

Online Information on the Treatment of Burning Mouth Syndrome: Quality and Readability

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Aims: To evaluate the quality and readability of online information about the treatment of burning mouth syndrome (BMS). **Methods:** An internet search using the phrase “burning mouth syndrome treatment” was carried out on the Google search engine (www.google.co.uk) on 8 June 2015, and the first 100 websites listed were examined. Data collection included DISCERN score, the *Journal of the American Medical Association* (JAMA) benchmarks for website analysis score, the presence of the Health on the Net (HON) Foundation seal, and the Flesch Reading Ease Score (FRES). Descriptive statistics were performed using Microsoft Office Excel. **Results:** The search strategy initially yielded 635,000 links; following the application of the exclusion criteria, 53 sites remained for analysis. The overall DISCERN score varied between websites, with half of all websites achieving an overall score of 2 and none of these websites achieving the maximum score of 5. The mean score \pm standard deviation (SD) was 2.4 ± 0.7 . Only 10 (18.9%) of the websites achieved the four JAMA benchmarks while 3 (5.7%) of the websites did not achieve any of them. Only 9 (17%) displayed the HON seal. The FRES of the websites ranged from 32.4 to 82.2; the mean \pm SD rating was 55.4 ± 10.7 , which is considered to reflect fairly difficult reading. **Conclusion:** The information available online about BMS is of questionable quality and content. Perhaps engaging patients in determining what type and format of information they desire when searching online for health information could guide clinicians and researchers alike in providing reliable and readable information sources. *J Oral Facial Pain Headache* 2017;31:147–151. doi: 10.11607/ofph.1717

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The International Headache Society (IHS) defines burning mouth syndrome (BMS) as “an intraoral burning or dysaesthetic sensation, recurring daily for more than 2 hours per day over more than 3 months, without clinically evident causative lesions.”¹ Due to the emphasis on the absence of a clinically causative lesion, Scala et al classified BMS into primary/idiopathic BMS and secondary BMS, which is oral burning secondary to local or systemic causes.² Local factors can include candidiasis and xerostomia while systemic factors may refer to diabetes mellitus and vitamin B12 deficiency.³ In addition to oral burning, patients may also report subjectively dry mouth or excess saliva, elevated taste or loss of taste, and tingling or sensations of paresthesia.⁴

The diagnosis of BMS can present a challenge for clinicians and a diagnostic dilemma.⁵ Patients have often attended dentists, general medical practitioners, gastroenterologists, and neurologists prior to diagnosis.⁶ The diagnostic challenge presented by BMS can lead to diagnostic delays, with studies demonstrating an average delay of between 34 and 41 months from first presentation to diagnosis.^{7,8} Following the onset of symptoms, this diagnostic delay may result in increased anxiety in patients. Using patient-reported depression and anxiety scales, Gao et al found that patients with BMS had statistically significantly higher depression and anxiety scores in comparison to age-matched and sex-matched healthy controls.⁶ In another study, neither the anxiety nor the depression scores of patients with BMS decreased over time,

Table 1 A Summary of Website Categorization

Categorization	n (%)
Affiliation	
Commercial	35 (66)
Nonprofit organization	11 (20.8)
University or hospital	6 (11.3)
Government	1 (1.9)
Specialization	
Exclusively related to BMS	1 (1.9)
Partially related to BMS	52 (98.1)
Content type	
Medical facts	51 (96.2)
Clinical trials	5 (9.4)
Question and answer	23 (43.4)
Human interest stories	2 (3.8)
Presentation type	
Image	16 (30.2)
Video	2 (3.8)
Audio	0 (0)

irrespective of the treatment intervention and in spite of a statistically significant reduction in all other patient-reported outcomes recorded.⁹

Patient information has been proven to reduce anxiety levels and promote patient satisfaction in patients in a medical and surgical setting.^{10,11} More and more patients are using the internet to search for health-related information^{12,13} supplementary to that already supplied by health care professionals in a clinical setting. In a recent study of patients at risk of cardiomyopathy, Minto et al found that online health information usage has been associated with a reduction in patient anxiety.¹⁴ With the reported high levels of anxiety in BMS patient populations and the increasing use of the internet for health information, the aim of this study was to evaluate the quality and readability of online information about the treatment of BMS.

