

## Research Submission

# An Analysis of Cluster Headache Information Provided on Internet Websites

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**Objective.**—To evaluate the quality of websites providing cluster headache information for patients and healthcare providers.

**Background.**—The Internet has become an increasingly important source of healthcare information. However, limited data exist regarding the quality of websites providing headache information.

**Methods.**—This was a cross-sectional study conducted in February 2007. Websites providing cluster headache information were determined on the search engine MetaCrawler and classified as either patient oriented or healthcare provider oriented. The overall quality of each site was evaluated using a score system. Readability was evaluated using the Flesch-Kincaid Grade Level Readability Score (FKRS). Website quality was analyzed based on ownership, purpose, authorship, author qualifications, attribution, interactivity, and currency. The technical quality of the cluster headache information was analyzed based on content specific to cluster headache. The final ranking, based on the sum of the ranks of all 3 categories, was determined and then contrasted between the patient-oriented and healthcare professional-oriented websites using 2-sample *t*-tests.

**Results.**—Of the first 40 websites found on MetaCrawler, 72.5% were advertisements, unrelated to headache, or repeated websites. Although the standard US writing averages are at a seventh to eighth grade level, the mean FKRS of all sites was at a 12th grade level of difficulty, with no significant difference between the patient-oriented or healthcare provider-oriented websites ( $P = .54$ ). Of a total possible 14 points, the overall mean quality component score was 9.9 for all sites; and of a total possible 23 points, the overall mean technical component score was 13.9. There was no significant difference for either the quality or technical component scores between patient-oriented or healthcare provider-oriented websites ( $P = .45$  and  $P = .80$ , respectively).

**Conclusion.**—There are numerous cluster headache websites that can be found on the Internet. The quality of most of the websites dedicated to cluster headache is mediocre, and although there are some excellent cluster headache websites, these sites may be challenging for many users to locate. There was no significant difference in the overall quality of websites oriented for patients or healthcare providers providing cluster headache information evaluated in this study. In addition, websites providing high-quality cluster headache information are written at an educational level too high for a significant portion of the general population to fully utilize. Physicians should strongly consider providing lists of quality websites on cluster headache for their patients.

**Key words:** cluster headache, websites, World Wide Web, internet, Flesch-Kincaid Grade Level Readability Score

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## INTRODUCTION

According to census figures, more than half of all US households have one or more computers.<sup>1</sup> As a result, electronic resources, such as the Internet, are gaining greater accessibility to a growing portion of the population. In particular, the Internet has become an increasingly important source of health information.<sup>2</sup> In fact, in 2003, a survey by the Center for Studying Health System Change found that 16% of adults in the United States seek health information online.<sup>3</sup>

Specifically, a considerable amount of information exists via the Internet on cluster headache. Although the breadth and volume of information provided can be quite valuable, there is often a disparity in the accessibility, reliability, and quality of the healthcare information provided by these websites. Several factors should be considered by the healthcare providers who recommend and/or use the sites, as well as the patients who utilize them and the individuals and foundations responsible for the website's creation and maintenance.

In 1996, the Health on the Net Foundation set forth a code of conduct for websites (the HONcode) to standardize the reliability of health information provided on the World Wide Web. The HONcode defines a set of rules in regard to the basic ethical standards for the presentation of information in which to hold website developers to, as well as to help users know the source and purpose of the data they are reading. However, it is important to note that the HONcode does not rate the quality of the information provided by websites.<sup>4</sup>

As the Internet has become increasingly utilized to obtain healthcare information, it is important for physicians to be aware of the caliber of information provided on medical websites. However, limited research has been carried out in regard to the reliability, quality, and technical evaluation of headache websites.<sup>5</sup>

This study was designed to evaluate the websites that provide cluster headache information in order to assist physicians and patients identifying which websites provide the most reliable and valuable cluster headache information. Specifically, our aim was to evaluate the websites that provided cluster headache

information geared toward patients as compared with those for clinicians. We hypothesized that the cluster headache websites predominantly designed for healthcare professionals would have a higher grade level of readability and higher quality and technical information than those websites designed primarily for patient utilization.

