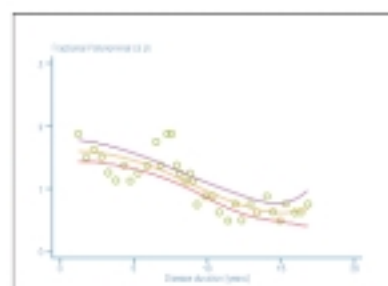
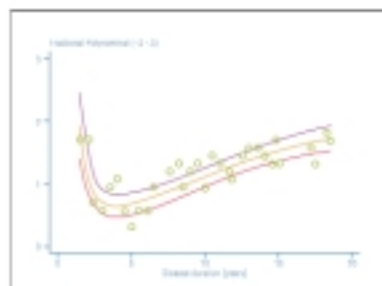
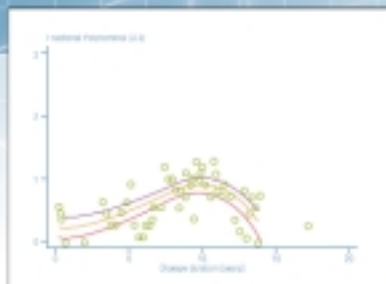


THE REPORT PROJECT

Using Health Status Questionnaires in Clinical Care







Using Health Status Questionnaires in Clinical Care

Two decades have passed since the introduction of Health Status Questionnaires (HSQ) into rheumatology. Originally confined to use in observational studies, they became a part of the ACR improvement criteria in 1995, and over the last decade have found increasing use in clinical practice.

The simplest rheumatology HSQ and the one used in the ACR improvement criteria, includes scales for ① measurement of pain, ② functional disability and ③ patient global severity. When included in an ordinary rheumatology visit, it allows the rheumatologist to assess and calculate the same variables that are part of the ACR criteria.

HSQ use can also document disease severity and improvement status required by insurance companies and governmental agencies when newer biologics or DMARDs are used. They can also help in providing documentation of higher level rheumatology visits, and can thereby increase reimbursement.

THE SIMPLEST HSQ

- MEASURES PAIN, PATIENT GLOBAL SEVERITY AND FUNCTIONAL DISABILITY
- IS A PART OF THE ACR 20-50-70 CRITERIA
- TAKES A SINGLE PAGE
- ADEQUATELY DOCUMENTS IMPROVEMENT IN THE CLINIC
- ACCUMULATED DATA OF INDIVIDUAL HAQ SCORES OVER TIME

Gaining Acceptance in the Clinic

The slow acceptance of HSQ in the clinic relates to two factors, feasibility and added value – a question of cost and benefit.

Factors Relating to Feasibility

The **feasibility** of HSQ use is determined by the perceived time and monetary resources required to administer, score, record and integrate the questionnaire into the clinic. A number of the potential impediments are described below.

POTENTIAL IMPEDIMENTS

Obtaining Questionnaires.

Although published, HSQ are not readily available. Obtaining questionnaires often means preparing them yourself or using unattractive photocopies. In addition, rheumatologists have to pay for the preparation of questionnaires; and there is usually no reimbursement for their use in the clinic.

Questionnaire Length

HSQ are usually given to patients to complete when they check into the clinic. Long questionnaires usually disrupt clinic operations. Imagine a detailed questionnaire that takes 30 minutes to complete. Not only does that represent unacceptable patient burden, but such questionnaires usually disrupt clinic schedules. In general, questionnaires should take no longer than 5 minutes to complete.

Questionnaire Scoring

Many questionnaires have complex scoring methods, including item reversal, statistical weighting, and scoring algorithms that require a computer. Complex scoring methods that are found in a number of HSQ are almost impossible to use in the ordinary clinic setting. Scoring of questionnaires should be simple and straightforward. In spite of HSQ that use simple questionnaire scoring methods, many rheumatologists still feel burdened when they have to score HSQ, and scoring remains a problem for some clinics.

Recording Results

To be most useful, HSQ results need to be displayed in flow sheet format, often together with other clinical data. Records have to be kept up by clinical personnel, and clinic personnel may change. Although a seemingly simple task, it often adds unacceptable complexity in some clinics.

Interpreting Results

The scores for many HSQ may be reported in unfamiliar and nonlinear scales; and even if scores are available, they are not easily interpretable or meaningful. Most clinicians are unfamiliar with the meaning of HAQ scores, for example. To be useful, HSQ scoring must be easily interpretable so that status, change in status, and prognosis can be determined when the scores are reviewed.



