Review article



Patient Reported Outcome Measures Assessing Health-Related Quality Of Life in Dupuytren'S Disease: A Systematic Review

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Abstract

Objective: The objective of this study is to carry out a systematic review of the outcome measures reported by the patient that are used to measure the quality of life of patients with Dupuytren's disease (DD), assessing their relevance and effectiveness.

<u>Methods</u>: A systematic literature search was carried out in the PubMed®, Web of Sciencie®, SciELO®, EMBASE®, Google Scholar® and Cochrane® databases. We searched for peer-reviewed articles evaluating health related quality of life (HR-QoL) in patients with DD diagnosed and/or treated until April 1, 2017, for English or Spanish language. The following keywords were used: "Dupuytren's disease (MeSH)" AND "health related quality of life (MeSH)". The documents were eligible for inclusion if they described data on the HR-QoL domains in relation to diagnosis or treatment of DD after a revision process by two independent authors. The checklist (STROBE) was used to evaluate the quality of the works.

<u>**Results:**</u> From 352 identified articles were finally selected 26 studies in the systematic review, mostly European. A total of nine outcomes measures specifically reported by the patient were identified: DASH (used in 13 of the 26 selected studies), Quick-DASH (8/26), MHQ (7/26), briefMHQ (1/26), URAM (4/26), POS-HAND/ARM (1/26), SDSS (1/26), DDSP (1/26) and CHFS (1/26) questionnaires. We analyze their quantitative results to evaluate the effectiveness and evaluate the methodological quality of the studies on the measurement properties of the results reported by patients related to health.

Conclusion: More work is urgently needed in these areas before we can reach a consensus on which instrument is the best to assess functional deterioration and improvement in patients with DD.

<u>Keywords</u>: Dupuytren's disease, evaluation questionnaire, health related quality of life, patient reported outcome measures, questionnaire validation.

Introduction

Dupuytren's disease (DD) is a common fibroproliferative disorder of the hand affecting 4-6% of the population in northern Europe^[1]. DD involves pathologic myofibroblast forming cords due to collagen deposits in the hand's palmar fascia, which can result in fixed flexion deformity of the affected finger impairing normal hand function. Depending on the degree of contracture and the resulting deformity of the hand, a patient's daily activities may become significantly affected as may the health-related quality of life (HR-QoL). HR-QoL refers to the physical, psychological and social domains of health that are influenced by a person's experiences, beliefs, expectations and perceptions^[2].

The impact of DD may vary according to age, sex, comorbidity, or lifestyle. In clinical practice, patient reported outcome measures (PROM) are increasingly used for outcome evaluation in addition to clinician-based outcomes, to gain further knowledge on domains such as symptoms, functioning, health perception, satisfaction and HR-QoL. PROM can be either general in nature or specific (region-specific and disease-specific). Specific PROM have greater face validity and credibility than generic PROM in DD, because they are designed to identify specific symptoms and their impact on the function of those specific conditions^[3], these specific PROM are uniquely able to quantify function and limitations from the patient's perspective^[4].

PROM assessing HR-QoL are increasingly used in patients with DD to assess the impact of disease upon individuals and carers and has found utility as a method of understanding chronic lifelong disease and impairment^[5]. PROM are commonly utilized in a self-report questionnaire format, which is predominantly quantitative, to facilitate a defined threshold for intervention^[4,6].

Several PROM have been used to evaluate DD, the most appropriate outcome measure in DD research has not yet been established^[4-6]. Unless a validated measure is used, a comparison cannot be made. The objective of this study is to perform a systematic review of the disease-specific and region-specific PROM used to measure the HR-QoL of patients with DD, assessing their relevance and effectiveness.

Methods

Information Sources and Searches

According to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, a comprehensive electronic search strategy was used to identify peer-reviewed articles assessing HR-QoL by patients with DD diagnosed and/or treated with up to 1 April 2017. The following keywords were used: "Dupuvtren's disease [medical subject heading (MeSH) terms]" combined using AND Boolean operator with "health related quality of life (MeSH)". A free search was carried out posteriorly with the same terms to assess the degree of information loss associated with this strategy. After the initial search was performed, studies were screened for eligibility; their relevance was initially assessed using titles and abstracts and finally the full review of papers. Searching and eligibility of target responses were carried out independently by two investigators (DGH and FJCH); any type of disagreements was resolved by consensus among these primary raters and a senior investigator (RSC). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)^[7] checklist was used to evaluate the quality of the papers to guarantee the quality of the selection of the articles included, by two independent authors.

Electronic research-literature databases searched included PubMed®, Web of Sciencie® (WOS®), SciELO®, EMBASE®, Google Scholar® and Cochrane® databases. In order to detect any missed articles during the literature search, reference lists of candidate articles were reviewed for further studies not yet identified. For each excluded study, we determined which elements of the electronic search were not addressed.

