Health Literacy Rates in a Population of Patients with Rheumatoid Arthritis in Southwestern Ontario

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ABSTRACT. ***Objective***. To determine the rate of low health literacy in the rheumatoid arthritis (RA) population in southwestern Ontario.

Methods. For the study, 432 patients with RA were contacted, and 311 completed the assessment. The health literacy levels of the participants were estimated using 4 assessment tools administered in the following order: the Single Item Literacy Screener (SILS), the Medical Term Recognition Test (METER), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Shortened Test of Functional Health Literacy in Adults (STOFHLA).

Results. The rates of low literacy as estimated by STOFHLA, REALM, METER, and SILS were 14.5%, 14.8%, 14.1%, and 18.6%, respectively. All 4 assessment tools were statistically significantly correlated. STOFHLA, REALM, and METER were strongly correlated with each other (r = 0.59–0.79), while SILS only demonstrated moderate correlations with the other assessment tools (r = 0.33–0.45). Multiple linear regression and binary logistic regression analyses revealed that low levels of education and a lack of daily reading activity were common predictors of low health literacy. Using a non-English primary language at home was found to be a strong predictor of low health literacy in STOFHLA, REALM, and METER. Male sex was found to be a significant predictor of poor performance in REALM and METER, but not STOFHLA.

Conclusion. Low health literacy is an important issue in the southwestern Ontario RA population. About 1 in 7 patients with RA may not have the necessary skills to become involved in making decisions regarding their personal health. Rheumatologists should be aware of the low health literacy levels of patients with RA and should consider identifying patients at risk of low health literacy. (J Rheumatol First Release August 1 2015; doi:10.3899/jrheum.141509)

Key Indexing Terms:
RHEUMATOID ARTHRITIS HEALTH LITERACY ONTARIO

Health literacy is defined as an individual's ability to acquire, process, and understand healthcare information for the purpose of making appropriate decisions related to personal health[1]. As reported by the initial results from the International Adult Literacy and Skills Survey, 60% of adult Canadians have inadequate health literacy[2]. Studies in different patient populations indicate that individuals with low health literacy levels are more prone to hospitalization, less likely to use screening and preventive services, and less compliant to treatment[3,4,5,6]. The effect of low health literacy in the management of chronic diseases such as AIDS, asthma, and diabetes has been well documented. Patients with low health literacy levels are not only less knowledgeable of their chronic diseases, but also demonstrate significantly worse treatment outcomes[7,8,9,10].

Rheumatoid arthritis (RA) is a chronic autoimmune disease with a complex and demanding treatment regimen[11] that often evolves over time, making adequate health literacy paramount to optimizing outcomes. To effectively manage RA and to make appropriate RA treatment decisions, it is often necessary for patients to take multiple medications, undergo periodic laboratory monitoring, attend frequent followup visits, and understand medication- and disease-related education materials. Inability to perform these tasks because of low health literacy may lead not only to suboptimal disease control, but also to other negative health consequences because of the significant risks and side effects associated with uncontrolled inflammatory arthritis[11]. Low health literacy in the RA population may place patients at higher risk of noncompliance and misunderstanding of medical instructions[5,6]. A recent study by Caplan, *et al*

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Funded through a grant from the Canadian Initiatives in Outcomes in Rheumatology Care.

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Accepted for publication May 6, 2015.

showed that in a RA population, low health literacy is associated with poorer functional status as measured by the Health Assessment Questionnaire Disability Index[12]. Therefore, it is important to appreciate the health literacy level of patients with RA and to recognize at-risk individuals so as to optimize the efficacy and safety of their treatments. Researchers in the United Kingdom and Australia have demonstrated that a substantial number of patients with RA had limited health literacy levels[13,14]. Although several different health literacy assessment tools were used in those studies, the prevalence of low health literacy was reported to be in the range of 10–15%[13,14]. There are currently no similar data available for the Canadian RA population.

The objectives of our study were to (1) determine the health literacy levels in a group of patients with RA living in southwestern Ontario, using 4 validated health literacy assessment tools; (2) assess the correlations among health literacy assessment tools, and examine any potential similarities and differences existing among these tools; and (3) determine what factors can aid in predicting lower health literacy levels.

