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Cognitive and Emotional Factors Predicting Decisional Conflict among High-Risk Breast Cancer Survivors Who Receive Uninformative *BRCA1/2* Results

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Abstract

Objective—To investigate high-risk breast cancer survivors' risk reduction decision making and decisional conflict after an uninformative *BRCA1/2* test.

Design—Prospective, longitudinal study of 182 probands undergoing *BRCA1/2* testing, with assessments 1-, 6-, and 12-months post-disclosure.

Measures—Primary predictors were health beliefs and emotional responses to testing assessed 1-month post-disclosure. Main outcomes included women's perception of whether they had made a final risk management decision (*decision status*) and decisional conflict related to this issue.

Results—There were four patterns of decision making, depending on how long it took women to make a final decision and the stability of their decision status across assessments. *Late decision makers* and *non-decision makers* reported the highest decisional conflict; however, substantial numbers of women—even *early* and *intermediate decision makers*—reported elevated decisional conflict. Analyses predicting decisional conflict 1- and 12-months post-disclosure found that, after accounting for controls and decision status, health beliefs and emotional factors predicted decisional conflict at different timepoints, with health beliefs more important one month after test disclosure and health beliefs more important one year later.

Conclusion—Many of these women may benefit from decision making assistance.

Keywords

breast cancer; genetic testing; decisional conflict; decision making; BRCA

Women with a strong family history of breast and/or ovarian cancer may choose to undergo genetic testing to determine whether they have a deleterious mutation in the *BRCA1* or *BRCA2* gene. Because the probability of identifying a mutation is highest if testing begins with an affected woman, the first person in a family to undergo *BRCA1/2* testing (the *proband*) is typically a woman who has had breast or ovarian cancer. If a mutation is detected, the proband is at elevated risk for a new breast cancer and ovarian cancer (Metcalf et al., 2004; Easton, Ford, & Bishop, 1995; Breast Cancer Linkage Consortium, 1999), and other members of the family can be tested for the identified mutation. Yet, the majority of probands receive an uninformative test result (Vink, van Asperen, Devilee, Breuning, & Bakker, 2004). That is, although a deleterious mutation was not detected, hereditary risk cannot be ruled out due to the possibility of an undetected mutation in *BRCA1* or *BRCA2* or a mutation in another cancer susceptibility gene. Counselors typically provide these women with a qualitative estimate of their residual risk of carrying a mutation and of developing a second cancer. These risk estimates, which are based on various characteristics of a woman's family pedigree, are highly heterogeneous and entail a great deal of uncertainty. The uncertainty of this situation greatly complicates individual decision making about breast cancer risk management in this population.

It is not currently clear how receiving an uninformative *BRCA1/2* test result influences the difficulty of women's risk management decisions. To our knowledge, no research has examined women's psychological experience of risk management decision making after an uninformative test result. One relevant indicator of the psychological experience of medical decision making is *decisional conflict*, or the extent to which a person feels uncertain, unclear about personal values, uninformed, and unsupported in decision making (Janis & Mann, 1977; O'Connor, 1995). Higher decisional conflict scores have been associated with decision regret (e.g., Brehaut et al., 2003), likelihood of blaming a physician for adverse effects of cancer screening (Gatteleri & Ward, 2004), and other adverse decision outcomes (see O'Connor, 1995, 2005). Women with higher decisional conflict may be more likely to vacillate between choices or to delay important decisions (O'Connor, 2005). To the extent this occurs, it could have serious consequences for women who are at high risk for new breast cancers, as is usually the case for women who receive uninformative *BRCA1/2* test results. Research addressing these issues would determine whether some of these women would benefit from additional decision support to reduce their uncertainty and distress and to help ensure that they engage in risk management activities that are appropriate for their degree of risk.

In light of the foregoing, our goal for this research was to investigate women's psychological experience of decision making following receipt of an uninformative *BRCA1/2* test result. We examined both their perception that they had made a final decision (*decision status*) and their decisional conflict. Decision status and decisional conflict were assessed 1-, 6-, and 12 months after disclosure of the uninformative genetic test result. First we sought to describe observed patterns of decision making across these three assessments. Second, we examined potential predictors of decisional conflict at 1- and 12-months post-disclosure in early to investigate correlates of elevated decisional conflict soon after test disclosure and one year later and to identify women at highest risk for poor decision making outcomes.

Potential Predictors of Decisional Conflict

The most commonly studied predictors of health decision making are health beliefs, which have a central place in leading social-cognitive theories of health protective behavior (see Weinstein, 1993). Perceived risk is one health belief that has received a great deal of research attention. For instance, research has shown that perceived risk for breast cancer is associated with health behaviors such as uptake of genetic counseling (Culver et al., 2001), use of mammography (e.g., Lerman, Rimer, Trock, Balshem, & Engstrom, 1990, McCaul, Branstetter, Schroeder, & Glasgow, 1996), and overuse of breast self-examination (Epstein et al., 1997).

