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What Did the Doctor Say? Health Literacy and Recall of Medical Instructions

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Abstract

Background—Limited literacy has repeatedly been linked to problems comprehending health information, although the majority of studies to date have focused on reading various print health materials. We sought to investigate patients' ability to recall spoken medical instructions in the context of a hypothetical clinical encounter, and whether limited health literacy would adversely affect performance on the task.

Methods—A total of 755 patients age 55–74 were recruited from one academic internal medicine clinic and three federally qualified health centers. Participants' health literacy skills and recall of spoken medical instructions for two standard, hypothetical video scenarios (wound care, GERD diagnosis)were assessed.

Results—The majority (71.6%) of participants had adequate health literacy skills, and these individuals performed significantly better in correctly recalling spoken information than those with marginal and low literacy in both scenarios: [wound care - mean (SD): low 2.5 (1.3) vs. marginal 3.5 (1.3) vs adequate 4.6 (1.1); $p<0.001$), GERD: low 4.2(1.7) vs. marginal 5.2(1.7) vs. adequate 6.5 (1.7);$p<0.001$]. Regardless of literacy level, overall recall of information was poor. Few recognized pain (28.5%) or fever (28.2%) as signs of infection. Only 40.5% of participants correctly recalled when to take their GERD pills.

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Conclusions—Many older adults may have difficulty remembering verbal instructions conveyed during clinical encounters. We found those with lower health literacy to have poorer ability to recall information. Greater provider awareness of the impact of low health literacy on the recall of spoken instructions may guide providers to communicate more effectively and employ strategies to confirm patient understanding.

Over the past two decades, the field of health literacy has emerged to document clear evidence that a large number of adults in the United States have difficulty comprehending existing health materials.(1–5) Specifically, studies have repeatedly examined patients' ability to understand health information conveyed via print, video or internet sources and have uncovered limited literacy and numeracy skills to be a strong risk factor for comprehension failure. The Institute of Medicine (IOM) and many professional organizations have weighed in on the health literacy problem through numerous seminal reports.(1, 6–10) They all agree that the root cause lies within the adequacy of the communication conveyed to patients and families by a health system. Thus, numerous efforts have been underway to improve the suitability, readability, and patient-centeredness of print and video communications in particular.(11, 12)

Health literacy, as described by the Institute of Medicine, is primarily divided into two categories: health-related print and oral literacy.(1) While print and multimedia communications have been thoroughly investigated, spoken communication as it relates to health literacy has been far less studied (13–16). From the field of education and learning sciences, there is a large body of literature evaluating the connections between oral language skills in childhood and the acquisition of reading skills, showing that the two are closely intertwined.(17) Within the medical literature, past studies have evaluated patterns of communication, different elements of spoken dialogue, the use of jargon in spoken interactions, and how physicians verbally assess patients understanding of information.(18–24)

Given the inadequacy of many health materials, patients may often rely on the oral communication and counseling that occurs in the medical encounter. This is especially true for those with limited literacy skills, as a prior study by Wolf and colleagues found that patients with limited literacy were more likely to solely rely on their physician for health information.(25)However, inadequate physician counseling has been previously implicated as a source of misunderstanding, which may be caused by time limitations, lack of skill, or distractions in the clinical environment.(26, 27)Yet even in the best circumstances, it is intuitive that patients may be limited in regards to how much they may be able to process and recall from a spoken encounter that typically is not accompanied by any tangible memory support (i.e. caregiver print summary).

Prior studies have examined oral literacy demand of conversations and found that individuals are less satisfied with conversations using medical jargon and more dense language.(28) Engel and colleagues examined recall of emergency department instructions, but did not isolate spoken information from written instructions.(29) Furthermore, little research has explicitly targeted patients' ability to recall verbal instructions without the assistance of external aids (i.e. print materials, accompanying caregiver), or associations with remembering spoken information and health literacy.

