Eklem Hastalıkları ve Cerrahisi
Joint Diseases and Related Surgery

Current Concepts / *Güncel Yaklaşımlar*

Joint Dis Rel Surg
2007;18(2):95-100

Monitoring outcomes of arthritis and longitudinal data collection using patient questionnaires in routine care

Rutin bakımda hasta formlarını kullanarak artritli olguları izleme ve longitudinal veri toplama

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At the present time, clinical decisions in routine rheumatology practice generally are based on qualitative impressions, rather than on quantitative data, which might lead to improved information for clinical decisions. Patient questionnaires are the quantitative tools whereby 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. Yet, patient questionnaires, which can be used in all rheumatic diseases including osteoarthritis, systemic lupus erythematosus, fibromyalgia, scleroderma, and ankylosing spondylitis, are not included in routine care by most rheumatologists. 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. If data are not collected and recorded, an opportunity is lost forever. Rheumatologists would find it valuable to adapt questionnaires to the care they provide for all their patients, to document and improve the care they provide, and add quantitative data to standard clinical care.

Key words: Arthritis, rheumatoid; health status indicators; quality of life; questionnaires; rheumatology.

Günümüzde rutin romatoloji pratiğinde klinik kararlar, niceliksel verilerden ziyade genellikle niteliksel izlenimlere dayanmaktadır. Niceliksel verilerin önemi, klinik kararlar için gereken bilgi düzeyini yükseltmesidir. Hasta formları romatologların hastalarının sağlık durumlarını ve tedaviye yanıtlarını izleyebilecekleri araçlardandır. Sağlık değerlendirme formu ve türevlerinin, forksiyonel ve çalışma kayıplarını, maliyetleri, eklem replasman cerrahisi gereğini ve mortaliteyi değerlendirmede en iyi öngördürücüler olduğu ortaya konmuştur. Bunlar, eklem sayımları, radyografiler ve laboratuvar testleri kadar iyi, hatta bunlardan genellikle daha iyi öngördürücülerdir. Buna rağmen, osteoartrit, sistemik lupus eritematozus, fibromiyalji, skleroderma ve ankilozan spondilit de dahil tüm romatoid hastalıklarda kullanılabilen hasta formları, çoğu romatolog tarafından rutin bakım işlemleri içine alınmamaktadır. Hastanın romatologla her karşılaşması veri toplamak için iyi bir fırsat demektir. Klinik uygulama sırasında toplanması mümkün olan veriler, hastalarımızın ne durumda olduklarını niceliksel olarak değerlendirmemizin tek yoludur. Bu veriler toplanmıyor ve kaydedilmiyorsa, fırsat tamamen kaçırılmış olmaktadır. Romatologlar, hastalarına sundukları bakım uygulamalarına hasta formlarını da dahil etmelerinin ve standart klinik bakıma niceliksel veri eklemenin, verdikleri hizmeti izleme ve geliştirme açısından ne kadar değerli olduğunu göreceklerdir.

Anahtar sözcükler: Artrit, romatoid; sağlık durumu göstergeleri; yaşam kalitesi; anket; romatoloji.

Rheumatologists depend primarily on two sources of information when making clinical decisions: *(i)* results of randomized clinical trials (RCT) and *(ii)* their own 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]

- *Received: October 19, 2006 Accepted: October 26, 2006*

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For example, in data collected by the author in 123 RA patients seen in routine care, only four patients were eligible for 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 usual rheumatology practice generally are based on qualitative impressions, rather than on quantitative data, which might lead to improved information for clinical decisions.

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 laboratory tests such as erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP). However, at initial presentation, about 40% of patients have normal ESR,[2] and up to 30% have no rheumatoid factor. Radiographs are commonly obtained, but the most effective treatment is usually initiated prior to radiographic damage.

