



Chemotherapy Side Effects and YouTube Platform; What Do Patients Watch?

Kemoterapi Yan Etkileri ve YouTube Platformu; Hastalar Ne İzliyor?

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ÖZET

Amaç: Bu araştırma ülke örnekleminde Kemoterapinin Yan etkilerinin anlatıldığı YouTube videolarının içeriği, niceliği ve güvenilirliğini değerlendirmek amacıyla yapılmıştır. **Gereç ve Yöntem:** YouTube'da 29 Ağustos 2022 tarihinde arama çubuğuna 'kemoterapinin yan etkileri' anahtar kelimesi kullanılarak taranmıştır. Sıralama kriteri olarak "Alaka Tabanlı Sıralama" uygulanmıştır. Kemoterapi yan etkileri ile ilgili olmayan, Türkçe dışındaki diller, sesi olmayan, tekrarlı ve 20 dakikadan uzun videolar değerlendirmeye alınmadı (n=23). 0-20 dakika arasındaki videolar incelendi. 0-20 dakika arasındaki 55 video Tüketici Sağlığı Bilgileri için Kalite Kriterleri Ölçeği (Quality Criteria for Consumer Health Information -DISCERN) ve Global Quality Scale (GQS) kullanılarak 3 ayrı bağımsız uzman tarafından eş zamanlı değerlendirilmiştir. **Bulgular:** En yaygın üç yükleyici profilin doktor, hasta ve sağlıkla ilgili web siteleri olduğu belirlendi. Videoların içeriklerinin büyük bir kısmını kemoterapi ve yan etkiler, hasta deneyimleri oluşturdu. DISCERN puan ortalaması 56, GQS ise 3.00 olarak belirlenmiştir. Video yükleyiciler ile puanlar karşılaştırıldığında DISCERN (p=0.245), GQS (p=0.647) olup puanları arasında anlamlı fark olmadığı saptandı. Video süresi, beğenilme ve yorum sayısı, yorum oranında gruplar arasında anlamlı fark saptandı (sırasıyla p=0.001, 0.049, 0.004, 0.003). **Sonuç:** Sonuç olarak videolardaki bilgilerin kalitesinin iyi, eğitimsel değerinin orta düzeyde olduğu; hastalar tarafından yüklenen videoların daha fazla izlendiği, daha çok beğeni aldığı ve daha sık görüntülediği belirlenmiştir.

Anahtar kelimeler: E-sağlık, hasta, kanser, kemoterapi yan etkileri, YouTube.

ABSTRACT

Objective: This study was aimed to evaluate the content, quantity and reliability of YouTube videos in which the side effects of chemotherapy are explained in a country sample. **Materials and Methods:** It was searched in the search bar on YouTube™ on 29 August 2022 using the keyword 'chemotherapy side effects'. 55 videos between 0-20 min were evaluated simultaneously by 3 independent experts using the Quality Criteria for Consumer Health Information (DISCERN) scale and the Global Quality Scale (GQS). **Results:** The three most common uploader profiles were physician, patient and health-related website. The most of contents of the videos consisted of general chemotherapy and side effects, patient experiences. The DISCERN score average was 56, and the GQS was 3.00. When the scores of the video uploaders were compared, it was found that there was no significant difference between the scores of DISCERN (p=0.245) and GQS (p=0.647). There was a significant difference between the groups in the video duration, the number of likes and comments, and the rate of comments (p=0.001, 0.049, 0.004, 0.003, respectively). **Conclusion:** As a result, the quality of the information in the videos is good and the educational value is moderate. It has been determined that the videos uploaded by the patients are watched more, receive more likes and are viewed more frequently.

Keyword: Cancer, chemotherapy side effects, e-health, patient, YouTube.

