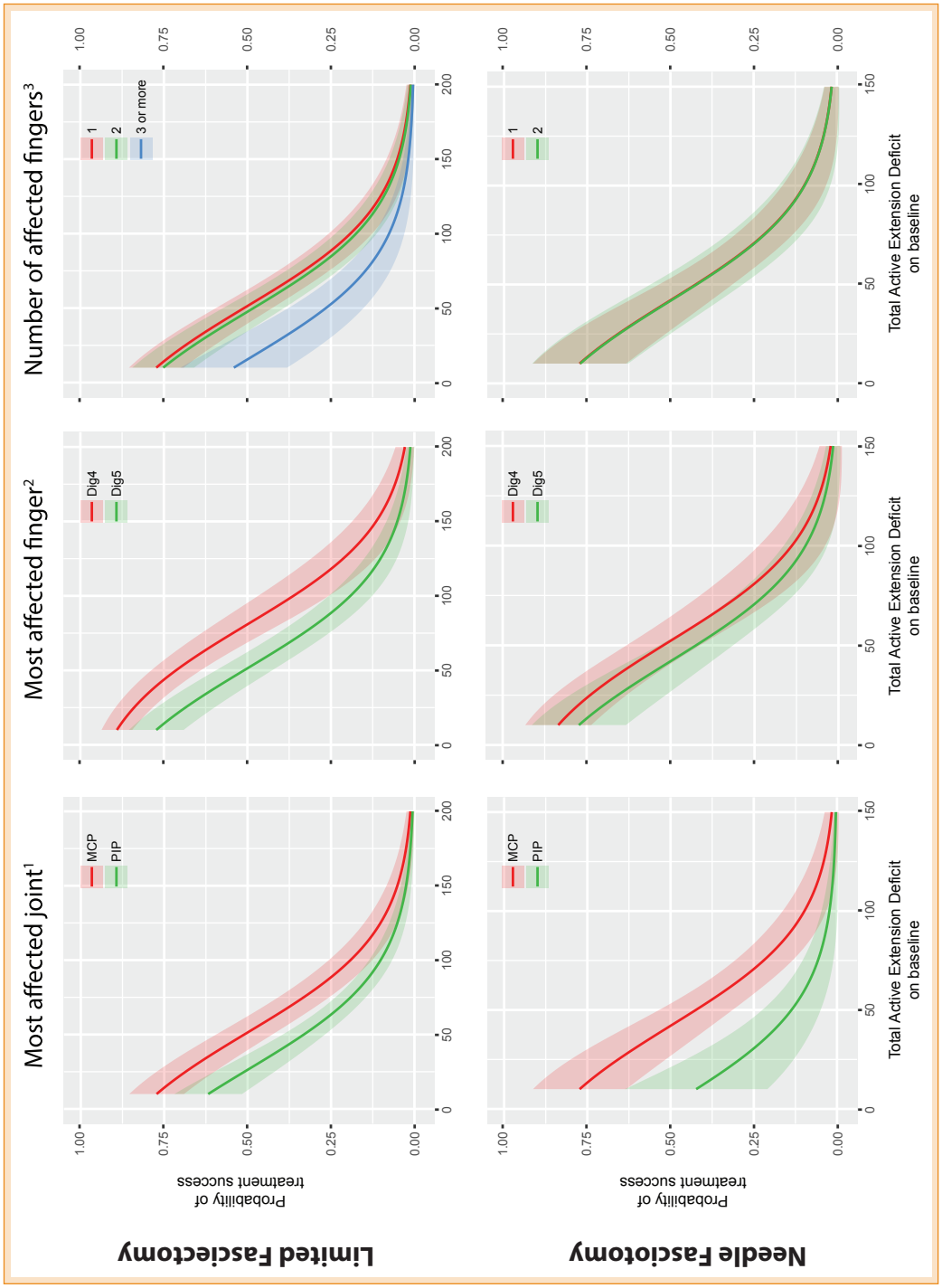
TAED, Total Active Extension Deficit; MCP, Metacarpalphalangeal joint; PIP, Proximal Interphalangeal joint

Figure 2. Receiver Operator Curves (ROC) of the final models for Limited Fasciectomy and Needle Fasciectomy.



The AUC's of the 'Patient model' and 'Disease model' in the LF-group were 0.77 (95% CI: 0.76-0.78) and 0.78 (95% CI: 0.77-0.79), respectively (see Figure 2). To illustrate the influence of the various variables on the probability of obtaining complete finger extension, effect plots were constructed (see Figure 3). Overall, the probability of obtaining a straight finger after surgery decreases with a higher baseline contracture. Furthermore, patients where the MCP-joint is most affected and where the ring finger is more affected have higher probability of obtaining a straight finger, compared to PIP-joint and small finger, respectively. The same result can be seen for patients where one or two fingers are affected compared to 3 or more fingers. For example, a patient with a TAED of 40 degrees of the ring finger and where the MCP-joint is most affected has a probability of 0.77 (95% CI: 0.70-0.84) of achieving a straight finger at follow-up. However, a patient with a TAED of 40 degrees of the small finger and where the PIP-joint is most affected has a probability of 0.40 (95% CI: 0.33-0.47) of achieving a straight finger at follow-up. In both examples one finger was affected.

In the PNF-group, similarly to the LF-group, none of the patient characteristics in the 'Patient model' had a significant association with the chances of complete finger extension (see Table 2). Of the disease characteristics the 'TAED on baseline' and 'most affected joint' showed a significant association.


Limited Fasciectomy
Needle Fasciotomy
Most affected joint[1]
Most affected finger[2]
Number of affected fingers[3]
Probability of treatment success
Total Active Extension Deficit on baseline
MCP
PIP
Dig4
Dig5
1
2
3 or more
0.00
0.25
0.50
0.75
1.00
0
50
100
150
200

Again, no confounding of the disease characteristics by the patient characteristics was observed. Sensitivity analyses showed no significant benefit or influence when including smoking and diabetes status as a variable (see Supplementary Table S3).

The AUC's of the 'Patient model' and 'Disease model' in the PNF-group were 0.75 (95% CI: 0.73-0.77) and 0.77 (95% CI: 0.75-0.78), respectively (see Figure 2). Again, effect plots were constructed to illustrate the influence of the various variables on the probability of complete finger extension (see Figure 3). Similarly to the LF-group, the probability of obtaining a straight finger after surgery decreases with a higher baseline contracture and patients where the MCP-joint is most affected have higher probability of obtaining a straight finger, compared to PIP-joint. However, there are no differences in probability depending on which finger is affected or the number of affected fingers. For example, a patient with a TAED of 30 degrees of the small finger and where the MCP-joint is most affected has a probability of 0.61 (95% CI: 0.47-0.75) of achieving a straight finger at follow-up. However, a patient with a TAED of 30 degrees of the small finger and where the PIP-joint is most affected has a probability of 0.25 (95% CI: 0.11-0.40) of achieving a straight finger at follow-up. In both examples one finger was affected.

DISCUSSION

The aim of this study was to explore to what extent pre-operative patient-

Figure 3 (opposite page). Probabilities of treatment success based on the 'Disease model'. The figure illustrated the effect of the various variables. For each graph all variables are kept constant expect the variables displayed. For example, for the probability of treatment success according to the TAED and which joint is most affected (far left), the 'most affected finger' and the 'number of affected fingers' are kept constant. The QR-code below redirects to interactive versions of the models.

[1] 'Most affected finger' is Dig 5 and 'number of affected fingers' is 1
[2] 'Most affected joint is MCP and 'number of affected fingers' is 1
[3] 'Most affected joint is MCP and 'Most affected finger' is Dig 5

TAED, total extension deficit; MCP, metacarpophalangeal; PIP, proximal interphalangeal

and disease characteristics can reliably predict complete finger extension after treatment. We found that complete finger extension can be reliably predicted with a limited set of variables. The 'predictive' disease variables included the TAED at baseline, the most affected finger, the most affected joint and the number of affected fingers. Classical patient characteristics, such as age and sex, did not have any predictive value. In general, patients with a smaller TAED, an affected ring finger and MCP-joint had a better change of complete finger extension compared to those patients with a larger TAED, an affected small finger and PIP-joint.

Various previous studies have demonstrated that contractures with a large baseline TAED and contractures in the PIP joint and 5th digit are more challenging to correct.[5,11,12] The current study confirms these findings in a large cohort where variables could be tested independent of each other. In contrast, variables such as age, sex and family history, which are part of the so-called Dupuytren's diathesis,[13] were not associated with complete finger extension after surgery. However, it is well known that these factors are associated with more aggressive forms of Dupuytren's disease and higher recurrence rates.[13,14] Therefore, these factors are still important to take into consideration when discussing treatment options with patients. Especially in recurrent disease, this group of patients however was not the aim of our study.

