YouTube™ and oral lichen planus: an appraisal of the educational quality of information

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Abstract: The objective of this study was to analyze the quality of videos on oral lichen planus (OLP) available in YouTube™. A cross-sectional analytical study was conducted by searching the video sharing platform YouTube™. Videos aimed at clarifying the etiological and clinical characteristics, diagnostic criteria, treatment, and prognosis of OLP were included. A total of 481 videos were retrieved and 37 were included in the study according to the selection criteria established. Most of the videos evaluated (86.5%; n = 32) were produced by independent users. The average reliability was 1.8 and quality assessment classified only three videos (8.1%) as having good/excellent quality. A significant correlation was observed between the length of the video analyzed and its quality and reliability (p < 0.05), as well as between the reliability and usefulness of the video (p = 0.03). YouTube™ has become a leading source of information for the general population. However, a significant number of these videos have a low quality. Students, professionals, and healthcare providers must be more actively involved in providing clear, accurate, and reliable evidence-based information in an accessible language in order to enable significant improvement in patient care delivery.

Keywords: Lichen Planus, Oral; Health Communication; Self-Directed Learning as Topic.

Introduction

Lichen planus is an immune-mediated chronic inflammatory disease of unknown etiology that affects 0.22 to 5% of the population.[1] The oral cavity is one of the main sites involved.[2] Among the variants of oral lichen planus (OLP), the erosive and reticular subtypes are the most common. The erosive variant is frequently associated with painful symptoms.[2,3] The World Health Organization (WHO) classifies OLP as a potentially malignant disorder; however, the rates of malignant transformation reported in the literature vary considerably.[4]

In fact, OLP is an enigmatic disease due to peculiarities related to its etiopathogenesis and biological behavior. The disease is known to be a cell-mediated immune response, although the antigen triggering this response has not been identified.[5,6] Management of the disease is complex and often requires a multidisciplinary approach.[7] Traditionally,

it is the role of the healthcare worker to establish the diagnosis and to provide patients with disease-related information. However, the past decade has witnessed the growing use of the internet for seeking medical information as a result of its high penetration and accessibility.[8]

YouTube™ is one of the most popular video sharing platforms, with about 1.9 billion monthly logged-in users.[9] According to Duncan et al.,[10] the use of YouTube™ provides a new educational approach, facilitating the connection between theory and practice and promoting users' discussion and critical thinking. Recent studies report the use of YouTube™ for patient self-education related to oral health issues, such as burning mouth syndrome, leukoplakia, and oral cancer.[11,12,13]

No study has so far addressed the real impact of YouTube™ videos on the diffusion of information about OLP. The aim of this study was to evaluate the quality and accuracy of the content of YouTube™ videos on OLP for the general population.

Methods

Study design and search strategy

This was a cross-sectional, analytical, retrospective study in which the video sharing platform YouTube™ (www.youtube.com) was searched using the keywords "lichen planus" and "oral lichen planus" and the corresponding terms in Portuguese and Spanish. The study was conducted in August 2019 and all videos available on the platform since the foundation of YouTube™ were considered for evaluation. Previous studies indicate that 95% of users who perform a YouTube™ search do not watch more than the first 60 videos listed in the search results and most studies employing YouTube™ as a search mechanism use the first 60 to 200 videos for analysis.[14] The initial proposal of our study was to watch and analyze the first 200 videos obtained for each search term in the three languages analyzed (totaling 1,200 videos), if this number of videos was available.

Selection and analysis of videos

During initial screening, all videos were analyzed independently by two evaluators and disagreements

were solved in a consensus meeting. Videos aimed at clarifying the etiological and clinical characteristics, diagnostic criteria, and prognosis of OLP were included. Duplicate videos, videos in languages other than English, Spanish, or Portuguese, videos without sound, videos on other types of diseases, videos reporting animal or *in vitro* studies, and videos demonstrating surgical procedures for removal of the lesion were excluded. Videos describing the findings of a study/research project and videos targeting a specialized audience (for example, a conference/scientific meeting presentation or a lecture in the medical/dental area) were also excluded.

