



YouTube™ as a source of information for patients undergoing laryngectomy: a thematic analysis

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Abstract

Purpose Total laryngectomy and end tracheal stoma formation are often required to treat advanced laryngeal cancer. Resources on the internet are commonly accessed by patients as a source of healthcare information. YouTube™, the most popular video-hosting website, is one such resource. The aims of this study were to assess the thematic content of the most viewed YouTube™ videos concerning laryngectomy for laryngeal cancer and to evaluate user response to these videos.

Method A search of YouTube™ was performed and data were extracted from videos with > 100 views. Upload source, number of views, likes, dislikes and comments were collected and the content of comments was analysed. User response was compared between upload sources using Kruskal–Wallis testing. Inductive thematic analysis of video content was performed to identify overarching themes and subthemes.

Results A total of 96 videos were identified, 16 uploaded by patients, 24 by individual healthcare professionals and 56 by professional healthcare institutions. There were 1214,503 views and no significant differences in the number of views, likes or dislikes between upload sources. Three overarching themes and 17 subthemes were identified. Comments were most frequently characterised as offering praise.

Conclusion YouTube™ has been shown to be a popular platform for sharing information about laryngectomy for laryngeal cancer. There is a lack of data concerning the quality of this information, however, and future work should focus on assessing this. Trusted institutions could make use of this medium to disseminate high-quality information to their patients, and to the wider public.

Keywords Laryngectomy · Laryngeal cancer · YouTube · Health information · Head and neck

Introduction

Laryngeal cancer is diagnosed in over 150,000 patients worldwide each year [1]. Radiotherapy, endolaryngeal excision and laryngectomy (partial or total) are used to treat laryngeal cancer. The choice of modality is dependent on the stage of disease, patient co-morbidities, as well as

patient preference. Although laryngeal preserving options are increasingly used first line [2–4], open laryngectomy maintains its place in cases of advanced disease or salvage treatment following failure of first-line therapy [3, 5]. However, laryngectomy with formation of a laryngeal stoma is a life-altering event with a significant impact on subsequent quality of life, psychosocial state and economic potential of the individual [6, 7]. It is imperative that the patient has the necessary information to make an informed decision to proceed with laryngectomy. Patient preference regarding laryngectomy varies significantly, with some favouring it because of the associated survival benefits, whilst others may be more reluctant because of perceived issues with post-operative quality of life [8]. Unfortunately, patients with laryngeal cancer do not always receive adequate information from the healthcare team in the pre-operative period [9].

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Traditionally, patients have accessed health information primarily from doctors and allied health professionals [10]. With the inception of the internet, health information is more widely available and readily accessible than ever before [11]. In a United Kingdom survey on internet usage, 71% of the population were internet users, of whom 73% had looked up health information online on at least one occasion [12]. 75% of US patients with a chronic disease stated that information gained online affected their decision making [13]. Accordingly the range, quality and impact of online health information is increasingly the subject of academic interest [14–17]. There is also an acceptance by professionals that internet information has a role to play in clinical care, and the Royal College of Surgeons encourages the use of online resources as part of supported decision making prior to surgery [18].

One popular source of online information is YouTube™ (www.youtube.com), an open-access platform on which users can publish videos that will be streamed worldwide. Audiences can interact with content creators by liking, disliking or commenting on their videos. Medical and health information produced by institutions, professionals and patients appear on the site. Several studies have examined the content and quality of YouTube™ content related to specific health conditions [19–22]. Previous reviews of otolaryngological content on YouTube™ have been performed, focusing on rhinosinusitis and paediatric tonsillectomy [23, 24], but no such study exists for laryngectomy-related material. This group believes that a thematic review of YouTube™ content relating to this surgery is warranted. Laryngectomy and stoma formation are life-changing procedures with a significant functional and psychosocial impact on the patient. Patients facing surgery with unmet information needs may turn to internet resources to supplement knowledge from health professionals. This review of YouTube™ content will identify what themes are explored on this platform, and how patients respond to this material. This information may improve the ability of health professionals to provide information that meets patient needs in the run up to laryngectomy surgery.