Eligibility Criteria

Papers were eligible for inclusion if they were research reports in English and Spanish language describing data on HR-QoL domains in relation to DD diagnosis or treatment. We focused on studies examining quality of life in patients with DD using region-specific and disease-specific questionnaires. Based on this inclusion criterion, we selected studies referring to specific PROM by consequently excluding research reports assessing quality of life with general or non-specific questionnaires. We excluded peerreviewed single-case studies, meta-analyses, letters to the editor and commentaries, conference abstracts, books, and papers that were clearly irrelevant. No limit was set with regard to publication date.

Analysis and Data Synthesis

The heterogeneous nature of the identified studies (in terms of design and measures) did not permit a formal meta-analysis. Studies were categorized based on the object of the study. Significant information for each study was summarized and compared by means of a structured form previously arranged by the researchers.

Results

Clinical study design

The database search, supplemented by further manual search, initially provided a total of 352 articles (Figure 1). After excluding duplicate studies and reviewing the compiled abstracts to identify studies that did not meet the inclusion criteria, 48 studies were preselected for a full-text review. After a full read of each of the remaining studies, 20 were eliminated owing to insufficient data, one for cross-references with previous studies, and one for being in the Polish language. Ultimately, 26 studies were qualitatively analyzed in the systematic review. Quality of studies was assessed using the STROBE checklist. Table 1 shows the articles that were identified as relevant for the review, the characteristics and quality of each, and the demographic and clinical characteristics of the population on which each of the studies was conducted.

Patient reported outcome measures review

A total of nine different specific questionnaires used to measure the quality of life of patients with DD were identified in this review: the Disability of Arm, Shoulder and Hand (DASH) scale, the QuickDASH (short version of the DASH), the Michigan Hand Outcomes Questionnaire (MHQ), the briefMHQ (short version of the MHQ), "the Unité Rhumatologique de Affections de la Main" (URAM), the Patient Outcomes of Surgery-HAND/ARM (POS-HAND/ARM), the Southampton Dupuytren's Scoring System (SDSS), the Dupuytren's Disease Scale of Subjective Well-Being of Patients (DDSP) and the Cochin Hand Function Scale (CHFS). The quantitative results available from the DASH, QuickDASH, MHQ and URAM questionnaires in each of the articles analyzed in this review are shown in table 2. These four questionnaires were most commonly used to measure the quality of life of patients with DD. Their characteristics and the interpretation of their results. together with the DDSP and SDSS questionnaires, specific to DD, are described in table 3.

DASH was used in 13 of the 26 selected studies, representing a total of 1465 patients with DD. The validity of the DASH for patients with DD were evaluated in six studies^[8-13]: in three of them, the questionnaire was used to evaluate the satisfaction of DD patients during a follow-up of 3 to 12 months^[8-10], the range of the mean pre-surgery DASH value was 17.0 $(7.0-28.0)^{[8]}$ to 21.0 (SD 14.0)^[9], and post-surgery from 7.0 $(3.0-12.0)^{[10]}$ to 12.0 (SD 13.0)^[9]; in three other studies besides evaluating the emotional disability produced in patients with no prior treatment, the correlation with the severity of the contracture was studied^[11-13], the range pre-treatment resulting mean DASH value was 13.7 (SD 17.2)^[11] to 15.9 $(0-62.0)^{[13]}$. The study by Forget et al.^[14] evaluated

the psychometric properties of DASH for DD. The content and construct validity and reliability of the DASH for DD were evaluated in a cross-sectional study, with a post-treatment followup of up to five years, showing pre-treatment results of 27.0 (23.0-31.0), and post-treatment measures of 11.0 (9.0-13.0)^[15]. In another five studies, the DASH questionnaire was used as a comparator questionnaire for the development or validation of another specific questionnaire^[16-20].

The Quick DASH measure was used in eight studies, which meant a total of 859 patients with DD. The validity of the questionnaire for patients with DD, as well as its suitability as a post-surgical PROM, were evaluated in two studies obtaining range of the mean pre-surgery values of 15.1 (SD 13.1)^[21] to 22.0 (SD 27.0)^[19], and post-surgery from 7.9 (SD 12.3)^[21] to 17.0 (SD 23.0)^[19], during a follow-up of 110 days to 21 month. In two other studies also used this questionnaire to measure the quality of life of patients with DD, obtaining a mean post-treatment result of 2.0 (0-18.0)^[22], and another with a mean post-operative result of 2.5 (0-15.9)^[23], during a follow-up of six months to two years. In four studies, Quick DASH was used as a comparator^[15,24-26].

