Assessing the Quality of Patient Information for Vestibular Schwannoma on the Open Source Video Sharing Platform YouTube

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Background: Patients frequently use the internet to gain information and make decisions about their health conditions. This work aims to assess the quality of information about Vestibular Schwannoma on a popular video sharing platform, YouTube (Alphabet Inc.).
Objectives: To assess quality of the most popular vestibular schwannoma videos using recognized scoring systems and whether video quality metrics correlated with video popularity based on metadata analysis.
Setting: Public domain.
Study Design: Cross-sectional Study
Methods: The YouTube website was systematically searched on separate days with a formal search strategy to identify videos relevant to vestibular schwannoma. Each video was viewed and scored by three independent assessors, using scores for quality and disease specific accuracy. Popularity metrics were analyzed and compared to video quality. Patient surveys were conducted to further assess their perspectives of the included videos.
Results: A total of 23 YouTube videos were included. In terms of Essential and Ideal Video Completeness Criteria, the mean scores ranged from 4.8 to 5.0 (out of 12), indicating moderate video quality. The average DISCERN score ranged from 30.0 to 36.7, indicating lower reliability. The mean JAMA scores ranged from 1.96 to 2.48, indicating average quality. Based on metrics including DISCERN and JAMA instruments, the information in the YouTube videos were of low to average quality and reliability. Rater scoring was reliable. Viewer engagement correlated poorly with video quality except for JAMA metrics.
Conclusion: Video quality on YouTube with respect to Vestibular Schwannoma is of low to average quality. Viewer engagement and popularity correlated poorly with video quality. Clinicians should direct their patients to high quality videos and should consider uploading their own high-quality videos. **Key Words:** Acoustic neuroma—Acoustic tumor—Acoustic tumour—Vestibular schwannoma—YouTube.

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With the advent of the internet and social media, patients are increasingly turning toward online sources of information for education and decision making regarding their health. Some studies suggest that up to 90% of patients (1) research their medical condition on the internet, and in over 80% of cases (2,3), this information seems to influence their decision regarding treatment in some way.

Online search engines such as Google (Alphabet Inc., Mountain View, CA) provide patients access to internet information based on the key words they enter. YouTube (Alphabet Inc., Mountain View, CA) is an online repository of user-generated videos, and is the third most visited website worldwide with greater than five billion unique views daily (4). Any user can generate and upload videos, as well as produce comments, likes and dislikes on existing content. Although such online resources have tremendous potential for medical education, it is largely unregulated and lacks peer-review. Misinformation or incorrect information may be disseminated to patients. If patients base their medical decision making on this information, there may be significant safety consequences (5). There are surveys showing that some patients trust internet sources of information more than their own physicians (6).

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Vestibular schwannoma is an uncommon neurotological condition that has three distinct treatment options and variable outcomes with significant quality of life impact (7,8). The lesion presents as a slow growing tumor and the treatment algorithms are often complicated when applied to the individual patient (9). Since the condition is uncommon and patients often have few direct reference points in their social network, they may be using the internet significantly in their understanding and decision-making process for the treatment of these lesions. High quality, unbiased information would therefore, be of great assistance to the patient. The aim of this work is to analyze the quality of information for vestibular schwannoma on the open source online platform YouTube.

METHODS

Ethical Considerations

Ethics approval was awarded by the Northern Sydney Local Health District (NSLHD) Human Research Ethics Committee (reference number LNR/18/HAWKE/38) for conducting patient surveys, in order to understand the perspective and experience of the patients themselves. Ethics approval was not required by the local Research Ethics Board for the video information, as this global data was already available in the public domain. All gathered data was de-identified for the analysis and publication. Researchers conformed to YouTube user guidelines of 2019.

Search Strategy

Google Trends was searched on September 2019 for Vestibular Schwannoma and related pathological diagnosis terms. Using this data, YouTube was then searched on September 2019 for ''Vestibular Schwannoma,'' ''Acoustic Neuroma,'' ''Acoustic Neurinoma,'' ''Acoustic tumor,'' and ''Acoustic tumour.'' The searches were undertaken by three different authors using Google Chrome browsers versions 76.0.3809.132. The cache of each computer, search history and cookies of the browser were reset before each search and the authors were not signed into their Google account. The default reference filter was chosen as most users do not adjust filters. To simulate patient searches across the English speaking world a Virtual Private Network (VPN) was used and settings for IP addresses were floated across Australia.

