Functional Health Literacy of Patients with Rheumatoid Arthritis Attending a Community-Based Rheumatology Practice

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ABSTRACT. ***Objective.*** To determine the health literacy of patients with rheumatoid arthritis (RA) attending community-based rheumatology practice.

Methods. Eighty patients were administered the Test of Functional Health Literacy in Adults (TOFHLA), a 50-item reading comprehension and 17-item numerical ability test (score 0-100); the Rapid Estimate of Adult Literacy in Medicine (REALM), which asks participants to read aloud 66 words of varying difficulty (score 0–66); and the Test of Reading Comprehension (TORCH), which asks participants to read a short text and then fill in the gaps of another version by using one or more of their own words (score 1-9).

Results. The study group included 60 women (75%), mean age (SD) 60.29 (15.02) years, median duration of RA 8 years (range 0.3–39). Nineteen of 80 (24%) had completed ≤ 8 years of formal education, 24/80 (30%) had completed 9 or 10 years, and 37/80 (46%) had completed ≥ 11 years. TOFHLA and REALM scores ranged from 39–100 and 41–66 respectively. Scores for 8 patients (10%) indicated they would have difficulty reading and interpreting health texts and struggle with most currently available patient education materials. Of those who attempted the TORCH, 8/65 (12%) scored low or below average and 23/65 (35%) scored average compared with students completing 9th grade. All 3 literacy tests were significantly correlated with education level, but use of educational level alone as a measure of literacy would have misclassified more than 10% as health literate/illiterate.

Conclusion. A significant number of patients with RA have limited health literacy and may not understand even simple written instructions or prescription labels. (First Release Mar 1 2006; J Rheumatol 2006;33:879–86)

Key Indexing Terms:
LITERACY RHEUMATOID ARTHRITIS COMMUNICATION DETERMINANTS

A minimum level of literacy is required to be able to use the health care system and function effectively as a patient. Health literacy, a term first coined in 1974, refers to an individual's overall capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions[1]. For example, patients are expected to be able to read and comprehend instructions and prescriptions, appointment cards and informed consent forms; and to use written directions to find a pathology laboratory or get a radiograph. The ability to perform these tasks is referred to as functional health literacy[2]. Literacy skills of reading, writing, and numeracy are becoming more necessary as health care providers increasingly use written patient materials to supplement their verbal communication, as patients look to consumer groups and the Internet for additional sources of information, and as patients take an increasing role in shared decision-making about their care.

Communication of information is particularly important in the context of chronic diseases like rheumatoid arthritis (RA), as without adequate knowledge of the condition it is difficult for patients to participate in decisions regarding treatment options, comply with complex regimens, and monitor their own condition[3-5]. Rheumatologists commonly provide written information about longterm drug therapy to their patients with RA[6]. In providing patients with written information it is generally assumed that most or all patients are functionally literate. However data from national literacy surveys suggest that this may not be the case. Based upon the 1992 US National Adult Literacy Survey, one-quarter of the American population are estimated to be functionally illiterate such that they

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would be unable to read a medicine bottle label[7]. A similar survey conducted in Australia in 1996 found that almost half of Australians aged 15-74 years (6.2 million people) have "poor" or "very poor" literacy skills, implying that they would have considerable difficulties in using many printed materials that are encountered in everyday life[8]. Results from a similar survey performed in Canada in 1994–1995 also showed that 48% of the adult population were either not able to read at all or had very serious problems with reading[9].

Illiteracy has been shown to be strongly associated with poorer health status, independent of other associated sociodemographic factors, and those with the lowest literacy skills require far greater medical care than those with even marginal literacy skills[10-13]. Low literacy and its resultant poorer medical outcomes have a major impact on the cost of health care[14,15]. Low literacy may also be an important barrier to receiving optimal health care[12] and in patients with chronic disease, poor literacy skills have been found to be associated with a lack of knowledge about the disease process and poor self-management skills[16-18].

In view of the consequences of poor literacy, it is important for health professionals to be aware of the literacy skills of their patients, yet this is, thus far, a neglected area of clinical practice and training. Many adults with poor literacy skills effectively cover up their problem, so simply asking patients if they can read is not a reliable predictor of their skills[19,20]. While education attainment has been used as a proxy for literacy, it may also be a poor indicator of health literacy[10,21], and surveys have consistently shown that the years of school completed overestimates true reading level[10,22,23].

Two studies, one in the USA and one in the UK have found illiteracy to be a substantial problem among patients with RA[24,25]. As illiteracy may have adverse consequences on health, it may be important to identify patients with RA who have limited literacy skills in order to provide them with alternate modes of communication.

