

Qualitative Assessment of YouTube Videos as a Source of Patient Information for Corneal Transplant Surgery

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Abstract

Purpose: Healthcare information is easily accessible on YouTube, however it is unregulated and the quality may vary considerably. This study characterised and evaluated the content on YouTube regarding corneal transplantation surgery.

Methods: YouTube was searched using 'corneal transplant' and the variations for penetrating and lamellar transplants. The results were deduplicated and screened for inclusion by two independent reviewers. A modified DISCERN tool was used to evaluate the quality of each video by two observers independently. Discrepancies were resolved through discussion and a third adjudicator where necessary.

Results: 53 videos were included in this study and the mean overall DISCERN score was 1.91 out of 5 (SD = 0.90). Videos scored highest in relevance to corneal transplant (mean 3.89) and lowest in explaining which patients are unsuitable (mean 1.00) and offering sources of information (mean 1.11). The video with the highest viewer engagement (VPI) was a patient vlogging their experience of the procedure.

Conclusion: Quality of YouTube content is variable and the lack of clarity over subtypes of corneal transplant can be confusing for patients. There is considerable scope to improve the use of visual aids, animations and diagrams within videos in order to supplement verbal information in clinic. Essential components needed to make an informed decision about corneal transplant are lacking in many videos, meaning videos may be a useful supplement but should not be relied on for comprehensive material.

Introduction

The internet has revolutionised the way individuals consume healthcare information. During the COVID-19 global pandemic the public's dependence on the internet for healthcare information was apparent [1], however the accompanying misinformation outbreak [2] also highlighted the importance of accurate and reliable information sources. YouTube is one of the most popular websites on the internet and the most popular video sharing website on the internet [3]. The ability of video to convey complex concepts in an accessible format makes YouTube an engaging resource. However, the accuracy of medical information on YouTube is variable and should be utilised with caution [4].

Corneal transplant surgery is one of the most frequently performed transplantation surgeries in the UK [5] but it can be difficult to navigate the internet when seeking reliable healthcare information [6].

Patients need to be offered reliable information on both advantages and risks in order to make a decision and provide informed consent. In light of the need for accurate, unbiased information and the ever-rising use of social media in healthcare, this study analysed YouTube videos as a source of information for corneal transplant.

Materials And Methods

YouTube was searched on 25th October 2020 using the terms "corneal transplant", "penetrating keratoplasty", "lamellar keratoplasty" and "cornea transplant for patients". Screening was performed under YouTube's default setting, which automatically sorts by 'most relevant'. The first 50 videos from each search were combined and deduplicated prior to screening for eligibility. Videos were included if they were in English, about corneal transplantation and directed towards lay audiences. Videos were excluded from analysis if they were aimed at healthcare professionals (most of these were teaching surgical techniques). Each video was reviewed by two independent observers at the screening and data extraction stages. Disagreements were resolved through discussion and a third independent adjudicator where no resolution was achieved by the initial two reviewers. In addition to the qualitative assessment, video metrics were collected including the number of views, 'likes' and 'dislikes' and video length.

The DISCERN instrument [7] (Institute of Health Sciences, University of Oxford, UK) was used to assess the videos. It is a validated qualitative assessment tool used to assess the reliability and quality of published medical information with regards to treatment choice. Questions 1-8 address the reliability of the publication, questions 9-15 focus on specific details of the treatment choice and question 16 is an overall quality score for the assessment target. The instrument uses a 5-point Likert scale: 1 means the quality criterion has not been met, 2-4 reflects a partially met quality criterion, and 5 if quality criterion has been completely met. Minor modifications were made to the second part of the DISCERN instrument so that sections pertaining to specific parts of the procedure e.g. benefits and risks, contained the relevant information for corneal transplantation. This information, considered important for patients to know, was derived from the National Institute for Health and Care Excellence interventional procedure guidance [IPG304] and Royal National Institute of Blind People (RNIB) [8,9]. The modified DISCERN instrument is shown in Table I.

Video Power Index (VPI) was used as a metric to assess each video's popularity and quantify the degree of audience engagement [10,11]. VPI was calculated using the following formula [11] for each video with more than 0 likes or dislikes:

$$VPI = \frac{likes \times 100}{likes + dislikes} \times \frac{total\ views/day}{100}$$

$$VPI = \frac{likes \times 100}{likes + dislikes} \times \frac{total\ views/total\ days\ since\ Youtube\ publication}{100}$$

Spearman's Rank test was used to assess correlations between video rank, 'likes' and overall DISCERN score. Ordinal variables were assessed using the Mann-Whitney U test; a p value of 0.05 or lower was considered statistically significant.

Results

The video search was conducted on October 25th 2020 and 200 videos were selected (the first 50 from each of the 4 search terms). 53 videos met the inclusion criteria; the remaining videos were excluded as they targeted at healthcare professionals (e.g. surgical videos).