The search was limited to the first 23 English language videos as determined by YouTube's relevance algorithm, representing more than the average user would search. The website results were displayed according to the default algorithm. To capture the commonly used ''snowballing method'' of search, as clips were viewed, the site offered additional suggestions which in turn offer more suggestions. This strategy is in line with work by previous groups (10). For each of the top 10 videos for a search terms, the top 3 suggested videos were also scored. Videos were included if they appeared to provide patient-focused information regarding vestibular schwannoma. Videos were excluded if they did not involve the diagnosis or if the focus of the video was of a research nature.

The initial search, subsequent screening, analysis, and scoring of videos was performed independently by the three authors (NP and NJ both neurotologists, and LO neurotology Registrar). Any discrepancies were resolved by consensus.

Metadata Acquisition

YouTube provides additional information on published videos as popularity metrics. This ''metadata'' was gathered on September 2019. The metrics included in this analysis were hits (number of video views), likes and dislikes (cumulative user-based votes of approval or disapproval that are assigned to videos), duration of the video, and date the video was uploaded.

Development of a Gold Standard for Vestibular Schwannoma Information

A ''gold standard'' for sufficient and appropriate patient information was developed using an expert based heuristic model (11). A minimum criteria set were taken from the website of the Acoustic Neuroma Association (USA) and the British Acoustic Neuroma Association. Additional detail was also provided by the senior authors (NP and NJ) who regularly treat VS patients, to create a set of essential and ideal criteria (Table 1). Essential criteria were deemed to be the minimum

TABLE 1. *Inter-rater reliability amongst three otolaryngology raters based on Essential and Ideal Video Completeness Criteria for videos on acoustic neuroma, vestibular schwannoma, and acoustic tumors*

Essential and Ideal Video Completeness Criteria	Fleiss Kappa For Inter-rater Reliability
1. Explanation of pathology, including definition epidemiology, natural history	0.667
2. Three treatment options—observe, Microsurgery (MS), Stereotactic Radiation therapy (SRT)	
3. Indications and contraindications for observation serial MRI	
4. Natural History and Prognosis of observation serial MRI	
5. Indications and contraindications for SRT	
6. Natural History and Prognosis of SRT	
7. Indications and contraindications for MS	
8. Natural History and Prognosis of MS	
9. Preoperative pathway	
10. Operation	
11. Postoperative pathway	
12. Risks of operation	

Kappa values indicate the level of reliability in brackets: <0.020 (poor), 0.21–0.30 (fair), 0.41–0.60 (moderate), 0.61–0.80 (good), and 0.81–1.00 (very good).

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TABLE 2. *Inter-rater reliability amongst three otolaryngology raters using Video Quality Audiovisual Metric Scale (1 = yes, 0 = no)*

Video Quality Audiovisual Metric Scale (1 = yes, 0 = no)	Rater 1 (Mean)	Rater 2 (Mean)	Rater 3 (Mean)	Fleiss Kappa for Inter-rater Reliability
Based on: - Video resolution adequate - Language intelligible	19	19	18	0.621

Kappa values indicate the level of reliability in brackets: <0.020 (poor), 0.21–0.30 (fair), 0.41–0.60 (moderate), 0.61–0.80 (good), 0.81–1.00 (very good).

information points required by a patient to make an informed decision regarding consent for Vestibular schwannoma treatment. Additional points were further information which was felt a reasonable and experienced clinician in the field would communicate to patient to make an informed decision on the treatment options.

Video Evaluation

Video characteristics that were reported including who created the video (academic, private physician, patient, company/advertisement, and unclassified) as well as the nature of the content (patient experience, patient-focused education, health care practitioner education, intra-operative videos, and advertisements).

To assess the quality of the videos, two neurotologists and one otolaryngology registrar who routinely treat vestibular schwannoma patients scored the videos independently using the DISCERN instrument and Journal of the American Medical Association (JAMA) benchmark criteria, which are traditionally indicated for quality control of written materials. The DISCERN instrument was developed at Oxford University is a questionnaire used to assess the quality of written information and offered treatment choices with a set of 16 questions on a five-point scale (www.discern.org.uk). Although the JAMA benchmark criteria was originally designed for assessing the quality and credibility of written sources, this study utilized the JAMA benchmark criteria to assess the accuracy, utility, and reliability of each video source on a five-point scale ranging from 0 to 4 and suggested by Silberg et al. (12): 1 point: insufficient data about video source; 2 to 3: partially sufficient data about video source; and 4: Completely sufficient data about video source (Table 2). Video/audio quality was assessed using a two-point scale, with scores 0 or 1 for parameters video resolution adequate, and language intelligibility.

Popularity Driven Measures gathered from metadata including view count, public ratings, and viewership share were tabulated for cross comparison with expert driven quality measures.