In this study, we sought to assess how well patients remember spoken physician medical instructions, and examined whether those with limited literacy skills were less able to retain this information. We standardized physician communications by using video recreations of clinical encounters for common diagnoses (wound care, gastroesophageal reflux disease (GERD)); this eliminated the variable quality of the provider interaction to determine the

extent to which patients may require assistance to remember medical explanations and instructions.

METHODS

Sample

Individuals between the ages of 55–74, were recruited for a National Institute of Aging study [R01AG030611] referred to as LitCog that examined the relationship between health literacy, cognition, and the ability to complete health-related tasks. Patients receiving care from one academic general internal medicine clinic (NMFF) or one of three federally qualified health centers (ACCESS) in Chicago, Illinois were recruited to the study between August 2008 and November 2010. The Northwestern University Institutional Review Board approved the study procedures and all patients gave informed consent.

As part of the broader interests for the LitCog study, participants were screened and determined eligible if: 1) they were between the ages of 55 and 74, 2) had a primary physician associated with NMFF or ACCESS, 3) did not have an uncorrectable hearing or vision problem, 4) had fluency in English language, and 5) did not have a severe cognitive impairment as determined by the “six-item screener” assessment.(30) Eligible participants were scheduled for an appointment with the research team for study data collection. A total of 3176 patients were identified through electronic health records as initially eligible to participate by age and were notified of the study by mail and followed up via phone by research staff. A sample of 1768 of these eligible patients could be reached and were invited to participate in the study. Initial screening deemed 192 subjects as ineligible due to severe cognitive or hearing impairment, limited English proficiency, or not being connected to a clinic physician (defined as < 2 visits in two years). In addition, 738 refused, 14 were deceased, and 20 were eligible but had scheduling conflicts. The final sample included 803 participants, for a determined cooperation rate of 51 percent following American Association for Public Opinion Research guidelines.(31) However, 48 subjects were excluded from analyses due to incomplete data for a total of 755 participants (94%).

Measurement

For the purposes of this study, we created two standardized healthcare scenarios that provided patients with verbal information about their diagnosis and instructions for further care via video. The first scenario was based on wound care for a laceration upon discharge from an emergency department. The second scenario focused on giving information and instructions about a new diagnosis of GERD. Participants were asked to imagine they had the particular condition or symptom (laceration, burning pain in chest) and were subsequently receiving care by a physician in the context of an emergency department (ED) admission or primary care visit. Videos lasting approximately two minutes each were then shown to patients, displaying an actual emergency (KGE) or internal medicine (DWB) attending physician whom during taping were told to replicate how they would typically counsel patients for the specified condition. No scripts were prepared. The videos themselves were filmed close-up containing only the chest to head image of each physician in their white lab coat. For the wound care scenario, counseling included step-by-step instructions about how to properly care for the injury, a review of signs of infection (presented as a verbal list, e.g. “signs of infection include…”), and instructions regarding follow-up. For the GERD scenario, the physician reviewed the diagnosis and provided brief pathophysiology, recommended dietary and behavioral changes (presented as a verbal list, e.g. “foods to avoid include…”), and prescribed a medication with directions on when to take it. An analysis of the video transcripts using the mean of three readability indexes

(Gunning Fogg, Flesh Kincaid, and Lexile) revealed that the GERD and wound care videos had a mean language complexity of 9th and 12th grade respectively.(32)

In order to best assess patients' ability to recall and retain spoken information during a medical encounter, participants were asked a series of questions by interviewers rigorously trained in question administration and scoring. Interviewers received extensive training, including repeat simulations of the interview protocol prior to recruitment. All questions were asked in a structured, open-ended format and developed using a reverse-engineered process that only sought recall of information actually included in the physician communications (see Tables 2 and 3 for actual items). This process has been repeatedly used by the study team and is also a common approach applied in cognitive psychology investigations.(6, 33–35) For the wound care scenario, there were seven points possible if all questions were answered completely and correctly (5 of the points from information in list format). Following the GERD video, the patients were assessed for immediate recall, similar to the wound care scenario, with ten possible points (7 of the points from information in list format). As part of the LitCog protocol, participants were then given other distracting tasks. After approximately 15 minutes, they were asked the same set of questions to assess delayed recall of the GERD scenario. If the interviewer could not determine how to score a response, the verbatim answer was recorded and later reviewed and reconciled by the study team.

