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Do patient-reported outcome measures capture functioning aspects and environmental factors important to individuals with injuries or disorders of the hand?

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ABSTRACT

Study design: Qualitative study.
Introduction: Clinical outcome evaluation needs to consider the patient perspective for an in-depth understanding of functioning and disability.
Purpose of the study: To explore whether patient-reported outcome measures (PROMs) used in the field of hand injuries or hand disorders, capture functioning aspects and environmental factors important to the patients.
Methods: We performed a qualitative study and a systematic literature review. The focus group sessions were recorded, transcribed verbatim, and the identified concepts were linked to the ICF. We searched in MEDLINE for reviews, related to injuries or disorders of the hand, reporting on PROMs. We linked the items of the identified PROMs to the ICF and compared the qualitative data with the content of the PROMs.
Results: Statements from 45 individuals who participated in eight focus groups were linked to 97 categories of the ICF. From 15 reviews included, eight PROMs were selected. The selected PROMs capture 34 of the categories retrieved from the qualitative data.
Conclusions: PROMs used in the context of hand injuries or hand disorders capture only in parts the functioning aspects important to the patients.
Level of evidence: N.A.

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Introduction

Hand impairments arising from injury (e.g. fracture, laceration, amputation) or hand disorders (e.g. carpal tunnel syndrome, Dupuytren's disease) are associated with disability or poor functioning. People with hand impairment are limited in a variety of day-to-day activities, such as mobility,[1] self-care[2–4] and domestic life,[2] and are restricted in their participation.[4–8]

In clinical practice, patient-reported outcome measures (PROMs) 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 (health-related) quality of life" (Brettschneider 2011, p. 4).[9] Existing PROMs differ according to the domains they contain and the populations and diseases for which they were designed.[10–12] Some, such as the Boston Carpal Tunnel Questionnaire (BCTQ),[13] are disease-specific measures developed to address specific impairments or limitations in the hand following a certain disease. Others, are joint-specific such as the Patient Rated Wrist/Hand Evaluation (PRWHE)[14] or regional measures such as the Disabilities of the Arm

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Shoulder and Hand Questionnaire (DASH)[15]; that can be used across a spectrum of injuries and disorders of the hand.

The decision on the appropriate PROM to use depends on its psychometric properties, on existing reference data and on its applicability for the population under investigation. Content validity (i.e. whether the instrument contains the relevant domains[16]) is an important criterion to decide whether a certain PROM is applicable for the population of interest. Thus, for clinicians and researchers it is crucial to know which aspects are covered in the outcome measures they use.

There have already been efforts in reviewing the literature on outcome measures to be used in the context of hand injuries or hand disorders. van de Ven-Stevens et al[17] and Schoneveld et al[18] focus on outcome measures developed to address limitations in activities and participation. Changulani et al[10] provide a detailed analysis of four commonly used outcome measures for evaluating wrist and hand function. Metcalf et al.[19] give an overview of 25 upper limb outcome measures by categorizing their assessment focus based on the International Classification of Functioning, Disability and Health (ICF).[20] These reviews add valuable information regarding purpose and psychometric properties of a number of outcome measures.

In addition, it would be useful to compare the content of outcome measures frequently applied in clinical practice. This would facilitate the decision on the adequate outcome measure to use with regard to the therapeutic goals. The patient perspective of functioning should be taken into account to enrich this comparison. Depending whether the specific contents of the PROMs are important to people with hand injuries and disorders, the respective instrument can be chosen. Thus, selection of instruments can be tailored to the needs of individuals affected by hand injuries or disorders.

Purpose of the study

The overall aim of the study is to investigate whether PROMs used for outcome evaluation in the field of hand injuries or hand disorders capture functioning aspects and environmental factors important to the patients. The specific aims are (1) to compare the content of PROMs by using the ICF as a framework and (2) to examine content validity of these PROMS based on qualitative data retrieved from focus group sessions of people with injuries or disorders of the hand.

Methods

Design

A systematic literature review was performed to identify PROMs used for outcome evaluation in the field of hand injuries or hand disorders. The content validity of these PROMs was examined based on data derived from focus groups including people with injuries or disorders of the hand. According to Fitzpatrick et al[21] content validity deals with the adequacy of a PROM to measure the relevant parts of the health components. Commonly, experts and/or patients are involved in the process of determining these relevant parts, both, (1) in the development process of a questionnaire and (2) in the validation process of a questionnaire. In our study, we determined the content validity of the PROMs by comparing the constructs captured in the questionnaires with the health experience stated by the patients themselves using the ICF as a framework. Thus, this paper combined the results of a qualitative study and a systematic literature review. By using the ICF as a content reference, it was possible to compare different kind of data even if data were collected in different studies and in different languages.[22,23]

The focus group procedure was approved by the ethics committee of the Ludwig-Maximilians-University Munich (Germany) and was performed according to the principles of the Declaration of Helsinki 1996.

Systematic literature review

Search

A systematic search was performed in the electronic database MEDLINE for published reviews – that report about PROMs for outcome evaluation in the field of hand injuries or hand disorder – by using the keywords “assessment”, “measure”, “measurement”, “instrument”, “test”, “evaluation”, “questionnaire”, “outcome”, “scale”, and “score”. Further, we searched for the keyword “hand” related to “injury”, “condition”, “disability”, “disorder”, “function”, “impairment” “rehabilitation”, “therapy”, “surgery”, in addition to “arm”, “forearm”, “wrist”, “upper limb” and “upper extremity”. Search steps were combined using the Boolean operators ‘OR’ and ‘AND’. The search was limited to reviews published between 2002 and 2012 in English or German language. Reviews were excluded if they (1) did not refer to patient-reported outcome measures, (2) focused on outcome measures used in children and (3) included patients with neurological diseases (e.g. stroke) or systemic diseases (e.g. rheumatoid arthritis), since these reviews potentially would have revealed a number of instruments (e.g. the Stroke Impact Scale,[24] the Functional Independence Measure[25]) not typically used in the type of hand patients we focused on in the qualitative study.

Analysis of the PROMs

The ICF was used as a common framework to analyze the content of the PROMs. The data analysis included the following steps:

(1) Selection of PROMs: The retrieved reviews were checked by two health professionals (SK, MC) regarding the outcome measures reported. We selected only validated patient-reported outcome measures – i.e. outcome measures in which individuals respond to a number of standardized questions asked in a paper-pencil form – which can be used for outcome evaluation in the field of hand injuries or hand disorders. We considered a PROM validated if respective psychometric properties have been reported in the literature and if information on its psychometric properties have been examined in various study populations comparable to the patients included in the qualitative study. Generic PROMs, such as the 36-Item Short Form Health Survey (SF-36)[26] or the Disability Rating Index (DRI)[27] were not included. In addition, we excluded PROMs developed exclusively for a body region other than the hand (e.g. shoulder, elbow, neck), as well as, PROMs developed for neurological (e.g. stroke, Parkinson’s disease) or systemic diseases (e.g. rheumatoid arthritis). Moreover, PROMs to be used in children were excluded, too.

(2) Linking to the ICF: each item of a selected PROM was linked to the ICF in a systematic and standardized way. The ICF is based on the bio-psycho-social perspective and contains four components, namely Body functions, Body structures, Activities and Participation as well as Environmental factors. The ICF contains 1424 units called ICF categories, each allotted to the named components of the classification. Each ICF category is denoted by an alphanumerical code. The code is composed of a letter referring to the components of the classification (b: Body functions; s: Body structures; d: Activities and participation and e: Environmental factors), followed by a numeric code. This numeric code starts with the chapter number (one digit), followed by the second level (two digits) and the third and fourth

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