Abstract

Though quantitative data might lead to improved information for clinical decisions, at the present time decisions in routine rheumatology practice generally are based largely on qualitative impressions, rather than on data. Patient questionnaires are readily accessible tools that the rheumatologist can use to go beyond impressions and to institute evidence-based guidelines appropriate to his or her own patient population and practice style. The Health Assessment Questionnaire (HAQ) and its derivatives have been shown to be the best predictors of functional and work disability, costs, joint replacement surgery, and mortality. Such questionnaires are at least as good as joint counts, radiographs, and laboratory tests in predicting these outcomes. Every encounter of a patient with a rheumatologist provides an opportunity to collect data. Based on experience with the Brooklyn Outcomes of Arthritis Registry Database, the author advocates distributing a waiting-room questionnaire to every patient who comes for an office visit. Potential benefits of recording questionnaire-based information include identifying trends or important changes in a patient’s pain or physical function, providing a baseline for success with various treatment strategies for conditions of the rheumatologist’s own practice, allowing patients an opportunity to express concerns, encouraging patients to disclose information they may feel is too minor to mention, and providing control data for research studies. A short questionnaire designed specifically for clinical, rather than research, use does not create a burden for office staff. Consistent use of patient questionnaires and systematic storage of the information gained can help document, track, and improve patient care in routine rheumatology practice.

Evidence-based medicine has become the holy grail of modern medical practice. Whole journals are devoted to holding clinical research up to an ideal research standard that can generate practice guidelines. Yet practicing clinicians often depend primarily upon their own impressions or the impressions of trusted colleagues of what has worked in the past, with just a nod to the results of randomized clinical trials (RCTs). This review argues that every clinician has available in his or her own office the resources needed to go beyond impressions and to institute evidence-based guidelines appropriate to his or her own patient population and practice style.

This personal experience-based approach is not unreasonable. Evidence abounds that the majority of the patients seen in routine care would not qualify to participate in contemporary rheumatoid arthritis (RA) clinical trials because of their restrictive inclusion and exclusion criteria. For example, in surveying the charts of 123 RA patients seen in routine care, the author found that only 4 would have met the enrollment criteria for current tumor necrosis factor alpha (TNF-α) trials. Furthermore, RCTs do not provide evidence that bears on many concerns in chronic illnesses. The trials are usually of short duration, typically less than a year, and do not provide substantial information about important long-term outcomes such as work disability, joint replacement surgery, and mortality.

Office-based Quantification of Clinical Observations

The most important tools that rheumatologists have to monitor their patients’ health status and response to therapy are a pencil and paper. Results of the Health Assessment Questionnaire (HAQ) and its derivatives have been shown to be the best predictors of functional and work disability, costs, joint replacement surgery, and mortality. They are at least as good as joint counts, radiographs, and laboratory
tests in predicting these outcomes.\textsuperscript{6-9} Yet, patient questionnaires, which can be used in all rheumatic diseases, including osteoarthritis, systemic lupus erythematosus, fibromyalgia, scleroderma, and ankylosing spondylitis,\textsuperscript{10} are not included in routine care by most rheumatologists. Most rheumatologists, when asked what the most important resistance points to questionnaire use are, cite that “it takes too much time,” “patients will not cooperate,” or “staff will not cooperate.”

These comments usually are made by rheumatologists who have no experience with the use of short patient questionnaires in the course of usual clinical care and whose only experience involves lengthy clinical trial and other research questionnaires.\textsuperscript{1}

Questionnaires used in clinical trials are generally long and time-consuming from the perspective of the patient and staff. Their practical utility is further limited because the

![Figure 1 Page 1 of patient questionnaire used at NYU Hospital for Joint Diseases.](image)
physician rarely has time to review the data. Clinical care questionnaires are different. They generally are no longer than one sheet of paper (both sides may be utilized) and include basic information that is useful for improved care of the patient, with items that can predict and monitor response. Patient questionnaires can improve efficiency and quality of patient visits considerably. In most cases, the bulk of the work is done by the patient, not the physician or the staff.\(^1\) Although quantitative measures are acknowledged to be the best basis for making clinical decisions, in the United States, fewer than 10\% of rheumatologists use questionnaires in routine clinical care, and fewer than 15\% perform a formal joint count at each visit.\(^11\) The only quantitative data collected at the majority of visits are results of laboratory tests such as erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP). However, at initial presentation

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**Figure 1** Page 2 of patient questionnaire used at NYU Hospital for Joint Diseases.
about 40% of patients have normal ESR,² and up to 30% have no detectable rheumatoid factor. Radiographs are commonly obtained but have little bearing on treatment decisions; few clinicians would wait until radiographic damage is detected before initiating treatment.

Experience with Routine Office Use of Patient Questionnaires

In 2001, the author implemented a system of administering questionnaires to all patients seen in the office. The Brooklyn Outcomes of Arthritis Registry Database (BOARD)¹² was initiated in April 2001 in Brooklyn, NY. The aim was to collect quantitative data from all rheumatology patients seen as part of routine care, each and every time the patient was seen. The questionnaires were distributed not only to RA patients or patients with a definite diagnosis, but to all patients who came in for office visits.

