



Article

Is YouTube a Reliable Source of Information for Sacral Neuromodulation in Lower Urinary Tract Dysfunction?

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Abstract: Background/Objectives: YouTube is an open-access video streaming platform with minimal regulation which has led to a vast library of unregulated medical videos. This study assesses the quality of information, understandability and actionability of videos on YouTube pertaining to sacral neuromodulation (SNM). **Methods:** The first 50 videos on YouTube after searching “sacral neuromodulation for bladder dysfunction” were reviewed. Thirty-eight of these videos met the inclusion criteria. These videos were reviewed by two Urology Registrars and the videos were scored using two standardised tools. The DISCERN tool assesses quality of information and the Patient Education Materials Assessment Tool for Audiovisual Material (PEMAT-A/V) tool assesses user understandability and accessibility. **Results:** Forty-two percent of videos were deemed to be poor or very poor, with 58% being fair, good or excellent according to the DISCERN standardised tool. For PEMAT-A/V the average score for understandability was 74% (43–100%) and actionability was 38% (0–100%). We found statistical significance comparing the duration of videos to the DISCERN groups ($p = 0.02$). We also found significance comparing the understandability of videos using the PEMAT-A/V score to the DISCERN groups ($p \leq 0.05$). **Conclusions:** Forty-two percent of videos on SNM are of poor or very poor quality. The actionability score for consumers to seek out further information is also low at 38%. This raises concerns about the quality of information that is widely available on YouTube and how consumers will use this information when making decisions about their health.



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Keywords: sacral neuromodulation; bladder dysfunction; YouTube

1. Introduction

Sacral neuromodulation (SNM) is a minimally invasive technique that uses electrical stimulation of the sacral nerve root to modulate a neural pathway [1].

SNM is a treatment option most commonly for patients with refractory overactive bladder, followed by faecal incontinence and non-obstructive urinary retention who have failed initial medical management [1]. An overactive bladder encompasses the lower urinary symptoms of urgency, with or without incontinence, frequency and nocturia. First- and second-line treatment options include behavioural therapies, biofeedback, physical therapy (such as pelvic floor physiotherapy) and medications (antimuscarinics and beta-3-agonists) [2]. SNM is recommended by the American Urological Association (AUA) as a third-line treatment for refractory overactive bladder (OAB) [2,3].

A quadripolar tined lead is inserted through the third (or fourth) sacral foramen, which stimulates the sacral spinal nerves that innervate the bladder, urethral sphincter and pelvic floor muscles [2]. SNM for overactive bladder is thought to inhibit the detrusor muscle during the storage phase without effecting detrusor contractility or urethral resistance during the voiding phase [4]. It is also thought to modulate spinal cord reflexes and brain networks by peripheral afferents [4]. For patients with non-obstructive urinary retention, SNM works by lowering the sphincter tone to allow for bladder emptying [4].

The significant growth of social media has made it an easily accessible and vital source of information, especially for patients to seek out medical information [5]. Data have shown that one-third of patients watch health education videos on YouTube [6]. YouTube is the second most popular website followed by Google [7]. YouTube is an open-access video streaming platform with minimal regulation. The ability to upload videos without any verification process has led to a vast library of medical videos [7]. However, due to this unverified process, the quality of educational videos is varied and risks the potential of spreading incorrect or false information [7].

A patient's motivation to seek out information is driven by a desire to learn more about their conditions and explore treatment options, sometimes due to anxiety and hesitation in asking questions to healthcare workers directly [6]. However, if the information patients view on YouTube is unreliable and misleading, this can lead to additional stress, confusion and worry [6], emphasising the need for correct, high-quality and factual information on social media platforms.

The quality and accuracy of YouTube videos for other urological conditions have been explored previously [5–8], with the majority of studies revealing the low quality of medical information within these videos [8]. However, to our knowledge this is the first research assessing the quality and accuracy of YouTube videos on SNM.

2. Materials and Methods

2.1. Video Selection Criteria

On the 22 July 2024, we searched “sacral neuromodulation for bladder dysfunction” on YouTube. The search was conducted in an incognito web browser to limit the bias of results based on the viewer's previous search history, and the first 50 videos were included. Videos were included if there was a major focus on SNM as a treatment option for lower urinary tract dysfunction and were in English. Videos longer than 15 min that only briefly mentioned SNM, and videos related to SNM for faecal incontinence were excluded. Video characteristics were also recorded, including name of uploader, uploader's subscribers, uploader's country of origin, type of video, animation, presence of advertising, date video was uploaded, number of likes, number of dislikes and number of comments. Video types included patient experience, health organisation or service and for-profit organisations.

