ADAPTATION TO LIVING WITH A *BRCA1/2* MUTATION IN CARRIERS AND THEIR PARTNERS

by

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ABSTRACT

Background: Women who carry *BRCA1/2* mutations have a significantly elevated risk for breast and ovarian cancer. While the genetic testing experience can be a major stressor in the lives of these women, it is only one of many to come. Following a positive result, many decisions must be made, particularly in regards to surveillance and risk-reducing surgery. Both screening and surgical options can cause distress and anxiety, not only for the carriers themselves, but for their intimate partners as well. There has been little exploration of potential positive impacts of living with a *BRCA1/2* mutation, though some qualitative work, as well as research in similar populations indicates that there are positive aspects to be found. Currently, there is limited understanding of how these women adapt to living with genetic risk. Further, their partners' adaptation to living with this risk remains unexplored.

Objective: This study seeks to understand the process of adaptation in unaffected BRCA1/2 positive women and their intimate partners. This is the first study to examine psychological adaption in individuals living with genetic risk for cancer, as well as the first dyadic-level study of *BRCA1/2* carriers and their partners. Understanding the experiences of these couples may help identify areas for future intervention studies to improve adaptation in similar populations.

Methods: Female *BRCA1/2* carriers and their partners were invited to complete surveys designed to quantitatively explore the relationships between the appraisals and timing of risk-related stressors, dyadic coping, and the outcomes of adaptation and dyadic adjustment.

Results: Of the many stressors examined, women who had undergone prophylactic bilateral mastectomy had significantly higher levels of adaptation than those who had not. Further, their partners had significantly higher adaptation as well. Among women who had not had prophylactic mastectomy, those with higher perceived risk scores were less adapted. In general, the participants had high levels of dyadic adjustment and dyadic coping, indicating good overall relationship quality.

Conclusions: These results aid in the understanding of the experience of living with cancer risk and the factors related to adaption. The relatedness of carrier surgical status to partner adaptation points to the importance of including intimate partners in the genetic counseling and risk management decision-making processes of *BRCA1/2* carriers. Further, these results provide direction for future study to further elucidate the relationship between PBM and adaptation.

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INTRODUCTION

The Experience of *BRCA1/2* Carriers

Women with a *BRCA1/2* mutation have a lifetime breast cancer risk of up to 75% and a lifetime ovarian cancer risk of up to 40% (Chen and Parmigiani, 2007). Additionally, they are at increased risk for other cancers including melanoma and pancreatic cancer. Male carriers have an increase in breast and prostate cancer risk. The children of carriers each have a 50% chance of inheriting the mutation.

Extensive research has been done exploring distress and anxiety related to the genetic testing process and to testing positive for a *BRCA1/2* mutation. A meta-analysis of 20 studies on *BRCA1/2* testing found that, overall, there are emotional consequences of testing, including increased cancer-specific distress, but that this distress decreases with time (Hamilton et al. 2009). One challenge in comparing the data across studies was the use not only of different measures, but different phrasing within measures. The Impact of Event Scale (IES) was used in reference to "cancer" "hereditary cancer" and "risk of cancer" and yielded different results depending on the referent. The researchers also postulated that measures of general anxiety might be too generic to capture distress accurately in this population. Further, these instruments do not measure many possible outcomes, including guilt and relief.

An instrument introduced in 2002, the Multidimensional Impact of Cancer Risk Assessment (MICRA) Questionnaire can correct for some of the shortcomings seen in studies relying solely on tools such as the IES (Cella et al. 2002). It measures distress, uncertainty and positive experiences specifically related to receiving a genetic test result for a hereditary cancer syndrome and demonstrates strong discriminate validity in differentiating between *BRCA1/2* carriers and women not found to carry *BRCA1/2* mutations over time (Graves et al. 2012).

While distress due to genetic testing decreases with time, testing is not the only risk-related stressor impacting *BRCA1/2* carriers. Following a positive result, many risk-management decisions must be made, not only in the following months, but for many years. The emotional impact of screening, such as mammography, on high-risk women has been examined both quantitatively and qualitatively in numerous studies (e.g. Lerman and Schwartz, 1993; Werner-Lin, 2008). Risk-reducing surgeries, mastectomy and oophorectomy, reduce the uncertainty that accompanies surveillance but bring their own challenges, such as impacting sexuality and body image (Frost et al, 2000; Dennerstein et al. 2006; den Heijer et al, 2012).

Qualitative research on female *BRCA1/2* carriers has brought additional nuances to our understanding of the psychosocial issues faced by these women over time, providing insight into the stress of surveillance, the impact of prophylactic surgeries and the experience of a compressed childbearing timeline. In semi-structured interviews with young *BRCA1/2* mutation carriers, a major theme that emerged for many women was that of urgency: for single women to find a partner, and for partnered women to have children (Werner-Lin, 2008). Importantly, these women also used their family histories in the development of frameworks for thinking about their own risk (Werner-Lin, 2007). The themes from this qualitative work could inform the types of stressors and appraisals to be measured in future quantitative studies with high-risk women and their partners. This research also suggests that adaptation to high-risk status is an ongoing, fluctuating experience, with multiple risk-related stressors, and that partners should be included in future research on this experience.

Prophylactic mastectomy, and decision making around mastectomy, is one of the more widely studied risk related stressors in *BRCA1/2* carriers. While most women are satisfied overall, in one study, 23% of women experienced adverse effects in sexual relationships following prophylactic bilateral mastectomy (Frost et al, 2000). A significant increase in problems with both breast-related and general body image in the first six months following surgery has also been seen (den Heijer et al, 2012). Despite these negative effects in the short term, research indicates that women who choose prophylactic mastectomy later experience a decrease in psychological morbidity compared to their counterparts who choose breast screening (Hatcher et al. 2001). In addition to the decision to have surgery, there is further the question of types of surgery, such as whether to preserve the nipple-areolar complex and what, if any reconstruction to have. The psychological impact of type of surgery is unclear, and much of the research on surgical impact has focused on women with cancer, rather than those at risk. One study found that nipple-sparing surgery did not have an impact on measures of body image or sexual functioning in high-risk women, though research on women with cancer found that this type of surgery lead to better outcomes in body image and sexual functioning (Metcalfe et al. 2004). To date, only one small study has directly examined the impact of such surgeries on partners (Lloyd et al, 2000). Partners can also be integral to the decision-making process when considering prophylactic mastectomy, and their opinions can, for some, carry a tremendous weight in determining the decision (Hoskins et al, 2012).

Prophylactic oophorectomy can also have a major impact in the shared lives of a couple, particularly when performed prior to menopause. In natural menopause, there is a gradual decrease in estrogen levels due to the progressive decline in ovarian function. By contrast, in surgical menopause, there is not only an abrupt drop in estrogen levels, but also of progesterone and testosterone levels, resulting in greater symptom severity (Rocca et al. 2009). The physiological effects of surgical menopause include issues that impact not only the woman, but the couple as a unit, such as decreased libido and increased sexual dysfunction. In research on women suffering from these issues, they endorsed negative emotions and psychological states, such as: unhappy, disappointed, sad, frustrated, inadequate, and (most frequently) "letting my partner down" (Dennerstein et al. 2006).

Partners of *BRCA1/2* Carriers

Though research on partners of *BRCA1/2* carriers has expanded in the last ten years, it remains limited, particularly in contrast to the broader literature on partners of individuals affected with cancer. Most studies have focused on the genetic testing experience rather than taking a broader view of living at high-risk. Further, most of the studies have had an inherently negative bias, focusing on measures of distress and anxiety, constraining our understanding of the full range of outcomes and failing to capture the full picture of adaption in partners and couples.

Existing research on partners indicates that they experience personal challenges resulting from their partners' high-risk status. One review identified nine studies that examined psychological adjustment among partners of women at high risk (Sherman et al. 2010). Four of these studies looked at only the period preceding genetic testing and/or the immediate post-test period. The remaining five studies did explore psychosocial issues over time. One employed interviews with ten high-risk women and eight of their partners to study the experience of risk-reducing mastectomy (Lloyd et al. 2000). Some men experienced the surgery as an upheaval, and a minority felt that the couple's physical relationship deteriorated. A later study focused exclusively on partners, and included seven husbands of mutation carriers (Mireskandari et al, 2006). Partners who described their wives' anxiety and distress levels as high, and who felt unable to respond to this anxiety, experienced a greater relationship impact. Additionally, some reported often having extremely upsetting thoughts about losing their wives to cancer.

A larger study took a more long-term view, in which 59 partners of affected and unaffected women with a BRCA1/2 mutation completed surveys 1-5 years following genetic test result disclosure (Metcalfe et al, 2002). The major concern expressed by participants, their spouse dying of cancer, did not differ significantly based on their spouse's cancer status. The researchers used the Impact of Event scale (IES) and found that few spouses experienced clinical levels of distress. However, the event was having a spouse with a BRCA1/2 mutation, rather than a specific event (e.g. receiving a test result or having a mastectomy) so this may not be the most appropriate measure. Further, like much of the research, the scope is limited by measuring only distress.

Another study employing the IES focused on the partners of women undergoing breast cancer surveillance (den Heijer et al, 2010). Researchers concluded that the distress associated with waiting is an experience shared within the couple and that partners should be involved in interventions. This study helps fill in the understanding of high-risk stress beyond the test period and highlights the importance of including partners in research, but was not conducted in a population with homogeneous risk levels. The inclusion criterion for risk was at least a 15% lifetime risk based on Claus tables, and there was no information about mutation status.

A study of 95 women at varying levels of increased cancer risk and their partners (Mireskandari et al, 2007) used the IES, as well as the Depression, Anxiety, and Stress Scale–Brief version (DASS), and found that a small proportion of partners experienced high levels of distress that should be addressed with clinical interventions. Greater perceived breast cancer risk was associated with higher cancer-specific and general distress in partners. Nearly a third of partners indicated they would like more support in dealing with their wife's risk. A second paper published from the same study (Watts et al, 2011) examined dyadic coping and adjustment in the 95 couples. The authors found that most couples were well adjusted, with perceived support and a collaborative approach as predictors of relationship quality. They stressed the importance of viewing the experience of living at high risk as a shared experience. However, neither paper from this study explored these issues in the context of specific life events, such as having children or undergoing surveillance or surgery.

Relationship strain around the time of genetic testing (Manne et al, 2004) has been described in a study of women undergoing *BRCA1/2* testing and their partners prior to testing and six months after results disclosure. The researchers found that partners did experience distress but that this distress was less in those who received support from their partners undergoing testing. It is unclear what factors might facilitate increased partner support and whether this strain persisted in the years following testing.

A recent survey of partners of high-risk women queried specifically about their needs and preferences for support (Tercyak et al, 2012). 143 partners participated, including 91 partners of unaffected women. Participants expressed interest in all psychoeducational topics, particularly normalizing their role as informed supporter, and having training in coping and communication skills. While the results of this study should prove helpful in guiding therapeutic interventions, the study was limited by the lack of a psychosocial assessment of the participants, leaving a lack of clarity regarding who may be most in need of such interventions and which specific outcomes these interventions may be trying to achieve.

Adaptation

Adaptation, as a psychological concept, refers to both the process of coming to terms with the implications of a health threat and the observable outcomes of that process. Taylor's theory of cognitive adaptation to threatening events centers on three themes: a search for meaning, an attempt to regain mastery, and an effort to enhance self-esteem (1983). Based on Taylor's theory and Lazarus and Folkman's Transaction Model of Stress and Coping (1984), the Psychological Adaptation Scale (PAS) is a new instrument designed to measure levels of adaptation at a single point in time. While the PAS has not been used in spouses, it has been effective in measuring adaptation in affected individuals, including those living with Klinefelter syndrome or Neurofibromatosis type 1, as well as those at risk for Huntington disease (HD). It has also been effectively used in caregiver populations, namely parents of children with genetic conditions including autism, Down syndrome and Rett syndrome. (Biesecker et al., 2013). The PAS has also been applied to measuring adaptation in siblings of affected individuals (Pappa, 2012).

This study adds to the current understanding of adaptation to genetic risk. Compared to the previously studied population at risk for HD, *BRCA1/2* carriers encounter very different challenges throughout their adult lives. Unlike HD, the onset of breast or ovarian cancer is not a certainty. Further, there are measures for early detection, risk reduction and treatment. This study furthers our understanding of adaptation to not only the knowledge that one is at risk, but also to the risk-related events and choices that follow. Additionally, this provides some understanding of the experience of partners of individuals living with genetic risk.

It is clear from the available literature on dyadic coping and adjustment to living with chronic illness, cancer, or genetic risk that these phenomena indeed occur on the level of the couple (Berg and Upchurch, 2007; Richards and Williams, 2004). And though these concepts are theoretically and conceptually linked to adaptation, adaptation as defined above has yet to be measured in partners in any health setting. Populations coping with hereditary cancer risk are ideal for the exploration of adaptation in couples because the myriad issues associated with living at risk impact not only the mutation carrier, but also her partner and their children who are at risk of inheriting the mutation.

Adaptation is a concept of clinical importance to genetic counselors and other healthcare professionals working with *BRCA1/2* carriers and their partners. Understanding the process of adaptation and the impact of risk-related stressors in these couples will aid in the identification of those who would benefit from interventions in the facilitation of adaptation to living at high risk. The relevance also extends beyond the HBOC community to those living at increased risk for other hereditary cancers and genetic diseases.

Conceptual Framework

The conceptual model of this study (Figure 1) is largely based on Lazarus and Folkman's Transactional Model of Stress and Coping (1984), a model of adaptation to stressful events. This model guides studies of adaptation through its delineation of the process and predictors involved. In response to a stressor, individuals make cognitive and emotional appraisals that inform coping behaviors, which in turn lead to adaptation. The theory has been used to conceptualize adaptation to chronic illness and disability, and to living with a genetic condition. While this model applies to individual adaptation, it has been adapted (Bodenmann, 1995) to conceptualize the process in dyads as well.

Unlike models that conceive of the partner as one of many social supports, dyadic models see the partner as having an integral role throughout the process. In models of dyadic adjustment, rather than a single pathway through appraisals and coping, individuals make their own primary appraisals that inform a common appraisal. The common appraisal informs individual secondary appraisals and so on. Similarly, coping is performed on not only an individual level, but also on a dyadic level, in a transactional, inter-personal process. Dyadic coping takes on different forms, from unidirectional support to equal collaboration. It may be positive or negative in nature, and like individual coping, may be problem-focused or emotion-focused. Effective dyadic coping is seen to relate to overall dyadic adjustment. In a series of studies, higher dyadic coping scores were significantly correlated with better marital functioning and higher relationship satisfaction (Bodenmann, 1997). This process has also been applied specifically to couples dealing with chronic illness (Berg and Upchurch, 2007).

Bodenmann's concept of dyadic adjustment is qualitatively different from the concept of adaptation as described previously. This concept is not related to coming to terms with the implications of a health or other threat. Rather, it is a measure of the quality of a couple's relationship. The adjustment refers to how the partners are adjusted to each other and to their relationship.

