

Web based information on the treatment of oral leukoplakia – quality and readability

Running title:

Online information on oral leukoplakia

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Abstract

Objective: To categorise the content and assess the quality and readability of the online information regarding the treatment of oral leukoplakia.

Methods: An online search, using the term 'leukoplakia treatment' was carried out on June 8th 2015 using the Google search engine. The content, quality and readability of the first 100 sites were explored. The quality of the web information was assessed using the following tools, the DISCERN instrument and the Journal of the American Medical Association (JAMA) benchmarks for website analysis and the HON seal. Readability was assessed via the Flesch Reading Ease Score.

Results: The search strategy generated 357,000 sites on the Google search engine. Due to duplicate links, non-operating links and irrelevant links, a total of 47 of the first 100 websites were included in this study. The mean overall rating achieved by included websites using the DISCERN instrument was 2.3. With regard to the JAMA benchmarks, the vast majority of examined websites (95.7%) completely fulfilled the disclosure benchmark and less than 50% of included websites met the three remaining criteria. A mean total readability score of 47.5 was recorded with almost 90% of websites having a readability level ranging from fairly difficult to very difficult.

Conclusion: Based on this study the online health information regarding oral leukoplakia has challenging readability with content of questionable accuracy. As patients often search for health information online it would be prudent for clinicians to highlight the caution with which online information should be interpreted.

Introduction

'White plaques of questionable risk, having excluded (other) known diseases or disorders that carry no increased risk for cancer' is the WHO definition of a leukoplakia (1). Leukoplakia is considered a clinical description, broadly categorised as homogeneous or non-homogeneous, with no specific histopathological pattern (2). These chronic lesions have reported rates of malignant transformation ranging from 0.13% to 36.4% (3) with a weighted average annual oral cancer incidence attributable to leukoplakia of 1.36% (4). This malignant transformation is more commonly seen in non-homogeneous types of leukoplakia with for example a sevenfold increase reported in a Danish population (5).

The importance of the locus of control in patients with chronic conditions has been established since the 1950s. Although locus of control has not been explored specifically in patients with oral leukoplakia there have been numerous studies in chronic diseases which highlight the influence of locus of control in the patient's ability to cope with their illness, including diabetes mellitus, breast cancer and laryngeal cancer (6, 7). In a study by Härkäpää et al the authors found that patients with chronic lower back pain, a high locus of control was associated with successful treatment outcomes. Patients with this high internal locus of control believe that their health related outcomes are linked to their own informed choices and actions (8). Information provided in a healthcare setting can contribute to these informed choices and actions; however, patients often augment this information by searching for information online themselves. In a study of dental patients by Ni Riordain et al the

authors found that over a third of patients presented for dental treatment had researched their dental/oral conditions online (9). Studies have been conducted regarding the content and quality of the web-based information for patient with oral conditions including oral ulcers, head and neck cancer and even oral leukoplakia (10-12). However we could find no study that assessed both the quality and readability of information on oral leukoplakia. Therefore the aims of this study were to categorise the content and assess the quality and readability of the online information regarding the treatment of oral leukoplakia.

Materials and Methods

An online search, using the term 'leukoplakia treatment' was carried out on June 8th 2015 using the Google search engine without any further refinements after the initial search. The content, quality and readability of the first 100 sites were explored. The list website compiled was firstly screened for any duplicate sites or non-operative links. The exclusion criteria applied included scientific articles, book reviews, websites with no contents related to leukoplakia, websites which denial direct access to the content or where membership/subscriptions were requirement and non-english language links. Based on the categorisation outlined by Ni Riordain and McCreary (11), the remaining websites were grouped based on affiliation (commercial, non-profit organisation, university/medical centre and government), specialisation (exclusively related to leukoplakia, partly related to leukoplakia), content type (medical facts, clinical trials, human interest stories, question and answer) and content presentation (image, video and audio).

