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Chapter 5B

Is YouTube useful as a source of information for Sjögren's Syndrome?

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Abstract

Objectives: To quantitatively and qualitatively assess the characteristics of You-Tube videos dealing with Sjögren's syndrome.

Materials & Methods: A comprehensive electronic search was performed for "Sjögren's syndrome" in YouTube. After excluding duplicates, irrelevant videos and non-English language domains, 70 videos were included for analysis. Videos were classified as useful, misleading or personal experience. The overall quality of videos was scored according to the Global Quality Scale (GQS). Useful videos were assessed for reliability and comprehensiveness based on two 5-point scales. Key points of the misleading videos were explored and patients' personal experiences were further investigated.

Results: Thirty six videos (51.4%) were classified as useful, 6 (8.6%) as misleading and 28 (40%) as patients' personal experience. Independent users tend to upload videos with personal experience while university channels/professional organizations share useful videos with evidence-based information. Significant difference was observed in GQS among useful, misleading videos and patients' experiences. The mean reliability, comprehensiveness and GQS scores of useful videos were 2.5 (SD:1.2), 2.6 (SD:1.4) and 3.4 (SD:1.0) respectively, whereas only 6 videos (16.7%) were rated as complete vis-à-vis content. The most frequently misleading topics were etiology and treatment.

Conclusions: Specialists should refer their patients to validated e-information resources and actively participate in the development of video-sharing platforms.

Introduction

Sjögren's syndrome (SS) is the second most common rheumatic disease after rheumatoid arthritis, with prevalence of 60.8 (95% CI: 43.7 to 77.9) cases per 100,000 inhabitants in the total population [1]. SS is a chronic inflammatory and lymphoproliferative disorder that is principally characterized by chronic infiltration of the exocrine glands and is regarded as the most concerning autoimmune disorder for oral health care professionals [2]. The most prominent symptom of SS is xerostomia (sensation of dry mouth), due to reduced saliva production. This symptom is often accompanied by dysgeusia, difficulty in eating dry food (e.g., crackers), problems in speaking for long period of time, burning sensation of the mouth, discomfort while wearing dentures and increased risk of dental caries, especially cervically, as well as candidiasis and periodontal disease [2]. Nearly a third of SS patients present systemic manifestations, and due to the multiple organ involvement, general symptoms like fatigue, polyathralgia and myalgia, sleep disturbances, anxiety and depression are often evident, leading to diminished quality of life [3].

The Internet has grown through the years into a popular source of health information both for patients as well as for healthcare providers [4,5]. More than 70% of the adult Internet users in the United States searched online for health topics in 2012 [6]. YouTube is the most popular free video-sharing platform with more than 1 billion users and 300 hours of uploaded new video material per minute [7], increasingly being used for disseminating health information. According to Alexa's Internet traffic estimates, YouTube ranked third in 2014 in terms of page views and visitors, following Google and Facebook [8]. A recent systematic review on You-Tube healthcare information concluded that YouTube portrays misleading information, primarily anecdotal that contradicts the reference standards [9]. Under this spectrum, lay YouTube users being suspected for or diagnosed with SS and their caregivers are highly likely to access patient education materials of such quality. Therefore, the aim of this study was to assess the potential of YouTube videos as a valid source of information on SS.

Materials and methods

Search strategy

YouTube (http://www.youtube.com) was searched using the keyword phrase 'Sjögren's syndrome', on May 21, 2015 for videos uploaded anytime since the advent of YouTube. These videos should contain information about the epidemiology, pathogenesis, clinical features, diagnosis and treatment of the disease.

'Sjögren's syndrome' without Umlaut (") was identified by the 'Google Trends' application as the most commonly used search term for SS [10]. Google Trends measures search interest in topics by calculating the frequency a search term is entered in relation to the total search-volume across various regions of the world. The 'Incognito'/'Worldwide' settings were selected to limit filtering to previous user history and expand the search results [11].

The search generated a total of 3940 videos. The first 100 videos (first 5 pages) ranked by relevance were analyzed for information about SS. Non-English language videos, duplicated in part or whole or containing information irrelevant to SS were excluded [12]. Multipart videos were counted as one and the viewer interaction parameters were averaged for the purposes of the analysis.

Video classification

All videos were scrutinized by 2 reviewers independently (KD, CL) and interexaminer discrepancies were resolved in a consensus meeting. The content of included videos was classified according to the following system [12-15]:

- i. useful, if they contained scientifically sound information about any aspect of SS.
- ii. misleading, if they contained scientifically erroneous or unproven information about any aspect of SS.
- iii. personal experience, if the videos described a user's personal experience while being diagnosed with or treated for SS.

