



Documenting limited health literacy in a clinical setting[☆]

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ABSTRACT

Objective: Health literacy is important in lung cancer care, where treatments and symptoms are difficult to navigate. This study aims to describe how a single-item measure of health literacy can facilitate health literacy system capacity. **Methods:** Data include retrospective medical records from 456 patients with lung cancer. Limited or adequate health literacy was based on participant response to the Single Item Literacy Screener (SILS). Data were collected over a 12-month period following diagnosis for each patient. **Results:** One-third of patients had limited health literacy; they were more likely to have lung cancers of stage IIIB or higher and greater median levels of depression based on the PHQ-9 questionnaire. Patients with limited health literacy were also more likely to have at least one emergency department visit or unplanned hospitalization and had these visits sooner. **Conclusion:** These data document need for interventions to buffer the association between limited health literacy and poor health outcomes. **Innovation:** Routine intake screens should include the SILS to measure health literacy among lung cancer patients. New models that address health literacy at the organizational and patient levels can be implemented in health care settings using the SILS.

1. Introduction

Health literacy exists at the intersection of patient and provider, where people interpret and act upon the information that is provided to them. Efforts to build health literacy must look beyond individual patient education and counseling to systemic innovations in information technology, intersectoral collaboration, and people-centered services [1]. We argue that a single measure of reading comprehension can document need for services at the aggregate level and referral to services at the individual level.

Health literacy is particularly critical for chronic illness and cancer care due to complicated treatments, decision-making, and self-management [2-3]. At the prevention stage, individuals with limited health literacy are less aware of information about cancer prevention and screening and rely heavily on healthcare providers for information [4-6]. Limited health literacy is also associated with more emergency department visits and hospitalizations among patients with cancer and elderly patients, independent of related explanations, such as greater disease knowledge and healthier behaviors [3,7]. During cancer care, patients with limited health literacy tend to have relatively poor outcomes in physical, functional, emotional, and social well-being [8]; activities of daily living; physical function; and mental health [9]. A systematic review further illustrates these points,

showing that patients with limited health literacy were less likely to use preventative measures and adhere to treatment [3]. These patients were more likely to present with more advanced cancers at time of diagnosis and were more prone to fatalistic attitudes towards cancer, resulting in heightened anxiety and depression [3,10]. The healthcare disadvantages that accompany limited health literacy present obstacles to effective cancer care.

There are many validated measures of health literacy in the literature. One example is the Test of Functional Health Literacy in Adults (TOFHLA), which consists of a 50-item reading comprehension component and a 17-item numerical ability component, taking up to 22 minutes to administer [11]. Its shorter counterpart, the Short TOFHLA (S-TOFHLA) is reduced to 36 reading comprehension items and 4 numeracy items, taking up to 12 minutes to administer [12]. The Health Literacy Questionnaire (HLQ) consists of 44 questions across 9 separate scales [13]. A more behavioral example is the Newest Vital Sign (NVS), where the patient is presented with a nutrition label from an ice cream container and asked 6 questions about the label; this takes 2 to 3 minutes [14]. Although these items are validated and comprehensive, they are time-consuming within the time-limited context of cancer care [15]. The Single Item Literacy Screener (SILS) was developed to address patient health literacy in a simple and direct manner with a

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single question to identify how often patients need help with written health-related materials. The SILS measures the most basic level of health literacy: reading and understanding health content and directions from healthcare professionals. Limitations at this level indicate limitations with more advanced health literacy skills, like numeracy, patient navigation for continuity of care, communication in the decision-making process, and the act of decision-making itself [16]. SILS is shown to be a valid measure of health literacy, as it correlates with more complicated, validated measures such as the S-TOFHLA ($r = -0.308$) and NVS ($r = -0.679$) [15,17-19].

Given the importance of health literacy for outcomes in lung cancer care, health systems attempt to incorporate it into health screens without adding to screen fatigue and burden of care. Currently, however, there are no studies that analyze SILS and other clinical data in the context of lung cancer care. We focus on clinic patients who were recently diagnosed with lung cancer because this represents a large proportion of people who are navigating the early phases of cancer diagnosis, symptom management, and treatment. Lung cancer is the second most common cancer and the leading cause of cancer death, with a high incidence of comorbidities that require active management such as chronic obstructive pulmonary disease (COPD) [20]. The focus on a single disease site reduces potentially confounding influences of treatment modalities and patient experiences that may differ by disease site. This study aims to describe how a single-item measure of health literacy is associated with health outcomes and health system usage among patients with lung cancer.

