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Distress and the Parenting Dynamic among *BRCA1/2* Tested Mothers and their Partners

Darren Mays¹, Tiffani A. DeMarco¹, George Luta¹, Beth N. Peshkin¹, Andrea F. Patenaude², Katherine A. Schneider², Judy E. Garber², and Kenneth P. Tercyak¹

¹ Georgetown University Medical Center, Lombardi Comprehensive Cancer Center, Washington, DC

² Dana-Farber Cancer Institute, Boston, MA

Abstract

Objective.—To investigate the influence of dyadic parenting relationships on psychological distress among mothers tested for *BRCA1/2* genetic mutations and their untested partners.

Methods.—Data were from a prospective study of mothers suspected to be at risk for hereditary breast/ovarian cancer who underwent genetic counseling and *BRCA1/2* testing and their untested parenting partners ($n = 109$ parenting dyads). Participants completed assessments before and 1-month following genetic testing. Structural equation modeling was used to examine relationships among mothers' and partners' psychological distress, decisional conflict surrounding communication of test results to their offspring, and the parent-child communication relationship. Psychological distress was measured using items modified from the Brief Symptom Inventory.

Results.—Among mothers, greater psychological distress ($B = 0.29, p < .001$) and poorer parent-child communication ($B = -0.12, p < .01$) at baseline predicted greater distress at follow-up. Among partners, greater distress at baseline predicted greater distress at follow-up ($B = 0.67, p < .001$). Mother and partner decisional conflict at baseline were equally associated with the other dyad member's distress at follow-up (B 's = 1.17, $p < .01$), but not their own distress.

Conclusions.—Our findings indicate conflicted decision-making over family communication of hereditary breast/ovarian cancer genetic test results for one member of a parenting dyad adversely affects the other dyad member's psychological well-being. Interventions to improve outcomes for mothers who may be at-risk for hereditary breast and ovarian cancer and undergoing *BRCA1/2* genetic testing should attend to both mothers' and their partners' preferences regarding family communication about hereditary cancer risk.

Keywords

breast/ovarian cancer; genetic testing; family communication; psychological distress

Introduction

Genetic counseling and testing for *BRCA1/2* mutations are established components of the identification and management of hereditary breast/ovarian cancer syndrome among women who are determined to be at-risk (Peshkin & Isaacs, 2005). Although the *BRCA1/2* genetic counseling and testing process does not generally generate clinically significant distress, evidence suggests that testing can lead to elevated distress among vulnerable groups, such as women who have a family history of cancer, receive test results indicating the presence of a mutation, and those who are confronted with difficult choices about surgery or other medical interventions (Graves et al., 2012; Hamilton, Lobel, & Moyer, 2009; Schwartz et al., 2002). Consequently, a range of meaningful and potentially actionable distress reactions may occur among tested women. This points to the need for research to understand how distress may relate to women's decision-making (e.g., communicating test results, medical interventions) when faced with the potential risk of familial cancer (Schwartz et al., 2005).

While women who undergo genetic testing bear much of the burden of coping with the risk of cancer, their family members' psychological well-being may be affected as well. *BRCA1/2* genetic testing is viewed as a familial process that involves tested women's spouses and parenting partners, herein referred to as "partners" (DeMarco & McKinnon, 2007). Partners are women's major source of social support during the genetic testing process and are integral to women's decision making surrounding genetic testing (Patenaude et al., 2006; Tercyak et al., 2012). Studies examining the impact of partner support for these women demonstrate that greater partner support predicts improved psychological outcomes among couples, while less support and maladaptive coping (e.g., hiding worries, avoidant behaviors) can lead to poorer outcomes (DeMarco et al., 2008; DeMarco et al., 2010; Tercyak et al., 2001). Although evidence in this area is limited, available data suggest that partners can experience levels of distress similar to women who undergo *BRCA1/2* testing (den Heijer et al., 2010; Mireskandari et al., 2007).

