

Health Literacy Predicts the Discrepancy Between Patient and Provider Global Assessments of Rheumatoid Arthritis Activity at a Public Urban Rheumatology Clinic

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ABSTRACT. *Objective.* Numerous studies report that significant discordance exists between patient and provider [physician] measures of rheumatoid arthritis (RA). We examined whether health literacy explains this discordance.

Methods. We recruited English-speaking adult patients with RA for this cross-sectional study. Subjects completed 2 versions of patient global assessments of disease activity (PTGA), using standard terminology from the Multi-Dimensional Health Assessment Questionnaire (MDHAQ) and the 28-joint count Disease Activity Score 28 (DAS28). The provider global assessment (MDGA) was also obtained. The discrepancy between PTGA and MDGA was calculated as the absolute difference between these assessments. We used validated instruments [Short Test of Functional Health Literacy in Adults (S-TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM)] and linear regression to determine whether health literacy predicts disease measure discrepancy.

Results. The study included 110 subjects. Limited health literacy was a common finding by both the REALM and S-TOFHLA. PTGA and MDGA showed fair to good correlation ($r = 0.66\text{--}0.68$), although both versions of the PTGA were significantly higher than MDGA by the t-test ($p < 0.001$). The S-TOFHLA and REALM both were associated with the absolute difference between the MDGA and PTGA by linear regression, and results remained statistically significant in multivariate analysis.

Conclusion. Health literacy was independently associated with the extent of discrepancy between PTGA and MDGA in English-speaking patients with RA at an urban clinic. This finding should influence our interpretation of disease measures. (First Release March 15 2010; J Rheumatol 2010;37:961–6; doi:10.3899/jrheum.090964)

Key Indexing Terms:

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The 1992 and 2003 US National Center for Education Statistics surveys indicate that about half the adults in the United States exhibit limited health literacy — i.e., they cannot obtain, process, and understand basic health information and services needed to make appropriate health decisions¹. The literacy skills of US adults did not improve over the 11 years between these assessments¹. Limited health literacy is also more prevalent among the elderly, persons with fewer years of schooling, and minorities². As minority patients are more likely to be recruited for research trials³, understanding the influence of health literacy on disease assessment is critical.

Patient measures of rheumatoid arthritis (RA) disease activity and severity predict outcomes⁴ and are included in most composite indices used in clinical trials⁵. Many studies, however, report a poor correlation between patients' and providers' assessment of RA disease activity^{6–9}. There is little knowledge about the factors responsible for this discrepancy⁹. Specifically, the effect of limited health literacy on

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patient assessment of RA disease activity and discordance with provider [physician] assessment has not been investigated.

We hypothesized that patients with RA in an urban medical system demonstrate low levels of health literacy. We further hypothesized that patients with RA who have low levels of health literacy assess their disease as more active and have a greater discrepancy with the provider assessment than patients with adequate health literacy. This hypothesis is based on numerous studies showing that patients with limited health-related literacy more often report poorer health compared to persons with adequate health literacy^{5,10-14}.

MATERIALS AND METHODS

We used a cross-sectional study design to investigate the effect of health literacy on differences in patient and provider global health assessments of RA activity. The subjects were recruited on the day of a patient visit to the Denver Health rheumatology clinic in Denver, Colorado, from June 2008 to March 2009. The Denver Health and Hospital Authority is an urban "safety net" system that serves 150,000 patients annually, of which 78% are minorities and 50% do not have health insurance¹⁵. To enroll subjects, our research assistant searched the daily clinic schedule and medical charts for adult patients with RA who self-identified English as their primary language. We recruited subjects at the end of their rheumatology clinic visits by first providing patients with a verbal description of the study prior to the use of any written materials. The recruitment process was conducted in a confidential workroom with sensitivity and respect to ensure the dignity of persons with limited literacy¹⁶. We excluded subjects under 18 years of age, prisoners, persons with uncontrolled psychiatric illness, and patients with vision worse than 20/100, as measured by a Snellen eye chart. Subjects received a nominal fee to participate in the study.

