How well do patients understand written instructions?: health literacy assessment in rural and urban rheumatology outpatients

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How well do patients understand written instructions? Health literacy assessment in rural and urban Rheumatology out-patients

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Abstract

Objective. To assess literacy (word recognition and comprehension) in patients at a rural Rheumatology practice and to compare this to literacy levels in patients from an urban Rheumatology practice.

Methods. Inclusion criteria for this cross-sectional study: ≥ 18 yo patients at a rural Rheumatology practice (Mid-North Coast Arthritis Clinic, MNCAC, Coffs Harbour, Australia) and an urban Sydney Rheumatology practice (Combined Rheumatology Practice, CRP, Kogarah, Australia). Exclusion criteria: ill-health precluding participation; poor vision/hearing, non-English primary language. Word recognition was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM). Comprehension was assessed using the Test of Functional Health Literacy in Adults (TOFHLA). Practical comprehension and numeracy was assessed by asking patients to follow prescribing instructions for five common Rheumatology medications.

Results. At the rural practice (MNCAC), 124/160 patients agreed to participate (F:M, 83:41, mean age 60.3 ±12.2) while the corresponding number at the urban practice (CRP) was 99/119 (F:M, 69:30, mean age 60.7±17.5). Urban patients were more likely to be born overseas, speak another language at home and be employed. There was no difference in REALM or TOFHLA scores between the two sites and so data was pooled. REALM scores indicated 15% (33/223) of patients had a reading level ≤ Grade 8 while 8% (18/223) had marginal or inadequate functional health literacy as assessed by the TOFHLA. Dosing instructions for Ibuprofen and MTX were incorrectly understood by 32% (72/223) and 21% (46/223) of patients, respectively.

Conclusion. Up to 15% of rural and urban patients had low literacy and < 1/3 of patients incorrectly followed dosing instructions for common Rheumatology drugs.
There was no significant difference in word recognition, functional health literacy and numeracy between rural and urban Rheumatology patients.

**Short Title**

Health literacy in rural and urban Rheumatology out-patients

**Key Indexing Terms**

Literacy, Rheumatoid arthritis, Rural, Communication
INTRODUCTION

Literacy is defined as “the ability to read and use written information and to write appropriately in a range of contexts”. ¹ Health literacy is a more specialised aspect of literacy and is “the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions”. ²

The National Assessment of Adult Literacy (NAAL) in the United States (US) found that 5% of 19,000 participants were non-literate and 43% of participants had either basic or below basic English literacy. ³,⁴ The Adult Literacy and Life Skills Survey found that up to 60% of Australians aged 15 to 74 years achieved scores below Level 3 for the health literacy domain, where Level 3 is the 'minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy'. ⁵ Similar results were reported from Canada.⁶

Low literacy is associated with poorer health outcomes, for example increased asthma morbidity⁷,⁸, poorer diabetic control⁹,¹⁰, less stable anti-coagulation¹¹ and increased mortality.¹²,¹³ Those accessing healthcare require adequate health literacy and numeracy (the ability to use and understand numbers in daily life)¹⁰ skills to understand written instructions regarding medication, appointments with healthcare professionals and to calculate correct medication doses.¹⁴,¹⁵ Patient self-reported reading skills correlated poorly with actual reading scores.¹⁶ Limited health literacy is associated with medication non-compliance and misunderstanding of instructions on medication prescription labels.¹⁷-¹⁹ Patients with poorer health literacy were less likely to keep appointments with healthcare professionals, participate in health screening programs or seek medical assistance.²⁰ Poor health literacy has also been linked to
less health knowledge and fewer self-care behaviours.\textsuperscript{21, 22}

Limited health literacy affects use of healthcare resources and expenditure.\textsuperscript{23-28} Poor health literacy also raises questions regarding informed consent, the right to quality care and anti-discrimination.\textsuperscript{29} Limited health literacy can be a significant source of shame and embarrassment.\textsuperscript{30, 31}

Despite significant rural populations in countries such as the US, Canada and Australia, there is limited data regarding health literacy among rural residents. The largest published study addressing this examined 3850 rural residents (population centre < 50 000 people) and 14 260 urban dwellers from the NAAL database.\textsuperscript{32} Rural residents performed worse in all domains of literacy and health literacy. However, there was no difference in health literacy between the two groups once age, gender, ethnicity, education and income were corrected for.\textsuperscript{32}

Ten percent of patients with rheumatoid arthritis attending a community-based Australian Rheumatology practice had inadequate or marginal functional health literacy or a reading age at or below the US high school grade equivalent of 7th–8th grade.\textsuperscript{33} However, as that practice was located in an affluent suburb of a major capital city, these findings may not be generalisable to other demographic areas. Up to 24\% of Rheumatology patients at an academic US medical centre had a reading level of eighth grade or less.\textsuperscript{34} One in six Rheumatology patients at a Scottish hospital were illiterate and struggled to understand education materials and prescription labels.\textsuperscript{23} These findings are concerning, as Rheumatologists often use medications such as methotrexate or biologic therapies with severe side effects if taken incorrectly.
Given the lack of data regarding literacy in rural patients we sought to 1) determine the level of health literacy (word recognition, comprehension and numeracy) in outpatients attending a rural Rheumatology practice; 2) compare the health literacy of these patients to those attending an urban Rheumatology practice; and 3) determine whether patients were able to follow written dosing instructions for common medications used in Rheumatology practice.

