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Functional Health Literacy, Chemotherapy Decisions, and Patient Outcomes within a Cohort of Colorectal Cancer Patients

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Abstract

Background—Functional health literacy—including the ability to read or understand medication labels, physician instructions, and educational materials—is essential for self-management of chronic diseases and preventive health behaviors. Cancer patients with low health literacy may be at greater risk for worse care and outcomes.

Methods—We assessed health literacy using the Short Test of Functional Health Literacy in Adults (S-TOFHLA) in 347 colorectal cancer (CRC) patients nested within a prospective observational study of system, provider, and patient characteristics influencing cancer outcomes.

Results—We found that having adequate health literacy increased the chances that Stage III/IV patients received chemotherapy (odds ratio [OR] = 3.29, 95% Confidence Interval [CI] 1.23, 8.80) but had no effect on cancer stage at diagnosis or vital status at last observation during post-enrollment follow-up. Examining survey responses among Stage III and IV patients, we found no differences by health literacy status regarding patient beliefs and preferences about chemotherapy, nor in patients' roles in deciding whether to receive chemotherapy.

Conclusions—Patients with lower health literacy were less likely to receive chemotherapy compared with patients with higher health literacy. Clearer communication around such key healthcare decisions may lead to less disparities by health literacy level.

Keywords

Colorectal neoplasms; chemotherapy; health literacy; outcomes; treatment decisions

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Background

Functional health literacy—including the ability to read and understand medication labels, educational materials, hospital directional signs, and appointment slips—is essential for self-management of chronic diseases and preventive health behaviors.¹ Unfortunately, individuals with the greatest health care needs may have the least ability to read and comprehend information needed to function successfully as patients.^{1,2} Inadequate health literacy could decrease the chances that these high-risk individuals will have beneficial health outcomes.

Having inadequate or marginal functional health literacy places patients at increased risk for medication non-adherence, hospital admission, poor health status, and worse clinical outcomes.^{1,3-5} It has also been associated with lower patient information seeking.⁶ Consequently, patients with poor reading ability have important problems accessing the health care system, understanding recommended treatments, and following the instructions of providers. The American Medical Association “recognized that limited patient literacy is a barrier to effective medical diagnosis and treatment” and has adopted policies to increase recognition of, and effect change in, functional health literacy.¹

Health literacy levels might especially influence cancer outcomes. New patients receive large amounts of unfamiliar technical information about their diagnosis. Often, clinicians invite patients to participate in choosing among complicated treatment options. Adhering to chosen treatments can be a byzantine process of understanding and complying with surgery, radiation therapy, multiple and varying chemotherapy regimes, and follow-up visits involving several providers.

To evaluate the role of health literacy in cancer treatment decisions and estimate its impact on patient outcomes, we assessed health literacy in a set of colorectal cancer (CRC) patients enrolled in a cohort study of health care processes. CRC has one of the largest disease burdens of any form of cancer with about 140,000 new cases and 50,000 deaths annually in the United States⁷, making it a good test case of the effects of health literacy on cancer outcomes. We hypothesized that greater health literacy would be associated with early-stage disease, greater patient participation in treatment decisions, receipt of more appropriate treatment, and improved survival.

Methods

Study Population

Subjects were enrolled in the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS), a prospective, population-based, multi-site observational study of lung and colon cancer patients, which has been described previously.⁸ The population was diverse with respect to race, socioeconomic status, and geography. The purpose of the study was to assess the impact of system, provider, and patient factors on cancer outcomes. Patients were at least 21 years of age at the time of CRC diagnosis and were enrolled within 3 months of diagnosis during 2003-06. The study collected patient surveys, surrogate surveys for patients who were deceased or too ill to participate, and medical records data.

Abstractors at each site collected medical-records information on tumor characteristics and cancer treatments received. Patient and, when necessary, surrogate surveys were completed using computer-assisted telephone interviews. Surveys included items about demographic and socioeconomic factors (age, insurance coverage, income), communication with physicians, and beliefs and preferences regarding cancer treatments. The surveys have been described previously.⁹ The wording of survey items examined in this study is presented in Table 3.

CanCORS included colorectal and lung cancer cases who were enrolled by seven groups of investigators.⁸ North Carolina only recruited CRC cases (n=990). In addition, North Carolina was the only site to administer health literacy assessments.

