
A database in private practice: the Brooklyn Outcomes of Arthritis Rheumatology Database (BOARD)

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Clin Exp Rheumatol 2005; 23 (Suppl. 39):
S182-S187.

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RHEUMATOLOGY 2005.

Key words: MDHAQ, patient questionnaires, routine care, databases.

ABSTRACT

Rheumatologists generally use few quantitative measures in making clinical decisions. In the US, fewer than 10% use questionnaires in routine clinical care, and fewer than 15% perform a formal joint count at each visit. Patient questionnaires are the quantitative tools rheumatologists have to monitor their patients' health status and response to therapy. 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 as good as and usually better predictors than joint counts, radiographs and laboratory tests. The Brooklyn Outcomes of Arthritis Registry Database was initiated with the aim of collecting quantitative data using a multi-dimensional health assessment questionnaire (MDHAQ) from all rheumatology patients seen as part of routine care, each and every time the patient was seen. Data that are feasible to collect in routine clinical care provide the only way to assess quantitatively how our patients are doing. If data are not collected and recorded, an opportunity is lost forever. If there is a reason for the visit, there is a reason to complete a questionnaire.

Introduction

Rheumatologists depend primarily on two sources of information when making clinical decisions: (i) the results of randomized clinical trials (RCT) and (ii) their personal experience (1). Emerging evidence suggests that a majority of the patients seen in routine care would not qualify to participate in contemporary rheumatoid arthritis (RA) clinical trials on the basis of inclusion and exclusion criteria (2-4). For example, of the data collected by the author on 123 RA patients seen in routine care, only 4 patients qualified for inclusion in current tumor necrosis factor

alpha (TNF- α) trials (5). In addition, RCTs are usually of short duration, typically less than a year, and do not provide any information about long-term outcomes such as work disability, joint replacement surgery and mortality. At the present time clinical decisions in routine rheumatology practice are generally based on qualitative impressions rather than on quantitative data, when the latter might provide information for improved clinical decisions.

Physicians in different specialties use information from different sources in their clinical decision making. A cardiologist checks the patient's blood pressure and cholesterol levels, both of which have been shown to be prognostic, when elevated, of higher mortality rates and other cardiac-related outcomes. Endocrinologists check thyroid stimulating hormone levels to monitor the response to therapy and adjust medications. Because these are either blood tests or are measured by sophisticated instruments, most patients and physicians regard them as "objective," and they are well accepted and even expected by patients to be performed at most visits. It is unimaginable that a patient would not expect their cardiologist to check their blood pressure or cholesterol level – often rheumatology patients even demand this from their rheumatologists.

The patient questionnaire: A quantitative data collection tool

Rheumatologists generally use few quantitative measures in making clinical decisions. In the US, fewer than 10% use questionnaires in routine clinical care, and fewer than 15% perform a formal joint count at each visit. The only quantitative data collected at the majority of visits are the results of laboratory tests such as the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP). However at initial presentation about 40% of patients have a

normal ESR (2), and up to 30% exhibit no rheumatoid factor. Radiographs are commonly taken, but for treatment to be most effective it usually must be initiated prior to radiographic damage.

Patient questionnaires are the best quantitative tools available to rheumatologists for monitoring their patients' health status and response to therapy. 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 as good as and usually better predictors than joint counts, radiographs and laboratory tests (6-9). Yet patient questionnaires, which can be used for all rheumatic diseases, including osteoarthritis, systemic lupus erythematosus, fibromyalgia, scleroderma, ankylosing spondylitis, etc. (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 "the staff will not cooperate". These comments usually are made by rheumatologists who have no experience with short patient questionnaires in clinical care and whose only experience involves lengthy clinical trial and other research questionnaires (1).

Questionnaires used in clinical trials are long, take time for the patient and staff to complete, and the 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 can be useful for the improved care of the patient, with items that predict and monitor response. Patient questionnaires can considerably improve the efficiency and quality of patient visits. In most cases the "work" is done by the patient, not the physician or the staff (1).

