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ORIGINAL ARTICLE – GLOBAL HEALTH SERVICES RESEARCH

Readability Analysis of Online Breast Cancer Surgery Patient Education Materials from National Cancer Institute-Designated Cancer Centers Compared with Top Internet Search Results

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ABSTRACT

Background. The National Institutes of Health (NIH) recommends patient education materials reflect the average reading grade level of the US population. Due to the importance of shared decision-making in breast cancer surgery, this study evaluates the reading level of patient education materials from National Cancer Institute-designated cancer centers (NCI-DCC) compared with top Internet search results.

Methods. Online materials from NCI-DCC and top Internet search results on breast cancer, staging, surgical options, and pre- and postoperative expectations were analyzed using three validated readability algorithms: Simplified Measure of Gobbledygook Readability Formula, Coleman–Liau index, and Flesch–Kincaid grade level. Mean readability was compared across source groups and information subcategories using an unpaired *t*-test with statistical significance set at $p < 0.05$. Mean readability was compared using a one-way analysis of variance.

Results. Mean readability scores from NCI-DCC and Internet groups ranged from a 9th–12th grade level, significantly above the NIH recommended reading level of 6th–7th grade. There was no significant difference between reading levels from the two sources. The discrepancy between actual and recommended reading level was most pronounced for "surgical options" at a 10th–12th grade level from both sources.

Conclusions. Patient education materials on breast cancer from both NCI-DCC and top Internet search results were written several reading grade levels higher than the NIH recommendation. Materials should be revised to enhance patient comprehension of breast cancer surgical treatment and guide patients in this important decision-making process to ultimately improve health outcomes.

Health literacy describes an individual's ability to understand and use health information to empower healthcare ownership.[1] Low health literacy has been associated with decreased preventative care (e.g., screening mammography, influenza vaccination), increased emergency care usage, increased hospitalizations, and increased post-surgical mortality.[2,3] Patient populations previously identified with lower health literacy often have a lower education level, lower socioeconomic status, experience chronic disease, and/or are racial and ethnic minorities.[4–9] Therefore, gaps between health information provided and patient health literacy has the potential to widen healthcare disparities.

Breast cancer remains the most common cancer diagnosis in women, with nearly 300,000 new cases of invasive breast cancer expected in 2023.[10] There are several different surgical treatment options (lumpectomy versus mastectomy, with or without breast reconstruction) available for patients with resectable breast cancer. The variety of surgical options can complicate the decision-making process. To promote shared decision-making, the surgeon should provide

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treatment-related information that meets the health literacy needs of each patient.

Prior breast cancer literature exploring patient satisfaction with their surgeons found that physicians spend about 19 min before and after surgery with patients with breast cancer discussing diagnosis and next steps.[11] Unfortunately, due to time constraints, patients often leave these appointments confused, with further unanswered questions that they may seek to clarify on the Internet. The 2009 National Health Interview Survey data found that 51% of women ages 18 years and over have used the Internet for health information.[12] The Internet provides a platform for healthcare institutions, including National Cancer Institute (NCI)-designated cancer centers (NCI-DCC), to provide information regarding breast cancer surgery. In addition to academic resources available online, patients may access non-academic websites that publish information regarding breast cancer surgery. The use and applicability of such Internet-based information depends on the readability of that information. The National Institutes of Health (NIH) recommends that health materials for patients be written at a 6–7th grade reading level to meet the reading grade level of the average adult in the USA.[13,14]

While prior studies describe the importance of patient education materials on breast cancer, this study aims to determine if these materials are understandable and accessible to the average US adult. This study describes the readability of online patient education materials on breast cancer surgery in relation to the recommended reading level proposed by the NIH. In this study, we hypothesized that the readability of patient education materials on breast cancer surgery would be above the NIH recommended reading grade level for both NCI-DCC and top Internet search results.

METHODS

Content Selection

NCI-DCC were identified using the NCI website (n = 71). Seven basic laboratory cancer centers and one pediatric center were excluded, leaving 63 NCI-DCC, termed the "NCI group." To evaluate the accessibility of patient education materials on breast cancer to an Internet user, the number of clicks required to find the breast cancer information webpage from the homepage of each NCI-DCC was recorded.

