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Article type : Original Article

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Informative title: Cross-Sectional Study on the Quality of Oral Lichen Planus Videos on YouTube™

Running title: YouTube™ content analysis for OLP

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Acknowledgments

This study was not funding resources.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/JOP.13128](https://doi.org/10.1111/JOP.13128)

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Abstract

Background: YouTube™ is one of the most used platforms for patients looking for health-related information. The purpose of this cross-sectional study was to analyze the available information about oral lichen planus on YouTube™ and how users interact with it. **Methods:** A YouTube™ search for oral lichen planus was performed, setting English UK (language) and United Kingdom (country). Two hundred-fifteen results were screened, and 36 videos met the inclusion criteria. Videos' quality was evaluated using the DISCERN and the Global Quality Scale tools, and by categorizing them through quality assessment, source, duration, views, likes, and dislikes of each video were noted. **Results:** According to quality assessments, 55.6% of the videos were classified as useful, while the 35.1% were classified as misleading/dangerous. The DISCERN and GQS values were generally low (31.56 ± 10.38 and 2.33 ± 1.07 , respectively); DISCERN and GQS were positively correlated to the video length and negatively correlated with the data of upload ($p < 0.05$). **Conclusions:** This study corroborates the results of others that a great number of health-related videos available on YouTube™ feature misleading or potentially dangerous information; although the quality seems to slightly improve over time, medical associations and researchers ought to plan strategies aimed at improving the quality of the information delivered through YouTube™ and other social media.

Keywords: YouTube™, misleading information, dangerous content, oral lichen planus

1 Introduction

Nowadays, an increasing number of patients is using social media in order to obtain information about health issues^{1,2}. Billions of users have visited profiles of healthcare professionals on Facebook™ and Twitter™. Healthcare-related hashtags have recorded over 134 million tweets³; 2. YouTube™ is also a leading platform – where two billion videos are watched every day – and it has the potential to serve as an important source for sharing and disseminating health-related information⁴. However, due to the significant amount of information present⁵ and the lack of revision of the content on this platform⁶, there is very high possibility that inexperienced users might be misled⁴. The adequacy of information diffused on social media is particularly important when patients are living with chronic pathological conditions such as oral lichen planus (OLP)⁴. Moreover, the string ‘oral lichen planus’ is a frequently used search key on the web according to ‘Google Trends’ with a maximum search rate in the United Kingdom (100) (Google Trends, 2019).

The etiology of OLP is complex, and the disease presents multifactorial pathogenesis⁷. A differential diagnosis should always take into consideration other mucosal lesions such as dyskeratosis congenita, leukoplakia, frictional keratosis, pseudomembranous candidosis, oral pemphigus, mucous membrane pemphigoid that may show clinical similarities to OLP and oral squamous cell carcinoma^{8 ; 9}. Various treatments have been employed to treat OLP: from topical and systemic corticosteroids⁷, other immunosuppressive molecules like cyclosporine¹⁰, topical retinoids¹¹ and also natural extracts¹².

The purpose of this study was to analyze the content of information on YouTube™ concerning etiology, local and general manifestations, comorbidities, and treatment of OLP, and to compare it with current scientific knowledge and guidelines. For this reason, this study analyzes OLP-related videos by using the Global Quality Scale (GQS)¹³, the DISCERN tool¹⁴ and by the quality assessment, classifying the videos as useful, misleading, or dangerous¹⁵ in order to measure the scientific quality of these videos.

2 Materials and Methods

Study design

This was an analytical cross-sectional study. Since it was determined that it might be difficult for amateur users to evaluate the quality of the videos appropriately, the latter was correlated with the number of likes and dislike to assess viewers' aptitude to appreciate high- and low-quality content. In addition, the topics covered in the videos and upload sources were analyzed in order to obtain a broad analysis of OLP-related YouTube™ videos.

2.1 YouTube™ search

In this cross-sectional study, YouTube was queried on July 14, 2020, using the term “oral lichen planus” and the filter settings English UK (language) and United Kingdom (country) ordering videos based on the number of views (sort by view count), using the Google Chrome browser in incognito settings. The string ‘oral lichen planus’ is a frequently used search key on the web according to “Google Trends”. In the current study, United Kingdom was set as the default location for Youtube™ search since this country showed the highest interest by region on Google Trends from 2004 onwards, meaning the highest proportion for all “oral lichen planus” queries compared to the other countries (100).

