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YouTube as a source of patient information on brain aneurysms: a content-quality and audience engagement analysis

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ABSTRACT

Introduction: The internet allows patients to access a vast amount of health information. We aimed to evaluate the credibility of YouTube videos that members of the public are accessing on brain aneurysms, and to evaluate what characteristics drive audience engagement.

Material and methods: The first 50 videos for each of the following search terms were taken for analysis: 'brain aneurysm', 'cerebral aneurysm' and 'intracranial aneurysm'. The quality of each video was evaluated by two neurosurgeons and two medical students independently using the Journal of the American Medical Association (JAMA) and the DISCERN instruments. Qualitative and quantitative video data was analysed for quality and audience engagement. Inter-rater agreement was ascertained.

Results: Out of a total of 150 videos, 70 met the inclusion criteria. The mean total DISCERN score was 36.5 ± 8.4 (out of 75 points), indicating that the videos were of poor quality. The mean JAMA score was 2.7 ± 0.7 (out of 4 points). Inter-rater agreement between the four raters was excellent (intraclass correlation coefficient 0.90 for DISCERN and 0.93 for JAMA). Most videos were uploaded by hospitals (50%) or educational health channels (30%). Videos had a higher number of average daily views when they included animation (P = 0.0093) and diagrams (P = 0.0422).

Conclusions: YouTube is a poor source of patient information on brain aneurysms. Our quality and audience engagement analysis may help content creators (i.e. hospital staff and physicians) to create more holistic, educational and engaging medical videos concerning brain aneurysms. Physicians could usefully refer their patients to the highest quality videos that we have found.

Key words: aneurysm, brain aneurysm, cerebral aneurysm, intracranial aneurysm, YouTube, internet, quality

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Introduction

With an estimated 58% of the world having access to the internet, patients often use online sources to acquire health information on various conditions, possible future medical procedures, and therapeutic options [1, 2]. YouTube is the world's second most popular website, and is a popular source of healthcare information for patients [3–5]. However, the quality of YouTube information is highly variable since there is no quality control [5]. Therefore, we thought it imperative to assess the information that is available as it often affects a patient's decision to accept or reject a particular treatment [6–8].

The quality and reliability of YouTube videos have been previously evaluated for hydrocephalus, lumbar disc herniation, stereotactic radiosurgery, and several other conditions [9–17], but analysis has not yet been carried out for intracranial aneurysms.

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Intracranial aneurysms are a type of cerebrovascular disease and may carry high morbidity and mortality due to haemorrhage [18]. It is estimated that between 1 in 20 and 1 in 30 adults will experience an unruptured intracranial aneurysm [19]. Sufficient patient knowledge of cerebral aneurysms is critical because aneurysm rupture can sometimes be predicted, and patients can undergo treatment before aneurysm rupture [20].

Clinical rationale for study

YouTube videos have been shown to influence patient decision-making both positively and negatively [6–8]. Positively, by helping them come to a more informed decision, and negatively by damaging the patient-doctor relationship and providing biased views of certain diseases and treatments. Thus, in the case of intracranial aneurysms, YouTube videos may influence a patient's choice between endovascular coiling, surgical clipping, or conservative treatment.

We aimed to evaluate the credibility of YouTube videos that the public is accessing on intracranial aneurysms. We also sought to assess what visual and educational features drive the greatest audience engagement (i.e. understanding symptoms of a ruptured aneurysm) so that YouTube content creators can create more engaging content in the future.

Material and methods

Search strategy and data collection

The phrases 'brain aneurysm', 'cerebral aneurysm' and 'intracranial aneurysm' were typewritten into YouTube's search bar, and the first 50 videos for each search term were recorded, giving a total of 150 videos. More videos for each search term were not collected since 90% of YouTube users do not look after the 30th video [21]. All searches were done with default 'relevance' sorting on 24 February, 2019. Google Chrome incognito mode was used to collect the videos so that no personal recommendations influenced the results. The videos were evaluated independently by two final-year medical students (S.A. and A.K.) and two neurosurgeons (T.Z. and D.R.). All four raters had more than five years of experience of using the DISCERN and JAMA criteria. Both neurosurgeons had more than 14 years of neurosurgical experience treating cerebral aneurysms at a university hospital.

