

Cancer Information Seeking in the Digital Age: Effects of Angelina Jolie's Prophylactic Mastectomy Announcement

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Objective. This study used digital surveillance to examine the impact of Angelina Jolie's prophylactic mastectomy announcement on cancer information seeking. **Methods.** We analyzed 4 categories of breast cancer-related Internet search queries from 2010 to 2013 in the United States. **Results.** Compared with the preceding 6 weeks, general information queries were 112% (95% confidence interval [CI], 79–146) higher the day of the announcement and remained 35% (95% CI, 22–49) higher over the week after the editorial. Risk assessment queries were 165% (95% CI, 110–222) higher the day of the announcement and 52% (95% CI, 31–75) higher across the week. Genetics and treatment queries showed little volume before the announcement but increased 2154% (95% CI, 1550–7076)

and 9900% (95% CI, 3196–1,064,000) the day of, respectively, and remained higher across the week (812% [95% CI, 402–3913] and 2625% [95% CI, 551–317,000]). All query categories returned to normal volumes by the beginning of the second week. **Conclusion.** Jolie's unique announcement spurred significant information seeking about breast cancer genetic testing and treatment procedures, although the surge in queries returned to preannouncement levels after 1 week. Future research should apply digital methods to advance our understanding of cancer information seeking in the digital age. **Key words:** breast cancer; cancer information seeking; digital surveillance; genetic testing; prophylactic mastectomy; cancer communication. (*Med Decis Making* 2015;35:16–21)

Public figure or celebrity announcements about cancer can have substantial effects on patient

decision making about medical procedures.¹ One of the earliest examples was First and Second Ladies Betty Ford and Margaretta “Happy” Rockefeller, whose mastectomies in 1974 garnered significant media attention² and increases in mammography screening.³ More than a decade later, First Lady Nancy Reagan's choice of mastectomy was widely followed by the public⁴ and led to short-term decreases in breast-conserving surgery,⁵ despite longer-term trends in the opposite direction.⁶

Several studies suggest that the most proximal effect of public figure announcements about cancer is information seeking.^{7–9} For instance, in the month after President Ronald Reagan's colon cancer surgery, calls to the Cancer Information Service for colon cancer increased 4-fold, followed by a 28% increase in colon cancer screening over the subsequent year.⁹

Received 31 July 2014 from the School of Journalism and Mass Communication, University of North Carolina, Chapel Hill (SMN, DBF); Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill (SMN, KMR); Santa Fe Institute, Santa Fe, New Mexico (BMA); Graduate School of Public Health, San Diego State University, San Diego, California (JWA); and Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina, Chapel Hill (KMR). Financial support for this study was provided by a grant from University Cancer Research Fund and Lineberger Comprehensive Cancer Center at the University of North Carolina at Chapel Hill. The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report. The following author(s) are employed by the sponsor: Seth M. Noar and Kurt M. Ribisl. Benjamin Althouse and John Ayers share an equity stake in a consulting group, Directing Medicine, which helps others implement some of the ideas embodied in this work. The data generation procedures, however, are not proprietary and rely on public archives. Revision accepted for publication 20 September 2014.

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DOI: 10.1177/0272989X14556130

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Other studies have similarly demonstrated increases in information seeking in the wake of celebrity cancer announcements, foreshadowing later increases in screening behavior.^{1,10,11}

The events studied above predate the advent of the Internet and online cancer information seeking, and the media landscape has changed significantly over the past decade.¹² Despite this, cancer information-seeking research continues to rely largely on survey research methods,^{13–15} which have limitations, including false recall, social desirability, and a lack of sensitivity to serendipitous events. Novel digital tools, such as digital surveillance of web data (also known as “infodemiology” or “infoveillance”), have recently become available.^{16–18} These methods hold several advantages over traditional methods such as availability in near real time, public availability, low cost, and lack of self-report.¹⁹

The current study applied digital methods^{16,20} to examine cancer information seeking in response to a novel celebrity cancer announcement. Angelina Jolie is the well-known actress who on May 14, 2013, disclosed in a prominent *New York Times* editorial that she had tested positive for the genetic mutation *BRCA1* and had undergone a prophylactic double mastectomy. Several media outlets picked up the story,²¹ and 3 of every 4 American adults were exposed to it.²² However, the impact of this exposure on the public remains unknown. In particular, did Angelina Jolie’s announcement stimulate cancer information seeking, and if so, what topics were searched? We hypothesized that Ms. Jolie’s announcement would stimulate significant online cancer information seeking about breast cancer.

