



Evaluating Youtube as a Resource for Postherpetic Neuralgia Patient Education

 Rekip Sacaklıdır¹,  Ekim Can Ozturk²

¹ Department of Physical Medicine and Rehabilitation, Pain Medicine, Hatay Training and Research Hospital, Hatay, Türkiye

² Department of Physical Medicine and Rehabilitation, Pain Medicine, Goztepe Prof. Dr. Suleyman Yalcin City Hospital, Istanbul, Türkiye

Abstract

Aim: Postherpetic neuralgia (PHN) is one of the common complications of herpes virus and is the most common neuropathic pain syndrome after an infectious disease. YouTube is a widely used source for information, but the quality of YouTube videos in terms of medical content is questionable. Therefore, our aim was to evaluate the PHN-related quality of YouTube videos.

Methods: This study was carried out by evaluating YouTube videos up to April 2023. A total of 65 videos were evaluated. The number of views and duration of the videos, the number of likes and views, the number of comments, the age of the videos and the source of the videos were recorded. We evaluated all videos for overall educational quality and creator bias. Content creators were categorized as physicians, health-related websites, and patients, and we compared overall DISCERN scores and bias scores between creator type and search term.

Results: The average view count of the videos was 119224.62. The mean DISCERN and DISCERN Bias Scores were 2.01 and 2.14 respectively. Most of the videos were uploaded by the physicians. The DISCERN and DISCERN Bias scores were significantly higher in the videos uploaded by physicians ($p < 0.001$, $p: 0.002$ respectively).

Conclusions: Educational value of YouTube videos about PHN uploaded by different sources is poor or moderate. Although physician-created videos have higher quality and less bias, health-professionals should warn their patients to be cautious when referring to social media platforms about their disease.

Keywords: Postherpetic Neuralgia, YouTube, video

1. Introduction

Postherpetic neuralgia (PHN) is defined as neuropathic pain in a dermatomal distribution that persists for three months or more after the acute onset of herpes zoster. It is the most common long-term complication of herpes zoster and the most frequently seen neuropathic pain syndrome after an infectious disease¹. Data from the UK database showed that the incidence of postherpetic neuralgia increases from 8% in early 50s to 21% in early 80s². It is also shown that patients with chronic diseases or immunodeficiency are more likely to develop PHN^{3,4}. The pain often affects individuals' quality of life, psychological and functional status and poses a significant health burden^{1,5}. In the last decades, in conjunction with the progress of social media, patients often use online tools in a manner to learn more about their disease.

YouTube is the biggest video platform in the world, which is widely preferred for obtaining medical information due to its rapid accessibility. Various studies have examined the credibility of YouTube videos in patient education regarding several pain syndromes like fibromyalgia, migraine, or trigeminal neuralgia⁶⁻⁸. Since postherpetic neuralgia is a serious problem in elderly or immunocompromised patients, we should know the reliability of social media content on this subject. Therefore, in the present study our aim was to evaluate the educational value of YouTube videos about PHN.

2. Materials and methods

2.1. Video selections

This cross-sectional study was conducted through April 2023 by searching the phrases "postherpetic neuralgia", "zoster pain" and "herpes neuralgia" on YouTube (www.youtube.com). Ethics committee approval is not required as there are no human or animal participants. For each of these phrases the top 20 videos were evaluated based on views and relevance (top 20 videos sorted by views and top 20 videos sorted by relevance). Search history was reset prior to initiation of the study and a total of 120 videos were planned to be reviewed. Only English videos were included. Duplicate videos, videos without audio or subtitles were excluded.

* Corresponding Author: Rekip Sacaklıdır,

e-mail: rakipsacakli@hotmail.com

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2.2. Video features

The number of views and duration of the videos, the number of likes and comments, the rate of views (number of views / day), the age of the video and the uploaded source were recorded. The uploaded source was categorized as physician, patients, and health-related websites.

2.3. Assessment of video quality

Video contents were evaluated by two pain medicine specialists. The DISCERN scale, consisting of 16 questions, was used to evaluate the quality of the videos⁹. Each question is scored between 1-5 and higher scores refer to better quality of the video. An average of 16 questions was determined as one DISCERN score for the present analysis with respect to previous research. Besides, a DISCERN bias score of 1 indicates a completely biased source, while 5 indicates a completely unbiased source of information⁷.

2.4. Statistical analysis

The Shapiro-Wilk test was used to assess the normality of the data. Mean and standard deviation (SD), minimum and maximum values and frequency were used when expressing continuous variables. The Kruskal-Wallis test was used to detect statistical differences between more than two independent variables. Inter-rater agreement was evaluated with the kappa coefficient. A p value of <0.05 was considered statistically significant for the study.

3. Results

A total of 120 videos were evaluated, 65 (54%) videos were unique, the rest were duplicate. The mean time passed since the videos were uploaded was 58.62 months. The average view count of the videos was 119224.62. The mean video duration was 3919.22 seconds. The mean number of comments and likes were 312.69 and 939.09, respectively. DISCERN treatment and quality scores were 2.11 and 2.07, respectively. The mean DISCERN and DISCERN Bias Scores were 2.01 and 2.14 respectively (Table 1). The Cohen kappa score was calculated as 0.866 for the mean DISCERN score and 0.845 for the DISCERN Bias Scores. The mean DISCERN and DISCERN Bias Scores were highest for the search phrase herpes neuralgia. In addition, videos sorted for this search phrase were mainly uploaded by physicians (75%). The highest number of likes were seen for the search phrase zoster pain (Table 2).

