

Research article

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Percentile benchmarks in patients with rheumatoid arthritis: Health Assessment Questionnaire as a quality indicator (QI)Eswar Krishnan^{1,2}, Peter Tugwell³ and James F Fries²¹Clinical Research Center of Reading, West Reading, PA, USA²Division of Immunology and Rheumatology, Department of Medicine, Stanford University School of Medicine, Stanford, CA, USA³University of Ottawa, Ottawa, CanadaCorresponding author: Eswar Krishnan, Eswar_krishnan@hotmail.com

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Arthritis Res Ther 2004, **6**:R505-R513 (DOI 10.1186/ar1220)© 2004 Krishnan *et al.*; licensee BioMed Central Ltd. This is an Open Access article: verbatim copying and redistribution of this article are permitted in all media for any purpose, provided this notice is preserved along with the article's original URL.**Abstract**

Physicians are in need of a simple objective, standardized tool to compare their patients with rheumatoid arthritis, as a group and individually, with national standards. The Disability Index of the Health Assessment Questionnaire (HAQ-DI) is a simple, robust tool that can fulfill these needs. However, use of this tool as a quality indicator (QI) is hampered by the unavailability of national reference values or benchmarks based on large, multicentric, heterogeneous longitudinal patient cohorts. We utilized the 20-year longitudinal prospective data from 11 data banks of Arthritis Rheumatism and Aging Medical Information to calculate reference values for HAQ-DI. Overall, 6436 patients with rheumatoid arthritis were longitudinally followed for 32,324 person-years over the 20 years from 1981 to 2000. There were

64,647 HAQ-DI measurements, with an average of 19 measurements per person. Overall, 75% of patients were women and 89% were Caucasian; the median baseline age was 58.4 years and the median baseline HAQ-DI was 1.13. Few patients were treated with biologics. The HAQ-DI values had a Gaussian distribution except for the approximately 10% of observations showing no disability. Percentile benchmarks allow disability outcomes to be compared and contrasted between different patient populations. Reference values for the HAQ-DI, presented here numerically and graphically, can be used in clinical practice as a QI measure to track functional disability outcomes and to measure response to therapy, and by arthritis patients in self-management programs.

Keywords: benchmark, disability, Health Assessment Questionnaire, percentile, rheumatoid arthritis**Introduction**

Quality indicators (QIs) are a set of measures helpful in assessing the quality of medical care, using data that can be easily obtained in day-to-day practice of medicine. Functional disability is an outcome in rheumatoid arthritis that is modifiable with good medical care and is therefore an important QI. With the availability of effective treatment strategies, there is increasing recognition of the value of performing audits involving quality assessment for rheumatoid arthritis patients, so that they are appropriately stratified for risk and are treated using optimal combinations of medications and other interventions. Furthermore, many third-party payers, such as Medicare in the USA, demand documentation of objective treatment benefit among those receiving expensive medications such as infliximab (<http://www.hgsa.com/professionals/policy/i20d.html>, accessed 9 March 2004).

Since clinicians can often spend less than 15 minutes per patient with rheumatoid arthritis per month, there is little time to collect all the traditional QIs such as joint counts. Although the Disability Index of the Health Assessment Questionnaire (HAQ-DI) or similar instruments have been recommended as useful tools that are as robust as composite measures [1,2], the HAQ-DI has not gained popularity, for various reasons. Firstly, many clinicians lack an understanding of the significance of its numerical value. In a clinical setting, the questionnaire gives a single measurement of HAQ-DI – a numerical value that is of little use to the clinician or the patient unless it is placed in the context of the universe of rheumatoid patients. Secondly, the HAQ-DI has been used most extensively in clinical trials and other studies to measure change in functional capacity rather than status of functional capacity. That is, the discussion has focused on average *change* in the mean HAQ-DI within individuals and groups [3] and not on the clinical

significance of a change in the numerical value of the HAQ-DI in a real-world situation.

The underlying problem for both of these issues is the absence of standards or benchmarks for the HAQ-DI. As an example, there are benchmarks for height and weight progression with age in children (commonly known as growth charts). Typically, such a chart would include the reference median and the 10th, 25th, 75th, and 90th percentiles of height and weight as a function of age, with separate charts for boys and girls. Children being followed up over time have their height and weight taken and plotted on the growth charts. This provides visual information on how the child is doing compared with others, as well as how the child's height and weight have been increasing over time. If the growth curve flattens out, that is an early indicator of a potential problem and triggers further evaluation. For tracking disability over time, it would be very useful for clinicians to have similar 'disability growth curves'. It would help to place individual disability index measurements in the context of a wider population with rheumatoid arthritis as well as to track disability over time. In addition, the group mean and median HAQ-DI will help educate the clinician about how well his/her patients are doing compared with those outside the practice and will serve as an important QI for rheumatoid arthritis care.