METHODS

To assess the effects of Jolie’s announcement, we analyzed online search queries for breast cancer from 2010 to 2013 in the United States using a quasi-experimental design.²³

Search Query Trends

Aggregate query trends were downloaded from Google Trends (www.google.com/trends/). We monitored 4 categories of searches relating to breast cancer: general information, risk assessment, genetics, and treatment. General information queries included all queries *only* containing the term *breast cancer*; risk assessment included all queries including *breast cancer risk(s)*, *breast cancer cause(s)*, and *breast*

cancer prevent(ion); genetics queries included all queries containing the terms *brca1*, *brca2*, *breast cancer gene(s)*, and *breast cancer genetic(s)*; and treatment queries included all queries containing the terms *breast cancer treatment(s)*, *mastectomy*, and *nipple delay*. We also monitored searches for “Angelina Jolie” from 2004 to 2013 to compare the event with typical search volume for “Angelina Jolie.” Trends were analyzed on a relative search volume (RSV) scale, with queries normalized to the period with the highest search proportion (e.g., RSV = 100 is the highest search proportion period [breast cancer queries v. all search queries], and RSV = 50 is 50% of the highest search proportion). This approach corrects for trending in absolute search volume that is usually increasing over time.²⁴

Analysis Strategy

Data were analyzed on a daily time scale. Visual inspection of the data suggested that the likely impact of Jolie’s announcement was a pulse effect: an immediate change in mean query volume rather than a durable shift. We specified interrupted time series to estimate the mean volumes on the day of the editorial and up to a week after, comparing these volumes with the mean query volume for the preceding 6 weeks (April 1, 2013, to May 13, 2013). Confidence intervals around these quotients were estimated by simulating 5000 random draws from the multivariate normal sampling distribution with mean equal to the maximum likelihood point estimates and variance equal to the variance-covariance matrix—that is, $\hat{\beta}_{est} \sim MVN(\hat{\beta}_{mle}, V(\hat{\beta}_{mle}))$, where $\hat{\beta}_{mle}$ are the vector of the regression coefficients and $V(\hat{\beta}_{mle})$ their variance-covariance matrix from the regression.²⁵ Estimates of volume were limited to being greater than 1 to stabilize the estimate of the increase (RSV cannot be negative, and an RSV of 0 indicates censoring due to low volume).

RESULTS

Figure 1 shows breast cancer-related trends around Jolie’s editorial. Compared with the previous 3 years, both genetics and treatment search queries reached all-time highs. General information and risk assessment queries, while exhibiting higher volume than would be expected for May, did not reach highs comparable to Breast Cancer Awareness Month (shaded in Figure 1a). Query trends spiked on the day

