PATIENT PREFERENCES FOR AN APPROPRIATE TIME FOR CANCER GENETIC COUNSELING AND BRCA TESTING FOR WOMEN DIAGNOSED WITH BREAST CANCER

Master’s Thesis

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Barbara Lerner CGC, Advisor

In Partial Fulfillment of the
Requirements for the Degree

Master of Science

By
Christy Ferlatte

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ABSTRACT

Patient preferences for an appropriate time for cancer genetic counseling and BRCA testing for women diagnosed with breast cancer

A thesis presented to the Genetic Counseling Program

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Christy Ferlatte

The point at which genetic counseling and testing is offered following a woman’s diagnosis of breast cancer may be of importance to her surgical decision-making. Whether she receives counseling between diagnosis and treatment or after treatment may be important with respect to her emotional well-being and may influence treatment decision-making options. Few studies have focused on patient attitudes toward the timing of their counseling sessions and receipt of test results or how the timing may influence any surgical decisions. The purposes of this study were to determine if women diagnosed with breast cancer have a preference about when they should receive genetic counseling and testing for hereditary breast cancer risk assessment and to gain a better understanding of whether genetic counseling and testing influence surgical decision making. We recruited 60 women from Women and Infants’ Hospital in Providence, RI, and the Facing Our Risk of Cancer Empowered online support group, who were diagnosed with breast cancer and received genetic counseling between September 2006 and September 2008, to participate in an online anonymous survey. The survey consisted of 31 multiple-choice...
and open-ended questions addressing demographics, personal and family cancer history and preferences for timing of genetic counseling. Most women (56%) preferred genetic counseling and testing prior to their surgery. None of our participants preferred counseling later than when they actually received it. Almost 80% of our sample who received counseling and testing prior to surgery (n=13) felt their counseling and genetic test result influenced their surgical decision. Only 15% of our sample felt psychologically overwhelmed by the information received during counseling regardless of whether they received counseling before or after surgery. Our results provide evidence to support the practice of referring women diagnosed with breast cancer to genetic counseling for BRCA testing prior to surgical treatment.
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INTRODUCTION

Genetic counseling and testing for Hereditary Breast and Ovarian Cancer syndrome (HBOCS) has been available for over ten years. The majority of HBOCSs are caused by mutations in one of two tumor suppressor genes, \textit{BRCA1} and \textit{BRCA2} (Wooster et al, 1995). Testing of these genes allows healthcare professionals to identify patients who are carriers of a germline mutation that puts them at an increased risk to develop hereditary breast and ovarian cancer. A genetic counseling session regarding HBOC typically consists of creating a detailed personal and family history of cancer, performing a risk assessment, reviewing the increased cancer risks and medical management options. Following a woman’s diagnosis of breast cancer, the timing of when she receives counseling regarding genetic testing may be of importance. Whether she receives the counseling between diagnosis and treatment, or after treatment, may be important with respect to her emotional well-being, and may influence her treatment decisions. From a patient’s perspective, genetic counseling and testing can also provide health information that would not otherwise be available and the patient can use this information in conjunction with her healthcare professionals in making more informed decisions about her treatment plan.

Because of the increased risk of developing cancer that is associated with \textit{BRCA1}/2 mutations (up to an 87\% risk for breast cancer and up to a 44\% risk for ovarian cancer) the impact of testing on individuals at high risk of having a mutation has been intensely studied (Ford et al, 1998). The psychological impact of genetic counseling and BRCA testing on patients with breast cancer has also been extensively studied. Two recent studies described finding no adverse psychological effects from actively
approaching women, who have a personal history of breast cancer, to discuss genetic testing, (Schlich-Bakker, 2007; Smith, 2007). Both studies assessed patients at various time points, including prior to the counseling session, after the session and at various times after receiving test results.

Few studies have focused on patient attitudes toward the timing of their counseling sessions and receipt of test results or how the timing may influence any surgical decisions. Two studies give initial insights into when breast cancer patients feel is an appropriate time to offer genetic counseling and testing. One study found that patients did not feel there was a perfect time for genetic counseling (Ardern-Jones et al, 2005), while the other study found the majority of patients felt the timing of their genetic counseling was appropriate or would have preferred it to be earlier (Schlich-Bakker, 2007). Four studies have focused on the effect of genetic counseling and testing on surgical decisions in women who have been newly diagnosed with breast cancer (Weitzel et al, 2003, Schwartz et al 2004, 2005, van Dijk et al 2008). These findings indicated that many women would have preferred to receive genetic counseling prior to their treatment (Weitzel et al, 2003, Schwartz et al, 2004, 2005), while others were not greatly influenced during their decision-making by the disclosure of their BRCA positive results (van Dijk et al, 2008). Limitations of these studies include: small sample size, recruitment from a single site, thereby limiting the diversity of the samples, the potential for the researchers to influence the patients’ opinions of genetic counseling and the genetic counseling that occurred was not a typical representation of genetic counseling in a clinical setting. In addition, all of these studies except one occurred outside of the US in countries with socialized medical systems.
One study in the US tried to assess attitudes towards breast cancer susceptibility testing prior to any surgical interventions. Boni et al (2007) surveyed genetic counselors in regards to counseling and testing newly diagnosed breast cancer patients and found that most counselors would prefer to see patients prior to their surgery but worried about psychologically overwhelming them at that time. While this study highlights genetic counselors’ opinions on the timing of counseling and testing it does not touch upon patient preferences. The opinions of patients on the optimum timing of their counseling and testing has not been explored thoroughly nor has the impact of their test results on surgical decisions.

It is important for healthcare professionals who work with women with a diagnosis of breast cancer to be aware of their patients’ opinions of when is the most appropriate time to have counseling and testing and how timing can influence surgical decisions. By recognizing how the timing of genetic counseling and testing affects patients with breast cancer, providers will have the potential to provide better care for their patients. While all of the prior studies provide some data to support the impact of genetic counseling on surgical decisions in breast cancer patients, more research needs to be done in order to have a more accurate representation of the population. One purpose of this study was to determine if women diagnosed with breast cancer have a preference as to when they would like to receive cancer genetic counseling. A second purpose was to gain a better understanding of whether genetic counseling and testing influence surgical decision-making.
METHODS

This study involved an anonymous online quantitative survey of women affected with breast cancer who had received genetic counseling, and in most cases genetic testing, regarding their risk to carry a germline BRCA gene mutation.

