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Orofacial Granulomatosis and Dietary Interventions: Health Information on the Internet

ABSTRACT

Purpose

To assess the content, quality, and readability of health information on the internet for patients with orofacial granulomatosis, including material on benzoate and cinnamon-free diets.

Methods

The first 100 websites drawn from searches using 8 key terms (2,400 websites) across 3 search engines (Yahoo, Google, and Bing) were analysed. Duplicates or websites with unrelated information were excluded, which brought the number of websites included in the study to 12. To assess the quality of the information, we used the DISCERN questionnaire, Journal of the American Medical Association (JAMA) Benchmark Criteria, and Health on Net Seal. The readability was then analysed by applying the Flesch-Kincaid Reading Ease and Grade Level tests, the Automated Readability Index, and global traffic ranking (ALEXA).

Results

Separate assessment for both orofacial granulomatosis, and its management with a benzoate and cinnamon-free diet, showed that most websites (75%) were either 'very poor' or 'poor' in quality, with a mean DISCERN score of 31.4 out of 80. No website met all four JAMA benchmarks. Only two websites displayed the HONcode seal. Generally, health information was considered difficult to read, with a FRES ranging from 21.5 to 68, with a mean score of 48 (±13.2). To comprehend this information, readers would need to have, on average, a 10th grade US level education.

Conclusion

The quality and readability of online information on orofacial granulomatosis is poor and difficult to read.

INTRODUCTION

Orofacial-granulomatosis (OFG) is an uncommon chronic granulomatosis disorder usually characterised by oral and maxillofacial soft-tissue swelling, and oral mucosal ulceration and erythema.

The term OFG was introduced in 1985 by Weisenfeld *et al.* who reported sixty cases of patients who presented with pathological features consisting of lymphoedema and the presence of multiple non-caseating giant cell granulomata. Previous descriptions of the condition were provided by Miescher in 1945 as a granulomatous cheilitis and as part of Melkersson-Rosenthal syndrome, a triad of facial paralysis, fissued tongue and facial swelling. [1]

OFG is considered an idiopathic condition, which can be diagnosed through clinical examination and appropriate investigation to exclude other granulomatosis disorders such as Crohn's disease, sarcoidosis, and tuberculosis, conditions which can present with similar orofacial features to those of OFG. A small subgroup of patients with OFG, particularly those who developed the condition in childhood, later go onto develop intestinal Crohns's disease, or on occasion, sarcoidosis. In both cases, it is important to revise and redefine the patient's diagnosis. [2]

OFG is a debilitating condition, in which the patient experiences painful ulceration, and potentially permanent facial disfigurement, leading to emotional distress and discomfort. [3] While its aetiology is unclear, limited success of cinnamon and benzoate-free diets in the management of a small sub-group of OFG patients suggests that an allergic component may be one causative factor [2,4,5]. Other exclusion diets are available, as well as allergen avoidance and medical and surgical management options, but the authors of this paper believe that a cinnamon and benzoate-free diet might represent a pragmatic and non-pharmacological attempt to reduce the manifestations of the disease, before turning to the possibility of intralesional or systemic corticosteroid or immuno-modulatory therapy.

The internet is a vital source of information for patients, with 71% of Europeans using this resource for health purposes[6]. Patients with a chronic illnesses such as OFG are particularly likely to conduct internet searches on their conditions, while up to a third of dental patients who presented for treatment report that they researched their oral/dental conditions on-line.[7,8] Such information has empowered patients, and led to improvements in treatment compliance and health outcomes; it also facilitates the more efficient utilisation of health services and reduces costs[9]. However, these benefits are offset by the ubiquity of inaccurate, misguided, or confusing information, which can lead to physical, emotional and financial harm for patients[10]

An analysis of the quality and readability of online information about OFG is necessary to establish whether action is needed to improve such materials. To our knowledge, no other assessment of this kind has been undertaken.

METHODS

Search Methods

Three search engines were used in our assessment of the quality of health information concerning both OFG, and its management through a cinnamon and benzoate-free diet: Google™, Yahoo®, and Bing™. These engines account for 96% of search engines worldwide[11]. Separate searches were performed for OFG and the exclusion diet. For the former, four search terms were entered: ~~Eight search terms were entered:~~ 'orofacial granulomatosis', 'OFG', 'Granulomatosis cheilitis', 'Oral Crohn's'. For the latter topic, the following search terms were used: 'benzoate and cinnamon free diet', 'benzoate and cinnamon exclusion diet', 'orofacial granulomatosis diet', and 'E210 E211 E212 E213 E214 E215 E216 E217 E218 E219 free diet'.