Inclusion and exclusion criteria

We included the first 50 videos under each search term. We excluded 1) duplicate videos, 2) videos in languages other than English, 3) completely unrelated videos (e.g. music videos), and 4) advertisements (that YouTube explicitly highlighted as an AD on the top of the search page).

Variables extracted

Quantitative data was extracted using the extension 'vidIQ Vision for YouTube' for Google Chrome (browser version 72.0.3626 for Windows, Google Inc.). This plugin extracted the following: the number of comments, view count, likes, dislikes, words spoken per minute, duration, upload date, video referrers, video description word count, video description link count, channel mean daily views, channel mean daily subscribers, and channel subscribers.

Qualitative content extracted included: symptoms of a ruptured aneurysm, symptoms of an unruptured aneurysm, treatments for a ruptured aneurysm, treatments for an unruptured aneurysm, risk factors of aneurysm formation, prognosis, animation, radiological images, diagrams, vessel anatomy, a doctor narrator, and a patient's experience.

Each video was also categorised as deriving from one of the following six sources: a hospital, an educational channel, a physician, a patient, a news channel, or a miscellaneous source (when the uploader could not be determined).

Scoring systems

Two validated instruments were used for video evaluation: the DISCERN score and the Journal of the American Medical Association (JAMA) benchmarks [22–24]. The DISCERN instrument, set out in Table 1, is a 16-item questionnaire with each question allocated a score of 1 to 5 [23, 24]. Question 16 of DISCERN is unique in that it asks the user to rate the overall quality of the publication. Interpretation of the total DISCERN score has been established in previous literature as excellent (63–75 points), good (51–62 points), fair (39–50 points), poor (27–38 points), or very poor (16–26) [25]. Only the video itself was taken into account for the assessment, and the video description was omitted unless the video referenced the information in the video description. Each YouTube video was publicly stamped with an upload date. However, the date on which content is produced and the date on which a video is uploaded may differ. Thus, we interpreted question 7 of DISCERN (which asks when the information was produced and reported) accordingly.

The JAMA benchmark, set out in Table 2, is a four-point scoring system that allocates one point for the inclusion of each of four criteria: authorship, attribution, disclosure, and currency [22]. When analysing the total JAMA score, zero points is the minimum/worst score and four points the maximum/best. Inter-observer agreement between the JAMA and DISCERN scores was statistically analysed to ensure the evaluation of videos was reliable and consistent between raters.

Audience engagement analysis

A like ratio [(likes/likes +dislikes)*100], Video Power Index (VPI) [(like*100/(like + dislike))*(views/day)/100], and average daily views [total views/days since upload] were calculated for each video to measure relative audience approval and engagement for each one. Next, the qualitative video content (e.g. if the video contained information about prognosis) was analysed against the quantitative video characteristics (i.e. the like ratio, average daily views, VPI, and the

Table 1. 16-question DISCERN instrument to evaluate health information

Number	Question	Score				
1	Are the aims clear?	1	2	3	4	5
2	Does it achieve its aims?	1	2	3	4	5
3	Is it relevant?	1	2	3	4	5
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	2	3	4	5
5	Is it clear when the information used or reported in the publication was produced?	1	2	3	4	5
6	Is it balanced and unbiased?	1	2	3	4	5
7	Does it provide details of additional sources of support and information?	1	2	3	4	5
8	Does it refer to areas of uncertainty?	1	2	3	4	5
9	Does it describe how each treatment works?	1	2	3	4	5
10	Does it describe the benefits of each treatment?	1	2	3	4	5
11	Does it describe the risks of each treatment?	1	2	3	4	5
12	Does it describe what would happen if no treatment is used?	1	2	3	4	5
13	Does it describe how the treatment choices affect overall quality of life?	1	2	3	4	5
14	Is it clear that there may be more than one possible treatment choice?	1	2	3	4	5
15	Does it provide support for shared decision making?	1	2	3	4	5
16	Based on the answers to all of these questions, rate the overall quality of the publication as a source of information about treatment choices	1	2	3	4	5

Table 2. Journal of the American Medical Association scoring benchmarks to evaluate credibility of a source of information

Criterion	Description	Score
Authorship	Authors and contributors, their affiliations, and relevant credentials should be provided	0–1
Attribution	References and sources for all content should be listed clearly, and all relevant copyright information should be noted	0–1
Disclosure	Website 'ownership' should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest	0–1
Currency	Dates when content was posted and updated should be listed	0–1

number of comments). In this way, the inclusion of certain health information could be correlated with a higher or lower audience engagement.

