Assessing the Reading Level of Online Sarcoma Patient Education Materials

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Abstract

Cancer patients rely on patient education materials (PEMs) to gather information regarding their disease. Patients who are better informed about their illness have better health outcomes. The National Institutes of Health (NIH) recommends that PEMs be written at a sixth- to seventh-grade reading level. The purpose of this study was to evaluate the readability of online PEMs of bone and soft-tissue sarcomas and related conditions.

We identified relevant online PEMs from the following websites: American Academy of Orthopaedic Surgeons, academic training centers, sarcoma specialists, Google search hits, Bonetumor.org, Sarcoma Alliance, Sarcoma Foundation of America, and Medscape. We used 10 different readability instruments to evaluate the reading level of each website's PEMs.

In assessing 72 websites and 774 articles, we found that none of the websites had a mean readability score at or below 7 (seventh grade). Collectively, all websites had a mean readability score of 11.4, and the range of scores was grade level 8.9 to 15.5.

None of the PEMs in this study of bone and soft-tissue sarcomas and related conditions met the NIH recommendation for PEM reading levels. Concerted efforts to improve the reading level of orthopedic oncologic PEMs are necessary.

The diagnosis of cancer is a life-changing event for the patient as well as the patient's family, friends, and relatives. Once diagnosed, most cancer patients want more information about their prognosis, future procedures, and/or treatment options.[1] Receiving such information has been shown to reduce patient anxiety, increase patient satisfaction with care, and improve self-care.[2-6] With the evolution of the Internet, patients in general[7-9] and, specifically, cancer patients[10-17] have turned to websites and online patient education materials (PEMs) to gather more health information.

For online PEMs to convey health information, their reading level must match the health literacy of the individuals who access them. Health literacy is the ability of an individual to gather and comprehend information about their condition to make the best decisions for their health.[18] According to a report by the Institute of Medicine, 90 million American adults cannot properly use the US health care system because they do not possess adequate health literacy.[18] Additionally, 36% of adults in the United States have basic or less-than-basic health literacy.[19] This is starkly contrasted with the 12% of US adults who have proficient health literacy. A 2012 survey showed that about 31% of individuals who look for health information on the Internet have a high school education or less.[8] In order to address the low health literacy of adults, the National Institutes of Health (NIH) has recommended that online PEMs be written at a sixth- to seventh-grade reading level.[20]

Unfortunately, many online PEMs related to certain cancer[21-25] and orthopedic conditions[26-31] do not meet NIH recommendations. Only 1 study has specifically looked at PEMs related to an orthopedic cancer condition.[32] Lam and colleagues[32] evaluated the readability of osteosarcoma PEMs from 56 websites using only 2 readability instruments and identified 86% of the websites as having a greater than eighth-grade reading level. No study has thoroughly assessed the readability of PEMs about bone and soft-tissue sarcomas and related conditions nor has any used 10 different readability instruments. Since each readability instrument has different variables (eg, sentence length, number of paragraphs, or number of complex words), averaging the scores of 10 of these instruments may result in less bias.

The purpose of this study was to evaluate the readability of online PEMs concerning bone and soft-tissue sarcomas and related conditions. The online PEMs came from websites that sarcoma patients may visit to obtain information about their condition. Our hypothesis was that the majority of these online PEMs will have a higher reading level than the NIH recommendations.

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Materials and Methods

In May 2013, we identified online PEMs that included background, diagnosis, tests, or treatments for bone and soft-tissue sarcomas and conditions that mimic bone sarcoma. We included articles from the *Tumors* section of the American Academy of Orthopaedic Surgeons (AAOS) website.[33] A second source of online PEMs came from a list of academic training centers created through the American Medical Association's Fellowship and Residency Electronic Internet Database (FREIDA) with search criteria narrowed to *orthopedic surgery*. If we did not find PEMs of bone and soft-tissue cancers in the orthopedic department of a given academic training center's website, we searched its cancer center website. We chose 4 programs with PEMs relevant to bone and soft-tissue sarcomas from each region in FREIDA for a balanced representation, except for the *Territory* region because it had only 1 academic training center and no relevant PEMs. Specialized websites, including Bonetumor.org, Sarcoma Alliance (Sarcomaalliance.org), and Sarcoma Foundation of America (Curesarcoma.org), were also evaluated. Within the *Sarcoma Specialists* section of the Sarcoma Alliance website,[34] sarcoma specialists who were not identified from the FREIDA search for academic training centers were selected for review.