2. Methods

Data were gathered retrospectively from electronic medical records (EMR) for adults diagnosed with lung cancer at the Ann B. Barshinger Cancer Institute (ABBCI) of Penn Medicine Lancaster General Health (LGH) between May 2016 and May 2018. The resulting sample included 456 patients with up to 12 months of follow-up data. The dataset was deidentified at LGH for analysis at University of the Sciences (Philadelphia, PA). Because all data were available within the existing medical record and were deidentified, the study was determined to be non-human subjects research.

In this sample of 456 patients, approximately half were over the age of 70 (50.88%) and approximately half were female (50.88%) (Table 1). Additionally, most spoke English as their primary language (98.46%) and approximately half had lung cancer of stage IIIB or higher at first diagnosis (48.20%).

Table 1
Descriptive statistics and differences between health literacy categories

	Total (n = 456)	Adequate ^a (n = 304)	Limited ^b (n = 152)	P
Female	50.88%	50.33%	51.97%	0.7405
Age > 70	50.88%	47.04%	58.55%	0.0204*
Married	54.82%	56.91%	50.66%	0.2062
English speaker	98.46%	99.34%	96.71%	0.0312*
Insurance				0.7959
None	2.85%	2.63%	3.29%	
Medicare	53.07%	52.30%	54.61%	
Private	44.08%	45.07%	42.11%	
Stage IIIB or higher	48.20%	42.76%	59.18%	0.0011*
Treatment use				
Chemotherapy	37.28%	37.17%	37.50%	0.9454
Immunotherapy	17.76%	16.78%	19.74%	0.4355
Targeted therapy	3.73%	4.28%	2.63%	0.3822
Radiation therapy	52.41%	54.28%	48.68%	0.2597
Surgery	18.42%	21.38%	12.50%	0.0211*
Number of comorbidities				0.2844
0	29.82%	31.91%	25.66%	
1-2	55.70%	54.93%	57.24%	
3+	14.47%	13.16%	17.11%	

^a Single Item Literacy Screener (SILS) score of 1-2.

^b SILS score of 3-5.

The explanatory variable of interest was health literacy as determined by the SILS, which was implemented into standard care for use in ambulatory care and inpatient admissions at LGH starting May 2016. The SILS asks the question, “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” and is scored on a 5-point Likert scale. The possible responses include: 1 - Never, 2 - Rarely, 3 - Sometimes, 4 - Often, 5 - Always [15]. Scores are then divided into two categories. In accordance with the scoring system employed by LGH and the EMR, a score of 3-5 reflects limited health literacy while a score of 1-2 reflects adequate health literacy, based on prior studies [15].

Health outcomes were assessed by psychological well-being, health service utilization, and support service encounters. Average distress was self-reported approximately once a month following diagnosis and scored on a scale from 0-10, with 0 being low distress and 10 being high distress; depressive symptoms were also self-reported and based on the PHQ-9, with 0 being minimal depression and 27 being severe depression [21,22]. Emergency department (ED) utilization data include number of visits during the 12-month follow-up period and the number of days from diagnosis to first ED visit. Unplanned hospitalization data included number of visits during the 12-month follow-up period, the number of days from diagnosis to first unplanned hospitalization, and the average length of unplanned hospitalizations. Support service encounters included number of patient encounters and time to first encounter for physical support services (symptom management and nutrition) and psychosocial support services (nurse navigator, social work, financial counseling, chaplaincy, and oncology clinical counseling). Emergency department and hospitalization data were included from all health systems found in the EMR, but supportive service data were limited to services provided within the LGH system.

Sociodemographic control variables included gender, age (grouped 18-70 and greater than 70 based on median age), marital status, English-speaking status, and insurance (grouped into no insurance, private insurance, and Medicare). Clinical control variables included cancer stage (grouped into I-IIIA and stage IIIB or higher), treatment use (chemotherapy, immunotherapy, targeted therapy, radiation therapy, and surgery), and number of comorbidities (grouped into 0, 1-2, and 3+).