The quality of the web information was assessed using the following tools, the DISCERN instrument (13) and the Journal of the American Medical Association (JAMA) benchmarks for website analysis (14) and the Health on the Net (HON) seal (15). To facilitate standardized data collection a proforma was created using Microsoft Excel.

DISCERN is a validated 16-point questionnaire, developed in the University of Oxford, comprising of 15 questions which examine the reliability (section 1: questions 1-8) and specific details of information on treatment choices (section 2: question 9-15) plus an overall quality rating (section 3: question 16). Each question is rated on a numerical scale from 1 to 5 (1 = very poor, 2 = poor, 3 = moderate, 4 = good, 5 = excellent). DISCERN has proven inter-observer reliability and construct validity when used either by medical professionals or laypersons (16). Owing to the subjective nature of the DISCERN assessment, a second reviewer was used to assess the website quality.

JAMA benchmarks were used to analyse the quality of each of the website. The instrument requests that a website should prominently display these core standards including authorship of medical content (authors and contributors, their affiliations and relevant credentials), attribution (list of references and sources of information), disclosure (presence of website ownership, sponsorship, advertising, commercial funding arrangements, conflicts of interest) and currency (dates content posted and updated) (14).

Health on the Net, founded in 1995, is a Swiss-based non-profit organisation dedicated to guiding both medical professionals and patients or health consumers to the reliable sources of online health and medical information. It accredits websites that abide by the HON code of ethical conduct, which is composed of eight outlined principles including authority, complementarity, privacy, attribution, justifiability, transparency, financial disclosure and advertising policy.

Readability was assessed via the Flesch Reading Ease Score. This system was developed by Rudolph Flesch in the 1940s and based upon a formula that incorporates formula average sentence length and the average number of syllables per word (17). The higher the score the easier the passage is to read, for example a score of 90-100 approximately equates to the reading age of a 10 year old while a score of 30-49 represents the reading age of university students (18).

Ethical approval was not necessary for this study.

Results

The search strategy generated 357,000 sites on the Google search engine. Of the first 100 sites, 11 were duplicated links and 5 non-operating links. Of the remaining 84 websites, 21 were links to scientific articles, 13 web pages had no contents specific to oral leukoplakia, 2 web pages with inaccessible due to password requirement and 1 online medical dictionary were further excluded. A total of 47 websites were included in this study.

Of the 47 websites analysed over half were commercial with no website had content exclusively dedicated to leukoplakia. Almost all websites (93.6%) included medical facts and only 16 websites contained images both clinical photographs and some histopathological images (Table 1). The mean overall rating achieved by included websites using the DISCERN instrument was 2.3 (± 0.7) out of 5, with no any websites yielding the maximum rating and five receiving the minimum overall achievable rating (Table 2). With regard to the JAMA benchmarks, the vast majority of examined websites (95.7%) completely fulfilled the disclosure benchmark and less than 50% of included websites met the three remaining criteria. Two websites did not achieve any benchmarks while nine websites fulfilled all four benchmarks (Table 3). Only eight of the 47 websites (17%) displayed the HON seal.

Regarding readability of selected websites, Flesch Reading Ease ratings varied from 23.5 to 72.9, with mean total readability score of 47.5 (± 11.1). Almost 90% (41/47) of websites had readability level ranging from fairly difficult to very difficult (Figure 1).

Discussion

The Internet is increasingly becoming a prevailing source of medical-oriented information and has revolutionized patients' access to healthcare information (19). In an interview-based study of a population sample across 7 European countries more than 70% of the Internet users went online to seek for health information during the pervious year (20). Hu et al highlighted that those who

sourced online health information were more often patients with long-term conditions who believed they had control over their illness (21). While increased patient accessibility to health information may appear to be positive, the reliability and quality of the online content remain a pivotal issue for e-health consumers as the information on the internet is entirely unregulated and has the potential to misguide health (22). Not only do these websites need to provide the reliable and accurate contents, it is also essential that the content be readable for the target audience. The majority of the websites included in this study (n=26) had readability levels as difficult or very difficult when assessing the content of the text.

