Health Literacy in Surgical Oncology Patients: An Observational Study at a Comprehensive Cancer Center

Luke D. Rothermel, MD, MPH^{1,*}; Claire C. Conley, PhD^{2,3,*}; Anuja L. Sarode, MPH⁴; Michael F. Young, BS⁵; Zulema L. Uscanga, MPH, CPH²; McKenzie McIntyre, MPH²; Jason B. Fleming, MD⁶; and Susan T. Vadaparampil, PhD²

ABSTRACT

Background: Low health literacy is associated with increased resource use and poorer outcomes in medical and surgical patients with various diseases. This observational study was designed to determine (1) the prevalence of low health literacy among surgical patients with cancer at an NCI-designated Comprehensive Cancer Center (CCC), and (2) associations between health literacy and clinical outcomes. **Methods:** Patients receiving surgery (N=218) for gastrointestinal (60%) or genitourinary cancers (22%) or sarcomas (18%) were recruited during their postsurgical hospitalization. Patients self-reported health literacy using the Brief Health Literacy Screening Tool (BRIEF). Clinical data (length of stay [LoS], postacute care needs, and unplanned presentation for care within 30 days) were abstracted from the electronic medical records 90 days after surgery. Multivariate linear and logistic regressions were used to examine the relationship between health literacy and clinical outcomes, adjusting for potential confounding variables. **Results:** Of 218 participants, 31 (14%) showed low health literacy (BRIEF score ≤ 12). In regression analyses including 212 patients with complete data, low health literacy significantly predicted LoS ($\beta = -1.82$; 95% CI, -3.00 to -0.66 ; $P=.002$) and postacute care needs (odds ratio [OR], 0.25; 95% CI, 0.07–0.91). However, health literacy was not significantly associated with unplanned presentation for care in the 30 days after surgery (OR, 0.51; 95% CI, 0.20–1.29). **Conclusions:** This study demonstrates the prevalence of low health literacy in a surgical cancer population at a high-volume NCI-designated CCC and its association with important clinical outcomes, including hospital LoS and postacute care needs. Universal screening and patient navigation may be 2 approaches to mitigate the impact of low health literacy on postsurgical outcomes.

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¹Department of Surgery, University Hospitals Seidman Cancer Center, Cleveland, Ohio; ²Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, Florida; ³Department of Oncology, Georgetown University, Washington, DC; ⁴University Hospitals Research in Surgical Outcomes and Effectiveness Center, University Hospitals, Cleveland, Ohio; ⁵Morsani College of Medicine, University of South Florida, Tampa, Florida; and ⁶Department of Gastrointestinal Oncology, Moffitt Cancer Center, Tampa, Florida.

*These authors contributed equally to this study and are co-first authors.

Background

Health literacy consists of a set of complex and interconnected abilities that people need to function effectively in the healthcare environment.^{1–3} These skills impact multiple dimensions of communication and include print literacy, or the ability to read, understand, and act upon text and to locate and interpret health information in documents; and oral literacy, or the ability to speak and listen effectively about health information (eg, communicating needs to health professionals, understanding professionals' instructions). Only 12% of the US adult population is considered to have a "proficient" level of health literacy; most (53%) have "intermediate" health literacy.⁴ This finding has been referred to as the "health literacy epidemic."⁵

Low health literacy is associated with difficulty in communicating about health, including objectively poorer ability to understand and follow medical advice⁶ and to interpret written information in medical and surgical contexts.^{6–11} Low health literacy is also correlated with lower adherence to care recommendations and screening guidelines^{6,12} and negatively influences clinical outcomes related to the management of chronic diseases, including asthma,¹³ diabetes,^{14,15} congestive heart failure,^{10,16,17} and end-stage renal disease.^{18,19} Finally, given the importance of health literacy for self-management after discharge, low health literacy has also been shown to be associated with a higher incidence of unplanned readmissions after hospitalization²⁰ and an increased rate of acute care and emergency department (ED) visits in certain patient populations.²¹

Compared with evidence about the relationship between health literacy and outcomes for patients with chronic medical conditions, there is a relative dearth of research on the effects of low health literacy on postoperative outcomes. A recent systematic review of health literacy in surgery identified 51 studies addressing this topic, with only 6 that investigated the association of health literacy and surgical outcomes.²² In all studies, the prevalence of low health literacy was reported in more than one-third of patients, although this was determined in heterogeneous patient populations using various assessment tools

between studies. Low health literacy is reported to impact whether patients undergo certain surgical procedures, such as breast reconstruction after mastectomy,²³ or whether they are listed for kidney transplant.^{7,24} In addition, low health literacy was predictive of developing minor postoperative complications in patients undergoing radical cystectomy.⁸ Finally, lower health literacy is independently associated with increased hospital length of stay (LoS) in patients who are undergoing major abdominal surgery.⁹

