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Quality of Popular Online Resources About Vestibular Migraine

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Abstract

Objective. To evaluate the readability, understandability, actionability, and accuracy of online resources covering vestibular migraine (VM).

Study Design. Cross-sectional descriptive study design.

Setting. Digital collection of websites appearing on Google search.

Methods. Google searches were conducted to identify common online resources for VM. We examined readability using the Flesch Reading Ease (FRE) and Flesch-Kincaid Grade Level scores, understandability and actionability using the Patient Education Materials Assessment Tool (PEMAT), and accuracy by comparing the website contents to the consensus definition of "probable vestibular migraine."

Results. Eleven of the most popular websites were analyzed. Flesch-Kincaid Grade Level averaged at a 13th-grade level (range: 9th-18th). FRE scores averaged 35.5 (range: 9.1-54.4). No website had a readability grade level at the US Agency for Healthcare Research and Quality recommended 5th-grade level or an equivalent FRE score of 90 or greater. Understandability scores varied ranging from 49% to 88% (mean 70%). Actionability scores varied more, ranging from 12% to 87% (mean 44%). There was substantial inter-rater agreement for both PEMAT understandability scoring (mean $\kappa = 0.76$, SD = 0.08) and actionability scoring (mean $\kappa = 0.65$, SD = 0.08). Three sites included all 3 "probable vestibular migraine" diagnostic criteria as worded in the consensus statement.

Conclusion. The quality of online resources for VM is poor overall in terms of readability, actionability, and agreement with diagnostic criteria.

Keywords

actionability, Flesch-Kincaid Grade Level (FKGL), Flesch Reading Ease (FRE), health literacy, Internet, patient education, Patient Education Materials Assessment Tool (PEMAT), readability, understandability, vestibular migraine

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Online resources, including informational websites and online support communities, have emerged as an important source of health-related information, with 35% of US adults reporting that they have searched the Internet to help diagnose a suspected medical condition.[1] Online searches related to headaches and migraines have increased by 158% and 15%, respectively, between 2004 and 2016.[2] Vestibular migraine (VM), a subtype of migraine characterized by recurrent symptoms of dizziness or vertigo, is thought to be underdiagnosed and yet perhaps the most common cause of episodic dizziness.[3-6] There is growing interest in evaluating the quality of online resources for common medical conditions aimed at the public.

Readability is a measure of the difficulty experienced by an individual reading a text. The average adult in the United States reads at an education level between seventh- and eighth-grade, yet most online resources discussing health-related information are written at education levels far above that.[7,8] Information aimed at the public should be at a reading level which is easily understood by a general audience, avoiding complex medical vocabulary. Actionability refers to the reader's ability to identify potential "next steps" based on the information provided by the resource.[9,10] Information aimed at the public should be actionable, to facilitate and encourage those who need professional consultation to seek it readily.

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While various studies in the otolaryngology literature have examined the readability and actionability of patient resources for various diagnoses, none have evaluated online sources of information for VM. Herein, we sought to investigate the quality of popular sources of online health information that educate patients about VM.

Methods

A Google search was performed on November 30, 2022, with the terms "vestibular migraine," "migraine with vertigo," and "migraine with dizziness." Searches were performed in a private window using the Safari web browser (version 15.2; Apple Inc) while connected to a nonuniversity-affiliated Wi-Fi network. The first 40 results for each term (equivalent to 4 pages on Google) were recorded in order of appearance. An ad-blocking web browser extension prevented sites that paid for Google's sponsored listing from appearing at the top of the first page. Inclusion criteria included websites written in English providing information about VM. We excluded duplicate websites, those not written in English, had access restrictions (eg, a paywall), were primarily nontext media (such as videos and audio), or contained less than 100 words. Of the 120 websites identified, 11 met the criteria for study inclusion. These sites were categorized based on their publishing organization, defined as the following[11]:

- For-profit: An entity primarily engaged in business activities to make a monetary profit from providing services or promoting a product for a fee;
- Nonprofit: Academic (hence referred to as "academic"): An institute dedicated primarily to education and research activities such as a university;
- Nonprofit: Other (hence referred to as "nonprofit"): Organizations whose purpose is to benefit the public, in this instance—aimed at providing information about a subject without monetary benefit.

