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YouTube® and inflammatory bowel disease☆

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Abstract

Background and aims
Nearly half of all patients with inflammatory bowel disease (IBD) use the Internet as a source of information for their disease. We analyzed the source, content and accuracy of IBD videos found on YouTube® – one of the most popular websites in the United States – and assessed the demographic variables of the viewers.
Methods: The 100 most viewed videos with relevant information on IBD were analyzed. We included only English language videos that were less than 20 min in length and primarily focused on IBD. Those with no sound/poor sound quality were excluded. More than 30 variables were analyzed.
Results: Adults of 45–54 years old (95.1%) comprised the most common age group of viewers. Forty-eight percent of videos focused on Crohn's disease (CD), 32.0% on ulcerative colitis (UC), and 20.0% on both. Overall content for patient education was poor. Videos discussing alternative treatment options were more likely to depict patients' personal experience (73.9% vs. 2.4%) ($p<0.001$) and be an advertisement compared to patient education videos (78.3% vs. 0) ($p<0.001$). Videos discussing patient education had a higher number of favorites (mean 25.0 vs. 5.5) ($p<0.001$), comments (mean 22.0 vs. 5.0) ($p<0.022$) and "likes" (mean 19.0 vs. 9.0) ($p=0.025$) than the ones discussing alternative treatment options.
Conclusions: YouTube® videos on IBD are popular but a poor source of patient education. Healthcare providers and professional societies should provide more educational materials

Abbreviations: ASA, aminosalicylic acid; CCFA, the Crohn's Colitis Foundation of America; CD, Crohn's disease; HRQOL, health-related quality of life; IPAA, ileal pouch anal-anastomosis; IBD, inflammatory bowel disease; NSAID, non-steroidal anti-inflammatory drugs; TNF, tumor necrosis factor; UC, ulcerative colitis.

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using this powerful Internet tool to counteract the misleading information, especially for the targeted age group (45–54 years).

1. Introduction

The incidence and prevalence of inflammatory bowel disease (IBD) has been increasing worldwide. The estimated prevalence is 200 cases per 100,000 inhabitants in the West.[1] A recent study showed that 24% of patients with IBD are unsatisfied with the educational materials provided to them at the time of their diagnosis, and only 31% are moderately satisfied.[2] Patient education with proper, up-to-date information is critical for management of IBD.

The Internet is now the primary source of health information for patients because it is readily available and easy to use.[3] In addition, it provides a platform for patients to communicate with their peers and discuss their experiences and concerns. Studies have estimated that more than 50% of patients with IBD use the Internet as a source of information for disease management.[4,5] However, studies looking at the accuracy and quality of website suggest that there is a marked variation in the content quality.[6–9] Thus, Internet use is popular and widely prevalent amongst IBD patients, but quality of information is highly variable.

YouTube® (www.youtube.com) is one of the three most popular websites on the Internet (ranked the third after google.com and facebook.com).[10] It is a video sharing Internet website created in 2005 that provides free video streaming, and it currently has more than 3 billion viewers per day.[11] More than 24 h of video is added every minute.[11] YouTube® has a variety of information on health-related issues ranging from patient experiences and education to non-conventional treatments. It has been studied in the past in relation to tobacco use,[12] vaccination,[13,14] cardiopulmonary resuscitation,[15] prostate cancer[16] and kidney stones.[17]

Similar to other health-related conditions, YouTube® contains many IBD-related videos. However, the quality and accuracy of IBD-related contents posted in YouTube® have not been evaluated. As a practicing clinician, it is important to know where and how IBD patients obtain health care-related information and whether the information is accurate. For example, Internet-surfing patients can be influenced by the personal experience of other patients, advertisements of commercial sources and information from health-care providers and professional societies. We hypothesized that the quality of information on YouTube® from different sources greatly varies with inaccurate information being posted. The aims of the study were to assess source, content, and accuracy of the most commonly viewed YouTube® videos related to IBD and to gather and assess demographic data of the viewers.

2. Materials and methods

2.1. Study design

This was a cross-sectional study, which was exempted from Institutional Review Board approval. On March 27, 2011, authors S.M. and P.M. searched YouTube® using the key words, "Inflammatory Bowel Disease", "Ulcerative Colitis" and "Crohn's Disease". Disagreements between observers were resolved by a senior IBD specialist (B.S.). "Video Count" was selected to sort the videos so that the search results were arranged in a descending order based on the number of views. The first 50 videos with relevant information on IBD were analyzed. On April 3, 2011, an additional 50 videos were searched. As YouTube® is a dynamic site with view counts changing every minute, none of the videos that appeared on March 27, 2011 in the top 50 search results re-appeared on April 3, 2011 in the next top 50 search results.

2.2. Inclusion and exclusion criteria

The 100 most viewed videos with relevant information on IBD were analyzed. We included only English language videos that were less than 20 min in length and primarily focused on IBD (CD or UC) were included. Videos with no sound/poor sound quality and not in English language (Spanish/French/German) were excluded. Videos in multiple parts were counted as one video, and a mean of all parameters (view count, duration, rating, comments, "likes"/"dislikes") was used for analysis.