The upload sources were categorized into government agency/government organization/professional organization or independent users.[15] The following data were extracted from each video: upload date, country of origin, number of views, number of likes, number of dislikes, and video length. Based on these data, the interaction score was calculated as follows: (number of likes – number of dislikes × 100 / number of views).

The quality of the videos was classified according to the criteria adapted from Bernard et al.,[16] assigning the following scores: 1 = poor quality, lack of information on OLP, not useful for patients; 2 = overall poor quality, some information provided but few important topics addressed, very limited use for patients; 3 = moderate quality, some important information is adequately addressed but other information is little discussed, somehow useful for patients; 4 = good quality, most of the relevant information is provided but some topics are not addressed, useful for patients; 5 = excellent quality, very useful for patients. Therefore, scoring was done in a five-point Likert scale based on the quality of information. To analyze the quality of the videos included in the present analysis, the following topics were considered: a) Epidemiology; b) Pathogenesis; c) Clinical features; d) Diagnostic tests; e) Treatment; f) Prognosis.

The usefulness of the videos was evaluated based on the quantity/quality of information on important topics related to OLP, such as etiology, clinical characteristics, diagnosis, and prognosis (Table). The videos were classified as follows based

on the sum of scores: 0 = not useful; 1 to 3 = slightly useful; 4 to 7 = moderately useful, and 8 to 10 = very useful. Disagreements between examiners were solved by a third researcher. The usefulness of the videos was classified according to the criteria adapted from Kovalski et al. [13]

The reliability of the videos was analyzed as described by Singh et al.[17] based on five questions. The videos received 1 point for each aspect addressed, according to the presence of the information in the video. Finally, reliability could vary from 0 to 5, counting the total number of questions evaluated. The questions used in this analysis were: a) Are the aims clear and achieved? b) Are the sources of information used reliable? c) Is the information presented in a balanced and unbiased manner? d) Are additional sources of information listed for patient reference? e) Are areas of uncertainty mentioned?.[17] The quality, usefulness, and reliability of the included videos were analyzed independently by three evaluators. After assessment of the data, disagreements were discussed in a consensus meeting.

Statistical analysis

The collected data were analyzed statistically using IBM SPSS Statistics 20 (SPSS, Chicago, Illinois, USA). The Mann-Whitney test was used to correlate usefulness, reliability, and quality of the videos with the number of views, interaction, and video length.

Table 1. Usefulness scoring criteria.

Scoring item	Score
Does the video describe the etiopathogenesis of OLP?	1
Does the video describe the clinical-pathological characteristics of OLP?	2
Does the video mention the main signs/symptoms of OLP?	2
Does the video use representative images of OLP?	2
Does the video describe the main therapeutic modalities of OLP?	2
Does the video correctly describe the management and possible implications of the diagnosis of OLP?	1

OLP: oral lichen planus. Score 0 = not useful; scores 1–3 = slightly useful; scores 4–7 = moderately useful; scores 8–10 = very useful.

