

Misperceptions of Medical Understanding in Low-Literacy Patients: Implications for Cancer Prevention

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Background: Patients with limited literacy skills often have difficulty understanding medical information, are less likely to undergo cancer screening, and present with cancer at later stages than patients with better literacy skills. Since primary care physicians are responsible for performing or initiating the majority of cancer screening in the United States, they need to be able to not only identify patients who might not understand medical information but also communicate effectively with them about cancer prevention and screening.

Methods: To determine whether family medicine residents could identify patients who might have difficulty understanding medical information because of limited literacy, we measured the literacy skills of patients in a university-based family medicine clinic using the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA). After the patients completed their office visits with a physician, we asked family medicine residents to rate the patients' ability to understand medical information.

Results: Among 140 patients who met with 18 family medicine resident physicians, 24% had limited literacy skills based on testing with the S-TOFHLA. Residents identified only about half of these patients as having poor or below average understanding of medical information.

Conclusions: In many cases, family medicine residents are unable to identify patients who, based on assessment of their literacy skills, are likely to have difficulty understanding medical information. When working with residents, medical educators should promote the habit of taking poor literacy into account when communicating with patients.

Introduction

According to the 2003 National Assessment of Adult Literacy conducted by the US Department of Education, approximately 48% adults in the United States have very basic or below basic English-language literacy skills.¹ Most individuals have limited health literacy, ie, the degree to which they are able to obtain, process, and understand basic health information and services needed to make appropriate health decisions.² The problems faced by individuals with limited health literacy were recently summarized in a report by the Institute of Medicine.³

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Abbreviations used in this paper: S-TOFHLA = short form of the Test of Functional Health Literacy in Adults.

Limited literacy is associated with several outcomes related to cancer and cancer prevention. Persons with limited literacy present with cancer at more advanced stages than persons with better literacy skills.⁴ They are less knowledgeable about cancer prevention and less likely to undergo appropriate cancer screening.^{5,6} Indeed, many individuals with limited literacy do not know what a screening test is, and they do not know the meaning of words such as colon, tumor, or blood in the stool.⁷

To effectively communicate with patients who have limited literacy and educate them about cancer screening, physicians must be able to provide information in a format and at a literacy level that their patients will understand. This often requires a special approach and special skills.⁸⁻¹¹ It is not easy, however, to identify patients who have limited literacy skills during routine clinical encounters.^{12,13} Asking questions such as "Can you read?" and "How many years of school did you complete?" does not accurately predict a patient's literacy level.^{8,14} Furthermore, many health professionals are not aware that low literacy is common; they assume patients do not understand medical information because of a lack of capacity to learn.

More individuals receive medical care in the offices of primary care physicians than from physicians in any

other setting. Thus, primary care physicians have a particularly important role in identifying patients who have limited literacy and in communicating effectively with them about cancer screening and prevention.¹⁵ Indeed, according to the National Ambulatory Medical Care Survey, 90% of preventive services such as Pap smears and colorectal cancer screening are performed by or ordered by primary care physicians, not specialists.¹⁶

The purpose of this study was to determine whether primary care physicians can accurately identify patients who have limited understanding of medical information based solely on their clinical interactions with patients during an office visit. Medical understanding, which is part of the broad definition of health literacy, was used as a marker for health literacy in this study. We studied family medicine residents, as residency training in family medicine emphasizes communication skills. We specifically studied experienced (ie, second- and third-year) residents to increase the likelihood that these physicians would be able to discern whether patients could understand what they were being told. We hypothesized that even these upper-level residents would be inaccurate in their estimation of patients' ability to understand medical information.

Methods

Overview

Family medicine residents were asked to estimate the ability of patients, whom they had just seen during an office visit, to understand medical information. The patients themselves underwent testing to determine their actual literacy skills. Assessments by the residents concerning the ability of their patients to understand were then compared to the patients' measured literacy skills. The Institutional Board at the University of Tennessee Graduate School of Medicine-Knoxville approved the study protocol.

Subjects

A total of 155 English-speaking patients attending a university-based family medicine clinic were recruited to participate in this study. Patients were approached while waiting in an examination room to see a resident physician and were considered for participation if they were 18 years of age or older, were currently enrolled in either Medicare or TennCare (Tennessee's Medicaid program), were not being seen for an acute life-threatening emergency, and were able to meaningfully converse with project staff. We did not include any subjects who required sign language translators, were severely mentally retarded, or were psychotic or agitated in this study.

Using these criteria, we then specifically targeted older patients (ie, those currently receiving Medicare) since they are at greater risk of having limited health

literacy skills¹⁷ and are also at higher risk for cancer. Some were continuity patients and thus familiar to the residents from prior encounters. Others were acute-care patients, seeing any resident who was available at the time the patient presented for care. These two categories of patients were not separated in our analyses.

