

# The benefit of online education in twin-to-twin transfusion syndrome: could it be an eye-opening platform?

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#### Abstract

**Objective:** This study intends to objectively review the quality and reliability of laser photocoagulation for twin-to-twin transfusion syndrome (TTTS) videos on the YouTube<sup>®</sup> platform in terms of integrity and educational value for patients and medical professionals.

**Methods:** YouTube<sup>®</sup> (http://www.youtube.com) search was performed for videos pertaining to fetal laser surgery in TTTS, using the terms fetoscopic laser ablation or/and fetoscopic laser surgery or/and fetoscopic laser twin-to-twin transfusion syndrome. A total of 42 videos were analyzed. Video sources were categorized as follows: INDIVIDUAL, ACADEMIC INSTITUTION, and COMMER-CIAL. Source of videos, time since upload (days), total duration of videos (seconds), total views, and likes were recorded. Video power index (VPI) was used to report video popularity. Educational quality and integrity were reviewed using the DISCERN, JAMA, GQS, and a novel YouTube<sup>®</sup> TTTS content - integrity score (TTTS-IS).

**Results:** The mean duration was 336.43±351.8 seconds, and the total views were 172.076±82.6. Surgical risks were stated only in 33% of videos, and the success rate of surgery was mentioned in 35%. In all groups, the median value of DISCERN scores is 32.50, 42, and 26, which refers to poor, fair, and very poor quality, respectively. Videos uploaded by an academic institution had statistically insignificant DISCERN and JAMA scores along with lower GQS and TTTS-IS (p>0.05). In regards to the video source, academic institutions were prominent (47.6%), and the most popularized videos were conducted by commercial websites and individuals related to VPI. The VPI was poorly correlated with all scoring systems. Negative correlations were detected between total views and JAMA scores and positive correlations were determined with the GQS and TTTS-IS.

**Conclusion:** Despite having VPI score highly in each group, YouTube<sup>®</sup> provides low-quality videos regarding fetal laser surgery of TTTS. There is an urgent need to regulate the context of those videos according to medical guidelines.

**Keywords:** Twin-to-twin transfusion syndrome, fetal laser photocoagulation, online education.

# Özet: İkizden ikize transfüzyon sendromu üzerine çevrimiçi eğitimin yararları: Ufuk açıcı bir platform olabilir mi?

Amaç: Bu çalışma, hastalar ve tıp uzmanları için doğruluk ve eğitim değeri bakımından YouTube<sup>®</sup> platformundaki ikizden ikize transfüzyon sendromu (TTTS) videoları için lazer fotokoagülasyonun kalitesini ve güvenilirliğini objektif şekilde incelemeyi amaçlamaktadır.

Yöntem: TTTS'de fetal lazer cerrahisi ile ilgili videolar için fetoskopik lazer ablasyon ve/veya fetoskopik lazer cerrahisi ve/veya fetoskopik lazer ikizden ikize transfüzyon sendromu terimleri kullanılarak YouTube<sup>®</sup> (http://www.youtube.com) platformunda arama yapıldı. Toplam 42 video analiz edildi. Video kaynakları şu kategorilere ayrıldı: KİŞİ-SEL, AKADEMİK KURULUŞ ve TİCARİ. Video kaynakları, yükleme tarihinden itibaren geçen zaman (gün), videoların toplam süresi (saniye), toplam izleme sayısı ve beğeni sayısı kaydedildi. Video popülerliğini raporlamak için video güç indeksi (VPI) kullanıldı. DISCERN, JAMA, GQS ve yeni bir YouTube<sup>®</sup> TTTS içeriği - doğruluk puanı (TTTS-IS) kullanılarak eğitsel kalite ve doğruluk değerlendirildi.

**Bulgular:** Videoların ortalama süresi 336.43±351.8 saniye, toplam izleme sayısı ise 172.076±82.6 idi. Cerrahi risklerden videoların yalnızca %33'ünde, cerrahi başarı oranından ise %35'inde bahsedildi. Tüm gruplarda DISCERN puanlarının medyan değerleri sırasıyla 32.50, 42 ve 26 olup, kötü, orta seviye ve çok kötü kalite anlamına gelmektedir. Akademik bir kuruluş tarafından yüklenen videolar, istatistiksel olarak anlamlı olmayan DISCERN ve JAMA puanlarına sahipken, daha düşük GQS ve TTTT-IS puanlarına sahipti (p>0.05). Video kaynağı bakımından akademik kuruluşlar belirgindi (%47.6) ve VPI ile ilgili olarak en popüler videolar ticari İnternet siteleri ve kişisel kullanıcılar tarafından oluşturulmuştu. VPI, tüm puanlama sistemleriyle zayıf şekilde koreleydi. Toplam izleme sayıları ve JAMA puanları arasında negatif korelasyonlar, GQS ve TTTS-IS ile pozitif korelasyonlar tespit edildi.

