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Association for Academic Surgery

Readability, complexity, and suitability analysis of online lymphedema resources



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ARTICLE INFO

Article history:

Received 18 January 2017

Received in revised form

14 February 2017

Accepted 24 February 2017

Available online 6 March 2017

Keywords:

Health literacy

Lymphedema

Readability

Complexity

Suitability

ABSTRACT

Background: Over 72% of Americans use online health information to assist in health care decision-making. Previous studies of lymphedema literature have focused only on reading level of patient-oriented materials online. Findings indicate they are too advanced for most patients to comprehend. This, more comprehensive study, expands the previous analysis to include critical elements of health materials beyond readability using assessment tools to report on the complexity and density of data as well as text design, vocabulary, and organization.

Methods: The top 10 highest ranked websites on lymphedema were identified using the most popular search engine (Google). Website content was analyzed for readability, complexity, and suitability using Simple Measure of Gobbledygook, PMOSE/iKIRSCH, and Suitability Assessment of Materials (SAM), respectively. PMOSE/iKIRSCH and SAM were performed by two independent raters. Fleiss' kappa score was calculated to ensure inter-rater reliability.

Results: Online lymphedema literature had a reading grade level of 14.0 (SMOG). Overall complexity score was 6.7 (PMOSE/iKIRSCH) corresponding to "low" complexity and requiring a 8th-12th grade education. Fleiss' kappa score was 80% ($P = 0.04$, "substantial" agreement). Overall suitability score was 45% (SAM) correlating to the lowest level of "adequate" suitability. Fleiss' kappa score was 76% ($P = 0.06$, "substantial" agreement).

Conclusions: Online resources for lymphedema are above the recommended levels for readability and complexity. The suitability level is barely adequate for the intended audience. Overall, these materials are too sophisticated for the average American adult, whose literacy skills are well documented. Further efforts to revise these materials are needed to improve patient comprehension and understanding.

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Accepted for presentation at Academic Surgical Congress Meeting 2017, Las Vegas, Nevada.

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<http://dx.doi.org/10.1016/j.jss.2017.02.056>

Introduction

In the era of the World Wide Web, Internet access is ubiquitous.¹ The use of online resources as a primary source of health information is extremely common among US adults.² As many as 72% of Americans use online health information to aid them in health care decision-making.² In contrast to the preinternet era when patients relied exclusively on their health care provider, modern day patients can more readily conduct extensive research before their initial medical appointment. This increased access to health information has coincided with a shift away from paternalistic approach to patient care and increased emphasis on patient autonomy. Studies indicate that such changes are efficacious because a well-informed patient is more likely to participate in the decision-making process of their care, resulting in improved compliance, satisfaction, and overall outcomes.³⁻⁵

In reality, although online health care resources are being increasingly used, many of the benefits from such usage are unclear.³⁻⁵ This is, in part, due to a paucity of studies that examine the accessibility of these resources. To maximize the benefit of the online information, the materials need to be presented in a manner that can be easily comprehended by patients. Population studies have demonstrated that an average adult in the United States reads at approximately the eight-grade level.⁶ Websites too difficult for adults creates unnecessary barriers to meaningful health information. To address this issue, the National Institute of Health (NIH) and American Medical Association (AMA) have recommended that medical information should be written at a sixth-grade level.^{7,8}

Although the readability of online resources for many medical conditions have been previously studied and often found to be higher than the recommended sixth-grade level,⁹⁻¹⁶ only one single prior study has attempted to evaluate the readability of online resources for lymphedema. Seth *et al.* reported that these online resources are written at a higher than recommended reading level.¹⁷ However, this study, along with prior studies evaluating readability of online information in other medical conditions, lacks analysis of the nontextual content of the resources. For example, two resources with similar reading grade can be interpreted differently if one of them is accompanied by supporting figures/graphics or if one provides headings and subheadings to highlight specific content areas and key points. Analysis of this aspect of online resources, captured by studying their complexity and suitability, is missing in most of the aforementioned studies.