Patient Survey on Video Source and Preferences

Thirty-two consecutive patients at our clinic with vestibular schwannoma were surveyed on their sources of online videos and weather they found it useful or not. Specifically, the survey questions included: After your diagnosis of Vestibular Schwannoma did you access any online content to educate yourself? If you did access online VS content, what did you search for (specific written online information websites, video content, patient forums including social media, e.g., facebook), If you search videos, where did you go? (YouTube, Vimeo, custom video website), Was the online VS information helpful to you? If so what content? (No, Yes specific websites, Yes, videos including YouTube, Yes, online forums such as Facebook), did the online information influence your decision making in any way?

Statistical Methods

Continuous variables were expressed as mean ± SD or median (interquartile range [IQR]) and compared across groups using the independent Student *t* test or Mann–Whitney *U* test, respectively. Categorical variables were reported as frequency (percentage) and compared between groups using the χ^2 test. The primary outcome to be investigated as part of the video scoring was categorical. Therefore, Fleiss kappa statistics were performed to determine the level of interobserver reliability-statistic (13). The following standards for strength of agreement for the kappa coefficient have been previously proposed: poor (0.01–0.20); slight (0.21–0.40); fair (0.41–0.60); moderate (0.61–0.80); and substantial (0.81–1.00) (14). All statistical analysis was conducted using the Statistical Package for Social Sciences (SPSS) 24 software package (SPSS Inc., Chicago, IL).

RESULTS

Characteristics of Included Videos

After search a total of 23 YouTube videos were included for analysis. The characteristics of the videos are summarized in Table 3. The most common topic was acoustic neuroma (65%) followed by vestibular

TABLE 3. *Summary of included YouTube videos*

Parameter	Total (n = 23)
Video topic	
Acoustic neuroma	15 (65%)
Vestibular Schwannoma	5 (21.7%)
Acoustic tumor	3 (13%)
Source type	
Academic institution	19 (82.6%)
Unclassified	2 (8.7%)
Private physician	2 (8.7%)
Content type	
Health care practitioner	8 (34.8%)
Patient education	9 (39.1%)
Patient experience/advertisement	4 (17.4%)
Intraoperative video	2 (8.7%)
Viewer statistics	
Mean views	9386.1
Mean likes	64.7
Mean dislikes	2.6
Mean duration (min)	11.3

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TABLE 4. *Inter-rater reliability amongst three otolaryngology raters using the DISCERN instrument*

DISCERN Criteria Assessed (5-Point Scale)	Rater 1 (Mean)	Rater 2 (Mean)	Rater 3 (Mean)	Fleiss Kappa for Inter-rater Reliability
1. Explicit aims	2	2	2	0.554
2. Achieves aims	2.3	1.9	2.0	0.512
3. Relevant	3.3	3.1	3.1	0.6
4. Information source explicit	3.2	1.7	2.2	0.303
5. Date information explicit	4.4	2.8	4.1	0.191
6. Balanced unbiased information	2.7	2.5	2.8	0.685
7. List additional sources	1.3	1.4	1.2	0.592
8. Refer areas uncertainty	1.7	1.6	1.7	0.858
9. Describe how treatment works	2.4	2.1	2.4	0.602
10. Benefits	2.4	2.2	2.2	0.451
11. Risks	1.9	2.1	2.0	0.636
12. What happens with no treatment	2.0	1.5	2	0.566
13. Effects treatment choice on QOL	2.1	1.4	2.0	0.431
14. Clear there are more than one option	2.9	2.1	2.8	0.575
15. Support for Share decision	2	1.6	1.8	0.590
Total DISCERN score	36.7 + −15.2	30 + −14.2	34.4 + −15.5	–

Kappa values indicate the level of reliability in brackets: <0.020 (poor), 0.21–0.30 (fair), 0.41–0.60 (moderate), 0.61–0.80 (good), and 0.81–1.00 (very good).

schwannoma (21.7%) and acoustic tumor (13%). Despite there being no distinction between these terms, the separators were created to capture all the likely search terms. The most common source was from academic institution (82.6%) followed by unclassified (8.7%) and private physician (8.7%). Content type was most common with patient education (39.1%) followed by health care practitioner (34.8%), patient experience/advertisement (17.4%) and intraoperative video (8.7%).

Video Quality Assessment and Inter-rater Reliability

In terms of Essential and Ideal Video Completeness Criteria, the mean scores across 3 raters ranged from 4.8 to 5.0 (out of 12), indicating moderate video quality. In terms of inter-rater reliability of this metric across 3 raters, the correlation was good with a kappa score 0.667 (Table 1).