The MHQ questionnaire was employed in seven articles, adding up to a total of 616 patients with DD. The study by Thoma et al.^[27] measured the quality of life of the patients after surgical treatment; the mean of the results obtained before surgery was 74.0 (SD 15.0), while post-surgery it was 90.0 (SD 16.0). The validity of the questionnaire were evaluated too as a post-treatment PROM in other two studies during a follow-up of 12 weeks to one year^[28,29]. This PROM has also been translated into German and validated by Knobloch et al.^[20] obtaining a mean post-surgery value of 76.0 (SD 19.0). In three other studies, the MHQ was used as a comparator questionnaire^[17,18,26].

The URAM questionnaire was used in four articles representing a total of 350 patients. The URAM was the first PROM developed and validated for patients with DD which analyzed content validity, reliability, criterion validity and responsiveness^[30]. The Bernabé et al.^[16] study proved the convergent validity and ease of use of the URAM scale for patients with DD, using DASH and CHFS as comparative questionnaires, the latter developed to measure hand function in pathologies other than DD. Another study had as its goal the assessment of patient reports for DD surgery in a hand surgery clinic in the United Kingdom and compared them with the items on the URAM scale^[31]. In the study by Verstreken et al.^[32], the URAM questionnaire was used to measure the quality of life of patients with DD, prior to and one month after being treated with CCH; the average result obtained pre-treatment was 29.4 (SD 11.0), and 12.9 (SD 6.3) post-treatment.

The DDSP questionnaire was developed and validated for patients with DD, with the objective of subjectively measuring their psychosocial state^[33].

The SDSS questionnaire was designed and validated with the objective of quantifying the degree of patient disability produced by DD prior to and six months after surgery. It is a self-administered questionnaire that was developed based on a study of 61 patients with DD^[24].

Another study investigated the reliability, validity, responsiveness and interpretability of the brief MHQ questionnaire for patients with DD. This study was conducted on 57 patients who completed the study before and after being treated, either surgically or with CCH. The follow-up of the patients was up to one year after treatment. The questionnaires that were used as comparators in this study were the MHQ and the Quick DASH^[26].

The POS-HAND/ARM questionnaire was developed in the United Kingdom to measure the quality of life of patients with hand pathologies (23% DD)^[17].

The CHFS is a scale that was initially developed in France to assess the level of functional disability in the hands of rheumatoid arthritis patients. In this review was used as a comparator in a single study, together with the DASH, to analyze the properties of the URAM scale^[16].

Discussion

Our review serves to highlight the heterogeneity of the outcome measures used to determine quality of life outcomes for DD, as well as and the challenges faced when trying to interpret the data to determine best practices.

Over the last three decades, PROM have become established as tools to illustrate patient concerns and perspectives. They play an important role in alluding to the results of HR-QoL and identify differences in patient outcomes among treatment protocols. PROM can be used both as detection tools to identify specific problems as well as to facilitate specific procedures. Consensus-based standards have been developed for the selection of instruments measuring health status (COSMIN)^[34].

The DASH questionnaire, developed to evaluate all upper limb functions, was the most commonly used PROM for patients with DD, but the results showed that there is a poor correlation between the severity of the contracture produced by DD and the functional disability measured with the DASH^[13]. In addition, DASH contains elements related to pain, so it is probably inappropriate, as well as difficult for patients to self-assess^[35]. It may also lack sufficient sensitivity to detect significant improvement after treatment due to a "low baseline effect," which is a relatively low score prior to treatment. It is difficult to be sure if this represents a genuine problem, since only six studies reported DASH scores before and after treatment, although all showed comparatively low values^[8-10,14,15,19]. A difference of 15 points is considered to be the minimal clinically important difference (MCID) indicating an improvement. However, the exact figure is controversial, and may vary depending on the pathology affecting the upper extremity being considered^[36]. No study showed an MCID equal to or greater than 15 points, and only two studies showed a 10-point MCID^[8,10], which can be attributed in part to the relatively low reported values before treatment. The studies that analyzed content and construct validity and reliability of DASH for DD did not show evidence of an adequate measure of validity for this population^[14,15].

QuickDASH was developed from DASH using article reduction methodology. It was used by numerous studies, but it is not clear if it is prone to a "low baseline effect" when used for DD. Five publications^[13,15,19,21,22] reported both pre- and post-treatment data, and all of them showed a reduction in post-treatment scores, indicative of improvement. In the study by Rodrigues et al.^[15] using a follow-up of up to 5 years, an MCID value equal or superior to 16 points was measured for QuickDASH, although this value has not been confirmed specifically for DD^[36,37]. Although QuickDASH is more acceptable to patients and is more feasible for use in a clinical setting than DASH, they both have the same limitations in their use for DD^[4-6,21].