Sample

Only women who had been diagnosed with breast cancer and had been to at least one cancer genetic counseling session regarding BRCA gene testing were recruited to be in this study. The genetic counseling session must have occurred between September 2006 and September 2008. Participants must have been older than 18 years and fluent in English. The study participants could be at any stage during or after the course of their treatment for breast cancer. The majority of their treatments must have occurred within the United States. Participants were recruited from both the Cancer Risk Assessment & Prevention Program at Women & Infants’ Hospital (WIH) in Providence, Rhode Island, and the Facing Our Risk of Cancer Empowered (FORCE) support group website whose mission is to support women affected with hereditary breast and ovarian cancer (www.facingourrisk.org).

Women & Infants’ Recruitment

A retrospective chart review of 542 charts was performed to identify 182 patients fulfilling eligibility requirements for participation. Eligible patients were mailed a letter (Appendix A) detailing the study and directing those interested in participating to the online survey web address. Participants were required to acknowledge a participation agreement (Appendix B) explaining that this data was being collected for research purposes. Following their acceptance of the agreement they were forwarded onto the
survey, which was hosted on SurveyMonkey.com (Appendices C & D). Roughly two weeks after the first recruitment letter was sent, another letter was sent to the same population reminding them of the study (Appendix E) and included the web address of the survey again. Printed copies of the survey were mailed to two women who wished to participate in the study but who did not have access to a computer.

FORCE Recruitment

A recruitment letter was posted in the message boards on the FORCE website (Appendix F). The recruitment letter contained a brief description of the study, qualifying criteria and a direct online web address where participants were presented with qualifying questions (Appendix G). If they qualified, they were forwarded to a participation agreement (Appendix H) explaining that this data was collected for research purposes. After acknowledging the participation agreement they were forwarded onto the survey, which was hosted on SurveyMonkey.com (Appendix C). Roughly two weeks after the recruitment letter was posted, a brief description of the study was also sent out through the national and regional FORCE listserves reminding members of the survey (Appendix I) and included a link to the full recruitment letter, which was posted online.

Data Collection

The data was separately collected for each of the two recruitment sources; however the survey questions were the same for both groups. The anonymous online survey consisted of a combination of 31 multiple-choice, fill-in-the-blank and optional short answer questions (Appendix C). The confidential electronic survey was posted online and hosted by SurveyMonkey.com for roughly four weeks.
Survey questions included demographics such as, age, ethnicity, education level, economic status, employment status, marital status, number of children and religion. Participants were also asked questions regarding their personal and family history of cancer, past experience with genetic counseling and testing, the impact of timing of their genetic counseling session on initial surgical decisions, whether they felt that the timing of referral for cancer genetics services was appropriate and at what point they would have preferred to receive genetic counseling.

Data Analysis

The data from survey responses were descriptively analyzed using SurveyMonkey.com’s analysis tool as well as in Microsoft Excel. The data for the two groups were analyzed separately and in combination. Chi-square analysis on specific data was carried out using SPSS software.

This study was approved by the Institutional Review Board (IRB) at Women & Infants’ Hospital and was deemed exempt by the IRB at Brandeis University.

RESULTS

Demographics

A total of 60 women completed the survey. We had a 22.5% response rate from our WIH group (n=41). We were not able to assess a response rate for our FORCE group (n=19) as the survey was openly posted. Our sample ranged in age from 33 to 82 years, with an average age of 52.45 years. Approximately 68% of our sample was non-Jewish Caucasian, 56% held at least an undergraduate degree, 70% of our sample had a household income greater than $60,000 per year and 57% of our sample were employed. Approximately 78% were married or living with their partner and roughly 75% were
Christian. Each woman had on average approximately two children. Refer to Table 1 for a complete list of demographical information.

<table>
<thead>
<tr>
<th>Table 1. Demographics of study population</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n=60 unless noted</strong></td>
</tr>
<tr>
<td><strong>Average age (n=53)</strong>: 52.45 years</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
</tr>
<tr>
<td>Caucasian-non-Jewish: 68.85%</td>
</tr>
<tr>
<td>Caucasian-Jewish (Ashkenazi): 18.03%</td>
</tr>
<tr>
<td>Other: 6.56%</td>
</tr>
<tr>
<td>Caucasian-Jewish (non-Ashkenazi): 3.28%</td>
</tr>
<tr>
<td>Native American: 1.64%</td>
</tr>
<tr>
<td>Hispanic: 1.64%</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
</tr>
<tr>
<td>Undergraduate degree: 35.00%</td>
</tr>
<tr>
<td>Some college: 20.00%</td>
</tr>
<tr>
<td>High school diploma or equivalent: 11.67%</td>
</tr>
<tr>
<td>Associate degree: 10.00%</td>
</tr>
<tr>
<td>Masters degree: 10.00%</td>
</tr>
<tr>
<td>Professional degree: 5.00%</td>
</tr>
<tr>
<td>Some graduate school: 5.00%</td>
</tr>
<tr>
<td>Doctorate: 1.67%</td>
</tr>
<tr>
<td><strong>Economic status (per year) (n=55)</strong></td>
</tr>
<tr>
<td>Greater than $100,000: 29.09%</td>
</tr>
<tr>
<td>$80,000-$100,000: 27%</td>
</tr>
<tr>
<td>$60,000-$79,999: 14.54%</td>
</tr>
<tr>
<td>$20,000-$39,999: 10.90%</td>
</tr>
<tr>
<td>$40,000-$59,999: 9.09%</td>
</tr>
<tr>
<td>Less than $20,000: 9.09%</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
</tr>
<tr>
<td>Employed: 57%</td>
</tr>
<tr>
<td>Retired: 18.03%</td>
</tr>
<tr>
<td>Unemployed: 11.47%</td>
</tr>
<tr>
<td>Self-employed: 11.47%</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
</tr>
<tr>
<td>Married/living with partner: 78.69%</td>
</tr>
<tr>
<td>Divorced: 8.20%</td>
</tr>
<tr>
<td>Widowed: 4.92%</td>
</tr>
<tr>
<td>Never married: 4.92%</td>
</tr>
<tr>
<td>Separated: 1.64%</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
</tr>
<tr>
<td>Christian: 75.41%</td>
</tr>
<tr>
<td>Jewish: 15%</td>
</tr>
<tr>
<td>None: 4.92%</td>
</tr>
<tr>
<td>Other: 3.28%</td>
</tr>
<tr>
<td><strong>Average number of children</strong></td>
</tr>
<tr>
<td>1.78</td>
</tr>
</tbody>
</table>

**Referral and Genetic Counseling Experiences**

Approximately 36% of our sample were referred to genetic counseling by an oncologist, 31.15% by a breast surgeon, 13.11% were self-referred, 8.2% by an Obgyn, 6.56% were referred by other means, 3.28% by a primary care physician and 1.64% did not remember
who referred them. All participants reported they attended the first genetic counseling session that had been scheduled for them. Ninety-five percent of our sample had no prior experience with genetic counseling. The 5% who had experienced genetic counseling prior to the counseling regarding their breast cancer, reported they had been referred for prenatal reasons, discussion of congenital abnormalities found in their children or a family history of a genetic disorder. Approximately 88% of our sample was offered BRCA genetic testing during their first genetic counseling appointment (Table 2).