The search returned 215 videos, counted manually. The preliminary analyses of all videos were executed independently by the examiners (AL, DL). After comparing the data, discrepancies were discussed with a third examiner (RS) and a consensus was achieved.

2.1.2 Selection of videos

All the results were examined, and, among these, videos were excluded according to the following exclusion criteria (Figure 1):

- Videos of non-human animals
- Non-English videos
- Videos without sounds or subtitles
- Channels from non-anglosphere countries
- Duplicate videos
- Irrelevant videos (other subjects and controversial subjects)

2.2 Video Quantitative analysis

In this study quantitative data (duration, upload date, source of upload, number of likes/dislikes, ~~category~~, country of origin) were collected by two examiners (FF, MD).

Firstly, the topics of the video clips were collected. If a video covered more than one topic, each topic was listed separately. The content was subsequently categorized according to commonalities and by topics and categories, as discussed in previous studies ^{13; 15; 16; 17}. ~~Multiple categories may apply to each video.~~ Since the title often does not reflect the actual content of the clip, unlike other studies that only used titles to categorize topics, we considered for categorization both titles and contents, as well as producers’ descriptions below each video.

2.2.1 Video Source Encoding

An investigator (AR), who screened the videos initially, determined the video source. Source categories included Dentists/Scientists featured, Independent users, Health information websites, Alleged patients featured, Complementary/alternative promoting, and University Channels.

- Dentist/Scientists featured: a person qualified to practice oral medicine, such as a dentist, or diagnose and treat mucocutaneous disorders, such as a dermatologist;
- Independent users: an individual or a channel with non-professional credentials provided contents related to their own experience;
- Health information websites: user-friendly health sites which can be considered as reliable for delivering health topics;
- Alleged patients featured: someone self-identifies who is likely referring to his personal clinical history;
- Complementary/alternative promoting: channels and/or individual promoters of complementary and alternative medicine;
- University channels: institutions set up to offer public service or provide health-care reliable contents

2.3 Video Qualitative analysis

In this study qualitative data were collected, and overall quality of the videos was assessed by 3 clinicians with experience on OLP management (RS, AL, DDS) using two assessment tools such as GQS and DISCERN¹⁸. The clinicians underwent training sessions to become familiar with quality assessment tools and the rating policy and criteria, in order to optimize inter-rater agreement on the videos. The scientific accuracy of the contents was defined based on the international guidelines and the international scientific literature on the topic OLP^{10; 18 19; 20}. Besides this, videos were classified into useful or misleading or dangerous (quality assessment)^{15; 21} and categorized by topic or content, presence, and profession of a presenter (to be seen in the video, health or non-health professional), and upload sources. In case of differing assessments by the analyzing clinicians, the corresponding video was reassessed by the principal investigator.

2.3.1 DISCERN tool

The DISCERN instrument is used to measure the quality of health information about treatment choices provided in video clips¹⁴. Initially developed for the standardized assessment of written medical

information, in this study a modified version of the DISCERN tool, proposed by Mueller et al. has been used¹⁵. This tool consists of 15 key questions and an evaluation of overall quality with which the publication's reliability (questions 1 to 8), quality of information (questions 9 to 15), and overall quality of a publication (question 16) can be assessed by assigning 1 to 5 points per question: a higher total value means a higher quality of the video clip.

2.3.2 GQS assessment

The GQS, which is based on a 5-point scale, was developed in 2012 by Singh et al.¹³ for the evaluation of YouTube videos and has since been applied in numerous studies. The score measures the quality and flow of information and the value of an information source for lay users.

2.4 Statistical Analysis

Descriptive statistics and Spearman correlation coefficients to calculate the number of likes and dislikes with the values of DISCERN and GQS were, respectively, performed using R software version 3.6.1. The Kruskal-Wallis test was used to highlight differences among the six different source categories. The level of significance was set as $P\text{-value} \leq 0.05$. The comparisons between each source category was evaluated with Mann-Whitney U-test; the level of significance was set as $P\text{-value} \leq 0.008$ (Bonferroni correction for multiple tests). Intraclass correlation (ICC) were calculated, to assess the inter-rater reliability.

