The Health Assessment Questionnaire (HAQ)

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ABSTRACT

Patient-reported outcomes (PROs) provide intrinsic knowledge about a patient's health, functional status, symptoms, treatment preferences, satisfaction, and quality of life. They have become an established approach for assessing health outcomes. The Health Assessment Questionnaire (HAQ), introduced in 1980, is among the first PRO instruments designed to represent a model of patient-oriented outcome assessment. The HAQ is based on five patient-centered dimensions: disability, pain, medication effects, costs of care, and mortality. It has been validated by mail, in the office, by telephone, and by comparison with paraprofessional and physician judgments as a reliable instrument, and has been significantly correlated with other PRO instruments. Typically, one of two HAQ versions is used: the Full HAQ, which assesses all five dimensions, and the Short or 2-page HAQ, which contains only the HAQ disability index (HAQ-DI) and the HAQ's patient global and pain visual analog scales (VAS). The HAQ-DI and the global and pain VAS (i.e., the short HAQ) have essentially retained their original content since their inception, while the Full HAQ undergoes periodic revision to address issues of contemporary scientific interest. The HAQ-DI has been translated or culturally adapted into more than 60 different languages or dialects and has become part of the National Institutes of Health "Roadmap" Project, the Patient-Reported Outcomes Measurement Information System (PROMIS).

Introduction

Improving health outcomes is among the most important challenges of our society (1). Use of patient reported outcomes (PROs) has become an established approach to help tackle these challenges. PROs provide fundamental knowledge about a patient's health, functional status, symptoms, treatment preferences, satisfaction and quality of life from their own personal perspective. Accordingly, self-reported measures help to inform patient assessment, diagnosis determination, care planning, and the evaluation of progress towards treatment goals. The Health Assessment Questionnaire (HAQ), published in 1980 by the Stanford Arthritis Center (2), is among the first PRO instruments that was initially designed to represent a model of patient-oriented outcome assessment. The HAQ, which assesses multiple dimensions based on patient-centered values, is one of the most cited and employed PRO instruments, particularly but not exclusively in the rheumatic disease literature. The original article is a citation classic (2).

Through many demonstrations of its reliability, validity, adaptability, and ease of use, the HAQ has played a major role in the paradigm shift from reliance on biochemical and physical measurements to emphasis on outcomes that are relevant to the patient. The HAQ has been successfully implemented in numerous diverse areas, such as prediction of successful aging, inversion of the therapeutic pyramid in rheumatoid arthritis (RA), quantification of nonsteroidal anti-inflammatory drug gastropathy, development of risk factor models for osteoarthrosis, and examination of mortality risks in RA(3).

The HAQ: A hierarchial basis

Creation of the HAQ was based on studies of patient-centered health values that have tended to yield five generic outcome dimensions. Patients report that they want: 1) to avoid disability; 2) to be free of pain and discomfort; 3) to avoid adverse effects of treatment; 4) to keep medical costs low; 5) and to postpone death (4-7). Altogether, these five dimensions along with more specific sub-categories form the HAQ's hierarchial structure (Fig. 1).

At the apex of the HAQ's hierarchy is the overall entity of global health, which is a function of the five dimensions. To operationalize global health without sacrificing patient information, the HAQ's

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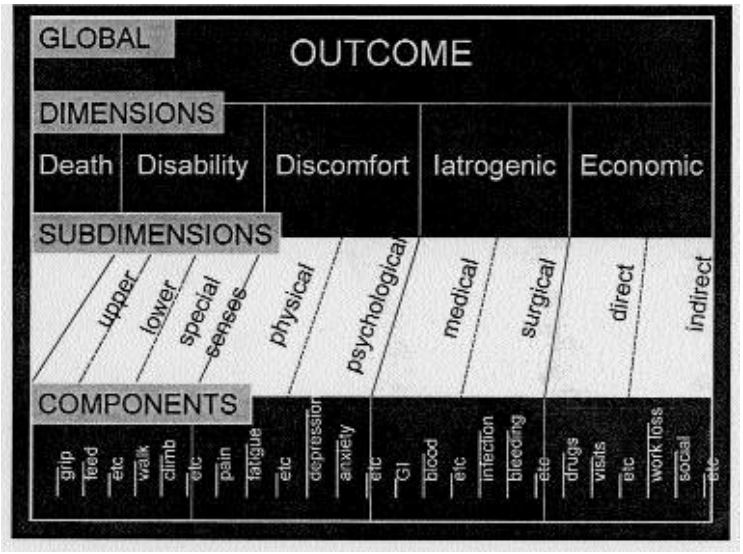


Fig. 1. The hierarchy of patient outcome.

five dimensions are further subdivided into more discrete categories that appear lower in the hierarchy. For example, the measurement of physical function is calculable from specific questions at a lower level that include activities which involve the upper extremities, lower extremities, or both.