The chance of obtaining a straight finger after treatment depends on the type of treatment. Patients with a mild or moderate diathesis have a similar contracture reduction with wide variety of treatments.[4,5,15,16] On the contrary, for patients with more severe diathesis minimal invasive treatments are less advisable.[5,17] These various indications for various treatments result in the selection of patients for certain treatments. Although this is the cornerstone of good surgical practice, it makes comparing the current models for limited fasciectomy and needle fasciotomy treacherous and inadvisable. As the models are built in a 'post-hoc fashion', they model the chance of complete finger extension *after* the decision for a treatment is made. Therefore, these models cannot be used to set indications for patients. However, they can be useful as informative tools to illustrate what patients can expect from their treatment.

In the current study complete finger extension is defined as less than ten degrees of TAED after surgery. However, the chance of achieving a straight finger after surgery is not the only consideration in the decision for a certain treatment. Other important considerations could be complication – and recurrence rates or return-to-work, each requiring its own model with, most likely,

different variables. The decision for a certain treatment will remain a trade-off between these considerations. However, it has been shown that complete finger extension is important to patients,[18] making these models valuable tools in pre-operative counseling.

The large cohort of patients treated for Dupuytren's disease combined with a solid statistical analysis represents the major strength of this study. This study does however have some limitations. Not all variables of interest are available. Most importantly, it is unknown if a visible or palpable cord was observed and if a capsulotomy was performed to straighten the finger. These variables could be important in predicting the success of a treatment. While a strength of this study is that the data is a more natural reflection of patients with Dupuytren's disease in clinical practice compared to patients in a trial setting, a drawback is that patients could be less inclined to return for follow-up measurements. The consequential loss to follow-up (53 to 59%) may have led to under- or overestimation of the identified associations. However, our analyses did not show clinically relevant differences in baseline characteristics between patients who were included or excluded, reducing the likelihood of biased results. Furthermore, we were only able to predict the probability of a straight finger (<10 degrees residual TAED) after surgery, not how much residual contracture would be left after surgery. The reason for this analysis is the highly skewed distribution of the extension deficit after surgery; statistically such a distribution is very difficult to predict in a non-logistic regression model. Finally, the current models are based on post-operative results for primary Dupuytren's disease and cannot be used for long-term predictions or recurrent cases of Dupuytren's disease.

In conclusion, this study demonstrates that baseline extension deficit, the type of finger and joint, as well as the number of affected fingers, independently determine if a straight finger can be achieved after treatment. In contrast, classical patient characteristics, such as age, sex and family history, have no significant influence on the chance of achieving a straight finger after treatment. Furthermore, the models presented in this study provide reliable predictions and could be helpful in informing patients and managing their expectations.

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Supplementary Table S1. Patient- and disease characteristics of patients with and without follow-up measurements.

	LF – with follow-up (N = 812)	LF – without follow-up (N = 906)	*p*-value	PNF – with follow-up (N = 287)	PNF – without follow-up (N = 414)	*p*-value
Patient Characteristics						
Age (years, mean(sd))	64 (9)	63 (10)	*0.41*	66 (9)	67 (9)	*0.21*
Sex (% male)	75	75	*0.95*	76	70	*0.08*
Smoking (%)	16*	16**	*0.83*	14$	11$$	*0.33*
Diabetes (%)	6*	7**	*0.31*	13$	12$$	*0.82*
Occupational intensity (%)			*0.55*			*0.02*
Unemployed/retired	54	54		58	63	
Light (e.g. office work)	27	27		31	22	
Medium(e.g. cleaning)	13	12		8	9	
Heavy (e.g. construction work)	6	7		3	7	
Positive family history (%)	48	46	*0.43*	44	50	*0.13*
Duration of complaints (months, median (IQR))	24 (12-48)	24 (12-48)	*0.43*	28 (12-60)	24 (12-60)	*0.37*
Surgery on dominant hand (%)	51	54	*0.27*	54	55	*0.91*

* N = 655
** N = 712
$ N = 118
$$ N = 242

Supplementary Table S1 (continued). Patient- and disease characteristics of patients with and without follow-up measurements.

	LF – with follow-up (n = 812)	LF – without follow-up (n = 906)	*p*-value	PNF – with follow-up (n= 287)	PNF – without follow-up (n= 414)	*p*-value
Disease Characteristics						
TAED - baseline (mean (sd))	69 (34)	72 (38)	*0.05*	57 (28)	59 (32)	*0.29*
Most affected finger (%)			*0.52*			*0.18*
Dig 4	29	30		40	45	
Dig 5	71	70		60	55	
Most affected joint (%)			*0.02*			*0.49*
MCP	44	39		79	81	
PIP	56	61		21	19	
Number of affected fingers (%)			*0.01*			*0.22*
1	52	58		71	73	
2	35	33		26	23	
3 or more	12	8		2	4	

sd, standard deviation; IQR, Interquartile Range; TAED, Total Active Extension Deficit; MCP, metacarpophalangeal; PIP, proximal interphalangeal

	Patient model 1 N = 812	Patient model 2 N = 655	Patient model 3 N = 655	Disease model 1 N = 812	Disease model 2 N = 655
Patient Characteristics (95% CI)					
Age (years)	0.98 (0.95-1.00)	0.99 (0.97-1.02)	0.99 (0.97-1.02)	-	-
Sex (female = 0, male = 1)	0.73 (0.49-1.09)	0.72 (0.46-1.13)	0.73 (0.47-1.13)	-	-
Smoking (no = 0, yes = 1)	-	0.86 (0.51-1.46)	-	-	-
Diabetes(no = 0, yes = 1)	-	0.96 (0.44-2.12)	-	-	-
Work (no work = 0, work = 1)	0.96 (0.62-1.49)	1.00 (0.62-1.61)	0.99 (0.61-1.59)	-	-
Positive family history (no = 0, yes = 1)	1.11 (0.79-1.57)	0.92 (0.63-1.34)	0.93 (0.64-1.35)	-	-
Duration of complaints (months)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)	-	-
Surgery on dominant hand (no = 0, yes = 1)	0.95 (0.68-1.33)	0.94 (0.65-1.36)	0.94 (0.65-1.36)	-	-
Disease Characteristics (95% CI)					
TAED – baseline (degrees)	0.97 (0.97-0.98)	0.97 (0.97-0.98)	0.97 (0.97-0.98)	0.97 (0.96-0.98)	0.97 (0.96-0.98)
Most affected finger (dig4 = 0, dig5 = 1)	0.40 (0.28-0.58)	0.46 (0.31-0.69)	0.46 (0.30-0.69)	0.42 (0.29-0.60)	0.48 (0.32-0.71)
Most affected joint (MCP = 0, PIP = 1)	0.44 (0.31-0.63)	0.40 (0.27-0.59)	0.41 (0.28-0.60)	0.48 (0.34-0.67)	0.43 (0.30-0.63)
Number of affected fingers					
1	REF	REF	REF	REF	REF
2	0.89 (0.62-1.27)	0.86 (0.58-1.27)	0.86 (0.58-1.27)	0.89 (0.62-1.27)	0.85 (0.58-1.25)
3 or more	0.36 (0.20-0.64)	0.34 (0.17-0.66)	0.35 (0.17-0.67)	0.35 (0.19-0.61)	0.34 (0.17-0.66)
AUC (95% CI)	0.77 (0.76-0.78)	0.76 (0.75-0.78)	0.77 (0.76-0.78)	0.78 (0.77-0.79)	0.78 (0.76-0.79)

Supplementary Table S2 (opposite page). Sensitivity analyses for *limited fasciectomy* models. Regression coefficients (odds ratios) and AUC's for the various models are shown. *Patient model 1* assesses the performance of the 'Patient model' when all patients in the study are included, but does not include smoking and diabetes status as a variable. *Patient model 2* does include smoking and diabetes status as a variable, but patients with an unknown smoking and diabetes status are not included (resulting in a smaller sample size). *Patient model 3* includes the same patients as model 2, but does not include smoking and diabetes status as a variable to explore if potential differences between the first two models could be explained by a different sample size.

Disease model 1 includes the same patients as *Patient model 1*. *Disease model 2* includes the same patients as *Patient model 2 and 3*.