We assessed the health literacy skills of a group of patients with RA attending our community-based private rheumatology practices in Australia in order to determine whether this was an issue about which we should be concerned in our setting. We also compared the results of our health literacy assessment to an assessment of general reading comprehension and studied the association between the literacy tests, education level, age, gender, and duration of RA.

MATERIALS AND METHODS

Setting and study participants. Eighty-three consecutive patients aged ≥ 18 years with stable well-controlled RA, attending their regular review appointment with their community-based rheumatologist (RB or SH) at Cabrini Medical Centre, Malvern, a socioeconomically advantaged inner suburb of Melbourne, Australia[26], were invited to participate. Since knowledge of the purpose of the study was likely to result in those with poorer literacy skills declining to participate, patients were blinded to the exact purpose of the study. They were informed that we were interested in finding out what health care information is understood by patients, and what is confusing to them as part of an overall plan to improve the written information that we provide to them. We avoided using terms such as "literacy," "health literacy," or "reading ability". If they agreed to take part in the study, they met with one of 2 experienced research assistants (JY or GG), both of whom had undergone literacy test training. The research assistants were skilled in not making or revealing any judgments about an individual's performance in completing any of the tasks. Patients were invited to participate at a time suitable to them. The Cabrini Hospital Ethics Committee approved the study and all patients signed written informed consent.

Measures. Demographic and clinical data were collected including age, sex, marital status, country of birth, native language, employment status, highest level of education achieved, and duration of RA.

Health literacy skills were assessed by administration of the Test of Functional Health Literacy in Adults (TOFHLA), an instrument that assesses both reading comprehension and numeracy related to health care issues[27]; and the Rapid Estimate of Adult Literacy in Medicine (REALM), a health-related reading recognition test[28]. The TOFHLA was developed with input from a literacy expert from a sample of commonly used hospital texts[27]. It consists of a 50-item reading comprehension test that uses the modified Cloze procedure[29]; every fifth to seventh word in a passage is omitted and 4 multiple-choice options are provided, one of which is correct and 3 of which are similar but grammatically or contextually incorrect. There are 3 health care passages: the first selected from instructions for preparation for an upper gastrointestinal tract radiograph series; the second from the patient's "Rights and Responsibilities" section of a Medicaid application; and the third from a standard hospital informed consent document. The TOFHLA also contains a 17-item numeracy section that tests a reader's ability to comprehend directions for taking medicines, monitoring blood glucose, keeping medical appointments, and obtaining financial assistance. The reader is presented with cue cards and asked to respond to questions about the information on the cards. Participants are allowed up to a maximum of 22 minutes to complete the entire test.

The reading comprehension section is scored from 0 to 50, with one point for each correct response. The numeracy section is also scored from 0 to 50, by multiplying the number of correct responses (out of 17) by 2.941. The sum of the reading comprehension and the weighted numeracy scores yields a TOFHLA score of 0 to 100. Based upon patients' scores on individual TOFHLA items in a study of 2659 predominantly indigent and minority patients presenting for acute care at 2 urban hospitals in Atlanta, Georgia, and Torrance, California, TOFHLA scores are divided into adequate, marginal and inadequate functional health literacy as outlined in Table 1[12]. The TOFHLA has been shown to have high internal consistency (Cronbach's alpha = 0.98), and good correlation with other word pronunciation and reading recognition tests[27,30].

All participants also completed the shortened 66-item version of the REALM, a reading recognition test, which was developed as a quick screening tool to assist physicians in identifying patients with limited reading skills and in estimating patient reading levels[28]. It measures a patient's ability to pronounce common medical words and lay terms that adult primary care patients are expected to recognize. Sixty-six words are arranged in columns according to the number of syllables and in ascending level of difficulty. The words were originally chosen from patient education materials and patient intake forms used in university-based primary care clinics[28]. Item reduction from 125 to 66 words was based upon psychometric estimates of item difficulty and discrimination and the frequency of retained words in written material given to patients[30]. It has a high concentration of items at lower difficulty levels, which increases its discriminatory power when administered to patients with limited reading ability. Participants are asked to read aloud as many words as they can, beginning with the first word in column one. When they encounter a word they cannot read, they are asked to do the best they can or say "blank" and go onto the next word. The raw score is the number of correctly pronounced words with the dictionary pronunciation taken as the scoring standard. The 66-item version of the REALM takes 1-2 minutes to complete by personnel with minimal training.

The raw scores are used to derive US high school grade range estimates as an approximation of literacy as shown in Table 1[30]. These estimates were

Table 1. Interpretation of the Test of Functional Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM) raw scores and Test of Reading Comprehension (TORCH) stanines. Raw scores were divided into 9 categories evenly spread along the baseline of the curve of the normal distribution.