2.3. Information extracted

2.3.1. Video characteristics

March 27, 2011 and April 3, 2011: Date of upload, days since upload, duration (in seconds), numbers of views, favorites, comments, and "likes" or "dislikes" were recorded on Microsoft Excel® sheet. Using the audience map feature (Audience map on YouTube® reflects the popularity of each video in different countries on a world map, using different shades of green color: the darkest shade of green reflects the most popular country/countries, and lighter shades reflect the other popular countries) and demographics, the most popular country/countries, other popular countries where videos were viewed, the most popular self-reported age groups (13 to 17, 18 to 24, 25 to 34, 35 to 44, 45 to 54, 55 to 64 years) and gender were also recorded. December 28, 2011 — seven months later, we re-analyzed the videos and recorded the numbers of views, favorites, comments, and "likes" and "dislikes", to assess the change in the values after seven months.

Videos were sorted according to main theme (CD and/or UC).

2.3.2. Video source

The source of videos was categorized as: patients; healthcare providers (e.g. hospitals, physicians or educational institutions); pharmaceutical companies or research institutions; professional societies (e.g. non-profit organizations such as Crohn's Colitis Foundation of America [CCFA]) or media (e.g. news reports).

Table 1 General characteristics of inflammatory bowel disease-related YouTube® videos classified by groups providing information.

Factor	Overall (N = 93)	Patients (N = 44)	Healthcare professionals (N = 22)	Pharmaceutical company (N = 12)	Professional societies/ media (N = 15)	p-Value
Days since upload	959.8 ± 374.0	990.2 ± 382.6	996.0 ± 324.0	774.8 ± 395.4	965.6 ± 393.3	0.33
Duration (s)	226.0 [136.0, 384.0]	225.5 [158.5, 384.0] [a]	362.5 [219.0, 443.0] [a]	122.0 [64.5, 152.5] [b,c]	239.0 [105.0, 320.0]	<0.001
Focus						0.013
Ulcerative colitis	29 (31.2)	12 (27.3)	8 (36.4)	7 (58.3)	2 (13.3)	
Crohn's disease	45 (48.4)	28 (63.6)	7 (31.8)	2 (16.7)	8 (53.3)	
Both	19 (20.4)	4 (9.1)	7 (31.8)	3 (25.0)	5 (33.3)	
Type						
Personal experience	56 (60.2)	36 (81.8) [c]	3 (13.6) [a,b,d]	8 (66.7) [c]	9 (60.0) [c]	<0.001
Advertisement	20(21.5)	3 (6.8) [a]	3 (13.6) [a]	12 (100.0) [b,c,d]	2 (13.3) [a]	<0.001
Patient education	17 (18.3)	1 (2.3) [c,d]	12 (54.5) [a,b]	0 [c]	4 (26.7) [b]	<0.001
Alternative treatments	23 (24.7)	7 (15.9) [a]	3 (13.6) [a]	11 (91.7) [b,c,d]	2 (13.3) [a]	<0.001
Gross images	11 (11.8)	7 (15.9)	4 (18.2)	0	0	0.16
Increasing awareness	10 (10.8)	2 (4.5) [d]	0 [d]	0 [d]	8 (53.3) [a–c]	<0.001
Medical professionals education	7 (7.5)	0 [c]	7 (31.8) [b]	0	0	<0.001
Intended audience						<0.001
Layperson	86 (92.5)	44 (100.0) [c]	15 (68.2) [b]	12 (100.0)	15 (100.0)	
Medical	7 (7.5)	0	7 (31.8)	0	0	
Number of views	10,419 [7271, 18,109]	12,821 [7916, 18,113] [d]	9461 [7858, 22,524]	13,763 [9692, 20,726]	6585 [5957, 9255.0]	*0.017*
Favorites [e]	13.0 [7.0, 25.0]	15.0 [11.0, 27.0] [a]	21.0 [10.0, 36.0] [a]	3.5 [1.00, 8.5] [b,c,d]	13.0 [7.0, 23.0] [a]	<0.001
Comments [e]	22.0 [7.0, 48.0]	41.0 [22.8, 93.5] [a,b,d]	13.0 [5.0, 25.0] [b]	1.00 [0.00, 11.5] [b]	10.0 [2.0, 25.0] [b]	<0.001
Opinion						
Like	16.0 [8.0, 28.0]	26.0 [12.8, 36.0] [a,c]	14.5 [7.0, 20.0] [a,b]	4.0 [2.0, 9.5] [b,c,d]	15.0 [8.0, 20.0] [a]	<0.001
Dislike	1.0 [0.0, 3.0]	1.0 [0.0, 3.0]	1.0 [1.0, 3.0]	1.0 [0.0, 2.5]	1.0 [0.0, 2.0]	0.74

