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Prostate Cancer Social Media: In YouTube We Trust?

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Changes in practice guidelines for prostate cancer screening has had a major impact on the treatment of localized prostate cancer, and amplified the importance of shared decision making between patients and health care providers. In addition, the approach to the treatment of men with prostate cancer continues to evolve with the emergence of new data on both surgical and medical management. As a result, it has become an ever-increasing challenge to ensure shared decision making between providers and patients, particularly in the context of relatively constrained office visits.

Perhaps making matters even more challenging is the reality of access to information. The era where the provider was the conduit to medical knowledge has long past. Today, we are living in a world where information is freely accessible, where patient communities actively engage, and where information is posted on multiple forums, both private and public. In this era of “networked knowledge” [1], clinicians are no longer the expert; instead, expertise is found in communities gathered around shared interests, where members are educating and are also being educated, and clinicians may or may not be aware that these channels exist, let alone the information being discussed. While multiple channels exist, video remains one of the more interesting and powerful platforms. Indeed, Lauckner and Whitten [2] conducted an evaluation on volunteers who had a cancer risk reduction (CRR) message delivered on Facebook, Twitter, YouTube, or within blogs, to see which forum resulted in higher comprehension. They discovered that YouTube did a better job in enhancing comprehension and attitudes toward CRR than Twitter, and resulted in a stronger attitude toward CRR compared with Facebook. These results suggest that while the message is always important, the *format* by which it is delivered can matter.

The rapid growth of videos related to health issues exposes strengths and vulnerabilities of digital platforms. In this month's issue of *European Urology*, Loeb and colleagues [3] sought to evaluate the top YouTube videos on prostate cancer as these were related to overall quality of information being disseminated and for evidence of bias. The authors included 150 videos and reported that while the median quality of the videos was rated as moderate (using a validated framework for health care information), only half promoted support for shared decision making. An astonishing 77% of the videos were potentially misinformative and 27% were rated as being commercially biased. The highest-quality videos were those produced by medical societies or governmental agencies, yet they also had the lowest number of views per month (635). In contrast, videos from health/wellness and commercial media had 14 858 views per month. More striking perhaps is that over a quarter of them appeared biased toward the use of new technologies. They also found that the most viewed videos appeared to be those with the most questionable scientific merit. In addition, they reported that poor-quality videos were associated with far greater views than the videos rated to have good quality (5 million vs <900 000).

Therefore, why should clinicians, researchers, advocates, and patients care about this? The simple answer is because it matters. In the era of networked knowledge, information online is influencing patient choices. For example, according to one survey, 41% said that their choice of a specific physician or institution would be influenced by social media [4]. In a separate survey of over 400 patients in Saudi Arabia, over 40% reported stopping treatment based on advice received on a social media platform [5]. As indicated in this timely report, as it relates to prostate cancer, the most

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frequently accessed information may not be the best information out there, and at the most extreme potential outcome, their availability may prevent or postpone men at risk (or even, men with cancer) from seeking medical attention or accessing appropriate treatment. Although mostly a hypothetical risk, the sum total of these findings indicate that the medical community can no longer afford not to pay attention.

What response can we make as an individual, an institution, or a medical community? Unfortunately, there is no simple answer. The sheer breadth of sites, apps, platforms, and channels make policing the Internet an impossible proposition. In addition, search and sharing of information happen in both public and protected spaces, and in some cases, are not accessible to clinicians most likely to provide valid input. Even more importantly, the information era is already upon us and there is no way we are going back. Therefore, instead of fighting it, the medical community must embrace it more widely. This means engaging directly on social media to lend a credible voice to the conversation and to point the public to reliable sources. It means commenting on sites that are providing misinformation, and it means being clear about conflicts of interest—both perceived and real. Would such an effort work? Although one cannot be certain, sufficient data suggest that it would. After all, even as information is now at everyone's fingertips, at least in the USA the data indicate that physicians remain the single most trusted voice in health care. This was shown in the 2002–2008 Health Information National Trends Surveys, which showed that trust in doctors

or health care professions was consistently above 68%, while trust in information obtained in the Internet ranged between 19% and 23% [6].

In conclusion, the report by Loeb et al. [3] should serve as a wake-up call for all of us. Not only patients are finding information on prostate cancer on the Internet, at least on YouTube, but they also appear to be gravitating toward unreliable material (or “fake news”). If we believe that we all have a role to play in ensuring quality health care for all men with prostate cancer (and health, in general), we must address this issue, and it starts with engaging ourselves online.

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