Other commonly studied health beliefs are perceived benefits of and barriers to decision options (Weinstein, 1993). Research has generally found that perceived benefits are positively associated with screening behaviors such as mammography and pap tests whereas perceived barriers are negatively associated with them (e.g., Aiken, West, Woodward, & Reno, 1994; Rakowski et al., 1997; Russell, Champion, & Skinner, 2006). It may be that women are less conflicted about risk management decision making, in general, when they perceive that an option is associated with more benefits and fewer barriers. In the present study this seemed particularly likely to occur with respect to risk-reducing mastectomy (i.e., removal of non-diseased breast tissue as a prophylactic measure). Although risk-reducing mastectomy is not routinely recommended to women who receive uninformative results, it is an option that many of these women might consider. In fact, rates of risk-reducing mastectomy as high as 24% have been reported in the first year following an uninformative *BRCA1/2* test result in a sample of newly diagnosed breast cancer patients (Schwartz et al., 2004). We also examined perceived benefits and barriers to mammography, because this is the risk management option most frequently selected by women who receive an uninformative test result.

In addition, a characteristic of this population that is likely to have implications for their decision making is the fact that receiving an uninformative test result elicits various emotional responses. Evidence shows that women who receive an uninformative result experience distress that is not diminished by test disclosure, nor does it dissipate in the subsequent months. That is, their pre-testing levels of distress persist (Bish et al., 2002; O'Neill et al., in press; Schwartz et al., 2002; van Dijk et al., 2006). Follow-up assessments have documented elevated distress lasting as long as one year (O'Neill et al., in press), and some studies have shown comparable levels of distress among women who receive an uninformative test result and those found to carry a deleterious mutation (Schwartz et al., 2002; van Dijk et al., 2006). Although distress in both groups is generally modest on average, emotional reactions to an uninformative result vary across women (e.g., Hallowell et al., 2002). For instance, in a recent study of women who received an uninformative result we found significant individual variation in generalized distress, cancer-specific distress, and distress related to various aspects of genetic testing, with some women reporting highly elevated levels of distress (O'Neill et al., in press).

Importantly, there is growing evidence that emotions such as distress influence health decision making, and this evidence has revealed a way to advance understanding of health decision making beyond its current emphasis of health beliefs. Several theoretical approaches are relevant. For instance, Peters and her colleagues have suggested that emotions are a source of information that guides decision making, in addition to influencing decisions in other ways (Diefenbach et al., 2008; Peters, McCaul, Stefanek, & Nelson, 2006; Peters, Västfjäll, Gärling, & Slovic, 2006). Similarly, in Lazarus's cognitive-motivational-relational theory, emotions are said to denote core themes that describe the appraised relationship between a person and a potential stressor (Lazarus, 1999), an approach that is

relevant for understanding responses to an uninformative *BRCA1/2* test. For instance, anxiety reflects the appraisal that one is facing “uncertain, existential threat” (Lazarus, 1999, p. 96; also Lazarus, 1993). In this theory, as in Lazarus and Folkman’s (1984) well-known transactional model of stress and coping, subjective responses to a potentially stressful event are viewed as an important determinant of whether it will evoke a stress response and emotions are viewed as an important determinant of how individuals will cope with a stressor.

Another emotion theory, developed by Consedine and colleagues, discusses emotion in evolutionary terms. They posit that discrete emotions evolved to direct motivational, cognitive, behavioral, and physiological responses to environmental conditions that have implications for survival (Consedine & Moskowitz, 2007). In this model different emotions have different implications for decision making. For instance, anxiety may hinder or facilitate risk management decision making depending on its focus. If it is focused on the result itself (e.g., genetic testing distress), anxiety may be reduced by avoiding the decision. However, if it is focused on adverse effects of not acting or selecting a particular option (e.g., anxiety regarding risk for breast cancer), anxiety may be reduced by reaching a decision and acting on it. Consistent with this general perspective is a study in which breast cancer-specific distress predicted overuse of breast self-exams, whereas generalized distress did not (Erblich, Bovbjerg, & Valdimarsdottir, 2000).

Of course, there is also the potential to experience positive emotions after genetic testing (e.g., Low, Bower, Kwan, & Seldon, 2008; Kinney et al., 2005). Positive emotions are rarely investigated with respect to decision making. To begin the process of understanding how positive experiences might influence decision making among women who receive uninformative genetic test results, we examined whether these were associated with decision making in addition to investigating the role of various types of emotional distress.

In sum, distress of various kinds is elevated among some women who receive uninformative genetic test results, and theory and research suggest that these emotional responses will have implications for risk management decision making. Moreover, some women report positive experiences after genetic testing and theory states that they, too, should influence decision making. Consequently, in addition to describing women’s decisional conflict in the year following test disclosure and their patterns of decision making during that time (i.e., whether they felt they had made a final risk management decision), we investigated predictors of decisional conflict, focusing on decisional conflict 1- and 12-months post-disclosure (although we incorporated the 6-month post-disclosure outcomes for analyses focused on the trajectory of change in decisional conflict). These analyses allowed us to examine predictors of decisional conflict soon after test disclosure as well as later, after women had more time to consider their situation and their risk management options. Guided by social-cognitive theories of health protective behavior and theories positing a role of emotions in health decision making, predictors included frequently studied health beliefs (perceived risk for developing another breast cancer, benefits of and barriers to mammography and risk-reducing mastectomy) and generalized, cancer-specific, and genetic testing-related emotions (generalized anxiety, depressive symptoms, cancer-specific intrusion and avoidance, and genetic testing distress and positive experiences), all assessed at the 1-month post-disclosure assessment. We also investigated whether different patterns of decision making had implications for decisional conflict. Analyses predicting 1-month post-disclosure decisional conflict investigated concurrent relations, whereas analyses predicting 12-month post-disclosure decisional conflict investigated prospective relations.