The most common cause of lymphedema in the United States is secondary to cancer extirpations for breast cancer. Given long-term survival rates of breast cancer patients reported over 90%, the quality of life after treatment is an area of increasing scrutiny and importance.¹⁸ One of the most devastating long-term complications of breast cancer treatment is lymphedema, which has been attributed to axillary dissections and/or axillary radiation therapy.¹⁹⁻²² Resulting impaired flow of the lymphatic system can result in life-long swelling of the extremity with no known cure to

date. Lymphedema can occur in up to 40% of breast cancer patients.¹⁹⁻²²

Pathophysiology, diagnosis, and treatment of lymphedema are highly complex topics that further emphasize the importance of critically evaluating existing patient-oriented online information on lymphedema. In this study, we examine expanded metrics including readability, complexity, and suitability to provide a comprehensive multidimensional analysis of the written and visual content of the available on-line patient resources for lymphedema. Secondly, we hope to provide opportunities for revision of the online content by focusing on the specific areas of weakness that can be readily improved.

Methods

Website and content selection

Top 10 highest ranked websites on “lymphedema” were identified using Google (Google Inc, Mountain View, CA), the largest online search engine. All websites were accessed on August 10, 2016. Location of search and user account information were withheld to avoid inadvertent search bias. All sponsored results were excluded. Patient-intended information was recorded and included in the content analysis. Advertisements, references, and external links were excluded. The study design is depicted in [Figure 1](#).

Material assessment

Content of each website was recorded and analyzed for readability using the Simple Measure of Gobbledygook (SMOG), rated as one of the strongest tools because it considers both word and sentence length. SMOG analysis was performed with Readability Studio Professional Edition, v20112.1 software (Oleander Software, Ltd, Vandalia, OH). Text from all websites was copied into Microsoft Word (Microsoft Corp, Redmond, WA). The SMOG readability formula ($G = 1.0430 \times \sqrt{C} + 3.1291$) calculates reading material, intended grade level based on word complexity, and sentence length yielding ratings ranging from fourth grade to college level ([Fig. 2](#)). Each website had content evaluated, and the overall readability was assessed. Of note, SMOG hard words are those with 3+ syllables, numerals fully syllabized. In addition, the SMOG formula, unlike other readability assessments, includes attention to sentence as well as word length, both of which influence reading ease.

Important health information is often presented visually in lists, charts, or graphs. The complexity of such presentations was assessed with the PMOSE/iKIRSCH scoring system, which grades materials based on three criteria: structure, density, and dependency. This tool was developed specifically to examine lists, charts, and graphical display. Structure examines the overall organization of a document with score ranging from 1 (simplest) to 4 (most complex). Density of a document is based on both number of labels and number of items, with the highest score of 10. Dependency assesses