MATERIALS AND METHODS

The institutional review board of Western University, London, Ontario, Canada, approved this research. Our study involved 5 outpatient rheumatology practices located at St. Joseph's Hospital, affiliated with Western University. Collectively, these rheumatologists provide service to a referral population of about 1.3 million, more than half of the region's overall population.

Participants. A total of 432 consecutive followup patients with a known diagnosis of RA were contacted by telephone between August and November 2011. Two research assistants (ZG, WC) informed participants of the purpose of the study while minimizing disclosure of the details of each test component. This was done to prevent individuals with lower health literacy from becoming discouraged and declining to participate. The reason for any patient who declined was documented.

Screening. Participants were screened for the following inclusion criteria: (1) age ≥ 18 years, (2) clinical diagnosis of RA, (3) no prior participation in our study, (4) able to read English, and (5) visual acuity better than 20/100.

Measures. The data collection process for each participant was completed in a period of 30 min prior to the scheduled appointment. Research assistants were formally trained to conduct each literacy test according to instructions provided by the test suppliers.

Demographic data collected in our study included age, sex, marital status, country of origin, years lived in Canada, first language, language most often used, employment status, level of education, and income. Other information collected included location of primary residence (urban, suburban, or rural), daily reading, and use of government financial support. In addition, participants were asked to rate the degree of difficulty encountered in accessing and paying for medications, affording assistive devices, meeting rheumatologists, and getting to appointments. Clinical data collected in our study included patient global assessment visual analog scale scores, self-rated general health scores, smoking history, and current medications. The latter results will be reported separately.

Health literacy levels were estimated using 4 assessment tools. The Single Item Literacy Screener (SILS) asks the patient, "How confident are you filling out medical forms by yourself?" The available answers are "very confident, confident, somewhat confident, not confident"[15]. A confidence level below "confident" constituted a positive test in our study. The SILS was embedded into the demographics information portion of the survey, and was completed before the other assessment tools, as recommended by its creators[15]. Next, the Medical Term Recognition Test (METER) was administered. The METER is a brief word-identification test that can be self-completed by patients. It is scored based on the number of correct medical words selected minus the number of non-medical words selected from a list of 80 words[16]. METER scores can be converted to the corresponding literacy levels: low (0–20), marginal (21–34), and functional (35–40)[16]. Participants were classified as having low health literacy levels if they scored 34 or lower. Following the METER, the Rapid Estimate of Adult Literacy (REALM) was administered. This is a reading recognition test consisting of 66 health-related words. REALM scores can be converted to corresponding reading levels: sixth grade or less (scoring 0–46), seventh to eighth grade (scoring 45–60), and ninth grade or above (scoring 61–66)[17]. In our study, participants were classified as having low health literacy levels if they scored 60 or lower. Lastly, the Short Test of Functional Health Literacy in Adults (STOFHLA) was administered. It consists of 2 passages: 1 describes how to prepare for a radiograph, and the other describes the responsibilities of a Medicaid applicant. Each sentence in the passages is missing 1 or 2 words, and for each word missing, the subject is asked to choose a word from 4 available choices so that the completed sentence makes sense[18]. STOFHLA is scored out of 36, with 0–16 indicating illiteracy, 17–22 indicating marginal literacy, and 23–36 indicating adequate literacy[18]. In our study, participants who scored 22 or lower were considered to have low health literacy. The STOFHLA has a time limit of 7 min; this was enforced by the research assistants.

Analysis. Descriptive statistics were used to characterize the data. Pearson product-moment correlation coefficients were calculated for the scores of STOFHLA, REALM, METER, and SILS. Multiple linear regression with backward elimination was used to determine the variables that significantly predicted low health literacy level as measured by STOFHLA, REALM, and METER. Variance inflation factors were calculated for each variable used in the multiple linear regression analyses to rule out potential multicollinearity between variables. Binary logistic regression with backward elimination was used to determine the variables that significantly predicted low health literacy level as measured by SILS. All statistical analyses were completed using SPSS version 20.

RESULTS

A total of 432 patients were contacted by telephone for our study. Forty-six declined to participate (11 were not interested and 35 did not have sufficient time to complete the assessment). Among the 386 patients who agreed over the phone, 64 were unable to complete the health literacy assessments because of unforeseen circumstances, such as missing the appointment, and 11 did not meet the study inclusion criteria. A total of 311 patients completed the assessments.

