Literacy in Primary Care Populations
Is it a Problem?

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ABSTRACT

Background: Almost half of Canadians experience difficulty using print media, according to the 1994 International Adult Literacy Survey. Our objectives were to estimate the prevalence of low-literacy patients in our practice, to determine whether reading grade level is associated with self-perceived health status in primary care, and to evaluate the reading difficulty of commonly used patient education pamphlets.

Methods: We surveyed a random sample of 229 patients aged 18 to 85 years presenting for scheduled and walk-in care. Main outcome measures were reading ability as estimated by word decoding skill with the validated Rapid Estimate of Adult Literacy in Medicine (REALM) and self-perceived health status using COOP/WONCA functional health measures. We assessed the reading difficulty of 120 commonly used patient education pamphlets using the Simple Measure of Gobbledygook (SMOG) formula.

Results: The prevalence of low-literate patients was 9%. Poor reading ability in English was most likely among patients under 45 years of age not having completed high school, and among those whose maternal language was neither English nor French (immigrants). REALM scores and self-perceived health were weakly correlated but not significant statistically. The mean reading grade level of pamphlets was grade 11.5 (SD: 1.5). Seventy-eight percent of pamphlets required at least a high school reading level.

Conclusion: Literacy levels were higher than expected in our patient population; this finding may be due to the rapid assessment tool used, which may have underestimated the difficulty of using print media. Clearly, the vast majority of commonly used patient education materials would not meet the needs of low-literate patients, who may be more likely to experience poorer health. Providers need to be sensitive to the reading limitations of patients and patient education materials should be written at a lower reading level.

La traduction du résumé se trouve à la fin de l'article.

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to 85 years and had clinical encounters in English, because our instrument for measuring reading level was validated only for English. They were excluded if they said they were “too ill” or had “poor vision”. Parents accompanying patients aged less than 10 years were also selected. The hospital Research Ethics Committee approved the study.

Consenting participants first completed the functional health status measurement with COOP/WONCA Charts.17 Reading level was then assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM).18 The selection of measurement instruments was constrained by the practical need to complete consent process and data collection in approximately 10 minutes before patients’ clinical encounters. One research assistant administered both after the consent form was read aloud and the patient had agreed to participate.

COOP/WONCA Functional Health Charts
The COOP/WONCA Charts,17 based on Nelson’s COOP Charts,19 were developed to measure primary care patients’ perceptions of their overall health and well-being. Our main construct of interest was perceived overall health but we also measured the dimensions of daily activities, social activities and feelings (emotional problems). There is one item per dimension. Each category is illustrated with a pictogram and accompanying qualitative word(s). Patients are asked to rate each health dimension during the last two weeks on a scale from 1 (excellent) to 5 (poor). To differentiate between current and overall health, we also asked patients to rate their health “today”.

The Overall Health scale has been found to perform as well as the General Health Perception scales of the Medical Outcomes Study Short Form (SF-36) in discriminating between people with and without recent work absenteeism (ROC=0.74 and 0.72, respectively) in a representative sample of the Dutch population.20 It correlates well with the five EuroQol items of Mobility (r=0.61), Self-care (r=0.69), Usual Activities (r=0.79), Pain/Discomfort (r=0.66), and Anxiety/Depression (r=0.68). It has a correlation of 0.62 with the SF-36 General Health Perceptions scale and 0.46 with the General Health Questionnaire.17

Rapid Assessment of Adult Literacy in Medicine (REALM)
The REALM18 measures a patient’s ability to correctly pronounce 66 common lay medical words in ascending order of difficulty. It does not assess their understanding of them, but inability to pronounce words is assumed to indicate a problem with comprehension and use of print. It has been used widely to profile the reading skills of patient populations.22 A raw score of 44/66 translates to a reading grade estimate of Grade 6, the cut-off point for designating low literacy. Test-retest reliability is 0.99 (p<0.001). There is a high correlation between REALM raw scores and the raw scores of three standardized reading tests used with adults: Sort-R (r=0.96), PIAT-R (r=0.97) and WRAT-R (r=0.88).18

Readability of written material
Parallel to the patient survey and using the Simple Measure of Gobbledygook (SMOG) formula,23 we assessed the readability level of 120 educational pamphlets that were most used by nurses and family physicians in the practice.24 Polysyllabic words in portions of text were counted and results translated to a reading level estimated to be accurate within 1.5 grades.23 This method does not take into account the layout of the material nor the patient’s interest and familiarity with the topic.25-27

Analysis
A priori, we estimated that a sample of 200 consenting patients would detect a prevalence of low literacy between 15% and 40% with a 5% margin of error and, for that prevalence, would detect a 1-point difference in the 5-point Overall Health scale between low- and high-literacy patients with 90% power (alpha of 0.05). The association between reading level and perceived overall health was examined by correlation analysis and multivariable linear regression controlling for observed confounders. To profile low-literacy patients, we used multivariable modeling to find the best explanatory model, with low literacy status as the dependent variable.
The selection of the 229 participating patients is illustrated in Figure 1. Characteristics of consenting and non-consenting patients are compared in Table I. Non-consenting patients had fewer years of education and were more likely to have a maternal language other than English or French. The educational achievement level in our study sample is higher than primary care patients as a whole in Quebec.