Breast-cancer-related search terms were entered in the Google™ (Google, Inc, Mountain View, CA) search engine to identify and evaluate websites from top Internet search results, termed the "Internet group." Search terms are listed in Table 1. Prior to each search, the browser was cleared, including location tools, user information, and cookies to minimize search bias. The search was performed in "incognito mode" using the Chrome browser (Google, Inc, Mountain View, CA) to avoid further search bias. The number of clicks needed to navigate to breast cancer information was not collected for the Internet group, as only information found within one click was analyzed. The first 60 search results of each search term were analyzed, excluding ads and any NCI-DCC websites.

TABLE 1 Breast cancer terms utilized in the Google search engine

Information subcategory	Terms searched
Breast cancer information	"What is breast cancer?"
Breast cancer staging	"What is staging in breast cancer?"
Surgical options	"What is mastectomy?" "What is lumpectomy?"
Preoperative expectations	"How to prepare for breast cancer surgery?"
Postoperative expectations	"What to expect after breast cancer surgery?"

For the NCI and the Internet groups, the following information subcategories were analyzed for readability: general breast cancer information, staging, surgical options, preoperative expectations, and postoperative expectations. The number of graphics, defined as tables, videos, images, was recorded for each group.

Readability Assessment

The text collected from each website was analyzed using three different validated readability algorithms: Simplified Measure of Gobbledygook Readability Formula (SMOG), Coleman–Liau index, and Flesch–Kincaid grade level (FKGL). The SMOG Readability Formula evaluates and analyzes the number of words with three or more syllables, along with the average number of sentences.[15,16] The Coleman–Liau index analyzes the average number of letters and number of sentences per 100 words.[17,18] The FKGL analyzes number of syllables per word and words per sentence.[19,20] These readability scores are expressed as grade levels. Each respective readability score has been validated, with the SMOG Formula used most frequently in healthcare analyses.[16,18–25]

Statistical Analysis

Analysis was performed using Microsoft Excel (Microsoft Corporation, Redmond, WA) and JMP V.17 (SAS Institute, Inc, Campus Drive, Cary, NC). The mean readability grade level and standard deviation (SD) for each group (NCI and Internet) and information subcategory were determined with each readability algorithm. Mean readability was compared across groups and information subcategories using an

unpaired *t*-test with statistical significance set at $p < 0.05$. Mean readability was compared using a one-way analysis of variance (ANOVA).

RESULTS

NCI Group Resources

Of the 63 included in the NCI group, 57% of centers provided online general breast cancer information ($n = 36$), 48% provided staging information ($n = 30$), and 63% provided information on surgical options ($n = 40$). Fewer sites provided information on preoperative expectations ($n = 11$) or postoperative expectations ($n = 17$) (Table 2). Of the 21 centers with no information available online, 14 provided a link to external resources.

TABLE 2 Types of online patient education materials provided by NCI-designated cancer centers (N = 63)

Information subcategory	Number of centers with education materials
Breast cancer information	36
Staging of breast cancer	30
Surgical options	40
Preoperative expectations	11
Postoperative expectations	17
No information provided	21

Readability

Overall, the readability of patient education materials from both the NCI group and the Internet group were well above the NIH recommended reading grade level of 6th–7th grade by each of the three readability scoring methods (Table 3). The mean reading grade level ranged from 9.0 to 11.2 in the NCI group and 9.4 to 10.9 in the Internet group, depending upon the information subcategory being discussed. Overall, no statistically significant difference was found in the means of all of the readability algorithms between the NCI and Internet groups. However, the mean readability by Coleman–Liau Index was found to be significantly higher in the NCI group (11.9) compared with the Internet group (11.1, $p = 0.02$) within the surgical options subcategory. In contrast, the mean readability by FKGL was significantly higher in the Internet group (11.2) than in the NCI group (9.2, $p = 0.04$) for breast cancer staging information.