The study population was a random sample of 347 patients from the NC-CanCORS study. The sample was stratified by self-reported years of education, with oversampling of lower strata, to achieve similarly-sized strata of adequate versus inadequate or marginal health literacy, with the goal of enhancing power for planned analyses. We used the following sampling fractions for the respective ranges of years of education: 0-8 years (100%), 9-11 years (100%), 12 years (70%), and greater than 12 years (40%).

The sample included all cancer stages. The Institutional Review Board at the University of North Carolina at Chapel Hill approved the protocol. All subjects provided informed consent.

Measure of Health Literacy

Functional health literacy was assessed using the Short Test of Functional Health Literacy in Adults (S-TOFHLA).^{10,11} A trained interviewer visited patients' homes to administer the assessment in person. The assessment tested reading comprehension using 36 total questions in response to 2 prose passages.

Across the entire sample, four different interviewers were used, but only one interviewer administered the assessment for a given subject. All interviewers were trained together in how to administer TOFHLA. The interviewer read a scripted introduction and instructions to the subject, then remained silent while the subject completed the questionnaire. Subjects were given up to 7 minutes to complete the questionnaire, but were not told beforehand that the assessment would be timed.

Scores were categorized as inadequate (0-16 correct), marginal (17-22 correct), or adequate (23-36 correct). For analysis, we combined marginal and inadequate scores into one category.

Chemotherapy Decisions

As part of the patient surveys, CanCORS subjects answered questions about whether they received adjuvant chemotherapy, how the chemotherapy decision was made, and the patients' beliefs and preferences regarding chemotherapy. Chemotherapy is generally recommended for colon cancer patients diagnosed with Stage III or IV disease.¹² We examined responses about chemotherapy decisions among CRC subjects in whom health

literacy was assessed and who were diagnosed with either Stage III or IV disease. Survey responses of “Don’t know,” “Declined to answer,” “Not applicable,” or that were missing were considered non-informative. Non-informative responses were excluded when conducting Fisher exact tests to compare survey responses by health literacy level.

Outcomes

CanCORS tumors were staged according to the TNM classification system. We considered Stages I and II “early-stage disease” and Stages III and IV “late-stage disease.”

Subjects were followed for survival after baseline data collection. Vital status for all subjects was verified using the Social Security Death Index on 4 May 2010, providing at least 42 months of follow-up observation time for each person. We defined patient survival as dichotomous vital status (alive or dead) at last observation.

Statistical Analysis

Among subjects in the literacy sample with any stage of cancer (N=347), we calculated overall and health literacy-stratified descriptive statistics for demographic and socioeconomic characteristics. Chi-square tests of association were conducted to examine differences in subject characteristics by health literacy level. We performed logistic regression analyses to estimate associations between health literacy and 1) whether patients received chemotherapy (for Stage III/IV patients), 2) cancer stage at diagnosis (for all patients), and 3) all-cause mortality at last observation after baseline (for all patients). Across all stages, we estimated the marginal effect of health literacy on survival as well as its effect conditional on demographic and socioeconomic covariates.

Among Stage III and IV patients in the health literacy sample (N=130), we calculated overall and health literacy-stratified descriptive statistics for responses to survey questions about patient beliefs and preferences regarding chemotherapy, communication with physicians about chemotherapy, and the patient’s role in making the decision whether to receive chemotherapy. We used Fisher exact tests to evaluate whether survey responses differed by patient health literacy level.

For all tests of association, p-values less than 0.05 were considered statistically significant. Analyses were performed at the University of North Carolina at Chapel Hill, which was the CanCORS site for all patients included in this study. We used CanCORS core data (Version 1.16), medical record data (Version 1.12), and patient survey data (Version 1.12). All analyses were performed using SAS 9.3 for Windows (SAS Institute, Cary, NC).

Results

Table 1 presents descriptive statistics among the 347 subjects in whom health literacy was assessed. Despite our goal of a sample with approximately equal numbers with adequate and marginal/inadequate health literacy, 105 (30%) were categorized as marginal/inadequate. Compared to those with adequate health literacy, patients with marginal/inadequate health literacy were more frequently male, non-white, at least 65 years old, not currently married or

living with a partner, had not completed high school, and had annual household incomes below \$40,000.

