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Dissemination of Misinformative and Biased Information about Prostate Cancer on YouTube

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Abstract

YouTube is a social media platform with more than 1 billion users and >600 000 videos about prostate cancer. Two small studies examined the quality of prostate cancer videos on YouTube, but did not use validated instruments, examine user interactions, or characterize the spread of misinformation. We performed the largest, most comprehensive examination of prostate cancer information on YouTube to date, including the first 150 videos on screening and treatment. We used the validated DISCERN quality criteria for consumer health information and the Patient Education Materials Assessment Tool, and compared results for user engagement. The videos in our sample had up to 1.3 million views (average 45 223) and the overall quality of information was moderate. More videos described benefits (75%) than harms (53%), and only 50% promoted shared decision-making as recommended in current guidelines. Only 54% of the videos defined medical terms and few provided summaries or references. There was a significant negative correlation between scientific quality and viewer engagement (views/month $p = 0.004$; thumbs up/views $p = 0.015$). The comments section underneath some videos contained advertising and peer-to-peer medical advice. A total of 115 videos (77%) contained potentially misinformative and/or biased content within the video or comments section, with a total reach of >6 million viewers.

Patient summary: Many popular YouTube videos about prostate cancer contained biased or poor-quality information. A greater number of views and thumbs up on YouTube does not mean that the information is trustworthy.

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YouTube is a social media platform used to share and obtain health information via a repository of >7 billion videos and a social networking interface that allows users to comment on and rate videos. YouTube has high visibility, with >1 billion registered users and 5 billion videos watched daily. Numerous studies have examined the quality of information on YouTube about various health topics [1–3]. Unfortunately, many revealed poor quality, biased, and/or commercial content, which might have dangerous consequences for users. For example, YouTube videos portraying immunization negatively were more highly rated by users, but 45% contained misinformation [1].

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Many prostate cancer (PCa) videos on the first page of a YouTube search have >100 000 views, showing its popularity as a source of PCa information. However, only a few studies have reported on YouTube videos about PCa [4,5]. A study of 51 YouTube videos performed in 2008 reported that 73% had fair to poor information content and 69% were biased towards screening or treatment [4]. The authors concluded that YouTube is an inadequate source of PCa information. Since then, there has been a more than 1000-fold increase in YouTube videos about PCa [6] but there are limited data on the nature and quality of current information. Basch et al. [5] examined the 100 most viewed PCa videos. There were numerous videos about screening that were commercial and/or biased. More recently, Struck et al. [7] reported that from 2015–2016 there were 536 YouTube videos with "prostate cancer" in the title with >100 views (median 75 937) and the dominant category was information/support. None of these studies used a validated instrument for content evaluation or examined user interactions for the videos.

The extent to which the public currently receives biased, incorrect, or commercial information about PCa through videos and/or interactions on YouTube that could affect decision-making is unknown. Our objective was to perform a comprehensive study of YouTube videos on PCa that included validated instruments for content evaluation and comparisons between quality and user popularity and dissemination.

We reviewed the first 150 English-language YouTube videos on default searches for "prostate cancer screening" (75 of ~173 000) and "prostate cancer treatment" (75 of ~444 000) using the validated DISCERN quality criteria for consumer health information [8]. This framework incorporates key elements of PCa guidelines, including whether the item being assessed describes benefits and risks or supports shared decision-making. The framework has 16 items ranked from 1 to 5 (minimum to maximum). Videos were also scored using several study-specific constructs defined by the study team, including intended audience, favoring new technology, recommending complementary/alternative medicine, commercial bias, and extent of misinformation (scored from 1 to 5, similar to DISCERN).

For a subset of 50 videos, online software was used to determine the Flesch-Kincaid reading level of written transcripts. We also scored videos using the Agency for Healthcare Research and Quality Patient Education Materials Assessment Tool (PEMAT; audiovisual version), a systematic method for evaluating understandability and actionability (ie, viewers can identify what they can do based on the information presented) of patient education materials [9,10]. PEMAT contains 17 items (13 on understandability and 4 on actionability) that are scored as agree, disagree, or not applicable.

For all videos we calculated two engagement metrics for YouTube users: the number of views per month (to account for different time intervals for which videos were online) and the ratio of the number of users who gave a video a thumbs up to the number of total viewers. Using SAS v.9.4 software (SAS Institute, Cary, NC, USA), we calculated Pearson correlation coefficients between quality (DISCERN) and YouTube user popularity (views/month and thumbs up/views). In addition, we examined comments underneath each video to further characterize viewers' responses and the type of user-generated content being shared. Finally, we examined dissemination by calculating the number of views