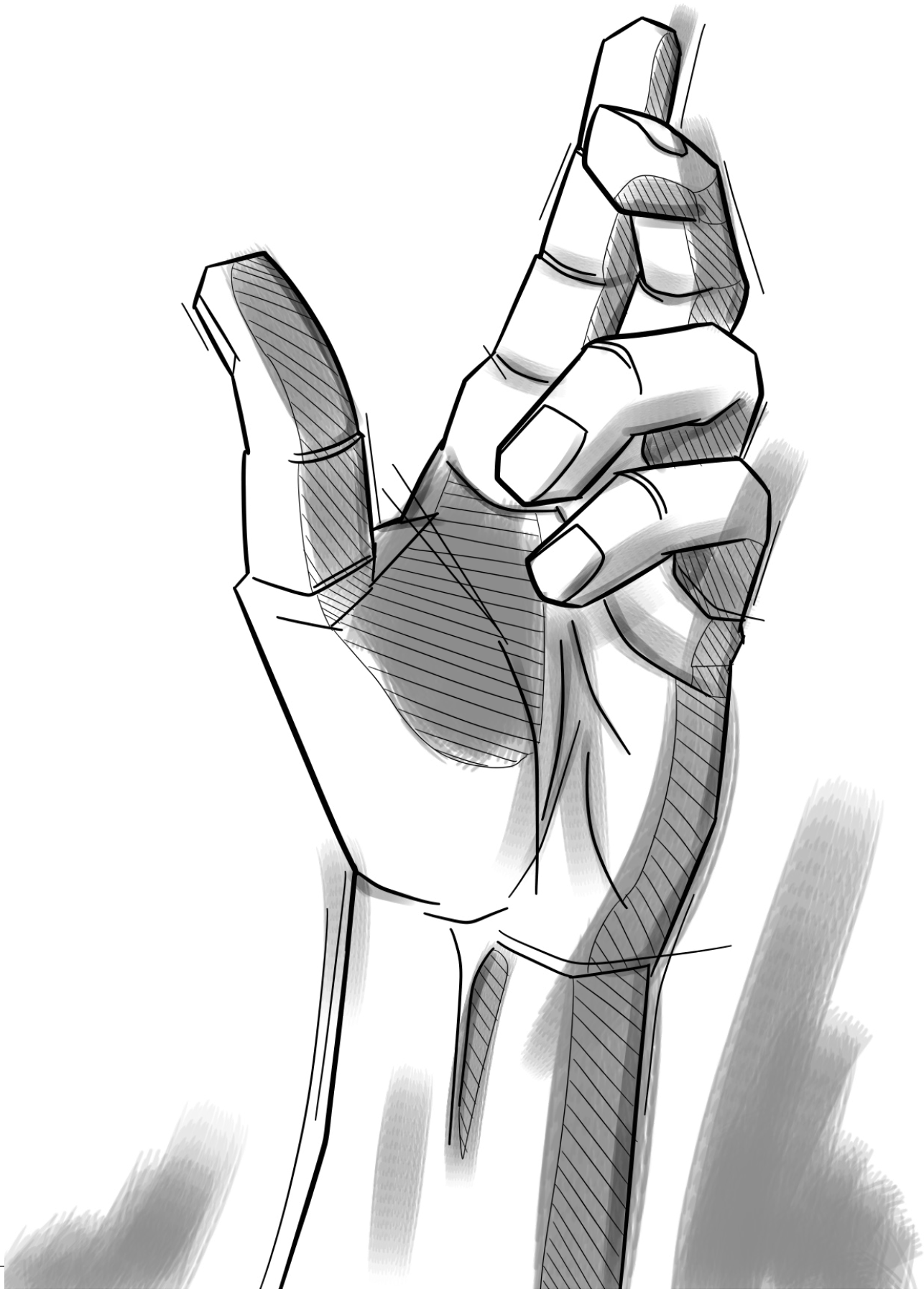
AUC, Area Under the Receiver-Operator Curve; 95% CI, 95% confidence interval TAED, Total Active Extension Deficit; MCP, Metacarpalphalangeal joint; PIP, Proximal Interphalangeal joint

	Patient model 1 N = 281	Patient model 2 N = 186	Patient model 3 N = 186	Disease model 1 N = 281	Disease model 2 N = 186
Patient Characteristics (95% CI)					
Age (years)	0.98 (0.93-1.02)	0.96 (0.91-1.01)	0.97 (0.92-1.02)	-	-
Sex (female = 0, male = 1)	0.71 (0.36-1.02)	0.64 (0.26-1.52)	0.64 (0.27-1.52)	-	-
Smoking (no = 0, yes = 1)	-	0.81 (0.29-2.32)	-	-	-
Diabetes(no = 0, yes = 1)	-	2.89 (0.93-10.1)	-	-	-
Work (no work = 0, work = 1)	0.96 (0.45-2.04)	0.75 (0.29-1.88)	0.95 (0.39-2.30)	-	-
Positive family history (no = 0, yes = 1)	1.46 (0.83-2.57)	1.10 (0.55-2.23)	1.16 (0.59-2.33)	-	-
Duration of complaints (months)	1.00 (1.00-1.01)	1.00 (0.99-1.01)	1.00 (0.99-1.01)	-	-
Surgery on dominant hand (no = 0, yes = 1)	0.67 (0.38-1.16)	0.59 (0.28-1.19)	0.64 (0.31-1.27)	-	-
Disease Characteristics (95% CI)					
TAED – baseline (degrees)	0.96 (0.95-0.98)	0.96 (0.94-0.98)	0.96 (0.94-0.98)	0.96 (0.95-0.98)	0.96 (0.94-0.98)
Most affected finger (dig4 = 0, dig5 = 1)	0.68 (0.38-1.21)	0.65 (0.32-1.34)	0.65 (0.32-1.34)	0.68 (0.38-1.20)	0.62 (0.31-1.24)
Most affected joint (MCP = 0, PIP = 1)	0.20 (0.08-0.44)	0.23 (0.08-0.59)	0.25 (0.09-0.64)	0.22 (0.09-0.46)	0.28 (0.10-0.68)
Number of affected fingers					
1	REF	REF	REF	REF	REF
2	1.00 (0.53-1.86)	0.91 (0.41-2.00)	0.91 (0.41-1.96)	0.99 (0.53-1.82)	0.98 (0.46-2.04)
3 or more	-	-	-	-	-
AUC (95% CI)	0.75 (0.73-0.77)	0.73 (0.71-0.75)	0.73 (0.70-0.75)	0.77 (0.75-0.78)	0.75 (0.73-0.77)

Supplementary Table S2 (opposite page). Sensitivity analyses for *needle fasciotomy* models. Regression coefficients (odds ratios) and AUC's for the various models are shown. *Patient model 1* assesses the performance of the 'Patient model' when all patients in the study are included, but does not include smoking and diabetes status as a variable. *Patient model 2* does include smoking and diabetes status as a variable, but patients with an unknown smoking and diabetes status are not included (resulting in a smaller sample size). *Patient model 3* includes the same patients as model 2, but does not include smoking and diabetes status as a variable to explore if potential differences between the first two models could be explained by a different sample size.

Disease model 1 includes the same patients as *Patient model 1*. *Disease model 2* includes the same patients as *Patient model 2 and 3*.

AUC, Area Under the Receiver-Operator Curve; 95% CI, 95% confidence interval TAED, Total Active Extension Deficit; MCP, Metacarpalphalangeal joint; PIP, Proximal Interphalangeal joint



Chapter 10

General Discussion and Future Perspectives

GENERAL DISCUSSION

The general aims of this thesis were: to describe the data collection of the cohort of patients used for this thesis; to study to what extent psychological factors and context play a role in Dupuytren's disease; to study alternative outcome measures in Dupuytren's disease; to study to which extent post-operative extension deficit can be reliably predicted in Dupuytren's disease. The Discussion is structured accordingly in four parts: 1. The Hand and Wrist cohort, 2. Psychology and context, 3. Treatment and outcome, 4. Prediction. Afterwards, the general limitations of this thesis are discussed, followed by the future perspectives.

In *Part 1*, we provide insight in the Hand and Wrist Cohort. This routine outcome measurement cohort, which forms the base of the studies performed in this thesis, has a similar structure as an open inception cohort and includes patients with a wide variety of hand- and wrist conditions. The cohort is unique in the field of hand- and wrist surgery due to its combination of size and detail of information per patient. More specific for this thesis, the cohort currently includes more than 3000 patients with Dupuytren's disease with various outcome measurements, such as total active extension deficit, patient-reported outcome measurements, return to work and satisfaction with outcome. Inception cohorts can be helpful in answering a multitude of clinically-relevant questions, but are especially powerful for prognostic studies and prediction modeling, which form the majority of this thesis. Furthermore, successful implementation of routine outcome measurements in a clinic can provide direct feedback to both patients and physicians and might improve daily care.

In *Part 2*, we study to what extent psychological factors and context play a role in Dupuytren's disease. We found that patients with Dupuytren's disease do not perceive their illness as very threatening compared to other chronic hand disorders and to systemic diseases such as type 2 diabetes and glaucoma.[1-3] These findings suggest that preoperative interventions focused on changing illness perceptions may not be necessary for the large majority of patients with Dupuytren's disease. On the other hand, we found that patients with Dupuytren's disease who reported more positive experiences with the way their care was delivered, also showed more positive treatment outcomes. A good experience with the communication of healthcare providers and treatment information had the strongest association with more positive treatment outcome. Optimizing communication and information in healthcare delivery is in our opinion a valuable opportunity to improve outcomes.