2.2. Video Evaluation

The videos were independently reviewed by two Urology Registrars. Two standardised tools were used, the DISCERN tool to assess quality of information and the Patient Education Materials Assessment Tool for Audiovisual Material (PEMAT-A/V) to assess user understandability and accessibility. The quality of information was compared to the International Continence Society best practice for sacral neuromodulation [9] and the AUA/SUFU (Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction) guidelines on the diagnosis and treatment of idiopathic overactive bladder [3].

DISCERN is a standardised tool for both health providers and lay people to assess the quality of information. Initially, this tool was used for written information but has been adapted to video formats [10]. There are 16 questions; the first 1–8 questions address

the reliability of information and how well the information can be trusted. The next 9–15 questions assess the quality of information. Question 16 is an overall quality rating. Each question is ranked from 1 to 5, with 1 being a definitive no and 5 being a definitive yes. The scores from questions 1 to 15 are added up, giving an overall score of 15–75. Scores of 63–75 are considered “excellent”, 51–62 are “good”, 39–50 are “fair”, 28–38 are “poor” and <27 are “very poor” [10].

PEMAT-A/V is another standardised tool adapted to audiovisual sources to evaluate the understandability and actionability of patient education materials [11]. In the PEMAT-A/V tool the first 13 questions are related to understandability and the final 4 questions are related to actionability. Questions are scored as agree “1” or disagree “0” with some questions having a not applicable score. The Understandability Score is the percentage of the total points divided by total points $\times 100$. The same is calculated for the Actionability Score. A score of 90% is considered more understandable than a score of 60% [11].

2.3. Data Analysis

For statistical analysis, the DISCERN tool categories were grouped into very poor or poor as one category and fair, good or excellent as the other category.

Basic video characteristics were analysed on excel. Univariate analysis was performed using Fisher’s exact test, the chi-square test and the Mann–Whitney U test.

3. Results

A total of 38 videos were included in the study. The descriptive analysis of the video characteristics are shown in Table 1. The mean duration of the videos was 277 s (range from 52 to 759 s). The average views were 9008 per video (range from 45 to 104,372), the average comments were 6 per video (range from 0 to 74), the average likes were 51 per video (range from 0 to 567) and the average subscribers were 64,574 for each video author (range from 77 to 824,000). No videos had any dislikes.

The locations of the video authors were from the USA (37%), UK (26%), India (8%) and 29% did not have a location available.

Of the total videos, 16% were animated. In terms of advertising, 53% were either authored by companies producing SNM devices, or the company was mentioned in the video. Health organisations comprised 71% of the video authors, 24% by commercial health companies, 3% by media sources and 3% unlisted.

Regarding the standardised tools for consumer health information in the DISCERN tool, the average score for the poor or very poor group was 31 (21–38) out of 75. For the average or good group, the average score was 49 (39–65). Based on the DISCERN score and designated groups, 42% of videos were either very poor or poor (13% very poor and 29% poor) and 58% were fair, good or excellent (37% fair, 18% good and 3% excellent).

For PEMAT-A/V, the average score for understandability was 74% (43–100%) and actionability was 38% (0–100%).

The variable analyses for the DISCERN tool are shown in Table 2. We observed significant differences in the duration of the videos in the DISCERN tool between the poor or very poor and the average or high group ($p = 0.02$). There were also significant differences between the DISCERN tool categories of poor or very poor and the average or high group when comparing the PEMAT-A/V Understandability score ($p \leq 0.05$).

The variable analyses for the PEMAT-A/V tool are shown in Table 3. In the remaining variables analysed in the univariate analysis, we found no statistically significant differences.

Table 1. Descriptive analysis of the video characteristics.

Characteristics		
Video		38
Duration (minutes)		277 (52–759)
Views		9008 (45–104,372)
Comments		6 (0–74)
Likes		51 (0–567)
Dislikes		0 (0–0)
Subscribers		64,574 (77–824,000)
Author Location		
	USA	14 (37%)
	UK	10 (26%)
	India	3 (8%)
	Not Available	11 (29%)
Animation		
	Yes	6 (16%)
	No	32 (84%)
Advertising		
	Yes	20 (53%)
	No	18 (47%)
Type of Author		
	Health Organisation	27 (71%)
	Commercial Health Company	9 (34%)
	Media (Other)	1 (3%)
	Not listed (Other)	1 (3%)
DISCERN Tool		
Average Score		41 (21–65)
Very poor or poor		31 (21–38) 42% of videos
Average or good		49 (29–65) 58% of videos
PEMAT-A/V		
Understandability		74% (43–100%)
Actionability		38% (0–100%)

Table 2. Descriptive characteristics of video by Discern category.