TOFHLA	
Raw score	Interpretation
0–59	Inadequate functional health literacy: may be unable to read and interpret health texts
60–74	Marginal functional health literacy: difficulty reading and interpreting health texts
75-100	Adequate functional health literacy: can read and interpret most health texts
REALM	
Raw score	US high school grade equivalent
0–18	3rd grade and below: may not be able to read most low-literacy materials; may need repeated oral instructions, materials composed primarily of illustrations, or audio- or videotapes
19–44	4th–6th grade: may need low-literacy materials: may not be able to read prescription labels
45–60	7th–8th grade: may struggle with most currently available patient education materials
61–66	9th grade and above: should be able to read most patient education materials
TORCH	
Stanines	Reading ability compared to finishing Australian Year 9 students
1	Low
2–3	Below average
4–6	Average
7–8	Above average
9	Superior

determined by linear regression analysis using REALM raw scores to predict scores on the Slossan Oral Reading Test-Revised (SORT-R), which is a widely used national standardized test in the US[31]. The shortened version of the REALM has been shown to be a valid and reliable indicator of a patient's ability to read health-related materials with high test-retest reliability and a strong correlation with general literacy tests[30].

General reading comprehension was measured by the Test of Reading Comprehension (TORCH), developed by The Australian Council for Education Research (ACER) and first published in 1987 to measure reading comprehension in school students in Years 3 to 10[32]. The TORCH is a set of 14 untimed reading tests of varying difficulty designed for use with students in Years 3 to 10. It assesses the extent to which readers are able to obtain meaning from text. Like the reading comprehension section of the TOFHLA, the TORCH is based upon a modified cloze format in which the reader is presented with a passage of text, and a retelling of the passage in different words. The retelling of the passage contains gaps corresponding to details in the original text. The reader is asked to fill the gaps using one or more of their own words. A number of different answers are acceptable, provided they make sense in the context of the passage. While, in practice, the tests are tailored to the ability of individual students, for the purpose of this study, all participants were given the same non-fiction passage: "The Killer Smog of London" which is suitable for testing students completing Years 6 to 9.

The raw score is the total number of correct responses. This can be converted onto a common scale of 0 to 100 and interpreted from normative data based on Australian references groups. For the purpose of this study we compared participant results to the reading ability of students finishing Year 9, using stanines, which divide the raw scores into 9 categories evenly spread along the baseline of the curve of the normal distribution, ranging from a low of 1 to a high of 9 as shown in Table 1. The TORCH has been used extensively throughout Australian schools. It takes about 15 to 20 minutes to complete. It has been shown to correlate with the Progressive Achievement Tests Reading Comprehension, another test of reading ability, as well as the teacher's ratings of reading ability[33].

Analysis. Descriptive statistics were used to summarize the demographic, clinical, and literacy characteristics of study participants. Comparisons were made between patients who did and did not attempt the TORCH test with respect to education level, age, gender, and their TOFHLA and REALM results. Pearson correlation coefficients were used to examine associations between the results of the 3 literacy tests, education level, age, and duration of RA and one-way analysis of variance was used to determine association with gender. To increase our understanding of the validity and performance of each of the literacy tests we also examined the results for individual items of both the TOFHLA and REALM. All statistical analyses were performed using SPSS version 11.0.

RESULTS

Eighty patients participated in the study and 3 patients declined. Of those who declined, one Australian-born patient disclosed that he was a poor reader, one patient whose primary language was not English disclosed an inability to read English, and the third patient did not specify a reason for not participating. Table 2 displays the demographic and clinical characteristics of those who participated. There were 60 women (75%), the mean age (SD) of participants was 60.29 (15.02) years and the median duration of RA was 8 years (range 0.3 to 39 years). Most patients were Australian born (65/80, 81.3%) and English was the primary language of 79 patients (97%). Almost a quarter of the patients had completed 8 years or less of formal education (19/80, 24%), 30% had completed up to 9 or 10 years (24/80), and the remainder had completed 11 years or more (37/80, 46%).

Literacy scores according to the TOFHLA, REALM, and TORCH are shown in Table 2. One patient did not attempt the TOFHLA test and 7 patients (9%) had either inadequate or marginal functional health literacy according to TOFHLA scores. Eight patients (10%) had REALM scores below 9th grade. Fifteen patients (19%) did not attempt the TORCH, and scores for those who did attempt it indicated that 8 patients had low or below average literacy compared to students completing 9th grade. Patients who attempted the TORCH were significantly younger [mean age (SD): 58.6 (15.5) yrs vs 67.7 (10.2) yrs, p = 0.032], had a higher mean education level (p =

Table 2. Demographic characteristics of the participants (n = 80) and overall results of the Test of Functional Health Literacy in Adults (TOFHLA), Rapid Estimate of Adult Literacy in Medicine (REALM), and Test of Reading Comprehension (TORCH).