Method

Participants

Potential participants were adult, English-speaking women with a history of breast cancer who were probands being tested for *BRCA1/2* mutations at Lombardi Comprehensive Cancer Center, Ruttenberg Cancer Center, or Englewood Hospital between April, 2001 and July, 2004. All had received an uninformative test result after either full sequencing of *BRCA1* and *BRCA2* or targeted testing for the three Ashkenazi Jewish founder mutations. They had to have at least a 10% probability of carrying a mutation prior to testing. For these analyses they also had to have at least one breast intact at the beginning of the study. Women were excluded if they were adopted ($n = 4$), missing decision status data at any assessment ($n = 64$), or missing decisional conflict data at all assessments ($n = 3$). Note that decision status data, which were needed to code women's pattern of decision making, were missing because some women missed all or part of a particular assessment; thus, women missing decision status data at a particular study assessment were also missing decisional conflict at that assessment. Compared to the 182 women in the final sample, the 71 women who were dropped were younger ($M_s = 52.60$ and 49.06 years old, respectively; $p = .02$); reported more benefits of mammography ($M_s = 3.03$ and 3.22 ; $p = .01$) and risk-reduction mastectomy ($M_s = 2.53$ and 2.76 ; $p = .05$); reported more barriers to mammography ($M_s = 1.54$ and 1.81 ; $p = .001$); were more likely to undergo bilateral mastectomy during the study (3% and 9%, $p = .03$); and more likely to have full *BRCA1/2* sequencing (37% and 54%; $p = .02$). They did not differ on other demographic or medical characteristics, other study variables or, when available, on decision status or decisional conflict.

Procedure

Participants were self-referred to the genetic counseling programs at each site. After providing consent, they received extensive pre- and post-test genetic counseling that was standardized across sites and monitored for fidelity. Pre-test counseling included discussion of the process of *BRCA1/2* testing, their risk for mutations, cancer risks associated with *BRCA1/2* mutations, interpretation of test results (including uninformative results), risk management, and potential benefits and risks of testing (see Schwartz et al., 2002, for a more detailed description). Post-disclosure counseling included disclosure of test results, discussion of implications of the specific test result received, and risk management recommendations. Women who received uninformative results were also given a qualitative estimate of their residual risk for breast and ovarian cancer based on their specific test result and their personal and family history. Because this was a high-risk population (10% probability of carrying a mutation), surveillance recommendations were consistent with recommendations for high-risk individuals (Burke et al., 1997), except that ovarian cancer screening and prophylactic oophorectomy were not discussed unless there was a family history of ovarian cancer. Women received a letter summarizing recommendations. Study measures were completed during telephone interviews conducted by trained research assistants prior to testing (Pretest) and 1, 6, and 12 months after disclosure of test results. Study procedures were approved by the Internal Review Boards at the study sites.

Measures

Decisional conflict was measured at 1-, 6-, and 12-months post-disclosure with the Decisional Conflict Scale (O'Connor, 1995), which assesses uncertainty about a decision (3 items), feeling uninformed (3 items), feeling unsupported in decision making (3 items), feeling unclear about values (3 items), and the perceived quality of the decision (4 items). Items such as "It's clear what choice is best for me" are rated on a scale from 1 (*Strongly agree*) to 5 (*Strongly disagree*). Women who had not made a final decision at a particular assessment were not asked questions about the perceived quality of their decision. In order

to create comparable scales for women who had made a final decision and those who had not, only the 12 items from the first four subscales were used. Items were averaged so that higher scores indicated higher decisional conflict. Cronbach's α s ranged from .85 to .93.

Decision Status was measured at the 1-, 6-, and 12-months post-disclosure with the question, "Have you made a final decision about how to manage your breast cancer risk?"

Depressive symptoms and generalized anxiety were measured 1-month post-disclosure with 12 items from the Brief Symptom Inventory (six items each for depressive symptoms and generalized anxiety; Derogatis & Melisaratos, 1983). Women were presented with a list of symptoms (e.g., "nervousness or shakiness inside") and rated how much discomfort each symptom had caused them in the past two weeks on a scale from 1 (*not at all*) to 4 (*extremely*). Items were summed; higher scores indicated greater symptomatology ($\alpha = .85$ both subscales).