The MHQ questionnaire is a specific outcome measure in the 37-item range which includes six subscales for daily activities. It has been shown that the MHQ detects changes in function after treatment for DD, and that it has an acceptable correlation with changes in fixed flexion deformity^[20,28,29]. The MHQ focuses on

the hand, evaluating the functional impact on each hand separately. This can be especially relevant to conditions such as DD, which can affect each hand to a different degree. It also includes questions that may be of greater relevance to people with DD, such as aesthetics, which may be important to some patients; for example, when shaking hands, or when extending the hand palm-up, such as receiving change in a transaction^[38]. Pain, which is included in both the DASH and the MHQ, is rarely reported by people with DD, and so can reduce the sensitivity of both tools^[35]. While the MHQ may seem adequate for evaluating the DD outcomes, it is long and may not always be duly completed^[27,39,40]. The use of the brief MHQ, which saves time in patient evaluations, was the subject of only one study covering 57 DD patient outcomes, although it has shown goodreliability, validity, and high response capacity for patients with DD^[26].

The URAM scale was designed specifically to evaluate DD, and its design methodology appears sound. It is the first outcome measure for a validated functional domain specific to DD^[30]. It does not take pain into account, and covers the reduction in finger flexion and extension typical of DD. The study of the development and validation of this questionnaire showed good internal consistency; test-retest reliability was excellent, adding support to the reliability of the scale, convergent validity, and content validity through its high correlation with the Tubiana scale (used in clinical studies on DD). The clinically significant estimated change in the URAM score was 2.9 (corresponding to a change of approximately 6% in the 45-point range of the total score). The two studies with URAM pre- and post-treatment data showed significant clinical response capacity of this scale after treatment^[30,32]. In the study by Bernabé et al.^[16] the favorable psychometric properties of this questionnaire and its ease of use for patients with DD were confirmed^[39].

The SDSS and DDSP questionnaires, both developed for use with patients with DD, have only been used in their respective development and validation studies. In an effort to find a more valid scale for DD, Mohan et al.^[24] developed the SDSS, which resulted from reducing many functional problems associated with DD to only five domains each. SDSS demonstrated good internal consistency and better performance than QuickDASH in terms of test-retest reliability and change sensitivity, and showed superior field test attributes that suggest that it is a relatively more patient and practitioner-oriented scoring system, but it also demonstrated a lack of correlation between angular deformity and hand functionality^[4-6,24]. The DDSP was developed in Poland by Tyrbus et al.^[33] using a very small number of patients with DD, with results that were never confirmed by other studies or in other populations.

The POS-HAND/ARM and CHFS questionnaires were not developed specifically for patients with DD, and even when they have been used to assess these patients, as in the case of the studies included in this review, there is no evidence of their validation for this pathology.

The exclusion of articles not published in English or Spanish may have led to potential bias, and the heterogeneity of the studies precluded pooling data for a meta-analysis. The inclusion of low quality studies that present retrospective data may be seen as a limitation, but an exclusive approach would have resulted in an incomplete picture of the current methods in use.

PROM, although subjective, are critical measures of treatment efficacy, since the benefit perceived by the patient is the final goal of treatment. Therefore, they should complement the data derived from physical measurements, as they provide the context for the functional impact on the individual.

The studies to date on the HR-QoL outcomes for patients with DD are heterogeneous and highlights the variety of region-specific and disease-specific questionnaires used for DD evaluation purposes. However, few of these studies have specifically assessed the validity, reliability, responsiveness and the correlation with objective measures of each questionnaire. More work is urgently needed in these areas before we can reach consensus on which instrument is best to assess functional impairment and improvement in patients with DD.

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Declaration of conflicting interests

The authors declare that have no conflicts of interest with regard to the content of this article.

References

- [1] Ball C, Pratt AL, Nanchahal J. Optimal functional outcome measures for assessing treatment for Dupuytren's disease: a systematic review and recommendations for future practice. BMC Musculoskelet Disord. 2013;14:131.
- [2] Broekstra DC, Lanting R, Werker PMN, van den Heuvel ER. Intra- and inter-observer agreement on diagnosis of Dupuytren disease, measurements of severity of contracture, and disease extent. *Man Ther.* 2015;20:580-586.
- [3] Weldring T, Smith SMS. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Health Serv Insights*. 2013;06:61-68.
- [4] Warwick D. Dupuytren's disease: my personal view. J Hand Surg Eur Vol. 2017;42:665–672.
- [5] Warwick D. Collagenase: What we may never know (a discussion). In: Werker PMN, Dias J, Eaton C, Reichert B, Wach W, eds. *Dupuytren disease and related diseases the cutting edge*. Cham, Switzerland: Springer; 2017:145–149.
- [6] Warwick D. Correlation of function with deformity in Dupuytren disease: The condition-specific Southampton scoring scheme outperforms the generic QuickDASH. In: Werker PMN, Dias J, Eaton C, Reichert B, Wach W, eds. Dupuytren disease and related diseases - the cutting edge. Cham, Switzerland: Springer; 2017:199–203.
- [7] Von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *Int J Surg.* 2014;12:1495–1499.
- [8] Engstrand C, Borén L, Liedberg GM. Evaluation of activity limitation and digital extension in Dupuytren's

contracture three months after fasciectomy and hand therapy interventions. *J Hand Ther*. 2009;22:21–27.