In a study of patients with potentially malignant changes on cervical biopsy Hellsten et al found that women who were provided with extensive information during lengthy consultations were still dissatisfied with the amount of information provided (23). High anxiety levels were also noted in this patient population after the initial diagnosis. Likewise in patients with oral premalignant lesions, Lin et al found high levels of anxiety, which were more prevalent in patient with unmet health information needs (24). This heightened anxiety in patients will not only have a negative impact on the well being of the patient but anxiety has also been associated with noncompliance with medical treatment, which is of concern for clinicians (25). This further emphasises the need for reliable and readable online information in patients with oral precancerous lesions including oral leukoplakia.

Limited availability of reliable and readable information has also been found to impede a patient's ability to make decisions about various treatment options

presented to them by their healthcare provider (26). One of the DISCERN questions which yielded the lowest scores in this study was related to the information provided on the risks of treatment. As early as the late 1980s clinicians were encouraging a shift from the unidirectional traditional consultations where clinicians informed patients of the risks and benefits of treatments to an informed decision making process encouraging meaningful dialogue between the clinician and a well informed patient (27). This informed decision making process is thought to improve communication and trust and hence enhancing the patient-clinician relationship (28). Without adequate reliable information regarding the risks of the treatment options in oral leukoplakia this improved patient-practitioner relationship cannot flourish.

In a study by Meric et al, assessing the quality of online information regarding breast cancer, the authors found that the 16 websites that met all four of the JAMA benchmarks contained the most accurate health information (29). It is of concern therefore that in this study only 9 of the websites reviewed achieved all of the JAMA benchmarks, calling into question the accuracy of the information presented in the remaining 38 sites. Further to the questionable accuracy of websites with fewer JAMA benchmarks, commercial sites were also found to have more inaccurate medical statements (29). Twenty-five of the websites included in this study were commercial in origin with only 3 of these displaying the HON seal. Again highlighting the uncertain accuracy of the information on the websites reviewed.

In conclusion, based on this study the online health information regarding oral leukoplakia has challenging readability with content of questionable accuracy.

With the high levels of anxiety in patients with oral potentially malignant diseases (30) and those with inadequate health information it is critical for clinicians to direct patients to websites with accurate readable e-information regarding oral leukoplakia.

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Conflict of Interest Statement

There are not conflicts of interest.

References

1. WARNAKULASURIYA S, JOHNSON NW, VAN DER WAAL I
Nomenclature and classification of potentially malignant disorders of
the oral mucosa. *J Oral Pathol Med* 2007; 36: 575-80.
2. NAPIER SS, SPEIGHT PM Natural history of potentially malignant oral
lesions and conditions: an overview of the literature. *J Oral Pathol Med*
2008; 37: 1-10.
3. ARDUINO PG, BAGAN J, EL-NAGGAR AK et al. Urban legends
series: oral leukoplakia. *Oral Dis* 2013; 19: 642-59.
4. PETTI S Pooled estimate of world leukoplakia prevalence: a systematic
review. *Oral Oncol* 2003; 39: 770-80.
5. HOLMSTRUP P, VEDTOFTE P, REIBEL J et al. Long-term treatment
outcome of oral premalignant lesions. *Oral Oncol* 2006; 42: 461-74.
6. TRENTO M, TOMELINI M, BASILE M et al. The locus of control in
patients with Type 1 and Type 2 diabetes managed by individual and
group care. *Diabet Med* 2008; 25: 86-90.
7. BREMER BA, MOORE CT, BOURBON BM et al. Perceptions of
control, physical exercise, and psychological adjustment to breast
cancer in South African women. *Ann Behav Med* 1997; 19: 51-60.
8. HARKAPAA K, JARVIKOSKI A, MELLIN G et al. Health locus of
control beliefs and psychological distress as predictors for treatment
outcome in low-back pain patients: results of a 3-month follow-up of a
controlled intervention study. *Pain* 1991; 46: 35-41.
9. NI RIORDAIN R, MCCREARY C Dental patients' use of the Internet. *Br
Dent J* 2009; 207: 583-6; 575.

