

Analysis of YouTube as a source of information for restless leg syndrome

Análise do YouTube como fonte de informação para a síndrome das pernas inquietas

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ABSTRACT

Background: YouTube is one of the major resources for health related videos around the world. **Objective:** The aim of this study was to evaluate the quality of information available on YouTube about restless leg syndrome (RLS). **Methods:** A YouTube search was carried out on <https://www.youtube.com> for videos pertaining to “restless leg syndrome” by using the keyword “restless leg syndrome”. The first 100 relevant videos were included in the study. The videos were accepted as “useful” if they provided scientifically correct information about any aspect of RLS. The videos containing scientifically unproven information are defined as “misleading”. The overall quality of all videos was subjectively graded using the global quality scale (GQS), a 5-point Likert scale. **Results:** The median video length for the included videos was 3.39 (0.11–85) minutes, and the median views were 6,055 (32–2351490). The median GQS of useful videos was 3 (1–5). The median number of likes and the median number of comments of personal experience videos were significantly higher than that of the useful and misleading videos. Videos uploaded by the university hospitals frequently issued pharmacological treatment of the RLS; however, those uploaded by practitioners, individual users, and TV or social media accounts were about the non-pharmacological treatment of the RLS. **Conclusions:** This study demonstrates that 77% of the videos uploaded on YouTube regarding RLS are in the useful category, whereas only 16 videos were providing misleading information. However, even videos in the useful category do not provide a full and complete description of the RLS.

Keywords: Restless Legs Syndrome; YouTube; Information.

RESUMO

Introdução: O YouTube é um dos principais recursos no mundo para vídeos relacionados à saúde. **Objetivo:** O objetivo deste estudo foi avaliar a qualidade das informações disponíveis no YouTube sobre a síndrome das pernas inquietas (SPI). **Métodos:** Realizou-se uma busca no YouTube (<https://www.youtube.com>) para vídeos pertencentes à ‘síndrome das pernas inquietas’ usando a palavra-chave ‘síndrome das pernas inquietas’. Os primeiros 100 vídeos relevantes foram incluídos no estudo. Foram aceitos como ‘úteis’ vídeos que fornecessem informações cientificamente corretas sobre qualquer aspecto da SPI. Os vídeos que contêm informações não comprovadas cientificamente são definidos como ‘enganosos’. A qualidade geral de todos os vídeos foi avaliada subjetivamente usando a escala de qualidade global (GQS), uma escala Likert de 5 pontos. **Resultados:** A duração média dos vídeos incluídos foi de 3,39 (0,11–85) minutos e as visualizações médias foram de 6.055 (32–2.351.490). A GQS média dos vídeos úteis foi 3 (1–5). O número médio de curtidas e o número médio de comentários de vídeos de experiências pessoais foram significativamente maiores do que os de vídeos úteis e enganosos. Vídeos enviados por hospitais universitários frequentemente divulgam tratamento farmacológico da SPI; no entanto, aqueles carregados por profissionais, usuários individuais e contas de TV ou mídia social eram sobre o tratamento não farmacológico da SPI. **Conclusões:** Este estudo demonstrou que 77% dos vídeos carregados no YouTube sobre a SPI estão na categoria útil, enquanto apenas 16 vídeos forneceram informações enganosas. No entanto, mesmo os vídeos na categoria útil não fornecem uma descrição extensa e completa da SPI.

Palavras-chave: Síndrome das Pernas Inquietas; YouTube; Informação.



INTRODUCTION

Restless leg syndrome (RLS) is characterized by an irresistible urge to move the legs in rest. Subjects with RLS frequently have poor sleep quality, disturbed daytime productivity, and

cognitive problems¹. About 5–10% of the general population are estimated to suffer from RLS². Given the significant morbidity caused by RLS, clinicians are expected to provide sufficient and satisfactory information to their patients regarding the etiology, pathogenesis and the treatments of this

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Conflict of interest: There is no conflict of interest to declare.

Authors' contributions: Concept: AA, MD.; Design: AA, MD, MUA; Supervision: AA, MD; Materials: AA, MD; Data collection and/or processing: AA, MD, MUA; Literature search: AA, MD; Writing: AA, MD.

