ORIGINAL RESEARCH ORIJINAL ARAŞTIRMA

# Assessing YouTube Videos on Lymphedema for Patient Education: A Comprehensive Evaluation

Hasta Eğitimi Açısından Lenfödem ile İlgili YouTube Videolarının Değerlendirilmesi: Kapsamlı Bir İnceleme

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ABSTRACT Objective: Limited access to lymphedema healthcare professionals prompts patients to seek information on alternative sources like YouTube. Few studies evaluate YouTube video quality and reliability. However, assessing video quality alone isn't enough for patient education. Our aim was to critically analyze lymphedema videos for reliability, accuracy, understandability, actionability, and popularity. Material and Methods: Fifty four most relevant videos were analyzed. Video popularity analytics encompassed viewing rate, like ratio, number of comments, and the Video Power Index (VPI). We assessed content quality using the Global Quality Scale (GQS), the modified DISCERN questionnaire score, the Journal of the American Medical Association (JAMA) benchmark criteria score, and Patient Education Materials Assessment Tool for Audio/Visual Materials. Results: A significant portion of the analyzed videos originated from private health institutions (25.9%) and private health professionals (24.1%). The view rate was 11.5 and VPI was 11.1. Content quality scale scores were higher in videos where lymphedema specialists/therapists provided information. The understandability and actionability of videos correlate with VPI, view rate, video duration, and image quality. GQS was correlated with the VPI and view rate. The JAMA benchmark criteria was correlated with the like ratio and video duration. Conclusion: Our findings suggest that lymphedema-related videos on YouTube are characterized by average content quality and understandability, but a lack of reliability and actionability. To ensure individuals seeking accurate lymphedema information on social media platforms, we recommend directing them to videos uploaded by lymphedema specialists/therapists.

ğerlendirmek yeterli değildir. Amacımız, lenfödem videolarını güvenilirlik, doğruluk, anlaşılabilirlik, uygulanabilirlik ve popülerlik açısından eleştirel bir şekilde analiz etmektir. Gereç ve Yöntemler: En uygun 54 video analiz edildi. İzlenme oranı, beğeni oranı, yorum sayısı ve Video Güç İndeksi [Video Power Index (VPI) incelendi. İçerik kalitesi, Global Kalite Ölçeği [Global Quality Scale (GQS)], modifive DISCERN anketi puani, Journal of the American Medical Association (JAMA) kriterleri puanı ve Hasta Eğitim Materyalleri Değerlendirme Aracı-Sesli/Görsel Materyaller kullanılarak değerlendirildi. Bulgular: Analiz edilen videoların önemli bir kısmı özel sağlık kuruluşları (%25,9) ve özel sağlık profesyonelleri (%24,1) tarafından yayınlanmıştır. İzlenme oranı 11,5 ve VPI 11,1 idi. Lenfödem uzmanları/terapistler tarafından bilgi verilen videolarda içerik kalitesi daha yüksekti. Anlaşılabilirlik ve uygulanabilirlik, VPI, izlenme oranı, video süresi ve görüntü kalitesi ile ilişkiliydi. GQS, VPI ve izlenme oranı ile ilişkiliydi. JAMA kriterleri, beğeni oranı ve video süresi ile ilişkiliydi. Sonuc: Bulgularımız, YouTube'daki lenfödemle ilgili videoların orta düzeyde içerik kalitesi ve anlaşılabilirlikle karakterize olduğunu, ancak güvenilirlik ve uygulanabilirlik eksikliği olduğunu göstermektedir. YouTube'da lenfödem ile ilgili bilgi arayan bireylerin, lenfödem uzmanları/terapistleri tarafından yüklenen videolara yönlendirilmesini öneririz.

ÖZET Amaç: Lenfödemde; sağlık profesyonellerine sınırlı erişim, has-

taları YouTube gibi alternatif kaynaklarda bilgi aramaya yönlendirir.