In *Part 3*, we underline the difficulties of assessing outcome after treatment for Dupuytren's disease, as best illustrated by the lack of correlation between clinician-measured hand function and patient-reported hand function.[4, 5] A possible explanation for this lack of correlation is that fixed-item PROMs commonly-used in Dupuytren's disease might not evaluate the individual problems concerning patients with Dupuytren's disease.[6] This phenomenon can clearly be observed by the lack of improvement in the ADL- and work subscales of the MHQ. This is further underlined by the wide range of functional problems reported by patients with Dupuytren's disease, which are impossible to capture fully by pre-defined PROMs, such as the MHQ and the DASH and even the disease-specific URAM.

To overcome this problem of traditional, pre-defined PROMs we used the Patient Specific Functional Scale (PSFS) in Dupuytren's disease, a so-called individualized PROM relying on patient-generated items instead of pre-defined, fixed items. Although conceptually completely different from traditional PROMs, the PSFS promises to be a viable alternative for measuring patient-reported hand function in patients with Dupuytren's disease. Potential difficulties with comparing patients who report a large variety of problems need further addressing. Nonetheless, the self-generated items and measurement of such items, may better reflect the needs and problems of the individual patient and how they improve after treatment. These characteristics could make individualized PROMs, such as the PSFS, be the next step forward in patient-centered healthcare.

In addition to functional problems, very little is known about non-functional problems perceived by patients with Dupuytren's disease. This might further explain the discrepancy between performance-based and patient-reported hand function. One of these problems might be hand appearance. Although often overlooked, the appearance of the hand is an essential part of human interaction, communication and social integration and might be a serious concern in patients with Dupuytren's disease.[7-9] This would be in line with results seen in rheumatoid arthritis, where surgery is usually performed for functional or pain-related problems, but were hand appearance showed the strongest relation with improvement in satisfaction.[10, 11] In this thesis we have demonstrated that, from a patient's perspective, the treatment of Dupuytren's disease mainly improves the aesthetics of the hand and the satisfaction with the hand function. However, whether hand appearance is the main reason patient seek treatment for their contractures or if aesthetic improvement is

just a positive side effect remains unknown.

More than half of the patients with Dupuytren's disease are employed at the time of treatment. For these patients, return to work might be a relevant outcome parameter. We demonstrated that return to work after treatment for Dupuytren's contractures is high and relatively soon after treatment for both needle fasciotomy and limited fasciectomy, although much sooner after needle fasciotomy than after fasciectomy, respectively within days and 2 weeks. This resulted in a much lower loss of productivity costs after a needle fasciotomy. However, recurrent contractures are more frequent after percutaneous needle fasciotomy, making the need for an additional procedure and thus additional costs more likely. In the absence of long-term data, this will remain unknown for the foreseeable future.

Despite the relatively high prevalence of recurrent contractures in Dupuytren's disease, little is known about treatment outcomes of recurrent contractures. In this thesis we demonstrated that repeated treatment was as effective as the initial treatment with similar complication rates. As treatment choice will remain a trade-off, e.g., between short recovery with higher recurrence rates *vs.* longer recovery with low recurrence rates, this information could benefit decision making as repeated treatments of the same finger do not seem to harm hand function after surgery.

In *Part 4*, we explored to what extent pre-operative patient- and disease characteristics can reliably predict post-operative outcomes. We demonstrated that contractures with a large baseline TAED and contractures in the PIP joint and 5th digit are challenging to correct. With the use of these parameters it is possible to reliably predict which patients achieve a straight finger after treatment, which could be helpful in illustrating patients what to expect from their treatment. Interestingly, variables such as age, sex and family history, which are part of the so-called Dupuytren's diathesis,[12] were not associated with complete finger extension directly after surgery. However, it is well known that these factors are associated with more aggressive forms of Dupuytren's disease and higher recurrence rates.[12, 13] Therefore, these factors are still important to take into consideration when discussing treatment options with patients.

LIMITATIONS

The studies in this thesis have some limitations which are worth considering. The current cohort is the result of routine outcome measures collected as

part of daily clinical practice at a consortium of hand clinics. While a strength of this system is that the data is a more natural reflection of patients with Dupuytren's disease in clinical practice compared to patients in a trial setting, a drawback is that patients could be less inclined to return for follow-up measurements and complete questionnaires. This did introduce missing values and therefore potential bias. The influence of this potential bias is hard to determine, especially compared to results of (randomized) clinical trials. The in- and exclusion criteria of these trials as well as the willingness of patients to participate in these trials does introduce selection of patients prior to entering the study. In our cohort all patients with baseline measurements are included and those who did not return for follow-up were lost. This study design also introduces selection of patients. Which study design is preferable most likely depends on the aim of the study. Although we believe that the potential bias in our studies is limited, as none of our sensitivity analyses showed any significant effect, there is some baseline selection in our cohort. For example, patients with severe systemic disease (American Society of Anesthesiologists (ASA) classification of 3 or higher) cannot be treated in these clinics due to national laws and guidelines. However, there is currently no evidence that patients with systemic disease would have different outcomes. Furthermore, patients in the current cohort who were treated with collagenase are from a time when collagenase was introduced in the Netherlands and our clinics were appointed as training centers. Afterwards, insurance companies in the Netherlands decided not to reimburse treatment with collagenase. This made the use of collagenase very limited in the Netherlands and severely limits our possibilities to study this treatment.

Limitations more specific to *Part 2* include the timing when the Illness Perception Questionnaire (IPQ) was collected. Illness perception can be influenced in many ways, starting with information about the disease, its prognosis and treatment options. As the IPQ was collected after patients received their diagnosis and information about the disease, the consulting physician would be able to influence the illness perception of patients. Furthermore, in the absence of an interventional study, it is impossible to provide a definitive conclusion about the direction of this association between treatment context and health outcome. With other words, it is impossible to tell if patients with a better experience will have a better outcome or visa versa.

Finally, specific to *Part 4*, complete finger extension was chosen as the outcome of interest. However, the chance of achieving a straight finger after sur-

gery is not the only consideration in the decision for a certain treatment. Other important considerations could be complication– and recurrence rates. Currently, none of the available treatments is superior across all considerations, making the decision for a certain treatment a trade-off between these considerations. To aid this decision making each considerations requires development of a specific prediction model with, most likely, different prognostic variables.

FUTURE PERSPECTIVES

Dupuytren's disease will stay an interesting topic for research for the foreseeable future and many challenges lay ahead. First of all, there is currently no definitive cure for Dupuytren's disease. Although not the focus of this thesis and therefore not discussed, at least part of the research efforts made in the field of Dupuytren's should focus on finding this cure and preventing the digital contractions associated with the disease. Besides this more fundamental research, Dupuytren's disease is also of great interest to other fields of research. In contrast to most other hand disorders, Dupuytren's disease is one of few hand disorders which has a clear, objective outcome measure in the form of extension deficit. This objective outcome measurement combined with patient-reported outcome measurements serves as an intriguing platform for future research, whether it be evaluating the outcome of (new) surgical techniques or exploring the influence of psychological aspects in Dupuytren's disease. In the following paragraphs we will discuss future perspectives related to this thesis.

In *Part 1* we introduce the Hand and Wrist Cohort, which is currently unique within the field of hand and wrist disorders since it contains a large number of patients with a relatively great detail of data, covering both outcomes, treatment information and patient characteristics. Further optimization of the current cohort is possible by minimizing patient burden. A lower patient burden can potentially improve follow-up and reduce missing data. Furthermore, it would be of great value if more healthcare providers in hand and wrist care would routinely measure outcomes. Data of a variety of healthcare providers would lead to a more heterogenous study population and wider variety of treatments. This would facilitate comparison and collaborations between healthcare providers and researchers.

In *Part 2* we examined the psychological aspects and influence of context in patients with Dupuytren's disease. As literature in this field is relatively limited

for Dupuytren's disease, multiple future research focuses are possible. First, it is worthwhile to evaluate other psychological aspects in patients with Dupuytren's disease. Of these psychological aspects, expectations might be the most interesting. Expectations are known to be an important aspect of placebo-like effects.[14] It has been demonstrated that expectations can be modulated in various ways, which in turn can have beneficial effects on treatment.[15-18] The role of expectations in Dupuytren's disease or hand surgery in general is currently unclear, but could play an important role in perceived hand function. Second, for most psychological aspects, it is unknown how they relate to hand function prior and after treatment. For example, it is unknown if patients who perceive their illness as more threatening also report a worse hand function in general or worse outcome after treatment. Insight into these relations could guide new treatment- and research strategies. Third and last, interventional studies are needed to provide insight into the direction of the relation. Our study on the relation between healthcare delivery and treatment could not provide a definitive answer if there is a causal relation and its direction. A well-designed study where, for example, healthcare providers receive communication training could provide insight into the direction of the relation.

