
Development of a multi-dimensional health assessment questionnaire (MDHAQ) for the infrastructure of standard clinical care

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ABSTRACT

The HAQ has become the pre-eminent patient questionnaire used in rheumatology. It is easily completed by patients, but not easily reviewed and scored in standard clinical care and has some minor psychometric limitations, as do all questionnaires. Modifications of the HAQ have been made to facilitate use in standard care, particularly to include 8-10 activities of daily living, along with scores for pain and global status and other information on one side of one page for rapid review by the clinician. A patient questionnaire for standard care should be limited to 2 sides of 1 page, in a format amenable to "eyeball" review by the clinician in 5 seconds or less. It can be scored formally in 15-20 seconds or less, and is useful in patients with all rheumatic diseases.

The current version of a multi-dimensional HAQ (MDHAQ) includes scoring templates on the questionnaire to allow formal scoring in less than 15 seconds by a rheumatologist or an assistant, for possible entry onto a paper and/or computerized flow sheet. Various versions of the MDHAQ may also include a "constant" region of physical function, pain and patient global status, and "variable" regions of fatigue, morning stiffness, psychological distress, change in status, a review of systems, a rheumatoid arthritis disease activity self-report joint count (RADAI), review of recent health events, and review of medications. The MDHAQ can be used in the infrastructure of rheumatology care to include quantitative data in standard care of all patients with all rheumatic diseases.

Introduction

Over the last 25 years, since its landmark publication in April 1980, the Health Assessment Questionnaire (HAQ) (1) has become the pre-eminent

patient questionnaire in rheumatology. The HAQ queries 20 activities of daily living (ADL) (Table I) for which the patient is asked to respond in 4 categories as to whether he or she can perform the activity "without any difficulty" (= 0), "with some difficulty" (= 1), "with much difficulty" (= 2), and "unable to do" (= 3) (2). The 20 activities are classified into 8 categories of 2 or 3 each. The HAQ also queries the use of 16 aids and devices. A score for each of the 8 categories is based on the maximum score for any of the 2 or 3 activities in the category, with an increase in the score by 1 for any category in which patients use an aid or device. The total score is the mean of the scores for the 8 categories (1). The HAQ is discussed in detail in this Supplement by its developer, James Fries with Bonnie Bruce (3).

Some limitations of the HAQ

The HAQ has proven a major advance in rheumatology clinical research. However, as is the case with all measurement methods, certain limitations are seen, which are not of major consequence but may detract from its psychometric validity (Table I). A HAQ score may be increased artefactually by a rheumatologist recommending a device to aid a patient's function; for example, if a patient responds that she walks, opens jars, or performs another activity "with some difficulty", and is given a cane, jar opener, or other device, but continues to respond "with some difficulty", the score will be increased from 1 to 2, even though the patient's physical function may be improved.

Different activities may determine the HAQ scores on different completions, as only 1 of 2 or 3 activities within each category determines the score for the category. The categories of the HAQ do not necessarily group related activities

Table I. Items included on the HAQ, 8 ADLMDHAQ, 14 ADLMDHAQ, 10 ADLMDHAQ and HAQII. (The codes of the items are the same as used in other tables).

	HAQ (1)	8 ADL MHAQ (4)	14 ADL MDHAQ (24)	10 ADL MDHAQ (2)	HAQII (5)
DRESSING & GROOMING:					
Dress yourself, including tying shoelaces and doing buttons ?	1a	a	a	a	
Shampoo your hair ?	1b	-	-	-	
ARISING:					
Stand up from a straight chair ?	2a	-	-	-	÷
Get in and out of bed ?	2b	b	b	b	
EATING:					
Cut your meat ?	3a	-	-	-	
Lift a full cup or glass to your mouth ?	3b	c	c	c	
Open a new milk carton ?	3c	-	-	-	
WALKING:					
Walk outdoors on flat ground ?	4a	d	d	d	÷
Climb up 5 steps ?	4b	-	-	-	
Walk 2 miles or 3 kilometers ?	-	-	i	i	
HYGIENE:					
Wash and dry your entire body ?	5a	e	e	e	
Take a tub bath ?	5b	-	-	-	
Get on and off the toilet ?	5c	-	-	-	÷
REACH:					
Reach and get down a 5 pound object from above your head ?	6a	-	-	-	÷
Bend down to pick up clothing from the floor ?	6b	f	f	f	
GRIP:					
Open car doors ?	7a	-	-	-	÷
Open previously opened jars ?	7b	-	-	-	
Turn regular faucets on and off ?	7c	g	g	g	
OTHER ACTIVITIES:					
Run errands and shop ?	8a	-	k	-	
Get in and out of a car, bus, train, or airplane ?	8b	h	h	h	
Do chores such as vacuuming or yard work ?	8c	-	-	-	
Participate in sports and games as you would like ?	-	-	j	j	
Climb up a flight of stairs ?	-	-	l	-	
Run or jog two miles ?	-	-	m	-	
Drive a car 5 miles from your home ?	-	-	n	-	
PSYCHOLOGICAL STATUS:					
Get a good night's sleep ?	-	-	o	o	
Deal with the usual stresses of daily life ?	-	-	p	p	
Deal with feelings of anxiety or being nervous ?	-	-	q	-	
Deal with feelings of depression or feeling blue ?	-	-	r	-	
HAQII ITEMS NOT LISTED ABOVE					
Go up two or more flights of stairs ?					÷
Lift heavy objects ?					÷
Move heavy objects ?					÷
Wait in line for 15 minutes ?					÷
Do outside work (such as yard work) ?					÷