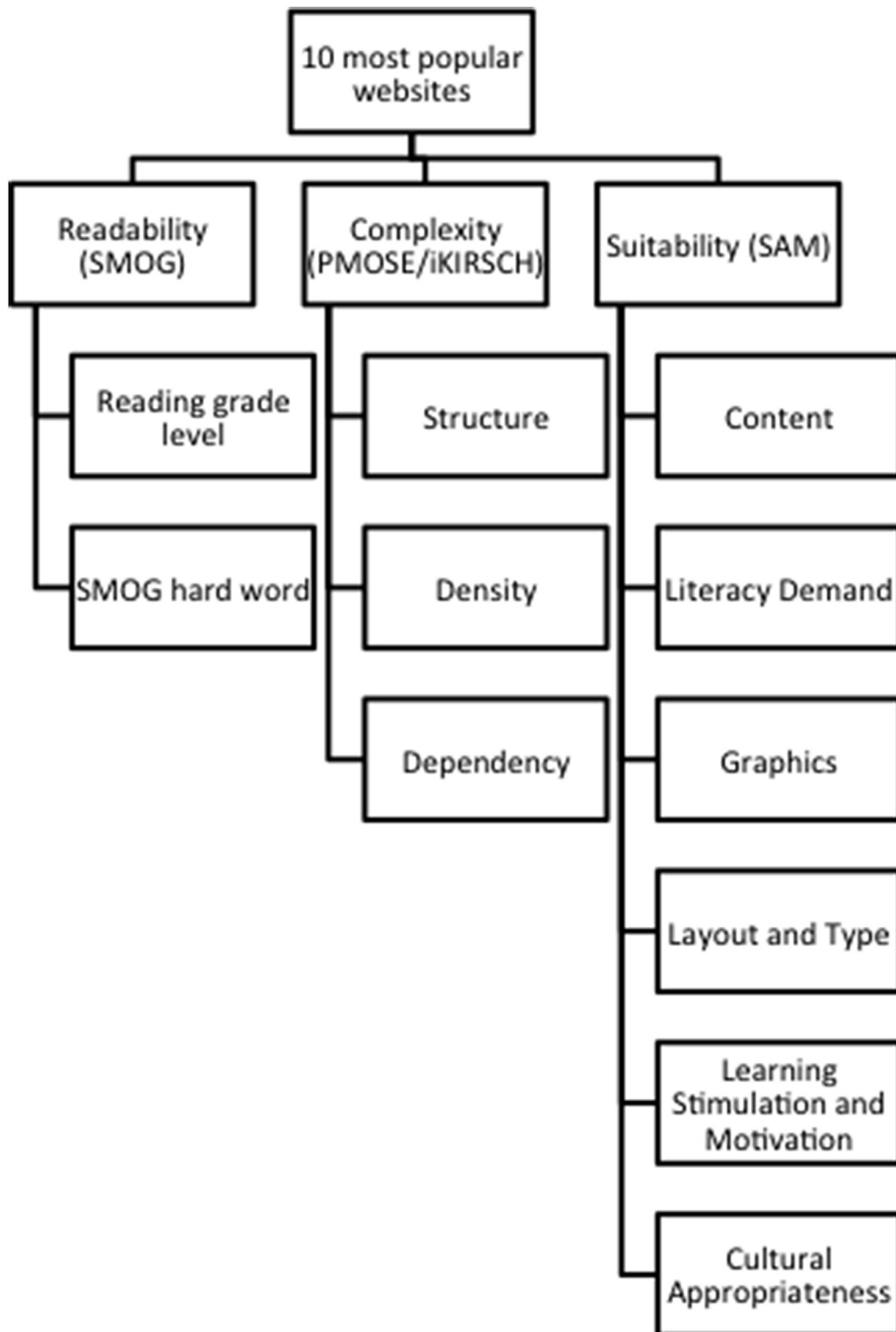


Fig. 1 – Study methods.

whether the document makes reference to information not included in the document. The overall scores are then converted to standard complexity levels ranging from “very low” to “very high” and also correspond with traditional levels of formal education according to the grade level. Higher scores

correspond to higher complexity and higher school equivalence (Fig. 3).

Finally, suitability was assessed with the Suitability Assessment of Materials (SAM) tool, which offers a systematic method to assess lay-out, design, organization, voice, and