In *Part 3* we explored a variety of outcome parameters, including extension deficit, hand function from a patient's perspective, hand appearance, return to work and outcome after repeated treatment. Future studies could focus on which parameter best capture the patient's needs. The individualized aspect of PROMs, such as the PSFS, overcomes limitations of fixed-item PROMs, such as the MHQ and DASH, when evaluating patients with Dupuytren's disease. Their flexible nature makes them ideal for evaluating the wide array of functional problems in Dupuytren's disease. Furthermore, the PSFS is quick and easy to complete, making it interesting for further evaluation in the field of Dupuytren's disease. Besides functional problems, an effort could be made in understanding non-functional problems in Dupuytren's disease. Hand appearance might be a reason for patients to seek treatment, as the social burden associated with hand deformities is large. The evaluation of recurrent contractures and their treatment will remain challenging, as well-designed, big cohorts with long term follow-up are needed to answer a number of questions.

In *Part 4* we demonstrated that a limited set of baseline characteristics can be used to reliably predict if a straight finger can be achieved after treatment. However, the decision for a certain treatment currently is a trade-off between

considerations such as complication rate, recurrence rates, and return-to-work. Each of these outcome parameters requires its own model with, most likely, different variables. These models, or a combination of different models, could then be used in informing patients. Further research should focus on how to best use these models when informing patients, what effects this would have on the patients' expectations and if the use of these models result in improvement of outcome.

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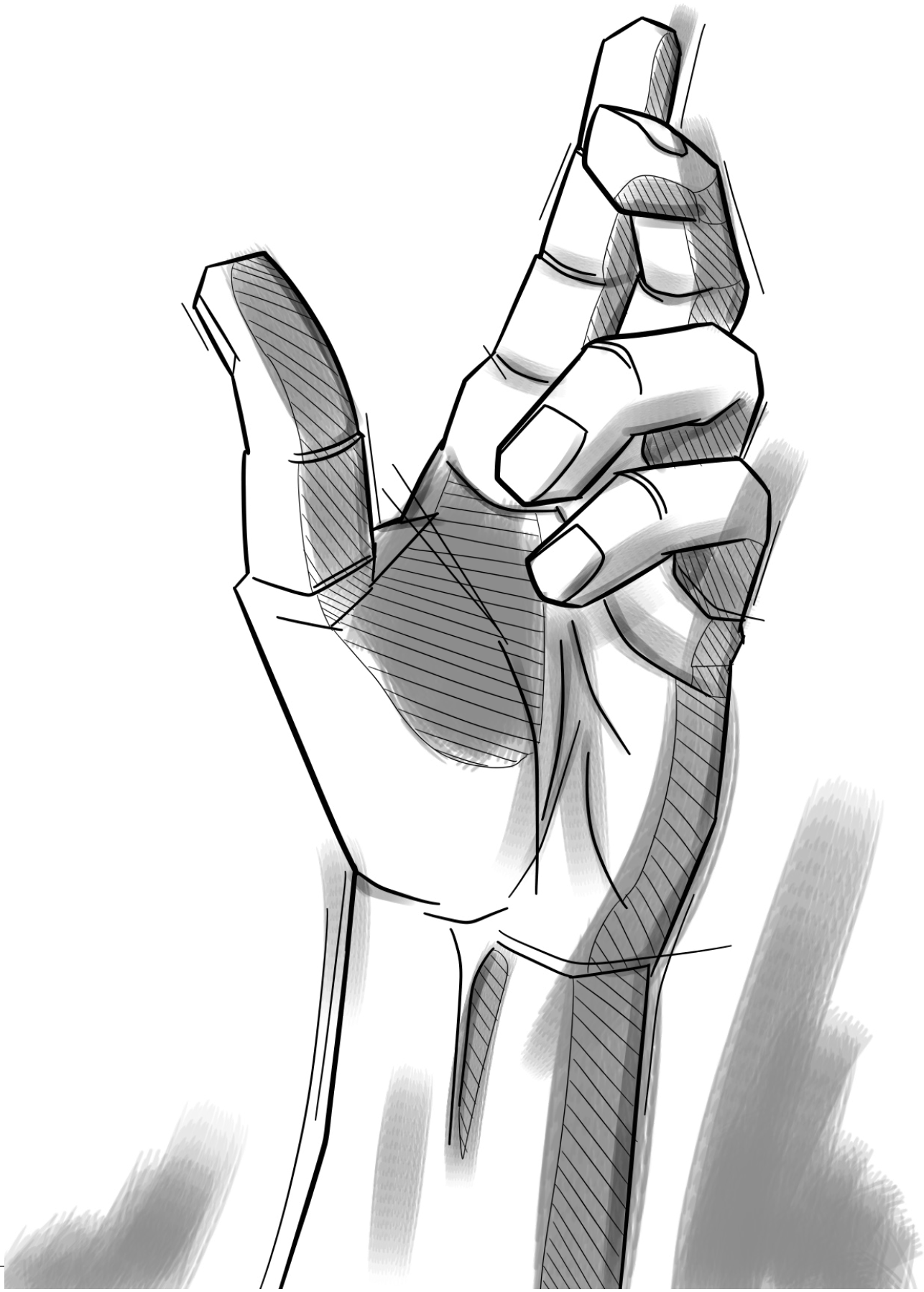


Chapter 11

Summary

This thesis explored various outcome measures in Dupuytren's disease and their relationship with patient and disease characteristics and treatment outcomes in order to better understand what matters to patients with Dupuytren's disease and what is important in the treatment of their disease.

To do so, this thesis is structured in four parts: 1. introduction of the Hand and Wrist Cohort, 2. psychology and context, 3. treatment and outcome, 4. predicting outcome.

PART 1. INTRODUCTION OF THE HAND AND WRIST COHORT

The Hand and Wrist Cohort (**Chapter 2**) is a routine outcome measurement cohort, which has a similar structure as an open inception cohort. The cohort forms the base of the studies performed in this thesis. The data is collected at fixed times in the treatment of patients via web-based, open-source software. Besides a wide array of patient and disease characteristics, various outcome measurements are collected, including total active extension deficit, patient-reported outcome measurements, return to work, and satisfaction with the outcome. The cohort currently holds over 52.000 patients. More specific for this thesis, it includes over 3000 patients with Dupuytren's disease. Inception cohorts can be helpful in answering a multitude of clinically-relevant questions, but are especially powerful for prognostic studies and prediction modeling. Furthermore, successful implementation of routine outcome measurements in a clinic can provide direct feedback to both patients and physicians and might improve daily care.

PART 2. PSYCHOLOGY AND CONTEXT

Many psychologically-orientated factors potentially have a role in perceived hand function and in how patients respond to treatment. However, little is known about the influence of these factors in Dupuytren's disease. This thesis focuses on two of those factors: illness perception and experience with healthcare delivery.

In **Chapter 3**, illness perceptions were explored in patients scheduled to undergo surgery for four major illnesses in hand surgery. The Brief Illness Perception Questionnaire (Brief-IPQ) was used to rapidly assess the cognitive and emotional representation of the disorder in patients. On a scale ranging from zero (not threatening) to 80 (most threatening), the average Brief-IPQ sum scores for these subgroups were 42 for carpometacarpal osteoarthritis, 28 for Dupuytren's disease, 39 for carpal tunnel syndrome and 33 for trig-

ger finger syndrome. These findings suggest that patients with Dupuytren's disease do not perceive their illness as very threatening compared to other chronic hand disorders and that preoperative interventions focused on changing illness perceptions may not be necessary for the majority of patients with Dupuytren's disease.

In **Chapter 4**, the experience with healthcare delivery was assessed using a patient-reported experience measure related to post-operative treatment outcomes assessed using the Michigan Hand Outcomes Questionnaire (MHQ) and the total active extension deficit. We found that a better experience with health care delivery was associated with better patient-reported outcomes while the association with residual extension deficit was minimal. A good experience with the communication of healthcare providers and treatment information had the strongest association with positive treatment outcomes. Experience with the treatment explained up to twelve percent of the variance in treatment outcome. These findings indicate that optimizing communication and information in healthcare delivery could be a valuable opportunity to improve outcomes.

PART 3. TREATMENT AND OUTCOME

Measuring and understanding what is important for a patient is fundamental to understand the burden of disease and the success of treatment. However, measuring outcome can be done in multiple ways, all with their unique advantages and pitfalls. This part of the thesis focuses on exploring some of these outcome measures.

Traditional, fixed-item PROMs may not capture all functional problems of patients with Dupuytren's disease. The Patient-Specific Functional Scale (PSFS) is an individualized questionnaire that enables patients to specify those activities with which they have difficulty in daily life. In **Chapter 5**, the content validity and responsiveness of the PSFS were determined in patients with Dupuytren's disease. Content validity, assessed with the International Classification of Function scale, was appropriate for patients with Dupuytren's disease. The responsiveness of the PSFS was superior to the responsiveness of the MHQ score, as indicated by a larger effect size (1.0 vs. 0.58). These results support the concept that measuring self-generated items may better reflect the needs and problems of the individual patient and how they improve after treatment. These characteristics could make individualized PROMs, such as the PSFS, be the next step forward in patient-centered healthcare.

