

A Web-Compatible Instrument for Measuring Self-Reported Disease Activity in Arthritis

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ABSTRACT. *Objective.* To describe a Web-based computer health assessment survey for patients with rheumatoid arthritis (RA) and to evaluate the survey in comparison with current paper versions.

Methods. Utilizing data from a study on RA, we compared results from 43 patients attending a university-based clinic who were each given a paper and a demonstration computer version of a patient self-assessment questionnaire including multiple-choice questions from a multi-dimensional Health Assessment Questionnaire (HAQ); visual analog scales (VAS) for pain, fatigue, and global disease severity; and a tender and swollen joint count reporting tool. Patients were given optional followup surveys to determine their opinion of the computer program.

Results. High correlations (intraclass correlation coefficient > 0.9) were seen across methods for the 10-item HAQ and psychological distress scores and the VAS scores for pain and global disease severity. Moderate correlation was observed for the self-efficacy scores, the VAS scores for fatigue, and tender joint counts. The data also revealed a small shift in the mean scores for the HAQ and self-efficacy questions, with patients reporting slightly higher scores on the computer instrument. Overall, patient opinions of the uniquely designed joint count tool were good, with 71% of responding patients answering favorably.

Conclusion. Web-based computer versions of patient self-assessment surveys in RA are comparable to paper versions, and their use in clinics or over the Internet could dramatically facilitate the ability of physicians to monitor patients' health. (J Rheumatol 2004;31:223–8)

Key Indexing Terms:

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OUTCOMES

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PAIN SCALE
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Assessment of patients' responses to treatment in rheumatoid arthritis (RA) has traditionally used composite measurements, such as those in the American College of Rheumatology (ACR) 20% criteria or the Disease Activity Score. These multidimensional outcomes include physician observations, counts of tender and swollen joints, laboratory tests, and patient self-reported data of functional disability, pain and global disease severity. Recent work by Pincus, *et al* suggests that a combined index of patient self-report measures may be as informative as a full ACR 20%¹. This finding suggests that patient self-report measures may have increasing importance in the evaluation of outcomes of RA

treatments. We investigated the role of computer software in measurement of outcomes using self-report data.

There is a long history of using patient self-report measures to assess disease activity in RA. One well validated and important measure of functional ability is the multiple-choice Health Assessment Questionnaire (HAQ)². This survey asks the patient to rate his or her degree of difficulty in performing 24 activities of daily living (ADL). While the 24-item HAQ is the most commonly used, many modified or shortened versions of the HAQ have also been shown to be effective measures of disease activity^{3,4}. The HAQ is widely used in research and some authors have advocated its use for monitoring clinical disease activity^{5,6} and for therapeutic decision-making⁴. Other studies have shown that functional disability measurements also correlate with mortality rates in RA patients⁷ and work disability status⁸.

In addition to multiple-choice questions, visual analog scale (VAS) ratings of more subjective attributes are frequently administered with the HAQ. One of the first VAS measures used in RA was a pain scale, a much more sensitive measure than previously used descriptive scales⁹. Other outcome assessments in RA measured with a VAS include fatigue¹⁰ and global severity of disease.

Joint counts have been shown to correlate significantly with important outcomes in RA¹¹⁻¹³. Buchbinder, *et al* reported that tender joint counts are the most responsive to

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changes in disease activity, and can be used as a gold standard when determining the relative efficiency of other measures¹⁴. Self-administered joint counts also correlate significantly with other self-reported measures such as ratings of pain and impairment and the objective performance index¹⁵, and have demonstrated adequate reproducibility in clinical environments^{16,17}; however, there is some disagreement^{15,16,18} whether these reports are accurate enough to replace physician-reported counts in measures of outcomes such as the ACR 20%.

The HAQ, along with VAS and joint count instruments, is routinely administered in clinics and in clinical trials as a paper survey. Our study examines the feasibility of an alternative form — automated computerized structured interviews (ACASI). We first describe the Web-based ACASI instrument containing a modified, multidimensional HAQ (MDHAQ) that includes measures of psychological distress and self-efficacy, analog scales of pain, fatigue and global health, and counts of painful and swollen joints. We then tested a demonstration version of this software in a sample population of patients with RA. To assess the validity of the software, we compared computer and paper-based versions of these measures to find out whether mode of administration had important effects on certain types of measurements. Ultimately, we sought to assess the feasibility of using automated tools to collect data in clinics and monitor patients' symptoms over the Internet.