**Sonuç:** Her grupta oldukça yüksek VPI puanı olsa da, YouTube<sup>®</sup> TTTS için fetal lazer cerrahisi ile ilgili düşük kalitede videolar sunmaktadır. Bu tür videoların içeriğinin tibbi kılavuzlara göre düzenlenmesi konusunda acil bir ihtiyaç bulunmaktadır.

Anahtar sözcükler: İkizden ikize transfüzyon sendromu, fetal lazer fotokoagülasyon, çevrimiçi eğitim.

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# Introduction

Twin-to-twin transfusion syndrome (TTTS) impacts approximately 15% of every monochorionic diamniotic (MCDA) twin pregnancies.<sup>[1,2]</sup> It is defined by sonography detecting polyhydramnios in the recipient twin and oligohydramnios in the donor twin.<sup>[3]</sup> Based on the Quintero criteria, stages III and IV are the advanced stages which require interventional procedures. Briefly, stage III refers critically abnormal Doppler waveforms, and stage IV is described as hydrops fetalis in recipient twins.<sup>[4,5]</sup> The prognosis for untreated severe twin-totwin transfusion syndrome is a disastrous condition along with approximately 90 percent perinatal mortality and morbidity rates as well as high rates of neurologic complications.<sup>[6,7]</sup> As a result, various strategies have been developed, including selective fetal reduction, serial amnioreduction, and fetal laser surgery (FLS) in current treatment options.<sup>[2,5]</sup>

Current management approaches defined for TTTS are categorized into two parts: (1) Conservational methods (expectant management), (2) interventional methods (amnioreduction, septostomy, laser photocoagulation, selective fetal reduction). Today, laser photocoagulation of placental anastomoses is accepted by most perinatologists as the prime available approach for all stages except TTTS stage I in ongoing pregnancies less than 26 weeks.<sup>[1,2,6]</sup> Apart from this, procedure-related fetal loss and severe neurological disability stand out as the main complication.<sup>[3,7]</sup> Comprehensive consulting should be provided to the pregnant women complicated by TTTS, including the natural progress of the disease, management plans, and risks along with benefits.

Fetoscopic laser surgery, also known as laser photocoagulation, is a unique procedure that aims to destroy placental vascular anastomoses responsible for intertwining blood shunting.<sup>[2,7,8]</sup> There is robust evidence that laser photocoagulation of placental anastomoses allows interruption of these shunting and improves neonatal survival and morbidity.<sup>[5,7]</sup> On the contrary, fetal interventions extend no direct medical advantages to the mother; therefore, maternal risks should be insignificant and tolerable related to ethical perspective.

Due to the complex nature of TTTS and limited treatment options, patients seek alternative information lines to mitigate this detrimental disease. Information concerning the safety of fetal surgery is essential for counseling and informed decision-making; nevertheless, robust data on maternal outcomes of fetal surgery are not satisfactory. Consequently, social networking platforms and other communication channels can play a crucial role in educating patients and addressing accessible resources.<sup>[9–15]</sup>

YouTube<sup>TM</sup> (YouTube<sup>®</sup>, San Bruno, CA, USA, 2005) is a popular online video sharing site with more than 2 billion users every month and over a billion hours of video views on a daily basis.<sup>[16]</sup> It broadcasts in 80 different languages in more than 100 countries. More than 70% of YouTube<sup>®</sup> views come from mobile devices; the number of YouTube users is almost one-third of the all Internet users.<sup>[17]</sup> Thus, the popularity of YouTube has reached an astonishing point among medical professionals and patients who have begun to opt for this easily accessible platform.

Given the tremendous popularity of YouTube, many patients state that information from the Internet encourages them to communicate with their doctors and helps them make health-related decisions. At the same time, studies show that almost half of them consult Internet resources before their physicians on healthrelated questions.<sup>[12,18-20]</sup> Consequently, physicians should provide counseling services by being aware of the quality and accuracy of their patients' information online.

Due to the increasing popularity of social media, there is an urgent need to validate the content of those interactive technologies. This study intends to evaluate the quality and reliability of fetoscopic laser treatment of TTTS videos on the YouTube platform regarding integrity, complexity, and educational value.

