

# Health literacy among cancer survivors

## Results from the 2016 behavioral risk factor surveillance system survey

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### Abstract

Health literacy is a set of knowledge and skills that enables individuals to obtain, communicate, process and understand information, and services to make appropriate health decisions and to successfully navigate the health care system. Health literacy is important to quality of cancer survivorship care and patient self-management of their disease.

We examined health literacy among cancer survivors, using data from the 2016 Behavioral Risk Factor Surveillance System. We compared health literacy across various demographic and socioeconomic groups and estimated the adjusted odds in favor of low health literacy for these characteristics.

We found that about 16% of the cancer survivors had low health literacy. The prevalence was higher among Hispanic and Black individuals, and among those with poor health status, low income and educational attainment.

A sizeable percentage of cancer survivors have low health literacy which is likely to complicate their ability to self-manage their disease and navigate the health care system for optimal care. In order to ensure the quality and appropriateness of cancer survivorship care, effective interventions are needed to address low health literacy in these populations.

**Abbreviation:** BRFSS = behavioral risk factor surveillance system.

**Keywords:** cancer, cancer survivors, health literacy

### 1. Introduction

Health literacy is a set of knowledge and skills that enables individuals to obtain, communicate, process and understand information and services to make appropriate health decisions, and to successfully navigate the health care system.<sup>[1]</sup> Health literacy skills can be defined as the personal characteristics and social resources needed for individuals to access, understand, appraise and use information and services, to make decisions

about health.<sup>[2]</sup> Health literacy includes oral literacy (listening and speaking), print literacy (reading and writing), and numeracy as well as the ability to obtain and use information to make health-related decisions.<sup>[1]</sup> More than one-third of United States adults have limited health literacy, which affects health care access and quality, and contributes to poor health outcomes.<sup>[3]</sup> Low health literacy has been associated with poor self-management of chronic conditions, increased hospitalizations, and higher rates of mortality.<sup>[4]</sup> Studies have shown that lower health literacy skills are associated with an increased risk of long-term life-limiting health conditions and more difficulty managing medications.<sup>[4,5]</sup>

As cancer patients complete their treatment and enter the survival period, they face challenges about how to manage self-care and have an ongoing need for effective communication with health care providers and navigation of the healthcare system.<sup>[6]</sup> Cancer survivors who have completed primary therapy for the disease often have complex health care needs that include surveillance for recurrent disease or second primary malignancies, and the management of cancer-related morbidities.<sup>[7,8]</sup> Appropriate care during the post-initial treatment survivorship phase includes preventive care visits and screening for cancer recurrence.<sup>[7]</sup>

We examined health literacy among cancer survivors, using data from the 2016 Behavioral Risk Factor Surveillance System (BRFSS).

### 2. Methods

BRFSS is a cross-sectional telephone-based survey of United States residents 18 years of age and older, which collects information about health-related risk factors, chronic health

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The datasets generated during and/or analyzed during the current study are publicly available.

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conditions and use of preventive services. Participating jurisdictions are required to include all core questions and may also include optional modules. The Centers for Disease Control and Prevention developed a 3-question health literacy module that focused on obtaining health information and advice, oral literacy, and print literacy. This module was offered in 2016 and administered by 13 states (Alabama, Alaska, Georgia, Illinois, Iowa, Louisiana, Maryland, Minnesota, Mississippi, Nebraska, North Carolina, Pennsylvania, and Virginia) and Washington, DC to representative samples of randomly selected adults. The mean and median combined (landline and cell phone) weighted response rates for this group of states and Washington, DC were 45.08 and 42.50 percent, respectively.

Three health literacy questions were asked: a) “How difficult is it for you to get advice or information about health or medical topics if you need it?”, b) “How difficult is it for you to understand information that doctors, nurses and other health professionals tell you?”, c) “You can find written information about health on the Internet, in newspapers and magazines, and in brochures in the doctor’s office and clinic. In general, how difficult is it for you to understand written health information?”. We created a dichotomous variable for each question, coded “0” for “no difficulty” (including “very easy” or “somewhat easy”) and “1” for “having difficulty” (“somewhat difficult” or “very difficult”). “Don’t know,” “refused,” and not applicable responses were considered missing. We then created another outcome variable, low health literacy (yes, no), in which participants were classified as having low health literacy if they reported difficulty with 1 or more of the 3 health literacy tasks. A participant was identified as a cancer survivor if they answered “Yes” to the following question: “Ever told you have any other types of cancer (than skin cancer)?”.