Received on February 12, 2020; Received in its final form on March 25, 2020; Accepted on May 6, 2020.

disorder. However, many healthcare professionals do not have sufficient time to give the required information to their patients concerning RLS. Moreover, as a consequence of the considerable complexity and heterogeneity in the etiology, symptoms, signs, and treatment of the RLS, even clinicians may have misconceptions in the understanding of the etiology and treatment of the RLS, leading to the patients seeking for additional information from various sources.

The internet is currently the primary source for medical information³. YouTube is the third most visited internet property globally and one of the most popular source for internet-based medical information. YouTube allows easy and free access to numerous videos associated with any kind of disorder. However, since the videos are uploaded not only by health care providers or professionals but also by users with little or no curation, the accuracy of the medical content accessed through the YouTube is questionable. Previous studies on YouTube videos have revealed that one-third to one-half of the videos regarding type II diabetes, retinopathy of prematurity, peripheral neuropathy, and Parkinson's disease provide misleading information^{4,5,6,7}. More importantly, videos with misleading content are more popular than videos with reliable content⁷.

Currently, no study has evaluated the information on RLS disseminated by YouTube videos. The aim of this study was to assess the quality of information available on YouTube regarding the epidemiology, risk factors, examination, pathogenesis, and the treatment of RLS.

MATERIALS AND METHODS

Due to the fact that this study is an observational study and direct patient contact is lacking, the study was exempted from Institutional Review Board approval. Between December 10 and 16, 2019, a YouTube search was carried out on <https://www.youtube.com> for videos pertaining to "restless leg syndrome" by using the keyword "restless leg syndrome". The computer history and cookies were deleted before searching since they can affect the search results. Given that users rarely go beyond the first few pages of any search result, only videos from the first 10 pages (10 videos per page) were screened. Consequently, the first 100 videos for this keyword were included in the analyses. Videos that were not in English were excluded.

The videos were viewed independently by A.A. and M.U.A. Disagreements between the two raters were resolved by M.D. The videos were divided into three categories as follows: "useful" (contains scientifically accurate information regarding any aspect of RLS), "misleading" (contains information that is incorrect or scientifically unproven), or "patient experiences" (contains patients' personal experiences rather than medical information on RLS.)

The number of views, source of upload, video length, and the number of "likes" and "dislikes" were collected for each video on December 16, 2019. Upload source was classified

into university hospitals, private hospitals/clinics, practitioners, individual users, TV/social media, healthcare information websites, or advertisements. Each video was assessed for the presence or absence of information for three content domains: epidemiology/risk factors, pathogenesis, and treatment. Videos providing treatment content were assessed for the presence or absence of information for pharmacologic treatment, non-pharmacologic treatment, and surgical treatment. The overall quality of all videos was subjectively graded using the global quality scale (GQS), a 5-point Likert scale, based on the quality of information, the ease of use, and how useful the reviewer thought the video would be to a patient⁸.

Statistical analysis

All analyses were performed on SPSS v21 (SPSS Inc., Chicago, IL, USA). For the normality check, the Shapiro-Wilk test was used. Data are given as mean±standard deviation or median (minimum-maximum) for continuous variables with regard to the normality of distribution for quantitative variables and frequency (percentage) for categorical variables. Non-normally distributed variables were analyzed with Kruskal-Wallis test. Tamhan's T2 test was used for post hoc analysis of the non-normally distributed variables. Normally distributed variables were analyzed with one-way ANOVA test. Tukey test was used for *post hoc* analysis of the normally distributed variables. Pearson chi-square and Fisher's exact tests were used for the analysis of the categorical variables. P<0.05 was accepted as statistically significant result.

RESULTS

The first 100 videos from the first 10 pages (10 videos per page) were included in the analysis. The characteristics of the included videos are presented in Table 1. The median GQS of

Table 1. General features of the videos included in the study.

Upload source	n=100
University hospital, n (%)	9 (9%)
Private hospital/clinic, n (%)	11 (11%)
Practitioner, n (%)	18 (18%)
Individual user, n (%)	8 (8%)
TV/social media, n (%)	39 (39%)
Healthcare information website, n (%)	13 (13%)
Advertisement, n (%)	2 (2%)
Median views, n (min-max)	6055 (32-2351490)
Median length, minutes (min-max)	3.39 (0.11-85)
Median likes, n (min-max)	38.5 (0-6539)
Median dislikes, n (min-max)	3.5 (0-372)
Median number of comments, n (min-max)	7 (0-2160)

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Table 1. Continuation.