Development of such progress charts of disability would ideally require longitudinal data from a large, nationally representative sample of patients with rheumatoid arthritis. As such data are not available in the USA, the next-best data set would be drawn from multiple centers across the country involving a large number of HAQ disability measurements and involving all stages of disease and a demographically broad sample. Prospective rather than cross-sectional measurements have important advantages, in guarding against cohort bias (differences between age groups in a cross-sectional study that are due to generational differences rather than to age per se). The longitudinal data sets from the Arthritis, Rheumatism and Aging Medical Information System (ARAMIS) cohorts of patients with rheumatoid arthritis fulfill these requirements.

Materials and methods

Patients

The subjects for the present study were derived from the Arthritis, Rheumatism and Aging Medical Information System, a US national arthritis data resource based at Stanford University. This system includes multiple data-bank centers in the United States and Canada and follows about 17,000 patients with specific arthritis conditions as well as normal populations of aging seniors [4,5]. As a part of this program, 6436 patients with rheumatoid arthritis have been enrolled and their functional disability has been regularly assessed with mailed HAQs. The disability data used in this

report include those collected from 11 diverse data banks in 8 centers across the United States and Canada. These centers served consecutive patients from two private rheumatology practices, two geographically defined communities, and four university clinics. Patients were entered into the cohort by their clinicians in the respective centers or by direct advertising in particular centers [6]. All patients had a diagnosis of rheumatoid arthritis as defined by the 1958 American Rheumatism Association [7] or the 1987 American College of Rheumatology classification criteria [8], depending on time of enrollment.

Instrument

After giving informed consent, each patient completes a full HAQ at the time of entering the study and every six months thereafter. Consecutive patients enrolled through the year 2000 were followed with semiannual Health Assessment Questionnaires that included the HAQ-DI consistently from its introduction in 1980 [9]. The Health Assessment Questionnaire (HAQ) is a widely used and validated tool to quantify self-reported functional disability in rheumatoid arthritis [10]. The questionnaire is usually self-administered but may also be completed face-to-face in a clinical setting or in a telephone interview format by trained outcome assessors. Eight functional categories are assessed specifically by the HAQ: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and common daily activities. For each of these domains, patients report the amount of difficulty they have had in performing two to three specific activities in the previous week. Patients usually find items in the HAQ easy to understand and the questions are entirely self-explanatory. If a question within a domain does not apply (e.g. if an individual doesn't shampoo the hair or take tub baths), then the item is left blank. There are four possible responses and corresponding scores for each question: without any difficulty (score = 0), with some difficulty (1), with much difficulty (2), and unable to do (3). The highest score reported by the patient for any component question in each domain determines the score for that domain. A complete copy of the instrument and coding rules can be downloaded from <http://aramis.stanford.edu>. The data collection and quality control protocols have been described in detail [4,5,10].

Scoring and interpreting the HAQ-DI

By convention, the Disability Index is expressed on a scale from 0–3 units, representing the mean of the eight domain scores. A HAQ-DI of 0 indicates no functional disability, while a Disability Index of 3 indicates severe functional disability. A healthy individual is expected to have a HAQ-DI of 0. While there is no official consensus as to what constitutes mild, moderate, or severe disability, a score of ≤ 1.0 is regarded as indicating mild disability, and a score ≥ 2.0 is considered to indicate severe disability. The Disability Index values in between can be considered moderate.

Statistics

The 10th, 25th, 50th, 75th, and 90th percentiles were used as reasonable benchmarks for the computation of data for various strata of age, sex, and disease duration. For plotting the smoothed growth curves, we used cubic splines. For calculating the 95% confidence bands, we fitted fractional polynomial regression. In this method, the disability is regressed as a function of disease duration modified to various powers and the best fit achieved by an iterative process.

Median values of HAQ-DI across groups were compared using the nonparametric median test [11]. In each test, the hypothesis K-samples were drawn from the population of the same median. The test χ^2 statistic was calculated with and without a continuity correction (reference median). Correlation between age, disease duration, and HAQ-DI was calculated using Pearson's correlation coefficient (r).

Comparison with nondiseased population

To better appreciate the differences in the distribution of the HAQ-DI in patients with rheumatoid arthritis compared with that in nondiseased populations and to benchmark disability in these populations, we used data from two other longitudinal studies going on in our center: the University of Pennsylvania Alumni study [12] and Stanford University Staff used as controls in the Stanford Runners study [13]. The University of Pennsylvania Alumni study comprised 23,414 Disability Index measurements in 2843 alumni (77% men), and there were 587 controls (56% men) in the runners study, observed through 5751 Disability Index measurements. Age-specific median curves from these subjects are presented alongside those from patients with

rheumatoid arthritis as illustrations and not as scientific comparisons, since the population denominator for these data is much different from that of patients with rheumatoid arthritis.

Results

Baseline characteristics

Table 1 gives the baseline descriptive statistics of our population of patients. Overall, there were 6436 patients (4768 [74%] of them women), and there were 64,647 observations. The median age was 58.5 years, the median disease duration at baseline was 8.0 years, and the median baseline HAQ-DI was 1.13. The mean (standard deviation) baseline HAQ-DI was 1.18 (0.79) units. The median test showed that the women studied were younger ($P < 0.001$), more disabled ($P < 0.001$), and less educated ($P = 0.038$) than the men. The overall attrition rate of the cohort was 3.8 per 100 living patients per annum [14].