All videos were also categorized by source into 5 groups [12]:

- i. independent users
- ii. government/news agencies
- iii. university channels/professional organizations
- iv. health information Web sites
- v. medical advertisements/profit companies

Videos rated as useful were further examined for reliability using a 5-item questionnaire modified from the DISCERN validation tool for assessment of written consumer health information [16]. In this questionnaire, items 1, 2, 3, 6, 7 and 8 of DISCERN/ reliability section have been implemented, while items 4 and 5 were not applicable, because of the different nature of videos, compared to written information. Positive responses scored 1 point, whereas negative responses scored 0 points (Table 1). Comprehensiveness of video information regarding 5 different areas of the disease (epidemiology, pathogenesis, clinical features, diagnostic tests, treatment) was also analyzed; videos were awarded with 1 point for each aspect covered, leading to a possible score range of 0-5 points [12]. The key points of the misleading videos were as well explored. Patient personal experiences were labeled positive (when providing either emotional support to the audience or useful information on SS

 Table 1: Questions adapted from DISCERN tool intending to evaluate the reliability of videos (1 point is given for every Yes and 0 points for No) [16].

Item Questions

- 1. Are the aims clear and achieved?
- **2.** Are reliable sources of information used? (i.e., publication cited, speaker is specialist in SS)?
- 3. Is the information presented balanced and unbiased?
- 4. Are additional sources of information listed for patient reference?
- 5. Are areas of uncertainty mentioned?

and its treatment) or negative (negatively depicting evidence-based remedies or promoting therapeutic alternatives with unproven scientific benefits).

Furthermore, the overall quality of the videos was graded using a 5-point scale, namely the global quality score (GQS), based on the quality of the information and how useful the reviewer assumed the particular video would be to a patient (Table 2) [17].

Data collection

Video features such as length and time since upload were recorded. Additionally, video popularity defined as the ratio of total views for video per number of days on YouTube since upload, number of 'likes', 'dislikes' and comments were noted.

Statistical analysis

Statistical analysis of the collected data was carried out with IBM SPSS Statistics 20 (SPSS, Chicago, Illinois, USA). One way ANOVA was performed to compare the means of variables. A p value <0.05 was considered significant.

Results

The first 100 videos were screened for relevance based on our selection criteria. A sample of 70 videos was finally included. In particular, 7 non-English, 15 duplicated in whole or in part, and 8 irrelevant videos were excluded (Figure 1). The mean length of the included videos was 5:27 (SD: 4:04) minutes and the mean video popularity was 10.37 (SD: 42). The videos were posted on YouTube on average 1,063 (SD: 2,018) days ago. Among the selected videos, 36 (51.4%) were classified

Table 2: Global quality scale (GQS) criteria used to score videos with information about SS on YouTube [17].

Item Characteristics

- 1. Poor quality, poor flow of the video, most information missing, not at all useful for patients
- 2. Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients
- 3. Moderate quality, suboptimal flow, some important information is adequately discussed but others poorly discussed, somewhat useful for patients
- 4. Good quality and generally good flow. Most of the relevant information is listed, but some topics not covered, useful for patients
- 5. Excellent quality and flow, very useful for patients

as useful, 6 (8.6%) as misleading and 28 (40%) as patient's personal experience (Table 3). Significant difference was observed in global quality among useful, misleading videos and patient's personal experiences.

The overall content of videos based on source of information is shown in Table 4. It appears that independent users usually upload videos with their personal experience. University channels/professional organizations usually share useful videos with evidence-based information, while no misleading videos have been accredited to them. Interestingly, there were no videos distributed by health information Web sites.

Useful videos

The mean reliability, comprehensiveness and GQS scores were 2.5 (SD: 1.2), 2.6 (SD: 1.4) and 3.4 (SD: 1.0), respectively. We observed that 21 videos (58.3%) used reliable source of information, while 8 videos (22.2%) listed additional sources of information for patient reference and 9 videos (25.0%) mentioned areas of uncertainty. From a content perspective, 17 videos (47.2%) discussed the epidemiology of SS, 15 videos (41.7%) explained the basic pathogenetic principals, 31 videos (86.1%) presented the most common clinical features, 12 videos (33.3%) analyzed the importance and scope of diagnostic tests, and 17 videos (47.2%) provided information regarding treatment options. Only 6 videos (16.7%) were rated as complete vis-à-vis content (score 5/5). The overall quality of useful videos based on source of information is shown in Table 5. Government/news agencies and university channels/professional organizations scored significantly higher (p<0.05) with regard to GQS, 4 (SD: 0.89) and 4 (SD: 0.92), respectively.