To our knowledge, there are no published studies focusing on the role of health literacy in complex general surgical oncology. Surgical interventions for cancers such as gastrointestinal and genitourinary malignancies and sarcomas require hospitalization and extended periods of recovery. The physical toll of these surgeries is substantial and often requires adjustments to a patient's dietary habits, functional mobility, or digestive processes, among other changes. Within the complex setting of these surgical procedures and the postoperative course, the impact of health literacy is poorly understood.

To fill this gap, the present study reports on health literacy among a sample of patients presenting for complex cancer surgery at an NCI-designated Comprehensive Cancer Center (CCC). The study aims were 2-fold: (1) to define the prevalence of low health literacy for surgical patients with cancer at an NCI-designated CCC, and (2) to examine the associations of health literacy with clinical outcomes. We hypothesized that (1) using the Brief Health Literacy Screening Tool (BRIEF) with a cutpoint of 12, approximately 30% of surgical oncology patients would show low health literacy, defined as scores ≤ 12 on the 4-question version of BRIEF; and (2) compared with patients with marginal or adequate health literacy, those with low health literacy would have longer hospital LoS, more postacute care needs, and more unplanned presentations for care in the 30 days after surgery.

Methods

Procedures and Participants

An observational, longitudinal, single-group design was used. All procedures were approved by the University of South Florida Institutional Review Board (protocol #00038579). Because the BRIEF has not been used previously in the surgical literature, the data points necessary to conduct a formal power analysis were not available. Thus, the target sample size for this study (200 cases with complete data) was based on prior studies of health literacy in surgical populations.²² To achieve this goal, a convenience sample of patients presenting for care at an NCI-designated CCC was used. Recruitment occurred from March 2019 through September 2019.

Eligible participants were (1) aged ≥ 18 years; (2) presenting for surgical treatment of primary gastrointestinal cancer, genitourinary cancer, or sarcoma; (3) admitted to the hospital for ≥ 1 night; and (4) English speakers. Study staff reviewed lists of recent admissions and patient electronic medical records (EMRs) to identify patients meeting eligibility criteria. Eligible participants were approached by study personnel during their postsurgical inpatient stay and, if interested, provided written informed consent. After obtaining consent, study personnel assisted participants in completing a self-report survey. After survey completion, participants received a \$20 gift card in appreciation for their time and effort. Clinical data were abstracted from the EMR 90 days after surgery; thus, clinical data abstraction took place between June and December 2019.

Measures

The primary predictor of interest was health literacy. The primary outcomes of interest included hospital LoS, postacute care needs, and 30-day unplanned presentations for care postsurgery. Sociodemographic and clinical characteristics were examined as covariates.

Demographic Characteristics

Participants reported their age, sex, race/ethnicity, education level, and insurance status.

Clinical Characteristics

Medical comorbidities (Charlson-Deyo comorbidity index score²⁵), functional status (ECOG performance status²⁶), and surgical complications (Clavien-Dindo grade) were abstracted from the EMRs.

Health Literacy

The 4-item BRIEF²⁷ assesses the ability to read and discuss health-related information. This screening tool is built upon the 3-question BHLS (Brief Health Literacy Screen),^{28–33} with the addition of 1 question to assess oral literacy in a quick and validated measure.^{27,34} Responses were scored based on a 5-point Likert scale ranging from 1 (never) to 5 (always). Final scores ranged from 4 to 20, and a cutpoint of 12 is used to determine low versus marginal or adequate health literacy.

Clinical Outcomes

Data abstracted from the EMR 90 days after surgery included (1) hospital LoS (days); (2) postacute care needs, including home-based physical therapy or occupational therapy, home nursing, or discharge to a skilled nursing or rehabilitation facility (yes/no); and (3) unplanned presentations for care in the 30 days after surgery, including ED visits and/or hospital readmissions (yes/no).

Statistical Methods

Descriptive statistics were used to examine the distribution of health literacy in this sample. Continuous variables are presented with mean [SD], and categorical variables are presented with frequency (percent). The chi-square test of association or Fisher exact test in case of cell value <5 was used for comparison between categorical variables. For comparing means, ANOVA was used.

