


Evaluation of Youtube™ Videos That are Informative on ‘How to Use Subcutaneous Immunoglobulin?’

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ABSTRACT

Objective: In recent years, YouTube™, a social platform, has become a source used to access health-related information, but there are concerns about the accuracy and quality of the information in the content. In this study, we aimed to evaluate videos related to the use of subcutaneous immunoglobulin (SCIG) in terms of content, quality, understandability, and applicability.

Materials and Methods: On 06.02.2024, the keyword “How to use subcutaneous immunoglobulin” was typed into the YouTube™ (<http://www.youtube.com>) search bar in English and Turkish. Out of 101 videos, 31 (30:English, 1:Turkish) met the evaluation criteria. The videos were evaluated using the Modified DISCERN (mDISCERN), Global Quality Scale (GQS) and Patient Education Materials Assessment Tool (PEMAT-A/V). In addition, the steps of SCIG use were examined.

Results: A total of 30 English video recordings were evaluated in our study. The median mDISCERN score of the video content was 4 (range 1-5), the GQS score was 4 (range 2-5), and the PEMAT/A and PEMAT/V percentages were 85% (range 25-100) and 100% (range 33-100), respectively. The content was found to be 73.3% understandable. The median mDISCERN score ($p=0.006$), GQS score ($p=0.004$), and PEMAT/A percentage ($p=0.025$) of the videos uploaded by healthcare institutions were significantly higher than those of the videos uploaded by other content producers. Additionally, a positive correlation was found between video duration and mDISCERN score ($r=0.459$, $p=0.011$), GQS score ($r=0.406$, $p=0.026$), and PEMAT/A percentage ($r=0.401$, $p=0.028$). Three of the videos’ contents included all SCIG usage steps. Only one of the videos in Turkish was about SCIG use.

Conclusion: There was a lack of SCIG use steps in the accessible video content. We believe that there is a need for videos that include complete usage steps by non-profit academic institutions and health professionals who are experts in this field regarding SCIG usage in our country and around the world.

Keywords: Subcutaneous immunoglobulin, Youtube, education

INTRODUCTION

Inborn errors of immunity (IEI), also known as primary immunodeficiency (PID), is a rare and heterogeneous group of disorders resulting from defects in various components of the immune system. To date, more than 485 different genetic mutations have been identified (1). Depending on the affected immune component, these conditions can lead to infections and/or non-infectious conditions such as autoimmunity, malignancy, and allergies (2). The infections associated with IEI are chronic, recurrent, and potentially life-threatening (3,4). Immunoglobulin

(Ig) replacement therapy (IGRT) is considered the standard of care for preventing infections in patients with IEI who have impaired antibody production and function (5,6).

The variety of products and routes of administration available for IGRT today allows physicians to collaborate with their patients to find the most appropriate treatment (6). Currently, IGRT can be administered either as intravenous Ig (IVIG) or subcutaneous Ig (SCIG) (5). Compared to IVIG, SCIG treatment has several advantages: it does not require venous access, is less time-consuming, can be

self-administered at home, provides more stable IgG concentrations, improves quality of life, reduces healthcare costs, and causes fewer systemic adverse reactions (6-13). However, SCIG can cause transient (24-hour), mild, local inflammatory symptoms at infusion sites, and SCIG (except for hyaluronidase-enhanced SCIG) requires more frequent (usually weekly or biweekly) administration and a greater number of infusion sites than IVIG (6,8,14).

The internet and social media, which have become an inseparable part of daily life, have become frequently used sources of information for individuals with chronic diseases and their relatives to access health information (15,16). Among social media, YouTube has a high usage rate for health information with approximately 2.5 billion users (16,17). YouTube allows its users to upload, watch, share videos, and share information quickly, making it a very important tool for sharing information (17). However, the lack of a robust content control mechanism and the platform's extensive access and rapid interaction capabilities have led to concerns about the accuracy and quality of health information on YouTube (18-20).

Proper administration of SCIG can enhance patients' quality of life, but it is crucial to protect patients from potential side effects arising from incorrect usage. These side effects include injection site reactions, inadvertent intravenous administration, infections due to lack of aseptic techniques, and fears related to self-administration. Therefore, the accuracy of information in YouTube videos about SCIG administration is highly important. Our study aims to evaluate the quality, reliability, comprehensibil-

ity, and applicability of YouTube videos related to SCIG administration, alongside assessing the steps involved in SCIG application.