Participant demographics and health literacy scores according to STOFHLA, REALM, METER, and SILS are listed in Table 1. The majority of participants were women (75.6%) with an average age of 62.8. Almost one-third (27.7%) had less than a high school level of education, which is higher than the population average for southwestern Ontario (17%). Only 27% were currently employed. Of the remaining 73% who were not employed, the majority were retirees (50.5%) or homemakers (10.9%).

The rates of low health literacy as measured by the 4 tests were 14.5% (STOFHLA), 14.8% (REALM), 14.1% (METER), and 18.6% (SILS).

There were significant correlations between the 4 instruments (Table 2). The REALM and METER were the most

Table 1. Participant demographic characteristics and health literacy levels (n = 311). Values are n (%) unless otherwise specified.

Variables	Values
Age, yrs, mean (SD)	62.8 (12.7)
Female	235 (75.6)
Born in an English-speaking country	271 (87.1)
First language is English	259 (83.3)
Primary language spoken at home is English	300 (96.5)
Currently employed	84 (27.0)
Using any form of financial support, not including old-age benefits	59 (19.0)
Highest education level achieved	
Below high school	86 (27.7)
High school	95 (30.5)
Postsecondary	139 (41.8)
Reading on a daily basis	288 (92.6)
Type and population of the community currently residing in:	
Urban, > 50,000	123 (39.5)
Suburban, 10,000–50,000	74 (23.8)
Rural, < 10,000	114 (36.7)
Smoking status	
Never smoked	128 (41.2)
Previous smoker	134 (43.1)
Current smoker	49 (15.8)
STOFHLA score, 0–36	
0–16, inadequate	19 (6.1)
17–22, marginal	26 (8.4)
23–36, adequate	266 (85.5)
Median score (range)	34 (0–36)
REALM score, 0–66	
0–18, third grade or lower	1 (0.3)
19–44, fourth to sixth grade	8 (2.6)
45–60, seventh to eighth grade	37 (11.9)
61–66, ninth grade or above	265 (85.2)
Median score (range)	65 (6–66)
METER score, 0–40	
0–20, low	10 (3.2)
21–34, marginal	34 (10.9)
34–40, functional	267 (85.9)
Median score (range)	38 (2–40)
SILS score	
Very confident	131 (42.1)
Confident	122 (39.2)
Somewhat confident	42 (13.5)
Not confident	16 (5.1)

STOFHLA: Shortened Test of Functional Health Literacy in Adults; REALM: Rapid Estimate of Adult Literacy in Medicine; METER: Medical Term Recognition Test; SILS: Single Item Literacy Screener.

Table 2. Pearson correlation coefficients between the participants' scores in STOFHLA, REALM, METER, and SILS.

Tests	STOFHLA	REALM	METER
STOFHLA	—	—	—
REALM	0.588*	—	—
METER	0.600*	0.789*	—
SILS	0.450*	0.400*	0.328*

* $p < 0.01$. STOFHLA: Shortened Test of Functional Health Literacy in Adults; REALM: Rapid Estimate of Adult Literacy in Medicine; METER: Medical Term Recognition Test; SILS: Single Item Literacy Screener.

Table 3. Multiple linear regression results for significant predictors of low health literacy as estimated by STOFHLA.

Variables	OR (95% CI)	SE	p
Older age, > 65	0.12 (0.06–0.17)	0.03	< 0.001
Born in a non-English-speaking country	2.25 (0.23–4.28)	1.03	0.03
Not speaking English at home	12.13 (8.44–15.82)	1.88	< 0.001
Not reading daily	5.07 (2.68–7.46)	1.21	< 0.001
Low level of education	1.91 (1.13–2.68)	0.39	< 0.001

STOFHLA: Shortened Test of Functional Health Literacy in Adults; SE: standard error.

Table 4. Multiple linear regression results for significant predictors of low health literacy as estimated by REALM.

Variables	OR (95% CI)	SE	p
Male	2.59 (1.01–4.17)	0.80	0.001
Not speaking English at home	12.74 (9.12–16.36)	1.84	< 0.001
Not reading daily	5.77 (3.11–8.44)	1.35	< 0.001
Low level of education	1.85 (1.02–2.68)	0.42	< 0.001

REALM: Rapid Estimate of Adult Literacy in Medicine; SE: standard error.