All analyses were conducted with Stata version 14.0 and used BRFSS sampling weights to adjust for the complex sampling design. We first examined the prevalence of health literacy by demographic and socioeconomic factors among cancer survivors. We then used multiple logistic regression analysis to estimate the adjusted odds in favor of low health literacy for demographic (age, sex, and race), socioeconomic (household income, employment status and marital status) and health status and healthcare access (self-reported general health condition and health insurance coverage) covariates in this group of cancer survivors. This study, which was based upon anonymous public use data, was determined to be exempt from Institutional Review Board Review.

### 3. Results

Our study sample consists of 8339 cancer survivors. About 62% of the study participants were female and 38% were male. More than half (52%) of the cancer survivors in our sample were elderly (age 65+), and about one-third (31%) were of age 50 to 64 years. About three-fourth (77%) of the study participants were non-Hispanic White, 13% were non-Hispanic Black, and 6% were of Hispanic ethnicity. Around one-fourth of the study participants did not have high school diploma, and about 60% had some postsecondary education (some college or college degree). While 4 in ten cancer survivors reported household income of \$50,000 or more, about one-third reported household income being less than \$25,000.

About 16% of the cancer survivors in the sample reported low health literacy, which gradually decreased with age, educational attainment and household income. Around 5% of the participants reported difficulties in understanding medical advice, while 9% reported difficulties in understanding oral or written instructions (Table 1). Participants without a high school diploma reported a 27.5% higher prevalence ( $P < .000$ ) of low health literacy compared with their peers with a college degree. Similar to the educational attainment gradient, higher household income was associated with a lower prevalence of low health literacy. Black and Hispanic cancer survivors reported a significantly higher ( $P < .000$ ) low health literacy compared to white participants. The prevalence was also higher ( $P < .000$ ) among those who were not employed and did not have health insurance coverage.

Table 2 shows the adjusted odds ratios in favor of low health literacy for various demographic and socioeconomic characteristics. The adjusted odds for Black and Hispanic participants were 1.4 and 2.5 times that of their white peers, respectively. Participants with less than a high school diploma showed a 3.7 times higher likelihood of low health literacy compared to participants with a college degree. The education gradient persisted at every level of educational attainment. Finally, those who reported poor health status had an adjusted odds of low health literacy of nearly 5 to 9 times that of those who reported excellent health status.

### 4. Discussion

The results of this study indicate that nearly one in every 6 cancer survivors reported low health literacy. The prevalence of low health literacy was higher among Hispanic and Black cancer survivors and among those with lower educational attainment and household income. Cancer survivors who reported poor health status were also more likely to report low health literacy. Individuals who experience disparities in cancer incidence and outcomes (for example, racial and ethnic minorities and low-income persons) are also those who are most likely to have low health literacy.<sup>[9]</sup>

These results have important implications for cancer survivorship care. Low health literacy is a barrier to good self-care and clinical care. Cancer survivors have an ongoing need for effective communication with primary care providers and oncologists.<sup>[6]</sup> Cancer survivors often have complex health care needs that include surveillance for recurrent disease or second primary malignancies, and the management of cancer-related morbidities.<sup>[7,8]</sup> Health literacy is important to quality cancer survivorship care and patient self-management of their disease. Low health literacy negatively impacts individual health behaviors such as adherence with weight control and tobacco cessation interventions, and cancer screening or surveillance recommendations.<sup>[10,11]</sup> Adults with limited health literacy obtain less information from disease prevention and control materials, and may be less likely to successfully manage their illness. For example, health literacy is associated with obesity, dietary choices and exercise.<sup>[12]</sup> Low health literacy is also associated with having an inadequate understanding of complex medical information.<sup>[13,14]</sup> Patients’ understanding of their disease, treatment, and healthcare decision-making can be impaired by low health literacy.<sup>[4]</sup>

Inadequate health literacy has been shown to negatively impact health-related quality of life in patients with cancer of the breast,

**Table 1****Prevalence of having difficulty understanding instructions and low health literacy by sociodemographic characteristics.**

