A Multimetric Evaluation of Online Spanish Health Resources for Lymphedema

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Background: Breast cancer is a leading cause of death in US Hispanic females. This demographic is more likely to present with later-stage disease and require more extensive surgical treatment, including axillary lymph node dissection, which increases risk of lymphedema. The Spanish-speaking Hispanic population has a lower health literacy level and requires materials contoured to their unique needs. The aim of this study was to evaluate online Spanish lymphedema resources.

Methods: A web search using the Spanish term "linfedema" was performed, and the top 10 websites were identified. Each was analyzed using validated metrics to assess readability, understandability, actionability, and cultural sensitivity using the SOL (Simplified Measure of Gobbledygook, Spanish), Patient Education and Materials Assessment for Understandability and Actionability (Patient Education and Assessment Tool), and Cultural Sensitivity and Assessment Tool (CSAT), respectively. Online materials were assessed by 2 independent evaluators, and interrater reliability was determined.

Results: Online lymphedema material in Spanish had a mean reading grade level of 9.8 (SOL). Average understandability and actionability scores were low at 52% and 36%, respectively. The mean CSAT was 2.27, below the recommended value of 2.5. Cohen κ for interrater reliability was greater than 0.81 for the Patient Education and Assessment Tool and CSAT, suggesting excellent agreement between raters.

Conclusions: Available online Spanish lymphedema resources are written at an elevated reading level and are inappropriate for a population with lower health literacy levels. As patients continue to use the internet as their primary source for health information, health care entities must improve the quality of provided Spanish resources in order to optimize patient comprehension.

Key Words: cultural sensitivity, health disparities, health literacy, lymphedema, online health information, readability

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The internet has revolutionized our ability to rapidly access information of varying quality and accuracy. Health care consumers are increasingly using the internet as opposed to consulting their care providers as their primary means of obtaining health information. Whereas in the past such consultations may have been consumers' primary response to health concerns or queries, now they are increasingly likely to forgo interpersonal interaction in favor of seeking out information on the web. Approximately 72% of Americans use online materials to assist in health care decision making.[1–3] Although these materials can provide value, they must be consumed with a healthy skepticism regarding their accuracy and reliability. However, such skepticism is beyond consumers who do not have suitable levels of health literacy.

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Health literacy is defined by the Institute of Medicine as the degree to which individuals have the capacity to obtain, process, and understand basic health information and the services needed to make appropriate health decisions.[4,5] Furthermore, it has been described as the single most important predictor of health status and is associated with multiple poor health outcomes as well as increased health care costs.[6,7] These factors underscore the need to scrutinize materials readily available to the consumer. Organizations including the American Medical Association and the National Institutes of Health recommend that materials be written at a sixth- to eighth-grade reading level.[1,2] However, other evidence supports a third- to fifth-grade reading level for populations with lower health literacy.[8,9]

Despite these recommendations, multiple readability studies in English[1,2,6,10–20] and Spanish[8,21,22] have found that online health materials are written at inappropriately elevated reading levels. Additionally, national literacy data demonstrate that 65% of Hispanics living in the United States have limited health literacy levels compared with 28% of white adults.[8] Evidence supports that 50% of US Hispanics self-report an ability to speak English very well.[23] This underscores the need to develop appropriate materials that meet their linguistic needs.

An additional reason that comprehensible online health information is of increased importance for the Hispanic population is their increased risk of lymphedema.[24] Breast cancer is the leading cause of breast cancer–related death in Hispanic women.[25] Furthermore, breast cancer–related lymphedema is the no. 1 cause of lymphedema in the United States.[2,26–28] This cohort is more likely than white women to present with advanced-stage disease and require more extensive surgical intervention, including axillary lymph node dissection,[29–31] compared with white women. The confluence of advanced disease presentation need for axillary node dissection and adjuvant radiotherapy has an additive effect on lymphedema risk. A meta-analysis showed that risk of lymphedema increases from 5% with simple lumpectomy to as high as 60% after modified radical mastectomy and nodal radiation.[32–34]

