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Evaluation of Educational Value of YouTube Videos for Patients with Coeliac Disease

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1. Introduction

Coeliac disease (CD) is an autoimmune disease of the gastrointestinal tract that results from gluten in food. CD prevalence is about 0.71% in the United States (1 in 141). This is similar to the prevalence found in European countries and minority groups. Most of the affected persons were un-diagnosed with CD, especially those following gluten free diet [1].

CD was thought historically to be a rare disease. Rates of positive antibodies for CD in blood donors screening were approximately 1:133 in non-at-risk individuals [2,3]. The prevalence of CD in first-degree relatives is around 10% with significantly higher prevalence figures in mono-zygotic twins, families with multiple persons affected, or siblings whom share the HLA susceptibility alleles [4,5].

CD usually presents with gastrointestinal symptoms that appear at age 9-24 months after the introduction of gluten-containing foods. Many patients with CD present at a later age with subtle symptoms. Gastrointestinal symptoms may include abdominal pain, diarrhea or constipation, bloating, and excessive gas. Diagnosis of CD is usually first suggested by the presence of tissue transglutaminase antibody, but established by biopsy of the small intestine by upper intestinal endoscopy [6].

Treatment of CD is lifelong avoidance of gluten. Complete elimination of gluten-containing grain products (including wheat, rye, and barley) is essential to treatment [7]. To facilitate elimination of gluten from the diet, the US Food and Drug Administration (FDA) has released rules providing uniform food-label definitions of (gluten-free) [8].

Avoidance of gluten-containing food is clearly dependent on patient education. Patient education sources are diverse; from handouts to web-based educational material. According to the results of a PwC Health Research Institute survey, a full one-third of U.S. consumers are using YouTube, Facebook and Twitter to find medical information [9]. YouTube is a popular open-access website that depends on video sharing. Videos in general are an easier educational tools than most printed materials. Nevertheless, YouTube is used as a medium for promoting unscientific therapies and drugs that are yet to be approved by the appropriate agencies and has the potential to change the beliefs of patients concerning controversial topics such as vaccinations [10].

We decided to evaluate the quality of patient education material delivered through YouTube videos. That helps bring a realistic idea on possible improvement in patient education resources.

2. Materials and Methods

YouTube (www.youtube.com) was searched using the keyword "Coeliac disease" on Dec 12th, 2015 for videos containing pertinent information on epidemiology, risk factors, symptoms, diagnosis, treatment, and other information regarding CD.

The search yielded 3820 videos in total. As studies on Internet search engines have shown, > 90% of search engine users click on a result within the first 3 pages of search results [11]. We decided to study the first 100 videos (first 5 pages). YouTube videos ranks videos by relevance (default option on YouTube, which uses a complex algorithm based on view count, upload date, rating, comments, bookmarks, age of user, etc.). All videos were viewed and analyzed for content by an independent researcher. In the event of an unclear decision, a second researcher was involved to resolve it.

All selected videos were classified as useful, personal experience-based, or irrelevant [12]:

(1) Useful-if the video contained correct and accurate information that is useful in patient education on CD at the level of general population;

(2) Irrelevant-if the video does not have useful information to patient education on CD;

(3) Patient views-if the video describes a patient's personal experience related to CD. Categories 2 and 3 were counted together as non-useful videos.

All useful videos were also categorized based on the uploaded into 2 groups: independent users; and

professional organizations; defined as government/news agencies, university channels, and health care professionals.

Other properties of the videos were studied including the duration and audience interaction. Audience interaction was assessed by the number of views and video viewer "likability" (number of "likes" and "dislikes" for a video and the likability ratio (measured by dividing the average likes by the average views for the same category of the videos). All videos rated as useful were further analyzed for reliability and completeness of information. Reliability of information was scored from 1 to 5 (reliability score), based on 5 questions (adapted from the DISCERN tool for assessment of written health information) as shown in Table 1 [13].

Table 1. Reliability of information score

Reliability of information (1 point for every Yes, 0 points for No)
1. Are the aims clear and achieved?
2. Are reliable sources of information used?
3. Is the information presented balanced and unbiased?
4. Are additional sources of information listed for patient reference?
5. Are areas of uncertainty mentioned?

All videos were assessed for content based on a scale developed by authors. The CD- patient education goals scale (C-PEG) (Table 2). The score is developed specifically to grade the health information given to CD patients. C-PEG scale is an 8-point scale which contains; pathogenesis, demographics, clinical presentation, diagnosis, treatment and avoidance of gluten, sources of gluten (wheat, rye, barely, cross reactivity with oats), importance of reading labels for (gluten-free) sign, and awareness of gluten-free diet resistance. We gave 1 point for each item and the video is scored out of 8. Data entry and analysis were done using Excel software and performed by the first author.

Table 2. C-PEG score to assess content of videos

C-PEG score (1 point for every Yes, 0 points for No)
1. pathogenesis
2. Demographics
3. Clinical presentation
4. Diagnosis
5. Treatment and avoidance of gluten
6. Sources of gluten
7. Importance of reading labels for (gluten-free) sign
8. Awareness of gluten-free diet resistance

3. Results

Search phrase ''Coeliac disease" returned 3,820 videos sorted by default filter of "relevance". We studied the first 100 videos (the first 5 pages of the search). Videos were 4 minutes and 16 seconds long on average, with 5,707 views, 52.57 likes and 1.48 dislikes. Likability score was 0.0092 (Table 3).