Because 8 of 10 individuals looking for health information on the Internet start their investigation at search engines, we also looked for PEMs through a Google search (Google.com) of *bone cancer*, and evaluated the first 10 hits for PEMs.[8] Of these 10 hits, 8 had relevant PEMs, which we searched for additional PEMs about bone and soft-tissue cancers and related conditions. We also conducted a Google search of the most common bone sarcoma and soft-tissue sarcoma, *osteosarcoma* and *malignant fibrous histiocytoma*, respectively, and found 2 additional websites with relevant PEMs. LaCoursiere and colleagues[35] surveyed cancer patients who used the Internet and found that they preferred WebMD (Webmd.com) and Medscape (Medscape.com) as sources for content about their medical condition.[35] WebMD had been identified in the Google search, and we gathered the PEMs from Medscape also. It is worth noting that some of these websites are written for patients as well as clinicians.

Text from these PEMs were copied and pasted into separate Microsoft Word documents (Microsoft, Redmond, Washington). Advertisements, pictures, picture text, hyperlinks, copyright notices, page navigation links, paragraphs with no text, and any text that was not related to the given condition were deleted from the document to format the text for the readability software. Then, each Microsoft Word document was uploaded into the software package Readability Studio Professional (RSP) Edition Version 2012.1 for Windows (Oleander Software, Vandalia, Ohio). The 10 distinct readability instruments that were used to gauge the readability of each document were the Flesch Reading Ease score (FRE), the New Fog Count, the New Automated Readability Index, the Coleman-Liau Index (CLI), the Fry readability graph, the New Dale-Chall formula (NDC), the Gunning Frequency of Gobbledygook (Gunning FOG), the Powers-Sumner-Kearl formula, the Simple Measure of Gobbledygook (SMOG), and the Raygor Estimate Graph.

The FRE's formula takes the average number of words per sentence and average number of syllables per word to compute a score ranging from 0 to 100 with 0 being the *hardest to read*.[36] The New Fog Count tallies the number of sentences, easy words, and hard words (polysyllables) to calculate the grade level of the document.[37] The New Automated Readability Index takes the average characters per word and average words per sentence to calculate a grade level for the document.[37] The CLI randomly samples a few hundred words from the document, averages the number of letters and sentences per sample, and calculates an estimated grade level.[38] The Fry readability graph selects samples of 100 words from the document, averages the number of syllables and sentences per 100 words, plots these data points on a graph, with the intersection determining the reading level.[39] The NDC uses a list of 3000 familiar words that most fourth-grade students know.[40] The percentage of difficult words, which are not on the list of familiar words, and the average sentence length in words are used to calculate the reading grade level of the document. The Gunning FOG uses the average sentence length in words and the percentage of hard words from a sample of at least 100 words to determine the reading grade level of the document.[41] The Powers-Sumner-Kearl formula uses the average sentence length and percentage of monosyllables from a 100-word sample passage to calculate the reading grade level.[42] The SMOG formula counts the number of polysyllabic words from 30 sentences and calculates the reading grade level of the document.[43] In contrast to other formulas that test for 50% to 75% comprehension, the SMOG formula tests for 100% comprehension. As a result, the SMOG formula generally assigns a reading level 2 grades higher than the Dale-Chall level. The Raygor Estimate Graph selects a 100-word passage, counts the number of sentences and number of words with 6 or more letters, and plots the 2 variables on a graph to determine the reading grade level.[44] The software package calculated the results from each reading instrument and reported the mean grade level score for each document.

Results

We identified a total of 72 websites with relevant PEMs and included them in this study. Of these 72 websites, 36 websites were academic training centers, 10 were Google search hits, and 21 were from the Sarcoma Alliance list of sarcoma specialists. The remaining 5 websites were AAOS, Bonetumor.org, Sarcoma Alliance, Sarcoma Foundation of America, and Medscape. A list of conditions and treatments that were considered relevant PEMs is found in **Appendix 1**. A total of 774 articles were obtained from the 72 websites.

None of the websites had a mean readability score of 7 (seventh grade) or lower (**Figures 1A, 1B**). Mid-America Sarcoma Institute's PEMs had the lowest mean readability score, 8.9. The lowest readability score was 5.3, which the New Fog Count readability instrument calculated for Vanderbilt University Medical Center's (VUMC's) PEMs (**Appendix 2**). The mean readability score of all websites was 11.4 (range, 8.9-15.5) (**Appendix 2**).