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INTRODUCTION

Due to the advances in early diagnosis and treatment, more people are diagnosed with cancer every year because of the prolongation of the average life expectancy (Ozdemir, Unubol, Akyüz, 2021). According to World Health Organization-the International Agency for Research on Cancer (IARC) report, 19.9 new cancer diagnoses were made worldwide in 2023. According to these data, 1 out of every 5 people worldwide is diagnosed with cancer (World Health Organization, 2023). Although there are options such as chemotherapy, radiotherapy, surgery, immunotherapy, gene, etc. in cancer treatment, chemotherapy is still the most preferred treatment for different cancers (Behranvand et al., 2021). However, chemotherapy has many mid-term (vomiting, nausea, gastrointestinal disorders, and stomatitis) and long-term (eg, fatigue, hair loss, kidney toxicity) side effects (Magalhães, Fernandes, Lima, Martinez-Galiano, Santos, 2020; Sahin and Seyyar 2023; Van Dongen et al., 2020). If these side effects are not managed effectively, they may lead to delayed cancer treatment, non-adherence in treatment, and deterioration in overall quality of life (Van Dongen et al., 2020; Magalhães et al., 2020).

In recent years, chemotherapy has begun to take an active role in the prevention or management of chemotherapy-related or disease-related symptoms in patients, since chemotherapy is mostly administered in outpatient units or in the hospital for short periods (Coolbrandt et al., 2020). While managing this process, patients apply to internet resources with the developing technology (Dadkhah, Mehraeen, Rahimnia, Kimiafar, 2021; Wittenberg-Lyles, Parker Oliver, Demiris, Swarz, Rendo, 2014). 60% of all videos on the Internet are found on YouTube, the second most popular website in the world behind Google (Alexa, 2018; Auxier & Anderson, 2021). With more than 2.1 billion users in 2020, over one billion hours of video were viewed daily and more than 500 hours of new content were posted every minute on YouTube (Osman, Mohamed, Elhassan, Shoufan, 2022). Previous studies have revealed that individuals seeking cancer-related information primarily want to learn about it from YouTube, instead of consulting healthcare personnel (Maddock, Lewis, Ahmad, Sullivan, 2011; Dadkhah et al., 2021; Wittenberg-Lyles et al., 2014; Wong & Ingledew, 2024). It has been reported that individuals in Turkey have a high level of internet access and health-related information is followed closely (Tosun & Tosun, 2022).

Although Youtube is preferred worldwide due to its easy accessibility, it can be a very important problem because the accuracy, up-to-date and security of the information shared on this platform is not clear (Madathil, Rivera-Rodriguez, Greenstein, Gramopadhye, 2015; Osman et al., 2022; Tosun & Tosun, 2022). Despite the fact that there are research assessing the

caliber of YouTube videos concerning cancer in the literature (Godskesen, Holm, Anna, Höglund, Eriksson,2023; Hassona, Taimeh, Marahleh, Scully,2016; Ozdemir et al., 2021; Reinhardt,Steeb,Mifka, Berking,Meier,2023; Sahin, Sahin, Schwenter, Sebahjang,2019) as far as we know, there are a limited number of specific studies evaluating the side effects of chemotherapy (Sahin & Seyyar, 2023; Semerci, Şimşek, Savaş, Orhan, Erbey,2023).

In this research, it is aimed to evaluate the content, quantity and reliability of YouTube videos in which the side effects of chemotherapy are explained in the Turkish sample.

MATERIAL AND METHODS

Design

A descriptive, cross-sectional study design was applied to analyse information on videos for chemotherapy side effect on YouTube.

Search Strategy

On August 29, 2022, the search history was deleted on YouTube and the search bar was searched using the keyword 'chemotherapy side effects'; thus, videos were listed according to popularity.

Inclusion and Exclusion Criteria

Videos in languages other than Turkish, without sound, repetitive and longer than 20 minutes, which are not related to chemotherapy side effects, were not included in the evaluation. Videos between 0-20 minutes were reviewed. Studies have shown that on average, videos that are longer than 15 minutes decrease in viewing rates and viewers stop watching (Lewandowski, 2008; Guo, Kim, Rubin,2014) “Relevance-Based Ranking” was applied as a ranking criterion. As a result, 55 videos remained (see figure 1 for the criteria). The videos taken in the evaluation order were recorded and numbered. The analysis of these videos was made simultaneously by 3 independent experts. Two of the experts are faculty members in the field of oncology and the other in the field of communication.

