AMERICAN JOURNAL OF INDUSTRIAL MEDICINE 29:602-608 (1996)

Development of an Upper Extremity Outcome Measure: The DASH (Disabilities of the Arm, Shoulder, and Head)

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This paper describes the development of an evaluative outcome measure for patients with upper extremity musculoskeletal conditions. The goal is to produce a brief, self-administered measure of symptoms and functional status, with a focus on physical function, to be used by clinicians in daily practice and as a research tool. This is a joint initiative of the American Academy of Orthopedic Surgeons (AAOS), the Council of Musculoskeletal Specialty Societies (COMSS), and the Institute for Work and Health (Toronto, Ontario).

Our approach is consistent with previously described strategies for scale development. In Stage 1, Item Generation, a group of methodologists and clinical experts reviewed 13 outcome measurement scales currently in use and generated a list of 821 items. In Stage 2a, Initial Item Reduction, these 821 items were reduced to 78 items using various strategies including removal of items which were generic, repetitive, not reflective of disability, or not relevant to the upper extremity or to one of the targeted concepts of symptoms and functional status. Items not highly endorsed in a survey of content experts were also eliminated. Stage 2b, Further Item Reduction, will be based on results of field testing in which patients complete the 78-item questionnaire. This field testing, which is currently underway in 20 centers in the United States, Canada, and Australia, will generate the final format and content of the Disabilities of the Arm, Shoulder, and Hand (DASH) questionnaire. Future work includes plans for validity and reliability testing.

KEY WORDS: outcomes, health status assessment, research, upper extremity dysfunction, HRQOL

INTRODUCTION

Health-related quality of life (HRQOL) has become an important part of the way health professionals think about disease and injury. A view of disease as a strictly biological phenomenon is no longer adequate; psychosocial consequences and functional impact are most relevant to patients and therefore are key components in an assessment of the

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Accepted for publication December 15, 1995.

effect of disease or injury on health. Both generic and disease-specific HRQOL measures have been recommended as components of an outcome assessment which captures these effects. Generic tools tend to provide a broad picture of health across a range of conditions, whereas disease or domain-specific measures are more sensitive to the disorder under consideration and are therefore more likely to reflect clinical changes [Bergner, 1987; Patrick and Deyo, 1989; Beaton et al., 1996; Bombardier et al., 1995].

The need for an outcome measure which reflects the impact on function of a variety of musculoskeletal diseases and injuries in the upper extremity was independently identified by researchers from the American Academy of Orthopedic Surgeons' (AAOS) Outcomes Research Committee and the Institute for Work and Health (IWH). Existing scales are either generic or too specific, addressing a particular upper extremity joint (e.g., shoulder) or condition (e.g., carpal tunnel syndrome). The decision was made to proceed with a collaborative project to develop a regional outcome measure which conceptualizes the upper extremity as a single functional unit. A tool which could be used for the evaluation of any joint or condition of the upper extremity would potentially have wide applicability and would allow for comparisons across different upper extremity conditions. Availability of a standardized outcome measure would promote greater uniformity in research and allow for greater patient relevance and input than measures traditionally used to quantify patient status related to musculoskeletal disorders (e.g., X-rays, range of motion, blood counts, grip strength). Insurers and others seeking to understand the full impact of a disorder and subsequent treatment on function would potentially find such a measure useful.

The objective of this report is to provide an overview of the development of this outcome measure called the DASH. Its aim is to assess symptoms and functional status, with a focus on physical function, in populations with upper extremity musculoskeletal conditions. The items tap upper extremity-related symptoms and measure functional status at the level of disability. Disability is defined as "difficulty doing activities in any domain of life (the domains typical for one's age-sex group) due to a health or physical problem" [Verbrugge and Jette, 1994].

SCALE DEVELOPMENT

There are three stages to scale development [Guyatt et al., 1986; Streiner and Norman, 1991]: Stage 1 Item Generation, Stage 2 Item Reduction, and Stage 3 Reliability and Validity Testing. In this paper we report only on the results of Stages 1 and 2a, Initial Item Reduction. Our plans for Stage 2b, Further Item Reduction, are also presented.