Each subject's RA diagnosis was verified using the 1987 American College of Rheumatology (ACR) revised criteria¹⁷. The subjects provided a global assessment of disease activity using a horizontal visual analog scale (VAS) 100 mm in length in response to the standard terminology used in the Multi-Dimensional Health Assessment Questionnaire (MDHAQ), "Considering all the ways in which illness and health conditions may affect you at this time, please make an 'X' on the line below to indicate how you are doing." A score of 100 signified "very poorly" and a score of zero signified "very well"¹⁸.

The subjects also provided a global assessment of their disease severity over the course of the previous 7 days [patient global 2 assessment (PTGA2)] in response to the standard terminology used in the 28-joint count Disease Activity Score 28 (DAS28) using a 100 mm horizontal VAS in response to the question, "How active has your rheumatoid arthritis been during the past seven days?"¹⁹.

The investigator who compiled a medical history and did an examination also provided a global assessment of disease activity [provider global assessment (MDGA)] using a 100 mm horizontal VAS. A score of 100 signified "very poorly" and a score of zero signified "very well"¹⁸. The provider was blinded to PTGA and health literacy testing scores.

Demographic information was obtained by written self-report from the subjects regarding their age, sex, race, marital status, years of schooling, tobacco use history, duration of RA, and employment status.

We performed chart review to determine results of rheumatoid factor (RF) and anticyclic citrullinated peptide antibody (anti-CCP) tests. Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) levels were obtained following the completion of enrollment procedures and health literacy testing.

We determined subjects' history of biologic disease-modifying antirheumatic drug (DMARD) use by chart review.

The subjects provided an assessment of pain by circling a number between zero and 10 using a horizontal scale in response to the question, "How much pain have you had because of your condition over the past week?"¹⁸.

The subjects reported morning stiffness in response to the 2-part question, "When you wake up in the morning, do you feel stiff?" and "If yes, how long is it until you will be as limber as you will be for the day?"

The MDHAQ and DAS28 were performed in standard fashion to measure disease activity and severity. The DAS28 was calculated based on assessment of 28 joints, the subject's global assessment, and the ESR. If no ESR was available, the DAS28 was calculated using the CRP¹⁹.

We used 2 validated instruments to assess functional health literacy: the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA). The REALM is a 3-minute medical English word recognition and pronunciation test for screening adult reading ability in medical settings²⁰. The REALM was provided to subjects in 14-point type. The large-print version of the S-TOFHLA is a 7-minute test that contains 2 reading comprehension sections about medical subjects²¹.

The discrepancy between patient and provider assessment was calculated as the absolute difference between these assessments.

The readability of the wording of the PTGA, PTGA2, and MDHAQ was determined by the Gunning-Fog Index using an online calculator²². The Gunning-Fog Index indicates the years of educational attainment required to understand text on the first reading²³.

With patients' informed consent, all patient data were obtained by self-report on questionnaires. The staff physician who evaluated the patient gave the MDGA. Interviewer bias could be a potential source of information bias, because researchers aware of the study's hypothesis tested the subjects. To mitigate this potential bias, the MDGA was obtained prior to the PTGA and health literacy testing. All laboratory analyses were performed at the Denver Health Medical Center clinical laboratory.

Statistical methods. To achieve an α level of 0.05 with power of 0.8, a sample size of 102 subjects would be required, assuming 10 predictor variables are included in a model with a coefficient of determination (R^2) of 0.15. We represented the global assessments as continuous variables. We modeled the study in this fashion as there are no data to support dichotomizing or grouping discrepancies between patient and provider assessments. Health literacy, estimated by either the REALM or S-TOFHLA, was also modeled as a continuous score, as has been done previously¹².

In terms of statistical tests, enrolled subjects and patients who were not enrolled were compared by the unpaired t-test for continuous variables (age, duration of RA, ESR, CRP, and DAS28) and the chi-squared test for dichotomous variables (sex, race, tobacco use history, RF, anti-CCP). The unpaired t-test was used to compare PTGA (terminology from the MDHAQ) and PTGA2 (terminology from the DAS28) scores, and to compare MDGA and PTGA. Pearson correlation coefficients were also employed to describe the relationship of PTGA and MDGA. We initially performed univariate linear regression to determine the contribution of health literacy to discrepancies (absolute differences) between PTGA and MDGA. We then progressed to multivariate linear regression. The models were constructed by including all predictors and using a backward stepwise procedure, dropping variables in which $p > 0.10$. Variables found to be significant at a 2-sided p of 0.05 were retained and confidence intervals were set at 95%. All analyses were performed using Stata software version 10 (StataCorp, College Station, TX, USA).

