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YouTube as a source of information for patients considering surgery for ulcerative colitis

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ABSTRACT

Background: With the range of health information online, assessing the resources that patients access may improve the content of preoperative information. Our aim was to assess the content of the most viewed videos on YouTube related to surgery for ulcerative colitis (UC).
Methods: YouTube was searched for videos containing information on surgery for UC. The 50 most viewed videos were identified and user interaction analyzed. Upload source was classified as patient, individual health care professional (HCP), or hospital/professional association. Video content was categorized using an inductive thematic analysis on a purposive sample list of videos. The overarching theme of each video was classified once data saturation was achieved.
Results: Thirty videos were uploaded by patients, 15 by hospitals and 5 by HCPs. Seventeen videos (34%) discussed life after surgery. Sixteen of these were uploaded by patients who had previously undergone surgery for UC. No videos of this theme were uploaded by HCPs. Ten videos (20%) described a number of different operations. Other themes identified were alternative health therapies (12%), colonoscopy (12%), life with UC (8%), miscellaneous (8%), and education for HCPs (6%). Patient uploaded videos had significantly more comments ($P = 0.0079$), with 28% of comments on patient videos being users requesting further information.
Conclusions: Understanding the sequelae of surgery is most important to preoperative patients. There are a lack of professional videos addressing this topic on YouTube. HCPs must participate in the production of videos and adapt preoperative consultations to address common preoperative concerns.

Introduction

In the first 10 y following a diagnosis of ulcerative colitis (UC), 1 in 10 patients will require a colectomy, with 20%-30% of patients requiring surgery in the long term.[1,2] Surgery may be performed acutely for severe active disease, perforation, or excessive bleeding. More commonly, surgery is performed electively for disease refractory to medical treatment.[3,4]

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The decision to opt for surgery is difficult both for the individual facing the choice and clinicians providing the advice. This is particularly the case when considering elective surgery; patients may not be acutely ill, and the option of further medical treatment exists. A surgical option can offer an improved quality of life and reduced drug side effects but may itself also be associated with significant complications.[5] Current guidance emphasizes the importance of information about treatment options for people considering surgery, including specific information about what to expect in the short and long term after surgery.[6] However, it was acknowledged that there was inadequate guidance on the specific content of such information.

It is estimated that 50% of patients with inflammatory bowel disease use the Internet for information relating to their condition.[7] Patients may seek health information from the Internet at least as frequently as from their gastroenterologist (38% *versus* 36%, respectively).[8] A key principle in the consent process is to give the patient time to consider their decision by conducting further research—both with extra reading and searching the Internet.[9] With this, patients and their carers will look to the Internet for information to support their decision.

YouTube (www.youtube.com) is a video hosting website. Strings of free text can be searched in a natural language format, with a list of videos produced in order of perceived relevance based on keyword density in the title of the video and access by other users. Content is free to access, widely accessible in geographic terms, and is not peer reviewed. Site features include the ability to "like" or "dislike" a video, provide written comments on it, or search for specific videos on the site. Users who are unregistered can watch videos; however, they cannot upload their own material. Registered users are capable of uploading an unlimited number of videos that must respect certain "guidelines" such as no graphic content or copyrighted materials.[10] The only limitation across the website is where content is deemed inappropriate for all ages, users must be registered, and over the age of 18 y old to watch the video.[11]

Currently, there are no studies assessing YouTube videos about surgery for UC. We believe that assessing commonly viewed videos on YouTube could provide a description of what patients access outside the clinical encounter. Our research question was: what is the content of the most commonly viewed videos on YouTube when directly searching for information about surgery and UC?

The aim of this study was to assess the thematic content of the most viewed videos on YouTube discussing UC and surgery. A secondary aim was to ascertain to user response to these videos.

Method

A YouTube search was conducted on the June 3, 2016, using the search term "ulcerative colitis and surgery." This search term was established from concurrent qualitative interviews with patients who had surgery for UC and was confirmed as the most popular search term that patients would use, or have used, by patients involved in a public-patient involvement day for related trials for inflammatory bowel disease. The use of additional search terms was deemed as unnecessary as preliminary searches illustrated large content overlap between different search terms, for example, "Ulcerative Colitis colectomy."

Videos were subsequently filtered according to the number of views. In a systematic approach, the top 50 videos were independently analyzed by two medical student researchers, with training in qualitative methodologies (D.M.B. and J.H.M.). The first 50 videos were set as the cutoff for a number of reasons. First, this methodology is a hybrid of a citation analysis and a thematic analysis. We chose 50 videos as, during preliminary searches, we noted videos appearing after the 50th video had a lower view count. We also felt that 50 videos were more than adequate to achieve a robust thematic analysis without coding an unnecessary volume of data. Finally, previous work using qualitative methods to assess YouTube uses similar sample sizes to that used in our analysis.[12,13]

Video demographics including number of views, likes, and dislikes were recorded. Any disagreements over the number of views, like or dislikes, or discrepancies in categorization were solved by an independent reviewer who is a specialist in general surgery (M.J.L.).

The upload source of each video was classified as patient, individual health care professional (HCP), or hospital/professional association (PA) based on the "about" section of their YouTube profile. A patient uploader was someone with UC or inflammatory bowel disease. Hospital/PA uploaders were specific hospitals/clinics or medical societies. Individual HCP uploaders were professionals acting individually to upload videos. Some PA videos talked to HCPs as part of their video; however, they were classified as PA if they were uploaded by specific hospitals or clinics.

The top 10 comments on each video were analyzed and were classified as further information requests, comment praising or critiquing the video, user sharing their own personal experience, or irrelevant comment. Comments were classified as irrelevant if they were unable to be understood or they were not related UC and surgery. Some videos had comments disabled, and this was noted for later analysis.

Categorization of video content

A thematic construct was developed using purposive sampling of 14/50 of the videos to represent the upload sources with varied characteristics (male/female, age, pre-op/post-op). This method facilitates identification of themes until saturation is achieved, and other content can then be fitted into this framework. Videos from the sample were transcribed verbatim and analyzed using an inductive thematic analysis model on the QSR NVivo 11 Computer-Assisted Qualitative Data Analysis Software (QSR International, Melbourne).[14] Codes produced from the analysis were used to generate emergent subthemes in each video. Using these themes, we categorized the overarching theme of each video. Emergent themes and video transcripts were discussed collaboratively by three reviewers (D.M.B., M.J.L., and G.L.J.) to ensure consensus was achieved.