Concepts covered by the DASH questionnaire are symptoms and functional status (Table I). The decision to focus on these concepts evolved from review of the conceptual literature on quality of life and health status measurement, discussions with experts, and review of concepts included in existing outcome measurement scales. The components included under the concept of symptoms are pain, weakness, tingling/numbness, and stiffness. There are three dimensions within functional status: physical, social, and psychological functioning. Components within physical functioning are daily activities, house/yard chores, shopping/errands, recreational activities, self-care, dressing, eating, sexual activities, sleep, and sports/performing arts (optional). Components within social functioning are family care, occupation, and socializing with friends/relatives. Only one component, self-image, has been included in psychological functioning. The items in the questionnaire oversample upper extremity activities and are intended to measure disability.

TABLE I. Concepts, Dimensions, and Components Included in the DASH* Questionnaire

Concept	Dimensions	Components
Symptoms		Pain
		Weakness
		Stiffness
		Tingling/numbness
Functional status	Physical	Daily activities
		House/yard chores
		Shopping/errands
		Recreational activities
		Self-care
		Dressing
		Eating
		Sexual activities
		Sleep
		Sports/performing arts (optional)
	Social	Family care
		Occupational
		Socializing with friends/relatives
	Psychological	Self-image

*DASH = Disabilities of the Arm, Shoulder, and Hand.

The process of development of the DASH questionaire is shown in Table II and described in the text below.

Stage 1, Item Generation

Methods

Literature review. Published outcome measurement scales and other unpublished scales known to members of the col-

TABLE II. Development of Upper Extremity Outcome Measure: The DASH*

Stage	Methods	Results
Stage 1 Item Generation	Literature review	13 scales
	Review of items included in scales of various upper extremity conditions	List of 821 items
Stage 2 Item Reduction		
2a Initial Reduction (judgement based)	Review of 821 items by three members of collaborative group	List of 177 items
	Rating of 177 items by content experts and members of collaborative group	List of 75 items
	Review of expert rating and selection/formatting of remaining items by collaborative group	75 formatted questions
	Pretesting on 20 patients	Revised formatted questionnaire including 78 questions (plus 5 optional questions)
2b Initial Reduction (data based)	Administration of the 78-item questionnaire and clinical assessment form to 420 patients in 20 centers in Canada, Australia, and the United States	Not available; data collection in progress
	Analysis of responses using statistical and judgemental data reduction techniques	
Stage 3 Reliability and Validity	Protocol under development	

*DASH = Disabilities of the Arm, Shoulder, and Hand.

laborative group and applicable to a variety of disorders in the arm, shoulder, and hand were collected (Appendix).

Review of items. Items from the reviewed scales were pooled and broadly classified according to the taxonomy developed by the World Health Organization [WHO, 1980]. These are representative of musculoskeletal symptoms (e.g., pain, numbness), impairment (e.g., upper extremity weakness), disability (e.g., ability to open a jar), and handicap (e.g., ability to pursue usual occupation).

Results

Literature review. Thirteen scales were identified and reviewed; no single published scale adequately represented the range of clinical conditions or the concepts of upper extremity function which were the goals of this project; the available scales were either generic, specific to an upper extremity joint (e.g., shoulder) or condition (carpal tunnel syndrome), or interviewer administered.

Review of items. The 13 scales were combined to produce an initial pool of 821 potential items.

The results of classification of items into concepts and components, as well as into the WHO taxonomy, were used to identify items which fell outside the targeted components or clearly did not reflect symptoms or disability. This information was used for part of the judgement-based item reduction described below.

Stage 2a, Initial Item Reduction (Judgement Based)

Methods

Expert opinion. The original items taken from existing measurement scales were reviewed by three members of the collaborative group (D.B., A.D., M.M.). Items were then stripped of scaling and attribution to a specific disorder. They were regrouped to eliminate those that were repetitive or obviously unrelated to the upper extremity. This reduced item list was then sent to content experts (acknowledged) and the Upper Extremity Collaborative Group for their input as to content/face validity and the importance of the items for further item reduction. Items were rated by these content experts (n = 15) on a 5-point scale (2 = definitely yes to −2 = definitely no) in response to the question of which items should be included in an upper extremity outcome measurement scale. Items with mean frequency endorsement scores of less than 0 were removed unless removal of the item

meant that an identified component was not represented. Finally, items which were outside the components identified in Table I or which did not reflect symptoms or disability were removed.