MATERIALS and METHODS

Study Design

For this study, a new YouTube membership account was created on 06.02.2024. The keyword "How to use subcutaneous immunoglobulin" was written in both Turkish and English in the YouTube™ (<http://www.youtube.com>) search bar. Research on users' video viewing habits on YouTube shows that more than 90% of users watch the content on the first three pages, and more than 95% watch the content on the first ten pages (18,21). For this reason, the first 101 videos were evaluated by us. Seventy videos were excluded due to repetitive content, patient experience, lack of relevance to SCIG use, and medical lectures (Figure 1). The content of 31 videos that met the evaluation criteria was reviewed and evaluated by two independent researchers with expertise in allergy and immunology, both of whom have experience in initiating and monitoring SCIG therapy in patients with PID. Thirty of the videos were in English and 1 was in Turkish, and statistical analysis was performed between the videos narrated in English (Figure 1). The modified DISCERN (mDISCERN) scale was used to assess the reliability and integrity of the information in the videos (18). We evaluated the accuracy of the information about the SCIG application in the videos according to the reviews of Kara and Somer and Kobrynski (22,23). The Global Quality Scale (GQS) was employed to evaluate

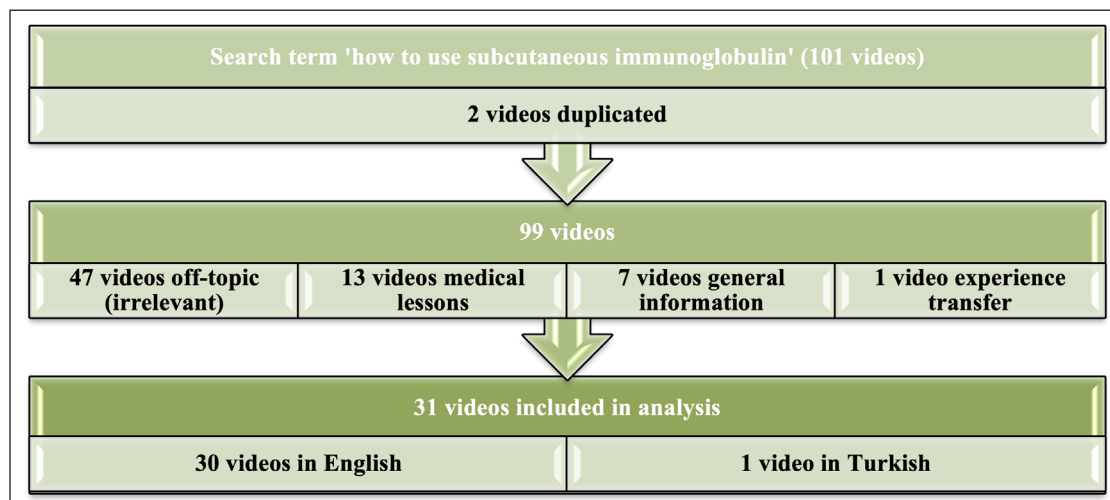


Figure 1. The algorithm of videos included along with the reasons for exclusion of all videos evaluated in the study.

and compare the quality of the videos (24). Patient Education Materials Evaluation Tool (PEMAT-A/V) scales was used to evaluate the understandability and applicability of the videos (21). The videos were reviewed simultaneously by both researchers, and a consensus was reached to assign scores according to the evaluation scales. In addition, the upload date of the videos, the time from upload to our evaluation (days), video duration (seconds), number of views, number of likes and dislikes, uploader category (1. Health institution/ health professional, 2. Pharmaceutical company, 3. TV/YouTube channel, 4. Patient association) and the application steps of SCIG usage were recorded. Since no human or animal data was used, and only publicly available YouTube videos were analyzed, no ethics committee approval was sought, in line with similar studies (19,20).

Steps of SCIG Administration

While watching the videos, it was noted whether they contained information about the main steps of SCIG administration as divided into three phases: pre-administration preparation, steps during administration, and post-administration considerations. The pre-administration preparation phase included notes on whether the following were observed: sterility (hand hygiene, sterile preparation of materials, cleaning of the application site, sterile opening or disinfecting of the drug's protective cap, and sterile opening of the butterfly needle), verification of drug characteristics (temperature, appearance, expiration date), verification of materials to be used (suitability of disinfectant, syringe, butterfly needle gauge/length, adhesive tape/bandage, preparation of application tools, cotton/gauze, and waste disposal container), and the drug preparation stages (drawing the immunoglobulin into the syringe, removing the syringe needle, attaching the butterfly catheter, and removing air). The steps during administration were recorded as providing information about subcutaneous injection (defining the injection site, fixing the needle with adhesive tape, checking whether there was blood, applying the drug if there was no blood), and whether the amount of drug applied and the duration of application were included. The post-administration steps were assessed based on whether they included recording the date and drug barcode on the application schedule, explaining local and systemic side effects, and disposing of used materials as medical waste (25).