The identification of a *BRCA1/2* mutation among tested women may indicate an increased risk of cancer for family members, especially their biological offspring who have a 50% chance of inheriting their mother's mutation. Along with the possibility of facing difficult choices surrounding risk management interventions following receipt of their test results (e.g., prophylactic mastectomy/oophorectomy, chemoprevention), tested women and their partners must also consider whether to communicate genetic risk information to their offspring (Tercyak, Peshkin, Streisand, & Lerman, 2001). The decision to disclose *BRCA1/2* genetic test results to children is a complex and emotional process in which parents face multiple unknowns. This includes determining whether, when, and how to discuss genetic cancer risk information with their children, what to communicate, and anticipating the potential reaction and impact on the child (Gallo, Angst, Knafl, Hadley, & Smith, 2005; Tercyak et al., 2002).

Despite these uncertainties, a majority of parents who undergo *BRCA1/2* genetic testing choose to share their results with their offspring and the most common motives parents report for doing so include promoting the parent-child bond and maintaining positive family functioning (Sharff et al., 2012; Tercyak et al., 2002). Yet, the potential impact of disclosing

hereditary cancer risk information on children's well-being is largely unknown. Children are asymptomatic, their risk for adult-onset disease is not known, and genetic testing of children younger than age 18 is not recommended due to ethical concerns, potential adverse psychological consequences, and the lack of available medical interventions in the event of a positive test (Malpas, 2006). In light of this context, tested mothers and their partners may experience conflict as they weigh difficult decisions about the potential risks and benefits of sharing genetic cancer risk information with their child (Malpas, 2006). Research in this area suggests that greater decisional conflict among women who are considering communicating *BRCA1/2* genetic test results to their children is associated with a greater perceived need for supportive resources among these women (Tercyak et al., 2007). To date, no study has examined the association between decisional conflict and other family-related factors that may influence the decision to communicate results and psychological distress among tested women and their partners.

Despite partners' integral role in supporting women who undergo *BRCA1/2* genetic testing, research in this area has predominantly examined psychological outcomes of women and their partners independently, rather than investigating interrelated processes among tested women and their partners from a dyadic perspective (Sherman, Kasparian, & Mireskandri, 2010). Yet, findings of recent studies among couples affected by breast cancer more generally (i.e., not necessarily hereditary breast cancer) suggest that women's and partner's outcomes are interdependent. These studies suggest that heightened anxiety and distress in one member of a couple influences the other couple member's psychological outcomes (Dorros, Card, Segrin, & Badger, 2010; Segrin, Badger, Dorros, Meek, & Lopez, 2007). Social support and active coping among women and their partners have also been shown to improve psychological outcomes among couples, such as those facing late-stage breast cancer (Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010).

One study examined the impact of interdependent relationships in family communication about cancer on decisions to seek genetic testing among female survivors of breast/ovarian cancer and their adult female relatives (Mellon et al., 2009). The results of this study demonstrate a conflicting relationship among survivors and family members with respect to family communication. On one hand, more family communication about cancer increased the likelihood that survivors and partners themselves would seek cancer risk information. On the other hand, a contradictory "partner" effect was evident where greater family communication in one dyad member (either the survivor or the female family member) decreased the likelihood that the other dyad member would seek out cancer risk information (Mellon et al., 2009). Taken together, these studies provide support for applying a dyadic approach to understanding factors influencing psychological outcomes among women undergoing *BRCA1/2* genetic testing and their parenting partners as they consider communicating maternal test results to their offspring.

Theoretical models of interdependent influences on health-related outcomes also offer a substantive context for this research. These dyad-level theories emphasize interrelated psychological processes among couples, taking into account both the *interpersonal* (i.e., self) and *intrapersonal* (i.e., partner) influences on health outcomes (Lewis et al., 2006). Lewis and colleagues' (2006) interdependence model characterizes how couple members

influence one another's motivation and decision-making for health-related behavior change. In the context of hereditary breast/ovarian cancer, this model suggests that couples who face cancer risks as a "we" disease – characterized by positive communication, shared decisions, and active, mutual coping – will experience better outcomes (Kayser, Watson, & Andrade, 2007). Interventions fostering such mutual relationships among couples have had a positive impact on psychosocial outcomes among both women and their partners (Cochrane & Lewis, 2005; Kayser et al., 2007). Adopting a dyadic perspective to understand how processes at the level of the couple affect psychological outcomes among individuals can help guide and inform the development of more effective couples-focused interventions for those facing hereditary breast/ovarian cancer risk (Cochrane & Lewis, 2005).