Follow-up data

The number of observations per patient ranged from 1 to 38 (median 7, interquartile range 3–15). The median time between successive questionnaires was 184 days (interquartile range 172–198 days). Overall, in about 9.9% of all observations the HAQ-DI was recorded as 0. Figure 1 shows the distributional plot of all 64,647 HAQ-DI measurements. Aside from a spike representing about 10% of observations for which the HAQ-DI = 0 ($n = 1423$, $N = 6307$), the distribution of the Disability Index values in the study population was Gaussian. The mean (standard deviation) overall HAQ-DI was 1.27 (0.82). Interestingly, 249 patients (4%) had no disability at all revealed in any of their observations.

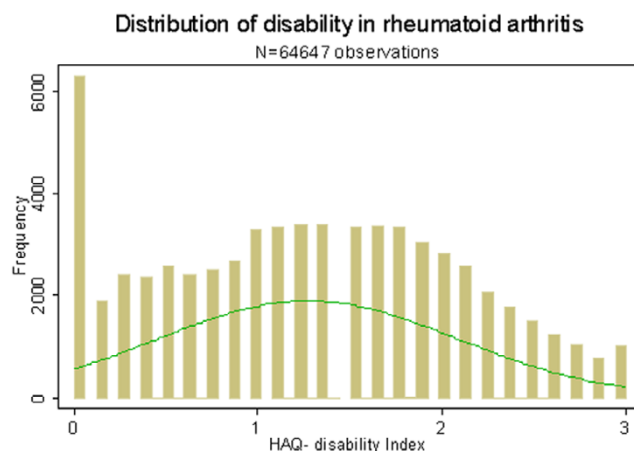
Table 1

Baseline characteristics of 6436 patients with rheumatoid arthritis observed for 32,324 person-years with semiannual Health Assessment Questionnaires

Patients	Age (years)	Level of education (years)	Disease duration (years)	Number of HAQ-DI measurements	HAQ-DI	Patients receiving methotrexate	Patients receiving prednisone
Women						21.2%	23.7%
Median	57.3	12.0	8.1	7	1.25		
IQR	46.8–67.0	12.0–14.0	2.4–16.7	4–14	0.63–1.88		
Men						18.5%	23.9%
Median	61.0	12.0	7.4	7	1.00		
IQR	51.4–69.0	11.0–14.0	2.0–16.6	3–12	0.25–1.50		
All patients						20.5%	23.8%
Median	58.5	12.0	8.0	7	1.13		
IQR	48.0–67.4	12.0–14.0	2.3–16.7	4–13	0.5–1.8		

HAQ-DI, Health Assessment Questionnaire Disability Index (range 0–3); IQR, interquartile range.

Figure 1



Distribution of scores on the Health Assessment Questionnaire (HAQ) Disability Index in 6436 patients (64,647 observations) with rheumatoid arthritis.

Percentiles of HAQ-DI values are reported, according to patient's age and duration of disease, for women (Table 2) and men (Table 3). HAQ-DI increased with age in both men and women. Women had slightly higher levels of functional disability than men. The HAQ-DI was only modestly correlated with disease (correlation coefficient 0.28; 95% confidence interval 0.28–0.29). The corresponding correlation coefficients for men and women were 0.30 (0.29–0.32) and 0.28 (0.27–0.29), respectively.

The curves showing overall duration versus HAQ-DI, with 95% confidence bands (fitted using fractional polynomial modification of ordinary least squares regression), are shown in Fig. 2. Figures 3 and 4 show the percentile curves of HAQ-DI as a function of disease duration in strata of age and sex.

In order to visualize the relation between age and disability, we plotted the age-specific median HAQ-DI (Fig. 5). Age-related increases were less marked than duration-related increases. The correlation coefficients for age and HAQ-DI among patients with rheumatoid arthritis were 0.20 (0.18–0.22) for men and 0.17 (0.16–0.18) for women. In comparison with the University of Pennsylvania Alumni study and population controls used in the Stanford Runners study, the percentile values were substantially higher in younger age groups. However, as age advanced, the disability gap between the rheumatoid arthritis and comparator populations narrowed. Detailed percentile curves for each age and for subgroups according to sex are given in the Additional files (Figs 6–18).

Discussion

Disability outcomes in rheumatoid arthritis have indeed improved in the past 20 years, in parallel with the availability of better treatments [15,16], even though a number of patients continue to suffer substantial functional limitations [15,16]. The idea of benchmarking functional disability among populations using the Health Assessment Questionnaire is not new. To our knowledge, the idea of benchmarking using the HAQ-DI in clinical practice was first put forward by Marissa Lassere and her colleagues in 1995 [17]. The main limitation in their report was small sample size and the cross-sectional nature of the analysis. Subsequently, Wolfe and colleagues published benchmarks on the HAQ-DI in addition to other variables such as tender and swollen joint counts [18]. While their sample size was much larger than that of Lassere and colleagues, the data presented were cross-sectional in nature. The median (IQR) HAQ-DI for that group of patients with rheumatoid arthritis was 0.6 (0.2–1.3). In none of these reports were disease-duration-specific values or curves provided, making it difficult to use their suggested benchmarks in a longitudinal fashion or to compare them directly with our results. In this report, we have carried forward the idea of disability as a QI among patients with rheumatoid arthritis, while attempting to overcome some of the limitations of the previous work.