3 Results

3.1 Video selection

The selection of the videos was carried out according to the exclusion criteria described in the materials and methods. As shown in the Flow-Chart (Figure 1), of 215 videos appeared, only 36 were included. Most of the excluded videos were from India (148 out of 179 – 82.7%), 14 out of 179 (7.8%) were from not Anglosphere Countries (four from Jordan, three from Greece, three from Pakistan, one from Japan, one from Syria and one from Taiwan) and 11 out of 179 (6.1%) were deemed as not scientific or irrelevant videos. Moreover, 5 out of 179 videos were not in English, and one video, even if uploaded by a UK channel, was excluded since the speaking language was Urdu.

3.2 Video quantitative analysis

The majority of the videos were uploaded from the United States (22/36 – 66.1%), whereas 19.4% (7/36) were of unknown origin. Video clips were uploaded between April 2009 and May 2020. In two videos, the comment function was disabled, and the YouTube statistics were not available. Among the 36 videos, two

belonged to a channel with a Creative Common License, allowing the download of the video and even the use the whole clip or part of it for user's purposes.

The most featured topics were about "clinical features" (65%) and "treatment" (61.1%), while the less treated subjects were comorbidities such as hepatitis C virus (HCV) (presented in the 25% of videos), "epidemiology" (27.8%) and "potential malignant transformation" (30.6%); contents about "ethiopathogenesis" and "diagnosis" were covered, respectively, in 50% and 38.9% of the videos analyzed (Table 1).

Information provided are 63.9% based on healthcare professionals' opinions or experiences (Dentist/scientist featured, Healthcare Information Websites and University Channels), whereas the 36.1% is carried out by Independent Users, Alleged Patient featured (personal opinion experience) and Complementary/Alternative Promoting, as shown in figure 2.

The videos collected a total of 1166136 views, with a mean of 32392.67 views for each video. The total duration of the videos collected was 3:41:07 hours (mean duration per video, 0:06:08, standard deviation, 338.981 seconds). The minimum duration recorded was 36 seconds, whereas the maximum duration amounted to 23:50 minutes.

The videos received a total of 4186 likes, and 235 dislikes yielding a like to dislike ratio of 17.81 (4186:235). It shall be reported that in two videos, interactions, including likes and dislikes, were disabled.

However, two videos were considered outliers by the statistical analysis. Those two videos reached 1800 and 767 likes respectively, whose sum is 2567 out of 4186 (61.32% of total likes). The video length was 00:08:25 and 00:05:29 respectively. In addition, the number of dislikes was 72 and 21, while they have totalized a number of views equal to 144282 and 66598.

3.3 Video Qualitative analysis

The ratings using the DISCERN and GQS scores were consistent, yielding the categorizations shown in Figure 3. The quality of the videos, expressed by the mean overall DISCERN and GQS rating scores, was generally low (31.56 ± 10.38 on a 15 to 75 scale and 2.33 ± 1.07 on a 1 to 5 scale, respectively), with 75 and 5 being the maximum scores.

During the quality assessments, 20 videos (55.6%) were classified as useful, 9 (25%) were classified as misleading, and 4 (11.1%) were classified as dangerous. Particularly, videos deemed as dangerous showed

incompletes or wrong information and they were misinforming in terms of diagnosis, treatment, decision sharing and referring to the appropriate clinician with a high risk for the patient.

In our analysis, we considered 3 (8.3%) of the videos as not classifiable in one of these three categories (neither misleading nor dangerous).

The intraclass correlation (ICC) has been evaluated for DISCERN, GQS, and quality assessment tools leading to a value of 0.986, 0.997, and 0.934 respectively highlighting a very high ratio of agreement between the assessors.

3.3.1 DISCERN scoring

Detailed analysis of the DISCERN values revealed that the major shortcomings were a lack of information about the evidence and source of the posted information (mean $1.67\pm 1.37/5$ – median 1); areas of uncertainty (mean $1.61\pm 1.18/5$ – median 1) and risks of the praised therapy (mean $1.28\pm 0.78/5$ – median 1); and missing recommendations for shared decision making (mean $1.78\pm 1.29/5$ – median 1) or links to additional sources of information (mean $1.56\pm 0.97/5$ – median 1).