Source: Reference (2)

effectively; “stand up from a straight chair” in the category of “arising” and “get on and off the toilet” in the category

of “hygiene” are correlated at higher levels of significance with one another than with the other activities within the

categories of “arising” and “hygiene” (4). A patient may hypothetically improve on 1 to 12 of the 20 activities on the HAQ, but show no change in HAQ score.

Floor effects are seen, namely that patients may have normal HAQ scores, but nonetheless feel that there exist functional limitations. A change in score of a given interval, say from 0.25 to 0.5, may not represent a similar change as a change from 0.25 to 1.5 (5). As noted, none of these matters limit the HAQ severely in the documentation and monitoring of status in clinical trials, and in predicting work disability and mortality in observational clinical research, as the HAQ or a derivative – rather than a joint count, laboratory test or radiograph – is the best predictor in rheumatoid arthritis (RA) of functional status (6, 7), work disability (8-10), costs (11), joint replacement surgery (12) and premature death (6, 13-19).

The HAQ is generally easily completed by most patients in 5-10 minutes. However, pragmatic considerations may limit use of the HAQ in standard clinical care, as few clinicians – with some notable exceptions such as Dr. Frederick Wolfe (20) – use the HAQ routinely. Some HAQ activities, such as “shampoo your hair” and “do chores such as vacuuming or yard work” are not performed by some patients, causing some interruption in completion by some patients. Since the HAQ involves 2 sides of 1 page, it cannot be quickly reviewed (“eyeballed”) by a clinician to get a simple overview of patient status. The scoring system is somewhat complex, generally requiring at least a minute. The HAQ does not include data concerning psychological distress, fatigue, change in status, morning stiffness, or other constructs which some clinicians may wish to monitor in standard care.

These considerations have led to efforts to develop simpler patient questionnaires for use in standard clinical care, in a more easily scored format, which can be scanned (“eyeballed”) by a clinician in 5 seconds or less, scored in less than 10-20 seconds, and that provide additional information concerning psy-

chological status, fatigue, change in status, morning stiffness, review of systems, medications used, all on 2 sides of 1 page. The modified HAQ (MHAQ) and multi-dimensional HAQ (MDHAQ) were developed to meet these goals.

Development of a modified HAQ (MHAQ)

A modified HAQ (MHAQ) was described in 1983 (4), which includes 8 activities of daily living, 1 from each category of the HAQ (Table I), with no aids and devices, for rapid review by a clinician and scoring in less than half the time needed for the HAQ. MHAQ scores are correlated significantly with HAQ scores (as would be expected for the same items) (4), and with traditional joint counts, radiographs and laboratory indicators of inflammation (21). The MHAQ appears to be as sensitive as the HAQ in clinical trials to recognize differences between active and control treatments (22), and as informative in longitudinal clinical studies of morbidity (17), mortality (16, 17) and work disability (8) in RA. The MHAQ also includes 10 cm visual analog scales for pain and global status, to assess the 3 patient questionnaire measures on the ACR Core Data Set (23). The activities chosen for the MHAQ were generally the simplest of the 2 or 3 within each HAQ category (Table I), as the deleted activities were some that certain patients do not perform, such as "shampoo your hair", "vacuuming or yard work", or "take a tub bath." Therefore, MHAQ scores were systematically 0.3–0.4 units lower than HAQ scores, and "floor effects," i.e., scores of 0 in people who had some functional disability, were more common than seen on the HAQ (24). This problem became more prominent during the 1990s as the status of patients with RA improved substantially with the aggressive use of low dose methotrexate and low dose prednisone (25).

