

Benign prostatic hyperplasia related content on YouTube: unregulated and concerning

Raman Tanwar¹, Nikhil Khattar¹, Rajeev Sood¹, Arun Makkar¹

Summary. Introduction. Information derived from social media sources is being used to save lives and take vital life altering decisions. YouTube is one of the most widely used social media for seeking medical information. Quality of information available to patients and medical professionals on YouTube with regards to benign prostatic hyperplasia (BPH), a common urological condition, was assessed. **Materials and methods.** First 100 videos results on BPH were analysed by three independent observers and graded based on the quality of information provided using an indigenous grading system of five points ranging from not useful to Informative for the Medical Professional. Correlation of this score with rank, number of views and "likes" was performed. Source of videos was identified along with analysis of comments. **Results.** A large proportion of videos (63%) was found to be irrelevant to the search, projected wrong facts or provided very basic information about prostate and the disease. A small but significant number of videos contained useful and relevant information. Only a handful of videos were useful for the urologist and adequate to guide the patient. A negative correlation between the quality of videos and their ranking on search was observed. **Conclusions.** YouTube offers very few high quality resources for patients and physicians. There is a significant negative correlation between useful videos and higher ranks in search results, but no correlation with number of views and likes. The first video in such results should be issued by a governing body that serves as the gold standard for patients and physicians.

Key words. Benign prostatic hyperplasia, prostate, social media, YouTube.

Introduction

Social media has been widely embraced as a tool for dissemination of medical knowledge and promotion of health¹. The coming together of web 2.0 and social media has enabled self-determined learning which in health care sector translates to forming an opinion by viewing focussed content². YouTube is the largest searchable online video resource on the internet which has become an important resource

Informazioni sull'iperplasia prostatica benigna su YouTube: non regolamentate e preoccupanti.

Riassunto. Introduzione. Le informazioni che derivano dai social media vengono utilizzate per salvare vite umane e prendere decisioni fondamentali. Scopo dello studio è stato valutare la qualità delle informazioni dirette ai pazienti e agli operatori sanitari relativamente all'iperplasia prostatica benigna (IPB) disponibili su YouTube, uno dei social media maggiormente utilizzato per la ricerca di informazioni mediche. **Materiali e metodi.** I primi 100 video sull'IPB sono stati analizzati da tre osservatori indipendenti e, mediante un sistema di valutazione a punteggio, la qualità delle informazioni contenute è stata classificata da "non utile" a "informativa" per il medico. Il punteggio ottenuto è stato poi correlato alla graduatoria e al numero di visualizzazioni e di "mi piace". È stata inoltre identificata la fonte di ciascun video, effettuando una analisi dei relativi commenti. **Risultati.** Gran parte dei video (63%) è risultata inconsistente e contraddistinta dall'esposizione di informazioni errate od elementari sulla prostata e sulla patologia prostatica. Un limitato ma significativo numero di video conteneva invece informazioni utili e pertinenti, e solo pochissimi video erano di utilità per l'urologo e costituivano una guida adeguata per il paziente. È stata osservata una correlazione negativa tra la qualità dei video e il loro posizionamento nella graduatoria. **Conclusioni.** YouTube offre pochissime risorse di elevata qualità sia per i pazienti che per i medici. Emerge una correlazione negativa significativa tra i video utili e il loro posizionamento in alto della graduatoria, mentre non esiste alcuna correlazione con il numero di visualizzazioni e di "mi piace". Sarebbe auspicabile che come primo video ne risultasse uno realizzato da un ente governativo, che serva da gold standard tanto per i pazienti quanto per i medici.

Parole chiave. Iperplasia prostatica benigna, prostata, social media, YouTube.

for patients and doctors to gain information about a disease. The quality of that information has not been properly studied. A study was done to assess the quality of information provided by this resource on benign prostatic hyperplasia (BPH) and whether the information available can be of use to either the patient or the attending physician in decision making. The study also tries to assess how the information is being perceived by the users. We chose BPH as it is common and management of BPH has

¹Department of Urology, PGIMER and Dr. RML Hospital, New Delhi, India.
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to be individualized to patients' circumstances and personal choices³ and thus the patient has a significant role to play in governing treatment.

Materials and methods

An independent search was performed on YouTube using the keywords "Benign Prostatic Hyperplasia" as a string.

The information provided on the subject was assessed and analysed independently by three urologists under training. Based on the assumption that users tend to review only the first few pages of results for the conditions they search⁴, the first 10 pages of the search results were taken into consideration and the first 100 videos were watched from the beginning to end by each analyst separately. We used a sequential screening approach to be able to cover and keep track of all search results. Search results were saved offline.

