Health Literacy in the Information Age: Communicating Cancer Information to Patients and Families

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INTRODUCTION

In this issue of CA: A Cancer Journal for Clinicians, authors Terry C. Davis et al. address the crucial topic of health literacy with regard to cancer communication. They describe the barriers that can keep people from understanding the information they receive—barriers referred to collectively as a lack of health literacy. The US Department of Health and Human Services defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”

Nearly half of the adult population in the United States has low or limited literacy skills. The authors indicate that people with low literacy skills come from a variety of backgrounds: they may be native-born or immigrants and they come from all races and classes. They tend to have more health problems, live in poverty, have fewer years of education, and are older.

Low literacy adversely impacts cancer incidence, mortality, and quality of life:

- Cancer screening information may be ineffective; as a result, patients may be diagnosed at a later stage.
- Treatment options may not be fully understood; therefore some patients may not receive treatments that best meet their individual needs.
- Informed consent documents may be too complex for many patients and consequently, patients may make suboptimal decisions about accepting or rejecting interventions.

The authors explore these and other implications of low health literacy and offer recommendations for improving written and oral communication. They observe that it is easier to change the communication skills of the health care provider than those of the patient. In other words, it is incumbent upon the information provider to make the information as understandable as possible.

DETERMINING READING GRADE LEVEL

Davis et al. refer to the reading grade level (RGL) of written materials as just one of the components that contribute to a document’s overall comprehensibility. There are numerous formulas used to determine a document’s RGL—both computer-based and hand-calculated. The first formulas appeared in the 1920s and have proliferated in the decades since. Some of the most
commonly used formulas include the FOG Index, the SMOG, the Flesch–Kincaid, and the Fry Formula.†

Nearly all of the formulas base their results on two factors: sentence length and word difficulty. The latter correlates to word length. Words of more than two syllables are assumed to be more difficult. The results are usually expressed as a reading grade level, sometimes as a decimal or fraction, e.g., “8th RGL” or “12.5 RGL.” It must be noted, however, that there is not a one-to-one correspondence between the highest grade level completed and the literacy skills of an individual. While most adults in this country have completed high school, the average reading grade level is eighth to ninth grade.³ Like many other skills, reading skills atrophy if not used regularly, so people who read very little after they finish school will have correspondingly lower reading levels.⁴

Computer-based formulas may appear to provide a quick and easy way to assess a document’s reading grade level. Microsoft Word, for example, provides the option of displaying the results of several formulas that determine RGL by selecting the spelling and grammar check function in the drop-down display menu under Tools. When the readability option is enabled, one first clicks through the spelling and grammar check to reach a display of statistics: word count, number of passive sentences, and the document’s readability results expressed as the Flesch Reading Ease Score and the Flesch–Kincaid Grade Level.

But computer-based assessments have some significant drawbacks. Because the software programs recognize every occurrence of a period as a sentence, abbreviations such as Dr., numerical expressions with decimals, and bulleted lists will be counted as very short sentences, thus artificially lowering the RGL. Therefore, documents should first be edited to remove these and other constructs that compromise the accuracy of the results.

Studies have shown that computer-based analyses of documents can yield significantly different reading grade level scores and that the Microsoft Word program provides consistently lower grade level scores.⁵ For example, an analysis of this editorial by Microsoft Word indicates a Flesch–Kincaid reading grade level of 11.8, while hand calculation using SMOG yields a score of 14.1. Calculating the RGL by hand can be done almost as quickly as formatting a document for computer assessment, and in our opinion, the results are more reliable. Instructions for using the SMOG Readability Formula are provided below.

The SMOG Readability Formula⁶

Using material consisting of at least 30 sentences:
1. Select ten sentences at random from the beginning, middle, and end of the text for a total of 30 sentences. Exclude titles, lists, or sentence fragments.
2. Find the total number of words with three or more syllables in these 30 sentences.
3. Find the square root of that total number and then add a constant of 3. This is the RGL.

For text consisting of fewer than 30 sentences:
1. Count the number of polysyllabic words.
2. Calculate the average number of poly-syllabic words per sentence.
3. Multiply that average number by the number of sentences.

†The origin of the acronyms FOG and SMOG is uncertain, however, they are most commonly referred to in the field by these acronyms. FOG and SMOG have been said to stand for “Frequency of Gobbledygook” and “Simple Measure of Gobbledygook” respectively.
4. Add that figure to the first total.
5. Find the square root of that number and add the constant of 3.