Methods

Search strategy

A search of YouTube™ was performed on 11th June 2018 using the terms “laryngectomy surgery”, “laryngectomy operation”, “laryngectomy stoma,” “laryngectomy life,” “laryngectomy patient” and “laryngectomy post op”. These terms were established through discussion between two authors (TAMM and EGH) with the aim of emulating typical search strategies amongst patients with laryngeal cancer. Previously published studies were also reviewed to inform

the style of search [22, 25, 26]. The results were filtered in descending order by the number of views. Playlists, those in a non-English language and videos with fewer than 100 views were excluded. Duplicates were removed and data were extracted from the remaining videos.

Data extraction

Quantitative data were collected independently by four reviewers, with conflicts resolved independently by TAMM and EGH. Demographic data were collected for each video, including the video title, year of upload, YouTube™ username and upload source. The latter was classified as being patients, an individual healthcare professional or a professional healthcare institution using the video title, upload username and ‘about’ section of the YouTube™ channel. Video popularity was characterised by the number of views, number of likes and number of dislikes. Summary characteristics of videos were described using the median and interquartile range as the data demonstrated a positive skew. User response was compared between upload source using Kruskal–Wallis analysis, with statistical significance set as $p < 0.05$ a priori. All tests were performed using GraphPad Prism version 7.04 (GraphPad Software, La Jolla, California). The first ten comments for each video were explored and classified as being either a comment requesting further information, a comment praising the video, a comment criticising the video, a comment sharing the user’s experiences or an irrelevant comment. Video comment classification was established by the authors after initial screening of video comments, ensuring all video comments fit into one classification. Irrelevant comments were defined as being either incomprehensible or unrelated to the topic of laryngectomy.

Thematic analysis

Inductive thematic analysis was performed in accordance with Braun and Clarke’s guidance [27]. Purposive sampling of 32 videos was performed to elicit themes from the most data-rich sources in the first instance. A varied assortment of videos produced by each user type was selected for purposive sampling. This included the most and least viewed, the most and least liked, the oldest and newest and those with the most comments. These videos were transcribed verbatim.

Thematic analysis of the transcribed text was performed using NVivo (QSR International, Melbourne) with emergent themes being assigned codes for classification. Transcription continued until data saturation, defined as the point at which no new themes emerged from the data, was achieved. Assessment following analysis of the 32nd video demonstrated that data saturation had not yet been reached. Transcription, therefore, continued until the 36th video, at

which point data saturation was achieved. From the codes generated by this process, a system of overarching themes and secondary subthemes was produced through discussion between five authors. All remaining videos were viewed and classified into the system by their overarching theme. As data saturation had been achieved, it was possible to assign these videos to one of the overarching themes generated by analysis of the first 36 videos.

Results

The search identified 96 videos eligible for inclusion, uploaded between 2009 and 2018 (Table 1). Fifty-six (58.3%) videos were uploaded by professional institutions, 24 (25%) videos were uploaded by individual healthcare professionals and 16 (16.7%) videos were uploaded by patients. Professional institutions constituted a variety of official sources including hospitals, research centres and medical device manufacturers based in several countries. Videos were also uploaded by a quality improvement collaborative, a University and a charity based in the UK.

There was a total of 1214,503 views, ranging from 147 to 307,059 views per video. The median number of views per video was 2,447. Although videos posted by professional institutions were the most numerous, there was no significant difference between upload sources in the median number of

views per video ($p=0.68$). There was a median of 7 (IQR 2–24) likes and 0 (0–2) dislikes per video and there were no significant differences between upload sources in the number of likes ($p=0.57$) or dislikes ($p=0.38$) (Table 1).