	Have difficulty to understand			Low health literacy%
	Medical advice%	Oral instruction%	Written instruction%	
All	5.19 (4.30, 6.09)	9.39 (8.17, 10.61)	9.36 (8.18, 10.54)	16.25 (14.77, 17.73)
Age				
18 to 49	9.89 (6.10, 13.68)	10.52 (6.75, 14.29)	8.65 (5.13, 12.17)	19.31 (14.62, 23.99)
50 to 64	4.9 (3.56, 6.23)	10.67 (8.31, 13.03)	8.88 (6.84, 10.93)	16.89 (14.15, 19.64)
65+	3.82 (2.97, 4.68)	8.26 (6.85, 9.66)	9.87 (8.34, 11.41)	14.89 (13.17, 16.60)
Sex				
Male	4.03 (2.78, 5.27)	10.88 (8.58, 13.18)	10.9 (8.74, 13.05)	17.4 (14.79, 20.02)
Female	5.91 (4.69, 7.14)	8.46 (7.11, 9.81)	8.42 (7.06, 9.79)	15.53 (13.79, 17.27)
Race				
White	4.45 (3.52, 5.37)	8.26 (7.05, 9.47)	7.78 (6.61, 8.95)	14.46 (12.93, 16.00)
Black	4.31 (2.31, 6.31)	11.9 (7.21, 16.60)	14.85 (10.09, 19.62)	19.87 (14.64, 25.10)
Hispanic	15.17 (8.21, 22.12)	17.94 (10.88, 25.00)	17 (10.90, 23.11)	30.62 (22.92, 38.32)
Other	7.38 (3.69, 11.06)	9.56 (5.36, 13.76)	10.08 (5.60, 14.56)	16.28 (10.87, 21.68)
Education				
Less than HS diploma	10.89 (6.80, 14.99)	21.91 (16.85, 26.97)	24.71 (19.21, 30.20)	34.08 (28.46, 39.69)
High school diploma	6.21 (4.54, 7.87)	10.51 (8.18, 12.85)	11.45 (9.32, 13.59)	19.14 (16.27, 22.00)
Some college	4.28 (2.93, 5.63)	6.84 (5.12, 8.56)	5.78 (4.15, 7.42)	12.46 (10.21, 14.72)
College graduate	1.88 (1.19, 2.57)	3.33 (2.20, 4.47)	2.9 (2.02, 3.78)	6.32 (4.93, 7.72)
Household income				
< \$15,000	15.46 (10.70, 20.23)	19.98 (14.74, 25.23)	19.98 (15.80, 24.16)	33.1 (27.60, 38.60)
\$15,000 to \$24,999	8.04 (5.27, 10.81)	14.14 (10.59, 17.70)	15.77 (11.67, 19.86)	24.71 (20.42, 28.99)
\$25,000 to \$34,999	3.67 (1.96, 5.39)	10.88 (6.48, 15.29)	10.09 (6.26, 13.92)	16.9 (12.20, 21.61)
\$35,000 to \$49,999	2.53 (1.00, 4.05)	6.87 (3.66, 10.08)	7.24 (4.15, 10.34)	12.81 (8.96, 16.66)
\$50,000 or more	1.67 (0.88, 2.47)	3.61 (2.54, 4.68)	2.81 (1.88, 3.75)	6.53 (5.04, 8.02)
Employment status				
Not employed	5.82 (4.78, 6.86)	10.59 (9.09, 12.09)	10.76 (9.28, 12.25)	18.17 (16.38, 19.97)
Employed	3.42 (1.74, 5.11)	6.58 (4.49, 8.66)	5.93 (4.08, 7.77)	11.37 (8.84, 13.89)
Marital status				
Not married	7.24 (5.57, 8.91)	10.77 (8.79, 12.75)	11.57 (9.65, 13.49)	19.63 (17.22, 22.04)
Married	3.59 (2.68, 4.50)	8.31 (6.78, 9.84)	7.64 (6.16, 9.13)	13.55 (11.74, 15.35)
Health insurance				
No coverage	29.76 (18.40, 41.12)	28.33 (17.76, 38.91)	16.37 (8.20, 24.55)	43.14 (32.28, 53.99)
Had coverage	4.25 (3.49, 5.01)	8.65 (7.47, 9.83)	9.09 (7.91, 10.27)	15.20 (13.76, 16.63)
Health condition				
Excellent	1.27 (−0.42, 2.96)	1.78 (0.58, 2.98)	2.79 (0.74, 4.83)	3.95 (1.80, 6.11)
Very good	2.22 (1.12, 3.32)	3.58 (1.87, 5.29)	4.72 (2.92, 6.53)	8.6 (6.14, 11.06)
Good	2.92 (1.67, 4.18)	7.6 (5.83, 9.37)	8.5 (6.49, 10.50)	14.25 (11.82, 16.67)
Fair	9.29 (6.74, 11.84)	14.59 (11.25, 17.93)	14.29 (11.10, 17.49)	23.5 (19.83, 27.18)
Poor	11.23 (7.97, 14.49)	18.85 (14.68, 23.02)	15.14 (11.95, 18.33)	28.38 (23.82, 32.95)
Sample size	7894	8279	7769	8339

95% confidence intervals are in parenthesis. Estimates were obtained using complex survey weights.  
HS = high school.