Seven months later (additional)						
Number of views	2492 [1105, 5937]	2537 [1029, 7621]	2613 [1655, 4596] [d]	2665.5 [1770, 7749]	595 [293, 3122] [c]	0.042
Favorites	1.0 [0.0, 3.0]	1.0 [0.0, 6.0]	2.0 [2.0, 4.0] [d]	1.0 [0.0, 2.0]	0.0 [0.0, 1.00] [c]	0.022
Comments	2.0 [0.0, 8.0]	7.0 [1.1,20.0] [a,d]	2.0 [1.0, 4.0]	0.0 [0.0, 0.5] [b]	1.0 [0.0, 3.0] [b]	<0.001
Like	2.0 [0.25, 5.0]	3.5 [1.0, 12.0]	2.0 [1.0, 4.0]	1.0 [0.0, 3.5]	1.0 [0.0, 4.0]	0.037
Dislike	0	0.0 [0.0, 1.0]	0	0	0	0.074
Most popular country [e]						
USA	72 (88.9)	30 (90.9)	17 (81.0)	12 (100.0)	13 (86.7)	0.38
UK	9 (11.1)	3 (9.1)	4 (19.0)	1 (8.3)	1 (6.7)	0.6
Canada	6 (7.4)	4 (12.1)	0	0	2 (13.3)	0.21
Most popular age group, years [e]						0.49
13–17	1 (1.2)	1 (3.0)	0	0	0	
35–44	1 (1.2)	0	1 (4.8)	0	0	
45–54	77 (95.1)	32 (97.0)	20 (95.2)	11 (91.7)	14 (93.3)	
55–64	2 (2.5)	0	0 (0.0)	1 (8.3)	1 (6.7)	
Most popular sex [e]						0.32
Male	58 (71.6)	22 (66.7)	18 (85.7)	9 (75.0)	9 (60.0)	
Female	23 (28.4)	11 (33.3)	3 (14.3)	3 (25.0)	6 (40.0)	

Values presented as Mean ± SD with ANOVA; Median [P25, P75] with Kruskal–Wallis test, or N (%) with Pearson's chi-square test.
A significance level of 0.008 was used for pairwise ad-hoc comparisons.
[a] Significantly different from pharmaceutical company.
[b] Significantly different from patients.
[c] Significantly different from healthcare professionals.
[d] Significantly different from professional societies/media.
[e] Data not available for all subjects. Missing values: alternative treatments; favorites = 12, comments = 1, most popular country = 12, most popular age group = 12, and most popular sex = 12.

2.3.3. Content analysis

The content of videos was categorized as: personal experience (patient's discussing their experience), advertisement (by drug companies, hospitals or private medical professionals), patient education (with appropriate medical information), medical professional education (e.g. histopathology videos, and surgery videos), alternative treatments (e.g. herbal products), increasing IBD awareness (e.g. CCFA Team Challenge — Marathon to raise funds for IBD) and/or gross images (colonoscopy, stoma, and surgery videos).

2.3.4. Personal experience videos

Videos discussing personal experience were further analyzed for the depicted patients and topics of discussion — including symptoms, medications, diagnostic investigations and procedures. In addition, the attitude of the depicted patient towards conventional treatment was assessed and categorized as positive, negative or ambivalent. If positive, the reason for positive attitude was further categorized as surgery or medication therapy (corticosteroids, anti-tissue necrosis factor [TNF] biologics). If negative, the reason for the negative attitude was further categorized as due to adverse effects of medications, failure of medical therapy, problems after surgery and/or financial burden.

2.3.5. Patient education videos and scoring system

Videos discussing patient education were further analyzed for their contents. As there are no guidelines currently for rating YouTube® videos for medical education we decided to create a scoring system. S.M. and the IBD-specialist B.S. developed the PEVIS-IBD (Patient Education Video Score for Inflammatory Bowel Disease) system to judge the patient education videos. This was based on the Quality Evaluation Instrument (QEI) scoring system, which is used to evaluate patient education websites.[6] The minimum score was 0 and the maximum score was 28. CD-focused and UC-focused videos were scored separately. Furthermore, the overall quality of patient education videos were rated according to Global Quality Score (GQS) used to assess IBD education websites,[6,8] on a scale of 1 to 5. Thus, each video received a score from 0 to 28 for UC education, 0 to 28 for CD education and 1–5 for overall quality. The PEVIS-IBD score is attached as Appendix A and GQS score as Appendix B.

The intended audience was recorded as patients or health-care professionals.

2.4. Statistical analysis

Descriptive statistics were computed for all factors. These were means, standard deviations and percentiles for continuous factors and frequencies and percentages for categorical variables. A univariable analysis was performed to compare videos by type of focus. Analysis of variance (ANOVA) or the non-parametric Kruskal–Wallis test were used to assess differences in continuous variables and Fisher's Exact tests were used for categorical factors, ad-hoc pair-wise comparisons were done using a significance criterion of 0.017 (0.05/3) in order to account for multiple comparisons. Similarly, univariable analysis was done to assess differences between videos by who provided the information, ad-hoc comparisons for this were done using a significance criterion of 0.008 (0.05/4). A $p<0.05$ was considered statistically significant. All analyses were performed using SAS version (9.2 software, The SAS Institute, Cary, NC).

3. Results

A total of 100 videos were analyzed, including 88 individual videos (not part of series) and 12 videos as a part of a series of videos (a total of 5 series with 4, 2, 2, 2 and 2 videos). Thus, 93 videos (88 individuals and 5 series) were included in the final analysis. The weighted kappa statistics for the agreement on characterization of the videos between the two viewers was 0.96. Overall, the mean duration of the videos was 960 ± 374 days and the median video length was 226 s (interquartile range [IQR] 136, 384). Forty-eight percent of the videos focused on CD only, 31.0% on UC only and 20.0% on both. Table 1 summarizes video popularity. Strikingly, adults between the ages of 45 and 54 years (95.1%) comprised the most common age group of viewers. There was a median increase of 2492 views (IQR, 1105, 5937) seven months later.