YouTube videolarının kalitesi ve güvenilirliği hakkında az sayıda ça-

lışma mevcuttur. Ancak hasta eğitimi için yalnızca video kalitesini de-

Keywords: Lymphedema; education; patients; YouTube

Anahtar Kelimeler: Lenfödem; eğitim; hasta; YouTube

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Lymphedema is a chronic condition arising from the exceeding of the transport capacity of the lymphatic system due to deficiencies and malformations in the number or functions of lymph vessels. It can be classified into primary and secondary lymphedema based on its etiology. Primary lymphedema is a rare occurrence (approximately 1 in 100,000 individuals) and is the result of hereditary genetic predisposition and structural abnormalities in the lymphatic system. Secondary lymphedema is more commonly observed. In developing countries, parasitic infections affecting approximately 300 million people worldwide are the most prevalent cause of lymphedema.<sup>1</sup> In contrast, in developed countries where parasitic infections are rare, lymphedema emerges as a significant complication of cancer treatment. Cancer-associated lymphedema represents a substantial complication arising from cancer treatment, exhibiting a reported incidence that varies between 5% and 60%. The occurrence of lymphedema is contingent upon factors such as the specific type of cancer (as delineated below), the modality of treatment employed, and the duration of the follow-up period. In recent years, with advancements in early cancer detection and effective treatments leading to prolonged patient survival, the incidence of lymphedema has been on the rise.<sup>2</sup> The global availability of professionals dedicated specifically to providing health services for lymphedema is severely limited.<sup>3</sup> This situation leads patients to turn to alternative sources of information.

In recent years, patients have increasingly utilized the internet as a source of information. YouTube stands (Google, San Bruno, California, USA) out as one of the most frequently consulted platforms.<sup>4</sup> Various content targeting different audiences is available on YouTube, encompassing educational videos for medical students and professionals, informative videos for patients, and content sharing patient experiences. The accuracy of information on this platform significantly varies depending on the expertise and credibility of the content publishers. Given the absence of a mechanism to verify the evidence-based and reliable nature of information on social media platforms, inaccurate content that deviates from scientific evidence may be present.<sup>5</sup>

Recent research on YouTube videos in the field of rehabilitation indicates certain deficiencies in the content. Notable shortcomings include deficiencies in content quality, objectivity, reliability, and comprehensibility. In the literature, there are few studies evaluating the quality and reliability of YouTube videos about lymphedema.<sup>6</sup> However, merely assessing the quality of videos is insufficient to determine their value for patient education. Considering the clinical significance of these videos in patient education, it is highly important to utilize tools that evaluate educational materials. This approach can guide recommendations for videos suitable for patient education, contributing to the creation of popular, accurate, and comprehensible content that can reach a larger number of patients in the future. Within the framework of this investigation, our principal aim was to critically examine and assess the reliability, accuracy, understandability, actionability, and popularity of lymphedema-related videos accessible on YouTube. We particularly directed our attention to appraising their appropriateness as informational resources for individuals requiring content pertinent to this medical condition.

## MATERIAL AND METHODS

### VIDEO SEARCH

A study was conducted using Google Trends (Google, Mountain View, California, USA). to identify the most searched keywords related to lymphedema worldwide within the past year. It was observed that the most searched term was "lymphedema", followed by "lymphedema treatment" as the second most searched term. On December 15, 2023, videos on YouTube were reviewed using these keywords. Given research indicating that most individuals tend to confine their online searches to the first few pages, the search was restricted to the first 60 videos. Prior to the search process, all cookies and search history were purged, and the Google Chrome (Google, Mountain View, California, USA) web browser was configured to operate in incognito mode to ensure anonymity. This precautionary measure was undertaken due to the personalized nature of YouTube's search results. The search was conducted utilizing a "relevance-based ranking" as the default selection, mirroring the typical user behavior when performing searches on the platform. Contents excluded encompassed various categories, including (1) advertisements, (2) duplicate videos, (3) videos falling outside the temporal range of 60 seconds to 30 minutes, (4) recordings of scientific meetings and medical lectures, (5) videos presenting language-related issues or lacking audio-visual components, and (6) materials deemed irrelevant to the research objectives. The publishers, countries of origin, and content of the videos were recorded. Following the completion of the inclusion review process, URL links corresponding to the included videos were systematically documented within an Excel spreadsheet to facilitate subsequent analysis. Given that our study did not involve human subjects, the necessity for approval from a clinical research ethics committee was exempted, in accordance with precedent practices observed in prior analogous investigations.<sup>6-8</sup>