Variable	n (%)
Mean (SD) age, yrs	60.3 (15.0)
Median (range) duration RA, yrs	8 (0.3–39)
Female	60 (75)
First language-English	78 (97.5)
Australian born	65 (81.3)
Marital status	
Single	6 (7.2)
Widowed	12 (14.5)
Divorced	13 (15.7)
Married	49 (59.0)
Education: completed year/grade level	
6	4 (5.0)
7 or 8	15 (18.8)
9 or 10	24 (30)
11 or 12	17 (21.3)
Tertiary study	20 (25)
TOFHLA score (0–100) (n = 79)	
0–59 (inadequate)	3 (3.8)
60–74 (marginal)	4 (5.1)
75–100 (adequate)	72 (91.1)
Median score (range)	95 (39–100)
REALM score (0–66) (n = 80)	
0–18 (3rd grade & below)	0 (0)
19–44 (4th - 6th grade)	1 (1.3)
45–60 (7th - 8th grade)	7 (8.8)
61–66 (9th grade and above)	72 (90.0)
Median score (range)	66 (41–66)
TORCH*	
Not attempted	15 (18.8)
Attempted and completed	61 (76)
Attempted and not completed	4 (5.0)
Stanine categories (1–9) (n = 65)	
1 (low)	5 (7.7)
2–3 (below average)	3 (4.6)
4–6 (average)	23 (35.4)
7–8 (above average)	11 (16.9)
9 (superior)	23 (35.4)

* Unless otherwise stated TORCH raw scores converted into 9 reading ability categories based upon finishing year 9 students.

0.006), and significantly higher mean TOFHLA and REALM scores [93.2 (7.5) vs 75.8 (19.2), $p < 0.001$; and 64.8 (1.9) vs 61.3 (7.6), $p = 0.001$, respectively].

There was a significant correlation between all 3 literacy instruments (Table 3). All 3 literacy tests were significantly correlated with education level, while only the TOFHLA and TORCH correlated with age, and none correlated with gender.

The TORCH score was also significantly correlated with duration of RA. After accounting for education level, age was no longer a significant contributing factor to TOFHLA and TORCH scores.

Table 4 displays the results of participants who scored poorly on one or more literacy tests and their educational level. There was some discordance between test results. For example, 5 of the 8 patients with inadequate or marginal health literacy according to TOFHLA (including the patient who didn't attempt the test) achieved a REALM grade equivalent of ≥ Year 9. One of these participants also had a low score on the TORCH and the other 4 participants did not attempt the TORCH. Similarly 5 of 8 participants who had scores below the 9th grade level on the REALM had adequate functional health literacy according to the TOFHLA although 2 also had low scores on the TORCH and the other 3 did not attempt the TORCH. There were 11 patients (13.8%) who either did not attempt the TORCH (n = 6) or had low scores (2 with low and 3 with below average compared to students completing Year 9) who had adequate health literacy according to both the TOFHLA and REALM.

Table 3. Pearson correlation coefficients between literacy scores, duration of RA, education level, and age (n = 80 except TOFHLA: n = 79; TORCH: n = 65).

	REALM	TORCH	Duration of RA	Education Level	Age
TOFHLA	0.298**	0.393**	0.088	0.502**	–0.397**
REALM		0.358**	0.070	0.345**	0.029
TORCH			–0.350**	0.419**	–0.296*
Duration of RA				0.059	0.131
Education level					–0.455**

* $p < 0.05$, ** $p < 0.01$.

Forty-nine (62%), 34 (43%), and 44 (56%) participants had perfect scores for the patient preparation, patient rights, and informed consent passages of the TOFHLA reading comprehension sections, respectively, (Table 5). The number of correct responses for individual numeracy items ranged from 82 to 100% apart from the last numeracy item where only 34 patients (43%) answered the question correctly. This question asks the reader to indicate whether their family is eligible for financial assistance dependent upon their annual income and number of children. The correct answer assumes a 2-parent household, but this is not made clear in the question.

DISCUSSION

We found that a significant proportion (8/80, 10%) of patients with RA attending one of 2 community-based rheumatology practices had inadequate or marginal functional health literacy as determined by the TOFHLA test, or a reading age at or below the US high school grade equivalent of 7th–8th grade as indicated by their REALM scores. These test results are in keeping with those of the Australian national literacy survey, which found that 10.3% of the Australian adult population were functionally illiterate[34]. Although the wording of one numeracy item of the TOFHLA was ambiguous and a large proportion of participants answered it incorrectly, it is unlikely that this would have significantly biased our results.