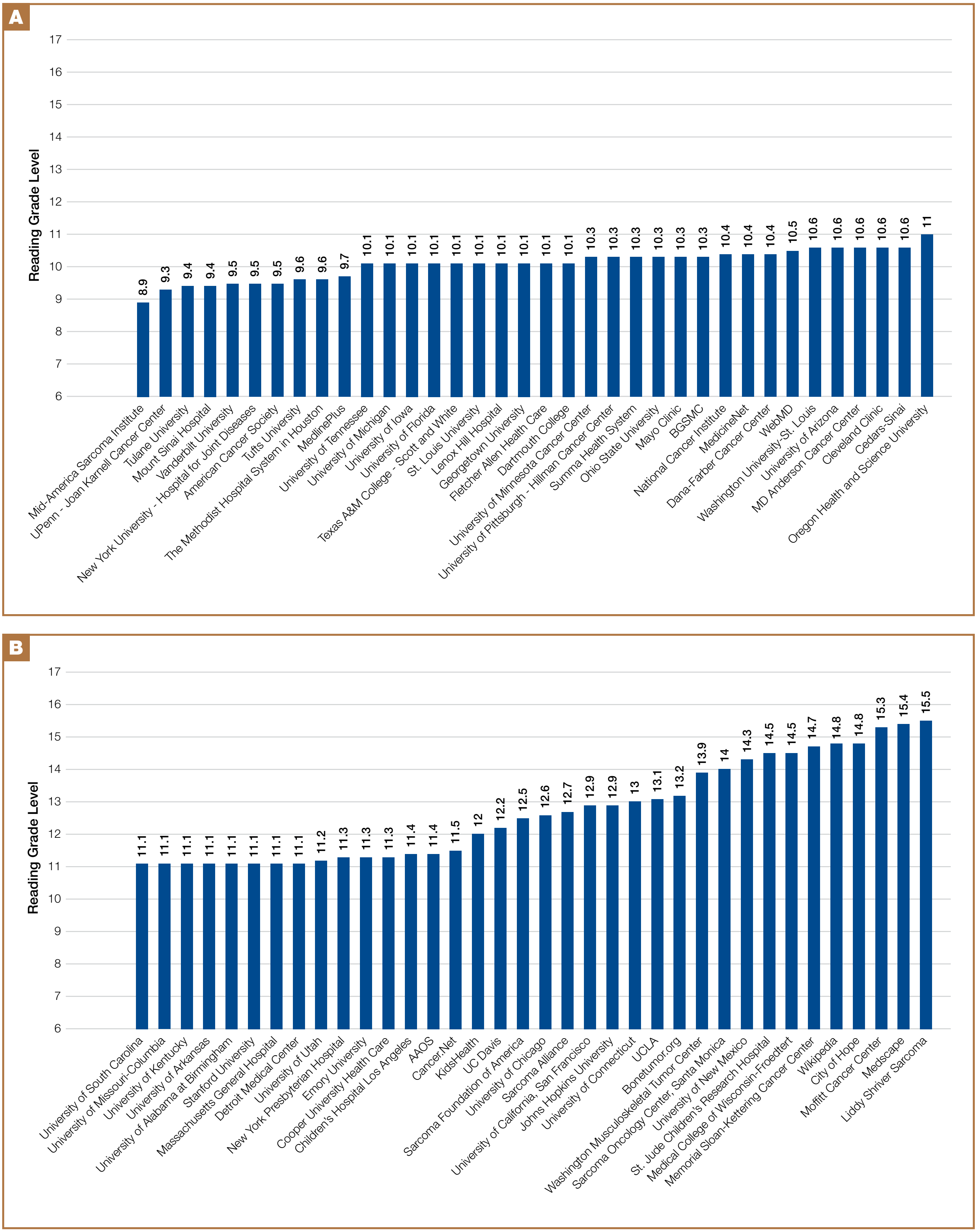

Figure 1. (A, B) Graphs showing mean readability scores of each website's online patient education materials. Abbreviations: BGSMC, Banner Good Samaritan Medical Center; UPenn, University of Pennsylvania; AAOS, American Academy of Orthopaedic Surgeons; UC Davis, University of California, Davis; UCLA, University of California, Los Angeles.