Implementing the use of a questionnaire in a private practice setting

The decision to implement a system of administering questionnaires to each and every patient seen in his office was

made by the author in 2001. The Brooklyn Outcomes of Arthritis Registry Database (BOARD) was initiated in April 2001 in Brooklyn, NY. The aim was to begin collecting quantitative data from all rheumatology patients seen as part of routine care, each and every time the patient was seen. Questionnaire distribution is not limited only to rheumatoid arthritis (RA) patients nor to patients with a definite diagnosis. Every patient who walks through the door, even if he or she is seen every day that week, must fill out a questionnaire at every visit. If there is a reason for the visit, there is a reason to complete a questionnaire. There are several advantages to this practice:

1. Any system in office practice has a better chance of success if it is uniformly applied, simplifying the procedure at the front desk as much as possible by instructing the staff that they do not have to identify patients "for enrollment" based on their diagnosis, but must simply hand out the questionnaire to all patients.
2. If patients see that everyone is filling out a questionnaire, they are more likely to accept this system.
3. It provides a method of collecting data on different diseases and a unique opportunity to compare and evaluate diseases not routinely studied in a formal manner in RCT. These patients can also provide disease controls for eventual research studies.
4. Distribution of questionnaires at periodic intervals leads to data collection that may miss important changes in pain or physical function which should be documented.
5. Data concerning pain and physical function are best obtained directly from the patient.
6. Data are more reproducible when a patient responds to a query on a piece of paper, as there is only a single observer. When a health professional makes the query, the reproducibility of the information is reduced rather than enhanced by the introduction of a second observer.

The work flow

Below is a schematic description of the

work flow currently in place, which has changed very little from when it was begun in 2001

1. The patient arrives at the office. There are signs on the waiting room tables and on the announcement board explaining that every patient must complete a questionnaire and that the information from these questionnaires will make an important contribution to the quality of the patient's care.
2. When the patient checks in, the receptionist presents a 1-page, 2-sided multi-dimensional health assessment questionnaire (MDHAQ). If the patient is being seen for the first time, a 2-page, 4-sided version is used, which includes the patient's past medical history, any surgeries, hospitalizations, allergies, and a complete review of systems.
3. Patients complete the questionnaire while waiting to be conducted into the examination room. Some patients (about 20%) need help in completing the questionnaire (11), and seek it from a family member or a staff member. As noted, the accuracy and reproducibility of the data gathered depends greatly on whether the questionnaire is completed by the patient him or herself, but help is willingly provided when needed. The fact remains that staff time is expensive and the patient's time has no cost, at least to the physician's practice. Patients can usually complete the 2-page form in less than 5 minutes, and the 4-page form for new patients takes less than 10 minutes. It is very important that the patient complete the questionnaire before going into the examination room, so the data is available for the physician to go over. The most feasible procedure is for the patient to be given the questionnaire as soon as he or she arrives, since most patients spend at least 10 minutes waiting to see a rheumatologist, and often much longer. Once the patient is in the examination room, a different phase of the visit begins and patients wish to concentrate on their physician and discussing their symptoms. Once the visit with the physician is over, the

MDHAQ - Office Visit Note

NAME _____

DATE: _____

1. Please check (✓) the ONE best answer for your abilities at this time:

OVER THE PAST WEEK, were you able to:	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Get in and out of bed?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Lift a full cup or glass to your mouth?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Walk outdoors on flat ground?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Wash and dry your entire body?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Bend down to pick up clothing from the floor?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Turn regular faucets on and off?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Get in and out of a car, bus, train, or airplane?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Walk two miles?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Participate in sports and games as you would like?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Get a good night's sleep?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Deal with feelings of anxiety or being nervous?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Deal with feelings of depression or feeling blue?	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

2. How much pain have you had because of your condition OVER THE PAST WEEK? Please indicate below how severe your pain has been:

NO PAIN ○○○○
0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10
PAIN AS BAD AS IT COULD BE

3. When you awakened in the morning OVER THE PAST WEEK, did you feel stiff?
☐ No ☐ Yes If "Yes," for how long? Please write the duration: minutes _____, or hours _____

4. How much of a problem has UNUSUAL fatigue or tiredness been for you OVER THE PAST WEEK?
Place indicate below:

FATIGUE IS A MAJOR PROBLEM

8. How do you feel **TODAY** compared to **ONE WEEK AGO**? Please check (✓) only one.

(1) Much Better ☐, (2) Better ☐, (3) the Same ☐, (4) Worse ☐, (5) Much Worse ☐

6. Considering all the ways in which illness and health conditions may affect you at this time, please indicate below how you are doing:

VERY WELL ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ **VERY POORLY**

7. At this time, are you? Please check (✓) all that apply:

☐ Working full time ☐ Retired ☐ Working part time ☐ Student ☐ Homemaker—full time ☐ Disabled
☐ Other (describe): _____ Your occupation _____

PLEASE TURN OVER

Fig. 1. The 2-page Brooklyn Outcomes of Arthritis Registry Database (BOARD) questionnaire.

