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ORIGINAL ARTICLE

Are Youtube Videos a Useful Source of Information on Avoidant/Restrictive Food Intake Disorder?

Elif Akçay^{1,2} 💿 Büşra Bahadır¹ 💿

1 Ankara Bilkent City Hospital, Department of Child and Adolescent Psychiatry, Ankara, Türkiye

2 University of Health Sciences Türkiye, Gülhane Faculty of Medicine, Department of Child and Adolescent Psychiatry, Ankara, Türkiye

Abstract

Background: Social media platforms are widely used to share health information via videos. Avoidant/restrictive food intake disorder (ARFID) is a new eating disorder term that is one of the most searched topics online. This study aims to determine the quality and content of videos about ARFID on YouTube.

Methods: On May 6, 2024, the term "Avoidant/restrictive food intake disorder and/or ARFID" was searched on YouTube. The videos' quality was assessed using three scoring systems: DISCERN, Global Quality Score (GQS), and the Journal of the American Medical Association (JAMA). DISCERN scores defined the top 25% of videos as the most reliable and top-quality (Q1).

Results: Videos (N = 295) were assessed, and 192 videos met our inclusion criteria. The most common video topic was the symptoms and diagnoses of ARFID (64.6%). Videos associated with ARFID were fair to poor quality according to DISCERN (90.6%) and GQS (79.7%). 80.2% of the videos targeted patients, and they had lower quality scores than those targeting healthcare providers. 68.42% of videos for healthcare providers were high-quality (Q1), while only 14.29% of videos targeting patients were Q1. The GQS and JAMA scores showed a negative correlation with the viewer interaction scores of the videos.

Conclusions: Our findings underline the low quality of YouTube videos about ARFID. It is concerning to find that viewer interaction with the videos increases as video quality decreases. The present study highlights the risk of spreading poor-quality information via YouTube videos to the public, particularly patients.

Key words: avoidant/restrictive food intake disorder (ARFID), eating disorders, information seeking behavior, internet, health literacy



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INTRODUCTION

Avoidant/Restrictive Food Intake Disorder (ARFID) is an eating disorder that is characterized by avoidant/restrictive eating behaviors that lead to a failure to meet appropriate nutrient and/or energy needs, with consequent physical or psychosocial consequences (1). ARFID diagnosis emerged first in the DSM-5, which extends the DSM-IV diagnosis of feeding disorder in infancy or early childhood to any age and is also distinct from other eating disorders due to not being driven by concerns about shape or weight (2).

ARFID is a heterogeneous disorder due to three different presentations: selective/picky eating, lack of interest in eating, and fear of the aversive consequences of eating, such as vomiting or choking (1, 3). Although the DSM-5 provides detailed criteria and presentations for ARFID, its development and clinical features can vary significantly among individuals, resulting in diverse symptomatic profiles. These different ARFID profiles lead to uncertainties in clinical practice, treatment modalities, and clinicians' diagnostic difficulties (4). Moreover, professionals' knowledge and awareness of ARFID may impact the diagnosis and treatment approach (5). For example, a lack of experience differentiating ARFID from "normative picky eating" can lead to overdiagnosis (6). Clinicians who have not previously cared for pediatric ARFID report less confidence in clinical management than those who have cared for ARFID (5). This low experience and confidence in the clinical management of ARFID by healthcare professionals may lead clinicians to search for other information sources, such as the Internet, to gain more knowledge about ARFID approaches and therapies or patient experience. Besides healthcare providers, patients often use the Internet to access medical issues and information or share their own experiences about the illness. Notably, individuals with eating disorders (EDs) often prefer to deal with their difficulties on their own and look for support and information on the Internet (7).

The Internet has become a common platform for accessing medical information, with YouTube emerging as one of the most widely used websites in the world. This platform hosts a wealth of health-related content and videos that can be freely shared by individuals, including patients and healthcare professionals (8, 9). Although You-Tube is an effective platform for sharing useful medical information, the lack of a peer-review process can lead to the dissemination of misleading information. Indeed, the potential benefits of the videos and websites depend on their content and quality. Research on the quality and reliability of YouTube videos with various medical topics is increasing (10-15). In this regard, few studies evaluating social media content on eating disorders such as anorexia nervosa (AN), binge eating disorder (BED), and bulimia nervosa (BN) have shown heterogeneity in the quality of information (16-18). However, there is no research on the quality and content of YouTube videos related to ARFID. Accordingly, this study aims to (a) evaluate the characteristics (e.g., like ratio, daily viewing rate, popularity index, viewer interaction, target audience, upload source of videos, contents of videos) and quality of the YouTube videos about ARFID, and compare characteristics and quality of the videos between the target audience (healthcare providers and patients), (b) determine the associations of characteristics and quality levels of the videos.