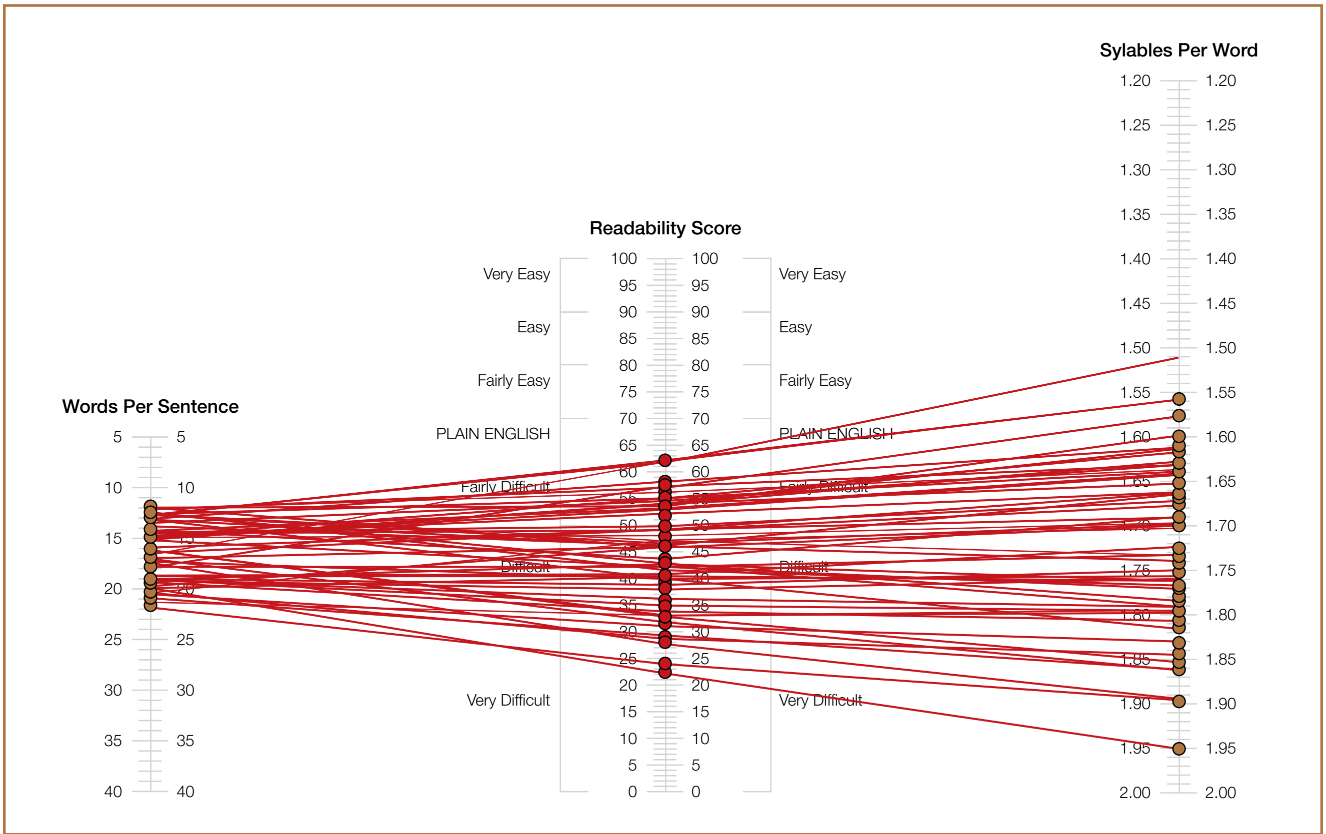

Figure 2. Chart showing the results of the Flesch Reading Ease readability instrument for each website's patient education materials.

Seventy of 72 websites (97%) had PEMs that were *fairly difficult* or *difficult*, according to the FRE analysis (**Figure 2**). The American Cancer Society and Mid-America Sarcoma Institute had PEMs that were written in *plain English*. Sixty-nine of 72 websites (96%) had PEMs with a readability score of 10 or higher, according to the Raygor readability estimate (**Figure 3**). Using this instrument, the scores of the American Cancer Society and the University of Pennsylvania–Joan Karnell Cancer Center were 9; Mid-America Sarcoma Institute's score was 8.