Accounts uploading the videos could be categorised (n) as follows: healthcare organisation or practitioner (42), charity (3), news media (3), retailer (1), education organisation (3) and patient vlog (1). Education organisation comprised 2 videos published by different Universities and 1 video uploaded by an independent science channel. Uploaders (n) were based in the USA (39), UK (3), India (5), Australia (3), South Korea (1), South Africa (1) and Canada (1).

The mean number of views was 5705 (range 59 to 43,523). Mean video length was 3 minutes 16 seconds (range 49 seconds to 26 minutes). Mean likes was 25.42 (median 6) and mean dislikes 1.79 (median 0).

Across all 53 videos, the mean overall DISCERN score was 1.91 (SD = 0.90). Figure 1 is a heat map representing the distribution of video scores, with darker shades indicating more videos assigned that score. The videos scored best in being relevant (Q3) to corneal transplant patients, describing what a corneal transplant is and how it works (Q9) and defining suitable patients (Q10), with mean scores (SD) of 3.89 (0.61), 2.75 (1.62) and 2.66 (1.27) out of 5 respectively. The videos scored lowest in defining unsuitable patients (Q11), offering sources of information (Q5) and supporting shared decision making (Q18), with mean scores (SD) of 1.00 (0), 1.11 (0.38) and 1.11 (0.61) respectively.

The video with the highest total DISCERN score was created by a group of students undertaking a 'Demystifying Medicine' course at McMaster University (total score = 70/95), which also had the highest VPI (VPI = 18.71). Its notable strength was its comprehensive use of graphics, illustrations and anatomical diagrams; a feature that other videos would have benefitted from.

The video with the lowest total DISCERN score (total score = 24/95) had a very low VPI of 1.91, which was made by the Cleveland Clinic and focussed on a single patient's experience.

The 'patient vlog' video had the second highest VPI of 18.27 and the videos released by charities had the lowest mean VPI of 1.14 (SD=4.18). The vlog detailed her experiences of the procedure in length, which highlights the type of information patients are looking for on YouTube. However, there may be significant heterogeneity between patients' personal experiences, especially between countries, which could lead to confusion and/or concern at a later stage.

As a subgroup, videos uploaded by an educational organisation had the highest mean overall DISCERN scores of 2.33 (SD = 0.92), whilst charity and news videos had the lowest means of 1.33 and 1.67 respectively (SD = 0.58 for both).

Engagement scores (measured in VPI) could not be statistically analysed against DISCERN scores because not all videos had at least 1 like and at least 1 dislike, meaning a VPI could not be calculated. This would have been an interesting statistical test to evaluate how accurately the viewer's engagement aligns with quality of videos.

Discussion

Corneal transplantation is a costly intervention that requires long term specialist follow up. Undergoing the procedure entails risks such as graft rejection and irreversible sight loss; as such patients must carefully consider the risks and benefits of the procedure in order to provide informed consent. YouTube has become the most popular video sharing website in the world, and it is a well-recognised resource for both general and specialised technical information. This is the first study to assess the quality of patient information videos on YouTube regarding corneal transplant surgery.

This study revealed that videos described the procedure and patient suitability well but lacked in the DISCERN domains of shared decision making and patient unsuitability. Focussing on the positive aspects of the procedure is common in these types of videos⁴ and does not offer unbalanced and unbiased information required for the patient to make an informed decision.

Previous research has highlighted⁴ a difference in style between US and non-US videos so these two groups were compared in order to establish whether this was consistent across specialties. The Mann-Whitney U Test revealed no statistical difference between US and non-US videos for Q19 overall score ($p=0.405$) or any other domain (see Table 2). However, in addition to the majority (74%) of videos being uploaded from American accounts, there was not a single NHS video, despite it being the principal healthcare provider in the UK. This could leave British patients unclear as to where to find relevant, accurate information on the service they would receive. Many videos in the 'healthcare organisation or practitioner' category involved patients describing an overwhelmingly positive outcome at a particular hospital or with a particular ophthalmologist, whereas prospective patients might find it more helpful to hear about the surgery itself and the decision-making process behind it.

There is scope for considerable confusion for patients over the different types of corneal transplant. Some videos are dedicated to comparing partial and full thickness transplants, others solely cover one and some do not specify the technique. Furthermore, patients may not be aware of interchangeable terms and acronyms such as deep anterior lamellar keratoplasty (DALK) and partial-thickness corneal transplant, whilst others may assume that all videos under the search terms "corneal transplant" are referring to the procedure they would have.

YouTube lacks regulation so the platform has the potential to propagate false and even dangerous information, hence the need for proper evaluation of videos. Twenty seven videos (51%) failed to mention any risks associated with corneal transplants, meaning that patients are not always receiving the holistic and balanced information needed for informed consent.

