Measuring quality of life and patient satisfaction in hand conditions

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Abstract

Background: Patient reported outcomes (PROs) are important for the assessment of the effectiveness of surgical interventions. If patient reported outcome measures (PROMs) are used to prioritise resources then it is important to ensure that the instruments are scientifically valid. This review aims to assess whether the currently available PROMs in hand surgery adhere to international development guidelines and whether they incorporate the use of item response theory (IRT) or Rasch Analysis (RA).

Methods: A systematic review was performed to identify all PROMs that are relevant to the field of hand surgery. An a priori protocol with strict inclusion and exclusion criteria was followed. Only instruments developed in the English language were included. A comprehensive search of nine databases was undertaken. The development methodology of the identified instruments was then analysed, followed by examination of the domain content and initial psychometric validation of each instrument.

Results: A total of 3,039 article citations were retrieved, 139 citations went on to a full text review. A total of 24 patient reported outcome instruments were identified. This consisted of 10 regional upper limb, six hand and/or wrist specific and a further eight condition specific instruments. Documentation of the details of PROM development was lacking for many instruments.

Conclusion: The field of hand surgery has many instruments available but few fulfil international development guidelines or use IRT or RA psychometric techniques. There are limitations in either the breadth of the domains explored or the developmental methodology used in all currently available instruments.
Keywords: psychometrics, patient reported outcome measures, surveys and questionnaires, hand, upper extremity

Background

In the current health landscape it is important to collect meaningful information on the outcome of interventions performed in order to justify their value.1,2 Increasingly, outcome measurement is broadening to include patient reported metrics that gauge satisfaction and health-related quality of life.3 In hand surgery, traditional indicators such as mortality or rate of postoperative complications are not sensitive enough to distinguish variations.4 Clinical measurements such as range of motion or grip strength do not take into account the patient's perspective. Constructs such as pain, or a patient's perception of their ability, cannot be directly measured and this is where self-reported outcomes are useful.5 Patient reported outcomes (PROs) have become an important contributor to the overall picture of appraising outcomes at both the individual and health service level. Therefore, it is important that scientifically rigorous PROMs are used when evaluating the impact of an injury or disease and the associated treatment.6

Operative interventions that reduce symptoms, improve functionality or change the appearance of the hand produce effects that influence multiple domains. As hands are a highly functional body part, it is logical that measuring physical function is a priority. However, hands are also integral in much of our day-to-day ability to perform in our social, professional and personal lives. Questionnaires and instruments that are limited to the measurement of only a single domain, such as physical function, do not capture the full spectrum of change produced by surgical or therapeutic interventions.

For hand conditions, there are different categories of PROMs: those that relate to the upper extremity as a whole functional unit, those that focus on the region of the hand (with or without the wrist) and those that are focused on the symptoms and disability that result from a specific pathology. There are benefits to each of these approaches, depending on the requirement for use. Ideally, instruments should be developed in keeping with the internationally established criteria of the scientific advisory committee of the Medical Outcomes Trust (SAC) for health related outcome measures.7

There is robust debate in the field of psychometrics concerning the best methodology for PROM development.8 Classical test theory (CTT) is being increasingly overtaken by item response theory (IRT) and Rasch analysis (RA).9 The benefits of IRT and RA are numerous; they allow for both person and item parameters to be placed on the same scale and can be used to compare results between different populations.

Methods

A systematic review of English-language literature was performed using a broad range of relevant databases to identify PROs developed for use in patients with hand or upper limb conditions and/or surgery. Search terms included: ‘quality of life’, ‘health related quality of life’, ‘quality adjusted life years’, ‘health status’ or ‘functional status’ or ‘well being’ or ‘wellbeing’ or ‘patient reported outcome’ or ‘PROM’ or ‘PRO’ or ‘PROS’. Other search terms used included the specific names of hand PROs: DASH (disabilities of the arm, shoulder and hand), PRWE (patient-rated wrist evaluation) MHQ (Michigan hand outcomes questionnaire), PEM (patient evaluation measure), POS–Hand/Arm (patient outcomes of surgery-hand/arm) and PROMIS (patient-reported outcomes measurement information system). The terms ‘hand’, ‘metacarpus’, ‘finger/s’, ‘wrist’, ‘thumb’ and ‘surg*’ were used to limit the results to the anatomical region of interest: the hand.