A total of 482 comments were identified from the top 10 responses to each included video (Table 2). The comment function was disabled by content creators in 21 videos, preventing audiences from writing verbal responses. Excluding the 372 irrelevant comments, those remaining most frequently offered praise (51/110, 46.4%) with only a minority criticising the videos (4/110, 3.6%). Of the relevant comments offered for videos by patients, 10/27 (37%) shared user experiences. Similar comments were left on 3/29 (10.3%) of videos by healthcare professionals and 16/54 (29.6%) of videos by professional institutions. Comments requesting further information were offered for 7/27 (26.0%) of videos by patients, 8/29 (27.5%) of videos by healthcare professionals and 11/54 (20.4%) of videos by professional institutions (Table 2).

A total of 36 videos were transcribed until data saturation was reached. The thematic analysis identified 3 overarching themes and 17 subthemes (Table 3). The most common theme was educational material aimed at healthcare professionals. Subthemes generated from these 45 (46.9%) videos ranged from cadaveric anatomy demonstration to live intra-operative demonstration and theoretical teaching. These were mostly uploaded by healthcare professionals (20/45,

Table 1 Baseline video characteristics

Characteristic	All videos	Patient	Healthcare professional	Professional institution	<i>P</i> value
Total number of videos	96	16	24	56	–
Total number of views	1214,503	180,372	182,661	851,470	–
Median (IQR) views	2447 (1034–9510)	3578 (737–15,605)	2152 (877–7774)	2447 (1190–9508)	0.68
Total number of likes	2277	277	354	1646	–
Median (IQR) likes	7 (2–24)	11 (2–29)	6 (3–22)	6 (1–23)	0.57
Total number of dislikes	213	31	44	138	–
Median (IQR) dislikes	0 (0–2)	1 (0–2)	1 (0–2)	0 (0–1)	0.38

Table 2 Comment characteristics

Characteristic	Patient	Healthcare professional	Professional institution	All videos
Total number of videos (number with comments disabled)	16 (2)	24 (5)	56 (14)	96 (21)
Total number of comments	81	49	352	482
Number of comments requesting information	7	8	11	26
Number of comments praising	10	16	25	51
Number of critical comments	0	2	2	4
Number of comments sharing user experiences	10	3	16	29
Number of irrelevant comments	18	9	42	69
Number of miscellaneous comments	36	11	256	303

Table 3 Thematic analysis of video content

Theme	Subtheme	Example quote
The clinical journey (<i>n</i> = 13)	Pre-operative period	“I had basically two weeks to make a decision and Dr Dusek told me I had no choice but to do this because the tumour was so big it was closing off my airway”
	Intra-operative period	“I’ve been a speech language pathologist for 31 years and most of my work has been in the area of laryngectomy. Very briefly I’d like to tell you about what a laryngectomy is”
	Post-operative period	“The challenge was dealing with all the new mucus, dealing with changing the seals every day, learning how to re-talk, learning how to re-swallow, how to eat”
	Patient perspective	“Having a laryngectomy is a life-changing experience and there is a lot of important information you’ll need to know”
	Healthcare professional perspective	“This video was created to help walk you through the steps in your journey”
Life after laryngectomy (<i>n</i> = 38)	Breathing	“So with the hole in the neck, the air flows into the lungs, it flows out to the air when you exhale, but it feels very different to how it did when you had a voicebox there. It takes some getting used to”
	Communication	“There are several ways that you can speak. I speak through a voice prosthesis, but there is an electrolarynx, there is oesophageal speech, you can also communicate by other means like writing or silent articulation”
	Swallowing and feeding	“At the end of the surgery we will put in place a feeding tube, either in the nostril or we will ask our General Surgery colleagues to place a percutaneous gastrostomy tube, or feeding tube, into the stomach”
	Stoma care	“After surgery, you’ve now realised you have a stoma and this is where the windpipe is sewn directly to the skin. It’s very important to take care of this area of your body after surgery”
	Post-operative complications	“The main reason laryngectomees need emergency respiratory care is mucus plug”
	Benefits	“If you need to be resuscitated, it’s very easy to do it”
	Integration into society	“A lot of people think if you’re a laryngectomee you’re obsolete. Well, you’re not”
	Support for patients	“Family must hang together and understand that they have obstacles that they’ve got to overcome too, but life does go on”
Educational information for healthcare professionals (<i>n</i> = 45)	Cadaveric anatomy demonstration	“The first step after we lift the flap and identify the strap muscle is what?”
	Live demonstration of laryngectomy	“Today this is a demonstration of a patient who is suffering from CA larynx. The surgery which is being performed is total laryngectomy”
	Other clinical procedure demonstration	“If a tracheostomy tube has been removed during the emergency management of a patient, then it may need to be replaced”
	Theoretical teaching	“A new interactive e-learning module, designed to be accessible to a broad spectrum of professionals”

