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Health literacy and ophthalmic patient education

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Abstract

In 1997, Ebrahimzadeh, Davalos and Lee wrote in this journal that only 32% of the ophthalmic patient educational materials reviewed were written at or below the recommended eighth grade reading level. Since that time, the National Assessment of Adult Literacy found that more than one third of adult Americans possess only basic or below basic health literacy skills, defined as the ability to understand written information in a healthcare setting. Subsequently, investigators have shown that poor health literacy skills are associated with poor prescription medication adherence, increased hospital admissions and increased mortality. We review the readability of currently available ophthalmic educational materials, with particular attention to the health literacy status of the patient population for which the materials are intended. Examples of prose at various readability levels are provided. Optimizing patient education and improving clinical outcomes requires understanding the attributes that the patient brings to the patient–physician relationship, including health literacy.

Keywords

literacy; ophthalmic patient educational materials; adherence

- From a patient information sheet: “Therefore, patients should be monitored for extraocular CMV infections and retinitis in the opposite eye, if only one infected eye is being treated.”[23]

The National Adult Literacy Survey of 1992 revealed that nearly one fourth of the American adult population is functionally illiterate.¹ Of particular interest to healthcare providers is the newer concept of “health literacy.” The American Medical Association’s Council on Scientific Affairs defines health literacy as “the ability to apply reading and numeracy skills in a healthcare setting.”[1] In 2003, the National Assessment of Adult Literacy reported that more than 75 million adult Americans possess basic or below basic health literacy skills.[19] In practical terms, a person with inadequate health literacy skills cannot properly read and act on instructions on a prescription label nor understand a consent form.

Poor health literacy negatively impacts individual health outcomes and the healthcare system as a whole. Patients with inadequate health literacy are more likely to demonstrate a poor understanding of their disease and less likely to adhere to the prescribed treatment

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regimen than their more literate peers.[31,32] Perhaps as a consequence, poor health literacy is associated with more frequent hospital admissions[2] and increased mortality.[3] On the societal level, poor health literacy is associated with increased medical costs and inefficient use of healthcare services.[14]

In recent years, attention to the problem of poor health literacy has included investigation into the relationship between health literacy status and ophthalmologic disease. In a study of more than 400 subjects with type 2 diabetes, possessing poor health literacy skills was independently associated with prevalence of diabetic retinopathy.[29] In patients with glaucoma, poor health literacy is associated with poor medication adherence,[21] worsening of the visual field,[15] poor disease understanding,[15] and increased self-reported dependency.[22] In a sample of 200 subjects with glaucoma, we found that, although three-quarters of subjects reported having graduated from high school, less than half could read at a ninth-grade level or above. Perhaps more concerning, over 10 percent of subjects possessed health literacy skills at the third grade level or below.[21]

Written materials, including discharge instructions,[26] consents,[4] and patient educational materials,[7] are often written at readability levels above the skills of many patients. In 1997, Ebrahimzadeh, Davalos and Lee reported on the average readability levels of ophthalmic patient educational materials from the American Academy of Ophthalmology (AAO) and found that only 32% were written at or below the eighth-grade reading level.[9]

Lower socioeconomic status correlates with higher risk of morbidity from chronic disease.[24] Although lower socioeconomic status, lower educational attainment, and poor health literacy are not synonymous, the concepts overlap in populations vulnerable to poor health outcomes. Health literacy encompasses a variety of experiences and personal resources related to healthcare and may change over time as the personal and societal context changes. As such, health literacy is more closely related to health outcomes, including mortality, than is educational attainment.[3] If our educational efforts neglect those patients with lower health literacy skills, we may fail to provide adequate resources to those most at risk for poor visual outcomes.