10. NI RIORDAIN R, HODGSON T Content and quality of website information on the treatment of oral ulcers. Br Dent J 2014; 217: E15.
11. NI RIORDAIN R, MCCREARY C Head and neck cancer information on the internet: type, accuracy and content. Oral Oncol 2009; 45: 675-7.
12. LOPEZ-JORNET P, CAMACHO-ALONSO F The quality of internet information relating to oral leukoplakia. Med Oral Patol Oral Cir Bucal 2010; 15: e727-31.
13. CHARNOCK D, SHEPPERD S, NEEDHAM G et al. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health 1999; 53: 105-11.
14. SILBERG WM, LUNDBERG GD, MUSACCHIO RA Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor--Let the reader and viewer beware. JAMA 1997; 277: 1244-5.
15. HEALTH ON THE NET FOUNDATION. HONcode section for medical professionals. . In.: <http://www.hon.ch/HONcode/Pro/intro.html>, July 2015.
16. REES EC, FORD JE, SHEARD CE Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. Patient Educ Couns 2002; 47: 273-275.
17. FLESCH R A new readability yardstick. J Appl Psychol 1948; 32: 221-233.
18. WARD K. Flesch Readability Formula. In. trans4mind.com: http://www.trans4mind.com/personal_development/writing/Readability_software/flesch.htm 2015.

19. KUMMERVOLD P, CHRONAKI C, LAUSEN B et al. eHealth Trends in Europe 2005-2007: A Population-Based Survey. *Journal of Medical Internet Research* 2008; 10: e42.
20. ANDREASSEN HK, BUJNOWSKA-FEDAK MM, CHORONAKI CE et al. European citizens' use of E-health services: A study of seven countries. *BMC Public Health* 2007; 7.
21. HU X, BELL RA, KRAVITZ RL et al. The Prepared Patient: Information Seeking of Online Support Group Members Before Their Medical Appointments. *Journal of Health Communication: International Perspectives* 2012; 17.
22. PAPANICOLAOU U Conceptualising information literacy as social practice: a study of pregnant women's information practices. *Information Research* 2013; 18: 280.
23. HELLSTEN C, SJOSTROM K, LINDQVIST PG A 2-year follow-up study of anxiety and depression in women referred for colposcopy after an abnormal cervical smear. *British Journal of Obstetrics and Gynaecology* 2008; 115: 212-218.
24. LIN H-Y, CHEN S-C, PENG H-L et al. Unmet information needs and clinical characteristics in patients with precancerous oral lesions. *European Journal of Cancer Care* 2015.
25. DIMATTEO MR, LEPPER HS, CROGHAN TW Depression Is a Risk Factor for Noncompliance with Medical Treatment. *Archives of Internal Medicine* 2000; 160: 2101-2107.
26. STAIRMAND J, SIGNAL L, SARFATI D et al. Consideration of comorbidity in treatment decision making in multidisciplinary cancer

team meetings: a systematic review. *Annals of Oncology* 2015; epublication ahead of print January 20, 2015.

27. LIDZ CW, APPELBAUM PS, MEISEL A Two Models of Implementing Informed Consent. *Archives of Internal Medicine* 1988; 148: 1385-1389.
28. BRADDOCK CH, EDWARDS KA, HASENBERG NM et al. Informed Decision Making in Outpatient Practice. Time to Get Back to Basics. *Journal of the American Medical Association* 1999; 282: 2313-2320.
29. MERIC F, BERNSTAM EV, MIRZA NQ et al. Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. *British Medical Journal* 2002; 324: 577-581.
30. KORAY M, DULGER O, AK G et al. The evaluation of anxiety and salivary cortisol levels in patients with oral lichen planus. *Oral Dis* 2003; 9: 298-301.