PATIENTS AND METHODS

Design

This was a cross-sectional study involving two community-based Rheumatology practices, a rural one in Coffs Harbour and the other in Kogarah, Sydney both in New South Wales (NSW), Australia.

Setting and study participants

Coffs Harbour (pop. 70 000 people, pop. density 60.4 persons/km²) is located halfway between the major cities of Sydney and Brisbane but provides specialist medical services to another 50 000 people in the surrounding area. Rheumatology services are provided by two resident Rheumatologists (HB and PKKW) at the private Mid-North Coast Arthritis Clinic (MNCAC). Kogarah (pop. 60 000 people, pop. density 3790.7 persons/km²) is a suburb located approximately 10 km southwest of Sydney CBD. The Combined Rheumatology Practice (CRP) is a private group practice (participating Rheumatologists, FJ and PB) located in Kogarah that provides Rheumatology services to the surrounding area.

Every fifth patient attending either the rural (MNCAC, n= 161) or urban (CRP, n= 130) practice was contacted by a combination of mail and telephone over a five-
month period using a standard *proforma*. Patients were offered study participation at a
time of their convenience, usually before or after the next scheduled appointment with
a Rheumatologist. As knowledge of the purpose of this study may have resulted in
those with poor literacy declining participation, patients were blinded to the exact
study aim. Instead, they were told the aim was to assess what they understood from
reading material used by the practice. This would assist with design of better patient
educational brochures.

Exclusion criteria were as follows: age < 18 years, low vision preventing reliable
reading of assessment tools, poor hearing limiting ability to reliably follow verbal
instructions, inability to speak English or severe ill-health.

**Outcome measures**

All structured interviews were performed under no significant time constraints in a
quiet well-lit room by one observer (LC). Study participants wore hearing and visual
aids if these were usually worn. Corrected vision was tested using a non-alphabet
Snellen chart. Hearing was assessed by asking the participant if they could hear
speech at normal conversational levels. The following patient demographics were
recorded: age, sex, ethnicity, marital status, occupation, country of birth, primary
language spoken at home, Aboriginal or Torres Strait Islander heritage, years
completed at school, further education and internet use (“Do you use the internet at
least once per week?”) Participant occupations were classified into eight major
categories according to the Australia and New Zealand Standard Classification of
Occupations (ANSCO).37

Word recognition was assessed using the Rapid Estimate of Adult Literacy in
Medicine (REALM), a standardised test widely used as a health literacy screening tool (Table 1).\textsuperscript{38-40} This tool (maximum possible score 66) requires less than five minutes to administer and assesses recognition of common medical words. For this study, American-English spellings were changed to Australian-English spellings, for example ‘behavior’ to ‘behaviour’. Testing involved presenting participants with a laminated sheet containing three lists of 22 words each, arranged in ascending order of number of syllables and pronunciation difficulty.\textsuperscript{38} Patients were asked to read aloud as many words as possible beginning with the first word in the first column. If they were unable to pronounce several consecutive words, they were asked to scan down the list and pronounce as many of the remaining words as possible. The scoring standard was dictionary pronunciation.\textsuperscript{38} The final score was used to derive US high school grade range estimates (equivalent to Australian school grades 1-12)\textsuperscript{41} as an approximation of health literacy.

Functional health literacy and numeracy was assessed using the Test of Functional Health Literacy in Adults (TOFHLA).\textsuperscript{42} This is a well-validated instrument developed to assess patient functional health literacy using material from healthcare settings such as prescription labels and appointment slips.\textsuperscript{43} The final score (range 0 – 100) allows allocation into categories of functional health literacy (Table 1).\textsuperscript{42} As the TOFHLA was designed for a US population, minor modifications were made to some words to improve cultural appropriateness for an Australian setting.\textsuperscript{44,45}

While a critical appraisal of 19 health literacy assessment instruments found the REALM and TOFHLA had the strongest psychometric properties, these do not contain specific items relevant to routine Rheumatological practice.\textsuperscript{45} Hence, to assess practical literacy and numeracy skills participants were asked to follow standard
prescribing instructions for five commonly used Rheumatology medications (Table 2). These instructions were on average, ‘readable’ for those with the equivalent of the upper level of a sixth grade education (6.954) by Flesch-Kincaid Reading Ease analysis (63.7/100). However, as these were not a validated literacy assessment tool this instrument will be referred to as the Rheumatology Literacy Guide (RLG).