Cancer-specific intrusion and avoidance were measured 1-month post-disclosure with the Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979), which is commonly used to assess distress associated with a stressor (in this study, the experience of cancer in women's family). It includes seven items for intrusive thoughts and feelings (e.g., "I thought about it when I didn't mean to") and eight items for avoidance (e.g., "I stayed away from reminders of it"). Responses are made on a 4-point scale (0 = *not at all*, 1 = *rarely*, 3 = *sometimes*, 5 = *often*) to indicate how frequently each symptom occurred in the prior seven days. Items were summed to yield scales in which higher scores indicate greater intrusion ($\alpha = .84$) or avoidance ($\alpha = .80$).

Emotional responses to genetic testing were measured 1-month post-disclosure with the Multidimensional Impact of Cancer Risk Assessment Questionnaire (Cella et al., 2002). Three subscales are used to assess responses to the receipt of genetic test results (e.g., "feeling upset about your test result" and "feeling relieved about your test result"), including distress (six items), positive experiences (four items), and uncertainty (nine items). Responses are made on a 4-point scale (0 = *not at all*, 1 = *rarely*, 3 = *sometimes*, 5 = *often*), and items are summed to indicate higher distress ($\alpha = .72$), positive experiences ($\alpha = .74$), or uncertainty. In this study we did not use the uncertainty subscale because of conceptual overlap with decisional conflict.

Perceived risk for developing another breast cancer was assessed with a single question, "On a scale from 0 to 100, where 0 means that you definitely won't get breast cancer again and 100 means that you definitely will get breast cancer again, how likely would you say you are to develop breast cancer again?" This question has been recommended as an assessment of perceived risk (e.g., Fischhoff, 1999) and is widely used (Bowen et al., 2004; Taylor et al., 2002).

Perceived benefits of and barriers to mammography were measured 1-month post-disclosure with a 15-item scale developed for this study. Seven items described potential benefits (e.g., early detection) and eight described potential barriers (e.g., radiation exposure). Women rated the importance of each item on a scale from 1 (*not at all important*) to 4 (*very important*). Ratings were averaged to create scales, with higher scores indicating greater importance of benefits or barriers. As might be expected given the diverse nature of these items, internal reliability was low for benefits ($\alpha = .65$), although it was adequate for barriers ($\alpha = .78$).

Perceived benefits of and barriers to risk-reducing mastectomy were measured at 1-month post-disclosure with a 16-item scale developed for this study. Seven items described potential benefits (e.g., reduced worry about breast cancer) and nine items described

potential barriers (e.g., risks of major surgery). Women rated the importance of each on a scale from 1 (*not at all important*) to 4 (*very important*). Ratings were averaged to create scales, with higher scores indicating greater importance of benefits ($\alpha = .85$) and barriers ($\alpha = .78$).

Sociodemographic characteristics were self-reported at Pretest and included age, marital status (married/other), race/ethnicity (White/non-White), educational attainment (high school or less/some college or more), annual household income, and having at least one child (yes/no).

Medical and genetic testing information was self-reported and included date of diagnosis, personal medical history, current treatment status (chemotherapy or radiotherapy), and personal and family history of cancer. For these analyses, risk for carrying a genetic mutation was calculated using Myriad Tables (Spring 2006 table; see Frank et al., 2002). Genetic test type was also recorded (Jewish panel negative versus full *BRCA1/2* sequencing negative).

Data Analyses

First, descriptive statistics were computed and a small number of missing values were mean or mode replaced (for continuous and categorical variables, respectively). Income was missing for 22 women and had limited variability (78% of women reported income in the highest category); therefore, income was not examined in these analyses. Next we examined women's reports of whether they had reached a final decision about how to manage their breast cancer risk at each study assessment (their decision status). Distinct patterns of decision making across the 1-, 6-, and 12-month post-disclosure assessments were investigated with descriptive analyses, and paired-sample *t*-tests and descriptive statistics were used to examine associations between patterns of decision making and changes in decisional conflict over time. Finally, we conducted hierarchical multiple regression analyses predicting 1- and 12-month post-disclosure decisional conflict. We focused on these two assessments (omitting analyses predicting 6-month post-disclosure decisional conflict) for several reasons. First, the differences between the 1- and 12-month assessments were expected to be larger and more easily interpretable than differences between the 1- and 6-month or the 6- and 12-month assessments. Second, examining predictors of 1- and 12-month post-disclosure decisional conflict allowed us to contrast concurrent and prospective relations observed for these two distinct timepoints. These regression models enabled us to examine the unique contribution of health beliefs and emotion variables as predictors of decisional conflict after controlling for other relevant variables, as described below.

Results

Women in the sample were, on average, 52 years old ($SD = 10$ years). Most were married (72%), White (96%), had completed at least some college (96%), and had moderate to high annual household income (median > \$75,000). They had been diagnosed with breast cancer nearly six years earlier, on average ($M = 5.96$, $SD = 7.80$). Thirty-seven percent had undergone full *BRCA1/2* sequencing and the rest had undergone Jewish panel testing. Mean decisional conflict for the full sample at the 1-, 6-, and 12-month post-disclosure assessments was 2.00 ($SD = .63$), 1.94 ($SD = .63$), and 1.86 ($SD = .60$), respectively. Paired sample *t*-tests comparing sample means indicated no change from 1- to 6-months post-disclosure, $t = 1.35$, $p = .18$ and a trend toward a reduction in decisional conflict from 6- to 12-months post-disclosure, $t = 1.74$, $p = .08$. The reduction in decisional conflict from 1- to 12-months post-disclosure was significant, $t = 2.88$, $p = .004$.