While it is possible that the high refusal rate to attempt the TORCH may have been due to respondent fatigue (it was the last of the 3 tests to be completed), patients who attempted the

Table 4. Results of the TOFHLA, REALM, and TORCH for those participants who scored poorly on one or more instruments defined as either didn't attempt test, or inadequate or marginal for the TOFHLA, below 9th grade for the REALM and low or below average for the TORCH.

TOFHLA		REALM		TORCH		Education
Score (0–100)	Functional health literacy category	Score (0–66)	Grade equivalent	Stanines (1–9)	Reading ability*	Level Completed
–	–	41	4–6	–	–	Year 8
45	Inadequate	57	7–8	–	–	Year 6
39	Inadequate	65	≥ 9	–	–	Year 10
49	Inadequate	66	≥ 9	–	–	Year 8
64	Marginal	59	7–8	6 (63)	Average	Year 8
68	Marginal	65	≥ 9	–	–	Year 8
68	Marginal	65	≥ 9	–	–	Year 11
66	Marginal	66	≥ 9	1 (38)	Low	Year 10
78	Adequate	48	7–8	–	–	Year 8
88	Adequate	58	7–8	–	–	Year 11
86	Adequate	60	7–8	–	–	Year 10
88	Adequate	59	7–8	1 (35)	Low	Year 6
89	Adequate	59	7–8	1 (35)	Low	Year 8
97	Adequate	66	≥ 9	1 (22)	Low	Year 12
85	Adequate	63	≥ 9	1 (35)	Low	Year 12
91	Adequate	65	≥ 9	2–3 (47)	Below average	Year 8
98	Adequate	66	≥ 9	2–3 (47)	Below average	Tertiary
78	Adequate	62	≥ 9	2–3 (47)	Below average	Year 8
94	Adequate	65	≥ 9	–	–	Tertiary
84	Adequate	66	≥ 9	–	–	Year 6
87	Adequate	65	≥ 9	–	–	Year 9
95	Adequate	66	≥ 9	–	–	Year 7
83	Adequate	66	≥ 9	–	–	Year 10
97	Adequate	66	≥ 9	–	–	Year 10

* Compared to finishing year 9 students.

TORCH were significantly younger, had higher mean education levels, and significantly higher mean TOFHLA and REALM scores than those who did not. Even excluding those patients who did not attempt the TORCH (15/80, 19%), among those who did complete it, there was a high proportion with scores indicating low or below average literacy in comparison to students completing year level 9 (8/65, 12.3%). A further 2 of 3 patients who refused to participate in the study were known to have low literacy levels. Given that this work was undertaken in the private health setting (where patients are known to be more highly educated), and in a socioeconomically advantaged area of Melbourne, the extent of the problem is probably underestimated.

To our knowledge, there have been no studies that have used the TOFHLA to measure functional health literacy in patients with RA. Our results are however in keeping with the findings of previous studies that measured reading ability in patients with RA or other chronic rheumatic conditions using either the standardized Jastak Wide Range Achievement Test revised level 2 (WRAT-R2), a non-medical word recognition test similar to the REALM, or the REALM[24,25,35]. The reading ability of 100 patients with varying rheumatological conditions from a US urban Veterans Administration (VA) arthritis medical center was measured using the WRAT-R2[21]. Over 50% of the patients read below the 10th grade level and 31% read below the 7th grade. In a study of 100 patients with systemic lupus erythematosus whose mean educational level completed was 12th grade, REALM scores correlated with a mean reading level of 7th-8th grade in a university clinic and 9th grade in a private clinic[35]. Pincus, *et al* used the REALM to estimate health literacy in 88 patients with various types of rheumatic diseases attending an academic rheumatology unit and found that 12.5% had REALM scores below 60, indicating a reading level of 8th grade or less[24]. In addition patients with lower REALM scores had poorer health status as assessed by the MHAQ, an arthritis-specific functional measure, poorer global status scores, and appreciably more hospital outpatient visits (median 6 vs 2 in a 1-year period). Unfortunately function was not measured in our sample of patients.

A study conducted in Glasgow, Scotland of 127 patients with RA found 15% of patients were functionally illiterate with a REALM score of less than 60[25]. Low literacy was also associated with significantly more hospital outpatient visits, but no difference in the median number of previous disease modifying antirheumatic drugs, joint replacements, or function (as assessed by the HAQ score). The authors suggested that more hospital visits were needed to achieve the same therapeutic goal.