Papers that had been published in peer-reviewed literature and that discussed the development or psychometric analysis of PROMs used in hand conditions were included. Eligible instruments were limited to hand or upper limb or conditions specific to this region (for example, carpal tunnel, Dupuytren's disease). Relevant review articles were also included using manual searching to identify any missing PROMs evaluating quality of life, impairment and disability or patient satisfaction after hand surgery.
Exclusion criteria were if an instrument was clinician reported (therefore not a true PRO instrument) or if they were specific for an anatomical site other than the hand (for example, of the elbow or shoulder). Also excluded were articles reporting on a non-English instrument. Instruments that were developed specifically for a subpopulation such as children, the elderly or workers compensation claimants were likewise excluded.

Two reviewers independently screened titles and abstracts for duplicates, discussed any discrepancies and established consensus. The lead author conducted the full text review and data extraction. Identified instruments were appraised according to their adherence to SAC and the United States Food and Drug Administration (FDA) guidelines. The consensus-based standards for the selection of health measurement instruments (COSMIN) checklist was not used as synthesis of measurement properties was not the primary interest of this review but rather the methodology used for PROM development.

Information regarding the development process and psychometric evaluation of the PROMs was extracted from the articles. The identified PROMs that met the inclusion criteria were then analysed for content. In the case where more than one version of a tool was available, all versions were included in the analysis to ensure a thorough review. Guidelines for preferred reporting items for systematic reviews and meta-analyses were adhered to where pertinent.

Results

The search resulted in 3,039 papers after the removal of duplicates. Following screening of titles and abstracts, 139 relevant papers underwent full text review. A total of 87 articles met the inclusion criteria, 20 instruments were identified as being relevant to hand surgery. Further searching identified another four eligible instruments. In summary, 24 instruments were identified; 16 regional instruments (consisting of 10 upper extremity and six hand/wrist instruments) and eight condition specific instruments (Figure 1).
Table 1: Identified patient reported outcome instruments relevant to hand conditions and the key papers that describe their development

| Instruments                                      | Key publications                                      |
|-------------------------------------------------|------------------------------------------------------|
| **Upper extremity**                             |                                                      |
| DASH                                            | Disabilities of the arm, shoulder and hand           |
|                                                 | Hudak 1996,18 Kennedy 201119                        |
| M2DASH                                          | Manchester modified DASH                             |
|                                                 | Khan 2008 and 200921, 22                             |
| MAM 16                                          | Manual ability measure 16                            |
|                                                 | Chen 200523                                          |
| MAM 36                                          | Manual ability measure 36                            |
|                                                 | Chen 201026                                          |
| POS-HA                                          | Patient outcome of surgery hand-arm                  |
|                                                 | Cano 200423                                          |
| PROMIS-PF-UE                                    | Patient reported outcome measurement information     |
|                                                 | system—physical function upper extremity            |
|                                                 | Hays 2013,20 Doring 201429                          |
| QD                                              | Quick DASH                                           |
|                                                 | Beaton 200520                                        |
| UEFI                                            | Upper extremity functional index                     |
|                                                 | Stratford 200117                                     |
| UEFI 15                                         | Upper extremity functional index 15                  |
|                                                 | Hamilton 201313                                      |
| ULFI                                            | Upper limb functional index                          |
|                                                 | Gabel 200626                                        |
| **Hand-wrist specific**                         |                                                      |
| BMHQ                                            | Brief Michigan hand outcomes questionnaire           |
|                                                 | Waljee 2011*                                         |
| HAT                                             | Hand assessment tool                                 |
|                                                 | Naidu 200922                                        |
| MASS07                                          | Modernised activity subjective survey                |
|                                                 | Alexander 200824                                    |
| MHQ                                             | Michigan hand outcomes questionnaire                 |
|                                                 | Chung 199850                                        |
| PEM                                             | Patient evaluation measure                           |
|                                                 | Macey 199523                                        |
| PRWHE                                           | Patient rated wrist/hand evaluation                  |
|                                                 | MacDermid 19967                                    |
| **Condition specific**                          |                                                      |
| 6-CTS SS                                        | 6-item carpal tunnel syndrome symptom scale          |
|                                                 | Atroshi 2009,9 Atroshi 201117                        |
| AUSCAN                                          | Australian/Canadian osteoarthritis hand index        |
|                                                 | Bellamy 200218,60                                    |
| BCTQ                                            | Boston carpal tunnel questionnaire                   |
|                                                 | Levine 199316                                       |
| NELSON SCORE                                    | NELSON hospital score                                |
|                                                 | Citron 200752                                       |
| SDSS                                            | Southampton Dupuytren’s scoring scheme               |
|                                                 | Mohan 201425                                        |
| TASD                                            | Trapeziometacarpal arthrosis symptoms and            |
|                                                 | disability questionnaire                             |
|                                                 | Becker 201641                                       |
| TDX                                             | Thumb disability exam                                |
|                                                 | Noback 20161                                        |
| VAS-HAND                                        | Visual-analogue scale hand                           |
|                                                 | Massy-Westropp 200228                               |
### Table 2a: Development and validation criteria—regional PRO instruments