Table 1 – Characteristics of YouTube videos and user-generated comments

Parameter	Result
YouTube metric	
Median length of video, h:min:s (range)	4:33 (0:19–1:47:16)
Median total number of views, *n* (range)	2508 (20–1 348 172)
Median views/mo (range)	66.6 (1.5–112 347.7)
Median thumbs up, *n* (range)	6 (0–3000)
Median thumbs down, *n* (range)	1 (0–880)
Median thumbs up/views (range)	0.003 (0–0.078)
Median number of comments, *n* (range)[a]	0 (0–548)
Video content	
Intended audience, *n* (%)	
Anyone/general public	101 (67)
Specifically for patients	37 (24)
Health care providers	12 (8)
Discusses racial disparities in prostate cancer, *n* (%)	
Yes	23 (15)
No	111 (74)
Not applicable	16 (11)
Favors new technology, *n* (%)[b]	
Yes	38 (26)
No	94 (63)
Not applicable	18 (11)
Recommends alternative therapy, *n* (%)	
Yes	28 (19)
No	100 (67)
Unknown	22 (14)
Commercial bias, *n* (%)	
Commercial bias	41 (27)
No commercial bias	100 (67)
Unclear/missing	9 (6)
Misinformation level, *n* (%)	
No misinformation	89 (59)
Very little misinformation	31 (21)
Moderate misinformation	16 (11)
High misinformation	10 (7)
Extreme misinformation	4 (3)
Comments on videos	
Evidence of behavior change, *n* (%)	
Yes	5 (3)
No	30 (20)
Mixed response	14 (9)
Unknown/no comments	101 (67)
Medical advice requested, *n* (%)	
Yes	17 (11)
No	47 (31)
Not applicable	86 (57)
Medical advice given, *n* (%)	
No advice given	51 (34)
Advice refused/referred to doctor	1 (1)
Some advice given	8 (5)
Not applicable	90 (60)
Advertising in comments, *n* (%)	
Yes	9 (6)
No	57 (38)
Not applicable	84 (56)
Social support in comments, *n* (%)	
Yes	10 (7)
No	56 (37)
Not applicable	84 (56)

[a] A total of eight videos (5%) had comments disabled.
[b] Favors new technology was defined as bias toward use of expensive new treatment technologies without evidence of clinical superiority over traditional methods.

for videos containing different categories of misinformative or biased content.

Table 1 shows the characteristics of the videos and user-generated comments (see Supplementary Table 1 for topics). The median expert-rated quality of the videos with up to 1 348 172 views was moderate (3 out of 5 overall DISCERN score; see Supplementary Table 2 for individual DISCERN items). More videos had a moderate to good description of benefits (75%) than harms (53%). Only 50% of videos provided moderate to good support for shared decision-making, as current PCa guidelines recommend. A quarter of these popular videos were biased toward the use of new technologies in PCa treatment and 19% recommended complementary or alternative medicine.

The mean Flesch-Kincaid reading level for videos was 12th grade (range 7th grade to college graduate). The median scores on PEMAT were 67% (range 27–100%) for understandability and 75% (range 0–100%) for actionability (see Supplementary Table 3 for full PEMAT scores). Most videos had clear objectives, a logical flow of information, and good audio quality. However, few discussed multiple options, provided sources, or summarized the information. Only approximately half of the videos defined medical terms, divided information into sections, or addressed users directly when describing actions.

Statistical analysis revealed a significant negative correlation between scientific quality and viewer engagement, measured as views/mo (-0.24; $p = 0.004$) or thumbs up/views (-0.20; $p = 0.015$). Commercial/health-wellness and patient-posted videos had the highest engagement (by views/mo and thumbs up/view, respectively) but worse quality than videos from health care providers and professional/government groups (Supplementary Table 4).

Many videos had no user-generated comments (range 0–548). However, comments underneath some videos contained advertising (6%), requests for medical advice (11%), and actual medical advice from users (5%). Some users also used the comments section for social support (7%). Although several users indicated that YouTube videos increased their confidence in decision-making about standard PCa treatments, we also noted significant persuasion of users to pursue guideline-discordant treatment or unproven natural remedies by videos and/or social interactions with other users.

Table 2 – Dissemination of videos with content or comments about prostate cancer that is biased, contains misinformation, and/or lacks scientific evidence of efficacy or superiority

	Videos (*n*, %)	Views (*n*)
Moderate to poor quality (DISCERN score <3)	93 (62)	5 158 189
High misinformation (DISCERN score >2)	30 (20)	890 728
Complementary/alternative medicine	28 (19)	3 718 262
Favors new technology[a]	38 (25)	1 302 966
Commercial bias	41 (27)	3 136 882
Comments contain medical advice	8 (5)	215 224
Total unique videos and views	115 (77)	6 395 489

[a] Favors new technology was defined as bias toward use of expensive new treatment technologies without evidence of clinical superiority over traditional methods.

Table 2 shows the total reach for videos with poor quality or potentially misinformative or biased content in the video or comments. In our sample of 150 videos, 115 (77%) contained potentially misinformative and/or biased content within the video or comments section, with a total reach of >6 million viewers.

In summary, many popular videos about PCa on YouTube lack key elements of shared decision-making and contain biased content. The significant inverse relationship between expert ratings of information quality and the popularity of videos on YouTube is highly concerning because of the facilitation of wide dissemination of potentially misinformative content.

Author contributions: Stacy Loeb had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Loeb, Braithwaite, Byrne, Walter, Langford.
Acquisition of data: Loeb, Sengupta, Butaney, Macaluso, Czarniecki, Robbins, Gao, Byrne, Walter, Langford.
Analysis and interpretation of data: Loeb, Robbins, Braithwaite, Byrne, Walter, Langford.
Drafting of the manuscript: Loeb.
Critical revision of the manuscript for important intellectual content: Loeb, Sengupta, Butaney, Macaluso, Czarniecki, Robbins, Braithwaite, Gao, Byrne, Walter, Langford.
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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.eururo.2018.10.056.

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