Once patients were in the examination room, a research assistant invited them to participate in the study. Patients were offered a \$1.00 parking pass for our clinic and entry into a random drawing for one of four \$25.00 grocery certificates as compensation for time spent during the study. Among the 155 patients approached who met the criteria described above, 140 agreed to participate in the study (90.3% participation rate). Thus, only 9.7% (n = 15) of those approached declined our invitation to participate in the study.

Physicians

All second-year (n = 8) and third-year (n = 10) residents in the University of Tennessee-Knoxville family medicine residency program were asked to participate in the study. All agreed to do so. Three of the residents were international medical graduates, but all were native English speakers.

Patient Interviews and Literacy Assessments

While participating patients were waiting to see the physician, we collected demographic information (sex, age, race/ethnicity, educational attainment) from each of them. Demographic characteristics were assessed using questions from the 2004 Behavioral Risk Factor Surveillance Survey.¹⁸

Following the collection of demographic information, we measured the literacy skills of each participating patient using the short form of the *Test of Functional Health Literacy in Adults* (S-TOFHLA, 14-point font, English version).¹⁹ The S-TOFHLA is a 36-item timed reading comprehension test that uses a modified Cloze procedure, in which every fifth to seventh word in a passage of text about medical information is omitted and replaced with a blank space. The subject must select a word to fit into the blank spaces from the four multiple-choice options provided for each space. Cronbach's alpha is 0.97 for the 36 items in the S-TOFHLA passages.¹⁹

The S-TOFHLA is scored on a scale of 0 to 36, with 36 representing the highest level of literacy. Using established convention, we categorized patients as having *adequate* literacy if the S-TOFHLA score was 23 to 36, *marginal* literacy if it was 17 to 22, and *inadequate* literacy if the score was 0 to 16. Individuals who scored as having inadequate or marginal literacy (ie, score 22 or lower) cannot be expected to understand all the medical information they receive, and they would likely require special assistance to achieve learning goals for health information.¹⁹

Assessment by Physicians of Patients' Understanding

Immediately following their interaction with each patient, the research assistant asked residents the question "What is your perception of the patient's medical understanding?" without reference to the specific encounter that day. The residents rated their perception of each patient's medical understanding with a 5-point Likert-type scale ranging from 1 (very poor understanding) to 5 (superior understanding). The number of patient visits per resident ranged from 5 to 11.

We felt that the term *medical understanding* encompassed a more familiar and general concept by which the residents could generally evaluate these patients, rather than asking the residents about the patients' literacy skills. Furthermore, using this specific question kept residents unaware of the specific goals of the study and avoided the possibility that they might be sensitized to probe patients about their literacy skills. While this approach sacrificed a direct relationship between instrument-measured literacy and residents' ratings of understanding, we felt the advantages of this question were worth slightly less precision.

Statistical Analysis

The Statistical Package for the Social Sciences (SPSS+ for Windows, Version 12.0) was used for all statistical analyses. Statistical significance was set at a 0.05 a priori. Descriptive statistics (means, standard deviations, percentages, frequencies) were calculated to describe the demographic characteristics of the sample. An inde-

pendent *t* test was used to determine if measured health literacy differed as a function of mean age. Sensitivity and specificity were calculated to assess concordance between physicians' assessments of patients' medical understanding and measured health literacy skills. Our sample size (N = 140) was adequate to generate results within $\pm 5\%$ margin of error with 95% confidence, assuming that 10% percent of the sample had inadequate/marginal literacy skills.²⁰

Results

Demographic Characteristics of Patients

The demographic characteristics of the study population are shown in Table 1. Most patients were women (63.6%) and Caucasian (87.1%). Nearly half of the patients had some high school education, and most (77.1%) were current enrollees in TennCare (Tennessee's Medicaid program). The mean age of patients was 51.9 ± 16 years (range = 19 to 86).

Health Literacy Skills of Patients

Patients' mean score on the S-TOFHLA was 27.5, which is on the low end of the "adequate" range. There was, however, considerable variation in scores, which ranged from 0 to 36. Among the 140 patients, 34 (24.3%) scored as having inadequate or marginal literacy (ie, scores of 22 or lower). Younger patients (less than 60 years of age, n = 95) had significantly higher literacy skills compared to older patients (60 years or greater, n = 45) (29.0 ± 8.6 vs 24.3 ± 11.5 , $t = 2.7$, $P < .01$).

Concordance Between Residents' Assessments of Patients' Understanding and Patients' Actual Health Literacy

Literacy skills were inadequate/marginal in 34 patients (24.3%), but residents perceived only 16 (47.1%) of these 34 patients to have very poor or below average medical understanding (Table 2). Conversely, residents identified 26 (24.5%) of the patients whose S-TOFHLA scores indicated adequate literacy as having very poor or below average medical understanding. The sensitivity of physicians' assessment of patients' medical understanding was 47.1% and the specificity was 75.5%, using patients' actual literacy skills measured by the S-TOFHLA as the reference standard.