| Criteria                  | Upper Extremity | Hand /Wrist |
|---------------------------|-----------------|-------------|
| **Item generation**       |                 |             |
| Patient interviews        | *               |             |
| Literature                | *               |             |
| Expert opinion            | *               |             |
| Develop conceptual model  | *               |             |
| **Item reduction**        |                 |             |
| Expert opinion            | *               |             |
| Item redundancy            |                 |             |
| Endorsement frequencies   | *               | *           |
| Missing data              |                 |             |
| Factor analysis           | *               |             |
| Tests of scaling assumptions |             |             |
| Rasch/item response theory | *             |             |
| **Psychometric analysis** |                 |             |
| Acceptability             | *               |             |
| Internal consistency reliability | *          |             |
| Item total correlations   | *               |             |
| Interrater reliability    |                 |             |
| Validity within scale     | *               |             |
| Validity comparison with other measures | * |             |
| Validity hypothesis testing |             |             |
| Responsiveness            | *               |             |

* Item generation based on pre-existing instrument
Table 3a: Development and validation criteria—condition-specific PRO instruments

| Criteria                             | SDSS | BCTQ | 6 CTS SS | Hand-VAS | AUSCAN | TDX | TASD | NELSON Score |
|--------------------------------------|------|------|----------|----------|--------|-----|------|--------------|
| **Item generation**                  |      |      |          |          |        |     |      |              |
| Patient interviews                   | •    | •    |          |          |        |     |      |              |
| Literature                           |      |      |          |          |        |     |      |              |
| Expert opinion                       |      |      |          |          |        |     |      |              |
| Develop conceptual model             |      |      |          |          |        |     |      |              |
| **Item reduction**                   |      |      |          |          |        |     |      |              |
| Expert opinion                       |      |      |          |          |        |     |      |              |
| Item redundancy                       |      |      |          |          |        |     |      |              |
| Endorsement frequencies              | •    | •    |          |          |        |     |      |              |
| Missing data                         |      |      |          |          |        |     |      |              |
| Factor analysis                      |      |      |          |          |        |     |      |              |
| Tests of scaling assumptions         |      |      |          |          |        |     |      |              |
| Item misfit (ra/irt)                  |      |      |          |          |        |     |      |              |
| **Psychometric analysis**            |      |      |          |          |        |     |      |              |
| Acceptability                        |      |      |          |          |        |     |      |              |
| Internal consistency reliability     | •    | •    |          |          |        |     |      |              |
| Item total correlations              |      |      |          |          |        |     |      |              |
| Interrater reliability               |      |      |          |          |        |     |      |              |
| Test-retest reliability              | •    | •    |          |          |        |     |      |              |
| Validity within scale                |      |      |          |          |        |     |      |              |
| Validity comparison with other measures | •    | •    |          |          |        |     |      |              |
| Validity hypothesis testing          |      |      |          |          |        |     |      |              |
| Responsiveness                       | •    | •    |          |          |        |     |      |              |
Table 2b: Domain analysis—regional PRO instruments