The mean score on the REALM instrument was 60 out of 66; the median was 64, equivalent to a mean reading grade level of at least high school. The prevalence of low-literacy patients among consenting patients was 7% (95% CI: 3.4 to 9.8%). If we assume that the 8 patients who refused to participate for reading-related reasons (“forgot my glasses”, “can’t read today”, “I don’t need to be tested”) had low literacy and that the 7% prevalence of low literacy applies to the remaining non-consenters, then the estimated prevalence among the eligible patients would be 9% (95% CI: 6.0 to 12%). Still, this is considerably lower than our lowest a priori estimate of 15%.

Nine of the fifteen low-literacy patients had only primary school education or less. The perceived overall health of low-literate patients was poorer on average than that of high-literate patients, but the difference was not statistically significant (3.3 vs. 3.0, t=1.10, p=0.27, 1 excellent – 5 poor). The relationship between reading level and overall health did not change in a multivariable regression model controlling for confounding factors of age, maternal language and smoking (Table II). Education was not included in the model because it was collinear with the REALM score.

The multivariable model that best predicted the reading level of patients was: maternal language other than English or French, years of education, and age. Patients whose maternal language was neither English nor French (immigrants) scored on average 4.4 points lower on the REALM. The REALM score was positively correlated with years of education (Pearson r=0.40, 95% CI: 0.30 to 0.62) (Table I), but age modified the effect of educational achievement. Patients aged 45 years and over with less than high school education had significantly higher reading levels than did patients aged less than 45 years with similar educational attainment. For patients with at least high school education, age had no effect on reading level. Of the observed variance in reading level, 16.7% was explained by educational level alone.

The reading level of patient education materials ranged from grades 7 to 15 but the mean reading level was grade 11.5 (SD: 1.5 yrs). Only two pamphlets had a reading level of grade 7 to 8 (<1%); 78% were written at a grade 10 to 12 reading level.

### RESULTS

#### DISCUSSION

The 9% prevalence of low-literacy patients in the practice was considerably lower than our lowest projection (15%) or the estimated Quebec prevalence of 28%. This difference may be attributed to the difference in measurement instruments. REALM is a 2-3 minute test of word pronunciation ability whereas the International Adult Literacy Survey procedure takes an hour to administer and measures three dimensions of literacy: prose (reading and understanding a written passage such as the instructions on a medication label), documentation (such as practical use of bus schedules), and quantitative skills (such as completing an order form).

The REALM instrument may have overestimated literacy, as patients able to correctly pronounce words may not have understood them. Scoring decisions in our multi-ethnic practice population were often problematic because it was difficult to judge between a strong accent and mispronunciation. However, patients seen to understand them had significantly higher reading levels than those with borderline low literacy. Some experts recommend further assessment of those attaining a REALM score of 60 or over using a more sensitive instrument.

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### TABLE I

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Consenting Patients (n=229)</th>
<th>Non-consenting Patients (n=35)</th>
<th>Test of Significant Difference</th>
<th>Population of Quebec*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (yrs)</td>
<td>47</td>
<td>52</td>
<td>t=1.35 p=0.18</td>
<td>48.9 (SD: 18.7)</td>
</tr>
<tr>
<td>Female (%)</td>
<td>61</td>
<td>59</td>
<td>χ²=0.37 p=0.85</td>
<td>65</td>
</tr>
<tr>
<td>Education (yrs)</td>
<td>13.5</td>
<td>10.2</td>
<td>t=3.70 p&lt;0.001</td>
<td>11.1 (SD: 3.5)</td>
</tr>
<tr>
<td>Maternal language (%):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>51</td>
<td>34</td>
<td>χ²=4.22 (2df)</td>
<td>—</td>
</tr>
<tr>
<td>French</td>
<td>12</td>
<td>9</td>
<td>p=0.04</td>
<td>—</td>
</tr>
<tr>
<td>Other</td>
<td>32</td>
<td>56</td>
<td></td>
<td>—</td>
</tr>
<tr>
<td>Current smoker (%)</td>
<td>26.6</td>
<td>20.0</td>
<td>χ²=0.51 p=0.47</td>
<td>27</td>
</tr>
</tbody>
</table>