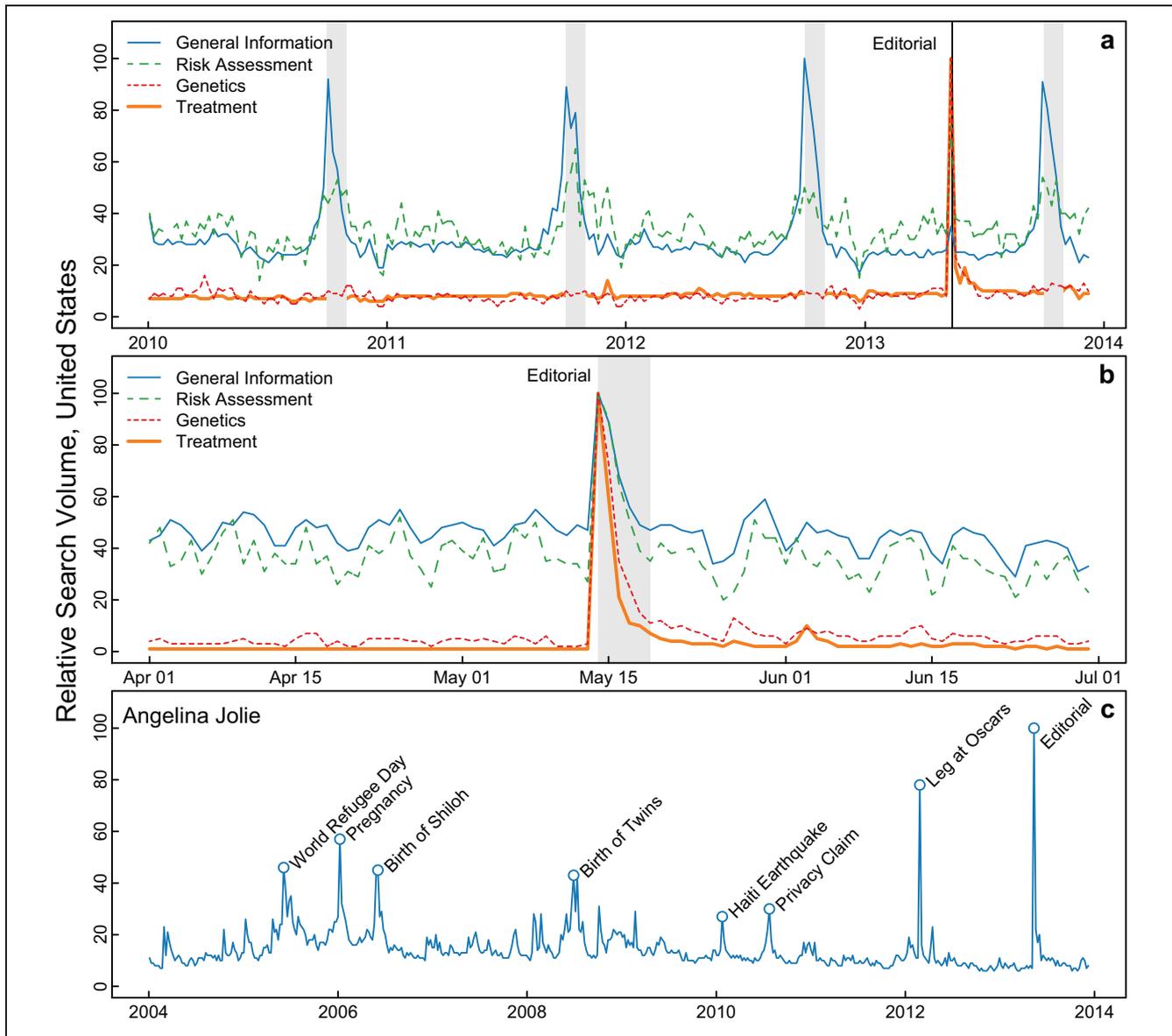


Figure 1 Search query trends in relation to Angelina Jolie's New York Times editorial (a) shows interest in the 4 categories over time. Shaded regions highlight Breast Cancer Awareness Month (October), and the black vertical line indicates Jolie's editorial. (b) Search volume around the editorial. Shaded area highlights the week after the editorial. (c) Search volume for "Angelina Jolie." Note: "Leg at Oscars" denotes search interest around Jolie's red carpet photograph at the 2012 Academy Awards.

of the editorial compared with the month before and stayed elevated over the week after the editorial.

The editorial was also associated with elevated search behavior for Jolie herself, with the week of the editorial exhibiting more searches for "Angelina Jolie" than any previous event since search tracking began in 2004 (Figure 1c). Compared with normal search volume for "Angelina Jolie" (i.e., with the

events in Figure 1c removed), the searches were 261% (95% confidence interval [CI], 187–368) higher over the week of the editorial and 120% (95% CI, 69–191) higher over the second week.

