The Angelina Jolie Effect: Assessing the Impact of a Celebrity's Story on Cancer Genetic Counseling

Master's Thesis

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The Faculty of the Graduate School of Arts and Sciences
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Gretchen Schneider, MS, CGC, Advisor

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in
Genetic Counseling

by
Morgan MacCuaig

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ABSTRACT

The Angelina Jolie Effect: Assessing the Impact of a Celebrity’s Story on Cancer Genetic Counseling

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
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Waltham, MA

By Morgan MacCuaig

On May 14, 2013 The New York Times printed an op-ed piece by Angelina Jolie entitled, “My Medical Choice” in which she disclosed that she carries a mutation in one of her BRCA1 genes. Since mutations in this gene increase a woman’s lifetime risk of breast and ovarian cancer, to as high as 87% and 50%, respectively, Ms. Jolie elected to have a prophylactic double mastectomy and her public disclosure of this decision put a spotlight on hereditary cancer and genetic testing. We sought to assess the impact of her story, now known as the “Angelina Jolie Effect”, on cancer genetic counseling and patient decision-making. We distributed an anonymous online survey via e-blast to the National Society of Genetic Counselors’ listserv recruiting individuals who provide cancer genetic counseling. We analyzed 178 complete surveys and found that 89% of respondents experienced increases in calls requesting appointments for risk assessment and/or genetic testing, 84.4% saw increases in the number of low risk individuals requesting genetic testing, and 64.4% reported increases in the number of patients seen per week since the publication of the op-ed piece. A majority of genetic counselors (69.4%) also felt that low-risk individuals were more likely to push for genetic testing. Additionally, respondents believed
that, since the publication of The New York Times op-ed piece, there was an increased likelihood that BRCA1/2 mutation carriers would ask about and/or have a prophylactic mastectomy or oophorectomy, though the increase was greater for mastectomy. Our study provides the first data on the impact of Angelina Jolie’s story on cancer genetic counseling. Genetic counselors need to be prepared for the effects of celebrity stories, on their clinical practices and patients, and take an active role in helping the media to better communicate the complex issues associated with stories like Angelina Jolie’s.

Keywords: Angelina Jolie; breast cancer; BRCA1/2; genetic testing; hereditary breast and ovarian cancer (HBOC); prophylactic mastectomy
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INTRODUCTION

Breast cancer is a disease that predominantly affects women but, in rare cases, men as well. The current estimate is that one out of every eight women will receive a diagnosis of breast cancer at some point in her life (Howlader et al., 2012). As a result, approximately 234,500 new cases of invasive breast cancer occur each year in the United States and studies have shown that early detection and treatment increase long-term survival tremendously (Shen et al., 2005). Current breast screening recommendations for women in the general population include breast self-exams beginning in their twenties, and clinical breast exams every three years until the age of forty, at which time they should occur annually. While the American Cancer Society recommends yearly mammograms for women over age 40, the U.S. Preventive Services Task Force (USPSTF), an independent panel of experts appointed by the Department of Health and Human Services, recently released new recommendations that women beginning at age 50 and through age 74 should have mammograms, but every two years (American Cancer Society, USPSTF). While less common than breast cancer, approximately one out of every seventy-two women will receive a diagnosis of ovarian cancer at some point in her life, with a projected 22,000 new cases being diagnosed in the United States in 2014 (Ovarian Cancer National Alliance). Screening for ovarian cancer is not nearly as effective as breast cancer screening, with methods currently used to detect ovarian cancer including CA-125 blood test, transvaginal ultrasound, and pelvic exam typically identifying it at later stages.
In families with multiple individuals affected with breast cancer, particularly if the diagnosis occurs under the age of 40, the likelihood of an underlying genetic mutation is substantial. In 1990, Hall, et.al, published data from genetic studies on 23 extended families with 146 cases of breast cancer and determined that the chromosome 17q21 region was a candidate location for a gene that could increase one’s risk of developing early onset breast cancer. The following year, Narod et al., demonstrated that the same 17q21 chromosomal region is also associated with hereditary ovarian cancer. In 1994, Miki et al. identified the causative gene, named BRCA1, on chromosome 17. The same year, Wooster et al. discovered a second breast cancer susceptibility locus on chromosome 13q12-13 and their group identified the gene in this region, now known as BRCA2, a year later.

**BRCA1 and BRCA2** are the major genes implicated in hereditary breast and ovarian cancer families. Individuals found to have a pathogenic mutation in either gene are at increased risk for breast, ovarian, and other types of cancer, usually at a younger age than that seen in the general population (Narod, 1991 and Wooster, 1994). Therefore, it is important that individuals with a personal or family history of breast and ovarian cancer, specifically if diagnosed under the age of 45, undergo genetic counseling and consider genetic testing to determine their personal risks and management options as well as the risks to other family members.

Since individuals with a **BRCA1 or BRCA2** mutation typically have earlier onset breast and/or ovarian cancer, specific guidelines exist to better monitor this high-risk population. The most recent National Comprehensive Cancer Guidelines recommend that females who carry a **BRCA1 or BRCA2** mutation begin self-breast exams at age 18 and clinical breast exams every 6-12 months starting at age 25. They recommend annual
mammograms and breast MRI screening, at alternating six-month intervals, starting at age 25 or 10 years younger than the earliest breast cancer diagnosis in a family. The guidelines also encourage a discussion of risk-reducing mastectomy but do not advocate for recommending it to patients. Lastly, NCCN guidelines recommend that patients have a risk-reducing salpingo-oophorectomy either between the ages of 35-40, upon completion of child bearing, or prior to the earliest age of ovarian cancer diagnosis in the family (NCCN Guidelines, v.4.2013). In keeping with these recommendations, a 1996 study by Lerman et al. found that more women with a BRCA1 mutation intended to have a prophylactic oophorectomy (33%) than mastectomy (17%). Additionally, a more recent study by Laitman et al. (2014) showed that 49% of Israeli women with BRCA1/2 mutations had a prophylactic oophorectomy compared to 13% who had a mastectomy.

**Celebrity impact on cancer screening and treatment**

Despite the existence of specific cancer screening guidelines for both the general population and high-risk individuals, numerous studies have demonstrated an increase in both the number of screening tests and diagnostic procedures, and/or the overall awareness of a particular type of cancer after a celebrity has made a public announcement about their diagnosis, treatment and/or management choices. While increased awareness may be beneficial to the general population, it is complicated by the fact that some of the screening, prevention, and treatment choices made and discussed publicly by celebrities are not in sync with federal guidelines and recommendations.