## Methods

On January 31st, 2020, a YouTube (http://www. youtube.com) search was performed for videos pertaining to fetal laser surgery in TTTS, using the terms fetoscopic laser ablation or/and fetoscopic laser surgery or/and fetoscopic laser twin-to-twin transfusion syndrome. Videos are classified using standard YouTube filters. Duplicates, non-English language, no presence of narratives, irrelevant contents that do not include words of 'fetal laser surgery' and 'TTTS' during the record were excluded from further analysis (**Fig. 1**).

A total of 237 videos were blindly and independently analyzed by two experienced obstetricians and gynecologists (S.M. and M.M.I.), and the average of the scores given by them was recorded. Videos were categorized into 3 groups related to upload sources: individual/non-profit organization (Group A, n=12), academic institution (Group B, n=20), and commercial (Group C, n=10). Nine out of 42 (21%) videos targeted medical professionals as an audience.

The quality of the data was appraised with the DIS-CERN score, the Global Quality Scale (GOS), and the Journal of the American Medical Association (JAMA) score.<sup>[15,21,22]</sup> The DISCERN includes sixteen questions scored from 1 to 5 and total scores ranging between 6 to 80, with a higher score reflective of superior quality. The GQS uses a 5-point scale (1 to 5) to rate the overall quality of the video, based on the value of the information and how useful the reviewer thought the particular video would be to a patient (Table 1). One point was scored to represent low quality (most of the information is missing, not useful for viewers at all) and 5 points to high quality (beneficial for viewers). The JAMA score assesses the character of information regarding authorship, attribution, disclosure, and currency. One point is granted for available criteria, outcoming in scores from 0 to 4, with a higher score indicating superior quality. However, there is no specific scoring system based on fetal laser surgery in TTTS to evaluate the quality of videos. Furthermore, there is no tool to assess the diagnostic, educational, and surgical information in particular. On this occasion, we have developed a new scoring system, YouTube® TTTSvideo content integrity score (TTTS-IS), which evaluates the educational quality and reliability of video content for fetal laser surgery based on standardized criteria; sufficient technical information about the procedure, patient selection criteria, alternative treatment options, risks of the procedure, surgical success rates, and information with regard to potential complications. (Table 2). Objective measurement criteria were

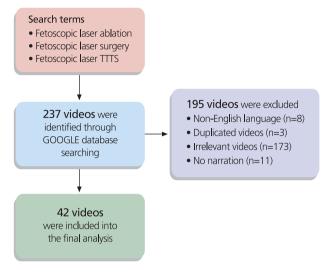


Fig. 1. Study flow diagram.

created by introducing a scoring system of 1 for each standard, with a total score of 10. TTTS-IS was categorized as excellent (9–10), good (7–8), fair (5–6), poor (3–4), and very poor (1–2).

Video characteristics including duration of time since uploading (days), total length in seconds, total amount of views, likes, dislikes, number of comments, and VPI (like × 100 / [like + dislike]) were recorded.

This study was exempted from IRB (Institutional Review Board) approval, as it only included the use of open access data for all. Therefore, the current study does not require the informed consent of participants.

#### Statistical analysis

Statistical calculations were carried out using SPSS version 25 (IBM Corp., Armonk, NY, USA). Categorical values were indicated as the frequency, whereas continuous data were given as the mean, median, standard

Criterion	Points
Poor quality, poor flow of the video, most information missing, not at all useful for patients	1
Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients	2
Moderate quality, suboptimal flow, some vital information is adequately discussed but others poorly discussed, somewhat useful for patients	3
Good quality and generally good flow. Most of the relevant information is listed, but some topics not covered, useful for patients	4
Excellent quality and flow, very useful for patients	5

Table 2. YouTube® TTTS-video content integrity score (TTTS-IS).

Criteria	Points
1.Sufficient information about the details of the surgical procedure	1
2. Patient selection criteria	1
3. Alternative treatment options	1
4. Risks of the procedure	1
5. Surgical success rate	1
6. Quintero or stage classification	1
7. Cervical length	1
8. Selective fetal reduction	1
9. Laser videos (Solomon or sequential laser)	1
10. Neurological injury risks	1

deviation, and interquartile range. The Shapiro-Wilk test was chosen to evaluate the normal sequence and Levene's test for variance homogeneity. To assess the relationships between quantitative variables, the Spearman correlation test was used. Quantitative variables were compared using the Mann-Whitney U test for two groups and the Kruskal-Wallis with the Dunn-Bonferroni post-hoc test to the intergroup analysis of non-normally distributed data. Inter-observer agreement was determined with Cohen's kappa score (≤0 no agreement, 0.01-0.20 slightly, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 substantial, 0.81-1.00 excellent). Correlation was categorized as poor (0.00-0.20), fair (0.21-0.40), moderate (0.41-0.60), good (0.61-0.80), or excellent (0.81-1.00). The threshold for significance was accepted p<0.05.