Strengths

The data we have presented are based on a large number of disability measurements drawn from a wide variety of clinical settings including the community, university settings, and private practices, prospectively collected, and encompassing a long period. We have presented disability reference values for all strata of disease duration and age groups and for both sexes. Our results are consistent with the previously published data. We believe that our benchmarks represent an advance over the existing data and propose that they be considered for day-to-day use in clinical practice.

How to use the data presented

Disability 'growth curves'

We have provided percentile values as well as a percentile growth curve similar to growth curves that can be easily visualized and interpreted by physicians who are already familiar with the concept of growth charts. These data also help the clinician to place his or her individual patient in comparison with the nationally available data. It also enables practices to compare the functional disability of their own patients with the national cohorts and to track disability through time. Nurses and allied health professionals can use this to direct special attention to those who are not doing well in follow-up. Furthermore, patients themselves are likely to find the percentile charts an important tool for

Table 2

Percentile values of semiannual scores on the Health Assessment Questionnaire Disability Index found for 4768 women with rheumatoid arthritis observed for for 50,047 person-years

Age group (years)	Percentile	Disease duration (years)								
		<2	2–3.9	4–5.9	6–7.9	10–11.9	12–13.9	14–15.9	16–17.9	18–19.9
<50	10	0	0	0	0	0	0	0.125	0	0
	25	0.25	0.25	0.375	0.375	0.5	0.5	0.625	0.5	0.625
	50	0.875	0.75	0.875	0.875	1.125	1.125	1.125	1.25	1.25
	75	1.375	1.375	1.375	1.5	1.625	1.625	1.625	1.75	1.875
	90	1.75	1.75	1.875	1.875	2	2	2.125	2.125	2.25
	95	2.125	2.125	2.125	2.25	2.25	2.25	2.375	2.375	2.5
50–59.9	10	0	0	0.125	0.25	0.125	0.125	0	0	0.125
	25	0.375	0.375	0.625	0.625	0.625	0.5	0.5	0.5	0.75
	50	1	1	1.125	1.25	1.125	1.1875	1.125	1.25	1.375
	75	1.5	1.5	1.75	1.75	1.75	1.75	1.75	1.875	2
	90	1.875	2	2.125	2.25	2.25	2.25	2.125	2.25	2.375
	95	2.125	2.125	2.375	2.375	2.375	2.375	2.5	2.5	2.625
60–69.9	10	0	0	0	0.25	0.125	0.25	0.25	0.375	0.375
	25	0.25	0.25	0.5	0.75	0.75	0.75	0.75	0.75	1
	50	0.75	0.875	1.125	1.25	1.375	1.5	1.5	1.5	1.625
	75	1.25	1.5	1.75	1.875	2	2	2	2	2.125
	90	1.875	2	2.125	2.25	2.375	2.375	2.5	2.375	2.625
	95	2.125	2.25	2.375	2.5	2.5	2.625	2.625	2.625	2.875
≥ 70	10	0.125	0.125	0.125	0.125	0.25	0.375	0.375	0.375	0.625
	25	0.5	0.5	0.5	0.625	0.875	1	1	1.125	1.25
	50	1	1.125	1.125	1.25	1.5	1.625	1.75	1.75	1.875
	75	1.625	1.625	1.75	1.875	2	2.125	2.25	2.375	2.375
	90	2.125	2.125	2.375	2.375	2.375	2.5	2.625	2.75	2.75
	95	2.375	2.5	2.625	2.625	2.625	2.75	2.75	2.875	2.875

self-management. Overall, our study will be helpful in establishing useful benchmarks of QI in North America.

Z-scores for disability

Another way to use the data we have presented would be to calculate Z-scores for the HAQ-DI similar to the method of standardizing bone mineral density. The Z-score for an item indicates how far and in what direction that item deviates from the mean of its distribution, expressed in units of the distribution's standard deviation. The mathematics of the Z-score transformation is such that if every item in a distribution is converted to its Z-score, the transformed scores will have a mean of 0 and a standard deviation of 1. Z-scores are sometimes called 'standard scores'. The Z-

score transformation is especially useful when there is a need to compare the relative standings of items from distributions with different means and/or different standard deviation. The Z-scores for patients with rheumatoid arthritis can be calculated by using an age- and sex-matched distribution of the HAQ-DI. Individual Z-scores can then be used to assess the relative progress of individual patients and to establish reasonable therapeutic end points. Caution must be exercised in doing so, because these metrics assume a Gaussian distribution of HAQ-DI (i.e. a bell curve), an assumption that may not be accurate in all situations.