Bodenmann defines two types of dyadic stress, both of which may apply to couples in which a partner is high-risk. The first type is individual stress that affects both members of the couple, either because it is too intense for one member to cope with alone, or because the coping efforts result in stress to the couple. In the example of the high-risk woman and her partner, this may be experienced if a screening appointment is very stressful to her, even if it is not to her partner. The second type is genuine dyadic stress, which directly concerns the couple as a unit. In the same example, dyadic stress may be experienced if both she and her partner have a lot of cancer worry and anxiety that is activated by the screening appointment. This could also be used to describe shared concerns about fertility and childbearing.

The present study seeks to understand adaptation in *BRCA1/2* carriers and their partners, with an examination of risk-related stressors and appraisals as predictors, and coping as a mediator. The specific appraisals of interest include cancer worry (emotional appraisal) and risk perception (cognitive appraisal). Timing is included in the model because time has been seen to be a significant factor in distress following genetic testing, screening, and prophylactic surgery, and thus it is expected to affect adaptation as well. The study examines not only the carriers and partners as individuals, but also as dyads, examining both dyadic predictors of individual outcomes (e.g. dyadic coping and carrier/partner adaptation) and individual predictors of dyadic outcomes (e.g. carrier/partner adaptation and dyadic adjustment).

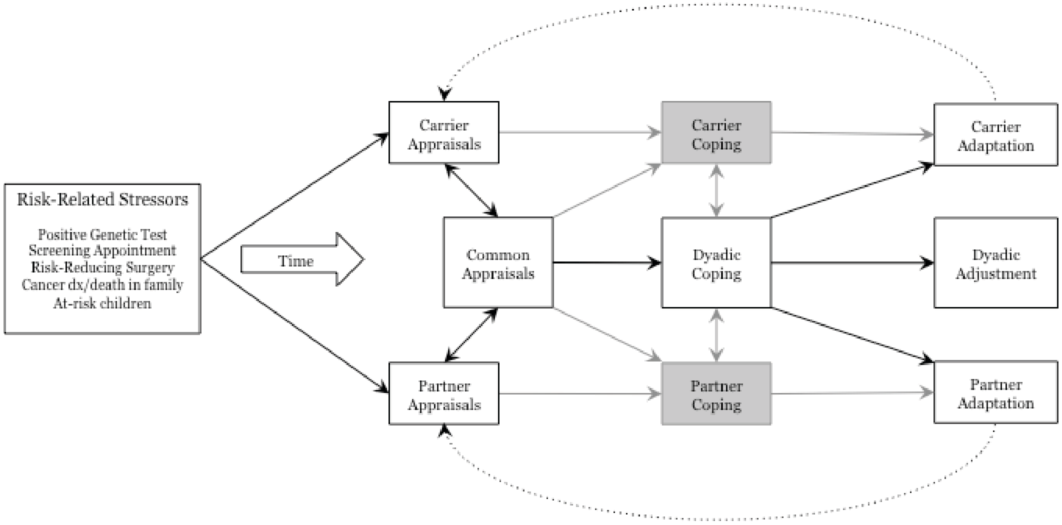


Figure 1: Proposed integrative model of individual and dyadic stress and coping theories.

Significance of Study

This is the first study to examine psychological adaption in individuals living with genetic risk for cancer, as well as the first dyadic-level study of *BRCA1/2* carriers and their partners. This study not only adds to our understanding of the experience of previvors and their partners, but also aids in the understanding of similar populations. The relevance of the study extends not only to those working with *BRCA1/2* previvors and their partners, such as genetic counselors, couples counselors and support organizations, but also to those working with individuals and couples living with genetic risk in general.

OBJECTIVE AND SPECIFIC AIMS

The objective of this study was to understand the process of adaptation in unaffected BRCA1/2 positive women and their intimate partners.

- **Aim 1:** To measure levels of adaptation and dyadic adjustment in female BRCA1/2 carriers and their partners.
- **Aim 2:** To examine the relationship between the presence of and time since risk-related stressors, appraisals, and adaptation in female BRCA1/2 carriers and their partners
- **Aim 3:** To examine relational correlates of adaptation and dyadic adjustment, including appraisals, dyadic coping, and concordance of appraisals and dyadic coping between partners.

METHODS

Study Sample

The study population consisted of women aged 18 or older who have a *BRCA1/2* mutation and their (male or female) partners. Carriers had no personal history of cancer, but partners were not excluded based on cancer history. Individuals of all ethnic, religious, and educational backgrounds and from a variety of geographic locations were included. Non-English speaking/reading individuals were excluded from the study because it utilizes measures that have not been validated in non-English speaking/reading populations. Power analysis resulted in a recruitment target of 230 dyads (230 carriers and 230 partners), a sample size that would enable the detection of a small-to-medium effect, or when a key variable explains approximately 3% of the variance in the outcome, with 80% power.

Recruitment and Procedures

Participants were recruited from local and national support groups, email listservs, and social media outlets. National and international support organizations were approached to see if they might post a link to the online survey on their website, distribute the link to their electronic mailing list, or share the link via social media on their Facebook page or Twitter account. The posts included a brief explanation of the study and how to participate, including a link to the SurveyMonkey site, on which the landing page included the contact/consent letter.

Numerous organizations participated in recruitment efforts. The majority of participants learned of the study through FORCE: Facing Our Risk of Cancer Empowered, who shared the link in local group and national emails, as well as on Facebook. Bright Pink shared the link with their Twitter followers. Additional organizations including BRCA Umbrella, Previvorsandsurvivors.com, and BRCA Sisterhood shared the information on their websites and/or Facebook pages.

Ultimately, all interested individuals were invited to visit the survey website (https://www.surveymonkey.com/s/BRCAStudy) to view the full study notice (Appendix A) and complete the survey, or to contact RS for a print version. The electronic version of the survey was posted on a secure site (https) provided by SurveyMonkey. The survey was anonymous; no identifying information was collected in the online survey or by SurveyMonkey. The landing page on the survey website was the contact/consent letter, and individuals were instructed to print out a copy to keep for themselves.

Individuals who preferred to complete the survey on paper were instructed to contact the researcher (RS), to receive a printed survey and copy of the study notice for each member of the couple, along with two stamped return envelopes. Surveys were pre-coded so that carrier and partner could be linked in the analysis. Participants were asked not to put their names on the survey, and any identifying information that was obtained for the purpose of mailing the survey was destroyed after mailing in order to ensure confidentiality.

This study was approved by the National Human Genome Research Institute (NHGRI) Institutional Review Board (Protocol #T-HG-0090).

Study Design and Instrument

Most of the instruments in this survey have not been previously used in partners of *BRCA1/2* carriers but have been shown to be valid and reliable in similar populations. The survey measured individual and dyadic appraisals and coping, dyadic adjustment, and individual adaptation; in addition, it included BRCA-related questions and questions about demographics. Table 1 outlines the variables included in the study: the types of variables, the constructs they map to, and the instruments used to measure them.

Demographic Information: Participants were asked to provide information about their income, age, gender, race/ethnicity, marital status, number of children, and level of education in order to evaluate these variables' potential as confounders in multivariate analyses.

Risk Related Stressors: Stressors measured include aspects of family and medical history. All participants were asked about their family history of cancer. Carriers were asked about breast and ovarian cancer specifically, as well as other cancers. Partners were asked about cancer in general. Questions inquired about the timing and emotional impact of the cancer experiences of relatives. Medical history questions focused on cancer risk-management, including screening and risk-reducing surgery.

Cancer Worry: Participants were asked to answer three questions from the Lerman Cancer Worry Scale (LCWS) about how frequently they worry about cancer and how much of an impact the worry has on their lives.

Risk Perception: Participants were asked to answer six questions about the carrier's risk, 3 questions each about breast and ovarian cancer. One question about each cancer measured “risk magnitude judgments” on a 7-point scale *(1 = almost zero, 2 = very small, 3 = small, 4 = moderate, 5 = large, 6 = very large, 7 = almost certain)*. Two questions about each cancer measured “feeling at risk” by asking participants to rate their level of agreement or disagreement with each item on a 4-point scale *(1 = disagree strongly, 2 = disagree somewhat, 3 = agree somewhat, 4 = agree strongly)*. Risk perception scales in these formats have been found to be better predictors of behavior and are more accurate at capturing true judgments and feelings about risk than other constructs such as percentage scales (Weinstein et al. 2007).

Test-related Distress and Uncertainty: The Multidimensional Impact of Cancer Risk Assessment (MICRA) is 21-item instrument with subscales measuring distress, uncertainty and positive experiences related to one’s genetic test result (Cella et al. 2002). In addition to usage in numerous studies to measure the short-term outcome of genetic testing, it has also effectively been used in a population of *BRCA1/2* carriers who were at least three years out from testing (Graves et al. 2012). The MICRA was modified for the partner survey to refer to “my partner” rather than “me” and “my partner’s” rather than “my” test. Including the MICRA allows for comparison of the findings of this study to the well-characterized distress-related outcomes in the *BRCA1/2* carrier literature.

Coping: The Dyadic Coping Inventory (DCI) is a 37-item scale that consists of four factors: stress communication, supportive, negative, and joint dyadic coping, as well as quality of self-perceived dyadic coping. Participants were asked to rate the items on a 5-point scale *(1 = very rarely,* 2 = *rarely,* 3 = *sometimes,* 4 = *often, and* 5 = *very often)* (T. Ledermann et al. 2010).

Adaptation: The Psychological Adaptation Scale (PAS) is a 20-item scale that measures four domains of adaptation: Positive Social Impact, Positive Self-Concept/Esteem/Worth, Coping Efficacy, and Positive Spiritual/Existential Impact. Participants were asked to rate their level of agreement or disagreement with each item on a 5-point scale *(1 = strongly disagree, 2 = disagree, 3 = unsure, 4 = agree, and 5 = strongly agree)*. Carriers' selections were in response to "Being a *BRCA1/2* carrier has…" Partners' selections were in response to "Being the partner of a *BRCA1/2* carrier has…" This measure is found to be valid and reliable in studies of adaptation to a health condition or genetic risk. This is the first study to use the PAS to measure adaptation in *BRCA1/2* mutation carriers. While the PAS has been used to measure adaptation in parents and siblings of affected individuals, this is also be the first time it has been used to measure adaptation in partner's of high-risk individuals (Biesecker et al. 2013).

Dyadic Adjustment: The Abbreviated Dyadic Adjustment Scale (ADAS) is a 7-item scale that measures a couple's adjustment. Participants were asked to indicate the degree to which each item describes their relationship using a Likert-type scale with 6- and 7-point response formats. Though not specifically related to illness, the DAS has been used with couples adjusting to cancer, including breast and prostate, and with couples undergoing predictive testing for Huntington Disease.

Table 1: Outline of Variables

	Variable	Variable type	Measure
Stressors	Genetic testing	Dichotomous	-
	Time since testing	Interval	
	Screening	Dichotomous	-
	Screening Modality	Categorical	
	Time since screening	Interval	
	Time until screening	Interval	
	Surgery	Dichotomous	-
	Type of surgery	Categorical	
	Time since surgery	Interval	
	Cancer death/diagnosis in	Dichotomous	-
	family	Ordinal	
	Impact on self	Dichotomous	-
	At-risk children		
Appraisals	Cancer worry	Ordinal	LCWS
	Risk perception		-
	Risk magnitude	Ordinal	
	Feeling at risk	Ordinal	
	Distress	Ordinal	MICRA
	Uncertainty	Ordinal	MICRA
Moderators	Demographics		-
	Gender	Dichotomous	
	Age	Interval	
	Race	Nominal	
	Ethnicity	Dichotomous	
	Ashkenazi descent	Dichotomous	
	Location	Nominal	
	Education	Ordinal	
	Relationship factors		-
	Relationship status	Nominal	
	Relationship length	Interval	
	Together at time of testing	Dichotomous	
Mediators	Dyadic coping	Ordinal	DCI
Outcomes	Adaptation	Ordinal	PAS
	Dyadic adjustment	Ordinal	ADAS

Data Analysis

Data were analyzed using SPSS 20.0 (Statistical Package for the Social Sciences). The primary outcome variables, adaptation and dyadic adjustment, were analyzed in parallel. Each potential confounder was tested as a predictor of the outcome variable using a Pearson's correlation coefficient, ANOVA or t-test. Any variables that resulted in a p-value ≤ 0.20 were considered as candidates for inclusion in all subsequent multivariate regression models. Multivariate regression modeling was used to test for the association of one covariate on the outcome measure while controlling for other covariates.

RESULTS

Recruitment and Response Rate

During the recruitment period from June to November 2013, 229 individuals (168 carriers and 61 partners) visited the survey website. 187 individuals (134 carriers and 53 partners) completed the initial section (eligibility, informed consent, and dyad-matching). Of the 134 eligible carriers who began the survey online, 103 completed the survey in its entirety (that is, reached the demographic section, the last in the instrument). Of the 53 partners, 43 completed the survey in its entirety. Sections located later in the survey instrument had lower completion rates than those located earlier; there was not any apparent pattern of drop-out, suggesting that time/length of the survey was the deterrent to finishing. As individuals were allowed to leave items blank, the sample sizes for the different analyses performed vary.

Data on recruitment source was available for 146 respondents. The majority of carriers were recruited from a local support group or online support organization. The majority of partners learned of the survey from the carriers. An overall response rate could not be calculated, as it was not known how many eligible individuals received notification of the study through the organizations' various communication channels.

Demographics

The average age of carriers was 39.7 ± 10.1 years and ranged from 20 to 62 years (n = 101). Participants were largely White (98.0%), non-Hispanic (93.9%), not of Ashkenazi Jewish descent (70.6%) and had a college or graduate degree (79.4%). Most were married (77.5%) and about two thirds had at least one child (65.7%).

The partners' demographics were very similar. The average age of partners was 41.9 ± 11.2 years and ranged from 22 to 61 years (n = 41). Participants were again largely White (97.5%), non-Hispanic (97.5%), not of Ashkenazi Jewish descent (82.5%) and had a college or graduate degree (85.4%). Most were married (78.0%) and about half had at least one child (53.7%) with their current partner.