Table 5. Number of participants with correct responses for TOFHLA reading comprehension sections and individual numeracy items.

TOFHLA	All Correct (%)	1 Item Incorrect (%)	2 or More Items Incorrect (%)
Reading comprehension sections			
Patient preparation (16 items)	49 (62)	13 (17)	17 (22)
Patient rights (20 items)	34 (43)	20 (25)	25 (32)
Informed consent (14 items)	44 (56)	13 (17)	22 (28)
Numeracy items	Correct		
Timing of medication			
1	79 (100)		
2	79 (100)		
3	74 (94)		
Medicine expiry date	74 (94)		
Medicine every third day			
1	66 (84)		
2	65 (82)		
Blood sugar	73 (92)		
Clinic appointment date	69 (87)		
Clinic appointment place	76 (96)		
No pills to take	69 (87)		
Refill prescription			
1	72 (91)		
2	73 (92)		
3	68 (86)		
When to take medication			
1	76 (96)		
2	71 (90)		
Reapply after 6 months	69 (87)		
Application for financial assistance	34 (43)		

While all 3 literacy tests were significantly correlated with education level, use of educational level alone as a surrogate measure of literacy would have misclassified a number of participants as health literate/illiterate. For example, one participant with completion of Year 10 had inadequate functional health literacy according to the TOFHLA and 2 participants with completion of Years 10 and 11, respectively, had marginal functional health literacy. In contrast, 7 participants who had 8 or less years of schooling (i.e., ≤ Year 8) had adequate functional health literacy according to the TOFHLA. This is in keeping with the results of previous studies, which have also found that although education level is highly correlated with literacy skills, the number of years of school alone does not reliably predict functional health literacy[12].

We found no correlation between age and REALM scores, and, after accounting for education level, age was no longer an independent predictor of TOFHLA and TORCH scores. Other studies have shown that inadequate or marginal literacy as measured by the TOFHLA is significantly higher in those 60 years and over[12,20,36]. However this may reflect age-related difficulty with skills required for performance in the TOFHLA rather than purely health literacy problems[37].

In contrast to previous studies that have found a strong correlation between the TOFHLA (or a shortened version of the TOFHLA, S-TOFHLA) and REALM scores (r = 0.84 and 0.80 respectively)[27,38] we found a somewhat lower but still significant correlation between the 2 tests (r = 0.298, $p < 0.01$). Even so, only 3/8 patients (37.5%) were found to have poor literacy skills on both tests, suggesting that they may be measuring somewhat different traits. While reading recognition tests in which subjects read unrelated words aloud are useful predictors of general reading ability, some patients may correctly pronounce words but do poorly in reading comprehension testing. The ability to correctly pronounce words may also be dependent upon other factors such as familiarity with particular medical terms (e.g., repeated exposure in patients with chronic illness) and the language that literacy is being assessed in. Direct assessment of a person's comprehension of both prose and numerical information may be a better predictor of their ability to comprehend medical terminology or oral and/or written instructions. Some patients may be able to understand medical terms in the context of actual health care situations even though they may have difficulty pronouncing words in isolation[38].

Both the TOFHLA and REALM have been shown to be useful in clinical care. The TOFHLA has been shown to be an independent predictor of patients' knowledge of chronic disease and self-management skills, health status, use of health services, and risk of hospitalization[14,17,39,40]. The REALM score has been found to be more accurate than the reported grade level for estimating understanding of post-operative care instructions[15]. Both tests require interviewer administra-

tion, which may limit their usefulness in routine clinical care although shortened versions of both instruments have been developed including an 8-item version of the REALM[16] and the S-TOFHLA, which has reliability and validity similar to the full TOFHLA but requires a maximum of 12 minutes to complete versus 22 minutes for the full length TOFHLA[38].

We blinded our patients to the true purpose of our study because of the potential for those with limited literacy to decline participation. Previous studies have found that many patients with reading problems are ashamed and may be unwilling to disclose their inability to read[20,41]. Despite our precautions, one patient who declined to participate felt obliged to reveal his inability to read as the reason for nonparticipation. He had never previously disclosed his reading difficulties despite a longterm therapeutic relationship with one of the investigators.

The health literacy tools we used, the REALM and TOFHLA, assume that adequate reading and writing skills are needed to be functionally health literate. Yet, as others have pointed out[42], it is conceivable that people can be functionally health literate with minimal reading and writing skills, depending on how health literacy is defined. They may be able to comprehend directions given orally and/or visually as opposed to in writing, and may be adept at finding information they need in other ways. Further studies are needed to examine these issues.