The Colorado Multiple Institutional Review Board approved this study.

RESULTS

The 118 patients recruited for the study represent about 70% of the eligible subjects in our clinic. Two persons declined to participate in the study because of complete functional illiteracy. Four persons declined to participate because of

lack of time or transportation issues. One person declined to participate for unspecified reasons. One patient was excluded after identifying English as his primary language, but requiring a translator for the informed consent. All 110 subjects who were enrolled completed the study.

Patient demographic data for this study cohort appear in Table 1. The subjects were predominantly women, unmarried, not currently employed, and nonwhite. The majority was RF-positive and had active disease of long duration. Thirty-six subjects never had anti-CCP antibody testing performed. Two subjects did not complete the PTGA. Five subjects did not have ESR testing and 4 subjects did not have CRP testing. There were no differences between the enrolled subjects and patients who were not enrolled with regard to age, race, ESR, CRP, DAS28, sex, tobacco use history, or anti-CCP status (data not shown). Duration of RA was longer ($p < 0.01$) and RF seropositivity more common ($p = 0.04$) for enrolled subjects compared to those who were not enrolled.

The Gunning-Fog Index estimated the literacy demands of the MDHAQ to be 4.98. The PTGA2 and PTGA produced literacy demands of 11.47 and 14.06, respectively.

Results of global assessments and health literacy testing appear in Table 2. The patient global assessments of health derived from the MDHAQ (PTGA) and DAS28 (PTGA2) were not different by the t-test ($p = 0.20$), although the DAS28 version trended higher. PTGA and MDGA showed

fair to good correlation ($r = 0.66-0.68$), although both versions of the PTGA produced scores that were statistically significantly higher than MDGA by the t-test ($p < 0.001$; Table 2). Limited health literacy was a common finding by both the REALM and S-TOFHLA, with mean REALM scores equivalent to a 7th to 8th grade literacy level and 34% of subjects demonstrating inadequate (score 0–16) or marginal (score 17–22) literacy on the S-TOFHLA^{20,21}.

We performed univariate linear regression analysis to determine if health literacy predicted global disease assessment discrepancies between patients and providers (Table 3). Both the REALM and S-TOFHLA scores predict (in a similar direction) the difference in patient and provider estimates of global disease activity, regardless of whether global assessments rely upon language from the MDHAQ or the DAS. For example, the difference in PTGA and MDGA narrows by about half a point for each point the S-TOFHLA improves (i.e., better health literacy). The relationship between the S-TOFHLA and absolute difference of PTGA and MDGA remained statistically significant in multivariate analysis that controlled for the effect of current biologic DMARD use, years of education, sex, and age (Table 4). Results were similar for the REALM.

Lastly, to explore whether the severity of patients' or providers' assessments account for the difference in global disease activity, we performed univariate linear regression, examining either patient scores (PTGA) or provider scores

Table 1. Patient demographic data.

Variable	No.*	Mean or Proportion**	SD	Minimum	Maximum
Age, yrs	110	53.21	12.39	22	77
Male, %	110	0.21			
Education, yrs	110	12.35	3.09	0	23
Current smoker, %	110	0.30			
Caucasian, %	110	0.27			
Hispanic, %	110	0.45			
Black, %	110	0.16			
American Indian, %	110	0.11			
Asian, %	110	0.03			
Married currently, %	110	0.24			
Currently employed, %	110	0.19			
Disabled, %	110	0.65			
Retired, %	110	0.07			
Duration of RA, yrs	110	12.51	10.20	0.10	49
Positive RF, %	110	0.88			
Positive anti-CCP, %	74	0.85			
MDHAQ	110	1.00	0.61	0	2.7
DAS28	110	4.37	1.53	1.39	7.78
ESR, mm/h	105	29.39	23.94	3	114
CRP, mg/l	106	15.83	23.29	0.35	120

* N = number of non-missing responses/values. ** Variables denoted as percentage indicate the proportion of the cohort with the stated characteristic, rather than a mean value. RA: rheumatoid arthritis; RF: rheumatoid factor; anti-CCP: anti-cyclic citrullinated peptide antibody; MDHAQ: Multi-Dimensional Health Assessment Questionnaire; DAS28: Disease Activity Score 28; ESR: erythrocyte sedimentation rate; CRP: C-reactive protein.

