Online Information on the Treatment of Burning Mouth Syndrome –

Quality and Readability

Authors

Shatha Alnafea, University College London, UCL Eastman Dental Institute London, UK

Stefano Fedele, University College London, UCL Eastman Dental Institute London, UK; NIHR University College London Hospitals, Biomedical Research Centre, London, United Kingdom

Stephen Porter, University College London, UCL Eastman Dental Institute London, UK; NIHR University College London Hospitals, Biomedical Research Centre, London, United Kingdom

Richeal Ni Riordain, University College London, UCL Eastman Dental Institute London, UK

Corresponding author:

Richeal Ni Riordain, NIHR Academic Clinical Lecturer, UCL Eastman Dental Institute, 256 Grays Inn Rd, London, WC1X 8LD

richeal.niriordain@gmail.com

Key words

Burning mouth syndrome; Patient information; Online health information; Shared-decision making; Quality of life

Abstract

Aims: the aims of this study were to evaluate the quality and readability of online information regarding the treatment of 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 June 8th 2015. The first 100 websites listed were then 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) seal and the Flesch Reading Ease Score. Descriptive statistics were performed using Microsoft Office Excel.

Results: The search strategy initially yielded 635,000 links and 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 (2.4 ± 0.7). Only 18.9% (10) of the websites achieved the four JAMA benchmarks while 5.7% (3) of the websites had not achieve any of them. Nine of the 53 assessed websites (17%) displayed the HON seal. The Flesch Reading Ease scores (FRES) of the websites ranged between 32.4 and 82.2. The mean rating was 55.4 (±10.7), which is considered to reflect fairly difficult reading.

Conclusion: In conclusion, the information available online regarding 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 such reliable and readable information sources.

Introduction

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 or idiopathic BMS and secondary BMS. Secondary BMS is oral burning secondary to local or systemic causes[2]. Local factors can include candidiasis and xerostomia whilst 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, alerted taste or lost of taste and tingling or paraesthetic sensations[4].

Diagnosing BMS can present a challenge for clinicians with Klasser et al referring to BMS as 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 delay, with studies demonstrating an average delay of between 34 months 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 significant higher depression and anxiety scores in comparison to age and sex matched healthy controls[6]. In a study by Ni Riordain et al neither the anxiety nor the depression scores of

patients with BMS decreased over time 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]. Increasing numbers of patients using the Internet to search for health-related information [12, 13], with this information adding to that already supplied by the healthcare professional in a clinical setting. In a recent study of patients at risk of cardiomyopathy by Minto et al the authors 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 aims of this study were to evaluate the quality and readability of online information regarding 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 June 8th 2015. The first 100 websites listed were then examined. Due to the highly variable context of group discussions these sites were excluded along with sites containing duplicate content, irrelevant content, non-functional sources, scientific articles, advertising products and password-required access. A

proforma was used to facilitate standardized data collection, recording the following data: site affiliation (commercial, non- profit organisation, government, university/ medical centre) [15], content type be it exclusively related to BMS or in part related to BMS (medical facts, clinical trials, human interest stories, question and answer), multimedia presentations (image, video, and audio), DISCERN score, the *Journal of the American Medical Association* (*JAMA*) benchmarks for website analysis score and the Health on the Net (HON) seal.

DISCERN is a 16-point questionnaire, used to judge the quality and reliability of published health information, it aims to help determine good quality evidence-based information on treatment choices [16]. These questions are subjective rating; hence all websites were reviewed by two reviewers (SA and SP). 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. There are eight components of the HON code of conduct – 'Authoritative, Complementarity, Privacy, Attribution, Justifiability, Transparency, Financial disclosure, Advertising policy' [18].

Readability was evaluated using the Flesch Reading Ease Score [19]. The following automated formula, 206.835 – (1.015 x average sentence length) –

(84.6 x average number of syllables per word), was used through a website (www.readability-score.com) to indicate the textual comprehension difficulty of a text. The higher the score the easier the passage is to read.