The diagnosis of breast cancer and revelation of its early detection by mammography in Nancy Reagan in October of 1987 resulted in women’s heightened awareness of their lifetime risk of breast cancer and more importantly, an increase in the
number who contacted their health care providers and had their first mammogram (Lane, 1989). In addition, the number of mastectomy procedures increased in the year following Nancy Reagan’s modified radical mastectomy and women were 25% less likely to undergo a breast-conserving surgery (Nattinger, 1998).

A little more than ten years later, Katie Couric’s husband Jay Monahan died of colon cancer at age 42 and a weeklong series promoting colon cancer awareness and screening aired on the *Today Show*, during which Ms. Couric underwent an on air colonoscopy. Studies showed that, after this campaign, the number of colonoscopies performed by individual physicians increased from 15.0 to 18.1/per month. In addition, there was also a 4% increase in the number of women who had a colonoscopy (Cram, 2003). Similarly, in the months following the May of 2005 announcement that 36 year old Australian singer Kylie Minogue had breast cancer, Chapman et al. found that there was a 20-fold increase in the news coverage related to the topic of breast cancer in her native country. The number of mammograms booked in Australia also rose 40% in the two weeks after Ms. Mingoue’s story went public (Chapman, 2005).

While the visibility from celebrity stories has the potential to improve public health and awareness, there is legitimate concern it also may encourage certain screening and testing in people for whom it is inappropriate. In 2008, actress Christina Applegate was diagnosed with breast cancer after having a breast MRI. At that time, mammogram was the recommended method for early detection, especially for those at average risk for breast cancer. This raised concerns that Ms. Applegate’s diagnosis would result in increased demand for screening that the National Cancer Institute did not promote in the general population (Hoffman and Tan, 2013). In 2008, Kelaher et al. looked at the rates of breast
imaging in Australian women between the ages of 25-44 following the announcement of Ms. Minogue’s diagnosis, and saw a 20% increase in the number of women who received mammograms. Further examination of this group noted that despite the increase in imaging and breast biopsies in this low risk population, there was no change in the detection rate of breast cancer. This led Kelaher et al. to conclude there was an increase in inappropriate breast screening. Chapman (2005) and Cram (2003) further suggested that the medical community pay closer attention to celebrity promotion of screening for inappropriate and/or low risk individuals. Finally, Larson et al. commented that while it is appropriate for celebrities to promote safe sex and address other public health matters, when it comes to communication about complex issues like cancer screening, they feel that celebrities do not have an obvious role (Larson, 2005).

On May 14, 2013 The New York Times printed an op-ed piece written by Angelina Jolie entitled, "My Medical Choice”. In this article, Ms. Jolie disclosed that she carries a mutation in one copy of her BRCA1 gene. This mutation increases her lifetime risks of developing breast and ovarian cancer to as high as 87% and 50%, respectively, and because of this, Ms. Jolie chose to have a prophylactic double mastectomy. This surgical procedure reduced her risk of breast cancer over her lifetime to less than 5%. Ms. Jolie stated that by writing this editorial she hoped to, “encourage every woman, especially those with a family history of breast and ovarian cancer to seek the information and medical experts who can help them through this aspect of their lives” (Jolie, 2013).

Kamenova et al. recently looked at the type of news media coverage that Ms. Jolie’s disclosure generated. They found that, while the press covered many important issues around genetic testing for hereditary breast and ovarian cancer and the preventative
options available to at-risk women, the rarity of HBOC and Angelina Jolie’s situation was not properly communicated to the general public (Kamenova et al., 2013). Furthermore, this study concluded that the news media presented an overly positive perspective on Ms. Jolie’s mastectomy by describing it as brave, heroic and lifesaving. Finally, Kamenova et al. noted the importance of learning whether the increased media coverage surrounding Angelina Jolie’s medical decisions as described in her op-ed piece, has had an effect on the demand for HBOC testing and prophylactic mastectomies.

In a second study, Borzekowski et al. conducted an online survey of adults in the United States to assess the messages that the public took from Angelina Jolie’s story in The New York Times. They found that three quarters of the 2572 participants were aware of Angelina Jolie’s mastectomy. However, they also discovered that fewer than 10% of respondents could accurately state Ms. Jolie’s risk of developing cancer with a BRCA mutation relative to a woman in the general population (Borzekowski et al., 2013). They concluded that their data demonstrates a need for better communication to help the public understand the complex information in stories like Angelina Jolie’s.

In light of previous findings on the potential negative effects of the publicity surrounding celebrities’ medical decisions, it is possible that there has been an increased demand for inappropriate genetic testing and prophylactic surgeries since the publication of The New York Times article. Conversely, it is also possible that there has been an increase in appropriate genetic testing and prophylactic mastectomies from high-risk individuals since Ms. Jolie’s announcement. To date, there has been no research published looking at the impact of her story on clinical practices offering cancer risk assessment and genetic counseling. In addition, to our knowledge, there is currently no study investigating
the “Angelina Jolie Effect” to determine whether the number of individuals seeking and having genetic testing for hereditary breast and ovarian cancer has increased. Finally, there is no literature to date that reports on a celebrity genetic test result disclosure and its perceived impact on clinical practice.

The purpose of the present study was to examine genetic counselors’ perceptions of the “Angelina Jolie Effect”, as well as its impact on clinical practices offering cancer genetic counseling and testing. The study also looked to determine whether genetic counselors felt that, since the publication of Angelina Jolie’s story, there was an increase in the demand for genetic testing in both low and high-risk populations and or changes in decision-making with regard to prophylactic surgeries.
METHODS

STUDY DESIGN

We invited genetic counselors to complete an online anonymous survey assessing the impact of Angelina Jolie’s story entitled, “My Medical Choice”, on their clinical practice. Data collected by the survey included demographic information such as the participants’ age, gender, years of clinical practice, the geographic region in which they work, type of clinical setting, and the number of other genetic counselors in their practice. We assessed general awareness of Angelina Jolie’s op-ed piece by asking if participants were aware of it, how they heard about it, if they read it, and their initial reaction to the op-ed piece. The survey also asked participants if they discussed the op-ed piece with patients, in what context, and whether they felt the op-ed piece had a role in their patients’ decision-making process on how to manage their cancer risk. Finally, we asked participants to indicate if they thought the op-ed piece had an impact on aspects of their clinical practice including wait time for appointments, referral rates, requests for testing, and delays in test results and laboratories used for genetic testing.