**Statistical analyses**

Descriptive summary statistics (means and medians, as appropriate) were used to summarise participant demographic characteristics. Student’s t-test was used to compare means of normally distributed parameters. As many of the variables were skewed the Mann-Whitney U test was used to compare medians of the two groups. Frequency data were analysed using chi-square testing. For all statistical tests, p<0.05 was considered significant. Spearman correlation coefficients were used to examine associations between non-normally distributed variables. Data analysis was undertaken using IBM SPSS Statistics version 19, Armonk, NY, USA.

**Ethical approval**

Approval was obtained from the North Coast Area Health Service Human Research Ethics Committee (HREC) for the Coffs Harbour site and the University of New South Wales HREC for the Sydney site.

**RESULTS**

There were 223 participants in the study, n=124 from the rural practice (MNCAC, Coffs Harbour) and n=99 from the urban practice (CRP, Kogarah). One patient at each practice was excluded due to poor vision and ten patients at the urban practice were excluded, as their primary language was not English.
Characteristics of study participants are shown in Table 3. The mean age of participants at both sites was 60 years, while approximately two-thirds of participants were female. A higher proportion of participants from the urban practice was born overseas (p=0.007) and spoke a primary language other than English at home (p=0.006). Subjects from the rural practice (MNCAC) had lower levels of education, were more likely to be unemployed and if employed, were less likely to managers or professionals.

Thirty-six out of 160 patients (22.5%) approached at the rural practice (MNCAC) declined participation, compared to 20 out of 119 participants (16.8%) at the urban site (CRP, p >0.05). Overall, 56 out of 279 (20%) patients approached declined study participation. There was no difference between the two practices in mean age, sex or proportion born overseas in those declining participation (data not shown). There was also no difference in mean age or sex between those who declined participation compared to study participants (data not shown). Reasons for declining participation are outlined in Table 4. Three patients at the rural site (MNCAC) admitted they had poor literacy and declined study participation due to embarrassment. These were excluded from the analysis.

**Health literacy scores by practice**

Results of health literacy assessment (REALM, TOFHLA and RLG) are shown in Table 5. The REALM scores indicated more subjects from the rural practice compared to the urban site had a Grade 8 or lower word recognition level [23/124 (19%) versus 10/97 (10.3%), respectively]. However this difference was not statistically significant (p=0.09 by chi-square analysis).
The TOFHLA scores indicated that 12/124 (9.7%) of rural patients had inadequate or marginal functional health literacy compared to 6/97 (6.2%) of urban subjects (Table 5). This difference was not statistically significant (p=0.35).

Approximately one-third of participants answered Question 2 (Ibuprofen) and up to one quarter of participants answered Question 4 (MTX) incorrectly (Table 5). Questions dealing with Tramadol, Prednisone and Alendronate were answered correctly by most participants.

**Correlations between health literacy scores and demographic variables**

Spearman correlation coefficients examining the relationship between relevant study variables are shown in Table 6a. There was a moderately strong positive correlation (r= 0.39; p<0.01) between REALM and TOFHLA scores. The RLG scores correlated weakly (r=0.27; p<0.01) with REALM scores and moderately strongly with TOFHLA scores (r= 0.43; p<0.01). There was a moderately strong negative correlation between TOFHLA scores and increasing age (r= -0.32; p<0.01) but a moderately strong positive correlation with school years completed (r= 0.42; p <0.01) and internet use (r= 0.45; p<0.01). Scores on the RLG correlated moderately strongly with school years completed (r= 0.34; p<0.01) and internet use (r= 0.39; p<0.01). REALM scores also correlated moderately strongly with internet use (r= 0.32; p<0.01).

Table 6b shows median health literacy scores from the REALM, TOFHLA and RLG stratified by demographic variables. Females scored better on the TOFHLA (p=0.036) and REALM (p=0.009) compared to males. As expected, those whose primary
language spoken at home was English, were university educated or currently employed performed better on the REALM, TOFHLA and RLG than those who spoke another primary language at home, had not attended university or were currently unemployed. Internet users also performed better on all three measures than those who did not use the internet.

DISCUSSION

Previous studies of literacy in Rheumatology patients have examined urban populations in tertiary referral centres. We extend these findings to show comparable levels of low literacy in rural residents. There was no significant difference in word recognition, comprehension and understanding of common Rheumatology medication dosing instructions between rural and urban Rheumatology patients. Despite a higher proportion of rural compared to urban participants having Grade 8 or lower word recognition ability (18.5% at MNCAC versus 10.3% at CRP, respectively) using the REALM and having marginal or inadequate functional health literacy using the TOFHLA (9.7% at MNCAC versus 6.2% at CRP, respectively) these differences were not statistically significant. We also found up to one-third of patients were unable to correctly follow written dosing instructions for commonly prescribed potent Rheumatologic medications.