The like ratio, average daily views, VPI, and the number of comments were correlated with the DISCERN and JAMA scores to see whether a higher quality video resulted in greater audience engagement.

Statistical methods

The mean, range and standard deviation in our paper are presented as mean ± standard deviation (range). The Kolmogorov-Smirnov test tested for normality, the Mann-Whitney U test found differences between categorical variables, the intraclass correlation coefficient ascertained inter-rater agreement with JAMA and DISCERN, and the Pearson correlation coefficient measured linear bivariate correlations. $P < 0.05$ was deemed significant. Google Sheets (Google LLC) was used for illustrations. MedCalc version 9.1.3 (MedCalc Software, Acacialaan 22, 8400 Ostend, Belgium) and Past (Hammer and Harper, Øyvind Hammer, Natural History Museum, University of Oslo, Norway) were used for statistical analysis. We have provided an electronic supplementary document online with all the raw data [26].

Results

Video contents

Of the 150 videos included, 70 met our inclusion criteria. Figure 1 shows that two thirds of videos, 46 (65%), featured a doctor speaking, and more than half, 40 (57%), discussed treatments for an unruptured aneurysm. Only 10 videos (14%) discussed symptoms of unruptured aneurysms, and only six (9%) explained vessel anatomy.

Video upload source

Figure 2 shows the sources of the videos uploaded. Most were uploaded by hospitals (50%) and educational channels (30%). Only a small minority of videos were uploaded by a physician (8.6%), a news channel (5.7%), or a patient (4.3%).

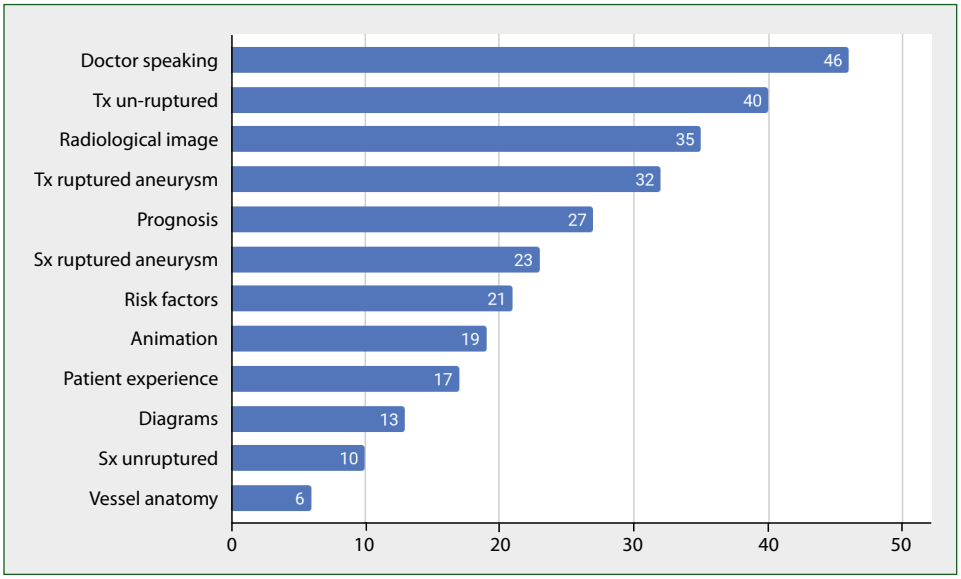

Figure 1. Brain aneurysm video contents on YouTube. Sx — symptoms; Tx — treatment