SAMPLE POPULATION AND RECRUITMENT

Brandeis Committee for Protection of Human Subjects approved this study. We distributed a recruitment notice (Appendix A) by e-blast to all National Society of Genetic Counselors (NSGC) members on the NSGC listserv. Genetic counselors practicing in a clinical setting that currently offers genetic testing for Hereditary Breast and Ovarian
Cancer (HBOC) were eligible to participate in this study. This study remained open to participants for approximately three weeks, with a reminder e-blast e-mailed to the membership approximately two weeks after the initial invitation to participate.

DATA COLLECTION AND DATA ANALYSIS

We developed and distributed the research tool as an online anonymous survey using Qualtrics®. The survey contained multiple-choice questions that allowed for single or multiple selections depending on the question, Likert scale questions, as well as open-ended responses that gathered data regarding the impact of *The New York Times* op-ed piece on cancer genetic counseling (Appendix B).

We completed data analysis using SPSS 21.0.0 for calculating descriptive statistics and correlations and analyzed the open-ended responses for common themes and trends.
RESULTS

DEMOGRAPHICS

There were a total of 226 survey respondents representing all six NSGC regions, of which 48 were incomplete and not included in our analysis (Table 1). The majority of participants were female (96.2%) and Caucasian, non-Hispanic (93.1%) and their ages ranged from 24 to 64 years old, with an average age of 34.25 years old. Respondents had, on average, 7.68 years of experience as genetic counselors and 5.43 years as cancer counselors and slightly more than half (54.3%) indicated that, in the past year, they had spent between 75-100% of their time counseling patients for HBOC. The vast majority of participants reported they worked in a private hospital/medical facility (35.8%), public hospital/medical facility (29.6%) or University Medical Center (24.7%).
Table 1. Demographics of Survey Respondents

<table>
<thead>
<tr>
<th>NSGC Region</th>
<th>N=157</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1: CT, MA, ME, NH, RI, VT, Maritime Provinces</td>
<td></td>
<td>15.3</td>
<td>24</td>
</tr>
<tr>
<td>Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec</td>
<td></td>
<td>22.3</td>
<td>35</td>
</tr>
<tr>
<td>Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN</td>
<td></td>
<td>11.5</td>
<td>18</td>
</tr>
<tr>
<td>Region 4: AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, WI, Ontario</td>
<td></td>
<td>28</td>
<td>44</td>
</tr>
<tr>
<td>Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan</td>
<td></td>
<td>10.2</td>
<td>16</td>
</tr>
<tr>
<td>Region 6: AK, CA, HI, ID, NV, OR, WA, British Columbia</td>
<td></td>
<td>12.7</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years as a Cancer Genetic Counselor</th>
<th>N=162</th>
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</thead>
<tbody>
<tr>
<td>0-4.99</td>
<td>54.3</td>
</tr>
<tr>
<td>5-9.99</td>
<td>28.4</td>
</tr>
<tr>
<td>10-14.99</td>
<td>9.9</td>
</tr>
<tr>
<td>15-19.99</td>
<td>6.1</td>
</tr>
<tr>
<td>&gt;20</td>
<td>1.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Work Setting</th>
<th>N=162</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private Hospital/Medical Facility</td>
<td>35.8</td>
</tr>
<tr>
<td>Public Hospital/Medical Facility</td>
<td>29.6</td>
</tr>
<tr>
<td>University Medical Center</td>
<td>24.7</td>
</tr>
<tr>
<td>Physician’s Private Practice</td>
<td>4.3</td>
</tr>
<tr>
<td>Other: HMO, managed care organization, public hospital but associated w/university</td>
<td>2.5</td>
</tr>
<tr>
<td>Not-For-Profit Organization</td>
<td>1.9</td>
</tr>
<tr>
<td>Government Organization of Laboratory</td>
<td>0.6</td>
</tr>
<tr>
<td>University/Non-Medical Center</td>
<td>0.6</td>
</tr>
</tbody>
</table>

*Participants were not required to answer each question to continue with the survey*

We asked participants to describe their patient populations’ insurance coverage and found that the largest proportion (35%) of patients seen by our respondents had adequate private health insurance. Overall, respondents indicated they believed that 80% of their patients were either highly or adequately insured.

**KNOWLEDGE OF ANGELINA JOLIE OP-ED PIECE**

Of the 161 participants who responded to the question, “Did you read the op-ed?” 73.9% indicated that they read the article by Angelina Jolie entitled, “My Medical Choice” in its entirety. Of the 162 respondents who specified how they first heard about Ms. Jolie’s story, the largest proportion (35.8%) reported that it was via the Internet/social media.

When asked to select, from a list of different sources, the ways in which they had heard about the op-ed piece, participants most often cited coworkers (74.2%) and the Internet/social media (71.9%).
GENETIC COUNSELORS’ INITIAL REACTIONS TO ANGELINA JOLIE’S STORY

A total of 122 participants answered an open-ended question in which we asked them to provide their initial thoughts on how they felt *The New York Times* op-ed piece would affect their clinic. We generated thirteen different themes from these responses, however many responses contained multiple themes. Numerous (41.8%) respondents expressed concern that they would see an increase in overall referral rates and of those who did, 47% specifically felt the op-ed piece would increase inappropriate and/or self-referrals, as illustrated by one respondent who said,

“I thought we would have a lot of unnecessary self-referrals which usually happens with any new media discussing genetic testing.”

Furthermore, 18% of respondents indicated that they expected the op-ed piece to increase the number of patient inquiries and/or patients seen in clinic. In addition to potential increases in clinic volumes, 13.1% of respondents also noted that they expected to see a greater number of patients wanting *BRCA1* and *BRCA2* testing.

A few (2.4%) respondents also stated that they thought the op-ed piece would generate a larger interest in, questions about, and desire for prophylactic surgery, specifically mastectomy. Two respondents stated,

“I felt we would have an increase of patients wanting to undergo BRCA testing and choose prophylactic surgery.”

and

“I initially thought it would bring up a lot more questions about whether a mastectomy is REQUIRED.”

While some felt the op-ed piece would increase awareness of this testing, a small proportion of respondents (4.9%) expressed concern that low risk individuals might not
understand why testing was not appropriate for them. One respondent demonstrated this in the following quote:

“I thought that more newly diagnosed breast cancer patients would ask for BRCA1/2 testing. Also, more women with family histories of breast cancer would start asking their doctors to be tested. I expected volume in my clinic would increase some. I also thought that it may be harder to explain to women who have a low risk to have a BRCA1/2 mutation why they are not good candidates for testing because these women may be more insistent to have the test done.”

