Angelina Jolie and Medical Decision Science

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INTRODUCTION

Movie stars lead glamorous lives, attract enormous attention, and inspire popular lifestyle trends. Angelina Jolie, in particular, has been Hollywood's highest paid actress in multiple years, cited as one of the world's most beautiful women, married to perhaps the sexiest man alive, and empowered as a formidable marketing force. Her latest movie, *Maleficent*, generated total revenues greater than $700 million, an amount that could fund an entire medical center for more than a year. Her humanitarian efforts include being appointed Goodwill Ambassador for the United Nations High Commissioner for Refugees and channeling millions of dollars toward funding worthwhile charities. Many clinicians, scientists, and politicians might dream about having the influence of Angelina Jolie.

On May 14, 2013, Angelina Jolie disclosed in an editorial titled ''My Medical Choice'' that she had tested positive for a breast cancer gene (BRCA1) and undergone prophylactic bilateral mastectomies with breast reconstruction.[1] The immediate reaction led to widespread public attention including front-page stories in mainstream media and a doubling of subsequent referrals for BRCA1 genetic counseling at some hospitals.[2] Her disclosure is also credited for helping shape the US Supreme Court deliberations on June 13, 2013, disallowing patents for isolated genes and potentially prohibitively expensive gene testing.[3] In our opinion, no single study in medical decision science is likely to receive this amount of instant high-profile media attention.

In the present issue of the journal, Seth Noar and colleagues provide a rigorous analysis tracking online search activity before and after the Angelina Jolie disclosure.[4] The methods involved accessing the Google Trends database from January 1, 2010, to December 31, 2013, for daily searches related to breast cancer genetics and treatment queries (along with other relevant search terms). The findings indicated a large temporary surge in queries about genetics and treatment, a modest increase in queries about general information and risk assessment, and a rapid return to baseline after about 1 week. The implication is that Angelina Jolie spurred significant information-seeking about breast cancer genetic testing for a short time. The lack of sustained activity also underscores the fleeting nature of fame and public attention.

Researchers in other fields might apply the same methods for informing their own studies of acute illnesses, chronic diseases, medical treatments, or unforeseen crises. The Google Trends database allows single or multiple combined word searches to organize each investigation toward relevant items. The resulting data are numerical, longitudinal, reproducible, accessible, immediate, and free. Another strength is the ability to stratify online trends by geographic region and thereby avoid selective reporting from a few outliers. A downside, however, is the need for statistical sophistication since the actual data are normalized as ''relative search volume,'' which hides the actual count of people involved (a restriction that protects the proprietary interests of Google Inc.).

This type of research has been termed *infodemiology* and defined as the science examining the determinants and distribution of health information on the Internet.[5] The general design involves monitoring

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the supply (e.g., blogs) and demand (e.g., queries) for health information on digital media. One exemplar of this research has been in tracking flu-related searches to predict H1N1 influenza outbreaks around the world.[6] The common limitation of this research is overinterpretation because online data indicate an awareness of the issue but cannot distinguish genuine understanding, misunderstanding, or idle curiosity. Online trend analysis, for example, would not work to determine if we are truly succeeding in efforts to curb cancer or pneumonia.

The methods of Seth Noar and colleagues might still benefit from future improvements. One opportunity is to corroborate data with other search engines (eg, Bing, Ask, Aol Search, Yahoo! Search) and social media (eg, Twitter, Tumblr, Facebook, reddit). A second opportunity relates to distinguishing searches from individuals, since the data do not separate 1 person with 5 queries from 5 persons with 1 query. A related challenge is how to avoid ecological bias since community rates sometimes mischaracterize changes at the individual level.[7] A final issue involves assessing knowledge, since an initial query is easily dismissed by a subsequent query. These methodologic opportunities represent the frontier of infodemiology.

The case of Angelina Jolie is sufficiently important that it also raises a few more specific caveats. For Angelina Jolie, the online data do not indicate whether her decision truly saved her life. A lack of hard outcomes also prevents us from knowing whether her disclosure will eventually save other women (most patients with breast cancer are not BRCA1 positive). The gap extrapolating the online world to the real world is further accentuated because of breaks in the chain of access, effectiveness, adherence, and outcomes for patients. Moreover, we have no easy way of assessing potential adverse effects, including whether her movies glorifying reckless driving (eg, *Gone in Sixty Seconds*) contribute to an offsetting increase in traffic deaths (killing twice as many as breast cancer each year).[8]

Angelina Jolie has inspired countless moviegoers with her portrayals of strong, intelligent, courageous, resilient, beautiful women. Her disclosure proves that the heroism is more than just an act. The work by Seth Noar and colleagues now shows how rigorous methods can help analyze subsequent online information searches. Most decision science is not sexy and does not attract nearly as much public attention as the Angelina Jolie's disclosure. Medical decision science, however, is ultimately what informed Angelina Jolie's action (a treatment estimated to decrease her lifetime risk of dying from breast cancer from about 87% to 5%).[9] Similar to the directors who work with Angelina Jolie, medical decision scientists stay hidden behind the scenes working to guide people in life-threatening situations.

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