Alternatively, rather than assess the five dimensions individually, a single global outcome question can be directly asked using an analog scale. Such a question will capture in part the patient's trade-offs between the different outcome dimensions, but will also be a broader perspective that may include other idiomatic values such as spirituality, disability-friendly environments, and family support. Instruments that use a single-item global health visual analog scale (VAS) have been recommended as representing meaningful outcomes and have been suggested internationally as one of the six core patient outcomes (i.e., disability, pain, patient global, physician global, swollen joint count, and tender joint count) to be measured in clinical studies of rheumatoid arthritis (RA) (8-10). Several scales, including the HAQ, contain such a scale (11-13).

The "Short" or"2-page" or the "Full" HAQ: What's the difference ?

Over its more than two decades of use, the meaning of the term "HAQ" has been interpreted differently. Typically, it refers to one of two versions. The **Full HAQ** assesses all five dimensions of health outcome which includes drug side effects and medical costs, as well as supplemental sections on demographics, lifestyle and health behaviors, while the **Short or 2-page HAQ** is comprised of only the HAQ disability index (HAQ-DI) and the HAQ's patient global and pain VAS. In the Full HAQ, drug side effects, dollar costs and other items are periodically tailored and supplemented with additional questions when contemporary issues, specific hypotheses or research questions arise by ARAMIS or other investigators, while the HAQ-DI and the patient global and pain VAS have remain unchanged.

The Full HAQ was one of the first instruments deliberately designed to capture prospectively and by protocol the long-term impact of chronic illness. It is generic in nature and was developed initially for use in multiple illnesses so that the impact of different disease processes could be compared, although much of its early work emanated from the rheumatology field. In its early development, the full HAQ was originally called the "Arthritis Assessment Questionnaire" or "AAQ". However, after it was recognized that the five patient-centered outcome dimensions represented general concepts and were not restricted to any single specific disease area, the current HAQ name was adopted. In all, the HAQ was designed to be efficient, structured for practical application during clinic visits, and compatible with high return rates when administered by mail or telephone.

The Full HAQ was adopted by the Arthritis, Rheumatism, and Aging Medical Information System (ARAMIS) in 1980 and has been deployed more than 100,000 times by our unit to assess clinical status, evaluate effectiveness in clinical and observational trials, and to define health outcomes (3). A myriad of populations have been studied with the HAQ: among them are HIV/AIDS patients, normal aging populations**,** adults and children with rheumatic diseases, and disabled workers (14-18).

Nonetheless, overall, it has been the **Short or 2-page HAQ** or the **HAQ-DI** that has received the widest attention, most frequent use, and that is most commonly referred to as "the HAQ." The short HAQ permits an expedient assessment of three of the six American College of Rheumatology (ACR) outcome measures for rheumatoid arthritis (9). It can be self-administered in five minutes and scored in less than one minute. But as with any instrument, it has limitations, and as generally used does not capture disability associated with sensory organ dysfunction or psychiatric dysfunction and does not directly measure patient satisfaction or social networking. However these variables, or other variables of interest to the user, can be readily appended as separate items.

The short HAQ has been employed in population-based studies, including the follow-up to the National Health and Nutrition Examination Survey (NHANES) (19). It has also been administered in a variety of diseases and conditions, including osteoarthritis, juvenile rheumatoid arthritis, systemic lupus erythematosus, ankylosing spondylitis, fibromyalgia, psoriatic arthritis, and systemic sclerosis (3).

Both the short and the full HAQ are copyrighted for the purposes of insuring that they will be used unmodified to preserve validity and contribute to stan-

dardization of assessment across studies. However, the HAQ is considered to be in the public domain, and permission for its use is customarily given without charge. A "HAQ-PAK" containing a recent version of the Full HAQ (which includes the short HAQ) and scoring directions is available on the ARAMIS website at ARAMIS. Stanford.edu.