Video Parameters

For each video, the following data were collected: video upload time, date, video duration (minutes), uploaded (Healthcare provider, Patient, Healthcare professional), views, likes, and engagement index— $([likes-dislikes] / \text{total number of views} \times 100\%)$ was recorded.

Data Collection

The quality and content of the video were evaluated using the DISCERN (Quality. Criteria for Consumer Health Information) scale and the Global Quality Scale (GQS) scale.

DISCERN evaluates the reliability of a publication, the quality of information provided to a patient about treatment options. DISCERN sets standards and gives guidelines to users for the evaluation of health information (Godskesen et al.,2023). This scale consists of 3 parts and 16 questions. While reliability is measured in the first 8 questions and the quality of the information presented on treatment/care options in the other 7 questions, the general evaluation of the material is made in the third section. Each question is scored from 1 to 5. A score between 15-75 is obtained from DISCERN. Excellent scores range from 63 to 75, decent scores range from 51 to 62, middling scores range from 39 to 50, insufficient scores range from 27 to 38, and severely deficient scores range from 16 to 26. The 16th item, which gives the general evaluation, is scored separately (Discern,2022).

The Global Quality Scale (GQS) determines the educational value of a video. GQS: 1 score denotes the lowest quality, and 5 points the highest. It receives 1-2 point3 points for medium quality, and 4-5 points for great quality for low quality, (Bernard et al.,2007).

Ethical Consideration

Ethics committee permission was not required because this study used publicly accessible footage and did not involve any human or animal participants.

Statistical Analysis

The Statistical Package for Social Sciences (SPSS) 26.0 (IBM Corp. Armonk, NY) was used for analysis. Frequency, percentage, median, and interquartile range were used for descriptive data. The Kruskal-Wallis test was used to compare more than two independent variables that were non-normally distributed. P value of less than 0.05 in the 95% confidence interval was considered to indicate statistical significance.

RESULT

After 78 videos were included in the search criteria, 55 videos were evaluated (Figure 1). The three most common uploader profiles were physician (n=20), patient(n=18), and health-related website (n=17). The most of contents of the videos of general chemotherapy and side effects, patient experiences. According to the result of Kappa analysis to determine the harmony between experts evaluating YouTube videos; It was determined that there was agreement among experts in all evaluations. (DISCERN (Kappa = 0.728), GQS (Kappa = 0.801)).

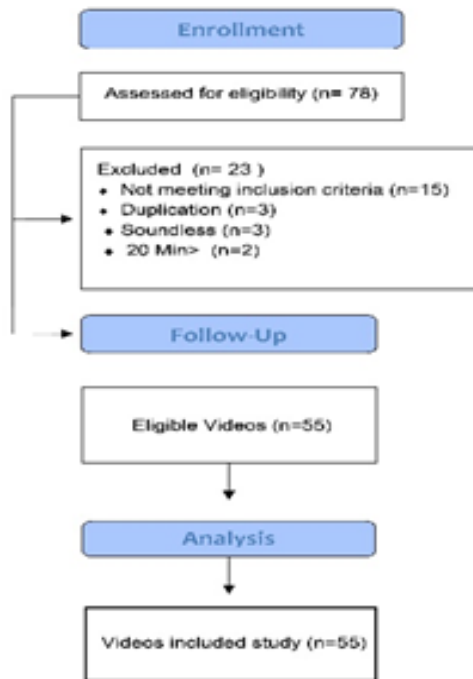


Figure 1. Flowchart of YouTube videos

The Discern score average was 56, and the GQS was 3.00 (Table 1). The median time (days) after uploading of the examined videos was determined as 1205, the median duration (minutes) was 2.09, the median number of likes was 28.00, the median number of comments was 1.24, the number of dislikes was 0, and the median of views was 27.23 (Table 1)

Table 1. Video Features, Quality, and Reliability Scores of Videos

Video features	Median (IQR)
Duration (minutes)	2.09 (0.54-7.64)
Time since upload (day)	1205 (670-2399)
Number of likes	28.00 (3.00-130)
Like Ratio	0.86 (0.34-2.58)
Number of contents	1.24 (0.00-15.00)
Number of views	27.23 (10.07-333.00)
Views Rate	4.15 (0.6-14.40)
DISCERN	56 (44-61)
Global Quality Scale	3.00 (2.00-4.00)

IQR: Inter quartile range

When the scores of the video uploaders were compared, it was found that there was no significant difference between the scores of DISCERN ($p=0.245$) and GQS ($p=0.647$).