Analyses were determined by variable distributions in this sample. Count variables measuring depressive symptoms and distress were described with medians; Wilcoxon rank sum tests examined differences in these outcomes between health literacy groups (Table 2) and Poisson

Table 2
Health outcomes and differences between health literacy categories

	Total	Adequate ^a	Limited ^b	P
Quality-of-life				
Distress	2.6 (1.7)	2.5 (1.7)	3.0 (1.7)	0.0526
Depression	3.3 (4.2)	3.0 (4.0)	4.0 (4.7)	0.0082*
Healthcare utilization				
Emergency department visit	52.19%	48.03%	60.53%	0.0118*
Time to first emergency department visit (days)	121.5 (147.4)	197.0 (148.8)	67.5 (131.4)	<0.0001*
Unplanned hospitalization	49.56%	44.74%	59.21%	0.0036*
Time to first unplanned hospitalization (days)	115.0 (149.0)	176.0 (151.6)	68.0 (134.1)	<0.0001*
Length of unplanned hospitalization (days)	4.0 (3.6)	4.0 (3.0)	4.0 (4.3)	0.4296
Support service encounters				
Support service encounter	74.56%	79.28%	65.13%	0.0011*
Support service encounter (excluding nurse navigator)	59.87%	62.17%	55.26%	0.1560
Dietitian encounter	30.04%	28.95%	31.58%	0.5626
Nurse navigator encounter	64.69%	68.75%	57.24%	0.0152*
Social work encounter	36.18%	37.83%	32.89%	0.3013
Financial counselor encounter	30.70%	31.25%	28.95%	0.6146
Chaplaincy encounter	21.93%	24.34%	17.76%	0.1107
Oncology clinical counselor encounter	6.36%	5.92%	7.24%	0.5873

^a Single Item Literacy Screener (SILS) score of 1-2.

^b SILS score of 3-5.

regression models examined factors associated with poor psychological well-being while controlling for sociodemographic and clinical factors (Table 3). Categorical variables measuring utilization were described with percentages; chi-square tests examined differences in utilization between health literacy groups (Table 2) and binary logit regression examined odds of utilization while controlling for sociodemographic and clinical factors (Table 4). Kaplan-Meier failure probability curves were used to represent the time to health service utilization event. *P*-values < 0.05 were considered significant and all analyses were performed in SAS software, version 9.4 (SAS Institute, Cary, NC).

3. Results

Two-thirds of the patients in the overall sample had adequate health literacy, whereas one-third had limited health literacy (Table 1). This means that 1 out of 3 newly diagnosed lung cancer patients sometimes, often, or always need help understanding written materials from doctors or pharmacy [15]. The adequate and limited health literacy groups differed in age, English-speaking status, stage of lung cancer at diagnosis, and treatment type. Patients with limited health literacy were more likely than patients with adequate health literacy to be over the age of 70 (58.55% vs. 47.04%, *p* = 0.0204) and have lung cancer of stage IIIB or higher at initial diagnosis (59.18% vs. 42.76%, *p* = 0.0011). Patients with limited health literacy were less likely to have English as their primary language (96.71% vs. 99.34%, *p* = 0.0312) and to have received surgery for their cancer (12.50% vs. 21.38%, *p* = 0.0211). There were no significant differences between the two groups concerning the number and type of comorbidities. Utilization of nurse navigator services was less likely for patients with limited health literacy (57% vs. 68%); rates of utilization for other services were low, with less than 10% for oncological clinical support specialist.

Patients with limited health literacy had significantly higher PHQ-9 depression scores compared to patients with adequate health literacy (4.0 vs. 3.0, *p* = 0.0082) (Table 2). This association remained positive and significant after controlling for significant sociodemographic and health controls (β = 0.21, *p* = 0.0007) (Table 3). In the regression analysis, age, marital status, and English-speaking status also remained significantly associated with PHQ-9 scores across all models. The other quality-of-life measure, average distress score, was not significantly associated with health literacy.

Patients with limited health literacy were more likely to have an ED visit within the 12 months following diagnosis compared to patients with adequate health literacy (60.53% vs. 48.03%, *p* = 0.0118) (Table 2). Patients with limited health literacy were also more likely to have an unplanned

hospitalization within the 12 months following diagnosis (59.21% vs. 44.74%, *p* = 0.0036). These associations remained positive and significant after controlling for sociodemographic health factors. Health literacy was the only variable significantly associated with having an ED visit (OR = 1.596, 95% CL = 1.042 - 2.445). Health literacy was one of two variables significantly associated with having an unplanned hospitalization (OR = 1.814, 95% CL = 1.176 - 2.797). The other health service utilization measure, support service encounter, was not associated with health literacy. Time to first ED visit and time to first unplanned hospitalization was significantly sooner for patients with limited health literacy (*p* < 0.0001), but there was no significant difference in timing for support service encounters.