Categorization	
Useful, n (%)	77 (77%)
Misleading, n (%)	16 (16%)
Personal experience, n (%)	7 (7%)
Global Quality Scale score	
1, n (%)	9 (9%)
2, n (%)	26 (26%)
3, n (%)	24 (24%)
4, n (%)	11 (11%)
5, n (%)	30 (30%)
Content	
Epidemiology/risk factors, n (%)	21 (21 %)
Pathogenesis, n (%)	1 (1%)
Treatment, n (%)	34 (34%)
Epidemiology/risk factors+treatment, n (%)	35 (35%)
Pathogenesis+treatment, n (%)	3 (3%)
Epidemiology/risk factors + pathogenesis+treatment, n (%)	6 (6%)
Content of treatment videos	
Pharmacologic treatment, n (%)	17 (21.8%)
Non-pharmacologic treatment, n (%)	41 (52.6%)
Pharmacologic+non-pharmacologic treatment, n (%)	19 (24.4%)
Surgical treatment, n (%)	1 (1.3%)
Content of non-pharmacologic treatment videos	
Lifestyle changes, n (%)	8 (8%)
Yoga, n (%)	5 (5%)
Massage, n (%)	2 (2%)
Diet, n (%)	4 (4%)
Vitamin supplements, n (%)	8 (8%)
Radiofrequency, n (%)	1 (1%)
Acupuncture, n (%)	1 (1%)
Lifestyle changes+vitamin supplements, n (%)	9 (9%)
Device, n (%)	6 (6%)
Lifestyle changes+yoga+massage, n (%)	1 (1%)
Lifestyle changes+device+massage, n (%)	3 (3%)
Lifestyle changes+device+vitamin supplements, n (%)	2 (2%)
Aromatherapy, n (%)	3 (3%)
Kratom, n (%)	1 (1%)
Diet+vitamin supplements, n (%)	2 (2%)
Reiki, n (%)	2 (2%)
Lifestyle changes+massage+vitamin supplements, n (%)	1 (1%)
Anxiety treatment, n (%)	1 (1%)

useful videos was 3 (1–5). Of the videos, 39% were uploaded by TV/social media accounts, whereas 18% by practitioners, 11% by private hospital/clinic, and 9% by university hospitals. In addition, 13% of the videos were uploaded by health-care information websites, 2% were uploaded advertisement and 8% were uploaded by individual users. The median video length for the included videos was 3.39 (0.11–85) minutes, and the median views were 6,055 (32–2351490). Of all videos, 77% were classified as useful, 16% were deemed misleading, and 7% were personal experiences. The median GQS score of the useful videos were significantly higher than that of the misleading videos and patient experience videos [4 (1–5), 2 (1–3), and 1 (1–3), respectively, $p < 0.001$]. Of the videos, 78% were about the treatment options, and 83% of the treatment videos provided information regarding the non-pharmacological treatment options.

The median number of likes and the median number of the comments of personal experience videos were significantly higher than that of the useful and misleading videos. Almost all videos uploaded by university hospitals and private hospitals or clinics were useful. While 67% of the videos uploaded by practitioners were classified as useful, 33 of these videos were misleading. In addition, 82% of the videos uploaded by TV or social media accounts were also useful (Table 2). Table 3 demonstrates the content of the

Table 2. The analysis of the YouTube parameters according to uploader and usefulness.

	Useful n=77	Misleading n=16	Patient experience n=7	p-value
Median views, n (min–max)	6251 (32–1023420)	5758 (263–435871)	10694 (80–2351490)	0.775
Median length, minutes (min–max)	3.32 (0.20–85)	3.15 (0.11–58.41)	10.1 (3.01–14.51)	0.118
Median likes, n (min–max)	27 (0–2825)	32 (0–6539)	351 (70–814)	0.008
Median dislikes, n (min–max)	4 (0–372)	3 (0–210)	29 (0–160)*	0.159
Median number of comments, n (min–max)	5 (0–2160)	10 (0–1086)	190 (0–370)*	0.025
Upload source				
University hospital, n (%)	9 (11.7%)	0 (0%)	0 (0%)	<0.001
Private hospital/clinic, n (%)	10 (13%)	1 (6.3%)	0 (0%)	
Practitioner, n (%)	12 (15.6%)	6 (37.5%)	0 (0%)	
Individual user, n (%)	1 (1.3%)	1 (6.3%)	6 (85.7%)	

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Table 2. Continuation.