3.1. Source of information

Table 1 compares the information sources. Videos made by patients had significantly more views than those provided by professional societies or media ($p=0.003$) and elicited more comments than all other groups ($p<0.001$). Videos uploaded by healthcare providers were least likely to discuss personal experiences ($p<0.001$), in contrast to the videos posted by other sources and were more likely to discuss topics on patient education than those uploaded by patients or pharmaceutical companies ($p<0.001$). Videos made by pharmaceutical companies were more likely to be advertisements ($p<0.001$) that included discussions of alternative treatment options ($p<0.001$) and had the lowest number of favorites ($p<0.001$) and "likes" ($p<0.001$). In addition, they were shorter in duration ($p<0.001$) than those uploaded by patients or medical institutions. The videos created by professional societies or media were more likely to discuss increasing awareness of IBD than all other groups ($p<0.001$).

3.2. Personal experience videos

Table 2 details the videos discussing personal experience. Sixty percent of videos dealt with personal experience. Of these, 62.0% depicted a male patient and 80.0% a young patient. In the personal experience videos, the patients mainly discussed symptoms (84.0%). Surgery was the most common reason for a positive attitude towards conventional treatment (60.0%) and failure of medical treatment was the most common cause for a negative attitude (80.0%).

3.3. Seven months later

There was a median increase of 2492 views (IQR, 1105, 5937) seven months later. During seven months, videos by healthcare providers had greater number of views than those by professional societies or media ($p=0.042$). Videos by patients had greater comments than pharmaceutical companies and

Table 2 Characteristics of YouTube® videos discussing personal experience of inflammatory bowel disease patients.

Factor	Overall N = 56 (%)
Male patient depicted	35 (62.5)
Young patient depicted	45 (80.3)
Discusses symptoms	47 (83.9)
Useful suggestions	6 (10.7)
Discusses colonoscopy	10 (17.9)
Discusses medications (steroids, ASA)	24 (42.9)
Discusses medications (anti-TNF biologics)	9 (16.1)
Discusses surgery	10 (17.9)
Attitude towards traditional line of treatment	
Positive	10 (17.9)
Negative	15 (26.8)
Ambivalent	31 (55.4)
Reason for positive attitude (non-exclusive)	
Surgery	6 (60.0)
Medications	5 (50.0)
Anti-TNF biologics	4 (40.0)
Corticosteroids	1 (10.0)
Reason for negative attitude (non-exclusive)	
Side effects of medications	5 (33.3)
Surgical complications	0
Financial problems	2 (13.3)
Failure of treatment	12 (80.0)

professional societies/media ($p<0.001$). Videos by healthcare professionals had greater number of favorites than professional societies/news reports ($p=0.022$).

During seven months, videos by healthcare providers had greater number of views ($p=0.042$) and favorites ($p=0.022$) than those by professional societies or media. Videos by patients had greater comments than pharmaceutical companies and professional societies/media ($p<0.001$).

3.4. Patient education

Figs. 1 and 2 demonstrate scores for CD and UC-related patient education videos. Only one CD education video scored 5 on GQS score and 23 on PEVIS-IBD score. Majority of the other videos had lower scores on both the scales.

3.5. Alternative treatment options

Twenty-three (24.7%) videos discussed alternative treatment options. Eleven (47.8%) discussed herbal products, 5 (21.7%) discussed dietary modifications, 6 (26.1%) discussed other options — 2 videos discussed religious approaches, 1 video discussed meditation, 1 video discussed probiotics, 1 video discussed marijuana, 1 video discussed homeopathic treatment. Seventeen (73.8%) of the 23 videos were in the form of personal testimonials by patients.

Table 3 compares videos discussing alternative treatment options and appropriate information for patient education. Patient education videos were mainly uploaded by healthcare providers (70.6%), whereas, videos on alternative treatment

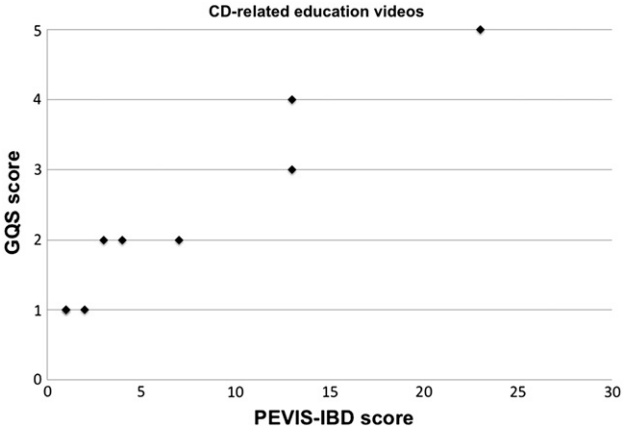

Figure 1 Relationship of the Global Quality Score (GQS) and the Patient Education Video Score for IBD (PEVIS-IBD) score used to evaluate Crohn's disease related YouTube® videos.

options, were often uploaded by pharmaceutical companies (47.8%) ($p<0.001$). Videos discussing alternative options were more likely to depict patients' personal experiences (73.9% vs. 2.4%) ($p<0.001$) and be an advertisement (78.3% vs. 0%) ($p<0.001$) than the patient education videos. Videos discussing patient education had a larger number of favorites (mean 25.0 vs. 5.5) ($p<0.001$) and comments (mean 22.0 vs. 5.0) ($p=0.022$) and were liked more often (mean 19.0 vs. 9.0) ($p=0.025$) than the videos discussing alternative treatment options.

