In Brief

Star Power: The Effect of Angelina Jolie’s Personal Story of BRCA1 Mutation on Testing Rates among Commercially Insured Women

Lina Walker
AARP Public Policy Institute

Pamela Morin
Optum Labs

Following Angelina Jolie’s May 2013 op-ed article in the New York Times, BRCA testing rates increased among women enrolled in a large U.S. health insurance carrier. Her story heightened awareness of BRCA mutations and probably contributed to those higher testing rates.

Background
Angelina Jolie published her personal story of testing positive for a harmful mutation in the BRCA1 gene on May 14, 2013, in the New York Times. The BRCA1 and BRCA2 genes produce proteins that protect the stability of a cell’s genetic structure. When these genes are altered in a way that prevents them from functioning properly, it increases a woman’s risk of developing breast or ovarian cancer. Because of her positive test result, Jolie chose to have a preventive double mastectomy, even though she did not have a diagnosis of breast cancer.

Angelina Jolie wrote:

My doctor estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer ... I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one that I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don't need to fear they will lose me to breast cancer.

Widespread Reaction Following Jolie’s Story
Given her iconic celebrity status, media coverage of her story was immediate and widespread, and the coverage lasted several months. Her story lit up the social and entertainment media outlets, and it was featured prominently in newspapers around the world.

Her story also prompted a surge in the number of people seeking information about BRCA testing and mastectomies. On the day of her announcement, Wikipedia searches for BRCA1 shot up to nearly 30,000, compared with just under 800 searches the day before. Page views for the National Cancer Institute's fact sheet on preventive mastectomy spiked to more than 69,000 views that day, compared with only 87 views the previous Tuesday. Jolie's story also increased referrals and BRCA testing at cancer clinics in Canada and the United Kingdom.

For more information on this article, please visit www.aarp.org/ cgi-bin/policy/ consumerguide/ og/ inbrief/1502-033.pdf.
Increase in BRCA Testing Rates in the United States

Our study is the first to document an increase in BRCA testing rates among women enrolled in a large U.S. health insurance carrier. Between April and May 2013, BRCA testing rates (reported as number of tests per 10,000 women) increased by nearly 40 percent and remained elevated for the rest of the year. The number of tests rose from about 1,400 in April to more than 2,000 in May (see figure 1).

Jolie’s announcement was published in the second week of May 2013. Our study shows that the spike in testing rates occurred during the week of her announcement. Two other news events could have contributed to higher testing rates at that time; however, given the patterns in the data, we conclude that the spike was largely attributable to Jolie’s story.

Women Similar to Jolie More Likely to Get BRCA Testing

After her story was published, twice as many women without a cancer diagnosis had the test, compared with women with a breast or ovarian cancer diagnosis. These women were probably concerned about their risk and sought testing for reasons similar to Jolie’s. Interestingly, before Jolie published her story, the reverse was true—more women with those cancer diagnoses got the test.

In addition, women who were white, Hispanic, or 64 years of age and younger were more likely to get the test than older, black, or Asian women (see figure 2).

Discussion

Although media coverage of Jolie’s story heightened awareness of the elevated risk of breast cancer with the BRCA gene mutation, its coverage of the rarity of having the harmful
BRCA mutation was much more limited. Only a third of the stories in traditional elite newspapers mentioned the rarity of the mutation in the general population. On average, only about 1 percent of all women are likely to have the mutation; consequently, genetic testing is not appropriate or recommended for all women.

Nevertheless, Jolie’s story shined a spotlight on and increased conversations about breast cancer. Before she shared her story, many women were probably unfamiliar with the risks associated with inherited BRCA mutations. Her experience facilitated conversations between women and their doctors or genetic counselors about testing and preventive measures. Those conversations enable women to make better-informed choices about their health care, which may save their lives or—at least—reduce their risk of cancer.

1 See fact sheet on BRCA by National Cancer Institute at: http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA.

2 This In Brief provides a synopsis of our results. We refer readers to Insight on the Issues 2015:100 for a fuller discussion of our findings, data limitations, and implications.

3 The other two potential influences are (a) news related to the U.S. Supreme Court hearing and ruling on the case against Myriad Genetics, which was the company that had a monopoly over BRCA genetic testing at that time, and (b) a clinical expert panel release of guidelines that clarified for whom it is clinically appropriate to obtain a BRCA test.