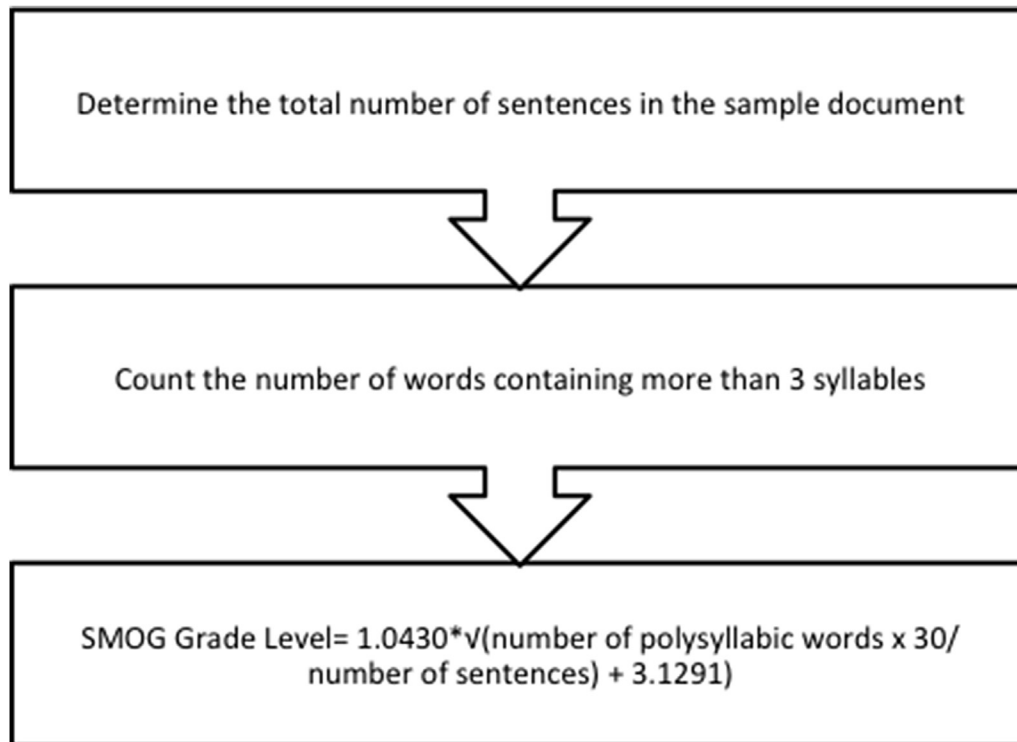


Fig. 2 – Readability analysis. SMOG calculates the necessary level of reading grade to understand a sample text based on word complexity and number of sentences.

vocabulary. Material is rated on six factors that affect readability and comprehension: content, literacy demand, graphics, layout and type, learning stimulation and motivation, and cultural appropriateness. Each factor has multiple elements; some factors have more elements than other and therefore, weigh more overall. For example, Literacy demand and Graphics contain the most scored elements (10/42), whereas the cultural appropriateness category has the least assigned number of elements (4/42). Material is rated as 2-superior, 1-adequate, and 0-not suitable for each of the factor. Analysis of individual categories provides information about specific areas of deficiency that can be improved to increase the suitability to the intended audience. The scores are then combined to an overall assessment of “superior,” “adequate,” or “not suitable.” The three levels of suitability are: 70%-100% superior, 40%-69% adequate, and 0%-39% not suitable (Fig. 4).

Both PMOSE/iKIRSCH and SAM scoring was performed by two independent raters, Bao Ngoc N. Tran and Mansher Singh, to determine inter-rater agreement.

Statistical analysis

All statistical analyses were performed using Stata, version 12.0, software (StataCorp LP, College Station, TX). Overall, the mean score of SMOG, PMOSE/iKIRSCH, and SAM were calculated for all websites. Inter-rater reliability for PMOSE/iKIRSCH and SAM were performed using weighted Fleiss’ kappa statistic. Using a weighed kappa analysis allows the relative

degree of discrepancy between ordinal scores to be accounted for in the statistical results (i.e., difference between “low” and “very low”, “moderate” and “low”). A kappa score of zero means the observed inter-rater agreement is no better than expected by chance. Conversely, a kappa score approaching 1 indicates almost perfect agreement. Intermediate values of kappa are interpreted as followed: 0-0.20, “slight” agreement; 0.21-0.40, “fair” agreement; 0.41-0.60 “moderate” agreement; 0.61-0.80, “substantial” agreement; and 0.81-1, “nearly perfect” agreement.

Results

The top 10 highest ranked websites by Google were: Mayoclinic.org, Breastcancer.org, Wikipedia.org, Lymphnet.org, Emedicine.medscape.com, Cancer.gov, Cancer.org, Medicinenet.com, Medlineplus.gov, and WedMD.com (Table 1).

Readability analysis

The mean percentage of SMOG scores hard words across all websites was 21.07%. Individual website ranged from 13.60% (Cancer.gov) to 32.60% (Emedicine.medscape.com) (Table 2).

Overall SMOG reading grade level across all 10 websites for lymphedema was 14, well above the recommended sixth-grade level by the American Medical Association and NIH. Individual website SMOG reading grade level ranged from