4. Discussion

This is the first study in the literature to systematically analyze IBD-related YouTube® videos. Overall, we found that most of the videos were uploaded by patients and narrated their personal experience. They were the most discussed videos and had a high number of views and "likes". These videos provided

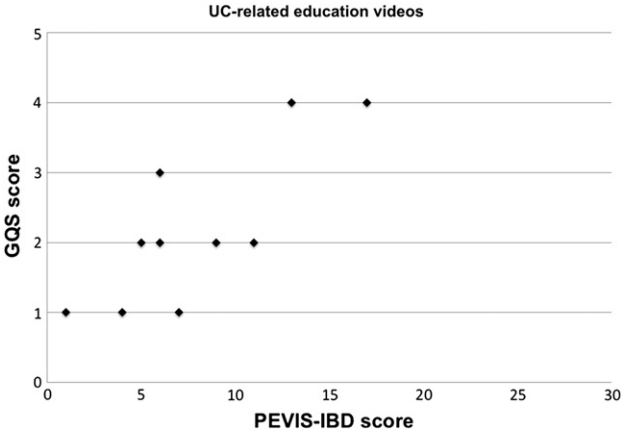

Figure 2 Relationship of the Global Quality Score (GQS) and the Patient Education Video for IBD (PEVIS-IBD) score used to evaluate ulcerative colitis related YouTube® videos.

Table 3 Comparison between YouTube® videos discussing alternative treatment options and appropriate information for patient education.

Factor	Alternative treatment options (N=23)	Appropriate information for patient education (N=17)	p-Value
Days since upload	814.4±397.5	1025.1±347.7	0.089
Duration (s)	184.0 [122.0,239.0]	320.0 [123.0,417.0]	0.15
Information provided by			<0.001
Patients	7 (30.4)	1 (5.9)	
Healthcare provider	3 (13.0)	12 (70.6)	
Pharmaceutical company	11 (47.8)	0	
Professional societies	1 (4.3)	1 (5.9)	
Media	1 (4.3)	3 (17.6)	
Type			
Personal experience	17 (73.9)	5 (29.4)	0.005
Advertisement	18 (78.3)	0	<0.001
Attitude towards traditional line of treatment			0.002
Positive	0	2 (11.8)	
Negative	13 (56.5)	1 (5.9)	
Ambivalent	10 (43.5)	14 (82.4)	
Favorites [a]	5.5 [3.0,12.0]	25.0 [13.0,51.0]	<0.001
Comments [a]	5.0 [1.0,20.0]	22.0 [8.0,48.0]	0.022
Opinion			
Like	9.0 [3.0,15.0]	19.0 [8.0,22.0]	0.025
Dislike	1.0 [0,2.0]	2.0 [1.0,3.0]	0.34

Values presented as Mean±SD with *t*-test; Median [P25, P75] with Wilcoxon rank sum test, or N (%) with Pearson's chi-square test.

[a] Data not available for all subjects. Missing values favorites=12, comments=1.

a platform for IBD patients to share their personal experience with peers.

Previous YouTube® studies[14,16] attempted to analyze bias of videos for/against conventional treatment and found variable results. A study by Steinberg et al.[16] revealed that a significant number of prostate cancer-focused videos on YouTube® had a bias for screening with PSA and treatment with surgery, which was contradictory to the guidelines for management of prostate cancer. Keelan et al.[14] noted that although most videos (48%) viewed immunization of children positively, almost a third were biased against immunization.

Our findings were different from these previous studies in that we had a larger number of videos depicting a negative attitude than positive attitude [16 (17.2%) vs. 11 (11.8%)] towards conventional treatment options. Six of the 11 patients with positive attitude towards traditional treatment, felt that this was secondary to surgery and 5 of these were UC patients. These findings are consistent with excellent health-related quality of life (HRQOL) in previously reported UC patients undergoing surgery.[18–20] In four of the 11 patients with a positive attitude towards traditional treatment, it was secondary to biologics, and all 4 were CD patients, which is consistent with the known beneficial effects of biologics in CD patients.[21] A negative attitude was mainly due to either failure of medical therapy or medicine-associated adverse effects. These videos were mainly advertisements by pharmaceutical companies depicting patients unsatisfied with their current treatment by a physician. We speculate that they may not truly represent the perception of IBD patient towards the conventional medical care.

There is a growing concern about patients receiving remuneration for uploading such personal testimonials, raising ethical questions.[22] Given the relapsing nature of the disease these videos may influence YouTube® viewers with IBD to abandon their regular treatment. Thus, YouTube® videos discussing patients' personal experience have differing attitudes towards conventional treatment options with the majority of videos having a negative bias.