# Results

Regarding fetal laser surgery in TTTS, a total of 42 videos were evaluated in the final analysis. According to the DISCERN score, 8 (19%) videos were excellent, 3 (7%) were good, 6 (14%) were fair, 12 (29%) were poor, and 13 (31%) very poor. Based on the TTTS-IS scores, 3 (7%) videos were excellent, 3 (7%) videos were good, 3 (7%) videos were fair, 8 (19%) videos were poor, and 25 (60%) videos were poor quality. The vast majority of videos were 720p resolution (31%) (median value 720p, range 240p–1080p). The oldest video included was uploaded in 2009.

The par of total views per video was  $172.076 \pm 82.6$ , with a total overall view count of 7,227,221. The average number of likes and dislikes per video is 341.55 and 70,

	Mean	Minimum	Maximum	Standard deviation
DISCERN	40.29	16.00	80.00	19.40
JAMA	2.33	.00	4.00	1.20
GQS	1.95	1.00	4.00	1.08
TTTS-IS	3.42	.00	10.00	2.76
Duration (minutes)	336.43	50.00	1964.00	351.80
Likes	341.55	.00	8900.00	1480.20
Dislikes	70.00	.00	2150.00	347.60
Total views	172.076	89.00	5,065,924.00	82.6
Total number of comments	5.20	0.00	143.00	22.20
VPI	89.56	.00	100.00	25.90
Time since upload (days)	2011.54	335.00	4380.00	1152.60

Table 3. Video characteristics.

Plus-minus values are means ± SD. GQS: Global Quality Scale; TTTS-IS: YouTube® twin-to-twin transfusion syndrome-video content integrity score; VPI: video power index.

Scoring systems	Individual (n=12)	Academic institution (n=20)	Commercial (n=10)	p-value
DISCERN	32.50 (16.00-80.00; 53.00)	42.00 (19.00-68.00; 25.00)	26.00 (16.00–77.00; 15.00)	.115
JAMA	2.00 (.00-4.00; 3.00)	3.00 (1.00-4.00; 2.00)	1.50 (.00–4.00; 1.00)	.093
GQS	2.00 (1.00-4.00; 1.75)	1.00 (1.00-4.00; 1.25)	2.00 (1.00-4.00; 2.25)	.879
TTTS-IS	3.00 (.00–10.00; 2.00)	2.00 (.00v8.00; 2.50)	2.00 (.00–10.00; 4.50)	.944
VPI	95.87 (.00–100.00; 10.63)	100.00 (.00–100.00; 7.95)	100.00 (84.16–100.00; 5.21)	.582

Table 4. Comparison of scores among the video source groups.

Kruskal-Wallis test is presented as median (min-max; interquartile range). GQS: Global Quality Scale; TTTS-IS: YouTube® twin-to-twin transfusion syndrome-video content integrity score; VPI: video power index.

respectively. The mean total duration of videos in seconds was 336.43. A detailed descriptive analysis of 42 videos is shown in **Table 3**.

Due to the Global Quality Scale, the average score was 1.9524 out of 5. In all groups (A, B, C), the median value of DISCERN scores is 32.50, 42, and 26, which refers to poor, fair, and very poor quality in order. DIS-CERN scores between videos uploaded by Group A, B, and C were statistically insignificant (p=0.115). Moreover, no significant difference was detected among those groups according to the TTTS-IS score (p=0.944). A comparison of scores is presented in **Table 4**.

The DISCERN positively correlated with JAMA (p<0.001), whereas negatively correlated with GQS and TTTS-IS (p=0.028 and p=0.093, respectively). Furthermore, a remarkable association emerged between TTTS-IS and GQS (rho= 0.866, p<0.001). Even though there were negative correlations of VPI, total duration of videos, and total views with DIS-CERN and JAMA scores, a positive correlation was detected with GQS and TTTS-IS scores. **Table 5** summarizes the correlation among DISCERN, JAMA, GQS, VPI, and TTTS-IS scoring systems.

The inter-observer reliability (Kappa coefficient of agreement) was found at 0.89 (p<0.001) for the DIS-CERN scoring and 0.96 (p<0.0001) for the TTTS-IS. External validation was not formally assessed as there is no accepted criterion standard for YouTube video quality.