8. Please check (✓) if you have experienced any of the following over the last week:

- | | | |
|-------------------------------------------------------|----------------------------------------------------------|---------------------------------------------------------------|
| <input type="checkbox"/> Fever | <input type="checkbox"/> Lump in your throat | <input type="checkbox"/> Paralysis of arms or legs |
| <input type="checkbox"/> Weight gain (>10 lbs) | <input type="checkbox"/> Cough | <input type="checkbox"/> Numbness or tingling of arms or legs |
| <input type="checkbox"/> Weight loss (<10 lbs) | <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> Fainting spells |
| <input type="checkbox"/> Feeling sick | <input type="checkbox"/> Wheezing | <input type="checkbox"/> Swelling of hands |
| <input type="checkbox"/> Headaches | <input type="checkbox"/> Pain in the chest | <input type="checkbox"/> Swelling of ankles |
| <input type="checkbox"/> Unusual fatigue | <input type="checkbox"/> Heart pounding (palpitations) | <input type="checkbox"/> Swelling in other joints |
| <input type="checkbox"/> Swollen glands | <input type="checkbox"/> Trouble swallowing | <input type="checkbox"/> Joint pain |
| <input type="checkbox"/> Loss of appetite | <input type="checkbox"/> Heartburn or stomach gas | <input type="checkbox"/> Back pain |
| <input type="checkbox"/> Skin rash or hives | <input type="checkbox"/> Stomach pain or cramps | <input type="checkbox"/> Neck pain |
| <input type="checkbox"/> Unusual bruising or bleeding | <input type="checkbox"/> Nausea | <input type="checkbox"/> Use of drugs not sold in stores |
| <input type="checkbox"/> Other skin problems | <input type="checkbox"/> Vomiting | <input type="checkbox"/> Smoking cigarettes |
| <input type="checkbox"/> Loss of hair | <input type="checkbox"/> Constipation | <input type="checkbox"/> More than 2 alcoholic drinks per day |
| <input type="checkbox"/> Dry eyes | <input type="checkbox"/> Diarrhea | <input type="checkbox"/> Depression - feeling blue |
| <input type="checkbox"/> Other eye problems | <input type="checkbox"/> Dark or bloody stools | <input type="checkbox"/> Anxiety - feeling nervous |
| <input type="checkbox"/> Problems with hearing | <input type="checkbox"/> Problems with urination | <input type="checkbox"/> Problems with thinking |
| <input type="checkbox"/> Ringing in the ears | <input type="checkbox"/> Gynecological (female) problems | <input type="checkbox"/> Problems with memory |
| <input type="checkbox"/> Stuffy nose | <input type="checkbox"/> Dizziness | <input type="checkbox"/> Problems with sleeping |
| <input type="checkbox"/> Sores in the mouth | <input type="checkbox"/> Losing your balance | <input type="checkbox"/> Sexual problems |
| <input type="checkbox"/> Dry mouth | <input type="checkbox"/> Muscle pain, aches, or cramps | <input type="checkbox"/> Burning in sex organs |
| <input type="checkbox"/> Problems with smell or taste | <input type="checkbox"/> Muscle weakness | <input type="checkbox"/> Problems with social activities |

Please check (✓) here if you have none of these symptoms _____

9. Please write below all the drugs or medicines you have taken over the last 2 weeks.

NAME OF MEDICINE	DOSE	How many per day or week	NAME OF MEDICINE	DOSE	How many per day or week
1. _____	_____	_____	6. _____	_____	_____
2. _____	_____	_____	7. _____	_____	_____
3. _____	_____	_____	8. _____	_____	_____
4. _____	_____	_____	9. _____	_____	_____
5. _____	_____	_____	10. _____	_____	_____