Multiple studies have assessed the use of the Internet and available Internet information for patient education in IBD. A study by Bernstein et al.[2] showed that 55% IBD patients were not completely satisfied by information provided at the time of diagnosis. Cima et al.[4] showed that nearly 54% North American IBD-patients used the Internet as a source of information and found it either trustworthy or very trustworthy. A study by Angelucci et al.[5] in Italy showed similar results. In addition, they showed that educated patients with a higher household income and those with severe disease were more likely to use Internet as a source of information. Another European study from Spain, showed that greater than 80% of patients would like their gastroenterologist to refer them to a trustworthy website and more than 65% were willing to pay for this.[23] However, studies of IBD websites showed a marked variation in available information, with only a few websites providing high-quality materials.[6–9] In addition, most online materials are written at a level that is difficult for the general population to understand.[6–9] Another interesting study by Promislow et al.,[9] evaluated quality of websites based on patient information needs and found that websites could be strengthened by providing more information that deem to be important to the patients. Almost all the online websites are also not peer-reviewed and thus, potentially contain incorrect or outdated information. Previous YouTube® studies[14–17] have demonstrated similar findings with variation in content and a poor overall quality of the patient education materials. Our findings, in regards to patient education, are consistent with what were found in other studies. Overall, the content was poor. Only one video in CD education scored 23/28 on PEVIS-IBD scale and 5/5 on GQS scale ("Crohn's disease pt" series, uploaded April 10, 2008: http://www.youtube.com/watch?v=EeAmYqn81PQ and http://www.youtube.com/watch?v=gnTZmSO5mqU). Correspondingly, only two videos in UC education scored

4/5 on GQS scale but had a moderate score of 13/28 and 17/28 on PEVIS-IBD scale ("Ulcerative colitis", uploaded April 11, 2008: http://www.youtube.com/watch?v=HcSmVKGnGPE and "Inflammatory bowel disease", uploaded Aug. 2, 2008: http://www.youtube.com/watch?v=TSLKKzZ04Dk, respectively). IBD patients are unsatisfied with the medical information provided and use Internet as a source of information, but information content on Internet including YouTube® is highly variable.

The use of alternative treatments is widely prevalent amongst patients with IBD, with 34% to 51%[24] of IBD patients using some form of alternative therapy. A number of factors are associated with increased interest in alternative therapies: skepticism towards conventional treatment, treatment failure, side effects of conventional treatment, poor perception of health status and a lack of satisfaction with a physician.[25–27] In addition, IBD patients are more likely to seek alternative therapies if they are single, in a higher income bracket, and an urban dweller, have longer duration of disease and concerns about surgery, and generally feel out of control.[24,28]

The popular alternative treatment options varied from exercise and prayer[24] to homeopathy and special diets.[28] An interesting YouTube® study on kidney stone by Sood et al.[17] showed that 18% discussed misleading/alternative treatment options, of which 50% discussed herbal remedies and 19% discussed faulty dietary habits. A recent study on YouTube® videos discussing movement disorders[29] found that 66% videos showing movement disorders were psychogenic and many of them contained harmful suggestions for the treatment of movement disorders. Our current study on IBD revealed that 24% of videos discussed alternative treatment options, of which nearly half discussed herbal treatment and 22% discussed dietary modifications. However, 74% of these videos were in the form of personal testimonials compared with 42% by Sood et al.[17] The use of alternative treatments appears prevalent among IBD patients with a substantial number of YouTube® videos discussing these options.

Additionally, we compared alternative treatment option videos with patient education videos and noted some interesting findings. There were more videos discussing alternative treatment options. Majority of them were posted by pharmaceutical companies and discussed patients' personal experiences with a negative attitude towards conventional treatment options. These results are concerning. A study in cancer patients by McGinnis et al.[30] found that 5% of patients abandoned appropriate therapy and pursued potentially harmful alternative treatments. The number might have been underestimated, as the study included only patients who were visiting a clinic, so many other non-visiting patients were missed. The large number of such videos raises a concern that patients responding poorly to conventional therapy will be persuaded to choose alternative treatment options and may even abandon their regular treatment, hence, potentially leading to worsening of the illness and adverse consequences.

This is the first study to describe demographic data of viewers on YouTube®. Surprisingly, the predominant age group with the most viewers was middle-aged adults, 45 to 54 years old. These perhaps were either IBD patients themselves or parents of IBD patients. Alternatively, this could be due to the fact that young IBD patients did not create their personal profile on YouTube and hence reflecting an inappropriately low proportion. On the other hand, the patients uploading videos were mostly young adults and males. Although, most viewers were from the United States of America, YouTube® has been very popular in other English speaking countries.

A previous study by Cawdron et al.[31] discusses the need of young IBD patients to learn more about their disease and chat with other IBD patients anonymously about their condition and their struggles. Recent review by Fortinsky et al.[32] provided a comprehensive review of Internet for IBD. They discussed how social media sites like Facebook®, Twitter® and YouTube® were being increasingly used by healthcare providers and IBD patients. Patients appear to discuss a great amount of personal health information on such sites, which can be potentially risky. None of the previous studies have systematically analyzed social media sites as an educational resource for IBD. In our current study, we analyzed YouTube® in detail to assess the quality of IBD related information. We found that the majority of YouTube® videos were by uploaded by patients and discuss their personal experience demonstrating the role of YouTube® as a platform for communicating with other IBD-patients.