A small proportion of participants (9%) indicated that they were unsure or did not think that the op-ed piece would have an impact on their clinic. The following quote illustrates this:

“I honestly did not think it would have as much of an impact as it did. I did not think that one person’s experience in an op-ed piece would be more successful than a whole field of gc's who have been advocating for years.”

Finally, some (18%) respondents felt the op-ed piece would raise overall awareness of hereditary breast and ovarian cancer and genetic risk factors, as demonstrated by the following quote:

“I thought it was very courageous of her to share her story. I thought it would increase awareness of HBOC and hopefully improve recognition of hereditary cancer.”

IMPACT OF ANGELINA JOLIE’S STORY ON CLINICAL PRACTICE

The vast majority of respondents (89%) indicated that, since the op-ed piece and ensuing publicity, calls requesting appointments for risk assessment and/or genetic testing had either “greatly increased” or “increased.” Furthermore, study participants indicated that the number of low-risk individuals requesting genetic testing “greatly increased” or “increased” (84.4%) and more than half (59.6%) also indicated that the wait time for new patient appointments had either “greatly increased” or “increased.” The average increase in wait time for a new appointment ranged from up to one week (22.1%) to more than
three months (8.8%). However, the largest proportion of (30%) respondents indicated that the average wait time for a new appointment was one to three weeks. In addition to the increase in new patient requests, 64.4% of survey respondents also indicated that the number of patients seen per week either “greatly increased” or “increased.” Despite these increases, only 8.1% of respondents indicated their clinics hired additional genetic counselors.

We then looked to compare genetic counselors’ overall initial reactions to Ms. Jolie’s story, as reported in their open-ended responses, to how participants perceived that the op-ed piece actually affected their clinical practice. While only 20.5% percent of respondents specified that they initially thought the op-ed piece would increase calls requesting appointments for risk assessment and/or genetic testing, 89% reported an actual increase in the number of calls to their clinic since its publication. Similarly, only 19.6% of respondents wrote that they thought the op-ed piece would lead to an increase in the number of requests for genetic testing from low risk individuals, while 84.4% of respondents reported seeing this in their clinical practice. Lastly, 10.6% of respondents stated they initially thought the number of patients seen per week would increase because
of the op-ed piece, while 64.4% reported that this occurred in their clinic (Figure 1).

Figure 1. Initial beliefs as to how the op-ed piece would impact clinical practice versus reported impacts on clinical practice.

IMPACT OF OP-ED PIECE ON PATIENT DISCUSSIONS

When we asked participants how often Angelina Jolie’s story came up during general discussions with patients, the majority of survey respondents (86.4%) stated it occurred “often” or “sometimes.” Participants also indicated that, when Ms. Jolie’s story did come up, patients were more likely to introduce the topic themselves (85%). While 58.4% of respondents reported that Angelina Jolie’s story either “sometimes”, “often”, or “always” entered into conversations about a patient’s decision to pursue prophylactic mastectomy, only 24.4% reported discussing the story with similar frequency when a patient was deciding whether to pursue prophylactic oophorectomy. Finally, we asked respondents to select what they felt were the top three reasons their patients initiated a conversation about Angelina Jolie’s story and Table 2 summarizes their answers.
Table 2. Perceived reasons why patients initially brought up the Angelina Jolie op-ed piece in their genetic counseling sessions. N=178.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concern about risk based on a family history of cancer</td>
<td>53.4</td>
<td>95</td>
</tr>
<tr>
<td>Anxiety over increased lifetime risk of breast cancer</td>
<td>43.8</td>
<td>78</td>
</tr>
<tr>
<td>Stronger inclination to pursue mastectomy</td>
<td>36</td>
<td>64</td>
</tr>
<tr>
<td>Desire to hear a medical professional’s opinion of the story</td>
<td>32</td>
<td>57</td>
</tr>
<tr>
<td>Worry about risk based on their personal history of cancer</td>
<td>28.1</td>
<td>50</td>
</tr>
<tr>
<td>Questions regarding insurance coverage for prophylactic surgery</td>
<td>13.5</td>
<td>24</td>
</tr>
<tr>
<td>Concern about whether or not increased surveillance is an effective option</td>
<td>11.2</td>
<td>20</td>
</tr>
<tr>
<td>Other (Please specify):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desire to learn more about reconstructive surgery options</td>
<td>7.9</td>
<td>14</td>
</tr>
<tr>
<td>Stronger inclination to pursue an oophorectomy</td>
<td>2.8</td>
<td>5</td>
</tr>
</tbody>
</table>

PERCEIVED IMPACT OF THE OP-ED PIECE ON PATIENT DECISION-MAKING

The majority of survey respondents felt that Angelina Jolie’s story had an impact on the decisions made by patients regarding genetic testing, with (69.4%) indicating that they “agreed” or “strongly agreed” that since the op-ed piece, there was an increase in the likelihood that patients determined to be low risk would push for genetic testing. Similarly, slightly more than half of respondents (55%) also indicated that they “agreed” or “strongly agreed” that patients determined to be high risk were more likely to pursue genetic testing.

For their patients who underwent genetic testing, 35% of respondents indicated that they “agreed” or “strongly agreed” that, since the publicity surrounding Angelina Jolie’s story, those with a \textit{BRCA1/2} mutation were more likely to ask about prophylactic mastectomy. However, only 17.7% of genetic counselors indicated that they “agreed” or “strongly agreed” that patients with a \textit{BRCA1/2} mutation were actually more likely to go
through with a prophylactic mastectomy. Similarly, 31.2% of respondents indicated that since the op-ed piece, they “agreed” or “strongly agreed” that even patients without a \textit{BRCA1/2} mutation were more likely to ask about prophylactic mastectomy. A small proportion (4.4%) of respondents felt that their patients without a \textit{BRCA1/2} mutation were actually more likely to undergo a prophylactic mastectomy.

When comparing genetic counselors’ perceptions regarding patient decision-making among individuals with different genetic testing results, respondents felt that, on average, the publication of the op-ed piece increased the likelihood of patients with a \textit{BRCA1/2} mutation asking about prophylactic mastectomy more than for those that did not have a mutation (sig.=0.002; CI=95%), or those found to have a variant of unknown significance (VUS) in \textit{BRCA1/2} (sig.=0.001; CI=95%). There was no significant difference between genetic counselor perceptions of the likelihood of \textit{BRCA1/2} negative patients and those with a VUS asking about prophylactic mastectomy. Similarly, respondents felt that, after Angelina Jolie’s story, there was a significantly greater increase in the likelihood that patients with a \textit{BRCA1/2} mutation would actually have a prophylactic mastectomy than for those that did not have a mutation (Sig.=0.000; CI=95%), or those found to have a VUS in \textit{BRCA1/2} (Sig.=0.000; CI=95%) (Figure 2).
Figure 2. Participant agreement that patients are more likely to ask about/undergo prophylactic mastectomy since Angelina Jolie story

Note: For simplification, we combined “Neither agree nor disagree” and “I am not sure” together in our analysis.