Figure 1 Frequency distribution of Flesch Reading Ease score of included websites

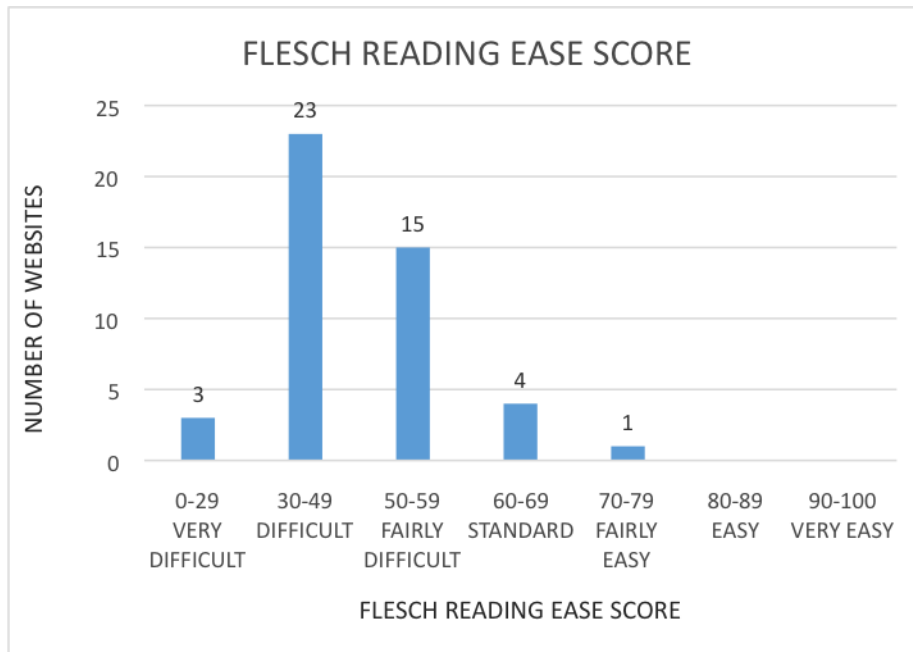


Table 1 Categorisation of websites based upon specialisation, content type and content presentation.

Categorization	Number (%)
<i>Specialisation</i>	
Exclusively related to leukoplakia	0 (0)
Partly dedicated to leukoplakia	47 (100)
<i>Content</i>	
Medical facts	44 (93.6)
Clinical trials	2 (4.3)
Question and answer	8 (17.0)
Human interest stories	3 (6.4)
<i>Content presentation</i>	
Image	16 (34.0)
Video	1 (2.1)
Audio	2 (4.3)

Table 2 Means and standard deviations (SD) of the included websites (N=47) measured by the DISCERN instrument

Section	Question	Mean (SD)
Reliability	Explicit aims (5)	2.1 (1.0)
	Aims achieved (5)	3.0 (1.3)
	Relevance (5)	2.9 (1.1)
	Explicit sources (5)	2.4 (1.6)
	Explicit date (5)	2.4 (1.5)
	Balanced and unbiased (5)	3.3 (1.2)
	Additional sources (5)	1.8 (1.3)
	Areas of uncertainty (5)	1.9 (1.3)
Treatment options	How treatment works (5)	1.7 (0.8)
	Benefits of treatment (5)	1.7 (0.8)
	Risks of treatment (5)	1.2 (0.5)
	Effects of no treatment (5)	3.4 (1.4)
	Effects on quality of life (5)	1.1 (0.5)
	All alternatives described (5)	2.9 (1.4)
	Shared decision (5)	2.0 (1.0)
	Overall rating (5)	2.3 (0.7)

Table 3 Website content based on JAMA benchmarks

JAMA benchmarks	Number (%)
Authorship	19 (40.4)
Attribution	21 (44.7)
Disclosure	45 (95.7)
Currency	21 (44.7)