Discussion

Many cancer patients have turned to websites and online PEMs to gather health information about their condition.[10-17] Basch and colleagues[10] reported almost a decade ago that 44% of cancer patients, as well as 60% of their companions, used the Internet to find cancer-related information.[10] When LaCoursiere and colleagues[35] surveyed cancer patients, they found that patients handled their condition better and had less anxiety and uncertainty after using the Internet to find health information and support.[35] In addition, many orthopedic patients, specifically 46% of orthopedic community outpatients,[45] consult the Internet for information about their condition and future surgical procedures.[46,47]

This study comprehensively evaluated the readability of online PEMs of bone and soft-tissue sarcomas and related conditions by using 10 different readability instruments. After identifying 72 websites and 774 articles, we found that all 72 websites' PEMs had a mean readability score that did not meet the NIH recommendation of writing PEMs at a sixth- to seventh-grade reading level. These results are consistent with studies evaluating the readability of online PEMs related to other cancer conditions[21-25] and other orthopedic conditions.[26-31]

The combination of low health literacy of many US adults and high reading grade levels of the majority of online PEMs is not conducive to patients' better understanding their condition(s). Even individuals with high reading skills prefer information that is simpler to read.[48] In many areas of medicine, there is evidence that patients' understanding of their condition has a positive impact on health outcomes, well-being, and the patient–physician relationship.[49-61] Regarding cancer patients, Davis and colleagues[54] and Peterson and colleagues[57] showed that lower health literacy contributes to less knowledge and lower rates of breast[54] and colorectal cancer[57] screening tests. Even low health literacy of family caregivers of cancer patients can result in increased stress and lack of communication of important medical information between caregiver and physician.[52] Among cancer patients, poor health literacy has been associated with mental distress[60] as well as decreased compliance with treatment and lower involvement in clinical trials.[55]

The disparity between patients' health literacy and the readability of online PEMs needs to be addressed by finding

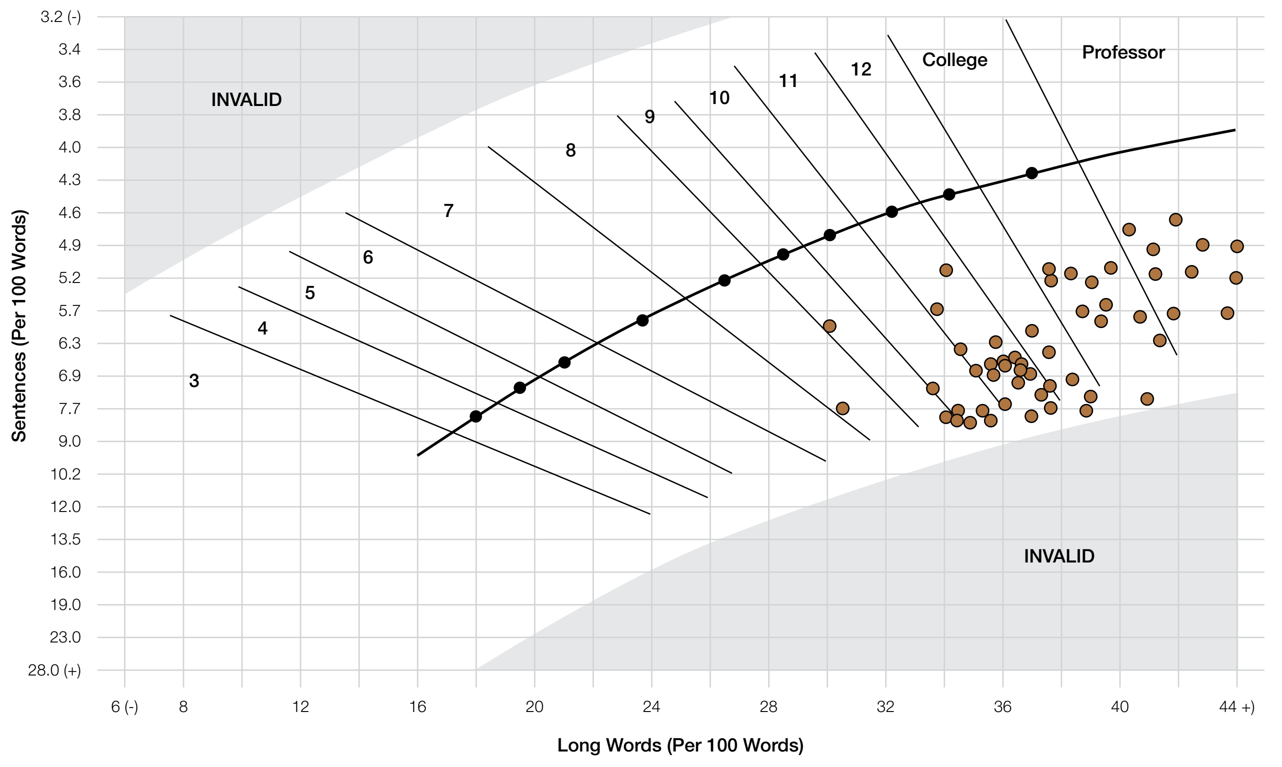

Figure 3. Scatter plot showing the results of the Raygor readability estimate for each website's patient education materials.