4. Discussion and conclusion

4.1. Discussion

Our results show that need for help understanding written health information is associated with poorer health outcomes in patients with lung cancer. The patients with limited health literacy are more likely to be at an advanced cancer stage upon initial diagnosis, report moderate depressive symptoms, and use emergency and inpatient health services sooner compared to those with adequate health literacy. These results align with findings from previous empirical studies on health literacy, while measuring ability to understand written materials with the SILS as part of clinical EMR data. We also found lower likelihood of using nurse navigator supportive services for those with limited health literacy (57% vs. 68%) and overall low use of dietician and social work support services (less than 33%), and oncology clinical support specialists (<10%).

Our study introduced a timing component to the use of emergency health services. Patients with limited health literacy utilize emergency health services sooner than patients with adequate health literacy, independent of cancer stage and treatment modality. Emergency department and inpatient hospital visits contribute significantly to the cost of cancer care [23-24] and can be highly disruptive if occurring early on in cancer care or treatment [25]. The incidence and acuity of these inpatient visits could be mitigated for patients with limited health literacy by documenting limited health literacy at intake and then acting upon this information. Health systems can flag patients for follow-up with a longer clinical encounter or automatically refer patients to supportive services. Proactive efforts to improve how health systems treat patients with limited health literacy will go a long way to improve system capacity and patient outcomes [1].

This study has some limitations. The sample was drawn from an ethnically homogenous patient population, which could potentially obscure the effects of race and ethnicity on health literacy. In addition, the data were gathered retrospectively with self-reported health literacy, preventing us from reaching a causal conclusion. It is, however, near impossible to designate patients with limited versus adequate health literacy status in an experimental study design. One study has shown that subjective estimates of health literacy in general have a risk of misclassification, but suggests that the SILS improves the ability to identify patients with limited health literacy compared to demographic predictors alone [26].

4.2. Innovation

The SILS is shown to be a clinically useful, easily administered tool that can be incorporated into patient intake workflows. This simple question measures need for assistance to understand written health materials, and may indicate need for help with more advanced health literacy skills like numeracy, navigation, and communication [16]. Routine documentation of SILS data in electronic medical records can assess the need for, and facilitate implementation of, health literacy interventions at both the organizational and personal levels; this multi-level approach is essential to improve the health literacy of systems [1].

At the personal level, limited health literacy is associated with limited ability to self-manage the symptoms of chronic illness [2]. COPD, a common comorbidity with lung cancer, also presents challenges with self-

Table 3
Poisson regression analyses for quality-of-life variables

	Distress		Depression	
	β	<i>P</i>	β	<i>P</i>
Limited health literacy ^a	0.0704	0.3274	0.2072*	0.0007
Sociodemographic controls				
Female	0.1410*	0.0428	-0.0152	0.8052
Age over 70	-0.1405	0.0565	-0.2421*	0.0002
Married	-0.0797	0.2384	-0.1961*	0.0008
English speaker	0.0822	0.7477	-0.8389*	<0.0001
Clinical controls				
Stage IIIB or higher	0.2604*	0.0020	0.4221*	<0.0001
No comorbidities	0.0450	0.6898	-0.2023*	0.0296
1-2 comorbidities	0.0784	0.4489	-0.0481	0.5603
3+ comorbidities	Reference	-	Reference	-
No insurance	-0.1710	0.3787	0.0887	0.6033
Medicare	-0.0258	0.7181	0.2214*	0.0004
Private insurance	Reference	-	Reference	-
Chemotherapy	-0.0600	0.3942	-0.0012	0.9845
Immunotherapy	-0.1377	0.1114	-0.1165	0.0956
Targeted therapy	-0.1655	0.3184	-0.2500	0.0733
Radiation therapy	-0.0774	0.3893	-0.1403	0.0635
Surgery	-0.0016	0.9896	-0.2753*	0.0208

^a Single Item Literacy Screener (SILS) score of 3-5 (reference category is adequate health literacy, SILS score of 1-2).

Table 4
Binary logit regression analyses for healthcare utilization.

