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Patient information vs. The Algorithm

The social media lens on medicine has typically focused on X/Twitter as the scene of the action. The ability to crawl hashtag data — and the fact that it is where the academics hang out — has made publication of data-first studies common and (until recent changes) simple.¹ Drs. Wong & Ingledew have done the more challenging work of analyzing and taxonomizing YouTube™ videos, as well as a foray into the most obvious space in medicine, the patient perspective. They used a well-articulated data acquisition and analysis plan to identify a surprisingly high-quality batch of popular videos in the complications-of-prostate-cancer-treatment space.² The authors identified no “false information,” a high proportion of physicians as presenters, and 82% “accurate and detailed” information. This is heartening to see.

Prostate cancer on YouTube does not have a storied history in the literature. A zoomed-out “prostate cancer” search, 100 videos with 50M views, found that half of the videos were uploaded by “consumers,” and these were seen to be less driven by data dissemination.³ #urotwitter legend Dr. Loeb and colleagues, looked at the top 150 videos on “prostate cancer screening” and “prostate cancer treatment” with the validated DISCERN and PEMAT quality tools. These are tools for assessing the veracity and quality of written information on treatment choices. They identified commercial bias in 27% of videos, and moderate to extreme disinformation in one-fifth.⁴ Even this issue’s subtopic, post-prostatectomy incontinence, has been seen through different search criteria to serve a lower-quality cohort of videos, with two-thirds beneath DISCERN criteria for quality, even though two-thirds were produced by professional societies or physicians.⁵

Why does the work of Wong and Ingledew in *CUAJ* look better? Could their work reveal a toolkit for finding better information on YouTube? They used quite specific search queries, including terms like “radiotherapy” and “prostatectomy;” perhaps instead of more colloquial “radiation” and “prostate surgery.” I have a notion, however, that YouTube parent Alphabet (read: Google) has mechanisms to accommodate such variances in their search queries — a butchered-spelling search for “poratatetcomy” is managed just fine, for example. The authors’ three-point scale for accuracy may “Will

Rogers phenomenon” marginal papers into the “mostly accurate” middle category. Perhaps, as the authors note, the use of their own profile as the basis for the search may skew results toward their prior preferences in some way. In any case, it is nice to see balanced and accurate information delivered at the top of search rankings.

This matters, because more of users’ time is spent on a relatively small number of mega-sites and services. Fifteen years ago, a patient or their advocate might plunk “prostate cancer” into Yahoo! or Google and be directed to blog posts or advocacy group sites. Now, the search is conducted within YouTube or Reddit or Facebook or even TikTok, because that is where their time is being spent.

Physicians are not the drivers of the discourse on these sites and are generally less suited to navigating the norms of success there. YouTube success depends at least as much on production excellence — sound, video editing, and adjuncts like animation — than on message. A well-intentioned but tinny-sounding doctor at a desk riffing factually on prostate cancer doesn’t stand a chance against slick production and an attention-grabbing thumbnail pic.

Is video skills acquisition the next frontier of patient-facing knowledge translation? We’ve seen here that quality can grab eyes and views, so perhaps this is a clue.

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