Scoring System

The mDISCERN scale was developed to assess the integrity and reliability of information presented in visual media. The mDISCERN scale is scored from 0 to 5 based on the answers to the questions asked, with higher scores indicating higher reliability of the information presented in the video (18). To evaluate the quality of the videos, the Global Quality Scale (GQS), which ranges from 1 to 5, was utilized. In the GQS, a score of 1-2 indicates low quality, a score of 3 indicates medium quality, and a score of 4-5 indicates high quality (24). The PEMAT-A/V, developed to evaluate the comprehensibility and applicability of content in audiovisual materials, was used in this study (21). The PEMAT-A/V consists of 13+4 items: 13 items assess the processing and explanation of the basic messages for the comprehensibility of the videos, and 4 items evaluate what patients can do in an information-oriented manner for the applicability of the videos (21). After calculating the scores for all items and obtaining percentages, the higher the percentage, the greater the comprehensibility or applicability of the video. In our study, the content of the videos was classified as comprehensible and applicable if the average scores on each scale were above 70% (21,26).

Statistical Analysis

All data in the study were analyzed using the SPSS (Statistical Package for the Social Sciences) software, version 28. Descriptive statistics were presented as frequency and percentage for categorical variables, and as median (minimum-maximum) values for continuous variables. Independent group comparisons for categorical variables were performed using the χ^2 or Fisher's exact tests. The normality of distribution for continuous variables was assessed both visually (via histograms and probability plots) and analytically (using the Kolmogorov-Smirnov/Shapiro-Wilk tests). For non-normally distributed continuous variables, independent group comparisons were conducted using the Mann-Whitney U test. Correlations between two continuous variables, where at least one did not follow a normal distribution, were analyzed using the Spearman test. A Type-1 error level of less than 5% was considered statistically significant.

RESULTS

General Features of the Videos

Of the 31 videos included in our study, 30 were in English and 1 was in Turkish. Statistical analysis was performed among the 30 videos in English. The 30 videos in our study were uploaded by 26 different channels. Of the content producers, 13 (43.3%) were healthcare institutions, 13 (43.3%) were TV/YouTube channel, 3 (10%) were patient associations, and 1 (3.3%) was a pharmaceutical company. The upload date of the first uploaded video out of the 30 videos was 31.12.2010, and the date of the last uploaded video was 18.02.2023. The median upload date was 18.02.2020. The median duration of these videos was 960 (range: 169-4869) seconds, and the median time since upload was 51 (range: 16-164) months. The total number of views of the videos was 470443 and the median number of views was 4031 (range: 131-136955). The median like value of the videos from the viewers was 31 (range: 0-5200). Comments were disabled for 4 of the videos. The number of comments for the video with comments open ranged from 0 to 321, with a median comment count of 3. There was 1 video published in Turkish in our study and the publication date was 21.03.2020. The number of views of the video was 306, its duration was 378 seconds, and the number of likes was 12. The video uploader was a TV/YouTube channel.

Evaluation of Steps Associated with SCIG Administration

Three of the video contents included all SCIG usage steps. Five of the video contents included all preparation steps before administration, six of them included all steps related to administration, and seven of them included all steps after administration. When we evaluated the pre-administration steps one by one, 9 of the video contents included information on sterility, nine on drug properties, 18 on materials to be used, and 17 on drug preparation stages. When we evaluated the administration steps separately, nine of the video contents included information on subcutaneous injection, while 11 videos included information on the amount of drug applied and duration of administration. In terms of post-administration steps, nine videos provided information on recording the date and drug barcode on the administration schedule, while most of the videos (22 videos) discussed local and systemic side effects. Ten videos emphasized the disposal of the materials used as medical waste. The SCIG administration steps included in the content of the videos are shown in Table I.

