Women's concerns about the emotional impact of awareness of heritable breast cancer risk and its implications for their children

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Abstract Women tested for mutations in *BRCA1/2* genes who have minor-aged children confront difficult decisions about if, when, and how to share information about hereditary cancer risk with their children. These choices are often seemingly influenced by how mothers anticipate the emotional burdens they and their children will experience in response to test results. Here, we investigate the association between maternal cognitions, pretest psychological well-being, and coping style with mothers' anticipated emotional reactions to learning that they are *BRCA1/2* mutation carriers ($N=205$). In a linear regression model adjusted for maternal demographics, stronger tendencies to ruminate about information ($B=.14$, $p=.03$), greater psychological strain ($B=.14$, $p<.001$), and poorer appraisals of one's ability to cope with genetic test results conveying increased breast cancer risk information ($B=-.25$, $p<.001$) were significantly associated with anticipating more negative affect surrounding *BRCA1/2* mutation identification in mothers. Our data contribute to the growing awareness of special concerns that mothers have about knowing their *BRCA1/2* mutation status and highlight the need for more tailored patient education and counseling resources to improve outcomes among women at risk and their children.

Keywords Cancer · Genetics · *BRCA1/2* · Mothers · Children · Affective forecasting

Introduction

Women who are counseled and tested for mutations in *BRCA1/2* genes who have minor-aged children confront difficult decisions about if, when, and how to share hereditary breast cancer risk information with their children (Sharff et al. 2012; Tercyak et al. 2013). Most of the findings in this area have centered on decisions and outcomes surrounding disclosure or nondisclosure to potentially at-risk relatives (Patenaude et al. 2006). This includes recent research demonstrating that mothers with greater emotional distress and poorer parent–child communication before genetic testing are more likely to experience distress following genetic testing (Mays et al. 2013). Another recent study demonstrates that tested mothers who learn they are harboring a *BRCA1/2* mutation are less likely to convey this information to their children than those who received negative or uninformative results. However, mothers who inform their children of their genetic test results also report greater satisfaction and less post-decisional conflict and regret compared with mothers who do not communicate this information to their offspring (Tercyak et al. 2013). Given the complex decision that tested mothers face and subsequent impacts on psychological outcome, it is not surprising that many women report needing additional guidance and resources to successfully navigate the communication landscape with their offspring (Sharff et al. 2012; Tercyak et al. 2007).

Although many women report pursuing *BRCA1/2* counseling and testing to learn about hereditary cancer risk information for the benefit of their family members (Tercyak et al. 2002), patient decisions to disclose results to their kindred are often driven by anticipation of how they will react emotionally to learning their test result (Dorval et al. 2000; Farkas Patenaude et al. 2013). Therefore, greater attention to emotional forecasting of the outcomes of this decision-making process could allow for interventions to reduce negative

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anticipation among mothers. These interventions could, in turn, empower families to engage in important, potentially life-saving conversations about familial cancer risk at earlier stages (Patrick-Miller et al. 2010). Importantly, children share half of their DNA with their mothers and stand a 50 % chance of inheriting a mother's risk-conferring *BRCA1/2* mutation. A mother's positive test result has implications for her children's future testing despite recommendations that children will not undergo such testing until they reach adulthood (Davies et al. 2013; Roisman et al. 2012). Eliminating barriers that mothers have to engaging in conversations with their children is an important goal to foster positive outcomes for families with a risk of hereditary cancer.

Affective forecasting (Gilbert et al. 1998), or the process of predicting how one will feel following future events, has been shown to have powerful effects on health decision-making (Elwyn and Miron-Shatz 2010; Halpern and Arnold 2008). Despite the influence that affective forecasts can have on major life choices, these predictions often inaccurately portray actual responses (Wilson and Gilbert 2003). Such inaccuracies can lead individuals to make choices based on anticipated future emotional states without considering the full range of options. This biased decision-making leads to poorer outcomes across a range of medical decisions from disease prevention to end-of-life care (French et al. 2005; Halpern 2012; Ruby et al. 2011).