Risk for hereditary breast/ovarian cancer presents women and their partners with difficult choices that may lead to a range of meaningful distress reactions, particularly the decision to communicate genetic test results to their offspring. The familial nature of hereditary breast/ovarian cancer necessitates an approach that considers the interrelated psychological processes and outcomes among women and their partners to understand how they adapt – independently and conjointly – to hereditary cancer risk within the family. Unfortunately, our limited understanding of the familial processes that affect psychological outcomes among partnered couples will hamper the development of couples-focused interventions unless more data are available (Lewis et al., 2006; Sherman, Kasparian, & Mireskandri, 2010). To address this gap, this study examined the influence of parenting exchanges among mothers undergoing *BRCA1/2* genetic counseling and testing and their untested parenting partners on the decision to communicate maternal *BRCA1/2* test results to their offspring. Specifically, we investigated the impact of these dyadic parenting exchanges on psychological distress responses among tested mothers and their untested parenting partners.

Methods

Setting

Data were analyzed from a larger prospective study of predictors and outcomes associated with family communication of *BRCA1/2* genetic test results. A complete description of the parent study methods is available elsewhere (DeMarco et al., 2008; Tercyak et al., 2007). Briefly, participants were mothers who underwent genetic counseling and testing for *BRCA1/2* and their untested parenting partners. In order to participate in the parent study, women had to: (1) be at least 18 years of age; (2) obtain *BRCA1/2* testing by providing a DNA sample; and (3) be mother to at least one child between 8 and 21 years of age. The lower age limit was chosen because research suggests children begin to learn of their mothers' genetic breast/ovarian cancer risk at this time (Tercyak et al., 2001; Tercyak et al., 2002). The upper age limit was chosen because young people may be considered for genetic testing beginning at age 18, although medical interventions for risk reduction are not recommended until age 25 (National Comprehensive Cancer Network, 2012). Partners completed assessments but did not undergo *BRCA1/2* testing. Mothers and partners were enrolled at three east coast cancer centers, all of which host well-established hereditary breast/ovarian cancer clinical research programs.

Procedures

The Institutional Review Boards at each participating site approved all procedures. Mothers were approached for participation by a cancer genetic counselor at the conclusion of a pre-test genetic counseling appointment and after providing a DNA sample for testing. For mothers sharing the responsibility of raising a child with a partner, they were also informed of the opportunity for their partner to participate in the study. Written informed consent was obtained from all participants. Mothers provided information about their children, including children's ages, gender, birth order, and birth relationship (e.g., biological, step-child). For mothers with more than one child, a computer algorithm was used to randomly select a target child within the study age range for reference on all assessments. This process was designed to reduce parental selection bias in choosing a target child for assessments (Peshkin et al., 2009). Mothers and their partners completed assessments via telephone interview at baseline immediately following pretest counseling and one month after the posttest counseling session where they were informed by a genetic counselor of the mother's *BRCA1/2* genetic test results. A modest incentive of a \$5 gift card was provided upon completion of each assessment.

Participants

A total of 221 mothers and 111 partners were enrolled in the parent study and completed baseline and follow-up assessments. The sample for this analysis included 109 mother-partner dyads where both members of the couple completed baseline and follow-up assessments. Compared with mothers who were not included in analyses because their partners did not enroll or due to missing follow up data, those who were included were more likely to be married (91% vs. 78%, $p = 0.005$), less likely to be employed (46% vs. 60%, $p = 0.04$), more likely to be a breast/ovarian cancer survivor (64% vs. 51%, $p = 0.05$), and to have had a younger target child (M age 12.4 years [SD 3.3] vs. M age 13.6 years [SD 4.1], $p = 0.02$). In total, 98% ($n = 107$) of the partners were male and 89% ($n = 97$) were biological parents of the target child.

Measures

Demographic and clinical information—Demographic information was obtained for mothers and partners (gender, age, race, education, household income, marital status), and their target child (age, gender). Maternal clinical information about personal and family history of breast/ovarian cancer was collected, and genetic test results were recorded from clinical records.

Psychological distress—Items from the anxiety and depression subscales of the Brief Symptom Inventory (BSI) were used to assess psychological distress at baseline and follow-up (Derogatis & Melisaratos, 1983). The BSI is a valid and reliable assessment of distress that has been widely used in cancer-related research (Zabora et al., 2001). The assessment included 12 items with a modified 4-point Likert-type response ranging from *not at all* to *extremely*. This modified version of the BSI has been shown to have good reliability and temporal stability in studies examining psychological distress in *BRCA1/2* genetic testing among both men and women (Graves et al., 2011; Hooker et al., 2011). Responses were

summed to create an overall score with higher values indicating greater distress (range 12 – 48, all Cronbach α 's > 0.80).

