Spiritual Faith and Genetic Testing Decisions among High-Risk Breast Cancer Probands

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Abstract
Despite widespread access to genetic testing for the BRCA1 and BRCA2 breast cancer susceptibility genes, little is known about rates or predictors of test use among individuals from newly ascertained high-risk families who have self-referred for genetic counseling/testing. The objective of this study was to examine rates of test use within this population. In addition, we sought to determine whether spiritual faith and psychological factors influenced testing decisions. Participants were 290 women with familial breast cancer. All were offered genetic counseling and testing for alterations in the BRCA1 and BRCA2 genes. Baseline levels of spiritual faith, cancer-specific distress, perceived risk, and demographic factors were examined to identify independent predictors of whether participants received versus declined testing. The final logistic model revealed statistically significant main effects for spiritual faith [odds ratio (OR), 0.2; 95% confidence intervals (CIs), 0.1 and 0.5] and perceived ovarian cancer risk (OR, 2.4; 95% CIs, 1.3 and 4.7) and a statistically significant spiritual faith by perceived risk interaction effect. Among women who perceived themselves to be at low risk of developing breast cancer again, those with higher levels of spiritual faith were significantly less likely to be tested, compared with those with lower levels of faith (OR, 0.2; 95% CIs, 0.1 and 0.5). However, among women with high levels of perceived risk, rates of test use were high, regardless of levels of spiritual faith (OR, 1.2; 95% CIs, 0.4 and 3.0). These results highlight the role that spirituality may play in the decision-making process about genetic testing.

Introduction
The BRCA1 and BRCA2 genes are believed to account for most HBC cases (1). Among women affected with breast cancer, inherited mutations in BRCA1 or BRCA2 are associated with a significantly increased risk of developing new primary cancers (2–4). Preliminary reports suggest that 40–80% of HBC family members elect to learn their genetic status for BRCA1/2 (5, 6), with somewhat higher rates among persons with cancer as compared with those who are unaffected (5). However, these reports were based on a few large HBC families, most of whom were members of hereditary cancer registries and participants in prior genetics research. These participants may not be representative of newly ascertained individuals who self-refer for genetic counseling (5). In the present study, we evaluated BRCA1/2 test use among women who had self-referred to a free genetic counseling/testing research program. The study focused on women who were affected with breast cancer, because standard clinical practice is to first screen for mutations among a likely carrier in the family before proceeding to unaffected relatives.

A novel goal of this study was to explore the role of spirituality in testing decisions. Although spirituality has been linked to the avoidance of health risk behaviors (7) and decreased mortality for a variety of diseases (8), little is known about its effects on medical decision making or on genetic testing, in particular. However, research and theory on coping with illness suggests that spirituality may actually deter participation in genetic testing for cancer risk. For example, research has shown that highly spiritual individuals are more optimistic (7), have greater acceptance of their cancer diagnoses (9), and are more likely to attribute health threats to external forces than to factors such as heredity (10). Thus, a woman with breast cancer who is highly spiritual may question the need for genetic testing because she accepts her condition and believes that whether she becomes ill or not is out of her hands. This is consistent with a previous study showing an inverse relationship between spirituality and interest in prenatal testing (11). Therefore, we hypothesized that highly spiritual individuals would be less likely than less spiritual individuals to receive BRCA1/2 testing.

The present study also focused on cancer-specific distress and perceived risk, two psychological variables that have been implicated in BRCA1/2 testing decisions. Perceived risk and cancer-specific distress have predicted intentions to obtain BRCA1/2 testing (12). For example, among women from HBC families, we found that cancer-specific distress predicted BRCA1/2 test use (13). Similarly, in a recent study, both perceived risk and cancer worries were associated with genetic testing for colorectal cancer susceptibility (14). Therefore, in

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The abbreviations used are: HBC, hereditary breast cancer; CARE, Cancer Assessment and Risk Evaluation; OR, odds ratio; CI, confidence interval.
the present study, we predicted that perceived risk and cancercpecific distress would increase the likelihood of BRCA1/2 testing, whereas spirituality would reduce test use.

Materials and Methods

Participants. Participants were 290 adult breast cancer patients (proband s) who had self-referred to the CARE program at the Lombardi Cancer Center. To be eligible, participants were required to have a family history of breast/ovarian cancer that resulted in a minimum 20% prior probability of having a BRCA1/2 mutation (15). If a risk-conferring mutation was identified in the proband, then enrollment in the CARE program was extended to other family members. However, the present report is limited to the first 290 probands to enter CARE.