When examining bias in affective forecasting, individuals can predict the overall valence (i.e., positive or negative qualities) of their affect, but overestimate the strength of this reaction, which can contribute to information processing biases (Levine et al. 2012). These biases are strongest in the direction of forecasting negative emotional reactions (i.e., catastrophic or bad reactions) (Mathieu and Gosling 2012). Peters and colleagues (2014) recently provided a commentary on the potential role of affective forecasting and impact bias in the context of clinical genetic testing. They reported that among those seeking predictive genetic testing, such as testing for *BRCA1/2* gene mutations, impact bias may ensue when focusing on the affective response to a single event (i.e., testing positive) rather than integrating its impact in light of other contextual factors (i.e., support from family and friends, connection to one's child, and refocusing on one's health). Such bias may result from a failure to cognitively and emotionally integrate risk information with available risk reduction strategies and one's own psychological or psychosocial strengths, resiliencies, and past life experiences that influence responses to untoward outcomes. Biased affective forecasting could result in a failure to fully discuss the implications of positive test results, and poorer outcomes might ensue (Tercyak et al. 2013). Patient education and genetic counseling efforts often focus on addressing such biases (Weil 2003) and in this context could be tailored to promote healthier outcomes for tested women and their families.

The failure to recognize one's coping resources is well-captured by Lazarus and Folkman's (1984) construct of coping appraisals. Their transactional model of stress and coping posits that predictions about future emotional states are influenced by an appraisal of the stressfulness of a situation (primary appraisals) and the ability to cope with that situation (secondary coping appraisals); for example, the perceived ability to cope with the stress of testing positive for a *BRCA1/2* mutation and the potential impact of this outcome on maternal health, children, and the family. Previous studies demonstrate that such coping appraisals are related to women's distress following genetic testing (O'Neill et al. 2009). Prior efforts have not fully attended to mothers' coping appraisals of the impact of *BRCA1/2* carrier status on herself and her children or how coping skills may relate to anticipated negative affect after cancer genetic testing. Affective forecasting heuristics could be intervention targets during genetic pretest counseling to increase awareness of these biases, challenge assumptions, and promote more accurate self-evaluation of patients' ability and resources to adjust to potentially threatening health information (Dunn et al. 2007; Peshkin et al. 2010; Peters et al. 2014).

Beyond women's perceived coping resources, other individual differences may also influence the nature and degree to which biased affective forecasting arises (Dunn et al. 2007; Peshkin et al. 2010; Peters et al. 2014). For instance, the emotional state of mothers who have received genetic test results—and the experience of anxious and/or depressive symptomatology in particular—are associated with both psychological (O'Neill et al. 2009) and behavioral (Heiniger et al. 2013; Rini et al. 2009; Schwartz et al. 2012) outcomes following genetic testing. Beyond current symptoms, stable trait-like factors, such as one's "need for cognition," may also result in biased predictions of a future emotional state following genetic testing. "Need for cognition" refers to an individual's tendency to engage in effortful cognitive endeavors (Cacioppo et al. 1984). Those with a high need for cognition often have better decision outcomes as a result of these thought processes (Dunphy et al. 2010). However, they also tend to experience cognitive side effects of effortful thought processes, including worry, rumination, and catastrophizing (Petty et al. 2009). The impact of *BRCA1/2*-tested mothers' need for cognition on their anticipated emotional outcomes has not been studied. This may be an important intervention target to foster more accurate emotional forecasting and favorable outcomes as mothers consider the implications of genetic test results for themselves and their children.