Parent-child communication—The 20-item Parent-Adolescent Communication (PAC) scale was administered at baseline to capture the quality of the parent-child communication relationship (Barnes & Olson, 1982). The PAC is a valid and reliable measure of openness and problems in parent-child communication. Items are based on a 5-point Likert-type response and are summed to create a total score (range 20 – 100). Higher values indicate more open, less problematic communication. The PAC had good reliability among mothers and partners (Cronbach α 's > 0.75).

Decisional conflict—Conflict surrounding the decision to communicate maternal *BRCA1/2* genetic test results to children was measured at baseline using the 10-item version of the Decision Conflict Scale (DCS) (Cronbach α 's > 0.85) (O'Connor, 1995). The DCS is based on the Ottawa Decision Support Framework, which seeks to understand patient decision-making for complex health and social issues (O'Connor et al., 1999). Items used a 3-point Likert-type response format and were summed and converted to an overall score ranging from 0 – 100, where higher scores indicate greater conflict over the communication decision (O'Connor, 1995). For DCS variables, mothers and partners reported a wide range decisional conflict, which is commensurate with expected responses within this clinical population where the decision to communicate *BRCA1/2* genetic test results takes on diverse meanings and occurs in the context of other familial interactions (Tercyak et al., 2002; Patenaude et al., 2012). However, this range of responses created a positively-skewed data distribution. Based on transformations recommended by Tabachnick and Fidell (2007), we used log-transformed scores to improve normality and enhance precision of the estimated relationships in our statistical models.

Analyses

The statistical analysis involved several steps. First, descriptive statistics were used to examine distributional properties of all variables and to characterize the sample. Bivariate tests (i.e., *t*-tests, Pearson's *r* correlation) were used to examine differences between mothers and partners on focal variables and to assess correlations of predictor and outcome variables among mothers and partners. Structural equation modeling was then used to examine the interdependent relationships of mothers' and partners' psychological distress using the Actor Partner Interdependence Model (APIM) as a framework (Kenny, Kashy, & Cook, 2006). The APIM method allows for examination of relationships among interdependent dyads by modeling both "actor" (i.e., own) and "partner" effects (i.e., spouse or parenting partner) (Kenny et al., 2006). The APIM estimates actor effects controlling for partner effects and vice versa, while taking into account the correlated nature of observations within dyads (Kenny et al., 2006).

Dyad members were distinguishable in the dataset as either the tested mother or her partner. Following the APIM approach for distinguishable dyads, a just-identified (i.e., saturated) model with zero degrees of freedom was created first based on the hypothesized relationships (Kenny et al., 2006). In order to obtain initial model fit estimates and to

provide a basis of comparison for subsequent models, a zero correlation constraint was applied for two predictor variables based on bivariate analyses (Hasson-Ohayon et al., 2010). Additional constraints were imposed to test whether actor and partner effects were equal by using the Wald χ^2 statistics. A p -value > 0.05 from the Wald test was considered to indicate that the parameters of interest can be constrained to be equal without diminishing model fit (Kenny et al., 2006).

Model fit was evaluated based on the following criteria: a non-statistically significant model χ^2 test ($p > 0.05$), a Comparative Fit Index (CFI) > 0.96 , and a Root Mean Square Error Approximation (RMSEA) < 0.05 (Hu & Bentler, 1999). Demographic and clinical characteristics were assessed as potential covariates, including child age and maternal *BRCA1/2* carrier status, which have been identified as factors that influence parental communication of *BRCA1/2* test results to children (Tercyak et al., 2001). We evaluated the assumptions of our modeling approach, including examining the potential role of these covariates and the decision to use log-transformed DCS scores through ancillary analyses.

Results

Sample Characteristics

Participant characteristics are displayed in Table 1. Mothers and partners were mostly non-Hispanic white (86.2%), had attained a college education or higher (78%), and married or living as married (90%; Table 1). Compared with partners, mothers reported significantly greater psychological distress at baseline ($t = 2.45, p = 0.02$) and a more open parent-child communication relationship ($t = 4.40, p < 0.001$). Compared with mothers, partners were significantly older ($t = 4.48, p < 0.001$) and reported greater baseline decisional conflict than mothers ($t = 2.28, p = 0.03$).