In regression analyses, we combined the populations with marginal and adequate health literacy (BRIEF score >12) to highlight the impact of low health literacy (BRIEF score ≤12) on clinical outcomes, as has been done previously.^{19,35} Multivariate linear regression analysis was used to examine the relationship between health literacy (low vs marginal or adequate) and hospital LoS in days (continuous). Multivariate logistic regression analysis was used to predict the odds of re-presentation to the ED/rehospitalization (yes/no) and postacute care needs (yes/no) by health literacy (low vs marginal or adequate). Initial models included sociodemographic and clinical covariates (age, sex, race/ethnicity, education level, insurance status, Charlson-Deyo scores, and Clavien-Dindo grade III or IV complications). To ensure parsimony of the final models, only those variables that were significant predictors ($P < .05$) in the multivariate models were retained for the final model. All tests were 2-tailed, and a P value <.05 was considered statistically significant. All analyses were conducted using SAS 9.4 (SAS Institute Inc).

Results

Preliminary and Descriptive Analyses

We approached 255 patients, and 225 (88%) consented to participate (Figure 1). Seven patients (3%) were deemed ineligible after consent due to having a secondary surgery related to their cancer (ie, ileostomy takedown); thus, a total of 218 patients were included in the descriptive analyses. For regression analyses examining the relationship between health literacy and resource use, we excluded 4 outliers (Clavien-Dindo grade V, $n=1$; LoS >25 days, $n=3$). Because 2 patients had incomplete sociodemographic data, the final analytic sample included 212 patients with complete data. For a complete description of the sample, see Table 1. Health literacy groups significantly differed on education, such that a greater proportion of patients with low health literacy had less than a high school diploma (12.9% vs 6.1% for marginal and 2.5% for adequate). Groups also significantly differed on Charlson-Deyo score, such that a greater proportion of patients with low health literacy had ≥1 comorbid condition (61.3% vs 51.5% for marginal and 31.4% for adequate).

Figure 1. Study flowchart.

Abbreviation: EMR, electronic medical record.

Prevalence of Low Health Literacy

The mean [SD] BRIEF score for the sample was 16.49 [3.18]. Of 218 participants, 31 (14%) showed low health literacy according to BRIEF scores. Marginal health literacy was identified in 66 patients (30%), and adequate health literacy was identified in 121 (56%).

Associations With Postsurgical Outcomes

All linear and logistic regression analyses included health literacy, age, sex, race/ethnicity, education level, insurance, Charlson-Deyo scores, and Clavien-Dindo grade III or IV complications as predictors. Results of the multivariate linear regression predicting average LoS are presented in Table 2. In the initial model, only health literacy ($P=.002$), education level ($P=.01$), and Clavien-Dindo grade III or IV complications ($P<.0001$) significantly predicted average LoS. Thus, these 3 variables were retained in the final model for LoS. In the final model, on average, patients with marginal and adequate health literacy had significantly shorter hospital LoS than those with low health literacy ($\beta = -2.04$; 95% CI, -3.19 to -0.89 ; $P=.0006$). In other words, on average, LoS was 2.04 days less for those with marginal or adequate health literacy than for those with low health literacy after adjusting for education and Clavien-Dindo grade III or IV complications.

Table 1. Cohort Characteristics by Health Literacy Score Category (N=218)