MATERIALS AND METHODS

On May 6th, 2024, a search was conducted on the You-Tube website (http://www.youtube.com) using the keyword "Avoidant/restrictive food intake disorder and/ or ARFID". All videos in English, uploaded at any time, were eligible for analysis. Individual accounts were not used in the video search to avoid bias. The search resulted in 295 videos. Irrelevant videos (n=74), duplicates (n=7), short videos including playlists (n=14), and videos with a non-English language (n=8) were excluded (Supplemental Figure S1). The videos were independently evaluated in duplicate by two authors of the article (EA and BB), who are child and adolescent psychiatrists.

Data was collected for each video, including the URL, upload source, upload date, video length, number of views, likes, dislikes, and comments (see all URL addresses of YouTube videos in Supplementary material). The daily viewing rate (number of views divided by the number of days since upload) and viewer interaction [(number of likes-number of dislikes)/total number of viewsX100)] were calculated. The like ratio is defined as the like/ (like + dislike) percentage. Additionally, we calculated the video popularity index of the video (like ratio X viewing rate/100) (19). We also recorded the video sources (universities or professional societies, commercial organizations, websites providing health-related information, general educational websites, patient personal websites, and others) and target audience (healthcare providers, patients). We determined healthcare providers as the target audience if the video stated that it was intended for healthcare professionals in the video content or description or if medical terminology was frequently used with detailed explanations. Videos that focused on patients' awareness, knowledge, and behavioral approach regarding ARFID and directly appealed to individuals with ARFID identified their target audience as patients. Each video was evaluated for content information related to ARFID, including symptoms and diagnosis based on DSM-5, treatment, outcomes, comparison to other eating disorders, the patient's experience, therapist treatment session, patient education, and professional education.

We used three different scoring systems to evaluate the quality of medical videos. The first system we used was the DISCERN scoring system, which consists of 15 questions, each scored from 1 to 5 (20). This system classifies items as excellent (63-75 points), good (51-62 points), fair (39-50 points), poor (27-38 points) and very poor (15–26 points). This system is widely used for evaluating the reliability and quality of medical videos (8, 21). We also determined the quartile (Q) of the videos according to the DISCERN scores. The top 25% of videos were classified as the most reliable and top-quality videos (Q1), while the rest were classified as others (Q2-4). The second scoring system we used was the global quality score (GQS) system. This system was defined by Bernard et al. in 2007 and is used to assess the instructive aspects of a video (22). The overall quality of the video is evaluated between 1 and 5 points using this system, and it is commonly used to assess the quality of medical videos (9, 23, 24). The third scoring system we used was the Journal of the American Medical Association (JAMA) scoring system. This system was published by Silberg et al. in 1997 and consisted of four criteria, with one point awarded for each criterion, resulting in a total possible score of four points (25). The JAMA scoring system is frequently used to evaluate the reliability and quality of medical videos, and we used it to ensure consistency in our evaluations (21, 24). Assessment questions and criteria for all score systems (DISCERN, GAS, and JAMA) are presented in the Supplementary material.

Our study complied with the ethical principles of the Declaration of Helsinki. Since YouTube videos are publicly available and free of charge, no ethical approval was required.

Statistical analysis

The normality of variables was assessed using the Shapiro-Wilk test. Median (interquartile range-IQR) was used for continuous variables, and the Mann-Whitney U-test was used to compare continuous variables due to skewed distribution. Categorical variables were expressed as percentages, and Pearson's chi-squared and Fisher's exact analysis were used to compare categorical variables. Spearman's correlation coefficient was calculated to investigate the association among the continuous variables. Inter-rater reliability was assessed for the three scoring systems (JAMA, GQS, and DISCERN) using intra-class correlation estimates and their 95% confidence interval (intraclass correlation > 0.80 for all scoring systems). Intrarater reliability for categorical variables (e.g., target audience) was assessed using Cohen's kappa (k) coefficient. Kappa values were interpreted according to criteria defined by Landis and Koch (k coefficient > 0.90; almost perfect agreement) (26). Statistical significance was determined with p-values less than .05. The Statistical Package for Social Science (SPSS version 20.0, IBM Corp., Armonk, New York, USA) software was used for all analyses.

