

YouTube and Prolactinoma: Assessing the Impact on Patient Knowledge

YouTube e Prolactinoma: Avaliando o Impacto no Conhecimento do Paciente

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ABSTRACT

Purpose With the increasing access to the internet worldwide, in medicine, patients have been using this tool to look for treatment for some medical topics. In recent years, there have been several pieces of information on the internet regarding treatment options for Prolactinoma. This study is intended to analyze the pros and weaknesses of currently available videos on YouTube regarding treatment options for Prolactinoma.

Methods A YouTube search was conducted using the terms "prolactinoma treatment," "prolactinoma cure," "prolactinoma therapy," and "pituitary tumor treatment.". Videos were evaluated for the target audience, its source, the general descriptive statistics, and five areas of content; The DISCERN scoring system was used to assess the quality of videos.

Results Sixty-one videos met the inclusion criteria for further analysis. The majority (70.49%) were targeted toward the general population. In contrast, 26 videos (42.6%) were categorized as professional, and 18 (29.51%) were intended for Physicians. Of the 61 videos, 44 (72%) reviewed first-line treatment details, 6 (10%) included eligibility criteria, and 23 (38%) mentioned alternatives of treatment. Seven videos (11%) discussed the risks of surgery, and 17(28%) showed a surgical success rate.

Conclusion Only 6 of the 61 videos included all assessed categories (First-line treatment details, Alternatives of treatment, eligibility criteria for surgery, surgical risks, and success rate). This study highlights the flaws of YouTube videos regarding information about prolactinoma treatment. There is a need for additional research, randomized studies regarding YouTube content about Prolactinoma treatment, and the necessity of practice guidelines for patients.

Keywords Prolactinoma, DISCERN, GQS, YouTube, Treatment, Patient Education, Internet

RESUMO

Objetivo Com o crescente acesso à internet em todo o mundo, os pacientes têm utilizado essa ferramenta para buscar informações sobre diversos temas médicos. Nos últimos anos, houve um aumento de informações disponíveis na internet sobre opções de tratamento para prolactinoma. Este estudo tem como objetivo analisar os pontos positivos e as limitações dos vídeos disponíveis no YouTube sobre opções de tratamento para prolactinoma.

Métodos Foi realizada uma busca no YouTube utilizando os termos "tratamento de prolactinoma," "cura do prolactinoma," "terapia do prolactinoma" e "tratamento de tumor hipofisário." Os vídeos foram avaliados quanto ao público-alvo, origem, estatísticas gerais descritivas e cinco áreas de conteúdo. O sistema de pontuação DISCERN foi utilizado para avaliar a qualidade dos vídeos.

Resultados Sessenta e um vídeos atenderam aos critérios de inclusão para análise. A maioria (70,49%) era direcionada ao público geral. Em contrapartida, 26 vídeos (42,6%) foram categorizados como profissionais e 18 (29,51%) eram destinados a médicos. Dos 61 vídeos, 44 (72%) abordaram detalhes do tratamento de primeira linha, 6 (10%) incluíram critérios de elegibilidade e 23 (38%) mencionaram alternativas de tratamento. Sete vídeos (11%) discutiram os riscos da cirurgia e 17 (28%) apresentaram taxas de sucesso cirúrgico.

Conclusão Apenas 6 dos 61 vídeos incluíram todas as categorias avaliadas (detalhes do tratamento de primeira linha, alternativas de tratamento, critérios de elegibilidade para cirurgia, riscos cirúrgicos e taxa de sucesso). Este estudo destaca as falhas nos vídeos disponíveis no YouTube sobre o tratamento do prolactinoma. Há necessidade de pesquisas adicionais, estudos randomizados sobre o conteúdo do YouTube sobre o tratamento do prolactinoma e a criação de diretrizes práticas para os pacientes.