- [9] Engstrand C, Krevers B, Kvist J. Factors affecting functional recovery after surgery and hand therapy in patients with Dupuytren's disease. *J Hand Ther*. 2015;28:255–260.
- [10] Engstrand C, Krevers B, Nylander G, Kvist J. Hand function and quality of life before and after fasciectomy for Dupuytren contracture. *J Hand Surg Am*. 2014;39:1333-1343.
- [11] Wilburn J, McKenna SP, Perry-Hinsley D, Bayat A. The impact of Dupuytren disease on patient activity and quality of life. *J Hand Surg Am.* 2013;38:1209–1214.
- [12] Degreef I, Vererfve PB, De Smet L. Effect of severity of Dupuytren contracture on disability. Scand J Plast Reconstr Surg Hand Surg. 2009;43:41–42.
- [13] Jerosch-Herold C, Shepstone L, Chojnowski A, Larson D. Severity of contracture and self-reported disability in patients with Dupuytren's contracture referred for surgery. *J Hand Ther*. 2011;24:06–10.
- [14] Forget NJ, Jerosch-Herold C, Shepstone L, Higgins J. Psychometric evaluation of the Disabilities of the Arm, Shoulder and Hand (DASH) with Dupuytren's contracture: validity evidence using Rasch modeling. *BMC Musculoskelet Disord*. 2014;15:361.
- [15] Rodrigues J, Zhang W, Scammell B, et al. Validity of the disabilities of the arm, shoulder and hand patientreported outcome measure (DASH) and the QuickDASH when used in Dupuytren's disease. *J Hand Surg Eur Vol.* 2016;41:589–599.
- [16] Bernabé B, Lasbleiz S, Gerber RA, et al. URAM scale for functional assessment in Dupuytren's disease: A comparative study of its properties. *Joint Bone Spine*. 2014;81:441–444.
- [17] Cano SJ, Browne JP, Lamping DL, Roberts AHN, Mcgrouther DA, Black NA. The patient outcomes of surgery-hand/arm (Pos-Hand/Arm): a new patient-based outcome measure. *J Hand Surg Br.* 2004;29:477–485.
- [18] Van de Ven-Stevens LAW, Graff MJL, Peters MAM, Van der Linde H, Geurts ACH. Construct validity of the canadian occupational performance measure in participants with tendon injury and Dupuytren disease. *Phys Ther.* 2015;95:750–757.
- [19] Gummesson C, Ward MM, Atroshi I. The shortened disabilities of the arm, shoulder and hand questionnaire (Quick DASH): validity and reliability based on responses within the full-length DASH. BMC Musculoskelet Disord. 2006;07:44.
- [20] Knobloch K, Kuehn M, Papst S, Kraemer R, Vogt PM. German standardized translation of the Michigan hand outcomes questionnaire for patient-related outcome measurement in Dupuytren disease. *Plast Reconstr Surg.* 2011;128:39-40.
- [21] Budd HR, Larson D, Chojnowski A, Shepstone L. The QuickDASH score: a patient-reported outcome measure for Dupuytren's surgery. *J Hand Ther*. 2011;24:15–21.
- [22] Lauritzson A, Atroshi I. Collagenase injections for Dupuytren's disease: prospective cohort study assessing 2-year treatment effect durability. *BMJ Open*. 2017;07:1-7.
- [23] Valbuena Sebastián E, Pereira Emanuel F, Massa Leandro N, Cocozzella Luis A. Colgajo comisural palmar: su utilidad en el abordaje de la enfermedad de