Factors Related to Usefulness or ADDED VALUE

The central question regarding the use of HSQ in the clinic is whether their use adds clinically useful information to the patient-physician encounter. The clinical interview is generally concerned with 4 items:

- ① The status of the patient compared to other patients with RA and compared to individuals without RA;
- ② change in status, including changes that are related to

treatment; and ③ prognosis for long-term outcomes. An important additional consideration is ④ documentation of the 3 above items: *status, change in status, and prognosis.*

THE CLINICAL VISIT IS CONCERNED WITH

- | |
|--|
| • DETERMINATION OF CLINICAL STATUS |
| • CHANGE IN STATUS |
| • PROGNOSIS FOR LONG-TERM OUTCOMES |
| • DOCUMENTATION OF STATUS AND CHANGE IN STATUS |

Assessment in Clinical Practice

The capable clinician makes a wide range of assessments during the clinical interview/examination. These may include examination of joints for swelling and/or tenderness, review of laboratory data, and assessment of pain, function, and psychological status. In addition, the physician's relationship with the patient includes information regarding work, social support, and response to therapy.

In the usual clinical interview a number of short cuts are taken. For the joint examination, the clinician may note that few (or many) joints are involved (are swollen and tender), but may not record the specific joints and their involvement. Pain may be ascertained as better or worse, or in terms of being mild, severe, acceptable, and so on. Functional ability may be ascertained by observation of the patient or in response to patient complaints. Psychological status is usually not formally assessed. In most instances, however, the shortened assessment is adequate for immediate patient care. For example, a patient in a flare or one who is responding to a new therapy may be adequately assessed by these usual methods.

But the overall consequence of shortened examinations is to provide less accurate and non-quantifiable data. We may be able to tell whether the overall disease is mild, moderate or severe, but the fine gradations are lost, and the ability to compare a patient's status over time is impaired. Similarly, assessment of the degree of disability, the best overall prognostic indicator, is determined crudely, at best.

On the other hand, through the use of simple pain, function, global and psychological scales, reliable and accurate information can be obtained. So why not use such HSQ? There are a number of answers. Foremost, in many patients these data do not seem necessary for clinical care. A patient with mild and stable disease may not be understood or cared for better by repeated detailed assessment. The case against HSQ is that they are only sometimes useful in the usual clinical setting.

The Advantages of HSQ

When measuring pain, global severity and function and/or ancillary constructs such as anxiety, depression, fatigue and sleep disturbance, HSQ always provide results that are more accurate and reliable than the clinician can obtain by usual interview. HSQ make it possible to detect smaller increases or decreases in RA activity than can be detected by the usual clinical measures. HSQ have a number of other advantages. They can provide substantial information regarding concepts like anxiety, depression and fatigue that the clinician knows are important but

rarely attempts to assess. Finally, HSQ provide quantitative rather than qualitative data, and they enable documentation.

COMPARED TO THE CLINICAL INTERVIEW, HSQ

- ARE MORE ACCURATE AND RELIABLE
- DETECT SMALLER DIFFERENCE IN CLINICAL STATUS
- ARE QUANTITATIVE NOT QUALITATIVE
- PROVIDE DETAILED DOCUMENTATION
- ALLOW FOR MEASUREMENT OF LONGITUDINAL CHANGE
- ASSESS IMPORTANT ITEMS THAT ARE MISSED IN THE CLINICAL INTERVIEW

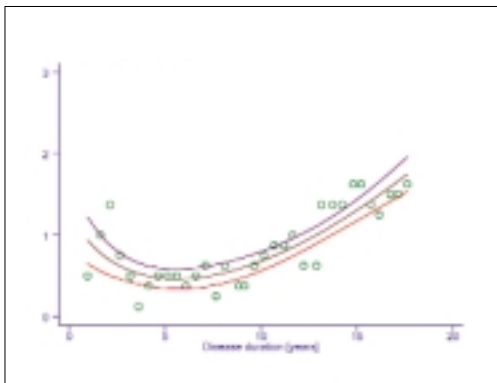
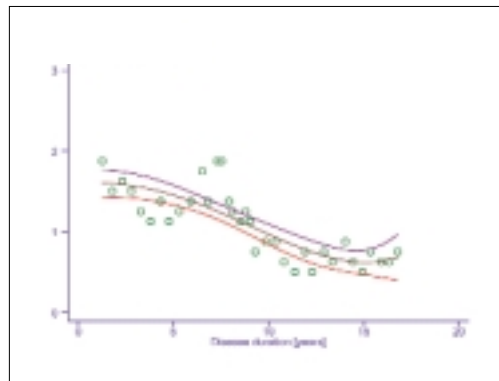


Figure 1 & Figure 2:

Real data - assessing functional disability in individual patients.