Patient questionnaire is a quantitative tool whereby 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.[6-9] Yet, patient questionnaires, which can be used in all rheumatic diseases including osteoarthritis, systemic lupus erythematosus, fibromyalgia, scleroderma, ankylosing spondylitis, etc.[10] are not included in routine care by most rheumatologists. When asked what the most important resistance points to questionnaire use are, most rheumatologists cite that "it takes too much time", "patients will not cooperate", or "staff will not cooperate". These comments are usually made by rheumatologists who have no experience with short patient questionnaires in their clinical care and whose only experience involves lengthy clinical trial and other research questionnaires.[1]

Questionnaires used in clinical trials are long, take time of the patient and staff -the physician rarely has time to review the data. In contrast, clinical care questionnaires are generally no longer than a single sheet of paper (both sides may be utilized), and include basic information that is useful for improved care of the patient, with items that predict and monitor response. Patient questionnaires can improve efficiency considerably and quality of patient visits. In most cases, the work is done by the patient, not the physician or the staff.[1]

A decision to implement a system of administering questionnaires to each and every patient seen in the office was made by the author in 2001. The Brooklyn Outcomes of Arthritis Registry Database (BOARD).[11] 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 to only RA patients or patients with a definite diagnosis.

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. At each visit, each patient fills out a patient questionnaire (Appendix 1, see back pages of the article) available in English and Spanish. The patients are also asked to participate in the ARMD database. A RAPID (Routine Assessment Patient Index Data), score is calculated using the indices to be used in treatment decisions. Data are later entered into a database which also generates reports and flow sheets about individual patients for their rheumatologists to review.

In both instances, every patient who walks through the door, even if they have been seen every day that week, fills 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 of this practice:

(i) Any system in office practice has a better chance of success if it is uniformly applied and keeps the demand on the front desk to a minimum. They do not have to identify the patients according to diagnosis and simply give the questionnaire to all patients.

(ii) If patients see that everyone is filling out a questionnaire, they are more inclined to adopting this system.

(iii) It creates 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 serve as disease controls for potential research studies.

(iv) Distribution of questionnaires only at periodic intervals may miss important changes in pain or physical function which are of particular importance for documentation.

(v) Data concerning pain and physical function are best obtained from a patient.

(vi) 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 inquires, reproducibility of the information is reduced, rather than enhanced, by inclusion of a second observer.

Some practical considerations in use of the Multidimensional Health Assessment Questionnaire (MDHAQ) or any other brief patient questionnaire designed for standard care are summarized below:[12]

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 10-30 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. Office staff members respond positively if they 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.

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 six months. This approach generally fails in standard care because: a) it is virtually impossible to organize distribution of questionnaires selectively, any more than to assess vital signs only in certain patients; b) a simple MDHAQ is useful in all people with all rheumatic diseases,[13,14] as functional disability, pain, fatigue, and/or psychological distress are common to all rheumatic diseases; c) questionnaire data only at periodic intervals may miss important changes in patient status, which should be recognized for better care. If there is a reason for a visit, there is a reason for a questionnaire.

The questionnaire ideally should be completed in the waiting room, not in the examination room. Most patients spend at least 10 minutes in the waiting room before seeing a rheumatologist – often much longer. This is the time when it is most desirable and convenient for the patient to complete a questionnaire, although the questionnaire may, of course, be completed in the examination room. Completion before the encounter helps the patients to focus their concerns, and 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.[15] When a patient completes a questionnaire, there is only a single observer. If a health professional is introduced into the process, reproducibility of the information is reduced, rather than enhanced, by inclusion of a second observer. The more the questionnaire is completed by the patient, the more accurate and reproducible it is likely to be, and the less staff time is involved in obtaining 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. The five seconds for such a review gains information that would often involve five 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, 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 enter this data also includes fields for laboratory tests and radiograph scores.

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. If data are not collected and recorded, an opportunity is lost forever. I believe that rheumatologists would find it valuable to adapt questionnaires to the care they provide for all their patients, to document and improve the care they provide, and add quantitative data to standard clinical care.

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Appendix 1. Patient questionnaire used at NYU Hospital for Joint Diseases.

ARMD-MDHAQ*

Your name: .... **Date of birth:** .... **Today's date:** ....

Your: Sex: ☐ Female ☐ Male

Ethnic Group: ☐ Asian ☐ Hispanic ☐ Other ☐ Black ☐ White

Marital status: ☐ Single ☐ Married ☐ Divorced ☐ Widowed ☐ Separated

Your diagnosis/condition: ....