* Source: Reference 28

### TABLE II

<table>
<thead>
<tr>
<th>Variable</th>
<th>Multivariate β (95% CI)</th>
<th>Semi-partial R²†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>2.6</td>
<td>0.009</td>
</tr>
<tr>
<td>REALM (z-score) *</td>
<td>-0.11 ( -0.25, 0.03)</td>
<td>0.071</td>
</tr>
<tr>
<td>Age (Z-score) b</td>
<td>0.35* (0.17, 0.44)</td>
<td>0.060</td>
</tr>
<tr>
<td>Smoking c</td>
<td>0.25* (0.12, 0.37)</td>
<td>0.021</td>
</tr>
<tr>
<td>Maternal language d</td>
<td>0.35* (0.06, 0.64)</td>
<td>0.128</td>
</tr>
</tbody>
</table>

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### Footnotes:

* REALM z-score: 0=60.6, 1SD =8.9 (An upward shift of 0.6 represents the highest possible score, a 1SD downward shift approximately represents Grade 7–8 reading level; 2 SD, Grade 4-6).

b Age: 0=47 yrs, 1SD=19 yrs. (A 1SD upward shift is 66 yrs, a 1SD downward, 28 yrs).

c Smoking: 0=never, 1=ex-smoker, 2=current light, 3=current heavy

d Maternal language: 0=English/French, 1=neither English nor French

† Semi-partial r-squared represents the proportion of variance in observed general health that is explained uniquely by this variable after accounting for the effects of other variables in the model.
Using more global tests of functional health literacy, others have found that approximately 42% of inner city hospital patients had marginal or inadequate literacy skills, but that the proportion of patients who had specific difficulties with interpreting medication instructions or appointment information varied between practice populations depending on the ethnic mix and educational level. A more demanding instrument, such as the Test of Functional Health Literacy in Adults (TOFHLA) — which requires filling in blanks in a medical text to test reading comprehension and assesses numeracy skills using items such as medicine labels and hospital forms — might have permitted us to detect more patients with literacy problems.

We did not find a significant correlation between reading level and perceived general health. This is likely due to lack of statistical power; with a prevalence of low literacy of 7%, we would have needed a sample size of 500 to detect a 1 point difference on the health scale. Larger studies have shown that persons with low literacy skills are more likely to report poor health, hospitalization and to present with late stage disease. The limitations of this study are the lack of statistical power to detect a significant health-literacy relationship, and the limited sensitivity of the rapid assessment tool.

Either a more sensitive literacy test or a larger sample size would have permitted us to detect a statistically significant association. We are certain that use of a more complex literacy assessment would have resulted in a higher prevalence of low health literacy.

One interesting finding was that literacy levels did not decrease with age, however this was only true among those with a high school level education. The Ad Hoc Committee on Health Literacy found inadequate literacy prevalent among the elderly with almost half scoring in the low literacy range. This is likely due to lack of statistical power; with a prevalence of low literacy of 7%, we would have needed a sample size of 500 to detect a 1 point difference on the health scale. Larger studies have shown that persons with low literacy skills are more likely to report poor health, hospitalization and to present with late stage disease.

The high level readability of our generally dense and detailed patient education materials is not unusual. Using both SMOG and computerized Flesch-Kincaid to evaluate the same materials, found that Flesch-Kincaid assessment resulted in a readability level 0.9 to 3.2 grades lower than standard readability formulas. Consequently, using a more sophisticated measure of readability would have yielded an even more negative picture.

Since print is a major means of disseminating information to promote healthy lifestyles and disease prevention, low-literate persons will be disadvantaged. Among the 37% of our subjects whose maternal language was neither English nor French, 42 different maternal languages were represented. It is unrealistic to provide written health information for all patients in their own language, but it is certainly achievable and practical to provide low-literacy materials in English or French. The highly literate may not be offended by low-literacy materials, whereas the vast majority of patient education pamphlets are inaccessible to those with literacy problems. Health care providers need to be innovative in educating this population, employing alternate media such as demonstrations, diagrams, pictures, videos and audiotapes in lieu of, or in addition to, the printed word to ensure their understanding so that low-literate patients will receive appropriate, effective care.

REFERENCES


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permis de dresser une liste de questions à approfondir sur chacun de ces thèmes.

Ce n’est qu’en fouillant ces questions dans le cadre d’études systématiques, en utilisant dans la mesure du possible une approche participative, que nous pourrons déterminer si la littératie liée à la santé pose ou non un problème au Canada à l’heure actuelle, et si oui, quelles en sont les causes et les conséquences, et quelles initiatives pourront y remédier efficacement. Le Programme national de recherche sur l’alphabétisation et la santé a pour objectif d’élaborer et de mener de telles études. Il ne pourra pas y parvenir sans le soutien du milieu de la santé publique. Je vous exhorte donc à vous joindre à nos efforts et à ceux du Programme national sur l’alphabétisation et la santé.