Table 1
General Features and Video Quality of the Videos

Video features (n:65)	Mean	Min–Max
Duration (s)	3919.22	43-216000
Time since upload (m)	58.62	1-168
Number of views	119224.62	126-850000
View ratio	93.25	0.63-1075
Number of comments	312.69	0-4295
Number of likes	939.09	0-10000
Mean DISCERN	2.01	1-4.2
Mean DISCERN Bias score	2.14	1-4
Mean DISCERN treatment	2.11	1-4
Mean DISCERN quality	2.07	1-5

The DISCERN and DISCERN Bias scores were significantly higher in the videos uploaded by physicians (p<0.001, p:0.002 respectively). There was no significant difference between the video sources in terms of number of likes, views, duration and age of the videos (Table 3). Most of the physicians who created videos were pain medicine specialists (37%). Other videos were uploaded by physiatrists (4), neurologists (2), dermatologists (4), an ophthalmologist (1) and a rheumatologist (1). The current study is the first to assess medical content on YouTube related to postherpetic neuralgia. The mean DISCERN and DISCERN bias scores of all videos subject to this analysis were 2.01 and 2.14 (out of 5) respectively. The highest DISCERN and DISCERN bias scores which were 2.31, and 2.48 respectively, pertained to videos created by physicians.

Table 2
Video Characteristics By Search Term

Search Term	Mean DISCERN Score	Mean Views	Made by Physician (%)	Mean DISCERN Bias Score	Mean Video Age (m)	Number of likes
Postherpetic neuralgia	1.99 ± 0.88	120845.9 (126-815000)	43	2.11 ± 0.96	63.89 (1-168)	941.2 (0-10000)
Zoster pain	1.85 ± 0.68	247236.0 (4900-815000)	45	2.00 ± 0.76	59.28 (6-120)	1811.3 (80-10000)
Herpes neuralgia	2.31 ± 0.95	31289.0 (126-327000)	75	2.33 ± 1.09	39.63 (1-144)	317.0 (2-3700)
All terms combined	2.01 ± 0.85	119224.62 (126-850000)	54	2.14 ± 0.94	58.62 (1-168)	939.09 (0-10000)

Table 3
Video quality assessments according to the source of the videos

	Mean DISCERN Score	Mean DISCERN Bias Score	Number of likes	Mean Views	Mean Video Age (m)	Duration
Physician (35)	2.31± 0.95	2.48 ±1.01	828.7 (0-10000)	108713.2 (126-815000)	58.91 (1-144)	7019.9 (43-216000)
Health-related Websites (22)	1.49 ± 0.49	1.77± 0.63	1213.1 (0-5300)	153401.6 (437-815000)	53.27(1-168)	277.6 (58-606)
Patient (8)	1.28 ± 0.30	1.37 ± 0.51	668.8 (24-2600)	71225.0 (4500-283000)	31.87 (12-120)	367.6 (73-802)
p	0.001	0.002	0.460	0.301	0.553	0.710

4. Discussion

Even from an optimistic point of view these results demonstrate that YouTube videos regarding postherpetic neuralgia have significant shortcomings and barely reach moderate quality.

As patients do not always have opportunity to contact with health professionals, they tend to seek information from unprofessional sources without concerning the accuracy of the data. The widespread use of the Internet and the inevitable rise of social media platforms provide quick access to information on health-related issues. However, the quality of the medical content on social media needs to be questioned. When it comes to the most popular video-sharing platform, YouTube lacks any reviewing process for the informative videos about medical conditions. Inaccurate, exaggerated or overlooked medical information may interfere with patients' decision-making process, leading to long-term effects on their physical or mental health.

To date several studies were conducted regarding informative YouTube videos about chronic pain syndromes. Hornung et al. investigated videos about low back pain and found the overall quality and reliability unsatisfactory¹⁰. Similarly, Zhang et al analyzed the videos related to neck pain and indicated low quality and reliability¹¹. In contrast, Altun et al. showed that the quality of complex regional pain syndrome videos were partially sufficient¹². Chaudhry et al. reviewed the videos on cluster headache and reported 52% of the videos were of low quality.

PHN is a disabling chronic neuropathic pain syndrome that is often accompanied by depression, anxiety, and sleep disturbances¹³. For patients suffering from a chronic neuropathic pain syndrome, it is of utmost importance to attain correct and complete information about the course of their disease¹⁴. As previously offered official health organizations may provide online, easily accessible, educational tools (official YouTube channels etc.) for patients while ensuring a thorough reviewing process¹⁵. A standardized criteria should also be utilized for medical YouTube videos uploaded by health professionals as the present study established that even PHN videos created by physicians could not exceed moderate quality.

As far as known this is the first analysis to investigate the educational value of YouTube videos related to PHN. Including only English videos, utilizing a scale (DISCERN) created for written material are the main limitations of our study. Furthermore, although we assessed the top results concerning view number and relevance separately, the top list sorted by relevance may change over time due to YouTube algorithm.

5. Conclusions

In conclusion, the educational value of YouTube videos about PHN uploaded by different sources is poor or moderate. Although physician-created videos have higher quality and less bias, health-professionals should warn their patients to be cautious when referring to social media platforms about their disease. Official health organizations should also consider providing easily accessible educational material for patients with PHN

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Statement of ethics

This is a cross-sectional study that included no human or animal participants, so ethical approval was not required and consent was waived.

Conflict of interest statement

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Author contributions

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