lung, colorectal, prostate, and head and neck.<sup>[6,15–17]</sup> In general patient populations, low health literacy has been related to inadequate utilization of health care services, higher mortality, worse self-rated health, and poorer physical functioning.<sup>[17–19]</sup> Health literacy is a particularly important issue for cancer patients who must navigate a complex health care system after being diagnosed with a potentially life-threatening condition.<sup>[17,20]</sup>

Health literacy is based on skills of the individual patient and also on the communication skills of health care providers.<sup>[11]</sup> The investments that health care organizations make in reducing health literacy-related barriers within their systems also play a role. Health literacy interventions such as information handouts, audiovisual offerings and online resources have been found to improve patients' health literacy and adherence to treatment.<sup>[1,21]</sup> Having a care coordinator is

also likely to be helpful.<sup>[20]</sup> Effective interventions to improve health literacy may include interventions to improve patient-provider communication or to develop skills in low literate people.<sup>[5]</sup>

With respect to limitations, the results may not be generalizable to all cancer survivors in the United States because of the low response rate. In addition, only 7 states implemented the module on health literacy. The use of self-reported information is also a potential limitation.

In conclusion, a sizeable percentage of cancer survivors have low health literacy which is likely to complicate their ability to self-manage their disease and navigate the health care system for optimal care. In order to ensure the quality and appropriateness of cancer survivorship care, effective interventions are needed to address low health literacy in these populations.<sup>[9,20]</sup>

**Table 2**  
Adjusted odds ratios in favor of having low health literacy.

	(1) Model-I: Demographic covariates	(2) Model-II: Socioeconomic covariates	(3) Model-III: Health covariates	(4) Model-IV: All covariates
Age group				
18–49	Reference			
50–64	0.908 (0.636, 1.297)			0.958 (0.655, 1.401)
65+	0.784 (0.563, 1.091)			0.702* (0.479, 1.027)
Sex				
Male	Reference			
Female	0.862 (0.689, 1.079)			0.675*** (0.518, 0.879)
Race				
White	Reference			
Black	1.433** (1.015, 2.024)			0.992 (0.683, 1.440)
Hispanic	2.504*** (1.716, 3.655)			1.290 (0.855, 1.946)
Other	1.103 (0.718, 1.695)			1.092 (0.650, 1.835)
Education				
College graduate		Reference		
Less than high school diploma		3.671*** (2.399, 5.618)		3.285*** (2.164, 4.986)
High school diploma		2.200*** (1.552, 3.118)		2.085*** (1.450, 2.998)
Some college		1.623** (1.145, 2.300)		1.529** (1.076, 2.173)
Household income				
\$50,000 or more		Reference		
< \$15,000		4.825*** (3.108, 7.490)		3.592*** (2.266, 5.693)
\$15,000 to \$24,999		3.319*** (2.269, 4.854)		2.912*** (1.987, 4.266)
\$25,000 to \$34,999		2.292*** (1.481, 3.547)		2.280*** (1.491, 3.487)
\$35,000 to \$49,999		1.902** (1.226, 2.950)		1.824*** (1.174, 2.833)
Employment status				
Not employed		Reference		
Employed		1.142 (0.832, 1.567)		1.012 (0.722, 1.420)
Marital status				
Not married		Reference		
Married		1.131 (0.873, 1.465)		1.076 (0.828, 1.399)
Health insurance				
No coverage			Reference	
Had coverage			0.269*** (0.167, 0.432)	0.418*** (0.256, 0.682)
Health condition				
Excellent			Reference	
Very good			2.272** (1.186, 4.351)	2.937*** (1.392, 6.199)
Good			3.836*** (2.101, 7.004)	3.220*** (1.598, 6.491)
Fair			7.140*** (3.907, 13.051)	4.095*** (2.004, 8.365)
Poor			8.965*** (4.869, 16.508)	5.072*** (2.414, 10.659)
Constant	0.217*** (0.152, 0.310)	0.040*** (0.028, 0.058)	0.149*** (0.072, 0.308)	0.048*** (0.018, 0.128)
Observations	8,339	7,021	8,283	6,989

\*\*\* $P < .001$ , \*\* $P < .05$ , \* $P < .10$ . 95% confidence intervals are in parenthesis. Estimates were obtained using complex survey weights.

## Author contributions

**Conceptualization:** Steven Coughlin.

**Data curation:** Biplab Datta.

**Formal analysis:** Biplab Datta.

**Writing – original draft:** Steven Coughlin.

**Writing – review & editing:** Steven Coughlin, Biplab Datta, Marlo Vernon, Christos Hatzigeorgiou, Varghese George.

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