Scale: 1= Strongly disagree, 2= Disagree, 3= Neither agree nor disagree & I am not sure, 4= Agree, 5= Strongly agree

When asked whether they agreed that since, the op-ed piece, patients were more likely to ask about or undergo a prophylactic oophorectomy, only 10.8% of genetic counselors indicated that, since the op-ed piece, they “agreed” or “strongly agreed” that there was an increase in the likelihood of BRCA1/2 positive patients asking about prophylactic oophorectomy. Respondents also agreed that there was a greater likelihood of patients with a BRCA1/2 mutation asking if they should have a prophylactic oophorectomy than those without a mutation (Sig. =0.006; CI=95%). Additionally, while only 5.1% of respondents agreed that, since the Angelina Jolie story, there was an increase in the likelihood that patients with a BRCA1/2 mutation would actually undergo prophylactic oophorectomy, this was significantly greater than their perceived likelihood that those identified as having a VUS (Sig. =0.004; CI=95%), or no mutation (Sig. =0.000; CI=95%) would go through the same procedure (Figure 3).
Finally, while genetic counselors felt there was an increased likelihood that BRCA1/2 mutation carriers would ask about and/or have both prophylactic mastectomy and prophylactic oophorectomy since the publication of the op-ed piece, the level of agreement with this statement was significantly greater for patients asking about prophylactic mastectomy vs. oophorectomy (Sig.=0.000; CI=95%). Similarly, respondents’ level of agreement that, as a result of the publicity of Ms. Jolie’s story, there was an increase in the likelihood BRCA1/2 positive patients underwent a prophylactic mastectomy was significantly greater than for oophorectomy (Sig.=0.000; CI=95%) (Figure 4).
Figure 4. Comparison of participant agreement that patients with \textit{BRCA1/2} mutations are more interested in or likely to pursue prophylactic surgical procedures.

Note: For simplification, we combined “Neither agree nor disagree” and “I am not sure” together in our analysis.

Scale: 1= Strongly disagree, 2= Disagree, 3= Neither agree nor disagree & I am not sure, 4= Agree, 5= Strongly agree
DISCUSSION

This was the first study to look at the impact of Angelina Jolie’s op-ed piece in *The New York Times* on the practice of cancer genetic counseling and patient decision-making. We queried cancer genetic counselors regarding their initial thoughts on how the op-ed piece would affect their clinic, the actual impact of Ms. Jolie’s story on their practice, and their perceptions of its influence on patient decision-making. We had a 65.2% response rate from clinical cancer genetic counselors based on the most recent NSGC Professional Status Survey and the demographic characteristics of our respondents were generally consistent with those of the broader genetic counseling population with respect to gender, age, and region of practice (NSGC PSS, 2012).

**Familiarity with Angelina Jolie’s story**

We found that, of those participants who responded to the question, “Did you read the op-ed?”, 73.9% indicated that they read it in its entirety. This high interest in Ms. Jolie’s story likely reflects its direct relevance to the clinical practice of the genetic counselors who answered the survey. Health care providers may be more apt to read news stories that pertain to their own profession, particularly if they perceive that the publicity could have an impact on patient care. A large proportion (71.9%) of respondents selected Internet/social media as one of the sources from which they heard about the Angelina Jolie story, with 35.8% of respondents who specified how they *first* heard about Ms. Jolie’s story selecting this source. In today’s society, there is a growing tendency to disseminate
information via the Internet through portals such as online newspapers, blogs, news sites, social networks, and the features of mobile phones such as SMS news, and tweets (Meikle & Guy, 2011) with a subsequent decline in traditional daily newspaper readerships. Thus, it is not surprising the largest number of respondents first heard about the op-ed piece through Internet and social media news sources, as this is in sync with the trend seen in the general population by Meikle and Guy. The largest proportion of respondents (74.2%) selected “coworkers” as a source from which they heard about the op-ed piece. Similar to why individuals would read an article in its entirety that is directly related to their field, the high proportion of genetic counselors hearing about the op-ed piece from coworkers may be a result of an increased mutual interest among individuals in the same practice area and the desire to discuss, with each other, the accuracy of the facts portrayed in this article and the potential impact of the story on their practice.

While the high level of participant familiarity with the op-ed piece by Ms. Jolie was expected, it was surprising to find that 3.1% of our study population did not read the op-ed piece or any ensuing commentary, given the publicity surrounding her story. Ms. Jolie’s picture and story was on the cover of People magazine in the two consecutive weeks following her op-ed piece, as well as the front page of every British national newspaper, and countless other American, European, and Asian periodicals (Borzekowski et al., 2013). Furthermore, Ms. Jolie’s story incurred mention in 223 printed articles published in Australia in the first week following the initial publication of Ms. Jolie’s story (James et al., 2013). Therefore, the reasoning behind even a small number of genetic counselors that specialize in cancer counseling not reading the op-ed piece or other forms of publicity is unclear. It is possible that these respondents were among those that did not think the
article would have an impact on their clinic and thus did not take the time to read media associated with Ms. Jolie and her story.

Initial impressions of the Angelina Jolie op-ed piece vs. actual effects on clinical practice

Studies have shown that celebrity stories like those of Nancy Reagan, Katie Couric, and Kylie Minogue have resulted in increased procedural rates of mastectomy, colonoscopy, and mammography respectively. However, only 2.4% of our participants felt that, after first hearing about and/or reading Angelina Jolie's story, they would see an increase in the interest in, questions about, and desire for prophylactic mastectomies from their patients. It is possible that many respondents saw an increase in prophylactic mastectomies as a downstream effect rather than a primary impact on their clinical practice and therefore did not mention increases in mastectomy rates as part of their initial reaction to The New York Times article. The finding that a larger number of genetic counselors (41.8%) initially believed the op-ed piece would increase referrals to their clinics is more in keeping with this notion of primary versus downstream impacts. While our study did not specifically inquire about observed increases in referral rates, James et al. (2013) found that the number of actual referrals for individuals concerned about their family history more than doubled in two large familial cancer centres in Victoria, Australia immediately following Ms. Jolie's story.