Materials and Methods

An Internet search using the phrase "burning mouth syndrome treatment" was carried out on the Google search engine (www.google.co.uk) on 8 June 2015, and the first 100 websites listed were examined. Due to the highly variable context of group discussions, these sites were excluded along with sites containing duplicate content, irrelevant content, nonfunctional sources, scientific articles, password-required access, or those that were advertising products. A pro forma was used to facilitate standardized data collection, recording the following data: site affiliation (commercial, nonprofit organization, government, university/medical center),¹⁵ content type (exclusively related to BMS or partially related to BMS; medical

facts, clinical trials, human interest stories, question and answer), multimedia presentations (image, video, audio); DISCERN score; the *Journal of the American Medical Association* (JAMA) benchmarks for website analysis score; and the Health on the Net (HON) Foundation seal.

DISCERN is a 16-point questionnaire used to judge the quality and reliability of published health information that aims to help determine good-quality, evidence-based information on treatment choices.¹⁶ These questions are subjectively rated; hence, all websites were reviewed by two reviewers (S.A. and S.P.). JAMA benchmarks for website analysis require the clear presentation of four individual facets. These are the authorship of medical content (details of the author credentials), attribution (references of information provided), disclosure (website ownership, conflicts of interest revealed), and currency (dating the initial content and any subsequent updates).¹⁷ The display of HON seal was also recorded. Compliance with the HON code of conduct is required for the seal to be awarded, and there are eight components of the code of conduct: authoritative, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, and advertising policy.¹⁸

Readability was evaluated using the Flesch Reading Ease Score.¹⁹ To indicate the textual comprehension difficulty of a text, the following automated formula was used through a website (www.readability-score.com):

$$206.835 - (1.015 \times \text{average sentence length}) - (84.6 \times \text{average number of syllables per word})$$

Descriptive statistics were performed using Microsoft Office Excel.

Results

The search strategy initially yielded 635,000 links, of which the first 100 websites were included. After applying exclusion criteria, 47 websites were excluded: 6 group discussion, 6 websites with duplicate content, 12 irrelevant content, 4 nonfunctional sources, 16 scientific articles, 1 website with password-required access, and 2 that were advertising products. After exclusion, 53 websites remained for the assessment.

Regarding the affiliation and specialization, 66% of the 53 websites analyzed were commercial, and only 1 website was exclusively dedicated to BMS. Almost all of the websites (n = 51) included medical facts, with a third of the websites reviewed including images (30.2%) (Table 1). The overall DISCERN score varied between websites, with half of all websites achieving

an overall score of 2 and none of these websites achieving the maximum score of 5. The overall mean score \pm standard deviation (SD) for all of the assessed websites was 2.4 ± 0.7 . Questions with the poorest responses were “does it describe the risks of each treatment?” and “does it describe how the treatment choices affect overall quality of life?”; 88.7% and 81.1% of the websites scored 1 to these questions, respectively. Table 2 provides an overview of DISCERN results. Summaries of the JAMA benchmark results are presented in Tables 3 and 4. Only 18.9% of the websites achieved the four benchmarks, while 5.7% of the websites did not achieve any of them. Only 9 of the 53 assessed websites (17%) displayed the HON seal.

The FRES of the websites ranged from 32.4 to 82.2. The mean rating was 55.4 ± 10.7 , which is considered to reflect fairly difficult reading. The highest readability score was achieved by a personal blog website where no information about the author was available, while the lowest score was achieved by a website designed by a private dental practice.

Discussion

In 2014, the National Health Service (NHS) in the UK launched an initiative to encourage patients to take control of their health. The goal of this proposal was to persuade patients to become better informed about their health concerns and thereby engage with clinicians in their own health care management.²⁰ Studies have demonstrated the clinical benefits of a well-informed patient, with better compliance and improved clinical outcomes reported.²¹ As part of this process of patient empowerment, however, readable and reliable health information must be available to patients. While information leaflets are commonplace in medical and dental practices, patients frequently search online for information about their ailments to augment the material.²² This process allows patients to confirm the validity of the information provided by

Table 2 Means, Standard Deviations (SD), and Ranges of the Included Websites (n = 53) Assessed by DISCERN

