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Web-based information on oral dysplasia and precancer of the mouth – Quality and readability

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ABSTRACT

Objectives: The numbers of individuals with oral cancer are increasing. This cancer is preceded by oral epithelial dysplasia (OED). There remains no detailed study of the online information presently available for patients with OED or indeed what information such patients may require to be appropriately informed regarding their condition. Hence, the aim of the present study is to assess the patient-oriented web content with respect to OED. *Methods:* The first 100 websites yielded from nine searches performed using different search terms and engines were considered. These were assessed for content, quality (DISCERN instrument, Journal of the American Medical Association benchmarks, and Health on Net seal) and readability (Flesch Reading Ease Score and Flesch-Kincaid Grade Level).

Results: There was a general scarcity of OED content across the identified websites. Information about authors, sources used to compile the publication, treatment, and shared decision were limited or absent. Only 6% and 27% of the websites achieved all the four JAMA benchmarks and HON seal, respectively. The average readability level was at 10th grade (US schools), which far exceeds the recommended levels of written health information. *Conclusion:* At present patients seeking information on OED are likely to have difficulty in finding reliable information from the Web about this disorder and its possible impact upon their life. Further work is thus required to develop a web-based resource regarding OED that addresses the shortfalls demonstrated by the current study.

Introduction

Oral epithelial dysplasia (OED) is a histopathological finding associated with an increased risk of malignant transformation of the oral epithelium [1,2]. The World Health Organisation (WHO) describes dysplasia as an altered epithelium that shows various architectural and cellular changes on the surface epithelial layer as a result of accumulated genetic changes [3]. It is estimated that OED affects 0.25% to 0.5% of populations [4]. Clinically, it can present as white, red, or mixed lesion, categorised under the umbrella of oral potential malignant disorders (OPMD), which precede oral cancers in up to 70% of cases [5].

In 2016, the estimated Internet penetration was at 46% and 92% of the world and UK populations respectively [6]. A US population-based survey showed that around 80% of the web users have searched for online health information (OHI) in the previous year to find information about a medical condition, treatment options, medications, and other topics related to lifestyle [7]. Concerns exist regarding access to online information and also the quality of web-based health information which refers to how reliable, accurate, trustworthy, current [8], and readable the information is. In addition, there may be concerns regarding the subjectivity of commercial bias [9], whether the content is peer reviewed [10], and compliance with rules and regulations [11].

To make the most of their OHI patients require an acceptable level of health literacy. Health literacy empowers individuals by providing the cognitive and social skills needed to 'gain access to, understand and use information in ways which promote and maintain good health' [12]. Those with poor health literacy are believed to have a reduced awareness of their disease process and management as well as limited appreciation of the way health system work. This makes this group at greater risk of poor health, lower quality of life, and higher mortality than those with good or high health literacy [13–15]. It is thought that health literacy is associated with general literacy, a term which includes the ability of a person to read, write, speak and problem solve [16]. Therefore a key element of general literacy and in turn health literacy is the readability of the text material. Current evidence indicates that the readability scores of various web-based health information are higher than recommended reading levels [17–19], thus making the currently

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available potentially incomprehensible and unusable.

There is limited knowledge about the patient-oriented web content with respect to OED. The use of validated assessment instruments could ease the identification of search engines and websites with relevant content, higher quality, and recommended readability levels for written health information. The aim of this study is thus to evaluate the content, quality, and readability of web-based information on OED.

Materials and methods

Search strategy

Web searches for the terms 'oral dysplasia', 'treatment of oral dysplasia', and 'treatment of precancer of the mouth' was carried out between February and May 2017 using the most commonly employed search engines in the UK: Google.com, Yahoo.com, and Bing.com [20]. For each term, the first 100 websites per search engine were selected with no refinement.

Exclusion criteria

Links to scientific content (e.g. books or journals), websites that required membership or subscription, websites promoted by search engines, sites that advertise for clinical services or techniques, community-based forums without professional guidance, and websites with only video or audio content were excluded [21,22].

Content assessment

The content of the included web sites was assessed following the categorisation method used by Ni Riordain and McCreary [23], which grouped the websites according to affiliation (commercial, non-profit organisation, governmental, or university/medical centre), specialisation (the site is entirely or partly related to the searched topic), content type (medical facts, clinical trials, human interest stories, and question and answer), and content presentation (image, video, and audio).