## METHODS

Sites were initially screened using MetaCrawler (<http://www.metacrawler.com>) in February 2007 as previously described, using the key words "cluster headache."<sup>6</sup> MetaCrawler was chosen as it integrates several well-known search engines, including MSN, Google, Ask Jeeves, About, Looksmart, and Yahoo. Searching MetaCrawler would approximate what patients and healthcare providers searching for online information in regard to cluster headache information would find. According to previous research, Internet users visit 2 to 5 sites starting from the top of a set of search engine returns when looking for health information.<sup>2,7</sup> As previous studies evaluating website quality evaluated the first 10 to 30 uniform resource locators (URLs),<sup>6,8</sup> we screened the first 40 URLs that were retrieved using the key words "cluster headache" for inclusion. Sites that did not contain headache information were predominantly Internet stores or advertisements, and private practice websites were not included. In addition, websites referenced by the cluster websites identified for inclusion from the screening search and websites that were previously identified by the authors as Internet sources of cluster headache information were added to the evaluation.<sup>9</sup>

Based on the "about us" section of each website, sites were classified into one of 2 groups: (1) patient oriented or (2) healthcare professional oriented. Each website was then evaluated based on readability, quality, and technical information.

**Readability.**—Five paragraphs were evaluated for the websites' readability, 3 of which were randomly chosen. The fourth paragraph came from the first original-to-site paragraph that described cluster headache and the fifth paragraph came from the "about us" or general descriptive section about the site from each website. Each of these 5 individual

paragraphs were copied and pasted into a Microsoft Word document (Microsoft Office, 2000).

The average sentence length (ASL) was determined by counting the number of words in a paragraph and dividing it by the number of sentences; and the average syllables to words (ASW) was determined by counting the number of syllables in a paragraph and dividing it by the number of words. Readability was then calculated using the Flesch-Kincaid Grade Level Readability Scores (FKRS) based on the following formula:

$$\text{FKRS} = (0.39 \times \text{ASL}) + (11.8 \times \text{ASW}) - 15.59.$$

The mean FKRS for each website was determined.<sup>10</sup> As the standard US writing averages are at a seventh to eighth grade level, a FKRS between 7.0 and 8.0 is the accepted standard for most documents. Thus, sites were ranked in order of lowest to highest mean

FKRS. FKRS were initially scored by one of 2 authors (EGS or BLP) and all were reviewed by BLP.

**Quality.**—A quality score system, based on the HONcode principles and on quality scoring systems previously utilized for medical website evaluations, with modifications for the specific purpose of evaluating cluster headache, was used.<sup>4,11-13</sup> All websites were scored on ownership (statement of the website provider), purpose, authorship, author qualification (expertise with cluster headache), attribution (references and sources citation), interactivity (contact information), and currency (posting of first date and subsequent revision dates). These categories were then subdivided and scored from 0 to 2 based on the amount of information provided, with a total possible score of 14 (Table 1).

**Technical.**—Each website was given a technical score based on the information it provided in regard

**Table 1.—Quality Component Scoring System**

Criteria	Score
Ownership	
No ownership/sponsorship identified	0
Some indications of ownership/sponsorship	1
Clearly identified ownership/sponsorship	2
Purpose	
No statement of purpose	0
Purpose stated as educational but financial profit from the site exists	1
Clear distinction is made as to whether the information provided is for educational or commercial purposes, or both	2
Authorship	
No indication of authorship	0
Some indication of authorship	1
Name of person(s) supplying information clearly provided	2
Author qualification	
Author has no officially recognized experience in the field or no such information is provided	0
Information about qualifications is vague, or if the author has no professional experience but has direct personal experience	1
Author is a healthcare professional	2
Attribution	
No references provided for requiring statements	0
References are provided for some, but not all, statements requiring factual information	1
Attribution for all statements conveying factual information is present	2
Interactivity	
No contact provided	0
Telephone number, email, or mailing address provided	1
Clear invitation to comment or ask questions by an email address or link to a form	2
Currency	
No dates provided	0
Date of original posting provided but no information about last revision or frequency of updates	1
Date of original posting and date of last revision or frequency of updates clearly stated	2

**Table 2.—Technical Component Score System**

Criteria
1. Diagnosis of cluster headache (CH) Divided into 5 subcategories based on criteria A-E of the International Classification of Headache Disorders, 2nd edition
2. Epidemiology of CH
3. Risk factors for CH Divided into 3 categories to include mention of male sex, alcohol, smoking
4. Pathophysiology
5. Acute treatment of CH
6. Preventative treatment of CH
7. Prognosis of CH

Total possible technical score ranged from 0 to 23, where each site was scored as follows: 0 = not discussed on the site, 1 = some mention, 2 = detailed explanation, with the exception of risk factors, which were scored 0 = no mention or 1 = mentioned.

to cluster headache for the following categories: definition (based on the International Classification of Headache Disorders criteria,<sup>14</sup> epidemiology, risk factors, pathophysiology, acute treatment, preventive treatment, and prognosis. The definition and risk factor categories were further subdivided and scored based on the total from these subdivisions (Table 2). A score of 0, 1, or 2 was assigned to each category, except for risk factors, which were scored as 0 or 1, for a total score of 23. The same investigator (BLP) performed all evaluations for the technical and quality component scoring and then reviewed them with a second investigator (JRL).