Table 5. Multiple linear regression results for significant predictors of low health literacy as estimated by METER.

Variables	OR (95% CI)	SE	p
Male	2.23 (0.86–3.59)	0.69	0.001
Born in a non-English-speaking country	2.57 (0.64–4.50)	0.98	0.009
Not speaking English at home	4.71 (1.22–8.21)	1.78	0.008
Not reading daily	4.72 (2.42–7.02)	1.17	< 0.001
Low level of education	1.20 (0.49–1.92)	0.37	0.001

METER: Medical Term Recognition Test; SE: standard error.

Table 6. Binary logistic regression results for significant predictors of low health literacy as estimated by SILS.

Variables	OR (95% CI)	p
Born in a non-English-speaking country	3.89 (1.68–9.01)	0.002
Not reading daily	4.93 (1.82–13.33)	0.002
Low level of education	1.89 (1.25–2.88)	0.003

SILS: Single Item Literacy Screener; SE: standard error.

strongly correlated tests, while SILS only demonstrated weak correlations with all the other tests.

Table 3, Table 4, and Table 5 show the results of multiple linear regression analyses for determining the predictors of low health literacy as measured by STOFHLA, REALM, and METER. Table 6 shows the result of binary logistic

regression analysis for determining the predictors of low health literacy as measured by SILS. Lower levels of education and a lack of daily reading activities were significant predictors of low health literacy using all 4 tests.

DISCUSSION

Rates of low health literacy. We report that low health literacy rates among patients with RA in Southwestern Ontario range from 14.1–18.6%, as measured by STOFHLA, REALM, METER, and SILS. These rates are similar to those reported in samples of patients with RA in Australia (10%) and the United Kingdom (15%)[13,14]. In the United States, Hirsh, *et al* reported a higher prevalence of low literacy among patients with RA (34%) as measured by STOFHLA[19]. However, the discrepancy could be explained by the fact that the Hirsh study took place in an urban "safety net" clinic that served disproportionally more socially disadvantaged minorities[19].

The low health literacy rates as measured by the 4 tests were remarkably similar, and the degree of similarity was reflected by the significant correlations existing among them. There was a strong correlation between REALM and METER, confirming results reported by Rawson, *et al*[16]. The STOFHLA, however, correlated with the other instruments to a lesser degree, possibly because it places a greater emphasis on reading comprehension than do the REALM or METER tests[18]. As expected, SILS demonstrated only weak correlation with the other instruments, because SILS is a self-reported health literacy assessment in contrast to the other objective, test-based instruments[15].

Daily reading and education as important predictors of health literacy. Through multiple linear regression and binary logistics analyses, we found a lack of daily reading activities and low education level to be significant predictors of low health literacy, as measured by all 4 tests used in our study. Education is an important determinant of literacy, and education level achieved has been shown to significantly correlate with health literacy[8,13,20]. Therefore, lower education level being a significant predictor of low health literacy in all 4 tests used in our study was expected. However, an unexpected finding was that reading on a daily basis was a more powerful predictor of health literacy than education in 3 of the 4 tests. Past research has indeed demonstrated that the frequency of reading activities is significantly correlated with health literacy[21], particularly in an older population like the one in our study. Daily reading contributes to better health literacy, potentially through 2 mechanisms. First, effective reading is thought to be a skill that needs to be maintained. It has been suggested that an individual could prevent the decline of reading skills through daily practice[21]. Second, mentally engaging activities such as reading have been found to preserve cognitive functions in the elderly[22]. Because of these positive effects of daily reading activities, it is possible that daily reading is indeed a stronger predictor of health literacy than education in an older population.

Similarities and differences in the predictive factors of low health literacy in STOFHLA, REALM, and METER. In our study, STOFHLA, REALM, and METER demonstrated strong correlations with each other while they showed only moderate correlations with SILS. For STOFHLA, REALM, and METER, not speaking English at home was a significant predictor of low health literacy, in addition to lack of daily reading activities and low levels of education. For STOFHLA and REALM, in particular, not speaking English at home was the strongest predictor of low health literacy. Previous reports have shown that patients whose primary language spoken at home is not English are less knowledgeable about the management of their diseases and are less likely to seek preventive care[23,24,25]. The results of our study support these observations.