The REPORT Project: Overcoming Barriers to HSQ Use

HSQ provide clinically useful information for many patients and for physicians desiring documentation, but issues of feasibility can be barriers, and for some clinicians HSQ appear to be more trouble than they are worth. *The REPORT project was designed to solve the feasibility problem.*

THE REPORT PROJECT PROVIDES WITHOUT CHARGE

| |
|---|
| • HSQ ASSESSMENT FORMS |
| • IMMEDIATE 'FAX BACK' REPORTING |
| • LONGITUDINAL SUMMARY 'FLOW SHEET' REPORTING BY FAX AND MAIL |
| • LONGITUDINAL DATA BASE OF PATIENT RESULTS |
| • SCORING INTERPRETATION USING THE PERCENTILE METHOD |
| • DOCUMENTATION FOR INSURANCE AND REGULATORY PURPOSES |

HSQ Forms

The project will make available to rheumatologists, without charge, 2 versions of a HAQ (Health Assessment Questionnaire) ⁽¹⁾ based HSQ. These forms are included in the attached packet.

First, there is a simple short form that includes 1) the HAQ functional disability index, and visual analog scales (VAS) for the measurement of 2) pain, 3) patient global severity, 4) fatigue and 5) sleep disturbance. In addition, a more comprehensive questionnaire that includes the above items plus scales for 6) anxiety, and 7) depression is also available.

The 7-item questionnaire is called the CLINHAQ (Clinical Health Assessment Questionnaire) and has been used in large series of observational studies. The CLINHAQ-short form (CLINHAQ-SF) refers to the HAQ and the visual analog scales. The anxiety and depression scales come from the Arthritis Impact Measurement Scales (AIMS) ^(2,3).

The REPORT project versions of the CLINHAQ and CLINHAQ-SF also offer the opportunity to incorporate physician data such as swollen and tender joint counts and ESR/CRP. Therefore, the full ACR improvement criteria ⁽⁴⁾ and Disease Activity Scale (DAS) ⁽⁵⁾ can be recorded, and the ACR-20, ACR-50, ACR-70, and DAS responses calculated and scored.

The REPORT Project: Overcoming Barriers to HSQ Use (cont.)

Scoring, Recording and Patient Databases: Using the REPORT Fax Back System

The REPORT project provides services to score, report using a longitudinal flow sheet, and maintain a secure database of your patient's scores. In a typical setting the patient completes the CLINHAQ-SF in 3 minutes while still in the waiting room. The full CLINHAQ can take another minute or two to complete. Your staff then faxes the forms to our fax servers where they are scored instantaneously. The results are then faxed back to you within a minute of receipt.

If you and your patient consent to have us store the patient's data, we report all of the patient's data back to you by fax in the form of a longitudinal flow sheet. Up to 16 patient visits can be reported back on a single form. With an average of 4 patient visits per year, the flow sheet will report at least 4 year's data. Depending on whether you use the CLINHAQ or CLINHAQ-SF, and whether you include clinical data, the fax back flow sheet will report all available variables as well as DAS scores. For those who may be interested in other HAQ scales, the report will also include scores from the MHAQ ^(6,7), MDHAQ ⁽⁷⁾, the full 20-item HAQ (HAQ-20) ⁽⁸⁾, and the D-HAQ (difficult HAQ) ⁽⁸⁾.

Interpreting the Data

The final difficulty in the use of HSQ is interpreting the results. The report fax back program provides percentile values for those of each of the HSQ items (Table 1). For example, the 50th percentile value of the HAQ is 1.0 and the 75th percentile is 1.6. Using the percentile chart, rheumatologists can obtain the patient's status ("How does my patient compare with all other RA patients?") and change in status ("How much has my patient improved or worsened in percentile units?"). Elsewhere in this booklet we present guides for using HSQ values as prognostic tools.