Figure 1: Flowchart diagram of the selection process.



Misleading videos

The most frequently misleading areas to be discussed appeared to be etiology and treatment. Dysbiosis, i.e. microbial imbalance in the body, low levels of vitamin D and Helicobacter pylori were presented as the sole cause of SS and not discussed with a broader view/perspective. Regarding treatment, essential oils against dryness, herbal natural remedies and pills with unknown ingredients were offered as the panacea against SS. With regard to source of the misleading videos, 2 were uploaded by independent users, 2 by news agencies and 2 by profit companies. No misleading videos were uploaded by university channels or professional organizations.

 Table 3: Quantitative characteristics of videos characterized as useful, misleading and personal experience in mean values.

	Useful (n=36)	Misleading (n=6)	Personal experience (n=28)	p-value
uploaded since (days)	751.5	791	1522	0.34
duration (min)	4:27	6:16	6:35	0.05
views	8754	1780	4031.3	0.42
popularity	11.65	2.25	2.6	0.48
likes	29	8.3	18.5	0.56
dislikes	1.7	0.5	2.1	0.81
comments	10	1.3	23.5	0.45
GQS	3.42	1.83	2.14	<0.01

Patients' personal experience videos

Twenty eight videos were classified as patients' personal experience. Out of these, 20 videos provided emotional support to patients, shared useful information about SS and communicated treatment experience positively, and therefore deemed positive. By endorsing treatment alternatives lacking of scientific evidence or presenting the course of the disease or treatment in a negative way, the rest 8 videos were considered as negative.

Discussion

Nowadays, patients are increasingly turning to Internet and video-sharing Web sites like YouTube to make informed healthcare decisions. However, the diversity of authorship and the lack of peer-review process on this platform have led to dissemination of inaccurate and misleading information [18]. Practically speaking, any YouTube user without exception regarding his/her background, medical qualifications, professionalism and intentions is authorized to upload video clips. To the authors' knowledge, few studies have been published so far on the available Web information on oral medicine topics [19-22], but none of them has dealt with YouTube videos.

Our study showed that more than half of YouTube videos relevant to SS were deemed useful, a finding lying close to the range of 54.9-63.0% reported by studies with similar methodology [12-15,23]. Unlike misleading videos, useful videos seemed more recently uploaded, of shorter duration, with more views, likes, and higher popularity and GQS. However, the latter was the only outcome that reached statistical significance.

Table 4: Distribution of useful, misleading and personal experience videos by source.

	content		
	useful	misleading	personal experience
independent users	13	2	21 _a
government/news agencies	6	2	2
university channels/professional organizations	8 _b	0	1
health information Web sites	0	0	0
medical advertisements/profit companies	9	2	4

^a Independent users predominantly uploaded a personal experience video (p<0.05). ^b University channels/professional organization predominantly uploaded useful videos (p<0.05). In the other categories of video source, no statistical significance was detected regarding the content of videos.

Popularity is the second most frequently cited quality measure on YouTube videos, often defined in relation to view counts [24]. Caution has to be taken with regard to popularity as a quality measure, since the number of views can easily be manipulated by, e.g., marketing strategies investing in pseudopopularity of products as well as by the YouTube viral effect attributed to longer availability or spreading across multiple Web pages of a YouTube video, which may account for higher view counts [24]. Moreover, negative popularity in the form of user comments and posts on YouTube has been claimed to harm the effectiveness of public health campaigns and reverse the initial positive attitude of laypeople towards a particular recommendation; the human papillomavirus vaccination is a well-known example [25]. In our study, we could not detect significant differences in numbers of 'dislikes' and comments among useful, misleading videos and personal experiences.

Incomplete information on the etiology of SS and drugs of unknown ingredients were posted by the misleading videos of the study. This observation confirms previously expressed safety concerns in retrieving YouTube information for healthcare decision making; promotion of unscientific therapies without authority approval, and dissemination of contradicting information to reference guidelines [9]. Useful videos were found, per definition, to discuss the abovementioned topics in a reliable way, sometimes incomplete or simplified, but never misleading.