methods to improve patients' understanding of their condition and to lower the readability scores of online PEMs. Better communication between patient and physician may improve patients' comprehension of their condition and different aspects of their care.[59,62-66] Doak and colleagues[63] recommend giving cancer patients the most important information first; presenting information to patients in smaller doses; intermittently asking patients questions; and incorporating graphs, tables, and drawings into communication with patients.[63] Additionally, allowing patients to repeat information they have just received/heard to the physician is another useful tool to improve patient education.[62,64-66]

Another way to address the disparity between patients' health literacy and the readability of online PEMs is to reduce the reading grade level of existing PEMs. According to results from this study and others, the majority of online PEMs are above the reading grade level of a significant number of US adults. Many available and inexpensive readability instruments allow authors to assess their articles' readability. Many writing guidelines also exist to help authors improve the readability of their PEMs.[20,64,67-71] Living Word Vocabulary[70] and Plain Language[71] help authors replace complex words or medical terms with simpler words.[29] Visual aids, audio, and video help patients with low health literacy remember the information.[64]

Efforts to improve PEM readability are effective. Of all the websites reviewed, VUMC was identified as having PEMs with the lowest readability score (5.3). This score was reported by the New Fog Count readability instrument, which accounts for the number of sentences, easy words, and hard words. In 2011, VUMC formed the Department of Patient Education to review and update its online and printed PEMs to make sure patients could read them.[72] Additionally, the mean readability scores of the websites of the National Cancer Institute and MedlinePlus are in the top 50% of the websites included in this study. The NIH sponsors both sites, which follow the NIH guidelines for writing online PEMs at a reading level suitable for individuals with lower health literacy.[20] These materials serve as potential models to improve the readability of PEMs, and, thus, help patients to better understand their condition, medical procedures, and/or treatment options.

To illustrate ways to improve the reading grade level of PEMs, we used the article "Ewing's Sarcoma" from the AAOS website[73] and followed the NIH guidelines to improve the reading grade level of the article.[20] We identified complex words and defined them at an eighth-grade reading level. If that word was mentioned later in the article, simpler terminology was used instead of the initial complex word. For example, *Ewing's sarcoma* was defined early and then referred to as *bone tumor* later in the article. We also identified every word that was 3 syllables or longer and used Microsoft Word's thesaurus to replace those words with ones that were less than 3 syllables. Lastly, all sentences longer than 15 words were rewritten to be less than 15 words. After making these 3 changes to the article, the mean reading grade level dropped from 11.2 to 7.3.

This study has limitations. First, some readability instruments evaluate the number of syllables per word or polysyllabic words as part of their formula and, thus, can underestimate or overestimate the reading grade level of a document. Some readability formulas consider medical terms such as *ulna*, *femur*, or *carpal* as "easy" words because they have 2 syllables, but many laypersons may not comprehend these words. On the other hand, some readability formulas consider medical terms such as *medications*, *diagnosis*, or *radiation* as "hard" words because they contain 3 or more syllables, but the majority of laypersons likely comprehend these words. Second, the reading level of the patient population accessing those online sites was not assessed. Third, the readability instruments in this study did not evaluate the accuracy of the content, pictures, or tables of the PEMs. However, using 10 readability instruments allowed evaluation of many different readability aspects of the text. Fourth, because some websites identified in this study, such as Bonetumor.org, were written for patients as well as clinicians, the reading grade level of these sites may be higher than that of those sites written just for patients.

Conclusion

Because many orthopedic cancer patients rely on the Internet as a source of information, the need for online PEMs to match the reading skills of the patient population who accesses them is vital. However, this study shows that many organizations, academic training centers, and other entities need to update their online PEMs because all PEMs in this study had a mean readability grade level higher than the NIH recommendation. Further research needs to evaluate the effectiveness of other media, such as video, illustrations, and audio, to provide health information to patients. With many guidelines available that provide plans and advice to improve the readability of PEMs, research also must assess the most effective plans and advice in order to allow authors to focus their attention on 1 set of guidelines to improve the readability of their PEMs.

