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Celebrity Influence? An Observational Study of
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Paper No: 2015-012

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Celebrity influence? An observational study of consumer responses on social media and on an internet search engine to news of Angelina Jolie's prophylactic mastectomies

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Abstract

We sought to explore US individuals' internet and social media behavior before and after Ms Angeline Jolie's disclosure of her BRCA status and prophylactic surgery. All US individuals using Google's search engine to search for keywords 'double mastectomy,' 'breast cancer,' or 'BRCA gene' between April 21 and May 20, 2013, and all US individuals mentioning keywords on Twitter, blogs and online forums between February 21 through July 20, 2013 were captured. We performed a descriptive analysis of relative daily number of Google searches for keywords and absolute daily mentions on social media of keywords. Google searches for and social media mentions of keywords were immediately but transiently elevated in the several days following Ms Jolie's article. Celebrity news can impact individuals for health behavior. Despite apparent transient elevation of US consumer interest in relevant keywords, it is not yet known whether utilization of BRCA gene testing and/or prophylactic surgery will change.

Keywords: Patient decision-making, media influence, celebrity influence, breast cancer, BRCA gene testing, prophylactic mastectomy

Introduction

Patients can be influenced by medical information in the media. Widespread media reports of increased risk with vaginal births after cesarean sections were associated with a rapid drop in the rate of this procedure.[1] Popular celebrities may accentuate this effect. Following news in the traditional media of President Reagan's colon cancer, early detection with fecal occult blood tests increased. [2]

The advent of social media and online activity may accentuate these effects too. Social media use is part of individuals' need for autonomy, competence and relatedness with others.[3] Consumers use the internet to deal with their own or close others' life and health issues.[4] One in four Americans with a significant health change say the internet has helped them deal with major life decisions.[5]

However, less benevolent effects are also possible. Misleading or overly salient media information could drive sub-optimal consumer decisions. One example is celebrity influence on vaccination rates based on autism fears.[6] Another example, the subject of this study, lies in the context of hereditary breast cancers.

While prevention and screening are desirable in appropriate risk strata, overuse of BRCA gene screening in patients with a low pre-test probability would be undesirable.[7] More than a third of US women with BRCA1 or 2 mutations already choose prophylactic mastectomy, higher than in many other countries.[8] Overuse of non-medically indicated prophylactic surgery in women with lower risk would be another concern.[9]

In this context, Angelina Jolie revealed her prophylactic double mastectomy for BRCA1 gene marker status in the New York Times online on May 13, and in print on May 14.[10] While other options such as MRI monitoring exist,[11] consumers may decide to follow Ms Jolie's lead regardless of true risk stratum or procedure appropriateness. Indeed, Ms Jolie (2013) hoped that women:

"... will be able to get gene tested, and that if they have a high risk they, too, will know that they have strong options."

Patient-centered care requires care that is respectful of patient preferences.[12] Yet fear of cancer may increase the trend towards aggressive risk-reducing procedures. For example, a blogger wrote on the same day as Ms Jolie's article:

"Angelina Jolie went from having an 87% chance of getting breast cancer to 5% chance. ... If I am accepted for BRCA testing, and my results show that I, too, am carrying the BRCA gene, I am certain my decision will be crystal clear as well."[13]

I hypothesized that Ms Jolie's widely-disseminated medical information could lead individuals to increase their interest in prophylactic, risk-reducing mastectomies and BRCA gene test screening. I assessed individuals' responses by examining private search behavior on Google as well as public disclosures in traditional media and on social media.

Google search behavior can provide a measure of consumers' private preparatory steps to undertake purchases. Google search volume has been used to accurately predict US private

consumption.[14] Social media disclosures on tweets, blogs, forum and other postings can be monitored using social media access platforms, and similarly provide a measure of consumers' public interest in and attitudes towards products, services and news items.[15]

In this study, my overall aim was to consider whether individuals' private search and public social media behavior was temporally and content-wise related to celebrity media disclosures of health-related information. These relationships were found, although the association between such individual activity and subsequent use of healthcare must await utilization data.

METHODS

Two sources of data on consumer interest were used. I used Google Trends to explore search volumes of selected terms. Google Trends is a free analytical service available through Google for registered users. It provides summaries of daily search volume for user-selected terms, but allows users to visualize this data only as percentages of the peak search volume within a period for the most common user-selected term.