Decision Status and Patterns of Decision Making

The percentage of women who reported having made a final decision was 66% at 1-month post-disclosure, 84% at 6-months post-disclosure, and 87% at 12-months post-disclosure. Several patterns were apparent. Fifty-nine percent of women had made a final decision across all three assessments (*early decision makers*). The second most common pattern was for women to say they had not made a final decision at 1-month post-disclosure, and then to say they had made one at 6- and 12-months (18%; *intermediate decision makers*). Next, 6% of women had not made a decision at 1- and 6-months post-disclosure but had made one at 12-months (*late decision makers*). The remaining 19% either transitioned from saying they had made a final decision to saying they had not, demonstrated a complex pattern that changed from assessment to assessment, or had not made a final decision at any assessment (*non-decision makers*).

These patterns had implications for decisional conflict (see Figure 1). Paired-sample *t*-tests revealed a significant decline in decisional conflict for early decision makers between 6- and 12-months post-disclosure, $t = 2.30$, $p = .02$, and a significant decline in decisional conflict between 1- and 12-months post-disclosure for intermediate decision makers, $t = 5.04$, $p < .001$, and late decision makers, $t = 2.68$, $p = .03$. In contrast, non-decision makers demonstrated a marginally significant increase in decisional conflict from 1- to 12-months post-disclosure, $t = -1.77$, $p = .09$.

Next we examined the percentage of women in each group who had high decisional conflict using a cutoff of 2 based on evidence that decisional conflict scores greater than 2 have been associated with adverse decision making outcomes (O'Connor, 1995, 2005). Among early decision makers, the percentages of women with decisional conflict scores greater than 2 at 1-, 6-, and 12-months post-disclosure were 24%, 31%, and 22%, respectively. Among intermediate decision makers, these percentages were 73%, 42%, and 21%; among late decision makers, they were 91%, 55%, and 64%; and among non-decision makers, they were 54%, 79%, and 67%.

Predicting 1-Month Post-Disclosure Decisional Conflict

Prior to testing this model, we evaluated the need to control medical and demographic factors by examining bivariate associations between 1-month post-disclosure decisional conflict and potential control variables. No medical or demographic variables were significantly associated with decisional conflict at this timepoint. Therefore, we conducted a hierarchical multiple regression in which 1-month post-disclosure decisional conflict was regressed on 1-month post-disclosure decision status (a dummy coded variable comparing women who had made a final decision at this timepoint to those who had not; Step 1), health belief variables (Step 2), and emotion variables (Step 3). The results of this analysis are shown in Table 1. The full model was significant, $F(12,169) = 8.08$, $p < .001$, and predicted 36% of the variance in the outcome. In Step 1, women who had made a final decision one month after test disclosure reported significantly lower concurrent decisional conflict than those who had not, $t = -8.30$, $p < .001$. Decision status predicted 28% of the variance in 1-month post-disclosure decisional conflict. In Step 2, health beliefs accounted for an additional 7% of the variance in this outcome. Of the five health belief variables, two predicted a significant proportion of variance: women with higher perceived risk, $t = 3.51$, $p = .001$, and those who perceived more benefits of risk-reducing mastectomy, $t = 2.17$, $p = .03$, had greater 1-month post-disclosure decisional conflict. In contrast, none of the emotion variables emerged as significant predictors in Step 3.

Predicting Decisional Conflict One Year After Test Disclosure

Before testing a model investigating predictors of 12-month post-disclosure decisional conflict, we evaluated the need to control medical and demographic factors by examining their bivariate associations with this outcome, both before and after partialling out 1-month post-disclosure decisional conflict. We found that higher risk for carrying a genetic mutation (according to women's Myriad scores; Frank et al., 2002) was associated with lower 12-month post-disclosure decisional conflict after controlling the effect of 1-month post-disclosure decisional conflict ($p = .04$). Therefore we conducted a hierarchical multiple regression in which 12-month post-disclosure decisional conflict was regressed on risk for carrying a genetic mutation and 1-month post-disclosure decisional conflict (Step 1), three dummy coded variables testing the effects of the four decision status patterns (with non-decision makers as the comparison group; Step 2), health belief variables (Step 3), and emotion variables (Step 4). Because 1-month post-disclosure decisional conflict was controlled, all findings refer to residualized change in decisional conflict from 1- to 12-months post-disclosure.