The etiology, diagnosis, and management of lymphedema are complex topics that a sophisticated health consumer on the internet would have difficulty understanding. A population with lower health literacy levels should have access to comprehensible materials that are contoured to their own beliefs and needs. Prior studies have examined the readability of online health materials for lymphedema written in English and found that they were written at an elevated reading level and not suitable for the average consumer.[2,27] In this study, we assess the readability, understandability, actionability, cultural sensitivity, and content of websites offering information about lymphedema in Spanish. We intended to appraise whether an individual accessing the site would be able to read, understand, and apply the information gleaned from the online health material. Additionally, we will provide opportunities for improvement of online materials for this patient demographic.

METHODS

Website Selection

A search for "linfedema," the Spanish word for lymphedema, was performed using the most popular search engine, Google (Google, Mountain View, Calif), by 1 researcher. All location and personal

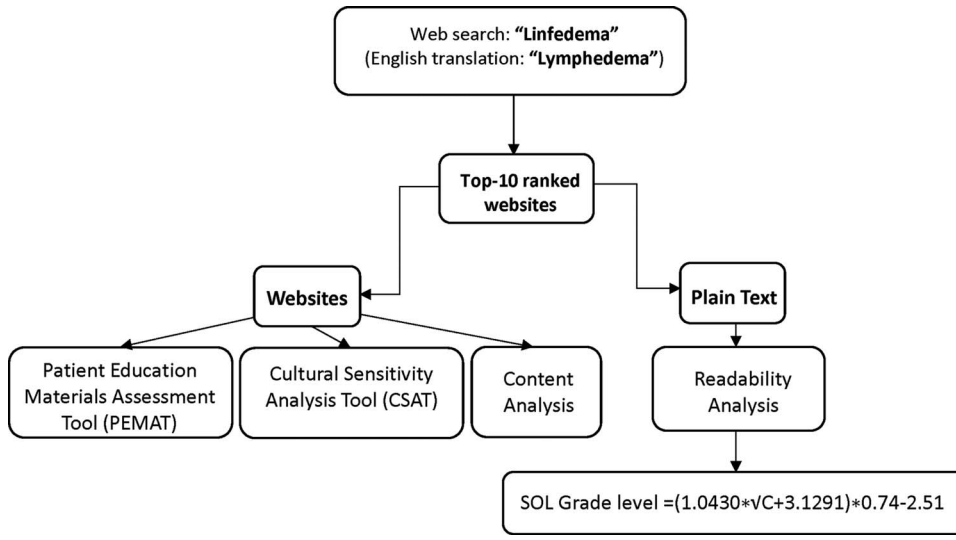

FIGURE 1. Study design overview.

account settings were disabled to avoid inadvertent search bias and ensure reproducibility. The top 10 ranked websites yielded from this search were included for analysis. All patient-directed information that belonged to the native site was included in the analyses in order to capture all pertinent content available on the web page. Links to external websites, advertisements, and references were excluded. All websites were accessed on January 11, 2018.

Readability Assessment

All patient-directed content for each website was copied and formatted into plain text format using Microsoft Word 2011 (Microsoft Corp, Redmond, Wash). Accompanying graphics, including visual images and tables, were removed for this analysis. When present, tables, photographs, citations, colons, semicolons, parentheses, and dashes within sentences were removed to avoid the skewing of readability score, as recommended by several groups.[35,36]

Readability analysis for each document was conducted using Readability Studio Professional Edition v2015.1 Software (Oleander Solutions, Vandalia, Ohio). The SOL readability formula, a Spanish-language modification of the Simplified Measure of Gobbledygook (SMOG) was used. The SOL is a measure of the comprehensibility of information. It determines reading grade level based on word complexity and sentence length.[37,38] The SOL formula adjusts for the comparatively higher syllable counts found in Spanish text (Fig. 1). The number of SMOG complex words, defined as words consisting of more than 3 syllables, was also determined.