Table 2: Demographic characteristics of carriers

Demographic Characteristic		Percent
Age	Under 25	5.2
	25-39	44.8
	40+	50.0
Race*	White/Caucasian	98.0
	Black/African American	1.0
	Asian	2.6
	Native American	2.6
Ethnicity	Not Hispanic or Latino	93.9
	Hispanic or Latino	6.1
Ashkenazi Jewish	Yes	22.5
	No or don't know	77.5
Highest Level of Education	High school/GED	2.9
	Technical school	4.9
	Some college	12.7
	Completed college	45.1
	Post-graduate	34.3
Relationship Status	In a relationship, not living together	4.9
	In a relationship, living together	11.8
	Engaged	2.0
	Married	77.5
	Civil union/domestic partnership	3.9
Biological Children*	Daughters	42.3
	Sons	44.2
	No children	32.7
Location	United States	85.3
	Other	14.7
Partner Participation	Partner completed survey	38.1
	Partner did not complete survey	61.9

*Percentages do not equal 100%, as participants were allowed to choose more than one response

Table 3: Demographic Characteristics of Partners

Demographic Characteristic		Percent
Age	Under 25	5.1
	25-39	43.6
	40+	51.3
Race*	White/Caucasian	100.0
	Native American	2.2
Ethnicity	Not Hispanic or Latino	97.5
	Hispanic or Latino	2.5
Ashkenazi Jewish	Yes	12.5
	No or don't know	87.5
Highest Level of Education	High school/GED	7.3
	Technical school	4.9
	Some college	2.4
	Completed college	51.2
	Post-graduate	34.1
Marital Status	In a relationship, not living together	7.3
	In a relationship, living together	7.3
	Engaged	2.4
	Married	78.0
	Civil union/domestic partnership	4.9
Biological Children*	Daughters	33.3
	Sons	35.6
	No children	37.8
Location	United States	90.2
	Other	9.8

*Percentages do not equal 100%, as participants were allowed to choose more than one response

BRCA1/2-Related Stressors
Genetic testing

Approximately half of the carriers had *BRCA1* mutations (51.1% *BRCA1*); the remaining half had *BRCA2* mutations. The average age at time of testing was 36.4 ± 9.4 years, with a range of 18 to 60 years old. Their genetic testing was done, on average, 3.2 ± 3.0 years ago, ranging from occurring in the last year to 13 years ago. The vast majority (91.7%) were in a relationship with their current partner at the time of testing. About a quarter of the women (26.5%) were the first person in their family to be tested.

Screening

Carriers were asked about two breast screening modalities, mammography and breast MRI, and two ovarian screening modalities, CA-125 blood test and transvaginal ultrasound (TVS). The majority of carriers have had at least one mammogram (94.3%) and at least one breast MRI (87.6%). While most have also had ovarian screening, the numbers are considerably smaller for both CA-125 (59.2%) and TVS (69.9%).

Risk-reducing surgery

Approximately half of the carriers have had risk-reducing surgery, including bilateral mastectomy (48.5%) and bilateral oophorectomy (46.1%). Almost one third of the carriers have undergone both surgeries (31.6%). Of the fifty women who had not had mastectomy, 48 (96.0%) reported that they would consider it. Of those 48 women, 28 (58.3%) reported that they definitely planned to have the surgery. Of the 50 women who had not had oophorectomy, 47 (94.0%) would consider it. Of those 47 women, 40 (85.1%) said they definitely planned to have the surgery.

Of the subset of carriers whose partners completed the survey as well, the breakdown was similar. Approximately half of them have had bilateral mastectomy (46.2%) and half have had bilateral oophorectomy (43.6%).

Cancer experience in family

All of the 120 carriers who completed the family history portion of the survey had a family history of breast and/or ovarian cancer; 95 (79.2%) had at least one family member with breast cancer, and 60 (50.0%) had at least one family member with ovarian cancer. Almost half of the carriers (45.8%) had a family history of both breast and ovarian cancer.

More specifically, 47 carriers (45.2%) reported that their mothers had breast cancer, and 24 carriers (23.1%) reported their mothers had ovarian cancer. Six women had mothers with a history of both breast and ovarian cancer. Of the mothers with breast cancer, most (78.7%) were survivors, while a majority of those with ovarian cancer (79.8%) passed away from the disease.

Of the 45 partners who completed the family history portion of the survey, 34 (75.6%) reported some history of cancer in their own families, including 13 (28.9%) with a family history of breast cancer and three (6.7%) with a family history of ovarian cancer. One partner reported a personal history of cancer, diagnosed with leukemia seven years prior.

At-risk children

Of the participants who completed the demographics sections, 67 carriers (65.7%) had children, and 22 partners (53.7%) had children with the carrier. Four carriers (4.0%) were pregnant at the time they completed the survey. In terms of future planning, 17 carriers (16.8%) and 5 partners (12.5%) report that they plan to have (more) children.

Appraisals

Cancer worry

Participants' cancer worry was assessed using the three-question Lerman Cancer Worry Scale (LCSW). Questions were modified for the partner version to assess cancer worry about the carriers rather than themselves. These questions asked about cancer in general, rather than specifically breast or ovarian cancer. Using a six-point Likert scale anchored at "never" (1) and "often" (6) the frequency of worry and the impact it has on their lives was measured. Participants reported, on average, worry at a level lower than the scale midpoint, though it was slightly higher in carriers. Both carriers and partners reported a greater frequency of cancer worry than frequency of that worry impacting their mood or daily life.

Table 4: Carriers' Cancer Worry

Frequency	n	Mean	SD
Worry about cancer	104	3.79	1.41
Worry affects mood	105	2.76	1.46
Worry interferes with daily activities	105	1.96	1.12
Overall Worry	**104**	**2.84**	**1.23**

Table 5: Partners' Cancer Worry

Frequency	n	Mean	SD
Worry about cancer	41	3.12	1.12
Worry affects mood	41	2.02	1.04
Worry interferes with daily activities	41	1.48	1.01
Overall Worry	**41**	**2.21**	**0.87**

Risk perception

Participants were asked six questions about the carrier's cancer risk, three questions each about breast and ovarian cancer. These questions measured risk magnitude judgments on a 7-point Likert scale *(1 = almost zero, 7 = almost certain)* and feeling at risk on a 4-point Likert scale *(1 = disagree strongly, 4 = agree strongly)*. Two items assessed slightly different aspects of feeling at risk: feeling that one is going to get cancer and feeling that one is vulnerable to cancer. Carriers' risk perception was highly dependent on surgery status (Table 6). Those who had PBM had lower perceived breast cancer risk. Those who had PBSO reported lower perceived ovarian and breast cancer risk. The difference in risk perception was most pronounced when the carrier was asked about vulnerability.

Partners' perception of cancer risk was similarly associated with carriers' surgical status (Table 7). However, there was not an association seen between having PBSO and lowered breast cancer risk perception. It may be the case that while carriers understand that pre-menopausal PBSO reduces breast cancer risk, their partners are less aware of this benefit.

Table 6: Carriers' risk perception and surgical status

	PBM			**PBSO**			**PBM and PBSO**		
	Yes Mean n=52	**No Mean** n=48	**t p-value**	**Yes Mean** n=46	**No Mean** n=54	**t p-value**	**Yes Mean** n=31	**No Mean** n=69	**t p-value**
Breast Cancer									
Risk magnitude	2.33	5.44	10.475 **.000**	3.00	4.76	4.453 **.000**	2.06	4.80	7.259 **.000**
Feel will get	1.64	2.85	6.464 **.000**	1.87	2.61	3.528 **.001**	1.53	2.59	4.874 **.000**
Feel very vulnerable	2.28	3.57	6.530 **.000**	2.44	3.38	4.269 **.000**	2.00	3.37	6.312 **.000**
Ovarian Cancer									
Risk magnitude	2.73	4.00	3.609 **.000**	2.13	4.43	7.820 **.000**	1.81	4.10	7.003 **.000**
Feel will get	1.77	2.06	1.625 .107	1.47	2.30	5.206 **.000**	1.39	2.16	4.381 **.000**
Feel very vulnerable	2.42	2.82	1.754 .083	1.96	3.19	6.122 **.000**	1.87	2.97	4.822 **.000**

Table 7: Partners’ risk perception and surgical status

	PBM			**PBSO**			**Both PBM and PBSO**		
	Yes Mean n=18	**No Mean** n=21	**t p-value**	**Yes Mean** n=17	**No Mean** n=22	**t p-value**	**Yes Mean** n=11	**No Mean** n=28	**t p-value**
Breast Cancer									
Risk magnitude	2.47	4.48	4.037 **.000**	3.00	4.05	1.829 .076	2.73	3.93	1.917 .063
Feel will get	1.69	2.25	1.810 .079	1.94	2.05	.346 .731	1.82	2.08	.752 .457
Feel very vulnerable	2.00	3.35	4.380 **.000**	2.25	3.10	2.359 **.024**	1.91	3.08	3.168 **.003**
Ovarian Cancer									
Risk magnitude	3.00	3.30	0.593 .557	2.00	4.05	5.445 **.000**	2.36	3.50	2.187 **.036**
Feel will get	1.78	1.52	-1.123 .269	1.41	1.82	1.836 .074	1.55	1.68	.524 .603
Feel very vulnerable	2.22	2.57	1.069 .292	1.59	3.05	6.285 **.000**	1.64	2.71	3.350 **.002**

Test-related distress, uncertainty, and positive impact

Appraisals related to genetic testing were assessed using the Multidimensional Impact of Cancer Risk Assessment (MICRA), a 21-item instrument with subscales measuring distress, uncertainty and positive experiences related to one’s genetic test result. The MICRA was modified for the partner survey to refer to “my partner” rather than “me” and “my partner’s” rather than “my” test. Items were measured on a 4-point Likert scale (*0=never, 1=rarely, 3=sometimes, 5=often)*.

On the distress and uncertainty subscales, as well as the overall score, a higher score indicates more negative impact of testing. On the positive scale a higher score indicates more positive impact of testing. For both carriers and partners, there was a correlation between time since testing and impact of testing; higher scores were associated with more recent testing. In additional analysis of the carriers, the difference in mean overall scores between those tested three or fewer years ago, and those tested four or more years ago was significant at the .01 level (p=.009).

Table 8: Carrier MICRA Scores

	N	Range	Mean	Std. Deviation
Distress subscale	101	0-28	9.00	7.50
Uncertainty subscale	96	0-45	13.99	10.62
Positive subscale	97	0-20	11.13	4.73
Overall Score	93	7-85	36.45	16.63

Time since testing	Total MICRA Score	t p-value
≤ 3 years ago N=58	39.78	**2.691*** **.009**
> 4 years ago N=30	30.60	

* Equal variances not assumed.

Table 9: Partner MICRA Scores

	N	Range	Mean	Std. Deviation
Distress subscale	40	0-23	7.34	6.59
Uncertainty subscale	40	0-29	10.58	7.15
Positive subscale	40	0-20	12.82	5.09
Overall Score	40	12-54	33.37	10.68

Table 10: Correlation of Time Since Testing and MICRA Scores

		Pearson Correlation	P-value
Carrier	**Distress**	-.273	**0.007****
	Uncertainty	-.287	**0.006****
	Positive	0.14	0.185
	Total	-.288	**0.006****
Partner	**Distress**	-.423	**0.013***
	Uncertainty	-.407	**0.017***
	Positive	.399	**0.019***
	Total	-0.231	0.189

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Dyadic Coping

Dyadic coping was measured using the Dyadic Coping Inventory (DCI), a 37-item scale that consists of four factors: stress communication, supportive, negative, and joint dyadic coping, as well as quality of self-perceived dyadic coping. Participants rated the items on a 5-point Likert scale *(1 = very rarely, 2 = rarely, 3 = sometimes, 4 = often, and 5 = very often)*. The two major subscales of “Total Dyadic Coping by Oneself” and “Total Dyadic Coping by Partner” were used in the analysis; each is comprised of 11 items with possible scores of 5-55, in which higher scores indicate greater dyadic coping. The “Total Dyadic Coping” score is the sum of these two subscales plus stress communication and joint dyadic coping subscales, totaling 35 items with a possible score of 35-175. Additionally the 2-item “Evaluation of quality of dyadic coping” scale was included as a separate measure as it is not factored into the total scores. Overall, carriers’ and partners’ score were very similar (Tables 11, 12).

Table 11: Carrier Dyadic Coping Inventory Scores

	N	Range	Mean	Std. Deviation
DC by Oneself	98	33-55	43.77	4.67
DC by Partner	98	21-55	43.02	7.61
Evaluation of DC	101	2-10	7.94	1.97
DC Total	95	94-175	132.76	17.40
DC Total (if partner completed survey)	38	94-175	137.61	16.50

Table 12: Partner Dyadic Coping Inventory Scores

	N	Range	Mean	Std. Deviation
DC by Oneself	40	31-53	43.47	5.07
DC by Partner	38	22-54	42.51	7.59
Evaluation of DC	40	2-10	7.50	2.20
DC Total	36	92-166	132.24	18.58

Outcome Variables

Adaptation

Adaptation to living with a *BRCA1/2* mutation was measured using the 20-item Psychological Adaptation Scale (PAS). Using a 5-point Likert scale anchored at “strongly disagree” (1) and “strongly agree” (5), participants rated their level of agreement or disagreement with each item. Adaptation scores ranged from 1 to 5, with higher scores indicating greater levels of adaptation to living with a BRCA1/2 mutation. A total of 105 carriers and 45 partners completed this portion of the survey.

Figure 2 depicts the distribution of scores on the adaptation measure, as well as the normal curve, for carriers and partners, respectively.

Table 13: Adaptation Scores

	N	Mean	Std. Deviation
All participants who completed the survey			
Carriers	105	3.04	1.11
Partners	45	2.72	0.96
Couples in which both members completed the survey			
Carriers	37	2.85	1.18
Partners	37	2.83	0.95

Figure 2: Frequency Distribution of Adaptation in Carriers

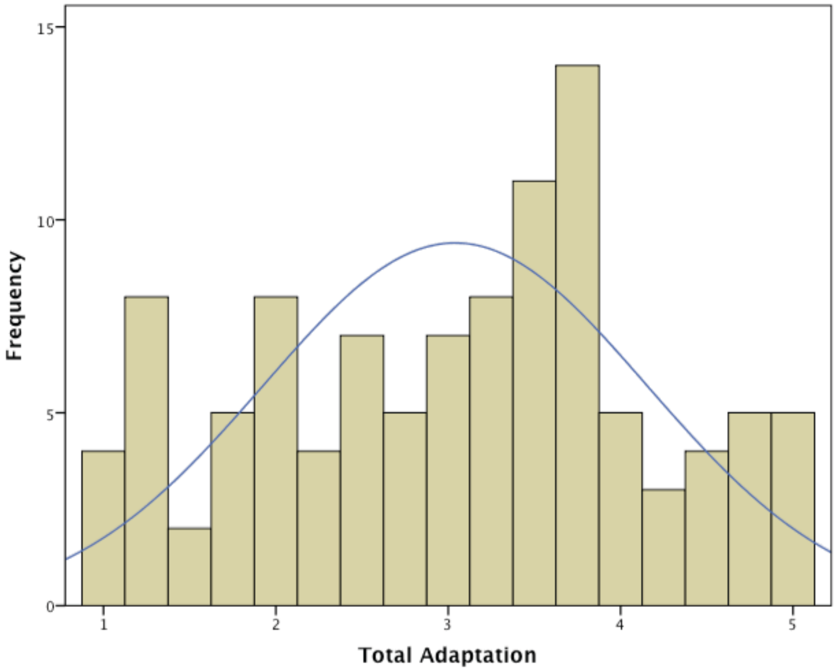
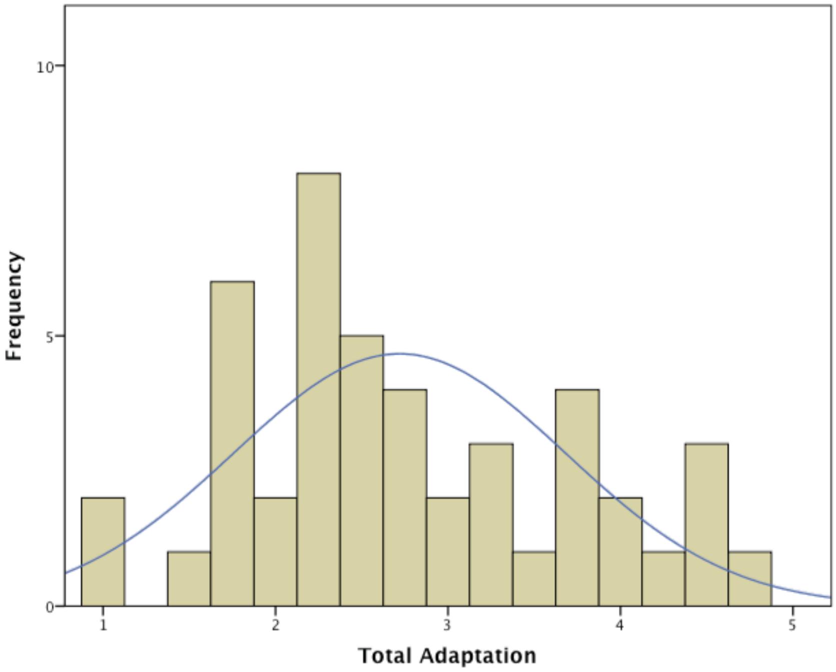


Figure 3: Frequency Distribution of Adaptation in Partners



Dyadic Adjustment

Dyadic adjustment was measured using he Abbreviated Dyadic Adjustment Scale (ADAS) is a 7-item scale that measures a couple's adjustment. Using a 6-point Likert scale, participants indicated the degree to which each of 6 items describes their relationship. An additional item asked participant's to rate the overall level of happiness in their relationship, on a scale of 0-6. Possible total scores on the ADAS range from 0-36, with higher scores indicating greater relationship quality. 101 carriers and 42 partners completed this portion of the survey.