Among Stage III/IV patients—those for whom chemotherapy is recommended—having adequate health literacy increased the odds of receiving chemotherapy compared to those with marginal/inadequate health literacy (odds ratio [OR] = 3.29, 95% Confidence Interval [CI] 1.23, 8.80). However, across all stages, having adequate health literacy did not increase the odds of presenting with early-stage (Stage I/II) disease compared with presenting with late-stage (III/IV) disease (OR=1.11, 95% CI 0.68, 1.80).

For subjects with Stage III or IV disease, Table 2 presents responses to survey questions about patient beliefs and preferences regarding chemotherapy, patients' roles in deciding whether to receive chemotherapy, and their communication with physicians about chemotherapy. Of 130 Stage III/IV patients, 89 (68%) had adequate health literacy and 41 (32%) had inadequate/marginal health literacy, percentages that were comparable to those for the sample across all stages. We found no statistically significant differences in patient responses by health literacy level. Subjects of all health literacy levels overwhelmingly thought that, after discussing chemotherapy with a doctor, the treatment was substantially likely to help them live longer (89% of adequate health literacy and 100% of marginal/inadequate health literacy) and to help them with problems related to their cancers (82% of adequate health literacy and 100% of marginal/inadequate health literacy).

Though the differences were not statistically significant, Stage III/IV subjects with adequate health literacy played a more prominent role in deciding whether to have chemotherapy than those with inadequate/marginal health literacy (Table 2). Among those with informative responses, 75 of 83 (90%) with adequate health literacy reported either making the decision to have chemotherapy themselves or together with their doctors (as opposed to the doctors making the decision), compared with 20 of 25 (80%) among those with inadequate/marginal health literacy. Only 3 of 83 subjects (4%) with adequate health literacy and informative responses reported the doctors making the decision about chemotherapy with little or no patient input compared with 5 of 25 (20%) among those with inadequate/marginal health literacy and informative responses.

In the unadjusted regression of survival on health literacy, those with marginal/inadequate health literacy had higher odds of being deceased at last observation compared with those with adequate health literacy, but the effect was not statistically significant and disappeared when conditioned on cancer stage as well as demographic and socioeconomic covariates (Table 3). Male sex and Stage III/IV disease were associated with greater odds of being deceased at last observation, but no other notable effects were detected.

Discussion

Functional health literacy in cancer patients could play a crucial role in successful treatment and outcomes. Importantly, it is distinct from formal education. For example, 63% of patients with 9-11 years of education, and 34% of patients who graduated from high school, have been found to have an inadequate or marginal level of functional health literacy.¹³

Unfortunately, low rates of adequate functional health literacy are common, particularly among persons who are elderly and have less formal education.^{4,10,14-17} One study found that, among elderly (> 60 years) patients at urban public hospitals, 81% of English speakers and 83% of Spanish speakers had inadequate or marginal functional health literacy.¹⁷ Functional health literacy has been found to be markedly lower among older age groups even after adjusting for differences in mental status, newspaper reading frequency, health status, and visual acuity.¹⁸ Physical health of subjects with extremely low reading levels has been found to be poor compared with that of subjects with higher reading levels even after adjusting for confounding sociodemographic variables.^{2,19} Individuals with inadequate health literacy are more likely to report depressive symptoms that were mostly explained by their worse health status.^{2,20}

Clinicians must be sensitive to their patients' functional health literacy when they provide information regarding treatment options and prognoses. Analyses of the readability of patient education materials, discharge instructions, and consent forms have almost uniformly found that these materials are written at too complex a level for many or most patients.^{21,22} There is some evidence that tailoring communications for low-literacy adults can be effective.²³ Ultimately, however, patients with a variety of health literacy levels can have difficulty understanding health information, and improving communication may help patients across all health literacy levels.

To mitigate health literacy barriers, physicians should take steps when meeting with patients to ensure that communication is clear and that patients understand what is being taught. One recommended strategy involves the physician asking the patient questions towards the end of a clinical encounter to assess whether the patient recalls and understands the information or instructions provided.²⁴ For example, the physician might ask the patient about the name, dose, and frequency of a medication that the physician has just prescribed. This approach—often called the “teach-back” method—provides physicians with an opportunity to confirm patient understanding and gives patients the opportunity to solidify their understanding.

Given the potentially large impact of patient functional health literacy on cancer treatment decisions and outcomes, we hypothesized that greater health literacy would be associated with early-stage disease, more involvement with treatment decisions, receipt of more appropriate care, and better survival. To evaluate our hypotheses, we assessed healthy literacy in a set of CRC patients nested within a prospective, population-based observational study of system and provider characteristics that influence cancer outcomes.