### VIDEO ANALYTICS

The metrics encompassing the numbers of views, likes, dislikes, and comments up to the search date were recorded. Additionally, attributes such as the quality of the video image, delineated into categories of low, standard, or high-definition based on the provided video resolution information from YouTube, alongside video duration (in seconds) and the elapsed time since publication, were documented. Complementary to this, the view rate and like ratio were computed using established formulas, denoted as the ratio of the number of views to the number of days since publication, and the ratio of the number of likes to the sum of likes and dislikes, respectively. Furthermore, the Video Power Index (VPI), serving as a quantitative measure to evaluate the popularity and impact of the video content, was calculated as the product of the like ratio and the view rate, divided by 100.9

### EVALUATION OF CONTENT QUALITY

The evaluation of video content quality involved the utilization of multiple assessment instruments, including the Global Quality Scale (GQS), the modified DISCERN questionnaire score, the Journal of the American Medical Association (JAMA) benchmark criteria score, and the Patient Education Materials

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The GQS is a Likert scale with 5 points utilized to assess the overall quality of content, spanning from poor to excellent, taking into account factors such as accuracy and coherence. Elevated scores on this scale indicate heightened quality and utility.<sup>10</sup>

The modified DISCERN questionnaire comprises 5 inquiries designed to gauge content reliability, clarity, and impartiality. Each query is assigned a score of either 1 or 0, contingent upon whether the content satisfies the stipulated criteria. The cumulative sum of these scores determines the overarching quality, with higher totals denoting more dependable and unbiased information.<sup>10</sup>

JAMA benchmark criteria center on facets such as authorship, appropriate citation of sources, currency of information, and disclosure of conflicts of interest. Evaluation within each domain employs a binary scoring system, wherein elevated scores indicate greater reliability of content.<sup>11</sup>

The PEMAT-A/V evaluates the clarity and quality of patient education materials, encompassing videos and multimedia presentations, with an emphasis on effectively conveying health-related information to patients in an easily understandable and actionable manner. This assessment tool comprises 12 items pertaining to understandability and 5 items concerning actionability domains, with the cumulative score presented as a percentage.<sup>12</sup>

To uphold the reliability of the content evaluation process, two authors (AUK and LK) conducted independent assessments of the videos. Any disparities or disagreements between these authors were resolved through a secondary review of the videos, during which both authors collaboratively reconciled their assessments.

### STATISTICAL ANALYSIS

The statistical analysis was performed using IBM SPSS Statistics for Windows, Version 27.0 (Armonk, NY: IBM Corp). Nominal data were presented as frequencies and percentages. The Shapiro-Wilk test was utilized to assess the normality of continuous variables. Continuous variables were reported as median (minimum-maximum). To assess the reliability between the two raters, an intraclass correlation coefficient (ICC) analysis was conducted using the absolute agreement method within a two-way mixed model. The correlation between content quality scales and video analytics was examined using Spearman's rank correlation coefficient. The Kruskal-Wallis test was employed to compare video analytics and content quality among different publishers.

### RESULTS

In the study, sixty videos were evaluated using the terms "lymphedema" and "lymphedema treatment". Out of the 120 videos assessed, 66 were excluded. More detailed information regarding video selection is presented in Figure 1.

A total of 54 YouTube videos were analyzed. Of these, 90.7% (n=49) were produced in the United States. It was observed that the majority of the examined videos were created by healthcare professionals. The descriptive characteristics of the examined videos are summarized in Table 1.

When the content of the examined videos was evaluated, it was observed that the majority of the

videos provided general information (27.8%). The distribution of video content was as depicted in Figure 2. Based on the content of the videos, no statistically significant difference was observed in the comparison of video analytics (p>0.05).

When the image quality of the examined videos was evaluated, it was found that 68.5% had high quality ( $\geq$ 720p). In these videos, information about lymphedema was mostly provided by healthcare professionals (physician 27.8%; lymphedema therapist 31.5%; physical therapist 5.6%). The video analytics and content quality scales are summarized in Table 2.