MATERIALS AND METHODS

We developed an ACASI program that asked patients, among other tasks, to complete a computerized version of the UCSD Center for Innovative Therapy Patient Self-Assessment Questionnaire, a multi-instrument questionnaire routinely administered to patients at this clinic in paper format. This questionnaire was based on the MDHAQ, which includes questions assessing psychological distress, and the Rheumatology Attitudes Index, which assesses the psychological construct of self-efficacy or helplessness¹⁹. In this questionnaire, patients answer 21 multiple-choice questions, which include 10 questions derived from those in the original HAQ, 3 questions on psychological distress, and 8 additional self-efficacy questions. The instrument also includes 3 VAS — one for pain, one for fatigue, and one for global health — and 2 homunculus-style figures on which patients can indicate painful or swollen joints.

Except for the joint count measures, the ACASI program exactly mirrors the paper survey. Rather than having patients indicate pain and swelling on 2 separate figures, patients are able to report painful and swollen joints on the same figure (Figure 1). The human figure itself was positioned to help orient patients better to left and right sides of the body — a top-down view of a person sitting in a chair looking at a computer (the position the user was thought likely to be in at the time of rating). The computer version also included 72 joints through the use of computer animation to enhance the detail of the figure, while the paper format was limited to 50 joints.

After completion of the survey, the program generates a summary page designed to be printed and attached to a patient's chart. The page contains summary scores of the questionnaires and displays affected joints. The ACASI program was implemented in Flash 5.0 (Macromedia, San Francisco, CA, USA). The software runs on all types of computer operating systems that support Flash and was designed to be deployed in both Web-based surveys and as a stand-alone application in patient clinics. A version

of the software used can be downloaded at <http://preferences.ucsd.edu/> at no cost to investigators.

To validate the computer instrument, we asked a convenience sample of 63 patients with RA attending a university-based rheumatology clinic to complete a computer survey on quality of life in RA. During the same visit, patients also completed a paper form of the MDHAQ and VAS measures, and a 50-joint count self-report form. (Figure 1 shows a diagram of the computer version of the joint count reporter and the mannequin used to report swollen and tender joints on paper.) Depending upon the physician's protocol for administering the paper surveys, the patient completed either the computer survey first ($n = 23$, 53%) or the paper survey first ($n = 20$, 47%).

When using the computer, patients were offered a choice of pointing devices including a mouse, a trackball, touchpad, and touchscreen to complete the survey. Patients who were not able to interact with the computer at all due to their disabilities dictated their responses to the research assistant, who entered them into the computer. After completion of both surveys, patients were given a followup questionnaire to evaluate their experience using the ACASI software. Two free-response questions relating to the joint-count aspect of the program were:

Question 1: What was your opinion of the joint reporting survey?, and
Question 2: Was this way of reporting joints easier or more difficult than the paper format?

Favorable responses to Question 1 were considered all responses that indicated the patient liked the computer version, found it easy to use, or found it helpful. Unfavorable responses indicated confusion in using the computer or a preference for the paper version. Neutral responses were those that expressed no particular emotion or preference. For Question 2, a favorable response was one in which the patient indicated that the computer was easier or faster to use than the paper; unfavorable responses indicated that the paper survey was easier or faster. Neutral responses indicated that both methods were similar in terms of time and ease of use. Categories of response were tabulated and summarized.

Statistical analyses were carried out on the measurements to determine the calibration and correlation between ACASI and the paper versions of the questionnaire. Each scale was examined separately. Joint count score analyses were limited to the joints displayed on the paper instrument. Calibration was determined using the 95% confidence interval of the paired difference between computer and paper methods. The correlation between modalities of administration was measured using the intraclass correlation coefficient (ICC) and a 2-way random effects model. All calculations were performed using SPSS 5.0 software for the PC (SPSS Inc., Chicago, IL, USA) and Microsoft Excel (Microsoft Inc., Redmond, WA, USA).

RESULTS

Of the 63 patients enrolling in the study, complete data were available for 43. Seven patients had partially incomplete or missing data for the computer survey. Forty-seven of the 63 enrollees completed the paper survey, resulting in a total of 43 persons with complete data for both instruments. Of the 43 patients, 4 had required assistance from the research assistant to enter data. However, the assistance required was minimal and data from these patients were considered valid for the purposes of this study.