Statistical analysis suggested Jolie's editorial was associated with increases in breast cancer search queries (Figure 2), and while similar patterns were seen across the categories, volume was by far the

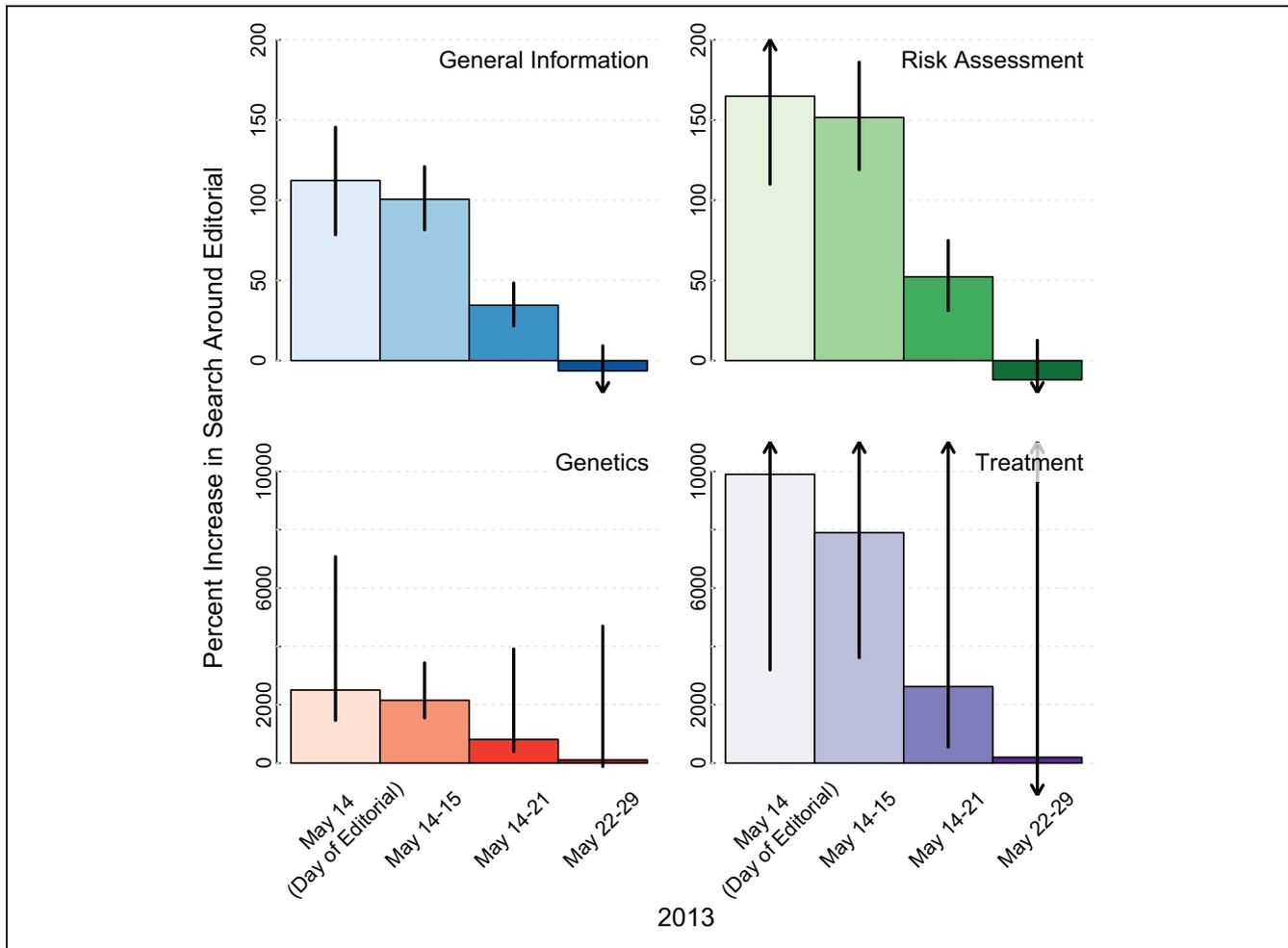


Figure 2 Changes in search query volume around Jolie's editorial. Note top panel on 0 to 200 scale and bottom panel on 0 to 10,000 scale.

highest for genetics and treatment queries. General information queries were 112% (95% CI, 79–146) higher the day of the editorial and remained elevated at 35% (95% CI, 22–49) higher over the week of the editorial. Risk assessment queries were 165% (95% CI, 110–222) higher the day of the editorial and 52% (95% CI, 31–75) higher across the week. Genetics and treatment queries showed little volume before the editorial but demonstrated significant spikes in response to it, increasing 2154% (95% CI, 1550–7076) and 9900% (95% CI, 3196–1,064,000) the day of, respectively, and remaining high across the week (812% [95% CI, 402–3913] and 2625% [95% CI, 551–317,000]). All query categories returned to normal volumes (difference not statistically significantly different from 0) by the beginning of the second week.