Readability of textual information was objectively quantified using the Flesch Reading Ease (FRE) score and Flesch-Kincaid Grade Level (FKGL) formula via https://app.readable.com. Reading scores are calculated based on the average sentence length (in words) and word length (in syllables) used throughout the text. The FRE score is interpreted as follows: 0 to 60 difficult to read, 60 to 70 standard, and 70 to 100 easy to read, while FKGL describes the US grade level of education needed to understand the text.[12] Both tests have been widely used to assess the readability of written material across many industries.[11,13,14]

The Patient Education Materials Assessment Tool (PEMAT), a validated instrument developed for evaluating the understandability and actionability of patient education materials, was used to assess each web page.[9,10] Understandability describes how easily individuals from diverse backgrounds and varying levels of health literacy can comprehend and explain the key messages, whereas actionability describes whether the individual can identify an action to take from the information provided. Materials with domain scores greater than 70% are considered understandable and actionable, respectively.[9] Five individuals (2 physicians and 3 medical students with clinical research experience) reviewed each website while performing PEMAT scoring. When identified, discrepancies in the interpretation of PEMAT questions were resolved as a group. Fleiss κ interrater reliability analysis was performed using R software (Version 1.4.1103) to determine the level of agreement among reviewers. Values for κ are interpreted as: 0 poor agreement, 0.01 to 0.20 slight, 0.21 to 0.40 fair, 0.41 to 0.60 moderate, 0.61 to 0.80 substantial, 0.81 to 1.00 almost perfect.[15]

Accuracy of the website information was measured based on compatibility with the 2022 updated consensus definition of "probable vestibular migraine" from The Bárány Society and International Headache Society.[6] Based on this definition, an accurate diagnosis of probable VM must satisfy the following criteria:

1. At least 5 episodes with vestibular symptoms of moderate or severe intensity, lasting 5 min to 72 hours;
2. Only one of the following is fulfilled:
   a. Current or previous history of migraine with or without aura according to the International Classification of Headache Disorders (ICHD-3);
   b. One or more migraine features with at least 50% of the vestibular episodes:
      i. Headache with at least 2 of the following characteristics: 1-sided location, pulsating quality, moderate, or severe pain intensity, aggravation by routine physical activity;
      ii. Photophobia and phonophobia;
      iii. Visual aura;
3. Not better accounted for by another vestibular or ICHD diagnosis.

Two board-certified otolaryngologists reviewed the content of the 11 selected websites and reached a consensus regarding how many of the above criteria (1, 2, and 3) each site satisfied. The degree to which the website portrayed the symptoms of VM in line with consensus was used as a marker for content accuracy. Statistical significance of differences in readability, understandability, actionability, and accuracy between different publishing organization types was evaluated using unpaired heteroscedastic Student's t tests as measurements of the 3 sample populations (for-profit, academic, nonprofit) were independent–unpaired–and had different variances.

This study does not constitute human subjects research and is, therefore, exempt from Institutional Review Board review.

Table 1. Overview of Readability, Understandability, and Actionability Results

Website	Organization type	Flesch-Kincaid Grade Level[a]	Flesch-Kincaid Reading Ease[b]	PEMAT—Understandability[c]	PEMAT—Actionability
https://americanheadachesociety.org/wp-content/uploads/2020/09/AHS-Fact-Sheet_Vestibular-Migraine.pdf	Nonprofit—Academic	17.6	9.1	49%	12%
https://health.clevelandclinic.org/vestibular-migraines-why-this-dizzying-type-of-migraine-is-a-little-strange/	Nonprofit—Academic	10.3	47.9	88%	76%
https://dizziness-and-balance.com/disorders/central/migraine/mav.html	For-profit	10.8	47.8	62%	60%
https://www.enthealth.org/be_ent_smart/understanding-vestibular-migraines/	Nonprofit—Academic	12.3	36.6	82%	87%
https://www.healthline.com/health/vestibular-migraine	For-profit	9	54.4	83%	56%
https://www.hopkinsmedicine.org/health/conditions-and-diseases/vestibular-migraine	Nonprofit—Academic	16.1	21.8	69%	32%
https://www.medicalnewstoday.com/articles/320244#outlook	For-profit	12.6	38.7	81%	32%
https://www.menieres.org.uk/information-and-support/symptoms-and-conditions/migraine-associated-vertigo	Nonprofit—Other	12	37.7	63%	32%
https://migrainetrust.org/understand-migraine/types-of-migraine/vesibular/	Nonprofit—Other	14.5	28.3	72%	24%
https://vestibular.org/article/diagnosis-treatment/types-of-vestibular-disorders/vestibular-migraine/	Nonprofit—Other	16.9	15.9	55%	24%
https://www.webmd.com/migraines-headaches/vestibular-migraines	For-profit	9.5	52.3	68%	48%