The sample population (summarized in Table 1) consisted of 36 women and 7 men (83.7% female). The largest ethnic groups were non-Hispanic white (81.4%) and Asian (9.3%). The most common age group was 55–64 years (25.5%), with 20.9% aged 45–54, 20.9% aged below 45, and 32.6% over the age of 64 years. The range of years since diagnosis was very broad; the population included

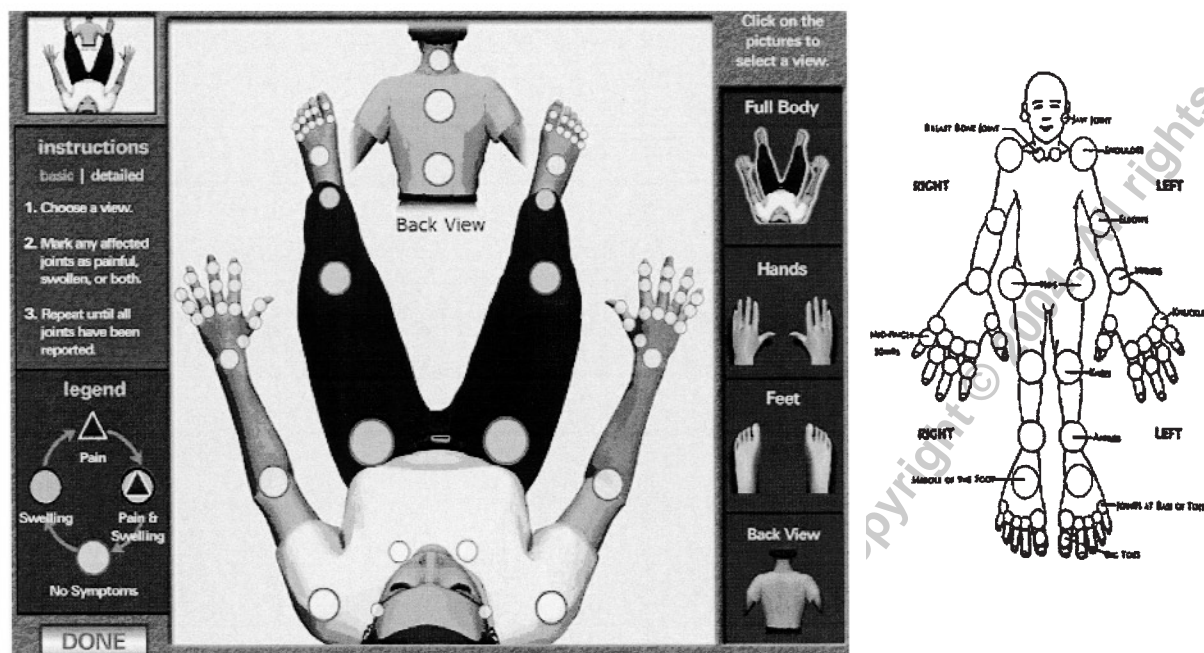


Figure 1. Joint-count reporting tools. Left, the screen from the computer version; right, the mannequin used in the paper forms.

Table 1. Demographic data.

Demographic Variables	N (%)
Total Sample, n	43
Male	7 (16)
Female	36 (84)
Age group, yrs	
18–24	1 (2.3)
25–34	4 (9.3)
35–44	4 (9.3)
45–54	9 (20.9)
55–64	11 (25.6)
65–74	7 (16.3)
75+	7 (16.3)
Race	
Non-Hispanic white	35 (81.4)
African American	1 (2.3)
Asian	4 (9.3)
Hispanic	2 (4.7)
Other	1 (2.3)
Mean years with diagnosis	8.98

patients who had been diagnosed within one year and those that had lived 30 years with the diagnosis. The median years with this diagnosis was 6 years and 75% of patients had been living with the disease ≤ 12 years.

Results of comparisons of the paper and computer instruments are shown in Table 2. The highest correlations were between paper and computer-based versions of the 10 HAQ questions (ICC 0.959), the psychological distress score (ICC

0.908), and the VAS scores for pain (ICC 0.941) and global disease severity (ICC 0.911). These measures were highly comparable across methods. Three other measures exhibited moderate correlation; their ICC were: self-efficacy score (0.881), VAS score for fatigue (0.833), and painful joint count (0.852). The mean scores across methods were very similar, indicating that the computer instrument was calibrated well with the paper instrument for most measures; however, there were small but noticeable shifts in the mean scores for the HAQ and self-efficacy questions in which the patients indicated greater disability and helplessness on the computer. The order of administration (whether the computer or paper survey was seen first) had no significant effect on the data.

About one-half of subjects ($n = 21$) evaluated their experience using the computer, with subjects missing due primarily to their lack of willingness to continue participation in the study after their physician visit. Results from respondents are shown in Figure 2. The majority of respondents preferred using the computer to report symptoms and felt that the computer was either easier than or at least as easy to use as the paper survey.