Quality assessment

The DISCERN instrument [24], Journal of the American Medical Association (JAMA) benchmarks [25], and Health on the Net (HON) seal [26] were used to evaluate the quality of identified websites. DISCERN is a validated 16-item tool rated by a 5-point scale (5 = complete fulfilment of the quality criterion and 1 = none) thataims to ensure making informed choices based on trusted evidence by evaluating the quality of written health information. It includes questions about the reliability of information (items 1-8), treatment choices (items 9-15), and an overall rating question (item 16). JAMA quality benchmarks ensure the accountability of web-based health information by considering the authorship (authors, their affiliations and credentials), attribution (citations, sources, and copyright), disclosure (acknowledging the ownership, sponsorship, advertising, underwriting, funding and support, and possible conflict of interest), and currency (demonstrate the dates and updates) of the given information. HON is a non-profit foundation that aims to assess the quality and transparency but not the accuracy of web-based health information. HON code of conduct includes eight criteria: authority, complementarity, confidentiality, attribution, justifiability, transparency, financial disclosure, and advertising policy.

Readability assessment

The readability, described as 'the reading comprehension level a person must have to understand written materials' [27], was assessed using an online tool (https://readable.io) considering two readability formulae: Flesch Reading Ease Score (FRES) [28] and Flesch-Kincaid Grade Level

(FKGL) [29]. FRES assesses the readability on a 0–100 scale (0 = hardest and 100 = easiest), while FKGL estimates the number of years of education in the US needed to understand a passage of written material. There are no available readability guidelines of the patient-related health information in the UK [30]. Therefore, an approach that considers a range of difficulty as easy (4th, 5th, and 6th grade), average difficulty (7th, 8th and 9th grade), and difficult (10th grade and above) was followed [31].

Data analysis and representation

The data was collected using a study specific proforma and recorded in Microsoft Excel to facilitate descriptive statistics. The representation of variables was performed by IBM SPSS (version 22.0). To ensure the intra-rater agreement of DISCERN, one of the identified websites was randomly selected and re-assessed by the same investigator (AA), two months after the initial evaluation and the intraclass correlation coefficient (ICC) was determined [22]. Also, the ICC was calculated to ascertain the level of agreement on DISCERN scores between two investigators (AA and RNR) using one randomly selected site. Ethical approval was not required for this study.

Results

Only 80 out of 900 websites met the inclusion criteria however 36 sites were considered for the summary evaluation after eliminating the duplicates. The screening results for all searches are summarised in Fig. 1. For all searches, Google yielded the highest relevant content to patients, with less non-operating and duplicating links than both of Yahoo! and Bing. Regarding the search terms, "treatment of precancer of the mouth" generated the most relevant websites to patients with all search engines (n = 35) followed by 'treatment of oral dysplasia' (n = 23), and 'oral dysplasia' (n = 20). The categorisation of the identified websites is summarised in Table 1.

The quality assessment of the 36 identified websites by DISCERN showed a mean overall rating of 2.24 (\pm 0.90) out of 5 with no website obtained the highest score (Table 2). The average measure ICC for intrarater and inter-rater assessment of DISCERN were at 0.789 [95% C.I. = 0.419, 0.925 (P < 0.001)] and 0.789 [95% C.I. = 0.403, 0.926 (P < 0.001)] respectively. There is no consensus available to interpret the ICC estimate based on 95% confidence interval, however, a score between 0.75 and 0.90 demonstrates good reliability [32,33]. HON seal was presented in ten of the identified websites (27%). The number and percentage of websites per obtained JAMA benchmark are demonstrated in Fig. 2. With regard to the total number of benchmarks obtained, four benchmarks were met in 2 websites (6%), three benchmarks met in 5 websites (14%), two benchmarks met in 11 websites (31%), one benchmark was met in 14 websites (39%), and no benchmark was found in 4 websites (10%).

With regard to the readability assessment, an analysis with the FKGL showed a range of grade levels from 5th grade to university level (14th grade) with a mean around 10th grade. Using the FRES formula showed a range of scores between 18.1 and 71.9 with a mean of 47.65 (\pm 13.63). The categorisation of the 36 selected websites based on FRES scores is outlined in Fig. 3.

Discussion

Individuals are motivated to seek health information online in an attempt to seek reassurance, to find alternative opinions on medical interventions and to better comprehend information delivered in the clinical setting [34]. This information-seeking behaviour can aid the 'shared-decision making' model being promoted in healthcare interactions [34]. For example, those affected by OPMD and other potentially malignant conditions frequently use the Internet to obtain information about their condition and treatment options in spite of the potential for

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