Highest DISCERN scores results from University channels (40.4 ± 13.20), dentist/scientists featured channels (34.54 ± 9.26), and health information websites (30.40 ± 3.58) as shown in Table 2. This difference seems to not be significant when compared with other video providers ($p>0.008$).

3.3.2 GQS scoring

Four videos presented unsatisfactory audio quality, with background noise that made it difficult to watch the video. In some cases, the subtitles and, therefore, the contents were able to compensate this problem, allowing to reach GQS scores of a moderate and good level. One of those videos obtained minimum GQS scores (poor quality).

Highest GQS scores were provided by University channels (2.80 ± 1.10), dentist/scientists featured channels (2.77 ± 1.01), and health information websites (2.60 ± 0.55) while the lowest were provided by complementary/alternative promoting channels (1.00) and patients featured videos (1.33 ± 0.58); Kruskal-Wallis test highlighted the differences within the group ($p=0.043$ – Table 2).

3.4 Data correlation

At first, the correlation between DISCERN (sum and mean) and the number of likes was found to be significant ($\rho=0.396$ - $p=0.019$ and $\rho=0.373$ - $p=0.27$) as well as the number of dislikes ($\rho=0.434$ - $p=0.009$ and

$\rho=0.467$ - $p<0.001$ respectively). Once the two outliers were excluded, only the correlation between DISCERN (sum and average) and dislikes was found to be statistically significant ($\rho=0.369$ - $p=0.035$ and $\rho=0.408$ - $p=0.018$). A correlation has been also found between video length and number of dislikes ($\rho=0.356$ - $p=0.036$). No correlation between GQS, number of likes and dislikes, video length, and number of views ($p>0.05$) has been found.

Video Length positively correlate with DISCERN ($\rho=0.434$ - $p=0.008$) and GQS ($\rho=0.358$ - $p=0.032$) and the number of likes ($\rho=0.378$ - $p=0.023$) and dislikes ($\rho=0.345$ - $p=0.039$). Curiously, a negative correlation between DISCERN, GQS and days since the video was uploaded has been found (respectively $\rho=-0.342$ - $p=0.041$, $\rho=0.400$ - $p=0.016$). Once the two outliers were excluded, only the correlation between DISCERN ($\rho=0.434$ - $p=0.008$), GQS ($\rho=0.358$ - $p=0.032$) and video length was found to be statistically significant. Otherwise, number of likes and number of dislikes positively correlate with number of views (respectively $\rho=-0.675$ - $p<0.001$, $\rho=0.750$ - $p<0.001$), highlighting that videos with higher views also had greater user interaction.

4 Discussion

There is a large number of studies in the literature dealing with YouTube™ and oral health, but this is the first study that analyzes the quality of videos on OLP.

OLP is a chronic inflammatory mucocutaneous disease and is classified as a potentially malignant condition by the World Health Organization (WHO) with a predominance in the general population of 1-2%²⁶, it is, therefore, essential to evaluate the content on social media. Furthermore, some previous publications showed that YouTube™ is heavily accessed as a source of information on oral mucosa diseases by non-experienced clinician or lay users^{16; 17; 21; 21; 23}. Notwithstanding the prevalence of the topic examined by the present work, only 215 videos were found on YouTube™. This number can be considered small if compared with other topics previously analyzed on YouTube™ such as oral cancer, Sjögren's Syndrome¹⁶ or oral leukoplakia¹⁷. Such a small number of videos could be due to the presence of filters that have been inserted in the search engine and described in M&M, according to previous studies¹⁵. However, even if you remove the filters, those videos are still the most viewed ones.

This study has pointed out that 21,6% of the videos presented subjective personal experiences, focusing on topics such as treatment (including alternative treatment options, nutritional advice) or whose topic was not clearly explained. Interestingly, the 30,6% of the videos provide misleading or worse, dangerous information for the patient, to which can be added videos that are not found to be dangerous or misleading consistently with the previous literature (24,3%)¹⁵. Among the videos labeled as "dangerous" one video did

not mention the necessity of being evaluated by a clinician and proposes a therapy based on self-medication using purslane. Another video suggested treating oral lichen planus only having a check-up with the naturopath and claims that dietary change alone can cure OLP. The last two videos seemed to show inappropriate clinical features and laser surgical treatment of a single white lesion (supporting a diagnosis of OLP).