(MDGA) as potential predictors for the absolute difference in scores. Interestingly, provider scores demonstrated no relationship with the PTGA-MDGA discrepancy ($p = 0.35$), while patient scores demonstrated a statistical association ($p < 0.001$). Specifically, for each point of worse health that patients rated their global health, the difference between patient and provider assessments increased by 0.28 points (95% CI 0.18–0.37).

DISCUSSION

Our study demonstrates that, among English-speaking patients with RA attending an urban safety net clinic, limited health literacy is common. Health literacy was also independently associated with the extent of discrepancy between patient and provider assessment of global disease activity. After adjustment for the use of biologic agents, education, sex, and age, lower S-TOFHLA scores predicted a wider gap between patient and provider assessments. In addition, patients who rated their global health worse were more likely to be discordant with the assessment of their provider.

There are several mechanisms that might explain this discordance. It has long been recognized that patients and providers perceive disease activity differently²⁴⁻²⁶. Studies of patients with systemic lupus erythematosus and RA have shown that providers place greater value on objective findings, while patients focus upon subjective manifestations and their perception of functional status^{27,28}. Patients with RA also weigh fatigue, sleep, and overall well-being in their

assessment of disease activity, and these are often not measured well by providers²⁹. Cardiovascular and respiratory complications of RA are associated with social class and material deprivation³⁰ and these are additional potential causes of high disease activity ratings in patients with limited health literacy. Low levels of health literacy have been associated with anxiety and depression in patients with RA, a situation that also might influence the patient's global assessment³¹.

Effective communication between the patient with RA and the provider is necessary for the provider to best understand the full extent of the patient's symptoms and functional impairment and to help achieve concordance with the patient regarding disease activity. Limited health literacy is associated with reductions in verbal fluency, proactive oral communication, and shared decision-making³²⁻³⁶. Another obstacle to communication is that patients with lower levels of health literacy have less knowledge about their medications and chronic illnesses^{12,37-39}.

Few studies have looked at the factors responsible for the discrepancy between patient and provider global assessment of RA disease activity. To our knowledge, ours is the first to investigate the effect of health literacy. Low levels of education rather than health literacy *per se* were found in Brazilian patients with RA who rated their disease less active than their physicians did⁸. We did not find a similar association with education in our more ethnically diverse and larger cohort of patients with a broader range of educational attainment. It is not surprising that health literacy was associated with a discrepancy between patient and provider

Table 2. Results of global assessments and health literacy testing.

Measure	No.	Mean	SD	Minimum	Maximum
PTGA	108	44.51	27.38	2	100
PTGA2	110	49.12	25.51	0	100
MDGA	110	32.50	25.51	0	92
S-TOFHLA	110	27.55	9.20	6	36
REALM	110	54.14	14.20	10	66

PTGA: patient global assessment (MDHAQ); PTGA2: patient global 2 assessment (DAS28); MDGA: provider global assessment; S-TOFHLA: Short Test of Functional Health Literacy in Adults; REALM: Rapid Estimate of Adult Literacy in Medicine; MDHAQ: Multi-dimensional Health Assessment Questionnaire; DAS: Disease Activity Score.

Table 4. Results of multivariate analysis of S-TOFHLA and absolute difference of PTGA and MDGA.

Variable	Coefficient	p	95% CI	
Age	0.0503813	0.690	-0.199284	0.300046
Sex	3.690053	0.082	-17.2583	1.050691
S-TOFHLA	-0.39706	0.031	-0.75795	-0.03618
Current biologic	5.64341	0.059	-0.211152	11.49796
Education, yrs	-0.450206	0.413	-1.53566	0.6352489

S-TOFHLA: Short Test of Functional Health Literacy in Adults; PTGA: patient global assessment; MDGA: provider global assessment.