I searched for the key search terms of 'double mastectomy,' 'breast cancer,' and 'BRCA gene' between April 21 and May 20, 2013 originating in the United States and classified by Google as belonging to a 'general search category'. [16] Google also classifies searches as belonging to one of many specialized categories, including a 'medical facilities & services subcategory.' These categorizations are based on Google's proprietary assessment of term-category match. The effect of these categorizations is to segment searches into economically

meaningful categories that facilitate and enhance Google's commercial sponsored search and display advertisement business model.

I also used a commercial tool, Sysomos by Marketwire, to search social and traditional media. Sysomos' MAP media access platform tool searches within more than 230 billion online media documents across all major platforms. In this study I restricted search activity to microblogger Twitter (the full 'firehose' of more than a billion tweets every five days), blogs (e.g. Blogger), online forums (e.g. cafemom.com) and all traditional media.

These restrictions reflected media access platform limitations which include a lack of access where the proprietary platform blocks such access (the major example being Facebook, which allows only access to the most recent 6 weeks of public updates), or where users have used password protection to limit outsiders from viewing content (e.g. Youtube pin numbers), or where the platform requires registration and credentialed log-ins to view content (e.g. LinkedIn).

I used Sysomos to count United States originating mentions of relevant terms over the periods April 21 through May 20, 2013 as well as February 21 through July 20, 2013. To compare total number of mentions to an arbitrary, more familiar search term, I also counted mentions of the term 'coffee'.

Finally, I used Sysomos to analyze sentiment as to whether users' views, attitudes or opinions were positive, negative (e.g. fear, anxiety, sadness) or neutral about their content.[17,18] The Sysomos tool employs a proprietary contextual sentiment engine using

Natural Language Processing, in which all text is automatically classified with an accuracy of 85% compared to gold-standard, human-classified sentiment analyses.

In this exploratory analysis, the analytical strategy chosen was simple and descriptive. To show temporal relations between Ms Jolie's article and private or public individual behavior, I graphed trends in Google searches and social media mentions over the periods of interest. To show content relations between the article and such searches or disclosures, I summarized frequencies of search terms per day (Google Trends) and frequencies of mentions of search terms per day as well as summary social media sentiment over the period examined (Sysomos).

As this study used publicly available aggregated and deidentified data, Institutional Review Board approval was not required by the study institution.

FINDINGS

Google Search Trends Data

Results of the analyses of Google search engine activity revealed large transient peaks in general Google searches for 'double mastectomy' and 'breast cancer' and a smaller transient peak for 'BRCA gene' around the time of Ms Jolie's article (Figure 1).

<< Figure 1 about here >>

Increase in search activity for 'double mastectomy' immediately prior to the online publication of her article may reflect leakage from or research by the newspaper's staff, or may simply reflect smoothing of datapoints by Google. Restricting searches to those Google

classified as in the 'medical facilities & services subcategory' showed that only volume for 'double mastectomy' searches were transiently elevated (data not shown).

Social and Traditional News Media Data

To understand the baseline of online social media activity, I first examined the longer period between February 21 and July 20, 2013. Aggregating mentions of 'double mastectomy', 'BRCA gene' and 'breast cancer' showed a very low baseline and a large, transient elevation immediately around the publication of Ms Jolie's article (Figure 2).

<< Figure 2 about here >>

Disaggregating mentions of the three key terms around the shorter period between April 21 and May 20, 2013 showed (Figure 3) that mentions of 'double mastectomy' and 'breast cancer' showed a similar time signature of immediate, but transient elevation with very activity for 'BRCA gene' mentions.

<< Figure 3 about here >>

A total of 275,384 mentions of 'breast cancer', 108,563 mentions of 'double mastectomy' and 4,175 mentions of 'BRCA gene' occurred in the month between April 21 and May 20 (Table 1). For all three terms, Twitter was the dominant platform. To put these counts into perspective, there were 4,706,256 mentions of an arbitrary control term 'coffee' over the same period (data not shown).

Sysomos identified sentiment regarding 'double mastectomy' as six times more likely to be negative than positive (Table 1). Sentiment towards 'breast cancer' and 'BRCA gene' was approximately one and a half times more likely to be negative than positive. In contrast, sentiment towards the control term of 'coffee' was 39% positive, 48% neutral and only 13% negative.

