



Quality and Reliability of Youtube Videos as A Source of Information on Complementary and Alternative Cancer Treatments

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Abstract

Background: YouTube is one of the most widely used social networks as an information source. The scientific quality of the information available, however, is questionable. This study aims to characterise this by analysing videos about complementary and alternative cancer treatments on YouTube.

Methods: This cross-sectional study evaluated the 150 most viewed videos for global quality and reliability using modified DISCERN (mDISCERN), Journal of the American Medical Association (JAMA) and Global Quality Score (GQS). The popularity, duration and interaction of the videos with viewers were assessed. Categories of source (professional/non-professional) and speaker (doctor/non-doctor) were identified.

Results: 80 videos were included in the study. The most popular video category (71.3%) was informative videos for patients. In the videos, 66.3 per cent of the narrators were medical doctors. Between the video sources, modified DISCERN, JAMA and GQS scores were significantly different ($p < 0.001$, $p < 0.001$, $p < 0.001$) respectively. mDISCERN (mean: 3.09 ± 0.15), GQS (mean: 2.79 ± 0.16), JAMA (mean: 2.47 ± 0.13), scores were relatively high in the health professionals group. A positive correlation was found between the three scoring points ($p < 0.001$ for all pairwise comparisons).

Conclusions: YouTube is not an entirely reliable source of information on complementary and alternative cancer therapies. More comprehensive, reliable and accurate videos should be created and published by health professionals.

Keywords: Complementary And Alternative Treatments; Youtube; Global Quality Score; Modified DISCERN Scoring

Introduction

Cancer is one of the most deadly diseases worldwide [1]. In recent years, modern medicine has made rapid progress in the treatment of cancers with the introduction of chemotherapy, radiotherapy modalities, surgical interventions as well as molecular targeted therapies and immunotherapy treatments. With these new methods, many early stage cancers can now be treated and life expectancy can be prolonged in late stage cancers. However, the fact that treatment options are often accompanied by various toxicities often leads cancer patients and their relatives to search for alternative or complementary treatments. The terms “alternative

medicine”(AM) and “complementary medicine” (CM) are often used interchangeably and often referred to as “complementary and alternative medicine” (CAM) [2]. Alternative medicine is seen as an alternative to conventional treatment. In contrast, complementary methods are used in conjunction with conventional treatment and are used as supplements to conventional treatment strategies. It is difficult to make a clear distinction between which methods are considered alternative and which are considered complementary medicine. Many techniques and methods are used in both contexts [2]. There is a wide range of CM used by cancer sufferers,

including herbs and spices, vitamins, traditional Chinese medicine, homeopathy, mind-body modulation and specialised diets [3]. To improve their quality of life and feel more hopeful, cancer patients choose to use CM [4]. It is estimated that more than half of patients with cancer use CAM as part of their treatment [5,6,7]. However, it is known that the majority of this patient group refrain from sharing their CAM use with their oncologists. Differences in the perspectives of oncology physicians on CAM treatment and the lack of sufficient consensus on this issue play a role in this issue. For this reason, patients may use social media for CAM use and may have to seek support from non-physician treatment practitioners. In recent years, the increasing popularity of social media all over the world has been reflected in the field of health, and it is observed that there is an increase in information sharing in the field of cancer [8]. Youtube, one of the most widely used social media content in the world, provides video-based educational content with more than 2 billion users [9]. In this context, managing the reliability and quality of the data delivered to millions of users on video-sharing platforms such as YouTube is critical. The aim of this study was to evaluate the content, quality and scientific reliability of the most popular YouTube videos found using the keywords “complementary and alternative treatments in cancer”, using internationally accepted scoring systems.

Material and Methods

When starting to work, the Google Trends application was used to determine the keywords to be searched on 26 September 2023. The terms “cancer and complementary treatment”, “cancer and alternative treatment”, “complementary and alternative treatment in cancer” were chosen as keywords. Then, on the same day, a new Google and YouTube account was created to avoid potential bias from personalised algorithms, and an online search for these keywords was conducted on YouTube using standard US search preferences. As 95% of online searchers do not go beyond the first three pages viewed, the top 50 videos for each keyword were analysed [10]. Filters were selected as “worldwide” and “most viewed”. The “most viewed” filter was used to determine the videos that reached the most people, and the 150 most viewed videos were included in the study. Videos in languages other than English, restricted videos, and videos that were shorter than 1 minute were not included in the study. Repeated versions of the same video were excluded to avoid duplication. The URLs of all videos meeting the inclusion criteria were saved and all preliminary searches were reviewed separately by two experienced oncologists.