Increases in referral rates typically lead to a rise in the number of patients seen in a clinical practice. So, while it is not surprising that the second most common theme identified in 18% of participants' initial reactions, was that the op-ed piece would increase the number of patients seen, this percentage was lower than expected. In fact, a far higher number of respondents (64.4%) agreed that their patient volume had increased when
asked about the actual effects of Angelina Jolie’s story on their clinical practice. This discrepancy may be the result of participants initially thinking that clinic staff would properly triage referrals and inquiries, preventing low risk patients from getting appointments. Alternatively, the higher patient volume observed could be the result of more genuinely high-risk individuals either recognizing their own risk factors or having the courage to come forward after reading about Angelina Jolie’s story and making appointments for cancer risk assessment.

In addition to expected increases in referral rates and patient volume, another theme identified in the initial reactions of study participants to *The New York Times* op-ed piece was that 13.1% of genetic counselors felt there would be an increase in the number of patients wanting HBOC genetic testing. These respondents may have envisioned an increase in requests for HBOC testing after the op-ed piece was published because it is the first story to publicly address genetic testing for cancer susceptibility in a celebrity. Furthermore, respondents may have seen Ms. Jolie’s story as the impetus that some high-risk individuals needed to push them to pursue genetic testing. For the larger proportion of individuals who did not initially feel there would be an increase in HBOC testing, it is conceivable that those respondents felt that this too would be a downstream effect seen only if patient volume increased and testing was actually warranted for those additional patients seen.

Finally, a small proportion of our respondents (9%) indicated that they were unsure or did not think that the op-ed piece would have an impact on their clinical practice. This small amount of uncertainty among genetic counselors surrounding what, if any, impact *The New York Times* op-ed piece would have could be related to the fact that Ms. Jolie’s
story was novel. While numerous studies have documented the impact that celebrities’ stories had on screening tests and procedural rates, no celebrity has ever publicly disclosed their decision to have genetic testing or discussed the medical choices they made based on their genetic test results. Therefore, a few participants may have considered this lack of precedent when initially reacting to Ms. Jolie’s story.

The op-ed piece had an impact on patient discussions

The majority of respondents indicated that Angelina Jolie’s story came up at least sometimes during patient discussions, and that the patients themselves were more likely to introduce the topic. This is not surprising, given the incredible amount of media attention surrounding her story and the fact that this study assessed its impact within the 9 months immediately after its publication in The New York Times. Ms. Jolie’s high-profile celebrity status as both an actor and humanitarian is likely to make the general public pay closer attention to news media reports about her, potentially translating into more patients bringing up her story during genetic counseling visits. Patients might also be the ones more likely to bring up Ms. Jolie’s story because they mistakenly believe their own story is the same as hers and are less capable than genetic counselors of understanding how the choices discussed in the op-ed piece may or may not, apply to their own situations.

When asked to indicate what they perceived were the top three reasons for patients discussing the op-ed piece, the largest proportion of respondents selected concerns about risk based on a family history of cancer (53.4%), anxiety over increased lifetime risk of breast cancer (43.8%), and having a stronger inclination to pursue mastectomy (36%). These responses directly correlate with and mirror the opening lines of Ms. Jolie’s op-ed piece, “My mother fought cancer for almost a decade and died at 56... We often speak of
‘Mommy’s mommy,’ and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a ‘faulty’ gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer. My doctors estimated that I had an 87 percent risk of breast cancer” (Jolie, 2013). She went on to share that, “Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventative double mastectomy” (Jolie, 2013). It is possible that many patients seen after the op-ed piece’s publication came in for genetic counseling and testing, in large part, because Ms. Jolie’s story mirrored their own family history or their concerns about cancer risks. These patients might then, also be more inclined to bring up and discuss the op-ed piece during their clinic visits for risk assessment and genetic counseling.

The perceived impact of the op-ed piece on patient decision-making

A proportion of participants in our study reported that they felt, since the publication of the op-ed piece, there was an increase in the likelihood their patients would ask about prophylactic mastectomy after receiving their genetic test results regardless of their mutation status. This may be due to increased visibility of mastectomy as a method of risk reduction and might be an indicator that patients saw prophylactic mastectomy as a more viable option after hearing Angelina Jolie’s story regardless of whether they were BRCA1/2 positive or negative. In fact, even in the general population, there was heightened awareness of prophylactic mastectomy with a study by Borzekowski et.al finding that 74% of survey respondents were aware of Angelina Jolie’s mastectomy.

In addition, it is possible that some individuals believe, because Angelina Jolie chose to have a prophylactic mastectomy, it is the best risk reducing option and therefore they
should also have the procedure. Thus, it is not surprising that, when asked to indicate whether they felt there was an increase in the likelihood their BRCA1/2 positive patients would actually undergo a prophylactic mastectomy, 17.7% of participants agreed. This is higher than the proportion of respondents who felt there was an increase in the likelihood that patients without a mutation have a prophylactic mastectomy and likely reflects that the mutation positive patients are, a priori, a high-risk group for which prophylactic mastectomy is known to be most beneficial.

An even smaller proportion (10.8%) of genetic counselors indicated that they felt there was an increase in the likelihood their patients with BRCA1/2 mutations would inquire about prophylactic oophorectomy after the publication of The New York Times op-ed piece. Again, this perceived increase in likelihood was significantly greater than for those patients without a mutation, which also is likely due to the difference in risk of ovarian cancer in mutation positive versus mutation negative individuals. Overall, the increases in the likelihood, indicated by participants, of patients in either group actually undergoing an oophorectomy were even lower, and are likely linked to the lower lifetime risk developing ovarian cancer in at risk families, which Ms. Jolie sites as one of the reasons she chose not to have an oophorectomy at that time. Furthermore, had there been increased publicity about Ms. Jolie's story because she also had chosen to have her ovaries removed, we might have seen more than 5.1% of respondents perceiving an increased likelihood that BRCA1/2 mutation carriers would undergo prophylactic oophorectomy.

Finally, while the lifetime risk of an individual with a BRCA1/2 mutation developing ovarian cancer is lower than that of breast cancer, current guidelines recommend that women with a BRCA1/2 mutation have a risk-reducing salpingo-oophorectomy since
screening methods are so ineffective. A recent study demonstrated that, in a group of BRCA1/2 positive Israeli women, they were more likely to undergo salpingo-oophorectomy than mastectomy (Laitman et al., 2014). One might have expected then, that in our study more participants would have felt there would be a greater increase in the likelihood that BRCA1/2 mutation carriers would inquire about and/or have a risk-reducing salpingo-oophorectomy. However, genetic counselors in our study felt more strongly that, since the op-ed piece, an increase in the likelihood that BRCA1/2 mutation carriers would both ask about and/or have prophylactic mastectomy versus oophorectomy. This may be due to Angelina Jolie’s story focusing primarily on mastectomy and while Ms. Jolie speaks to her increased lifetime risk of developing ovarian cancer as a carrier of a BRCA1 mutation, the op-ed piece centered around on her decision to have her breasts removed. This may have influenced what options patients considered and brought up for discussion in their genetic counseling sessions.

