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What might parents read: Sorting webs of online information on vascular anomalies

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ABSTRACT

Introduction: The internet is increasingly a source of healthcare information utilized by parents, especially in rarer pathologies such as vascular malformations. The quality, validity and thoroughness of these websites is variable and unregulated. The goal of this study was to evaluate the quality and understandability of websites related to vascular malformations.
Methods: The terms "hemangioma", "vascular malformation", and "vascular anomalies" were searched in Google. The first 30 websites meeting inclusion and exclusion criteria were evaluated. Quality and readability were assessed using the DISCERN criteria and the Flesh-Kincaid Reading Grade Level (FKGL), respectively. Date of last update, HONcode accreditation, and the website category were recorded.
Results: Most websites were owned by academic institutions (n = 19, 63.3%). The mean DISCERN score for all websites was 2.97, or a partially valid source of information on a 1–5 scale. The average reading level estimated by FKGL was grade 12; only one website was scored at less than a grade 9 level. Two websites were HONcode accredited. Of the 18 sites giving an explicit date of last update, 12 (67.7%) had been updated in the previous 12 months.
Conclusions: Websites relating information about vascular anomalies may not be understandable to the general public, including parents. Health care providers should be cognizant of the quality and availability of such information as it may impact parent perspectives and bias toward treatment options.

1. Introduction

The process of patient-centered care is predicated upon several characteristics of care including clear, high-quality information and education for the patient and family [1]. This concept of shared decision-making has been included in the benchmark Institute of Medicine report, *Crossing the Quality Chasm*, as an avenue to improve the quality of healthcare in America [2]. Shared decision-making is inherent upon both parties having sufficient knowledge to make an informed decision.

Obtaining information regarding a condition or diagnoses requires health literacy. Health literacy is the ability to obtain, process and understand basic health information and services needed to appropriately participate in making healthcare-related decisions [3]. Similarly, parent health literacy is required to make medical decisions on behalf of a child or minor. Inadequate levels of parent health literacy have been linked to higher rates of emergency department visits among their children, poor adherence to medication dosing and treatment plans, and difficulty understanding healthcare-related tools such as a growth charts [4,5].

The internet is increasingly a source of healthcare information utilized by the general public, including parents, for immediate, available, and free or low-cost content. Nearly 85% of American adults regularly use the internet, and this is estimated to be even higher in the 20–40 year old adult demographic with an estimated 93–96% using the internet [6]. In 2012, an estimated 72% of internet users reported looking online for health information within the past year [7].

The quality, validity and thoroughness of healthcare websites is variable and unregulated. The ability for a reader to comprehend the presented information is termed readability. Readability, in other words, is the ease in which text can be read and understood.

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Similar to many aspects of healthcare, the techniques to evaluate the readability of a text are rooted in the military. The Flesch–Kincaid Reading Grade Level (FKGL) and Flesch Reading Ease Score test numerically quantifies a text's readability based factors such as the average number of words per sentence, average sentence length, and the average number of syllables per word. Initially used to evaluate military training manuals, these formulas are readily available in modern word processors such as Microsoft Word for widespread use across disciplines. The FKGL computed score reflects an estimated grade level education required to understand the analyzed text. The National Institutes of Health recommends that the readability of patient education materials should be equal to or less than the 6th grade United States reading level. The FRES is well established in evaluating medical literature; a "plain language" reading level is estimated to a score of 65.

In addition to readability, the quality of the content found online is vital for health literacy. The DISCERN instrument is a validated tool which numerically objectifies the quality of health-related information on websites. The DISCERN instrument is composed of 16 questions assessing consumer health information. Importantly, it does not evaluate the accuracy of the information.