#### Discussion

This study intends to compare the educational and informative value of YouTube on laser photocoagulation, the current treatment option in TTTS, according to the well-known scoring systems in the literature. Our findings indicate no significant difference between the groups despite the use of various scoring scales. Moreover, we found a statistically significant correlation between a novel scoring system (TTTS-IS) developed by us and a well-known classical scoring system (GQS) widely accepted worldwide. This is the first study to evaluate the role of YouTube, video-based web platform, in surgical obstetrics and introduce a new scoring system that might provide a novel perspective on the patient-physician relationship.

	DISCERN (p; rho)	JAMA (p; rho)	GQS (p; rho)	TTTS-IS (p; rho)
DISCERN	-	.000; .734	.028;.343	.093; .266
JAMA	.000; .734;	-	.550;.097	.930; .140
GQS	.028; .340	.550; .097	-	.000; .866
TTTS-IS	.093; .266	.930; .014	.000; .866	-
Total views	.149;.230	.659 ;072	.000; .863	.000; .901
VPI	.755;050	.180; .216	.009;405	.006;421
Total duration in seconds	.057; .299	.126; .246	.798; .041	.909; .018

Table 5. Correlations of different scoring systems.

GQS: Global Quality Scale; p; rho: p-value; Spearman's rho; TTTS-IS: YouTube® twin-to-twin transfusion syndrome-video content integrity score; VPI: video power index.

Given the abovementioned criteria, the reliability and quality of videos on a broad-based platform such as YouTube that can provide content in many languages will be tremendously important shortly to improve communication between patients and medical professionals.<sup>[9,18,23-25]</sup> According to the research by Lagan et al., 83% of pregnant women mentioned the importance of Internet-based information as one of their decisionmaking processes.<sup>[24]</sup> When Yuksel et al. analyzed the health concerns of pregnant women and their difficulties in obtaining accurate information during the COVID-19 pandemic, they showed that videos with incorrect content could cause more concern.<sup>[18]</sup> In our study, the majority of videos were uploaded by academic institutions followed by personal users; however, our findings show that the quality of the fetal laser videos of TTTS was substantially below average, and the educational content was profoundly lack of scientific facts, including patient selection criteria, surgical risks, alternative options and so forth. Accordingly, surgical risks were stated only in 33 percent of videos, and the success rate of surgery was pointed at 35 percent of them. Furthermore, Stage classification, which is still the most up-to-date parameter in determining treatment, was mentioned in 37 percent of them.

For this reason, the necessity of information provided on online platforms to be clear, informative, and scientifically proven comes to the fore in the cybernetic era.

Many studies have shown that high-quality videos take a longer duration; nevertheless, our research found that the DISCERN and JAMA scores, which are the quality indexes, are also lower for videos that last longer.<sup>[10,26]</sup> VPI score is another parameter to evaluate the popularity of videos. The median value was significantly greater for videos in which the video upload source was categorized as an academic institution and commercial.<sup>[17,27]</sup> Notwithstanding, analysis of these data points out a negative or poor correlation between VPI and other scoring systems. This means lower quality and reliability among YouTube videos. Therefore, this situation can lead to detrimental consequences, especially in the field of obstetric.

According to actual statistics, 95% of the global Internet population watches YouTube.<sup>[16]</sup> Unfortunately, the absence of a control mechanism triggers an utmost uncertainty regarding the reliability, accuracy, and appropriateness of those video sources.<sup>[17,23]</sup> Our newly developed scoring system (TTTS-IS) shows a negative correlation with VPI, whereas it indicates a significant correlation with a total number of views (rho=0.903, p<0.001). As a matter of fact, laser photocoagulation can only be performed in the tertiary centers for a robust infrastructure. In doing so, it could be seen as an expected situation that the videos coming from these centers have a high viewing rate regardless of the quality.

Until now, the quality and value of videos addressing fetal laser surgery for TTTS as a patient-centered resource have not been explored in the literature. Apart from this specific point, indeed, there are some limitations in our study. First, the major concern is the dynamic structure of YouTube which emerges totally different results depending on the time-based search. Second, content quality scoring could not be assessed standardized due to a lack of consensus among Internetbased videos.

# Conclusion

Given the above, the content of videos should be independently evaluated and standardized by international professional organizations while increasing the number of videos uploaded by academic institutions on social media sites such as YouTube. Incomplete or inaccurate information may expose patients to unscientific treatments and cause severe damage to the physician-patient relationship. Therefore, there is an imperative requirement to critically analyze the quality of YouTube's health-related videos in the field of high-risk pregnancies.

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**Compliance with Ethical Standards:** The authors stated that the standards regarding research and publication ethics, the Personal Data Protection Law and the copyright regulations applicable to intellectual and artistic works are complied with and there is no conflict of interest.

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