<table>
<thead>
<tr>
<th>Table 2. Referral and genetic counseling experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred to genetic counseling by:</td>
</tr>
<tr>
<td>Oncologist</td>
</tr>
<tr>
<td>Breast surgeon</td>
</tr>
<tr>
<td>Self-referred</td>
</tr>
<tr>
<td>Obgyn</td>
</tr>
<tr>
<td>Primary care physician</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Did not remember</td>
</tr>
<tr>
<td>Experience with genetic counseling prior to cancer counseling:</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Offered genetic testing at first cancer counseling appointment:</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Did not remember</td>
</tr>
</tbody>
</table>

**Personal and Family History**

The average age at diagnosis for our sample was 46.79 years. Only 18% of our sample had been diagnosed with bilateral breast cancer. While the majority of medical characteristics for the WIH group and the FORCE group were reasonably similar the following characteristics were statistically different between the groups and therefore they were kept separate during the analysis: US state where majority of treatment occurred, breast cancer pathology, BRCA test results and those participants with affected family member.
Women & Infants’ Hospital

Approximately 87% (n=36) of this group received the majority of their treatment for breast cancer in Rhode Island, 7.32% (n=3) received treatment in Massachusetts, 2.44% (n=1) received treatment in Maryland and 2.44% (n=1) received treatment in Pennsylvania. Approximately 29% (n=12) of this group reported a diagnosis of infiltrating ductal carcinoma, 24.39% (n=10) had been diagnosed with ductal carcinoma in situ, 24.39% (n=10) were not sure or did not remember their diagnosis and roughly 22% (n=9) reported another diagnosis including infiltrating lobular carcinoma and combinations of pathologies. Approximately 74% (n=26) of this group reported to be BRCA negative, 17% (n=6) were BRCA positive, almost 6% (n=2) did not remember their status and almost 3% (n=1) had a variant of uncertain significance. Approximately 39% (n=16) reported having at least one first-degree family member affected with breast cancer, while 51% (n=22) had at least one second-degree family member affected with breast cancer. When asked about ovarian cancer, 2.44% (n=1) reported at least one affected first-degree relative and 19.51% (n=8) reported at least one affected second-degree relative (Table 3).

FORCE Support Group

This group received treatment for their breast cancer throughout 15 different US states. Approximately 57% (n=11) of this group reported a diagnosis of infiltrating ductal carcinoma, 15.79% (n=3) reported another diagnosis such as a combination of pathologies, 10.53% (n=2) reported a diagnosis of ductal carcinoma in situ, 10.53% (n=2) did not remember their diagnosis and 5.26% (n=1) were diagnosed with infiltrating lobular carcinoma. Approximately 89% (n=17) of this group reported to be BRCA
positive while the rest were \textit{BRCA} negative. Fifty-seven percent (n=11) of this group had at least one first-degree relative affected with breast cancer, while 78.95% (n=15) had at least one second-degree relative affected with breast cancer. When asked about a family history of ovarian cancer, 15.79% (n=3) reported at least one affected first-degree relative, while 31.58% (n=6) reported at least one affected second-degree relative (Table 3). A large proportion of women utilizing the FORCE support group are known \textit{BRCA} mutation carriers, which could explain the percentage of known carriers in this group as compared to the WIH group. Similar reasons would explain the difference between the two groups regarding the number of women who had a family history of cancer.

\textit{Appropriateness of Timing of Genetic Counseling}

Approximately 63\% of the total sample felt that the timing of their genetic counseling session was appropriate and did not feel there was a better time to have their counseling (Fig. 1). Sixty-eight percent of this group received their counseling after at least one surgical intervention. This group of participants had an average of 6.86 years between diagnosis and receiving genetic counseling.

Roughly 22\% of the total sample felt the timing was appropriate, however, if given a choice they would have preferred counseling at a different stage in their treatment plan (Fig. 1). Approximately 92\% of this group received their genetic counseling after at least one surgical intervention. This group had an average of 4.09 years between diagnosis and receipt of genetic counseling. Four women were not included in this average as \textit{BRCA} testing was not clinically available when they were diagnosed.

Fifteen percent of all participants felt the timing of the genetic counseling they received was not appropriate (Fig. 1). All of the participants in this group received their
genetic counseling after surgical interventions. This group of participants had an average of 5.13 years between diagnosis and receiving genetic counseling.

<table>
<thead>
<tr>
<th>Table 3. Personal and family history</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong> = 60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Average age at diagnosis</th>
<th>46.34 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bilateral breast cancer diagnosis:</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>82%</td>
</tr>
<tr>
<td>Yes</td>
<td>18%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th><strong>U.S state where breast cancer treatment occurred:</strong></th>
<th><strong>WIH (n=41)</strong></th>
<th><strong>FORCE (=19)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>10.53%</td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>Florida</td>
<td>10.53%</td>
<td></td>
</tr>
<tr>
<td>Georgia</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>Indiana</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>Kentucky</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>Maryland</td>
<td>2.44%</td>
<td></td>
</tr>
<tr>
<td>Massachusetts</td>
<td>7.32%</td>
<td>10.53%</td>
</tr>
<tr>
<td>New Jersey</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>New Mexico</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>New York</td>
<td>10.53%</td>
<td></td>
</tr>
<tr>
<td>Oregon</td>
<td>5.26%</td>
<td></td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>2.44%</td>
<td></td>
</tr>
<tr>
<td>Rhode Island</td>
<td>87.80%</td>
<td>5.26%</td>
</tr>
<tr>
<td>Texas</td>
<td>10.53%</td>
<td></td>
</tr>
<tr>
<td>Wisconsin</td>
<td>5.26%</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Specific breast cancer diagnosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infiltrating ductal carcinoma</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Ductal carcinoma in situ</td>
</tr>
<tr>
<td>Did not remember</td>
</tr>
<tr>
<td>Infiltrating lobular carcinoma</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>BRCA test results:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
</tr>
<tr>
<td>Negative</td>
</tr>
<tr>
<td>Did not remember</td>
</tr>
<tr>
<td>Variant of uncertain significance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Portion of individuals with affected family members:</th>
</tr>
</thead>
<tbody>
<tr>
<td>First degree relatives affected with:</td>
</tr>
<tr>
<td>Breast cancer</td>
</tr>
<tr>
<td>Ovarian cancer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second degree relatives affected with:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
</tr>
<tr>
<td>Ovarian cancer</td>
</tr>
</tbody>
</table>
A chi-square analysis was performed to determine if participants’ opinions about when they received genetic counseling were affected by the timing of their first session.