In **Chapter 6**, the effect of the treatment of Dupuytren's disease on the different domains of patient-reported hand function, such as hand appearance and satisfaction with hand function, is explored. The largest effects of surgery were seen in the change in extension deficit, the appearance of the hand, and the satisfaction with hand function. All associations between MHQ-(sub) scores and extension deficit remained weak with relatively low explained variances. This study underlines the importance of assessing other domains than hand function in Dupuytren's disease.

In **Chapter 7**, return to work after treatment for Dupuytren's disease is assessed. At intake, 53% of the patients with Dupuytren's disease were gainfully employed. Within a year, 90% of those patients returned to work. Of those who underwent a limited fasciectomy, 50% returned to work after two weeks, while for the percutaneous needle fasciotomy, 50% returned to work after only one day. Physically strenuous work, female sex, and higher age were associated with a longer time to return to work. These results show that the majority of patients returned to work. The time to return to work is much shorter after a percutaneous needle fasciotomy compared to a fasciectomy.

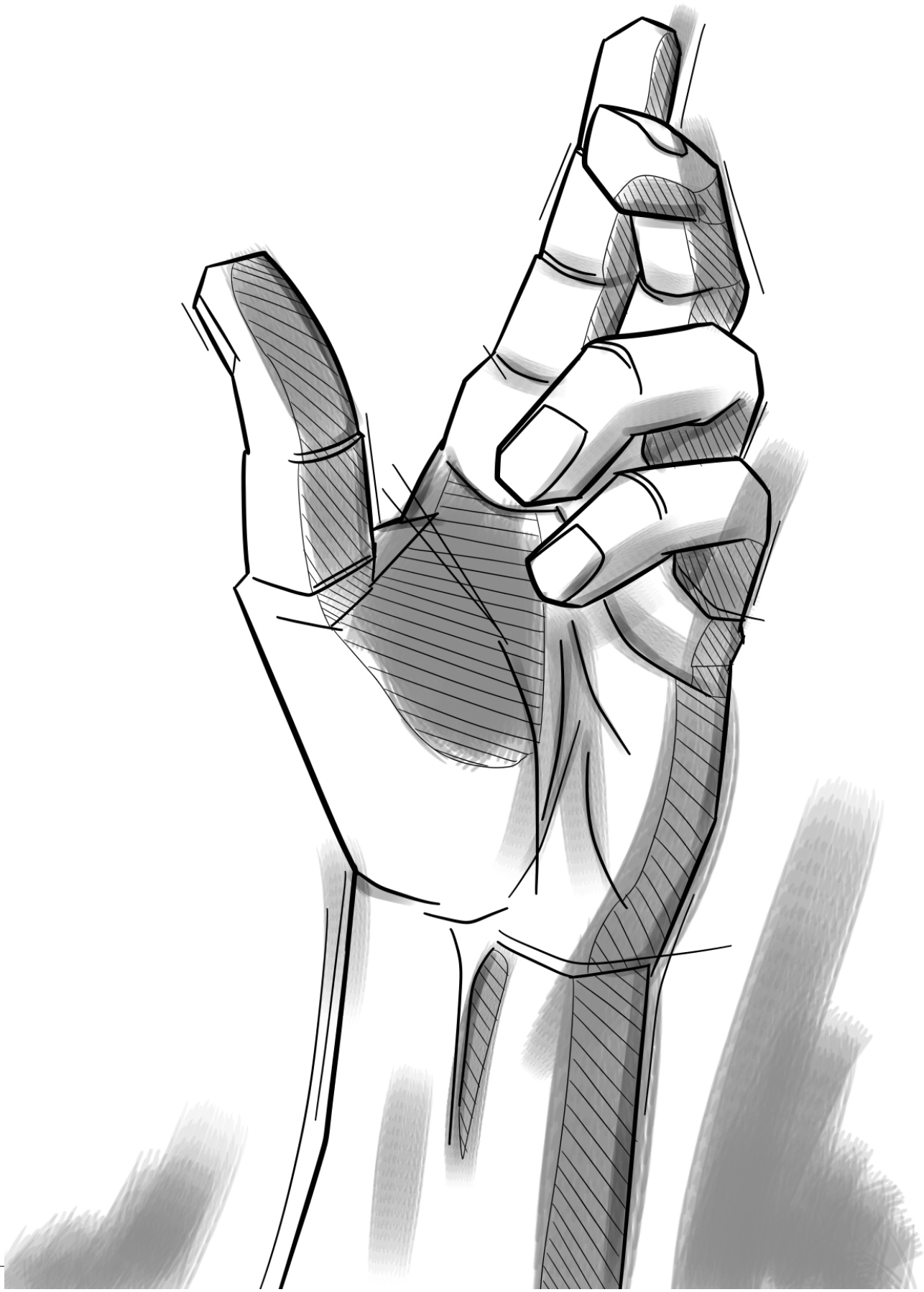
In **Chapter 8**, the treatment effectiveness of initial and repeated surgery in patients with Dupuytren's disease is compared. Improvement in extension deficit and MHQ outcomes was equal for initial and repeated treatments. In addition, patients who initially underwent needle fasciotomy achieved a better contracture reduction after repeated treatment. Complication rates were similar for initial and repeated treatments. The results suggest that repeated treatment in Dupuytren's disease can be done with comparable effectiveness.

PART 4. PREDICTING OUTCOME

In **Chapter 9**, we explore to which extent pre-operative patient and disease characteristics can reliably predict if a straight finger will be obtained with surgery for Dupuytren's disease. For both limited fasciectomy and percutaneous needle fasciotomy, baseline extension deficit, the type of finger and affected joint, as well as the number of affected fingers, independently determine if a straight finger can be achieved. Classical patient characteristics, such as age and sex, had no additional predictive value. The models presented in this study provide reliable predictions and could be helpful in informing patients and managing their expectations.

CONCLUSION

In conclusion, this thesis demonstrated that Dupuytren's disease is more than simply an extension deficit of the finger. Many different outcome measures are available and many outside influences are involved. All of these matter to various extents. Which measurements and influences are important to which patients will remain the subject of further research. Finally, combining all this knowledge should enable us to predict which patients benefit most from what treatment and with that truly deliver patient-centered care.



Chapter 12

Nederlandse samenvatting

Dit proefschrift onderzocht verschillende uitkomstmaten bij de ziekte van Dupuytren en hun relatie met patiënt- en ziektekenmerken en behandelresultaten om beter te begrijpen wat belangrijk is voor patiënten met de ziekte van Dupuytren en wat belangrijk is bij de behandeling van hun ziekte.

Om dit te doen is dit proefschrift gestructureerd in vier delen: 1. introductie van het 'Hand and Wrist Cohort', 2. psychologie en context, 3. behandeling en uitkomst, 4. voorspellen van uitkomsten.

DEEL 1. INTRODUCTIE VAN HET 'HAND AND WRIST COHORT'

Het 'Hand and Wrist Cohort' (**Hoofdstuk 2**) is een cohort met routinematige uitkomstmetingen, dat een vergelijkbare structuur heeft als een open inceptiecohort. Het cohort vormt de basis van de onderzoeken die in dit proefschrift zijn uitgevoerd. De gegevens worden op vaste tijden verzameld bij de behandeling van patiënten via web-based, open source software. Naast een breed scala aan patiënt- en ziektekenmerken, worden verschillende uitkomstmetingen verzameld, waaronder de extensiebeperking van een vinger, door de patiënt gerapporteerde uitkomstmaten, terugkeer naar het werk en tevredenheid met de uitkomst. Het cohort heeft momenteel meer dan 52.000 patiënten. Meer specifiek voor dit proefschrift omvat het meer dan 3000 patiënten met de ziekte van Dupuytren. Inceptiecohorten kunnen nuttig zijn bij het beantwoorden van een groot aantal klinisch relevante vragen, maar zijn vooral krachtig voor prognostische studies en voorspellingsmodellering. Bovendien kan succesvolle implementatie van routinematige uitkomstmetingen in een kliniek directe feedback geven aan zowel patiënten als artsen en kan het zo de dagelijkse zorg verbeteren.

Deel 2. Psychologie en context

Veel psychologisch georiënteerde factoren spelen potentieel een rol in de waargenomen handfunctie en in hoe patiënten reageren op een behandeling. Er is echter weinig bekend over de invloed van deze factoren op de ziekte van Dupuytren. Dit proefschrift richt zich op twee van die factoren: ziekteperceptie en zorgbeleving.