RESULTS

Of the 295 videos that were evaluated, 192 videos met our inclusion criteria. Thirty videos (15.6%) were closed for comments, while four videos (2.1%) were turned off to dislike and like by video sources on YouTube. The target audience of videos were 19.8% (n=38) healthcare providers and 80.2% (n=154) patients. The median duration of the videos was 425 (IQR=790) seconds and significantly higher for videos that targeted healthcare providers (p < 0.001). The number of views was higher for videos that targeted patients (p = 0.005). The median number of comments in the sample was 3 (IQR=26), and significantly higher for videos that targeted patients (Mdn=7) than the healthcare providers (Mdn=3), U = 2919, p <0.001. The median number of likes of the videos was 27 (IQR=138), and significantly higher for videos that targeted patients (Mdn=36) than the healthcare providers (Mdn=6), U =3871, p <0.001. Additionally, the videos targeted patients had more dislikes for their videos than the healthcare providers group, U = 3392, p=0.008. However, the like ratio and daily viewing rate of the videos were similar in the groups (p=0.063, p=0.101, respectively). Consid-

	Total,	Healthcare providers,	Patients,	Test sta-	<i>p</i> -value	
	<i>n</i> = 192	<i>n</i> = 38 (19.8%)	n= 154, (80.2%)	tistics		
Duration in seconds; median (IQR) ^a	425 (790)	3175 (3785)	343 (573)	1302	<0.001	
Views; median (IQR) ^a	1391.50 (6838)	398 (2371)	2114 (7326)	3786	0.005	
Number of days since upload	787.50 (1277.25)	403.50 (1131)	889 (1363.75)	3628.50	0.022	
Like ratio ^a	100 (2.21)	100 (0)	100 (2.56)	1576.50	0.063	
Daily viewing rate; median (IQR) ^a	2.19 (11.53)	1.22 (5.84)	2.52 (11.62) 2423		0.101	
Viewer interaction; median (IQR) ^a	1.88 (2.74)	1.37 (2.01)	1.98 (2.74)	3366.50	0.014	
Popularity index; median (IQR) ^a	2.83 (11.14)	1.55 (6.08)	3.07 (11.36)	1660	0.123	
Video sources; <i>n</i> (%)						
Commercial organization ^s	42 (21.9)	8 (21.1)	34 (22.1)	34 (22.1) 0.019		
University or society	15 (7.8)	12 (31.6)	3 (1.9)	-	<0.001	
Health-related websites	74 (38.5)	16 (42.1)	58 (37.7)	0.335	0.562	
General educational websites	10 (5.2)	1 (2.6)	9 (5.8)	-	0.690	
Patient personal websites	41 (21.4)	0	41 (26.6)	12.86	<0.001	
News channel ^s	10 (5.2)	1 (2.6)	9 (5.8)	_	0.690	

Note: IQR: Interquartile range; a: Mann Whitney U; b: Pearson Chi-Square; c: Fisher's Exact Test; Like ratio: like/ (like + dislike) percentage; video popularity index: (like ratio X viewing rate/100); the daily viewing rate (number of views divided by the number of days since upload); viewer interaction [(number of likes-number of dislikes)/total number of viewsX100)]

ering the video sources, we found that they consisted of health-related websites (n=74, 38.5%), commercial organizations (n=42, 21.9%), patient personal websites (n=41, 21.4%), the university or society (n=15, 7.8%), general educational websites (n=10, 5.2%), news channel (n=10, 5.2%). The characteristics of the videos and comparisons between two target audience groups (healthcare providers vs. patients) are summarized in Table 1.