Palavras-chave Prolactinoma, DISCERN, GQS, YouTube, Tratamento, Educação de Pacientes, Internet

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INTRODUCTION

The Internet has become a very popular and massive resource, containing a large amount of information for patients interested in seeking health content. One of the main sources is videos, one of the strongest and most content-generating social networks today, which allows the visualization of moving images, sounds, and text, creating multisensory experiences that allow information to be transmitted more comprehensively, deeply, and effectively for many viewers. YouTube is the largest video access site in the world, with nearly 2.5 billion monthly users and more than 500 hours of video content every minute.¹ In the healthcare setting, it is used as educational dissemination for patients. That is why videos with an educational focus for patients who consult these platforms must be of high quality, avoiding errors or generating wrong ideas about their treatment.

Pituitary adenomas are benign tumors arising from the anterior pituitary (adenohypophysis) and account for 10-15% of non-metastatic tumors of the Central Nervous System (CNS).² Pituitary tumors are classified into functional (or secreting) and nonfunctional. The diagnosis of pituitary adenoma requires a careful history, examination, and measurement of hormone oversecretion of prolactin (PRL), Growth hormone (GH), gonadotrophins, ACTH (adrenocorticotrophic hormone), and thyrotropin. Most secreting adenomas are Prolactinomas (Prolactin-Secreting-Tumors) compromising around 50% and frequently occur among women aged 20 to 50.³ The over-secretion of Prolactin (PRL) can cause amenorrhea-galactorrhea syndrome, impotence in males, loss of libido, osteoporosis, and symptoms due to mass effect (bitemporal hemianopsia, obstructive hydrocephalus, compression of the cavernous sinus, and pituitary apoplexy).³

Once the diagnosis of hyperprolactinemia has been made, it is necessary to discard other causes of PRL elevations, such as hypothyroidism and pregnancy, among others.⁴ The next step is evaluating a tumor's presence with MRI (magnetic Resonance Imaging) and verifying its size. The treatment of prolactinomas aims to restore hormonal values and reduce tumor size. Most patients are treated with dopamine agonists (cabergoline and bromocriptine).⁴ Other therapeutic options include transsphenoidal surgery, craniotomy, and Radiotherapy.^{5,6}

Hence, although it is quite understandable that patients and their relatives are increasingly using online educational resources, the reliability of online educational resources is controversial. This platform enables the distribution of data to a broad audience, regardless of the source or quality of the information being shared; Therefore, this study intends to analyze the pros and weaknesses of currently available videos on YouTube regarding treatment options for Prolactinoma.

MATERIALS AND METHODS

As the study exclusively utilized publicly accessible videos and did not involve the participation of human subjects or animals, there was no requirement for ethics committee approval. Hence, this cross-sectional investigation was deemed exempt from ethical review.

Data collection

On March 04, 2023, a search was conducted on YouTube using four different sets of keywords: "prolactinoma treatment," "prolactinoma cure," "prolactinoma therapy," and "pituitary tumor treatment," "pituitary adenoma treatment." The search history was cleared before the search, and no user ID or password was provided. The investigation was conducted using the default method of sorting by relevance, and the first 30 videos from each search were recorded, resulting in a total of 150 videos. Based on empirical evidence that indicates most internet users tend to confine their browsing activity to the first few pages of search results, the adequacy of the number of videos selected from the search was determined.⁷

Video Selection

The scope of the review encompassed two distinct categories of videos: those presented in the English language and those that provided informative content on the treatment details, alternative treatment approaches, criteria for eligibility in surgical interventions, surgical risks, and success rates for managing prolactinomas. The screening process excluded videos that were either redundant or not germane to the subject matter under investigation, as well as those lacking narration in English. Duplicate videos were also carefully eliminated. Following the rigorous screening process, 61 videos were deemed suitable for further analysis.

Video Analysis

To ensure the accuracy of the assessment process, two authors were responsible for evaluating the collected videos. If either of the assessors had any concerns or uncertainties regarding a specific variable, they collaborated with the other author to establish a consensus and determine the variable.