Documentation

The REPORT fax back system also provides documentation for reporting to third party carriers. This can be of some help in documenting patients' status for insurance companies that require such data to support prescription of certain DMARDs and biologic agents. The report system allows for reporting ACR criteria based on questionnaire items. But if you provide ESR/CRP and joint data, we will report back the van der Heidje Disease Activity Score (DAS) ⁽⁵⁾, and you will early be able to calculate the ACR 20, 50 and 70 changes scores ⁽⁴⁾. Of course, the flow sheet system also provides simple clinic documentation so that you can see how your patients are doing.

| PERCENTILE | PAIN | GLOBAL | HAQ | ANXIETY | DEPRESSION | FATIGUE | SLEEP | M-HAQ | HAQ20 | D-HAQ |
|------------|-------|--------|-------|---------|------------|---------|-------|-------|-------|-------|
| 1 | 0.00 | 0.00 | 0.000 | 0.00 | 0.00 | 0.00 | 0.00 | 0.000 | 0.000 | 0.000 |
| 10 | 0.50 | 0.50 | 0.000 | 1.32 | 0.66 | 0.50 | 0.00 | 0.000 | 0.000 | 0.000 |
| 20 | 1.00 | 1.00 | 0.250 | 1.98 | 0.99 | 1.50 | 0.50 | 0.000 | 0.125 | 0.125 |
| 25 | 1.50 | 1.50 | 0.375 | 1.98 | 1.32 | 2.00 | 0.50 | 0.000 | 0.125 | 0.250 |
| 30 | 2.00 | 1.50 | 0.500 | 2.31 | 1.32 | 2.00 | 1.00 | 0.125 | 0.250 | 0.250 |
| 40 | 2.50 | 2.50 | 0.750 | 2.97 | 1.98 | 3.00 | 2.00 | 0.250 | 0.375 | 0.500 |
| 50 | 3.50 | 3.00 | 1.000 | 3.63 | 2.31 | 4.50 | 3.00 | 0.375 | 0.500 | 0.750 |
| 60 | 4.50 | 4.00 | 1.250 | 4.29 | 2.64 | 5.00 | 4.50 | 0.500 | 0.750 | 0.875 |
| 70 | 5.50 | 5.00 | 1.500 | 4.95 | 3.30 | 6.50 | 5.50 | 0.750 | 0.875 | 1.125 |
| 75 | 6.00 | 5.50 | 1.625 | 4.95 | 3.30 | 7.00 | 6.50 | 0.875 | 1.000 | 1.250 |
| 80 | 6.50 | 6.00 | 1.750 | 5.28 | 3.96 | 7.50 | 7.00 | 1.000 | 1.125 | 1.375 |
| 90 | 8.00 | 7.00 | 2.000 | 6.27 | 4.95 | 8.50 | 8.00 | 1.125 | 1.375 | 1.750 |
| 99 | 10.00 | 10.00 | 3.000 | 9.90 | 9.90 | 10.00 | 10.00 | 3.000 | 3.000 | 3.000 |

Table 1: Percentile values for HSQ items from 10,728 RA patients treated by US Rheumatologists. National Databank, 2001.

How to use HSQ in the clinic (9-11)

There are five pillars of wisdom:

- Physical Examination
- Laboratory Data
- HSQ
- Psychosocial Variables
- Prior Knowledge

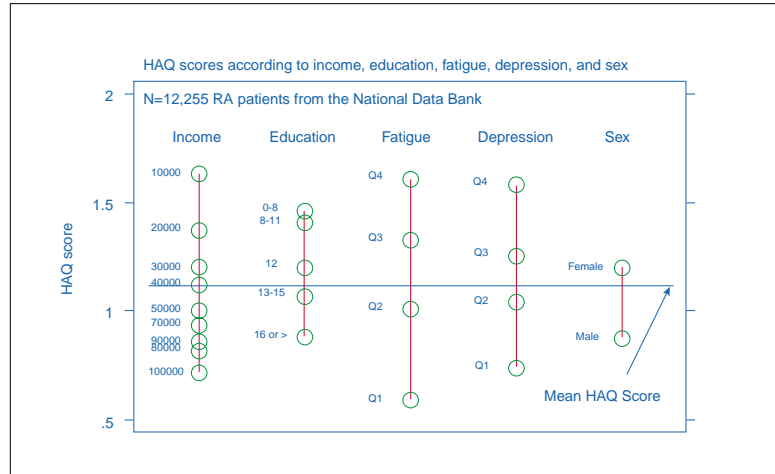


Figure 3: Categories of psychosocial variables.