Questionnaire format. Formatting the resulting items into a questionnaire suitable for field testing required consideration of a number of issues: time frame, scaling and wording of response options, wording of questions to reflect capacity or performance, attribution to the most involved, and/or either upper extremity and comorbidity. Literature review of current practices in questionnaire development methodology and subsequent group discussion formed the basis for decisions regarding questionnaire format.

Wording of questions to reflect capacity (''could do,'' ''can do'') or performance (''did do,'' ''do do'') can have a significant effect on the response obtained from questionnaires. Anderson et al. [1977] found 15% less dysfunction when questions were asked in capacity vs. performance mode; this difference was attributed to respondents' denial of dysfunction or limitation [Patrick and Erickson, 1993]. There are issues to be considered when using either of these approaches.

Capacity wording allows for greater ease in scoring than performance since individuals are asked to respond to all items, providing a hypothetical response for those activities which were not actually done. Items can be included which may not have been done within a given time frame; in this way, the questionnaire may be able to tap more positive attributes of health including seasonal or infrequently performed activities such as gardening or particular outdoor activities. Parsons [1990] defined good health as ''the state of optimum capacity for the effective performance of valued tasks''; in this way, positive health may be viewed as capacity rather than performance. There is, however, some concern that individuals may exaggerate their healthiness when questioned about capacity.

Performance wording requires that unless only ''usual'' or ''typical'' items are included in the questionnaire, a not applicable response option be provided. The result of this, essentially, is that everyone answers a different questionnaire (because the denominator changes) and scoring becomes more difficult. There are many factors other than ill health that restrict behavior, including weather, season, need, availability, and preference. Since there is no obvious choice between performance and capacity, the decision of which to use is a judgement call. Little research has been done to explore the impact of all the potential issues mentioned here; more methodological work is required to document the presence and magnitude of potential differences in score between the two approaches.

Pretesting. The formatted questionnaire was pretested on 20 individuals with upper extremity problems to ensure readability, absence of ambiguity, and understanding of scaling and content, as well as to confirm that an adequate number/type of response options were available. Patients were asked to indicate whether or not they understood what was being asked.

Results

Expert opinion/pretesting. The initial item reduction by members of the Upper Extremity Collaborative Group revealed significant overlap between questionnaires; based on this work, items were reduced from 821 to 177 (Fig. 1). The result of initial item reduction, based on the feedback of the content experts and Upper Extremity Collaborative Group and pretesting, was a list of 78 compulsory and 5 optional items. Items on self-image, recreational activities, and sports/performing arts were added because the working group and content experts felt these domains were not well represented by items taken from existing questionnaires. Feedback received from patients in the pretesting were discussed by the collaborative group and subsequent changes to the questionnaire made. The changes required were predominantly clarifications of wording rather than additions of new items.

Questionnaire format. The response options for each item were presented as 5 or 7-point Likert scales. The recall period chosen was 1 week to minimize problems with recall over a more extended time interval. Items were framed to reflect capacity because of greater ease of administration and scoring. Because of the paucity of information on the effect of wording items to investigate performance of a specific activity rather than the capacity to do the same activity, a subset of questions were framed as both performance and capacity questions. For example, the same question in capacity mode would read ''Could you, if you tried, have done heavy household chores during the past 1 week,'' and in performance mode, ''How much difficulty did you have doing heavy household chores during the past 1 week.'' These items will be compared in the analysis. Because the intent of the questionnaire is to measure disability, individuals were asked about their ability to do activities regardless of which arm, shoulder, or hand they used. It was thought that attribution to a specific extremity would possibly overestimate the impact of a disorder on the patients' overall disability. We did, however, ask patients to attribute difficulties in the areas of family care, occupation, socializing with friends/relatives, sleep, sexual activities, and sports/performing arts to the involved extremity since these domains could potentially be confounded by factors independent of the upper extremity disease or disorder. Although it is anticipated that the SF-36 [Wave et al., 1993] and DASH will usually be administered together, items from the physical and social functioning domains of the