Characteristics	Discern Category		<i>p</i> -Value
	poor or very poor	average or high	
Type			
Health organisation	13 (65.0)	14 (77.8)	0.48 a
Health company/other	7 (35)	4 (22.2)	
Animation			
No	17 (85.0)	15 (83.3)	1 a
Yes	3 (15.0)	3 (16.7)	
Advertising			
No	8 (40.0)	10 (55.6)	0.34 b
Yes	12 (60.0)	8 (44.4)	
Duration			
median (IQR)	211 (104, 318)	313 (216, 378)	0.02 c

Table 2. Cont.

Characteristics	Discern Category		<i>p</i> -Value
Subscribers			
median (IQR)	10,255 (4360, 26,650)	5850 (704, 11,300)	0.22 c
Views			
median (IQR)	3662 (454, 13,137)	492 (188, 1799)	0.055 c
Understandability			
median (IQR)	0.67 (0.58, 0.79)	0.96 (0.70, 1.0)	<0.05 c
Actionability			
median (IQR)	0.33 (0, 0.67)	0.50 (0.33, 1.0)	0.11 c

Note: a: *p*-values are based on Fisher's exact test; b: *p*-value is based on the chi-square test; c: *p*-values are based on the Mann–Whitney U test; IQR: interquartile range.

Table 3. Descriptive characteristics of video by PEMAT category.

Characteristics	PEMAT			
	Understandability	<i>p</i> -Value	Actionability	<i>p</i> -Value
Type				
Health organisation	0.7 (0.6, 1)		0.3 (0, 0.7)	
Health company/other	0.8 (0.7, 1)	0.57 c	0.5 (0.3, 1)	0.17 c
Animation				
No	0.7 (0.6, 1)		0.3 (0.1, 0.7)	
Yes	0.8 (0.6, 1)	0.73 c	0.8 (0.3, 1)	0.13 c
Advertising				
No	0.8 (0.6, 0.9)		0.3 (0, 0.7)	
Yes	0.8 (0.6, 1)	0.85 c	0.4 (0.3, 0.8)	0.14 c
Duration				
correlation	0.33	0.04	0.01	0.9
Subscribers				
correlation	−0.23	0.15	0.12	0.46
Views				
correlation	0.02	0.9	0.16	0.32

Note: c: *p*-values are based on the Mann–Whitney U test.

4. Discussion

The growth of health information on social media and YouTube has transformed the way individuals access health-related knowledge. This shift is driven by a desire for accessible, relatable content that empowers consumers to take control of their own health [6].

YouTube has more than two billion active monthly users, making it the most popular video sharing platform [6]. YouTube is an open-access video streaming platform with limited regulation, allowing users to upload videos without any verification process [7]. This has resulted in a vast collection of easily accessible medical content. However, the lack of verification means that the quality of these educational videos can vary widely, increasing the risk of disseminating incorrect or misleading information [7].

Urological health information is no exception to this expanding collection of free-to-access videos on YouTube. Previous studies have examined the quality and accuracy of YouTube videos related to various urological conditions, with most findings indicating that the medical information presented in these videos is often of low quality [8].

In this study, less than half of the videos (42%) were either deemed poor or very poor for the DISCERN categories which assess the quality of health information for consumers. However, this does indicate that 58% were average, good or excellent. Generally, the videos performed well in terms of understandability; however, they scored poorly across the board in actionability, indicating poor or little direction offered to consumers for where to seek further information or who to discuss potential treatment planning with. Overall, we have demonstrated a clear gap in accessible, useful, peer-reviewed resources available to patients in treatment options for urinary incontinence, particularly SNM. Whilst the moderation of content in social media is beyond the scope of this study, our findings call for greater engagement between reliable bodies (such as non-profit organisations and health advisory bodies) and social media platforms in this area of interest.