The source of the video content was categorized based on three criteria: professional, personal, or other. A video was classified as professional if it originated from a verified hospital YouTube channel or featured the trademark of a recognized healthcare institution, such as

the Mayo Clinic or Barrow Neurological Institute. On the other hand, videos uploaded by personal YouTube accounts portraying patients' or family members' experiences were classified as personal. Lastly, videos that did not conform to the classification criteria were labeled as other.

The determination of the target audience was predicated upon defined parameters. Specifically, if the video content featured medical terminology without adequate layman's explanations or solely focused on surgical footage without accompanying discussion or explication, it was designated for medical professionals. In contrast, videos that did not meet those criteria were ascribed to the general public. The study collected descriptive statistics on the video length, number of comments, view count, likes and dislikes, subscribers, and referrers associated with the examined videos. The content of the videos was then evaluated based on the presence or absence of five specific criteria developed by the authors, which were deemed to be fundamental categories of information regarding prolactinoma treatment. The evaluation was conducted in a binary fashion, with each criterion either included or not included in the video content. These criteria were developed in a manner consistent with previous research studies that examined YouTube content⁸ and included the following components: 1) first-line treatment details, 2) Alternatives of treatment, 3) eligibility criteria for surgery, 4) surgical risks, and 5) success rate.

Reliability and Quality Scoring Systems

The DISCERN scoring system was employed to evaluate the quality of video content based on its reliability and the efficacy of the information presented to patients regarding treatment options. This system facilitates an assessment of the video's comprehensive quality and the precision of the information conveyed, thereby contributing to a more robust and informed evaluation of the content in question.⁹ Consistent with the approach used by Paulina Sledzinska et al.,¹⁰ we present the composite DISCERN score as the summation of individual ratings for the initial 15 questions, each rated on a scale of 15 to 75. These scores are subsequently categorized into five discrete DISCERN groups, namely "excellent" (63-75 points), "good" (51-62 points), "fair" (39-50 points), "poor" (28-38 points), and "very poor" (15-27 points), respectively.

In addition, it is used The Global Quality Scale (GQS) to assess the overall quality of all selected videos categorizing information as useful and effective for patients. The GQS has five points: 1) Poor quality, poor flow of the site, most information missing, not at all useful for patients; 2) Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients; 3) Moderate quality, suboptimal flow, some important information is adequately discussed but others

poorly discussed, somewhat useful for patients; 4) Good quality and generally good flow, most of the relevant information is listed, but some topics not covered, useful for patients; and 5) Excellent quality and excellent flow, very useful for patients.¹¹

RESULTS

The study involved a comprehensive analysis of 150 videos about five specific keywords related to prolactinoma treatment. Forty-six duplicate videos were identified and subsequently removed during the initial screening process. Upon applying the pre-defined inclusion and exclusion criteria, 61 videos were deemed suitable for further analysis (Figure 1).

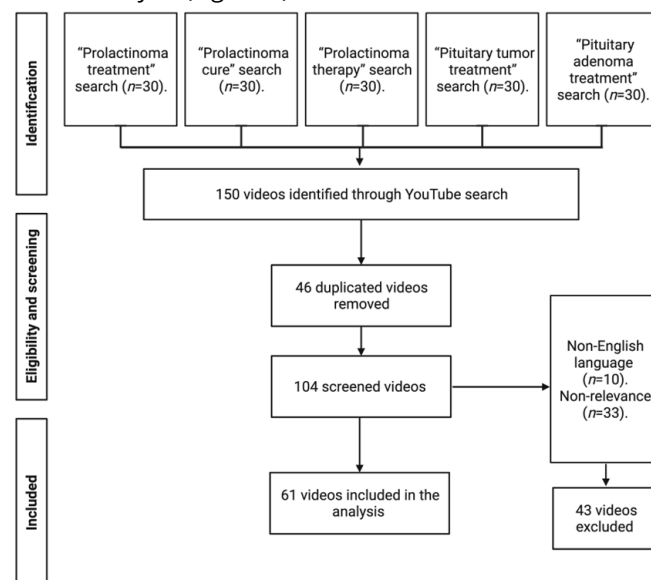


Figure 1 - The flow chart of video search.