DISCUSSION

Both medical²² and popular²¹ literature has raised the question of whether there was an “Angelia effect” resulting from Jolie’s announcement. Our data suggest that there was a strong effect, particularly on information seeking about breast cancer genetic testing and treatment. Consistent with previous celebrity cancer announcements,^{7,8} we observed a “pulse effect” in which information seeking greatly (but briefly) increased immediately following the announcement.

Given these findings, the Jolie editorial was a significant public event for breast cancer genetic testing. Prior to this event, online searches for such genetic testing were almost nonexistent. But how will this affect risk perceptions and decision making about

BRCA testing? Research to assess whether trends in genetic testing change as a result of this event are needed. While there are still several barriers to *BRCA* testing, including cost,²⁶ this announcement may well affect counseling and testing rates.

Also noteworthy is the fact that prophylactic²⁷ and contralateral prophylactic²⁸ mastectomies are on the rise. Jolie's announcement will further raise the profile of prophylactic mastectomies. Given that Nancy Reagan's surgery showed effects on surgery choice,^{3,5} health care providers should be aware of increased patient interest in such treatments. One study suggested the Jolie announcement did *not* increase women's understanding of breast cancer risk, and thus patients may be more interested but not better informed. That same study also found 73.5% of women thought Jolie made the right choice and 57.4% would have had the surgery themselves.²² Whether this event affects decision making around breast cancer treatments is a question for future research.

Limitations and Implications for Cancer Information-Seeking Research

This study was limited in that we do not know the precise population who sought information online, and digital data may not be representative of the population. Also, our data represent the volume of searches, *not* individuals who searched, and searches were analyzed on a relative (not absolute) scale. As more individuals go online, however, digital data may be increasingly representative of population trends.^{19,20}

The current study revealed important trends in online cancer information seeking in response to Angelina Jolie's unique announcement. Future research should apply digital methods to advance an understanding of cancer information seeking in the digital age. The Internet is the first place most people go for health information,^{29,30} and the changing communication landscape demands that we adapt our methodologies accordingly.¹² While studies have begun to apply these methods,^{7,8,31,32} much work remains to be done.

REFERENCES

- Noar SM, Willoughby JF, Myrick JG, Brown J. Public figure announcements about cancer and opportunities for cancer communication: a review and research agenda. *Health Commun.* 2014;29:445–61.
- Corbett JB, Mori M. Medicine, media, and celebrities: news coverage of breast cancer, 1960–1995. *Journal Mass Commun Q.* 1999; 76:229–49.
- Fink R. Effects of news events on response to a breast cancer screening program. *Public Health Rep.* 1978;93:318–27.
- Lane DS, Polednak AP, Burg MA. The impact of media coverage of Nancy Reagan's experience on breast cancer screening. *Am J Public Health.* 1989;79:1551–2.
- Nattinger AB, Hoffmann RG, Howell-Pelz A, Goodwin JS. Effect of Nancy Reagan's mastectomy on choice of surgery for breast cancer by US women. *JAMA.* 1998;279:762–6.
- Du X, Freeman DH Jr, Syblik DA. What drove changes in the use of breast conserving surgery since the early 1980s? The role of the clinical trial, celebrity action and an NIH consensus statement. *Breast Cancer Res Treat.* 2000;62:71–9.
- Metcalfe D, Price C, Powell J. Media coverage and public reaction to a celebrity cancer diagnosis. *J Public Health (Oxf).* 2011;33:80–5.
- Noar SM, Ribisl KM, Althouse BM, Willoughby JF, Ayers JW. Using digital surveillance to examine the impact of public figure pancreatic cancer announcements on media and search query outcomes. *J Natl Cancer Inst Monogr.* 2013;2013:188–94.
- Brown ML, Potosky AL. The presidential effect: the public health response to media coverage about Ronald Reagan's colon cancer episode. *Public Opin Q.* 1990;54:317–29.
- Casey GM, Morris B, Burnell M, Parberry A, Singh N, Rosenthal AN. Celebrities and screening: a measurable impact on high-grade cervical neoplasia diagnosis from the 'Jade Goody effect' in the UK. *Br J Cancer.* 2013;109:1192–7.
- MacArthur GJ, Wright M, Beer H, Paranjothy S. Impact of media reporting of cervical cancer in a UK celebrity on a population-based cervical screening programme. *J Med Screen.* 2011;18:204–9.
- Blake KD, Chou WY, Prestin A, Hesse BW. Cancer prevention and control in the changing communication landscape. *J Natl Cancer Inst Monogr.* 2013;2013:131–2.
- Rutten LJJ, Squiers L, Hesse B. Cancer-related information seeking: hints from the 2003 Health Information National Trends Survey (HINTS). *J Health Commun.* 2006;11:147–56.
- Smith-McLallen A, Fishbein M, Hornik RC. Psychosocial determinants of cancer-related information seeking among cancer patients. *J Health Commun.* 2011;16:212–25.
- Hartoonian N, Ormseth SR, Hanson ER, Bantum EO, Owen JE. Information-seeking in cancer survivors: application of the comprehensive model of information seeking to HINTS 2007 data. *J Health Commun.* In press.
- Brownstein JS, Freifeld CC, Madoff LC. Digital disease detection—harnessing the web for public health surveillance. *N Engl J Med.* 2009;360:2153–5.
- Ayers JW, Althouse BM, Dredze M. Could behavioral medicine lead the web data revolution? *JAMA.* 2014;311:1399–400.
- Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. *J Med Internet Res.* 2009;11:e11.
- Santillana M, Zhang DW, Althouse BM, Ayers JW. What can digital disease detection learn from (an external revision to) google flu trends? *Am J Prev Med.* 2014;47(3):341–7.
- Hubbard DW. *Pulse: The New Science of Harnessing Internet Buzz to Track Threats and Opportunities.* Hoboken, NJ: John Wiley; 2011.