44.4%) and professional institutions (12/45, 26.7%) with the remainder uploaded by patients (4/45, 8.9%). In one, an anatomy demonstrator teaches his students how to perform a total laryngectomy. He dissects the neck of a cadaver, discussing anatomical structures and asking his students what would be found after they “lift the flap and identify the strap muscles”.

Thirty-eight videos (39.6%) were on the theme of life after laryngectomy and included subthemes such as breathing, communication, swallowing, feeding and stoma care. The majority of these (26/38, 68.4%) were uploaded by

professional institutions involving promotion of a product. Eight videos (21.1%) were uploaded by patients and four (10.5%) by healthcare professionals. One patient shared their experiences of verbal communication, explaining to viewers that “there are several ways that you can speak. I speak through a voice prosthesis, but there is an electrolarynx, there is oesophageal speech, you can also communicate by other means”. Another reassured the viewers that though “a lot of people think if you’re a laryngectomee you’re obsolete. Well, you’re not.”

Thirteen videos (13.5%) were categorised thematically as discussing the clinical journey from the pre-operative phase (“I had basically two weeks to make a decision”) to the immediate post-operative phase (“the challenge was dealing with all the new mucus”). No videos in this category were uploaded by healthcare professionals, four (30.8%) were uploaded by patients and nine (69.2%) were uploaded by professional institutions (Table 3).

Discussion

Using a well-established method of thematic analysis, we have established the origins and thematic content of the most popular YouTube™ videos on laryngectomy for laryngeal cancer. User response to these videos has also been characterised, providing a thorough overview of material on the website. The results have important implications for future information provision to laryngectomy patients. First, our review has shown the potential impact of YouTube™ in disseminating surgical information to patients. With over one million views across the 96 videos included in this study, it is clear that there is a demand for information about laryngectomy for laryngeal cancer, and that a sizeable number of people are attempting to meet this need through YouTube™. As has been noted previously, patients facing this operation have unmet information needs and it is possible that YouTube™ fills this gap to some extent. The variety of sources demonstrated, from individuals sharing personal experiences to official institutions offering professional advice, may provide patients with a range of benefits. They may be comforted by hearing from those who have completed treatment whilst gaining practical knowledge from professional videos regarding the technicalities of laryngectomy and post-operative stoma care. Otolaryngologists should be aware that this content exists and is readily accessible by patients. On reviewing the content themselves, they may choose to guide individuals to particular videos that they feel could offer benefit.

Some previous studies investigating YouTube™ as a source of surgical information have identified patients as the primary creators of material [23, 25]. In contrast, the majority of videos identified in this study were produced by professional institutions, with patient-created videos comprising the smallest group. The reason for this difference is unclear. Laryngeal cancer patients could be less likely to produce online content than other patient groups, but further research is needed to identify the specific reason for this. Audience response to the videos as assessed by the comments was shown to be largely positive regardless of the upload source. A substantial proportion of the comments requested more information, further suggesting that viewers were seeking to

satisfy an unmet information need regarding laryngectomy and its impact on individuals undergoing surgery.