Abbreviations: AHRQ, US Agency for Healthcare Research and Quality; FRE, Flesch Reading Ease; PEMAT, Patient Education Materials Assessment Tool.
[a]The AHRQ recommends patient education material be written at a 5th-grade level to subvert inadequate health literacy, equivalent to an FRE score of 90.[16]
[b]Flesch-Kincaid Reading Ease interpretation: 0 to 60 difficult to read, 60 to 70 standard, 70 to 100 easy to read.[9]
[c]Materials with scores of 70% or more are deemed to be adequately understood and actionable.[9]

Results

Of the 11 websites analyzed, 4 were from academic institutions, 3 were from nonprofits, and 4 were from for-profit organizations (**Table 1**).

Overall FRE scores averaged 35.5 (range: 9.1-54.4). Overall FKGL averaged at a 13th-grade level (range: 9th-18th, SD = 2.9) (**Figures 1** and **2**). Both results indicate that the average website's content was difficult to read.[9] There was no significant difference in readability between sites from any type of institution. Understandability scores averaged 70% but varied greatly between sites (range: 49%-88%, SD = 11.8%). There was no significant difference in understandability between sites published by different types of organizations. Actionability scores varied even more, ranging from 12% to 87% (mean: 44%, SD = 22.4%). For-profit sites featured content that was more actionable than that of nonprofit sites ($P = .029$) but not as actionable as that of academic sites (**Figure 3**).

There was substantial inter-rater agreement for both PEMAT understandability scoring (mean $\kappa = 0.76$, SD = 0.08) and actionability scoring (mean $\kappa = 0.65$, SD = 0.08).

In evaluating accuracy of the website content, 3 sites described all 3 diagnostic criteria for probable VM, another 3 sites described 2, 1 described 1, and 4 mentioned none (**Table 2**). For-profit sites described on average 2.5 out of 3 criteria (range: 2-3, SD = 0.58). Academic sites averaged 0.75 (range: 0-2, SD = 0.96). Nonprofit sites averaged 1 (range: 0-3, SD = 1.7). For-profit sites on average referred to more criteria from the consensus definition of VM than academic sites ($P = .026$) (**Figure 4**).

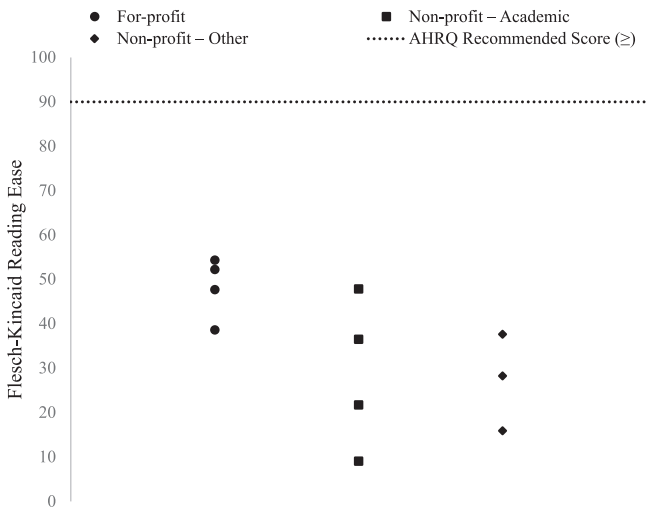

Figure 1. Distribution of Flesch Reading Ease (FRE) by organization type. The US Agency for Healthcare Research and Quality (AHRQ) recommends an FRE score greater than or equal to 90 (demarcated by the dotted line). As seen in this figure, none of the datapoints land above this line.[16]

