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TikTok and Prostate Cancer: Misinformation and Quality of Information using Validated Questionnaires

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TikTok is a social network launched in 2016, which is used to create and share short videos (≤60 seconds). TikTok was the most downloaded app in the U.S. in 2018 and 2019 and is currently available in >55 countries. Similar to other social networks, TikTok users can follow other content creators and view a feed of videos. Users may associate their videos with captions and hashtags, and comment on others' videos. TikTok has 800 million total active users with >1 billion videos viewed daily.[1]

Despite the popularity of TikTok, its role in healthcare remains nascent. To date, <20 articles on PubMed reference TikTok and none has examined the type and quality of prostate cancer (PCa) content.

We have previously reported a significant amount of biased and misinformative content about PCa on other video-sharing networks such as YouTube, and found an inverse relationship between accuracy and viewer engagement.[2] Other studies have similarly noted the rising yet questionable role social media plays in disseminating quality PCa information.[3-5] Our objective was to review the nature and quality of TikTok videos about PCa using validated metrics.

We reviewed all TikTok videos (n=65) with the hashtag #prostatecancer between 6/12/16 and 6/30/20. Ten were excluded (7 private and 3 non-English), leaving 55 for analysis. Objective data including video length, number of views and comments, associated description, and hashtags were collected. Videos were examined using 2 validated instruments: DISCERN quality criteria for consumer health information with 16 items ranked from 1=poor to 5=excellent,[6] and the Patient Materials Assessment Tool (PEMAT) with 17 items evaluating understandability and actionability.[7-8] Videos were also scored for the presence of misinformation, using a published 5-point Likert scale.[4] In addition, reviewers annotated the topic and target audience, as well as the perceived demographics of the TikTok user who published

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the content. Finally, we examined comments associated with each video to characterize viewers' responses. Inter-rater reliability was 99.6% between two coders with PCa expertise.

Table 1 shows the characteristics of the videos. The 55 videos comprised a total of 134944 individual views. The median length was 17.1 seconds with 202 views, 15 likes, and 0 comments. Nearly all videos had audio. Content was primarily directed at raising awareness (30%) or sharing a patient's story (29%)(e.g., asking for thoughts/prayers, memorial tribute, or survivor story). Only 14% were informational videos about screening, treatment, and/or side effects. There were 3 (6%) videos each encouraging the use of complementary/alternative medicine and new technology. No increase in videos published during September (Prostate Cancer Awareness Month) or November ("Movember") was noted, though videos related to raising awareness did increase in November (Figure 2).

53 unique publishers were identified, with a median of 786 followers and 6294 likes, respectively. The majority were perceived as male (57%), white (72%), and age <50 (76%). Only 3 publishers (6%) were medical doctors. The remainder were laypeople (50%), family/friend of a patient (27%), for-profit companies, and patients (6%).

The median expert-rated quality of videos was 2/5 on DISCERN. Fifty-four (98.2%) videos were moderate to poor quality, accounting for 134752 or 97.4% of total views. Six (10.1%) videos had apparent commercial bias (e.g, advertising incontinence pads), with 1156 (0.83%) total views. Among 17 videos (totaling 95285 views) with objective information, 7 (41%, 3795 views) had a significant amount of misinformation (e.g., promoting routine PSA screening beginning at age 30, promoting a "miracle cure" beverage).

The median scores on PEMAT were 75% for understandability and 0% for actionability. Approximately half of the videos (48%) had a clear purpose, and the vast majority used common everyday language. Most videos included clear audio, text, and illustrations/photographs where applicable.

Among 41% of posts with comments from other TikTok users, most were providing support (63%). No comments involved requesting/giving medical advice or discussed an intended behavior change. There were no commercial advertisements in the comments.

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We found that that given the format of TikTok videos, it was difficult to apply pre-existing validated measures meant for longer audiovisual content that is intended to provide patient education. For example, just 14 videos had any call to action, rendering the PEMAT actionability score difficult to calculate. Given the heterogenous nature of content across different social networks such as the short-form videos with associated captions seen with TikTok, conventional tools may not readily apply, and novel tools may be necessary to evaluate the quality of such heterogenous content.

While the number of videos analyzed is low, indicating that TikTok is not currently a common platform for dissemination of PCa information, the small number of videos enabled a comprehensive analysis of a major global social network. Our study is novel as the first to examine the role of TikTok in oncology and urology, specifically focusing on PCa, the most common cancer in men. Given the novelty of using TikTok to disseminate health information, we were able to study every video associated with PCa to create a foundation of knowledge to be expanded upon in the future.

As social media's role in disseminating health information continues to grow, so does the need to examine the quality of information. We examined for the first time how a rising social media platform – TikTok – intersects with PCa. Overall, we found that most publishers were young white men without clear ties to healthcare or personal experience with PCa, and most posts focused on raising awareness or paying tribute to specific individuals. Most posts lacked substantive information for health consumers. Of the few with educational information, about half contained significant misinformation. While certifications like the Health on the Net Foundation (HON) attempt to guide consumers toward more trustworthy websites, there is a great need for additional methods for vetting of health-related content on social networks. Finally, while the videos were generally easily comprehensible, most did not encourage any specific health promotion behavior.