All searches were made in the incognito mode where the users identity could not be identified. Videos that did not have English as the primary language were excluded. The ranking of the videos, number of views, time since upload, number of likes and dislikes and underlying associations were recorded. The videos were categorized into videos providing general information including medical management, advertisements of products, lectures, operative techniques and patient experiences. The quality of information was assessed by grading each video on a scale of 1 to 5. A score of 1 was given to videos that were irrelevant to the topic or provided wrong information. A score of 2 was given to a video that gave very basic information to the patient about prostate and the disease and which would essentially be known to the patient after consultation with a medical practitioner. A score of 3 was given to videos that provided information in some detail to the patient and had the potential to influence treatment decisions and develop further understanding about the disease. Videos that were rich in medical jargon and provided highly reliable information were graded as 4 and 5. Videos that provided basic information for medical students were given a score of 4 while those which were useful for the urologist were given a score of 5. Such videos were released by medical institutions, health care providers and central bodies in Urology. Data was entered into the spread sheet and analysis done using SPSS Version 22. The degree of agreement of the three observers was calculated using the kappa coefficient. Correlation between the ranking on search results, quality of videos based on the indigenous scoring, number of views and number of likes was studied. A note of the number of comments associated with each video was made.

Results

Search for the term "Benign Prostatic Hyperplasia" was performed on YouTube on 18th June 2014 and delivered 3927 video results. A total video content on the first ten pages selected, amounted to 9.77 hours. The average duration of videos was 5 minutes and 52 seconds and the average rating of videos by the analysts was 2.41. All videos on the first 10 pages were in English. Of the total of 100 videos, 23 videos were advertisements featuring non allopathic cures for BPH. 56 videos provided general information about the disease with only 12 videos among these discussing various aspects of treatment. No duplicate videos were found. Many of these videos were not relevant to the search and discussed prostatic enlargement in dogs, prostate cancer or use of prostate supplements in women! The remaining 21 videos were lectures (9), operative techniques (8) or personal experiences of patients and doctors (4) (Table 1). Mean number of views were 9767.38 and the first 18 videos accounted for 91% of the views.

15.66 % of the videos were graded with a score of 1. Almost half of the videos (47.33%) provided very basic information that was not useful to the patient or the physician and were given a score of 2. Overall only 22% of the videos from the search results were considered useful and technically correct for viewing by the patient. Such videos were given a score of 3. 11.33% of the videos received a score of 4 by the reviewers while 3.66% received a score of 5. Thus only 15% of the videos were useful for medical professionals.

The level of agreement between the three observers was positive. The kappa coefficient between analyst one and two was 0.843, between two and three was 0.767 and between three and one was 0.692. All these values had a p value of 0.001 suggesting high clinical significance. A negative and statistically significant correlation was seen between the final rating and the overall ranking of the search results (Pearson's coefficient of -0.362) which implies that videos useful for the patients and doctors showed up later on the search results. No statistically significant correlation could be found between the grading, and the number of views, likes or dislikes (Coefficient 0.052, 0.118, 0.010 respectively). There

Table 1. Categorization of videos into various types along with basic information.

Category	Advertisement	General information	Lecture	Operative technique	Personal experience	Total
Number	23	56	9	8	4	100
Views	257,719	382,268	231,475	89,398	15,908	976,768
Likes	226	191	384	71	214	1086
Dislikes	35	51	21	5	1	113
Total Score	44.66	117	40	30.66	9	241.32
Avg Score	1.941	2.089	4.44	3.83	2.25	

was a significant positive correlation between the number of views and the number of likes, dislikes and time since upload (0.696, 0.932, and 0.754 respectively). The maximum number of likes per video was highest for videos in the lecture category. The average score was highest for videos under the operative technique or Lecture category.

On close analysis we could delineate only 30 videos to be with “no strings attached”. All the other videos had a subtle essence of advertising. Of these 30 videos, 5 videos were on operative techniques, 18 portrayed general information about the disease and treatment options and 7 videos were lectures. The average score of advertisement based videos and other videos taken together was comparable (2.42 vs 2.41). The mean number of comments per video were 2.56. A significant positive correlation was observed between the number of views and the number of comments (Pearson’s coefficient of 0.716), but all comments could not be classified into positive or negative.

Discussion

Web 2.0⁵ makes social media a reality, although its content is ungoverned and of variable quality⁶. Social media has been well embraced by the patient population, relatives and caregivers to gather health related resources⁷. Social media in the form of video based platforms from healthcare institutions can help to speed up communication and provide information to families and doctors alike to alleviate the level of health care⁸. Hospitals recognize that patients employ Internet and social media to research their conditions, doctors, and hospitals⁹ which has led to an increasing number of social media content being released by healthcare institutions¹⁰.

YouTube, Twitter, and Facebook are by far the most popular social media and the search function of each is simple and easy to use¹¹. YouTube™ is home to more than 60% of all videos on the internet, and thus has become an important source for patient information¹². It has been acknowledged that online videos are becoming a popular medium of knowledge and personal expression¹³. YouTube is also a rapidly increasing area of study for health researchers¹⁴ and provides a fertile ground for research¹⁵. YouTube is a potential source of disseminating information on common diseases, but the quality of such information has been analysed sparingly. In an analysis of 18 peer reviewed articles, Madathil et al.¹⁰ emphasized upon the increasing popularity of YouTube for gathering and disseminating healthcare related information.