	Useful n=77	Misleading n=16	Patient experience n=7	p-value
TV/social media, n (%)	32 (41.6%)	6 (37.5%)	1 (14.3%)	
Healthcare information website, n (%)	12 (15.6%)	1 (6.3%)	0 (0%)	
Advertisement, n (%)	1 (1.3%)	1 (6.3%)	0 (0%)	

*p<0.05 in post hoc analysis when compared with the videos categorized as useful or misleading.

videos in the useful category according to the uploading source.

Table 4 shows the content of the videos regarding the treatment information in comparison with the uploading source. Videos uploaded by the university hospitals frequently issued pharmacological treatment of the RLS; however, those uploaded by practitioners, individual users, and TV or social media accounts were about the non-pharmacological treatment of the RLS. As shown in Table 5, lifestyle changes, yoga, vitamins supplements, and device treatment were the most common non-pharmacologic treatment issues.

Table 3. The contents of the videos in useful category according to the upload source.

	University hospital n=9	Private hospital/ clinic n=10	Practitioner n=12	Individual user n=1	TV/social media n=32	Healthcare information website n=12	Advertisement n=1	p-value
Epidemiology/risk factors, n (%)	1 (5.3%)	5 (26.3%)	1 (5.3%)	0 (0%)	7 (36.8%)	4 (21.4%)	1 (5.3%)	0.339
Treatment, n (%)	3 (15%)	1 (5%)	2 (10%)	1 (5%)	12 (60%)	1 (5%)	0 (0%)	
Epidemiology/risk factors+treatment, n (%)	1 (16.7%)	0 (0%)	2 (33.3%)	0 (0%)	2 (33.3%)	1 (16.7%)	0 (0%)	
Epidemiology/risk factors+pathogenesis+treatment, n (%)	4 (12.5%)	4 (12.5%)	7 (21.9%)	0 (0%)	11 (34.4%)	6 (18.8%)	0 (0%)	

Table 4. Contents of the videos regarding the treatment information in comparison with the upload source.

	University hospital n=9	Private hospital/ clinic n=10	Practitioner n=12	Individual user n=1	TV/social media n=32	Healthcare information website n=12	Advertisement n=1	p-value
Pharmacologic treatment, n (%)	7 (41.2%)	2 (11.8%)	1 (5.9%)	1 (5.9%)	6 (35.3%)	0 (0%)	0 (0%)	<0.001
Non-pharmacologic treatment, n (%)	0 (0%)	1 (2.4%)	9 (22%)	7 (17.1%)	20 (48.8%)	3 (7.3%)	1 (2.4%)	
Pharmacologic + non-pharmacologic treatment, n (%)	1 (5.3%)	2 (10.5%)	6 (31.6%)	0 (0%)	4 (21.1%)	6 (31.6%)	0 (0%)	
Surgical treatment, n (%)	0 (0%)	1 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	

Table 5. Comparison of the video contents regarding the non-pharmacologic treatment options with respect to the category.

	Useful n=77	Misleading n=16	Patient experience n=7	p-value
Lifestyle changes, n (%)	8 (100%)	0 (0%)	0 (0%)	<0.001
Yoga, n (%)	5 (100%)	0 (0%)	0 (0%)	
Massage, n (%)	2 (100%)	0 (0%)	0 (0%)	
Diet, n (%)	0 (0%)	2 (50%)	2 (50%)	
Vitamin supplements, n (%)	2 (25%)	4 (50%)	2 (25%)	
Radiofrequency, n (%)	0 (0%)	1 (100%)	0 (0%)	

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Table 5. Continuation.