Question (max score)	Mean (SD)	Range	Interquartile range
Reliability	22.3 \pm 6.6	12–38	16.5–26
Explicit aims (5)	3.2 \pm 1	1–5	3–4
Attainment of aims (5)	3.7 \pm 1.1	1–5	3–5
Relevance (5)	3.3 \pm 1	1–5	3–4
Explicit sources (5)	2.2 \pm 1.5	1–5	1–4
Explicit date (5)	2.6 \pm 1.4	1–5	1–3
Balanced and unbiased (5)	3.0 \pm 1	1–5	2.5–3
Additional sources (5)	1.9 \pm 1.4	1–5	1–3
Areas of uncertainty (5)	2.7 \pm 1.6	1–5	1–4.5
Treatment options	13.0 \pm 4.1	6–24	9.5–16
How treatment works (5)	1.6 \pm 0.8	1–4	1–2
Benefits of treatment (5)	2.4 \pm 0.9	1–4	2–3
Risks of treatment (5)	1.2 \pm 0.5	1–3	1–1
Effects of no treatment (5)	1.7 \pm 1.3	1–5	1–2
Effects on quality of life (5)	1.3 \pm 0.6	1–3	1–1
All alternatives described (5)	2.8 \pm 0.8	1–5	2–3
Shared decision (5)	2.1 \pm 1.6	1–5	1–3
Overall (5)	2.4 \pm 0.7	1–4	2–3

Table 3 Summary of JAMA Benchmarks

JAMA benchmarks	n (%)
Authorship	33 (62.3)
Attribution	18 (34)
Disclosure	49 (92.5)
Currency	33 (62.3)

Table 4 Total Number of Achieved JAMA Benchmarks

Number of JAMA benchmark achieved	n (%)
4	10 (18.9)
3	19 (35.8)
2	15 (28.3)
1	6 (11.3)
0	3 (5.7)

the health care provider and also to search for advice and support from others who may have a similar illness or condition.²⁰

In an era of shared decision-making, it is laudable that the NHS would promote patient education. However, how well informed will patients who rely on web-based information be when the achieved DISCERN and FRES scores are considered in this study? Over half of the websites reviewed scored 2 or less with the DISCERN instrument, and the average FRES score indicated a fairly difficult reading level. It can therefore be concluded that the majority of the material reviewed was of questionable quality and challenging readability.

The positive influence of online health information in chronic illnesses such as diabetes mellitus has been established in the literature, with diabetic patients seeking information about their symptoms and the suitability of the treatment being used to manage their condition.^{23,24} In the case of chronic pain conditions, internet-based self-management interventions have proven to be effective in the management of chronic lower back pain.²⁵ Patients have reported searching for information to provide a greater understanding of their pain and searching for others with chronic pain to overcome their social isolation secondary to the pain experienced.²⁶ Like BMS, fibromyalgia presents a diagnostic challenge,

with Choy et al reporting that the diagnosis of fibromyalgia could take an average of 2.3 years, with over a third of patients seeing three or more physicians prior to diagnosis.²⁷ Means for coping with the pain and types of treatment available were the most common topics searched by patients with fibromyalgia following diagnosis.²⁸ Although the quality of online information has not been assessed for chronic pain conditions or for fibromyalgia, the trend for patients seeking online information has been established, and the positive influence of this information on patients' self-care and empowerment has been demonstrated in the literature.²⁹

The negative impact of BMS on the daily life of patients has also been reported in the literature.^{9,30} As highlighted in a review of the literature, the evaluation of patient-reported outcomes, including quality of life (QoL), is vital to assess the psychosocial impact of BMS on patients and also to determine the effectiveness of any interventions used, as no clinically detectable changes are expected.³¹ This is an area that is poorly addressed in the online information, with a mean DISCERN score of 1.3. International support groups, which can provide information and emotional support to patients and their families, have been established for other chronic oral conditions such as for oral lichen planus. These organizations can address some of the psychosocial issues faced by patients with chronic diseases.³² Perhaps the establishment of an international BMS support group could address some of the deficiencies online about QoL in BMS.

A vital component of any doctor-patient interaction is the consent process. For consent to be considered valid in a patient who is deemed capacitous, it must be both voluntary and informed.³³ Part of the information that must be provided includes the risks and benefits of the treatment options being considered, and another of the DISCERN questions that was poorly addressed was "does it describe the risks of each treatment?" According to the General Medical Council in the UK, doctors must inform their patients if investigations or treatments may cause serious adverse effects, even if the likelihood is very small. Less grievous complications should also be explained to patients if they occur frequently.³⁴ Clinicians should take particular care in discussing the risks of any proposed treatments in consultation with patients with BMS, as access to this information will not be easily gleaned elsewhere.

Conclusions

The information available online about BMS is of questionable quality and content. The present findings, although not universally applicable due to the limitation of the study to English-language information, reflect the findings of other studies in which online health information of different disorders has been assessed. Engaging patients in determining what type and format of information they desire when searching online for health information will undoubtedly guide clinicians and researchers alike in developing reliable and readable information sources that are truly beneficial to patients.

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