



Clinical Study

Comparison of neurological healthcare oriented educational resources for patients on the internet



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ABSTRACT

The internet has become a major contributor to health literacy promotion. The average American reads at 7th–8th grade level and it is recommended to write patient education materials at or below 6th grade reading level. We tried to assess the level of literacy required to read and understand online patient education materials (OPEM) for neurological diseases from various internet resources. We then compared those to an assumed reference OPEM source, namely the patient education brochures from the American Academy of Neurology (AAN), the world's largest professional association of neurologists. Disease specific patient education brochures were downloaded from the AAN website. OPEM for these diseases were also accessed from other common online sources determined using a predefined criterion. All OPEM were converted to Microsoft Word (Microsoft Corp., Redmond, WA, USA) and their reading level was analyzed using Readability Studio Professional Edition version 2012.1 (Oleander Software, Vandalia, OH, USA). Descriptive analysis and analysis of variance were used to compare reading levels of OPEM from different resources. Medline Plus, Mayo clinic and Wikipedia qualified for OPEM analysis. All OPEM from these resources, including the AAN, were written above the recommended 6th grade reading level. They were also found to be “fairly difficult”, “difficult” or “confusing” on the Flesch Reading Ease scale. AAN OPEM on average needed lower reading level, with Wikipedia OPEM being significantly ($p < 0.01$) more difficult to read compared to the other three resources. OPEM on neurological diseases are being written at a level of reading complexity higher than the average American and the recommended reading levels. This may be undermining the utility of these resources.

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1. Introduction

The understanding of neurological conditions involves a level of complexity that can be hard for patients and their caregivers to understand. Hospitals, clinics and professional associations often provide patient education materials (PEM) to enable and enhance this understanding. The availability of PEM has surged with the advent and easy accessibility to the internet. Three quarters of American adults have access to the internet and 80% of them have looked online for information related to health topics [1]. This is a potentially very beneficial trend as several studies have documented a correlation between poor patient understanding and poorer health outcomes [2,3]. The usefulness of these readily available PEM may be limited by their readability. Readability refers to the comprehension level, determined by school grade education that people must have to understand the information they are

reading [4]. Reportedly, the average American reads at a level between the 7th and 8th grade [5]. Accordingly, the American Medical Association, National Institutes of Health, the United States Department of Health and Human Services and the Institute of Medicine recommend the readability of PEM be equal to or less than the 6th grade reading level [6,7,18].

Several online resources are available to the public, written with the specific purpose of informing and educating the public about neurological diseases. In order to determine the written complexity and thus the impact of these online patient education materials (OPEM), our study assessed the reading level required to understand OPEM from various internet resources. The American Academy of Neurology (AAN) is the largest professional organization of neurologists [8] and it provides patient education brochures, which are disease specific documents, available online for free. Our study compares OPEM of common neurological diseases from various resources to OPEM provided by the AAN. The AAN OPEM were included in our analysis as a reference OPEM source since they are “quality resource[s] developed by experts

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in the field” and “cover topics such as causes, symptoms, diagnosis, and treatment.” [9].

2. Methods

All patient education brochures available on the AAN website were downloaded in December 2012. An internet search using the search engine Google (Mountain View, CA, USA) was performed between 12–14 February 2013 for each disease with OPEM available on the AAN website. An internet source was chosen for readability assessment analysis only if it appeared on first search webpage for 12 or more of the 14 diseases with OPEM available on the AAN website. Text from these OPEM was copied into a Microsoft Word document (Microsoft Corp., Redmond, WA, USA), and analyzed using the software package Readability Studio Professional Edition version 2012.1 for Windows (Oleander Software, Vandalia, OH, USA). Text that included promotional materials, copyright notices, images, references, disclaimers, other non-educational materials, or disease sub-topics not included in AAN brochures was not included in the analysis.

Readability assessment scales that are commonly utilized to evaluate either educational or healthcare oriented materials were used. Readability scores were assessed using the following tests: Flesch Reading Ease (FRE) [10], Flesch–Kincaid Grade Level (FKGL), Simplified Measure of Gobbledygook Grading (SMOG) [11], Coleman–Liau Index [12], Gunning–Fog Index (GFI) [13], the New Fog Count Formula (NFC), the New Dale–Chall Readability Formula (NDC) [14], FORCAST formula [15], Raygor Readability Estimate (RRE) [16], and the Fry Graph [17] (Supp. Table 1). The average reading level from each article was calculated based upon the raw scores from each scale. All assessment scales, except FRE, calculate the grade level needed to comprehend a given document. FRE describes ease of reading and comprises a score from 0 to 100, with a higher score corresponding to greater ease of reading (Supp. Table 2).

Statistical analysis was carried out using the Statistical Package for the Social Sciences version 19.0 (SPSS Inc., Chicago, IL, USA). Analysis of variance (ANOVA) and Bonferroni correction were used to analyze the difference between reading levels needed to understand PEM from different online sources.