YouTube video contents are summarized in Table 2. Symptoms and diagnosis of ARFID were mentioned in 64.6% of the videos, and its rate was higher in videos that targeted healthcare providers. Treatment and outcomes of ARFID were mentioned in 38.5% and 42.7% of the total videos, respectively. Videos targeting healthcare providers had more content about ARFID treatment (78.9%) and outcomes (73.7%) (both p values <0.001). Comparison to other eating disorders (e.g., anorexia nervosa, bulimia nervosa, binge eating disorder) and differences from picky eating were mentioned more frequently in videos targeting healthcare providers than those targeting patients (p<0.001, p=0.002, respectively). However, videos targeting patients presented the patients' experiences more than those targeting healthcare providers (28.6% vs. 13.2%), p=0.050). Regarding the video presenters, psychologists (26%) were the most frequent, followed by patients (22.4%) and therapists (11.5%). However, the percentage of psychiatrists (5.2%), dietitians (4.7%), and medical doctors (3.6%) as presenters in YouTube videos was low. The presenters of 16.7% of videos consisted of other health providers (nurses, social workers, family coaches, life coaches, documentary producers, and announcers), and 9.9% were unknown presenters.

	Total,	Healthcare providers,	Patients,	χ2	<i>p</i> -value
	<i>n</i> = 192	<i>n</i> = 38 (19.8%)	n=154~(80.2%)		
ARFID symptoms and diagnosis; $n (\%)^a$	124 (64.6%)	34 (89.5%)	90 (58.4%)	12.83	<0.001
ARFID treatment; n (%) ^a	74 (38.5%)	30 (78.9%)	44 (28.6%)	32.65	<0.001
Outcomes of ARFID; $n (\%)^a$	82 (42.7%)	28 (73.7%)	54 (35.1%)	18.57	<0.001
Comparison to other EDs; $n (\%)^a$	64 (33.3%)	24 (63.2%)	40 (26.0%)	18.96	<0.001
Experience of the patient; n (%) ^a	49 (25.5%)	5 (13.2%)	44 (28.6%)	3.81	0.050
Therapist session; n (%) ^b	7 (3.6%)	0 (0%)	7 (4.5%)	-	0.348
Case example; n (%) ^b	14 (7.3%)	11 (28.9%)	3 (1.9%)	-	<0.001
Exposure therapy; $n (\%)^{b}$	14 (7.3%)	0 (0%)	14 (9.1%)	-	0.076
Differences from picky eating; n (%) ^a	41 (21.4%)	15 (39.5%)	26 (16.9%)	9.26	0.002

	Total, <i>n</i> = 192	Healthcare providers, n= 38 (19.8%)	Patients, n= 154 (80.2%)	U statistics	p-value
DISCERN; median (IQR)	30 (12)	47 (17.25)	28 (8)	810.50	< 0.001
Very poor; <i>n</i> (%)	56 (29.2%)	3 (7.9%)	53 (34.4%)		
Poor; <i>n</i> (%)	91 (47.3%)	9 (23.7%)	82 (53.2%)		
Fair; <i>n</i> (%)	27 (14.1%)	10 (26.3%)	17 (11.0%)		
Good; <i>n</i> (%)	17 (8.9%)	15 (39.5%)	2 (1.3%)		
Excellent; n (%)	1 (0.5%)	1 (2.6%)	0 (0%)		
GQS; median (IQR)	2 (1)	4 (2)	2 (1)	1288.50	< 0.001
Poor; <i>n</i> (%)	8 (4.2%)	3 (7.9%)	5 (3.2%)		
Generally poor; <i>n</i> (%)	93 (48.4%)	5 (13.2%)	88 (57.1%)		
Moderate; n (%)	52 (27.1%)	5 (13.2%)	47 (30.5%)		
Good; <i>n</i> (%)	23 (12%)	12 (31.6%)	11 (7.1%)		
Excellent; n (%)	16 (8.3%)	13 (34.2%)	3 (1.9%)		<u></u>
JAMA; median (IQR)	2 (0)	2 (1)	2 (0)	1843	< 0.001

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Duration of videos	1	002	.083	.029	.027	.065	078	.574***	.641***	.116
2. Comments		1	.824***	597***	.659***	.667***	.255**	076	049	125
3. Views			1	647***	.700***	.778***	.030	.050	.109	.023
4. Like ratio				1	347***	436***	.234**	.030	.051	.026
5. Popularity index					1	.961***	028	.068	.096	.031
6. Daily viewing rate						1	.151*	.109	.127	.031
7.Viewer interaction							1	133	167*	310***
8. DISCERN								1	.737***	.357***
9. GQS									1	.238***
10. JAMA										1