Characteristic	BRIEF Score			P Value
	Low (6–12) n (%)	Marginal (13–16) n (%)	Adequate (17–20) n (%)	
Total, n	31	66	121	
Sociodemographic characteristics				
Age, y, mean [SD]	69.8 [10.0]	66.4 [11.1]	64.5 [13.5]	.09
Sex				.32
Male	22 (71.0)	37 (56.1)	69 (57.0)	
Female	9 (29.0)	29 (43.9)	52 (43.0)	
Race/Ethnicity				.96 ^a
Non-Hispanic White	27 (87.1)	58 (87.9)	104 (86.7)	
Other	4 (12.9)	8 (12.1)	17 (14.1)	
Education				.04 ^a
Less than high school diploma	4 (12.9)	4 (6.1)	3 (2.5)	
High school diploma or greater	27 (87.1)	62 (93.9)	118 (97.5)	
Insurance				.25
Medicaid/Uninsured	3 (9.7)	6 (9.1)	5 (4.2)	
Private/Medicare/Military	28 (90.3)	60 (90.9)	114 (95.8)	
Clinical variables				
Charlson-Deyo score				<.01
0	12 (38.7)	32 (48.5)	83 (68.6)	
≥1	19 (61.3)	34 (51.5)	38 (31.4)	
ECOG performance status				.93 ^a
0–1	29 (93.6)	61 (92.4)	114 (94.2)	
2–3	2 (6.5)	5 (7.6)	7 (5.8)	
Surgery type				.56 ^a
Gastrointestinal	18 (58.1)	36 (54.6)	75 (62.0)	
Genitourinary	9 (29.0)	14 (21.2)	26 (21.5)	
Sarcoma	4 (12.9)	16 (24.2)	20 (16.5)	
Clavien-Dindo grade III or IV				.12 ^a
Yes	1 (3.3)	6 (9.1)	3 (2.5)	
No	29 (96.7)	60 (90.9)	118 (97.5)	
Hospital LoS, mean (SD), d	8.71 (4.1)	7.50 (5.6)	6.63 (4.9)	.10
Re-presentation to ED/hospital				.17
Yes	10 (32.3)	12 (18.2)	21 (17.4)	
No	21 (67.7)	54 (81.8)	100 (82.6)	
Postacute care needs				.02 ^a
Yes	28 (90.3)	42 (63.6)	85 (70.3)	
Home health visit	26 (83.9)	39 (59.1)	81 (66.9)	
Skilled nursing/rehabilitation facility	2 (6.5)	3 (4.6)	4 (3.3)	
No	3 (9.7)	24 (36.4)	36 (29.8)	

P values were derived by ANOVA, chi-square test of association, and Fisher exact test; $P < .05$ was considered statistically significant. Abbreviations: BRIEF, Brief Health Literacy Screening Tool; ED, emergency department; LoS, length of stay.

^aFisher exact test.

Table 2. Linear Regression Analysis for Factors Predicting Hospital Length of Stay in Days (n=212)

Variable	β (95% CI)	P Value
Model 1: all covariates ($R^2 = 0.1951$)		
Intercept	6.140 (3.445 to 8.836)	<.0001
BRIEF score, marginal or adequate (13–20) vs low (6–12)	−1.612 (−3.000 to −0.656)	.002
Age, y	0.030 (−0.004 to 0.064)	.080
Sex: female vs male	−0.551 (−1.378 to 0.274)	.189
Race/Ethnicity: other vs non-Hispanic White	0.638 (−0.624 to 1.900)	.320
Education: less than high school vs high school or greater	2.315 (0.480 to 4.150)	.014
Insurance: Medicaid/uninsured vs private/Medicare	−0.893 (−2.568 to 0.782)	.294
Charlson-Deyo score: ≥ 1 vs 0	0.112 (−0.717 to 0.941)	.790
Clavien-Dindo grade III or IV: yes vs no	5.092 (3.016 to 7.167)	<.0001
Model 2: parsimonious model ($R^2 = 0.1667$)		
Intercept	8.170 (7.086 to 9.254)	<.0001
BRIEF score: marginal or adequate (13–20) vs low (6–12)	−2.040 (−3.191 to −0.890)	.0006
Education: less than high school vs high school or greater	1.947 (0.137 to 3.756)	.0351
Clavien-Dindo grade III or IV: yes vs no	5.115 (3.033 to 7.198)	<.0001

Bold indicates statistically significant *P* value.

Abbreviation: BRIEF, Brief Health Literacy Screening Tool.

Results of the multivariate logistic regression analyses predicting the odds for re-presentation to the ED/rehospitalization are presented in Table 3. In the initial model, none of the specified predictors were significantly associated with re-presentation to the ED/rehospitalization.

Results of the multivariate logistic regression analyses predicting the odds for postacute care needs are presented in Table 4. In the initial model, only health literacy (odds ratio [OR], 0.25; 95% CI, 0.07–0.91), age (OR, 1.05; 95% CI, 1.02–1.08), and sex (OR, 2.10; 95% CI, 1.06–4.18) significantly predicted the odds for postacute care needs. Thus, these 3 variables were retained in the final model for the odds of postacute care needs. In the final model, patients

with marginal and adequate health literacy were 77% less likely to need postacute care than those with low health literacy (OR, 0.23; 95% CI, 0.07–0.82) after adjusting for age and sex.