The findings of our current study have several clinical implications. Videos need to be uploaded by hospitals/health care professionals discussing the details of IBD disease, including the personal experiences of patients. Ideally, videos uploaded by physicians with IBD in which they discuss their personal experiences are likely to be more popular and accurate in educating the IBD population, especially in the targeted age group (45–54 years).

Our study has several limitations. First, only a limited number of IBD-related videos were analyzed. Although, we analyzed the 100 most viewed videos, these may not appropriately represent the amount of information available and perception of viewers towards treatment options. Second, the search was performed using "view count" and not by "relevance", which is generally the default option for searching videos. Third, due to the language barrier of our research team non-English videos (French/Spanish/German) were excluded, which comprise nearly 15 to 20% of the IBD-related videos. Furthermore, YouTube® content changes over time and this study only provides a snap shot of YouTube® on March 27, 2011 and April 3, 2011. In addition, as YouTube® is a dynamic site and if the videos are visited multiple times by the same user it would inappropriately elevate the view count. Finally, YouTube® is not regulated and users may not always provide their true demographic information. Hence the demographic results in our study may not be accurate.

In summary, the YouTube® videos on IBD assessed in this study were predominantly viewed by middle-aged adults (45–55 years old). Most of the videos were uploaded by patients or pharmaceutical companies and had a negative bias towards conventional treatments. IBD-related education content on YouTube is mostly poor in quality. Videos discussing alternative treatments were uploaded by patients or pharmaceutical companies and were greater in number than the patient education videos. Healthcare professionals and professional societies need to counteract the incorrect "education materials" in the Internet, particularly for the targeted population.

Conflict of interest

The authors declared no conflict of interest.

Acknowledgment

SM contributed to study concept and design, acquisition, analysis and interpretation of data, drafting of the manuscript. PM and BS contributed to study concept and design, analysis and interpretation of data and critically revised the manuscript. XW and RL conducted statistical analysis. All authors read and approved the final manuscript.

Appendix A. PEVIS-IBD: Patient Education Video Score for IBD (1 to 28)

Definition of IBD (1 point)

- ☐ Generally describes Crohn's disease as a disease of chronic inflammation of the GI tract.
- ☐ Generally describes ulcerative colitis as a disease of chronic inflammation of the large intestine.

Etiology

Max. 2 points (1–2 discussed; 1 point; 3–4 discussed: 2 points)

- ☐ Unknown etiology
- ☐ Genetic predisposition
- ☐ Potential environmental trigger — organism or food
- ☐ Abnormal immune response

Symptoms

- ■ UC: Max. 3 points (1 to 3 symptoms: 1 point; 4 to 6: 2 points; 7 and more: 3 points)
  - ☐ Rectal bleeding/blood in stool
  - ☐ Mucus in stool
  - ☐ Diarrhea/increased bowel frequency
  - ☐ Urgency
  - ☐ Tenesmus/false urge
  - ☐ Abdominal cramping or pain/discomfort
  - ☐ Loss of appetite
  - ☐ Fatigue
  - ☐ Weight loss

- ■ CD: Max. 3 points (1 to 2 symptoms: 1 point; 3 to 4: 2 points; 6 and more: 3 points)
  - ☐ Abdominal pain, may be right lower quadrant
  - ☐ Diarrhea
  - ☐ Loss of appetite
  - ☐ Weight loss
  - ☐ Ulcers in mouth
  - ☐ Fatigue
  - ☐ Perianal disease

Extraintestinal manifestations

Max. 2 points (1 to 3 manifestations: 1 point; 4 or more: 2 points)

- ☐ Eye symptoms (iritis/uveitis)
- ☐ Ankylosing spondylitis (axial arthropathies)
- ☐ Joint pain/arthritis (especially joints of lower extremities)
- ☐ Erythema nodosum/pyoderma gangrenosum
- ☐ Hepatic/biliary disease (primary sclerosing cholangitis.)

Diagnosis

- ■ For UC: max. 3 points: 1 point for each of these
  - ☐ Based on symptoms and physical exam.
  - ☐ Discusses role of blood work (CBC, CRP, ESR, albumin, LFTs)
  - ☐ Sigmoidoscopy/colonoscopy with biopsies

- ■ For CD: max. 4 points: 1 point for each of these
  - ☐ Based on symptoms and physical exam.
  - ☐ Discusses role of blood work (CBC, CRP, ESR, albumin, LFTs)
  - ☐ Barium enema X-ray/Upper GI series with small bowel follow through, CT/MRI
  - ☐ Endoscopy/sigmoidoscopy/colonoscopy

Disease Course: Discusses the nature of Crohn's disease and UC with respect to disease course

Max. 2 points (1 to 2 of these: 1 point; 3 or more: 2 points)

- ☐ Variable disease course: describes Crohn's disease and/or ulcerative colitis as often waxing and waning with flare-ups of symptoms and spontaneous remissions or persistent disease or disease that spontaneously resolves.
- ☐ Hospitalization may be necessary if flare-ups are severe.
- ☐ Surgery is a possibility to treat complications or for severe disease.
- ☐ Discusses that stress may aggravate existing symptoms but does not cause IBD symptoms or IBD.
- ☐ Smoking may adversely affect disease course in Crohn's disease and may lead to start of UC in first 2 years after quitting.