- [24] Mohan A, Vadher J, Ismail H, Warwick D. The Southampton Dupuytren's scoring scheme. J Plast Surg Hand Surg. 2014;48:28–33.
- [25] Van Vliet MM, Maradey JA, Homa KA, Kerrigan CL. The usefulness of patient-reported measures for clinical practice. *Plast Reconstr Surg.* 2013;132:105–112.
- [26] Wehrli M, Hensler S, Schindele S, Herren DB, Marks M. Measurement properties of the brief Michigan hand outcomes questionnaire in patients with Dupuytren contracture. *J Hand Surg Am.* 2016;41:896–902.
- [27] Thoma A, Kaur MN, Ignacy TA, et al. Health-related quality of life in patients undergoing palmar fasciectomy for Dupuytren's disease. *Plast Reconstr Surg.* 2014;133:1411–1419.
- [28] Zhou C, Hovius SER, Slijper HP, et al. Predictors of patient satisfaction with hand function after fasciectomy for Dupuytren's contracture. *Plast Reconstr Surg.* 2016;138:649–655.
- [29] Zhou C, Hovius SER, Slijper HP, et al. Collagenase clostridium histolyticum versus limited fasciectomy for Dupuytren's contracture: outcomes from a multicenter propensity score matched study. *Plast Reconstr Surg.* 2015;136:87–97.
- [30] Beaudreuil J, Allard A, Zerkak D, et al. Unité Rhumatologique des Affections de la Main (URAM) scale: development and validation of a tool to assess Dupuytren's disease-specific disability. *Arthritis Care Res.* 2011;63:1448-1455.
- [31] Rodrigues JN, Zhang W, Scammell BE, Davis TRC. What patients want from the treatment of Dupuytren's disease - is the Unité Rhumatologique des Affections de la Main (URAM) scale relevant?. J Hand Surg Eur Vol. 2015;40:150–154.
- [32] Verstreken F, Degreef I, Decramer A, et al. Effectiveness and safety of collagenase clostridium histolyticum in Dupuytren's disease: an observational study in Belgium. *Acta Orthop Belg*. 2016;82:397–404.
- [33] Trybus M, Bednarek M, Lorkowski J, Teul I. Psychologic aspects of Dupuytren's disease: a new scale of subjective well-being of patients. *Ann Acad Med Stetin*. 2011;57:31–37.
- [34] Prinsen CAC, Mokkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res.* 2018;27:1147-1157.
- [35] McMillan CR, Binhammer PA. Which Outcome Measure is the Best? Evaluating responsiveness of the disabilities of the arm, shoulder, and hand questionnaire, the michigan hand questionnaire and the patient-specific functional scale following hand and wrist surgery. *Hand*. 2009;04:311–318.
- [36] Franchignoni F, Vercelli S, Giordano A, Sartorio F, Bravini E, Ferriero G. Minimal clinically important difference of the disabilities of the arm, shoulder and hand outcome measure (DASH) and its shortened version (QuickDASH). *J Orthop Sports Phys Ther.* 2014;44:30– 39.
- [37] Kennedy CA, Beaton DE, Smith P, et al. Measurement properties of the QuickDASH (disabilities of the arm, shoulder and hand) outcome measure and cross-cultural

adaptations of the QuickDASH: a systematic review. *Qual Life Res.* 2013;22:2509–2547.

- [38] Thoma A, Kaur MN, Ignacy TA, et al. Psychometric properties of health-related quality of life instruments in patients undergoing palmar fasciectomy for Dupuytren's disease: A prospective study. *Hand*. 2014;09:166–174.
- [39] Broekstra DC, van den Heuvel ER, Lanting R, Werker PMN. Measurement properties of the dutch Unité

Rhumatologique des Affections de la Main and its ability to measure change due to Dupuytren's disease progression compared with the Michigan hand outcomes questionnaire. *J Hand Surg Eur Vol.* 2018;43:855-863.

[40] London DA, Stepan JG, Calfee RP. Determining the Michigan hand outcomes questionnaire minimal clinically important difference by means of three methods. *Plast Reconstr Surg.* 2014;133:616–625.

Figure 1: Flowchart of the systematic search.