The DISCERN, GQS, and JAMA scores of the videos were significantly higher for the videos targeting healthcare providers than those targeting patients (all p values < 0.001; see Table 3). While the DISCERN had a strong correlation with GQS (r=0.737, p < 0.001), the DISCERN and GQS scores had a weak correlation with the JAMA score (r=0.357, p < 0.001; r=0.238, p < 0.001). The GQS and JAMA scores negatively correlated with the viewer interaction scores (r=-0.167, p = 0.022; r=-0.310, p < 0.001, respectively), while they had no associations with other features of the videos (comments, views, like ratio, popularity index, daily viewing rate).



Figure 1: Distribution of target audience according to DISCERN quartile of the videos (Left panel); distribution of DISCERN quartile according to video upload sources (Right panel)

The DISCERN and GQS scores had positively moderate correlations with the duration of the videos (r=0.574, p =0.022; r=0.641, p < 0.001, respectively). The association between quality scores and the features of the videos are summarised in Table 4. According to the DISCERN score, 22.92% of the videos in Q1 were obtained from the university or society, while the other video sources were as follows in order of frequency: health-related websites (45.83%), commercial organizations (18.75%), patient personal websites (10.42%) and news channel (2.08%). While 68.42% of the videos prepared for the healthcare providers were among the Q1, only 14.29% of the videos targeted the patients were among the Q1. The distribution of the DISCERN quartile according to the target audience and video sources is illustrated in Figure 1.

DISCUSSION

Social media platforms are widely used for sharing health information with the public. One prominent form of social media is YouTube, a popular platform offering people free and unlimited access. However, the quality of the information in shared videos is critical for help-seeking patients due to the lack of a peer-review process. Our results showed that most YouTube videos associated with ARFID had fair to poor quality according to both DISCERN (90.6%) and GQS (79.7%). The primary upload sources of moderate-poor quality (Q2-4) videos were health-related websites (36%) and patient personal websites (25%). We found that all personal patient website videos targeted patients as the audience. Our findings suggest that these low-quality videos can risk spreading misinformation to the public, particularly patients.

In our study, most YouTube videos about ARFID (80.2%) targeted patients, and the quality of those videos was lower than those that targeted healthcare providers. While more than half of the videos prepared for the healthcare providers were among the high-quality (Q1), only 14.29% of the videos targeted the patients belonged to this top quality. This was expected because a significant proportion of videos were from the websites of ARFID patients. Moreover, videos targeting patients had fewer sources from universities or society compared to those targeting healthcare providers. Similar to our findings, the quality of the videos targeting patients was poor in videos related to various medical topics (8, 21). Even though the quality of these videos was low, their viewer interaction

was higher than videos that targeted healthcare providers. With high viewer interaction and poor quality, these patient-targeted videos indicate the risk of spreading false and inaccurate information about ARFID. While the popularity of videos does not directly indicate the quality of the content, prior evidence has demonstrated that online crowding can lead healthcare consumers to make unsafe healthcare decisions (27, 28). Individuals who are not confident in their answers to health questions are 28.5% more likely to be influenced to change their views when provided with online social feedback from other people (27). Also, it was concerning to find that as video quality decreases, viewer interaction with the videos increases, suggesting that viewers cannot realize high-quality videos on social media. Our findings align with studies that have shown that patients can be receptive to false information on YouTube videos based on the discrepancy between the quality of videos and interaction parameters (8). Healthcare providers should be aware of the deceptive nature of social media videos and the potential for patients to be exposed to misinformation about ARFID. They should direct patients to accurate online resources during face-to-face meetings.

Regarding the content of the videos, 58.4% of YouTube videos that targeted patients focused on ARFID symptoms and diagnosis. The heterogeneous presentations of ARFID may have contributed to a larger number of videos about its symptoms and diagnosis. It is a new diagnosis introduced in the DSM-5 eating disorder category as an umbrella term to encompass a range of feeding problems previously described in ICD-10 and DSM-IV (29, 30). Diagnostic challenges may arise due to the ambiguous definition of ARFID, as current criteria do not clearly define weight and nutritional symptoms or psychosocial impairment (6). These diagnostic challenges may have increased the sharing of videos by health-related websites or commercial organizations to inform patients about ARFID. Regarding the video presenters, psychologists (26%) were the most frequent, followed by patients (22.4%) and therapists (11.5%). However, medical doctors, including pediatricians and psychiatrists, were less common as presenters. The first point of contact for ARFID patients is usually the family doctor or general pediatrician since it is typically identified in children and young people who experience significant eating difficulties, usually between 2 and 6 years of age (31). The low rate of video sharing by medical doctors

about ARFID may be related to low awareness of the diagnosis of ARFID.