Fig. 1. Question algorithm for appropriateness and preferences for timing of genetic counseling
relative to their first surgical procedure. As shown in Table 4, none of the participants, regardless of whether they had genetic counseling before or after surgery, stated that they would have preferred to have genetic counseling later in their treatment process.

Approximately 92% of participants who received genetic counseling prior to surgical intervention (n=13) felt that was an appropriate time to have genetic counseling and did not prefer another time (Fig 2a). One woman who received genetic counseling prior to her surgery would have preferred the counseling to take place prior to her neoadjuvant chemotherapy. In comparison, approximately 55% of participants who received genetic counseling after surgical intervention (n=47) felt that was an appropriate time to have genetic counseling and did not prefer another time (Fig. 2b). When the preferences of the two groups were compared to each other, genetic counseling was more likely to be preferred prior to surgical intervention ($\chi^2(1) = 3.70, p = .05$).

<table>
<thead>
<tr>
<th>Timing of genetic counseling</th>
<th>Appropriateness of genetic counseling</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Better time (earlier)</td>
<td>No better time</td>
</tr>
<tr>
<td>Before surgery</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>After surgery</td>
<td>21</td>
<td>26</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>36</td>
</tr>
</tbody>
</table>

Table 4. Crosstabulation of timing of genetic counseling with appropriateness of genetic counseling

![Figure 2a](image)

![Figure 2b](image)
A separate chi-square analysis was performed on those participants who received genetic counseling after surgery. We did not find any correlation in regard to age, medical history, the number of surgeries undergone or the number of family members affected with breast or ovarian cancer between our participants who preferred their counseling earlier and those who preferred counseling after surgery. However, while it was not statistically significant, we did see a trend towards women with BRCA mutations preferring to have genetic counseling earlier (data not shown).

Timing Preferences

Approximately 56% of the entire sample felt the best time to receive counseling was prior to surgery. This group consisted of both those who received counseling prior to surgery and those who did not. In comparison, 43% of the sample felt that receiving counseling after surgical intervention was the best option for them (Fig. 3).
Approximately 30% of participants who received genetic counseling after surgery but thought there was a better time to have counseling, would have preferred to receive their counseling immediately after their diagnosis (Fig. 4). Roughly 6% would have preferred to receive genetic counseling prior to diagnosis, based on their family history. Approximately 6% had received genetic counseling many years after their diagnosis (10 years, 10 years and 18 years, respectively) and would have preferred their genetic counseling immediately after their surgery. Finally, one woman stated she would have preferred to receive genetic counseling after her second diagnosis but prior to her second surgery. This participant received counseling approximately nine years after her first diagnosis. When analyzed without the women who received counseling 10 or more years after their diagnosis, all of the participants in this group would have preferred to have their counseling immediately after diagnosis and before any surgical intervention. It is useful to analyze this group without these women as none of them would have had an opportunity to have genetic counseling regarding BRCA testing immediately after diagnosis, as the testing was not yet available.

![Figure 4. Preferences for timing of genetic counseling in participants who received genetic counseling after initial surgery (n=47)](image)

* These women received counseling 8-18 years after initial surgery
Impact of Genetic Counseling on Surgical Decisions

Almost 80% of participants who received genetic counseling and *BRCA* testing prior to any surgical interventions felt that their counseling and *BRCA* test result influenced their initial surgical decisions, while approximately 8.5% of participants who received genetic counseling and *BRCA* testing after some type of surgical intervention felt their counseling and *BRCA* test result influenced their later surgical decisions (Fig. 5).

### Figure 5. Influence of genetic counseling and testing on surgical treatment and future prophylactic options

- **Received counseling & testing pre-surgery** (n=13)
- **Received counseling & testing post-surgery** (n=47)

Psychological Implication

Approximately 15% of the total sample stated they felt psychologically overwhelmed by the information presented during their genetic counseling session regardless of the timing of their genetic counseling (Fig. 6).
**DISCUSSION**

*Appropriateness of Timing of Genetic Counseling*

While the majority of participants in our study felt that the timing of their genetic counseling was appropriate, whether they received counseling before or after surgery, there were still women who felt that they would have liked to receive counseling at an earlier time. The majority of these participants indicated that they would have preferred to receive counseling prior to surgery. Fifteen percent of participants felt the timing of their genetic counseling was inappropriate and would have preferred to have counseling earlier in their treatment process. None of our sample wished to have had the counseling at a later time than when it occurred. We found these results to be similar to a larger study that found 81% of women approached for genetic counseling within a year of diagnosis, agreed that the timing of their counseling was appropriate or would have preferred it to be earlier (Schlich-Bakker et al 2007).

All of our participants who received counseling prior to surgery felt that the timing of counseling was appropriate. Only one participant in this group felt the timing
could have been better. This woman had received her counseling after her neoadjuvant chemotherapy and would have preferred to receive counseling immediately after her diagnosis. Almost half of our participants who received counseling after at least one surgical intervention would have preferred to receive their genetic counseling earlier. All of our participants who did not feel the timing was appropriate fell into this group.

The fact that nearly half of those participants who received counseling after surgery would have preferred to receive it earlier, whereas none who received counseling before surgery preferred to receive it later, suggests that genetic counseling should be offered before surgical decisions are made. While Ardern-Jones et al (2005) found that the majority of women they interviewed felt they could not have coped with cancer and a genetic diagnosis at the same time, our study gives evidence that there are women who would prefer to have counseling earlier even if that means they are in the middle of coping with their cancer diagnosis. Very few of the women interviewed by Ardern-Jones et al had actually received genetic counseling prior to their surgery; therefore the majority of the women’s responses were hypothetical. This could help to explain why our results differed, as we had a higher proportion of women who did not respond hypothetically. However, our study seems to agree with Ardern-Jones et al that there is no perfect time to offer genetic counseling or testing and the right time may be patient dependent.