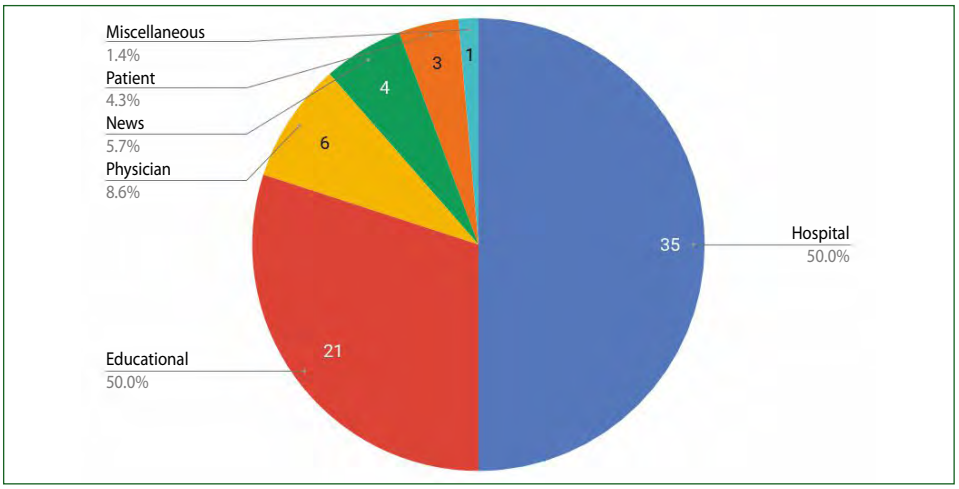

Figure 2. Sources of YouTube video uploads on brain aneurysms

Video statistics

The following are the mean and range for all the quantitative metrics measured: view count 64,443 (32–1,518,180), number of comments 29 (0–428), number of likes 381 (0–8,798) number of dislikes 16 (0–340), average daily views 41 (0–630), like ratio 93.9 (50–100), video referrers 24 (0–182), duration 268.4 (22–1,369) seconds, video description word count 89 (0–460), video description link count 1 (0–17), words spoken per minute 111 (0–184), and days since upload 1,903 (30–4,330).

The following metrics quantify the mean channel popularity of the videos: subscribers 155,519 (32–3,000,000), daily views 92,209 (16–2,100,00) and daily subscribers 5,894 (0–178,700).

DISCERN and JAMA evaluation

The overall DISCERN score between the four raters for the first 15 questions was 36.5 ± 8.4 (18–65); this is regarded as a poor score (the 'poor' scoring range being from 27 to 38). The first neurosurgeon rater, second neurosurgeon rater, first student rater, and second student rater had DISCERN scores of 39.9 ± 9.99 (19–69), 38.4 ± 8.19 (26–62), 39.3 ± 9.33 (21–66) and 39.2 ± 9.18 (22–68) respectively.

The overall score between the four raters for question 16 of DISCERN (which requires a global evaluation of the entire video) was 2.73 ± 1.0 (1–5). Raters had mean scores of 2.7 (1–5), 2.9 (1–5), 2.6 (1–5), and 2.7 (1–5) respectively.

Figure 3 illustrates the mean DISCERN score for each of the 16 questions. Questions 1 to 3 had the highest scores (above 3). These questions relate to the aims and relevance of the information. Questions 4 to 16, however, all had much lower scores (below 3). Questions 4, 7, 10, 11, 12 and 13 had particularly low scores (below 2). These questions ask about references to the sources of information used, additional

sources for supporting patients, benefits of treatment, risks of each treatment, the possibility of no treatment, and how treatment would affect quality of life.

The total mean JAMA score between the four raters was 2.7 ± 0.9 (1–4). Raters had JAMA scores of 2.7 ± 0.9 (1–4), 2.6 ± 0.9 (1–4), 2.7 ± 0.9 (1–4) and 2.7 ± 0.9 (1–4) respectively. Figure 4 shows that while most videos included currency, authorship and disclosure information, they rarely included attribution information.

As shown in Table 3, the intraclass correlation coefficient for absolute agreement was 0.90 for DISCERN and 0.93 for the JAMA score between all four raters; this is regarded as 'excellent' reliability by Koo et al. [27]. This indicates that the scores of the neurosurgeons and of the medical student raters were consistent and reliable with one another.