|                        | Upper Extremity | Hand/Wrist |
|------------------------|-----------------|------------|
| **Physical functioning**| DASH            |            |
| Limitations of whole upper limb | DASH          |            |
| Limitations of hand/wrist          | POS-HA | MAM 16  |
| Limitations of hand/digits                | MAM 36 | ULFI     |
| Limitations of thumb                     | UEFI   | UEFI 36  |
| Ability to perform ADLs                  | PROMIS  | MHQ      |
| Ability to use smart phone / modern technology | UEF    | BMHQ     |
| Ability to work                        | BMHQ   | PRWHE    |
| Ability to travel                       | PRWHE  | HAT      |
| Ability to participate socially         | HAT    | PEM      |
| **Symptoms**                        |              |            |
| Pain issues                          |              |            |
| Sensory changes (tingling/numbness)     |              |            |
| Stiffness                             |              |            |
| Swelling                              |              |            |
| Weakness                              |              |            |
| Reduced ROM                           |              |            |
| Insomnia                              |              |            |
| Change in appetite                     |              |            |

**Note:** DASH: Disabilities of Arm, Shoulder and Hand; POS-HA: Patient Outcomes Score—Hand and Arm; MAM: Measure of Ability to Manipulate; ULFI: Upper Limb Function Inventory; UEFI: Upper Extremity Function Inventory; PROMIS: PatientReported Outcome Measures Information System; MHQ: Modified Health Questionnaire; BMHQ: Basic Modified Health Questionnaire; PRWHE: Patient Report of Work Hobbies Evaluation; HAT: Health Assessment Tool; PEM: Physical Energy Measure; MASS 07: Modified Assessment of Upper Limb Strength.
| Health-related QOL                                                                 | Upper Extremity | Hand/Wrist |
|---------------------------------------------------------------------------------|----------------|------------|
|                                                                                   | DASH | QD  | M2 | POS-HA | MAM 16 | MAM 36 | ULFI | UEFI | UEFI 36 | PROMIS UEF | MHQ | BMHQ | PRWHE | HAT | PEM | MASS 07 |
| Satisfaction with treatment                                                        |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Satisfaction with outcome/overall assessment                                       |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Inconvenience of medical/hospital                                                  |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Concerns re: post op complications/recovery                                        |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Expectations                                                                      |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |

| Psychological functioning                                                          |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Self confidence/self esteem                                                        |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Avoidance of uncomfortable situations                                              |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Negative feelings about self                                                       |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Change in mood                                                                    |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |

| Body image                                                                        |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Concerns regarding scarring                                                       |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Self-consciousness                                                                |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
| Satisfaction with hand appearance                                                 |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |

| Sexual functioning                                                                |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
|                                                                                   |      |     |    |        |        |        |      |      |         |            |     |      |       |     |     |         |
Table 3b: Domain analysis—condition specific PRO instruments