Table 14: Dyadic Adjustment Scores

	N	Range	Mean	Std. Deviation
All participants				
Carrier	101	13-34	31.18	4.29
Partner	42	10-35	24.80	4.82
Couples in which both members completed the survey				
Carriers	38	18-33	26.18	3.26
Partners	38	10-35	25.25	5.07

Figure 4: Frequency Distribution of Dyadic Adjustment in Carriers
N=101

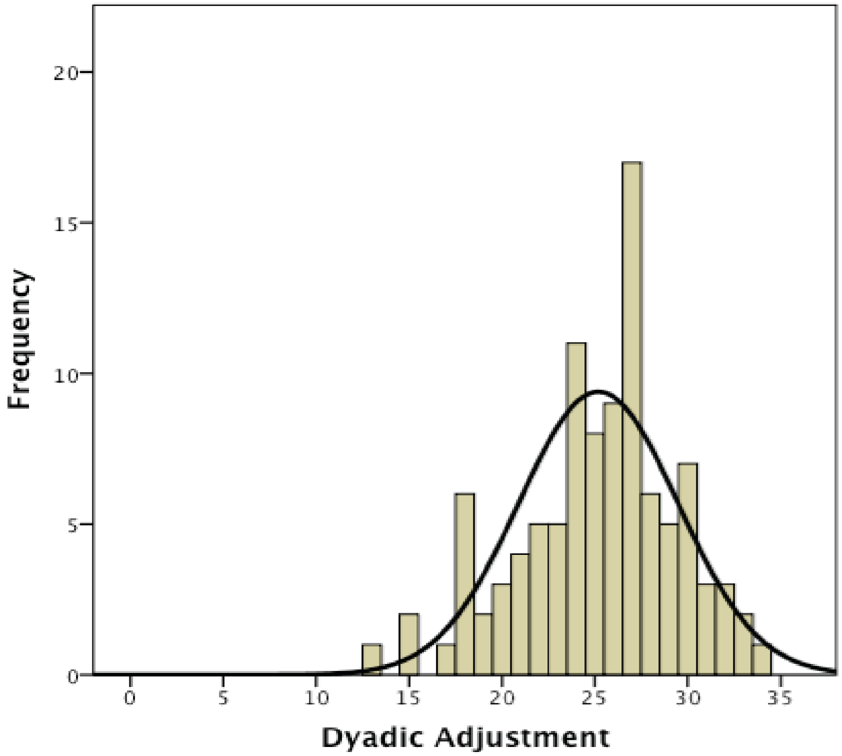
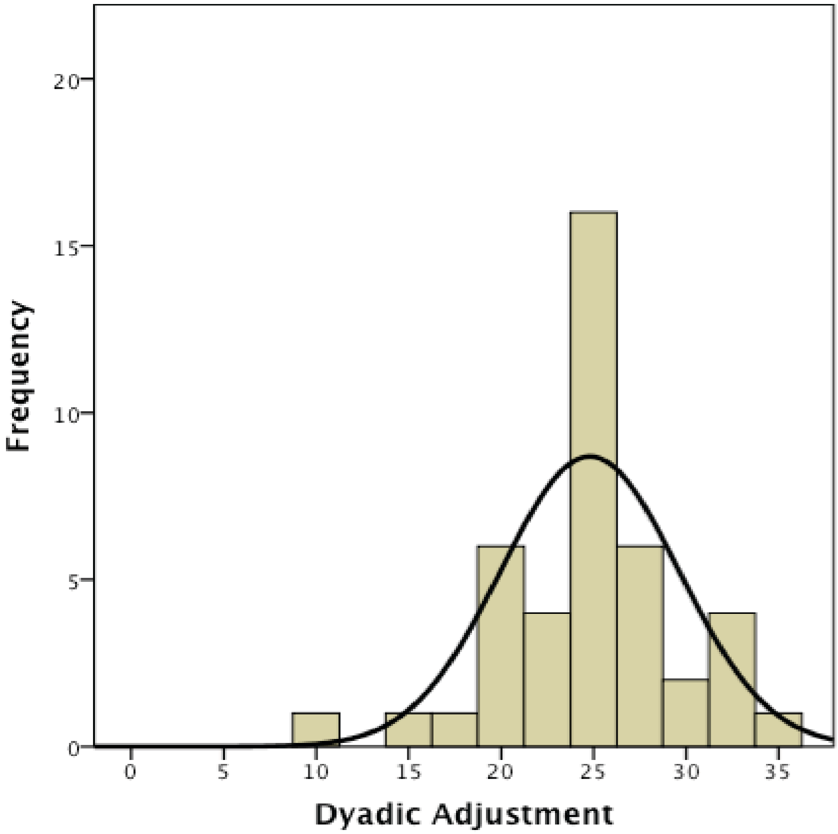


Figure 5: Frequency Distribution of Dyadic Adjustment in Partners
N=42



Predictors of adaptation

Bivariate analysis was performed to determine which demographic variables may be acting as confounders in the relationship between key variables and adaptation. All demographics and potential confounders that were found to be significant at the p<0.2 level in the bivariate analyses were entered into a regression model with adaptation as the dependent variable. Only two variables proved to be significant for carriers, level of education (p =0.009) and years with partner (p=0.083). To estimate the amount of variance in adaptation explained by these variables, a regression model containing these variables was created. For partners, none of the demographic variables reached a significance level of $p<0.2$

Table 15: Regression of Carrier Adaptation on Confounders

MODEL **($R^2 = .107$)**	Unstandardized Coefficients	Std. Error	P-value
(Constant)	4.475	0.561	0.000
Highest level of education	-0.299	0.110	0.008
Years with partner	-0.001	0.001	0.072

Simple linear regression analyses were conducted to estimate the influence of a single key predictor variable on the outcome, adaptation, while controlling for potential confounders. One at a time, adaptation was regressed on a single key predictor variable and all potential confounders from above.

The association between adaptation and prophylactic mastectomy was profound and immediately apparent. Further, it applied both to carriers themselves and their partners. Because this relationship was so significant, additional simple linear regression was performed separately for carriers who had PBM and those who had not had the surgery. The same demographic variables were tested initially. Within the subset of carriers who have had bilateral mastectomy, neither education nor relationship length variables were significant, but one other demographic variable was, having Ashkenazi Jewish descent ($p=0.017$).

Table 16: Regression of Carrier Adaptation on Confounders (PBM group)

MODEL (R^2 = .125)	Unstandardized Coefficients	Std. Error	P-value
(Constant)	2.531	0.416	0.000
Ashkenazi Jewish	0.572	0.230	0.017

Table 17: Regression of Carrier Adaptation on Confounders (No PBM group)

MODEL (R^2 = .148)	Unstandardized Coefficients	Std. Error	P-value
(Constant)	4.001	0.703	0.000
Highest level of education	-0.302	0.133	0.029
Years with partner	-0.001	0.000	0.108

Table 18: Adaptation and Prophylactic Mastectomy

		N	**Mean**	**SD**	**t** **p-value**
All participants who completed the survey					
Carriers	PBM	47	3.50	0.93	4.857
	No PBM	51	2.53	1.04	**.000**
Partners	PBM	18	3.30	0.94	3.458
	No PBM	20	2.37	0.70	**.001**
Couples in which both members participated					
Carriers	PBM	17	3.69	0.98	4.954
	No PBM	20	2.18	0.86	**.000**
Partners	PBM	17	3.39	0.88	3.751
	No PBM	19	2.36	0.76	**.001**

Table 19: Simple Linear Regression of Carrier Adaptation on Predictors

Variable	Unstandardized Coefficients (Std. Error)	Standardized Coefficients	P-value	R^2 change
Among all carriers*				
Had PBM	1.042 (0.196)	0.478	0.000	0.222
Among carriers who have not had PBM				
Feel vulnerable to BC	-0.471 (0.203)	-0.338	0.025	0.095
Time since genetic test	-0.103 (0.050)	-0.295	0.046	0.079
Among carriers who have not had PBM or PBSO				
Think chances of BC	-0.254 (0.124)	-0.335	0.049	0.109
Feel vulnerable to BC	-0.703 (0.265)	-0.466	0.013	0.168

Confounders and demographic variables controlled for: highest level of education, relationship length.
*Carriers who have had PBM are not included as a separate group as no predictor was significant in the model.

Table 20: Linear regression with all variables stratified by PBM status

PBM Group	Variable	Beta	Sig
All Carriers	Highest level of education	-0.197	0.030
	Years with current partner	-0.138	0.122
	Had PBM	0.465	0.000
No PBM	Highest level of education	-0.369	0.007
	Years with current partner	-0.269	0.061
	Feel vulnerable to breast cancer	-0.399	0.007
	Time since genetic test	-0.368	0.010
Had PBM	Ashkenazi Jewish descent	0.354	0.017

Relational correlates of adaptation and dyadic adjustment between partners

Dyadic analysis was performed on the data provided by only those couples in which both members completed the survey (n=38). Bivariate analysis was performed to examine correlations between carrier and partner responses.

Table 21: Concordance between appraisals

	Pearson's Correlation between Carrier and Partner	P-value
MICRA		
Uncertainty Subscale	0.123	0.473
Distress Subscale	0.078	0.647
Positive Experience Subscale	0.734**	0.000
Overall	0.110	0.530
Cancer Worry		
Frequency of worry about cancer	0.387*	0.018
Overall	-0.058	0.732
Risk Perception		
Breast cancer risk magnitude	0.309	0.066
Feel will get breast cancer	0.265	0.124
Feel vulnerable to breast cancer	0.463**	0.004
Ovarian cancer risk magnitude	0.471**	0.003
Feel will get ovarian cancer	0.151	0.374
Feel vulnerable to ovarian cancer	0.604**	0.000

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Table 22: Concordance in measures of dyadic coping

	Pearson's Correlation between Carrier and Partner	P-value
Overall dyadic coping	0.596**	0.000
Satisfaction with dyadic coping	0.477**	0.002
Carrier's rating of dyadic coping by self / Partner's rating of dyadic coping by Carrier	0.491**	0.003
Partner's rating of dyadic coping by self / Carrier's rating of dyadic coping by Partner	0.333*	0.041

Table 23: Concordance in adaptation and dyadic adjustment

	Pearson's Correlation between Carrier and Partner	P-value
Individual Adaption	0.583**	0.000
Dyadic Adjustment	0.499**	0.001

Table 24: Correlations between one's adaptation and the other's dyadic adjustment

	Pearson's Correlation	P-value
Carrier Adaptation / Partner dyadic adjustment	-0.199	0.231
Partner Adaptation / Carrier dyadic adjustment	0.356*	0.030

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

DISCUSSION

The present study enhances our understanding of the experience of unaffected *BRCA1/2* carriers through quantitative analysis of psychosocial aspects of living with increased risk for cancer. It builds on previous qualitative work as well as quantitative studies about the impact of genetic testing and risk-reducing surgery. This is the first study to use the PAS to study adaptation to living with genetic risk for cancer, not only for individuals with a genetic mutation, but also for their partners. Through an exploration of many potential stressors and appraisals related to psychological adaptation, the most profound was the association between having risk-reducing mastectomy and greater adaptation. This was also the first study to examine *BRCA1/2* carriers and their partners in dyads, examining dyadic coping and adjustment, as well as concordance between partners across multiple appraisals and outcomes.

Adaptation in Unaffected *BRCA1/2* Carriers

Much previous research has utilized measures such as the Impact of Events Scale (IES), Hospital Anxiety and Depression Scale (HADS), or Center for Epidemiological Studies Depression Scale (CESD), which may not be ideally suited to gaining an understanding of this population. Specifically, the IES is designed to address a singular traumatic event or experience, rather than the long-term experience of living with genetic risk. The HADS and CESD are intended for evaluating whether there are clinical levels of depression and anxiety, which most *BRCA1/2* have not been found to have. Further, these measures are all inherently negative. For these reasons, the aforementioned scales were not used in the present study.

As this is the first study to use the PAS in this population, the MICRA was utilized, both as a measure of appraisals, but also as a means of comparing the study participants to those of other studies. Initially developed to distinguish between *BRCA1/2* positive and negative testers in terms of psychosocial needs following genetic testing, the MICRA has also been found to have value as a measure of long-term impact of genetic testing. Compared to a previous study that included 47 unaffected *BRCA1/2* carriers an average of 5 years after genetic testing (Graves et al. 2012), the mean scores across all three subscales were higher in the current study, indicating more test-related distress and uncertainty, as well as more positive experiences. In the previous study, the means with standard deviations were 2.6 (4.6), 5.1 (6.7), and 6.1 (5.8) on the distress, uncertainty, and positive subscales, respectively. In the current study, the same scales produced mean scores of 9.0 (7.5), 14.0 (10.6), and 11.1 (4.7). While the scores are very different, the standard deviations in both studies are quite large, indicating a great deal of variability between individuals. Despite the differences, there were also similar findings. More time since testing and risk-reducing surgery were both associated with lower distress and uncertainty scores. On average, more time had passed between genetic testing and follow-up survey (Median = 5.0 years; Range = 3.4–9.1 years) compared to the current study (Median = 2.0 years; Range = 0-13 years). The closer proximity to testing contributes to the higher scores in the present study. Further, as the previous study was a clinic-based sample, and the present study participants were primarily recruited from support organizations, the different selection biases may impact these results.