Understandability and Actionability Assessment

The Patient Education and Assessment Tool (PEMAT) was used to evaluate the understandability and actionability of health materials. The understandability metric is based on 17 items, which include evaluation of material content, word choice and style, use of numbers, organization, layout and design of web page, and use of visual aids (Fig. 2). It assesses whether readers of diverse health backgrounds and varying levels of health literacy can comprehend and explain key messages conveyed on the site. The actionability metric is based on 7 items and evaluates the degree to which the reader knows the necessary steps to take action based on the provided information.[38,39] The scores for each metric were calculated, and a percentage was obtained for each web page. PEMAT has no recommended cutoff for acceptable scores. Scores are intended to be a relative measure of the quality of material.[38] Higher scores reflect more understandable and actionable materials.

Cultural Sensitivity Assessment

The Cultural Sensitivity and Assessment Tool (CSAT) is a metric that allows for formal evaluation of cultural sensitivity (Fig. 3). Cultural sensitivity is defined as "an awareness and utilization of knowledge

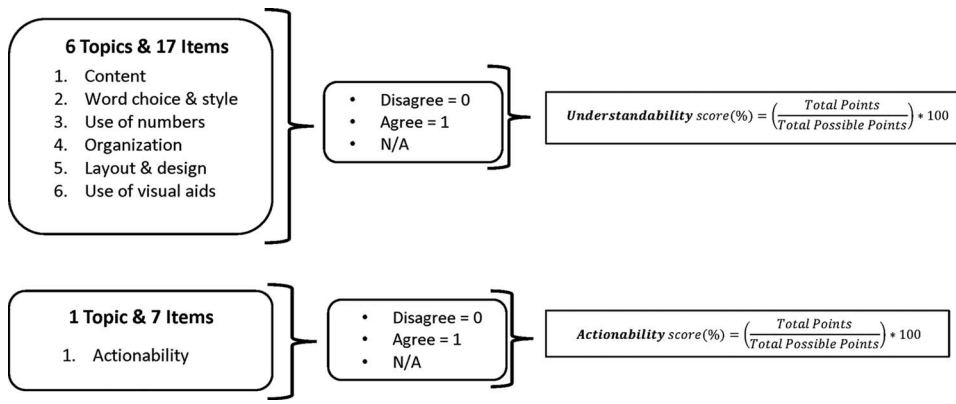

FIGURE 2. PEMAT scoring.

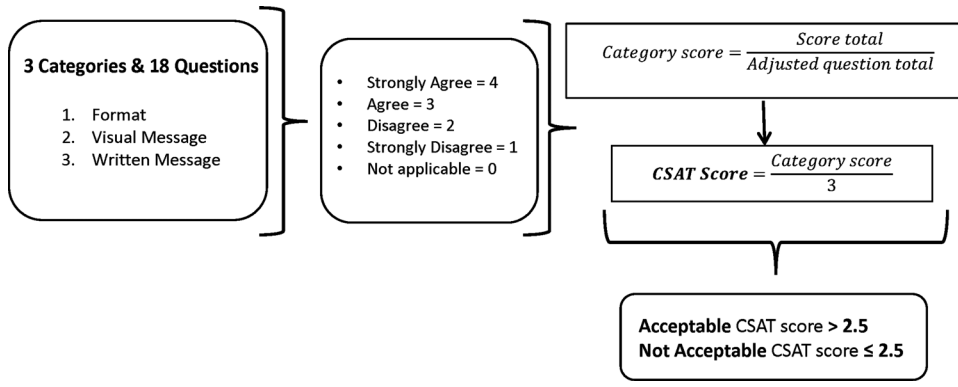

FIGURE 3. CSAT scoring.

related to ethnicity, culture, gender, or sexual orientation in explaining and understanding situations and responses of individuals in their environment."[40] When this concept is applied to patient health materials, it means that the message and content are understandable to the intended audience and congruent with cultural norms and behavior.[41] The CSAT provides an evaluation of the format, written message, and visual message of materials on a scale of 1 (strongly disagree that the material is culturally sensitive) to 4 (strongly agree that the material is culturally sensitive). A score of 0 is given if the statement was not applicable to the material analyzed. Scores are calculated for each of 3 categories, and a mean overall score is determined. The mean scores were compared with the acceptable benchmark scores set forth by CSAT authors of greater than 2.5.