In the evaluation conducted based on the profession of those providing information in the videos, the video analytics were similar across groups. But differences were observed among groups in the scales used to determine the quality, reliability, understandability and actionability of the videos as patient education material. It was noted that scores were higher in videos where lymphedema specialists/therapists provided information (Table 3). When considering the specialties of the physicians, 11 were surgeons (47.8%), 9 were internal medicine specialists (39.1%), and only 3 (13%) were experts in lymphedema.



FIGURE 1: Information regarding video selection.

TABLE 1: Descriptive characteristics of videos.			
	n=54	%	
Country of origin			
USA	49	90.7	
Canada	1	1.9	
United Kingdom	2	3.7	
India	2	3.7	
Publisher			
Academic medical organizations	13	24.1	
Non-academic health care givers	27	50.0	
Others	14	25.9	
Uploaders			
University	8	14.8	
Medical academic organizations	5	9.3	
Private health institutions	14	25.9	
Private health professionals	13	24.1	
Lymphedema treatment manufacturers	6	11.1	
YouTube/TV channels	8	14.8	



FIGURE 2: Distribution of video contents; MLD: Manual Lymphatic Drainage.

<b>TABLE 2:</b> Characteristics of video analytics and content quality scales.			
Video analytics	Median (minimum-maximum)		
Video duration (seconds)	261.5 (80-1462)		
Number of likes	169.5 (0-33991)		
Number of dislikes	6 (0-1073)		
Like ratio (%)	96.6 (75.7-100.0)		
Number of comments	85.4 (0-1128)		
View rate (views/days)	11.5 (0.1-879.7)		
Video Power Index	11.1 (0.1-785.8)		
GQS	3 (1-5)		
JAMA benchmark criteria	2 (1-4)		
Modified DISCERN	2 (0-5)		
PEMAT-A/V understandability	63.6 (33.3-100)		
PEMAT-A/V actionability	0 (0-100)		

GQS: Global Quality Scale; JAMA: Journal of the American Medical Association; PEMAT-A/V: The Patient Education Materials Assessment Tool for Audio/Visual Materials. In the examination of the correlation between video analytics and quality scales, it was observed that certain video analytics correlate with quality scales (p<0.05). This relationship is summarized in Table 4. All content quality scales had high interrater ICC values (Table 5).

The median scores on the JAMA benchmark criteria and modified DISCERN were 2, indicating poor quality. Items not adequately covered included proper citation of sources and disclosure of conflicting interests (JAMA benchmark criteria), citing valid sources, providing additional references and addressing controversies, uncertainties (modified DIS-CERN) (Figure 3, Figure 4).

### DISCUSSION

In this investigation, a comprehensive analysis was undertaken on 54 YouTube videos in the English language, with the aim of evaluating their efficacy as informational resources for patients regarding lymphedema. The results indicated that a significant portion of the analyzed videos originated from healthcare institutions and academic entities. Although the visual quality of the videos generally met high standards, their viewership and popularity levels were relatively modest in comparison. In the evaluation conducted based on the profession of those providing information, the video analytics were similar across groups but differences were observed in the scales used to determine the quality, reliability, understandability, and actionability of the videos as patient education material. It was noted that scores were higher in videos where lymphedema specialists/therapists provided information. It was observed that the understandability and actionability of videos correlate with popularity and impact of the videos and also view rate, video duration, and image quality. The quality, flow, and relevance of information in the videos (GQS) were correlated with the popularity and impact of the videos and view rate. The JAMA benchmark criteria, which evaluate authorship, appropriate citation of sources, currency of information, and disclosure of conflicts of interest, were correlated with the like ratio and video duration.

In content prepared for patients, factors that demonstrate the value of these materials as patient