References	Country	Study design	PROM	No. study subjects (% DD)	Age Mean (range/SD)	% Male	Treatment	Assessment schedule	Quality STROBE checklist (Max. 22)
Beaudreuil J ^[30] 2011 et al.	France	Cohort study	URAM	53 (100)	63.2 (8.9)	83.0	Needle aponeurotomy	Pre and 1 month Pt	15
Bernabé B ^[16] 2014 et al.	France	Cohort study	URAM (CHFS and DASH)	83 (100)	63.0 (9.0)	81.0	θ	Baseline	15
Budd HR ^[21] 2011 et al.	United Kingdom	Cohort study	QuickDASH	69 (100)	69.9 (10.5)	83.0	Surgery	Pre and Ps (at a mean 110 day follow-up)	16
Cano SJ ^[17] 2004 et al.	United Kingdom	Cohort study	POS- HAND/ARM (DASH and MHQ)	132 pre- surgery (23) 204 post- surgery (21)	57.0 (15.0)	43.0 pre 50.0 post	Surgery	Pre and 3 months Ps	17
Degreef I ^[12] 2009 et al.	Belgium	Cohort study	DASH	80 (100)	60.0 (21.0-78.0)	86.0	θ	Baseline	15
Engstrand C ^[9] 2015 et al.	Sweden	Cohort study	DASH	81 (100)	68.0 (8.0)	88.0	Surgery and hand therapy	Pre and 3 months Ps	20
Engstrand C ^[10] 2014 et al.	Sweden	Cohort study	DASH	90 (100)	68.0 (9.0)	85.0	Surgery	Pre and 3, 6 and 12 months Ps	18
Engstrand C ^[8] 2009 et al.	Sweden	Cohort study	DASH	60 (100)	66.5 (43.0-87.0)	92.0	Surgery	Pre and 3 months Ps	17
Forget NJ ^[14] 2014 et al.	Canada	Cohort study	DASH	153 (100)	67.0 (10.0)	78.0	Surgery	Pre and 3, 6 and 12 months Ps	20
Gummesson C ^[19] 2006 et al.	Sweden	Cohort study	QuickDASH (DASH)	105 (12)	52.0 (18.0-23.0)	43.0	Surgery	Pre and 6 to 21 months Ps	20
Jerosch-Herold $C^{[13]}$ 2011 et al.	United Kingdom	Cohort study	DASH	154 (100)	67.4 (9.6)	78.0	θ	Baseline	15
Knobloch K ^[20] 2011 et al.	Germany	Cohort study	MHQ (DASH)	113 (100)	54.0 (12.0)	θ	Surgery	Ps	17
Lauritzson A ^[22] 2017 et al.	Sweden	Cohort study	QuickDASH	48 (100)	68.0 (51.0-83.0)	79.0	ССН	Pre and 2 years Pt	19
Mohan A ^[24] 2014 et al.	United Kingdom	Cohort study	SDSS (QuickDASH)	61 (100)	θ	θ	Surgery	Pre and 6 months Ps	18
Rodrigues J ^[15] 2016 et al.	United Kingdom	Cohort study	DASH (QuickDASH)	523 (100)	68.0 (34.0-94.0)	78.0	Surgery and needle aponeurotomy	Pre and Pt (3 weeks to 5 years post)	17
Rodrigues JN ^[31] 2015 et al.	United Kingdom	Cohort study	URAM	110 (100)	68.0 (34.0-90.0)	76.0	θ	Baseline	20
Thoma A ^[27] 2014 et al.	Canada	Cohort study	MHQ	26(100)	64.2 (7.3)	85.0	Surgery	Pre and 1, 3, 6 and 12 months Ps	20
Trybus M ^[33] 2011 et al.	Poland	Cohort study	DDSP	38 (100)	θ	θ	θ	Baseline	15
Valbuena SE ^[23] 2015 et al.	Argentina	Cohort study	QuickDASH	12 (100)	66.6 (60.0-77.0)	75.0	Surgery	At 6 months Ps	15
Van de Ven-Stevens LA ^[18] 2015 et al.	Netherlands	Cohort study	(DASH and MHQ)	72 (29)	θ	θ	Surgery	At 3 months Ps	20
Van Vliet MM ^[25] 2013 et al.	Lebanon	Cohort study	(QuickDASH)	262 (29)	59.6 (13.4)	θ	θ	Baseline	20

Table 1: Study characteristics and	l demographic and clinical	l characteristics of the study population
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Verstreken $F^{[32]}$ 2016 et al.	Belgium	Cohort study	URAM	110 (100)	64.4 (10.9)	77.0	ССН	Pre and 1 month Pt	17
Wehrli M ^[26] 2016 et al.	Switzerland	Cohort study	briefMHQ	57 (100)	65.0 (8.9)	81.0	CCH and surgery	Pre and 1 year Pt	17
			(MHQ and						
			QuickDASH)						
Willburn J ^[11] 2013 et al.	United	Cohort study	DASH	34 (100)	64.2 (13.0)	74.0	θ	Baseline	15
	Kingdom								
Zhou C ^[28] 2016 et al.	Netherlands	Cohort study	MHQ	194 (100)	63.0 (9.0)	73.0	Surgery	Pre and (6 months-1	19
								year) Ps	
Zhou C ^[29] 2015 et al.	Netherlands	Cohort study	MHQ	132 (100)	62.0 (9.5)	81.0	CCH and surgery	Pre and Pt (6-12 weeks)	19

DD: Dupuytren's disease; CCH: Collagenase Clostridium histolyticum; Ps: post-surgery; Pt: post-treatment

Table 2: Number of study subjects with Dupuytren's disease using DASH, QuickDASH, MHQ and URAM, and reporting data.