Thematic analysis showed that the most frequent theme was in fact videos produced for the benefit of healthcare professionals. Some reviews that have attempted to assess the quality and reliability of YouTube™ videos have suggested that such educational pieces might be of most benefit to patients, in terms of the reliability and quality of the information contained [19, 23, 24]. Open-access platforms such as YouTube™ by definition allow patients to find and engage with material intended for medical professionals. This may have advantages and disadvantages, allowing patients’ access to more reliable and detailed information on the topic of laryngectomy but possibly exposing them to alarming material (e.g. cadaveric dissection) or excessively complex information. For otolaryngologists, this content may represent a useful educational resource to supplement their learning and professional development. Life after laryngectomy was the second most common theme. Several videos with this theme were produced by institutions that were promoting a product, usually a speech system. This should highlight to clinicians that commercial health organisations may also utilise YouTube™, with potential for there to be conflicts of interest as a result. The second and the third most frequent themes, life-after laryngectomy and patient journey, again indicate that viewers are seeking to satisfy an unmet information need regarding laryngectomy and its impact on quality of life.

This review does possess limitations. The personal history of those accessing these YouTube™ videos is not available to researchers. It is, therefore, impossible to determine exactly the extent to which videos are being viewed by laryngectomy patients and health professionals, or by ‘lay’ members of the public. Even assuming that many viewers are indeed patients, it is possible that those looking for material on YouTube™ are not representative of the wider cohort of laryngectomy patients. Laryngeal cancer typically affects an older age group [28]. It may be that patients searching for videos on YouTube™ represent a younger or more technologically literate group than a typical sufferer of laryngeal cancer. However, around 80% of 65–74 year olds in the UK, and 45% of those aged 75 years or older, have used the internet in the last 3 months [29]. It is possible that a cancer diagnosis and treatment discussion would prompt relatively infrequent users of the internet to conduct a search for information. There is, therefore, no clear evidence that the audience of these videos is significantly unrepresentative of laryngeal cancer patients.

A more fundamental problem with health information on YouTube™ is the lack of formal quality assurance or peer review for material on the site. There are, therefore, concerns regarding the accuracy of the information available for both otolaryngological and non-otolaryngological

conditions, and the resulting adverse influence on patients' behaviour and decision making [19, 22–24]. We have not assessed the accuracy of the videos included in our study as our primary aim was to assess the thematic content of videos and audience response to them. Future work could involve an assessment of the quality of the resources we have identified on YouTube™. This is made difficult, however, by the lack of a validated quality assessment tool for health information videos. Some groups have attempted to assess the quality of information on YouTube™ relating to a specific health topic using their own scoring systems, but none of these have been externally tested [19, 20, 22, 24]. ReFaey et. al have suggested that producers of YouTube™ material use the validated DISCERN tool to quality control their output, along with formal peer review [26]. The DISCERN tool was, however, developed for use specifically with written health information and not videos [30], and it may therefore have to undergo further testing before it can be used in this environment.

Despite concerns regarding quality, it is likely that YouTube™ will remain a popular source of health information for patients with many conditions including laryngeal cancer. Our study has demonstrated a clear demand for information on the platform about specific aspects of laryngectomy, such as life after surgery. It is, therefore, important that health professionals engage with this medium to ensure that patients facing difficult decisions about surgery are given the most reliable information available.

Conclusion

YouTube™ has been shown to be a widely used and effective means of communicating information regarding laryngectomy. Its scope extends to both patients, to aid their understanding of the operation and subsequent lifestyle changes, and to other healthcare professionals as a tool in medical education. There is a lack of data concerning the quality of this information, however, and future work should focus on assessing this. Healthcare professionals and professional institutions should make use of this medium to disseminate high-quality information to their patients, and to those outside of their care.

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Compliance with ethical standards

Conflict of interest The authors have no conflict of interest to declare.

Human and animal statements This study did not involve human participants and/or animals.

Informed consent Informed consent was not required as the study did not involve human participants.

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