One of the initial efforts to identify the quality of internet based information was made by Steinberg et al.¹⁶ who studied the relevance and quality of information delivered through YouTube videos on prostate cancer. These videos were analysed for information content (excellent, fair, poor) and bias (for, against, neutral, or balanced) and videos

on radiotherapy, PSA and surgery were included. Similar to our findings, the authors found a larger segment of videos to be carrying inadequate information with regards to prostate cancer. In another study by Sajadi et al.¹⁷ that analysed the relevance of social media for urinary incontinence, it was found that less than one half (40%) of the content on social media was medically informative and varied widely with the platform, from 13% on Facebook to 60% on Twitter. Only the first 30 YouTube videos were reviewed in this study. Of the 14 videos that were informative, 9 (64%) were from healthcare professionals or organizations.

Similar to some of the former studies, 63% of videos were rated as being of no benefit to the patients in our analysis. This is a large fraction of content that provides no extra information to the patient or medical professional. Like other studies done in this regard, we found that YouTube can be categorized as an unreliable source for patient information, which adds little to what is already known. Watching videos with scientifically incorrect content adds to the effort required by the physician in the form of counselling to change the perception based on this content. A large fraction of videos (70%) were released with the motive of advertisement of products, doctors or health institutions. A whiff of intent to publicize and popularize a brand could be appreciated in such videos.

Social media is informative but at the same time dynamic and powerful in swaying decisions to either side¹⁸. Online opinion can also mislead the consumer especially when the consumer is not confident and well informed. In such situations online social feedback can make the consumer up to 30% more likely to change decision¹⁹. As evident in our study a significant proportion of videos (15.66%) that appeared in the search results was irrelevant or provided misinformation. Hence, there is a substantial chance that watching such videos will adversely affect treatment related decisions.

Only a small number of videos were suitable for medical professionals (15%). Videos with high scientific content were released by central organizations or healthcare institutions. Bezner et al.¹⁴, in a similar study in the field of paediatric surgery, observed that videos uploaded by medical centres and professionals were of a higher quality while those uploaded by lay persons focused mainly on the emotional aspect of diagnosis and course of the disease.

A frequently-used concept to assess patient education information is by grading the quality of content provided by the video. Independent assessment by expert health professionals related to the field is the most accurate way to point out the deficiencies and misinformation provided. In our study the content of videos was graded based on a scoring system by surgeons undergoing training in the field of Urology who were dealing with BPH patients on a daily basis. Alternatively view count is a fair and frequently used criterion for quality

assessment. It relies on the presumption that the audience represents a healthy cohort and would include feedback from those having knowledge on the subject and possibly health professionals. A correlation was done between the score provided by the analyst expert and the number of views, likes and dislikes which revealed no statistically significant correlation (coefficient of 0.052, 0.118, 0.010 respectively). Additionally, promoted and marketed videos may be associated with a viral effect leading to false high viewership and may thus not be an accurate indicator of higher quality of content. Similarly videos that have been uploaded earlier may have more views than relatively newer videos.

Comments have been found to have significant impact on the viewership, irrespective of who and with what authority posts the comments. A direct impact was observed during the Human Papilloma Virus Promotion campaign on YouTube which was marred by negative comments and reshaped public opinion²⁰. In the present study the mean number of comments per videos of 2.56. However we did not adjudge whether they were positive or negative for the given video.

Search results are often dependent on the key words used which produces variability in information sought often for the same topic. We decided to use only one keyword "Benign Prostatic Hyperplasia" which is readily and occasionally the only available medical term on the prescription. This choice was helpful in concentrating on only the medically relevant videos as non-medical terms associated with BPH and videos on other diseases of the prostate such as prostate cancer were filtered out by using this highly specific keyword.

The delivery of misleading information plagues social media like YouTube. In a systematic review, health related information on YouTube contradicted reference standards and recommended practices¹¹. Study on quality of information on YouTube regarding kidney stones realized the need of authoritative videos by trusted sources²¹. Brooks et al.²² recommend that a thought be given to the quality of videos before uploading and accepting them. Cañon et al.²³ have proposed a semiautomatic moderation web service that may be useful in controlling the quality of videos. During a pilot study, more meaningful search results could be presented when moderation service was used. Certificate of quality Health on the Net Foundation Code of Conduct (HONcode) is a useful measure to standardize the reliability and scrupulousness of medical information over the internet in which an expert committee ensures compliance with ethical principles. If the minimum requirements are met the website can use the HONcode logo to portray its reliability²⁴. Such a recognized system is a pressing need for videos disseminating medical information. The first result on any health care term should be a video released and regulated by a known scientific body displayed in a fashion similar to the sponsored result on YouTube. Such a

video should highlight all important aspects of the disease and its treatment and serve as a guideline for other videos that follow.

Conclusions

There is a need to direct the consumer to resourceful and accurate videos in the field of healthcare to assist in effective decision making in the right direction. Content useful for both the patient and medical professional is lacking on YouTube and urologists can play a lead role in improving the medical content generated over YouTube and set example for other subspecialties to follow. It has been recognised that videos released by government bodies and health practitioners are trustworthy and contain high quality information. Such uploads should be encouraged and all health related videos should be testified by a central regulating body to start with.

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