The quality of health information for other urological topics has been explored in the literature. Similarly, Batur et al. [7] found that almost half of the videos pertaining to primary bladder pain syndrome they reviewed were unreliable, which is comparable to our rate of 42% being poor or very poor in nature. Loeb et al. [12] found that 77% of the videos they reviewed on prostate cancer had potentially incorrect information. However other studies had better results; Sood et al. [13] found that only 18.2% of the videos they reviewed pertaining to kidney stones were unreliable. Garcia et al. [5] reviewed the quality of bladder cancer information; they found similar scores for PEMAT-A/V understandability and actionability, 71.67% understandability compared to our 74% and 35.5% actionability compared to our 38%. Saad et al. [14] reviewed the quality of renal cancer information on YouTube and found 49.2% of videos had misinformation, with 22.5% scoring moderate to extreme levels of misinformation [14]. The reliability, understandability and actionability of urological videos found on YouTube varies between studies; however, overall, the quality of information of these videos are low [8]. Our study has produced similar results to the current literature.

On univariate analysis of the results, we only found statistical significance in two results. The first was video duration compared to their DISCERN score. The second was comparing the understandability of the video to the two DISCERN groupings ('poor or very poor' to 'fair, good or excellent'). Although the other variables did not show statistical significance, the overall scores from the DISCERN and PEMAT-A/V show variable quality, understandability and actionability of videos pertaining to SNM. Half the videos being poor or very poor is concerning to know for health consumers.

The ability to easily upload an unverified video on YouTube has significant consequences for the viewers. YouTube's lack of regulation is a major issue, as it allows unverified and often misleading content to spread widely. Unlike traditional media which is subject to fact-checking, anyone can upload videos without oversight. This creates an environment where misinformation can flourish, particularly on health-related topics, where viewers may be misled by incorrect advice or pseudoscience. Without proper moderation, users may struggle to differentiate between credible sources and harmful content, which can have serious consequences, especially when it comes to medical or mental health information. Furthermore, these videos lack opportunities for the viewers to find additional resources [15] or provide opportunities for the viewer to conduct shared decision making with their health care provider [15].

Fortunately, there were no apparent examples of incorrect information in the videos. However, the videos were of poor quality due to lack of information and limited actionability recommendations for consumers. The quality of information in these videos could be improved by including a list of resources used to ensure the videos are well researched and unbiased. Furthermore, majority of the videos lacked details about alternate treatments, risks associated with SNM or what would occur with no treatment. The quality

of information could be easily improved if these topics were addressed in the videos to ensure patients are making well-informed decisions about SNM. Lastly, the videos lacked actionability for consumers; this could be improved by clearly identifying how to access more information or how to be referred to a qualified health professional in this field.

For SNM, there are a finite number of companies that make these devices. Fifty-three percent of our videos were either produced by these companies or featured these devices as a form of advertising. The videos produced by these companies were often of higher production value and would appeal to the format of a video viewing platform; however, interestingly, we did not find any significant difference in quality of information, understandability or actionability of these videos.

Our study has limitations as it only reviewed videos on YouTube and no other social media sites; however, this is a major source of information for patients. It also only examined videos that were in English and were less than 15 min in duration. Of note, although the maximum duration was 15 min, there were only three videos longer than 10 min and 30 of the 38 videos were between 1 and 6 min. Some videos may have been missed that were not found with our standard search of “sacral neuromodulation for bladder dysfunction” as they may have used variations of this nomenclature. The videos analysed were from a wide variety of sources which was discovered during the review process, which may cause a biased interpretation of results. However, all videos that met the inclusion and exclusion criteria were included. Furthermore, there were a small number of videos that met the inclusion criteria which were academic videos from the International Continence Society Conference. The decision to include these videos was based on upholding the integrity of the study methodology, seeing as these videos met the criteria and were easily accessible information for consumers. However, given the academic nature of these videos and the target audience of urological or other health professionals, including these videos is a significant limitation of this study. The content of these videos is likely above the understanding of most consumers, and it has likely biased the interpretation of results as these videos are not very comparable to the other video sources.

We used two standardised tools to evaluate the videos. However, there is no consensus about how health videos should be evaluated and there are other tools available which could have been used. Although standardised tests were used to assess quality of information, our data may not be wholly representative of a patient’s perspective and understanding drawn from these videos. Studies involving feedback from patient focus groups may help guide more specifically the forms of information deemed understandable, accessible and actionable.

5. Conclusions

Our research has some limitations in terms of methodology and including a wide variety of videos from differing sources. However, overall, within these limitations we found that a large proportion of videos on SNM for the treatment of urinary incontinence presented poor quality of information with poor actionability. These results are in line with other studies looking at urological videos on YouTube, raising overall concern regarding the standard of information that is easily accessible by consumers. Our findings allude to the lack of high quality, peer-reviewed and useful resources available for consumers on social media in urinary incontinence and SNM. It is our recommendation that these shortcomings could be overcome if credible scientific organisations produce easily accessible, high-quality and reliable information for all consumers.

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