In **Hoofdstuk 3** werd ziekteperceptie onderzocht bij patiënten die gepland waren voor een operatie voor vier belangrijke ziekten bij handchirurgie. De Brief Illness Perception Questionnaire (Brief-IPQ) werd gebruikt om snel de cognitieve en emotionele representatie van de stoornis bij patiënten te beoordelen. Op een schaal variërend van nul (niet bedreigend) tot 80 (meest

bedreigend), waren de Brief-IPQ somscores voor deze subgroepen gemiddeld 42 voor carpometacarpale artrose, 28 voor de ziekte van Dupuytren, 39 voor carpaal tunnelsyndroom en 33 voor trigger finger syndroom. Deze bevindingen suggereren dat patiënten met de ziekte van Dupuytren hun ziekte niet als zeer bedreigend ervaren in vergelijking met andere chronische handaandoeningen en dat preoperatieve interventies gericht op het veranderen van ziektepercepties mogelijk niet nodig zijn voor de meerderheid van de patiënten met de ziekte van Dupuytren.

In **Hoofdstuk 4** werd de zorgbeleving beoordeeld aan de hand van patiënt-gerapporteerde scores gerelateerd aan postoperatieve behandelresultaten, beoordeeld met behulp van de Michigan Hand Outcomes Questionnaire (MHQ) en het totale tekort aan actieve extensie. We ontdekten dat een betere zorgbeleving geassocieerd was met betere patiënt-gerapporteerde resultaten, terwijl de associatie met een tekort aan resterende extensie minimaal was. Een goede ervaring met de communicatie van zorgverleners en behandelinformatie had de sterkste associatie met positieve behandelresultaten. Ervaring met de behandeling verklaarde tot twaalf procent van de variantie in het behandelresultaat. Deze bevindingen geven aan dat het optimaliseren van communicatie en informatie in de gezondheidszorg een waardevolle kans kan zijn om de resultaten te verbeteren.

DEEL 3. BEHANDELING EN RESULTAAT

Het meten en begrijpen van wat belangrijk is voor een patiënt is van fundamenteel belang om de ziektelast en het succes van de behandeling te begrijpen. Het meten van de resultaten kan echter op meerdere manieren worden gedaan, allemaal met hun unieke voordelen en valkuilen. Dit proefschrift richt zich op het verkennen van enkele van deze uitkomstmaten.

Traditionele patient-reported outcome measures (PROM's) met vaste items bevatten mogelijk niet alle functionele problemen van patiënten met de ziekte van Dupuytren. De Patient-Specific Functional Scale (PSFS) is een geïndividualiseerde vragenlijst waarmee patiënten kunnen specificeren met welke activiteiten zij in het dagelijks leven moeite hebben. In **Hoofdstuk 5** worden de geschiktheid van de vragen (content validity) en responsiviteit van de PSFS bepaald bij patiënten met de ziekte van Dupuytren. De inhoud van de vragen, beoordeeld met de Internationale Classificatie van Functieschaal, was geschikt voor patiënten met de ziekte van Dupuytren. De responsiviteit van de PSFS was superieur aan de responsiviteit van de MHQ-score, zoals

aangegeven door een grotere effectsize (1,0 vs. 0,58). Deze resultaten ondersteunen het concept dat het meten van zelf-gegenereerde items mogelijk beter aansluit bij de behoeften en problemen van de individuele patiënt en hoe deze verbeteren na behandeling. Deze kenmerken maken dat individuele PROM's, zoals de PSFS, van waarde kunnen zijn om een volgende stap voorwaarts te maken in patiëntgerichte gezondheidszorg.

In **Hoofdstuk 6** wordt het effect van de behandeling van de ziekte van Dupuytren op de verschillende domeinen van door de patiënt gerapporteerde handfunctie, zoals het uiterlijk van de hand en tevredenheid met de handfunctie, onderzocht. De grootste effecten van chirurgie werden gezien in de verandering in extensiebeperkingen, het uiterlijk van de hand en de tevredenheid met de handfunctie. Alle associaties tussen MHQ- (sub)scores en extensie beperkingen bleven zwak met relatief lage verklaarde varianties. Deze studie onderstreept het belang van het beoordelen van andere domeinen dan de handfunctie bij de ziekte van Dupuytren.

In **Hoofdstuk 7** wordt werkhervatting na behandeling van de ziekte van Dupuytren beoordeeld. Bij opname had 53% van de patiënten met de ziekte van Dupuytren een baan. Binnen een jaar ging 90% van die patiënten weer aan het werk. Van degenen die een beperkte fasciectomie ondergingen, ging 50% na twee weken weer aan het werk, terwijl voor de naaldfasciotomie 50% na slechts één dag weer aan het werk ging. Lichamelijk zwaar werk, vrouwelijk geslacht en hogere leeftijd waren geassocieerd met een langere tijd om weer aan het werk te gaan. Deze resultaten laten zien dat de meerderheid van de patiënten weer aan het werk ging. De tijd om weer aan het werk te gaan is veel korter na een naaldfasciotomie in vergelijking met een fasciectomie.

In **Hoofdstuk 8** wordt de effectiviteit van de initiële en recidief behandeling bij patiënten met de ziekte van Dupuytren vergeleken. Verbetering van extensie beperking en MHQ-resultaten was gelijk voor initiële en recidief behandelingen. Bovendien bereikten patiënten die aanvankelijk een naaldfasciotomie ondergingen een betere contractuurvermindering na recidief behandeling. Complicaties waren vergelijkbaar voor initiële en recidief behandelingen. De resultaten suggereren dat recidief behandeling bij de ziekte van Dupuytren met vergelijkbare effectiviteit kan worden gedaan.

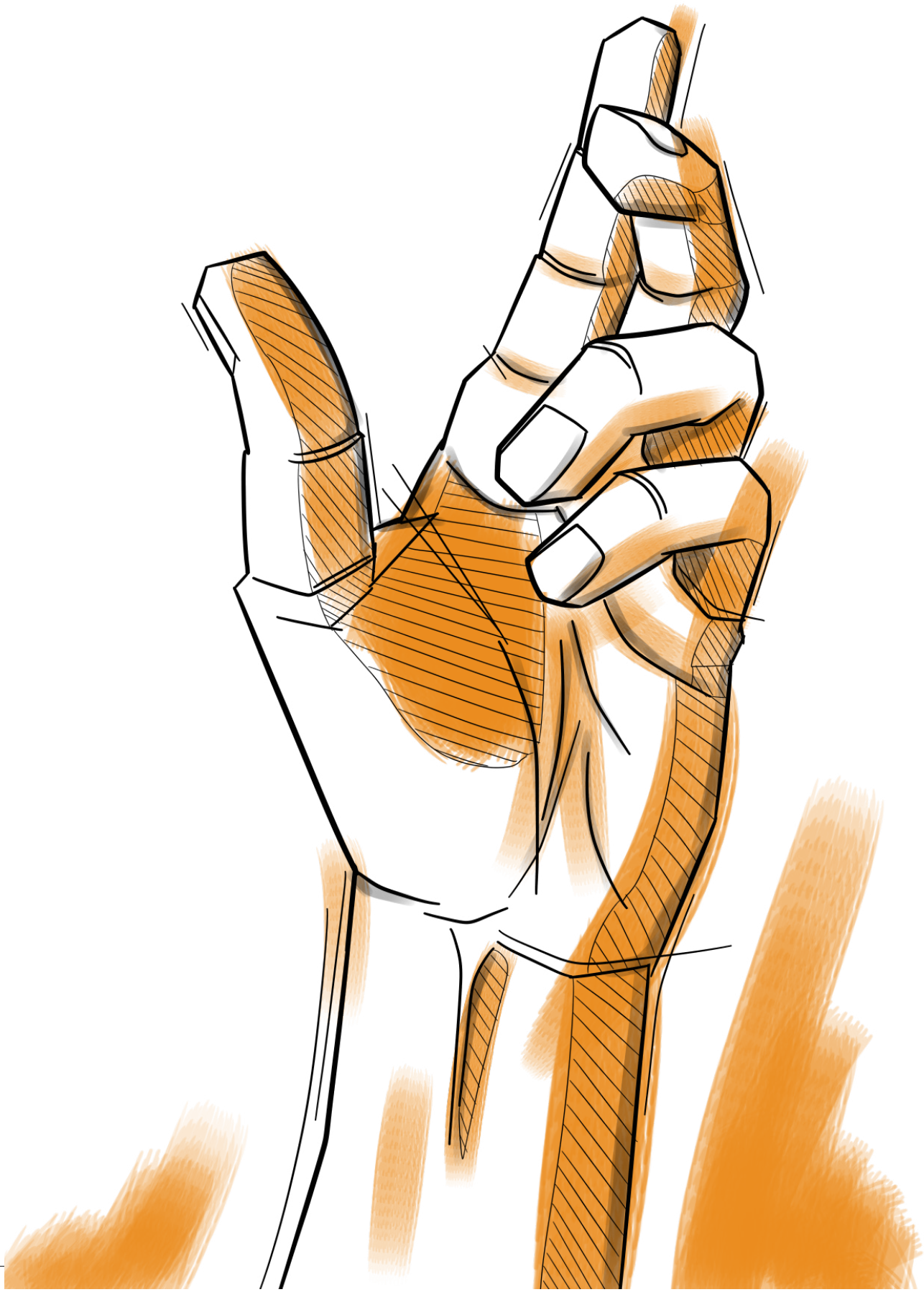
DEEL 4. RESULTAAT VOORSPELLEN

In **Hoofdstuk 9** onderzoeken we in hoeverre preoperatieve patiënt- en ziektekenmerken betrouwbaar kunnen voorspellen of een rechte vinger kan

worden verkregen met een operatie voor de ziekte van Dupuytren. Voor zowel een beperkte fasciectomie als een naaldfasciotomie voorspellen vier kenmerken of een rechte vinger kan worden verkregen: de extensie beperking op baseline, welke vinger is aangedaan, welk gewricht is aangedaan en het aantal aangedane vingers. Klassieke patiëntkenmerken, zoals leeftijd en geslacht, hadden geen aanvullende voorspellende waarde. De modellen die in dit onderzoek worden gepresenteerd bieden betrouwbare voorspellingen en kunnen nuttig zijn bij het informeren van patiënten en het inspelen op hun verwachtingen.