Content Evaluation

All web materials were systematically evaluated by 2 independent evaluators for content based on inclusion of disease-related information regarding (1) background and disease etiology, (2) prevention, (3) risk factors, (4) symptoms, (5) causes, (6) diagnostic modalities, and (7) treatment.

Statistical Analysis

All statistical analyses were performed using SPSS Statistics 24.0 (IBM Corp, Armonk, NY). A Cohen κ value was calculated for the PEMAT and CSAT to determine interrater agreement. A κ score of 1 indicates perfect agreement, whereas a κ of 0 suggests that the results yielded are equal to those expected by chance. Cohen κ are interpreted as follows: a score of 0.1 to 0.2 indicates "no" agreement, 0.21 to 0.39 indicates minimal agreement, 0.41 to 0.59 indicates "weak agreement," 0.60 to 0.79 indicates moderate agreement, 0.80 to 0.90 indicates strong agreement, and greater than 0.90 indicates almost perfect agreement.[42]

TABLE 1. Websites Accessed

Search Yield	Website	Organization
1	medlineplus.gov	MEDLINE
2	cancer.org	American Cancer Society (ACS)
3	cancer.net	American Society of Clinical Oncology (ASCO)
4	mayoclinic.org	Mayo Clinic
5	wikipedia.org	Wikipedia
6	aecc.es	Asociación Española Contra el Cáncer (AECC)
7	breastcancer.org	BreastCancer.org
8	leucocitos.org	Leucocitos
9	cancer.gov	National Cancer Institute (NCI)
10	northshore.org	North Shore Health System (NSHS)

RESULTS

The top 10 highest ranked web pages yielded by the Google search were medlineplus.gov, cancer.org, cancer.net, mayoclinic.org, wikipedia.org, aecc.es, breastcancer.org, leucocitos.org, cancer.gov, and northshore.org (Table 1).

Readability Analysis

The overall reading grade level for online materials using SOL was 9.8. Readability scores ranged from 8.1 to 12.5. All websites exceeded the recommended minimum sixth- to eighth-grade reading level for health information. The mean percentage of SOL complex words was 34.03%. Individual websites ranged from 30.22% to 39.30% (Table 2).

Understandability and Actionability Analysis

The mean PEMAT for material understandability was 51.56%, with scores ranging from 24% to 87%. The mean PEMAT actionability score was 38%, with scores ranging between 10% and 60%. There was strong interrater agreement for the PEMAT (κ = 0.878). Four websites had mean actionability scores less than or equal to 40%. No website included an interactive tool, which would engage the reader to take action. Additionally, there were a limited number of websites that included visual aids to simplify information (Table 3).

TABLE 2. Readability Analysis

	SOL (Spanish SMOG)	
Online Source	Reading Grade Level (SOL)	% Complex Words
1. MEDLINE	8.1	32.03%
2. ACS	10	34.07%
3. ASCO	8.9	35.40%
4. Mayo Clinic	9.1	36.53%
5. Wikipedia	11.2	39.30%
6. AECC	10.1	37.13%
7. Breastcancer.org	12.5	31.73%
8. Leucocitos	9	30.22%
9. NCI	9.3	32.33%
10. NSHS	9.8	31.60%
Mean	9.8	34.03%

TABLE 3. Understandability, Actionability, and Cultural Sensitivity Assessment

	PEMAT		CSAT	
Online Source	Understandability	Actionability	Score	Acceptability
1. MEDLINE	59%	40%	2.69	Acceptable
2. ACS	87%	60%	3.70	Acceptable
3. ASCO	42%	60%	1.80	Not acceptable
4. Mayo Clinic	35%	50%	2.87	Acceptable
5. Wikipedia	24%	20%	2.20	Not acceptable
6. AECC	50%	40%	2.09	Not acceptable
7. Breastcancer.org	33%	10%	1.81	Not acceptable
8. Leucocitos	50%	20%	1.83	Not acceptable
9. NCI	73%	20%	2.03	Not acceptable
10. NSHS	58%	40%	1.72	Not acceptable
Mean	51.56%	38%	2.27	Not acceptable