References	No. study subjects with DD	Specific measure of quality of life	Pre-treatment (range/SD)	Post-treatment (range/SD)
Beaudreuil J ^[30] 2011 et al.	53	URAM	13.2 (10.0)	7.6 (8.6)
			13.0 (0-54.0) for validity study	
Bernabé B ^[16] 2014 et al.	53 for validity study	DASH	18.0 (0-68.0) for time study	θ
	30 for time study	URAM	13.0 (10.0) for validity study	
			11.0 (0-62.0) for time study	
Budd HR ^[21] 2011et al.	69	QuickDASH	15.1 (13.1)	7.9 (12.3)
Degreef I ^[12] 2009 et al.	80	DASH	15.0 (0-69.0)	θ
Engstrand C ^[9] 2015 et al.	81	DASH	21.0 (14.0)	12.0 (13.0)
Engstrand C ^[10] 2014 et al.	77	DASH	20.0 (17.0-23.0)	7.0 (5.0-8.0)
Engstrand C ^[8] 2009 et al.	60	DASH	17.0 (7.0-28.0)	7.0 (3.0-12.0)
Forget NJ ^[14] 2014 et al.	153	DASH	15.9 (14.5)	6.7 (12.3)
Gummesson C ^[19] 2006 et al.	13	DASH	19.0 (23.0)	15.0 (23.0)
		QuickDASH	22.0 (27.0)	17.0 (23.0)
Jerosch-Herold C ^[13] 2011 et al.	154	DASH	15.9 (0-62.0)	θ
Knobloch K ^[20] 2011 et al.	113	DASH	θ	17.0 (20.0)
		MHQ		76.0 (19.0)
LauritzsonA ^[22] 2017 et al.	48	QuickDASH	11.0 (2.0-21.0)	2.0 (0-18.0)
Rodrigues J ^[15] 2016 et al.	523	DASH	27.0 (23.0-31.0)	11.0 (9.0-13.0)
		QuickDASH	28.0 (24.0-32.0)	12.0 (10.0-15.0)
Thoma A ^[27] 2014 et al.	26	MHQ	74.0 (15.0)	90.0 (16.0)
Valbuena SE ^[23] 2015 et al.	12	QuickDASH	θ	2.47 (0-15.9)
Van de Ven-Stevens LA ^[18] 2015 et al.	21	DASH	θ	20.1 (9.1)
		MHQ		68.8 (12.7)
Van Vliet MM ^[25] 2013 et al.	76	QuickDASH	11.3 (10.0)	θ
Verstreken F ^[32] 2016 et al.	104	URAM	29.4 (11.0)	12.9 (6.3)
Wehrli M ^[26] 2016 et al.	57	QuickDASH	17.0 (17.0)	θ
		MHQ	74.0 (16.0)	
Willburn J ^[11] 2013 et al.	34	DASH	13.7 (17.2)	θ

Zhou C ^[28] 2016 et al.	194	MHQ	θ	θ
Zhou C ^[29] 2015 et al.	132	MHQ	74.0 (14.5)	76.0 (13.5)

Table 3: Principal patient reported outcome measures used in Dupuytren's disease.

Instrument	Dimensions	No. of Items/Levels	Scoring	Interpretation
DASH (region-specific)	Difficulty in performing various physical activities because of problems in a shoulder, arm, or hand; the severity of each of the symptoms of pain, activity-related pain, tingling, weakness, and stiffness. And the problem's effect on social activities, work, and sleep, and its psychological impact	30	Each item can be scored on a five-point scale ranging from "no difficulty" to "unable to perform". At least 27 of the 30 items must be completed for a score to be calculated. The sum of all items is used to calculate the total DASH score, which ranges between 0 and 100, from "no disability" to "severest disability"	Higher score indicates more severe disability
QuickDASH (region-specific)	Physical function and symptoms in people with any or multiple musculoskeletal disorders of the upper limb	11	Each item can be scored on a five-point scale ranging from "no difficulty" to "unable to perform". At least 10 of the 11 items must be completed for a score to be calculated. The responses to the items were summed to form a raw score, then converted to a 0-to-100 scale with the same formula used to calculate the DASH score	Higher scores reflecting greater disability
URAM (disease-specific)	Physical disability associated with Dupuytren's disease	9	The resulting URAM scale is a 9-item patient-reported questionnaire with total scores for Dupuytren's disease-associated disability ranging from 0 (best) to 45 (worst)	High scores suggest high levels of disability and disturbance
MHQ (región-specific)	Overall hand function, activities of daily living, pain, work performance, aesthetics, and patient satisfaction with hand function	37	The subjects respond to each question on every item on a Likert like scale ranging from 1–5; these responses are then added to give a domain score for each of six scales; each respondent must answer 50% or more of the items within the scale for responses to be considered sufficient; the scores from each scale are then converted to 0–100 based on algorithm	Higher scores represent better performance for all health domains but pain
DDSP (disease-specific)	Four areas (subscales) of the quality of life: self -esteem, family life, occupational life, and social life	12	Each subscale comprised three items. A seven-point Likert-like response format from "Definitely not" to "Definitely yes"	Higher scores indicated greater problems
SDSS (disease-specific)	Physical disability associated with Dupuytren's disease	5	Each question was scored from 0–4, with a score of 0 for no problem and 4 for severe problem. The SDSS was thereby generated with a total score from 0–20	Higher scores reflecting greater disability