In the present study, our goal was to investigate the association between maternal concerns about heritable breast cancer risk and their implications for parenting in the context of pretest genetic counseling for *BRCA1/2*. Our specific objective was to better characterize, prior to the disclosure of women's results, mothers' anticipation of negative affect in

light of their possibly testing positive for a *BRCA1/2* mutation and its impact on themselves and their minor-aged children. We also examined the roles of maternal tendency to ruminate on information, psychological well-being, and coping appraisals. We expected that reports of greater need for cognition, higher pretest psychological distress, and lower appraisals of coping resources would be associated with anticipating more adverse psychological consequences to testing positive for *BRCA1/2*. These data will enable us to better anticipate the needs of mothers during the pretest counseling and education session.

Materials and methods

Study design and patients

Data for the current analysis were drawn from the pretest survey of an ongoing trial of *BRCA1/2* genetic counseling outcomes. All participants ($N=205$) were female patients who self-identified as mothers to one or more children aged 8 to 17 years old. This represented 77 % of the 283 patients approached for inclusion in this trial and 94 % of those who consented ($N=217$).

Study procedures

All participants were screened and approached at the time of their *BRCA1/2* pretest education and genetic counseling session and after providing a DNA sample for genetic testing at a hereditary cancer program in DC or MA participating in this research from 2008 to 2013. At enrollment, participants enumerated their children. As we and others have done in the previous research (Burrows and Kelley 1983; Tercyak et al. 2013), for those with more than one child, we used a computerized randomization software to designate a target child of interest within the study age range to alleviate parental selection, reduce bias, and maintain 1:1 parent–child dyads for statistical analysis. Participants completed telephone interviews within several days of genetic counseling. A modest incentive (\$10 gift card) was offered to acknowledge each completed patient interview. All procedures were approved by the Institutional Review Boards at participating study sites.

Independent study variables

Sociodemographic and medical variables Participants self-reported their age, race, education, marital status, gender and age of their children, and household income. We also assessed the history of cancer in the family and the participants' personal cancer history.

Need for cognition We assessed the trait-like variable of need for cognition using a seven-item version of the original Need for Cognition Scale (Cacioppo et al. 1984) (Cronbach's $\alpha=.77$), with a seven-point Likert response ("strongly disagree" to "strongly agree"). Higher scores indicate a greater need for cognition, reflecting the extent to which people prefer effortful cognitive activities (total score=7–49).

Psychological distress To assess the participants' state of psychological well-being prior to test result disclosure, we administered the anxiety and depression subscales of the 12-item Brief Symptom Inventory (BSI) (Zabora et al. 2001) (Cronbach's $\alpha=.88$), with a four-point Likert response ("not at all" to "extremely"). Higher scores correspond to poorer psychological well-being and greater distress, with a total score ranging from 12 to 48. This measure has been used extensively in genetic testing outcomes research (Esplen et al. 2013; Hooker et al. 2011).

Coping appraisals We assessed the participants' perceived anticipatory ability to cope with the psychological impact of potentially being informed that they carry a *BRCA1/2* mutation and the potential risk of passing down a mutation to their child using a three-item face-valid scale (Cronbach's $\alpha=.78$). These items include "Talk to your child about the test result; Deal with the impact of the test result for yourself; Deal with the impact of the test result for your child," using a four-point Likert response ("not at all confident" to "very confident"). Items were summed to create a total score, and higher scores indicate more confidence in coping abilities (range of 3–12).

Dependent study variable

Anticipated negative affect We assessed the participants' anticipation of negative (i.e., adverse) emotional states in response to learning that they may harbor a *BRCA1/2* mutation with a five-item, four-point Likert response assessing how intensely mothers would expect to feel sadness, guilt, anger, worry, and uncertainty ("not at all intensely" to "very intensely"). These items were summed to create an overall score with a range of 5–20 (Cronbach's $\alpha=.75$): Higher scores denote greater anticipation of more negative affect.