The results of this analysis are shown in Table 2. The full model was significant, $F(16,165) = 7.97$, $p < .001$, and predicted 44% of the variance in 12-month post-disclosure decisional conflict. In Step 1, having higher decisional conflict one month after test disclosure predicted higher decisional conflict at the 12-month post-disclosure assessment, $t = 7.52$, $p < .001$. Further, women at high risk for carrying a genetic mutation reported lower 12-month post-disclosure decisional conflict, $t = -2.03$, $p = .04$. Together these variables accounted for 25% of the variance in 12-month post-disclosure decisional conflict. In Step 2, early decision makers reported lower 12-month post-disclosure decisional conflict than did non-decision makers, $t = -4.82$, $p < .001$. The same was true for intermediate decision makers, $t = -4.99$, $p < .001$, and late decision makers, $t = -1.97$, $p = .05$. Together, these variables accounted for an additional 11% of the variance. In Step 3, health beliefs were not significant predictors of 12-month post-disclosure decisional conflict, either individually (ps from .14 to .81) or as a group (p for step = .37). However, several emotion variables emerged as significant predictors in Step 4. Specifically, more positive genetic testing experiences 1 month after test disclosure was associated with lower 12-month post-disclosure decisional conflict, $t = -2.36$, $p = .02$, as was having higher generalized anxiety one month after test disclosure, $t = -2.87$, $p = .01$. Having higher depressive symptoms one month after test disclosure was associated with higher 12-month post-disclosure decisional conflict, $t = 2.78$, $p = .01$. Unique variance associated with other emotion variables did not predict a significant amount of variance in 12-month post-disclosure decisional conflict (ps ranged from .30 to .65). Together, emotional factors accounted for an additional 5% of the variance in this outcome beyond other variables in the model. In addition, after controlling for emotional factors in this step, perceived benefits of risk reduction mastectomy emerged as a significant predictor of 12-month post-disclosure decisional conflict, $t = 1.98$, $p = .049$.

Discussion

Women who receive an uninformative *BRCA1/2* test result must make risk management decisions without the benefit of knowing whether their cancer was due to a genetic mutation that also increases their risk for developing a new breast cancer. The results of the present study suggest that risk management decision making is a complex process for many of these women. We focused on decision making during the year following test disclosure because it is an ideal time to intervene to ensure that women engage in appropriate and effective risk management strategies. Nineteen percent of our sample demonstrated a pattern of decision making that suggested they had a difficult time reaching what they perceived to be a final risk management decision during that time. An additional 6% did not make what they felt was a final decision until a full one year after test disclosure. Of course, high risk breast

cancer survivors may be presented with new information at any time that could cause them to revisit their risk management decision (e.g., a suspicious screening test or the diagnosis of a second breast cancer).

An important issue revealed by our findings is that having made a final decision—even one that was seemingly stable—did not necessarily protect women from decisional conflict. That is, a substantial proportion of women who appeared to have made an early decision (i.e., “early decision makers”) nonetheless remained at risk for poor decision outcomes, as indicated by their high decisional conflict scores. Clearly, even women who have made what they feel is a final risk management decision can experience lingering dissatisfaction with or lack of confidence in their decision. Notably, decisional conflict was highest among women who appeared to have struggled with decision making (i.e., “late decision makers” and “non-decision makers”), suggesting a need for further research to understand why women fall into these groups.

However strong, the association between decision status and decisional conflict was not perfect. To gain a more complete picture of decisional conflict after receipt of an uninformative BRCA1/2 test result, we investigated several sets of predictors of decisional conflict. The first set of predictors we investigated were health beliefs drawn from leading social-cognitive theories, namely, women’s beliefs about their risk for developing another breast cancer and their beliefs about the benefits of and barriers to two potential risk management strategies: risk-reducing mastectomy and mammography. The role played by these health beliefs depended on the time point being examined. One month after test disclosure, women reported higher decisional conflict if they had higher perceived risk for developing another breast cancer or if they perceived more benefits of risk-reducing mastectomy. One year later the association between perceived benefits of risk-reducing mastectomy and decisional conflict was still apparent (albeit only after controlling for emotional factors). However, there was no prospective association between perceived risk and decisional conflict a year after test disclosure. Nonetheless, it should be noted that perceived risk could have an indirect effect on later decisional conflict through several channels. For instance, women with higher perceived risk were less likely to have made a final risk management decision at each assessment, less likely to be an early decision maker, and more likely to be a non-decision maker. One goal of genetic counseling is to ensure accurate risk perceptions. Therefore, women who have undergone genetic counseling should hold risk perceptions that are relatively accurate and it may not be appropriate to attempt to lower them. Rather, it may be that women with high perceived risk would benefit from decision aids. In our own research we have found that an interactive decision aid was particularly beneficial among *BRCA1/2* carriers who were having the most difficulty reaching a management decision in the month following receipt of test results (Schwartz et al., in press).

The positive association between perceived benefits of risk-reducing mastectomy and elevated decisional conflict suggests that women who were considering risk-reducing surgery found decision making to be more difficult than those who were not considering it. In support of this interpretation, post hoc analyses (not shown) revealed that women who perceived more benefits of risk-reducing mastectomy were more likely to say they were considering the surgery. This finding is not surprising; the decision about whether or not to undergo risk-reducing mastectomy is a difficult one. It may be even more difficult for women with uninformative test results, for whom actual risk is difficult to quantify. We note that objective risk was not associated with decisional conflict or perceived benefits of and barriers to risk-reducing mastectomy. Thus, it was not the case that decisional conflict was primarily elevated among those at the highest risk for breast cancer.