In addition to recall questions, subjects' literacy skills were assessed using the full version of the Test of Functional Health Literacy in Adults (TOFHLA). The TOFHLA is one of the most common measures used in health literacy research, and consists of a 50-item reading comprehension and 17-item numerical ability test.(36) A total score was computed and categorized into low (0–59), marginal (60–74) and adequate (75–100) health literacy. Additional information including age (55–59, 60–64, 65–74), gender, race (African American, White, Other), highest level of education completed (less than high school diploma, high school/GED graduate, some college, college graduate), and prior exposure to each scenario, either by having GERD or a laceration themselves or caring for someone with those diagnoses, was collected from the participants.

Data Analysis

Percent correct on individual items and mean differences in total scenario scores were compared across the three health literacy groups using Pearson χ^2 tests and one way ANOVA tests, respectively. Potential confounding factors in the relationship between literacy and scenario total scores, including age, gender, race, education, exposure to wound care, and exposure to GERD were similarly assessed. Multivariable linear regression analyses were then conducted to assess performance by literacy level controlling for age, gender, race, education, and prior experience with the scenario. These analyses were conducted for each task, with the task total scores serving as the dependent variable. Generalized linear models were used on the total scores for each task, treating the scores as continuous variables, and therefore a Gaussian distribution and identity link were specified. All statistical analyses were performed using Stata® 10.1 (Stata Corp., College Station, TX).

RESULTS

Demographic characteristics of the sample are displayed in Table 1. Participants had a mean (SD) age of 63.0 (5.4), were predominantly female (67.9%) and White (51%) with over half having at least some college education and 214 (28.4%) patients having limited literacy (89 (11.8%) low; 125 (16.6%) marginal). Those with limited literacy were more likely to be African American (76.6%; $p<0.001$) and have a high school education or less (61.6%; $p<0.001$). There was no significant association between literacy skills and age or sex.

Table 2 summarizes performance on the individual items for the wound care scenario as well as the total score used to assess recall of spoken instructions. Participants performed most poorly in recognizing fever and pain as signs of infection, with only 213 (28.2%) recalling fever and 215 (28.5%) pain. Overall, individuals with lower literacy performed significantly worse in recalling information (mean score (SD): low 2.5 (1.3) vs. marginal 3.5 (1.3) vs. adequate 4.6 (1.1), $p<0.001$).

Both the immediate and delayed GERD scenario recall demonstrated similar trends as the wound care scenario across the literacy groups (Table 3). Overall, individuals with lower literacy skills performed significantly worse in recalling information immediately after the encounter(mean score (SD): low 4.2 (1.7) vs. marginal 5.2(1.7) vs. adequate 6.5(1.7), $p<0.001$). The delayed recall GERD scenario also showed differences across literacy levels (mean score (SD): low 3.5 (1.6) vs. 4.8 (1.6) vs. adequate 6.0 (1.8), $p<0.001$). All literacy levels recalled less information from the encounter at the 15 minute delayed assessment compared to immediately after the encounter.

On several questions, the adequate health literacy group had minimal loss of information while the low and marginal groups demonstrated nearly a 50 percent reduction in recall. For example, performance on the question “when does Dr. Baker want you to take your pill?” was relatively unchanged in the adequate group (immediate 48.7% vs delayed 48.1%). However, the low and marginal literacy groups showed markedly lower scores (marginal: immediate 25.8% vs. delayed 14.5%; low: immediate 11.2% vs. delayed 4.6%).