In short, TikTok videos about PCa are primarily casual content that may raise awareness but do not provide high-quality educational material. Further research is needed to examine the impact of online content on patients' understanding and experience of their disease processes as well as how to combat the spread of misinformation.

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Parameter	Result
Total number of videos	55
Median length of video, sec.ms (range)	17.7 (4.7-59.7)
Median total number of views, n (range)	202 (27-46900)
Median number of comments, n (range)	0 (0-69)
Median number of likes, n (range)	15 (0-2407)
Publisher Type	
Doctor, n (%)	3 (5.7%)
Non-Doctor Healthcare Provider, n (%)	1 (1.9%)
Patient, n (%)	3 (5.7%)
Family Member/Friend, n (%)	14 (25.5%)
Layperson, n (%)	27 (50.9%)
For-profit company, n (%)	3 (5.7%)
Other/Unknown, n (%)	4 (7.5%)
Publisher Gender	
Male, n (%)	30 (56.6%)
Female, n (%)	18 (33.9%)
Unknown, n (%)	7 (13.2%)
Publisher Race	
White, n (%)	39 (73.6%)
Black, n (%)	4 (7.5%)
Asian, n (%)	1 (1.9%)
Hispanic, n (%)	0
Unknown, n (%)	11 (20.8%)
Publisher Age Group	
<30, n (%)	19 (34.8%)
30-50, n (%)	21 (39.6%)
>50, n (%)	5 (9.4%)
Unknown, n (%)	10 (18.9%)
Median number of followers, n (range)	786 (1-330800)
Median number of likes, n (range)	6294.5 (1- 2700000)
Intended Audience	
Anyone/General Public, n (%)	50 (90.1%)
Specifically for patients/men, n (%)	5 (9.1%)
Setting	
Clinical, n (%)	2 (3.6%)
Home, n (%)	21 (38.2%)
No setting (ie just text), n (%)	9 (16.4%)
Unknown/Other, n (%)	23 (41.8%)
Main Topic	
Raising awareness, n (%)	17 (30.9%)
Patient story, n (%)	16 (29.1%)
Screening/Treatment/Side Effects, n (%)	8 (14.5%)
Commercial advertisement, n (%)	3 (5.5%)
Other, n (%)	11 (20%)
Discusses Screening/Treatment/Biopsy	10 (18.2%)

Table 1. Characteristics of the 55 TikTok videos associated with #prostatecancer analyzed by two independent reviewers with CaP expertise.

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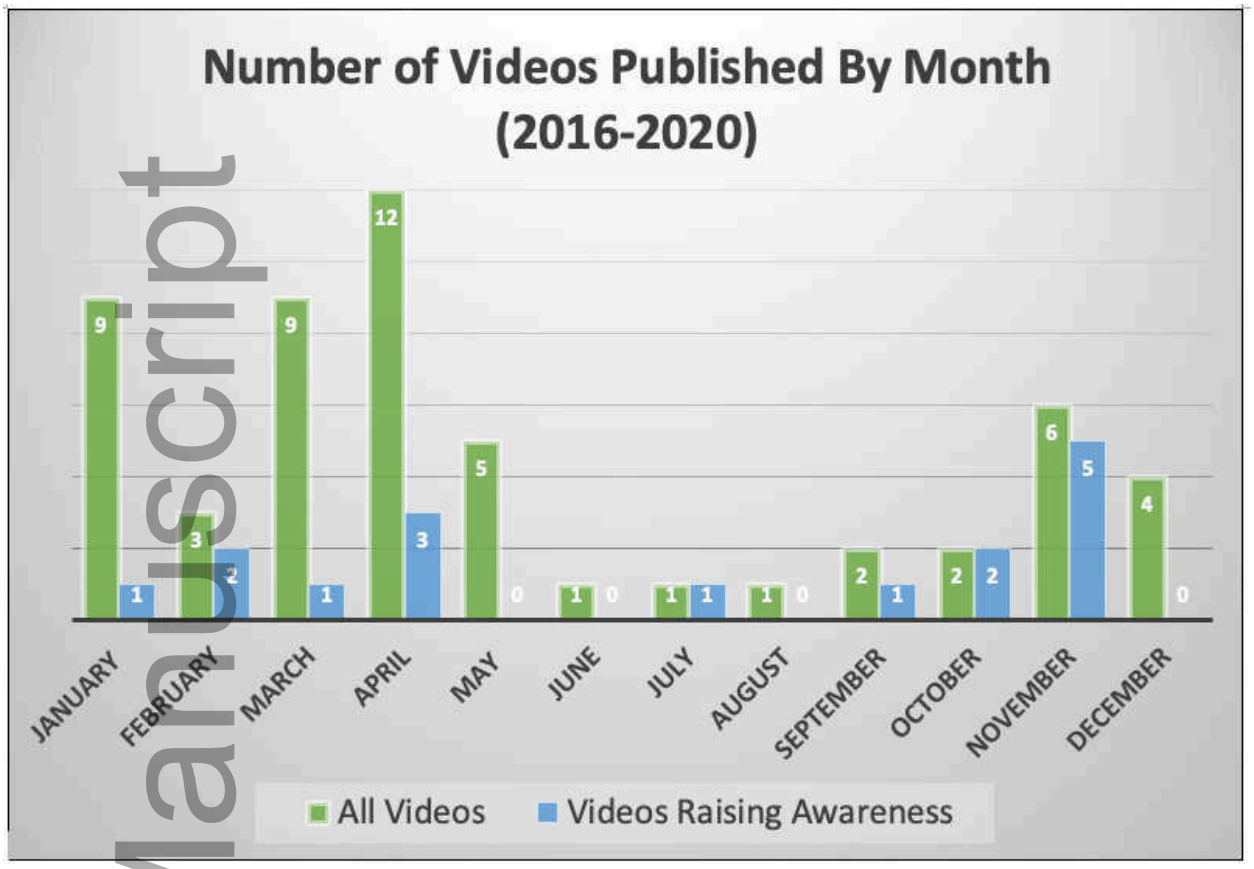

