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Readability, complexity, and suitability analysis of online lymphedema resources

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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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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. Secondarily, 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