Discussion

Low health literacy is associated with increased resource use^{6,12,20,21} and poorer clinical outcomes^{6,10,11} in medical and surgical patients with various diseases. Despite the demonstrated importance of health literacy in the perioperative period,^{35,36} the role of health literacy in complex surgical oncology has not previously been delineated. Because surgery for cancer is especially complex in terms of shared decision-making, perioperative instructions, and

Table 3. Logistic Regression Analysis for Factors Predicting Re-Presentation to ED/Rehospitalization 30 Days After Surgery (n=212)

Variable	OR (95% CI)
Model 1: all covariates (AUC, 0.646)	
BRIEF score: marginal or adequate (13–20) vs low (6–12)	0.508 (0.200–1.291)
Age, y	1.006 (0.976–1.038)
Sex: female vs male	2.000 (0.971–4.118)
Race/Ethnicity: other vs non-Hispanic White	0.909 (0.297–2.781)
Education: less than high school vs high school or greater	0.659 (0.121–3.587)
Insurance: Medicaid/uninsured vs private/Medicare	3.033 (0.873–10.542)
Charlson-Deyo score: ≥ 1 vs 0	1.527 (0.740–3.150)
Clavien-Dindo grade III or IV: yes vs no	2.768 (0.324–23.653)

Abbreviations: AUC, area under the curve; BRIEF, Brief Health Literacy Screening Tool; ED, emergency department; OR, odds ratio.

Table 4. Logistic Regression Analysis for Factors Predicting Postacute Care Needs (n=212)

Variable	OR (95% CI)
Model 1: all covariates (AUC, 0.713)	
BRIEF score: marginal or adequate (13–20) vs low (6–12)	0.254 (0.071–0.908)
Age, y	1.052 (1.023–1.082)
Sex: female vs male	2.101 (1.058–4.175)
Race/Ethnicity: other vs non-Hispanic White	0.716 (0.272–1.884)
Education: less than high school vs high school or greater	2.879 (0.499–16.605)
Insurance: Medicaid/uninsured vs private/Medicare	1.223 (0.279–5.363)
Charlson-Deyo score: ≥ 1 vs 0	0.937 (0.486–1.807)
Clavien-Dindo grade III or IV: yes vs no	2.768 (0.324–23.653)
Model 2: parsimonious model (AUC, 0.689)	
BRIEF score: marginal or adequate (13–20) vs low (6–12)	0.232 (0.065–0.821)
Age, y	1.049 (1.022–1.077)
Sex: female vs male	1.970 (1.017–3.816)

Bold indicates statistically significant *P* value.

Abbreviations: AUC, area under the curve; BRIEF, Brief Health Literacy Screening Tool; OR, odds ratio.

the postoperative course, there is an urgent need to understand the role of health literacy in outcomes after cancer surgeries. The present study fills this gap. Our data show that only a small proportion (14%) of patients presenting for complex cancer surgery at a high-volume NCI-designated CCC had low health literacy. Nonetheless, lower health literacy was related to increased resource use in the form of hospital LoS and postacute care needs. Taken together, these data have clinical implications for the identification and management of patients with low health literacy.

Our first hypothesis, that approximately 30% of participants would show low health literacy, was not supported. The incidence of low health literacy in this cohort (14%) is lower than the previously reported average rate in other surgical cohorts (~33%).²² Because 12% of the patients approached refused participation, it is possible that these patients may have disproportionately represented the low health literacy group, thereby skewing our data. Alternatively, this lower rate of low health literacy may reflect differences in the types of patients who present to regional CCCs; across most cancer diagnoses, patients are more likely to be treated at NCI-designated CCCs if they are non-Hispanic White, are privately insured, and have high socioeconomic status.³⁷ These characteristics have also been associated with higher health literacy.^{6,38–40} Seeking treatment at a stand-alone NCI-designated CCC often requires a high level of patient engagement to obtain a referral or navigate care between medical systems. Thus, higher levels of health literacy may be necessary to establish care at these institutions.