Nutrition and IBD

Max. 3 points (1 to 3 of these: 1 point; 4 to 6: 2 points; 7 and more: 3 points)

- ☐ Discusses that diet does not cause ulcerative colitis or Crohn's disease but may affect symptoms depending on the individual; individuals may have food intolerances.
- ☐ Discusses the importance of maintaining a healthy, balanced diet.
- ☐ Discusses malabsorption and malnutrition in IBD: as a result of inflammation, diarrhea, bleeding, or surgical resection of the bowel.
- ☐ Discusses possibility of lactose intolerance in IBD and the recommendation to avoid milk products.
- ☐ Discusses tube feeding.
- ☐ Discusses TPN.
- ☐ Discusses elemental diets.
- ☐ Discusses simple sugars as aggravating diarrhea (causing an osmotic diarrhea).
- ☐ Discusses nutrient deficiencies including sequelae from treatment: vitamin and/or nutrient deficiencies in general, vitamin B12 deficiency, folate deficiency, iron deficiency, calcium and vitamin D (also related to corticosteroids)

Disease complications

Discusses the complications that may arise from Crohn's or UC.

- UC: Max. 3 points (1 to 2 complications: 1 point; 3 to 4: 2 points; 6 and more: 3 points)
  - ☐ Bowel perforations
  - ☐ Malabsorption
  - ☐ Iron deficiency anemia/low albumin
  - ☐ Bleeding
  - ☐ Toxic megacolon or fulminant colitis
  - ☐ Greater risk of colon cancer
  - ☐ Progressive disease unresponsive to treatment requiring surgery

- CD: Max. 3 points (1 to 4 complications: 1 point; 5 to 8: 2 points; 9 and more: 3 points)
  - ☐ Strictures/bowel obstruction
  - ☐ Perforations
  - ☐ Abscesses
  - ☐ Fistula
  - ☐ Perianal disease
  - ☐ Malabsorption
  - ☐ Iron deficiency anemia
  - ☐ Low albumin
  - ☐ Bleeding
  - ☐ Toxic megacolon or fulminant colitis
  - ☐ Greater risk of colon cancer
  - ☐ Progressive disease unresponsive to treatment requiring surgery.

Medical treatment

- UC: Max. 3 points (1 to 2: 1 point; 3 to 4: 2 points; 5 and more: 3 points)
  - ☐ 5-ASA preparations
  - ☐ Role of steroids
  - ☐ Side effects and complications of steroids
  - ☐ Role of calcium and vitamin D supplementation with corticosteroids
  - ☐ Role of immunosuppressive therapy — azathiaoprine/6-mercaptopurine/methotrexate
  - ☐ Biologic agents (infliximab)

- CD: Max. 3 points (1 to 2 symptoms: 1 point; 3 to 4: 2 points; 6 and more: 3 points)
  - ☐ 5-ASA preparations
  - ☐ Role of steroids
  - ☐ Side effects and complications of steroids
  - ☐ Role of calcium and vitamin D supplementation with corticosteroids
  - ☐ Role of broad spectrum antibiotics — metronidazole and ciprofloxacin
  - ☐ Role of immunosuppressive therapy — azathioprine/6-mercaptopurine/methotrexate
  - ☐ Biologic agents (infliximab, adalimumab, certazumimab)

Surgical treatment

Discusses the possibility, indications and fears for surgery

- UC: Max. 3 points (1 to 2: 1 point; 3 to 4: 2 points; all 5: 3 points)
  - ☐ Discusses total proctocolectomy
  - ☐ With ileostomy
  - ☐ With Kock pouch (continent reservoir ileostomy)
  - ☐ With ileo-anal pelvic pouch anastomosis (J-pouch or S-pouch)
  - ☐ Discusses potential complications of surgery

- CD: Max. 2 points (1 to 2: 1 point; 3 or more: 2 points)
  - ☐ Bowel resection
  - ☐ Surgery for small bowel obstruction
  - ☐ Surgery for abscesses and fistulas
  - ☐ Discusses ileostomy and colostomy

Psychosocial and quality of life issues

Max. 2 points (1 to 4: 1 point; 5 or more: 2 points)

- ☐ IBD and sexuality (e.g., drive, function, medication-related)
- ☐ Effect of IBD on fertility and pregnancy
- ☐ IBD and travel
- ☐ IBD and insurance issues
- ☐ Costs of living with IBD (e.g., drug costs, drug plans, etc.)
- ☐ IBD and depression
- ☐ IBD and children/youth/young adults
- ☐ IBD and relationships (marriage/spouse, social functioning)

New treatments and alternative therapies

1 point: if addresses any of these:

- ☐ Discusses the existence of complementary (naturopathic, diet, etc.) therapies and describes their evidence/lack of evidence. Discusses new/future treatments and their evidence.
- ☐ Discusses new treatments and complementary therapies.

Appendix B. Global Quality Score (GQS)

Range: 1 to 5 points
Global score description

- 1: Poor quality, poor explanation, most information missing, not at all useful for patients
- 2: Generally poor quality, poor/average explanation, with some information listed but many important topics missing, of very limited use to patients
- 3: Moderate quality, poor/average explanation, some important information is adequately discussed but others poorly discussed, somewhat useful for patients
- 4: Good quality and good explanation, most of the relevant information is discussed, but some topics not covered, useful for patients
- 5: Excellent quality and excellent explanation, very useful for patients

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