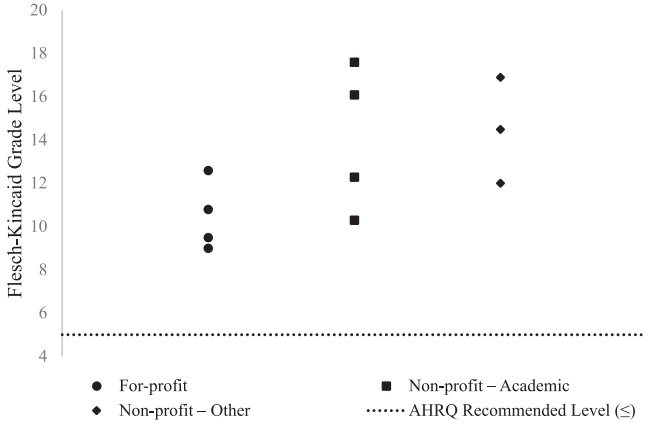

Figure 2. Distribution of Flesch-Kincaid Grade Level (FKGL) by organization type. The US Agency for Healthcare Research and Quality (AHRQ) recommends an FKGL less than or equal to the 5th-grade (demarcated by the dotted line). As seen in this figure, none of the datapoints land below this line.[16]

Discussion

The relative limitation of online health resources in the field of otolaryngology-head and neck surgery has been previously demonstrated for a variety of diagnoses.[11,14,17,18] This study adds to that list by examining the resources pertaining to VM, one of the most prevalent and underdiagnosed vestibular disorders in the United States.[4] For the websites examined in this study, the average FRE was 35.5, and the average FKGL stood at a 13th-grade level, which is a significant degree of difficulty greater than the reading

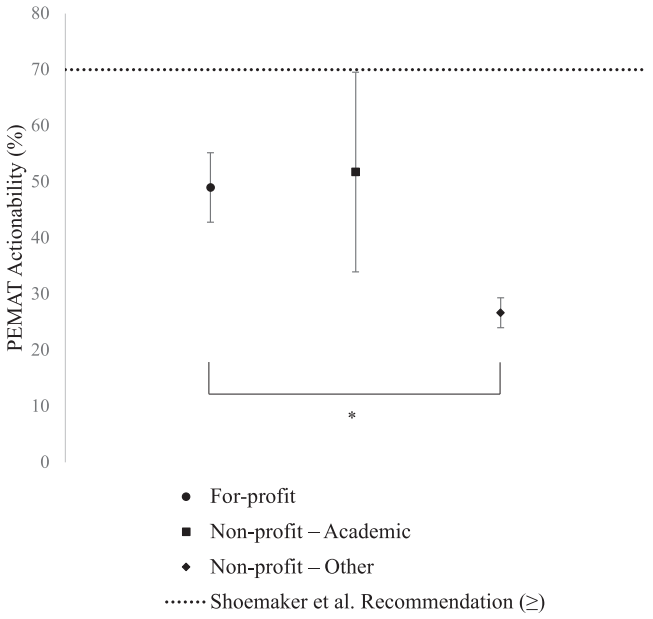

Figure 3. Average actionability by organization type. *$P = .03 < .05$ calculated via unpaired heteroscedastic Student's t test. The creators of the Patient Education Materials Assessment Tool (PEMAT) (Shoemaker et al) recommend an actionability score greater than or equal to 70% (demarcated by the dotted line). As seen in this figure, none of the datapoints land above this line.[9] Error bars represent the Standard Error of each group of data.

Table 2. Overview of Coherence with Consensus Definition of "Probable Vestibular Migraine"

Website	Organization type	Describes criterion 1?	Describes criterion 2?	Describes criterion 3?	# of criteria met
https://americanheadachesociety.org/wp-content/uploads/2020/09/AHS-Fact-Sheet_Vestibular-Migraine.pdf	Nonprofit—Academic	No	Yes	No	1
https://health.clevelandclinic.org/vestibular-migraines-why-this-dizzying-type-of-migraine-is-a-little-strange/	Nonprofit—Academic	No	No	No	0
https://dizziness-and-balance.com/disorders/central/migraine/mav.html	For-profit	Yes	Yes	Yes	3
https://www.enthealth.org/be_ent_smart/understanding-vestibular-migraines/	Nonprofit—Academic	Yes	Yes	No	2
https://www.healthline.com/health/vestibular-migraine	For-profit	Yes	Yes	Yes	3
https://www.hopkinsmedicine.org/health/conditions-and-diseases/vestibular-migraine	Nonprofit—Academic	No	No	No	0
https://www.medicalnewstoday.com/articles/320244#outlook	For-profit	Yes	Yes	No	2
https://www.menieres.org.uk/information-and-support/symptoms-and-conditions/migraine-associated-vertigo	Nonprofit—Other	No	No	No	0
https://migrainetrust.org/understand-migraine/types-of-migraine/vesibular/	Nonprofit—Other	Yes	Yes	Yes	3
https://vestibular.org/article/diagnosis-treatment/types-of-vestibular-disorders/vestibular-migraine/	Nonprofit—Other	No	No	No	0
https://www.webmd.com/migraines-headaches/vestibular-migraines	For-profit	Yes	Yes	No	2