The average total DISCERN score ranged from 30 to 36.7, indicate lower reliability of the information presented (Table 4). For the components of the DISCERN instrument: Moderate correlation was achieved with explicit aims (κ 0.554), achieve aims (κ 0.512), relevance (κ 0.6), date of information (κ 0.691) listed additional information moderate (κ 0.592) described treatment as good (κ 0.602), benefits of treatment as moderate (κ 0.451), risks of treatment (κ 0.636), what happens if no treatment (κ 0.566), clearly more than one option (κ 0.575), and support for shared decision (κ 0.59). Fair correlation was achieved for information source explicitly (κ 0.303). Correlation for balanced unbiased was good (κ 0.685), refer areas as uncertainty was excellent (κ 0.858).

The mean JAMA quality scores ranged from 1.96 to 2.48, indicating average quality of videos based on the benchmark criteria (Table 5). In terms of rater reliability, there was moderate correlation for JAMA scores component attribution of references and source (κ 0.564) and disclosures (κ 0.532). There was good correlation for authorships (κ 0.717) and excellent for current (κ 0.831). Good correlation existed between raters for audiovisual quality (κ 0.621) (Table 2). We found no difference in video scores based on source (Table 6).

Popularity Metrics and Correlation with Video Quality

In terms of popularity metrics, the mean views were $9{,}386 \pm 4{,}511$, mean likes 64.7 ± 23, mean dislikes 2.6 ± 1.1, and mean duration of video 11.3 ± 4.1 minutes. minutes. We found no significant correlation between likes/views with the DISCERN Score, Essential and Ideal Video Completeness Criteria, or Audio-Visual quality index. However, a significant positive correlation between found between the JAMA score with the number of views ($p = 0.003$), as well as the number of likes ($p = 0.012$) (Supplementary Table 1, http://links.lww.com/MAO/B401).

Survey of Source of Video and Preferences for Vestibular Schwannoma Patients

Based on a survey of 32 consecutive patients at our clinic, we found 77.4% of patients had access to online tools for self-education. 60.5% used specific written online information websites, 15.8% used video content, and 23.7% used patient forums, such as Facebook groups. Of those who searched videos, 62.5% used YouTube. Overall, 91% of patients found online information useful, of this 50% found specific websites useful, 18.8% found videos including YouTube useful, and 21.9% found online forums useful. 54.2% of patients stated that the online information influenced their decision make with regards to vestibular schwannomas.

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TABLE 5. *Inter-rater reliability amongst three otolaryngology raters using the Journal of American Medical Association Benchmark Criteria*

JAMA Benchmark Criteria	Rater 1 (Mean)	Rater 2 (Mean)	Rater 3 (Mean)	Fleiss Kappa for Inter-rater Reliability
1. Authors and contributors, their affiliations, and relevant credentials should be provided	0.9	0.8	0.9	0.717
2. References and sources for all content should be listed clearly, and all relevant copyright information noted	0.4	0.2	0.2	0.564
3. Disclosures: Web site ownership should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest	0.2	0.04	0.2	0.532
4. Currency: Dates that content was posted and updated should be indicated	0.9	0.9	0.95	0.831
Total JAMA score	2.48 + −1	1.96 + −0.8	2.26 + −0.75	–

Kappa values indicate the level of reliability in brackets: <0.020 (poor), 0.21–0.30 (fair), 0.41–0.60 (moderate), 0.61–0.80 (good), 0.81–1.00 (very good).

DISCUSSION

Prevalence

This is the first in-depth study objectively assessing the quality and reliability of video information pertaining to Vestibular Schwannoma on YouTube. There were on average 9,400 views per video included in this study, highlighting the internet and YouTube as sources of health information in this target population.

Scoring System Valid for All Instruments

The quality and reliability of videos was assessed using several instruments, including DISCERN and the JAMA benchmark criteria that are well validated for written health information quality. This was supplemented with Audiovisual (11). An ''essential and ideal video scale'' for other areas of medicine has been established as a valid instrument if congruence is achieved between specialists in the field (15–17). The instruments used in this study demonstrated consistent scores across the different metrics applied with good to excellent correlation, between the three raters in this work.