Previous studies of health literacy found that lower literacy was correlated with being male,¹⁶ elderly,^{4,15-17} and having less formal education^{15,16} and income.¹⁶ The demographic and socioeconomic characteristics of our sample followed these patterns (Table 1).

In evaluating our hypotheses, we found that adequate health literacy increased the chances of receiving chemotherapy among patients with Stage III and IV disease. This suggests that greater health literacy might help patients to receive better care. However, we detected no other clear differences by health literacy level in patient beliefs, preferences, or decision-

making about chemotherapy. We did not find an association between health literacy and either cancer stage at diagnosis or vital status at last observation.

Our study had several limitations. First, our small sample limited our power to detect differences by health literacy status. Second, TOFHLA might not precisely capture the desired construct of health literacy. Instead, it could be better regarded as a test of reading comprehension in a healthcare context rather than a test of the broader concept of health literacy.²⁵ Specifically, TOFHLA might not evaluate aspects of health literacy other than reading, such as oral health literacy, navigation, and culture. The limitations of the instrument as a measure of health literacy could attenuate its association with some health outcomes. A third potential limitation that might be more general to health literacy research is the challenge of including sufficiently large numbers of marginal/inadequate literacy subjects to detect the effects of health literacy levels. As noted, our goal was a sample with about 50% marginal/inadequate health literacy, but our actual sample had 30% marginal/inadequate health literacy. Since we targeted patients for inclusion in the health literacy sub-study using formal education as a proxy, this result reinforces the conclusion of prior research that formal education and health literacy, while related, are distinct.¹³ Several previous studies of health literacy using TOFHLA (not all on cancer) obtained samples with even lower percentages of marginal/inadequate health literacy.^{15,16,26}

The lower than expected numbers of subjects with marginal/inadequate proficiency in studies of health literacy suggest that a selection bias might influence which patients enter these studies. To be eligible for inclusion in our sample, patients had to enroll in CanCORS, complete a baseline survey, and be administered TOFHLA. Patients who died before completing any of these steps could not have participated in the sample. For included subjects, the mean number of days from cancer diagnosis to CanCORS enrollment and baseline survey was 150 days, and from diagnosis to TOFHLA administration was 640 days.

It is possible that, if health literacy were associated with survival, CRC patients who died before they could enroll in CanCORS, or before they could complete the baseline survey or TOFHLA, might have had disproportionately low health literacy. The poorer health and greater difficulty completing surveys for those with low health literacy might systematically limit their participation in studies of health literacy. Future studies of health literacy should be designed to account for this possibility.

In the context of previous research, CRC patients could benefit from providers' sensitivity towards, and adjustment to, different levels of patient health literacy. Even more importantly, providers might consider that any of their patients could have difficulty understanding and making decisions about health care. Clear communication is likely to help both lower and higher health literacy patients.

In conclusion, among Stage III/IV patients, those with lower health literacy were less likely to receive chemotherapy compared with patients with higher health literacy. To provide high-quality, patient-centered care, physicians and care teams should consider strategies of clear communication and patient engagement, recognizing that health literacy could affect patient-provider interactions and choices in medical care.

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Table 1

Patient Characteristics

Characteristic	Overall		Adequate Literacy		Marginal/Inadequate Literacy		p-value ^b
	(n=347) ^a		(n=242) ^a		(n=105) ^a		
	n	%	n	%	n	%	
Sex							
Male	159	47	101	43	58	57	0.02
Female	178	53	134	57	44	43	
Race							
White	264	78	201	86	63	62	<0.0001
Non-white	73	22	34	14	39	38	
Age							
<65	160	47	130	55	30	29	<0.0001
>=65	177	53	105	45	72	71	
Education							
Less than High School	72	23	36	16	36	43	<0.0001
High School/GED	112	36	80	35	32	39	
More than High School	82	26	76	33	6	7	
Other	44	14	35	15	9	11	
Marital Status							
Currently Married/Living With Partner	211	63	158	67	53	52	0.008
Widowed/Divorced/Separated/ Never Married	126	37	77	33	49	48	
Household Income, past year							
<\$20,000	75	24	42	19	33	40	<0.0001
\$20,000-<\$40,000	82	27	56	25	26	31	
\$40,000-<\$60,000	52	17	42	19	10	12	
\$60,000+	78	25	73	32	5	6	
Refused/Don't Know	22	7	13	6	9	11	
Cancer Stage							
I/II	187	59	132	60	55	57	0.7
III/IV	130	41	89	40	41	43	
Received Chemotherapy							
Yes	164	53	129	57	35	42	0.02
No	146	47	98	43	48	58	
Vital Status at Last Observation							
Alive	260	77	187	80	73	72	0.1
Dead	77	23	48	20	29	28	

^a Differences between numbers of patients for each column and number of patients for each characteristic are missing data. Percentages are for non-missing data for the characteristic.