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?	☐ 0	☐ 1	☐ 2	☐ 3
Get in and out of bed?	☐ 0	☐ 1	☐ 2	☐ 3
Lift a full cup or glass to your mouth?	☐ 0	☐ 1	☐ 2	☐ 3
Walk outdoors on flat ground?	☐ 0	☐ 1	☐ 2	☐ 3
Wash and dry your entire body?	☐ 0	☐ 1	☐ 2	☐ 3
Bend down to pick up clothing from the floor?	☐ 0	☐ 1	☐ 2	☐ 3
Turn regular faucets on and off?	☐ 0	☐ 1	☐ 2	☐ 3
Get in and out of a car, bus, train, or airplane?	☐ 0	☐ 1	☐ 2	☐ 3
Walk two miles?	☐ 0	☐ 1	☐ 2	☐ 3
Participate in sports and games as you would like?	☐ 0	☐ 1	☐ 2	☐ 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 ○ **Pain as bad as it could be**
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

3. When you awakened in the morning **over the past week,** did you feel stiff? ☐ No ☐ Yes
If **"Yes,"** for how long does this stiffness last?
☐ Less than 30 minutes ☐ 30 minutes to 1 hour ☐ 1 to 2 hours ☐ More than 2 hours

4. How much of a problem has **unusual** fatigue or tiredness been for you **over the past week?** Place indicate below:

Fatigue is no problem ○ **Fatigue is a major problem**
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

FN
☐
1=0.3
2=0.7
3=1.0
4=1.3
5=1.7
6=2.0
7=2.3
8=2.7
9=3.0
10=3.3
11=3.7
12=4.0
13=4.3
14=4.7
15=5.0
16=5.3
17=5.7
18=6.0
19=6.3
20=6.7
21=7.0
22=7.3
23=7.7
24=8.0
25=8.3
26=8.7
27=9.0
28=9.3
29=9.7
30=10
PN
☐
PTGL
☐
RAPID
☐
(0-30)

5. How do you feel **today** compared to **one week ago?** Please check (√) only one.
(1) **m**uch **b**etter ☐ (2) **b**etter ☐ (3) the **s**ame ☐ (4) **w**orse ☐ (5) **m**uch **w**orse ☐

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**
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

7. How many years of school have you completed? Please circle the number of years of school.
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

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*ARMDMDHAQ: Arthritis Registry Monitoring Database-Multidimensional Health Assessment Questionnaire

8. Please place a check (√) in the appropriate spot to indicate the amount of pain you are having today in each of the joint areas listed below:

	None	Mild	Moderate	Severe		None	Mild	Moderate	Severe
Left fingers	☐ 0	☐ 1	☐ 2	☐ 3	Right fingers	☐ 0	☐ 1	☐ 2	☐ 3
Left wrist	☐ 0	☐ 1	☐ 2	☐ 3	Right wrist	☐ 0	☐ 1	☐ 2	☐ 3
Left elbow	☐ 0	☐ 1	☐ 2	☐ 3	Right elbow	☐ 0	☐ 1	☐ 2	☐ 3
Left shoulder	☐ 0	☐ 1	☐ 2	☐ 3	Right shoulder	☐ 0	☐ 1	☐ 2	☐ 3
Left hip	☐ 0	☐ 1	☐ 2	☐ 3	Right hip	☐ 0	☐ 1	☐ 2	☐ 3
Left knee	☐ 0	☐ 1	☐ 2	☐ 3	Right knee	☐ 0	☐ 1	☐ 2	☐ 3
Left ankle	☐ 0	☐ 1	☐ 2	☐ 3	Right ankle	☐ 0	☐ 1	☐ 2	☐ 3
Left toes	☐ 0	☐ 1	☐ 2	☐ 3	Right toes	☐ 0	☐ 1	☐ 2	☐ 3
Neck	☐ 0	☐ 1	☐ 2	☐ 3	Back	☐ 0	☐ 1	☐ 2	☐ 3

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 ....

10. Over the last 6 months, have you had: [please check (√)]

An operation ☐ No ☐ Yes Side effects of any drugs ☐ No ☐ Yes
A new illness ☐ No ☐ Yes Any inpatient hospitalization ☐ No ☐ Yes

Please explain any "Yes" answers below:

....
....
....
....

11. Please check (√) if you have **any of these conditions**:

☐ High blood pressure
☐ Stomach ulcers
☐ Chronic bronchitis
☐ Thyroid disease
☐ Coronary artery disease
☐ Kidney disease
☐ Cancer
☐ Osteoporosis
☐ Heart attack
☐ Diabetes
☐ Stroke
☐ Psoriasis
☐ High cholesterol
☐ Asthma
☐ Parkinson's disease
☐ Psychiatric disease

Please check (√) here if you have none of these conditions ☐

12. 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 is/was ....

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	