The origin, source, content category, narrator, duration (minute), upload date, total number of views, likes, comments and scores from each scoring were recorded separately by both oncologists. Video age (the amount of days between the upload date and 27.09.2023), and the view rate (views/video age) were calculated. Then the data were compared and the differently evaluated videos were reassessed together. If both oncologists still found their scores reasonable, the scores of these videos were recorded by averaging the scores. The origin of the videos, by whom they were recorded,

who the narrator was, which treatment modality was mentioned, their information content, whether they provided information about a specific type of cancer, and the opinions expressed about CAM in the video were recorded. The reliability and quality of video content were measured using the modified DISCERN (mDISCERN) scoring system, the Journal of the American Medical Association (JAMA) score, and the Global Quality Score (GQS). The mDISCERN is a 5-point Likert scale adapted from a tool used to rate written health information. In this scale, a score of 0 or 1 is given according to the criteria of precision/clarity, reliability, balance, source and uncertainty, with higher scores indicating greater reliability [10]. The JAMA Score is a quality assessment technique that can be used to rate the accuracy and reliability of medical information on the internet. This scale awards points according to 4 criteria (authorship, attribution/references, declaration/conflict of interest and validity). Zero is the lowest score and 4 is the highest [12]. The GQS is a subjective rating system for the overall quality of video content on a scale of 1-5 [13].

This study analysed publicly available YouTube videos and therefore did not involve human subjects or animals. In addition, this study was conducted outside of working hours. Therefore, as with previous YouTube studies, ethical approval was not required [14]. SPSS version 23.0 (IBM Corp., Armonk, NY, USA) was used for statistical analysis. Descriptive data were presented as numbers and minimum-maximum (min-max) values. The distribution of data was assessed using the Kolmogorov-Smirnov test. Independent T test was used to compare the two groups for data that have a normal distribution. Mann-Whitney U test was used to compare two groups for not normal distribution. Spearman correlation analysis was used for non-parametric variables. $P < 0.05$ was considered statistically significant.

Results

A total of 150 videos were evaluated. Videos that met the exclusion criteria were removed from the study, and 80 videos that met the inclusion criteria were analysed (figure 1) by two medical oncologists who were blinded to each other. The mDISCERN, JAMA and GQS scores of the evaluators were found to be in strong agreement with an intraclass correlation coefficient value of less than 0.90 and Spearman correlation of $p < 0.001$, $\rho = 0.882$, $p < 0.001$, $\rho = 0.893$, $p < 0.001$, $\rho = 0.904$, $p < 0.001$ respectively. Regarding country of publication; 43 (53.8 %) videos were from the United States of America, nine (11.3%) videos from the United Kingdom eight (10.3%) videos from India, eight (10.0%) videos from the Chinese and 12 (15 %) videos from other countries. Among video providers, health programmes on TV channels were the most popular (33%). The most popular video category (71.3%) was informative videos for patients. In the videos, 66.3 per cent of the narrators were medical doctors. In the videos, it was observed that information on the holistic approach (28.8 %), information on CAM (21.3 %), special diets (15.0 %), spices (12.5 %) and integrative oncology (11.3 %) were given, respectively. 65% of the videos provided information about complementary

medicine. A specific cancer subtype was mentioned in a quarter of the videos. The most frequently mentioned cancer subtype in the videos was breast cancer. The descriptive features of the videos were summarized in Table 1 and Table 2. When analysing the relationship between video narrators and video quality, it was found that the quality of videos produced by health professionals was higher than those produced by non-health professionals ($p < 0.001$). Between the video sources, modified DISCERN, JAMA and GQS scores were significantly different ($p < 0.001$, $p < 0.001$, $p < 0.001$ respectively). mDISCERN (mean: 3.09 ± 0.15), GQS (mean: 2.79 ± 0.16), JAMA (mean: 2.47 ± 0.13), scores were relatively high in the health professionals group. The videos narrated by health professionals were longer than the others. There was no difference

between the two groups in the number of views, view rate, likes and comments (Table 3). There was a significant difference in the mDISCERN, JAMA and GQS scores between the different categories of videos ($p \leq 0.001$ for each). Most (71.3%) of the CAM videos on YouTube were in the category of informative videos for patients. These videos were longer ($p: 0.021$). In addition, these videos were found to be of moderate quality for mDISCERN [mean: $2.95(1-5)$], JAMA [mean: $2.37(1-4)$], GQS [mean: $2.69(1-5)$]. The mDISCERN, JAMA and GQS scores for each video category are shown in Table 4. A correlation was found between mDISCERN, JAMA and GQS scores ($p < 0.001$). Correlations between mDISCERN score, JAMA score, GQS score and number of likes and view rate are shown in Table 5.