Examination of readability of currently available ophthalmic patient educational materials

We examined the readability of ophthalmic patient educational materials currently available from the AAO with particular attention to changes from materials available in 1997 and with attention to the reported health literacy levels of older adults. Multiple methods of assessing readability are available to educators and investigators, and we employed the commonly used Flesch-Kincaid Grade Level formula. This formula uses the quantity of words, sentences, and syllables in a selection of text to generate a number representative of the grade level a person would need to have obtained to understand the selection. For example, if the Flesch-Kincaid Grade Level for a selection of text is 9.4, it should be comprehensible to the average student in the ninth grade in the United States school system. A selection of text with a Flesch-Kincaid Grade level score of 5.5 would be more easily understandable, such that a fifth grader would be able to interpret the text.[18] The Flesch-Kincaid Grade Level score is commonly employed by educators and is incorporated into software packages such as Microsoft Word.

Thirty-eight patient educational brochures published by the AAO in 2008 were reviewed for readability. The Flesch-Kincaid Grade Level scores ranged from 5.1 to 11.4, median 8.0, mean 8.3. As a comparison, we reviewed a variety of glaucoma educational brochures from governmental agencies (including the National Institutes of Health and the National Eye

Institute) and non-profit organizations (including the Glaucoma Research Foundation, Prevent Blindness America and the American Glaucoma Society). Of the 11 glaucoma patient educational brochures from these organizations, the Flesch-Kincaid Grade Level ranged from 8.4 to 12.0 (mean 9.7, median 9.1).

The readability of 15 patient educational brochures available from AAO in 1997 were compared to the 2008 versions.. The mean Flesch-Kincaid Grade Level in 1997 was 9.6 and median 9.1. In 2008, the mean Flesch-Kincaid Grade Level of the same 15 patient educational brochures was 8.0, median 7.8 (Table). Examples of prose written at a Flesch-Kincaid Grade Level of 9.2 and 6.0 are provided in Figure 1, parts A and B, respectively.

Implications

Illiteracy is not a new problem in American society, but the scope and magnitude of the problem is increasing. Although the absolute majority of American adults with inadequate health literacy skills are native-born English speakers,[23] the prevalence and proportion of poor health literacy is particularly high for adults who speak English as a second language. [33] Over the next 20 to 25 years, the number of Americans over the age of 65 years is projected to grow by 13% to 20%.[12] The aging of the American population and changing ethnic demographics is expected to lead to a substantial increase in the proportion of Americans with poor health literacy skills.[25] Additionally, aging and changing demographics are expected to contribute to greater burden of chronic disease, including a 50% increase in the prevalence of glaucoma over the next 15 years.[11]

Baker et al showed that even when socioeconomic status and baseline health status are accounted for, poor health literacy is associated with increased mortality.[3] If indeed the relationship is causal, the mechanism by which poor health literacy leads to unfavorable health outcomes is not well understood. Poor literacy is associated with nonadherence to preoperative instructions and[5] HIV antiretroviral treatment[20] and lack of self-management skills in patients with diabetes.[17] Inadequate health literacy is also associated with poor disease understanding,[20,31,32] so perhaps patients less able to understand written and verbal information in the healthcare setting do not use medications properly because they do not realize the risks of the untreated disease. But even patients who understand their disease and the need for treatment may not appropriately self-manage if their poor literacy skills prevent them from following dosing instructions properly. In a group of glaucoma patients, we found an association between poor health literacy and medication nonadherence.[21] Although the linkage between literacy and self-management is multifaceted, we can address one variable by improving the readability of the educational resources we provide to patients.

Research in diabetes suggests that literacy-level appropriate education may improve disease self-management in those subjects with poor literacy skills. Poorly-controlled diabetics with worse health literacy skills who were randomized to a low-literacy appropriate educational intervention demonstrated improved hemoglobin A1C levels 12 months after the intervention compared to their peers randomized to standard care.[28] In addition to improving self-management, literacy-appropriate interventions may improve medication adherence for patients dependent on caregivers for dosing, as approximately 20 percent of glaucoma patients are.[16] In a study of low-income parents, subjects randomized to a low-literacy educational intervention using pictograms demonstrated fewer dosing errors with liquid medications prescribed for their children compared to subjects who received standard instructions.[34]