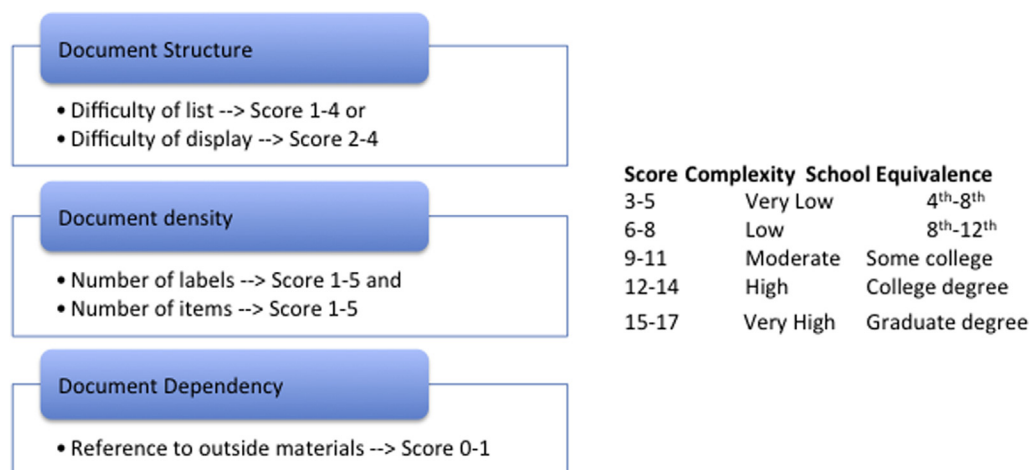


Fig. 3 – Complexity analysis. PMOSE/iKIRSCH evaluates a document based on structure, density, and dependency. Total score is calculated and corresponds to school equivalence. (Color version of figure is available online.)

10.7 (Cancer.org) to 18.7 (Wikipedia.org). Every website far exceeded the recommended reading level.

Complexity analysis

All lists, charts, graphs, and information displays in all materials were assessed with the PMOSE/iKIRSCH formula, which focuses on document structure, content density, and information dependency. The mean complexity score for all websites was 6.7, corresponding to “low” complexity and requiring an 8th-12th grade education (Table 3). There were two websites (Breastcancer.org and Emedicine.medscape.com) rated as moderate to high in complexity, requiring some college education for comprehension. Only two websites (Medlineplus.gov and WebMD.com) were written at appropriate level of complexity, very low or 4th-eighth grade level by both raters. Fleiss’ kappa score was 80% ($P = 0.04$), interpreted as “substantial” agreement between two raters.

Suitability analysis

Overall SAM score was 45% correlating to “adequate” suitability; however, this was borderline low for “adequate” category (0%-39% not suitable, 40%-69% adequate; Table 4). Inter-rater agreement Fleiss’ kappa score was 76% ($P = 0.06$), interpreted as “substantial” agreement; however, this finding was not statistically significant. Two websites were identified as not suitable for intended audience (Breastcancer.org and Emedicine.medscape.com). The remaining eight websites were all rated as adequate for suitability ranging from 40.5 (Wikipedia.org) to 61.9 (Cancer.org)

Discussion

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic

health information and services needed to make appropriate health decision.”²³ It has been shown to be the best single predictor of health status, ahead of income, age, employment, and level of education.²⁴ Health literacy, or lack thereof, has become a source of health care disparity, especially in the surgical patient population.²⁵⁻²⁷ Repeated national surveys undertaken by the education sector have demonstrated that nearly half of the adult population in the United States has limited literacy skills, and analyses indicated that more than half are limited in health literacy.^{28,29} The goal of this study was to evaluate the accessibility of available online health care resources for lymphedema and move beyond mere attention to readability level. Using expanded metrics, we also analyzed the complexity and suitability of the materials by studying the available resources in more depth.

Our study demonstrated that the average readability of the most commonly accessed websites for lymphedema was at 14th grade level, far exceeding the recommended sixth-grade level. Individually, each website was also written at higher than recommended level of readability. Interestingly, the websites endorsed by American Cancer Society (Cancer.org) and NIH (Cancer.gov) had the lowest readability scores at 10.7 and 11, respectively, but were still above the recommended reading level.

Because government sponsored websites are often deemed more credible and thus used more often by the public, it is critically important to ensure information on these websites is appropriately presented to the general public. In addition, the popular websites assessed such as Wikipedia.org had a readability level of 18.7, which is concerning since such websites are more familiar to the general public. Furthermore, websites dedicated exclusively to medical resources (breastcancer.org, emedicine.medscape.com) and websites affiliated to renowned medical centers (Mayoclinic.org) were also above the recommended level of readability.

The higher than recommended level of readability has two major consequences. First, it excludes a large portion of Americans from fully taking advantage of such resources.