TABLE 3: Video analytics and content quality scales based on the profession of information providers.				
	Physician (n=23)	Lymphedema therapist (n=21)	Others (n=10)	p value
Video duration (seconds)	196 (83-1462)	379 (80-908)	193.5 (118-552)	0.037
Number of likes	88 (4-33991)	246 (0-6800)	222.5 (55-1700)	0.217
Number of dislikes	2 (0-1073)	10 (0-1021)	8.5 (0-47)	0.346
Like ratio (%)	99.1 (88.4-100)	98.6 (75.7-100)	97.2 (94-100)	0.589
View rate (views/days)	5.99 (0.1-879.7)	31.5 (0.6-757)	16.3 (6.4-50.1)	0.226
Video Power Index	5.6 (0.1-785.8)	46.1 (0.6-612)	16.0 (6.2-49.5)	0.162
GQS	2 (1-5)	4 (1-4)	2 (1-4)	0.006
JAMA benchmark criteria	2 (1-3)	2 (1-4)	1 (1-3)	0.012
Modified DISCERN	2 (0-3)	2 (1-5)	1.5 (0-3)	0.008
PEMAT-A/V understandability	60 (33.3-100)	80 (44.4-90.9)	63.6 (54.5-90.9)	0.024
PEMAT-A/V actionability	0 (0-100)	66.7 (0-100)	0 (0-66.7)	<0.001

Kruskal-Wallis; GQS: Global Quality Scale; JAMA: Journal of the American Medical Association; PEMAT-A/V: The Patient Education Materials Assessment Tool for Audio/Visual Materials.

<b>TABLE 4:</b> Correlation coefficients between content quality scores and video analytics.					
Video analytics	GQS	Modified DISCERN	JAMA Benchmark Criteria	PEMAT-A/V Understandability	PEMAT-A/V Actionability
VPI	0.333*	0.186	-0.21	0.308*	0.403**
View rate	0.359**	0.216	-0.038	0.332*	0.492**
Like ratio	0.033	-0.031	0.310*	-0.80	-0.103
Number of comments	0.265	0.233	0.049	0.199	0.403
Video duration	0.265	0.265	0.376**	0.402**	0.551**
Image quality	0.252	0.046	0.216	0.278*	0.360**

\*Spearman correlation coefficient with p<0.05; \*\*Spearman correlation coefficient with p<0.01; GQS: Global Quality Scale; JAMA: Journal of the American Medical Association; PEMAT-A/V: The patient education materials assessment tool for audiovisual materials; VPI: Video Power Index.

TABLE 5: Results of interrater ICC analyses of content quality scales.			
Content Quality Scale	ICC	95% CI	
GQS	0.933	0.869-0.963	
Modified DISCERN	0.878	0.737-0.938	
JAMA benchmark criteria	0.943	0.889-0.969	
PEMAT-A/V understandability	0.962	0.934-0.978	
PEMAT-A/V actionability	0.981	0.967-0.989	

ICC: Intraclass correlation coefficient; CI: Confidence interval; GQS: Global Quality Scale; JAMA: Journal of the American Medical Association; PEMAT-A/V: The patient education materials assessment tool for audiovisual materials.



FIGURE 3: Percentages of videos fulfilling individual items of JAMA benchmark criteria.

JAMA: Journal of the American Medical Association.

YouTube videos on lymphedema as patient education materials by focusing on their quality, understandability, and actionability. In the study conducted by Küçükakkaş and İnce, they investigated the value and reliability of YouTube videos by assessing them

education resources include understandability and actionability as least as much as quality. While there are limited studies evaluating YouTube videos on lymphedema, these studies do not assess the understandability and actionability of the videos as patient education materials.<sup>6</sup>To our knowledge, this study is the first study to investigate the suitability of



FIGURE 4: Percentages of videos fulfilling individual items of modified DISCERN questionnaire.

with GQS and modified DISCERN in lymphedema rehabilitation. Understandability and actionability of the videos were not evaluated in this study.<sup>6</sup> In this study, alongside patient education videos, educational videos for healthcare professionals, and commercials and promotional videos were also evaluated (with patient education-related videos comprising 57.8%). Additionally, the search terms used in the YouTube search were different from those in our study. Nevertheless, the GQS and modified DISCERN results were similar to our results. These findings suggest that the quality of YouTube videos related to lymphedema is not very high. Moreover, in our study, it was observed that videos where the information provider was a lymphedema therapist/expert had higher scores on the content quality scale. There could be several reasons for the lower content quality scale evaluations of videos where physicians provide information, which differs from the study by Küçükakkaş and İnce.<sup>6</sup> Firstly we included videos aimed at patient education, excluding video commercials and educational videos for healthcare providers. Additionally, in our study the information providers were primarily physicians specializing in surgery and internal medicine. The physicians uploaded videos on more specific topics related to their areas of expertise. Also, there were no videos produced by physical therapy and rehabilitation specialists or associations focusing on lymphedema. It was observed that there is a need for patient education videos uploaded by specialized experts in this field.