Schlich-Bakker et al (2007) found that patients who declined counseling early in their treatment process disagreed with the timing of their counseling and wished it had occurred later. Because our sample reported that they had all attended the first scheduled counseling session we cannot assess why some patients might not attend their first session. Therefore, there might still be a population who wish to receive their counseling
later but we were unable to study them. This could be because our sample was mainly recruited from a high-risk cancer genetics clinic and consisted only of women who had received genetic counseling. If our population had been recruited from an oncologist or breast surgeon’s office we may have been able to enroll women who were referred to genetic counseling but never attended an appointment.

**Timing Preferences**

When we looked at the group of women who received genetic counseling after their surgery we found that almost half felt that there would have been a better time. The majority of those who preferred a different time felt that receiving counseling immediately after their diagnosis would have been the best. It is interesting to note that most of the women in this group had their surgeries within a few weeks of diagnosis and therefore it could have been difficult for them to receive counseling and their test results prior to their respective surgeries. However, this still provides evidence that more women would prefer to have counseling earlier and could then have the option of discussing with their surgeon if they should wait for the results of genetic testing before proceeding with surgery.

Only two women stated that they would have preferred to receive counseling prior to their diagnosis, based on their family history. Neither of the women who had this preference had a particularly strong family history. This may be a reflection of the mental state or level of anxiety felt by these women. One of the women stated,

“"I like to know what I am dealing with. I need to make medical decisions and I absolutely want all the information I can get so that I can make good choices. Being given information reduces stress and makes me comfortable with my doctors.”"

- 56 years, *BRCA* negative
Three women who received counseling years after their surgery would have preferred to have received counseling immediately after their surgery. For two of these women, BRCA testing was not available when they received their diagnosis or their surgery, however testing had become recently available clinically for the third woman. Another woman would have preferred to receive her counseling after her second diagnosis but prior to her second surgery. BRCA testing was available during her first diagnosis; she received her second diagnosis seven years after her first and did not receive counseling for another two more years. While these women did not express a preference for having counseling prior to their surgeries, they still provide evidence that women would prefer not to wait years after their diagnosis or surgery in order to determine their BRCA status. Unfortunately, we were not able to ascertain why these women preferred having their counseling years earlier but still after their respective surgeries.

*Impact of Genetic Counseling on Surgical Interventions*

Testing for breast cancer susceptibility genes is an important factor to consider for women who may be at risk for carrying a mutation. Currently, women who presymptomatically test positive for a BRCA mutation are given the option of pursuing increased surveillance, with or without chemoprevention, or having a prophylactic bilateral mastectomy. A woman with a diagnosis of breast cancer who learns she has a BRCA mutation prior to her surgery could face having to decide whether to have a lumpectomy, unilateral mastectomy or bilateral mastectomy that includes removal of the unaffected breast. Currently women are referred to genetic counseling at various times in their diagnosis and treatment process, to discuss the possibility of hereditary breast
cancer. Some women may not receive a referral for genetic counseling until after they have already completed surgical treatment.

Currently there is debate in the literature regarding whether genetic counseling and the disclosure of *BRCA* mutation status has an influence on surgical decisions. In 2004, Schwartz et al found that a positive test result was associated with a three-fold increase in the odds of receiving a bilateral mastectomy, but did not decrease the use of breast-conserving therapy. In 2005, Schwartz et al reported that 21% of women chose to proceed with definitive treatment before receiving their test results. Recently, however, van Dijk et al found that the women they studied were not greatly influenced during their decision-making by the disclosure of their *BRCA* positive results (2008). This discrepancy could be because Schwartz et al studied patients’ actual decisions, while van Dijk et al addressed patient’s self-reported decision-making process. We found that, while not statistically significant, there was a trend towards *BRCA* positive women preferring counseling earlier. This would support the idea that a woman’s mutation status could influence her treatment decisions and therefore women should be referred to genetic counseling prior to surgery.

In our sample, few women had the opportunity to use the information they were given during their genetic counseling session to help them decide what type of surgical treatment they would have. Some of the few who did receive counseling prior to surgery expressed how the information they received was used while deciding what type of surgery they would choose to undergo. One woman stated:

“I knew if I tested positive, I would change my surgical decision from lumpectomy to bilateral [mastectomy]”

- 55 years, *BRCA1* positive
While the majority of our participants did receive genetic counseling after having their surgery, at least one woman felt that had she received counseling prior to her surgery, she would have changed her surgical decision.

“It [genetic counseling] was after my lumpectomy that I found out. Had I known, I would have had a double mastectomy.”

- 52 years, *BRCA2* positive

Weitzel et al (2003) found a similar result with many of the patients who received genetic counseling after treatment expressing regret at not have counseling at the time of initial diagnosis.

While our study did not assess other factors that might influence a woman’s surgical decision, other studies have found that physician recommendations were also an important determinant (Schwartz, 2004). Van Dijk et al (2008) stated that women appeared to make their decisions regarding risk management at a relatively early stage of genetic counseling, further supporting the utility of counseling at an earlier time during treatment. Our study, along with both Schwartz et al studies (2004; 2005), found evidence that newly diagnosed patients are interested and willing to undergo pre-surgery genetic counseling.

**Psychological Implications**

Previous studies have found that women diagnosed with breast cancer do not suffer negative psychological effects from being approached to discuss genetic counseling (Schlicht-Bakker, 2007; Smith, 2007). Additionally, mutation carriers were found to have greater distress three months after receiving test results as compared to non-carriers. However, this distress appeared to lessen over the long term. While it is to be expected that mutation carriers have a greater perceived risk over time as compared to
non-carriers, it has also been shown that individuals who do not receive testing also have a higher perceived risk (Smith, 2007).

In our sample, 15% of participants felt psychologically overwhelmed by the information presented to them during their genetic counseling session, regardless of when they received counseling. One of two such participants who received counseling prior to surgery was also pregnant at the time of her breast cancer diagnosis and genetic counseling session. The pregnancy likely had an influence on the emotional state of this participant, therefore it is hard to say whether she would have felt overwhelmed with the information had she not been pregnant at the time. Of the participants who received genetic counseling after their surgery and felt psychologically overwhelmed, the majority felt burdened at having to make more medical decisions regarding their cancer.