HAQ-DI: Development and validation

The physical function scale of the HAQ, the HAQ-DI, was the original HAQ section to be developed and validated in the late 1970s under the auspices of the Stanford Arthritis Center. It was created by parsing questions and components from a variety of instruments extant at the time (20). The HAQ-DI evolved over numerous iterations through a series of subjective and objective assessments. Statistical evaluation, physician appraisal, and patient feedback modalities were used in the developmental process (2, 20). A comprehensive validation of each item set was performed to yield the final instrument. Correlation matrices were constructed, and inter-correlations, item-total correlations, correlations with existing "gold standards" such as performance of activities of daily living, physiological and biochemical measures, and chart reviews were evaluated. Items with correlations of ≥ 0.90 and those with correlations of ≤ 0.50 were deleted, since such items did not accurately measure the dimension represented by the other items in the index or had ambiguous, inconsistent or incomplete responses. Additional details of the development of the HAQ-DI are described in Fries, Spitz, Kraines, and Holman (1980) (2) and Fries, Spitz and Young (1982) (20).

The HAQ-DI has been repeatedly validated as a reliable PRO instrument by mail, in the office, by telephone, and by comparison with paraprofessional and physician judgments (2). Evaluations of the psychometric properties of the HAQ-DI have provided consistent and substantial demonstrations of both its reliability and validity across many applications and in different patient populations and are reported in detail with related publications (3, 18). Test-retest correlations demonstrating reproducibility have ranged from 0.87 to 0.99, and correlations between interview and questionnaire formats have ranged from 0.85 to 0.95. Validity has been demonstrated in numerous studies. There is consensus that the HAQ-DI possesses face and content validity, and correlations between questionnaire or interview scores and task performance have ranged from 0.71 to 0.95 demonstrating criterion validity. The construct/convergent validity, predictive validity, and sensitivity to change have also been established in numerous observational studies and clinical trials (18). More recently, it was compared with the Western Ontario McMasters Universities Osteoarthritis Index (WOMAC) and was found to be similarly and significantly correlated (HAQ: $R = 0.67$, $p < 0.0001$) (21). In another study of RA patients by Wolfe (22) that was designed to determine the performance of distributional characteristics, detection of functional loss and identification of change in functional ability – where the HAQ-DI was compared with the modified HAQ (MHAQ) and the RA-HAQ (both shortened versions of the HAQ-DI) – the HAQ was better at detecting change and assessing functional ability than either of the two comparators.

HAQ-DI: Assessment of physical function

The HAQ-DI includes items that assess fine movements of the upper extremity, locomotor activities of the lower extremity, and activities that involve both the upper and lower extremities. Standard scoring takes into account the use of aids and devices or assistance from another person. There are 20 items in eight categories that represent a comprehensive set of functional activities – dressing, rising, eating, walking, hygiene, reach, grip, and usual activities. The stem of each item assesses a patient's functional ability using their usual equipment during the past week. Each category contains at least two specific sub-category questions. For example, under the category "walking", patients are asked about their ability to walk outdoors on flat ground and to climb up five steps.

Scoring of the HAQ-DI is modeled after the American Rheumatism Association/American College of Rheumatology functional classes (23). For each item, there is a four-level response set that is scored from 0 to 3, with higher scores indicating more disability (0 = without any difficulty; 1 = with some difficulty; 2 = with much difficulty; and 3 = unable to do). To calculate the HAQ-DI, the highest sub-category score determines the value for each category, unless aids or devices are used (see below); there must be responses in at least 6 of the 8 categories or else a HAQ-DI cannot be computed. The category scores are then averaged into an overall HAQ-DI from zero to three. The HAQ-DI scale has 25 possible values (i.e., 0, 0.125, 0.250, 0.375 … 3). Scores of 0 to 1 generally represent mild to moderate difficulty, 1 to 2 represent moderate to severe disability, and 2 to 3 indicate severe to very severe disability. The use of aids or devices or physical assistance increases a score of zero or one to a two to more accurately represent underlying disability; scores at a 3 are not modified.

The aids used for adjustments by category are: dressing – devices used for dressing (button hook, zipper pull, long handled shoe horn and so on); rising – built up or special chairs; eating – built up or special utensils; walking – canes, walkers, or crutches; hygiene – raised toilet seats, bathtub seats, bathtub bars, long handled appliances in bathroom; reach – long-handled appliances for reaching; and grip – jar openers (for jars previously opened). A complementary scoring method ignores the scores for aids and devices when computing the category scores and represents residual disability after compensatory efforts.