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. Applying exclusion criteria, 47 websites were excluded. Specifically, 6 group discussion, 6 websites with duplicate contents, 12 irrelevant contents, 4 non-functional sources, 16 scientific articles, 2 advertising products and 1 website with password-required access. After exclusion, 53 websites remained for the assessment.

Regarding the affiliation and specialization, of the 53 websites analysed, 66% were commercial whilst only 1 website was exclusively dedicated to burning mouth syndrome. Almost all of the websites (n=51) included medical facts with a third of the websites reviewed included 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 for the all 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?" where 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 Table 3 and 4. Only 18.9% (10) of the websites achieved the four benchmarks while 5.7% (3) of the websites had not achieve any of them. Only 9 of the 53 assessed websites (17%) displayed the HON seal.

The Flesch Reading Ease scores (FRES) of the websites ranged between 32.4 and 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 - were no information about the author was available - while the lowest score 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 regarding their health concerns and thereby engage with clinicians in their own healthcare management [26]. Studies have demonstrated the clinical benefits of a well-informed patient with better compliance and improved clinical outcomes reported [27]. As part of this process of patient empowerment, however, readable and reliable health information must be available to patients. Whilst information leaflets are commonplace in medical and dental practices,

patients frequently search online regarding their ailments, not to replace the information provide but to augment the material [28]. This process allows patients to confirm the validity of the information provided by the healthcare provider and also search for advice and support from others who may have similar illness or condition [29]. In an era of shared decision making it is laudable that the NHS would promote patient education, however, how well informed will our patients relying on web-based information when we consider the DISCERN and FRES scores achieved 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. We can therefore conclude that the majority of the material reviewed was of questionable quality and changeling 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 regarding their symptoms and the suitability of the treatment being used to managed their condition[20, 21]. When looking at chronic pain conditions Internet based self-management interventions have proven to be effective in the management of chronic lower back pain[22]. Patients have reported searching for information to provide a greater understating of their pain and searching for others with chronic pain to overcome their social isolation secondary to the pain experienced[23]. Like BMS, fibromyalgia presents a diagnostic challenge, with Choy et al reporting that the diagnosis of fibromyalgia could take on average 2.3 years with over a third of patients

seeing 3 or more physicians prior to diagnosis[24]. Means for coping with the pain and types of treatment available were the most common topics searched by patients with fibromyalgia following diagnosis[25]. Although the quality of online information has not been assessed for chronic pain conditions nor for fibromyalgia the trend for patients seeking online information has been established and the positive influence of this information in patients' self-care and empowerment demonstrated in the literature.

The negative impact of BMS on the daily life of patients has been reported in the literature [9, 30]. As highlighted in a review article by Ni Riordain and McCreary the evaluation of patient reported outcomes, including 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 have been established for other chronic oral conditions such as oral lichen planus, which can provide information and emotional support to patients and their families. These organisations 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 regarding 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 to be provided includes the risks and benefits of the treatment options being considered. Another of the DISCERN questions which was poorly addressed was "does it describe the risks of each treatment?". According to the General Medical Council a doctor must inform patient 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.

In conclusion, the information available online regarding BMS is of questionable quality and content. These findings, although not universally applicable due to the limitation of this study to English language information, reflect other studies in which online health information of different disorders have 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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Table 1 A summary of website categorization

Categorisation	Number (%)
Affiliation	
Commercial	35 (66)
Non-profit organisation	11 (20.8)
University or hospital	6 (11.3)
Government	1 (1.9)
Specialisation	
Exclusively related to BMS	1 (1.9)
Partly 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)

Table 2 Means, standard deviations (SD), and ranges of the included websites (N=53) assessed by DISCERN

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

Table 3 A summary of JAMA benchmarks

JAMA benchmarks	Number (%)
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	Number (%)
4	10 (18.9)
3	19 (35.8)
2	15 (28.3)
1	6 (11.3)
0	3 (5.7)