“...I had just spent 2 years dealing with all of this.... The thought of being tested and learning that I do have the BRCA [mutation] and facing a possible oophorectomy or hysterectomy or both, and the possibility of pancreatic…cancer, was just too much to handle psychologically.”
- 48 years, did not have BRCA testing

The majority of participants who did not feel overwhelmed after their genetic counseling session were either glad to have the information for themselves and their family members,

“ [I] was concerned about the impact on other family members if I did have the [mutation] and wanted to know so that they would have the option of early testing etc.”
- 56 years, BRCA negative

or felt relief over having a reason why they had developed breast cancer.

“I was relieved to know why I have been plagued by three breast cancer tumors since I am still relatively young.”
- 53 years, BRCA1 positive
Provider Perceptions

Several studies surveying practitioners have found that there is concern regarding whether counseling patients during the time surrounding their diagnosis may be psychologically overwhelming. Arden-Jones et al’s (2005) interviews with breast surgeons regarding the appropriate time to discuss genetic testing with breast cancer patients revealed that physicians are concerned about overwhelming their patients with information during this time. Boni et al (2007) found similar views while surveying genetic counselors.

Our study supports the idea that while some women do feel overwhelmed with the amount of information they receive during counseling, it does not appear to matter whether counseling occurs immediately after diagnosis or after surgical treatment. This could lead to greater reason for women to be counseled immediately after diagnosis and could alleviate some concern felt by the medical professionals who work with women with breast cancer. Our study could not find any factors that would differentiate between those who felt overwhelmed by the information and those who did not.

Limitations

One limitation of our study was the small sample size. This could have influenced why we were unable to find any correlation between demographical, or personal or family history information and a woman’s preference for the timing of counseling. We also had a low response rate, therefore there could have been selection-bias among the women who chose to participate. For example, women who were the most unsatisfied with their genetic counseling may have been less likely to participate. While the vast majority of the women in this study were Caucasian and may represent the population seen at WIH and
other cancer centers, it is not representative of the diversity of women who are affected with breast cancer and could limit the generalizability of this study. Another limitation to the study was that some eligible participants may not have had access to the Internet in order to take the survey and may not have felt comfortable in contacting the researchers in order to participate. We tried to limit the retrospective nature of the study by limiting the time at which the participants received genetic counseling to the last two years. However, recall bias and the possibility that participants’ feelings regarding the appropriateness of the timing of genetic counseling could still have changed over time and may have influenced responses.

Future Research

A longitudinal study could focus on patients’ perceptions of genetic counseling before and directly after their appointment, as this may help to better identify patient feelings at each point in time more accurately. It could have been helpful to give our sample a variety of timing scenarios and ask them to rank them in order of preference or give participants an opportunity to list the various treatment events in the order of their preference. Additionally, a qualitative follow up study could help to expand upon the reasons why women preferred counseling at a different time. This could help to gain more insight into the differences between women who prefer counseling earlier and those who prefer it later.

CONCLUSION

We surveyed women diagnosed with breast cancer recruited from both a high risk clinic and support group and found that there is a high percentage of women who would prefer to have genetic counseling immediately after their diagnosis. Our study helps to
provide more support for giving women diagnosed with breast cancer an opportunity to receive genetic counseling earlier in their treatment process. It is important for healthcare professionals who work with women with a diagnosis of breast cancer to be aware that, while it is true that some patients’ prefer counseling after surgery, there are a large number patients who would prefer to have counseling prior to surgery and would use the information gained to make decisions regarding surgery.

In addition our study helps to alleviate concern felt by both physicians and genetic counselors, that counseling women immediately after diagnosis could be too psychologically overwhelming. Our findings suggest that there will always be a percentage of women who feel overwhelmed by the information they receive in counseling, regardless of the time at which they receive that information. However, the medical benefit of counseling prior to surgery could outweigh the possibility of psychologically overwhelming patients; therefore healthcare professionals should give greater thought to referring patients for genetic counseling earlier.
REFERENCES


cancer risk. *Psycho-Oncology* [Epub ahead of print]


Some time ago you visited the Cancer Risk Assessment & Prevention Program at Women & Infants Hospital for genetic counseling related to your diagnosis of breast cancer. We are writing to invite you to participate in a research project focused on genetic counseling for women diagnosed with breast cancer. The purpose of this study is to assess women’s opinions regarding the timing of their genetic counseling session. It is our hope that the information we learn from the research study will help to guide health care providers involved in the diagnosis and treatment of women with breast cancer.

This survey should take approximately 30 minutes to complete and is available online at www.surveymonkey.com/TBA. This link will take you directly to the first page of the survey, which is a required participation agreement. Once you acknowledge that you wish to participate you will be taken directly to the survey.

Participation in the study is completely voluntary and the questionnaire is anonymous. No one will be able to connect you to your responses. SurveyMonkey.com collects IP addresses for system administration and record keeping, however no connection is made between you and your computer’s IP address in regard to your survey responses. This survey and all collected responses will be deleted from SurveyMonkey.com servers by May 2009. This research has been approved by the Institutional Review Boards at both Women and Infants Hospital and Brandeis University as this has been a collaborative effort.

The survey will be available online until March 9, 2009. If any questions are unclear or you would like further information regarding this project or its outcome or if you do not have internet access please feel free to contact Christy Ferlatte by email at ferlatte@brandeis.edu or by telephone at (781) 736-3179. Thank you in advance for your time and participation.

Sincerely,

Christy Ferlatte
Master’s Candidate, Genetic Counseling
Brandeis University

Jennifer Scalia Wilbur, MS
Clinical Program Manager

Jessica L. Kent, MS
Cancer Genetic Counselor

Robert D. Legare, MD
Medical Director

Cancer Risk Assessment & Prevention Program
APPENDIX B: PARTICIPATION AGREEMENT - WOMEN & INFANTS’ HOSPITAL

Participation agreement:

I understand this is a research study attempting to understand patients’ opinions of the timing of cancer genetic counseling during or after treatment for breast cancer. I understand that any information gained from this study may be used in future publications or presentations. I understand that being in this study only involves this one-time survey.

I understand that this survey will last approximately 30 minutes and is anonymous. I understand that no link will be made between my responses and my medical health record.

I understand there is no potential benefit to myself for participating. I understand that this study is voluntary and I am under no obligation to contribute. I understand that I may stop my participation at any time without any consequence.

Although this study is thought to result in minimum risk, if I experience any feelings of distress or emotional discomfort due to my participation, I am aware that I can contact Jennifer Scalia Wilbur, MS, Clinical Program Manager/Cancer Genetic Counselor, at (401) 453-7540. She will be available to talk with me and to offer appropriate referrals if necessary.

