

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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Low literacy levels place individuals at greater risk of negative health experiences, reducing their capacity to protect, maintain, and manage their health.¹ Individuals with poor literacy skills are more likely to report poor health,² encounter difficulties in using the health care system^{3,4} and experience greater levels of stress in these situations than do the higher literate.⁵ They develop potentially counter-productive strategies to avoid exposing their illiteracy,^{5,6} such as not working through written decision aid materials with a provider.⁷ They are less likely to seek preventive care,⁸⁻¹² understand discharge instructions,¹³ use medications appropriately, or attend follow-up appointments.^{14,15}

According to the 1994 International Adult Literacy Survey,¹⁶ 22% of Canadians and 28% of Quebecers have severe difficulty using printed materials. A similar proportion have less difficulty but are able to use only simple, clearly presented information. These startling statistics, combined with the paucity of data on the implications of low literacy for Canadian family practice, motivated us to estimate the prevalence of low literacy patients in our practice and to determine whether reading ability is associated with self-perceived health. We also evaluated the reading difficulty of the most commonly used patient education materials to see how appropriate they were for the low literate.

METHODS

We conducted a survey of reading skills and self-perceived health among patients attending the Herzl Family Practice Centre during a three-week period in November and December 1997. The practice, a university-affiliated teaching unit in a tertiary care hospital in Montreal, receives about 27,000 visits annually from a multi-ethnic population. Scheduled patients were randomly selected from appointment lists at morning (n=128) and afternoon (n=199) clinics. We also approached all non-scheduled patients seen in randomly selected walk-in clinics (n=115). To determine eligibility and to profile the practice population, we collected information on age, gender, maternal language, language used during clinical encounters, highest educational level achieved, profession/current occupation and smoking status. Patients were eligible if they were aged 18

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

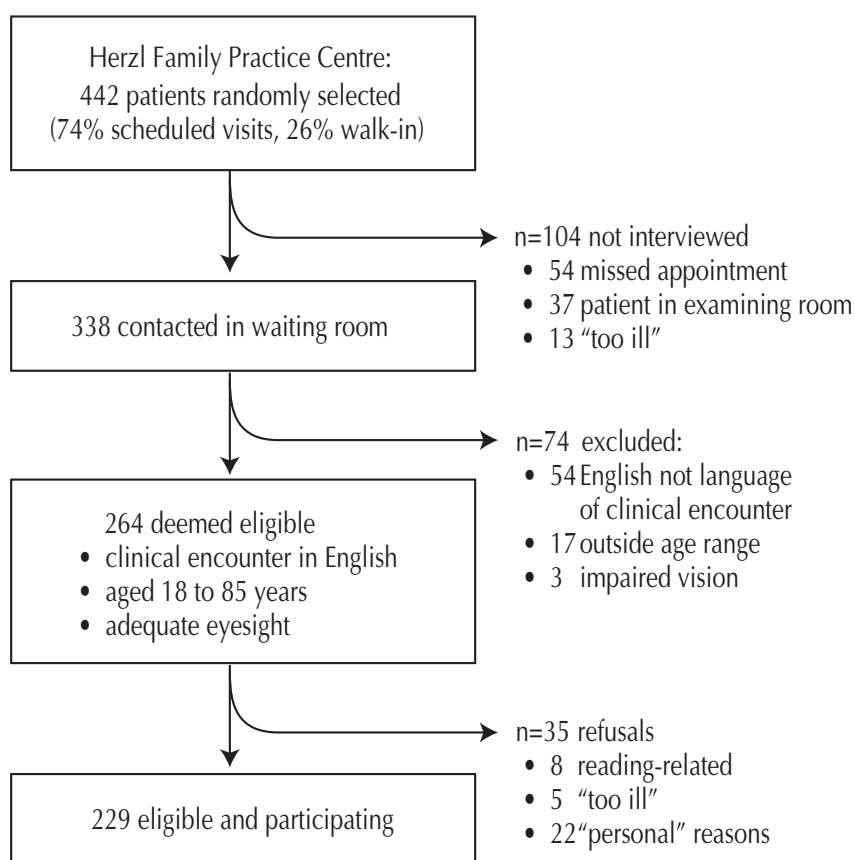


Figure 1. Flow chart of subject selection for the study

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^{18,21} 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.