Statistical analysis

Descriptive statistics and bivariate tests (χ^2 tests, t tests) characterized the study sample and identified independent variables associated with the anticipated negative affect-dependent variable. Independent variables associated at $p<0.10$ were then regressed onto the dependent variable in a multivariable linear regression model with hierarchical variable entry. We entered the sociodemographic covariates on step 1, need for cognition and psychological well-being on

step 2, and coping appraisals on step 3. We tested for potential moderation. None of these relationships reached significance, and we eliminated them from our final model. Data were analyzed using SPSS 22.0.

Results

Participant characteristics

Table 1 displays characteristics of study participants and their children. Participants were on average, about 45 years old, predominantly White race (72 %), had at least a college degree (73 %), with incomes above \$75,000 (78 %), and were in a

partnered relationship (79 %). Most (81 %) had a family history of breast or ovarian cancer, and half (49 %) had a personal history of cancer (i.e., were breast and/or ovarian cancer survivors). Among participants' children, half were female (53 %) and under 13 years of age (49 %) (Table 2).

Maternal or child variables related to our dependent variable were maternal race, education, and income level. White women (10.9 vs. 9.5, $t=2.74$, $p=.007$) and those with higher education (10.9 vs. 9.6, $t=2.52$, $p=.012$) and income levels (10.8 vs. 9.5, $t=2.52$, $p=.013$) anticipated experiencing significantly greater negative emotions in response to learning that they carried a *BRCA1/2* mutation compared to others. We adjusted for these variables in our final model. Other maternal variables, such as family history of cancer and cancer-affected status, were not associated with our outcome, nor were any of the child variables. These were excluded for further analysis.

Table 1 Characteristics of the study sample ($N=205$)

Characteristic	Number (%)	M (SD)
Maternal demographics		
Age, in years		44.65 (5.29)
Race		
Non-White	57 (28)	
Non-Hispanic White	148 (72)	
Education		
<College degree	56 (27)	
≥College degree	149 (73)	
Marital status		
Unmarried/single	42 (21)	
Married/partnered	163 (79)	
Annual household income		
<\$75,000	44 (22)	
≥\$75,000	162 (78)	
Maternal clinical characteristics		
Family cancer history		
0 affected relatives	39 (19)	
≥1 affected relative	166 (81)	
Personal cancer history		
No	101 (49)	
Yes	104 (51)	
Child characteristics		
Child gender		
Female	108 (53)	
Male	96 (47)	
Child age		
<13	101 (49)	
>13	104 (51)	
Psychosocial functioning		
Need for cognition		39.81 (7.01)
Psychological distress		17.18 (5.51)
Coping		9.31 (2.18)
Anticipated negative affect		10.56 (3.21)

Cognition, well-being, coping, and negative affect anticipation

With respect to the participants' preferences for cognitive activities and their overall psychological well-being, they reported experiencing relatively high levels of need for cognition ($M=39.81$ out of 49, $SD=7.01$) and moderate levels of emotional distress ($M=17.18$ out of 48, $SD=5.51$). The BSI scores reported in this sample were comparable to those in other *BRCA1/2* genetic testing studies (Hooker et al. 2011). Mothers were relatively confident in their ability to cope with the impact of testing *BRCA1/2* positive for themselves and for their children ($M=9.31$ out of 12, $SD=2.18$), but they anticipated a moderately high negative affect load when considering their response to learning that they may harbor a *BRCA1/2* mutation ($M=10.56$ out of 20, $SD=3.21$).