Table 3

Percentile values of semiannual scores on the Health Assessment Questionnaire Disability Index (HAQ-DI) found for 1668 men with rheumatoid arthritis observed for 14,600 person-years

Age group (years)	Percentile	Disease duration (years)								
		<2	2–3.9	4–5.9	6–7.9	10–11.9	12–13.9	14–15.9	16–17.9	18–19.9
<50	10	0	0	0	0	0	0	0	0	0
	25	0.375	0.375	0.5	0.375	0.375	0.25	0.375	0.375	0.625
	50	0.75	0.8125	1	1	0.875	0.75	0.875	0.875	0.9375
	75	1.125	1.375	1.5	1.375	1.5	1.5	1.625	1.625	1.5
	90	1.75	2	2	2	2	2	2	1.875	1.875
	95	2	2.375	2.125	2.25	2.375	2.25	2.125	2.25	2
50–59.9	10	0	0	0	0	0	0	0	0	0
	25	0.5	0.4375	0.5	0.625	0.625	0.75	0.6875	0.875	0.75
	50	1	0.875	1	1	1.125	1.125	1.125	1.375	1.375
	75	1.375	1.375	1.5	1.5	1.625	1.75	1.625	2.125	1.75
	90	1.75	1.75	2	1.875	2	2.125	2.25	2.375	2.25
	95	2	2	2.25	2.125	2.5	2.5	2.5	2.625	2.5
60–69.9	10	0	0	0	0	0.125	0.125	0.125	0.125	0
	25	0.375	0.4285	0.625	0.625	0.75	0.625	0.75	0.75	0.75
	50	0.875	0.875	1.125	1.25	1.125	1.125	1.25	1.25	1.375
	75	1.25	1.375	1.625	1.625	1.625	1.75	1.75	1.75	1.9375
	90	1.5	1.75	2	2.125	2	2.125	2.125	2.25	2.375
	95	1.75	2	2.25	2.375	2.25	2.375	2.5	2.5	2.5
≥ 70	10	0	0	0	0	0	0	0.125	0.125	0.25
	25	0.375	0.375	0.625	0.75	0.875	0.5	0.625	0.625	0.9375
	50	0.875	0.875	1	1.25	1.375	1.125	1.25	1.25	1.5
	75	1.25	1.25	1.375	1.625	1.75	1.625	1.875	1.875	2
	90	2	1.625	1.875	2.125	2.375	2.125	2.25	2.5	2.5
	95	2.125	2	2.125	2.375	2.5	2.25	2.5	2.625	2.75

Disability as a dichotomous entity

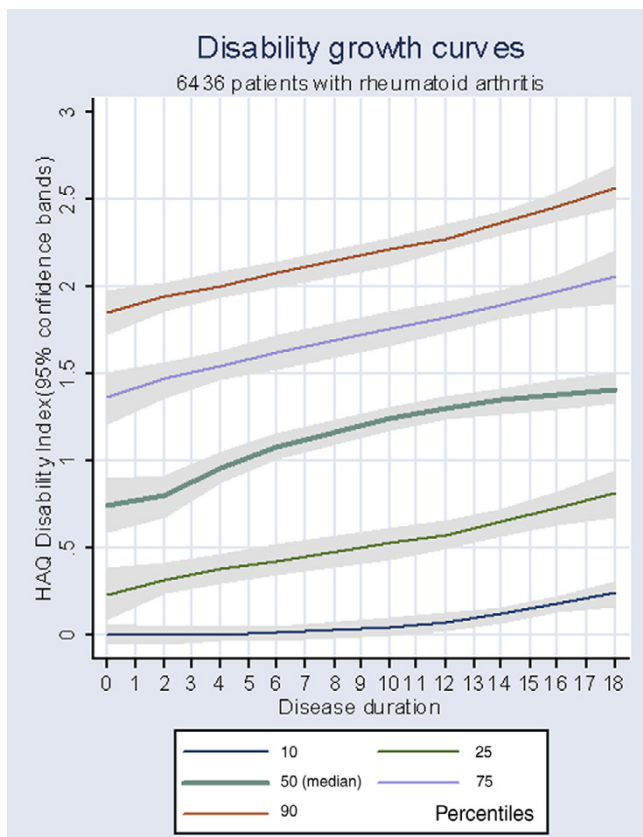
Yet another way to use our data would be to define disability as an (artificially) dichotomous entity, for example HAQ-DI ≥ 1 . Here the age- and sex-specific prevalence rates of disability in our population could be applied to the clinical samples to derive the expected number of disabled patients. The ratio of the observed to the expected number of patients with an HAQ-DI greater than a threshold value can serve as a standardized 'morbidity ratio' of that particular patient population. Using this method, Sokka and colleagues compared the HAQ-DIs of rheumatoid arthritis patients with those of the underlying general population in Finland and found an eightfold higher prevalence of disability among patients with rheumatoid arthritis [16]. One could

also potentially calculate and compare the costs and could cost utility measures such as disability-adjusted life years (DALYs) across populations. Benchmarks for the HAQ-DI in a general population are also available for such computations [19].