The analysis of videos using DISCERN and GQS tools showed that most videos exhibit insufficient quality. Previous studies have reported a similar low quality of the videos when analyzing videos that address other oral diseases and other health topics, also in other search engines^{15; 16; 21; 22; 23; 24}.

In the present study higher quality videos were provided by University channels and Health information websites (Table 2). These data seem to be in agreement with data reported by Delli et al¹⁶ who highlighted that University channels videos, classified as useful, showed a significantly higher GQS. Other studies that analyzed the contents about OLP on other websites, different from YoutubeTM, have also highlighted that information provided by Universities or medical centers had relatively higher DISCERN scores²⁵. Unfortunately, in our study, this difference is neither significant nor for the DISCERN and the GQS ($p>0.008$).

In particular, only one video reaches highest GQS values, and therefore its vision can be recommended to users, in line with what is reported by Kovalski et al. ¹⁷. However, there are other sixteen videos on the OLP that present a quality that ranges from moderate to good and therefore, whose vision is not discouraged to the patients (Figure 3).

Regarding the DISCERN scoring system, it provides important additional information, as reported by Mueller et al. ¹⁵. In this work, the most significant results seem to be the correlation between reliability and video length, and the negative correlation with the days since the videos has been uploaded (upload date).

Delli et al found that the most valuable videos lasted around 7 min ¹⁶. In our study, all the videos that lasted less than 5:29 minutes borrowed insufficient DISCERN scores as shown in Figure 4. Moreover, the mean duration of the most reliable videos was 9:57 minutes (597,43± 290,44 seconds). In this way, our data seem to agree with what was stated by Kovalski et al. ¹⁷ who claims that the length of this kind of video should be long enough for developing the content, but not so long as to lose user's attention. The associations between the duration of YouTube videos and their quality it could be important in order to find the optimal durations of video clips.

Finally, in the video analysis, two of these were deemed outliers for the number of likes. These videos were uploaded from two health information websites, specifically nutritionfacts.org and osmosis.org. The videos were rated as useful in the quality assessment. However, in the GQS analysis, only the nutritionfacts.org video has moderate quality (3/5), while the other offers poor quality (2/5). Besides, the DISCERN values are respectively 60 and 31, with a video quality that seems to be rather moderate. Probably, the highest interaction of these videos lies in the cross-platform configuration of these channels. Both channels are present on other social media such as Facebook™, Twitter™, and Instagram™. In particular, nutritionfacts.org has 811561 followers on Facebook™, 938000 on Instagram™, and 116815 on Twitter™; osmosis.org presents 211000 followers on Instagram, 114381 on Facebook and 17889 on Twitter. Also, both have an app downloadable from the App Store and Google Play: this results in a YouTube™ user base of 593000 and 1.67 million, respectively. Finally, while nutritionfact.org is aimed at patients, osmosis.org is intended for educational and informational purposes only.

Despite the evident strengths, such as the complete analysis of all of the videos on OLP and the use of two distinctive tools like GQS and DISCERN, there are some limitations to our work. For example, results may change according to the date of the query, because of the nature of the Youtube™ platform. Every second, an hour of video is uploaded on this platform and 65000 new videos every day (<http://www.onehourpersecond.com/>). Another limitation might be the use of the tools to assess the quality of video content given the current lack in the literature of standardized methods to evaluate the quality of patient health information videos on YouTube™. For example, one of the analyzed videos showed good quality of contents, science-based but not evidence-based, because of the lack of references. It aimed to address patients, but information revealed to be suitable for healthcare professionals only.

Moreover, we analyzed only videos in English language, excluding a good part of the video, and probably omitting the analysis of some relevant videos notwithstanding the point that other languages could be more spoken than English.

According to our results and in agreement with previous health-related YouTube™ studies^{15; 21; 27}, medical associations and researchers must recognize the reasons of the users' conduct. This would allow them, in conjunction with social media platforms and institutions, to plan strategies aimed at improving the quality of the information delivered through YouTube™ and other social media. As reported by Steinberg et al²⁷, videos presented on YouTube™ are not subject to examination in the same way as content on Wikipedia, which is refereed. Video providers should disclose the references for their videos or to state whether their videos are up to date. According to Fortuna et al.²¹, insofar anybody is allowed to upload a video, it could

be crucial to create protective measures thus assuring the user that the video being viewed has undergone certified review for accuracy of the contents, though an external certification of quality of health-related videos is not an easy work²⁴. Anyhow, this refereed material should be easily found by search engines and appear among the first results. A positive note could be represented by the negative correlation between DISCERN, GQS and days since the videos were uploaded: this could probably be since, in the last three years, there is a trend on the part of healthcare professionals who publish more videos, with a resulting in higher quality.