Quality

Based on quality scoring metrics including DISCERN and JAMA instruments, the information in the YouTube videos of Vestibular Schwannoma were of low to average quality and reliability. This finding is not unique to the current study. The first evaluation of the quality of YouTube videos in the context of medicine was performed by Keelan et al. (18) in 2007. The authors assessed videos on the topics of vaccination and immunization. They found that 45% of their negative videos conveyed messages that contradicted the reference standard with regards to immunization. Since this study, a number of further reports questioning the quality and accuracy of YouTube videos have been published (3,19–22). However, few studies have focused on otolaryngology and none on otology specifically (23–25). One study focused on YouTube videos specifically on Rhinoplasty, the authors found quality of information average, with ''rhinoplasty'' videos being less popular than ''nose job'' videos (23).

Quality Based on Source

It has been previously suggested that video quality depended on the source of the video. Ferhatoglu et al. (26) analyzed YouTube videos on the topic of sleeve gastrectomy, and found that patient experience and advertisement videos has significantly lower DISCERN, JAMA, Global Quality Scale scores compared to videos published by academic centers. Interestingly in our subgroup analysis, we found no significant differences between video quality based on source. This may be due to the low number of videos found in the

TABLE 6. *Video scores stratified according to video characteristics (who created the video and content of video)*

Category	Health Care Practitioner (n = 8)	Patient Education (n = 9)	Patient Experience/ Advertisement (n = 4)	Intraoperative video (n = 2)	*p*
Views	12582	1973	27337	942	0.175
Likes	64.9	16	189.5	34	0.219
Essential and ideal video completeness criteria	5.5	6.3	2.3	2.0	0.215
DISCERN instrument	38.1	37.9	31.3	36	0.902
JAMA instrument	2.9	1.9	2.75	3	0.184
Video quality AV metric	0.75	0.78	1.0	1.0	0.676

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intraoperative (n = 2) and patient experience/advertisement groups (n = 4) relative to academic videos, which limited statistical power of analysis. There was a trend toward higher scores in the Health Care Practitioner and Patient Education group but this did not reach statistical significance. Higher views and likes were also observed for the patient experience/advertisement group, suggesting that this type of video appeals more to the public, despite their lower reliability and quality scores. DISCERN scores were not significantly higher for videos produced by academic institutions. It may be because that there are no consensus guidelines globally with regards to what education video content creation. It may also be that videos have been adapted for a lay nonmedical audience.

Popularity

Identifying metadata (like, dislikes, view count) for popularity metrics has a strong correlation to viewer engagement and retention (27). In this work, no significant correlation was found between DISCERN, Essential and Ideal Video Completeness Criteria, or Audiovisual quality and these popularity metadata. However, there was a significant positive correlation between JAMA benchmark criteria and views/likes. Therefore, the components in JAMA benchmark criteria may be considered more relevant factors which influence public user perception and views. It may be that videos which clearly list author credentials, sources and are more recent may appear more credible and appealing to the public. However, it appears overall that neither video educational quality nor accuracy significantly affects public engagement.

Limitations

This study has a few limitations. Videos were only limited to the English language. Only the top 23 videos returned upon keyword search were included in the study for analysis. This was a reflection from real-world practicality that most users go through search pages 1 to 2, and very few users click beyond those pages (28). Although several quality and reliability metrics were analyzed in this study, these are not universally standardized tools and thus the results may not be generalizable to all audiences. YouTube default settings may vary user to user and be based on geographical location, and thus the top searched results captured in this study may not be the same videos seen across different populations globally. The search terms themselves may be a limitation in yielding appropriate information, such as the various descriptions of the same condition. These terms may not be searched specifically by the patient users, nor incorporated as keywords by the video uploader. Another consideration is to the yield of different search results depending on varying search times.

Furthermore, DISCERN instrument and JAMA benchmark tools are not intended to evaluate videos such as those of YouTube, but rather written material. Despite the increasing use of these tools to analyze the quality of online content, currently, there is no standardized protocol that can help researchers to enhance their research publications and ensure that adequate and accurate data have been collected and analyzed. Future research should be directed at developing a standardized instrument and protocol for evaluation of medical education YouTube videos.

Additionally, a proxy measure of public interaction with the video is assessed via the numbers of views and likes, but there is much that remains unknown about both who is accessing the videos and for what purpose. Finally, the number of views for videos is relatively low (average 9,386.1) and individuals may access videos multiple times from different IP addresses, which brings into question the validity of this particular metric, as well as that of ''likes.''

CONCLUSION

Online resources such as YouTube hold significant promise as free and easy to access forms of health information. However, this analysis and those in other medical and surgical topics, demonstrate that such information is often less accurate and reliable. Health practitioners should guide patients to videos which are free from misleading information and commercial exploitation. Clinicians may consider uploading their own educational and promotional material to improve upon the lack of reliable, high-quality information on YouTube.

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