DISCUSSION

This study examined the within-subject correlation of measurements performed by ACASI for the MDHAQ, VAS for pain, fatigue and global disease severity, and joint counts. The results show a high degree of similarity between computer measures and paper-based measures. While the

Table 2. Correlations and calibration of computer compared to paper instruments.

Measurement	ICC	Mean (computer)	Mean (paper)	95% CI of Difference	
				Lower	Upper
10-question HAQ (ADL)	0.959	0.742	0.654	0.0257	0.151
3-question psychological distress scale	0.908	0.535	0.574	-0.129	0.0514
8-question self-efficacy measure (RAI)	0.881	2.24	2.01	0.0788	0.369
VAS score for pain	0.941	29.8	27.9	-1.90	5.63
VAS score for unusual fatigue	0.833	35.5	40.9	-12.2	1.31
VAS score for overall health	0.911	67.3	71.0	-8.51	1.10
Total number of affected joints	0.797	8.98	8.35	-1.81	3.07
Painful joints, n	0.852	6.09	7.28	-2.97	0.597
Swollen joints, n	0.603	5.19	3.88	-1.17	3.78

ADL: activities of daily living, RAI: Rheumatology Attitudes Index, VAS: visual analog scale.

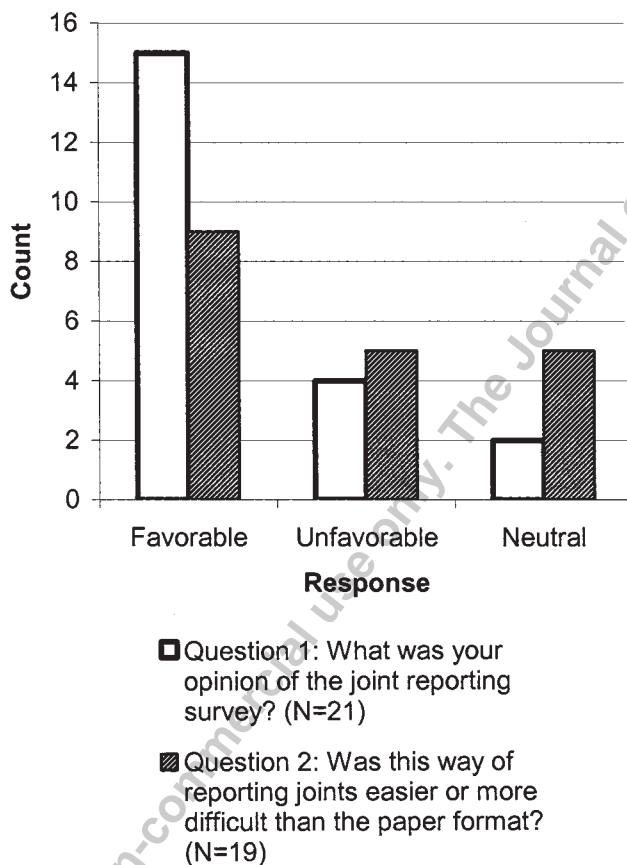


Figure 2. Responses to qualitative followup questions. For Question 2, a favorable response corresponds to the patient indicating that the computer was easier to use than the paper joint count instrument; an unfavorable response means that the patient had more difficulty on the computer instrument.

correlation is high for the multiple-choice questions as well, a comparison of means reveals a statistically significant shift for the HAQ and self-efficacy scores that shows that patients rate these measures slightly higher on the computer than on paper. For VAS ratings of pain and of global disease severity, ratings were virtually identical ($ICC > 0.9$). The strong correlations for the HAQ, pain, and global health scores are significant findings; Pincus, et al have shown that these 3 measures are as effective as the ACR 20% Core Data Set measures at determining changes in disease activity¹. Correlations between counts of painful joints and swollen joints were lower but still acceptable, probably as a result of the lesser reliability of this type of measure. Previous reports suggest that patients have more problems recognizing swollen joints than tender joints^{12,16}. The correlation observed here is similar to the observed test-retest reliability of patient joint count measures¹¹. Thus, the reliability of the measure itself was one of the causes of the merely modest correlation between paper and computer methods observed in this study. Another possible source of variance in the joint counts was the difference between the homunculus figures for the paper and computer instruments (Figure 1). This difference accounts for some of the variance in these scores compared to the multiple-choice or VAS questions, which were presented in very similar formats in both media.