A similar system, the NYU Hospital for Joint Diseases Arthritis Registry Monitoring Database (ARMD), was started in 2005 with the aim of collecting patient-derived data from all patients seen in the rheumatology clinics at NYU Hospital for Joint Diseases. These questionnaires are available in both English and Spanish. At each visit, each patient fills out a questionnaire (Fig. 1). Patients are also asked to participate in the ARMD database. A RAPID (Rheumatology Assessment Patient Index Data) score is calculated using the indices, and this score is used in treatment decisions. Data are later entered into a database, which also generates reports and flow sheets for individual patients for their rheumatologists to review.

In both BOARD and in ARMD, all patients who walk through the door, even if they were seen every day that week, fill out a questionnaire at every visit. The rationale is that if there is a reason for the visit, there is a reason to complete a questionnaire. This practice has several advantages:

1. Any system in office practice has a better chance of success if it is uniformly applied, keeping the demand on the front desk staff members to a minimum, since they do not have to identify the patients according to diagnosis; they simply give the questionnaire to all patients.
2. If patients see that everyone is filling out a questionnaire, they are more accepting of this system.
3. A method of collecting data on different diseases is put in place, creating a unique opportunity to compare and evaluate diseases not routinely studied in a formal manner in RCTs. The data collected may have utility as disease controls for research studies conducted in the same setting.
4. Distribution only at periodic intervals may miss important changes in pain or physical function that should be documented.
5. Data concerning pain and physical function are best obtained from a patient.
6. Data are more reproducible when a patient responds to a query in writing, as only a single observer is involved. When a health professional conducts the interview and records the information, the introduction of a second observer reduces, rather than enhances the reproducibility of the information.
7. Allowing patients an opportunity to express concerns provides the possibility of an added psychological benefit. It also has the advantage that the questionnaire can serve as a reminder or a way to encourage disclosure—patients may forget to mention something that is bothering them or may feel it is too minor to bring up to the busy physician.

Some practical considerations in use of the multidimensional HAQ (MDHAQ) or any other brief patient questionnaire designed for standard care are summarized below.¹³

A questionnaire designed for standard care, not for research, should be used. Substantial differences exist between questionnaires for research versus clinical care. There is no need for a patient in standard care to complete a lengthy questionnaire designed for clinical research or clinical trials, which may require 10 to 30 minutes to complete and is not amenable to rapid “eyeball” review and/or scoring by the clinician.

Staff should be educated regarding the importance of patient questionnaires in patient care. Patient questionnaires streamline the flow of information from patient to physician with quantitative data concerning the primary concerns of patients—functional disability, pain, fatigue, psychological distress, and global status. If office staff members are made aware of the importance of a questionnaire to the physician to recognize whether a patient is better, worse, or the same over time, they respond positively.

The questionnaire should be part of the infrastructure—to be completed by every patient (with any diagnosis) at every visit. Many rheumatologists suggest that patient questionnaires be used only in certain patients, such as those with RA, or periodically, for example, every 6 months. This approach generally fails in standard care because: a) organizing distribution of questionnaires selectively is virtually impossible, just as assessing vital signs only in certain patients would be very difficult; b) a simple MDHAQ is useful in all people with all rheumatic diseases,¹⁴,¹⁵ as functional disability, pain, fatigue, and/or psychological distress are common to all rheumatic diseases; c) questionnaire data taken only at periodic intervals may miss important changes in patient status,
which should be recognized for better care.

The questionnaire ideally should be completed in the waiting room, not the examination room. Most patients spend at least 10 minutes in the waiting room before seeing a rheumatologist—often much longer. This is the most desirable time for the patient to complete a questionnaire, although the questionnaire may, of course, be completed in the examination room. Completion before the encounter helps to focus concerns for patients and also provides information to the physician at the time of care.

Let the patient do the work—the office staff should do as little as possible. Most data concerning physical function, pain, fatigue, and global status are ascertained more accurately by patient self-report than by health professionals. The more often the patient completes the questionnaire, the more accurate and reproducible the questionnaire is likely to be, and the less staff time is involved in ascertaining the information.

The clinician must review the questionnaire with the patient. Improvement of the quality and efficiency of a patient visit through a patient questionnaire requires an "eyeball" review by the physician, generally with the patient present. The 5 seconds for such a review gains information that would often involve 5 minutes of query, and greater efficiency is inevitable.

Data that are routinely collected from all patients include functional status in the HAQ format, visual analog scales (VAS) for pain, fatigue, patient and physician global assessment of disease activity, review of systems, and assessment of morning stiffness, medications, and allergies. In RA patients, a 42-joint count for tender joints and 38-joint count for swollen joints is completed. In this manner, all components of the ACR Core Data Set are collected as part of standard care. An Access database created to record and evaluate this data also includes fields for laboratory tests and radiograph scores.

Data collected in this manner can provide clinicians with quantitative information about how patients in their practices are doing. The inherent ability of a database to sort and categorize can facilitate comparisons between various regimens, various patient types, and various points in time. Clinicians who collect and store questionnaire data systematically in a database will readily be able to check their reality against the clinical evidence by determining whether their experience matches what is being reported in the literature.

Every encounter of a patient with a rheumatologist provides an opportunity to collect data. Data that are feasible to collect in clinical care provide the only way to assess quantitatively how our patients are doing and how we are doing measures up against successes reported in the literature. The opportune time to collect and record data is at the time of the patient visit. Consistent use of patient questionnaires in routine rheumatology practice can add quantitative assessment to standard clinical care, thereby helping rheumatologists to document, track, and improve the care they provide.

References
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