As the MICRA has been primarily used to compare populations based on genetic test result and personal history of cancer, it remains to be seen what a typical MICRA score is in unaffected *BRCA1/2* carriers. Additionally, as this was the first study to utilize the MICRA with partners of *BRCA1/2* carriers, there is no point of comparison on this measure for partners. While the partners had lower distress and uncertainty, and higher positive mean scores than the carriers in the present study, their numbers were still higher than those of carriers in the previous study.

Adaptation to Living with a *BRC1/2* mutation

This is the first study to examine psychological adaptation to living with the genetic risk associated with a *BRCA1/2* gene mutation. Using the Psychological Adaptation Scale (PAS) to measure adaptation as an outcome, the mean score in carriers was 3.04 (SD=1.11), near the scale midpoint of 3.0. These scores were comparable to those found in similar populations. While this scale has not been used with other populations living with an increased risk for cancer, it has been used in populations with other genetic conditions. In a study of adults with Neurofibromatosis 1, the average PAS score was 2.66, indicating a slightly lower level of adaptation in that population (Cohen, 2009). In a study of individuals at risk for Huntington Disease, the average score was 3.21, both for individuals with a positive test result and for those who had not undergone genetic testing (Adcock, 2008).

This study is also the first to examine adaptation in the partners of individuals living with genetic risk. The mean PAS sore in partners was 2.72, again, near the midpoint of the scale. While the PAS scale has not been used in partners, it has been used in a population of siblings of individuals with Duchenne Muscular Dystrophy (DMD), in which the mean score was 3.64 (Pappa, 2012). While this does not provide a useful comparison point for the experience of partners, it does provide evidence of the value of the scale in individuals who lives are impacted by a genetic condition, even though they are not personally affected.

Both demographic and BRCA1/2-related variables were found to be associated with adaptation score. The most significant relationship seen was that with risk-reducing mastectomy. Further, the association between higher adaptation and having had the surgery was present for both carriers and their partners. Given Bodenmann's conceptualization of shared stressors in intimate relationships, this is perhaps unsurprising. While the partners are themselves not at an increased risk for cancer, it appears they indeed share this stress in a way that is significant to their individual psychological adaptation.

Dyadic Adjustment

Despite a similarity in name, these data indicate dyadic adjustment is a distinct concept from psychological adaptation. The 7-item ADAS is a measure of relationship quality and cohesion. Both carriers and their partners had high levels of dyadic adjustment, with mean scores of 31.18 and 24.8, respectively, out of a possible 36. By comparison, a previous study of 545 participants from the general population found average scores to be somewhat lower, 23.2 for married individuals and 23.7 for cohabitating individuals (Sharpley and Rogers, 1984). Also included in this study were separated and divorced individuals, with mean scores of 13.4 and 15.2, respectively.

Like adaptation, dyadic adjustment is not expected to remain constant over time, and previous research indicates that genetic testing and the passage of time both impact it. A previous study utilizing the 32-item DAS found that dyadic adjustment levels changed in couples in which an individual was undergoing genetic testing for Huntington disease (Richards and Williams, 2004). In the 20 couples in the non-testing group, there was little change in dyadic adjustment over time; however, the results for the testing group were quite different and dependent on results. In the six carrier couples, there was an increase in dyadic adjustment from baseline to 18 months post-result. In the non-carrier couples, the trend was the opposite. The HD study did not publish mean individual scores, but rather the change in score, so it is not possible to make a direct comparison to the current study. However, it does provide some evidence that a positive genetic test result may positively impact a couple's relationship.

It remains unclear why the carriers in the present study whose partners *did not* participate reported such high levels of dyadic adjustment, relative to the partners and to previous studies. Interestingly, the average score was lower in the subgroup of only those carriers whose partners completed the survey as well.

Risk-Reducing Mastectomy

The most striking finding of the current study was that of the association between prophylactic mastectomy and adaptation. Not only did those carriers who had undergone the surgery have higher levels of psychological adaptation than those who had not, so did their partners. One may hypothesize numerous explanations for this finding. It may be that having the surgery actually promotes greater adaptation. It may be that women with higher levels of adaptation are more likely to choose to have this surgery.

Alternatively, there may an aspect of the surgical decision-making process that lowers adaptation in carriers. As adaptation is conceived of as a process, rather than simply an outcome, it may be that struggling with such a decision causes some psychological disruption. The data did not support an argument that adaptation is greater once a decision is made; there was no significant difference between those who were definitely having the surgery and those who were considering it. Thus it appears that decision-making alone is not the cause of the difference in adaption. One could postulate that women whose surgery was approaching within the next year, may harbor ambivalence about the decision, or may simply be anxious about undergoing major surgery, a surgery that is directly tied to their genetic risk. Further research will be needed to elucidate this relationship.

This difference in adaptation may also be related to other factors associated with surgical status, particularly risk perception. Perceived breast cancer risk was much lower in women who have had the surgery, and lower risk perception was associated with greater adaptation. In regression modeling, the variable of feeling very vulnerable to breast cancer remained in the model for the No-PBM group. This feeling of vulnerability to cancer may, at least in part, explain why these women are less adapted. Perhaps addressing this aspect of perceived risk in women who choose not to undergo surgery could aid in their adaptation.

In the regression models, no other tested variables had a significant relationship with adaptation in the PBM group. Some of these variables may indeed be related to adaptation; however, the small sample size (52 carriers who had PBM) makes small effect sizes undetectable.

Dyadic Concordance

While the sample of complete couples participating in the present study was small, this is the only study of *BRCA1/2* carriers to date that has examined concordance between partners. There were high levels of concordance seen across appraisals, coping, dyadic adjustment and adaptation. This may simply be due to the fact that couples that volunteer for research together are more likely to be cohesive, or it may be tied to having a *BRCA1/2* mutation. For example, it may be that less cohesive couples are unable to weather the strain of a *BRCA1/2* mutation.

Concordance in and of itself is not necessarily positive. Concordance in high levels of distress, for instance, would not be desirable. Nor would concordance in low levels of adaptation. However, the concordance seen in these couples was encouraging rather than concerning. The strongest correlations were seen in positive measures with average to high scores: the positive MICRA subscale, dyadic coping, dyadic adjustment and psychological adaptation. In addition to high levels of dyadic adjustment, this may further indicate good relationship quality.

In some cases, discordance can be of value, even necessary, to a couple's functioning. Dyadic coping is not merely joint coping with shared stressors. While this is one aspect, dyadic coping is frequently, and perhaps most importantly the way that couples deal with stressors that primarily impact one individual. Two aspects of dyadic coping measured by the DCI are delegated and supportive dyadic coping, both of which apply to cases where one individual requires more support. Dyadic coping is bidirectional, but the amount of support given and received fluctuates. Thus if the *BRCA1/2* carrier is experiencing a high level of risk-related stress, her partner is in a position to bear some of the weight of that burden. Participants reported, on average, high levels of dyadic coping performed by their partners (supportive and delegated), as well as high levels of dyadic coping performed by themselves. Thus, both the carriers and the partner seem satisfied with the support given and received in the relationship. Given that these couples have high levels of dyadic adjustment as well, it would seem that they are managing individual stressors in shared ways. Further, because the DCI and ADAS are not specifically asking about issues related to cancer risk, it may be the case that the giving and receiving support is balanced in other aspects of the couples' relationships.

As fewer than half of the carriers' partners completed (or even began) the survey, it is not possible to surmise whether similar levels of concordance would be seen in the remaining couples. It may be that concordance would be dramatically lower. Given that the ADAS addresses issues such as agreement on things believed important and frequency of working together on a project, it may be that couples in which only the carrier participated would have quite discordant dyadic adjustment scores. In the dyadic measures, coping was similar when comparing all carriers to those whose partners completed the survey. Interestingly, dyadic adjustment was somewhat lower in the latter group. These data are difficult to interpret, especially due to the lack of a corresponding partner group, in which the carriers did not complete the survey. Unfortunately, it is impossible to know why most partners did not participate. Further we cannot know whether all of the carriers shared the link with their partners; some carriers may have forgotten or chosen not to share it. Additionally, we cannot know whether partners intended to take the survey but simply forgot, or perhaps whether they reached the landing page and upon reading the consent letter, decided not to participate.

CLINICAL IMPLICATIONS

First and foremost, this study may have implications for the way that genetic counselors and other health professionals discuss risk-reducing mastectomy with patients. The National Comprehensive Cancer Network (NCCN) guidelines for HBOC syndrome management state that PBSO is recommended for *BRCA1/2* positive women, ideally between age 35 and 40, upon completion of childbearing; however, the guidelines regarding PBM are quite different, suggesting that it should be discussed. Specifically the guidelines state, “Counseling may include a discussion regarding degree of protection, reconstruction options, and risks“ (NCCN, HBOC-A, 2013). Medically, these two surgeries should be treated differently, especially given the lack of effective screening for ovarian cancer. Further, risk-reduction, reconstruction and risks should, without question, be discussed and well-understood prior to surgery. However, these guidelines do not take into account the psychological aspects of the surgery, positive or negative. The NCCN guidelines are a tremendous resource for any professional working with patients who have or are at risk for cancer, and they are intended to provide up-to-date medical recommendations. However, it is important for genetic counselors and others working with this population to be aware of potential issues outside the bailiwick of these guidelines. The present study may aid in the creation of educational materials, directed at both professionals and patients, to help address aspects not covered by NCCN. Before such materials can be developed, future research will be required to clarify the directionality of the relationship between risk-reducing mastectomy and psychological adaptation.

The present study also has implications for the inclusion of partners in genetic counseling. The importance of the inclusion of intimate partners in genetic counseling and discussions of risk-reducing surgery is neither a new, nor a surprising idea. However, their inclusion has often been seen as important because they are in a support role.

Dyadic models and the current study support the idea that they are personally affected by the choices and actions of their partners, as the carrier is not the only member of the couple whose adaptation is associated with surgical status. Partners' adaptation scores were significantly associated (p=.001) with it as well. There may also be a role for additional education for partners; while carriers correctly perceived lower breast risk associated with PBSO, their partners did not. A better understanding of the reduction in breast cancer risk following PBSO may aid in partners' adaptation.

STUDY LIMITATIONS

Because this study was cross-sectional, conclusions could only be drawn regarding associations between variables, but not about causal pathways or temporal relationships. In addition, the cross-sectional nature means that adaptation was studied as an outcome at a single point in time, rather than as a process over time. However, this study is strengthened by the use of a theoretically-grounded conceptual framework and previous empiric research to guide the design, analyses, and interpretation of results.

Another limitation of this study is the recruitment methods. As the majority of participants were drawn from HBOC organizations, this might have biased the findings in favor of individuals who actively seek out support groups. It is possible that those individuals differ in important ways from individuals not involved in HBOC activities, such as in their level of cancer worry or adaptation. Some findings of the present study support what has already been seen in studies with clinical populations; lower perceived cancer risk and lower psychological distress have been observed in women following risk-reducing mastectomy (Graves et al. 2012, den Heijer et al. 2012). Given these findings, adaptation levels may be more similar than different in a clinical sample, but future research will be necessary to discover whether this is the case. Demographically, there is a lack of racial and ethnic diversity in the study sample, so the experiences of under-represented minorities may not have been adequately captured.

Finally, while the sample size of *BRCA1/2* carriers was adequate for in-depth data analysis, the sample size of partners was lacking. As such it is difficult to interpret the partner data, as well as the couple-level data. As partners were primarily recruited by the carriers, rather than reached directly, the study sample may be biased in favor of couples with certain qualities, such as more open communication. Further, this study did not capture the experiences of couples that have split up due to, either directly or indirectly, the carrier's *BRCA1/2* mutation.

AREAS FOR FUTURE RESEARCH

Longitudinal studies will be helpful to clarify the temporal relationships among the constructs in the conceptual model, and to examine how individuals' levels of adaptation change over time. Specifically, this could help elucidate the precise relationship between risk-reducing mastectomy and adaptation. While a strong correlation was seen in the current study, it is unclear whether having the surgery promotes greater adaptation, or whether better-adapted individuals are more likely to have the surgery.

Additionally, there has been little research on the impact of having a *BRCA1/2* gene mutation on male carriers. While screening recommendations are different and fairly minimal, and risk-reducing surgery is not an issue, there may be other aspects of being a mutation carrier that impact their psychological adaptation. Perhaps because of the lower associated personal cancer risks, or lack of medical intervention, this population has not been studied extensively. However, they should not be neglected based on the assumption that they do not need attention. The psychological needs of this population are largely unknown.

Finally, similar research should be done in more diverse populations. Like most research on this population, the sample was largely white and highly educated. The experiences of minorities may differ from the experiences of this population, and their voices should be actively sought out for participation in future research. Additionally, while Hereditary Breast and Ovarian Cancer syndrome is the most well studied cancer syndrome, and thus a good starting point for research on adaptation to living with cancer risk, similar research should be conducted with those living at risk for other cancers, such as individuals with Lynch syndrome.

APPENDIX A: Contact letter/consent form

Dear Previvors and Partners,

You are invited to participate in a study conducted by researchers at the National Institutes of Health and the Johns Hopkins University.

Why is this study being done?

People with BRCA1/2 mutations have an increased risk for cancer, particularly breast and ovarian. We want to learn more about how couples cope and adapt when a woman has a BRCA1/2 mutation. This information will help us to improve counseling and support recommendations for couples living with high risk. We are interested in hearing from carriers and their partners who may be learning to adjust and also from carriers and their partners who feel well-adjusted.

Who can take part in this study?

We are looking for couples in which both members wish to participate. If you are interested in taking part, please pass a copy of this letter along to your partner. You both must be 18 years of age or older and in a committed relationship. Carriers must be women with a BRCA1 or BRCA2 mutation and no personal history of cancer.

What is involved in this study?

Both members of the couple will be asked to complete a survey on their own. Each survey takes approximately 15-30 minutes to complete. Both versions of the survey ask about your thoughts and feelings about your experience as a BRCA carrier or partner.

What are the risks of the study?

There are no physical risks of this study. There is some risk that certain questions may be upsetting to think about. If taking the survey makes you feel upset, you can stop taking the survey at any time. If it causes you to become upset or worried about yourself or your partner, you can also contact the researchers (see below) and they will help direct you to the appropriate resources. This is also a small risk of a loss of privacy and/or confidentiality, but we have taken measures to minimize these risks. It is unlikely that participants will be identifiable based on the information collected. Further, all data will be stored securely and only available to researchers. Data may be shared with other researchers in the future, but no personally identifiable information will be shared with them.

Are there benefits to taking part in the study?

You will not personally receive any benefits from taking part in this study. We hope to learn more about how couples adjust to living at high risk for breast and ovarian cancer.

Will I be paid for my time?