Figure 4. Average Number of consensus definition criteria met. *$P = .03 < .05$ calculated via unpaired heteroscedastic Student's t test. Error bars represent the standard error of each group of data.

level of the average American. The US Agency for Healthcare Research and Quality (AHRQ) reports to be at the 8th-grade level. Furthermore, the AHRQ estimates that 20% of Americans read at a 5th-grade level or below and therefore recommends that patient materials be written at a 5th-grade level or an equivalent FRE of 90.[16] None of the 11 websites analyzed in this study met these guidelines. This finding suggests that many patients, particularly those with low health literacy, will struggle to understand the content of these sites, hindering their ability to participate in their own health decisions and widening health disparities.[19]

To supplement the scoring from the readability tests, we also used the PEMAT tool to evaluate understandability and actionability. Materials with scores of 70% or more are deemed to be adequately understandable and actionable. Out of 11 sites, only 5 sites met the criteria for understandability, and only 2 sites met the criteria for actionability. Thus, a majority of the sites are not sufficiently understandable, and even more do not provide enough guidance to help patients act on the information presented.

When segmenting the websites by organization type, for-profit sites tended to feature content that was more actionable and more accurate to the consensus definition of "probable vestibular migraine" than the content provided by their nonprofit or academic counterparts. Several factors could have contributed to this finding. The first relates to incentives. For-profit sites may generate revenue based on website traffic and volume of clicks. This may incentivize them to write content that is more actionable than institutions that publish similar content with less financial stake. Second, we identified greater variance in readability, actionability, and accuracy in content on the academic (SD = 3.4) and nonprofit (SD = 2.5) sites versus those on for-profit (SD = 1.6) ones. This could stem from the fact that the for-profit websites analyzed in this study may have had greater standardization of their content as they belonged to the same parent media organization. For example, one of the

sites analyzed–Medical News Today–was acquired by Healthline (another site analyzed) in 2016, and they both fall under the umbrella of Red Ventures.[20] We see this similarity represented in the alignment of their understandability scores (81% vs 83%, respectively). This discrepancy in variance would impact the results of the Student's *t* test we used to find statistically significant differences between sites from different organization types. Finally, in attempting to include the top sites returned during a Google search, we evaluated a limited sample size dependent on Google's search algorithm, which could skew statistically significant findings.

The readability, understandability, actionability, and accuracy of popular online resources regarding VM are increasingly important as recent evidence points to a much higher prevalence of VM in the United States than previously suggested.[4] While these popular websites do not explicitly function as decision aids, 28% of people use the Internet to help make medical decisions.[21] Therefore, improving the quality of these widely accessible resources should be a public health priority. For a highly prevalent but controversial disorder such as VM, it is particularly important that Academic sources contribute to the public's understanding of the condition so that incorrect information does not take root in online communities and hinder efforts to educate and treat individuals who present to clinicians for care. In our analysis, resources from Academic sources fell short of recommendations for readability, understandability, and actionability and actually performed worse than resources from nonprofit and for-profit entities in some cases. These failings point to important opportunities for academic otolaryngologists to positively impact the online materials for VM. Clinicians should recognize that current online resources may be inadequate in quality and should supplement with counseling and well-constructed aids in order to help patients better participate in their own health care decisions. Future studies should analyze other forms of popular media, such as videos (short form and long form) and social media posts, in order to obtain a better picture of the resource landscape for this diagnosis.

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Author Contributions

Oren Wei, ideation, design, data collection, data analysis, manuscript drafting, manuscript review, presentation of research; **Pavan S. Krishnan**, ideation, design, data collection, manuscript review; **Jenny X. Chen**, design, data collection, manuscript review; **Wesley W. Schoo**, design, data collection, manuscript review; **John P. Carey**, design, manuscript review; **Desi P. Schoo**, ideation, design, data collection, data analysis, manuscript drafting, manuscript review.

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