Development of a multi-dimensional HAQ (MDHAQ)

The lower scores with a greater level of "floor effects" of the MHAQ compared to the HAQ was addressed by the addition of 6 complex activities in a multi-

dimensional HAQ (MDHAQ) (Table I) (24). The term "multi-dimensional" is used in recognition that the questionnaire had been further modified over the years to include not only the queries of 8–10 activities of daily living, and visual analog scales for pain and global status from the ACR Core Data Set (23, 26, 27), but also scores for fatigue, psychological distress, morning stiffness and change in status on one side of one page, and review of systems and medications on the reverse side of the page. The additional activities reduced the number of patients with floor effects from 16% on the HAQ and 30% on the MHAQ, to less than 3% on the MDHAQ.

More recently, a further revision of the MDHAQ with only 2 of 6 additional activities, "walk 2 miles or 3 kilometers" and "participate in recreation and sports as you would like," has been reported (Table I) (2). This format further advanced ease of scoring, as scores for 10 activities may be divided by 10 and scored 0–3, as in the HAQ, or divided by 3 and scored 0–10, so that scores for functional disability are scored 0–10, as are scores for pain, global status and fatigue (2). The prevalence of floor effects was 10%, but most patients with a score of "0" were in a clinical remission status.

The initial report of the MDHAQ included 4 items to address psychological distress, including anxiety, depression, sleep and dealing with stress (24), in the patient-friendly HAQ format of 4 response items – "without any difficulty," "with some difficulty," "with much difficulty," "unable to do." The depression item was found to be correlated significantly with the Beck Depression Inventory and Centers for Epidemiologic Studies Depression Inventory (CES-D), which takes up a page or more ($r > 0.6$, $p < 0.001$). In the revised MDHAQ (2), scores for psychological distress were found to be similar with removal of the "stress" item, and 3 items for anxiety, depression and sleep have been retained. Each item is scored on a 0 to 3.3 scale, 0 = with no difficulty, 1.1 = with some difficulty, 2.2 = with much difficulty, and 3.3 = unable to do. The total score for this psycho-

logical distress scale is the total of the 3 items, i.e. 0 – 9.9, again giving a total near 10 as for the other scales.

The recently reported MDHAQ (Fig. 1) includes 7 scores: physical function, pain, global status, psychological distress, and fatigue, each of which is scored 0–10 (or 0–3 for physical function, if preferred), as well as change in status and morning stiffness in minutes, all on 1 side of 1 page which can be easily scanned in 5 seconds to gain an overview of a patient's situation. While it is pragmatically desirable that the same questionnaire be completed by each patient within each clinical setting, it is not necessary that every patient questionnaire used in every rheumatology setting be identical. All versions of the MDHAQ (available at website mdhaq.org) include a "constant" region, analogous to immunoglobulins, of physical function, pain, and global status, the 3 patient self-report measures from the ACR Core Data Set (23), as well as strongly encouraged and optional "variable" regions. "Variable" regions regarded as "strongly encouraged" include scales for psychological distress, fatigue, change in status, morning stiffness, and an RADAI-self-report joint count (Table II). "Variable" regions regarded as "optional" include (Table II): a review of systems list of medications used, recent medical events, demographic data, and physician assessment of global status. One of the authors (YY) includes a physician note on a 1-page 2-sided form.

One example is illustrated in Figures 1 and 2. One side of the page (Fig. 1) includes 10 activities of daily living, 3 items to assess psychological distress,

Fig. 1. (next page) A version of the multi-dimensional health assessment questionnaire (MDHAQ) designed for use in standard medical care, which includes scores for physical function, psychological distress, pain, morning stiffness, global status, self-report functional class, change in status, fatigue, and disease activity from the rheumatoid arthritis disease activity index (RADAI) self-report joint count, on one side of one page. Scoring templates and space to enter scores are provided on the questionnaire, as discussed in the text (translated versions of MDHAQ are available in French, German, Italian, Spanish, Danish and Finnish at www.MDHAQ.org).

Multi-Dimensional Health Assessment Questionnaire (R729-NP2)

This questionnaire includes information not available from blood tests, X-rays, or any source other than you. Please try to answer each question, even if you do not think it is related to you at this time. There are no right or wrong answers. Please answer exactly as you think or feel. Thank you.