You will not receive compensation for your participation in this study.

Do I have to participate?

No, you do not have to take part in this study if you do not want to. We ask that if you choose not to participate, your partner does not participate either. Your decision to take the survey will not have an effect on your or your partner's healthcare. If you begin the survey, you can choose to skip any question that you don't want to answer. You can also stop taking the survey at any time. If you submit the survey and then change your mind, we will not be able to delete it.

Who else will know that I am in the study?

We do not ask for your full name or contact information on this survey. If you provide us with your name by calling or writing to us, we will not link your name with your responses. This study will not be part of any medical record. When we report our research results, it will be done with no identifiable information from individual participants. Your partner will know that you are participating, but you will not see each other's responses.

How do I participate?

The survey can be found online at https://www.surveymonkey.com/s/BRCAStudy. If you prefer to complete a paper version of the survey, please contact Rachel Shapira at shapirar@mail.nih.gov or 773.808.9127 to receive the survey and a pre-addressed and stamped return envelope. Any contact information you give to the researchers in order to mail the survey will be immediately destroyed after it is mailed.

Thank you for your interest and time! If you are taking this survey online, please print a copy of this consent form so that you have the researchers' contact information.

Rachel Shapira
Associate Investigator, JHU/NHGRI
Genetic Counseling Training Program
rachel.shapira@nih.gov
773.808.9127

Gillian Hooker
Primary Investigator, JHU/NHGRI
Genetic Counseling Training Program
gillian.hooker@nih.gov
301.443.2635

APPENDIX B: Social Media Recruitment Messaging

1. Twitter Messages

Help NIH researchers understand how couples adapt when a woman has a BRCA1/2 mutation. Learn more and take the survey! [LINK]

Join a study to help NIH researchers learn how couples cope and adapt when a woman has a BRCA1/2 mutation. [LINK]

NIH researchers are looking for women with BRCA1/2 mutations and their partners to participate in an online study. Click here! [LINK]

Calling previvors and their partners! Join an online study to help NIH researchers learn how couples cope with high risk. [LINK]

2. Facebook post

Researchers at the National Institutes of Health and the Johns Hopkins University are seeking previvors and their partners to participate in a study. We want to learn more about how couples cope and adapt when a woman has a BRCA1/2 mutation. The study consists of a survey that both members of the couple are asked to complete on their own. Each survey takes approximately 15-30 minutes.

For more information about the study or to take the survey, please click here: https://www.surveymonkey.com/s/BRCAStudy

APPENDIX C: Survey Instrument, Carrier Version

Survey -
Adaptation to Living with a BRCA1/2 Mutation in Carriers and their Partners

STATEMENT OF CONFIDENTIALITY.
All of the information you provide will be kept confidential. The information you provide will be used for research purposes only. The information you provide will not be released to anyone other than the researchers of this study. Filling out this survey is voluntary.

Please check the responses that are true for you:

☐ I am 18 years old or older and in a committed relationship

☐ I am a BRCA1/2 mutation carrier

☐ I have no personal history of cancer

If you check all 3 boxes, you are eligible to complete this survey. Please complete every question in the survey.

If you did not check all 3 boxes, you are not eligible to complete this survey. Thank you for your time and interest.

Please **check the box below** if you have read and understand the information presented in the consent form.

☐ I understand the purpose and procedures of the study and do not have any questions.

****Please follow the instructions at the beginning of each Section. Thank you for your time****

Section A

To confidentially match your survey to your partner's, please enter the following information. If you choose to enter a nickname, please be sure that both you and your partner enter the same nickname.

Your birthday

_______/_______
Month Day

Your partner's birthday

_______/_______
Month Day

Your first name

____

Your partner's first name

____

Section B

Please answer the following questions about your experience with genetic testing.

When did you have BRCA1/2 testing?

_______/_______
month year

How old were you?

_______ (years)

Were you in a relationship with your current partner at that time?

☐ Yes
☐ No

In which gene do you have a mutation?

☐ BRCA1
☐ BRCA2
☐ Don't know/unsure
☐ Other: ____________________________

Have you had any other genetic testing?

☐ Yes
☐ No
If so, please describe what the testing was for and what the result was.
____

How many members of your family (not including yourself) have had BRCA1/2 testing?

____

How many of them tested positive for a BRCA1/2 mutation?

____

Were you the first person in your family to have BRCA1/2 testing?

☐ Yes
☐ No
☐ Don't know

If not, who was the first person in your family?

Relationship: __________
Year: _________
Result: ☐ Positive
☐ Negative
☐ Don't know/unsure

Section C

Please answer the following questions about your family's history with cancer.

Have any of the following members of your family been diagnosed with breast cancer?

For the questions about the impact of the individual's cancer experience on you, use the following scale:
1 = Strongly disagree 2 = Somewhat disagree 3 = Somewhat agree 4 = Strongly agree

If you have more affected relatives than there are boxes (e.g. more than two sisters with breast cancer) please use the "other" boxes at the end.

	Relative's age at diagnosis	Your age at their diagnosis (0 if not born yet)	Cancer survivor (Y/N)	This person's cancer experience has had a significant impact on the way I view my risks for cancer.	This person's cancer experience has had a significant impact on my worries about cancer.	This person's cancer experience has had a significant impact on my confidence in my ability to cope with cancer risks.
☐ Mother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Father				1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandfather				1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister				1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister				1 2 3 4	1 2 3 4	1 2 3 4
☐ Brother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt				1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt				1 2 3 4	1 2 3 4	1 2 3 4
☐ Uncle				1 2 3 4	1 2 3 4	1 2 3 4
☐ Daughter				1 2 3 4	1 2 3 4	1 2 3 4
☐ Son				1 2 3 4	1 2 3 4	1 2 3 4
☐ Other___ *Please specify:*				1 2 3 4	1 2 3 4	1 2 3 4
☐ Other___ *Please specify:*				1 2 3 4	1 2 3 4	1 2 3 4
☐ Other___ *Please specify:*				1 2 3 4	1 2 3 4	1 2 3 4

Have any of the following members of your family been diagnosed with ovarian cancer?

For the questions about the impact of the individual's cancer experience on you, use the following scale:
1 = Strongly disagree 2 = Somewhat disagree 3 = Somewhat agree 4 = Strongly agree

If you have more affected relatives than there are boxes (e.g. more than two sisters with ovarian cancer) please use the "other" boxes at the end.

	Relative's age at diagnosis	Your age at their diagnosis (0 if not born yet)	Cancer survivor (Y/N)	This person's cancer experience has had a significant impact on the way I view my risks for cancer.	This person's cancer experience has had a significant impact on my worries about cancer.	This person's cancer experience has had a significant impact on my confidence in my ability to cope with cancer risks.
☐ Mother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother				1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister				1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister				1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt				1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt				1 2 3 4	1 2 3 4	1 2 3 4
☐ Daughter				1 2 3 4	1 2 3 4	1 2 3 4
☐ Other *Please specify*				1 2 3 4	1 2 3 4	1 2 3 4
☐ Other *Please specify:*				1 2 3 4	1 2 3 4	1 2 3 4

Have any of the following members of your family been diagnosed with other cancers?

For the questions about the impact of the individual's cancer experience on you, use the following scale:
1 = Strongly disagree 2 = Somewhat disagree 3 = Somewhat agree 4 = Strongly agree

If you have more affected relatives than there are boxes (e.g. more than one sister with other cancers) please use the "other" boxes at the end.

	Type of cancer	Relative's age at time of diagnosis	Your age at time of their diagnosis (0 if not born yet)	Cancer survivor (Y/N)	This person's cancer experience has had a significant impact on the way I view my risks for cancer.	This person's cancer experience has had a significant impact on my worries about cancer.	This person's cancer experience has had a significant impact on my confidence in my ability to cope with cancer risks.
☐ Mother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Father					1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandfather					1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister					1 2 3 4	1 2 3 4	1 2 3 4
☐ Brother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt					1 2 3 4	1 2 3 4	1 2 3 4
☐ Uncle					1 2 3 4	1 2 3 4	1 2 3 4
☐ Daughter					1 2 3 4	1 2 3 4	1 2 3 4
☐ Son					1 2 3 4	1 2 3 4	1 2 3 4
☐ Other *Please specify*					1 2 3 4	1 2 3 4	1 2 3 4
☐ Other *Please specify*					1 2 3 4	1 2 3 4	1 2 3 4

If there is anything else you would like to share about your experience with cancer in your or your partner's family, please do so here.

Section D

*Some women say that a positive BRCA test result can have unexpected **positive** effects on them. Please reflect on whether any of the following statements apply to you.*

Being a BRCA carrier has…

	Not At All	A Little Bit	Somewhat	Quite a Bit	Very Much
Helped me accept the way things work out	**1**	**2**	**3**	**4**	**5**
Helped me learn to deal better with uncertainty	**1**	**2**	**3**	**4**	**5**
Taught me how to adjust to things I cannot change	**1**	**2**	**3**	**4**	**5**
Helped me take things as they come	**1**	**2**	**3**	**4**	**5**
Helped me to look at things in a more positive way	**1**	**2**	**3**	**4**	**5**
Helped me learn to handle difficult times	**1**	**2**	**3**	**4**	**5**
Helped me become more comfortable with who I am	**1**	**2**	**3**	**4**	**5**
Helped me become a stronger person	**1**	**2**	**3**	**4**	**5**
Helped me feel better about my ability to handle problems	**1**	**2**	**3**	**4**	**5**
Helped me become a better person	**1**	**2**	**3**	**4**	**5**
Helped me know who I can count on in times of trouble	**1**	**2**	**3**	**4**	**5**
Made me more willing to help others	**1**	**2**	**3**	**4**	**5**

Being a BRCA carrier has…

	Not At All	**A Little Bit**	**Somewhat**	**Quite a Bit**	**Very Much**
Helped relationships become more meaningful	**1**	**2**	**3**	**4**	**5**
Helped me become closer to people I care about	**1**	**2**	**3**	**4**	**5**
Helped me become more aware of the love and support available from other people	**1**	**2**	**3**	**4**	**5**
Helped me learn my life is more meaningful	**1**	**2**	**3**	**4**	**5**
Given me a greater appreciation for life	**1**	**2**	**3**	**4**	**5**
Helped me develop a deeper sense of purpose in life	**1**	**2**	**3**	**4**	**5**
Helped me feel peaceful	**1**	**2**	**3**	**4**	**5**
Helped me find strength in my faith or spiritual beliefs	**1**	**2**	**3**	**4**	**5**

Section E

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible.
Please respond to any item by marking the appropriate case, which is fitting to your personal situation. There are no wrong answers.

How you communicate your stress to your partner	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I let my partner know that I appreciate his/her practical support, advice, or help.	☐	☐	☐	☐	☐
I ask my partner to do things for me when I have too much to do.	☐	☐	☐	☐	☐
I show my partner through my behaviour when I am not doing well or when I have problems.	☐	☐	☐	☐	☐
I tell my partner openly how I feel and that I would appreciate his/her support.	☐	☐	☐	☐	☐

What your partner does when you are feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
My partner shows empathy and understanding to me.	☐	☐	☐	☐	☐
My partner expresses that he/she is on my side.	☐	☐	☐	☐	☐
My partner blames me for not coping well enough with stress.	☐	☐	☐	☐	☐
My partner helps me to see stressful situations in a different light.	☐	☐	☐	☐	☐
My partner listens to me and gives me the opportunity to communicate what really bothers me.	☐	☐	☐	☐	☐
My partner does not take my stress seriously.	☐	☐	☐	☐	☐
My partner provides support, but does so unwillingly and unmotivated.	☐	☐	☐	☐	☐
My partner takes on things that I normally do in order to help me out.	☐	☐	☐	☐	☐
My partner helps me analyze the situation so that I can better face the problem.	☐	☐	☐	☐	☐
When I am too busy, my partner helps me out.	☐	☐	☐	☐	☐
When I am stressed, my partner tends to withdraw.	☐	☐	☐	☐	☐

How your partner communicates when he/she is feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
My partner lets me know that he/she appreciates my practical support, advice, or help.	☐	☐	☐	☐	☐
My partner asks me to do things for him/her when he has too much to do.	☐	☐	☐	☐	☐
My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	☐	☐	☐	☐	☐
My partner tells me openly how he/she feels and that he/she would appreciate my support.	☐	☐	☐	☐	☐

What you do when your partner makes known his/her stress	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I show empathy and understanding to my partner.	☐	☐	☐	☐	☐
I express to my partner that I am on his/her side.	☐	☐	☐	☐	☐
I blame my partner for not coping well enough with stress.-	☐	☐	☐	☐	☐
I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	☐	☐	☐	☐	☐
I listen to my partner and give him/her space and time to communicate what really bothers him/her.	☐	☐	☐	☐	☐
I do not take my partner's stress seriously.	☐	☐	☐	☐	☐
When my partner is stressed I tend to withdraw	☐	☐	☐	☐	☐
I provide support, but do so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.	☐	☐	☐	☐	☐
I take on things that my partner would normally do in order to help him/her out.	☐	☐	☐	☐	☐
I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.	☐	☐	☐	☐	☐
When my partner feels he/she has too much to do, I help him/her out.	☐	☐	☐	☐	☐

What you and your partner do when you are both feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
We try to cope with the problem together and search for solutions.	☐	☐	☐	☐	☐
We engage in a serious discussion about the problem and think through what has to be done.	☐	☐	☐	☐	☐
We help one another to put the problem in perspective and see it in a new light.	☐	☐	☐	☐	☐

We help each other relax with such things like massage, taking a bath together, or listening to music together.	☐	☐	☐	☐	☐
We are affectionate to each other or make love.	☐	☐	☐	☐	☐

How you evaluate your coping as a couple.	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I am <u>satisfied</u> with the support I receive from my partner and the way we deal with stress together.	☐	☐	☐	☐	☐
I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is <u>effective</u>.	☐	☐	☐	☐	☐

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always disagree	**Almost always disagree**	**Frequently disagree**	**Occasionally disagree**	**Almost always agree**	**Always agree**
Philosophy of life	☐	☐	☐	☐	☐	☐
Aims, goals and things believed important	☐	☐	☐	☐	☐	☐
Amount of time spent together	☐	☐	☐	☐	☐	☐

How often would you say the following events occur between you and your partner?

	Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**
Have a stimulating exchange of ideas	☐	☐	☐	☐	☐	☐
Calmly discuss something together	☐	☐	☐	☐	☐	☐
Work together on a project	☐	☐	☐	☐	☐	☐

The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness in most relationships. Please select the dot that best describes the degree of happiness, all things considered, in your relationship.

0	1	2	3	4	5	6
•	•	•	•	•	•	•
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

Section F

The next questions are about some specific responses you may have had after receiving your genetic test results. Please indicate whether you have experienced each statement *never, rarely, sometimes or often* in the past week.