In multivariable analysis of the ED discharge scenario, those with low and marginal literacy performed worse than those with adequate literacy skills(low $\beta=-1.54$,95% Confidence Interval (CI) −1.86 to −1.22, $p<0.001$; marginal $\beta=-0.76$ 95% CI −1.01 to −0.51 $p<0.001$). In addition, participants who were older, African American, or had less education performed worse on the task (Table 4, Model I). Those with low and marginal literacy also performed worse compared to those with adequate literacy in both the GERD immediate scenario (low $\beta=-1.53$ 95% CI −1.98 to −1.08, $p<0.001$; marginal $\beta=-0.79$ 95% CI −1.15 to −0.44 $p<0.001$), and the delayed scenario (low $\beta=-1.54$ 95% CI −1.99 to −1.08, $p<0.001$; marginal $\beta=-0.65$ 95% CI −1.01 to −0.30 $p<0.001$). In both the immediate and delayed GERD models, participants who were African American or had less education performed worse on the task(Table 4, Models II & III). The only difference between the two GERD models was with sex; females performed better on the delayed questions, but not the immediate(female $\beta=0.38$ 95% CI 0.12 to 0.64 $p=0.004$).

DISCUSSION

In our study, participants had considerable difficulty remembering spoken physician instructions when questioned immediately after a simulated medical encounter. Their knowledge substantially decreased within a 15-minute period. Specifically, on average, these older individuals were able to recall only approximately half of the medical instructions provided to them, and rates of recall were significantly worse among participants with low and marginal literacy skills. Even among those with adequate literacy, recall of some individual items was as low as 31 percent, suggesting the ability to retain spoken communication was a very challenging task for all. Differences were also seen across education and race in both scenarios. It is widely accepted that education and health literacy level are highly correlated.(1, 37, 38) Differences seen in race could be explained by the very strong associations with both literacy and educational attainment; findings that have been repeatedly found in prior studies and surveys, including the National Assessment of Adult Literacy (NAAL).(1, 4, 6, 7)

Interestingly, immediate recall was poorest for spoken information that was conveyed in the form of lists (i.e. signs of a wound infection, foods or drinks to avoid with GERD). This should not be surprising, as Wilson and Wolf previously describe known limitations to working memory capacity.(39) In particular, individuals can only process a small number of new concepts at a time, and this may be even harder when one is acutely ill or if information is not linked to an explicit behavior. On the other hand, recall was greatest for spoken information that addressed follow-up (e.g. when to have stitches removed and timing of follow-up visit). This is likely due in part to the information being provided at the end of both encounters. As such, it seems apparent that patients might have an easier time remembering closing statements. In light of the considerable amount of information reviewed within approximately two minutes (the length of both simulated encounters), it is not surprising that patients are unable to fully absorb what they are told and have the best recall for final instructions.

Very few studies have evaluated the relationship between literacy and recall of spoken information (without tangible supports). Sudore et al, in their study examining a modified informed consent process, found that patients with lower literacy required more “passes” through an informed consent process to reach comprehension. However, in their study patients also had access to the tangible support of a document written at a 6th grade level. Although a consent form was utilized rather than verbal communication in isolation, they had similar findings regarding race and literacy to the present study.

Clearly, our study has limitations. We intentionally isolated patient’s recall of spoken instructions without any additional intervening resources, such as print discharge instructions in the wound care scenario or a list of foods to avoid in the GERD scenario. While print tools serve as a tangible support for recall and comprehension in the real world that patients can revisit as needed, health literacy research has found that most print materials exceed the reading skills of the target audience.(12, 40–42)Another limitation was the use of video-based hypothetical scenarios to recreate physician-patient interactions. The use of a unidirectional video for communicating information does not accurately reproduce the interactive dialogue of a clinical scenario. This was done for standardization, but could have affected participants’ understanding and attention to the task. Specifically, most participants did not have a history of laceration or GERD and therefore, may not have been invested in retaining the information, as it was not directly relevant to their current personal health. However, personal histories of a wound or GERD were not predictors of performance. Alternatively, one could argue that the lack of stress associated with being a patient may have allowed our study subjects to more clearly focus on the task at hand and recall more information than they would in a clinical setting. We acknowledge that issues of trust, as well as race concordance are important in understanding patients’ motivation to recall and follow medical instructions; however, these factors were not measured as part of our study protocol and obtaining a realistic measurement of trust would have been difficult to reproduce in this hypothetical clinical encounter.