Scoring System Results

The median mDISCERN score of the videos was 4 (range: 1-5). One video had an mDISCERN score of 1, two videos had a mDISCERN score of 2, four videos had

Table I: Evaluation of the Steps Associated with SCIG Administration in the Video Content.

Steps of SCIG Administration	Number of Videos Containing Relevant Steps			
	Healthcare Institutions	TV/YouTube Channel	Patient Associations	Pharmaceutical Company
Pre-Administration Preparation				
Sterility	6	2	-	1
Verification of drug characteristics	3	5	-	1
Verification of materials to be used	7	9	1	1
The drug preparation stages	6	9	1	1
During Administration				
Subcutaneous injection information	4	5	-	-
Drug administration phase	5	4	1	1
Post-Administration Considerations				
Drug record (date and barcode)	4	4	-	1
Local and systemic side effects	10	9	2	1
Medical waste information	5	4	-	1
All Application Steps	2	1	-	-

an mDISCERN score of 3, 13 videos had an mDISCERN score of 4, and 10 videos had an mDISCERN score of 5. The median GQS score of the videos was 4 (range: 2-5). Five videos were rated as low quality, five as medium quality, and 20 as high quality. The median PEMAT-A/V percentages for the videos were assessed as 85% (range: 25-100) for understandability and 100% (range: 33-100) for actionability. Upon evaluation of the PEMAT-A/V scores, it was found that 22 videos (73.3%) were understandable, while 17 videos (56.7%) were actionable. The understandability scores of the videos rated as understandable ranged from 70 to 100, while the actionability scores of the videos rated as actionable ranged from 75 to 100. There were seven videos with both understandability and actionability scores of 100, four of which were uploaded by healthcare institutions. Of the remaining three videos, one was uploaded by a TV/YouTube channel, one by a patient association, and one by a pharmaceutical company. In our study, the video published in Turkish had an mDiscern score of 4, a GQS score of 4 (high quality), and both PEMAT-A/V

percentages were 100%. The video was evaluated as understandable and applicable (Table II).

The median DISCERN score ($p=0.006$), GQS score ($p=0.004$), and PEMAT-A percentage ($p=0.025$) of the videos uploaded by healthcare institutions were found to be significantly higher compared to those uploaded by other content creators (Table II). On the other hand, the median DISCERN score ($p<0.001$), GQS score ($p=0.001$), and PEMAT A percentage ($p=0.001$) of the videos uploaded by TV/YouTube channels were significantly lower compared to the remaining video content (Figure 2). Additionally, a positive correlation was observed between video duration and mDISCERN score ($r=0.459$, $p=0.011$), GQS ($r=0.406$, $p=0.026$), and PEMAT-A percentage ($r=0.401$, $p=0.028$).

DISCUSSION

There are concerns about the quality, reliability, understandability and applicability of health-related information on social media and the internet. In our study, 'how

Table II: Score results of video content.

Video Language, n (%) Video uploader, n (%)	mDISCERN	GQS	PEMAT-A	PEMAT-V
English video; 30 (96.7%); p value	0.006	0.004	0.025	0.509
Healthcare institutions, 13 (43.3%)*	5 (3-5)	5 (3-5)	92 (63-100)	100 (33-100)
Other content creators, 17 (56.7%)*	4 (1-5)	4 (2-5)	72 (25-100)	67 867-100)
Turkish video, 1 (3.3%)				
TV/YouTube channel, 1 (100%)	4	4	100	100

Other content creators: TV/YouTube channel (13 (43.3%)), Patient associations (3 (10%)), Pharmaceutical company (1 (3.3%)); mDISCERN: modified DISCERN, GQS: Global Quality Scale, PEMAT-A/V: Patient Education Materials Evaluation Tool A/V, *: median (minimum-maximum)