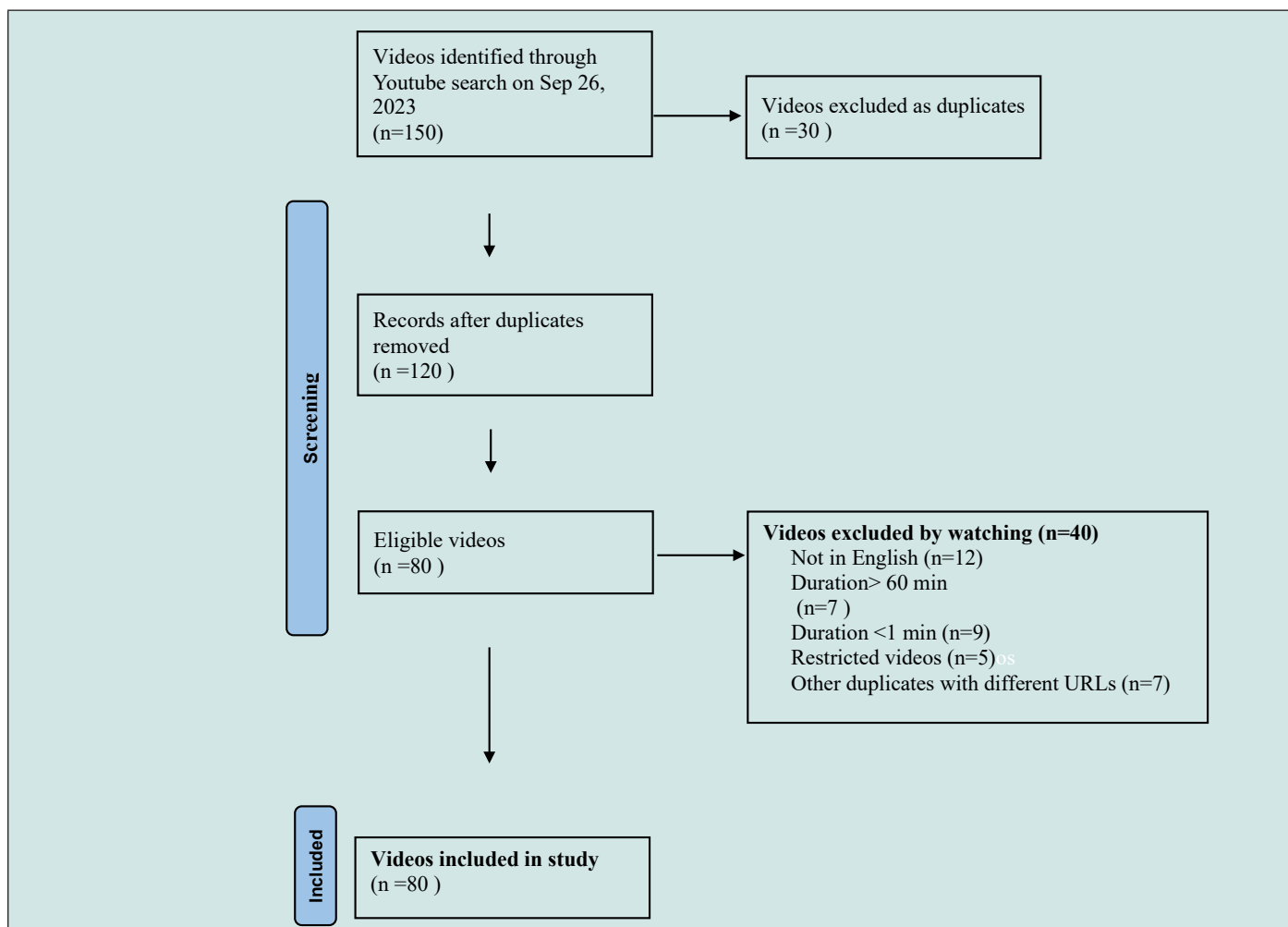


Figure1: Flow chart of the search results and screening process.

Table 1: Descriptive statistics of the videos on YouTube about complementary and alternative medicine and therapies.