Bivariate Analyses

Bivariate correlations among psychological distress, parent-child communication, and decisional conflict are shown in Table 2. Among mothers, greater psychological distress at follow-up was associated with poorer communication with their child ($r = -0.37, p < 0.001$) and greater psychological distress ($r = 0.39, p < 0.001$) at baseline. Mothers' psychological distress at follow-up was also associated with greater distress among their parenting partners at follow-up ($r = 0.24, p = 0.01$), as well as greater decisional conflict among their parenting partners at baseline ($r = 0.19, p = 0.05$) (Table 2). Among partners, greater psychological distress at follow-up was associated with partners' own baseline psychological distress ($r = 0.68, p < 0.001$), communication with their child ($r = -0.22, p = 0.02$), and decisional conflict ($r = 0.26, p = 0.01$). Greater distress among partners at follow-up was also associated with greater decisional conflict among mothers at baseline ($r = 0.20, p = 0.01$).

The results of bivariate analyses between mothers' and partners' psychological distress at follow-up and the demographic and clinical characteristics shown in Table 1 indicate that none of these characteristics were significantly associated with psychological distress among mothers or partners (data not shown). Therefore, we did not adjust for these covariates in the multivariable models.

Actor-Partner Interdependence Models

To obtain an initial APIM fit estimate from the just-identified model, the correlation between mothers' baseline decisional conflict and partners' baseline psychological distress was constrained to equal zero. This constraint was chosen because the correlation between these two variables was close to zero and not statistically significant ($r = 0.03, p = 0.77$; see Table 2). This initial model fit the data moderately well ($\chi^2 [1] = 0.09, p = 0.76, CFI = 1.00, RMSEA = 0.0 [90\% CI = 0.0, 0.17]$).

The final model was created by testing equality constraints to determine if actor and partner effects were equivalent to one another. The final model fit the data well (Model $\chi^2 [2] = 0.11, p = 0.95; CFI = 1.00; RMSEA = 0.0 [90\% CI = 0.0, 0.03]$) and is shown in Figure 1. An equality constraint ($\chi^2 [1] = 0.9, p = 0.35$) revealed that mothers' and partners' conflict about the decision to communicate genetic test results to their offspring at baseline equally influenced the dyad partner's psychological distress at follow-up (B 's = 1.17, $p < 0.01$), but not their own level of distress. Another equality constraint tested whether the impact of mothers' and partners' own baseline psychological distress on their own follow-up outcomes was equivalent. This test indicate the effects for baseline distress were not equivalent among mothers and partners ($\chi^2 [1] = 11.3, p < 0.001$), therefore they were not constrained to be equal in the final model. Results of the final model further suggest that, among mothers, greater distress ($B = 0.29, p < 0.001$) and poorer parent-child communication ($B = -0.12, p < 0.01$) at baseline predicted greater distress at follow-up. Among partners, greater distress at baseline also predicted greater distress at follow-up ($B = 0.67, p < 0.001$). Overall, the model explained 27% and 52% of the variance in follow-up distress among mothers and partners, respectively.

We conducted ancillary analyses to evaluate alternative approaches to our modeling strategy and to confirm the validity of our approach. First, we replicated our analyses using raw (i.e., untransformed) decisional conflict scores to determine whether our decision to use log-transformed DCS variables in the final model had an impact on our findings. In analyses using raw DCS scores, the statistical decisions and primary findings were not changed. The final model with raw DCS scores fit the data well (Model $\chi^2 [2] = 0.46, p = 0.79; CFI = 1.00; RMSEA = 0.0 [90\% CI = 0.0, 0.12]$), albeit less so than the final model with log-transformed scores reported above and shown in Figure 1.

Second, although our bivariate analyses did not identify demographic or clinical factors that were significantly associated with mothers' and partners' follow-up distress and warrant inclusion in the model as covariates, we created an adjusted model to account for the putative effects of covariates identified in prior research as factors that may influence psychological outcomes among couples facing hereditary breast/ovarian cancer risk and considering disclosure of maternal genetic test results to their children (Tercyak et al., 2001), including the child's age and mothers' *BRCA1/2* mutation status. When these covariates were included in the model, the statistical relationships and principal findings were unaffected.