TABLE I
Comparison Between Eligible Consenting and Non-Consenting Patients

Characteristics	Consenting Patients (n=229)	Non-consenting Patients (n=35)	Test of Significant Difference	Population of Quebec*
Mean age (yrs)	47	52	t=1.35 p=0.18	48.9 (SD: 18.7)
Female (%)	61	59	$\chi^2=0.37$ p=0.85	65
Education (yrs)	13.5	10.2	t=3.70 p<0.001	11.1 (SD: 3.5)
Maternal language (%):				
English	51	34	$\chi^2=4.22$ (2df) p=0.04	—
French	12	9		—
Other	37	56		—
Current smoker (%)	26.6	20.0	$\chi^2=0.51$ p=0.47	27

* Source: Reference 28

TABLE II
Comparison of the Effects of Realm Score on Perceived General Health According to the COOP/WONCA Charts

Variable	Multivariate β (95% CI)	Semi-partial R^2 †
Intercept	2.6	
REALM (z-score) ^a	-0.11 (-0.25, 0.03)	0.009
Age (Z-score) ^b	0.35* (0.17, 0.44)	0.071
Smoking ^c	0.25* (0.12, 0.37)	0.060
Maternal language ^d	0.35* (0.06, 0.64)	0.021
Adjusted R-squared		0.128

^a 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, 1 SD=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

* p<0.05

† 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.

RESULTS

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",²³ "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.

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%.¹⁶ This difference may be attributed to the difference in measurement instruments. REALM is a 2-3 minute test of word pronunciation ability¹⁸ whereas the International Adult Literacy Survey¹⁶ 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.^{29,30} 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 be at ease with a term but not pronouncing it exactly were given credit for that word. The REALM may have accurately detected persons with truly low reading levels, but may also have failed to detect 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.^{22,31}

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.¹⁴ A more demanding instrument, such as the Test of Functional Health Literacy in Adults³¹ – 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,² hospitalization³² and to present with late stage disease.³³

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 Literacy³⁴ found inadequate literacy prevalent among the elderly with almost half scoring in the lowest reading level. Gazmararian³⁵ found that reading ability declined dramatically with age: 15.6% of those aged 65-69 years had inadequate health literacy, which increased to 58% in those aged 85 years or over, suggesting that the elderly may have limited ability to read and comprehend medical information pertinent to their health. Our study controlled for education. High school completion in the elderly represents

a higher level of educational attainment than in a cohort of 25 year olds.

Despite the low prevalence of low literacy in our sample, we still found cause for concern about how well primary care providers are meeting the needs of patients with low literacy skills. Our results indicate that immigrants and younger patients with low educational attainment are likely to have literacy problems and also experience poorer health in all measured domains. With their greater health needs, the gap observed between their reading levels and the readability of most patient education materials underlines an important unmet need in health promotion in our primary care system.

The high level readability of our generally dense and detailed patient education materials is not unusual.^{25,36-39} Estrada,³⁶ 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.

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RÉSUMÉ

Contexte : Selon l'Enquête internationale sur l'alphabetisation des adultes (1994), près de la moitié des Canadiens ont du mal à utiliser les médias imprimés. Nous avons voulu estimer la prévalence des patients faiblement alphabétisés dans notre clinique pour déterminer si la capacité de lecture est associée à l'état de santé autoperçu dans le domaine des soins primaires et pour évaluer la lisibilité des dépliants d'usage courant servant à l'éducation des patients.

Méthode : Nous avons sondé un échantillon aléatoire de 229 patients de 18 à 85 ans se présentant à la clinique, avec ou sans rendez-vous. Nos principales mesures étaient la capacité de lecture, estimée selon les compétences de décodage des mots obtenues par l'instrument REALM (Rapid Estimate of Adult Literacy in Medicine), et l'état de santé autoperçu selon les mesures fonctionnelles de santé de COOP/WONCA. Nous avons aussi évalué selon la formule SMOG (Simple Measure of Gobbledygook) la lisibilité de 120 dépliants d'usage courant destinés à l'éducation des patients.

Résultats : La prévalence des patients faiblement alphabétisés était de 9 %. Les patients les plus susceptibles d'avoir une piètre capacité de lecture en anglais étaient ceux de moins de 45 ans qui n'avaient pas terminé leurs études secondaires et ceux dont la langue maternelle n'était ni l'anglais, ni le français (les immigrants). Les scores obtenus par le REALM et l'état de santé autoperçu présentaient une corrélation faible, mais non significative. Le niveau de lecture moyen des dépliants était à mi-chemin entre la 11^e et la 12^e année (11,5) (déviation sensible : 1,5). Soixante-dix-huit p. cent des dépliants exigeaient au moins une capacité de lecture du niveau de l'école secondaire.

Conclusion : Les niveaux de littératie étaient plus élevés que prévu chez nos patients; cela pourrait s'expliquer par l'outil d'évaluation rapide que nous avons utilisé, qui a peut-être sous-estimé la difficulté d'utiliser les médias imprimés. De toute évidence, la grande majorité des documents d'usage courant servant à l'éducation des patients ne répondraient pas aux besoins de patients faiblement alphabétisés, qui ont parfois tendance à être en moins bonne santé. Les fournisseurs de soins doivent être sensibles aux difficultés de lecture des patients, et les documents d'éducation des patients devraient être rédigés à un niveau de lecture plus bas.