Disease Activity, HSQ, and Quality of Life

The clinician's goal is to measure 1) disease activity, 2) the effect of disease activity on the patient, and 3) the psychosocial factors that influence its expression. Robert Kaplan, developer of the Index of Well Being (IWB) quality of life (QOL) scale ⁽¹²⁾ has described 'Quality of Life' as 'function plus symptoms,' and QOL in the clinical setting may be defined simply as the patient determined aspects of disease activity and its interaction with patient psychosocial factors. Specifically, QOL represents measurement of one or more of the following: pain, patient global, function, anxiety, depression, fatigue, and sleep disturbance – factors that are influenced both by disease activity and psychosocial factors.

9

The Key Importance of Psychosocial Variables in the Care and Evaluation of the Patient

Although psychosocial factors are 'randomized out' in clinical trials, they play a central role in the clinical interview and in the interpretation of HSQ. For example, as shown in **Figure 3**, patients with depression and less income report higher levels of HAQ functional disability. Other measurable factors that may play a role include education, fatigue, depression, ethnic origin, marital status and social support.

Psychosocial variables are important in and of themselves, but they are particularly important in determining how to interpret variables such as pain, function, and global severity.

Prior Knowledge: Knowing Your Patient Makes Accurate and Useful Interpretation Possible

Of equal importance, however, is the clinician's knowledge of how each specific patient responds. For example, some patients with serious, active disease may report low levels of pain and global severity, while others may always report high levels of these variables in spite of mild disease. Still, some may respond to changes in disease activity with slight and some with exaggerated responses on the pain, physical function and global severity scales. This knowledge and the display of HSQ variables, including psychosocial variables, on a flow sheet makes interpretation practical, useful, and easy.

How to use HSQ in the clinic (9-11)

RELIABILITY: MAKING THE MOST OF HSQ IN THE CLINIC

In research studies, much is written about reliability and validity. These concepts are even more important when applying data to a real patient rather than to a group of patients who have participated in a clinical trial. Although reliability is a complicated subject, one important aspect is the length of the questionnaire or evaluation. In general, the more detailed the examination and the more detailed the questionnaire, the more accurate and reliable will be the results. There are two practical implications. For func-

tional assessment questionnaires, longer questionnaires are more reliable. Therefore the HAQ questionnaire that makes use of all 20 items (HAQ-20) is more reliable than the usual HAQ that makes use of 8 categories based on the 20 items, and that in turn works better than an 8-item scale. These differences are small, but real, and represent a trade-off between reliability, questionnaire length, and time for completion. For additional discussion on questionnaire differences, see Wolfe 2001⁽⁸⁾.

The Difference Between the Use of HSQ in Research Studies and Clinical Practice

Using the HAQ as an example, in any individual patient HAQ scores may differ between two observations for reasons that are unrelated to RA activity. Such reasons include other changes in non-RA physical status or pain, error in assessment, psychosocial factors, and the sheer randomness of the world. The extent of changes unrelated to clinical activity can be large, and it has been suggested by some⁽¹³⁾ and disputed by others⁽¹⁴⁾ that this amount of 'error' limits the usefulness of the HAQ in the clinic. In passing, it should be noted that greater degrees of variability exist in measures like the ESR and joint count⁽¹⁴⁾.

Clinical trials overcome this error variability in two ways: by the use of an index (ACR-20, DAS, etc), which thereby increases reliability by increasing length, and by the use of a large sample size. It is important to understand that the summary measures (ACR-20 and DAS) are measuring an underlying (or latent) concept that we call disease activity. Although clinicians cannot increase the sample size, they make use of summary measures. The clinician's summary measure can include all of the measures used in clinical trials, but it also includes more. It includes all of the prior knowledge the clinician has about the patient, including psychosocial factors such as long and short-term anxiety and depression, marital status, social support, education, income, insurance status, and comorbid conditions. It also includes knowledge of how this patient responds to therapy, and which variables are useful and which are not useful; and how the variables change and are expressed in this particular patient. It is this extra knowledge that the clinician has that reduces error variability in the assessment of the underlying concept of disease activity, and makes it possible to use HSQ and physical examination and laboratory data in the care of the patient. The clinician's extra knowledge must be combined with the use of HSQ questionnaire items to realize the full value of HSQ. As a minimum, HAQ, pain and global should be used. But the assessment is enhanced when other variables such as anxiety, depression, fatigue and sleep disturbance are included.