We included the first 100 results from each search, and excluded duplicate sites, scientific articles, patient forums without professional guidance, advertisements, sites that required a subscription/membership, and any other irrelevant sites.

Data processing

The selected websites were assessed independently by the two authors, using subjective tools (DISCERN/JAMA benchmark-criteria). To ensure the correct deployment of these tools, the authors undertook training, and conducted a pilot-study on an unrelated topic (oral cancer).

One author assessed the websites for objective data, through application of the HONcode and the Alexa Global Ranking. Microsoft Excel allowed for descriptive statistics, including means and standard deviations.

Quality assessment

The DISCERN instrument is a previously validated tool, with good inter-user reliability; it helps the general public and health professionals to assess the quality of written health information[13,14,15]. This tool asks 16 questions, sub-divided into three sections: section 1 (Qus.1-8) assesses the credibility of the information; section 2 (Qus.9-15) considers the quality of material pertaining to treatment choices; and section 3 (qu.16) gives an overall quality rating. Each question is graded on a

scale of 1-5, where 1=very poor and 5=excellent. As in previous studies, an overall assessment of 'very poor' was given for websites scoring 16-26, 'poor' = 27-38, 'fair' = 39-50, 'good'= 51-62, and 'excellent' = 63-80[16].

The JAMA benchmark criteria, developed in 1997, recommends that websites displays four key features: authorship, attributions, disclosure, and currency: a score is provided for each [17].

Health on The Net (HONcode) is a financially independent, non-profit-making organisation. It promotes transparent and reliable health-information online, and provides certification and a code of conduct seal to websites that meet its code. It comprises 8 core principles: authority, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, and advertising policy[18].

Readability

Readability is the ease at which pages of text are read. Health information should aim to provide written content comprehendible to a US-grade 5 child (11-12 years)[19]. We assessed the readability of text using three readability score tools: Flesch-Kincaid Reading Ease (FRES), Flesch-Kincaid Grade Level (FGL), and the Automated-Readability-Index (ARI).

The FRES and FGL are two of the mostly commonly used reading scores available. FRES provides a score (0-100) based on sentence length, and number of syllables per word; the higher the score, the greater ease of reading: 90-100=very easy, 80-90=easy, 70-80=fairly, 50-60= fairly difficult, 30-50=difficult, 0-30=very difficult[20]. The FGL invokes the same core measures (though weighted differently), but the results are translated into a U.S school grade-level. A score of 6.0 indicates that a 6^{th}-grade student would be able to understand the information. The ARI assesses the number of letters per word, and words per sentence. Like the FGL, it provides a score that corresponds to a U.S school grade-level. A segment of text from each website (200-500 words) was pasted into a previously-validated online readability calculator (http://www. online-utility.org) [21,22].

Popularity

The Alexa Global Traffic Ranking Tool assesses website popularity and ranking, based on the amount of website traffic over the past three months. We used this tool on 31/07/18 for each of the selected websites.

RESULTS

Search results

The website search strategy brought up 2,400 websites, but once the inclusion/exclusion criteria had been applied, this number was reduced to 12. Of the 2,388 excluded websites, 1405 were not relevant, 637 were scientific papers, 139 were duplicates, 45 were patient forums, 23 required membership/subscription access, and 139 were targeted at medical professionals (Figure 1a & 1b).

Quality

The mean DISCERN score for the included websites was 31.4 out of 80, with an average score of 1.9 (±0.7) out of 5 per question. Inter-rater reliability was 90.6%. Nine websites were considered 'very poor' or 'poor', with only four websites deemed 'Fair' (Chart 1). No websites were rated "good" or "Excellent" for quality. The lowest scoring questions (Q.9,10,11,12,13) were associated with all treatment choices, with an average score of 1.15 (±0.1). No website met all the JAMA-benchmark criteria, and only half the websites satisfied one criterion or more; authorship (16%) and currency (16%) received the lowest scores. Only two websites displayed the HONcode Seal (16%).

Readability & Popularity

The FRES ranged from 21.5 to 68, with a mean score of 48 (±13.2). The readability levels 'fairly difficult' to 'very difficult' accounted for 75% (9/12) of all websites reviewed. The FGL ranged from 7 to 13.4, with an average of 10.4 (10^{th} Grade), while the ARI varied between 6.4 to 13.4, with an average reading level of 10.1 (10^{th} Grade). The popularity of websites is shown in Table 1.

DISCUSSION

In Europe, over 80% of adults aged between 15-39 use the internet to research health matters, and 90% of users are satisfied with the information they uncover[23]. OFG is a chronic condition, presenting at a median age of 28 years, an age-group most likely to use the internet for health information.[4] Unfortunately the quality of online health information available on conditions relating to dentistry and oral medicine is of poor to moderate quality, as indicated by previous studies [24,25]. Our study shows that the same can be said of websites dealing specifically with OFG: only 8 were dedicated wholly to this condition, and just 4 discussed its management with an exclusion diet.