Using benchmarks in the office

There are several ways to apply the information we have provided, in both clinical practice and observational studies. We recommend that the choice of method be dictated by the nature of the data at hand and the application in question. The benchmarks we have discussed represent relative standards to be used for comparisons only. We certainly do not suggest that any particular value for HAQ-

Figure 2



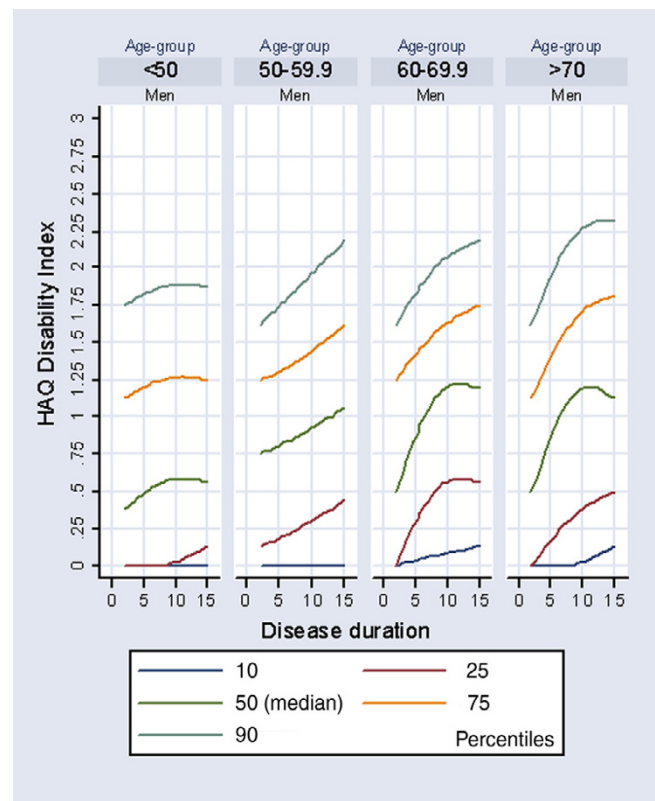
Percentile Health Assessment Questionnaire (HAQ) Disability Index scores plotted against disease duration for 6436 patients (64,647 observations) with rheumatoid arthritis, with 95% confidence band.

DI greater than 0 is 'normal' or desirable for an individual patient. In fact, an argument for using the absolute benchmark for functional disability – i.e. HAQ-DI > 0 – can be made, since the goal of treating an individual patient is to ameliorate disease activity and entirely prevent joint damage. However, even the most optimistic randomized, controlled trials of biologic agents indicate that such an expectation may not yet be realistic for most individuals. Until a remission-inducing agent is available, the use of an HAQ-DI = 0 as an absolute benchmark may not be practical in most clinical situations. Furthermore, the HAQ-DI is one of several yardsticks for measuring functional disability, and an HAQ-DI = 0 does not guarantee that a person is fully functional.

Minimum significant change

There are no studies that have answered the question: what is the clinically meaningful change in HAQ-DI in an average patient with rheumatoid arthritis and in a patient group in a rheumatology practice? The available literatures have been based on a posteriori analyses of data from randomized, controlled trials and small, qualitative research

Figure 3



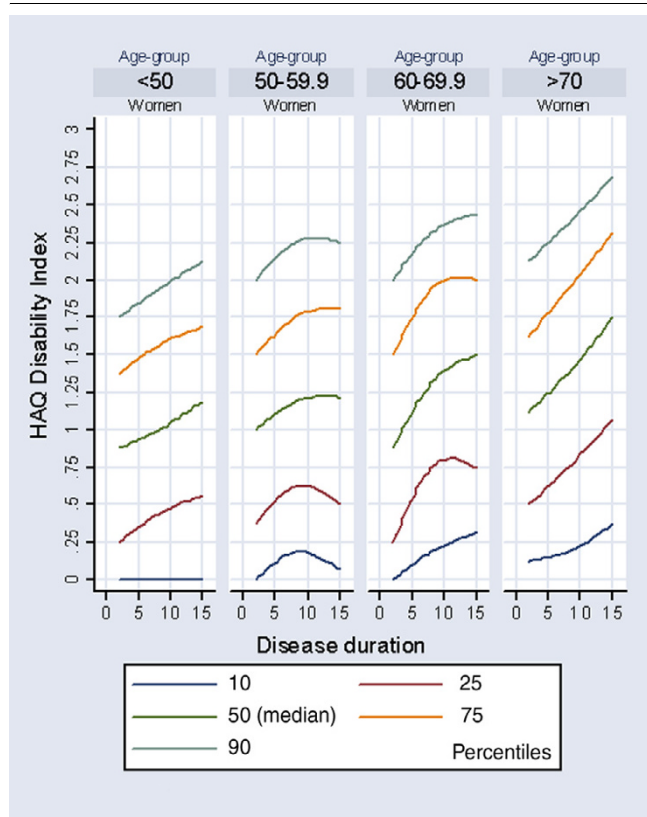
Percentile Health Assessment Questionnaire (HAQ) Disability Index scores plotted against disease duration for 1668 men with rheumatoid arthritis followed with 14,600 observations.