Summary

HSQ are valuable and add to clinical knowledge when multiple variables (HAQ, pain, global severity, psychosocial) are assessed longitudinally. Previous results must be available, and the clinician must interpret all of the data in the light of psychosocial factors and the clinician's prior knowledge of the individual patient.

Practical Use of the CLINHAQ and the REPORT Program

- ✓ Choose the full CLINHAQ or the short form. Both are included in your packet. Even if you chose one, you can always switch to the other.
- ✓ The first time a patient uses a form the patient must sign the informed consent giving us permission to store the data and to fax the results back to you. After the patient signs the consent, it is not necessary to sign the consent for subsequent, follow-up assessments.
- ✓ It is best to have the patient complete the CLINHAQ or CLINHAQ-SF before the patient is seen by the clinician. If done that way, the form can be faxed to us for instantaneous scoring and fax back. That way you will have the results at the time you see the patient. Good times and places to have the patient complete the forms are after checking in and before you see the patient, often best done in the waiting room or while waiting to see the physician in the examining room.
- ✓ If you wish to score the CLINHAQ forms yourself, you can still participate in the data bank program by faxing or mailing back the forms, either one at a time or in bulk.
- ✓ If you are using the program, we will be happy to provide you additional forms at no charge in packages of 500 on your request (email: CLINHAQ@arthritis-research.org, tel: 316-263-2125, ext. 124)

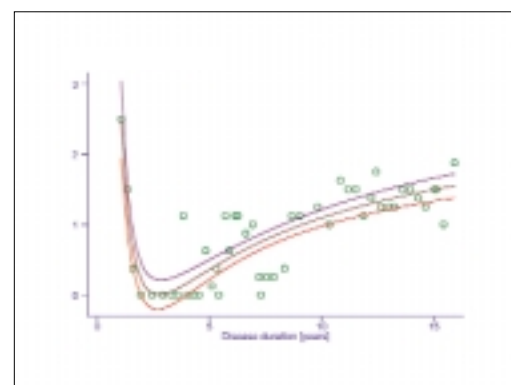
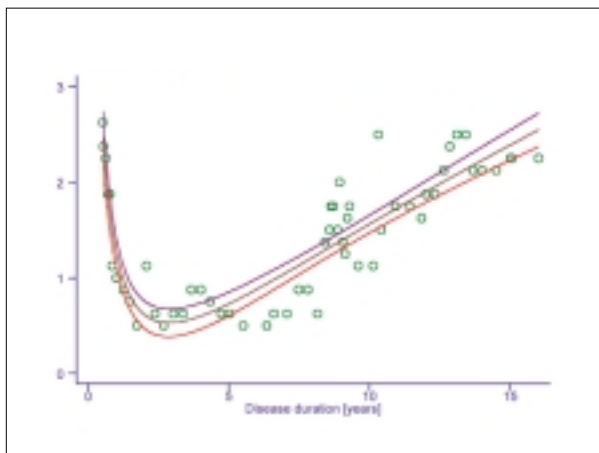


Figure 4 & Figure 5: Progression of functional disability in two patients with rheumatoid arthritis.

How to Interpret CLINHAQ and CLINHAQ-SF Results.

Any new test requires familiarity that is best achieved through use. Here are some suggestions.

Percentile Charts—Determining Status

A copy of the percentile chart (Table 1, page 8) will be attached to each fax back form so that you can refer to it immediately. The percentile chart will also include information on other HAQ formats, such as the MHAQ, and we will report your HAQ results in the other HAQ formats as well.

Although patients may vary in the percentile for individual questionnaire items, usually the percentiles of the individual questionnaire items are in general agreement (Figure 6), and it is possible to look at the scores and determine your patient's position (status). As a rule, patients in the 1st quartile (Q1 – 25th percentile or below) are doing well. Those in Q4 (75th percentile or above) are doing very poorly, and those in Q2 and Q3 occupy intermediate positions.

Percentile Charts—Determining Prognosis

Using the CLINHAQ, Wolfe F and Choi HK (Presented at EULAR – 2001) reported that the risk of mortality increased 1.64 times for each 1 unit increase in HAQ and 1.45 times for depression scores of 4 or above. Using the percentile chart shown in Table 1, it can be seen that this degree of change (1 unit) occurs between the 30th and 70th percentile, and that similar risk is seen in those with depression scores at the 80th percentile level [Here depression may be a marker for serious comorbidity that is not detected by usual HSQ questionnaires]. Similarly, a 1 unit change in HAQ associates with a 2.11 times increase in the risk of work disability⁽¹⁵⁾, and a 2.12 increase in the risk of total joint replacement⁽¹⁶⁾.