Unlike consultations, YouTube videos cannot be tailored to an individual patient's level of health literacy, although they may empower some patients in their decision-making process.

Given the variation in DISCERN scores with clear lack of information about more negative elements of the procedure such as the risks, YouTube could act as a supplement to information from clinician and reliable internet resources such as the RNIB. When accessing YouTube patients should be advised to watch videos made by a variety of different organisations. Table 2 details the best videos by way of a reference list for those looking for high-quality information.

Many videos (particularly those published by American hospitals) included patients discussing their experience at the clinic or their opinions on a named clinician but did not delve into their decision-making process, which might be more helpful for prospective patients attending other hospitals.

We would recommend YouTube video creators utilise the DISCERN tool as a guide so as to ensure their content is of sufficient standard and detail [7] Furthermore, videos offer the ideal media in which to use both anatomical diagrams to explain the procedure and pictograms to represent risks associated with the surgery. However, only 13 of the videos (24.5%) actively used drawings, diagrams or animations, which reflects a lost opportunity to supplement explanations in clinic with further visual aids.

Conclusion

These results show that whilst there are a few highly valuable videos, the quality of many YouTube videos is poor and there are significant shortcomings in the information targeted at patients considering corneal transplantation. These findings are in agreement with previous studies [12-17] and highlight a deficiency in resources on YouTube. Patients should be aware of the limitations of YouTube videos even if they do provide a helpful supplement to clinical Consultations.

Declarations

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Tables

Table 1 Mann-Whitney U test comparing each domain US v Non-US

	Modified DISCERN instrument	All videos mean score n=53 (SD)		US only mean score (SD) n=39		non-US mean score (SD) n=14		P-value (US v non-US)
1	<i>Are the aims clear?</i>	2.58	(1.41)	2.46	(1.37)	2.93	(1.49)	0.265
2	<i>Does it achieve the aims?</i>	2.66	(1.48)	2.54	(1.45)	3.00	(1.57)	0.265
3	<i>Is it relevant?</i>	3.89	(1.19)	3.77	(1.18)	4.21	(1.19)	0.216
4	<i>Is it clear what sources of info were used to make the video?</i>	1.11	(0.61)	1.05	(0.32)	1.29	(1.07)	0.427
5	<i>Is it clear when the information used in video was produced?</i>	1.23	(0.85)	1.31	(0.98)	1.00	(0.00)	0.217
6	<i>Is it balanced and unbiased?</i>	1.42	(0.72)	1.49	(0.76)	1.21	(0.58)	0.189
7	<i>Does it provide details of additional resource of support / information?</i>	1.83	(0.64)	1.79	(0.47)	1.93	(1.00)	0.908
8	<i>Does it refer to areas of uncertainty?</i>	2.19	(1.40)	1.79	(1.13)	3.29	(1.54)	0.002
9	<i>Does it explain what a corneal transplant is and how it works?</i>	2.75	(1.62)	2.74	(1.67)	2.79	(1.53)	0.867
10	<i>Does it describe who corneal transplant is suitable for?</i>	2.66	(1.27)	2.72	(1.23)	2.50	(1.40)	0.499
11	<i>Does it describe who corneal transplant is unsuitable for?</i>	1.00	(0.00)	1.00	(0.00)	1.00	(0.00)	1.000
12	<i>Does it describe benefits of corneal transplant surgery?</i>	2.60	(1.26)	2.82	(1.21)	2.00	(1.24)	0.036
13	<i>Does it describe risks of corneal transplant surgery?</i>	1.77	(0.97)	1.62	(0.91)	2.21	(1.05)	0.036
14	<i>Does it describe what to expect preoperatively / on the day of surgery?</i>	1.72	(1.15)	1.72	(1.10)	1.71	(1.33)	0.609
15	<i>Does it describe patient follow up / rehab?</i>	2.08	(1.36)	2.08	(1.24)	2.07	(1.69)	0.450
16	<i>Does it describe how treatment choice affects Quality of Life?</i>	2.17	(1.14)	2.21	(0.98)	2.07	(1.54)	0.286
17	<i>Does it describe alternatives?</i>	1.75	(1.07)	1.82	(1.10)	1.57	(1.02)	0.395
18	<i>Does it provide support for shared decision making?</i>	1.11	(0.38)	1.13	(0.41)	1.07	(0.27)	0.720
19	<i>Overall Rating of the video.</i>	1.91	(0.90)	1.79	(0.80)	2.21	(1.12)	0.240
	<i>VPI</i>	3.07	(4.18)	2.95	(3.94)	3.38	(4.90)	0.221

Table 2 Reference list of the videos with the highest DISCERN scores. The following 4 videos ranked highest in cumulative total and were the only videos to achieve an overall DISCERN score of 4.