| SDSS | BCTQ | 6 CTS SS | Hand-VAS | AUSCAN | TDX | TASD | NELSON Score |
|------|------|----------|----------|--------|-----|------|---------------|
| **Physical Functioning** | | | | | | | |
| Limitations of whole upper limb | | | | | | | |
| Limitations of hand / wrist | • | | | | | | |
| Limitations of hand / digits | • | • | • | • | • | • | |
| Limitations of thumb | • | • | • | • | • | • | |
| Ability to perform ADLs | • | • | | • | • | • | • | |
| Ability to use smart phone / modern technology | | | | | | | |
| Ability to work | | • | | | | | |
| Ability to travel | | • | | | | | |
| Ability to participate socially | | • | | | • | | |
| **Symptoms** | | | | | | | |
| Pain issues | • | • | • | • | • | • | • | |
| Sensory changes (tingling/numbness) | • | • | | | | | |
| Stiffness | • | • | | | | | |
| Swelling | | • | | | | | |
| Weakness | • | • | • | • | • | • | |
| Reduced ROM | • | • | • | • | • | • | • | |
| Insomnia | • | • | • | | | | |
| Change in appetite | • | • | • | | | | |
| **Health-related QOL** | | | | | | | |
| Satisfaction with treatment | | | | | | | |
| Satisfaction with outcome / Overall assessment | | | | • | • | • | |
| Inconvenience of medical / hospital | | | | | | | |
| Concerns Re: post op complications / Recovery | | | | | | | |
| Expectations | | | | | | | |
| **Psychological functioning** | | | | | | | |
| Self confidence / self esteem | | | | | | | |
| Avoidance of uncomfortable situations | | | | | | | |
| Negative feelings about self | | | | | | | |
| Change in mood | • | | | | | | |
| **Body Image** | | | | | | | |
| Concerns regarding scarring | | | | | | | |
| Self-consciousness | | | | | | | |
| Satisfaction with hand appearance | • | | | | | | |
| **Sexual functioning** | | | | | | | |
Regional PROMS—upper extremity

Patient outcomes of surgery-hand/arm—POS–HA
The POS–HA developed by Cano et al. in 2004 is the only instrument identified in this review that satisfies the gold-standard methodology of the SAC. This instrument includes a post-surgery component that asks the patient about their satisfaction and whether expectations have been met. However, the POS–HA does not employ IRT or RA. Instruments that have been developed using IRT or RA include: the manual ability measure (MAM–16, MAM–36) PROMIS physical function upper extremity or PROMIS PF–UE, and the upper extremity functional index (UEFI–15) however, these instruments are focussed mainly on function and do not explore other domains as demonstrated in Table 3a.

Disabilities of the arm, shoulder and hand—DASH, QuickDASH and M‘DASH
The DASH, developed in 1996, is designed as a brief, self-administered instrument that measures upper extremity disability at the individual level. Content was developed from literature review, expert panels and existing scales. A shorter version, the QuickDASH, was developed in 2005 using concept retention methodology. It has been reported that neither instrument is specific to the upper limb, with the DASH unable to reliably differentiate between upper and lower limb pathology if completed by an individual with pathology in both regions. The M‘DASH (Manchester-modified DASH), developed in 2008, was designed to alleviate this issue by the retention of items that are upper limb-specific.

Upper limb functional index—ULFI
The ULFI developed in 2006 is unique in that it is composed of three sections including a patient-specific index and a visual analogue scale rating overall status.

Regional PROMS—hand/wrist

Michigan hand outcomes questionnaire — MHQ and BMHQ
The MHQ developed in 1998 is a hand-specific outcomes instrument composed of 25 questions to be answered for each hand and a further 12 questions relating to both hands, totaling 62 questions. These items are separated into six domains: overall hand function, activities of daily living, pain, work performance, aesthetics and patient satisfaction with hand function. Each hand is evaluated separately and this is the only PROM identified that performs this analysis. The MHQ has been developed using robust methodology, however, information regarding item reduction is minimal in the literature. The psychometric validation of the MHQ has been thorough.

The same developers produced the brief MHQ (BMHQ) in 2011. Item reduction was performed using a concept-retention technique that allows items that are deemed to be clinically relevant regardless of their statistical value. Two items were retained from each scale, resulting in 12 items in the BMHQ. The items selected were chosen based on their correlation with the original MHQ score, thus the psychometric properties of the original MHQ are maintained. Unlike its forbearer, the BMHQ does not differentiate between the hands.