	Emergency department visit		Unplanned hospitalization		Support service encounter	
	OR	95% CL	OR	95% CL	OR	95% CL
Limited health literacy ^a	1.596*	(1.042 – 2.445)	1.814*	(1.176 – 2.797)	0.688	(0.392 – 1.206)
Sociodemographic controls						
Female	0.755	(0.497 – 1.148)	0.833	(0.545 – 1.271)	1.053	(0.613 – 1.808)
Age over 70	0.702	(0.450 – 1.097)	0.660	(0.421 – 1.035)	0.537*	(0.309 – 0.933)
Married	0.670	(0.443 – 1.014)	0.683	(0.450 – 1.037)	1.113	(0.653 – 1.898)
English speaker	0.485	(0.089 – 2.651)	0.182	(0.021 – 1.593)	0.349	(0.047 – 2.571)
Clinical controls						
Stage IIIB or higher	1.356	(0.839 – 2.191)	1.419	(0.869 – 2.318)	1.181	(0.629 – 2.218)
No comorbidities	1.131	(0.597 – 2.143)	1.190	(0.620 – 2.282)	0.761	(0.340 – 1.707)
1-2 comorbidities	1.591	(0.889 – 2.848)	1.702	(0.938 – 3.086)	0.500	(0.241 – 1.039)
3+ comorbidities	Reference	-	Reference	-	Reference	-
No insurance	1.222	(0.369 – 4.041)	1.763	(0.515 – 6.036)	0.471	(0.100 – 2.211)
Medicare	1.233	(0.798 – 1.905)	1.278	(0.822 – 1.986)	0.816	(0.474 – 1.402)
Private insurance	Reference	-	Reference	-	Reference	-
Chemotherapy	1.137	(0.728 – 1.777)	1.350	(0.861 – 2.114)	15.768*	(7.766 – 32.016)
Immunotherapy	1.259	(0.711 – 2.230)	1.069	(0.602 – 1.897)	10.737*	(3.385 – 34.056)
Targeted therapy	0.527	(0.187 – 1.489)	0.600	(0.209 – 1.720)	1.567	(0.335 – 7.328)
Radiation therapy	1.595	(0.972 – 2.618)	2.426*	(1.457 – 4.039)	2.748*	(1.447 – 5.218)
Surgery	0.965	(0.485 – 1.921)	1.837	(0.909 – 3.712)	2.480*	(1.057 – 5.818)

^a Single Item Literacy Screener (SILS) score of 3-5 (reference category is adequate health literacy, SILS score of 1-2).

management that require intervention and could be improved with communication [27]. A limited health literacy flag in an EMR could direct more time and resources toward helping that person develop the skills and self-confidence that they need to manage their illness. Although it may not be easy to improve health literacy or well-being outcomes [28-29], there is evidence that self-management interventions can improve distress and depression outcomes, which are associated with limited health literacy [30-31]. Referral to appropriate services could help those with limited health literacy prepare for and understand self-management, which could reduce frustration for lung cancer patients managing life after diagnosis [32].

A brief intake screen for ability to understand written health materials should serve as a prompt for referral to supportive services that will help those in need to understand, communicate, make decisions, and navigate their health care. Our results showed that those with limited health literacy were less likely to visit a nurse navigator compared to those with adequate health literacy (57% vs. 68%). Overall, utilization of these supportive services is low, with less than 1/3 seeing a dietician or social worker, and less than 6% seeing an oncological clinical counselor. While it may not be feasible to change someone's level of health literacy, referrals to supportive services, uptake of those referrals, and appropriate reimbursement for these services could help bridge the gap between limited health literacy and self-management.

At the organizational level, aggregate estimates of limited health literacy can prompt innovation. For example, the Optimizing Health Literacy and Access (Ophelia) Project developed a protocol to collect and act upon health literacy data; specifically, the eHQL [33]. Participating health systems in Australia codesigned studies and interventions tailored to the documented health literacy needs of their clients [34]. These people-centered services based on intersectoral collaboration highlight how innovation can be driven by increasing health literacy capacity [1], which can influence health outcomes more strongly than personal health literacy [35-36]. Routine documentation of basic health literacy trends would provide insight into patient populations, and should direct priorities in organizational change to improve health literacy, such as referral practices that facilitate supportive care service use [37].

4.3. Conclusion

The SILS could be considered for implementation into routine care and act as a supplemental indicator of the need for intervention during cancer care. Future studies should be repeated in other clinical settings with different disease sites and more diverse patient populations. This study does,

however, add to the body of literature on health literacy with a simplified, easily accessible clinical tool.

Available upon request

- Regression tables for survival analysis
- Kaplan-Meier curves for time to ED visit and unplanned hospitalization

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Declaration of Competing Interest

None.

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