In addition, an average of the 20 items on the HAQ-DI has been used by some but is not validated well and not recommended. Some investigators interested in determining the effects of aids and devices upon disability have scored the HAQ-DI with and without the aids and devices questions, and this is acceptable practice.

The HAQ-DI: Correlations with other health status measures

The HAQ-DI has been significantly correlated with other self-report, biochemical and clinical measures, comorbidities, health care resource utilization and cost estimations, and mortality (18). Self-report measures that have been correlated with the HAQ-DI include the AIMS (24), AIMS2 (25), Beck Depression Scale (26), Carstairs Index (27), Nottingham Health Profile (28, 35), Disease Activity Score (26, 29, 30), Dutch Arthritis Impact Measurement Scale (31), EuroQol (32), Hollingshead Index (26), Life Event Interview (33), London Handicap Scale (34), SF-36 (32, 36, 37), and WOMAC (21, 32). Correlations with clinical measures include joint and muscle activity (14, 38-40), bone health and x-rays (14, 24, 41, 42), body fat (43, 44), and health behaviors (43, 45). Biochemical assessments have included C-reactive protein (30, 46), human leukocyte antigen (HLA) typing (47, 48), protein mircoarray, rheumatoid factor and others.

Furthermore, the HAQ-DI has been utilized as a predictor variable in investigations of productivity, morbidity, health care utilization, health care costs, and death. The HAQ-DI has been significantly correlated with work-related measures such as work capacity, household work performance, occupation, and the ability to live independently (18,49-52). In investigations related to health care, the HAQ-DI has been associated with a myriad of factors related to health care utilization such as direct cost, hospital admissions, length of the hospital stay, post-surgery delirium, use of aids and devices in post total knee replacement surgery and in miscellaneous other areas (such as specialty care, and patient satisfaction with health care workers) (18, 21, 53).

HAQ-DI: Translations and cultural adaptations

The HAQ-DI was originally developed and validated for English-speaking populations in North America. Since its inception it has been translated or culturally adapted into more than 60 different languages or dialects, often with only minor changes. A recent review in 2003 by Bruce and Fries (3) presents a resource listing of translations. In general, translations and cultural adaptations of the HAQ-DI are usually carried out by administering investigators.

Translated HAQ-DIs have generally been fully validated, using methods such as test-retest reliability, back translations, item-total correlations, convergent validity, interviewer vs. self-administered formats, and factor analyses. To date, culturally adapted HAQ-DI instruments have proved as equally reliable and valid as their parent. To adapt the HAQ-DI culturally, modifications of individual items have sometimes been necessary. The types of items most frequently in need of adaptation have included colloquial expressions or those for which names or types of items or utensils are culturally idiosyncratic. For example, some cultures do not consume milk in cartons; thus, an appropriate substitution in keeping with the original intent of the item is made. In some countries a bathtub is much more commonly used than is a shower, requiring question modification. Many translations have also been performed by the MAPI Research Institute in Lyon, France, and the Health Outcomes Group in Palo Alto, California, both of which have had extensive experience in translating and culturally validating the HAQ-DI; fees are sometimes charged by these vendors.

The next phase: What's in store for the HAQ-DI?

Over its long history, the HAQ-DI has played an influential role in the paradigm shift to establishing PROs as valid, reliable, and responsive hard data endpoints, and because of its long history, has enabled the conduct of longitudinal studies. Although the HAQ-DI is one of the most studied and widely used PROs, it – like other instruments – is not ideal and does not universally meet all needs.

Our group is part of the National Institutes of Health "Roadmap" project, the Patient-Reported Outcomes Measurement Information System (PROMIS) (54). PROMIS is designed to provide improved assessment of health status across all chronic illnesses as part of an improved infrastructure for clinical science. As envisioned, PROMIS will improve patient value-based PRO items with regard to verbal clarity and comprehension issues, face validity, patient relevance, uniqueness, comprehensiveness and, finally, psychometric qualities such as degree of difficulty and fit with a particular content area. Effectiveness of new items will be compared with more traditional approaches (such as the HAQ-DI or the SF-36) by clinical trials with particular attention focused on the ability to detect clinically important change. Ultimately, the goal is the ability to compare the results of PROs across diseases and conditions, thereby improving treatment and health outcomes. The HAQ is working to supercede itself. The new instruments will permit more precise estimation of disability and physical function, and will enable reductions in study sample sizes while retaining statistical power.

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