	Useful n=77	Misleading n=16	Patient experience n=7	p-value
Acupuncture, n (%)	0 (0%)	1 (100%)	0 (0%)	
Lifestyle changes+vitamin supplements, n (%)	9 (100%)	0 (0%)	0 (0%)	
Device, n (%)	6 (100%)	0 (0%)	0 (0%)	
Lifestyle changes+yoga+massage, n (%)	1 (100%)	0 (0%)	0 (0%)	
Lifestyle changes+device+massage, n (%)	3 (100%)	0 (0%)	0 (0%)	
Lifestyle changes+device+vitamin supplements, n (%)	2 (100%)	0 (0%)	0 (0%)	
Aromatherapy, n (%)	0 (0%)	1 (33.3%)	2 (66.6%)	
Kratom n (%)	0 (0%)	1 (100%)	0 (0%)	
Diet+vitamin supplements, n (%)	2 (100%)	0 (0%)	0 (0%)	
Reiki, n (%)	1 (50%)	1 (50%)	0 (0%)	
Lifestyle changes+massage+vitamin supplements, n (%)	1 (100%)	0 (0%)	0 (0%)	
Anxiety treatment, n (%)	0 (0%)	1 (100%)	0 (0%)	

DISCUSSION

YouTube is the most viewed video broadcasting website worldwide. Following the registration, any individual has the opportunity to upload videos on YouTube™. The widespread use of YouTube makes it a perfect social media platform for direct consumer education and marketing. Consequently, YouTube has currently become a generous source of medical information for patients and their families^{9,10,11}. However, the content uploaded on YouTube does not necessarily undergo confirmation for accuracy. Thus, information on YouTube may not be reliable or accurate^{12,13,14}. Several studies have shown that the proportion of YouTube videos providing reliable information regarding type II diabetes, retinopathy of prematurity, peripheral neuropathy, and Parkinson’s disease vary from one-third to one-half^{4,5,6,7}.

The present study is the first to demonstrate the reliability of YouTube videos regarding the RLS. Videos posted by health-care providers are highly useful than those of non-healthcare professional users. Our findings demonstrate that 77% of the videos uploaded on YouTube regarding RLS were in useful category, whereas only 16 videos were providing misleading information. The median GQS score of the useful videos were significantly higher than that of the misleading videos and patient experience videos. However, useful videos were not comprehensive, and a complete description of the RLS by epidemiology, risk factors, pathogenesis evidence-based treatment of RLS indicates that vitamins C and E treatment are likely efficacious for the treatment of RLS, particularly in uremic patients¹⁵. Pneumatic compression devices and three weekly intradialytic cycling sessions have also regarded as likely efficacious in the non-pharmacological treatment of the RLS.

Of all videos, treatment options were discussed at 78%. About 78% of the videos discussing the treatment options of the RLS targeted non-pharmacological treatment options.

Lifestyle changes in combination with vitamin supplements, device treatment, and yoga were the most common discussed non-pharmacological treatment options in these videos. The revised guideline of MDS on treatment modalities, such as aromatherapy, yoga, and acupuncture, were also uploaded on YouTube.

An interesting finding of the present study is that YouTube videos categorized as “patient experience” seems to have a higher median view count, as well as the likes and comments, compared to the videos which are in the “useful” or “misleading” category. We speculate that patients’ own experience attracts more attention on YouTube compared to the reliable information provided by the health-care professionals. We suggest that the videos uploaded by healthcare services or professionals may improve their popularity on YouTube, not only providing reliable information but also attracting the patients’ attention.

The study has some limitations to be mentioned. First, the evaluation and categorization of the videos were subjective, although the agreement between two independent reviewers was fairly high. Second, only videos in English were included in this study. Third, the number of views, as well as the likes and comments, can be manipulated by any user. Finally, this study evaluated the medical information regarding RLS on YouTube at a single time point. Since the content of YouTube may change over time, our findings are peculiar to the time that the videos were evaluated. These results therefore need to be interpreted with caution.

CONCLUSION

Findings of the present study demonstrate that 77% of the videos uploaded on YouTube regarding RLS are in the useful category, whereas only 16% videos were providing

misleading information. However, even videos in the useful category do not provide a comprehensive and complete description of the RLS by epidemiology, risk factors, pathogenesis, and treatment. Given the high view counts and likes

of the videos categorized as “patient experience”, the videos uploaded by more credible sources such as hospitals, universities, and practitioners should aim to provide more attractive videos besides the reliable content.

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