Results

Video search and selection

The search using the term oral lichen planus and its synonyms and corresponding terms in Portuguese and Spanish retrieved 481 videos; 337 remained after the removal of duplicates. Screening of these videos resulted in 239 videos that were evaluated qualitatively according to the criteria established. After excluding 202 videos, 37 videos were included in our analysis (Figure). Table 2 shows the characteristics of the sample and the overall performance of the videos
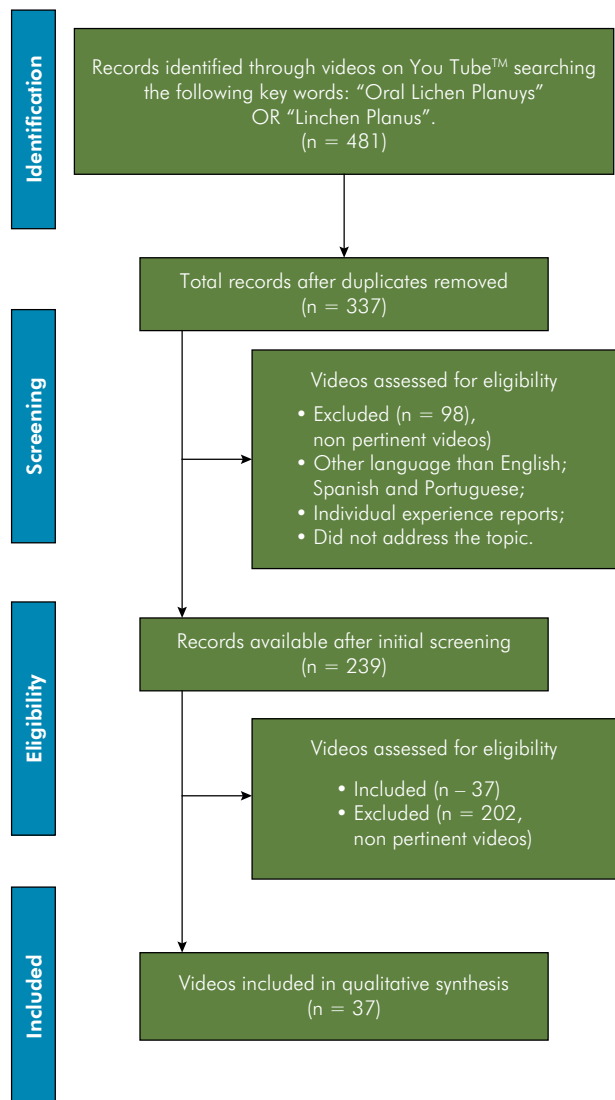

Figure. Flow diagram the identification and screening process of the included videos.

Table 2. Sample characteristics.

Variable	
Source	n (%)
Independent users	32 (86.5
Professional organizations / Government agencies / professional organization	5 (13.5)
Uploaded since (days)	
Mean	1,074.00
Min-Max.	152–3,830
Duration (min:s)	
Mean	09:03
Min-Max.	00:27–50:41
Views	
Mean	19,48
Min-Max.	76–106,524
Likes	
Mean	151
Min-Max.	3– 960
Deslikes	
Mean	8.7
Min-Max.	0–40
Viewer's Interaction	
Mean	1.5
Min-Max.	0.1–8.7
Usefullness	(1–10)
Mean	4.5
Min-Max.	0–10
Realibility	(1–5)
Mean	1.8
Min-Max.	0.0–5.0
Quality,	n (%)
Poor	9 (24.3)
Limited	7 (18.9)
Moderate	13 (35.1)
Good	5 (13.5)
Excellent	3 (8.1)

evaluated. Most of the videos (86.5%; n = 32) were produced by independent users. The mean video length was 9.3 min (range: 1.27 to 50.41).

Four (10.8%) of the videos selected were in Portuguese, 11 (29.7%) were in Spanish, and 22 (59.4%) were in English.

Characteristics and usefulness of YouTube™ videos on OLP

Regarding visibility, the least viewed video among those selected had 76 views and the most viewed had 106,524 views. Most videos (48.6%) were classified as moderately useful, followed by slightly useful (27.02%), very useful (13.5%), and not useful (10.8%). Mean reliability was 1.8 and quality only three videos (8.1%) were classified as having good or excellent quality.

The treatment of OLP was addressed in 64.8% of the videos evaluated. Epidemiology (43.2%), etiopathogenesis (72.9%), detailed clinical characteristics (43.2%), and diagnostic methods (45.9%) were also frequently cited. With respect to diagnosis, the cut-off for assessment was the mentioning of clinical features and the need for biopsy, although some videos discussed the use of immunofluorescence as a complementary diagnostic technique. The mention of still poorly established events, such as the autoimmune nature of OLP and the association with hepatitis C virus, was striking in part of the videos. In some videos, especially those in English and Spanish, the speaker did not make a clear distinction between OLP and lichenoid reactions, even attributing the use of medications and heavy metals to OLP. The most frequently cited treatment modality were topical corticosteroids; however, systemic corticosteroids, laser therapy, and alternative therapies (*e.g.*, herbal medicine and homeopathy) were also mentioned. Fifty-one percent of the videos mentioned differential diagnosis. Furthermore, the implications of OLP, such as the possibility of malignant transformation, chronicity of the lesions, and need for regular dental visits, were addressed in 64.8% of the videos.