Table 2 Multivariable regression analysis of anticipated negative affect

	β	SE β	Standardized β	P value
Race				
Non-Hispanic White	.23	.10	.16	.02
Non-White ^a				
Education				
≥College	.10	.10	.07	.34
<College ^a				
Annual household income				
<\$75,000	.09	.11	.06	.40
≥\$75,000 ^a				
Psychosocial functioning				
Need for cognition	.24	.11	.25	.03
Psychological distress	.03	.01	.14	<.001
Coping appraisals	-.07	.02	-.25	<.001

^a Denotes reference group

Associations with negative affect anticipation

We modeled the association between need for cognition, psychological well-being, and coping appraisals on reported anticipated negative affect. We first controlled for the significant effects of race, as well as education and income on step 1, and these variables accounted for a small proportion of the model's variance (overall $R^2=.05$). When examined simultaneously, women who were White anticipated experiencing significantly greater negative emotional reactions to testing positive for a *BRCA1/2* mutation than women from other races. Both greater need for cognition (standardized $\beta=.14$, $p<.001$) and general distress (standardized $\beta=.14$, $p<.001$) were significantly related to greater anticipated negative affect on step 2, accounting for 16 % of the total model variance. Women's perceived ability to cope with the psychological impact of potentially being informed that they carry a *BRCA1/2* mutation and the potential risk of passing down a mutation to their child was significantly and inversely related to greater anticipated negative affect on step 3 (standardized $\beta=-.25$, $p<.001$, $R^2=.21$). Women who perceived themselves as being less able to cope with the psychological impact of receiving positive genetic test results reported experiencing greater anticipated negative affect.

Discussion

Inaccuracies in affective forecasting can lead individuals to make decisions without considering the full range of options available to them (Halpern 2012; Ruby et al. 2011). Our data contribute to the growing understanding of women's expectations regarding their response to genetic testing and, specifically, mothers' concerned surrounding *BRCA1/2* mutations. We found that mothers anticipated experiencing moderate levels of negative affect in the face of confronting news about their increased susceptibility to familial breast cancer. This may place some women at risk for poorer outcomes following genetic testing, as well as their children (Tercyak et al. 2002).

Mothers' greater need for cognition was associated with anticipating worse outcomes. Higher levels of this trait are often associated with better decision outcomes (Dunphy et al. 2010), perhaps reflecting the effort these individuals devote to cognitive processing of information to inform their choices. However, those with a high need for cognition also tend to experience cognitive biases stemming from effortful thought processing, including worry and rumination (Chiou and Yang 2010; Petty et al. 2008, 2009). Petty and colleagues (2008) note those highly in need for cognition are more susceptible to subtle (vs. blatant) priming effects or the effect that having been exposed to one stimulus might have on one's response to another later stimulus. Together with our findings, it suggests that women undergoing *BRCA1/2* genetic counseling and

testing with higher need for cognition may be more susceptible to certain aspects of the genetic counseling and testing process that prime them to consider the potential experience of negative affect (e.g., imagining the emotional burden of discussing hereditary cancer risk information with their children).

Our results are complementary to the early work of Dorval and colleagues (2000) who assessed anticipated versus actual emotional reactions following *BRCA1/2* and *p53* genetic testing. Although not focused on mothers and children, participants in both studies scored at the midpoint for many anticipated negative emotional reactions (i.e., sadness, anger, and worry). In contrast to the cross-sectional analysis reported here in the Dorval study was prospective and compared differences between anticipated and actual reactions. It found that while on average, tested women accurately predicted their emotional reaction to their test result; unaffected carriers were significantly more likely to overestimate feelings of negative affect than affected carriers, who tended to underestimate their reactions. Underestimation at pretest of one or more distress emotions predicted significantly higher distress scores at 6 months post-disclosure. Differential outcomes across affected and carrier statuses would have implications for future intervention planning. While the present analyses focus on potential overestimation of actual feelings, there may also be impacts related to under-estimation of these feelings. This should be examined further in future research.

As we also expected, maternal anxiety/depression was directly related to levels of anticipated negative affect. Anxiety and depression surrounding genetic counseling have long been tied to poorer emotional (O'Neill et al. 2009) and behavioral (Heiniger et al. 2013; Rini et al. 2009; Schwartz et al. 2012) outcomes among those seeking *BRCA1/2* testing. Whether this finding reflects women's accurate understanding of their tendency to experience negative affect and/or reflects biased forecasting as noted above is unclear. However, our finding adds to the literature that general psychological well-being should be screened at the time of the pretest genetic education and counseling session to identify those who are more susceptible to adverse emotional reactions following testing.