Given the rural centre had higher unemployment (8.3% for Coffs Harbour versus 5.5% for Kogarah), lower mean annual income ($38,578 for Coffs Harbour versus $50,261 for Kogarah) and fewer managers/professionals (71% for Coffs Harbour versus 78% for Kogarah) it is surprising there was no significant difference in literacy between rural and urban patients. While the NAAL study found rural residents performed worse in all domains of literacy and health literacy, this
difference disappeared once age, gender, race/ethnicity, education and income were controlled for. As the rural site was a private practice where consultation fees were charged, we wondered whether patients may not have been representative of a poorer rural population. However, as expected rural participants had a lower level of school and higher education completion and were more likely to be unemployed than their urban counterparts (Table 3). The urban study sample had a higher proportion of overseas-born patients and more patients who spoke a non-English primary language at home. These factors may have counteracted the disadvantage associated with poorer education and higher unemployment status of the rural study sample.

The higher proportion of patients declining participation at the rural site (22.5% at MNCAC versus 16.8% at CRP, respectively) may also have biased towards the null hypothesis. Three rural patients declined study participation due to embarrassment from poor literacy and were excluded from the analysis. None at CRP did so for this reason. Others declined participation with no reason offered, or with reasons such as “I’m feeling unwell” or “I don’t have enough time” (Table 4). Those at risk of poor literacy may decline study participation citing reasons other than embarrassment. This is not surprising as formal literacy assessment can be threatening, with a fear of decreased self-esteem and social acceptance on the part of the participant. Health practitioners should be alert to these issues because many patients are unwilling to admit they have literacy problems. The proportion of patients with poor health literacy is therefore probably under-reported.

Regardless of geographic location, up to 15% of Rheumatology patients would have difficulty reading and understanding most patient education materials. This may even be an under-estimate as 20% (n=56/279) of our pooled study sample declined study
participation (Table 4). Some of those declining may have been at risk of poor literacy.

Although participants generally performed well on both the REALM (median score 65 from a possible maximum score of 66) and TOFHLA (median score 95 from a possible maximum score of 100), up to one-third of patients could not correctly follow dosing instructions for Ibuprofen or MTX (Table 5). This is concerning as these medications are commonly used in Rheumatology practice, and if taken incorrectly can cause serious complications - even death. This suggests literacy assessment tools such as the REALM and TOFHLA may not necessarily be predictive of a patient’s ability to follow medication dosing instructions, possibly due to a “ceiling effect”.

This study identified several possible risk factors for poor health literacy: male sex, non-English primary language, lack of university education, lack of employment and failure to use the internet (Table 6a). While many of these have been previously identified\(^3\)-\(^5,20\) no single factor is a robust predictor of poor literacy. However, all these factors are easily elicited during clinical assessment, and when taken together may assist in identifying those at risk of low health literacy. A novel finding of our study was that internet use correlated moderately strongly with all three health literacy assessment tools. While this requires further analysis in larger studies, poor information/technological literacy as exemplified by limited computer and internet use has previously been associated with poor overall literacy.\(^50\) Despite the benefits and increasing use of eHealth applications for patient education, these may be of limited utility in those with poor health literacy.\(^50\)
Improving healthcare professionals’ awareness of health literacy is important as patients are unlikely to disclose difficulty understanding medication instructions\textsuperscript{31} and also over-estimate their reading ability.\textsuperscript{16} Helpful strategies to address poor health literacy include assessing baseline patient understanding of their condition before providing information, use of plain language rather than medical jargon, emphasizing less than three main points which are repeated several times during the consultation and use of the ‘teach back’ technique which involves asking patients to explain or demonstrate what they have been told.\textsuperscript{51,52} As most Rheumatology patient education materials are written at readability levels above the recommended sixth-grade reading level \textsuperscript{53}, assessment of design and readability of such material is recommended with use of pictures and videos instead of written text.\textsuperscript{31,54} Resources such as the Health Literacy Universal Precautions Toolkit are readily available to assist clinicians to reduce the complexity of medical care and ensure patients successfully navigate the healthcare system.\textsuperscript{54}

Our results show that up to 15% of patients from either a rural or urban location have poor health literacy. It is concerning that up to one-third of patients in this study were unable to correctly follow written dosing instructions for commonly prescribed Rheumatologic medications. This may not be well predicted by traditional literacy assessment tools such as the REALM and TOFHLA. Although poor health literacy is a sensitive and challenging issue for patients and clinicians, it needs to be addressed. Risk factors for poor health literacy which can be easily elicited during a consultation may be male sex, overseas birth, a non-English primary spoken language at home, lack of university education, lack of current employment and lack of internet use.
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