A characteristic observed with both REALM and METER, but not STOFHLA, was that sex is a significant predictor of performance, with women more likely to achieve a higher score. This difference can possibly be attributed to the different approach that each test takes to assess health literacy. Research indicates that women are more likely to perform significantly better in tasks involving word recognition and verbal fluency than men[26,27,28,29]. These are precisely the instrumental skills needed to excel in REALM and METER, which help explain women's statistically better performance on these tests. However, although women perform better in word recognition and verbal fluency, literature also suggests that there are no overall differences between the sexes with respect to comprehension[26]. This observation coincides with our findings. We found no sex differences in performance demonstrated with STOFHLA, which emphasizes comprehension. Because the management of RA frequently requires the patient to have a concrete understanding of complex education materials and instructions, the STOFHLA may be a more relevant gauge of health literacy in this population. Further, because of the RA population being older and having a greater proportion of women, a test such as the STOFHLA, which demonstrated no sex differences in performance and a high sensitivity to decline in comprehension, may be more desirable. The disadvantage of STOFHLA compared with REALM, METER, and SILS is that it is a longer and more intensive test; thus, it may not be convenient to use in a clinical setting.

Strengths and limitations. The strengths of our study are its large patient population and the number of health literacy assessment tools examined. The number of participants in this study exceeded those of previous reports from the United States, United Kingdom, and Australia[13,14,19]. In addition, patients in our study were from both rural and urban populations; thus, the result may be generalizable to a regional and possibly national level. This study is also, to our knowledge, the only one that examined 4 commonly used health literacy assessment tools and allowed them to be compared directly.

Our study serves as a reminder that poor health literacy is

widely prevalent in Canada. While identifying the most appropriate health literacy assessment tools to use in a population of patients with RA is important from a research perspective, it is important to remember that in the routine clinical setting, validated assessment tools should not replace motivational communication strategies that allow patients to ask questions and be engaged in their own healthcare decisions. Indeed, such tools might serve as useful adjuncts to motivational communication approaches in the clinical setting.

There are potential limitations of our study. One was the possible bias introduced by patients who declined to participate. Previous literature showed that individuals with low literacy tend to be embarrassed by their reading difficulties[30]. Despite our best effort to present the tests in a neutral way and to treat the patients with utmost respect, we still had a significant number of participants who declined to participate. The majority of patients could not participate because of time constraints; however, it is possible that some declined because of perceived low literacy. It is also possible that some predictors of low health literacy could have been missed. We used a multiple stepwise linear regression model to identify variables that were predictive of low health literacy. While this model is widely used in the literature, stepwise regression tests multiple hypotheses and is based on methods that were intended to test prespecified hypotheses. The results of the multiple linear regression analyses were based on 11 predictors we hypothesized to be related to low health literacy. However, there could be other significant predictors of low health literacy that we did not explore as part of our model. Survey error might have arisen from sampling, non-coverage, and instrument measurement error. We tried to minimize the potential for these errors by training a limited number of research assistants to administer the tests, by sampling over a 4-month period, and by including more than half the hospital-based rheumatology clinics in the region. Finally, we did not use any numeracy tests to evaluate the literacy of our sample. Numeracy skills have been reported to play a role in health literacy and have also been shown to decline with health status[31].

Our study demonstrated that low health literacy levels are highly prevalent in the RA population of southwestern Ontario. Given previous studies indicating that individuals with low health literacy levels have more difficulty navigating the healthcare system and experience worse treatment outcomes, it is important to raise awareness of poor health literacy rates in the RA population. The adoption of validated health literacy assessment tools could prove to be beneficial in improving overall patient care[5,7] and serve as adjuncts to routine patient interviews and encounters. Although STOFHLA, REALM, METER, and SILS are all validated tools that can be used to assess health literacy levels of patients, the results of our study suggest that some differences exist among the 4 tests. For the RA population, STOFHLA may be the most appropriate test to use.

ACKNOWLEDGMENT

We acknowledge the entire Division of Rheumatology at Western University, our support staff including our Research Coordinator Wendy Curren, and the research participants who made this study possible. We also thank Jon Tingey, a research student who helped collect the data for this study, and Christina Clark for editorial support.

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