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

FOR OFFICE
USE ONLY

OVER THE LAST WEEK, were you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do
a. Dress yourself, including tying shoelaces and doing buttons?	0	1	2	3
b. Get in and out of bed?	0	1	2	3
c. Lift a full cup or glass to your mouth?	0	1	2	3
d. Walk outdoors on flat ground?	0	1	2	3
e. Wash and dry your entire body?	0	1	2	3
f. Bend down to pick up clothing from the floor?	0	1	2	3
g. Turn regular faucets on and off?	0	1	2	3
h. Get in and out of a car, bus, train, or airplane?	0	1	2	3
i. Walk 2 miles or 3 kilometers, if you wish?	0	1	2	3
j. Participate in recreational activities and sports as you would like, if you wish?	0	1	2	3
k. Get a good night's sleep?	0	1.1	2.2	3.3
l. Deal with feelings of anxiety or being nervous?	0	1.1	2.2	3.3
m. Deal with feelings of depression or feeling blue?	0	1.1	2.2	3.3

FN



1 0.0 16 2.2
2 0.0 17 2.3
3 0.0 18 2.3
4 0.1 19 2.4
5 0.7 20 2.5
6 0.9 21 2.6
7 1.1 22 2.6
8 1.2 23 2.7
9 1.4 24 2.7
10 1.5 25 2.8
11 1.6 26 2.8
12 1.8 27 2.9
13 1.9 28 2.9
14 2.0 29 3.0
15 2.1 30 3.0

PSY



PN



GL



RAPID



(=FN+PN+GL)



FATIG



JTACT



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 0.0 0.5 0.9 1.2 1.4 1.6 1.8 2.0 2.1 2.2 2.3 2.4 2.5 2.6 2.7 2.8 2.9 3.0 PAIN AS BAD AS IT COULD BE

3. When you awakened in the morning OVER THE LAST WEEK, did you feel stiff? ☐ No ☐ Yes
If "No," please go to Item 4. If "Yes," please indicate the number of minutes or hours _____ until you are as limber as you will be for the day.

4. 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 0 0.0 0.5 0.9 1.2 1.6 1.9 2.2 2.4 2.6 2.8 3.0 3.1 3.3 3.4 3.5 3.6 3.7 3.8 3.9 4.0 VERY POORLY

5. Which of the following best describes you TODAY in your every day life?

Please check (✓) only one:

- 1: I can do **everything** I want to do.
2: I can do **most** of the things I want to do, but have **some** limitations.
3: I can do **some**, but not all, of the things I want to do, and I have **many** limitations.
4: I can do **hardly any** of the things I want to do.

6. How much of a problem has UNUSUAL fatigue been for you OVER THE PAST WEEK?

FATIGUE IS 0 0.5 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10 MAJOR PROBLEM

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

Much Better || (1), Better || (2), the Same || (3), Worse || (4), Much Worse || (5) than one week ago

8. In terms of joint tenderness (i.e. joint pain associated with light touch) and joint swelling (joint enlargement due to inflammation), how active would you say your rheumatic condition is TODAY?

NOT AT ALL 0 0.5 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10 EXTREMELY ACTIVE

R729-NP2

PLEASE TURN TO THE OTHER SIDE

Page 1 of 2

9. Please place a check (✓) in the appropriate box 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

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

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

11. In general, how active has your rheumatic condition been over the PAST SIX MONTHS?

NOT AT ALL ☐ 0 ☐ 0.5 ☐ 1.0 ☐ 1.5 ☐ 2.0 ☐ 2.5 ☐ 3.0 ☐ 3.5 ☐ 4.0 ☐ 4.5 ☐ 5.0 ☐ 5.5 ☐ 6.0 ☐ 6.5 ☐ 7.0 ☐ 7.5 ☐ 8.0 ☐ 8.5 ☐ 9.0 ☐ 9.5 ☐ 10 ACTIVE

12. Over the last 6 months have you: [Please check (✓)]

☐ No ☐ Yes	Had an operation	☐ No ☐ Yes	Change(s) of arthritis drugs or other drugs
☐ No ☐ Yes	Inpatient hospitalization	☐ No ☐ Yes	Change(s) of address
☐ No ☐ Yes	A new illness, accident or trauma	☐ No ☐ Yes	Change(s) of marital status
☐ No ☐ Yes	An important new symptom	☐ No ☐ Yes	Change job or work duties, quit work, retired
☐ No ☐ Yes	Side effect(s) of any drug	☐ No ☐ Yes	Change of medical insurance, Medicare, etc.
☐ No ☐ Yes	Smoke cigarettes regularly	☐ No ☐ Yes	Change of primary care or other doctor

Please explain any "Yes" answer below, or indicate any other health matter that affects you:

Your Name _____ Today's Date _____ Date of Birth _____
 SEX: ☐ Female, ☐ Male ETHNIC GROUP: ☐ Black, ☐ White, ☐ Asian, ☐ Hispanic, ☐ Other _____

Your Occupation _____

Work Status: ☐ Full-time, ☐ Part-time ☐ Disabled

☐ Homemaker, ☐ Seeking work, ☐ Other _____

Please circle the number of years of school you have completed:

1 2 3 4 5 6 7 8 9 10

11 12 13 14 15 16 17 18 19 20

FOR OFFICE
USE ONLY

JT ☐

1	0.23	25	5.21
2	0.12	26	5.12
3	0.63	27	5.63
4	0.83	28	5.83
5	1.01	29	6.01
6	1.25	30	6.25
7	1.16	31	6.16
8	1.67	32	6.67
9	1.88	33	6.88
10	2.08	34	7.08
11	2.29	35	7.29
12	2.50	36	7.50
13	2.71	37	7.71
14	2.93	38	7.93
15	3.13	39	8.13
16	3.33	40	8.33
17	3.54	41	8.54
18	3.75	42	8.75
19	3.96	43	8.96
20	4.17	44	9.17
21	4.38	45	9.38
22	4.58	46	9.58
23	4.79	47	9.79
24	5.00	48	10.00

SX

☐

AC6

☐

Table II. Three types of components of MDHAQ for standard clinical care: “Constant” - required, and “variable” - strongly encouraged and optional.

“Constant”- Required	“Variable”- Strongly Encouraged	Variable – “Optional”
Physical function	Psychological distress	Review of systems
Pain	Fatigue	Medications used
Patient global	Change in status	Recent medical events
	Morning stiffness	Physician global
	RADAI-self-report joint count	Physician note on 2-page form

Table III. Patient questionnaires in clinical research and clinical care.

Feature	Clinical research	Clinical care
Design considerations	Complete, long	Patient friendly, can be completed by patient within 5–10 min
Effect on patient visit	Adds time, interferes with flow	Saves time for MD and patient
Type of questionnaire	May be “generic”, “disease specific”, other research goals	Applicable to patients with all rheumatic diseases
Scoring	Complex, requires computer	Simple, may “eyeball” results; scored in < 20 seconds
Goal of data	Add to research database	Add to clinical care
Focus of analysis	Groups of patients in clinical trials or observational databases	Individual patients cared for by individual physicians
Data management	Send to data center	Review for patient care; may enter into flow-sheet to compare to previous visits
Major criteria for use	Validity, reliability; assess minimum clinically important significant difference (MCID)	Document status, medical and medico-legal rationale for aggressive therapies
Disposition of questionnaire	Enter into computer	Enter into flow sheet in medical record

Table IV. A practical system for routine assessment of functional status, pain, global status, fatigue and psychological distress.

1. Patient is given 2-page questionnaire by receptionist; it generally is most feasible to include each patient with each diagnosis at each visit in the infrastructure of clinical care.
2. Patient completes simple questionnaire with minimum interruption of patient flow, usually in waiting room; help is needed by 5-25% of patients.
3. Nurse or staff member may help patients when needed, review questionnaire for completeness, and may score questionnaire.
4. Physician does as little as possible, but should scan (“eyeball”) contents - may score questionnaire and/or perform formal joint count.
5. Office staff may enter data into flow sheet with laboratory and medication data.

Fig. 2. (previous page) Reverse side of the MDHAQ, which includes a review of systems, the rheumatoid arthritis disease activity index (RADAI) self-report joint count (28), recent medical events, and demographic data.

visual analog scales (VAS) for pain, global status, and fatigue, and scores for change in status and morning stiffness, and on the other side (Fig. 2) a review of systems, the rheumatoid arthritis disease activity index (RADAI)

self-report joint count (28), recent medical events, and demographic data. Simple questionnaires such as a 10-item HAQ II (5, 29) or 12-item ROAD (30), present reasonable alternatives to the MDHAQ. Differences in the patient questionnaire appear acceptable, so long as the critical “constant” region is included.

It should be emphasized that there is no need to involve a computer in any of these scoring activities, which are easily accomplished using pencil and paper in any clinical setting, although a computer database may be desirable. The acquisition of additional information on one page concerning psychological distress, fatigue, morning stiffness, and change in status, and ease of scoring may be the advantages of an MDHAQ compared to the HAQ. A change in scores for pain, fatigue, global status, and psychological distress often is at least as important in clinical care as a change in the functional disability score.

Patient questionnaires for clinical research and for standard clinical care

As noted, the primary purpose of modifying the HAQ to develop the MDHAQ was to facilitate the application of patient questionnaires beyond clinical research (31-33) to standard clinical rheumatology care. Many reasons have been cited to explain why patient questionnaires are not included in standard care. The first may be that data from a physician and/or high-technology imaging and laboratory source are regarded as “objective” clinical information in the traditional “biomedical model” paradigm, the basis for most of the spectacular advances in 20th century medicine. By contrast, data from a patient are regarded as “subjective” – with the primary purpose of leading to “objective,” definitive data. However, no study has documented greater significance for an imaging method or laboratory test compared to a patient questionnaire in the prognosis or documentation of important clinical outcomes in rheumatoid arthritis, such as functional status (6, 7), work disability (8-10), costs (11), joint replacement surgery