The DISCERN instrument highlights the low quality of information offered on OFG, with every website judged to be of 'very poor' to 'fair quality'. No website was deemed to provide 'good' or 'excellent' quality information. The low scores for DISCERN questions relate to all treatment choices, and their associated benefits and risks, together with the perceived impact of these conditions and their therapies on quality of life. Patient receiving a diagnosis of OFG within the UK are likely to be asked to consider a trial benzoate and cinnamon avoidance diet . This advice is often issued by oral medicine specialists on the basis of expert opinion and widespread clinical practice within the UK underpinned by relatively weak evidence. More research is required to fully explore the benefits of such an avoidance diet and whether it is beneficial to the whole OFG cohort of patients or simply to a subset. Whilst the purpose of this paper is not to explore the justification or evidence base of this diet, it is a reasonable inference that patients receiving an OFG diagnosis are likely to be considering such a diet and engaging with internet based information in the coming years.[5,6]. Given that this diet can be complex and challenging to adhere to in practice, it is absolutely essential to supply patients with helpful, clear, and accurate guidelines about how best to achieve this diet, though of course such advice should not replace the role played by health professionals. None of the websites demonstrated full compliance with JAMA benchmarks, which raises concerns about the accuracy of information, and the risk of potential bias. The HONcode Seal recognises and promotes websites containing high quality, up-to-date, and regularly monitored information. This was obtained by only two websites. The paucity of certification may be due to a lack of awareness about the HONcode, along with the financial cost involved in applying and maintaining accreditation.

If we wish to educate and empower patients, we must ensure that online health information is accessible as well as accurate. The US Department of Health and Human Services, the American Medical Association (AMA), and the National Institutes of Health (NIH) recommend that information should be written at a level that a 6th-grade (11-12 years old) US student can comprehend[26]. The readability scores in this study shows that most of the websites (9/12) were 'fairly difficult' to 'very difficult' to read, requiring on average a 10th-Grade US education to comprehend. According to the ALEXA ranking system, Wikipedia was the most popular website, but OFG pronounces its content 'difficult' to read. For patients with lower health literacy, it is particularly important that health information is accessible, as they are more likely to have chronic disease, lower self-management skills, poorer compliance to prevention and treatment regimens, and inferior outcomes [27]. Information that is difficult to read can lead to the misinterpretation of material, and poorly informed decision-making.

The concept of 'shared decision making' has become a standard principle in modern medical practice. It requires physicians to work collaboratively with their patients, sharing health information, identifying their values, and recognising the patient's right to take control of their own bodies and treatments. It has been shown that this collaborative approach is greatly facilitated when patients are well informed about their conditions, and have access to clear and reliable information about treatment options. Such material not only enriches patients' medical knowledge and decision making, but also improves their treatment adherence, coping skills, and health behaviours. In view of these benefits, and the obvious disadvantages faced by OFG patients who lack ready access to this information, it is imperative that steps are taken to improve the quality and readability of online information. To this end, is will be desirable for oral physicians to work closely with website health providers and 'expert patients' on the type and style of information given on this condition and its treatments[28,29].

It must be acknowledged that this study does have its limitations. The searches were restricted to the English language, and conducted on just three – albeit the largest – search engines. The DISCERN tool used in this study was developed for use by laypeople as well as health professionals, and yet both authors are Oral Medicine physicians, who may be more critical of health information than most patients. Another possible limitation is that DISCERN does not allow for the evaluation of scientific papers or subscription websites to which some patients might have access.

Furthermore, this instrument is subjective, and may not protect against bias, in spite of the training underwent by the authors and their pilot study. Having said this, previous studies *have* validated the use of DISCERN, and confirmed adequate levels of inter-user reliability[14]. The readability score may also have its weaknesses, such as the fact that the scores do not take into account the layout of a website, nor the use of images and figures. Finally, while our study focused on the disorder OFG, we did also consider the management of OFG through a benzoate and cinnamon-free diet. The authors acknowledge that there is conflicting evidence concerning the nature of this diet, and that there are many other exclusion diets, and medical and surgical therapies available for OFG.[2[Despite these issues, the fundamental findings of this study are clear – there is a real opportunity here to improve the quality of patients' lives through better online education.

CONCLUSION

The quality of information related to both OFG and its management with a benzoate and cinnamon-free diet is poor and difficult to read. We recommend that clinicians, in collaboration with expert

patients, devise accurate, accessible, and readable information, which can be viewed by anyone who wishes to find out more about this condition, and especially by OFG patients and their families.

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