Other limitations affecting the generalizability of findings include a predominantly older, educated and female sample all of whom were English speaking; this may not be reflective of the population of adults receiving care in emergency departments and internal medicine practices. However, given the strong association between literacy skills and recall of spoken medical instructions, our findings may under-represent the extent of the problem among those receiving care in safety net settings that will have higher rates of limited literacy and limited English proficiency as well.

Despite these tasks being hypothetical, we believe the findings present conservative estimates of the problem of poor comprehension of spoken counseling. It can be presumed

that if a patient is not able to recall information as demonstrated by our study, it is unlikely they would be able to fully comprehend instructions and take appropriate action. Poor communication and recall could adversely affect the safety and quality of the care that patients receive and health outcomes.(1, 4, 43) Although this task was hypothetical, it raises concern that there may be a mismatch between the learning needs of patients and the teaching that can be provided through our current healthcare system.

It is important to recognize that the ability to learn in a healthcare setting is likely related to a broader set of cognitive abilities (e.g. attention and working memory) than can be measured by health literacy metrics alone.(44) Given the multi-dimensional nature of learning in healthcare, future strategies must be comprehensive to adequately convey the retention of medical instructions and information. Efforts to improve patients' ability to learn and retain health information will likely need to target both physician counseling strategies and the use of appropriate print or multimedia communication as tangible supports beyond the medical encounter. For example, physicians can use evidence-based techniques to clearly communicate explicit information within a medical encounter.(45, 46) Enhanced written discharge instructions could also then be provided and serve as an external aid to support patients' memory of what transpired during the clinical encounter. This approach may be especially useful for items that require patient vigilance (signs of a complication or progression of disease). A piece of paper that could later be reviewed at home and used as a reference is potentially very valuable. Physician awareness of this association is an important first step; creative solutions are necessary to address the multi-dimensional aspects of learning in the health care setting.

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Table 1

Sample Characteristics.

Variable	N(%)
Health Literacy	
Low	89 (11.8)
Marginal	125 (16.6)
Adequate	541 (71.6)
Age Group	
55–59	241 (31.9)
60–64	238 (31.5)
65–74	276 (36.6)
Gender	
Female	513(67.9)
Race	
African American	317 (42.0)
White	385 (51.0)
Other	53 (7.0)
Education	
High Schoolor less	203 (26.9)
Some College	162 (21.5)
College Graduate	152 (20.1)
Graduate Degree	238 (31.5)
History of personal wound care	389 (51.9)
History of assisting others with wound care	490 (64.9)
History of GERD	260 (34.4)
History of assisting others with GERD	86 (11.4)

Table 2

Percent correct by item and mean total scores on ED discharge scenario by literacy level.

Questions	All n=755	Low n=89	Marginal n=125	Adequate n=541	p-value
ED Discharge Scenario					
When does Dr. Engel want you to come back in to have your stitches removed?	92.2	69.7	89.6	96.5	<0.001
What does Dr. Engel say are the signs of wound infection?					
Pus from the wound	66.0	41.4	58.4	71.7	<0.001
Swelling	49.0	25.3	42.4	54.3	<0.001
Increased Pain	28.5	11.5	16.0	34.1	<0.001
Redness	85.3	55.2	78.4	91.7	<0.001
Fever	28.2	8.1	20.0	33.3	<0.001
After the first 24 hours, how often should you change the bandages on your wound?	71.5	41.6	45.6	82.4	<0.001
Total Correct, Mean(SD)	4.2 (1.4)	2.5 (1.3)	3.5 (1.3)	4.6 (1.1)	<0.001

Table 3

Percent correct by item and mean total scores on GERD scenario by literacy level.