STUDY LIMITATIONS

This study had several limitations. Having the name “Angelina Jolie” in the e-blast may have introduced a sample bias by making genetic counselors who noticed an effect on their clinical practice more likely to complete the survey. In contrast, it is possible that some genetic counselors were less likely to participate in the study if they were already tired of hearing about Ms. Jolie’s story and dealing with the aftereffects of the ensuing publicity.

We recruited study participants through NSGC and therefore only full NSGC members received the e-blast. While it was possible to forward the recruitment notice to non-members, there is no way to determine whether this occurred and, as a result, the
study population may not reflect the perceptions of the genetic counseling community as a whole if the analysis included only NSGC members. We also only asked participants to indicate the NSGC region they practice in rather than the specific state or country, thus it is not clear whether the geographical representation seen in our study population is similar to that seen in the profession as a whole.

Only one question asked for data about the insurance coverage of participants’ patient populations. Given the wide variability in healthcare coverage, especially public insurance from state to state and the different healthcare system in Canada, it was not possible to analyze whether this was an additional factor impacting patient decision-making.

This study was retrospective and included numerous questions about the participants’ own opinions on the effect of Angelina Jolie’s story on clinical practice, patient discussions and patient decisions. Therefore, there may be recall bias particularly with regard to genetic counseling sessions with patients that happened in the past. In addition, given that we did not directly survey patients themselves about how Ms. Jolie’s story affected their risk perception and decision-making, it is possible that the respondents’ perceptions do not accurately reflect those of their patient populations. We also did not specifically define “low-risk” or “high-risk” when referring to patient populations and therefore cannot assume that respondents all used the same definitions when responding to our survey.

Finally, at nearly the same time as the release of Angelina Jolie’s op-ed piece, the Supreme Court unanimously ruled that the patents held by a single laboratory on both the \textit{BRCA1} and \textit{BRCA2} genes were no longer valid and as a result, there was a substantial
increase in the number of laboratories offering genetic testing for HBOC. Therefore, it is possible that the effects on cancer genetic counseling and patient decision-making reported by our study participants may be partially due to the Supreme Court Ruling as well as other news and/or media coverage on hereditary cancer and genetic testing.
CONCLUSION

This study explored the impact of Angelina Jolie’s *The New York Times* op-ed piece on cancer genetic counselors and their clinical practice as well as patient decision-making. The results of our study provide evidence that the “Angelina Jolie Effect” is real and that genetic counselors experienced increases in the number of new patient requests, inappropriate referrals, the number of patients seen per week, as well as wait times for new appointments. Participants reported an increase in requests for genetic testing from low-risk individuals and felt that this group was also more likely to push for testing. In addition to the impact the op-ed piece has had on cancer genetic counseling practices, genetic counselors in this study felt that the publicity behind Ms. Jolie’s story increased the likelihood of patients asking about and/or having a prophylactic mastectomy. In light of these findings, it is evident that genetic counselors should be prepared for the effects of stories like that of Ms. Jolie on their clinical practice and patients and take an active role in educating the general public in order to prevent misinterpretation of risk information, and misuse of genetic testing resulting from celebrity focused media.

Lastly, future research should focus on investigating the impact of the op-ed piece from the perspective of women who are thinking about genetic testing for hereditary breast and ovarian cancer or have undergone genetic testing, and are making decisions based on their test results. Medical record reviews since the publication of the op-ed piece would also be helpful in quantifying the increases in genetic testing for hereditary breast
and ovarian cancer, as well as prophylactic surgical procedures. This information would also allow us to substantiate the genetic counselor perceived impact of *The New York Times* op-ed piece on clinical practice and patient decision-making, as well as better define the “Angelina Jolie Effect.”
REFERENCES

American Cancer Society. 


APPENDICES

APPENDIX A: Recruitment Notice

An Investigation of the Effect of Angelina Jolie’s New York Times Story on Cancer Genetic Counseling

Have you worked in a clinical practice that offers testing for Hereditary Breast and Ovarian Cancer (HBOC) in the past year? Did you hear about and/or read the op-ed in The New York Times, “My Medical Choice” by Angelina Jolie?

If so, I invite you to participate in a research study investigating the impact that Angelina Jolie’s disclosure of her BRCA1 mutation and choice to have a double mastectomy has had on the clinical practice of genetic counseling, the interest in and uptake of genetic counseling and testing, as well as the decision-making in patients concerned about their cancer risks. I am conducting this research study for my master’s thesis, and the research protocol has been approved by the Brandeis University IRB.

Participation in this research study is open to all genetic counselors who have worked in a clinical practice that offers testing for Hereditary Breast and Ovarian Cancer (HBOC) in the past year.

Participation in this study is completely confidential and voluntary. Participation will involve completing an online, anonymous survey, which should take approximately 15 minutes to complete. To participate in the study, please follow the link below to access the online survey:

WEBSITE LINK

Upon completion of the survey respondents will be eligible to enter a raffle for one of three $50 Amazon.com gift-cards.

If you have any questions or comments, please feel free to contact me at:

maccuaig@brandeis.edu  gretchen@brandeis.edu
Morgan MacCuaig  Gretchen Schneider

Thank you in advance for your participation.

Sincerely,
Morgan MacCuaig
Brandeis University Genetic Counseling
Student, Class of 2014
APPENDIX B: Survey

An Investigation of the Effect of Angelina Jolie’s New York Times Story on Cancer Genetic Counseling

Thank you for agreeing to participate in this study. The goal of this research is to assess genetic counselors’ perceptions of the “Angelina Jolie Effect” on their clinical practice. Participation in this study is voluntary, and all responses will remain anonymous. No identifying information will be asked or required for the completion of this survey. You may choose to skip questions or exit the survey at any time. At the conclusion of the study you can choose to enter into a raffle for a $50 amazon.com gift card.

This study was reviewed and approved by the Institutional Review Board of Brandeis University of Waltham, MA. By clicking the "Next" button below you are consenting to participate in this study.