Assessing Change

Data from a number of sources^(17,18) suggests that, using the HAQ alone, a change of about 0.25 is 'clinically significant' (Table 1, page 8), it can be seen that this level of change is equivalent to a 10% shift in percentile position. This is equivalent to about a 1 unit change in pain and global severity.

However, we have noted above that all clinical measures are 'noisy,' and may vary importantly between visits for factors that are not related to RA. Therefore one must not look at just one measure, but must look at all of the measures together, including physical examination, laboratory, and psychosocial variables. CLINHAQ variables are usually concordant, as shown in Figure 3. When most of the disease activity variables are going in the same direction, it is safe to conclude that clinical change is occurring. In such a setting, it is often possible to detect and document percentile shifts as small as 5%.

Among the most important methods to evaluate change is to observe CLINHAQ scores longitudinally (Figure 7-11, page 13). This provides information regarding stability and reliability of measures, and allows one to detect small changes. Also important is to look at the fatigue and mood variables since they give important clues to interpretation of the disease activity variables.

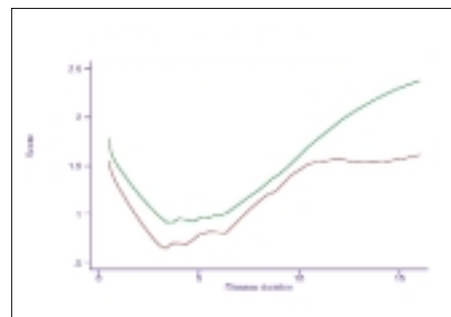


Figure 6: Concordance between HAQ (green line) and patient global severity (red line) over time. Global severity is rescaled for better display.

Psychosocial Factors and the Interpretation of Disease Activity and Functional Ability

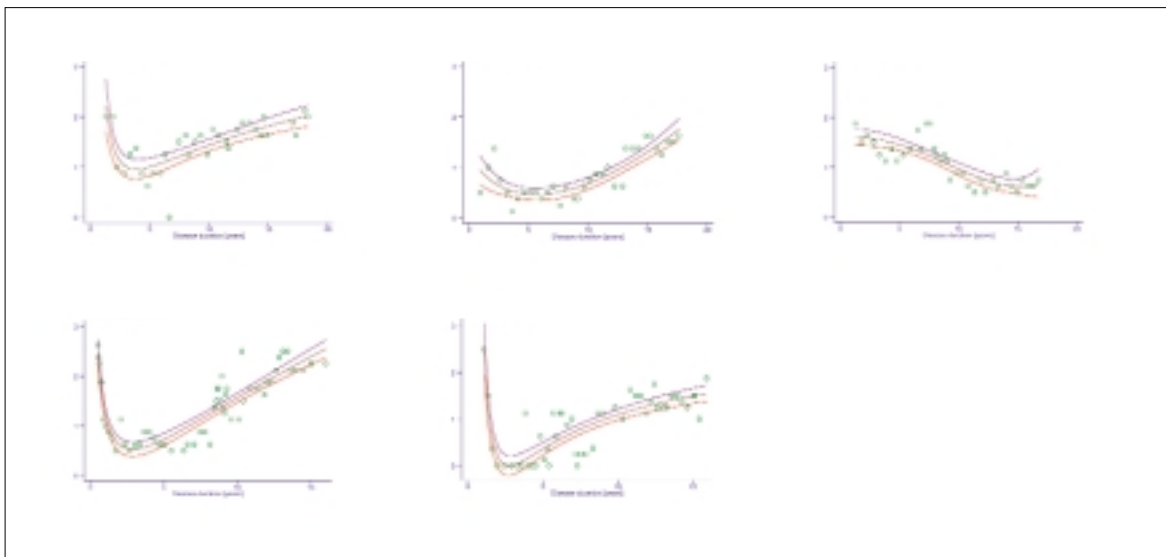
There are some patients who always report high levels of abnormality for HAQ variables, just as there are some patients who report few problems in the face of progressive, destructive disease. The clinician can easily detect such patients and, therefore, place their data into proper perspective. It is a fundamental mistake only to look at disease

activity scores without interpretation. Even in persons who seem to be over- or underreporting, change is often easily discernable using CLINHAQ data. It is this extra knowledge that the clinician has that makes HSQ data of particular use in the clinic.