	Immediate					Delayed				
Questions	**All n=755**	**Low n=89**	**Marginal n=125**	**Adequate n=541**	**p-value**	**All n=746**	**Low n=87**	**Marginal n=124**	**Adequate n=535**	**p-value**
When does Dr. Baker want you to take your pill?	40.5	11.2	25.8	48.7	<0.001	37.5	4.6	14.5	48.1	<0.001
What food and drinks does Dr. Baker say you should avoid?										
Coffee	54.7	48.3	56.8	55.3	<0.001	42.6	39.1	48.4	41.8	0.32
Tea	44.6	28.1	45.6	47.1	<0.001	34.2	24.1	36.3	35.4	0.11
Alcohol	38.9	30.3	26.4	43.3	<0.001	33.1	27.6	21.8	36.6	0.004
Anything with caffeine	70.9	37.1	64.0	78.0	<0.001	69.8	33.3	67.7	76.3	<0.001
Chocolate	31.3	23.6	23.2	34.4	0.01	27.7	16.1	22.8	30.7	0.008
Fatty foods	71.4	52.8	53.6	78.6	<0.001	68.1	43.7	54.0	75.3	<0.001
Acidic foods	77.5	58.4	68.8	82.6	<0.001	73.5	50.6	62.9	79.6	<0.001
How long should you wait to lie down after you finish eating?	87.8	73.0	82.4	91.5	<0.001	90.1	71.3	86.3	94.0	<0.001
When does Dr. Baker want to see you again?	84.8	57.3	76.0	91.3	<0.001	71.3	42.5	61.3	78.3	<0.001
Total Correct, Mean(SD)	6.0 (1.9)	4.2 (1.7)	5.2 (1.7)	6.5 (1.7)	<0.001	5.5 (1.9)	3.5 (1.6)	4.8 (1.6)	6.0 (1.8)	<0.001

Table 4

Multivariable Models

Variable	Model I ED Discharge Scenario Range 0–7			Model II GERD Scenario -Immediate Range 0–10			Model III GERD Scenario -Delayed Range 0–10		
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
Health Literacy									
Adequate	--								
Marginal	−0.76	(−1.01,−0.51)	<0.001	−0.79	(−1.15,−0.44)	<0.001	−0.65	(−1.01,−0.30)	<0.001
Low	−1.54	(−1.86,−1.22)	<0.001	−1.53	(−1.98,−1.08)	<0.001	−1.54	(−1.99,−1.08)	<0.001
Age Group									
55–59	--								
60–64	−0.03	(−0.24,0.18)	0.77	0.25	(−0.05,0.54)	0.10	0.07	(−0.23,0.36)	0.66
65–74	−0.22	(−0.42,−0.02)	0.03	0.21	(−0.08,0.49)	0.16	−0.04	(−0.33,0.25)	0.80
Female	0.17	(−0.01,0.35)	0.06	0.13	(−0.13,0.39)	0.32	0.38	(0.12,0.64)	0.004
African American	−0.49	(−0.69,−0.29)	<0.001	−0.84	(−1.13,−0.55)	<0.001	−0.72	(−1.01,−0.43)	<0.001
Education									
< High School	−0.39	(−0.66,−0.12)	0.005	−0.44	(−0.83,−0.06)	0.02	−0.74	(−1.12,−0.35)	<0.001
High School Grad	−0.21	(−0.46,0.04)	0.10	−0.42	(−0.77,−0.06)	0.02	−0.66	(−1.02,−0.30)	<0.001
Some College	−0.02	(−0.26,0.22)	0.88	−0.23	(−0.57,0.11)	0.18	−0.38	(−0.72,−0.04)	0.03
≥ College Grad	--								
Exposure	0.17	(−0.01,0.34)	0.06	0.10	(−0.15,0.35)	0.43	0.17	(−0.08,0.42)	0.19
Constant	4.90	(4.65,5.15)	<0.001	6.79	(6.48,7.10)	<0.001	6.54	(6.23,6.85)	<0.001