Across all information subcategories examined, the mean readability of materials from the NCI group was significantly above the NIH recommended reading grade level. This difference between observed and recommended level was most pronounced for the surgical options subcategory, with a mean readability of 11.2 (11th grade reading level). Similarly, the mean readability of materials from the Internet group was above the NIH recommended reading grade level and was also most notable for surgical options.

TABLE 3 Mean readability scores of patient educational materials from NCI-designated cancer centers and top 60 internet search results

	SMOG[a]		Coleman–Liau index		Flesch–Kincaid grade level		Mean of all algorithms	
	Mean (SD[a])	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value	Mean (SD)	*p*-value
Breast cancer information		0.80		0.66		0.50		0.63
NCI ($n = 36$)	8.3 (1.9)		10.3 (1.2)		8.8 (2.4)		9.2 (1.7)	
Internet	8.4 (2.2)		10.4 (1.9)		9.2 (2.7)		9.4 (2.2)	
Staging of breast cancer		0.12		0.98		**0.04**		0.13
NCI ($n = 30$)	8.4 (1.6)		9.3 (1.6)		**9.2 (2.1)**		9.0 (1.5)	
Internet	9.4 (3.4)		9.3 (2.7)		**11.1 (4.9)**		9.9 (3.4)	
Surgical options		0.92		**0.02**		0.85		0.41
NCI ($n = 40$)	10.5 (1.7)		**11.9 (1.6)**		11.2 (2.2)		11.2 (1.7)	
Internet	10.5 (1.9)		**11.1 (1.6)**		11.1 (2.4)		10.9 (1.8)	
Preoperative expectations		0.30		0.60		0.15		0.25
NCI ($n = 11$)	9.0 (2.0)		9.9 (1.7)		8.8 (2.9)		9.2 (2.1)	
Internet	9.7 (2.0)		10.2 (2.0)		10.1 (2.7)		10.0 (2.0)	
Postoperative expectations		0.45		0.97		0.38		0.50
NCI ($n = 17$)	10.0 (4.0)		10.0 (2.1)		10.8 (6.3)		10.3 (4.0)	
Internet	9.4 (2.3)		10.0 (2.3)		9.9 (3.1)		9.8 (2.4)	

Bold denotes statistical significance, with $p < 0.05$

A total of 21 NCI-designated cancer centers provided no online information.

[a]*SMOG* Simplified Measure of Gobbledygook Readability Formula, *SD* standard deviation

Graphics and Accessibility

In all patient education materials assessed, the NCI group and Internet group had a mean of one graphic per page for each of breast cancer information, staging, preoperative and postoperative expectations. In contrast, for surgical options, the NCI group had a mean of two graphics per page and the Internet group had one. The mean number of clicks needed to navigate to the breast cancer page in the NCI group was three (SD 1.6). The number of clicks needed in the Internet group was not recorded and was one, given that the webpage was only included if it was the top result of the targeted search for each information subcategory.

DISCUSSION

In this cross-sectional evaluation of readability of patient education materials on breast cancer, this study found that online materials are written at a reading level well above the NIH recommendation, regardless of the source. Subcategories including breast cancer information, staging, surgical options, preoperative and postoperative expectations all demonstrated mean readability between a 9th and 12th grade reading level for both the NCI group webpages and top Internet search results. The most pronounced disparity in readability between the information available online and the NIH recommendation was observed in materials discussing surgical options. Online preoperative and postoperative expectations education materials were not available from the majority of NCI-DCC websites. While previous studies have analyzed readability of education materials, this study is the first to characterize both readability and accessibility of patient education materials on breast cancer surgery.[26–29]