We observed a significant relationship between video length and the quality and reliability of the videos analyzed ($p < 0.05$), as well as between reliability and usefulness ($p = 0.03$). However, there was no association of interaction and number of views with quality or reliability (Table 3). In addition, no significant differences were found regarding the quality, usefulness, and reliability of the videos according to the language ($p = 0.12$).

Table 3. Analyses of usefulness and quality assessment score in relation to length in minutes, views, viewer's interaction, and reliability score.

Characteristics	Usefulness					Quality					
	Very useful	Moderately useful	Slightly useful	Not useful	p-value	Excellent	Good	Moderate	Limited	Poor	p-value
Views	19.833 ± 29.171	10.548 ± 16.502	35.594 ± 34.620	17.966 ± 14.312	> 0.05*	2.722 ± 3.904	25.243 ± 28.087	6.354 ± 23.401	36.385 ± 10.639	26.462 ± 17.049	> 0.05*
Video length in minutes (mean ± SD)	28.4 ± 23.9	9.02 ± 6.2	6.9 ± 4.6	4.51 ± 4.01	**0.001***	28.93 ± 21.74	19.3 ± 18.4	8.5 ± 6.1	7.1 ± 5.5	5.6 ± 3.09	**0.001***
Viewer's Interaction	1.6 ± 2.3	1.6 ± 1.6	0.7 ± 0.5	2.45 ± 4.1	> 0.05*	2.1 ± 3.2	0.8 ± 0.3	1.6 ± 1.6	1.8 ± 3.05	1.1 ± 1.4	> 0.05*
Realibility	2 ± 1	1.6 ± 1.09	1.6 ± 0.5	1.25 ± 0.5	**0.03***	2.3 ± 1.1	1.4 ± 0.5	1.4 ± 0.7	2.0 ± 1.2	2.0 ± 1.4	> 0.05*

*Mann-Whitney test. Bold values indicate statistically significant results.

Most of the videos (64.8%) mentioned the sources of information or advised viewers on where to find more information about OLP. Interaction with the videos was generally positive, with a mean interaction score of 1.5.

Discussion

Previous studies have analyzed YouTube™ as a source of information on different pathological processes that can affect oral health.[11-13,18-20] Our study is the first to examine the content of YouTube™ videos on OLP and to evaluate the quality of the information provided.

Oral lichen planus is commonly associated with painful symptoms and consequently with a decline in the quality of life of patients. In addition, education level and socio-economic status might affect the psychological well-being of patients with OLP.[21] The symptoms range from a burning sensation to severe pain and rarely regress spontaneously. Most patients with OLP have periods of recurrence and remission, indicating the chronic nature of this lesion.[22] The different treatment modalities for OLP mainly focus on pain control, and long-term follow-up is essential because of the risk of malignant transformation.[7]

As a result of these features inherent to OLP, patients frequently search YouTube™ as an additional source of information about the disease. There are videos with more than 100,000 views on the topic. Unfortunately, the lack of accurate and unbiased information can be potentially harmful to patients since many reports are often uploaded as individual experiences and personal testimonials. In addition, they may encourage patients to undergo a treatment that is not suitable for their particular circumstance.[23] Interestingly, one finding was the lack of a clear distinction between OLP, of unknown etiology, and lichenoid reactions, of known and measurable etiology, which also contributes to the propagation of inaccurate information to YouTube™ users. The focus of videos on etiological factors, clinical characteristics of the lesion, and the importance of early detection would be a potential strategy to increase population awareness about OLP.