Author contributions

Antonio Romano had substantial contribution on acquisition, analysis and interpretation of data for the work. Doina Lauritano revised it critically and gave the approval of the final version to be published. Alberta Lucchese and Rosario Serpico contributed in the study conception, verified the analytical methods, revised it critically and approved the final version of the manuscript. Iquebal Hasan contributed on drafting and revising the manuscript. Fausto Fiori performed the statistical analysis. Marco Di Petrillo and Fausto Fiori collected the data and drafted the manuscript. Dario Di Stasio contributed to the work designing, analyzing the data and revising it critically for important intellectual content. He also gave the approval of the final version to be submitted.

Conflicts of interest

Conflicts of interest: none to declare

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Table 1 Information Providers and topics covered in the videos

	Dentist/Scientists featured n= 13	Independent users n= 8	Health information websites n= 5	(Alleged) patients featured n= 3	Complementary /alternative promoting n= 2	University channels n= 5
Epidemiology(%)	5 (38.4)	2 (25)	2 (40)	0	0	1 (20)
Pathogenesis (%)	7 (53.8)	3 (37.5)	3 (60)	0	1 (50)	4 (80)
Comorbidities(%)	2 (15.4)	4 (50)	1 (20)	0	1 (50)	1 (20)
Potential malignant transformation (%)	6 (46.2)	1 (12.5)	1 (20)	0	0	3 (60)
Clinical features(%)	11 (84.6)	7 (87.5)	5 (100)	0	2 (100)	3 (60)
Diagnosis (%)	8 (61.5)	2 (50)	2 (40)	0	0	2 (40)
Treatment (%)	9 (69.2)	3 (37.5)	4 (80)	0	1 (50)	4 (80)

Table 2 Quantitative data, DISCERN and GQS (mean, and standard deviation) for each source of upload. Kruskal-Wallis test was performed to assess the differences within groups ($p \leq 0.05$)

	Video Length	Likes	Dislikes	Views	DISCERN	GQS
Dentist/Scientists featured	545.54 (±453.53)	40.54 (±92.80)	2.69 (±3.97)	6735.08 (±12280.23)	34.54 (±9.26)	2.77 (±1.01)
Independent users	209.63 (±207.80)	14.75 (±26.09)	1.75 (±2.71)	2531.25 (±5764.70)	28.63 (±10.78)	1.88 (±1.13)
Health information websites	234.20 (±152.06)	413.40 (±781.24)	18.80 (±30.91)	151723.60 (±234318.60)	30.40 (±3.58)	2.60 (±0.55)
(Alleged) patients featured	313.00 (±273.17)	4.67 (±5.03)	1.67 (±1.53)	7722.33 (±4704.20)	21.33 (±2.31)	1.33 (±0.58)
Complementary/alternative promoting	297.50 (±362.75)	156.00 (±210.72)	6.50 (±7.78)	11069.00 (±10012.63)	20.00 (±2.83)	1.00 (±0.00)
University channels	358.60 (±199.07)	229.60 (±307.09)	14.80 (±10.87)	50881.40 (±39808.72)	40.40 (±13.20)	2.80 (±1.10)
Sig. (Kruskal-Wallis Test)	0.439	0.082	0.094	0.010*	0.011*	0.043*