Cultural Sensitivity Analysis

The mean cultural sensitivity score was 2.27, below the recommended value of 2.5. Individual CSAT scores ranged from 1.72 to 3.70. Only 3 websites were considered culturally sensitive, with individual CSAT scores in the "acceptable" range. The remaining majority of websites (70%) were deemed culturally insensitive. There was strong interrater agreement ($\kappa = 0.835$).

Content Analysis

There was significant heterogeneity in the content of online materials (Fig. 4). All websites (100%) included information about disease background and etiology, and 80% discussed risk factors. Sixty percent described management strategies. Of these, 67% described manual lymphatic drainage and 100% included information regarding wrapping and bandaging techniques. Surgical interventions for chronic lymphedema, including lymph node transplant and lymphaticovenous bypass, were not included in any individual web page. Furthermore, only 20% of websites included information regarding disease prevention, despite increasing awareness of preventive surgical techniques for breast cancer patients undergoing axillary nodal dissection. Information regarding the various symptoms and myriad diagnostic modalities was included in 60% of websites.

DISCUSSION

To our knowledge, this is the first study evaluating online Spanish lymphedema health information using a multimetric approach to assess understandability, actionability, cultural sensitivity, and written content. The majority of existing readability studies examining online health materials have focused on assessment of reading grade level. Our study revealed an average reading grade level of 9.8. This finding can be misleading, as a lower reading grade level may imply ease of comprehension. A sole readability analysis, based on sentence length and word complexity, would preclude any discussion on critical, nontextual factors including graphics, tables, and figures, which have been shown to improve understanding, especially for populations with low health literacy levels.[8,43,44] The adjunct tools of PEMAT and CSAT allowed us to analyze these factors to facilitate a more comprehensive analysis. The average word complexity was 34.03% in our study. This suggests incorporation of unnecessarily complex terminology, which also can contribute to poor reader comprehension.

Furthermore, despite the lack of reference scores for the PEMAT tool, the mean understandability and actionability scores of 51.56% and 24%, respectively, suggest that there is significant room for improvement in promoting reader comprehension and engagement. This would help facilitate patient participation in the decision-making process and contribute to patient empowerment. Additionally, some commonalities observed across web materials were the lack of informative headers, incorporation of medical jargon, and use of dense paragraphs without a clear focus. This is concerning, as the use of lengthy paragraphs without headers has also been shown to decrease the ease of website navigation and compromise understanding.[45] The images incorporated in online materials tended to be unnecessarily complex and failed to assist readers in learning more about their condition. For example, an anatomic graphic of the human lymphatic system was used in multiple websites to illustrate the concept of lymphedema. These images were often accompanied by text written in English. These factors added an additional, unnecessary layer of complexity and are likely to further diminish a patient's ability to process this material. Moreover, no web page included a summary of the information presented. A lack of summary creates uncertainty and can leave patients unsure of what their next steps should be.

Online web material content included some key concepts of lymphedema. However, there was significant variability in selection of content included and even instances of key information omission (Fig. 5). For example, prevention was rarely addressed. This is concerning in the era of preventive procedures, including Lymphatic Microsurgical Preventive Healing Approach surgery, which has been associated with reduced rates of lymphedema.[46–50] Additionally, surgical treatment options including lymph node transplantation, lymphaticovenular bypass, and debulking procedures (ie, liposuction) were surprisingly not addressed in any individual web page. Lymph node transplantation is associated with improved quality of life in patients living with chronic lymphedema.[51] The omission of this surgical option in the top 10 ranked web materials bespeaks the absence of a crucial means for