In our study, the number of views and interaction score were not significantly associated with the usefulness or quality of the videos analyzed, indicating that patients seeking information about OLP on YouTube™ are likely to receive non-useful and/or insufficient information. The paucity of institutional/ government videos (corresponding to only 13.5% of our sample) corroborates our results since such videos are associated with a greater quality score and interaction/view ratio.[24] Lorenzo-Pouso et al.[25] reported that the information on OLP provided by websites to the general public has large quality deficits. In our study, following the criteria adapted by Bernard et al.,[16] only one video achieved the maximum score in all items.

Our study identified most videos as moderately useful, because they mentioned the clinical characteristics of the disease and provided information about treatment and prognosis. Despite methodological differences, this was also found in a study by Passos et al.,[19] in which most of the

analyzed videos on YouTube about mouth cancer were also considered to be moderately useful. Although the Internet enables free debate on various issues, identifying information without scientific evidence is difficult. Assessing the quality of information on the Internet is a complex task, and no single criterion that considers all content exists, resulting in a superficial evaluation. To help Internet users analyze this information, several methods and tools have been created. In our study, we adapted tools used in previous articles[11,12,13,15,19] to analyze the reliability, usefulness, and quality of the videos on the OLP.

Although the etiology and pathogenic mechanisms underlying the development of OLP are not fully understood, some etiological factors such as genetic predisposition, bacterial and viral infection, autoimmunity, immunodeficiency, and allergies have been proposed.[5] Clarifying the possible factors related to the etiology of the disease is an important approach to improve patient understanding of OLP. In one of the videos analyzed, the information was structured in order to establish a line of reasoning between the cofactors associated with OLP, such as secondary infection with *Candida* spp, and exacerbating cofactors such as stress, diet, and secondary infection with *Candida* spp. A possible pathogenic role of *Candida spp* in OLP has been evaluated in recent studies, but its etiopathological role is not yet fully understood.[26]

Since patients with OLP frequently exhibit an altered psychological profile characterized by anxiety and depression, this situation must be addressed.[27] In fact, special emphasis must be given to relevant controversies regarding OLP, such as its potential of malignant transformation or its relationship with hepatitis C virus infection. During data collection, several contents related to these topics emerged, such as videos indicating that all patients with OLP are at an "increased risk" of malignant transformation. Although malignant transformation of OLP is uncommon, it is one of the most covered problems in YouTube™ videos related to this lesion. Such information must be disseminated with caution, considering that it is strongly associated with psychological stress of patients with OLP.[27,28]

The patient is nowadays understood as an active agent in treatment decisions and shared decision making is extremely important in current clinical practice.[29] The first-line treatment for OLP is based on topical steroids such as clobetasol propionate. In addition, the systemic corticosteroids cyclosporin and tacrolimus can be used in patients who are unresponsive to topical steroids.[30,31] Despite the potential of these drugs for the clinical and symptomatic control of OLP, they are associated with side effects related to their long-term use.[32] Hence, alternative therapies for the management of OLP are reported in several videos. However, many videos on the treatment of OLP are biased because they mention only one possible therapeutic modality and describe it as "effective", although the sources of information on treatment effectiveness are not cited. This fact was observed especially in videos on the use of herbal medicines for OLP treatment. Knowledge of patients about the different existing treatment modalities is therefore important so that they can discuss with the responsible professional the use of a specific treatment in their individual case. However, low-quality and biased information undermines this possibility.

We suggest the creation of a mechanism by YouTube™ that allows patients to identify videos with better quality in the health area as a fundamental step to avoid exposure of the population to inaccurate and/or low-quality information. For this purpose, a quality seal should be created for videos revised and approved by specialists in the area in order to ensure the accuracy of the content. However, it is important to emphasize that patients should always be aware that the information found on YouTube™ or on any other online platform is not a substitute for medical advice, which is necessary for the diagnosis and management of OLP.

Conclusion

YouTube™ has become a leading source of information for the general population over the last few decades. Unfortunately, most of the videos contain low-quality and little reliable information. However, this mass communication system, by its inherent

nature, provides access to an immediate intervention thus allowing for an educational opportunity. Students, professionals, and healthcare providers must be more actively involved in providing clear, accurate, and reliable evidence-based information in an accessible language in order to enable significant improvement in patient care delivery.

Acknowledgments

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