Procedures. Probands who contacted the CARE program were screened by telephone to determine eligibility. Eligible probands completed a structured telephone interview that assessed sociodemographics, cancer family history, spirituality, perceived risk, and psychological distress. Following this interview, participants were invited to a pretest education session with a genetic counselor. Information provided to probands during this 1.5–2-h session included qualitative risk assessments based on their personal and family history, details about the process of testing for BRCA1/2 mutations and interpretation of test results, cancer risks associated with BRCA1/2 mutations, options for cancer prevention and surveillance (based on published guidelines; Ref. 16), details about the benefits and risks/limitations of testing, and details about the possible psychosocial impact of testing.

Following the educational session, participants were offered the opportunity to provide a blood sample for BRCA1/2 mutation testing after providing written consent. When a participant’s test result became available, the participant was invited to a disclosure/counseling session. Participants could decline to continue at any point in the process (i.e., before education, after education, or before the receipt of test results). Thus, uptake was defined as the actual receipt of BRCA1/2 test results.

Measures

Predictor Variables. All predictor variables were assessed at baseline (i.e., before the education session and the offer of BRCA1/2 testing).

Sociodemographics. We assessed age, race, religion, education, and marital status.

Family History of Cancer. We assessed the number of first-degree relatives (i.e., parents, siblings, children) who were affected with breast and/or ovarian cancer. We dichotomized family history as one to two affected relatives versus three or more affected relatives.

Spirituality. Spirituality was assessed with the following item adopted by the NIH Cancer Genetics Studies Consortium: “How strong would you say your religious or spiritual faith is?” Participants responded using a four-point Likert scale ranging from not very strong to very strong. To create groups of as close to equal in size as possible, we dichotomized this item into very strong (n = 123) versus not very strong/a little strong/ moderate strong (n = 167).

Cancer-specific Distress. We used The Intrusion Subscale of the Impact of Events Scale (17) to measure the frequency and severity of intrusive thoughts, worries, and feelings about being at increased risk for breast and ovarian cancer. Responses were on a Likert scale ranging from not at all to often. The seven-item Intrusion subscale had good internal consistency (Cronbach’s α, 0.84) and has been used in previous studies to measure cancer-specific distress (13, 18).

Breast Cancer Perceived Risk. We measured perceived risk for breast cancer with the following Likert-style item (19): “In your opinion, compared to other women your age, what are your chances of developing breast cancer again?” (1 = much lower to 5 = much higher). Because responses to this item were not normally distributed, we dichotomized the item as close to the median as possible [much higher (n = 151) versus somewhat higher/the same/lower (n = 139)].

Ovarian Cancer Perceived Risk. We measured perceived risk for ovarian cancer with the following Likert-style item: “In your opinion, compared to other women your age, what are your chances of developing ovarian cancer?” (1 = much lower to 5 = much higher). We dichotomized this item as close to the median as possible [much higher/somewhat higher (n = 148) versus the same/lower (n = 142)].

Dependent Variable. We classified test uptake based on whether or not participants underwent testing and received their result versus declined testing or test results (i.e., declined to attend the pretest education session, declined to provide a DNA sample, or declined to learn their test result).

Results

Sample Characteristics. Sample characteristics are shown in Table 1. The majority of participants were Caucasian, 45 yr of age and older, married, and had a college education. Forty-two percent of participants reported that their spiritual faith was very strong, 52% reported that their risk for developing breast cancer was much higher than an average woman of the same age, and 51% reported that their risk for ovarian cancer was somewhat or much higher than an average woman of the same age.