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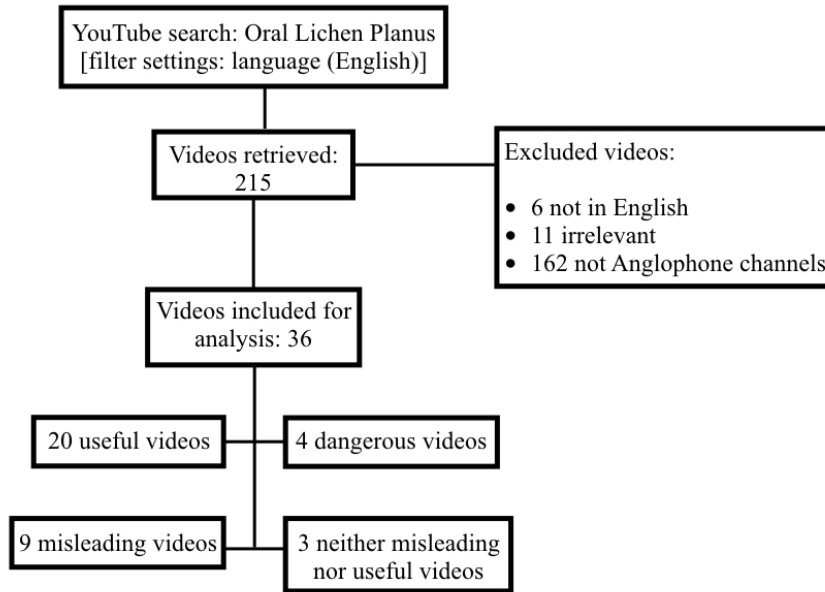
Figure Legends

Figure 1 Flowchart diagram of the selection process

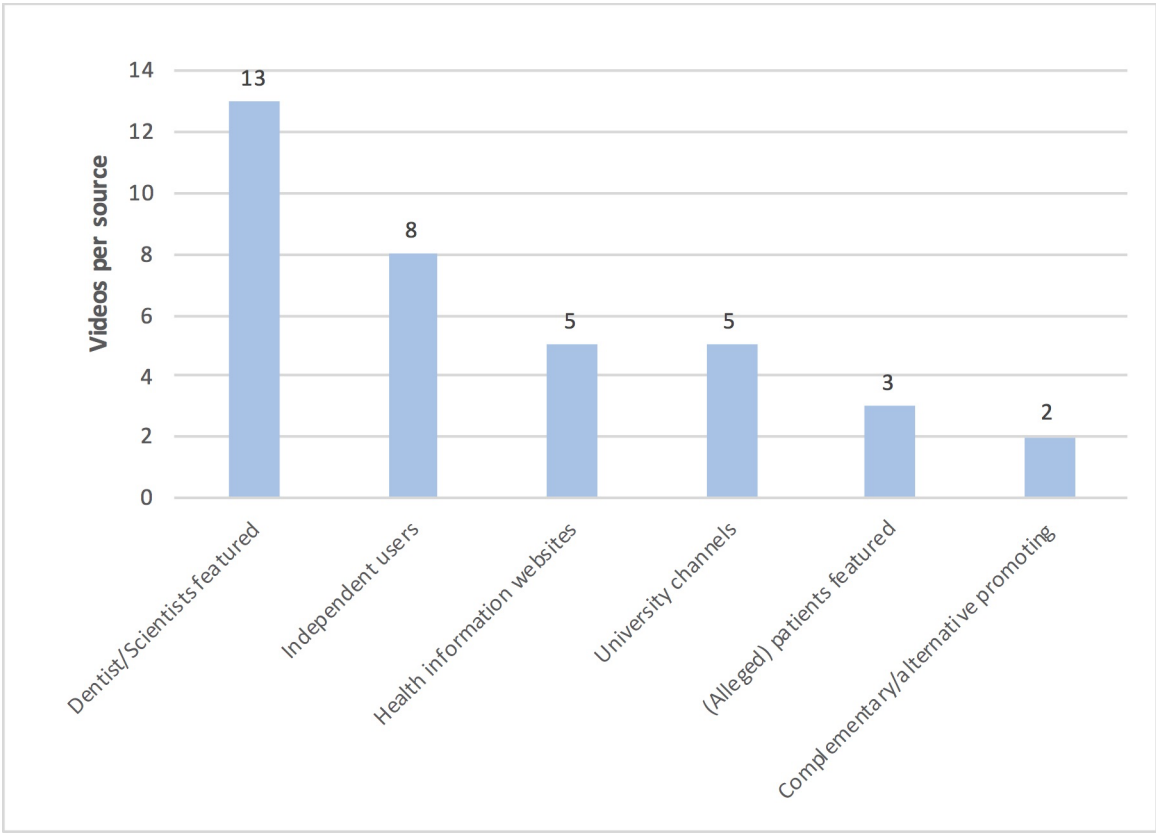
Figure 2 Information providers and/or upload sources