Video Title	Uploaded by	Link	Total DISCERN score (maximum of 95)	VPI
<i>Corneal Transplant Surgery: A Patient Information Video</i>	Demystifying Medicine	https://www.youtube.com/watch?v=hZkdFFAlbc0&list=PLBJfh5CnwXCJ-a0jOt9n2TRil4u2luHh1&index=4	70	18.72
<i>Penetrating Keratoplasty - The Procedure and Risks Explained for Patients</i>	Dr Brendan Cronin	https://www.youtube.com/watch?v=kNEJbMAuFyo&list=PLHeLXPzYlqVq3jb_7eLs8a2woqOombsNf&index=7	60	1.62
<i>DMEK Surgery Explained - a Guide for Patients</i>	Dr Brendan Cronin	https://www.youtube.com/watch?v=KmfRTIGA9Xs&list=PLHeLXPzYlqVq3jb_7eLs8a2woqOombsNf&index=21	54	0.45
<i>What do patients experience after corneal transplantation and corneal grafts?</i>	Clinica London Ltd	https://www.youtube.com/watch?v=FKBNTxUTYvY&list=PLHeLXPzYlqVq3jb_7eLs8a2woqOombsNf&index=9	52	1.43

Figures

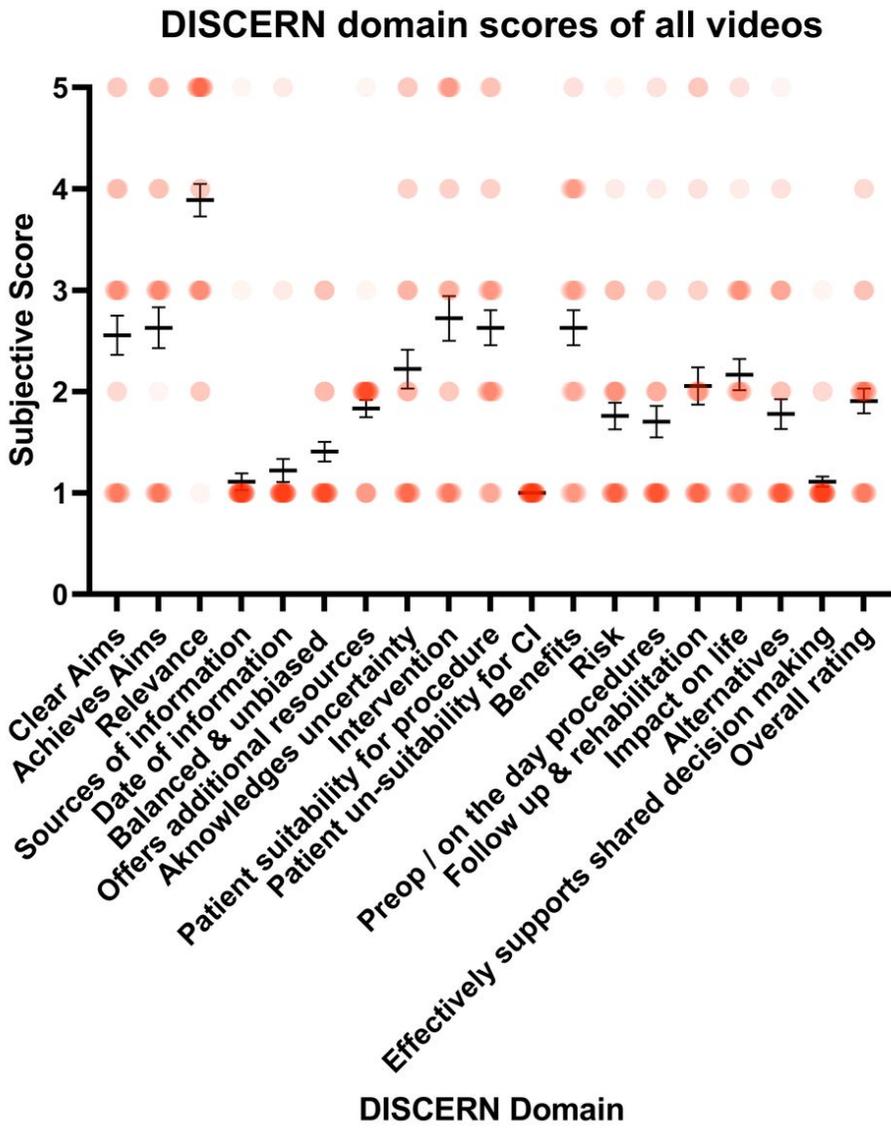


Figure 1

Heatmap charting the distribution of DISCERN scores by domain for all videos, with darker shades indicating more videos achieving that score