Table 3. Relationship of health literacy to the discrepancy between patient and provider global assessments.

Predictor Variable	Outcome Variable (Absolute Difference of)	Coefficient	p	95% CI	
REALM	MDGA-PTGA	-0.24246	0.024	-0.45215	-0.03276
S-TOFHLA	MDGA-PTGA	-0.49627	0.002	-0.81349	-0.17906
REALM	MDGA-PTGA2	-0.24263	0.017	-0.44086	-0.04439
S-TOFHLA	MDGA-PTGA2	-0.3425	0.029	-0.64963	-0.03538

PTGA: patient global assessment (MDHAQ); PTGA2: patient global 2 assessment (DAS28); MDGA: provider global assessment; S-TOFHLA: Short Test of Functional Health Literacy in Adults; REALM: Rapid Estimate of Adult Literacy in Medicine; MDHAQ: Multi-Dimensional Health Assessment Questionnaire.

assessment but that education was not, since research has shown only a modest correlation between literacy and educational attainment^{21,40}. In an analysis of 31 patients with RA, Yazici, *et al* reported that younger patients assessed their disease more severely than their physicians assessed it⁴¹. We did not identify a statistical relationship between age and the discrepancy between provider and patient assessment. There are some data to support Hispanic patients with RA having higher PTGA than African American or Caucasian patients^{3,42}, but discrepancy between provider and patient assessments has not been documented according to race. We found no association between race and global disease activity discrepancy.

It is possible that the relatively high literacy burden of the instruments used to assess disease activity may be contributing to the discrepancy between patient and provider assessments. We did not observe a statistically significant difference between the patient global assessments of health derived from the MDHAQ (PTGA) and DAS28 (PTGA2), but a trend existed between higher scores with the more easily understood instrument.

Difficulty with numerical concepts is another potential source of discordance between patient and physician global assessments. More than 50% of US residents have basic or no quantitative numeracy skills¹. Recent data suggest that innumerate patients have difficulty understanding self-administered written tools⁴³. Additionally, the validity of VAS in patients with lower levels of educational attainment has been questioned, but there is little information about this and health literacy⁴⁴.

This study had several limitations. Its cross-sectional design did not permit us to determine whether limited health literacy was causally associated with discrepancy. It is possible that health literacy is a marker for a factor not controlled for in our regression analysis, such as income. Although the validity of the REALM and S-TOFHLA has been extensively documented in a myriad of patient populations, there are few data about these tools in patients with RA. It is theoretically possible that subjects had difficulty concentrating because of pain or fatigue, leading to lower scores on the REALM and S-TOFHLA. The results of our study may not be generalizable to patients whose primary language is not English. It is also possible that our study failed to identify subjects with the greatest deficits in health literacy because patients with the lowest literacy may have declined to participate because of shame and embarrassment. Our study cannot address the effect of innumeracy since neither the S-TOFHLA or REALM provides information about numeracy. We did not assess several factors that might contribute to the discrepancy between patient and provider assessments such as communication, depression, and cardiovascular or respiratory disease.

There are a very limited number of investigations regarding the effect of health literacy on the evaluation and

assessment of patients with RA. Our study included a broad range of patients in terms of sex, age, race, and literacy skills. The results likely have external validity when applied to other diverse patient populations, but may not apply to more homogenous subpopulations.

Our findings are relevant to both rheumatology practice and research and should influence interpretation of disease measures. Patient-centered outcomes and patient-derived measures are ubiquitous in composite indices of disease activity used in clinical research and practice^{4,6,29}. Our study is the first to investigate the relationship between health literacy and the discrepancy between the patient and provider global assessments included in these indices. The discrepancy between patient and provider global assessment seen in patients with lower levels of health literacy makes the introduction and ongoing evaluation of therapy challenging and creates the risk of patient dissatisfaction. Patients with limited functional health literacy can ill afford an additional stumbling block as they receive their medical care. Better understanding of this discordance may facilitate both patient satisfaction and more effective communication between doctors and patients²⁴.

Research is needed regarding how to capture the patient global assessment in patients with limited health literacy including the testing of written instruments with lower literacy burden and gathering data through oral communication, telephone, or computer entry. The relationship of innumeracy and patient global assessments is another important area of future study.

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