21. Kluger J, Park A. The Angelina effect: her preventive mastectomy raises important issues about genes, health and risk. *Time Magazine*. May 27, 2013.
22. Borzekowski DL, Guan Y, Smith KC, Erby LH, Roter DL. The Angelina effect: immediate reach, grasp, and impact of going public. *Genet Med*. 2014;16:516–21.
23. Shadish WR, Cook TD, Campbell DT. *Experimental and Quasi-Experimental Designs for Generalized Causal Inference*. Boston: Houghton Mifflin; 2002.
24. Dutka AF, Hanson HH. *Fundamentals of Data Normalization*. Reading, MA: Addison-Wesley; 1989.
25. King G, Tomz M. Making the most of statistical analyses: improving interpretation and presentation. *Am J Pol Sci*. 2000; 44:341–55.
26. Weldon CB, Trosman JR, Gradishar WJ, Benson AB III, Schink JC. Barriers to the use of personalized medicine in breast cancer. *J Oncol Pract*. 2012;8:e24–e31.
27. Metcalfe KA, Birenbaum-Carmeli D, Lubinski J, et al. International variation in rates of uptake of preventive options in BRCA1 and BRCA2 mutation carriers. *Int J Cancer*. 2008;122:2017–22.
28. Tracy MS, Rosenberg SM, Dominici L, Partridge AH. Contralateral prophylactic mastectomy in women with breast cancer: trends, predictors, and areas for future research. *Breast Cancer Res Treat*. 2013;140:447–52.
29. Hesse BW, Moser RP, Rutten LJJ, Kreps GL. The Health Information National Trends Survey: research from the baseline. *J Health Commun*. 2006;11:7–16.
30. Rutten FLJ, Davis T, Beckjord EB, Blake K, Moser RP, Hesse BW. Picking up the pace: changes in method and frame for the Health Information National Trends Survey (2011–2014). *J Health Commun*. 2012;17:979–89.
31. Weeks BE, Friedenbergl LM, Southwell BG, Slater JS. Behavioral consequences of conflict-oriented health news coverage: the 2009 mammography guideline controversy and online information seeking. *Health Commun*. 2012;27:158–66.
32. Ayers JW, Althouse BM, Noar SM, Cohen JE. Do celebrity cancer diagnoses promote primary cancer prevention? *Prev Med*. 2014;58:81–4.