3. Results

There were 14 disease related PEM (Table 1) available on the AAN website. Three other internet resources, MedlinePlus (<http://www.nlm.nih.gov/medlineplus/>), Mayo clinic (<http://www.mayoclinic.com/health-information/>), and Wikipedia (<http://www.wikipedia.org>) fulfilled inclusion criteria for readability analysis and comparison with AAN OPEM. They respectively had OPEM on 12 (except sleep disorders and tremors), 12 (except sleep disorders, and migraine) and 14 diseases that were used for analysis.

Readability analysis of AAN OPEM showed that all except one (OPEM on peripheral neuropathy on NFC scale) was above the recommended level of 6th grade on all scales. The analysis produced error messages for six OPEM on Fry and seven on RRE scale (Table 1), citing that the text is “too difficult to be classified at a specific grade level because contain too many high syllabi words”. Brain tumor, myasthenia gravis, Parkinson’s disease, peripheral neuropathy, amyotrophic lateral sclerosis and tremors OPEM were “too difficult to be classified” on both scales and Alzheimer’s disease only on the RRE scale. OPEM scored between 41 to 58 on FRE scale (Fig. 1), making them “difficult” to “fairly difficult” to understand with an average of 50.1 (“fairly difficult”). The average reading level for each OPEM was calculated after exclusion of FRE (Table 1). Every OPEM was found to need a reading level above the average American and the recommended reading levels (Fig. 2).

Readability analysis performed for MedlinePlus, Mayo clinic and Wikipedia showed that none of the OPEM were below the recommended level of 6th grade, except for a PEM by MedlinePlus, which scored a reading level of 4.5 on NFC scale (Supp. Table 3–5). Four OPEM (epilepsy, multiple sclerosis, Parkinson’s disease, and peripheral neuropathy) from the Mayo clinic produced error message on both Fry and RRE scale. On the FRE scale, OPEM from the Mayo clinic and MedlinePlus scored 46.1 and 48.8 respectively, putting them in the “difficult” category of readability. Raw readability scores of OPEM from Wikipedia showed that most of them exceeded or reached maximum calculable reading levels on the NDC, FKGL, Fry, GFI, NFC, RRE, and SMOG scales. On the FRE scale, with the exception of tremors, all OPEM scored below 30, meaning they were “very confusing”. Figure 3 compares the four OPEM resources by averaging the reading levels needed to understand them on each scale. It shows that Wikipedia OPEM needed much higher reading levels to understand the material on each scale. Average reading levels needed to read the materials from the AAN was lower on each scale than the other three sources (Table 1, Supp. Table 3–5, Fig. 3), except for levels equal to MedlinePlus on FORCAST and Fry scales. Comparing average FRE scores shows that AAN OPEM were less difficult compared to the other three resources.

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Table 1
American Academy of Neurology patient education materials readability scales raw scores

Document	CLI	NDC	FKGL	FRE	FORCAST	Fry	GFI	NFC	RRE	SMOG	Average grade
ALS	10.8	9–10	8.6	58	10.8	D*	10.3	6.4	D*	11.2	9.65
Alzheimer’s Disease	12.9	9–10	10.4	47	11.8	14	11.1	7.3	D*	12.7	11.2
Brain tumor	11.5	11–12	9.2	53	11.4	D*	11	6.5	D*	11.5	10.3
Concussion	12.8	11–12	10.7	44	11.4	15	13.1	8.3	13	13.5	12.1
Epilepsy	12.1	9–10	10.3	47	11.5	13	11.8	7.6	12	12.4	11.1
Myasthenia gravis	11.4	9–10	9.4	53	11.1	D*	10.2	6.6	D*	11.5	9.95
Multiple sclerosis	11.3	9–10	9.2	54	11.2	11	10.7	7	11	11.6	10.2
Migraine	14.5	11–12	11.4	41	11.8	16	12	7.7	13	12.8	12.3
Parkinson’s Disease	12.9	9–10	10	48	11.4	D*	11.9	7.3	D*	12.2	10.7
Peripheral neuropathy	13.5	11–12	9.9	44	12	D*	10.7	5.6	D*	11.7	10.7
Sleep disorders	13.3	11–12	11.2	46	11.4	13	11.9	7.9	13	13.6	11.8
Spinal cord injury	10.7	9–10	9.2	55	10.9	10	11.5	7.8	11	11.8	10.2
Stroke	11.8	9–10	9.4	58	10.3	10	10.8	8.1	11	11.9	10.3
Tremors	11.3	11–12	8.9	54	11.3	D*	10.7	6.6	D*	11.4	10.2
Average score	12.2	10.4	9.8	50.1	11.3	12.8	11.2	7.1	12	12.1	

D* errors = “Text is too difficult to be classified to a specific grade level because it contains too many high syllable words,” and “Text is too difficult to be classified to a specific grade level because it contains too many 6+ character words,” by the Fry and Raygor Readability Estimate scales, respectively.

ALS = amyotrophic lateral sclerosis, CLI = Coleman–Liau Index, FKGL = Flesch–Kincaid Grade Level, FRE = Flesch Reading Ease, GFI = Gunning–Fog Index, NDC = New Dale–Chall Readability Formula, NFC = New Fog Count Formula, RRE = Raygor Readability Estimate, SMOG = Simplified Measure of Gobbledygook.

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