^b P-values were based on chi-square tests of each characteristic by levels of health literacy.

GED=General Educational Development

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Table 2Patient Preferences and Role in Receipt of Chemotherapy by Literacy Level^a

Survey Question	Total (n=130)	Number of Patients (%)		p ^b
		Adequate Literacy (n=89)	Marginal/ Inadequate Literacy (n=41)	
Did any of your doctors tell you not to have chemotherapy?				
Yes	2	1 (1)	1 (4)	0.4
No	108	84 (99)	24 (96)	
After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would help you live longer?				
Not likely/a little likely	9	9 (11)	0 (0)	0.1
Somewhat likely/very likely	95	71 (89)	24 (100)	
After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would help you with problems you were having because of your (cancer)?				
Not likely/a little likely	9	9 (18)	0 (0)	0.1
Somewhat likely/very likely	61	42 (82)	19 (100)	
Which statement best describes the role you played when the decision was made about chemotherapy?				
You made the decision with little or no input from your doctors	5	4 (5)	1 (4)	0.2 ^c
You made the decision after considering your doctors' opinions	32	27 (33)	5 (20)	
You and your doctors made the decision together	58	44 (53)	14 (56)	
Your doctors made the decision after considering your opinion	5	5 (6)	0 (0)	
Your doctors made the decision with little or no input from you	8	3 (4)	5 (20)	
If you had to make a choice now, would you prefer treatment that extends life as much as possible, even if it means having more pain and discomfort, or would you want treatment that focuses on relieving pain and discomfort as much as possible, even if it means not living as long?				
Extend life as much as possible	58	45 (58)	13 (52)	0.6
Relieve pain or discomfort as much as possible	44	32 (42)	12 (48)	
If you had to make a choice now, would you prefer treatment that extends life as much as possible, even if it means using up all of your financial resources, or would you want treatment that costs you less, even if means not living as long?				
Extend life as much as possible	65	46 (61)	19 (73)	0.3
Treatment that costs less	37	30 (39)	7 (27)	

^aThis analysis is limited to Stage III and IV patients, i.e. those for whom chemotherapy is recommended. For each item, differences between presented frequencies and total number of subjects represent missing or non-informative responses (e.g. "Don't know").

^bP-values were based on 2-sided Fisher exact tests excluding missing and non-informative responses.

^cFor Fisher exact test, responses dichotomized as “Patient principally made the decision/patient and doctors made decision together” vs. “Doctors principally made the decision.”

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Table 3

Factors Associated with Being Dead at Last Observation, n=347

Variable ^a	Univariate		Multivariate ^b	
	OR	95% CI	OR	95% CI
Health Literacy (Inadequate/Marginal vs. Adequate)	1.55	0.91, 2.64	0.90	0.42, 1.94
Sex (Male vs. Female)	1.93	1.15, 3.24	2.16	1.09, 4.28
Race (Non-white vs. White)	1.50	0.84, 2.70	1.45	0.66, 3.19
Age (>=65 vs. <65)	1.46	0.87, 2.45	1.59	0.82, 3.08
Education (Less than high school vs. completed high school/GED)	1.63	0.90, 2.97	1.46	0.70, 3.03
Marital Status (Not living with anyone vs. married/living with a partner)	1.55	0.92, 2.59	1.40	0.68, 2.88
Household Income (<\$40,000 vs. >=\$40,000)	1.46	0.82, 2.59	1.23	0.57, 2.67
Cancer Stage (III/IV vs. I/II)	2.62	1.52, 4.52	2.25	1.21, 4.20

^aFor each variable (a vs. b), a=index group and b=reference.^bResults from a model with all variables in the table simultaneously included as independent variables.

OR=Odds Ratio, CI=Confidence Interval, GED=General Educational Development