In our study, videos primarily consist of general information, patient experiences, and surgical con-

tent. Due to the use of search terms "lymphedema" and "lymphedema treatment", the number of videos addressing more specific treatment-related topics may be fewer than the numbers in the study by Küçükakkaş and İnce.<sup>6</sup> However, in a topic like lymphedema where the number of specialist healthcare personnel is often insufficient, it is expected that patients would initially search with more general terms to access information. Indeed, before commencing our study, we identified the most searched keywords worldwide in Google Trends over the past year and found that these 2 terms were much more commonly searched than the specific treatment-related terms.

Although the JAMA benchmark criteria and modified DISCERN score are commonly utilized in the literature for evaluating YouTube videos, deficiencies in specific items of these evaluations are often not specified.<sup>6-8,11</sup> In our study upon individual examination of the items in the modified DISCERN questionnaire and JAMA benchmark criteria, it was observed that there were deficiencies across the majority of videos in disclosing copyright information, referencing and citing sources, disclosing conflicts of interest, funding, sponsorship, advertising, support, and video ownership, providing additional resources, as well as indicating controversy and uncertainty. Ensuring that future uploaded videos do not repeat these shortcomings may enhance the quality of videos from a patient education perspective.

There are studies in the literature demonstrating the correlation between video duration and content quality metrics.<sup>7,8,11</sup> In our study, consistent with the literature, we found an association between video duration and JAMA benchmark criteria. Furthermore, it was observed that video duration positively affected understandability and actionability. Considering the challenges of accessing expert healthcare personnel specializing in lymphedema, preparing videos of sufficient length to provide understandable and applicable practical information on self-care could be beneficial for patients. However, it is a known fact that on platforms like YouTube, when the video duration is excessively long, the number of viewers tends to decrease.<sup>13</sup> Therefore, videos that are easily understandable for patients, share necessary information, but do not excessively prolong the duration with distracting details, could be beneficial. There is a need for studies on video length optimization in patient education.

Our study was subject to several limitations that merit attention. Firstly, anonymity was maintained during the video search process to minimize user bias. Consequently, there is a possibility that individuals searching for the same keywords may encounter different videos compared to those included in our study, potentially affecting the generalizability of our findings. Our study was structured as a cross-sectional investigation due to the dynamic nature of YouTube's content, precluding the feasibility of longitudinal research. Although the GQS, modified DISCERN, and JAMA benchmark criteria are commonly utilized for evaluating video content quality, their definitive validity remains a matter of debate. To address this concern, we employed the PEMAT-A/V.

Our search terms were determined entirely in English. Therefore, videos prepared in Turkish language did not appear in our YouTube search results. Due to this language limitation, videos originating from Türkiye were not included in this analysis. This highlights how language barriers can affect access to digital health information and underscores the challenges encountered in accessing health information. It is evident that there is a need for comprehensive studies evaluating the quality and effectiveness of educational YouTube videos prepared in Turkish. Such studies can provide more detailed insights into accessing health information in digital environments for patients in countries like Türkiye. Therefore, future research should aim to collect more extensive data while considering language diversity, as this is crucial for assessing the availability and effectiveness of health information resources.

## CONCLUSION

The limited availability of professionals worldwide dedicated to providing health services for lymphedema often leads patients to seek information from alternative sources. In recent years, there has been an increasing reliance on YouTube videos for patient education purposes. The quality of YouTube videos, including their reliability, comprehensibility, and ability to motivate patients to take action, is of utmost importance. We believe that it is crucial for future YouTube videos on lymphedema to be prepared by experts or associations in the field. Furthermore, ensuring the quality and reliability of future uploads by paying attention to factors such as disclosing copyright information, referencing and citing sources, disclosing conflicts of interest, funding, sponsorship, advertising, support, and video ownership, providing additional resources, as well as indicating controversial and uncertain topics, would be beneficial.

#### Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

#### **Conflict of Interest**

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

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