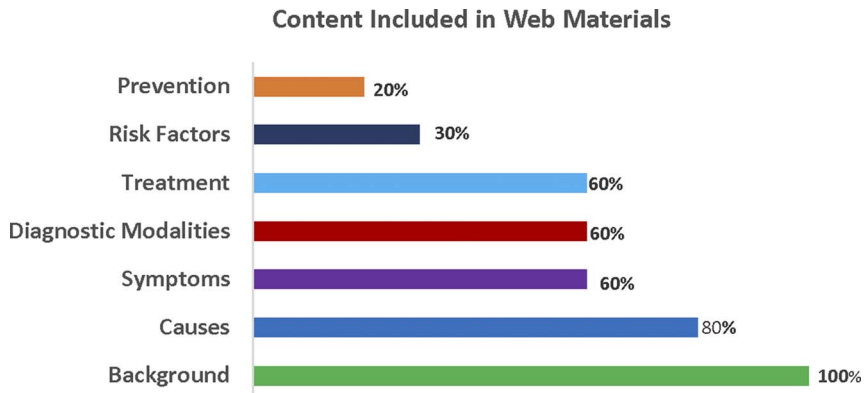

FIGURE 4. Content included in web materials.

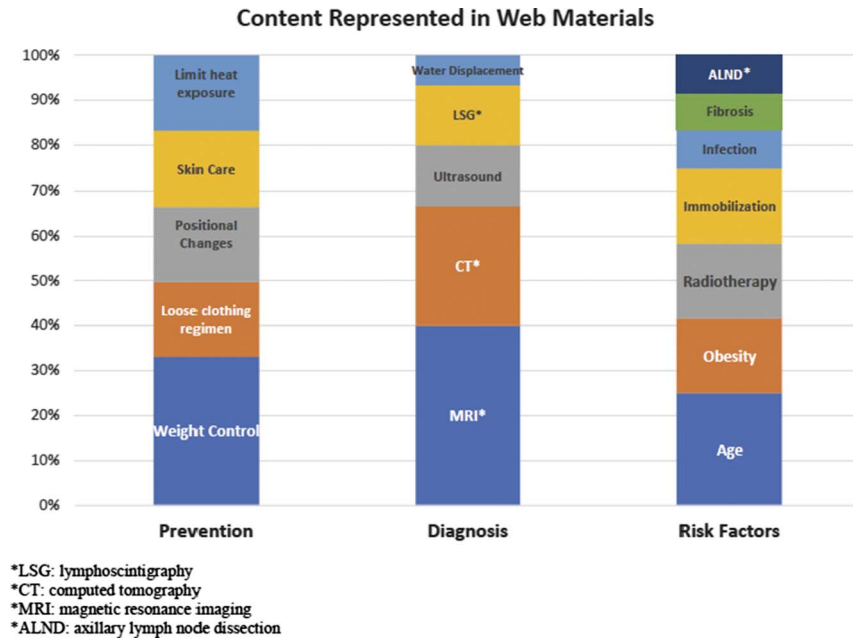

FIGURE 5. Subtopic variation across web materials.

addressing this disease. Viewed in its all its complexity, lymphedema is an abstruse, chronic medical condition that has various modalities for diagnosis, management, and treatment. Information was largely presented in a manner that has an inimical effect on readers' understanding by further complicating already sophisticated health information. For better patient understanding, the different modalities for diagnosis, management, and treatment should be presented in a stepwise manner, organized from the most used modality to the less often used. By doing this, patients can have a clearer idea about what would be the diagnostic, management, and treatment strategies that he/she would face during the course of the disease.

Cultural sensitivity analysis revealed an unacceptable evaluation of all web materials. There was no website that included materials contoured toward the cultural background of the Hispanic population. This has important implications as even web materials with a neutral cultural focus may compromise reader self-identification and consequently comprehension of materials. In fact, many websites with Spanish text included images with accompanying English. This added an additional layer of confusion and only served to make the information less understandable. The diverse elements of each patient population demand recognition in order to create culturally sensitive materials. Failure to appreciate the unique cultural and contextually relevant aspects of lymphedema risks curtailing reader understanding.