Descriptive statistics	Mean ± SD	Median (Min-Max)
Duration (minute)	8.54 ± 11.19	4.13 (1.05-54.00)
Age (day)	2545.11 ± 1580.67	2281.00 (120 - 6205)
Number of total views	76240.06 ± 246429.00	6088.50 (533 - 1300000)
View ratio (number of views per day)	74.98 ± 254.11	3.38 (0.12 - 1785.70)

Number of likes	1223.61 ± 4694.56	46.50 (0 - 33000)
Number of comments	214.04 ± 1079.34	4.00 (0 - 8934)
mDISCERN score	2.69 ± 1.18	2.50 (1 - 5)
JAMA score	2.16 ± 0.98	2.00 (0 - 4)
GQS score	2.46 ± 1.13	2.00 (1 - 5)

Table 2: General features of the videos on YouTube about complementary and alternative medicine and therapies.

	Number	Percentage
Video narrator		
Doctor	53	66.3
Patient	7	8.8
unknown	14	17.5
Speaker	6	7.5
Video source		
Doctor	8	10.0
Private hospital	2	2.5
Academic institution	10	12.5
Health-related website	21	26.3
TV health programme	25	31.3
Independent user	14	17.5
Video category		
Patient information	57	71.3
Patient experience	15	18.8
Advertisement	3	3.8
Medical education	5	6.3
Video origin		
United States	43	53.8
United Kingdom	9	11.3
India	8	10.0
China	8	10.0
Canada	4	5.0
Europe	8	10.0
Complementary or alternative state		
Complementary	52	65.0
Alternative	13	16.3
Complementary and alternative	15	18.8
Video information content		
Herbs and spices	10	12.5
Holistic approach	23	28.8
Homeopathy	5	6.3
Identifying information	17	21.3
Integrative oncology	9	11.3
Immune support	4	5.0
Specialized diets	12	15.0
Presence of a specific type of cancer		
Yes	20	25.0

No	80	75.0
Cancer subtypes		
Breast	14	16.6
Colorectal	1	1.3
Liver	1	1.3
Melanoma	1	1.3
Prostate	1	1.3
Skin	1	1.3
Testicular	1	1.3

Table 3: The characteristics of YouTube videos by video sources.

	Health professional (n=53)	Non-Professional (n= 27)	P value*
	Mean±SE	Mean±SE	
Video duration (min)	10.03±1.78	5.60±1.06	0.036
Views (number)	69414.53±34299.40	89638.33±46956.41	0.731
View ratio (daily views)	89.87±41.03	45.74±24.62	0.359
Like (number)	1004.98±503.05	1652.78±1214.90	0.625
Comments (number)	82.92±65.75	471.41±332.09	0.261
Modified DISCERN score	3.09±0.15	1.89±0.16	<0.001
JAMA score	2.47±0.13	1.56±0.13	<0.001
GQS score	2.79±0.16	1.81±0.13	<0.001

*Independent T- test; GQS, Global Quality Scale; JAMA, Journal of the American Medical Association; SE, Standart Error

Table 4: mDISCERN score, JAMA score, GQS score, according to the categories of videos.

	Patient information (n=62)	Patient experience (n=18)	P value*
	Mean±SE	Mean±SE	
Video duration (min)	9.52±1.55	5.15±1.27	0.021
View ratio (daily views)	81.82±35.22	51.41±35.90	0.308
Like (number)	965.32±433.37	2113.28±1818.92	0.087
Comments (number)	98.95±61.29	610.44±492.34	0.030
mDISCERN score	2.95±0.14	1.78±0.19	<0.001
JAMA score	2.37±0.12	1.44±0.16	<0.001
GQS score	2.69±0.14	1.78±0.19	<0.001

SE: Standard error; mDISCERN, modified DISCERN score; JAMA, journal of the American medical association; GQS, Global Quality Score.