Discussion

This study examined how interdependent processes among women undergoing *BRCA1/2* genetic counseling and testing and their untested parenting partners affect psychological distress as they considered communication of maternal test results to their offspring. The findings indicate that a conflicted decision surrounding communication of genetic test results in one member of the couple may lead to increased psychological distress for their parenting partner. Although baseline levels of decisional conflict were significantly higher among partners than mothers, the impact of conflicted decision making in either member of the couple on follow-up distress of the other member of the couple was equal across dyad members. Finally, among both couple members, greater distress at baseline was associated with significantly greater distress at follow up, although this effect was stronger among partners. These results suggest that couples-oriented interventions that seek to foster shared decisions and open communication surrounding the communication of *BRCA1/2* genetic test results to children may mitigate adverse psychological outcomes among couples. Identifying women and partners with elevated distress prior to testing and offering adjunctive psychological counseling during genetic counseling may further improve outcomes. This study makes a unique contribution to the nascent literature on the impact of genetic counseling and testing for hereditary breast/ovarian cancer risk among partnered couples by examining issues specific to family communication of genetic test results. The results demonstrate the potential impact of partners' decisions on one another's well-being around this decision and point to important directions for future research to inform the development of couples-focused interventions.

Although parents may be motivated to communicate information about hereditary breast/ovarian cancer risk to their offspring for various reasons, research in this area primarily points to family-focused motives, such as promoting children's well-being and fostering positive family functioning (Malpas, 2006; Tercyak et al., 2002). Emerging evidence suggests, however, that mothers and their partners may disagree on their reasons for or against communicating genetic test results to their offspring, with divergent motives for disclosure (Sharff et al., 2012). This lack of consensus among couples is one possible explanation for our findings regarding the effect of decisional conflict on psychological distress within couples. Mothers and partners who are in disagreement regarding the decision to communicate maternal genetic test results to children may experience conflict and uncertainty, which may, in turn, influence distress experienced by the other couple member. This mechanism is consistent with research on patient decision-making surrounding cancer and other health conditions, which suggests that minimizing decisional conflict is central to promoting effective decision making (O'Connor et al., 1999). Currently, little is known about how psychological distress that couples may experience influences subsequent behavioral outcomes, including their decisions to communicate *BRCA1/2* test results to their children (Hamilton et al., 2009). Research to prospectively examine how distress among couples affects their communication decision-making in this context will be valuable to inform the development of supportive interventions to promote positive psychological outcomes among couples (Peshkin et al., 2010; Tercyak et al., 2007).

Our findings provide new insights into the experience of partnered couples as a unit when women undergo *BRCA1/2* genetic counseling and testing and they and their parenting partners are considering communicating maternal genetic test results to offspring. Partners of women undergoing genetic testing for *BRCA1/2* may face an especially challenging dilemma: they are a primary source of support for women who undergo genetic testing, yet they may also experience distress themselves and have limited access to supportive resources (Tercyak et al., 2012; Mireskandari et al., 2007; Patenaude et al., 2006; Sherman, Kasparian, & Mireskandari, 2010). Indeed, emerging data suggest that partners of women who are at risk for hereditary breast/ovarian cancer perceive a need for supportive interventions to help them cope with their partner's risk of cancer and to better prepare them to provide support during the genetic counseling and testing process (Tercyak et al., 2012). Through a dyadic perspective, our results provide empirical support for the need to develop targeted interventions to help parents engage in shared decision making surrounding the communication of *BRCA1/2* test results to their children.

Although not examined in this study, factors specific to couples' relationship functioning, such as women's/partner's perceived relationship quality, relational coping, and adoption of a relational perspective may play an important role in partnered couples' decision-making surrounding communication of genetic test results to their offspring (Lewis et al., 2006; Manne, Kashy, Weinberg, Boscarino, & Bowen, 2012). Research among couples facing metastatic breast cancer suggests that positive dyadic coping (e.g., joint problem solving, mutual calming) is associated with better adjustment to cancer (Badr & Taylor, 2008). A recent study examining colorectal cancer screening behaviors similarly demonstrated that couple members' relational perspective towards screening behavior leads to shared decisions surrounding colorectal cancer screening (Manne et al., 2012).