Example of patient flowsheet monitoring using the multi-dimensional health assessment questionnaire (MDHAQ)

PT: 35 yo F 1st Visit: 03/05/2003 DX ICD9: 714.0 Onset: 02/2003 Education: 12

VISIT DATE	3/5/03	3/11/03	3/25/03	5/20/03	6/19/03	11/11/03	4/25/06
PATIENT SELF-REPORT QUESTIONNAIRE DATA							
FUNCTIONAL STATUS (FN) [0-10]	6.33	2.00	2.00	1.67	1.00	0.67	0
PSYCHOLOGICAL STATUS (PS) [0-10]	7.70	3.30	1.10	3.30	3.30	3.30	3.30
PAIN (PW) [0-10]	7.8	5.6	1.8	1.7	1.3	0.7	0.8
AM STIFFNESS (AM) [0-300 min]	60	60	60	120	60	45	45
FATIGUE (FT) [0-10]	9	4.4	5.7	0.5	0.9	1.1	1.5
CHANGE OVER 2 WEEKS (CH) [1-5]	M Worse	Better	Better	Same	M Better	Same	Better
GLOBAL STATUS (GL) [0-10]	9.1	5.6	2.8	2.4	1.8	0.3	0.8
SYMPTOMS (SY) [0-60]	25	27	16	9	18	6	12
WEIGHT (lbs)		170.2	166	178	180.4	188.2	191
BLOOD PRESSURE (mmHg)	NA	106/64	110/60	106/65	108/66	106/64	106/78
LABORATORY DATA							
ESR (mm/hr) [M:0-20 / F:0-30]		17	11	30	16	20	6
CRP (mg/L) [0-10]		3	3	6	4	11	1.7
WBC (thou/uL) [4-11]	10.2	10.8	7.1	12.1	12.7	4.1	8
HGB (g/dL) [M:14-16/F:12-16]	13.6	11.8	12.5	13	13	13	13.3
HCT (%) [M:42-50/F:37-44]	40.9	36	37	39	42	40	41
PLATELETS (thou/uL) [150-400]	307	414	328	348	387	237	311
ALBUMIN (g/dL) [3.5-5.0]	3.7	3.7	4.4	4.2	4.5	4.3	4.7
ALK PHOS (U/L) [40-100]	108	88	87	80	88	87	84
SGOT (U/L) [1-40]	26	14	14	30	19	22	49
CREATININE (mg/dL) [0.7-1.5]	0.7	0.7	0.8	0.8	0.7	0.7	
DRUGS (C=Change from Baseline; Q=QW=Quadrant; B=Biweekly; P=Peroral; D=Dose; PRN=As Needed; T=Time; L=Level; K=Keg)							
Prednisone	N-10 QD	C-5 BID	T-5 QD	5 QD	C-4 QD	4 QD	4 QD
Methotrexate	N-15 QW	15 QW	15 QW	C-20 QW	20 QW	20 QW	20 QW
Etanercept		N-25 BIW	25 BIW	25 BIW	25 BIW	25 BIW	50 QW
Folic Acid	N-1 QD	1 QD	1 QD	1 QD	1 QD	1 QD	1 QD
Ibuprofen	C-200 PRN	200 PRN	200 PRN	200 PRN	200 PRN	200 PRN	200 PRN
Hydrocodone-APAP 10/325	C-1 Q6H	1 Q6H	1 Q6H	D-1 Q6H			
% Improvement FN		66%	66%	73%	64%	66%	100%
% Improvement PS		28%	77%	76%	63%	81%	90%
% Improvement GL		38%	69%	74%	82%	97%	91%

Fig. 3. A patient seen initially on 5 March 2003, who developed rheumatoid arthritis in a post-partum period with a 3-month old baby, who she could not care for because of functional disability. All MCP, PIP joints, wrists and knees were tender and swollen. Her initial scores on 5 March 2003 were 6.3 for functional distress, 7.8 for pain, and 9.1 for global status. She was initially begun on prednisone 10 mg/day and methotrexate 15 mg/week. One week later she showed substantial improvement with her functional status score declining to 2.0, pain to 5.6, and global status to 5.6. However, it was apparent that she had very aggressive disease, and was begun on etanercept. Over the next 8 months clinical improvement is documented, with declines in the patient's scores for functional status to 0.67, pain to 0.7, global status to 0.3, as well as other scores. Two years later she continues in near-remission status, albeit with low dose methotrexate, low-dose prednisone, and etanercept.

(12) or death (6, 13-19). If a laboratory test for, say, a T-cell marker or cytokine were available with the robust value of the HAQ or MHAQ in the prognosis and monitoring of rheumatoid arthritis, it would surely be incorporated into standard rheumatology care by all rheumatologists.