DRUG ALLERGIES

DO NOT WRITE BELOW THIS — FOR DOCTOR'S USE ONLY

VERY WELL ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○ **VERY POORLY**

0	0.5	1	1.5	2	2.5	3	3.5	4	4.5	5	5.5	6	6.5	7	7.5	8	8.5	9	9.5	10
---	-----	---	-----	---	-----	---	-----	---	-----	---	-----	---	-----	---	-----	---	-----	---	-----	----

CC:

Do 1. _____
2. _____
3. _____

Plan:

1. _____
2. _____
3. _____
4. _____
5. _____

VITALE _____

Heart/Lung RR, S₁, S₂, N, CTA B. ☐

WFO

Ext: Hands _____

Wrists/Elbows _____

Shareholders

Solving

Address: _____

Ankle/Foot _____

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Fig. 1. (continued)

Table I. Median levels of demographic and ACR Core Data Set measures according to ethnic group.

Ethnic group	No.	% > 4 swollen jts.	Demographic measures		Health-professional measures			Lab measures	Patient MDHAQ measures		
			Age	Education (years)	Swollen joints	Tender joints	MD global assessmt.	ESR	Physical function	Pain	Pt. global assessmt
Caucasian	31	32%	53	12	1.0	7.0	2.8	18	0.8	5.2	4.8
African American	43	40%	53	12	2.0	6.0	3.0	20	0.7	5.5	4.2
Hispanic	37	43%	49	12	2.0	9.5	2.9	24	1.4	7.1	6.2
Asian	7	14%	62	14	0.0	1.5	2.0	25	0.6	2.5	5.0
Total	118	37%	53	12	1.5	7.0	2.7	20	0.8	5.7	4.9
Pvalue					0.42	0.40	0.76	0.57	0.04	0.01	0.08
Padjusted for swollen joints					—	0.37	0.59	0.89	0.63	0.27	0.29

patient is anxious to leave the office and return to his or her usual activities.

4. The nurse ushers the patient into the examination room and reviews the questionnaire, asking the patient to fill in the missing data, if any.
5. When the physician sits down with the patient, they go over the questionnaire together. This practice conveys to the patient that his/her responses are important and helps to focus the dialogue between physician and patient on important issues rather than irrelevant considerations.
6. The physician fills in the space at the bottom of the second page in the author's version of the MDHAQ with his observations (Fig. 1).

This procedure allows the most important data from a visit to be presented on a single sheet of paper that is easy to review and enter into a database without having to look for various pieces of data in the patient's chart. The results of laboratory tests from that visit are also entered weekly in the database by the staff.

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

tests and radiograph scores.

Thus far, about 1700 patients have been entered into the BOARD database, with data from all of their visits. Most of these patients have also given their consent to participate in clinical trials and for us to analyze their data. Questionnaire data collection as a part of routine care has enabled us to study rheumatologic conditions as they occur in the real world.

Initial results from the BOARD database

In view of the multi-ethnic and multi-racial backgrounds that characterize the borough of Brooklyn, New York, we examined the differences in ACR Core Data Set measures (joint count, laboratory, and patient self-report questionnaire measures) among patients presenting for the first time with RA, in order to determine whether there were any differences in the patterns of disease severity that could be linked to racial or ethnic group (12). Physical function, MDHAQ and pain scores were highest in Hispanic patients, followed by African-American and Caucasian patients, and were lowest in Asian patients. These differences were statistically significant (due to their small numbers, Asian patients were not included in the analysis) ($p < 0.05$), while differences in other measures were not. When the analyses were adjusted for the number of swollen joints, however, the differences in physical function and pain became statistically insignificant, although the differences in the number of swollen joints between the groups did not differ in a statistically significant manner. No significant differences

were seen between ethnic groups when patients were stratified based on whether they had 4 or more swollen joints or fewer than 4 swollen joints (Table I). These findings could be important in interpretation of clinical trial results and possible differences in the prognosis and outcomes of patients with RA at this time compared to earlier times. In addition, these data – which have been collected as part of routine care at a rheumatology office – are not available from RCT (13) and provide a more complete picture of the status of RA patients.

Each encounter of a patient with a rheumatologist provides an opportunity to collect valuable clinical data. Data that can be collected in the setting of clinical care provides the only means of assessing quantitatively how patients are doing. If data are not collected and recorded at this time, an opportunity is lost forever. I believe that rheumatologists would find it invaluable to adopt questionnaires for use in the routine clinical care of every patient, to document and improve the care they provide, and add quantitative data to standard clinical care.

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