Innovative strategies for improving health literacy may improve health outcomes. These may include simplifying written information for those with limited literacy; provision of visual and/or interactive materials such as computer multimedia modules; instituting screening programs in clinical practice; education and training of health professionals to vary how they communicate depending upon the literacy skills of their patients; education of family and friends; and creative use of the Internet as a tool for health education. Some evidence-based data suggest that simplifying written patient information improves patient comprehension and health outcomes[43]. For example, Eaton and Holloway showed that adjusting the readability of informational materials to the reading level of patients could improve comprehension[44]. Patients in their study were provided with warfarin information written at either grade 5 or 10 level. Comprehension was significantly better for those who received 5th grade materials. Among those who received 10th grade materials, perception of clarity was highly dependent upon reading skill.

Patients with lower literacy skills are more likely to report problems communicating with their health care providers and have less understanding about their medical conditions and medications[45-47]. They commonly report that physicians do not adequately explain illness or treatments in understandable terms[48]. This implies that health providers may need to vary how they communicate depending upon the literacy skills of their patients. However health professionals are not expressly taught or trained to cater to the needs of those with poor literacy and often have limited awareness of the problem[49]. A recent randomized controlled trial screened all patients for limited health literacy using the S-TOFHLA and then randomized physicians to be notified if their patients had limited health literacy skills[50]. Intervention physicians were more likely than control physicians to use management strategies recommended for patients with limited health literacy and 64% of intervention physicians and 96% of patients felt health literacy screening was useful.

Our results have highlighted that limited health literacy skills are a common problem. Routine formal measurement of health literacy may help to identify those with limited skills who may not otherwise disclose their difficulties. This may lead to better interactions with the health care system, provided health care professionals are both sensitive and responsive to the results. Unresolved issues include unauthorized disclosure of this information, and whether or not to document information relating to literacy/numeracy problems or deficits in the medical chart[51]. Further studies are also needed to determine whether health literacy in individual patients with chronic disease improves due to their increased exposure to the health system. Trials are also required to assess whether interventions to improve communication with patients with limited literacy can translate into improved health outcomes and reduced health care costs.

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REFERENCES

1. Simonds SK. Health education as social policy. Health Educ Monogr 1974;2:1-25.
2. American Medical Association, Ad Hoc Committee on Health Literacy. Health literacy: report of the Council on Scientific Affairs. JAMA 1999;281:552-7.
3. Barlow JH, Wright CC. Knowledge in patients with rheumatoid arthritis: a longer term follow-up of a randomized controlled study of patient education leaflets. Br J Rheumatol 1998;37:373-6.
4. Punchak SS, Kay EA. Educating arthritis patients about their drugs. Pharm J 1988;20:22-4.
5. Kirwan JR. Patient education in rheumatoid arthritis. Curr Opin Rheumatol 1990;2:336-9.
6. Buchbinder R, Hall S, Grant G, Mylvaganam A, Patrick MR. Readability and content of supplementary written drug information for patients used by Australian rheumatologists. Med J Aust 2001;174:575-8.
7. Kirsch IS, Jungelbut A, Jenkins L, Kolstad A. Adult literacy in America: a first look at the results of the National Adult Literacy Survey. Washington: US Department of Health, Education and Welfare; 1993.
8. Australian Bureau of Statistics (ABS). Aspects of literacy: assessed skill levels. Canberra: 1996.
9. Statistics Canada. Reading the future: A portrait of literacy in Canada. Ottawa: Statistics Canada; 1996.
10. Jackson RH, Davis TC, Bairnsfather LE, George RB, Crouch MA, Gault H. Patient reading ability: an overlooked problem in health care. South Med J 1991;84:1172-5.
11. Weiss BD, Hart G, McGee DL, D'Estelle S. Health status of