There are, however, a few potential limitations of computer-based methods in measuring outcomes in RA, such as the effect of the disorder on patients' hands, making certain types of computer pointing devices difficult to use. By allowing patients to choose the pointing device that they were most comfortable with, or no device at all (as in a

touchscreen), a substantial proportion of RA patients (> 90%) were able to use computers to provide input. For some, the use of a computer may pose less of a challenge than writing. For example, some patients who are unable to grip a pencil are able to use a touchscreen or a mouse. As well, the size of buttons and text on a computer screen can be enhanced to improve legibility for patients with visual impairment.

Another limitation is that some patients, especially those over the age of 50, are unfamiliar with computers and may have some difficulty in running an application over the Web. The additional time required to complete a computer survey instead of a paper survey is small compared to the time saved by electronic data collection and processing. In this instance, only 30% of the patients felt the computer application required more effort. Further, computer applications are capable of performing internal consistency checks to monitor logical errors in patients' responses, thus preventing some errors that might not be caught in paper surveys. This application did not incorporate specific checks; such checks can be added in future versions with little difficulty.

Previous work with computer-based instruments in rheumatology. The results of comparisons of computer and paper modalities for the multiple-choice and VAS measures are predictable from previous research. Reports have shown that for most types of instruments, including other health status measures commonly used in arthritis, such as the Medical Outcome Study Short Form-36 questionnaire, there is typically good agreement between computer and paper versions of the same instrument²⁰⁻²². Less information exists on comparisons of paper and computer versions of visual analog scales. Lenert, *et al* found a Spearman rho of 0.47 between ratings scale measures of quality of life of individuals and vertical VAS measures, suggesting that the form of questions has an important influence on ratings²³. When both methods use scales with similar appearances, correlations between paper and computer methods may be high. High correlations, similar to those seen in this study, were found in patients using computer and paper versions of a set of pain-related VAS scores in the Western Ontario and McMaster Universities (WOMAC) Osteoarthritis Index²¹. Jamison, *et al* also found high correlations among VAS ratings of pain stimuli²⁴.

While further evaluation is required, our results illustrate how use of computerized methods could potentially improve the precision of measurements of outcomes of RA. By using graphic design and animation, researchers can create instruments to help patients more accurately specify their symptoms that would be impossible to duplicate on paper.

Advantages of electronic instruments. Computer surveys were first introduced over 30 years ago in clinical settings²⁵. The use of computer software to replace paper-and-pencil self-reported scores has numerous potential advantages. The

primary advantage of computer-based methods is that data from ACASI assessments are automatically stored electronically and can be directly entered into electronic medical records or study databases without the time-consuming processes of transcription and data entry, which increase the potential for error. By making data on patients' symptoms and responses to treatments available in computer-readable form, ACASI software will enable the design of expert systems^{26,27} to monitor a patient's response to RA treatments and alert physicians to a deterioration in health or an improvement due to a particular treatment regimen.

Our study was conducted in a clinical setting. However, perhaps the greatest value in the use of these tools will be their ability to measure outcomes in the home. The value of collecting data in computer-readable form is enhanced by the increasing use of the Internet by patients²⁸. Web-compatible ACASI tools for collecting symptoms from patients with arthritis could have profound effects on outcome studies of treatments. The software described here looks exactly the same as and works equally well as a website for access over the Internet as it does for a stand-alone "kiosk" for the office. Thus, it can be applied in both the home and clinic. Physicians will be able to monitor patients in their homes using the same tools they use in the office, compare results to the office measurements, and potentially utilize the information to manage patients' arthritis care with fewer costly and inconvenient physician visits. This capability is especially relevant with the introduction of biological agents such as tumor necrosis factor inhibitors that have a rapid onset of action.

In addition, the availability of validated Web-based tools for assessment of outcomes is likely to influence how RA research is conducted. Researchers will also be able to follow the responses of patients at home in clinical trials, increasing the number of measurements and the precision of trials. Valid approaches for home measurement of outcomes also enables researchers to conduct RA treatment and outcome studies in online populations²⁹. While not suitable for high-risk therapies, the availability of validated outcome measures will greatly facilitate administration of online studies of low-risk, low-impact treatments that would be prohibitively costly to study in other ways. This might include, for example, studies of the effects of alternative medicines, stress reduction, and dietary modifications on RA.

Our results, combined with recent work by Pincus, *et al* on the validity and responsiveness of patient-reported outcomes¹, suggest that it is now possible to automate the process of outcomes measurement in RA. By supporting data-capture into electronic medical records of patient outcomes during office visits and reporting back to physicians the effects of treatments between visits over the World-Wide Web, this software opens new opportunities for patient monitoring, disease management, and clinical research.

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