studies, and as such are not generalizable to real-world medicine [20,21]. Patients with rheumatoid arthritis are known to have day-to-day fluctuations of the HAQ-DI, and these have not been well studied. Thus, changes in the HAQ-DI within individual patients are sometimes difficult to distinguish from the underlying 'noise'. Our recommendations to overcome this noise are to use these benchmarks on individual patients with caution; to use an average of 2–3 consecutive HAQ-DI measurements rather than a single one; and to use other easily obtained measures, such as pain or physician's and patient's global assessments, in conjunction with the HAQ-DI.

Other significant findings in these data

In addition to providing points of reference for functional disability, some other observations regarding these data merit discussion. Rheumatoid arthritis is a disease whose activity varies with time. The HAQ-DI accurately tracks the fluctuating disease activity even in long-standing rheumatoid arthritis [22]. Our finding that about 10% of all observations had an HAQ-DI of 0 reflects this heterogeneity in disease activity within and across patients, and not a 'floor effect'.

Figure 4



Percentile Health Assessment Questionnaire (HAQ) Disability Index curves plotted for 4768 women with rheumatoid arthritis with 50,047 observations.

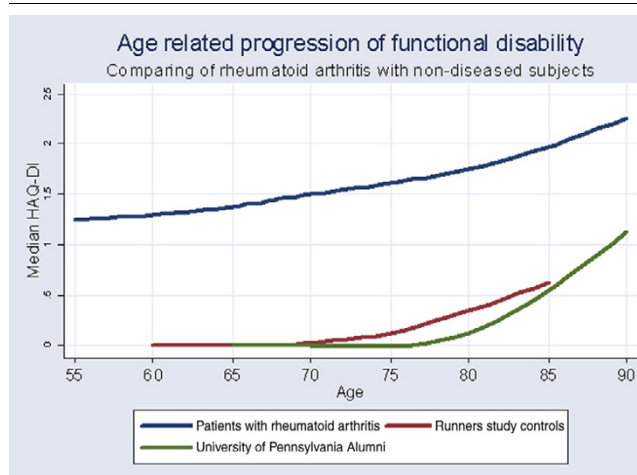
The concern in studying the progression of functional disability in longitudinal studies is the potential confounding by age-associated changes. Our observation that disease duration is a stronger correlate of the HAQ-DI than age suggests that as patients are followed up over time, an increase in disability is more from the disease process and the damage it inflicts than from age or age-related disability.

In a comparison with two diverse nondiseased populations, we found that there was little excess disability in older patients (>60 years) with rheumatoid arthritis. Among younger age groups, the excess disability was substantial. These findings are in line with those from a population-based study from Finland [16].

Limitations of the present study

Caveats apply to our results. Ideally, benchmarks should be obtained from a nationally representative sample of patients with rheumatoid arthritis: our patient group was not such a sample. However, as such a national sample is not available, the next-best data would be from large, longitudinal data banks with long follow-up, such as ours. We did have information on racial minorities, but these were few, dispa-

Figure 5



Age-related changes in median Health Assessment Questionnaire Disability Index (HAQ-DI) in 64,647 observations in 6436 patients with rheumatoid arthritis compared with 5751 observations in 587 nondiseased controls of the Stanford Runners study and 23,414 observations in 2843 subjects in the University of Pennsylvania Alumni study.

rate, scattered, and divided among different subsets. While large observational studies like ours tend to have the problem of volunteer bias, our attrition rates were very small.

Patients in this cohort have been treated with various disease-modifying antirheumatic drugs according to various regimens (differing in drug potency and dosage and in duration of treatment). Furthermore, none of our patients had been exposed to biologics, a class of medications whose effect on long-term functional disability can be expected to be substantial. In the future our benchmark curves may be replaced by population benchmarks of functional disability [19]; until such a time, our benchmarks will prove useful.

Conclusion

Short of full restoration of the premonitory functional capacity, the objective of treatment in rheumatoid arthritis should be to minimize disability. Comparison of patients and patient groups across different practice settings requires standards or benchmarks for disability outcomes, such as the HAQ-DI. We have provided age-specific, sex-specific, and disease-duration-specific percentile values for the HAQ-DI in numerical and graphical forms and this information can be used for following individual patients, as a QI, and as a tool for self-management. We also report that disease duration is a stronger correlate of functional disability, independent of the concomitant increase in age and age-related comorbidities.

Competing interests

None declared.

Additional files

The following Additional file is available online:

Additional file 1

Figures 6–18 An MS Word file containing figures showing progression of HAQ-DI with disease duration by age and sex categories. Generally a HAQ-DI ≤ 1.0 is considered to indicate mild disability and a HAQ-DI ≥ 2.0 is considered to indicate severe disability. Assessing whether a change in HAQ-DI is 'significant' or not should take into account other information such as pain and the patient's and physician's assessments of general wellbeing.