DISCUSSION

This study finds that private Google searches for, and public social media disclosures of interest in, breast cancer, double mastectomies and BRCA genes increased immediately but transiently following a celebrity's announcement of her treatment and gene mutation status.

This interest was captured by Google web searches in specific categories that are used by advertisers to place sponsored advertisements and generally can forecast private consumption.

[14] This interest was also visible in social media disclosures generally thought to be associated with genuine consumer interest and purchase behavior.

If this interest leads to increased awareness of genetic risks for breast cancer and a broad discussion of diagnostic and therapeutic options, high-risk patients are likely to benefit.

However, concerns exist about over-adoption of innovative medical technology in general, and potential overuse of BRCA gene screening and preventive breast surgery in women of very low risk in particular.

While BRCA screening and double mastectomies are indicated in some patient subsets, the use of screening in low pre-test probability settings and subsequent use of non-indicated risk-

reduction procedures remain serious phenomena. In related settings, non-BRCA carriers have undertaken risk-reducing procedures for ovarian cancers, presumably to allay deep-seated fears.[19] In closely related settings, addressing women's legitimate fears and need for peace of mind may lead to unnecessary contralateral prophylactic mastectomies,[20] despite National Comprehensive Cancer Network guidelines that discourage such procedures except for BRCA mutation carriers.[21] Recent studies show that among women receiving a contralateral prophylactic mastectomy together with mastectomy of the affected breast, 70% did not have a clinical reason for having one done.[22,23]

Future studies will show whether Ms Jolie's choices were associated with increases in appropriate BRCA screening and informed, clinically indicated risk reduction procedures. I conjecture that discontinuous increases in both will occur in the short term, and so will not be confounded by the recent Supreme Court decision allowing more competitive entry into the BRCA gene testing market which is likely to lower prices and increase demand for this test over the medium to long term.[24]

Limitations

This study's strength lies in its ability to track the complete set of all Google search engine internet searches and all Twitter, blog, forum and traditional media sources on a daily basis within the US population. This allowed a fine characterization of consumer interest in the days before and after Ms Jolie's article.

Yet this study has several important limitations. Most fundamentally, this study is limited by its inability to associate contemporaneous online behavior with contemporaneous breast cancer screening and surgery decisions. It is entirely possible that online searches and social media disclosures related to Ms Jolie's article were only passing interests. It may be more than a year before utilization data is made available for analysis in future studies.

A demographic limitation of this study is that users of social media and internet search engines do not necessarily correspond to the incident breast cancer population. For example, Sysomos estimated (data not shown) that around 40% of tweets relating to 'double mastectomy' were male, while 51% of blog authors were male.

Another demographic limitation lies in differences in technology adoption and use. While 78% of American adults use the internet, and 35% own a smart, internet-enabled cellphone, the corresponding usage patterns differ by age, ethnicity, race, and socio-economic status. An estimated 59% of American adults have used the internet, but only 15% of adults have used their smartphone for this purpose.[25] Since the young aged 18-29 years, and those belonging to minority populations are far more likely to have smartphone than fixed internet access, it is clear that the types of sites and the types of online activities will differ accordingly due to constraints on the screen, data speed and expense of access.

These demographic mismatches between incident breast cancer population and online user population may be mitigated to some unknown extent by survey results which suggest that individuals go online to obtain information for other friends or family members.[4]

Finally another limitation is that large numbers of social media mentions do not necessarily imply a cascade of interest in the focal terms driven by social media. A highly active view of online consumers sharing and spreading information online and within social networks much like a highly contagious epidemic has been questioned. [26] For example, the vast majority of information cascades grows slowly and fails to reach 'epidemic' proportions. On one social media platform, Digg, these cascades reached fewer than 1% of users. The high degree of clustering on such social networks may mean that most people who are aware of a story have already been exposed to it via multiple connections. [27]

CONCLUSION

Patients and consumers are exposed to health-related information in the media, especially through celebrities. Counseling patients on serious, prevalent diseases such as breast cancer is more challenging in a setting of celebrity influences and media hyperawareness of options. An unanswered question is whether such influence might contribute to costly over-utilization of screening in low-risk patient subsets. Over-screening could lead to costly, potentially harmful or unnecessary surgery. [7,8,9] Policy-makers and practitioners should strive to ensure that patients receive true patient-centered care which requires patients to understand all their screening and treatment options and make informed choices.[28]

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Acknowledgements: I would like to thank Marketwire for training on how to use their Media Access Platform Sysomos MAP which was used for the social media analyses.