illiterate adults: relation between literacy and health status among persons with low literacy skills. J Am Board Fam Pract 1992;5:257-64.
12. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate functional health literacy among patients at two public hospitals. JAMA 1995;274:1677-82.
13. Schwartzberg JG. Low health literacy: what do your patients really understand? Nurs Econ 2002;20:145-7.
14. Baker DW, Parker RM, Williams MV, Clark WS, Nurss J. The relationship of patient reading ability to self-reported health and use of health services. Am J Public Health 1997;87:1027-30.
15. Conlin KK, Schumann L. Literacy in the health care system: a study on open heart surgery patients. J Am Acad Nurse Pract 2002;14:38-42.
16. Bass PF 3rd, Wilson JF, Griffith CH. A shortened instrument for literacy screening. J Gen Intern Med 2003;18:1036-8.
17. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. Arch Intern Med 1998;158:166-72.
18. Gazmararian JA, Williams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. Patient Educ Couns 2003;51:267-75.
19. Miles S, Davis T. Patients who can't read. Implications for the health care system. JAMA 1995;274:1719-20.
20. Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. Patient Educ Couns 1996;27:33-9.
21. Larson I, Schumacher HR. Comparison of literacy level of patients in a VA arthritis center with reading level required by educational materials. Arthritis Care Res 1992;5:13-6.
22. Doak CC, Doak LG, Root JH. Teaching patients with low-literacy skills. 2nd edition. Philadelphia: JB Lippincott; 1996.
23. Williams DM, Counselman FL, Caggiano CD. Emergency department discharge instructions and patient literacy: a problem of disparity. Am J Emerg Med 1996;14:19-22.
24. Pincus T, Sokka T, Swearingen C, Swearingen T, Daltroy L, Davis T. Analysis of a rapid estimate of adult literacy in medicine (REALM) and education level in patients with rheumatic diseases. Arthritis Rheum 2000;43 Suppl:S109.
25. Gordon M-M, Hampson R, Capell HA, Madhok R. Illiteracy in rheumatoid arthritis patients as determined by the Rapid Estimate of Adult Literacy in Medicine (REALM) score. Rheumatology Oxford 2002;41:750-74.
26. Australian Bureau of Statistics 2003. Census of Population and Housing, Socio-Economic Indexes for Areas. Australia 2001. Catalogue No. 2039.0. Canberra: ABS; 2003.
27. Parker RM, Baker DW, Williams M, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med 1995;10:537-41.
28. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: A shortened screening instrument. Fam Med 1993;25:391-5.
29. Taylor WL. "Cloze procedure": A new tool for measuring readability. Journal Q 1953;30:415-33.
30. Davis TC, Crouch MA, Long SW, et al. Rapid assessment of literacy levels of adult primary care patients. Fam Med 1991;23:433-5.
31. Slosson RL. Slosson oral reading text (SORT) — revised. East Aurora, NY: Slosson Educational Publications; 1990.
32. Mossenson LH, Hill P, Masters G. TORCH Tests of Reading Comprehension Manual. Melbourne: Australian Council for Educational Research; 1998.
33. Burgon JR. Tests of Reading Comprehension (TORCH) Pilot Study. Wellington: New Zealand Council for Educational Research; 1988.
34. Goyen J. Reading ability of Australian adults. Current Affairs Bulletin 1985;22-4.
35. Hearth-Holmes M, Murphy PW, Davis TC, et al. Literacy in patients with a chronic disease: systemic lupus erythematosus and the reading level of patient education materials. J Rheumatol 1997;24:2335-9.
36. Gazmararian JA, Baker DW, Williams MV, et al. Health literacy among Medicare enrollees in a managed care organization. JAMA 1999;281:545-51.
37. Gausman Benson J, Forman WB. Comprehension of written health care information in an affluent geriatric retirement community: use of the Test of Functional Health Literacy. Gerontology 2002;48:93-7.
38. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. Patient Educ Couns 1999;38:33-42.
39. Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. J Gen Intern Med 1998;13:791-8.
40. Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. Am J Public Health 2002;92:1278-83.
41. Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. Arch Fam Med 1996;5:329-34.
42. Rootman I, Ronson B. Literacy and health research in Canada. Where have we been and where should we go? Can J Public Health 2005;96 Suppl 2:S62-S77.
43. Andrus MR, Roth MT. Health literacy: a review. Pharmacotherapy 2002;22:282-302.
44. Eaton M, Holloway R. Patient comprehension of written drug information. Am J Hosp Pharm 1980;37:240-3.
45. Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. Fam Med 2002;34:383-9.
46. Youmans SL, Schillinger D. Functional health literacy and medication use: the pharmacist's role. Ann Pharmacother 2003;37:1726-9.
47. Schillinger D, Bindman A, Wang F. Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. Patient Educ Couns 2004;52:315-23.
48. Mayeaux EJ, Murphy PW, Arnold C, Davis TC, Jackson RH, Sentell T. Improving patient education for patients with low literacy skills. Am Fam Physician 1996;53:205-11.
49. Tooth L. Poor functional health literacy — the silent disability for older people. Aust J Ageing 2000;19:14-22.
50. Seligman H, Wang FF, Palacios JL, et al. Physician notification of their diabetes patients' limited health literacy. A randomized, controlled trial. J Gen Intern Med 2005;20:1001-7.
51. Montalto NJ, Spiegler GE. Functional health literacy in adults in a rural community health center. W V Med J 2001;97:111-4.