See <http://www.biomedcentral.com/content/supplementary/ar1220-S1.doc>

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References

- Wolfe F, Pincus T: **Data collection in the clinic.** *Rheum Dis Clin North Am* 1995, **21**:321-358.
- Wolfe F, Pincus T, Fries JF: **Usefulness of the HAQ in the clinic [letter].** *Ann Rheum Dis* 2001, **60**:811.
- Wiles NJ, Scott DG, Barrett EM, Merry P, Arie E, Gaffney K, Silman AJ, Symmons DP: **Benchmarking: the five year outcome of rheumatoid arthritis assessed using a pain score, the Health Assessment Questionnaire, and the Short Form-36 (SF-36) in a community and a clinic based sample.** *Ann Rheum Dis* 2001, **60**:956-961.
- Krishnan E, Fries JF: **Reduction in long-term functional disability in rheumatoid arthritis from 1977 to 1998: a longitudinal study of 3035 patients.** *Am J Med* 2003, **115**:371-376.
- Singh G: **Arthritis, Rheumatism and Aging Medical Information System Post-Marketing Surveillance Program.** *J Rheumatol* 2001, **28**:1174-1179.
- Krishnan E, Singh G, Tugwell P: **Long-term observational studies.** In *Targeted Therapies in Rheumatology* Edited by: Smolen J, Lipsky P. London: Martin Dunitz; 2003:667-677.
- Ropes MB, Bennett GA, Cobb S, Jacox R, Jessar RA: **1958 Revision of diagnostic criteria for rheumatoid arthritis.** *Bull Rheum Dis* 1958, **9**:175-176.
- Arnett FC, Edworthy SM, Bloch DA, McShane DJ, Fries JF, Cooper NS, Healey LA, Kaplan SR, Liang MH, Luthra HS, et al.: **The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis.** *Arthritis Rheum* 1988, **31**:315-324.
- Fries JF, Spitz P, Kraines RG, Holman HR: **Measurement of patient outcome in arthritis.** *Arthritis Rheum* 1980, **23**:137-145.
- Bruce B, Fries JF: **The Stanford Health Assessment Questionnaire: a review of its history, issues, progress, and documentation.** *J Rheumatol* 2003, **30**:167-178.
- Statacorp: **Median.** In *Stata Reference Manual* Volume 3. 7.0th edition. College Station, TX: Stata Press; 1999:424-431.
- Fries JF, Williams CA, Morfeld D: **Improvement in intergenerational health.** *Am J Public Health* 1992, **82**:109-112.
- Lane NE, Bloch DA, Jones HH, Marshall WH Jr, Wood PD, Fries JF: **Long-distance running, bone density, and osteoarthritis.** *JAMA* 1986, **255**:1147-1151.
- Krishnan E, Murtagh K, Bruce B, Cline D, Singh G, Fries J: **Attrition bias in rheumatoid arthritis databanks: A case study of 6346 patients in 11 databanks and 65,649 administrations of the Health Assessment Questionnaire.** *J Rheum* in press.
- Krishnan E, Fries JF: **Time trends in cumulative disability in rheumatoid arthritis 1980–1998 [abstract].** *Arthritis Rheum* 2002, **44**:378.
- Sokka T, Krishnan E, Hakkinen A, Hannonen P: **Functional disability in rheumatoid arthritis patients compared with a community population in Finland.** *Arthritis Rheum* 2003, **48**:59-63.
- Lassere M, Wells G, Tugwell P, Edmonds J: **Percentile curve reference charts of physical function: rheumatoid arthritis population.** *J Rheumatol* 1995, **22**:1241-1246.
- Wolfe F, Choi HK: **Benchmarking and the percentile assessment of RA: adding a new dimension to rheumatic disease measurement.** *Ann Rheum Dis* 2001, **60**:994-995.
- Krishnan E, Sokka T, Hakkinen A, Hubert H, Hannonen P: **Normative values for the Health Assessment Questionnaire disability index: benchmarking disability in the general population.** *Arthritis Rheum* 2004, **50**:953-960.
- Wells GA, Tugwell P, Kraag GR, Baker PR, Groh J, Redelmeier DA: **Minimum important difference between patients with rheumatoid arthritis: the patient's perspective.** *J Rheumatol* 1993, **20**:557-560.
- Kosinski M, Zhao SZ, Dedhiya S, Osterhaus JT, Ware JE Jr: **Determining minimally important changes in generic and disease-specific health-related quality of life questionnaires in clinical trials of rheumatoid arthritis.** *Arthritis Rheum* 2000, **43**:1478-1487.
- Drossaers-Bakker KW, de Buck M, van Zeben D, Zwinderman AH, Breedveld FC, Hazes JM: **Long-term course and outcome of functional capacity in rheumatoid arthritis: the effect of disease activity and radiologic damage over time.** *Arthritis Rheum* 1999, **42**:1854-1860.