Out of the 61 videos that were examined, it was found that only 26 videos (42.6%) were categorized as professional. Meanwhile, 18 videos (29.51%) were classified as "other," which came from different sources such as a charity organization, news source, publishing company, and an unknown YouTube user. The remaining 17 videos (27.87%) were personal videos created by patients. A significant proportion of the videos, specifically 70.49% (43 videos), were intended for the general population as opposed to medical professionals, which accounted for 29.51% (18 videos).

According to descriptive statistics on video source and target audience (Table 1), the videos varied in length, with the shortest being 1.24 minutes and the longest being 91.17 minutes. In comparison, the average length was 11.28 minutes. The average number of views for videos was 39,404.31, and the range of views varied widely, from 10 to 450,121. Statistical analysis showed that the average number of views differed significantly depending on the video category: professional videos had an average of

53,855.50 views, personal videos had an average of 22,414.29 views, and videos in the "other" category had an average of 29,933.67 views. This difference in averages was found to be statistically significant ($p=0.02$). Regarding the number of likes and dislikes, each video ranged from 1 to 4,073 likes and 0 to 139 dislikes, with an average of 444 likes and 12.74 dislikes. The number of subscribers per video ranged from 25 to 967,000, with an average of 75,623. Additionally, the number of referrers (i.e., links posted on the video description) ranged from 0 to 8, with an average of 1.49. Lastly, the number of comments per video ranged from 2 to 897, with an average of 109.51, except for five videos where the content creator disabled comments.

Table 1 - Descriptive statistics based on the source of video content and the intended audience.

Video source	Number of videos (n=61)	M* length (min)	M* number of views	M* number of comments	M* number of Likes	M* number of Dislikes	M* number of subscribers	M* number of referrers
Professional	26 (42.62%)	13.01	53,855.50 [†]	91	494	15.54	93,231.42	1.69
Personal	17 (27.87%)	12.40	22,414.29 [†]	160.06	385.29	10.12	9,211.94	1.59
Other	18 (29.51%)	12.66	29,933.67 [†]	73.71	389.11	9.78	95,140.24	1.17
Target audience								
General public	43 (70.49%)	13.35	32,358.56	128.59	459.02	14.28	74,958.14	1.51
Medical professionals	18 (29.51%)	10.42	42,353.70	63	408.33	9.06	77,306.29	1.44

* M Mean.

[†]Statistical significance ($p=0.02$)

Out of the 61 videos, only 6 (10%) included the five specific criteria developed by the authors, 44 (72%) reviewed first-line treatment details, 23 (38%) discussed alternatives of treatment, 19 (31%) mentioned eligibility criteria for surgery, 7 (11%) included surgical risks and 17 (28%) debated success rates (Table 2).

Table 2 - Content criteria met by video source.

Video source	Number of criteria met					Number of specific criteria met*				
	0/5	1/5	2/5	3/5	4/5	5/5	0/5	1/5	2/5	3/5
Professional (n=26)	2	6	4	6	2	6	2	24	13	7
Personal (n=17)	8	5	3	0	1	0	8	7	4	1
Other (n=18)	5	6	1	4	2	0	5	13	6	0
Total (n=61)	15	17	8	10	5	6	15	44	23	17

* Count of videos that satisfied a particular criterion among the five criteria devised by the authors.
Quality Assessment

Based on the DISCERN groupings, approximately 29.51% of the YouTube videos were categorized as being of very poor quality, while 19.67% were labeled as poor, 24.59% as fair, 18.03% as good, and 8.20% as excellent (Figure 2). The mean total DISCERN score for the videos was 41.64, with a standard deviation [SD] of 15.39.