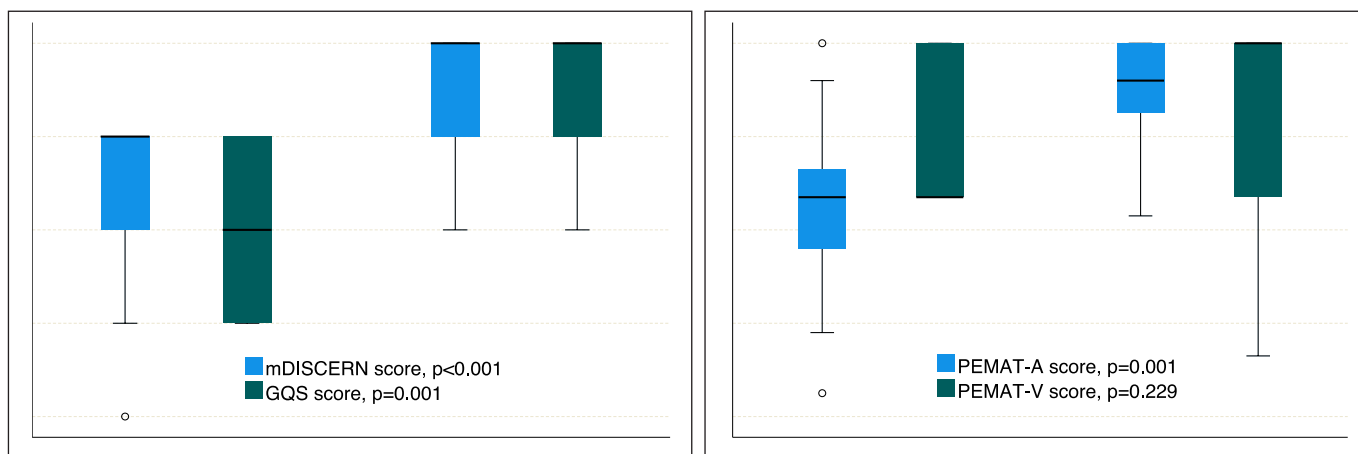


Figure 2. Scoring system comparisons of videos uploaded by TV/YouTube channels and other video uploaders.

to use subcutaneous immunoglobulin?’ was typed into the YouTube search bar on 06.02.2024 and 30 English videos were evaluated with video evaluation criteria. The median reliability, quality, and understandability percentage of the videos uploaded by health institutions were found to be significantly higher compared to videos uploaded by other content producers.

Today, it is known that the internet and social media are actively used for health information and practices. Anaphylaxis is a life-threatening disease with a prevalence as high as 2%, and in a recent study evaluating video content on the use of adrenaline autoinjectors, which are vital in its treatment, 112 video content was evaluated and the median number of video views was found to be 5538 (20,27). It is generally accepted that allergic rhinitis (AR) affects approximately 10% to 20% of the global population (28), and two different studies evaluated video content on YouTube regarding the steps of intranasal steroid use for AR treatment, and included 33 and 26 videos, respectively (29,30). The median number of views of the videos in the study, which included 26 videos, was found to be 10862,5 (30). The study, which evaluated the educational quality of asthma-related information on YouTube for asthma, which is estimated to affect 300 million people worldwide, included 200 videos and the median number of video views was found to be 18073,5 (31). Despite IEI being classified as a rare disease, our study evaluated 30 YouTube videos featuring the use of SCIG, with a median view count of 4031. This finding suggests that, compared to studies evaluating YouTube video content related to more common diseases, the number of videos analyzed in our study focused on rare disease treatment is satisfactory and indicates that IEI patients actively use YouTube in their search for health information.

Although YouTube is a popular social media platform for accessing health-related information, it may contain inaccurate, incomplete, and/or misleading content and can potentially pose a significant threat to patient health. In our study, while evaluating the video content related to SCIG administration steps, it was seen that very few videos (3 videos, 10%) covered all the necessary steps, revealing a significant lack of information in the video content on this subject (Table I). In particular, the missing steps in the implementation phase were: sterility, verification of drug characteristics, subcutaneous injection information, drug administration phase, drug record (date and barcode), and medical waste information. Similar studies

have shown that video content related to the use of inhaler therapy and intranasal steroids also provided inadequate information on proper medication administration, with the percentage of videos containing complete information being notably low (15%, and 7.7%, respectively) (30,31). In a study evaluating intranasal corticosteroid use videos uploaded by healthcare professionals and pharmaceutical companies, the rate of videos containing more than 75% of the steps was found to be 15% (29). In our study, 2 of 3 videos containing all steps and 4 of 8 videos containing more than 75% of the steps were uploaded by healthcare institutions. Considering the potential complications of improper SCIG use, our findings highlight an area for improvement in YouTube video content related to SCIG administration.