The substantial proportion of YouTube video material related to personal experiences is also calling attention. Patient testimonials may be driven by financial motives. For example, plastic surgery clinics have rewarded patients with favorable opinion in testimonials with treatment discounts [26]. When merging misleading and patient experience video rates, our results related to SS are in line with previous YouTube reviews on other disease related videos [12-15,23]. Table 5: Quality of useful videos on SS (n = 36) based on source of information.

		independent users n=13	government/ news agencies n=6	university channels/ professional organizations n=8	medical advertisements/ profit companies n=9
GOS (SD)		3.15 (0.7)	4 (0.8)	4 (0.7)	2.9 (1.2)
Reliability (SD)		2.2 (0.9)	3.2 (0.4)	2.75 (1.3)	2.1 (1.5)
1.	The aims clear and achieved (%)	7 (53.8)	6 (100)	6 (75)	3 (33.3)
2.	Reliable sources of infor- mation are used (%)	7 (53.8)	4 (66.7)	6 (75)	4 (4.4.)
3.	The information is presented balanced and unbiased (%)	10 (71.4)	5 (83.3)	7 (87.5)	7 (77.8)
4.	Additional sources of information are listed for patient reference (%)	3 (23.1)	5 (83.3)	1 (12.5)	2 (22.2)
5.	Areas of uncertainty are mentioned (%)	2 (15.4)	2 (33.3)	2 (25)	3 (33.3)
С	omprehensiveness (SD)	2.8 (1.4)	3.3 (1.1)	2.75 (1.5)	1.75 (1.5)
1.	Epidemiology (%)	7 (53.8)	4 (66.7)	5 (62.5)	1 (11.1)
2.	Pathogenesis (%)	6 (45.3)	2 (33.3)	4 (50)	3 (33.3)
3.	Clinical features (%)	12 (92.3)	6 (100)	8 (100)	5 (55.6)
4.	Diagnostic tests (%)	5 (38.5)	3 (50)	2 (25)	2 (22.2)
5.	Treatment (%)	6 (45.3)	5 (83.3)	3 (37.5)	3 (33.3)

In terms of global quality, reliability and comprehensiveness of information, government/news agencies appeared to be the most creditable contributors. On the other hand, university channels/professional organizations presented as high GQS as government/news agencies, while none video was classified as misleading. Therefore, to increase the chances of accessing high quality information on SS, YouTube users should seek for videos of reliable origin. Nevertheless, this contradicts the search habits of Internet users, in which 75% of the e-health seekers occasionally or never trace the source of information [27].

By gaining knowledge over SS, patients can become more compliant, and at the same time, more active, keeping pace with the international trend in healthcare field. However, they are usually not able to identify an incomplete or misleading video, thus becoming prone to be deceived. YouTube users should be aware of the current shortcomings while searching for online health information for SS and seek advice from specialists regarding evidence-based videos.

Individuals searching at the Web tend to limit their search within the first eight to ten results of a search engine [28,29]. The broad inclusion of links that exceeded the first page in YouTube may be considered methodologically advantageous.

The results of our study underline the need for quality filtering of YouTube videos displaying health information on SS. YouTube encourages it's users to 'flag' videos of inappropriate content, however, such an option may be intentionally misused [30]. The social networking approach could offer the benefits of collective intelligence in assessing the trustworthiness of YouTube videos. Peer reviews by the crowd, like patient support groups, have been found capable of identifying and fixing incorrect information [31]. As indicated by our study, university and governmental institutions should be represented in these examination bodies. Interfaces that enable coupling of YouTube with evidence-based references could enhance the dissemination of accurate information [9]. Other researchers suggested modification of YouTube's ranking search algorithm to extract first the health related videos of trustworthy origin when a medical term is entered in YouTube's video search engine [32].

Limitations

As with any YouTube investigation, a number of limitations applied to our study. First, we focused on the analysis of English-language videos directly available on YouTube and not linked to other Web sites, at a single time-point. Although this approach might limit generalization of our findings, it has to be mentioned that English is acknowledged by Internet usage and population standings as the prevailing language [33]. Additionally, given the current lack of standardized tools to assess quality of patient health information videos on YouTube [24], we ran and further developed a multi-level but rather flawed by subjectivity evaluation system [12-15,23]. Lastly, the participation of a second examiner in applying the criteria optimized to some extent the evaluation process.

Conclusions

This study classified more than half of the included YouTube videos posting information on SS as useful. There was significant difference in global quality among useful, misleading videos and personal experiences. Government/news agencies and university channels/professional organizations appeared to be the most trustworthy sources of information. The vast majority of videos was found to be incomplete with regard to completeness of content. Specialists should be actively involved in the development of e-information resources and video-sharing platforms and should also refer their patients to evidence-based videos.

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