When provided information does not meet the health literacy needs of patients, shared decision-making becomes incredibly challenging. Patients with low health literacy are less likely to participate in treatment decision-making, are more likely to have decreased patient satisfaction, and experience higher rates of hospitalization, morbidity, and mortality.[30–32] Lack of understanding and communication has also been shown to increase malpractice claims.[33] The comprehension and alignment of provided healthcare information with the healthcare goals of the patient is critical in breast cancer surgery, where a plethora of treatment options are available. Accordingly, the surgical options subcategory demonstrated the highest readability scores from both the NCI and the Internet groups, approximately four grade levels above what is recommended. The higher readability scores may be due to the inherent complexity of the terms and techniques described in breast cancer surgery. Examples of this include terminology such as "nipple-sparing mastectomy" and "breast conserving therapy." With the knowledge of how readability scales calculate grade level, using fewer syllables and shorter sentence lengths will improve the readability of the text.[15–18] However, this may not always be possible when listing surgical procedures. Thus, providing patients with definitions for complex terms, such as "removal of the breast but keeping the nipple for appearance" for nipple-sparing mastectomy will help facilitate greater understanding. Without such, patients are more likely to turn to the Internet for information, which may lead to further confusion or miscommunication.[34–36] Of note, a recent study has found that most individuals utilize the Internet right after cancer diagnosis versus during treatment and/or follow-up, exemplifying a need for reliable and accurate information to be given to the patient near the time of diagnosis.[37]

Delving further into the ability to navigate these websites, the number of clicks to get to the desired content was also analyzed in this study. Utilizing the Internet for healthcare information can be time consuming and may be difficult for patients to navigate.[38] This study identified a mean of three clicks to navigate to the main breast cancer home page for NCI-DCC sites. From the home page, subcategories could further be accessed. For patients with access to technology, those with less technological experience may struggle to navigate to the main page.[39,40] Providing patients with a direct website uniform resource locator (URL) or instructions on how to access reliable online patient education materials may reduce this technology barrier.

In addition to accessibility of online materials, the presence of graphics or other visual aids may provide greater comprehension of patient education materials.[41–43] This study found that the average number of graphics for each subcategory of patient education materials was between one and two graphics. Although the readability algorithms utilized in this study do not include graphics within the calculation, prior studies have found that images, figures, and graphics are all useful tools to convey patient information and increase understanding of material content and ensure understanding in patients who may have reading difficulties.[44–46] Furthermore, given the complexity of surgical terminology described previously, the inclusion of images may increase patient understanding of such procedures. A study by Hung and Stones found that patients with low health literacy had higher rates of satisfaction when materials included visuals.[47] Specifically, typeface and color designs, as well as realistic photos, were associated with highest rates of satisfaction.[47] These patients also preferred visual designs that took into account cultural factors. This aligns with other studies that have found that patients prefer graphics with similar demographics to the individual reviewing the materials.[41] This emphasizes the importance of providing a wide range of images, illustrations, and videos that match the diversity of the patient population in breast surgery.[48,49]

Differences between the observed and recommended reading levels in online patient education materials have

been similarly demonstrated in other surgical fields, including trauma, orthopedic surgery, vascular surgery, and plastic surgery.[14,50–52] This current study further demonstrates the need for various surgical subspecialties, in this case breast surgical oncology, to revisit education materials to ensure patients understand their healthcare materials. This study demonstrates the need for revision and/or creation of online patient education materials on breast cancer that can be displayed on reliable and accurate websites such as NCI-DCC webpages.

This study has certain limitations as only free, online materials were assessed. It is possible that these centers have different written materials available for their patients that would not have been captured in this study. Materials may also be available online exclusively through patient portals and would not be accessible through a free online search without login credentials. Additionally, 14 of the 21 NCI-DCC websites without their own unique information included vetted links to outside education materials from other organizations. However, these were not included in our analyses due to the materials being created from organizations outside of the NCI-DCC center; providing patients with a list of trusted sources is another option for centers that may not be able to create patient education materials on their own due to limitations such as funding or staffing. Lastly, this study only evaluated materials written in English. Future studies should expand to evaluate patient education materials in different languages to best understand and characterize the readability of these materials.

CONCLUSIONS

Online patient education materials on breast cancer are written at several reading grade levels higher than the NIH recommended reading level, regardless of the source. To improve patient understanding of and participation in breast cancer treatment option decision-making, education materials should be revised for improved readability to empower and guide patients in this important decision-making process.

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