**Overall Ranking.**—The final ranking of each website was determined by the sum of the ranks of the 3 individual categories, including readability, quality component, and technical component. In this way, each of the 3 criteria was weighted equally.

**Statistical Analysis.**—All statistical analyses were performed in Data Desk by Data Description of Ithaca, New York. Comparisons between patient-oriented and healthcare professional-oriented sites were carried out using independent sample *t*-tests. For each *t*-test, Cohen's *d* statistics are reported as indicators of effect size.

## RESULTS

By using the words “cluster headache,” a total of 96 URLs were returned from the search engine. Of

the first 40 website URLs identified on the Meta-Crawler search, 47.5% (19/40) were predominantly advertisements, 10% (4/40) were not related to headache, 15% (6/40) were private websites, 15% (6/40) were repeated websites which were previously found, and 12.5% (5/40) were websites included in this study. These sites included: <http://www.clusterheadaches.com>, <http://www.wikipedia.org>, <http://www.emedicine.com>, <http://www.familydoctor.org>, and <http://www.headaches.org>. Ten additional websites that were referenced by the included websites or previously identified by the authors were identified for inclusion as well and included <http://www.achenet.org>, <http://www.chhelp.org>, <http://www.ouch-uk.org>, <http://www.ouch-us.org>, <http://www.americanheadachesociety.org>, <http://www.bash.org.uk>, <http://www.brainandspine.org.uk>, <http://www.headacheaustralia.org>, <http://www.i-h-s.org>, and <http://www.w-h-a.org>. Thus, a total of 15 websites were identified for inclusion in this study; 8 of these websites were classified as predominantly healthcare provider oriented and 7 predominantly patient oriented.

The mean FKRS for all cluster websites was 12.4. The mean FKRS for cluster websites predominantly for patient utilization was 12.2 (Tables 3 and 4). The mean FKRS for the cluster websites for healthcare professionals and patient utilizations was 12.7. There was no statistical difference in the mean FKRS between patient-oriented and healthcare professional-oriented sites ( $P = .54$ ; Table 3).

No website had an FKRS less than or equal to an eighth grade level. Only 20% (3/15) were even below

**Table 3.—Descriptive Statistics for Sites Included in the Study (n = 15)**

Criteria	Mean	Minimum	Maximum	Standard deviation
Flesch-Kincaid Grade Level	12.43	10.10	14.76	1.48
Readability Score	9.93	7.0	13.0	1.67
Quality Technical	13.0	4.0	21.0	5.32

**Table 4.—Comparisons of Patient-Oriented and Healthcare Professional Websites That Provide Cluster Headache Information in Regard to Readability, Quality, and Technical Components**

Criteria	Patient sites (n = 7)	Healthcare provider sites (n = 8)	Student's <i>t</i>	<i>P</i> value	Cohen's <i>d</i>
Flesch-Kincaid Grade Level Readability Score	12.2	12.7	−0.64	.54	0.40
Quality	9.6	10.3	−0.78	.45	0.29
Technical	14.3	13.5	−0.09	.80	0.20

an 11th grade level. Fifty-three percent (8/15) were at or below a 12th grade level and 47% were greater than 12th grade level or above (see Table 3). Overall, the top 5 websites for lowest FKRS scores in alphabetical order were <http://www.chhelp.org>, <http://www.familydoctor.org>, <http://www.headaches.org>, <http://www.ouch-us.org>, and <http://www.w-h-a.org>.

Of a total possible 14 points, the overall mean quality component score was 9.9 with a range of 7–13. For the patient-oriented websites, the mean quality component score was 9.6, while the healthcare professional oriented-sites had a mean of 10.3 points. The top 5 websites with the highest quality component score, in alphabetical order, were <http://www.achenet.org>, <http://www.americanheadachesociety.org>, <http://www.headaches.org>, <http://www.i-h-s.org>, and <http://www.w-h-a.org>. There was no statistical difference in the mean quality component score between patient-oriented and healthcare professional-oriented sites ( $P = .45$ ).

Of a total possible 23 points, the overall mean technical component score was 13.9 with a range of 4–22. For the patient-oriented websites, the mean technical component score was 14.3, while the healthcare professional oriented-sites had 13.5 points. The top 5 websites with the highest technical component score, in alphabetical order, were <http://www.americanheadachesociety.org>, <http://www.clusterheadaches.com>, <http://www.i-h-s.org>, <http://www.ouch-uk.org>, and <http://www.ouch-us.org>. There was no statistical difference in the mean technical component score between patient-oriented and healthcare professional-oriented sites ( $P = .80$ ).