Patient-rated wrist evaluation—PRWE
The PRWE was developed in 1996 to measure the outcome following distal radius fracture. It was developed from a survey of wrist experts to determine the structure and content of the scale. They identified the most important issues to be pain, functional ability and patient satisfaction. The PRWE was modified to the PRWHE in 2004 by changing the word ‘wrist’ to ‘wrist/hand’ throughout the questionnaire.
Patient evaluation measure—PEM

The PEM developed in 1995 originated from an international consensus meeting of multidisciplinary hand surgery experts in Derby, United Kingdom. There is no published detail on the development process used for item generation, item reduction or initial validation.49,50

Modern activity subjective survey—MASS07

The MASS07, developed in 2008, is designed to specifically assess hand function during high-frequency activities such as mobile phone or computer use.34

Hand assessment tool—HAT

The HAT developed in 2009 measures activity limitation for the hand, wrist and forearm axis. The majority of items relate to function but some ask about pain, hand appearance and sensory issues. The HAT, MASS and the PRWHE do not assess broader concepts such as patient satisfaction and the psychological impact of the hand condition.

Condition-specific PROMs

Boston carpal tunnel questionnaire—BCTQ

The BCTQ, developed in 1993, is the original condition-specific PROM relevant to hand surgery. This instrument is composed of a symptom severity scale and functional status scale. Atroshi shortened the scale in 2009 using IRT to create the six-item CTS.9

The Southampton Dupuytren’s scoring scheme (SDSS) was developed in keeping with the recommendations of the Derby outcomes conference. For osteoarthritis patients, the Australian-Canadian osteoarthritis hand index (AUSCAN) was developed to measure pain, stiffness and physical function using separate scales.

The only instrument specific to rheumatoid arthritis was the visual analogue scale – hand (VAS-Hand). This is a single item measure that asks patients the impairment level due to rheumatoid arthritis in their hands. The Nelson Hospital score is specific for base of thumb arthritis but has been widely criticised for employing poor methodological quality.41 In 2016, two alternative instruments for this pathology were developed: the thumb disability examination (TDX) and the trapeziometacarpal arthrosis symptoms and disability questionnaire (TASD).3,41 Both have used sound techniques but neither have used IRT or RA in their development processes.

Discussion

All of the instruments discussed in this review aim to measure patients’ subjective experiences of their hand surgery or hand condition. The quality of the questionnaires is variable in terms of their development and psychometric properties. Despite the multitude of instruments that have been identified, it remains the case that ‘no gold standard, objective criterion measurement tools for patient-rated hand outcomes exist’.46 The POS–HA is the only instrument that has been developed in accordance with the criteria of the SAC and FDA guidelines.7,15,51

The most widely used PROM for the upper limb is commonly accepted as the DASH.32 As evident in Table 2a, this instrument fails to reach accepted international guidelines15 due to the lack of qualitative patient input during development.52 Furthermore, it has been proven to fail unidimensionality testing which is a requirement for accurate measurement and, as a result, the meaning of the overall DASH score is compromised.53,54

The assessment of the upper limb as a whole functional unit is attractive in terms of simplicity of implementation, however, this approach results in significant disadvantages. Instead of measuring the effects of a given intervention on the hand, the score may reflect other injuries or conditions affecting the upper limb. Due to the frequency of coexisting upper limb pathologies, the DASH cannot discriminate the changes specific to the intervention of interest.3 Due to the heterogeneity of hand surgery, no single scale will be able to measure clinically important change in all treatments and therefore the use of a regional instrument has the risk of marginalising the effects of interventions.55 Another consideration is that the
DASH is not specific for upper limb disability, as it has been shown to reflect lower limb and cervical spine pathology.\textsuperscript{21,44}

Since the development of the most commonly used hand PROMS in the 1990s, there has been much progress in the field of psychometrics. Classical test theory (CTT) is based on the assumptions that:

1. the more items on a scale, the less it will affect by random error
2. reliability and validity estimates are only applicable to the sample studied or a population well represented by the sample, and
3. any changes to the scale would require re-evaluation of the psychometrics of the scale.\textsuperscript{56}

Traditional instruments that are widely used, such as the DASH, MHQ, PRWHE, provide scores in ordinal format which is not suitable for measuring change (ordinal data does not have consistent spacing between digits and therefore measuring change cannot be accurately performed). An advantage of IRT and RA psychometric techniques is that they produce an interval scoring system which makes it mathematically sound to compare measurement outcomes over time.\textsuperscript{13} These are also suitable for use in clinical practice for individual patients, as opposed to traditional instruments which are only valid for use in comparing groups of patients.