A Database for Patient Care and Research

Patients who consent to have their CLINHAQ data stored and reported back to their clinicians by longitudinal flow sheet fax back will be offered the opportunity to participate in a long-term study of RA outcome. In this voluntary project, patients will be asked to complete detailed questionnaires about their arthritis at 6-month intervals.

We will make such data on your patients available to you in several formats. At 6-month intervals we will summarize data on all of your patients and send it to you. In addition, we will make the data available to you in electronic format for your further analysis. As a practical point, rheumatologists who make extensive use of the REPORT system will have at their disposal a clinical and research data bank on their patients. This is a good, no cost way to get started in clinical research. At the same time, it provides clinicians with benchmarks regarding their patients and their patient care.



Figures 7-11: Five patients with rheumatoid arthritis, HAQ scores over time.

Can you explain the how the data bank works? There are 3 levels of participation.

- ① If the patient does not consent to data bank participation, the CLINHAQ or CLINHAQ-SF will be scored and faxed back to you, but we will have no identifying information about the patient and therefore cannot build a flow sheet or data bank for you. This is the least useful way to utilize the project.
- ② If the patient consents to databank participation, she provides identifying information so that she can be contacted by data bank staff. She also provides basic demographic information. At this level of participation we are able to make a data bank and flow sheets for this patient because we are able to identify the patient uniquely.
- ③ With this consent, the patient will also receive a mailed invitation to participate in detailed data bank research by completing a mailed questionnaire sent every 6 months. Participating at this level requires that the patient sign a more detailed consent form that will be mailed to her. She can opt out of the program at any time. If the patient participates in the data bank at this level, we will collect data on treatment, costs, adverse events, work, and all of the important outcomes of RA.

What happens to the data? In addition to the fax back program and flow sheets,

- ① Every 6 months, we will send you summary reports of your patients' data that will include the 6-month mailed questionnaire data.
- ② You may have the actual data if you wish, including the data from the 6-month questionnaires. In this instance we will send you data on each patient in electronic format (e.g. Excel, SAS, Stats, etc). You are free to use these data in any way you wish, including publishing them.
- ③ The data will be used for general National Databank (NDB) research and reported in peer-reviewed forums, such as ACR meeting and peer-reviewed journals.

What about privacy?

- ① We will never sell or otherwise make available any data to commercial sources such as mailing lists or pharmaceutical companies. Even for research purposes, we do not make data available to pharmaceutical companies, though we may permit outside statistical review.
- ② We will never disclose information that would allow you to be identified, nor permit any research project that compares one rheumatologist with another.
- ③ Regardless of the extent of data base participation, absolute patient privacy is guaranteed. No one, not even researchers, will have access to your patient's data in a format that permits the patient to be identified.

What about costs?

There are no costs to you or to your patient.

How do I get more forms?

If you are using the program, we will be happy to provide you additional forms in packages of 500 on your request (email: CLINHAQ@arthritis-research.org, or call Amy Yearout at 316-263-2125, ext. 124)

Can I score the forms myself?

Yes you can. An enclosed instruction sheet explains how to do this, or see the instructions at www.arthritis-research.org. If you do score the forms yourself, you can still participate in the database and flow sheet program by faxing or mailing the forms to the National Databank.

How is this project supported?

The start-up costs of the REPORT project are supported by an educational grant from Centocor, Inc.

What is the National Databank (NDB)?

The National Databank for Rheumatic Diseases (NDB) is a non-profit entity whose purpose is to perform research in rheumatic disease. The NDB first began operation in 1988 as an outgrowth of the Wichita Arthritis Center Data Bank. The Wichita Databank was founded in 1974. To date, 49,000 patients, with approximately 250,000 observations, have been NDB participants. The NDB regularly reports results at the annual ACR meeting. A number of manuscripts have already been published, are in press, or are under review. Frederick Wolfe MD is the NDB director.

Can I use the CLINHAQ and CLINHAQ-SF for osteoarthritis or fibromyalgia?

Yes. Percentiles scores for these disorders are available at <http://www.arthritis-research.org>. We will also maintain a database for you for such patients. But the diagnosis must be clearly stated at the time of the first CLINHAQ form submission.

What if I have additional questions?

Feel free to call Dr. Wolfe (316-263-2125, ext. 0) or send an email (fwolfe@arthritis-research.org).

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