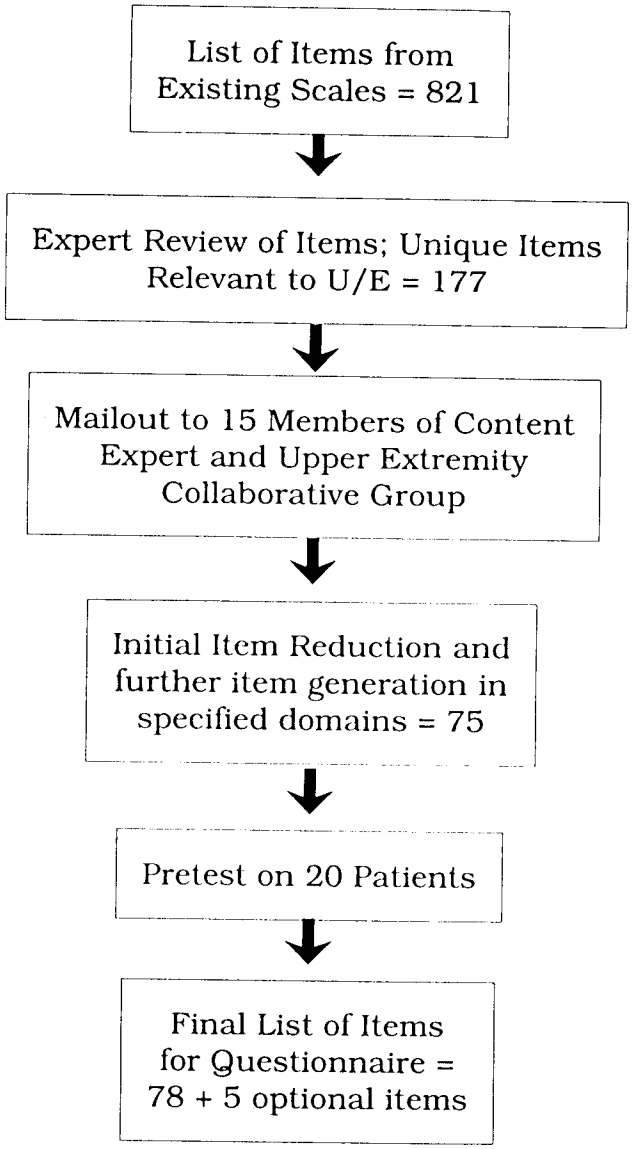

FIGURE 1. Stage 2a, Initial Item Reduction.

SF-36 have been included in the DASH with attribution to the upper extremity; the intent is to get some indication of how much of disability is specifically related to the upper extremity as opposed to general health.

Symptom questions, reflecting intensity, frequency, and duration, are asked with attribution to the more severely affected arm, shoulder, or hand. An example of a symptom question is "How severe is the feeling of weakness in your arm, shoulder, or hand?" An optional component of the questionnaire is intended for athletes and performing artists; the intent with these questions is to tap into the high-performance issues that may impact on individuals involved in these pursuits. A section on comorbidity is included and an open-ended question was incorporated to allow individuals to indicate areas of interest or importance that we had missed as well as to provide feedback on the clarity of the questionnaire.

WORK IN PROGRESS FOR STAGE 2B, FURTHER ITEM REDUCTION (DATA BASED)

Clinical Assessment Form

A clinical assessment form was developed and field tested. This form, which includes the basis of the diagnosis (e.g., examination, X-rays, electrodiagnostic studies), will be completed by the participating investigators in Stage 2b, Further Item Reduction. It is used to obtain information on the characteristics of the patients sampled and to ensure that target diagnostic categories (Colles fracture, carpal tunnel syndrome, symptomatic hand osteoarthritis, rheumatoid arthritis, painful arc in the shoulder, lateral elbow pain, and nonspecific soft tissue pain) are adequately represented. Clinical severity, certainty of diagnosis, and comorbid conditions are also recorded, as is a pain diagram.

Field Testing

Field testing of the questionnaire will be used to generate data from targeted patient populations for further item reduction. Analysis of these data should allow us to reduce the measure to a 30-item self-report questionnaire. There are 20 investigators and centers across Canada, Australia, and the United States presently involved in field testing. IWH, Toronto, Ontario is the coordinating center for data collection and analysis.

Sample

Individuals with upper extremity musculoskeletal problems seen during regular outpatient clinic hours by the participating investigators are being approached to complete the questionnaire. It is hoped that this will provide a representative sample of patients routinely seen as part of the investigators' clinical outpatient practice.