While these are considerably different disease contexts, parallels can be drawn with hereditary breast/ovarian cancer risk within families. For example, dyad members' conflict over the decision to communicate genetic test results to their offspring may be influenced by their perceived quality of the relationship with their partner, and elevated distress may ensue for some couples. Clinical factors such as women's *BRCA1/2* mutation carrier status may also be important moderating variables (Tercyak et al., 2001). Research that considers both dyad members' perceptions of their relationship quality, coping responses, and relationship perspective, as well as potential moderators, will be important to inform couples-focused interventions.

Questions also remain regarding the optimal approaches to deliver partner-oriented interventions, which is another important avenue for future research. Women who undergo *BRCA1/2* genetic counseling and testing express a high level of need for supportive resources offered through diverse delivery methods (e.g., in-person, print materials) (Sharff et al., 2012; Tercyak et al., 2007). Recent data show that partners express a similarly high level of need for supportive resources delivered through both electronic (e.g., internet) and more traditional media (e.g., print materials) (Sharff et al., 2012; Tercyak et al., 2012). While the clinical context of genetic counseling may be an opportunity to engage partners who attend counseling sessions with tested mothers, couples-oriented interventions that can be offered as adjuncts to clinical care may be optimal, as a minority of partners attend

genetic counseling sessions with tested women (DeMarco et al., 2010). Research is ongoing to evaluate an intervention designed to facilitate mothers' decision to communicate *BRCA1/2* genetic test results to their children offered as an adjunct to clinical *BRCA1/2* genetic counseling and testing (Peshkin, DeMarco, & Tercyak, 2010). The results of this study may be particularly informative to guide future research.

Finally, studies characterizing the impact of parental communication of *BRCA1/2* test results on children's well-being remain scarce. Mothers and parenting partners may choose to communicate genetic test results to their children to promote psychological adaptation to disease risk and foster family health (Sharff et al., 2012). Early findings suggested that among families with mothers undergoing *BRCA1/2* testing, children with greater psychological stress had more frequent thoughts of becoming sick and greater worries about cancer (Tercyak, Peshkin, Streisand, & Lerman, 2001). More recent research demonstrates that outcomes for parents and children in this context are influenced by several factors, such as the strength of the parent-child relationship and how genetic risk information is conveyed (Patenaude et al., 2012). There remains a need for empirical research determining how decision-making and psychological distress surrounding family communication of *BRCA1/2* test results drive children's well-being so that supportive interventions can be developed and deployed.

Limitations

The findings of this study should be interpreted in light of important limitations. Data for this analysis were drawn from one of the largest and best characterized prospective clinical cohorts studying family communication of *BRCA1/2* genetic test results among tested women and their parenting partners (Tercyak et al., 2007). However, participants were demographically homogenous, received a high level of clinical care during the genetic counseling and testing process, and dyads that were excluded from the analysis differed in some ways from those included. These factors may limit the generalizability of our findings to non-clinical populations. Although our data provide insights into the relationship between conflict over the decision to communicate mothers' genetic test results to children and psychological distress among parenting dyads, we did not examine how psychological distress between members of the parenting dyad influenced communication decision-making. This is an important area for future investigation. Nearly all partners in this study were males who were biological parents of the target child, which prevented subgroup analyses based on partners' gender. Emerging data suggest a need to address diversity among partners of those tested for *BRCA1/2* mutations, such as among same-sex couples, which is an important avenue of future research (Tercyak et al., 2012).

Our sample size was appropriate for analyses conducted; however, larger studies in the future may improve the ability to detect subtle patterns in the observed dyadic relationships using the APIM approach (Kenny et al., 2006). The measure of psychological distress used in this study was clinically-oriented and captures the broad range of potential psychological responses that mothers and partners may experience during the process of *BRCA1/2* genetic counseling and testing. Research also supports the reliability and temporal stability of this measure in clinical context of *BRCA1/2* counseling and testing (Schwartz et al., 2002;

Graves et al., 2012). Future studies can build from this work by deploying more sensitive measures that capture specific psychological reactions (e.g., cancer-specific distress, anxiety) that women and their parenting partners may experience in this context and conduct subgroup analyses based on factors that may influence psychological outcomes (e.g., type of genetic test result received).