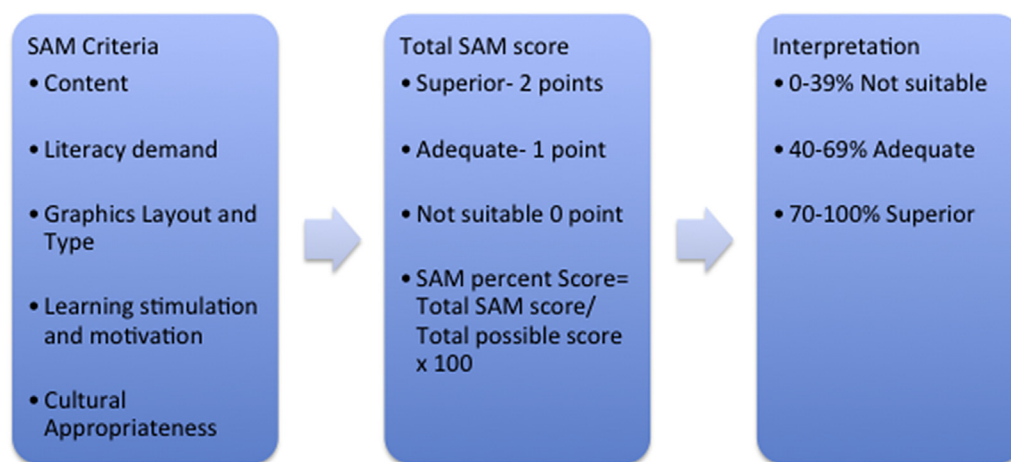


Fig. 4 – Suitability analysis. SAM evaluates content, literacy demand, graphics, layout and type, learning simulation and motivation, and cultural appropriateness using a descriptive scale. Points are assigned and interpreted as percent of total possible and are determined as “superior”, “adequate”, or “not suitable.” (Color version of figure is available online.)

Second, it can cause misinterpretation of the material, which can potentially result in mistrust between the patients and their health care providers and adversely affect health care outcomes.

Readability alone however, does not provide a comprehensive assessment of reading material. Nontextual content of health information should also be examined using complexity and suitability analysis. The PMOSE/iKIRSCH formula offers insight into the structure and format used to present important data. This instrument, as mentioned previously, focuses on document structure, content density, and information dependency.³⁰ The overall PMOSE/iKIRSCH score was 6.7 corresponding to “low” complexity and requiring 8th-12th grade education. Only [Mayoclinic.org](#) and

[Medlineplus.gov](#) had “very low” complexity, which would require less than eighth grade education level. All the other websites had “low” or “moderate” complexity level requiring high school/college level of understanding. The nontextual component of the online resource is a key component for comprehension. Materials with simple structure, organization, less dense, and less outside references will likely be less complex and more comprehensible for patients.

A thorough evaluation of online resources also includes their suitability across a wide spectrum of considerations with regards to easing the burden of reading for the intended audience. The overall SAM score was 45% correlating to “adequate” suitability; however, this is borderline low for “adequate” category (0%-39%, not suitable and 40%-69%, adequate). Two websites found to be “not suitable” were “[Breastcancer.org](#)” and “[Emedicine.medscape.com](#).” Most of the remaining websites were borderline low for “adequate” suitability highlighting the need to improve the suitability of lymphedema online resources. Interestingly, the website with lowest readability levels, [Cancer.org](#) and [Cancer.gov](#), also had the highest levels of suitability at 63% and 55.9%, respectively. This reaffirms that readability alone does not determine the comprehensibility of online resources. In addition to textual content, a simple graph, picture, video or a relatable example, or interactive learning experience can help explain or elaborate a difficult concept. We use different sensory modalities to process information according to Neil Fleming’s VARK (visual, auditory, read-write, and kinesthetic) neurolinguistic programming model.³¹ Visual learners might be attracted to using illustration heavy resources, whereas read-write learners may prefer a densely written document. Not only is there a need for revision of lymphedema resources to a more suitable level, it is also important to know patients learning modality preferences so that we can direct them to a more “suitable” online resource.

While pooling our results together, we found that the online health care resources for “lymphedema” have higher than

Table 1 – Websites evaluated.