The transition away from traditional psychometric techniques, used in the majority of the instruments identified in this study, to those based on IRT and RA (such as UEFI–15, MAM16, MAM36 and the PROMIS PF–UE) has resulted in instruments that are more scientifically sound and allow for valid application between populations and more meaningful measurement of change over time.

**Condition-specific instruments**

There has been an increase in the PROMs available to measure the outcome of specific hand conditions such as the BCTQ,\textsuperscript{36} SDSS\textsuperscript{35} and the TDX.\textsuperscript{3} Condition-specific instruments are more sensitive to relevant surgical intervention offering improved face validity, less likelihood of missing data and more appropriate measurement of change (although few use interval format which makes measuring change more scientifically robust). The difficulty with the implementation of condition-specific instruments as a routine clinical measure is that, in any given hand clinic, a whole suite of different questionnaires would be required, each with their own instructions, format and scoring systems. This would simply not be practical in the majority of hand services.

**Hand aesthetics measures**

The aesthetic appearance of the hands is an important issue for many hand surgery patients; particularly those with osteoarthropathies and Dupuytren’s contracture.\textsuperscript{57,58} Hands are highly visible within daily practices and anomalies of the hands often draw unwanted attention. Despite the acknowledged importance of this, there is no accepted measure for hand aesthetics.\textsuperscript{57} Hand aesthetics is a scale in the MHQ and a single question in the PRWHE. A possible reason why a hand aesthetics PROM has not been suitably explored may be due to the objective of scale designers to have a single overall score. Hand aesthetics may not align itself with other measures of outcome and thus is not suitable to be summed in with other domains such as function or satisfaction.

**Patient satisfaction**

Patient satisfaction and the perioperative experience is an area that is not adequately explored by existing instruments. There are several areas within hand surgery where the functional outcomes between different surgical approaches are deemed equivalent. Therefore, the patient’s preference should be a consideration in assessing which technique is used. Patient satisfaction is a complex concept that is not suitably measured by a single item, as has been the common practice.\textsuperscript{59} Indeed, as Graham states, ‘it is crucial that we approach the measurement of satisfaction with the same methodological rigour and insight that we consider all of our clinical outcomes’.\textsuperscript{59} Currently available PROMs that attempt to measure patient satisfaction do not tend to address the complexity of the concept. The PEM, POS–HA and the MHQ all have a scale dedicated to measuring patient satisfaction. The POS–HA asks about scar lumpiness, the speed of recovery compared to patient expectation and whether...
the patient would recommend the operation to a friend with a similar issue. The MHQ has a cluster of six questions exploring patient satisfaction with their hand function, motion, strength, pain and sensation. The PEM has three items that explore patient satisfaction with hospital and their hand and attempts to gauge whether the patient’s expectations have been met given their original injury. This is something that the field of hand surgery needs to establish a better understanding of so that we can improve the experience of hand surgery for our patients.

This review has systematically examined seminal papers on all identified PROMs with a focus on instrument development. It does not include all papers that have reported on the use or measurement properties of the included PROMs. In order to perform a comprehensive review of the measurement properties of these instruments a further review based on the COSMIN recommendations would be required. This review only included instruments developed in English and this could certainly be considered a limitation as it excluded instruments such as the measure of manual ability in chronic stroke patients called ABILHAND and Unité Rhumatologique des Affections de la Main (URAM).

**Conclusion**

Despite the number of PROMs that have been developed for patients with hand conditions there are few instruments that satisfy international guidelines for PROM development. There are no condition-specific instruments that have been developed using IRT or RA. There is still much work to be done in this field to achieve accurate, clinically integrated outcome measurement.

There is need for an instrument to be developed according to international guidelines, to allow for measurement of all the concepts relevant to patients with hand conditions. The use of IRT or RA will result in interval level scores that can be accurately used to measure change over time and to compare scores across patient populations. This would ensure that the most sensitive and specific scales are being used but with the convenience and clinical utility of a single PROM system.

**Disclosure**

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