Various scales, such as the mDISCERN, GQS, PEMAT-A/V, have been developed to evaluate the content of videos on the internet and social media (18,21,24). The median mDISCERN score of the 30 videos evaluated in our study was 4, and most of the videos received incomplete scores because their content did not provide additional sources for information. The GQS assesses video quality by evaluating image quality, data flow speed, and information content. Although the videos in our study performed well in terms of image quality and flow speed, their GQS scores were particularly impacted by insufficient informational content. This finding aligns with the result of previous studies evaluating YouTube videos related to Alzheimer’s disease (19).

In our study and a recent study evaluating adrenaline autoinjectors, according to PEMAT-A/V evaluation, the median understandability value of the videos was 85 vs 60.4; the median actionability value was 100 vs 79.5; the understandable video rate was 73.3% (n=22) vs 22.4% (n=25); the actionable video rate was 56.7% (n=17) vs 54.4% (n=61), respectively (20). In this study, the authors compared their PEMAT-A/V values with other studies and explained their higher results with several different reasons despite using the same scale. One of these reasons is that the evaluation is done with a scale, but it has the potential to create a subjective effect, another reason is that the content and number of videos in the studies are different from each other, and another reason is to provide one-on-one training by healthcare personnel on the application to patients prescribed adrenaline autoinjectors (20). In our study, PEMAT-A/V evaluation results were found to be higher than the adrenaline autoinjector study.

We think that this finding draws attention to the high level of knowledge of the people who upload videos about SCIG use. It is essential for IEI patients to receive comprehensive, step-by-step training from an experienced healthcare professional before continuing SCIG treatment independently (8). After being approved by healthcare professionals that they can continue their treatment, patients continue to apply their treatment themselves. We think that this finding draws attention to the importance of providing detailed professional training on application while arranging treatment for patients.

Although there are studies showing that a large portion of those watching videos about health information are not interested in the source uploading the video, studies have found that videos from non-profit organizations and academic sources have the highest values for information (18,32). Similar to these studies, in our study, the median mDISCERN score ($p=0.006$), GQS score ($p=0.004$) and PEMAT-A percentage ($p=0.025$) of videos uploaded by health organizations were found to be significantly higher compared to videos uploaded by other content producers. Additionally, a positive correlation was observed between video duration and mDISCERN score ($r=0.459$, $p=0.011$), GQS ($r=0.406$, $p=0.026$) and PEMAT-A percentage ($r=0.401$, $p=0.028$). There are studies in the literature showing that as the duration of the video increases, its quality and reliability increase and the video content becomes richer, and this finding is also supported by our study (20,33).

Our study has several limitations. One limitation is that only YouTube among social media platforms was evaluated, and due to the dynamic nature of YouTube, where videos are frequently uploaded and removed, there is potential for the results to be influenced. Additionally, another limitation is that although we aimed to evaluate videos in Turkish, only one video was deemed suitable for inclusion. This highlights a significant lack of informative videos in Turkish. Furthermore, our study underscores the importance of video duration, in line with findings from existing literature. Another key finding of our study is the emphasis on the importance of professional education for patients regarding treatments. Lastly, our study points out the shortcomings in video content related to SCIG usage, particularly in the instructional steps, shedding light on areas that need improvement in future educational videos on SCIG administration.

Videos containing misinformation related to health have the potential to negatively impact patient health. While videos on SCIG administration can help patients overcome their fears of self-administration, incorrect or incomplete content may lead to adverse effects. In our study, we found that the video content on YouTube related to SCIG administration is particularly lacking in detailed information on the procedural steps, and there is also an insufficient number of videos available in Turkish. Therefore, we believe there is a critical need for video content that comprehensively covers all steps of the SCIG administration process, as well as for video content specifically prepared in Turkish. Additionally, whether related to SCIG or other health topics, we believe that videos should be created by non-profit organizations, professional medical associations, and academic institutions with sufficient expertise and experience in the field. These videos should be simple, fluent, understandable, and practical, targeted at patients and their caregivers, and supported by appropriate visual and auditory materials.

Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Authorship Contributions

Concept: **Makbule Seda Bayrak Durmaz, Nurgul Sevimli**, Design: **Makbule Seda Bayrak Durmaz**, Data collection or processing: **Makbule Seda Bayrak Durmaz, Nurgul Sevimli**, Analysis or Interpretation: **Makbule Seda Bayrak Durmaz, Nurgul Sevimli**, Literature search: **Makbule Seda Bayrak Durmaz**, Writing: **Makbule Seda Bayrak Durmaz, Nurgul Sevimli**, Approval: **Makbule Seda Bayrak Durmaz, Nurgul Sevimli**.

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