Although small numbers of patients in this sample showed low health literacy, BRIEF scores were still related

to longer hospital LoS and greater postacute care needs when accounting for the sociodemographic and clinical variables that were significantly related to outcomes of interest. Even at an NCI-designated CCC that has incorporated perioperative interventions that reduce LoS after surgery,⁴¹ we still observed differences in clinical outcomes by level of health literacy. Thus, our second hypothesis was partially supported. We did not observe any relationship between BRIEF scores and unplanned presentation for care within 30 days after surgery. This contradicts the findings in certain medical conditions showing that low health literacy is related to higher incidence of unplanned readmissions after hospitalization²⁰ and an increased rate of acute care and ED visits²¹ in the 30 days after surgery. There are several potential explanations for our null findings. First, our results could be confounded in part by the source of data on unplanned presentation for care. These data were abstracted from the institutional EMRs, which may not capture readmissions and ED visits at outside facilities. Thus, the data presented here may underestimate unplanned re-presentations for care in the 30 days after surgery. In addition, our patient population included patients who underwent complex surgeries for multiple types of cancers (gastrointestinal, genitourinary, and sarcoma), for whom different degrees of morbidity and postacute care needs would be expected, depending on the surgery performed. Although different trends existed for resource use by cancer types, the low number of patients in these independent groups precluded subgroup analyses. Therefore, this heterogeneity may limit the sensitivity of our analysis.

These data have important system-level implications. Specifically, screening for low health literacy in

the postsurgical setting was feasible; we did not observe patient unwillingness to participate due to stress, postoperative pain, or medication-related impairment. Other studies that have reviewed health literacy postoperatively have done so in the outpatient clinic setting.^{7,23,42} Therefore, the feasibility of health literacy screening during this postoperative admission is a novel contribution to the literature.

Although universal health literacy screening has been criticized for its potential to result in negative profiling of patients through perceived or actual stigmatization,^{43–48} the present study suggests that screening for health literacy may allow a targeted intervention approach to reduce the clinical impact of low health literacy. This aligns with recent recommendations for the use of universal health literacy screening in addition to universal precautions (eg, plain language and teach-back communications for all patients) as best practices for managing patients with low health literacy.⁴⁹ With multiple studies demonstrating increased resource use by patients with low health literacy (ie, LoS), a proactive realignment of resources (eg, high-touch interaction with the clinical team, patient navigation, social work, home care assistance) earlier in the perioperative period could help these patients adhere to standard treatment courses and mitigate the impact of low health literacy on clinical outcomes.

Once patients with low health literacy are identified, evidence-based interventions could be used to improve the postoperative outcomes and resource requirements of this population.⁵⁰ For example, intensive self-management interventions (eg, tailored educational materials about disease management and scheduled telephone follow-up) have been shown to reduce ED visits and hospitalizations.^{51,52} However, to our knowledge, these interventions have not been tested in the surgical oncology context. Future studies are needed to assess whether the positive intervention results observed in other populations would translate to this setting. In addition, there has been a recent push for the integration of nurse navigators in the postsurgical setting.^{53,54} Emerging data show that nurse navigation interventions can reduce hospital LoS and postsurgical readmissions.⁵⁵ Future research should examine the potential of navigation interventions specifically for surgical patients with low health literacy.

Strengths of our study include the direct clinical applicability and the novel application of health literacy screening in the postsurgical setting. Furthermore, this study is among the first to examine health literacy in the complex surgical oncology setting. To our knowledge, this is the first evaluation to focus on health literacy in surgical patients at a high-volume, freestanding, NCI-designated CCC. We also used an established measure to assess health literacy: the BRIEF.²⁷

Several limitations must also be acknowledged. Data from a single institution may not be generalizable across all surgical practice settings. We had limited ability to examine the potential confounding role of sociodemographic characteristics due to the homogeneous sample (ie, 87% non-Hispanic White patients, 95% high school diploma or higher education level, 93% insured). Furthermore, this homogeneous sample reduces the generalizability of results to diverse patient populations. EMR data exclusive to our institution may underrepresent ED visits and readmissions if they occurred at outside facilities. The convenience sample of patients presenting for surgery may be subject to selection bias, and self-reported health literacy may be subject to demand characteristics and social desirability. Lastly, there may be additional predictors of resource use (eg, psychologic symptoms, social support, quality of or satisfaction with care) that were not assessed in this study.

Conclusions

Low health literacy adversely affects clinical outcomes and resource use in medical and surgical patients. This pilot study demonstrates the prevalence of low health literacy in a surgical cancer population at a high-volume NCI-designated CCC and its association with important clinical outcomes, including hospital LoS and postacute care needs. Health literacy is a patient-level determinant of health that should be considered among other biologic, psychologic, social, and health system determinants of health when evaluating patients' ability to navigate their complex medical care.

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Correspondence: Luke D. Rothermel, MD, MPH, Department of Surgery, University Hospitals Seidman Cancer Center, Lakeside 7010, 11100 Euclid Avenue, Cleveland, OH 44139. Email: luke.rothermel@uhhospitals.org

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