Although investigation of health beliefs has proven useful in understanding health protective decision making, social-cognitive theories exclude other potentially important classes of variables, including emotions. In light of this fact, we extended our investigation of health beliefs by also investigating associations between decisional conflict and women's emotional responses to *BRCA1/2* testing one month after test disclosure. As noted earlier, we and others have found enduring elevated distress among some women who receive uninformative test results (e.g., Bish et al., 2002; O'Neill et al., in press; Schwartz et al., 2002; van Dijk et al., 2006), and this distress may influence women's risk reduction decision making. In the present study emotions did not predict concurrent decisional conflict after accounting for women's decision status and their health beliefs. However, we found prospective associations between early emotional responses and later decisional conflict. Women who reported greater generalized anxiety and more positive genetic testing experiences one month after test disclosure reported lower decisional conflict one year later, whereas women who reported more depressive symptoms one month after test disclosure reported higher decisional conflict one year later. These findings suggest that depressive symptoms shortly after test disclosure could be used to identify women who need assistance with decision making. Notably, depression has been associated with cognitive styles such as pessimism (Corcoran et al., 2006) and underestimation of performance (Fu et al., 2005). It has also been found to have an adverse influence on decision outcomes (Damasio, 1997).

We also found a negative prospective association between generalized anxiety and decisional conflict. Anxiety and depression tend to co-occur, yet they were not so highly correlated in this sample that multicollinearity was a likely explanation for our findings. Furthermore, when depression was dropped from the model (analysis not shown), the effect of generalized anxiety remained negative, although it was no longer significantly related to decisional conflict. This pattern of results suggests that it was the unique variance associated with anxiety, controlling for other variables in the model, that was prospectively related to lower decisional conflict. The nature of that unique variance is unclear; however, the tripartite model of anxiety and depression (Clark & Watson, 1991) suggests that it may be worthwhile to focus on general physiological tension and hyperarousal in future research, in that these are characteristics that differentiate anxiety from depression.

The salutary effect of positive genetic testing experiences observed in this study is, to our knowledge, the first evidence for an association between positive emotions and testing-related decision making. Lazarus (1993, 1999) noted that positive emotions signal that progress is being made toward important life goals, and Consedine and his colleagues (Consedine & Moskowitz, 2007) suggest that they may affect health outcomes and medical decision making through cognitive pathways as well as more effective problem solving and cognitive flexibility (Isen & Labroo, 2003). Thus, positive genetic testing experiences may indicate that adaptive self-regulatory processes have been engaged. In the present study, women who reported more positive genetic testing experiences were more likely to report having reached a final risk management decision at each study assessment. They were also more likely to be an "early decision maker" and less likely to be a "non-decision maker." Such associations are consistent with the idea that these women were motivated to act quickly to reduce their risk and that they may have engaged in more effective cognitive processing concerning their options and the implications of each.

Notably, situation-specific domains of distress, including cancer-specific intrusion and avoidance and genetic testing-related distress, were not predictive of decisional conflict. Clearly, more research is needed to clarify the associations between specific emotions and decision making in this population. Recall that Consedine and colleagues (Consedine & Moskowitz, 2007) theorize that discrete emotions direct motivational, cognitive, behavioral, and physiological responses to environmental conditions. Given our findings, future

research on the decision making of women who have received an uninformative *BRCA1/2* test result should include measures that assess specific emotional responses most likely to occur among these women. These measures should capture differences in the focus of emotional responses (e.g., anxiety about the potential for a breast cancer recurrence versus anxiety about selecting a risk-reduction option that could later be regretted) and assess both positive and negative emotional responses to the test result and potential risk reduction options. For instance, some women may experience relief following receipt of an uninformative test result, and their cognitions, motivational states, risk reduction behaviors, and physiological responses may differ from those of women who do not experience this emotion.

There are some limitations of this study that should be noted. First, generalizability of these findings may be limited by several characteristics of our sample. Because all participants received free genetic counseling, they may differ from women who receive counseling in a clinical setting. Further, most participants were White, employed, college educated, and affluent, reflecting the population currently most likely to use *BRCA1/2* testing. Our sample also included only women who had been diagnosed with breast cancer who were at high risk for carrying a genetic mutation. It is currently unclear how decision making processes may differ in unaffected women, lower risk women, or women with ovarian cancer. In addition, missing data led us to drop a group of women who had skipped some assessments and who tended to be younger and to endorse greater benefits and barriers to risk reduction options. Although statistically significant, the small size of the observed differences and the lack of differences on most key study variables suggest that biases introduced as a result of missing data were minimal. However, the characteristics of the women dropped for missing data may indicate a need for further research on the unique needs of younger women facing this decision. Second, several of our measures could have been improved. Perceived risk was assessed with a single item, albeit one that is commonly used in the literature and has demonstrated validity. We should note that we also collected data using another commonly used measure of perceived risk that asked women to rate how likely they were to have a recurrence on a scale from “not at all likely” to “definitely.” Results did not differ when this alternative variable was used in analyses. In addition, our measure of residual risk was relatively crude. It is possible that had we better characterized residual risk, we might have observed stronger associations between residual risk and decisional conflict. Finally, these data are correlational, and associations observed in these findings are not necessarily causal. Of course, in addition to emotions influencing decisional conflict, decisional conflict may elicit emotional responses. Yet, the longitudinal, prospective study design revealed associations that are consistent with a causal relations. Furthermore, the plausibility of these associations is supported by theory and research. Nonetheless, research will be needed to clarify the causal direction of these results. Such research is particularly important if these findings are to guide development of interventions.