Discussion

The most important finding of our study was that family medicine residents were unable to correctly identify patients with inadequate or marginal literacy as individuals who might have poor or below average ability to understand medical information. In fact, residents

Table 1. — Demographic Characteristics and Health Literacy Skills of Study Sample (N = 140)

Characteristic	Mean \pm SD/Number (%)
Age (yrs)	51.9 \pm 16.4
Sex	
Female	89 (63.6)
Male	51 (36.4)
Race	
Caucasian	122 (87.1)
African-American	18 (12.9)
Speak and read English	140 (100)
Education	
Some high school	60 (42.8)
High school graduate or equivalent	48 (34.3)
Some college or college graduate	32 (22.9)
Health Insurance Status	
TennCare (Medicaid)	108 (77.1)
Medicare	32 (22.9)
S-TOFHLA*	
Mean score	27.5 \pm 9.8
Inadequate (0–16)	21 (15.0)
Marginal (17–22)	13 (9.3)
Adequate (23–36)	106 (75.7)

* S-TOFHLA = Short Test of Functional Health Literacy in Adults

Table 2. — Numbers of Patients Scoring Inadequate/Marginal and Adequate on the S-TOFHLA and Family Medicine Residents' Perceptions of the Patients' Ability to Understand Medical Information

Residents' Assessment**	S-TOFHLA Category*		Total
	Inadequate/Marginal	Adequate	
Very poor/below average	16 (11%)	26 (19%)	42 (30%)
Average/above average/superior	18 (13%)	80 (57%)	98 (70%)
Total	34 (24%)	106 (76%)	140 (100%)

* S-TOFHLA = Short form of the Test of Functional Health Literacy in Adults. (inadequate = 0–16, marginal = 17–22, adequate = 23–36)
 ** Responses based on a 5-point Likert-type scale (1 = very poor; 5 = superior)

correctly identified only 47% of such patients. Thus, for just over half of the patients with inadequate or marginal literacy skills — individuals who likely do not understand medical information — family medicine residents incorrectly assumed that these patients had an adequate understanding of such information.

This finding is important because it replicates and extends the findings of Bass et al¹² and Lindau et al,¹³ who studied physicians in more specialized fields. We believe our results are even stronger than those of Bass, however, because we used a more elaborate measure of literacy, thus making our results more reliable and valid. Furthermore, our study involved family medicine residents — physicians for whom physician-patient communications and biopsychosocial aspects of care are emphasized during training. Even with this emphasis, however, residents were unable to correctly identify many patients who had limited literacy, incorrectly believing that half of patients with limited literacy could effectively understand medical information. Such misunderstandings can lead to patients' receiving inadequate education about their medical conditions, which in turn could result in inadvertent noncompliance, treatment errors, and worse health outcomes.

Our study has several limitations that should be considered when interpreting the results. First, our study was conducted in a single residency program, and results in other programs might differ, especially if the topic of health literacy is specifically included in the residency curriculum at other programs. Second, residents may not be representative of the larger population of practicing family physicians. It may be that experienced practicing physicians are more adept at estimating their patients' ability to understand health information. Third, patients who enrolled in the study were not randomly selected, raising the possibility of selection bias. The extent and direction of such bias, however, cannot be determined. Fourth, we did not specifically ask residents to rate patients' health literacy. Instead, for the reasons explained earlier, we asked them to rate patients' ability to understand medical information. It is possible that our results might have differed if we specifically asked for an assessment of the patients' literacy. The ability to understand medical information, however, is part of the

definition of health literacy, so we do not believe this factor materially affected the study results.

Conclusions and Implications for Cancer Care

Upper-level family medicine residents in our program were unable to correctly differentiate between patients with adequate literacy on the one hand, and inadequate or marginal literacy on the other, as individuals who would be likely or unlikely to understand medical information. In fact, after encounters with patients whose S-TOFHLA scores indicated inadequate or marginal literacy skills, residents incorrectly believed that nearly half of these patients would have a good understanding of medical information.

Based on the fact that residents overestimate patients' understanding, it is possible and even likely that the residents provide their patients with information about cancer prevention in terms the patients may not understand. Since primary care physicians, and particularly family physicians, provide most of the nation's preventive care, inadequate communication about cancer prevention has potentially important implications for our health care system.

Medical educators should foster in residents the habit of taking poor literacy into account. This includes sensitivity to the stigma associated with low literacy, attention to individualized informational needs of patients, avoidance of medical jargon, and use of visuals (eg, models, pictures/pictograms, drawings).⁹ Further, the use of interactive teaching strategies, such as the *Teach Back* or *Show Me* technique (ie, having patients explain in their own words what has been told to them) should be encouraged.⁹ This may be particularly important where cancer prevention and screening recommendations are concerned, since patients may see no immediate need for these services and may not understand why their physicians are suggesting them. The *Ask Me 3* program,²¹ which encourages patients to ask questions during the medical encounter (“*What’s wrong with me?*” “*What do I need to do?*” “*Why is it important for me to do this?*”), provides another

potentially useful model that physicians can use when providing advice and direction to patients.

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