Table 3. Analysis of videos

Average	All videos	Useful			Non-useful		
			Professional sources	Non-professional sources		Patient views	Irrelevant
Number of videos	100	56	25	31	44	28	16
Length (minutes:seconds)	4:16	7:54	6:13	9:16	4:40	5:22	3:27
Views	5,707	7,159	9,747	5,071	3,860	5,184	1,543
Likes	52.57	29.76	42.84	19.22	163.18	254.07	4.125
Dislikes	1.48	1.57	1.88	1.32	1.36	2.1	0.0625
Reliability score+ (standard deviation)		3.0179 (0.637)	3.2 (0.645)	3 (0.607)			
C-PEG content score+(standard deviation)		3.3571 (1.94)	2.64 (1.77)	3.5 (1.855)			
Likablity ratio (likes/views)	0.0092	0.0041	0.0043	0.0037	0.0422	0.0490	0.0026

Of the 100 videos studied, 56 videos were useful. On average, they were 7 minutes and 54 seconds long, with 7,159 views, 29.76 likes and 1.57 dislikes. Likability score was 0.0041. Average reliability score 3.0179 with standard deviation 0.637, and average C-PEG content score was 3.3571 with standard deviation 1.94.

Of the 56 useful videos, 25 were from professional sources. On average, videos were 6 minutes and 13 seconds long, with 9,747 views, 42.84 likes and 1.88 dislikes. Likability score was 0.0043. Average reliability score 3.2 with standard deviation 0.645, and average C-PEG content score was 2.64 with standard deviation 1.77.

Of the 56 useful videos, 31 were from non-professional sources. on average, videos were 9 minutes and 16 seconds long with 5,071 views, 19.22 likes and 1.32 dislikes. Likability score was 0.0037. Average reliability score 3 with standard deviation 0.607. Average C-PEG content score was 3.5 with standard deviation 1.855.

Of the 100 videos, 44 videos were non useful according to the definition mentioned above. On average, videos were 4 minutes and 40 seconds long, with 3,860 views, 163.18 likes and 1.36 dislikes. Likability score was 0.0422. Of the 44 non-useful videos, 28 videos were categorized as patient views. Average length of the videos labelled as patient views was 5 minutes and 22 seconds. Average views 5,184, 254.07 likes and 2.1 dislikes. Likability score was 0.0490.

Of the 44 non-useful videos, 16 videos were categorized as irrelevant. Average length of the videos labelled as irrelevant was 3 minutes and 27 seconds. Average views were 1,543 with average 4.125 likes and 0.0625 dislikes. Likability score was 0.0026.

3.1. Audience Interaction with Videos

The number of views of useful videos was higher than that of non-useful videos (5,707 and 3,860 respectively).

Non-useful videos had more average likes than useful videos (163.18 and 52.57 respectively). Non-useful videos also had higher likability score than useful videos (0.0422, and 0.0041 respectively). There was no significant difference in average dislikes for both useful and non-useful videos (1.48 and 1.36 respectively).

3.2. Audience Interaction with Useful Videos

Videos from professional sources were 25 while those from non-professional sources were 31. Professional videos showed more audience interaction with average views 9,747 (compared to 5,071), average likes 42.84 (compared to 19.22), and average dislikes 1.88 (compared to 1.32). There was no significant different between the likability score of professional and non-professional videos (0.0043 and 0.0037 respectively).

There was no significant difference in the average reliability score in both professional and non-professional videos (3.2 with SD 0.637 and 3 with SD 0.607 respectively). Unexpectedly Non-professional videos had higher C-PEG score than professional videos (3.5 with SD 1.855 and 2.64 with SD 1.77).

3.3. Audience Interaction with Non-useful Videos

Patient views videos were 28 while irrelevant videos were 16. Patient views videos had significantly higher audience interaction than irrelevant videos with views (5,184 compared to 1,543), likes (254.07 compared to 4.125), and dislikes (2.1 compared to 0.625). Likability score was much high in patient views rather than irrelevant videos (0.0490 and 0.0026 respectively).

Professional videos had the highest number of average views (9,747). Patient views videos had the highest number of average likes (254.07).

4. Discussion

CD treatment majorly depends on patients avoiding gluten in diet. As mentioned above, the educational material on YouTube have a huge impact on patients' safety and wellbeing. Assessing the quality of information on CD on YouTube, we found that half the videos were useful for patient education on CD (56/100). Only half of the useful videos were uploaded by professional organizations (25/56). These videos had double the number of views and likes of non-professional ones. Reliability of professional videos was higher than that of non-professional videos as expected.

Unexpectedly, the C-PEG content score of useful professional videos was lower in average of that of non-professional ones (2.6 in comparison to 3.5). This unexpected finding could be due to the fact that professional organizations tend to create small different videos for each aspect of the disease. There are a few videos that contain the whole spectrum of C-PEG content score including clinical presentation, diagnosis, avoidance of gluten, etc.

Non-useful videos had much less views than useful videos (3,860 and 5,707). Nevertheless, the non-useful videos had more likes than useful videos (163.18 and 52.57). This could be attributed to the fact that non-useful videos are non-educational that has more interesting material to general population. These results emphasize the need to present educational information in an interesting manner.

Our study was limited to analysis of only English-language videos on YouTube in a single snapshot. YouTube content changes over time. Moreover, our study was restricted to a direct YouTube search and did not include YouTube videos viewed at other sites. We did not study videos on other health information websites. The videos were analyzed by a single researcher and conflicts were resolved by a more experienced research with evidence-based knowledge on CD. Seeking the public's opinion on this subject would have been helpful.

5. Conclusion

Patient education in CD would potentially save much costs spent on CD complications. Our study evaluates the contents of educational videos for patients with CD. Our results showed that about 50 % of the available videos are useful. This should encourage physicians educating patients to recognize useful information on the Internet and avoid misleading ones. To improve usability of online healthcare information, physicians should provide patients with guidelines to evaluate both the content and reliability when accessing medical information on the web.

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