Search result rank	Lymphedema source website	Organization
1	Mayoclinic.org	Mayo Clinic
2	Breastcancer.org	Breastcancer.org
3	Wikipedia.org	The Wikimedia Foundation, Inc
4	Lymphnet.org	National Lymphedema Network
5	Emedicine.medscape.com	WebMD LLC
6	Cancer.gov (NIH)	National Institute of Health
7	Cancer.org (ACS)	American Cancer Society
8	Medicinenet.com	MedicineNet, Inc
9	Medlineplus.gov	U.S. National Library of Medicine
10	WebMD.com	WebMD LLC

Table 2 – Readability, complexity, and suitability results for lymphedema literature.

Online source	SMOG		Total score	PMOSE/iKIRSCH		SAM	
	SMOG hard words (%)	Reading grade level		Complexity	School equivalent, grade	Score (%)	Suitability
Mayoclinic.org	17.20	11.2	6	Low	8th-12th	50	Adequate
Breastcancer.org	15.50	13.3	12	High	College degree	38.1	Not suitable
Wikipedia.org	27.40	18.7	6	Low	8th-12th	40.4	Adequate
Lymphnet.org	23.30	15.5	6	Low	8th-12th	41.6	Adequate
Emedicine.medscape.com	32.60	18.7	9	Moderate	Some college	29.7	Not suitable
Cancer.gov (NIH)	13.60	11	6	Low	8th-12th	55.9	Adequate
Cancer.org (ACS)	11.20	10.7	6	Low	8th-12th	63.0	Adequate
Medicinenet.com	23.20	14.5	6	Low	8th-12th	44.0	Adequate
Medlineplus.gov	31	14.9	5	Very low	4th-8th	41.6	Adequate
WebMD.com	15.50	11.9	5	Very low	4th-8th	45.2	Adequate
Total	21.07	14.0	6.7	Low	8th-12th	45	Adequate

the recommended sixth-grade level of readability, typically require higher than eighth grade level of complexity and are at the borderline low end of “adequate” suitability. Websites of well-known societies such as NIH (Cancer.gov) and American Cancer Society (Cancer.org) have the lowest readability level and highest degree of suitability.

Implications

Improved outcomes and survival rates for breast cancer patients have shifted the focus from survivability to quality of life. In that sense, breast cancer patients can be compared to patients with chronic diseases in which management of complications from primary disease is as important as managing the disease itself. Lymphedema is a chronic medical condition without known cure and has a tremendous effect on patient quality of life. A sound understanding of the pathophysiology and treatment of this condition requires a meaningful discussion between the patient and the health care provider. With increased emphasis on efficient utilization of

health care resources, the time available to see each patient might be limited. As such, the dependence on additional supplemental online materials cannot be over emphasized to aid in better understanding of disease process and treatment options.

Our study shows that the online resources for “lymphedema” are generally inadequate in terms of readability, complexity, and suitability. This corroborates with the findings of Seth *et al.*,¹⁷ who demonstrated higher than recommended reading levels for “lymphedema”. However, the analysis of complexity and suitability was lacking in this study, which limited the interpretation of their results. These findings align with previous studies on other types of surgery and readability,^{10,13,14,32-39} as well as studies examining readability, complexity, and suitability.³⁹ The overall conclusion is that online resources for most surgical topics are too difficult for patients to comprehend.

Expanded metrics such as PMOSE/iKIRSCH and SAM have been used in the field of Public Health studying family health history tools, insurance application for children, and Medicaid

Table 3 – Complexity analysis.

Online source	Structure	Density	Dependency	Total	Complexity	School equivalent
Mayoclinic.org	2	3	1	6	Low	8th-12th
Breastcancer.org	4	7	1	12	High	College degree
Wikipedia.org	2	3	1	6	Low	8th-12th
Lymphnet.org	3	2	1	6	Low	8th-12th
Emedicine.medscape.com	4	4	1	9	Moderate	Some college
Cancer.gov (NIH)	2	3	1	6	Low	8th-12th
Cancer.org (ACS)	2	3	1	6	Low	8th-12th
Medicinenet.com	3	2	1	6	Low	8th-12th
Medlineplus.gov	2	2	1	5	Very low	4th-8th
WebMD.com	2	2	1	5	Very low	4th-8th
Total				6.7	Low	8th-12th

Table 4 – Suitability analysis.