Figure 3 Comparison of the videos achieved with the DISCERN instrument (light-blue bars) and the Global Quality Scale (grey bars)

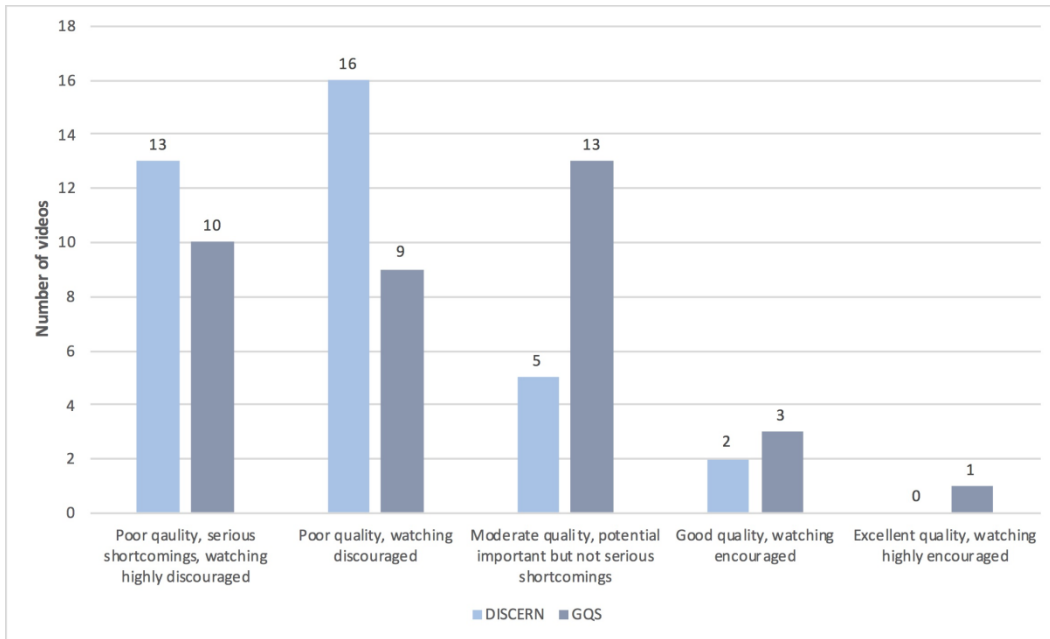
Figure 4 The scatter plot described the distribution of DISCERN values related to the length of the videos. The dotted lines highlight the cutoff for sufficient DISCERN values (horizontal line) and the minimum duration threshold of the video to obtain a DISCERN value > 38 .



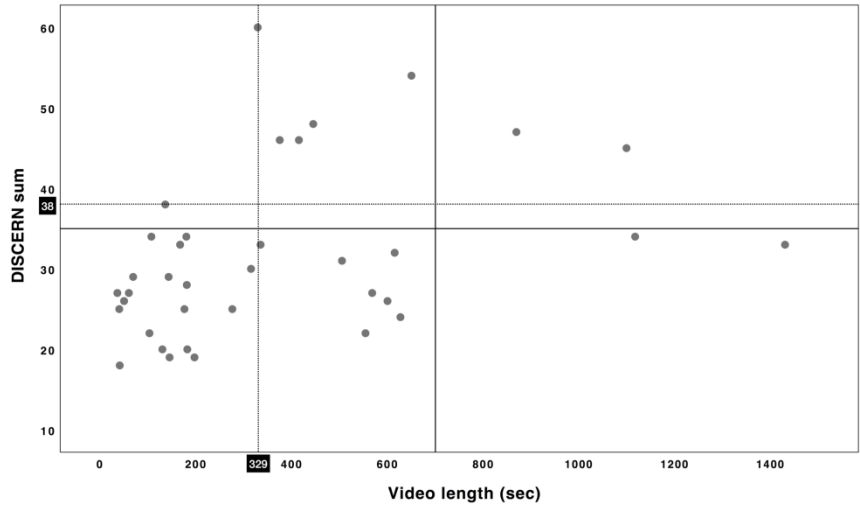
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