Of a total possible range of 3–45, websites were given an overall ranking. The website that ranked number one in the overall ranking for cluster head-

ache websites was <http://www.ouch-us.org>. The overall top 5 sites (in alphabetical order) were <http://www.achenet.org>, <http://www.headaches.org>, <http://www.i-h-s.org>, <http://www.ouch-us.org>, and <http://www.w-h-a.org>. There was no statistically significant difference in the overall ranking between patient-oriented and professionally oriented websites ( $P = .84$ ).

## DISCUSSION

This study showed that there was no statistically significant difference between the patient-oriented and healthcare professional-oriented sites in regard to the readability, quality, or technical components. However, it should be noted that although all websites included in this study do provide information on cluster headache on their sites, the primary purpose of several of these websites is to provide headache information and not solely cluster headache information. Nonetheless, this study revealed several important findings in regard to Internet websites that provide cluster headache information.

First, similar to what Peroutka found with Internet headache websites, although an expansive array of information is available via the Internet on cluster headache, locating quality websites is a monumental task even if users understand how to evaluate the validity and quality of websites. As previous studies have shown that Internet users visit just 2 to 5 of the top URL websites returned from a search engine, only one of the URL websites included in this study would have been located by users unfamiliar with cluster headache websites. In addition, if our search was limited to the top 10 URLs on MetaCrawler, all but 2 of these websites were for advertising and the second was a repeat of the first website. Even when

expanding the search to the first 40 website URLs, 72.5% of the websites were primarily advertisements, not related to headache (let alone cluster headache) or were repeated website addresses. This emphasizes that users are often forced to screen multiple websites with little value before finding one quality website with reliable, useful information.

Second, the reading level of the websites included in this study may be too difficult. The mean FKRS for the websites in our study was 12.4, indicating a 12th grade level of difficulty. This is similar to what Kaphingst et al found in a study evaluating colorectal cancer website reading levels. In their study, the average reading level was 12.8 (or at the 13th grade level).<sup>2</sup> As most standard documents are at the eighth grade level to be accessible to the majority of the general population, this indicates that like colorectal cancer websites, all of the cluster headache websites are at a level that may require assistance to be properly utilized by a significant proportion of the population. The applicability of this finding is not certain in cluster headache sufferers. This could be a limitation as lower education is a risk factor for several headache disorders, although not specifically for cluster headache sufferers.<sup>15,16</sup> However, if the reading levels of these sites would be at too basic of a level for this specific population, this could also be a deterrent to the utilization of a website. Thus, future studies may evaluate the educational level of cluster headache sufferers to fully determine the applicability of this finding.

The third point to make from this study is that several of the websites clearly provide extremely high-quality information technically, yet did not score as high on the overall ranking because of the actual website quality (quality component score). Many of these factors are readily changeable and would significantly alter their standing. For example, 40% of sites were missing both components of currency (providing an original posting date and date of last revision), and 87% were missing one component. Although all sites had at least one component of interactivity (providing an option for the website to be contacted with a clear invitation for users to do so), 73% were missing a clear invitation for questions or comments. Similarly, although several of the sites

have high standards in regard to the quality of the information posted on their websites, several received low technical scores. Their technical component score could easily be increased with minor efforts.

Our study does have limitations and caution should be taken when drawing conclusions. First, privately run websites were not attempted to be included in this evaluation and no comment can be made in regard to their overall quality or lack thereof. Second, although objectivity was attempted by using well-defined quantitative standard scores, as the initial search on MetaCrawler failed to identify a significant proportion of websites known to provide cluster headache information, a degree of selection bias was introduced by their inclusion. This limitation was deemed necessary in order to provide a meaningful analysis of sites that are known to be utilized by cluster headache sufferers and physicians. Third, our sample size did not provide a large degree of statistical power and only large differences between the websites could be found to be statistically significant. However, we have presented effect size estimates to place the size of the observed differences in context. Finally, although several important variables of quality websites were evaluated, the usefulness of a particular website will always have a degree of individual preference which is not readily quantifiable.

## CONCLUSION

Although an abundance of information on cluster headache is available on the Internet, not all is of high quality. In addition, merely locating the sites with quality information may present a significant challenge to patients. Furthermore, even if a quality website is found, it may be difficult for a significant portion of the population to utilize the site. Therefore, it is important that headache specialists and professional headache societies help to develop high-quality and accessible websites for cluster headache sufferers. Many simple or minor changes could significantly improve the overall quality of the available cluster headache websites.

Finally, physicians should strongly consider providing lists of high-quality or "approved" websites for their cluster headache sufferers. In this manner, physicians will become stronger advocates for their

patients, helping them to avoid the pitfalls and reap the benefits of entering the World Wide Web.

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