It was determined that the scores of the videos uploaded by the physician group, the patient, and the health-related website were close to each other ($p > 0.05$) (Table 2).

Table 2. Comparison of Video Uploaders and Ratings

	Discern Median (IQR)	Global Quality Scale Median (IQR)
Physician (n=20)	56 (43-60)	3.00 (2.00-4.00)
Patient (n=18)	58 (53-69)	2.00 (2.00-3.00)
Health-related websites (17)	54 (47-59)	2.33 (1.00-3.00)
p†	0.245	0.647

Discern: Quality Criteria for Consumer Health Information; IQR: Inter quartile range ; † Kruskal Wallis-H test * $p < 0.05$

Video uploaders and video features were compared (Table 3). There were significant differences between the groups in the video duration, the number of likes and comments, and the rate of comments ($p=0.001$, 0.049, 0.004, 0.003, respectively). The number of likes was found to be significant (0.049) at the doctor-patient border. It was determined that there was a difference between the duration of the video, the number of comments and the rate of comments between the doctor and the patient. The patients' video duration was longer than the Physician and the difference was statistically significant ($p=0.001$). Physician had more video likes than patients and health-related websites. The number of comments and views from patients were higher than those on physician and health-related websites.

Table 3. Comparison of Video Uploaders and Video Features

Source of upload	Duration (minutes)	Time since upload (day)	Number of likes	Like Ratio	Number of comments	Number of views	Views Rate
Physician	1.08 (0.47-3.43)	1294(828-2506)	14(2.00-87.00)	0.74 (0.3-136)	0.00 (0-2.00)	90.00 (10.08-677)	1.1(0.3-8.5)
Patient	11.03 (2.43-14.06)	1048(532-1228)	81 (28-296)	2.57(0.5-4-2.89)	14(3-185)	18.14 (10.06-84.37)	15.7(4.8-80)
Health-related websites	2.04 (1.18-2.04)	2292 (135-2300)	3(1-3.5)	0.33(0.0-2-0.40)	0.00	27.23(4.31-27.3)	1.3(0.7-2.1)
p †	0.01*	0.421	0.049*	0.094	0.004*	0.593	0.003*

IQR: Inter quartile range; † Kruskal Wallis-H test ; * $p < 0.05$

DISCUSSION

Chemotherapy severity causes many symptoms ranging from mild to life-threatening, and patients are affected by these symptoms with different biopsychosocial severity (Pekmezci, Köse, Akbal, Özdemir, Çol, 2022; Sahin and Seyyar 2023). In order to reduce the frequency and severity of the symptoms experienced and to improve their quality of life by providing

appropriate management, patients often seek useful, practical and quickly accessible information resources. However, it should be noted that it is not easy for many users to determine the accuracy of the information accessed via the internet, and most of the time, only the videos that can be accessed are watched without knowing which reliable content is (Hassona et al.2019; Wong and Ingledew 2024).

In this study it was determined that the DISCERN average was good and the GQS average score was moderate in videos included in our study. Ozdemir et al.,2022, Reinhardt et al.2023, Rodriguez Rodriguez et al.,2022, Semerci et al.2023, similar results as our study. A study evaluating the quality of YouTube videos about radiotherapy and prostatectomy for prostate cancer showed that, similar to our research findings, informational videos covered the side effects of the treatment well (Wong&Ingledew, 2024). However, in a literature review regarding the quality of health information and educational videos available on YouTube, they found that the quality of these videos was average to below average (Osman et al.,2022). Another study, it has been determined that most chemotherapy-related YouTube videos, although beneficial to patients, are moderately low in content quality and reliability (Sahin & Seyyar, 2023). The reason why the results of these other studies differ from ours may be that they include data from many countries. Another reason can be considered to include more than one Youtube presenter such as a doctor, a patient, or a television program.