The development of patient educational materials is a complex and benefits from the expertise of professional educators and behavioral psychologists, but there are simple

guidelines for improving the readability of written materials that are useful to the practicing clinician. Minimizing dense text and increasing the amount of “white space” on the page results in a presentation that may be less intimidating to patients with limited literacy skills. [8] Many software packages, including Microsoft Word, include readability formulas such as the Flesch-Kincaid. The Flesch-Kincaid formulas are limited in that they are determined by word number and length rather than vocabulary and syntax, but as a readily available tool, represents an excellent starting place for assessing the readability of a document. One might worry that more highly literate patients will be offended by text written at a lower literacy level; however, in a randomized controlled trial, both highly literate and less literate subjects preferred a low literacy consent document to a document written at a higher level. [6]

Multimedia educational programs hold great promise for reducing the burden of low health literacy, but to date have resulted in only limited success.[10,13,27] Perhaps this is because patients with limited health literacy skills struggle with verbal as well and written information. In one-on-one verbal communications, “teach-back” can facilitate understanding of health information. In “teach-back” technique, the educator communicates the health information and then asks the patient to verbalize his or her understanding of the information in his or her own words.[8] Simplified pictures and diagrams with little text can assist in health communications. Telephone calls can supplement written appointment reminders. Figure 2 outlines suggestions for improving provider-patient communication in the low literacy setting.

The American Academy of Ophthalmology continues to be a leader in providing patient-centered educational materials to eye care providers. In 1997, less than one third of patient educational materials available from AAO were written at an eighth grade level or below. Currently, about half of the patient educational brochures from AAO are written at a Flesch-Kincaid Grade Level less than nine. For the glaucoma patient educational materials we reviewed, the brochures published by governmental and non-profit organizations are more appropriate for patients with greater literacy skills. Unfortunately, there is still a dearth of written ophthalmic educational materials available from any agency for the least literate patients, precisely those who are at the greatest risk of blindness. In the Baltimore Eye Survey, the prevalence of blindness amongst those with less than seven years of schooling was more than twice that of subjects who completed at least twelve years of formal education.[30] By providing patient education appropriate for patients with low health literacy skills, eye care providers have the opportunity to improve clinical outcomes and reduce healthcare disparities.

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Part A

Flesch-Kincaid Grade Level 13.9

"Glaucoma is an ocular disorder which embodies a group of conditions that have in common optic nerve damage, predominantly as a result of elevated intraocular pressure (IOP). When there is such pressure on the fragile optic nerve, which is attached to the eye's rear surface, defects in peripheral vision occur. Although the eye continues to produce fluid to keep itself inflated, the drains that allow fluid out are not working sufficiently." (National Association for Visually Handicapped)

Part B

Flesch-Kincaid Grade Level 6.0

"Open angle glaucoma is a problem with the eye.

No one knows exactly what causes open angle glaucoma. Sometimes it runs in families. Often people with glaucoma have high eye pressure.

Some people go blind from glaucoma. But catching it early helps keep people from going blind."

Figure 1.

Creating and evaluating educational materials

- Limit information to no more than four important points.
- Use active voice and conversational style.
- Increase “white space” on the page (limit dense text).
- Use visuals but ensure that figures are relevant to the message with little extraneous detail.
- Consider use of audio and/or video materials in addition to print.

Direct communication with patients

- Assess the patient’s current knowledge with open-ended questions.
- Link new information to existing knowledge.
- Provide opportunity for feedback.
- Demonstrate and ask patient to demonstrate eye drop instillation technique

Figure 2.

Suggestions for effective education for patients with poor literacy skills

Table

Comparison of Flesch-Kincaid Grade Level scores for patient educational brochures available from the American Academy of Ophthalmology in 1997 and 2008.

Educational topic	Flesch-Kincaid Grade Level	
	1997	2008
Cataract	9.0	9.8
Floater and flashes	7.5	4.9
Glaucoma	8.0	8.1
Macular degeneration	11.0	9.2
Detached retina	2.7	5.8
Diabetic retinopathy	14.3	10.1
Dry eye	7.4	7.8
Headache	9.2	7.8
Uveitis	7.0	7.7
Eyelid surgery	9.3	11.1
Laser surgery	13.5	6.7
Refractive surgery	9.5	9.5
Vitreectomy	8.1	7.7
Corneal transplant	8.4	6.5
Cataract surgery	7.5	7.7