	Never	**Rarely**	**Sometimes**	**Often**
Feeling upset about your test result.	0	1	3	5
Feeling sad about your test result.	0	1	3	5
Feeling anxious or nervous about your test result.	0	1	3	5
Feeling guilty about your test result.	0	1	3	5
Feeling relieved about your test result.	0	1	3	5
Feeling happy about your test result.	0	1	3	5
Feeling a loss of control.	0	1	3	5
Having problems enjoying your life because of your test result.	0	1	3	5
Worrying about your risk of getting cancer.	0	1	3	5
Being uncertain about what your test result means about your cancer risk.	0	1	3	5
Being uncertain about what your test result means for your child(ren) and/or your family's cancer risk	0	1	3	5
Having difficulty making decisions about cancer screening or prevention (e.g., having preventive surgery or getting medical tests done).	0	1	3	5
Understanding clearly your choices for cancer prevention or early detection.	0	1	3	5
Feeling frustrated that there are no definite cancer prevention guidelines for you.	0	1	3	5
Thinking about your test results has affected your work or family life.	0	1	3	5

	Never	Rarely	Sometimes	Often
Feeling concerned about how your test results will affect insurance status.	0	1	3	5
Having difficulty talking about your test results with family members.	0	1	3	5
Feeling that your family has been supportive during the genetic counseling and testing process.	0	1	3	5
Feeling satisfied with family communication about your genetic test result.	0	1	3	5
Worrying that the genetic counseling and testing process has brought about conflict within your family.	0	1	3	5
Feeling regret about getting your test results	0	1	3	5
If you have children, please answer the following:				
Worrying about the possibility of your children getting cancer.	0	1	3	5
Feeling guilty about possibly passing on the disease risk to your child(ren).	0	1	3	5

Section G

The following questions are about cancer worry and risk. Again, there are no right or wrong answers. Please be as honest as possible.

Some women worry about cancer a lot, while others worry less often or not at all. Please answer the following questions about the frequency of your cancer worry.

	Never					Often
How frequently do you worry about getting cancer?	1	2	3	4	5	6
How frequently does worry about cancer affect your mood?	1	2	3	4	5	6
How frequently does worry about cancer interfere with your ability to do daily activities?	1	2	3	4	5	6

The following questions are about your risk of getting breast or ovarian cancer. I am interested in what you personally think and feel about your cancer risk.

I think my chances of developing **breast** cancer are:

☐ almost zero
☐ very small
☐ small
☐ moderate
☐ large
☐ very large
☐ almost certain

I feel that I am going to get **breast** cancer.

☐ disagree strongly
☐ disagree somewhat
☐ agree somewhat
☐ agree strongly

I feel that I am very vulnerable to **breast** cancer.

☐ disagree strongly
☐ disagree somewhat
☐ agree somewhat
☐ agree strongly

I think my chances of developing **ovarian** cancer are:

- ☐ almost zero
- ☐ very small
- ☐ small
- ☐ moderate
- ☐ large
- ☐ very large
- ☐ almost certain

I feel that I am going to get **ovarian** cancer.

- ☐ disagree strongly
- ☐ disagree somewhat
- ☐ agree somewhat
- ☐ agree strongly

I feel that I am very vulnerable to **ovarian** cancer.

- ☐ disagree strongly
- ☐ disagree somewhat
- ☐ agree somewhat
- ☐ agree strongly

Section H

Please answer the following questions about your medical management.

Have you ever had a mammogram?

- ☐ Yes
- ☐ No

If yes, when was your most recent mammogram?

- ☐ Within the last month
- ☐ 1-6 months ago
- ☐ 6-12 months ago
- ☐ Over 1 year ago

Do you plan to have a mammogram in the future?

- ☐ Yes, in the next month
- ☐ Yes, in the next 1-6 months
- ☐ Yes, in the 6-12 months
- ☐ Yes, over a year from now
- ☐ No

Have you ever had a breast MRI?

- ☐ Yes
- ☐ No

If yes, when was your most recent breast MRI?

- ☐ Within the last month
- ☐ 1-6 months ago
- ☐ 6-12 months ago
- ☐ Over 1 year ago

Do you plan to have a breast MRI in the future?

- ☐ Yes, in the next month
- ☐ Yes, in the next 1-6 months
- ☐ Yes, in the 6-12 months
- ☐ Yes, over a year from now
- ☐ No

Have you had surgery to remove your breasts for the prevention of cancer?

- ☐ Yes
- ☐ No

If yes: Date: ________/________
month year

What type of surgery did you have?

- ☐ Nipple-sparing mastectomy
- ☐ Skin-sparing mastectomy
- ☐ Other: Please specify: ______________________

Did you have breast reconstruction surgery?
☐ Yes
☐ No
If yes, what type: ______________________________

Did you have any surgical complications?
☐ Yes
☐ No
If yes, please describe: _________________________

Are you satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:_________________________

Is your partner satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:_________________________

If no, is this a surgery you would consider?
☐ Yes
☐ Maybe
☐ No

If you would consider it, when do you think you might have surgery?
☐ I have already started making arrangements for surgery
☐ I will definitely have the surgery within a few years
☐ I will definitely have the surgery at some point in the future
☐ I might have the surgery at some point in the future

Have you had a CA-125 blood test to screen for ovarian cancer?
☐ Yes
☐ No
☐ Don’t know or never heard of it

If yes, when was your most recent CA-125 test?
☐ Within the last month
☐ 1-6 months ago
` ☐ 6-12 months ago
☐ Over 1 year ago

Do you have a CA-125 test scheduled for the future?
☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No

Have you had a transvaginal ultrasound (TVS) to screen for ovarian cancer?
☐ Yes
☐ No
☐ Don’t know or never heard of it

If yes, when was your most recent TVS?
☐ Within the last month
☐ 1-6 months ago
` ☐ 6-12 months ago
☐ Over 1 year ago

Do you have a TVS scheduled for the future?
☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No

Have you had your ovaries removed?
☐ Yes, one ovary
☐ Yes, both ovaries
☐ No

If yes, when?
________/________
month year

Did you have your ovary (ovaries) removed for (select all that apply):
☐ Prevention of ovarian cancer
☐ Prevention of breast cancer
☐ Other medical reason: Please specify: ________________________________

Are you satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:________________________

Is your partner satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:________________________

If you have not had this surgery, is this a surgery you would consider?
☐ Yes
☐ Maybe
☐ No

If you would consider it, when do you think you might have surgery?

- ☐ I have already started making arrangements for surgery
- ☐ I will definitely have the surgery within a few years
- ☐ I will definitely have the surgery at some point in the future
- ☐ I might have the surgery at some point in the future

If you have done any other screening or risk-reduction related to your BRCA1/2 mutation, please describe it here.

Section I

Please answer a few final questions about yourself.

1. What is your gender?
☐ Female
☐ Male

2. What is your age? _______ (years)

3. What is your racial background? (*Choose all that apply*)
☐ Caucasian
☐ Asian
☐ Black or African American
☐ Native American
☐ Other

4. What is your ethnic background?
☐ Hispanic or Latino
☐ Not Hispanic or Latino

5. Are you of Ashkenazi Jewish descent?
☐ Yes
☐ No
☐ Unsure

6. Where do you live?
☐ United States
☐ Canada
☐ United Kingdom
☐ Other

7. What is your highest level of education completed?
☐ Elementary/Junior High
☐ High School/GED
☐ Technical School
☐ Some college
☐ Completed college
☐ Post-graduate

8. What is your current relationship status?
☐ Single, in committed relationship but not living together
☐ Single, in committed relationship and living together
☐ Engaged
☐ Married
☐ In a civil union/domestic partnership
☐ Other ______________________________

9. How long have you been with your current partner? _________ (years)

10. Do you have any biological children?

	Age 18 and over	Under age 18 Born before your BRCA1/2 testing	Under age 18 Born after your BRCA1/2 testing
Number of daughters with current partner			
Number of daughters with previous partner(s)			
Number of sons with current partner			
Number of sons with previous partner(s)			

11. Do you plan to have (more) children in the future?
- ☐ Yes
- ☐ No
- ☐ Unsure

12. Are you (or your partner) currently pregnant?
- ☐ Yes
- ☐ No
- ☐ Unsure

13. Are you a member or participant of a BRCA support group or organization?
- ☐ Yes
- ☐ No

14. How did you hear about this survey? (select all that apply)
- ☐ From a local support group
- ☐ From an online support organization
- ☐ From a medical clinic
- ☐ From an email listserv
- ☐ From your partner
- ☐ Other: ______________________________

15. Is there anything else that you want us to know about that we have not asked?

APPENDIX D: Survey Instrument, Partner Version

Survey -
Adaptation to Living with a BRCA1/2 Mutation in Carriers and their Partners

STATEMENT OF CONFIDENTIALITY.
All of the information you provide will be kept confidential. The information you provide will be used for research purposes only. The information you provide will not be released to anyone other than the researchers of this study. Filling out this survey is voluntary.

Please check the responses that are true for you:

☐ I am 18 years old or older and in a committed relationship

☐ I am a partner of a BRCA1/2 mutation carrier

If you check both boxes, you are eligible to complete this survey. Please complete every question in the survey.

If you did not check all 3 boxes, you are not eligible to complete this survey. Thank you for your time and interest.

Please **check the box below** if you have read and understand the information presented in the consent form.

☐ I understand the purpose and procedures of the study and do not have any questions.

****Please follow the instructions at the beginning of each Section. Thank you for your time****

Section A

To confidentially match your survey to your partner's, please enter the following information. If you choose to enter a nickname, please be sure that both you and your partner enter the same nickname.

Your birthday

________/________
Month Day

Your partner's birthday

________/________
Month Day

Your first name

____

Your partner's first name

____

Section B

Please answer the following questions about your experience with genetic testing.

When did your partner have BRCA1/2 testing?

________/________
month year
☐ Don’t know/unsure

Were you in a relationship with her at that time?

☐ Yes
☐ No

In which gene does she have a mutation?

☐ BRCA1
☐ BRCA2
☐ Don’t know/unsure
☐ Other: ____________________________

Have you personally had any genetic testing?

☐ Yes
☐ No
If so, please describe what the testing was for and what the result was.
____

Section C

Please answer the following questions about your family's history with cancer.

Have any of the following members of your family been diagnosed with cancer?

For the questions about the impact of the individual's cancer experience on you, use the following scale:
1 = Strongly disagree 2 = Somewhat disagree 3 = Somewhat agree 4 = Strongly agree

If you have more affected relatives than there are boxes (e.g. more than one sister with cancer) please use the "other" boxes at the end.

	Type of cancer	Relative's age at diagnosis	Your age at their diagnosis (0 if not born yet)	Cancer survivor (Y/N)	This person's cancer experience has had a significant impact on the way I view my risks for cancer.	This person's cancer experience has had a significant impact on my worries about cancer.	This person's cancer experience has had a significant impact on my confidence in my ability to cope with cancer risks.
☐ Mother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Father					1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandmother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Grandfather					1 2 3 4	1 2 3 4	1 2 3 4
☐ Sister					1 2 3 4	1 2 3 4	1 2 3 4
☐ Brother					1 2 3 4	1 2 3 4	1 2 3 4
☐ Aunt					1 2 3 4	1 2 3 4	1 2 3 4
☐ Uncle					1 2 3 4	1 2 3 4	1 2 3 4
☐ Daughter					1 2 3 4	1 2 3 4	1 2 3 4
☐ Son					1 2 3 4	1 2 3 4	1 2 3 4
☐ Other___ *Please specify:*					1 2 3 4	1 2 3 4	1 2 3 4
☐ Other___ *Please specify:*					1 2 3 4	1 2 3 4	1 2 3 4

Have you personally been diagnosed with cancer?

☐ Yes
☐ No

If yes, please complete the following:

Type of cancer: ________________
Date of diagnosis:
________/________
month   year

Are you currently in treatment?
☐ Yes
☐ No

If there is anything else you would like to share about your experience with cancer in your or your partner's family, please do so here.

____

____

____

____

____

____

____

Section D

*Some people say that a positive BRCA test result can have unexpected **positive** effects on them. Please reflect on whether any of the following statements apply to you.*

Being a partner of a BRCA carrier has…

	Not At All	A Little Bit	Somewhat	Quite a Bit	Very Much
Helped me accept the way things work out	**1**	**2**	**3**	**4**	**5**
Helped me learn to deal better with uncertainty	**1**	**2**	**3**	**4**	**5**
Taught me how to adjust to things I cannot change	**1**	**2**	**3**	**4**	**5**
Helped me take things as they come	**1**	**2**	**3**	**4**	**5**
Helped me to look at things in a more positive way	**1**	**2**	**3**	**4**	**5**
Helped me learn to handle difficult times	**1**	**2**	**3**	**4**	**5**
Helped me become more comfortable with who I am	**1**	**2**	**3**	**4**	**5**
Helped me become a stronger person	**1**	**2**	**3**	**4**	**5**
Helped me feel better about my ability to handle problems	**1**	**2**	**3**	**4**	**5**
Helped me become a better person	**1**	**2**	**3**	**4**	**5**
Helped me know who I can count on in times of trouble	**1**	**2**	**3**	**4**	**5**
Made me more willing to help others	**1**	**2**	**3**	**4**	**5**

Being a partner of a BRCA carrier has…

	Not At All	**A Little Bit**	**Somewhat**	**Quite a Bit**	**Very Much**
Helped relationships become more meaningful	**1**	**2**	**3**	**4**	**5**
Helped me become closer to people I care about	**1**	**2**	**3**	**4**	**5**
Helped me become more aware of the love and support available from other people	**1**	**2**	**3**	**4**	**5**
Helped me learn my life is more meaningful	**1**	**2**	**3**	**4**	**5**
Given me a greater appreciation for life	**1**	**2**	**3**	**4**	**5**
Helped me develop a deeper sense of purpose in life	**1**	**2**	**3**	**4**	**5**
Helped me feel peaceful	**1**	**2**	**3**	**4**	**5**
Helped me find strength in my faith or spiritual beliefs	**1**	**2**	**3**	**4**	**5**

Section E

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible.
Please respond to any item by marking the appropriate case, which is fitting to your personal situation. There are no wrong answers.