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Appendix 1. **Types of Articles Evaluated**

Condition/Treatment/Topic	No. of PEMs
Acral myxoinflammatory fibroblastic sarcoma (foot and ankle)	1
Adamantinoma/ameloblastoma	3
Aggressive digital papillary adenoma/adenocarcinoma (foot and ankle)	1
Alveolar soft-part sarcoma	1
Aneurysmal bone cyst	4
Angiosarcoma	5
Avulsive cortical irregularity/"tug lesion"	1
Benign fibrous histiocytoma	1
Bone cancer/tumor (general)	40
Bone island	1
Brown tumor	1
Calcific periarthritis	1
Chondroblastoma	18
Chondromyxoid fibroma	6
Chondrosarcoma (includes subtypes)	31
Chordoma	11
Clear-cell sarcoma	1
Collagenous fibroma (desmoplastic fibroblastoma)	1
Desmoid tumor	10
Desmoplastic fibroma	1
Enchondroma	18
Eosinophilic granuloma	1
Epithelioid hemangioendothelioma	1
Epithelioid sarcoma	4
Erdheim-Chester disease	1
Ewing sarcoma	57
Fibrosarcoma	6
Fibrous dysplasia	26
Florid reactive periostitis	1
Ganglion cyst (foot and ankle)	1
Gastrointestinal stromal tumor	11
Giant cell reparative granuloma	1
Giant cell tumor of bone	19
Giant cell tumor of tendon sheath	1
Giant dell tumor of tendon sheath (foot and ankle)	1
Glomus tumor (tympanum or jugulare)	14
Granulocytic sarcoma in bone	1
Granuloma annulare (foot and ankle)	1
Hemangioma	24
Hemangiopericytoma	1
Hibernoma	1
Histiocytosis	6
Intraosseous venous drainage anomaly	1
Jaffe-Campanacci syndrome	1
Juxtacortical chondroma	1
Leiomyosarcoma	20
Lipoma	11
Liposarcoma	5
Liposclerosing myxofibrous tumor of bone	1
Lymphoma of bone	5
Maffucci syndrome	3
Malignant fibrous histiocytoma	13
Malignant melanoma (metastasis to bone)	2
Malignant mixed tumor; myoepithelial tumors of soft tissue (foot and ankle)	1
McCune-Albright syndrome	10
Melorheostosis	4
Metastatic bone disease	9
Metastatic breast cancer	1
Metastatic kidney cancer	1
Metastatic lung cancer	1
Metastatic prostate cancer	1
Multiple myeloma	63
Myositis ossificans	4
Neurofibroma	1
Nonossifying fibroma	4
Ollier disease	4
Osteoblastoma	3
Osteochondroma	23
Osteochondromatosis	1
Osteofibrous dysplasia	1
Osteoid osteoma	6
Osteoma	7
Osteomyelitis	23
Osteopoikilosis	1
Osteosarcoma (includes subtypes)	61
Paget disease	32
Periosteal chondroma	2
Pigmented villonodular synovitis	5
Plantar fibroma (foot and ankle)	1
Post-Paget sarcoma	1
Rhabdomyosarcoma	21
Runner's bump (foot and ankle)	1
Sarcoma (general)	13
Schwannoma of bone	2
Soft-tissue sarcomas (general)	32
Solitary fibrous tumor of bone	1
Solitary myeloma	1
Spine tumor	2
Subchondral cyst	2
Synovial chondromatosis	7
Synovial sarcoma	5
Treatment (general)	9
Tumor mimics (general)	1
Tumoral calcinosis	1
Unicameral bone cyst	6
Total	**774**

Abbreviation: PEM, patient education materials.