Online source	Content 6	Literacy demand 10	Graphics 10	Layout and type 6	Learning stimulation and motivation 6	Cultural appropriateness 4	Total SAM score 42	% Score	Interpretation
Mayoclinic.org	2	6	5	5	3	2	23	54.8	Adequate
Breastcancer.org	2	3	0	3	2	2	12	28.6	Not suitable
Wikipedia.org	2	3	5	4	2	2	17	40.5	Adequate
Lymphnet.org	1	3	5	5	2	2	18	42.9	Adequate
Emedicine.medscape.com	1	2	4	3	1	2	13	31.0	Not suitable
Cancer.gov (NIH)	2	6	4	6	2	2	22	52.4	Adequate
Cancer.org (ACS)	4	5	5	5	5	2	26	61.9	Adequate
Medicinenet.com	3	8	7	6	2	2	18	42.9	Adequate
Medlineplus.gov	4	5	0	6	3	2	20	47.6	Adequate
WebMD.com	2	9	0	6	3	2	22	52.4	Adequate
Total								45.5	Adequate

application.⁴⁰⁻⁴² Our group was one of the very first to utilize such metrics in analyzing health-specific online materials.³⁹

There are three significant potential interventions by which the discrepancy between the online materials and health literacy can be minimized. The first would be to improve the health literacy of average adult American population. While this is possible, it would require fundamental, long-term changes in the national education system. Another option would be modifying the readability, complexity, and suitability of the available resources. Although this is relatively easier than improving the health literacy and a must-do task, it would require detailed analysis of specific areas of weakness leading to comprehensive revision of online resources. While revising the online resources, health professionals must address the complexity and suitability of the resources along with the appropriate reading level. In the interim, the more feasible course of action is modifying physician practices to provide personalized counseling based on health literacy needs of the patients.

We must disseminate findings from the recent assessments of Adult Literacy Skills and recognize that the majority of adults in our society have relatively weak literacy skills.⁴³ Such awareness can result in better counseling and directing for patients and encourage colleagues to supplemental resources that would offer a better match for patients' skills. A sound understanding of health literacy research findings and insights for practice would also encourage the health care providers to apply techniques that help modify talk as well as writing. This can improve the patient-physician relationship resulting in improved patient compliance, satisfaction, and overall outcomes.

Limitations

There are several limitations to this study. Locations of search and user account were deactivated to prevent a search bias, but a change in user preferences, location, or timing could alter the resulting websites. Also, it is possible that many patients use terms other than "lymphedema" while looking for complications from breast cancer surgery, however, there are no standard layperson terms for lymphedema. Although Google was used to identify websites, there are other search engines available. The top three search engines in the United States are Google, Bing, and Yahoo. According to a Pew Research study in 2012, 83% of survey participants reported Google as their main search engine.⁴⁴ When comparing Google to other search engines Yahoo and Bing, there is a 90% overlap of website results. Instead of Medlineplus.gov, Yahoo and Bing listed Ncbi.nlm.nih.gov in their top 10 search results. Based on these findings, using Google seemed a reasonable approach for this study and would most closely simulate a patient search. Finally, there may have been subjective scoring bias for PMOSE/iKIRSCH and SAM; however, this was minimized by high independent interobserver agreement.

Conclusion

Online lymphedema literature is written above recommended level for readability and complexity. It is rated as only

adequately suitable for intended audience. Overall, online lymphedema literature is too sophisticated for the average American reader. Further efforts to revise these materials are needed to improve patient's comprehension and understanding. Physicians need to be sensitive to health literacy levels while counseling patients and help direct them to appropriate resources. This would improve patient-physician relationship and overall outcomes.

Acknowledgment

Authors' contributions: B.N.N.T. conceived and designed the study; analyzed and interpreted the data; wrote the manuscript; and approved the final version of the manuscript. M.S. conceived and designed the study and collected the data; provided critical revisions that are important for the intellectual content; and approved the final version of the manuscript. D.S. conceived and designed the study; provided critical revisions that are important for the intellectual content; and approved the final version of the manuscript. R.R. conceived and designed the study and analyzed and interpreted the data; provided critical revisions that are important for the intellectual content; and approved the final version of the manuscript. B.T.L. conceived and designed the study and analyzed and interpreted the data; provided critical revisions that are important for the intellectual content; and approved the final version of the manuscript.

Disclosure

The authors reported no proprietary or commercial interest in any product mentioned or concept discussed in this article.

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