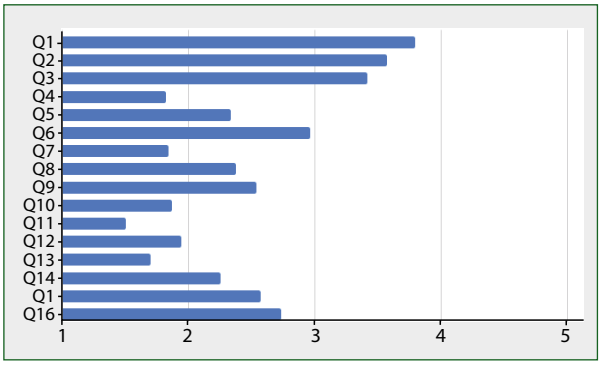

Figure 3. Mean DISCERN scores for each of 16 parts of evaluation

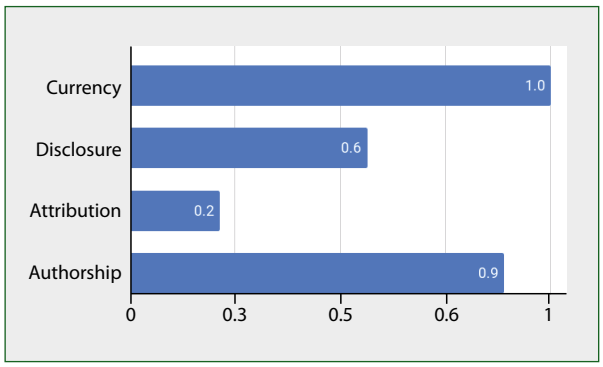

Figure 4. Mean JAMA scores of currency, disclosure, attribution and authorship for YouTube videos on brain aneurysms

Video quality correlations

We observed that videos all had a significantly higher DISCERN score when they included the following qualitative information: symptoms of a ruptured aneurysm (P = 0.0039); risk factors for aneurysm formation (P = 0.0055); treatments for a ruptured aneurysm (P = 0.0007); prognosis (P = 0.0120); diagrams (P = 0.0013); vessel anatomy (P = 0.0156); and a doctor speaking (P < 0.0001). Notably, educational channels had a significantly lower DISCERN score (P = 0.0180). Hospital channels did not obtain a significantly higher or lower DISCERN score. All other qualitative information analysed resulted in no significant results (P > 0.05).

Audience engagement analysis

Videos had a higher number of average daily views when they included animation (P = 0.0093) and diagrams (P = 0.0422). Videos had a higher like ratio when they included the risk factors of aneurysm formation (P = 0.0139) and prognosis (P = 0.0014). Videos had a higher VPI when they included animation (P = 0.0106) or vessel anatomy (P = 0.0216). Videos had a higher number of comments when they included the symptoms of a ruptured aneurysm (P = 0.0162). Videos that had a doctor speaking had a lower number of average daily views (P = 0.0092), a lower number of comments (P = 0.0202), and a lower VPI (P = 0.0085). All other differences between the video groups were not statistically significant (P > 0.05). The like ratio, average daily views, VPI, and the number of comments did not strongly correlate with the DISCERN or the JAMA score (Pearson correlation coefficient < 0.7 or > –70).

Top quality videos

Table 4 sets out the top five highest quality brain aneurysm videos, based on the DISCERN criteria. However, even these videos are only of good quality (51 to 62 DISCERN points) and not of excellent quality (63–75 DISCERN points). It is noteworthy that all these videos are either from hospitals or neurosurgeons.

Table 3. Intraclass correlation coefficient

DISCERN score	Intraclass correlation*	95% Confidence interval
Single measures†	0.9015	0.8618 to 0.9329
Average measures‡	0.9734	0.9615 to 0.9823
JAMA score		
Single measures†	0.9329	0.9035 to 0.9550
Average measures‡	0.9823	0.9740 to 0.9884

*Degree of absolute agreement among measurements; †Estimated reliability of single ratings; ‡Estimated reliability of averages of DISCERN and JAMA ratings; JAMA — Journal of the American Medical Association

Table 4. Top five highest quality brain aneurysm videos based on DISCERN criteria

DISCERN	JAMA	Title	Uploader	YouTube ID
60.3	3.8	#MayoClinicNeuroChat about Brain Aneurysms	Mayo Clinic	8VwV8qmed5s
59.5	4.0	Treatment Options for Unruptured Brain Aneurysms	Mayfield Brain & Spine	L7oXjpL1QVc
55.0	3.0	CEREBRAL ANEURYSMS: Complete Overview	David W Newell MD	kXE3zdXrKTw
54.8	4.0	Brain Aneurysms: FAQs with Rafael Tamargo	Johns Hopkins Medicine	5ZCGwuaapgs
49.5	4.0	Flow Diversion for Cerebral Aneurysms: A Discussion of Controversies	Aaron Cohen-Gadol, M.D.	LrpkJEvSBig