One important concern that has not received much emphasis involves the differences between questionnaires designed for clinical research versus those intended for clinical care (Table III). The experience of most rheumatologists with patient questionnaires has involved lengthy questionnaires in clinical trials and other clinical research, and many rheumatologists have limited experience with short questionnaires adapted for standard clinical care. A patient questionnaire designed for standard clinical care may differ considerably from one designed for clinical research (Table III), much as a test for rheumatoid factor or C-reactive protein developed in a research laboratory may be adapted in a simplified form for standard care.

In clinical research, the primary goal is to acquire data that is as complete as might be needed to address the study questions. Patients and clinicians therefore recognize and accept the inconveniences of lengthy questionnaires. The scoring may be quite complex and the data are not interpreted at the clinical site; rather they are sent to a data center for entry into a large common database (Table III). The clinician does not review the data; indeed, in clinical trials the clinician is generally expected not to review the questionnaire data at all. By contrast, a questionnaire for standard care must be feasible and practical (Table III). Requirements for such a questionnaire include (Table IV) that it can be completed by a patient within 5-10 minutes, scanned ("eyeballed") by a health professional for a clinical overview in less than 5 seconds, and scored by a health professional within 20-30 seconds, and is amenable to entry onto a flow sheet to compare with previous visits within 30 seconds. Further, a questionnaire for standard patient care must be clinically applicable to patients with all diagnoses (24, 34), and provide

time-saving information to the physician by enhancing a patient's capacity to describe concerns in the limited time allotted for a clinical encounter. The MDHAQ meets these requirements.

Use of patient questionnaires in standard care

A very simple system has been implemented effectively over the last 20 years, which can assure completion of a questionnaire by almost every patient at every visit (35) (Table IV). When the patient registers for the visit, the receptionist asks him or her to complete a questionnaire – provided on a clipboard together with a soft pencil or felt-tip pen – while waiting to see the physician. The questionnaire should be presented as an important component of medical care, contributing to provide data regarding functional status, pain, global status, fatigue, and psychological status that cannot be obtained in any other way. A cheerful and enthusiastic manner is important – the patient loses interest if the staff projects a general disdain of questionnaires.

The questionnaire is completed by the patient before being called into an examining room. Most patients wait at least 5-10 minutes before seeing a rheumatologist. The questionnaire helps the patient to focus on problems and summarize the overall evaluation. Most patients do not need help from a health care professional, although about 20% of patients to ask for help from a family member or health professional to complete the questionnaire, which is willingly provided.

The questionnaire may be reviewed with a nurse or another member of the office staff, when the weight or blood pressure are checked, or when the patient is placed in an examination room. This review is not necessary, but may include the identification and completion of missing data, medications, patient inquiries, and scoring of the questionnaire scales, as described below.

The questionnaire should be scanned briefly by the physician to review the patient's clinical status. Patients have commented that they have felt unhappy after completing questionnaires in physician's offices if there was no evidence

that the information was reviewed by a health professional.

Scoring of the MDHAQ

Another relatively neglected matter involves the scoring of patient questionnaires in standard clinical care. Of course, it is possible to recognize the extent of functional disability and pain without a need for formal scoring, just as a physician can recognize a fever or tachycardia without formally measuring the patient's temperature or pulse. However, formal quantitative information enhances the information needed for care, and formal scores for physical function, pain and global status may also improve care.

The MDHAQ has scoring templates that allow a health professional to formerly depict a quantitative number for each scale within 15 seconds, directly on the questionnaire. The 10 activities of daily living can be quickly totaled without a calculator, computer or any other device (other than a human brain); the total is divided by 10 to reach a 0-3 score, with scores comparable to the HAQ. One can also divide the score by 3 to derive a 0-10 score, which will then be similar to scores for pain and global status. Also included is a logarithmic scale, which has been found to be more sensitive than an arithmetic scale to distinguish active from control treatment in certain clinical trials (Koch and Pincus, unpublished data).

The visual analog scales for pain and global status as well as fatigue, are presented as 21 circles rather than the traditional 10 cm line, to facilitate scoring without a ruler. One version of the MDHAQ includes an arithmetic scale of 0-10 below the circles, and a logarithmic scale above the circles – the rheumatologist may choose either format. The logarithmic scale has a range of 0-3 for physical function, 0-3 for pain and 0-4 for global status, for a total range of 0-10. This score has been termed the "rheumatology assessment patient index data" (RAPID), and represents an index of patient scores with a range of 0-10 that provides an absolute score which is as sensitive as the disease activity score (DAS) in distin-

guishing active from control treatment in certain clinical trials (Koch and Pincus, unpublished data). Although the format of labeling each circle may appear quite "busy," the inclusion of only a few numbers along the visual analog scale tends to lead patients to cluster responses primarily in labeled circles. Therefore, it appears best to label each circle or none at all, although if there are no labels more time is required to score the scales. Formal scores can be entered into flowsheets as illustrated below.