According to our study findings, there was no difference between video uploaders and DISCERN and GQS scores. We may assume that patients are describing what they actually experienced as side effects of chemotherapy. One interesting finding of the study that how important it is to accurately describe what patients experience. In a study on cancer rehabilitation, although academic institutions and university hospitals uploaded more videos than other uploaders, the GSQ scores of academic institutions were found to be lower, similar to our study (Ozdemir et al.,2022). In the study where radiotherapy videos were examined, similar to our research, the Video Power Index of patient providers doctor has shown that the number of providers is almost three times higher (Wong & Ingledew,2024). However, aspect of these studies differs from our research. This difference; DISCERN, GQS score, etc. in doctors' YouTube videos. It was determined that the scores were statistically significantly higher than those of independent users or patients (Kasıkcı &Yıldırım,2021; Rodriguez Rodriguez et al.,2022; Sahin& Seyyar,2023; Semerci et al.,2023; Tosun & Tosun, 2022).

In our study, it was observed that the videos uploaded by the patients were watched and liked more than the videos uploaded by the physician and health-related website. This finding

may be related to the desire of cancer patients to learn about experiences from people who have had similar problems with them. As a matter of fact, studies indicate the importance of sharing patient stories and experiences as a communication tool among cancer patients. It has been shown that sharing cancer and treatment-related experiences, such as the course of the disease, responses to treatments, and medical practices, have a positive effect on cancer patients (Tang, Olscamp, Choi, Friedman,2017). Other studies have found similarly results that our study in cancer and different patient groups. Videos uploaded by independent users or patients had significantly higher views than videos by physicians (Kasıkçı &Yıldırım,2021; Rodriguez Rodriguez et al.,2022; Sahin& Seyyar,2023; Semerci et al.,2023; Tosun & Tosun, 2022).

Another finding that made a difference between the groups in our study was that the length of the video uploaded by patients was longer than that of doctors or health sites. Sahin and Seyyar 2023; Semerci et al.2024 similar results as our study. Indeed, in their study, it is stated that useful videos tend to be longer than unreliable ones, and this may decrease the viewing rate (Biggs,Bird,Harries, Salib,2013). It is seen that videos containing misleading or poor quality information, which users can easily access in a short time by scanning the YouTube database less, can also receive high appreciation (Madathil et al.,2015; Osman et al.,2022). However, there are also studies showing that a significant portion of those who watch health-related videos are not interested in the source and quality of the video (Biggs et al.2013; Osman et al.2022; Tosun &Tosun,2022).

Although it has been stated in the studies conducted to evaluate the educational videos on YouTube that the videos of the healthcare personnel for patient education have accurate and qualified information (Osman et al.,2022; Rodriguez Rodriguez et al.,2022; Sahin& Seyyar 2023; Semerci et al.,2024; Tosun&Tosun 2022). There is no standard for the health-related and widely watched YouTube videos (Azer,2020; Osman et al.,2022). Our study findings were also thought to be related to these results in the literature.

Limitations

This study had some limitations. First, limitations of the study are that the videos examined are only in this country, they are evaluated by fewer experts, and the sample is limited. Second, because the data analysis was cross-sectional, the findings from our study on YouTube involve analysis of the information available regarding chemotherapy side effects at a specific time. However, it also has its strengths. The quality and content of the side effects of chemotherapy were analyzed on the most watched platform.

CONCLUSION

The quality of the information in the videos examined in our study is good and the educational value is moderate; It has been determined that the videos uploaded by the patients are watched more, receive more likes and are viewed more frequently. YouTube videos are important in terms of providing simple and easily accessible information in the management of chemotherapy-related side effects that significantly affect the quality of life of cancer patients and their caregivers from many different perspectives. However, it should not be overlooked that video content should include evidence-based practices, results published in clinical guidelines and scientific references. Therefore, the fact that educational videos are of high quality, the information content is reliable, and prepared or approved by health professionals can be an important data source for cancer patients who are trying to obtain information from YouTube. In addition, care must be taken to ensure that the video to be broadcast is safe, contains sufficient information, and is of a length that does not distract attention.

Conflict of Interest

The authors declare no conflict of interest regarding the publication of this study.

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Author Contribution

Research Idea/Concept: NBA, UÖY

Research Design: NBA, UÖY

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