Sample size requirement was estimated at 420 individuals (7 categories × 60 individuals/category = 420). A sample of this size should provide reasonable variability in each of the target categories—Colles fracture, carpal tunnel syndrome, symptomatic osteoarthritis, rheumatoid arthritis, painful arc in the shoulder, lateral elbow pain, and nonspecific soft tissue pain—and should allow for multivariate or factor analysis. Although these categories were intentionally oversampled, individuals with any upper extremity disease or disorder were included (including postoperative cases). Each of the 23 centers was asked to recruit 30 participants.

Proposed Analysis

Frequency of endorsement and internal consistency (e.g., Cronbach's alpha) will be assessed using the data

generated by the field testing. Items with very high or low endorsement rates or excessively high correlations with other items in the same scale would be eliminated. Factor analysis will also be used to empirically validate (or modify) our aggregation of items into subscales.

DISCUSSION

There are many physical measurements that can be done to assess the upper extremity clinically, such as range of motion, grip strength, and timed performance of specific tasks; but all of these fall short in their ability to translate measurable impairments into symptoms, disabilities, and handicaps as perceived by the patient. At present, there is little standardization of these latter assessments for the upper extremity. We believe there is much to gain from a standardized assessment of upper extremity symptoms and functional status.

A standardized assessment would lend uniformity to patient assessment, a uniformity which does not now exist. An assessment based upon patient reporting would help to include the patient more explicitly in the assessment process. A standardized measure would permit comparison across various groups of patients or treatments. Such comparisons are valuable for clinical research and can also meet the needs of government agencies and third-party payers for a means of assessing the relative impact of various conditions and treatments on upper extremity symptoms and function. Finally, such an instrument could be used to serve large populations (e.g., of workers or patients with a specific diagnosis) to measure the impact of activity or illness on health status as reflected in upper extremity function.

The question arises as to whether one broad upper extremity tool will suffice for most cases, or whether condition-specific or treatment-specific instruments will be needed. Further, there is a question as to how broad a net should be cast; too widely, and extraneous factors may confound analysis; too narrowly, and generalizability may be lost. To a large extent, these questions can only be answered with experience. They will be addressed by the results of our field trials and subsequent use in other populations, and thus are more properly the subject of later reports.

This paper summarizes our plan and progress to date for the development of an outcome measure for upper extremity conditions. Item generation and initial reduction in Stage 1 and 2a produced a 78-item questionnaire. Further data reduction will result from the administration of this questionnaire in Stage 2b across a variety of upper extremity conditions with concurrent clinical data collection. The aim is to finalize the format and content of a short self-administered questionnaire with wide applicability in upper extremity conditions. Reliability and validity of this questionnaire will be undertaken in a subsequent project.

To supplement this general overview of the project, a series of subsequent papers will address in more detail the various stages of development of this questionnaire as well as general aspects of scale development and disability assessment. Ultimately, an understanding of the relationship of this measure (and changes in this measure) to other patient outcomes will be needed to evaluate care provided to patients and to enrich our awareness of the impact of functional status on patients' health.

ACKNOWLEDGMENTS

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APPENDIX

Upper Extremity Measurement Scales Included in Literature Review

1. Arthritis Impact Measurement Scales (AIMS2) [Meenan et al., 1992]
2. American Shoulder and Elbow Surgeons Standardized Shoulder Assessment Forms [Richards et al., 1994]
3. Health Assessment Questionnaire (HAQ) [Fries et al., 1982]
4. MFA Questionnaire (personal communication, Marc F. Swiontkowski, MD, Harbor View Medical Center, Seattle, WA, October 1994)
5. Neck and Upper Limb Index (NULI; courtesy of Susan Stock, MD, McGill University, Montreal, Quebec, Canada)
6. St. Michael's Upper Extremity Reconstructive Service Patient Self Evaluation Form (St. Michael's Hospital, Toronto, Ontario)
7. MOS Short-Form General Health Survey (SF-36) [Ware et al., 1993]
8. Shoulder Pain and Disability Index (SPADI) [Roach et al., 1991]
9. Shoulder Severity Index (SSI) [Patte, 1987]
10. Subjective Shoulder Rating Scale (SSRS) [Kohn et al., 1992]
11. Simple Shoulder Test (SST) [Lippitt et al., 1993]
12. Toronto Extremity Salvage Score (TESS) [Davis, 1994]
13. Symptom Severity and Functional Status Scales for Carpal Tunnel Syndrome [Levine et al., 1993]