There is an emerging body of literature regarding the quality and readability of websites for pediatric otolaryngologic diagnoses and conditions such as microtia and aural atresia, glue ear, and tympanostomy tubes. Thus far, the evidence has shown that high-quality websites with easily read content are lacking, and that there is wide variability in the content [8–10]. These diagnoses are somewhat rare, and often managed by pediatric otolaryngologists alone. Hemangiomas and vascular malformations are the most common congenital and neonatal abnormalities [11]. Vascular anomalies are often treated by a multidisciplinary care team comprised of physicians from different specialties such as otolaryngology, pediatrics, oral and maxillofacial surgery, interventional radiology, dermatology, and plastic surgery. The goal of this study was to evaluate the quality and understandability of websites related to vascular anomalies. Additionally, we hypothesized that an increase in DISCERN score, as a metric of quality, would correlate with decreased readability scores as represented by a high reading level (FKGL) and low score on FRES (higher scores represent greater ease of reading).

2. Methods

2.1. Strategy

The search terms "hemangioma", "vascular malformation", and "vascular anomalies" were searched separately in Google (www.google.com, Google Inc., Mountain View, CA) on a single date, October 18, 2015. The first 30 websites meeting inclusion and exclusion criteria were evaluated. Duplicate websites were only evaluated once. Websites must have been written in the English language and must have been functional at the time of access for inclusion. Exclusion criteria included newspaper articles, sponsored websites, information consisting of less than 30 sentences, images-only websites, and online dictionaries.

Quality and readability were assessed using the DISCERN criteria and the Flesh-Kincaid Reading Grade Level (FKGL)/Flesch Reading Ease Score (FRES), respectively. The written content was pulled into a word processor with identifying information removed, such as an associated hospital, as to protect the reviewers from bias. All included websites were independently reviewed by two attending physicians (NJ — pediatric otolaryngologist; AM — pediatrician and medical director of vascular anomalies center) for quality using the DISCERN criteria questions. Scores within 1 point of each other were averaged. When the raters differed by more than 1 point, the raters discussed the disagreement and developed a consensus score. The written content was then evaluated in Microsoft Word (Microsoft Corp., Redmond, WA) for the FKGL by a single evaluator (KD).

Date of last update, HONcode accreditation, and the website category were also recorded.

2.2. Measures

2.2.1. DISCERN

The DISCERN is the first standardized index of quality of consumer health information. It has been designed to help users of consumer health information judge the quality of written information about treatment choices [12]. DISCERN consists of 15 key questions plus an overall quality rating. Questions 1-8 address the reliability of the publication and help one consider its trustworthiness as a source of information about treatment options. Questions 9-15 address specific details of the information about treatment choices. Question 16 is the overall quality rating. Each question is rated on a 5-point scale ranging from No to Yes, with a 5 being a definite 'yes, the criterion has been completely fulfilled'.

2.2.2. Flesch-Kincaid Reading Grade Level (FKGL)

The formula to calculate the FKGL is as follows: 0.39*(average number of words per sentence) + 11.8*(average number of syllables per word) - 15.59. The weighting factors allow the score to be translated to a US grade level. For example, a score of 7.1 would indicate that the text is likely understandable by an average student in the 7th grade of the US education system, which is often between ages 12–13 years.

2.2.3. Flesch Reading Ease Score (FRES)

The formula to calculate the FRES is as follows: 206.835 - (1.015 × average sentence length) - (84.6 × average number of syllables per word). A score is determined from 0 to 100, with higher scores indicating greater ease of reading.

2.2.4. HONcode

HONcode is a widely used certification for health information websites, which is based on ethical principles such as transparency, disclosure, authority, and confidentiality. The request for certification is explicit and voluntary. The HONcode symbol is identifiable in a downloadable toolbar, and will be active if a website is HONcode certified [13]. For each website, the HONcode seal was checked on a single date (October 19, 2015).

2.2.5. Statistics

Descriptive statistics were calculated from all data, using the mean, range, and standard deviation, when applicable, for reporting. To test correlation between variables, the Pearson's 1-tailed test was performed. Prior to using this, D'Agostino and Peason omnibus normality test was run on DISCERN, FKGL and FRES data to determine normality of the data sets. Inter-rater agreement was tested using Spearman's correlation.

3. Results

3.1. Website characteristics

The website included are listed in Table 1. Most websites were maintained by academic institutions (n = 19, 63.3%). Of the 18 sites giving an explicit date of last update, 12 (67.7%) had been updated in the previous 12 months.