

Basic Original Report

Online palliative care and oncology patient education resources through Google: Do they meet national health literacy recommendations?

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Abstract

Purpose: The Google search engine is a resource commonly used by patients to access health-related patient education information. The American Medical Association and National Institutes of Health recommend that patient education resources be written at a level between the third and seventh grade reading levels. We assessed the readability levels of online palliative care patient education resources using 10 readability algorithms widely accepted in the medical literature.

Methods and materials: In October 2016, searches were conducted for 10 individual terms pertaining to palliative care and oncology using the Google search engine; the first 10 articles written for the public for each term were downloaded for a total of 100 articles. The terms included palliative care, hospice, advance directive, cancer pain management, treatment of metastatic disease, treatment of brain metastasis, treatment of bone metastasis, palliative radiation therapy, palliative chemotherapy, and end-of-life care. We determined the average reading level of the articles by readability scale and Web site domain.

Results: Nine readability assessments with scores equivalent to academic grade level found that the 100 palliative care education articles were collectively written at a 12.1 reading level (standard deviation, 2.1; range, 7.6–17.3). Zero articles were written below a seventh grade level. Forty-nine (49%) articles were written above a high school graduate reading level. The Flesch Reading Ease scale classified the articles as “difficult” to read with a score of 45.6 of 100. The articles were

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collected from 62 Web site domains. Seven domains were accessed 3 or more times; among these, www.mskcc.org had the highest average reading level at a 14.5 grade level (standard deviation, 1.4; range, 13.4–16.1).

Conclusions: Most palliative care education articles readily available on Google are written above national health literacy recommendations. There is need to revise these resources to allow patients and their families to derive the most benefit from these materials.

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Introduction

The Google search engine is among the most commonly used resources for patients to access health-related education information,¹ with previous research showing that more than 80% of Internet users use the Internet for health care information related to diseases, medical procedures, and medical treatments.^{1–5} This behavior has been attributed partly to the development of online articles intended for patients and an increased number of patients taking an active role in their health.^{6,7}

Online articles for patients can only be beneficial if patients can adequately comprehend them. Understanding is measured through a health literacy metric called readability, which quantifies the ease with which text can be read and understood.⁸ The average American adult reads at an eighth grade level, and national guidelines from the National Institutes of Health and American Medical Association recommend writing these articles at a level between the third and seventh grade levels.^{9,10}

Readable patient education materials are especially important in patients interested in palliative care services because they often have concerns about managing symptoms and understanding the roles of different medical providers involved in their care.¹¹ Informed decision-making is an important component of palliative care, as it is in all fields of medicine. Low health literacy affects more than 90 million American adults and 89% of adults older than age 80,¹² which may prevent informed decision-making and lead to poor health-related outcomes in stressful times.¹³ With the complexity of end-of-life issues, online patient education sources should have a strong interest in providing materials that are readable and understandable for these patients.¹⁴

Previous research has shown discrepancies between the readability levels of patient education materials in radiation oncology and the literacy skills of the average American citizen.^{15,16} One study sampled patient education materials from 5 national palliative care organizations and using 1 readability scale found that the materials were written at a higher level than the general public could understand.¹⁷ A survey study in the United Kingdom and Ireland also found that the majority of palliative care education leaflets were understood by less than half of the British population.¹⁸

This study examined online palliative care patient education resources searched through the Google search engine and aimed to assess their readability levels through

10 readability algorithms widely accepted in the medical literature. To the best of our knowledge, this is the first comprehensive study of publicly accessible online palliative care information using multiple readability assessment techniques to minimize the bias of any individual test.

Methods and materials

All data for this study were available online to the public, and institutional review board approval was not required. In October 2016, 10 terms pertaining to palliative care and oncology were individually searched using the Google search engine, and the first 10 articles written for the public for each term were selected (ie, academic journal articles were omitted). The terms included palliative care, hospice, advance directive, cancer pain management, treatment of metastatic disease, treatment of brain metastasis, treatment of bone metastasis, palliative radiation therapy, palliative chemotherapy, and end-of-life care. These articles were reformatted to plain text using Microsoft Word (Microsoft Corp, Redmond, WA), and text unrelated to patient education, including copyright notices, advertisements, author information, images, figures, acknowledgments, and hyperlinks, were removed.

A readability analysis was performed using the software package Readability Studio Professional Edition, version 2012.1 (Oleander Software, Ltd, Vandalia, OH). Nine readability scales that quantify reading level by individual grade levels (ie, a score of 8.0 corresponds to an eighth grade reading level) were used: Gunning Fog Index,¹⁹ FORCAST Formula,²⁰ Flesch-Kincaid Grade Level,²¹ Simple Measure of Gobbledygook,²² Coleman-Liau Index,²³ New Dale-Chall,²⁴ New Fog Count,²¹ Fry Readability,²⁵ and Raygor Readability Estimate.²⁶ The Flesch Reading Ease assessment, which reports scores on a 0 to 100 scale, was also used; higher numbers here correspond to text that is easier to read.²⁷ Table 1 provides detailed formulas for each of the 10 readability assessments.

We determined the mean reading level of each article by taking the average of 9 readability scale scores that correspond to grade level (Fig 1). Article characteristics regarding long words (6+ characters), complex words (3+ syllables), and unfamiliar words (words are defined as unfamiliar if not included on a predetermined list of 3000 words understood by an average fourth grader) were obtained through the New Dale-Chall readability scale.

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