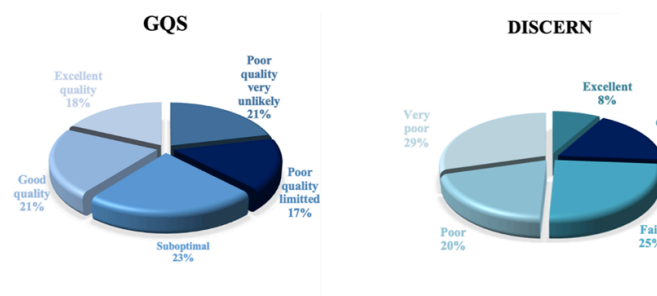


Figure 2 - Video quality distribution according to DISCERN and GQS scoring systems.

The DISCERN score analysis showed that the questions "Does it describe what would happen if no treatment is issued?" and "Does it describe the risks of each treatment?" received the lowest score of 1.66, while the question "Are the aims clear?" received the highest score.

On the other hand, in the assessment of content with the GQS, out of the 61 videos included, 14 were considered suboptimal quality (22.95%), 13 as good (21.31%), 10 as poor quality with limited usefulness for patients (16.39%), 11 as excellent (18.03%) and 13 were categorized as very poor quality (21.31%) (Figure 2).

This score was statistically evaluated with the existence or absence of the content criteria included in the study, the presence of content criteria (Eligibility criteria for surgery) showing higher GQS scores (4.0) ($p=0.03$) as well as the presence of success rate was associated with higher GQS scores (4.22) ($p=0.02$).

The relationship of both score systems was relevant in videos that contained alternatives of treatment and were significantly higher (GQS 3.50 and DISCERN 45.33) with a p-value of 0.03. Also, videos that comment on surgical risks were statistically significant for high scores (GQS 4.63 and DISCERN 54.44) with a p-value of 0.04. However, fundamental criteria such as treatment details or success rate were not statistically significant with a p-value of 0.10-0.05 respectively.

DISCUSSION

Prolactinomas represent around 50% of all pituitary tumors requiring medical attention.¹² The majority are small microadenomas with a predominance (25-60%) of lactotroph tumors based on immunohistochemistry;¹³ The predominance of PRL-secreting tumors is observed in women aged 25-44 compared to men (male to female ratio 1:5 to 1:10) while this difference disappears after menopause.¹⁴ the average annual incidence of prolactinomas is about 2.2 per 100,000 persons.¹⁵

Radiographic evaluation of Prolactinoma requires CT (Computed - tomography) or MRI. MRI is the test of

choice for pituitary tumors.¹⁶ Currently, 50% of pituitary tumors are at < 5 mm at the diagnosis. Pituitary tumors are classified as microadenomas (<1 cm) and Macroadenomas (>1cm). (4) CT may be appropriate when MRI is contraindicated (e.g., pacemakers); it should be done with contrast and show direct coronal reconstruction. Sometimes angiography and functional MRI are considered.¹⁷

Treatment approach

It is considered an expectant approach to monitoring PRL levels in the prolactinoma treatment in patients without bothersome galactorrhea. However, in premenopausal women with normal menstrual cycles and postmenopausal women, medical treatment has been the first line using dopamine receptor agonists (DA) (Bromocriptine, Cabergoline, and quinagolide) with Cabergoline considered the most recommended pharmacological agent due to its high efficacy.⁶ Focusing on restoring hormonal values and reducing the tumor size with periodical follow.¹⁸ Other pharmacologic treatments include temozolomide, used since 2006 in aggressive prolactinomas,¹⁹ pasireotide, everolimus, octreotide, lapatinib, nivolumab, ipilimumab, estrogen modulators, tyrosine kinase inhibitors, vascular endothelial growth factors (VEGF) targeted therapy, immunotherapy, and peptide receptor radionuclide therapy have had limited success in the management and are an object of trials and study.^{19,20}