EXAMPLES OF TEXT AT VARIOUS LEVELS OF DIFFICULTY

The examples below provide a comparison of health information written at various levels of difficulty. As noted above, RGL cannot be accurately calculated using only one sentence; thus, the RGL listed in the following examples is estimated:

With the onset of nausea, diarrhea, or other gastrointestinal disturbances, consult your physician immediately. (Approximately 13th RGL or college reading level and above.)

If you experience nausea, diarrhea, or other stomach or bowel problems, call your physician immediately. (Approximately 12th RGL.)

If you start having nausea, loose bowel movements, or other stomach or bowel problems, call your doctor immediately. (Approximately 8th RGL.)

If you start having an upset stomach, loose bowel movements, or other problems, call your doctor right away. (Approximately 4th RGL.)

It is important to keep in mind that the RGL is, at best, a rough measure of a document’s readability. The mathematical process for calculating RGL may give the impression of a greater degree of certainty than is warranted. Developing an ear for plain language is as important as testing printed materials for reading grade level. Of equal importance in assessing the readability of printed materials are factors such as the tone of the writing and design elements such as font size and style, use of white space, and use of appropriate graphics. Doak and Doak provide an excellent guide for assessing written health materials in Teaching Patients With Low Literacy Skills.4 There are also very good online resources to assist those preparing written health information. The following resources provide useful information:

- www.eastendliteracy.on.ca/clearlanguageanddesign
- www.keenangroupinc.com
- www.med.utah.edu/pated/authors/substitute2.html

WE ALL PREFER UNDERSTANDABLE INFORMATION

Even those individuals with better literacy skills face difficulties when confronted with unfamiliar medical terms at a time when they are under physical and emotional stress. At such times, comprehension of both written and oral information often diminishes. All people prefer information that is as easy to understand as possible.

Another approach to providing diverse audiences with complex medical information is to use a variety of formats. When it comes to health information, there is no “one size fits all.” Some people who are high-level information seekers want and can understand comprehensive information. Others find a high level of complexity overwhelming and want simpler, more condensed information. In our experience, however, people prefer information that is written in plain language. Plain language is not “dumbed down writing.” It is clear, conversational language designed to communicate effectively with a wide audience.

The issue of health literacy and effective cancer communication is not a new one. Research articles in the past have highlighted the gap between the average reading grade level of adults and the RGL of printed health materials distributed by the American Cancer Society (ACS) and others.7 What is new, however, is that there is an increased emphasis on the development of easier-to-read
materials. The National Cancer Institute and the Centers for Disease Control and Prevention, as well as other organizations, are setting examples for others to follow in the development of printed materials at lower reading grade levels.

We, at the American Cancer Society, are working with our writers and editors to promote an understanding of health literacy issues and to encourage the use of plain language in written materials whenever possible. Information about all of the major cancer sites distributed by the ACS National Cancer Information Center (800-ACS-2345) is available in two formats: a comprehensive version for people with very good literacy skills, and an overview version with condensed information written in plain language at an eighth reading grade level. Both versions can be accessed on the ACS Web site, www.cancer.org.

Also projected for future development are additional print pieces targeted for readers with minimal reading skills—fourth or fifth RGL. But Davis et al. caution that for some people, materials at any reading level are not an effective means of communicating health information. Thus, videotapes and peer-counseling programs often prove a better solution, especially when products and programs and the language used to promote them are developed in cooperation with the communities they are intended to reach. The ACS Tell-A-Friend program for promoting mammography, especially among medically underserved women, and the Reach to Recovery peer program in which breast cancer survivors provide information and support to newly diagnosed women are examples of successful peer-counseling programs.

Disparities in health literacy are an important factor contributing to inequalities in cancer incidence, mortality, and quality of life among medically underserved populations. It will be necessary to appreciate the synergy of appropriate information products and community-based cancer control interventions in reducing and, ultimately, eliminating such disparities. Clear communication must continue to be a high priority for health care providers as well as public health and patient advocacy organizations if we are to succeed in reducing the cancer burden among diverse and underserved populations. Good communication is not an option or a luxury; it is an integral component of health care that has a profound impact on individual health and public health outcomes.

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