How you communicate your stress to your partner	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I let my partner know that I appreciate his/her practical support, advice, or help.	☐	☐	☐	☐	☐
I ask my partner to do things for me when I have too much to do.	☐	☐	☐	☐	☐
I show my partner through my behaviour when I am not doing well or when I have problems.	☐	☐	☐	☐	☐
I tell my partner openly how I feel and that I would appreciate his/her support.	☐	☐	☐	☐	☐

What your partner does when you are feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
My partner shows empathy and understanding to me.	☐	☐	☐	☐	☐
My partner expresses that he/she is on my side.	☐	☐	☐	☐	☐
My partner blames me for not coping well enough with stress.	☐	☐	☐	☐	☐
My partner helps me to see stressful situations in a different light.	☐	☐	☐	☐	☐
My partner listens to me and gives me the opportunity to communicate what really bothers me.	☐	☐	☐	☐	☐
My partner does not take my stress seriously.	☐	☐	☐	☐	☐
My partner provides support, but does so unwillingly and unmotivated.	☐	☐	☐	☐	☐
My partner takes on things that I normally do in order to help me out.	☐	☐	☐	☐	☐
My partner helps me analyze the situation so that I can better face the problem.	☐	☐	☐	☐	☐
When I am too busy, my partner helps me out.	☐	☐	☐	☐	☐
When I am stressed, my partner tends to withdraw.	☐	☐	☐	☐	☐

How your partner communicates when he/she is feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
My partner lets me know that he/she appreciates my practical support, advice, or help.	☐	☐	☐	☐	☐
My partner asks me to do things for him/her when he has too much to do.	☐	☐	☐	☐	☐
My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	☐	☐	☐	☐	☐
My partner tells me openly how he/she feels and that he/she would appreciate my support.	☐	☐	☐	☐	☐

What you do when your partner makes known his/her stress	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I show empathy and understanding to my partner.	☐	☐	☐	☐	☐
I express to my partner that I am on his/her side.	☐	☐	☐	☐	☐
I blame my partner for not coping well enough with stress.-	☐	☐	☐	☐	☐
I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	☐	☐	☐	☐	☐
I listen to my partner and give him/her space and time to communicate what really bothers him/her.	☐	☐	☐	☐	☐
I do not take my partner’s stress seriously.	☐	☐	☐	☐	☐
When my partner is stressed I tend to withdraw	☐	☐	☐	☐	☐
I provide support, but do so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.	☐	☐	☐	☐	☐
I take on things that my partner would normally do in order to help him/her out.	☐	☐	☐	☐	☐
I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.	☐	☐	☐	☐	☐
When my partner feels he/she has too much to do, I help him/her out.	☐	☐	☐	☐	☐

What you and your partner do when you are both feeling stressed	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
We try to cope with the problem together and search for solutions.	☐	☐	☐	☐	☐
We engage in a serious discussion about the problem and think through what has to be done.	☐	☐	☐	☐	☐
We help one another to put the problem in perspective and see it in a new light.	☐	☐	☐	☐	☐
We help each other relax with such things like	☐	☐	☐	☐	☐

massage, taking a bath together, or listening to music together.					
We are affectionate to each other or make love.	☐	☐	☐	☐	☐

How you evaluate your coping as a couple.	**Very rarely**	**Rarely**	**Sometimes**	**Often**	**Very often**
I am satisfied with the support I receive from my partner and the way we deal with stress together.	☐	☐	☐	☐	☐
I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.	☐	☐	☐	☐	☐

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always disagree	**Almost always disagree**	**Frequently disagree**	**Occasionally disagree**	**Almost always agree**	**Always agree**
Philosophy of life	☐	☐	☐	☐	☐	☐
Aims, goals and things believed important	☐	☐	☐	☐	☐	☐
Amount of time spent together	☐	☐	☐	☐	☐	☐

How often would you say the following events occur between you and your partner?

	Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**
Have a stimulating exchange of ideas	☐	☐	☐	☐	☐	☐
Calmly discuss something together	☐	☐	☐	☐	☐	☐
Work together on a project	☐	☐	☐	☐	☐	☐

The dots on the following line represent different degrees of happiness in your relationship. The middle point, “happy,” represents the degree of happiness in most relationships. Please select the dot that best describes the degree of happiness, all things considered, in your relationship.

0	1	2	3	4	5	6
•	•	•	•	•	•	•
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

Section F

The next questions are about some specific responses you may have had after learning your partner's genetic test results. Please indicate whether you have experienced each statement *never, rarely, sometimes or often* in the past week.

	Never	**Rarely**	**Sometimes**	**Often**
Feeling upset about your partner's test result.	0	1	3	5
Feeling sad about your partner's test result.	0	1	3	5
Feeling anxious or nervous about your partner's test result.	0	1	3	5
Feeling guilty about your partner's test result.	0	1	3	5
Feeling relieved about your partner's test result.	0	1	3	5
Feeling happy about your partner's test result.	0	1	3	5
Feeling a loss of control.	0	1	3	5
Having problems enjoying your life because of your partner's test result.	0	1	3	5
Worrying about your partner's risk of getting cancer.	0	1	3	5
Being uncertain about what your partner's test result means about your cancer risk.	0	1	3	5
Being uncertain about what your partner's test result means for your child(ren) and/or her family's cancer risk	0	1	3	5
Having difficulty making decisions about cancer screening or prevention (e.g., having preventive surgery or getting medical tests done).	0	1	3	5
Understanding clearly your partner's choices for cancer prevention or early detection.	0	1	3	5
Feeling frustrated that there are no definite cancer prevention guidelines for your partner.	0	1	3	5
Thinking about your partner's test results has affected your work or family life.	0	1	3	5

	Never	Rarely	Sometimes	Often
Feeling concerned about how your partner's test results will affect insurance status.	0	1	3	5
Having difficulty talking about your partner's test results with family members.	0	1	3	5
Feeling that your family has been supportive during the genetic counseling and testing process.	0	1	3	5
Feeling satisfied with family communication about your partner's genetic test result.	0	1	3	5
Worrying that the genetic counseling and testing process has brought about conflict within your family.	0	1	3	5
Feeling regret about getting your partner's test results	0	1	3	5
If you have children, please answer the following:				
Worrying about the possibility of your children getting cancer.	0	1	3	5
Feeling guilty about possibly passing on the disease risk to your child(ren).	0	1	3	5

Section G

The following questions are about cancer worry and risk. Again, there are no right or wrong answers. Please be as honest as possible.

Some people worry about cancer a lot, while others worry less often or not at all. Please answer the following questions about the frequency of your cancer worry.

	Never					Often
How frequently do you worry about your partner getting cancer?	1	2	3	4	5	6
How frequently does worry about cancer affect your mood?	1	2	3	4	5	6
How frequently does worry about cancer interfere with your ability to do daily activities?	1	2	3	4	5	6

The following questions are about your partner's risk of getting breast or ovarian cancer. I am interested in what you personally think and feel about her cancer risk.

I think my partner's chances of developing **breast** cancer are:

☐ almost zero
☐ very small
☐ small
☐ moderate
☐ large
☐ very large
☐ almost certain

I feel that my partner is going to get **breast** cancer.

☐ disagree strongly
☐ disagree somewhat
☐ agree somewhat
☐ agree strongly

I feel that my partner is very vulnerable to **breast** cancer.

☐ disagree strongly
☐ disagree somewhat
☐ agree somewhat
☐ agree strongly

I think my partner's chances of developing **ovarian** cancer are:

- ☐ almost zero
- ☐ very small
- ☐ small
- ☐ moderate
- ☐ large
- ☐ very large
- ☐ almost certain

I feel that my partner is going to get **ovarian** cancer.

- ☐ disagree strongly
- ☐ disagree somewhat
- ☐ agree somewhat
- ☐ agree strongly

I feel that my partner is very vulnerable to **ovarian** cancer.

- ☐ disagree strongly
- ☐ disagree somewhat
- ☐ agree somewhat
- ☐ agree strongly

Section H

Please answer the following questions about your partner's medical management.

Has your partner ever had a mammogram?

☐ Yes
☐ No
☐ Don't know

If yes, when was her most recent mammogram?

☐ Within the last month
☐ 1-6 months ago
☐ 6-12 months ago
☐ Over 1 year ago
☐ Don't know

Does she plan to have a mammogram in the future?

☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No
☐ Don't know

Has your partner ever had a breast MRI?

☐ Yes
☐ No
☐ Don't know

If yes, when was her most recent breast MRI?

☐ Within the last month
☐ 1-6 months ago
☐ 6-12 months ago
☐ Over 1 year ago
☐ Don't know

Does she plan to have a breast MRI in the future?

☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No
☐ Don't know

Has your partner had surgery to remove her breasts for the prevention of cancer?

☐ Yes
☐ No
☐ Don't know

If yes: Date: ________/________
month year

Is she satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:____

Are you satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:____

Has your partner had any of the following tests to screen for ovarian cancer?

CA-125 (a blood test)
☐ Yes
☐ No
☐ Don't know or never heard of it

If yes, when was her most recent CA-125 test?
☐ Within the last month
☐ 1-6 months ago
` ☐ 6-12 months ago
☐ Over 1 year ago
☐ Don't know

Does she have a CA-125 test scheduled for the future?
☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No
☐ Don't know

Transvaginal ultrasound (TVS) for screening purposes, not pregnancy (A probe is inserted into the vagina to image the ovaries)

☐ Yes
☐ No
☐ Don't know or never heard of it

If yes, when was her most recent TVS?
☐ Within the last month
☐ 1-6 months ago
` ☐ 6-12 months ago
☐ Over 1 year ago
☐ Don't know

Does she have a TVS scheduled for the future?
☐ Yes, in the next month
☐ Yes, in the next 1-6 months
☐ Yes, in the 6-12 months
☐ Yes, over a year from now
☐ No
☐ Don't know

Has your partner had her ovaries removed?
☐ Yes, one ovary
☐ Yes, both ovaries
☐ No
☐ Don't know

If yes, when?
________/________
month year

Is she satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:________________________

Are you satisfied with the outcome?
☐ Very
☐ Somewhat
☐ Not at all
Please explain:________________________

Section I

Please answer a few final questions about yourself.

1. What is your gender?
☐ Female
☐ Male

2. What is your age? _______ (years)

3. What is your racial background? (*Choose all that apply*)
☐ Caucasian
☐ Asian
☐ Black or African American
☐ Native American
☐ Other

4. What is your ethnic background?
☐ Hispanic or Latino
☐ Not Hispanic or Latino

5. Are you of Ashkenazi Jewish descent?
☐ Yes
☐ No
☐ Unsure

6. Where do you live?
☐ United States
☐ Canada
☐ United Kingdom
☐ Other

7. What is your highest level of education completed?
☐ Elementary/Junior High
☐ High School/GED
☐ Technical School
☐ Some college
☐ Completed college
☐ Post-graduate

8. What is your current relationship status?
☐ Single, in committed relationship but not living together
☐ Single, in committed relationship and living together
☐ Engaged
☐ Married
☐ In a civil union/domestic partnership
☐ Other ______________________________

9. How long have you been with your current partner? _________ (years)

10. Do you have any biological children?

	Age 18 and over	Under age 18 Born before your BRCA1/2 testing	Under age 18 Born after your BRCA1/2 testing
Number of daughters with current partner			
Number of daughters with previous partner(s)			
Number of sons with current partner			
Number of sons with previous partner(s)			

11. Do you plan to have (more) children in the future?

☐ Yes
☐ No
☐ Unsure

12. Are you (or your partner) currently pregnant?

☐ Yes
☐ No
☐ Unsure

13. Are you a member or participant of a BRCA support group or organization?

☐ Yes
☐ No

14. How did you hear about this survey? (select all that apply)

☐ From a local support group
☐ From an online support organization
☐ From a medical clinic
☐ From an email listserv
☐ From your partner
☐ Other: ______________________________

15. Is there anything else that you want us to know about that we have not asked?

APPENDIX E: Literature Cited

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CURRICULUM VITAE

RACHEL SHAPIRA

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EDUCATION

Johns Hopkins University, Baltimore, MD January 2014
National Human Genome Research Institute, Bethesda, MD
ScM, Genetic Counseling Training Program
Thesis: Adaptation to Living with a *BRCA1/2* Mutation in Carriers and their Partners

Wesleyan University, Middletown, CT May 2000
Bachelor of Arts
Majors: Theater (Production & Stage Management); Science in Society (Psychology & Women's Studies)

CLINICAL & RESEARCH EXPERIENCE

Prenatal Genetic Counseling

- Howard County General Hospital, Columbia, MD — Nov 2011 – Jan 2012
  Center for Maternal and Fetal Medicine
- Walter Reed National Military Medical Center, Bethesda, MD — February – May 2012
  Prenatal Assessment Center

Adult/Pediatric Genetic Counseling

- Johns Hopkins Medicine, Baltimore, MD — March – May 2013
  McKusick-Nathans Institute of Genetic Medicine

Cancer Genetic Counseling

- Georgetown University Medical Center, Washington, DC — Sept – Dec 2012
  Lombardi Comprehensive Cancer Center
- Myriad Genetic Laboratories, Salt Lake City, UT — August 2012
- Greater Baltimore Medical Center, Towson, MD — Oct – Dec 2013
  Harvey Institute for Human Genetics

Specialty Genetic Counseling

- National Institute of Neurological Disorders and Stroke, Bethesda, MD — June – July 2012
  Neurogenetics Branch
- Johns Hopkins Medicine, Baltimore, MD — June – July 2012
  Comprehensive Neurofibromatosis Center
- National Human Genome Research Institute, Bethesda, MD — June – July 2013
  Genetic Disease Research Branch
- Johns Hopkins Heart and Vascular Institute, Baltimore, MD — Sept – Oct 2013
  Center for Inherited Heart Diseases
  Arrhythmogenic Right Ventricular Dysplasia/Cardiomyopathy Program

RELATED EXPERIENCE

FORCE: Facing Our Risk of Cancer Empowered, Chicago, Illinois
Helpline Volunteer 2009-2011

- Help callers from across the U.S. understand their risk, provide them with information and access to health care professionals, and connect them with local resources

Chicago Chapter Social Media Coordinator 2010-2011

- Maintain Facebook page, educate Chicago coordinators on social media, and elevate online presence

Bright Pink, Chicago, Illinois
PinkPal 2010-Present

- Provide one-on-one support and guidance to high risk women through sharing personal experiences

Chicago Center for Family Health, Chicago, Illinois 2001-2006
Administrative Coordinator (2005-2006)
Administrative Assistant (2001-2005)

- Supported the Co-Directors, John Rolland and Froma Walsh, and faculty of 30
- Managed the annual direct mail campaign
- Designed and coordinated publication of all marketing and advertising materials
- Assumed webmaster responsibilities and performed regular updates and improvements
- Overhauled Access database to utilize the full functionality of the program
- Managed training activities
- Maintained records of clinical referrals and reported on clinical activity

PRESENTATIONS

Neurofibromatosis 1: Disease Perception and Quality of Life May 9, 2012
NHGRI Post-Clinic Conference, National Institutes of Health

Stress and Coping in Couples: The Case of JP Dec 17, 2012
Georgetown Lombardi Comprehensive Cancer Center

Phenylketonuria and Disordered Eating Nov 13, 2013
NHGRI Post-Clinic Conference, National Institutes of Health

Adaptation in BRCA1/2 Carriers and their Partners (Poster) Dec 13, 2013
2013 NHGRI Scientific Symposium, National Institutes of Health

ADDITIONAL WORK EXPERIENCE

Weber Shandwick, Chicago, IL 2009-2011
Administrative Assistant

Google, Chicago, IL 2006-2009
Administrative Assistant

Jewish Community Centers of Chicago, Skokie, IL 2006
Administrative Aide/Support Specialist

Freelance Stage Manager 2001-2006
Companies included The Next Theatre, Rivendell Theatre Ensemble, Redmoon Theater, The Hypocrites, Theatre-Hikes, Factory Theatre, Defiant Theatre, Live Bait Theater, and Oakton Community College