☐ Next
☐ No, thank you
1. Have you worked in a genetic counseling clinic that offers testing for Hereditary Breast and Ovarian Cancer (HBOC) in the past year?
   - Yes
   - No (END SURVEY)

2. How long have you been seeing patients as a genetic counselor? ________

3. How long have you been providing cancer counseling? ____ years_____months

4. Over the past year, what proportion of your time in clinic was spent on cancer counseling for HBOC? ______

5. In what hospital or clinical setting do you practice cancer counseling?
   - Diagnostic Laboratory - Academic
   - Diagnostic Laboratory - Commercial
   - Government Organization of Laboratory
   - Not-For-Profit Organization
   - Physician’s Private Practice
   - Private Practice – Self Employed
   - Private Hospital/Medical Facility
   - Public Hospital/Medical Facility
   - University Medical Center
   - University/Non-Medical Center
   - Other (Please specify)_____________________________

6. Please describe your patient population by indicating the percentage of your patients utilizing the following insurance coverage?
   a. Uninsured ______
   b. Under-insured through private health insurance _____
   c. Under-insured through public health insurance
   d. Adequately insured through public health insurance
   e. Adequately insured through private health insurance
   f. Adequately insured through a mix of public and privately insurance _____
   g. Highly insured _____
   h. Do not know
7. How did you first hear about the op-ed, “My Medical Choice” that was written by Angelina Jolie and published in the New York Times?
- Social media
- Television
- Read it in the NY Times
- Read about it in another newspaper
- Friend or family member
- Coworker
- From a patient
- Other _______________________
- I have not heard of the article (END SURVEY)
- I don’t remember

8. From how many different sources did you hear about the op-ed piece? (Check all that apply)
- Social media
- Television
- Read it in the NY Times
- Read about it in another newspaper
- Friend or family member
- Coworker
- From a patient
- Other _______________________
- I don’t remember

9. Did you read the op-ed?
- Yes, in its entirety
- Yes, but I skimmed it
- No, but I read comments about it in other news outlets
- No, I did not read the article or commentary about it

10. How did you initially feel the op-ed piece would impact your clinic?
11. The following question asks about your perceived impact of Angelina Jolie’s story on your clinical practice and genetic testing for hereditary breast and ovarian cancer. Please indicate the extent to which there was an increase or decrease.

<table>
<thead>
<tr>
<th>Event</th>
<th>Greatly Increased</th>
<th>Increased</th>
<th>Neither Increased nor Decreased</th>
<th>Decreased</th>
<th>Greatly Decreased</th>
<th>I Am Not Sure</th>
</tr>
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<tbody>
<tr>
<td>Since the Angelina Jolie op-ed and the ensuing publicity...</td>
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<td>- calls requesting appointments for risk assessment and/or genetic testing.</td>
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<td>- wait time for new patient appointments at our clinic.</td>
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<td>- requests for genetic testing from low risk individuals.</td>
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<td>- the number of patients seen per week.</td>
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<td>- delays in obtaining patient results from our testing laboratory.</td>
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<td>- number of additional genetic counselors hired by our clinic due to increased patient volume.</td>
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12. If there was an increase in wait time for a new appointment, on average, what would you estimate was the length of the increase? _______

13. What percentage of new patients seen since May/June of 2013 in your clinic would you estimate made an appointment because of the media attention given to Angelina Jolie’s story? _______
14. If your clinic experienced a delay in receiving test results, please indicate, on average, the length of this delay.

- Up to two weeks
- Two weeks to a month
- One month to two months
- Two to three months

15. Please indicate the labs you sent HBOC samples to since May/June of 2013. (Check all that apply)

- Ambry
- DNA Traits
- Emory Genetics Laboratory
- Ethigen
- GeneDX
- Genzyme/Labcorp
- Myriad
- Other

16. The following question assesses the frequency with which a discussion of Angelina Jolie's story occurs between you and the patients in your clinical practice.

<table>
<thead>
<tr>
<th>A discussion of Angelina Jolie's story...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>I Am Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>- occurs during phone conversations with patients prior to their initial visits.</td>
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<td>- comes up in general discussion during patient visits.</td>
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<td>- is initiated by me during patient visits.</td>
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<td>- is initiated by my patients during their visits.</td>
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<td>- arises when patients are deciding whether to pursue genetic testing.</td>
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<tr>
<td>- arises when patients are deciding whether to pursue prophylactic mastectomy.</td>
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<tr>
<td>- arises when patients are deciding whether to pursue prophylactic oophorectomy</td>
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</table>
17. For your patients who have initiated a conversation about Angelina Jolie’s story themselves, what do you believe are the top three reasons for them bringing it up for discussion? (Choose up to 3)
- Concern about whether or not increased surveillance is an effective option
- Desire to learn more about reconstructive surgery options
- Stronger inclination to pursue mastectomy
- Stronger inclination to pursue an oophorectomy
- Anxiety over increased lifetime risk of breast cancer
- Questions regarding insurance coverage for prophylactic surgery
- Concern about risk based on a family history of cancer
- Worry about risk based on their personal history of cancer
- Desire to hear a medical professional’s opinion of the story
- Other (Please specify)______________________

18. The following set of questions asks about your perceived impact of the Angelina Jolie story on the decisions made by patients in your clinical practice. Please indicate how strongly you agree with each statement.

<table>
<thead>
<tr>
<th>Since the Angelina Jolie article and ensuing publicity...</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
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<td>-patients who are determined to be low risk are more likely to push for genetic testing.</td>
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<tr>
<td>-patients who are determined to be high risk are more likely to pursue genetic testing.</td>
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Since the Angelina Jolie article and ensuing publicity, my patients who have a **BRCA1/2 variant** are more likely to:
- ask about prophylactic mastectomy.
- undergo prophylactic mastectomy.
- ask if they should have their ovaries removed.
- undergo prophylactic oophorectomy.

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**DEMOGRAPHICS**

19. What is your gender?
   - □ Male
   - □ Female
   - □ Other

20. What is your age? _________

21. How would you describe your racial/ethnic background?
   - □ American Indian or Alaskan Native
   - □ Asian
   - □ Black or African American
   - □ Hispanic/Latino
   - □ Native Hawaiian or Other Pacific Islander
   - □ White or Caucasian, non-Hispanic
   - □ Other (please specify)

22. In what US region did/do you currently practice?
   - □ Region 1: CT, MA, ME, NH, RI, VT, Maritime Provinces
   - □ Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec
   - □ Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN
   - □ Region 4: AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, WI, Ontario
   - □ Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Saskatchewan
   - □ Region 6: AK, CA, HI, ID, NV, OR, WA, British Columbia

**Thank You!**

If you would like to enter a raffle for a $50 Amazon gift certificate, please e-mail me at maccuaig@brandeis.edu with your name and e-mail address. Your name and e-mail address cannot be connected with your survey responses.