Table 5: Correlation between mDISCERN, JAMA, GQS scores, number of likes, and VR.

	mDISCERN	JAMA	GQS	Comments	Likes	VR
mDISCERN	—	r = 0.893	r = 0.882	r = -0.212	r = -0.59	r = -0.45
		p < 0.001	p < 0.001	p = 0.060	p = 0.601	p = 0.785
JAMA	r = 0.893	—	r = 0.904	r = -0.230	r = -0.039	r = -0.031
	p < 0.001		p < 0.001	p = 0.040	p = 0.773	p = 0.895
GQS	r = 0.882	r = 0.904	—	r = -0.116	r = 0.040	r = 0.056
	p < 0.001	p < 0.001		p = 0.305	p = 0.722	p = 0.625

Spearman correlation test. mDISCERN; modified DISCERN score; JAMA, Journal of the American Medical Association; GQS; Global Quality score; VR, Viewing rates.s

Discussion

YouTube™, the most popular video network in recent times, allows users to share content on a variety of topics and easily access free of charge [15]. Researchers have reported that over 80% of patients use online resources to obtain information about their disease, and in more than 70% of cases, videos significantly influence the patient's treatment decisions [16]. However, despite their widespread use, the lack of adequate control and filtering may lead to the dissemination of inaccurate or low-quality information [17]. In the current study, we assessed the quality, reliability, and acceptability of YouTube videos about CAM in cancer patients. To the best of our knowledge, this study is the first to have a look at the content and quality of YouTube™ videos on CAM treatment in cancer patients. The mDISCERN score was 2.69 ± 1.18 (moderate quality), JAMA score was 2.16 ± 0.98 ("low-quality") and GQS score was 2.46 ± 1.13 (moderate quality). Previous studies show that the quality of youtube studies in cancer is low or moderate [18,19]. When we did our research, YouTube did not show public disliking. Therefore, the video power index [(number of likes/number of dislikes + number of likes) X 100] could not be calculated. But we can make a statement about interaction and therefore popularity when we look at the number of video views, view rates, comments and likes. When the videos in this study were categorized according to their source, similar to the literature, academic videos had the best quality rating (18).

One study found that the most important aspect in determining whether viewers perceive the knowledge in videos to be reliable and credible is the source of the video [20]. The most common video sources in our study were TV health programmes and health-related websites, respectively. We found that 65% of the videos we looked at gave information about complementary medicine. A quarter of the videos analysed gave information or advice about a specific type of cancer, and the most common cancer given information about was breast cancer. Being the most common type of cancer among women, the desire to reach large populations may have played an important role. When the video contents of TV health programmes were examined, it was observed that patient experiences were frequently included as well as patient information about CAM. On the other hand, it is positively striking that the narrators in the analysed videos were mostly physicians and more instructive information about CAM was given. While the duration of the informative videos was longer, it was observed that the number of comments was higher in the videos containing patient experience. Viewers tend to interact more in videos containing patient experience. The audience may have been encouraging the patients or asking questions in the belief that the cancer patients understood. Since this situation may cause the spread of false or incomplete information, it is important that the video content is under control [21]. It has been shown in a large-scale study by Skyler B. et al. that cancer patients' abandonment of conventional treatment methods by using alternative treatment methods worsens their survival time [22]. CAM in cancer patients has gained importance in recent years. It is seen that the lack of information in this field and the fact that

people other than health professionals are open to bad guidance has started to reveal the concept of integrative oncology, in which standard cancer treatments and CAM applications are handled together in some major cancer centres in the USA (Dana-Farber Cancer Institute in Boston, Memorial Sloan-Kettering Cancer Center in New York and MD Anderson Cancer Center in Houston, among others). It is pleasing to see the number of informative high quality videos about integrative oncology in YouTube video content. When the videos in our study were evaluated for information content, the most common content was related to holistic approaches such as acupuncture, yoga, meditation, mindfulness and massage. The fact that there is relatively little content related to herbal treatment and traditional Chinese medicine is due to the fact that only videos with English narration were included in our study. This is a limitation of our study. In addition, other frequently used social media platforms such as Twitter, TikTok and Instagram were not included.

Conclusion

Complementary and alternative medicine includes supportive modalities. When well coordinated with conventional cancer treatment, it can be used to improve each patient's quality of life, reduce treatment side effects and promote patient self-management. Therefore, appropriate explanation of the right modalities that can be used by patients independently by health professionals on social media platforms that reach a wide audience will help to learn and use the right information.

Statements

Statement of ethic

This study analyzed publicly available YouTube videos, and therefore the study did not involve any human subjects or animals. For this reason, ethical approval has been waived, as with previous YouTube studies.

Funding/Conflict of interest Statement

This research received no funding. The authors declare that they have no conflict of interest.

Author Contributions Statement

Conceptualization, design, data review, evaluation videos, analyzed, and interpreted the data; DBG and ES, drafting manuscript; DBG, editing; DBG and ES.

Data availability statement

The data of the study can be accessed by contacting DBG.

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