Conclusions

This study provides important initial insights into the parenting processes that may affect psychological distress among women undergoing *BRCA1/2* genetic testing for hereditary breast/ovarian cancer risk and their untested parenting partners. This work highlights the potential impact of couple's decision making regarding the communication of genetic test results to their offspring on psychological outcomes, and the need to develop interventions designed to facilitate shared decisions among couples to improve outcomes. There remains an unmet need for couples-focused interventions that attend to the preferences of both members of partnered couples as they face hereditary breast/ovarian cancer risk and consider communication of genetic test results to their offspring. Important directions for future research to inform the development of couples-oriented interventions include closely examining how relationship characteristics influence psychological outcomes, investigating the optimal methods to deliver couples-oriented interventions, and examining the impact of parental communication of genetic test results on their children's well-being.

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Figure 1.

Model $\chi^2 [2] = 0.11, p = 0.95$. Comparative Fit Index = 1.00. Root Mean Square Error Approximation = 0.0 (90% CI = 0.0, 0.03). Raw (unstandardized) parameter estimates are displayed. Shaded lines represent non-statistically significant parameters (estimates are not displayed). Solid lines are actor effects, dashed lines are partner effects. ^a Paths constrained to be equal based on Wald χ^2 test. *p* values: * < .05 ** < .01 *** < .001

Table 1Sample Characteristics ($n = 109$)

	Mothers	Partners
<u>Demographics</u>		
Age, years (M [SD]) *	45.9 (6.1)	47.8 (6.9)
Race		
Non-Hispanic white	86.2%	86.2%
Non-white	13.8%	13.8%
Education		
< College Education	22.0%	21.1%
College Education	78.0%	78.9%
Marital Status		
Married/Living as Married	90.8%	91.7%
Unmarried	9.2	8.3%
<u>Maternal Clinical Characteristics</u>		
Personal History of Breast/Ovarian Cancer		
Yes	64.2%	--
No	35.8%	--
Family History of Breast/Ovarian Cancer		
Yes	45.9%	--
No	54.1%	--
BRCA1/2 Test Results		
Negative/Uninformative	89.0%	--
Positive	21.0%	--
<u>Child Demographics</u>		
Age (M [SD])	12.4 (3.3)	12.4 (3.3)
Gender		
Female	54.1%	54.1%
Male	45.9%	45.9%
<u>Psychological Distress</u> (BSI, M [SD])		
Baseline *	17.0 (5.0)	15.7 (3.9)
Follow-Up	16.1 (4.8)	15.4 (4.0)
<u>Parent-Child Communication</u> (PAC, M [SD]) *	81.9 (10.4)	76.9 (9.4)
<u>Decisional Conflict</u> (DCS, M [SD]) *		
Summary Score	9.7 (17.1)	15.6 (21.7)
Log-Transformed	0.5 (0.7)	0.7 (0.7)

* Mothers and partners differed significantly at $p < 0.05$ BSI = Brief Symptom Inventory DCS = Decision Conflict Scale PAC = Parent Adolescent Communication scale

Table 2
Bivariate Correlations between Mothers' and Partners' Psychological Distress and Predictor Variables

	1	2	3	4	5	6	7	8	9	10
Mothers										
1. Follow-up Psychological Distress (BSI)	1.0									
2. Decisional Conflict (DCS)	.10	1.0								
3. Log-Transformed Decisional Conflict (DCS)	.15	.87**	1.0							
4. Parent-Child Communication (PAC)	-.37**	-.14	-.13	1.0						
5. Baseline Psychological Distress (BSI)	.39**	.04	.08	-.27**	1.0					
Partners										
6. Follow-Up Psychological Distress (BSI)	.24**	.23**	.20**	-.07	.07	1.0				
7. Decisional Conflict (DCS)	.19*	-.01	-.06	-.23**	-.08	.18*	1.0			
8. Log-Transformed Decisional Conflict (DCS)	.19**	-.04	-.11	-.25**	-.06	.26**	.88**	1.0		
9. Parent-Child Communication (PAC)	-.04	-.11	-.08	.31**	-.05	-.22**	-.18*	-.24**	1.0	
10. Baseline Psychological Distress (BSI)	.18*	.02	.03	-.05	.21**	.68**	.15	.25**	-.19*	1.0

* $p < 0.10$

** $p < 0.05$ BSI = Brief Symptom Inventory DCS = Decision Conflict Scale PAC = Parent Adolescent Communication scale