<p>| Table 1 Demographic, psychosocial, and cancer history characteristics of the study sample |</p>
<table>
<thead>
<tr>
<th>Variable</th>
<th>Levels</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>&lt;45</td>
<td>91 (31%)</td>
</tr>
<tr>
<td></td>
<td>≥45</td>
<td>199 (69%)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>212 (73%)</td>
</tr>
<tr>
<td></td>
<td>Unmarried</td>
<td>78 (27%)</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>276 (95%)</td>
</tr>
<tr>
<td></td>
<td>African American</td>
<td>14 (5%)</td>
</tr>
<tr>
<td>Education</td>
<td>&lt;College graduate</td>
<td>74 (26%)</td>
</tr>
<tr>
<td></td>
<td>≥College graduate</td>
<td>216 (74%)</td>
</tr>
<tr>
<td>Religion</td>
<td>Catholic</td>
<td>72 (25%)</td>
</tr>
<tr>
<td></td>
<td>Jewish</td>
<td>97 (33%)</td>
</tr>
<tr>
<td></td>
<td>Protestant</td>
<td>91 (31%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>30 (10%)</td>
</tr>
<tr>
<td>Spiritual faith</td>
<td>Not strong/a little strong/ moderately strong</td>
<td>167 (58%)</td>
</tr>
<tr>
<td></td>
<td>Very strong</td>
<td>123 (42%)</td>
</tr>
<tr>
<td>Relatives affected with breast and/or ovarian cancer</td>
<td>1–2</td>
<td>239 (82%)</td>
</tr>
<tr>
<td></td>
<td>3+</td>
<td>51 (18%)</td>
</tr>
<tr>
<td>Perceived risk for breast cancer</td>
<td>Low</td>
<td>139 (48%)</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>151 (52%)</td>
</tr>
<tr>
<td>Perceived risk for ovarian cancer</td>
<td>Low</td>
<td>142 (49%)</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>148 (51%)</td>
</tr>
</tbody>
</table>
The statistically significant ($P < 0.01$) spirituality by breast cancer perceived risk interaction (see Fig. 1) revealed that among women with high perceived risk for breast cancer, spirituality was unrelated to receipt of test results (OR, 1.2; 95% CIs, 0.4 and 3.0); however, among women with low perceived risk, those with high spirituality were 80% less likely to receive test results (OR, 0.2; 95% CIs, 0.1 and 0.5).

**Discussion**

Although *BRCA1/2* test use has been evaluated among research registry participants (5), this study is the first to examine test use among newly ascertained high-risk breast cancer probands. Overall, our 82% uptake rate was higher than the rates reported in previous studies (5, 6). This is not surprising because all participants had self-referred to a genetic counseling clinical research program and presumably were more highly motivated to have testing. This higher rate of testing probably reflects what can be expected among initial probands in clinical genetic testing programs. Not surprisingly, the majority of participants who declined testing/results declined to attend the initial education session. These individuals may have decided against testing before the baseline interview or based on the minimal information about the testing process provided at the conclusion of the baseline interview. In contrast, individuals who declined to provide a blood sample after the initial education session may have been dissuaded by the information received during the preliminary education session. Individuals who provided DNA but declined to learn the results of their gene test could have important implications for decision-making regarding ovarian cancer prevention and surveillance. Thus, women who believe that they are at high risk for ovarian cancer may be particularly motivated to learn their *BRCA1/2* status.

Although the role of spirituality in health and well-being has received extensive attention (20–22), the present...
Spirituality and Genetic Testing for Breast Cancer

likely to receive cancer patients with higher levels of spiritual faith may be less to terms with the fact that it has happened (23, 24). Breast understanding the cause of the disease, acceptance involves com- ing to terms with the fact that it has happened (9). Whereas finding meaning may involve attempts to find meaning in and to facilitate acceptance of their cancer experi- ence (9). Importantly, spiritual faith did not predict uptake of testing among women who perceived their cancer risk to be high. The modifying influence of perceived cancer risk is consistent with previous research showing that low levels of perceived cancer risk are associated with decreased readiness and interest in genetic testing (25, 26). Thus, women with high spiritual faith and low perceived risk would be least likely to obtain BRCA1/2 test results. However, as perceived cancer risk increases, motivation to reduce uncertainty may also increase, so that even highly spiritual women overcome their reluctance to obtain test results. There are a few caveats about these findings. First, this sample was limited to women who self-referred for genetic counseling and agreed to complete a baseline telephone interview. Thus, the 83% uptake rate may be higher than rates of test use in population-based or clinic-based samples in which the denominator includes all eligible women. Second, all study participants were affected with breast cancer and members of high-risk families. Thus, we cannot assume that rates of test use or predictors of use would apply to low risk or unaffected individuals. Third, all testing and counseling was offered free of charge and, therefore, may overestimate levels of uptake in fee-for-service settings. Finally, our measure of spirituality was based on a single item. The use of more sophisticated measures of spirituality could yield a better understanding of the association between spirituality and BRCA1/2 test use. Nonetheless, the primary finding regarding the role of spirituality in testing decisions is not likely to be influenced by factors such as the cost of testing; however, this may vary among members of different ethnic groups.

Despite these limitations, this study is the first to show that high levels of spiritual faith may deter genetic testing among some women with familial breast cancer. Future research should extend these findings by evaluating the role of spirituality in the testing decisions of unaffected individuals and members of different ethnic groups. Also, additional studies are needed to elucidate the cognitive and emotional correlates of spirituality that may deter genetic testing. Such research is important to better inform clinicians about how and when to incorporate discussions of spirituality into genetic counseling.

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References