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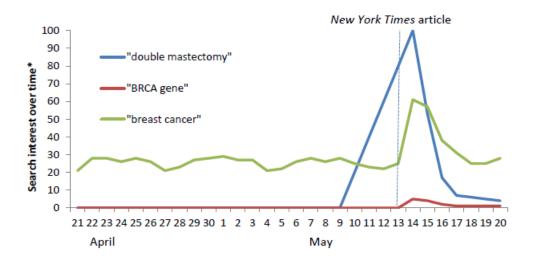
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Figure 1: Google Search Trends

(Google web searches in the United States for terms related to prophylactic mastectomy, BRCA gene testing and breast cancer in the 31 days around the time of Ms Angelina Jolie's May 13-14, 2013 article on her diagnosis and treatment.)



Note (*): vertical axis scale is normalized by Google so that 100 represents peak search volume in time and term range. Changes in normalized daily search volume are smoothed by Google.

Data obtained from Google Trends between April 21 and May 20, 2013.

Figure 2: Long Term Social and Traditional Media Trends

(Mentions of terms related to prophylactic mastectomy, BRCA gene testing and breast cancer in the 150 days around the time of Ms Angelina Jolie's May 13-14 article on her diagnosis and treatment. Data obtained using Sysomos MAP media access platform between February 21 and July 20, 2013.)

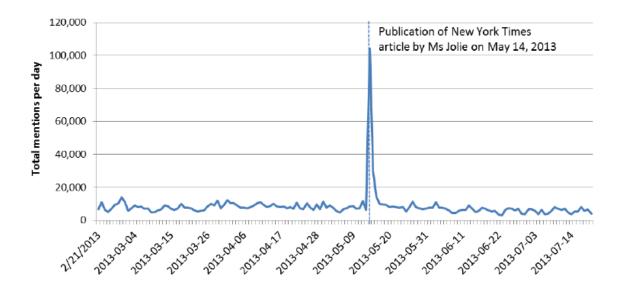


Figure 3: Short Term Social and Traditional Media Trends.

(Mentions of terms related to prophylactic mastectomy, BRCA gene testing and breast cancer in the 10 days around the time of Ms Angelina Jolie's May 13-14 article on her diagnosis and treatment. Data obtained using Sysomos MAP media access platform between May 10 and May 20, 2013.)

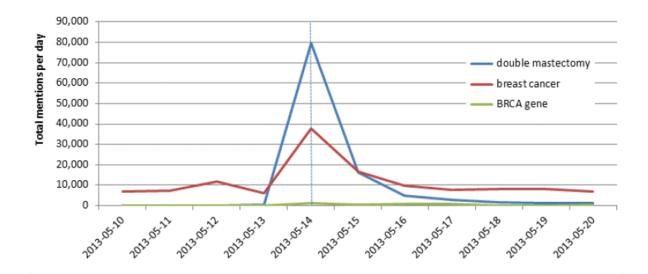


Table 1: Social and traditional media mentions and sentiment.

Social and traditional media mentions and sentiment around key search terms relating to Angelina Jolie's disclosure of prophylactic double mastectomy on May 13-14, 2013.

	Mentions ^a	Sentiment ^b (%)		
		Positive	Neutral	Negative
"Breast cancer"	275,384	22	43	35
Traditional media	26,266	31	26	43
Twitter social media	200,638	4	92	4
Blogs	25,923	22	26	52
Forums	22,557	30	28	42
"Double mastectomy"	108,563	8	43	49
Traditional media	6,997	9	22	69
Twitter social media	87,132	6	90	4
Blogs	6,748	10	25	65
Forums	7,671	8	35	57
"BRCA gene"	4,175	19	46	35
Traditional media	548	8	29	63
Twitter social media	2,748	6	92	2
Blogs	493	22	37	41
Forums	386	41	26	33

Results summarize Sysomos searches in public US online disclosures of social and traditional media over the period April 21-May 20, 2013

^a Mentions are counts of identified phrase in each media category

^b Sentiment summarizes a Sysomos proprietary semantic analysis of each mention