Moreover, videos targeting healthcare providers contained more information about ARFID symptoms, diagnosis, treatment, outcomes, comparison to other eating disorders, and differences from picky eating compared to videos targeting patients. Our findings suggest a tendency to share these differential diagnostic issues of ARFID among healthcare providers. The classification of diagnoses is mainly targeted at clinicians, and an element of clinical judgment is required when making a diagnosis (4). Some confusion exists amongst clinicians as to whether the experience of psychosocial impairment alone is sufficient to diagnose ARFID or whether people must also meet other criteria related to unmet energy or food needs (5). Uncertainties in diagnostic issues of ARFID may contribute to greater information sharing via YouTube videos to healthcare providers.

Contrary to the findings above, YouTube videos can be used as an advantage for patients seeking information about patient experience. Our results showed that 25.5% of the videos presented patients' experiences, and most of those targeted the patients as the audience. Recent studies have confirmed low help-seeking rates for eating problems among individuals with EDs (32, 33). There are several barriers to seeking help for EDs, including concern for others, self-sufficiency, fear of losing control, denial and failure to perceive the severity of the illness, and stigma and shame. (32). In the context of barriers to help-seeking, social media posts can raise awareness about the disease among patients, serving as the first step in seeking help. Social media platforms provide a relevant avenue for young women with eating disorders to communicate and exchange ideas related to the disease and health (34). Additionally, evidence suggests that help-seeking behavior is strongly associated with one's mental health literacy (35). Social media, such as videos, can help overcome traditional barriers (e.g., reading and/or writing skills) to health literacy by making information more accessible and engaging (28). However, using social media safely requires new e-health literacy skills. Our findings underlined that videos with shorter duration or higher viewer interaction index seem to be associated with lower quality. Healthcare providers should know how to access high-quality information on social media to guide people with eating disorders on e-health literacy in the digital platform.

This study had some limitations. YouTube is a dynamic social media platform whose content is continuously updated. Our study design was cross-sectional, so it only provides information for a specific point in time. We only assessed the videos published on YouTube, so the findings may not apply to other social media platforms. However, we analyzed all YouTube videos related to ARFID rather than a specific number of videos based on keywords. Also, we did not assess the reliability and validity of the scoring systems. However, we utilized three different scoring systems widely used to evaluate medical videos and found strong correlations between them in our study. Additionally, two child and adolescent psychiatrists independently assessed the quality of the videos using three objective scoring systems.

Considering the high rate of video sharing targeting patients, the quality and content of these videos are critical for individuals with EDs. In addition to receiving information about ARFID diagnosis and its results, sharing patient experiences is particularly prevalent in videos targeting patients. Also, it was concerning to find that as video quality decreases, viewer interaction with the videos increases, suggesting that viewers watch the video on social media regardless of their quality. Additionally, the videos targeting healthcare providers include more content on the differential diagnosis of ARFID, which may reflect uncertainties regarding diagnostic issues of ARFID and low confidence among professionals. Creating high-quality educational videos that bring healthcare professionals and patients together in the future would be beneficial for providing accurate information about ARFID.

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Abbreviations list

AN: Anorexia nervosa ARFID: Avoidant/restrictive food intake disorder BED: Binge eating disorder BN: Bulimia nervosa GQS: Global Quality Score DSM: Diagnostic and Statistical Manual of Mental Disorders EDs: Eating disorders JAMA: Journal of the American Medical Association

Ethics approval and consent to participate

Our study complied with the ethical principles of the Declaration of Helsinki. Since YouTube videos are publicly available and free of charge, no ethical approval was required.

Consent for publication

There is no data regarding any individual in this research.

Availability of data and materials

Data available on request from the authors.

Competing interests

The author(s) declare no competing interests.

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Authors' contributions

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