Figure 2. Number of TikTok videos associated with prostate cancer published by month between 2016 and 2020. Green bars indicate all videos and blue bars indicate videos coded to be raising awareness about prostate cancer.

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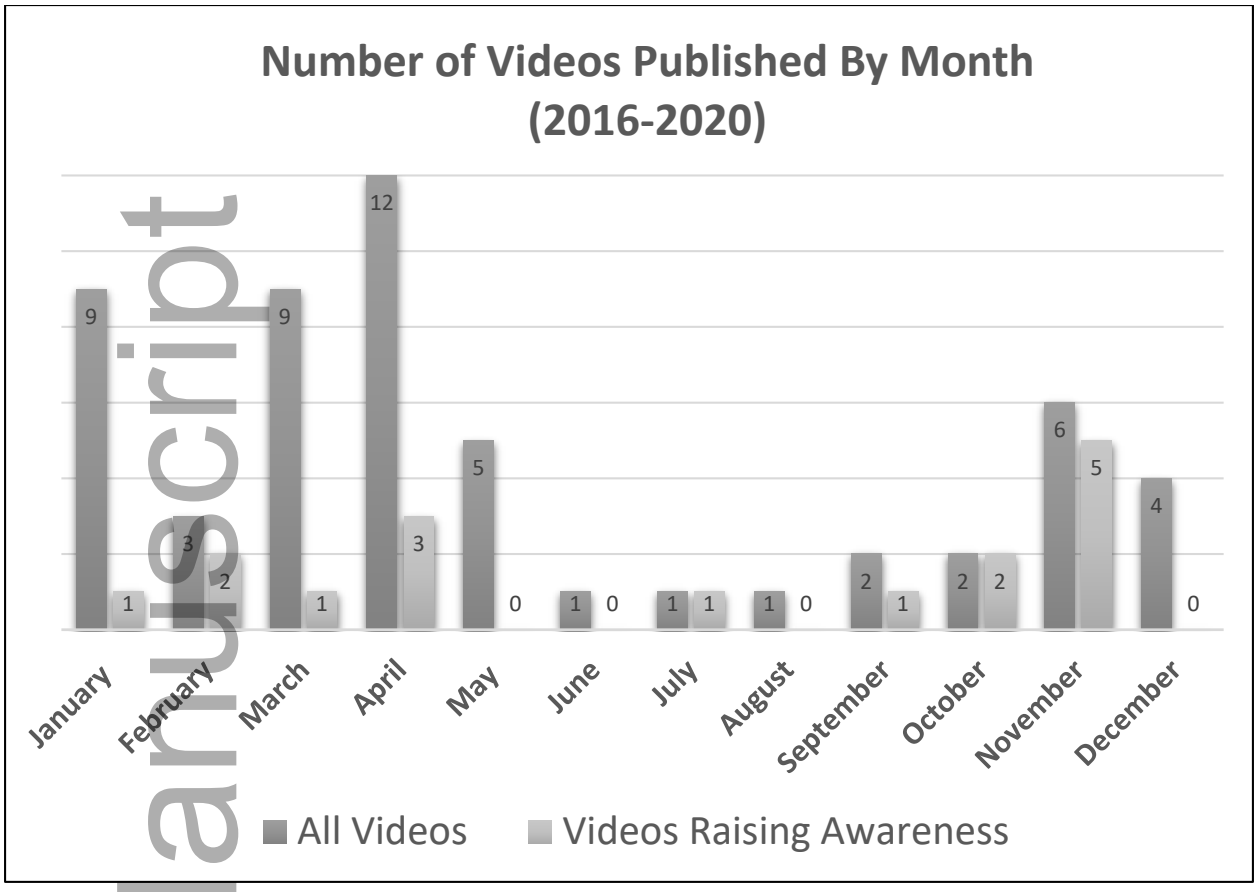

Figure 2. Number of TikTok videos associated with prostate cancer published by month between 2016 and 2020. Dark gray bars indicate all videos and light gray bars indicate videos coded to be raising awareness about prostate cancer.

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