To watch video, simply paste YouTube ID after this address: www.youtube.com/watch?v=

Discussion

Quality analysis

We found the quality and reliability of YouTube videos on cerebral aneurysms to be poor, with a mean DISCERN score of 36.5 (out of 75). This indicates that patients using YouTube for health information concerning brain aneurysms are obtaining incomplete and unreliable information. Thus, most health information from YouTube should not be regarded as credible or reliable. These findings are novel, as our paper is the first to analyse the quality and reliability of YouTube videos on intracranial aneurysms.

According to U.S. News & World Report, Mayo Clinic, Cleveland Clinic, and Johns Hopkins Medicine were the top three hospitals in the world in 2018-2019. All three of these hospitals uploaded educational videos on intracranial aneurysms. Our data shows that even these hospital YouTube channels have room for improvement when it comes to disseminating information. The quality of these videos is of the utmost importance as these channels have millions of subscribers and social media followers, and therefore have a considerable impact in terms of shaping the understanding of some diseases by the public. At the time of data collection, Mayo Clinic had 100,000 YouTube subscribers, 1.1 million Facebook followers, and 1.9 million Twitter followers. Cleveland Clinic and Johns Hopkins Medicine also had considerable YouTube and social media followings.

Suggestions for quality improvement

Most videos scored a low DISCERN score due to not providing enough information about the various treatment options. The JAMA benchmark revealed that YouTube videos frequently displayed when the video had been posted and the author(s) of the work. However, they did not disclose the ownership of the material, and rarely included references to information presented.

Thus, future videos should properly credit their videos and the various treatment options available. Figures 3 and 4 summarise the information lacking from most videos, allowing future medical video creators to use it as a guide to improve quality. Moreover, we suggest that video creators use the DICSERN criteria as a checklist before posting a video. We hope that this study may help hospitals, educational channels and physicians to create more robust content in the future.

Audience engagement analysis

Including animation led to a higher number of average daily views and VPI scores. This shows that the audience appreciates when medical information is simplified into easy-to-understand graphics. Moreover, including vessel anatomy led to a higher like ratio and VPI. Perhaps this is because video viewers felt empowered knowing the basic anatomical basis of aneurysm formation. A study on YouTube found that the most informative medical videos had lower audience engagement compared to lower quality videos [28]. This shows that the best quality videos are often not the most watched.

However, in our study, including diagrams, risk factors of aneurysm formation, and the symptoms of aneurysm rupture all led to a higher audience engagement (whether this was represented by average daily views, like ratio, or comments). These statistically significant findings regarding the most attractive and friendly way in which to present medical information on brain aneurysms may serve as a valuable guide for hospitals, educational health channels and physicians when uploading their videos.

Having a doctor narrate a video led to a lower average number of daily views, fewer comments, and a lower VPI score. We hypothesise that physicians present information in too technical a manner, and often use medical terminology that the average YouTube viewer is unfamiliar with. This may have led to low audience engagement.

No correlations were found with any of the audience engagement metrics analysed and the JAMA score or DISCERN score; this suggests that viewers may not care about the proper attribution of sources or the ownership of data that has been presented.

Context

The quality of YouTube videos on other neurological topics such as hydrocephalus, lumbar disc herniation, glioblastoma treatment, and stereotactic radiosurgery has been found to be poor and incomplete [10, 14, 15, 29].

Even though YouTube is one of the most popular sources for medical information, patients still use other sources such as Google or online health forums to develop understanding of their disease. However, a 2019 readability analysis of online health material on several cardiovascular diseases (including aneurysms) found that 99% of articles had a reading level too difficult for the average patient [30]. This problem can be exacerbated when educational content is mixed with promotional material. Moreover, patients with a new diagnosis of an unruptured intracranial aneurysm often discuss their medical concerns on online forums [12]. A study found that these patients often faced uncertainty, frustration and apprehension when choosing the optimal treatment [12]. Decision-making for patients is multifaceted, as it involves discussing statistical outcomes and financial costs while weighing risks against benefits and personal attitudes. This lack of easily-understood information in popular health articles, health forums and YouTube may make it difficult for patients to become better informed about their condition. Moreover, misinformation can actually lead to worse health outcomes, as several studies have shown [31–37].