CONCLUSIE

Concluderend toonde dit proefschrift aan dat de ziekte van Dupuytren meer is dan alleen een extensie beperking van de vinger. Er zijn vele verschillende uitkomstmaten beschikbaar en er zijn vele invloeden van buitenaf bij betrokken. Al deze zaken zijn in verschillende mate van belang. Welke metingen en invloeden belangrijk zijn voor welke patiënten zal onderwerp van onderzoek blijven. Tenslotte zou het combineren van al deze kennis ons in staat moeten stellen te voorspellen welke patiënten het meest baat hebben bij welke behandeling en daarmee werkelijk patiëntgerichte zorg te leveren.



Part V

Appendices

LIST OF PUBLICATIONS

Jonker PKC*, van der Plas WY*, Steinkamp PJ*, Poelstra R, Emous M, van der Meij W, Theunissen F, Bierman WFW, Struys MMRF, de Reuver PR, de Vries JPPM, Kruijff S. **Perioperative mortality, pulmonary complications and thromboembolic events in patients undergoing surgery during the COVID-19 pandemic: a Dutch multicenter matched-cohort clinical study.**
Acccepted for Surgery

van der Oest MJW, Teunissen JS, Poelstra R, Feitz R, Burdorf A, Selles RW & the Hand-Wrist Study. **Group factors associated with return to work after surgical treatment for carpometacarpal osteoarthritis of the thumb.**
Submitted

Blake S*, Poelstra R*, Andrinopoulou ER, Obdeijn MC, van der Oest MJW, Feitz R, Burdorf A, Selles RW. **Return to work and associated costs after treatment for Dupuytren's disease.**
Accepted for Plastic and Reconstructive Surgery

Poelstra R, Andrinopoulou ER, van Nieuwenhoven CA, Slijper HP, Feitz R, Selles RW, Hovius SER & the Hand-Wrist Study Group. **Predicting complete finger extension In Dupuytren's disease.**
Submitted

Van Kooij YE, Poelstra R, Porsius JT, Slijper HP, Warwick D, Selles RW & the Hand-Wrist Study Group. **Content validity and responsiveness of the Patient Specific Functional Scale in patients with Dupuytren's disease.**
Journal of Hand Therapy. 2020 April. [Epub ahead of print]

Selles RW, Wouters RM, Poelstra R, van der Oest MJW, Porsius JT, Hovius SER, Moojen TM, van Kooij YE, Pennehouat PY, van Huis R, Vermeulen GM, Feitz R, the Hand-Wrist Study Group, Slijper HP. **Routine health outcome measurement: Development, design and implementation of the Hand and Wrist Cohort.**
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Blackburn J, van der Oest MJW, Poelstra R, Selles RW, Chen NC, Feitz R & the Hand-Wrist Study Group. **Short-term outcome of three-ligament tenodesis for chronic scapholunate injuries. A prospective study of 203 patients.**
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van den Oest MJW, Poelstra R, Feitz R, Slijper HP, Selles RW, Porsius JT & the Hand-Wrist Study Group. **Illness perceptions of patients with first carpometacarpal osteoarthritis, carpal tunnel syndrome, Dupuytren contracture, or trigger finger.**
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Mendelaar NHA*, Poelstra R*, van Nieuwenhoven CA, Slijper HP, Feitz R, Hovius SER, Selles RW. **Outcome of recurrent surgery in Dupuytren's disease; comparison with initial treatment.**
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Tsehaie J, van den Oest MJW, Poelstra R, Selles RW, Feitz R, Slijper HP, Hovius SER, Porsius JT & the Hand-Wrist Study Group. **Positive experiences with the treatment process is associated with better outcome after surgery for carpometacarpal osteoarthritis.**
Journal of Hand Surgery (European Volume). 2019 Sep;44(7):714-721.

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Plastic and Reconstructive Surgery. 2019 Jun;143(6):1677-1684.

Poelstra R, Selles RW, Slijper HP, van der Oest MJW, Feitz R, Hovius SER, Porsius JT & the Hand-Wrist Study Group. **Better patients' treatment experiences are associated with better postoperative results in Dupuytren's disease.**
Journal of Hand Surgery (European Volume). 2018 Oct;43(8):848-854.

Poelstra R & Van der Hem LG. **Waar aneurysma van de arteria tibialis posterior.**
Nederlands Tijdschrift voor Heelkunde. 2016;25

* Authors contributed equally in the preparation of this manuscript

PhD Portfolio

Summary of PhD training and teaching

Name PhD student: R. Poelstra

Erasmus MC department: Plastic and Reconstructive Surgery and Hand Surgery

PhD period: March 2017 – April 2020

Promotor(s): Em. Prof. Dr. S.E.R. Hovius

Supervisor: Dr. R.W. Selles

1. PhD Training	**Year**	**Workload (ECTS)**
General academic skills		
R: statistical programming. Multiple online courses.	2017	3.0
Research skills		
Repeated Measurements	2018	1.4
Joint Models for Longitudinal and Survival Data	2017	0.7
Logistic Regression	2017	1.4
Advanced Analysis of Prognosis Studies	2017	1.4
Presentations		
Predicting complete finger extension after surgery for patients with Dupuytren's disease SASSH, Adelaide, Australia	2018	0.8
Predicting complete finger extension after surgery for patients with Dupuytren's disease FESSH, Copenhagen, Denmark	2018	0.8
Patients' treatment experience influences post-operative results in Dupuytren's disease FESSH, Copenhagen, Denmark	2018	0.8
De associatie tussen zorgbeleving en behandeluitkomsten na chirurgie bij Dupuytren NVPC-dagen, Hengelo	2017	0.8

Conference, symposium and workshop attendance		0.3
Delft Data Science Seminar - Visual Data Science and its role in Computational Medicine Delft	2018	
		0.5
useR! 2017 Brussels, Belgium	2017	
		0.3
Big Hand Event Symposium Utrecht	2017	
		0.3
25th Esser course: oncoplastic breast reconstruction Rotterdam	2017	

2. Teaching and Lecturing	**Year**	**Workload (ECTS)**
Lecturing & Skills		
Medical students – Minor	2017-2018	1.0
Medical students – Master	2017-2018	1.0
Wound care nurses: wound debridement	2017-2018	2.0
Microsurgery skills	2017-2018	2.0
Supervising Master's theses		
Nienke H.A. Mendelaar Hand Function of Patients with Recurrent Dupuytren's disease 01-11-2017 to 25-05-2018	2018	3.0
Shacara N. Blake Return to Work after Surgery for Dupuytren's Disease 27-08-2018 to 17-12-2018	2018	3.0

DANKWOORD

ABOUT THE AUTHOR

Ralph Poelstra was born January 28th, 1987 in Rotterdam. After graduating from the Libanon Lyceum (Rotterdam) he started medical school at the Erasmus University in 2005. During his years in medical school Ralph was involved in various teaching activities, most notably the Erasmus Anatomy Research Project. During his fourth year of medical school he started a Neuroscience research master from which he graduated 2 years later. After traveling for eight months in China, South-East Asia and Australia he started his internships and graduated from medical school in 2013. Thereafter, Ralph worked in general surgery in Aruba (Horacio E. Oduber Hospital), Deventer (Deventer Ziekenhuis) and Groningen (University Medical Centre Groningen), consecutively. In 2017 he started his PhD under the supervision of prof. dr. S.E.R. Hovius and dr. R.W. Selles, which led to this thesis. While pursuing his PhD-degree, Ralph competed in the Cape Epic, a grueling mountainbike stage race in South Africa, and finished an Ironman. He is currently working in Medisch Centrum Leeuwarden (dr. M. Emous) as part of the general surgery residency program.