If I have any questions regarding the research, I may contact Christy Ferlatte at ferlatte@brandeis.edu. If I have questions about my rights as a research subject, I may call Barbara Riter, Manager, Research Administration, at (401) 453-7677.

Please indicate whether you accept or decline this agreement: ACCEPT/DECLINE

(ACCEPT: Continue onto the survey)
(DECLINE: Skip to: Thank you for your initial interest.)
APPENDIX C: QUALIFYING QUESTIONS - WOMEN & INFANTS’ HOSPITAL

Key: [ ] = drop down menu
[ ] = comments regarding study questions

Qualifying questions
1. Will you/have you received the majority of your breast cancer treatment in the United States? Y N

If Y participant can proceed with rest of the survey.
If N then participant will be sent to:
   Thank you for your time and interest but unfortunately you do not fit our criteria for this study.

APPENDIX D: SURVEY QUESTIONS - WOMEN & INFANTS’ HOSPITAL & FORCE SUPPORT GROUP

Personal history: In this section you will be asked questions regarding your personal history with breast cancer.

1. In which US state will you/have you received the majority of your breast cancer treatment? [US States]

2. When were you diagnosed with breast cancer? [Month/ I don’t remember] [2006/ 2007/ 2008/ I don’t remember]

3. How old were you when you were first diagnosed? __ years old

4. What was your specific diagnosis?
   __ Infiltrating ductal carcinoma
   __ Infiltrating lobular carcinoma
   __ Ductal carcinoma in-situ
   __ Other ___________________________
   __ I don’t remember

5. Did you have bilateral breast cancer (cancer in both breasts)? Y N
   *N: Skip to question # 6.

   5a. Was each breast cancer diagnosed (please select the answer that best describes you): __ At the same time __ At different times

6. When did you first receive genetic counseling regarding your breast cancer? [Month/ I don’t remember] [2006/ 2007/ 2008/ I don’t remember]
7. Who referred you to genetic counseling?  
[Primary care physician/ breast surgeon/ oncologist/ OB/GYN/ Self-referred/ I don’t remember/ Other ______]

8. Prior to the genetic counseling and/or genetic testing you received regarding your breast cancer, had you received any genetic counseling or testing for any other possible genetic conditions, not necessarily related to breast cancer? Y/N

8a. (Optional) If yes, please explain: ___________________________________

9. Please place the following events in the order they occurred during your treatment for breast cancer. (1= first; 11= last) (Note: If you did not undergo a particular event please enter ‘0’)
   _First diagnosis_   _Chemotherapy_   _Radiotherapy/ radiation_
   _Unilateral mastectomy_   _Lumpectomy_   _Bilateral mastectomy_
   _Bilateral mastectomy (includes prophylactic)_   _Genetic counseling_
   _Blood draw for BRCA 1/2 testing_   _Receipt of genetic test results_
   _Second diagnosis_

10. To the best of your abilities, please state how much time occurred between each event.  
[Based on answers to question #9, “events” will show up in the order that was marked]
   _Event_   _[day(s)/ week(s)/ month(s)/ year(s)/don’t know]_
   _Event_   etc...

11. Were you offered genetic testing during your initial genetic counseling session regarding your breast cancer? [Y/N/I don’t remember]

12. (Optional) If you underwent genetic testing for the BRCA mutations and have received your results please state them.  
[Positive (mutation found)/ negative (no mutation found)/ variant of uncertain significance (uninformative result)/ I don’t remember]
[BRCA1/ BRCA2/Don’t remember] [Will show up only if positive or VUS]

**Impact:** In this section you will be asked questions regarding your experience with genetic counseling or genetic testing.

13. Did you go to the first genetic counseling appointment that was made for you regarding your risk of hereditary breast cancer? Y N

*If Y skip to question #14.
   13a: Why not? Please choose all that apply. [Too overwhelmed/Did not feel the need for the appointment/ Not available for the appointment/Fear of learning cancer]
14. Do you feel that the genetic counseling you did receive regarding your hereditary breast cancer influenced your initial surgical decisions? Y/N/I don’t remember

14a. Why or why not? ______________________________________________

15. Do you feel that the genetic testing you received regarding your hereditary breast cancer risk influenced your initial surgical decisions? Y/N/I don’t remember/I did not have testing

15a. Why or why not? ______________________________________________

16. Do you feel that the time at which you received genetic counseling was an appropriate time to discuss genetic testing? Y/N

*If answered Y to question #16 will skip to question #18.

17. When would you have preferred to receive genetic counseling regarding your diagnosis of breast cancer?
[Prior to diagnosis, based on your family history/ Immediately after diagnosis but prior to any surgical interventions/ After surgical intervention/ Not at any time/Other__________]

18. Do you feel there was a better time to receive genetic counseling regarding your diagnosis of breast cancer? Y/N

*If N skipped to question #19.

18a. When would you have preferred to receive genetic counseling regarding your diagnosis of breast cancer?
[Prior to diagnosis, based on your family history/ Immediately after diagnosis but prior to any surgical interventions/ After surgical intervention/ Not at any time/ Other ________]

19. Did you feel psychologically or emotionally overwhelmed by the information presented to you regarding hereditary breast cancer during your genetic counseling session? Y/N

19a. Why or why not? ________________________________________________

Family History: In this section you will be asked questions regarding your family’s experience with breast or ovarian cancer.
20. How many first-degree relatives (mother, father, brothers, sisters, children) do you have that have been diagnosed with breast cancer? __

20a. How many first-degree relatives have passed away from breast cancer? __

21. How many second-degree relatives (grandparents, aunts, uncles, grandchildren) do you have that have been diagnosed with breast cancer? __

21a. How many second-degree relatives have passed away from breast cancer? __

22. How many first-degree relatives (mothers, sisters, daughters) do you have that have been diagnosed with ovarian cancer? __

22a. How many first-degree relatives have passed away from ovarian cancer? __

23. How many second-degree relatives (grandmothers, aunts, granddaughters) do you have that have been diagnosed with ovarian cancer? __

23a. How many second-degree relatives have passed away from ovarian cancer? __

**Demographics**

24. Current age: __ years

25. Ethnicity: Please check all boxes that apply.
- Caucasian-Jewish (Ashkenazi)
- Caucasian- non-Jewish
- African American
- Caucasian-Jewish (non-Ashkenazi)
- Asian American
- Native American
- Hispanic
- Native American
- Other ________________