Appendix 2. **Readability Scores of Websites' Patient Education Materials**

Website	Minimum	Maximum	Range	Mode	Mean
AAOS	8.2	13	4.8	11	11.4
Bonetumor.org	8.2	17	8.8	14	13.2
Medscape	12	17.1	5.1	17	15.4
Sarcoma Alliance	9.5	16	6.5	11; 13	12.7
Sarcoma Foundation of America	9.8	15	5.2	13	12.5
Academic Training Center					
Banner Good Samaritan Medical Center	7.7	12.1	4.4	10; 11	10.3
Cedars-Sinai	7.9	12	4.1	11	10.6
Cleveland Clinic	7.1	12	4.9	11	10.6
Cooper University Health Care	7.2	13	5.8	11; 12	11.3
Dartmouth College	7.4	11.4	4	10	10.1
Detroit Medical Center	7.1	12.7	5.6	11; 12	11.1
Emory University	8	13	5	11	11.3
Fletcher Allen Health Care	7.4	11.4	4	10	10.1
Georgetown University	6.7	11.5	4.8	11	10.1
Lenox Hill Hospital	6.7	11.5	4.8	11	10.1
The Methodist Hospital System in Houston	6.3	10.9	4.6	10	9.6
New York Presbyterian Hospital	7.6	12.9	5.3	11; 12	11.3
New York University–Hospital for Joint Diseases	6	11	5	10	9.5
Oregon Health and Science University	7.2	12.4	5.2	11; 12	11
St. Louis University	6.7	11.5	4.8	11	10.1
Stanford University	6.6	12.9	6.3	12	11.1
Texas A&M College–Scott and White	6.7	11.5	4.8	11	10.1
Tufts University	5.9	11.1	5.2	11	9.6
Tulane University	5.7	11	5.3	10	9.4
University of Alabama at Birmingham	7.1	12.7	5.6	11; 12	11.1
University of Arizona	8.1	12.4	4.3	11	10.6
University of Arkansas	7.1	12.7	5.6	11; 12	11.1
University of California, Los Angeles	8.7	17	8.3	11; 13	13.1
University of Chicago	8.8	16	7.2	11; 13	12.6
University of Connecticut	9.9	15	5.1	13	13
University of Florida	6.7	11.5	4.8	11	10.1
University of Iowa	6.7	11.5	4.8	11	10.1
University of Kentucky	7.1	12.7	5.6	11; 12	11.1
University of Michigan	7.3	11.4	4.1	10	10.1
University of Missouri–Columbia	7.1	12.7	5.6	11; 12	11.1
University of New Mexico	10.6	17	6.4	14; 17	14.3
University of South Carolina	7.1	12.7	5.6	11; 12	11.1
University of Tennessee	6.7	11.5	4.8	11	10.1
University of Utah	6.8	13	6.2	11	11.2
Vanderbilt University	5.3	11.4	6.1	10	9.5
Washington University–St. Louis	7.2	12	4.8	11	10.6
Google Search					
American Cancer Society	7.9	10.8	2.9	9; 10	9.5
Cancer.Net	8.7	12.5	3.8	12	11.5
KidsHealth	10.8	13.6	2.8	11; 13	12
Liddy Shriver Sarcoma Initiative	11.9	17	5.1	17	15.5
Mayo Clinic	7	11.9	4.9	11	10.3
MedicineNet	7.4	11.9	4.5	11	10.4
MedlinePlus	6.4	11	4.6	10	9.7
National Cancer Institute	7	11.8	4.8	11	10.4
WebMD	7.8	11.9	4.1	11	10.5
Wikipedia	11.7	17	5.3	11; 17	14.8

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Website	Minimum	Maximum	Range	Mode	Mean
Sarcoma Specialists					
Children's Hospital Los Angeles	7.6	12.9	5.3	12	11.4
City of Hope	12.2	17	4.8	12; 15; 17	14.8
Dana-Farber Cancer Institute	7.2	11.8	4.6	11	10.4
Johns Hopkins University	10.3	16	5.7	11; 14	12.9
Massachusetts General Hospital	7.1	12.7	5.6	11; 12	11.1
MD Anderson Cancer Center	7.8	12.4	4.6	11	10.6
Medical College of Wisconsin–Froedtert	10.7	17	6.3	15; 17	14.5
Memorial Sloan Kettering Cancer Center	11.8	17	5.2	15; 17	14.7
Mid-America Sarcoma Institute	6.2	10.9	4.7	10	8.9
Moffitt Cancer Center	12.4	17	4.6	12; 16; 17	15.3
Mount Sinai Hospital	5.7	11	5.3	10	9.4
Ohio State University	6.9	11.5	4.6	11	10.3
St. Jude's Children Research Hospital	10.7	17	6.3	15; 17	14.5
Sarcoma Oncology Center, Santa Monica	11.7	17	5.3	11; 15	14
Summa Health System	6.7	12	5.3	11	10.3
University of California, Davis	9.7	13.6	3.9	13	12.2
University of California, San Francisco	10.9	15	4.1	11; 14	12.9
University of Minnesota Cancer Center	7.1	11.7	4.6	11	10.3
University of Pennsylvania–Joan Karnell Cancer Center	6	10.9	4.9	9	9.3
University of Pittsburgh–Hillman Cancer Center	6.8	11.6	4.8	11	10.3
Washington Musculoskeletal Tumor Center	10.5	17	6.5	15	13.9
All Patient Education Materials	**5.3**	**17.1**	**11.8**		**11.4**

Abbreviation: AAOS, American Academy of Orthopaedic Surgeons.