Management of MDHAQ data using a clinical flowsheet

Many options exist for the management of questionnaire data, ranging from simply scanning ("eyeballing") the questionnaire to assess patient status, to formally scoring it, to keeping a flowsheet (Table IV, Fig. 3). A flowsheet may be used to facilitate the recognition of possible changes in functional capacity, pain, fatigue, or psychological status from previous visits. A flowsheet appears very useful in the management of chronic disease in general, and many clinicians record medications, laboratory tests, joint examination findings, and other data on a flowsheet. The one-page flowsheet, which includes patient questionnaire scores, laboratory data and drugs, is very useful in standard clinical care.

One example of use of the flowsheet is presented in Figure 3. This illustrates a patient who was seen initially on 5 March 2003, who developed rheumatoid arthritis in a postpartum period with a 3-month old baby, which she could not take care of because of her functional disability. All MCP, PIP joints, wrists and knees were tender and swollen. Her initial scores on 5 March 2003, were 6.3 for functional distress 7.8 for pain, and 9.1 for global status. She was initially begun on prednisone 10 mg/day and methotrexate 15 mg/week. One week later she showed substantial improvement with her functional status score declining to 2.0, pain to 5.6, and global status to 5.6. However, it was apparent that she had very aggressive disease, and was begun on etanercept. Over the next 8 months, her

clinical improvement is documented with declines of her scores for functional status to 0.67, pain to 0.7, and global status to 0.3, as well as other scores. Two years later she continues in near-remission status, continuing to take low-dose methotrexate, low-dose prednisone, and etanercept.

Some principles of questionnaire use in standard care

Clinicians have expressed concerns that questionnaires may interfere with office routine and time management, with consequent increased costs and time. However, data from a brief questionnaire designed for standard care can provide an important saving of time (after a brief "learning curve," as is required with any new activity). Information concerning functional status, pain, psychological distress, fatigue, global status, review of systems, and medications are then known to the physician at the start of the visit, rather than when acquiring basic data from the patient. This facilitates a focus on matters that require attention, leading to more efficient and effective clinical care. The questionnaire contributes to clinical judgement, but all decisions must be made by the clinician.

Many specialized questionnaires such as the Short Form 36 (SF36) and disease-specific questionnaires for ankylosing spondylitis (36), fibromyalgia (37) and osteoarthritis (38), are available for different types of clinical research studies in which their use is unquestioned. However, it is generally not feasible to use additional questionnaires in standard clinical care. The MDHAQ can be useful for patients with any rheumatic disease (24, 34), all of whom may experience physical disability, pain, fatigue and psychological distress.

Many clinicians have suggested that it would be desirable to select patients to complete questionnaires on the basis of specific diagnoses, the interval since the last questionnaire, the beginning of new therapy etc. However, schemes that include only certain patients generally fail in standard clinical practice. It is considerably easier for the office staff to hand a questionnaire to each

patient at each visit. Collection of routine data from consecutive patients at each visit may be supplemented by additional data collection at intervals in certain subsets of patients, if desired. For example, all patients of one of the authors (TP) are invited to complete questionnaires every 6 months for the US National Database organized by Dr. Wolfe (39).

Concluding thoughts

The authors believe that rheumatologists enhance the lives of their patients as much as any physician, but improvements in status generally are not documented quantitatively. The absence of effective documentation adds a significant problem to people with rheumatic diseases, as the provision of many services are limited in the current climate of cost containment. Documentation of the effectiveness of rheumatology care is accomplished most cost-effectively through the routine distribution of patient self-report questionnaires in standard care (35).

There is a general viewpoint that "science" involves only high technology and laboratory activities. However, research over the last 25 years has documented that clinical rheumatology can be a most effective quantitative "science." A self-report questionnaire may be the only measure to recognize significant disease progression over 5-10 years, while joint tenderness, erythrocyte sedimentation rate (ESR), global severity, and morning stiffness may be unchanged or improved over 5-10 years (40). These observations suggest that self-report questionnaires (and radiographs) may be the optimal clinical measures through which rheumatologists might document improvement or prevention of disease progression over 5-10 years.

When data are not collected on any given day, information is not available to compare to previous and future visits or to document the potential value of patient care. It may be regarded as an intellectual responsibility of rheumatology health professionals to implement clinical rheumatology as a quantitative science, which is best accomplished using patient questionnaires.

This practice will help to advance rheumatology as a specialty to improve the lives of millions of people with rheumatic diseases.

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