26. Education level: Please check the highest level of education you have completed.
- Did not complete high school
- High school diploma/ GED/ or equivalent
- Some college
- Associate degree (for example: AA, AS)
- Undergraduate degree (for example: BS, BA, AB)
- Some graduate
- Master’s degree (for example: MS, MA MEng, Med, MSW, MBA)
- Professional degree (for example: MD, DDS, DVM, LLB, JD)
- Doctorate degree (for example: PhD, EdD)

27. Economic status: Please select the category that best describes your yearly household salary.
- Less than $20,000
- $20,000-$39,999
28. Employment status: Please select the best answer
   __Unemployed
   __Employed
   __Self-employed
   __Retired

29. What would best define your current marital status?
   __Never married
   __Married/living with partner
   __Divorced
   __Widowed
   __Separated

30. How many children do you have? __

31. Which religion do you most identify with?
   __Buddhism
   __Christian
   __Jewish
   __Hindu
   __Islam
   __None
   __Other_____________________

Thank you for participating in our study. Your time and answers are much appreciated.
APPENDIX E: REMINDER LETTER - WOMEN & INFANTS’ HOSPITAL

Dear Ms. ________,

We are writing to remind you of our online survey assessing women’s opinions regarding the timing of their genetic counseling session.

If you have already completed this survey, thank you for your time and participation. You can disregard the rest of this letter.

If you have not completed this survey please take time to do so, it is much appreciated.

This survey should take approximately 30 minutes to complete and is available online at www.surveymonkey.com/TBA. This link will take you directly to the first page of the survey, which is a required participation agreement. Once you acknowledge that you wish to participate you will be taken immediately to the survey.

The purpose of this study is to assess women’s opinions regarding the timing of their genetic counseling session. It is our hope that the information we learn from the research study will help to guide health care providers involved in the diagnosis and treatment of women with breast cancer.

Participation in the study is completely voluntary and the questionnaire is anonymous. No one will be able to connect you to your responses. SurveyMonkey.com does collects IP addresses for system administration and record keeping, however no connection is made between you and your computer’s IP address in regard to your survey responses. This research has been approved by the Institutional Review Boards at both Women and Infants Hospital and Brandeis University as this has been a collaborative effort.

The survey will be available until March 9, 2009. If any questions are unclear or you would like further information regarding this project or its outcome or if you do not have internet access please feel free to contact Christy Ferlatte by email at ferlatte@brandeis.edu or by telephone at (781) 736-3179. Thank you in advance for your time and participation.

Sincerely,

Christy Ferlatte  
Master’s Candidate, Genetic Counseling  
Brandeis University

Jennifer Scalia Wilbur, MS  
Clinical Program Manager

Robert D. Legare, MD  
Medical Director  
Cancer Risk Prevention & Assessment Program

Jessica L. Kent, MS  
Cancer Genetic Counselor

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APPENDIX F: RECRUITMENT LETTER - FORCE SUPPORT GROUP

Dear FORCE members,

I am writing to ask for your participation in a research project focused on the genetic counseling experience of women diagnosed with breast cancer. The purpose of this study is to assess women’s opinions regarding the timing of their genetic counseling session during or after treatment for breast cancer. It is my hope that the information I learn from the research study will help to guide health care providers involved in the diagnosis and treatment of women with breast cancer.

The survey should take approximately 30 minutes to complete and is available online at www.surveymonkey.com/TBA. This link will take you directly to the first page of the survey, which is a required participation agreement.

In order to be qualified for this study you must:
- be a woman
- have been diagnosed with breast cancer
- received genetic counseling related to your diagnosis of breast cancer between September 2006 and September 2008
- received the majority of your breast cancer treatment in the United States.

If you fulfill these criteria, please consider participating in this study.

Participation in the study is completely voluntary and the questionnaire is anonymous. No one will be able to connect you to your response. This research is part of a graduate thesis project. The Institutional Review Board at Brandeis University has approved this research.

The survey will be available online until March 9, 2009. If any questions are unclear or you would like further information regarding this project or its outcome please feel free to contact Christy Ferlatte by email at ferlatte@brandeis.edu. Thank you in advance for your time and participation.

Sincerely,

Christy Ferlatte
Master’s Candidate, Genetic Counseling
Brandeis University
APPENDIX G: PARTICIPATION AGREEMENT - FORCE SUPPORT GROUP

Participation agreement:

I understand this is a research study attempting to understand patients’ opinions of the timing of cancer genetic counseling during or after treatment for breast cancer. I understand that any information gained from this study may be used in future publications or presentations. I understand that being in this study only involves this one-time survey.

I understand that this survey will last approximately 30 minutes and is anonymous.

I understand there is no potential benefit to myself for participating. I understand that this study is voluntary and I am under no obligation to contribute. I understand that I may stop my participation at any time without any consequence.

Although this study is thought to result in minimum risk, if I experience any feelings of distress or emotional discomfort due to my participation, I am aware that I can contact Christy Ferlatte at (510) 703-4987. She will be available to talk with me and to offer appropriate referrals if necessary.

If I have any questions regarding the research, I may contact Christy Ferlatte at ferlatte@brandeis.edu. If I have questions about my rights as a research subject, I may call Lorrie Clark, Research Administration, Brandeis University, at (781) 736-7596.

Please indicate whether you accept or decline this agreement: ACCEPT/DECLINE

(Accept: Continue onto the survey)
(Decline: Skip to: Thank you for your initial interest.)

APPENDIX H: QUALIFYING QUESTIONS - FORCE SUPPORT GROUP

Qualifying questions (First page of questionnaire prior to all other questions)
1. Are you a woman that has been diagnosed with breast cancer? Y N
2. Will you/have you received the majority of your breast cancer treatment in the United States? Y N
3. Did you receive any genetic counseling regarding your breast cancer between September 2006 & September 2008? Y N

If all questions answered Y then participant can proceed with rest of survey.
If answered N to any questions then participant will be sent to:

Thank you for your time and interest but unfortunately you do not fit our criteria for this study.
APPENDIX I: EMAIL BLAST - FORCE SUPPORT GROUP

Dear FORCE members,

Would you like to participate in a research study regarding breast cancer and genetic counseling? If so, then please go to http://www.cryptio.net/~christy/Thesis-recruitment.html for more information. This research project is part of a thesis requirement for Brandeis University.

Sincerely,

Christy Ferlatte, BS
Master’s Candidate, Genetic Counseling
Brandeis University