Surgery is considered as a second line but is appropriate to consider as a first-line treatment option under certain circumstances such as newly diagnosed well-circumscribed micro prolactinomas and non-invasive macroprolactinoma; the desire for pregnancy; Cystic prolactinomas; Debulking in DA-resistant prolactinomas, aggressive prolactinomas, and carcinomas.²⁰ Other surgery indications are pituitary apoplexy, cerebrospinal fluid (CSF) leakage, and symptomatic tumor expansion during pregnancy.^{19,20} Transsphenoidal surgery and craniotomy, performed in reference centers by experienced surgeons, are safe and present low complications such as insipidus diabetes or (CSF) leakage of 2% and a mortality rate of 0.2%.^{19,20} In refractory patients to medical and surgical therapies, usually in highly aggressive or malignant tumors, treatment approaches such as radiotherapy, gamma-knife radiosurgery, and radiotherapy can be considered.

Prolactinoma treatment and YouTube information

Over the past few years, it has become increasingly common for patients to use online resources, including YouTube^{8,20,21,22}, to learn about prolactinoma treatment due to the ease of access and comprehension. However, while YouTube has gained popularity as a source of medical

information, this study indicates that most of the information presented in YouTube videos on prolactinomas needs to be improved for educational purposes. Although the platform can provide access to information from medical professionals and non-medical individuals, the quality of information available on YouTube regarding prolactinomas is insufficient.

Despite the massive amount of information that can be found about the treatment of prolactinomas and the stating that 70.49% of the video content is meant for the general population, most people are looking for professional videos since this category had 53,855 views, which was statistically significant. This finding suggests that viewers prefer this category to broaden their knowledge. As healthcare providers, there is a considerable need for improving and developing content with broad information about the treatment of this condition.

Within the 61 videos included, only six present all the criteria contained in this present study, while in the other categories, despite meeting some criteria, neither "personal" nor "other" met five of the five criteria. Only seven videos discussed surgical risks, and 17 mentioned treatment success rates in a supported evidence manner. This is concerning regarding the multiple studies that have been developed on this topic related to the risks of treatment approaches such as visual impairments, rhinorrhea, and pituitary apoplexy.^{23,24} Furthermore, the transsphenoidal surgery success rates have been described broadly by many studies concluding long-term disease remission after transsphenoidal surgery (67%, with 95% CI 60-74%, 25 studies) compared with dopamine agonist after withdrawal (34% with 95% CI 26-46%, 17 studies).²⁵ This was correlated with the question "Does it describe what would happen if no treatment is issued?" and "Does it describe the risks of each treatment?" Which rated the lowest DISCERN scores.

It is necessary to include this detailed information to improve the shared decision-making towards patients and healthcare providers, addressing that despite high success rates of treatment alternatives, some risks could dramatically affect the patient's quality of life. Given the DISCERN score system employed in our study, it is observed that the quality of the videos is very poor concerning the information on the treatment of prolactinoma as only 5 (8.20%) were categorized as excellent, and more than a half didn't reach a score superior to 50 points. These findings were positively correlated with the GQS scores where 60.66% of the videos were not of good quality.

It is worth clarifying that although this study emphasizes the treatment of prolactinoma, it would be good to consider other aspects within the criteria to broaden medical knowledge, such as its etiology, epidemiology, and diagnosis approaches so that patients can have a more robust understanding of this pathology.

There are several limitations to this study. We only looked at English - language videos on one platform,

YouTube. The search terms used were limited to the first 30 videos for each period at a specific time. Since the distribution of information on the internet changes continuously, data collection may have influenced the findings. Additionally, the YouTube search algorithm may provide different results depending on the location, which could exclude high-quality videos that meet all content criteria. The search terms employed could not be used by patients and caregivers who may encounter less relevant or misleading videos because they use different search terms to look for information on these platforms.

CONCLUSION

Even though people search online platforms such as YouTube for professional and quality information, most have access to poor-quality content. Healthcare professionals and institutions must ensure evidence-based content in their videos on platforms like YouTube so patients can access information wholly and accurately. Therefore, it can be said that YouTube is not the "master key" for patient education regarding the treatment of prolactinomas.

Declaration of interests

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Data availability

Available from the corresponding author on reasonable request.

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