Effective, clear communication of health education is a cornerstone of the provider-patient relationship. In our current health care environment, physicians are facing increasing time constraints, which can limit time spent with patients, including information exchange. Therefore, it would be logical to assume that health information, either online or in print, will serve to supplant or supplement traditional modes of health communication. Benefits of online health information include increased coping skills, self-efficacy, and patient-empowerment.[52] However, in order for patients to fully participate in these benefits, we must carefully evaluate the information we provide to populations less likely to make use of this information including Hispanics, individuals with low educational attainment, and individuals living in low-income households.[8]

Our findings demonstrate that current Spanish health online materials for lymphedema are overly sophisticated and unsuitable. There is no consensus regarding the recommended reading grade level for the Hispanic population. However, prior studies support that a third- to fifth-grade reading level may be appropriate for populations with lower health literacy levels.[8] The chasm between the increasing number of readily available online health materials and a patient population unequipped to comprehend this information continues to widen. In our current health care environment, the internet has been championed for its potential utility as a vehicle for delivery of health information. It is incumbent upon providers and health entities to ensure that materials developed are appropriate for the literacy levels of the target population.

There are several limitations to this study. Our study was designed to understand the popular online materials yielded while conducting a search using the Spanish term for lymphedema. An alteration in the chosen search term, online search engine, or search date could influence content yielded. We chose the search term "linfedema" as we felt it was the most straightforward and easily recognized. However, utilization of a different Spanish search term(s) for lymphedema could have influenced results. The use of Google as our primary search engine is also a limitation. However, according to a Pew study conducted in 2012, 83% of participants use Google as their primary search engine.[53] When we conducted a search using "linfedema" on search engines Bing and Yahoo, we found 90% overlap in web results (Table 4).

Another limitation includes the limitation of our search to the top 10 ranked websites on Google. Although these websites are the most visible, it can be argued that patients may prefer other web pages for health information, including those not captured in our search, such as personal blogs. Additionally, 2 evaluators independently rated web materials using the CSAT and PEMAT, introducing the possibility of subjective scoring bias. However, this was minimized because of the high interrater agreement observed.

Improving the readability and understandability of health materials required a multipronged approach. First, simplification of reading grade level of written content, ideally using conservative parameters, is needed to improve reading ease. The Office of Health Disease and Promotion has provided research-based guidelines to help write understandable and actionable materials. This includes organizational guidelines to develop material that is easy to comprehend and navigate. This online resource also includes information on writing "actionable"

TABLE 4. Search Term "linfedema" Using Bing, Yahoo, and Google Search Engines

	Bing	Yahoo	Google
1	Cancer.gov	Cancer.gov	Medlineplus.gov
2	Medlineplus.gov	Medlineplus.gov	Cancer.org
3	Mayoclinic.org	Mayoclinic.org	Cancer.net
4	Cancer.org	Wikipedia.org	Mayoclinic.org
5	Wikipedia.org	Cancer.org	Wikipedia.org
6	Cancer.net	Cancer.net	Aecc.es
7	Cigna.com*	Breastcancer.org	Breastcancer.org
8	Leucocitos.org	Cigna.com*	Leucocitos.org
9	Breastcancer.org	Leucocitos.org	Cancer.gov
10	Aecc.es	Aecc.es	Northshore.org

*Indicates unique web page not yielded using "linfedema" on Google search engine.

content to engage with the target population and promote patient empowerment. The development of culturally sensitive materials contoured toward the target demographic should involve discussion and dialogue with the community to glean insight into their perspective of the disease and its treatment. Materials specifically addressing cultural beliefs and needs are more likely to be understood and acted upon. Additionally, the incorporation of images consistent with the target demographic should be prioritized as it promotes reader identification with the materials. At the provider level, it is incumbent upon the physician that information patients read online does not, in any way, hamper their treatment of the disease. As part of this responsibility, physicians must ensure that the information they either provided to patients themselves or refer to patients is comprehended and utilized in an effective manner.

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