A 2015 systematic review of healthcare information found that users often found misleading medical information on YouTube, even though credible sources did exist that provided high-quality information [5]. In our study, however, not one video, even from the world's most respected hospitals, provided an 'excellent' quality of information according to DISCERN.

Most YouTube users look at videos on treatment procedures (e.g. surgery) when searching for brain aneurysm videos [11, 38]. Intracranial aneurysms require a procedure-based treatment (i.e. aneurysm clipping or endovascular coiling) so YouTube would probably be a platform that patients would visit in this case.

Our analysis found that the information concerning treatment was especially poor. This could potentially influence a patient's decision to undergo endovascular coiling or aneurysm clipping without understanding the full implications of each treatment. One of the main advantages of endovascular procedures is that they are minimally invasive. Therefore, patients may prefer this treatment over surgical clipping. We have had good patient outcomes with both procedures at our hospital, and we leave the decision to our patients after fully informing them of both options. Or in some cases, we may recommend one procedure over the other, e.g. surgical clipping for a complex aneurysm.

A previous study by Alotaibi et al. found that social media communications (e.g. YouTube, Facebook, Twitter) can be a platform for social and psychological support for patients with a brain aneurysm [11]. Patients and caregivers use online social platforms for inspiration, to share information, and to seek emotional support. Their analysis concluded that Facebook was the most common platform on which this occurred. While our study focused on YouTube as a source of patient education, we want to stress that the psychosocial needs of patients may also be reflected online.

Several YouTube quality evaluation studies have included physicians scoring the videos [9, 11, 15, 39, 40]. However, physicians are not necessarily required to use the DISCERN instrument as it was designed to be "not dependent on specialist knowledge of a health condition or treatment" [23]. Therefore, both medical students and physicians scored the videos in our study, in order to prove that specialist knowledge was not required to evaluate the quality of the videos.

Limitations

The DISCERN and JAMA tools do not take into account every quality or attribution criterion. However, these are validated instruments and have been used by several other YouTube quality evaluation studies and are regarded as reliable [9, 10, 14, 15, 29, 41, 42]. In our study, the interclass correlation between the four raters was excellent, indicating that our results were robust.

It might be argued that the three search terms in our paper ('brain aneurysm', 'cerebral aneurysm' and 'intracranial aneurysm') do not fully encompass the topic of brain aneurysms, as patients may use other terminology to describe the disease. However, an online study showed that the terms 'brain aneurysm' and 'cerebral aneurysm' were the most common online search terms used by people when referring to brain aneurysms and subarachnoid haemorrhages [43].

Our audience engagement analysis is limited by a selection bias, since not every viewer who likes/dislikes a video clicks the 'like' or 'dislike' button. However, this limitation is inherent to any YouTube evaluation study, and is not specific to ours.

Future directions

This study might be repeated in a few years to analyse whether the quality of YouTube videos has changed. Additionally, we suggest that hospitals use the quality and audience engagement analysis in our paper to prepare better educational content for YouTube. YouTube's potential value as a tool for enhancing telemedicine could also be analysed [44].

Even as relatively long ago as 2015, 65% of American adults were using social networking sites such as Facebook, Twitter, and LinkedIn [45]. Thus, social media platforms may be evaluated for the type, reliability and frequency of health information spread by users.

Clinical implications

YouTube has the potential to influence a patient's medical decisions [6–8]. Thus, we urge health professionals to be aware of the inadequate quality and credibility of most information found on YouTube concerning brain aneurysms. In the words of Ullrich et al., "information is a form of therapy", since a solid foundation of relevant medical knowledge is critical for ensuring patient compliance, establishing realistic treatment expectations, and facilitating follow-up visits [46].

We recommend that hospitals provide in-hospital brochures after patient visits, as this has been proven to improve

patient understanding, satisfaction and relationships with their healthcare provider [47].

Conclusions

YouTube is a poor source of patient information regarding intracranial aneurysms. In our paper, we have listed the most reliable YouTube videos so that physicians can recommend them to their patients.

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