Despite these limitations, our findings provide useful insight into decision making following receipt of an uninformative genetic test result and extend current knowledge in important ways, particularly with respect to the role of emotions in decision making among women who receive an uninformative *BRCA1/2* test result. The findings suggest that a substantial number of these women may benefit from assistance with risk management decision making. Genetic counselors are one potential source of such assistance. Moreover, there is growing evidence that decision aids can lower decisional conflict and improve decision outcomes (e.g., O'Connor et al., 2007; Schwartz et al., in press). The development of a decision aid for women who receive uninformative *BRCA1/2* test results may be warranted, particularly in light of the increasing availability and use of these tests. Any such development should attend to recent critiques of this area (Nelson et al., 2007). Specifically, extending the conclusions of Nelson et al., it may be particularly important to help women

manage the uncertainty associated with their uninformative test result and their future cancer risks.

These findings may also have implications for other groups undergoing genetic testing, for instance, unaffected women undergoing *BRCA1/2* testing or individuals being tested for hereditary colon cancer. As new tests become increasingly available to the public, more people will be faced with the need to manage their risk for cancer and other serious diseases in the face of complex information and uncertain risk. The present study highlights the importance of health beliefs in health decision making as well as the benefits of considering emotional factors in addition to more commonly studied cognitive factors associated with decisional outcomes. It also provides evidence supporting the need for supportive resources to facilitate decision making among individuals coping with the results of genetic testing.

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Figure 1.
Decisional conflict as a function of decision making pattern.

Table 1
Multiple Regression Predicting Decisional Conflict One-Month Post-Disclosure (N = 182)

Variable	Step 1		Step 2		Step 3	
	B	SE	B	SE	B	SE
Final Decision at Time 1	-.71	.09***	-.62	.09***	-.64	.09***
Perceived Risk For Developing Another Breast Cancer			.01	.002**	.01	.002**
Perceived Benefits of Mammography			.01	.09	.03	.09
Perceived Barriers to Mammography			-.02	.08	-.02	.09
Perceived Benefits of Risk-reducing Mastectomy			.11	.05*	.10	.05 [†]
Perceived Barriers to Risk-reducing Mastectomy			.01	.07	-.01	.08
Genetic Testing Distress ^a					-.01	.10
Genetic Testing Positive Experiences					-.001	.01
Cancer-Specific Intrusion					.01	.01
Cancer-Specific Avoidance					-.01	.01
Depressive Symptoms					-.003	.02
Generalized Anxiety					.02	.02
ΔF for Step	68.83***		3.96**		.64	
R ² for Step	.28		.07		.01	

[†] $p < .10$.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

^a Genetic testing distress was coded 1 = any genetic testing distress, 0 = no genetic testing distress.

Table 2
Multiple Regression Predicting Decisional Conflict 12-Months Post-Disclosure (N = 182)

Variable	Step 1		Step 2		Step 3		Step 4	
	B	SE	B	SE	B	SE	B	SE
Time 1 Decisional Conflict	.47	.06***	.45	.06***	.46	.07***	.47	.07***
Risk for Carrying a Genetic Mutation	-.01	.003*	-.01	.003*	-.01	.003*	-.01	.003**
Early Decision Maker			-.49	.10***	-.49	.11***	-.45	.10***
Intermediate Decision Maker			-.62	.12***	-.64	.13***	-.63	.13***
Late Decision Maker			-.34	.17*	-.36	.18*	-.38	.18*
Perceived Risk For Developing Another Breast Cancer					-.002	.002	-.003	.002
Perceived Benefits of Mammography					.03	.08	.02	.08
Perceived Barriers to Mammography					-.02	.08	-.02	.08
Perceived Benefits of Risk-reducing Mastectomy					.07	.05	.10	.05*
Perceived Barriers to Risk-reducing Mastectomy					.08	.07	.04	.07
Genetic Testing Distress ^a							.09	.09
Genetic Testing Positive Experiences							-.02	.01*
Cancer-Specific Intrusion							.004	.01
Cancer-Specific Avoidance							-.004	.01
Depressive Symptoms							.05	.02**
Generalized Anxiety							-.05	.02**
ΔF for Step	30.10***		10.22***		1.09		2.62*	
R ² for Step	.25		.11		.02		.05	

† $p < .10$.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

^a Genetic testing distress was coded 1 = any genetic testing distress, 0 = no genetic testing distress.