Also, consistent with our hypothesis, mothers who perceived that they would be less able to cope with the psychological impact of being a mutation carrier—both for themselves and their child—expected greater negative affect if they were to be informed they were at increased genetic risk for breast cancer. Pretest coping appraisals have predicted long-term adjustment among those receiving positive (Halbert et al. 2004) and uninformative (O'Neill et al. 2009) *BRCA1/2* test results, and coping is strongly linked to emotional functioning among mothers undergoing cancer risk counseling (Tercyak et al. 2001). These studies demonstrate that while distress remains high in the short term, most show steep declines in distress over

the year following testing. As noted by Peters and colleagues (2014) in their commentary on affective forecasting, this decrease in distress could reflect the effect of initial distress ameliorated by social support and recognizing one's own resilience over time. Maternal coping appraisals are a specific and actionable target for intervention, including interventions that address maternal decisions about talking to children about hereditary breast cancer risk (Peshkin et al. 2010). Ongoing research is investigating how such interventions impact decisional outcomes for mothers. Until results of this trial are available, clinicians could provide patients with resources, explore their coping concerns, and provide guidance and referrals as needed.

Finally, though not part of our predictions, race significantly contributed to our model, with White women reporting greater anticipated negative affect than others. The majority of our non-White sample was African-American (43 out of a total of 57). Previous studies have found high levels of cancer-related distress in women of African descent who present for testing (Cukier et al. 2013). Differences in samples could explain why our findings differ from previous work, such as being a mother of a young child and the social networks that may come with parenthood. This should be examined in future research.

In sum, our results suggest that mothers who ruminate and have higher levels of current distress and perceive that they do not cope well also imagine the poorest emotional outcomes after testing. We cannot comment on whether our findings reflect a pessimistic character, protective buffering (Melnik and Shepperd 2012), or a realistic understanding of their ability to cope with this potentially stressful situation. Given that a mother's positive test result would have implications for her children's future cancer risk (Davies et al. 2013; Roisman et al. 2012), our findings could reflect not only the mothers' consideration of their own ability to cope but also their understanding of their child's ability to cope. Due to the cross-sectional nature of the study, we cannot comment on parent-child reciprocal relationships. Future research should examine how dyadic coping processes function and their impact on emotional and behavioral outcomes in families facing increased genetic risks for cancer. Further, our results should inform clinical practice at this important time of evolving genetic risk assessment. Many women are now offered with the opportunity to pursue *BRCA1/2* testing as part of multi-gene next generation testing panels. More women will not only receive positive results but also uncertain or ambiguous results (i.e., variants of uncertain significance). Lessons learned from *BRCA1/2* testing can also help us understand the potential implications of such testing on mothers, children, and families and how to help them prepare for and cope with genetic risk information.

This study has several limitations, including its predominately non-Hispanic White sample with an above average

education and income profile. Participants were drawn from two clinical sites in major urban areas of Northeastern America, which limits our generalizability. Also, our project relied on brief, self-report measures that were collected at a single point in time and prior to mothers knowing their actual genetic test results. Observational assessment could help improve the reliability and validity of self-reported data. A prospective design could permit an examination of correspondence between anticipated and actual emotional reactions and contribute to our understanding of the directionality and causality of our findings.

Despite these limitations, our work contributes to furthering the understanding of mothers' concerns surrounding *BRCA1/2* testing for themselves and their children. As this testing continues to proliferate in more diverse clinical settings which may not offer extensive genetic counseling, clinicians should remain mindful of the specific concerns (both voiced and unvoiced) that mothers have about the prospect of harboring a *BRCA1/2* mutation. Future research should address tailored interventions for this population that minimized potential biases in affective forecasting.

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Compliance with ethical guidelines All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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